Designing technology for less literate people with Diabetes in Punjab, Pakistan

Kehkashan Zeb

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To my ,

Daughter, Parents and Husband.

Abstract

Digital health uses information communication technology to provide healthcare services effectively. This research uses Human-Computer Interaction methodologies such as participatory design and iterative prototype evaluation to effectively design technology for people in the rural areas of Punjab, Pakistan.

Many participants in this PhD research have a low literacy level, making it challenging for them to obtain the knowledge necessary to manage their common chronic health conditions, such as diabetes. The remoteness of these participants, the lack of transport, and the internet inaccessibility only exacerbate this healthcare self-management. The research focused on designing an Interactive Voice Response system using participatory design methodologies.

Interactive Voice Response (IVR) is an accessible method of transmitting knowledge because it allows voice-based interaction. To assist illiterate populations in managing chronic health conditions, hierarchical IVR systems are currently being developed and pose the challenge of navigating a large amount of information with hierarchy. Therefore, using a phone number-specific profile, this project iteratively develops a dynamic IVR that adapts information presented to people with diabetes to compensate for some of their challenges in healthcare support. Multiple design studies and deployments are conducted to validate the IVR system.

The IVR system was designed iteratively using Participatory Design (PD) to explore users' preferences. Although PD originated in Scandinavia, it poses several challenges since it assumes literacy and a cultural mindset associated with the Global North. Hence, it is necessary to adopt democratic, patient-centred, iterative participatory approaches to develop a comprehensive understanding of PD in a diverse and challenging environment, including both urban and rural contexts. Several PD techniques were used, including Wizard of Context, Narrative Scoping with Personas, an interactive framework that used videos, pictures and audio, and iterative PD.

After deploying the IVR system using servers built on the Asterisk platform, the system's usefulness for keeping people with diabetes informed about their condition and better managing their condition was demonstrated by gathering qualitative and quantitative data.

Declaration

This work has not previously been accepted in substance for any degree and is not being concurrently submitted in candidature for any degree.

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This thesis is the result of my own investigations, except where otherwise stated. Other sources are acknowledged by footnotes giving explicit references. A bibliography is appended.

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Declaration

A professional service provider proofreads the thesis content by checking grammatical and spelling mistakes.

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Chapter 1

Addressing Chronic Health Conditions in the Global South

Many rural areas in the Global South face unique challenges, including persistent poverty, high population growth outstripping service provision, low literacy levels, high rates of unemployment, and widespread poor health (as a result of poor nutrition, diseases, lack of access to healthcare, lack of clean water and the lack of food) [121] [183] [12]. These challenges have led to a rapid increase in the prevalence of chronic conditions, such as diabetes and hypertension, creating a burden on the economy [139] as it threatens a nation's ability to improve public health. Chronic conditions need regular self-management, and research demonstrates that when people suffering from chronic diseases have more information about self-management strategies, they become more involved in incorporating these strategies into their daily lives [129]. Therefore, appropriate information about chronic condition management is essential for individuals to better self-manage their conditions. However, the unique challenges already described, particularly low literacy, prevent many from accessing information about self-managing their condition.

Technology has the potential to play a central role in improving healthcare by enhancing doctor-patient interaction, reducing costs, and informing people with chronic conditions about self-management strategies.

Digital health uses technology to effectively deliver healthcare services to the general population. Digital health has different components, such as 1) Mobile health - using mobile devices such as smartphones and tablets to aid in healthcare delivery; this includes health monitoring applications, medication reminders and health education. 2)Telemedicine - to enable remote delivery of healthcare services; thus, patients can consult healthcare professionals through video/ audio calls or other virtual means. 3) Wearable Devices - the wearable devices that track steps taken, heart rate, and sleep patterns. Literacy and digital health access are interconnected, and their co-presence allows people to access self-management information online [125].

Human-Computer Interaction (HCI) is a multidisciplinary field that focuses on designing, evaluating, and implementing interactive computing systems for human use and studies the significant phenomenon of this process [239]. HCI is important due to technology integration in daily life, and it ensures that technology such as smartphones, websites, wearable devices, and smart home systems, along with complete functionality, is also user-centric and enjoyable.

Participatory Design (PD) is an HCI concept - an approach to design that actively includes the targeted people in the design process by eliciting participant's insights, needs and preferences. It is a crucial component of development projects, and its principles and practices are continuously evolving. The commitment to engage the participants in the design process needs (while following relevant PD guidelines) shows promise in designing usable IVR systems [193]. The uniformity of language, culture, norms, and values in the Global North, the high literacy rate and the awareness of the international language (English) facilitate participation in the design process.

In the Global South, the availability of mobile technology can play a vital role in healthcare at the individual and community levels [150] [118] [258]. However, many barriers need to be overcome in developing countries of the Global South, particularly the unpreparedness of the workforce to benefit from digital health. This leads to many projects failing at the pilot stage. Therefore, scaling up the existing healthcare pilot projects rather than starting new ones is recommended. In the Global South, the design of usable technology that is accessible with minimal financial burden can help achieve long-term health benefits. Although smartphones are globally available, many people, particularly those living in rural areas, still use low-end phones because of their availability and lower literacy requirements.

In the absence of smartphones, Interactive Voice Response (IVR) becomes an accessible alternative for these people as it does not require sophisticated digital devices [172]. However, the design of this IVR voice-only medium is challenging because it cannot capture information on a screen, allowing people to review content easily; it relies on a clear audio channel and is limited to keystroke interaction.

There is a lack of internet resources and literacy in rural areas of the Global South, which limits access to digital health. Using participatory design techniques can ensure the technology is adapted according to the end user's requirements. This thesis relies on adopting a participatory design methodology and uses an iterative participatory process to evolve an IVR system to keep people with diabetes better informed about diabetes. This IVR system is developed as a response to the user needs - this iterative PD process led to coming up with a novel PD method and a Dynamic and Scalable IVR system.

1.1 Diabetes Management in Pakistan - A Case Study

This thesis explores the barriers to supporting diabetes self-management in the rural areas of Punjab - a province in Pakistan - and it is important to understand this context (See more information about Pakistan in Appendix B). The scale of the challenge diabetes poses is enormous - it is estimated that over 33 million adults (26.7% of the adult population) live with diabetes in Pakistan. The majority have limited access to the support needed to manage their condition [41]. Medication is too expensive for many, but if information about self-management strategies (such as diet and exercise) was more readily available, implementing these strategies could help regulate glucose levels and lessen the impact of diabetes, resulting in better health. However, self-management strategies are still not easily accessible. Utilising the skills and knowledge in the Information Communication Technology for Development (ICTD) field can be a low-cost way of widely disseminating diabetes self-management information in this resource-constrained environment [153].

Implementing diabetes self-management strategies can lead to a long and healthy life. A tailored diabetes self-care plan includes a meal plan, physical activity in people's daily routines, and doctor-led medicine intake. However, the comorbidities commonly associated with diabetes exacerbate the self-management challenges and demand increased personal involvement to better self-manage the conditions. Appropriate knowledge about diabetes and its comorbidities is pivotal in managing them.

This PhD thesis focuses on adapting technology to the skill set of less-literate people to enable them to readily access the information and the support needed to manage their condition effectively. The design of such a targeted and usable diabetes healthcare system has the potential to impact many people's lives positively.

In this context, the use of PD in developing the technology to support diabetes self-management for socially or economically marginalised people is important, as it helps to identify and understand their needs [252]. PD is an approach that uses the active, equitable involvement of users and other stakeholders in the design process to ensure results meet their needs and are usable. PD provides a way to design for people with very different lived experiences in varied cultural circumstances [89]. However, employing PD methods in developing contexts is challenging because of barriers such as language, distance, and the infrastructure required. The research project focuses on the diabetes self-management challenge to learn more about problems associated with it in Punjab, Pakistan - it also explores the appropriate technology adaptation with PD techniques.

1.2 Research Questions

This research project takes action research to design a voice-based medium - IVR - using PD methodologies to overcome challenges such as lower levels of literacy, age-related health conditions, lower than average levels of technology familiarity and associated chronic health conditions in providing information on diabetes self-management.

Three Research Questions guide this research:

Research Question One: How can Participatory Design methodologies be adapted to work in rural regions in the global south? In particular, what changes are necessary to support rural people living with diabetes in Punjab, Pakistan?

The uniformity of the Global North's cultural contexts, societal attitudes, and literacy levels are not present, particularly in the rural areas of the Global South; therefore, the traditional PD methods (including PICTIVE, Card method, sketching, and storyboarding) become less appropriate [186] [260].

This thesis focuses on the specific context of rural Pakistan, where unique attitudes towards healthcare, low literacy levels and strong gender norms pose distinct challenges to engaging participants in the PD process. Investigating PD methodologies such as Narrative scoping, co-created Persona, Invisible Design Videos, and Wizard of Context studies will help develop guidelines on PD adaptation for local contexts. The PD process will confirm prior research's findings that IVR support overcomes various technical and literacy challenges [55] in our specific context. The work will also highlight the need for diabetes information access for less literate people to engage in behaviour change. Consequently, this PhD aims to advance research facilitating technology access, and this leads to the second question:

Research Question Two: How should the project facilitate designing and developing a voice-only medium to present important healthcare information to encourage regular user-system interaction over time?

The thesis focuses on designing a scalable IVR system to support less literate people with diabetes in low-resource settings and to go beyond information delivery by also overcoming practical diabetes self-management barriers because an IVR system designed to help less literate People with diabetes has the potential to deliver extensive information that can change their lives. Informed by scoping work in service of Question One, this thesis chooses to explore how the IVR system can provide 1) Diabetes Information, 2) Comorbid Conditions Information, 3) Experience Sharing between people with diabetes, and 4) Recorded questions answered by healthcare professionals. It will be developed using PD methodologies and different technologies, such as the 'Asterisk platform', and the Wi-Fi-enabled IVR - deployed over a cloud server to help develop an IVR system.

Research Question Three: What is the impact of the developed healthcare IVR system when deployed and evaluated through quantitative and qualitative analysis?

For any technology intervention, maintaining user engagement is crucial. The Quantitative and Qualitative analysis of different IVR features helped to understand the user's behaviours, preferences, likes/dislikes, etc. The qualitative study consisted of focus groups and interviews, whereas the quantitative study analysed the system usage logs to gain insight into user acceptability and system usability.

1.3 Contributions

Contribution One: Adaptation of PD in the local context.

Adapting existing PD techniques to suit the Pakistani context requires exploring and adjusting current methods. Different PD methods, such as Narrative scoping, Personas, and Participatory Videos (PV), were used in the localised context to devise a PD framework that includes personas, pictures, and videos that elaborate and explore design ideas and concepts.

Contribution Two: Exploration of features and approaches to IVR health delivery

People living in rural areas of the Global South often lack the information and motivation required to manage their condition. Therefore, this research addresses the design challenges and develops the system to deliver healthcare awareness and facilitate sharing experiences.

Contribution Three: Evaluation of behaviour for seeking information from the IVR, using quantitative and qualitative methodologies.

This research concluded with IVR deployment and subsequent analysis of participants' views and usage. The quantitative analysis determined the usage pattern for different IVR features, and qualitative research helped to understand the reason behind the IVR usage pattern.

1.4 Thesis Overview

Chapter Two explores diabetes and its impact in Pakistan. ICTD methods are presented, focusing on IVR systems. The design of the ICTD system is challenging, and this chapter reviews the methodologies used to perform design work. The PD approach is selected because of its ability to understand diverse stakeholder lived experiences and contexts, motivating stakeholders. However, PD in developing contexts has to overcome cultural assumptions, such as stakeholders' level of buy-in to the process and address methodological barriers, such as the assumption of stakeholder literacy on the part of stakeholders.

Chapter Four provides an overview of the initial scoping study that enabled discussion of the lifestyle of people with diabetes in rural Punjab, Pakistan, their challenges, and the opportunities to address them. The scoping study consisted of interviews and focus groups and suggested the IVR system as a viable method to facilitate users with diabetes information. The scoping study highlighted the need to adapt the PD to the local context using an iterative approach. 'Narrative Scoping using Persona' - helped to gain insight into the lifestyle of the target user group. A simple IVR prototype, 'Sugar-ka-Saathi' - version One, was designed and developed to understand the target users' interaction. Afterwards, the people with diabetes watched the 'Invisible Design Videos', followed by a conversation about the IVR's features.

The 'Wizard of Context' approach is an adaptation of the 'Wizard of Oz' approach; in this method, a Python prototype, 'Sugar-ka-Saathi' Version three, is presented to participants remotely. This Python prototype is modified according to the feedback and later shifted to designing and developing a working 'Sugar-ka-Saathi' (within the WiFi range). 'PD with media' used the participatory video approach and included pictures, audio and video (arranged as PowerPoint slides) in a PD session. This session helped to gain insight into the participants' lifestyles.

Chapter five presents the short-term deployment (for 15 days) of the IVR system amongst 38 people with diabetes, with the deployment being accompanied by iterative PD sessions to culminate in the design and development of 'Sugar-ka-Saathi' - Prototype Four - the final version. It was then deployed for 20 days, and using qualitative and quantitative methods, its ability to support better diabetes self-management was assessed. The qualitative research involved interviewing 13 participants (people with diabetes), while the quantitative research included IVR-based automated surveys with IVR users and log analysis to determine individual user behaviour.

Chapter Six summarises the thesis outcomes, maps the research results to the original questions, and discusses future design and deployment suggestions.

1.5 The Author's Contribution

The thesis author undertook almost all of the research tasks, including undertaking the following: HCI research, interaction design for IVR, PD for less literate people, IVR system development, and usability testing.

Most user scoping studies were undertaken by the author in collaboration with an HCI researcher from Lahore University of Management Sciences (LUMS). The author designed the method and the IVR and reiterated it with the HCI researcher from LUMS. The author developed the script, its verification with doctors, and its translation to Punjabi. The LUMS HCI researcher helped with script recording and ensured fluency and engagement. Later, the author conducted PD sessions, including focus groups, interviews and on-phone sessions. The author developed the helpline with the Asterisk platform, the PERL scripting and the SQL integration. The server setup to place the calls was outsourced. The author performed the usability analysis, both qualitative and quantitative.

Figure 1.1: PhD Chapter Highlights

Final deployment utilised cloud space from a company called RAPID [32]. For setting up the server to place calls, a telephony engineer's expertise helped configure the server so that the script worked locally and could initiate calls to the users.

The author's close ties with Punjab, Pakistan, being born and bred there, facilitated the research as her friends and family helped to arrange the PD session at various locations and recruit people in rural and urban areas. However, as discussed in this thesis, the author's limited exposure to rural life presented challenges and surprises.

Finally, the author undertook this PhD project in part-time study mode, which took seven years to complete. Completing the studies, such as the IVR deployment, was delayed due to COVID-19 and other out-of-my-control factors, including IVR deployment, ensuring script quality.

1.6 Publications Arising from Thesis

The Published Papers and related contributions are as follows. See Appendix A for details.

1. Kehkashan Zeb, Stephen Lindsay, Suleman Shahid, Matt Jones: Verbal Design: A Participatory Design Approach with Illiterate Patient User Groups. Conference on Designing Interactive Systems (Companion Volume) 2018: 271-275.
2. Kehkashan Zeb, Stephen Lindsay, Suleman Shahid, Waleed Riaz and Matt Jones. Sugar ka Saathi–A Case Study Designing Digital Self-Management Tools for People Living with Diabetes in Pakistan (Full Paper published in INTERACT 2019)
3. Kehkashan Zeb. Co-Design of an IVR system for management of Diabetes and Comorbid conditions – A Case Study of Rural Punjab, Pakistan (Doctoral Consortium Paper in INTERACT 2019)

Chapter 2

Literature Review

Those with diabetes - a worldwide and common chronic condition - must incorporate self-management strategies. However, limited awareness of these strategies and the motivation to incorporate them in the Global South led to worsening health and other complications. This research focuses on exploring relevant literature on topics including ICT for development (ICT4D), Interactive Voice Response (IVR), Human-Computer Interaction (HCI), Participatory Design (PD), Diabetes, and its management.

2.1 Introduction

In the Global South, various factors contribute to low diabetes awareness and adequate diabetes self-management, such as low literacy levels in a resource-constrained environment. Inadequate diabetes management often leads to impaired blood-glucose levels and other complications. Although the best approach for diabetes management is currently uncertain [39], there is consensus that raising diabetes awareness is essential - it often requires strong motivation to incorporate lifestyle changes, including maintaining a proper diet, taking medicine, and exercising regularly. In the Global South, physicians have little formal diabetes management training and often struggle with raising diabetes awareness for the less literate. Therefore, limited awareness of self-management strategies is a barrier to their adoption.

ICT4D attempts to overcome some of these challenges by investigating how technology can improve the lives of these underserved populations. However, the use of ICT4D to support better disease self-management in the Global South faces significant challenges, such as the diverse user base, limited resources and smartphone access, connectivity issues, and language barriers.

HCI is a multidisciplinary field that involves designing, evaluating, and implementing interactive computing systems. According to Simonsen and Robertson, PD is a key concept of HCI – it helps identify the problem areas, such as the need to raise awareness of healthcare conditions amongst less literate people [58]

Adopting a PD approach facilitates the design of a usable system, provided it is adapted to the localised contexts and the nature of the ICT environment being used [98].

Riaz et al. demonstrated that IVR technology could work in resource-constrained environments and amongst less literate people [224] [222]. Consequently, an IVR system for healthcare designed for the ICT4D sector may improve diabetes awareness and motivate people to incorporate self-management strategies.

In the next section, the influence of HCI on Digital Health is discussed.

2.2 Human Computer Interaction and Digital Health

HCI is an interdisciplinary field that intersects with discourses in digital health, e.g., on self-management of health care, mHealth, PD, and HCI4D.

Definition of 'health' by World Health Organization (WHO): [65]

> "not merely the absence of disease or infirmity but a state of complete physical, mental and social well-being".

Digital health is a broad and evolving concept that uses digital tools, technologies and platforms to improve the general population's health. Digital health comprises intersecting domains, including 1) Medicine and medication administration, 2) Devices for monitoring vital signs to deliver therapies, 3) Electronic health records - to record data, diagnosis and interventions., 4) Dashboards and patient portals, 5) Telecare and Self-management including Self-care Technologies, 6) Online Information Resources, 7) Digital Behaviour Change Interventions, and 8) Information and decision support systems.

Some benefits of digital health are better patient care, accessibility and convenience, improved diagnosis and treatment, and healthcare cost savings. However, some challenges associated with digital health are data privacy and security, healthcare regulations, and health inequalities, as not everyone has equal access to technology.

The use of digital health in everyday life greatly depends upon the appropriate design of technology that prioritizes the users' needs and preferences. Some key aspects of HCI, including user-centred design for mobile health applications, telemedicine platforms and wearable health devices - have become particularly important in the digital health domain. Appropriate implementation of HCI practices in digital health leads to enhanced user experience, improved adherence to treatment plans, medication schedules and lifestyle changes, and better communication. Despite these benefits, digital health poses challenges such as 1) Sensitive health data having significant security and privacy concerns, 2) The digital divide due to unequal access to technology or literacy creating disparities in healthcare access, 3) Regulatory compliance to comply with healthcare regulations and 4) Ethical concerns such as responsible use of AI and healthcare technologies.

Overall, HCI has the potential to reshape digital healthcare and make it more effective, patient-centric, and accessible.

The next section gives an overview of diabetes, its self-management strategies, the role of diabetes education, community support and how technology can aid in better managing the condition. Later, the focus shifts to Diabetes management in the Global South, particularly Pakistan.

2.3 Diabetes - A Global Problem

Diabetes is a non-communicable health condition in which the pancreas cannot use or produce insulin effectively (see Table 2.1). It has emerged as a leading cause of sickness and mortality, with its prevalence increasing at an alarming rate [255]. This prevalence varies for different ethnic groups, races, and cultures. It is highest in South Asia, amongst people from India, Pakistan, and Bangladesh, who are up to six times more likely to have diabetes than populations from other regions [6].

The World Health Organization (WHO) estimated that the number of people with diabetes would double in the next 25 years, primarily due to increases in developing countries [4]. People with diabetes are prone to high hospitalization rates, blindness, renal failure, and limb amputations (from non-traumatic causes), with 40% to 50% developing foot problems after ten years of diabetes diagnosis [48].

However, timely diabetes awareness and self-management approaches - such as healthy eating (the impact of diabetes is exacerbated by excessive carbohydrate intake [259]), being active, monitoring blood sugar levels, and taking medication - can help minimize these complications.

The economic costs of chronic diabetes health issues are high in all cultures. Often, people with diabetes have other comorbid conditions such as high blood pressure, obesity, anxiety, and depression. Educating people with diabetes regarding lifestyle choices, including sleep, eating, exercise, and socialisation, can significantly reduce these costs [72].

Diabetes management necessitates a holistic approach involving team-based healthcare and goal-setting to manage a person's physical, psychological, social, and spiritual well-being to effectively manage and prevent chronic health conditions. Team-based healthcare is defined as (according to [140]):

> *"Team-based healthcare is the provision of health services to individuals, families, and their communities by at least two health providers who work collaboratively with patients and their caregivers – to the extent preferred by each patient – to accomplish shared goals within and across settings to achieve coordinated, high-quality care"* .

In-person healthcare support, including team-based healthcare, can be impractical for many in the Global South, particularly those in rural areas. However, developments in communications now permit support to be offered at a distance via mobile phones - with its ability to track everyday behaviours - giving rise to the concept of mobile health to assist individuals in maintaining a healthy lifestyle. The embedded sensors enable health applications to monitor, model, and promote healthcare. According to Lane et al., a smartphone-based application, 'BeWell'(which automatically tracks physical activity and social interactions and providing valuable, intelligent feedback), is described as helping to improve well-being [170].

Community health workers play an essential role in low-income countries due to the shortage of trained healthcare professionals. Despite being lightly trained, community health workers can assist in assessing and treating minor conditions and referring patients according to healthcare protocol. Technology can ease their work, and HCI researchers have made a difference by designing such a technology. Derenzi et al. describe how the health workers are provided decision support, as they gain access to the personal information [104] [103]. Comparative feedback provided by the system introduces competition amongst community health workers-which motivates some but demotivates others.

Though appropriately recorded information ensures stakeholder education [154], the real benefit for people with diabetes lies in having a multifaceted system with different modules, such as clinical monitoring, electronic health records, remote patient monitoring, epidemic monitoring, disease classification, and medical emergency response. The development of such a system can prove vital for many.

Table 2.1: Important Diabetes Information

Diabetes	Diabetes is a chronic condition known as the inability to regulate glucose levels in the bloodstream.
Type 1 Diabetes	Type 1 diabetes is an autoimmune disease. Insulin-producing beta cells in your pancreas are irreparably attacked and destroyed by your immune system. There is no clear explanation for the attack. Though genetic and environmental reasons may contribute to this condition, lifestyle factors do not.
Type 2 Diabetes	About 90 % of people with diabetes are type 2 diabetics. Diabetes type 2 occurs when the body does not properly use insulin. Maintaining a healthy lifestyle, including physical activity and a healthy diet, is important to prevent and manage type 2 diabetes. Nevertheless, people with diabetes require oral medications or insulin over time to maintain a healthy blood glucose level.
Glucose	Glucose is one of the body's primary energy sources. Sugar builds up in the blood due to a lack of insulin or resistance to insulin- and many health problems may arise.
Pre-Diabetes	The blood glucose level is higher than normal but not high enough to be considered diabetic. Diabetes risk increases for people with pre-diabetes.
Hypoglycemia	Hypoglycaemia [19] refers to a condition in which blood glucose levels are lower than normal. The main source of energy in your body is glucose. There is often a connection between hypoglycemia and diabetes treatment. Other drugs and conditions - many of them rare - can cause low blood sugar in individuals who do not have diabetes. Too little glucose in the bloodstream causes hypoglycemia. Confusion, dizziness, and poor coordination are consequences of this condition. There may be more severe complications, such as loss of consciousness or death.
Hyperglycemia	Hyperglycemia arises from too much blood glucose in the body. The symptoms of this condition include fatigue and blurred vision, as well as more severe complications such as nerve damage and ketoacidosis. These high blood glucose levels can lead to cognitive impairment, seizures, loss of consciousness, and, in extreme cases, death. Strict Control of this diabetic condition is essential to reducing the severity of its effects. A constant healthy blood glucose level can only be achieved by involving patients in monitoring and treating their condition.

Diabetes Self-Management

Self-management refers to activities and practices performed to maintain or enhance health and well-being [146]. Self-management of health conditions, including diabetes and heart conditions, involves the strategies and methods used to care for people suffering from these conditions.

Research [146] demonstrates that low-literate people with diabetes have limited health knowledge, do not undertake adequate self-management activities, and usually fail to use prevention strategies or follow-up care. This failure worsens their healthcare condition, thus increasing the need for hospitalisation.

Diabetes self-management involves people establishing lifelong and appropriate healthcare strategies to manage their diabetes and improve their quality of life and its expectancy [271].

Such self-management strategies require alterations to one's behaviour and following established procedures, including 1) Diet Management, taking appropriate food in moderated quantity, following a diet plan reduces HBA1C in people with diabetes; 2) Regular exercise establishes a healthcare regime; 3) Medication adherence ensures one follows a medicine regimen; 4) Reflection by regularly keeping a record of blood-glucose readings to monitor and understand their condition.

However, it is challenging for healthcare professionals to support and optimise adaptive coping strategies and behaviours; people with diabetes need to be more educated about their condition to play a crucial role in preventing complications. Hence, diabetes education is an essential component of self-management.

Besides diabetes education, personal motivation is crucial to managing diabetes by sustaining behavioural changes such as healthy eating and exercise.

However, a single cognitive intervention for diabetes self-management is ineffective, as human behaviour is complex and needs a multifaceted approach, including educational, behavioural, and psychological elements. Such an approach results in lifestyle change, self-efficacy, and empowerment [162].

The Role of Diabetes Education

Diabetes Education has been considered crucial since self-management is necessary to achieve reasonable glycemic and blood pressure control and so help to prevent health complications by promoting changes to improve their lifestyle [123]. The American Diabetes Association maintains that self-management information is the cornerstone for people [53] to understand their condition and how to live with it. However, barriers to timely diabetes education, especially in the Global South's resource-constrained and low education and literacy levels, undermine effective self-management [221]. It is noted that less literate people with diabetes who have never received formal education have an increased rate of diabetes complications. Intensive efforts are needed to raise diabetes awareness amongst these people by educating them.

However, though education is a necessary condition for diabetes management, it is not sufficient as most times, despite knowing about management strategies, many people struggle to implement them. Behavioural intervention is a cost-effective way to prevent and manage diabetes. Behaviour intervention depends on psychological factors and healthcare beliefs, with psychological factors having more influence than healthcare behaviour.

Psychology and Diabetes Management

Diabetes diagnosis has a significant psychological impact as a change in a person's view is critical. Therefore, human behaviour theories, which seek to predict and describe behaviour, are necessary for designing a technological intervention to enhance the lifestyle while living with different chronic conditions [213]. Psychological-driven models and their role in diabetes management are significant in understanding people's behaviour.

Strategies for behaviour change include counselling, cognitive re-framing, goal setting, problem sets, and didactic approaches. These stages apply to people with diabetes self-management regime:

1. A newly diagnosed person needs counselling to adopt strategies to self-manage their condition.
2. This counselling helps in cognitive re-framing, resulting in setting goals for diabetes management and successful goal achievement in ideal situations.
3. However, it may be necessary to overcome any barriers to goal achievement and fix them.
4. Finally, the fixed issue teaches a lesson about what to do for diabetes management.

The ***Health Model*** proposes that there are five dimensions underpinning health behaviour:

1. The first dimension is the perceived severity of the condition - the intensity of diabetes self-management behaviour depends upon the perceived severity of the condition.
2. Susceptibility is the second dimension, meaning that diabetes perception and influence count and affect people's behaviour.
3. The third dimension concerns the perceived benefit of applying diabetes self-management techniques.
4. The fourth dimension concerns cost, implying that patients will only use self-management techniques if affordable, such as taking medication as prescribed by healthcare professionals.
5. The fifth dimension is the essential trigger that prompts individuals to make a healthcare decision, accepting a recommended healthcare action. These cues can be internal, such as chest pain or wheezing, or external, such as advice or a family member's illness.

The ***Health Belief Model*** [16] deals with why people change their behaviour and how healthy interventions affect it. This model advocates that people respond when they think they are at severe risk and will benefit from behaviour change. Nevertheless, barriers to behaviour change are not significant. Health interventions for behaviour change are most effective when intervention addresses these perceptions, such as the content and sequence of topics for health behaviour change.

People transit the following stages in the health belief model. First, they perceive themselves personally at risk and under serious threat. Second, they know how to reduce risk and benefit from it. Third, They agree that the barriers are not too prohibitive.

The Health Belief Model uses 'motivation to change behaviour, and it works by informing people about how to reduce risk. Simple vocabulary and context can describe different behaviours in the chronic health condition life cycle; behavioural information is easier to understand than disease processes, physiology, and statistics. When behaviour change is the focus of the education intervention, people can eliminate complex topics in lists, graphs, charts, and drawings whose formats may be unfamiliar to patients.

The ***Self-efficacy Theory*** [171] uses a person living with diabetes initial perception or experience that a task is doable. This theory advocates dividing complex tasks into smaller, easier-to-do tasks as repetition improves confidence and builds skills and self-efficacy. Some examples of building self-confidence are practising insulin injections, selecting low-sodium food from a list, and demonstrating rehabilitation exercises. Recognition, rewards, or reinforcement matters for completing tasks. It is essential for those with poor literacy - who have often guessed wrong and have low self-confidence to perform a task. Therefore, this recognition and reward help boost their confidence and increase motivation. Technological interventions can enhance learning by providing positive responses, and these small successes then provide recognition, reward, and reinforcement.

The ***Locus of Control Theory*** considers the impact of control people believe they have on their health. As in diabetes management, people have different views as some think their health is in God's hands as the doctors and are less inclined to take preventive actions. Others believe they are responsible for their health and will likely adopt healthy behaviours. This Locus of control theory is particularly significant for cultures with low literacy (such as Pakistan). However, it is essential to note that the external locus of control is not restricted to those with low literacy skills. This belief can even apply to people who have received higher education. For people with an external locus of power, it may be difficult to motivate them to adopt new health behaviours, and therefore, it is better to present health interventions indirectly.

The ***Cognitive Dissonance Theory*** is helpful for education intervention to decide and maintain the chosen behaviour once we choose it. Cognitive dissonance is information or behaviour that does not fit into or is at odds with our overall knowledge, behaviours, and decisions. Therefore, there is unease when a person keeps doing things perceived as bad for him. The more critical a knowledge, behaviour, or decision is to a person, the greater the cognitive dissonance that may arise. These pressures triggered by cognitive dissonance are positive or negative regarding health behaviour. Ideally, people try to reduce cognitive dissonance in their lives. The greater the dissonance, the greater the pressure to make a change that will reduce it.

For diabetes management, the ideal behaviour consists of proper food intake and an exercise routine. However, after making an excellent decision, patients need reinforcement to keep them from regressing. Reinforcement offers additional supporting information and role models and addresses environmental factors. Research shows that people try to be comfortable in their minds, and when there is discomfort, they try to reduce it. Therefore, diabetes educators may promote a behaviour change by increasing discomfort about undesirable behaviour. Multiple reinforcements are needed to maintain the desired behaviour change because mental conflict may arise from peer group pressure to revert to old, unhealthy behaviours.

The ***Diffusion theory*** [11] provides insight into how to successfully communicate new ideas and help adapt to a community or population. Diabetes Management becomes effective when the community collectively participates and individuals support each other. The theory recognises that the information path may be: *Centralised* (top-down from an authority figure) or *Diffused* (Horizontally from a series of persons). When considering community, everyone cannot accept a new behaviour recommendation simultaneously. Due to personal differences, information-seeking behaviour is not the same for everyone. It can categorise behaviour into the following types: Innovators, who adopt new ideas quickly as they are secure enough to make a change and can serve as models for others. They base their decisions on rational thinking or expectancy; late adopters are more conservative, impoverished, or less secure. They are adopted more by social influencers (friends, role models) than by rational thinking, as, for example, health information heard at neighbourhood parties is likely to have more influence on behaviour change than advice from a health expert on television.

Thus, diabetes educators can use diffusion theory to set more realistic goals for their programs as they can speed up the processes of health behaviour adoption by initially targeting the message to the innovators and early adopters in the community.

The diffusion theory adopts the behaviour of early adopters and late adopters. For early adopters, it recommends the following steps for diabetes educators: Each Message should include: 1) A Rational description of health risks - the reason for risk. 2) The rationale for change - how the change will improve that risk. 3) The benefit - what benefits you will get if you change yourself. However, the model recommends the following to promote the desired behaviour of late adopters: 1) Stress the social influencers for behaviour change. 2) When early adopters have adopted the desired behaviour, revise the messages to reinforce the behaviour. 3) Stress the social influencers for the desired behaviour, and 4) Target the local community organisations, including peer role models. Technological interventions for diabetes self-management are expected to use the above strategies and deliver the message according to the person's categorisations - which can be based on a survey result.

Stages of Readiness theory addresses a person's different stages in adopting new behaviour and belief and recommends that health education address the needs at the current state of readiness. These stages are:

1. Precontemplative: not aware or considering a change.
2. Contemplative: thinking about change but not acting.
3. Action: Has made a behaviour change and is practising it.
4. Maintenance: keeping the behaviour via reinforcement and learning.
5. Termination: the end of the intervention; the behaviour is now a routine part of life and is no longer seen as a change that needs attention or reinforcement.

When applying this theory to diabetes management, the content of the health message delivered through a technology intervention must be according to the current state of readiness. Most newly diagnosed people with diabetes are ready to take control of their condition; consequently, health messages should be drafted, considering the need for knowledge and skill building to enable them to take better care of their newly diagnosed diabetes. In most cases, their 'readiness stage' will not be so prominent. Therefore, conducting a focus group can help identify and address the readiness stage later.

2.3.1 Community Support for Diabetes Management

The World Health Organization (WHO) [130] reports that self-management of chronic conditions such as diabetes significantly affects the population's health. A person's health is impacted when they cannot follow the recommended healthcare plan. Poor diabetes self-management leads to complications such as kidney disease, heart attacks, amputations, and blindness.

People with diabetes always need support, but physicians' time and resources may be insufficient to support people's diabetes self-management strategies adequately. Intensive care management interventions that include medical visits and contact with a nurse can improve diabetes and other chronic conditions. However, this approach is resource and labour-intensive and, therefore, less practical. Accordingly, to supplement the information given in clinical settings, internet use can guide by providing information about diabetes or enabling support group formation where people with diabetes can share information and receive or provide emotional support.

Online or in-person, communal support is vital for effective diabetes management [130] and can be from family members, friends, local community groups, or online social networks.

Family support is essential for the ageing population, and technological interventions can support the elderly to live in their homes longer. These interventions can inform caregivers through medication monitoring, fall detection, and activity awareness. Regular monitoring, particularly of the elderly, provides peace of mind for family members with more persistent information. For people with diabetes, the first contact point is often family, and their support positively affects psycho-social functioning. However, many adults lack adequate family and friend support for their diabetes self-management - which often results in inadequate diabetes management [85]. Social influences help to improve behaviour by encouraging people to share emotional experiences and informational support about diabetes. People engage in self-performance by using these tools to exchange experiences and behaviours. *'One Drop'* [23] and *'T2D Healthline'* [17] are such applications as people with diabetes can share their experiences and learn from other people's shared experiences.

Formal or informal, community-based education and support is also essential for people with diabetes based on people's perceived problems. *'PatientsLikeMe'* [27] - an application that enables people with chronic conditions to document their needs, medications, and other aspects of their health condition and share them with people with similar conditions to help them learn about, and reinterpret their symptoms, thus improving effective self-management strategies. When people with chronic health conditions report their successes and problems, they receive support and encouragement from the group, which motivates them to continue their self-care. This social persuasion results in increased self-efficacy.

Additionally, Peer Support can help people manage chronic health conditions as they discover and develop the capacity to take responsibility for their lives. Peer Support can be a substitute for family support and can help to reduce the burden on the family members, and the Peer Support models are practical and economical. They are effective because of the non-hierarchical and reciprocal relationship created through knowledge sharing with others - who have faced or are facing similar challenges - to promote mastery of self-care behaviour [130]. Sharing the same age and life experiences will lead to more understanding and empathy between peers and more effective learning when taught by peers who can share everyday experiences.

An online peer mentor community called 'CareMentors' [85] suggests that the mentor relationship is most beneficial to newly diagnosed users with diabetes as they feel a loss of control of their diabetic condition. Similarly, Community Mosaic (CM) [232] is a system developed for exchanging community behaviour using photos and text; the community focuses collectively on their behaviour as people post these pictures, not for their benefit but the benefit of the community members. CM helps to overcome the barriers to healthy eating.

Community Support Models

Community support improves diabetes management [271] as it allows people to communicate the issues and problems they are facing with others to find a solution collectively. This problem-solving approach, in turn, helps to reduce depression, heighten self-esteem, and improve self-efficacy and quality of life, leading to decreased mortality risk and improved health outcomes. This social network benefits everyone, including the elderly with diabetes who lack the advantages of an extensive social network available through employment and other family responsibilities.

Peer-support models are a type of community support that facilitates sharing information about behaviours and stressors to improve medicine adherence, diet, exercise, and glucose monitoring through phone calls and face-to-face meetings with peer counsellors [271]. Contact methods are sometimes mixed. Phone calls are a suitable medium because of their anonymity, but general reluctance to share numbers and the call cost, especially between geographically distant peers, are barriers.

2.3.2 The role of Technology in Diabetes Management

Current technology interventions use the following diabetes management themes.

Diet

Mobile applications, such as *'Fooducate'* [93], inform patients which foods are best to keep blood glucose in a healthy range. Food tracking is an essential aspect of diabetes self-management, and applications such as '*Glucose Buddy*' [15] and *'Diabetes: M'* support this activity.

Task Management

Keeping track of regular tasks for managing diabetes becomes essential, and reminder applications, such as *'MySugr'* [21] and *'Diabetes: M'* [8], help to complete these tasks.

Diabetes management requires boosting physical activity, and mobile applications such as *'BeatDiabetes'* encourage this. Some applications such as *'Glucose Buddy'*[15] and 'Diabetes: M'[8] track daily steps to record the exercise by that person while '*Glucose Buddy*' undertakes A1C reporting. Spotting diabetes management trends helps individuals reflect on these trends later, with *'OneTouch Reveal'* [24] being one such application. Another is '*One Drop*' [23], which provides automated alerts and regular health statistics.

Education

Research shows that people newly diagnosed with diabetes need to know the strategies for diabetes self-management and support in this transition to living with diabetes. Applications such as '*BeatDiabetes*' [2] support newly diagnosed people with diabetes information according to their needs and their issues.

2.3.3 Diabetes in the Global South

Diabetes has a significant impact, and according to WHO, its spread is more in the Global South, with 77 % of people having diabetes. Over 80 % of diabetes-related deaths occur in low and middle-income countries of the Global South due to poorer awareness and education about diabetes among less-literate people. Some factors affecting diabetes self-management routine are:

1) The *lack of information* about diabetes management affects self-confidence and motivation to manage it effectively.

2) Moreover, diabetes management is inhibited by the *lack of financial resources* for medication and medical supplies.

3) In South Asia, *physicians are considered authoritative people* and an authentic source of diabetes knowledge and management strategies, and people prefer them to other sources of diabetes information.

4) *Healthcare workers face communication problems* because of language barriers, as people with diabetes cannot understand the information.

5) The *unavailability of doctors in rural areas* led to the limited doctor appointment time, which causes a lack of motivation for many people, as doctors' regular reinforcement encourages more consistent diabetes self-care.

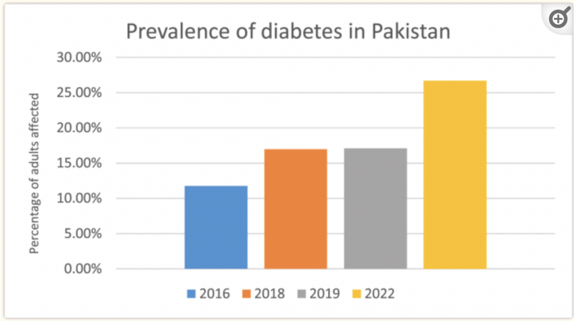
6) *Changing dietary practices* amongst people with diabetes is challenging due to its central role in different regions in the Global South, including South Asia. People with diabetes often lack a healthy diet as they are not aware of the food components and quantities in their diet.

7) Some *barriers to physical activity* are lack of knowledge, motivation, and misconception about physical activity. People are not good at diabetes self-management as they are unsure about their ability to prevent complications. Exercise has little cultural meaning for health and fitness, as it is commonly perceived that the elderly should rest. Extensive physical activity results in shortness of breath, which people perceive as an illness.

8) *Family and friends' support* play an essential role, and people with diabetes often need this support to manage their condition. Family involvement can encourage people with diabetes to remain motivated to follow different regimes to manage their condition more successfully.
Diabetes management becomes even more challenging in the presence of other comorbid conditions. Discordant chronic health conditions lead to medication and treatment plan conflicts, and medications can directly contradict each other. In addition, there is also likely to be a greater dependency on others to manage personal health.
Better diabetes management can be facilitated by addressing barriers such as the lack of knowledge, misconceptions, and lack of cultural adaptation. Specific facilitators, including trust in care providers, can be used for people with diabetes advantage by introducing diabetes management programs with care providers' advice. Moreover, adapting local and cultural diets and exercise regimes to conform to diabetes management standards can improve adherence to these strategies.
Information and Communication Technology (ICT) is vital to human development. The examples include access to knowledge about different chronic conditions; however, designing effective technology needs adaptation to users' requirements, which necessitates user involvement in the design process. ICT positively impacts the economic, social, political, and cultural contexts, facilitating development when people adopt and sustain it.
People's perception of technology matters - "people who believed that the task performed by the system was important would also perceive the system that performed it to be useful" [80].
Under-served populations interact with technology in diverse ways. HCI researchers work in the ICT4D to help understand how users use or can use technology. These emergent users have limited resources, leading to living in poor settings; they live in geographically dispersed locations with different cultures, languages, etc., and they have limited representation in ICT due to diverse requirements.

2.3.4 Diabetes in Pakistan

Regarding population, Pakistan is the fifth most populous country in South Asia. The country is estimated to have a population of approximately 22 crores based on the 2020 statistics [181]. Thirty-three million Pakistani citizens (26.7%) of Pakistani citizens suffer from diabetes, and this number is increasing every year.



In Pakistan, all the commonplace diabetes management challenges in developing contexts are seen, but some challenges may be unique. The Pakistani diet includes special carbohydrate-rich foods, recipes, and cooking practices. Furthermore, sharing large cooked meals with family is an essential part of social life, making it difficult for an individual to modify their diet, as people prefer their traditional diet and resist changing their dietary behaviour. These challenges are compounded by the widespread misconceptions about good and bad foods in a diabetic's diet. A lack of gender-specific facilities inhibits women from developing better exercising behaviours because exercise around members of the opposite gender is considered taboo, especially in rural areas [52].

There are also barriers to healthcare providers effectively communicating diabetes management strategies in Pakistan because of the difficulties accessing people living in rural areas, the diversity of languages spoken in Pakistan and the widespread concerns about the safety of medical advice and drugs. These barriers all contribute to a lack of willingness to participate in diabetes self-management through the limited available resources, such as online videos and pamphlets, and limited access to doctors' advice (their preferred type of support).

In Pakistan, for each known case of diabetes, there are two cases of undiagnosed diabetes and three issues of impaired glucose level [52]. When diabetes screening identifies someone's diabetes, other health complications may have arisen. The extent of the problem, together with diabetes prevalence increasing with age, suggests that diabetes screening should be compulsory for people aged over 45 years.

According to the World Bank's statistics, Pakistan's gross national income (GNI) per capita per year is around USD 1473.8 (PKR 415,621) [25]. The cost of diabetes management is higher than earnings, as the annual direct cost for each person is estimated to be PKR 93,677 - which is equivalent to 332 USD [62], – hence spending on diabetes medicine can be a significant proportion of income. Besides the cost challenges, people with diabetes also have limited access to doctors - for example, if a diabetic patient visits a diabetes clinic four times a year, their four hours with the doctor still leave over 8000 hours where they are unsupported. They cannot have their questions answered or their condition monitored, so this unsatisfactory situation requires a better system to provide ongoing support. A phone helpline system is an easily accessible medium for diabetic patient support and is considered an excellent option to guide in emergencies.

German research demonstrated the effectiveness of diabetes helplines for supporting glycemic control [46]. Similarly, a study showed the effectiveness of the helpline to self-manage diabetes for newly diagnosed people having no, or very little, information about diabetes, especially in glycemic episodes such as ***hyperglycemic*** situations [46]. The UK's NHS direct helpline is the world's largest telephone-based service and has supported over three million calls, providing important, culturally sensitive and practical advice to empower and reassure people with diabetes.

Self-management of diabetes in the Pakistani context depends on factors such as age, education and gender. Age influences diabetes management differently in different cultures; for example, older people with diabetes from China are more likely to take care of themselves [271]. Pakistan has mixed behaviour towards diabetes management depending on personal motivation, behaviour, and resources [270]. Education at higher levels influences diabetes management positively [191], but the role of gender in diabetes management remains unclear. Diabetes self-efficacy is the judgement of one's capability to plan, monitor, and perform activities to control diabetes. Improved diabetes self-management behaviour results in higher self-efficacy, which is behaviour-specific. In Pakistani culture, strong family bonds are essential and highly valued, and family members influence medical treatment and decision-making rather than this being solely decided by the individual.

2.4 Information and Communication Technology for Development (ICT4D) - An Overview

Information Communication Technologies, delivered with mobile phones, smartphones and computers, promote and support human development. In the last few years, there has been an ongoing increase in ICT technologies in low and middle-income countries(LMIC). ICT4D refers to using ICT to eliminate poverty, fight diseases and get everyone to be educated in primary education [18]. There are a variety of development domains, such as health, agriculture, enterprise, and poverty alleviation [168][33]. ICT4D's contribution to social and economic development has resulted in it receiving growing attention [60].

According to Heeks, ICT4D consists of initiatives by governments, businesses, and international organisations. Furthermore, there are different phases in ICT4D projects, such as initiation, implementation and post-implementation. The Implementation phases involves technology selection, procurement and installation, assimilation and use and adaptation of technology [57].

In ICT4D projects, the involvement of local and foreign researchers/actors complicates this process. In the Global South, many social structures are present, including designers, users and any of those affected by the process. Actors of the process are from different backgrounds, and technology preferences may vary. ICT4D literature reported that external donors with little trust in local actors decide to handle financial transactions themselves which; therefore reduces, influential local actors cooperation. Local actors are of primary importance in ICT4D projects, and their involvement eases the participatory aspects of project.

ICT4D projects have a high failure rate — including sustainability failure — systems abandoned after successful implementation. It is reported in earlier studies that there is a failure rate of 85% of projects alone in the government sector. Moreover, less than 60% of projects in ICT4D sectors have achieved or are expected to achieve their desired results. Sustainability beyond initial investment is an important goal in the ICT4D sector.

A country's economy affects its citizens' mobile phone usage; therefore, in Global South countries with developing economies, 46% of people own a smartphone, compared to 76% in the countries of Global North. Globally, the highest smartphone penetration rate among the population is in Germany, and the lowest penetration rate is in Pakistan [5]. This directly affects opportunities presented by smartphone applications to support individuals in caring for their healthcare, education, etc.

2.4.1 Thematic Analysis of ICT4D

A thematic analysis of ICT4D generates the following themes:

Locally Tailored Technology

However, even without smartphones, basic mobile phones can still support information given through a simple phone call, and especially through IVR technology. Many ICT4D research projects focus on IVR technology as a potential information-sharing medium with otherwise hard-to-reach populations. Low resources mean that such populations have reduced access to technology, and HCI researchers need to understand how these populations access and use technology. It has been stated in [83]:

> *"The developed world has witnessed a trend towards cloud-based services, green computing and so on whereas, in developing countries which are typically characterised by a high prevalence of cell phones, technology interventions should evolve differently".*

According to Joshi et al., technology should be innovative and compatible with cultural values. The success of this innovation depends upon factors such as the quality of the system or information, user satisfaction and the impact of the information system on an individual or organisation (DeLeon and Mclean) and even being perceived as successful by people not directly using it (Roger's Model) [147]. However, the system's success is not determined by how often it is used but by its usefulness. Seddon and Kiev argued that the high use of a system is not directly linked to the system's success, as despite its shortcomings, users might have no other option but to use it, and they argue instead that a technological system is helpful if it satisfactorily performs an essential task for the user [147].

According to Joshi et al., the Technology Acceptance Model (TAM) proposes that intention leads to a behaviour, and behaviour then carries out that intention. Two perceived behaviours for technology are ease of use and usefulness. Technology Acceptance Model 2 (TAM2) suggests that the technology acceptance model should incorporate the following factors: relevance, voluntariness, experience, subjective norm, image, job, output quality, and demonstrability. The integration of TAM1 and TAM2 leads to TAM3. [147].

Emergent Users

HCI researchers in the ICT4D field help understand how underserved people use technology. Technology users in the ICT4D sector are often referred to as emergent users and are categorised as follows:

1. Unexposed Stage - Not exposed to technology,
2. Novice Stage - Some exposure to technology,
3. Rote Learner - Low usage frequency,
4. Fluent -Lack of conceptual model,
5. The competent - The technology used by emergent users depends upon the following attributes:
   (a) Purchasing Power: Low purchasing power delays exposure to technology.
   (b) Literacy: Low literacy creates barriers to learning by limiting the cognitive abilities needed for abstract thinking and making it difficult to input text and read interfaces.
   (c) Low resources affect the population's interaction with technology differently.

According to Moore's Model, in the technology innovation process, different actors (same as emergent users) are the innovators, early adopters, early majority, late majority, and the laggards. These actors are characterised by the time taken to accept the technology [147]
The acknowledgement and incorporation of people's perception about technology matters: "People who believed that the task performed by the system was important would also perceive the system that performed it to be useful." [147]. The question arises of how to determine the participant's perception, mainly when geographical and cultural factors affect a person's priorities, necessitating the use of human-centred design (HCD) that can holistically involve users and employ different methods to improve the creation of a socio-technical system [163].

Story Telling

The value of storytelling is well understood in HCI and is employed in qualitative research, co-design and participatory methods [200]. Stories can be categorised based on content; the following two types are worth considering.

1. The stories design team creates fictional stories about a novel design concept.
2. User stories are collected from the prospective users of the system. Thus, they are a collection of actual experiences and emotions.

Overall, stories help to understand different views in varied cultural contexts. According to Frohlich et al., low literacy levels in rural areas of the Global South make textual information sharing challenging [115]. In such circumstances, storytelling becomes particularly important to gain insight into users' perceptions, build empathy and collaborate emotionally.

ICT4D Sustainability

The ICT4D project's sustainability is complex as it involves multiple actors from different backgrounds and social structures and has varied technology preferences. Most ICT4D initiatives are donor-funded and involve multinational enterprises. Thus, foreign actors are critical in the implementation process. Local actors are of primary importance in ICT4D projects, and their involvement eases the execution of the project. ICT4D literature reported that external donors with little trust in local actors decide to handle financial transactions themselves. However, utilizing influential local actors reduces external donor cooperation [95].

ICT4D projects are divided into phases: initiation, implementation, and post-implementation. The implementation phase involves selecting technology, procurement and installation, assimilation and use of the technology, and adaptation.

Role of Gender in ICT4D

In recent decades, despite the focus in ICT4D on addressing women's needs, the impact of these technologies has been limited due to prevalent gender norms. Women's equal participation in technology is a global concern, especially in the Global South, where women's participation varies according to geography, religion, culture, region, etc. For example, women's lives in rural Africa differ from those in urban India. These varied circumstances yield different attitudes towards technology [134] and impact the acceptability of ICT4D technology [135].

The HCI4D researcher has relied upon the voice forum in diverse groups, including low-income, low-literacy, rural, tribal and disabled communities. Compared to men, women's participation in these services is non-existent. For example, participation in Bang and Swara was dominated by men. In [249], a voice-only social media forum investigates the reasons for low women's participation - using High-Level Usage Patterns which demonstrated the significant effect of gender on total calls, likes, and dislikes - finding that women faced discrimination and encountered abusive content, flirting, threats and harassment.

Consequently, it is recommended to adapt the features of the voice-only forums to welcome women, prevent harassment and evolve behaviour through the society's good practices and policies. Changing service perception may lead to improvement in user behaviour. Therefore, existing rules and patterns of technology adoption may not support the behaviour change promoted by the researchers. The activity of designing for women's empowerment should consider all stakeholders. Technology can be used as a probe to better understand socio-technical aspects before preparing for the intended purpose - this also applies to other parts of ICT4D.

Ethics in ICT4D

Since ICT4D lacks a universally accepted definition due to variations in different cultural norms - and consequently different levels of acceptability across various cultures, ICT4D research is complex and has nominal outcomes due to social structure differences between different parts of the world.

Dearden et al. refer to bungee research [99]. It isn't easy to make informed decisions about research without a thorough understanding of the social, cultural, and linguistic environment. Most local communities view foreign researchers as essential visitors who significantly impact the communities with which they interact, regardless of their status in their home country. Similarly, Heek points out the frequency of gaps due to translators' use in ICT4D [127].

Moreover, there are concerns in ICT4D regarding the conflict between the researcher's goals and the development goals. Therefore, Dearden et al. proposed that ICT4D researchers who are new entrants to a particular region should get mentorship in their social setting [99]. The researcher's visiting plans should target transferring responsibilities and project ownership to the members of the local community and researchers. Additionally, the senior researchers can occasionally visit to demonstrate a commitment to work and maintain relationships.

Consistency plays a vital role in ICT4D research, and the research participants must be constantly involved over time.

Designing for People

ICT4D research can be categorised as 1) Ethnographic Action Research. 2) Inhabitant research and regulations 3) Locally produced media 4) Interview and diary study 5) Observation and workshop. The project inclusion goals should be explicitly added either in the research goals for the project or should be managed alongside research activities.

Working with people is vital in technological evolution, aiming for longer-term technology. Technology's focused but situationally aware aspect is essential to avoid designing and delivering against customer expectations. According to Dearden et al., researchers should seek individually and collectively - to be vigilant and reflexive to achieve desirable solutions meeting the needs of different stakeholders [99]. The linking researchers or the mediators between the community and research group can provide mentorship and assist in overcoming social distances. Therefore, training the target stakeholders matters in parallel with or as part of the research project [99].

Overall, as described above, different themes in the ICT4D sector are significant and allow this sector to be considered from different perspectives. The practical application of ICT4D mostly depends on using mobile phones, including smartphones and basic phones, as described in the next section.

2.5 Application of ICT4D - An Overview

The ICT4D sector has played an important role by promoting development, improving access to services and empowering individuals and communities in various ways. This includes using mobile phones in various aspects, such as access to information and providing support for the healthcare, agriculture and finance sectors [33].

ICT4D is delivered mostly using smartphone applications. Globally, smartphones provide new opportunities for communication, knowledge-seeking, and other activities. The smartphone application design must be adapted to an ICT4D environment with limited literacy and resources, including internet access [169]. Additionally, mobile applications can be adapted to work offline and have interfaces designed for less literate users [122].

