



Co-designing Community-based Digital Innovations for Maternal and Child Health (MCH)

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Signed:

Signed by candidate

Date: 12 February 2023

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ABSTRACT

Digital MCH (Maternal and Child Health) interventions improve access to, and awareness of, maternal and child healthcare. These interventions, however, often fail to receive uptake as the project objectives do not always align with community needs. This is attributable, in part, to the top-down nature of digital MCH programs, in which health and ICT experts typically inform the approach to these interventions, and the parents and caregivers being targeted, are excluded from the design process. This project aims to address this by directly including caregivers in the design of digital MCH interventions.

In this research, we worked with caregivers and community members from various low-income South African communities to ascertain their MCH concerns and prioritize them accordingly. The outcome of this engagement informed the development of a digital intervention aimed at addressing these priorities. This research was carried out in three core phases. *Phase 1* involved conducting community interviews with community members to learn about their current MCH contexts, and their digital MCH challenges and priorities. In *Phase 2*, we conducted co-design workshops with community members to ideate solutions to the challenges identified in *Phase 1*. Finally, *Phase 3* involved analysing the feedback from the workshops, and iteratively developing a digital intervention with feedback from community members.

This study identified and explored community-informed MCH priorities in South African communities that were not previously prioritised in the HCI community. These included accessibility to MCH information, building parenting skills in early life, and improving maternal mental health. Between the more rural and urban settings, we identified and distinguished the different nuances of these priorities, which we discovered were influenced by culture, socioeconomic conditions, and varying degrees of community involvement. Furthermore, we discovered that the communities value “connectedness” above access when addressing their MCH-related needs.

Informed by our community engagements, we developed a resultant digital innovation to improve access to digital MCH in low-income communities, which have since been deployed and used by community participants. Finally, we determined that co-design approaches for MCH in low-income communities can be very effective if the appropriate tools are put in place, such as Design Cards, local intermediaries, and facilitator training.

LIST OF PUBLICATIONS

The following journal articles contain work contributing to an overarching research project, Co-designing Community-based ICTs Interventions for Maternal and Child Health (CoMaCH - described in Section 2.1.3), to which this dissertation also contributes.

Journal articles in which I co-authored:

1. Sarina Till, Jaydon Farao, **Toshka Lauren Coleman**, Londiwe Deborah Shandu, Nonkululeko Khuzwayo, Livhuwani Muthelo, Masenyani Oupa Mbombi et al. 2022. Community-based co-design across geographic locations and cultures: methodological lessons from co-design workshops in South Africa. In *Proceedings of the Participatory Design Conference 2022-Volume 1*, pp. 120-132. 2022.
*Chapter 5 of this dissertation contains contributions from this article, and has been cited accordingly.
2. Sarina Till, Melissa Densmore, **Toshka Lauren Coleman**, and Nervo Verdezoto Dias. 2021 "Poster: Lessons from doing fieldwork with bandwidth-constrained communities online." In *ACM SIGCAS Conference on Computing and Sustainable Societies*, pp. 445-448. 2021.
3. **Toshka Coleman**, Sarina Till, Nervo Verdezoto Dias, Melissa Densmore. 2023. Reconsidering Priorities for Digital Maternal and Child Health: Understanding Community-centered Perspectives from South Africa. 1, 1 (January 2023). *ACM Conference on Computer-Supported Cooperative Work and Social Computing (2023)* <https://doi.org/XXXXXXXX.XXXXXXX>.
*Currently under review. The content of this article encompasses Chapter 5 of this dissertation.

Journal articles in which I was not a co-author:

1. Sonja Klingberg, Molebogeng Motlathledi, Gugulethu Mabena, Tebogo Mooki, Nervo Verdezoto, Melissa Densmore, Shane A. Norris, and CoMaCH network. 2022. "Must you make an app?": A qualitative exploration of socio-technical challenges and opportunities for designing digital maternal and child health solutions in Soweto, South Africa. *PLOS Global Public Health* 2, no. 12 (2022): e0001280.
2. Livhuwani Muthelo, Masenyani Oupa Mbombi, Mamare Adelaide Bopape, Tebogo M. Mothiba, Melissa Densmore, Alastair van Heerden, Shane A. Norris, Nervo Verdezoto Dias, Paula Griffiths, and Nicola Mackintosh. 2023. Reflections on digital maternal and child health support for mothers and community health workers in rural areas of Limpopo Province, South Africa. *International Journal of Environmental Research and Public Health* 20, no. 3 (2023): 1842

TABLE OF CONTENTS

DECLARATION OF AUTHORSHIP	i
ACKNOWLEDGEMENTS	ii
ABSTRACT	iii
LIST OF PUBLICATIONS	iv
TABLE OF CONTENTS	v
LIST OF FIGURES AND TABLES	viii
CHAPTER 1: Introduction	1
1.1. Context and Aim	1
1.2. Research Questions	1
1.3. Research Methodology Overview	2
1.4. Dissertation Layout	3
CHAPTER 2: Background and Related Work	5
2.1. Background	5
2.1.1. Motivation for Addressing Maternal and Child Health (MCH) in South Africa	5
2.1.2. Digital Maternal and Child Health (MCH) as a Potential Solution	6
2.1.3. The CoMaCH Project	7
2.1.4. Research Settings	7
2.1.5. The Bhabhisana Baby Project	8
2.2. Related Work	8
2.2.1. MCH and Digital MCH in Low-income Contexts	8
2.2.2. Participation Methodologies	10
2.2.3. Theories Adopted in Co-design and MCH	13
2.3. Chapter 2 Summary	17
CHAPTER 3: Community Challenges Related to MCH and Digital MCH	18
3.1. Introduction and Background	18
3.1.1. Current Approaches Addressing MCH Challenges	18
3.1.2. Asset-analysis of Devices in South African Households	19
3.2. Approach	20
3.2.1. Objective	20
3.2.2. Participants and Interview Methods	20
3.2.3. Thematic Analysis	21
3.3. Findings	22
3.3.1. Asset Analysis of Participants	22
3.3.2. Current Healthcare-seeking Behaviours and Sources	23

3.3.3.	Participant Experiences with Digital MCH.....	25
3.3.4.	Community Aspirations for Digital MCH	28
3.3.5.	Multistakeholder Ranking of Priorities for Digital MCH	29
3.4.	Discussion.....	31
3.4.1.	Characterizing the Current Status Quo for MCH and Digital MCH	31
3.4.2.	Informing Digital MCH Priorities and Opportunities	33
3.5.	Chapter 3 Summary	34
CHAPTER 4:	Design Cards Development and Effectiveness in Co-design.....	35
4.1.	Introduction.....	35
4.2.	Related Work	35
4.2.1.	Design Cards in Participatory Design	35
4.2.	Approach.....	36
4.2.1.	Design Cards Development	36
4.2.2.	Design Card Employment in Workshops.....	39
4.3.	Findings	40
4.3.1.	Workshop Outcomes	40
4.4.	Discussion.....	41
4.4.1.	Design Cards Contributions	41
4.4.2.	Considerations for Using Design Cards as a Co-design Tool.....	42
4.5.	Chapter 4 Summary	44
CHAPTER 5:	Community Co-design Workshop Outcomes	45
5.1.	Introduction.....	45
5.2.	Related Work	45
5.2.1.	Community-based Co-design for MCH in the Global South	45
5.3.	Approach.....	47
5.3.1.	Participants	47
5.3.2.	Facilitator Training and Intermediaries	47
5.3.3.	Challenge Cards Discussion and Ranking	48
5.3.4.	Brainstorming, Co-designing, and Prototyping	49
5.3.5.	Data Analysis	49
5.4.	Findings.....	49
5.4.1.	Community Priorities for Maternal and Child Health	49
5.4.2.	Community Experiences of Contextually-situated MCH Priorities.....	51
5.4.3.	Co-designed Solutions.....	54
5.4.4.	Parent Feedback from Co-design Approach	58
5.5.	Discussion.....	58
5.5.1.	Advancing HCI supporting Parental Well-being and Access to MCH information.....	58
5.5.2.	Contextually Addressing Access to Relevant MCH Information.....	60
5.5.3.	Understanding the Tensions between “Connectedness” and Access in Communities.....	62
5.5.4.	Co-design Readiness and Significance of Intermediaries.....	63

5.6. Chapter 5 Summary	64
CHAPTER 6: Prototype Development and Evaluations	65
6.1. Introduction.....	65
6.2. Related Work	65
6.2.1. Data Collection for Community Health Applications.....	65
6.3. Approach.....	66
6.3.1. Analysis Informing Prototypes	66
6.3.2. Objective	66
6.3.3. Prototype and Workshop Iterations	67
6.4. Findings.....	69
6.4.1. Iteration 1: Version 1 Initial Feedback.....	69
6.4.2. Final Iterations: Post-amendments Feedback	71
6.5. Discussion.....	74
6.5.1. Design Considerations and Tensions for Digital MCH Applications	74
6.6. Chapter 6 Summary	76
CHAPTER 7: Reflection and Conclusions	78
7.1. Characteristics of Existing Tools and Mediums to Address Key MCH Priorities	78
7.2. HCI Priorities for MCH and Digital MCH.....	79
7.3. Challenges and Opportunities Entailed in Co-Designing Digital MCH.....	80
7.4. Limitations and Future Work.....	81
REFERENCES	83
APPENDIX A: Full Set of Challenge and Ideation Design Cards in English.....	102
APPENDIX B: Community Interviews Script.....	105
APPENDIX C: Community Interviews Codebook.....	107
APPENDIX D.1: Phase 2 Community Workshops Protocol	114
APPENDIX D.2: Phase 3 Community Workshops Protocol	118
APPENDIX E: Informed Consent Form.....	120
APPENDIX F: Full Padlet with Comments.....	124
APPENDIX G: UCT FSREC Ethics Approval	126

LIST OF FIGURES AND TABLES

Figure 1: The Three Research Phases for this Research Methodology	3
Figure 2: Double Diamond Thinking Approach.....	13
Figure 3: Community Wishes for MCH Word Cloud.....	29
Figure 4: Padlet Containing Themes and Challenges with Network Members Votes.....	29
Figure 5: Design Card Revisions	37
Figure 6: Challenge Cards Sample for Parent Well-Being and Postpartum Care.....	38
Figure 7: Ideation Design Cards set for Technologies, Resources, People, and Places.....	38
Figure 8: Sample of Ideation Design cards Showing Resources, Stakeholders, and Technology	39
Figure 9: Ranking System Using Colour-Coded Stickers	48
Figure 10: Top Ranked Challenges Across Sites.....	51
Figure 11: Accessible and Affordable Health Information Solutions	56
Figure 12: Solution for Building Parenting Skills in Early Life in Soweto.....	56
Figure 13: Brainstormed Solution for Parent Well-being in Cape Town	58
Figure 14: Stages of Co-design Analysis	66
Figure 15: Mobile Application Version 1 Prototype	69
Figure 17: Storyboard example for how to stimulate a baby	70
Figure 16: RTHB Guide Poster	70
Figure 18: Posters Developed from Iteration 2 Feedback	71
Figure 19: Final User Application Screens.....	73

Table 1: Padlet Themes for The MCH Challenges and Priorities.....	30
Table 2: MCH Challenge Ranking Results Across Research Sites (out of 10)	50
Table 3: Phase 3 Iterations Overview	67
Table 4: NPO Staff User Portal Acceptance Results	73

CHAPTER 1

Introduction

1.1. Context and Aim

Digital Maternal and Child Health (MCH) approaches are increasingly being used to assist community health professionals in developing areas with data collection (Feroz et al., 2020), education (Kiss-Lane et al., 2019), and monitoring (Babar & Rahman, 2021). However, despite the value of digital MCH and the improved availability of antenatal and postnatal health resources (Lee et al., 2016), corresponding improvements in healthcare within low-income communities are not vastly evident. To date, researchers, and specifically Human-Computer Interaction (HCI) researchers predominantly approach digital MCH design and interventions through top-down methods (Lassi et al., 2016; Mustafa et al., 2020; Nair et al., 2020). This involves expert-led design and the use of community health workers (CHWs) as participants and intermediaries for families living in low-income communities. In this way, parents and caregivers have been under-leveraged as expert resources to fully grasp the socio-cultural contexts of the targeted communities. Introducing parental insight may result in new approaches to digital MCH that are more situated according to their community values and structures (Lassi et al., 2016; Mustafa et al., 2020).

As our knowledge of the opportunities of digital technologies for MCH in low-income South African communities is limited, and since digital MCH in this context is predominantly expert-led, this project seeks to address this gap by collaboratively co-designing digital initiatives for MCH with low-income community members and parents. We worked with four different low-income communities from both rural and urban settings, including Sweetwaters and Limpopo as the more rural sites and Cape Town and Soweto as the urban sites. This involved firstly learning community MCH priorities directly from community members and, thereafter, effectively implementing community-based digital methods addressing these priorities. Furthermore, we explore co-design tools, and the opportunities and tensions of using co-design approaches with communities for this context.

1.2. Research Questions

These research questions are framed in the context of the four low-income, South African communities that we engaged with. For more details on these communities, see Section 2.1.4

1. What are the characteristics of existing tools and mediums to address key MCH priorities?

Before approaching opportunities for new digital initiatives, we needed to contextualize the current status quo of these communities by first learning about the mediums that community members are

currently using to address their MCH needs, and the common characteristics among these. “Tools” refer to any tangible instrument used to attempt to address their MCH needs such as booklets, posters, mobile devices, radio, etc. and “mediums” may include community stakeholders, clinics, community leaders, etc. The characteristics being evaluated involve the accessibility, technical aspects, and level of literacy associated with accessing these tools and mediums. Through the *Phase 1* community interviews (described in Section 1.3. below), we aimed to identify their key priorities for MCH and learn about their prior experiences with MCH projects and digital resources.

2. What are the challenges and opportunities entailed in co-designing for digital MCH with community members?

- Co-design Aspect

We evaluate the effectiveness of this participatory design approach for digital MCH, considering the aspects of this methodology that we found to be both successful and challenging. This includes exploring the methods used for co-design, the use of design aids, the different stakeholders and the use of intermediaries, etc.

- Developmental Aspect

Drawing from the outcomes of the first research question, and by using this co-design approach with community members, we ideate what digital initiatives for MCH could be developed in the context of low-income South African communities.

3. How do HCI research priorities in MCH and digital MCH align with actual parent priorities?

The motivation for this research and its approach stems from the current prioritisation of top-down digital MCH research above parent and community-centred research. Through the interviews and workshops, we evaluate the commonalities and deviances between the MCH challenges that Human-computer Interaction (HCI) researchers are prioritising for MCH and digital MCH versus that which communities voice as their MCH and digital MCH priorities.

1.3. Research Methodology Overview

A community-based, Participatory Action Research (PAR) (Pain et al., 2007) methodology was adopted to conduct the research methods for this study. PAR prioritizes both inquiry and intervention, in which research is undertaken with communities impacted by a problem and possible solutions are designed in co-operation with them (Pain et al., 2007). This approach attempts to gain authentic insight into the realities of South African communities, and collaboratively devise solutions that are situated with their needs and values.

This project followed a phased approach, consisting of three core phases. *Phase 1* aimed to learn community MCH and digital MCH challenges, experiences and health-seeking behaviours through

interviews conducted with parents, caregivers, and community leaders. *Phase 2* explored the potential role of digital health opportunities to address the identified MCH challenges from the *Phase 1* interviews through generative community-based co-design. The findings from *Phase 2* were subsequently analysed. In *Phase 3*, prototyping and development of a digital innovation took place, based on the analysis from *Phase 2* outcomes. Development involved iterative evaluations and amendments of the prototype by community members. These three phases are presented in Figure 1 below.

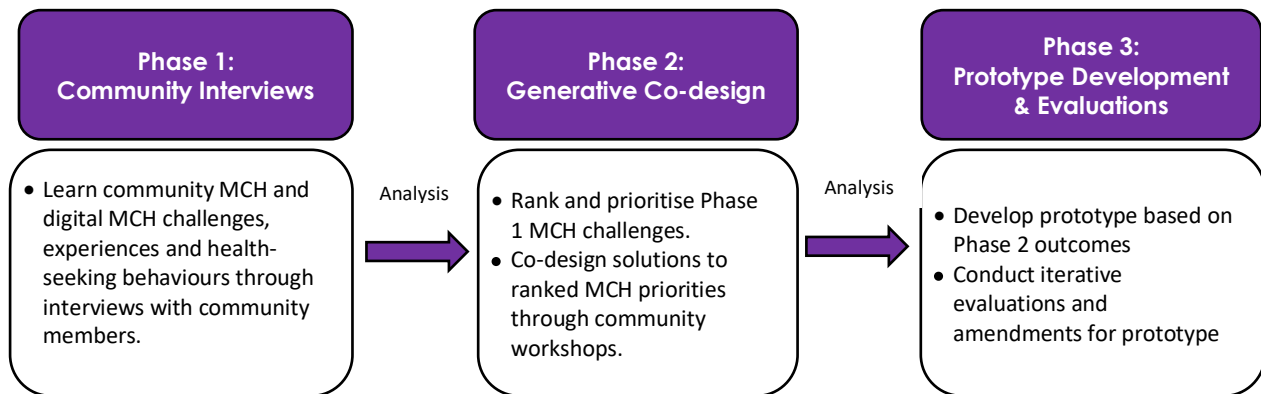


Figure 1: The Three Research Phases for this Research Methodology

1.4. Dissertation Layout

The content of this dissertation consists of the background, methods, results, and discussions that emerged from each of the above phases.

Firstly, the reader is introduced to the dissertation topic in this chapter, **Chapter 1**, and is given information on the motivation for the work. Additionally, this chapter provides the research questions that this dissertation attempts to address.

Before delving into each phase's respective chapters, **Chapter 2** provides the background and related work for this research holistically, looking at past similar studies for MCH and digital MCH. This chapter also provides an overview of the multidisciplinary project to which this research contributes, and the NPO with which we are collaborating.

Chapter 3 looks at the *Phase 1* interview data. We firstly look at how similar studies are approaching digital health and community engagement, and with whom they typically consult. We then provide an asset analysis of devices within South African communities. Next, we describe our approach to conducting the cross-site community interviews and analysing the findings with multi-stakeholders. The interviews insights on the participants' current MCH and digital health-seeking behaviour, and the community challenges and priorities identified for MCH and digital MCH are then presented and discussed.

In **Chapter 4**, we focus specifically on the development of the Design Cards used as design aids within the *Phase 2* co-design workshops, informed by Chapter 3's *Phase 1* interviews, and the effectiveness of the cards. In this chapter, we firstly define Design Cards and how they have been used for co-design in other work. We then describe the processes followed for the creation of the Design Cards and for deploying them in the co-design workshops. Their effectiveness as co-design aids is then evaluated and considerations for future work involving Design Cards are provided. In this chapter, we only focus on the interactions with the Design Cards in the co-design workshops, not the actual workshop outcomes.

In **Chapter 5**, we explore particularly the outcomes from the *Phase 2* co-design workshops, presenting ranked MCH priorities, as well as brainstormed solutions and prototypes addressing the MCH priorities identified in *Phase 1*. In this chapter, we firstly provide outcomes from related work on co-design for digital MCH in the Global South and the considerations proposed from these studies. The approach that we used for co-design across the sites is then described, including the methods used for ranking the *Phase 1* challenges and conducting the co-design activities. We then provide the emerging prototyped solutions from the co-design workshops and discuss the various elements of the solutions, situating what is known in the HCI community and that which requires more attention.

In **Chapter 6**, we focus on the development of the digital prototypes in *Phase 3*. Firstly, we explore other health applications that engaged with communities in their application development process. We then describe the iterative developments and feedback from evaluations with community members. This includes three iterations of development and evaluations on the application and its content. Following this, we discuss what we have learned from the evaluations and provide considerations for future community-based applications and research involving community members in health-based mobile application development.

Lastly, in **Chapter 7**, we provide a reflection and conclusion on this research, answering our research questions. We highlight what we learnt from this work and its contributions in conversation with other work. We then affirm what the HCI community knows about MCH in South African communities, what areas for MCH require more attention, and how such research could be approached according to identified community values. Finally, we identify this research's limitations and propose considerations for potential future research extending on this work.

CHAPTER 2

Background and Related Work

2.1. Background

In this section, we provide our motivation for addressing maternal and child health (MCH) in South Africa and consider digital (MCH) as a potential solution. We then describe the multidisciplinary project to which this research contributes, the research settings for this work, and the NPO with which we are collaborating.

2.1.1. Motivation for Addressing Maternal and Child Health (MCH) in South Africa

MCH concerns the health and well-being of pregnant women and mothers, as well as the health of children (Committee, 2015). During their antenatal and postnatal periods, women's healthcare and lifestyle decisions impact their own and their children's future wellbeing. The facilitation of appropriate MCH information and care allows complications after birth to be anticipated and prevented (Committee, 2015). Evidence presents that appropriately timed intervention, and management can mitigate the chances of maternal, perinatal and new-born morbidity and mortality. Unfortunately, access to appropriate maternal healthcare services is limited by restricted resources and infrastructure, particularly in low-to-middle-income-countries (LMICs) (Lee et al., 2016). The new Sustainable Development Goals (SDGs) for 2030 (Organization, 2015) seeks to reduce maternal mortality while also providing equitable access to maternal healthcare (Organization, 2015). In low-income countries, particularly within Africa, limited access to maternal health facilities contributes to an increase in maternal mortality (Dahab & Sakellariou, 2020a; Lawn, 2005)

South Africa is dedicated to achieving the Sustainable Development Goal (SDG) of eliminating preventable maternal and child deaths (Pillay & Barron, 2018). Although South Africa's maternal mortality rate (MMR) has decreased from 200/100,000 in 2012 to 113/100,000 in 2019, more work remains to be done in order to meet the SDG of achieving an MMR of less than 70/100,000 by 2030 (Goga et al., 2019). Between 2012 and 2019, the neonatal mortality rate in South Africa remained stable at 12/1,000 live births, exceeding the SA National Department of Health (NDOH) 2030 goal of 7/1,000 (Goga et al., 2019).

Worldwide evidence indicates that microlevel interventions, including interventions at health facilities, health care workers, and patient levels, can also reduce neonatal mortality rates (NMR) and stillbirth ratios. Complication readiness programs, facility-based births, community-based campaigns to improve preventative and caregiving practices such as family planning, and immunization utilization, improving women's educational level, and appropriate improvement

initiatives have all been successful interventions for this (D. Chou et al., 2015; Serbanescu et al., 2017; Srivastava et al., 2020a; Starbird et al., 2016). When compared to the SDG targets, South Africa's rate of adverse birth outcomes, such as stillbirths and preterm births, remains unacceptably high, despite international agreement that these are preventable through improved quality of care (Madhi et al., 2019; Moodley et al., 2018). According to health experts, approximately 60% of maternal deaths and up to 50% of neonatal deaths are potentially avoidable (Caniglia et al., 2021). This is consistent with data from 81 low-and middle-income-countries (LMICs), which indicates that between 2016 and 2020, roughly 25% of neonatal deaths and stillbirths might have been avoided with higher-quality pre- and postnatal care for pregnant women and new-borns (V. B. Chou et al., 2019). We recognised the severity of South Africa's current MMR and the urgency for improving MCH, and thus aim to contribute to this SDG through a community-based intervention strategy.

2.1.2. Digital Maternal and Child Health (MCH) as a Potential Solution

The significant expansion of Information Communication Technologies (ICTs) has allowed for the advancement of “digital MCH” or “mobile” health (mHealth) to extend healthcare access beyond physical barriers. mHealth or digital MCH involves the use of ICTs to support health and healthcare (H. Chen et al., 2018). According to Human-Computer Interaction (HCI) research, mHealth interventions are associated with improved maternal health-care utilization, including the increased use of recommended prenatal and postnatal care consultations, and vaccinations (Flax et al., 2014; Jiang et al., 2013). For instance, HCI research in digital MCH proposed that delivering prenatal breastfeeding interventions, via SMS, rather than routine prenatal care, can increase rates of breastfeeding initiation and improve the probability of exclusive breastfeeding for up to six months (Flax et al., 2014; Jiang et al., 2013; Sellen et al., 2014). However, there is minimal HCI research on the impact of postnatal digital MCH in low-income, developing populations (Lee et al., 2016).

Parents and caregivers across the world are increasingly turning to digital resources to answer their questions surrounding early childhood development and maternal and child health (Duggan et al., 2015; Oscarsson et al., 2018). However, widespread access to online resources has shown to be both empowering and problematic, with access to information competing with the dangers of information overload and misinformation (Zhao, 2009). Furthermore, barriers such as poor technical infrastructure, finances, lack of trust in technology within the Global South prevent parents from taking up digital resources (Natarajan & Parikh, 2013; Rothstein et al., 2021; Zhao, 2009). This work considers these challenges and seeks to engage directly with community members to voice their MCH and digital MCH challenges and priorities, actively participate in the addressing their community MCH concerns, and to develop interventions intended to benefit them.

2.1.3. The CoMaCH Project

The Co-designing for Maternal and Child Health (CoMaCH)¹ project is an initiative co-founded by Prof. Melissa Densmore that aims to explore the role of communities and co-design in the creation of digital MCH initiatives through community engagements in South Africa. The project's network consists of an interdisciplinary team based in South Africa and the United Kingdom, with community engagements taking place in Limpopo, Cape Town, Soweto and Sweetwaters. The research provided in this dissertation contributes to the CoMaCH project.

2.1.4. Research Settings

South Africa is a culturally diverse country with nine provinces and eleven official languages². To ensure cultural diversity, this research settings included two rural and two semi-urban areas of South Africa and purposefully selected different geographical locations leveraging the existing relationships with local communities of our project partners. The four research sites, where we conducted interviews and workshops, are as follows:

- *Sweetwaters - KwaZulu-Natal Province:* Sweetwaters is zoned as a rural area³ in Kwazulu-Natal (KZN) and is representative of the Zulu population in KZN, with 100% of the population listed as Zulu speakers⁴.
- *Soweto - Gauteng Province:* Soweto is a peri-urban, low-to-middle-income area in the Gauteng province with the dominant language being isiZulu⁵.
- *Ga-Dikgale - Limpopo Province:* Ga-Dikgale is zoned as a rural, low-income area⁶ in Limpopo and is representative of the Sepedi community with 95% of population listed as speaking Sepedi⁷.
- *Cape Town - Western Cape Province:* This area is zoned as urban in the Western Cape, with the population predominantly English speaking with approximately 44% of the population listed as English speaking followed by 36% Afrikaans and 15% isiXhosa⁸. The participants from Cape Town consisted of members and beneficiaries of a local Non-profit Organisation (NPO) that is based in Athlone and described next in Section 2.1.5.

¹ <https://comach.melissadensmore.com/>

² <https://www.brandsouthafrica.com/south-africa-fast-facts/geography-facts/language>.

³ <http://www.statssa.gov.za/publications/P0318/P03182019.pdf>

⁴ <https://wazimap.co.za/profiles/municipality-KZN225-the-msunduzi>

⁵ <http://www.statssa.gov.za/publications/P0318/P03182019.pdf>.

⁶ <http://www.statssa.gov.za/publications/P0318/P03182019.pdf>

⁷ <https://wazimap.co.za/profiles/ward-94703017-makhuduthamaga-ward-17-94703017>

⁸ <https://wazimap.co.za/profiles/ward-19100044-city-of-cape-town-ward-44-19100044>

2.1.5. The Bhabhisana Baby Project

The Bhabhisana Baby Project (BBP)⁹ is a Cape Town-based NPO that works with mothers and caregivers of babies born with disabilities or developmental problems. The organisation provides physiotherapy, occupational therapy, and speech therapy to babies during the three-to-six-month wait for public health appointments and until they have been fully integrated into the state health system. During 2020 with the COVID-19 pandemic, the organisation replaced in-person sessions with WhatsApp video messages to continue their work. In this research, we engaged with the members and beneficiaries of this NPO during interviews and workshops in Cape Town throughout all three phases.

2.2. Related Work

2.2.1. MCH and Digital MCH in Low-income Contexts

In this section, we identify challenges for MCH in low-income countries based on past research and provide studies and initiatives in digital MCH addressing these MCH Challenges. We also look at the current challenges of integrating digital MCH in low-income contexts.

MCH Challenges in Low-income Countries

In low-income countries, inadequate access to and poor utilization of maternal health services are major contributors to maternal mortality (Dahab & Sakellariou, 2020). Research such as Three Delays (Barnes-Josiah et al., 1998) and similar studies related to digital MCH (Dahab & Sakellariou, 2020b; Lawn, 2005) propose that this is primarily due to hesitancy in mothers to seek appropriate medical healthcare, limited accessible transport to appropriate healthcare, and lack of timely support and appropriate resources at medical facilities (Dahab & Sakellariou, 2020; Lawn, 2005).

Furthermore, the impact of cultural beliefs and poor education in seeking MCH care is a recurring theme in MCH studies conducted in low-income countries (Dahab & Sakellariou, 2020; Kyei-Nimakoh et al., 2017). Research in MCH (Dahab & Sakellariou, 2020; Elmusharaf et al., 2015; Kyei-Nimakoh et al., 2017) proposes that this matter related to poor MCH education is due to improper methods and quality of MCH education received by women, partly attributable to poor communication between women and healthcare workers. For instance, studies shows that the traditional postpartum care information booklets only provide one-way communication, primarily intended for the distribution of information (Elmusharaf et al., 2015; Kyei-Nimakoh et al., 2017). In this way, it is not developed in co-operation with and for continuous interaction with local women and assumes a high level of literacy among them (Kyei-Nimakoh et al., 2017).

⁹ <https://bhabhisana.org.za/>

Studies also reveal a mismatch between individuals' actual demands and the circumstances under which healthcare is delivered (Exavery et al., 2014; Kyei-Nimakoh et al., 2017) as a contributing factor to maternal morbidity. It is proposed that when planning or administering their programs, program designers typically do not consider the social, cultural, political, and other sensitive issues inside the community (Exavery et al., 2014; Kyei-Nimakoh et al., 2017).

Research and Initiatives in Digital MCH Addressing MCH Challenges

According to research in HCI, mHealth technology has proven to be an effective medium for developing patient-centred health services that promotes education and self-management by expanding patients' involvement in MCH care through a reliable source (Bogale et al., 2020; Dansharif et al., 2021). Patients can engage in their clinical care and are empowered to make informed health decisions, in consultation with their healthcare providers (Bogale et al., 2020; Dansharif et al., 2021). As a result, informed patients have the potential to increase the quality of care they receive through healthcare providers (Dansharif et al., 2021; Desta et al., 2014). Using such digital MCH innovations addresses the challenge presented regarding poor communication between women and healthcare workers.

With regards to the challenge of poor access and use of MCH facilities, interventions that use such mHealth technology, specifically those that educate mothers via SMS, are associated with improved health-care access and utilization, including the increased use of recommended prenatal and postnatal care consultations, and vaccinations (Bogale et al., 2020; Desta et al., 2014). Studies have also shown that delivering prenatal breastfeeding interventions via SMS improved breastfeeding behaviours (Bogale et al., 2020; Desta et al., 2014; Flax et al., 2014; Jiang et al., 2013). This is particularly presented in two studies (Flax et al., 2014; Jiang et al., 2013) which compared the effect of mHealth interventions using SMS over routine health care, encouraging breastfeeding in Nigeria and China. The results of the studies showed that the rates of EBF for six months were higher in the intervention group than in the control group. The research also found that SMS was more frequently utilized in low-middle-income-countries, providing features such as health education or promotion, appointment reminders, and data collection (Flax et al., 2014; Jiang et al., 2013). SMS based programs also showed positive results in the prevention of mother-to-child transmission (PMTCT), childhood disease management, and family planning (H. Chen et al., 2018).

