GUIDELINE FOR LOST-TO-FOLLOW-UP TYPE-1 DIABETES PATIENTS AT PUBLIC HOSPITALS IN ETHIOPIA

by

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I proclaim that this thesis is my own work and that all the sources used or cited have been recognised and acknowledged using a comprehensive list of references.

This thesis has also been subjected to reliable software testing to check its originality.

I further confirm that this thesis has never been submitted at any institution of higher learning elsewhere before, including submission to UNISA for any degree purposes.

Signature:  Date: October 10, 2025

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DEDICATION

This thesis is dedicated to the memory of my late supervisor, Dr Hendry van der Heever, a Senior Lecturer at the UNISA School of Social Sciences, who guided and inspired me through the first half of this journey. His wisdom, encouragement, and faith in my work left a lasting mark on both this study and on me personally. May his soul rest in eternal peace.

ABBREVIATIONS

CKD	Chronic Kidney Disease
DM	Diabetes Mellitus
FBS	Fasting Blood Sugar
HbA1C	Glycated Haemoglobin
HBM	Health Belief Model
HEP	Health Extension Programme
HEWs	Health Extension Workers
HWs	Healthcare Workers
IDF	International Diabetes Federation
LTFU	Lost-To-Follow-Up
MOHE	Ministry of Health, Ethiopia
NCD	Non-Communicable Disease
PDR	Proliferative Diabetic Retinopathy
RHB	Regional Health Bureau
SCDM	Structured Consensus Development Meeting
T1D	Type-1 Diabetes
WHO	World Health Organization

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ABSTRACT

Introduction: Lost-to-follow-up (LTFU) among Type-1 diabetes patients presents a significant challenge in diabetes care, leading to poor health outcomes and increased disease complications.

Aim: The study aims to explore the experiences of patients and healthcare workers to understand lost to follow-up among patients with Type 1 diabetes, and develop guidelines to address LTFU.

Method: The study was conducted in four phases, with Phases 1 and 2 focusing on data collection, analysis, and presentation of empirical findings, and Phases 3 and 4 were dedicated to guideline development and validation. Using a qualitative phenomenological design, data for the empirical study were collected from patients and healthcare workers through semi-structured interviews guided by the Health Belief Model. The guideline was developed based on evidence generated from empirical findings, a literature review, and expert input from focused discussions. Finally, the guideline was validated by a panel of experts through a structured consensus development meeting.

Result: The findings reveal the real-world experiences of healthcare workers and patients, leading to the development of comprehensive guidelines to reduce lost-to-follow-up among Type 1 diabetes patients. The study developed and validated comprehensive guidelines covering eight key areas: patient education, financial support, trac-

ing of patients lost to follow-up, quality of care, reduction of waiting times, establishment of robust cohort follow-up systems, reinforcement of patient support mechanisms, and monitoring and evaluation.

Conclusions: The study identified interconnected patient and healthcare workers' related challenges and developed validated, context-specific guidelines to improve T1D patient retention. The guidelines are designed to inform policymakers, healthcare institutions, and practitioners in enhancing patient retention and strengthening follow-up services for Type 1 diabetes patients in the public hospitals in Ethiopia.

Keywords: *Type-1 diabetes, lost to follow-up, guideline, patient education, tracing lost to follow-up, quality of follow-up care, waiting time, cohort follow-up, support system, healthcare workers*

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1. CHAPTER ONE: OVERVIEW OF THE STUDY

1.1 INTRODUCTION

Chapter one provides the structured framework of the study. It begins with background information that establishes the context of diabetes, effectively orienting the reader to the critical nature of lost-to-follow-up (LTFU) among Type 1 diabetes (T1D). It outlines the research problem and objectives of the research. The theoretical framework provides foundational concepts of the study. The methodology chapter details the research method, design and the phase-based approach, which further orients the reader to the study's process. Overall, this chapter provides a comprehensive understanding of the study's aims, methods, and the presentations of subsequent chapters.

1.2 BACKGROUND INFORMATION ABOUT THE RESEARCH PROBLEM

1.2.1 Background information about diabetes and follow-up care

Diabetes Mellitus (DM) is a rapidly increasing global health concern, affecting individuals across all age groups (Gebreyes, Goshu, Geletew, Argefa, Zemedu, Lemu, Waka, Mengesha, Degefu, Deghebo, Wubie, Negeri, Tesema, Tessema, Regassa, Eba, Beyene, Yesu, Zeleke, Mengistu & Belayneh 2018:6). According to the International Diabetes Federation (IDF 2025:42), over half a billion people live with diabetes, with Type 1 Diabetes (T1D) accounting for about 9% of cases. In 2024 alone, 503,000 new cases of T1D were diagnosed. Projections estimate this number to rise to 9.7 billion in 2050 (IDF 2025:43). Furthermore, diabetes remains a major cause of mortality worldwide, responsible for an estimated 3.4 million deaths in 2024 and contributing to about 9.3% of all deaths among adults aged 20–79 years (IDF 2025:59).

In Africa, diabetes prevalence is increasing rapidly, driven by urbanization, aging populations, unhealthy diets, sedentary lifestyles, obesity, and other risk factors (Boshe, Yimar, Dadhi & Bededa 2021:12). The number of people with diabetes in Africa was

estimated at 25 million in 2024 and is expected to reach 60 million by 2050, representing the highest growth rate among IDF regions (IDF 2021:74). Ethiopia alone had 2.3 million diabetes cases in 2024, with a prevalence estimated at 3.6% (IDF 2025:74).

Studies indicate that poor follow-up contributes to inadequate blood sugar control and higher rates of complications (Ketema, Leshargie, Kibret, Assemie, Alamneh, Kassa & Alebel 2020:7). According to Bitew, Alemu, Jember, Tadesse, Getaneh, Seid, and Weldeyonnes (2023:7), only one-third (32.6%) of diabetes patients in Ethiopia have good glycemic control. This means that two-thirds have poor glycemic control. The national STEPS survey also reported that only 24% of DM patients achieved blood sugar control (EMOH 2020b:5). Poor glycemic control in diabetes patients in Ethiopia range from 33.6% in Jimma, 35.3% in Gondor, 40.8% in South West Shoa, and 29.2% in Northeast Ethiopia, which was predominantly associated with lack of adherence to recommended follow-up care services (Belay & Adugna 2022:8).

In Ethiopia, chronic disease care such as diabetes services are typically conducted in follow-up units in public hospitals, with patients routinely allocated time slots to refill their medications and receive long-term monitoring of their diseases. They are therefore linked with clinic registers in health facilities and used to track attendance, if the patients do not turn up as scheduled (Belay & Adugna, 2022:2).

1.2.2 The source of the research problem

Effective diabetes management requires lifelong self-care, including daily insulin administration, regular blood glucose monitoring, and professional medical support (WHO 2021:7). Ethiopian guidelines recommend that diabetes patients attend follow-up visits at least once every three months (EMOH 2023:135-139). However, many patients become lost-to-follow-up after initiating follow-up care, with Ethiopia reporting a 38% dropout rate (EMOH 2022:19). LTFU rates vary globally. For example, they are 18% in Malaysia, 5.5% in Germany, and 6.5% in New Zealand (Tino, Wekesa, Kamacooko, Makhoba, Mwebaze, Bengo, Nabwato, Kigongo, Ddumba, Mayanja, Kaleebu, Newton & Nyerinda 2019:4). In developing countries, the proportion of LTFU diabetes

patients is very high. A dropout rate of 46% was reported in India (Olickal, Chinnakali, Suryanarayana, Rajanarayanan, Vivekanandhan, Saya, Ganapathy & Subrahmanyam *20*23:3), 34.9% in Uganda (Tino et al. *20*19:3), 31% in Kenya (Wamalwa, Mungai, Laigong, Omar & Amolo 2025:4), and 38% in Ethiopia (EMOH 2022:22).

Barriers to follow-up attendance include patient-related factors (demographics and behaviour), health system limitations (organisational and administrative), and insufficient social or family support (Belay & Adugna 2022:4). Studies highlight the need for health systems to shift their focus from curative to preventive care in order to enhance patient retention (Hayden 2022:58-90). Although Ethiopia has made efforts to expand diabetes care as part of the integrated NCD programs, follow-up adherence remains suboptimal. Addressing the problem of LTFU is crucial to improving diabetes care in Ethiopian public hospitals (MOHE 2022:22).

1.3 RESEARCH PROBLEM

Patients with Type 1 diabetes require structured follow-up and regular contact with a diabetes clinic (Boshe et al. 2021:8). An important practical problem in the management of diabetes is poor blood sugar control, and a key reason for this is the high rate of lost-to-follow-up among patients with diabetes. Several studies in different settings have reported that patients with diabetes had substantial problems complying with recommended follow-up visits to diabetes clinics (Alodhaib, Alhusaynan, Mirza & Almogbel 2021:4-7; Oluma, Mosisa, Abadiga, Tsegaye, Habte & Abdissa 2020:8). Although diabetes requires regular support and consultation from health professionals, more than 38% of confirmed diabetic patients in Ethiopia drop out of the prescribed follow-up care services (MOHE 2022:22).

Unattended blood glucose levels in diabetes patients can cause both acute and chronic complications. Research by Kim, Lee, Kim, Seo, Chae, and Kim (2021:7) reveals that most diabetic complications arise during the period when patients are lost to follow-up. Other studies also show that poor glycemic control is more prevalent in patients who are lost to follow-up, and often these patients present after developing

acute and/or chronic complications such as hypoglycaemia, nephropathy, retinopathy, and neuropathy (Kim et al. 2021:7; Tino et al. 2019:4).

Although the threat of developing Type 1 diabetes cannot be eliminated, the risk of diabetes complications can be substantially reduced with regular follow-up care (Olickal et al. 2023:3). With regular follow up assessments, care, education, and support, many of the complications associated with diabetes can be prevented or delayed (Tino et al. 2019:4). Therefore, reducing lost-to-follow-up among Type 1 diabetes patients should be of great importance in improving the quality of diabetes care.

1.4 AIM OF THE STUDY

1.4.1 Research purpose

The purpose of this study was to explore the experiences of Type 1 diabetes patients and healthcare workers regarding lost-to-follow-up diabetes care in Ethiopia and to develop and validate guidelines to improve follow-up care utilisation.

1.4.2 Objectives

Specifically, the study had the following objectives:

1.4.2.1 Describe T1D patients' lived experience of being lost-to-follow-up.

1.4.2.2 Describe healthcare workers' experience of LTFU among T1D patients.

1.4.2.3 Develop guidelines to reduce LTFU among T1D patients.

1.4.3 Research questions

The research questions originated from the objective of understanding the problem of being lost to follow-up among patients with Type 1 diabetes (T1D). Therefore, this study aimed to address the following research questions:

- How do T1D patients experience being lost-to-follow-up?
- How do healthcare workers experience LTFU among T1D patients?

- Can guidelines be developed and validated to reduce the likelihood of LTFU among patients with Type 1 diabetes (T1D)?

1.5 SIGNIFICANCE OF THE STUDY

This study examined the experiences of patients with Type 1 diabetes and healthcare workers regarding patients who are lost to follow-up. The findings from the first two phases were used to develop guidelines; thus, many stakeholders (patients, healthcare workers, and experts in public health policy) participated in compiling the final guidelines to improve utilisation of follow-up care services among Type 1 diabetes patients. Policymakers at higher levels can utilise these guidelines to develop effective policies and facilitate their implementation. The study enables healthcare workers to reflect on their experiences providing follow-up care for T1D patients, helping them consider evidence-based approaches to service delivery. The proposed guidelines are aligned with Ethiopia's integrated chronic care system, ensuring compatibility with existing diabetes follow-up and service delivery structures.

The study offers actionable guidance for clinical practice by translating practical evidence into strategies that enhance continuity and quality of care for Type 1 diabetes patients. It supports the health program administration by providing a structured framework to strengthen system performance, including patient retention mechanisms and service organisation. Furthermore, the findings of this study contribute to the existing body of knowledge by improving the understanding of factors related to LTFU and play a role in increasing the use of diabetes follow-up care services.

1.6 DEFINITIONS OF KEY CONCEPTS

The key terms and concepts predominantly used in this study include diabetes (DM), Type 1 diabetes (sometimes written as Type-1 diabetes, abbreviated as T1D), follow-up care services, lost-to-follow-up (LTFU), and guidelines.

1.6.1 Diabetes Mellitus (DM)

'Diabetes' is defined by the World Health Organisation (WHO) as a metabolic disorder characterised by chronic hyperglycaemia associated with disturbances of carbohydrate, fat and protein metabolism resulting from defects in insulin secretion, insulin action, or both. A diagnosis of diabetes must be confirmed by appropriate laboratory testing to rule out transient hyperglycaemia. The diagnosis is established when any of the following two criteria are met on two separate occasions or confirmed by repeat testing: Fasting Blood Glucose (FBG) ≥ 126 mg/dL (7.0 mmol/L), a random plasma glucose ≥ 200 mg/dL (11.1 mmol/L), followed by confirmatory testing (EMOH 2023:2). The diagnosis of diabetes may fall into one of three main categories: Type 1 diabetes, Type 2 diabetes, or gestational diabetes, each with distinct causes, risk factors, and management approaches.

1.6.2 Type 1 diabetes (T1D)

T1D is a type of diabetes caused by an autoimmune process in which the body's immune system attacks the insulin-producing beta-cells of the pancreas. As a result, the body produces very little or no insulin (IDF 2021:13). In this study, T1D refers to the type of diabetes caused by an autoimmune process as defined by the IDF.

1.6.3 Guideline

According to the WHO (2014:3), a guideline is any document containing recommendations about health interventions, whether these are clinical, public health or policy recommendations. A recommendation provides information on what policymakers, healthcare workers, or patients should do. It implies a choice between different interventions that have an impact on health and implications for resource allocation. In this study, guidelines refer to evidence-based areas of emphasis and actions intended to support policymakers, healthcare workers, patients, and other stakeholders in optimising diabetes follow-up care. These guidelines aim to enhance patient retention in care by reducing loss to follow-up for individuals living with Type 1 diabetes.

1.6.4 Healthcare workers

The WHO defines healthcare workers as health professionals engaged in providing preventive, curative, rehabilitative and promotional health services based on an extensive body of theoretical and factual knowledge in diagnosis and treatment of disease and other health problems (WHO 2020:1). In this study, healthcare workers refer to those healthcare workers providing diabetes follow-up care services at chronic care units such as nurses, health officers, medical doctors, and those healthcare workers engaged in health program management such as the head of a health facility, the Medical Director, or a diabetes focal person at the offices of the study area.

1.6.5 Lost to follow-up (LTFU):

In healthcare, 'lost-to-follow-up' refers to patients who were once actively engaged in treatment but have become unreachable or have discontinued participation without formal notice (Patel, Kumar, Khan & Salaria 2021:1). Diabetes patients are considered LTFU if they had missed their medical follow-up visits for six or more consecutive months from the date they last visited the same clinic to seek treatment for the same episode of illness. Transfer to other facilities or the death of a patient were not considered as LTFU (Tino et al. 2019:2). In this study, LTFU refers to those T1DM patients who started treatment, were registered in the cohort, but did not return for follow-up for at least six months.

There is a technical distinction between lost to follow-up (LTFU) and adherence. Specifically, LTFU reflects a more advanced stage of disengagement in which patients discontinue follow-up care for a defined period and are no longer in active contact with the health system. Whereas adherence refers to the extent to which patients follow prescribed treatment and recommended care. This distinction highlights the continuum from poor adherence to complete disengagement from care among patients with diabetes (Patel et al., 2021:1).

1.6.6 Type-1 diabetes patients

T1D patients are those patients confirmed by the diagnosis of a clinician as 'Type-1 Diabetes' using the WHO diagnostic criteria (EMOH 2023:12). In this study, T1D patients will refer to those patients declared by the clinician as T1DM patients and documented in the patient's chart at the respective health facility.

1.6.7 Type-1 diabetes follow-up care services

Follow-up refers to the timely surveillance of a patient's health status and guidance on a medication regimen provided to patients who have visited or were visited by healthcare workers (Tino et al. 2019:2). T1D patients are expected to visit the diabetes care clinic for their follow-up at least once every six months. The cohort registration of each T1D patient is updated every six months. Patients who miss a visit at least once in six months are considered LTFU (EMOH 2023:73). In this study, Type 1 diabetes follow-up care services refer to the prescribed medical diagnosis, treatment, and care expected for T1 diabetes patients during their follow-up visits.

1.6.8 Semi-structured interview

A semi-structured interview is a qualitative data collection method that combines predetermined questions with the flexibility to explore emerging topics during the conversation. This approach enables researchers to delve deeply into participants' experiences while maintaining a consistent framework across interviews (Holloway & Galvin 2023:105). In this study, semi-structured interviews were organised around a set of predetermined open-ended questions consistently assembled across the constructs of the HBM, with additional questions emerging from the dialogue between the interviewer and interviewees.

1.7 THEORETICAL FOUNDATIONS OF THE STUDY

1.7.1 Research paradigm

The research paradigm is the framework in which the theories and practices of the

discipline fit to create the research plan (Paley 2024:91). The paradigmatic positioning of the researcher governs their view of the nature of knowledge (epistemological point of view), reality (ontological point of view), and the way of acquiring knowledge (methodology). According to Paley (2024:112), people actively construct their own notions of reality through cognition, thereby making multiple realities possible.

In this study, the constructivist paradigm was employed to explore and describe the experiences of patients who were LTFU and healthcare workers involved in the delivery and coordination of the diabetes program. According to Paley (2024:254), the constructivist paradigm is suitable when a researcher seeks to investigate participants' opinions and experiences regarding a specific phenomenon.

The ontology of the constructivist paradigm posits that realities are subjective and dynamic, in contrast to the positivist notion that reality is objective and unchanging. Constructivists are interested in developing subjective interpretations and comprehensions of individual lived experiences in the particular situation based on one's social and historical background (Liamputtong 2022:220-232). The constructivist ontology acknowledges the potential for multiple realities. According to constructivists, realities are socially and experientially based, and they are local and specific in nature (Frechette, Bitzas, Aubry, Kilpatrick & Lavoie-Tremblay 2020:5).

The constructivist epistemology is based on the idea that reality is relative; hence, the different views of the world are "constructed" rather than "discovered." People can construct realities based on their prior experiences and knowledge, as well as their political and social status, gender, race, class, and cultural values (Paley 2024:135). Thus, the constructivist paradigm appreciates subjectivity and encourages the researcher to pay close attention to understand the participant's lived experience, including their emotions and practices.

According to the constructivist paradigm, qualitative research methodology is appropriate to understand the meanings that people attach to their experiences (Aurini,

Heath & Howells 2021:35). It is an approach to exploring and understanding the meaning individuals or groups ascribe to a social or human problem (Paley 2024:91). Therefore, this study was guided by the epistemology, ontology, and methodology of the constructivist paradigm to explore the lived experience of patients and healthcare workers of LTFU.

1.7.2 Theoretical Framework

This study is broadly informed by the Health Belief Model (HBM) to provide a conceptual orientation for understanding lost to follow-up among patients with Type 1 diabetes. The model offers a lens to consider how individuals' perceptions and beliefs may influence engagement with follow-up care and treatment adherence. In this study, the HBM serves as a guiding framework for exploring patients' and healthcare workers' experiences, while a detailed description of its constructs and application is presented in Section 2.2 under Chapter 2.

1.8 RESEARCH METHODOLOGY AND DESIGN

1.8.1 RESEARCH APPROACH

This study adopted a qualitative research approach, the details of which are presented in Chapter 3 (see Section 3.2). Qualitative research enables an in-depth understanding of individuals' experiences and their interactions with others and institutions, making it especially valuable in healthcare research (Fushimi 2021:9). Unlike quantitative methods that focus on numerical data and trends, qualitative research emphasises meanings, perspectives, and contextual understanding. This approach has proven effective in exploring the experiences of healthcare workers, patients, and their families to improve service delivery (Holloway & Galvin 2023:123).

Exploring the experiences of follow-up visits from those who have direct experience of them can play a key role in developing guidelines to decrease lost-to-follow-up among Type 1 diabetes patients (Bogale, Wondiye, Debela, Anagaw, Worku & Kebede 2022;

Tino et al. 2019; Zhu et al. 2021). Given the lack of qualitative studies on the experience of lost-to-follow-up (LTFU) among patients with Type 1 Diabetes, this study addresses a significant gap, as previous research in this area has relied mainly on quantitative methods, which do not fully capture the underlying reasons behind LTFU (see Section 3.2).

1.8.2 RESEARCH DESIGN

1.8.2.1 Phenomenological study design

This study employed an interpretative qualitative phenomenological research design, detailed further in Chapter 3 (see Section 3.3). This approach uses rich, descriptive narratives to explore and interpret the lived experiences of individuals, making it well-suited for understanding complex health-related phenomena. Specifically, the design enabled the researcher to investigate the lived experiences of both patients and healthcare workers in relation to lost-to-follow-up among Type 1 diabetes patients. According to Larsen and Adu (2021:40), phenomenological research is particularly appropriate for examining perceptions and experiences in health contexts (see Section 3.3.1). This exploration provided critical insights that informed the development of guidelines aimed at improving the quality and utilisation of diabetes follow-up care services.

1.8.2.2 Phases of the study design

The study was conducted in four phases, utilising various data sources and data gathering techniques. Phase 1 and Phase 2 focused on data gathering, analysis and presentation of the empirical findings from patients and healthcare workers. Phases 3 and 4 focused on guideline development and validation (see Section 3.5). The summary of the different phases, objectives and participants is illustrated in Figure 1.1.

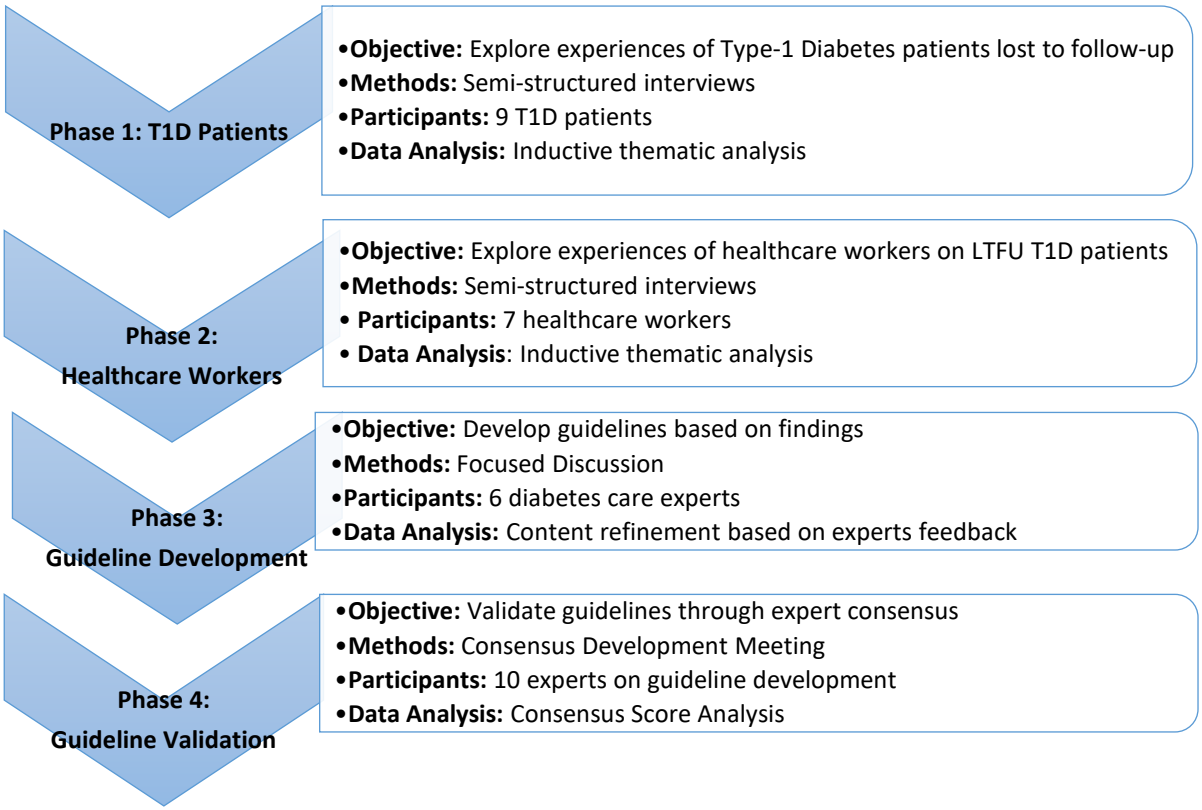


Table 1.1: Schematic presentation of the study phases

1.8.3 RESEARCH METHOD

1.8.3.1 Study setting

This study was conducted in the Oromia Region, the most populous in Ethiopia, comprising numerous administrative zones and districts with a wide network of public health facilities. Two hospitals were selected as study sites: Hospital A, a referral hospital in the Southwest Shoa area serving a catchment population of approximately 1.2 million, and Hospital B, a district hospital in Becho District serving over 113,000 people. Both hospitals provide outpatient diabetes care and report a high burden of diabetes patients, including a notable proportion of Type 1 diabetes (T1D) cases. However, both facilities face significant challenges with patient retention, as evidenced by their high loss-to-follow-up (LTFU) rates. Detailed descriptions of the study setting are provided in the methodology section (see Section 3.4).

1.8.3.2 Phased methodological approach

The study was conducted in four phases, utilising various data sources and diverse data collection techniques. Phase 1 and Phase 2 focus on data gathering, analysis and presentation of the empirical findings. Phases 3 and 4 focus on the development and validation of guidelines. See the details in Section 3.5.

1.8.3.3 Phase one

1.8.3.3.1 Study population and selection of participants in Phase 1

The study population in Phase 1 involve patients with Type 1 diabetes receiving follow-up care at the two hospitals. There were 169 registered T1D patients in the two hospitals (99 in Hospital A and 70 in Hospital B) at the time of data collection. This study employed purposive sampling to select participants with a lived experience of lost-to-follow-up Type 1 diabetes care. From the two hospitals, 14 eligible T1D patients were identified, and nine were interviewed using semi-structured interviews until data saturation was reached, ensuring depth and rigour in the findings. For detailed participant selection procedures in Phase 1, refer to Section 3.5.1.2.

1.8.3.3.2 Data collection in Phase 1

After obtaining ethical clearance and official permission, the researcher conducted Phase 1 data collection in July 2024 through face-to-face semi-structured interviews designed to explore participants' lived experiences and using the HBM framework. A total of nine interviews were conducted in either Amharic or Afan Oromo, depending on the participant's preference, using a translated and culturally adapted interview guide that comprised 13 open-ended questions with additional probes to encourage deeper responses. The interviews were conducted by the principal investigator and a trained assistant, an experienced nurse fluent in both languages, who had undergone thorough training and signed a confidentiality agreement. Data collection took place in private settings within participants' villages, with the support of local health extension workers serving as gatekeepers. Each session lasted between 30 and 60 minutes,

was audio-recorded with the participant's consent, and was accompanied by field notes to capture non-verbal cues and contextual factors. For detailed data collection methods and procedures in Phase 1, refer to Section 3.5.1.4.

1.8.3.3.3 Data analysis in Phase 1

This study employed an inductive thematic analysis using Atlas.ti (Version 25) software to analyse qualitative data. Data analysis began concurrently with data collection, with interview audio transcribed verbatim, translated from Amharic and Afan Oromo to English, and reviewed by the researcher. Coding was conducted through a systematic process involving in-vivo (open), axial, and selective coding, with continuous collaboration between the researcher and co-coders to ensure reliability and theoretical saturation. A total of 95 initial codes were distilled into 13 categories, aligned with the HBM constructs, providing insights into both patient and healthcare worker perspectives on lost-to-follow-up. The detailed procedures for data management and analysis are further described in Chapter 3 (see Section 3.5.1.6). The results derived from the thematic analysis are presented in tables and narratives, reflecting the study participants' opinions on LTFU, in Chapter 4.

1.8.3.4 Phase Two

1.8.3.4.1 Study population and selection of participants in Phase 2

In Phase 2 of the study, a total of 21 healthcare workers with at least one year of experience in diabetes care were purposively selected. Accordingly, a total of seven health professionals from the two hospitals and the district health offices were interviewed. These participants were selected for their direct involvement in T1D follow-up services and their ability to offer insights into both service delivery and systemic challenges related to patient dropout. Participant selection prioritised relevant experience, active engagement in diabetes care, and willingness to participate, with interviews conducted privately at their workplaces. Further details on the study population and participant selection in Phase 2 are provided in Section 3.5.2.1.

1.8.3.4.2 Data collection and analysis in Phase 2

Data collection in Phase 2 was conducted concurrently with Phase 1 in July 2024 and involved semi-structured interviews with seven healthcare workers engaged in diabetes care at the two study hospitals. Interviews, guided by two main themes, experiences in providing diabetes follow-up care and experiences with lost-to-follow-up among T1D patients, were held in the hospital meeting halls, lasting 30 to 60 minutes each. All sessions were audio-recorded with consent, transcribed verbatim, and supplemented by field notes to capture non-verbal insights. The data collection process in Phase 2 followed a similar approach to that used in Phase 1. The data, aimed at understanding healthcare workers' experience of lost-to-follow-up, also served to validate findings from patient interviews. Analysis was conducted using inductive thematic analysis with Atlas.ti software, consistent with the approach described in the phase. Further details on data collection and analysis in Phase 2 are provided in Sections 3.5.2.3 and 3.5.2.5, respectively.

1.8.3.5 Phase Three: Guideline development

In Phase 3, the researcher developed 10 guidelines based on the empirical findings of Phase 1 and Phase 2, as well as a review of relevant literature. Focused discussions with panellists were utilised to refine the 10 developed guidelines by incorporating the opinions of each expert panellist participating in the focused discussion sessions (see Section 3.5.3). In this study, 'Focused Discussions' refer to structured engagements with expert panellists for the purpose of refining and contextualising the draft guidelines.

1.8.3.5.1 Selection of the panellists, data gathering and analysis

For Phase 3, six panellists were selected by the researcher based on their relevant experience in delivering T1D follow-up care services and/or programs (see Section 3.5.3.1). These include healthcare workers in the diabetes care unit (3), the diabetes focal person in public hospitals (1), and the NCD program expert in the district health

office (2). The panellists were healthcare professionals, as detailed in their biographies in Table 3.3.

1.8.3.5.2 Data Gathering and Analysis

In Phase 3, data collection and analysis focused on refining the 10 draft guidelines through expert consultation. Following an email invitation, all contacted experts agreed to participate in a focused in-person discussion on February 25, 2025. During the session, panellists reviewed the initial draft and provided feedback, which was subsequently incorporated into a revised version. This updated guideline was shared with the panellists via email to ensure their concerns were adequately addressed, with further exchanges continuing until a complete consensus was reached after rounds of discussions and inputs. The researcher integrated all relevant inputs to produce the guideline, which is now ready for validation. Further details on the data collection and analysis process in Phase 3 are provided in Sections 3.5.3.2 and 3.5.3.4, respectively.

1.8.3.6 Phase Four: Guideline validation

1.8.3.6.1 Study population and selection

A purposively selected panel of 10 multidisciplinary experts participated in the validation process. Experts were selected based on a minimum of five years of experience in the field, having demonstrated expertise in diabetes care, public health, health systems, and policy (see Table 3.4 in Section 3.5.4.1). The selection ensured representation from key professional roles such as medical doctors experienced in managing diabetes programs (1), diabetes nurse educators (1), public health educators (1), health system researchers (4), and policymakers (4) with attention to gender and regional diversity to ensure contextual relevance within the Ethiopian setting.

1.8.3.6.2 Data gathering

Data were collected through a structured Consensus Development Meeting (CDM), a widely accepted approach for refining health guidelines (Section 3.5.4.2). Before the

meeting, panellists received the draft guideline, supporting evidence, and a validation tool. They independently scored each area of emphasis using a 9-point Likert scale. In the context of this study, the term ‘areas of emphasis’ refers to suggested points included within each guideline for implementation. Each guideline may contain 5 to 20 actions for implementation (Florez, Brouwers, Kerkvliet, Spithoff, Alonso-Coello, Burgers & Straus 2020:5). The SCDM proceeds through multiple facilitated rounds or sessions, involving a presentation of the draft, discussion, re-scoring, and synthesis of results, that was designed to ensure informed, inclusive, and equitable expert engagement (see Section 3.5.4.2).

1.8.3.6.3 Data analysis

All proposed actions of emphasis were analysed using predefined consensus thresholds: strong consensus (≥80% of experts score 7-9), moderate consensus (≥70% score 6-9), and no consensus (<70% agreement or significant dissent) (Section 3.5.4.3.1). Based on these thresholds, the proposed areas of emphasis were accepted, revised, or removed. This structured approach ensured that guideline validation was grounded in both scientific evidence and collective expert judgment. Final actions and refinements were determined during the closing sessions, with full documentation and transparency maintained to uphold trustworthiness (Section 3.5.4.3).

1.9 RIGOUR

The study ensured the rigour and quality of the research by applying the widely recognised trustworthiness criteria: Credibility, Transferability, Dependability, Confirmability, and Authenticity. Credibility was strengthened through participant feedback on emerging themes and transcript verification, which involved both the researcher and a research assistant. Transferability was addressed by offering rich, detailed descriptions of the research process and context, enabling replication in other settings. Dependability was reinforced through strategies like double-coding with a time gap, theme validation with a co-coder, and maintaining comprehensive documentation of the research process.

Confirmability was ensured by preserving both reflexive and observational records, allowing others to verify that interpretations stemmed from the data rather than researcher bias. Authenticity was pursued by establishing transparent and ethical engagement with participants, including informed consent and mechanisms to manage disagreements. The study employed multiple techniques, including reflexive journaling, co-coding, peer debriefing, and member checking, to establish the trustworthiness of the findings. The detailed application of these principles is fully discussed in Chapter 3, the methodology chapter (see Section 3.6).

1.10 ETHICAL PRINCIPLES

The study adhered to comprehensive and well-established ethical principles to ensure the protection, dignity, and rights of all human participants involved in the research. Recognising the sensitive and in-depth nature of qualitative research, the researcher took deliberate steps to address ethical concerns throughout the study process, as outlined in Chapter 3 (see Section 3.7). Ethical clearance was obtained from the UNISA College Research Ethics Committee (see Annexure A and Annexure D) and the Oromia Regional Health Bureau (see Annexure B), alongside letters of support and acceptance from the study hospitals (see Annexure D). Informed written consent was secured from each participant, using translated information letters in local languages to ensure informed consent (see Annexure L, Annexure M, Annexure N, Annexure O). The researcher guaranteed confidentiality and anonymity by assigning ID codes, storing data securely, and collecting information in private settings. All records are kept under strict security and scheduled for destruction after five years to protect participant privacy.

Additionally, the study emphasised minimising harm (non-maleficence) and maximising benefits (beneficence), ensuring participants were not exposed to physical or emotional risks. Participants were assured of their right to withdraw or decline participation without consequence. Although no direct incentives were offered, the study's findings are expected to indirectly benefit patients through improved healthcare practices.

Justice and inclusiveness were also upheld, ensuring fair treatment of all participants, with additional safeguards in place for vulnerable groups. The researcher employed independent, fair, and transparent ethics review procedures to ensure no individual was discriminated against or unfairly burdened. Special attention was given to protecting the rights and interests of vulnerable participants and avoiding any form of exploitation in the name of scientific research. These ethical safeguards and procedures are detailed in Chapter 3 of the study (see Section 3.7).

1.11 STRUCTURE OF THE THESIS

The structure and contents of the thesis are summarised below in Table 1.1.

Table 1.2: Structure of the thesis

CHAPTER	NAME OF THE CHAPTER	PURPOSE/CONTENT
Chapter 1	Overview of the study	The chapter provides an overview of the study's purpose, objectives, and methodology.
Chapter 2	Literature review	Literature review on: • Theoretical framework • Diabetes and diabetic services • The national strategy for diabetes
Chapter 3	Methodology	The methodology of all phases of the study
Chapter 4	Phases 1 and 2:	Phases 1 and 2: Data gathering, analysis, presentation and literature control
Chapter 5	Development of the guideline	• Literature review on the principles of guideline development • Phase 1 and Phase 2 data integration • Focused discussions: Data gathering, analysis and interpretation • Draft guideline ready for validation
Chapter 6	Validation of the guideline	• The process and methodology followed

CHAPTER	NAME OF THE CHAPTER	PURPOSE/CONTENT
		• Data gathering and analysis of the Structured Consensus Development Meeting • The validated guideline
Chapter 7	Conclusion, recommendations, and limitations	Conclusion, recommendations, and limitations of the study

1.12 SUMMARY

Chapter one provides a comprehensive overview of the study. It starts by introducing and contextualising the research background and rationale, followed by presenting the purpose and objectives of the study, defining key terms to ensure conceptual clarity, and outlining the theoretical framework that underpins the research. The chapter provides a comprehensive overview of the research methodology employed. Additionally, it reveals the scope and limitations of the study, as well as the key ethical considerations observed throughout. Finally, the chapter concludes by presenting the overall structure and organisation of the thesis.

2. CHAPTER TWO: LITERATURE REVIEW

2.1 INTRODUCTION

2.1.1 Background information

According to Brink, Van der Walt and Van Rensburg (2022:105), qualitative researchers conduct an initial review of the literature to determine the need for research, confirm the lack of evidence for the phenomena studied, and provide guidelines on data collection methods. The main literature review can be postponed until after the data are collected and analysed to avoid biases in analysis and interpretation.

In this study, the literature review conducted prior to data collection aimed to determine the need for research, confirm the existing lack of evidence on the phenomenon studied, and provide guidelines on appropriate data collection methods. An initial review of existing literature helped to identify gaps in knowledge, justifying the necessity of the study and ensuring its relevance (Renjith et al. 2021:2). Moreover, this review informed the research design by offering insights into effective qualitative data collection techniques suited for exploring the topic. Specifically, the review helped the researcher identify in-depth interviews and focus group discussions as effective tools for gaining a deep understanding of participants' perspectives and lived experiences about lost-to-follow-up among Type 1 diabetes patients. The methods of data collection and analysis are presented in detail in Chapter 4.

While it is common in qualitative research to postpone a comprehensive literature review until after data collection to minimise bias, the preliminary review in this study was carefully structured to avoid influencing data interpretation while still ensuring methodological rigour. This approach enabled the researcher to collect data with an open mind, while maintaining a foundational understanding of the subject, ultimately enhancing the credibility and relevance of the findings. The literature was then further integrated into the discussion to gain a better understanding of the results and determine how other researchers conceptualise and explain similar results (Brink et al.

2022:105). Table 2.1 shows the orientation of the research progress and how the thesis unfolds.

Table 2.1: Research progress

CHAPTER	NAME OF THE CHAPTER	PURPOSE/CONTENT
Chapter 1	Overview of the Study	The chapter provides an overview of the purpose, objectives and methodology of the study.
Chapter 2	Literature Review	Literature review to discuss: • The theoretical framework • Diabetes and diabetic services • The national strategy for diabetes

2.1.2 Searching for literature on the study topic

The literature search was conducted using a keyword search, with terms such as "Diabetes," "Follow-up care," and "Lost-to-follow-up," in databases such as Google Scholar, PubMed, and the UNISA library. Relevant journals, research reports, WHO reports, and books were also consulted to suit the literature needs of the study. Beyond the main research topic, the literature review also covered the aspects related to the principles and methods of qualitative research used in previous research, mainly phenomenology. The main areas covered in the literature review include the global and local burden of diabetes, the description of diabetes follow-up care services, the policy environment and use of diabetes follow-up care service in Ethiopia, the consequences of LTFU and diabetes complications, LTFU among diabetes patients including its magnitude and associated factors, areas of emphasis to reduce LTFU, and, finally, guidelines and policies on diabetes follow-up care.

2.2 THEORETICAL FRAMEWORK OF THE STUDY

2.2.1 Description of the theoretical framework

The theoretical framework of research helps to conceptualise and guide the overall process of the research undertaking (Haugan & Eriksson 2021:35). According to the study of Varpio, Paradis, Uijtdehaage, and Young (2020:6), the theoretical framework provides the foundation of the research, unites them through logical connections, and

relates these concepts to the study that is being carried out. The theoretical framework used to conceptualise research guides the structure of the research process, including data collection methods, analysis, and presentation. Different theories are best suited to different units of practice, such as individuals, groups, and organisations (Haugan & Eriksson 2021:35). The Health Belief Model (HBM) is applicable in understanding the real-life experience of lost-to-follow-up among Type 1 diabetes patients (Hassen et al. 2023; Zhu et al. 2021).

2.2.2 The Health Belief Model as the theoretical framework of the study

The HBM, initially developed in the 1950s, aimed to explain the lack of participation in preventive health programmes (Nigusie, Azale, Yitayal & Derseh 2022:6). Since then, numerous studies have applied the HBM to understand how the beliefs of individuals impact their choices regarding adherence to medication and disease screening. Similarly, the HBM has also been used to study behaviours including compliance with self-management of other chronic diseases, such as diabetes and its medication regimens (Hassen et al. 2023:5; Zhu et al. 2021:7).

The HBM argues that people can be more motivated to behave in healthy ways if they believe they are vulnerable to a particular negative health outcome and perceive the grave consequences of the disease, as well as the individual's beliefs about the benefits and barriers to adopting healthy behaviours. It can also be substantiated by the cues to prompt action and self-efficacy (Nigusie et al. 2022).

2.2.3 The constructs of the Health Belief Model

The Health Belief Model incorporates the key components that explain how people take action to prevent or manage illness. These components encompass susceptibility, severity, benefits, and self-efficacy (Prestwich et al. 2024:33). According to (Hayden (2022:59), an individual is more inclined to follow the recommended course of action if they perceive themselves as susceptible to the disease, view the disease as

serious, recognise the benefits of the health action, perceive minimal barriers to undertaking the action, and receive a cue to initiate the action.

The illustration in Fig. 2.1 provides a summary of the main components of the Health Belief Model (HBM) and their interrelationships. At the centre, there are individual health beliefs which encompass susceptibility, severity, benefits, barriers, and self-efficacy. Modifying factors are aspects that influence health perceptions, including knowledge and sociodemographic characteristics. The modifying factors and cues to action both influence individual perceptions. The HBM constructs are described in detail below the figure.

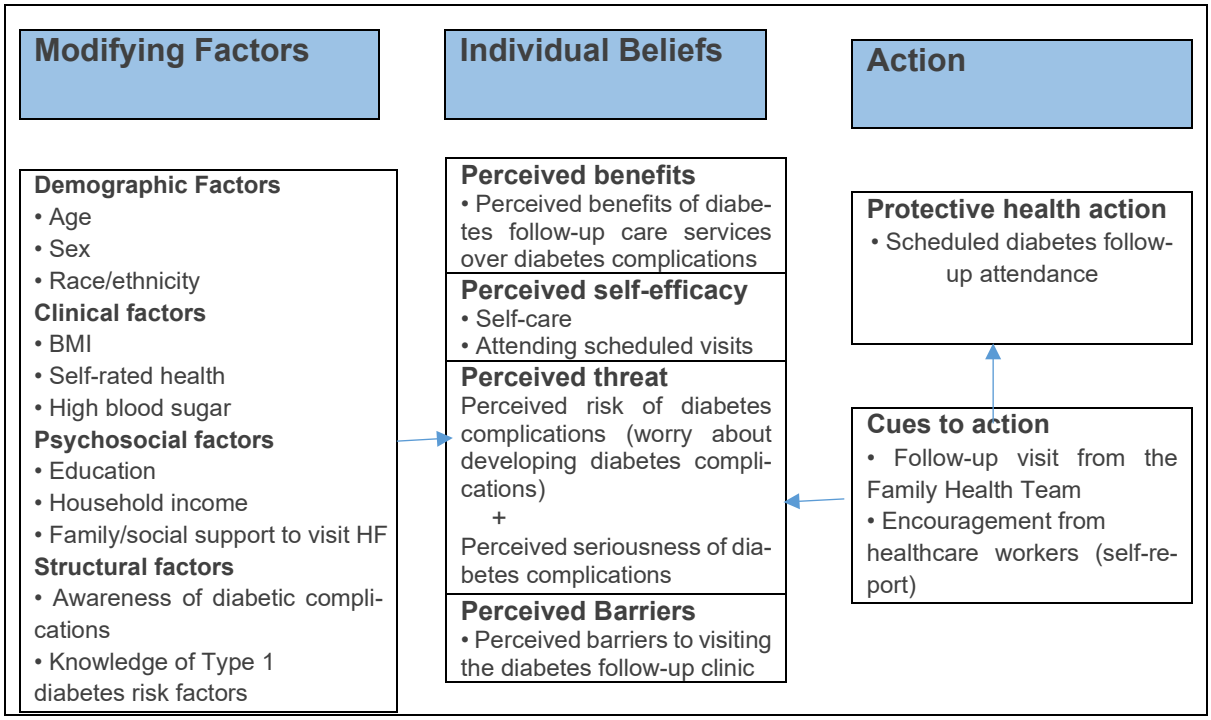


Figure 2.1:Domains of the Health Belief Model to predict diabetes LTFU: (Adapted from Joiner et al. (2022:2)

2.2.3.1 Perceived Susceptibility

Perceived susceptibility refers to the belief regarding the probability of contracting a disease or condition (Nigusie et al. 2022:6). According to Heydarabadi, Nouhjah & Mehr (2022:4), patients must believe that there is a possibility of complications with

diabetes to motivate themselves to attend the observation appointment. Furthermore, patients who observe complications in others feel threatened by these complications. Therefore, they make more frequent visits and follow the recommendations more closely. According to Esquives, Ramos and Stoutenberg (2021:6), a higher proportion of people who neglect to attend preventive health services reported being in good or very good health than those who agree that it is important to attend but do not do so. Those who participated in prevention health services consider themselves at risk of future diabetes complications and those who have accepted the disease adhere to the recommendations of healthcare workers, pay attention to treatment, and come for visits regularly (Esquives et al. 2021:6). The perception of defaulters about the possible negative outcome of not complying with the follow-up visit and consequently the likelihood of developing diabetic complications or shortening life expectancy, is relevant in the research context.

2.2.3.2 Perceived severity

Perceived severity refers to people's perceptions about the seriousness of acquiring an illness or not seeking treatment for it (Prestwich et al. 2024:34). According to Joiner et al. *(*2022:10), the perception of severity related to chronic diseases encompasses self-assessment of health outcomes (e.g., death, disability, and pain), as well as potential social consequences, for example, the impact on work, family life, and social relationships.

According to Esquives et al. (2021:7), fear of complications is one of the reasons that encourages patients to attend follow-up visits. Most patients develop fear about possible complications if they see other patients with complications, and strive to visit their doctor to prevent such complications. According to Joiner et al. (2022:6), most people do not attend preventive health services because they are not aware of their health status. Therefore, health education regarding the potential complications of diabetes should be provided to encourage patients to follow up on their visits. Patients who are aware of the progression of the disease can assess the consequences of loss to follow-up (Heydarabadi, Nouhjah & Mehr 2022:5). The perception of diabetes patients

about the seriousness of diabetes as a health problem, as well as the severity of medical complications arising from uncontrolled diabetes, is applicable in this research study.

2.2.3.3 Perceived benefits

In addition to the perception of susceptibility and severity, a person's decision to change a behaviour can be influenced by their perception of the potential benefits of the available actions to reduce the threat of the disease (Nigusie et al. 2022). According to Hayden (2022:58-90), individuals who believe that they are at risk and understand the severity of the condition do not take recommended health actions unless they also see them as beneficial in reducing the threat. Perceived benefits mean the belief in the effectiveness of the recommended measures or treatment to reduce the risk of disease.

According to Heydarabadi, Nouhjah and Mehr (2022:6), patients with better relationships with their doctors and healthcare workers can better understand and follow their advice, want to consult them on time, have compassion with them, and this has a positive impact on disease control (Joiner et al. 2022:8; Letta, Aga, Yadeta, Geda & Dessie 2021:6). Easy access to health facilities also positively increases patient visits. According to Esquives et al. (2021:5), patients who value the health services have a higher likelihood of regularly using them than those who do not. Another perceived benefit is the financial and spiritual support that a family provides. It motivates regular visits and disease control (Mulat, Mao, Bharali, Balkew & Yamey 2022:8). The benefits that diabetes patients consider when attending diabetic follow-up clinics are applicable in this study.

2.2.3.4 Perceived barriers

The potential negative aspects of a particular health action can hinder individuals from adopting recommended behaviour (Prestwich et al. 2024:34). A cost-benefit analysis

is performed, where individuals weigh the expected benefits of the action against perceived barriers such as cost, adverse side effects, inconvenience, and time. According to the HBM, the combination of perceived susceptibility and severity motivates one towards action, while the perception of benefits minus barriers determines the preferred course of action (Hayden 2022:58-90).

According to Heydarabadi, Nouhjah and Mehr (2022:6), perceived barriers are the most important factors affecting the behaviour of lost-to-follow-up from healthcare. The common barriers perceived by patients and healthcare workers include being too busy or lacking time, physical disability, lack of employment and poverty, medical costs, local traditions, low family support, transport difficulties, and adverse weather (Haugan & Eriksson 2021; Joiner et al. 2022; Letta et al. 2021:6). Guided by the HBM, this study explores the perceived barriers for patients with T1D to attend follow-up visits with the purpose to utilize the evidence to develop guidelines that will enhance follow-up adherence and improve health outcomes among individuals living with Type 1 diabetes.

2.2.3.5 Cues to action

Cues to action are factors that trigger an individual to take action or adopt a particular kind of behaviour (Joiner et al. 2022:13). A cue can be a transient environmental event or a conscious intervention such as media publicity.

According to Heydarabadi, Nouhjah and Mehr (2022:6), the readiness of a person to act can be activated by internal or external factors. External factors include exposure to health-related television programmes, educational posters, follow-up visits, and interactions with healthcare assistants. Internal factors, such as the experience of pain and fear of potential complications, also play a significant role in shaping how patients respond to medical advice and treatment. Some external events, such as the advice of healthcare workers, and some internal events, such as pain and fear of complications, affect patient behaviour in visiting follow-up clinics. According to Nigusie et al. (2022:6), high cues to action, including discussions at home and follow-up by

healthcare workers, were significantly associated with increased utilisation of institutional health services. This underscores the importance of consistent and encouraging information from healthcare workers in promoting adherence to recommended health behaviours. The current study examines potential signals that encourage or discourage patients with Type 1 diabetes from following up on care services.

2.2.3.6 Self-efficacy

Self-efficacy is the belief in one's ability to successfully perform the necessary actions to achieve desired outcomes (Hayden 2022:87). Self-efficacy was added as one of the constructs of the HBM in the late twentieth century, complementing the original constructs of perceived susceptibility, severity, benefits, and barriers (Nigusie et al. 2022). Self-efficacy in diabetes refers to a person's confidence in their ability to manage their diabetes (Prestwich et al. 2024:35). The person's goal (to stay healthy) needs to be aligned with the outcome expectations of the results (to prevent diabetes complications). This alignment synergises an increase in the self-efficacy of that person and, thus, makes them more likely to perform this healthy behaviour. Moreover, regular attendees are more confident in their ability to self-care compared to defaulters (Esquives et al. 2021:11).

According to Nigusie et al. (2022:6), patients who regularly visit the hospital for follow-up have higher self-efficacy in taking actions than defaulters. The belief of diabetic patients in their ability to attend follow-up visits influences their behaviour in making consecutive follow-up visits; thus, investigating their confidence in receiving the recommended follow-up care is crucial for understanding and improving adherence to follow-up appointments.

2.2.3.7 Other variables

Various demographic, psychosocial, and structural factors can indirectly influence individuals' perceptions and, in turn, affect their health-related behaviour (Nigusie et al.

2022:6). Demographic factors include age, sex, and race/ethnicity. Psychosocial factors involve aspects such as the level of educational attainment, annual household income, employment status, and the presence of family or social support to attend health facilities. Structural factors refer to broader health system or knowledge-related elements, such as awareness of diabetic complications and knowledge of risk factors associated with Type 1 diabetes (McEwen, Hurst, Joiner & Herman 2022:6). For instance, psychosocial factors, particularly educational attainments, are thought to influence behaviour by shaping perceptions of susceptibility, severity, benefits, and barriers. Therefore, to prevent loss to follow-up (LTFU), individuals must understand the importance of follow-up care in managing diabetes.

2.2.4 Conclusion

The Health Belief Model is widely used as a theoretical base in studies involving health-seeking behaviour, including that of the behaviour of diabetes patients (Zhu et al. 2021:4). According to Feleke, Feleke, Kassahun, Adane, Fentahun, Girma, Alebachew, Misgan, Desyibelew and Bayih (2021:9), the constructs of the Health Belief Model are relatively good predictors of self-care, including regular attendance of follow-up visits in patients with diabetes mellitus.

Therefore, the current study explores the phenomenon of LTFU among patients through the lens of the HBM. This understanding sets the basis for the development of a guideline to reduce LTFU among patients with T1D.

2.3 DIABETES AND DIABETES CARE SERVICES

2.3.1 Defining diabetes follow-up care and LTFU

Diabetes is a long-term health condition that occurs when high blood glucose levels persist because the body cannot produce enough of the hormone insulin or cannot effectively use the insulin it produces (IDF 2021:12). Diabetes mellitus, in most cases, is simply called ‘Diabetes’. Diabetes is defined by the World Health Organisation (WHO) as a metabolic disorder characterised by chronic hyperglycaemia associated

with disturbances in carbohydrate, fat and protein metabolism resulting from defects in insulin secretion, insulin action, or both (EMOH 2023:2). Type 1 diabetes is a type of diabetes caused by an autoimmune process in which the body's immune system attacks the insulin-producing beta cells of the pancreas. As a result, the body produces very little or no insulin (IDF 2021:13). In short, T1D refers to the type of diabetes caused by an autoimmune process as defined by the IDF. It is a complex metabolic disorder characterised by lifelong demands of self-care and motivation to adhere to strict treatment recommendations.

Follow-up care refers to the timely surveillance of health status and guidance on a medication regimen using various methods among patients who have visited or were visited by healthcare workers (Tino et al. 2019:2). Patients with T1D are expected to visit the diabetic care clinic for their follow-up on the list once every six months. The cohort registration for each patient with T1D was updated every six months. Patients who miss their visit once every six months are considered to be LTFU (EMOH 2020:73). Therefore, Type 1 diabetes follow-up care services include the diagnosis, treatment, and care provided to T1D patients during their follow-up visits.

Patients with diabetes are considered LTFU if they have missed their scheduled follow-up visits for six or more consecutive months from the date they last visited the same clinic to seek treatment for the same episode of illness. Transfer to other facilities or the death of a patient are not regarded as LTFU (Tino et al. 2019:2). In this study, LTFU refers to patients who started their treatment and were registered in the cohort but did not return for follow-up for at least six months.

2.3.2 Prevalence of diabetes globally and in Ethiopia

According to the IDF (2025:42), an estimated 589 million people (representing about 11% of the global adult population) were living with diabetes globally in 2024, and out of these, Type 1 diabetes accounts for about 9 % of all diabetes cases. This underscores the growing global burden of diabetes. Besides, Diabetes is a significant cause of mortality worldwide, accounting for an estimated 3.4 million deaths in 2024 and

contributing to approximately 9.3% of all global deaths among adults aged 20–79 years (IDF 2025:59). Its incidence is increasing exponentially. Liu, Ren, Qiang, Wu, Shen, Zhang, and Lyu (2020:4) reported a 102.9% increment in 25 years (1990 to 2017), with the increase being largest in Sub-Saharan Africa (203.6%).

Diabetes mellitus is one of the four major NCDs that cause high morbidity and mortality (EMOH 2023:4). The incidence of Type 1 diabetes among children and adolescents is estimated to increase in many countries. The overall annual increase is estimated to be around 3% with strong indications of geographic differences. The number of new and existing cases of Type 1 diabetes is increasing each year due to increasing incidence in many countries and reductions in mortality. In total, 1.81 million children and adolescents under 20 years are estimated to have Type 1 diabetes globally. It is estimated that around 219,000 children and adolescents under 15 years of age are diagnosed in 2024 (IDF 2025:36). This number rises to 149,500 when the age range extends to those under 20 years (Ogle, James, Dabelea, Pihoker, Svennson, Maniam, Klatman & Patterson 2022:2). This growing burden across the life course suggest the long-term demands placed on health systems for the improvement of the follow-up and care.

In Africa, the prevalence of diabetes is estimated at 5%, with projections indicating a 142% increase, reaching approximately 60 million people by 2050 (IDF 2025:74). A significant proportion of this burden is concentrated in a few populous countries, including South Africa (2.3 million), Nigeria (3.0 million), Tanzania (2.9 million), Ethiopia (2.3 million), and the Democratic Republic of the Congo (2.8 million). About 60% of all adults with diabetes in the region live in one of these five countries (IDF 2025:102). This regional trend reflects both increasing incidence and challenges in prevention and long-term management.

In Ethiopia, the prevalence of diabetes is estimated at 3.6% (IDF 2025:102). Another study conducted in Ethiopia by Gebreyes et al. (2018:7) indicates a prevalence of 9.1% for impaired fasting blood glucose (IFG, 100–125 mg/dL) according to the IDF criteria. More than half of diabetes patients in Ethiopia have poor diabetes self-care practices, and nearly two-thirds of patients have poorly controlled diabetes (Ketema

et al. 2020:8). This suggests the need for programmes focusing on improving follow-up care services.

2.3.4 Diabetes follow-up care services

Diabetes mellitus requires lifelong regular support and consultation with a healthcare professional. Through ongoing follow-up contacts with health professionals, patients with T1D can live healthily and delay or prevent many of the complications associated with diabetes (WHO 2021:7). Diabetes patients are expected to attend regular follow-up visits to the diabetic clinic at least once every three months. Furthermore, follow-up visits may be more frequent if indications are present, such as a change in dose, hypoglycaemia, recent illness or the development of microvascular or macrovascular complications (EMOH 2023:135).

2.3.4.1 The goal of diabetes follow-up care services

Although the threat of developing Type 1 diabetes cannot be eliminated, the risk of diabetes complications can be substantially reduced with regular follow-up care (Abdelmotaal, Ibrahim, Sharaf & Abdelazeem 2020:4; Olickal et al. 2023:3; Tino et al. 2019:3). With regular healthcare check-ups, education, and support, they can prevent and delay many of the complications associated with diabetes (Tino et al. 2019:3). Therefore, reducing lost-to-follow-up (LTFU) should be of great importance in improving the quality of diabetes care.

According to the Ethiopian Ministry of Health (EMOH 2023:41-56), the goals of clinical monitoring in diabetic patients include achieving glycaemic control, identifying and controlling associated risk factors, assessing medication adherence, preventing, early identification, and treatment of chronic complications. The treatment targets are HbA1C < 7 %, fasting glucose 90 to 130 mg/dl, total cholesterol <4 mmol/l or a 25% reduction, LDL cholesterol < 2 mmol/l or a 30% reduction, BP </= 130/80 mm Hg, and exercise 30 minutes of aerobic exercise on most days of the week (EMOH 2023:41).

2.3.4.2 Components of follow-up care services for Type 1 patients

- *Ongoing medical evaluation and screening for diabetes complications*

Regular monitoring and screening are essential components of follow-up care for patients with Type 1 diabetes, as they enable early detection and timely management of complications, thereby preventing disease progression and reducing morbidity and mortality (EMOH 2023:8).

The recommended follow-up care services for patients with Type 1 include monitoring of weight/BMI, BP, laboratory investigations (such as HbA1C, creatinine, fasting lipids and LFTs, urine test for proteinuria and microalbuminuria), foot assessment, microfilament testing for peripheral neuropathy and evaluation of pedal pulses, referral for retinal screening, and screening for depression. During the consecutive follow-up, healthcare workers review the treatment plan, the status of glycaemic control, lifestyle modifications, choosing drugs for the management of diabetes, the detection and treatment of complications and comorbidities, and indications for referral. Additionally, referrals to specialists can be considered for any of the following reasons: if proteinuria persists after three months, laboratory tests (lipid profile, SGOT/SGPT/ALP, Serum Creatinine (if not available), or any signs of diabetes complications (MOHE 2021b:78).

Therefore, failure to attend follow-up care (i.e., lost to follow-up) may result in missed opportunities for early detection and management of complications, ultimately leading to poorer health outcomes.

- *Patient and family education*

The other, more important component of diabetes follow-up care is patient and family education. The education topics include dietary management, nature of the disease, importance of non-pharmacologic and pharmacologic management, insulin therapy, self-care (with adequate emphasis on oral hygiene, foot and skin care, and self-monitoring of blood glucose), acute and chronic complications of diabetes, physical exercise, and psychosocial issues (EMOH 2023). An extended duration of education is

recommended for newly diagnosed patients, which can be delivered through group sessions followed by individualised sessions based on patient risk profiles and needs of the patient (Chan, Lim, Wareham, Shaw, Orchard, Zhang, Lau, Eliasson, Kong & Ezzati 2020:20-24).

- *Psychosocial care and support*

Psychosocial care is an ongoing component of diabetes management during follow-up visits. Psychosocial care and support include assessment, management and referral for acute psychosocial problems such as depression, diabetes-related distress, anxiety, eating disorders, and cognitive impairment. Additionally, healthcare workers assess patients' attitudes about the illness, expectations for healthcare and outcomes, affect/mood, and general and diabetes-related quality of life. Moreover, emotional well-being is an important part of care (EMOH 2023:64). Therefore, healthcare workers involved in providing diabetes FUC play a crucial role in establishing a lifetime of positive health-related behaviour in diabetes patients (Peeters, de Haan, Bal, van Staa & Sattoe 2022:6).

- *Patient empowerment in diabetes self-management*

Patient empowerment in diabetes self-management is another crucial role of healthcare workers engaged in diabetes follow-up care services. However, studies indicate that healthcare professionals spend more time and effort on clinical disease management than on patient consultations (Peeters et al. 2022:6). Continuing consultations enable healthcare professionals and patients to develop a shared understanding of how diabetes care is integrated with other aspects of patients' daily lives. Person-centred communication facilitates this by empowering patients to take an active role and express their needs, preferences, values, and concerns. Previous studies have confirmed that providing care from a holistic perspective, investing in building positive relationships with patients, and facilitating an active role for patients in care are conducive to positive health outcomes (Peeters et al. 2022:6).

In addition, follow-up care services also include most of the components of the initial comprehensive healthcare evaluation. These include the assessment of overall health status and screening for cardiovascular risk, hypoglycaemia risk, behavioural factors (diet, alcohol, tobacco, physical activity, substance use), medication use, and social life (EMOH 2023:2).

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2.3.4.3 Morbidity and mortality related to diabetes complications

2.3.4.3.1 What is a diabetes complication?

The health risks of glycaemic variability can be immediate and life-threatening and could lead to long-term complications (EMOH 2023:4). Chronic complications of diabetes are divided into vascular and nonvascular complications and are similar for Type

1 and Type 2 DM. The vascular complications of DM are further subdivided into microvascular (retinopathy, neuropathy, nephropathy) and macrovascular (coronary heart disease, peripheral arterial disease, cerebrovascular disease). Non-vascular complications include gastroparesis, infections, sexual dysfunction, skin changes, periodontal disease, arthropathy, uropathy, cataracts, glaucoma, and hearing loss (EMOH 2023:43).

2.3.4.4 Morbidity and mortality associated with diabetes complications

Diabetes and its complications remain the leading cause of early death globally. In 2024, an estimated 3.4 million deaths were attributed to diabetes and its related complications, accounting for 9.3% of all deaths among adults (IDF 2025:59). These figures highlight the substantial impact of diabetes on the health outcomes of the population.

Evidence from the literature further indicates that losT to follow-up care significantly increases the risk of diabetes complications. Studies have shown that patients who are lost to follow-up are more likely to experience poor glycaemic control and present later with both acute and chronic complications, including hypoglycaemia, nephropathy, retinopathy, and neuropathy (Abdelmotaal et al., 2020:6). Prolonged disengagement from care has also been associated with the progression of severe complications such as proliferative diabetic retinopathy and deterioration in visual outcomes(Kim et al. 2021:6). Similarly, findings from South Africa demonstrate a higher prevalence of chronic kidney disease among patients lost to follow-up compared to those who remain engaged in care (Pillay 2020:8).

Overall, the literature suggests that loss to follow-up is closely linked to increased morbidity and mortality among patients with diabetes, underscoring the importance of continuous care and early intervention to prevent complications.

2.3.5 Lost to follow-up among Type-1 diabetes patients

Lost to follow-up (LTFU) is commonly defined as the discontinuation of scheduled care for a specified period, typically six or more consecutive months, among patients who were previously engaged in treatment (Tino et al. 2019:2; EMOH 2023:38). While definitions may vary slightly across studies, the concept consistently reflects a breakdown in continuity of follow-up care, which has important implications for treatment outcomes and long-term disease management. In the context of diabetes care, LTFU is increasingly recognised as a critical challenge affecting patient retention and health system performance.

2.3.5.1 Prevalence of LTFU among diabetes patients

Several studies indicate that a significant number of diabetes patients are lost-to-follow-up after they started their treatment (Belay & Adugna 2022:4; Green, Tien & Ness 2020:3; Tino et al. 2019:3). The proportion of LTFUs to diabetes clinics varies in different regions and countries. The rate of LTFU among patients with diabetes is low in developed countries. For example, the rate in Malaysia is 18%, Germany 5.5% and New Zealand 6.5% (Tino et al. 2019:4). In developing countries, the proportion of LTFU among diabetes patients is very high. A dropout rate of 46% was reported in India (Olickal et al. 2023:3), 34.9% in Uganda (Tino et al. 2019:3), 31% in Kenya (Wamalwa et al. 2025:4) and South Africa (Pillay 2020:3), and 38% in Ethiopia (Belay & Adugna 2022:4).

Evidence from previous studies indicates that loss to follow-up among diabetes patients is associated with serious adverse health outcomes. Patients who disengage from care are more likely to present with acute complications such as diabetic ketoacidosis (DKA) and hyperglycaemic hyperosmolar state (HHS), as well as long-term complications including nephropathy, retinopathy, and renal failure (Sendur & Adas 2021:6). In addition, LTFU contributes to underreporting of morbidity and mortality, as many cases remain undocumented within health systems, particularly in low- and middle-income countries (Michelle, Victoria & Sing 2023:15). These findings highlight that

discontinuity of care can lead to disease progression, late presentation, and increased risk of severe complications.

Overall, the literature demonstrates that LTFU is a significant and growing concern, particularly in resource-limited settings, where health system constraints and patient-level challenges contribute to poor retention in care. These variations highlight the need for context-specific strategies to improve follow-up and continuity of care among patients with diabetes.

2.4 THE GLOBAL AND NATIONAL STRATEGIES FOR DIABETES

2.4.1 The public health importance of diabetes

Diabetes is now a worldwide epidemic that requires public health attention (Vaughan, Adjaye-Gbewonyo & Mika 2021:4). Globally, diabetes imposes a significant impact on the socio-economic and healthcare system beyond the individual medical problem. Its prevalence, economic costs, and disproportionate population burden require priority public health attention (Hill-Briggs, Adler, Berkowitz, Chin, Gary-Webb, Navas-Acien, Thornton & Haire-Joshu 2021:8). However, diabetes does not receive adequate attention despite its huge social, human and economic costs (Walker et al, 2023).

The high global burden of diabetes has a negative impact on the healthcare systems of nations. The increasing health expenditures, combined with the already escalating individual, social, and economic costs, distress the quality of life, mainly in low-income countries. According to Boshe et al. (2021:2), the global annual expenditure on the management of diabetes and its complications in 2013 was US$548 billion. In Sub-Saharan Africa, annual expenditure on diabetes was reported to be US$19.5 billion in 2015, according to a Lancet report (Atun, Davies, Gale, Bärnighausen, Beran, KIengne & Werfalli 2017:28).

Furthermore, in sub-Saharan Africa, the interactions between diabetes and key infectious diseases highlight a severe public health concern called ‘double burden of disease’ (Atun et al. 2023:2). Evidence from the literature indicates that diabetes causes

other lethal diseases, both non-communicable diseases, such as cardiovascular disease and renal disease, and communicable diseases such as pneumonia, bacteraemia, and tuberculosis. This is common in Africa region which is already known for the high rates of communicable diseases, including the highest global prevalence of HIV, Tuberculosis and Malaria (Liu et al. 2020:10). Additionally, the persistent problems of economic instability, low level of literacy, and service unreachability to healthcare facilities played a significant role in LTFU among diabetes patients in Ethiopia (Boshe et al. 2021:2). Similarly, defaulters can experience additional costs for the treatment of diabetes related complications, which has a significant economic impact on the patients, their families, and society. Therefore, the public health intervention for diabetes requires an understanding and mitigation of the impact of broader social determinants.

