8. A HEALTH INFORMATICS MODEL FOR USER-CENTRED DESIGN USING A POSITIVE DEVIANCE APPROACH: A CASE FOR DIABETES SELF-MANAGEMENT

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1 Abstract

Over the past twenty years there have been substantive efforts across the African continent to ensure penetration and reach of mobile technology to the citizenry. However there continues to be a debate on precisely how developmental outcomes may be forged through this escalating penetration of communications technologies. This paper responds to the question of how development outcomes in the area of health, and specifically that of diabetes mellitus, can be achieved through the effective application of ICTs in the context of mobile applications.

Diabetes Mellitus is a leading cause of morbidity in low-income and middle-income countries, with the number of patients projected to increase globally to 205 million by 2035. The increased number of patients in countries with limited resources requires innovative approaches to support a regime of patient self-management. In pursuance of this, and given the increasing pervasiveness of communications infrastructure amongst communities in South Africa, the role of Information and communications technology (ICT) in addressing the problem requires investigation. In particular, issues in relation to the adoption and effective use of ICTs, especially amongst previously disadvantaged and underserved communities, warrants exploration.

The paper thus assesses the role of m-health at primary care level and posits a user-centred design approach to involve patients in designing an m-health intervention which meets their needs.

2 Keywords

Information Communication and Technology (ICT), Information Communication and Technology for development (ICT4D), user-centred design (UCD), positive deviance, mobile health (m-health), diabetes self-management

3 Introduction

Over the past decade, governments across Africa have been hard pressed to create enabling policies to realize the goals of the Information Society. As a result we have witnessed substantive efforts across the continent to ensure penetration and reach of broadband internet to larger numbers of the citizenry. In South Africa, for example, a broadband plan was adopted in 2012, and the expansion of broadband infrastructure is currently a high priority given that it is being coordinated at the highest level of government as a Presidential Infrastructure Coordinating Commission, as a component of the South African National Infrastructure Plan. There are 18 Strategic Integrated Projects (SIPs) of which SIP 15 concerns expanding access to communication technology and ensuring broadband coverage to all households by 2020 (Presidential Infrastructure Coordinating Commission, 2012).

The constantly improving penetration of infrastructure to enable the use of modern ICT is evident in the statistics which reveal that in 2016 there were 25.1% internet users in Africa (ITU, 2016) as compared to 9.6% in 2010 (ITU, 2010). It is clear that on the African continent, the environment is becoming more enabling from a technology infrastructure perspective. However, the burning question which follows from this is to what effect is all of this infrastructure expansion on that of development? This question has been high on the international agenda of the United Nations (UN), the International Telecommunications Union (ITU), and World Bank, amongst others. In particular, attention has been focused on how modern Information and Communications Technologies (ICTs) can become an enabler in the achievement of the Millennium Development Goals, and in the current era, the Sustainable Development Goals. The envisioned benefits of ICT and development programs vary and include economic gains, increased innovation, and human development (Intel Labs, 2010: 19).

From a human development perspective, the application of ICTs within various spheres of Health has gained much traction. Since the 1990s, there has been a constantly growing body of literature in the area of Health Informatics, e.g. Friede et al (1995), Eysenbach Jadad (2001), Darkins *et al.* (2008) and Coiera (2015). In the international arena, the role of ICTs was acknowledged in the Millennium Declaration as an important factor to achieve various goals, including the delivery of healthcare and education (United Nations, 2000).

The international focus on health has been retained in the 2030 Agenda for Sustainable Development (United Nations, 2015) which includes seventeen developmental goals. Amongst these, Goal 3 focuses on *healthy lives and the promotion of well-being for all at all ages*. This goal includes the treatment of Non Communicable Diseases (NCDs), which are priorities for health authorities in both the developed and developing world, due to the challenge it constitutes to sustainable development (United Nations, 2015). Of these NCDs, diabetes mellitus (DM) has come under the spotlight especially since the United Nations passed a landmark resolution recognising diabetes as a chronic, debilitating and costly disease (International Diabetes Federation (IDF), 2007).

