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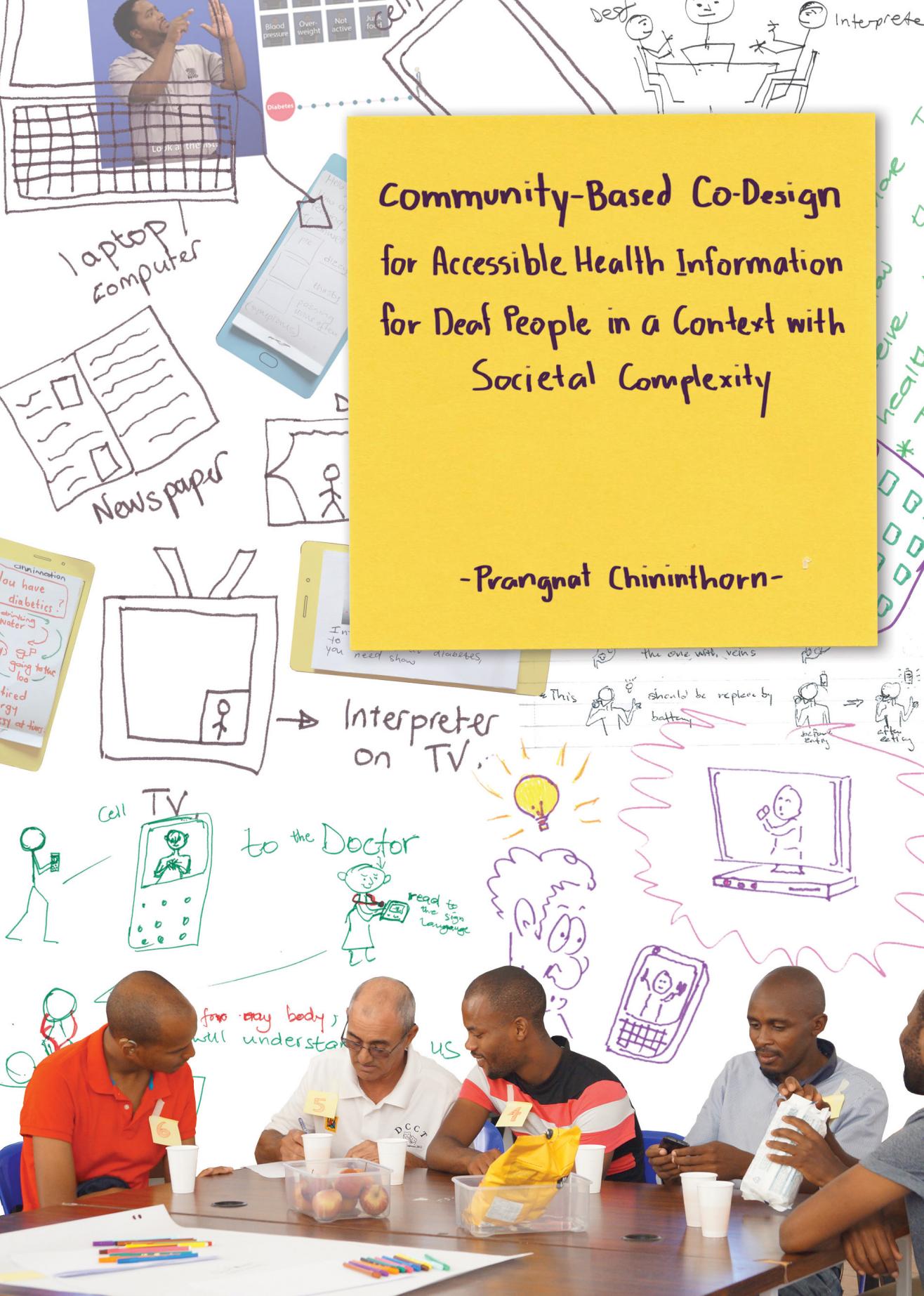
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Community-Based Co-Design for Accessible Health Information for Deaf People in a Context with Societal Complexity

-Prangnat Chininthorn-



Community-Based Co-Design for Accessible Health Information for Deaf People in a Context with Societal Complexity

Dissertation
for the purpose of obtaining the degree of doctor
at **Delft University of Technology**
by the authority of the Rector Magnificus
Prof. dr. ir. T.H.J.J. van der Hagen,
Chair of the Board for Doctorates
to be defended publicly on
Tuesday 16, November 2021 at 12:30

by

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List of Abbreviations

€	Euro currency sign
APD	Association of People with Disability
ASLI	American Sign Language Interpreter
BMA	British Medication Association
BANG	Bridging Application and Network Gaps
BMI	Body Mass Index
BSLI	British Sign Language Interpreter
CBCD	Community-Based Co-Design
CC	Creative Commons
CDC	Centers for Disease Control and Prevention
CDE	Centre for Diabetes and Endocrinology
CHC	Community Health Center
CODAs	Children of Deaf Adult
CWD	Cape Winelands District
DCCT	Deaf Community of Cape Town
DeafSA	Deaf Federation of South Africa
Diabetes SA	Diabetes South Africa
DOH	Department of Health
DOHWC	Department of Health Western Cape
FET	Further Education and Training
GP	General Practitioner
GSM	Global System for Mobile communications
GUI	Graphical User Interface
HHRP	Health and Human Rights Programme
HKTS	Health Knowledge Transfer System
HIV/AIDS	Human Immunodeficiency Virus/Acquired Immuno Deficiency Syndrome
HOH	Hard-of-Hearing
HGT	Hemoglobin Glucose Test
ID	Identity Document
ICT	Information and Communication Technology
IFAP	Information for All Program
IM	Instant Messaging
MRQ	Main research question
M.Sc.	Master of Science
NHS	National Health Services
NID	National Institute for the Deaf
ODEP	Office of Disability Employment Policy
OS	Operating System
PAC 101	Primary Care 101 Guideline
pt	Point
px	Pixel

Q&A	Questions and answers
R	The South African Rand
RTT	Record Text Testing
SASL	South African Sign Language
SASLI	South African Sign Language Interpreter
SEMDSA	Society for Endocrinology, Metabolism, and Diabetes of South Africa
SIM	Subscriber Identity Module
SLED	Sign Language Education and Development
SMS	Short Message Service
STTR	Speech-to-text-reporter
TB	Tuberculosis
TTY	teletypewriter
TU Delft	Delft University of Technology
TV	Television
UCT	University of Cape Town
UK	United Kingdom
UNESCO	United Nations Educational, Scientific and Cultural Organization
USA	United States of America
UWC	University of the Western Cape
WASLI	World Association of Sign Language Interpreters
WFD	World Federation of the Deaf
WCAG	Web Content Accessibility Guideline

Samenvatting

Dove mensen, die voornamelijk gebarentaal gebruiken om te communiceren, kijken tegen verschillende uitdagingen aan in hun dagelijkse leven, als het gaat om toegankelijkheid tot informatie. Vitale informatie, zoals over gezondheid, is slechts beperkt beschikbaar voor dove mensen wereldwijd, inclusief voor mensen die wonen in de Westkaap, Zuid Afrika, de bestudeerde regio van dit proefschrift.

Het gebrek aan toegang tot gedetailleerde gezondheidsinformatie voor dove mensen heeft als gevolg dat zij medicijn informatie en voorschriften niet altijd naleven.

Door het bestuderen van de achtergrond van dove mensen en het gezondheidszorgsysteem in de West Kaap, heeft de onderzoekerster meerdere onderling verbonden sociale barrières geïdentificeerd, die dove mensen ervan hebben weerhouden gedetailleerde gezondheidsinformatie te verkrijgen.

Het beperkte besef van de overheid en de ‘horende’ maatschappij, met betrekking tot doofheid, wordt beschouwd als een van de voornaamste sociale drempels, hetgeen heeft geresulteerd in diverse tekortkomingen in het voorzien van de communicatiebehoefte, het leren over, en toegang tot gezondheidsdiensten, en informatie hierover, voor dove mensen.

Deze geïdentificeerde sociale drempels worden nader toegelicht in [hoofdstuk 1](#) van dit proefschrift. De onderlinge relatie van deze sociale drempels heeft tot gevolg, dat het slechts leveren van gezondheidsinformatie in gebarentaal onvoldoende is, aangezien het mogelijkwijs niet past bij de minder geletterde wijze waarop een doof persoon informatie verwerkt. Voorts is het minder bruikbaar voor de overige belanghebbenden bij het verstrekken van gezondheidsinformatie.

Zodoende dienen alle sociale barrières in samenhang aangepakt te worden, alsook in samenwerking met dove mensen en relevante belanghebbenden. Demaatschappelijke vraagdienaar bovenkwam was welke ontwerpinterventie samen met dove mensen en belanghebbenden ontworpen kon worden. Diverse potentiële ontwerpen met betrekking tot de geïdentificeerde sociale drempels zijn geïnventariseerd.