In general, diabetes is a preventable and controllable disease. It requires an integrated public health program and basic clinical facilities appropriate for the prevention and control of the disease in all areas of interventions at the primary, secondary and tertiary healthcare levels (EMOH 2023:5). Patient education is an important component of diabetes treatment, not merely to transfer information but also to attain behavioural change as well. For example, knowledge of the prevention and risk factors for ocular complications is essential to prevent vision loss among DM patients (Karim & Habib 2022:3).

2.4.2 Policy and health system context of diabetes follow-up care in Ethiopia

2.4.2.1 The healthcare system of Ethiopia

Ethiopia's healthcare system is structured into a three-tier system, comprising primary, secondary, and tertiary levels of care. The primary level of care encompasses services provided in 353 primary hospitals, 3,735 health centres, 17,550 health posts, and a community outreach programme. The PHC unit comprises five satellite health posts (the lowest level of facility in the health system, located at the village level) and a referral health centre. Ethiopia's Health Extension Programme (HEP), operated under

the PHC system, is based at health posts and involves 39,878 health extension workers (HEWs). The secondary level of care consists of general hospitals that serve 1 to 1.5 million people. The tertiary level of healthcare, specialised hospitals, serves 3.5 to 5.0 million people (MOHE 2021a:10).

Ethiopia is implementing the five-year Health Sector Transformation Plan (HSTP II) from 2020/21 to 2024/25. The plan aims to improve the health of the population by accelerating progress towards Universal Health Coverage (UHC), protecting people from emergencies, creating Woreda transformation and making the health system responsive to people's needs and expectations. The HSTP II includes 14 key strategic directions that define the main strategic areas and initiatives of the strategic period. From the 14 strategic directions, the Ministry of Health in Ethiopia has identified five priority areas that are the top-priority issues for the sector. These include the quality and equity of health services, the information revolution, a motivated, competent, and compassionate health workforce, health financing, and leadership.

2.4.2.2 The national strategy for diabetes care in Ethiopia

According to the Ministry of Health, Ethiopia (2021a:20), the country is currently facing the double burden of diseases (communicable and non-communicable diseases) that affect all age groups. In Ethiopia, the share of NCDs has increased from 17% to 35% in the past two decades. As NCDs are becoming public health concerns, the MOHE has developed a strategic plan for the prevention and control of NCDs mainly through the integration of these services into the primary healthcare system (MOHE 2021a:4). However, the 2018 Service Readiness and Availability (SARA) survey reported that only 36%, 49%, 53% and 9% of health facilities, excluding health posts, offered diagnosis and treatment for diabetes, cardiovascular diseases, chronic respiratory diseases, and cervical cancer, respectively (Defar, Zeleke, Berhanu, Lemango, Bekele, Alemu & Biadgilign 2024:9).

In line with the International Diabetes Federation (IDF) guidelines, the Ministry of Health, Ethiopia, has provided a protocol for the management of diabetes care that

includes a set of minimum follow-up care services. The guideline provides recommendations for the minimal, basic and comprehensive standards of care which programmes should strive for when developing responsive and effective diabetes follow-up care services. These domains include care delivery, education, psychological care, lifestyle management counselling, clinical monitoring, glucose control with oral therapy, glucose control with insulin therapy, blood pressure control, cardiovascular risk protection, eye screening, kidney damage, foot care, nerve damage, pregnancy, children and in-patient care (EMOH 2023:135).

2.4.3 Policy and practices to reduce LTFU diabetes patients

Several guidelines are produced at international, regional, and local levels to guide the implementation of diabetes follow-up care services. The World Health Organisation (2014:3) distinguishes between two main types of guidelines based on their intended purpose: standard guidelines and full guidelines. Standard guidelines are typically produced in response to a change in practice or controversy in a single clinical or policy area, such as a protocol for diabetes follow-up care services. However, a full guideline provides complete coverage of a health topic or disease, such as diabetes, and is expected to include recommendations for all aspects of the topic, including screening, diagnosis, public health, and clinical interventions) and to be fully based on systematic reviews of the evidence (WHO 2014:3).

2.4.3.1 Standards of healthcare in diabetes

The 24-page guideline, published by the American Diabetes Association (ADA) in 2023, serves as a quick reference for primary care providers. The ADA standards of medical care for diabetes are updated and published annually to supplement the primary care providers. Standards include the most current evidence-based recommendations for diagnosing and treating adults and children with all forms of diabetes. The guideline provides the recommended actions during ongoing follow-up visits. These

include emotional well-being, tolerability checks, glycemic status monitoring, and medical check-ups, including SMBG, weight, HbA1C, blood pressure, and lipids (American Diabetes Association 2023:5).

2.4.3.2 The National Non-Communicable Disease Management Protocols of Ethiopia

This guideline is considered to be the first standard NCD management protocol published by the Ministry of Health, Ethiopia, in November 2021. The 124-page pocket-sized guide includes quick references for five major NCDs: Diabetes, Hypertension, CVD Risk Assessment, Rheumatic Heart Disease, and Chronic Respiratory Disease. The guideline dedicates 21 pages to diabetes (MOHE 2021:68-89).

2.4.3.3 National Strategic Plan for the Prevention and Control of Major NCDs in Ethiopia

The 5-year strategic plan for the Prevention and Control of Major Non-Communicable Diseases was published by the Ministry of Health of Ethiopia in July 2022. It outlines the strategy for the prevention and control of cardiovascular diseases, diabetes mellitus, chronic kidney disease, and chronic respiratory diseases. The strategy emphasises the delivery of essential promotive, preventive, curative, and rehabilitative health services within the integrated framework of the country's three-tiered healthcare system. It further focuses on cascading the integration of NCD services within the primary healthcare level, including health posts. The document highlights five priority areas for the prevention and control of major NCDs, aimed at strengthening national response and service integration across all levels of care (MOHE 2021a:10).2.4.3.4 National guideline for the detection and comprehensive management of diabetes in Ethiopia

The guideline was published by the Ministry of Health in Ethiopia in June 2023. The 180-page guide was also used as the standard training manual to train nurses, health officers and medical doctors on diabetes care in the country (EMOH 2023:1-180).

2.4.4 Interventions at the global and local level to reduce LTFU

In Section 2.2.3, the major factors affecting LTFU were discussed. These include the lack of trust in treatment, the unaffordability of treatment, lack of social support, and institutional and administrative barriers. Therefore, addressing the factors related to LTFU can improve the quality of diabetes care (Abdelmotaal et al. 2020:6). In the context of the various challenges posed by public health, health authorities should prioritise their health programmes towards averting the considerable morbidity and mortality (Vaughan et al. 2021:6).

According to Kim et al. (2021:6), patients who understand the importance of follow-up visits, even when there are no diabetes complications, have a lower probability of LTFU. Furthermore, Letta et al. (2021:8) stress the importance of focused patient education beyond the procedural consent form and its importance to broaden patient awareness of the condition and how it is managed. According to Heydarabadi, Nouhjah and Mehr (2022:15), diabetes patients are individuals with diverse personalities and need information tailored to their specific needs.

Policies and services that improve healthcare quality and accessibility (for example, improving the communication skills of the healthcare workers) can also improve patient trust (World Bank 2020:2). Moreover, Esquives et al. (2021:12) argue that patients who value the services have a higher likelihood of using them than those who see less value in the services.

2.4.5 Availability and quality of diabetes follow-up care service in Ethiopia

According to the nationwide SARA survey report, the services for diagnosing and managing diabetes in Ethiopia were found to be inadequate. Fifty-nine per cent of health facilities offer services for diabetes; of these, 40% have diagnostic capacity for blood glucose testing, while 56% have capacity for urine protein testing, and 52% have capacity for urine glucose testing. Almost all hospitals in Ethiopia offer diabetes care services (Defar et al. 2024:9). Furthermore, the availability of basic medicines required

for the treatment of diabetes in Ethiopia is very low; only 11% of them had Metformin, 28% had Glibenclamide, and 9% of them had injectable insulin, and only 15% of them had injectable glucose solution. However, hospitals were more likely to have the drugs for diabetes treatment than other health centres and clinics, ranging from 90% in referral hospitals to 4% in private for-profit facilities. Among all facilities that offer diabetic services, only 6% of the HWs received in-service diabetes training (Defar et al. 2024:9).

According to a qualitative study by Karim and Habib (2022:6), the structure of the health system is a key contributor to loss-to-follow-up (LTFU). The system is primarily focused on curative medicine. This focus prevents doctors from addressing the root causes of patients' problems and limits their ability to provide adequate health education. According to Chan et al. (2020:20-24), the efficiency of diabetes follow-up care delivery can be improved by reorganising care with non-physician personnel. This can address the psychosocial and informational needs of patients, improving self-care and treatment adherence, especially in individuals who have not yet developed complications and may have low motivation to change their habits.

2.5 THE PRINCIPLES AND PROCESSES OF GUIDELINE DEVELOPMENT AND VALIDATION

Health program guidelines serve as structured frameworks to enhance the quality, consistency, and effectiveness of healthcare services. Their development necessitates a systematic approach that integrates the best available evidence, stakeholder expertise, and contextual considerations to ensure applicability across diverse healthcare settings.

2.5.1 Methodological approaches of guideline development

The development of health program guidelines often employs both deductive and inductive methodologies to ensure comprehensiveness and relevance. The deductive approach involves a systematic review of existing literature and guidelines to establish

a theoretical foundation. For instance, in developing the International Guideline Evaluation Screening Tool (IGEST), researchers conducted a deductive review of existing appraisal tools and standards to define its scope and items (D'angelo, Coclite, Napoletano, Gianola, Castellini, Latina, Lacorossi, Fauci & Iannone 2022:2). Following the deductive phase, inductive methods such as focus groups and interviews can be utilised to refine the guideline based on empirical data. Combining these approaches allows for a robust guideline development process that is both evidence-based and context-sensitive.

2.5.2 Core principles in health program guideline development

Developing high-quality health program guidelines involves adherence to several core principles. These include:

- **Outcome-focused development**: Guidelines should be designed with clear objectives aimed at improving specific health outcomes. This involves identifying measurable goals and establishing indicators to assess the effectiveness of the implemented recommendations (WHO 2024:6).
- **Evidence-based recommendations**: Recommendations within the guidelines must be grounded in the best available evidence. This includes conducting systematic reviews and appraising the quality of evidence to ensure that the guidelines reflect current knowledge and best practices (Carmona, Baxter & Carroll 2022:3).
- **Multidisciplinary collaboration**: The development process should involve a diverse group of stakeholders, including healthcare professionals, researchers, policymakers, and patient representatives. Such collaboration ensures that the guidelines are comprehensive and consider various perspectives (Florez et al. 2020:5).
- **Transparency and clarity**: The processes and methodologies used in guideline development should be transparent. Clear documentation of decision-making processes, evidence appraisal, and consensus methods enhances the credibility and trustworthiness of the guidelines (Hatakeyama, Seto, Onishi, Hirata, Matsumoto, Wu & Hasegawa 2023:2).
- **Applicability and flexibility**: Guidelines should be adaptable to different contexts and resource settings. They must consider local healthcare infrastructures, cultural factors, and resource availability to ensure the practical implementation (Carmona, Baxter & Carroll 2022:6).

- **Regular updates and revisions**: To maintain relevance, guidelines should include mechanisms for periodic review and updates in response to new evidence or changes in healthcare practices (WHO 2024:4).
- **Stakeholder engagement**: Engaging stakeholders throughout the development process ensures that the guidelines address the needs and preferences of those affected. This includes soliciting feedback during draft stages and incorporating public consultations (Hatakeyama et al. 2023:6).
- **Consideration of resource implications**: Guidelines should assess the economic impact of recommendations, considering cost-effectiveness and resource allocation to facilitate feasible implementation (Florez et al. 2020:3).

2.5.3 Validation and appraisal of guidelines

Ensuring the validity and reliability of guidelines is crucial. Tools like the AGREE II instrument assess various domains, including scope, stakeholder involvement, rigour, clarity, applicability, and editorial independence (Florez et al. 2020:3). Moreover, the IGEST tool can also serve as a screening instrument to evaluate the trustworthiness of guidelines, focusing on aspects such as development processes and potential biases (D'angelo et al. 2022:3).

2.6 CONCLUSION

Diabetes causes serious health problems, permanent disability, considerable suffering and untimely deaths. It increases the risk of early death and diabetes-related complications, which lowers the quality of life. It can lead to heart disease, stroke, kidney failure, blindness, lower-limb amputation, dementia, hearing loss, and some forms of cancer. Therefore, the goal of diabetes follow-up care is to minimise complications and maximise quality of life.

In Ethiopia, efforts to improve access to diabetes services are improving. At the national level, the mean availability of diabetes supplies is improving from 37% in 2014 to 48% in 2018 (Defar et al. 2024:10). However, the utilization of follow-up care services among Type 1 diabetes patients did not show the anticipated improvement with a dropout rate of 38% (EMOH 2022:22). Thus, lost-to-follow-up among patients with T1D remains a critical challenge affecting the quality of diabetes care services in public

hospitals in Ethiopia. Several studies indicate that patients who frequently LTFU are more likely to lack control over risk factors, develop complications, enter emergency departments, or be hospitalised than patients receiving ongoing care (Abdelmotaal et al. 2020:6; Belay & Adugna 2022:4; Green, Tien & Ness 2020:3; Tino et al. 2019:3). Thus, reducing LTFU is one of the most important determinants of the quality of diabetes care (Chan et al. 2020:20).

With the double burden of disease and limited resources, diabetes must compete for political attention and financial investment. It requires greater consideration of the clinical outcomes following diabetes, such as chronic complications, infections and mortality, as well as economic costs (Vaughan et al. 2021:6).

3. CHAPTER THREE: RESEARCH APPROACH, DESIGN AND METHOD

3.1 INTRODUCTION

Chapter three presents the research methods and design utilised in this study, which aimed to explore the experiences of patients with Type 1 diabetes and healthcare workers regarding lost-to-follow-up care. The study was conducted in four phases: Phase 1 and Phase 2 focus on data gathering, analysis, and presentation of the empirical findings from the data collected from patients and healthcare workers, while Phase 3 focuses on the development of the guidelines based on these empirical findings, and Phase 4 focuses on the validation of the guidelines through a structured consensus development meeting.

The study employs a qualitative research approach, specifically a phenomenological design, which enables an in-depth understanding of the participants' lived experiences. The data were collected through semi-structured interviews with purposively selected participants, including T1D patients who had missed follow-up visits, and healthcare workers involved in diabetes care. The data analysis was conducted using inductive thematic analysis using Atlas.ti (version 24) computer software. The research progress is illustrated in Table 3.1

Table 3.1: Research progress

CHAPTER	NAME OF THE CHAPTER	PURPOSE/CONTENT
Chapter 1	Overview of the study	The chapter provides an overview of the purpose, objectives and methodology of the study.
Chapter 2	Literature review	Literature review to discuss: • Theoretical framework • Diabetes and diabetic services • The national strategy for diabetes
Chapter 3	Methodology	Research methodology: Phases 1-4

3.2 RESEARCH APPROACH

This study adopted a qualitative research approach to gain in-depth insights into participants' experiences related to lost-to-follow-up among Type 1 diabetes patients. According to Lim (2025:2), qualitative research is a methodological approach that seeks to understand human experiences, behaviours, and social contexts through the collection and analysis of non-numerical data, particularly narratives, interviews, and observations. Unlike quantitative research, which relies on statistical analysis, qualitative research values the depth, richness, and complexity of narrative data to reveal how individuals make sense of their lived realities (Brink et al. 2022:103). According to Liamputtong (2022:220-232), qualitative research generates insights independent of any quantification techniques or formats. It is possible to comprehend the specific experiences of people and their interactions with individuals and institutions through qualitative research (Fushimi 2021:9).

According to Holloway and Galvin (2023:123), narrative data in qualitative research offer unique insights into meaning-making processes, cultural influences, and emotional dimensions that cannot be captured through numerical data alone, making them especially valuable in fields such as health, education, and the social sciences. Similarly, Brink et al. (2022:103) emphasise that qualitative research involves the systematic collection, organisation, and interpretation of textual material derived from talk or observation, aiming to explore the meanings of social phenomena as experienced by individuals in their natural contexts. Furthermore, qualitative research, as described by Liamputtong (2022:220-232), allows researchers to understand how people make meaning of their lives and their place in the world through the stories they tell.

3.2.1 Relevance of qualitative research in Health Studies

Qualitative research methods are increasingly popular in health and medical research. By using a qualitative approach, researchers in healthcare addressed various questions that are difficult to answer using quantitative approaches (Holloway & Galvin 2023:123). Unlike quantitative research, which is deductive and tends to analyse phenomena in terms of trends and frequencies, qualitative research seeks to determine

the meaning of a phenomenon through description. Furthermore, using a qualitative research approach that focuses on the meanings, experiences, and perspectives of the participants, one can better comprehend the phenomenon being examined within the context of the environment in which it has been studied (Paley 2024:159).

Qualitative research is more relevant to healthcare because it helps to understand the perspectives of healthcare workers, patients, and their families. To improve the quality of health service delivery, it is important to understand the experiences of both healthcare workers and patients. Different scholars have studied and presented the perceptions of patients and healthcare workers about health behaviour and health services using the qualitative research method (Bogale et al. 2022; Zhu et al. 2021:4). Furthermore, Peters and his colleagues (2022:5) used a qualitative research method to explore barriers to behavioural change by observing the interaction between patients and healthcare workers. According to Heydarabadi, Nouhjah and Mehr (2022:5), qualitative methods are also valuable in helping health educators understand health problems and their behavioural and environmental causes and contributors through the lived experiences of people, particularly in chronic conditions such as diabetes

3.2.2 Appropriateness of qualitative methods for exploring LTFU in T1D patients

Qualitative research offers a distinct advantage for this study by enabling exploration of the complex and under-researched issue of lost-to-follow-up among Type 1 diabetes patients in Ethiopia, a context in which most previous studies have relied on quantitative methods (Belay & Adugna 2022:4; Tino et al. 2019:3). This approach allows for a rich understanding of the lived experiences and perspectives of both patients and healthcare workers, uncovering personal, relational, and systemic factors that contribute to LTFU- insights that often remain invisible in numerical data alone (Lim 2025:2). Unlike closed-ended surveys or statistical analyses, qualitative methods facilitate direct engagement with participants, capturing the subjective meanings individuals attach to their experiences.

Busetto, Wick, and Gumbinger (2020:4) state that qualitative methods are particularly

effective in producing contextually grounded insights essential for developing meaningful and responsive healthcare services. Furthermore, the participatory nature of qualitative research fosters the co-creation of practical, patient-centred guidelines, improving their cultural relevance and acceptability (WHO 2024:4). This is especially critical in low-resource settings, where recent evidence supports the value of qualitative inquiry in understanding health service utilisation and guiding implementation strategies (Carmona, Baxter & Carroll 2022:3).

From the literature search, it was determined that there is a scarcity of published studies investigating the experience of LTFU among patients with T1D. To date, studies related to LTFU among Type 1 diabetes patients in Ethiopia have been predominantly quantitative (Belay & Adugna 2022:4; Tino et al. 2019:3). Their findings are primarily based on statistical correlations drawn from self-reported responses to closed-ended questions. Therefore, this study explored the lived experiences of lost-to-follow-up patients and healthcare workers using a qualitative research method.

3.3 RESEARCH DESIGN

3.3.1 Phenomenological study design

Interpretative phenomenology involves using rich, thick descriptions to explain the phenomenon being studied, thereby answering the research questions (Frechette et al. 2020:4). This study employed an interpretative phenomenological research design. The Interpretative Phenomenological method allows participants to articulate their experiences in their own words while giving the researcher the ability to interpret the meanings behind those experiences. In the context of this study, it provides the necessary depth to examine how both patients and healthcare workers perceive and experience the issue of lost-to-follow-up (Larsen & Adu 2021:123). Such a detailed understanding is vital for informing context-specific interventions (Renjith, Yeso-dharan, Noronha, Ladd & George 2021:6).

Phenomenology was first introduced by the German philosopher Edmund Husserl and later developed by his student, Martin Heidegger. The Husserian-derived approach,

also called descriptive phenomenology, states that the researcher's presuppositions should be bracketed so that the researcher imaginatively explores the 'pure' description of the phenomenon's essential features (Hajar 2021:1). However, Heidegger, the student of Husserl, later derived an interpretive approach in which the researcher's perspectives, experiences, and interpretations of the data are interwoven, allowing the researcher to provide an 'interpretation' rather than just a description of the phenomena (Starr & Smith 2021:8). In the interpretative phenomenological approach, the self and relational dialogues are considered crucial for the understanding of the phenomena being explored. The interpretative phenomenological approach involves using rich and thick descriptions to explain the phenomenon being studied (Larsen & Adu 2021:123).

Therefore, the interpretative phenomenological study design was chosen in this study because it aligns well with the objective of the study, to gain an in-depth understanding of the lived experiences of both patients and healthcare workers regarding lost-to-follow-up among individuals with Type 1 diabetes. This approach enabled the researcher to explore the perceptions and meanings participants attach to diabetes follow-up care. As noted by Larsen and Adu (2021:215), phenomenological designs are particularly suitable for investigating how patients and healthcare workers perceive their roles and abilities in managing health-related challenges. Furthermore, other literature supports the value of this design in health research, where rich, contextual insights are critical for informing practical and policy-level decisions (Larsen & Adu 2021:125).

In this study, the empirical findings captured through this methodology informed the development of contextually grounded guidelines aimed at improving the quality and utilisation of diabetes follow-up care services.

3.4 STUDY SETTING

This research was conducted in the Oromia region of Ethiopia. The Oromia region is the most populous in Ethiopia, accounting for 37.4% of the country's total population.

The population of the Oromia region was 44.2 million in 2022, according to projections based on the 2007 Ethiopian census. There are 22 administrative zones, 320 administrative districts, and 14 town administrations in the region. The region has 107 public hospitals, 1,421 health centres, and 7,090 health posts serving the health needs of the population (OrRHB 2023:1).

Hospital A is a referral hospital for the Southwest Shoa area of the Oromia region, with a catchment area of approximately 1.2 million people, located 120 km from Addis Ababa, the capital of Ethiopia. The hospital has a 200-bed capacity and offers outpatient clinics with specialist services, including follow-up care for patients with diabetes. According to the DHIS2 report, in 2022, the hospital had 4,807 new patients and 14,671 repeat patients. The hospital had 526 diabetes patients registered in the cohort, of which 99 are T1D patients. LTFU is also high at this hospital, with a 19% dropout rate reported in 2022/23.

Hospital B is a district public hospital located in Becho District, Oromia Region, serving a population of 113,264. The hospital is located 86 km southwest of Addis Ababa. It has 35 beds. According to the DHIS2 report, in 2022, the hospital had 2573 new patients and 6940 repeat patients. The hospital had 737 diabetes patients registered in the cohort, of whom 69 had T1D. Like other hospitals in Ethiopia, the LTFU rate is high at this hospital, with a reported dropout rate of 24% in the first semester of 2022/23.

3.4.1 Selection of the study setting

The Oromia region was specifically selected because its DM patient load is higher, accounting for 40% of all new DM patients in the country in 2021/22. According to the MOHE (2022:22) annual report, almost 40% (46,800 of 123,050) of the new diabetes patients in Ethiopia are found in the Oromia region. The proportion of individuals with elevated blood sugar among those screened in 2021/22 in the Oromia region was 14% (72875 out of 5,360,44), which is significantly higher than the national average of 9% (EMOH 2022:8).

Two hospitals in the Oromia region have been selected from the total of 107 public

hospitals in the region that offer diabetes follow-up care services. Two important parameters are considered for selecting these two sites. The first consideration is to include urban and rural contexts, which also represent the two levels of hospitals (Rural/District hospital and Urban/Specialised hospital). The other consideration is the high proportion of patients with T1D. Consequently, Hospital-A in Woliso town is a zonal hospital with a proportion of patients with T1D of 19% (99/526), which is higher than the national average (10%). Hospital-B is a district-level hospital located in Becho Woreda, with a proportion of patients with DM1 at 9% (69/737), which is among the highest in rural settings in Ethiopia.

3.5 STUDY PHASES AND METHODOLOGICAL APPROACH

The research design was structured into four phases to explore the phenomenon of lost to follow-up among Type 1 diabetes patients and, ultimately, to develop and validate a relevant guideline. The phased qualitative research design is commonly used in health research. Bonell, Warren, and Melendez-Torres (2022) highlight how phased qualitative designs help structure complex studies, enabling the development of interventions grounded in participants' experiences. Similarly, Wang and Hu (2025) used a multi-phase qualitative approach to co-create culturally relevant health messages. The structure of the study is methodologically sound and consistent with contemporary qualitative research practices. It progresses from the exploration of empirical findings using qualitative methods (Phases 1 and 2) to the development and validation of guidelines (Phases 3 and 4).

In all four phases, the study used different populations and methods to address its specific objectives. Phases 1 and 2 explored patients' and healthcare workers' perspectives on lost-to-follow-up, while Phases 3 and 4 focused on developing and validating guidelines (see Table 3.5). Although data gathering, analysis, and presentation in Phase 1 and Phase 2 were conducted simultaneously, each phase aligned with a specific research objective and engaged distinct participant groups and data collection approaches.

Table 3.2: Summary of the study methods in the 4 phases

PHASE	FOCUS	OBJECTIVES	PARTICIPANTS	DATA GATHERING	DATA ANALYSIS	COMMENT
Phase 1	Data gathering, analysis and presentation of the empirical findings from patients	Explore experiences of T1D patients lost to follow-up	9 T1D patients	Semi-structured interviews	Inductive thematic analysis	Phase 1 and 2 focus on gathering qualitative data through semi-structured interviews with T1D patients and healthcare workers. The interviews were semi-structured and analysed using inductive thematic analysis.
Phase 2	Data gathering, analysis and presentation of the empirical findings from HWs	Examine healthcare workers' perspectives on LTFU	7 healthcare workers	Semi-structured interviews	Inductive thematic analysis	
Phase 3	Guideline development	Develop guidelines based on the literature review and the empirical findings in Phases 1 &2	6 experts in diabetes care	Focused discussion	Content refinement based on expert feedback	In Phase 3, guidelines were developed based on the findings from the first two phases, followed by a focused discussion to refine the guidelines.
Phase 4	Guideline validation	Validate guidelines through expert consensus	10 experts in guideline/ curriculum development	Structured Consensus Development Meeting t	Content Validity Index (CVI) assesses	Phase 4 involves validating the guidelines through expert structured consensus development meetings and feedback using CVI to ensure consensus among experts.

3.5.1 Phase One

In this study, Phase 1 focuses on understanding the lived experiences of T1D patients who were lost to follow-up. Phase 1 addressed the first research objective by exploring patient perspectives through semi-structured interviews.

3.5.1.1 Study population

The study population in Phase 1 comprised patients with Type 1 diabetes receiving follow-up care at two public hospitals in Ethiopia. At the time of data collection, a total of 169 T1D patients were registered in the two facilities, with 99 patients in Hospital A

and 70 patients in Hospital B. These patients formed the primary population for exploring the patterns and challenges related to follow-up care. The focus was particularly on identifying those who had missed their appointments to understand the experiences related to being lost to follow-up.

3.5.1.2 Selection of study participants

In qualitative research, sampling serves a specific purpose. The sampling procedures and sizes are intended to reflect the diversity of the population under study rather than to serve as a statistical representation (Busetto, Wick & Gumbinger 2020:6). Accordingly, this study employed purposive sampling, a nonprobability technique commonly used in qualitative research, where participants are selected based on specific characteristics relevant to the research questions (Hennink, Hutter & Bailey 2020:92).

In the current study, the researcher selected LTFU T1D patients through purposive sampling. To identify potential participants, the researcher reviewed patient records from the two hospitals after obtaining the necessary permissions. Seventeen T1D patients (11 from Hospital A and six from Hospital B) were identified as having missed follow-up appointments in the past six months. Contact information was available and verified for 14 patients, from whom nine were interviewed using semi-structured interviews, based on participants' availability and willingness to participate. Patients with Type 2 diabetes (T2D), gestational diabetes, those who had transferred to another facility, or had recorded deaths were excluded. All eligible participants were over 18 years of age and contacted by the gatekeeper via their registered phone numbers.

In Phase 1, the researcher conducted interviews with 9 T1D patients. This sample size aligns with recommendations for qualitative phenomenological studies, which often include around 10 participants (Frechette et al. 2020:4). It is also consistent with similar studies using the Health Belief Model (Heydarabadi, Nouhjah & Mehr 2022). Interviews continued until data saturation was reached, at which point no new themes or insights emerged; two additional interviews were then conducted to confirm saturation. The researcher ensured both sufficient depth and breadth of information, meeting the

accepted standard of rigour for qualitative data collection (Busetto, Wick & Gumbinger 2020:6).

3.5.1.3 Data Gathering Instrument

In Phase 1, qualitative data were collected using semi-structured interviews (SSIs). SSI is a widely used method in healthcare research to understand the lived experiences of patients and service providers (Holloway & Galvin 2023:105). Using SSI combines predetermined questions with the flexibility to explore emerging topics during conversation (Adeoye-Olatunde & Olenik 2021). This method allows the interviewer to engage in a guided dialogue supported by follow-up questions and probes. Unlike rigid survey formats, SSIs use a flexible question sequence and phrasing, allowing for deeper exploration of participants' beliefs, feelings, and behaviours.

The interviews were guided by a semi-structured interview tool comprising 13 open-ended questions aligned with the constructs of the Health Belief Model (HBM), including perceived susceptibility, severity, benefits, and barriers. Additional questions were asked spontaneously as they emerged during the interviews to encourage participants to elaborate on their experiences. The first question addressed the overall research inquiry, followed by five to seven probing questions exploring different aspects of the topic in more detail. The interview guide was translated into commonly spoken languages in the study area (Amharic and Afan Oromo) by certified translators to ensure clarity and cultural relevance. The final version of the interview guide is included in Annexure P.

3.5.1.4 Data gathering

The interviews were conducted in July 2024, following ethical clearance from the Ethics Committee of the College of Human Sciences (UNISA) and permission from the Oromia Regional Health Bureau and the participating hospitals (see Annexures A and B). Data collection was carried out by the principal researcher with the support of a trained assistant data collector. The assistant, a qualified nurse with over one year of

experience in diabetic care and fluent in both Amharic and Afan Oromo, received training (comprising one day of in-person training and two days of online training) and signed a confidentiality agreement (Annexure O). Interviews were conducted face-to-face by the researcher in the participants' villages, with six interviews in Amharic and three in Afan Oromo, depending on participants' preference. The trained assistant was responsible for translating questions and answers to ensure accurate interpretation during analysis. Each interview lasted between 20 and 40 minutes and was facilitated interactively, incorporating free listings to clarify local terms. Participants were interviewed in a private setting by the researcher. The local health extension worker supported the process only by linking the researcher with eligible participants and arranging initial contact. They were not present during the interviews and had no role in data collection. With consent (see Annexure L), all interviews were audio-recorded and later transcribed verbatim. Field notes were also taken to capture non-verbal cues and contextual impressions.

3.5.1.5 Trustworthiness

To ensure the trustworthiness of the study, the researcher adhered to established qualitative research principles encompassing credibility, dependability, transferability, and confirmability. Credibility was achieved through purposive sampling, prolonged engagement with participants.A study by Daniel, Asil, and Carr (2024:2) states that credibility in qualitative research is strengthened when researchers use multiple data sources and remain immersed in the field for an extended period to build trust and gain meaningful insights. Dependability was supported by the systematic documentation of procedures and collaborative coding with a co-coder to verify the consistency of themes, aligning with Johnson's (2020:8) assertion that detailed methodological records and peer examination help ensure stable and dependable findings. Transferability was enhanced by providing a detailed account of the study context, participant characteristics, and data collection processes. This allows others to determine the applicability of the findings to similar contexts (Amin, Nørgaard, Cavaco, Witry, Hillman, Cernasev & Desselle 2020:6). Confirmability was ensured through reflexive journaling,

audio recordings, verbatim transcription, and grounding the results in participants' actual words and reducing researcher bias. Johnson (2020:5) emphasises that linking interpretations directly to data fosters objectivity and transparency. Additionally, the use of Atlas.ti software supported a rigorous thematic analysis and contributed to the auditability of the research process (Johnson 2020:7).

3.5.1.6 Data analysis

This study employed inductive thematic analysis using Atlas.ti (Version 25) computer software. Inductive thematic analysis entails searching for and discovering commonalities in data, as well as interpreting such commonalities and participants' experiences in order to provide a refined understanding of data gathered from participants (Braun & Clarke 2021:8).

The process of data analysis began concurrently with data collection (Frechette et al. 2020:10). The audio recordings of each interview were transcribed verbatim. Then, the Amharic and Afan Oromo language transcripts of each interview were translated into English by a language translator. The translated English version was reviewed by the researcher and cross-checked by the assistant data collector. Then, the researcher uploaded the transcript to Atlas.ti computer software. By coding and categorising consecutive interviews, the co-coders and the researcher compared existing codes and new categories and checked for fit with existing categories. Similarities and differences were discussed with the researcher and the co-coders throughout the process (Klooster, Koenders, Vermeulen-Holsen, Vos, Van der Wees & Hoogeboom 2022:3). Theoretical saturation was reached when categories became dense, and no new open codes were generated from the data (Holloway & Galvin 2023:155).

Transcripts were coded line by line using in vivo coding (open coding). Then, the open codes were grouped into categories (axial coding). Preliminary themes were constructed (through selective coding) concurrently with the open and axial coding of the transcripts. The selective codes were discussed between the co-coder and researcher until a consensus was reached on the key themes. Finally, the researcher and the co-

coder met to reach consensus on key themes (Klooster et al. 2022:4).

The data analysis resulted in the extraction of 95 initial codes, which were categorised into 13 categories based on the Health Belief Model. The main categories include patient knowledge and awareness, perceived barriers to follow-up care, satisfaction of patients with the services, patients perception of effectiveness and quality of follow-up care, perceived ability of patients to do the follow-up care, perception of HWs on the effectiveness and quality of follow-up care, perceptions of HWs on patients' compliance, challenges in service delivery, challenges to maintain patient engagement, and triggers and support system to follow-up care. The constructs of the HBM (perceived susceptibility, perceived severity, perceived barriers, and perceived benefits) were used as a guide to extract the themes and sub-themes. The results derived from the thematic analysis are presented in tables and texts reflecting the study participants' experience of LTFU. The data obtained from Phase 1 (patients' interviews) were triangulated with the data obtained in Phase 2 (healthcare workers' interviews).

The results derived from the thematic analysis were presented in tables and texts reflecting the study participants' opinions on LTFU, and further elaborated on the identified themes against the constructs of the Health Belief Model in Chapter 4 (see 4.4).

3.5.2 Phase Two

Phase 2 focuses on exploring the experiences and perspectives of healthcare workers regarding LTFU among T1D patients, corresponding to the second research objective. Healthcare professionals with experience in diabetes care were interviewed. This phase was conducted concurrently with Phase 1, and the combination of patients' and healthcare workers' insights offered a more holistic understanding of the phenomenon of LTFU. Themes were analysed inductively and supported the foundation for later phases of guideline development.

3.5.2.1 Study population

The study participants in Phase 2 are healthcare workers with at least one year of experience in diabetes care in the two study hospitals, and NCD program coordinators

with over a year of experience in the study district. In this phase, 21 healthcare workers involved in the provision of diabetes follow-up care services were included, 13 from Hospital A and eight from Hospital B. Additionally, healthcare workers coordinating diabetes services at the woreda, zonal, and regional health office levels were interviewed to gain insights into systemic and service-delivery challenges contributing to patient drop-out. In qualitative research, study units can be selected based on specific reasons to answer the research questions (Hennink, Hutter & Bailey 2020:92).

3.5.2.2 Selection of study participants

In this study, the researcher selected healthcare workers who have adequate experience and knowledge of the subject matter through purposive sampling. The selected healthcare workers, including those actively involved in T1D follow-up care and NCD program managers with over a year of experience, were interviewed at their respective hospitals, ensuring privacy. The researcher obtained the list of participants by asking the head of the diabetes care unit in each of the study hospitals. Participants were selected based on their availability, willingness, and active involvement in follow-up care, while those with less than one year of experience, those not directly engaged in diabetes care, or those unavailable or unwilling to participate were excluded.

3.5.2.3 Data gathering

As indicated in Section 3.5.3.2, data collection for Phases 1 and 2 was conducted simultaneously in July 2024. The data in Phase 2 were collected through semi-structured interviews with seven healthcare workers engaged in diabetes service delivery at the two study hospitals. The interviews with healthcare workers were conducted in the meeting hall of the hospital, which is the only available free space with adequate privacy.

The semi-structured interview guide for the healthcare workers (Annexure Q) is organised under two major topics. The first question focuses on ‘the experiences of offering diabetes follow-up care service in this hospital’, and the second theme focuses on ‘the experiences of LTFU among T1D patients in the hospital’. Each interview lasted 30 to

60 minutes, was audio-recorded with the participant's consent, transcribed verbatim, and supplemented with field notes that captured non-verbal cues and impressions. The purpose was to understand healthcare workers' perspectives on barriers to patient retention in FUC services. All interviews were recorded, backed up, and later transcribed for analysis.

In general, the inclusion of the perspectives of healthcare workers in this study provided a comprehensive understanding of lost-to-follow-up among Type 1 diabetes patients, which further served to validate the results acquired from the patient interviews.

3.5.2.4 Trustworthiness

Since data collection and analysis for Phase 1 and Phase 2 were conducted concurrently, the same trustworthiness strategies outlined in Section 3.5.1.5 applied. The study ensured credibility, dependability, transferability, and confirmability through the use of purposive sampling, data triangulation, prolonged engagement, systematic documentation, co-coding, and detailed contextual descriptions. Reflexive journaling, verbatim transcription, and the use of Atlas.ti software further supported the rigour and transparency of the analysis. These measures collectively enhance the trustworthiness of both phases of the study (see Section 3.5.1.5).

3.5.2.5 Data analysis

As indicated above in Section 3.5.1.6, the data analysis in Phase 1 and Phase 2 was conducted simultaneously using the same technique, that is, inductive thematic analysis using Atlas.ti (Version 25) computer software (see Section 3.5.1.6).

3.5.3 Phase three: Guideline development

Phase 3 focuses on developing guidelines to address LTFU. The researcher developed 10 guidelines based on the empirical findings obtained from Phase 1 and Phase 2, as well as a thorough literature review of the topic. This phase also included a focused discussion with diabetes care experts. Participants reviewed and gave feedback on the proposed guidelines, which were then revised and refined based on their input.

To further refine these guidelines, thoughts from experts involved in the focused discussion were incorporated.

3.5.3.1 Study population and selection of study participants

For Phase 3, six panellists were selected by the researcher on the basis of their relevant experience in the delivery of T1D follow-up care services and/or programs. These include three healthcare workers in the diabetes care unit, one diabetes focal person in public hospitals, and two NCD program experts in the district health office. The panellists, as detailed in their biographies below, were healthcare professionals (see Table 3.3).

Table 3.3: The biography of panellists in guideline development

	PROFESSION	EDUCATION	QUALIFICATION	WORKPLACE
1	General Practitioner	Medical Doctor	Outpatient Department	Hospital
2	Public Health Expert	Master of Public Health	MEAL Officer	Hospital
3	Public Health Expert	Master of Public Health	NCD Coordinator	Zonal Health Office
4	Nurse	BSc degree in Nursing	Outpatient Department	Hospital
5	Nurse	BSc degree in Nursing	Chronic Care Unit	Hospital
6	Health Officer	BSc degree in Public Health	Chronic Care Unit	Hospital
7	Health Officer	BSc degree in Public Health	Outpatient Department	Hospital

3.5.3.2 Data collection

In this study, the process of developing the guideline involved two phases. First, the existing gaps were identified, and the content and scope of the guideline were determined from the empirical findings. Then, the guidelines were developed through expert-focused discussion and feedback.

To initiate the expert review process, the first draft guidelines were developed from the empirical findings obtained from Phases 1 and 2 and from the existing literature (see

Annexure S). This draft was shared via email with a panel of volunteer experts who had been invited to participate in the focused discussion (see the Information Sheet- Annexure H, the Invitation Letter- Annexure K, and Consent form- Annexure M). All invited experts agreed to participate in the process and agreed on a time, date, and venue for the focused discussion. The face-to-face focused discussion with these panellists was conducted on February 25, 2025, during which the initial draft was presented for detailed review and inputs. The experts provided comments, highlighted areas for improvement, and offered suggestions to strengthen the content (see Chapter 5).

Following this session, the researcher revised the guideline based on the most relevant and frequently raised expert inputs. The revised version was sent back to the panellists via email to confirm whether their comments had been addressed. This iterative feedback process continued through email exchanges until all panellists confirmed that their feedback had been adequately incorporated. Two rounds of feedback were conducted before the final agreement was reached. This structured engagement ensured expert approval of the content and helped refine the guideline into a comprehensive and practical tool. This process of data collection and analysis, which combines a literature review, empirical findings, and expert inputs, is reflected in detail in Chapter 5.

3.5.3.3 Trustworthiness

Trustworthiness in Phase 3 was ensured through rigorous expert engagement and transparent documentation. Credibility was enhanced by involving a panel of experts who reviewed the initial draft guideline through an in-person discussion and iterative email feedback, enabling consensus and refinement informed by both theoretical evidence and empirical findings. The use of a structured, two-phase development process, starting with a literature review and evaluation of existing guidelines (deductive), followed by incorporation of findings from empirical findings of patients and healthcare workers' interviews (inductive) further reinforced the confirmability and dependability

of the guideline. Transferability was supported by clearly defining the scope and content development process. The researcher maintained detailed records of all expert inputs, revisions, and correspondence, ensuring an auditable trail and reflective alignment with established principles of trustworthy qualitative research.

3.5.3.4 Data analysis

The analysis in Phase 3 was guided by a combination of deductive and inductive reasoning. Initially, a deductive approach was employed to define the content and scope of the guideline by reviewing existing literature and evaluating relevant guidelines related to lost-to-follow-up. This provided the theoretical foundation and established domains, consistent with recommendations by Taylor, Garner, Oliver, and Desmond (2024:12), who emphasise that literature reviews help define the structure of a guideline, while empirical findings contribute to its substance.

Following the deductive phase, an inductive approach was applied through the thematic analysis of expert inputs collected during the in-person discussion and subsequent email feedback. The researcher systematically reviewed and categorised expert suggestions, identifying recurring themes, and essential content revisions. This iterative analysis ensured that the final guideline reflected both evidence-based practices and field-relevant insights.

Feedback that aligned with the empirical findings from earlier study phases was prioritised, while new suggestions were evaluated against the study's objectives and scope. The development process not only strengthened the content's credibility but also enhanced the overall rigour and applicability of the guideline. The process and guiding principles for developing guidelines, and the purpose, objectives, and scope of the current guideline, are outlined in Chapter 5.

3.5.4 Phase Four: Guideline validation

In Phase 4, the researcher validated the guideline through a Structured Consensus Development Meeting (SCDM) with a panel of multidisciplinary experts. The SCDM

utilises established consensus methodologies to systematically assess and refine areas of emphasis based on scientific evidence and expert judgment. The use of the SCDM approach for guideline validation enhances the guideline's scientific credibility, contextual relevance, and implementation feasibility. Consensus development processes are widely used in health research to enhance the validity of guidelines (Roberts, Carter, Barnett, Mugglestone & Pilling 2023). By integrating empirical evidence with expert deliberation, CDMs help bridge the gap between research and practice, ensuring that guidelines reflect real-world constraints and opportunities.

3.5.4.1 Population and selection of study participants

The validation process involved a carefully selected panel of 10 multidisciplinary experts, using a purposive sampling technique. Experts were selected based on their demonstrated expertise in diabetes care, clinical practice, public health, and health systems. As suggested by Roberts et al. (2023:7), the composition of the committee reflected a balanced representation across clinical, policy, and service sectors to enhance the acceptability and relevance of the resulting guidelines.

Participants who met the following selection criteria were included. A minimum of five years of relevant experience in the field, representation from key professional roles including diabetes nurse educators, public health experts, health system researchers, and policymakers, people who have demonstrated involvement in public health research, guideline development, health policy implementation, and gender and regional diversity to ensure broad representation of perspectives within the Ethiopian context. This approach follows the recommendations of Jung, Braun, Armijo-Olivo, Challoumas, and Luedtke (2024:4), who highlight that a blend of clinical and methodological experts significantly strengthens the quality and relevance of health guidelines. Diversity in professional backgrounds enriches insights and fosters a more comprehensive validation process. The distribution of the panellists involved in the consensus process is presented in Table 3.4, which outlines their professional backgrounds and areas of expertise. The recruitment process is clearly documented in the Recruitment Letter (Annexure J), which specifies the purpose of their involvement, their expected

contributions, and the means of communication throughout the process. This letter is based on the Information Letter provided in Annexure I, which has been adapted to serve as the formal recruitment letter.

Further details on participant selection and consent procedures for Phase 4 are provided in Section 6.2. In summary, a panel of 10 multidisciplinary experts was purposively selected by a gatekeeper (Annexure U) based on predefined criteria, who also obtained preliminary verbal consent and shared the contact details of willing participants with the researcher. Additional information is presented in the last paragraph of this section and supporting documents (Annexures I, J, and N).

Table 3.4: The biography of panellists in SCDM

	PROFESSION	EDUCATION	QUALIFICATION	WORKPLACE
1	Nurse Educator	MSC degree in Nursing	Nursing College Instructor	Health Science College
2	Public Health Educator	Master of Public Health	Public Health Instructor	Health Science College
3	Health Policy Expert	Master of Public Health	NCD Coordinator	Regional Health Bureau
4	Health Policy Expert	Master of Public Health	Health Policy Advisor	Ministry of Health
5	Health Policy Expert	Master of Public Health	NCD Coordinator	Ministry of Health
6	Health System Researcher	PHD in Public Health	Health Policy Researcher	Consultant Firm
7	Health System Researcher	PHD in Public Health	Health Policy Researcher	Regional Health Bureau
8	Health System Researcher	PHD in Public Health	Health Policy Advisor	NGO
9	Program Manager	MSC degree in nursing	Diabetes Care Unit Head	Hospital
10	Medical Doctor	Medical Doctor	Diabetes Program Manager	NGO

3.5.4.2 Data gathering through a Structured Consensus Development Meeting

3.5.4.2.1 Materials provided in advance to the SCDM

Prior to the structured consensus development meeting, the panellists received the recruitment letter (see Annexure J), including the draft guideline and a structured validation tool (see Annexure R), electronically. The validation tool used a nine-point Likert scale to assess the appropriateness of the proposed areas of emphasis in the guidelines. Experts had one week to review the draft document and submit their preliminary ratings and comments. The advance packages shared included the draft guideline (see Annexure R) and the pre-rating validation scale (validation tool) for each action, implemented using a 9-point Likert scale (see Annexure R). The pre-meeting distribution of the mentioned documents provides structure and minimises cognitive overload during a meeting session (Wu, Pralat, Leong, Carter, Fritz & Martin 2024:4). Experts independently reviewed and rated each action to be implemented using a 9-point Likert scale (1-3 Not Appropriate, 4-6 Uncertain, Needs Modification, and 7-9 Appropriate as Written).

3.5.4.2.2 Session 1 of the SCDM: Opening and context setting

An introductory session lays the groundwork for the consensus process by creating a shared understanding among participants. A clear explanation of consensus-building processes at the outset is essential for participant engagement and legitimacy of decisions (Arakawa & Bader 2022:3).

The facilitator began by welcoming the panellists and stating the purpose and goals of the meeting: to validate the guidelines derived from the Phase 1&2 study findings (interviews with patients and healthcare workers). After participant introductions, a brief overview of the guideline development process was provided in writing (see Annexure I), emphasising the significance of the empirical findings and how they informed the draft areas of emphasis. The trained facilitator presented and explained the consensus methodology to be followed, including the scoring system, consensus thresholds (e.g., ≥80% agreement as strong consensus), and the rules for discussion and voting.

Ground rules for respectful, inclusive participation, as explained by Arakawa and Bader (2022:3) and Roberts et al. (2023:6), were also established to manage power dynamics, ensure balanced contributions and provide assurance that all voices were equally important. This session was essential for aligning expectations and preparing participants to engage thoughtfully and equitably throughout the process.

3.5.4.2.3 Session 2: Presentation of draft guidelines

In this session, the researcher, as the guideline developer, presented the draft areas of emphasis in clearly grouped thematic sections (e.g., service delivery, referral pathways, follow-up care). For each section, the researcher explained the empirical findings by referring to the results presented in Chapter 4. The discussion focused on highlighting key insights and areas requiring input from the expert panel.

Immediately following each thematic section, the facilitator shared the aggregated pre-meeting validation scores and median ratings (Annexure R), highlighting levels of consensus and disagreement. This enabled participants to see how others interpreted the content and prepared them for deeper discussion in the following session. Reviewing individual and group pre-scores can highlight areas of disagreement and help focus the discussion (Wu et al. 2024:5). The goal here was familiarisation and clarification, not debate, ensuring all panellists have a common understanding before entering the discussion and voting.

3.5.4.2.4 Session 3: Facilitated discussion

Session 3 entailed the core decision-making session. For each proposed area of emphasis, the facilitator opens the floor to a structured, time-bound discussion using the round-robin technique, where each participant takes a turn to speak in a predetermined order, ensuring that everyone has an equal opportunity to contribute. The facilitator ensures equal participation, prevents any individual from dominating, and probes for clarification when needed. In this session, the facilitator's neutrality and management of power dynamics within the discussion created productive consensus (Roberts et al. 2023:8). The facilitated discussion focused on divergent ratings, evidence gaps

or conflicting views, and suggested modifications. Areas of concern, such as language clarity, feasibility, cultural appropriateness, or alignment with health system realities, were explored.

3.5.4.2.5 Session 4: Post-discussion re-scoring

After discussion and consideration of evidence and differing viewpoints, participants rescored the areas of emphasis using the 9-point Likert scale (1= not appropriate, 9= highly appropriate). The definition of consensus was applied to the voting results: Strong consensus was defined as ≥80% agreement of voters as appropriate, moderate consensus: ≥60% agreement of voters as appropriate, and no consensus: <60% agreement of voters as appropriateor significant opposing views. The 9-point Likert scale and consensus thresholds are commonly employed in SCDMs to evaluate the appropriateness of areas of emphasis (Unni, Schougaard, Aiyegbusi, Mate, Austin, Greffin, Roberts, Grove, Muehlan & ISOQOL Clinical Practice SIG PROs in Telehealth Working Group 2025:4).

3.5.4.2.6 Session 5 of the CDM: Refinement and action points

Once all areas of emphasis had been reviewed and voted on, the group reconvened to reflect on overall trends and determine next steps. The facilitator summarised the areas of emphasis that achieved strong or moderate consensus, those that required minor or major revision, and those that were rejected or needed further evidence. Documenting areas of non-consensus and providing a rationale for revisions enhances transparency (Roberts et al. 2023:6; Wu et al. 2024:6).

Participants openly shared their suggestions with the researcher on how to address unresolved issues. The researcher documented the proposed solutions, including action points with timelines. Such a session typically promotes ownership of the revision process and ensures that outcomes from the consensus meeting translate into actionable follow-up steps (Wu et al. 2024:5). It also allows space to address implementation feasibility and any practical considerations for guideline adoption at different system levels (Roberts et al. 2023:6).

3.5.4.2.7 Session 6 of the CDM: Closing and post-meeting activities

The final session provides a structured closure to the meeting. The facilitator would thank participants and recap key achievements, including the number of areas of emphasis validated, revised, or flagged for further input. Participants are invited to share brief reflections on the process, including what worked well and any suggestions for improvement in subsequent phases. The next steps for finalising the guidelines are clearly outlined. These include the timeline for revisions and the expected date of guideline dissemination. This session reinforces shared ownership and commitment to implementation, thereby strengthening the likelihood of uptake and long-term use (Arakawa & Bader 2022:6). The researcher integrated and edited the final version of the guideline. The detailed report of the consensus methodology is presented in Chapter 5.

3.5.4.3 Data Analysis

3.5.4.3.1 Consensus criteria and decision rules

To determine the level of agreement, predefined thresholds were applied. Strong consensus was achieved when 80% or more of participants rated the areas of emphasis between 7 and 9; Moderate consensus was defined as ≥60% but <80% of participants scoring an item between 7 and 9; and no consensus was recorded when agreement fell below 60% or when there were significant opposing views (Bucyibaruta, Doriccah, Bamford, Van der Wath, Dyer, Murphy, Gatabazi, Anokwuru, Muhire & Coetzee 2023:5). This process helped ensure that final decisions were grounded in a collective, evidence-informed perspective while allowing for the refinement of areas of emphasis through multiple rounds if needed.

The decision rules are applied based on the above consensus criteria. For a ‘strong consensus’, the areas of emphasis were accepted with no change. For ‘moderate consensus’, rewording or refinement may be needed so that the decision made reflects the panellists’ discretion. For ‘no consensus’, areas of emphasis were removed. These

thresholds are consistent with various studies that utilised consensus-seeking methods. Different authors have different opinions about the level at which consensus is reached, typically between 70% and 80% (Unni et al. 2025:4). In this study context, consensus refers to the aforementioned proportion of agreement across all items in the guideline. Items lacking consensus were documented for further revision and shared for another round of SCDM (Arakawa & Bader 2022:4; Roberts et al. 2023:8).

3.5.4.4 Trustworthiness

Methodological transparency in consensus development enhances external validity and stakeholder trust (Roberts et al. 2023:6). To ensure methodological integrity, the consensus development process incorporated the following strategies aligned with Lincoln and Guba's trustworthiness criteria (Amin et al. 2020:3). Credibility was achieved by selecting highly experienced and diverse experts, providing structured pre-meeting materials, and enabling equitable participation in discussions. To ensure dependability, a transparent, replicable process was followed, including a clearly defined consensus methodology, structured facilitation, and documented decision-making protocols. To ensure confirmability, all sessions were recorded and documented, including individual scores, group decisions, and revisions. To ensure transferability, the validation model aligns with scientifically recognised practices that can be applied to similar contexts and processes in other low- and middle-income countries. These measures ensure that the experts' judgments are verifiable and methodologically sound. Moreover, informed consent was obtained from the participants in the consensus development meeting, and the data were anonymised during analysis and in the report.

Table 3.5: Summary of consensus development meeting in phase 4

Phase	Component	Description	Justification / Source
Preparatory phase	Expert panel selection	8–12 multidisciplinary experts selected based on subject relevance, sectoral representation, and diversity.	Ensures credibility and broad applicability (Roberts et al. 2023)

Phase	Component	Description	Justification / Source
Consensus Meeting	Pre-meeting distribution and first round scoring	- Draft guideline and SCDM 9-point Likert scale scoring tool sent two weeks in advance. - The panellists sent the completed first round score results to the researcher before the meeting.	Reduces cognitive load, enables early reflection (Wu et al. 2024)
	Session 1: Opening & context setting	Clarify objectives, process, and present evidence/findings alongside the proposed guidelines.	Enhances engagement and shared understanding (Arakawa & Bader 2022)
	Session 2: Guideline presentation	Thematic display of the proposed areas of emphasis with the pre-SCDM feedback.	Helps identify contentious items (Wu et al. 2024)
	Session 3: Facilitated discussion	- Discussion on items with moderate consensus - Revise or merge items with moderate consensus and remove non-consensus items; document decisions.	Structured, transparent decision-making (Roberts et al. 2023)
	Session 4: Post-discussion re-scoring	- Second round anonymous voting on a 9-point scale.	Supports transparency and follow-through (Wu et al. 2024)
	Session 5: Closing	Recap, reflection, and outline of next steps for final guideline dissemination.	Reinforces commitment and shared ownership (Arakawa & Bader 2022)
Post-Meeting	Session 6: Closure of the meeting	-Thank participants, and recap key achievements. - Participants share brief reflections on the process.	Enhances rigour and stakeholder trust (Roberts et al. 2023)

3.6 ENSURING RIGOUR

The quality of qualitative research can be ensured by applying the trustworthiness criteria that are agreed upon in the literature (Johnson 2020:7). Each research approach employs different criteria to ensure the rigour of the investigation. For example, quantitative researchers consider reliability, objectivity, and validity to ensure the trustworthiness of the inquiry. In contrast, qualitative researchers consider dependability, credibility, transferability, confirmability and authenticity as trustworthiness criteria for a qualitative investigation (Daniel et al. 2024).

Therefore, trustworthiness in this study was achieved by employing dependability, credibility, transferability, confirmability, and, more recently, authenticity (Johnson 2020:4). Each of these trustworthiness criteria and how they were applied during the research process is discussed below.

3.6.1 Credibility

Credibility refers to confidence in the truthfulness of the research findings (Amin et al. 2020). Credibility determines whether the research findings represent trustworthy information retrieved from the original data of the participants and are a correct interpretation of the participants' original thoughts (Daniel et al. 2024:3). To establish credibility in this study, the researcher asked for feedback from participants on the emerging categories and themes. Transcript credibility was achieved by spot-checking a subset of the transcripts by the researcher, and involving the research assistant in spot-checking and co-coding (Johnson 2020:5).

3.6.2 Transferability

The degree to which the findings of qualitative research can be translated to other contexts or settings with different respondents is referred to as transferability (Daniel et al. 2024:3). According to Daniel et al. (2024:3), keeping the 'rich description' can facilitate the transferability assessment. The detailed description includes all research processes, from data collection and study context to final report preparation (Amin et al. 2020:6). In the research report, the researcher provides a wealth of information on the approach and context. It enables other researchers to duplicate the study in other contexts or situations using similar conditions.

3.6.3 Dependability

Dependability refers to the consistency of findings over time (Amin et al. 2020). Dependability involves evaluating the study's findings, interpretation, and recommendations, ensuring they are supported by the data collected from the study's informants. Dependability can be established using a code-recode strategy and peer examination

(Johnson 2020:8).

In this study, the researcher coded the same data twice, with two weeks between codings. The results of the two codings were compared to determine whether they were the same or different. Moreover, the researcher ensured dependability by comparing the themes and categories with a co-coder. Moreover, the researcher kept all relevant documents for any cross-checking of the inquiry process. These include raw data, interview and observational notes, documents, and field records, as well as signed consent forms and other related documents.

3.6.4 Confirmability

According to Matin and Alam (2021:6), confirmability is concerned with demonstrating the data and interpretations of the findings drawn from the data, but not the product of the inquirer's imagination. To establish confirmability in this study, the researcher kept all reflexive documents, including field notes of all events, personal reflections on the study, such as issues that arose during data collection, and all electronic (tape-recorded) and non-electronic (i.e., field notes, documentary materials) records throughout the investigation. The records were used to cross-check with the data during the analysis and writing of the research (Johnson 2020:5).

3.6.5 Authenticity

Authenticity refers to the degree to which a researcher captures the multiple perspectives and values of the participants in the study and adopts change between the participants and the systems during analysis. Certain initial conditions are prerequisites for achieving authenticity sub-criteria, including fairness, ontological authenticity (development of meaning), educative authenticity (development of meaning and learning potential), catalytic authenticity (action potential), and tactical authenticity (learning potential and for changing) (Amin et al. 2020:8-10).

To ensure authenticity, the researcher practised informed consent for all participants, nurtured caring and trusting relationships and collaboration between the participant and the researcher, and made the inquiry procedures transparent to all participants by

reading the statement on the participant consent form. Moreover, the researcher indicated on the participant form the mechanism to handle disagreements in case they occur. At the conclusion of the study, the researcher will make the research report available to the respondents and the broader audience. Therefore, the researcher applied all necessary strategies to ensure the research's trustworthiness.

3.7 ETHICAL CONSIDERATIONS

Human participants must be protected in all research studies by adhering to ethical norms (Matin 2021:4).

3.7.1 Permission to conduct the study

Ethical clearance and support letters were obtained from UNISA and the local authorities before contacting the study participants. In this study, the researcher obtained Ethics approval from the Research Ethics Committee of the College of Human Sciences UNISA (see Annexure A and D), permission from the respective authorities (see Annexures C) and Institutional Review Boards (see Annexure B) consent from all study participants (see Annexure L, Annexure M, Annexure N and Annexure O), and guaranteed the confidentiality and privacy of the participants as was explained in the information sheet (Annexure F, Annexure G, Annexure H and Annexure I) and recruitment letters of all types of participants (Annexure J and Annexure K).

3.7.2 Informed consent

Written consent was obtained from all study participants before data collection commenced. A language editor translated the consent form and the interview guide into Afan Oromo and Amharic to ensure accuracy. Participants were given a copy of the informed consent form, which includes the names, phone numbers, and addresses of the necessary contacts, primarily the researcher and the IRB focal person at OrRHB. See the information sheet of patient interview in Annexure F, healthcare workers interview in Annexure G, SCDM participants in Annexure I, and Focused Discussion participants in Annexure H. The data collector also signed to confirm that he had read the consent form to the participants. See the consent form of patient interview and

healthcare workers interview in Annexure L, Focused Discussion participants in Annexure M and SCDM participants in Annexure N.

3.7.3 Protection of privacy and confidentiality

The researcher assured the participants of the confidentiality of the information they provided and the anonymity of their personal details. See the information sheet of patient interview in Annexure F, healthcare workers interview in Annexure G, Focused Discussion participants in Annexure H, and SCDM participants in Annexure I. In Phases 1 and 2, each study participant was assigned an identification code to maintain anonymity, and the results were presented in aggregate form. Data collection was conducted in private settings (both audio and visual privacy). In Phases 3 and 4, while complete confidentiality could not be ensured due to the group-based nature of the meetings, efforts were made to uphold research rigour by fostering a respectful environment and by focusing data analysis on anonymised, content-based contributions rather than individual identities.

Except during use, all materials generated during data collection were stored in a locked file cabinet. The researcher had sole access to the data. All electronic data files were password-protected and stored solely on the researcher's computer; backup discs were kept in a locked file cabinet. These records will be destroyed after five years.

3.7.4 Description of risks and potential benefits

The researcher/data collector assured the participants that they would not be exposed to any physical risks. All precautions were taken to maintain participants' privacy. The researcher told participants they could decline to participate or openly share their thoughts with the researcher. Participants in this study did not receive any direct rewards. However, they were told that the study's findings were believed to benefit patients indirectly by improving the healthcare system through the guidelines developed by the current research.

3.7.5 Non-maleficence and beneficence

The researcher was guided by the important principle of research ethics, which is minimising harm (non-maleficence) and maximising benefit (beneficence) (Matin 2021:7). Although there was no foreseen harm to the study participants, the researcher acted responsibly to avoid, prevent and minimise any harm to participants throughout the research process. Furthermore, the participants were not exposed to any unnecessary risks of harm during the research process. The researcher explained to the participants the aim and objectives of the research, namely, to generate new knowledge and contribute to the academic field in a way that benefits the entire society, including the participants themselves.

3.7.6 Justice and inclusiveness

In the field of research, justice implies fairness and equity for all participants (Matin 2021:6). Justice is fundamental in research ethics, particularly with respect to human participants. In this research, justice was ensured through the use of independent, fair, and transparent ethics review methods that adhere to established standards. The researcher carefully monitored the entire research process to ensure that no participant group was unfairly burdened and that no individual was discriminated against or neglected. Moreover, attention was given to vulnerable participants to protect their rights and interests, ensuring they were not mistreated or exploited in the name of scientific research, and to uphold the autonomy of researchers and academic institutions.

3.8 CONCLUSION

Chapter three outlines the research methodology. The study employed a qualitative research approach to explore the experiences of patients with Type 1 diabetes and healthcare workers regarding lost-to-follow-up care. The study employs a phenomenological design, which facilitates an in-depth understanding of participants' lived experiences. It is structured into four phases: the first two phases focus on gathering and analysing data from both patients and healthcare workers, while the third phase involves developing guidelines based on these empirical findings. The fourth phase is dedicated to validating the guidelines.

Phase 1 involves interviewing T1D patients who have missed follow-up visits, while Phase 2 focuses on healthcare workers' experiences with these patients. In both cases, the study utilises semi-structured interviews for data collection. The data collected in Phases 1 and 2 were analysed using inductive thematic analysis. The findings in Phases 1 and 2 helped identify key themes and patterns related to lost-to-follow-up among Type 1 diabetes patients. The guidelines developed in Phase 3 are refined through expert feedback. Finally, in Phase 4, a structured consensus development meeting was employed to validate the guideline.

4. CHAPTER FOUR: ANALYSIS AND PRESENTATION OF THE RESEARCH FINDINGS IN PHASE 1 AND PHASE 2

4.1 INTRODUCTION

Chapter 4 presents the data-gathering, analysis, presentation, and literature review for Phases 1 and 2 of the study. The chapter examines the experiences of both patients and healthcare workers in relation to lost-to-follow-up among patients with Type 1 diabetes. It begins with a brief description of data management procedures, followed by the analysis and presentation of the main findings, which are organised into themes, categories, and subcategories. The findings are structured into two main sections: Phase One – the experience of lost-to-follow-up among T1D patients, and Phase Two – the experiences of healthcare workers with lost-to-follow-up patients. Table 4.1 presents the current status of research progress.

Table 4.1: Research progress

CHAPTER	NAME OF THE CHAPTER	PURPOSE/CONTENT
Chapter 1	Overview of the Study	The chapter provides an overview of the purpose, objectives and methodology of the study.
Chapter 2	Literature Review	Literature review to discuss: • Theoretical framework • Diabetes and diabetic services • The national strategy for diabetes
Chapter 3	Methodology	Research methodology: Phases 1-4
Chapter 4	Phases 1 and 2:	Data gathering, analysis, presentation, and literature control

4.2 DATA MANAGEMENT AND ANALYSIS

The study employed an inductive thematic analysis to explore the experiences of patients and healthcare workers regarding LTFU. The analysis comprises a total of nine semi-structured interviews with patients who had been lost to follow-up in the past six months, and seven semi-structured interviews with healthcare workers involved in diabetes service delivery at the two hospitals. All the interviews conducted in Amharic were first verbatim transcribed by an experienced translator into Amharic and then into English, and reviewed by the researcher while listening to the original audio. Interviews conducted in Afan Oromo were verbatim transcribed by an experienced translator while listening to the original audio. Moreover, each transcript was compared with the researcher's field notes.

The researcher first familiarised himself with the transcripts' content through repeated readings. Following this initial immersion, each transcript was examined in detail, and inductive coding was applied to relevant sections of text, as outlined in Section 3.5.1.6. The analysis was supported by Atlas.ti 25 qualitative data analysis software, which facilitated data organisation and management. Some of the codes emerged in vivo, directly reflecting participants' own words, while others were developed through the researcher's interpretive judgment to capture the underlying concepts in the data most effectively.

4.3 BIOGRAPHICAL PROFILE OF THE PARTICIPANTS

A total of 16 participants were interviewed. The profiles of the patients and the healthcare workers who participated in the semi-structured interview are described in Tables 4.2 and 4.3, respectively.

4.3.1 CHARACTERISTICS OF T1D PATIENTS PARTICIPATED IN THE STUDY

A total of nine individuals living with Type 1 diabetes were interviewed to address Objective 1, which aimed to explore the experiences of patients who had been lost to follow-up. The demographic characteristics of the participants reflected considerable

diversity in age, educational background, and socioeconomic status. Most were young adults, generally between their late twenties and early forties, and a notable proportion were married. In terms of education, the group was mixed: some participants had completed secondary education, others held higher education degrees, while a few reported no formal schooling (see Table 4.2).

Table 4.2: Characteristics of the T1d patients who participated in the study

S/N	PARTICIPANT CODE	AGE	SEX	EMPLOYMENT	RELIGION	MARITAL STATUS	HF ATTENDING DIABETES CARE	EDUCATIONAL STATUS
1	P8	45	F	Cleaner	Orthodox	Married	Hospital A	G-9
2	P9	55	M	Lawyer	Orthodox	Married	Hospital A	12+2
3	P10	42	F	Self-employed	Protestant	Married	Hospital A	G-11
4	P11	28	M	Farmer	Protestant	Single	Hospital A	12+4
5	P12	23	M	Farmer	Orthodox	Married	Hospital B	0
6	P13	48	M	Daily labourer	Orthodox	Married	Hospital B	G-3
7	P14	32	M	Teacher	Protestant	Married	Hospital B	12+2
8	P15	20	M	Farmer	Orthodox	Single	Hospital B	G-4
9	P16	37	F	Merchant	Orthodox	Married	Hospital B	0

4.3.2 CHARACTERISTICS OF THE HEALTH WORKERS PARTICIPATED IN THE STUDY

Seven healthcare workers were interviewed to address Objective 2, which explored their experiences with Type 1 diabetes patients who had been lost to follow-up. The participants varied in terms of education, professional experience, and roles. Most were young adults, generally between their late twenties and early forties. The group included nurses, physicians, and public health officers. Educational levels varied:

some held bachelor's degrees, while others had advanced training in public health or related fields. Most of the healthcare workers were married (see Table 4.3).