Such digital MCH interventions are able to educate women on MCH, addressing the challenges associated with poor MCH awareness and education. These interventions have been implemented in Africa but are limited in South Africa (Dahab & Sakellariou, 2020). For example, Mobile Midwife (LeFevre et al., 2017) is a Ghanaian-based mobile application that aims to improve its users' knowledge of important health information during pregnancy and postpartum period. It also encourages timely and appropriate service utilization. It accomplishes this by sending audio messages in local languages about MCH education and care, as well as SMS messages on their mobile phones that are timed to a woman's gestational age or the gestational age of her child (LeFevre et al., 2017). A study that evaluated its efficacy discovered that Mobile Midwife's advice influenced women's

decisions to pursue vital obstetric care. Women were more aware of the importance of providing professional care during pregnancy and childbirth, as well as identifying signs of illness in their newborn (Entsieh et al., 2015). Another effective digital MCH initiative included the use of mobile phones in Egypt that sped up response times for obstetric crises (Mechael, 2007).

Similar studies (Desta et al., 2014; Limaye et al., 2018) in low-income countries found that adding an entertainment aspect to digital MCH tools and using context-specific scenarios and identifiable characters such as how husbands positively influenced women's knowledge of MCH and promoted digital MCH in their communities (Desta et al., 2014). The above interventions allowed the actual barriers to MCH in communities to be identified through community engagement, addressing the above challenge of interventions not typically taking socio-cultural factors into account. However such interventions are limited in low-income, South African communities (Dahab & Sakellariou, 2020).

Current Challenges of Digital MCH in Low-income Countries

Research in HCI shows that digital MCH is more difficult to deploy in marginalized areas with limited health literacy, resources, technology and competing priorities such as prioritising providing for the family (Limaye et al., 2018). Neglecting these challenges and inequalities in digital access across different communities' results in the advantages of using digital health solutions only benefitting those who have the resources and skills to use technology effectively. This could exacerbate inequities in communities that are already vulnerable (Guendelman et al., 2017).

Furthermore, in low-income countries, mothers' reluctance to digitalization constitutes a barrier to furthering the digitalization of health information in underdeveloped nations (Nilsen et al., 2016; Numair et al., 2021). A qualitative investigation in Kenya (Numair et al., 2021) found that mothers lack trust in digital systems and have concerns about their privacy and confidentiality. Moreover, their reluctance also stems from unfamiliarity with digital devices and cultural disapproval of modernity as it is believed to oppose traditional remedies and methods (Nilsen et al., 2016; Numair et al., 2021).

Another issue identified in these digital programs was the 'novelty' effect associated with them, whereby engagement with the digital programs decreased over time. Alternative formats for the content such as videos or gamified features were suggested as a way to rekindle interest (LeFevre et al., 2017).

2.2.2. Participation Methodologies

In this section, we discuss and compare various participation methodologies and approaches including Action Research, Participatory Design, Participatory Action Research, Design Thinking, and the Double-diamond Approach, and relate them to our research approach.

Action Research, Participatory Design and Participatory Action Research

Action Research (AR) is defined as a family of social research involving collaboration between researchers and practitioners, through an iteration of activities, to create or actualize change. This research approach merges theory and practice through participation in order to develop realistic solutions to challenges that are of actual value to people, while conducting research (Meyer, 2004).

Participatory action research (PAR) is a subset of AR that focuses particularly on the inclusion of the participants in the process of gathering and analysing data, and to make decisions about what action should be taken next (Baum et al., 2006). This varies slightly from Participatory Design (PD), where the fundamental purpose is to investigate elements of human behaviour, contributing to knowledge through cooperative collaborations with stakeholders, rather than immediately changing the communities, organizations, or groups being observed (Sohng, 1996). Our work adopts a PAR approach by including community members in the ideation and development of an MCH intervention.

User-centred Design (UCD), Co-design and Community-based Co-design (CBCD)

User-centred design (UCD) encompasses a framework of processes that focuses on the end-users' needs, wants and limitations, and includes them throughout the phases of design of a product. Gould and Lewis defined (1985) UCD's essential concepts as "early and continuous attention on users; empirical assessment of usage; and iterative design". The user is regarded as a subject as opposed to a partner in the design process (Gould & Lewis, 1985).

UCD concepts generally apply in HCI research, whereas PD is the larger theoretical framework focusing mainly on direct user interaction. Both PD and UCD approaches emphasise user involvement in creating user-friendly solutions, but differ in the nature of user participation. PD includes users as designers in the design process, while UCD typically emphasizes user feedback and usability testing (Antonini, 2021). Co-design subsequently expands upon the principles and methods of both PD and UCD, as an approach to design in which designers work creatively with people often without professional design training. A fundamental tenet of co-design is involving *all stakeholders* in the design process, as this promotes greater adoption rates and results that better meet the needs of all parties involved (Antonini, 2021).

Moreover, a branch of co-design, Community-based co-design (CBCD), is a participatory approach that facilitates community design innovations, wherein community members are considered as equal partners in the design process. This strategy transcends standard participatory approaches by fostering and deepening equal co-operation amongst individuals who are affected by an issue. In essence, the research strategy changes from a "research on" to a "research with" approach (H. Chen et al., 2018; Reynolds-Cuellar & Delgado Ramos, 2020). Furthermore, its design prioritizes community value structures, ideals, needs, and realities to ensure that solutions are more likely to be implemented, used and sustained (H. Chen et al., 2018). Such interventions allow the actual barriers to MCH in communities to be identified and addressed (H. Chen et al., 2018; Reynolds-Cuellar & Delgado Ramos, 2020).

With regards to its application, participatory methodologies have recently been used to engage healthcare workers and users in examining, intervening, and executing new systems. These methods are typically used to address health inequalities and improve the patient experience for vulnerable communities, as well as groups that have historically been marginalized and discriminated against in traditional research (H. Chen et al., 2018; Guendelman et al., 2017). Traditional health research uses top-down approaches wherein safety and functionality are prioritized but participatory methodologies place additional emphasis on ensuring that the intervention maximises target-user satisfaction (H. Chen et al., 2018; Guendelman et al., 2017). The necessity of knowing participants' environments before including them the design process to achieve this target-user satisfaction is highlighted in HCI research. This practice also encourages individuals to participate freely in the study and maintain intervention utilisation (Hussain et al., 2012; Mburu et al., 2018). For instance, Mburu et al. (2018) found that stakeholders were more eager to engage in the study since they had previously established a rapport with them. They suggest that researchers should aim to understand their participants' environments prior to engagements with them, particularly when conducting research on sensitive and under-researched issues (Mburu et al., 2018). In our work, we attempted to build this rapport with community members through initial interviews and discussions on their MCH experiences before co-designing with them.

Research on mothers and family groups can be approached in a variety of ways, according to Mackay and Fayard (1997). In their work, they employed triangulation, a methodology that includes combining different methodologies to attain in-depth findings from an investigation (Mackay, 1997). They used workshops, observations, interviews, and prototyping. This aided in developing a comprehensive understanding of the research being explored and has shown to support validity of research (Mackay, 1997). Similarly, in our research a combination of interviews, co-design workshops using Design Cards, storyboarding, group discussions and prototyping are used.

Design Thinking and Double Diamond Thinking Approach

Design thinking is a human-centred approach to innovation that integrates diverse disciplinary expertise. It prioritizes real user needs as opposed to historical data (Brown & Wyatt, 2010). Brown and Katz (2010) outlined the three iterative steps of the design thinking process: *inspiration*, which entails problem identification, *ideation*, which involves developing and testing creative ideas, and *implementation*, which effectively puts the created artifact into practice (Brown & Wyatt, 2010). Design thinkers are tasked with gaining meaningful insights centred on understanding user experiences during the ideation phase, rather than acquiring a surface understanding that might arise when conventional research methodologies are utilized (Brown & Wyatt, 2010). In our research, we apply design thinking principles in practice by identifying and learning digital MCH concerns directly from users, and combining expertise with researchers and health experts, to collaboratively prototype innovations.

Another valuable model associated with community-based co-design is the double diamond thinking model developed by the British Design Council (2005) for illustrating the practice of divergence and convergence during the design and innovation process. This model reinforces the importance of exploring and defining a problem first, before focusing on developing and delivering the solution (as seen in Figure 2 below) (Banathy, 2013). We use this approach in our work, whereby we prioritise learning general MCH concerns first from community members before focusing on specific domains too address. When developing the solutions, we brainstormed and co-designed a wide range of ideas before narrowing down to a prototype, in collaboration with community members and researchers.

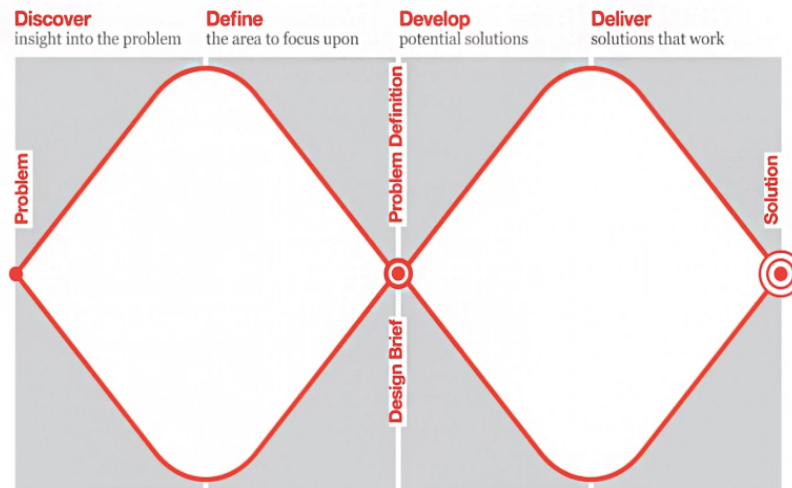


Figure 2: Double Diamond Thinking Approach (British Design Council, 2005)

2.2.3. Theories Adopted in Co-design and MCH

In their work on co-design and healthcare, Knowles, Erica, et al (2021) shared that co-design approaches are often criticized for neglecting theory and evidence by prioritising user engagement. However, they proposed that studies demonstrate that there exists theoretical insight alongside stakeholder input which, together, is able to lead to more sustainable change as opposed to theory per se (S. E. Knowles et al., 2021).

They posit that co-design processes utilize existing evidence, by creating user personas based on synthesized qualitative data or by analysing co-design products using theoretical frameworks (S. Knowles et al., 2018). Additionally, co-design uses theories from behavioural science to guide the design of particular interventions by relating behavioural characteristics to interventional elements (S. Knowles et al., 2018). In this section, we look at underlying theories supporting co-design approaches, including the actor-network theory, social cognitive theory.

Actor-network theory

The Actor Network Theory (ANT) studies the interactions between actors, and is applied in design studies where design occurs concurrently with creation, by forming relationships between designers,

users, products, and other actors such as devices and technology (Storni et al., 2015). In co-design, ANT analyses the different roles actors play in co-design approach. Different actors in the design process shape the overall interactions of co-designers, and the various types of networks and their impact on the design process are determined by comparing co-design cases. ANT provides an analytical framework for describing and comprehending socio-technical aspects of design, and considers the hybrid nature of events in co-design. Palmas and Von Busch (2015) were able to contribute research to PD participation by adopting ANT in their research in PD participation and perceiving study participants as networks in PD, contributing that PD partially exists in all elements of a design project and that there is no gold standard for participation (Palmås & Von Busch, 2015).

Social Cognitive Theory

Another theory that interacts with co-design values is Social Cognitive Theory (SCT) (Bandura, 1998, which describes the social and environmental influences on human behaviour. SCT encompasses, “Reciprocal determinism”, which is a process that the theory explains as the interaction and impact of people with their surroundings (Benight & Bandura, 2004). Core SCT constructs are used to anticipate behaviour and direct the creation of innovations and programs (Bandura, 1998). Research has shown that knowledge of health risks and benefits, observational learning, and self-regulation are some of the personal factors that influence behaviour (Glanz et al., 2008). According to SCT, a prerequisite for change and a crucial component for influencing behaviour is knowledge of the advantages and dangers of health (Benight & Bandura, 2004). In order to exert self-control over behaviour, people must develop a variety of skills known as self-regulation (Bandura, 1998). According to (Glanz et al., 2008), self-regulation is achieved by the following actions: (1) identifying and adopting proximal goals; (2) receiving feedback on the performance quality and areas for improvement; and (3) finding social support in those who support their efforts (Glanz et al., 2008); (4) "environmental facilitators"—factors that provide enabling conditions to enable behaviour. This demonstrates the significance of knowledge acquisition and contribution in behavioural changes, and in the context of our study, MCH seeking-behaviours, as employing co-design for MCH aids in empowering, raising awareness and subsequently acquiring information of MCH among the community members.

In a study using activity cards in co-design and studying the interaction between SCT and co-design for peer programs, social support, a key SCT construct, was a key theme for parents in co-creating innovations (Hurley et al., 2021). Specifically, the researchers remarked that collaborations and interactions with other parents would be helpful in supporting the development of peer-to-peer support networks as well as enabling idea sharing and feedback among participants. (Hurley et al., 2021). This shows us the importance of group-settings and community for co-design research, which is applied in our research across the various community settings.

2.2.2. Critical Reflections for Participation in HCI4D research

In this section, we provide critical reflections for Participation in HCI4D research. This includes discussions on associated frameworks such as Feminist HCI, Asset-based participation, Value Sensitive Design (VSD), and Postcolonial computing.

Feminist HCI

Feminist HCI tackles the development and evaluation of interactive computer systems from a feminist perspective (Bardzell, 2010). It emphasises the values of feminism in HCI work, such as equity and social justice, and understanding the impact of gender on the design and evaluation of interactive systems. This is practiced by building off the epistemology of feminist standpoint theory, which acknowledges that women are limited to certain roles, such as child-rearing and breastfeeding, and as a result have different types of knowledge compared to their male counterparts (Bardzell, 2010).

In Bardzell's 2010 book, *Feminist HCI: Taking Stock and Outlining an Agenda for Design* (Bardzell, 2010), the term "feminist HCI" refers to interactive systems that "are imbued with sensitivity to the central commitments of feminism — agency, fulfilment, identity and the self, equity, empowerment, diversity, and social justice," and "entails critical perspectives that could help reveal unspoken values within HCI's dominant research and design paradigms and underpin the development of new approaches, methods and design variations".

A study by Shooshtari et al. (2018) focused on the empowerment of women and its relationship to mental health improvement. It explores how empowering women in all spheres of life, such as through knowledge and decision-making, may have a positive impact on their mental health. This dovetails with Galderisi et al.'s definition of mental health (2015), which advocates for the presence of holistic mental well-being. The authors propose that emotional and social components should all be included when discussing mental health, with a focus on elements like resiliency, self-determination, and life satisfaction. Through this work and our direct engagements with mothers which aims to learn their actual MCH priorities, we attempt to empower mothers and prioritise their voices which are usually silenced in the creation of interventions intended to benefit them.

Post-colonial Computing and Decolonising HCI

In their 2010 work, *Postcolonial Computing: a lens on design and development*, Irani, Vertesi et al. (2010) define postcolonial computing as "an alternative sensibility to the process of design and analysis." It communicates a set of issues and concerns influenced by postcolonial contexts but applicable to any design endeavour.

Irani, Vertesi et al. (2010) propose that Postcolonial Computing is not aimed at only improving design for different cultures or locations but is rather an approach investigating how all design research and practise is culturally placed and burdened by power. They highlight that understanding this helps us to expand the discussion about what additional behaviours may be considered good design. Thus, it is a paradigm change inspired by the difficulties and complexities of transmitting technical knowledge, notably in ICT4D and HCI (Irani et al., 2010).

Furthermore, we dovetail Postcolonial Computing in conversation with the decolonisation of HCI through a South African standpoint. As posited by Bidwell (2016), such colonial epistemologies are further reinforced within HCI contexts where African identity is commonly underrepresented in HCI research and outputs. Lazem et al. (2012) adds to this by arguing that the foundations for HCI innovation are located in Western contexts and this underrepresentation is exacerbated by the tendency of technological systems and standards to emerge from these contexts but aspire to universality. Thus, technological standards are frequently defined in one part of the world and thereafter globalized. These standards are suited to the experiences of people in the region of the world where they were defined, potentially ignoring or underrepresenting the rest of the world. (Lazem et al., 2022)

In this work, we acknowledge and explore the weight that varying cultures and power imbalances across the different sites carry in implementing digital interventions. We consider the above viewpoints of Irani, Vertesi et al. (2010) in the context of working with four multicultural, low-income South African communities and exploring their culturally-situated MCH needs. Furthermore, we explore the opportunity of innovating and adding to HCI outputs through the lens of underrepresented populations in South African HCI work.

Needs vs Asset-Based Participation and Value-Sensitive Design

A needs-based approach to interventions entails a thorough assessment of individual and community holistic requirements. Thereafter, significant issues and priorities are identified and addressed through the necessary assistance and resources (Pameijer, 2006).

On the other hand, asset-based community development accounts for that which is already existing in the community and builds on the assets and capacities of individuals, groups, and institutions (McKnight & Kretzmann, 1993). Instead of focusing on what is lacking or defective in the community, Kretzmann and McKnight (1993) advocated a strategy that incorporates the community's engagement in its own development. In this work, we conducted an asset analysis to learn what communities currently use for their MCH needs, and apply an asset-based approach to incorporate these assets in a digital intervention.

Besides their assets, we also wish to maintain the community values and socio-economic sensitivity by incorporating value-sensitive design (Friedman et al., 2013). Value-sensitive design aims to use theory and methodology to account for human values throughout the design process. Engaging both our moral and technical understandings is essential to this strategy, whereby we consider the ethical implications before developing the technology (Friedman et al., 2013).

2.3. Chapter 2 Summary

This chapter explored related work that influenced this work, providing literature, theories, and past research related to this research topic. Firstly, we discussed MCH and Digital MCH in low-income contexts. This involved identifying current MCH challenges in low-income regions such as mother hesitancy, lack of timely support, poor transport infrastructure, low awareness of MCH and other challenges highlighted by the Three Delays and similar studies. We then looked at the ways in which digital MCH has been used to address such MCH challenges, such as SMS systems that increased use of prenatal and postnatal vaccinations and applications which increased awareness of expecting mothers of pregnancy care. The challenges of digital MCH were briefly described, including competing priorities of mothers, inadequate deployment, and low digital health literacy. Next, we discussed various participation methodologies and how they relate and differentiate from one another, and align with this research. This included discussions on Action Research, Participatory Research and Participatory Action Research, as well as related approaches including design thinking and the diamond thinking approach. We also highlighted the different levels of participation of different stakeholders in each methodology. We then looked at theories related to co-design which included the actor-network theory and Social Cognitive Theory. Finally, we provided critical reflections on participation in HCI4D research in order to situate what we are doing in HCI discourse and describe the ethical issues therein. This includes discussions on related frameworks such as Feminist HCI, Asset-based participation, Value Sensitive Design (VSD), and Postcolonial computing. In the next chapter, we discuss the first phase of the project, which focuses on the community interviews on the community members' experiences and challenges with MCH and digital MCH

CHAPTER 3

Community Challenges Related to MCH and Digital MCH

3.1. Introduction and Background

In this chapter we explore *Phase 1* of this research, the community interviews, which involved interviews with South African parents, caregivers and other community members in the four research settings (described in Section 2.1.4.). The aim of the interviews was to learn about how communities are currently seeking MCH care, what tools they are using and have access to in order to do so, and identify their MCH and digital MCH experiences and challenges. We present our findings from the interviews and in doing so, we identify key MCH community challenges, and contribute to answering our first research question on the characteristics of current existing tools and mediums to address key MCH priorities. The discussion of our third research question—*how do actual parent priorities correspond with HCI priorities for MCH and digital MCH?*—is initiated by the findings on the MCH challenges and priorities, but this is expanded upon in Chapter 5, which focuses on the outcomes of the community workshop.

3.1.1. Current Approaches Addressing MCH Challenges

In the previous chapter on related work, we described MCH challenges and barriers emerging from research in low-income countries in the Global South. These barriers included poor healthcare infrastructure, poor affordability of healthcare, low awareness of MCH services, inadequate transport infrastructure to MCH services, shortages of trained CHWs, and cultural norms dissuading communities from seeking public healthcare (Dahab & Sakellariou, 2020a; Rothstein et al., 2021). The identified priorities for Digital MCH in the HCI space in the Global South aim to address these barriers using technology, but there has been a prioritisation in the HCI space primarily on the development and evolution of ICTs for healthcare monitoring (Babar & Rahman, 2021), especially for HIV and its prevalence (Kapuire et al., 2010; Natarajan & Parikh, 2013), as well as for pregnancy (Mbuthia et al., 2019; Odeny et al., 2014). This deviation between the identified priorities and what is currently being targeted may be because HCI research on MCH in the global south may stem from top-down research (Kaufman et al., 2017; Rothstein et al., 2021). Thus, we aim to gain deeper insights on how this may compare to actual parent challenges and priorities and explore additional challenges and priorities that we may learn through our engagements with the four communities.

Additionally, we take note of how researchers are currently addressing MCH challenges in the HCI space and with whom they are consulting in order to learn about these challenges and address them. MCH studies in low-income African communities primarily target engagements with CHWs, rather than the parents and other caregivers who would directly benefit from interventions (Layton & Elaluf-Calderwood, 2016). Studies show that this is the case because CHWs are often deemed as

trustworthy proxies for the actual targeted communities and possess health expertise (Layton & Elaluf-Calderwood, 2016). However, most digital MCH co-design studies focus on expert health education (Lamont et al., 2016) and digitising health systems for CHWs and medical centres, (Hackett et al., 2018; Maleka et al., 2016; Thomas & Lupton, 2016) and often do not immerse themselves in qualitative research on the lived experiences of parents in communities.

Moreover, another issue we observe in current studies is that participants and users are frequently only consulted after the design process, or provide feedback after some “expert” design has already taken place (Layton & Elaluf-Calderwood, 2016). According to Sanders and Stappers (2008), consulting with users and co-design are separate from one another as co-design entails participant involvement from the beginning of the design process. This delayed involvement of CHWs and other caregivers in the design of interventions may explicate some of the present gaps in digital MCH.

Furthermore, in the cases where parents are involved in the design, other family roles are most often disregarded in parent studies. However, communities possess their own distinctive notions of knowledge, as stated by Kapuire et al. (2010), and these groups should be given the opportunity to develop digital interventions in a way that honours and portrays their cultural identity. Thus, community entities such as family structures including grandparents and aunts etc., should also be involved in community-based design (Kapuire et al., 2010). This may also explain contribute to gaps in the design of MCH studies.

3.1.2. Asset-analysis of Devices in South African Households

We continue to see a digital gap between various populations in South Africa as a result of socio-economic differences. According to a Stats SA 2021¹⁰ study on South African assets in homes, household access to the Internet at home is greatest in the Western Cape (25,9%) and Gauteng (16,4%), and lowest in Mpumalanga (1,7%) and Limpopo (1,9%). While 17,2% of urban households had access to the Internet at home, just 1,2% of rural households in general and fewer than 1% of rural households in the Eastern Cape (0,2%), North West (0,3%), and KwaZulu Natal (0,2%) had access to the Internet at home. A higher proportion of families (17,6%) access the Internet at work, Internet cafés, or educational institutions than at home (10,4%). Households in Gauteng (27,8%) and the Western Cape (22,2%) were the most likely to use the Internet at work, while those in North West (6,6%) were the least likely.

Solely 2,2% of homes in South Africa did not have access to either landlines or cellular phones, while 0,5% of South African households only utilised landlines. In comparison, cellular phones are used solely by 90,8% of South African homes. Cell phone use was most widespread in the Eastern Cape (94,2%) and least common in KwaZulu-Natal (86,3%). Households that used both cellular phones and landlines were most prevalent in the Western Cape (9,7%) and KwaZulu-Natal (9,6%).

¹⁰ statssa.gov.za/publications/P0318/P03182020.pdf

Accessing the Internet through mobile devices involves utilising cellular phones or mobile access devices such as 3G cards. Mobile Internet connectivity has made the Internet considerably more accessible to rural homes. Nationally, mobile Internet connection (69.4%) was the most frequent method for Internet access. Although the usage of mobile Internet access devices in rural regions (59,2%) remains lower than in urban (73,7%) and metro (73,4%), it is far more widespread than any of the other options.

3.2. Approach

3.2.1. Objective

Semi-structured digital and in-person interviews with community members, including fathers, mothers, other caregivers, and community leaders were conducted to explore and understand the challenges faced in their communities when accessing MCH information. Interviews with community participants included exploratory questions related to the participants' healthcare-seeking behaviours, their usage of MCH applications and government healthcare resources, an asset analysis of their household devices, and their digital MCH concerns and wishes. As part of this inquiry, we asked participants about their experiences with the Road to Health Book (RTHB)¹¹, a guide that is distributed by the South African National Department of Health¹² to district health departments for all new births. The book is used collaboratively by health workers and caregivers to record children's development, immunizations, and health interventions. We also asked participants about their awareness of and experience with MomConnect¹³, which is a South African National Department of Health initiative supporting maternal health through cell phone-based technologies integrated into MCH services. The platform provides targeted health promotion messages for pregnant women and a helpdesk feature allowing women registered on the system to ask MCH-related questions and to provide feedback on public health clinics (Xiong et al., 2018).

3.2.2. Participants and Interview Methods

The research settings for the interviews (described in Section 2.1.4) varied between rural, semi-urban and urban contexts to diversify the range of data obtained, and more accurately reflect the realities of communities across South Africa. I¹⁴ conducted semi-structured digital interviews with eight mothers from Cape Town. Six other co-researchers that were based near the other three research settings conducted interviews with community members in the local language. These local researchers possessed qualitative research backgrounds in health, computing, and social science disciplines. The interview participants in the other three sites included four community health workers (CHW's)

¹¹ <https://sidebyside.co.za/resources/road-to-health-book/>

¹² <http://www.health.gov.za/>

¹³ <https://www.health.gov.za/momconnect/>

¹⁴ Methods in this work will be written in first-person, "I", for project work I have explicitly conducted myself, and "we" for collaborative work. When the word "we" is used, I also specify who the collaborators are.

and eight mothers from rural Limpopo; five CHWs, three mothers and two fathers from rural Sweetwaters; and eight mothers, two of which are also CHWs from semi-urban Soweto.

Written and verbal informed consent were obtained before the interviews started. We also used this opportunity to invite the participants to take part in the co-design workshops which we discuss in Chapter 4. In Cape Town, which is considered an urban site, I opted to do interviews remotely due to COVID-19 lockdown restrictions and all participants having access to WhatsApp. Each participant was asked whether they preferred to do a voice or Whatsapp call, with all of them choosing to use WhatsApp audio calls for the interviews. Caregivers were given 1GB of mobile data (120 ZAR airtime) to cover the amount of data used in the interviews, with excess intended for the participants' personal use. Interviews in the other locations were conducted online or in person, depending on the COVID-19 lockdown restrictions in the particular community setting. The local researchers recorded, transcribed, and translated the interviews from the local language into English and stored the outputs on a secure data cloud only accessible to the researchers. This data cloud is only available through an invitation and accessed through usernames and passwords. Interview transcripts were subsequently coded and thematically analysed (Clarke et al., 2015) as described in the next subsection.

Our research was approved by the ethics committees from the University of Cape Town (shown in Appendix G), Cardiff School of Computer Science and Informatics, the Human Sciences Research Council (HSRC), as well as the University of the Witwatersrand, and the University of Limpopo. Prior to the interviews and after confirming their availability, we obtained informed consent either in written or oral form. The research consent form is found in Appendix E.

3.2.3. Thematic Analysis

All interviews were recorded and transcribed into transcripts for analysis. We imported the transcripts into NVivo software¹⁵ to support this analysis. I initiated the coding process by creating the initial codebook based on the research questions and interview questions (and subcodes based on interview feedback – described below) and sent the codebook to the local researchers who conducted the interviews in each respective site. All the sites' researchers then came together and collaboratively cross-referenced the codes. The themes were discussed and finalised with all researchers. The thematic analysis of the data followed Clarke and Braun's (2015) six phases of the thematic analysis process. The following steps are included in these phases: 1. familiarizing oneself with the data by carefully reading and rereading the transcripts; 2. methodically assigning codes, descriptive or conceptual labels that capture potentially meaningful parts of the transcripts; 3. identifying themes by looking for deeper meaning and recurring patterns across the coded data; 4. revising identified themes by making sure the themes capture the fundamental idea of the dataset and provide a framework for further research.

¹⁵ <https://www.qsrinternational.com/nvivo-qualitative-data-analysis-software/>

A deductive coding approach was used for the initial coding whereby we used predefined codes for the codebook, referencing the various aspects covered in the interview questions across the sites. These included codes such as “Sources of MCH assistance”, “Devices used in household”, “Current MCH challenges, and “MCH community wishes.” Within these codes, more specific and inductive subcodes were created based on participant responses to these codes. For example, for the code “Sources of MCH assistance”, subcodes such as “Social Media”, “Google”, “Community” were prescribed. The full codebook for the interviews is presented in Appendix C. The co-researchers from the other research sites added to these subcodes based on their interview data.

After this thematic analysis process of collating the outcomes from the interviews across the sites and identifying pertinent MCH challenges, 20 members of the project’s interdisciplinary network of researchers and practitioners from health, computing and social science disciplinary backgrounds were invited to vote on the most important challenges. Each voter voted for three challenges to address. We created a Padlet¹⁶, which is a virtual collaborative bulletin-board, to do this (shown later in Figure 4 in the Findings Section 3.3.5.), which included the emerging MCH challenges and opportunities represented as different themes and nodes of related data under each theme. For example, the theme for “Peer support” included nodes “Parent well-being and agency” and “Fostering Peer support”, and “Advocacy for working moms”. The network researchers voted on the different nodes, and the top voted notes were chosen as MCH priorities to be addressed in the *Phase 2* workshops. These priorities are presented in Section 3.3.5. Furthermore, through the coded data related to technology devices and social media usage, we completed an asset analysis, which later informed the technology and resources included in our Design Cards discussed in Chapter 4.

3.3. Findings

In this section, participant quotes are anonymised and replaced with identifiers as follows: MSW (mother from Sweetwaters), MSO (mother from Soweto), MLI (mother from Limpopo), MCT (mother from Cape Town), FSW (father from Sweetwaters), FSO (father from Soweto), FLI (father from Limpopo), FCT (father from Cape Town), CSW (caregiver from Sweetwaters), CSO (caregiver from Soweto), CLI (caregiver from Limpopo), CCT (caregiver from Cape Town), CHSW (CHW from Sweetwaters), CHSO (CHW from Soweto), CHLI (CHW from Limpopo), CHCT (CHW from Cape Town). A description (role and location) of the participant is provided for each quote.

3.3.1. Asset Analysis of Participants

In terms of their access to digital MCH-associated resources, the majority of the participants interviewed across the sites stated that they have access to mobile phones and laptops, with all participants from Cape Town owning a mobile device in their household. However, it was found that many participants from all four sites experienced “network challenges”. In Cape Town, this largely entailed participants not having persistent access to WIFI (wireless fidelity) and having limited data

¹⁶ <https://padlet.com/>

plans, while for the participants from the other, more rural sites, network challenges referred to poor network coverage, and them being unable to afford any mobile data.