This paper responds to the question of how development outcomes in the area of health, and specifically that of diabetes mellitus, can be achieved through the effective application of ICTs in the context of mobile applications. The focus on m-health in particular is recognition that in Africa, mobile penetration rates are quite encouraging. For example, in 2016 the total mobile subscriptions penetration in Sub-Saharan Africa was estimated at 85%, and is anticipated to reach 105% by 2022 with over 1 billion mobile subscriptions (Ericsson, 2016). Furthermore, the integration of mobile interventions into the healthcare system in low and middle income countries (LMICs) may be a feasible way to complement and improve strategies toward prevention and control of chronic diseases. Yet success in scaling up and sustainability depends on other factors besides mobile phone technology, such as the healthcare context, social values, and culture (Beratarrechea et al., 2014).

Given the compelling reasons to investigate the how mobile technologies can address health issues, this paper seeks to:

- Assess how m-health interventions can be incorporated at primary care level to improve self-management for patients with diabetes in previously disadvantaged communities in the Western Cape, South Africa;
- Identify potential challenges for the implementation of the ICT intervention;
- Propose a user-centred design approach to involve patients in designing ICT interventions that meets their needs and lastly
- Recommend a model for implementation of an m-health intervention amongst patients with diabetes.

4 Literature review

Given the topics outlined in the foregoing section, the literature is organised in terms of:

- The South African Context and the role of information technology to manage diabetes;
- Implementing mobile heath (m-health) for diabetes self-management in South Africa;
    - o M-health for DM in previously disadvantaged communities in the Western Cape, South Africa;
    - o Measuring the adoption and effective use of mobile health (m-health) for DM self-management in South Africa and
- M-health design considerations.

4.1 NCDs in the South African Context

In the South African context, the strategic plan for the prevention and control NCD 2013-2017 includes the following goals and targets for 2020:

- Increase the percentage of people controlled for hypertension, diabetes and asthma by 30% by 2020 in sentinel sites; and
- Target a 25% relative reduction in overall mortality from cardiovascular diseases, cancer, diabetes, or chronic respiratory diseases (Health Systems Trust, 2007).

Given the above targets, the South African Health Review 2003/2004 recognised the need to implement interventions that address risk factors for chronic conditions. The risk factors for patients with diabetes include tobacco use, food consumption or diet (eating and related behaviours), physical inactivity, and alcohol use. For diabetes, associated behaviours are eating (Health Systems Trust, 2004) and physical inactivity (American Diabetes Association, 2014). Therefore, ongoing patient self-management education and support are critical to preventing acute complications and reducing the risk of long-term complications (Abubakari et al., 2015).

4.2 Role of technology in self-management of diabetes

The role of technology in assisting with self-management is important given that it makes it possible to empower patients to learn new practices and routines related to their illness. Diabetes self-management includes monitoring physical activity, eating habits, and medication taking (Celler, Lovell, & Basilakis, 2003; Gaikwad & Warren, 2009). This monitoring can be supported through technology as it has been found that adherence was often poor (Celler *et al.*, 2003). ICT interventions can facilitate the process of self-care by providing educational and motivational support in daily decision making (Siminerio, 2010).

Diabetes, in particular, is well suited to the use of clinical information technology (IT) because its management is characterised by quantifiable outcomes, such as HbA1c levels, and process measures (Siminerio, 2010). IT innovation, including advances in microprocessor technology have allowed the design of small, portable, and inexpensive sensors that measure a wide range of objective clinical indicators and provide instantaneous feedback (Siminerio, 2010). ICT innovations include the insulin pump (delivers insulin) and continuous glucose monitoring (CGM) that monitors blood glucose levels (Nikita, Lin, Fotiadis, & Arredondo Waldmeyer, 2012). It was found that CGM, when used properly, with intensive insulin delivery, was a useful tool for patients with type 1 diabetes (American Diabetes Association, 2014).

Whilst ICT is increasingly being used in management of chronic conditions in LMICs, evidence of the effectiveness, such as the use of m-health, has been inconclusive (Wilhide III, Peeples, & Anthony Kouyaté, 2016). ICT interventions need to be integrated into primary health care (Celler *et al.*, 2003). The interventions should be tailored so that they are effective, affordable and accessible, especially for disadvantaged groups (Beratarrechea *et al.*, 2014).