Table 4.3: Characteristics of the health workers who participated in the study

S/N	PART. CODE	AGE	SEX	PROFESSION	POSITION	RELIGION	MARITAL STATUS	ORGANISATION/HF**	EDUCATIONAL STATUS
1	P1	28	M	Nurse	Nurse	Orthodox	Married	Hospital B	12+4
2	P2	32	M	Medical Doctor	Medical Doctor	Wake feta	Married	Hospital A	12+7
3	P3	29	F	Medical Doctor	Medical Doctor	Orthodox	Married	Hospital A	12+7
4	P4	47	M	Health Officer	Health Officer	Orthodox	Married	Hospital A	12+4
5	P5	43	M	Health Officer	Health Officer	Protestant	Married	Hospital A	12+4
6	P6	29	F	Nurse	NCD Head Nurse	Protestant	Married	Hospital B	12+4
7	Part-7	40	M	Health Officer	NCD Coordinator	Protestant	Married	Woliso WrHO*	12+6
Key: WrHO- Woreda Health Office; **HF- Health Facility*									

4.4 ANALYSIS AND PRESENTATION OF THE FINDINGS

The data analysis revealed a rich landscape of insights, with nine key themes and 39 categories that emerged in both Phase 1 and Phase 2.

4.4.1 Analysis and presentation of themes, categories and sub-categories in Phase 1

Phase 1 of the analysis revealed five key themes and 23 distinct categories. These five themes include (1) Patient knowledge and awareness, (2) Challenges negatively associated with follow-up attendance, (3) Support system, (4) Patients' perception of follow-up care quality, and (5) Patients' perception of the importance of follow-up care. The emerged themes and categories, including the related direct quotations, are illustrated in Table 4.4.

Table 4.4: Themes, categories and sub-categories in Phase 1

MAIN THEMES	CATEGORIES	SUBCATEGORIES AS DIRECT QUOTATIONS
4.5.1. Patient knowledge and awareness	4.5.1.1. Importance of patient knowledge in diabetes management	· *"The information I got from doctors helped me to control my diabetes" (P10)* · *"Because of the health workers' counselling, I got my health back" (P12).*
	4.5.1.2 Misconceptions about diabetes management	· *"I have no signs and symptoms of illness. I have no fear this (diabetes complication) could happen to me" (P11)* · *"I stopped coming and taking medicine because I was in church taking religious treatment like holy water" (P12)*
	4.5.1.3. Awareness of complications	· *"I don't know anything about diabetes complications" (P12)* · *"I know some information about the associated diseases like hypertension" (P10)*
	4.5.1.4. Lack of patient education program	· *"In this hospital, there is no such education for patients" (P10)* · *"If the health workers tell me to come every six months, there is nothing to keep me from coming" (P11)*
	4.5.1.5. Need for a comprehensive education program	· *The hospital should provide training to diabetes patients; it might be a 20-minute education program" (P10)* · *"The health workers should teach the patients how to take the medication, when to come for the follow-up, and the importance of follow-up care" (P7)*
	4.5.1.6. The impact of health literacy on follow-up adherence	· *"I was trained in BLH hospital that we have to eat after 30 minutes of taking the medication." (P10)* · *"The health workers told me the consequences I would encounter if I stopped taking the medicine. So, I will not discontinue the medicine and the follow-up" (P16).*
4.5.2. Challenges negatively associated with follow-up attendance	4.5.2.1. Financial constraints	***4.5.2.1.1. Out-of-pocket payment*** · *"No one can do the medical and laboratory examinations for free. I don't have the financial capacity to pay for it" (P11)* · *"Except for the cost issue, the service quality in this hospital is very good" (P9).* · *"I always struggle to cover the medical expenses" (P8)* ***4.5.2.1.2. Lack of healthcare insurance coverage***

MAIN THEMES	CATEGORIES	SUBCATEGORIES AS DIRECT QUOTATIONS
		· *"I wish to continue my follow-up in this hospital if the cost is covered by insurance" (P9)* · *"I have medical insurance coverage here. But, most of the time, the hospital stocks (run) out of medicine" (P13).*
	4.5.2.2. Challenges with transportation	***4.5.2.2.1. Distance to the facility*** · *"It requires me 3 hours to walk on foot to reach the hospital" (P12)* · *"Sometimes I use a horse to come hospital. If I don't succeed in getting a horse, I miss the follow-up and the treatment" (P12).* ***4.5.2.3.2. Transportation costs*** · *"Transportation cost is another problem…. it is difficult for me to come always" (P15).* · *I know my neighbour died of diabetes just recently because of a lack of money for treatment and transportation" (P8)*
	4.5.2.4. Work obligations	· *"I am a daily labourer. I fear not losing my job…Sometimes I can't take time off to go for my check-up" (P15).* · *"It is difficult for me to be late or absent from my work. If they provide the service on time, it will be good" (P8)*
	4.5.2.5. Cultural influences	***4.5.2.3.1. Cultural beliefs about diabetes*** · *"In my village, diabetes is considered an urban disease…..My family and community are confused about how I brought diabetes while I am a rural resident" (P12)* · *"My family and relatives are insisting on me to go to prayer and holy water instead of medicine because they consider it as God's punishment on me" (P12)* ***4.5.2.3.2. Influence of traditional medicine*** · *"The only reason I want to stop the treatment is that I believe the prayer and holy water will heal me" (P12)* · *"The community I live in and my family push to stop my medicine and try religious treatment" (P12)* ***4.5.2.3.2. Stigma and discrimination***

MAIN THEMES	CATEGORIES	SUBCATEGORIES AS DIRECT QUOTATIONS
		· *"I realised that you can get a better service if you have someone you know in the hospital" (P10).*
4.5.3. Support system	4.5.3.1. Family support	· *"Some of my family tell me to follow doctors' advice, the others tell me to go to holy water" (P12)* · *"My husband and my children always support me" (P8)* · *"My children also advise me not to interrupt the treatment" (P9)*
	4.5.3.2. Community support	· *"If the health workers link us with psychosocial support groups like EDA, we can get many benefits" (P8)* · *"There is no support group for diabetes patients in our community" (P16)* · *I have got diabetes education from the diabetes association in Addis Ababa" (P10)*
	4.5.3.3. Psychosocial support	· *"If the health workers link us with psychosocial support groups, we can get many benefits. There is no support group for diabetes patients in our community" (P8)* · *I appreciate if the doctors are compassionate and serving to their patients" (P11)*
	4.5.3.4. Peer support	· *"Seeing many other patients at the diabetes association makes me feel like I am not alone in the journey" (P10).*
4.5.4. Perception of quality of follow-up care	4.5.4.1. Lack of comprhensive care	· *"No other medical steps have been done for me other than the blood sugar test whenever I come for follow-up" (P16)* · *"I feel bad if I get sick in the hospital where I came to be cured" (P11)*
	4.5.4.2. Long waiting times	· *"Long waiting time in the hospital is another problem …I feel hungry, shivering, and sometimes even faint while waiting" (P13)* · *"Some patients faint, and some convulse while waiting for a long time" (P9)*
	4.5.4.3. Availability of physical resources	· *"All the time I come to this hospital, they say the Insulin is in stock-out" (P11)* · *"I missed my insulin dose for one day because of a lack of Insulin in both the hospital and private pharmacies" (P10)* · *"I don't have a Glucometer…..I can't afford to buy" (P9)*
	4.5.4.4. Attitude of healthcare workers	· *"We may lack knowledge on what to do and what not to do. So, doctors' advice is always helpful" (P14)* · *"I appreciate that the doctors need to be compassionate and serve their patients" (P11)*

MAIN THEMES	CATEGORIES	SUBCATEGORIES AS DIRECT QUOTATIONS
		· *"Because of the health workers' counselling, I get my health back (P12)*
	4.5.4.5. Organisational environment of the hospital	· *"If the service quality is better in the hospitals, I can continue my follow-up" (P10).* · *"The outpatient department has no connection with the diabetes follow-up clinic" (P10)*
4.5.5. Perception of importance of follow-up care	4.5.5.1. Underestimation of associated risks	· *"I have no signs and symptoms of illness. I have no fear this (diabetes complication) could happen also in the future. If I feel any pain in my kidney, I will go to the hospital" (P11)* · *"In my village, people think that diabetes is not serious, so many don't bother with follow-ups" (P14)*
	4.5.5.2. Follow-up is optional	· *"I miss the appointment if someone relative dies. Also, in the rainy season, I can't come because the roads are usually muddy in summer" (P14)* · *"If I get the insulin and Glucometer at home, why should I travel to the hospital every time?" (P11)*
	4.5.5.3. Narrow perception of follow-up care	· *"I thought that coming here was just to check my sugar and get my insulin" (P16).* · *"I go to the hospital to check my blood sugar and collect Insulin monthly or every 2 months" (P11)*
	4.5.5.4. Misconception about treatment efficacy	· *"I want to stop the treatment because I believe that the prayer and holy water will heal me" (P12).* · *"I check my sugar level on a monthly or two-monthly basis. Sometimes earlier and sometimes longer than a month (P16).*

4.4.2 Analysis and presentation of themes, categories and sub-categories in Phase 2

In Phase 2, four themes and 16 categories emerged. The four themes in Phase 2 were patient retention to follow-up care, systemic challenges in health facilities, diabetes cohort follow-up and patient tracking systems, and effectiveness and quality of follow-up care. The emerged themes and categories, along with the related direct code, are illustrated in Table 4.5.

Table 4.5: Themes, sub-themes, and categories in Phase 2

MAIN THEMES	SUB-THEMES (CATEGORIES	· SUB-CATEGORIES AND DIRECT CODES
4.6.1. The experience	4.6.1.1. Role of healthcare workers	· "*If the counselling is strong, the patients will care about their health, so they will not be lost to follow-up* (P7)

MAIN THEMES	SUB-THEMES (CATEGORIES	· SUB-CATEGORIES AND DIRECT CODES
of HWs in maintaining patient retention	in patient engagement	· "*Most of the time, patients do not tell us their financial problem. Once they know that the hospital service fee is high, they are lost to follow-up"* (P5). · *"Some patients just interrupt the follow-up and start using traditional medicine. Then, they come with complications. Therefore, HWs should teach the patients continuously" (P5).*
	4.6.1.2 Communication challenge between HWs and patients	· "*You might not succeed in getting the patients who live in rural areas in one call. Their telephone battery will be low because there is no electricity in rural areas to charge it"* (P5). · "*They don't give enough time for teaching patients"* (P2)
	4.6.1.3. Consequences of lost to follow-up	· *"Type-1 diabetes patients who present after being lost to follow-up usually come after they develop acute complications like HHS and DKA. Sometimes they also come with chronic complications" (P1)* · *"Defaulters encounter several health problems when they present" (P6)*
4.6.2. Operational and systemic challenges within health facilities	4.6.2.1. Inadequate health Information systems	· "*There's a problem with registration. The nurse working in the chronic care unit hasn't received any training. ….. It needs training"* (P3)
	4.6.2.2. Limited access to essential supplies and medications	· *Once the patients know the price is high, they can go outside and buy the medication from a private pharmacy. Then they disappear and are lost to follow-up"* (P5)
	4.6.2.3. Shortage of trained healthcare workers	4.6.2.3.1. **Lack of training for healthcare workers** · "*I am not trained on diabetes. I am working as per my medical background. And all the other healthcare workers did not receive formal training on DM. Assignment of healthcare workers there is not based on the special training"* (P2) · "*The nurse working in the chronic care unit hasn't received any training"* (P3) 4.6.2.3.2. **The need for structured training programs** · "*There should be trained health workers in all health facilities. If there are no trained health workers, no one can pay attention"* (P7) · "*There should be training and guidelines for the proper utilisation of charts and registers in the chronic care unit to improve the quality"* (P2)
	4.6.2.4. Patient-health worker ratio	**4.6.2.4.1. Lack of dedicated healthcare workers in the diabetes care unit** · "*The problem in this hospital is we (health workers) change routinely. The newly assigned physicians don't know the trend of which patients have lost or not*" (P3).

MAIN THEMES	SUB-THEMES (CATEGORIES	· SUB-CATEGORIES AND DIRECT CODES
		· "*Any physician working in the hospital can be assigned there as per the daily/weekly schedule on a rotation basis*" (P2). **4.6.2.4.2. Busy healthcare workers leave little room for patient education** · "*Health workers do not give adequate time for teaching patients because of patient load*" (P2). **4.6.2.4.3. Emotional toll of overburdened healthcare workers** · "*If our service was compassionate, the patients could trust us……there should be some additional healthcare workers in the chronic OPD unit*" (P5). **4.6.2.4.4. Recommendations for Working in the Diabetes Care Unit** · "*If someone is assigned there permanently or at least for six months, it's better for the patient and the hospital*" (P3).
	4.6.2.5. Misalignment of service delivery with patient needs	· "*We check their blood sugar whenever they come. Depending on the result, we define if there's any need for further intervention, and we do that. If not, we tell them to come to the next appointment*" (P3) · "*Health workers are not given enough time because of patient load*" (P2).
4.6.3. Patient tracking in diabetes follow-up care	4.6.3.1. Inconsistent record-keeping practice	· *"I don't know how many patients are currently doing their follow-up strictly in our hospital …I don't know exactly the outcome of the patients registered in the cohort"* (P3). · *"I don't have experience with how to track whether patients are missed from follow-up. We don't have a mechanism to detect who was lost. We just record those who come, but I don't know what to do for those who are missed" (P6)*
	4.6.3.2. Absence of a functional patient tracking system	· *"The number of patients coming to our clinic every month is less than the expected number when compared to the number registered"* (P3) · *"The cohort registration is not complete, which means it can be difficult to understand whether the patient is in follow-up, lost to follow-up or died.... the health workers sending back the patients just give the medicine" (P7)* · *"I don't have experience with how to track if the patients are missed from follow-up. We don't have a means to detect who was lost. We just record those who come, but I don't know what to do for those who are missed" (P6)*

MAIN THEMES	SUB-THEMES (CATEGORIES	· SUB-CATEGORIES AND DIRECT CODES
	4.6.3.3. Consequences of inadequate record-keeping	· "*One of my patients lost and came after he lost his vision"* (P6) · "*Defaulters encounter several health problems when they present. For example, one of my patients came after he lost his vision"* (P6)
	Tracing patients lost to follow-up	· "*We don't have experience with how to track if the patients are missed from follow-up"* (P6) · "*We have to work in collaboration with the diabetes association. If we link patients to the association, they can also get financial support"* (P5)
	4.6.3.4. Interventions to optimise cohort registration and follow-up systems	· "*I think it would be good if we had the follow-up charts….that we can monitor the outcomes"* (P4) · "*If the cohort follow-up system is strengthened, the health workers can track immediately those lost to follow-up cases…..If this is not strengthened, we can't reduce lost to follow-up"* (P7) · "*There should be strict follow-up mechanisms like ART therapy. If patients disappear from ART, they call and communicate with the patients to come back to the follow-up"* (P5) · "*Training is important for health workers to practice the existing guidelines"* (P7)
4.6.4. HWs' perception of the quality and effectiveness of follow-up care	4.6.4.1. Emphasis on routine tasks	· "*We check their blood sugar whenever they come…. we tell them to come to the next appointment"* (P3) · "*We don't have a follow-up monitoring chart"* (P4)
	4.6.4.2. Perceptions about regular follow-up care	· "*Sometimes patients discontinue their medication after one-month treatment, maybe they feel as if they were cured"* (P7) · "*Some people will disappear to prefer holy water or the church to prayer things; Some people disappear to try traditional medicine like plant leaves"* (P5) · *"The health workers should teach the patients how to take the medication, when to come for the follow-up, and the importance of follow-up care"* (P7)
	4.6.4.3. Failure to implement individualised care	· *"Sometimes the health workers assume patients as if they know everything themselves"* (P2) · *"If the health worker fails to provide individualised care, patients can disappear, and even you can't recognise when they are lost to follow-up"* (P7)

These themes, subthemes, and categories, also referred to as the codes (direct quotations) used, provide a structured understanding of patients' and healthcare workers' experiences with diabetes follow-up care, highlighting barriers, perceptions, and recommendations for improving care quality.

4.5 PHASE ONE: THE EXPERIENCE OF PATIENTS ON LOST TO FOLLOW-UP

Phase one of the study explored the experiences of patients with Type 1 diabetes who had been lost to follow-up. The findings are organised around seven main themes that align with the revised analysis.

The first theme (Section 4.5.1) examines patients' knowledge and awareness of their condition. It highlights the role of education in diabetes management, as well as gaps in understanding and common misconceptions about the disease and its complications. The second theme (Section 4.5.2) discusses barriers to follow-up care. These include financial difficulties, transportation problems, and psychosocial challenges that limit patients' ability to attend appointments. The third theme (Section 4.5.3) focuses on support systems. It considers how family and community support can both enable and hinder continued care. The fourth theme (Section 4.5.4) looks at patients' perceptions of the quality of follow-up care. It touches on satisfaction levels, waiting times, and access to medicines and diagnostic services. The fifth theme (Section 4.5.5) explores how patients experience the effectiveness of follow-up care. Some appeared to underestimate the risks of missing appointments and saw follow-up as optional rather than necessary.

4.5.1 Theme 1: Patients' knowledge and awareness

Theme 1 presents the critical aspects of patients' experiences regarding their knowledge and awareness of Type 1 diabetes and its management, with a focus on follow-up care. It begins by emphasising the significance of patient education and the gaps in understanding that can adversely affect health outcomes. The theme explores patients' awareness of diabetes complications and the common underestimation of risks associated with the condition. Additionally, it addresses misconceptions about the necessity of regular follow-up visits, with many patients believing they can manage their diabetes without consistent healthcare intervention. Finally, the theme offers recommendations for comprehensive education programs aimed at empowering patients

and enhancing their adherence to follow-up care. The section begins with a schematic representation of the overarching theme and its associated categories (see Fig. 4.1).

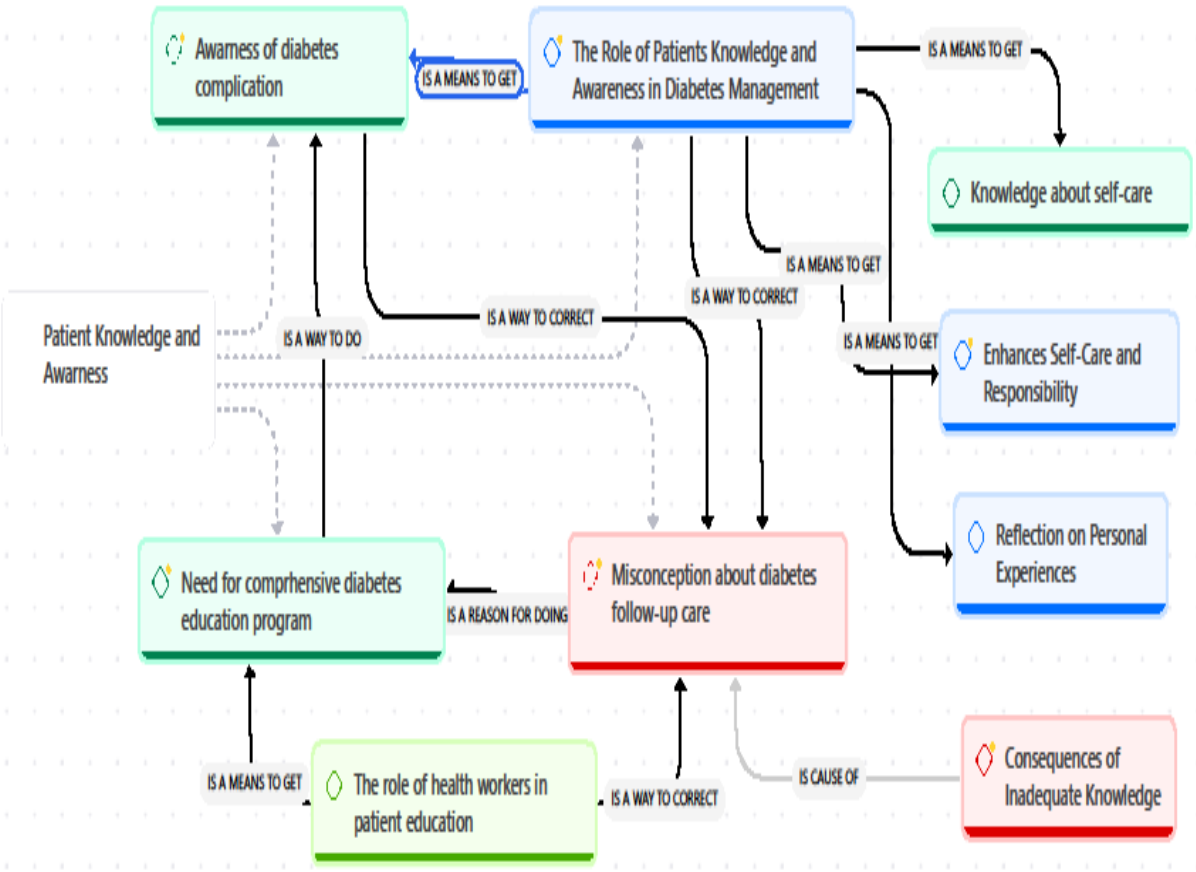


Figure 4.1: Schematic presentation highlighting the role of patient knowledge and awareness

4.5.1.1 Role of patient education in diabetes self-care

The narrative data obtained from patients' experiences emphasise the critical role of patient education in empowering individuals with Type 1 diabetes to take charge of their health. Participants acknowledged that being educated about diabetes is crucial, with one patient stating, *"The information I got from doctors helped me to control my diabetes"* (P10). This sentiment aligns with the work by Letta et al. (2021:6), which found that patients with higher levels of diabetes knowledge were more likely to engage in self-management behaviours, leading to better glycemic control. Structured

educational interventions can improve patients' understanding of their condition and available treatment options.

Patients with a better understanding of diabetes demonstrated awareness of recommended lifestyle choices, medication adherence, and regular follow-up care. One patient explained, "*We have to eat after 30 minutes of taking the medication. However, most DM patients take their medication after they eat*" (P10). This indicates the need for diabetes education on self-care. The American Association of Diabetes Educators (2020:9) recommends an extended duration of education or contact time for newly diagnosed patients through group sessions, followed by individualised sessions based on patient risk profiles and the needs of the patient.

Education will significantly enhance patients' knowledge, contributing to improved self-care behaviour, including self-monitoring and adherence to treatment regimens (Berhanu, Feyissa, Geleta & Sudhakar 2022:8). Healthcare workers have a key responsibility to provide clear, consistent, and ongoing education that strengthens patients' understanding of their condition. Muscat, Shepherd, Nutbeam, Trevena, and McCaffery (2021:3) also highlight the importance of structured health education in promoting adherence. Participants emphasise the desire for more comprehensive education programs to help them manage their diabetes effectively. As one patient said, *"The hospital should provide training to diabetes patients; it might be a 20-minute education program"* (P10) (see details in Section 4.5.1.5).

Moreover, patient education interventions enhance the self-efficacy of patients to attend follow-up care (Defar et al. 2024:11). As one patient said, "*Because of the healthcare workers' counselling, I got my health back"* (P12). This indicates that when patients understand their condition and demonstrate awareness of the recommended follow-up care, they are more likely to engage in proactive health behaviours, including attending follow-up visits.

4.5.1.2 Misconception about diabetes follow-up care

The study reveals significant gaps in understanding diabetes follow-up care and the consequences of LTFU among patients. Participants in the study expressed various misconceptions that directly impact their health outcomes. For instance, many patients consider follow-up appointments as optional rather than essential, often underestimating the risks associated with diabetes complications. One patient said, "*I have no signs and symptoms of illness. I have no fear this (diabetes complication) could happen to me"* (P11). This reflects a risky misconception that can lead to neglecting necessary follow-up care and monitoring. Similarly, a systematic review by Zarora, Immanuel, Chivese, MacMillan, and Simmons (2022:7) highlighted that misconceptions about diabetes significantly hinder patients' motivation to attend follow-up care.

Some patients believe that they can manage their condition without healthcare intervention, often turning to traditional remedies and religious practices instead. One patient noted, "*I stopped coming and taking medicine because I was in church taking religious treatment like holy water. After all, they say I will heal there"* (P12). Similarly, some patients believe that they can manage their diabetes without regular healthcare follow-up, which often results in non-adherence to treatment plans. One patient said, "*I ate whatever I found at home. For how long can I be able to get food in choice?? Since my diabetes happened because of stress, I can get well if I manage my stress"* (P16). This highlights a misconception that can lead to risky health outcomes, as patients may discontinue necessary treatments.

The study also indicates that misconceptions about follow-up care lead patients to gaps in their understanding of ongoing healthcare support. One patient said, *"My family and relatives are insisting that I go to prayer and holy water instead of medicine because they consider it as God's punishment on me"* (P12). Similarly, another patient said, "*Some people advise me to drink local alcohol (Areke and Tella) to relieve my pain. I want to ask you if this is bad for diabetes patients"* (P16). This indicates patients were not equipped with the necessary knowledge on self-care practices. This indicates

that the presence of misconceptions in the community contributes to being lost to follow-up. Other studies have also reported widespread misconceptions about diabetes and follow-up care services (Sun, Taylor, Levin, Renda & Han 2021:7; Zarora et al. 2022).

4.5.1.3 Awareness of complications

The study highlights that patients lack knowledge about diabetes complications and the potential health issues associated with diabetes. Many participants in the study exhibited a limited awareness of the complications due to a lack of structured patient education. For instance, when one patient was asked what he knew about diabetes complications, he openly stated, "*I don't know anything about diabetes complications"* (P12). This indicates that diabetes patients are not well aware of all the risks associated with diabetes after their diagnosis, which underscores the need for more comprehensive education and health promotion interventions.

Moreover, while some patients were aware of specific complications, their understanding was often superficial. One of the T1D patients who discontinued follow-up visits for more than six months said, *"For how long can I get food in choice?? Since my diabetes happened because of stress, I can get well if I manage my stress"* (P16). This indicates that the lack of comprehensive knowledge about diabetes complications also deters patients' commitment to attend follow-up care. On the other hand, the participants' experience shows that some patients do not perceive diabetes as a serious health issue. One participant said, "*I don't have any fear that these diabetes complications can happen to me……I'm very healthy and I'm taking the medicines"* (P11). This risky misconception can lead to neglecting necessary follow-up care and monitoring, potentially resulting in severe health consequences.

The study also found that personal health concerns, such as fear of complications from diabetes, serve as powerful motivators for patients to seek follow-up care. One patient expressed, "*I fear that the disease (diabetes) will progress if I stop the follow-up"* (P8). This aligns with the findings of Letta et al. (2021:7), who reported that patients

who are more aware of the potential complications of their condition are more likely to engage in proactive health management. On the contrary, patients who do not have symptoms underestimate the risks associated with diabetes complications, which leads them to believe that regular follow-up care is unnecessary. One patient expressed, "*I have no signs and symptoms of illness. I have no fear this (diabetes complication) could happen also in the future. If I feel any pain in my kidney, I will go to the hospital"* (P11). This suggests a lack of awareness about the potential for developing complications even when symptoms are not present. This finding is echoed in a study by Sendur and Adas (2021:6), which highlighted that patients often do not recognise the importance of preventive care when they are healthy.

4.5.1.4 Lack of patient education program

The study highlights significant deficiencies in the education of patients with Type 1 diabetes. Participants in the study frequently expressed concerns about the lack of structured educational programs, with one patient stating, *"In this hospital, there is no such education for patients. I have got some diabetes education from a diabetes association in Addis Ababa"* (P10). This highlights a critical gap in the healthcare system: T1D patients often rely on external organisations for essential knowledge to manage their condition.

Patients experienced a wide range of knowledge gaps about diabetes, follow-up care, and self-care practices. One patient said, *"I discontinued the follow-up and insulin for 4 months and started using holy water"* (P12). This underscores that healthcare workers have less persuasive power than traditional healers. Participants often do not receive essential education on the importance of medication and diabetes follow-up care. One patient said, "*The doctors are not teaching us adequately. We may lack knowledge on what to do and what not to do. So, a doctor's advice is helpful"* (P14). This aligns with the study by Wondm et.al. (2024:4), which found that nearly two-thirds (64.9%) of patients in Ethiopian health facilities did not receive adequate diabetes education from healthcare workers.

4.5.1.5 Need for comprehensive education programs

Study participants highlight the need for educational programs to improve their understanding of self-care practices and adherence to follow-up care. They expressed frustration over the lack of educational resources available at their healthcare facilities, indicating that many received little to no education about managing their diabetes. As one patient said, *"In this hospital, there is no such education for patients" (P10).* Similarly, other patients (P8, P12, P16) expressed a desire for more structured educational programs that address various aspects of diabetes follow-up care and management.

The study underscores the essential role of education in empowering patients to take control of their health. One patient suggested, *"The hospital should provide training to diabetes patients; it might be a 20-minute education program"* (P10). In support of this finding, the American Association of Diabetes Educators (2020:1016) found that patients who engaged in structured diabetes education programs exhibited improved self-management skills and better glycemic control compared to those who did not receive such education. Patients emphasise the need for tailored educational interventions that address the specific needs of diabetes patients. Similarly, the importance of comprehensive diabetes education is echoed by other studies (Caro-Bautista, Villa-Estrada, Gómez-González, Lupiáñez-Pérez, Morilla-Herrera, Kaknani-Uttumchandani, García-Mayor & Morales-Asencio 2021:6; Rodriguez, Ryan, Dickinson & Phan 2022:4).

The desire for more comprehensive education programs that address various aspects of diabetes follow-up care and the consequences of LTFU was a key finding in the current study (P8, P10, P12, P16). Moreover, as indicated in the experiences of healthcare workers (Section 4.6.1.1), educated patients with positive experiences are more likely to continue attending than those who are not educated and have negative experiences with follow-up care services. This suggests that education and access to information influence patient behaviour. This need is echoed in the recommendations by Caro-Bautista et al. (2021:6), who advocated for tailored educational interventions

that consider the unique needs of diabetes patients, including cultural and socioeconomic factors.

Participants emphasised the necessity for health education on medication adherence (P12), the timing of follow-up visits (P8), and the advantages of continuous care (P16). One participant articulated, *"The healthcare workers should teach the patients how to take the medication, when to come for the follow-up, and the importance of follow-up care"* (P7). This aligns with the findings of the American Association of Diabetes Educators (2020:9), which found that patients who received clear, consistent communication from healthcare workers demonstrated improved adherence to treatment regimens. This highlights the crucial role of healthcare workers in addressing the knowledge gaps that many patients encounter. Moreover, Zarora et al. (2022:11) highlighted that structured educational programs led by healthcare workers resulted in enhanced self-management among patients with diabetes.

The study identifies several missed opportunities for counselling and diabetes education during their follow-up visit. One patient said, *"The healthcare workers never told me to come for the follow-up visit other than the visit to collect my insulin and the check-up of my blood sugar level"* (P11). This suggests that the role of healthcare workers should extend beyond mere healthcare; they are crucial in empowering patients through education. In general, the study findings, based on the participants' experiences, emphasise the importance of comprehensive education programs in increasing diabetes follow-up care service utilisation and decreasing the consequences of LTFU. Addressing knowledge gaps and correcting misconceptions are essential to empowering patients and enhancing their self-care capabilities.

4.5.1.6 The impact of health literacy on follow-up adherence

The study reveals a critical relationship between patient education and their perceived ability to attend follow-up visits for diabetes follow-up care and management (see details in Section 4.5.1.5). Patients who received education about follow-up care expressed greater confidence in their ability to attend the follow-up visit. For instance,

one patient noted, "*If I hear from doctors the importance of follow-up visit, I'll come. This is my responsibility*" (P11). This statement underscores the empowering effect of knowledge on patient self-efficacy and engagement in their health management.

The study highlights that patients who received organised diabetes training are more likely to apply the recommended self-care practices. One participant said, "*I was trained in BLH hospital that we have to eat after 30 minutes of taking the medication.*" (P10). This illustrates how education fosters self-awareness and proactive management, reinforcing the notion that informed patients are more likely to adhere to self-care practices. Similarly, Flores-Luevano, Pacheco, Shokar, Dwivedi, and Shokar (2020:6) emphasise that structured educational initiatives are essential for improving patient outcomes in diabetes follow-up care and management.

A desire to prevent complications motivates patients to attend future follow-up visits. One patient said, "*Now I understand that if I miss coming for follow-up, I become sick with diabetes or it will progress to other diseases*" (P8). This understanding of the consequences of neglecting follow-up care creates intrinsic motivation, which, in turn, enhances their perceived ability to engage in care. However, a lack of knowledge about diabetes follow-up care was prevalent among most patients in this study. Some believed that if they felt fine, they did not need to attend follow-up visits. Similarly, the study by Rodriguez et al. (2022:4) points out that a lack of awareness about the necessity of regular check-ups significantly impacts patient compliance with the recommended treatment.

According to study participants' experience, the awareness of positive outcomes stimulates attendance at follow-up visits. One patient said, "*The healthcare workers told me the consequences I would encounter if I stopped taking the medicine. So, I will not discontinue the medicine and the follow-up*" (P16). A similar pattern was observed in other studies, which demonstrate an increase in patients' attendance rate with educational interventions (Berhanu et al. 2022:8; Caro-Bautista et al. 2021:6).

4.5.1.7 Summary

Theme 1 emphasises the critical importance of patients' knowledge and awareness of Type 1 diabetes and its management, particularly regarding follow-up care. The participants' experience reveals significant gaps in understanding of diabetes follow-up care, with many patients demonstrating a misunderstanding about the risks of diabetes complications and follow-up visits. Participants expressed a desire for structured educational interventions to enhance their understanding of diabetes management, including medication adherence and lifestyle modifications. The findings highlight the need for comprehensive education programs that empower patients, as increased knowledge is linked to better self-management behaviours and improved health outcomes. Overall, the theme underscores the urgent need for healthcare workers to prioritise patient education to foster adherence to follow-up care and mitigate the risks of complications associated with diabetes.

4.5.2 Theme 2: Challenges negatively associated with follow-up attendance

Theme 2 presents the various aspects of patients' experience regarding the challenges negatively associated with diabetes follow-up visits. It begins with a schematic representation of the overarching theme (see Fig. 4.2) and its associated categories, which further elaborate on the various perceived barriers to follow-up care. Participants experienced various barriers that affect their ability to attend follow-up care, which are summarised under three categories: financial barriers, distance and lack of transportation, and psychosocial and cultural barriers.

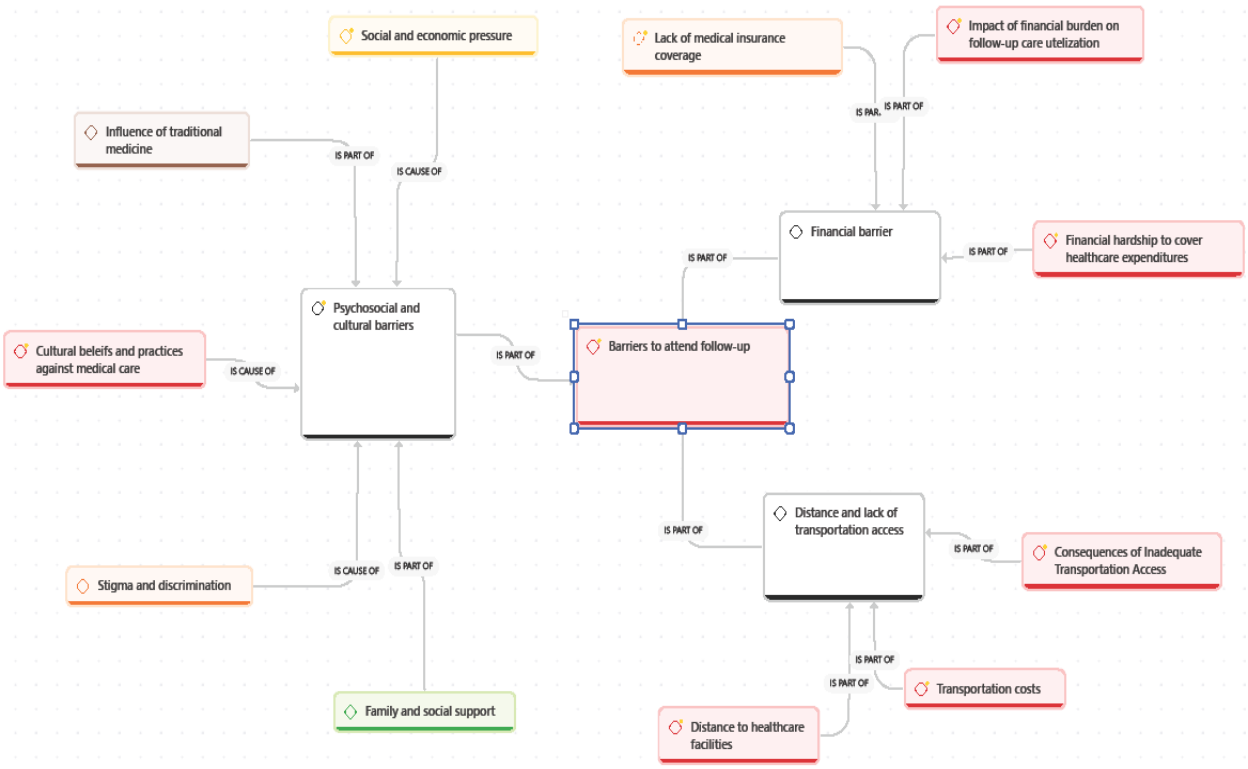


Figure 4.2: Schematic presentation highlighting perceived barriers to diabetes follow-up care

4.5.2.1 Financial constraints

The study highlights financial barriers that significantly impact patients' ability to access diabetes follow-up care. These include the high cost of medications, lack of medical insurance coverage, and out-of-pocket medical and non-medical expenses, all of which collectively hinder patients from attending necessary follow-up appointments.

4.5.2.1.1 Out-of-pocket payment

Participants in the study highlighted the significant financial barriers they face in accessing diabetes care, with many expressing concerns about the high costs of medications, diagnostic tests, and related services. One patient stated, *"I don't have the financial capacity to pay for the medical and laboratory examinations"* (P11). Similarly, the other participant disclosed that he lost to follow-up because of the high cost of medical expenses, saying *"The financial issue is the problem to attend the diabetes follow-up care.…otherwise the service quality in this hospital is very good"* (P9). These

statements reflect the burden of out-of-pocket expenses that prevent low-income patients from obtaining necessary follow-up care, even when quality services are available. A third participant, a cleaner at a children's school, noted, "*Here, the cost of everything increased…. I am a cleaner working in a children's school. I always struggle to cover the medical expenses from here and there (ከዚህም ከዚያም ብየ ነዉ የማመጣዉ)*" (P8). This emphasises the challenge of how healthcare costs often compete with other essential living needs.

The burden of out-of-pocket health expenses can result in lost to follow-up and, consequently, significant health consequences. One patient said, "*I know my neighbour died of diabetes just recently because of a lack of money for treatment*" (P8). This highlights the negative outcomes that can result from financial constraints, emphasising the urgent need for affordable healthcare solutions. The findings of this study align with those of other studies in similar settings, which consistently demonstrate the devastating economic impact of diabetes care costs on low-income individuals. For instance, Tsega, Getaneh, and Taddesse (2021:8) report that diabetic patients frequently face catastrophic health expenditures, with many forced to compromise on necessities like food to afford treatment.

The out-of-pocket burden is particularly severe among the poorest and unemployed individuals. One patient said, *"I don't have money for transportation and service fee"* (P15). Consistent with this study finding, Letta et al. (2021:8) confirmed that nearly 60% of diabetic patients incurred catastrophic costs, and 5% were pushed into poverty. Moreover, in Ethiopia, out-of-pocket healthcare expenditure accounted for 34% in 2017 and 31% in 2020, underscoring the financial strain on households and the need for systemic interventions to ensure affordable diabetes care (Mulat et al. 2022:7; Tsega et al. 2021:8).

4.5.2.1.2 Lack of medical insurance coverage

Participants reported that the absence of medical insurance coverage significantly affected their ability to access care. One patient said, *"I wish to continue my follow-up in*

this hospital if the cost is covered by insurance" (P9). Similarly, the other patient said, "*In this hospital, the medical expenses of diabetes patients are not covered by insurance. So, the patients are expected to cover their expenses from their pocket"* (P10). This restricts the utilisation of follow-up service, decreases treatment satisfaction, and consequently exposes patients to the risks of diabetes complications and discomfort. The findings are in line with those reported by Letta et al. (2021:6) that T1D patients could not receive free Insulin from public hospitals if they did not have a health insurance certificate. As a result, patients were forced to go to private pharmacies where they do not receive comprehensive diabetes follow-up care, resulting in poor glycemic control.

This study highlighted that the high out-of-pocket costs of diabetes treatment remain a significant concern, even among those with insurance coverage. At one of the study hospitals, although medical insurance is available, uninsured patients face substantial disadvantages in accessing care. Furthermore, frequent stock-outs of essential medicines at the health facility limit insured patients' ability to fully utilise their benefits. As one patient explained, *"I have medical insurance coverage here to get medicines free. However, many times this hospital runs out of medicine"* (P13). This frequent problem with the stock of medicine created patient dissatisfaction and diminished trust (Abdelmotaal et al. 2020:4) in healthcare workers, which can ultimately lead to increased rates of lost to follow-up. This indicates that uninsured patients are less likely to seek follow-up care due to the financial burden of out-of-pocket costs.

For Type 1 diabetes patients, access to affordable treatment, including insulin, is critical to their survival. The CBHI (Community-Based Health Insurance) and SHI (Social Health Insurance) systems in Ethiopia, intended to provide health services free of charge in public health facilities, were not fully implemented. Moreover, most SHI providers in Ethiopia do not cover the expenses related to the treatment of NCD, including diabetes. These underscore the importance of effective medical insurance to access the necessary diabetes follow-up care services (World Bank 2020:3).

Overall, the findings reveal significant insights into the financial challenges faced by individuals with Type 1 diabetes. The study found that financial constraints affect patients' ability to access diabetes care, including the high costs of medications and the lack of insurance coverage, which collectively hinder their attendance at follow-up appointments and contribute to worsening health outcomes.

4.5.2.2 Transportation barrier

The study highlights the impact of transportation access on patients' ability to attend follow-up care. This study presents keynotes from participants, illustrating their experiences with transportation challenges, the implications for their health, and the need for systemic changes to improve access to care.

4.5.2.2.1 Distance to healthcare facilities

Participants frequently mentioned the challenges posed by the distance to healthcare facilities. One patient explained, "*It requires me 3 hours to walk on foot to reach the hospital*" (P12). This highlights how geographical barriers can limit access to necessary healthcare services, particularly for those living in rural areas. In agreement with this finding, Hendrix, Warkaye, Tesfaye, Woldekidan, Arja, Sato, Memirie, Mirkuzie, Getnet, and Verguet (2023:6) reported that long travel distances and inadequate transportation options remain major barriers to timely healthcare access in rural settings, leading to missed appointments and poorer health outcomes.

Rural residents are especially affected due to the long distances they must travel to reach health facilities, often through areas with poor infrastructure. One patient said, "*Sometimes I use a horse to come hospital. If I don't succeed in getting a horse, I miss the follow-up and the treatment*" (P12). Consistent with this finding, the study conducted by Abdelmotaal et al. (2020:4) indicates a positive correlation between difficult transportation and patient non-compliance. This suggests that providing transportation to healthcare appointments can increase patient compliance and decrease the need for social support.

4.5.2.2.2 Transportation costs

Patients from low-income backgrounds often struggle to afford transportation, leading to missed appointments and disengagement from care. One patient said, "*It is difficult for me to come always. I miss when I lack the money for transportation"* (P15). These barriers negatively affect continuity of routine follow-up care, consequently leading to being lost to follow-up. One healthcare worker remarked, "*I know my neighbour died of diabetes just recently because of a lack of money for treatment and transportation. He was young and lastly passed away because he had nothing to cover the cost of medical care and transportation"* (P8). This observation aligns with the finding of Shimelash, Belay, Aknaw, Shibabaw, Adebabay, Gedefaw, and Zemariam (2023:4), which reported a threefold higher mortality in rural children with DKA, mainly due to a lack of transportation access. This suggests that transportation challenges may be linked to poor attendance at diabetes follow-up appointments. Thus, preventing these barriers could reduce the incidence of diabetes-related complications.

4.5.2.3 Work obligation

Work obligations are also another challenge, creating pressure on some patients, as many prioritise work and financial stability over their health. One patient explained, *"I am a daily labourer. I fear losing my job…Sometimes I can't take time off to go for my check-up" (P15).* Similarly, the other patient said, "*I have to work during the day, and the hospital hours don't always align with my availability. Sometimes I can't take time off to go for my check-up"* (P8). This pressure can lead to missed appointments and a lack of focus on health management. Consistent with this finding, Abdulai, Marable, Wadus, and Asante (2022:5) underscore that for many low-income and daily-wage workers, economic necessity routinely outweighs health-seeking behaviours. These socio-economic pressures converge, limiting patients' capacity to attend scheduled visits.

4.5.2.3 Cultural influence

This report analyses cultural and social factors as perceived barriers to follow-up care among diabetes patients. The findings are based on qualitative interviews conducted with patients and healthcare workers, highlighting how cultural beliefs and social dynamics impact patients' adherence to follow-up care.

4.5.2.3.1 Cultural beliefs and practices against medical care

Participants often attribute diabetes to spiritual or supernatural causes, prioritising traditional or religious remedies over biomedical follow-up care. One patient said, "*My family and relatives are insisting on me to go to prayer and holy water instead of medicine because they consider it as God's punishment on me*" (P12). Similarly, another patient said, "*In my community, people think that diabetes is not serious; many people don't care about follow-up visits"* (P14). This aligns with Abdulai et al. (2022:7), who point out the significant impact of cultural beliefs on health-seeking behaviour and adherence to healthcare advice. This highlights that culturally rooted beliefs influence patients to substitute healthcare with spiritual alternatives, undermining adherence to follow-up care attendance.

4.5.2.3.2 Influence of traditional medicine

Many patients attribute their diabetes to spiritual or supernatural causes, prompting them to seek traditional or religious remedies instead of formal healthcare. One patient said, "*The only reason I want to stop the treatment is that I believe the prayer and holy water will heal me"* (P12). This shows that some patients give less weight to the healthcare treatment than to alternative interventions. A similar pattern was observed in a study conducted by Molla, Hagger, Rothmann, and Rasmussen (2025:10), which found that many diabetes patients consider biomedical interventions deceptive and rely on folk medicines (both spiritual and herbal) as substitutes.

An inclination towards spiritual etiologies can deter attendance at follow-up care. One patient said, "*If you go for holy water, you have to choose one; either the holy water*

or the medicine. So I chose the holy water" (P12). This belief leads to undermining ongoing engagement with healthcare and an inclination to turn to prayer or herbal treatments rather than clinic-based therapy. The findings are in line with those reported by Ekpor, Osei, and Akyirem (2024:6), namely, substantial diabetes complications as a result of the substitution of Insulin with herbal medicine. Similarly, Kifle, Bayleyegn, Yimer Tadesse, and Woldeyohanins (2021:2) reported that 58.5% of diabetes patients use herbal medicine. This suggests the strong impact of cultural belief systems on healthcare service utilisation, as belief in spiritual causation was directly linked to poor adherence to healthcare appointments.

4.5.2.3.3 Stigma and discrimination

Patients reported experiencing stigma related to their diabetes, which can discourage them from seeking care. A participant shared, "*I realised that you can get a better service if you have someone you know in the hospital"* (P10). This highlights the social dynamics at play, where patients feel they need connections to receive adequate care, leading to feelings of inadequacy and reluctance to seek help. "Recent research highlights that diabetes-related stigma is highly prevalent affecting up to 70% of adults with diabetes and is associated with reduced self-care behaviors, increased psychological distress, and poorer clinical outcomes such as higher HbA1c (İşleyen & Özdemir 2024:4). Moreover, studies in low and middle income countries show that stigma can lead patients to conceal their diagnosis, avoid hospital visits, and delay treatment particularly when they perceive lack of social support or feel judged by health professionals (Eitel, Pihoker, Barrett & Roberts 2024:6).

4.5.2.4 Summary

Overall, theme 2 explores the various challenges that hinder patients from attending necessary follow-up care appointments. Financial constraints emerge as a significant obstacle, with patients citing high costs for medications, diagnostic tests, and transportation as major deterrents to seeking care. Distance from the health facility and

work obligations are also imposing considerable challenges to attending follow-up appointments. Additionally, the study highlights the impact of cultural beliefs that undermine diabetes follow-up care. The emotional and psychological challenges faced by patients, such as feelings of isolation or frustration stemming from negative past experiences with healthcare services, further complicate their willingness to engage in follow-up care. Overall, the findings underscore the need for targeted interventions to address these multifaceted barriers and improve patient adherence to follow-up care, thereby enhancing health outcomes for individuals with diabetes.

4.5.3 Theme 3: Support system

Theme 3 explores participants' experiences with support systems in the management of Type 1 diabetes, focusing on how family and social support influence patients' adherence to treatment and attendance at follow-up appointments. The findings highlight the encouragement from family members. Additionally, it examines the availability and impact of community support systems, including support groups and educational programs. It also presents the participants' experience on how emotional and psychological support from family and healthcare workers affects patients' ability to attend follow-up care.

4.5.3.1 Family and social support

The study reveals the significant impact that family dynamics and social networks have on diabetes follow-up care. Current defaulters who receive support from family members are more optimistic about resuming follow-up visits. One patient said, "*My husband and my children always support me"* (P8). Similarly, another patient stated, "*My children also advise me not to interrupt the treatment"* (P9). This indicates that the encouragement from family members can influence patients' decisions to attend follow-up visits. This aligns with the study by Letta et al. (2021:8), which found that strong family support correlates with improved health outcomes in diabetes follow-up care and management. On the contrary, patients also experienced confusion because of conflicting advice from family members. One patient mentioned, "*Some of my family*

tell me to follow doctors' advice, and the others tell me to go to holy water" (P12). This underscores the need to involve family members during follow-up visits to clarify misconceptions about follow-up care. Conflicting advice from family members can lead to confusion and decrease adherence to healthcare recommendations (Kimbell, Lawton, Boughton, Hovorka & Rankin 2021:6).

Lack of support from family and friends can lead to feelings of isolation (see Section 4.5.2.2.3) and decrease the desire to attend follow-up visits. One patient noted, "*In my village, diabetes is considered an urban disease…..My family and community are confused about how I brought diabetes while I am a rural resident"* (P12). Because of the fear of this discouraging reaction, diabetes patients can not openly discuss their condition with their family members. Thus, patients may feel disheartened from seeking care. A similar pattern was observed in the study conducted by Pamungkas, Chamroonsawasdi, and Usman (2021:10), which reported that diabetes patients tend to avoid expressing their needs due to negative responses from family members, especially regarding eating behaviours and unhealthy lifestyle choices.

Moreover, this study demonstrates the influence of social perceptions on diabetes follow-up care and management. Some patients expressed that social pressures to seek alternative treatments detracted from following healthcare advice. For instance, one patient said, *"My relatives are insisting on me to go to prayer and holy water instead of medicine because they consider it as God's punishment on me" (P12).* This aspect is crucial to address in diabetes management, as it reflects the broader social context in which patients experience their daily interactions.

4.5.3.2 Community support

The study highlights the essential role that community support plays in diabetes follow-up care and management. The study presents participants' experiences in accessing community resources, such as support groups and educational programs. Patients reported a lack of community-based support in their area, hindering their ability to access these resources. One patient said, *"There is no support group for diabetes in our*

community" (P16). This underscores the need for community support that can enhance patients' ability to maintain follow-up care and self-care. Consistent with this finding, Dietz, Sherrill, Ankomah, Rennert, Parisi, and Stancil (2023:6) reported better self-management skills and increased attendance among patients who engaged in community support groups.

Moreover, the study indicates a disconnect between healthcare systems and community resources. One healthcare worker mentioned, "*I heard that there is a diabetes association in the town. If the healthcare workers link us with that, we can get many benefits"* (P8). This suggests that while community resources may exist, they are not effectively integrated into the healthcare system, leading to missed opportunities for patient support. The lack of collaboration between health systems and community organisations can result in patients being unaware of available resources that could aid in their diabetes follow-up care and management. One patient said, *I have heard sometimes before about a diabetes patient's association in this hospital. Currently, I think the association is not present"* (P10).

Additionally, community resources can provide essential education and support, helping patients navigate their health challenges more effectively. One patient said, *"I have got this education from the diabetes association in Addis Ababa"* (P10). The other patient said, *I managed my eating habits as per the education I got from the EDA (Ethiopian Diabetes Association) in Addis Ababa"* (P10). This indicates that community engagement serves as a stimulus for health-seeking behaviours. This finding is consistent with the study by Higa, Davidson, and Loos (2021:5), which highlights that patients who engage with community resources are more likely to adhere to treatment regimens and maintain regular healthcare appointments. Similarly, Zeidi, Morshedi, and Otaghvar (2021:10) underscore the role of community-based intervention to improve behavioural change in diabetes patients.

In general, the study underscores the important role of community support in diabetes follow-up care and management. While patients express a need for more accessible community support, the existing resources are often underutilised due to a lack of

awareness and integration with healthcare systems. Addressing these gaps through improved collaboration between healthcare workers and community organisations is essential for enhancing patient adherence to follow-up care and overall health outcomes. By fostering a more supportive community environment, healthcare systems can empower patients to take an active role in managing their diabetes effectively.

4.5.3.3 Psychosocial support

Psychosocial support emerged as an important theme in the management of Type 1 diabetes in this study. Participants emphasised the importance of emotional and psychological support from family, healthcare workers, and the community, which significantly influences their ability to adhere to treatment and manage their condition effectively. One patient said, "*If the healthcare workers link us with psychosocial support groups, we can get many benefits. There is no support group for diabetes patients in our community"* (P8). This suggests that diabetes follow-up care should address the psychological needs of patients beyond clinical care. Consistent with this finding, Van Wilder, Pype, Mertens, Rammant, Clays, Devleesschauwer, Boeckxstaens, and De Smedt (2021:7) highlighted evidence showing that patients with chronic illnesses who received psychosocial support showed better health outcomes and improved quality of life.

Moreover, patients expressed a desire for more compassionate and attentive care from healthcare workers. One patient remarked, *"I appreciate it if the doctors need to be compassionate and serve their patients"* (P11). This shows the importance of psychological treatment from healthcare workers in the diabetes care unit. Consistent with this finding, Atinga, Gmaligan, Ayawine, and Yambah (2024:5) noted that patients who felt emotionally supported were more likely to engage in their treatment plans.

The lack of psychosocial support significantly affects patients' commitment to attend follow-up care. One patient stated, "*those who have no one to know might not get the medical service"* (P10). This suggests that a lack of trust in the caregiver leads to feelings of remoteness and a decreased motivation to attend subsequent follow-up

visits. This observation corresponds with the results of Abdelmotaal et al. (2020:6), which show a positive correlation between lack of psychosocial support and the presence of disabling comorbidities. Similarly, Feleke et al. (2021:8) reported a high LTFU rate among vulnerable groups (old age, people with disability, children and critically ill patients) who lack social and family support. It was also emphasised that this group of patients is more often socially deprived, with an increased likelihood of other medical conditions (İşleyen & Özdemir 2024:4), and they often have a poor attendance history (Tino et al. 2019). Therefore, psychosocial support should be considered an essential component of diabetes follow-up care.

4.5.3.4 Peer support

Lastly, interactions with peers can motivate individuals to attend follow-up care. The study found that sharing experiences among patients fosters a sense of belongingness and accountability. One patient said, "*Seeing many other patients at the EDA makes me feel like I am not alone in the journey"* (P10). This suggests that peer support groups play a crucial role in enhancing adherence to follow-up care by offering emotional and motivational support. Thus, peer education is an effective method for addressing the behavioural and emotional aspects of diabetes and promoting ongoing self-care (Castillo-Hernandez, Espinosa, Molina-Segui, Ayuso-Peraza, Mena-Macossay, Mendez-Dominguez, Bastarrachea & Laviada-Molina 2024:8).

4.5.3.5 Summary

To sum up, theme 3 highlights the role of support systems in the management of Type 1 diabetes, emphasising how family and other social support significantly influence patients' adherence to follow-up care. The study reveals that encouragement from family members often leads to better health outcomes, as patients who receive strong support are more likely to engage in their care. However, complexities within family dynamics, such as conflicting advice, can hinder treatment adherence. Community support, including support groups and educational programs, is identified as essential for enhancing diabetes follow-up care, yet many patients report limited access to these

resources. Additionally, psychosocial support is underscored as a vital component of effective diabetes management, with emotional and psychological backing from both family and healthcare workers significantly impacting patients' ability to attend follow-up care. Moreover, the experiences shared among peer groups can foster a sense of belongingness and accountability. Overall, the findings suggest that enhancing family and social support and integrating psychosocial support into diabetes care strategies are crucial for improving patient adherence and health outcomes.

4.5.4 Theme 4: Patients' perception of follow-up care quality

The quality of diabetes follow-up care was one of the most emerging themes in this study. It explores participants' experience with the quality of diabetes follow-up care, focusing on several critical aspects that influence their perceptions of the follow-up care. Key categories include patient satisfaction with services, the impact of waiting times on patient experiences, medication availability, the attitude of healthcare workers, and the organisational environment of the healthcare facility. The section also incorporates patients' recommendations for improving follow-up services. The section begins with a schematic representation of the overarching theme and its associated categories (see Fig. 4.3).

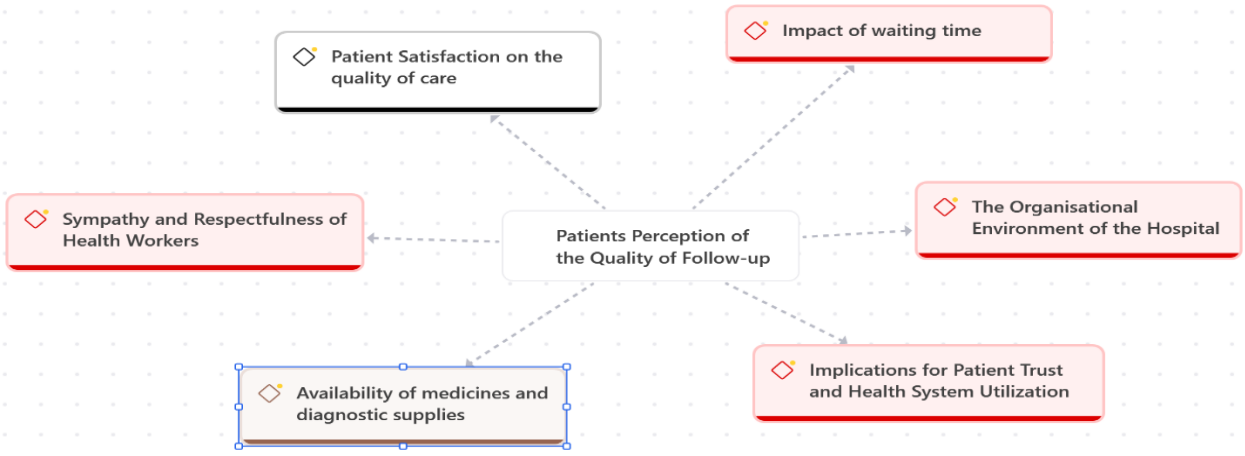


Figure 4.3: Schematic presentation highlighting patients' perception of quality of follow-up care

4.5.4.1 Lack of quality of care

The lack of quality follow-up care services for diabetes patients affects their satisfaction with the healthcare system. Participants expressed dissatisfaction with the limited scope of services provided during follow-up visits, often feeling that their needs were not adequately addressed. When asked about the services he received during the follow-up visit, one patient responded, "*No other medical steps have been done for me other than the blood sugar test whenever I come for follow-up"* (P16). This sentiment reflects a broader concern that the follow-up care patients receive is often insufficient, focusing primarily on routine tasks rather than comprehensive management of their condition.

Likewise, the absence of comprehensive follow-up services, including patient education and counselling on self-care practices, undermines the quality of diabetes follow-up care. One patient noted, *"I don't believe the service quality is good in this hospital"* (P11). This indicates that patients who perceive their follow-up care as lacking in quality tend to disengage from necessary health management. These results align with the findings of Kabir, Karim, Islam, Romero, and Billah (2022:12), who found that a lack of quality healthcare leads to poor compliance with care, resulting in complications and worsening health conditions.

Moreover, the unpleasant emotional impact of inadequate follow-up care was evident in participants' responses. One patient expressed her emotion, saying, "*Whenever I come, they give me the medicine without any investigation, and I did not get well since now* (P16). This reflects a sense of frustration and helplessness that can arise when patients feel their concerns are not being adequately addressed. Similar insights were reported by Defar et al. (2024:11), indicating that patients who experience poor care often report higher levels of anxiety and dissatisfaction, which can deter them from seeking necessary treatment.

In general, poor follow-up care services can erode trust in the healthcare system, prompting patients to seek care elsewhere. As one participant noted, "*If I get the insulin and Glucometer at home, I will not go to the hospital at all"* (P11). This suggests that if patients feel they can obtain medicine independently elsewhere, they may disengage from the follow-up system altogether, thereby undermining the importance of regular follow-up. This is consistent with the study conducted at the University of Gondar Comprehensive Specialised Hospital in Ethiopia, which found that patients with chronic disorders who were dissatisfied with the healthcare services provided were more likely to disengage from follow-up care (Melkam & Kassew 2023:6).

4.5.4.2 Long waiting time

Waiting times negatively impact patient satisfaction with healthcare services. Participants consistently expressed frustration with prolonged wait times at healthcare facilities, which they felt reduced their willingness to attend scheduled follow-up visits. One patient articulated, *"We come here to do a blood sugar test before breakfast. Sometimes they start the work at 10 am. It is difficult for me to be late or absent from my work"* (P8). Similarly, the other patient said, *"The other problem for us is that we wait until the doctors and laboratory start work after 8:30 am. This is a challenge for us; some patients faint, and some convulse while waiting for it"* (P9). This sentiment underscores a common theme where long waiting times not only create logistical challenges but also contribute to emotional distress, leading patients to question the quality of care.

Extended waiting times are a primary source of dissatisfaction among patients, leading to decreased trust in healthcare workers (McIntyre & Chow 2020:6) and reluctance to return for follow-up visits (Aburayya, Alshurideh, Albqaeen, Alawadhi & Ayadeh 2020:5). Patients who experience long waits develop negative perceptions of their healthcare experience, which can adversely affect their adherence to treatment plans. One patient said, "*It doesn't encourage us to go to that hospital at all…..It makes you sick rather than a place to heal"* (P11).

Moreover, the emotional toll of waiting was evident in the participants' responses. One patient noted, *"Long waiting time in the hospital is another problem. I don't have the money to buy and eat something like snacks (ቆጮና ሻይ). I feel hungry, shivering, and sometimes even faint while waiting" (P13).* The other patient said, *"This is a challenge for us, some patients faint, and some convulse while waiting long for it" (P9).* Similarly, the other patient said, *"The only service we come and wait all this long is to get the blood sugar test and collect Insulin"* (P11). This reflects a broader concern for prolonged waiting periods, which can lead to physical discomfort and anxiety, further complicating patients' health management. A study by Aburayya et al. (2020:5) corroborated this, indicating that patients who wait longer for services often report higher levels of stress and dissatisfaction, which can deter them from seeking necessary care.

The findings suggest that healthcare facilities must prioritise reducing waiting times to enhance patient satisfaction. Participants in this study recommended improvements in service delivery, emphasising the need for timely care. One patient suggested, *"It is difficult for me to be late or absent from my work. If they provide the service on time, it will be good"* (P8). This aligns with recommendations from recent studies advocating for systemic changes in healthcare delivery to streamline processes and minimise delays. For instance, a study by Havlir, Kamya, and Petersen (2024:6) proposed implementing triage systems and optimising appointment scheduling to improve patient flow and reduce waiting times.

To summarise, the impact of waiting times on patient satisfaction is a critical issue that healthcare workers must address. The emotional and physical well-being of patients is closely tied to their perceptions of care quality, making it essential for providers to prioritise timely service delivery as a fundamental aspect of patient-centred care.

4.5.4.3 Availability of physical resources

A lack of essential medications significantly impacts patient satisfaction. Participants expressed frustration regarding the frequent unavailability of insulin, which forced

them to purchase medications from private pharmacies at higher costs. One participant noted, "*All the time I come, they say the Insulin is out of stock. Then, I have to buy from a private pharmacy, which is expensive"* (P11). This highlights the emotional and financial burden placed on patients when medications are not readily accessible, ultimately impacting their overall satisfaction with the healthcare system. A similar pattern was observed in the study conducted by Muscat et al. (2021:10), who found that patients who frequently encountered medication shortages reported lower satisfaction levels and were more likely to seek care elsewhere. Therefore, consistent access to medications is crucial for maintaining patient trust and satisfaction with healthcare services.

Patients often felt neglected when their essential medications were unavailable, which led to feelings of helplessness and dissatisfaction with the healthcare system. One patient said, *"Sometimes we can't get the Insulin here. They tell us to buy from a private pharmacy"* (P14). This emotional toll can discourage patients from seeking necessary follow-up care, further exacerbating health issues. These results align with the study by Kvarnström, Westerholm, Airaksinen, and Liira (2021:10), which highlighted that medication availability directly correlates with treatment adherence.

Similarly, patients who experienced regular shortages were less likely to adhere to their prescribed treatment regimens, resulting in poorer health outcomes. Participants expressed that the inability to access insulin affected their diabetes follow-up care and management and overall health. One patient said, *"I missed my insulin dose for one day because of a lack of Insulin in both the hospital and private pharmacies"* (P10). Similarly, a study in Ethiopia by Asamrew, Endris, and Tadesse (2020:7) confirms that the lack of medication in health facilities correlates with patients' dissatisfaction with healthcare.

4.5.4.4 The organisational environment of the hospital

Participants expressed the lack of organised service for diabetes follow-up care in the hospitals. One patient said, "*If I need any further medical checkups, I go to the adult*

outpatient department and ask for an appointment to see a doctor. The OPD have no connection with the diabetes care unit" (P10). This creates a delay in the referral and consultation system between speciality clinics, which is the other reason for extended stay periods in the health facility. One patient said, "*If the service quality is better in the hospitals, I can continue my follow-up"* (P10). This is in agreement with the conclusions drawn by Defar et al. (2024:9), who reported that the health infrastructure for diabetic care in Ethiopia falls short of standards.

4.5.4.5 Attitude of healthcare workers

The relationship between healthcare workers and patients influences patients' perception of the quality of follow-up care. Patients in this study expressed a desire for more compassionate and attentive care from healthcare workers, indicating that effective communication is crucial for fostering trust and adherence to medical advice. One patient noted, *"I don't know much about what the follow-up care services for diabetes patients are"* (P11). Similarly, the other patient said, "*I always return with doubt thinking about the effectiveness of the medication"* (P16). This highlights a critical communication gap, where patients are often left uninformed about the importance of follow-up care and the necessary steps they should take. Clear communication between healthcare workers and patients significantly enhances adherence to follow-up care. The study by Muscat et al. (2021:3) shows that patients who were less informed about their condition were more likely to disengage from follow-up care.

Moreover, as highlighted in Section 4.6.2, healthcare workers acknowledged that inadequate patient education by healthcare workers contributed to LTFU. One patient said, "*The doctors are not teaching us adequately. We may lack knowledge on what to do and what not to do. So, doctors' advice is always helpful"* (P14). This reflects a systemic issue in which healthcare workers may assume patients have a sufficient understanding of their condition, leading to a lack of proactive education and counselling. Such assumptions can result in missed opportunities to reinforce the importance of regular visits and comprehensive care. Similarly, Wei, Corbett, Ray and Wei (2020:4) highlighted that misunderstandings about treatment and follow-up care often

stem from inadequate communication, which can lead patients to seek alternative remedies instead of adhering to healthcare advice. This underscores the urgent need for improved educational initiatives that address both medical and lifestyle aspects of diabetes follow-up care and management.

Some patients misunderstand the role of healthcare workers, considering them primarily as dispensers of medication rather than as partners in their health management. This can hinder effective communication and collaboration. One patient said, *"The healthcare workers never told me to come for the follow-up visit other than the visit to collect my insulin and the check-up of my blood sugar level.* (P11). This indicates a missed opportunity for healthcare workers to provide counselling and patient education. Participants provided recommendations for improving healthcare workers' approach to patients. One patient suggested, "*I appreciate it if the doctors need to be compassionate and serve their patients"* (P11). This indicates that patients desire not only better logistical aspects of care but also a more compassionate approach from healthcare workers.

Compassionate care plays a crucial role in enhancing patients' overall quality of care and satisfaction, particularly in settings involving chronic disease management. One patient said, "*Because of the healthcare workers' counselling, I get my health back* (P12). This indicates compassionate, patient-centred communication significantly enhances treatment adherence and patient satisfaction. Therefore, healthcare workers should be collaborative partners of patients (Watts, Patel, Kostov, Kim & Elkbuli 2023:4).