However, in remote rural areas where mobile services are not readily available due to the lack of smartphone or mobile infrastructure, IVR provides an opportunity to create an inclusive environment for people with low-end phones. Using an IVR system becomes essential when smartphone application use is not an option.

The next section discusses the prospective use of mobile phones within the ICT4D sector.

2.5.1 Smart Phone Applications

With the continuous development in the ICT4D sector, the use of smartphone applications has become popular. In many countries of the Global South, a diverse user base exists due to multiple factors such as digital literacy, diverse linguistic abilities and various cultural backgrounds, making it challenging to adapt the mobile application to the needs of a wide audience. Previous research highlighted attempts to design smartphone applications in the localised context, as discussed below:

One approach is presented in [211] to use voice-over with physical objects having QR codes to identify them. The drawback of this approach in reaching many participants is that all participants must be supplied with the material containing QR codes and the reading content. Even if the accessibility of the reading material having QR Codes is not an issue, in that case, reading content containing information about different diseases can be supplied to IVR system users so they can take photos. The difficulty experienced with our target audience during this study is that they have basic phones without a camera, making it challenging to use this technique.

The visual display is another technique that uses displays located in busy town centres or inside quiet village cafes [180]. The digital display, combined with the option for the targeted low-literacy users to listen to the system, can prove helpful. This information spread through this interactive media can prove motivating for many.

Brown et al. discussed Water Alert [79] - an application that informs about water quality in South Africa - where drinking water is often not of an acceptable standard. This prototype is a symbol-based design perceived as appropriate for its users. The consumers' understanding of water quality increases with this application. However, the design of the applications adapted to a low literacy context is challenging.

Mehdi et al. discussed the challenges encountered while designing smartphone applications for communities in the Global South [179]. According to them, limited education directly affects navigating a smartphone application, even when the interface is text-free. Therefore, design recommendations for UI hierarchies for people with limited education are provided. These recommendations are 1) Further support for good formal education, 2) Simplified UI, keeping navigational UI linear to the extent possible and limiting the hierarchical navigation, 3) UI designers should not assume that the reading inability is the only obstacle and need to be facilitated for non-literate users.

2.5.2 Interactive Voice Response

IVR systems can benefit countries in the Global South - characterised by limited technology and lack of communication infrastructure access. The Global South IVR systems have been implemented in various contexts, such as healthcare, agriculture, education, and disaster management. One of the most significant benefits of IVR systems in the Global South is their ability to reach even those without the internet or smartphones. Users can access information and services through voice navigation with a basic mobile phone. This makes IVR systems an effective tool for addressing the digital divide in many countries in the Global South.

IVR Usage

Despite IVR use being straightforward, disseminating it to those unfamiliar with technology and the unconnected masses is still challenging. IVR is a technology that can reach literacy-challenge, non-tech-savvy users; the users must be adequately trained to use the technology [149]. Furthermore, using IVR can keep users motivated, engaged, and grounded in these voice-based interactions. Moreover, ensuring sustained user IVR engagement can still be difficult due to the challenges of making this service appealing and attractive. In summary, though ICTD requirements for training, dissemination, engagement, and retention can be supported, they are nevertheless difficult to achieve simultaneously.

IVR Examples

Several IVR applications for the ICT4D sector have been reviewed:

Mobile-Vaani [227], operates as follows: 1) User placed a missed call to a central server. 2) The server calls back 3) Users can record and listen to calls. 4) Moderators check the recordings' quality. 5) There are a variety of topics, such as job openings, social issues, songs, etc.

Agarwal et al. propose an alternate web for the underprivileged population living in areas without access to the internet; this web is known as 'Spoken Web' [45]. In developing countries, the use of cell phones is significantly higher than the use of the internet, and low literacy makes voice communication possible. The concept behind the 'Spoken Web' is to enable the construction of voice-only sites that can be created and browsed using an ordinary phone line. In other words, the 'Spoken Web' works as a service on telephone infrastructure like the World Wide Web works on internet infrastructure. It supports users without needing extra infrastructure and extensive investment from the end user.

Dhanesha et al. [105] presented an audio navigation technique to navigate a large amount of audio content over the phone delivered with the 'Spoken Web'. Usually, while navigating a website, content that is less interesting is skimmed easily, but this skimming is difficult with audio content. Therefore, Dhanesha et al. introduced navigation features in the 'Spoken Web', such as medium speed control, markers, pause retrieve and high-speed control. The evaluation of navigation features proved their usefulness and usability [105].

Raza et al. [222]proposed an IVR-based inclusive social network in, which reached 10,000 people and enabling them to share 44178 posts and 343542 votes. It is noticeable that amongst Baang users, 69% were blind.

Patel et al. contributed by developing an IVR system called 'Avaaj Otalo' [207]. This IVR system delivered the latest information about farming practices, enabling farmers to interact with agriculture experts by posting their questions.

IVR systems - 'Avaaj-Otalo' (proposed by Patel et al.) [207] and 'Sehat-ki-Vanni' (proposed by)[155] were able to help community members by delivering information in their respective settings. Because IVR via phone lines require no formal technology literacy, it can overcome barriers to technology adoption.

Vashistha et al. contributed by outlined a new ICT4D approach by developing a scalable voice forum, as they enabled the integration of commercial tools (Voxeo Prophecy) and freely available services such as YouTube to enable rapid development of an IVR system. This tool, called IVR Junction, enabled phone-based users to connect with internet-based users. Both users could contribute and retrieve messages from a repository hosted on the Internet. The moderator reviewed the content before dissemination. Additionally, IVR Junction scales across the geographically distributed access points [250].

Moderators can assist with managing IVR content, usually on the server side [159]. Community radios such as 'CGNet-Swara' [185] and 'Gram Vaani' [184] are examples where moderators can sort and rate IVR radio content.

Kumar et al. presented the concept of the worldwide telecom web (WWTW), a network of interconnected voice sites created by users and hosted in the network. WWTW enabled the underprivileged population to join the next-generation converged networked world. WWTW connects Voice sites, a voice-driven application with one or more voice pages hosted in telecom infrastructure. Voice sites have specific numbers and can be accessed by calling the associated site number, which leads to further interaction with an application using a voice interface. Different voice sites are linked to each other through a link to the following.

This research, however, presents several challenges, such as usability (a simple interface to reduce the cognitive load on the caller), browsing (keeping track of site numbers becomes difficult), scalable search (searching a large number of sites is challenging), accessibility, and infrastructure [166] [165].

Raza et al. presented an IVR-based inclusive social network known as 'Baang' that aims to achieve greater spread and uptake along with deeper and long-term engagement with the system. Baang viral nature helped to overcome user recruitment and content diversity challenges. A survey found that 69% of Baang users were blind, therefore showing the greater acceptability amongst people with visual impairment [222].

IVR Design

The normal ageing process is usually accompanied by vision, cognition, and physical impairments, which impact web usability if designs are not senior-friendly. Moreover, a negative association between literacy skills and age appears to increase after sixty-five years of age [161]. There has been substantial evidence that literacy declines with age, regardless of education level and cognitive impairment. Therefore, an IVR system that minimises input reliance and, thus, the need to remember and process new information and comprehend text simultaneously can benefit the elderly.

In [262], a hierarchical system is proposed for reusable IVR, emphasising how the IVR operates, but this study focuses on the IVR system's working. This paper defines IVR system functionality depending on voice cards (recording and playing sound), functionality layer, and XML. The XML file structure helps to create the menu configuration from XML files. This integrated IVR design using different layers, such as Presentation and Service layers, helps develop a configurable and reusable IVR as a call centre module.

The basis of the IVR system is the interaction between telephone and computer as a dual-tone multi-frequency (DTMF) or touch-tone interface. Touch-tone systems have input entered by pressing numbers on the telephone keypad, and the output is a series of prerecorded messages [75]. One of the limitations of DTMF input is its user interface.

Automated speech recognition (ASR) technologies are often unavailable in many languages, such as the Punjabi language in Arabic dialect. Therefore, IVR interfaces should exclude the use of ASR technologies. The lack of ASR systems in the Global South involves significant challenges in converting the spoken language into written text. The diversity of languages spoken in the Global South makes it impractical to develop an ASR system separately for every language. In this challenging situation, DTMF technology helps by enabling user interaction with automated systems using touch-tone keypad inputs. Particularly in the ICT4D sector, DTMF is preferred over speech input [206] for accuracy, limited vocabulary, language and accent independence, speed and efficiency, privacy and excellent consideration, and low resource requirements. Privacy can contribute to using DTMF over speech as these button presses remain confidential when transferring to the network.

The three components needed to create an IVR model are [233]:

1. **Get input**, which has been optimized for DTMF use in healthcare;
2. **Error-recovery**, consists of graphical content (icons or images), speech, and explicit and implicit confirmation prompts;
3. **Playing Results** (the output) should be presented in the local language with particular attention paid to translation, personas, and metaphors relating to the user interface.

The appropriate IVR menu length plays a significant role in IVR usage, and many researchers agree that short IVR menus help with the human memory system. However, some studies argue that reduced menu length and complex hierarchical structure burden users' working memories, leading to inadequate performance and satisfaction [91].

Another way of designing an IVR is the dynamic structure created during runtime without requiring programming [151]. The IVR system becomes the front end of the call centre, and this computing system paradigm shifts the conventional call centre agents to a self-serving system. Therefore, it allows minimal interaction between customers and companies, thus optimising the resources, and the IVR system becomes vital as it streamlines the staff according to the incoming call query. This automation generated with the IVR becomes essential for the optimal design and management of call centres, which involves increased revenue and decreased cost. However, currently, an IVR design needs an experienced programmer's efforts. The proposed, dynamic IVR platform proposed uses actions to create customised flows [151].

According to Kharal et al., although IVR systems are comparatively more costly than conventional web hosting, advertisements have the potential to minimize the financial commitment for the host organisation [157]. Using these IVR systems, illiterate people with diabetes can receive medication reminders, symptom descriptions, and self-management tips to assist them in monitoring their condition.

IVR for Healthcare.

IVR has been used to address the healthcare needs of people with diverse literacy levels and IVR has demonstrated its ability to be used by populations with limited literacy in these systems. It does not require a reading ability or a basic level of numeracy to select options, and it is suitable for individuals with limited technology access, the system can be delivered on mobile phones and landline numbers, and the technology is cost-effective.

The use of IVR for healthcare is equally widespread in the Global South and North, and several examples are now presented. As cited previously, the NHS Direct helpline available in England and Wales since 2000 - is the world's largest telephone-based service and has supported over three million calls, providing culturally sensitive advice that is practically important in empowering and reassuring people with diabetes.

The NHS helpline usage survey showed that people living in low socio-economic settings were less likely to have used the service than others [164]. This creates a challenging situation as the people living in low socio-economic settings may be the greatest beneficiaries of this service and, therefore, it is necessary to work with this user group to identify the drivers behind their behaviour and how to better engage with them in their diabetes management journey. Similarly, a patient medicine helpline service is available from some parts of the NHS to provide medicine information to hospital patients and carers [256].

'Baqai Institute of Diabetology and Endocrinology' (BIDE) tested the first diabetes helpline in Pakistan in 1996 [46]. BIDE initially assessed people with diabetes by taking their medical history, taking their blood pressure, and examining their feet, followed by nutritional counselling and diabetes self-management information. People with diabetes develop acute complications because of poor diabetes control, and prompt advice given to people with diabetes can help reduce the frequency of complications. The idea behind the helpline is to assist in hyperglycemic/ hypoglycemic emergencies and provide support to achieve target glucose levels and guide people with diabetes and their carers. Notably, people who used the service several times and learned to manage diabetes are less likely to call the system.

It proved effective in aiding newly diagnosed people with little information about diabetes, especially in glycemic episodes such as hyperglycemic or hypoglycemic. This helpline provides a 24-hour facility to its registered 2665 users, initially by taking a detailed history, including blood pressure and examination of feet, followed by dietary counselling and diabetes self-management information offered on a one-to-one basis. People who have used the service several times and learned to manage diabetes have a reduced likelihood of calling the system.

Several projects have used IVR to address the healthcare needs of less literate people in the Global South. For example, [149] demonstrates the successful deployment of the IVR in India. The IVR system was named 'TAMA', and it facilitated better AID self-management, therefore encouraging future researchers to follow this path for the management of chronic health conditions such as diabetes. 'TAMA' called its users thrice a week to remind them to take their medication, promoting medication adherence. 'TAMA' interactions with users were saved in a database as detailed logs, such as noting how many participants accessed health tips, symptoms, etc. The testing of the 'TAMA' features involved using a PIN to secure participants' IVR usage details, and it became easy for people with AIDS to protect their identities.

[242] utilized IVR for Syrian people with diabetes, and it provided medication reminders, descriptions of symptoms, and self-management tips.

A healthcare intervention [263] provides personal information to support community health workers, and using the PD approach led to creating a system providing voice and web-based feedback for users having poor literacy. The comparative input provided by the system introduces competition amongst community health workers which may be either motivating or demotivating.

To support the management of Type 2 diabetes and maternal health in two communities in North India, a real-time IVR platform called 'Sehat-ki-Vaani' was implemented [155].

Peer support plays an essential role in healthcare and IVR can support connecting peers as reported in [132] where peer groups proved effective amongst older adults with heart failure; these groups were formed based on a baseline survey concerning taking medication, exercising, modifying diet, etc. The careful design of an IVR system can help manage diabetes by achieving goals and addressing barriers to adherence by encouraging users to remain motivated in their healthcare regime[202].

In [103], IVR supports community health workers by allowing them to communicate. With these systems, illiterate populations can use IVR due to its minimal literacy and numeracy requirements. It is possible to deliver the systems on mobile phones or home phones, and the technology is low-cost, so it is suitable for people with limited technology access.

Research demonstrates that IVR can moderate health-related behaviour, and further investigation is recommended [215]. Despite IVR limitations being a voice-only medium, it is a helpful tool to engage with rural populations in a time and resource-efficient way [251].

PD methodologies in developing IVR systems ensure the elicitation of user needs and lay the foundation for a usable system that contributes to improved communication and service delivery. Therefore, this approach helps create a more effective and user-centric healthcare IVR system.

The next section gives an overview of the use of PD methodologies and particularly highlights the use of Personas, Videos, Wizard of Oz, Design Probes and the effect of cultural differences on the PD process.

2.6 Participatory Design.

Traditionally, user-centred design assigns users to test and evaluate the system. PD encourages user engagement in the design process that leads to designing a usable system [223]. This active and direct user involvement in the design process leads to defining - PD - as a social activity for societal transformation through a democratic process that supports innovation [244]. PD enables users to inform the design process by sharing their needs and preferences, such as users' technology preferences, and this approach delivers a more tailored system [240]. PD processes involve the use of brainstorming activities along with low-tech prototyping tools to demonstrate the participants [223].

In the Global South, different areas have cultural differences. According to Hofstede et al., culture is defined as the [137]:

> *"The collective programming of the mind which distinguishes the member of one group or category of people from another".*

In other words, it defines people's behaviour and sets standards for appropriate and inappropriate behaviours. Culture influences people's actions, feelings, perceptions, and beliefs. The 'Hofstede model' is recognised for understanding cultural distances and has different cultural dimensions, two of which are discussed below [137]:

1. Power Distance is the degree to which members of a society accept differences in power and authority. High power distance means people accept power inequality as good and acceptable; in contrast, low power distance means that society considers all members equal. The power distance also influences PD practices in different countries, and people participating in PD activities in countries with high power distance have different expectations than countries with lower power distance.

2. Individualism and Collectivism: Collectivism is the degree to which individuals are integrated into groups (societies in which people are integrated into strong, cohesive groups such as uncles, aunts and grandparents). Individualism refers to the loose ties between society (individuals are expected to look after only themselves only or their immediate family).

Moreover, the development opportunity depends on users being active participants - not passive consumers - in the development process. Active behavioural responses imply that consumers decide about approaching or avoiding a technology intervention - in contrast, passive behavioural responses indicate that consumers make little effort to change their status and would instead come or prevent passively. Therefore, the PD approaches require local adaptation to show commitment and ownership. Active and passive behavioural responses depend on the Power distance [49].

Alborzi et al. advocate that the start of the project is when the expectation should be set. This enables teams to know each other better and work together effectively [49]. Druin et al. used brainstorming as an initial part of the design project; it encourages the feeling that anything is possible [106]. PD can be described with approaches based on the degree of participation. Moreover, PD has different modes: informant, balanced, and facilitated. Informant design has no contribution of design participants; facilitated design has a 100% contribution of design participants, and balanced design has a 50 % contribution of design participants.

PD methods often rely upon interviewing, and conducting interviews are often used for understanding the ICT4D project domain. The involvement of foreign and local researchers leads to differences in interview quality. Therefore, it can be said that there is a difference between foreign and local interviewers. Here, foreign interviewers are characterised as researchers who need a translator to interact with the PD participants. However, local interviewers grew up in the same neighbourhood as the participants, so they could speak their language, etc. A translator is often required when a foreign interviewer conducts a study; the response bias resulting from the presence of two interviewers rather than a single interviewer affects the user's demand characteristics. Differences also influence low-income individuals' attitudes toward social status between local and foreign interviewers.

Another determining factor to PD research is the high travelling costs due to dispersed geographical and time zone differences that make remote synchronous communications difficult. Moreover, poor telecommunication infrastructure can be a hurdle for activities that could be followed up from a distance.

This research elaborates on how participants were engaged in a PD process by utilising different PD tools, including Personas, Videos, Narration [195], and Scenarios - discussed briefly below:

2.6.1 Personas.

User personas are fictional user descriptions that facilitate the interaction between users and designers. A persona is a model of a user who focuses on a specific individual's goals while using an artefact during the system design process [66]. By developing personas, one can understand and distinguish between the characteristics of the intended users, allowing designers to focus on features specific to a target audience. The fictionalised setting of Persona helped develop assumptions about target audiences and helped users work in different contexts. Without personas, it isn't easy to communicate the assumptions about the product user [219]. Personas allow designers to focus on features specific to a target audience.

There are different types of personas, including goal-directed, role-based, engaging, and fictional personas.

1. The goal-directed persona focuses on how the technological solution meets user requirements and examines the system workflow that may help users achieve their goals (e.g. Cooper [92]).
2. A role-based persona is based on the user's behaviour, goals, and quantitative and qualitative research data e.g. Grudin, Pruitt and Adlin [219].
3. Engaging Personas use stories to engage users and gain insight into their perspectives e.g. Nielsen [195].
4. A fictional persona is developed from the researcher's personal experience rather than direct research, and assumptions are made based on previous interactions with the user base e.g. Blythe [67]

Designing personas involves risk, and creating them correctly can be challenging [219]. Personas can be created in two ways:

1. Qualitative Persona creation (QUAL): Manual data collection and analysis. Examples of data collection can be focus groups and interviews. The QUAL approach has Complexity, Depth, Descriptive, Emotions, Empathy, Evaluation, Experiences, Personalised, and Specificity.
2. Quantitative Persona creation (QUANT): The QUANT approach relies on automatic data collection and analysis. The QUANT approach has several strengths: Evaluation, Precision, Presentation, Repeatability, Simplicity, Speed, Testing, Validity, and Volume.

Combining QUANT and QUAL approaches captures current user behaviour and better interprets the complexities of different situations and users. The mixed approach has strengths such as Completeness, Diversity, Flexibility, Test-ability, and Support. Building awareness about Qualitative and Quantitative persona creation methods and knowing each option's strengths and weaknesses are vital for persona users.

According to Nielsen [196], the process of Persona Creation is an opportunity to enter the lives of the users. Furthermore, the number of personas to create for a project depends on how many users are within the focus area. The number of personas also becomes important due to our memory limitations of who we can work with and remember; therefore, more than six are usually not recommended. Another benefit of using personas is that they help prioritise audiences and lead to focusing on the most important user sets, and therefore, the right problems are solved. Furthermore, Nielsen recommended ten steps divided into four main parts: 1) Data collection and Analysis, 2) Persona Description, 3) Scenarios for problem analysis and idea development, 4) Organizational acceptance and team involvement [196].

According to Cooper, personas are used as a discussion tool or a medium of communication [219]— 'Why 'Does person X' use this tool?' and this helps in knowing user behaviour in different scenarios. The scoring technique for personas helps to find the usability of a feature. The scores and their values are discussed below: -1 - Persona confused or annoyed with the feature. 0 - The Persona does not care about the feature. +1 - Feature presents some value to Persona. +2 - The feature does something valuable for the Persona and is loved by the Persona.

According to Nielsen, personas are data-driven are usually developed using ethnographic fieldwork and user interviews. Furthermore, one of the limitations of manually creating personas is that they are based on a small amount of data, so quantitative method use is inappropriate.

'Persona Development' usually uses 'Narration' to help collect the subjective knowledge of the study participants' relevant personal experiences by utilising their unconscious knowledge. Therefore, the ideation phase helped to distinguish personas based on their characteristics. Personas helped to establish the conversation with participants and capture storytelling results with the narrative scoping.

The **Theory of Action** is a process of idea generation, and ideas depend upon the subject's unconscious and spontaneously created knowledge (Idealistic Theory), as shown in the figure. Therefore, the theory of Action in this research relates to presenting a Persona to users in the PD session. In contrast, generating ideas about the Persona is associated with the idealistic theory. The simplest method of creativity is 'Balloon', with its two stages; the first stage helps to generate 'Divergent thinking' ideas, and the second stage focuses on 'Convergent Thinking' [175].

2.6.2 Narration and Design Videos

Narration is an act of storytelling that facilitates conveying messages, including information, to less literate people.

Rosson et al., defined scenarios as stories - they consist of a setting or situation, with one or two actors with personal motivations [225]. There is a close similarity between the term highlighted by Rosson et al. - 'Actor' and the team highlighted by Cooper and Nielsen, known as 'Personas'.

According to Rosson et al., scenarios involve actions and events leading to an outcome. He further relates the scenario with a usage context with specific goals, plans and actors' reactions. Scenarios are helpful for designers to envision different possibilities and get a concrete solution. Scenarios enable rapid communication about different possible situations and concerns amongst different stakeholders.

The close connection between scenarios and stories leads to exploring this topic in detail. Storytelling is used for ideation and has the potential to benefit creativity while collaborating, which is known as 'Creative Narration'. According to the 'Idealistic theory', ideas can be either dependent upon a subject's unconscious or are spontaneously created. However, according to the 'Theory of Action', ideas creation results from the process followed to generate them [175]. This research led to the creation of ideas using Personas. Narration helps to know the subject's unconscious and spontaneously created knowledge. There is a specific process followed to generate this unconscious knowledge.

The videos have previously supported NGO practices, such as instructional videos for maternal healthcare explained in [167]. Video watching has become a common practice worldwide, and in the Global South, it has flourished. Mark Zuckerberg named the 'Video-First Approach' (based on video contributors' choice of this medium in 2017) [20]. World-wide-web videos are based on a variety of agendas. Watching videos on mobile phones made these media universally accessible.

Videos can also be used in the design process, particularly the creation of Participatory Video (PV), which involves a group, community, or individual contributing to developing a film. These PVs also provide a platform for less- literate people to express themselves and reflect on their experiences.

The use of videos in ethnographic practice is well-established in HCI and design research. Vyas et al. conducted a study where participants planned and produced video narratives about 'who they are' and 'what their life is like' [253]. Videos are useful throughout the design process, including field observations, brainstorming, design and evaluation. Additionally, videos can effectively mobilise marginalised groups and engage participants in action research. According to Varghese et al., practitioners can engage in community storytelling and participate in design through Participatory Video 2.0 [247].

Video can be used to better convey designers' ideas to users in PD design workshops, resulting in higher levels of user engagement. Briggs et al. defined a specific type of design video, called an invisible design video, which is described in [78]. By allowing a fictional user to run the designed system without showing its interface, this invisible design video conveyed system design ideas by relying on imagination and ambiguity. Using invisible design videos, personas were shown using different scenarios to demonstrate how the system behaves in a particular situation. As a result, it was easier to discuss ideas with study participants and gain insight into their thinking without relying on abstract reasoning.

2.6.3 Cultural Differences.

Collaboration with the community is a defining factor of PD that involves developing community relationships. Different areas in the developing world have cultural differences. Therefore, the PD approach requires local adaptation to show commitment.

According to Hofstede:

> *'Authority cannot be separated from conditions such as uneven economic, legal, and racial relations that ground transnational cultural life'* [138].

These disparities among people in developing countries give rise to greater Power Distances. Consequently, participants can become hesitant to express their opinions when the investigator is perceived as having higher social status and power than the participants [112]. Demand characteristics are a type of response bias that can affect research participants. Demand characteristics refer to participants adjusting their behaviour according to the researcher's expectations and ownership [112].

Dell et al. highlighted the participant's response bias due to the interviewer's demand characteristics and reported in their paper that 450 interviews were conducted in Banglore, India, and it was found that respondents responded positively (2.5 times more) if they believed that the interviewer developed the technology artefact. This bias increases to 5 times if the interviewer is a foreign researcher requiring a translator [102]. Therefore, while designing for less privileged populations, special attention should be given to response bias, as demand characteristics, such as usability evaluation, affect the reliability of studies.
Gender issues are significant in some developing regions as women feel comfortable expressing their opinions to the same gender due to various cultural issues. Incompatibility of PD techniques with host community values and communication standards and uncertainty about which method/technique will be appropriate as there are many ways to collaborate in PD. However, low literacy levels can hinder appropriate collaborative activities between users and designers. Participants are often assumed to be available, to have relevant skills, and to be capable of working together equally, but this is not always the case.
Giving prominence to the verbal ability of the participants is essential when they are less literate, as that is how they can best express themselves. Therefore, talking with people is necessary to engage with them in PD, using interviews, focus groups, or workshops. Interviews require focus by participants, but less literate people with no formal education find this more difficult, resulting in a reluctance to talk. Participation in the design process is also inherently motivating for participants, as expressing their opinions helps them feel the importance of having a voice.

2.6.4 Wizard of Oz

Wizard refers to an experiment conducted in the laboratory setting to simulate the behaviour of a theoretical computer application. It can be with or without the participant's prior knowledge to encourage natural behaviour while using the computer application. Technology components were designed using the Wizard of Oz as a guideline and helped develop prototypes and avoid the considerable effort required to implement these components.
Wizard of Oz experiments explored a voice-only interaction that relied on examining the dialogues in more detail [229]. This process enabled the development of rich dialogue models as well as the exploration of the naturalness of an interaction. Therefore, with natural language interfaces, Wizard of Oz studies are an effective way of achieving this.

To overcome the burden of conducting user studies using Wizard of Oz, Porcheron et al. have contributed to voice-only interaction by designing an application, 'NottReal', was designed to simulate voice interfaces using the Wizard of Oz method. The voice user interface can be delivered with different mediums, such as smartphones, IVR and smart speakers. 'NottReal' is designed to deliver a message quickly to participants in a reasonable time for voice user interface latency. Pre-scripted messages are delivered in tracked slots, and all activities of 'NottReal' were logged.
The IVR design can be facilitated with Wizard of Oz, using speech-enabled input. The design of an IVR system has been improved with Wizard of Oz (without utilising any application) in [199].

2.6.5 Design Probes

'Design Probes' help to adopt technology according to users' expectations in a flexible and adaptable manner and accommodate user requirements gleaned from prototype testing. However, one limitation of the study highlighted in the previous chapter is that participants could not use them in real-world settings and access their usefulness in their daily lives. 'Technology Probes' overcome the limitation of 'Design Probes' as they facilitate envisaging radically new technology or applications through high-fidelity prototypes.
A technology probe is a high-fidelity prototype deployed with a target audience to enable people to determine the value of new technology in their daily lives. In a technology probe, social scientists observe how technology is used in real-world settings, engineers develop test beds, and designers consider new approaches to utilising technology to meet their needs through the design objective of inspiring new approaches. However, there is still risk associated with deploying 'Technology Probes' as they can fail or yield unexpected results.

2.6.6 Participatory Design for Global South

In resource-constrained environments, though less literate people lack confidence in their skills, engaging them in PD methodologies empowers them with the feeling of ownership, which enhances their motivation and commitment to solving local challenges - all of which contribute to the project's success.

Thus, PD facilitates the creation of tailored solutions that address local challenges more effectively. Such solutions are culturally appropriate, user-friendly, and sustainable because users are involved at every stage of the development process. Moreover, PD enables creation through user-driven ideas honed through feedback and prototyping. The PD considers the local ecosystem and involves using locally available materials and resources to be more cost-effective.

In summary, PD can offer a unique perspective and approach to problem-solving in the developing world, and involving users in the design process promotes user-centred solutions that address local challenges and empower users to take ownership of the solutions.

2.7 Technology for Diabetes Management - A Case Study of Rural Punjab, Pakistan

In the Global South, healthcare challenges include dismal water quality, a lack of hygiene, overpopulation, malnutrition, food shortage, and healthcare problems. These factors are significant causes of morbidity and mortality - though - people are often unaware of these issues and do not actively focus on them. This research considers one such health challenge - diabetes in Pakistan.

Diabetes self-management concerns the activities and behaviour of an individual to control and treat their condition, and their knowledge and awareness of their condition and consistent motivation to apply self-management strategies is vital to maintain their health and prevent costly health complications [9].

Diabetes awareness refers to diabetes-specific knowledge, including information about its control with medicine, food, and exercise. Since diabetes is a lifelong chronic condition, its self-management requires continuous motivation. However, motivation usually fluctuates, necessitating some external sources of inspiration to maintain.

Unfortunately, in Pakistan - especially in rural areas - people have minimal support to manage diabetes. They have insufficient resources to inform themselves about self-management strategies and trends.

According to the diabetes education framework listed in [9], there are three levels of diabetes education as follows: Level one includes diabetes information and one-to-one advice and is a formal way of education; Level two includes informal learning through peers, while Level three is related to structured education that meets some standard level (such as NICE/SIGN) - it follows an evidence-based curriculum, delivered with high-quality teaching methods and is accompanied by regular monitoring.

The resources needed to create diabetes awareness in rural Pakistan are insufficient due to healthcare staff shortages in these areas. Regular visits to the nearest city for diabetes check-ups are not an option for many. This research aims to design a technology that empowers people with diabetes to be aware of their condition in their lifelong journey. The use of PD techniques makes a user-appropriate technology design a reality.

PD activities seek to include all stakeholders in the design process to better model users' intrinsic knowledge to design more customised digital solutions. This participation and decision-making process empowers users [252]. PD is developed in the Global North and considers the cultural norms and practices that are uniformly distributed compared to the Global South. In the context of the Global South and its cultural norms, the PD techniques must, therefore, be adapted to the local context.

This research focuses on bridging the gap between PD methodologies and the abilities of people with diabetes in rural Punjab, Pakistan. The use of participatory and invisible design videos has been discussed previously. However, a structured session using the design-before-design approach has been investigated to bridge this gap.

2.8 Literature Gap

Diabetes self-management is a major issue in Pakistan, and 26.7% of the population suffers from this chronic condition. The use of technology to address this diabetic condition is under-addressed in healthcare literature.

The lifelong burden of diabetes and the limited healthcare resources, including the availability of doctors overwhelmingly, affect a country's healthcare system - Pakistan is currently struggling to meet these challenges - especially in rural Pakistan, where diabetes-related facilities, including doctors, are rare, requiring those who can to travel long distances to access such services. Moreover, due to limited literacy, an appropriate automated service could mitigate the lack of resources and help support less literate or illiterate people by providing a computer-based diabetes awareness tool.

This research project aims to develop IVR solutions - targeted at people with diabetes in rural and urban Punjab settings that address healthcare challenges and realise the full potential of IVR technology. IVR can be useful for training and support services associated with diabetes, especially for people living in resource-constrained, rural environments [133]. Therefore, an IVR system can aid people with diabetes, keep them aware of their condition, and engage them in their self-management regime [187]. Communal support plays an important role in effective diabetes management, and the IVR platform can connect communities in their diabetes management lifelong journey [268]. Therefore, this research aims to investigate IVR's use as a suitable technology for less literate people living in resource-constrained environments.

However, designing a usable IVR system for people with diabetes needs further investigation. The PD approach is a collaborative design process involving users in the development process to create solutions centred around the users' needs.

This PhD research aims to co-design for people with diabetes living in different rural and urban areas of Punjab, Pakistan. Despite the benefits of using PD in the ICT4D sector, these techniques are still underdeveloped to utilise in the localised contexts of the Global South. Design techniques such as Personas, Narration, Participatory Videos, Wizard of Oz, and Design Probes are discussed in Section 2.6 p41-48. This study led us to work with less literate participants and adapt these techniques in localised contexts.

Chapter 3

Methodology

3.1 Introduction

This research aimed to improve by innovating on established methods for participation in Design in the form of an Interactive Voice Response (IVR) system by considering the abilities and experiences of the involved stakeholders. Because the project ran for seven years and was interrupted by COVID-19, in this chapter, the research and design processes are summarised to give the reader a sense of the timescales for the work. This section also addresses the necessary ethics review processes underpinning this research because multiple research iterations were required. The analysis techniques that are used are also discussed. Chapter Four presents the stages of the design process that led to the creation of prototypes one and two. Chapter Five presents the field deployments of prototypes three and four.

3.2 Understanding the Real World

This Ph.D. project's initial focus was to design a mobile application using Participatory Design (PD) methodologies with input from different stakeholders. The research undertaken during the early phases of the project is discussed below.

3.2.1 Feasibility of Mobile Application

An Android application prototype was designed and developed (Figures 3.1 and 3.2), having different features, such as delivering information videos and storing prescription pictures. This prototype works while the mobile phone is connected to the internet.

While testing this prototype in the feasibility study (involving 13 participants from Faisalabad and Lahore - cities in Pakistan), it was evident that most people used button phones instead of smartphones. This research was conducted in 2015, and smartphones were not very popular then, which is the limitation of this research.

Figure 3.1: Android Application Prototype Part One.

The prototype evaluation showed the suitability of an IVR system; however, before focusing on designing an IVR system, a wider-scale scoping study was done to authenticate user preferences, as described in Chapter 4, Section 4.2., p72 - p87

3.2.2 Participatory Design in the Localised Context

Participatory Design is a belief in the right of people to co-determine their working and living conditions, an awareness of how people can lead to a more appropriate and usable system. Different PD techniques were studied in detail, such as engaging stakeholders with prototypes, scenarios, mockups, and character-based techniques.

Figure 3.2: Android Application Prototype Part Two.

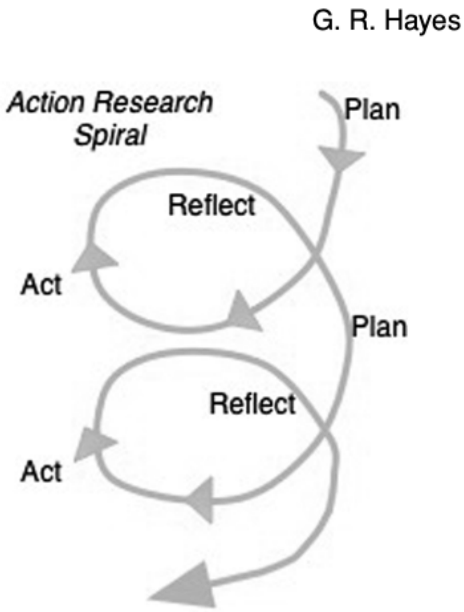


Figure 3.3: Action Research Spiral.

According to Muller et al., PD technique - 'PICTIVE' relies on participants communicating their viewpoints by drawing pictures on paper [186]. The study participants were middle to old-aged, less-literate women who have diabetes. Most were not confident about sharing their viewpoint with pen and paper and refused to do so. This leads us to modify our initially designed PD session to semi-structured interviews to get an insight into the study participants' lifestyles, as highlighted in the scoping section.

3.3 Methodology

This PhD project uses action research - an approach to research and problem-solving that focuses on actively addressing real-world problems in collaboration with people facing those problems. In the HCI context, action research addresses human issues through computer solutions [126]. It is an iterative process, as shown in Figure 3.3 [126].

The research iteratively refined the Participatory Design process while testing the IVR prototypes designed and developed at different stages. **This section provides an overview of the methodology, with more details provided in detail in Chapters Four and Five.**

The initial scoping was undertaken with 65 people with diabetes and four healthcare professionals in DIPL and less privileged areas in and around Faisalabad. After the initial scoping study, personas were designed and utilised in the PD session to check their validity with users. This technique is called "Narrative Scoping using Personas" [269]. These PD sessions involved 15 people with diabetes living in less privileged areas in and around Faisalabad city.

IVR Prototype One was designed and developed using Perl, Asterisk and MySQL. Later, the prototype working within the range of WiFi was tested with 57 people with diabetes living in and around less privileged areas of Faisalabad city. This testing was followed by presenting invisible design videos to thirteen people with diabetes (a subset of the 57 people involved in IVR Prototype One testing.)[270].

The PD studies showed that the IVR Prototype One needs improvements. Therefore, the IVR system was redesigned as a scalable and dynamic system that can deliver diabetes and comorbid condition knowledge regularly to aid participants in their diabetes management routine. This IVR system was designed and developed iteratively in two phases. 1) The Python Prototype was initially designed, developed, and evaluated using the 'Wizard of Context' technique. 2) Later, the prototype was converted to PERL code, working on the Asterisk platform, so actual calls could be placed using the 'Wizard of Context' technique. These one-to-one PD sessions were done on the phone with thirteen people with diabetes, as highlighted in Table 3.1.

Conducting the PD process became clearer after initial PD studies. The experience of working with illiterate user groups led to the Design of the 'Participatory Design with Visual and Auditory Content' method, in which the content was presented using PowerPoint slides; these slides enabled transitioning to discussing different ideas in PD sessions. These PD sessions resonated well with 59 people with diabetes and were done in less privileged areas in and around Faisalabad city. Personas were designed after these PD sessions, which clarified different design usage scenarios.

The next research step was designing and developing an IVR Prototype Three, followed by deployment. Prototype Three evaluation was undertaken with the PD Method, and as its deployment lasted four weeks, four one-to-one PD sessions were conducted with each of the 14 participants(as highlighted in row eight of Table 3.1). All PD sessions were video recorded and later analysed thematically.

Prototype Three testing led to some design changes. Instead of the recruited participants giving missed calls to the IVR system, IVR system-initiated calls were placed. Participants were recruited in preferred slots (morning, afternoon, or evening slots). Participants were given the option to sign up for a fixed slot. Some technical glitches identified from the Prototype Three deployment led to the Design of Prototype Four, which was deployed with 216 recruited participants in May 2022.

Prototype Four was evaluated using qualitative and quantitative approaches. Overall, Prototype Four was accepted well amongst the recruited participants, who expressed an eagerness to receive regular calls from the IVR system.

No.	Description	Participants	Location	Technique	Chapter
0	Pre-Scoping Research	13 people with diabetes, Four healthcare professionals	DIPL, less Privileged areas in and around Faisalabad	Interview, Focus Groups	4
1	User Scoping	65 people with Diabetes, Four healthcare professionals	DIPL, Less Privileged areas in and around Faisalabad	Interview, Focus Groups	4
2	Narrative Scoping using Persona	15 people with diabetes	Less Privileged areas in and around Faisalabad	PD session(, one-to-one More than One	4
3	IVR Prototype-One Testing	57 people with diabetes	Less privileged areas in and around Faisalabad	IVR Prototype (Perl, Asterisk, MySQL)	4
4	Invisible Design Video	13 people with diabetes	Less Privileged areas in and around Faisalabad	Filmed Video one-to-one PD session	4
5	IVR Prototype-Two Testing with Wizard of Context	Five people with diabetes, Two doctors	Less privileged rural areas in outskirts of Faisalabad	On the phone one-to-one PD session	4
7	Participatory Design with Visual and Auditory Content	59 people with diabetes	Less privileged rural areas near Faisalabad	Participatory, Slides including Audio, Video, Images	4
8	Iterative PD Evaluation of Prototype-Three	14 people with diabetes	Less Privileged areas in and around Faisalabad	IVR Prototype-Four Four PD sessions	5
9	IVR Prototype-Four Deployment	216 people with diabetes	On Phone	Automated Calls	5

Table 3.1: Methodology Table

3.3.1 Data Collection and Analysis

Prototype testing was done using qualitative and quantitative methods.

The Qualitative method used PD techniques to evaluate prototypes at different stages. The research data was collected using interviews, focus groups, one-to-one PD sessions, and one-to-many PD sessions.

The video or audio recordings of interviews, focus groups, and PD sessions were collected in one-to-one and many-to-one settings. To collate and interpret the results, the videos were transcribed, translated from Punjabi to Urdu or English, and analysed thematically.

Thematic Analysis is a technique used to analyse qualitative research data by identifying, analysing, and reporting patterns within the dataset. The thematic analysis process starts with data familiarisation, coding based on codes from collected data, theme generation, reviewing and refining themes, defining themes, and data extraction for all relevant text segments that belong to one theme. Thematic analysis, when undertaken iteratively, brings rigour to the process, thus ensuring that the findings are grounded in the data [77].

The Quantitative method involved analysing IVR system database logs containing various user interactions. These logs were used to analyse IVR prototypes. Later, graphs presented the results of SQL queries representing different statistics.

IVR prototype testing consisted of analysing logs or interviewing or involving participants in the PD evaluation sessions. Below are some details of how each prototype was evaluated:

1) Prototype One was analysed qualitatively and quantitatively. The invisible design technique was used for qualitative evaluation while testing Prototype One. For quantitative evaluation, Prototype One database logs were evaluated.

2) Prototype Two was evaluated over the phone using Wizard of Context techniques, and results were analysed thematically.

3) Prototype Three was evaluated quantitatively and qualitatively. The Qualitative Iterative Evaluation of Prototype Three lasted three weeks.

4) Prototype Four was evaluated quantitatively and qualitatively. For qualitative evaluation, interviews were analysed thematically, and for the quantitative evaluation, IVR logs were analysed.

3.3.2 Research Challenges

During the tenure of this PhD research project, the following challenges were encountered:
1. Getting approval from the hospital was challenging, and when the research commenced, the author made a personal effort by visiting many hospitals and asking them for research permission. Notwithstanding, the hospitals still refused to let the author conduct the research involving people with diabetes. Later, the author, a Pakistani national, knows two healthcare personnel through friends and family who had contacts in the National Hospital Faisalabad and Diabetes Center Lahore; these contacts helped to arrange research after obtaining formal permission.
2. This research project consists of iteratively designing and developing an IVR system using four prototypes of which two were deployed so that participants could receive calls on their phones using telephony services. The deployment setup arrangement was challenging, including a server and telephony services.
The next section will define different methods used in this research.

3.4 An Overview of Research Methods

This PhD project used different research methods, highlighted in Figure 3.1. Let's discuss them in detail.

3.4.1 User Scoping

Semi-structured interviews and focus groups were conducted as part of the *User Scoping process* to understand the lifestyle, challenges, and strategies of people with diabetes. Thematic analysis of the interviews and focus groups identified several themes, and the process is explained in Section 3.3.1 p59. Personas were developed based on the participants' different diabetes awareness and technology interests.

3.4.2 Narrative Scoping with Persona

This research relied upon creating ideas using the Persona approach. Throughout this creative narration, knowledge is spontaneously created by the subject.
A new method called *Narrative Scoping with Personas* was developed as part of this PhD research. Using this scoping method, the researcher validated their views regarding the personas of different stakeholders. The participants in a professional development session were presented with two personas and were asked to comment on their technological usage

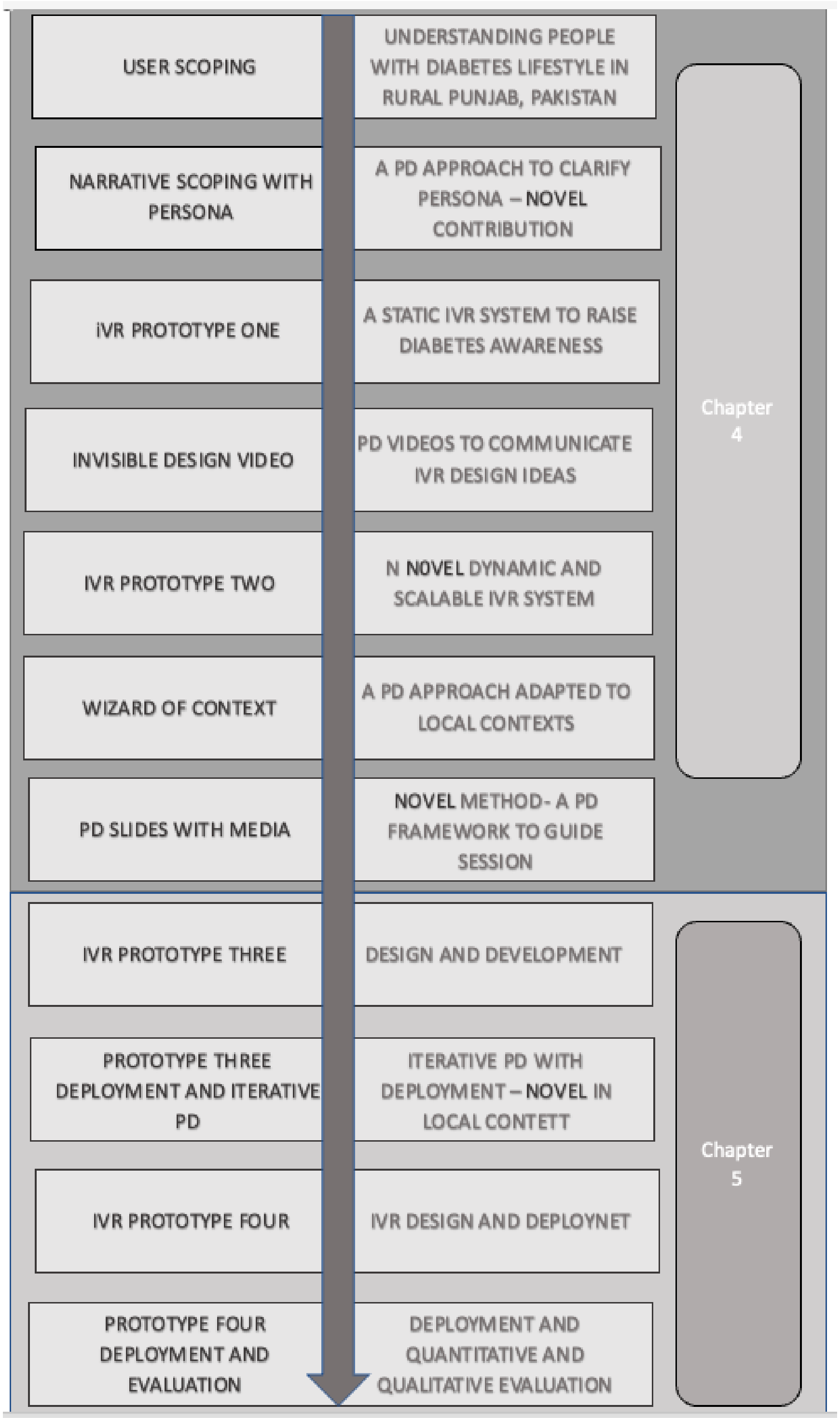


Figure 3.4: Research Processes.

and their awareness of diabetes. Through verbal skills, participants expressed their tacit knowledge of the user groups represented by the personas. Participants must express their tacit understanding of the user groups represented by the personas through verbal skills. There is a deliberate contrast between the personas that spark discussion in the participant groups with obvious observations at the beginning of the process. Still, more nuanced perspectives become evident as the interaction progresses. If, for instance, the Persona of an older woman, unemployed or retired and living in a rural area, was paired with the Persona of a middle-aged man characterised by living in a city and having a job, Their conversation might initially elicit a simple, direct exchange of information. However, over time, it was hoped that a more nuanced discussion might develop regarding whether the older lady persona might be motivated to engage with technology if she is provided with adequate support or understands its benefits.

3.4.3 IVR Prototype One

The Participants' verbal abilities and the prevalence of basic mobile phones rather than smartphones were highlighted in the scoping study. Therefore, this research focused on IVR, a simple phone-based method of voice-only communication, as the most appropriate communication medium. However, keeping participants engaged in IVR communication as a voice-only medium was challenging.

Prototype-One of *"Sugar-ka-Saathi"* - Prototype One was developed in response to these challenges using content from reliable websites, including [41] [10], which was first verified by a diabetes physician at the National Hospital of Faisalabad, Pakistan, verified the content presented by the system. Prototype One was developed using Perl, MySQL, and Asterisk and was tested on the researcher's phone using the Zoiper application (which uses the same IP address as the "Asterisk" server on the laptop to establish a connection). A prototype of *"Sugar-ka-Saathi"* presents limited content because of structural limitations in IVR; nevertheless, testing this prototype demonstrated that users would listen to information regarding diabetes.

3.4.4 Invisible Design Videos

Invisible design videos were used to generate ideas and insights with the PD participants during the early stages of designing the IVR [78]. This study reiterated the idea of invisible design videos. In the script, two characters, a doctor and a person with diabetes, discussed the IVR system's advantages, including its capability to deliver information and facilitate community communication. By viewing this invisible design video in the PD session, participants became familiar with IVR ideas and helped facilitate the subsequent discussion.

3.4.5 IVR Prototype Two

Prototype Two, developed after testing Prototype One, revealed the user's expectations regarding listening to various information led to the development of a '"Dynamic and Scalable'" IVR system that allows users to listen to healthcare information which had been prioritised using input from doctors and individuals with diabetes. Prototype Two also incorporated new community features to try and encourage peer support in the group by sharing their experiences; Doctors' advice and feedback helped to prioritise the healthcare information presented through the IVR system. Prototype Two was later developed using Python and MySQL Workbench and ran as a laptop computer program.

3.4.6 Wizard of Context

This research also created a novel method of developing the IVR called the *Wizard of Context* - a modification of the Wizard of Oz. The Wizard of Context technique recorded and played IVR content through a computer program. Because this phase required conducting remote testing of Prototype-Two with a Python program that delivered IVR content, the Wizard of Context helped to verify the quality of recorded audio prompts and considered the user's input to design IVR flowcharts which described how a user would journey through the IVR system.

3.4.7 PD utilising Visual and Auditory Content

PD utilising Visual and Auditory Content contributes to this research and involves presenting a slideshow covering various topics to be introduced during the PD session. It included pictures, audio, and videos, as described below.

1. Pictures: Different visuals were presented in PS to convey different ideas and topics, including pictures of institutions participating in research, rural areas, people with diabetes lives, phones, and diabetes management.
2. Audio: The recorded audio presented in PS allowed the audience to hear and validate the IVR content.
3. Participatory Design Videos (PDVs): These videos helped rural PD participants understand ideas more clearly. A particular emphasis was placed on script writing and filming so that participants could understand the issue and actively engage in the discussion. The following videos were used in the session:

’Persona-based Narrative Video’: This video is an improvement of the ’Narrative Scoping using Persona’ approach and presenting the Persona as a video which facilitated discussions among participants and resonated well with them, indirectly exploring their lives and experiences while utilising their tacit knowledge.

’Elaboratory Video’: This video illustrates a design idea in the late stages of conception as a design feature to stakeholders, such as a doctor and a patient.

’Explanatory Video’: This video illustrates a design idea. Participants discussed a new design idea in the early conception stage.

PDVs contributed to the IVR system design by clarifying the users’ expectations of the IVR system features, particularly the more complex ones, such as the community features that allowed users to communicate with each other, including connecting with friends, forming peer support groups, and sharing. The users’ feedback helped clarify their confusion about using these community features focused on experience-sharing.

3.4.8 IVR Prototype Three

Prototype Three of Sugar-ka-Saathi was developed following the ’Participatory Design with Visual and Auditory Content’ iteration to incorporate the users’ suggestions from Prototype Two. Prototype Three changed the diabetes information prioritisation according to the user’s suggestion to present food and exercise information with a higher priority. It also included a fully realised experience-sharing system where users can have their audio-recorded experiences embedded in different categories and can listen to other people’s recorded experiences.

Prototype Three was deployed in December 2020 for one month using the servers of Lahore University of Management Sciences, Lahore, Pakistan.

3.4.9 Prototype Three Deployment and Iterative Participatory Design

This deployment was concurrent with four one-to-one PD sessions guided by scripts with different evaluation themes.

Initially, 38 users called the IVR system phone number to receive automated callbacks. This mechanism reduced the cost of phone calls for study participants who hardly meet both ends. Fourteen users were selected to participate in four PD sessions to evaluate the IVR system. Despite being given the option to place calls to enrol in the diabetes IVR system during this research, some participants did not have enough interest or money to do so. The experience-sharing section was relatively less popular amongst users than the diabetes information section. The four PD discussions revealed users' perspectives on the IVR system and its design, as discussed in Chapter Five.

3.4.10 IVR Prototype Four

Based on the feedback received from the users of Prototype Three, the *"Sugar-ka-Saathi"* Prototype Four was designed to address the limitations of Prototype Three. Both sections of the IVR system were reiterated, further information was added in the diabetes information section, and pre-recorded experiences of people with diabetes were added to the IVR system to seed the system and ensure that, even though study participants were not eager to volunteer their own experiences, they could listen to authentic experiences. Moreover, the user-recorded experiences are inaccessible to other users because of the authenticity and sensitivity of healthcare information.

3.4.11 Prototype Four Deployment and Evaluation

Recruiting a telephony engineer and purchasing server time led to the *"Sugar-ka-Saathi"* Prototype Four deployment in May 2022. A total of 216 participants with diabetes were recruited from the regions of 79 GB South, Faisalabad, 80 GB South, Faisalabad, 82 GB South, Faisalabad, and Lahore. Participants received daily automated calls in their selected morning, afternoon, and evening slots. The computerised calls to users helped ensure they could listen to information even if they did not have enough credit on their mobile phones to dial the IVR. IVR prototype four was evaluated both quantitatively and qualitatively. The quantitative evaluation was undertaken using the recorded system logs and gave an overview of the usage of different features of IVR. The qualitative evaluation was based on interviews with 14 people with diabetes (study participants) and established the usefulness of IVR for raising diabetes awareness.

3.5 Research Ethics

This research is conducted according to the highest standards, with minimal risk of adverse or harmful outcomes or consequences. Specifically, ethics emphasises the importance of informed consent, confidentiality, and patient autonomy, particularly in the healthcare sector -which helps to ensure that healthcare professionals respect patients' choices.

Before establishing the research studies, the researcher and supervisors considered the sensitive nature of information in the healthcare sector and considered the participant's well-being. Therefore, formal ethics applications were submitted four times during this PhD research project. These applications are included in **Appendices C, D, E, F, G, and H (Pg. 200 - 258), giving the detailed documents submitted for ethical approval**. Swansea University's Ethics and Risk Assessment Committee approved all ethics applications and relevant materials before conducting the research.

It was made clear to participants during the evaluation of IVR prototypes that the information provided was complementary to the advice of doctors, not a substitute for it. Accordingly, they were advised to follow their doctor's instructions and to take their medication at the right time and in the correct amount.

The study was conducted at various locations in Punjab, Pakistan, including hospitals and villages. Formal permission from the National Hospital Faisalabad and the Diabetes Institute Pakistan, Lahore, was granted to conduct hospital research. Similarly, the research study was conducted with the permission of village heads in 75 GB South, Faisalabad, 79 GB South, Faisalabad, 80 GB South, Faisalabad, and 82 GB South, Faisalabad. The research was also undertaken with the consent of the participants in Ashraf Town, Malikpur, and Guru Nanak Pura, Faisalabad (these participants were introduced through the two residents of those areas who provided space at their homes to conduct the sessions).