4.3 Implementing m-health for DM self-management

According to the South African Health Review 2013/2014 (Health Systems Trust, 2014), the Minister of Health published the national health normative standards framework for interoperability in e-health on 23 April 2014 (Government notice no. 314 of 2014, Government gazette no. 37583, 23 April 2014). However, there have been challenges in its implementation:

- *"Widely differing levels of e-health maturity across and within provinces;*
- *A large number of disparate systems between which there is little or no inter-operability and communication;*
- *Inequity of e-health services provided and expenditure on e-health across provincial and national departments of health;*
- *Expensive broadband connectivity;*
- *The absence of a national master patient index;*
- *The absence of a national unique identification system of patients; and*
- *Limited capacity within the public sector for implementation."*

M-health has been identified as a mechanism to addresses some challenges in LMICs such as limited financial resources, limited workforce, high population growth, high burden of disease and the difficulties experienced in extending healthcare to hard-to-reach populations (de Jongh *et al.* 2012).

This is due to the fact that low-cost handsets are becoming available, and currently three-quarters of the world's population have access to a mobile phone (Beratarrechea *et al.*, 2014).

The amount of literature for m-health interventions in developing countries is not as prolific as in developed countries (Vandelanotte *et al.*, 2016). However, it was noted in reviews of other literature on m-health interventions in developed countries, that research primarily used text messages as part of the intervention (Free et al. 2013).

It was noted that a study analysed 600 diabetes-related m-health (mobile health) applications (apps). It was found that the apps generally have one (54, 1%) or two functions (28, 2%), did not have data forwarding/communication functions (68, 9%) and did not offer an interface to a measurement device (95, 4%) (Miele, Eccher, & Piras, 2015).

A study analysing 6520 medical apps, of which 227 were for DM self-management, found that *'most medical mobile phone apps lack expert involvement and do not adhere to relevant medical evidence'.* In the case of DM apps, it measured the adherence to evidence based on 'inclusion of behaviours' recommended by the American Association of Diabetes Educators (Subhi *et al.* 2015).

Another study found that typical medical or fitness apps have a **90-day user retention rate of only 27% to 30%.** In addition, 50% of these apps are downloaded less than 500 times (Birnbaum *et al.* 2015).

In another qualitative study, the benefits and challenges of m-health in community-based services (CBS) in South Africa were reviewed. It found that the South African health system had a weak ICT environment and limited implementation capacity. As a result it remains uncertain that the potential benefits of m-health for CBS would be retained with immediate large-scale implementation (Leon, Schneider, & Daviaud, 2012). Large-scale implementation would be required to meet the increase in number of patients with DM. However, there are few examples of successful health systems implementation (Nundy *et al.*, 2012).

In respect of m-health for DM in previously disadvantaged communities in the Western Cape, there is a dearth of literature. There were two articles dealing specifically with deaf patients, a previously disadvantaged group in the Western Cape, using a mobile application called SignSupport (Chininthorn, Diehl, & Tucker, 2015). An extension for SignSupport, Health knowledge transfer system (HKTS), was designed for diabetes care (Chininthorn, Diehl, Glaser, & Tucker, 2016). The application assists the communication and interactions between the Deaf patient and each staff/health professional involved the diabetes care process.

The only other article found related to testing the feasibility and acceptability of a mobile phone–based peer support intervention among women in resource-poor settings to self-manage their diabetes. Secondary goals were to evaluate the intervention's effectiveness to motivate diabetes related health choices. However, the population sampled only included twenty two participants and therefore the results may not be generalised (Rotheram-Borus et al. 2012).

The only other information obtained was published by GSMA (who represents the interests of mobile operators worldwide) and contained the information shown in Table 1.

Key findings	**Key implications**
Fragmented, nascent industry: 101 services identified in South Africa, many of which are 'small' services addressing the same areas (e.g. 42 services addressing HIV/AIDS, 50 services claiming to support health systems in various ways).	**Ecosystem development**: Closer cooperation is needed to reduce fragmentation and increase success of m-Health.
Unsustainable business models: 75% of all services have received catalytic donor investment. There are few examples of revenue generation beyond catalytic donor investment.	**High risk for discontinuation of services**: Innovative business models that take into account the constraints of a country's health system and other specific variables need to be developed in order to reduce the risk.
Scale is a moving target: a handful of services show	**Replication**: Scale should be considered for

promising adoption and active user rates. Clearer demonstration is needed to compare addressable target markets with actual user rates.	implications of replication, partnerships development and the ability to manage the growth of services. Scale as a term used to define the target for the number of end-users should be avoided.
Mixed findings on reaching at risk populations: Basic phones dominate devices but access channels target those users with data and web access.	**Limited reach to the Bottom of pyramid (BOP)**: Most at risk population groups remain disadvantaged and the actualisation of mobile to increase service access remains limited.
Disproportional distribution throughout the country: Gauteng and Western Cape are 2 Provinces with the most mHealth services opposite of Free State, Limpopo and Eastern Cape.	**Replication**: Importance of developing strong business case in Gauteng and Western Cape, and replicating it to other Provinces.
Regulators not sufficiently engaged: limited scientific (health-economic) evidence base for vast majority of services and inadequate incentives for mobile industry to provide socio-economic services.	**Insufficient evaluations and prohibitive price structures:** limit integration of mobile into the health system.