4.5.4.6 Summary

Overall, Theme 4 explores patients' perceptions regarding the quality of diabetes follow-up care, revealing significant dissatisfaction with the services provided. Participants highlighted several challenges, including long waiting times, limited diagnostic services, and frequent medication shortages, which collectively contribute to their negative experiences. Many patients expressed feelings of neglect and frustration, noting

that their needs were often inadequately addressed during follow-up visits. The emotional impact of these experiences was evident, with patients reporting increased anxiety and a sense of helplessness when they felt their concerns were not taken seriously. Additionally, the study emphasises the importance of respectful and compassionate interactions with healthcare workers, as these factors significantly influence patient satisfaction and adherence to follow-up care. Overall, the findings underscore the need for healthcare systems to address the quality of diabetes follow-up care services.

4.5.5 Theme 5: Patients' perception about the importance of follow-up care

Theme 5 outlines patients' perceptions of the effectiveness of follow-up care in diabetes management, focusing on their beliefs about the necessity of regular appointments and the risks associated with diabetes complications. It discusses the misconceptions that lead patients to view follow-up visits as optional, the lack of awareness of the comprehensive nature of diabetes management, and the reliance on traditional medicine rather than follow-up care. It begins with a schematic presentation that highlights patients' perceptions of the effectiveness of follow-up care. The section begins with a schematic representation of the overarching theme and its associated categories (see Fig. 4.4).

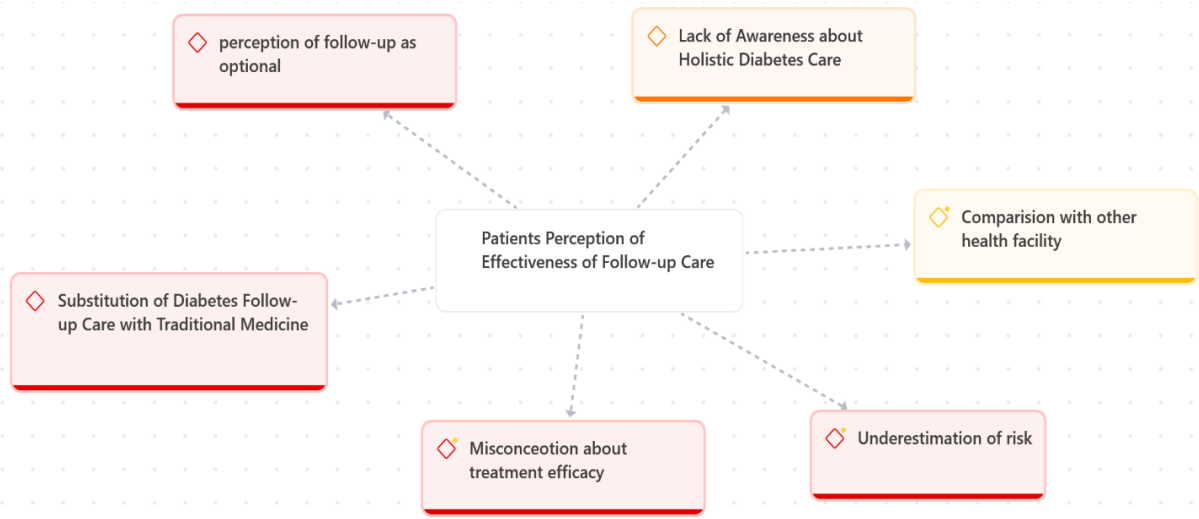


Figure 4.4: Schematic presentation highlighting patients' perception of the effectiveness of follow-up care

4.5.5.1 Underestimation of associated risk

This study reveals significant insights into patients' perceptions regarding the risk of diabetes complications. Patients underestimate the risks associated with diabetes complications, leading them to believe that regular follow-up care is unnecessary. One patient said, *"I have no signs and symptoms of illness. I have no fear this (diabetes complication) could happen also in the future. If I feel any pain in my kidney, I will go to the hospital"* (P11). This suggests a lack of awareness of the potential for developing complications even when symptoms are absent.

Patients may not fully understand the potential complications of diabetes, leading to a belief that follow-up care is not critical for their health. One patient said, "*In my village, people think that diabetes is not serious, so many don't bother with follow-ups"* (P14). This highlights the need for better education regarding the consequences of missed follow-up care. Moreover, patients often do not recognise the importance of ongoing follow-up care in managing chronic conditions like diabetes. According to Sendur & Adas (2021:6), patients who neglect necessary lifestyle changes and follow-up appointments often exhibit poor health outcomes and present with complications.

4.5.5.2 Perception of follow-up as optional

This study found that patients perceive diabetes follow-up visits as optional rather than mandatory, leading to missed appointments and disengagement from care. One patient said, "*I miss the appointment for social reasons mainly if someone relative dies. Also, in the rainy season, I can't come because the roads are usually muddy in summer"* (P14). This suggests a casual attitude toward regular follow-up. Recent studies have shown that such perceptions, combined with contextual barriers such as transportation challenges, are associated with decreased appointment attendance and disengagement in diabetes care (Kumar, Velu, Pardhan, Sapkota, Ruamviboonsuk, Tadarati, Chotcomwongse, Nganthavee, Pattanapongpaiboon & Raman 2023:10).

Some patients undervalue the importance of regular check-ups. One patient said, "*If the service quality is better in the hospitals and the health centres near my village, I can get the service here"* (P10). Another patient noted, "*If I get the insulin and Glucometer at home, why should I travel to the hospital every time?"* (P11). This suggests a belief that home-based testing could replace clinic visits, which undermines the necessity of follow-up care. Complementing these findings, Angnes, Ginting, and Wienaldi (2024:8) confirm that when follow-ups are seen as routine, patients' motivation and engagement significantly decline, and clinics are perceived more as burdens than healing spaces.

The perception of follow-up visits as routine rather than integral to health management can lead to complacency. One patient said, "*The only service we come and wait for is to get the blood sugar test and collect Insulin. It doesn't encourage me… It makes you sick rather than a place to heal"* (P11). This indicates a lack of engagement and misunderstanding. This finding aligns with the systematic review by Yao, Zhou, Xu, Lehman, Haroon, Jackson, and Cheng (2021:19), which highlights that when visits are handled mechanically, devoid of education, counselling, and meaningful communication, patients disengage, view clinics negatively, and often skip future appointments.

On the other hand, patients who recognise the effectiveness of follow-up care intend to attend. One patient said, "*When I come for a follow-up, I ask the doctor to examine my eyes"* (P8). This shows that follow-ups are seen as essential preventive steps, such as regular eye examinations. These results align with the findings of Gow, Rashidi & Whithead (2024:4), which reported that patients who recognise the value of diagnostic and complication-prevention services are more likely to attend follow-up appointments and actively engage in their care.

4.5.5.3 Narrow perception of follow-up care

Most diabetes patients often do not recognise that comprehensive diabetes care involves a holistic approach, including dietary counselling, physical activity recommendations, and psychological support. This misunderstanding led to LTFU. One patient

said, "*I thought that coming here was just to check my sugar and get my insulin"* (P16). This reflects a gap in education regarding the multifaceted nature of diabetes management. This is consistent with Sendur and Adas. (2021:6), which reported suboptimal glycemic control and increased complications among patients with limited awareness about the broader components of diabetes care.

Many patients equate follow-up care solely with the act of testing blood sugar levels and collecting medications, overlooking the broader aspects of diabetes management, such as education, lifestyle modifications, and regular health assessments. One patient stated, "*I go to the hospital to check my blood sugar and collect Insulin monthly or every 2 months. However, I don't know about the follow-up program other than this"* (P11). This highlights the limited understanding of the comprehensive nature of diabetes follow-up care. Consistent with this finding, the study by Letta et al. (2021:6) emphasised that when follow-up visits focus narrowly on biomedical procedures without structured education and behavioural support, patients often miss the opportunity to benefit from preventive and holistic care models.

4.5.5.4 Misconception about treatment efficacy

Many participants expressed scepticism about the effectiveness of diabetes treatment. One patient said, "*I want to stop the treatment because I believe that the prayer and holy water will heal me" (P12).* This indicates a significant misconception among patients regarding the efficacy of treatment, which can lead to dangerous health outcomes if they discontinue their treatment.

Patients also believe that their current treatment regimen is sufficient without the need for regular monitoring and adjustments that follow-up care provides. One patient said, *"I check my sugar level on a monthly or two-monthly basis. Sometimes earlier and sometimes longer than a month* (P16). This reflects a misconception about the importance of regular follow-up care attendance.

4.5.5.5 Summary

Overall, Theme 5 explores patients' perceptions of the effectiveness of follow-up care in diabetes management, revealing a significant underestimation of the risks associated with diabetes complications. Many patients believe that regular follow-up visits are unnecessary, often citing a lack of symptoms as a reason for their disengagement. This theme highlights the need for better education about the potential complications of diabetes and the importance of ongoing care. Additionally, patients frequently perceive follow-up visits as optional rather than essential, leading to missed appointments and a reliance on home-based testing. The study also uncovers misconceptions about the holistic nature of diabetes management, with many patients equating follow-up care solely with medication collection and blood sugar testing, neglecting other critical aspects such as dietary counselling and psychological support. Overall, this theme underscores the urgent need for improved patient education and support to enhance the perceived value of follow-up care and encourage adherence.

4.5.6 Summary of Phase One

Phase one of the study presented the experiences of Type 1 diabetes patients who were lost to follow-up. Seven themes and 27 categories (sub-themes) were identified and discussed, each highlighting critical aspects of patient experiences and their perceptions regarding lost to follow-up care.

Theme 1: Patients' knowledge and awareness revealed significant gaps in understanding diabetes management, with many patients underestimating the importance of regular follow-up care and the risks associated with complications. This lack of awareness often led to misconceptions about the necessity of ongoing healthcare intervention, with some patients believing they could manage their condition independently.

Theme 2: The various challenges negatively associated with follow-up attendance were identified and discussed. These include financial constraints, transportation issues, work obligations, and cultural influences. Patients shared their experiences in which these challenges contributed to being lost to follow-up.

Theme 3: Support system emphasised the role of family and community resources in facilitating care. Patients who had strong support systems were more likely to engage in follow-up care, while those lacking such support faced greater challenges.

Theme 4: Patients' perception of quality of follow-up care discussed dissatisfaction with the quality of care received, highlighting issues such as long waiting times, inadequate access to medications, and a perceived lack of empathy from healthcare workers. This dissatisfaction often discouraged patients from returning for follow-up visits.

Theme 5: Patients' perception of the importance of follow-up care indicated that many patients viewed follow-up care as optional, often substituting it with traditional healing practices. This perception was linked to a general underestimation of the risks associated with diabetes.

4.6 PHASE TWO: EXPERIENCES OF HEALTHCARE WORKERS ON LOST TO FOLLOW-UP PATIENTS

In Phase 2, the study explored the experiences of healthcare workers in relation to lost-to-follow-up T1D patients. This phase comprises four major themes: Theme 8: Experience of HWs in maintaining patient retention, which discusses the findings on the communication barriers, systemic challenges in healthcare facilities, the role of healthcare workers in influencing compliance, and the consequences of non-compliance; Theme 9: Systemic challenges in health facilities, covering inadequate HMIS, shortage of trained healthcare workers, and fluctuations in medication availability; Theme 10: Record-keeping and patient tracking systems; and Theme 11: Perceptions

of healthcare workers on the effectiveness and quality of follow-up care. These interconnected themes provide a comprehensive understanding of healthcare workers' experiences with lost to follow-up among Type 1 diabetes patients.

4.6.1 Theme 6: The experience of healthcare workers in maintaining patient retention

Theme 6 presents the experiences of healthcare workers in maintaining patient retention for Type 1 diabetes follow-up care. It highlights communication barriers that hinder effective engagement. It also discusses the role of healthcare workers in maintaining patient engagement and the consequences of non-compliance.

4.6.1.1 Role of healthcare workers in patient engagement

The study highlights the critical role of healthcare workers in patient adherence to diabetes follow-up care and management. Healthcare workers highlighted the importance of effective communication and counselling to ensure patients understand the necessity of adhering to their treatment regimens. One healthcare worker stated, "*If the counselling is strong, the patients will care about their health, so they will not be lost to follow-up* (P7). This underscores the pivotal role that healthcare workers play in shaping patient perceptions of follow-up attendance and self-care behaviours. These findings are consistent with those of Wei et al. (2020:4), which highlight the importance of effective communication and strong relationships between healthcare workers and patients in enhancing adherence to treatment plans. Similarly, Muscat et al. (2021:3) found that patients who receive clear guidance and support from their healthcare workers are more likely to engage in their care and attend follow-up appointments.

Moreover, healthcare workers expressed frustration over the systemic challenges affecting patients, since it is beyond their capacity to control patients' engagement. One healthcare worker shared his experience, saying, "*Most of the time, patients do not tell us their financial problem. Once they know that the hospital service fee is high, they are lost to follow-up"* (P5). The interplay between socioeconomic factors and patient

compliance (Burnier 2024:3) highlights the need for healthcare workers not only to offer healthcare but also to recognise the barriers patients encounter. Although healthcare workers may not always be in a position to address these barriers directly, they must acknowledge these challenges and advocate for meaningful change.

Additionally, healthcare workers report that many patients fail to attend follow-up appointments due to personal circumstances, which they attribute to a lack of motivation. One healthcare worker expressed his frustration, stating, "*Some patients just interrupt the follow-up and start using traditional medicine. Then, they come with complications. Therefore, HWs should teach the patients continuously" (P5).* This indicates that patients were seeking alternative treatments, such as traditional healers and herbal medicines (Letta et al. 2021:8), rather than adhering to prescribed healthcare, due to a lack of awareness about the efficacy of diabetes follow-up care (see Section 4.5.2.2). Therefore, healthcare workers have the responsibility to correct these misconceptions. Moreover, healthcare workers can enhance patient engagement by involving family members in the care plan (see Section 4.5.3.1). As one healthcare worker noted, "*The attention of the family or some relatives who are living with the sick person is needed to put positive pressure on them to follow up"* (P5).

4.6.1.2 Communication challenge between healthcare workers and patients

The study highlights the communication gap that healthcare workers face in tracing lost-to-follow-up patients. Healthcare workers reported difficulties in reaching patients, particularly those living in rural areas, due to a lack of reliable contact information. One healthcare worker noted, "*We might not succeed in getting the patients in one call. Their telephone battery will be low because there is no electricity in rural areas to charge it"* (P5). This indicates that effective communication during a clinic visit is very important to maintain patient engagement (Wondm et al. 2024:4), especially in rural settings where access to technology is limited.

On the other hand, ineffective communication during clinic visits was identified as a barrier contributing to loss to follow-up among patients with type 1 diabetes (T1D).

One healthcare worker stated, "*If the healthcare workers do not effectively counsel the patients, that's why they are lost to follow-up"* (P7). Similarly, healthcare workers often assume patients already understand their condition and treatment regimen, leading to insufficient time allocated for patient education. As one healthcare worker said, "*Healthcare workers are not giving enough time for teaching patients…. they think that diabetes patients know everything about their health"* (P2). This routine-based approach can lead to missed opportunities to reinforce key messages or clarify misconceptions, particularly among newly diagnosed individuals or those with limited health literacy.

Moreover, participants emphasised the importance of tailored, continuous patient-provider communication to enhance retention in care. One healthcare worker said, *"If the patient has not given enough information, they will take the medicine today and discontinue the next month"* (P7). This suggests that if patients leave the clinic without a clear understanding of their disease management, they are more likely to disengage from care or fail to attend follow-up visits. The findings are in line with those reported by Kirk and his colleagues (2023:4), who emphasised personalised patient counselling as a core component of chronic disease management. This underscores the need for consistent, patient-centred communication strategies (Kirk, Khan, Davidov, Sambamoorthi & Misra 2023) that prioritise education and ensure comprehension at every stage of care.

4.6.1.3 Consequences of non-compliance

Non-compliance with diabetes treatment and follow-up protocols is consistently associated with severe, sometimes irreversible health consequences. Healthcare workers in the study emphasised that patients who disengage from care frequently return with advanced complications. One healthcare worker described that *"Type-1 diabetes patients who present after being lost to follow-up usually come after they develop acute complications like HHS and DKA. Sometimes they also come with chronic complications" (P1).* This is echoed by Sendur & Adas (2021:6), who found that non-adherence

to treatment significantly increases the risk of acute events such as diabetic ketoacidosis (DKA) and hyperglycemic hyperosmolar state (HHS), alongside long-term complications including nephropathy and retinopathy.

Beyond physiological outcomes, the uncertainty surrounding the status of patients lost to follow-up is a major concern for healthcare workers. One healthcare worker noted, *"We don't know what happened to those lost to follow-up cases. We don't know whether they died, or are receiving treatment in another health facility" (P2).* This indicates that patients lost to follow-up are often not captured by health data, leading to underreporting of morbidity and mortality associated with diabetes. This is consistent with the conclusions of Michelle, Victoria, and Sing (2023:15), who reported that many mortality and morbidity cases in low- and middle-income countries are invisible because they are not captured in national databases.

Healthcare workers also noted the consequences of non-compliance, as they experienced that many defaulters return only when complications have advanced to the point of being life-threatening or requiring hospitalisation. As one healthcare worker reported, *"Defaulters come after they lose their vision and the complication happens. Some patients also come after they develop renal failure, and others with foot infections" (P6).* These findings align with the findings of Sendur and Adas (2021:6), who identified late-stage complications, including renal failure and lower-limb amputations, as common outcomes among patients who disengaged from care in Sub-Saharan Africa.

Moreover, healthcare workers experienced the delayed return (re-engagement) of T1D patients to follow-up care, as they pursued traditional healers or spiritual interventions. One healthcare worker said, *"Diabetes patients go to try the holy water and finally some with complications, and some we hear about after they passed away" (P5).* Overall, both the qualitative data and the current literature underscore the urgent need for robust patient tracking systems and proactive follow-up mechanisms. Healthcare workers emphasised that early detection and continuous engagement are crucial to prevent both acute emergencies and chronic deterioration.

4.6.1.4 Summary

The study examines the challenges faced by healthcare workers in ensuring patient retention for follow-up care of Type 1 diabetes. It highlights significant communication barriers, particularly with rural patients, as well as systemic issues within healthcare facilities, such as inadequate staffing and poor patient-tracking systems. Healthcare workers emphasised the critical role of effective communication and counselling in fostering patient adherence, noting that many patients disengage due to misunderstandings about their treatment or external socioeconomic factors. Additionally, frustrations were expressed regarding the lack of resources and support, which hindered their ability to provide individualised care. The findings underscore the urgent need for improved communication strategies, better resource allocation, and proactive follow-up mechanisms to enhance patient retention in diabetes care.

4.6.2 Theme 7: Systemic challenges in health facilities

The study highlights systemic challenges that healthcare workers face in engaging patients in diabetes follow-up care. The study reveals key systemic challenges that hinder effective engagement of T1D diabetes patients in follow-up care in public health hospitals. These challenges are rooted in structural, organisational, and human resource limitations. Common issues include inadequate health information systems, a shortage of trained health workforce, limited access to essential supplies and medications, poor patient education and counselling services, financial and geographic barriers, and weak community linkages and follow-up mechanisms.

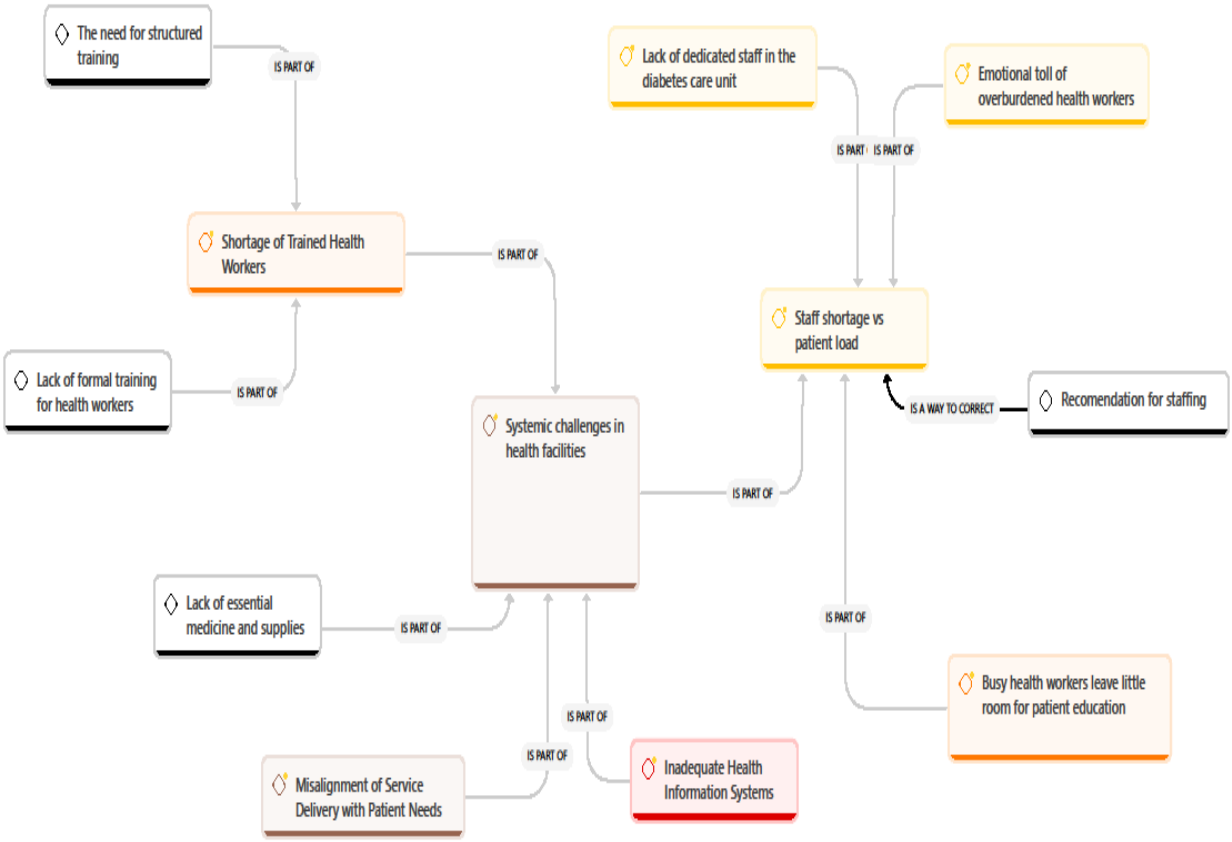


Figure 4.5: Schematic presentation highlighting the triggers and deterrents to diabetes follow-up care

4.6.2.1 Inadequate health information systems

Many health facilities in Ethiopia continue to rely on paper-based record systems, which limit their capacity to track and follow up with patients with diabetes. One healthcare worker said, "*The cohort registration is not complete, which means it can be difficult to understand whether the patient is in follow-up or lost to follow-up, or died*" (P7). Similarly, another healthcare worker said, "*The problem in recording essential patient data is the main problem for us*" (P2). This fragmentation undermines the ability to identify patients lost to follow-up and weakens continuity of care. This finding aligns with the conclusions of Yimer, Ahmed, Addissie, Kidane, Reja, and Abdela (2025:5), which highlight the absence of robust data systems as a major barrier to chronic disease management in Ethiopia.

4.6.2.2 Shortage of trained healthcare workers

The shortage of trained healthcare professionals in diabetes care, coupled with high patient loads, negatively affects the quality of follow-up services. Healthcare workers reported challenges in providing effective diabetes care due to insufficient training and education. This section synthesises key quotations from participants, illustrating their experiences with training gaps, the implications for patient care, and the need for improved educational programs.

4.6.2.2.1 Lack of formal training for healthcare workers on diabetes

A significant concern among healthcare workers was the lack of formal training in diabetes management. One healthcare worker stated, "*I am not trained on diabetes. I am working as per my medical background. And all the other workers working there did not receive formal training on DM. Assignment of workers is not based on the special training"* (P2). Similarly, another healthcare worker said, "*The nurse working in the chronic care unit hasn't received any training"* (P3). This lack of specialised knowledge can lead to suboptimal patient care, as healthcare workers may not be equipped to address the complexities of diabetes follow-up care and management. These findings are consistent with Defar et al. (2024:9), who found that only 6 % of the HWs working in Hospitals were trained in diabetes care. It indicates that healthcare workers without proper training may struggle to deliver effective patient care. As a result, patients often discontinue their medication and skip follow-up visits in favour of herbal medicines and traditional healers (see Section 4.5.5.4). This is in agreement with the conclusions drawn by Letta et al. (2021:8), who found that diabetes patients in Ethiopia have misperceptions about the need for lifelong follow-up care because of 'untrained nurses' and 'busy physicians' who fail to educate patients.

4.6.2.2.2 The need for structured training programs

Participants expressed a strong desire for more structured training programs for healthcare workers. One healthcare worker suggested, "*There should be trained*

healthcare workers in all health facilities. If there are no trained healthcare workers, no one can pay attention" (P7). This highlights the need for ongoing education and resources to ensure that healthcare workers are adequately equipped to deliver high-quality care. The lack of structured training not only affects the quality of care provided but also contributes to healthcare workers' feelings of inadequacy and frustration (Defar et al. 2024:10).

Similarly, participants expressed a strong desire for improved training in record-keeping practices. One healthcare worker suggested, "*There's a problem with registration…. It needs training"* (P3). This indicates that the lack of specialist training among nursing workers can hinder effective patient tracking and follow-up care, contributing to lost-to-follow-up rates.

Moreover, participants provided recommendations for improving training and education for healthcare workers. One healthcare worker stated, "*There should be proper guidelines for the proper utilisation of charts and registers in the chronic care unit to improve the quality"* (P2). This highlights the importance of having clear guidelines and training resources to support healthcare workers in providing effective follow-up care for individuals with diabetes. In general, the study reveals significant gaps in the education and training of healthcare workers in diabetes care. The finding illustrates how these training deficiencies can lead to poor patient outcomes, including being lost to follow-up.

4.6.2.3 Healthcare Workers - Patient ratio

Worker shortages are a significant challenge in providing adequate diabetes care. Healthcare workers often rotate between departments, which can disrupt the continuity of care and hinder the establishment of strong patient-provider relationships. Most healthcare workers commented on the challenges they experienced in delivering diabetes care due to the high patient load. The study demonstrates that healthcare workers often deal with high patient volumes, which compromises the quality of care.

4.6.2.3.1 Lack of dedicated workers in the diabetes care unit for a prolonged time

Participants frequently expressed concerns about a lack of continuity in diabetes care due to frequent staff rotation and the absence of a dedicated team leader. In this context, 'dedicated' refers to healthcare workers who are consistently assigned to the diabetes care unit for an extended period, rather than rotating staff, to ensure continuity of care (Awumee & Dery 2023:2). Frequent personnel changes and the absence of stable workers in the diabetes care unit significantly disrupt the continuity and quality of patient care. One healthcare worker stated, "*The problem in this hospital is we alternate routinely. The newly assigned physicians don't know the trend of which patients have lost or not*" (P3). Similarly, another healthcare worker said, "*Any physician working in the hospital can be assigned there as per the daily/weekly schedule on a rotation basis"* (P2). This also indicates a lack of continuity of care, making it difficult to track patient progress effectively. The constant rotation of workers can also limit the development of specialised skills, weaken patient-provider relationships, and hamper the implementation of long-term care plans (Garrib, Njim, Adeyemi, Moyo, Halloran, Luo & Santos 2023:6).

4.6.2.3.2 Busy healthcare workers leave little room for patient education

The high patient load often results in insufficient time for healthcare workers to educate patients adequately. One healthcare worker explained, "*They don't give enough time for teaching patients. They always experience the same scenario and consider that the patients know everything. Also, they (healthcare workers) are not given enough time because of patient load"* (P2). Although healthcare workers recognise the importance of patient education, they often fail to practice it. One healthcare worker said, "*Most educated patients do not miss their follow-up"* (P1). This highlights a critical gap in patient education, suggesting that healthcare workers may not adequately address patients' needs for information and support due to time constraints. These findings are consistent with a study by Letta et al. (2021:6) that discusses how inadequate staffing can lead to rushed consultations, ultimately affecting the quality of care provided to patients. Similarly, Wei et al. (2020:4) found that high patient volumes significantly

strain healthcare resources, resulting in insufficient time for patient education and follow-up.

4.6.2.3.3 Emotional toll of overburdened healthcare workers

Healthcare workers managing high patient volumes, particularly in diabetes care, are at risk of burnout and compassion fatigue. The emotional toll of managing high patient volumes was evident in participants' responses. One healthcare worker expressed, "*If our service was compassionate, the patients could trust us……there should be some additional workers working in the chronic OPD unit"* (P5). This highlights the importance of compassionate healthcare delivery, which can be challenging to maintain under high patient loads. Similarly, a survey in the UK revealed that 71% of General Practitioners experience compassion fatigue, leading to emotional exhaustion and impacting the quality of care provided (Kartsonaki, Georgopoulos, Kondili, Nieri, Alevizaki, Nyktari & Papaioannou 2023:4). This highlights the need for adequate workers' support systems to mitigate burnout among healthcare professionals.

Therefore, a high patient load poses a significant challenge for healthcare workers to deliver quality diabetes care. The quotations illustrate how factors such as insufficient time for patient education, lack of continuity in care, and the emotional toll on healthcare workers can impact the quality of services provided. Overall, addressing these issues through improved workers, dedicated diabetes care units, and systematic changes is essential for enhancing patient satisfaction and encouraging adherence to follow-up care. Implementing these changes could lead to better health outcomes and a more positive experience for patients managing diabetes.

4.6.2.3.4 Recommendations for Working in the Diabetes Care Unit

Participants expressed a strong desire for improvements in how workers manage patient loads. One healthcare worker suggested, "*If someone is assigned there permanently or at least for six months, it's better for the patient and the hospital"* (P3). This emphasises the need for stable staffing in chronic care units to ensure patients receive

consistent, high-quality care. Stable, consistent staffing in diabetes care units is crucial to delivering high-quality patient care. This recommendation is consistent with a study from Denmark that emphasised the importance of stable staffing to ensure consistent and effective diabetes management (Lundberg, Vestergaard, Sandbæk & Prior 2025:4).

The necessity for dedicated diabetes care was highlighted by several participants. One healthcare worker said, "*Our chronic care OPD is very congested (a single room of about 10sqm), so we are not educating patients adequately, especially for those with blood sugar controlled*" (P6). This suggests that creating specialised units with dedicated staff could alleviate the burdens associated with high patient loads and enhance the overall quality of care. Consistent with this finding, a study by Carter, Hassan, Walton, Yu, Donelan, and Thorndike (2021:6) shows a reduction in readmission rates when specialised workers are used compared to standard care. This underscores the value of dedicated, specialised workers in providing focused and effective diabetes care.

4.6.2.4 Lack of essential supplies and medications

Frequent stock-outs of insulin, test strips, and other essential diabetes management supplies are common in public health facilities. One healthcare worker expressed his frustration, "*Once the patients know the price is high, they can go outside and buy the medication from a private pharmacy. Then they disappear and are lost to follow-up*" (P5). This disrupts continuity of care and forces patients to either purchase medications privately or forego treatment altogether. This finding is consistent with research by Defar et al. (2024:4), who reported that the lack of essential medicines in health facilities discourages follow-up attendance, especially in low-income patients. This is presented in more detail in Section 4.5.4.3.

4.6.2.5 Misalignment of service delivery with patient needs

Participants indicate that the health service delivery in the diabetes care unit is structured around acute, curative care models. As a result, they overlook the holistic needs of patients with chronic conditions. One healthcare worker stated, "*We check their blood sugar whenever they come. Depending on the result, we define if there's any need for further intervention, and we do that. If not, we tell them to come to the next appointment*" (P3). This misalignment limits opportunities for patient-centred care, health education, and preventive support, contributing to poor adherence and being lost to follow-up. Similarly, Mantilla, Gomez, Camacho-López, Otero-Wandurraga, Novella, González-Medina, Valdez-Tiburcio, Lanas, Rocha-Lezama, and Alonzo-Arias (2025:4) published research indicating that the health system inspired by curative medicine prevents doctors from getting to the root causes of patients' problems and from providing health education.

Healthcare workers frequently expressed frustration over the absence of structured educational programs. Structured patient education is often lacking due to time constraints, inadequate staffing, and the absence of standardised teaching materials. As a result, many patients leave health facilities without a clear understanding of their condition, medication, or the importance of regular follow-up. One healthcare worker said, "*First, the patients themselves are always in a hurry to leave fast. Second, we (the HWs) didn't give attention to patient education*" (P6). This indicates a lack of a defined system for both healthcare workers and patients. This underscores a critical gap in the healthcare system where TID patients often do not receive essential education about how to manage their diabetes.

Moreover, healthcare workers expressed concerns about their overwhelming patient loads, which limit their ability to provide individualised care. One healthcare worker noted, "*Healthcare workers are not given enough time because of patient load*" (P2). This indicates that inadequate staffing can lead to rushed consultations (Aburayya et al. 2020:5). On the other hand, overwhelmed clinical workers (Umoke, Umoke, Nwimo, Nwalieji, Onwe, Emmanuel-Ifeanyi & Samson Olaoluwa 2020:4) have insufficient time

for patient education, which in the long run contributes to lost to follow-up. In general, the root cause of these structural gaps emanates from the curative-oriented health service delivery system that overlooks the holistic needs of patients with chronic conditions (see Section 4.6.4.3).

4.6.2.6 Summary

The study identifies significant systemic challenges that healthcare workers encounter in engaging Type 1 diabetes patients in follow-up care within public health hospitals. Key issues include inadequate health information systems, a shortage of trained healthcare professionals, limited access to essential supplies and medications, and poor patient education and counselling services. These challenges are compounded by financial and geographic barriers, as well as weak community linkages and follow-up mechanisms. Healthcare workers expressed frustration over their reliance on outdated paper-based record systems, which hinder their ability to track patient progress and identify those who are lost to follow-up. The findings highlight the urgent need for structural improvements in healthcare facilities, including better training for workers, enhanced patient tracking systems, and more robust community support to facilitate effective diabetes management.

4.6.3 Theme 8: Patient Tracking in Diabetes Follow-up Care

Effective diabetes management requires robust record-keeping and patient-tracking systems. However, the current study highlights significant gaps in these areas, as experienced by healthcare workers. These include record-keeping practices, a patient tracking system, and a mechanism to trace lost-to-follow-up patients. Theme 10 presents healthcare workers' experiences with the systems for tracking patients in the diabetes cohort and for tracing patients who are lost to follow-up.

4.6.3.1 Inconsistent record-keeping practices

Participants frequently expressed concerns about the inconsistency and unreliability of patient records. One healthcare worker said, *"The problem in recording essential*

patient data is the main problem for us. ….. There should be proper guidelines for the proper utilisation of charts and registers in the chronic care unit to improve the quality" (P2). Similarly, another healthcare worker said, *"Currently, in our hospital, there is no focal person responsible for controlling the recording of patient data in the cohort book and monitoring their status regularly"* (P5). This statement highlights the absence of a permanent and standardised record-keeping system, which restricts the ability of healthcare workers to monitor patient progress, outcomes, or treatment adherence.

The finding suggests that inadequate record-keeping results in significant gaps in patient care, particularly for chronic illnesses such as diabetes. One healthcare worker said, "*I don't have experience on how to track if patients are missed from follow-up. We don't have a mechanism to detect who was lost. We just record those who come, but I don't know what to do for those who are missed"* (P6). This indicates that the lack of a robust cohort registration system makes it difficult to effectively assess their health outcomes. This is also evidenced during data collection, when the researcher observed in one of the study hospitals that there was missing and outdated information (see Fig. 4.8). The lack of up-to-date information can lead to delayed care, complications, or even irreversible health outcomes (Suraya, Wisuda & Dioso 2023:5). As indicated in Figure 4.6, the status of patients under follow-up is not updated in the cohort registration.

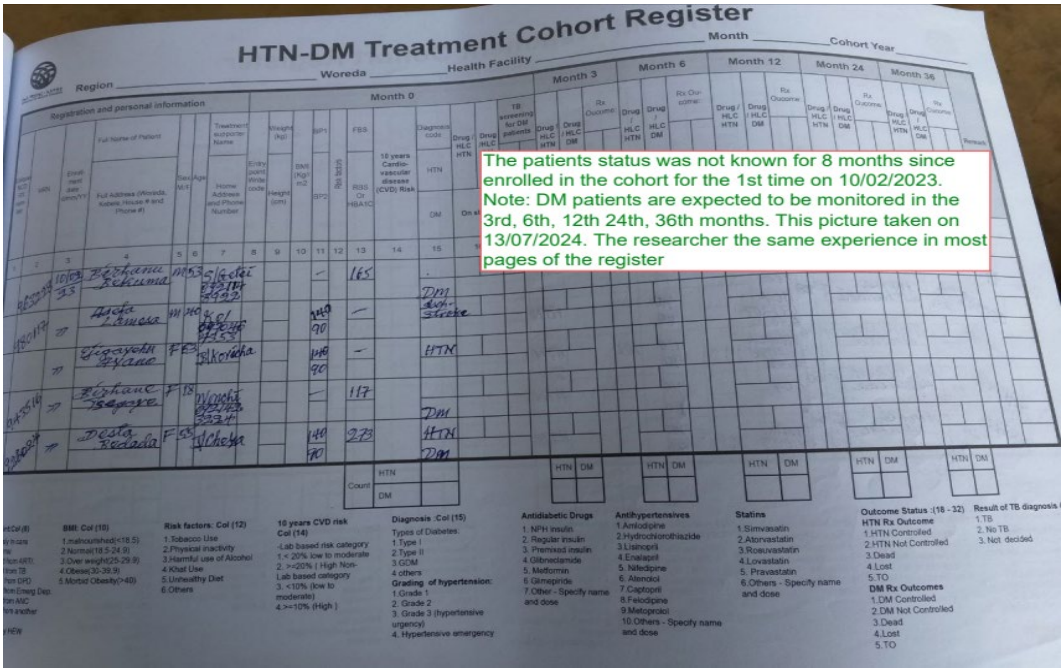


Figure 4.6: The photograph shows data incompleteness in cohort registration (dm register_pic 13072024)

4.6.3.2 Absence of a functional patient tracking system

Another recurring theme was the lack of an effective system to track patient follow-up. Healthcare workers reported difficulties in identifying patients who were lost to follow-up or those who missed appointments. One participant stated, *"The number of patients coming to our clinic every month is less than the expected number in the records of the cohort register"* (P3). The discrepancy between enrolled patients and those attending the follow-up appointments indicates systemic failures in monitoring and follow-up. The robust tracking systems, as noted by Shah, Yeheskel, Hossain, Kerr, Young, Shakik, Nichols, and Yu (2021:8), are essential for identifying patients who drop out of care.

One health officer from a district health office elaborated, "*The cohort registration is not complete, which means it can be difficult to understand whether the patient is in follow-up or lost to follow-up, or died"* (P7). Similarly, one healthcare worker said, *"I don't know how many patients are currently doing their follow-up strictly in our hospital …I don't know exactly the outcome of the patients registered in the cohort"* (P3). This reflects broader system-level weaknesses that make patient monitoring difficult. The

researcher confirmed this during data collection and field observations that the TID patients' data in the cohort registration were incomplete and not updated in the two hospitals. Another healthcare worker shared, *"I don't have experience on how to track if patients are missed from follow-up. We don't have a means to detect who was lost. We just record those who come, but I don't know what to do for those who are missed"* (P6). Such statements point to both a lack of tools and inadequate training in managing follow-up systems.

Moreover, healthcare workers lack the tools to monitor patients effectively. One healthcare worker affirms this by saying, "*For now, we don't have any defined strategy to trace lost to follow-up diabetes patients"* (P2). Without such systems, it becomes challenging to identify patients who are lost to follow-up or those experiencing complications. These results align with the findings of Suraya et al. (2023:5), who noted that the lack of structured tracking contributes to discontinuity of care. Without real-time data, HWs may misjudge the effectiveness of their interventions. Implementing digital or manual patient-tracking systems can greatly enhance follow-up.

4.6.3.3 Consequences of Inadequate Record-Keeping

The consequences of poor documentation and tracking systems extend beyond administrative challenges. Healthcare workers noted that patients often present with advanced complications due to missed follow-ups and lack of early interventions: "*One of my patients lost and came after he lost his vision"* (P6). Moreover, he highlighted the implications of these shortcomings and said, "*Defaulters encounter several health problems when they present. For example, one of my patients came after he lost his vision"* (P6). This illustrates how failures in record maintenance can contribute to severe complications that could otherwise be prevented with timely interventions. This reinforces findings by Suraya et al. (2023:5), who emphasised that poor record-keeping is directly associated with increased morbidity and mortality among patients with chronic diseases.

4.6.3.4 Tracing lost to follow-up patients

The study highlights the inadequacy of patient tracking systems as a significant barrier to effective diabetes follow-up care. Healthcare workers reported that they lack mechanisms to trace patients who have missed follow-up appointments. One healthcare worker said, "*We don't have experience on how to track if the patients are missed from follow-up"* (P6). This lack of effective tracking mechanisms makes it difficult for healthcare workers to monitor patient compliance and address issues promptly. To minimise the gap, Pascoe, Scott, Fong, Murphy, Huber, Moolla, Phokojoe, Gorgens, Rosen and Wilson (2020:11) emphasised the importance of robust patient-tracking systems. Without these systems, healthcare workers are not able to identify lost-to-follow-up patients, leading to potential diabetes complications.

There is limited integration between health facilities and community-level structures, such as health extension workers or patients' associations, for tracing patients who miss appointments. One healthcare worker suggested, "*We have to work in collaboration with the diabetes association. If we link patients to the association, they can also get financial support"* (P5). The absence of a system to link with other support services, including psychosocial, economic, and spiritual (Yimer et al. 2025:5), further exacerbates the issue of lost to follow-up.

4.6.3.5 Interventions to Optimise Cohort Registration and Follow-up Systems

Participants provided several recommendations for improving current systems. The need for structured follow-up charts was frequently cited as a priority area. One healthcare worker said, "*I think it would be good if we had the follow-up charts….that we can monitor the outcomes"* (P4). Similarly, the other healthcare worker said, *"There should be proper guidelines for the proper utilisation of charts and registers in the chronic care unit to improve the quality"* (P2). Introducing standardised follow-up tools can facilitate real-time monitoring and reduce the number of lost cases. Similarly, the study by Shah et al. (2021:8) emphasises the importance of structured guidelines and tracking protocols to improve continuity of diabetes care and outcomes.

In addition, participants highlighted the importance of system-wide reform for diabetes cohort follow-up care. One healthcare worker said, "*If the cohort follow-up system is strengthened, the healthcare workers can track immediately those lost to follow-up cases…..If this is not strengthened, we can't reduce lost to follow-up"* (P7). This underscores the need for a well-designed health information system supported by guidelines and policy. Similarly, another healthcare worker stated, "*There should be strict follow-up mechanisms like ART therapy. If patients disappear from ART, they call and communicate with the patients to come back to the follow-up"* (P5). This suggests the need for strong follow-up mechanisms for diabetes care.

The other underlying issue raised throughout was the limited capacity of healthcare workers to maintain comprehensive records and track patients efficiently. Healthcare workers expressed a lack of training and confidence in managing follow-up data. One healthcare worker said, "*Training is important for healthcare workers to practice the existing guidelines"* (P7). Providing targeted training on patient documentation and follow-up strategies can empower healthcare workers and enhance the quality of care. These results reinforce the conclusions of Shah et al. (2021:8), who pointed out the importance of capacity building for operationalising effective chronic care models.

The findings of this study reveal that poor record-keeping and ineffective patient tracking systems are the root cause of lost to follow-up among Type 1 diabetes patients. Inconsistent documentation, inability to monitor follow-up status, and insufficient training collectively contribute to patients being lost to follow-up. The experiences of healthcare workers in this study emphasise the need for systematic improvements and standardised guidelines for diabetes cohort follow-up care.

4.6.4 Theme 9: Healthcare workers' Perception of the Quality and Effectiveness of Follow-up Care

This study presents diverse perceptions of HWs about the effectiveness and quality of follow-up care for Type 1 diabetes patients. These include overemphasis on routine

clinical tasks, misconceptions about the necessity of regular follow-up care, and failure to implement individualised care.

4.6.4.1 Overemphasis on Routine Clinical Tasks

The study identifies significant challenges in managing diabetes during follow-up visits. Healthcare workers often focus primarily on routine tasks, such as blood sugar testing and medication distribution, while underestimating the broader benefits of comprehensive diabetes follow-up care, including patient education and lifestyle counselling. One healthcare worker stated, "*We check their blood sugar whenever they come. Depending on the result, we define if there's any need for further intervention, and we do that. If not, we tell them to come to the next appointment*" (P3). This narrow focus indicates a limited scope of services perceived as the only part of follow-up care. Another healthcare worker noted, "*There should be other psychological support and patient education……only the drug is not enough. Diabetes care should be multidimensional*" (P3). The focus on clinical tasks over patient education (Nutbeam & Lloyd 2021:5) can lead to missed opportunities to reinforce patient education, self-care practices and regular follow-up visits.

Healthcare workers in the current study expressed frustration over the lack of effective tracking systems. One healthcare worker said, "*We don't have a follow-up monitoring chart…I think it would be good if we had the follow-up charts*" (P4). This indicates a systemic issue that affects the perceived effectiveness of follow-up care. This tendency to equate diabetes follow-up care as merely blood sugar testing and medication distribution can lead to inadequate patient education, poor tracking of patient progress, and a misunderstanding of patients' needs.

4.6.4.2 Perceptions of HWs on the Necessity of Regular Follow-Up Care

Healthcare workers frequently encounter patients who believe they can manage their condition without attending a follow-up clinic. One healthcare worker noted, "*Sometimes patients discontinue their medication after one-month treatment, maybe they*

feel as if they were cured" (P7). This perception is echoed by Zarora et al. (2022:7), who found misconceptions among both patients and healthcare workers about follow-up care, leading to reluctance to follow up on the scheduled appointment.

Moreover, healthcare workers expressed frustration over patients who turn to alternative remedies, such as traditional medicine or spiritual practices, instead of adhering to prescribed treatments. One healthcare worker stated, "*Some people disappear in preference to holy water or prayers; Some people disappear to try traditional medicine like plant leaves"* (P5). This trend mirrors the findings of Boshe et al. (2021:10), who reported that diabetes patients often seek alternative treatments due to a lack of understanding of the importance of ongoing healthcare. The role of healthcare workers in addressing these misconceptions is crucial (see Sections 4.5.1.5, 4.5.4.4, and 4.6.1.2).

4.6.4.3 Failure to Implement Individualised Care

The study indicates that healthcare workers often adopt a one-size-fits-all approach, which can overlook individual circumstances and the importance of tailored care. One healthcare worker noted, *"Sometimes the healthcare workers assume patients as if they know everything themselves"* (P2). This assumption can lead to inadequate support and education for patients, ultimately affecting their engagement in their care. Similarly, Asmat, Dhamani, Gul, and Froelicher (2022:4) found that healthcare workers often fail to recognise the unique challenges faced by individual patients, leading to a lack of personalised care. This can result in patients feeling neglected or misunderstood, which may discourage them from adhering to treatment plans or attending follow-up appointments.

Moreover, the study revealed that healthcare workers did not fully appreciate the barriers that prevent patients from attending appointments. One healthcare worker stated, "*Our people are still unchanged. They didn't accept diabetes as a disease. They drop the medication and go to some religious areas and other places like traditional healers or Herbal medicines"* (P2). This reflects a lack of understanding of the complexities

behind patient adherence. Therefore, healthcare workers should take into consideration the sociocultural dynamics and belief systems of the society. Consistent with this finding, Kwame and Petrucka (2021:5) underscored that cultural beliefs and socioeconomic factors can significantly influence health-seeking behaviours.

The consequences of misunderstanding patients' needs can be severe, resulting in complications and worsening of health conditions. One patient remarked, *"If the healthcare worker fails to provide individualised care, patients can disappear, and even you can't recognise when they are lost to follow-up"* (P7). This highlights the critical nature of tailored care. Similarly, a systematic review by Peimani, Nasli-Esfahani, and Sadeghi (2020:4) found that when healthcare workers do not adequately address the needs of patients, it can lead to increased rates of complications and hospitalisations.

Additionally, the perception towards the risks of complications associated with Type 1 diabetes leads to a lack of determination in patients regarding their follow-up care. One healthcare worker stated, *"Type-1 diabetes patients have less risk of developing chronic complications because they show symptoms in the early stage"* (P3). This misinterpretation can result in healthcare workers underestimating the importance of regular follow-up visits, as they may perceive T1D patients as being at low risk for chronic complications.

4.6.4.4 Summary

To sum up, theme 9 presents the diverse perceptions among healthcare workers regarding the effectiveness and quality of follow-up care for diabetes management. It highlights the experiences of healthcare workers, including an overemphasis on routine clinical tasks, such as blood sugar testing and medication distribution, which often leads to a neglect of comprehensive patient education and lifestyle counselling. Healthcare workers expressed concerns about inadequate patient monitoring and tracking systems, which hinder their ability to assess patient progress effectively. Additionally, the theme discusses the failure to individualise care to patient needs, with

many healthcare workers adopting a one-size-fits-all approach that overlooks each patient's unique circumstances. Misunderstandings about the risks of diabetes complications further contribute to complacency regarding the necessity of follow-up care. Overall, the findings underscore the urgent need for improved training, enhanced tracking systems, and a more comprehensive approach to diabetes follow-up care to improve patient outcomes.

4.6.5 Summary of Phase 2

In Phase 2 of the study, the study synthesises the experiences of healthcare workers regarding lost to follow-up in Type 1 diabetes patients, revealing four major themes. Theme 6 focuses on healthcare workers' experiences in maintaining patient engagement, highlighting barriers such as communication difficulties, particularly with rural patients, and systemic issues, including inadequate health information systems and staffing shortages. Theme 7 addresses systemic challenges in service delivery, including inadequate training for workers, poor record-keeping, and fluctuations in medication availability, which collectively hinder effective diabetes care. Theme 8 discusses patient tracking in diabetes follow-up care, emphasising the need for robust systems to monitor patient progress and identify patients who are lost to follow-up. Finally, Theme 9 presents healthcare workers' perceptions of the effectiveness and quality of follow-up care, revealing an overemphasis on routine clinical tasks at the expense of comprehensive patient education and individualised care.

In conclusion, the findings from Phase Two underscore the urgent need for systemic improvements in diabetes management practices. Addressing the identified barriers, such as communication gaps, inadequate training, and resource limitations, is crucial for enhancing patient retention and overall health outcomes for individuals with Type 1 diabetes. The study emphasises the importance of empowering healthcare workers through enhanced training and support, as well as implementing effective patient tracking systems, to ensure that individuals receive the comprehensive care they

need. By fostering a more proactive and patient-centred approach to diabetes management, healthcare systems can significantly reduce the incidence of complications associated with lost to follow-up.

4.7 CONCLUSION

This study's exploration of the experiences of Type 1 diabetes patients and healthcare workers revealed significant insights into the phenomenon of patients being lost to follow-up among those with Type 1 diabetes. The data management and analysis employed an inductive thematic approach, which included semi-structured interviews with both patients and healthcare workers. The participants' biographical profiles highlighted a diverse group with varying ages, educational backgrounds, and socioeconomic statuses. The analysis of the collected data revealed nine critical themes and 39 sub-themes (categories).

Phase one of the study (Section 4.5) focuses on the experiences of T1D patients who were lost to follow-up, identifying five major themes and 23 sub-themes that capture the experiences of these patients. The findings indicate significant gaps in patients' knowledge and awareness of diabetes management, compounded by financial constraints, transportation issues, and cultural beliefs. The emotional burden of managing diabetes, coupled with societal stigma, contributed to T1DM patients' being lost to follow-up.

In Phase two (Section 4.6), the experiences of healthcare workers regarding lost-to-follow-up T1D patients were explored, revealing four major themes and 16 sub-themes. The findings indicate healthcare workers' experiences in maintaining patient engagement. They also elaborated on systemic issues within healthcare facilities, including inadequate training, poor record-keeping, and resource constraints, which hindered their ability to provide quality follow-up care. Additionally, healthcare workers highlighted the need for proactive follow-up mechanisms to reduce LTFU among TID in diabetes.

Overall, this study underscores the urgent need for systemic changes in diabetes management practices. By addressing the barriers identified in the research, including financial constraints, inadequate education, and insufficient follow-up mechanisms,

healthcare systems can enhance patient outcomes and mitigate the risk of complications associated with diabetes. Empowering both patients through education, resources, and structured guidelines is essential for fostering a proactive approach to diabetes management and ensuring that individuals with T1D receive the comprehensive care they need.

Finally, the empirical findings from this qualitative inquiry not only contribute to the understanding of the challenges faced by T1D patients in maintaining follow-up care but also provide a foundation for the development of guidelines aimed at improving diabetes management in Ethiopia. The development and validation of the guidelines are presented in Chapter 5.

The findings presented in Chapter 4 reflect the lived experiences of both patients lost to follow-up and healthcare workers engaged in diabetes service delivery, offering rich insights into the phenomenon called ‘Lost to Follow-up’ among Type 1 diabetes patients. Through the lens of these experiences, key elements of the Health Belief Model (HBM) become evident, particularly in how individuals perceive the severity of diabetes, the benefits and barriers to follow-up care, and the internal and external cues that influence follow-up behaviour. The phenomenological approach enabled a nuanced understanding of how meanings surrounding follow-up care are constructed, shaped by personal, relational, and systemic factors. These findings provide a foundation for grounding the HBM in real-world experiences, thereby supporting its relevance as a guiding framework for interpreting the complexities of lost-to-follow-up cases.

5. CHAPTER FIVE: GUIDELINE DEVELOPMENT

5.1 INTRODUCTION

Chapter five presents the development of guidelines aimed at reducing the number of Type 1 diabetes patients lost to follow-up. The chapter begins by presenting the underlying principles of guideline development (Section 5.2), which provide the theoretical and methodological foundation for the process. It then explains how the findings from Phases 1 and 2 were integrated to identify the key aspects of follow-up care (Section 5.3). Building on these insights, the chapter describes the development of the preliminary guidelines (Section 5.4), followed by the process used: a focused discussion, data gathering, analysis, and interpretation (Section 5.5). Finally, the chapter presents the draft guideline ready for validation (Section 5.6). The research progress is as illustrated in Table 5.1.

Table 5.1: Research progress status

CHAPTER	NAME OF THE CHAPTER	PURPOSE/CONTENT
Chapter 1	Overview of the Study	The chapter provides an overview of the purpose, objectives and methodology of the study.
Chapter 2	Literature Review	Literature review to discuss: • Theoretical framework • Diabetes and diabetic services • The national strategy for diabetes
Chapter 3	Methodology	The methodology of all phases of the study
Chapter 4	Phases 1 and 2:	Data gathering, analysis, presentation and literature control
Chapter 5	Development of the guideline	• Literature review on the principles of guideline development • Phase 1 and Phase 2 data integration • Focused discussions, data gathering, analysis and interpretation • Presentation of the draft guideline is ready for validation

5.2 PRINCIPLES OF GUIDELINE DEVELOPMENT

In guideline development, a foundational principle is the systematic integration of empirical data, typically qualitative evidence, into both the scope and content of proposed areas of emphasis (Kim 2022:3). The process of guideline development can be realistic if it reflects the lived experiences and operational realities of stakeholders, thereby enhancing their contextual validity and practical applicability. Moreover, expert opinion plays a critical role in filling gaps that might evidence lack. Therefore, these contributions must be systematically collected and reported to maintain transparency and methodological rigour.

According to Logullo, Florez, Antoniou, Markar, López-Cano, Silecchia, Tsokani, Mavridis, Brouwers, and Antoniou (2022:3-8), the core principles of guideline development include defining the scope and purpose, stakeholder involvement, the rigour of guideline development, the link between evidence and proposed areas of emphasis, applicability and implementation considerations, and clarity and presentation. The following sections provide a detailed examination of each of these principles.

5.2.1 Scope and Purpose

Defining the guideline's objective, target population, and key questions is foundational. This phase should be informed by both global priorities and empirical findings that reflect local operational realities. Integrating qualitative evidence into this stage ensures contextual alignment, enhancing practical relevance (Fotteler, Kocar, Willems, Voigt-Radloff, Leinert, Dallmeier, Hertneck & Denkinger 2025:3). In this study, the empirical data, particularly qualitative findings from lived experiences, assisted in defining the purpose and scope of the guideline, which were further shaped by nine core themes from the findings (see Chapter 4). This supports evidence-based, tailored solutions which are practically and culturally applicable (Logullo et al. 2022:3).

5.2.2 Stakeholder Involvement

According to Logullo et al. (2022:4), robust guideline development involves participation from all relevant actors or stakeholders. The stakeholders involved in this study included healthcare workers, public health researchers and policymakers (see Table 3.4). These formal representations of stakeholders, achieved through focused discussion sessions (see Section 5.5), enabled participatory depth through the iterative inclusion of expert inputs.

In developing a draft guideline to improve follow-up for T1D patients, focused discussions with diabetes care experts (see Section 5.5) were used to obtain practice-based insights. These interactions, which included in-person meetings and follow-up communications, enhance the clarity and acceptability of the guideline. Such participatory strategies are particularly valuable when formal consensus methods are infeasible (Schünemann, Reinap, Piggott, Laidmäe, Köhler, Põld, Ens, Irs, Akl & Cuello 2022:3).

5.2.3 Link between evidence and proposed areas of emphasis

In guideline development, each proposed area of emphasis should be directly linked to supporting evidence (Logullo et al. 2022:5). Empirical findings and transparent rationale grounded in lived data, such as themes on patient experiences with lost to follow-up, should be explicitly cited as justifications for the proposed areas of emphasis. Documenting these links supports confirmability and dependability (Johnson 2020:8) and enhances transparency (Amin et al. 2020:6) as illustrated in Table 5.2.

5.2.4 Clarity and presentation

The proposed areas of emphasis must be specific, actionable, and unambiguous. Incorporating real-world terminology and examples from empirical interviews or expert discussions makes guidelines more accessible and relevant to end-users (Logullo et al. 2022:5). Empirical examples support actionable phrasing. In this study, suggestions from expert discussions were used to clarify phrasing around patient tracking protocols

in the T1D guideline (see Section 5.6.8). This ensures that language resonates with local practitioners and aligns with user-centred design principles.

Moreover, it needs a transparent presentation of how empirical and expert inputs are incorporated and verified. Documentation of the feedback incorporation process, including rejected suggestions with rationale, helps maintain credibility. In the case of the T1D guideline, expert contributions were tracked and revised across two feedback rounds, supporting trust and accountability.

5.2.5 Applicability and Implementation Considerations

Feasibility, resource use, and cultural relevance are crucial to ensuring the guideline's applicability. Local empirical evidence is especially critical in this domain, as it helps developers assess whether interventions are deliverable and acceptable (Logullo et al. 2022:7). Expert feedback can reveal how health system constraints (e.g., the availability of essential healthcare supplies, communication barriers) affect implementation. These findings inform adaptations that make global evidence actionable in specific local contexts (Schünemann et al. 2022:4). In this study, the integration of empirical data through qualitative evidence and focused expert discussion (see Section 5.3) strengthened the credibility and contextual validity of guidelines.

5.2.6 Rigour of the guideline development

Rigour requires a transparent, systematic approach to evidence collection, synthesis, and proposed areas of emphasis formulation (Daniel et al. 2024:6). The integration of empirical findings (Phases 1-2 in this study context), the literature review, and expert inputs (Phase 3 in this study context) followed a structured process consistent with accepted standards for qualitative trustworthiness such as confirmability, dependability, credibility and transferability (Johnson 2020:7).

Moreover, effective guideline development should align with globally recognised frameworks such as the WHO Guideline Development (WHO 2014:4), GRADE (Pig-

gott, Langendam, Parmelli, Adolfsson, Akl, Armstrong, Braithwaite, Brignardello-Petersen, Brozek & Gore-Booth 2021:5), and AGREE II (Brouwers, Kho, Browman, Burgers, Cluzeau, Feder, Fervers, Graham, Grimshaw & Hanna 2010:1). Adhering to them helps to produce credible, implementable, and trustworthy guidelines. In this study, the researcher adopted an iterative approach, involving the drafting and refining of guidelines based on empirical findings and a literature review, alongside a participatory approach through focused discussions, to ensure that the guidelines are evidence-based, feasible, and tailored to the real-world context of users.

5.3 PHASE 1 AND PHASE 2 DATA INTEGRATION

The participants proposed priority areas for each guideline, emphasising aspects requiring greater attention. This section presents the proposed areas of emphasis derived from the data obtained from participants in Phases 1 and 2. The presentation begins with an assessment of current guidelines and their implementation in clinical practice, followed by 10 proposed areas of emphasis. These proposed areas of emphasis are supported by direct quotations from participants' experiences, which are presented in *italic text* and referenced with participant identifiers in brackets (e.g., P1). This approach illustrates how individual perspectives underpin the findings. These include: (1) Patient education, (2) Cohort registration and follow-up, (3) Tracing of LTFU patients, (4) Financial support, (5) Quality of follow-up care, (6) Support system, (7) Patient retention, (8) Waiting time, (9) Enhance patient motivation, and (10) Monitoring and evaluation.

5.3.1 Implementation of guidelines in clinical practice

This paragraph describes the current landscape of guidelines for T1D follow-up care and how they are applied in practice, drawing on the literature. The study highlights that, although a few guidelines exist, their implementation is often inconsistent. Participants noted that the primary issue lies not only in the absence of guidelines but also in their lack of integration into daily healthcare practices. Many healthcare workers

expressed the need for better training and resources to apply these guidelines. Furthermore, the study underscores the necessity for guidelines that not only outline treatment protocols but also establish robust follow-up mechanisms to ensure effective patient management.

Participants frequently noted that while guidelines for diabetes care exist, their application in practice is inconsistent. One healthcare worker stated, *"There is a problem in applying the existing guidelines in practice"* (P7). This highlights a critical issue: the challenge lies in applying the existing guidelines to healthcare practices. Similarly, the same participant expressed, *"There should be trained healthcare workers in all health facilities. If there are no trained healthcare workers, no one can pay attention"* (P7). This underscores the importance of equipping healthcare workers with the necessary knowledge and skills to implement guidelines effectively. These results align with the findings of Ryan, Burke, Litchman, Bronich-Hall, Kolb, Rinker, and Yehl (2020:4), which emphasise that healthcare workers often struggle with the practical application of diabetes follow-up care and management guidelines due to inadequate training and resources.

Participants also expressed a desire for more specific guidelines tailored to diabetes follow-up care and management. One healthcare worker noted, "*It would be better if diabetes had its guidelines, because diabetes is a huge metabolic disease by itself*" (P2). This finding aligns with the study by Karachaliou, Simatos, and Simatou (2020:5), who argue that specialised guidelines can address the unique challenges associated with managing diabetes.

5.3.2 Proposed Areas of Emphasis on Diabetes Patient Education

The proposed areas of emphasis, derived from participants' data, aimed to improve educational initiatives and empower diabetes patients with the knowledge necessary for effective self-management. Participants expressed a strong desire for more structured educational programs that address various aspects of diabetes follow-up care and management. One healthcare worker said, "*I suggest giving enough education to*

patients" (P6). This highlights the importance of allocating dedicated time and resources to deliver comprehensive education to patients. Similar studies found that comprehensive education programs can significantly improve patient knowledge and self-management skills (Berhanu et al. 2022:8; Caro-Bautista et al. 2021:6; Rodriguez et al. 2022:4).

Letta et al. (2021:7) emphasised the importance of involving a family in the education process to reinforce healthy behaviours. The role of family in patient education was also highlighted in this study. One patient shared, *"It always needs the attention of the family or some relatives who are living with the sick person to put positive pressure on them to follow up. The family members need to have some educational materials"* (P5). This indicates that family support can enhance a patient's ability to manage their condition effectively.

Participants also emphasised the importance of having accessible educational materials. One healthcare worker noted, *"Last year, we distributed a guideline for patients which is written in the local language. It is helpful"* (P6). This indicates the need for educational materials for patients. According to Hong, Jo, Cardel, Huo, and Mainous III (2020:4), effective learning can be achieved if the educational materials are in a language and format that patients can understand

5.3.3 Proposed areas of emphasis on cohort registration and follow-up

The necessity for guidelines that establish robust follow-up care mechanisms is crucial. Participants highlighted the importance of strengthening cohort registration and patient follow-up. One healthcare worker remarked, *"I suggest strengthening the cohort registration and patient follow-up"* (P1). This underscores the importance of effective follow-up systems in enhancing patient adherence and improving health outcomes, as noted by Tino et al. (2019:5).

Moreover, having dedicated personnel to manage cohort registration effectively was suggested, with participants advocating for a case management model similar to those

used in HIV care. One healthcare worker said, *"If someone is assigned there permanently or at least for six months, it's better for the patient and the hospital"* (P3). Such an approach could enhance follow-up care for diabetes patients, indicating a need for dedicated appointment managers. Participants also expressed the necessity for clear guidelines to improve the quality of diabetes follow-up services, emphasising the need for structured protocols in chronic care units(Shah et al. 2021:6). One healthcare worker remarked, "*There should be a guideline for the proper utilisation of charts and registers in the chronic care unit to improve the quality"* (P2). This suggests a need for clear guidelines to address the gaps in record-keeping and patient tracking.

5.3.4 Proposed Areas of Emphasis on Tracing Lost to Follow-up Patients

The challenge of tracing lost-to-follow-up patients requires dedicated personnel to oversee diabetes follow-up care services. Participants indicated that replicating the case management model used in HIV care could significantly improve follow-up for diabetes patients. One healthcare worker said, *"I recommend duplicating the experience of HIV follow-up care for diabetes care. There should be a case manager to trace lost to follow-up patients"* (P7). Inadequate case management and insufficient training hinder the ability to trace patients who have disengaged from care.

Participants emphasised the importance of systematic changes to address lost-to-follow-up cases, noting the lack of structured tracing mechanisms. One healthcare worker said, "*We need a defined strategy to trace lost to follow-up diabetes patients"* (P2). This suggests the need for clear guidelines which indicate a structured protocol for tracing lost-to-follow-up diabetes patients. This aligns with the findings of Suraya et al. (2023:5), who suggest that implementing structured follow-up mechanisms can significantly reduce the number of patients lost to follow-up.

5.3.5 Proposed Areas of Emphasis on Financial Support

Financial burdens can hinder adherence to follow-up care (Tsega et al. 2021:8). Participants highlighted the importance of community-based financial support systems,

including collaboration with local organisations, such as diabetes associations, to create a support network for patients. One healthcare worker noted, "*We have to work in collaboration with the diabetes association. If we link patients to the association, they can also get financial support"* (P5). This suggests that leveraging existing community resources could provide much-needed financial relief to patients struggling with the costs of medications and follow-up care.

The findings revealed that guidelines that dictate affordable healthcare services to diabetes patients are needed, as out-of-pocket medical fees and adherence to follow-up care are closely related (Tsega et al. 2021:8). One patient remarked, "*The service fee should be cheap for diabetes patients"* (P5). This aligns with findings. It suggests that reducing the costs of diabetes care significantly improved treatment adherence among patients. The integration of affordable services into healthcare systems facilitates access to follow-up care without financial strain.

Moreover, expanding insurance coverage for diabetes-related expenses emerged as a recurring theme, indicating that such measures could significantly improve access to necessary treatments. One patient explained, *"In this hospital, the patients are expected to cover their expenses from their pocket. It should be covered by insurance"* (P10). This illustrates the urgent need for comprehensive insurance solutions to facilitate better access to care (Mulat et al. 2022:7).

5.3.6 Proposed areas of emphasis on the quality of diabetes follow-up care

A holistic approach to diabetes follow-up care encompasses not only medical treatment but also preventive services, education, and emotional support. One healthcare worker suggested, "*There should be guidelines for the proper utilisation of charts and registers in the chronic care unit to improve the quality"* (P2). This suggests the need to maintain comprehensive healthcare to improve the overall health outcomes of diabetes patients (Kwame & Petrucka 2021:4).

To enhance the quality of diabetes follow-up care, the integration of emotional and

psychological support was also highlighted. One healthcare worker said, *"To ensure the quality of care, diabetic patients need not only the drug but also psychosocial support and education"* (P3). This suggests the critical role of psychosocial and emotional care in diabetes management. This aligns with the understanding that supportive care is vital in managing chronic conditions like diabetes (Tesema, Abimbola, Mulugeta, Ajisegiri, Narasimhan, Joshi & Peiris 2021:11).

Overall, the study highlights the importance of a holistic approach for diabetes management that integrates medical treatment, preventive services, education, and emotional support. The findings underscore the necessity for improved patient education regarding comprehensive care, as well as the integration of nutritional and psychological support to enhance patient outcomes. Thus, the study highlights the urgent need for structured guidelines to enhance the quality of diabetes follow-up services.

5.3.7 Proposed Areas of Emphasis on Support Systems

The role of support systems, including family involvement and community resources, is vital for enhancing Type 1 diabetes patient adherence to follow-up care. Family encouragement was described as a strong positive force for follow-up adherence. A healthcare worker emphasised, *"The attention of the family or some relatives who are living with the sick person is needed to put positive pressure on them to follow up"* (P5). This suggests the role of family involvement in improving treatment outcomes in diabetes care (Letta et al. 2021:8). Health systems should therefore actively involve family members in education and counselling sessions to reinforce continuity of care at home.