Responses from mothers in Sweetwaters related to this include:

“Yes, we have lots of challenges with the network because it happens sometimes you try to contact someone and the person is offline, and then when you follow up the person you find that he was not offline it was a bad network coverage. That delays the communication a lot.” - Mother from Sweetwaters (MSW1)

“There are places in areas where the network towers haven't been installed... another issue could be of data because it's not cheap to get data.” - Mother from Sweetwaters (MSW2)

All participants from Cape Town owned a smartphone, while the participants from the other sites did not all have access to a smartphone and expressed that this prevented them from accessing the Internet. However, participants from rural Sweetwaters and Limpopo expressed that many of them in the community cannot afford electricity to own and maintain any mobile device. Similarly in Soweto, many participants expressed that access to the Internet and mobile devices was inconsistent and that unaffordability of electricity further complicates technology-based solutions as long periods without power mean people cannot even receive SMSs. Most participants in Cape Town had access to the internet at home, while the participants from other communities expressed that they mainly only access to the internet at internet cafes. A mother from Soweto expressed: *“No, we don't have internet access like Wi-Fi, I use Internet Café for access. It doesn't make sense to not buy food for the children just to pay for Wi-Fi.”* - Mother from Soweto (MSO1)

3.3.2. Current Healthcare-seeking Behaviours and Sources

In this section, we explore the participants' health-seeking behaviours and sources of healthcare. These included family and friends, community spaces, traditional healers, online platforms, and government clinics.

Seeking MCH Socially through Community and Online platforms

Across the sites, participants expressed that asking family members and close community members for MCH advice was their preferred method for seeking MCH guidance. In Cape Town, this only included family members, while other sites included community members as well, expressing a more communal view to seeking MCH information. The participants across the sites expressed that they believe in learning from persons they trust that have personal, first-hand experience with MCH, showing a need for familiarity and trust when seeking MCH information. Some responses when asked where participants acquire their MCH information from include:

“I ask people that I am living with especially my mum, if it is something that she does not also understand then I will only take the child to the clinic” – Father from Sweetwaters (FSW1)

"I ask my mother when I need help. She will always give me advice." - Mother from Cape Town (MCT1)

"From my family members of granny, they can get someone that can communicate the information relating to all issues of maternal and child health". – Caregiver from Limpopo (CLI1)

"I think the community caregivers are useful to facilitate or spread information; it reaches lots of people in the community" - Mother from Sweetwaters (MSW3)

"Our grannies, mothers, aunts they are the ones who make sure that we understand these things, even though they are still using the old ways but we grow." – Caregiver from Soweto (CSW1)

In the Sweetwaters and Limpopo interviews particularly, culture plays a significant role in community members' approach to MCH. In Sweetwaters, the community members expressed that fathers are typically not involved in MCH and child development as part of their culture, with their primary role being financial assistance.

A father from Sweetwaters commented on this: *"On the male perspective there is lack of information about the father of the child, it is always only the mother's information. The lack of involving men from onset makes them not to be supportive on the pre- and post-delivery journey."* - Father from Sweetwaters (FSW2)

In Limpopo, it is customary for community members to seek traditional healers first before consulting commercial doctors. A participant from Limpopo stated: *"Home, traditional I will start at home because we believe in tradition. I have a traditional healer at home, so if the traditional healer fails, then we can go to the clinic. The traditional healer assesses if they could be able to assist with the maternal and child health problem, and if they can't then, I will go to the clinic"*. – Mother from Limpopo (MLI1)

Moreover, it was found that community members often provide conflicting advice, for example, traditional healers and friends will have different opinions to their doctors and CHWs. For instance, a mother from Sweetwaters stated:

"My neighbours said a lot of things that were different from what they were saying at the clinic." – Mother from Sweetwaters (MSW4)

In Soweto, traditional healers were not described as a common source of health information or care, and younger participants expressed concern and scepticism about older relatives or elders in the community promoting traditional cures or harmful health advice. A caregiver from Soweto stated:

"There was an instance where a child got a red patch at the back of their head, only to find that it was nothing major... However, when elders made wind of it, they made it a major issue and then a child goes through a painful procedure. We fall for this as desperate new mom who wants the best

for their child only to find that this makes things worse. If people can come and urge us to go to clinics to get more knowledge and ask questions, that will help a lot.” - Caregiver from Soweto (CSO1)

In Cape Town, all the caregivers expressed that they mainly use WhatsApp for seeking MCH from others. Participants from Cape Town and Sweetwaters also stated that they used the internet for looking up MCH material. For example, a mother from Cape Town stated: *“I will Google something like if I am not sure about medication that they gave, then I would like Google it and find out more about the medication for my sons.”* – Mother from Cape Town (MCT2)

Participants from Limpopo and Sweetwaters also use more traditional pamphlets, radio and TV for MCH queries. A response on this from a CHW in Sweetwaters was:

“There are handouts or pamphlets that they can read. They get them if they go to the clinic. And also can easily access them from the tuck shops and read them.” - CHW from Sweetwaters (CHSW1)

Clinics as an Inaccessible MCH Source

Participants from all sites use their government local clinics to access healthcare and expressed challenges associated with using the government clinics, with common issues being long lines and waiting times, and limited staff. Participants also expressed a shortage of clinics close to them and lack of transport money to the clinics. A participant response regarding this transport issue was: *“You find that sometimes the clinics are far and others cannot afford to reach those clinics; they have no money.”* - Mother from Sweetwaters (MSW5)

Participants expressed clinic waiting times, over-crowdedness, and long lines as evident MCH-related challenges in their communities. Participant comments supporting this included:

“Because the clinics are always full and you find that there's lots of people waiting to be assisted and the pregnant woman and the children are vulnerable to infections from people who are older and very sick in the clinic waiting room.” - Mother from Sweetwaters (MSW6)

“Sometimes people will complain about the services at the clinic...and about the long lines that they have to stand in” - Participant from Cape Town (MCT2)

“Our clinic is bad, it doesn't have space for one, it's overcrowded and then the people there don't want to give out the medication... It's always full, sometimes they tell us to turn back because it is full.” – Father from Limpopo (FLI1)

We observed that these issues with local clinics occurred in both rural and urban settings.

3.3.3. Participant Experiences with Digital MCH

Experiences with the Internet and Social Media

We found that the above sources of MCH information takes preference over MCH applications, although some mothers from all sites were aware of and have tried using MCH apps such as MomConnect. Some participants stated that using the Internet, social media and radio is easier for them and more easily accessible as it was what they are accustomed to using.

Furthermore, it was discovered that Facebook and WhatsApp are the preferred social media mediums for communicating and accessing MCH information as these applications do not tend to use as much data as others, and are thus more affordable for the participants across all sites. A CHW from Sweetwaters stated the following regarding using Facebook for MCH information:

“I think Facebook is a good platform because Facebook does not take a lot of data. There are also ways where you can access Facebook without data.” – CHW from Sweetwaters (CHSW2)

Moreover, it was noticed, that across the sites, caregivers mainly seek MCH information only when they are experiencing a child development or MCH-related difficulty. Thus, such material is rarely sought after prior to childbirth or throughout the early phases of infant development.

Challenges with Current MCH and Digital MCH

In Cape Town, the most common reasons for not using digital MCH were a lack of awareness of the applications and a preference for using family members, whereas the reasons in the other sites were additionally more socioeconomic in nature. These issues included a lack of affordability for necessary resources like mobile devices and mobile data, as well as inadequate connectivity and network issues. Some comments on this include:

“I know nothing about the apps but what I know is that in this area, network connection is a problem.” – CHW from Limpopo (CHLI2)

“The problem is network connection whether MTN or VODA - we struggle to connect.” - Mother from Limpopo (MLI2)

Other barriers to acquiring digital MCH raised included language barriers for understanding MCH and a lack of trust on online information. For example, a participant stated: *“It was too much what they were saying on WhatsApp (WhatsApp-based MCH intervention) because people were saying a lot of things, so I did not know which one to trust”* – Mother from Sweetwaters (MSW4)

In Soweto, a few participants felt that technology is not expected to solve their problems. Young women and caregivers rarely highlighted technology solutions and were reluctant when prompted to think specifically about such directions. One participant from Soweto asked: *“Must you make an app?”* (Klingberg et al., 2022) – Caregiver from Soweto (CSO1)

MomConnect was largely unknown and unused by the caregivers in Cape Town, with only one interviewee having used it previously. The caregivers from the other sites shared mixed views on the application with some benefits and challenges regarding the application mentioned:

The caregivers were pleased with the notification system of MomConnect, whereby they would be sent reminders for clinic appointment dates. They were also happy about the information they received weekly related to childcare. A mother from Limpopo noted: *“Mom-connect will notify me about my next visit....and informs me about the baby's development. They send a lot of information every week about childcare e.g. if a child is vomiting what you should do and if the child is not improving when should you go to the clinic.”* – Mother from Limpopo (MLI2)

Challenges associated with MomConnect mainly comprised accessibility barriers. Lack of affordability of mobile devices, data, and network coverage to access the application often came up as barriers. Non-economic accessibility issues included language barriers as the application does not have translations in their home language, as well as exclusion of fathers as it was stated that the application is ‘available’ at the clinics only for mothers. Participants from Limpopo stated the following on this:

“Though I have used mom-connect during pregnancy, network in this area is a serious challenge”. – Mother from Limpopo (MLI3)

“MomConnect can work better if they can improve the network coverage and connection wherein even those who cannot afford to buy data can have a free connection and access the information” – CHW from Limpopo (CHLI1)

Regarding the Road to Health booklet, participants from all sites found that the booklet was effective in monitoring their infants' records, but some were not as pleased with the booklet. Language and jargon barriers was a recurring barrier to MCH in Sweetwaters and Limpopo. Participants from these areas were unable to understand the booklet, and many others preferred using their mobile devices over reading a booklet. A mother from Sweetwaters stated:

“I do not understand the booklets, most of the things written there is in big words and language that I find it hard to understand. It would be better to have an App that would explain all the steps and the important of the booklet the way we can understand” – Mother from Sweetwaters (MSW3)

Multiple caregivers from Cape Town did not find the Road to Health Booklet personally useful as their children who have preterm disabilities did not always follow or meet the prescribed milestones. A mother commented: *“I could not really use all the information in there [RHB] because my baby did not meet the milestones.”* - Mother from Cape Town (MCT1).

3.3.4. Community Aspirations for Digital MCH

Suggestions for digital MCH were made by some participants. They voiced the need to implement cost-effective strategies that allow caregivers from rural areas and those who can't afford smartphones and data to access MCH information. A mother from Sweetwaters stated: *"I think it will be wise to develop a free app because most of the people are unemployed and they do not have money to buy data to access information on the internet"* – Mother from Sweetwaters (MSW3)

Regarding existing MCH sources, participants from Sweetwaters suggested that the Road to Health booklet be made available on mobile devices, and allow for translation to home languages. A comment on digitising the book included: *"I prefer to access information through the phone because unlike the road to health book which you put it away, but with the phone, we spend a lot of time using it even when I'm bored, I read the information sent through mom-connect"* - Mother from Limpopo (MLI1)

Participants from Limpopo also suggested that the information from the booklet and MCH information be made available in video or audio format as people prefer these formats over reading through an overload of information. A mother from Limpopo stated the following on this: *"You see people are attracted to videos than reading, if nurses can shoot a video about pregnancy or child health care the information will spread fast through Facebook, WhatsApp and we can also share with those we know they are pregnant"* - Mother from Limpopo (MLI2)

Others suggested that MCH material be played in waiting rooms at clinics for caregivers to listen to while waiting at the clinic. A comment from a CHW in Limpopo stated: *"The clinic can give them recordings or let them listen to such recordings. These could be done by separating mothers from other community members in the waiting areas so that they can listen or watch the videos about pregnancy and child development."* - CHW from Limpopo (CHLI2)

In Soweto, it was highlighted that information should be delivered to communities in a way that "sticks," as community members are frequently informed or taught MCH material but do not grasp or retain it. Furthermore, the need for increased involvement of fathers was re-iterated in Limpopo. Another CHW from Limpopo stated: *"We can have more projects involving men wherein they can gather or share ideas as males using WhatsApp or Facebook on how to assist the mothers in taking care of our children, women do that more often but us men we don't"*. - CHW from Limpopo (CHLI1)

Figure 3 below presents a word cloud produced from the NVivo software showing most frequently occurring words surrounding the theme for community MCH wishes across the four sites.

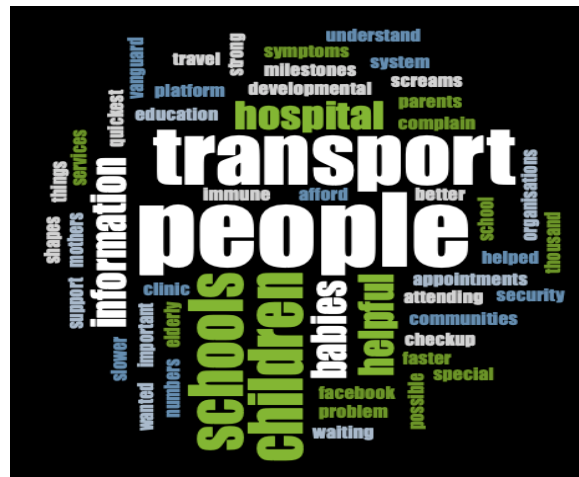


Figure 3: Community Wishes for MCH Word Cloud

3.3.5. Multistakeholder Ranking of Priorities for Digital MCH

As discussed in Section 3.2.3, members of the CoMaCH project’s interdisciplinary network of researchers and practitioners from health, computing and social science disciplinary backgrounds were invited to vote on the most important challenges using a Padlet tool. This Padlet is shown below in Figure 4.

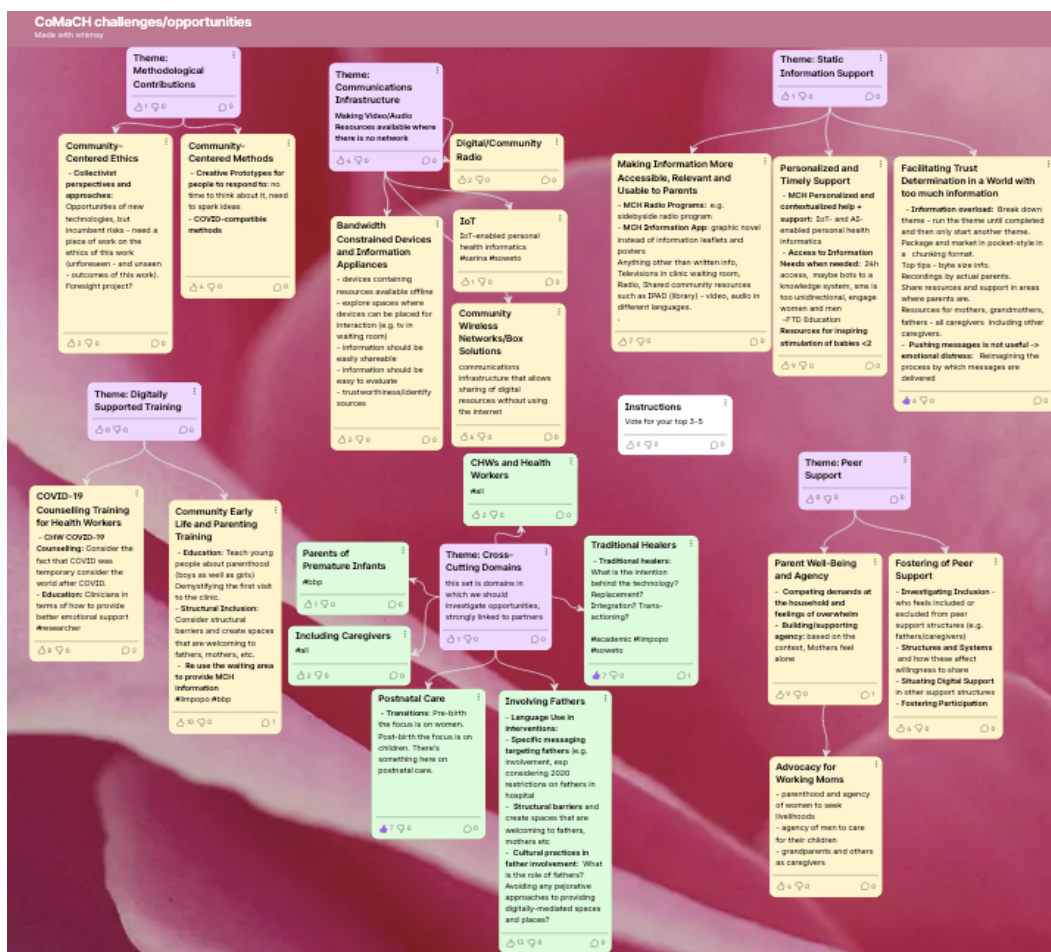


Figure 4: Padlet Containing Themes and Challenges with Network Members Votes

The MCH challenges and priorities presented in the Padlet above is available in Table 1 below, with the top-voted nodes highlighted and their number of votes received shown in brackets. The full Padlet with comments is provided in Appendix F.

Table 1: Themes for The MCH Challenges and Priorities Emerging from the Community Interviews with the Top-voted Nodes Highlighted

Theme	Nodes
Communications Infrastructure	• Bandwidth Constrained Devices and Information Appliances (2) • Digital/Community Radio (2) • IoT (1) • Community Wireless Networks/Box Solutions (6)
Digitally Supported Training	• COVID-19 Counselling Training for Health Workers (8) • Community Early Life and Parenting Training (10)
Static Information Support	• Making Information More Accessible, Relevant and Usable to Parents (7) • Personalized and Timely Support (9) • Facilitating Trust Determination in a World with too much information (7)
Cross-Cutting Domains	• Traditional Healers (7) • Involving Fathers (13) • Postnatal Care (7) • Including Caregivers (2) • Parents of premature infants (1)
Peer Support	• Parent Well-Being and Agency (9) • Fostering of Peer Support (4) • Advocacy for Working Moms (4)
Methodological Contributions	• Community-Centred Ethics (3) • Community-Centred Methods (4)

Nine key community challenges were finalised based on the top-voted nodes. In addition, “COVID-19 Vaccine Hesitancy” was added by researchers and health professionals as it was a timely challenge being faced in South Africa at the time. The process for the wording and phrasing of each challenge is discussed in the next chapter, Chapter 5. The final ten MCH challenges and priorities consisted of the following:

- **Traditional healers:** The impact of traditional healers on MCH health-seeking behaviours.
- **Parent well-being:** The importance of and lack thereof parental emotional well-being in communities.
- **Affordable and accessible health information:** The challenge of accessing relevant MCH information in local languages despite data costs and literacy.
- **Misinformation:** The challenge of sifting through competing and conflicting information sources.
- **COVID-19 vaccine hesitancy:** Considering issues around vaccine uptake.
- **Building parenting skills in early life:** Many parents felt like they did not have sufficient parenting skills, or were unaware of the importance of early childhood development.

- **Health worker emotional support:** Poor health worker empathy is a key problem in public healthcare; resulting in often hostile interactions.
- **Personalized and timely support:** Parents felt that the support available during times of need was never appropriate for the immediate situation.
- **Postpartum care:** The lack of and need for postpartum care in these communities.
- **Involving Fathers:** The absence of fathers and importance of increasing their involvement in MCH.

3.4. Discussion

3.4.1. Characterizing the Current Status Quo for MCH and Digital MCH

The Challenges and Opportunities of Digital MCH

The *Phase 1* findings provided insights into the current MCH and digital MCH situation within these communities, including their existing resources and mediums, and associated challenges experienced by community members. According to the interviews with the parents, MCH-related applications are not widely used by caregivers due to language and accessibility barriers, and lack of awareness of such applications. This finding and the others related to digital MCH challenges align with recognised reasons for poor usage of digital health, including lack of trust in using digital health technologies, poor affordability of mobile data and smartphones and accessibility (Elliot et al., 2022; Watkins et al., 2018). Digital MCH platforms are limited and those which are available are often underutilised. For example, according to a national study of MomConnect’s interactive helpdesk feature, approximately only 8% of registered users of the application engaged with the interactive feature for health information, partially due to poor advertising and training of using the feature (Xiong et al., 2018). Furthermore, a qualitative study conducted in South Africa using a combination of key informant interviews and site visits suggests that the use and scaling of mHealth in community-based services is negatively impacted by a lack of digital communication technology and information privacy (Leon et al., 2012).

Although this gap of the usage of MCH applications emerged, we take note that the participants from Cape Town were pleased with the WhatsApp-based MCH communication of MCH resources provided by the NPO, and found it useful. WhatsApp utilization for MCH has shown to be useful in many LMICs such as Brazil and India, due to being widely used and incurring low data costs (Kaur et al., 2019; Trude et al., 2021). Studies using WhatsApp for digital health education have shown positive uptake and outcomes of increased health-related knowledge (Kaur et al., 2019; Sartori et al., 2020; Trude et al., 2021). For example, Praekelt¹⁷, a South African non-profit organization, created a COVID-19 WhatsApp interactive chatbot available to all WhatsApp users in South Africa and answers common questions about COVID-19 myths, symptoms, and treatment. Within one month of its deployment, it had reached over 3.5 million users. The chatbot is recognized for providing

¹⁷ <https://www.praekelt.org/>

accurate information to citizens and the government, allowing them to take proper action during the crisis (Andersen, 2020). This as well as our findings provide a positive stance for digital interventions for MCH, particularly already-used technology, that could address the aforementioned challenges. This finding is also consistent with the amplification theory, which characterises technology as reinforcing and amplifying existing institutional forces rather than reforming them (Toyama, 2011). Therefore, specifically, WhatsApp should be considered in the digital health space. However, we note that not all parents interviewed had access to WhatsApp on their feature phones, and to mobile data, especially those from the under-resourced communities.

In terms of MCH resources, the participants from the more rural communities primarily used more traditional mediums such as pamphlets, TV and radio, and the road to health booklet. Those from the more urban regions were more aware of applications such as MomConnect, but both groups have experienced challenges in using such mediums and applications. These include language barriers, misunderstanding of jargon used, network and affordability challenges. This aligns with research in Nigeria and China previously discussed (Flax et al., 2014; Jiang et al., 2013), whereby we see the integration of digital health in communities is able to improve and increase access to MCH care, but challenges such as lack of smartphones and poor network coverage are evident in South Africa, especially in rural areas.

Consistent MCH Challenges and Asset Analysis

The MCH challenges identified were mostly related to difficulties and shortages of current infrastructure for MCH care such as the lack of transport to clinics, shortages of facilities from clinics and long waiting periods at clinics. The constraints to digital MCH and MCH in the more rural areas included lack of affordability of mobile devices and electricity, language barriers, and poor proximity to clinics. This aligns with recognised MCH barriers in the Global South. For example, as mentioned earlier in this paper, the Three Delays model identified transport and inadequate care as major barriers to MCH care (Barnes-Josiah et al., 1998), and other papers noted infrastructural and accessibility barriers to MCH in the Global South (Dahab & Sakellariou, 2020b; Kyei-Nimakoh et al., 2017; Rothstein et al., 2021). The findings from the assets analysis were also consistent with the aforementioned Stats SA statistics across the settings, with Cape Town participants generally having more access to smartphones and the internet compared to other sites, who primarily make use of internet cafes and other public facilities for internet. They expressed the need to address other essential needs above WiFi or mobile data. These findings highlight the difference in challenges and barriers between different South African communities who are all considered “low-income”, but endure different socio-economic conditions. Through this, we reiterate the importance of HCI researchers approaching design and development holistically and sensitively to all contexts. Regarding this sensitivity, in their book, *Seven HCI Grand Challenges*, Stephanidis et al. (2019) stresses the possibilities in which people may unintentionally be denied opportunities due to the reinforcing of already-existing disparities for vulnerable user groups, which could result from insensitive design. This is understood through Value Sensitive Design (VSD). Friedman et al. (2013) speak about how VSD can be used to address questions such as: which values are important in a

given design case?; whose values are they and how are they defined with respect to the given context?; which methods are suited to discover, elicit, and define values? (Friedman et al., 2013).

The Parent Mental Health Gap

Psychological challenges were also expressed whereby mothers often experienced distress and lack of emotional support. This is also consistent with known research on limited mental health support systems in South Africa, with prevalent shortages of mental health services and professionals, and poor awareness of mental health in rural communities. (Burns, 2011). We observe that mental health is currently undervalued in low-income communities although it presents a significant impact on communities. In their work, Pendse, Karusala et al. (2019) highlighted the importance of addressing mental health in HCI4D studies in the Global South and propose that it be prioritised and considered with consideration to stigma and sensitivity associated with mental health. Thus, we believe that researchers should prioritise this gap in future work by learning specific mental health needs from different South African communities. We explore this mental health and well-being gap further in the next chapter.

Nuances of Challenges between Rural and Urban Communities

As stated before, many of the identified challenges are not unknown to the HCI community, however, their existing nuances between different rural and urban settings are currently not widely acknowledged and addressed in the HCI space. For instance, the interviews captured the different mediums in which MCH information is currently acquired by caregivers across different regions in South Africa. The participants “choice” of medium is influenced by what is available and affordable to them, their cultural norms, and the resources that they are aware of. This was influenced by whether they were from more urban or rural regions. In all regions, communication with family and friends was the preferred method for acquiring MCH information as participants from all communities expressed that they prefer to talk to someone they trust and who has personal experience. In terms of how this is acquired, participants from the more urban regions, Cape Town and Soweto, opted for using social media to ask family members and friends. The participants from the more rural regions, Limpopo and Sweetwaters, expressed that they would seek help from traditional healers and ask family, as well as community members (Klingberg et al., 2022; Muthelo et al., 2023). Culturally, community members in these regions are accustomed to meeting communally and collectively sharing MCH experiences and advice (Madhavan et al., 2008). We suggest that HCI researchers take this into consideration and focus more on collaborating with existing systems, like traditional healers, rather than moving away from such traditional mediums.

3.4.2. Informing Digital MCH Priorities and Opportunities

Participants find the current available resources for MCH such as pamphlets, radio, internet, and Road to Health Booklet overloaded with information that is difficult to understand. Because of this, they opt for more quickly accessible and personalised mediums such as social media, and the internet.

In terms of human resources, they preferred family members and traditional healers over doctors due to comfortability and closer proximity. This echoes studies proposing that people from low-income and low-literacy communities were more likely to use and trust of information from social media and peers than health workers (Al-Dmour et al., 2020). However, this often results in misinformation which the parents acknowledged. Thus, we recognise the importance of the dissemination and democratization of accurate, informative and accessible health information for communities. Furthermore, we recognise that potential digital solutions cannot be homogenous as the current challenges faced across South Africa are diverse and deeply influenced by socio-economic and cultural circumstances. Therefore, the solutions would need to be inclusive, taking such factors into account.

3.5. Chapter 3 Summary

In this chapter we presented findings and discussions from the *Phase 1* interviews with community participants. These interviews included an asset analysis and questions related to the participants' current healthcare-seeking behaviours, usage of MCH applications and government healthcare resources, and their MCH concerns and wishes. We recognised that many of the emerging MCH challenges were acknowledged by the HCI community but described their existing nuances that are disregarded. We identified overarching nuances amongst the two rural and two semi-urban communities in all topics covered. Firstly, the importance of trust and familiarity in health sources was highlighted, but the manifestation of this varied between rural and urban regions whereby the more urban communities primarily use local Google and social media to access MCH information, while the rural communities mostly use pamphlets, traditional healers, radio and TV. The importance of community was also highlighted across all sites. Secondly, we discovered that there is currently a poor uptake of digital MCH in all regions, but the reasons for this in urban areas were more related to a lack of awareness of specific applications, whereas the reasons for this in other sites were more socioeconomic in nature, such as a lack of infrastructure to support such applications. Next, the lack of accessibility was identified as the major barrier preventing caregivers from acquiring MCH information across all sites, with the factors affecting accessibility coinciding and differing across the sites, influenced by socio-economic, cultural, and circumstantial factors. Furthermore, we identified the current gap for parent emotional being that we highlight as a pertinent priority. Through this chapter, we gained insights into the rural vs urban nuances regarding MCH uptake, recognised that MCH challenges in low-income South Africa communities are not homogenous, and thus begin to observe how this may shape design of digital MCH interventions among different communities. We also proposed that HCI researchers take these nuances into account and work toward collaborating with such traditional systems. In the next chapter, we look at the development and effectiveness of the Design Cards that were informed by these *Phase 1* interviews, and used in the co-design workshops.

CHAPTER 4

Design Cards Development and Effectiveness in Co-design

4.1. Introduction

Following the *Phase 1* community interviews, Design Cards, including Challenge and Ideation Design cards, were developed to support the subsequent *Phase 2* community-based co-design workshops. These co-design workshops aimed to 1.) discuss and rank the MCH challenges identified in the *Phase 1* interviews, and 2.) brainstorm potential digital MCH solutions to the ranked and prioritised MCH challenges. The Challenge Design Cards, consisting of illustrations representing the ten digital MCH community challenges provided in Section 3.3.5., were used during the community workshops to elicit the discussion of the challenges, and to rank and prioritise the challenges that will be focused on when brainstorming co-designing initiatives. The Ideation Design Cards, which consisted of illustrations of various digital MCH-associated resources, technology, stakeholders, and places, were then used to brainstorm and co-create solutions to the selected challenges.

This chapter will be structured as follows. Firstly, we provide related work on Design Cards used in past participatory design. The methods section will follow and describe the iterative development process for creating the Design Cards and employing them in the workshops. We then present findings and contributions on the effectiveness of using the Design Cards in practice for co-design, and finally, considerations to account for when using Design Cards as a co-design aid in community engagements. Through this chapter, we also contribute to answering our second research question by describing the challenges and opportunities provided by Design Cards for co-designing digital MCH with community members.

It should be noted that the focus of this chapter is particularly on the participants' interactions and feedback from using Design Cards during co-design. The next chapter, Chapter 5, will report specifically on the outcomes from the MCH challenge ranking and the participant solutions that were ideated and prototyped to address those challenges.

4.2. Related Work

4.2.1. Design Cards in Participatory Design

In order for research outcomes to more usable and sustainable within a community context, community members need to be actively involved in the design and prototyping process of the intervention (H. Chen et al., 2018). However, community members may not feel comfortable in the design environment or “sufficiently qualified” to do so (Golembewski & Selby, 2010; Seita et al., 2022). Design cards are paper-based design aids with illustrations intended to assist in participatory design and provide structure to the design process, while still allowing creativity (Wölfel & Merritt,

2013). These artifacts can be used as probing materials to support user participation in design without requiring expertise in the field. Thus, the inclusion of Ideation Design Cards in our work was intended for participants to leverage existing illustrations and to simplify sketching to arrows or connectors between elements that could be grouped together. Furthermore, Design Cards are non-digital and can easily be manipulated by community members from low-literacy, poorly resourced communities (Wölfel & Merritt, 2013).

Moreover, studies employing card-based mediums for design such as the PLEX cards (Lucero et al., 2016) and IDEO Method Cards (Wölfel & Merritt, 2013) have demonstrated to promote design exploration and effectively provide cues to potential ideations in research solutions. Design studies have also shown that familiarity with existing elements is necessary for the generation of new ideas. (Golembewski & Selby, 2010). Thus, Design Cards are able to fulfil this by using materials familiar with communities, but incorporating new concepts to generate novel ideas. Design cards used in past participatory research have also shown to improve communication between users and designers. An example exhibiting this is a study which used Inspiration Cards (Halskov & Dalsgård, 2006) as Design Cards and found that they were good initiators of discussions and established a forum for creative interchange between participants. Also, according to the study, including “technology cards” made it easier to incorporate new perspectives, and thus new ideas, into the design process (Halskov & Dalsgård, 2006). Additionally, we take note of Envisioning cards created by Hendry and Friedman (2012) which were used in co-design for a study on mobile phones and youth homelessness. The cards are described as “a versatile toolkit for attending to human values during design processes” and includes elements of stakeholders, time, values, and pervasiveness. Each card provides an explanation of the elements in more detail and prompts a specific design task.

