# Co-Design for Development: Lessons Learnt from an Information Systems Project in Underserved Communities

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**Abstract.** This paper is a reflection on the lessons learnt during an information systems development for development (ISD4D) project in underserved community contexts. The level of participation of health intermediaries and community members is considered for the design of an mHealth application to facilitate access to relevant health information. The paper highlights two key aspects to be incorporated in the co-design of IS interventions, namely the importance of contextual factors and the dynamic nature of intermediaries' work and life practices. Lessons learnt are organised according to the following components of an IS for societal development: people, information, technology, practice and purpose, context, and ethics. The key lesson derived is that IS design and development has to consider *practices for a purpose*. These are influenced by the context of development, the manner in which a community functions, the capabilities of community members, their literacy levels and cultural practices.

**Keywords:** Co-design  $\cdot$  User participation  $\cdot$  IS for development  $\cdot$  Design for development  $\cdot$  Underserved communities  $\cdot$  Participatory action research

## 1 Introduction

The theme of the 6th Scandinavian Conference on Information Systems is 'System design for, with and by users'. This paper addresses the theme from the viewpoint of communities in resource-restricted contexts in Southern Africa. How can such information systems be designed that are explicitly intended to benefit such communities? How can the communities become active co-designers?

Introducing ICT solutions in an underserved community context is adding to an already complex environment. Typically, underserved communities are affected by complex socio-economic factors that influence the characteristics of the design and development process as well as the final information system (IS). The aim of this paper is to consider the aspects relevant to the design and development of an IS in underserved community contexts. We specifically focus on the people, information, technology, practices and context(s) that could be part of the proposed IS. In addition, we examine

the *level of participation* of the social actors (people) in the design and development process. In the IS field, there is still a paucity of literature on the real-life challenges of doing participatory design in underserved communities, exploring which methods and tools are suitable to that end [1]. The research question that we consider for this paper is:

What are the factors that influence the level of participation during the design and development of an IS in an underserved community?

The paper is organised as follows: we firstly provide a brief literature review, followed by a background of the INDEHELA-ISD4D project. We then reflect on our experiences during the empirical part of the project to propose the considerations for designing and developing an IS with the active involvement of all the social actors in an underserved community.

The context relevant to this paper is the consideration of an IS to facilitate better health and wellbeing services in underserved communities. mHealth is found to be suitable for information recording, processing and reporting by stakeholders operating in these underserved contexts. The role of intermediaries in providing health and wellbeing services at the point of care and extending these services to the homes of patients, is recognised as an important component of community services. Intermediaries and community members do not have easy access to the vast amount of health and wellbeing information [2–6]. It was also found that these intermediaries can work better if appropriate technologies are designed with their involvement [2–5]. The intermediaries that we involved in our project are the health and wellbeing service providers located in a peri-urban and semi-agricultural community in the Western Cape, including local non-government organisations, nurses, caregivers and health promoters.

## 2 Information Systems and Societal Development

In this section, we first discuss the components of 'real-life information systems', followed by a discussion specific to the creation and use of IS in an underserved community. The INDEHELA-ISD4D project, from which we draw our lessons, is then described.

#### 2.1 Information System Design

Within an information systems approach, an information system is not always a systemic entity but rather composed of "bits and pieces" of processes and technology incorporated in a systemic work activity [7]. We also agree with Alter [8] that the notion of the 'artefact' may not best describe the different components of the IS as proposed by Lee et al., for example [9]. Instead of trying to define the different components of our IS, we would rather regard information systems as consisting of **people**, **information** and **technology** (both electronic and non-electronic) that are linked together by a **practice** directed towards a **purpose**. This holistic approach to IS recognises both static and dynamic components that are "always embedded in some time, place, discourse and

community emerging from ongoing social and economic practices" [8, 10]. In our study, the context of the underserved community requires us to consider the constraints typically associated with such an environment to understand the time, place and discourses that will influence the proposed IS.