Furthermore, community-based education and psychosocial support initiatives should be scaled up to reinforce follow-up behaviours. One participant noted, *"I heard that there was a psychosocial support group (diabetes association) that could help to reduce lost to follow-up"* (P6), pointing to the need for established linkages between health facilities and community organisations. Consistent with this finding, the study by Tesema et al. (2021:8) emphasised that connecting community healthcare workers

and local associations to clinical systems reduces loss to follow-up. The incorporation of structured psychosocial services, such as counselling and group therapy, emerges as a critical component in managing diabetes effectively.

5.3.8 Proposed Areas of Emphasis on Patient Retention in Follow-Up Care

Healthcare workers proposed adapting strategies used in HIV care to improve follow-up in diabetes programs. As one participant noted, *"There should be strict follow-up mechanisms like ART therapy. If patients disappear from ART, they call and communicate with the patients to come back to the follow-up"* (P5). These areas of emphasis align with findings of Pascoe et al. (2020:11), who highlighted the importance of robust tracing systems in managing long-term conditions and reducing patient drop-out rates.

Participants emphasised the need for structured tools to monitor patient outcomes more effectively. As one healthcare worker suggested, *"I think it would be good if we had the follow-up charts… that we can monitor the outcomes"* (P4). Supporting this, Shah et al. (2021:6) advocated for standardised tracking protocols to improve diabetes care and reduce patient attrition.

5.3.9 Proposed Areas of Emphasis on Patients' Waiting Time

The study suggests that healthcare facilities must prioritise reducing waiting times to enhance patient satisfaction. Participants in this study recommended improvements in service delivery, emphasising the need for timely care. One patient suggested, *"If they provide the service on time, it will be good"* (P8). This aligns with the areas of emphasis in recent studies advocating systemic changes in healthcare delivery to streamline processes and minimise delays. For instance, a study by Havlir, Kamya, and Petersen (2024:6) proposed implementing triage systems and optimising appointment scheduling to improve patient flow and reduce waiting times.

To sum up, the impact of waiting times on patient satisfaction is a critical issue that healthcare workers must address. By implementing strategies to reduce delays and

enhance the patient experience, healthcare systems can foster greater patient engagement and adherence to follow-up care. The emotional and physical well-being of patients is closely tied to their perceptions of care quality, making it essential for providers to prioritise timely service delivery as a fundamental aspect of patient-centred care.

5.3.10 Proposed areas of emphasis on the motivation of patients to attend diabetes follow-up care

Direct encouragement and reminders from healthcare workers play a significant role in motivating individuals to attend follow-up care. The study highlights that direct encouragement and reminders from healthcare workers significantly motivate patients to attend follow-up care. One patient noted, "*If the healthcare workers tell me to come every six months, there is nothing that keeps me from coming"* (P11). Another study by Caro-Bautista et al. (2021:8) found that patients who received regular reminders from their healthcare workers were more likely to attend follow-up appointments, indicating that provider engagement is crucial for improving health outcomes. It emphasises the importance of healthcare worker engagement in enhancing patient adherence to follow-up care.

Moreover, family and social support are other critical triggers identified in the study. Patients reported that encouragement from family members significantly influenced their decisions to attend follow-up visits. One patient stated, "*Family support is very essential. My children also advise me not to interrupt the treatment"* (P9). This finding is consistent with research by Letta et al. (2021:6), which found that social support networks positively impact patients' health behaviours, including adherence to follow-up care.

5.3.11 Proposed areas of attention on monitoring and evaluation of diabetes follow-up care

Monitoring and evaluation are essential components of diabetes follow-up care programs. Participants emphasised the need for guidelines that address these components. One healthcare worker stated, "*There should be enough budget allocated for monitoring and evaluation"* (P7). This highlights the importance of allocating resources to evaluate the effectiveness of guidelines and make necessary adjustments based on real-world outcomes. The impact of diabetes follow-up care can be recognised by establishing effective monitoring and evaluation mechanisms (Yimer, Shentema, Gufue, Zemelak, Asfaw, Getachew & Aweke 2024:8).

Moreover, participants expressed that monitoring and evaluation should be integral to the guidelines to ensure continuous improvement in diabetes care. One healthcare worker noted, "*If we have a monitoring system, we can identify which patients are lost to follow-up and why"* (P2). This aligns with the findings of the American Association of Diabetes Educators (2020:9), which highlight that effective monitoring mechanisms are essential for assessing the impact of diabetes follow-up care and management guidelines on patient outcomes. Without adequate resources for monitoring, the effectiveness of any guidelines remains questionable.

5.3.12 Summary

This section integrates findings from Phase 1 and Phase 2 to propose areas of emphasis aimed at reducing the number of patients lost to follow-up in Type 1 diabetes care. It begins by assessing the current guidelines and their practical application (5.3.1). The section outlines proposed areas of emphasis based on participant experiences, including enhancing patient education (5.3.2), establishing cohort registration and follow-up systems (5.3.3), tracing lost patients (5.3.4), financial support (5.3.5), and improving the quality of follow-up care (5.3.6), support system (5.3.7), enhance patient retention (5.3.8), reduce waiting time (5.3.9), enhance motivation of patients to attend diabetes (5.3.10, and robust monitoring and evaluation mechanisms (5.3.11).

Table 5.2 summarises the link between the empirical evidence and the proposed areas of emphasis.

Table 5.2: Summary of the proposed areas of emphasis linked with the empirical findings

PROPOSED ACTION	EMPIRICAL FINDING FROM PARTICIPANTS QUOTES
5.3.1 Implementation of guidelines in clinical practice	• *"There is a problem in applying the existing guidelines in practice"* (P7). • *"There should be trained healthcare workers in all health facilities. If there are no trained healthcare workers, no one can pay attention"* (P7).
5.3.2 Proposed focus areas for diabetes patient education	• "*I suggest giving enough education to patients"* (P6). • *"Always it needs the attention of the family or some relatives who are living with the sick person to put positive pressure on them to follow-up. The family members need to have some education materials"* (P5).
5.3.3 Proposed focus areas for cohort registration and follow-up	• *"I suggest strengthening the cohort registration and patient follow-up"* (P1). • "*There should be a guideline for the proper utilisation of charts and registers in the chronic care unit to improve the quality"* (P2).
5.3.4 Proposed focus areas for tracing lost-to-follow-up patients	• *"I recommend duplicating the experience of HIV follow-up care for diabetes care. There should be a case manager to trace lost to follow-up patients"* (P7). • "*We need a defined strategy to trace lost to follow-up diabetes patients"* (P2).
5.3.5 Proposed focus areas for financial support	• "*We have to work in collaboration with the diabetes association. If we link patients to the association, they can also get financial support"* (P5). • *"In this hospital, the patients are expected to cover their expenses from their pocket. It should be covered by insurance"* (P10).
5.3.6 Proposed focus areas to improve the quality of diabetes follow-up care	• "*There should be guidelines for the proper utilisation of charts and registers in the chronic care unit to improve the quality"* (p 2). • *"To ensure the quality of care, diabetic patients need not only the drug but also psychosocial support and education"* (P3).
5.3.7 Proposed focus areas on support systems towards diabetes follow-up care	• *"The attention of the family or some relatives who are living with the sick person is needed to put positive pressure on them to follow up"* (P5). • *"I heard that there was a psychosocial support group (diabetes association) that could help to reduce being lost to follow-up"* (P6)
5.3.8 Proposed focus areas to enhance patient retention in follow-up care	• *"There should be strict follow-up mechanisms like ART therapy. If patients disappear from ART, they call and communicate with the patients to come back to the follow-*

PROPOSED ACTION	EMPIRICAL FINDING FROM PARTICIPANTS QUOTES
	up" (P5). • *"I think it would be good if we had the follow-up charts… that we can monitor the outcomes" (P4).*
5.3.9 Proposed focus areas to reduce waiting time	• *"If they provide the service on time, it will be good" (P8).*
5.3.10 Proposed focus areas to enhance the motivation of patients to attend diabetes follow-up care	• "*If the healthcare workers tell me to come every six months, there is nothing that keeps me from coming"* (P11). • "*Family support is very essential. My children also advise me not to interrupt the treatment"* (P9).
5.3.11 Proposed focus areas for monitoring and evaluation of diabetes follow-up care	• "*There should be enough budget allocated for monitoring and evaluation"* (P7). • "*If we have a monitoring system, we can identify which patients are lost to follow-up and why"* (P2).

5.4 DEVELOPMENT OF THE PRELIMINARY GUIDELINES

The researcher developed the preliminary guidelines based on the empirical findings and a comprehensive literature review. To identify the appropriate content and define the scope of the guideline on LTFU, the researcher adopted a deductive approach based on a review of the literature and an evaluation of existing guidelines, followed by an inductive analysis of the empirical findings obtained from the interviews with patients and healthcare workers in Phases 1 and 2. In line with this, the study by D'Angelo et al. (2022:2) proposes combining both deductive and inductive methods, as a literature review provides the theoretical basis for defining the domain, while empirical findings identify the actual elements of the guideline. Similarly, WHO (2014:31-36) advocates developing guidelines based on a comprehensive and objective assessment of available evidence.

Based on the empirical findings and literature review, the researcher formulated ten guidelines for LTFU Type 1 diabetes patients. Since the guidelines recur at several points in the review process, presenting all ten here would be redundant. Instead, one preliminary guideline, "Guideline for diabetes patient education and awareness creation", is presented below as an example in box 1. The full set of preliminary draft guidelines is provided in Annexure S for detailed reference.

Box 1: Preliminary Guidelines for diabetes patient education and awareness creation

Preliminary Guidelines for diabetes patient education and awareness creation

Based on the findings from the study, the following are the areas of emphasis for implementing diabetes patient education:

1. **Develop structured educational and sensitisation programs**
   - ***Create a comprehensive curriculum***: Design structured educational programs that cover various aspects of diabetes management, including medication adherence, dietary areas of emphasis, physical activity, and monitoring blood sugar levels. This curriculum should be tailored to meet the needs of different patient demographics.
   - ***Incorporate interactive learning***: Utilise interactive teaching methods, such as group discussions and hands-on demonstrations, to engage patients actively in their learning process. This can enhance the retention and application of knowledge.
   - ***Regular reminders and encouragement:*** Implement systematic reminder systems where healthcare workers actively encourage patients to attend follow-up visits. Direct communication from healthcare workers has been shown to motivate patients significantly.
2. **Involve family members in education.**
   - ***Family-centric educational initiatives:*** Develop programs that include family members in the education process, recognising their role in supporting patients' adherence to dietary and lifestyle changes. This can help reinforce healthy behaviours at home. Moreover, family support has been identified as a critical factor influencing patients' attendance at appointments.
   - ***Provide resources for families:*** Create educational materials specifically designed for family members to help them understand diabetes management and how they can support their loved ones.
3. **Ensure accessibility of educational materials.**
   - ***Develop multilingual resources:*** Provide educational materials in multiple languages and formats that are easy to understand for all patients. This includes brochures, videos, and online resources that cater to different literacy levels.

- ***Utilise local context:*** Ensure that educational materials are culturally relevant and consider local dietary practices and beliefs. This can enhance the effectiveness of the education provided.

4. Train healthcare workers on patient education.

- ***Implement training programs for healthcare workers:*** Provide comprehensive training for healthcare workers on effective patient education techniques, focusing on communication skills, empathy, and the importance of patient engagement.
- ***Cultural sensitivity training:*** Provide cultural sensitivity training for healthcare workers to better understand and address the cultural beliefs that may discourage patients from seeking follow-up care.

5. Foster a supportive environment.

- ***Create support groups:*** Establish support groups for patients to share experiences and challenges in managing diabetes. This can provide emotional support and reinforce the education that has been received.
- ***Community support programs:*** Develop community programs that foster social support networks, allowing patients to share experiences and encourage each other to prioritise follow-up care.
- ***Encourage community involvement:*** Collaborate with local organisations and diabetes associations to enhance educational outreach and provide additional resources for patients.

6. Increase awareness of health risks and benefits of follow-up care

- ***educational initiatives:*** Awareness of health risks can serve as a powerful motivator for patients. Implement educational programs that inform patients about the potential complications of diabetes and the importance of regular follow-up care.
- ***Utilise testimonials:*** Share success stories from other patients who have benefited from regular follow-up care to inspire and motivate others.
- ***Highlight positive outcomes:*** Clearly communicate the benefits of regular follow-up care, such as better management of diabetes and prevention of complications. This can be done through brochures, workshops, and community health events.
- ***Combat complacency***: Develop targeted services to address complacency among patients regarding their health. This can include motivational interviewing techniques to help patients recognise the importance of ongoing care.

7. Leverage community health education initiatives.

- ***Engage in community programs:*** Collaborate with local health organisations to create community health initiatives that promote diabetes awareness and the importance of follow-up care.
- ***Utilise mass media:*** Use mass media campaigns to raise awareness about diabetes management and the importance of follow-up visits, targeting both patients and their families.
- ***Incorporate visual aids:*** Use visual aids and infographics to illustrate the benefits of follow-up care, making the information more accessible and engaging for patients.

8. Monitor and evaluate educational effectiveness.

- ***Establish feedback mechanisms:*** Create systems for patients to provide feedback on the educational programs they receive. This can help identify areas for improvement and ensure that the education provided meets patients' needs.
- ***Conduct regular assessments:*** Implement regular assessments to evaluate the effectiveness of educational initiatives in improving patient knowledge and self-management skills. This can include pre- and post-education surveys to measure changes in understanding.

Implementing these areas of emphasis helps to create a robust guideline for diabetes patient education, empowering patients with the knowledge and skills necessary for effective self-management. By focusing on structured education, family involvement, accessibility, healthcare worker training, and continuous evaluation, healthcare systems can significantly improve patient outcomes in diabetes management.

5.5 FOCUSED DISCUSSION: DATA GATHERING, ANALYSIS AND INTERPRETATION

5.5.1 Population

The target population for this phase of the study comprised healthcare professionals with relevant experience in the follow-up care of patients with Type 1 diabetes and diabetes program managers. Specifically, the selected participants had a minimum of three years of experience in delivering, managing or coordinating Type 1 diabetes care services. Six professionals were involved in the focused discussion. These included healthcare workers from diabetes care units (3), a diabetes focal person from a public

hospital (1), and two diabetes program officers from district health offices (see Table 3.4 in Chapter 3).

5.5.2 Sampling

The selection of participants for the focused discussion was facilitated through purposive sampling, supported by a gatekeeper. The Head of the South West Shewa Zone Health Department served as the gatekeeper and was formally approached with a letter outlining the study's objectives, selection criteria, and the ethical considerations of his role in the recruitment letter (see Annexure V).

Based on the inclusion criteria, the gatekeeper identified and listed healthcare professionals who had at least three years of experience in the follow-up care of Type 1 diabetes patients. He also obtained preliminary verbal consent by explaining the purpose and voluntary nature of the discussion to potential participants.

The researcher then formally contacted the identified individuals by sending a recruitment letter (Annexure K) and an information letter (see Annexure H) by email. All six selected experts agreed to participate and attended the discussion voluntarily. Participants were compensated for their time through the provision of a daily subsistence allowance and transportation reimbursement, in line with ethical standards for stakeholder engagement in public health research.

5.5.3 Study technique

As part of the guideline development process, a focused discussion was conducted to gather expert input on draft areas of emphasis developed from empirical findings. The discussion took place on February 25, 2025. During the discussion, each draft's areas of emphasis were presented individually, and participants were asked a series of open-ended questions to guide reflection and feedback. Prompts included: "What are your thoughts on these areas of emphasis?", *"How feasible is this action in your context?", "Do these areas of emphasis address the root causes of lost to follow-up?", and "How could this be improved or adapted?"*

All participants provided written informed consent prior to the focused discussion, including consent for audio recording of the session (see Annexure M). The discussion was audio-recorded and supplemented with field notes taken by the researcher. The data collection instrument, procedure, and overall process for the focused discussion are described in detail in Chapter 3 (see Section 3.5.3.2).

Participants reflected their insights and suggestions, which were documented in field notes by the researcher. This qualitative data was later analysed and used to refine the content and format of the final guidelines below.

5.5.4 Guideline 1: Diabetes patient education and awareness creation

5.5.4.1 Data gathering

During the focused discussion, the panel of six experts provided feedback on the proposed patient education and awareness guideline. They emphasised the practicality and relevance of the components while also offering suggestions to enhance feasibility and cultural appropriateness. Participants stated:

> *"The idea of using interactive teaching is good. In my experience, patients understand much better when we use simple visuals or show them how to use glucometers rather than just talk*" Health Officer- Diabetes Care Unit.

> *"Training healthcare workers on how to educate and engage patients is often overlooked. This section is really important, especially the emphasis on empathy and communication,"* NCD Program Expert, District Health Office.

> *"This all sounds good, but we do need to think about feasibility. For example, is there enough time during clinic hours to conduct these structured sessions?"* Diabetes Focal Person- Public Hospital.

> *"Mass media and visual aids can really reach people who don't come to the clinic regularly. But we should make sure the messages are in the local language,"* NCD Program Expert- District Health Office.

5.5.4.2 Analysis and Interpretation

The feedback gathered from this expert panel played a critical role in shaping the revised version of the guideline. The researcher incorporated participants' feedback into the revised guideline as follows:

- The guideline emphasised the section on healthcare worker training to include communication and motivational counselling techniques.
- The guideline clarifies how to make patient education sessions more structured, targeted, and feasible within the constraints of limited workers and time.
- Based on suggestions for mass outreach, the revised version proposes local-language messaging and community radio campaigns.

Table 5.3 below presents an example of how feedback pertaining to the focused discussion was incorporated. To prevent duplication of content, a brief summary of the suggested integration is presented in Table 5.3. The complete draft guideline, incorporating the inputs, is presented in Annexure S.

Table 5.3: Integration of the experts' feedback into the revised guideline on patient education

PRELIMINARY GUIDELINE	REVISED GUIDELINE (AFTER FOCUSED DISCUSSION FEEDBACK)
1. Develop structured educational and sensitisation programs • Comprehensive curriculum covering medication, diet, activity, and monitoring • Interactive learning methods	Education sessions *structured, targeted, and feasible* within clinic constraints (time, worker shortages). -Emphasis on *simple visuals, practical demonstrations* (e.g., glucometer use) instead of only verbal instruction.
3. Ensure accessibility of educational materials - Multilingual resources - Local context adaptation	- **Strengthened** to include *local language messaging* for both clinic and mass outreach. - Added *community radio campaigns* for broader accessibility.
4. Train healthcare workers on patient education - Training in education techniques, communication, and empathy - Cultural sensitivity training	**- Expanded** to explicitly include *motivational counselling techniques* alongside communication and empathy. - Reaffirmed as a *critical priority* given its role in improving patient engagement.
7. Leverage community health education initiatives - Engage in community programs - Mass media outreach - Use of visual aids	**- Strengthened:** added *local language messaging and community radio campaigns,* as emphasised by experts. - Visuals highlighted as highly effective (e.g., posters, infographics, demonstrations).

5.5.5 Guideline 2: Financial support to T1D patients

5.5.5.1 Data gathering

The expert panel appreciated the inclusion of financial support mechanisms as a critical component in improving diabetes follow-up care. They also highlighted areas that require practical consideration, especially in terms of feasibility and sustainability.

> *"This part of the guideline addresses the real-life struggles our patients go through. Many simply don't come back because they can't afford transport or medications. Financial support is not optional; it's essential,"* Nurse, Diabetes Care Unit.

> *"The sliding scale idea is good, but implementation might be difficult unless facilities are given clear criteria and budget support. Still, I think it's worth advocating for,"* NCD Program Expert, District Health Office.

> *"I liked the part about insurance expansion, especially awareness-raising. Many patients are eligible but don't even know how to register or what they're entitled to."* NCD Program Expert, District Health Office.

> *"The idea of reducing the service fee is great, but we also have to be realistic. Can the hospital implement this? We need to make sure that the hospital can make up for the lower fees. If not, it might not be sustainable,"* Health Officer- Diabetes Care Unit

5.5.5.2 Analysis and Interpretation

The researcher incorporated participants' feedback into the revised guideline. The experts' reflections were instrumental in refining the financial support guideline. Their contributions were used to enhance the clarity of the proposed areas of emphasis:

- The section on direct cash and voucher support was expanded to include transportation reimbursement as a common and urgent need among patients.
- A new area of emphasis was added under sliding-scale fees to develop clear eligibility criteria and to encourage piloting in selected facilities to assess feasibility.
- The insurance awareness segment now includes an emphasis on on-site insurance registration support during clinic days.
- Feedback on sustainability led to the inclusion of a note encouraging advocacy for government subsidies to reduce service fees at public facilities.

These revisions aim to maintain the guideline's comprehensiveness while aligning with the realities of the Ethiopian healthcare system and the capacities of frontline providers.

Table 5.4: Integration of the experts' feedback into the revised guideline on financial support

Preliminary guideline	Revised guideline (after focused discussion feedback)
1. Establish financial assistance programs - Sliding scale fees - Direct cash and voucher assistance	- **Expanded** direct cash/voucher support to include transportation reimbursement. **- Sliding scale fees revised**: added need for clear eligibility criteria and suggested to pilot in selected facilities for feasibility.
2. Implement affordable healthcare services - Reduce service fees	**- Retained but emphasised sustainability concerns:** revised to encourage advocacy for government subsidies to support reduced fees at public facilities.
3. Enhance insurance coverage - Expand coverage options - Increase awareness of insurance benefits - Advocate for policy changes	- **Strengthened awareness section:** added on-site insurance registration support during clinic days. - Reaffirmed expansion of coverage and policy advocacy as critical.

5.5.6 Guideline 3: Tracing lost-to-follow-up patients

5.5.6.1 Data gathering

The expert panel recognised the critical importance of tracing patients who are lost to follow-up to improve diabetes management outcomes. They affirmed the need for clear, structured approaches while emphasising the value of practical monitoring tools.

> *"I appreciate that the guideline mentioned the ways of tracing patients who miss appointments. This is one of the biggest challenges we face, in which each healthcare worker approaches differently. Thus, a clear protocol will help standardise how we act across all workers involved in diabetes care service delivery,"* Nurse, Diabetes Care Unit.

"Reviewing our tracing efforts is essential to know if our methods work. Collecting feedback from healthcare workers will help improve the system continuously," Diabetes Focal Person, Public Hospital.

5.5.6.2 Analysis and Interpretation

The researcher incorporated participants' feedback into the revised guideline. The expert feedback was essential in enhancing the clarity, feasibility, and patient-centeredness of the revised guideline:

- The guideline recommends developing a standard protocol on how to trace lost-to-follow-up cases.
- The monitoring framework includes simple metrics for tracking effectiveness and a feedback mechanism that allows healthcare workers to regularly report challenges and successes.

These updates ensure the guideline supports effective and systematic tracing, which helps reduce loss to follow-up and improve patient outcomes.

Table 5.5: Integration of the experts' feedback into the revised LTFU guideline

Preliminary guideline	Revised guideline (after focused discussion feedback)
4. Create clear guidelines for tracing lost patients - Use of structured charts and registers	**Strengthened**: Emphasis on developing a **standard protocol** for tracing to ensure uniformity across all workers.
5. Monitor and evaluate tracing effectiveness	Introduce simple monitoring metrics (e.g., the number of patients traced, the proportion successfully returned to care, and reasons for loss to follow-up) to assess tracing effectiveness.

5.5.7 Guideline 4: Improve the quality of diabetes follow-up care

5.5.7.1 Data gathering

Experts strongly endorsed a multifaceted approach to enhancing diabetes follow-up care quality:

"Compassionate care builds trust. When patients feel cared for, they're more likely to return for follow-up visits," Health Officer, Diabetes Care Unit.

"I appreciate the guideline indicating the importance of complication preventive examination like eye exams, foot care, kidney function tests, and cardiovascular risk assessments", Diabetes Focal Person, Public Hospital.

5.5.7.2 Analysis and interpretation

The researcher incorporates participants' feedback into the revised guideline as follows:

- Compassionate care training was expanded to incorporate practical patient-centred care principles.
- The guideline specified the recommended schedule for complication preventive examination during follow-up visits, such as eye exams, foot care, kidney function tests, and cardiovascular risk assessments.

These refinements ensure a robust and patient-centred guideline that addresses both the clinical and psychosocial aspects essential for improving diabetes follow-up care quality.

Table 5.6: Integration of the experts' feedback into the revised quality of follow-up care guideline

Preliminary guideline	Revised guideline (after focused discussion feedback)
5. Foster a supportive healthcare environment: Train in compassionate care	**Strengthened:** Compassionate care training expanded to include **patient-centred care principles** that foster empathy and trust.
6. Adopt a holistic approach to diabetes management Integrate comprehensive care - Focus on preventive services	**Strengthened:** Preventive care services emphasised with a recommended schedule for monitoring (eye exams, foot care, kidney function tests, cardiovascular risk assessments) during follow-up visits.

5.5.8 Guideline 5: Reduce patients' waiting time in the health facility

5.5.8.1 Data gathering

The expert panel endorsed the proposed strategies and provided valuable insights based on their firsthand experiences in clinical management.

> *"Waiting long is one of the top complaints we hear from patients. The suggestions in this guideline are really practical to reduce waiting time,"* Nurse, Diabetes Care Unit.

> *"Having a dedicated diabetes care room or unit would help, which allows us to manage patients more efficiently and on time",* Diabetes Focal Person, Public Hospital.

> *"If patients have something to read or learn while waiting, they get less frustrated, and it can even be educational",* Nurse, Diabetes Care Unit.

> *"We often don't notice where the delays are happening until someone points it out. A system for review can help us fix problems early,"* Diabetes Focal Person, Public Hospital

5.5.8.2 Analysis and interpretation

The experts' feedback led to some important refinements that enhanced the practical applicability and patient-centred nature of the final guideline:

- The proposal for a dedicated diabetes care unit now includes guidance to prioritise it in high-volume hospitals and integrate it within existing NCD care services where possible.
- On extending diabetes care unit hours, the revised guideline suggests tailoring appointments throughout the day, and fixing some appointments in late-hour or weekend slots once a week, particularly in urban or busy settings.
- The improvement of the waiting area was strengthened to include low-cost patient education materials (such as posters, brochures, or diabetes tip cards, television) and basic comfort enhancements (e.g., seating arrangements).

These refinements ensure that the guideline to reduce waiting time is feasible, thereby improving patient satisfaction and follow-up adherence.

Table 5.7: Integration of the experts' feedback into the revised guideline to reduce patients' waiting time

Preliminary guideline	Revised guideline (after focused discussion feedback)
5. Create dedicated diabetes care units: Establish specialised diabetes units.	**Strengthened:** Establish specialised diabetes units to improve patient flow and efficiency in high-volume hospitals. Where feasible, integrate diabetes units into existing NCD services for cost efficiency.
8. Offer extended hours: Extend clinic hours to reduce congestion	**Refined:** Appointments tailored throughout the day, with late-hour or weekend slots once a week suggested in urban/busy facilities.
10. Foster a supportive environment: Comfortable waiting areas with educational materials.	**Expanded:** Incorporates low-cost patient education resources (posters, brochures, tip cards, TV programs) and basic comfort improvements (better seating arrangements).

5.5.9 Guideline 6: Implementing robust cohort follow-up mechanisms in diabetes care

5.5.9.1 Data gathering

Experts recognised the critical role of systematic follow-up and documentation in ensuring continuity of care for diabetes patients. They stressed the importance of clear protocols and robust tracking to improve patient adherence and health outcomes.

> *"Strong patient tracking and record-keeping are the backbone of managing chronic diseases like diabetes. Without them, it's easy to lose patients along the way. Electronic data recording is also important,"* Nurse, Diabetes Care Unit.

> *"Clear, step-by-step guidelines make it easier for healthcare workers to know what to do at each follow-up visit. This helps standardise care across all healthcare workers,"* Diabetes Focal Person, Public Hospital.

> *"If we regularly review the data on attendance, treatment adherence, and patient outcomes, the service will improve",* Diabetes Focal Person, Public Hospital

5.5.9.2 Analysis and interpretation

The researcher incorporated participants' feedback into the revised guideline. The expert panel's suggestions informed several enhancements to the revised guideline, improving clarity, usability, and responsiveness:

- The patient tracking system section was expanded to recommend digital or paper-based registers with standardised formats to ensure completeness and ease of use.
- The protocols were designed to include stepwise patient engagement, monitoring, and intervention processes, making them easier for frontline healthcare workers to implement.
- Monitoring and evaluation were updated to include simple indicators such as attendance rates, medication adherence, and complication rates.
- Feedback mechanisms were formalised as periodic review meetings and suggestion channels to continuously improve follow-up care.

These refinements aim to support health facilities in providing consistent, patient-centred follow-up care, thus improving long-term diabetes management outcomes.

Table 5.8: Integration of the experts' feedback into the revised diabetes cohort follow-up guideline

Preliminary guideline	Revised guideline (after focused discussion feedback)
3. Enhance patient tracking and documentation: Robust tracking systems	**Expanded:** Recommend digital or paper-based registers with standardised formats to ensure completeness, consistency, and usability by frontline workers.
4. Create clear guidelines for follow-up care: Structured protocols	**Refined:** Protocols now include stepwise guidance for patient engagement, monitoring, and intervention to standardise care.
6. Monitor and evaluate follow-up care effectiveness: Monitoring mechanisms and Feedback loops	**Strengthened:** Monitoring includes simple indicators (attendance rates, medication adherence, complication rates). Feedback mechanisms are formalised via periodic review meetings and suggestion channels.

5.5.10 Guideline 7: Enhance the support system

5.5.10.1 Data gathering

Experts appreciated the concise and targeted nature of this guideline, especially the inclusion of caregivers and family in the support care. While supportive, they emphasised the importance of tailoring the implementation strategies to different family dynamics, literacy levels, and health system realities.

> *"Many of our patients rely entirely on their relatives for remembering appointments, preparing special meals, or even giving insulin. Educating families is not optional; it is critical,"* Diabetes Focal Person, Public Hospital.

> *"Sometimes the caregiver is a teenager or an elderly parent. We should design tools that suit different family roles,"* NCD Program Expert, District Health Office.

5.5.10.2 Analysis and interpretation

The researcher incorporated participants' feedback into the revised guideline. In response to feedback from the focused discussion, the revised guideline was refined to strengthen its relevance and applicability. For example, the guideline addressed the family education component, recommending age-appropriate, literacy-sensitive sessions. These revisions ensure the guideline supports not only patient care, but also recognises the lived experience of caregivers, empowering families as key partners in diabetes management.

Table 5.9. Integration of the experts' feedback into the revised family support guideline

Preliminary guideline	Revised guideline (after focused discussion feedback)
1. Develop family education programs: Create structured educational sessions	**Refined:** Sessions tailored to different age groups and literacy levels to ensure accessibility for all caregivers (teenagers, elderly, or low-literacy participants).
8. Evaluate family support programs	**Expanded:** The guideline now extends to broader psychosocial and community support, not limited to family support. The guideline is renamed as "Guideline on support system".

5.5.11 Guideline 8: Enhancement of patient retention in follow-up care

5.5.11.1 Data gathering

The expert panel supported the proposed strategies to enhance patient retention in follow-up care and enriched them with practical insights drawn from their clinical experiences.

> *"Service providers should take responsibility for maintaining patients in follow-up, they have to be proactive to do whatever they can",* a Health Officer from a diabetes care unit.
>
> *"I appreciate that the guideline underscores the importance of replicating the successful HIV cohort follow-up system",* a Diabetes Focal Person from a public hospital.
>
> *"Our services must be designed around the needs of patients",* said a nurse working in a public hospital.

5.5.11.2 Analysis and Interpretation

The researcher integrated the expert feedback into the revised guideline, leading to the following enhancements:

- Inclusion of patient-centred care principles.
- Adaptation of lessons and best practices from HIV cohort follow-up protocols.

These refinements strengthen the guideline by promoting sustained patient retention and improving the overall quality of diabetes follow-up care.

Table 5.10: Integration of the experts' feedback into the revised patient retention guideline

Preliminary guideline	Revised guideline (after focused discussion feedback)
1. **Strengthen patient-provider communication**: Tailored communication, literacy consideration, education time, reinforcement tools.	**Expanded:** Explicit incorporation of patient-centred care principles to ensure communication is responsive to individual patient needs.

4. Establish robust patient tracking mechanisms	**Refined:** Incorporates lessons from **successful HIV cohort models**, emphasising proactive follow-up and structured protocols.

5.5.12 Guideline 9: Enhance the motivation of patients to attend diabetes follow-up care

5.5.12.1 Data gathering

The expert panel supported the proposed strategies to enhance patient motivation to attend follow-up care:

"The SMS and phone reminder idea is good, but we also need backup options like health extension workers for patients without phones or poor network access".

"Family involvement is useful, but it should always be based on the patient's consent to respect privacy and individual preferences".

"Risk communication should not rely too heavily on fear of complications; balancing it with positive outcomes from regular follow-up would be more motivating".

"Improving patient experience is key, maybe introduce simple appointment scheduling to reduce waiting time frustration".

5.5.12.2 Analysis and interpretation

The researcher integrated the expert feedback into the revised guideline, leading to the following enhancements:

- Add community/health extension worker-based reminders as an alternative to SMS/phone systems for patients without access.
- State explicitly that family participation in follow-up should only occur with the patient's consent and preference.
- Shift from fear-driven messages to a balanced approach combining risk communication with positive outcomes of consistent follow-up.

Table 5.11: Integration of the experts' feedback into the revised guideline to enhance patients' motivation

Preliminary guideline	Revised guideline (after focused discussion feedback)
1. Optimise HWs communication: SMS/phone-based reminder systems tailored to patient language and literacy.	**Expanded:** SMS/phone-based reminder systems complemented with health extension worker follow-up for those without phone/network access.
2. Leverage family and social support systems: Involve family members during counselling sessions.	Involve family members during counselling sessions **based on patient consent and comfort**.
Address personal health concerns through risk communication	Incorporate patient testimonials and experiences, balancing risk information with positive reinforcement of the benefits of regular follow-up.

5.5.13 Guideline 10: Monitoring and evaluation of diabetes follow-up care program

5.5.13.1 Data gathering

The expert panel emphasised the importance of strong monitoring and evaluation (M&E) systems as foundational for improving diabetes care. They highlighted the need for actionable data, continuous learning, and guideline adaptability to respond to evolving challenges.

> *"Monitoring and evaluation are important. But we don't have the time and workers to fill out extended forms at the hospital level. It needs the support of the management personnel," Diabetes Focal Person- Public Hospital.*

> *"Too often we collect information and do nothing with it. Data should not just be collected for reporting but actively used to improve services,"* NCD Program Expert, District Health Office.

5.5.13.2 Analysis and Interpretation

The researcher incorporated participants' feedback into the revised guideline. Based on the expert inputs, the revised guideline pointed out the practical use of data and ongoing learning:

- The guideline emphasises the importance of data analysis meetings at the facility level to translate monitoring results into actionable improvements.
- A new area of emphasis encourages the establishment of a learning culture, supported by routine training and reflection sessions for workers, based on M&E findings.
- The feedback loop mechanism was addressed to include anonymous workers' surveys and regular multidisciplinary team meetings.

These refinements ensure that the M&E guideline not only promotes accountability but also empowers healthcare teams to continuously adapt and improve diabetes follow-up care.

Table 5.12: Integration of the experts' feedback into the revised M&E guideline

Preliminary guideline	Revised guideline (after focused discussion feedback)
1. Establish systematic monitoring frameworks: Monitoring protocols, technology for data collection	**Expanded:** Emphasises practical use of data at the facility level, including regular analysis meetings to translate monitoring results into actionable improvements.
3. Incorporate feedback mechanisms: Regular feedback loops, patient engagement	**Refined:** Feedback loops now include anonymous workers' surveys and routine multidisciplinary meetings to strengthen guideline adaptability.
5. Foster a culture of continuous improvement: Learning environment, review and update guidelines	**Expanded:** Highlights routine workers' training and reflection sessions to support continuous learning and guideline adaptation.

5.5.14 Summary

The focused discussion with diabetes care experts provided valuable, practical insights that enriched the preliminary guidelines. Their feedback guided enhancements that ensure the guidelines are feasible, patient-centred, and tailored to local healthcare contexts. Implementation of these guidelines can improve patient education, financial support, follow-up adherence, and overall quality and effectiveness of diabetes follow-up care.

The researcher revised the guidelines in response to the feedback received. Rather than aiming for full consensus, the purpose of the discussion was to gather expert reflections and incorporate diverse perspectives to enhance the clarity, relevance, and practicality of the guidelines. The researcher used this feedback to make informed revisions, while maintaining the flexibility to apply professional judgment where expert views diverged (see Section 3.5.3). Then, the researcher developed the revised guideline to be presented for validation.

To ensure the trustworthiness of the guidelines, the researcher employed a combination of deductive and inductive reasoning throughout the analysis. The deductive phase involved reviewing existing literature to establish a theoretical foundation, while the inductive phase focused on thematic analysis of expert inputs. This dual approach enhances the credibility of the guidelines and indicates the reflection of evidence-based practices. The structured engagement with experts and the transparent documentation of the process contributed to the overall rigour and applicability of the final guidelines, making them a valuable tool for diabetes care professionals.

5.6 GUIDELINE READY FOR VALIDATION

After the preliminary guidelines were developed, expert feedback was collected through focused discussions and incorporated into ten revised guidelines, which are now ready for validation. These 10 guidelines are guidelines on (1) Diabetes patient education, (2) Financial support, (3) Tracing lost-to-follow-up patients, (4) Quality of

care, (5) Reduce waiting time, (6) Implement cohort follow-up, (7) Support system, (8) Patient retention, (9) Enhance motivation of patients, (10) Monitoring and evaluation. To illustrate the revised guidelines, the 'Guideline on diabetes patient education and awareness' is presented below (see Section 6.2.1), while the complete set of the revised guidelines is provided in Annexure T.

5.6.1 Guideline 1: Diabetes patient education and awareness creation

Section	Description
Background	Diabetes is a chronic condition that requires ongoing patient engagement and lifestyle modification. The study's findings revealed gaps in patient knowledge, cultural barriers, and limited family involvement, all of which hinder effective self-management. Both patients and healthcare workers emphasised the need for structured and culturally relevant education to improve adherence and outcomes.
Goals of the guideline on patient education	– To strengthen patient knowledge and skills for diabetes self-management. – To foster family and community support in managing diabetes – To enhance healthcare workers' capacity to deliver effective patient education – To increase awareness of the health risks of poor diabetes management and the benefits of follow-up care.
Scope	This guideline focuses on health facilities, community-based programs, and diabetes associations in Ethiopia. It applies to education strategies for patients with Type 1, their families, and communities.
Target users	– Healthcare workers (nurses, doctors, health officers, educators) – Diabetes associations and community-based organisations – Patients living with diabetes and their families – Policymakers and program implementers in the Ministry of Health.
Key recommendations	**1. Implement structured educational programs:** – Create a comprehensive curriculum covering medication adherence, dietary recommendations, physical activity, and monitoring blood sugar levels, tailored to patient demographics, culture, and language.

	– Incorporate interactive teaching methods such as group discussions and hands-on demonstrations to enhance patient engagement and knowledge retention. 2. **Involve family members in education**: – Develop family-centric educational initiatives that recognise the role of families in supporting patients' adherence to lifestyle and treatment plans. – Provide resources and materials designed specifically for family members to strengthen their ability to support patients. 3. **Ensure accessibility of educational materials:** – Develop multilingual resources in different formats (brochures, videos, online content) tailored to varying literacy levels. – Ensure cultural relevance by aligning materials with local dietary practices and beliefs. 4. **Train healthcare workers on patient education:** – Implement training programs for healthcare workers on effective education techniques, communication skills, and patient engagement. – Provide cultural sensitivity training to address beliefs that may discourage patients from follow-up care. 5. **Establish linkages to diabetes education programs in the community:** – Create patient support groups for sharing experiences and challenges. – Develop community support programs that strengthen social networks for patients. – Encourage collaboration with local organisations and diabetes associations to expand outreach. 6. **Increase awareness of health risks and benefits of follow-up care:** – Implement awareness programs highlighting the complications of uncontrolled diabetes and the benefits of regular follow-up. – Share patient testimonials and success stories to motivate adherence. – Highlight positive outcomes of follow-up care through workshops, brochures, and health events. – Use motivational interviewing to address complacency among patients. 7. **Leverage community health education initiatives:** – Partner with local health organisations to implement diabetes awareness initiatives. – Engage community leaders and faith-based influencers to dispel myths. – Use mass media (radio, TV) for awareness campaigns.

	– Incorporate visual aids and infographics to simplify information. 8. **Monitor and evaluate educational effectiveness:** – Establish feedback mechanisms for patients to assess the relevance and effectiveness of education programs. – Conduct pre- and post-assessments to measure changes in patient knowledge and practices.
Conclusion	Implementing structured educational programs that involve families and ensuring the availability of accessible, culturally relevant materials empowers patients to manage diabetes effectively. Training healthcare workers and linking them to community programs strengthens knowledge retention and practical application. Continuous monitoring and evaluation ensure ongoing improvement in patient education outcomes.

5.6.2 Summary

The guidelines cover essential areas, including diabetes patient education, financial support, tracing patients lost to follow-up, and monitoring and evaluation of diabetes follow-up care. Each guideline has been tailored to address specific challenges identified through empirical data and expert discussions, ensuring they are practical and culturally relevant (see Annexure T). The anticipated implementation of these guidelines aims to enhance patient education, improve financial support mechanisms, reduce waiting times, and improve patient retention, ultimately leading to better health outcomes for individuals with diabetes.

5.7 CONCLUSION

Chapter 5 presented the comprehensive, iterative process used to develop guidelines for diabetes follow-up care. Initially, the guidelines were shaped by identifying gaps in existing literature and empirical findings from interviews with patients and healthcare workers. This foundational phase was crucial for determining the content and scope of the guidelines, ensuring they were grounded in real-world experiences and the challenges stakeholders face.

Subsequent phases involved refining the preliminary guidelines through focused discussions with diabetes care experts, who provided valuable insights that enhanced the guidelines' practicality and cultural relevance. Their feedback emphasised the importance of incorporating family involvement, financial support, and effective patient education into the guidelines, which were subsequently revised to better meet the needs of both patients and healthcare workers.

The final guidelines are designed to be actionable and adaptable, promoting a holistic approach to diabetes care that encompasses medical treatment, mental health support, and community engagement. The document emphasises the importance of continuous monitoring and evaluation to ensure that the guidelines remain relevant and effective in improving patient outcomes.

6. CHAPTER SIX: VALIDATION OF THE GUIDELINE

6.1 INTRODUCTION

The detailed methodology used for the guideline validation is presented in Chapter Six. It outlines the data collection and analysis processes and describes the expert dialogue that contributed to refining the guidelines. The chapter also highlights the levels of consensus reached on the proposed areas of emphasis. Finally, it presents the eight validated guidelines. The research progress is presented in Table 6.1.

Table 6.1: Research progress status

CHAPTER	NAME OF THE CHAPTER	PURPOSE/CONTENT
Chapter 1	Overview of the Study	The chapter provides an overview of the purpose, objectives and methodology of the study.
Chapter 2	Literature Review	Literature review to discuss: • Theoretical framework • Diabetes and diabetic services • The national strategy for diabetes
Chapter 3	Methodology	The methodology of all phases of the study
Chapter 4	Phases 1 and 2:	Data gathering, analysis, presentation and literature control
Chapter 5	Development of the guideline	• Literature review on the principles of guideline development • Phase 1 and Phase 2 data integration • Focused discussions, data gathering, analysis and interpretation • Presentation of the draft guideline is ready for validation
Chapter 6	Validation of the guideline	• The process and methodology followed • Data gathering and analysis of the Structured Consensus Development Meeting • The validated guideline
Chapter 7	Conclusion, recommendations, and limitations	Conclusion, recommendations, and limitations of the study

6.2 THE PROCESS AND METHODOLOGY OF GUIDELINE VALIDATION

The guideline validation process involves a Structured Consensus Development Meeting (SCDM) aimed at validating the guidelines through expert dialogue and feedback. A panel of 10 multidisciplinary experts were purposively selected by a gatekeeper (see Annexure U) based on their expertise in diabetes care, public health policy development/analysis, and health systems research, ensuring a diverse representation of perspectives (see Table 3.4). Based on the inclusion criteria, the gatekeeper identified and listed healthcare professionals who had at least three years of experience in the follow-up care of Type 1 diabetes patients. He also obtained preliminary verbal consent by explaining the purpose and voluntary nature of the discussion to potential participants. The gatekeeper subsequently shared with the researcher the contact information of participants who had provided informed consent to be included in the study.

Before the SCDM, the researcher informally contacted each selected panellist, who agreed to have their contact details shared. Then, the researcher shared the recruitment letter (see Annexure J), including the draft guideline and a structured validation tool (see Annexure R), with the experts via email one week before the SCDM. The purpose was to first require the experts to independently review and rate each proposed area of emphasis to be implemented using a 9-point Likert scale, and also to add narrative information to provide additional inputs. The first-round evaluation score was shared back with the researcher by email before the actual SCDM date (See Section 6.2.1). The researcher consolidated the data from all scorers into a single dataset. The mean scores of each item were summarised and interpreted.

The consensus levels were determined according to participants' scores, which ranged from 1 (strongly disagree) to 9 (strongly agree). The consensus criteria were as follows: Strong consensus was achieved when ≥80% of participants rated an item between 7 and 9; Moderate consensus applied when ≥60% to <80% of participants scored an item between 7 and 9; and No consensus applied when <60% of participants rated an item between 7 and 9 (see Section 3.5.4.2).

The actual SCDM, held at a predetermined venue agreed upon by all panellists, was then structured into three sessions, beginning with an opening session that set the context and clarified the researcher's objectives for the meeting. The second session involved a presentation of the overview of the draft guidelines by the researcher (see Section 6.2.2); thus, the rationale behind each area of emphasis proposed in every guideline was explained, followed by a review of the pre-meeting scores to identify areas of consensus and disagreement.

The core of the SCDM is situated on the facilitated discussion, where participants engage in guided dialogue about the proposed areas of emphasis (provide a reference for a focused facilitated discussion. The session focused on addressing divergent ratings and on exploring concerns about clarity, feasibility, and cultural appropriateness. The facilitator managed the session, providing equal opportunity for all panellists to participate (using the round-robin technique). The facilitator also ensured respectful participation, used probes for clarity, and effectively managed power dynamics by giving equal voice to all participants, redirecting dominant speakers, and encouraging quieter members to share their perspectives.

Following the discussion, participants re-scored each of the recommended areas of emphasis, applying the same consensus rule applied in the first round using the 9-point Likert scale from 1 (strongly disagree) to 9 (strongly agree). The same decision rules were applied based on the predefined consensus criteria (See Section 3.5.4.2.4). Accordingly, the proposed areas of emphasis to implement were ‘Accepted’, ‘Revised’, or ‘Removed’ based on these results. The researcher then summarised the outcomes and presented the final guidelines (Annexure T).

6.3 DATA GATHERING AND ANALYSIS

6.3.1 Findings: First Round Validation

The first round of the validation process involved a systematic review of the draft guidelines by the 10-member multidisciplinary panel of experts. The researcher shared the

draft guidelines, including an embedded validation tool (see Annexure R), with the panellists by email. All ten panellists confirmed receipt. Then, each item across the 10 proposed guidelines was independently scored by the 10 panellists on relevance, clarity, and feasibility. In addition to the score on the given items, panellists also provided qualitative feedback highlighting areas of overlap, gaps, and the need for rephrasing. The panellists then returned the completed validation form to the researcher.

Through this process, the researcher identified domains/items that achieved Strong Consensus (SC), Moderate Consensus (MC), and No Consensus (NC). The outcomes of the first round laid the groundwork for focused revisions and set the stage for further refinement in the second round of validation. A compiled summary of the quantitative data is provided below, together with the qualitative description provided below. The consensus levels and proposed revisions to the guideline from the first round of panel scoring are presented in the table below, using different font colours to indicate the level of agreement and type of change: items with strong consensus are shown in black, those with moderate consensus in red, and newly proposed items in blue font.

6.3.1.1 Guideline 1: Type-1 diabetes patients' education and awareness

In the guideline for 'Patient Education and Awareness', strong consensus (≥80%) was reached on 20 of the 21 items, and the remaining 1 item fell under moderate consensus (≥60% to <80%), with no items falling under no consensus (<60%). One item, "Regular reminders and encouragement", fell into the moderate consensus category (n = 6; p = 60%).

In addition to the score, panellists provided comments and suggestions on the draft guidelines. They emphasised the importance of context-specific detail. For example, they recommended *"specifying systematic reminder systems (e.g., SMS messages, automated database prompts)"*. Other repeated suggestions included expanding outreach via *"radio and television programs in local languages"* and ensuring that *"mass communication also provides exemplary actions".* These frequently raised concerns

were presented to the panellists during the SCDM session, and the items with moderate consensus were modified and re-scored by the panellists for validation (see Table 6.2).

Table 6.2: First round consensus scores of the guideline on diabetes education and awareness

ITEM NO.	EVALUATION QUESTION	N*	P (%)*	CONSENSUS
Domain 1: Develop structured educational and sensitisation programs				
1	***Create a comprehensive curriculum***: Design structured educational programs that cover various aspects of diabetes management, including medication adherence, dietary recommendations, physical activity, and monitoring blood sugar levels. This curriculum should be tailored to meet the needs of different patient demographics.	**10**	100%	SC*
2	***Incorporate interactive learning***: Utilise interactive teaching methods, such as group discussions and hands-on demonstrations, to engage patients actively in their learning process. This can enhance the retention and application of knowledge.	**9**	90%	SC
3	***Regular Reminders and Encouragement:*** Implement systematic reminder systems where healthcare workers actively encourage patients to attend follow-up visits. Direct communication from healthcare workers has been shown to significantly motivate patients.	**6**	60%	MC*
Domain 2: Involve family members in education				
1	***Family-centric educational initiatives:*** Develop programs that include family members in the education process, recognising their role in supporting patients' adherence to dietary and lifestyle changes. This can help reinforce healthy behaviours at home and patients' decisions to attend appointments.	**10**	100%	SC
2	***Provide resources for families:*** Create educational materials specifically designed for family members to help them understand diabetes management and how they can support their loved ones.	**9**	90%	SC
Domain 3: Ensure accessibility of educational materials				
1	***Develop multilingual resources:*** Provide educational materials in multiple languages and formats that are easily understandable for all patients. This includes brochures, videos, and online resources that cater to different literacy levels.	**10**	100%	SC
2	***Utilise local context:*** Ensure that educational materials are culturally relevant and consider local dietary practices and beliefs. This can enhance the effectiveness of the education provided.	**10**	100%	SC

ITEM NO.	EVALUATION QUESTION	N*	P (%)*	CON-SENSUS
Domain 4: Train healthcare workers on patient education				
1	***Implement training programs for healthcare workers:*** Provide comprehensive training for healthcare workers on effective patient education techniques, focusing on communication skills, empathy, and the importance of patient engagement.	**8**	80%	SC
2	***Cultural sensitivity training:*** Provide cultural sensitivity training for healthcare workers to better understand and address the cultural beliefs that may discourage patients from seeking follow-up care.	**9**	90%	SC
Domain 5: Foster a supportive environment				
1	***Create support groups:*** Establish support groups for patients to share experiences and challenges in managing diabetes. This can provide emotional support and reinforce the education received.	**10**	100%	SC
2	***Community support programs:*** Develop community programs that foster social support networks, allowing patients to share experiences and encourage each other to prioritise follow-up care.	**9**	90%	SC
3	***Encourage community involvement:*** Collaborate with local organisations and diabetes associations to enhance educational outreach and provide additional resources for patients.	**8**	80%	SC
Domain 6: Increase awareness of health risks and benefits of follow-up care				
1	***Educational initiatives:*** Awareness of health risks can serve as a powerful motivator for patients. Implement educational programs that inform patients about the potential complications of diabetes and the importance of regular follow-up care.	**8**	80%	SC
2	***Utilise Testimonials:*** Share success stories from other patients who have benefited from regular follow-up care to inspire and motivate others.	**10**	100%	SC
3	***Highlight positive outcomes:*** Clearly communicate the benefits of regular follow-up care, such as better management of diabetes and prevention of complications. This can be done through brochures, workshops, and community health events.	**9**	90%	SC
4	***Combat complacency***: Develop targeted interventions to address complacency among patients regarding their health. This can include motivational interviewing techniques to help patients recognise the importance of ongoing care.	**8**	80%	SC
Domain 7: Leverage community health education initiatives				

ITEM NO.	EVALUATION QUESTION	N*	P (%)*	CONSENSUS
1	***Engage in Community Programs:*** Collaborate with local health organisations to create community health initiatives that promote diabetes awareness and the importance of follow-up care.	**9**	90%	SC
2	***Utilise mass media:*** Use mass media campaigns to raise awareness about diabetes management and the importance of follow-up visits, targeting both patients and their families.	**8**	80%	SC
3	***Incorporate visual aids:*** Use visual aids and infographics to illustrate the benefits of follow-up care, making the information more accessible and engaging for patients.	**9**	90%	SC
Domain 8: Monitor and evaluate educational effectiveness				
1	***Establish feedback mechanisms:*** Create systems for patients to provide feedback on the educational programs they receive. This can help identify areas for improvement and ensure that the education provided meets patients' needs.	**10**	100%	SC
2	***Conduct regular assessments:*** Implement regular assessments to evaluate the effectiveness of educational initiatives in improving patient knowledge and self-management skills. This can include pre- and post-education surveys to measure changes in understanding.	**10**	100%	SC
n= number of panellists scored 7-9; P(%)*= percentage of the panellists (out of the total 10 panellists) who scored 7-9;* *SC*= Strong Consensus; MC*= Moderate Consensus; NC*= No consensus*				

6.3.1.2 Guideline 2: Financial support for diabetes patients

The guideline on financial support achieved strong consensus (≥80%) on 13 of 15 items, and the remaining two items fall under moderate consensus (≥60% to <80%), with no items falling under no consensus (<60%). The item 'sliding scale fees' achieved moderate consensus (n = 6; p = 60%), where panellists highlighted feasibility challenges within the current healthcare framework. Instead, participants suggested reframing the areas of emphasis to advocate for the inclusion of diabetes care services in the exempted services list, which was perceived as more practical and sustainable. While for the item on direct cash and voucher assistance (n = 7; p = 70%), panellists noted that although such programs might be helpful in humanitarian or crisis contexts, they pose sustainability risks. These frequently raised concerns were presented to the

panellists during the SCDM session, and the items with moderate consensus were modified and re-scored by the panellists for validation (see Table 6.3).

Table 6.3: First round consensus scores of the guideline on financial support to T1D patients

ITEM NO.	EVALUATION QUESTION	N	P (%)	CON-SENSUS
Domain 1: Establish financial assistance programs				
1	***Collaborate with local organisations:*** Develop partnerships with local organisations, such as diabetes associations, to create a support network for patients. This collaboration can help provide financial assistance for medications and follow-up care.	**10**	100%	SC
2	***Create awareness of available resources***: Ensure that patients are informed about the financial assistance programs available to them through community organisations. This can be achieved through educational campaigns.	**9**	90%	SC
3	***Sliding scale fees:*** Implement sliding scale fees for patients based on their income, ensuring that those without adequate insurance can still access necessary care.	**6**	60%	MC
4	***Direct cash and voucher assistance programs:*** Establish direct cash and voucher assistance programs specifically for diabetes patients who face unexpected medical expenses and transportation costs.	**7**	70%	MC
Domain 2: Implement affordable healthcare services				
1	***Reduce service fees:*** Advocate for the reduction of service fees associated with diabetes care to make healthcare more accessible for patients. This can help alleviate the financial burden that often prevents patients from seeking necessary treatment.	**10**	100%	SC
2	***Integrate affordable services into healthcare systems:*** Work towards integrating affordable healthcare services into existing healthcare systems to ensure that patients can access the care they need without financial strain.	**10**	100%	SC
Domain 3: Enhance insurance coverage				
1	***Expand insurance coverage options:***			
	Advocate for policies that expand eligibility for insurance coverage to include more individuals, particularly those with low income or those who are currently uninsured.	**10**	100%	SC
	Develop insurance plans that cover a wider range of diabetes-related services, including medications, regular check-ups, and necessary diagnostic tests.	**10**	100%	SC
2	***Increase awareness of insurance benefits:***			

ITEM NO.	EVALUATION QUESTION	N	P (%)	CON-SENSUS
	Implement educational campaigns to inform patients about the benefits of insurance coverage and how to navigate the enrollment process.	**10**	100%	SC
	Organise community workshops that provide information on how to apply for insurance and the specific benefits that come with coverage for diabetes management.	**10**	100%	SC
3	***Advocate for policy changes:***			
	Lobby for legislative support and work with policymakers to advocate for changes in legislation that would require insurance companies to cover essential diabetes care services.	**10**	100%	SC
	Collaborate with related advocacy groups that focus on diabetes programs to push for systemic changes in insurance coverage policies.	**10**	100%	SC
Domain 4: Monitor and evaluate financial support programs				
1	***Establish monitoring mechanisms:*** Implement systematic approaches to assess the effectiveness of financial support programs. This includes tracking patient outcomes and adherence to treatment plans.	**9**	90%	SC
2	***Data collection:*** Collect data on the impact of insurance coverage on patient outcomes, including adherence to treatment and health complications. This data can be used to advocate for further improvements in insurance policies.	**9**	90%	SC
3	***Incorporate feedback loops:*** Create feedback mechanisms for patients to share their experiences with financial support programs. This can help identify areas for improvement and ensure that the programs meet patients' needs.	**9**	90%	SC
n= number of panellists scored 7-9; P(%)*= percentage of the panellists (out of the total 10 panellists) who scored 7-9;* *SC*= Strong Consensus; MC*= Moderate Consensus; NC*= No consensus*				

6.3.1.3 Guideline 3: Reduce patients' waiting time in the health facility

The guideline on 'Patients' waiting time' reached a strong consensus (≥80%) on six of the 10 proposed items. However, four out of the 10 items, such as appointment scheduling, triage systems, extended hours, and group visits, fell into the category of moderate consensus (≥60% to <80%). Participants noted concerns around sustainability, cost implications, and health workforce availability. Importantly, no items fell under the no consensus (<60%) threshold (see Table 6.4).

Feedback highlighted the need for practical and resource-sensitive solutions. One participant noted, *"extending working hours is important but may not be sustainable with the current workforce".* Concerns also emerged about duplication, with comments such as *"some measures overlap with quality improvement initiatives already included in other guidelines"*. These frequently raised concerns were presented to the panellists during the SCDM session, and the items with moderate consensus were modified and re-scored by the panellists for validation.

Table 6.4: First round consensus scores of the guideline to reduce patients' waiting time in the health facility

ITEM NO.	EVALUATION QUESTION	N*	P (%)*	CONSENSUS
1	**Streamline appointment scheduling:** Implement an efficient appointment scheduling system that allows for better management of patient flow. These can include online booking options and automated reminders to reduce no-shows and last-minute cancellations	**6**	60%	MC*
2	**Increase staffing during peak hours:** Analyse patient flow data to identify peak hours and ensure adequate staffing during these times. Increasing the number of healthcare workers available can help manage patient load and reduce waiting times	**8**	80%	SC*
3	**Implement triage systems:** Establish a triage system to prioritise patients based on the urgency of their needs. This can help ensure that patients requiring immediate attention are seen promptly, while those with less urgent needs can be scheduled accordingly	**6**	60%	MC
4	**Utilise technology for patient tracking:** Implement electronic health records (EHR) and patient tracking systems to monitor patient status and streamline the check-in process. This can help reduce administrative delays and improve overall efficiency	**9**	90%	SC
5	**Create dedicated diabetes care units:** Establish specialised units for diabetes care within healthcare facilities. This can help streamline services and ensure that patients receive focused and comprehensive care, reducing the time spent waiting for appointments	**9**	90%	SC
6	**Enhance communication with patients:** Improve communication strategies to keep patients informed about expected waiting times and any delays. Providing updates can help manage patient expectations and reduce frustration	**8**	80%	SC

ITEM NO.	EVALUATION QUESTION	N*	P (%)*	CONSEN-SUS
7	**Conduct regular process evaluations:** Implement a system for regularly evaluating and optimising patient flow processes. Gathering feedback from both patients and healthcare workers can help identify bottlenecks and areas for improvement	**10**	100%	SC
8	**Offer Extended Hours:** Consider extending clinic hours to accommodate patients who may have difficulty attending during regular hours. This can help distribute patient visits more evenly throughout the week and reduce congestion during peak times	**6**	60%	MC
9	**Implement Group Visits:** Organise group visits for patients with similar needs, such as education on diabetes management. This can reduce the number of individual appointments and allow healthcare workers to address multiple patients simultaneously	**6**	60%	MC
10	**Foster a Supportive Environment:** Create a welcoming and efficient environment in waiting areas. Providing comfortable seating, educational materials, and engaging activities can help improve patient satisfaction while they wait	**10**	100%	SC
n= number of panellists scored 7-9; P(%)*= percentage of the panellists (out of the total 10 panellists) who scored 7-9;* *SC*= Strong Consensus; MC*= Moderate Consensus; NC*= No consensus*				

6.1.3.4 Guideline 4: Tracing lost-to-follow-up diabetes patients

The guideline on tracing lost-to-follow-up patients reached strong consensus (≥80%) on 11 of the 12 items, and the remaining 1 item reached moderate consensus (≥60% to <80%), with no items falling under no consensus (<60%). One item, “Comprehensive Training Programs”, fell into the moderate consensus category (n=7; p=70%), reflecting the lack of specificity on how the training program addresses LTFU (see Table 6.5).

Feedback underscored both the importance of context-specific strategies and the constraints on feasibility. One panellist emphasised the involvement of HEWs (Health Extension Workers), saying *“HEWs are already present in the grassroots health system, so they should be central to tracing patients”.* Others cautioned that *“mobile phone reminders are important with additional options in rural areas where access and literacy are limited”.* Concerns were also raised about human resource implications, with

one participant noting, *"hiring dedicated tracing workers is impractical; better to integrate this into existing roles".* Overall, the feedback reflected the intention to incorporate community-based, low-cost, and integrated approaches to tracing lost-to-follow-up patients. These frequently-raised concerns were presented to the panellists during the SCDM session, and the items with moderate consensus were modified and re-scored by the panellists for validation.

Table 6.5: First round consensus scores of the guideline on tracing of lost to follow-up diabetes patients

ITEM NO.	EVALUATION QUESTION	N*	P (%)*	CONSENSUS
Domain 1: Establish Dedicated Personnel for Patient Tracking				
1	***Implement Case Management Models:*** Introduce dedicated case managers for diabetes care, similar to those used in HIV care. This can enhance follow-up care by ensuring that patients receive consistent support and monitoring.	**10**	100%	SC*
2	***Assign Roles Clearly:*** Clearly define the roles and responsibilities of healthcare workers involved in tracing lost patients to improve accountability and streamline processes.	**10**	100%	SC
Domain 2: Improve Training for Healthcare Workers				
1	***Comprehensive Training Programs***: Develop and implement training programs focused on diabetes management and follow-up protocols. This should equip healthcare workers with the necessary skills to manage diabetes effectively.	**6**	60%	MC*
2	***Ongoing Education:*** Encourage continuous professional development for healthcare workers to keep them updated on best practices in diabetes care and patient engagement strategies.	**10**	100%	SC
Domain 3: Enhance Patient Tracking and Documentation				
1	***Implement Robust Tracking Systems:*** Develop systematic patient tracking systems to monitor attendance and follow-up care. This can help identify patients who are lost to follow-up and facilitate timely interventions.	**10**	100%	SC
2	***Standardise Record-Keeping Practices***: Establish clear guidelines for record-keeping and documentation in chronic care units to improve the quality of diabetes follow-up services.	**10**	100%	SC
Domain 4: Create clear guidelines for tracing lost-to-follow-up patients				

ITEM NO.	EVALUATION QUESTION	N*	P (%)*	CON-SENSUS
1	***Develop Structured Protocols:*** Create detailed protocols for tracing lost patients that outline the necessary steps for patient engagement, monitoring, and intervention.	**10**	100%	SC
2	***Utilise charts and registers effectively:*** Provide guidelines for the proper utilisation of charts and registers in chronic care units to enhance the quality of follow-up services.	**10**	100%	SC
Domain 5: Foster a supportive environment				
1	***Encourage Family Involvement:*** Involve family members in the education and support process, as their encouragement can significantly boost patients' confidence in attending follow-up care.	**10**	100%	SC
2	***Create peer support networks:*** Establish peer support groups where patients can share experiences and motivate each other to prioritise follow-up care.	**9**	90%	SC
Domain 6: Monitor and evaluate tracing effectiveness				
1	***Establish Monitoring Mechanisms:*** Implement systematic approaches to assess the effectiveness of tracing lost patients. This includes tracking patient outcomes and adherence to treatment plans.	**10**	100%	SC
2	***Incorporate feedback loops:*** Create feedback mechanisms for healthcare workers to share their experiences and challenges in tracing lost patients. This can help inform necessary adjustments to improve care quality.	**10**	100%	SC
n= number of panellists scored 7-9; P(%)*= percentage of the panellists (out of the total 1(panellists) who scored 7-9;* *SC*= Strong Consensus; MC*= Moderate Consensus; NC*= No consensus*				

6.1.3.5 Guideline 5: Diabetes cohort follow-up and patient monitoring system

Strong consensus (≥80%) was achieved on 10 of 12 proposed areas of emphasis on this guideline. The remaining two items fell under moderate consensus (≥60% to <80%). No item fell into the no consensus (<60%) range. The two items that fell under moderate consensus are 'implement case management models' and 'encourage family involvement' (see Table 6.6).

The feedback on 'family involvement' highlighted caution on avoiding duplication with other guidelines. The feedback on the 'implement case management models' was

around implementation feasibility. Participants expressed concern that *"dedicated cohort officers are unrealistic; instead, integrate responsibilities within current health teams".* Other panellists also noted the importance of workers' stability: *"frequent worker rotations in diabetes units disrupt continuity and weaken cohort follow-up. So it needs a strong guideline to maintain trained and experienced workers".* These frequently raised concerns were presented to the panellists during the SCDM session, and the items with moderate consensus were modified and re-scored by the panellists for validation.

Table 6.6: First round consensus scores of the guideline to improve diabetes cohort follow-up

ITEM NO.	EVALUATION QUESTION	N*	P (%)*	CONSENSUS
Domain 1: Establish dedicated personnel for cohort management				
1	***Implement case management models:*** Introduce dedicated case managers for diabetes care, similar to those used in HIV care. This can enhance follow-up care by ensuring that patients receive consistent support and monitoring.	**7**	70%	MC*
2	**Assign roles clearly:** Clearly define the roles and responsibilities of healthcare workers involved in diabetes cohort management to improve accountability and streamline processes.	**10**	100%	SC*
Domain 2: Improve training for healthcare workers				
1	***Comprehensive Training Programs:*** Develop and implement training programs focused on diabetes management and cohort registration practices. This should equip healthcare workers with the necessary skills to manage diabetes effectively.	**8**	80%	SC
2	***Ongoing education***: Encourage continuous professional development for healthcare workers to keep them updated on best practices in diabetes care and patient engagement strategies.	**9**	90%	SC
Domain 3: Enhance patient tracking and documentation				
1	***Implement robust tracking systems:*** Develop systematic patient tracking systems to monitor attendance and follow-up care. This can help identify patients who are lost to follow-up and facilitate timely interventions.	**10**	100%	SC
2	***Standardise record-keeping practices:*** Establish clear guidelines for record-keeping and documentation in chronic care units to improve the quality of diabetes follow-up services.	**10**	100%	SC
Domain 4: Create clear guidelines for follow-up care				

ITEM NO.	EVALUATION QUESTION	N*	P (%)*	CON-SEN-SUS
1	***Develop Structured Protocols:*** Create detailed protocols for diabetes cohort follow-up that outline the necessary steps for patient engagement, monitoring, and intervention.	**10**	100%	SC
2	***Utilise charts and registers effectively:*** Provide guidelines for the proper utilisation of charts and registers in chronic care units to enhance the quality of follow-up services.	**10**	100%	SC
Domain 5: Foster a supportive environment				
1	***Encourage Family Involvement:*** Involve family members in the education and support process, as their encouragement can significantly boost patients' confidence in attending follow-up visits.	**7**	70%	MC
2	***Create peer support networks:*** Establish peer support groups where patients can share experiences and motivate each other to prioritise follow-up care.	**9**	90%	SC
Domain 6: Monitor and evaluate follow-up care effectiveness				
1	***Establish monitoring mechanisms:*** Implement systematic approaches to assess the effectiveness of diabetes cohort follow-up programs. This includes tracking patient outcomes and adherence to treatment plans.	**10**	100%	SC
2	***Incorporate feedback loops:*** Create feedback mechanisms for healthcare workers to share their experiences and challenges in implementing follow-up care guidelines. This can help inform necessary adjustments to improve care quality.	**10**	100%	SC
n= number of panellists scored 7-9; P(%)*= percentage of the panellists (out of the total 1(panellists) who scored 7-9; SC*= Strong Consensus; MC*= Moderate Consensus; NC*= No consensus*				

6.1.3.6 Guideline 6: Monitoring and evaluation of diabetes follow-up care program

Strong consensus (>80%) was reached on 8 of 10 items across the five domains of this guideline. The remaining two items (develop a comprehensive monitoring plan and electronic health record use) fell under moderate consensus (≥60% to <80%); none of the items dropped into the no consensus (<60%) category (see Table 6.7).