Vervolgens is de hoofdvraag van het onderzoek geformuleerd, om te bepalen of deze potentiële ontwerpen kunnen passen binnen de bestudeerde context en om ze aan te bevelen aan onderzoekers en ontwerpers, die als doel hebben de situatie te verbeteren:

Welke interventie kan worden ontworpen om dove mensen te voorzien in bruikbare informatie over hun gezondheid met als doel een hogere effectiviteit van de behandeling en de naleving van de voorgeschreven medicatie?

Er was beperkt literatuur beschikbaar met betrekking tot toegang tot gezondheidsinformatie. Zodoende is literatuur over meer algemene informatie, die beschikbaar was voor doven, bestudeerd, ter voorbereiding van de opzet van het empirische onderzoek. Daarnaast is er literatuur bestudeerd gericht op het actief betrekken van dove mensen in wetenschappelijk onderzoek. Op basis van de uitkomsten van de literatuurstudie is een conceptueel raamwerk voor algemene informatie toegankelijkheid voor dove mensen ontworpen. Het conceptueel raamwerk beschrijft de eisen op drie aspecten:

- 1) Geschiktheid
- 2) Ervaring
- 3) Motivatie

voor iemand die informatie zoekt, en iemand die informatie verstrekt, om een interventie als toegankelijk te beoordelen (zie [hoofdstuk 2](#)).

Aangezien deze studie gericht is op het bepalen van welke interventies geschikt kunnen zijn voor de bestudeerde context, zijn de hiervoor genoemde eisen ontwerpgericht geformuleerd. Daarbij wordt uitgegaan van een intensieve samenwerking met dove mensen en belanghebbenden in de West Kaap. Deze eisen zijn later gebruikt om het Conceptueel Model voor Informatie Toegankelijkheid voor Doven te ontwikkelen.

Een conceptueel model informeert onderzoekers en ontwerpers over de eisen en de relaties voor een interventie, die dove mensen en de informatieverstrekker als toegankelijk ervaren. Op basis van dit model zijn onderzoeks vragen geformuleerd, als leidraad voor het empirische onderzoek.

Voor het uitvoeren van onderzoek met dove mensen adviseert de literatuur de onderzoekers om een groep dove mensen en relevante belanghebbenden actief te betrekken om tot betere resultaten te komen. De deelnemers zouden daar baat hebben bij het beoogde dagelijks gebruik van de interventies; zij zouden trots zijn op het door hen ontworpen resultaat. Tegelijkertijd zouden de onderzoekers profiteren van een beter gedefinieerd onderzoeksdoel, gericht op de interventie waar de deelnemers behoeft aan hebben. Community-Based Co-Design (CBCD) is een onderzoeks methode, die actief groepen betrekt in alle ontwikkelingsfases. Een onderzoeksteam in Zuid Afrika heeft de CBCD benadering voorheen ontwikkeld en toegepast door een groep dove mensen bij de ontwerp- en ontwikkelingsprocessen

te betrekken, om een brug te slaan met hulpmiddelen tussen dove en horende mensen. De CBCD benadering is uitstekend, als het gaat om onderzoekers de mogelijkheid te bieden kleine aanpassingen te maken, om te kunnen werken met complexiteit in een real-life systeem om een bepaalde interventie te realiseren. Aangezien de voordelen op één lijn liggen met de aanbevelingen van de literatuur, is deze aanpak toegepast binnen het empirische onderzoek.

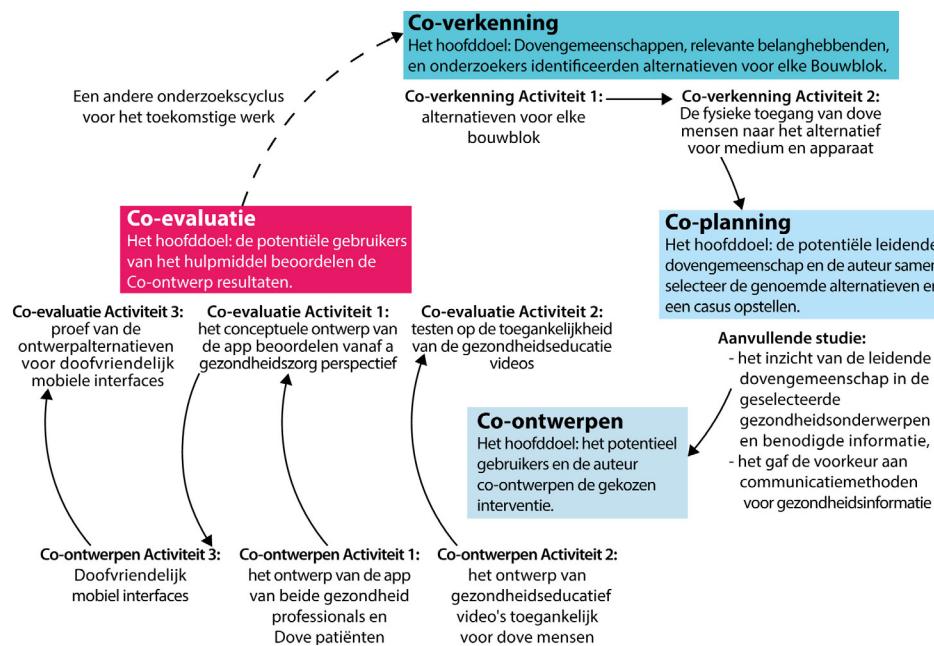
Deze CBCD benadering bestond uit 4 fases: Co-verkenning, Co-planning, Co-ontwerp, en Co-evaluatie (zie [hoofdstuk 3](#)). Het hoofddoel en de onderzoeksopzet voor elke fase zijn samengevat in [Figuur 1](#).

Binnen dit empirische onderzoek is een omvangrijke case study uitgevoerd, om een interventie stap voor stap te identificeren, selecteren, ontwerpen, en evalueren.

De case study is beschreven op basis van 6 bouwblokken:

- 1) De betrokken dovengemeenschap.
- 2) Gezondheidsonderwerpen, die interessant zijn voor doven.
- 3) Dove gebruikers van de beoogde interventie.
- 4) Gebruikers van de beoogde interventie, die gezondheidsinformatie verstrekken.
- 5) Methodes om gezondheidsinformatie te communiceren.
- 6) Een medium en apparaat om precieze en toegankelijke gezondheidsinformatie aan dove mensen te verstrekken.

De alternatieven voor deze bouwblokken zijn geïdentificeerd gedurende de Co-verkenningsfase en er is samen met de dovengemeenschap een selectie gemaakt in de Co-planningsfase.



Figuur 1. De samenvatting van de toegepaste community-based co-design aanpak.

De Co-verkenningsfase (zie [hoofdstuk 4](#)) is verdeeld in twee activiteiten. Gedurende de Co-verkenning activiteit 1, hebben gemeenschappen van dove mensen, belanghebbenden, en de onderzoeker alternatieven geformuleerd voor de zes bouwblokken. Deze activiteit resulterde in de volgende alternatieven:

- Deaf Community Cape Town (DCCT) als een potentiële leidinggevende dovengemeenschap (Bouwblok 1).
- Kanker, diabetes en hoge bloeddruk als gezondheidsonderwerpen (Bouwblok 2).
- Alle dove personen (Bouwblok 3).
- Gezondheidsprofessionals, werkend bij primaire gezondheidscentra, als beoogde gebruikers van de interventie; drama in gebarentaal, een korte presentatie met beelden.
- Een platform voor vragen en antwoorden als de gecombineerde methode om gezondheidsinformatie te communiceren (Bouwblok 5).
- Een app die geschikt is voor Android.
- Smartphones als het medium en het apparaat (Bouwblok 6).

Co-verkenning activiteit 2 stelde vast dat dove mensen in de West Kaap fysieke toegang tot een smartphone hebben, en het gebruik ervan om toegang tot gezondheidsinformatie te verkrijgen (Bouwblok 6). Hun fysieke toegankelijkheid werd geverifieerd door het aantal dove mensen dat toegang had tot een mobiele telefoon, en wisten hoe ze het apparaat moesten bedienen.

De Co-planningsfase ([Hoofdstuk 5](#)) bestond uit het door de betrokken dovengemeenschap en de onderzoeker gezamenlijk selecteren van de beste alternatieven om de case study in te richten. De CBCD aanpak werd op dit punt aangepast, door het toevoegen van een studie binnen de tweede dovengemeenschap. Deze aanpassing is gemaakt, vanwege het feit, dat de eerste potentiële dovengemeenschap om hun moverende redenen had besloten om niet verder aan het onderzoek deel te nemen. Het Nationaal Instituut voor Doven (NID) nam de positie als deelnemende dovengemeenschap over, ondermeer vanwege hun interesse in de diverse alternatieven geïdentificeerd tijdens het onderzoek bij DCCT.