Although our aim is to consider an information system, we also recognise that a new information technology (IT) artefact will need to be designed and developed to eventually become part of the proposed IS. In our case, this artefact was envisioned as a mobile application to enable access to health information and educational services. In this case, it may be useful to conceptualise the IT artefact in terms of Design Science Research (DSR). Design science research has recently been considered as a suitable approach to design IT artefacts while considering the prescriptive knowledge created during the design process and the characteristics of the design outcome as an artefact, method, instantiation or model [11-13]. DSR has been considered as an alternative to behavioural studies based on Simon's well-known concept of the artificial world [14]. Whereas a behavioural approach considers human behaviour in interaction with artefacts, design science is concerned with the creation of the artefact for a specific purpose that has a utility value. The IT artefact, when implemented, becomes part of the social world, and human behaviour in interaction with it can then be studied. DSR provides the methodology to consider the aspects relevant to the design and development process and the behaviour of the designer/developer as they interact with the users of the proposed IT artefact as well as with the design and development tools, methods and constructs. This approach provides a valuable contribution to IS research considering the IT artefact [11-13, 15, 16].

The IT artefact, although it can have different components, is still a "thing" and by focusing only on that does not provide for the other components of an information system.

#### 2.2 IS for Human and Societal Development

The introduction of information systems in underserved communities needs to be carefully considered to establish whether it is desirable and feasible for the potential beneficiaries [17–19]. Underserved communities refer to those groups on the peripheries of society – that are marginalised, and without opportunities or capabilities to empower themselves or improve their position. According to Lorini et al. [20], there is a "worrisome trend of exclusion" in the IS for human and societal development literature. The authors, supported by Diaz Andrade and Urquhart [21], go on to state that grassroots beneficiaries of IS interventions/solutions are often not formally involved in the development process, be it in conceptualisation or implementation. In the Southern African context, particularly, information and digital exclusion is recognised as a significant obstacle in addressing issues of social, economic and cultural equality [20].

When introducing information systems in complex environments, it is important to consider who will benefit and who loses out – an IS solution should not lead to exclusion of some. Information systems do have the potential to stimulate economic growth and ultimately contribute to human development. The practice and notion of human development is here highly complex; we therefore regard it as a holistic and dialogical

enterprise in which participants (including researchers, designers and developers) *negotiate* the intended outcomes to avoid failure.

Indeed, the field of information and communication technology for development (ICT4D) has a long history of project failure. Da Silva and Fernandez [22] argue that to achieve sustainability, projects should be regarded as nuanced social-technical processes that intend to maximise both technological and social outcomes. To achieve this, they suggest that sustainable IS use must be a priority throughout the IS development life cycle.

In participatory design, it is assumed that every participant is an expert in their work and life practices, and that design ideas are jointly created by all so that persons who are affected by a decision or event should have an opportunity to influence it. Hussain et al. [1] identify the barriers to the level of participation in design interventions as human, social, cultural and religious, financial, and organisational. In overcoming these barriers, participatory design should not only seek different levels of participation, but also foster capacity development for future projects, i.e. to empower local community members [1, 23].

# 3 Methodology

This paper is a meta-level reflection on the experiences of implementing an information systems development project in Southern African communities (see Sect. 3.1). In what follows, we will reflect on the design and development activity of the project, as well as on respective design methods, probes and outcomes. From this reflection, we derive several 'lessons learnt'. We establish some considerations based on these lessons for designing an IS in underserved communities with the active participation of community members and service providers.

#### 3.1 INDEHELA-ISD4D: A Holistic Information Systems Development Approach for Community Development

INDEHELA (Informatics Development for Health in Africa) is a long-term initiative to strengthen the capacity of participating African higher education institutions to contribute to socio-economic and human development in their countries, particularly in the scientific field of Health Informatics and the practice of e-health. The network involves universities from Finland, Mozambique, Nigeria and South Africa. Previous research projects within the initiative have focused on the methods [24] and contextual issues [25] of information systems development.

The current flagship project of INDEHELA is named ISD4D (2011–2015), and aims at creating a holistic information systems development approach that is geared towards community development in disadvantaged contexts, unlike mainstream textbook methodologies and approaches that usually focus on business development in well-to-do contexts. The project draws from previous experience in the INDEHELA initiative and methodological literature from other sources. Methods consolidated from these sources are experimented with in real-life information systems analysis and design settings in South Africa and Mozambique, mostly in the area of maternal and home care services

for local communities. The results are reported in two forms – firstly, academic papers, and secondly, in practicable guidelines intended for use by system analyst-designers, development project managers and community leaders as well as in university education.