We observe that existing Design Cards and toolkits are emerging primarily from Western and developed countries, with a dearth of those that are African-centred and can be applied in contexts within the Global South. We also note that these cards are typically created with set activities written on each card. However, reading and understanding these activities require higher literacy than the current literacy levels of low-income communities in developing regions (Khuluvhe, 2021).

4.2. Approach

4.2.1. Design Cards Development

Development of the Challenge Design Cards

In Chapter 3, we presented ten MCH challenges that were chosen to be addressed after a multi-stakeholder voting process discussed in Section 3.2.3. and 3.3.5. We subsequently created ten Challenge Design Cards representing these challenges. Firstly, we created a spreadsheet with the name of each Challenge Design Card, an explanation of the concept conveyed, and suggestions for how they should be depicted. Translations for each card’s title and text were provided by local researchers who spoke the local language within each of the four sites. We then presented the

spreadsheet to a graphic designer who subsequently prepared sketches for us based on the spreadsheet. Next, these sketches were reviewed with the local researchers from each community. The depiction of the challenge illustrations and the phrasing of the challenges were refined over time. Some of these revisions are presented in Figure 5 below. For example, for the “Misinformation” Challenge Card, it was suggested by network members to add WhatsApp and Google icons as sources of misinformation as it often came up in conversations in the community interviews. Also, local researchers thought that the children were standing too far behind their parents and gave the impression that the parents were ignoring them. They were thus moved closer to the parents. For the “Traditional Healers” Challenge Card, it was suggested to make the healer’s gender clearer as a woman through her attire as traditional healers are more typically women in the local communities. In terms of card phrasing, “Parent well-being” was initially phrased as “Parent well-being and agency” but the “agency” part was removed as we recognized well-being and agency as separate challenges that would be difficult to depict together on a single design card. The father figure was also asked to be removed to accurately reflect the reality of absent fathers (Madhavan et al., 2008). Additionally, the phrasing of “Health worker emotional support” was originally “Health worker empathy” but was changed because our co-researchers advised that the word ‘empathy’ may not be widely understood by the community members. Lastly, “Affordable and Accessible Health information” was revised from “Affordable Access to Health information” to include accessibility barriers not related to affordability as well, such as transport and language barriers. It was proposed by co-researchers that the illustrations be printed back-to-back with the text printed in the local language on the reverse side, as English was not all participants’ first language. This was done by asking project researchers that spoke the sites’ local language to translate the text.

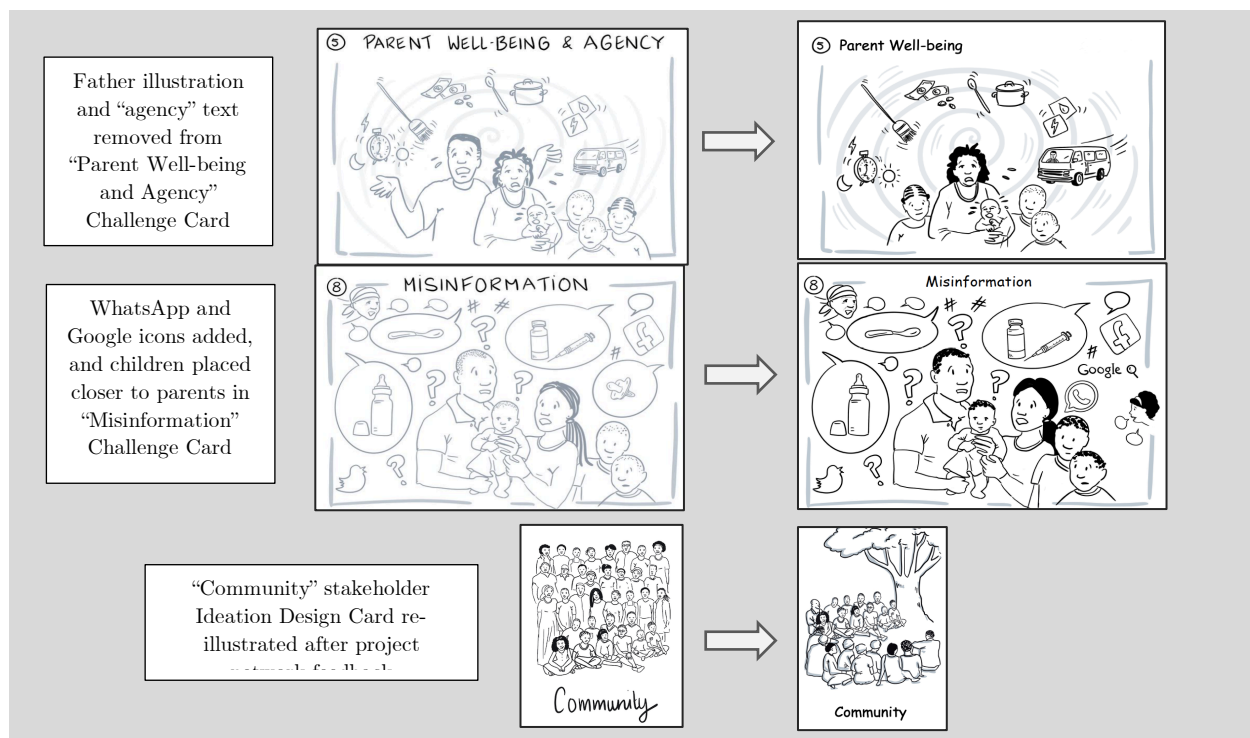


Figure 5: Design Card Revisions

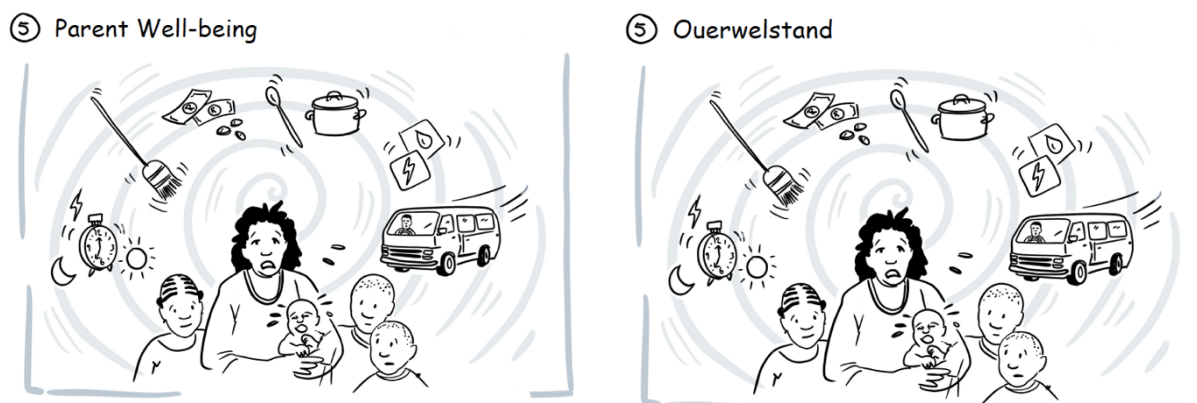


Figure 6: Challenge Cards Sample for Challenges Related to Parent Well-Being and Postpartum Care

Under Figure 5, Figure 6 presents the Challenge Card for Parent Well-being and its Afrikaans Translation. The full set of ten Challenge Cards are shown in Appendix A.

Development of the Ideation Design Cards

The study researchers and I developed various scenarios to construct the Ideation Design Cards used for brainstorming. Using physical elements identified from our community interviews, and taking previous studies that employed Design Cards and its principles into account, a draft set of Ideation Design Card ideas were scoped out (Golembewski & Selby, 2010; Wölfel & Merritt, 2013). This resulted in design ideas for the stakeholders, places, technology, and resources that would potentially be involved in the co-design of a digital MCH initiative within this specific context (as shown in Figure 7 below). Once again, we communicated these ideas with the graphic designer in a series of iterations of feedback from the co-researchers on the correctness of the Ideation Design Cards' depictions. Example pictures were also sent to the graphic designer as a guide, especially for unfamiliar technology. An example of a revision of the Ideation Design Cards is the Community" stakeholder card shown in Figure 5 above. For this card, the co-researchers found that the card initially resembled a church choir and suggested to illustrate the group sitting under a tree to provide more of a neutral setting.

Technologies	People	Places
Community Radio	Mother	Public Health Centre
Wearables	Baby (newborn – 18m)	Home (shack, apartment, house?)
Sensors and Data	Toddler (18m – 2y)	Community Centre
Community Wireless Networks	Father	Hospital
Internet-in-a-Box-type Solutions	Other Caregivers (Grandparents, relatives)	ECD Centre
Information Appliances	Siblings	Faith-based Building (e.g. mosque, church, temple)
Mobile Data Collection	Community Health Worker	
Mobile App with educational videos	Nurse	
WiFi – connected to internet	Doctor	
WiFi – not connected to internet	Community	
Mobile Data	Community Leaders	
Mobile Phone		
Tablet		
Laptop		
Social media – WhatsApp, Facebook, etc		
Road to Health Booklet		

Figure 7: Ideation Design Cards set for Technologies, Resources, People, and Places

Figure 8 below is a sample of the ideation Design Cards. The full set of cards are presented in Appendix A.

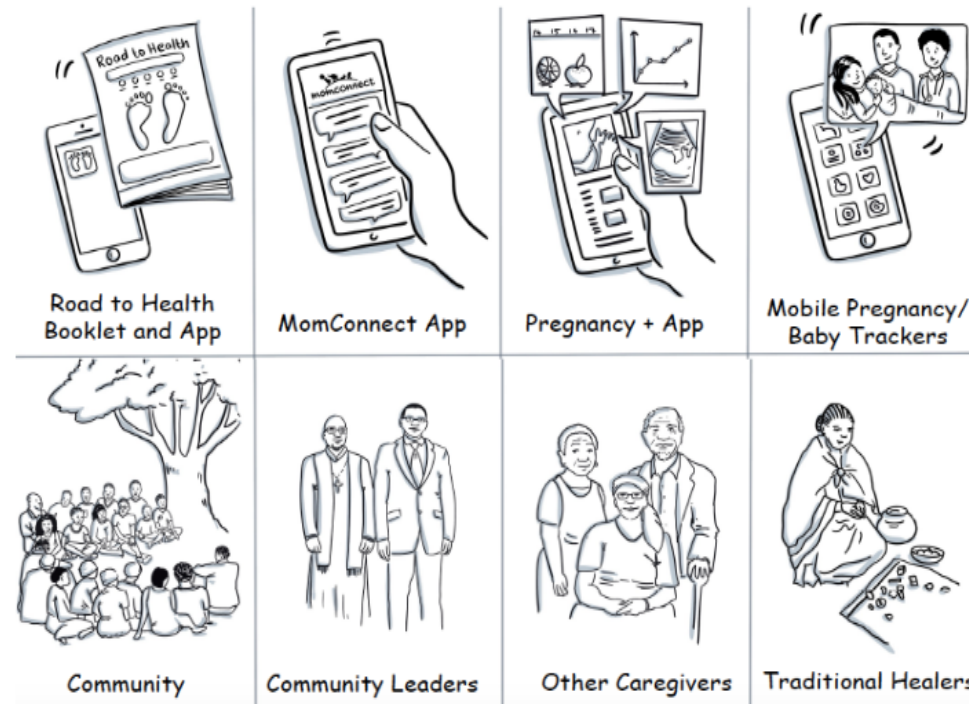


Figure 8: Sample of Ideation Design cards Showing Resources, Stakeholders, and Technology

4.2.2. Design Card Employment in Workshops

Co-design Workshops Overview

Four co-design workshops took place in the same four settings as the *Phase 1* interviews, including Sweetwaters, Soweto, Limpopo, and Cape Town. *Phase 2* involved parents, caregivers and community facilitators from each site participating in generative co-design activities. The objective of the workshops was to rank the MCH challenges (prioritising top 3 challenges) according to what they would want to address in their community using the Challenge Design cards, and brainstorm solutions to the prioritised challenges using the Ideation Design Cards. The next chapter, Chapter 5 provides more in-depth details on the workshop participants, methods and outcomes. In this Chapter, we focus only on the feedback and effectiveness of using Design Cards.

Challenge Design Cards Employment

The Challenge Cards were used during the co-design workshops as follows. The participants were each provided with a set of A5 Challenge Design Cards, while a workshop facilitator presented A3 versions of the cards. The participants were asked to describe and interpret what they saw in each Challenge Card. Thereafter, the facilitator asked follow-up questions regarding how the challenges presented could be seen as a challenge in their community and how it has affected them personally. Finally, participants were asked to rank the Challenge Design Cards in order of perceived community

value. A sticker ranking system was used in which participants placed stickers on each Challenge Card, whereby each sticker colour represented a different level of ranking.

Ideation Design Cards Employment

After the challenges were discussed and ranked by the community members using the Challenge Design Cards, the next phase of the workshop involved brainstorming and prototyping solutions to the challenges. The community members were tasked to use the Ideation Design Cards (each A6 in size) to brainstorm multiple solutions to the top two ranked community challenges, and prototype one or two final designs. Before using the cards, the facilitator described the technology Ideation Design Cards and offered supporting examples to try and ensure that the participants understood the principles of the technology cards.

4.3. Findings

4.3.1. Workshop Outcomes

Challenge Cards Feedback

The Challenge Design Cards assisted as an ice breaker for the participants to open up and relate their personal experiences to the illustrated challenges and scenarios represented in each card. In this way, it initiated a conversation between the community members and allowed them to feel more comfortable through shared experiences. They would often point at a mother figure, and say, *“That’s me!”*, *“I know that feeling”* or *“I have been there”* and other mothers would agree and add their personal experiences with the challenge.

The majority of the participants were able to easily recognize and describe what was happening in each illustration, as well as who and what the different stakeholders, environments and resources were. For example, when shown the “Involving fathers” cards, a father from Limpopo (FLI) stated *“This is a problem in our community. Fathers get bored with their children at home and go to the tavern. They are like visitors in their own homes. We need to teach men about raising children.”*

We found that the use of familiar family roles, places, items, and emotions informed by their previous community interviews facilitated this understanding and recognition of the images.

Using the Challenge Design Cards as a medium to communicate the challenges also helped ensure that all participants had a shared understanding of what the challenges represented. Language and cultural barriers were able to be mitigated using illustrations as opposed to text or reading the challenges aloud. This was apparent in the affirming responses such as above from the participants across all the sites, with varying backgrounds and cultures.

Ideation Design Cards Feedback

In terms of practicality, the Ideation Design Cards made it easier for participants to piece together their ideas and solutions by simply sticking them down to create their intended solutions. It enabled

them to spend less time drawing illustrations and more time brainstorming new ideas, allowing us to get more results out of the workshops. In terms of effectiveness, the Ideation Design Cards allowed for probing of ideas from participants and helped elicit ideas more easily from them. Oftentimes, they would start their brainstorming process by identifying one resource or technology device they intend to use, and then simply added appropriate stakeholders and environment cards to piece together a solution.

Additionally, the Ideation Design Cards were effective in introducing and incorporating technology concepts that were foreign to the participants and otherwise would have been discounted as possible elements for a solution, consequently extending the capacity of the prototypes. For example, the illustrations of the community wireless network (CWNs) and internet-in-a-box were unknown to most participants, but were used in the majority of their solutions across all four sites. The field of digital MCH was unknown to most of them and one of the co-facilitators from Sweetwaters stated, *“Had we not had the Ideation Design Cards, the participants would have really struggled and we would not have had the ideas that we have.”* The Ideation Design Cards were also shown to be effective for low-fidelity prototyping whereby their final prototypes also incorporated the Design Cards. However, although some new technology concepts such as CWNs were understood and used correctly by participants, we observed that they struggled to contextually understand other technology concepts such as IoTs (Internet of Things), wearable technology and sensors.

4.4. Discussion

4.4.1. Design Cards Contributions

Tool for Establishing Shared Understanding and Community Empowerment

It is often difficult to discuss concepts such as the identified health challenges, especially when there are language barriers and communities from different cultures taking part in the co-design processes. Chauhan and Leefe (2021) speaks about this and how planning for language barriers is essential for co-design. The Challenge Design Cards assisted in translating and sharing the abstract health challenges and sparked meaningful and robust conversations around the challenges which allowed us to create a shared understanding of the challenges represented in each of the cards. This align with what Brandt & Messeter (2004) found evident in their work with Design Cards, that these tools "help create a common ground and encourage participation in the co-design process." The Ideation Design Cards were effective in introducing and incorporating technology concepts that were foreign to the participants, that otherwise would have been discounted as possible elements for a solution, consequently extending the capacity of the prototypes. This aligns with Deng, Antle, & Neustaedter (2014) who described Design Cards as an "effective knowledge transfer vehicle to apply theory-informed cultural knowledge to design practice". Moreover, this finding also highlighted the significance of awareness as a tool to empower low-income communities, whereby they would otherwise not even be aware of the possibilities and opportunities for their communities.

These outcomes of Design Cards aiding in addressing communication barriers, establishing shared understanding and transferring participants' knowledge should be considered for future co-design research and developments, and not only limited to this context. We believe that this design aid possesses great prospects for community research beyond digital MCH, especially when working in digital spaces with low-income, low-literacy communities.

Contributions to Workshop Objectives and Initiators of Conversation and Design

The Design Cards effectively initiated conversations surrounding MCH, helped us collaboratively identify key challenges related to digital MCH within the respective communities, and ideate possible solutions for them. Through the cards, community members contributed to our insights and research regarding what community priorities for digital MCH are and how they could see them being addressed in the community, as discussed in the next chapter. This outcome also aligns with the findings of the aforementioned study which used "Inspiration" Design Cards (Halskov & Dalsgård, 2006) and found that they were good initiators of discussions and established a forum for creative interchange between participants. As opposed to the previous interview format, the Challenge Design Cards allowed participants to visually see themselves in the depicted challenges and we observed how this allowed them to open up more than they did in the interviews. Also, using these cards allowed us to visually perceive their ideas, reducing possible misinterpretations and inadvertent assumptions. Furthermore, as stated in the findings, the cards also acted as effective initiators for design, whereby participants were given probes to assist in the design process as opposed to needing to think from a "blank canvas", which has shown to be less effective in community design (Golembewski & Selby, 2010; Seita et al., 2022). This subsequently resulted in them ideating and brainstorming more potential solutions. Additionally, the publishing and distribution of the Design Cards will allow them to be used for and contribute to similar studies.

4.4.2. Considerations for Using Design Cards as a Co-design Tool

Iterative Feedback from Stakeholders

Learning about the communities directly from actual community members in our community interviews prior to the workshops provided us with a more realistic depiction of the existing contexts when portraying the challenges, community members, settings, and present resources in the Design Cards. For example, when asked about their current health-seeking behaviours in the interviews, community members, clinics and social media platforms were often emphasized across the sites, and were thus incorporated in the Design Cards. Consequently, the participants felt comfortable and familiar with using the depictions in the workshop brainstorming. This supports Mburu et al.'s (2018) recommendation regarding understanding participants' environments prior to design engagements with them, particularly when conducting research on sensitive and under-researched issues (Mburu et al., 2018).

Furthermore, we found that performing numerous iterations of feedback from a transdisciplinary network of community members, graphic experts, field experts (in this case, health and technology),

for the cards allowed us to produce more appropriate and useful cards. For instance, as discussed in the methods, rephrasing cards such as the “Parent well-being and agency card” for the community and changing the traditional healer’s gender. Had we only conducted one iteration of feedback from one stakeholder group, we would not have had the final set of cards. Jacobi, Llanque et al. (2022) speak about this in their work where they partially conclude that research that engages with transdisciplinary stakeholders enables research for development projects to utilise knowledge at multiple degrees and to co-create new types of knowledge that support sustainable transitions. Furthermore, they state that non-academic actors’ participation and expertise are not only advantageous, but also essential for sustainable transitions that are reflective and supported by data (Jacobi, Llanque et al., 2022). However, one would need to factor in enough time for such an iterative approach.

New Technology Cards and Researcher-participant Bias

As discussed in the findings, the inclusion of unfamiliar technology concepts in the Design Cards allowed solutions that would have been discounted to be ideated by the community participants. However, in doing so, there are some points to consider. Firstly, ensuring the participants’ understanding of the concepts. We spent more time explaining the technology cards and using them in examples than the other cards. We also asked the community members questions about them such as “*How would you see this helping in your community?*” to help ensure their understanding. However, this was not enough for them to fully grasp technology concepts such as wearable technologies and sensors in context. We believe that short videos may have been more beneficial in providing contextual understanding of some concepts, as with our technology cards. There is plethora research in education and health supporting this, positing that video media formats enhance learning and understanding of new concepts most effectually (Bodjrenou et al., 2020; Desta et al., 2014; Gadbury-Amyot et al., 2014).

Another issue to consider when using new technology cards is addressing researcher-participant bias. We found that only using technology cards that were newly introduced to the participants was potentially insufficient in helping them understand the feasibility and related costs of implementing the solutions in their community. Hence, they would sometimes opt for the most “modern and new” options. Furthermore, they would often choose the technology that we spent the most time explaining as it may have seemed to be what we would want them to choose, introducing said researcher-participant bias. Pallesen, Rogers et al. (2020) consider this in their study and states that facilitators of co-design initiatives should be mindful of developing and sustaining a true relationship with the participants as equal partners and co-creators. They accomplished this during their co-design process by continuously using feedback, letting the participants guide the workshop, and minimising the amount of input from the researcher. They propose that, through their approach, participants may feel more comfortable expressing their genuine concerns and opinions as they build a relationship with you and feel less judged and also more valued (Pallesen, Rogers et al., 2020). In future workshops, we would spend more time asking the participants to explain their ideas and personal choice of cards to ensure they understand its use and value in their life - not because of researcher

influence. We would also reiterate that they are the experts in the situation and that we cannot do the research without their input. Furthermore, we would give participants enough time to familiarise themselves with the cards before asking them to incorporate them into a solution.

4.5. Chapter 4 Summary

In this chapter, we specifically focused on providing insights on the usage of Design Cards as a design aid in the *Phase 2* co-design workshops. We firstly discussed the development process of the Design Cards, which consisted of iterations of feedback between researchers, the graphic artist and health and technology experts. We describe how these elements, language and phrasing used in the cards changed over time due to reasons such as not aligning with cultural contexts or not being well understood by the community groups.

From our experiences with using the Design Cards in workshops, we found that the Design Cards played an imperative role in probing ideas from the community members that otherwise would not have been ideated. We thereon recognize Design Cards as an effective tool in working with stakeholders who are not familiar with certain concepts, particularly in the field of technology. The use of salient materials that could easily be manipulated was a key element in this design process as a way to empower community members through tools familiar with them, but also extend their knowledge through new concepts represented on the Design Cards. The outcomes of the workshop contributed to the development of the digital initiative. We found that overall, the Design Cards were effective in: 1) eliciting conversations on digital MCH from participants and making them feel comfortable with the topic and within the research environment; 2) probing new ideas for digital MCH from community members that would otherwise be discounted; 3) creating a tool to empower low-income communities, whereby they would otherwise not be aware of the possibilities and opportunities for their communities. In the next chapter, we discuss the outcomes from the co-design workshops, including the parents' experiences with the challenges presented to them and their brainstormed solutions to them.

CHAPTER 5

Community Co-design Workshop Outcomes

This chapter encompasses “Reconsidering Priorities for Digital Maternal and Child Health: Understanding Community-centred Perspectives from South Africa,” which is currently under review for the ACM CSCW 2023 Conference.

5.1. Introduction

Previously in Chapter 3, we identified ten community MCH challenges based on the outcomes of the *Phase 1* interviews. The development of the Design Cards, which were influenced by the *Phase 1* interviews, and their effectiveness in the *Phase 2* co-design workshops were then discussed in Chapter 4. This chapter focuses specifically on the outputs from the four co-design workshops, including the top MCH challenges to prioritize in communities and community brainstormed solutions to address these challenges. These community co-design workshops included parents, caregivers and community leaders and facilitators to participate in generative co-design activities.

In this chapter, we provide related work on co-design work for MCH in the Global South, discuss our approach to the co-design workshops, and provide the workshop outcomes (ranked priorities and brainstormed solutions to priorities). In our discussion, we address our third research question and contribute to our knowledge of how the identified priorities and possible solutions align with current HCI priorities and developments, and propose focus areas for HCI developments in digital MCH. We also present co-design challenges and considerations we learnt through the workshops such as the importance of including intermediaries and accounting for co-design readiness.

5.2. Related Work

5.2.1. Community-based Co-design for MCH in the Global South

The use of co-design methods for MCH in particular, has become increasingly prominent (Obasola et al., 2015). The improvement of healthcare quality and access has been exemplified in participatory research with, and for, mothers to design interventions that support them during the period from conception until two years after birth (Ratele et al., 2012; Zunza et al., 2017) .

Co-design projects that have been conducted in low-resourced regions provide valuable considerations for co-design with communities. For example, Wardle et al. (2018) work on co-design and breastfeeding highlighted the need to empower mothers through positive reinforcement during design activities, as well as the large amount of time and preparation required to participate in design activities when participants are caring for a baby as this affects active involvement. We took this into account when planning our workshops and prepared thorough protocols and facilitator training.

Another study applying community-based participatory research techniques in low-income settings include research by Limaye et al. (2018), who carried out a project in rural communities in Peru with community health workers (CHW) and mothers. Using CBCD to develop and share community-created content, the researchers facilitated the identification of community-specific MCH needs and attempt to address them collaboratively through digital storytelling workshops with community health workers (CHW) (Limaye et al., 2018). They concluded that the digital stories addressed community-specific challenges through narrative persuasion using local voices and photography. The initiative was well received by the intended audience and could be used as a model for creating instructional initiatives that are adapted to the needs of the local community. Finally, D'Ignazio et al. (2016) and Gibson and Hanson (2013) also worked with mothers using co-design approaches for designing digital postpartum technologies. Their work proposed that Feminist HCI (Bardzell, 2010) and human-centred design offers an important and effective framework for designers to understand postpartum experiences, and promote the use of new technologies to improve these experiences (D'Ignazio et al., 2016; Gibson and Hanson, 2013).

Although co-designing is an innovative way to develop with and for mothers, it is not without challenges. Besides the challenges that involve contrasting priorities and objectives between researchers and communities and financial and skill limitations, there exists interpersonal and socio-cultural challenges that need to be considered. For example, Mustafa et al. (Mustafa et al., 2020) shows how religion and patriarchal norms influence mothers' lack of control over their own health, the sharing of misinformation, and the overall design of maternal and child health interventions in low-resource Pakistani settings. When socio-cultural factors are overlooked, unsuitable and unsustainable interventions may arise (Aranda-Jan et al., 2014), also posing challenges in relation to "transferability" of methods or solutions (Kapure et al., 2010) and ensuring that locally-relevant interventions are community-owned. In addition, when the inequalities to digital access of health services are neglected, it reinforces these inequalities of those who already have resources and digital literacy skills (Guendelman et al., 2017).

Despite the expansion of work done in the HCI research community on MCH in South Africa, current research prioritizes addressing physical illnesses such as obesity (Basu et al., 2010), HIV (Odeny et al., 2014), and diabetes (Sartori et al., 2020) contributing to adverse maternal outcomes and complications during pregnancy, with limited work on mental health for pregnant women or new mothers. Furthermore, as stated in the previous section, the majority of HCI and MCH research in African countries, and particularly in South Africa, have engaged mainly with CHWs and other intermediaries (Odeny et al., 2014) rather than working directly with community members and parents who are the direct beneficiaries of the planned interventions.

5.3. Approach

5.3.1. Participants

The same participants who were interviewed in *Phase 1* interviews discussed in Chapter 3 were subsequently invited to attend the workshops as participants. Most of the interviewed participants availed themselves for the workshops, and a few new participants joined the workshops. I led the Cape Town workshop, which consisted of eight mothers, with two co-facilitators and two members from BBP who support the mothers. For the three other sites, the local researchers facilitated the workshops, using the standardised protocol I developed. Eleven participants attended the workshop in Limpopo. The Limpopo participants constituted of four fathers (two of which were community leaders), two CHWs (who were also mothers), and five mothers. The two community leaders were from the local royal family and referred to by the tribal office. In Soweto, eleven participants attended the workshop. All participants were women and included young mothers and a grandparent, as well as a CHW. The workshop in Sweetwaters had eight participants, including seven mothers and other caregivers, and one father. Two children accompanied their mothers: a one-week-old baby and a 23-month-old toddler. We attained informed consent from participants at the start of each workshop by reading the consent form found in Appendix E and gathering participant signatures.

5.3.2. Facilitator Training and Intermediaries

The co-design workshops were conducted by me and six other local CoMaCH facilitators. The co-facilitators were researchers from each site who spoke the local languages and were from health and social sciences, qualitative research backgrounds. As they were not from HCI backgrounds, they received training from my supervisor and another HCI expert prior to the co-design activities guiding them on how to conduct the generative co-design approaches.

With feedback provided from my supervisor and network members, I developed a standardised protocol for the co-design workshops, presented in Appendix D.1, that was distributed for use across the workshop sites. The facilitator training included a walk-through of this workshop protocol. This also allowed local facilitators to discuss how best to communicate the activities to the participants in different cultural contexts. Facilitators staged a mock workshop with the trainers as the “participants”. Facilitators were also guided through the use of the Design Cards as these are important in the creative phases of the workshops. The technology cards such as “community wireless networks” and “internet-in-a-box”, as well as other unfamiliar concepts needed to be explained with relevant examples. Their familiarization with the cards was achieved through a discussion and reflection based on their upcoming engagement with the community as it relates to the cards. This was approached similarly to what was expected of them during the workshop.

South Africa's cultural diversity with the eleven official spoken languages presented the potential to introduce unintended complexities as the spoken language and cultural practices can differ between provinces as well as rural and urban settings. Language per se, is recognised as a significant barrier

to collaborative co-design settings between researchers and community members who do not speak the same language (Robles et al., 2019; Teeters et al., 2016). Cultural nuances presented in the community interviews, which are often missed or not understood by researchers who are not a part of the particular culture or who do not know the culture well can also introduce unintended consequences (Ntuli, 2012). We thus decided to make use of intermediaries as co-facilitators that not only spoke the local language, but also understood the different cultures well. We up-skilled these intermediaries (local research facilitators with similar levels of experience in qualitative research) in co-design methods and design thinking. In Limpopo, Soweto, and Sweetwaters, the intermediaries were local community leaders and tribal leaders; in Cape Town, they were NPO members who supported the participants by providing therapeutic services for their children.