De toegevoegde studie werd vervolgd met de volgende stappen:

- 1) Het begrip van de doven binnen de NID gemeenschap van type 2 diabetes, en de specifieke informatiebehoefte.
- 2) De communicatie methode, die de voorkeur heeft, en of die zou verschillen van de voorkeur van DCCT.

Geleidelijk werd de case study voor een interventie geformuleerd. De interventie die geschikt was binnen de context van de West Kaap werd gedefinieerd als een Android app (Bouwblok 6), om de communicatie te overbruggen tussen een dove patiënt (Bouwblok 3) en een gezondheidsprofessional. Als focus werd gekozen voor de behandeling van type 2 diabetes in een primair gezondheidscentrum (Bouwblok 4), teneinde toegankelijke gezondheidsinformatie aan te bieden met betrekking tot diabetes (Bouwblok 2).

Gezondheidsinformatie zou gepresenteerd moeten worden via een combinatie van Zuid-Afrikaanse gebarentaal (SASL), visuele materialen, en ondertiteling in een video formaat via de app (Bouwblok 5). Alhoewel het ontwerpen van een app voor doven eenvoudig lijkt in het tijdperk van het internet, is er de unieke uitdaging dat het moet functioneren in de West Kaap, waar slechts beperkte dekking was van het mobiele netwerk alsook beperkte financiële middelen.

De laatste twee fasen van de CBCD benadering werden in grote mate parallel opgezet met de bedoeling om een begrijpelijke uitwerking van het

ontwerp van de app en de gezondheidsinformatie te realiseren.

Elke fase was opgebouwd uit 3 activiteiten.

De Co-ontwerpfase ([hoofdstuk 6](#)) beschreef het ontwerp van de app, inclusief het openen van een mogelijkheid voor het generaliseren van het ontwerp naar een andere context, vergelijkbaar met die van de West Kaap. Co-ontwerp activiteit 1 betrok gezondheidsexperts en dove participanten bij het ontwerp van de app. Dit resulteerde in een conceptueel ontwerp van een app om de communicatieactiviteiten tussen een dove patiënt en gezondheidsmedewerkers, gedurende de patiënt journey bij een primair gezondheidscentrum, te ondersteunen, inclusief overzichten met gezondheidsinformatie, die aan de eisen van de belanghebbenden voldeed.

Vervolgens, hield Co-ontwerpactiviteit 2 zich bezig om samen met een groep dove mensen educatieve gezondheidsvideo's te maken, met informatie, geselecteerd uit de lijst met gezondheidsinformatie van Co-ontwerpactiviteit 1. Dit resulteerde in educatieve films over type 2 diabetes voor dove patiënten. Het ontwerp voor de educatieve video's werd vormgegeven en beschreven door:

- 1) Hoe scripts voor te bereiden voor de gezondheidsinformatie waarmee de meerderheid van dove geletterden bereikt kan worden.
- 2) Verhaallijnen in SASL.
- 3) Toevoegen van ondertiteling.
- 4) Implementatie van geschikt visueel materiaal.
- 5) Voice-over voor slechthorende patiënten, en hun horende verzorger.

Co-ontwerp activiteit 3 voor een doven-vriendelijke mobiele interface vond plaats in een dovengemeenschap in India, met een soortgelijk profiel als die van de NID. Het resultaat van Co-ontwerp activiteit 3 was een aantal ontwerpalternatieven, gerepresenteerd door een combinatie van iconen met woorden in plaats van knoppen, interactieve gidsen in SASL, en gebruikspatronen voor informatietoegang en invoer binnen de app om de mobiele interfaces voor een dove patiënt te verbeteren.

De Co-evaluatiefase ([Hoofdstuk 7](#)) betrof het beoordelen van de resultaten van de voorafgaande Co-ontwerpactiviteiten door gezondheidsexperts en dove participanten.

Gedurende Co-evaluatie activiteit 1, hebben de gezondheidsexperts het conceptuele ontwerp van de app beoordeeld vanuit een gezondheidszorg perspectief. Zij waren tevreden met de mogelijkheden van de app,

als het ging om het praktische nut bij de primaire gezondheidscentra. De gezondheidsexperts gaven aan deze app te willen gebruiken bij gezondheidsconsultaties met een dove patiënt, om zelfmanagement doelen te kunnen bereiken, alhoewel een langere interactie de voorkeur zou hebben. Co-evaluatie activiteit 2 nodigde de dove participanten uit om de toegankelijkheid van de educatieve gezondheidsvideo's te testen. Zij vonden de educatieve gezondheidsvideo's toegankelijk met betrekking tot de boodschap en visuele verduidelijking. Daarnaast toonden ze ook een toename in kennis over de verschillende type 2 diabetes onderwerpen. Animatie werden gebruikt als ondersteuning voor de participanten bij het begrip krijgen van het proces hoe het menselijk lichaam energie krijgt. De illustraties lieten duidelijk type 2 diabetes symptomen zien, op een waarschuwend manier, die niet grafisch was. Desondanks zou een video met interactieve onderdelen moeten worden vermeden, het zou dove participanten kunnen verwarren.

Co-evaluatie activiteit 3 bracht de ontwerpalternatieven, verkregen van de input van de Indiase doven, naar de NID dove deelnemers voor een evaluatie. De interactieve gids in SASL gaf de deelnemers een effectieve interactie met de app en een dokter. Iconen zonder woorden, die simpele functies weergaven, werden goed ontvangen door de participanten. Specifieke bewegwijzering is handig om dove participanten te laten navigeren door een lange lijst met mogelijkheden. Deze bevindingen zijn toegevoegd aan de verbeterde versie van het conceptuele ontwerp van de app voor betere doven-vriendelijke interfaces.

Een set van initiële richtlijnen voor het actief betrekken van de participanten die van diverse achtergronden afkomstig waren, werd geformuleerd, om passend en interactief met deze participanten bezig te zijn gedurende de vier fases. Antwoorden op sub-onderzoeks vragen werden verfijnd naarmate de CBCD aanpak vorderde. De bevindingen van deze aanpak gaven een indicatie van de mogelijkheid om het ontwerp van deze mobiele app (inclusief de educatieve gezondheidsvideo's) breder toe te passen in vergelijkbare contexten als die van de West Kaap. Deze bewering wordt ondersteund door het feit dat meerdere ontwerp alternatieven verkregen via doven in India eenvoudig te gebruiken waren door de NID dove participanten.

Na het voltooien van de CBCD aanpak, reflecteerden de onderzoekers op de kracht en het voordeel van de aanpak, alsook de uitdagingen, waar men is tegenaan gelopen gedurende de toepassing. Het nieuwe van deze studie, zijn de wetenschappelijke en maatschappelijke bijdragen, weergegeven in [Hoofdstuk 8](#). Het conceptueel model van toegankelijkheid tot gezondheidsinformatie voor dove mensen in een complexe context was ontwikkeld gebaseerd op de bevindingen van het empirische onderzoek,

en bestudeerd om bij te dragen aan de wetenschap. Het model adresseert belanghebbenden en betrokken bij het toegankelijk maken van de gezondheidsinformatie en vereist met betrekking tot de ervaringen en motivatie van de gebruiker, inclusief de geschiktheid van de interventie binnen de context.

De maatschappelijke bijdragen zijn begrijpelijke richtlijnen bestaande uit:

- 1) De richtlijnen voor het actief betrekken van een dovengemeenschap en relevante belanghebbenden bij het ontwerp van een interventie.
- 2) De richtlijnen voor het ontwerp van een app, die communicatie overbrugt tussen een dove patiënt en zorgpersoneel, en educatieve gezondheidsvideo's.

Lezers kunnen bovengenoemde bijdragen, gebaseerd op hun praktisch nut, toepassen.

Onderzoekers, die als doel stellen een CBCD benadering toe te passen in hun empirisch onderzoek, kunnen het eerste gedeelte van de richtlijnen volgen. Deze richtlijnen geven adviezen vanaf de eerste stap, vanaf de naleving van het onderzoek, en ethische regels door de onderzoeker, tot tijdmanagement tijdens het empirische onderzoek.

Voor onderzoekers, ontwerpers, doven gemeenschappen, en belanghebbenden, die mobiele telefoons als een interventie binnen hun context zagen, of de CBCD benadering wordt gebruikt, of niet, het tweede gedeelte van de richtlijnen zou een hint naar verkenning kunnen zijn, en deze richtlijnen kunnen testen met hun doel gebruikers.



Scan voor de samenvatting van het proefschrift in Zuid-Afrikaanse gebarentaal

Summary

Deaf people, who mainly use a signed language for communication, encounter multiple information accessibility challenges in their daily lives. Vital information, like health, has been limitedly accessible to Deaf people across the globe, including those in the Western Cape, South Africa—the studied context of this thesis. The lack of access to accurate health information causes some Deaf people to neglect medicine and treatment adherence.