As part of an ethics application, Swansea University's Computer Science Department approved the participant information sheet (explaining the purpose of the study) and a consent form requiring the participant's signature. The participant information sheet was read to illiterate participants, and the consent was audio-recorded. All participants were informed about their right to refuse to answer a question before the research began because their well-being was the most critical factor.

3.6 Conclusion

Diabetes self-management information can be provided to rural people with limited literacy via an IVR system; however, designing such a system is challenging.

This research led to the Design of an IVR system that provides diabetes management information and an experience-sharing system to assist people in the self-management of their condition. Overall, four IVR prototypes were evaluated, including features such as information about diabetes, comorbid conditions (such as heart disease and hepatitis), other healthcare problems (such as smoking and COVID-19), and the experiences of people with diabetes.

Literacy plays a significant role in the success of conducting effective PD sessions. Literacy amongst participants makes involving them in the design process smoother. However, this is not always the case, particularly in rural areas of the Global South. This research utilises the excellent verbal ability of our less literate participants and adapted PD techniques to the local contexts, therefore developing novel PD research techniques *"Narrative Scoping using Personas"*, *"Wizard of Context"* and *"Participatory Design using Visual and Auditory Content"*.

Chapter 4

Iterative Design

This chapter examines how we refined a verbal, Participatory Design(PD) process to evolve an interactive voice response system - ***"Sugar-ka-Saathi"*** - a **novel contribution** of this PhD work. The name of the system - "Sugar-ka-Saathi" - means "Diabetes Companion" and is given based on its potential role for people with diabetes as it is designed to assist less literate people in their diabetes self-management.

Personas were developed due to early scoping work, including interviews and focus groups. This PhD aims to examine these personas using a method known as **Narrative Scoping with Personas - a novel contribution**. Using personas as part of a scoping exercise, the technique was used to determine the perspectives of people with diabetes living in a rural Punjabi environment with varied conditions. Rather than only considering participants' reading and writing abilities, the scoping process considered their excellent verbal and storytelling abilities. Several PD sessions were conducted following the scoping session to develop prototypes for the IVR system.

4.1 Introduction

Although diabetes is prevalent in rural areas of the Global South, little awareness of diabetes management exists among the general population, leading to an uncontrolled glucose level resulting from not recognising the importance of a healthy diet and regular physical activity. Chapter Two discussed how ICT for development could play an essential role by using smartphones and basic phones. Furthermore, it addressed the use of technology to spread awareness of diabetes.

The user scoping showed that despite smartphones becoming more popular worldwide, many people in rural Pakistan still use basic phones. Therefore, the purpose of this research is to increase diabetes awareness through the use of IVR systems (IVRs) - which are supported by both basic phones and smartphones.

As a result of scoping activities, IVR was identified as a suitable technology, and its features were explored. Notably, current IVR systems in the Global South provide limited information. *"Sugar-ka-Saathi"* used the best practices to design and develop IVR. Prototype One was a basic IVR system, and simple testing showed that people desire to receive more information daily.

Developing practical, usable, voice-based systems is a challenging task, and to present more information, creating complex navigational structures is a norm. However, one of the limitations of the IVR structures is its difficulty to understand, particularly its limited usability for those without formal education. Therefore, PD methodologies were used to engage stakeholders to evolve a usable system. This research engaged different stakeholders in the design process through PD methodologies.

The PD methodologies developed in the Global North are adapted to the regional cultural norms and resources, including technology, human literacy, and awareness. However, the uniformity of the Global North is often not present in the Global South, where there are often stark differences in literacy levels, smartphone availability, etc., due to a lack of uniform resources. This difference between the Global South and Global North leads to adapting PD techniques to localised cultural contexts.

"Sugar-ka-Saathi" was adapted to deliver information using a "Scalable and Dynamic IVR" system. In prototype Two, 200 prompts were selected from authentic websites, such as [7] and [10]. The ***'Scalable and Dynamic IVR'*** is the ***novel contribution*** of this PhD project and facilitated more effective healthcare information delivery.

The healthcare information, being sensitive and safety-critical, needed authentication from a healthcare specialist. Therefore, a doctor from the National Hospital of Faisalabad [43] validated scripts for authenticity, advised on corrections, and assisted with translation from English to Punjabi.

For IVR recordings to be influential and maintain user attention, it is vital to ensure they are high quality. A research assistant from the Lahore University of Management Sciences assisted by recording the script. This recording took a few months due to the recorded script's length (recorded as 200 prompts, each lasting up to 30 seconds to one minute) and the effort required to maintain quality.

A version of *"Sugar-ka-Saathi"* Prototype Two was developed using Python and MySQL and was executed on the researcher's laptop. A *"Wizard of Context technique"* - a novel technique that used a Python prototype validated using Skype over a distance - The participants got an impression of listening to an IVR system. To validate the IVR flow, Prototype Two was presented remotely (via Skype) so the participants (recruited through a local contact person) could listen to the information delivered from Prototype Two). The participants liked Prototype Two and expressed interest in using the IVR system daily. *Using a wizard to conduct a remote PD session in this localised context is a novel contribution of this Ph.D.* project.

This research evolved as PD with visual and auditory content, which includes invisible design videos and narrative scoping techniques. The ***"Combination of Visual and Auditory Content"*** utilized in the PD is the ***novel contribution*** of this PhD Thesis. These PD sessions successfully clarified with the participants what they could expect from the role of the community in the IVR system.

The design and development of Prototype Three included an *'Experience-Sharing system'* (a basic form of a community system) that allows users to listen to and record their experiences. The Prototype Three and Prototype Final will have deployments with end-users, while the work documented here focuses more on design and simple 'lab' evaluations.

The sequence of different research activities is highlighted in Figure 4.1.

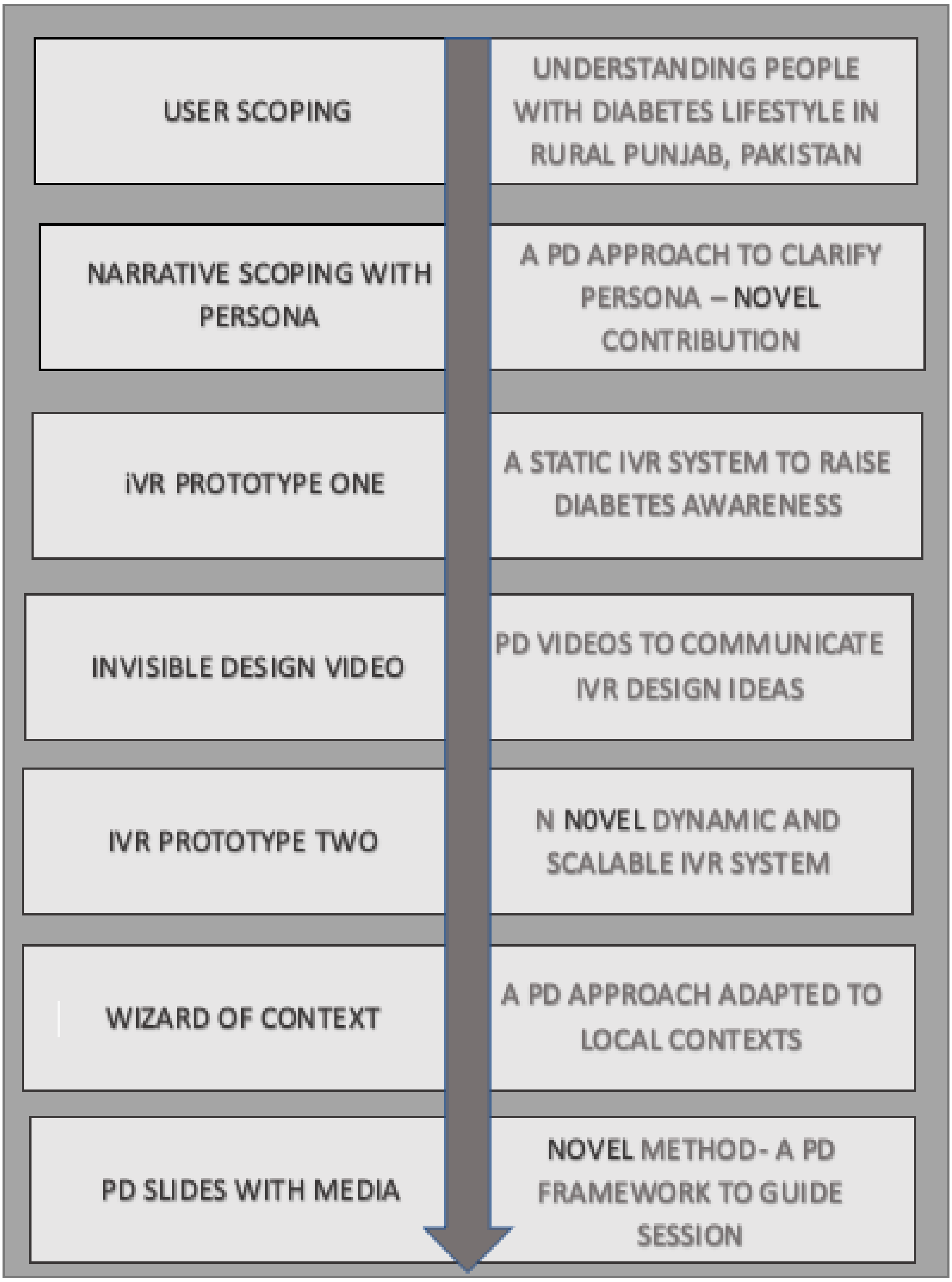


Figure 4.1: PhD Research Processes.

4.2 User Scoping

This research started with a *"User Scoping"* study to investigate people with diabetes lifestyle, their diabetes awareness, their strategies to manage it, and their technology use.

4.2.1 Method

While designing a technological intervention, understanding the user role and the purpose of using technology is critical. Therefore, user scoping becomes essential to understanding people with diabetes (being the potential users) behaviour towards diabetes and their technology use. User Scoping is a standard practice to become informed about users, particularly while tackling complex situations and unfamiliar users.

Participant Information

Sixty-five people with diabetes (21 men and 44 women), two diabetes educators, and two diabetes specialists participated in the scoping activities. The participants were recruited from various locations, including the rural areas of 79 G.B. South, Faisalabad, 80 G.B. South, Faisalabad, and 82 G.B. South, and the urban areas of Faisalabad and Lahore. Amongst the participants, 57% were not literate, 21.53% were less literate (were educated to Primary, Y-8, Y-10, and Y-12 levels), and 21.53% were fully literate(graduates).

Most participants (50 out of 65) used basic phones; smartphone usage was relatively low (11 out of 65). Four participants did not provide any information regarding their use of mobile phones. People with smartphones had access to data connections. Though some rural areas had weak network signals, getting internet access was difficult in some places where we travelled.

Forty-five participants were not working professionally, mainly women who were less literate or illiterate (35 out of 45). Other participants worked in various careers, including baking, clerical work, farming, warehouse management, policing, tailoring, and teaching.

Most study participants had Type 2 diabetes, and Table 4.1 below shows the participants' ages and diabetes duration.

Area Information

The study was conducted in villages in the outskirts of Faisalabad (79 G.B. South, Faisalabad, 80 G.B. South, Faisalabad, and 82 G.B. South Faisalabad), in Faisalabad (Masoorabad and Guru-Nanak pura), and the National Hospital Faisalabad (NHF) and Diabetes Institute Pakistan Lahore (DIPL).

Procedure

User scoping consisted of 14 one-to-one interviews (each typically lasting 20 minutes) and sixteen focus groups (two, three or four persons per group, with each session typically lasting 30 minutes).
Conducting an interview or focus group was dependent upon the situation, as in hospital settings, it was challenging to arrange focus groups, particularly in waiting areas; this led to interview participants; and in the home setting, organising focus groups was easy.
Participants were recruited through a local contact in villages who sorted out the approval from the village head. They gathered people at an arranged location (his relative's homes in different rural towns). In Mansoorabad and Gurunanak Pura, the exact recruitment mechanism is used as participants gathered at the local area contact house.
After the doctor's approval, participants waiting for the doctor's checkups were recruited in NHF and DIP healthcare centres.
Urdu is the national language of Pakistan, and Punjabi is the regional language of Punjab, Pakistan. Most interviews were done in the Punjabi language due to participants' fluency in the language. Few interviews with healthcare professionals and people with diabetes (literate) were done in Urdu.
All interviews and focus groups were recorded using smartphones with each participant's permission.
Participants were compensated with diabetes vitamins and incentivised to attend the session. Therefore, many participants were gathered from the village when they learned about the diabetes session. However, handling so many participants was challenging, presenting difficulties in organising focus groups, as the prior knowledge of participant recruitment in different groups could have made the process more organized. Therefore, it is advised that the local contact arrange group dynamics before the meeting with the researcher's input. Also, knowing the exact number of participants, their demographics, etc., helps the researcher conduct the studies more effectively.

Ethics Information

User scoping is conducted after the ethics approval from Swansea University's Computer Science department. Appendix E, Pages 217, 218, 219, and 220, presents the detailed questions asked during the User Scoping study.

Ethical approval required participants to receive participant information sheets and consent forms. The participant information sheet was read to participants, and participants' signatures or thumbprints were taken on the consent forms (in case they were illiterate).

Formal permission was taken from NHF and DIPL. Verbal permission was taken from the village heads.

Participant information, including demographics, phone number, and video or audio recordings, were carefully processed and stored with care according to the ethics process highlighted in the application. Participants were briefed in the Participant information sheet about how their data would be processed and kept. (see Appendix D, Page 212, Data Archiving/Destruction and Confidentiality).

Analysis Method

All interviews and focus groups were recorded in cases where video recording was not convenient or authorized audio recording was done.

The researcher transcribed all videos from Punjabi to English due to her knowledge of both languages. Therefore, all the recorded videos were first translated, and each participant's response was written. This data was then verified again with videos to overcome any shortcomings in data, such as unclear or misinterpreted meanings.

Later, a thematic analysis of the transcribed data revealed participants' generalized views and requirements that informed the design process [77].

Table 4.1: Participants Information including Age Range and Years with Diabetes

Age Range	No. of Years Living with Diabetes	No. of Participants
20-29	Up to 1 Year	14
30-39	1-5 Years	5
	Up to 1 Year	2
40-49	1-5 Years	4
	6-10 Years	2
	Up to 1 Year	5
50-59	1-5 Years	12
	6-10 Years	5
	Up to 1 Year	5
	10-20 Years	1
	Not Known	1
60-69	1-5 Years	10
	6-10 Years	6
	10-20 Years	1
	Up to 1 Year	1
	Not Known	1
70-80	1-5 Years	5
	1-5 Years	5

4.2.2 Thematic Analysis

The transcribed videos were thematically analyzed to identify patterns and themes. When evaluating the meaning of transcribed data, the researcher's subjective experience (owing to close ties to the local area) is crucial to understanding the data. We utilized thematic analysis to identify patterns in data collected from user scoping and to assist in the generalization of participants' preferences for other researchers. The following themes emerged from a thematic analysis of the collected information: Diabetes Awareness, Diabetes Management Behaviours and Routines, Stress, Alternative Medication, and Technology Adoption.

Figure 4.2: PD Session in Malikpur - a town in Faisalabad.

Diabetes Awareness

Diabetes education and awareness are recognized as essential to managing the health condition. Some of our participants were more aware of their diabetic condition than others. We observed and heard accounts explaining that this variation in diabetes knowledge is influenced by their location (rural or urban), literacy level, and access to knowledge (plenty of diabetes awareness resources are available, including internet resources).

For the less literate population, understanding their diabetic condition and how it develops is crucial but not a given. The lack of information about diabetes and its associated symptoms was a hurdle for people with diabetes, especially at the time of onset and early period of developing the condition, as many scoping participants recalled about diabetes diagnosis after experiencing the worst symptoms:

> *"The first sign that I had diabetes was tiredness. As a result of my ignorance about diabetes, my glucose levels rose to 600 milligrams per decilitre (mg/dL), resulting in my being unconscious for three days. At that moment, I realized the importance of following a doctor's advice to maintain optimal glucose levels."*

If the person knew the consequences of not taking appropriate measures to self-manage from the start, they would be less likely to develop the worst condition. Furthermore, preventing elevated glucose levels even before diabetes diagnosis can help prevent other complications.

An interview with a 55-year-old literate woman at the DIPL, demonstrated that people have different levels of awareness and that being literate made it easier for her to acquire knowledge. She described her experience as follows:

> *"People suffering from chronic conditions know how to address their condition within a few days of developing it".*

The woman and her family were literate, so developing knowledge was not a problem.

Role of Diabetes Educators

Diabetes awareness programs led by diabetes educators were observed at DIPL and NHF. *Rural areas often lack access to diabetes awareness resources.*

A doctor from the DIPL highlighted that diabetes educators play a vital role in educating patients on improving the self-management of their condition. *The core of effective diabetes management is incorporating appropriate self-management measures*, as he explained:

> *"It is more important to have information about Diabetes Management than to take medicine".*

Similarly, a diabetes educator from NHF stressed *the importance of regular diabetes management, which can only be achieved when people with diabetes seek timely care*. According to his experience:

> *"People with diabetes rarely understand their condition, so they rely solely on medication, even though medicine is only one factor in controlling the condition."*

Diabetes educators should consider psychological needs while delivering knowledge about healthy eating, regular exercise, and medication adherence. In an interview with a participant of the Diabetes Education Program at *DIPL*, a 55-year-old woman shared the following experience:

> *"Diabetes educators recommend taking small meals at regular intervals rather than one big meal to feel fuller. However, how can they teach that to older people? This works for kids, but not elderly people!"*

It is, therefore, essential for diabetes educators to receive adequate training to provide tailored diabetes care to their patients. Diabetes educators should also be trained to consider the circumstances and personality traits of people with diabetes since what works for one might not work for another. An effective diabetes educator can provide appropriate diabetes education [162], such as:

1. Didactic: "I want you to lose weight."
2. Goal setting: "Do you know how important weight loss is for your condition?",
3. Situational problem solving: "When dining out, follow these instructions",
4. Cognitive re-framing: "Think of the situations where people enjoy eating low-calorie food rather than feeling bad about it".

Diabetes Management Behaviour and Routine

It is essential to follow a diabetes management plan to keep the condition under control; however, many people have difficulty following the plan correctly. Similarly, a 60-year-old illiterate woman with diabetes from 80 G.B. South, Faisalabad, finds behavioural fluctuations in her lifelong diabetes management journey. According to her:

> *"After my diabetes diagnosis, I did not eat sweet things for the first two years. However, in the last six months, I have been finding it difficult to stick to my daily routine of walks and exercise."*

A diabetes management routine is also determined by the resources available. An illiterate woman with diabetes aged sixty living in 82 G.B. South, Faisalabad, said:

> *"Rich people can answer such questions as what you eat. I eat chapatti and drink water, as I cannot afford fruit and other fancy foods".*

Thus, in resource-constrained environments where people cannot afford medicine or meet their basic needs, preventative strategies for diabetes become the key to success. A national diabetes prevention program can also help the South Asian community at high risk of diabetes. The study categorises participants according to resource availability and literacy since diabetes management resources vary, including the availability of glucose-measuring devices (glucometers). As a woman pointed out:

> *"My body tells me if my glucose level is high or low based on changes in my body, such as shaking when my glucose level is high and fatigue when my glucose level is low".*

People have different diabetes management routines due to their motivations and the importance of self-care in managing their condition.
Diabetes self-management requires personal motivation throughout one's lifetime. According to a Diabetes Doctor from DIPL:

> *"Although there is no cure-all solution for diabetes, one can keep it under control by remaining motivated and keen to self-manage."*

However, this ideal behaviour is not always present during a person's lifetime, though the same people with diabetes adhere to their diabetes management routine more regularly. Overall, individual psychological factors determined by environmental factors are essential in determining a person's behaviour toward their diabetic condition. Therefore, while some people can easily adjust their life routines to manage diabetes, others find this more challenging. Some people showed they were resigned to living with diabetes and suffering because of their condition. During the study, a 55-years-old literate woman who had diabetes for six years commented:

> *"God decides that a person is suffering from a disease, and only God can cure it. I cannot spend the rest of my life keeping track of my glucose readings".*

Diabetes and Stress

Many factors induce stress, including financial, personal, career, or family matters, and
Among illiterate participants, financial matters are often a leading cause of stress and affect medicine intake. The best way to manage diabetes is to take medicine regularly and manage your diet properly. As a result of financial hardships, people cannot consume enough food and medicine to maintain their diabetes management routines. Stress is caused by not being able to buy medicines, etc.
Also, some stressful conditions are not under one's control and contribute to high blood glucose levels. A literate woman expressed her concern by saying:

"Several family matters beyond my control affect my glucose level".

Sharing problems and anxieties with others with diabetes can help eradicate this stressful condition.

Diabetes Medication Alternative

The affordability and the avoidance of medicine side effects often lead to people with diabetes relying on herbal or plant-based alternatives.

According to [178], a plant-based diet including legumes, whole grains, vegetables, fruits, nuts, and seeds reduces the risk of Type-2 diabetes. As a 45-year-old illiterate woman from the 79-G.B South, Faisalabad (village) said:

"I ate ground Jambolan (fruit), which helped reduce my diabetes medicine from two to one tablet daily."

The above statement indicates that, for some people, food is complementary to medicine for controlling blood glucose levels. When used appropriately, plant-based diets can be beneficial for people with diabetes.

The active ingredients in plant-based herbal medicines can be found in plants' leaves, roots, or flowers [42]. Some study participants used herbal medicine as an illiterate 60-year-old woman described her preference for herbal medicine:

"I had hepatitis, and local herbal medicine effectively cured it".

It is important to note that not all people prefer herbal medicine. For example, a 44-year-old literate woman from Guru Nanak Pur in Faisalabad city stated:

"Instead of using herbal or traditional medicine, I adhere to modern medicine".

According to [42], herbal medicine should be taken with care, as it affects the body and can potentially be harmful if not used correctly. Consequently, this scoping study and relevant research highlighted the importance of providing less literate people with accurate information about herbal medicines and their effects on diabetes management before taking them.

Technology Adoption

Technology adoption varies for the participants based on age, literacy, interest in acquiring skills, perceived usefulness, etc. Technology users can be classified into non-users, users and passive users. The difference between the users and non-users of the technology depends upon the technology readiness (TR) of the study participants [88]. A technology acceptance model (TAM) (discussed in Chapter Two) advocates that the successful utilization of healthcare resources depends upon their usefulness and usability.

Perceived enjoyment (PEN) is related to fun, and enjoyment is related to enjoying technology, and these can be an intrinsic motivator to adopt and use technology [88]. The technology readiness and acceptance model incorporates TR into TAM, as TR depends on personality traits and says that an individual's opinion and general beliefs about technology affect a person's acceptance and adoption behaviour [88]. Therefore, this scoping study focuses on knowing more about users and their behaviour towards technology to give them the best technological solution to help them with diabetes self-management. Thus, classifying users into different categories helped to narrow down the focus.

There was one non-user in this study who had limited or no prior use of technology; one particular scenario is a woman who travelled from a rural area to DIPL and disclosed that:

> *"I do not use a mobile phone; I do not even know how to receive the call."*

This user behaviour can be because of two factors: first, she has not used a phone, and second, she did not want to communicate about her phone usage. However, many study participants were not intensively exposed to mobile phones (usually less literate, did not have access to smartphones, and lived in rural areas) and only had basic mobile phones. We categorized them as passive users in this study; one particular study participant exhibited passive behaviour as follows:

> *"I rarely use the phone and only listen to the received call."*

Those with smartphones had access to mobile applications. A 35-year-old literate woman with diabetes said:

> *"I frequently use my mobile phone, which has internet access and can be used to access different applications like WhatsApp. I contact my doctor using my cellphone for advice about my condition, and I like to use mobile phone applications to track it.".*

This thesis focuses on facilitating passive users with technology and raising their technology awareness among them through our research. The IVR system, with the ability to deliver automated information, can be helpful for many people.

This section, *'User Scoping'*, helped to understand the lifestyle of less literate people with diabetes in Punjab, Pakistan, and the thematic analysis helped to identify related lifestyle and diabetes management themes. User Scoping also highlighted a non-uniformity amongst the participants as they have a varied demographic affecting their diabetes management behaviour and technology adoption. Therefore, section 4.3 explained the *'Personas Development'* process to develop an understanding of different user groups to distinguish among participants.

4.3 Persona Development

Personas are defined in Chapter Two as a design tool that represents 'fictitious user description' to facilitate user-designer interaction. The quantitative and qualitative results of user scoping helped to develop personas to distinguish between people with diabetes based on age, gender, personal motivation, and expectations for technology intervention [197]. Personas were defined with names, pictures, and descriptive narratives, including background, knowledge, skills, attitudes toward technology, and goals and concerns.

The Personas of different stakeholders were developed that represent different user groups of the scoping study. Different stakeholders were:

1. Healthcare professionals - doctors, diabetes educators,
2. People with diabetes -literate, illiterate, young, old age, professional, retired, aware/unaware of strategies for managing their condition.

The persona development activity helped to categorize users mainly based on rural and urban settings, as Table 4.3 and Table 4.4 highlighted the personas in urban environments, and Table 4.5 and Table 4.6 highlighted personas in rural settings.

The urban personas have some knowledge about diabetes and have access to diabetes awareness resources. Both urban men's personas used smartphones and were happy to utilize a mobile application to track glucose readings and later reflect on them. A younger woman persona - *'Naila Shakoor'*, showed interest in utilizing her smartphone to manage diabetes. However, the *'Saeeda Begum'* persona, a relatively old woman from an urban area, was less interested in using a mobile phone for diabetes management and considered it an extra burden.

The personas of three men living in rural areas are discussed in Table 4.5. The younger men's persona, *'Owais'*, has a smartphone and wants to listen to diabetes awareness information, while both older men's personas have a basic phone; with one, *'Talha'*, being literate up to a secondary level, and the other being illiterate. Both are willing to listen to diabetes awareness information, but persona *'Yaseen'* cannot afford to call and listen to information.

The developed personas are shown in Tables 4.2, 4.3, 4.4 and 4.5:

Table 4.2: Healthcare Professional Personas

PERSONA	DETAILS	GOALS
 **Dr Amir Saeed**	Diabetes Doctor. Age: 47 years. Lahore, Pakistan. Often use internet-based applications on mobile phones and computers.	Communicate with patient regularly for diabetes management. He is in contact with mostly literate people. He is interested in the use of mobile health applications for diabetes self-management. Goal: To raise awareness about diabetes care
 **Mr Anees Khan**	Diabetes Educator. Age: 25 years. Lahore, Pakistan. Often use internet-based applications on mobile phones and computers.	He is usually in contact with illiterate people with diabetes who have limited resou

Table 4.3: Urban Men with Diabetes Personas

PERSONA	DETAILS	GOALS
 **Mr Liaquat Hussain**	Suffering from diabetes for 12 years. Age: 57 years. Literate. Profession: Production Manager Residence: Faisalabad, Pakistan. Often seek information on the internet.	Although he tries to keep his glucose level in control by taking care of his food intake and doing exercise regularly, as recommended by the doctor, he often finds it difficult to concentrate on healthy food intake. To change his life, he will use a mobile application as he wants to: 1) Store the week's trend of his glucose reading to reflect later. 2) To keep track of food/exercise.
 **Mr Nauman Khalid**	Diabetes Patient diagnosed since last 6 years. Age: 37 years. Literate. Residence: Lahore, Pakistan. Often uses internet-based applications on computers and mobile phones.	He cares about his health and well-being, with the realisation that his diabetic condition needs lifetime maintenance. He has a smartphone and wants to interact with the doctor through a smartphone application to save his diabetic information and later reflect with the doctor or by himself. Goals: 1) To see the week's trend of his glucose reading. 2) To keep track of food/exercise. 3) To receive exercise reminders as he often forgets to spare time for exercise in his busy routine.

Table 4.4: Urban Women with Diabetes Personas

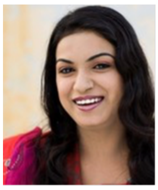
PERSONA	DETAILS	GOALS
 **Naila Shakoor**	Recently diagnosed with diabetes. Age: 35 years. Literate. Residence: Lahore, Pakistan. Often uses internet-based applications on computers and mobile phones.	Worried about her well-being as she was diagnosed with diabetes at a comparatively young age group. She follows regular exercise and asks about using a diabetes management IVR. She liked the following actions of the mobile application: 1) To store glucose readings to reflect on later. 2) To keep track of food/exercise.
 **Saeeda Begum**	Age: 55 years. Literate. Profession: Teacher. Residence: Lahore, Pakistan. Uses the phone usually to listen to calls.	Less interested in using a mobile phone, as she cannot maintain the habit of using a mobile diabetes management tool regularly. She already knows about diabetes management and believes that whenever a disease starts within a month, the person with the disease gets enough information about that disease.

Table 4.5: Rural Men with Diabetes Personas

PERSONA	DETAILS	GOALS
 **Owais**	Age: 43 years. literate (Bachelors). Residence: Village near Faisalabad, Pakistan. Has Smartphone.	Owais has had diabetes since last year. By profession, he is a clerk and started work in a nearby city after graduation. He takes medicine and walks regularly.
 **Talha**	Age: 60 years. literate (Secondary) Residence: Suburbs of Faisalabad, Pakistan. Limited Phone use.	He is illiterate and suffers from diabetes. He understands the importance of a proper diet to keep his glucose under control. He has a basic phone
 **Yaseen**	Age: 72 years. illiterate. Residence: Village near Faisalabad, Pakistan. He uses the phone to receive calls.	He has had diabetes for five years. He is not literate and lives in a rural area. He takes medicine regularly and sometimes walks. He has a basic phone, but cannot afford to call an IVR

Table 4.6: Rural Women with Diabetes Personas

PERSONA	DETAILS	GOALS
 **Mukhtaran Bibi**	Age: 70 years. illiterate. Residence: Faisalabad, Pakistan. She uses the phone to receive calls.	In this old stage of life, she is still struggling financially and getting help to meet both ends with her children. Her diet is not fancy, and she relies primarily on eating roti with curry
 **Shahida**	Age: 40 years. illiterate. Residence: Faisalabad, Pakistan. She uses the phone to receive calls.	Shahida has had diabetes for two years. She is illiterate, lives in a village, and looks after the household. She does not afford to take medicine and avoids sugary things.
 **Zareena Bibi**	Age: 70 years. illiterate. Residence: Village near Faisalabad, Pakistan. She uses the phone to receive calls.	Zareena Bibi has had diabetes for the last eight years. She needs help from family members to do household tasks. She avoids sugary things and sometimes takes medicine due to affordability.
 **Zubaida**	Age: 32 years. literate. Residence: Village near Faisalabad, Pakistan. She uses the phone to dial and receive calls.	She has had diabetes for two years. She is literate and works as a primary teacher in a rural area. She avoids sugary things, takes medicine, and walks regularly.

One of the aims of this PhD research project is to investigate using PD techniques in localised contexts. Therefore, this study started with a focus on one of the basic techniques, PICTIVE - that relies on participants' reading and writing abilities. However, this effort to utilise the PD methodology, PICTIVE, did not resonate well with our participants due to their low literacy levels; participants could not relate to conventional PD approaches, such as creating tangible design artefacts with the participants, including storyboards or paper prototypes. However, these design artefacts are helpful as they can be revisited and analysed during the design process.

Section 4.3 highlighted the personas designed as an outcome of the user scoping study. These personas are essential in categorizing study participants and later narrowing down the focus of the study. The user scoping study revealed that the participants have excellent verbal ability but no reading and writing ability. Merging the concept of personas and the exceptional verbal ability of our participants gave rise to the idea of Narrative Scoping with Personas. Therefore, building on the participant's oral skills, section 4.4 explains *a novel PD approach* - ***'Narrative Scoping with Personas'***. In place of tangible co-created artefacts of the design process, personas were used to prompt and capture the storytelling results in the Narrative Scoping sessions, as highlighted in the next section.

4.4 PD - "Narrative Scoping with Personas"

Verbal communication is essential for illiterate participants [107], leading to adopting a *Verbal Design Approach* was adopted to facilitate the PD process. Additionally, the scoping activities discussed in section 4.2 showed the participants' eagerness to share their experiences. This led to selecting the narrative scoping technique within the PD approach [261].

As shown in Figure 4.3, the narrative scoping technique is built on the 'Scoping' and 'Analysis' stages. Scoping is the first phase, consisting of interviews and focus groups; as a result of scoping activities, participants' storytelling ability was evident.

Personas were drawn while analysing the user scoping study, as highlighted in Section 4.3. 'Persona Character Development' is used to collect personal accounts of study participants' experiences and leads to the formulation of new ideas about the established persona, developed from interviews as a trigger to begin a conversation with users. Thus, attributes about the persona and stories about their activities were collected.

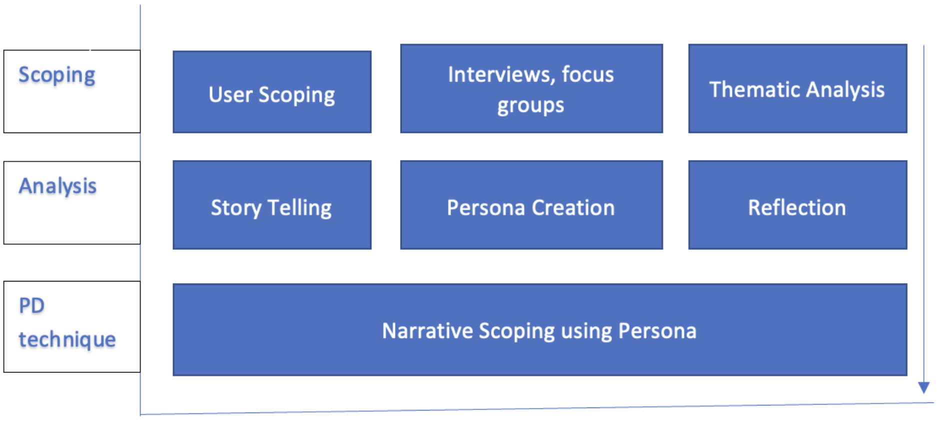


Figure 4.3: The Narrative Scoping Technique evolution at different stages) in the design process

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The use of narration to co-create a persona in the design process aims to better understand the persona's life experiences by utilising the participants' unconscious and spontaneously created information, thus providing the researcher with participants' indirect views about the lifestyles of the personas and their use of technology.
One rationale behind this PD approach is that the participants share their experiences in detail; as they are not the subject of conversation, they can engage without hesitation. The focus is not on accuracy but on building on our participants' strengths to develop a PD methodology. Previous research suggests that narrative work is more suitable because it supports participants' strengths in developing countries with lower literacy rates [269].

4.4.1 Method

The study procedure, participant information, ethics information and analysis method are discussed in the following section:

Procedure

A total of four PD sessions were conducted in 2017 (between August and September) to understand the personas of Liaquat Hussain (Table 4.3) and Mukhtaran Bibi (Table 4.6). The persona work was introduced after the initial narrative interview session, which served as an icebreaker. These personas provided a forum for deeper discussion.

Each PD session lasted 20 - 30 minutes, and smartphones were used to record videos after obtaining the participants' permission. The researcher could transcribe all videos from Punjabi to English due to her knowledge of both languages.

In the initial scoping study, participants were recruited with the help of a local contact. These participants were selected from the ones who participated in the initial scoping study. The communication language for focus groups was Punjabi due to the participant's fluency.

All PD sessions were recorded using smartphones with the participant's permission.

Participants were compensated with diabetes vitamins.

Participant Information

Fifteen people with diabetes (four men and eleven women) participated in this narrative scoping with personas. Nine of the fifteen participants were in the initial scoping study.

They were recruited from Ashraf Town, Malikpur, Faisalabad,

Ethics

This session was conducted after the ethics approval from Swansea University's Computer Science department. Appendix F p228 highlights the Narrative Scoping with Persona Procedure.

Ethics approval required participants to receive participant information sheets and consent forms. A participant information sheet was read to participants, and participants' signatures or thumbprints were taken on the consent forms.

Participant information, including demographics, phone number, and video or audio recordings, were carefully processed and stored according to the ethics process highlighted in the application. Participants were briefed in the Participant information sheet about how their data would be processed and kept. (see Appendix D, p205, Data Archiving/Destruction and Confidentiality).

Analysis

All interviews and focus groups were recorded, and where video recording was not possible, audio recording was done.

The researcher transcribed all videos from Punjabi to English due to her fluency in both languages. Therefore, all the recorded videos were first translated, and each participant's response was transcribed. This data was verified again with videos to overcome shortcomings, such as unclear or misinterpreted meanings.

Later, a thematic analysis of the transcribed data revealed participants' generalized views and requirements that informed the design process [77].

Table 4.7: Person Attributes

	**Mukhtaran Bibi**
Age	70
Gender	Woman
Occupation	House Wife
Diabetes	Type 2
Technology Use	The focus group participants agreed that Mukhtaran Bibi might not be willing to attend IVR system calls, but if her family members motivate her, then she might get convinced that the IVR system call will ultimately benefit her by facilitating better management of her condition

Table 4.8: Person Attributes

	**Mr Liaquat Hussain**
Age	57
Gender	Man
Occupation	Manager
Diabetes	Type 2
Technology Use	He has a smartphone and uses it to browse information on the internet. He is motivated to take care of his condition and happy to be contacted by the IVR

4.4.2 Findings

The *'Narrative Scoping with Persona'* is a PD session activity to co-develop a woman and a man persona. Tables 4.7 and 4.8 describe the illiterate woman's persona *'Mukhtaraan Bibi'* and literate man's persona *'Liaquat Hussain'*.

Displaying a persona picture helped in the PD workshop to brainstorm attributes such as Name, Age, Gender, Occupation, Attitude toward technology, etc. Therefore, after introducing the persona in the PD session, the persona's lifestyle with diabetes and the potential for using technology were discussed. It was agreed that IVR technology would benefit an older woman's persona; however, a middle-aged man would be more likely to have access to a smartphone and would use that to be aware of and manage his diabetes condition.

It was observed that group dynamics played an essential role in PD sessions, as some participants were active while others were passive. Therefore, few participants actively co-developed and discussed the Persona and its various attributes and the Persona character enthusiastically. Nevertheless, the participants contributed to a clear understanding of how technology interventions for people with diabetes might be developed.

Since the woman persona was dominant among respondents to the scoping study and had the least access to technology, the study's initial focus was the woman persona, 'Mukhtaran Bibi'. The IT intervention was considered an exciting way to raise diabetes awareness among the masses. Therefore, the focus of the PhD shifted to designing an IVR system considering the capability of the 'Mukhtaraan Bibi' persona. This IVR system was named "Sugar-ka-Saathi" (Diabetes Companion). The participant response about 'Mukhtaraan Bibi' is as follows:

> *"When she receives a call, she can listen to it, but it's difficult for her to make a call herself ".*

It's also evident that 'Mukhtaran Bibi' will become a passive system user and will not be comfortable with too many system interactions. However, this PhD research project also facilitated user groups represented by other personas.

The next step is to design and develop an IVR prototype. Therefore, IVR prototype one was designed and developed using the best practices, as explained in Section 4.5.

4.5 *"Sugar-ka-Saathi"* - Prototype One

This IVR Prototype One design (see below) is the first step in creating *"Sugar-ka-Saathi"* and raising awareness about diabetes among the less literate.

4.5.1 Design

This prototype used the accepted IVR design standards to test its validity with low-literate users in localized rural contexts. User scoping results highlighted two task flows for system IVR design that could be tested, including information about diabetes and strategies for diabetes management. Diabetes information was collected from various resources [7], and two diabetes specialists from the NHF reviewed the shortlisted information. Figure 4.4 illustrates a brief review of some information.

Later, the verified information was converted into a flowchart with the 'information prompts' and 'navigational prompts' (a prompt is an information prompt or navigational prompt; an information prompt delivers an information bit, and a navigational prompt provides a navigation instruction to retrieve relevant information). The flowchart is shown in Figure 4.6.

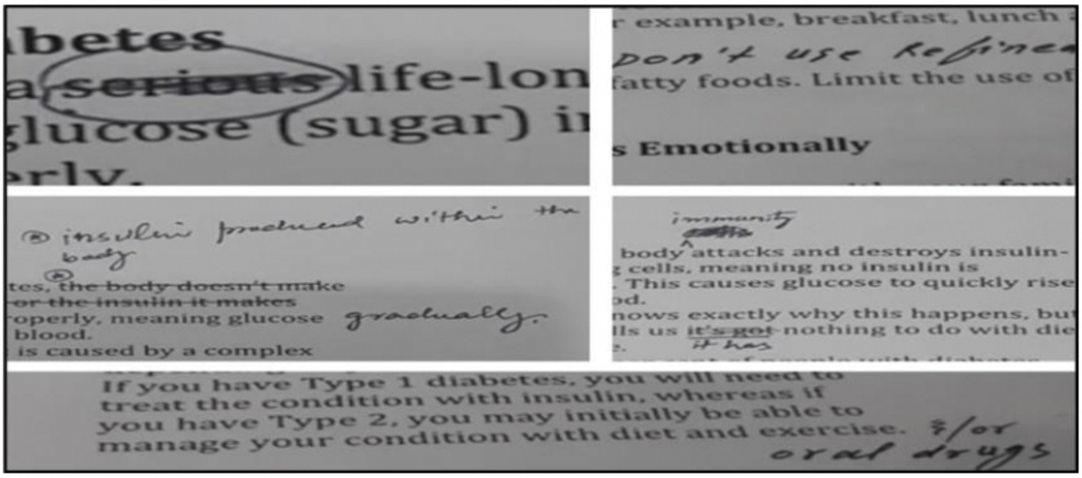


Figure 4.4: Corrections on *'Sugar-ka-Saathi'* Prototype One

After finalizing the design, all IVR prompts were translated from English into Urdu and Punjabi. Translation to Urdu was straightforward because of the availability of translation tools. However, translating it to Punjabi needed more effort, as no reliable translation tool was available to convert information from English to Punjabi. Therefore, the translation of eighteen Punjabi prompts was undertaken by the researcher. Later, all the audio prompts were recorded in an engaging voice tone.

The persona of a diabetes educator, *'Anees Khan'* (shown in Table 4.2), was used to deliver diabetes awareness and management information. The diabetes educator persona, being an authoritative person for diabetes care, was introduced at the start of the call and helped ensure the IVR's acceptability. At the beginning of the phone call, care was taken to inform users that this call was to raise diabetes awareness and not a replacement for the doctor's advice. Then after language selection (Punjabi or Urdu), the system prompts ask to select one of two main menus for either diabetes information or diabetes management. This menu is designed to respond to the findings from the user research phase that most semi-literate people with diabetes lack basic knowledge of their condition. Each option is supported by further sub-menus to disseminate relevant information to the users.

The maximum depth among all the sub-menus in IVR Prototype One is four levels, and the full width is three for the main menu. At the same time, most other sub-menus have a maximum width of two, as previous work has suggested [117]. This IVR system has two types of prompts: *navigational prompts* and *informational prompts*. On average, the prompt length is 15 seconds,

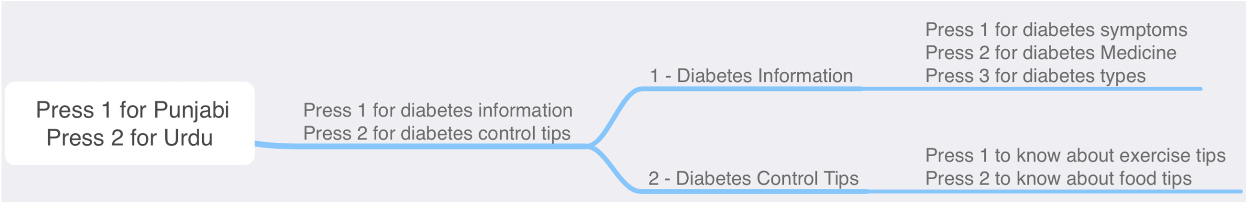


Figure 4.5: 'Sugar-ka-Saathi' Prototype One Design

and the maximum length is 25 seconds. The user can navigate to the previous menu from any sub-menu or end the call. If the prompt elicits no user input against a prompt, the IVR system waits for a few seconds and repeats that prompt. It also notifies the user of a wrong input at any stage before repeating the prompt.
The IVR usability was improved by paying particular attention to keeping most prompt lengths to 15 seconds, though sometimes, it extended to 25 seconds. Fig. 4.5 shows the information as a branching flowchart. The maximum depth amongst all the menus in *"Sugar-ka-Saathi"* Prototype One is four levels (the height of the flowchart in Fig. 4.5, and the maximum width ranges from 2 to 3, with only one instance where it is three, so maintaining compliance with research recommendations [117].

4.5.2 Development

"Sugar-ka-Saathi" Prototype One was developed using the Asterisk VOIP (Voice over Internet Protocol) platform and PERL Asterisk Gateway Interface (AGI). Furthermore, the MySQL server encapsulated the call logs, including detailed information about a call flow. SIP (Session Initiation Protocol) enabled telephone communication between the asterisk server and the user. This prototype was developed with the help of a project collaborator from the Lahore University of Management Sciences.

4.5.3 Prototype One Testing - Method

Through testing of Prototype One (see below), insight was gained into how users use IVR technology to become more aware of their diabetic condition. This study aimed to determine the users' acceptance of the IVR system since not all were familiar. This study also demonstrated how the participants interacted with the IVR system. The results of this testing were used to facilitate the design of subsequent IVR prototypes.

Procedure

"Sugar-ka-Saathi" Prototype One was introduced to participants to clarify their concerns about IVR functions and their usage. The users then tested the application and completed the following tasks:

1. Retrieving basic information about diabetes.
2. Accessing information about controlling and managing diabetes.
3. Navigating back to the main menu from a sub-menu.

When the user completed the above tasks, they gave feedback and suggestions to improve the IVR design.

The IVR system was tested using the researcher's mobile phone with *'Zoiper'* - a smartphone application to access the prototype. Every user was assigned a profile within *'Zoiper'* so that later, different user behaviours could be analyzed through the log maintained by *'Zoiper'* within *'MySQL'*.

Participants were asked how they found the IVR system, whether the information was delivered efficiently, if it was challenging to listen to the information they liked to listen to, if navigation was easy, and if they would use such a system in the future, what features would they like to be added.

Participant Information

"Sugar-ka-Saathi" Prototype One was tested with 57 participants (aged between 35 and 70 years), a subset of the 69 participants from the initial scoping study.

Despite initially being hesitant to use the system. Still, after a short briefing on its use and the information it could provide, participants gained confidence and found using it helpful.

The participants who had not used an IVR system before were given a demo of the system, and after a short introduction, they gained a clear idea of how to use an IVR system.

Area Information

The study was conducted in villages in the outskirts of Faisalabad (79 G.B. South, Faisalabad, 80 G.B. South, Faisalabad, and 82 G.B. South Faisalabad), in Faisalabad (Mansoorabad, Guru-Nanak Pura), and National Hospital Faisalabad (NHF).

Ethics Information

IVR Prototype One testing was conducted after gaining ethics approval from Swansea University's Computer Science department. Appendix F p228 highlights the IVR Prototype Testing Procedure.

Ethical approval required participants to receive Participant Information sheets and consent forms. Therefore, the Participant Information sheet was read to participants, and participants' signatures or thumbprints were taken on the consent forms.

Participant information, including demographics, phone number, and video or audio recordings, were carefully processed and stored with care according to the ethics process highlighted in the application. Participants were briefed in the Participant information sheet about how their data would be processed and kept. (see Appendix D, p205, Data Archiving/Destruction and Confidentiality).

Analysis Method

All interviews and focus groups were recorded, and in cases where video recording was not convenient or authorised, audio recording was used. Interviews and Focus Groups were analysed in conjunction with each other.

The researcher transcribed all videos from Punjabi to English due to her fluency in both languages. Therefore, all the recorded videos were first translated, and each participant's response was noted. This data was verified again with videos to overcome any shortcomings in interpreting data, such as unclear or misinterpreted meanings.

Database - MySQL workbench was used to record all user interactions with the IVR system. The records were maintained using SQL queries and later analysed to determine the extent to which the different features of the IVR were being used.

A thematic analysis of the transcribed data revealed participants' generalized views and requirements that informed the design process [77].

4.5.4 Prototype One Testing - Findings

IVR users found the system valuable and relevant to their diabetes management needs during testing. The quantitative analysis of IVR logs (Tables 4.7 and 4.8) showed the user's usage.

Mobile device owners who were frequent mobile users found the IVR relatively easy to understand and could independently use it. Infrequent and illiterate mobile users needed help with IVR usage, while literate users were confident. Several participants expressed their interest in getting the IVR system number to call from their mobile phones, which evidenced the value of the IVR system as a viable solution for supporting illiterate or less literate people with diabetes in Pakistan.

IVR system users were initially hesitant to use it. Still, after briefly explaining its use and the information disseminated through it, they gained confidence and found it helpful. Every study participant was given a set of tasks to complete during the evaluation. Among the 57 participants, 20 could complete their tasks comfortably without quick repetitions. The information retrieval times of 10 participants were faster than those of the other participants due to their prior experience with telephone helplines. Except for seven users who needed three audio-prompt repetitions, most participants completed their tasks after one audio-prompt repetition.

The users could comprehend navigational and informational audio prompts despite having no prior experience with the IVR system. Once the repeat functionality of the audio prompt was explained to users, they waited for audio prompts to repeat their selection if they failed to understand them the first time. Some users waited for the audio prompt to end before pressing the button, while others pressed it immediately after hearing the option they wished to choose. Some infrequent mobile users could not understand the navigational audio prompt when they called for the first time because they were confused about the IVR system. Ten users were unable to complete their tasks.

After completing the tasks, semi-structured interviews revealed a difference in behaviour; some participants understood the navigational audio prompts but repeated them the first time due to their lack of confidence that they were selecting the correct option. However, most participants could quickly determine the right choice before the audio prompt swiftly ended. Contrary to this, when they were presented with relatively longer informational audio prompts (20-25 seconds), they repeated them, indicating difficulty understanding them. Upon being asked to listen to healthy eating information twice, one participant responded:

> *"I found the information interesting and listened to it twice ".*

The users quickly understood informational audio prompts. Semi-structured interviews revealed that users found the navigational audio prompts in the IVR system clear, but their repetition helped them to complete their tasks. Additionally, even if the user accidentally presses two buttons simultaneously, they can still access the upper-level menu. One study participant talked about his IVR testing experience:

> *"The clear voice quality of the IVR audio prompts led me to engage with the provided diabetes information easily".*

People with diabetes listened to information about particular topics when given a chance to navigate through the IVR prototype. These topics include diet management, which was the most popular topic since many participants complained about difficulty controlling their glucose levels. To provide sufficient information about the effective diabetes management, the IVR prototype users found the exercises and healthy eating tips particularly helpful given the limited time available for doctor checkups.

Additionally, the IVR testing revealed that participants wanted information about their particular issues. As a participant commented:

> *"What if I could receive personalized information related to other healthcare issues and personal problems".*

Research showed that an IVR system could be used for various purposes, including medication reminders, glucose reading reminders, and motivational feedback based on weekly readings. However, IVR call affordability proved to be a significant problem.

User-scoping participants disclosed that they hesitated to engage with IVR because of its call costs. According to a person with diabetes, IVR was not affordable,

> *"I can receive a Free (Mufat) call, and am unable to afford IVR phone calls due to financial difficulties I am facing".*

Research showed that advertisements could make the IVR system more sustainable since advertising agencies can fund the call cost[157]. But when people struggle to afford even the basics of daily life, finding advertisers for this group is difficult. However, its feasibility can only be confirmed by implementing the advertisement strategy.

After using the IVR prototype, most of the participants were eager to use it again, one stating:

> *"I would love to listen to the IVR system call again".*

Most participants have agreed to use this system and provided their phone numbers, showing their willingness to receive the call from the IVR System.

Testing of the IVR demonstrated its acceptability for less literate users and provided guidelines for future improvements. One participant expressed interest in listening to phone calls:

> *"It would be great to receive a call from an IVR for diabetes awareness and management; please take my number and call me once it's up and running!"*

Similarly, another participant remarked:

> *"If there is a diabetes helpline (IVR) number, please write it down on paper, as I want to contact the helpline and listen to information about diabetes".*

Most study participants preferred to engage with *"Sugar-ka-Saathi"* in the Punjabi language; this shows the acceptability of The Punjabi language, especially in rural areas, compared to the Urdu language.

Navigational Prompts	No. of Repetition	No. of Users Opted-in for Repetition	No. of Inputs	No of Users Opted-in for Input
Main Menu	20	14	147	45
Diabetes Menu	5	5	45	27
Managing Diabetes Menu	18	13	70	45
Diabetes Types Menu	2	2	12	8

Showing Navigation prompts as described in column one, the total number of repetitions, the total number of users who request repetitions, the total number of navigation menu inputs and the number of users who do the input). This table gives an overview of interactions with Prototype One.. . .

Table 4.9: *"Sugar-ka-Saathi"* Prototype One Navigational Usage

The IVR system testing, with a fixed hierarchy, found that:

1. User is willing to listen to various information about diabetes. They do not want to listen to the same information in every call to the IVR system; Rather, they; want to listen to something new and informative.
2. Many people suffer from diabetes and comorbid conditions such as hepatitis and heart problems information.
3. Many people manage diabetes in isolation and require a common platform to exchange ideas with community members.

Section 4.5 showed the effectiveness of the IVR prototype in communicating diabetes information. IVR system testing (discussed in the last paragraph) highlighted the user's willingness to listen to new information about diabetes and the user's desire to listen to information on comorbid conditions. In response to these findings, a scalable and dynamic IVR system (*"Sugar-ka-Saathi"* Prototype Two) is discussed in section 4.9.

Additionally, IVR system testing showed the user's willingness to involve the community in managing their condition as they operate it in isolation. In other words, they want peer support for diabetes management. However, this community involvement idea needs further development to see how people see themselves using the community feature. The invisible design videos discussed in section 4.6 investigated two things: Community involvement in diabetes management through the IVR system. Visual IVR for diabetes management (A smartphone version of IVR that people can relate to visually).

Information Prompts	No. of Repetition	No. of Users Opted-in for Repetition	No. of Inputs	No of Users Opted-in for Input
Exercise	10	4	35	34
Healthy	9	6	50	43
Symptoms	6	4	43	21
Medicine	3	2	46	18
Type 1 Diabetes	0	0	4	7
Type 2 Diabetes	0	0	5	4

Showing information prompts as described in column one, the total number of repetitions, the total number of users who request repetitions, the total number of information menu inputs and the number of users who do the input. This table gives an overview of interactions with Prototype One. with Prototype One.. . .

Table 4.10: *"Sugar-ka-Saathi"* Prototype One Informational Usage

Figure 4.6: Researcher showing Demo of IVR in PD Sessions in Faisalabad.

4.6 Invisible Design Videos

Invisible Design Videos [78] uses ambiguous videos to generate ideas with PD participants without showing them technology directly. This study used the invisible design video method, and the methodology and results are discussed below:

4.6.1 Method

Participants with less literacy could communicate about the IVR system design with the help of the invisible design video. The study participants were presented with different design ideas and gave their opinions regarding their suitability.