The ISD4D project adopts a collaborative, participatory action approach to design an IS that will result in the improvement of the current health landscape in Southern African communities. Through this activity, the project aims to understand the contexts, needs and work practices of social actors in community health settings. Stakeholders include community members, healthcare professionals and -workers, researchers, designers and developers. Since the inception of ISD4D, the majority of these stakeholders actively participated in the design of the IS, in the form of co-design sessions, facilitated by various researchers from the project.

#### 4 Lessons Learnt from the ISD4D Project

In this section, we reflect on the lessons learnt so far based on our experiences and observations. We first examine the lessons according to our view of information systems as consisting of people, information and technology that are linked together by a practice directed towards a purpose. Subsequently, we identify some crosscutting issues.

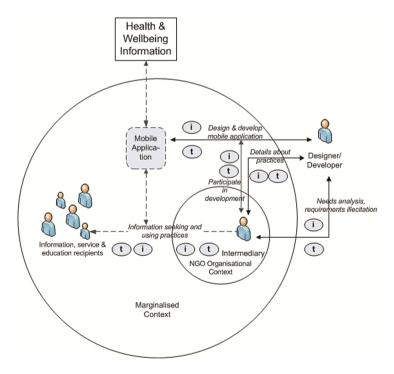


Fig. 1. Design and development of a mobile application to enable access to relevant health and wellbeing information with the active participation of intermediaries in the context of an underserved community.

We propose a diagram (Fig. 1) to depict the different components of a proposed mobile health application in the ISD4D project to enable access to health and wellbeing information. Three areas of participation are depicted; in each case, active participation is important. The t (technology) and i (information) are depicted as those components of the IS where they can influence the level of participation. The selection of these components are important to ensure that the proposed IS is designed and developed *with* the participation of the intermediaries on behalf of the community members instead of developing an IS *for* or *by* them.

#### 4.1 People

The parties and people involved in providing healthcare services in underserved communities are mostly non-governmental organisations (NGOs) and *intermediaries*: lay workers that "translate and adapt health-related information for local use, thus acting as conduits or dependable information sources" [3]. There are a limited number of health professionals in the region, and NGOs mostly have to rely on these lay workers with only basic training [6]. The NGOs are also in most cases responsible for the training of intermediaries.

We found that intermediaries are much more than local service providers. Since they are mostly from the communities in which they provide services, they are regarded as important spokespersons and gatekeepers. Community members rely on them as information sources. We found that the level of participation of community members is particularly influenced by the involvement of intermediaries. Community members will only participate in co-design sessions if approached by the intermediary and "instructed" to participate.

Many communities suffer from research exhaustion and are sceptical of 'promises' since their expectations are often not met. It is therefore important to form a trustworthy relationship with community representatives and to continue to actively manage the relationship. In our case, intermediaries already carry a heavy workload (there are often not enough resources) and any research or co-design sessions take them away from providing their healthcare services.

It is also difficult to observe health intermediaries' actual work practices since they work with patients. This raises an ethical question of engaging vulnerable groups in research and design activities. It is therefore important to rely on inputs from the personal reflections of intermediaries, and to use methods that could simulate their existing practices.

Literacy Levels (Including Digital Literacy). Literacy is no longer only about the ability to read or write but other types of literacy may now also need to be considered such as such informational, technological and digital literacy. Researchers, designers or developers also need to consider inter-cultural communication and multi-cultural literacy during the research and/or IS design and development process. When researchers are novices, the research literacy level also needs to be taken into account. One can therefore consider the literacy level of participants to determine how they will interact. It may even be possible to refer to the design or development literacy to reflect

the experience of the IS development team. The literacy level will influence the level of participation and therefore also an important consideration.

Health literacy entails the knowledge, motivation and competence of individuals to use relevant information for decision-making to maintain or improve the quality of their lives [26]. Furthermore, in an increasingly hyperconnected world with vast quantities of information, it is essential that individuals know how to seek, find, understand and appraise health and wellbeing information to address a health problem or to improve their wellbeing – this is defined as eHealth literacy [27]. The complexity around eHealth literacy is even more problematic in underserved community contexts where there may already be low literacy levels.