5.3.3. Challenge Cards Discussion and Ranking

The four CBCD workshops each consisted of a challenge ranking activity, brainstorming, co-design, and prototyping activities. The challenge ranking and prototyping was facilitated through Challenge and Ideation Design cards, which were discussed in Chapter 4. The challenge verification and ranking sessions started with the intermediaries using the Challenge Design Cards for an ice breaker activity. This was done by asking the participants what they saw depicted in the cards and to also provide an example of where they have faced similar challenges in their daily lives. The intermediaries facilitated discussions until the participants at each site agreed on the interpretation of the challenges depicted in the cards. The cards were then displayed on the walls, and we then asked the participants to rank the challenges in order of how prevalent or important the challenges were in their lives. Each participant was given ten stickers, each a different colour representing the numbers 1-10 and asked to rank the Challenge Cards one by one. The researchers asked the participants to take the sticker representing the number 1 (most important) and place it on the card that they believed represented the most important challenge (shown in Figure 9 below). This was done for all ten cards. Researchers then tallied the votes to identify the top two or three challenges as ranked by the community. The participants at each site were then asked to choose the top two health challenges they believed to have the highest priority.



Figure 9: Ranking System Using Colour-Coded Stickers

5.3.4. Brainstorming, Co-designing, and Prototyping

We next asked our participants to make use of the Ideation Design Cards and craft material to create low-fidelity prototypes of possible digital solutions to their chosen digital MCH priorities, leveraging all the resources represented by the cards. We divided the participants into two or three groups (depending on the size of the group) and first handed them the Ideation Design Cards, poster boards and markers. We briefed the groups to brainstorm as many solutions as they could come up with and to use the cards to assist them. We next asked the participants to select one or two ideas from their brainstorms and create more in-depth prototypes by utilising craft materials. The participants presented these prototypes to each other at the end of the session. These sessions were voice recorded, and photographs were taken, only after we reaffirmed consent to do so. One researcher per workshop also took detailed research notes, making notes of the comments the community made as well as the overall sentiment and atmosphere in the room.

5.3.5. Data Analysis

The audio recordings were translated, transcribed, and stored on the project's secure data cloud along with the research reports, photographic images of the prototypes and scanned copies of the research notes. We cross-referenced the ranked challenges between each site in order to identify the top challenges faced by all the communities. Following this, we coded the transcripts of the audio recordings, as well as the research notes and reports. We then made use of a thematic analysis (Castleberry & Nolen, 2018) in order to identify the overall themes discussed in the relevant sections in the findings of this chapter. The researchers cross-referenced and verified each generated theme against each other and made sure to agree on the themes or new codes that were generated during the analysis. We further drew on the experience and expertise of network members with extensive experience in qualitative data analysis and methods. In line with the recommendations of Castleberry and Nolen (2018), this method of constant communication, cross-checking for validity and leveraging the combined experience of the research network while we iteratively analysed this data, was followed to ensure the validity and rigor of the themes as the data was analysed.

5.4. Findings

5.4.1. Community Priorities for Maternal and Child Health

In this section, we provide a summary of the MCH challenges that participants felt were most important to address. These were chosen out of the ten MCH challenges, listed in Section 3.3.5.

Overall, the top three MCH challenges that participants selected as their priorities across all four research sites emerged as *Affordable and Accessible Health Information*, *Parent Well-being* and *Building Parenting Skills In Early Life*. We next discuss the two top-ranked challenges for each research site.

In Soweto, one of the semi-urban sites, *Building Parenting Skills in Early Life* and *Parental Well-being* emerged as the top MCH challenges selected as priorities to address in their community. The challenges were ranked similarly in the second semi-urban site in Cape Town, with the *Parental Well-being* card receiving the most votes, followed by *Affordable and Accessible Health Information*.

In the more rural research site in Limpopo, the selected priorities appeared to partly align with the previous sites, ranking the *Parent's Well-being* as their highest priority, followed by *Building Parenting Skills in Early life*. The participants from the second rural site, Sweetwaters, ranked *Affordable and Accessible Health Information* and *Health worker Emotional Support* challenges as their top priorities.

Overall, *Building Parenting Skills in Early Life* and *Affordable and Accessible Health Information* were both given top priority in two of the four sites, and *Affordable and Accessible Health Information* was ranked highly in all four sites. In addition, emotional health associated with parents was prioritised in all four sites with *Parent Well-being* being in the top 2 ranked in 3 out of the 4 sites, and *Health Worker Emotional Support* ranked as a top 2 priority in Sweetwaters. Table 2 below presents the overall ranking out of 10 provided by the participants for each MCH challenge, across the four research sites. The top two are highlighted in green.

Table 2: MCH Challenge Ranking Results Across Research Sites (out of 10)

MCH Challenge	Limpopo	Sweetwaters	Soweto	Cape Town
Involving Fathers	10	5	4	9
Traditional Healers	8	8	9	10
Affordable and Accessible Health information	3	1	3	2
Building Parenting Skills in Early Life	2	6	1	5
Parent Well-being	1	3	2	1
Health Worker Emotional Support	9	2	7	6
Postpartum Care	7	7	6	8
Misinformation	6	4	5	3
Personalised and Timely Support	4	9	8	7
COVID-19 Vaccine Hesitancy	5	10	10	4

While it is evident that there are common community priorities among the four sites, the community participants call for greater attention to emotional health and well-being. In addition, community participants also highlight the need for more accessible MCH resources and improved support for building parental abilities to implement early childhood development (ECD) practices with their children at home.

5.4.2. Community Experiences of Contextually-situated MCH Priorities

In this section, we provide the community conversations, interpretations and experiences regarding the top three contextually-situated MCH challenges and priorities. This differentiates from the previous chapter which focused on their experiences using Design Cards as artifacts and the accuracy of the representation of the Design Cards, rather than their experiences with the actual challenges presented to them.

In Figure 10 below, the top three prioritised MCH challenges are presented

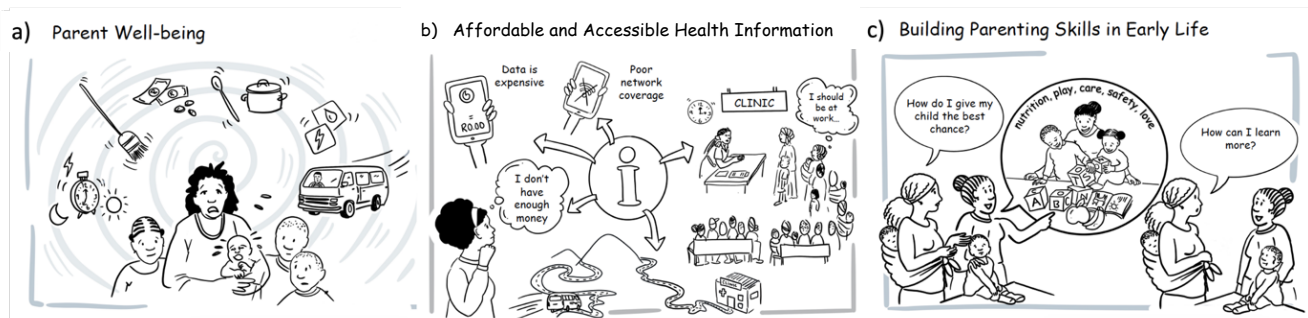


Figure 10: Top Ranked Challenges Across Sites a) Parent Well-being b) Affordable and Accessible Health Information c) Building Parenting Skills in Early Life

Poor Access to Appropriate MCH information and Services

When the *Affordable and Accessible Health information* card was presented to the participants across the sites, they related themselves to the depicted situations, referring to the visual representation of a clinic with a long queue, and the poor affordability of data was mentioned as major challenges in the community. Mothers across all sites also expressed that data for accessing online MCH content is often too expensive and prevented mothers in their communities from accessing MCH information.

Parents also lamented a lack of access to appropriate and useful content in the four sites, expressing that MCH information is usually too text-heavy and provides information that is too generalized, not in their local language, and not suited to their children's individual needs. In addition, community participants also stated that they often struggle to understand advice and guidelines provided from doctors and current MCH information due to the unfamiliar jargon used. For example, a mother from the semi-urban Cape Town site stated: “*We need personalised information for our children, their conditions are different, even children with the same conditions are different.*” – Mother from Cape Town (MCT1)

Socio-cultural practices also appeared to play a role in this priority as participants from the two rural communities expressed that they often opt for traditional healers instead of doctors as they are more accessible (closer to where they live), usually speak their home language, and that parents are desperate and seek any possible help. Participant responses supporting this include:

“There are no hospitals in rural areas and parents need help, they are willing to try everything to help their child- there is no taxi needed to take to a traditional healer, they are in your neighbourhood and sometimes some of their herbs do help. – Father from Sweetwaters (FSW1) and

“Traditional healers speak the same language as us, at the same level as us, which is sometimes helpful.” – Mother from Sweetwaters (MSW1). This shows how traditional practices and beliefs are important to consider for MCH.

Social Isolation and the Need for Parental Emotional Support

When shown the *Parent Well-being* card, participants from every research site highlighted the lack of emotional support available in their communities for parents, and particularly mothers. Mother participants expressed how difficult it is to balance their everyday activities and responsibilities with motherhood. In addition, many mothers touched on the fact that they have struggled with postpartum depression and often felt alone and overwhelmed. In Soweto, mothers provided comments on their emotional experiences during motherhood such as:

“It is emotionally draining to become a mom, I ended up with depression. Our people do not care about emotions, I ended up losing my milk”. - Mother from Soweto (MSO1). Another mother from Soweto elaborated on this by saying:

“This goes back to involving fathers, people think mothers are strong, they think we can multi-task, they say women are sent from God and then they treat us like we do not have feelings.” - Mother from Soweto (MSO2)

In addition, mothers also explained that it is not always easy to leverage support from family members, as stated by another mother from Soweto: *“You cannot complain to your mother, she will tell you that you are ungrateful and spoiled”. - Mother from Soweto (MSO3)*

In Limpopo, the mothers and fathers shared this sentiment with one father, who is also a community leader, stating: *“I see a mom without support. She needs to get the kids to school, cook and clean. She is alone. I keep looking for a man in the picture. Where is the father - why is he not present there?” – Father from Limpopo (FLI1)*

In Cape Town, mother participants expressed that they very much resonated with this challenge and have felt sad, alone, angry, and fearful, especially after hearing the news that their child had special needs or a disability. Participants agreed that having someone to talk to, especially someone in the same situation, can be very helpful and comforting. They voiced their emotional concerns and that they felt like they always needed to be strong in order to be a good parent to their children. Some comments on this from mothers in Cape Town included: *“There is a lot of depression, I had an unexpected baby and I needed to see a professional, I needed to work through a lot of fear”. – Mother from Cape Town (MCT2)*

“We don’t get to collapse, we have to heal for our children’s sake.” – Mother from Cape Town (MCT3)

“They need to realise that when you have a special needs child. You automatically need therapy”. – Mother from Cape Town (MCT4)

It was also reiterated that parents do not receive the necessary emotional support from healthcare workers, nor are they referred to specialists who can assist them. A mother in Soweto explained: *“Nurses are mean, we end up with more depression. One nurse told me...don't ever have another child.”* – Mother from Soweto (MSW2)

Another mother voiced the value of sharing with other mothers: *“It is good to share with other mothers, my baby was in hospital for 4 months, I was crying every day. I met a mom who told me, don’t cry, sing or scream or do something else, crying is not going to change where you are, your child will be the same when you are done crying”.* - Mother from Cape Town (MCT1)

Aspirations to Learn How to be Better Parents

When shown the *Building Parent Skills in Early Life* card, the participants from all sites expressed that this was a priority often neglected in their communities and expressed that they were never taught how to “be a good parent”. For example, a mother from Cape Town stated: *“We woke up as parents, but no one taught us to be parents, we had no idea how to raise a child, we all needed lessons. We want to raise good children”.* – Mother from Cape Town (MCT2)

In addition, the concept of "play", as depicted on the card, was discussed in Cape Town, where a mother stated that she learnt through experience that playing with children while they are young is crucial for a healthy development of their children, as parents can only send their children to the nursery from the age of six. Another mother voiced that nutrition is a prominent challenge for her due to her child’s inconsistent eating habits and needs. While participants recognized the need to improve their parenting skills and that some information is available, the information does not meet the needs of their children as one mother participant from Cape Town expressed: *“There is information in the road to health book about milestones, nutrition etc – but it is not for our babies. It does not help for special needs children.”* – Mother from Cape Town (MCT4)

In Soweto, mothers started the conversation on this challenge by stating: *“It is important to develop your child's skills from the get-go. We need to get educational toys and good food for our children. It is very important.”* – Mother from Soweto (MSO2)

However, mothers further elaborated that while this is an area that they truly believe should be addressed, they lack the resources, time, and skills to fully offer ECD skills to their children.

A comment from a mother supporting this was: *“Parent's don't have the skills regarding nutrition and the correct toys. Time is also a huge pressure.”* – Mother from Soweto (MSO4)

Another mother echoed this sentiment by adding: *“We face bigger issues like poverty, I cannot afford my own balanced diet. How must I balance my child's diet.”* – Mother from Soweto (MSO3)

One of the older mothers present addressed the young mothers, who were discussing the lack of resources and said: *“There are resources that you cannot always afford what your child needs, but you can make your own. I use to cut up pictures to make puzzles, there are always ways.”* – Mother from Soweto (MSO6)

In Limpopo, the participants discussed focusing more on what their responsibilities regarding ECD for their children are. A father started the discussion on this challenge by stating: *“A mother must choose the best way to raise a child.”*, – Mother from Limpopo (MLI1)

and a father joined the conversation by adding *“Yes, it is the way in which we much raise children, children could touch dangerous things and get hurt, we must be responsible for them”*. – Father from Limpopo (FLI1)

Mothers soon joined the conversation by expressing: *“Mothers should raise their children close to them, making sure they eat well, watching how the child is playing”* – Mother from Limpopo (MLI2)

and *“It is important to be present while your child grows, to use toys to identify the talents of our children, to make sure they eat and learn well”* – Mother from Limpopo (MLI3)

5.4.3. Co-designed Solutions

Re-designing and Adjusting Community Spaces to Enhance Parental Involvement

All the community participants included community spaces as an overarching strategy to co-design digital MCH initiatives that address the identified community priorities. Thus, we first describe how integrating and adapting community spaces played a key role while exploring the potential community-based solutions, before describing the co-designed solutions for the top three MCH challenges.

Central community structures and places, such as community halls, faith-based centres, and clinics appeared as an important contextual consideration for the interventions proposed by the community participants. When communities generated ideas for possible interventions, these were usually associated with a communal spaces, rather than a personal one, such as in their homes. An exception is the use of community radio, which is accessed personally, but is distributed communally. At communal locations, participants envisioned central access to resources and technology that could assist them with their MCH needs.

In the rural community of Ga-Dikgale in Limpopo, the community hall was a central meeting point for many community meetings. These meetings often involved providing updates on community events, news and information sessions on COVID-19 safety and vaccinations. The multi-purpose

centre lends itself to different ways in which health needs and well-being can be supported, especially as the community prioritises gatherings over individualised engagements. As such, this “community space” aspect was valued by the participants while co-creating ideas and prototypes during the workshops, with participants highlighting the importance of group communication and understandings of maternal and child well-being.

Even when physical shared spaces were not a dominant feature in the community, such as that of communities in Kwa-Zulu Natal and the Western Cape, the importance of a communal space remained relevant for designing support with and for mothers. Despite being more physically distant within the larger communities, community ideas centred around the facilitation of spaces, be it non-physical or in-person, to provide avenues of support. Part of this was due to the context of COVID-19 and its potential risk of infection, but another, was the socioeconomic challenges associated with travelling and meeting up to provide support. Support can thus be interpreted in various ways, but it fundamentally focuses on fostering a community which intends to help each other. Such was the nature of design ideas, including leveraging radio and online spaces such as social media platforms and mobile applications. Pairing this with the regular visits to the community clinic made the use of "community spaces" a significant consideration for designing for MCH in these contexts.

In general, the role of the community leaders and members as a support mechanism for initiatives addressing the priorities was evident. In Limpopo, participants stressed the role of the community and community leaders. These communities offered comments such as: "*The nurse needs to connect to the community. The community can then mobilise to support mummies who are not coping*" and "*Mothers can talk to the community for help, the community needs to be informed and they can help mothers*".

This blending of community spaces, community citizens and leaders, and in some cases government resources, presented as a common theme throughout all the prototyping sessions and is elaborated on in the next sections.

Co-designing to Facilitate Access to Health information and Support Parenting Skills

With the technology cards as probes, participants were introduced to new technology concepts such as CWNs and a wireless network with and without Internet, which would make it easier for community members to access content speedily, and would require less reliance on data. There were many CWN and internet-in-a-box-associated solutions, often involving central community spaces, thus leveraging the aforementioned community spaces. In the case of Sweetwaters, the participants stated that the CWN would provide greater opportunities for affordable access to health information, especially at vital communal spots such as the clinic or religious sites. In all sites, the inclusion of either the church leaders, community leader or member or traditional healers integrated as part of the digital developments to facilitate access to health information and support parental skills. On the left of Figure 11 below, the brainstormed solution for addressing *Affordable and Accessible MCH information* from the Sweetwaters workshop is shown. This solution depicts a community, a mobile

clinic and a CWN which provides the community with access to the clinic nurse and the church via a mobile phone from their homes. Similarly, in Cape Town, community participants' brainstormed solution for *Affordable and Accessible MCH information*, as shown in Figure 11 below, included a digital ECD platform whereby videos related to early childhood play, care, nutrition, and well-being would be made available without bandwidth costs. Community participants discussed that ECD information and videos could be made accessible through CD-ROMs, flash drives, internet-in-a-box and shared throughout the community through CWNs.



Figure 11: Accessible and Affordable Health Information Solutions in Sweetwaters (Left) and Cape Town (Right)

Soweto's participants' brainstormed solution for addressing *Building Parenting Skills in Early Life* in Figure 12 below includes a centrally located community centre that housed an Internet-in-a-box supported by a CWN to distribute educational ECD content. Using the cards, participants considered that the content on the Internet-in-a-box would include a digitised Road to Health booklet (RTHB).

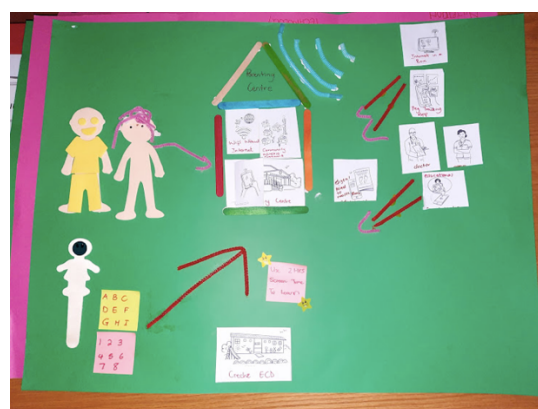


Figure 12: Solution for Building Parenting Skills in Early Life in Soweto

At both urban sites, Soweto and Cape Town, digitising the national Road to Health booklet, was a priority, with many mothers requiring more education on and exposure to the resource. Instead of just having the booklets individually, the suggestion put forward was firstly, access to an electronic

version of the platform, and secondly, collaborative learning sessions held at the community centre that guides mothers who were not familiar with the concepts detailed in the RTHB. Participants expressed that the booklet is often neglected in their communities and a participant indicated that she had not previously considered the details of healthy nutrition as it is presented in the booklet. It was evident that this mother was focused on many things in caring for her child but was not aware of the vital information in the booklet.

In the rural communities of Sweetwaters and Limpopo, community radio was the more prominent choice for information sharing, and more community and religious leaders were included in their brainstorming activities. In Sweetwaters, their solution for *Affordable and Accessible MCH information* included a community radio that could be used to share information regarding child rearing and maternal health. One participant stated the following:

"Moms need information over the community radio or on her smartphone. She can also talk to the community for help".

Finally, in Limpopo, community participants brainstormed solution for *Building parenting skills in early life* involved sharing information via community radio to strengthen parental skills and support mothers on how to manage their money, time, and other resources.

Co-designing for Parent Well-being

As with the previous examples, the involvement of communities, and community and religious leaders was prioritised in the ideas and prototyped solutions to enhance emotional support across the sites. Additionally, community members from Soweto emphasised that local clinics should be integrated into solutions for emotional support, to assist in distributing clinic-facilitated, maternal mental health information. Their solution for *Parent Well-being* included social media and the use of CWNs to share experiences and advice between mothers, religious leaders and clinic members. It was emphasised across the sites that community support was important for relieving their stressors. Interestingly, the mothers in Cape Town expressed that talking about their challenges in the workshop was therapeutic, and they decided to create a WhatsApp group to continue supporting each other.

In the two urban sites, the solutions for *Parent Well-being* typically involved a smartphone, CWN, and community members and leaders, and in rural Limpopo, community radio was once again included in their solution. In Limpopo, community participants designed a solution comprising a Wi-Fi network with community radio providing mothers with information as a form to support parental emotional well-being. It also included social networks to allow mothers to receive support and help from community members while managing their home.

As presented in Figure 13 below, the solution ideated for addressing parent well-being in Cape Town was an application that connects mothers who experience similar situations and stressors, The home page includes a list of stressors on which a mother can click. All mothers who click on the same

stressors would be connected and will be able to chat, and share experiences and advice. It was also mentioned that a community leader and professional in each chat be included to ensure correctness in advice and to provide additional support.

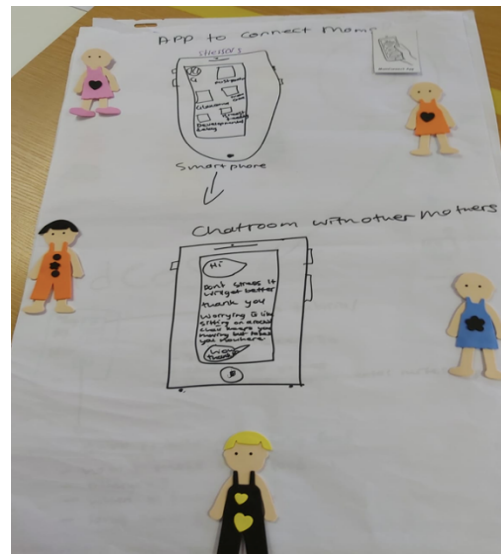


Figure 13: Brainstormed Solution for Parent Well-being in Cape Town

5.4.4. Parent Feedback from Co-design Approach

Overall, the participants expressed that the prototyping sessions made them feel more empowered to tackle and address their own problems. One of the community leaders in Limpopo added the following statement while presenting his group's prototype: *"It is nice to see that we can come up with our own solutions, to solve our own problems - we as a community need to do more of this."* and this sentiment was shared in Soweto with one of the mothers stating: *"I liked seeing that we all face the same problems, but it was nice to think about solutions and to see that we can come up with solutions. We need these solutions to become true."*

5.5. Discussion

5.5.1. Advancing HCI research supporting Parental Well-being and Access to MCH information

Bridging the Gap of Parental Emotional Well-being in South African Communities

All the research sites in our study highlighted mental and emotional well-being above physical health priorities such as postpartum care. Yet, the MCH research for the global South conducted in the HCI space largely focuses on nutrition and breastfeeding (Rothstein et al., 2021; Wardle et al., 2018), postpartum care (Mbuthia et al., 2019; Odeny et al., 2014) and healthcare monitoring (Babar & Rahman, 2021). A study by Pendse and Karusala et al. (Pendse et al., 2019) investigating mental

health and HCI in the Global South found very few research on this, stating "little work has been done in HCI4D addressing mental health directly" and further states that it prioritises other issues such as diabetes (Petersen et al., 2018) and HIV (Natarajan & Parikh, 2013). Furthermore, the CoMaCH research team's recent internet database search with search terms such as "Digital Maternal and Child Health", "Digital Maternal and Child Health Low-Income Countries", "Mhealth + maternal and Child health", "Maternal Health and technology", "Child Health and technology", "Mhealth women", "Mhealth children", "Mhealth pregnancy", "Mhealth antenatal" and "Mhealth well-being", "Health and well-being" revealed that very few HCI papers focus primarily on the co-design and development of technology artefacts aimed at emotional well-being, with the majority of the available papers focusing on mental health issues that arose during the isolation of the COVID-19 pandemic (Elliot et al., 2022; Al-Dmour et al. 2020), and mental illness associated with HIV/AIDS (Safren et al., 2009). We believe that this is potentially due to the prominence of expert-led and motivated research in the MCH field, as opposed to more research and co-design with actual parents on a more in-depth, qualitative level. Previous research (Ajayi & Akpan, 2020) in HCI and MCH posits that there is a definite shortage in community engagement and formative research, that is not expert-led, to ensure that cultural practices are considered in this space (Coleman, 2018; Kaufman et al., 2017; Rothstein et al., 2021). Thus, it is probable that in past studies, the community's evident demand for mental well-being developments did not appear as a prominent priority.

In South Africa, there are very few digital mental health and well-being projects for mothers, though we take note of existing innovations that provide mental MCH resources, such as Messages for Mothers¹⁸ from the Perinatal Mental Health Project (PMHP)¹⁹. Such platforms provide important MCH information to mothers about maintaining healthy mental healthcare habits. However, while some are not zero-rated (i.e., no data costs are charged for accessing the website), and access is limited by network coverage and device compatibility. Also, content is typically only available in limited languages e.g., usually English, Afrikaans, isiZulu, isiXhosa but not usually in other low-resourced languages such as isiNdebele and Setswana. This was also evident in our interviews and co-design workshops, as mothers expressed frustration in not being able to access MCH resources because they were not available in their local language. Similarly, in a South Africa study (Obasola et al., 2015), SMS messages were sent to pregnant HIV-positive women with information about the Human Immunodeficiency Virus (HIV) and reminders to improve treatment adherence. Over 90% of HIV-positive moms joined the treatment group, and the project noted increased self-esteem among members. The authors raised concerns about the limited availability of the local language utilized for the messages as well as the timeliness of the messages sent, both of which may have harmed the intervention's success (Obasola et al., 2015).

This shortage of available mental healthcare platforms within these South African communities may also be associated with cultural norms since expressing negative experiences and depressive emotions are considered inappropriate, and mental healthcare is largely undervalued in these communities

¹⁸ <https://messagesformothers.co.za/>

¹⁹ <https://pmhp.za.org/>.

(Hugo et al., 2003). From what we have observed in our workshops, mothers are expected to handle their emotions and balance motherhood demands on their own, despite experiencing mental distress. It was also evident that health professionals sometimes share this attitude toward community members, failing to provide mental health services, or refer them to experts, or have difficulties expressing sympathy for their mental concerns and experiences. Research on mental illness and health in South African supports this notion, with cases of poor attitudes of community health workers towards mental and emotional well-being (Kakuma et al., 2010). South African studies have explored the perceived levels of stigma in the community toward people with mental illnesses. Studies that have looked into this topic have all found high levels of stigmatizing views against people with mental illnesses in their communities (Kakuma et al., 2010). Furthermore, South African studies (Lethoba et al., 2006; Mavundla & Uys, 1997) looking at the attitudes of mental health nurses working in public hospitals discovered that a large number of nurses had negative and stereotypical attitudes toward mental health care users (Kakuma et al., 2010).

During the co-design workshops, participants also expressed the need for inclusion of these stakeholders while brainstorming their potential solutions and placed great value in them as having potential to help alleviating stressors and providing support. Parental well-being ideas frequently incorporated communal institutions such as churches, and social digital media such as chat bots and group chats, as well as merging of both. We recognise that including community stakeholders such as community leaders in this space may help reduce stigmatization of mental health. However, instances of inadequate empathy on the part of healthcare professionals may have an adverse effect on these engagements. Therefore, before we shift our focus to collaborating digital initiatives with community and religious leaders, training for empathy such as with the Secret History Strategy (Honikman et al., 2020) should be considered, in order to reduce the stigma associated with mental well-being and mental illness in these communities. The Secret History Strategy's objective is "to engender an ethos of care and compassion within maternity settings, so as to ultimately prepare these environments for mental health task shifting initiatives (Honikman et al., 2020)."

Taking all the above into account, our findings show that communities are favourable to, and would welcome digital interventions for MCH, but they have not yet been exposed to many useful and appropriate interventions. In addition, socio-cultural practices and norms need to be considered as they could influence community willingness to participate in co-design initiatives. Therefore, future research and developments should not only prioritize expanding the digital space for mental well-being in MCH in South African contexts, but also consider the assimilation of them with community structures when doing so, to create contextually-suited and cultural-relevant design interventions that collaboratively address mental health and well-being stigmas within the local communities and beyond.

5.5.2. Contextually Addressing Access to Relevant MCH Information

The other highly ranked priorities were *Building Parental Skills in Early Life*, with three of the four sites prototyping solutions to this challenge, and *Affordable and Accessible Health Information*, with

two out of four sites (and highly prioritised in the other two sites). These two challenges coincide in terms of the priority of expanding mothers' knowledge and their ability to apply that knowledge in their parenthood. However, research on HCI and ECD in South Africa is limited (Visser et al., 2021). We observed that mothers also expressed that they cannot use the MCH information they have access to because it is not available in their home language, not relevant nor applicable to their culture or uses unfamiliar jargon.

Community participants sought for community familiarity, and because of this, often opted for community-based solutions such as asking help from family, religious leaders, or traditional healers. We believe that we should be working with this sense of familiarity, and not focus away from it. This ties in with the idea of designing for community spaces presented in the above findings and the following section on designing for connectedness. With that being said, the community participants' co-created prototypes not only included these community connections but also opted for maintaining already-available resources, for example, the digitisation of the RTHB and incorporation of CD-ROMS and social media. Furthermore, the mothers in the workshops also largely opted for community radio and community spaces as opposed to mobile apps for MCH education and awareness, as they proposed that this would be more accessible for many mothers in their communities. In this way, we recognise that digital approaches should not negate communities' available resources when incorporating technology into developments, as these are often more appropriate and sustainable in low-resourced communities. Specifically, this was particularly true for the rural communities, bringing us to our next point on designing for rural versus urban communities.

In our workshops, we saw that community participants from the rural communities prioritised design elements that they feel more comfortable with, such as community radio and church structures. However, the participants from the more urban communities prioritised smartphones, mobile applications, and videos, due to being more familiar with these because of their increased access to technology (this was highlighted in the community interview findings that informed the Challenge Cards). It should also be noted that participants rarely used technology items such as wearables, Internet of Things, and sensors, probably, because they were newly introduced to these items and being unfamiliar with to how they can be used. Their lack of familiarity with these items is likely due to the shortage of ICT infrastructure within low-resourced regions in South Africa. This shortage and digital divide are evident in research on ICT in South Africa. According to a study exploring digital transforming challenges in rural areas (Aruleba & Jere, 2022), the integration of ICT infrastructure in post-Apartheid South Africa varies across the country. Rural communities have limited access to ICT services and infrastructure, putting them at a considerable disadvantage in comparison to urban areas. The majority of ICT infrastructure users in these rural communities are likewise novices, mostly using phone calls, SMS, and social networking. Furthermore, previous research (Oyedemi & Mogano, 2018) supports the notion that supplying technologies does not inevitably result in skills, partially because the educators available lack the necessary digital skills to teach individuals. Therefore, when implementing digital initiatives for South African communities, we do not need to develop homogenously; rather, our design should prioritize contextual approaches that communities are familiar with and have more potential to access, as this may increase the

viability and sustainability of the designed intervention. There is increasing research supporting such asset-based approaches, especially in digitally divided regions like South Africa (Brooks & Kendall, 2013; Eloff & Ebersohn, 2001). In their research, Brooks, and Kendall (Brooks & Kendall, 2013) proposed that asset-based interventions are beneficial because they focus on the capacities, skills, and assets within the social system and improving the inherent assets in a system. However, contrarily, we also saw most participants commonly include CWNs in their solutions even though the concept was newly introduced to them. We believe that is due to it aligning with their values of community and connectedness, which is discussed in the next subsection.