Procedure

In a one-to-one PD session, after introducing IVR and its use, a demo of the IVR system was given to participants. They used the IVR system for 15-20 minutes, going through all the menus. Later, after collecting feedback from participants, they were shown two videos based on invisible design [78], illustrating the concept of Community IVR and Visual IVR. Community IVR is when the community acts as a single unit, and members help manage the condition by exchanging views on medicine and other tips. Community Visual IVR is when the community visually exchanges their ideas and points of view through smartphone applications.

In our invisible design-based videos, a doctor is seen advising people to use technology interventions such as community-based systems and Visual IVR. It was noted that the participants listened to videos attentively and effectively grasped the idea of community radio. Because the concept of IVR was clear from the demo already shown, it was easy for participants to get the concept of community-based radio, and it was easy for them to imagine such technology.

However, the idea of Visual IVR was not very clear to participants. This result shows that participants can understand the visual IVR concept better if a prototype on a smartphone is offered to participants, followed by a video of invisible design [78], to increase the likelihood of participants grasping the idea.

This session occurred in September 2017. PD exercises were conducted in a one-on-one setting or in small groups of participants who felt comfortable with each other - acquaintances or friends (recruited together) or, if unfamiliar, participants were selected from similar demographic groups. The design process stressed verbal communication by allowing all participants to participate in the discussion.

After participants used the IVR Prototype One for 15-20 minutes navigating through various features such as basic information about managing diabetes, they watched two videos based on the 'Invisible Design' approach that stimulated ideas with PD workshop participants focused on more advanced concepts of IVR systems such as community-based IVR. Fig. 4.7 illustrates how a diabetes doctor and a diabetic person set up the context for the invisible design video.

Participant Information

Thirteen people with diabetes (Two men and 11 women) participated in these one-to-one PD sessions arranged in "75 G.B.", South Faisalabad and "Ashraf Town, Malikpur", Faisalabad. These 13 participants included two men and 11 women. All participants were illiterate or less literate.

All participants have used the IVR system described in section 4.5.3, and so had knowledge of the IVR system and how it is used. After watching the videos, they were asked about their views on the features of the proposed system.

Ethics Information

IVR Prototype One testing was conducted after ethics approval from Swansea University's computer science department. Appendix F p228 highlights the Invisible Design Videos Procedure.

Ethical approval required participants to receive Participant Information sheets and consent forms. Therefore, the Participant Information sheet was read to participants, and participants' signatures or thumbprints were taken on the consent forms.

Participant information, including demographics, phone number, and video or audio recordings, were processed and stored with care according to the ethics process highlighted in the application. Participants were briefed in the Participant information sheet about how their data would be processed and kept. (see Appendix D, p205, Data Archiving/Destruction and Confidentiality).

Analysis Method

All interviews and focus groups were recorded, and where video recording was not convenient or authorized, audio recording was used.

The researcher transcribed all videos from Punjabi to English due to her knowledge of both languages. Therefore, all the recorded videos were first translated, and each participant's response was noted. This data was then verified again with videos to overcome any shortcomings in data, such as unclear or misinterpreted meanings.

Figure 4.7: Invisible Design Video.

A thematic analysis of the transcribed data revealed participants' generalised views and requirements that informed the design process [77].

4.6.2 Findings

The Narrative Scoping sessions showed an ideal situation where everything goes according to plan. However, this is not always the case due to multiple factors, including the participants' lack of formal literacy. Furthermore, the researcher's experience may differ according to smartphone availability or internet access. Therefore, it is not advisable to pre-plan the whole experience. Instead, some room should be left for the natural flow of the activities.

Participants with less literacy responded well to the invisible design method, and their prior experience with Prototype One played an important role. Therefore, the invisible design video eased the IVR system features visualization and thus facilitated the discussion. Overall, it can be concluded that PD techniques that show videos followed by discussions can potentially engage illiterate or less literate participants.

Previous sections reiterated the IVR design ideas according to user preferences and clarified the IVR system design; section 4.7 presented the IVR re-design.

4.7 Re-Design of *"Sugar-ka-Saathi"*

In Prototype One testing, users mentioned a desire to receive customized information from the IVR system that is not repeated in subsequent calls. Therefore, Prototype Two addressed this shortcoming, and the information was delivered periodically to raise awareness of specific topics, including diabetes, heart disease, hepatitis, smoking and COVID-19. It is a common practice in traditional IVR to deliver information, often using a limited number of menus with the same information in every call.

Healthcare information about various conditions is available on the World Wide Web. This information's availability can help keep people engaged in their healthcare practices. However, less literate people living in rural areas often have access to limited information about their condition, which affects their healthcare behaviour.

Several challenges are associated with designing and developing a voice-only medium, as highlighted in Fig. 4.8. This research will address the challenges of User experience, Integration with other Systems, Performance and Scalability. Other challenges highlighted in Figure 4.8 are outside this research's scope.

With a conventional information hierarchy, navigating much information is practically impossible. Navigational menus enable users to select information while navigating the menu. However, being a voice-only medium, IVR becomes challenging to navigate in the presence of many navigational menus. Therefore, while brainstorming on *"Sugar-ka-Saathi"*, multiple flow charts were designed to overcome this navigational challenge. Figure 4.9 shows an attempt to design an IVR flow. Figure 4.10 is the outcome of developing multiple flow charts. Prototypes Two, Three and Four were further designed and developed based on this flow chart.

The iterative design of *'Sugar-ka-Saathi'* yields different prototypes, as discussed in Table 4.11.

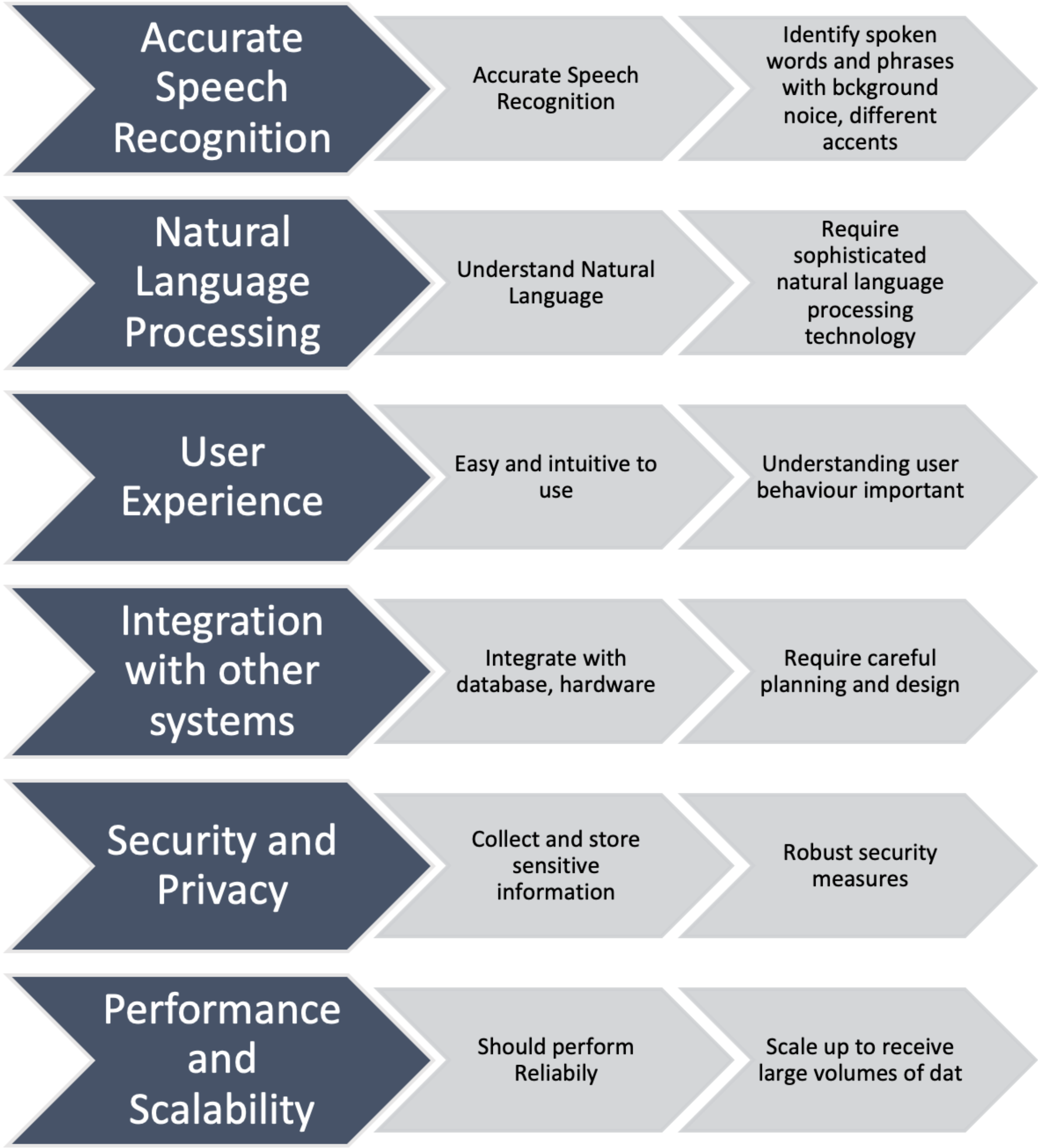


Figure 4.8: Challenges of designing a Voice-based System.

PNo.	**Functions**	Development	Deployment
One	Static IVR prototype	Developed with Asterisk, PERL, SQL	deployed within WIFI router range
Two	Scalable and dynamic IVR	Python Program	ran on laptop to play prompts
Three	Scalable and Dynamic IVR , Diabetes and Comorbid condition, Experience Sharing Information	Asterisk, PERL, MySQL Workbench	Server Deployment Missed call mechanism
Four	Scalable and dynamic IVR, Diabetes and Comorbid condition Experience Sharing Information	Asterisk, PERL, MYSQL Workbench	Server Deployment

Table 4.11: *"Sugar-ka-Saathi"* Iterative IVR Prototypes

For *"Sugar-ka-Saathi"*, Prototype Two focused on user journeys as they guided the IVR design. Two user journeys were considered: 1) Naive Users and 2) Intermediate Users. The primary focus of this study is to design an IVR system for the Persona "Mukhtaran Bibi" - a naive IVR user (as discussed in Section 4.3).

Therefore, the priority of the IVR system is to allow "Mukhtaran Bibi" and to let her use the IVR system with minimum effort and input. Thus, after the initial 'welcome', the IVR system conveys diabetes information. It is expected that "Mukhtaran Bibi" has limited motivation to use the system and will hang up after listening to only the first IVR feature that delivers diabetes information.

Another focus of this study is facilitating the Persona of "Liaquat Hussain". "Liaquat Hussain" persona already has some exposure to technology and is between the intermediate and expert level of IVR system usage. "Liaquat Hussain" can easily navigate through the IVR system. Therefore, focusing on the demand of persona, the IVR flows are defined to keep playing information and save the system's state when it is hung up.

4.7.1 Diabetes Information

The importance of raising diabetes awareness has been highlighted and addressed by adding diabetes information to the IVR system. The IVR design, therefore, began with collecting detailed information about diabetes from trusted websites [7] [10]. The sensitive nature of the healthcare information led to getting it approved by two doctors from Faisalabad, Pakistan; getting the doctor's approval was lengthy as their busy schedules made access difficult. Later, the prompt content was translated into Urdu and later Punjabi. After the Punjabi translation, the content was recorded (discussed in section 4.6.4.) in an engaging voice to sustain IVR users' interest and usage.

Figure 4.9 shows diabetes information sorted into different categories.

Figure 4.10 presents the scalable and dynamic IVR design flow chart.

4.7.2 Comorbid Conditions, Smoking and COVID-19 Information

User scoping showed the prevalence of comorbid conditions such as heart disease, hepatitis and other health issues such as smoking and COVID-19. While redesigning *"Sugar-ka-Saathi"*, special consideration was paid to adding information about other health conditions and issues. All information was prioritized.

Research shows that the information about comorbid conditions can be of two types: 1) Preventive information - to inform people how to care for their health to avoid the onset of different chronic conditions. 2) Management information - to help people manage their existing diabetes and comorbid conditions. The limitations of this research project led to adding only the preventive information about the specific healthcare issues (mentioned above).

4.7.3 Community System

Diabetes management is aided by extrinsic motivation and inspiration from other people with the condition [214]. Though people with diabetes long to manage their chronic condition by incorporating appropriate strategies, the level of self-motivation fluctuates over time while coping with this lifelong condition. Therefore, establishing a communal approach that advocates for people with diabetes to help each other manage their condition can be helpful. Technology can facilitate this communal approach by connecting people.

Consequently, the design of a community system was further investigated using the PD approach highlighted later in this Chapter (Section 4.10). An appropriate IVR system was developed based on the PD findings.

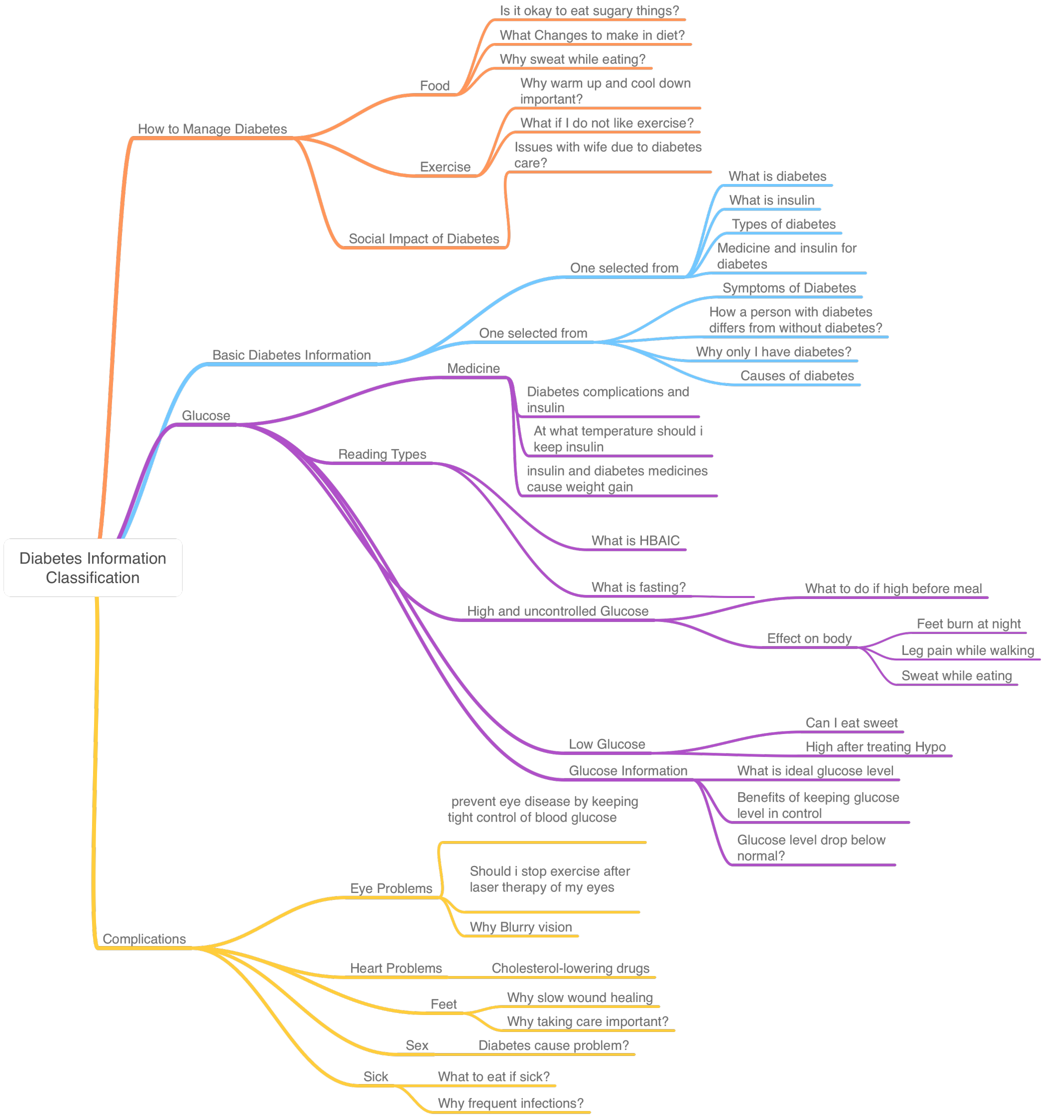


Figure 4.9: Flowchart - Categorizing the Diabetes Information

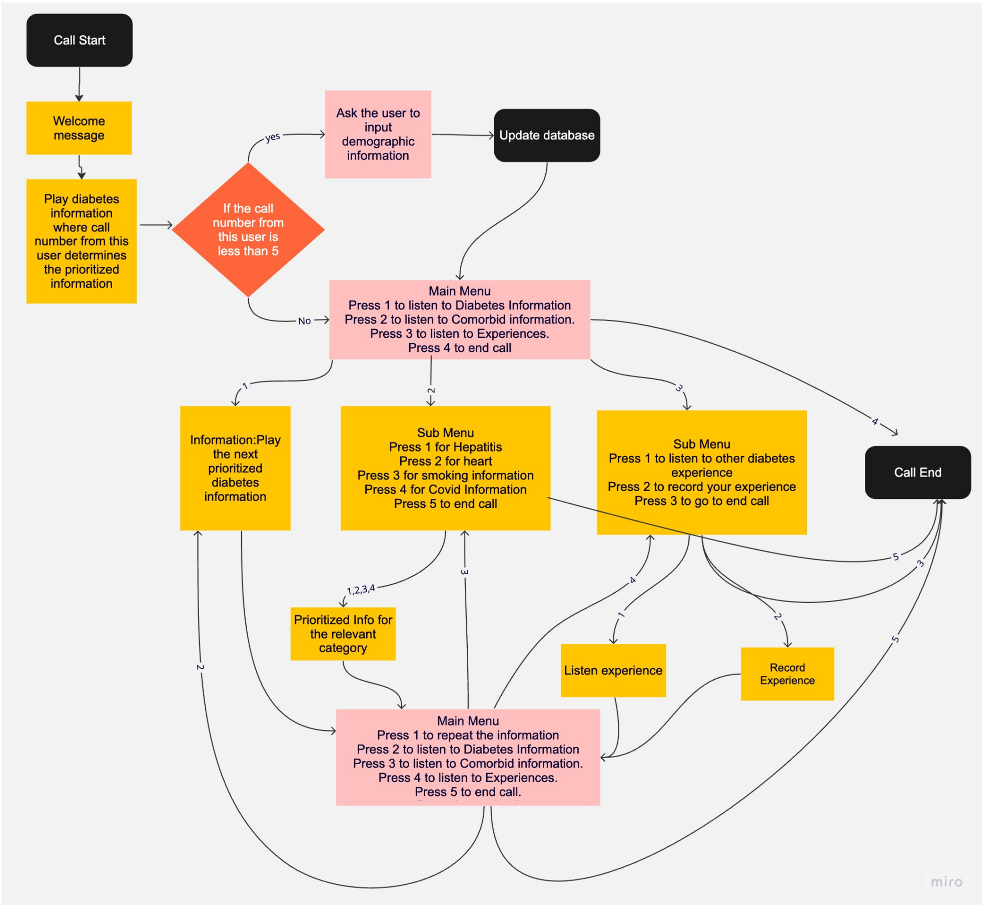


Figure 4.10: Sugar-ka-Saathi - Detailed Design of Scalable and Dynamic IVR System

An overview of the detailed design that captures the IVR system - "Sugar-ka-Saathi", is shown in Figure 4.10.

The novel attribute of the dynamic and scalable IVR is its ability to present various information chunks. Considering the sensitivity of healthcare topics, the information presented has to be reliable and valid, approved by healthcare practitioners, and then translated and recorded in an appropriate tone. Section 4.8 describes the process of creating IVR content.

4.8 *"Sugar-ka-Saathi"* Content

"Sugar-ka-Saathi" design delivers information on three topics: 1) Diabetes, 2) Comorbid Conditions, and 3) Experience Sharing; the detailed flow is shown in Fig. 4.10.

Initially, 132 diabetes prompts (information bits related to diabetes) were recorded using an appropriate voice.

Although there is a range of information about the comorbid conditions available on the internet, due to the limitation of this project, only information about heart disease, hepatitis, smoking, and COVID-19 was collected, and the total number of prompts (recorded information bits) was 70.

The script translation from English to Punjabi was a lengthy process due to the non-availability of a translator tool. The translation requires fluency in Punjabi, thus creating challenges for people lacking fluency in Punjabi. In the Global South, the co-existence of many regional languages and the absence of one common language makes adapting technology challenging, as it needs to be tailored to the local context.

The Python prototype testing helped to clarify the IVR navigational structure. A further benefit of the prototyping activity was identifying how to write code to retrieve such a large amount of information, resulting in the choice of a dynamic and scalable approach.

The translated script was then recorded in appropriate voice quality so that the information delivery facilitated engagement and provided a pleasant listening experience for users.

4.8.1 Content Validation

Ensuring good voice quality of the IVR system's information helps provide a good user experience. Therefore, special attention was given to the recording details. The recording equipment was of high quality, and the recording software helped to capture clear audio.

The recording quality of a person's voice received special attention because an impactful voice quality can engage and motivate people to listen to the IVR system; Users are the best judge of recorded audio quality. This study hired a professional voice talent to record the audio prompts.

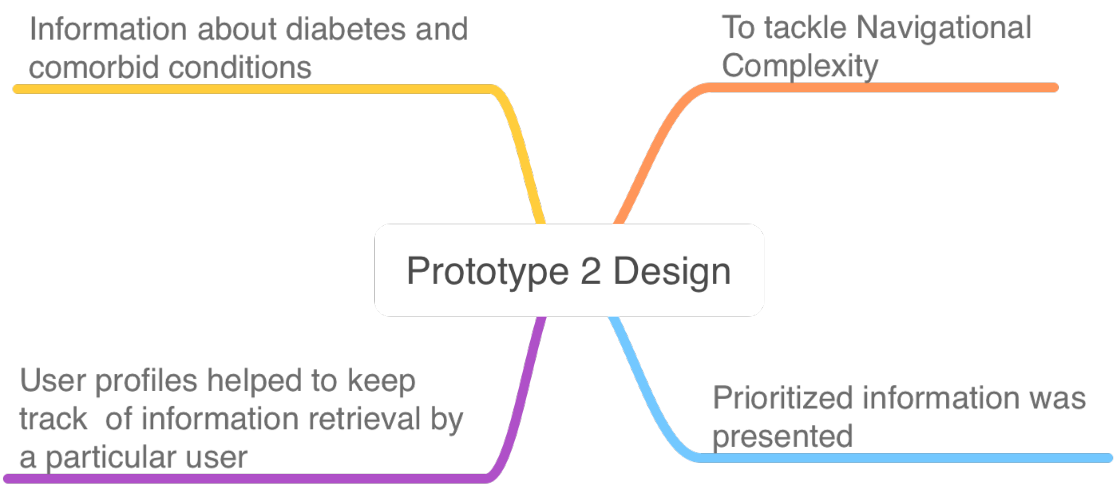


Figure 4.11: Flowchart - Prototype Two Design

Testing the audio prompts helped ensure the quality met the user's expectations. Eleven people with diabetes from 75 G.B. South, Punjab, were contacted through a local contact on WhatsApp and Skype (as the researcher was in the UK and could not travel due to COVID-19 restrictions). A playlist of the recording was played to participants who approved of the quality and showed interest in receiving calls from the IVR system. The rural people's approval of the recording and willingness to use the IVR system led to recording 200 prompts in Punjabi with the same voice quality and recording equipment.
After finalising the IVR content, Section 4.9 highlights the *"Sugar-ka-Saathi"* Prototype Two design, development and testing.

4.9 *"Sugar-ka-Saathi"* - Prototype Two

"Sugar-ka-Saathi" Prototype Two was the first step to developing a "Scalable and Dynamic" IVR system. Prototype Two aimed to deliver only diabetes information, initially, before being expanded to provide comorbid condition information.

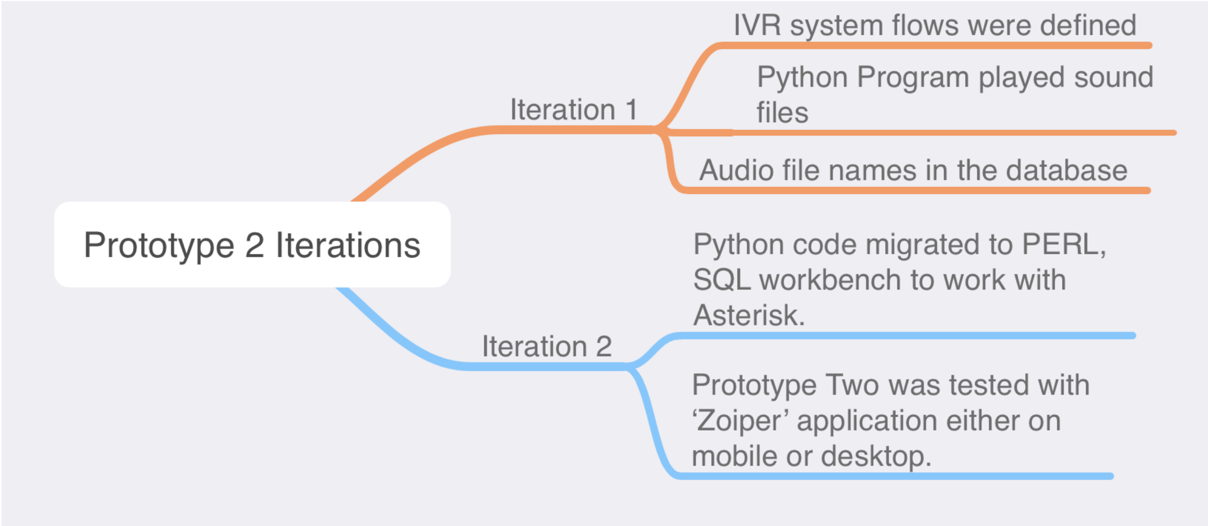


Figure 4.12: Prototype Two Iterations

4.9.1 Design and Development

Prototype Two aims to facilitate user engagement and maintain user interest while delivering diabetes information.

Information Delivery

"Sugar-ka-Saathi" Prototype Two presented various information to raise diabetes awareness. Section 4.6 presents three parts of the proposed IVR system: Diabetes, Comorbid Conditions and Community. Prototype Two only focused on the first two parts of IVR: Diabetes and Comorbid Conditions.

Prototype Two was developed in two iterations, as shown in Figure 4.9.1.

1. Iteration one consisted of the development of the Python program. This was the first step towards designing and developing a scalable and dynamic system. Some complexity is involved in creating a program representing many sound files. To resolve this issue, I stored the file names in a database, facilitating file retrieval as desired, using a generic code.

2. In iteration two, the Python program was migrated to the PERL program and the SQL workbench was used to perform the database queries on the back end. With the help of the PERL script on the Asterisk platform, it is possible to dial a call. With the Zoiper application on both a desktop and a mobile device, the call could be dialled to the Asterisk platform, and the logs would be displayed on the command line.
   This Zoiper application-based phone prototype has the limitation that it only works within the range of an internet connection, either WiFi or data connection. This limitation was resolved with a server deployment in later prototypes introduced in Chapter Five.

Navigational Complexity

One of the design goals is to deliver healthcare information on different topics with minimum dependence on navigating complex menus.

Another design goal is to reduce the programming complexity and to facilitate a wide range of information about various healthcare conditions that can be added to support people with diabetes by any authorized system user with appropriate access privileges.

The navigational complexity should be reduced to promote user engagement; therefore, the diabetes information stored as functions in the database was divided into the Main Menu navigation prompt having three options, as shown in Figure 4.10. This effort to reduce navigational complexity used the technique of information prioritization.

Prioritising Information

"Sugar-ka-Saathi" Prototype Two design presented prioritized information based on the input of different stakeholders, including two diabetes doctors and people with diabetes.

For this research, various methods to present information to people with diabetes were investigated, including recommendation techniques, collaborative filtering with user ratings, etc. However, information prioritisation was the most appropriate technique to give information through this voice-only medium. Because the IVR healthcare information is presented to the users for the first time, there was no prior test data to train the system. The lack of navigational menus made collecting data difficult.

User Profile

Maintaining a user profile was particularly important for our "Sugar-ka-Saathi" to present prioritized information to every user. Therefore, this research relies on maintaining a profile to provide appropriate healthcare information to people with diabetes by keeping track of their IVR system usage [94].

Demographic information (gender, name, age, literacy, use of insulin) was stored as part of the user profile. This information helped categorise the users based on their demographics. In this research, instead of collecting all of the demographic information in the first IVR call, a single piece of information was asked in a single call to keep users engaged with the system and to avoid over-burdening them in the first call.

Development Details

It is usual to call the audio file names to implement the logic of an IVR system. The initial attempt at developing Prototype Two started with calling file names directly from the code. However, the code structure became complex by calling every function with code. Later, this code complexity was resolved by storing filenames in the database. The recorded diabetes information (discussed in section 4.7, "Content Creation") is saved in the database, meaning that the diabetes information file names are stored in the database, and a standard function is used to group files. Table 4.12 highlights the filename arrangement in the database.

Figure 4.10 shows the flow of the complete IVR system ("Sugar-ka-Saathi"). Remember that the call can be ended at any step shown in Fig 4.10, and the relative state of the system is updated at every call.

4.9.2 Prototype Two Testing

Prototype Two was developed as a Python program that played the script on a laptop computer. The ultimate goal of this project is to establish an IVR system (integrated with a landline number) that users can call from their mobile phones.

Method

This testing led to quick verification of the logic of the program, which will ultimately be configured with an IVR system.

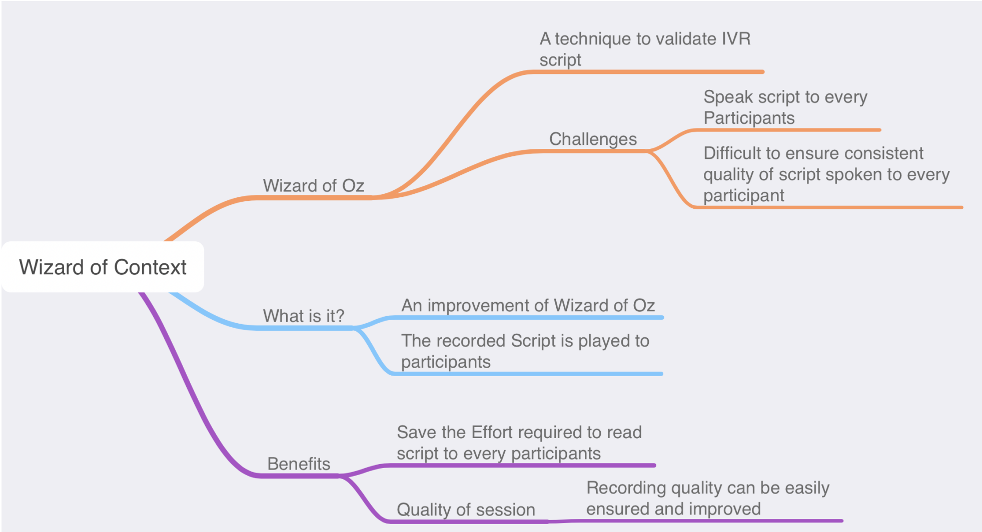


Figure 4.13: Wizard of Context - Process Overview

Prototype Two was tested with a *novel technique* - ***"Wizard of Context"*** *- similar to the Wizard of Oz (WoZ)*. WoZ is a rapid prototyping methodology to improve the user experience (UX), and it uses a script read by a human "Wizard" to perform tasks that simulate a product's behaviour. An overview of Wizard of Context is shown in Figure 4.9.2.
Wizard of Context differs from WoZ, as the recorded system script was played by Prototype Two - a Python program running on a laptop. This interaction helped determine the acceptability of recorded prompts and the IVR information flow design. The following section discusses the method and findings of prototype testing.
This on-phone session was undertaken with two diabetes doctors and five people with diabetes. Prototype Two was running on the researcher's laptop, and a Skype call was placed to relevant contacts in rural areas. The call was audio recorded, but only with participants' permission. Special consideration was given to the ethics process.

Ethics Information

IVR Prototype Two testing was conducted after ethics approval from Swansea University's computer science department. Ethical approval required participants to receive participant information sheets and consent forms. Therefore, the Participant information sheet was read to participants, and participants' signatures or thumbprints were taken on the consent forms.(Appendix F p229 highlights the IVR Prototype Testing Procedure study).

Participant information, including demographics, phone numbers, and video or audio recordings, were processed and stored with care according to the ethics process highlighted in the application. Participants were briefed in the Participant Information sheet about how their data would be processed and kept (Appendix D, p205, Data Archiving/Destruction and Confidentiality).

Analysis

All interviews and focus groups were recorded in cases where video recording was not convenient or authorized audio recording was done.

The researcher transcribed all videos from Punjabi to English due to her knowledge of both languages. Therefore, all the recorded videos were first translated, and each participant's response was noted. This data was then verified again with videos to overcome any shortcomings in data, such as unclear or misinterpreted meanings.

A thematic analysis of the transcribed data revealed participants' generalised views and requirements that informed the design process [77].

Findings

Participants prioritised the need for information about exercise and diet and were eager to listen to diabetes information using their phones.

The restricted time window for using Prototype Two was a limitation of this study, as developing a viewpoint about IVR needs some time. Therefore, long-term interaction with the IVR will help to gather more appropriate feedback as it will be used in real life. However, the technical equipment requirements for IVR system deployment using the server became challenging and were addressed in the next iteration.

Table 4.12: An overview of the functions defined in the database (Described to facilitate subsequent research in the field)

Function id	Function name	File1	File2	File3	File4
1	what is diabetes	22.wav	150.wav	NULL	NULL
2	symptoms of diabetes	30.wav	31.wav	NULL	NULL
3	causes of diabetes	34.wav	35.wav	NULL	NULL
4	why diabetes	36.wav	37.wav	NULL	NULL
5	appropriate gluose level	38.wav	39.wav	NULL	NULL
6	types of diabetes	26.wav	27.wav	NULL	NULL
7	glucose below level	42.wav	43.wav	NULL	NULL
8	glucose high before meal	121.wav	122.wav	NULL	NULL
9	food not at time	95.wav	NULL	NULL	NULL
10	why weight gain	115.wav	116.wav	NULL	NULL
11	why weight falls	54.wav	55.wav	NULL	NULL
12	why more hungry	24.wav	25.wav	NULL	NULL
13	why more thirsty	56.wav	57.wav	NULL	NULL
14	why these symptoms	50.wav	51.wav	NULL	NULL
15	why more urine	48.wav	49.wav	NULL	NULL
16	why wound take time	80,81.wav	82.wav	NULL	NULL
17	why feet care	83.wav	NULL	NULL	NULL
18	why see not clear	73.wav	74.wav	NULL	NULL
19	why heart disease	75.wav	NULL	NULL	NULL
20	why cholesterol medicine	76.wav	77.wav	NULL	NULL
21	why aspirin low	78.wav	79.wav	NULL	NULL
22	what food during illness	88,89.wav	90.wav	NULL	NULL
23	what is insulin	24.wav	25.wav	NULL	NULL
24	insulin temperature	113.wav	114.wav	NULL	NULL
25	why insulin important	111.wav	112.wav	NULL	NULL
26	why medicine insulin	28.wav	29.wav	NULL	NULL
28	why take breath	102.wav	103.wav	NULL	NULL
29	exercise after laser	71.wav	72.wav	NULL	NULL
30	benefit of glucose control	40.wav	41.wav	NULL	NULL
31	why get ill	91.wav	92.wav	NULL	NULL
32	what sexual problems	86.wav	NULL	NULL	NULL
33	why leg hurt	127.wav	128.wav	NULL	NULL
34	why more sweat	104-105.wav	106.wav	NULL	NULL
35	difference diabetic normal person	32.wav	33.wav	NULL	NULL
36	safe from disease	93.wav	94a.wav	NULL	NULL
37	social issues	96 a.wav	97.wav	98.wav	NULL
39	why extreme hunger	46.wav	47.wav	NULL	NULL

Function id	Function name	File1	File2	File3	File4
40	why more tired	52.wav	53.wav	NULL	NULL
41	symptoms created	58.wav	59.wav	NULL	NULL
42	eyesight	68.wav	69.wav	NULL	NULL
43	feet pain	146.wav	NULL	NULL	NULL
44	eatinghabit1	130.wav	131.wav	132.wav	NULL
45	eatinghabit2	133.wav	134.wav	135.wav	136.wav
46	lifestyle	137.wav	138.wav	139.wav	140.wav

Section 4.3 highlighted the persona picture displayed in the PD session and participants' eagerness to express their views to co-determine persona attributes. Section 4.5 highlighted the use of invisible design videos to facilitate participation in the design, and this approach resonated well with participants despite their low literacy levels. Moreover, the auditory content presented using the Wizard of Context approach was well understood.

This research highlighted that visual and auditory content significantly facilitates communication with less literate people. Combining the approaches mentioned above, Section 4.10 explains the process of facilitating PD sessions with participatory video, pictures, and audio to conduct it consistently with all users.

4.10 Facilitating Participatory Design with Visual and Auditory Content

This research focuses on facilitating PD in rural areas with illiterate or less literate people with diabetes in the outskirts of Faisalabad city. Re-iterating the PD process helped refine it to better work with the participants' abilities and overcome the design team's preconceptions. For example, the script can be changed when questions do not elicit strong responses, or the group size can be altered if the participants are not happy talking in front of that many people.

This iterative process required two levels of analytic awareness: first, the researcher engaged with and analysed the previous PD sessions to understand the design space, and second, the researcher examined the tools employed in the PD session and the suitability of the overall methodology.

4.10.1 Method

Let's discuss the detailed method:

Procedure

This PD Session aimed to introduce study participants to the helpline design ideas through Participatory Videos, pictures and audio - all presented in a slide show. Although this approach requires effort in the session design to film, using videos helped to conduct sessions consistently with all users. Media use also helped sustain participants' attention and carry the conversation to understand users' perceptions of diabetes-related problems and their solutions. An overview of the PD slides that explains the challenges encountered in previous studies and how those challenges could be overcome with PD slides is shown in Figure 4.14.
Therefore, participatory video, pictures, and audio arranged in a slide show guided this session (Table 4.13 and Table 4.14). The equipment used during the PD session is a camera to record the session, a laptop to display the slide show, a speaker so that videos are audible and a notebook to take session notes.
Visual and auditory content enabled session delivery to be consistent for all users, to get participants' attention and to drive the conversation to understand users' perceptions of diabetes and associated solutions to its related problems.
The study participants were fluent in Punjabi (the regional language of Punjab, Pakistan) rather than Urdu (the national language of Pakistan) led us to conduct interviews/focus groups in Punjabi.

Participant Information

Fifty-nine people with diabetes were recruited and were arranged into twenty groups.
Notably, the IVR system's primary goal is to cater to less literate participants, but some literate participants were included in the study. This is because when the researcher went to a rural area, the local contact had gathered people with diabetes from the village. So, restriction on literacy was not placed because, according to social norms, being illiterate is not desirable. Therefore, this study did not narrow down the participants based on illiteracy. This led to the inclusion of people with varied education levels. Notably, the education system in Pakistan has different names such as Matric - 10th standard, Middle -8th standard, FA - 12th standard, and participants distribution concerning literacy is described in Figure 4.15.

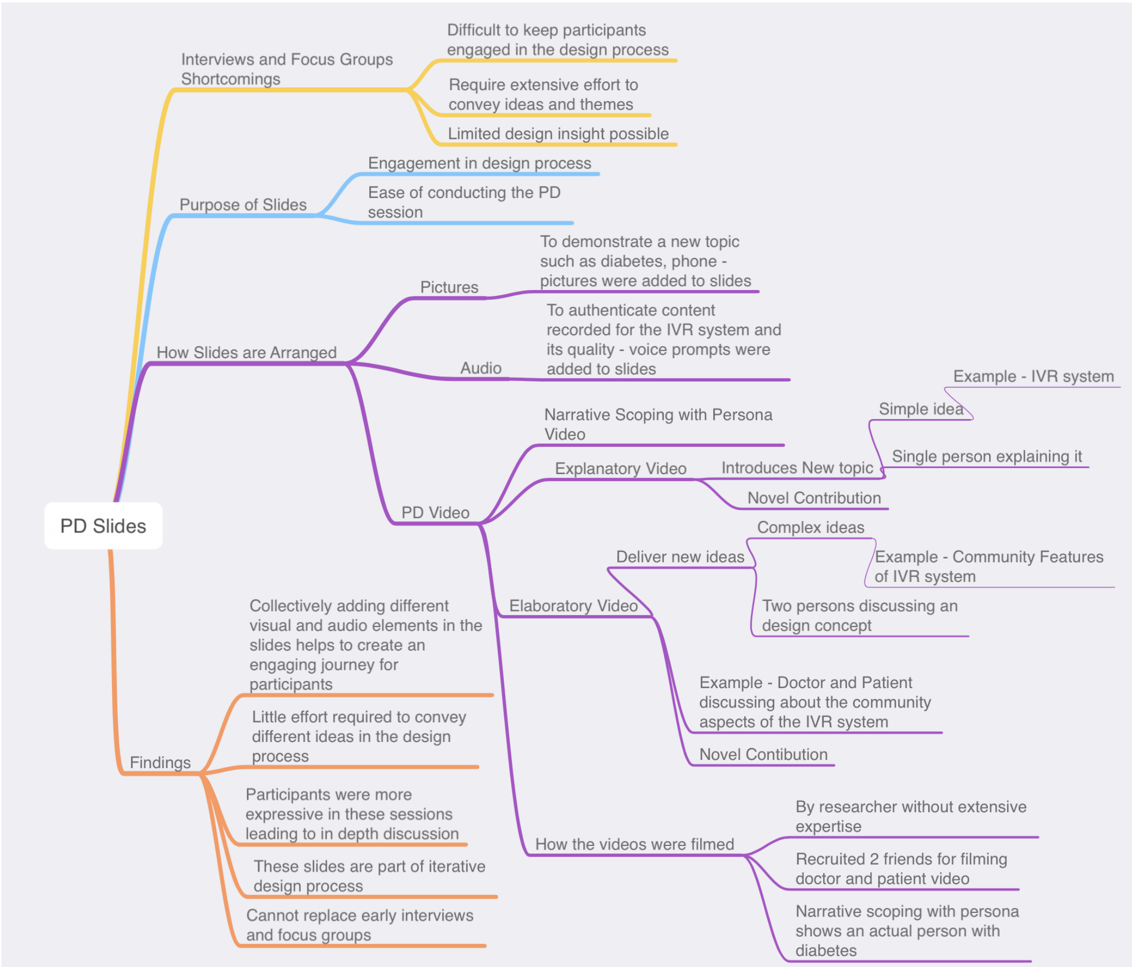


Figure 4.14: PD Slides - An Overview

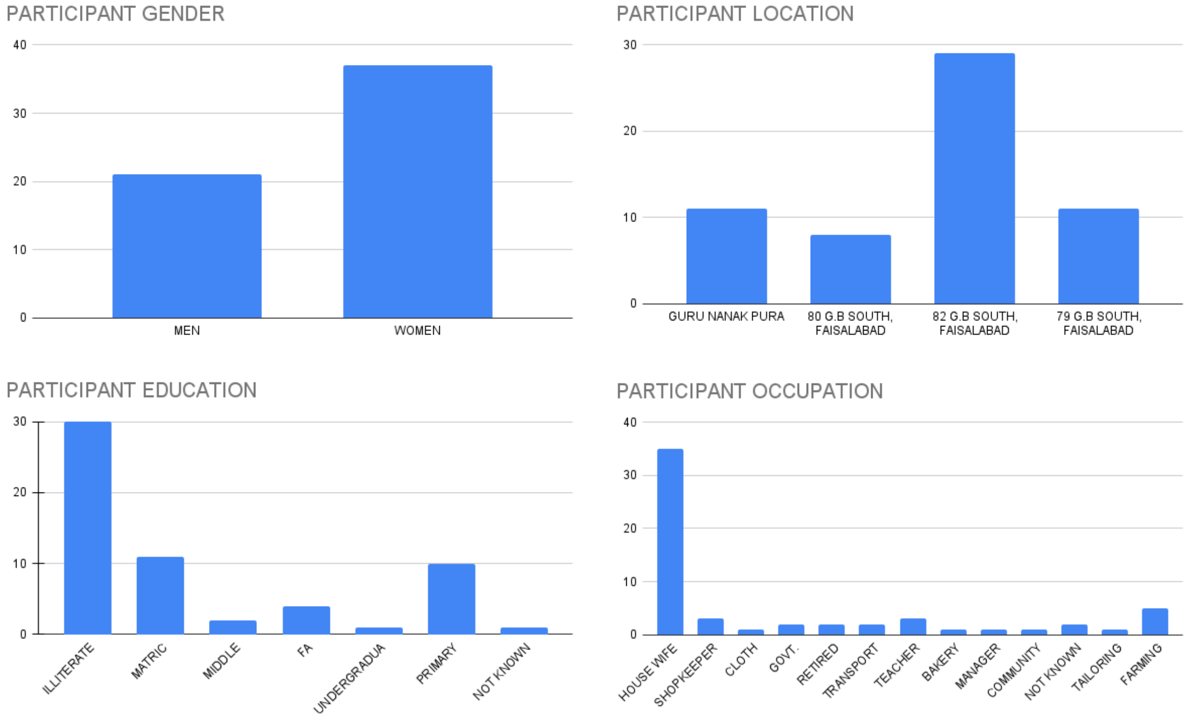


Figure 4.15: Participant's Demographics

In Figure 4.15, it is notable that women participants outnumbered men; the region-wise participant distribution is also shown, as the study was conducted in three villages and one city area. Different participant professions are also shown.

Ethics Information

These PD sessions were conducted after the ethics approval from Swansea University Computer Science department. Appendix F, p236, highlights the Design Finalization Process. A consent form and participant information sheet were provided to participants following the ethics procedure. Because the participants were illiterate or less literate, the participant information sheet was read to illiterate participants who could not read it. They signed the consent forms, and their thumbprints were taken in the case of illiteracy.

Participant information, including demographics, phone numbers, and video or audio recordings, were processed and stored with care according to the ethics process highlighted in the application. Participants were briefed in the Participant information sheet about how their data would be processed and kept. (see Appendix D, Page 212, Data Archiving/Destruction and Confidentiality).

Analysis Method

All interviews and focus groups were recorded in cases where video recording was not convenient or authorized audio recording was done.

The researcher transcribed all videos from Punjabi to English due to her knowledge of both languages. Therefore, all the recorded videos were first translated, and each participant's response was noted. This data was then verified again with videos to overcome any shortcomings in data, such as unclear or misinterpreted meanings.

A thematic analysis of the transcribed data revealed participants' generalised views and requirements that informed the design process [77].

Table 4.13: Participatory Slides to engage participants in the Design Process

No.	What is shown?	Details
1		Participatory slide#1 helps to convey the research background and universities involved.
2		After an initial discussion about diabetes management, slide#2 changed the topic as participants discussed mobile use.
3		Participatory slide#3 introduces 'Mansha', who explained his diabetes experience, thus facilitating conversation between the researcher and PD participant, which enables understanding of the participant's behaviour towards diabetes and the comorbid conditions.
4		This is followed by the Participatory slide#4, which included links to the IVR audio prompts; thus, listening to audio prompts gave the users a flavour of the IVR, which enabled them to imagine the system's use.
5		Participatory Video helped explain the diabetes IVR idea to first-time users as a doctor explained the IVR calls and the information it deliver.

Table 4.14: Participatory Slides to engage participants in the Design Process

No.	What is shown?	Details
6		The participatory video explained the role of the community in improving motivation to manage diabetes. A doctor explained the idea of collaboration among community members for sharing experiences about diabetes management by adding friends, etc. This led to exploring user preferences about this communal support with IVR.

4.10.2 Findings

The PD sessions' analysis generated the following themes:

Early Diagnosis and Improved Management

The high prevalence of diabetes in Pakistan leads to the essential nature of the problem and gives rise to the need for continuous screening of the condition [51]. Research shows a higher risk of diabetes for people with positive family history [245].

The economic burden of diabetes is high, including direct costs such as medicine and indirect costs such as the impact on the earning ability of participants. Undetected diabetes often leads to vascular complications, severe morbidity, and mortality.

Early diagnosis of diabetes makes it easier to manage, as a participant mentioned that her early diagnosis did not cause any severe problems.

> *"My diabetic condition was diagnosed with a regular glucose test. I did not experience any symptoms because of early detection. I started taking medicine, and the glucose level remains under control."*

Accessible technology intervention, an IVR system in this scenario, can raise diabetes awareness and the need for regular blood-glucose level checks, even among people without diabetes.

Figure 4.16: Participants discussed their views in Focus Groups conducted in 79 and 82 G.B. South Faisalabad. Media facilitated these sessions.

Rural Location a Barrier to Timely Care

Scoping highlighted a resource-constrained environment, such as the non-availability of doctors in rural areas of Punjab, Pakistan. Diabetes specialist doctors play an important role in this lifelong journey to keep diabetic conditions under control. Therefore, the resource-constrained environment in the Global South often requires people living in rural areas to go to the city for regular checkups. One participant talked about the challenges of getting healthcare services as follows:

> *"If my glucose level is very high, I must see a diabetes specialist in Faisalabad city even though there are two doctors in my village. But I rely on a diabetes specialist doctor due to his competence with raised glucose levels".*

This long-distance communication impacted the participants' checkups regularity. This research focused on developing an accessible, automated IVR system that delivers recorded diabetes information. This is the first step towards a fully automated system that assists people in their diabetes management journey.

Factors affecting the Lifestyle of People with Diabetes

Different reasons can contribute to non-compliance with the healthcare regime.

> *"I cannot regularly walk due to pain in my foot".*

IVR can regularly inform people to take care of and motivate them to keep diabetes under control.

Tiredness is a common symptom of diabetes, and various participants discussed feeling tired.

> *"I take readily available food like milk, yoghurt, sugar cane, spinach according to season, but still feel tired."*

Reporting symptoms to a doctor available via the IVR system, who can offer help accordingly.

Motivation for self-care helps to maintain glucose levels.

> *"When I take two meals per day and do regular walks, my glucose reading becomes normal without taking medicine."*

Numerous participants follow their religion closely and express their trust in God as they manage their condition.

> *"I want to ask my God to cure my condition rather than take medicines."*

Therefore, it is recommended to add a message from a religious clerk in the IVR system that motivates people to manage their diabetes care.

4.10.3 Further Understanding Personas

Personas were created from an early scoping study (Section 4.2.3). Understanding users living in different cultural and geographical contexts is not straightforward. This difference in the outlook of personas has been described previously, and the particular focus of this research shifted to people with diabetes living in rural areas as they needed specific awareness of their diabetic condition. Therefore, PD sessions were conducted with less literate people with diabetes, which led to the design of an IVR system using narrative scoping and invisible design techniques. Later, the PD reiteration led to getting a detailed overview of the lifestyles of less literate people with diabetes.

The early scoping study led to the selection of people from rural areas as the focus of the study. Therefore, a few selected personas representing rural people were revisited based on the findings of the PD session.

Table 4.15: Rural Men with Diabetes Views about the IVR System.

Appearance	Personal Information - A recap	Views about the IVR
	Forty years old, Owais has had diabetes since last year. By profession, he is a clerk and started work in a nearby city after graduation. He takes medicine and walks regularly.	He asked about communicating with the IVR, liked the idea of adding friends and gave suggestions to add a block feature. He wants to share videos as he has a smartphone.
	60 years old Talha lives in city. He is happy to use the community system. He is literate to a secondary level and has diabetes.	He is interested in seeking knowledge from the IVR. He is good at storytelling and interested in sharing his experiences. He has liberal views about the befriending option of social networks.
	Yaseen is a 68-year-old having diabetes for five years. He is not literate and lives in a rural area. He takes medicine regularly and sometimes walks.	He is interested in using an IVR to access information about diabetes and the sharing of experiences.

Table 4.16: Rural Views wit Diabetes Views about the IVR System.

Appearance	Personal Information - A recap	Views about the IVR
	Zubaida is 32-year-old had diabetes for two years. She is literate and works as a primary teacher in a rural area. She avoids sugary things, takes medicine, and walks.	She wants to hear the diabetes information from IVR and share and listen to other people with diabetes experiences *anonymously*.
	40-years-old Shahida has had diabetes for two years. She is illiterate, lives in a village, and looks after the household. She cannot afford to take medicine and avoids sugary things.	She is interested to hear diabetes information from the IVR. However, she *preferred In-Person communication* rather than using the IVR.
	70-year-old Zareena Bibi had diabetes for eight years. She needs help from family members to do household tasks. She avoids sugary things and only sometimes takes medicine because of affordability.	She is interested in hearing diabetes information delivered by the IVR but finds its use difficult because of literacy and eyesight issues. However, she has plans to use the system by *seeking help from her granddaughters*.

4.10.4 Reflection

Section 4.9.1 highlighted the PD process using visual and auditory content amongst illiterate people in rural Punjab. Section 4.9.2 explains the thematic analysis of the PD process. Section 4.9.3 highlighted revisiting the personas (shown in Tables 4.5 and 4.6) based on their views about the IVR-based community system use.
Summarizing the outcome in different sections:

PD Process

The PD process - in which users play a central role in developing a system - presents challenges when you try to implement it with less literate individuals because it depends on reading and writing skills. This research aimed to set up a pathway to overcome the challenges of engaging with less literate or illiterate people, a challenging task.

The use of videos as part of the PD has previously been documented [78]. Video and other media content, such as audio and pictures, can be used to communicate ideas without the need for reading or writing skills. This project relies on media to engage participants and drive the conversation to understand their perceptions of diabetes and its associated health issues.
This study extends our previous work discussed in Section 4.3 to represent a group of participants with personas pictures.
The **'Narrative Scoping with Persona Video'** presents a persona narrating his healthcare problem, as shown in Table 4.13 No. 3. This video effectively communicated the problems faced by the persona and concepts during the PD process and improved participants' engagement. In return, participants discussed the problems they were facing. Therefore, this video led to an effective discussion.
Furthermore, the IVR prompt audio recorded in the session allowed participants to understand the content and approve of its quality. Table 4.13 No. 4 illustrates the IVR content slide.
The **'Explanatory Video'** is a new concept that introduces an idea to participants and facilitates further exploration. As shown in Table 4.10 No. 5, a participatory video introducing the concept of a technology system, in this case, an IVR system, can be helpful for users without prior experience of such a system.
The use of **'Elaboratory Videos'** can help deliver new ideas, as can be seen in Table 4.14 No. 6 slide, where a doctor and a person with diabetes discussed the use of an IVR system to connect with community help.

Thematic Analysis

Earlier user scoping identified themes such as Diabetes Awareness, Diabetes and Stress, Diabetes Medication Alternatives, and Technology Adoption. Scoping can reveal these general themes in any region of the Global South or even the Global North. The early scoping study used only a set of questions, and the researcher had limited knowledge of the target audience. Through the use of media in the PD, the researcher was able to gain a deeper understanding of the participants' daily lives. This resulted in complex themes such as non-compliance with diabetes routines, faith in God, early diagnosis, and improved management. Introducing media into the qualitative process, including interviews and focus groups, allows the researcher to convey ideas more clearly without exerting much effort.