By learning about Deaf people's background and the healthcare system in the Western Cape, the author identified several interrelated social barriers that obstructed Deaf people from accessing accurate health information. Government and hearing society's low awareness of Deafness were considered as one major social barrier resulting in various shortages in catering to Deaf people's communication needs, learning, and access to health services and information. These identified social barriers are elaborated upon in [Chapter 1](#) of this thesis. Their interrelatedness indicated that only delivering health information in a signed language would be insufficient since it might not match Deaf people's information processing and literacy and suit the practices of stakeholders engaged in the health information distribution. Consequently, all social barriers should be comprehensively tackled, together with Deaf people and relevant stakeholders.

A societal question was raised for what design interventions Deaf people and the stakeholders could make. Several potential interventions were listed pertaining to the identified social barriers. Consequently, the main research question was formulated to determine which of these potential interventions would suit the studied context and recommend its design to researchers and designers who aim to alleviate the situation:

What intervention can be designed to provide Deaf people with health information for influencing medical and treatment adherence?

There was limited literature available regarding health information accessibility. As such, literature about general information accessibility to Deaf people was studied in preparation for the groundwork of the empirical research. As well, literature concerning approaches to research with Deaf people properly was reviewed. Based on the outcomes of the information-accessibility study, a conceptual framework for generic information accessibility to Deaf people was constructed. The conceptual framework described the requirements on three aspects: 1) suitability, 2) experience, and 3) motivation that urge an information seeker and an information provider to find an intervention accessible (see [Chapter 2](#)). Since this study aimed

to determine what interventions would suit the studied context through design, the mentioned requirements needed design-related elaborations in consultation with Deaf people and stakeholders in the Western Cape. These elaborations were later used to develop the conceptual model of health information accessibility to Deaf people. Such conceptual model would inform researchers and designers with the requirements and their relations towards an intervention that Deaf people and the information provider would find accessible. Consequently, sub-research questions were formulated to guide the empirical research in gaining the needed elaborations.

As for researching with Deaf people properly, the literature recommended researchers actively involving a Deaf community and relevant stakeholders for win-win benefits. The participants would feel winning from deriving the intervention they will use daily; they would be proud of the intervention designed by them and for them. At the same time, the researchers would benefit from a well-defined research objective upon the participants' needed intervention. Community-based co-design (CBCD) is a research approach that actively involves communities at all stages. A research team in South Africa had developed and applied the CBCD approach to involve a Deaf community throughout design and development processes of communication bridging tools for Deaf and hearing people. The CBCD approach is outstanding in allowing researchers to modify minor details for handling complexity in a real-life system to obtain a determined intervention. As its benefits align with the literature's recommendations, this approach was applied during this empirical research.

This CBCD approach consisted of four stages: Co-exploration, Co-planning, Co-design, and Co-evaluation (see [Chapter 3](#)). The main objective and the research design for each stage to handle the context complexity are summarized in [Figure 2](#). A case study was carried out through this empirical research to identify, select, design, and evaluate an intervention step-by-step. The case study was formulated based on six building blocks: 1) the leading Deaf community, 2) health topics of interest among Deaf people, 3) intervention users who are Deaf, 4) intervention users who are health-information providers, 5) methods for communicating health information, and 6) medium and device to provide accurate and accessible health information to Deaf people. The alternatives for these building blocks were identified during the Co-exploration Stage, and a selection was made with the leading Deaf community within the Co-planning Stage.

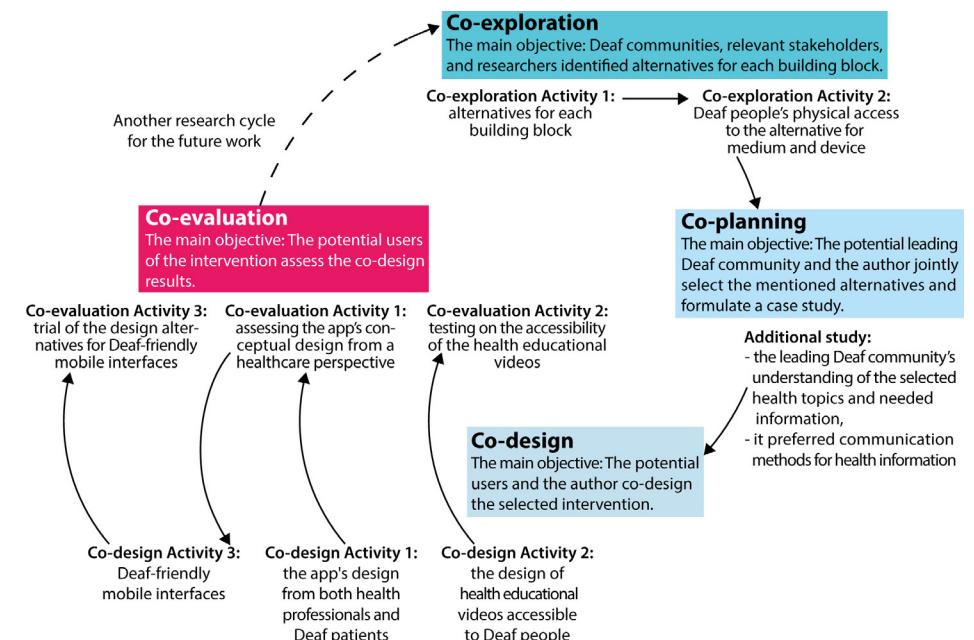


Figure 2. The summary of the applied community-based co-design approach.

The Co-exploration Stage (see [Chapter 4](#)) was broken down into two activities. During Co-exploration Activity 1, Deaf communities, relevant stakeholders, and the author identified alternatives for the six building blocks. This co-exploration activity resulted in the following alternatives: Deaf Community of Cape Town (DCCT) as a potential Deaf community to take the leading role (Building Block 1); cancer, diabetes, and hypertension for the health topics (Building Block 2); any Deaf people (Building Block 3) and health professionals working at primary health centers (Building Block 4) as the users of the intervention; drama in signed language, a short presentation with pictures, and a platform for questions and answers as the combined methods to communicate health information (Building Block 5), and app for Android smartphones as the medium and the device (Building Block 6). Co-exploration Activity 2 assured Deaf people's physical access to a smartphone and use of it to access health information (Building Block 6) in the Western Cape. Their physical access was verified by the number of Deaf people who had access to a mobile phone and knew how to use it.

The Co-planning Stage ([Chapter 5](#)) was for the leading Deaf community and the author to jointly select the best alternative to formulate the case study. The CBCD approach was adjusted at this stage by including an additional study within the second Deaf community that took the leading role. This modification was to handle a research-related change due to the

fact that the first potential Deaf community decided not to take the leading role. The National Institute for the Deaf (NID), as the second potential Deaf community, stepped in for the leading role with interest in several alternatives identified with DCCT. The additional study was proceeded to investigate 1) NID Deaf members' understanding about type 2 diabetes and information needs and 2) preferred communication methods that might differ from DCCT's. Gradually, the case study for an intervention was formulated. The intervention suitable to the Western Cape context was defined as an *Android app (Building Block 6) for bridging communication between a Deaf patient (Building Block 3) and a health professional engaged in type 2 diabetes treatment at a primary health center (Building Block 4) in order to deliver accessible health information regarding diabetes (Building Block 2). Health content should be presented via a combination of South African Sign Language, visual materials, and subtitles in a video format through the app (Building Block 5)*. Although designing an app for Deaf people might seem ordinary in the era of the Internet of things, it must uniquely function in the Western Cape, where there was limited mobile network coverage and limited financial resources.

The last two stages of the CBCD approach were designed to be interrelated for comprehensively elaborating on the design for the app and its health content. Each stage was proceeded with three activities. The Co-design Stage ([Chapter 6](#)) was to describe the design of the app, including opening an opportunity to generalize the design to a context similar to the Western Cape. Co-design Activity 1 involved health professionals and Deaf participants in designing the app. This resulted in a conceptual design of an app for bridging communication activities between a Deaf patient and healthcare personnel during the patient journeys at a primary health center, including listings of health content that met the stakeholders' requirements. Next, Co-design Activity 2 engaged a group of Deaf people to design health educational videos selected from a listing of the health content from Co-design Activity 1. Co-design Activity 2 resulted in health educational videos about type 2 diabetes for Deaf patients. The design for the health educational videos was described by 1) how to prepare scripts for the health content to accommodate Deaf majority's literacy, 2) narrations in South African Sign Language (SASL), 3) presentations of the subtitles, 4) implementation of appropriate visual material, and 5) voice-overs for Deaf patients with a residual hearing level and their hearing caretaker. Co-design Activity 3 for Deaf-friendly mobile interfaces took place at a Deaf community in India with a similar profile to the one of NID. The results of Co-design Activity 3 were design alternatives, proposed with combinations of icons with wording for buttons, interaction guides in SASL, and use patterns for information access and input within the app to improve the mobile interfaces for a Deaf patient.