Table 1. In-depth landscaping of m-Health in South Africa (Source: GSMA, 2013)

4.4 Measuring the adoption and effective use of mobile health (m-health) for DM self-management in South Africa

The benefits obtained from ICT interventions such as m-health need to be measured when determining successful implementation. Additional benefits would be that patients become familiar with ICT in order to improve and empower themselves.

A systemic review of literature for the effectiveness of e-& m-health interventions to promote physical activity and healthy diets in developing countries was assessed (Müller, Alley, Schoeppe, & Vandelanotte, 2016). The results of this systematic review suggest that e-& m-health interventions can be effective in improving physical activity and diet quality in developing countries (Müller *et al.*, 2016). Overall, the review showed that 50% of the e-& m-health interventions were effective in increasing physical activity, and 70% of the identified interventions were effective in improving diet quality. The result is consistent with the findings from previous systematic reviews of e-and m-health interventions conducted in developed countries (Müller *et al.,* 2016).

The capabilities, empowerment, and sustainability (CES) model, assumes that individuals and communities require a minimum set of capabilities, depending on the type of ICT, to gain access to and make effective use of ICT. The use of ICTs would in turn strengthen capabilities, empowerment, and the ability to maintain sustainable livelihoods. Each twist of the virtual spiral brings new insights and growing capabilities into areas such as health (Grunfeld, Hak, & Pin, 2011).

This view of ICT to empower individuals and communities is strongly linked to ICT for development (ICT4D) literature (Heffernan *et al.,* 2013; Breytenbach *et al.,* 2013; Grunfeld *et al.,* 2011; International Telecom Union Annual Report, 2013).

Linking to the CES virtual spiral model, sustainability for ICT projects are key in order to realise benefits within communities. This can be achieved by embedding them within local social structures with minimum disruption to existing social structures (Breytenbach *et al.*, 2013).

According to Hefferman *et al.* (2013), there needs to be a demand for ICT; in this case, ICT that will improve diabetes self-management. The adoption of the tool and/or content will be impacted by access, affordability and acceptability. This in turn leads to the diffusion of knowledge and behavioural changes. An m-health intervention would need to bring about behavioural changes in order for patients with diabetes to manage their condition better (Hefferman *et al.*, 2013). However, the measurement of ICT in order to derive these behavioural changes will be required and must be viewed over a period of time, spanning phases described by Heeks (2010):

- Readiness: Having the policies and infrastructure to make ICT availability possible.

- Availability: Rolling out ICTs to the poor to help them become users.
- Uptake: Implementing and applying ICT to make it useful.
- Impact: Using ICTs to make the greatest developmental impact.

According to Heeks (2010), readiness, availability, and uptake issues will remain relevant for at least a generation, but they will fade alongside greater interest in impact. However, Beratarrechea *et al.* (2014) found that despite a recent World Bank report that identified more than 500 m-health pilot studies in LMICs, little evidence was found about the likely uptake, or best strategies for engagement, efficacy, or effectiveness. This view is supported by Wilhide *et al.* (2016) who argue that evidence of their (m-health) effectiveness has been inconclusive.

5 Towards a model for user-centred m-health applications

Based on the key learnings from the literature, in this section of the paper, we examine design considerations and the concept of positive deviance to inform a preliminary conceptual model for the implementation of an m-health intervention amongst DM patients.