#### 4.2 Technology

In underserved communities, most of the available 'information systems' are still paperbased. In the ISD4D project, the following aspects will inform the proposed IS in addition to current paper-based practices.

(Mobile) Application Design and Development Tools/Methods. The (mobile) technology components in our study include those that are related to the IS itself, as well as those technologies and information used as tools to develop the IS. Examples of mHealth technologies can include mobile phones, patient monitoring devices, personal digital assistants (PDAs), and other wireless devices. From this, a key lesson is derived, namely that the technology components used in IS development itself influences the IS and that in an underserved context, these may be severely constrained. The design concepts and technology components may not form part of the final IS but are important building blocks towards the eventual IS. Examples include the design models and constructs that are used to understand the needs of users and their perceived views of the potential IS. Other examples include the architecture, interfaces, and code.

**Technology Infrastructure.** In an underserved community context, the availability of technology components is an important consideration since the infrastructures in these contexts are usually severely constrained. Examples of technologies that form part of the community's technology infrastructure are: connectivity (usually limited and has a cost implication); access to electricity; availability of handheld devices (usually previous generation devices).

**Technology Components.** Examples of the technologies that are part of the final IS may include: code; servers; protocols; modems; devices used to interface the back-end system; database; and user interfaces. All these components must be built and selected according to contextual dynamics and constraints.

#### 4.3 Information and Information Needs

Our results so far indicated that intermediaries have diverse information needs that are: locally defined information about treatments, prevention and health promotion;

information that supports the services provided including information about health facilities, resources, services, partners and training opportunities; and information about guidelines, policies, international best practices and laws [3]. Community members often rely on intermediaries to inform them about aspects relevant to them, e.g., safe sex, nutrition, child care, and the like. As health intermediaries and community members become more information and technologically literate, they may want to access global information as alternative information sources. Information is an important component of intermediaries' work practices since their efforts are both in processing patient information and using health information for health promotion and disease prevention.

#### 4.4 Practice and Purpose

Thus far, we found that the social aspect is a significant consideration that influences the design and development process, involvement of IS stakeholders, and proposed IS. This confirms the view that drivers for mHealth applications are socio-economic and even cultural, rather than purely technical [28, 29]. In underserved contexts, furthermore, people generally have limited to no access to information or information and communication technologies, and they do not have the means and resources to effectively participate as digital citizens [30]. The following themes were derived from our research that we now consider as considerations for the practices of community members as they interact with technology and information for a specific purpose.

People Interacting with Technology and Information. Many studies consider the interaction between humans and computers from a computer science perspective (human computer interaction (HCI)), a design perspective (interaction design), and the like. There are also considerations for interaction in underserved communities, for example, HCI4D [31]. The interactional aspect was identified as an important consideration for the ISD4D project and we refer to this as the interaction moment, i.e. the moment that/ when humans interact with technology. We also recognise that this moment is temporary for the duration of the interaction. Outside these moments, the technology artefacts are static and have at most the potential for performitivity [32]. We are interested in the interaction moments since these become the user interfaces of the IS. It is therefore important to design for the interaction moments by considering what happens during these moments. For example, when a caregiver provides a care service to a patient, how will the introduction of a mobile application and/or electronic information influence their care activities? A caregiver cannot simultaneously work with the patient and use a mobile phone. Humans also do not interact with technology and information artefacts in isolation. These interactions are influenced by the context of use and the purpose that necessitates the linking of people, technology and information as part of the interaction moment.

**Information Seeking and Using Behaviour.** This aspect deals with how information is obtained, recorded, shared, exchanged, used and reported and is influenced by how the information is interpreted, i.e. making sense of how it is used for a specific purpose.

It is therefore much more than the passing of information between the sender and receiver. If we consider the information seeking purposes of individuals and collectives (e.g. communities of practice), as proposed by Diaz Andrade and Urquhart [33], adapted from Dervin [34], we can investigate different purposes for information of both intermediaries and community members. In addition, we consider what information is needed to satisfy its purpose; the sources; media used; and relevancy. We can therefore regard the information seeking practice as the interaction between the human and the information, and possibly mediated by the technology. The information object or architecture can be regarded as static information while the information seeking and using behaviour can be regarded as the practice for a purpose (dynamic). It is important, furthermore, to consider communicative aspects in conjunction with information seeking and using behaviour [35].