5.5.3. Understanding the Tensions between “Connectedness” and Access in Communities

In terms of the participants' choices of technology elements to incorporate into their solutions, the co-created prototypes in each site included WIFI, Internet-in a-Box, a CWN or community radio. It is clear that community participants are looking for access to information, but, also to connect to each other in different ways. This can be seen by looking at the stakeholders the communities considered for addressing the challenges. For example, the solution for *Parent Well-being* in Cape Town included an application that connects mothers, community leaders and therapists together to support and engage with one another going beyond conventional therapy. We also observed this in their choice to create a WhatsApp group to continue connecting with one another to access and provide support to each other. This aligns with a study on bandwidth-constrained mothers by Dsane et al. (2022) which found that WhatsApp groups could help maintain cohesion and fostered mutual support between mothers.

The consideration of community members and leaders within the maintenance of their solutions aligns with the findings of Loges and Jung (2001) who explain that access to networks that enabled communication between members of the community does not automatically lead to connectedness. This access needs to be supplemented with a degree of connectedness to the system and to the community (Loges and Jung, 2001). Van Bel et al. (2009) describes connectedness as relationship salience which refers to the presence of relationships in one's mind. Closeness which relates to a sense of belonging and knowing each other's experiences in terms of actual life experiences. Connectedness is an important concept in African cultures. Perhaps the most pertinent example is *Ubuntu* which states "I am, because we are" (Nussbaum, 2003) or another well-known Africanism: "It takes a village to raise a child" (Swadener, 1997). Elements of community connectedness were manifested in every prototype and was discussed at great length during the workshops. The communities further touched on the fact that connectedness can be empowering. In line with this, Baron and Gomes (2012) explain that access, and in turn connectedness, leads to stronger personal connections that can translate into strong community development, societal inclusion and empowerment. Nanetti et al. (1994) echoes these finding by stating that social capital and community cohesion can be fostered from the following four features: 1) the existence of a dense range of local community networks and organizations, 2) high levels of civic engagement, 3) the presence of a strong local identity, a sense of equality and belonging with other community members, and 4) generalized norms of trust, all of which was

exhibited by the communities in this study. Perhaps, considering the work of Wang (2017) in his work, “After Access”, we can now see indications that South Africa no longer requires just access to internet connections, but are also starting to consider what happens after the communities in this country are connected to a digital medium. Overall, South African community participants highlighted the opportunities to make use of connectedness to address their own problems, create their own solutions and to empower themselves and their communities. This is also in line with the aforementioned third point of Social Cognitive Theory addressed in Section 2.2.3 which stated that behavioural changes are associated with “finding social support in those who support their efforts” (Benight & Bandura, 2004).

5.5.4. Co-design Readiness and Significance of Intermediaries

Upon reflection of the workshops and our methods described in Section 5.3, the inclusion of local intermediaries and design card aids played a significant role in preparing for expected co-design considerations, such as community understanding and building community rapport. Building empathy and understanding proved to be occasionally challenging during the *Phase 1* remote WhatsApp calls due to the inability to discern facial expressions and body language. Thus, for the workshops, we were concerned about how empathy would play out across social-cultural contexts. However, the use of intermediaries in the workshops significantly helped in communicating the MCH challenges with participants, and making them feel comfortable in the research space. This included providing language translations, and also a sense of familiarity that allows them to open up more about their experiences. Especially in Cape Town, when working with mothers with disabled children, it made it easier for them to open up with their physiotherapist present and engaging with them. Furthermore, the cultural leaders played a role in creating a familiar and culturally appropriate space for community members to feel comfortable and supported by their community leaders in expressing themselves, and additionally, not feeling any feelings of shame or guilt in doing so. Akama and Light (2020) highlight the importance of such appropriate preparation and co-design readiness for contingent situations that may arise in co-designing and group dynamics.

Participatory design studies support the inclusion of local intermediaries, for example, DePaula (2004) echoes this by proposing that the use of intermediaries in their ICT participatory design sessions encouraged participation from community users and addressed language or cultural gaps (DePaula, 2004). However, even with intermediaries providing language translation and Design Cards providing assistance in the interpretation of the Design Cards, as described in Section 4.4.2, the participants were not fully ready to co-design unfamiliar technology and may have included any new technology due to researcher-participant bias. They had a limited contextual understanding of the technology in use despite our re-explanations. This methodological limitation is described in a co-authored paper (Till et al., 2022) where we stated: *“participants had difficulty using the technology Design Cards when they did not fully understand all the technologies presented despite the facilitators explaining each technology before the brainstorming sessions. The facilitators re-explained whenever they were asked; however, terms like Internet-in-a-box, Community wireless networks, and chatbots were foreign to these communities leading to the participants defaulting to familiar concepts such as*

mobile data and WIFI. So it is possible that chatbots, data collection apps and sensor data were not explored due to their unfamiliarity to the community.“

We believe that time restraints also provided limitations in allowing participants to spend more time familiarising themselves with the new concepts. However, the length of the activities appeared to negatively affect the participants’ motivation as they grew tired by the final prototyping activity. We may have benefitted from dividing the activities over two days instead of one. Thus, overall, there were challenges that we were prepared for such as language translation and sense of community through intermediaries, but hiccups such as unexplored technology and researcher-participant bias (previously discussed in Section 4.4.2.) that we were not prepared to overcome. Future work in co-design should consider these challenges and hiccups experiences during design with communities to improve co-design readiness through appropriate preparation according to the target communities.

5.6. Chapter 5 Summary

In chapter 5, we provided the findings from the *Phase 2* co-design community workshops which aimed to address the challenges and priorities identified in *Phase 1*. We discussed the activities conducted in the co-design workshop, including the Challenge Card discussion and ranking, co-designing and prototyping. From the Challenge Card discussion and ranking, we found that the community participants highlighted the need for more accessible MCH resources and improved parental abilities to implement early childhood development (ECD) practices with their children at home. In addition, community participants also urge for greater attention to emotional parent health and well-being within their communities. In relation to the co-design outcomes, the design elements incorporated in the solutions also varied between the urban and rural settings, with the rural sites prioritising community radio, community and traditional leaders and community structures, and the semi-urban regions leaning more towards mediums such as mobile applications and videos. We believe that this should be considered when designing digital-based initiatives for communities, also proposing asset-based approaches for such contexts. To support emotional well-being, we highlighted the importance of including community participants in the design of any intervention aimed to address stigmas and to contextualise resources, according to community needs and preferences. Based on the co-created prototypes across all the sites, community participants seek more than only access to information, but seek meaningful connectedness with each other and their community leaders. This may manifest through social media, community spaces or places of worship. Finally, we described the importance of co-design readiness and intermediaries in communicating effectively with participants, not only through speaking the same language but through their vernacular and cultural awareness. This led to participants feeling more comfortable and opening up more about their experiences with less apprehension. From this chapter, we used the findings of the co-design workshops to shape the design of a digital prototype addressing the emerging MCH challenges, which is next discussed in Chapter 6.

CHAPTER 6

Prototype Development and Evaluations

6.1. Introduction

Based on the findings from the previous *Phase 2* workshops, we began prototyping a digital innovation approach in *Phase 3*. This phase involved three iterations of evaluations and amendments of the prototype by the NPO and community members in Cape Town. In this chapter, we firstly provide past related work on similar health applications and their data collection approaches. We then describe the methods used for the three iterations of prototyping, evaluations, and amendments, and provide the outcomes from each iteration. This includes community feedback on the type of content included and features of the prototype. Through this chapter, we provide contributions on design considerations and tensions for digital MCH applications, including designing for sensitivity and choosing appropriate formats. Furthermore, we also observe and describe the value that co-design can play in empowering communities through the co-development of an intervention intended for their benefit.

6.2. Related Work

6.2.1. Data Collection for Community Health Applications

There has been an increase of work involving community members in the development of community-targeted health mobile applications (Borrelli et al., 2019; Patrikakou, 2016). However, as with co-design and community interviews, these typically targeted CHWS and not parents and other caregivers directly (Campbell et al., 2014; Emmanuel et al., 2019; Yang et al., 2021). Barriers preventing more community members from participating in evaluations of digital health innovations (DHIs) include researchers' and parents' presumptions of parents being incapable of using the technology, or of the CHWs expert knowledge being most important, as well as privacy concerns from parents (Gorst et al., 2014; C. Sanders et al., 2012).

Furthermore, these studies generally only include evaluations and trials of more high-fidelity applications, rather than involvement of community members from the inception of design, and informing the format of the digital interventions (Mörelus et al., 2021; Ruiz-Baqués et al., 2018). For example, a study based in India (Fiore-Silfvast et al., 2013) observed and provided midwives' perspective on an application they developed called the Mobile Midwife Platform which only involved midwives' evaluation of the application and content after the application was developed.

Another important point to note about past parent-targeted health studies is that much of the evidence has been generated using quantitative methods, specifically for Randomized Controlled Trials (RCTs), which provide little detail or context of the real-world difficulties individuals face

(Goel et al., 2011) such as cultural and socio-economic barriers, and the cost and security of technology (O'Connor et al., 2015). Understanding these issues is especially critical for the transition from RCTs to engaging and enrolling patients and the general public in large-scale digital health deployments in real-world contexts. This knowledge gap, which occurs between early concept testing and full-scale implementation, is sometimes referred to as the second translation gap (Grimshaw et al., 2012). Although more qualitative studies have looked at some of these difficulties, they frequently only addressed a specific patient population or one piece of technology (Varsi et al., 2013). As a result, there are gaps in the research that make it difficult to understand the challenges and opportunities people have when enrolling in various DHIs.

6.3. Approach

6.3.1. Analysis Informing Prototypes



Figure 14: Stages of Co-design Analysis (Demirbilek and Mintzes, 2015)

Following the co-design workshops, we began analysing the outcomes from the workshops to ideate a prototype that may meet the needs of the community members. This analysis was described in more detail in Section 5.3.5, consisting of cross-referencing the top ranked challenges, identifying themes through a thematic analysis, and accumulating feedback from local-facilitators and CoMaCH network members with expertise in qualitative analysis. From their research on developing design fundamentals in co-design, Demirbilek and Mintzes (2015) present these stages in Figure 14 above.

6.3.2. Objective

Based on an analysis of the outcomes from the interviews and co-design outcomes, the major overarching obstacle to MCH revealed to be a lack of access by community members - access to affordable MCH resources that could improve MCH knowledge and ECD skills, as well as to materials that were available in local languages, and which used more simple, understandable jargon. As discussed in Section 5.4.3., most of the co-designed solutions included the development of a digital medium for accessing MCH and ECD information, and disseminating the information through community stakeholders using a CWN. As a result, we endeavoured to create a digital medium that local communities could use to easily and affordably access appropriate MCH information, that could also build parent skills through ECD education. While we included resources for emotional well-being within the application and acknowledge that access is only one of the top priorities voiced by community members, we also believe that mental health deserves its own attention and intervention

but was not directly focused on in the scope of this project. Video format was voiced as a preferred format in the community interviews due to being easier to understand and more entertaining (increasing the likelihood of being used), thus we include video playlists related to different MCH and ECD topics.

We pursued development of a mobile application containing videos on MCH information, that would be available in local communities' languages, and with low-bandwidth costs incurred. Due to research scope and time restraints, we focused on development of an application for Cape Town communities and partnered with the local NPO, BBP, in developing an application for their beneficiaries. The participants would be able to download the application and its contents from the BBP site using the site WIFI (thus free of cost) during their usual engagement times.

6.3.3. Prototype and Workshop Iterations

The mobile application development, evaluation and content-creation workshops, as well as amendments took place in three iterations. Verbal informed consent was obtained before each iteration's workshop. Table 3 below provides an overview of each iteration.

Table 3: Phase 3 Iterations Overview

Iteration	Overview
1 Initial Mobile Application Development	• Development of initial mobile application • Community workshop for evaluation on initial application's content and features with two BBP staff members and eight beneficiaries • Follow-up content creation workshop for application content ideas with two BBP staff members and two beneficiaries
2 Post-Evaluation Mobile Application Development	• Amend application features and content based on feedback from Iteration 1 evaluation and content workshops • Community workshop for evaluation on amended mobile application with two BBP staff members and seven beneficiaries
3 Final Workshop and Amendments	• Final amendments on application based on Iteration 2 workshop • Final evaluation of application and participant feedback on experience of project with two BBP staff members and eight beneficiaries

Iteration 1: Initial Mobile Application Development

I developed the first version of the mobile application with the aim of sharing digital videos with community members. This would be used by community members and involve the Cape Town NPO, BBP, by deploying the application at their locations and allowing the NPO members to add content to the application. After developing version 1 of the application, shown in Figure 15 in the Findings section below, I led a workshop with 2 NPO members and 8 community members who were 6 mothers and 2 fathers (NPO beneficiaries) to present the application and attain their feedback. In the workshop, the community participants were reminded of the outcomes from the previous co-design

workshops to which they contributed and asked to evaluate and provide feedback on the initial mobile application. The community participants were given mobile phones to navigate through and their feedback and amendments were presented and recorded. The protocol of activities for this workshop is found in Appendix D.2.

I then led a follow-up workshop conducted with 2 NPO members (2 mothers) and 2 NPO beneficiaries with the aim of brainstorming possible content ideas. This included reviewing the suggested content provided on the application, deciding which format is most appropriate for different content types (video vs audio vs pdf), and providing topics, layouts and storylines for videos and pdfs. The outcomes from both workshops were collated and analysed for development amendments.

Iteration 2: Post-Evaluation Mobile Application Development

In the second iteration of the application, I worked with 3 UCT Computer Science Honours²⁰ students, who implemented the proposed amendments from the feedback attained in Iteration 1 and co-facilitated the application evaluations²¹. One of the amendments included creating a user-friendly platform for NPO members to access and edit the application content. The digital medium thus included both a staff-facing web portal and user-facing web application. The staff-facing web portal was developed to be usable by non-technical NPO staff to create, manage and assign ECD content to their specific parents, which can be viewable through either the web or mobile application. I then led a workshop for evaluations of this second version of the application. The workshop participants included eight community members (7 mothers and 1 father) and was co-facilitated by the same two NPO members from previous workshops, the three Honours students and my supervisor. The evaluation activities included acquiring feedback on the functionality and ease of use of the application, and completing usability questionnaires. The application was then modified in response to workshop feedback.

Iteration 3: Final Workshop and Amendments

In the final iteration, the necessary amendments based on Iteration 2 were made for the application, and a final workshop was undertaken to ensure that the staff and community members could easily use the latest platforms and address any additional concerns. This workshop included 6 mothers, 2 fathers, and was co-facilitated by the same two NPO members from previous workshops, the Honours students, and my supervisor. Each iteration's workshop consisted of at least half of the same participants from the previous workshop.

²⁰ In South Africa, the Honour's degree is a one-year degree undertaken after completion of a 3-year Bachelor's degree that demonstrates a higher level of achievement in that field.

²¹ https://projects.cs.uct.ac.za/honsproj/cgi-bin/view/2022/chitamba_ramruthen_swanepoel.zip/

6.4. Findings

6.4.1. Iteration 1: Version 1 Initial Feedback

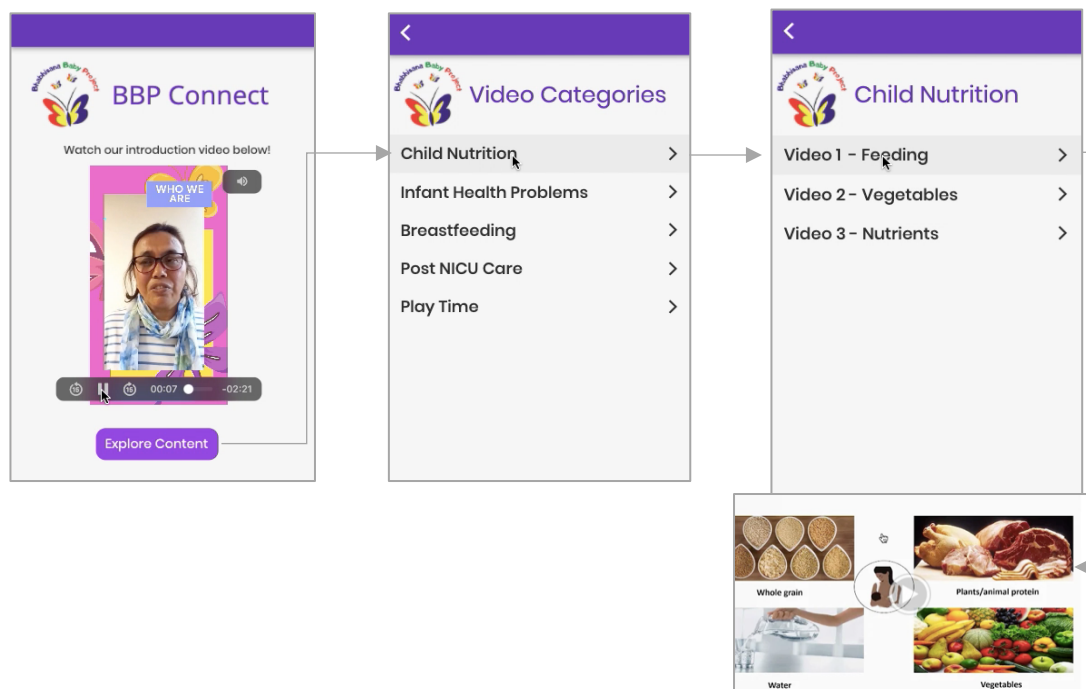


Figure 15: Mobile Application Version 1 Prototype

Mobile Application Feedback from Workshop 1

Version 1 of the application is shown in Figure 15 above. The home page includes an introductory video created by the NPO members, and a button titled “Explore Content” which directs a user to the video categories. A user then selects a video category such as “Child Nutrition” and is presented with videos related to that category. Thereafter, a user selects the video they want to watch, and the video plays, as shown below with the “Feeding” video selected. The categories included in this version consisted of “Child Nutrition”, “Infant Health Problems”, “Breastfeeding”, “Post NICU care”, and “Play Time.” The videos in these categories were sourced from BBP, DigitalMedic²² and Perinatal Mental Health Project (PMHP)²³, containing videos in four South African languages: English, Afrikaans, Sepedi, isiXhosa.

When presented with the application, the majority of the community members expressed that the initial version of the application was easy to use because it was similar to applications they already use, thus navigation felt intuitive. The NPO members were also pleased to see their logo on the application. The parents proposed content-based and developmental amendments. The proposed content changes included; additional languages (Shona, Chichewa), videos on personal wellness and

²² <https://digitalmedic.stanford.edu/>

²³ <https://pmhp.za.org/>

exercise, PEG feeding content, a guide on how to use the Road to Health Booklet, videos on protocols for emergency situations such as epilepsy, seizures, fever, protocol videos, and home school educational videos including how to stimulate baby, list of educare institutions, and links to home programs.

The parents also proposed the following developmental changes: 1.) group chat with probing conversation starters, 2.) a chatbot to reduce need to Google and scroll through videos by simply typing in a keyword, e.g. “breastfeeding” and acquire information on breastfeeding, 3) easy access to document resources and emergency numbers, and a search feature for nearest health institutes and transportation.

From this workshop, we realised that we needed more input from the community members on the types of content and respective format of content they would want to see in the application, and thus we conducted a follow-up content creation workshop.

Feedback from Content Creation Workshop

In the follow-up workshop, participants were invited to storyboard various content ideas for different respective formats. The storyboards created by the NPO staff involved a text-based outline on how to read to babies and a text-based storyboard outlining importance of choosing short stories with pictures and text and consistent reading routines. The other storyboards created by the community members and assisted by the NPO members included drawings of people depicting what to do during emergency seizures, how to improve mental health and how to stimulate your baby (as shown in Figure 16). Posters were expressed as the preferred medium for content cases where the content of the topic is crucial, and needs to be accessed by all mothers, including those who do not have access to digital mediums. These included 1.) a Road to Health Booklet Guideline and digital poster which indicating lookups in RTH booklet for quicker access to information on immunizations, nutrition and milestones (seen in Figure 17) and 2) a poster with baby development and immunizations at each stage. The participants proposed that these posters be put up in community centres, churches, clinics, schools, etc and be digitised.

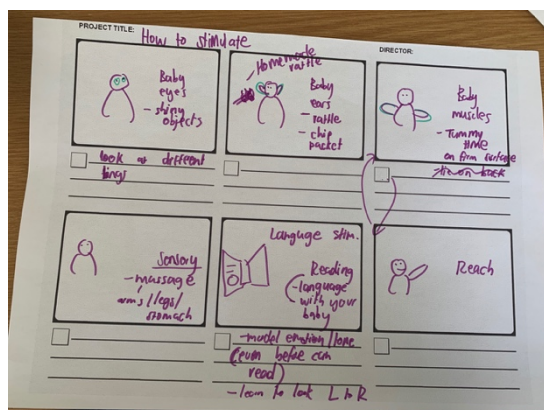


Figure 16: Storyboard Example for “How to Stimulate a Baby”

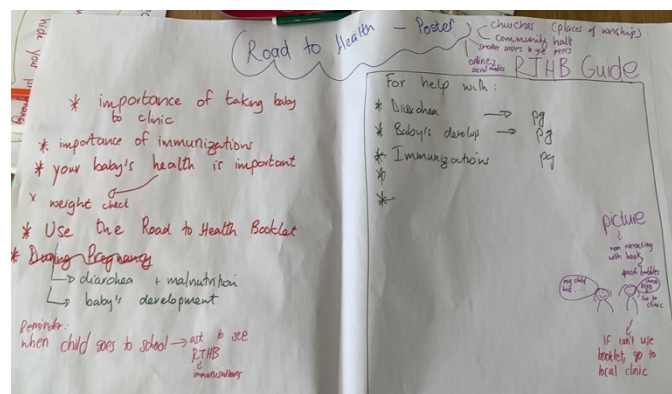


Figure 17: RTHB Guide Poster

6.4.2. Final Iterations: Post-amendments Feedback

ECD Application Features Feedback

Upon taking the feedback from the first iteration's workshops into account, we amended the mobile application's features with the following changes:

- Development of staff-facing application that allows BBP staff members to edit application content.
- Inclusion of article files and digitally created posters of brainstormed RTHB guide and immunisations chart (shown in Figure 18 below)
- Inclusion of search feature and map feature for nearby health facilities
- Inclusion of content on mental health

We observed that what the participants essentially wanted from the previously proposed chatbot was a lookup feature that allowed them to easily search for content using a keyword, thus we also included this through a search feature.

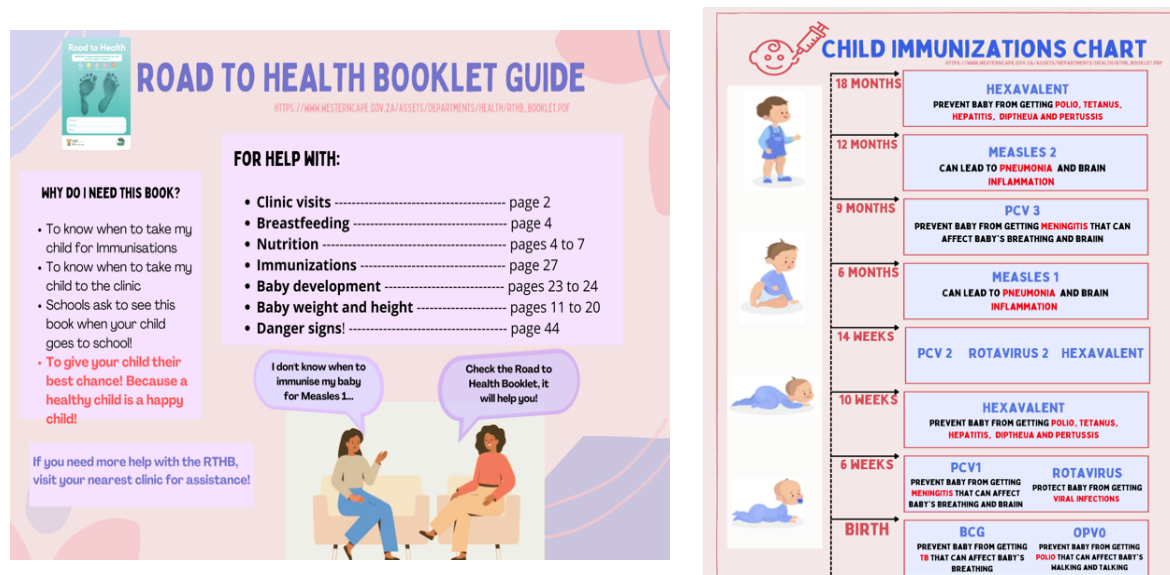


Figure 18: Posters Developed from Iteration 2 Feedback (Road to Health Booklet Guide on Left and Child Immunizations Chart on Right)

The remaining findings dovetail with the findings from the Honours students' project work (their reports on these findings can be found on the webpage provided in Footnote 21).

In the second and last iteration's workshops, the participants provided the following feedback on the updated user-facing application with the above amendments. This includes feedback on the ECD content and mobile application functionality.

ECD Application Content Feedback

The sensitivity of ECD content was found to be a significant factor in selecting the application content. The parents stated that the application content “should not increase the anxiety of already anxious parents.” They found the six different categories overwhelming and confusing. As a result, the category names were refactored into the categories: “Baby Health”, “Baby Development”, “Parent Health”, and “Assigned Content”. After consultation with the Bhabhisana NPO members and beneficiaries, six pieces of content were removed to reduce this anxiety. This included videos on delays in development as they were not applicable to all moms and could later be assigned individually to their respective assigned content. Furthermore, the parents requested the use language of, and addition of content that empowers and supports the parents, as opposed to just their children. Their comments included: *“I also want personal help and resources”* and *“I’d like counselling information.”* This inspired the development of the “Parents Health” category, which provides parents with resources for mental health. The parents responded to the emergency protocols content by expressing that they wanted to know about emergencies for themselves because they frequently can't access or use medical facilities. Although they claimed that this is the reason that they often use Google, “Dr Google” was frequently disparaged as parental sentiments toward Google were typically negative. Seven out of the eight parents used Google to retrieve information when searching about their babies - which often leads to distressing conclusions. In terms of content format, participants did not want any additional text-based mediums, as video format was still favoured. Some comments on this included: *“We don’t have time to read”* and *“We prefer to listen to audio or watch videos while we are busy”*.

User-facing Application Specifications and Functionality Feedback

In the previous workshop, the parents expressed that they had extremely limited space on their phone, confirmed by a staff member saying that they *“often can’t download a WhatsApp video we send them”*, which prompted development of a web-based version of the user-facing. The greatest concern of this web application was thus the users’ online data usage and loading times. The resultant application loads quickly within 1.5 seconds and takes minimal data per page at 147 KB. Other feedback on the application included; misperception about which content was the assigned content and the wording thereof, struggling with case-sensitivity for logins, and confusion between iPhone and Android Dialpad. These were indicative of more technology-based concerns but were easily overcome after initial guidance. Overall, the usability of the mobile application was rated highly by the parents. Direct feedback from our evaluations such as *“This is easy to use”* and *“It looks nice and interesting”* highlights the usability experiences parents had.

A System Usability Scale (SUS) (Lewis, 2018) evaluation was used to evaluate the usability of the user-facing application. The use of the SUS was a poor choice as its reliability of the SUS evaluation depends on the phrasing and usage of words. Our participants’ home languages were not all English, which meant we had to explain the questions further which ultimately hinders the evaluation itself. We had some conflicting results which was denoted with the complex use of English, and thereafter lack of understanding. We noticed that when we used the SUS, parents would only choose ‘strongly

agree' or 'strongly disagree.' This could allude to the fact that users find it difficult to quantify qualitative experiences.

Staff-facing Application Feedback

An evaluation of the staff-facing application followed. The BBP staff were keen on the application being accessible through the web browser, opposed to a local application. They stated: *"I am not technically advanced but can get use to this and will gain confidence"*. Following the conclusion of the sessions, a USE user evaluation was carried out to highlight the usability and satisfaction of the staff-facing web portal. The results shown in Table 4 below show high averages for user satisfaction and functionality.

Table 4: NPO Staff User Portal Acceptance Results

Topic	Scores out of 5	Average
Usefulness	5, 5, 5	5
Ease of Use	4, 5, 4	4.33
Ease of Learning	4, 5, 5	4.67
Satisfaction	4, 5, 5	4.67

The final application with the aforementioned changes, such as the inclusion of the staff and user-facing application, digitally created posters of brainstormed RTB guide and immunisations chart, and addition of a search feature and map feature for nearby health facilities is shown in Figure 19 below.

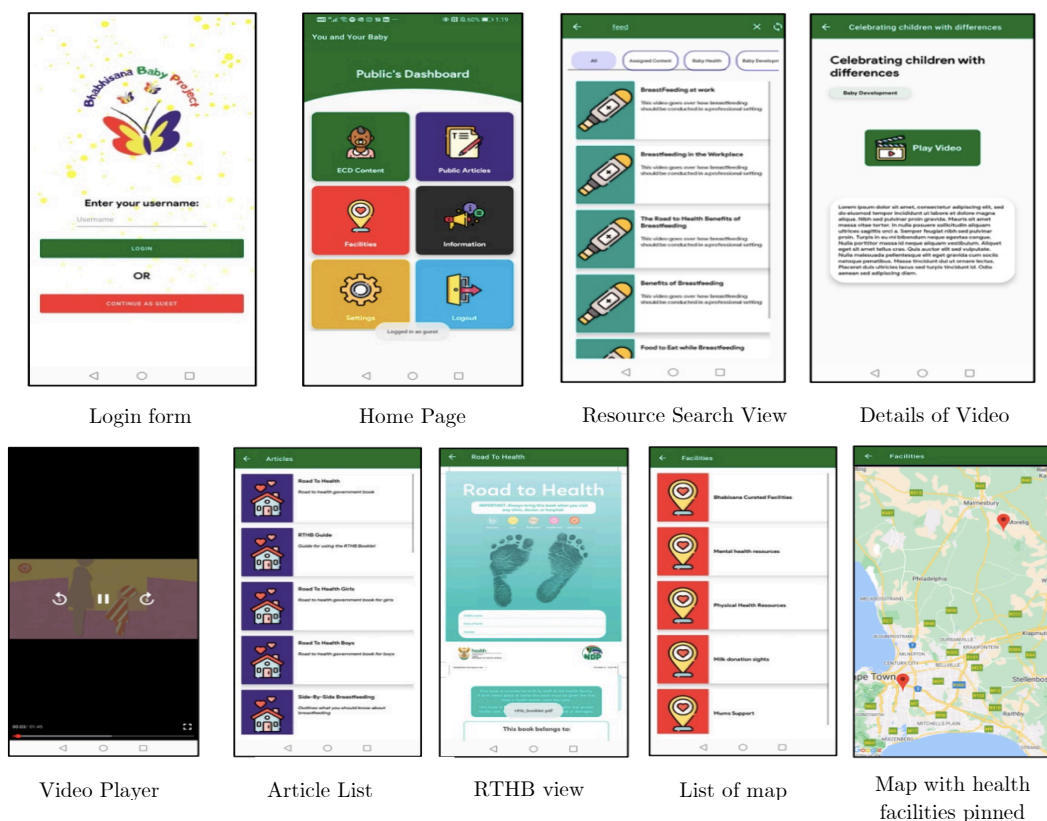


Figure 19: Final User Application Screens

Post-deployment Usage of Web App and User Experiences

The application was deployed, and the staff began assigning content to users. Within 4 days, the BBP staff created 12 user profiles and 4 parents logged into the web app. This highlights the readiness, paired with capability, these parents have in using the web app and viewing their assigned ECD Content. More time is needed to analyse trends or further findings within their usage. At the end of all the workshops, the participants expressed that they felt very accomplished and proud to be a part of the development of the applications. One participant exclaimed in joy: *“I’m an IT engineer!”*

6.5. Discussion

6.5.1. Design Considerations and Tensions for Digital MCH Applications

Choosing Content Mediums

An important aspect of conveying MCH information and knowledge is the format in which it is communicated, whether it is through more traditional mediums such as posters or brochures, or through digital mediums such as videos, audios, or digital posters. In the Iteration 1 content-creation workshop, the parents from Cape Town proposed that posters would be more effective than videos for distributing critical information such as immunisations, as they would be accessible to community members without mobile devices. These would be distributed in community halls, places of worship, clinics, and schools. They proposed that the posters be converted into digital formats and distributed digitally within communities. Through this finding, we also ascertained the significance Solutionism (Carr, 2013), particularly Techno-solutionism, played in our approach to this work, throughout the different phases. Techno-solutionism in HCI is the belief there exists technological solutions to complex social problems (Carr, 2013). Opposition to this was apparent in the workshops and prototype evaluations whereby, when approached with different and unfamiliar technological concepts, the mothers expressed that the suggested mediums were not the appropriate medium for conveying important information, that posters would be more favourable. Furthermore, this was previously evident in their reluctance to incorporate new technology card probes such as sensors in their co-designed solutions. This dovetails to our discussion on using asset-based approaches previously discussed in Chapter 4.