5.1 M-health design considerations

The use of health apps by healthcare professionals and the general public (uptake) has benefits and challenges. The major challenges associated with health apps include the following:

- *"Selecting health apps that provide value from the wide range of possibilities*
- *Health apps designed without consideration of users with low health literacy*
- *Information provided by health apps may not be accurate and accountable*
- *Privacy and security concerns*
- *Health apps lack evaluation*
- *Download and use of the health apps without any guidance*
- *Usability constraints such as small screens, difficulty in reading and typing, slow download speed"*

(Zhang, Zhang, & Halstead-Nussloch, 2014)

One way of involving users into design, even those with low health and ICT literacy, is to use a user-centred design (UCD). UCD design includes research prior to and during the development of the intervention. Its purpose is to *"understand the needs, values, and abilities of users, as well as iteratively assessing the design to improve users' perceptions of and interactions with the technology and content"* (Mayberry, Berg, Harper, & Osborn, 2016). The benefits of UCD are that there is a deeper understanding of users' organisational, social and ergonomic factors that affect usage as users are involved at every stage of the design and development of the product (Abras, Maloney-krichmar, & Preece, 2004). Focus groups can be included early in the design cycle in order to obtain requirements and issues which leads to the development of products that are more effective and safe (Abras *et al.*, 2004). The engagement takes into consideration the social environment and context which may also lead to a greater sense of ownership and user satisfaction. The social dynamics in the target communities are important indicators of if and how ICT will be used (Ramachandran, Kam, Chiu, Canny, & Frankel, 2007).

However, the time required and costs are higher using this level of engagement (Abras *et al.*, 2004).

5.2 Positive deviance

Given the costs and time required to implement UCD, and the fact that m-health services are mainly dependent on donor funding (GSMA, 2013), alternatives to traditional approaches need to be considered.

Positive deviance is *"the observation that in most settings a few at risk individuals follow uncommon, beneficial practices and consequently experience better outcomes than their neighbours who share similar risks"*. This approach has been used successfully in areas of health, such as cases to improve nutritional status, new born care, rates of contraception and safe sexual practices (Marsh, Schroeder, Dearden, Sternin, & Sternin, 2004)

In addition, positive deviance was used to explain why certain projects in public sector reforms, in developing countries, led to success while the majority did not. The author states that the *"Positive deviance approach has emerged as a way of identifying workable solutions to development's toughest problems. It emphasizes the importance of learning from the positive deviants within the contexts where failure is more normal; and focuses especially on learning about the strategies adopted to find and fit effective solutions"*(Andrews, 2015)

The benefits of this approach is that it is a low cost method to identify beneficial strategies used by few and then encouraging the rest of the community to adopt them (Marsh *et al.*, 2004).

6 Conceptual Framework

Based on the literature reviewed, the foregoing design considerations, and the notion of positive deviance, the following model is proposed as a foundation for a user-centred m-health intervention.