Personas

Personas are essential to understanding end users and categorising them according to their interaction with technology. Though personas were defined during the initial user scoping; however, it was difficult to determine the persona's attitude towards sharing information amongst community members.

This PD study occurred in rural areas and helped collect the participants' views on different topics, including the community system. The aim of investigating participants' opinions about the community is to know their potential use of the IVR feature that connects community members.

One of the findings is that users' attitudes towards this community system are liberal based on gender. Men participants wanted to add friends, share experiences, and seek diabetes awareness. On the other hand, women participants did not express much interest in listening to the IVR information and preferred in-person communication compared to phone communication. This behaviour is particularly evident in conversations with young or middle-aged women (two study participants) because of the cultural norms and the gender inequality women face. Previous research showed that women face gender inequality in Pakistan, are discriminated against based on their gender, and are seen as 'sexual objects' - a term used in [50].

Therefore, to accommodate both user groups, the focus of the community system shifted to an experience-sharing system that promotes sharing experiences without disclosing any personal information.

4.11 Conclusion

This chapter started with the scoping study to learn more about the lifestyle of people with diabetes living in rural or less privileged areas; scoping led to more about participants that helped to adapt PD techniques in localised contexts. The PD techniques were iteratively refined. Initially, Narrative Scoping with Personas and Invisible Design Videos was used with participants, while the next PD iteration gave rise to PD with Auditory and Visual content.

The outcome of PD sessions is that the participants were willing to know more about diabetes and showed eagerness to use an IVR system; they liked to listen to a variety of information on different topics, and this gave rise to the concept of a dynamic and scalable IVR system that presents prioritised information according to the user profile. The Wizard of Context technique helped to determine the flows of *"Sugar-ka-Saathi"*.

Research showed that community support for diabetes management played a significant role, and this study determined the definition of community support and showed a variety of views that are gender specific, as men were open to contributing to such a system. At the same time, women were hesitant to participate in a community system. Therefore, to accommodate both user groups, an experience-sharing system was designed that facilitates recording experiences and listening to other people's experiences.

Overall, the Participatory Design with Auditory and Visual content resonated well with participants; diabetes and comorbid condition information was well accepted, and mixed views about the experience-sharing system were influenced by gender.

Chapter 5

IVR Deployment

The organisation of this chapter is shown in Figure 5.1.

5.1 Introduction

Chapter Four detailed the generation of prototypes developed that led to a scalable and dynamic IVR system - *"Sugar-ka-Saathi"* - designed iteratively, and various prototypes were built. The IVR is termed "Dynamic and Scalable" because it can present prioritised information that can be updated sequentially.

Recognizing the importance of the user-friendliness of the IVR system, the level of navigational menus was minimized to reduce the cognitive burden on users. One of the challenges of designing a scalable and dynamic IVR system is presenting a lot of healthcare information with minimum navigation. After analyzing various ways of representing the information, the most appropriate method was to give the prioritised information initially based on the doctors' advice. It was adjusted later, iteratively, and people with diabetes helped to determine this update prioritisation.

Participatory Design Evaluation (PDE) ensured that the participants actively gave IVR system design insight and valuable feedback iteratively by engaging in the design process for four weeks.

This chapter presents the *"Sugar-ka-Saathi"* deployment in two phases. The first phase included a four-week deployment of Prototype Three and a weekly PDE session for each participant. Analysing these PDE sessions helped to refine the design and gain insight into participant behaviours, culminating in modification leading to *"Sugar-ka-Saathi"* (Prototype Four).

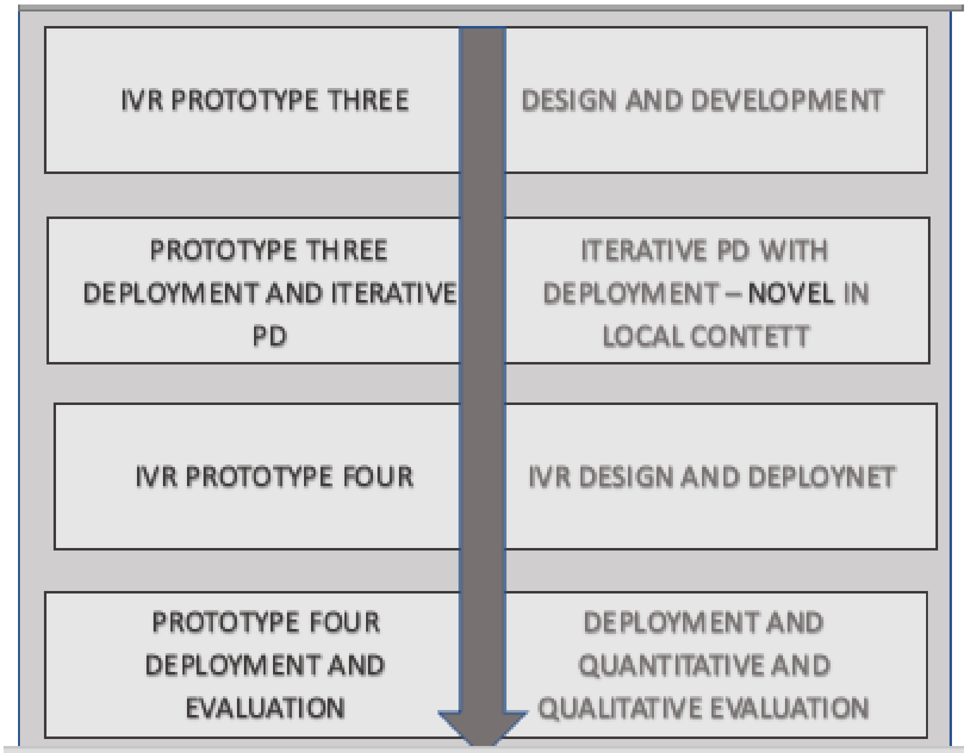


Figure 5.1: Chapter Five Outline.

5.2 *"Sugar-ka-Saathi"* - Prototype Three

The *"Sugar-ka-Saathi"* (Prototype-One and Prototype-Two) introduced in the previous chapter helped to adopt IVR technology according to the user's expectations gleaned from the prototype testing [143]. Overall, Prototype Two was well accepted amongst the study participants, as less literate participants understood the importance of diabetes awareness in improving their health. A few participants recommended helpful suggestions, accommodated in the Prototype Three design. Additionally, Prototype Three incorporated listening to others' recorded experiences with diabetes and allowed us to record our experiences.

However, one of the study limitations highlighted in the previous chapter is that participants could not use IVR in real-world settings, making it difficult to establish their usefulness in real life. Therefore, to overcome the limitation, Prototype Three was deployed on a server; and relevant details are discussed in the deployment section.

An overview of Prototype Three design, development and testing is provided in Figure 5.2.

5.2.1 Design

The testing of Prototype Two led to design recommendations, such as prioritising the information presented about food and exercise with the highest priority. A further improvement was to replay the menu choices until a selection is made - instead of terminating the call if no menu choice is made on the first attempt. Additional improvements included incorporating an experience-sharing system that enabled the end-user to record their personal experiences on different topics and listen to other people's experiences. Participants were given a topic to prompt their thinking about the experience to be recorded.

5.2.2 Development

Prototype Two development was challenging and was developed on a CentOS virtual machine with Asterisk software installed. The IVR system was developed using "PERL", "MYSQL Workbench", and "Asterisk VOIP" and was tested extensively locally using the Zoiper application.

It was time-consuming to write the PERL script and ensure it worked correctly. Storing the diabetes information and experience-sharing file names in the database allowed the IVR system to deliver a large amount of information since the code reads the file names from the database and presents them to users.

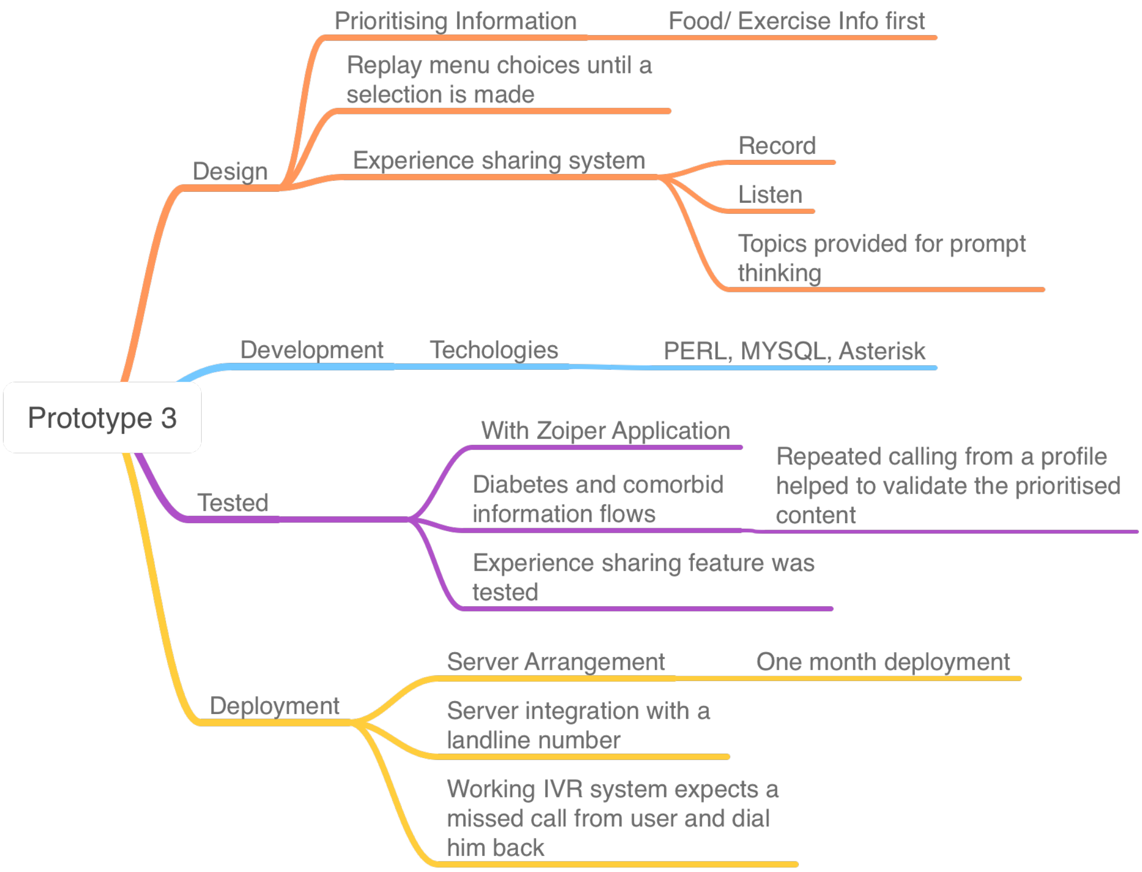


Figure 5.2: Prototype Three Overview

Different diabetes and comorbid information flows were tested repeatedly. The IVR system delivered new information in every call, and this extensive testing ensured that prioritised information was provided accurately. If the flow did not work, the code was corrected accordingly. The experience-sharing system was tested to check that it could record some information and, afterwards, that the experience recording could be listened to by another user.

5.2.3 Deployment

Deploying an IVR system on a server requires technical expertise, software knowledge and careful planning. IVR Prototype Three was deployed by following the steps below:

1. Server Arrangement.
2. Install the IVR software Asterisk and database software MYSQL workbench.
3. Upload the PERL and MYSQL scripts (this bit has been discussed in the development section earlier).
4. Configuring the IVR routing by setting it to determine the call routing through the IVR system involves setting up the destination number and routing rules.
5. The IVR system was tested.
6. The IVR system deployment was monitored to ensure optimal performance.

The *"Sugar-ka-Saathi"* (Prototype-Three) deployment and accompanying PDE process provided design insights and usability analysis. PDE refers to the mutual learning situations between designers and users while evaluating a prototype. This thesis used an iterative PDE approach.

5.3 Participatory Design Evaluation (PDE) - Method

Different activities and methods of conducting the sessions, including procedure, participant information, ethics information, and analysis, are discussed below.

5.3.1 Procedure

Prototype-Three deployment communicates information about Diabetes, Comorbid conditions and Experience sharing through an IVR system-enabled phone line that the study participants could call at their convenience.

Previous research highlighted that in a group setting, some participants (characterised as active participants) could dominate, while others are passive and find it hard to express themselves [58]. Consequently, a one-to-one PDE evaluation session was used to minimise this effect of group engagement and provide each participant with an equal opportunity to share their viewpoint.

The PDE process consisted of four sessions designed according to the research aims. A questionnaire addressing different topics was designed for each PDE session, and care was taken to keep questions short, impartial, and neutral. This attention to detail improved participant engagement to obtain a consistent response across all the interviews conducted as part of the PDE process. The details of each of the four PD sessions are as follows:

PDE Session One

The purpose of session one was to explain the purpose of Prototype Three to participants. Then, the participants were recruited in this PDE process and filled in a consent form (for illiterate participants, their verbal consent was followed by recording their thumbprints on the consent form), collecting their demographic information (Table 5.1) and giving them the phone number so they could engage with the Prototype Three before the next session. The questions asked in Session One questions are presented in Table 5.1.

Table 5.1: PDE Session-One

This research helped to evaluate:	If the study participants want to take part?
Questionnaire	Introducing the Purpose of research.
Profiling Information	
Participant Information.	1. Name 2. Age 3. When diabetes Started 4. Are you literate? If yes, to what level? 6. Family Support available
Do they need assistance in diabetes management?	1. What kind of assistance do they need? 2. They want to listen to the experiences of other. people with diabetes? 3. They want to share their questions about diabetes management?
Do they have healthcare problems other than diabetes?	1. Other than diabetes, they have healthcare problem ? 2. What healthcare problems do they have? 3. Do they want to listen to information about these problems? 4. Is it information about relevant healthcare problems? 5. Is it information about any health condition?
They were told about IVR calls that will deliver information.	1. For information delivery. 2. Community support 3. Comorbid conditions?

PDE Session Two

As a follow-up to Session One, a second session was held seven days later, giving time to participants to familiarise themselves with Prototype Three. This 20-minute session aimed to understand how the end-users valued the information delivered by the IVR - whether they considered the educational information indispensable, reliable, and trustworthy and whether they considered the shared diabetes-management experiences trustworthy. Participants were asked to rate the usability of the IVR system. Table 5.2 summarizes the session aims and related questions. In week one, participants made an average of four calls to the IVR system. In this session, it was easier to determine whether the IVR is accessible, such as whether it can be recalled for a single listen.

Table 5.2: PDE Session-Two

PDE Session-Two	
This research evaluated	1. About Hierarchy - Is getting information accessible? 2. Can they see themselves using the IVR system? 3. Imagine a family member helping them use the IVR system?
Questionnaire	Usability
IVR working	1. How do you think this helpline works? 2. What do you think about how it is being delivered over the phone?
Easy to Use	1. If easy to use? 2. If difficult to use, why?
Content **Usability**	1. What do you think about IVR content? 2. Is it helpful?
Comprehension	1. Did you find it helpful? 2. What is helpful or not helpful?
Retention	1. Do you remember the info? Do you need to listen more than once? 2. Can you recall the information? 3. Do you want to listen to the same information again? 4. Can you remember the information? 5. If they can recall - ask them what information you like the most. 6. What did you dislike?
Value	1. Do you think this information will help to raise diabetes awareness?
What else is needed?	1. Do you think any information is missing? If so what?
Trusting the Information	1. Why do they trust the information? 2. With NO, why do they not trust? 3. What if the doctor refers them to the information? 4. What if other people have successful experiences with the system.

PDE Session Three

The session was scheduled two or three days after Session Two. To avoid practical problems, such as availability, participants who frequently used the IVR were scheduled to attend session three immediately following session two.

In session three, we discussed study participants' views on the dynamic IVR information delivery system and whether they were comfortable recording questions for a doctor or community engagement.

Table 5.3: PDE Session-Three

Dynamic and Scalable IVR (DS-IVR).	
To establish the usability of DS-IVR	
Questionnaire?	
Dynamic Nature	Whether people with diabetes are interested in hearing new information in every call. Is exposing a large amount of information okay?
Scalable	Whether leaving recorded questions is of interest that are later answered by a healthcare professional.
Comorbidity	What is the perception of comorbid information? Is it helpful?
IVR Expectations	What are the participant's expectations about the IVR system?

PDE Session Four

This session occurred shortly after the third session or a few days later, depending upon the participant's availability.

This session's primary objective was to introduce the IVR's experience-sharing feature, which includes recording experiences related to medicine, food, and family. Additionally, the study examined whether individuals interested in hearing about the experiences of others with diabetes were keen to record their own experiences. As part of the IVR experience-sharing session, participants discussed their roles, including those of tellers and listeners, and how their groups would be organized.

Table 5.4: PDE Session-Four

IVR for Experience sharing.	
Participants wanted to support communication with an IVR system?	
Questionnaire	
Community Sharing System	Do they want information about life with diabetes only? or they wanted facilitation of communication amongst community members? Do people with diabetes want to communicate and support each other through such a system?
Use cases of offline community system.	Do you want to record your experience? Do you want to listen to others experience recording? What is the selection criteria for recommended experience? Do you want to listen to a shared experience based on: Gender, Distance etc
Group Forming	If this IVR will make groups of four people how to form these groups? Should there be separate groups for men and women? Should the group is formed of same age range or it has people off different ages?

Over these four weeks, each participant could call the IVR system regularly. Prototype Three utilized a missed call procedure in which the caller dialled the IVR system, the call was picked up, and the caller was informed that they would receive a callback shortly. Therefore, aside from the initial call, the user bore no further call costs since the funds of the IVR project covered these.

A total of 116 missed calls were received from 29 users who received a callback.

5.3.2 Participant Information

Thirty-eight people called the *"Sugar-ka-Saathi"* (Prototype Three), and 29 received a call back due to a call drop or the unavailability of the system.
Fourteen IVR users participated in all four PDE sessions. The participants comprised three men, eleven women, three literate and eleven illiterates; seven rural participants from 75 G.B. South, Faisalabad, 82 G.B. South, Faisalabad, and seven city participants from Faisalabad. Nine participants participated in in-person one-to-one PDE sessions, and five participated in telephone-based PDE sessions due to COVID-19. Two doctors also tested Prototype Three and gave design insight in later interviews.

5.3.3 Ethics

The IVR Prototype Three was tested after receiving ethics approval from Swansea University's Department of Computer Science. The approval required participants to receive participant information sheets and consent forms. Therefore, the Participant Information sheet was read to the participants, and they signed or thumbprinted the consent forms.
IVR Prototype Three testing was conducted after ethics approval from Swansea University's Computer Science Department. Ethical approval required participants to receive Participant Information sheets and consent forms. Therefore, the Participant Information sheet was read to participants, and participants' signatures or thumbprints were taken on the consent forms. Appendix F, Page 233, highlights the IVR design iterative procedure.
Participant information, including demographics, phone numbers, and video or audio recordings, was processed and stored with care according to the ethics process highlighted in the application. Participants were briefed in the Participant information sheet about how their data would be processed and kept. (see Appendix D, Page 205, Data Archiving/Destruction and Confidentiality).

5.3.4 Analysis

All four PDE sessions were recorded, where video recording was not convenient or authorized audio recording was done. The researcher transcribed all videos from Punjabi to English due to her knowledge of both languages. Therefore, all the recorded videos were first translated, and each participant's response was noted. This data was then verified again with videos to overcome any shortcomings in data, such as unclear or misinterpreted meanings.
A thematic analysis of the transcribed data revealed participants' generalized views and requirements that informed the design process [77].

Database - MySQL Workbench was used to record all user interactions with the IVR system. The records were maintained using SQL queries and later analysed to determine the extent to which the different features of the IVR were being used.

5.4 Participatory Design Evaluation (PDE) - Findings

PDE session recordings were thematically analysed and divided into the following categories:

5.4.1 IVR Design insight

Based on the thematic analysis, the following design insights have been identified:

IVR Content

IVR content included information about diabetes and comorbid conditions, including Heart problems, Hepatitis, Smoking and COVID. Two diabetes doctors from Faisalabad, Pakistan, were recruited to the IVR design and evaluation activities.
In the testing phase, doctor one listened to the IVR system and recommended adding more information about diabetes complications. He further highlighted some difficulties faced by people with diabetes having comorbid conditions and consistently high glucose levels adversely affecting them.
Doctor Two suggested that it would be helpful to raise awareness about diabetes complications, such as retinopathy and eye-related issues. This research's limitations made it impossible to include a full range of comorbid information in the design.
Study participants have realised the importance of their diet in regulating blood glucose levels in control, and they expressed interest in listening to food-related information.
Since diabetes, along with other comorbid conditions, becomes more complicated to self-manage. IVR information about comorbid conditions is therefore essential, as highlighted in PDE Session Two by Participant 11:

> *"People have different comorbid conditions along with diabetes and need help to manage them. Therefore, information about the comorbid conditions is helpful".*

The design complexity should be minimal, and the addition of information about the comorbid condition should not burden the IVR usage, as in PDE Session Two, Participants 10 and 12 remarked:

> *"IVR should be interactive to engage people. If someone using IVR has blood pressure and diabetes, he should receive information about both conditions."*

Participant 12, in PDE Session Two, added:

> *"I want to listen about other health conditions such as hepatitis so that even if I do not have that condition, other family members might have it, and I can help them with the IVR information I already learned."*

Similarly, in PDE Session Two, Participant 10 commented:

> *"I find the information about taking care of my feet and the effect of high diabetes on organs."*

Prototype Three has basic, preventive information about hepatitis, heart disease, and COVID-19 - which was found helpful by many participants.

As in PDE Session Two, Participant Six liked the IVR information provided about heart attacks, commenting:

> *"A person should know that if he has a heart attack, he can take the following steps."*

He continued:

> *"Preventive information about different conditions is helpful for a participant to be aware of their condition and its causes."*

Motivational Messages

People with diabetes can lead a long, healthy life if their glucose level remains within a healthy range. Some intrinsic or extrinsic motivations can help maintain their interest in diabetes management.

IVR can be helpful as it can be an extrinsic motivation for people (by delivering motivational messages) to sustain a proper diet and exercise regime to regulate their glucose levels better. The IVR system can also make people with diabetes aware of the importance of regular check-ups.

Therefore, a proper diet and exercise regime became crucial in such circumstances, and motivational messages to manage diet and exercise can help people keep their diabetes in check. Additionally, people who take medicine regularly could receive medication reminders from IVR, and whilst discussing this with a diabetes doctor, he commented that:

> *"It is impossible to send regular medication reminders, as it depends on when food is taken; that differs for people".*

Experience Sharing

Friends and family play an essential role in the lifelong diabetes management journey, as there is a pronounced emotional impact on diabetes sufferers. This study reviewed the role of friends and family in the IVR system and showed that healthcare, a sensitive topic, requires specialised care, and a doctor's advice is preferred. During PDE sessions, people with diabetes share this view. As a study participant commented:

> *"In this diverse culture, everyone is not right. However, the healthcare information must be accurate. Therefore, recording by people is not authentic".*

Different cultures have different attitudes about sharing their health condition, and the stigma of talking about healthcare problems exists amongst people in rural Punjab, Pakistan - as a doctor mentioned:

> *"People do not like to talk about their health issues; an example is the stigmatised attitude of people towards COVID-19. If a person has COVID-19, he does not want to tell others. So, it is uncertain how people will respond to the experience sharing using the IVR system".*

Study participants were introduced to the concept of IVR experience sharing in PDE Session Three, during which Participant Five and Participant Three both liked the idea and concluded:

> *"Community systems facilitating experience sharing will be beneficial as it allows us to share our views and ideas (empowerment) and seek guidance from other people's views and ideas."*

Furthermore, Participant Eleven said:

> *"I have not visited the experience sharing system yet, but If I get benefits from the certain strategy shared in an experience, then I will tell everyone."*

However, despite being enthusiastic about sharing experiences, in PDE Session Three, Participant 12 confessed that she would not rely on community experiences as it is not a doctor's advice:

> *"Problem sharing is important as people learn from other problems. Maybe people with diabetes are stressed about their condition, and it would be helpful to know about others' problems to tell them they are not alone in their journey".*

People do not rely on community experiences as it is not a doctor's advice; as in PDE Session Three, Participant 12 confessed that:

> *"I want to listen and record information, but I will only rely on doctors' information."*

However, Participant Two, in PDE Session Three, was more favourable to the usefulness of diabetes experience recordings and commented:

"When people share their diabetes feelings and symptoms using the IVR system, it will be beneficial as people will get guidance and share their unique experiences in this mutual learning experience."

Participants agree that age-based grouping should be avoided in the IVR as different symptoms are the same amongst other age groups. Other diabetes symptoms have different interpretations and remedies; Participant One in PDE Session Three said:

"I liked the concept of experience sharing system, and my advice is that groups should not be bound by age because if the IVR end-users describe their symptoms and the strategies they use to prevent them, all this information should be circulated amongst different age groups".

In the community/recorded experiences section, people could record their problems, and others can offer suggestions, as Participant Two, in PDE Session Four, suggested:

"Peer participants can receive guidance about symptoms of high glucose (hyperglycaemia) and low glucose (hypoglycaemia), and they can share their experiences of varying glucose levels and what to do to get rid of their adverse effects, thus helping each other."

5.4.2 Effectiveness of IVR Information

The quality of the IVR system information, both the content and the way it is recorded, is crucial for maintaining engagement.

Information Retention

Participants should be aware of the importance of healthcare information delivered by IVR. To ensure this, participants were asked whether they remembered the information they had heard to confirm their engagement with the content. In PDE Session Two, Participant Six answered:

"I remember the information about insulin."

The option to repeat information was critical for some participants because of their uncertainty about understanding the information by listening once. Therefore, in PDE Session Two, Participant Six and Participant Eleven agreed that:

"A person should listen to information repeatedly to remember it."

Trusting the Information

Trust is critical because of the sensitivity of healthcare information; people's usage of the IVR depends upon trust. The involvement of doctors in verifying IVR content led to authentic information that gained people's trust - they were already aware of the doctor's involvement from explaining how the doctor's persona was mapped to the IVR system. As in PDE Session Two, Participants Ten and Twelve responded as follows:

> *"The information is reliable and trustworthy."*

There are several reasons people trust the information, such as its delivery in a doctor's voice helped to win people's trust, as, in PDE Session Two, Participant Twelve trusted the IVR information and said:

> *"Whether I go to the doctor or listen to IVR information, both strategies will be helpful."*

Another person shared his views about the doctor's approved information as follows:

> *"I found the doctor's advice delivered by the IVR system helpful."*

Therefore, the observation from this study is that it can help many by acquiring the trust provided by local healthcare centres.

5.4.3 IVR Usage and Cost

IVR Usability

The perceived importance of IVR information motivates the participant to engage with it. As Participant Eleven said:

> *"The IVR doctor engagingly told important healthcare information."*

During the PDE Session One, end-users were asked if they understood the IVR dispensed information. Different participants gave a positive response, as Participant Ten in PDE Session One commented:

> *"IVR gave information about the ways of living with diabetes, which I did not know before."*

Similarly, Participant-four in PDE Session One said:

> *"The IVR is beneficial as I can get information about different aspects of diabetes management."*

Participant Nine, in PDE Session Two, said:

> *"I listen to IVR information regularly and find it helpful."*

The information delivered through an IVR can help address the literacy challenges. As in PDE Session One, Participants Six and Twelve said:

"I listened to IVR information, found it helpful, and recommended it to other people with diabetes."

Similarly, Participant Five recognised the benefit of information and said:

"IVR is informative and beneficial for people with diabetes in rural areas."

Exposure to health care information affects the management of chronic conditions. Participant 10 realised the importance of communication, observing that:

"People want to seek more information from the IVR, as it is essential to motivate them to better self-manage their condition."

Diabetes awareness information provided participants with various self-management strategies. As in PDE Session Two, Participant One said:

"Information seeking from the IVR has guided me a lot."

Similarly, Participant Twelve, in PDE Session Two, found that:

"System is simple to use; I can seek information easily from the IVR."

Excellent recording quality is essential to make the IVR usable. As in PDE Session Two, Participant Six remarked:

"Information is properly recorded and easy to understand; I am satisfied with the IVR information."

The language dialect must be understandable, as, in PDE Session Two, Participant 12 said,

"I liked the Punjabi accent of the IVR."

Participant Eight had hearing problems but found IVR audio audible and asked about listening to the IVR to get information. Less literate people in rural areas are unaware of different diabetes management strategies, and the IVR kept them informed in PDE Session Two; Participant 12, a 42-year-old lady, said:

"I liked the IVR guideline about what to eat and wanted to memorise it."

Participant Eleven, in PDE Session Two, further added:

"I liked the information about food, fat, and sugary things, and if I follow the advice, it will be beneficial."

Participant Thirteen, in PDE Session Three, relied on word of mouth and said:

"I will tell my friends and family to listen to it as I benefit from the IVR."

IVR Navigation

As a voice-only medium, the IVR requires significant attention to the design details. There is a trade-off between end-user control of which information they want to hear when a large pool of information is displayed. While creating this diabetes IVR, there was appropriate end-user control and information accessibility. After every information bit, there is an option for the end-user to listen again by pressing a number. However, in PDE Session Three, Participant Six, a literate person with diabetes, suggested:

> *"IVR Navigation menu should be repeated until a button is pressed; one of the examples is banking IVR systems. Therefore, if a person cannot press the button while using the system for the first time, the call should continue, and the navigational prompt should be repeated".*

One of the challenges of IVR navigation is listening to the most appropriate information and the end-user control of listening to the right information, as highlighted by a study participant who said:

> *"If a person does not want to listen to insulin information, the system should give some control to the end-user."*

This study showed that illiterate end-users quickly understood the IVR, as in PDE Session Two, Participant 11 commented: "The navigational prompts, such as pressing one or two, are easy to follow".

All stakeholders expressed the need to listen to information the IVR system user is willing to listen to. Doctor One expected the IVR to give relevant information quickly. He said:

> *"If a person wants to listen to the information about diabetic feet, why does he listen to other information? Why does not he come to diabetic feet information quickly? ".*

Ageing and IVR Usage

Though using "Sugar-ka-Saathi" is straightforward for many; however, elderly and less literate participants need assistance with its use, as evidenced by the PDE sessions. This support was provided by hiring a literate person local to the rural area who had used the IVR before and could help people with diabetes to engage with it.

Participant Eight, in PDE Session Three, who had not dialled the IVR number previously, required help to call the system. Therefore, during the 1-1 PDE session, I demonstrated calling the IVR system; Participant Eight did not get the idea to press navigational prompts on the first dialled call. She responded slowly and told the number to be pressed in the second call to the IVR. Finally, she got the idea of navigation and selected the options herself in the third IVR call.

Based on the above findings, repeating the IVR navigation prompt until a button is pressed will be beneficial. Furthermore, a hired local person can help to recruit study participants, as Participant Six expressed his views during PDE Session Three:

> *"Older people with diabetes have difficulty listening to IVR calls, and a responsible local person can help."*

IVR Cost

Calling the IVR system is expensive for many people, resulting in them not using the service. A realization from this study is that participants could not even afford to pay for a minute's phone call. IVR advertisement revenue would remedy this access issue by presenting appropriate city/rural advertisements. In PDE Session Three, Participant Six, a literate person from Faisalabad city who has internet access, suggested that:

> *"If this number is advertised, it will be better."*

However, the purpose of the IVR is to facilitate less literate people with diabetes living in rural areas having no direct internet access, so alternative approaches would be needed - as in PDE Session Three, as Participant Six said:

> *"Healthcare centres in different areas can advertise on the IVR."*
> Further research is needed on the sustainable cost model that fits well with the IVR system.

5.4.4 End-user Profiling and Group Forming

The end-user profiling is vital to give end-users a personalised experience. Moreover, Group Forming can facilitate end-users sharing their experiences in peer group settings easily.

The mechanism to save demographic information was chosen carefully after considering different views. Doctor One recommended that:

> "The end-user profile information should be collected in one go because I anticipate that end-users will only sometimes call the system."

However, to maintain the system's user-friendliness, it was decided to collect demographic information by asking one unanswered end-user profile question in each call rather than multiple questions simultaneously.

"Group Forming" is the idea that a group of people can communicate and help each other under the leadership of a group member. Participants ten and Eleven expressed satisfaction with this concept and said that:

> *"A mentor or group leader for each group will be helpful."*

One suggestion for end-user grouping is to group them according to the area they belong to (saved in the end-user profile), as Participant Ten suggested in PDE Session Four:

"People belonging to one area should be grouped."

Similarly, another suggestion about group forming is that men and women should be treated as separate groups, as Participant Ten in PDE Session Four added:

"People of the same gender can easily share ideas."

Experience sharing could benefit others, such as managing high or low glucose levels. Due to the sensitive nature of healthcare, the content should have been approved to ensure it supports people, and the authenticity of the experience-sharing system should be scrutinized.

As *"Sugar-ka-Saathi"* is expected to scale, it becomes necessary to sort experiences. Ratings of information can be used as a sorting mechanism. These become increasingly important with the system's scalability since this will give the end users control over when they listen to their own experiences. They can decide whether it is appropriate for them to hear.

5.4.5 Challenges

According to the thematic analysis, the participants faced the following challenges:

Limited Resources

Managing chronic conditions can be challenging for many people due to a lack of resources, especially those living in rural areas struggling to meet their basic needs. People's attitudes toward diabetes treatment are influenced by their ability to afford it since taking medicine has become a privilege for many. The cost of medicine has a significant impact on people's healthcare. In PDE Session Three, a woman participant from 82 G.B. South, Faisalabad (whose glucose was 600 (mg/DL) when checked in the PDE Evaluation session - note that glucose above 125 (mg/DL) is considered high) reported that:

> *My blood glucose levels usually remained high since I last checked them at 600 (mg/DL), but sometimes I cannot take medication since I do not have the money to buy it.*

The doctor's role in managing diabetes is crucial, including recommending appropriate treatment resources such as insulin and tablets. Most people with diabetes, including these study participants, would prefer to be treated by a specialist physician, but affordability often remains an obstacle.

Making money is an important aspect of a doctor's livelihood, as commented by a doctor:

> *"Most doctors want to make money, so helping people through the IVR system is not high on their priority list."*

People with diabetes can receive guidance using an automated IVR system. It is also significantly more affordable than other diabetes care resources and is readily accessible without waiting for and travelling to a doctor's appointment.

People in rural areas, however, cannot afford even two Pakistani Rupees (PKR) for the initial IVR call, so even the minimum IVR cost is unacceptable to them.

During PDE Session Three, Participant Seven expressed the following concern:

> *"I have to pay two PKR for every call, making it difficult to make calls without credit on my phone."*

It may be difficult for individuals to use IVR services if they do not have adequate mobile credit, forget about IVR services or are overwhelmed with other obligations.

Rural-Urban Commuting

This study confirmed that the resources across rural and urban areas are not uniform, and rural people have to travel to nearby urban areas to access medical help. People seldom visit doctors as a last resort to avoid this potential long-distance commute. This concern was raised by Participant 11 in PDE Session Three:

> *"Many people live in rural areas, and regular doctor visits mean travelling to the city; however, due to commuting issues, people are discouraged from going to the city".*

Technology can, therefore, play an essential role in facilitating communication at a distance, thus minimising the need to travel. This research showed the IVR system as an accessible system to facilitate rural-urban communication.

The same participant quoted earlier concluded:

> *"In these circumstances, the impact of IVR can be significant, and it could connect doctors and people with diabetes on the phone".*

Connecting people with diabetes to doctors is difficult, and the availability of doctors using an IVR system can make this process much more convenient; as highlighted in PDE Session Three, both Participant-10 and Participant-11 commented:

> *"If a doctor is available to advise on an IVR, it will benefit participants, as the people in rural areas must travel long distances to get checked up by a doctor".*

5.4.6 Summary

The PDE findings are summarized below:

IVR Design Insights

IVR content is of primary importance as it gives users awareness of their diabetic condition.

1. A doctor recommends adding more comorbid information, such as eye-related issues.
2. People with diabetes want to hear more about diet and exercise. Furthermore, they are interested in hearing about how to prevent comorbid conditions.
3. Daily messages from the IVR system, such as motivational messages, can help people remain motivated to monitor their glucose levels closely.

Through an experience-sharing system, people with diabetes can actively participate in their self-management practices.

1. Accuracy of experiences is important.
2. A doctor anticipates the stigma of sharing diabetes experiences openly and people's reluctance.
3. People with diabetes prefer doctor-delivered information, though some view listening to experiences as helpful.
4. Group forming was discussed. The participants agreed that groups sharing diabetes insight should not be age-specific; people of all ages should form these groups, giving diverse opinions. Similarly, groups can be location-specific and gender-specific.
5. A mentor in the group will be helpful.

Effective IVR Navigation can help to maintain people's interest and engagement.

1. Different inputs, such as the navigation menu, are recommended to repeat until a button is pressed.
2. Users need control over what information they wish to listen to - comments from literate people;
3. Reducing system complexity by prioritizing information is beneficial. It's like choosing between contradictory options.
4. It's a question of whether users have more control over selecting which information they listen to or if the information is prioritized without their control. This system relies on prioritization to reduce complexity.

IVR Information Effectiveness

1. People with diabetes were able to recall the information.
2. If they did not get the message on the first attempt, they listened to it again to understand.
3. The doctor's involvement in designing content and delivery by the doctor persona helped to gain participants' interest in IVR information.

IVR Usage and Cost

1. People with diabetes had positive comments about the system's usability.
2. It is common for older people with diabetes to have difficulty accessing and using a telephone, so an appointed local individual should assist more senior people in listening to information provided by the IVR system.
3. Regarding meeting IVR costs, including advertisements may be an option to negate costs. However, more research is required to determine the most efficient way to mitigate IVR costs.

Challenges

1. Calling the IVR system was difficult due to the call cost.
2. For people living in rural areas, seeing a doctor often requires much effort, including travel and cost. Therefore, the availability of a doctor on IVR can be helpful.

Prototype three deployment and testing showed some shortcomings in the design and development. These shortcomings are rectified in Prototype Four, as described in Section 5.5.

5.5 *"Sugar-ka-Saathi"* Prototype Four

"Sugar-ka-Saathi" Prototype Four implemented the improvements suggested by the following PDE feedback received from Prototype Three. Prototype Four overview is provided in Figure 5.3.

Considering Prototype Four's evolution in detail:

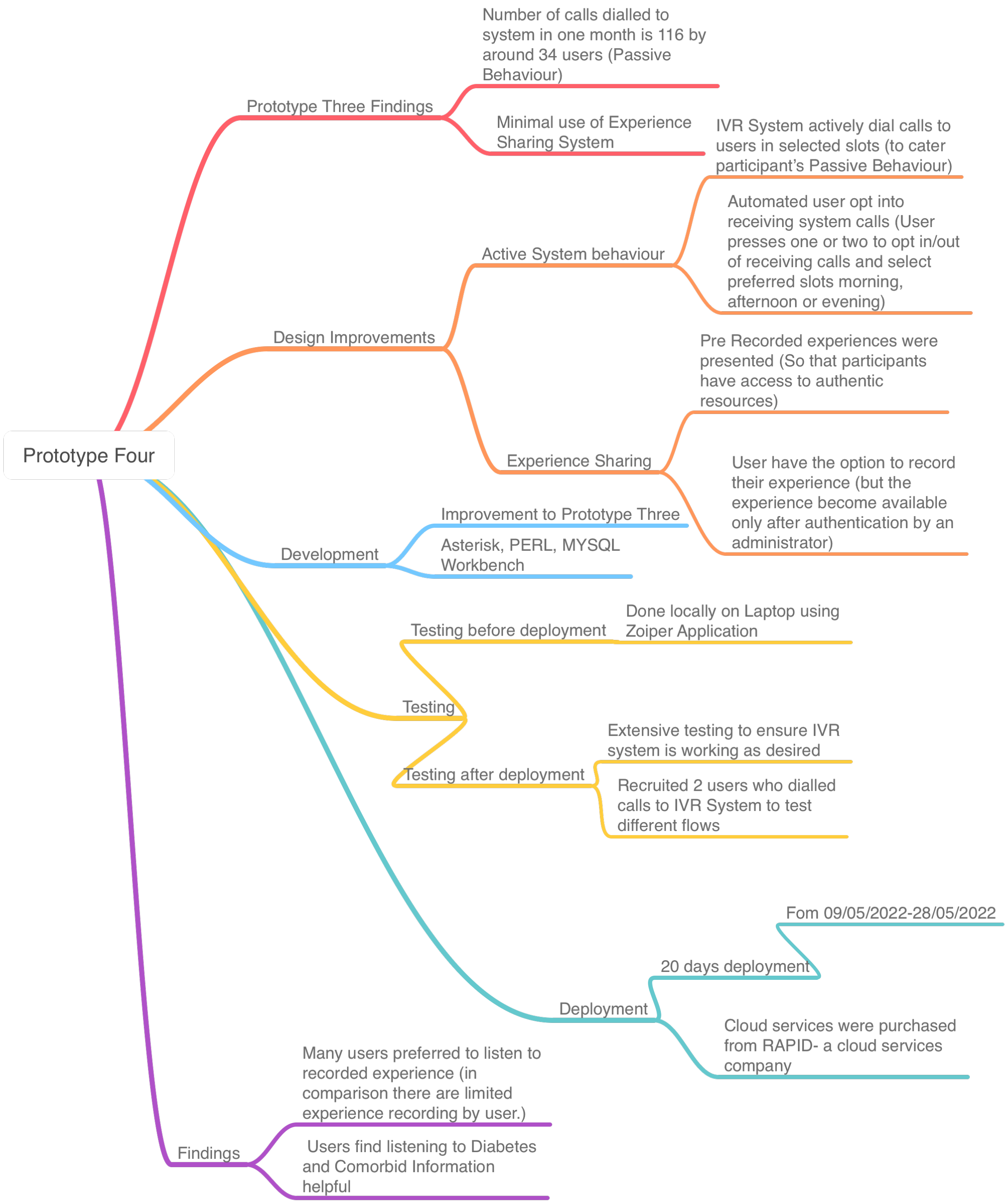


Figure 5.3: Prototype Four Overview

5.5.1 Design and Development

The experience-sharing section was refined further, as discussed in the following section:
The authenticity of shared experiences was identified as a challenge in a previous study, and one of the concerns was the reluctance to trust peers' experiences. Thus, Prototype Four focused on presenting only prerecorded experiences of diabetes garnered from trusted websites, such as [41] and [10].
Shortlisted information contains 132 prompts of diabetes information, 70 prompts of co-morbid condition information and 34 recorded experiences.
One noticeable shortcoming of the Prototype Three design is that there are limited calls dialled into the system. Prototype Three, therefore, used a missed call mechanism, and whenever the system received and missed a user's call, the IVR system played a message that they would receive an automatic call back.
This call mechanism needs Active user behaviour for dialling the call, and the user must also have some phone credit to first generate the missed call. Therefore, to overcome the limitation of Prototype Three, Prototype Four placed system-driven calls at regular intervals (selected by the users).
However, despite the feedback from the users that it is easy to use and understandable, they could not still dial a call to the system without incurring costs.
As with Prototype Three, Prototype Four was developed using the Asterisk platform, scripted in the PERL language and connected on the back end with MySQL Workbench. As previously discussed, the audio file names are stored in the database and are retrieved in code when selected to be played.
A few technical glitches in prototype Three were fixed in Prototype Four.

5.5.2 Deployment - Method

The researcher tested the IVR system (code and the database script) locally on her laptop before handing it over to a telephony engineer hired to initiate the deployment by setting up the server to place calls to end users.
The resources used for the deployment were the cloud space supplied by RAPID Cloud Services - a company in Karachi, Pakistan. Prototype Four was deployed for 20 days in May 2022 - the high server rental cost limited the deployment period.
This study aimed to recruit as many participants as possible, either people with diabetes or people with family members having diabetes.

"Sugar-ka-Saathi" was deployed amongst participants over 20 days - from 09/05/22 to 28/05/22.

Automating the user recruitment process t deliver the recruitment messages, including the ethics message and gaining consent from participants made it a more consistent process. Therefore, the end-users were first called, informed about the study's details (translated and recorded in Punjabi) and asked to enter 'one' or 'two' if they wanted to opt-in or opt-out of receiving IVR calls, respectively. If 'one' was selected, they could also select the 'Morning', 'Afternoon' or 'Evening' call slots for when they preferred to receive the system-generated calls. Participants were called four times in case they had missed the previous call. Therefore, the IVR system dials four calls to users sequentially; if the first call is not answered, the second call is dialled - then the third and fourth.

Interviews were conducted with selected participants, guided by a written questionnaire (See Appendix C).

Detailed logs were saved to note the interaction of IVR users with the system in the database. The quantitative analysis section shows how the call logs were examined and how the results were interpreted.

Participant Information

In this study phase, 213 participants were recruited in different time slots (half of the participants were recruited in the afternoon and another half in morning and evening slots, as shown in Fig. 5.2). Participants received *1984* system-initiated calls. The user-wise distribution of attended calls is shown in Fig. 5.6.

Participants were both literate and illiterate, with diabetes or with family members having diabetes. Participants were recruited in the Morning, Afternoon or Evening slots they had selected, and the IVR system placed calls in their preferred slots.

The NHF diabetes doctor helped to recruit 100 (of the 213) recruits. Sixty-six participants were recruited from the villages, including 75 G.B. South Faisalabad, 80 G.B. South Faisalabad, and 82 G.B. South Faisalabad and were the same as the previous studies. Forty-seven participants were hired from Lahore city through the researcher's local contact; 47 included mostly literate participants.

Ethics

The Swansea University Computer Science department approved ethics, and the procedure was carefully followed during the deployment.

IVR Prototype Four testing was conducted after ethics approval from Swansea University's Computer Science Department. The user recruitment was automated using the IVR system prompts. Ethical approval required participants to receive participant information sheets and consent forms. Therefore, the Participant Information sheet was read to participants, and participants were on automated IVR calls. The ethics consent form to be automatically played to the user was recorded, and participants agreed to receive calls in one of the three time slots. Participant information, including demographics, phone numbers, and video or audio recordings, was processed and stored with care according to the ethics process highlighted in the application. Participants were briefed in the Participant Information sheet about how their data would be processed and kept. (see Appendix D, p205, Data Archiving/Destruction and Confidentiality).

Appendix G p239 - p253 outlines the Prototype Four Deployment and Evaluation procedure.

Analysis

Both qualitative and quantitative analysis of the collected data was undertaken.

The qualitative analysis involved audio-recorded interviews with participants. The researcher transcribed all videos from Punjabi to English due to her fluency in both languages. Therefore, all the recordings were first translated, and each participant's response was noted. A thematic analysis of the transcribed data revealed participants' generalized views about the IVR system [77].

The quantitative study involves analysing IVR system logs derived from the MySQL Workbench recording of all user interactions with the IVR system. The records were maintained using SQL queries and later analysed to determine the extent to which the different features of the IVR were being used.

Section 5.6 and Section 5.7 describe the quantitative and qualitative analysis of the deployment, respectively.

5.6 Quantitative Analysis

Angus Maddison, a notable scholar of quantitative macroeconomic history, has defined quantitative analysis [38] as:

> *"Quantification clarifies issues that qualitative analysis leaves fuzzy. It is more readily contestable and likely to be contested. It sharpens scholarly discussion, sparks off rival hypotheses, and contributes to the dynamics of the research process."*

5.6.1 Method

The quantitative analysis involved analysing IVR system logs of the outgoing automated calls, which included detailed information, including the user interaction with different IVR features. Call Records were stored in MySQL workbench and were analysed using SQL queries.

5.6.2 Findings

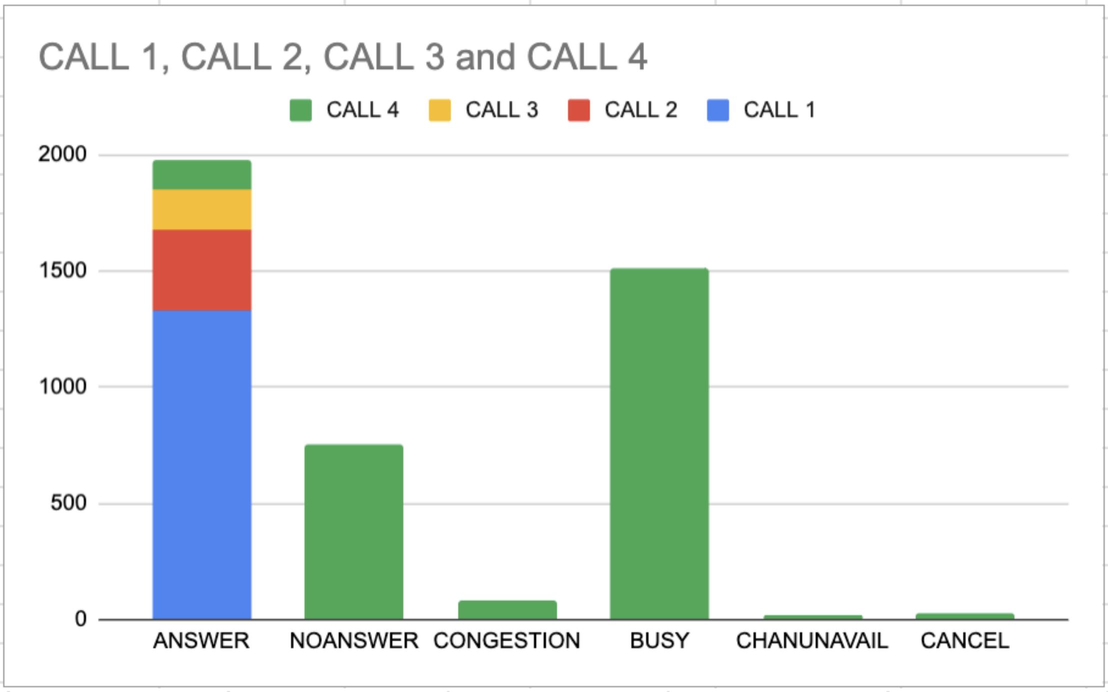
IVR Statistics

The IVR's first two days of deployment were assigned to setting up and testing the system, and the participant recruitment was completed on these days. During 19 days (from 09/05/2022 to 27/05/2022), 1982 calls were placed to around 213 participants. Figure 5.2 shows the day-by-day distribution of calls. The participant's recruitment from different locations over the study period showed the variance in the number of calls dialled out from the IVR system.

Considering that the automated IVR system placed four calls to registered users at a specified time. Consequently, participants showed mixed behaviour;

Figure 5.4 showed the number of calls picked in four instances; from 4373 outgoing IVR system calls, 1982 calls were answered (45.35% as shown by the blue indicator in the bar chart in Fig. 5.4). This call-receiving ratio is an encouraging statistic demonstrating the user's interest in using the IVR system. The most prominent reason for not listening to the call was that the user was busy; this and other reasons for unanswered calls are shown in Figure 5.4

Participants had the option to opt out of the study. Each participant was introduced to the IVR system in the first call from *"Sugar-ka-Saathi"*. Participants had the option to opt out of the study, and few users chose this option in the first call, and only those who showed interest in receiving a call were called – in compliance with the ethics procedure undertaken for this study. Few users received the call to test the system; therefore, when the number of calls was more than 20, these extra calls were the testing calls, dialled to test the system before making it live.



	CALL 1	CALL 2	CALL 3	CALL 4
ANSWER	1328	347	181	126
NOANSWER	0	0	0	753
CONGESTION	0	0	0	82
BUSY	0	0	0	1510
CHANUNAVAIL	0	0	0	21
CANCEL	0	0	0	24

Figure 5.4: Call Receiving Results

Table 5.5: Call Status Explanation (taken from [1])

Call Status	What does it mean?
ANSWER:	The call is answered. A successful dial. The caller reached the callee.
NOANSWER:	No answer. The dial command reached its number, and the number rang for too long, then the dial timed out.
BUSY:	Busy signal. The dial command reached its number, but the number is busy.
CHANUNAVAIL:	Channel unavailable. On SIP, peers may not be registered.
CONGESTION:	Congestion. This status is usually a sign that the dialled number is not recognised.
CANCEL:	The call is cancelled. The CANCEL: command means that the call went through the system, the caller hung up before the callee picked up.

Tip of the Day

After the user opt-in for this study during the automated recruitment phase, subsequent calls started with a brief introduction from a doctor followed by the participants listening to the *"Tip of the Day"* (about diabetes management - Fig. 5.5). The *"Tip of the Day"* feature presented new information for every user in every call according to the call number. Figure 5.5 presents the day-wise distribution of users receiving the call, the blue bar indicating that the end-user had listened to the IVR *"Welcome Message"* and the red bar indicating that the end-user had listened to the diabetes information presented as the *"Tip of the Day"*. Notably, the most used feature of Prototype Four is *"Tip of the Day"*.

Demographic Information

After listening to the *"Tip of the Day"*, participants were asked about demographic information, including Literacy, Age and Gender. The literacy and Age input features have been introduced in Call Three and Five, respectively, and the gender input feature is in Call Four.

Figure 5.6 highlights the input response for demographic information. By pressing one, two, three, and four, the user can select Age from a list of values specifying different age ranges; the input value details are shown in the left column of the Age Table in Fig. 5.6. The Gender and Literacy table left column shows the possible input options in Fig. 5.6.

Input statistics are presented in three tables described below:

1. The 'Not reached this feature' indicates that the user has not provided any information or has not reached this feature;
2. Participants were given options based on their age in the age table;
3. Similarly, the literacy and gender tables display the participants' responses.
4. The 'Wrong input' option indicates that the user has not entered the correct choices.

Notably, Literacy and Age received responses from 47.5% and 50%, as shown in the pie chart in Figure 5.6. However, the gender disclosure was relatively less and was only 2.3% (calculated by excluding the 'Not Reached this Feature' entry).

The gender input feature garners the least response. Noticeably, most study participants were women and were reluctant to disclose their gender information. This user behaviour confirms the gender bias in the local culture [249] and women's behaviour to protect themselves against any misuse of their identity.

It was helpful to keep track of these statistics to gain a better understanding of IVR usage.