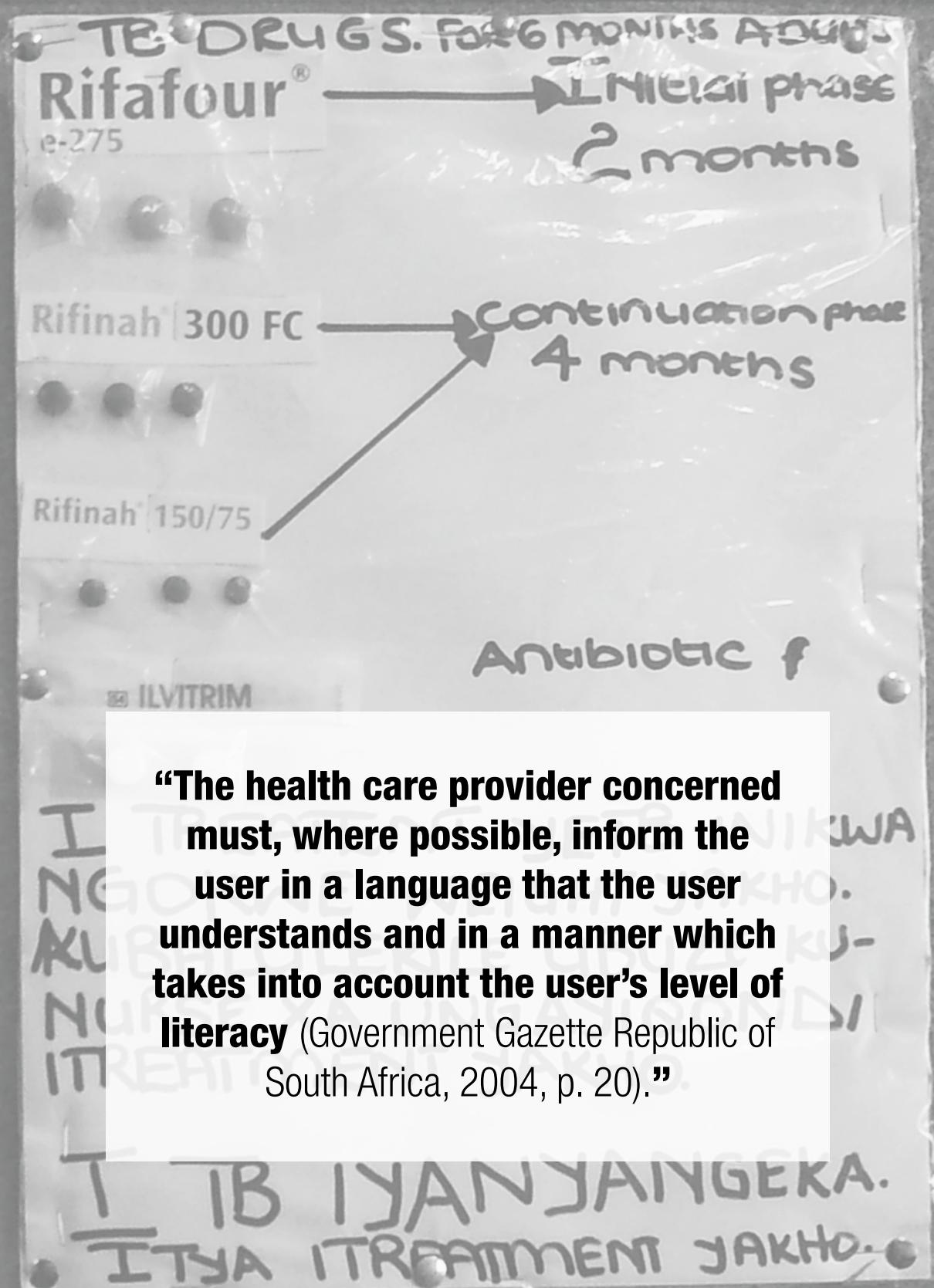
The Co-evaluation Stage ([Chapter 7](#)) involved the health professionals engaged in type 2 diabetes treatments and Deaf participants in evaluating the results from the preceding co-design activities. During Co-evaluation Activity 1, the health professionals assessed the app's conceptual design from a healthcare perspective. They were satisfied with the app's features in serving their practice at the primary health centers. They stated to be willing to use this app for health consultations with a Deaf patient to achieve one's self-management goals, although it would require a little longer interaction. Co-evaluation Activity 2 invited the Deaf participants to test the accessibility of the health educational videos. They found health educational videos accessible in terms of the messages and visuals. They also demonstrated increased understanding across type 2 diabetes topics. Animation helped the participants understand the process of how the human body gets energy, and illustrations clearly provided type 2 diabetes symptoms in a non-graphical warning way. However, a video with interactive features should be avoided as it confused the Deaf participants. Co-evaluation Activity 3 brought the design alternatives obtained from the Indian Deaf's inputs to the NID Deaf members for an evaluation. The interaction guide in SASL prompted the participants to interact with the app and a doctor effectively. Icons without wording conveying simple functions were well accepted by the participants. Some specific wayfinding was helpful for Deaf participants in navigating a long listing of options. These findings were implemented in the improved version of the app's conceptual design for better Deaf-friendly mobile interfaces.

A set of initial guidelines for the active involvement of the participants, who came from diverse backgrounds, was formulated to appropriately involve and interact with them during the four stages. Answers to sub-research questions were refined as the CBCD approach progressed. The findings from this approach implied the possibility that the design of this mobile app, including the health educational videos, can be generalizable to a context similar to the Western Cape. This statement is supported by the fact that multiple design alternatives obtained from Deaf people in India were easy to use for the NID Deaf members.

After completing the CBCD approach, the author and research fellows reflected on the approach's robustness and benefits, together with challenges experienced through its application. The novelty of this study is the scientific and societal contributions provided in [Chapter 8](#). The conceptual model of health information accessibility for Deaf people in a complex context was developed based on the findings from this empirical research and examined to contribute to science. The model addresses stakeholders involved in the health information accessibility provision and requirements concerning the users' experience and motivation, including the interventions' suitability

to the context. The societal contributions are comprehensive guidelines comprising 1) the guidelines for actively involving a Deaf community and relevant stakeholders in designing an intervention and 2) the guidelines for designing an app for communication bridging between a Deaf patient and healthcare personnel and health educational videos.

Readers can apply the above contributions based on their practice. Researchers who aim to apply a CBCD approach to their empirical research can follow the first part of the comprehensive guidelines. These guidelines provide recommendations from the very first step, since a researcher's compliance with the local research and ethics regulations until the time management during the empirical research. For researchers, designers, Deaf communities, and stakeholders who found mobile phones as an intervention suitable to their context, whether applying the CBCD approach or not, the second part of the comprehensive guidelines could be their reference to explore and test these guidelines with their target users.



“The health care provider concerned must, where possible, inform the user in a language that the user understands and in a manner which takes into account the user’s level of literacy (Government Gazette Republic of South Africa, 2004, p. 20).”

Chapter
1

Introduction about Deaf people and their health information inaccessibility

Deaf people frequently encounter communication problems with the hearing majority, who know so little about signed language and appropriate communication setup with a Deaf person. Consequently, Deaf individuals have to deal with confusion and frustration while communicating with hearing people; they get deficient access to needed information, such as health information, and end up with a lack of knowledge in several domains.

In healthcare context, the lack of accurate health information could result in medication and treatment non-adherence ([Chinithorn, 2011](#)), ineffective self-management ([The Deaf Health Charity, 2014](#)), and life-threatening situations ([Ismail, 2013](#)). As such, it is vital to provide Deaf people with access to health information that is accurate and in the language in which they are fluent.

This chapter introduces background information about Deaf people ([Section 1](#)), after which narrows down to Deaf people in Western Cape Province, South Africa—the area that this research was conducted ([Section 2](#)), and elaborates on the complexity in the healthcare context that limits Deaf people’s access to health information ([Section 3](#)). Social barriers were identified along with the elaboration to illustrate the societal complexity. Lastly, the societal question calls for suitable contributions that can improve health information accessibility to Deaf people ([Section 4](#)).

1. General information about Deaf people

This section discusses characteristics of Deafness, Deaf culture, and Deaf community that Deaf people from different countries share in common. Deafness describes two main differences in how people in a society perceive hearing loss and their choice of interventions for communication bridging. Deaf culture provides insights into Deaf people's language, values, and traditions. Deaf community's characteristics explain a typical formation of the community and the variety of its members.