Feedback underscored both enthusiasm and caution. One participant emphasised, *"monitoring indicators should be harmonized with national HMIS to avoid duplication"* Another added, *"workers' workload is already high so that the M&E systems must be simple and practical"* Concerns were also raised about accountability, with one noted,

"it must be clear who will use the data and how; otherwise, collection will not lead to improvement". The comments mainly focused on practicability, reflecting the existing infrastructural and systemic challenges. These frequently raised concerns were presented to the panellists during the SCDM session, and the items with moderate consensus were modified and re-scored by the panellists for validation.

Table 6.7: First round consensus scores of the guideline on M&E of the diabetes follow-up care program

ITEM NO.	EVALUATION QUESTION	N*	P (%)*	CONSENSUS
Domain 1: Establish Systematic Monitoring Frameworks				
1	***Develop Comprehensive Monitoring Protocols:*** Create structured protocols that outline the specific metrics and indicators to be monitored in diabetes follow-up care. This should include patient adherence rates, health outcomes, and the effectiveness of interventions.	**7**	70%	MC*
2	***Utilise Technology for Data Collection:*** Implement electronic health record systems that facilitate the collection and analysis of patient data, enabling healthcare workers to track patient progress and identify trends over time.	**6**	60%	MC
Domain 2: Allocate Resources for Monitoring Activities				
1	***Ensure Adequate Budgeting:*** Advocate for sufficient budget allocation, specifically for monitoring and evaluation activities within diabetes care programs. This is crucial for sustaining effective monitoring systems and ensuring that they are adequately staffed and resourced.	**9**	90%	SC*
2	***Train Healthcare Workers in Monitoring Practices:*** Provide training for healthcare workers on the importance of monitoring and evaluation, equipping them with the skills necessary to implement these practices effectively.	**9**	90%	SC
Domain 3: Incorporate Feedback Mechanisms				
1	***Establish Regular Feedback Loops:*** Create systems for healthcare workers to provide regular feedback on the challenges they face in implementing diabetes follow-up care guidelines. This feedback should be used to inform necessary adjustments to the guidelines.	**10**	100%	SC
2	***Engage Patients in Feedback Processes:*** Implement mechanisms for patients to share their experiences and outcomes related to follow-up care. This can help identify barriers to adherence and inform improvements in care delivery.	**10**	100%	SC

ITEM NO.	EVALUATION QUESTION	N*	P (%)*	CONSENSUS
Domain 4: Monitor Patient Outcomes and Adherence				
1	***Track Patient Progress Systematically:*** Develop a systematic approach to track patient outcomes, including glycemic control, diabetes complications, and adherence to follow-up appointments. This can help identify patients who are lost to follow-up and facilitate timely interventions.	**10**	100%	SC
2	***Utilise Data for Continuous Improvement:*** Analyse collected data to assess the effectiveness of diabetes management protocols and make necessary adjustments based on real-world outcomes. This can enhance the quality of care provided to patients.	**10**	100%	SC
Domain 5: Foster a culture of continuous improvement				
1	***Encourage a learning environment:*** Promote a culture within healthcare settings that values continuous improvement and learning from monitoring and evaluation activities. This can enhance the overall quality of diabetes care.	**10**	100%	SC
2	***Regularly review and update guidelines:*** Establish a process for the regular review and updating of monitoring and evaluation guidelines based on the latest research and patient outcomes to ensure they remain relevant and effective.	**10**	100%	SC
n= number of panellists scored 7-9; P(%)*= percentage of the panellists (out of the total 10 panellists) who scored 7-9;* *SC*= Strong Consensus; MC*= Moderate Consensus; NC*= No consensus*				

6.1.3.7 Guideline 7: Enhancing patient retention in Type-1 diabetes follow-up care

The guideline on patient retention achieved moderate consensus (≥60% to <80%) in all 22 items; no item fell under strong consensus (≥80%), and no consensus (<60%) threshold (see Table 6.8).

The experts added their feedback, mainly the comments related to repetition across guidelines. The experts noted that many of the proposed domains overlap with Guideline 4 and Guideline 5, stating that *"avoid redundancy with the other guidelines".* Additional concerns were raised about feasibility, such as the practicality of dedicating separate clinic days for patients travelling from rural areas, saying *"separate days might not be applicable"*, and the appropriateness of task shifting, *"counselling should only be delivered by trained professionals".* Suggestions emphasised integration of the

contents with other guidelines rather than a standalone guideline on 'Patient Retention'. These frequently raised concerns, including overlap and feasibility, were presented to the panellists during the SCDM session, and the items with moderate consensus were modified and re-scored by the panellists for validation.

Table 6.8: First round consensus scores of the guideline on enhancing patient retention in follow-up care

ITEM NO.	EVALUATION QUESTION	N *	P (%)	CONSENSUS
Domain 1: Strengthen patient-provider communication				
1	***Tailored communication*:** Ensure that healthcare workers use patient-centred communication strategies at each visit.	**7**	70%	MC *
2	***Language and literacy consideration:*** Use language appropriate to the patient's literacy level and local dialects where necessary.	**7**	70%	MC
3	***Dedicated education time:*** Allocate sufficient time for diabetes education during appointments, especially for newly diagnosed patients.	**7**	70%	MC
4	**Reinforcement Tools:** Use leaflets, posters, and visual aids to reinforce messages.	**7**	70%	MC
Domain 2: Enhance healthcare workers' capacity				
1	***Training Programs:*** Provide regular training for all chronic care workers on diabetes counselling	**6**	60%	MC
2	***Patient tracking and cohort registration:*** Use of follow-up tools and health information systems	**6**	60%	MC
3	***Supportive Supervision:*** Conduct routine mentoring and supportive supervision to ensure adherence to follow-up protocols.	**6**	60%	MC
Domain 3: Improve health information systems				
1	***Digitise Patient Records:*** Transition from paper-based systems to digital/electronic health records (EHRs) where feasible.	**6**	60%	MC
2	***Update Cohort Registers:*** Regularly update T1D cohort registers to reflect patient status (active, LTFU, deceased, transferred).	**6**	60%	MC
3	***Track Missed Appointments:*** Implement alerts for missed appointments and assign workers for follow-up tracing.	**6**	60%	MC
Domain 4: iv. Establish Robust Patient Tracking Mechanisms				
1	***Follow-up protocols:*** Develop and implement a standard protocol for tracing lost-to-follow-up patients.	**7**	70%	MC
2	***Appointment Reminder System:*** Use SMS or phone call reminders before appointments, especially for rural patients.	**7**	70%	MC

ITEM NO.	EVALUATION QUESTION	N *	P (%)	CONSENSUS
3	***Community healthcare worker involvement:*** Engage CHWs or health extension workers to follow up with defaulters in their communities.	**7**	70%	MC
Domain 5: Address socioeconomic barriers				
1	***Transport Support:*** Collaborate with local government or NGOs to provide transport subsidies or mobile follow-up clinics for rural patients.	**7**	70%	MC
2	***Subsidised medication access:*** Ensure regular supply of insulin and essential diabetes supplies at public health facilities.	**7**	70%	MC
3	***Social support linkages:*** Connect patients with diabetes associations or support groups for emotional and financial assistance.	**7**	70%	MC
Domain 6: Integrate community engagement				
1	**Partnership with local structures:** Partner with religious leaders, schools, and local media to raise awareness about the importance of diabetes follow-up.	**7**	70%	MC
2	***Peer support networks:*** Establish peer educator or support groups to enhance motivation and adherence.	**7**	70%	MC
Domain 7: Improve facility-level service delivery				
1	***Dedicated diabetes clinics:*** Create separate days or time slots for diabetes care to reduce waiting times.	**7**	70%	MC
2	***Task shifting:*** Delegate tasks like counselling and tracking to trained non-physician workers to reduce provider workload.	**7**	70%	MC
Domain 8: Monitor and evaluate retention outcomes				
1	***Performance metrics:*** Track indicators such as follow-up completion rates, LTFU rates, and complication rates.	**7**	70%	MC
2	***Data use for decision making:*** Use retention data during workers' meetings to inform improvements.	**6**	60%	MC
n= number of panellists scored 7-9; P(%)*= percentage of the panellists (out of the total 10 panellists) who scored 7-9; MC*= Moderate Consensus*				

6.1.3.8 Guideline 8: Quality of diabetes follow-up care

The guideline on 'Quality of Diabetes Follow-up Service' has achieved strong consensus (≥80%) on 18 of 20 items, and the remaining two items fall under moderate consensus (≥60% to <80%), with no items falling under the 'no consensus' (<60%) threshold. The two items that fell under moderate consensus are 'Increase staffing levels'

under Domain 2 and 'Utilise Technology for Patient Monitoring' under Domain 3 (see Table 6.9).

The feedback of panellists noted feasibility challenges. Panellists mentioned the challenges related to staffing, stating that "*hiring dedicated personnel… is impractical",* and health information systems, stating that *"hard-copy documentation in rural settings remains inevitable"*. These frequently raised concerns were presented to the panellists during the SCDM session, and the items with moderate consensus were modified and re-scored by the panellists for validation.

Table 6.9: First round consensus scores of the guideline on the quality of diabetes follow-up care

ITEM NO.	EVALUATION QUESTION	N*	P (%)*	CONSENSUS
Domain 1: Enhance training for healthcare workers				
1	***Implement comprehensive training programs***: Develop structured training initiatives focused on diabetes management for healthcare workers. This should include both theoretical knowledge and practical skills to ensure that workers are well-equipped to provide effective care.	**9**	90%	SC*
2	***Ongoing education and resources***: Establish continuous professional development opportunities for healthcare workers to keep them updated on best practices in diabetes care. This can help address gaps in knowledge and improve patient outcomes.	**9**	90%	SC
Domain 2: Address staffing shortages				
1	***Increase staffing levels:*** Advocate for hiring additional healthcare workers to reduce patient loads. This can help ensure that each patient receives adequate attention and care during follow-up visits.	**6**	60%	MC*
2	***Create dedicated diabetes care units:*** Establish specialised units for diabetes care to streamline services and improve the quality of care provided. This can help alleviate the burden on general healthcare facilities and enhance patient management.	**10**	100%	SC
Domain 3: Improve record-keeping and patient tracking systems.				
1	***Implement structured record-keeping systems:*** Develop and enforce standardised protocols for record-keeping to ensure consistency and accuracy in patient data management. This can help healthcare workers track patient progress and outcomes more effectively.	**9**	90%	SC

ITEM NO.	EVALUATION QUESTION	N*	P (%)*	CONSENSUS
2	***Utilise technology for patient tracking:*** Invest in electronic health record systems that facilitate better tracking of patient appointments, medications, and follow-up care. This can enhance communication among healthcare workers and improve patient management.	**6**	60%	MC
Domain 4: Ensure the availability of essential medications				
1	***Establish reliable supply chains:*** Improve logistics and supply chain management to ensure consistent availability of essential medications, particularly insulin. This can help prevent stock-outs that disrupt patient care.	**10**	100%	SC
2	***Create financial assistance programs:*** Develop programs to assist patients in affording their medications, especially for those from low-income backgrounds. This can help improve adherence to treatment regimens.	**8**	80%	SC
Domain 5: Foster a Supportive Environment				
1	***Encourage compassionate care:*** Train healthcare workers in effective communication and compassionate care practices. This can help build trust and improve patient satisfaction with the healthcare system.	**9**	90%	SC
2	***Involve family and community support:*** Engage family members and community resources in the care process to provide additional support for patients. This can enhance motivation and adherence to follow-up care.	**10**	100%	SC
Domain 6: Adopt a holistic approach to diabetes management				
1	***Integrate comprehensive care:*** Develop guidelines that emphasise a holistic approach to diabetes management, incorporating medical treatment, preventive services, education, and emotional support. This can help address the misconception that follow-up care is limited to blood sugar testing and medication collection.	**10**	100%	SC
2	***Focus on preventive services:*** Ensure that the guidelines include preventive care measures, such as regular screenings for diabetes-related complications, to enhance patient outcomes and reduce the incidence of severe health issues.	**10**	100%	SC
Domain 7: Enhance Patient Education				
1	***Implement structured educational programs:*** Create comprehensive educational initiatives that empower patients with the knowledge necessary for effective self-management. This should include information on diabetes management, the importance of follow-up care, and lifestyle modifications.	**9**	90%	SC
2	***Involve family members:*** Encourage the involvement of family members in educational programs to reinforce healthy behaviours and support patients in adhering to their treatment plans.	**10**	100%	SC

ITEM NO.	EVALUATION QUESTION	N*	P (%)*	CON-SEN-SUS
Domain 8: Improve communication and support systems				
1	***Train healthcare workers in effective communication:*** Provide training for healthcare workers to enhance their communication skills, ensuring they can effectively convey the importance of follow-up care and engage patients in their management plans.	**9**	90%	SC
2	***Establish support networks:*** Create support systems, including peer support groups and community resources, to help patients feel more connected and supported in their diabetes management journey.	**10**	100%	SC
Domain 9: Implement robust monitoring and evaluation mechanisms				
1	***Develop monitoring protocols:*** Establish clear protocols for monitoring patient progress and adherence to treatment plans. This can help identify patients who are lost to follow-up and facilitate timely interventions.	**10**	100%	SC
2	***Incorporate feedback mechanisms:*** Create systems for healthcare workers to provide feedback on the effectiveness of the guidelines and the challenges they face in implementing them. This can inform necessary adjustments to improve care quality.	**10**	100%	SC
Domain 10: Allocate resources for continuous improvement				
1	***Ensure adequate funding for diabetes care:*** Advocate for sufficient budget allocation to support diabetes management programs, including training for healthcare workers and resources for patient education.	**10**	100%	SC
2	***Regularly review and update guidelines:*** Establish a process for the regular review and updating of guidelines based on the latest research and patient outcomes to ensure they remain relevant and effective.	**10**	100%	SC
n= number of panellists scored 7-9; P(%)*= percentage of the panellists (out of the total 10 panellists) who scored 7-9;* *SC*= Strong Consensus; MC*= Moderate Consensus*				

6.1.3.9 Guideline 9: Enhance the motivation of patients to attend diabetes follow-up care

All 28 items of the guideline on 'Patient Motivation' fell under moderate consensus (<80%) (see Table 6.10). Participants provided critical reflections highlighting the re-appearance of the proposed domains in other guidelines. Panellists noted that *"though the motivational items are appropriate to maintain patient retention, most of the items*

are already included in previous guidelines and should be streamlined to avoid repetition".

The findings suggest that while panellists strongly endorsed motivational strategies appropriate in practice, the items were perceived as duplicative across other guidelines. These frequently raised concerns were presented to the panellists during the SCDM session, and the items with moderate consensus were modified and re-scored by the panellists for validation.

Table 6.10: First round consensus scores of the guideline on the motivation of patients to attend follow-up

Item No.	Evaluation Question	N*	P (%)*	Consensus
Domain 1: Optimise healthcare worker communication as a primary cue				
1	Institute routine verbal and written appointment reminders during every visit	**7**	70%	MC*
2	Develop SMS/phone-based reminder systems tailored to patient language and literacy	**7**	70%	MC
3	Encourage motivational interviewing techniques among providers	**7**	70%	MC
Domain 2: Leverage family and social support systems:				
1	Involve family members during counselling sessions	**6**	60%	MC
2	Provide family-targeted diabetes education materials	**6**	60%	MC
3	Encourage family-based follow-up contracts (e.g., joint follow-up reminders)	**6**	60%	MC
Domain 3: Address personal health concerns through risk communication				
1	Use visual tools to illustrate diabetes progression and complications	**7**	70%	MC
2	Incorporate patient testimonials about complications due to missed follow-ups	**6**	60%	MC
3	Highlight the risk of asymptomatic deterioration	**7**	70%	MC
Domain 4: Promote the benefits of regular follow-up: Patients are more likely to attend when they understand the benefits				
1	Provide individualised explanations of treatment outcomes during visits	**7**	70%	MC
2	Share positive stories of patients who have managed diabetes successfully	**7**	70%	MC
3	Develop culturally appropriate educational campaigns (radio, leaflets, posters)	**7**	70%	MC

Item No.	Evaluation Question	N*	P (%)*	Con-sen-sus
Domain 5: Institutionalise community-based health promotion programs				
1	Partner with diabetes associations, local NGOs, and health extension workers	**7**	70%	MC
2	Organise monthly health education sessions in communities	**6**	60%	MC
3	Utilise mass media and community radio to raise awareness	**7**	70%	MC
Domain 6: Foster peer support and role modelling				
1	Establish peer support groups at health facilities and community levels	**7**	70%	MC
2	Train diabetes champions to mentor others	**7**	70%	MC
3	Facilitate group counselling sessions or education talks	**7**	70%	MC
Domain 7: Counteract negative cultural and social messaging				
1	Engage community leaders and faith-based influencers to dispel myths	**7**	70%	MC
2	Develop culturally adapted myth-busting educational materials.	**7**	70%	MC
3	Provide counselling on navigating stigma and spiritual alternatives	**7**	70%	MC
Domain 8: Improve patient experience to prevent dropout				
1	Train workers in patient-centred care and respectful communication.	**7**	70%	MC
2	Establish patient feedback mechanisms to identify and resolve dissatisfaction	**7**	70%	MC
3	Reduce waiting times and improve follow-up visit organisation	**7**	70%	MC
Domain 9: Correct Misconceptions About Asymptomatic Phases				
1	Educate patients on the silent progression of diabetes and the importance of preventive care	**6**	60%	MC
2	Provide visuals showing how complications develop even without symptoms	**6**	60%	MC
3	Reinforce the idea that the absence of symptoms is not equal to the absence of disease	**6**	60%	MC
Domain 10: Monitoring and Evaluation				
1	Track rates of missed appointments pre- and post-implementation.	**7**	70%	MC
2	Measure patient knowledge, attitudes, and motivation via periodic surveys	**6**	60%	MC
3	Use patient feedback to adapt and refine cue-enhancing interventions	**7**	70%	MC
n= number of panellists scored 7-9; P(%)*= percentage of the panellists (out of the total 10 panellists) who scored 7-9; MC*= Moderate Consensus*				

6.1.3.10 Guideline 10: Support systems for Type-1 diabetes patients

The Guideline on 'support systems' achieved strong consensus across all domains, with nearly all items scoring 80 to 100% (see Table 6.11). According to panellists' feedback, this guideline was considered relevant and comprehensive as it integrates family, community, and institutional systems to support Type-1 diabetes patients. So, the panellists endorsed the guideline to maintain the presentation.

Table 6.11: First round consensus scores of the guideline on support systems for type 1 diabetes patients

ITEM NO.	EVALUATION QUESTION	N*	P (%)*	CONSENSUS
Domain 1: Strengthening family and social support				
1	***Promote positive family involvement***			
	o Encourage families to actively participate in patient care by attending follow-up appointments and engaging in diabetes education.	**10**	100%	SC*
	o Develop informational materials for families to clarify their role in supporting diabetes care, including how to assist with medication adherence and monitoring.	**9**	90%	SC
2	***Address conflicting advice***			
	o Provide structured education for families on evidence-based diabetes management to reduce the influence of contradictory traditional or religious practices.	**10**	100%	SC
	o Train healthcare workers to engage in culturally sensitive conversations to align family beliefs with medical advice.	**8**	80%	SC
3	***Enhance communication between healthcare workers and families***			
	o Conduct joint counselling sessions involving both patients and their families to create shared understanding and treatment goals.	**9**	90%	SC
	o Include family members in decision-making discussions to foster support and reduce misunderstandings.	**10**	100%	SC
Domain 2: Enhancing community resource accessibility				
1	***Establish and strengthen diabetes support groups***			
	o Facilitate the formation of local diabetes support groups within health facilities or community centres	**9**	90%	SC
	o Ensure these groups include peer educators, community healthcare workers, and patients sharing experiences and solutions.	**9**	90%	SC
2	***Integrate community-based organisations (CBOs)***			

ITEM NO.	EVALUATION QUESTION	N*	P (%)*	CONSENSUS
	o Partner with existing CBOs, religious institutions, and local leaders to promote awareness and reduce stigma or misinformation regarding diabetes treatment	**9**	90%	SC
	o Collaborate with organisations like the Diabetes Association to extend support and resource distribution (e.g., glucometers, strips).	**9**	90%	SC
	Promote community healthcare worker (CHW) engagement			
	o Train CHWs to provide follow-up reminders, home visits, and health education to support continuity of care, especially in rural or underserved areas.	**10**	100%	SC
3	o Equip CHWs with referral pathways to link patients with psychosocial or clinical services.	**10**	100%	SC
Domain 3: Providing psychosocial support services				
1	***Incorporate psychosocial assessment into routine care***			
	o Include regular screening for emotional distress, depression, and anxiety during diabetes follow-up visits using validated tools.	**10**	100%	SC
	o Offer on-site or referral-based psychosocial counselling services for patients needing mental health support.	**10**	100%	SC
2	***Train healthcare workers in compassionate communication***			
	o Develop continuous training modules for healthcare workers on patient-centred communication, empathy, and motivational interviewing.	**9**	90%	SC
	o Encourage providers to check patient understanding and satisfaction during each consultation to build trust and confidence.	**9**	90%	SC
3	***Promote multidisciplinary and holistic care***			
	o Create a referral and feedback mechanism between medical, psychological, and community support providers.	**9**	90%	SC
	o Encourage the development of a “diabetes care team” model comprising clinicians, psychologists, nutritionists, and CHWs.	**10**	100%	SC
Domain 4: Bridging gaps between the health system and community				
1	***Raise awareness of available services***			
	o Develop and distribute directories of existing diabetes care resources, support groups, and educational sessions in local languages.	**10**	100%	SC
	o Conduct outreach campaigns through radio, posters, and social media to inform patients of support systems and how to access them.	**7**	70%	MC
2	***Facilitate coordination between clinics and support systems***			

ITEM NO.	EVALUATION QUESTION	N*	P (%)*	CONSENSUS
	o Designate liaison officers or focal persons in healthcare facilities responsible for linking patients to community-based support and follow-up systems.	**9**	90%	SC
	o Create feedback loops between health facilities and community groups to track patient progress and reduce lost-to-follow-up.	**9**	90%	SC
Domain 5: Addressing financial and logistical barriers				
1	***Support Access to diabetes management tools***			
	o Advocate for subsidised or donated glucometers and strips through partnerships with NGOs and government programs.	**8**	80%	SC
	Identify and support vulnerable households with targeted material and financial support.	**9**	90%	SC
2	***Improve accessibility of follow-up services***			
	o Implement mobile health interventions such as SMS appointment reminders, health tips, and medication alerts.	**8**	80%	SC
	o Expand community-based clinics or outreach days to reduce the travel burden for patients.	**8**	80%	SC
Domain 6: Monitoring and evaluation				
1	***Track follow-up attendance and support engagement***			
	o Maintain a registry of patients with missed appointments and follow up through CHWs or peer supporters.	**9**	90%	SC
	o Document participation in community support programs and assess their impact on adherence and health outcomes.	**9**	90%	SC
2	***Evaluate patient and family satisfaction***			
	o Conduct regular surveys or focus groups to assess patient satisfaction with support systems and identify gaps.	**9**	90%	SC
	o Use feedback to refine and improve the integration of support services into follow-up care.	**9**	90%	SC

n= number of panellists scored 7-9; P(%)*= percentage of the panellists (out of the total 1(
panellists) who scored 7-9;*
SC= Strong Consensus*

6.1.3.11 Summary of Round 1

A strong consensus level (≥80%) was reached for only the Guidelines 10: Support system item. In comparison, a moderate consensus (60–80%) was reached on some items under Guidelines 2, 3, 4, 5, 6, and 8. All items in Guidelines 7 and 9 fell under moderate consensus. The frequently appearing comments on overlap/redundancy observed in Guidelines 7 and 9 indicate that much of their content is already covered in Guidelines 1, 4, 5, and 10. Cross-cutting themes, such as communication, education,

and M&E, repeatedly appeared across multiple guidelines, reinforcing their centrality but also raising concerns about redundancy. The frequently raised concerns can be presented to the panellists during the SCDM session, and the items with moderate consensus can be modified and re-scored by the panellists for validation.

6.3.2 Presentation of findings in the second round validation

Following the initial round of expert review, a second round of validation (Structured Consensus Development Meeting) was undertaken by the same panellists to validate the guidelines. This phase aimed to revisit areas where consensus had not been fully achieved (moderate consensus). They also addressed comments regarding the overlap of contents across guidelines and incorporated additional areas of emphasis. The second round provided panellists with the opportunity to engage in structured discussions to ensure the validation of the guidelines within the Ethiopian health system context, and re-score items to evaluate the final consensus level.

The consensus levels and corresponding revisions to the guideline from the second round of panel scoring are presented in the tables. They are presented with different font colours used to indicate the level of agreement and the type of decision made under each section. Specifically, ‘Modified’ items are shown in black, ‘Removed’ items in red, and ‘Newly added’ items in blue.

6.1.4.1 Guideline 1: Diabetes patients’ education and awareness

In the first round of scoring, this guideline achieved strong consensus on 20 of 21 items, and the remaining 1 item fell under moderate consensus. The item ‘Regular Reminders and Encouragement’ initially fell into the medium consensus category (60%) but was corrected by clarifying its scope and applicability before re-scoring. The modifications were made to enhance feasibility, clarity, and contextual fit, particularly in relation to systematic reminder systems. After revision and discussion in the SCD, the item reached a strong consensus (100%) in the second round score (see Table

6.12). Thus, the validated guideline on patient education received full endorsement in its final version comprising 21 items (see Section 6.3.1).

Table 6.12: Second round consensus scores of the guideline on diabetes patients' education and awareness

DO-MAIN/ ITEM NO.	AREAS OF EMPHASIS IN THE 2ND ROUND SCORE	N	P (%)	COMMENT
I/3	**Regular reminders and encouragement:** Establish systematic and context-appropriate reminder systems (e.g., phone calls, text messages, or community healthcare worker follow-ups) through which healthcare workers consistently encourage patients to attend scheduled follow-up visits. Clear and direct communication from healthcare workers should be prioritised, as it significantly improves patient motivation and adherence.	**10**	100%	Modified
n= number of panellists scored 7-9; P(%)*= percentage of the panellists (out of the total 10 panellists) who scored 7-9;*				

6.1.4.2 Guideline 2: Financial support for diabetes patients

In the first round of scoring, this guideline achieved strong consensus on 10 of 12 items, and the remaining two items fell under moderate consensus. The two items that fell under moderate consensus were 'Sliding Scale Fees' and 'Direct Cash and Voucher Assistance' under Domain 1, which underwent substantial revision.

During the SCDM, participants stressed that certain proposals were not feasible within the existing health system. Regarding sliding scale fees, participants suggested *"replace this with advocating for the inclusion of diabetes services in the exempted service list"* to ensure equity and long-term sustainability. On direct cash assistance, members noted that *"cash or voucher support may be useful in humanitarian settings but unsustainable for long-term care",* proposing advocacy for systemic reform. Comments also highlighted the importance of awareness strategies, suggesting *"community sensitisation to guide patients on navigating insurance enrolment and benefits"*.

Items that initially attracted moderate consensus were revised by clarifying sustainability, feasibility, and cultural alignment before re-scoring. After these targeted revisions, particularly refining the financial mechanisms to emphasise systemic, sustainable approaches rather than reactive solutions, all items achieved strong consensus (100%) in the second round.

In the revised version, both items reflected the panel's feedback on sustainability and feasibility. Accordingly, 'Sliding Scale Fees' was reformed to 'Inclusion of Diabetes in Exempted Service List', and 'Direct Cash/Vouchers' was reframed as 'Implement Direct Cash and Voucher Assistance' in a humanitarian setting while advocating sustainable financial support to diabetes care with emphasis on systemic and sustainable financial reforms (see Table 6.13).

Table 6.13: Second round consensus scores of the guideline on financial support to T1D patients

DOMAIN/ ITEM NO.	AREAS OF EMPHASIS IN THE 2ND ROUND SCORE	N	P (%)	COMMENT
I/3	**Inclusion of Diabetes Services in the Exempted Service List:** Advocate for the inclusion of diabetes services in the national exempted service list to ensure equitable access and long-term sustainability, rather than relying on sliding-scale fee mechanisms. Complementary efforts should focus on community awareness, such as workshops to guide patients in navigating insurance enrollment and benefits.	**10**	100%	Modified
I/4	**Implement Direct Cash and Voucher Assistance while advocating Sustainable Financial Support for Diabetes Care:** Implement direct cash or voucher assistance in humanitarian settings, and advocate for long-term sustainable systemic reforms that address financial barriers. This includes strengthening insurance coverage, subsidy schemes, and patient support systems to ensure continuity of care	**10**	100%	Modified
n= number of panellists scored 7-9; P(%)*= percentage of the panellists (out of the total 10 panellists) who scored 7-9;*				

6.1.4.3 Guideline 3: Patients' waiting time in health facilities

In the first round of scoring, this guideline achieved strong consensus on 6 of 10 items, and the remaining four items fell under moderate consensus. Panel discussions highlighted the importance of contextual adaptation of 'Streamline Appointment Scheduling' and 'Extended Working Hours'. Besides, they agreed to remove 'Implement Triage Systems' and 'Implement Group Visits' mainly due to concerns about sustainability, cost implications, and health workforce availability.

- On 'appointment scheduling', panellists recommended the use of text message reminders instead of online booking systems, given infrastructure limitations. After the proposed revision, it received 100% consensus.
- For 'extended working hours', panellists balanced the benefits with constraints, noting *"weekend services may improve accessibility but must consider healthcare worker workload and cost".* After the proposed revision, it received 100% consensus.
- Regarding the 'triage system', panellists emphasised that a dedicated triage system is not necessary for diabetes patients who are already attending appointment-based schedules once every three months, except in cases of medical emergencies. Given the structured nature of diabetes services, panellists considered these areas of emphasis to be impractical. In the second round of scoring, this item received 40%, falling under the 'no consensus' category. Therefore, this item was removed from the final version of the guideline in accordance with the consensus criteria (items rated as "no consensus" can be removed).
- On 'organising group visits', strong concerns were raised that diabetes follow-up care should primarily remain individualised. Accordingly, in the second round of scoring, this item received 40%, placing it in the "no consensus" category. Therefore, this item was removed from the final version of the guideline as per the consensus criteria (see Table 6.14).

Table 6.14: Second round consensus scores of the guideline on patients' waiting time in the health facility

DO-MAIN/ ITEM NO.	AREAS OF EMPHASIS IN THE 2ND ROUND SCORE	N*	P (%)*	COM-MENT
I/1	**Streamline appointment scheduling:** Implement an efficient and context-appropriate appointment scheduling system to improve patient flow. This may include staggered appointment slots and the use of text message reminders, which are more feasible than online booking systems in the current setting, to reduce no-shows and last-minute cancellations	**10**	100 %	Modified
I/3	**Implement triage systems:** Establish a triage system to prioritise patients based on the urgency of their needs. This can help ensure that patients requiring immediate attention are seen promptly, while those with less urgent needs can be scheduled accordingly	**4**	40%	Removed
I/8	**Offer extended hours:** Provide extended clinic hours selectively, such as on weekends or designated days, to improve accessibility for patients who face challenges attending during regular hours. Implementation should carefully consider workers' workload, resource availability, and financial sustainability to ensure that extended services do not compromise quality of care.	**10**	100 %	Modified
I/9	**Implement group visits:** Organise group visits for patients with similar needs, such as education on diabetes management. This can reduce the number of individual appointments and allow healthcare workers to address multiple patients simultaneously	**4**	40	Removed
n= number of panellists scored 7-9; P(%)*= percentage of the panellists (out of the total 10 panellists) who scored 7-9;*				

6.1.4.4 Guideline 4: Tracing lost-to-follow-up diabetes patients

In the first round, 11 of the 12 items achieved strong consensus, while the remaining one item (comprehensive training programs) fell under moderate consensus, due to a lack of tracing-specific focus of the guideline. Panellists noted that while training is essential, *"case management training should not be the main focus for tracing lost patients; instead, short targeted protocols on tracing LTFU are needed"*. Following targeted revisions based on panel feedback, the guideline was presented for re-scoring. However, during the second round of scoring, it received 50% consensus. Thus, removed from the guideline because it fell under 'no consensus'.

Moreover, panellists also emphasised the importance of digital solutions, leading to the addition of areas of emphasis on automated reminder and follow-up platforms. They recommended adding a new item in the guideline, that is, the *"Use of automated tools for communication, such as SMS reminders and interactive messaging, while ensuring confidentiality"*.

Another important contribution was the call to support healthcare workers themselves; participants proposed *"Introducing motivational schemes for providers handling lost-to-follow-up cases, including incentives, recognition, and supportive supervision"*. Both suggestions were incorporated into the revised guideline. Thus, these two new items achieved a strong consensus in the second-round scoring (see Table 6.15).

Table 6.15: Second round consensus scores of the guideline on tracing of lost to follow-up diabetes patients

DO-MAIN/ ITEM NO.	AREAS OF EMPHASIS IN THE 2ND ROUND SCORE	N*	P (%)*	COMMENT
II/1	Comprehensive Training Programs: Develop and implement training programs focused on diabetes management and follow-up protocols. This should equip healthcare workers with the necessary skills to manage diabetes effectively.	**5**	50%	Removed
IV/3	***Use automated tools for patient-provider interaction and communication:*** This should be promoted by integrating reminder systems, digital follow-up platforms, and interactive messaging services to support appointment adherence, medication compliance, and timely feedback, while ensuring data security and patient confidentiality. These include reminder SMS messages and digital follow-up monitoring mobile apps.	**10**	100 %	New
V/3	***Motivational scheme for healthcare workers working with tracing of LTFU cases:*** This should be established by introducing performance-based incentives, recognition programs, and supportive supervision, thereby encouraging proactive patient tracing, sustained engagement, and improved retention in care.	**10**	100 %	New
n= number of panellists scored 7-9; P(%)*= percentage of the panellists (out of the total 10 panellists) who scored 7-9;*				

6.1.4.5 Guideline 5: Diabetes cohort follow-up and patient monitoring system

In the first round, 10 of the 12 items achieved strong consensus, while the remaining two items ('Implement Case Management Model' and 'Family Involvement') fell under moderate consensus.

Panellists raised concerns about family involvement for its reappearance in Guideline 10: Support system. After discussion during the SCDM session, the statement was refined to stress its unique contribution to enhancing adherence in cohort follow-up. Moreover, cost implications were flagged for the case management model based on the comment to *"consider feasibility and resource requirements".* In the second round of scoring, panellists still endorsed the two items with 90% agreement (Strong Consensus). Overall, the revised guideline incorporated targeted, context-sensitive adjustments while respecting the original evidence-based content (see Table 6.16).

Table 6.16: Second round consensus scores of the guideline on diabetes cohort follow-up

DOMAIN/ ITEM NO.	AREAS OF EMPHASIS IN THE 2ND ROUND SCORE	N*	P (%)*	COMMENT
I/1	***Implement case management models (context-sensitive):*** Where feasible, introduce dedicated case managers for diabetes care, similar to models used in HIV programs. Case managers can strengthen follow-up care by ensuring consistent patient support and monitoring. Implementation should take into account feasibility and resource requirements.	**9**	90%	Modified
V/1	***Encourage family involvement in cohort follow-up:*** Involve family members in the education and support process, with emphasis on their unique role in enhancing adherence and improving attendance at follow-up visits.	**9**	90%	Modified
n= number of panellists scored 7-9; P(%)*= percentage of the panellists (out of the total 10 panellists) who scored 7-9;*				

6.1.4.6 Guideline 6: Monitoring and evaluation of diabetes follow-up care program:

In the first round, eight out of the 10 items achieved strong consensus, while two items fell under moderate consensus (60%). The two items that fell under moderate consensus (Develop Comprehensive Monitoring Protocols and Utilise Technology for Data Collection) were presented for discussion during the SCDM session and rescoring.

During the SCDM session, panellists placed stronger advocacy for digital transformation while recognising the continued reliance on paper-based documentation in the interim. Panellists acknowledged the importance of electronic health record systems but flagged infrastructural and resource limitations. A phased approach was recommended, combining advocacy for digital solutions with continued use of strengthened paper-based systems until digital capacity is more widely available.

Panellists also emphasised that monitoring indicators should be harmonised with existing national HMIS to avoid duplication. They also noted that workers' workload is already high, so protocols must remain simple and practical. Accountability was highlighted as essential, with clarity on who uses the data and how, to ensure that collection leads to meaningful improvements.

In the second round of scoring, the two items reached a strong consensus (100% agreement) (see Table 6.17). This adjustment reflected a balance between long-term system improvement and the current contextual limitations within Ethiopia's healthcare setting.

Table 6.17: Second round consensus scores of the guideline on M&E of the diabetes follow-up program

DOMAIN/ ITEM NO.	AREAS OF EMPHASIS IN THE 2ND ROUND SCORE	N*	P(%)*	COMMENT
I/1	***Develop Comprehensive Monitoring Protocols:*** Create structured protocols that outline the specific metrics and indicators to be monitored in diabetes follow-up care. These should include patient adherence rates, health outcomes, and the effectiveness of interventions. Protocols	**10**	100%	Modified

	should be harmonised with national HMIS to avoid duplication, designed to be simple and practical given the existing workers' workload, and include clear accountability for data use to ensure information leads to service improvements.			
I/2	***Utilise Technology for Data Collection (Phased and Context-Appropriate):*** Where feasible, implement electronic health record systems to support the collection and analysis of patient data, enabling healthcare workers to track progress and identify trends over time. Considering infrastructural challenges, adoption should follow a phased approach, with advocacy for digital solutions accompanied by strengthened paper-based systems until wider capacity is in place.	**10**	100%	Modified
n= number of panellists scored 7-9; P(%)*= percentage of the panellists (out of the total 10 panellists) who scored 7-9;*				

6.1.4.7 Guideline 7: Enhancing patient retention in Type-1 diabetes follow-up care

In the first round, the guideline on enhancing patient retention achieved moderate consensus (≥60% to <80%) in all 22 items. Panellists consistently noted that almost all the items of “Guideline 7” reappeared in the other guidelines. While the content was highly relevant, its scope largely overlapped with Guidelines 1, 2, 3, 4, 5, 6, and 10. As a result, the panel reached a collective decision not to retain Guideline 7 as a standalone document. Therefore, its essential elements were carefully reviewed and incorporated into the respective existing guidelines to ensure completeness without duplication.

The revisions involve aligning patient-provider communication and education items under Guideline 1 (education and awareness), training and supervision elements under Guideline 5 (diabetes cohort follow-up), and digital record-keeping and monitoring aspects under Guideline 6 (Monitoring and Evaluation). Socioeconomic support items were integrated into Guidelines 2 (financial support), and while facility-level delivery strategies were refined and absorbed under Guideline 8 (quality of care).

In this way, all important retention-related areas of emphasis were preserved and consolidated into Guidelines 1, 2, 3, 4, 5, and 6, depending on thematic relevance, ensuring no critical element was lost. Thus, the standalone guideline on “Enhancement of Patient Retention” was removed from the final revision.

6.1.4.8 Guideline 8: Quality of diabetes follow-up care

In the first round of scoring, 20 of the 22 items achieved strong consensus, while the remaining two items fell under moderate consensus (≥60% to <80%). The two items that fell under moderate consensus (Increase staffing levels and Utilise Technology for Patient Monitoring) were presented in the SCDM session and rescored by the panellists.

The proposal to ‘hire additional dedicated workers’ was modified because panellists highlighted that such a proposal is impractical under current health system constraints. Instead, the revised guideline recommends ‘Training and Assigning of Existing Health Professionals’ from other departments to meet workforce needs in the diabetes unit.

Similarly, while ‘Digitising Patient Records through Electronic Health Systems’ was supported, panellists emphasised the continued necessity of improving paper-based systems in rural areas where digital infrastructure is not yet available.

Moreover, panellists provided additional refinements to strengthen the guideline. The three key additions include:

- ‘Capacity building on the Continuous Quality Improvement (CQI) Model’: This suggests the provision of ongoing mentorship for healthcare workers on monitoring and using data for continuous quality improvement.
- ‘Strengthen logistics and supply chain systems’ through collaboration with the Ethiopian Pharmaceutical Supply Service (EPSS) and other associations working on NCD. This ensures uninterrupted access to essential supplies like insulin.

- ‘Engage patients in their management plans’ to raise a sense of ownership in the care plan and adherence. It can be achieved through shared decision-making, goal setting, and regular follow-up (see the revisions in Table 6.18).

Table 6.18: Second round consensus scores of the guideline on the quality of diabetes follow-up care

DOMAIN/ ITEM NO.	AREAS OF EMPHASIS IN THE 2ND ROUND SCORE	N*	P (%)*	COM-MENT
II/1	***Optimise workforce through training and task-sharing:*** Train and assign health professionals from other departments to support diabetes follow-up care. This approach can help address workforce gaps while ensuring patients receive adequate attention during visits.	**10**	100%	Modified
III/2	***Strengthen patient tracking systems (digital and paper-based):*** Invest in electronic health record systems to improve tracking of appointments, medications, and follow-up care, while simultaneously strengthening paper-based systems in rural and resource-limited settings where digital infrastructure is not yet available. This dual approach can enhance provider communication and improve patient management across diverse contexts.	**10**	100%	Modified
I/1	***Implement on-the-job training and mentorship on CQI (Continuous Quality Improvement model),*** with emphasis on routine monitoring and use of data to improve patient care.	**10**	100%	New
IV/3	***Strengthening logistics and supply chain management:*** This should be achieved by fostering collaboration with EPSS (Ethiopian Pharmaceutical Supply Service) to ensure the availability of stock, timely procurement, and distribution of essential supplies.	**10**	100%	New
VI/3	***Engaging patients in their management plan:*** This should be prioritised by involving them in shared decision-making, goal setting, and regular follow-up, thereby fostering a sense of ownership, improving adherence, and enhancing health outcomes	**10**	100%	New
n= number of panellists scored 7-9; P(%)*= percentage of the panellists (out of the total 10 panellists) who scored 7-9;*				

6.1.4.9 Guideline 9: Enhance the motivation of patients to attend diabetes follow-up care

In the first round, the Guideline on enhancing patient retention achieved moderate consensus (≥60% to <80%) in all 27 items. Panellists consistently noted that almost

all the items in this guideline had reappeared in the other guidelines. For this reason, instead of keeping Guideline 9 as a standalone guideline, panellists suggested redistributing its content into existing guidelines to avoid duplication.

The panel agreed that while motivation is a critical factor, its elements were already embedded within other guidelines and therefore did not warrant a standalone guideline. For instance, domains related to communication cues and reminders were integrated into Guidelines 4 and 5 (Tracing LTFU Patients and Cohort Follow-up), while Risk Communication, Benefits of Follow-up, and Correcting Misconception can be merged into Guideline 1 (patient education). Similarly, family and social support, and peer support networks can be incorporated under Guideline 10 (support systems), and aspects linked to M&E were aligned with Guideline 6 (monitoring and evaluation). Thus, the researcher redistributed the items in the relevant guidelines. This can avoid redundancy while ensuring motivational elements are embedded in the existing guidelines.

6.1.4.10 Guideline 10: Support systems for Type-1 diabetes patients

The panel achieved strong consensus across all items of Guideline 10, reaching >80% agreement by the second round. No changes and additions were proposed by the panellists. As a result, the existing guideline was endorsed as the final version. The guideline adequately reflected the important roles of family, community, and psychosocial support in sustaining adherence to diabetes follow-up care.

6.1.4.11 Overall summary of the 2nd round validation process

The second round of the consensus development process successfully validated eight guidelines. Across the guidelines, only items with a score of 80 to 100% consensus were reflected in the validated guideline. Broad alignment on the priority actions needed to strengthen diabetes follow-up care in Ethiopia. Panellists consistently emphasised practicality, feasibility, and alignment with the existing health system, which

led to several refinements such as merging overlapping domains, rephrasing redundant items, and tailoring areas of emphasis to better reflect both urban and rural contexts.

Important revisions were made based on panel feedback. Reappearing domains from Guideline 7 on patient retention and Guideline 9 on patient motivation were merged into the other guidelines to reduce duplication. Guideline 8 on quality improvement was strengthened by adding new areas of emphasis on continuous quality improvement training and patient re-engagement through shared decision-making. Guideline 10 on support systems for Type 1 diabetes patients was notably expanded to include psychosocial assessment, compassionate communication training, and the role of community healthcare workers in home-based support. Similar enhancements were made across other guidelines, such as stronger emphasis on family and community engagement, integration of culturally appropriate approaches, and the establishment of feedback loops to improve patient-centred care.

6.3.3 Summary of the Findings and Presentation of the SCDM

The two-round consensus development process engaged a multidisciplinary panel of experts to validate the guidelines aimed at strengthening diabetes follow-up care in Ethiopia. Through iterative review and structured scoring, the panel achieved strong agreement on eight guidelines. Refinements have been made to improve clarity, eliminate duplication, and enhance feasibility within the local health system. In addition to the primary items, further new items were incorporated based on the panellists' areas of emphasis during the SCDM.

This structured approach enhances the credibility of the guidelines. It also fosters a sense of shared ownership among the participants, increasing the likelihood of successful implementation. The validated guidelines provide a comprehensive, practical, and context-specific framework to reduce lost-to-follow-up among Type 1 diabetes patients. Moreover, it helps to improve diabetes follow-up care at the patient, provider, and system levels.

6.4 PRESENTATION OF THE FINAL VALIDATED GUIDELINES

After an iterative process of development, expert review, and validation, the guidelines were consolidated into a single comprehensive document encompassing eight core thematic areas. These core areas of emphasis address key aspects of diabetes follow-up care, including (1) Patient Education, (2) Financial Support, (3) Tracing of Lost-to-Follow-up Patients, (4) Quality of Care, (5) Reduction of Waiting Time, (6) Implementation of Robust Cohort Follow-up Systems, (7) Strengthening of Patient Support Systems, and (8) Monitoring and Evaluation. The integrated and validated guideline covering these eight domains is presented in Table 6.19.

6.4.1 Final validated guideline

Table 6.19: Final validated guideline on lost-to-follow-up T1d patients in Ethiopia

BACKGROUND:

Type 1 diabetes is a chronic, lifelong condition that requires consistent medical follow-up, adherence to treatment, and ongoing patient engagement to prevent complications and maintain quality of life. In Ethiopia, evidence indicates that a substantial proportion of patients with Type 1 diabetes are lost to follow-up, which negatively affects health outcomes. Factors contributing to LTFU include inadequate patient education, financial barriers, weak tracing systems, poor quality of care, long waiting times in hospitals, limited integration between facility-based and community-level support mechanisms, and a lack of an effective monitoring and evaluation system.

To address these challenges, a set of practical and culturally relevant guidelines was developed to strengthen diabetes follow-up systems and reduce patient attrition. The guidelines cover critical areas such as patient education and awareness, financial support, tracing of lost-to-follow-up patients, improving quality of follow-up care, reducing waiting times, implementing robust cohort tracking, enhancing support systems, and monitoring and evaluation of follow-up care. Each guideline directly addresses barriers identified through empirical research and expert validation, aiming to foster improved

patient retention and better health outcomes for individuals with Type 1 diabetes in Ethiopia.

GOALS OF THE GUIDELINES:

The overall goal of these guidelines is to improve diabetes follow-up care and strengthen mechanisms for retaining patients within the continuum of care. Specifically, the guidelines aim to:

- Strengthen patient knowledge and self-management through structured education and awareness creation.
- Reduce financial, psychosocial, and systemic barriers to consistent diabetes follow-up.
- Enhance the capacity of healthcare workers to deliver patient-centred, evidence-based diabetes care.
- Promote standardised, high-quality diabetes follow-up care through robust cohort management and monitoring mechanisms.
- Foster sustainable collaboration between health facilities, communities, and policymakers to improve follow-up care.

SCOPE:

These guidelines apply to all healthcare facilities and community-based programs providing diabetes care in Ethiopia, including hospitals, health centres, diabetes clinics, and outreach programs. They encompass strategies for improving patient follow-up, education, psychosocial support, and the use of cohort management systems. The guidelines are intended to inform healthcare workers, policymakers, and program implementers on best practices for minimising lost-to-follow-up and improving long-term patient outcomes.

TARGET POPULATION AND TARGET USERS:

Target Population:

- Patients living with Type 1 diabetes, particularly those at risk of discontinuing follow-up care.

Guideline Users:

- Healthcare workers (doctors, nurses, health officers, and case managers)

- Diabetes program managers and policymakers
- Ministry of Health and Regional Health Bureaus
- Diabetes associations, community-based organisations, and NGOs
- Patients' families, caregivers, and peer support groups

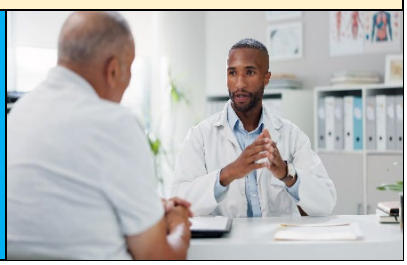
GOVERNMENT COMMITMENT:

The Government of Ethiopia, through the Ministry of Health, recognises non-communicable diseases (NCDs) as a growing public health challenge and has prioritised diabetes care within its national health strategies. The development and validation of these guidelines align with the National Strategic Action Plan for the Prevention and Control of Non-Communicable Diseases (2021–2025) and the National Health Policy (2019). The Ministry's commitment to improving the quality of diabetes care is reflected in its efforts to strengthen the chronic care model, integrate NCD services into primary healthcare, and enhance capacity for monitoring and evaluation of diabetes programs nationwide.

GUIDELINE REVIEW TEAMS INVOLVED:

The guidelines were developed through a participatory and consensus-based process that included both focused expert discussions and a Structured Consensus Development Meeting (SCDM). The review teams comprised multidisciplinary professionals, including endocrinologists, public health experts, program managers, and representatives from diabetes associations. Their expertise ensured that the guidelines are practical, evidence-based, and contextually relevant to the Ethiopian healthcare setting. The collaborative process also emphasised harmonisation with national policies and feasibility across diverse health facility levels.

GUIDELINE I:
KEY RECOMMENDATIONS RELEVANT TO DIABETES PATIENT EDUCATION AND AWARENESS CREATION



1. **Develop Structured Educational and Sensitisation Programs**
    - ***Create a Comprehensive Curriculum:*** Design structured educational programs that cover various aspects of diabetes management, including medication adherence, dietary recommendations, physical activity, and monitoring blood sugar levels. This curriculum should be tailored to meet the needs of different patient demographics.
    - ***Incorporate Interactive Learning:*** Utilise interactive teaching methods, such as group discussions and hands-on demonstrations, to engage patients actively in their learning process. This can enhance the retention and application of knowledge.
    - ***Regular Reminders and Encouragement:*** Establish systematic and context-appropriate reminder systems (e.g., phone calls, text messages, or community healthcare worker follow-ups) through which healthcare workers consistently encourage patients to attend scheduled follow-up visits. Clear and direct communication from healthcare workers should be prioritised, as it significantly improves patient motivation and adherence.
2. **Involve Family Members in Education**
    - ***Family-Centric Educational Initiatives:*** Develop programs that include family members in the education process, recognising their role in supporting patients' adherence to dietary and lifestyle changes. This can help reinforce healthy behaviours at home and patients' decisions to attend appointments.
    - ***Provide Resources for Families:*** Create educational materials specifically designed for family members to help them understand diabetes management and how they can support their loved ones.
3. **Ensure Accessibility of Educational Materials**
    - ***Develop Multilingual Resources:*** Provide educational materials in multiple languages and formats that are easily understandable for all patients. This includes brochures, videos, and online resources that cater to different literacy levels.
    - ***Utilise Local Context:*** Ensure that educational materials are culturally relevant

and consider local dietary practices and beliefs. This can enhance the effectiveness of the education provided.

4. **Train Healthcare Workers on Patient Education**
   - ***Implement Training Programs for Healthcare Workers:*** Provide comprehensive training for healthcare workers on effective patient education techniques, focusing on communication skills, empathy, and the importance of patient engagement.
   - ***Cultural Sensitivity Training***: Provide cultural sensitivity training for healthcare workers to better understand and address the cultural beliefs that may discourage patients from seeking follow-up care.
5. **Foster a Supportive Environment**
   - ***Create Support Groups:*** Establish support groups for patients to share experiences and challenges in managing diabetes. This can provide emotional support and reinforce the education received.
   - ***Community Support Programs:*** Develop community programs that foster social support networks, allowing patients to share experiences and encourage each other to prioritise follow-up care.
   - ***Encourage Community Involvement:*** Collaborate with local organisations and diabetes associations to enhance educational outreach and provide additional resources for patients.
6. **Increase Awareness of Health Risks and Benefits of Follow-up Care**
   - ***Educational Initiatives:*** Awareness of health risks can serve as a powerful motivator for patients. Implement educational programs that inform patients about the potential complications of diabetes and the importance of regular follow-up care.
   - ***Utilise Testimonials:*** Share success stories from other patients who have benefited from regular follow-up care to inspire and motivate others.
   - ***Highlight Positive Outcomes:*** Clearly communicate the benefits of regular follow-up care, such as better management of diabetes and prevention of complications. This can be done through brochures, workshops, and community health

events.

- ***Combat Complacency:*** Develop targeted interventions to address complacency among patients regarding their health. This can include motivational interviewing techniques to help patients recognise the importance of ongoing care.

7. **Leverage Community Health Education Initiatives**
   - ***Engage in Community Programs:*** Collaborate with local health organisations to create community health initiatives that promote diabetes awareness and the importance of follow-up care.
   - ***Utilise Mass Media:*** Use mass media campaigns to raise awareness about diabetes management and the importance of follow-up visits, targeting both patients and their families.
   - ***Incorporate Visual Aids:*** Use visual aids and infographics to illustrate the benefits of follow-up care, making the information more accessible and engaging for patients.
8. **Monitor and Evaluate Educational Effectiveness**
   - ***Establish Feedback Mechanisms:*** Create systems for patients to provide feedback on the educational programs they receive. This can help identify areas for improvement and ensure that the education provided meets patients' needs.
   - ***Conduct Regular Assessments:*** Implement regular assessments to evaluate the effectiveness of educational initiatives in improving patient knowledge and self-management skills. This can include pre- and post-education surveys to measure changes in understanding.

GUIDELINE 2:

KEY RECOMMENDATIONS RELEVANT TO FINANCIAL SUPPORT FOR DIABETES PATIENTS



1. **Establish Financial Assistance Programs**
   - ***Collaborate with Local Organisations:*** Develop partnerships with local organisations, such as diabetes associations, to create a support network for patients. This

collaboration can help provide financial assistance for medications and follow-up care.

- ***Create Awareness of Available Resources:*** Ensure that patients are informed about the financial assistance programs available to them through community organisations. This can be achieved through educational campaigns.
- ***Inclusion of Diabetes Services in the Exempted Service List:*** Advocate for the inclusion of diabetes services in the national exempted service list to ensure equitable access and long-term sustainability, rather than relying on sliding-scale fee mechanisms. Complementary efforts should focus on community awareness, such as workshops to guide patients in navigating insurance enrollment and benefits.
- ***Direct Cash and Voucher Assistance Programs:*** Establish direct cash and voucher assistance programs specifically for diabetes patients who face unexpected medical expenses and transportation costs.
- ***Implement Direct Cash and Voucher Assistance while advocating Sustainable Financial Support for Diabetes Care:*** Implement direct cash or voucher assistance in humanitarian settings and for diabetes patients who face unexpected medical expenses and transportation costs, and advocate for long-term sustainable systemic reforms that address financial barriers. This includes strengthening insurance coverage, subsidy schemes, and patient support systems to ensure continuity of care.

2. **Implement Affordable Healthcare Services**
   - ***Reduce Service Fees:*** Advocate for the reduction of service fees associated with diabetes care to make healthcare more accessible for patients. This can help alleviate the financial burden that often prevents patients from seeking necessary treatment.
   - ***Integrate Affordable Services into Healthcare Systems:*** Work towards integrating affordable healthcare services into existing healthcare systems to ensure that patients can access the care they need without financial strain.
3. **Enhance Insurance Coverage**
   - ***Expand Insurance Coverage Options:***

- Advocate for policies that expand eligibility for insurance coverage to include more individuals, particularly those with low income or those who are currently uninsured.
- Develop insurance plans that cover a wider range of diabetes-related services, including medications, regular check-ups, and necessary diagnostic tests.

- ***Increase Awareness of Insurance Benefits:***
  - Implement educational campaigns to inform patients about the benefits of insurance coverage and how to navigate the enrollment process.
  - Organise community workshops that provide information on how to apply for insurance and the specific benefits that come with coverage for diabetes management.
- ***Advocate for Policy Changes:***
  - Lobby for legislative support and work with policymakers to advocate for changes in legislation that would require insurance companies to cover essential diabetes care services.
  - Collaborate with related advocacy groups that focus on diabetes programs to push for systemic changes in insurance coverage policies.

4. **Monitor and Evaluate Financial Support Programs**

- ***Establish Monitoring Mechanisms:*** Implement systematic approaches to assess the effectiveness of financial support programs. This includes tracking patient outcomes and adherence to treatment plans.
- ***Data Collection:*** Collect data on the impact of insurance coverage on patient outcomes, including adherence to treatment and health complications. This data can be used to advocate for further improvements in insurance policies.
- ***Incorporate Feedback Loops:*** Create feedback mechanisms for patients to share their experiences with financial support programs. This can help identify areas for improvement and ensure that the programs meet patients' needs.

GUIDELINE 3:

KEY RECOMMENDATIONS RELEVANT TO TRACING LOST TO FOLLOW-UP PATIENTS



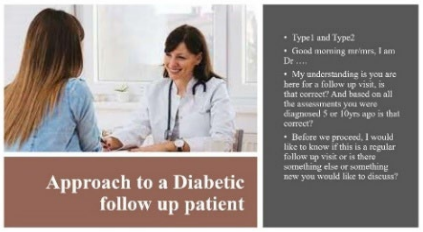
1. **Establish Dedicated Personnel for Patient Tracking**
   - ***Implement Case Management Models:*** Introduce dedicated case managers for diabetes care, similar to those used in HIV care. This can enhance follow-up care by ensuring that patients receive consistent support and monitoring.
   - ***Assign Roles Clearly:*** Clearly define the roles and responsibilities of healthcare workers involved in tracing lost patients to improve accountability and streamline processes.
2. **Improve Healthcare Workers' Knowledge and Attitude**
   - ***Ongoing Education:*** Encourage continuous professional development for healthcare workers to keep them updated on best practices in diabetes care and patient engagement strategies.
3. **Enhance Patient Tracking and Documentation**
   - ***Implement Robust Tracking Systems:*** Develop systematic patient tracking systems to monitor attendance and follow-up care. This can help identify patients who are lost to follow-up and facilitate timely interventions.
   - ***Standardise Record-Keeping Practices:*** Establish clear guidelines for record-keeping and documentation in chronic care units to improve the quality of diabetes follow-up services.
4. **Create clear guidelines for tracing lost-to-follow-up patients**
   - ***Develop structured protocols:*** Create detailed protocols for tracing lost patients that outline the necessary steps for patient engagement, monitoring, and intervention.
   - ***Utilise charts and registers effectively:*** Provide guidelines for the proper utilisation of charts and registers in chronic care units to enhance the quality of follow-up services.

- ***Use automated tools for patient-provider interaction and communication:*** This should be promoted by integrating reminder systems, digital follow-up platforms, and interactive messaging services to support appointment adherence, medication compliance, and timely feedback, while ensuring data security and patient confidentiality. These include reminder SMS messages and digital follow-up monitoring mobile apps.

5. **Foster a supportive environment:**
   - ***Encourage family involvement:*** Involve family members in the education and support process, as their encouragement can significantly boost patients' confidence in attending follow-up care.
   - ***Create peer support networks:*** Establish peer support groups where patients can share experiences and motivate each other to prioritise follow-up care.
   - ***Motivational scheme for healthcare workers working with tracing of LTFU cases:*** Implement performance-based incentives, recognition programs, and supportive supervision, thereby encouraging proactive patient tracing, sustained engagement, and improved retention in care.
6. **Monitor and evaluate tracing effectiveness**
   - ***Establish monitoring mechanisms:*** Implement systematic approaches to assess the effectiveness of tracing lost patients. This includes tracking patient outcomes and adherence to treatment plans.
   - ***Incorporate feedback loops:*** Create feedback mechanisms for healthcare workers to share their experiences and challenges in tracing lost patients. This can help inform necessary adjustments to improve care quality.

GUIDELINE 4:

KEY RECOMMENDATIONS RELEVANT TO IMPROVING THE QUALITY OF DIABETES FOLLOW-UP CARE



1. **Enhance training for healthcare workers.**
   - ***Implement comprehensive training programs:*** Develop structured training

initiatives focused on diabetes management for healthcare workers. This should include both theoretical knowledge and practical skills to ensure that workers are well-equipped to provide effective care.

- ***Ongoing education and resources:*** Establish continuous professional development opportunities for healthcare workers to keep them updated on best practices in diabetes care. This can help address gaps in knowledge and improve patient outcomes.
- ***Implement on-the-job training and mentorship on CQI (Continuous Quality Improvement model),*** with emphasis on routine monitoring and use of data to improve patient care.

2. **Address staffing shortages**
    - ***Optimise workforce through training and task-sharing:*** Train and assign health professionals from other departments to support diabetes follow-up care. This approach can help address workforce gaps while ensuring patients receive adequate attention during visits.
    - ***Create dedicated diabetes care units:*** Establish specialised units for diabetes care to streamline services and improve the quality of care provided. This can help alleviate the burden on general healthcare facilities and enhance patient management.
3. **Improve record-keeping and patient tracking systems.**
    - ***Implement structured record-keeping systems:*** Develop and enforce standardised protocols for record-keeping to ensure consistency and accuracy in patient data management. This can help healthcare workers track patient progress and outcomes more effectively.
    - ***Strengthen patient tracking systems (digital and paper-based):*** Invest in electronic health record systems to improve tracking of appointments, medications, and follow-up care. Simultaneously, strengthen paper-based systems in rural and resource-limited settings where digital infrastructure is not yet available. This dual approach can enhance provider communication and improve patient management across diverse contexts.

4. **Ensure the availability of essential medications.**
    - ***Establish reliable supply chains:*** Improve logistics and supply chain management to ensure consistent availability of essential medications, particularly insulin. This can help prevent stock-outs that disrupt patient care.
    - ***Create financial assistance programs:*** Develop programs to assist patients in affording their medications, especially for those from low-income backgrounds. This can help improve adherence to treatment regimens.
    - ***Strengthening logistics and supply chain management:*** This should be achieved by fostering collaboration with EPSS (Ethiopian Pharmaceutical Supply Service) to ensure the availability of stock, timely procurement, and distribution of essential supplies.
5. **Foster a Supportive Environment**
    - ***Encourage compassionate care:*** Train healthcare workers in effective communication and compassionate care practices. This can help build trust and improve patient satisfaction with the healthcare system.
    - ***Involve family and community support:*** Engage family members and community resources in the care process to provide additional support for patients. This can enhance motivation and adherence to follow-up care.
6. **Adopt a holistic approach to diabetes management.**
    - ***Integrate comprehensive care***: Develop guidelines that emphasise a holistic approach to diabetes management, incorporating medical treatment, preventive services, education, and emotional support. This can help address the misconception that follow-up care is limited to blood sugar testing and medication collection.
    - ***Focus on preventive services***: Ensure that the guidelines include preventive care measures, such as regular screenings for diabetes-related complications, to enhance patient outcomes and reduce the incidence of severe health issues.
    - ***Engaging patients in their management plan:*** This should be prioritised by involving them in shared decision-making, goal setting, and regular follow-up, thereby fostering a sense of ownership, improving adherence, and enhancing

health outcomes.

7. **Enhance patient education**
    - ***Implement structured educational programs:*** Create comprehensive educational initiatives that empower patients with the knowledge necessary for effective self-management. This should include information on diabetes management, the importance of follow-up care, and lifestyle modifications.
    - ***Involve family members:*** Encourage the involvement of family members in educational programs to reinforce healthy behaviours and support patients in adhering to their treatment plans.
8. **Improve communication and support systems.**
    - ***Train healthcare workers in effective communication:*** Provide training for healthcare workers to enhance their communication skills, ensuring they can effectively convey the importance of follow-up care and engage patients in their management plans.
    - ***Establish support networks:*** Create support systems, including peer support groups and community resources, to help patients feel more connected and supported in their diabetes management journey.
9. **Implement robust monitoring and evaluation mechanisms.**
    - ***Develop monitoring protocols:*** Establish clear protocols for monitoring patient progress and adherence to treatment plans. This can help identify patients who are lost to follow-up and facilitate timely interventions.
    - ***Incorporate feedback mechanisms:*** Create systems for healthcare workers to provide feedback on the effectiveness of the guidelines and the challenges they face in implementing them. This can inform necessary adjustments to improve care quality.
10. **Allocate resources for continuous improvement.**
    - ***Ensure adequate funding for diabetes care:*** Advocate for sufficient budget allocation to support diabetes management programs, including training for healthcare workers and resources for patient education.
    - ***Regularly review and update guidelines:*** Establish a process for the regular

review and updating of guidelines based on the latest research and patient outcomes to ensure they remain relevant and effective.

GUIDELINE 5:

KEY RECOMMENDATIONS RELEVANT TO REDUCING PATIENTS' WAITING TIME IN HEALTH FACILITIES



1. **Streamline appointment scheduling:**
   - Implement an efficient and context-appropriate appointment scheduling system to improve patient flow. This may include staggered appointment slots and the use of text message reminders, which are more feasible than online booking systems in the current setting, to reduce no-shows and last-minute cancellations.
2. **Increase staffing during peak hours:**
   - Analyse patient flow data to identify peak hours and ensure adequate staffing during these times. Increasing the number of healthcare workers available can help manage patient load and reduce waiting times.
3. **Utilise technology for patient tracking:**
   - Implement electronic health records (EHR) and patient tracking systems to monitor patient status and streamline the check-in process. This can help reduce administrative delays and improve overall efficiency.
4. **Create Dedicated Diabetes Care Units:**
   - Establish specialised units for diabetes care within healthcare facilities. This can help streamline services and ensure that patients receive focused and comprehensive care, reducing the time spent waiting for appointments.
5. **Enhance communication with patients:**
   - Improve communication strategies to keep patients informed about expected waiting times and any delays. Providing updates can help manage patient expectations and reduce frustration.
6. **Conduct regular process evaluations:**

- Implement a system for regularly evaluating and optimising patient flow processes. Gathering feedback from both patients and healthcare workers can help identify bottlenecks and areas for improvement.

7. **Offer extended hours:**
   - Provide extended clinic hours selectively, such as on weekends or designated days, to improve accessibility for patients who face challenges attending during regular hours. Implementation should carefully consider workers' workload, resource availability, and financial sustainability to ensure that extended services do not compromise quality of care.
8. **Foster a supportive environment:**
   - Create a welcoming and efficient environment in waiting areas. Providing comfortable seating, educational materials, and engaging activities can help improve patient satisfaction while they wait.

GUIDELINE 6:

KEY RECOMMENDATIONS RELEVANT TO IMPLEMENTING ROBUST COHORT FOLLOW-UP



1. **Establish Dedicated Personnel for Cohort Management**
   - ***Implement Case Management Models:*** Where feasible, introduce dedicated case managers for diabetes care, similar to models used in HIV programs. Case managers can strengthen follow-up care by ensuring consistent patient support and monitoring. Implementation should take into account feasibility and resource requirements.
   - ***Assign Roles Clearly:*** Clearly define the roles and responsibilities of healthcare workers involved in diabetes cohort management to improve accountability and streamline processes.
2. **Improve Training for Healthcare Workers**
   - ***Comprehensive Training Programs:*** Develop and implement training programs focused on diabetes management and cohort registration practices. This should equip healthcare workers with the necessary skills to manage diabetes

effectively.

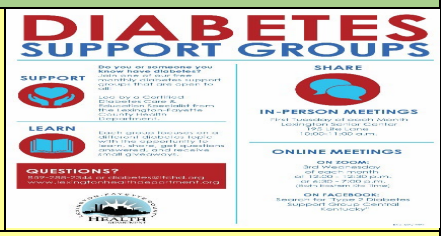
- ***Ongoing Education:*** Encourage continuous professional development for healthcare workers to keep them updated on best practices in diabetes care and patient engagement strategies.