#### 4.5 The Context for Development (Static and Dynamic)

The context of underserved communities is complex and has different layers. We found that it is necessary to identify these layers and to consider both static and dynamic contexts [3, 25]. The static aspect of the context could be regarded as the extant technologies and information. The moment these components are used for a purpose then this interaction or relationship between the humans and the technology and/or information is regarded as the dynamic context of the social artefact. An example would be a mobile phone (technology) that is used to access health information (information) where the interaction between these components, namely the information seeking and using behaviour, is regarded as the dynamic aspect of the IS (linking people with the technology and/or information for a purpose). When there is no autonomous interaction between the mobile phone (technology) and health information, these components are static.

The (Indigenous) Rhythms of Communities. Communities tend to exhibit dynamic and fluid rhythms that influence their practices, activities and social interactions. In our project, we found that community members will not participate in any co-design sessions on Fridays when those who are employed are paid their wages. Members often use their wages to buy essential foodstuffs but also generally for alcohol. This means that a Monday is also not a good day for co-design sessions since many people still recover from the weekend binge, and often do not show up for work. Other community-based interventions such as support groups and training sessions need to be considered when planning co-design activities. Any co-design session must therefore be planned carefully in terms of which days are feasible, what time to start the sessions, and how long the sessions should be. Even when a day and time are agreed upon, it is highly possible that community members arrive late or in some cases may not even arrive. Therefore, participation in research or co-design sessions has to be sensitively negotiated and adapted to the local context [22]. It is therefore important to have a good understanding of respective daily practices and to communicate with health intermediaries who could advise researchers, designers, and developers on the means of interaction.

Lost in Translation. In our research context, there are many local languages and researchers, designers, developers and users often have to communicate in their second or third language. This adds a layer of complexity to the co-design activity. We found, for example, that there are not direct translations for some concepts in the indigenous language. These need to be described using other means rather than translated. Furthermore, we observed 'abstracted interactions' between interpreters/translators and community members, in which the interpreter offers a summary of the discussion rather than a direct translation. Interpreters also often interpret what the community members have said instead of translating [23].

We also found that, since the researchers in the ISD4D project are local postgraduate students – often emanating from underserved communities – they are mostly novice researchers. Consequently, the research process is new to them and it is possible that they will miss important aspects due to their inexperience. There is therefore a need for the more experienced researchers of the project, who are often also the supervisors of the students, to be more involved than is normally the case.

The designers and developers of the proposed IS are also mostly inexperienced since they are generally postgraduate students. They may also be unfamiliar with the design and development methods and tools. The activity of translating needs into requirements, designs and code, may therefore be challenging and result in translation errors. This will influence their level of participation. Although this aspect could be seen as specific to the project, we found that community members do not have access to sophisticated design and development resources, methods, tools and technologies. They often have to rely on novices to design and develop an IS.

#### 4.6 Matters of Ethics

Introducing technology to promote desirable social outcomes raises ethical issues [36]. There is limited advice on the quantity, quality and detail of engagement for considering IS interventions in underserved communities and these should be investigated and debated.

The general ethical aspects such as voluntarily participation, informed consent, and permission for data collection may be differently interpreted in different contexts. For example, to collect data in one particular community, a rural village, we needed to obtain permission from the chief. Once permission is granted the chief then calls a meeting and instructs all community members to attend – participation is therefore not voluntarily. This is similar to the recent experiences of Sabiescu et al. [37] in conducting co-design sessions with remote-rural communities in Romania and Mozambique.

In our case, co-design session often took the form of a communal meeting, which is opened by one of the elders. Questionnaires are completed in groups since not all are able to read or write. Anonymity is therefore not possible. Poverty, limited healthcare services, illiteracy, cultural and linguistic differences, and limited understanding of the nature of scientific research by community participants could increase the risk of exploitation.