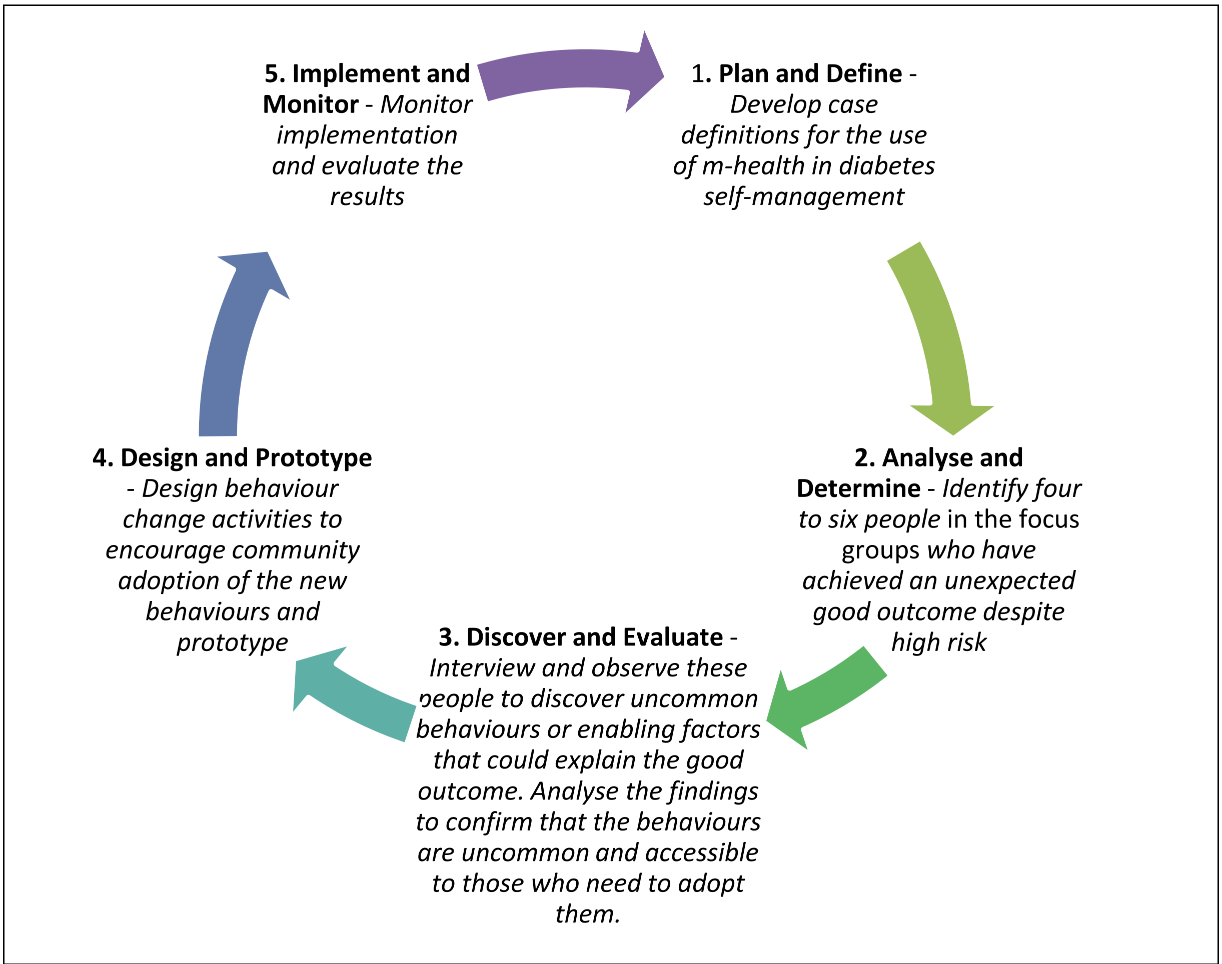

Figure 1. Positive deviance framework (Modified from source: Marsh *et al.*, 2004 and DSI, 2014).

7 Future work: recommended approach for the testing of the positive deviance model

The next phase of the study will entail testing the proposed model. Given all of the imperatives, it is proposed that a qualitative study is necessary given that an in-depth description of patients is required in order to gain an insider perspective (Mouton, 2001) into the challenges and opportunities to improve self-management.

The use of positive deviance in using ICT for diabetes self-management is a largely untapped area. In the initial interactions with a hearing diabetes focus groups, it was found that it was not immediately evident who demonstrated positive deviant behaviour and whether these behaviours could be rolled out to the community. However, further investigation, may make the identification easier. If not, then investigation into why there are not positive deviants may need to be taken into consideration.

The testing of the model should be undertaken within a participatory action research (PAR) paradigm. Community-based participatory action (CBPR) research is defined as a *"systematic inquiry, with the participation of those affected by the issue being studied, for the purposes of education and taking action or affecting social change"* (Leung, Yen, & Minkler, 2004). This form of research uses a constructivist rather than a positivist approach in which the experiential knowledge of the community is valued. The researchers work 'with' rather than 'on' communities in order to co-create knowledge (Leung *et al.*, 2004), rather than the researcher being seen as the 'expert'. Thus, a CBPR approach will serve to inform a mixed methods approach in order to understand and solve important community problems, such as health disparities (Giachello et al., 2003).

It was also noted that *"the most efficient way to improve health is to use locally available, sustainable, and effective approaches"* (Marsh et al., 2004). The effects of changes introduced by improvement projects, in a top-down approach is often not realised or sustainable (Baxter, Taylor, Kellar, & Lawton, 2016). In contrast, this research will be using a bottom-up approach with a lens of positive deviance. In this research, CBPR will include the positive deviance approach to identify patients who currently use ICT to improve diabetes self-management.

8 Conclusion

There has been to date significant debate on the role of ICTs in ensuring developmental outcomes. There is a large consensus that models which steer towards effective use of technology is a key factor to ensure such outcomes. However there is not sufficient literature which addresses how ICT interventions can be designed to ensure effective use and concomitant development outcomes, especially in the area of health. This paper has taken this into account and proposes a novel approach, based on positive deviance, to develop and test a user-centred m-health intervention for DM patients. The proposed model will also address new areas of using a low cost positive deviance approach in terms of diabetes self-management m-health. We suggest that the outcomes of the next phase of the study will result in new areas for m-health implementation.

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