3. **Enhance Patient Tracking and Documentation**
    - ***Implement Robust Tracking Systems:*** Develop systematic patient tracking systems to monitor attendance and follow-up care. This can help identify patients who are lost to follow-up and facilitate timely interventions.
    - ***Standardise Record-Keeping Practices:*** Establish clear guidelines for record-keeping and documentation in chronic care units to improve the quality of diabetes follow-up services.
4. **Create clear guidelines for follow-up care**
    - ***Develop structured protocols:*** Create detailed protocols for diabetes cohort follow-up that outline the necessary steps for patient engagement, monitoring, and intervention.
    - ***Utilise charts and registers effectively:*** Provide guidelines for the proper utilisation of charts and registers in chronic care units to enhance the quality of follow-up services.
5. **Foster a supportive environment**
    - ***Encourage family involvement in cohort follow-up:*** Involve family members in the education and support process, with emphasis on their unique role in enhancing adherence and improving attendance at follow-up visits.
    - ***Create peer support networks***: Establish peer support groups where patients can share experiences and motivate each other to prioritise follow-up care.
6. **Monitor and evaluate follow-up care effectiveness**
    - ***Establish monitoring mechanisms:*** Implement systematic approaches to assess the effectiveness of diabetes cohort follow-up programs. This includes tracking patient outcomes and adherence to treatment plans.
    - ***Incorporate feedback loops***: Create feedback mechanisms for healthcare workers to share their experiences and challenges in implementing follow-up

care guidelines. This can help inform necessary adjustments to improve care quality.

GUIDELINE 7:

KEY RECOMMENDATIONS RELEVANT TO ENHANCE SUPPORT SYSTEM FOR DIABETES PATIENTS



1. **Strengthening family and social support**
   - ***Promote positive family involvement***
     - Encourage families to actively participate in patient care by attending follow-up appointments and engaging in diabetes education.
     - Develop informational materials for families to clarify their role in supporting diabetes care, including how to assist with medication adherence and monitoring.
   - ***Address conflicting advice***
     - Provide structured education for families on evidence-based diabetes management to reduce the influence of contradictory traditional or religious practices.
     - Train healthcare workers to engage in culturally sensitive conversations to align family beliefs with medical advice.
   - ***Enhance communication between healthcare workers and families***
     - Conduct joint counselling sessions involving both patients and their families to create shared understanding and treatment goals.
     - Include family members in decision-making discussions to foster support and reduce misunderstandings.
2. **Enhancing community resource accessibility**
   - ***Establish and strengthen diabetes support groups***
     - Facilitate the formation of local diabetes support groups within health facilities or community centres.
     - Ensure these groups include peer educators, community healthcare workers, and patients sharing experiences and solutions.

- ***Integrate Community-Based Organisations (CBOs)***
  - Partner with existing CBOs, religious institutions, and local leaders to promote awareness and reduce stigma or misinformation regarding diabetes treatment
  - Collaborate with organisations like the Diabetes Association to extend support and resource distribution (e.g., glucometers, strips).
- ***Promote Community Healthcare worker (CHW) engagement***
  - Train CHWs to provide follow-up reminders, home visits, and health education to support continuity of care, especially in rural or underserved areas.
  - Equip CHWs with referral pathways to link patients with psychosocial or clinical services.

3. **Providing psychosocial support services**
   - ***Incorporate psychosocial assessment into routine care***
     - Include regular screening for emotional distress, depression, and anxiety during diabetes follow-up visits using validated tools.
     - Offer on-site or referral-based psychosocial counselling services for patients needing mental health support.
   - ***Train healthcare workers in compassionate communication***
     - Develop continuous training modules for healthcare workers on patient-centred communication, empathy, and motivational interviewing.
     - Encourage providers to check patient understanding and satisfaction during each consultation to build trust and confidence.
   - ***Promote multidisciplinary and holistic care***
     - Create a referral and feedback mechanism between medical, psychological, and community support providers.
     - Encourage the development of a “diabetes care team” model comprising clinicians, psychologists, nutritionists, and CHWs.
4. **Bridging gaps between the health system and community**
   - ***Raise awareness of available services***

- Develop and distribute directories of existing diabetes care resources, support groups, and educational sessions in local languages.
- Conduct outreach campaigns through radio, posters, and social media to inform patients of support systems and how to access them.

- ***Facilitate coordination between clinics and support systems***
  - Designate liaison officers or focal persons in healthcare facilities responsible for linking patients to community-based support and follow-up systems.
  - Create feedback loops between health facilities and community groups to track patient progress and reduce lost-to-follow-up.

5. **Addressing financial and logistical barriers**
   - ***Support access to diabetes management tools***
     - Advocate for subsidised or donated glucometers and strips through partnerships with NGOs and government programs.
     - Identify and support vulnerable households with targeted material and financial support.
   - ***Improve accessibility of follow-up services***
     - Implement mobile health interventions such as SMS appointment reminders, health tips, and medication alerts.
     - Expand community-based clinics or outreach days to reduce the travel burden for patients.
6. **Monitoring and evaluation**
   - ***Track follow-up attendance and support engagement***
     - Maintain a registry of patients with missed appointments and follow up through CHWs or peer supporters.
     - Document participation in community support programs and assess their impact on adherence and health outcomes.
   - ***Evaluate patient and family satisfaction***
     - Conduct regular surveys or focus groups to assess patient satisfaction with support systems and identify gaps.
     - Use feedback to refine and improve the integration of support services into

follow-up care.

GUIDELINE 8:

KEY RECOMMENDATIONS RELEVANT TO MONITORING AND EVALUATION OF DIABETES FOLLOW-UP CARE



1. **Establish systematic monitoring frameworks**
    - ***Develop comprehensive monitoring protocols:*** Create structured protocols that outline the specific metrics and indicators to be monitored in diabetes follow-up care. These should include patient adherence rates, health outcomes, and the effectiveness of interventions. Protocols should be harmonised with national HMIS to avoid duplication, designed to be simple and practical given the existing workers' workload, and include clear accountability for data use to ensure information leads to service improvements.
    - ***Utilise technology for data collection (phased and context-appropriate):*** Where feasible, implement electronic health record systems to support the collection and analysis of patient data, enabling healthcare workers to track progress and identify trends over time. Considering infrastructural challenges, adoption should follow a phased approach, with advocacy for digital solutions accompanied by strengthened paper-based systems until wider capacity is in place.
2. **Allocate resources for monitoring activities**
    - ***Ensure adequate budgeting:*** Advocate for sufficient budget allocation, specifically for monitoring and evaluation activities within diabetes care programs. This is crucial for sustaining effective monitoring systems and ensuring that they are adequately staffed and resourced.
    - ***Train healthcare workers in monitoring practices:*** Provide training for healthcare workers on the importance of monitoring and evaluation, equipping them with the skills necessary to implement these practices effectively.
3. **Incorporate feedback mechanisms**

- ***Establish regular feedback loops:*** Create systems for healthcare workers to provide regular feedback on the challenges they face in implementing diabetes follow-up care guidelines. This feedback should be used to inform necessary adjustments to the guidelines.
- ***Engage patients in feedback processes***: Implement mechanisms for patients to share their experiences and outcomes related to follow-up care. This can help identify barriers to adherence and inform improvements in care delivery.

4. **Monitor patient outcomes and adherence**
    - ***Track patient progress systematically:*** Develop a systematic approach to track patient outcomes, including glycemic control, diabetes complications, and adherence to follow-up appointments. This can help identify patients who are lost to follow-up and facilitate timely interventions.
    - ***Utilise data for continuous improvement:*** Analyse collected data to assess the effectiveness of diabetes management protocols and make necessary adjustments based on real-world outcomes. This can enhance the quality of care provided to patients.
5. **Foster a Culture of Continuous Improvement**
    - ***Encourage a learning environment:*** Promote a culture within healthcare settings that values continuous improvement and learning from monitoring and evaluation activities. This can enhance the overall quality of diabetes care.
    - ***Regularly review and update guidelines:*** Establish a process for the regular review and updating of monitoring and evaluation guidelines based on the latest research and patient outcomes to ensure they remain relevant and effective.

FACILITATORS AND BARRIERS TO IMPLEMENTATION:

Facilitators:

- Strong government commitment to improving NCD care and diabetes management.
- Existing diabetes programs and partnerships with NGOs and diabetes associations.

- Trained healthcare professionals and expanded chronic care systems, including diabetes
- The government's commitment to expand the use of digital tools and health information systems for patient tracking.

Barriers:

- Limited resources for implementing structured follow-up systems.
- Gaps in patient education and awareness about the importance of consistent follow-up.
- Financial constraints and lack of insurance coverage for diabetes services.
- Weak coordination between healthcare facilities and community-based programs.
- Inconsistent availability of essential medications and supplies.

TOOLS FOR THE GUIDELINES' IMPLEMENTATION:

Implementation of these guidelines relies on the use of standardised tools and frameworks to ensure consistency and effectiveness across health facilities. These include:

- **Patient education materials:** Brochures, posters, and other community education materials tailored to different literacy levels and languages.
- **Patient tracking tools:** Cohort registers, tracing forms, and reminder systems (SMS, phone calls, or community follow-up).
- **Monitoring and evaluation instruments:** Facility-based reporting formats and digital databases for tracking adherence, outcomes, and follow-up visits.
- **Capacity-building tools:** Training manuals and mentorship programs for healthcare workers
- **Referral and support tools:** Linkage forms and directories connecting health facilities with community and peer-support systems.

RESOURCE IMPLICATIONS AND MONITORING OF IMPLEMENTATION:

Most of the recommended interventions can be implemented in the existing health system without demanding additional resources. Therefore, effective implementation of these guidelines requires a planned utilisation of the existing human, financial, and logistical resources. Moreover, coordination with diabetes associations and NGOs can facilitate additional support through material resources and capacity building.

Monitoring should be conducted through periodic supervision and performance reviews. Monitoring results should inform continuous improvement and policy adjustments. Key indicators for monitoring include:

- Proportion of patients receiving regular follow-up visits,
- Reduction in LTFU rates over time,
- Proportion of facilities using standardised tracking tools,
- Patient satisfaction and treatment adherence.

LIMITATIONS, RISKS, AND SIDE EFFECTS:

Implementation may face limitations such as variability in facility readiness and workers' turnover. There is also a potential risk of inconsistent data reporting or low adherence to guidelines in remote sites. To mitigate these challenges, ongoing supervision, mentorship, and adaptation of the guidelines to local contexts are essential. No clinical side effects are associated with these guidelines; however, insufficient implementation could perpetuate existing service gaps and patient loss to follow-up.

RELATED LEGISLATION AND DOCUMENTS:

- National Strategic Action Plan for the Prevention and Control of Non-Communicable Diseases (2020/1–2024/5)
- National Health Sector Transformation Plan II (HSTP II) (2020/21–2024/25)
- WHO Global Action Plan for the Prevention and Control of NCDs (2013–2030)
- National Guideline for the Detection and Comprehensive Management of Diabetes in Ethiopia, 2023

- Standards of medical care in diabetes- 2018 abridged for primary care providers.

FEEDBACK:

All panel members provided feedback during the Focused Discussion and Structured Consensus Development Meeting (SCDM) sessions. Feedback was documented using the SCDM tool (Annexure R), which panel members completed and shared with the researcher.

The thesis supervisor, Professor Lizeth Roets, submitted her detailed feedback on this document through email correspondence directed to 20996896@mylife.unisa.ac.za

FUNDING SOURCES AND CONFLICTS OF INTEREST:

The development and validation of these guidelines were conducted as part of a broader research initiative supported by academic and institutional partners, with ethical approval from the IRB of UNISA and the local authority (Oromia Regional Health Bureau). No external funding or commercial sponsorship influenced the content or recommendations presented herein. The authors and reviewers declare no conflicts of interest.

6.5 SUMMARY

Chapter Six presents the validation of the guideline and its establishment for practical use. It explains the approach and methods used during the validation phase. The chapter then presents how the data were gathered and analysed, and summarises the findings from the first and second rounds of validation. Each round provided important feedback that helped refine and strengthen the guideline. A summary of these findings and the key discussions from the SCDM was indicated. The chapter concludes with the presentation of the final validated guideline. The next and final chapter presents the conclusions, Recommendations and Limitations of the study.

7. CHAPTER SEVEN: CONCLUSIONS, RECOMMENDATIONS AND LIMITATIONS

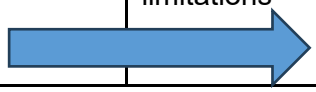
7.1 INTRODUCTION

Chapter 7 presents the conclusions, recommendations, and limitations of the study, drawn from the four-phase study. In this chapter, the conclusions are summarised under the three main objectives of the study. It also provides actionable recommendations for policymakers, healthcare institutions, practitioners, and researchers on who should have access to the guidelines for implementation. Moreover, the significance of the study findings to Public Health was highlighted. Finally, the study's limitations are explained, and recommendations for future research are provided. The study's progress is depicted in Table 7.1.

Table 7.1: The study's progress

CHAPTER	NAME OF THE CHAPTER	PURPOSE/CONTENT
Chapter 1	Overview of the study	The chapter provides an overview of the purpose, objectives and methodology of the study.
Chapter 2	Literature review	Literature review to discuss: • Theoretical framework • Diabetes and diabetic services • The national strategy for diabetes
Chapter 3	Methodology	The methodology of all phases of the study
Chapter 4	Phases 1 and 2	Data gathering, analysis, presentation and literature control
Chapter 5	Development of the guideline	• Literature review on the principles of guideline development • Phase 1 and Phase 2 data integration • Focused discussions, data gathering, analysis and interpretation • Draft guideline ready for validation
Chapter 6	Validation of the guideline	• The process and methodology followed • Data gathering and analysis of the Structured consensus development meeting • The validated guideline

Chapter 7	Conclusion, recommendations, and limitations	Conclusion, Recommendations, and Limitations of the Study



7.2 CONCLUSIONS

The study's conclusions are presented in accordance with its three main objectives. The first part summarises the findings on the lived experiences of T1D patients who are lost to follow-up (Objective 1). The second part outlines healthcare workers' experiences with the day-to-day and system-level challenges that influence patient retention (Objective 2). Finally, the third part describes the development and validation of evidence-based guidelines to reduce lost-to-follow-up among T1D patients in the Ethiopian context (Objective 3), which constitutes the study's central focus and ultimate goal. It synthesises insights from the first two objectives to inform practical, culturally relevant interventions.

7.2.1 Objective 1: Explore T1D patients' lived experience of lost-to-follow-up

In Phase 1, the study explored the lived experiences of Type 1 diabetes patients who were lost to follow-up. The study used a qualitative phenomenological design guided by the Health Belief Model. The findings revealed that patients' experiences of LTFU are complex and shaped by multiple interrelated factors that affect continuity of care. These include financial barriers, lack of social support, limited health literacy, and the psychological burden of managing a chronic condition. These insights demonstrate that LTFU is not merely a consequence of individual behaviour but is rooted in broader systemic, social, and contextual realities. The understanding gained from Phase 1

formed a critical foundation for the subsequent phases of the study. Phase 1 generated practical and evidence-based empirical findings, which served as a basis for developing the guideline on LTFU among Type 1 diabetes patients.

7.2.2 Objective 2: Explore healthcare workers' experience of LTFU among T1D patients

In Phase 2, the study explored healthcare workers' experiences with lost to follow-up among patients with Type 1 diabetes to address Objective 2. The same study model and methodological approach used in Phase 1 were applied in Phase 2. Phase 2 focused on the practical and emotional realities of providing follow-up care. Healthcare workers highlighted significant challenges in ensuring consistent patient follow-up, including inadequate resources, weak tracking systems, a disproportionate HW-patient ratio, poor-quality care, and communication gaps. They emphasised that system-level constraints undermine their ability to deliver continuous care, leading to LTFU. Their perspectives demonstrate that improving retention necessitates addressing both patient-level barriers and institutional weaknesses, underscoring the interconnected nature of the problem. In line with the study model, the findings from Phase 2 complement those from Phase 1, providing a more comprehensive understanding that informed the development and validation of the guideline.

7.2.3 Objective 3: Develop and validate guidelines to reduce LTFU among T1D patients

To address objective three, Phases 3 and 4 of the study focused on translating the empirical insights from earlier phases into practical action. In Phase 3, preliminary guidelines were developed, drawing on findings from patients and healthcare workers as well as supporting literature. These initial recommendations were refined through focused discussions with expert panellists, whose feedback helped align the guidelines with real-world constraints and possibilities within the Ethiopian health system. Phase 4 then moved from refinement to validation. Using a Structured Consensus Development Meeting (SCDM), a panel of multidisciplinary experts reviewed, debated, and adjusted the guidelines until a shared understanding was reached. This process

strengthened the scientific and contextual credibility of the final guideline.

7.2.4 The Validated Guidelines

Through an iterative process of development, expert consultation, and validation, the guidelines were finalised into a single, comprehensive document covering eight key thematic areas. These areas of emphasis cover the essential components of diabetes follow-up care, including: (1) patient education, (2) financial support, (3) tracing of patients lost to follow-up, (4) quality of care, (5) reduction of waiting times, (6) establishment of robust cohort follow-up systems, (7) reinforcement of patient support mechanisms, and (8) monitoring and evaluation (see Annexure T). The validated guidelines provide a practical framework for strengthening patient retention through improved patient education and quality of care, structured follow-up mechanisms, financial support, diabetes support care, and continuous monitoring and evaluation systems.

In summary, this study demonstrated that lost to follow-up among T1D patients is rooted in patients' lived realities, the constraints faced by healthcare workers, and systemic challenges within health facilities. By exploring both patient and healthcare worker perspectives, the study uncovered the lived experience and generated actionable solutions in the form of guidelines. The development and validation of targeted guidelines represent a critical step toward reducing lost-to-follow-up among T1D patients. Ultimately, the study contributes to strengthening diabetes care in Ethiopia by providing an evidence-based, context-sensitive framework that can inform policy, practice, and future research.

7.3 RECOMMENDATIONS

7.3.1 For policymakers and health authorities

- Support the integration of the validated guidelines into national diabetes care policies and protocols to ensure standardisation across healthcare facilities. The guidelines and the scientific evidence from which they were derived will be shared via email with the Ministry of Health, the Oromia Regional Health Bureau, the SWSZ health office, and the hospitals involved in the study to promote

the integration of the guidelines into care policies.

- It is recommended that healthcare institutions integrate the guidelines into routine practice and conduct internal training sessions to ensure their consistent use. Furthermore, the guidelines should be disseminated in electronic copy to the relevant policymakers, local health authorities, and the healthcare institutions involved in the study to support wider implementation.

7.3.2 For healthcare institutions

- Incorporate the guidelines into routine clinical practice, including structured follow-up schedules, patient education sessions, and psychosocial support services. Institutions should make the guidelines accessible to healthcare workers via printed copies, internal networks, or electronic platforms.
- Train healthcare workers in the practical application of the guidelines, emphasising patient-centred approaches and adherence strategies through improved patient education and quality of care, structured follow-up mechanisms, facilitating linkage to diabetes support care, and continuous monitoring and evaluation.
- Hospital medical directors should establish internal monitoring and evaluation mechanisms to track the effectiveness of guideline implementation and to make iterative improvements. Institutions should take responsibility for further dissemination to frontline staff such as Doctors, Nurses and midwives.

7.3.3 For healthcare workers

- Apply the guidelines consistently in day-to-day patient management, including individualised care planning and follow-up interventions. The hospital medical director should share the guidelines with the healthcare workers involved in diabetes patient follow-up care and give an orientation on the new guidelines.
- Healthcare workers should actively engage patients in understanding and adhering to the care plans outlined in the guidelines.
- Healthcare workers should provide continuous feedback and documentation to support adaptation of the guideline to different change situations. This improves

adherence monitoring and identifies challenges for continuous improvement.

7.3.4 Recommendations for the guidelines' dissemination and implementation

To promote its adoption, the researcher will take an active role in disseminating the guidelines and study findings to relevant stakeholders. The electronic and printed copies of the guideline will be formally submitted to the Ministry of Health for possible endorsement and integration into the national diabetes care programs. Copies will also be shared with regional health bureaus and selected hospitals that provide diabetes follow-up care, as well as with professional associations such as the Ethiopian Diabetes Association. These stakeholders are expected to play key roles in contextualising and scaling up the guideline at different levels of healthcare delivery.

It is recommended that the guidelines be presented during the annual Health Sector Review Meeting organised by the MOH. This platform brings together key decision-makers and implementers from regional health bureaus, zonal departments, and health offices, offering an opportunity to discuss the guideline's recommendations, assess implementation feasibility, and identify areas requiring policy or resource support. Additionally, dissemination should extend to national and international diabetes conferences, both online and in-person, to raise awareness and encourage adaptation in comparable contexts.

The study's findings and guidelines should be disseminated through academic publications, policy briefs, and social media platforms such as LinkedIn and ResearchGate to reach a broader professional audience. Over time, updates or modifications may be required based on new evidence, evolving practices, or feedback from implementing sites. Therefore, it is recommended that the MOH and regional health bureaus assign focal persons to oversee early implementation, provide continuous mentoring to healthcare workers, and conduct periodic reviews to evaluate progress and areas for improvement.

Successful implementation will depend on clear assignment of responsibilities, capacity building, and ongoing collaboration among the MOH, healthcare facilities,

and professional associations. The researcher will support these efforts by facilitating orientation and training sessions on the guideline's use and by remaining engaged in knowledge-sharing activities that strengthen its practical application and sustainability.

7.3.5 Recommendations for future research

- Conduct implementation research to assess the feasibility, acceptability, and effectiveness of the guidelines in various healthcare settings. It is recommended that a follow-up study be undertaken to assess the extent to which the guidelines have been effectively implemented in practice and to identify opportunities to enhance their usability and impact.
- Future researchers are encouraged to adopt and test the guideline with other chronic diseases, such as TB and HTN.
- Evaluate patient outcomes and follow-up retention rates following guideline implementation to inform future refinements.

7.4 PUBLIC HEALTH IMPACT OF THE STUDY

The findings of this study have important implications for public health practice in Ethiopia. The developed guideline addresses the problem of Type 1 diabetes patients being lost to follow-up. This strengthens continuity of care and reduces preventable complications. As a result, hospital admissions and premature deaths are likely to decrease if the guidelines are implemented.

The developed guideline extends beyond clinical aspects to address broader public health concerns, including access and community engagement. It emphasises that long-term management of chronic conditions requires attention to social, economic, and behavioural factors. While its broader impact will depend on health system readiness and policy integration, the guideline provides a practical framework to support Ethiopia's efforts to strengthen non-communicable disease services.

7.5 LIMITATIONS

This study was conducted in selected public hospitals, which may limit the generalisability of the findings and the developed guideline to other healthcare settings, such as health centres, private facilities, or different regions. Although the guideline is based on contextual evidence, its applicability to other settings or to the management of other chronic diseases may require further adaptation and validation.

In addition, the study's scope was limited to patients classified as lost to follow-up, defined as those who had discontinued care for six months or more. As a result, the experiences of individuals in the earlier stages of disengagement from care were not captured. Nonetheless, the study provides valuable insights into the long-term challenges faced by individuals living with Type 1 diabetes.

Finally, although experts validated the developed guidelines, their practical implementation and sustainability were not assessed in this study. Future research is encouraged to evaluate the applicability and effectiveness of these approaches in routine healthcare settings.

7.6. UNIQUENESS OF THE STUDY

This study makes several contributions to knowledge, practice, and policy in the field of diabetes care. The key unique contributions are:

- **Integration of patient and healthcare worker perspectives:** The study brings together the lived experiences of Type 1 diabetes patients and the practical experiences of healthcare workers, providing a comprehensive understanding of lost-to-follow-up from both patient and health system perspectives.
- **Context-specific evidence from Ethiopia:** The study generates empirical evidence grounded in the Ethiopian public health system, addressing a critical gap in locally relevant research on diabetes follow-up care in low-resource settings.

- **Linking empirical findings to guideline development:** The study moves beyond identifying challenges by translating empirical findings into practical, evidence-based guidelines aimed at reducing lost-to-follow-up among Type 1 diabetes patients.

7.7. SUMMARY

This chapter highlights the multidimensional factors that contributed to the development of guidelines for lost-to-follow-up among Type 1 diabetes patients. It emphasises the practical application of the guidelines developed to improve patient retention. The limitations of the study are acknowledged, providing direction for future research and the implementation of sustainable interventions in diabetes care.

Moreover, this chapter outlines multidimensional guidelines to support evidence-based practice in addressing lost to follow-up among Type 1 diabetes patients. The recommendations highlighted the practical application of these guidelines for sharing and making them available to enhance patient retention. Ensuring that the guidelines are accessible and understandable to all stakeholders, including healthcare workers, patients, and caregivers, is essential for their successful implementation.

"The effectiveness of health guidelines depends not only on their content but also on their accessibility and relevance to end users (Jin et. al., 2021:9)**.**

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WHO: See World Health Organization.

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9. ANNEXURES

Annexure A: Ethical Clearance letter of UNISA for Phases 1 and 2

UNISA university of south africa

COLLEGE OF HUMAN SCIENCES RESEARCH ETHICS REVIEW COMMITTEE

05 March 2024

NHREC Registration # :
Rec-240816-052
CREC Reference # :
20996896_CREC_CHS_2024

Dear Mr Berhanu Gulo Hawando

Decision:
Ethics Approval from 05 March 2024 to 05 March 2025

Researcher(s): Name: Mrs. B. G. Hawando
Contact details: 20996896@mylife.unisa.ac.za
Supervisor(s): Name: Dr. H. van der Heever
Contact details: vdheevh@unisa.ac.za

Title: Guideline Development for Lost-to-Follow-Up Type-1 Diabetes Patients at Public Hospitals in Ethiopia
Degree Purpose: PhD

Thank you for the application for research ethics clearance by the Unisa College of Human Science Ethics Committee. Ethics approval is granted for one year.

The ***medium-risk application*** *was reviewed by* College of Human Sciences Research Ethics Committee, in compliance with the Unisa Policy on Research Ethics and the Standard Operating Procedure on Research Ethics Risk Assessment.

The proposed research may now commence with the provisions that:

1. The researcher(s) will ensure that the research project adheres to the values and principles expressed in the UNISA Policy on Research Ethics.
2. Any adverse circumstance arising in the undertaking of the research project that is relevant to the ethicality of the study should be communicated in writing to the College Ethics Review Committee.
3. The researcher(s) will conduct the study according to the methods and procedures set out in the approved application.
4. Any changes that can affect the study-related risks for the research participants, particularly in terms of assurances made with regards to the protection of participants' privacy and the

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Annexure B: Ethical Clearance letter from the Local Authority IRB

Biiroo Eegumsa Fayyaa Oromiyaa
Oromia Health Bureau
Saarbet (Calcalii) - Finfinnee

የኦሮሚያ ጤና ጥበቃ ቢሮ
ሳርቤት(ጠልጠለ) - ፊንፊኔ

Lakk/Ref.NO ቢጤ/ሃ፬ፕ/1-16/1385
Guyyaa/Date 21/6/2016

To: **Berhanu Gulo**

Addis Ababa, Ethiopia

Subject: Ethical approval

The research project titled "**Guideline Development for Lost-to-Follow-Up Type-1 Diabetes Patients at Public Hospitals in Ethiopia: Patients and Health Workers in Focus."** is going to conduct in Oromia Region. Based on the principal investigator's request for ethical approval, the Oromia Regional Health Bureau research ethics review board has reviewed the aforementioned research protocol in an expedited manner. We are writing to advise you that Oromia Regional Health Bureau research ethics review board has granted full approval and decided to give this ethical approval letter internalizing the existing problem and the study eventually come up with possible solutions.

We, therefore, request you as your esteemed organization to ensure the commencement and conduct of the study accordingly and wish for the successful completion of the study. You are required to submit the final report to the IRB of Oromia Health bureau Health research team a year upon the completion of the study.

With Best regards

Biiroo Fayyaa Oromiyaatti Daayireektoreetii Hoogganssa B/T/Fayyaa Hawaasaa Qorannoo fi Tajaajila Dhiigaa
Oromia Health Bureau PHEM Research & Blood Bank Service Directorate

Berhanu Kenate (Bsc, MPH)
OHB Health Research team Coordinator

Name of PI: **Berhanu Gulo**
Phone: +251911735578

Email: b.gulo@cuamm.org

CC

- **To Berhanu Gulo**
  Addis Ababa

Annexure C: Support letters from the Study Hospitals



BIIROO FAYYAA OROMIYAATTI
HOSPITAALA WALIIGALAA TULLUU
BOOLLOO

OROMIA HEALTH BUREAU
TULBOLO GENERAL HOSPITAL

በኦሮሚያ ጤና ቢሮ የቱሉ ቦሎ አጠቃላይ ሆስፒታል

Date: 03/07/2024
Ref. #: ቱጠሆ/ሠ/ኮ/1576

To: Whom it may concern

Subject: Granting Permission to Access Research Data Collection

Mr Berhanu Gulo, came to our hospital for research data collection with a support letter from Oromia Regional Health Bureau ref. number BFO/MBTEF/1-16/138 on 01/03/2024. He has also presented the Ethical clearance letter from the ERC of University of South Africa (UNISA) and Oromia Regional Health Bureau.
Approval is here granted to Berhanu Gulo, a PHD student of UNISA, to collect data from the hospital for research titled *"Guideline Development for Lost-to-Follow-Up Type-1 Diabetes Patients at Public Hospitals in Ethiopia"*. During all works, personal information of participants should be kept confidential.

Best regards,

Dr Engida Kabeta

Chief executive officer/CEO/ of Tulu bolo general Hospitol



ቅዱስ ሉቃስ የኮቶሊክ ሆስፒታልና የነርሶች ኮለጅ
Cidoos Luuqaas Hospitaalaa Kaatoliki fi Kooleejii Narsootaf
St. Luke Catholic Hospital and College of Nursing

Ref: ሰ/ሆ/985/24
Woliso, 05/07/2024

To: Whom it may concern

Subject: *Granting Permission to Access Research Data Collection*

Mr Berhanu Gulo, came to our hospital for research data collection with a support letter from Oromia Regional Health Bureau ref. number BFO/MBTEF/1-16/138 on 01/03/2024.
He has also presented the Ethical clearance letter from the ERC of University of South Africa (UNISA) and Oromia Regional Health Bureau.
Approval is here granted to Berhanu Gulo, a PHD student of UNISA, to collect data from the hospital clinical records for research titled *"Guideline Development for Lost-to-Follow-Up Type-1 Diabetes Patients at Public Hospitals in Ethiopia"*.
During all works, personal information of participants should be kept confidential.

Best regards,

Dr. Flavio Bobbio
Medical Director
St.Lukes Catholic Hospital – Woliso
Phone No. +251925433341
e-mail: fbobbio@cuamm.org

Owned by
Ethiopian Catholic Church

Tel. +251-11-341 8754 / 341 0880
Fax +251-11-341 8158
e-mail: stluke.medicaldirector@gmail.com

P.O.Box 253 and 248
WOLISSO, Southwest
Shoa, Ethiopia

Annexure D: Ethical Clearance Letter of UNISA for Phases 3 and 4

UNISA university of south africa

COLLEGE OF HUMAN SCIENCES RESEARCH ETHICS REVIEW COMMITTEE

22 July 2025

NHREC Registration # :
Rec-240816-052
CREC Reference # :
20996896_CREC_CHS_2025

Dear Mr Berhanu Gulo Hawando

Decision:
Ethics Approval from 22 July 2025 to 21 July 2026

Researcher(s): Name: Mr. B. G. Hawando
Contact details: 20996896@mylife.unisa.ac.za
Supervisor (s): Name: Prof. L. Roets
Contact details: roetsl@unisa.ac.za

Title: Guideline Development for Lost-To-Follow-up Type-1 Diabetes Patients at Public Hospitals in Ethiopia
Degree Purpose: PhD

Thank you for the application for research ethics clearance by the Unisa College of Human Science Ethics Committee. Ethics approval is granted for one year.

The ***medium-risk application*** *was reviewed by* the College of Human Sciences Research Ethics Committee in compliance with the Unisa Policy on Research Ethics and the Standard Operating Procedure on Research Ethics Risk Assessment.

The proposed research may now commence with the provisions that:

1. The researcher(s) will ensure that the research project adheres to the values and principles expressed in the UNISA Policy on Research Ethics.
2. Any adverse circumstance arising in the undertaking of the research project that is relevant to the ethicality of the study should be communicated in writing to the College Ethics Review Committee.
3. The researcher(s) will conduct the study according to the methods and procedures set out in the approved application.
4. Any changes that can affect the study-related risks for the research participants, particularly in terms of assurances made with regards to the protection of participants' privacy and the

University of South Africa
Preller Street, Muckleneuk Ridge, City of Tshwane
PO Box 392 UNISA 0003 South Africa
Telephone: +27 12 429 3111 Facsimile: +27 12 429 4150
www.unisa.ac.za

Annexure E: Request for Permission to Conduct the Study

Dear Mr Berhanu Kenate- Research Coordinator
Oromia Regional Health Bureau
Addis Ababa, Ethiopia

PERMISSION LETTER TO CONDUCT RESEARCH

Request for permission to conduct research in Woliso St Luke and Tulu Bolo hospitals in Oromia region, Ethiopia

Research Title: Guideline for Lost-to-Follow-Up Type-1 Diabetes Patients at Public Hospitals in Ethiopia.

Dear Research Coordinator,
I, Berhanu Gulo, am doing research with Dr Hendry van der Heever, a senior lecturer in the Department of Human Sciences, towards a PHD at the University of South Africa. We are inviting you to participate in a study entitled "Guidelines to Reduce Lost-to-Follow-Up Among Type-1 Diabetes Patients Attending Public Hospitals in Ethiopia: Patients and Healthcare workers in Focus".

The aim of the study is to explore the experiences of patients and health care workers on Type-1 Diabetes follow-up care and develop possible guidelines to improve the follow-up care services for Type-1 diabetes patients in Ethiopia.
Your region has been selected because of the presence of diabetes patients' follow-up care services in public hospitals.

The study will entail interviewing healthcare workers and patients to understand their experiences related to lost to follow-up among T1DM patients. The interview with health workers will be done in their workplace during off-hours. Patients will be interviewed in their homes. Each interview will take 30 to 60 minutes. Moreover, the research will entail collecting participants' profile data from the hospital OPD register. I kindly request permission to get access diabetes cohort registration book and patients' database.

The benefits of this study are to uncover the lived experience of T1D patients and health care workers on lost to follow-up and to come up with guidelines that would improve the follow-up care services utilisation. There are no foreseen potential risks for study participants.
The feedback procedure will entail the submission of a copy of the thesis to your organisation.

Yours sincerely, 
Berhanu Gulo Hawando, UNISA PhD student

If you have any questions or concerns about this study, please contact: Berhanu Gulo on +251911735578 or berhanugulo@gmail.com or Dr H van der Heever @vdheevh@unisa.ac.za
This study has been reviewed and approved by the Research Ethics Board of the University of South Africa (UNISA). Any complaints about the study can be directed CREC Chairperson-College Research Ethics Committee of UNISA- Prof KB Khan on 012 429 6549 or email address khankb@unisa.ac.za

Annexure F: Participants' information sheet in Phase 1

PARTICIPANT INFORMATION SHEET FOR PATIENTS INTERVIEW

Research Title: Guidelines for Lost-to-Follow-Up Type-1 Diabetes Patients at Public Hospitals in Ethiopia

Researcher: Berhanu Gulo Hawando

July 10, 2025

Dear Prospective Participant,

My name is Berhanu Gulo, and I am doing research with Dr Hendry van der Heever, a senior lecturer in the Department of Human Science, towards a PhD at the University of South Africa. We are inviting you to participate in a study entitled “Guidelines for Lost-to-Follow-up Type-1 Diabetes Patients at Public Hospitals in Ethiopia”.

WHAT IS THE PURPOSE OF THE STUDY?

This study is expected to collect information that could help to understand the experiences of patients and health care workers on Type-1 Diabetes follow-up care and develop possible guidelines to improve the follow-up care services for Type-1 diabetes patients in Ethiopia.

WHY AM I INVITED TO PARTICIPATE?

You were selected to participate because of you have been registered for diabetes follow-up care in Woliso/ Tulubolo hospital. Your contact details were obtained from the cohort registry of diabetes patients at the chronic care unit. The approximate number of participants for this study are 16.

WHAT IS THE NATURE OF MY PARTICIPATION IN THIS STUDY?

The study involves interviews with audio/video taping at their home. The interview guide to ask questions is attached to this document as a research instrument. The expected duration of participation and the time needed to complete the interview would be around 45 to 60 minutes.

CAN I WITHDRAW FROM THIS STUDY EVEN AFTER HAVING AGREED TO PARTICIPATE?

Participating in this study is fully voluntary, and there is no penalty or loss of benefit for non-participation. If you do decide to take part, you will be given this information sheet to keep and be asked to sign a written consent form. You are free to withdraw at any time and without giving a reason.

WHAT ARE THE POTENTIAL BENEFITS OF TAKING PART IN THIS STUDY?

The study participants will not benefit directly. However, the findings of this study will benefit the patients indirectly through the improvement of diabetes follow-up care services in public hospitals, which will maximise the benefit and minimise the harm for T1DM patients. There is no direct financial benefit to the participant.

ARE THEIR ANY NEGATIVE CONSEQUENCES FOR ME IF I PARTICIPATE IN THE RESEARCH PROJECT?

This interview might require you to commit your time. Otherwise, there are no foreseen negative consequences if you participate in this study.

WILL THE INFORMATION THAT I CONVEY TO THE RESEARCHER AND MY IDENTITY BE KEPT CONFIDENTIAL?

Your name will not be recorded anywhere, and no one will be able to connect you to the answers you give. Your answers will be given a code number or a pseudonym, and you will be referred to in this way in the data, any publications, or other research reporting methods, such as conference proceedings.

Your answers may be reviewed by people responsible for making sure that research is done properly, including the transcriber, external coder, and members of the Research Ethics Review Committee. Otherwise, records that identify you will be available only to people working on the study, unless you give permission for other people to see the records.

Please be informed that your anonymous data may be used for other purposes, such as a research report, journal articles and/or conference proceedings. A report of the study may be submitted for publication, but individual participants will not be identifiable in such a report.

HOW WILL THE RESEARCHER(S) PROTECT THE SECURITY OF DATA?

Hard copies of your answers will be stored by the researcher for a period of five years in a locked cupboard/filing cabinet in the researcher’s office for future research or academic

purposes. Electronic information will be stored on a password-protected computer. Future use of the stored data will be subject to further Research Ethics Review and approval if applicable. After five years, hard copies will be shredded and electronic copies will be permanently deleted from the hard drive of the computer through the use of a relevant software programme.

WILL I RECEIVE PAYMENT OR ANY INCENTIVES FOR PARTICIPATING IN THIS STUDY?

There will not be any financial reward offered for participating in this study.

HAS THE STUDY RECEIVED ETHICS APPROVAL?

This study has received written approval from the College Research Ethics Committee of Unisa. A copy of the approval letter can be obtained from the researcher if you so wish.

HOW WILL I BE INFORMED OF THE FINDINGS/RESULTS OF THE RESEARCH?

If you would like to be informed of the final research findings, please contact Berhanu Gulo on +251911735578 or berhanugulo@gmail.com. The findings are accessible for a period of 5 years.

Should you require any further information or want to contact the researcher about any aspect of this study, please contact Berhanu Gulo on +251911735578 or berhanugulo@gmail.com. If you have any ethical concerns, you can also contact the research ethics chairperson of Oromia Regional Health Bureau Mr Berhanu Kenate +251911043813, and the CREC Chairperson-College Research Ethics Committee of UNISA- Prof KB Khan, on 012 429 6549 or email address khankb@unisa.ac.za.

Thank you for taking the time to read this information sheet and for participating in this study.

Thank you



Berhanu Gulo

Annexure G: Participant's information sheet in Phase 2

PARTICIPANT INFORMATION SHEET_ FOR HEALTH CARE WORKERS IN-TERVIEW

Research Title: Guidelines for Lost-to-Follow-Up Type-1 Diabetes Patients at Public Hospitals in Ethiopia

Researcher: Berhanu Gulo Hawando

July 10, 2025

Dear Prospective Participant,

My name is Berhanu Gulo and I am doing research with Dr Hendry van der Heever- a senior lecturer in the department of human science towards a PhD at the University of South Africa. We are inviting you to participate in a study entitled “Guidelines for Lost-to-Follow-up Type-1 Diabetes Patients at Public Hospitals in Ethiopia”.

WHAT IS THE PURPOSE OF THE STUDY?

This study is expected to collect information that could help to understand the experiences of patients and health care workers on Type-1 Diabetes follow-up care and develop possible guidelines to improve the follow-up care services for Type-1 diabetes patients in Ethiopia.

WHY AM I INVITED TO PARTICIPATE?

You were selected to participate because of you have been involved in providing diabetes follow-up care services in Woliso/ Tulubolo hospital. Your contact details were obtained from the hospital human resource roster. The approximate number of health workers participate in this study are 5 from Tulubolo and Woliso hospitals.

WHAT IS THE NATURE OF MY PARTICIPATION IN THIS STUDY?

The study involves interviews with audio/video taping at their home. The interview guide to ask questions is attached on this document as research instruments. The expected duration of participation and the time needed to complete the interview would be around 45 to 60 minutes.

CAN I WITHDRAW FROM THIS STUDY EVEN AFTER HAVING AGREED TO PARTICIPATE?

Participating in this study is fully voluntary and that there is no penalty or loss of benefit for non-participation. If you do decide to take part, you will be given this information sheet to keep and be asked to sign a written consent form. You are free to withdraw at any time and without giving a reason.

WHAT ARE THE POTENTIAL BENEFITS OF TAKING PART IN THIS STUDY?

The study participants will not benefit directly. However, the findings of this study will benefit the patients to improvement of diabetes follow-up care services in public hospitals; which will maximize the benefit and minimize the harm for T1DM patients. There is no direct financial benefit to the participant.

ARE THEIR ANY NEGATIVE CONSEQUENCES FOR ME IF I PARTICIPATE IN THE RESEARCH PROJECT?

This interview might require you to commit your time. Otherwise, there are no foreseen negative consequences if you participate in this study.

WILL THE INFORMATION THAT I CONVEY TO THE RESEARCHER AND MY IDENTITY BE KEPT CONFIDENTIAL?

Your name will not be recorded anywhere and no one will be able to connect you to the answers you give. Your answers will be given a code number or a pseudonym and you will be referred to in this way in the data, any publications, or other research reporting methods such as conference proceedings.

Your answers may be reviewed by people responsible for making sure that research is done properly, including the transcriber, external coder, and members of the Research Ethics Review Committee. Otherwise, records that identify you will be available only to people working on the study, unless you give permission for other people to see the records.

Please be informed that your anonymous data may be used for other purposes, such as a research report, journal articles and/or conference proceedings. A report of the study may be submitted for publication, but individual participants will not be identifiable in such a report.

HOW WILL THE RESEARCHER(S) PROTECT THE SECURITY OF DATA?

Hard copies of your answers will be stored by the researcher for a period of five years in a locked cupboard/filing cabinet in the researchers' office for future research

or academic purposes. Electronic information will be stored on a password protected computer. Future use of the stored data will be subject to further Research Ethics Review and approval if applicable. After five years, hard copies will be shredded and electronic copies will be permanently deleted from the hard drive of the computer through the use of a relevant software programme.

WILL I RECEIVE PAYMENT OR ANY INCENTIVES FOR PARTICIPATING IN THIS STUDY?

There will not be any financial reward offered for participating in this study.

HAS THE STUDY RECEIVED ETHICS APPROVAL?

This study has received written approval from the College Research Ethics Committee of UNISA. A copy of the approval letter can be obtained from the researcher if you wis

HOW WILL I BE INFORMED OF THE FINDINGS/RESULTS OF THE RESEARCH?

If you would like to be informed of the final research findings, please contact Berhanu Gulo on +251911735578 or berhanugulo@gmail.com. The findings are accessible for a period of 5 years.

Should you require any further information or want to contact the researcher about any aspect of this study, please contact Berhanu Gulo on +251911735578 or berhanugulo@gmail.com. If you have any ethical concern, you can also contact the research ethics chairperson of Oromia Regional Health Bureau Mr Berhanu Kenate +251911043813, and the CREC Chairperson-College Research Ethics Committee of UNISA- Prof KB Khan on 012 429 6549 or email address khankb@unisa.ac.za

Thank you for taking time to read this information sheet and for participating in this study.

Thank you.
Berhanu Gulo

Annexure H: Participant Information Sheet in Phase 3

PARTICIPANT INFORMATION SHEET_ FOR EXPERTS OF GUIDELINE DEVELOPMEMT

Research Title: Guidelines for Lost-to-Follow-Up Type-1 Diabetes Patients at Public Hospitals in Ethiopia

Researcher: Berhanu Gulo Hawando

July 10, 2025

Dear Prospective Participant,

My name is Berhanu Gulo and I am doing research with Prof Lizeth Roets - a senior lecturer in the department of human science towards a PhD at the University of South Africa.

We would like to invite you to take part in a Focused Discussion for the validation of a guideline under the research entitled "*Guidelines for Lost-to-Follow-up Type-1 Diabetes Patients at Public Hospitals in Ethiopia"*. Before you make any decision regarding participation you need to understand why the research is being done and what it would involve for you. Please take time to read the following information carefully. If you have any further questions, please contact the researcher and the other contact details provided at the end of this leaflet.

WHAT IS THE PURPOSE OF THE STUDY?

This study is expected to collect information that could help to understand the experiences of patients and health care workers on lost-to-follow-up among Type-1 diabetes patients and develop possible guidelines to improve diabetes follow-up care services at public hospitals in Ethiopia.

WHY AM I INVITED TO PARTICIPATE?

You were selected to participate in the Focused Discussion because you have expertise in diabetes follow-up care. The number of participants for this Focused Discussion are six.

WHAT IS THE NATURE OF MY PARTICIPATION IN THIS STUDY?

The study involves Focused Discussion among a panel of experts for the validation of guideline on LTFU for T1D patients. The expected duration of the Focused Discussion would be around 4 to 6 hours.

CAN I WITHDRAW FROM THIS STUDY EVEN AFTER HAVING AGREED TO PARTICIPATE?

A decision to take part in this study is entirely voluntary and it is entirely your decision whether to take part or not. Any decision regarding your participation will be confidential

between you and the research team. You are also free to withdraw from the study at any time without any repercussions to yourself.

WHAT ARE THE POTENTIAL BENEFITS OF TAKING PART IN THIS STUDY?

We hope you will find the experience of taking part in the Focused Discussion interesting and useful. You will have the opportunity to receive feedback from the study team in a short report of the overall Focused Discussion findings if you wish to. To cover your transportation and meal expenses for the date you participated in the Focused Discussion, you will be getting a compensation of 1-day honorarium from the researcher.

ARE THEIR ANY NEGATIVE CONSEQUENCES FOR ME IF I PARTICIPATE IN THE RESEARCH PROJECT?

This Focused Discussion might require you to commit your time. Otherwise, there are no foreseen negative consequences if you participate in this study. We understand that there are many demands on your time and there is some inconvenience in taking part in the Focused Discussion. To arrange this, the Focused Discussion will be organised at a time which is convenient to you and is likely to take place during in weekend day. You are free at any stage to withdraw from the focus group or take time out if you wish. The Focused Discussion is designed to be a supportive environment and the facilitator is the researcher himself who is experienced in this methodological approach. Only those involved in program management, evaluation and guideline development will be present at the Focused Discussion.

WILL THE INFORMATION THAT I CONVEY TO THE RESEARCHER AND MY IDENTITY BE KEPT CONFIDENTIAL?

Since the FOCUSED DISCUSSION is an open discussion among panelists, any opinion shared by one member may be heard by others. Therefore, the researcher cannot guarantee the confidentiality of each participant's opinion during the discussion. However, all information you provide will be treated confidentially by the researcher in any publication. The researcher will take notes during the discussion but any information you give during the Focused Discussion will be fully anonymised and combined with the experiences of other Focused Discussion members who agree to participate. However, no individual Focused Discussion member will be identifiable at any stage in discussions, publication or presentation of the findings. Please be informed that your anonymous data may be used for other purposes, such as a research report, journal articles and/or conference proceedings. A report of the study may be submitted for publication, but individual participants will not be identifiable in such a report.

HOW WILL THE RESEARCHER(S) PROTECT THE SECURITY OF DATA?

Hard copies of your answers will be stored by the researcher for a period of five years in a locked cupboard/filing cabinet in the researchers' office for future research or academic

purposes. Electronic information will be stored on a password protected computer. Future use of the stored data will be subject to further Research Ethics Review and approval if applicable. After five years, hard copies will be shredded and electronic copies will be permanently deleted from the hard drive of the computer through the use of a relevant software programme.

WILL I RECEIVE PAYMENT OR ANY INCENTIVES FOR PARTICIPATING IN THIS STUDY?

There will not be any financial reward offered for participating in this study.

HAS THE STUDY RECEIVED ETHICS APPROVAL?

This study has received written approval from the College Research Ethics Committee of UNISA and the IRB of Oromia Regional Health Bureau A copy of the approval letter can be obtained from the researcher if you so wish.

HOW WILL I BE INFORMED OF THE FINDINGS/RESULTS OF THE RESEARCH?

If you would like to be informed of the final research findings, please contact Berhanu Gulo on +251911735578 or berhanugulo@gmail.com. The findings are accessible for a period of 5 years.

Should you require any further information or want to contact the researcher about any aspect of this study, please contact Berhanu Gulo on +251911735578 or berhanugulo@gmail.com. If you have any ethical concern, you can also contact the research ethics chairperson of Oromia Regional Health Bureau Mr Berhanu Kenate +251911043813, and the CREC Chairperson-College Research Ethics Committee of UNISA- Prof KB Khan on 012 429 6549 or email address khankb@unisa.ac.za.

Thank you for taking time to read this information sheet and for participating in this study.

Thank you.



Berhanu Gulo

Annexure I: Participant Information Sheet in Phase 4

PARTICIPANT INFORMATION SHEET_ FOR EXPERTS OF GUIDELINE VALIDATION

Research Title: Guidelines for Lost-to-Follow-Up Type-1 Diabetes Patients at Public Hospitals in Ethiopia

Researcher: Berhanu Gulo Hawando

August 01, 2025

Dear Prospective Participant,

My name is Berhanu Gulo and I am doing research with Prof Lizeth Roets - a senior lecturer in the department of human science towards a PhD at the University of South Africa.

We would like to invite you to take part in a Structured Consensus Development Meeting (SCDM) for the validation of a guideline under the research entitled "*Guidelines for Lost-to-Follow-up Type-1 Diabetes Patients at Public Hospitals in Ethiopia"*. Before you make any decision regarding participation you need to understand why the research is being done and what it would involve for you. Please take time to read the following information carefully. If you have any further questions, please contact the researcher and the other contact details provided at the end of this leaflet.

WHAT IS THE PURPOSE OF THE STUDY?

This study is expected to collect information that could help to understand the experiences of patients and health care workers on lost-to-follow-up among Type-1 diabetes patients and develop possible guidelines to improve diabetes follow-up care services at public hospitals in Ethiopia.

WHY AM I INVITED TO PARTICIPATE?

You were selected to participate in the SCDM because you have expertise in diabetes follow-up care and experience on guideline development and validation. The number of participants for this SCDM are 10.

WHAT IS THE NATURE OF MY PARTICIPATION IN THIS STUDY?

The study involves SCDM among a panel of experts for the validation of guideline on LTFU for T1D patients. The expected duration of the SCDM would be around 4 to 6 hours.

CAN I WITHDRAW FROM THIS STUDY EVEN AFTER HAVING AGREED TO PARTICIPATE?

A decision to take part in this study is entirely voluntary and it is entirely your decision whether to take part or not. Any decision regarding your participation will be confidential between you and the research team. You are also free to withdraw from the study at any time without any repercussions to yourself.

WHAT ARE THE POTENTIAL BENEFITS OF TAKING PART IN THIS STUDY?

We hope you will find the experience of taking part in the SCDM interesting and useful. You will have the opportunity to receive feedback from the study team in a short report of the overall SCDM findings if you wish to. To cover your transportation and meal expenses for the date you participated in the SCDM, you will be getting a compensation of 1-day honorarium from the researcher.

ARE THEIR ANY NEGATIVE CONSEQUENCES FOR ME IF I PARTICIPATE IN THE RESEARCH PROJECT?

This SCDM might require you to commit your time. Otherwise, there are no foreseen negative consequences if you participate in this study. We understand that there are many demands on your time and there is some inconvenience in taking part in the SCDM. To arrange this, the SCDM will be organised at a time which is convenient to you and is likely to take place during in weekend day. You are free at any stage to withdraw from the focus group or take time out if you wish. The SCDM is designed to be a supportive environment and the facilitator is the researcher himself who is experienced in this methodological approach. Only those involved in program management, evaluation and guideline development will be present at the SCDM.

WILL THE INFORMATION THAT I CONVEY TO THE RESEARCHER AND MY IDENTITY BE KEPT CONFIDENTIAL?

Since the SCDM is an open discussion among panelists, any opinion shared by one member may be heard by others. Therefore, the researcher cannot guarantee the confidentiality of each participant’s opinion during the discussion. However, all information you provide will

be treated confidentially by the researcher in any publication. The researcher will take notes during the discussion but any information you give during the SCDM will be fully anonymised and combined with the experiences of other SCDM members who agree to participate. However, no individual SCDM member will be identifiable at any stage in discussions, publication or presentation of the findings. Please be informed that your anonymous data may be used for other purposes, such as a research report, journal articles and/or conference proceedings. A report of the study may be submitted for publication, but individual participants will not be identifiable in such a report.

HOW WILL THE RESEARCHER(S) PROTECT THE SECURITY OF DATA?

Hard copies of your answers will be stored by the researcher for a period of five years in a locked cupboard/filing cabinet in the researchers' office for future research or academic purposes. Electronic information will be stored on a password protected computer. Future use of the stored data will be subject to further Research Ethics Review and approval if applicable. After five years, hard copies will be shredded and electronic copies will be permanently deleted from the hard drive of the computer through the use of a relevant software programme.

WILL I RECEIVE PAYMENT OR ANY INCENTIVES FOR PARTICIPATING IN THIS STUDY?

There will not be any financial reward offered for participating in this study.

HAS THE STUDY RECEIVED ETHICS APPROVAL?

This study has received written approval from the College Research Ethics Committee of UNISA and the IRB of Oromia Regional Health Bureau A copy of the approval letter can be obtained from the researcher if you so wish.

HOW WILL I BE INFORMED OF THE FINDINGS/RESULTS OF THE RESEARCH?

If you would like to be informed of the final research findings, please contact Berhanu Gulo on +251911735578 or berhanugulo@gmail.com. The findings are accessible for a period of 5 years.

Should you require any further information or want to contact the researcher about any aspect of this study, please contact Berhanu Gulo on +251911735578 or berhanu-gulo@gmail.com. If you have any ethical concern, you can also contact the research ethics chairperson of Oromia Regional Health Bureau Mr Berhanu Kenate +251911043813, and the CREC Chairperson-College Research Ethics Committee of UNISA- Prof KB Khan on 012 429 6549 or email address khankb@unisa.ac.za.

Thank you for taking time to read this information sheet and for participating in this study.

Thank you.

 Berhanu Gulo

See the detail information about the SCDM process in the next page

Structured Consensus Development Meeting (SCDM) Overview

This information sheet provides a brief overview of SCDM. The sessions are designed to ensure that the guideline development process is transparent, participatory, and evidence-informed.

Session 1: Presentation of Draft Guidelines

- Presentation of the brief overview of the guideline development process by the researcher
- The consensus methodology will be explained by the session facilitator, including the scoring system, consensus thresholds, and the rules for discussion and voting.

Session 2: Presentation of Draft Guidelines

- The researcher will present the proposed actions to implementation organized into thematic areas
- For each recommendation, the empirical rationale and supporting evidence will be explained.
- The facilitator will present aggregated scores from the pre-meeting validation tool
- This session focuses on familiarization and clarification of content, not debate.

Session 3: Facilitated Discussion

- Structured discussion will be held for each recommendation, with equal opportunity for all panellists to contribute (round-robin technique).
- Facilitator ensures respectful participation, probes for clarity, and manages power dynamics.
- Focus will be on divergent scores, evidence gaps, clarity, feasibility, and contextual appropriateness.

Session 4: Post-Discussion Re-Scoring

- After discussion, participants will rescore each recommendation using a 9-point Likert scale (1= not appropriate, 9 = highly appropriate).
- The decision rules apply based on the predefined consensus criteria. Accordingly, the proposed actions to implement will be accepted, revised, or removed based on these results.

Annexure J: Participant's Invitation Letter in Phase 4

Subject: Invitation to participate in Structured Consensus Development Meeting (SCDM) on the Guideline Validation for Lost to Follow-up Type-1 Diabetes Patients

Dear Sir/Madam,

I hope this email finds you well.

My name is Berhanu Gulo Hawando, a PHD student at University of South Africa (UNISA). I am pleased to invite you to participate as a panellist in a SCDM on the validation of the guideline on lost-to-follow-up (LTFU) type-1 diabetes patients. This SCDM will present the preliminary guidelines, which have been developed based on the findings of a study entitled "*Guidelines for Lost-to-follow-up Type-1 Diabetes Patients at Public Hospitals in Ethiopia"*. The study was conducted as part of the requirements for a PhD in Public Health at UNISA, under the supervision of Dr Hendry van der Heever and Prof. Lizeth Roets.

Given your demonstrated expertise in diabetes care, clinical practice, public health, and health systems. I highly value your insights and contributions to this discussion.

Date and time: July 15, 2025 11am to 8:30 am
Venue: The Hub Hotel, Addis Ababa Ethiopia

Kindly confirm your availability at your earliest convenience.

I appreciate your time and look forward to your participation.

Kind regards,



Berhanu Gulo Hawando
Email: berhanugulo@gmail.com
Cell phone: +251911735578
skype: berhanu.gulo2

Annexure K: Participant's Invitation Letter in Phase 3

Subject: Invitation to participate in Focused Discussion on the guidelines for lost-to-follow-up type-1 diabetes patients

Dear Sir/Madam,

I hope this email finds you well.

My name is Berhanu Gulo Hawando, a PHD student at University of South Africa (UNISA). I am pleased to invite you to participate as a panellist in a focusd discussion on the development of the guideline on lost-to-follow-up (LTFU) type-1 diabetes care. This discussion will present the preliminary guidelines, which have been developed based on the findings of a study entitled "*Guidelines for Lost-to-follow-up Type-1 Diabetes Patients at Public Hospitals in Ethiopia"*. The study was conducted as part of the requirements for a PhD in Public Health at UNISA, under the supervision of Dr Hendry van der Heever and Prof. Lizeth Roets.

Given your expertise and experience as a service provider and/or professional in the field of type-1 diabetes follow-up care, I highly value your insights and contributions to this discussion.

Date and time: Tuesday, February 25, 2025 11am to 12:30pm
Venue: Public Health Meeting Hall of Woliso St Luke Hospital.

Kindly confirm your availability at your earliest convenience.

I appreciate your time and look forward to your participation.

Kind regards,



Berhanu Gulo Hawando
Email: berhanugulo@gmail.com
Cell phone: +251911735578
skype: berhanu.gulo2

Annexure L: Consent form for Phase 1 and 2 Participants

CONSENT TO PARTICIPATE IN THIS STUDY_ INTERVIEW

Research Title: Guidelines for Lost-to-Follow-Up Type-1 Diabetes Patients at Public Hospitals in Ethiopia

Researcher: Berhanu Gulo Hawando

I, _____, confirm that the person asking my consent to take part in this research has told me about the nature, procedure, potential benefits and anticipated inconvenience of participation.

I have read (or had explained to me) and understood the study as explained in the information sheet.

I have had sufficient opportunity to ask questions and am prepared to participate in the study.

I understand that my participation is voluntary and that I am free to withdraw at any time without penalty (if applicable).

I am aware that the findings of this study will be processed into a research report, journal publications and/or conference proceedings, but that my participation will be kept confidential unless otherwise specified.

I agree to the recording of the interview.

I have received a signed copy of the informed consent agreement.
Participant Name & Surname……
Participant Signature……..Date……
Researcher's Name & Surname ……
Researcher's signature……...Date……

Annexure M: Consent form in Phase 3 (Focused Discussion)

CONSENT TO PARTICIPATE IN THIS STUDY_ FOCUSED DISCUSSION

Research Title: Guidelines for Lost-to-Follow-Up Type-1 Diabetes Patients at Public Hospitals in Ethiopia
Researcher: Berhanu Gulo Hawando

I, _____ (*participant name*), confirm that the person asking my consent to take part in the focused discussion of the above mentioned research has told me about the nature, procedure, potential benefits and anticipated inconvenience of participation.

- I confirm that I have read and understood the information above.
- I understand that my participation is voluntary and that I am free to withdraw from the project at any time, without having to give a reason and without any consequences.
- I understand that the focus discussion data will remain confidential.
- I understand that my anonymised words may be used in reports and other publications.
- I consent to being a participant in the project.
- I consent to the focused discussion being audio recorded as part of the project.
- I have received a signed copy of the informed consent agreement.

Participant Name & Surname……
Participant Signature……..Date……
Researcher's Name & Surname ……
Researcher's signature……..Date……

Annexure N: Consent form in Phase 4 (SCDM)

CONSENT TO PARTICIPATE IN THIS STUDY_ SCDM

Research Title: Guidelines for Lost-to-Follow-Up Type-1 Diabetes Patients at Public Hospitals in Ethiopia

Researcher: Berhanu Gulo Hawando

I, _____ (*participant name*), confirm that the person asking my consent to take part in the Structured Consensus Development Meeting of the guideline validation has told me about the nature, procedure, potential benefits and anticipated inconvenience of participation.

- I confirm that I have read and understood the information above.
- I understand that my participation is voluntary and that I am free to withdraw from the project at any time, without having to give a reason and without any consequences.
- I understand that the focus discussion data will remain confidential.
- I understand that my anonymised words may be used in reports and other publications.
- I consent to being a participant in the project.
- I consent to the focused discussion being audio recorded as part of the project.
- I have received a signed copy of the informed consent agreement.

Participant Name & Surname……

Participant Signature……..Date……

Researcher's Name & Surname ……

Researcher's signature……..Date……

Annexure O: Consent Forms of Assistant Researcher

Data collector Confidentiality Agreement

Research title: ***Guidelines for Lost-to-Follow-up Type-1 Diabetes Patients at Public Hospitals in Ethiopia***.

This study is being undertaken by Berhanu Gulo (the researcher) and Dr Hendry van der Heever (a senior lecturer in the department of human science towards a PhD at the University of South Africa).

The study is expected to collect information that could help to understand the experiences of patients and health care workers on diabetes lost-to-follow-up care, and develop possible guidelines to improve the follow-up care services for Type-1 diabetes patients in Ethiopia.

The study involves data collection from T1DM patients who missed follow-up visit at list 6 months, and health care workers involved in the diabetes follow-up care services in study sites. The data will be collected through in-depth interview and FGD. The final report on the research will be presented to UNISA, and the results may be written up for publication or conference presentations.

I, _____, the data collector, agree to:

- keep all the research data collected confidential by not discussing or the research information in any form or format (e.g., paper, disks, tapes,) with anyone other than the researcher.
- keep all research information in any form or format (e.g., paper, disks, tapes, transcripts) secure although it is in my possession.
- Handover all the collected data in any form or format (e.g., paper, disks, tapes) to the researcher when I have completed the data collection tasks.
- after consulting with the researcher, erase or destroy all the data in any form or format (e.g., information stored on audio recorder or hard drive).

Translator: Name _____ Signature _____ Date _____

Researcher: Name _____ Signature _____ Date _____

If you have any questions or concerns about this study, please contact: Berhanu Gulo on +251911735578 or berhanugulo@gmail.com.

This study has been reviewed and approved by the Research Ethics Board of the University of South Africa (UNISA). Any complaints about the study can be directed CREC Chairperson-College Research Ethics Committee of UNISA- Prof KB Khan on 012 429 6549 or email address khankb@unisa.ac.za.

Annexure P: Data Collection Tool in Phase 1

<table>
<tr><td colspan="2"><u>Annexure 7.1</u>: Semi-structured interview guide for T1DM patient who missed to visit diabetic clinic in the past 6 month</td></tr>
<tr><td colspan="2">

Date of interview: _____ Start time: ___: ____Adjourned: ____: _____
Place of interview: _____
Name of the interviewer: _____
Name of note taker: _____
Participant code: _____
Address: (Region/Zone/Woreda/Kebele): _____
Age: _____ Religion: _____ Marital status: _____
Are you employed? (Yes/No)
Educational level: _____
Where did you receive diabetes follow-up care service? (Name of the HF)
When did you visit your last follow-up visit? _____

Major question to be asked: “Describe your experiences and views about diabetic follow-up care services” (Note: the interview guide is grouped by the HBM constructs)
</td></tr>
<tr><td>HBM con-structs</td><td>Question</td></tr>
<tr><td rowspan="3">Perceived susceptibility</td><td>How would you describe your health status?</td></tr>
<tr><td>How do you think about the risks of diabetes complications? (Note to the interviewer: Please consider to probe e.g. Low blood sugar, High blood sugar, Foot infection, Eye problems, Cardiovascular risk, Blood pressure problems, Cholesterol problems, Kidney disease)</td></tr>
<tr><td>How did your health status influence your decision not to attend the follow-up care offered at the hospital?</td></tr>
<tr><td rowspan="2">Perceived severity</td><td>What did you feel might be some of the consequences of not attending in the follow-up care?</td></tr>
<tr><td>What do you think your risk for getting long-term and short-term diabetes complications? (Note to the interviewer: probe the above diabetic complications</td></tr>
<tr><td rowspan="3">Perceived benefits</td><td>What would you consider to be the benefits of attending the follow-up care services like the one offered at the hospital?</td></tr>
<tr><td>What is your understanding of diabetic follow-up care services provided in health facilities? What are the services that should be given for the diabetic patients during follow-up visits?</td></tr>
<tr><td>How do you evaluate the quality of care you received from the health care workers before you interrupt the attendance?</td></tr>
</table>

Perceived barriers	What kept you from attending the follow-up care services offered at the hospital?
	In your opinion what are the reasons for a T1 diabetic patient not to utilise follow-up care services?
Cues to action	What might make you more likely to attend a follow-up care visit in the future?
	Do you think you might need help with making these changes?
Self-efficacy	How confident do you feel in your ability to take the recommended follow-up care services?
Is there anything else you would like to tell me? **Thank you for your participation!!**	

Annexure Q: Data Collection Tool in Phase 2

Annexure 7.2: Semi-structured interview guide for health care providers, and Diabetes care program coordinators at District Health Office, Zonal Health Department and Regional Health Bureau

- Name of District: _____
- Name of Health Facility: _____
- Name of Interviewer: _____
- Date of interview: _____ Start time: ___: ____Adjourned: ____: _____
- Place of interview: _____
- Participant code: _____
- Address (Region/Zone/Woreda/Kebele): _____
- Age: _____ Sex: _____ Religion: _____ Marital status: _____
- Educational level: _____
- Profession: _____ Job position: _____
- Type of institution working: _____

1st question to be asked: “Describe the experiences of offering diabetes follow-up care service in this hospital”

Interview guides:

- How is the follow-up care services utilisation among T1D patients in your community?
- What do you think about the T1D follow-up care being provided in health facilities?
- What are the benefits of follow-up care services for T1D patients?
- What are the problems in offering diabetes follow-up care services?
- What guidelines you are currently using to improve diabetes follow-up care services utilisation among T1D patients?
- What guidelines do you suggest to be put in place to improve utilisation of follow-up care services?

2nd question to be asked: “Describe the experiences of LTFU among T1D patients in this hospital”

Interview guides:

- How is LTFU among T1D patients in your community?
- What do you think about the effort to reduce LTFU of T1D patients?
- What are the reasons for LTFU among T1DM patients?
- Tell me the existing structure to track the patients lost to follow up

- Based on your experience, what are the problems that happen for defaulters?
- What guideline you are currently implementing to reduce LTFU among T1D patients?
- What guideline do you suggest to be put in place to reduce LTFU among T1D patients?

If you have any questions or concerns about this study, please contact: Berhanu Gulo on +251911735578 or berhanugulo@gmail.com.

This study has been reviewed and approved by the Research Ethics Board of the University of South Africa (UNISA). Any complaints about the study can be directed CREC Chairperson-College Research Ethics Committee of UNISA- Prof KB Khan on 012 429 6549 or email address khankb@unisa.ac.za.

Thank you for your participation!!

Annexure R: Data collection and evaluation tool in Phase 4 (SCDM)

I. Information Sheet

Instructions: Panelists should rate each question from 1 to 9 and enter the scores in the corresponding cells.