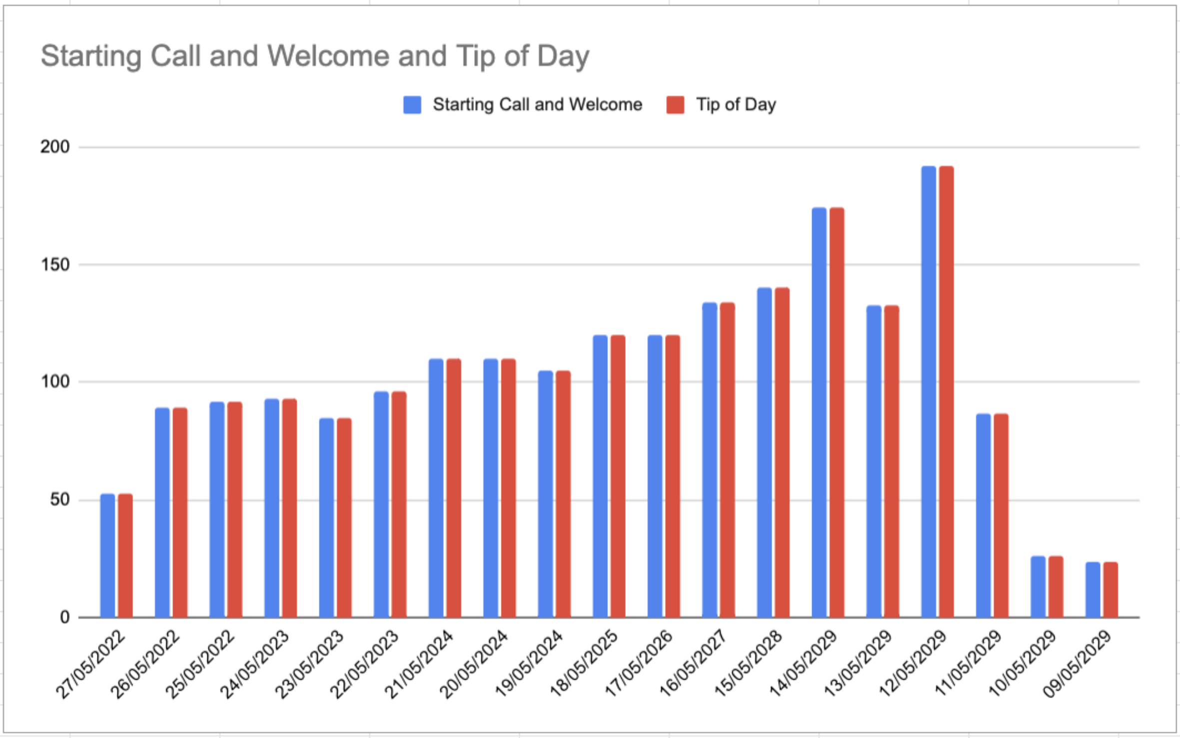
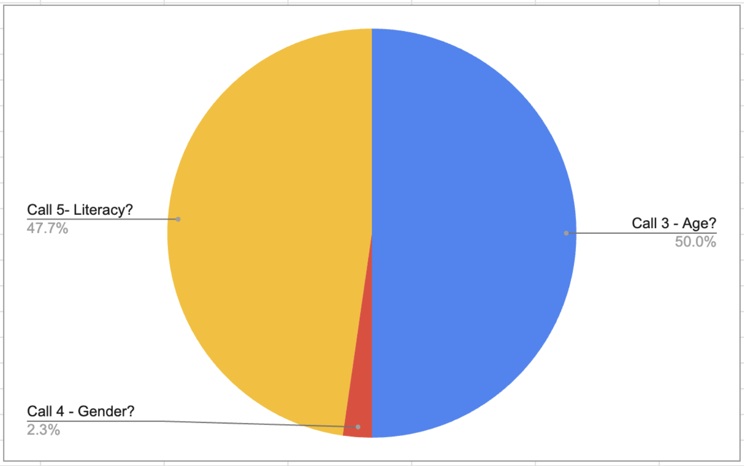


Figure 5.5: Welcome and Tip of Day

Table 5.6: IVR Features

IVR Feature	What does it mean?
Feature 1 Welcome	When a call is received, user is greeted and introduced to the purpose of call "Welcome, I am your doctor and will tell you information about diabetes".
Feature 2 Tip Of Day	The system plays information selected from the pool of diabetes information according to the call number by that particular user.



Age Feature	Input Statistics
Not reached this Feature	186
45 to 54	8
35 to 44	5
Less than 25	3
Wrong input	7
25 to 34	2
Greater than 65	3
55 to 64	2

Gender Feature	Input Statistics
Not Reached this feature	206
Male	1
Wrong Input	9

Literacy	Input Statistics
Not reached this Feature	189
Literate	15
Illiterate	6
Wrong input	6

Figure 5.6: Demographic Information analysed in the chart, and tables explained Participant Demographic Questions Response, including Age, Gender and Literacy

Most participants finish the call after listening to the *"Tip of the day"* feature, as shown in Fig. 5.7. The blue bar represents the *"Tip of Day"* feature, and the Red Bar indicates the *"Main Menu"* feature presented after the *"Tip of the Day"* feature, it is interesting that most people hang up the call after listening to the audio of diabetes management information played by this feature.

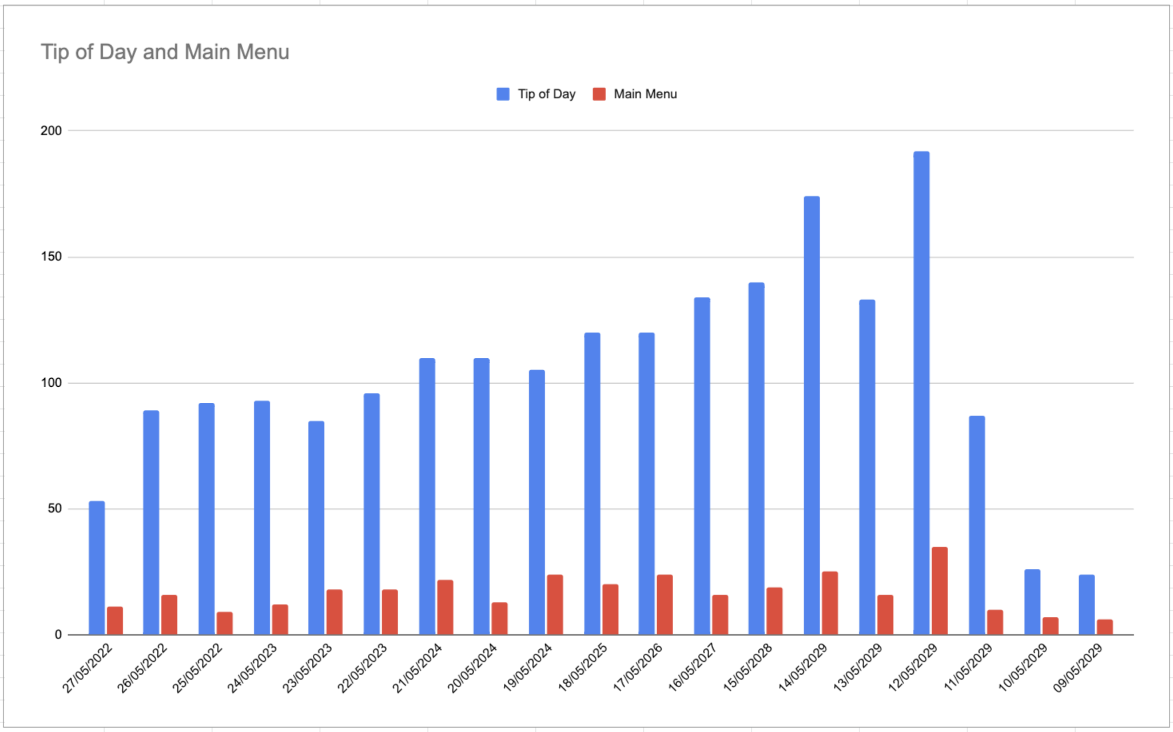


Figure 5.7: Tip of Day and Main Menu Usage Statistics

Table 5.7: IVR Features

IVR Feature	**What does it mean?**
Feature Two Tip of Day	Prototype Four called user daily in their selected slot and delivered One bit of diabetes information.
Feature Three Main Menu	After playing the Tip of Day feature, users will listen to the Main Menu and select from diabetes, comorbid information, or experience sharing

Comorbid Conditions

The information about *"Comorbid Conditions"* feature usage patterns is shown in Figure 5.13. This feature gave preventive information about hepatitis and heart problems and some basic information about COVID and Smoking. Figure 5.13 showed that people were interested in listening to information about Smoking, Hepatitis, and Heart issues, confirming the outcomes from the user scoping discussed in Chapter 4 showed that the users were interested.

Experience Sharing

The experience-sharing feature of the IVR was popular. However, most people preferred listening to other people's experiences rather than recording their personal experiences.

As shown in Fig. 5.9, the blue bars are high on day four of the calls - this is explained by 105 new participants being recruited and listening to the experiences on that day.

Listening to experiences with diabetes is more popular amongst users than the recording features of the IVR; it might be beneficial to add experiences of celebrities and influential personalities with diabetes, such as actors, players, singers, politicians, etc.

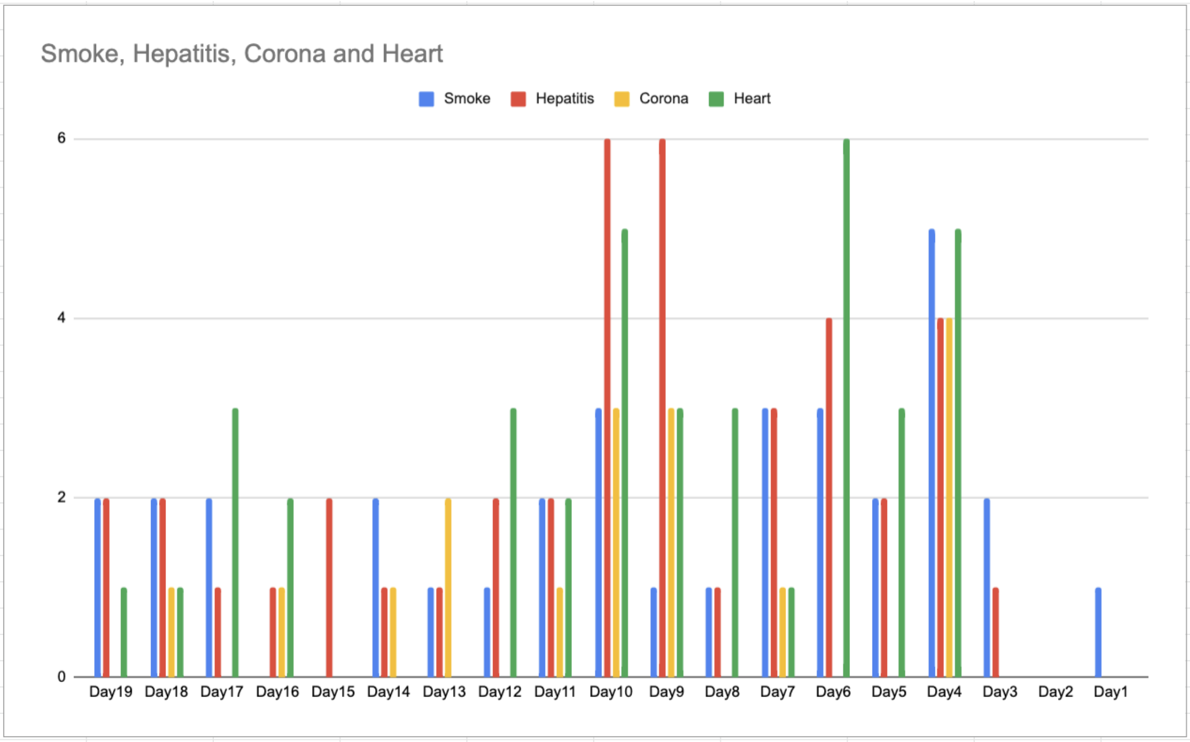
The statistics of experience sharing or community system input (one feature only) showed that a limited number of end-users use the experience-sharing feature on most days, as shown in Figure 5.9. The preference for listening to the IVR instead of recording experience is evident, as only three experiences were recorded in these 19 days.

In the IVR design, there is also the option to record feedback about an experience after listening. Five experience feedbacks were recorded, as shown in Figure 5.9.

Qualitative research combined with the above quantitative analysis would give a more comprehensive picture of the IVR system's usability. Section 5.7 highlights the qualitative analysis of the IVR system.

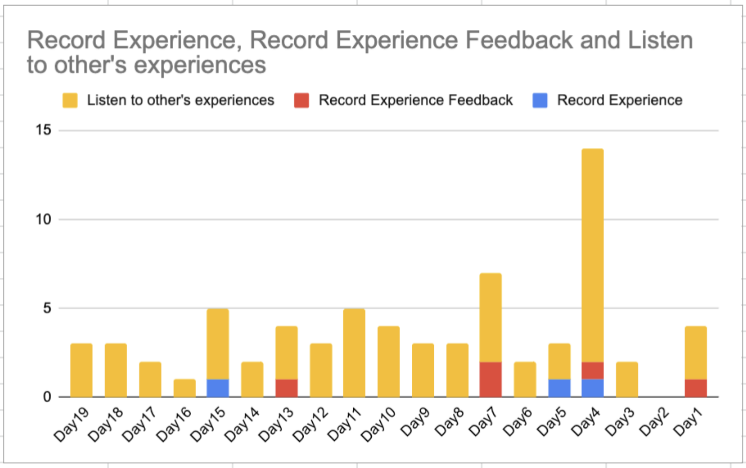
5.7 Qualitative Analysis

The final deployment will evaluate people's views about the IVR system with one-to-one interviews.



Feature	Usage
Smoke	33
Hepatitis	41
COVID	17
Heart	38

Figure 5.8: Comorbid Conditions Feature Usage Statistics (Days four, six, nine, 10 have higher usage statistics as additional participants were recruited)



Feature	Usage
Listen Experience	62
Record Experience Feedback	5
Record Experience	3

Figure 5.9: Experience Sharing Statistics

5.7.1 Method

When the IVR system deployment concluded, 13 of the participants involved in the deployment were randomly selected from the IVR system users. Of these, eight were from a rural village, five were from the city, and one was a doctor practising in a town.

The qualitative analysis started with designing a questionnaire to guide the interview. The details of the questionnaire are highlighted in the table. One-to-one interviews were conducted in a one-to-one setting on the phone, and participants' passive and active behaviour directed the interviews.

All interviews were recorded and transcribed in English.

The thematic analysis of interviews led to identifying themes, as highlighted in the next section.

5.7.2 Findings

Timely diabetes awareness can save many lives, and the research found that an effective IVR design can engage users and raise awareness of preventative strategies for diabetes.

Usability

Overall, "Sugar-ka-Saathi" Prototype Four participants found the IVR system easy to use, informative and understandable. The usability factors determined the people's attitude towards seeking knowledge since when people become more aware of their condition; it positively reinforces their behaviour.

Translating IVR content into the local Punjabi language helped maintain engagement with the service. The recording of *"Sugar-ka-Saathi"* was liked by many users; as one commented,

> *"Using the regional language - "Punjabi"- created a* positive impact as many study participants could only understand this language".

The recording quality of *"Sugar-ka-Saathi"* received special attention during the design process. As a voice-only interaction, users can only hear information; therefore, voice quality and its ability to successfully engage people affects IVR acceptability. Thus, in the final evaluation, people showed appreciation for the Punjabi recording, and one literate study participant who listened to the final version said:

> *"I liked the Punjabi accent; it is cool."*

Table 5.8: Prototype Four Usability Statistics

Participant Usability Response			
No.	Easy	Informative	Understandable
P1	Yes	Yes	Yes
P2	Yes	Yes	Yes
P3	Yes	Yes	Yes
P4	Yes	Yes	Yes
P5	Yes	Yes	Yes
P6	Yes	Yes	Yes
P7	Yes	Yes	Yes
P8	Yes	Yes	Yes
P9	Yes	Yes	Yes
P10	Yes	Yes	Yes
P11	Yes	Yes	Yes
P12	Yes	Yes	Yes
P13	Yes	Yes	Yes

Diabetes and Comorbid Conditions

The final evaluation showed that people liked the diabetes awareness provided. With IVR, people can learn about diabetes awareness with minimal effort. As an illiterate participant said:

> *"I receive a call daily about diabetes awareness in the morning, and I like the knowledge provided, as I have had diabetes for a long, as I am less literate, I did not know the information provided by IVR; this service should continue".*

People with diabetes suffering from other conditions need information relevant to other conditions they are suffering from.

It is worth considering that a person suffering from a particular condition preferred to listen to relevant information; interviews revealed that a person who used to smoke regularly accessed the smoking information first; similarly, a person with a heart problem accessed the relevant heart information. Heart problem-related information becomes crucial for people to manage their heart condition. Therefore, extensive information can be provided to a person by adjusting the system's behaviour according to the user profile.

The studies indicated that retrieving the information according to a user profile could help. User profile information could be of different types, such as demographic or chronic condition-related information.

Table 5.9: Diabetes and Comorbid Conditions - Participant's Response

No.	Diabetes Awareness	Comorbid Conditions Awareness	Should Continue
P1	Yes	No	Yes
P2	Yes	Yes	Yes
P3	Yes	Yes	Yes
P4	Yes	More Needed	Yes
P5	Yes	More Needed	Yes
P6	Yes	No	Yes
P7	Yes	No	Yes
P8	Yes	No	Yes
P9	Yes	No	Yes
P10	Yes	Yes	Yes
P11	Yes	Yes	Yes
P12	Yes	Yes	Yes
P13	Yes	Yes	Yes

Family Information Sharing

The IVR system is helpful even if someone does not have diabetes, as they can share information with other family members.

The role family can play in diabetic condition care is significant and cannot be neglected. Managing diabetes is a team effort, and with the support of family members, people with diabetes can help to lead a healthier life. The IVR usage pattern also revealed this fact, as Table 5.7 shows the role of the family in communicating knowledge about diabetes management.

Table 5.10: IVR Usage for family support

No.	Who
P1	Participant
P2	Participant
P3	Participant
P4	Family member
P5	He is a doctor.
P6	Family
P7	Family
P8	Family
P9	Participant
P10	Family
P11	Family
P12	Family
P13	Family

Experience Sharing

Experience sharing is less popular compared to doctor-approved information; people need to listen to the experience sharing section, there is no benefit, and more information is needed. When asked a system user about the experience-sharing system, a user was hesitant to share experiences while surrounded by others:

> *"I prefer the knowledge-sharing section to listen to other people's experiences.".*

It is anticipated that the experience-sharing section will not be well accepted. Still, one participant who was a doctor gave this response on the question of whether this feature will be helpful:

> *"Introduce the experience sharing system to check the motivation to use experience sharing system".*

Retrieving relevant information is tricky because of the navigation structure; however, building a suitable phone number profile could help adjust details according to a chronic condition.

The participant's use of the listening and recording features of the experience-sharing system is shown in Table 5.8; it showed that around 54% of participants had listened to the experience recordings; in contrast, not a single participant interviewed has recorded a new experience.

Table 5.11: Participant's Listening and Recording Feature Usage

Expeience Sharing		
No.	**Listen Experience**	**Record Experience**
P1	Yes	No
P2	Yes	No
P3	Yes	No
P4	No	No
P5	No	No
P6	No	No
P7	Yes	No
P8	Yes	No
P9	Yes	No
P10	No	No
P11	No	No
P12	No	No
P13	Yes	No

Suggestions

IVR is an effective source of information-giving and promotion of self-management for a rural area, which is often deprived of appropriate services and access to medicines due to the barrier that distance presents. IVR can reach all communities through healthcare workers who people trust.

Overall, the quantitative and qualitative analysis of the IVR system showed that this system could potentially improve the lives of people with diabetes by promoting lifestyle changes and exercise in the resource-constrained environment of the rural Global South. Diabetes medicine is crucial for many people with diabetes; however, with limited resources, access to treatment is often not the norm. This intervention can be essential in normalizing the blood glucose levels for many. The following Section, 5.8, presents the conclusion of this chapter.

5.8 Conclusion

These regular calls from the IVR system helped people with diabetes remain engaged in their self-management routine. Awareness about chronic health conditions, such as heart disease, diabetes, and hepatitis, can be effectively raised through IVR use.

Participants preferred the "information conveyed by doctors" to the "experience sharing" using the IVR. Most of the study participants did not record their experiences but listened to others' experiences with much interest.

Overall, the IVR system was accepted by study participants, who recommended continuing this IVR service as it could reach far-off rural areas and benefit people in their diabetes management routine.

Chapter 6

Discussion and Conclusion

This chapter reflects on the process we followed in the thesis and its outcomes. The chapter discusses the research contributions of this PhD thesis, and how this work can inform future efforts in this area, including identifying gaps in the research that still need to be explored.

6.1 Research Contributions

The research outcomes - concerning each of the three research questions presented in Chapter One – will now be discussed:

6.1.1 Adaptation of PD in the local context

Research Question One: How can Participatory Design(PD) methodologies be adapted to work in rural regions in the Global South? In particular, what changes are necessary to support rural people living with diabetes in Punjab, Pakistan?

Based on the PhD's early attempts to run studies in Pakistan, this work used a PD approach in which end-users are closely involved in the design process.

Participant passivity in early scoping studies raised concerns regarding the viability of the participatory processes. To a varying degree, this problem has been reported by other literature [98]. This PD research ultimately played a significant role by encouraging active engagement in the design process. The design process was revised based on participants' verbal feedback and engagement with the study.

The user-scoping process laid the foundation for the PD session. It helped better understand the participants' exceptional verbal ability, which would be critical in all subsequent PD activities. PD approaches must be adapted locally, especially in diverse cultural settings, and be built based on user scoping. For instance, given their low literacy levels, the participants' excellent verbal ability was utilised in all PD activities.

Adapting PD requires an understanding of the local context. To accomplish this, it is necessary to have a thorough knowledge of the local culture, social norms, and language. The participation of local people (helpers) in the research process positively impacted the PD process. These helpers' services led to understanding cultural norms better and facilitating effective communication with local communities due to their existing relationships within the community. Researchers must be flexible and adaptable to ensure the success of the PD. For example, a server deployment or a data connection (or WiFi) are the options used to test the IVR. Despite the availability of WiFi and data connections, IVR could not be deployed without a strong data connection. I modified my approach through action research and presented audio files to users in this situation.

A narrative scoping approach entails defining a problem, creating a persona, developing a narrative, and scoping the design. As part of this PD research, participants were asked to discuss a persona and express their views based on their tacit knowledge. This novel approach helped develop a user-centred design aligned with the needs and preferences of the target audience.

The Wizard of Oz is a PD technique used during the early stages of the design process to explore and refine IVR design. The script is read to the user while designing an IVR system using the Wizard-of-Oz technique. This research gave an automated touch to Wizard of Oz and created a Wizard of Context technique that relies on the IVR script being played to participants through a Python program; this reduces the need to read the script for each participant and makes the process more consistent.

Although participants' passive behaviour was evident in early scoping studies, this PD research played an important role in engaging them to participate in the design process actively. Through the use of Participatory Slides, which contain a variety of audio and visual content, the transition was made from passive to active participation in focus groups. Thus, showing participatory slides enabled participants to share their knowledge, skills, and expertise effectively and fluently using a verbal approach.

In addition to IVR audios that provide participants with an understanding of the concept of the IVR system, these PD slides also include PD videos that communicate the design ideas. Audio content is an alternative method of demonstrating the IVR system to participants (which was not feasible due to weak signals). Due to participants' illiteracy and inability to read, pictures were used in PD slides to transition from one idea to another. The PD Videos aimed to demonstrate different design concepts to the participants. An invisible design video is a type of participatory video that shows the software indirectly as the user uses it.
By extending the concept of PD video, three new types of videos are created: Elaboratory, Exploratory, and Narrative Scoping with Persona videos.

1. **Narrative Scoping with Persona Video :** Videos were first used to present the narrative Persona to the participants, revealing aspects of their daily lives and problems. The videos were popular and well-understood.
2. **Elaboratory Video:** This Video illustrates a design idea in the late stages of conception during the PD session.
3. **Explanatory Video:** This video illustrates a design idea in the early conception stage during the PD session.

Overall, all the above PD discussions worked in the localised context of this research and need further investigation in other geographical locations.

6.1.2 Approaches to Deliver Information with IVR

Research Question Two: How to design and develop a voice-only medium to present important healthcare information, thus enabling regular user-system interaction over time.
The second research question was designing and developing a voice-only system to support diabetes awareness. The first step in this design process was defining the system's purpose. Prior research shows that Information Delivery and Community Involvement are two popular ways of keeping people engaged, informed and motivated for the routine care of their chronic condition. Therefore, these features were adopted into the system design.
Identifying the target audience is the second process, and this research showed that the target audience is the less literate or illiterate people with diabetes, particularly the older age group. Understanding the user's capability was critical in designing an IVR system for this target audience. Therefore, considering our participants' capabilities, such as limited literacy and weak eyesight due to older age, led to designing voice-only systems that require minimal user interaction. Although a mixed age group used the finalised IVR system, the system design considered users' abilities requiring support to facilitate their diabetes management routine.

Choosing the voice-only medium platform that can reach the masses with any phone, regardless of whether the smartphone or basic phone, is a crucial step, and the IVR platform choice suited the needs of this research.

The following process is to design the user interface, which enables the less literate or even illiterate people with diabetes to seek knowledge to raise their diabetes awareness. Therefore, the design process caters to two categories of users: those with less than two or three minutes to use the system with minimum interaction and those interested in seeking information with more effort involved. This adaptation of the IVR system for different user categories was facilitated with system design, as highlighted in Chapter Four.

The IVR system delivers much information, and due to the sensitive nature of healthcare information and the limitations of interaction techniques, recommendations become less relevant. Therefore, it was safest to prioritise information about diabetes, comorbid conditions (including hepatitis and heart problems), and other healthcare issues (such as smoking and COVID).

The next IVR system feature developed was an experience-sharing system through this voice-only medium. This IVR system design initially started with the desire to build a community system, the voice-based version of an online community system like Facebook. However, considering the interaction capabilities of a voice-only medium, the user literacy level and the ability to use technology (especially for older people) - led to the development of an experience-sharing system.

6.1.3 Evaluation of IVR

Research Question Three: What is the impact of the developed healthcare IVR, evaluated by quantitative and qualitative analysis?

The IVR was evaluated in two phases; during the first phase, the IVR was deployed for four weeks with 38 people; during the second phase, the IVR was deployed for 19 days with 214 people.

The first phase was evaluated with four PD evaluation sessions done while users used the IVR system in their daily lives in their home setting. The session details are discussed in Chapter Five. These one-to-one sessions with selected participants led to further design improvements. Later, after incorporating the required changes, the final IVR deployment was undertaken, and this deployment was analysed quantitatively and qualitatively to evaluate whether the system was useful.

The evaluation of different features is as follows:

1. Most participants found the information-sharing system beneficial since they had no access to medical information before this, other than doctor's advice and word of mouth. The diabetes information feature is the most popular; many individuals listen exclusively to this feature. Quantitative analysis confirmed that most people receiving the IVR call during the final deployment listened to one piece of diabetes information daily and then hung up.
2. The information regarding comorbid conditions was popular among people suffering from them; for example, someone with a heart condition preferred to listen to information regarding their health condition. In the same manner, people with hepatitis or smoking issues are interested in hearing healthcare information that is relevant to their health condition.
3. Compared with the information-sharing feature, the experience-sharing feature of the IVR system was less popular and received mixed results, with more people listening to recorded experiences than recording them. After analysing the information quantitatively, it was determined that people preferred to hear the experiences of others and only recorded their experiences five times throughout the 19-day deployment of IVR.

6.2 Novel Contributions

The following are the novel contributions of this research:

1. Narrative Scoping with Persona.
2. Wizard of Context.
3. PD Videos.
4. Dynamic and Scalable IVR system.

Discussing each of these in turn.

6.2.1 Narrative Scoping with Persona

Storytelling has been employed in HCI methods such as qualitative research co-design and participatory methods [200]. Particularly in rural areas of the Global South, where participants are less literate, sharing textual information becomes challenging. In such situations, storytelling becomes particularly important, and user stories collected from prospective system users present actual experiences and emotions. Bonsignore et al. present a mobile storytelling application where the users were facilitated to develop their stories [71].

Narrative scoping techniques were chosen to rethink PD sessions after user scoping revealed participants wanted to share their personal or other experiences. In the Narrative Scoping work, personas were used instead of tangible artefacts from the co-creation process. In this creative narration, knowledge is spontaneously generated by the subject.

An account of a narrative is more structured and formal than a story; a story is an informal, subjective account of a personal experience [107]. A 'Persona character development' method was used to collect subjective accounts about the personal experiences of our study participants to develop new ideas based on the existing Persona. Based on the interviews, I shared different Persona attributes to begin conversations with our end users about the Persona and its activities. Participants contributed to the PD session by discussing various scenarios in Persona's life. This, in turn, helped the researcher gain deeper insight into users' lifestyles, likelihood to use technology and current practices of diabetes care.

6.2.2 Wizard of Context

Wizard of Context is another novel contribution of this project. It resembles the Wizard-of-Oz technique - where participants were given the impression that they were using an IVR system over the phone. One of the limitations is that the script is read to every participant. Instead, the Wizard-of-Context plays the prototype working on a laptop, and the person handling the call gives different user inputs to the Prototype. This eases the process of reading the script to every participant while testing the Prototype, making the user experience more uniform.

6.2.3 PD Videos

Design thinking is a concept used for innovation and creating value in various fields, including education and healthcare. Design Thinking has different phases, such as the 'Empathise Phase', which leads to understanding the problem from the user's perspective; the 'Define Phase', during which information gathered in the empathise phase is synthesised; the 'Ideate Phase' when a large number of creative ideas are presented, thus fostering a collaborative and open environment to stimulate creativity; the 'Prototype Phase' where low fidelity prototypes are created to test and iterate new concepts quickly; the 'Implement Phase' where the successful Prototype is fully implemented.

Using videos in PD helps engage people in the design process more effectively. This research started with designing, filming and presenting the Invisible design videos [78] as described in Section 4.6. Later, considering the less literate participants' acceptance of these videos, different videos were created, such as:

Narrative Scoping with Persona Video:
Videos were first used to present the narrative Persona to the participants, revealing aspects of their daily lives and problems. The videos were popular and well-understood.

Elaboratory Video:
This Video illustrates a design idea in the late stages of conception as a design feature was shown in a video to stakeholders.

Explanatory Video:
This Video illustrates a design idea in the early conception stage.
The significance of these videos is that they can help us better understand personas during the empathise phase. Additionally, they can help convey different design ideas in the early or late conception stage - the ideate phase. These videos do not directly present the IVR system design but rely on using personas to convey different ideas.

6.2.4 Dynamic and Scalable Healthcare IVR System

A scalable and dynamic IVR system presenting prioritised healthcare information, including diabetes and comorbid information, and sharing experiences.
Previous research highlights that the IVR system has been used in different capacities. IVR system examples have been discussed in Chapter 2, Section 2.5.2. A quick recap is given here. Agarwal et al. proposed a Spoken Web, enabling the development of voice-only sites created and browsed using an ordinary phone line [45]. Dhanesha et al. proposed the navigation of the Spoken web [105]. Avaaj Otalo is an IVR system that provides agriculture information [207]. IVR Junction connects phone-based users with internet-based users [250].
The research shows that helpline services are more popular in healthcare, and there is limited research on IVR systems for the healthcare sector. Some examples are the NHS UK helpline and Diabetes UK helpline, which provide customised information to users. Similarly, the 'Baqai Institute of Diabetes and Endocrinology' (BIDE) developed a helpline for people with diabetes; those currently under treatment at the healthcare centre were registered on the helpline. This helpline serves people with diabetes and a combination of initial in-person screening and then remotely responding to patient calls and queries.
The IVR system proposed in this research has unique and novel features that include delivering information about diabetes and comorbid conditions that many people living in resource-constrained settings are unaware of.

The IVR system was designed with novice and intermediate users in mind. Since novice users are expected to listen to only the first information prompt, a diabetes information prompt is played based on the prioritised content in every call. Following this, the main menu option plays, allowing users to choose from various IVR features.

The experience-sharing feature of the IVR system facilitated people with diabetes to share their problems and experiences, such as what went well and what was not well enough. Overall, the IVR system users were more inclined to listen to other people's experiences rather than to record their own (evidence from IVR system usage logs).

I propose that this IVR-based service, with the helpline service, can keep people with diabetes better engaged in their self-management routine. Therefore, this system has some automated features; however, in some scenarios, the healthcare professional intervention becomes important, and this automated system can direct users to healthcare professionals' support.

6.3 Research Scope and Limitation

The research scope and limitations have been highlighted below:

6.3.1 IVR Deployment

The IVR system "Sugar-ka-Saathi" was deployed in two iterations. Due to funding restrictions, it lasted one month in the first iteration and 19 days in the second iteration.

One of the research limitations is that to get varied views about the IVR system; it was deployed with 216 participants, including people with or without diabetes. It was done based on the assumption that the high prevalence of diabetes often leads to every family having at least one person with diabetes. Therefore, it's anticipated that people without diabetes could help their family members with diabetes to get appropriate information from the system. Similarly, the final IVR was deployed with people of varied education levels to elicit a broad range of usage patterns, views on IVR usability, and recommendations for further improvement.

6.3.2 Participants

Several studies in this thesis involved participants from villages living on the outskirts of Faisalabad and some less privileged areas within the city. This is only one region of Punjab, and people from other parts of the province may have different expectations and behaviours, which need to be investigated.

Most participants in the PD research had diabetes and were illiterate or had limited literacy. There is a reason for this since a local person gathered people with diabetes without considering that they were less educated or illiterate. Participant selection could have been better targeted to overcome this limitation.

Study participants vary widely from one study to another, e.g., the final IVR deployment had 216 participants; a study with more participants may yield more valuable results.

6.3.3 Devices Used

According to the scoping study, basic phones are most commonly used, but the increasing popularity of smartphone applications makes IVR technology less valuable. Despite the availability of smartphone applications, the use of basic phones continues to be popular in many areas of the Global South.

6.3.4 Psychology and Diabetes Management

The Diabetes Management Psychological Approaches have been discussed in section 2.3 to give an overview of different aspects of diabetes and the psychology of managing it. These theories have been discussed to give an overview of the different psychological approaches to managing a lifelong journey with diabetes affecting people's lives. However, these theories are not discussed later in the thesis due to the nature of action research I encountered during this PhD research project. This is a limitation of this research and can be further explored in subsequent future research.

6.4 Conclusion

This research presents output in two categories, as shown below:

1. This research attempts to reiterate the PD approaches, and the researcher adopted these PD techniques in localised contexts. This led to novel PD techniques such as Narrative Scoping with Persona, Wizard of Context, and Participatory slides with media and auditory content. This research also developed and introduced two types of PD videos: Elaboratory Videos and Exploratory Videos.
2. People with diabetes who are more informed make better daily diabetes management decisions. This research proposed that an IVR system can present diabetes information to manage diabetic conditions. It developed a Scalable and Dynamic System to deliver prioritised information about diabetes and comorbid conditions. Therefore, daily

automated IVR calls were placed on the recruited participants. The quantitative and qualitative analysis showed participant interest in the system. Experience sharing was widespread for listening to shared experiences, though participants showed reluctance to share diabetes experiences. Overall, it can be concluded that the IVR system can be successfully used to raise awareness of various healthcare topics to improve health self-management and help people overcome their inability to access healthcare services directly.

The proposed work is shown in the next section.

6.5 Future Recommendations

This section discusses the future recommendations as follows:

6.5.1 Participatory Design

In this study, it became evident that the PD techniques mentioned above resonated well with participants who were less literate or illiterate. There is, however, no evidence that these techniques are acceptable in other rural areas of the Global South. However, media (including pictures and videos) and audio are universal means of communication. There is a high likelihood of adapting these techniques to other contexts, though more research is required to substantiate this claim.

1. This research proposed the PD with Visual (pictures and videos) and Auditory content and PD videos (Narrative Scoping Videos, Elaboratory Videos, and Exploratory Videos). This visual and auditory content helped to guide PD sessions with less literate participants. These videos elaborate on different system concepts and demonstrate the system design ideas to participants.
2. The Wizard of Context concept is used to show a prototype to the users. IVR system, being a voice-only medium, was demonstrated on a phone call; however, in the case of visual content, this method can be used to share screens and show prototypes even with minimal functionality.

6.5.2 Healthcare System

The following recommendations are for developing a healthcare system to support people living in rural areas - particularly in the Global South:

1. Many rural residents cannot obtain accurate information about their chronic health conditions. We developed an IVR system to address this problem by making such information accessible, engaging, and cost-effective. In addition to enabling patients to manage their chronic health conditions better, this research indicates that healthcare professionals can use this IVR system to support rural residents.
2. This system, however, has limitations regarding the presentation of healthcare information. In the future, developing a technology containing various components of information about different conditions may be beneficial.
3. This proposed system can have different components. One component would be an interactive voice response system, and another would be a smartphone application. Healthcare centres may use this system to facilitate their patients.
4. The long-term usage patterns and IVR spread can be calculated by highlighting people's behaviour while using the IVR.

6.5.3 Cost

There is a need for specific research on determining the cost of IVR for people living in resource-constrained environments.

1. One way to mitigate the cost is through advertising, which may be restricted due to the limited purchasing power of people living in resource-constrained settings.
2. The people living in rural areas have limited access to healthcare, education and economic activities. Services tailored to the needs of people in such locations can be helpful. Furthermore, such services can be advertised on the IVR system to meet the costs.
3. Similarly, local businesses in a local area may want to advertise through this healthcare system. Further investigation is required on whether an advertisement will be a suitable means of distributing costs and who will promote the IVR system.
4. Alternatively, doctors may recommend this system to less literate persons who may benefit from it and charge a minimal fee. The practical application of these ideas will provide a more accurate assessment of their usefulness.

6.5.4 Regional Languages

1. In Global South countries, the prevalence of the local language is usually higher than that of the national language. Therefore, considering the local language when designing the technology intervention can result in a usable system.
2. Furthermore, the speech-to-voice provision is unavailable in many regional languages, including Punjabi, written in Arabic dialect, and further research will help progress this technology.

6.6 Reflection

Despite being a UK citizen and resident, I regularly visit Pakistan as my close family lives in Punjab, Pakistan. Thus, I could work with rural and less literate people because I understood cultural norms and common thinking patterns. I easily communicated with less literate people because I was familiar with Urdu and Punjabi. Study logistics, however, proved to be the most challenging part.

The logistics of conducting studies in the ICTD sector, especially in healthcare, can be challenging, such as obtaining hospital permission for the studies. When the project started, I visited many hospitals in Lahore and Faisalabad to get the hospital's approval on my own, but I was not successful; it was only when I involved relevant healthcare professionals with the help of family and friends that I was able to start the research.

This research follows the ethics approval procedure, which is particularly important for the healthcare sector due to the sensitive nature of information. The PD process used in this study helped to obtain sensitive healthcare information about different participants, most of which was recorded via video or audio. Following the ethics procedure helped to ensure that the participant's information and data were protected carefully. Therefore, I followed the ethics process approved by Swansea University, which consisted of a detailed procedure outlined. The iterative nature of this research project led me to submit four ethics applications to Swansea University's Department of Computer Science. In addition, I obtained formal permission from healthcare centres involved in the study. Due to my involvement in these processes, I better understood research processes in the healthcare sector.

The Global South, particularly the rural areas, has various cultures, languages and education levels. Early scoping studies highlighted the excellent verbal ability of the less literate study participants. It also led to selecting IVR as a feasible way to involve less literate people with diabetes to self-manage their condition by becoming more aware of information concerning their health condition. This process made me realise the importance of understanding users and adapting the process according to their needs rather than imposing a personal understanding of target users. As a takeaway, I will highly recommend working with end users to know their needs and wants while designing technology. Therefore, this action research project depends on user input and adapting processes according to their needs.

Knowing about the excellent verbal ability of the research participants led me to adapt the PD project according to these skills. Therefore, while working iteratively, I utilised the personas developed during the early scoping for the later design processes. The verbal ability and the importance of narration in the design process led me to create 'Narrative Scoping with Persona Technique', where the personas were discussed with research participants to refine them further. This process relied on participants' excellent verbal abilities and tacit knowledge to refine these personas further.

In the early research phase, an invisible design video was presented to participants based on the concept highlighted in [78]. Later, in the research project, I developed novel video concepts such as 'Narrative Scoping with Persona Video', 'Elaboratory Video', and 'Explanatory Video'. These videos had different design themes, distinguished based on their usage in the early or late stages of the design process. These videos are also attributed to their presentation of personas in different scenarios. This iterative process led me to design novel PD video approaches and use different ideas to generate new concepts.

The iterative design of a Scalable and Dynamic IVR system to aid diabetes self-management is another novel contribution of this PhD project. This involves recording a plethora of information available on the World Wide Web. This was particularly challenging for languages without an automated text-to-speech engine. I highly recommend developing a text-to-speech platform for regional languages to ease healthcare software development, such as an IVR system.

People living in the Global South have the advantage of conducting research in the ICTD sector due to their localised context and language awareness. Overall, prior experience and knowledge of local norms are important in ICTD research. However, such projects also need developing external collaboration, as in this project, collaboration was needed with hospitals due to its healthcare domain.

Concluding, during this research project, I faced many personal and project-related challenges, and at one stage, I thought I would be unable to finish this research. However, the fact that it was completed successfully is testimony to the continuous support of my supervisor, Prof. Matt Jones. Despite my challenges, completing this project was a source of great satisfaction and a great learning experience regarding the challenges involved with working with less literate people with diabetes. I hope this IVR system is an ongoing service to help many people in their lifelong diabetes journey.

Appendix A

My Publications

A.1 Short Paper

Kehkashan Zeb, Stephen Lindsay, Suleman Shahid, Matt Jones: Verbal Design: A Participatory Design Approach with Illiterate Patient User Groups. Conference on Designing Interactive Systems (Companion Volume) 2018: 271-275.

A.1.1 Abstract

"This paper presents a Participatory Design approach focused on applying primarily Verbal Design techniques working alongside illiterate People with Diabetes (PWD) from low socio-economic groups in Pakistan. After gathering a set of initial findings through classic Participatory Design and encountering several challenges, we discuss the development of our Verbal Design Approach in response which uses Narrative Scoping and Persona along with Invisible Design videos to structure and drives discussion and document design. Preliminary work showed that the approach resonated with our illiterate participants."

A.1.2 My contribution

With the guidance of my supervisor, I developed the concept behind this paper. As I wrote the paper, my supervisor provided feedback. This paper was presented as a poster at DIS 2018.

A.2 Full Paper

Kehkashan Zeb, Stephen Lindsay, Suleman Shahid, Waleed Riaz and Matt Jones. Sugar ka Saathi–A Case Study Designing Digital Self-Management Tools for People Living with Diabetes in Pakistan (Full Paper published in INTERACT 2019)

A.2.1 Abstract

"This paper presents the results of an iterative participatoryprocess to design a self-management tool for olderandless-literate people living with diabetes (PLWD) in Pakistan. Group interviews with 69 PLWD identified issuesthatthisuser groupfacesin self-management, including resource constraints, comorbidities,low-tech mobile phones, and poorinternet availability. We developedpersonas grounded in the scoping results that capture key requirementsto informtheParticipatory Design (PD) sessions. PD sessions,designedby paying careful attention tothese personas,were run with 17 participants. Theyhighlightedthat the most disadvantaged participants were older PLWD with low literacy and technologicalaccess. Incaterto theirspecificneeds, we designeda phoneline-deliveredInteractive Voice Response (IVR) system and adjusted our PD approach to focus on more tangible design artefacts.
A functional IVR Prototype, “Sugar kaSaathi” (Diabetes Companion), was developed with input from a group of 4 Pakistan-based healthcare professionals to act as a design probe in the PD process. The IVR probe was used with 57 original scoping participants, which validated IVR technology’s acceptability and revealed PLWD’s reliance upon their wider community. A community component to the“Sugar kaSaathi”system was designed with 14 participants through invisible design videos using our existing persona characters from the scoping studies. This final study suggested that an IVR-based community system has the potential for engaging older PLWD in managing their healthcare. Furthermore,itled us to thinkabout how lightweight recommendations based on user profiles canhelpincrease the system’s efficacy and overcome challengesassociated withnavigating a voice-based menu. "

A.2.2 My contribution

This paper resulted from my effort; I planned, ran, and analyzed the study with the assistance of LUMS Lahore. I presented the paper at Interact 2019. My supervisors provided feedback and advice while developing the concept and writing the paper.

A.3 Doctoral Consortium Paper

Kehkashan Zeb. Co-Design of an IVR system for management of Diabetes and Co-morbid conditions – A case study of Rural Punjab, Pakistan (Doctoral Consortium Paper in INTERACT 2019)

A.3.1 Abstract

"Diabetes management needs continuous support; however, in rural Punjab, Pakistan, illiteracy and poverty are barriers to effective management. My doctoral research explores Interactive Voice Response (IVR) as a feasible technology for illiterate people, followed by co-design activities, helpline development and tests addressing different needs highlighted in a scoping study. Different techniques such as dynamic IVR, recommender algorithm and voice-based Social Networks (SN) are investigated further."

A.3.2 My contribution

The doctoral consortium was presented at Interact 2019. I enjoyed participating in a group consortium and presenting my work. My supervisors provided feedback and advice as I developed the concept and wrote the paper.

Appendix B

Information about Pakistan

The following section will give background information about Pakistan, its economic condition, its impact on diabetes management, and the non-uniform distribution of healthcare services.

B.1 An Introduction of Pakistan

Pakistan is a South Asian country with a 796095 Km square area, making it the 36th largest country globally. It borders India, the Arabian Sea, Iran, India, Afghanistan and China. Urdu is the national language; there are four provinces, Punjab, Sindh, NWFP, and Balochistan. Each province has its local language, which is preferable to Urdu, especially in rural areas. Forty million people live below the poverty line, with the rural areas suffering the most, as 30 million poorer people belong there. Pakistan is the fifth most populous country globally, and its population is around 22 crores as per 2020 statistics [40].

Poverty affects the literacy rate, which affects the country's development and progress; in Pakistan, despite the government's efforts, about half of the population is illiterate. Government policies emphasise the importance of primary education; however, the actual implementation of policies is minimal, thus leading to poor literacy in the country. Continuously managing diabetes throughout a person's lifespan has unique hurdles, including illiteracy and poverty. Poor awareness of diabetes often causes people to take their diabetic condition lightly unless they experience extreme side effects because of very high glucose levels [254]. To overcome diabetes management difficulties, appropriate and timely access to diabetes management information can help keep glucose within a healthy range with regular monitoring, exercise tracking, and dietary planning [136] [174].

International Diabetes Federation (IDF) report published in 2019 said that Pakistan is amongst the ten countries worldwide for absolute diabetes prevalence [144]. Statistics on diabetes in different provinces of Pakistan are below. The IDF report stated that 19 million adults live with diabetes in Pakistan, thus putting a strain on healthcare services and making the

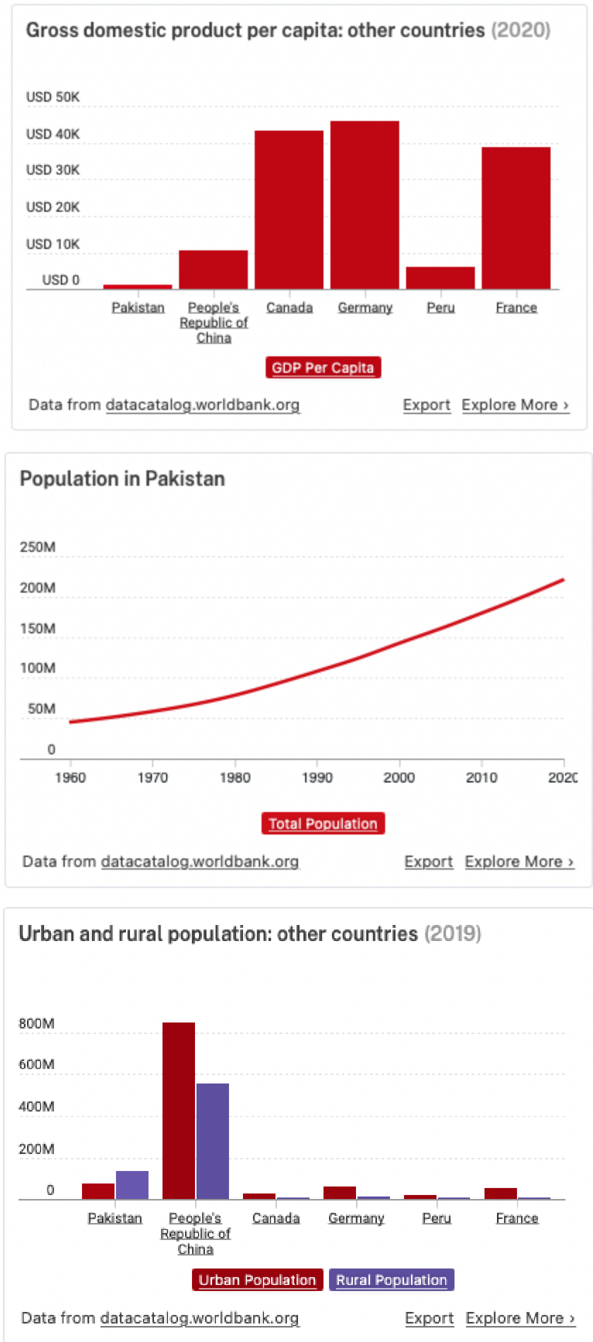


Figure B.1: Pakistan Statistics[40]

Figure B.2: Rural Pakistan

situation more challenging [235]. The diabetes epidemic does not have enough resources, and it has overburdened the healthcare system of Pakistan. There is a need to implement a diabetes healthcare service model amongst rural and urban populations to implement lifestyle changes and prevention strategies [59]. The late diagnosis often results in other complications. Therefore, screening should be compulsory for people above 45 at a higher risk of developing diabetes.

In Pakistan, healthcare services comprise the public and private sectors [255]. The public healthcare services are organised into four groups: 1) promotive, 2) preventive, 3) curative, and 4) rehabilitative. The private healthcare services are diverse and consist of doctors, nurses, pharmacists, traditional healers (homoeopathic) and unqualified practitioners. Although public healthcare services have continuously increased in workforce and infrastructure, the availability of one doctor or nurse has continually increased. Still, with high population growth, the non-uniform distribution of healthcare professionals across rural and urban areas is limited.

Moreover, healthcare delivery in Pakistan has numerous weaknesses, such as lack of access and unequal resources, poor quality of Health Information systems, corruption in the health system, and the lack of trained staff [267]. The high prevalence of chronic conditions is a barrier to the country's development goals, including poverty reduction and economic and health stability[190].

Appendix C

Research Consent Form Swansea University – Computer Science Department

This consent form, a copy of which has been given to you, is only part of the informed consent process. It should give you a basic idea of what the research is about and what your participation will involve. Please ask if you would like more detail about something mentioned here or information not included here. Please take the time to read this form carefully and to understand any accompanying information.

Research Project Title Using mHealth for self-management of chronic conditions in Pakistan.

Researcher Miss Kehkashan Zeb.

Experiment Purpose The purpose of this experiment is to observe and record the ways that mobile phones can help in the management of chronic diseases.

Participant Recruitment and Selection Literate and less literate People with chronic conditions from Punjab, Pakistan.

Procedure This session will require an hour. You will be asked to fill in a short questionnaire about your expectation of mobile health, particularly in the context of the Pakistani population, and then the potential scope of managing chronic conditions using mHealth applications on Android Mobile Phones. You may be asked to repeat variations of the problems. None of the tasks is a test, and there is no right or wrong answer– our objective is to find out how you approach the tasks.

Data Collection A questionnaire will be used to gauge your Mobile application experience at the beginning of the session. As you work on the task, your actions will be recorded and the interviewer will take notes. There will be video recorders.

Data Archiving/Destruction Data will be kept securely. The investigator will destroy study data after it is no longer in use. Usually, this will be at the end of the research project when results are fully reported and disseminated.

Confidentiality Confidentiality and participant anonymity will be strictly maintained. All information gathered will be used for statistical analysis only, and no names or other identifying characteristics will be stated in the final or any other reports.

Likelihood of Discomfort There is no likelihood of discomfort or risk associated with participation.

Researcher Miss K Zeb is working on her MPhil in the Computer Science Department at Swansea University. This study will contribute to her research on the scope of mHealth for chronic disease management. Her supervisor is Dr Stephen Lindsay and Prof. Matt Jones. K Zeb can be contacted in the Research Lab, 4th Floor, Faraday Tower, Swansea University. Her phone number is 07472668415, and her email address is 806259@swan.ac.uk

Finding out about Results

The Participants can find out the study results by contacting the researcher after October 1, 2016.

Agreement Your signature on this form indicates that you have understood to your satisfaction the information regarding participation in the research project and agree to take part as a participant. This does not waive your legal rights nor release the investigators, sponsors, or involved institutions from their legal and professional responsibilities. You are free to not answer specific items or questions in interviews or on questionnaires. You are free to withdraw from the study at any time without penalty. Your continued participation should be as informed as your initial consent, so you should feel free to ask for clarification or new information throughout your participation. If you have further questions concerning matters related to this research, please get in touch with the researcher.

Participant——————- Date————————

Investigator/Witness—————- Date———————

A copy of this consent form has been given to you for your records and reference.

Appendix D

Ethics Application Two

APPLICATION FOR ETHICAL APPROVAL OF PROJECTS INVOLVING HUMAN SUBJECTS
RESEARCH CAN NOT COMMENCE UNTIL ETHICAL APPROVAL HAS BEEN OBTAINED

D.1 TITLE OF PROJECT

Using Different Healthcare Approaches with Low Literacy Rural Communities in Pakistan

D.2 APPLICANT NAME(s)

Kehkashan Zeb

D.3 PROPOSED START DATE

August 2017

D.4 DURATION (months)

2 Months

D.5 OBJECTIVES

Briefly state what the project is designed to achieve. The project is based on exploring the potential scope of technology for people living with chronic conditions such as diabetes in developing countries, particularly Pakistan is selected for this project. Because the less literate people with chronic conditions are facing challenges with the self-management of the condition.

They require information from different sources, motivation to self-manage, etc. IVR can be a feasible solution for them, because IVR has different uses, such as information delivery on IVR, reminders, community-based radio, etc.
The project was structured around designing and developing a technological platform, such as 'IVR for Diabetes Care' using different participatory techniques.
Special importance will be given to selecting and evaluating participatory techniques for the less literate population using the participatory session. Because participatory design techniques can help us bridge the gap between our thinking and the needs of the stakeholders Different participatory techniques will be used for focus groups and workshops like characters, especially fictional characters in the form of personas, scenario-based designs using video clips, etc, for elaborating the concept to less literate workshop participants.
The technological platform will be designed and developed using an iterative cycle based on the gathered requirements. Therefore, PLWD will be involved in the design process; further, during the testing phase of the application, appropriate changes will be made in the IVR system based on the user's feedback gathered using participatory design.
We hope any novel information is distributed as paper for the wider community.

D.6 LOCATION OF STUDY

D.6.1 List the country and location(s) where the data will be collected

The project scope will initially be bound geographically to the province of Punjab in Pakistan. The project's target audience will be less literate or illiterate people, with the ultimate goal of getting insight into the expectations of less literate people using different participatory techniques. I selected Punjab in Pakistan because I am connected with Punjab and have links there, making it feasible for me to work there.

D.6.2 Identify the person(s) who will be present to supervise the research at that location

I, Kehkashan Zeb, will be present in the research with my external supervisor, Dr. Suleman Shahid and his student from LUMS Lahore.

D.7 STUDY DESIGN

D.7.1 Outline the study design (e.g. cross-section, longitudinal, intervention, RCT, questionnaire, etc.)

Session 1 - Narrative Scoping and Participatory Design Workshops Plan

There will be Narrative Scoping with Patients and Narrative Participatory Design Workshops. The emphasis in these sessions will be to get patients to tell us stories about their lives. We are not focusing on accuracy but trying to focus on experience with these tales while also playing to our participants' strengths. Previous research suggests narrative work is more suitable than conventional participatory design because it supports participants' strengths in developing countries with lower literacy rates. Essentially, what we are saying here is that the participants are not good at discerning the thematic or structural issues they are facing in response to very direct questioning, but can identify events that are "typical" in their life and which capture these structural issues at the first level of engagement. Beyond this, we can unpick the structural elements and tie them back into the individual stories to re-present our findings. This process will be iteratively refined in the execution to better work with the participants' abilities and to overcome the preconceptions of the design team. For example, the script can be changed when questions do not elicit strong responses, or the group size can be altered if the participants are not happy talking in front of that many people. This will require two levels of analytic awareness: first, the facilitator must engage with and analyze the PD session itself to gain an understanding of the design space, and second, it will require that the facilitator analyze the tools being employed in the design session and the suitability of the overall methodology.