However, in Iteration 3 of this phase, we note that the parents opted for videos over additional text-based posters within the application as it is less time-consuming and more entertaining. From this, we understood that when parents have access to digital mediums, they may prefer video or audio, or info-graphic formatted posters. Thus, when deciding which format is most appropriate for communicating digital MCH information, we find that this not only depends on the content urgency or topic being conveyed, but also within communities, there exists partialities due to accessibility and literacy levels. Within the same city, format preferences of participants differed depending on the technology available to them. Those who are accustomed to smartphones would rather use a mobile application and watch videos than read through brochures or posters, even if they are

available on their smartphones. A study conducted on effectiveness of leaflets and posters as a health education method (Hasanica et al., 2020) supports our findings and states that, in circumstances where it is important to communicate information with a large audience for a sustained length of time, the distribution of health-educational posters is preferred. Another study (Bodjrenou et al., 2020) looked at whether posters or brief nutrition education videos were more helpful in changing how children are fed in a rural area in Southern Benin that experienced severe food insecurity. According to the results of the study, variables including the age of the children, the age of the mothers, and the districts, had a big impact on their preferred format and feeding habits. Thus, we need to consider the appropriateness of designing for all and including multiple formats or designing specifically for a single community depending on their socio-economic circumstances. This includes designing according to reading and technical literacy, age and other factors (Bodjrenou et al., 2020)

Designing For Sensitivity and Shifting from General Health to Mental Health

As with our previous interviews and co-design workshop feedback, community members expressed that they feel overwhelmed when using Google for their MCH queries, as it overloads them with information, and often provides distressing and harsh responses. Similarly, when presented with this application content, participants expressed negative emotions of discomfort towards the category names and some videos, and stated that they evoked anxiety and needed to be redesigned more sensitively. The category names such as “Infant Health Problems” were thus subsequently changed and videos were removed, mostly videos alluding to infant disorders and delays. The parents also expressed the need for more “safe”, positive, and uplifting content.

This outcome deals with both the language used in the application as well as the content provided. More interestingly, it shows that parents not only want sensitive language and content, but language and content that empowers and uplifts them. This links to the previously discussed need to advance beyond only sharing health information in low-income communities, but impacting users positively and providing their needs above only general information.

This includes integrating content on parents’ emotional well-being and promoting encouraging, supportive content. We observed a noteworthy shift beyond achieving only basic physical health needs in low-income South African communities, but evolving their holistic well-being, mental health included. As previously discussed, HCI research on mental health in LMICs (Patel & Kleinman, 2003; Pendse et al., 2019) show that limited work has been done in HCI4D addressing mental health directly, with most studies targeting trauma as a result of violence against women, and the mental effects of physical health diseases such as HIV/AIDS (Safren et al., 2009; Sterling, 2013). Moreover, even fewer work has been done in the space of maternal mental health in LMICs. A study by Atif, Lovell et al. (2015) indicated that in most LMICs, the maternal mental health agenda has not been integrated into the primary health care system, and that educational and interventional approaches have been demonstrated to increase maternal MH.

HCI researchers and content and app developers for low-income communities should pay attention to this limitation, to the language used in their mediums, and that the “textbook” language can sometimes be insensitive and dissuade parents from engaging with content, and that positive language should be explored and implemented. A study (Yin et al., 2015) on diabetic health literacy indicated that empowerment tactics, as well as language and cultural consideration, appeared to help patients successfully implement behaviour change.

Participant and Intermediaries Empowerment through Co-design

Both the NPO staff members and community members were overall content with the final application and were able to successfully navigate it. They expressed joy and pride in themselves for collaborating on the development of the application. This sense of empowerment and accomplishment is essential to acknowledge as it is an important value of co-design and its objectives (Cantu & Selloni, 2013). Past research shows that people are more likely to engage with an initiative that they were actively involved in developing, and this was revealed in this study through the participants’ early engagement in the application immediately after its deployment. We also saw the importance of giving the NPO staff control over the distribution of the content to different community members as they are aware and knowledgeable of the specific needs and sensitivities of the community members. We believe that iterative development and feedback help achieve their contentment in the resultant application, to visibly identify their inputs between iterations.

6.6. Chapter 6 Summary

In Chapter 6, we reported on *Phase 3*, including the development process of the resultant digital intervention. This was a mobile application providing community members with free access to low-bandwidth MCH information catered to their needs in terms of language and content preferences. The iterative process of development and evaluations is described, including the application amendments and feedback provided by community and NPO members. Through these iterations, various feature-based and content-related amendments were suggested and implemented. These included the development of a staff-facing application that provides control to NPO staff members to edit application content, the inclusion of article files and digitally created posters of brainstormed RTB guide and immunisations charts, the addition of a search feature and map feature for nearby health facilities, and the inclusion of content on mental and emotional wellbeing.

In this chapter, we not only provide the content and development-based findings, but also research findings, which include; designing for sensitivity, as well as participant and intermediaries empowerment through co-design. The parents also expressed the need for more “safe”, positive and uplifting content. Through this and the request for more emotional health content, we recognised a shift beyond achieving only basic health needs in low-income South African communities, but evolving their holistic well-being. On the second research point, we heard both parents and NPO member express their sense of empowerment and pride in contributing to this project, and from this, their enthusiasm to use the application. This was also found evident through some early outcomes

provided on the uptake of the application post deployment, wherein most participants used the application within its first week, which we attribute to the effectiveness of co-design in increasing likelihood of participant uptake. This chapter provided key insights from the final phase of the project, touching on user and content preferences and also, the result of a co-designed intervention, and the impact of using its approach.

CHAPTER 7

Reflection and Conclusions

In this chapter, I reflect on the consolidated findings and discussions from the three phases of this research and provide conclusions in respect to my research questions.

7.1. Characteristics of Existing Tools and Mediums to Address Key MCH Priorities

Through our findings from the Phase 1 community interviews, we addressed our first research question, “*What are the characteristics of existing tools and mediums to address key MCH priorities?*”, by ascertaining the characteristics of existing tools and mediums for MCH in the targeted communities. We discovered that overarching nuances amongst the two rural and two semi-urban communities exist, and this finding carried on as a common theme throughout this work. Thus, in exploring and answering this question, we recognised variances and nuances rooted in differing socio-economic circumstances, network challenges, reading and digital literacy, community and traditional norms and language and technical accessibility. Therefore, we deduce that our understanding of MCH user behaviour and tools to address MCH challenges, and thereafter, a plausible solution, cannot be homogenous or without nuances.

Our interview findings supporting these urban and rural nuances included 1.) The participants' “connectivity challenges” in the more urban areas primarily included limited WIFI availability and unaffordable data plans, whereas for the participants from the rural sites, the barriers included poor network coverage, their inability to pay for any mobile data, and poor affordability of electricity to maintain (charge) mobile devices 2.) There exists differing current healthcare-seeking behaviour and sources, whereby the more urban communities primarily used local clinics, Google and social media to access MCH information, while the rural communities mostly seek community gatherings, pamphlets, traditional healers, radio and TV 3.) Although most of the participants across all the sites did not use digital MCH applications, the reasons provided for this in urban areas were mainly related to a lack of awareness of specific applications, whereas the reasons provided in rural sites were more socioeconomic in nature, such as a lack of infrastructure to support such applications.

Through our interview data, we observed that the current mediums and tools used by community members across the sites aligns with that which is accessible, familiar, and trusted by communities, as familiarity is what they evidently seek. Thus, familiar mediums such as WhatsApp and Google, as opposed to unknown mobile applications or devices were favoured. In both rural and urban contexts, in line with the motivations of asset-based approaches (Brooks & Kendall, 2013), a sense of community and familiarity was important, but this manifested more as communal and traditional spaces in rural areas and as close family and social media in more urban areas. Aligning with the work of Wang (2017) and principles of Social Cognitive Theory (Bandura, 1998), this element of

community proved to be significant in meeting the participants' MCH needs and served as a recurring theme toward an equitable digital intervention for MCH.

7.2. HCI Priorities for MCH and Digital MCH

In the community interviews, the identified barriers associated with using digital MCH included the lack of awareness of the applications and a preference for confiding in family members, a lack of affordability for necessary resources like mobile devices and mobile data, as well as inadequate connectivity and network issues, language barriers for understanding MCH and a lack of trust on online information. In response to our third research question, "*How do HCI research priorities in MCH and digital MCH align with actual parent priorities?*", we observe that these challenges from Phase 1 are mostly commonly recognised by the HCI community (Dahab & Sakellariou, 2020; Natarajan & Parikh, 2013; Rothstein et al., 2021). However, upon ranking and prioritising them within the additional discussions in the *Phase 2* workshops, we were able to recognise the ways in which their MCH needs are not currently being understood or addressed in accordance to community needs and existing tools and values. In *Phase 2*, the community participants prioritised the necessity for more accessible MCH resources and improved parenting skills to implement ECD practices with their children at home. Community participants also urged for greater attention to emotional maternal health and well-being within their communities.

In our study, all of the research sites prioritised mental and emotional wellness over physical health concerns including postpartum care. However, the HCI-based MCH research for the global South primarily concentrates on physical health such as breastfeeding, diabetes, HIV, monitoring and nutrition (Babar & Rahman, 2021a; Mbuthia et al., 2019; Rothstein et al., 2021; Wardle et al., 2018). Moreover, current HCI research on mental health in LMICs (Patel & Kleinman, 2003; Pendse et al., 2019) mostly target trauma as a result of violence against women, and the mental effects of physical health diseases such as HIV/AIDS (Safren et al., 2009; Sterling, 2013) as opposed to parent well-being per se. We also discovered that research in digital MCH primarily use top-down design that excludes the community (Kaufman et al., 2017; Rothstein et al., 2021) thus, it is likely that in previous research, the community's obvious need for mental well-being development did not appear as a significant priority. In South Africa, there are currently very few digital mental health and well-being projects for mothers, though there are current innovations that provide mental MCH resources, such as Messages for Mothers from the Perinatal Mental Health Project (PMHP) which found to be unused by most participants. While some are zero-rated (i.e. no data costs are charged for accessing the website), access is limited by network coverage and device compatibility. Furthermore, content is often only available in a limited number of languages, as was evident in our co-design workshops, when mothers expressed frustration at not being able to access MCH resources since they were not available in their local language. To support emotional well-being, we highlighted the importance of including community participants in the design of any intervention aimed to address stigmas and to contextualise resources, according to community needs and preferences.

We reiterate that digital health and MCH in sub-Saharan Africa is continually developing but is experiencing poor uptake by communities, as seen with MomConnect (Xiong et al., 2018), which we attributed to poor community involvement in the development of the interventions. In addressing the priority for accessible and affordable MCH information, community participants sought community familiarity, and because of this, often opted for community-based solutions such as asking for help from family, religious leaders or traditional healers. We echoed that connectedness is an important concept in African cultures as represented in *Ubuntu* (Nussbaum, 2003). We believe that this is what is neglected in current HCI work - we should be working with this sense of familiarity, and not focus away from it. This can be implemented through working with and including traditional and community leaders, and community spaces within interventions. As with the interviews, the co-designed solutions for the above priorities prioritised community and connectedness. Through our co-design workshops, we found that community participants seek more than only access to information, but seek meaningful connectedness with each other and their community leaders. This may manifest through social media, community spaces or places of worship. In relation to the co-design outcomes, the design elements incorporated in the solutions also varied between the urban and rural settings, with the rural sites prioritising community radio, community and traditional leaders and community structures, and the semi-urban regions leaning more towards mediums such as mobile applications and videos. We believe that this should be considered when designing digital-based initiatives for communities. Furthermore, we also propose the use of asset-based approaches for such contexts such as by using posters, community radio and other resources that community members are already using and are likely to use for improving MCH.

7.3. Challenges and Opportunities Entailed in Co-Designing Digital MCH with Community Members

In answering the second research question, “*What are the challenges and opportunities entailed in co-designing digital MCH with community members?*”, we reflect on our experiences during the co-design activities in *Phase 2* and *3*.

From our observation, the process of collaborating with communities on the development of an application resulted in a sense of empowerment and accomplishment amongst community members, which is an important value of co-design (Cantu & Selloni, 2013). By co-designing with community members, we were able to learn their actual MCH priorities and co-design, and subsequently develop a digital initiative that was based on their MCH needs and consequently initially well-received by community members.

An important aspect of PD that we discussed throughout this work was co-design preparation and readiness, whereby we found, as proposed by Akama and Light (2020), that preparing the appropriate tools, mediums and techniques are essential for successfully conducting co-design activities. Throughout our workshops, the use of intermediaries played a significant role in communicating the MCH challenges with participants from different cultural backgrounds, and making them feel comfortable in the research space. This includes language translation and sense of familiarity that

allows them to open up more about their experiences. We discovered the importance of intermediaries and the opportunities they provide in communicating effectively with participants, not only through speaking the same language but through their vernacular, humour, and cultural awareness. This led to participants feeling more comfortable and opening up more about their experiences with less apprehension. Furthermore, training the intermediaries and local facilitators on building empathy was imperative to creating an open and comfortable space for participant research. We next acknowledge the importance of having multiple iterations with different stakeholders in all three research phases. As recommended by Jacobi, Llanque et al. (2022), iterative development and feedback from multiple stakeholders proved essential in achieving the participants' contentment in the resultant application.

From our experiences with using the Design Cards in workshops, and supporting aforementioned work by Brandt & Messeter (2004) and Deng et al. (2014) on Design Cards, the Design Cards were effective in: eliciting conversations on digital MCH; probing new ideas from community members; creating a tool to empower low-income communities on opportunities for their communities; and establishing a shared understanding on topics. They also addressed differing literacy levels and cultural contexts. Additionally, we discovered that Design Cards are effective as co-design aids for brainstorming, but were challenging and less effective in providing participants with more contextual understandings of unfamiliar technology concepts, thus incorporating video mediums was suggested as well.

Overall, we deduce that community-based co-design *can* be effective and provide great opportunity for community research and outputs if the necessary tools and mediums are implemented. This involves the inclusion of intermediaries, Design Cards or aids, the communication of new technology concepts, and appropriate mediums for presentation (text vs illustrations vs videos) to support co-design. Finally, through our prototype development and evaluations, we highlighted the importance of designing sensitively and acquiring community feedback on content.

7.4. Limitations and Future Work

In reflection, my initial uncertainties regarding the outcomes of conducting work of this exploratory nature, not knowing what a "solution" would look like, prompted some concern, but I believe that we have gained enriching findings that would not have been discovered through typical top-down, more deductive, or techno-solutionism-based approaches.

We note some limitations and future work to consider for this research. Firstly, this research identified three significant priorities and ten pertinent challenges related to MCH, but due to scope, time, and funding, we have focused only on *Affordable and Accessible Health Information*, and partially addressed *Building parenting skills in early life* and *Parent well-being* through the application content. Moreover, we also note that the development of this intervention only included participants from Cape Town and their feedback, overlooking input from communities with differing socio-economic and cultural backgrounds. Future work should focus specifically on the other MCH challenges voiced by the communities, and conduct interventions across different communities. The

developed mobile application intervention should also be implemented and evaluated in the other community sites and for other NPOs. Furthermore, the other solutions emerging from the co-design workshops should also be explored further.

Secondly, regarding time, we found that we had insufficient time to properly complete all the co-design workshops and that participants grew tired by the final prototyping activity. Future workshops in community co-design should consider conducting such activities over multiple days as collaborative work often requires more time than expected due to factors such as communicating tasks. Furthermore, this work only acquired the usage of the application by participants less than one week after deployment. Future work should investigate the longevity and sustainability of the resultant intervention from this project. Long-term studies should also consider the ways in which such interventions can be maintained and managed, and to what extent participants should be involved in this process. Furthermore, future work should also upload the mobile application onto CWNs to distribute to communities. Finally, I acknowledge my positionality as a student and not a parent when interacting with the community members, which may have influenced their interactions with me and perpetuated researcher-participant bias. Furthermore, my interpretations of the findings may also be biased due to my background in Computer Science and Psychology.

Overall, this dissertation provides a foundation for future work by identifying pertinent MCH challenges and demonstrating how researchers can use this approach to address those challenges.

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APPENDIX A

Full Set of Challenge and Ideation Design Cards in English

The full Design Cards set can also be downloaded from:

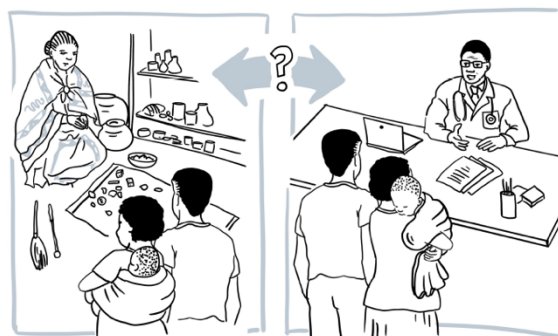
<https://comach.melissadensmore.com/topics/design-cards/>

A.1 Ten Challenge Design Cards

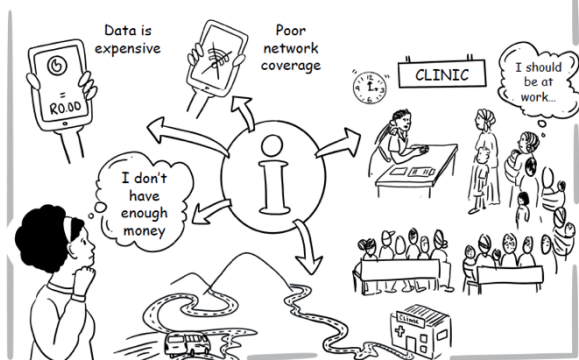
① Involving Fathers



② Traditional Healers



③ Accessible and Affordable Health Information



④ Building Parenting Skills in Early Life



⑤ Parent Well-being

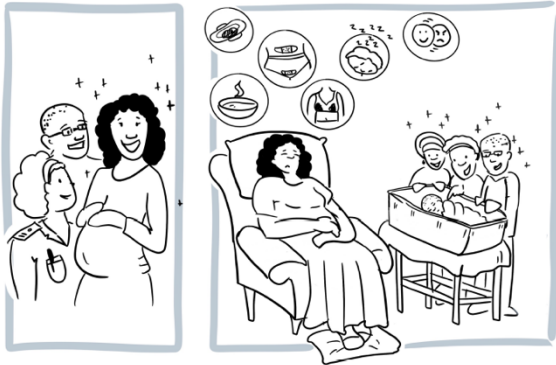


⑥ Health Worker Emotional Support for Parents/Caregivers



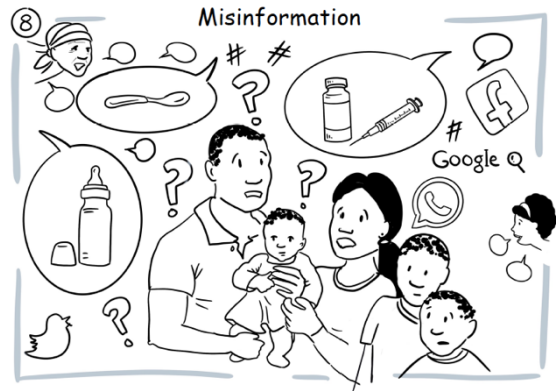
7

Post Partum Care

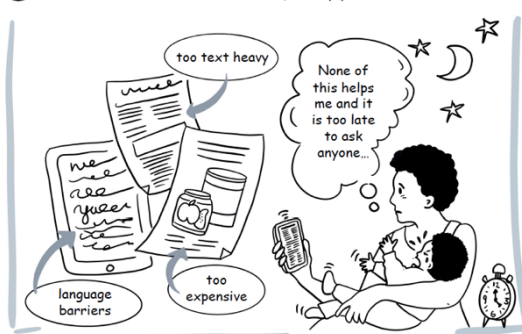


8

Misinformation



9 Personalised and Timely Support

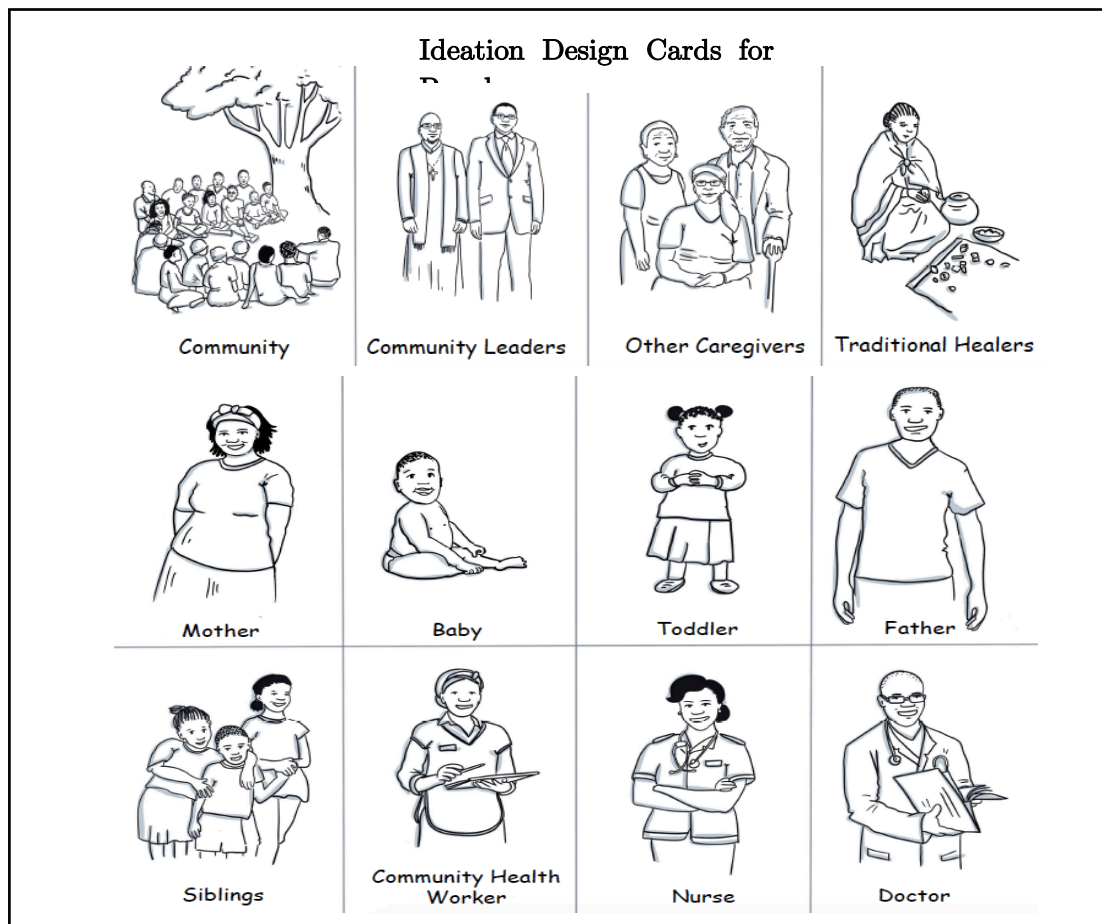


10

COVID-19 Vaccine Hesitancy



A.2 Ideation Design Cards



Ideation Design Cards for Resources and

				
Community Radio	Wearables	Sensors and Data	Community Wireless Networks	Mobile Data
				
Internet in a Box	Chat Bot	Mobile Data Collection Apps	Mobile App with Educational Videos	Social Media
				
Road to Health Booklet and App	MomConnect App	Pregnancy + App	Mobile Pregnancy/Baby Trackers	WiFi Connected to Internet
				
Tablet	Laptop	Feature Phone	Smartphone	WiFi Not Connected to Internet

Ideation Design Cards for

			
Early Childhood Development Centre	Faith-based Building	Community Centre	Hospital
			
Public Health Centre	Home		

APPENDIX B

Community Interviews Script

KII NUMBER:	DATE (DD/MMM/YY):	START TIME:	END TIME:	FACILITATOR INITIALS:

[Read to participants]

We are very happy that you took the time to meet with us today. [PARENTS] We are excited to hear your thoughts and opinions about the challenges and problems faced looking after your health and that of your child.

[community leaders/facilitator] We are excited to hear your thoughts in your community around maternal and child health. By understanding your needs and the needs of other community members like you, we hope to work towards a solution that is useful to you. I have already read through the consent form with you, which describes this project in detail and you have given us permission to speak with you. As a reminder, you are not required to answer all of our questions, and you may choose to skip questions. As a reminder, we will be audio recording our telephonic conversation today. The discussion will last approximately 45 minutes. You are the expert and so we are really eager to hear what you have to say. There are no “right” answers – just your own experience and thoughts. Do you have any questions before we begin the discussion?

Note to interviewers: Turn on digital recorder.

I am (FACILITATOR NAME) interviewing (KII ID#) on [DATE] [START TIME]

Theme 1: Demographics

- Ages of children in the household (EDD for pregnancy)
- Anyone else in the household which include other caregivers in the household
- Devices and internet access

Theme 2: Defining the problems

- Where do you go for help concerning the health of your children?
- How have you used your phone concerning maternal and child health?
 - Do you ever use WhatsApp or other social media to look for information or ask people for advice? Tell me more. Can you show me a recent conversation?
 - Do you use any maternal and child health apps? Which ones?

- Are you aware of any projects around maternal and child health?
 - If no – ask about specific projects (national and local, e.g. MomConnect)
 - What works about these projects?
 - What would make the projects work better for you?
- If you could create and plan- a project, what would it look like?
- What about your friends and neighbours that might not have phones, or live in areas that don't have a network? Can you talk about what their experience might be like, and what works for them?

Theme 3: Perception of and challenges around existing campaigns and interventions

- MomConnect
- NGO interventions
- Messages for Mothers
- Road to Health booklet
- Maternity Case Book
- ECD programs?
- Other resources?
- Customizable interfaces? Use of PHI, apps for MCH?
- Feedback from parents that don't have phones or smartphones (and therefore they find it is harder to communicate)
- For community leaders which ICT networks do they use to communicate
- For intermediaries/facilitators which ICT networks do they use to communicate

Theme 4: How to do research?

- Have you ever participated in a research study or survey before?
 - What was it like for you? Was there anything about it that made you uncomfortable?
- We want your input in how we can best work together to develop new approaches to the use of ICTs

Thank you for helping us understand more about the types of services and programs that can help women like you. The details you have shared here today are very valuable. They will help us as we plan and think about how we might be able to work with you to solve some of these problems.

Thank you for your participation.

Note to interviewers: Note the time the conversation is concluded. Turn off the digital recorder.