1.1 Deafness

Deafness refers to people who have hearing loss and their worldview. The terms: *deaf* and *Deaf* are used by people with hearing loss to differentiate themselves. Over the past few decades, people in a society has perceived deafness through two major perspectives ([Senghas & Monaghan, 2002](#)):

Perceiving deafness through medical perspective

The medical perspective comprises those who view deafness as an illness, hearing impairment, auditory deficit, or functional limitation that needs to be cured ([Arnos, Israel, & Cunningham, 1991](#); [Reagan, 1995](#)). The inability to communicate via listening or speaking is considered abnormal or inferior ([Power, 2005](#); [Reagan, 1995](#)). Hearing pathologists usually focus on the failure of the hearing mechanism, the origin of the failure, and types of loss. Cochlear implant surgery, hearing aid utilization, speech therapy, and practicing of lip-reading skills are interventions to make a person hear or become hearing-like ([Barnett, 1999](#); [Morgan, 2008](#); [Reagan, 1995](#)). Not only hearing people but also deaf people perceive deafness from this perspective. These deaf people usually undergo the interventions above and prefer to rely on a spoken or a written language for communication.

As opposed to the medical perspective, another group of people perceives and live through hearing loss with a different attitude.

Perceiving Deafness from sociocultural perspective

The sociocultural perspective comprises those who view Deafness as a linguistic and cultural condition. Deaf people see themselves as a minority group rather than as disabled ([Jones & Pullen, 1989](#); [Kravitz & Selekman, 1992](#); [Lane, 1995](#); [Power, 2005](#)). They refuse to be called deaf-mute or deaf-and-dumb. However, Deaf or hard-of-hearing are acceptable ([Cavender, Trewin, & Hanson, 2015](#); [Office of Disability Issues, n.d.](#)). Several researchers believe that the sociocultural perspective of Deafness is formed based on education, religion, vocational affiliation, social class, interactions with others—especially the families, and influences of the peer group ([Gregory & Hartley, 1991](#); [Power, 2005](#)). People who perceive Deafness from this perspective see no need to fix the inability of hearing. Instead, they

focus on enabling communication opportunities ([Benedict & Legg, 2010](#)).

Although both perspectives benefit people with hearing loss differently, this research focused on the sociocultural perspective to provide information accessibility to Deaf people who have to deal with societal complexity daily. The following subsections provide more details about Deaf people before diving into the societal complexity from which they seek health information.

1.2 Deaf culture

According to [Padden \(1991\)](#), a Deaf person who is a scientist in the field of communication, a Deaf culture is “a set of learned behaviors of a group of people who have their own language, values, rules, for behaviors, and traditions... Member[s] of the Deaf culture behave as Deaf people do, use the language of Deaf people, and share the beliefs of Deaf people toward themselves and other people who are not Deaf” (p. 344). Many Deaf people were born into their hearing families' culture, then grew up and were encultured into the Deaf culture later in life ([Padden, 1991](#)). Deaf people from different countries share multiple commonalities in the way they behave. The following commonalities can be described as characteristics of the Deaf culture:

Linguistic characteristics

Signed language is the primary characteristic of the Deaf culture ([Nash & Nash, 1981](#); [Padden, 1991](#); [Siple, 1994](#)). Signed language serves the Deaf community as the vernacular language and unites its members ([Reagan, 1995](#)). There are multiple signed languages across the world. Each signed language has been developed according to the view of its users in a particular location. Therefore, signed languages are not universal, although some of them may have some connections to each other. This is why Deaf people with different signed-language backgrounds find it challenging to understand each other. Even in the same country, there are variations of signs, so-called “dialects.” However, these dialects do not separate Deaf people from their unity ([Stokoe, 1980](#)).

Collectivistic characteristics

Collectivism is found in all Deaf communities. When one signs “Deaf,” it usually means “we Deaf people” ([Ladd, 2003](#)). Deaf people see themselves as part of a close-knit and interconnected community ([Padden, 1991](#)). They enjoy and feel comfortable being accompanied by each other because there is freedom of intercommunication in signed language—their *mother tongue* ([Gallaudet, 1887](#); [PEPNet-Northeast, 2003](#); [Siple, 1994](#)). Deaf people usually network or run organizations to serve their peers to support the companionship and maintain the cohesiveness of the Deaf community ([Reagan, 1995](#)).

Communication characteristics

Deaf people value face-to-face communication among their peers because they appreciate barrier-free communication while signing ([Porter & Samovar, 1988](#)). A conversation must start with eye contact of both communicating parties, and it is also important to maintain it throughout the interaction ([Siple, 1994](#); [PEPNet-Northeast, 2003](#)). During the communication, both interlocutors prefer seeing clear body gestures and facial expressions ([PEPNet-Northeast, 2003](#); [Reagan, 1995](#)). If staying in different geographic locations, Deaf people still prefer video-calling over other telecommunications to keep in touch. Video-calling provides them with interactions as close to a face-to-face meetup.

Deaf people are well-known for their directness in communication. In interpersonal communication, a Deaf interlocutor is likely to greet the other interlocutor by giving remarks on physical appearance. The acknowledgment of changes (e.g., weight or wrinkles) is considered polite in the Deaf culture. During a discussion, a Deaf interlocutor usually makes straightforward comments or intruding questions for some clarifications ([Porter & Samovar, 1988](#); [Reagan, 1995](#)). When giving a speech in public, a Deaf speaker states the points of the speech directly and gives several examples for elaborations. Thus, the flow of the speech given by Deaf speakers is usually different from hearing speakers, who tend to start a session by engaging the audience with some jokes or introductory stories before proceeding to the core of the speech ([Porter & Samovar, 1988](#); [Reagan, 1995](#)). Openness and transparency of information circulated in the Deaf community are important among members. Sharing intimate information is a kind of bonding that maintains the close-knit relationship and interconnectedness within the Deaf community ([Porter & Samovar, 1988](#); [Reagan, 1995](#)).

Social characteristics

All people in the Deaf culture have a name sign in addition to their birth name. When Deaf people gather, they normally introduce themselves or mention others with name signs. The name signs emphasize the collectivistic characteristics of the Deaf culture ([Mindess, 1990](#); [Siple, 1994](#)). Members of the Deaf community are the ones who give a name sign to a specific person. The name sign can quickly describe the prominent characteristics or physical appearance of the person. The name sign remains with the person for the rest of one's life ([Meadow, 1977](#); [Supalla, 1990](#)). Touching each other to gain attention or eye contact to start a conversation is common among Deaf interlocutors. Hugging is part of greetings and leave-taking ([Siple, 1994](#)). Since Deaf people enjoy the company of their peers, they tend to spend an extended period to complete a leave-taking.

As *Deaf community* is stated multiple times along with the descriptions

about the Deaf cultural characteristics, the next subsection explains the definition of this typical community.

1.3 The Deaf community and its members

[Padden \(1991\)](#) defined Deaf community as a group of people who share mutual goals and take a certain responsibility for each other; such term does not refer to a location or a village where the Deaf people are residing together. Deaf community may form themselves as an organization or an institution that has some degree of freedom to cooperate with others for improving the well-being of its members. A Deaf community is established in a particular location for the operation to achieve its goals.

Researchers have included Deaf community members in different ways. [Marschark and Spencer \(2003\)](#) and [Nash and Nash \(1981\)](#) broadly stated that the members have variations of hearing, but they all are fluent in signed language and acknowledge Deaf history. [Benedict and Legg \(2010\)](#) specified Deaf community members as people who are native signers, people who lose the hearing later in life and learn to use signed language, children of Deaf adult (CODAs), any hearing people with signed language skills, hearing people with signed language skills who work with Deaf people, and Deaf people's hearing parents with signed language skills. In contrast to the aforementioned definition, [Baker and Padden \(1978\)](#) and [Padden and Humphries \(2005\)](#) argued that there is no official identification of such membership; the membership is based on self-identification and the collective acceptance within the Deaf community.

According to the aforementioned information, who Deaf people are, their culture, the characteristics of their community and members are preliminarily understood. The next section narrows down to the information about Deaf people in Western Cape province, South Africa.

2. Deaf people in South Africa

Information about South Africa and its Deaf people, the development of South African Sign Language, the availability of South African Sign Language Interpreters, the education and functional literacy among the Deaf people, including their socioeconomic situation and accesses to infrastructure is delineated. Along with the narratives of this information, the societal complexity is defined through gradual depictions of each social barrier that is related to each other and limit Deaf people's access to health information.

2.1 South Africa and Deaf people

The estimated population of South Africa in mid-2019 was 59 million people ([Statistics South Africa 2019, 2019](#)). The people of South Africa are of diverse races, cultures, and languages. Since the abolishment of

Apartheid in 1994, the government, under different presidencies, has been trying to unite South Africa and has been reforming its systems toward equality in multiple aspects. In this process, *population groups* have been defined. These consist of *Black African* (or Black in short), *Coloured* (the mixed descendants of the African, European, and sometimes Asian), *Indian* or *Asian* (the descendants of the races who emigrated to the country from India or Asia), *White* (the descendants of the Europeans), and *Others*. There are 11 official languages recognized in the South Africa Language Bill ([The Constitution of the Republic of South Africa, 1996](#)).