1=Strongly Disagree, 2=Disagree, 3=Somewhat Disagree, 4=Disagree Slightly, 5=Undecided, 6=Agree Slightly, 7=Somewhat Agree, 8=Agree, 9=Strongly Agree

The following five parameters should be taken in to consideration when rating the recommendations:

- **Relevance and Need for the Guideline:** Assesses how important and timely the guideline is in addressing a clearly identified health issue or service gap.
- **Evidence Base and Content Quality:** Evaluates the extent to which the recommendation is supported by credible, up-to-date evidence and is scientifically sound.
- **Clarity and Usability:** Examines whether the recommendation is clearly written, well-structured, and easy to understand and apply in practice.
- **Feasibility and Implementation:** Considers how practical and achievable the recommendation is within the existing resources, systems, and context.
- **Inclusiveness and Ethical Considerations:** Reflects how well the recommendation accounts for diverse populations, promotes equity, and aligns with ethical standards.

Guideline 1: Type-1 Diabetes Patients' Education and Awareness

Purpose: Implementing the proposed actions informed by participants' experience will help create a robust guideline for diabetes patient education, empowering patients with the knowledge and skills necessary for effective self-management. By focusing on structured education, family involvement, accessibility, healthcare worker training, and continuous evaluation, healthcare systems can significantly improve patient outcomes in diabetes management.

Item No.	Evaluation Question	Score (1-9)
Domain 1: Develop Structured Educational and Sensitization Programs		
1	***Create a Comprehensive Curriculum***: Design structured educational programs that cover various aspects of diabetes management, including medication adherence, dietary recommendations, physical activity, and monitoring blood sugar levels. This curriculum	

	should be tailored to meet the needs of different patient demographics.	
2	***Incorporate Interactive Learning***: Utilize interactive teaching methods, such as group discussions, and hands-on demonstrations, to engage patients actively in their learning process. This can enhance the retention and application of knowledge.	
3	***Regular Reminders and Encouragement:*** Implement systematic reminder systems where healthcare workers actively encourage patients to attend follow-up visits. Direct communication from health workers has been shown to significantly motivate patients.	
Domain Average Score		
Comment: _____		
Domain 2: Involve Family Members in Education		
1	***Family-Centric Educational Initiatives:*** Develop programs that include family members in the education process, recognizing their role in supporting patients' adherence to dietary and lifestyle changes. This can help reinforce healthy behaviours at home, and patients' decisions to attend appointments.	
2	***Provide Resources for Families:*** Create educational materials specifically designed for family members to help them understand diabetes management and how they can support their loved ones.	
Domain Average Score		
Comment: _____		
Domain 3: Ensure Accessibility of Educational Materials		
1	***Develop Multilingual Resources:*** Provide educational materials in multiple languages and formats that are easily understandable for all patients. This includes brochures, videos, and online resources that cater to different literacy levels.	
2	***Utilize Local Context:*** Ensure that educational materials are culturally relevant and consider local dietary practices and beliefs. This can enhance the effectiveness of the education provided.	
Domain Average Score		
Comment: _____		

Domain 4: Train Healthcare Workers on Patient Education		
1	***Implement Training Programs for Health Workers:*** Provide comprehensive training for healthcare workers on effective patient education techniques, focusing on communication skills, empathy, and the importance of patient engagement.	
2	***Cultural Sensitivity Training:*** Provide cultural sensitivity training for healthcare workers to better understand and address the cultural beliefs that may discourage patients from seeking follow-up care.	
Domain Average Score		
Comment: _____		
Domain 5: Foster a Supportive Environment		
1	***Create Support Groups:*** Establish support groups for patients to share experiences and challenges in managing diabetes. This can provide emotional support and reinforce the education received.	
2	***Community Support Programs:*** Develop community programs that foster social support networks, allowing patients to share experiences and encourage each other to prioritize follow-up care.	
3	***Encourage Community Involvement:*** Collaborate with local organizations and diabetes associations to enhance educational outreach and provide additional resources for patients.	
Domain Average Score		
Comment: _____		
Domain 6: Increase Awareness of Health Risks and Benefits of Follow-up Care		
1	***Educational Initiatives:*** Awareness of health risks can serve as a powerful motivator for patients. Implement educational programs that inform patients about the potential complications of diabetes and the importance of regular follow-up care.	
2	***Utilize Testimonials:*** Share success stories from other patients who have benefited from regular follow-up care to inspire and motivate others.	
3	***Highlight Positive Outcomes:*** Clearly communicate the benefits of regular follow-up care, such as better management of diabetes	

	and prevention of complications. This can be done through brochures, workshops, and community health events.	
4	***Combat Complacency***: Develop targeted interventions to address complacency among patients regarding their health. This can include motivational interviewing techniques to help patients recognize the importance of ongoing care.	
Domain Average Score		
Comment: _____		
Domain 7: Leverage Community Health Education Initiatives		
1	***Engage in Community Programs:*** Collaborate with local health organizations to create community health initiatives that promote diabetes awareness and the importance of follow-up care.	
2	***Utilize Mass Media:*** Use mass media campaigns to raise awareness about diabetes management and the importance of follow-up visits, targeting both patients and their families.	
3	***Incorporate Visual Aids:*** Use visual aids and infographics to illustrate the benefits of follow-up care, making the information more accessible and engaging for patients.	
Domain Average Score		
Comment: _____		
Domain 8: Monitor and Evaluate Educational Effectiveness		
1	***Establish Feedback Mechanisms:*** Create systems for patients to provide feedback on the educational programs they receive. This can help identify areas for improvement and ensure that the education provided meets patients' needs.	
2	***Conduct Regular Assessments:*** Implement regular assessments to evaluate the effectiveness of educational initiatives in improving patient knowledge and self-management skills. This can include pre- and post-education surveys to measure changes in understanding.	
Domain Average Score		
Comment: _____		

Annexure S: Preliminary Draft Guidelines on LTFU T1D Patients

Guideline for Diabetes Patient Education and Awareness Creation

Based on the findings from the study, the following are the recommendations for implementing diabetes patient education:

9. Develop Structured Educational and Sensitization Programs

- ***Create a Comprehensive Curriculum***: Design structured educational programs that cover various aspects of diabetes management, including medication adherence, dietary recommendations, physical activity, and monitoring blood sugar levels. This curriculum should be tailored to meet the needs of different patient demographics.
- ***Incorporate Interactive Learning***: Utilize interactive teaching methods, such as group discussions, and hands-on demonstrations, to engage patients actively in their learning process. This can enhance the retention and application of knowledge.
- ***Regular Reminders and Encouragement:*** Implement systematic reminder systems where healthcare workers actively encourage patients to attend follow-up visits. Direct communication from health workers has been shown to significantly motivate patients.

10. Involve Family Members in Education

- ***Family-Centric Educational Initiatives:*** Develop programs that include family members in the education process, recognizing their role in supporting patients' adherence to dietary and lifestyle changes. This can help reinforce healthy behaviours at home. Moreover, family support has been identified as a critical factor influencing patients' decisions to attend appointments.
- ***Provide Resources for Families:*** Create educational materials specifically designed for family members to help them understand diabetes management and how they can support their loved ones.

11. Ensure Accessibility of Educational Materials

- ***Develop Multilingual Resources:*** Provide educational materials in multiple languages and formats that are easily understandable for all patients. This includes brochures, videos, and online resources that cater to different literacy levels.
- ***Utilize Local Context:*** Ensure that educational materials are culturally relevant and consider local dietary practices and beliefs. This can enhance the effectiveness of the education provided.

12. Train Healthcare Workers on Patient Education

- ***Implement Training Programs for Health Workers:*** Provide comprehensive training for healthcare workers on effective patient education techniques, focusing on communication skills, empathy, and the importance of patient engagement.
- ***Cultural Sensitivity Training:*** Provide cultural sensitivity training for healthcare workers to better understand and address the cultural beliefs that may discourage patients from seeking follow-up care.

13. Foster a Supportive Environment

- ***Create Support Groups:*** Establish support groups for patients to share experiences and challenges in managing diabetes. This can provide emotional support and reinforce the education received.
- ***Community Support Programs:*** Develop community programs that foster social support networks, allowing patients to share experiences and encourage each other to prioritize follow-up care.
- ***Encourage Community Involvement:*** Collaborate with local organizations and diabetes associations to enhance educational outreach and provide additional resources for patients.

14. Increase Awareness of Health Risks and Benefits of Follow-up Care

- ***Educational Initiatives:*** Awareness of health risks can serve as a powerful motivator for patients. Implement educational programs that inform patients about the potential complications of diabetes and the importance of regular follow-up care.

- ***Utilize Testimonials:*** Share success stories from other patients who have benefited from regular follow-up care to inspire and motivate others.
- ***Highlight Positive Outcomes:*** Clearly communicate the benefits of regular follow-up care, such as better management of diabetes and prevention of complications. This can be done through brochures, workshops, and community health events.
- ***Combat Complacency***: Develop targeted interventions to address complacency among patients regarding their health. This can include motivational interviewing techniques to help patients recognize the importance of ongoing care.

15. Leverage Community Health Education Initiatives

- ***Engage in Community Programs:*** Collaborate with local health organizations to create community health initiatives that promote diabetes awareness and the importance of follow-up care.
- ***Utilize Mass Media:*** Use mass media campaigns to raise awareness about diabetes management and the importance of follow-up visits, targeting both patients and their families.
- ***Incorporate Visual Aids:*** Use visual aids and infographics to illustrate the benefits of follow-up care, making the information more accessible and engaging for patients.

16. Monitor and Evaluate Educational Effectiveness

- ***Establish Feedback Mechanisms:*** Create systems for patients to provide feedback on the educational programs they receive. This can help identify areas for improvement and ensure that the education provided meets patients' needs.
- ***Conduct Regular Assessments:*** Implement regular assessments to evaluate the effectiveness of educational initiatives in improving patient knowledge and self-management skills. This can include pre- and post-education surveys to measure changes in understanding.

Implementing these recommendations will help create a robust guideline for diabetes patient education, empowering patients with the knowledge and skills necessary for effective self-management. By focusing on structured education, family involvement, accessibility, healthcare worker training, and continuous evaluation, healthcare systems can significantly improve patient outcomes in diabetes management.

Guideline on Financial Support to Diabetes Patients

Based on the findings from the study, the following are the recommendations for implementing a Guideline for Financial Support to Diabetes Patients:

1. **Establish Financial Assistance Programs**
    - ***Collaborate with Local Organizations:*** Develop partnerships with local organizations, such as diabetes associations, to create a support network for patients. This collaboration can help provide financial assistance for medications and follow-up care.
    - ***Create Awareness of Available Resources***: Ensure that patients are informed about the financial assistance programs available to them through community organizations. This can be achieved through educational campaigns.
    - ***Sliding Scale Fees:*** Implement sliding scale fees for patients based on their income, ensuring that those without adequate insurance can still access necessary care.
    - ***Direct Cash and Voucher Assistance Programs:*** Establish direct cash and voucher assistance programs specifically for diabetes patients who face unexpected medical expenses and transportation costs.
2. **Implement Affordable Healthcare Services**
    - ***Reduce Service Fees:*** Advocate for the reduction of service fees associated with diabetes care to make healthcare more accessible for patients. This can

help alleviate the financial burden that often prevents patients from seeking necessary treatment.

- ***Integrate Affordable Services into Healthcare Systems****:* Work towards integrating affordable healthcare services into existing healthcare systems to ensure that patients can access the care they need without financial strain.

3. Enhance Insurance Coverage

- ***Expand Insurance Coverage Options:***
  - ✓ Advocate for policies that expand eligibility for insurance coverage to include more individuals, particularly those with low income or those who are currently uninsured.
  - ✓ Develop insurance plans that cover a wider range of diabetes-related services, including medications, regular check-ups, and necessary diagnostic tests.
- ***Increase Awareness of Insurance Benefits:***
  - ✓ Implement educational campaigns to inform patients about the benefits of insurance coverage and how to navigate the enrollment process. Many patients expressed a lack of knowledge regarding available insurance options.
  - ✓ Organize community workshops that provide information on how to apply for insurance and the specific benefits that come with coverage for diabetes management.
- ***Advocate for Policy Changes:***
  - ✓ Lobby for legislative support and work with policymakers to advocate for changes in legislation that would require insurance companies to cover essential diabetes care services.
  - ✓ Collaborate with non-profit organizations that focus on diabetes care to push for systemic changes in insurance coverage policies.

4. Monitor and Evaluate Financial Support Programs

- ***Establish Monitoring Mechanisms:*** Implement systematic approaches to assess the effectiveness of financial support programs. This includes tracking patient outcomes and adherence to treatment plans.
- ***Data Collection:*** Collect data on the impact of insurance coverage on patient outcomes, including adherence to treatment and health complications. This data can be used to advocate for further improvements in insurance policies.
- ***Incorporate Feedback Loops:*** Create feedback mechanisms for patients to share their experiences with financial support programs. This can help identify areas for improvement and ensure that the programs meet patients' needs.

By establishing community-based financial assistance programs, implementing affordable healthcare services, expanding insurance coverage, addressing transportation barriers, and monitoring the effectiveness of these initiatives, healthcare systems can significantly alleviate the financial burdens faced by diabetes patients. These recommendations are essential for enhancing access to necessary treatments and improving health outcomes for individuals managing diabetes.

Guideline to Improve Patients' Satisfaction with the Services

Based on the study, the following are the key recommendations to improve the satisfaction of the patients with the service:

1. **Reduce Waiting Times**
    - ***Streamline Processes****:* Implement strategies to reduce waiting times for patients, such as optimizing scheduling and workersing during peak hours. This can help alleviate the frustration expressed by patients regarding long wait times for blood sugar tests and consultations.

- ***Establish Fast-Track Services**:* Consider creating a fast-track service for routine procedures like blood sugar testing, which can help patients who need to return to work or have other commitments.

2. Improve Medication Availability

- ***Ensure Consistent Stock**:* Work on improving the supply chain for essential medications, particularly insulin, to prevent stock-outs that force patients to seek expensive alternatives.
- ***Patient Education on Alternatives**:* Educate patients about alternative options and resources available in case of medication shortages, ensuring they are aware of where to find necessary medications.

3. Enhance Quality of Care

- ***Comprehensive Care Approach**:* Shift the focus from merely providing medications to offering a holistic approach that includes dietary counselling, lifestyle modifications, and psychological support.
- ***Training for Healthcare workers**:* Provide ongoing training for healthcare workers to enhance their communication skills and ability to deliver compassionate care, which patients have expressed as a significant need.

4. Improve Communication and Patient Engagement

- ***Regular Follow-Up Reminders**:* Implement a reminder system (e.g., SMS, phone calls) to encourage patients to attend follow-up appointments and understand the importance of these visits.
- Patient Feedback Mechanisms: Establish channels for patients to provide feedback on their experiences with the services, which can help identify areas for improvement and enhance patient satisfaction.

5. Foster a Supportive Environment

- ***Family Involvement**:* Encourage family members to participate in educational sessions and follow-up visits, as their support can significantly influence patients' adherence to care.

- ***Community Engagement****:* Collaborate with community organizations to provide additional support and resources for patients, helping to create a more supportive environment for diabetes management.

6. **Address Emotional and Psychological Needs**
   - ***Emotional Support Services***: Provide access to counselling and support groups for patients to address the emotional toll of managing diabetes, which can enhance their overall satisfaction with care.
   - ***Compassionate Care Training***: Train healthcare workers to deliver care with empathy and understanding, as patients have expressed a desire for more compassionate interactions.

By implementing these recommendations, healthcare workers can significantly enhance patient satisfaction with the services offered, leading to better health outcomes and increased adherence to follow-up care.

Guideline to Enhance Family Support

The study reveals the critical role that various forms of support play in managing the condition and attending follow-up care. Develop programs that educate and involve family members in the diabetes management process. Effective informational sessions can help families understand diabetes and how they can assist their loved ones. Family support is crucial for encouraging adherence to treatment and follow-up care.

Here are detailed recommendations to Enhance Family Support in diabetes management:

1. **Develop Family Education Programs:** Create structured educational programs specifically for family members of diabetes patients. These programs should cover the basics of diabetes management, the importance of support, and how family members can assist in daily care.

2. **Facilitate Family Involvement in Care Plans:** Encourage healthcare workers to include family members in the development of care plans. This collaborative approach can help ensure that family members understand their roles and responsibilities in supporting the patient.
3. **Organize Family Support Groups:** Establish support groups for families of diabetes patients. These groups can provide a platform for sharing experiences, challenges, and strategies for effective support, fostering a sense of community among families.
4. **Provide Resources for Family Members:** Distribute educational materials and resources that family members can use to better understand diabetes and its management. This can include brochures, online resources, and access to workshops.
5. **Encourage Open Communication:** Promote open lines of communication between patients and their families. Encourage patients to express their needs and concerns, and train family members to listen actively and provide emotional support.
6. **Promote Family Health Education:** Encourage families to adopt healthy lifestyle changes together. This can include family-oriented activities such as cooking classes, exercise programs, and health fairs that focus on diabetes management.
7. **Recognize and Address Family Stress:** Provide resources and support for family members who may experience stress or burnout from caregiving. This can include counselling services, respite care options, and stress management workshops.
8. **Evaluate Family Support Programs:** Implement a system for evaluating the effectiveness of family support initiatives. Collect feedback from both patients and family members to identify areas for improvement and ensure that support services meet their needs.

By implementing these recommendations, healthcare workers can significantly enhance the support system for families of diabetes patients, leading to improved management of the condition and better health outcomes for individuals living with diabetes.

Guideline for Tracing Lost to Follow-up Diabetes Patients

Based on the findings from the study, the following are the recommendations for implementing a Guideline for Tracing Lost to Follow-up Patients:

1. **Establish Dedicated Personnel for Patient Tracking**
   - ***Implement Case Management Models:*** Introduce dedicated case managers for diabetes care, similar to those used in HIV care. This can enhance follow-up care by ensuring that patients receive consistent support and monitoring.
   - ***Assign Roles Clearly:*** Clearly define the roles and responsibilities of healthcare workers involved in tracing lost patients to improve accountability and streamline processes.
2. **Improve Training for Healthcare Workers**
   - ***Comprehensive Training Programs***: Develop and implement training programs focused on diabetes management and follow-up protocols. This should equip healthcare workers with the necessary skills to manage diabetes effectively.
   - ***Ongoing Education:*** Encourage continuous professional development for healthcare workers to keep them updated on best practices in diabetes care and patient engagement strategies.
3. **Enhance Patient Tracking and Documentation**
   - ***Implement Robust Tracking Systems:*** Develop systematic patient tracking systems to monitor attendance and follow-up care. This can help identify patients who are lost to follow-up and facilitate timely interventions.

- ***Standardize Record-Keeping Practices***: Establish clear guidelines for record-keeping and documentation in chronic care units to improve the quality of diabetes follow-up services.

4. Create Clear Guidelines for Tracing Lost Patients

- ***Develop Structured Protocols:*** Create detailed protocols for tracing lost patients that outline the necessary steps for patient engagement, monitoring, and intervention.
- ***Utilize Charts and Registers Effectively:*** Provide guidelines for the proper utilization of charts and registers in chronic care units to enhance the quality of follow-up services.

5. Foster a Supportive Environment

- ***Encourage Family Involvement:*** Involve family members in the education and support process, as their encouragement can significantly boost patients' confidence in attending follow-up care.
- ***Create Peer Support Networks:*** Establish peer support groups where patients can share experiences and motivate each other to prioritize follow-up care.

6. Monitor and Evaluate Tracing Effectiveness

- ***Establish Monitoring Mechanisms:*** Implement systematic approaches to assess the effectiveness of tracing lost patients. This includes tracking patient outcomes and adherence to treatment plans.
- ***Incorporate Feedback Loops:*** Create feedback mechanisms for healthcare workers to share their experiences and challenges in tracing lost patients. This can help inform necessary adjustments to improve care quality.

By establishing dedicated personnel, improving training, enhancing patient tracking, creating clear guidelines, fostering a supportive environment, and implementing monitoring mechanisms, healthcare systems can significantly improve the tracing of lost to follow-up patients. These recommendations are essential for ensuring that patients receive the support they need to manage their condition effectively and to enhance overall health outcomes.

Guideline to Implement Effective Diabetes Cohort Follow-up

Based on the findings from the study, the following are the recommendations for implementing a guideline for diabetes cohort follow-up:

1. **Establish Dedicated Personnel for Cohort Management**
   - ***Implement Case Management Models:*** Introduce dedicated case managers for diabetes care, similar to those used in HIV care. This can enhance follow-up care by ensuring that patients receive consistent support and monitoring.
   - Assign Roles Clearly: Clearly define the roles and responsibilities of healthcare workers involved in diabetes cohort management to improve accountability and streamline processes.
2. **Improve Training for Healthcare Workers**
   - ***Comprehensive Training Programs:*** Develop and implement training programs focused on diabetes management and cohort registration practices. This should equip healthcare workers with the necessary skills to manage diabetes effectively.
   - ***Ongoing Education***: Encourage continuous professional development for healthcare workers to keep them updated on best practices in diabetes care and patient engagement strategies.
3. **Enhance Patient Tracking and Documentation**
   - ***Implement Robust Tracking Systems:*** Develop systematic patient tracking systems to monitor attendance and follow-up care. This can help identify patients who are lost to follow-up and facilitate timely interventions.
   - ***Standardize Record-Keeping Practices:*** Establish clear guidelines for record-keeping and documentation in chronic care units to improve the quality of diabetes follow-up services.
4. **Create Clear Guidelines for Follow-up Care**

- ***Develop Structured Protocols:*** Create detailed protocols for diabetes cohort follow-up that outline the necessary steps for patient engagement, monitoring, and intervention.
- ***Utilize Charts and Registers Effectively:*** Provide guidelines for the proper utilization of charts and registers in chronic care units to enhance the quality of follow-up services.

5. Foster a Supportive Environment

- ***Encourage Family Involvement:*** Involve family members in the education and support process, as their encouragement can significantly boost patients' confidence in attending follow-up visits.
- ***Create Peer Support Networks:*** Establish peer support groups where patients can share experiences and motivate each other to prioritize follow-up care.

6. Monitor and Evaluate Follow-up Care Effectiveness

- ***Establish Monitoring Mechanisms:*** Implement systematic approaches to assess the effectiveness of diabetes cohort follow-up programs. This includes tracking patient outcomes and adherence to treatment plans.
- ***Incorporate Feedback Loops:*** Create feedback mechanisms for healthcare workers to share their experiences and challenges in implementing follow-up care guidelines. This can help inform necessary adjustments to improve care quality.

By establishing dedicated personnel, improving training, enhancing patient tracking, creating clear guidelines, fostering a supportive environment, and implementing monitoring mechanisms, healthcare systems can significantly improve the effectiveness of diabetes cohort follow-up care. These recommendations are essential for ensuring that patients receive the support they need to manage their condition effectively and to enhance overall health outcomes.

Guideline for Monitoring and Evaluation of Diabetes Follow-up Care Program

Based on the findings from the study, the following are the areas of emphasiss for implementing a Guideline for the Monitoring and Evaluation of Diabetes Follow-up Care:

1. **Establish Systematic Monitoring Frameworks**
   - ***Develop Comprehensive Monitoring Protocols:*** Create structured protocols that outline the specific metrics and indicators to be monitored in diabetes follow-up care. This should include patient adherence rates, health outcomes, and the effectiveness of interventions.
   - ***Utilize Technology for Data Collection:*** Implement electronic health record systems that facilitate the collection and analysis of patient data, enabling healthcare workers to track patient progress and identify trends over time.
2. **Allocate Resources for Monitoring Activities**
   - ***Ensure Adequate Budgeting:*** Advocate for sufficient budget allocation specifically for monitoring and evaluation activities within diabetes care programs. This is crucial for sustaining effective monitoring systems and ensuring that they are adequately workersed and resourced.
   - ***Train Healthcare Workers in Monitoring Practices:*** Provide training for healthcare workers on the importance of monitoring and evaluation, equipping them with the skills necessary to implement these practices effectively.
3. **Incorporate Feedback Mechanisms**
   - ***Establish Regular Feedback Loops:*** Create systems for healthcare workers to provide regular feedback on the challenges they face in implementing diabetes follow-up care guidelines. This feedback should be used to inform necessary adjustments to the guidelines.
   - ***Engage Patients in Feedback Processes:*** Implement mechanisms for patients to share their experiences and outcomes related to follow-up care. This

can help identify barriers to adherence and inform improvements in care delivery.

4. **Monitor Patient Outcomes and Adherence**
   - ***Track Patient Progress Systematically:*** Develop a systematic approach to track patient outcomes, including glycemic control, diabetes complications, and adherence to follow-up appointments. This can help identify patients who are lost to follow-up and facilitate timely interventions.
   - ***Utilize Data for Continuous Improvement:*** Analyze collected data to assess the effectiveness of diabetes management protocols and make necessary adjustments based on real-world outcomes. This can enhance the quality of care provided to patients.
5. **Foster a Culture of Continuous Improvement**
   - ***Encourage a Learning Environment:*** Promote a culture within healthcare settings that values continuous improvement and learning from monitoring and evaluation activities. This can enhance the overall quality of diabetes care.
   - ***Regularly Review and Update Guidelines:*** Establish a process for the regular review and updating of monitoring and evaluation guidelines based on the latest research and patient outcomes to ensure they remain relevant and effective.

By establishing systematic monitoring frameworks, allocating resources, incorporating feedback mechanisms, monitoring patient outcomes, and fostering a culture of continuous improvement, healthcare systems can significantly enhance the effectiveness of diabetes follow-up care. These areas of emphasiss are essential for ensuring that patients receive the support they need to manage their condition effectively and to improve overall health outcomes.

Guideline on the Training of Healthcare Workers

The study emphasises the need for guidelines for health workers training to improve patient diabetes follow-up care. The following are the recommended guidelines to implement effective training for healthcare workers in diabetes management:

1. **Develop Comprehensive Training Modules**: Create structured training modules that cover various aspects of diabetes management, including patient education, medication management, psychosocial care, CRC (Compassionate and Respectful Caring) and the importance of follow-up care. These modules should be regularly updated to reflect the latest guidelines and best practices.
2. **Incorporate Simulation-Based Learning:** Utilize simulation-based training to provide healthcare workers with hands-on experience in managing diabetes cases. This approach can enhance their clinical skills and confidence in real-world scenarios.
3. **Facilitate Interdisciplinary Training:** Encourage interdisciplinary training sessions that involve various healthcare professionals, such as dietitians, nurses, and mental health specialists. This can foster a collaborative approach to diabetes care and improve overall patient management.
4. **Implement Regular Refresher Courses:** Schedule regular refresher courses to ensure that healthcare workers stay informed about new developments in diabetes care. Continuous education can help maintain high standards of care and improve patient outcomes.
5. **Utilize E-Learning Platforms:** Leverage e-learning platforms to provide flexible training options for healthcare workers. Online courses can be accessed at their convenience, making it easier for them to participate in ongoing education.
6. **Encourage Peer Learning and Mentorship:** Establish peer learning groups and mentorship programs where experienced healthcare workers can share their knowledge and skills with less experienced colleagues. This can enhance team cohesion and improve the quality of care provided.
7. **Monitor Training Effectiveness:** Implement a system for evaluating the effectiveness of training programs. Collect feedback from participants and assess

changes in their knowledge and skills to ensure that training meets the needs of healthcare workers.

8. **Address Emotional and Psychological Aspects:** Include training on the emotional and psychological aspects of diabetes management. Healthcare workers should be equipped to provide support and understanding to patients dealing with the emotional burden of chronic illness.
9. **Provide Cultural Sensitivity Training:** Provide cultural sensitivity training for healthcare workers to better understand and address the cultural beliefs that may influence patients' perceptions of diabetes and follow-up care. Some patients reported that cultural attitudes led them to prioritize traditional remedies over medical advice. Training can help providers communicate more effectively with patients from diverse backgrounds.
10. **Foster a Supportive Work Environment:** Create a supportive work environment that encourages continuous learning and professional development. Recognizing and rewarding healthcare workers for their commitment to training can motivate them to engage in ongoing education.

By implementing these areas of emphasiss, healthcare workers can significantly enhance the training and education of healthcare workers, leading to improved diabetes management and better health outcomes for patients.

Guideline to Enhance Motivation of Patients to Attend Diabetes Follow-Up Care

1. **Optimise health worker communication as a primary cue:**
   - Institute routine verbal and written appointment reminders during every visit.
   - Develop SMS/phone-based reminder systems tailored to patient language and literacy.
   - Encourage motivational interviewing techniques among providers.
2. **Leverage family and social support systems:**
   - Involve family members during counselling sessions.

- Provide family-targeted diabetes education materials.

3. **Address personal health concerns through risk communication:**
   - Use visual tools to illustrate diabetes progression and complications.
   - Incorporate patient testimonials about complications due to missed follow-ups.
4. **Promote the benefits of regular follow-up: Patients are more likely to attend when they understand the benefits.**
   - Provide individualised explanations of treatment outcomes during visits.
   - Share positive stories of patients who have managed diabetes successfully.
   - Develop culturally appropriate educational campaigns (radio, leaflets, posters).
5. **Institutionalise community-based health promotion programs:**
   - Partner with diabetes associations, local NGOs, and health extension workers.
   - Organise monthly health education sessions in communities.
   - Utilise mass media and community radio to raise awareness.
6. **Foster peer support and role modelling:**
   - Establish peer support groups at health facilities and community levels.
   - Train diabetes champions to mentor others.
7. **Counteract negative cultural and social messaging:**
   - Engage community leaders and faith-based influencers to dispel myths.
   - Develop culturally adapted myth-busting educational materials.
8. **Improve patient experience to prevent dropout:**
   - Train workers in patient-centered care and respectful communication.
   - Establish patient feedback mechanisms to identify and resolve dissatisfaction.
   - Reduce waiting times and improve follow-up visit organisation.
9. **Correct Misconceptions About Asymptomatic Phases:**
   - Educate patients on the silent progression of diabetes and the importance of preventive care.
   - Provide visuals showing how complications develop even without symptoms.
10. **Monitoring and Evaluation:**
    - Track rates of missed appointments pre- and post-implementation.
    - Measure patient knowledge, attitudes, and motivation via periodic surveys.
    - Use patient feedback to adapt and refine cue-enhancing interventions.

Guideline to Improve the Quality of Diabetes Follow-up Care

Based on the findings from the study, the following are the key areas of emphasiss to improve challenges in service delivery and quality of diabetes follow-up care:

1. **Enhance Training for Healthcare Workers**
   - ***Implement Comprehensive Training Programs***: Develop structured training initiatives focused on diabetes management for healthcare workers. This should include both theoretical knowledge and practical skills to ensure that workers are well-equipped to provide effective care.
   - ***Ongoing Education and Resources***: Establish continuous professional development opportunities for healthcare workers to keep them updated on best practices in diabetes care. This can help address gaps in knowledge and improve patient outcomes.
2. **Address Workersing Shortages**
   - ***Increase Workersing Levels:*** Advocate for hiring additional healthcare workers to reduce patient loads. This can help ensure that each patient receives adequate attention and care during follow-up visits.
   - ***Create Dedicated Diabetes Care Units:*** Establish specialized units for diabetes care to streamline services and improve the quality of care provided. This can help alleviate the burden on general healthcare facilities and enhance patient management.
3. **Improve Record-Keeping and Patient Tracking Systems**
   - ***Implement Structured Record-Keeping Systems:*** Develop and enforce standardized protocols for record-keeping to ensure consistency and accuracy in patient data management. This can help healthcare workers track patient progress and outcomes more effectively.
   - ***Utilize Technology for Patient Tracking:*** Invest in electronic health record systems that facilitate better tracking of patient appointments, medications, and follow-up care. This can enhance communication among healthcare workers and improve patient management.
4. **Ensure Availability of Essential Medications**

- ***Establish Reliable Supply Chains:*** Improve logistics and supply chain management to ensure consistent availability of essential medications, particularly insulin. This can help prevent stock-outs that disrupt patient care.
- ***Create Financial Assistance Programs:*** Develop programs to assist patients in affording their medications, especially for those from low-income backgrounds. This can help improve adherence to treatment regimens.

5. Foster a Supportive Healthcare Environment

- ***Encourage Compassionate Care:*** Train healthcare workers in effective communication and compassionate care practices. This can help build trust and improve patient satisfaction with the healthcare system.
- ***Involve Family and Community Support:*** Engage family members and community resources in the care process to provide additional support for patients. This can enhance motivation and adherence to follow-up care.

6. Adopt a Holistic Approach to Diabetes Management

- ***Integrate Comprehensive Care:*** Develop guidelines that emphasize a holistic approach to diabetes management, incorporating medical treatment, preventive services, education, and emotional support. This can help address the misconception that follow-up care is limited to blood sugar testing and medication collection.
- ***Focus on Preventive Services:*** Ensure that the guidelines include preventive care measures, such as regular screenings for diabetes-related complications, to enhance patient outcomes and reduce the incidence of severe health issues.

7. Enhance Patient Education

- ***Implement Structured Educational Programs:*** Create comprehensive educational initiatives that empower patients with the knowledge necessary for effective self-management. This should include information on diabetes management, the importance of follow-up care, and lifestyle modifications.

- ***Involve Family Members:*** Encourage the involvement of family members in educational programs to reinforce healthy behaviours and support patients in adhering to their treatment plans.

8. Improve Communication and Support Systems

- ***Train Healthcare Workers in Effective Communication:*** Provide training for healthcare workers to enhance their communication skills, ensuring they can effectively convey the importance of follow-up care and engage patients in their management plans.
- ***Establish Support Networks:*** Create support systems, including peer support groups and community resources, to help patients feel more connected and supported in their diabetes management journey.

9. Implement Robust Monitoring and Evaluation Mechanisms

- ***Develop Monitoring Protocols:*** Establish clear protocols for monitoring patient progress and adherence to treatment plans. This can help identify patients who are lost to follow-up and facilitate timely interventions.
- ***Incorporate Feedback Mechanisms:*** Create systems for healthcare workers to provide feedback on the effectiveness of the guidelines and the challenges they face in implementing them. This can inform necessary adjustments to improve care quality.

10. Allocate Resources for Continuous Improvement

- ***Ensure Adequate Funding for Diabetes Care:*** Advocate for sufficient budget allocation to support diabetes management programs, including training for healthcare workers and resources for patient education.
- ***Regularly Review and Update Guidelines:*** Establish a process for the regular review and updating of guidelines based on the latest research and patient outcomes to ensure they remain relevant and effective.

Annexure T: Ready for Validation Guidelines on LTFU of T1D Patients

This Annexure presents the 10 guidelines ready for validation

- ✓ Guideline 1: Diabetes Patient Education and Awareness Creation
- ✓ Guideline 2: Financial Support for Diabetes Patients
- ✓ Guideline 3: Tracing Lost-to-Follow-up Patients
- ✓ Guideline 4: Quality of Diabetes Follow-up Care

- ✓ Guideline 5: Reduce Patients' Waiting Time in Health Facilities
- ✓ Guideline 6: Implementing Robust Cohort Follow-up
- ✓ Guideline 7: Enhance Support System for Diabetes Patients
- ✓ Guideline 8: Enhance Patient Retention for Type-1 Diabetes
- ✓ Guideline 9: Enhance Motivation of Patients to Attend Diabetes Follow-up Care
- ✓ Guideline 10: Monitoring and Evaluation of Diabetes Follow-up Care

Guideline 1: Diabetes Patient Education and Awareness Creation

Section	Description
Background	Diabetes is a chronic condition that requires ongoing patient engagement and lifestyle modification. The study findings revealed gaps in patient knowledge, cultural barriers, and limited family involvement, which hinder effective self-management. Both patients and healthcare workers emphasized the need for structured and culturally relevant education to improve adherence and outcomes.
Goals of the Guideline on Patient Education	– To strengthen patient knowledge and skills for diabetes self-management. – To foster family and community support in managing diabetes – To enhance healthcare workers' capacity to deliver effective patient education – To increase awareness of the health risks of poor diabetes management and the benefits of follow-up care.
Scope	This guideline focuses on health facilities, community-based programs, and diabetes associations in Ethiopia. It applies to education strategies for patients with Type 1, their families, and communities.
Target Users	– Healthcare workers (nurses, doctors, health officers, educators) – Diabetes associations and community-based organizations – Patients living with diabetes and their families – Policymakers and program implementers in the Ministry of Health.
Key Recommendations	**9. Implement Structured Educational Programs:** • Create a comprehensive curriculum covering medication adherence, dietary recommendations, physical activity, and monitoring blood sugar levels, tailored to patient demographics, culture, and language. • Incorporate interactive teaching methods such as group discussions and hands-on demonstrations to enhance patient engagement and knowledge retention. **10. Involve Family Members in Education**:

	• Develop family-centric educational initiatives that recognize the role of families in supporting patients' adherence to lifestyle and treatment plans. • Provide resources and materials designed specifically for family members to strengthen their ability to support patients 11. **Ensure Accessibility of Educational Materials:** • Develop multilingual resources in different formats (brochures, videos, online content) tailored to varying literacy levels. • Ensure cultural relevance by aligning materials with local dietary practices and beliefs. 12. **Train Healthcare Workers on Patient Education:** • Implement training programs for healthcare workers on effective education techniques, communication skills, and patient engagement. • Provide cultural sensitivity training to address beliefs that may discourage patients from follow-up care. 13. **Establish Linkages to Diabetes Education Programs in the Community:** • Create patient support groups for sharing experiences and challenges. • Develop community support programs that strengthen social networks for patients. • Encourage collaboration with local organizations and diabetes associations to expand outreach. 14. **Increase Awareness of Health Risks and Benefits of Follow-up Care** • Implement awareness programs highlighting the complications of uncontrolled diabetes and the benefits of regular follow-up. • Share patient testimonials and success stories to motivate adherence. • Highlight positive outcomes of follow-up care through workshops, brochures, and health events. • Use motivational interviewing to address complacency among patients. 15. **Leverage Community Health Education Initiatives** • Partner with local health organizations to implement diabetes awareness initiatives. • Engage community leaders and faith-based influencers to dispel myths. • Use mass media (radio, TV) for awareness campaigns. • Incorporate visual aids and infographics to simplify information. 16. **Monitor and Evaluate Educational Effectiveness**

	• Establish feedback mechanisms for patients to assess the relevance and effectiveness of education programs. • Conduct pre- and post-assessments to measure changes in patient knowledge and practices.
Conclusion	Implementing structured educational programs, involving families, and ensuring accessible, culturally relevant materials empowers patients to manage diabetes effectively. Training healthcare workers and linking to community programs strengthens knowledge retention and practical application. Continuous monitoring and evaluation ensure ongoing improvement in patient education outcomes.

Guideline 2: Financial Support to Diabetes Patients

Section	Description
Background	Financial barriers are among the most significant challenges affecting diabetes follow-up care in Ethiopia. This revised guideline builds on study findings and expert feedback, ensuring that proposed financial support mechanisms are feasible, sustainable, and responsive to patient realities.
Goals of the Guideline	– To reduce financial barriers that hinder access to diabetes care – To establish sustainable and equitable financial assistance mechanisms – To expand insurance coverage and ensure affordability of essential diabetes services – To strengthen monitoring and evaluation of financial support interventions.
Scope	This guideline applies to healthcare facilities, diabetes associations, NGOs, policymakers, and community-based organizations in Ethiopia that play a role in designing and implementing financial support programs for diabetes patients.
Target Users	– Patients living with diabetes – Healthcare facilities and service providers – Policymakers and Ministry of Health – NGOs, diabetes associations, and donor agencies – Insurance providers
Key Recommendations	1. **Establish Financial Assistance Programs** • Partnerships with Local Organizations: Collaborate with diabetes associations, NGOs, and community-based groups to mobilize financial support for medications, diagnostics, and follow-up care • Awareness of Available Support: Conduct community campaigns and health education sessions to ensure patients are informed about existing financial assistance resources

	• Sliding Scale Fees: Introduce income-based service fees in facilities. Develop clear eligibility criteria and pilot this approach in selected facilities to test feasibility and sustainability • Direct Cash and Voucher Assistance: Provide cash or voucher support to cover urgent medical expenses. Expand this to include transportation reimbursement, addressing one of the most common barriers preventing patients from attending follow-up visits. 2. **Implement Affordable Healthcare Services** • Reduce Service Fees: Advocate for reduction of user fees for essential diabetes services • Government Subsidies for Sustainability: Encourage government subsidies or external donor support to ensure reduced fees at public facilities are financially sustainable • Integration into Healthcare Systems: Embed affordable service delivery models into existing health systems to promote equity and long-term access. 3. **Enhance Insurance Coverage** • Expand Coverage Options: Advocate for wider eligibility and benefits, ensuring insurance covers medications, diagnostic tests, and routine check-ups • Awareness and Accessibility: Launch campaigns to educate patients on the value of insurance and how to enrol. Advocate insurance registration during clinic days to patients not enrolled • Policy Advocacy: Collaborate with policymakers and non-profit partners to push for legislative reforms requiring coverage of essential diabetes services. 4. **Monitor and Evaluate Financial Support Programs** • Monitoring Mechanisms: Establish systems to regularly track patient access, service utilization, and adherence under financial support programs • Data Collection and Use: Collect and analyze data on the impact of financial support (e.g., improved adherence, reduced complications) to inform advocacy for broader reforms • Feedback Loops: Create accessible channels (suggestion boxes, patient interviews, hotline feedback) for patients to share their experiences with financial support schemes • Continuous Improvement: Use monitoring data and patient feedback to refine programs and advocate for systemic financing changes.
Conclusion	Financial assistance programs, affordable services, and expanded insurance coverage reduce barriers to diabetes care. Raising patient awareness and tracking program impact ensures that support reaches those in need.

	Ongoing evaluation allows adjustments to maintain sustainability and equitable access.

Guideline 3: Tracing Lost to Follow-up Patients

Section	Description
Background	Tracing patients lost to follow-up is critical to improving diabetes management outcomes. This revised guideline incorporates expert input to strengthen standardization, monitoring, and feedback mechanisms, ensuring a more systematic and patient-centered approach.
Goals of the Guideline	– To establish standardized approaches for tracing patients lost to follow-up – To strengthen healthcare worker capacity in tracing and patient-centered care – To promote family and peer support in sustaining follow-up – To monitor and evaluate tracing effectiveness systematically.
Scope	This guideline applies to healthcare facilities, diabetes clinics, and community health programs involved in supporting patients with diabetes in Ethiopia, with emphasis on improving continuity of care.
Target Users	– Healthcare workers (nurses, doctors, health officers, case managers) – Diabetes program managers and policymakers – Community-based organizations and peer networks – Patients and family members.
Key Recommendations	1. **Establish Dedicated Personnel for Patient Tracking** • Case Management Models: Assign case managers for diabetes care, following models used successfully in HIV programs, to ensure consistent support and monitoring • Defined Roles: Clearly define roles and responsibilities of healthcare workers engaged in tracing, ensuring accountability and efficiency in follow-up efforts. 2. **Improve Training for Healthcare Workers** • Comprehensive Training: Provide training on diabetes management, tracing protocols, and patient-centered engagement strategies • Ongoing Education: Facilitate continuous professional development opportunities to keep workers updated on best practices in tracing and diabetes care. 3. **Enhance Patient Tracking and Documentation** • Systematic Tracking Systems: Implement robust systems for monitoring patient appointments and identifying those who miss follow-up visits

	• Standardized Record-Keeping: Introduce clear guidelines for consistent documentation and use of registers in chronic care units to improve follow-up service quality. 4. **Create Clear Guidelines for Tracing Lost Patient** • Structured Protocols: Develop a standard tracing protocol to ensure uniform action across all workers. Protocols should outline key steps such as phone calls, home visits, and referral follow-ups • Effective Use of Registers: Strengthen the use of charts, appointment books, and registers to identify and trace lost patients promptly 5. **Foster a Supportive Environment** • Family Engagement: Encourage family members to support patients in attending follow-up appointments • Peer Support Networks: Establish peer support groups to provide encouragement, share experiences, and reduce the likelihood of missed follow-ups 6. **Monitor and Evaluate Tracing Effectiveness** • Monitoring Framework: Introduce simple metrics (e.g., number of patients traced, proportion successfully returned to care, reasons for loss to follow-up) • Healthcare Worker Feedback: Establish regular feedback mechanisms for healthcare workers to report challenges, innovations, and successes in tracing • Continuous Improvement: Use monitoring results and feedback to adjust tracing strategies and improve overall effectiveness.
Conclusion	Dedicated personnel, structured tracing protocols, and systematic patient tracking reduce loss to follow-up and improve adherence. Engaging families and peer networks reinforces patient support. Continuous monitoring and feedback loops ensure tracing strategies remain effective and sustainable.

Guideline 4: Quality of Diabetes Follow-up Care

Section	Description
Background	High-quality follow-up care is essential for improving diabetes outcomes and reducing complications. This revised guideline integrates expert input to emphasize compassionate, patient-centered care and structured preventive examinations, ensuring that both clinical and psychosocial needs of patients are addressed.
Goals of the Guideline	– Strengthen the quality of diabetes follow-up care – Ensure holistic, patient-centered, and evidence-based services

	– Reduce complications and improve patient outcomes through structured monitoring and support.
Scope	This guideline applies to diabetes follow-up care across all levels of the healthcare system in Ethiopia, including primary, secondary, and tertiary facilities. It is intended to guide improvements in clinical care, psychosocial support, and preventive interventions.
Target Users	– Healthcare workers (doctors, nurses, health officers – Ministry of Health and regional health bureaus – Diabetes associations and NGOs – Community health workers and peer educators
Key Recommendations	**1. Enhance Training for Healthcare Workers** – Comprehensive Training Programs: Provide structured training covering theoretical and practical aspects of diabetes management – Ongoing Education: Ensure continuous professional development opportunities to update workers on best practices. **2. Address Workersing Shortages** – Increase Staffing Levels: Advocate for the recruitment of additional healthcare workers to reduce patient-to-provider ratios – Dedicated Diabetes Care Units: Establish specialized units to streamline care delivery and improve follow-up quality. **3. Improve Record-Keeping and Patient Tracking Systems** – Structured Record-Keeping: Standardize documentation practices across facilities for consistency and accuracy. – Leverage Technology: Introduce electronic health records to support patient tracking and care coordination. **4. Ensure Availability of Essential Medications** – Reliable Supply Chains: Strengthen logistics systems to avoid medication stock-outs, especially insulin. – Financial Assistance Programs: Support patients through subsidies or assistance schemes to improve medication adherence. **5. Foster a Supportive Healthcare Environment** – Compassionate Care: Expand training to include patient-centered care principles that foster empathy and trust. – Family and Community Involvement: Engage family members and community groups to provide encouragement and strengthen patient adherence. **6. Adopt a Holistic Approach to Diabetes Management** – ***Comprehensive Care:*** Ensure guidelines integrate medical treatment, education, preventive services, and psychosocial support. – ***Preventive Examinations:*** Incorporate scheduled screenings

	during follow-up visits, including Eye exams, Foot care assessments, Kidney function tests, Cardiovascular risk assessments, and others based on clinical guidelines. 7. **Enhance Patient Education** – Structured Educational Programs: Empower patients with self-management skills through structured education. – Family Involvement: Encourage families to participate in education sessions to reinforce adherence. 8. **Improve Communication and Support Systems** – Healthcare Worker Training: Build workers' skills in effective communication for patient engagement. – Support Networks: Establish peer and community support systems to promote shared learning and encouragement. 9. **Implement Robust Monitoring and Evaluation Mechanisms** – Monitoring Protocols: Track patient progress and adherence systematically – Feedback Mechanisms: Allow healthcare workers to provide regular input on guideline implementation challenges. 10. **Allocate Resources for Continuous Improvement** – Adequate Funding: Advocate for sufficient budgets to sustain diabetes care programs. – Regular Review: Update guidelines periodically based on new evidence and outcomes from practice.
Conclusion	Enhancing workers' capacity, improving record-keeping, and ensuring availability of medications strengthen the quality of follow-up care. Holistic patient-centred approaches, preventive exams, and psychosocial support improve health outcomes. Regular monitoring and resource allocation promote continuous quality improvement.

Guideline 5: Reduce Patients' Waiting Time in Health Facilities

Section	Description
Background	Long waiting times are a major barrier to patient satisfaction in diabetes follow-up care. Addressing this issue can improve patient satisfaction, adherence, and outcomes. This guideline incorporates expert input, making it more practical, patient-centred, and feasible.
Goals of the Guideline	– Reduce patient waiting times in healthcare facilities – Improve patient satisfaction and adherence to follow-up care – Enhance efficiency and quality of diabetes services.
Scope	This guideline applies to public healthcare facilities providing diabe-

	tes follow-up care, mainly high-volume hospitals, focusing on systems that reduce waiting times and improve service flow.
Target Users	– Healthcare facility administrators and managers – Diabetes care providers (doctors, nurses, health officers) – Ministry of Health and regional health bureaus
Key Recommendations	**1. Streamline Appointment Scheduling** – Implement efficient scheduling systems (digital or manual) with clear time slots. – Use reminders (SMS/phone calls) to reduce no-shows and cancellations. **2. Increase Staffing During Peak Hours** – Monitor patient flow to identify peak times. – Allocate additional healthcare workers during high-demand periods. **3. Implement Triage Systems** – Develop triage protocols to prioritize urgent cases. – Ensure stable patients are scheduled appropriately without unnecessary delays. **4. Utilize Technology for Patient Tracking** – Apply electronic health records (EHR) to streamline check-in and follow-up. – Use patient tracking dashboards to minimize administrative delays. **5. Create Dedicated Diabetes Care Units** – Establish specialized diabetes units to improve patient flow and efficiency in high-volume hospitals. – Where feasible, integrate diabetes units into existing NCD services for cost efficiency. **6. Enhance Communication with Patients** – Provide updates on expected waiting times – Communicate reasons for delays promptly and respectfully. **7. Conduct Regular Process Evaluations** – Establish periodic reviews of patient flow to identify bottlenecks. – Gather feedback from both workers and patients to refine processes. **8. Offer Extended Hours** – Introduce tailored appointment slots across the day – In urban/busy settings, add late-hour or weekend slots (once weekly) to reduce congestion. **9. Implement Group Visits** – Organize group visits for diabetes education or counselling – Reduce repeat individual appointments while still delivering quality care.

	10. Foster a Supportive Environment – Provide basic comfort improvements (adequate seating, organized waiting areas) – Distribute low-cost education resources (posters, brochures, tip cards, videos/TV). – Encourage a welcoming atmosphere to reduce patient stress during waiting.
Conclusion	Streamlined appointment systems, workers allocation, triage protocols, and use of technology reduce patient waiting times. Enhancing communication, extending hours, and creating specialized diabetes units improve patient flow and satisfaction. Continuous process evaluation ensures efficiency and sustained improvements.

Guideline 6: Implementing Robust Cohort Follow-up

Section	Description
Background	Effective cohort follow-up is essential to ensure continuity of care for diabetes patients. This guideline incorporates expert input to enhance clarity, usability, and patient-centeredness, enabling health facilities to systematically track and support patients over time.
Goals of the Guideline	– Strengthen cohort follow-up mechanisms for diabetes care – Ensure systematic patient tracking and continuity of care – Improve adherence, reduce complications, and enhance overall outcomes for diabetes patients.
Scope	This guideline applies to healthcare facilities providing diabetes care at all levels, with a focus on strengthening systems for patient registration, follow-up, and monitoring through cohort management.
Target Users	– Healthcare workers (case managers, doctors, nurses, health officers) – Facility administrators and managers – Ministry of Health and regional health bureaus
Key Recommendations	**1. Establish Dedicated Personnel for Cohort Management** – ***Case management models:*** Assign dedicated case managers for diabetes care to provide consistent support and monitoring, similar to successful HIV care models. – ***Defined roles***: Clearly outline responsibilities of all healthcare workers involved in cohort follow-up to enhance accountability and streamline processes. **2. Improve Training for Healthcare Workers** – ***Comprehensive training programs:*** Train workers in diabetes management and cohort registration practices, covering both theoretical and practical skills

	– ***Ongoing education***: Encourage continuous professional development to maintain up-to-date knowledge on best practices in patient engagement and care. **3. Enhance Patient Tracking and Documentation** – ***Robust tracking systems:*** Implement digital or paper-based registers with standardized formats to monitor attendance, treatment adherence, and follow-up – ***Standardized record-keeping:*** Ensure consistent and accurate documentation across chronic care units to facilitate timely interventions. **4. Create Clear Guidelines for Follow-up Care** – ***Structured protocols***: Provide stepwise guidance for patient engagement, monitoring, and intervention to standardize care. – ***Effective use of charts and registers***: Utilize tracking tools systematically to identify and follow up with patients who miss appointments. **5. Foster a Supportive Environment** – ***Family involvement:*** Encourage families to support patients in attending follow-up visits. – ***Peer support networks***: Establish peer groups to share experiences and motivate adherence to care plans. **6. Monitor and Evaluate Follow-up Care Effectiveness** – ***Monitoring mechanisms:*** Track patient outcomes using simple indicators such as attendance, medication adherence, and complication rates. – ***Feedback loops:*** Implement periodic review meetings and suggestion channels for healthcare workers to provide insights and recommendations. – ***Continuous improvement***: Use monitoring data and feedback to refine follow-up practices and enhance patient care quality.
Conclusion	Structured cohort management with dedicated personnel, effective tracking, and standardized documentation improves continuity of care. Family and peer support enhance patient engagement and adherence. Monitoring outcomes and using feedback ensures ongoing refinement of follow-up mechanisms.

Guideline 7: Enhance Support System for Diabetes Patients

Section	Description
Background	Family and community support are critical in managing diabetes and ensuring adherence to follow-up care. This revised guideline incorporates expert feedback to make interventions age-appropriate, literacy-sensitive, and inclusive of broader psychosocial support, recognizing the role of caregivers as key partners.
Goals of the Guideline	– Strengthen family and community support systems for diabetes patients

	– Empower caregivers with knowledge, skills, and resources – Improve patient adherence, psychosocial well-being, and health outcomes.
Scope	This guideline applies to diabetes care programs across healthcare facilities and community settings, with a focus on empowering families, caregivers, and communities to actively support patients in their daily management and follow-up care.
Target Users	– Ministry of health and regional health bureaus – Healthcare workers (doctors, nurses, health officers) – Patients' families and caregivers – Community health workers and peer educators – Diabetes associations and psychosocial support organizations
Key Recommendations	**1. Develop Family Education Programs** – Create structured educational sessions tailored to different age groups and literacy levels – Cover basics of diabetes management, the importance of support, and practical guidance on assisting patients in daily care. **2. Facilitate Family Involvement in Care Plans** – Engage family members in care planning to clarify roles and responsibilities – Promote collaborative decision-making with patients and healthcare workers **3. Organize Family Support Groups** – Establish peer support networks for caregivers to share experiences, strategies, and challenges – Foster a sense of community and mutual encouragement among families **4. Provide Resources for Family Members** – Distribute educational materials (brochures, online resources, workshops) suitable for varying literacy levels – Include practical tools for daily diabetes management support **5. Encourage Open Communication** – Promote transparent and empathetic communication between patients and families – Train family members in active listening and providing emotional support **6. Promote Family Health Education** – Encourage healthy lifestyle changes for the entire family, such as group exercise, healthy cooking, and participation in community health events **7. Recognize and Address Family Stress** – Provide counselling services, respite care options, and stress management workshops for caregivers

	– Recognize the emotional and physical burden of caregiving and provide supportive interventions **8. Evaluate Support System Programs** – Collect feedback from patients, family members, and community participants – Assess effectiveness of family and psychosocial support initiatives – Extend support programs beyond family to include community-based psychosocial interventions, reinforcing a broader support system.
Conclusion	Family-centered education, supportive networks, and resources strengthen adherence and psychosocial outcomes. Evaluating and adapting programs ensures sustained community and family engagement.

Guideline 8: Enhance Patient Retention for Type-1 Diabetes

Section	Description
Background	Sustaining follow-up care for T1D patients requires a multi-faceted approach integrating patient-centred care, cohort tracking, education, systemic support, and community engagement. The study highlighted the need to adapt best practices from HIV cohort follow-up systems to ensure effective retention.
Goals of the Guideline	– Improve retention of patients with Type-1 Diabetes in follow-up care – Strengthen patient tracking and structured follow-up mechanisms – Address systemic, social, and economic barriers affecting continuity of care.
Scope	This guideline applies to health facilities providing care for patients with Type-1 Diabetes in Ethiopia, with a focus on patient retention mechanisms on follow-up care.
Target Users	– Healthcare workers (doctors, nurses, case managers) – Ministry of Health and regional health bureaus
Key Recommendations	**1. Strengthen Patient-Provider Communication** – Employ patient-centered communication strategies tailored to individual needs – Use language and materials appropriate to literacy levels and local dialects – Allocate dedicated education time, especially for newly diagnosed patients – Reinforce messages through visual aids, posters, and leaflets **2. Enhance Health Worker Capacity** – Provide regular training on diabetes counselling and follow-up protocols – Implement structured cohort registration and patient tracking systems

	– Conduct routine mentoring and supportive supervision – Integrate lessons from HIV cohort follow-up protocols for structured tracing and engagement **3. Improve Health Information Systems** – Transition to digital/electronic health records (EHRs) where feasible – Update cohort registers regularly to reflect patient status – Track missed appointments and implement alerts for proactive follow-up **4. Establish Standard Patient Tracking Mechanisms** – Develop standard protocols for tracing lost-to-follow-up patients – Implement appointment reminders via SMS or phone calls – Engage community health workers (CHWs) to follow up with defaulters – Emphasize proactive, structured follow-up based on successful HIV cohort practices **5. Address Socioeconomic Barriers** – Provide transport support via local government or NGOs – Ensure regular supply of insulin and essential diabetes medications – Link patients to diabetes associations or support groups for emotional and financial assistance **6. Integrate Community Engagement** – Partner with schools, religious leaders, and local media to raise awareness – Establish peer educator programs and support networks for motivation and adherence **7. Improve Facility-Level Service Delivery** – Create dedicated diabetes clinics or specific time slots to reduce waiting – Implement task-shifting for counselling and tracking to trained non-physician workers **8. Monitor and Evaluate Retention Outcomes** – Track indicators such as follow-up completion, LTFU rates, and complication rates – Use retention data in workers meetings to inform quality improvement decisions.
Conclusion	Structured tracking, effective communication, and systemic support improve T1D patient retention. Ongoing monitoring ensures sustained adherence and better clinical outcomes.

Guideline 9: Enhance Motivation of Patients to Attend Diabetes Follow-up Care

Section	Description
Background	Patient motivation plays a critical role in ensuring consistent attend-

	ance at diabetes follow-up care. Strengthening communication, family involvement, risk communication, peer support, and community engagement helps sustain adherence and reduces dropout rates.
Goals of the Guideline	– Increase patient motivation to consistently attend follow-up visits – Improve communication and counselling practices – Address misconceptions, cultural beliefs, and social barriers to attend follow-up care – Foster family, peer, and community support systems to enhance adherence.
Scope	This guideline applies to all health facilities providing diabetes care and follow-up services, with integration into community-based health promotion and patient support strategies.
Target Users	– Healthcare workers (doctors, nurses, counsellors) – Health extension workers and community health agents – Family caregivers and patient support groups – NGOs, diabetes associations, and community leaders
Key Recommendations	**1. Optimise Health Worker Communication as a Primary Cue** – Institute routine verbal and written appointment reminders during every visit – Develop SMS/phone-based reminder systems tailored to patient language and literacy, complemented by health extension worker follow-up for those without access – Encourage motivational interviewing techniques among providers **2. Leverage Family and Social Support System** – Involve family members during counselling sessions, based on the patient's consent and comfort – Provide family-targeted diabetes education materials – Encourage family-based follow-up contracts (e.g., joint follow-up reminders) **3. Address Personal Health Concerns Through Risk Communication** – Use visual tools to illustrate diabetes progression and complications – Incorporate patient testimonials and experiences – Balance risk information with positive reinforcement by highlighting how regular follow-up prevents complications and improves quality of life **4. Promote the Benefits of Regular Follow-up** – Provide individualised explanations of treatment outcomes during visits – Share positive stories of patients who have managed diabetes successfully – Develop culturally appropriate educational campaigns (radio, leaflets, posters)

	5. Institutionalise Community-Based Health Promotion Programs – Partner with diabetes associations, local NGOs, and health extension workers – Organise monthly health education sessions in communities – Utilise mass media and community radio to raise awareness **6. Foster Peer Support and Role Modelling** – Establish peer support groups at health facilities and community levels – Train diabetes champions to mentor others – Facilitate group counselling sessions or education talks **7. Counteract Negative Cultural and Social Messaging** – Engage community leaders and faith-based influencers to dispel myths – Develop culturally adapted myth-busting educational materials – Provide counselling on navigating stigma and spiritual alternatives **8. Improve Patient Experience to Prevent Dropout** – Train workers in patient-centred care and respectful communication – Establish patient feedback mechanisms to identify and resolve dissatisfaction – Reduce waiting times by introducing simple appointment scheduling or triage systems to improve organisation **9. Correct Misconceptions About Asymptomatic Phases** – Educate patients on the silent progression of diabetes and the importance of preventive care – Provide visuals showing how complications develop even without symptoms – Reinforce the idea that the absence of symptoms ≠ absence of disease **10. Monitoring and Evaluation** – Track rates of missed appointments pre- and post-implementation – Measure patient knowledge, attitudes, and motivation via periodic surveys – Use patient feedback to adapt and refine cue-enhancing interventions.
Conclusion	Optimizing communication, family support, peer engagement, and monitoring increases patient motivation. Continuous evaluation ensures interventions remain relevant and effective.

Guideline 10: Monitoring and Evaluation of Diabetes Follow-up Care

Section	Description

Background	Effective monitoring and evaluation (M&E) systems are crucial for improving the quality of diabetes follow-up care. Expert feedback highlighted the importance of actionable data, continuous learning, and guideline adaptability, ensuring that M&E processes translate into real-world service improvements.
Goals of the Guideline	– Establish systematic M&E frameworks to assess diabetes follow-up care – Use data to drive quality improvement and patient-centred outcomes – Foster continuous learning and adaptive guideline implementation.
Scope	This guideline applies to all healthcare facilities providing diabetes care, focusing on M&E activities, data collection, feedback mechanisms, and the use of findings for service improvement.
Target Users	– Healthcare workers and facility managers – M&E officers and data clerks- Ministry of Health and regional health bureaus – Diabetes associations and implementing partners
Key Recommendations	**1. Establish Systematic Monitoring Frameworks** – Develop structured protocols with clear metrics and indicators: patient adherence, health outcomes, and intervention effectiveness – Utilize technology (EHRs or digital tools) to facilitate data collection and analysis – Conduct regular facility-level data review meetings to translate results into actionable improvements **2. Allocate Resources for Monitoring Activities** – Ensure adequate budget and workersing support for M&E activities – Train healthcare workers on M&E principles, emphasizing practical data use for quality improvement **3. Incorporate Feedback Mechanisms** – Establish routine feedback loops for workers to report challenges in guideline implementation – Include anonymous workers surveys and regular multidisciplinary team meetings – Engage patients to provide feedback on care experiences and outcomes to inform improvements **4. Monitor Patient Outcomes and Adherence** – Track patient outcomes systematically, including glycemic control, complications, and appointment adherence – Use collected data to assess protocol effectiveness and make necessary adjustments **5. Foster a Culture of Continuous Improvement**

	– Promote a learning environment where workers reflect on M&E findings – Conduct routine training and reflection sessions to apply lessons learned – Regularly review and update guidelines based on the latest research and observed patient outcomes.
Conclusion	Systematic M&E, combined with feedback and continuous learning, strengthens follow-up care quality. Adaptive use of data ensures sustained improvements in patient outcomes.

Annexure U: Gatekeeper Information and Recruitment Letter in Phase 4

Subject: Gatekeeper Information and Recruitment Letter

Title of Study: Developing Guidelines to Strengthen Type 1 Diabetes Follow-up Care in Ethiopia

Researcher: Berhanu Gulo Hawando

Supervisor: Professor Lizeth Roets

Dear Gatekeeper,
Greetings. My name is Berhanu Gulo, and I am currently pursuing a PhD in Public Health at the University of South Africa. As part of the study title mentioned above, I am planning to conduct a Structure Consensus Development Meeting (SCDM) with expertise in Public Health Policy Development and Analysis, Public Health Research, Guideline Development and Validation. Ensuring a diverse representation of perspectives. As a Policy Advisor in the Ministry of Health Ethiopia, your support is requested in helping to identify and invite experts who meet the above criteria to serve as expert panellists for the SCDM.

If you are willing to assist, I kindly request that you share with me the list of suitable experts who meet the criteria outlined above. Your role will be limited to sharing the contact and so that I can reach out to them by email. I ensure that the recruitment will occur ethically and transparently.

Please note that you will not receive any direct benefit from this role, but your support is crucial in ensuring that qualified professionals are recruited without undue influence and that their participation remains voluntary and anonymous. Their contribution could play a significant role in shaping context-specific guidelines to improve diabetes care delivery at local health facility levels.

Should you have any questions or need additional information, feel free to contact me directly at +251 911735578 or via email at 20996896@mylife.unisa.ac.za. For academic oversight, you may also contact my supervisor, Prof. Lizeth Roets, at roetsl@unisa.ac.za, or reach out to Prof. Khan, Chairperson of the Research Ethics Committee (College of Human Sciences), via khankb@unisa.ac.za for any ethical concerns.

If you are unable to assist at this time, kindly let me know by return email.
Thank you in advance for considering this request and for your valuable support.

Kind regards, 

Berhanu Gulo Hawando; Email: berhanugulo@gmail.com; Cell phone: +251911735578

Annexure V: Gatekeeper Recruitment Letter in Phase 3

Subject: Gatekeeper Information and Recruitment Letter
Title of Study: Developing Guidelines to Strengthen Type 1 Diabetes Follow-up Care in Ethiopia

Researcher: Berhanu Gulo Hawando
Supervisor: Professor Lizeth Roets

Dear Gatekeeper,
Greetings. My name is Berhanu Gulo, and I am currently pursuing a PhD in Public Health at the University of South Africa. I am conducting a study entitled "*Guidelines for Lost-to-follow-up Type-1 Diabetes Patients at Public Hospitals in Ethiopia".* As the Head of Medical Services in West Shewa Zone Health Department, your support is requested in helping to identify and invite healthcare professionals who meet the inclusion criteria to serve as expert panellists for a focused discussion as part of this study. The panel members should be professionals who have been involved in the follow-up care of Type 1 diabetes patients for at least three years and are currently working within the South West Shewa Zone.
If you are willing to assist, I kindly request that you share with me the list of suitable healthcare workers who meet the criteria outlined above. Your role will be limited to sharing the contact and so that I will reach out them by email. I ensure that the recruitment will occur ethically and transparently.
Please note that you will not receive any direct benefit from this role, but your support is crucial in ensuring that qualified professionals are recruited without undue influence and that their participation remains voluntary and anonymous. Their contribution could play a significant role in shaping context-specific guidelines to improve diabetes care delivery at local health facility levels.
Should you have any questions or need additional information, feel free to contact me directly at +251 911735578 or via email at 20996896@mylife.unisa.ac.za. For academic oversight, you may also contact my supervisor, Prof. Lizeth Roets, at roetsl@unisa.ac.za, or reach out to Prof. Khan, Chairperson of the Research Ethics Committee (College of Human Sciences), via khankb@unisa.ac.za for any ethical concerns.
If you are unable to assist at this time, kindly let me know by return email.
Thank you in advance for considering this request and for your valuable support.

Kind regards,



Berhanu Gulo Hawando
Email: berhanugulo@gmail.com
Cell phone: +251911735578

Annexure W: Certificate of language editing

CERTIFICATE OF LANGUAGE EDITING

I, the undersigned, declare that I have edited the **Dlitt et Phil thesis of BERHANU BULO HAWANDO**, titled:

GUIDELINES FOR LOST-TO-FOLLOW-UP TYPE-1 DIABETES PATIENTS AT PUBLIC HOSPITALS IN ETHIOPIA

I have read the dissertation and made suggestions regarding the layout and use of UK English. I have also verified that all sources listed in the References were cited correctly in the dissertation and that all in-text references are accounted for in the list of references. While I tried to work as carefully as possible, some errors may have been overlooked, and I may also have made mistakes during the editing process.

Where figures in the dissertation were inserted as images, I was unable to make any corrections to them. I also refrained from correcting the English translations of interviewees' citations, except for a few spelling mistakes made by the translators.

I consulted the guide for doctoral students in the Department of Health Studies at UNISA and attempted to comply with the required regulations. Please note that the correct abbreviation for et al. is with a period, not et al as the guide states.

I cannot be held responsible for changes made to the dissertation after editing was completed and before it was submitted in its final form for examination, or for submission in the UNISA repository.

Signed: 

Prof (emeritus) P.J. Botha

(Member of the South African Translators' Institute, no. 1000048.)

Date: 24th November 2025