D.8 Overall Method(1.5-2 hours)

D.8.1 Facilitators:

2 (minimum)

D.8.2 Recording:

audio and notes on large sheets of paper with video for the final design ideas

D.8.3 Participants:

6 people

D.8.4 Duration:

2 hours

D.8.5 Equipment:

2 x Audio Recording Equipment, Video Recording, Large Sheets of Paper to take notes on

D.8.6 Room:

Table and Chairs, space to talk in groups of 3

D.8.7 Introduction (5 minutes)

1. Thank the participants for coming and explain the session structure
2. Talk to participants, introducing the broad idea of an IVR system to help them manage diabetes and explaining we need their help/perspective on our ideas.
3. Ask everyone to introduce themselves - Tell me about yourself.
    i. Name
    i. Age
    i. Where are you from?
    i. When did diabetes start?

Breakdown the participants into groups of 3
Breakdown should be based on common personality/other characteristics to make sharing experiences easier
Small focus groups for healthcare work allow everyone to contribute and stop louder participants from taking over early on

D.8.8 Scoping (45 minutes)

First, participants are broken down into groups of three for small discussions To get an overview of how patients are dealing with their diabetic condition, we start by talking about the following:
Format:

1. **Broad topic areas**
    (a) "Specific things we ask to elicit stories."
    (a) Follow-up questions to gain more information about the people that we are working with
2. **How do they manage their eating**
    (a) "Do you have any stories from when you forgot to eat a meal?"
    (a) "Why did you forget?"
    (b) What happened?"
3. "Do you have any stories about times when a meal delay affected your diabetic condition, such as making you feel like you had low energy levels or depressed?"
    (a) Why did you delay in eating food?
    (a) How did you recover?
    (a) "Does anyone else have similar stories?"
4. "If you never miss out on meals like this, why do you think that is? Were you ever in a situation similar to the one just described, and what happened to you?"
    (a) What information do they have about diabetes
5. "Can you tell me a story about how you learned what it means to have diabetes?"
    (a) Which resources helped you in gaining this information?
6. "Do you get any self-management strategies for diabetes management from doctors/ nurses/ any other resources?"
    (a) How much effort do they put into managing diabetes
    (b) "What is the thing you are most proud of about how well you cope with diabetes? What are you the best at doing out of all diabetes patients?"
    (c) "What is the thing that you are worst at doing regarding diabetes? What story would get you shouted at by your doctor - we promise not to tell them!"
    (d) How much has diabetes changed their life
7. "Can you tell me about the things that you miss the most that you did before you had diabetes?"

8. “Can you tell me about a time you were scared of what might happen because of your diabetes?”

Medication and doctor’s visits

1. “Tell me about your typical day and how managing diabetes affects it?”
    (a) How do you adhere to your routine
    (b) Are there any exceptions when you act differently?
    (c) How do you take care of medicine?
    (d) How often do you check your glucose level?
    (e) How do you record the glucose levels checked?
    (f) What if you are busy with some task and have to measure diabetes?
2. Is the management of glucose measurement always easy? Tell me a situation when it is hard to manage
    (a) What if you are busy with some tasks?
    (b) How do you manage your glucose measurement time?
    (c) What information do you have about diabetes?
    (d) Are you satisfied with your care plan?
    (e) What do you like about doctors in the diabetes institute?
    (f) What should be improved
    (g) Do you think diabetes educators play an important role in maintaining your diabetes level
3. “Tell a story when you find it difficult to resist temptations for sweets?”
    (a) How do you overcome such a situation
4. “Tell me about a situation when you shop and try to avoid buying something sugary?”
5. “Can you tell me a story about when you got upset visiting the doctors?”
    (a) How often do you see the doctor?
6. “Can you tell me a story about a time when you had a really good visit to the doctor and came away feeling happier than when you went in?”
7. Based on this, we will construct a scenario/narrative about a typical person with diabetes and the problems that they face in their day-to-day life. This person represents the people in the groups.

Concerns Related to Diabetes

    (a) “Are you happy to discuss your situation with others? If you ever discuss?”
        i. Tell me a story when discussing your situation with someone is hard.

ii. Is it hard to discuss with everyone? Why is it hard

iii. Is there anyone you are at ease with discussing your diabetic condition?

iv. If you think of something that would be for managing glucose well.

i. " What if you have to check your glucose level in public? Do you feel it comfortable or difficult?".

(a) Tell me a story about when you had to check your glucose level in a crowded place?

i. May be in front of some relatives or friends?

i. How they reacted?

i. Did you have comfortable feeling while discussing with others?

"What different experiences do you have with people in your family or from the public about diabetes?"

1. "Can you elaborate on a story which you feel is important to consider, that story can be about yourself or someone else you have seen with diabetes?"
   (a) Why is it important
   (b) What can be changed or improved

D.8.9 Scenario/Character Building (45 minutes)

1. In this part of the workshop, we construct a character (or more than one) together. The character is the general representative of the group.
2. __________
3. **Character**
   (a) Photo:
   (b) Name:
   (c) Age:
   (d) Gender:
   (e) Occupation:
   (f) Type of Diabetes:

Stories

(a) A story about a day where they do well and diabetes doesn't cause problems:

(b) A story about a character in a day where their diabetes causes them problems:

D.8.10 Initial Participatory Design (45 minutes)

Bring the participants together in a single group 6 for the workshop.

(a) Introduce the stories that they have created

(a) Technology Awareness

- i. What level of access to mobile phones does our character have?
- i. Tell me an instance when you used mobile for anything other than listening to a call
- i. Do you use a mobile phone?
- i. Has the character ever thought of using a mobile phone for recording diabetes readings
- i. Which mobile applications do you/the character use?
- i. Mobile phones have different latest models nowadays, Are you happy to adapt to the latest model?
  - A. Why?
- i. What if you receive a call from a helpline for diabetes management?
- i. Will the character be happy to receive a call?

(a) Will the character be able to afford some minimal charges?

We present IVR to Diabetes Patients using Iteration 0 as a prompt for this discussion

D.8.11 Explain what IVR is and how it works

Interactive voice response (IVR) technology allows a computer to interact with humans through voice and DTMF tone input via a keypad.

IVR technology does not require human interaction over the telephone, as the user's interaction with the database is predetermined by what the IVR system will allow the user access to. For example, banks and credit card companies use IVR systems so that their customers can receive up-to-date account information instantly and easily without speaking directly to someone. IVR technology is also used to gather information, as in the case of telephone surveys in which the user is prompted to answer questions by pushing the numbers on a touch-tone telephone

1. Explain how it might be used in Diabetes care

   (a) For diabetes care, IVR can be used for various purposes:
   (b) For delivery of information to less literate diabetes patients.
   (c) Reminders for medication
   (d) Help in maintaining a diary.
2. Do they think the IVR system is enough?
   (a) What if there is a website
   (b) Mobile application
3. Show them what the current IVR can do
   (a) Ask them to think about the scenarios they created and make up some new stories about the people in the scenarios and the possible new IVR. The purpose here is to relate experiences with the possible functionality of the system.
   (a) What are their expectations from an IVR system?
   (b) A telephone call telling them how to deal with their diabetes problem.
   (c) Do they want to listen to how to deal with diabetes problems?
   (d) What about this character? Is he happy to take advice about diabetes management?
   (e) Is one time calling enough for him, or does he need a repetition of information?
   (f) Will it be the same information?
   (g) Do they have any problem areas?
   (h) What kind of information does he want to listen to?
   (i) How to deal with diabetes?
   (j) What should he eat.
   (k) Exercise routine/ walk.
   (l) Do they need assistance in diabetes management?
   (m) Like reminders for the medicine.
   (n) Diary for the condition management.
   (o) Will it be helpful for them
   (p) Is it only for telling them how to live with diabetes?
   (q) Or they want to communicate and support each other through such a system.

D.8.12 Session 2 – IVR Design clarification using Participatory Design Workshop

There will be IVR Design clarification using the Participatory Design Workshop. The emphasis in these sessions will be to use the IVR system, which they already used as the prompt for a more effective design of the IVR system. We already mapped the themes that emerged from interviews to IVR design. We will discuss those IVR concepts with low literate PLWD and get their feedback to clarify the ideas.

Some of the IVR ideas are listed below:

1. Medicine reminders
2. Encouraging feedback if the recorded glucose level seems appropriate.
3. Constructive feedback if the recorded glucose level is higher than normal.
4. Once-a-day reminder from the system that you need to enter your glucose reading if the glucose reading is not being entered for a user that day.
5. If the glucose reading has not been entered in the last seven days, the system will receive motivational messages.
6. IVR System will incorporate a community Radio Program to help people with real-life problems by listening to problems and identifying how these problems will be addressed.
7. Questions and answer forum for people who miss the program.
8. Manage a community-based Diabetes Radio Program
9. The moderator can start a program, schedule a program, send reminders of the program
10. The system will receive motivational messages if the glucose reading has not been entered in the last seven days every person.
11. Doctors can add some contacts to their list.

Videos based on the above scenarios will be presented to diabetes patients during the session. These videos will help to bridge the gap between our and the study participant's thinking. Participant opinions will be collected on each video. Because it will give a clear idea of the IVR system in the next iteration.

D.8.13 State the number and characteristics of study participants

The study will include at least 15 diabetes patients with low literacy levels.

D.8.14 State the inclusion criteria for participants

It's anticipated that different hospitals will be contacted in the initial phase of the project. National Hospital based in Faisalabad city contact says they are happy to provide any help, like referring patients and doctors.

D.8.15 State the exclusion criteria for participants and identify any requirements for health screening

The inclusion of participants is based on whether they are suffering from diabetes and facing difficulty in self-management and want some help.

D.8.16 Will the study involve vulnerable populations (i.e. children, elderly, those with cognitive impairment or in unequal relationships, disabled, clinical, etc.) or people who cannot give informed consent? Yes/No – If yes, please justify.

(Please note that people with learning disabilities fall under The Mental Capacity Act 2005 and must be reviewed by the NHS; other vulnerable groups may not require NHS review but will typically require Disclosure Barring Service (DBS) clearance (formerly CRB checks) – Evidence for this will be required.
No.

D.8.17 Will parental/coach/teacher consent be required? Yes/No - If Yes, please specify which and how this will be obtained and recorded

No

D.8.18 Are there any requirements/commitments expected of participants (e.g. time, exertion level)?

Yes, participants are expected to use the IVR system for two weeks.

D.9 PARTICIPANT RECRUITMENT

D.9.1 Briefly outline how and from where participants will be recruited

The participants will be recruited from hospitals in Lahore and Faisalabad. If, for some reason, we cannot get permission from the hospital, then we will go to the rural area and conduct research there after getting permission from the head of the village.

D.10 DATA COLLECTION

D.10.1 Briefly describe the type of data that will be collected

The data will be collected in notes, audio and video.

D.10.2 Briefly describe how the data will be collected

The data will be collected using a mobile phone camera and written notes during the interview and focus group.

D.10.3 Will the data collection be undertaken by Swansea University staff or students? Yes/No - if No, please explain who is responsible for data collection and give permit details (permit number, date, issuing body) or explain why these are not needed

Yes. Swansea University Research student Kehkashan Zeb, along with external collaborators of research from LUMS, will undertake the collection of data.

D.10.4 Briefly describe how you propose to ensure participant confidentiality and anonymity. If anonymity is not to be preserved, explain why not

Decoding of research data during thematic analysis will ensure participant confidentiality and anonymity.

D.10.5 Will the research involve respondents to the Internet or other visual/vocal methods where they may be identified (e.g. IP address)

No

D.10.6 Will participants be given information on the study and consent forms? Yes/No - If No, please justify.

Yes

D.10.7 Will the research involve the sharing of data of confidential information beyond initial consent? Yes/No - If Yes please explain

No

D.10.8 Will the information be collected from participants without their knowledge and consent? (e.g. secondary use or re-use of social media content; covert observation/photos of people in non-public places, etc.) . Yes/No If Yes, please justify:

No

D.10.9 Will any substance be administered to participants? Yes/No - if Yes, please explain: (Please note that substances falling under the auspices of the Medicines for Human Use (Clinical Trials) Regulations 2004 will require additional review by the NHS.)

No

D.10.10 Will participants' tissue samples (including blood) be obtained? Yes/No - if Yes, please explain: (Please note that collection of tissue samples would fall under the terms of the Human Tissue Act 2004 and will require additional review by the NHS.)

No

D.10.11 Is a first aider needed? Yes/No – If Yes, please identify

No

D.10.12 Will the study discuss or collect sensitive information (e.g. terrorism, sexual activity, drug use, criminal activity)? Yes/No - If yes, please explain:

No

D.10.13 Will the research involve collecting administrative or secure data that requires permission before use? Yes/No - if Yes, please explain:

No

D.11 STORAGE AND DISPOSAL OF DATA and SAMPLES

D.11.1 Briefly describe the procedures to be undertaken for the storage and disposal of data and samples

Data will be stored on a laptop, protected by passwords, by the Swansea University PhD researcher Kehkashan.

D.11.2 Who will be responsible for storing and disposing of data and/or samples?

Swansea University Research student Kehkashan Zeb will be responsible for storing and disposing of data and samples.

D.11.3 For how long will the data and/or samples be retained after completion of the study? (normally five years, or end of award)

The data and samples will be retained till the end of my PhD (expected to finish in 2019).

D.12 POTENTIAL RISKS AND DISCOMFORTS

D.12.1 Are there any potential physical risks or discomforts to the participants in the study? Yes/No – if Yes, please explain

No

D.12.2 Are there any potential physical risks or discomforts to the study's researcher (s)? Yes/No – if Yes, please explain

No

D.12.3 OTHER ETHICAL ISSUES OF CONCERNS If none, then please state 'none.'

None

D.13 APPLICATION CHECKLIST

Tick as appropriate below. Yes No N/A

D.13.1 Have you included a Participant Information Sheet for participants in the study?

Yes

D.13.2 Have you included a Parental/Guardian Information Sheet for parents/guardians?

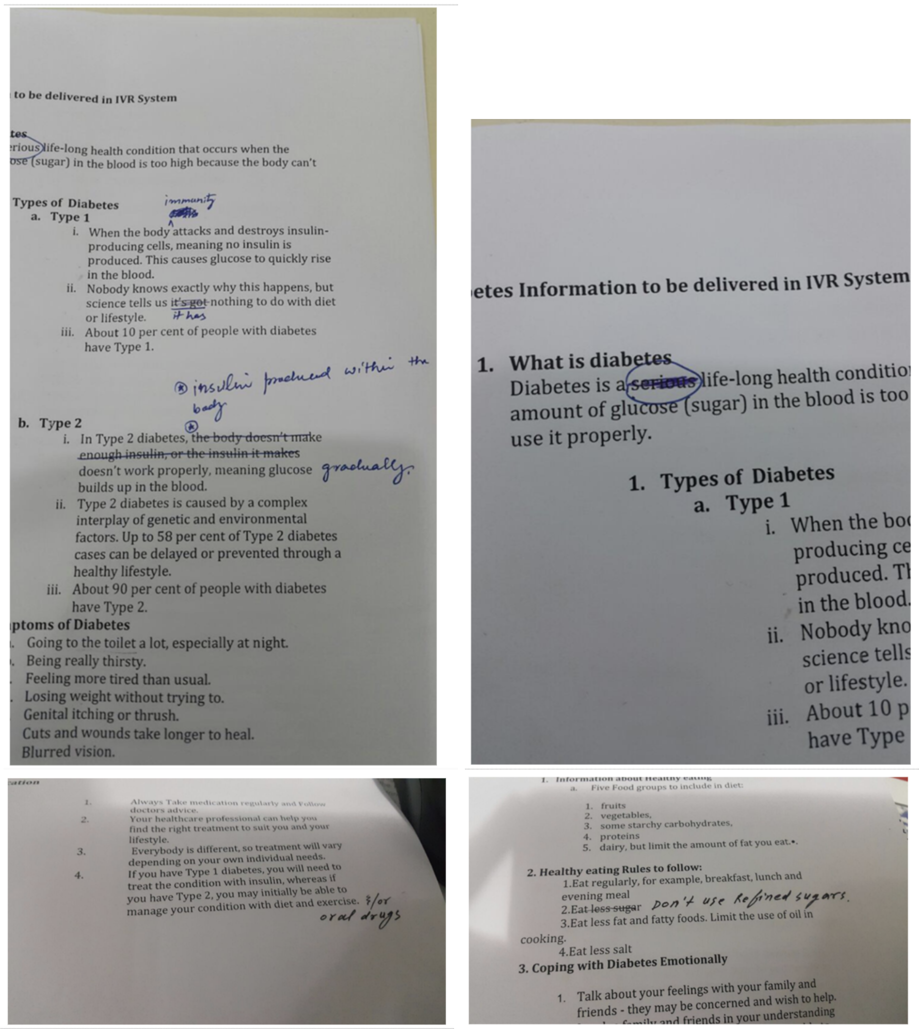
No

D.13.3 Have you included a Participant Consent (or Assent) Form for participants in the study?

Yes

D.13.4 Have you included a Parental/Guardian Consent Form for parents/guardians

No



to be delivered in IVR System

tes
~~rious~~ life-long health condition that occurs when the
ose (sugar) in the blood is too high because the body can't

Types of Diabetes
a. Type 1
i. When the body immunity attacks and destroys insulin-producing cells, meaning no insulin is produced. This causes glucose to quickly rise in the blood.
ii. Nobody knows exactly why this happens, but science tells us ~~it's got~~ it has nothing to do with diet or lifestyle.
iii. About 10 per cent of people with diabetes have Type 1.

insulin produced within the body

b. Type 2
i. In Type 2 diabetes, ~~the body doesn't make enough insulin, or the insulin it makes~~ doesn't work properly, meaning glucose builds up in the blood. gradually.
ii. Type 2 diabetes is caused by a complex interplay of genetic and environmental factors. Up to 58 per cent of Type 2 diabetes cases can be delayed or prevented through a healthy lifestyle.
iii. About 90 per cent of people with diabetes have Type 2.

ptoms of Diabetes
Going to the toilet a lot, especially at night.
Being really thirsty.
Feeling more tired than usual.
Losing weight without trying to.
Genital itching or thrush.
Cuts and wounds take longer to heal.
Blurred vision.

etes Information to be delivered in IVR System

1. What is diabetes
Diabetes is a ~~serious~~ life-long health conditio
amount of glucose (sugar) in the blood is too
use it properly.

1. Types of Diabetes
a. Type 1
i. When the bo
producing ce
produced. Th
in the blood.
ii. Nobody kno
science tells
or lifestyle.
iii. About 10 p
have Type

ation
1. Always Take medication regularly and Follow doctors advice.
2. Your healthcare professional can help you find the right treatment to suit you and your lifestyle.
3. Everybody is different, so treatment will vary depending on your own individual needs.
4. If you have Type 1 diabetes, you will need to treat the condition with insulin, whereas if you have Type 2, you may initially be able to manage your condition with diet and exercise. &/or oral drugs

1. Information about Healthy eating
a. Five Food groups to include in diet:
1. fruits
2. vegetables,
3. some starchy carbohydrates,
4. proteins
5. dairy, but limit the amount of fat you eat.

2. Healthy eating Rules to follow:
1.Eat regularly, for example, breakfast, lunch and evening meal
2.Eat ~~less sugar~~ Don't use Refined sugars.
3.Eat less fat and fatty foods. Limit the use of oil in cooking.
4.Eat less salt

3. Coping with Diabetes Emotionally
1. Talk about your feelings with your family and friends - they may be concerned and wish to help.

Figure D.1: IVR Content Corrections by Doctor

Appendix E

Ethics Application Three

E.1 TITLE OF PROJECT

Designing technology for low-literate people with Diabetes in Pakistan

E.2 APPLICANT NAME(s)

Kehkashan Zeb

E.3 PROPOSED START DATE

E.4 DURATION (months)

E.5 OBJECTIVES

This research project is based on exploring the potential scope of technology for less literate people living with diabetes (PLWD) in Pakistan in collaboration with LUMS, Pakistan. PLWD face numerous challenges with the self-management of the condition. Challenges to PLWD include:

1) Requiring information from different sources.

2) Motivation to self-manage, as research shows that diabetes can be controlled with effective self-management, necessitating lifestyle change alongside medication.

3) Barriers arising from low literacy levels.

The research is structured around designing and developing our technological platform, “IVR for Diabetes Care”, using different Participatory Design (PD) techniques, such as fictional characters in the form of personas and scenario-based designs in the form of video clips. PD techniques can help us bridge the gap between our thinking and the needs of the stakeholders, and changes will be made in our IVR for Diabetes Care system based on our users’ feedback. Based on the requirements gathered in this study, a technological platform will be designed and developed following an iterative development cycle.

In this study, we try to: Get detailed insight into our participants’ lifestyles by incorporating verbal design techniques for narrative scoping in stage 1 workshops. This insight will help to know more about participants’ needs and to design a better IVR system accordingly. The initial scoping study shows that our participants are not literate, are old, use low-end phones and are not inclined towards extensive use of technology. This leads us to select IVR as an acceptable technology for our less literate PLWD due to its suitability for them. IVR technology allows a computer to interact with humans through voice and Dual multi-frequency tone input via a keypad. Initially, we have developed a prototype within the WiFi range and will check its efficacy for diabetes patients by introducing it in Demo workshops. The invisible design videos will help us better understand the IVR system as they will introduce new ideas for IVR to our study partners and help us get feedback from them. The IVR system trial done for information delivery, question answer, and community-based radio will help to determine the suitability of Interactive Voice Response (IVR) as an effective solution for diabetes management. We will reiterate the IVR design, which will help establish an effective one.

E.6 LOCATION OF STUDY

E.6.1 List the country and location(s) where the data will be collected.

The scope of the project will be bound geographically to Punjab, Pakistan. It is anticipated that the work will be done in a safe and secure environment in a hospital or home setting. The target audience of the project will be less literate or illiterate PLWD. The reason for selecting Punjab in Pakistan is that Kehkashan Zeb belongs to Punjab, and being a native, she knows about the norms there. She speaks the same language as the participants, which will help conduct the study. Moreover, links with local hospitals and research groups will help conduct research, as we can access patients in hospital waiting areas. Moreover, we will deploy the IVR system server with LUMS’s help.

E.6.2 Identify the person(s) who will be present to supervise the research at that location

Doctoral candidate Miss. Kehkashan Zeb will be present to conduct the research.

E.7 STUDY DESIGN

E.7.1 Outline the study design (e.g. cross-section, longitudinal, intervention, RCT, questionnaire, etc.)

Participant Recruitment

E.7.2 Who will we approach?

Diabetes Patients, Diabetes Educators and Diabetes Doctors.

E.7.3 How many in total?

25 +.

E.7.4 How will we approach people?

Previous work has shown recruitment can be hard, and we rely on a snowballing approach, contacting people through social contacts that the researcher has in Pakistan, talking to friends of friends in a snowballing approach. We will work across multiple regions in Pakistan and believe that we can recruit the following:

Regions – Participant Numbers

75 Chak – 5 people with diabetes

80 Chak – 5 people with diabetes

Mansoorabad – 5 people with diabetes

If we are still short of participants, we will move to a hospital setting and work with Diabetes Educators in the hospital. We aim to do 3-5 workshops with up to 2-3 participants in each workshop. We anticipate problems working in a hospital; getting the same participants for Workshop B is complicated so I will over-recruit this population. If arranging workshop B with the same participants is not possible, the follow-up will be done by making phone calls to the study participants.

E.7.5 How will we take consent?

As most of the participants are illiterate and cannot sign the consent form, in cases where participants cannot sign the consent form, we will verbally explain the issues and do the recording of verbal consent. This verbal consent in the ethical process aligns with current best practices.

E.8 Methodology

E.8.1 Stage One. Participatory Design

This stage consists of 2 months, as shown below:

Overview of Work in Stage One

Month One, weeks one and two: Conducting a PD session with 25 participants.

Month One, week three and four: Thematic analysis of studies

Month Two, weeks one and two: Paper write-up.

Five to eight workshops will be conducted with two to three participants each, using a narrative scoping and invisible design methodology.

Facilitators: 2 (minimum)

Recording: audio and notes on large sheets of paper with video for the final design ideas.

Participants: 2-3 people.

Duration: 1 hour.

Equipment: 2 x Audio Recording Equipment, Video Recording, Large Sheets of Paper to take notes on.

Room: Table and Chairs, space to talk.

Recording details: The session will be recorded using voice memos, and a video recording will be done if possible. Pictures will be taken.

Session Analysis:

The sessions will be analysed later, and the recommended changes will be made to the IVR design.

Material Used: Phones, WiFi Portable Router/Hub.

Part A: Persona Discussion (20 minutes)

Thank the participants for coming to the workshop. Tell them the workshop's purpose and ask them to sign a consent form. Every workshop participant will be asked to introduce themselves by asking questions such as:

- *Tell me about yourself.* - Name - Age - Where are you from? - When did diabetes start?

The emphasis of this session will be on getting insight into the day-to-day lives of diabetes patients living in Pakistan and getting our participants to tell their viewpoints and life stories. The session will start with participant interviews. Then, a persona's picture will be presented. Then, participants will identify different requirements of this persona, including the technology used.

Part B: IVR prototype Testing (20 minutes)

An IVR prototype will be presented to participants in the second part of each workshop. This prototype has been developed with limited capability and works within the WiFi range. The IVR prototype was designed to create awareness of diabetes amongst patients and has different menus, such as diabetes information and how to manage diabetes.

Part C: Invisible Design (20 minutes)

Next, we will show an invisible design video to participants; in this invisible design video, a doctor asks her patients to use phones to seek information. The invisible design video conveys the idea of community-based IVR to know about participants' views on these technologies and whether they get the idea behind them through the invisible design video.

The personas developed after initial interviews will be used in ID videos for different scenarios. A story around these personas in a particular scenario will be introduced in these ID videos, and the presence of Persona characters makes these ID videos look real.

Participants will be shown different life situations for Persona 'Mukhtaraan Bibi' and 'Sabir Ali', explaining what difficulties 'Mukhtaraan Bibi' and 'Sabir Ali' may face while coping with their diabetic condition. These can be: Visiting a doctor from a rural area is difficult, so she wants another medium to communicate her situation. She does not have detailed information about her diabetic condition and needs help. Doctors have limited time for every patient and cannot tell them everything. She forgets to take medicine on time and needs a reminder. He gets demotivated sometimes and eats sugary products or does no physical activity. She needs continuous support.

Participants' Feedback on Invisible Design Videos We will then get input from our workshop participants and how they see the scenario. Ask them to tell possible solutions for these scenarios, and if they want some support, what can that support be?

E.8.2 Stage 2: Co-Design with Wizard of Oz

This stage consists of one month and is divided as follows: Overview of work in Stage 2 ——
——————————————————————————————-

Month.......................Activity

——————————————————————————————-

Month 3, week 1 —– Reiterate Version 1 of the IVR script with diabetes educators based on the study.

——————————————————————————————-

Month 3, week 2 —– Has the script been recorded?

——————————————————————————————-

Month 3, week 3 —– Test the script with ten patients through A Wizard of Oz.

——————————————————————————————-

Month 3, week 4 —– Reiterate the IVR script based on the study.

——————————————————————————————-

Provisional Detailed Schedule of Stage Two
Date Location Participants Duration Work
Month 3 On Phone 1 x Diabetes Patients 30 min Wizard of Oz
Month 3 On Phone 1 x Diabetes Patients 30 min Wizard of Oz
Month 3 On Phone 1 x Diabetes Patients 30 min Wizard of Oz
Month 3 On Phone 1 x Diabetes Patients 30 min Wizard of Oz
Month 3 On Phone 1 x Diabetes Patients 30 min Wizard of Oz
Month 3 On Phone 1 x Diabetes Patients 30 min Wizard of Oz
Month 3 On Phone 1 x Diabetes Patients 30 min Wizard of Oz
Month 3 On Phone 1 x Diabetes Patients 30 min Wizard of Oz
Month 3 On Phone 1 x Diabetes Patients 30 min Wizard of Oz
Month 3 On Phone 1 x Diabetes Patients 30 min Wizard of Oz
Month 3 On Phone 1 x Diabetes Patients 30 min Wizard of Oz
Month 3 On Phone 1 x Diabetes Patients 30 min Wizard of Oz

We will take phone numbers from study participants in Stage 1 workshops, and they will be contacted again to conduct a Wizard of Oz session. These sessions will be conducted as follows:

Time-span of the sessions: One week.

Number: Ten one-to-one phone calls.

Participants: With ten people.

Duration: 10-20 minutes.

Recording details: The session will be recorded using voice memos.

How will we analyse the sessions?

The sessions will be analysed by:

Using the navigation structure and getting insight into how users navigate the system. Which menu items are accessed most frequently so that they will be on top of the navigation tree?

In this part of the study, we propose to use 'Wizard of Oz' prototyping, which refers to a prototype of IVR created by the researcher playing the recorded messages as the actual IVR system is designed to do. Users will feel the system is calling, but it's the researcher testing the IVR design.

Wizard of Oz will be evaluated with the survey by calling the person again at the end of the system phone call, and the system's working will be discussed with them.

IVR Design has evolved from the initial interview themes emerging in an early study, and this Design has been attached as 'IVRDesign.docx' in the Supporting Documents Section.

Currently, there will be different sections of IVR design as follows:

Main Page: On the main page, the user's profile calling the system will be saved if it is not already saved. Then, the user will be navigated to different software sections such as Diabetes Information, Stories, Program and Peer Support.

Diabetes Information: In this system menu, diabetes information will be given to the user following the doctor's advice. However, it is ensured that system users are advised not to rely on the IVR system, to consult their doctor as usual, and to give doctors' advice priority.

Programs: In this section of the IVR system, different programs will be played containing information about diabetes management; these programs are recorded as per the advice of diabetes educators and diabetes doctors from National Hospital Faisalabad.

Question and Answer: In this system menu, pre-recorded questions and answers will be played in an appropriate order.

Peer Support System: A peer support system is used to communicate between diabetes peers to discuss their disease and everyday issues due to diabetes.
After the thematic analysis of Participatory Design was conducted in stage one of the study, we will re-iterate the first version of the IVR Design and make changes if needed. These changes in design will be discussed with two Diabetes Educators hired from the National Hospital Faisalabad. Later, we will develop a detailed script for IVR, taking help from diabetes educators. This script will then be recorded and validated in the Wizard of Oz session.

E.8.3 Stage Four: Design Finalization

Reiterate using the participatory design process and make amendments if needed.

E.8.4 Stage Four: IVR Field Deployment and Evaluation

This stage consists of 6 months and is divided as follows:
Overview of work in Stage Three
Month 4 - Month 6 —- System Development.
Month 7 —– Usability Testing with HCI Collaborators in Pakistan and rectification.
Month 8 - Weeks 3,4 Study Part A: Workshop A (during this workshop, an IVR software demo will be given to study participants, and IVR software will be left with them for 15 days).
Month 9 - Week 1 Study Part b: Field Deployment of IVR System for 15 days with 25 Participants.
Month 9 - Week 2 Study Part C: Workshop B (Evaluation Workshop B will be done with the same participants, and in this workshop, feedback will be collected for IVR system use).
Month 9- Weeks 3,4 Final results Analysis.
There will be 15-20 workshops with one-to-three participants for the deployment of the IVR prototype. The workshop will be conducted as follows:
Facilitators: 2 (minimum).
Recording: audio and notes on large sheets of paper with video for the final design ideas.
Participants: 1-3 people.
Duration: 1 hour.
Equipment: Working IVR system, 2 x Audio Recording Equipment, Video Recording, Large Sheets of Paper to take notes on.
Room: Table and Chairs, space to talk in groups.

E.8.5 Part A: Briefing participants Interviews and Workshops (40 mins)

Thank the participants for coming and explaining the session structure.

Every workshop participant will be asked to introduce themselves by asking questions such as:

1. - Tell me about yourself.
    (a) - Name
    (b) - Age
    (c) - Where are you from?
    (d) - When did diabetes start?

Talk to participants introducing the broad idea of an IVR system to help them manage diabetes and explaining to them that a system will be deployed in this session and participants will use the system for 15 days; participants can help by coming back to the session after the testing time of 15 days and by telling us their perspective about the system.

E.8.6 Part B: IVR System Deployment (15 days)

In the next part of the workshop, a demo of the IVR system will be given to Workshop Participants. The participants will be asked to use the IVR system at home.

The system will then be left with participants for 15 days; in these 15 days, each participant will be called twice to check the system's validity. Regular IVR call logging will be done, and call-related data will be evaluated.

E.8.7 Part C: Post-Deployment Interviews and Workshops (40 mins)

Thank the participants for coming and using the system.

Participants will be asked several questions about their experience with the IVR system and will be facilitated to tell us as much information as needed.

1. How do they find the system?
2. Was the system helpful?
3. Do they want to continue using the system?
4. What features of the system do they like?
5. What features of the system do they dislike?

Interview Alternative

If the workshop is not possible to conduct with some participants, then they will be phone called, and questions will be asked about how they find the system by asking different questions.

E.8.8 Stage 4 - Re-iterate on IVR Design:

Stage 4 consists of re-iteration on IVR design, based on the analysis done in stage 3. This stage consists of 4 months:

Overview of work in Stage Four

Month 10 -11 —– System Development.

Month 12 —- Usability Testing with HCI Collaborators in Pakistan and rectification.

Month 13 —- Week One Study Part A: Workshop A (during this workshop, an IVR software demo will be given to study participants, and IVR software will be left with them for 15 days).

Month 13 - week 2,3 There will be 15-20 workshops with 1-3 participants for the deployment of the IVR prototype. The workshop will be conducted as follows:

Facilitators: Two (minimum).

Recording: Audio and notes on large sheets of paper with video for the final design ideas.

Participants: One to three people.

Duration: One hour.

Equipment: Working IVR system, 2 x Audio Recording Equipment, Video Recording, Large Sheets of Paper to take notes on.

Room: Table and Chairs, space to talk in groups.

Thank the participants for coming and explaining the session structure.

Every workshop participant will be asked to introduce themselves by asking questions such as:

Tell me about yourself.

1. Name
2. Age
3. Where are you from?
4. When did diabetes start?

Talk to participants, introducing the broad idea of an IVR system to help them manage diabetes and explaining to them that a system will be deployed in this session and participants will use the system for 15 days; participants can help by coming back to the session after a testing period of 15 days and by telling us their perspective about the system.

Study Part B: Field Deployment of IVR System for 15 days with 25 Participants.

Month 13 - week 4

In the next part of the workshop, a demo of the IVR system will be given to Workshop Participants. The participants will be asked to use the IVR system at home.

The system will then be left with participants for 15 days; in these 15 days, each participant will be called twice to check the system's validity. Regular IVR call logging will be done, and call-related data will be evaluated.

Study Part C: Post-Deployment Interviews and Workshops (40 mins)

Workshop B (Evaluation Workshop B will be done with the same participants, and in this workshop, feedback will be collected for IVR system use).

Month 14 —- Final results Analysis.

Thank the participants for coming and using the system.

Participants will be asked several questions about their experience with the IVR system and will be facilitated to tell us as much information as needed.

1. How do they find the system?
2. Was the system helpful?
3. Do they want to continue using the system?
4. What features of the system do they like?
5. What features of the system do they dislike?

E.8.9 State the number and characteristics of study participants

The study will consist of at least 25 participants suffering from diabetes, are illiterate or less literate, middle to old age and belong to the province of Punjab. The study will include two diabetes educators and two diabetes doctors from Punjab, Pakistan.

E.8.10 State the inclusion criteria for participants

It's anticipated that different hospitals will be contacted. National Hospital based in Faisalabad city contact says they are happy to provide any help, like referring patients and doctors.

Moreover, less literate diabetes patients will be recruited through contacts from the less privileged area of Faisalabad city and different rural areas in Punjab.

E.8.11 State the exclusion criteria for participants and identify any requirements for health screening

The exclusion of participants is based on criteria that people who will NOT be suffering from diabetes and will NOT have a literacy level high enough to use other readily available technology.

E.8.12 Will the study involve vulnerable populations (i.e. children, elderly, those with cognitive impairment or in unequal relationships, disabled, clinical, etc.) or people who cannot give informed consent? Yes/No – If yes, please justify. (Please note that people with learning disabilities fall under The Mental Capacity Act 2005 and must be reviewed by the NHS; other vulnerable groups may not require NHS review but will typically require Disclosure Barring Service (DBS) clearance (formerly CRB checks) – Evidence for this will be required.

NO (The study participants are illiterate, primarily elderly and consent forms will be read to them.)

E.8.13

sectionWill parental/coach/teacher consent be required? Yes/No - If Yes, please specify which and how this will be obtained and recorded No

E.8.14 Are there any requirements/commitments expected of participants (e.g. time, exertion level)?

The participants are expected to attend the workshops and telephone calls. Participants will also use the IVR system for 15 days, and their daily interaction with the IVR system will be from 0-15 minutes.

E.9 PARTICIPANT RECRUITMENT

E.9.1 Briefly outline how and from where participants will be recruited.

The participants will be recruited from hospitals in Faisalabad, Lahore and rural areas in Punjab. We already got permission from the National Hospital Faisalabad and are planning to conduct research in a rural area after getting permission from the head of the village.

E.10 DATA COLLECTION

E.10.1 Briefly describe the type of data that will be collected

The data will be collected in the form of notes, audio, video and pictures.

E.10.2 Briefly describe how the data will be collected

The data will be collected using a mobile phone camera and written notes during the interview and focus group. The data will be kept secure using password-protected storage devices like mobile phones and laptops.

E.10.3 Will the data collection be undertaken by Swansea University staff or students? Yes/No - if No, please explain who is responsible for data collection and give permit details (permit number, date, issuing body) or why these are unnecessary.

Yes. Swansea University Research student Kehkashan Zeb and external collaborators of research from LUMS will undertake the collection of data.

E.10.4 Briefly describe how you propose to ensure participant confidentiality and anonymity. If anonymity is not to be preserved, explain why not.

Anonymisation (making changes to research data to keep secure original identities) of research data during the thematic analysis will ensure participant confidentiality and anonymity.

E.10.5 Will the research involve respondents to the Internet or other visual/vocal methods where they may be identified (e.g. IP address)

Yes. (We will get hold of their phone numbers to call again.)

E.10.6 Will participants be given information on the study and consent forms? Yes/No - If No, please justify

Yes

E.10.7 Will the research involve the sharing of data of confidential information beyond initial consent? Yes/No - If Yes, please explain.

No

E.10.8 Will the information be collected from participants without their knowledge and consent at the time? (e.g. secondary use or re-use of social media content; covert observation/photos of people in non-public places, etc.) .Yes/No If Yes, please justify:

No

E.10.9 Will any substance be administered to participants? Yes/No - if Yes, please explain: (Please note that substances falling under the auspices of the Medicines for Human Use (Clinical Trials) Regulations 2004 will require additional review by the NHS)

No

E.10.10 Will participants' tissue samples (including blood) be obtained? Yes/No - if Yes, please explain: (Please note that collection of tissue samples would fall under the terms of the Human Tissue Act 2004 and will require additional review by the NHS)

No

E.10.11 Is a first aider needed? Yes/No – If Yes, please identify

No

E.10.12 Will the study discuss or collect sensitive information (e.g. terrorism, sexual activity, drug use, criminal activity)? Yes/No - if Yes, please explain:

Yes - discussing a long-term health condition will be critical to the work. The need for this discussion is made clear in the information sheets.

E.10.13 Will the research involve collecting administrative or secure data that requires permission before use?Yes/No - if Yes, please explain:

No

Appendix F

Ethics Application Four

F.1 TITLE OF PROJECT

Designing technology for low-literate people with Diabetes in Pakistan

F.2 APPLICANT NAME(s)

Kehkashan Zeb

F.3 PROPOSED START DATE

1st March 2022

F.4 DURATION (months)

Three months

F.5 OBJECTIVES

Briefly state what the project is designed to achieve. This research continues the project: “Designing technology for low literate people with Diabetes in Pakistan”. This study continues the previous studies where an IVR system for diabetes was designed and developed iteratively. The purpose of this study is to deploy the outcome of the previous research – the finalized version of Sugar ka Saathi - to people with diabetes to determine its usability; therefore, the quantitative analysis of the IVR prototype is done.

F.6 LOCATION OF STUDY

F.6.1 List the country and location(s) where the data will be collected

The project's scope will be bound geographically to the Punjab, Pakistan. It is anticipated that the work will be done in a safe and secure environment on the phone. The target audience of the project will be less literate or illiterate PLWD. The final deployment of the IVR system for two months is outlined below. The server requirements will be outsourced to RAPID, as the locally working IVR on the researcher's machine will be deployed on RAPID's cloud server (The company is GDPR Compliant). The patient information access is confined only to the PhD research student, Kehkashan Zeb.

F.6.2 Identify the person(s) who will be present to supervise the research at that location

Doctoral candidate Miss. Kehkashan Zeb will be present to conduct the research.

F.7 STUDY DESIGN

F.7.1 Outline the study design (e.g. cross-section, longitudinal, intervention, RCT, questionnaire etc.)

Participant Recruitment

Quantitative Study

This study consists of initially recruited 200 people with diabetes.

Participants will be recruited to receive regular helpline calls as they are recruited either on the phone or in-person by NGO 'Akhwat' in morning or evening slots. Therefore, automated calls will be scheduled at the participant's preferred time. The helpline will also accept new callers, and they will receive calls in the morning or evening slots.

The usage statistics will be recorded for every user's interaction with the helpline. That includes the in-detail logs about every step of the call.

Qualitative Study

Twenty helpline users will be recruited for this study. There are 15-minute semi-structured on-phone interviews with helpline users conducted using Skype. The interview Script will be used as a guide. The participants will be regularly called using Skype.

Methodology

The Methodology consists of the following stages:

Overview of Work Month Activity 1 Week Technical aspects of IVR Deployment. 8 Weeks IVR Deployed with Users 2 Weeks Analysis

Part A: Technical Deployment Aspects A working IVR system will be presented to participants. RAPID has deployed this prototype, and its cloud services and data will be used. Only researcher 'Kehkashan Zeb' has direct access to the data.

Part B: IVR Deployed

The IVR will be deployed for two months. 200 people with diabetes will be recruited through an NGO, 'Akhuwat' (from their diabetic clinic) and a hospital 'National Hospital Faisalabad', by filling in a survey questionnaire as shown in Appendix A. All recruited participants will receive calls in their preferred time slot: morning, afternoon, or evening. Along with these robocalls In the helpline following questions will be asked:

1. How do they find the system?
2. Was the system useful?
3. Do they want to continue using the system?
4. What features of the system do they like?
5. What features of the system do they dislike?

Part C: Analysis

The data will be analysed using quantitative and qualitative methods as shown below:

Quantitative:

The following research questions will be answered in this study:

1. Is IVR usable and accepted well amongst the target audience, and do people engage with the IVR system?

2. Which IVR feature is most frequently used, and which is less frequently used?

The usage statistics will be recorded for every user's interaction with the helpline. That includes the in-detail logs about every step of the call.

Usage Metrics

The following questions will be answered by analysing logs.

1. What are the demographics of IVR users?
2. How many people respond and engage with the IVR calls?
3. How frequently does the user call the IVR/helpline?
4. Average weekly calls, they will call back.
5. How many repeat callers are in the system? What proportion of users are repeat callers?
6. How many people visited the story system one time and did not visit again?
7. How many people listened to stories in the story section?
8. How many people recorded the stories?
9. How many people listen to stories more than once?
10. People who listened to stories did they record the feedback?
11. How many stories have positive feedback?
12. How many of them have negative feedback?
13. Does demographics play any role in IVR engagement?
14. What proportion of users find the system helpful?

Qualitative:

The following research questions will be answered in this study:

1. What is the impact of IVR usage on People with Diabetes? Does it improve to improve their knowledge about their condition? Do users need a diabetes helpline?

2. Which feature is accepted well amongst participants and why?

3. Are the helpline users like to pay a minimal amount for this service? Or is it the doctor who should provide this service?

Fifteen one-to-one interviews will be conducted with two to three participants, using an interview script.

Facilitators: 1

Recording: audio and notes on large sheets of paper.

Participants: 15 people.

Duration: 15 min.

Equipment: 2 x Audio Recording Equipment, Large Sheets of Paper to take notes on.

Room: On Phone sessions.

Recording details: The session will be recorded using voice memos.

The following questions will be asked of people with diabetes.

1. Do you have any helpful suggestions?
2. Does the helpline use affect your ability to change the Diabetes Management routine?

   (a) Do you feel guided about the Food intake?
   (b) Do you feel guided about the Exercise?
   (c) Do you have helpful suggestions about the medicine intake?
3. Do you believe that the helpline doctor's advice is beneficial?
   (a) Why do you believe so?
4. Is the Diabetes knowledge delivered by the system new to you?
   (a) Did you have access to diabetes management resources before?
5. Which helpline feature is most valuable?
   (a) Is it information?
   (b) Is it stories?
   (c) Is it Doctor's assistance?
6. Does the helpline use easy? Do you use the helpline yourself or did a family member help?
7. What do you think about the new information in every call? Like currently, there are three flows in the helpline:
   (a) Information Delivery
   (b) Co-Morbid Disease information
   (c) Story sharing section

The following questions will be asked to the Diabetes Doctor

1. What is your perception of the Diabetes helpline?
2. Do you think the IVR system brings diabetes care that eventually benefits them?
3. If this program is available to doctors, are they ready to invest some amount to purchase this service?
4. State the number and characteristics of study participants

The study will consist of at least 200 participants suffering from diabetes, are illiterate or less literate, middle to old age and belong to the province of Punjab. The study will also include two diabetes doctors from Punjab, Pakistan.

F.7.2 State the inclusion criteria for participants.

It's anticipated that different hospitals will be contacted. National Hospital based in Faisalabad city contact says they are happy to provide help like referring patients and doctors.

Moreover, less literate diabetes patients will be recruited through contacts from less-privileged areas of Faisalabad city and different rural areas in Punjab.

F.7.3 State the exclusion criteria for participants and identify any requirements for health screening

The exclusion of participants is based on criteria that people who will NOT be suffering from diabetes and will NOT have literacy levels high enough to use other readily available technology.

F.7.4 Will the study involve vulnerable populations (i.e. children, elderly, those with cognitive impairment or in unequal relationships, disabled, clinical, etc.) or people who cannot give informed consent? Yes/No – If yes, please justify.

(Please note that people with learning disabilities fall under The Mental Capacity Act 2005 and must be reviewed by the NHS; other vulnerable groups may not require NHS review but will typically require Disclosure & Barring Service (DBS) clearance (formerly CRB checks) – Evidence for this will be required.

No(The study participants are illiterate, mostly elderly, and a consent form will be read to them).

F.7.5 Will parental/coach/teacher consent be required? Yes/No - If Yes, please specify which and how this will be obtained and recorded

No.

F.7.6 Are there any requirements/commitments expected of participants (e.g. time, exertion level)?

The participants are expected to attend the workshops and telephone calls. Participants will also use the IVR system for 15 days, and their daily interaction with the IVR system will be from 0-15 minutes.

F.8 PARTICIPANT RECRUITMENT

F.8.1 Briefly outline how and from where participants will be recruited.

The participants will be recruited from hospitals in Faisalabad, Lahore, and rural areas in Punjab. We already got permission from the National Hospital Faisalabad and are planning to conduct research in rural areas after getting permission from the head of the village.

F.9 DATA COLLECTION

F.9.1 Briefly describe the type of data that will be collected

The data will be collected through notes, audio, video, and pictures.

F.9.2 Briefly describe how the data will be collected

The data will be collected using a mobile phone camera and written notes during interviews and focus groups. The data will be kept secure using password-protected storage devices like mobile phones and laptops.

F.9.3 Will the data collection be undertaken by Swansea University staff or students? Yes/No - if No, please explain who is responsible for data collection and give permit details (permit number, date, issuing body) or why these are unnecessary.

Yes. Swansea University Research student Kehkashan Zeb, along with external collaborators of research from LUMS, will undertake the collection of data.

F.9.4 Briefly describe how you propose to ensure participant confidentiality and anonymity. If anonymity is not to be preserved, explain why not.

Anonymisation (making changes to research data to keep secure original identities) of research data during thematic analysis will ensure participant confidentiality and anonymity.

F.9.5 Will the research involve respondents to the Internet or other visual/vocal methods where they may be identified (e.g. IP address)

Yes. (We will get their phone numbers so they can call again.)

F.9.6 Will participants be given information on the study and consent forms? Yes/No - If No, please justify

Yes

F.9.7 Will the research involve the sharing of data of confidential information beyond initial consent? Yes/No - If Yes, please explain

No

F.9.8 Will the information be collected from participants without their knowledge and consent at the time? (e.g. secondary use or re-use of social media content; covert observation/photos of people in non-public places, etc.) .Yes/No If Yes, please justify:

No

F.9.9 Will any substance be administered to participants? Yes/No - if Yes, please explain: (Please note that substances falling under the auspices of the Medicines for Human Use (Clinical Trials) Regulations 2004 will require additional review by the NHS)

No

F.9.10 Will participants' tissue samples (including blood) be obtained? Yes/No - if Yes, please explain: (Please note that collection of tissue samples would fall under the terms of the Human Tissue Act 2004 and will require additional review by the NHS)

No

F.9.11 Is a first aider needed? Yes/No – If Yes, please identify

No

F.9.12 Will the study discuss or collect sensitive information (e.g. terrorism, sexual activity, drug use, criminal activity)? Yes/No - If yes, please explain:

Yes - discussing a long-term health condition will be critical to the work. The need for this discussion is made clear in the information sheets.

F.9.13 Will the research involve collecting administrative or secure data that requires permission before use?Yes/No - if Yes, please explain:

No

F.10 STORAGE AND DISPOSAL OF DATA and SAMPLES

F.10.1 Briefly describe the procedures to be undertaken for storing and disposing of data and samples.

Data will be stored on a laptop, protected by passwords, by the Swansea University PhD researcher.

F.10.2 10.2. Who will be responsible for storing and disposing data and/or samples?

Swansea University Research student Kehkashan Zeb will be responsible for storing and disposing data and samples.

F.10.3 For how long will the data and/or samples be retained after completion of the study? (normally five years, or end of award)

The data and samples will be retained till the end of my PhD, which is expected to finish in 2022.

F.11 POTENTIAL RISKS AND DISCOMFORTS

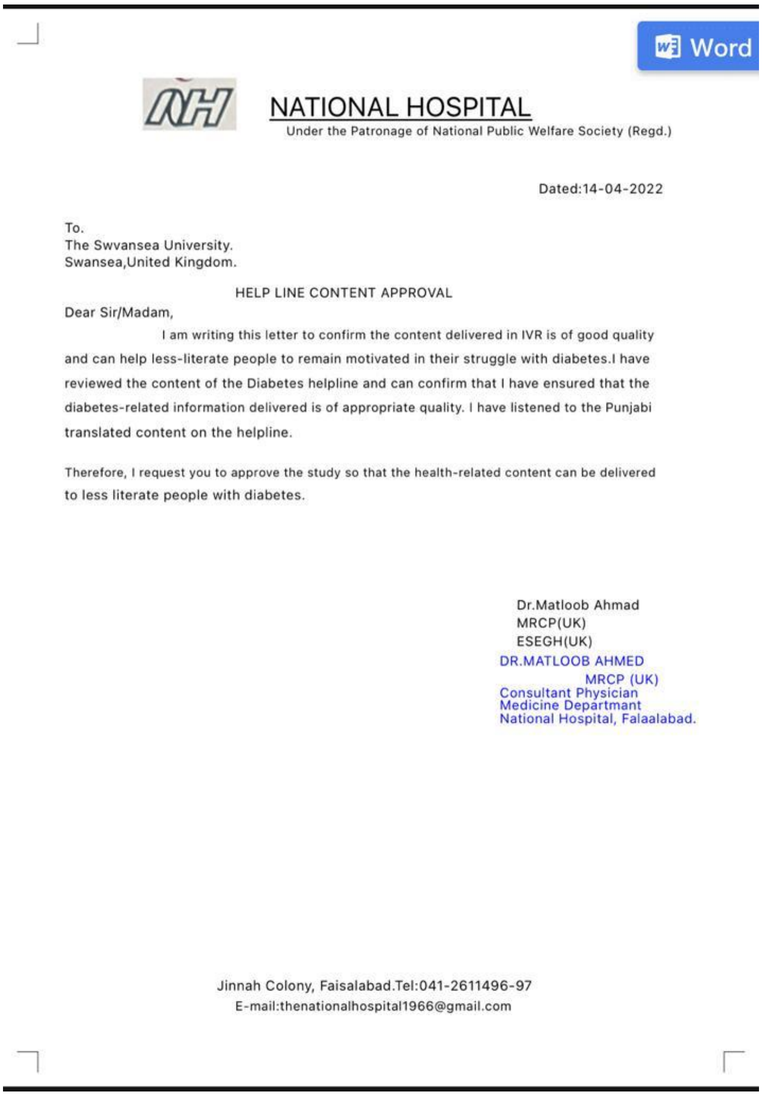
F.11.1 Are there any potential physical risks or discomforts to the participants in the study? Yes/No – if Yes, please explain

No

F.11.2 Are there any potential physical risks or discomforts to the study's researcher (s)? Yes/No – If yes, please explain

No

F.12 Appendices



Word

NATIONAL HOSPITAL
Under the Patronage of National Public Welfare Society (Regd.)

Dated:14-04-2022

To.
The Swvansea University.
Swansea,United Kingdom.

HELP LINE CONTENT APPROVAL

Dear Sir/Madam,

I am writing this letter to confirm the content delivered in IVR is of good quality and can help less-literate people to remain motivated in their struggle with diabetes.I have reviewed the content of the Diabetes helpline and can confirm that I have ensured that the diabetes-related information delivered is of appropriate quality. I have listened to the Punjabi translated content on the helpline.

Therefore, I request you to approve the study so that the health-related content can be delivered to less literate people with diabetes.

Dr.Matloob Ahmad
MRCP(UK)
ESEGH(UK)
DR.MATLOOB AHMED
MRCP (UK)
Consultant Physician
Medicine Departmant
National Hospital, Falaalabad.

Jinnah Colony, Faisalabad.Tel:041-2611496-97
E-mail:thenationalhospital1966@gmail.com

Figure F.1: National Hospital Letter

NATIONAL HOSPITAL
Under the Patronage of National Public Welfare Society (Regd.)

Dated:14-04-2022

To.
The Swansea University,
Swansea,United Kingdom.

PARTICIPANTS RECUITMENT

Dear Sir/Madam.

National Hospital Faisalabad recruit participants for this study, and while recruiting research, participants are made aware that the helpline is only providing general information about Diabetes Mellitus. If they have any adverse problems, they need to see a doctor.

Therefore.I request you to approve this studyIthat the health-related content can be delivered to less literate people with diabetes.

Thanks.