Community-based participatory research requires involvement and relationship building to establish trust and to ensure that the fieldwork is socio-politically, logistically, or ethically feasible [38]. Woodsong and Karim [39] propose a conceptual model of the informed consent process with the participation of community members. Co-design in underserved communities can involve vulnerable groups and it is possible that their very participation can result in stigma (e.g. in our case, caregivers treating HIV/AIDS). Care should also be taken to collect, store, protect, retain and destroy research data according to sound ethical principles. These principles also apply to the process of requirement-elicitation to inform the IS design. In the context of healthcare, the research often involves sensitive data, e.g. patient health records; reporting of conditions with an associated stigma; and the like. Care should thus be taken in identifying the participants and deciding which methods and tools to use during the design and the development of the IS.

#### 5 Conclusion

From the research conducted thus far in the ISD4D project, we derived a number of key lessons that were detailed in the previous section. What we have learnt, ultimately, is that IS design and development has to consider *practices for a purpose*. These are influenced by the context of development, the manner in which a community functions, the capabilities of community members, their literacy levels and cultural practices. These aspects also influence the level of participation of intermediaries and recipients of health services in the design and development process. Furthermore, information and technologies also form part of the design and development process; the manner in which they are used during this process will also influence the level of participation of the endusers of the proposed IS. The technologies and information used during development are to establish the needs of the users; to elicit their requirements and to develop the IS. The level of participation will be influenced by the choice of information and technologies during the development phases of the IS – from needs analysis to implementation.

The context of both the development and use of the IS needs to be considered specifically for IS-development-for-development. Regardless of literacy level and cultural practices, end-users (should) have the capability to participate in the design and development process. The level of participation can be increased if the right technologies and information are used to encourage active participation. It is also important to use methods with relevant technologies and information to "translate" the practices of the users of the proposed IS into IS processes. It is important to specifically consider the purposes of these practices and contextual factors influencing them to obtain a good understanding of what the IS should achieve. Again, methods with appropriate technologies and information should be used to involve the users of the IS.

During the design and development of the new IS knowledge is created about the characteristics of the technology components (designed and those used to design new ones). Focusing on the utility of the technology components during the design and development should be aligned to the purpose of the associated practise. It is then possible to create prescriptive knowledge during the three areas of participation illustrated in Fig. 1 around the characteristics of the designs of the technology components, as well as the process of designing these components.

The level of participation of community members will be influenced by contextual factors, and by the extent to which appropriate information and technologies are used to "bridge" the gap of what is *known* to what is *possible*. It is important to focus on the dynamic aspects of IS development by making an effort to understand community members' life and work practices in real-life situations.

We posed the following research question at the beginning of the paper: *What are the factors that influence the level of participation during the design and development of an IS in an underserved community?* Based on the lessons learnt the factors that influence the level of participation during the proposed three areas of participation are grouped around the following components: people (the role of the intermediaries); technology (the use of relevant tools/methods; consideration of infrastructural constraints); information (relevant to the practices of the users); contextual factors (both static and dynamic); and ethics considerations. It is important that the intermediaries, important representatives of the end-user in the case of underserved communities, participates actively in all areas of IS design and development. In all cases the linking of the people, technology and information around practices for a purpose needs to be considered. It is also important to consider the role of the IS for development of the underserved communities that should aim for a positive impact.

In this paper, we shift our focus from solely people, information and technology components toward dynamic practices for a purpose. This provided us with a holistic lens to consider the components of an IS in an underserved community context. We were able to draw from our experiences to indicate that social, cultural, economic, and ethical factors are highly significant in a context where the ultimate goal is to develop the capabilities of people. IS designers and researchers are responsible to facilitate appropriate, context-sensitive information systems in cases where information can directly affect the health status and wellbeing of people from underserved communities. Further research is required to understand how people make sense of available health information, to know what is relevant to their needs. The complex interactions between the different IS components – especially during the practices when these components link – remains unclear at this stage. This aspect needs to be further unpacked to understand the complexities of the design and development of the IS as well as its use in practice.

We have thus far sought to provide only a preliminary set of considerations for IS design and development in an underserved community context. These are by no means definitive and further research is required to fully understand the different considerations that influence the participation of all in the design and development process.

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