APPENDIX C

Community Interviews Codebook

Theme and Codes	Participant Comments
Theme: MCH Asset Analysis	
Mobile devices	<i>"I mainly use my phone, no computer at home"</i> – Participant from Cape Town <i>"We have a laptop, internet and phones"</i> – Participant from Cape Town <i>"We have a work laptop"</i> – Participant from Cape Town <i>"Everyone in the household has a smartphone"</i> – Participant from Soweto <i>"I use the small phone, not the one you touch"</i> – Participant from Soweto <i>"No I have no computer I only have a phone."</i> – Participant from Sweetwaters <i>"Yes, I use the cell phone to access the internet"</i> – Participant from Sweetwaters
Internet Access WIFI Mobile data	<i>"We only have access to the internet on cell phones."</i> – Participant from Cape Town <i>"No, no internet access at home"</i> – Participant from Cape Town <i>"Sometimes I run short of data to use for internet"</i> – Participant from Limpopo <i>"No, we don't have internet access like Wi-Fi, I use Internet Café for access....It doesn't make sense to not buy food for the children just to pay for Wi-Fi."</i> – Participant from Soweto <i>"There are many who cannot afford data"</i> – Participant from Limpopo <i>"No we have to buy data, ja it's very, very eish it's problematic to get Wi-Fi so it's... sometimes it's challenging let's say I need to go online to apply"</i>

	<i>for a job or something, then I have to go to the internet café to do my things.” – Participant from Soweto</i> <i>“I use data on my mobile phone but at home there is an installed Wi-Fi Since I'm not at home most of the time that's why I use my data” – Participant from Sweetwaters</i>
Electricity	<i>“The rural areas where they do not have network, they do not have smartphones, they do not have TVs and they do not even have electricity” – Participant from Sweetwaters</i> <i>“I'd emphasise more on the electricity issue, the electricity in Shawela is poor. You try to cook, only to find that it's off. You want to do something, it's off. You can help us with electricity.” – Participant from Soweto</i> <i>“When the power goes off, you see that person will suffer.” – Participant from Soweto</i>
Theme: Existing Sources for MCH care and Information	
Road to Health Booklet	<i>“My paediatrician uses my baby's file in the office, he adds immunizations to the booklet. I could not really use all the information in there because my baby did not meet the milestones.” – Participant from Cape Town</i> <i>“I do not understand the booklet, most of the things written there is in big words and language that I find it hard to understand. It would be better to have an App that would explain all the steps and the important of the booklet the way we can understand” – Participant from Sweetwaters</i> <i>“No, I do not use it – I have one , but the information in there does not really help me because my baby is different. The clinic fills it in for immunizations. The milestones in the book is different for my baby.” – Participant from Cape Town</i> <i>“I prefer to access information through the phone because unlike the road to health book which you put it away, but with the phone, we spend a lot of time using it even when I'm bored I read the information sent through mom-connect”. – Participant from Limpopo</i>
Community	<i>“I ask people that I am living with especially my mum, if it is something that she does not also understand then I take the child to the clinic” – Participant from Sweetwaters</i>

	<i>"I ask my mother when I need help. She will always give me advice."</i> - Participant from Cape Town <i>"For my family members of granny, they can get someone that can communicate the information about them relating to all issues of maternal and child health".</i> – Participant from Limpopo <i>"I think the community caregivers are used to facilitate or convey information; it reaches lots of people in the community"</i> - Participant from Sweetwaters <i>"Our grannies, mothers, aunts they are the ones who make sure that we understand these things, even though they are still using the old ways but we grow."</i> – Participant from Soweto
Traditional healers Cultural Beliefs	<i>"Home, traditional I will start home because we believe in tradition. I have a traditional healer at home, so if the traditional healer fails, then we can go to the clinic. The traditional healer assesses if they could be able to assist with the maternal and child health problem, and if they can't then, I will go to the clinic".</i> - Participant from Limpopo <i>"Late pregnancy booking is a major challenge because they first consult with traditional healers and consult in the clinic when it's already late".</i>- Participant from Limpopo <i>"There was an instance where a child got a red patch at the back of their head, only to find that it was nothing major... However, when elders made wind of it, they made it a major issue and then a child goes through a painful procedure. We fall for this as desperate new mom who wants the best for their child only to find that this makes things worse. If people can come and urge us to go to clinics to get more knowledge and ask questions, that will help a lot."</i> - Participant from Soweto
Clinics NPOs	<i>I'm only making use of a local clinic (for help concerning the health of children). Government clinics</i> – Participant from Cape Town <i>"I go to the clinic, and Bhabhisana."</i> - Participant from Cape Town <i>"I go to the clinic; they have social workers in the hall. We go to the clinic if the child is not feeling well or not growing properly, we go there for children's porridge"</i> – Participant from Soweto

	<i>“We go to the clinic. The service sometimes at clinics is very bad.” – Participant from Limpopo</i> <i>“I go to the clinic I go to the health facility” – Participant from Sweetwaters</i> <i>“I go to the clinic almost every month, they give you the dates for check ups then you go during those dates, and you tell them how old the baby is.” – Participant from Sweetwaters</i>
Theme: Current Technological Support for MCH	
Facebook	<i>“I think Facebook is a good platform because Facebook does not take a lot of data. There are also ways where you can access Facebook without data.” – Participant from Sweetwaters</i> <i>“I prefer Facebook a lot because even a person who does not have a smartphone can access Facebook. They could have a simple application form, and some easy questionnaire to complete and not get bored. So I think Facebook will allow mothers to share their stories.” – Participant from Soweto</i> <i>“You see people are attracted to videos than reading, if nurses can shoot a video about pregnancy or child health care the information will spread fast through Facebook, WhatsApp and we can also share with those we know they are pregnant” – Participant from Limpopo</i>
Google	<i>“I did not know what glaucoma was when my baby was born – I Googled A lot to find out everything I can do to help my child– Participant from Cape Town</i> <i>“I will Google something if I am not sure about medication that they gave him, then I would like Google it and find out more about the medication. – Participant from Cape Town</i> <i>“We Google for information, for whatever information that you need.” – Participant from Soweto</i> <i>“Ja sometimes; often when I ask around health issues I always ask my friend to Google for me concerning my health” – Participant from Soweto</i> <i>“I will Google if I see something that I don't understand in my child.” – Participant from Sweetwaters</i>

	<i>"Yes Google was useful to me because I had all the symptoms that they gave me."</i> – Participant from Sweetwaters
WhatsApp	<i>"I used WhatsApp. Or other social media to ask for people's advice"</i> – Participant from Cape Town
MCH Apps	<i>"Mom-connect will notify me about my next visit....and informs me about the baby's development. They send a lot of information every week about child care e.g. if a child is vomiting what you should do and if the child is not improving when should you go to the clinic."</i> – Mother from Limpopo
Theme: Existing MCH challenges	
Accessibility Healthcare challenges	<i>"Because the clinics are always full and you find that there's lots of people waiting to be assisted and the pregnant woman and the children are vulnerable to infections from people who are older and very sick in the clinic waiting room."</i> - Participant from Sweetwaters <i>"Sometimes people will complain about the services at the clinic, and about the long lines that they have to stand in"</i> - Participant from Cape Town <i>"Our clinic is bad, it doesn't have space for one, it's overcrowded and then the people there don't want to give out the medication... It's always full, sometimes they tell us to turn back because it is full."</i> – Participant from Soweto
Transport	<i>"Some people don't have transport to go to hospital. They don't have transport to go for the check-up or so"</i> – Participant from Cape Town <i>"There's those that can't get to the clinic themselves or can't afford to pay for transport because remember it costs money to be transported it's not free"</i> – Participant from Limpopo <i>"If one of the children is sick at that moment and I don't have transport or anything then I go to my neighbours tell them that my child is unwell and ask if they can help me by providing transport to go to the clinic"</i> – Participant from Soweto <i>"I'm suffering in terms of transport and time to reach there (the clinic); remember you've got to arrange transport first and then having to pay"</i> – Participant from Soweto
Traditional and cultural beliefs	<i>"Since you know, culturally you are not expected to go out (for healthcare) if you still have a small child."</i> – Participant from Sweetwaters
Theme: Existing Digital MCH barriers	

Lack of community infrastructure and devices	<i>“There are places in areas where the network towers haven't been installed.”</i> – Participant from Limpopo <i>“You’re talking about places where there’s no network and so forth; there are houses where they don’t even have TVs, there’s no phone because not one person in that house works”</i> – Participant from Soweto
Lack of affordability	<i>“Another issue could be of data because it's not cheap to get data.”</i> – Participant from Sweetwaters <i>“Now it's just normally where you get the experts that online (about MCH application) where ask questions, but I don't always save them money for it. You see, I see because they do charge”</i> – Participant from Cape Town <i>“There are those who cannot afford to buy data”</i> – Participant from Limpopo <i>“You need to make means to get it (internet access) and if you don’t have money you won’t get it you know... so you need to make means of having money to be connected”</i> – Participant from Soweto <i>“What can hinder me is not having money to buy data, I think that can be the only thing”</i> – Participant from Sweetwaters
Network issues	<i>“Though I have used mom-connect during pregnancy, network in this area is a serious challenge.”</i> – Participant from Limpopo <i>“It can work better if they can improve the network coverage and connection wherein even those who cannot afford to buy data can have a free connection and access the information.”</i> – Participant from Limpopo <i>“When we use phones, you find there’s network issues, others don’t have phones; so I think it’s effective.”</i> – Participant from Soweto <i>“There are places in areas where the network Towers haven't been installed.”</i> – Participant from Sweetwaters
Language	<i>“I think if they could access even a radio. Everyone listens to radio in different language but not all languages on radio.”</i> – Participant from Sweetwaters
Theme: MCH and Digital MCH community wishes	
More NPOs and projects	<i>“We can have more projects involving men wherein they can gather or share ideas as males using what's-up or Facebook on how to assist the</i>

	<i>mothers in taking care of our children, women do that more often but us men we don't". - Participant from Limpopo</i> <i>"I think we can have organization within the community that can go to the community and teach them or share information with them also remind them about the important of having information pertaining mother and child health during pregnancy and after giving birth" – Participant from Sweetwaters</i>
Information Access	<i>" I think it will be wise to develop a free mode app because most of the people are unemployed and they do not have money to buy data to access information on the internet" – Participant from Sweetwaters</i>
Digital resources	<i>"You see people are attracted to videos than reading, if nurses can shoot a video about pregnancy or child health care the information will spread fast through Facebook, WhatsApp and we can also share with those we know they are pregnant" - Participant from Limpopo</i>
More understandable resources	<i>"A mother will only know but some terminology without fully understanding what's that procedure is for example you will know that you have to do a PCR but you don't know what is the meaning of that, we need something understandable" – Participant from Sweetwaters</i> <i>"I was given the TB treatment information; they didn't tell me about its side effects and that the medication they were giving my child was for TB. I did not understand anything, and no one explained to me. We need help with this" – Participant from Sweetwaters</i>

APPENDIX D.1

Phase 2 Community Workshops Protocol

Pre-Co-design Activities

1. Ethics Clearance Amendments

The co-design activities will take place in person through workshop focus groups. Each focus group will consist of 10-12 participants + 3 facilitators, with COVID-19 safety regulations in place. This includes:

- Facilitating sanitizing stations to sanitize participants and facilitators before entering workshop.
- Enforcement of participants and facilitators wearing masks at all times (surgical masks will be provided).
- Socially distancing participants and facilitators: enforcing distance of 2 meters between each person.
- Excluding participants with comorbidities to the COVID-19 virus.
- Focus group will take place in a large well-ventilated area

Due to previous submissions taking place during more restricted COVID-19 regulations, Ethics Clearances may need to be this amended to account for this in-person, co-design approach.

2. Participant Recruitment

Participants will be recruited by contacting (via phone call or WhatsApp) caregivers who stated that they would be interested in engaging in co-design activities during the community engagement interviews. [to be replaced by site-specific details:] The caregivers contacts were provided from the organizations that provided lists of their beneficiaries for the community engagements.

This method of participants recruitment will apply during all COVID-19 lockdown levels

3. Facilitators Training

The co-design activities will be conducted and assisted by facilitators who will receive in-person training prior to the co-design activities. This training will involve guiding facilitators on how to conduct the co-design approaches. Facilitator training will include a walk-through of the co-design workshop protocol. This will provide local facilitators to trial translations of the activities and for a discussion on how best to communicate the activities to the participants. Facilitators can stage a mock workshop with the trainers as the “participants” and can learn from each other on ways to conduct the workshop. Facilitators will be guided through the use of the challenge and Design Cards as these are important in the creative phases of the workshop. Technology cards such as “community wireless networks” and “internet in a box”, as well as other unfamiliar concepts will need to be explained with relevant examples. Their familiarization with the cards will be done through a discussion and reflection based on their engagement with the community as it relates to the cards. This will be done similarly to what is expected of them during the workshop. If there is time during the training, the translations of the Challenge Cards will be completed on the cards during the session. If not, this will be done either before or after the training by the trainers.

This method of training will apply during all COVID-19 lockdown levels

4. Informed Consent

For the case of co-design activities taking place during COVID-19 lockdown levels 1-2:

Facilitators will read the consent form to participants, and they will provide their voluntary, oral informed consent to participate in the co-design activities prior to engaging with any co-design activities. Audio recording of this consent will take place. This consent form will be translated into the language of their preference.

For the case of co-design activities taking place during COVID-19 lockdown levels 3-5:

Facilitators will telephonically read the consent form to participants, and they will provide their voluntary, oral informed consent to participate in the co-design activities prior to engaging with any co-design activities. This consent form will be translated into the language of their preference.

Co-design Approaches and Activities

For the case of co-design activities taking place during COVID-19 lockdown levels 1-2:

Welcome and Orientation (5 minutes)

Participants will be gathered in focus groups of 10-12 participants. The research team will consist of the facilitator, and two research assistants, who will also serve as translators. The external researchers will also serve as assistants, especially when it comes to voice recording the sessions and organising and handing out the design materials.

To be done by Facilitators:

1. Informed consent will take place with each individual prior to the group activities.
2. Welcome participants and brief them on order of activities: icebreaker, discuss and rate community priorities, brainstorm ideas, co-design ideas.
3. Lay out stationary and Design Cards (bag of stuff), facilitator walks through the different Design Cards
4. Warm-up: Use the Design Cards to tell a story about a struggle they have faced as parents.

As a warm-up/ice breaker activity, participants will be requested to bring a recyclable item from home that is associated with an experience of caregiving. If the items are not brought, a back-up activity that takes the form of an introduction and sharing session will take place. With the consultation of the local facilitators, an appropriate activity should be decided upon beforehand.

Design cards consist of a deck of pictures representing people, places, things, and technologies that they might encounter in everyday life. Examples include:

Technologies	People	Places
Community Radio	Mother	Public Health Centre
Wearables	Baby (newborn – 18m)	Home (shack, apartment, house?)
Sensors and Data	Toddler (18m – 2y)	Community Centre
Community Wireless Networks	Father	Hospital
Internet-in-a-Box-type Solutions	Other Caregivers (Grandparents, relatives)	ECD Centre
Information Appliances	Siblings	Faith-based Building (e.g. mosque, church, temple)
Mobile Data Collection	Community Health Worker	
Mobile App with educational videos	Nurse	
WiFi – connected to internet	Doctor	
WiFi – not connected to internet	Community	
Mobile Data	Community Leaders	
Mobile Phone		
Tablet		
Laptop		
Social media – WhatsApp, Facebook, etc		
Road to Health Booklet		

Participants Choose Community Priorities (90 minutes)

This activity takes place as a card-sorting activity (cite card-sorting papers).

5. Present 9 community priorities to participants. These priorities will be presented to the community members via Challenge Cards. The Challenge Cards each depict one community challenge on an A5 card as an illustration.

The Challenge Cards will then be explained to participants as illustrations representing different community priorities that were raised by community members during community engagements.

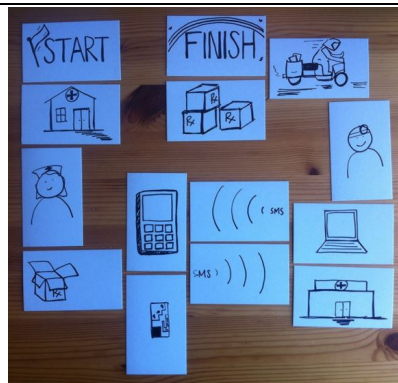
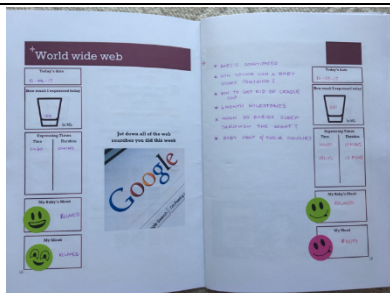
Challenges Cards:

- Personalized and Timely Support
 - Making Information More Accessible, Relevant and Usable
 - Parent Well-being and Agency
 - Involving Fathers
 - Community Early Life and Parenting Training
 - COVID-19 Counselling Training for Health Workers
 - Postnatal Care
 - Traditional Healers
 - Facilitating Trust Determination
6. Ask participants to describe what they see on the Challenge Cards
 7. Ask all the participants to individually sort/rank the cards by importance and relevance to the participants and their communities.
 8. Ask participants to present to the group their card rankings, and to explain why they felt that these challenges were most important and relevant to themselves and to their community. Depending on the context, the ways in which the ranking is done should be made clear. For example, if voting takes place on each card, how the cards are ranked should be communicated to the participants. If the ranking is done individually (30mins)
 9. The top 2 or 3 community priorities will be used for designing possible solutions.
 10. Focus group brainstorms ideas for possible solutions, with facilitator taking notes.

Break (Lunch – 1 hour)

Co-design Activities (2 hours)

11. Divide participants into two or three groups (of 3-6 persons each).
12. Give each group a Bag of Stuff and a Design Workbook and describe their contents to the participants. The Bag of Stuff includes 2 sheets of A3 paper, 3 sheets of colour paper, stationery including markers, pencils, erasers, and Design Cards related to various objects, scenarios or use cases, stickers, emoticons. The Design Workbook includes a structured booklet consisting of specific questions, areas for sketching and placing of images for specific community priorities. (5 minutes)
13. Describe what they need to do: Together they will use the bag of stuff to prototype solutions, using the design workbook for inspiration and guidance. Examples of output: *rough sketches for solutions to chosen priorities, storyboards, physical prototypes demonstrating system models.*
 - a. Participants sketch or create their ideas of possible solutions to the problems, using the stationery from the Bag of Stuff. Encourage rough design that attempts to convey an idea, concept or object rather than produce high-fidelity drawings. Participants will be encouraged to use the Design Cards to illustrate their idea as well as how it will fit into their context. This would be a combination of (a) and (c). (1 hour 45 minutes)
 - b. *Design Workbook:* Participants fill in the Design Workbook, and provide assistance where needed. (1 hour 45 minutes)
 - c. *Storyboard:* Participants create a storyboard using the Design Cards from the Bag of Stuff. This storyboard will include the different community challenges, and their proposed solutions to them presented by the Design Cards, with a written paragraph under each card stating how their proposed ideas could solve the challenges. (1 hour 45 minutes)
14. Debrief: participants will be asked to present their solution to the facilitator.
15. Facilitator will do a cognitive walkthrough with the participants to understand the solution in more depth. Facilitator will describe what they see (think aloud) in the presented solution, and ask if that matches the participant's intention.
16. Facilitator will ask participants to provide feedback regarding their experience with the co-design activities.
17. Thank participants for their participation and give a children's book or busy book as a gift to take home.

		
Example of Design Cards used to support storyboarding.	Group prototyping activity with "Bag of Stuff"	Example of a design workbook.

Take-home design (remote-co-design): For the case of co-design activities taking place during COVID-19 lockdown levels 3-5:

Each participant will undertake co-design activities individually.

To be done by Facilitators:

1. Call participant and discuss courier arrangements (address and date)
2. Describe what will be couriered to them: Bag of Stuff, Design Workbook.
3. Explain what they need to do using the items (same as above).
4. Communicate with participants via WhatsApp when package is received: go through what they need to do with the items again, but also state that instructions are included if needed.
5. To be completed by participants:
 - a. Ordering of importance of challenges presented through Design Cards,
 - b. Brainstormed ideas on paper,
 - c. Prototype: sketched brainstormed ideas on paper, storyboards using Design Cards.
6. Two options:
 - a. Participant completes activities independently and notifies facilitator when they are done.
 - i. Facilitator to check on participant after one week, and offer to do a synchronous walkthrough
 - b. Facilitator calls participant and they go through the activities synchronously.
7. Facilitator arrange time/place to collect their completed packages.
8. Collect packages from participants and thank participants for their participation: give a children's book or busy book as a gift to take home. Materials will be collected at the end of the two weeks regardless of whether the activities have been completed.

APPENDIX D.2

Phase 3 Community Workshops Protocol

January Bhabhisana CoMaCH Workshop Protocol

CoMaCH Co-investigators and Community Members

Pre-Workshop Activities

1. Ethics Clearance Amendments

The co-design activities will take place in person through a central workshop hosted in Johannesburg (TBC). The workshop will consist of x facilitators, and 4-5 participants being mothers supported by the Bhabhisana Baby Project. The following COVID-19 safety regulations will be in place:

- Enforcing sanitization by making sanitizing stations available and asking participants and facilitators to sanitize before entering workshop.
- Enforcement of participants and facilitators wearing masks at all times (surgical masks will be provided).
- Socially distancing participants and facilitators: enforcing distance of 2 meters between each person.
- Excluding participants with comorbidities to the COVID-19 virus.
- Workshop will take place in a large well-ventilated area

2. Participant Recruitment

This workshop will consist of the CoMaCH co-researchers, research facilitators, and representatives of the communities who participated in the *Phase 2* co-design workshops.

Caregivers will be recruited by BBP contacting (via phone call or WhatsApp) caregivers who participated in the *Phase 2* Co-design workshops.

3. Workshop Planning

The workshop will be conducted and assisted by CoMaCH facilitators and investigators. Prior to the workshop, planning will take place to recap and refine the workshop protocol, and decide who will be assigned moderators and scribes in the different breakout rooms.

4. Informed Consent

Facilitators will read the consent form to participants, and they will provide their voluntary, oral informed consent to participate in the co-design activities prior to engaging with any co-design activities. This consent form will be translated into the language of their preference.

Workshop Activities

Plenary Session:

1. Welcome and Orientation

- Head facilitators welcome everyone and introduce themselves.
- Ice breaker: Each CoMaCH community member introduces themselves + Highlight of your holiday? One word to describe your holiday season?
- Head facilitator describes workshop activities: Move into breakout groups, recap *Phase 2* community solutions, acquire feedback on *Phase 2* solutions from community, facilitators present and get feedback on initial digital prototypes, community members amend prototypes/ create new

prototypes and present to everyone.

2. Assign 2 co-investigators and 2 facilitators to each community breakout group

In breakout groups

3. Facilitators recap community solutions and prototypes identified in Phase 2 workshop

4. Community members provide feedback on Phase 2 solutions

This could be done in conjunction with step 3 – recap each solution and provide feedback after each one

- Ask community members to comment on each solution named if they have any feedback.
- Name each solution. Pause. If no one responds, ask “Do you think you could see this solution implemented in your community?”, “What do you like or not like about this solution?”
- Ask community members to choose top 3 solutions they would use in the community and ask them to provide reasons.

5. Facilitators present initial prototypes

- Video and resource-sharing services (JellyFin and NextCloud)
- Chatbot (on CWN)
- Mobile app for video and audio playlists (on CWN)
- Internet-in-a-box prototype
- Digital Road-to-health booklet

6. Community members and co-investigators provide feedback on initial prototypes

- Ask community members to comment on each prototype named if they have any feedback.
- Name each prototype presented. Pause. If no one responds, ask “Do you think you could see this solution implemented in your community?”, “What do you like or not like about this solution?”
- Ask community members to choose top 3 prototypes they would use in the community and ask them to provide reasons.

7. Community members add design elements and features to prototypes/ create new prototypes (Using prototyping Design Cards)

- Provide each group with designs of presented prototypes on paper
- Encourage group to add design card elements and write on paper to amend the prototypes OR use blank sheets and design card elements to create new prototypes of other solutions presented or own solutions.

8. Community members present amended/ new prototypes

- Each stakeholder group present prototypes to plenary group.

APPENDIX E

Informed Consent Form

Informed Voluntary Consent to Participate in Research Study

Invitation to participate, and benefits: You are invited as a Project Partner or Co-Investigator of the CoMaCH project, to participate in a research study together with parents, caregivers, policy makers and researchers focusing on maternal and child health. The study aims to explore the participation of community members in the design and evaluation of innovative information and communications technologies for maternal and child health in South Africa. We hope to work together to find out the different challenges and find ways to solve those challenges and make a difference for maternal and child health in the community. We believe that your experience and opinion would be important to the project, and hope that by participating you may benefit from interacting with other stakeholders in this space.

Procedures: During this study, you will be asked to take part in an interview or focus group to understand your perspectives on “co-design” and “community-based technologies”, and to draw on your experience or expertise in the use of digital technologies to support maternal and child health. You may also be invited to attend workshops to analyse findings and help design the future activities for this project.

Recording: We may take photographs, record audio, or record video as part of the study. Please do let us know if you are uncomfortable with any of these.

Risks: There are no potentially high risks related to your participation in this study. However, you will be participating with multiple people from different backgrounds and fields who might have very different opinions to yours. What will be important is for us to all work together and get more people on the ground involved in how we solve maternal and child health challenges.

Feedback: You will be invited to a workshop to share the findings we identified from the different activities of the project.

Disclaimer/Withdrawal: Your participation is completely voluntary; you may refuse to participate, and you may withdraw at any time without having to state a reason. If you decide to withdraw, the researcher will ensure that the information you provided will not be used without your permission. Note that the researcher may also withdraw you from the study at any time.

Confidentiality: As a Co-Investigator or Project Partner, you will be identifiable as a contributor to this research. You should let us know if any information you share should be excluded from the study, and will be given the opportunity to review any publications prior to their release. We will discuss as part of the study how and whether individuals and organisations should be identified. Also by taking part in group activities you will be required to respect all information shared within the group and keep it confidential. The information will be retained for up to 5 years when it will be deleted/destroyed. You can request to delete any information at any time.

What signing this form means: By signing this consent form, you agree to participate in this research study. The aim, processes to be used, as well as the potential risks and benefits of your participation have been explained verbally to you in detail, using this form. You are free to request further information, at any time during this research.

(Participant Initials)

(Researcher Initials)

Questions:

If you have any questions, please email the principal investigators or call them.

- Melissa Densmore (SA): melissa.densmore@uct.ac.za Phone: +27 21 650 4315
- Nervo Verdezoto Dias (UK): VerdezotiDiasN@cardiff.ac.uk Phone: +44 7484706408.

If you have any complaints or concerns about this study, please contact the Science Faculty Research Ethics Committee by sending an e-mail to Shanaaz Smith at shanaaz.smith@uct.ac.za.

I agree to participate in this research (tick one box).

☐ Yes ☐ No _____ (Initials)

I confirm that I have had the opportunity to ask questions.

☐ Yes ☐ No _____ (Initials)

I confirm data from my participation can be shared with researchers.

☐ Yes ☐ No _____ (Initials)

I understand that I can withdraw at anytime.

☐ Yes ☐ No _____ (Initials)

I understand that I can ask questions at anytime.

☐ Yes ☐ No _____ (Initials)

I understand that I can request to delete information at any time.

☐ Yes ☐ No _____ (Initials)

I agree to be photographed/screen-captured.

☐ Yes ☐ No _____ (Initials)

I agree to be audio-recorded.

☐ Yes ☐ No _____ (Initials)

I agree to be video-recorded.

☐ Yes ☐ No _____ (Initials)

Name of Participant

Signature of Participant

Date

Name of Researcher

Signature of Researcher

Date

(script for informed consent of community members continues on next page)

Script for Informed Consent of Community Members

This text to be read or sent as a WhatsApp message as appropriate. Note that we will liaise with Project Partners to recruit community members and facilitators. The project partner will identify the preferred language of the participant, and this script will be translated to that language.

[identification] I am [name and title of researcher], from [affiliation of researcher] for a project with the University of Cape Town called Co-Designing Community-based ICTs for Maternal and Child Health in South Africa (CoMaCH).

[participation] We are looking for people to participate in a study about the use of digital resources to support maternal and child health in South Africa. We are contacting you because you have been introduced to us by [Project Partner] as a(n) [expectant parent | caregiver of a child under two | community facilitator].

[benefits] Should you choose to participate in this interview, we will give you R100 in airtime to cover the costs of data used. We may also invite you for future meetings. We believe that your experience, opinions and ideas are important to the project. While we do not promise any benefit beyond the airtime, we hope that this will be interesting for both of us.

[procedures – Phase 1&2 interviews or focus groups] We want to learn more about how you use your mobile, video, or anything else to support health and well-being in your family. We will call you directly on your mobile number, by WhatsApp video or whatever is most convenient for you. This will take about 45 minutes, and it is perfectly fine if you are interrupted by children or anything else. You may leave the interview at any time.

[procedures – workshops] We are inviting you to join a meeting with other community members and everyone involved with the project. We would like for you to represent the ideas and opinions of others in your community. This workshop will take two days, three hours each (six total). We will arrange for data, technology, and childcare to support your participation. This will involve listening to us talk about what we learned from our interviews with you and others, as well as participation in discussion and other activities.

[recording] We would like to record this call – which we will use for data analysis. We will ask before sharing the recording outside of the project, and it is fine if you would rather we do not record it.

[risks] Please do not share anything with us that you are not comfortable sharing, and feel free to tell us to ignore or delete anything you have said previously. This is mostly a conversation, so there are no expected risks to you, but if you ever feel uncomfortable, please let us know. We are also sending you the Messages for Mothers helpline resource for you to refer to for any needs.

[feedback] We would be happy to share our final reports with you, please let us know if you would like to receive the outcomes of our study. If you have questions about the study, please ask. If you have concerns about the study, you may contact the research ethics committee by sending an email to Shanaaz Smith (shanaaz.smith@uct.ac.za).

[disclaimer/withdrawal] Your participation is completely voluntary; you may refuse to participate, and you may withdraw at any time without having to state a reason. If you decide to withdraw, the researcher will ensure that the information you provided will not be used without your permission. Note that the researcher may also withdraw you from the study at any time.

[confidentiality] In our reports, we will use fake names and not identify you by name or institution unless this is your preference. *[in focus groups/workshops, also include the following]* Please respect other participants by not sharing what you hear today.

[process from here]

Do you have any questions about the study? [allow time for questions and responses] Do you agree to participate in this study? [allow time for questions and response]

APPENDIX F

Full Padlet with Comments

Theme	Nodes	Comments
Communications Infrastructure	- Bandwidth Constrained Devices and Information Appliances (2) - Digital/Community Radio (2) - IoT (1) - Community Wireless Networks/Box Solutions (6)	- devices containing resources available offline - explore spaces where devices can be placed for interaction (e.g. tv in waiting room) - information should be easily shareable - trustworthiness/identify sources - communications infrastructure that allows sharing of digital resources without using the internet
Digitally Supported Training	- COVID-19 Counselling Training for Health Workers (8) - Community Early Life and Parenting Training (10)	- CHW COVID-19 Counselling: Consider the fact that COVID was temporary consider the world after COVID. - Education: Clinicians in terms of how to provide better emotional support - Teach young people about parenthood (boys as well as girls) Demystifying the first visit to the clinic. - Structural Inclusion: Consider structural barriers and create spaces that are welcoming to fathers, mothers, etc. - Re-use the waiting area to provide MCH information
Static Information Support	- Making Information More Accessible, Relevant and Usable to Parents (7) - Personalized and Timely Support (9) - Facilitating Trust Determination in a World with too much information (7)	- MCH Information App: graphic novel instead of information leaflets and posters - Anything other than written info, Televisions in clinic waiting room, Radio, Shared community resources such as IPAD (library) - video, audio in different languages. - MCH Personalized and contextualized help + support: IoT- and AI-enabled personal health informatics - Access to Information Needs when needed: 24h access, maybe bots to a knowledge system, sms is too unidirectional, engage women and men - FTD Education Resources for inspiring stimulation of babies <2 - Information overload: Break down theme - run the theme until completed and then only start another theme. - Package and market in pocket-style in a chunking format.

		• Recordings by actual parents. • Share resources and support in areas where parents are. • Resources for mothers, grandmothers, fathers - all caregivers including other caregivers. • Pushing messages is not useful -> emotional distress: Reimagining the process by which messages are delivered
Cross-Cutting Domains	• Traditional Healers (7) • Involving Fathers (13) • Postnatal Care (7) • Including Caregivers (2) • Parents of premature infants (1)	• Traditional healers: What is the intention behind the technology? Replacement? Integration? Trans-acting? • Language Use in interventions: - Specific messaging targeting fathers (e.g. involvement, especially considering 2020 restrictions on fathers in hospital) - Structural barriers and create spaces that are welcoming to fathers, mothers etc - Cultural practices in father involvement: What is the role of fathers? Avoiding any pejorative approaches to providing digitally-mediated spaces and places? • Transitions: Pre-birth the focus is on women. Post-birth the focus is on children. There's something here on postnatal care.
Peer Support	• Parent Well-Being and Agency (9) • Fostering of Peer Support (4) • Advocacy for Working Moms (4)	• Competing demands at the household and feelings of overwhelm • Building/supporting agency: based on the context, Mothers feel alone • Investigating Inclusion - who feels included or excluded from peer support structures (e.g. fathers/caregivers) • Structures and Systems and how these affect willingness to share • Situating Digital Support in other support structures • Fostering Participation • Parenthood and agency of women to seek livelihoods • Agency of men to care for their children • Grandparents and others as caregivers
Methodological Contributions	• Community-Centred Ethics (3) • Community-Centred Methods (4)	• Collectivist perspectives and approaches: Opportunities of new technologies, but incumbent risks - need a piece of work on the ethics of this work (unforeseen - and unseen - outcomes of this work) • Creative Prototypes for people to respond to: no time to think about it, need to spark ideas • COVID-compatible methods

APPENDIX G

UCT FSREC Ethics Approval



UNIVERSITY OF CAPE TOWN
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2 September 2021

Melissa Densmore
Department of Computer Science

Co-Designing Community-based ICTs for Maternal and Child Health in South Africa (CoMaCH)

Dear Melissa Densmore

I am pleased to inform you that the Faculty of Science Research Ethics Committee has approved the above-named application for research ethics clearance, subject to the conditions listed below.

- Restrictions on involving human participants in research must be adhered to, given current concerns about the spread of Covid-19. Please ensure that you are aware of and comply with UCT policy on this, as communicated by management.
- Implement the measures described in your application to ensure that the process of your research is ethically sound; and
- Uphold ethical principles throughout all stages of the research, responding appropriately to unanticipated issues: please contact me if you need advice on ethical issues that arise.

Your approval code is: **FSREC 091 – 2021**

I wish you success in your research.

Yours sincerely

Dr Shari Daya
Chair: Faculty of Science Research Ethics Committee