Western Cape, where this research was conducted, is a province located in the South of the country. The estimated population of the Western Cape in mid-2019, the latest statistic, was approximately 6.8 million ([Statistics South Africa 2019, 2019](#)). Cape Town is the capital city of the Western Cape. Two-thirds of the provincial population inhabit the metropolitan area of Cape Town. According to the South Africa Census 2011, the population in Western Cape speaks Afrikaans (49.7%), IsiXhosa (24.7%), and English (20.2%) ([Statistics South Africa 2011, 2012a](#)).

As for the Deaf population in South Africa, there is no accurate record on any South African database. However, according to the Deaf Federation of South Africa (DeafSA), a frequently cited source, there are around 600,000 South African Sign Language users in the country ([Deaf Federation of South Africa, 2011](#)). SASL is recognized as a language of the minority by the Constitution of South Africa to be promoted and developed ([Statistics South Africa 2011, 2012b](#)). If the Deaf people are distributed equally across the country, it is estimated that around 68,000 Deaf people are living in Western Cape.

2.2 South African Sign Language

South Africa Sign Language (SASL) serves multiple roles for Deaf communities in South Africa. It is the language that the Deaf people use for interaction and passing on cultural knowledge through generations ([Aarons & Akach, 2002](#); [Baker-Shenk & Cokely, 1981](#); [Lane, Hoffmeister, & Bahan, 1996](#); [Lawson, 2002](#); [Lombard, 2006](#)). SASL unites Deaf communities. This language conveys meanings of the intended messages through an essential combination of hand shapes, the orientation of hands, the location of hands, the movement of hands, and non-manual features (i.e., facial expressions, movements of shoulders, and head movements) ([National Institution for the Deaf \[NID\], n.d.](#)).

SASL has been developed over time by multiple groups of Deaf people under influences of multiple formal institutions. The developments from SASL links back to the roles of churches at the schools for Deaf learners, the effects of the Apartheid system, and influences from outside South Africa

([Aaron, 1998](#); [Chininthorn, 2020](#); [Wehrmeyer, 2011](#)). The Apartheid policy on racial and ethnic classifications had a tremendous effect on Deaf learners and their registrations in the schools assigned by race ([Aaron, 1998](#)). It obliged changes in the teaching methods at the schools for the learners with hearing loss and did not support the official development of SASL. As a result, the development of SASL took place at playgrounds and hostels at the schools. Deaf people usually learned SASL from their peers. [Penn \(1992\)](#) hypothesized that the differences in SASL were originated from these consequences affected by the racial and ethnic classifications during the Apartheid.

There are multiple dialects of SASL [Aaron \(1998\)](#). The dialects are similar in grammar, but they are semantically different ([Morgan & Aaron, 1999](#); [NID, n.d.](#)). In response to these different views on the dialects of SASL, [Selzer \(2010\)](#) explained that racial bias among Deaf people affected the individual's understanding of the signed messages. Nonetheless, Deaf people of different dialects were able to fine-tune their understanding of each other during a face-to-face interaction. The issues surrounding dialects in SASL have persisted ([Kellett Bidoli, 2001](#)), which some researchers note as a *red herring* that could distract Deaf people from understanding the intended messages.

At present, multiple stakeholders are trying to standardize SASL since the standardization will empower Deaf communities in receiving equal public services in the long run ([Selzer, 2010](#)). After 20 years of perseverance among Deaf organizations and relevant stakeholders, the Parliament of South Africa's Constitutional Review Committee is recommending the National Assembly recognize SASL as the twelfth official language of South Africa. Once there is an official approval, it will lead to the provision of accessible information and services amongst the governmental departments for Deaf people ([Essop, 2017](#)). Since 2018, SASL has officially become the medium of instruction at schools for Deaf learners ([TIMEsLIVE, 2018](#)).

2.3 South African Sign Language Interpreters

Signed language cannot be translated word-for-word to a spoken or written language, or vice versa, due to their grammatical structure differences ([Sandler, 2003](#)). Therefore, South African Sign Language Interpreters (SASLIs) need to interpret "the intent and spirit of everything that is signed and spoken" ([DeafSA, 2011, p. 14](#)) from one language source into the target language. A professional SASLI needs to possess multiple skills: a wide range of general knowledge, knowledge of the field in which the SASLI is interpreting for, and bicultural sensitivity.

Most interpretation work in South Africa is conducted by CODA, friends

or family of Deaf people, or teachers of the Deaf learners. However, many of these individuals are not trained to conduct professional interpretation. Based on DeafSA's database, in 2011, there was a total of 84 SASLIs in the country. This number included SASLIs who were untrained, those who had received Level 1 training, and those who had received Level 2 training. Out of the total number, there were 14 SASLIs in the Western Cape. The ratios of 84 SASLIs serving 600,000 Deaf people in South Africa and 14 SASLIs serving 67,700 Deaf people in the Western Cape present critical SASLI shortages on both national and provincial levels. With this scarcity, SASLIs have become expensive and unaffordable to many Deaf people. The standard rate for the accredited SASLIs' fees ranges between 250-350 South African Rand (R) or around 17 to 24 euro (€) per hour (DeafSA, 2011; Zulu, 2014). Still, the government does not subsidize the cost of hiring the SASLIs.

Base on the information in [Subsections 2.1 to 2.3](#), two social barriers that limit Deaf people's access to health information were identified (see [Figure 3](#)). The government's and hearing people's low awareness of Deafness was identified as Social Barrier 1 as they were perceived as one overarching barrier that limit Deaf people's access to health information in the Western Cape society. The government's insufficient promotion about Deaf people's communication requirements to hearing majority demonstrated their low awareness of Deafness. As a result, the hearing majority also had the similar low awareness. The shortage of support from the government also led to the restricted provision of SASLIs and subsidies allocated for hiring them to assist communication between Deaf and hearing people. Without the presence of a SASLI at a health facility, Deaf people have had another barrier to access health information. Scarce and expensive SASLIs were identified as Social Barrier 2.

Due to the influence that Social Barrier 1 has on Social Barrier 2, [Figure 3](#) presents them together to illustrate their relationship. Each curve denotes a social barrier in [Figure 3](#). The outer curve has some influence on the inner curve. The arrows pointing outward from the Deaf people signify attempts in getting information access across the identified barriers; the arrows pointing inward to Deaf people signify the experiences obstructed by the barriers. These meanings also apply to [Figures 4, 6, and 7](#), as these gradual social-barrier identifications move toward a complete model of social barriers (see [Figure 8](#)).

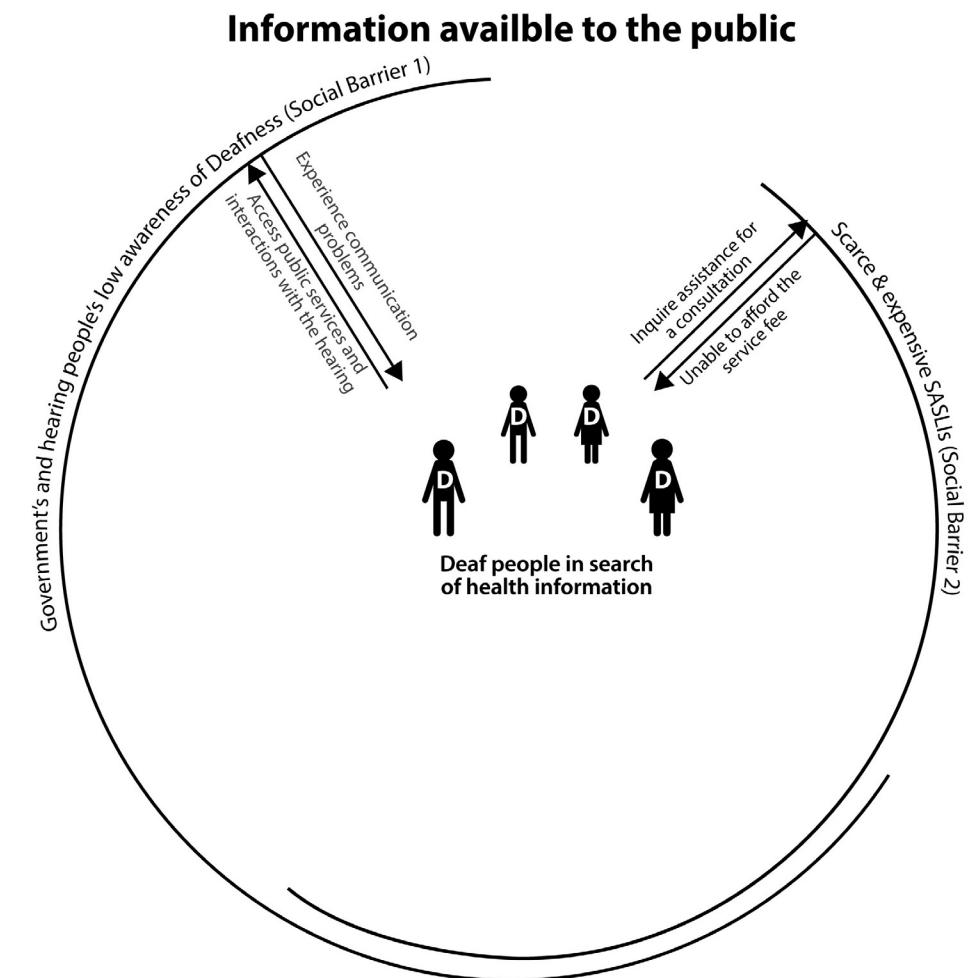


Figure 3. The first two identified social barriers.