Dr.Matloob Ahmad
MRCP(UK)
ESEGH(UK)
DR.MATLOOB AHMED
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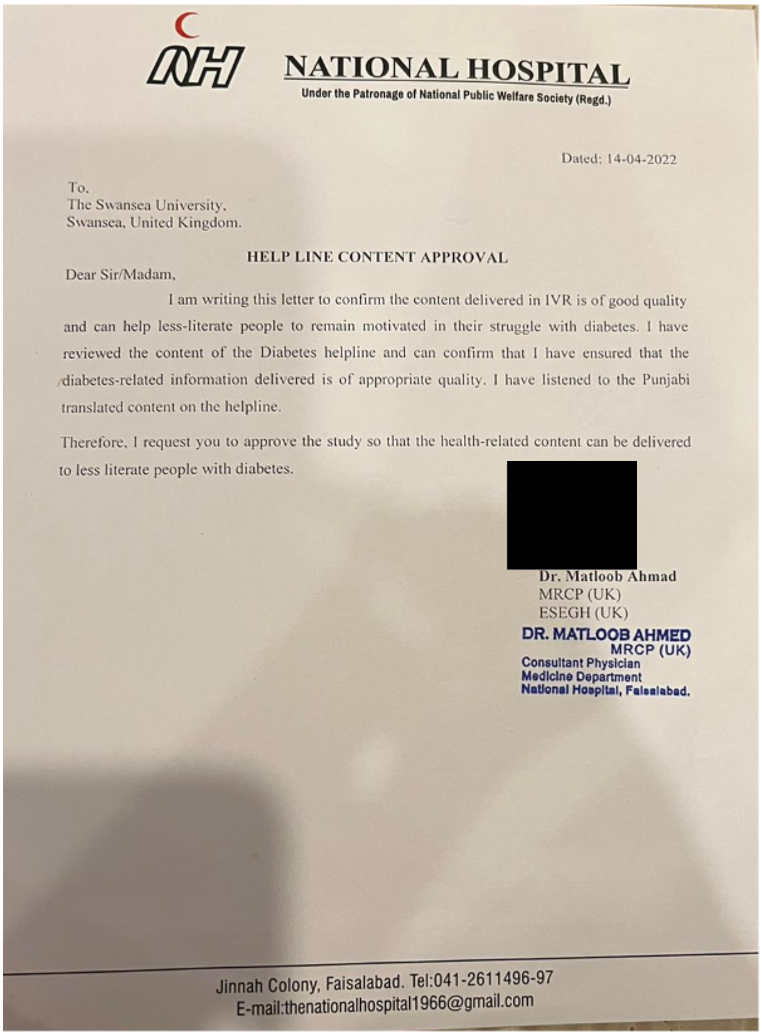
Figure F.2: National Hospital Letter



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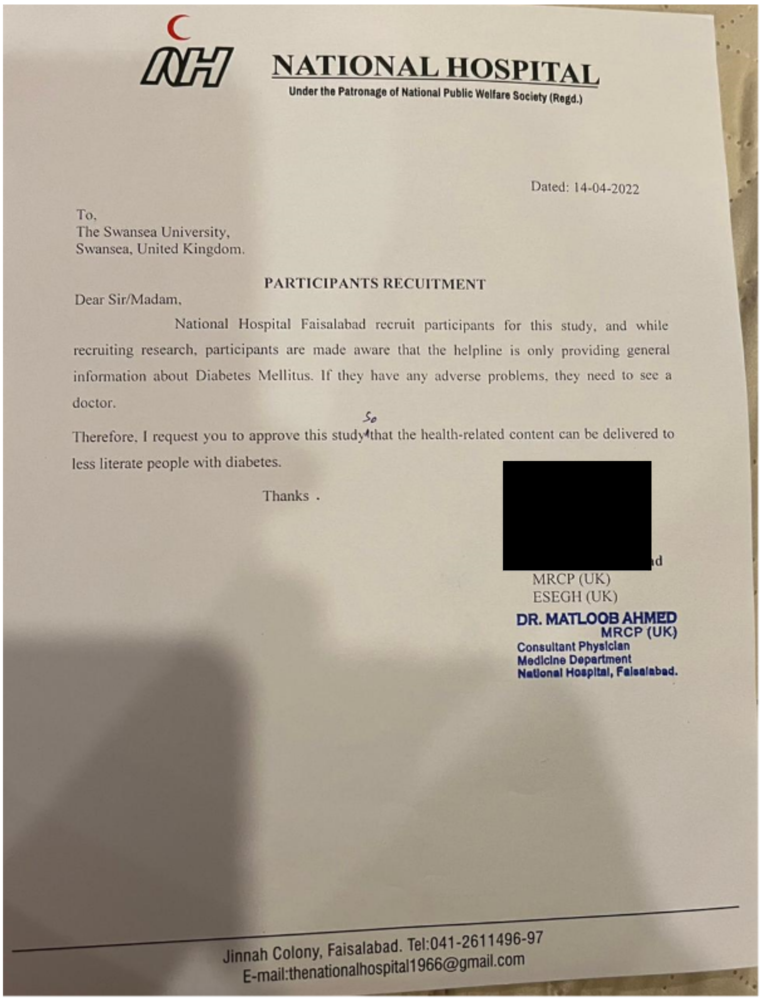

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Under the Patronage of National Public Welfare Society (Regd.)

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Thanks .

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Consultant Physician
Medicine Department
National Hospital, Faisalabad.

Jinnah Colony, Faisalabad. Tel:041-2611496-97
E-mail:thenationalhospital1966@gmail.com

Figure F.4: National Hospital Letter

Appendix G

IVR Content

The content presented in Prototype One is highlighted below:

G.1 "Sugar-ka-Saathi" Prototype One Content

My name is Anees Khan, and I am a diabetes educator who wants to educate the caller about diabetes-related health issues. I will tell you some basic information about diabetes.

However, the information I give does not replace your doctor's advice. Take the medicines as proposed by your doctor.

Medium delay 3-8 sec between choices

Diabetes Information to be delivered in the IVR System.

G.1.1 What is Diabetes

Diabetes is when the pancreas produces insufficient insulin to lower blood glucose (sugar). The body does not properly absorb it.

Types of Diabetes

Type 1

1. When insulin-producing cells are destroyed, the body stops producing insulin. Glucose levels in the blood rise as a result.
2. Science does not know why this occurs, but it is unrelated to diet or lifestyle.
3. Approximately 10

Type 2

1. The body does not make enough insulin in Type 2 diabetes, or the insulin it does make does not work properly, resulting in an accumulation of glucose in the blood.
2. A complex interplay of genetic and environmental factors leads to type 2 diabetes. A healthy lifestyle can delay or prevent up to 58% of Type 2 diabetes cases.
3. There is approximately 90 per cent of people with diabetes have type 2.

Symptoms of Diabetes

1. Repeatedly passing urine, especially at night.
2. The feeling of thirst.
3. Excessively tired.
4. Weight loss that occurs unintentionally.
5. Thrush or itching in the genital area.
6. It takes longer for minor injuries to heal.
7. Vision that is blurred

G.1.2 Your role in managing diabetes

Information about Healthy eating

Five Food groups to include in diet:

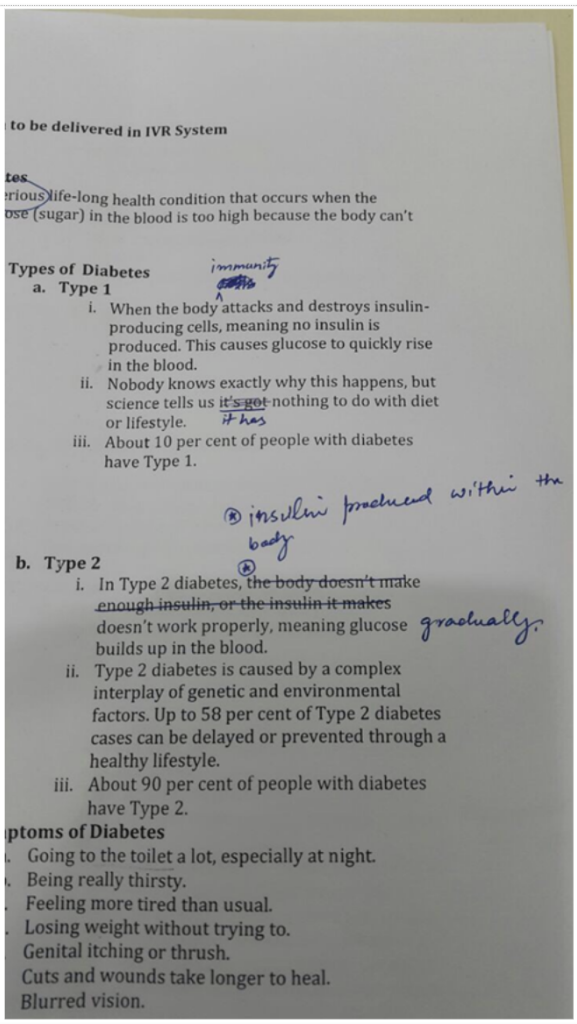
1. fruits
2. vegetables,
3. some starchy carbohydrates,
4. proteins
5. dairy, but limit the amount of fat you eat.

Healthy eating Rules to follow

1. Eat regularly, for example, breakfast, lunch and evening meal
2. Do not use refined sugar
3. Eat less fat and fatty foods. Limit the use of oil in cooking.
4. Eat less salt

Coping with Diabetes Emotionally

1. Speak to family and friends about your feelings - they may be concerned and want to assist you.
2. Encourage your family and friends to take an active role in your diabetes care and understanding - they may be able to assist you.
3. Bring someone with you to your appointment with your healthcare team, particularly if they provide you with care.
4. Get to know other people with diabetes.



to be delivered in IVR System

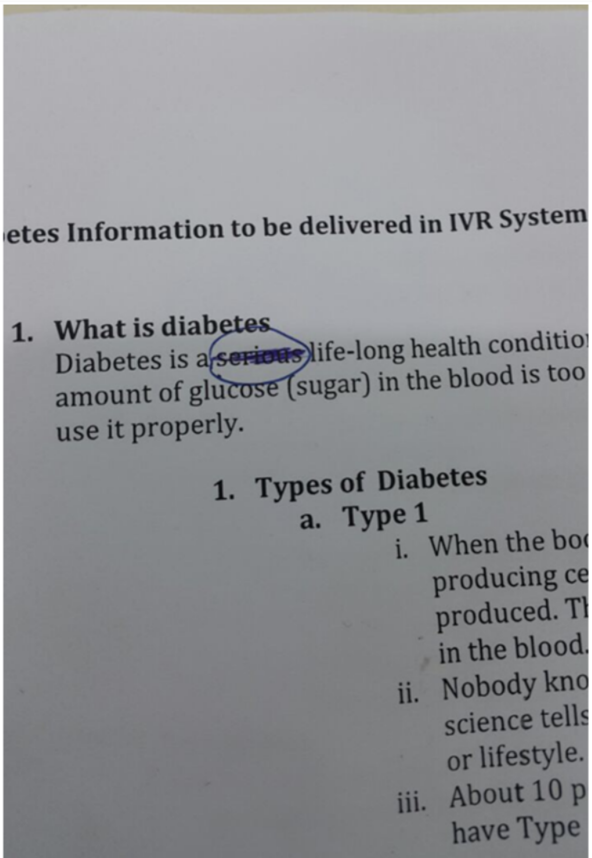
tes
rious life-long health condition that occurs when the
ose (sugar) in the blood is too high because the body can't

Types of Diabetes
a. Type 1
i. When the body immunity attacks and destroys insulin-producing cells, meaning no insulin is produced. This causes glucose to quickly rise in the blood.
ii. Nobody knows exactly why this happens, but science tells us ~~it's got~~ it has nothing to do with diet or lifestyle.
iii. About 10 per cent of people with diabetes have Type 1.

insulin produced within the body

b. Type 2
i. In Type 2 diabetes, ~~the body doesn't make enough insulin, or the insulin it makes~~ doesn't work properly, meaning glucose builds up in the blood. gradually.
ii. Type 2 diabetes is caused by a complex interplay of genetic and environmental factors. Up to 58 per cent of Type 2 diabetes cases can be delayed or prevented through a healthy lifestyle.
iii. About 90 per cent of people with diabetes have Type 2.

ptoms of Diabetes
Going to the toilet a lot, especially at night.
Being really thirsty.
Feeling more tired than usual.
Losing weight without trying to.
Genital itching or thrush.
Cuts and wounds take longer to heal.
Blurred vision.



etes Information to be delivered in IVR System

1. What is diabetes
Diabetes is a ~~serious~~ life-long health conditio
amount of glucose (sugar) in the blood is too
use it properly.

1. Types of Diabetes
a. Type 1
i. When the bo
producing ce
produced. Th
in the blood.
ii. Nobody kno
science tells
or lifestyle.
iii. About 10 p
have Type

Appendix H

Sugar-ka-Saathi Prototype Two, Three, Four Content

H.1 Diabetes Information

Prompt # 1 : Welcome to Sugar Ka Saathi.
Prompt # 2: I am your doctor here, and my team will tell you how to live with diabetes.
Prompt # 3: It is difficult to live with diabetes. During this phone call, you will receive information that will help you manage and treat your diabetes in a way that fits into your lifestyle, such as what foods to eat and how to manage your condition.
Prompt # 4 : Let's get started. We want to gather some information for you which will be stored in the Helpline.
Prompt # 5: Have you been diagnosed more than one year ago or less than one year? (Whether he needs early-stage diabetes information or late-stage diabetes information)
Prompt # 6: Press 1 for Yes
Prompt # 7: Press 2 for No
Prompt # 8:Are you literate or illiterate
Prompt # 9: Press 1 for literate
Prompt # 10: Press 2 for illiterate
Prompt # 11 : What is your gender? *
Prompt # 12: Press 1 for Male
Prompt # 13 : Press 2 for Female.
Prompt # 14: And the final question how old are you?
Prompt # 15: If you are over 65 press 1 otherwise press 2 to listen to the next choice.
Prompt # 16: If you are between 55-64 years press 1 otherwise press 2 to listen to the next choice.

1 : ذیابیطس کیا ہے؟

ذیابیطس ایک ایسی حالت ہے جس میں آپکے خون میں شوگر کی مقدار ضرورت سے زیادہ ہوجاتی ہے کیونکہ جسم اسے مناسب طور پر استعمال نہیں کر پاتا۔ ایسا اس لئے ہوتا ہے کہ لبلبہ شوگر کو جسم کے خلیوں میں داخل ہونے میں مدد دینے کیلئے انسولین پیدا نہیں کرتا یا پھر انتہائی ناکافی انسولین پیدا کرتا ہے جو اچھی طرح سے کام نہیں کرتی اور خون میں شوگر اکٹھی ہونا شروع ہوجاتی ہے، اس طرح ذیابیطس کا مرض ہوجاتا ہے۔ یہ بات انتہائی اہم ہے کہ ذیابیطس کا مرض صرف خون میں شوگر کی زیادتی تک ہی محدود نہیں رہتا بلکہ دھیرے دھیرے یہ مرض انسان کی تمام زندگی کو بھی متاثر کرتا ہے۔

Figure H.1: Prompt 38, 39

Prompt # 17: If you are between 45-54 years press 1 otherwise press 2 to listen to the next choice.

Prompt # 19: If you are between 35-44 years press 1 otherwise press 2 to listen to the next choice.

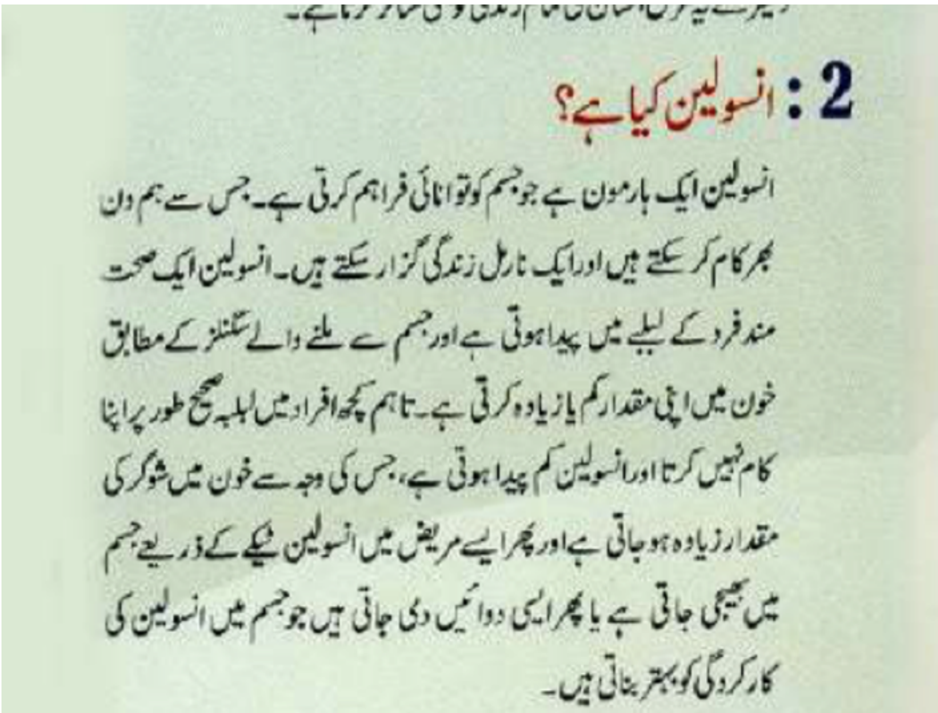
Prompt # 20: If you are between 25-34 years press 1 otherwise press 2 to listen to the next choice.

Prompt # 21: If you are between 18-24 years press 1 otherwise press 2 to listen to the next choice

Prompt # 44: Symptoms of diabetes:

Prompt # 45: The following are the diabetes symptoms:

1. Urination during the night is frequent.
2. Extreme thirst.
3. Excessively tired.
4. The act of losing weight without trying.
5. Thrush or itching in the genital area.



2 : انسولین کیا ہے؟

انسولین ایک ہارمون ہے جو جسم کو توانائی فراہم کرتی ہے۔ جس سے ہم دن بھر کام کر سکتے ہیں اور ایک نارمل زندگی گزار سکتے ہیں۔ انسولین ایک صحت مند فرد کے لبلبے میں پیدا ہوتی ہے اور جسم سے ملنے والے سگنلز کے مطابق خون میں اپنی مقدار کم یا زیادہ کرتی ہے۔ تاہم کچھ افراد میں لبلبہ صحیح طور پر اپنا کام نہیں کرتا اور انسولین کم پیدا ہوتی ہے، جس کی وجہ سے خون میں شوگر کی مقدار زیادہ ہو جاتی ہے اور پھر ایسے مریض میں انسولین ٹیکے کے ذریعے جسم میں بھیجی جاتی ہے یا پھر ایسی دوائیں دی جاتی ہیں جو جسم میں انسولین کی کارکردگی کو بہتر بناتی ہیں۔

Figure H.2: Prompt 40, 41

3 : ذیابیطس کی کتنی اقسام ہیں؟

ذیابیطس کی دو بنیادی اقسام ہیں، پہلی قسم ٹائپ 1 ہے جس میں انسولین بالکل بھی پیدا نہیں ہوتی کیونکہ لبلبے میں انسولین پیدا کرنے والے خلیے تباہ ہو جاتے ہیں جس سے جسم میں انسولین کی شدید کمی ہو جاتی ہے۔ یہ عموماً کم عمری میں ہوتی ہے کیونکہ انسولین بنانے والے خلیے دھیرے دھیرے یا پھر تیزی سے اپنا کام کرنا چھوڑ دیتے ہیں اور خون میں شوگر کی مقدار بڑھ جاتی ہے۔ ذیابیطس کی دوسری قسم ٹائپ 2 اس وقت ہوتی ہے جب جسم میں ناکافی انسولین پیدا ہو رہی ہو یا بلبہ وہ انسولین پیدا کر رہا ہو جو اچھی طرح سے کام نہ کر سکے۔ یہ قسم زیادہ تر بڑی عمر کے لوگوں میں ہوتی ہے۔

Figure H.3: Prompt 42, 43

Figure H.4: Prompt 44, 45

4 : ذیابیطس ہونے کی کیا کیا علامات ہو سکتی ہیں؟

ذیابیطس کی بنیادی علامات میں پیاس کا بڑھ جانا، بار بار پیشاب آنا، بہت
زیادہ تھکاوٹ ، وزن میں کمی، بینائی کا دھندلا جانا یا اندھا پن شامل
ہیں۔مزید پیچیدگیوں میں زیادہ بھوک لگنا، گلوکوز لیول کا بڑھ جانا یا جسم میں
شکر کی مقدار زیادہ ہو جانا، سانس کا پھولنا، چہرے کا رنگ زرد ہو جانا
، سر چکرانا، بلڈ پریشر کا بڑھنا، بے چینی محسوس ہونا، دل گھبرانا، جسم میں کپکپی
شروع ہو جانا، مریض کا وزن گرنا اور زخموں کا دیر سے بھرنا یا آرام نہ آنا شامل
ہے۔اگر یہ علامات موجود ہیں تو یہ ذیابیطس کا مرض ہے۔

Figure H.5: Prompt 30, 31

6. It takes longer for cuts and wounds to heal.
7. Vision blurred.

Prompt # 46: Why do people with diabetes experience extreme hunger?

Prompt # 47: Even after eating, you may still feel hungry. Your muscles are not receiving the energy they need from the food because your body's insulin resistance prevents glucose from entering the muscles and providing them with fuel. In order to gain more energy, muscles and other tissues send a "hunger" signal.

Prompt # 48: Why do people with diabetes experience frequent urination?

Prompt # 49: There is a connection between frequent urination and drinking so much more to satisfy your thirst. Due to the fact that you are drinking more, you will need to urinate more often. Moreover, the body will attempt to eliminate excess glucose through urination.

Prompt # 50: Why do people have these symptoms

5 : عام انسان اور ذیابیطس کے مریض میں کیا فرق ہے؟

عام انسان اور ذیابیطس کے مریض میں بنیادی فرق یہ ہے کہ عام آدمی کا جسم انسولین بنا سکتا ہے اور اس کا ضرورت کے مطابق بہتر استعمال کرتا ہے جبکہ ذیابیطس کے مریض کا لبلبہ انسولین کم مقدار میں بناتا ہے جو پوری طرح اثر بھی نہیں کرتی، یا پھر انسولین بالکل نہیں بناتا جس سے شدید بحران پیدا ہوتا ہے۔ ذیابیطس کا مریض آج کے جدید علاج اور طرز زندگی میں ضروری تبدیلیاں لا کر ایک نارمل زندگی گزار سکتا ہے۔ ذیابیطس کے فرد کی زندگی بھی ایک عام انسان کے برابر ہو سکتی ہے بشرطیکہ وہ اپنی بلڈ شوگر کو متوازن رکھے اور اپنے طرز زندگی کو بہتر بنائے۔ علاج کی ذمہ داری اپنے کندھوں پر اُٹھائے اور ڈاکٹر کے ساتھ رابطے میں رہے۔

Figure H.6: Prompt 32, 33

6 : ذیابیطس کی وجوہات کیا ہیں؟

ذیابیطس ٹائپ 1 جسم کے اندر کسی گہری "غلط فہمی اور سازش" کے نتیجے میں
ہوتی ہے۔ ذیابیطس ٹائپ 2 کی بنیادی وجوہات میں موروثی اثرات، خوش
خوراکی، موٹاپا، سستی، بلڈ پریشر، صدمہ اور ٹینشن سے بھرپور طرز زندگی شامل
ہے۔ اسی طرح میٹھا کھانے سے شوگر یا ذیابیطس نہیں ہوتی مگر زیادہ میٹھی
یا روغن والی غذائیں کھانے سے ذیابیطس ہو سکتی ہے، آپکو ذیابیطس چھوت
سے نہیں لگ سکتی جیسے زکام، حادثہ یا بیماری سے بھی ذیابیطس نہیں ہوتی مگر اس
سے علامتیں بگڑ سکتی ہیں، تاہم ذیابیطس کا مرض زیادہ تر غیر متوازن معیار
زندگی کی وجہ سے ہوتا ہے۔

Figure H.7: Prompt 34, 35

11 : آخر مجھے ہی ذیابیطس کیوں ہوئی؟

مریض کو ذیابیطس ہو جانے کا بہت رنج ہوتا ہے لیکن اسے مرض کو ذہنی طور پر
قبول کرنا چاہئے اور مرض کے ساتھ نبھاہ کی پالیسی اختیار کرنی چاہیے۔
ذیابیطس کوئی معذوری نہیں ہے اس لیے خود ترسی سے دامن بچاتے ہوئے
ذیابیطس کے ساتھ ایک نارمل زندگی کی طرف گامزن ہونا چاہئے۔ خدا کسی
انسان پر اُس کی سکت سے زیادہ بوجھ نہیں ڈالتا۔ آپ ذیابیطس میں تنہا نہیں
ہیں، آج بہترین علاج اور سہولتیں میسر ہیں۔ اہم نکتہ یہ ہے کہ ذیابیطس کے
ساتھ اپنے طرز زندگی کو بہتر بنا کر آپ خوشگوار زندگی گزار سکتے ہیں۔

Figure H.8: Prompt 36, 37

Figure H.9: Prompt 38, 39

Prompt # 51: The symptoms occur when glucose isn't used for energy because some or all of it stays in the blood. In order to reduce blood glucose levels, the body flushes excess glucose out through the urine. Thrush is caused by a fungal infection caused by high glucose levels in the urine. However, not everyone with Type 2 diabetes experiences symptoms. Six out of ten people have no symptoms.
Prompt # 52: Why do people with diabetes experience fatigue
Prompt # 53: The food you are eating does not provide your body with the energy it needs, so you may feel very tired as a result.
Prompt # 54: Why lose weight
Prompt # 55: It is possible that you are eating more but still losing weight despite eating more. As your body does not receive energy from food, it breaks down muscles and fat to produce energy. You will lose weight as a result of that.
Prompt # 56: People with diabetes feel extreme thirst. Why so

8 : ذیابیطس کو قابو میں رکھنے کے کیا فوائد ہیں؟

ذیابیطس کو قابو میں رکھنے کے لئے ہمیں کچھ چیزوں سے پرہیز کی ضرورت
ہے جن میں خوراک میں میٹھی اشیاء مثلاً مٹھائی، چاکلیٹ، بیکری کی چیزیں،
تلی ہوئی اشیاء، زیادہ مرغن غذائیں، مکھن یا گھی وغیرہ سے پرہیز کریں اور
ساتھ ہی ہری سبزیوں اور سلاد وغیرہ کا زیادہ سے زیادہ استعمال کریں۔ اس
کے ساتھ ساتھ ہلکی پھلکی ورزش یا سیر ذیابیطس کے مرض میں مبتلا مریضوں
کیلئے بہت مفید ہے۔ لیکن اگر پرہیز اور ورزش سے بھی کام نہ بنے یا مرض کی
شدت شدید ہو جائے تو ایسے میں ڈاکٹر ادویہ یا انسولین تجویز کرتے ہیں جن
کا استعمال لازم ہے۔

Figure H.10: Prompt 40, 41

9 : کیا شوگر کی سطح ضرورت سے کم بھی ہو سکتی ہے؟

خون میں شوگر کی سطح کا کم ہونا یا ہائپو تب ہوتا ہے جب آپ کے جسم میں
انسولین یا ادویات کی مقدار زیادہ ہو جائے اور خوراک کے حوالے سے کوئی
کوتاہی برتی گئی ہو۔ جب آپ کے جسم میں کاربوہائیڈریٹ ناکافی ہوں اور
جسمانی سرگرمی زیادہ ہو تو آپ ہائپو کی حالت میں چلے جائیں گے۔ اسی
طرح اگر مریض اپنی دوا یا انسولین مقررہ مقدار سے زیادہ لے یا لاپروائی
برتے تو بھی خون میں شوگر کی سطح ضرورت سے کم ہو سکتی ہے۔ ہائپو میں چند
علامات اہم ہیں جس میں شدید بھوک، بے چینی محسوس ہونا، پسینے سے شرابور
ہو جانا، ہاتھ پاؤں کا لڑکھڑانا، سر چکرانا یا تھکاوٹ محسوس ہونا شامل ہیں۔

Figure H.11: Prompt 42, 43

Prompt # 57: No matter how much water you consume, you are dehydrated. A high level of glucose in your blood causes your tissues (such as your muscles) to become dehydrated. Consequently, the body will pull fluid from the tissues in order to dilute the blood and counteract the high glucose levels, resulting in the dehydration of tissues. Urination is also increased as a result of this condition.
Prompt # 58: How the symptoms of diabetes develop
Prompt # 59: In the early stages of type 2 diabetes (also referred to as type 2 diabetes mellitus), the symptoms may seem unrelated. It is not uncommon for some people to be surprised when they are diagnosed with type 2 diabetes because they have gone to their doctor for another reason (e.g., fatigue or increased urination).
Prompt # 60: Press 1 to listen again
Prompt # 61: Press 2 to listen to the next prompt
Prompt # 62: Press 3 to return to the main menu
Prompt # 63: Press 1 to listen <information prompt title>
Prompt # 64: Press 2 to listen <information prompt title>
Prompt # 65: Press 3 to listen <information prompt title>
Prompt # 66: Press 4 to listen <information prompt title>
Prompt # 67: Diabetes-Related Complications
Prompt # 68: Eye Disease
Prompt # 69: Maintain a tight control of blood glucose levels to prevent eye disease
Prompt # 70: It is possible that you may experience temporary blurring of vision or worsening of your eye condition when your blood glucose returns to normal. However, over time, this will resolve. As a result of good blood glucose control, eye disease (retinopathy) will not progress and worsen over time.
Prompt # 71: After laser therapy on my eyes, should I stop exercising?
Prompt # 72: Following laser therapy for retinopathy, you should refrain from exercising for one month. It is important to keep in mind that blood vessels are fragile, and excessive pressure may cause ruptures or bleeding. There is no harm in taking a brisk walk. However, avoid eye-straining sports such as weightlifting, underwater diving, and tennis.
Prompt # 73: Why blurry vision
Prompt # 74: You may experience a drop in your vision as your body attempts to increase the amount of fluid in your blood to counteract a high blood glucose level. As a result, you may experience blurry vision due to difficulty focusing.

Prompt # 75: Heart disease

Prompt # 76: Why prescribed cholestrol-lowering drugs

Prompt # 77: As compared to the general population, people with diabetes are more likely to develop heart disease. Even diabetics who have borderline high cholesterol levels should receive lipid-lowering drugs since high cholesterol is another risk factor for heart disease.

Prompt # 78: What are the benefits of taking low-dose aspirin?

Prompt # 79: Low-dose aspirin (72-100 mg) is prescribed as a means of preventing heart attacks. Heart disease and stroke are more likely to occur in diabetic patients. The effect of aspirin is to thin the blood and prevent the formation of clots.

Prompt # 80:Feet

Prompt # 81:Why slow wound healing

Prompt # 82: The healing of wounds (even small cuts) may take longer than usual as a result of the body's inability to fight off infections. It is important to keep in mind that high blood glucose levels negatively affect the function of white blood cells (which are responsible for healing wounds).

Prompt # 83 : Why take care of feet

Prompt # 84:Diabetic neuropathy is a condition that causes numbness in the feet of diabetic patients. Due to this, they aren't aware of pain. Walking barefoot on hot floors or soaking in warm water can burn their feet. Shoes that are too tight can cause blisters without the wearer noticing. If you want to take care of your feet, never go barefoot, wear comfortable shoes that don't pinch, and examine them for sores, cracks, or blisters every day. Maintain healthy feet by cleaning them daily, applying moisturizer, and not cutting the nails too short. Every time you visit your doctor, ask him or her to examine the sensations in your feet. Podiatrists can help you if your toenails have grown or if you have calluses.

Prompt # 85: Sex and diabetes

Prompt # 86: Is diabetes associated with sexual problems?

Prompt # 87: Some patients with long-standing or uncontrolled diabetes may experience problems with erections in males and females may experience pain or reduced orgasm as a result of a dry vaginal environment. Consult your diabetes doctor if you have any questions regarding these issues. By controlling blood glucose levels, managing stress, and taking certain medications, they can be managed. An erection can be maintained by using estrogen creams or lubricants for women, and an erection can be maintained by use of drugs which increase blood flow for men.

Prompt # 88: Sick

Prompt # 89: What should I eat when I'm sick?

Prompt # 90: If you have a fever, flu, or stomach problem, you should continue taking your diabetes medicines. Blood glucose levels will rise during illness stress, so do not discontinue your diabetes medication during the illness. Taking small meals or snacks at regular intervals will help you maintain your energy level. The following foods can be considered healthy: soups, fruit juices, yoghurt, fruit, half a cup of ice cream, pudding, and rice. Water, juice, and soup should be consumed in sufficient quantities to prevent dehydration.

Prompt # 91: Why Frequent infections

Prompt # 92: You may experience frequent infections as a result of the effects of type 2 diabetes on your body's ability to fight infection. Infections of the vaginal region (yeast) and/or the bladder are common among women. When blood glucose levels are high, bacteria can flourish.

Prompt # 93: How to deal with infections

Prompt # 94: Diabetes does not ensure that you will become ill more frequently than others, but if your diabetes is not properly managed, you may become more susceptible to infections. Take care of yourself if you are not feeling well, and seek medical attention if necessary. Unwellness can result in high blood glucose levels (also called blood sugar levels) despite the fact that you are not eating. Infections and illness are fought by your body through this mechanism. High blood sugar levels can be caused by a variety of illnesses including colds, flu, chest infections, such as bronchitis, urinary tract infections, such as cystitis, vomiting and diarrhea, and skin infections, such as boils and abscesses. Blood sugar levels that are high can cause symptoms such as thirst, passing more urine than usual, fatigue, and a high level of sugar in the blood or urine.

Prompt # 94a: In spite of the fact that you may not enjoy eating your meals as usual when you are ill, you should still consume carbohydrates to sustain your energy. Staying hydrated is also essential, so consume plenty of sugar-free fluids. It is recommended that you consume 2.5-3.5 liters (4- 6 pints) of water per day. When you begin to vomit or are unable to drink fluids, seek medical attention immediately.

Prompt # 95: How to manage diabetes

Prompt # 96: Social impact of diabetes

Prompt # 97: I have observed that my wife has become the 'diabetic police'. She constantly instructs me on what to do and what not to do. I am irritated by this behavior; what can I do to stop it?

Prompt # 98: Generally, your family members or spouse will attempt to control your eating habits and exercise because they love you and do not want you to suffer from complications caused by diabetes. Your inaction on their advice frustrates them, as does their policing. In order to manage your diabetes in a friendly and stress-free environment, you should sit down with them and discuss what they expect from you and what type of help you would appreciate.
Prompt # 99: Exercise
Prompt # 100: In the event that I do not enjoy exercising, what should I do?
Prompt # 101: Start with a few minutes of physical activity every day, such as five minutes, and work your way up to 30 minutes every day if you don't like exercise. It would be advisable for you to choose an activity that you are interested in, such as brisk walking, swimming, dancing, or aerobics. You may take your dog for a walk or play with your grandchildren on a daily basis. In addition to exercising, you can also enjoy other pleasant activities such as listening to music or talking on the phone while you are exercising. Make arrangements to accompany a friend or member of your family. In your daily routine, you can increase your level of physical activity by taking the stairs rather than the elevator and walking to the local supermarket rather than driving.
Prompt # 102: Why warm up and cool down important in exercise
Prompt # 103: For the first five minutes after beginning your exercise program, you should warm up your muscles by walking or stretching the joints; this will increase blood flow to the joints and gradually raise your heart rate to 20% of your target rate. After that, you may begin your regular exercise routine. Exercises should be warmed up in order to reduce the risk of injury to muscles or joints. It is recommended that you cool down and stretch your joints after exercising, aerobics or brisk walking for five minutes. In addition to preventing sore muscles after exercise, it will also help to restore a normal heart rate after physical activity.
Prompt # 104: Food
Prompt # 105: Why sweat while eating food
Prompt # 106: It is common for autonomic neuropathy to develop after years of uncontrolled diabetes. The patient begins to sweat while eating food, which is one of its symptoms. Diabetes-related nerve damage is the cause of this condition. This condition cannot be treated with a specific medicine. In order to avoid excessive sweating, it is important to maintain good blood glucose control and avoid foods that cause excessive sweating
Prompt # 107: Is it ok to eat sugar

Prompt # 108: You don't have to eliminate sugar from your diet completely if you have diabetes. Sugary foods can be enjoyed occasionally as part of a healthy, balanced diet, and it's not a problem to include them as a treat. A hypo, or low blood glucose level, can be treated with sugary drinks or glucose tablets for some people with diabetes. In spite of this, we are consuming too much sugar, which in turn is harming our health. It can be difficult to control your diabetes if you are overweight, and you may also increase your risk of developing serious health problems such as heart disease and stroke in the future. . Prompt # 109: Glucose
Prompt # 110: Medicine
Prompt # 111: Diabetes complications and insulin
Prompt # 112: There is a common misconception that patients develop complications of diabetes as soon as they begin taking insulin. As a matter of fact, they begin to take insulin after some complications have occurred. If blood glucose is not controlled for five to ten years, complications may develop. By controlling blood glucose tightly with insulin, complications can be avoided. In order to prevent complications, it is better to initiate insulin therapy earlier rather than later.
Prompt # 113: The temperature at which insulin should be stored
Prompt # 114: If insulin containers have been opened more than a month ago, it is recommended that they should be used within that time period. Temperatures that are too high or too cold should not be applied to insulin. Insulin that is frozen or overheated becomes ineffective. In the summer, it is best to keep it in the refrigerator, and in the winter, it should be kept at room temperature. In order to prevent insulin from becoming too hot in the vehicle, keep it in a cooler when traveling. Don't pack insulin in your luggage if you are traveling by air or over long distances as it may be misplaced or you may require it before arriving at your destination. Insulin may be exposed to extreme temperatures and temperatures in the luggage compartment.
Prompt # 115: insulin and diabetes medicines cause weight gain
Prompt # 116: When your blood glucose level is too high you are excreting glucose in the urine, in that way number of calories is lost, and so you lose weight. But in the long term, it damages the kidneys and other vital organs. When you start insulin or medicines o the sulphonylurea group (glibenclamide, gliclazide, glipizide) you may gain weight initially as urine glucose loss is stopped. Insulin is an anabolic hormone that builds up muscles by protein deposition so you may gain a few pounds. But you can maintain your weight by reducing your diet and increasing exercise

Prompt # 117: Glucose reading types
Prompt # 118: Why is my HbA1c high when my fasting blood glucose is normal?
Prompt # 119: HbA1c gives you an average record of blood glucose over a period of 3 months. Whereas fasting blood glucose is the level at that point in time when you check blood glucose. Even when your fasting glucose is normal, there may be other times when your blood glucose is high for example 2 hours after a meal or during the night. You can check several times during the day or night to find out when your blood glucose is higher than normal and then work with your doctor to adjust meals or medicine doses to maintain proper steady control.
Why 3 months 117-19
translation of hyperglycemia 123-126
Translation of hypoglycemia
Prompt # 120: High and uncontrolled diabetes
Prompt # 121: What to do If high before starting a meal
Prompt # 122: If your blood glucose is too high before a meal, it means your liver is releasing stored glucose. In that case, you should take your insulin shot so that it signals the liver to stop releasing glucose into the blood. Wait for 60-90 min after insulin (instead of the regular 20-30 min wait) before you start your meal so that insulin gets a head start and normalizes blood glucose levels before you eat food.
Prompt # 123: What to do if sugar is high after treatment hyperglycemia
Translation of hyperglycaemia
Prompt # 124: When you have low blood sugar, your body releases hormones that try to raise blood sugar by releasing stored glucose or fats in the body. Secondly, when you eat something sweet to treat hypoglycemia, it may be more than what is required. Both factors combined together can raise blood glucose more than required. It is advised to take only 15-20 gram of carbohydrates like half a glass of juice or glucose tablets and recheck blood glucose level after 15-20 min to see if it is corrected
Prompt # 125: Can i eat sweets with hyperglycemia
Prompt # 126: When you have low blood sugar, your body releases hormones that try to raise blood sugar by releasing stored glucose or fats in the body. Secondly, when you eat something sweet to treat hypoglycemia, it may be more than what is required. Both factors combined together can raise blood glucose more than required. It is advised to take only 15-20 grams of carbohydrates like half a glass of juice or glucose tablets and recheck blood glucose level after 15-20 min to see if it is corrected

Prompt # 127: leg pain when I walk
Prompt # 128: The blood vessels supplying your legs tend to become narrow with time in diabetic patients. Thi leads to the inadequate blood supply to leg muscles when you walk hence the pain. This pain is relieved when you take rest. This is called intermittent indication. Your doctor will advise you to walk till you start having pain in your legs then rest for a few minutes and then start walking again, in this way you can increase your pain-free walking distance gradually. Another reason can be sore muscles due to fatigue, such pain will improve with rest.
Prompt # 129: Why do i sweat profusely while eating
Prompt # 130: After some years of uncontrolled diabetes, a complication called autonomic neuropathy develops. One of its symptoms is gustatory sweating, in which the patient starts to sweat while eating food. The cause is nerve damage due to long-standing diabetes. There is no specific medicine to treat this condition. You should keep good control of blood glucose and avoid certain foods that cause more sweating
Prompt # 131: feet burn at night
Prompt # 132: The burning sensation in the feet is caused by painful peripheral neuropathy. It is due to damage to nerves supplying your feet caused by persistent high blood glucose levels. Some patients also experience pins and needle sensations or leg cramps. These symptoms are more pronounced at night because there is nothing else to distract you at that time. It can be prevented by maintaining good glucose control. Once developed, neuropathy can benefit from anti-depressant medicines, vitamins or capsaicin cream (made from chillies)
Prompt # 133: Hepatitis B C,
Prompt # 134: Blood pressure
Prompt # 135: Heart disease
Prompt # 136: Obesity
Prompt # 137: Kidney disease
Prompt # 138: Peripheral vascular disease
Prompt # 139: Eye diseases
Prompt # 140: Cerebral vascular disease
Prompt # 141: TB
Prompt # 142: Smoking
Prompt # 143: Heart burn and diabetes

H.2 Smoking

Prompt # 144: Smoking

Prompt # 145: Do you smoke press 1 for yes and press 2 for no

Prompt # 146: Now let me tell you about smoking

Prompt # 147: It is no secret that smoking is bad for your health. Smoking hurts your lungs and your heart.

Prompt # 148: It lowers the amount of oxygen that gets to your organs, raises your badcholesteroland raises yourblood pressure. All of these can raise your risk of heart attack orstroke.

Prompt # 149: If you don't smoke, that's great. Make a plan to never start.

Prompt # 150: If you do smoke, there is something you can do: challenge yourself to quit smoking. Here are some steps to help you do it.

Prompt # 151: Let me tell you about the benefits of quitting smoking

Prompt # 152: Quitting helps your heart and lungs—and it lowers the risk of hurting your blood vessels, eyes, nerves and other organs. And quitting smoking can leave you with fewer wrinkles on your face; better-smelling hair, breath, and clothes; and less exposure for your family to secondhand smoke

Prompt # 153: Let me tell you about how to Prepare to quit smoking

Prompt # 154: Quitting is hard work, so approach it like any major project. Before you quit.

Prompt # 155: Set a quit date, and tell your friends and family. Make this a time when your life is fairly calm and stress levels are low.

Prompt # 156: Think of your reasons for quitting, and try to remember these reasons daily. You can also record these reasons in your mobile and listen to them daily.

Prompt # 157: Throw away your cigarettes, matches, lighters and ashtrays.

Prompt # 158: Ask others for their help and understanding. Ask a friend who smokes to consider quitting with you.

Prompt # 159: Let us discuss about how to choose a quitting strategy

Prompt # 160: Go cold turkey. Quitting all at once works for some people.

Prompt # 161: Taper off. Quit smoking gradually by cutting back over several weeks.

Prompt # 162: Use a nicotine patch, gum, inhaler or spray. Or ask your doctor for a prescription medicine.

Prompt # 163: When you stop smoking, you'll feel healthier right away, and you'll be healthier for the rest of your life.

H.3 Hepatitis

Prompt # 164: Hepatitis is the term used to describe inflammation of the liver. It's usually the result of a viral infection or liver damage caused by drinking alcohol.

Prompt # 165: There are several different types of hepatitis, most of which are outlined below.

Prompt # 166: If symptoms do develop, they can include: muscle and joint pain a high temperature feeling and being sick feeling unusually tired all the time a general sense of feeling unwell loss of appetite tummy pain dark urine pale, grey-coloured poo itchy skin yellowing of the eyes and skin (jaundice)

Prompt # 167: Long-term (chronic) hepatitis also may not have any obvious symptoms until the liver stops working properly (liver failure) and may only be picked up during blood tests.

Prompt # 168: In the later stages, it can cause jaundice, swelling in the legs, ankles and feet, confusion, and blood in your stools or vomit.

Prompt # 169: Hepatitis A is caused by the hepatitis A virus. It's usually caught by consuming food and drink contaminated with the poo of an infected person and is most common in countries where sanitation is poor.

Prompt # 170: Hepatitis A usually passes within a few months, although it can occasionally be severe and even life-threatening.

Prompt # 171: There's no specific treatment for it, other than to relieve symptoms like pain, nausea and itching.

Prompt # 172: Vaccination against hepatitis A is recommended if: you're at high risk of infection or severe consequences of infection if you're travelling to an area where the virus is common, such as the Indian subcontinent, Africa, Central and South America, the Far East and eastern Europe.

Prompt # 173: Hepatitis B is caused by the hepatitis B virus, which is spread in the blood of an infected person. It's a common infection worldwide and is usually spread from infected pregnant women to their babies, from child-to-child contact. In rare cases, it can be spread through unprotected sex and injecting drugs.

Prompt # 174: Hepatitis B is uncommon in the UK. Most cases affect people who became infected while growing up in parts of the world where the infection is more common, such as southeast Asia and sub-Saharan Africa.

Prompt # 175: Most adults infected with hepatitis B are able to fight off the virus and fully recover from the infection within a couple of months.

Prompt # 176: But most people infected as children develop a long-term infection. This is known as chronic hepatitis B, and can lead to cirrhosis and liver cancer. Antiviral medication can be used to treat it.
Prompt # 177: Hepatitis C is caused by the hepatitis C virus and is the most common type of viral hepatitis in the UK.
Prompt # 178: It's usually spread through blood-to-blood contact with an infected person.
Prompt # 179: Poor healthcare practices and unsafe medical injections are the main way it's spread
Prompt # 180: Hepatitis C often causes no noticeable symptoms, or only flu-like symptoms, so many people are unaware they're infected.
Prompt # 181: Around 1 in 4 people will fight off the infection and be free of the virus. In the remaining cases, it'll stay in the body for many years.
Prompt # 182: This is known as chronic hepatitis C and can cause cirrhosis and liver failure.
Prompt # 183: Chronic hepatitis C can be treated with very effective antiviral medications, but there's currently no vaccine available.

H.4 Heart Attack

Prompt # 184: A heart attack (myocardial infarction or MI) is a serious medical emergency in which the supply of blood to the heart is suddenly blocked, usually by a blood clot.
Prompt # 185: A heart attack is a medical emergency. Dial 999 and ask for an ambulance if you suspect a heart attack.
Prompt # 186: A lack of blood to the heart may seriously damage the heart muscle and can be life-threatening.
Prompt # 189: Symptoms of a heart attack can include:

1. chest pain – the chest can feel like it's being pressed or squeezed by a heavy object, and pain can radiate from the chest to the jaw, neck, arms and back
2. shortness of breath
3. feeling weak and/or lightheaded
4. the overwhelming feeling of anxiety

Prompt # 190: It's important to stress that not everyone experiences severe chest pain; the pain can often be mild and mistaken for indigestion.
Prompt # 191: The combination of symptoms is important in determining whether a person is having a heart attack and not the severity of chest pain.

Prompt # 192: While waiting for an ambulance, it may help to chew and swallow an aspirin tablet (ideally 300mg) – as long as the person having a heart attack isn't allergic to aspirin.
Prompt # 193: The aspirin helps to thin the blood and reduce the risk of a heart attack.
Prompt # 194: Recovering from a heart attack
Prompt # 195: The time it takes to recover from a heart attack will depend on the amount of damage to the heart muscle. Some people are well enough to return to work after two weeks. Other people may take several months to recover.
Prompt # 196: The recovery process aims to: reduce your risk of another heart attack – through a combination of lifestyle changes, such as eating a healthy diet, and medications, such as statins (which help lower blood cholesterol levels) gradually restore your physical fitness – so you can resume normal activities (known as cardiac rehabilitation)
Prompt # 197: Most people can return to work after having a heart attack, but how quickly depends on your health, the state of your heart and the type of work you do.
Prompt # 198: Complications of a heart attack can be severe and possibly life-threatening.
Prompt # 199: These include arrhythmia – is an abnormal heartbeat, where the heart begins beating faster and faster, then stops beating (cardiac arrest)
Prompt # 200: cardiogenic shock – where the heart's muscles are severely damaged and can no longer contract properly to supply enough blood to maintain many body functions heart rupture – where the heart's muscles, walls or valves split apart (rupture)
Prompt # 201: These complications can occur quickly after a heart attack and are a leading cause of death.
Prompt # 202: Many people die suddenly from a complication of a heart attack before reaching the hospital, or within the first month after a heart attack.
Prompt # 203: The outlook often depends on: age – serious complications are more likely as you get older
Prompt # 204: the severity of the heart attack – how much of the heart's muscle has been damaged during the attack
Prompt # 205: how long it take before a person received treatment – treatment for a heart attack should begin as soon as possible
Prompt # 206: Preventing a heart attack
Prompt # 207: There are five main steps you can take to reduce your risk of having a heart attack (or having another heart attack):

1. smokers should quit smoking

2. lose weight if you’re overweight or obese
3. take regular exercise – adults should do at least 150 minutes (2 hours and 30 minutes) of moderate-intensity aerobic activity each week unless advised otherwise by the doctor in charge of your care
4. eat a low-fat, high-fibre diet, including whole grains and plenty of fresh fruit and vegetables (at least five portions a day)

Appendix I

Full IVR Deployment

I.1 Quantitative Study

I.1.1 Background

The PhD research project focuses on supporting people with Diabetes in the self-management of their condition. The prevalence of Diabetes and scarcity of resources such as doctors and medicine give self-management strategies such as appropriate food and regular exercise primary importance. However, adherence to a self-management routine needs lifelong motivation from people with diabetes.

ICT for Development has the potential to help people with diabetes in better management of their condition by keeping them motivated and engaged in their self-care regime. The PhD project arranged Participatory Design (PD) sessions to involve people with Diabetes in technology design. Participatory Design shows that People with low literacy have difficulty using technology. Additionally, the use of smartphones is not expected due to accessibility issues. Therefore, an Interactive Voice Response (IVR) system has been designed iteratively using PD methodologies, which can be used on any phone.

I.1.2 Research Goal

This study continues the previous studies where an IVR system for diabetes was designed and developed iteratively. The purpose of this study is to deploy the outcome of the last research – the finalised version of Sugar-ka-Saathi - to people with diabetes to determine its usability; therefore, the quantitative analysis of the IVR prototype is done.

I.1.3 Research Questions

The following research questions will be answered in this study:

1. Is IVR usable and accepted well amongst the target audience, and do people engage with the IVR system?
2. Which IVR feature is most frequently used, and which is less frequently used?

I.1.4 Method Recruiting

This study consists of recruiting 200 people with diabetes.

Participants will be either recruited to receive regular IVR calls as they are recruited either on the phone or in-person by NGO ‘Akhwat’ in the morning or evening slots. Therefore, automated calls will be scheduled at the participant’s preferred time. The IVR will also accept new callers, and they will receive calls in the morning or evening slots.

The usage statistics will be recorded for every user’s interaction with the IVR. That includes the in-detail logs about every step of the call.

I.1.5 Usage Metrics

Analysing logs will answer the following questions.

1. What are the demographics of IVR users?
2. How many people respond and engage with the IVR calls?
3. How frequently does the user call the IVR/IVR?
4. Average weekly calls, they will call back.
5. How many repeat callers of the system? What proportion of users are repeat callers?
6. How many people visited the story system one time ever and did not visit again?
7. How many people listened to stories in the story section?
8. How many people recorded the stories?
9. How many people listen to stories more than once?
10. People who listened to stories did they record the feedback?
11. How many stories have positive feedback?
12. How many of them have negative feedback?
13. Does demographics play any role in IVR engagement?
14. What proportion of users find the system helpful?

I.2 Qualitative Study

I.2.1 Background

The PhD research project focuses on supporting people with Diabetes in the self-management of their condition. The prevalence of Diabetes and scarcity of resources such as doctors and medicine give self-management strategies such as appropriate food and regular exercise primary importance — however, adherence to a self-management routine needs lifelong motivation from people with diabetes.

ICT for Development has the potential to help people with diabetes in better management of their condition by keeping them motivated and engaged in their self-care regime. The PhD project arranged Participatory Design (PD) sessions to involve people with Diabetes in technology design. Participatory Design shows that People with low literacy have difficulty using technology. Additionally, the use of smartphones is not expected due to accessibility issues. Therefore, an Interactive Voice Response (IVR) system has been designed iteratively using PD methodologies, which can be used on any phone.

I.2.2 Research Goal

This study continues the previous studies where an IVR system for diabetes was designed and developed iteratively. This study aims to present the outcome of the previous research – the finalised version of Sugar ka Saathi to people with diabetes to verify its usability.

I.2.3 Research Questions

The following research questions will be answered in this study:

1. What is the impact of IVR usage on People with Diabetes? Does it improve to improve their knowledge about their condition? Do users need a diabetes IVR?
2. Which features are accepted well amongst participants and why?
3. Are IVR users like to pay a minimal amount for this service? Or is it the doctor who should provide this service?

I.2.4 Method Recruiting

I.2.5 Survey Script

Introduction

My name is Kehkashan. Thank you very much for participating in this study. This study is about knowing your feedback for the diabetes IVR, how you find it and how you think it can be improved.

Would you mind if I recorded this session for note-taking purposes? We will not share the recording with anyone outside of our team.

Questions

The following questions will be asked of people with diabetes.

1. Do you have any helpful suggestions?
2. Does the IVR use affect your ability to change the Diabetes Management routine?
3. Do you feel guided about the Food intake?
4. Do you feel guided about the Exercise?
5. Do you have helpful suggestions about the medicine intake?
6. Do you believe that the IVR doctor's advice is beneficial?
7. Why do you believe so?
8. Is the Diabetes knowledge delivered by the system new to you?
9. Did you have access to diabetes management resources before?
10. Which IVR feature is most valuable?
11. Is it information?
12. Is it stories?
13. Is it Doctor's assistance?
14. Does the IVR use easy? Do you use the IVR yourself or did a family member help?
15. What do you think about the new information in every call? Like currently, there are three flows in the IVR:
16. Information Delivery
17. Co-Morbid Disease information
18. Story sharing section

The following questions will be asked to the Diabetes Doctor

1. What is your perception of the Diabetes IVR?
2. Do you think the IVR system brings diabetes care that eventually benefits them?

3. If this program is available to doctors, are they ready to invest some amount to purchase this service so that

Wrap-up I appreciate you sharing your experience and insights with me. We will be able to build a better product with your assistance. Please let me know if you have any additional thoughts or comments at any time. I can be reached at 806259@swansea.ac.uk; I hope you have a wonderful day.

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