Since two social barriers have been identified, the next subsection moves on to another social barrier identified from the education scheme that limited Deaf people's access to information in society.

2.4 Education and functional literacy

There is nearly no trace of education for Deaf learners before the British colonization ([Aarons & Akach, 2002; Swift, 2012](#)). After colonization, the state authorities took very minimal responsibility for the setup of schools for Deaf learners. The education of Deaf learners relied on churches. Researchers assume that a vast majority of Deaf children did not go to school before 1996—the year that education for Deaf learners became

compulsory ([Aaron, 1998](#); [The Constitution of the Republic of South Africa, 1996](#)). Even after schooling was made compulsory, the teaching methods were still mismatched with the communication needs of Deaf learners. Being born to families with low socioeconomic status additionally suppresses Deaf children from attending school at the proper age and, again, obstructs them from completing the final year of high school ([Kiyaga & Moores, 2003](#)).

At present, there are approximately 43 schools for Deaf learners across South Africa ([Selzer, 2010](#)). These schools have been facing multiple challenges, especially with the scarcity of financial and human resources. Only 14% of the educators at the schools can sign fluently ([The World Association of Sign Language Interpreters \[WASLI\], 2013](#)), and there is a shortage of the SASLIs for the education context ([Swift, 2012](#)).

Resulted by the ineffective education for Deaf learners, 75% of current Deaf adults, who already left school, have low functional literacy ([WASLI, 2013](#)). [Penn and Reagan \(1990\)](#) found that functional literacy among Deaf people of different races varied as a result of the segregated education during Apartheid. Investigations in early 2000 indicated that the average reading and writing skills of Deaf adults who had attended school for the Deaf was lower than Grade 4 ([Aarons & Akach, 2002](#); [Aarons & Reynolds, 2003](#); [Glaser & Lorenzo, 2006](#); [Storbeck, 1999](#)). Another study conducted in 2016 showed poor academic performance among Deaf candidates who were entering the national exam for Grade 12: only 41 out of 143 candidates (28.67%) passed the exam ([Swift, 2017](#)).

Mismatched education for Deaf learners was identified as Social Barrier 3 (appearing in blue in [Figure 4](#)). Deaf students cannot learn effectively due to the mismatched education. As a result, they cannot develop sufficient functional literacy. [Figure 4](#), which currently comprises three social barriers, shows that Social Barrier 1 has quite some influence on the limited provision of education for Deaf learners. Social Barrier 2 has even more influence on education for the Deaf. As a small number of educators can sign fluently, communication in classrooms cannot be completed nor fully understood without assistance from the SASLIs.

Information available to the public

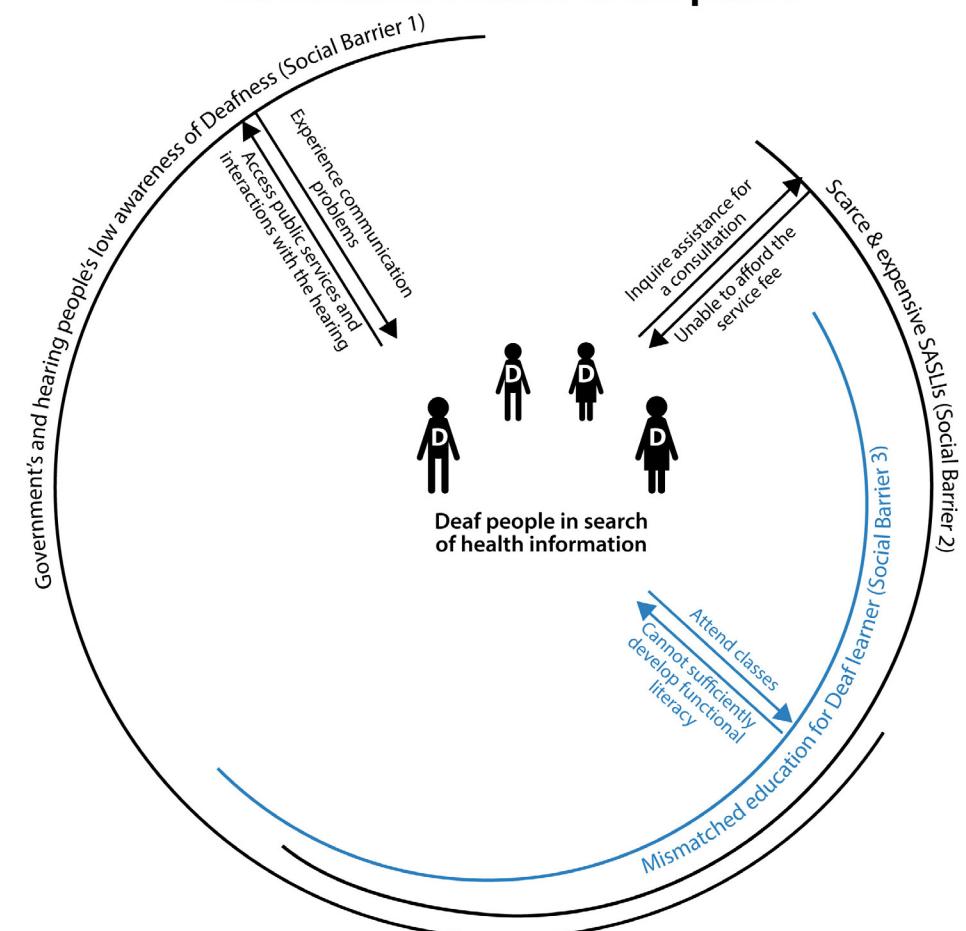


Figure 4. The three identified social barriers.

The next subsection unfolds Deaf people' socioeconomics and accesses to infrastructure in Western Cape province.

2.5 Socioeconomics and accesses to infrastructure

As a consequence of low functional literacy, 70% of Deaf people in South Africa are unemployed ([WASLI, 2013](#)). Unemployed Deaf people are eligible to apply for a Disability Grant of R1270 or €87 per month ([Zulu, 2014](#)). The rate depends on the disability which the applicant has. Low income directly affects living conditions, such as dwellings and accesses to infrastructure, of Deaf individuals. Dwellings and some types of infrastructure were studied because they might relate to the way Deaf people access a

health service and information. [Western Cape Government \(2015b\)](#) reported a challenge in providing adequate housing for the applicants in the province. In correspondence with the housing challenge in the Western Cape Government, multiple Deaf participants mentioned the difficulties in finding an affordable home ([Looijesteijn, 2009](#)). Deaf people have resided in informal dwellings, like shacks, in three townships around Cape Town and scattered across Western Cape ([van Pinxteren, 2012](#)).

According to the [Western Cape Government \(2015b\)](#), these informal settlements face a lack of networked infrastructure. The [Western Cape Government \(2015a\)](#) reported that many households still have low access to Internet Communication Technology (ICT) via landline internet. In contrast, the penetration of mobile phones in South Africa and users' access to ICT via the use of the mobile phone are rising exponentially ([Gillwald, 2018](#)). South Africa is the most significant mobile market in the sub-Saharan region. There were 38 million unique subscribers in South Africa ([Groupe Special Mobile Association \[GSMA\], 2015](#)). The number of smartphone users is steadily increasing, although the telecommunication costs in South Africa are more expensive than in many high-income countries ([The Statistics Portal, 2017](#)). [Rashid and Elder \(2009\)](#) indicated that the increase of mobile phone penetration was related to the rise of affordable prepaid schemes amongst mobile network providers, telecommunication liberalization, and deregulation.

Studies on Deaf people and their use of telecommunication in South Africa were insufficient while this research was being formulated. [Liebenberg and Lotriet \(2010\)](#) indicated that ICT had a history of a significant impact on the communication of the Deaf communities. Their Deaf participants, who had higher functional and technological literacy than other Deaf people, used instant messaging (IM) for business and personal communications and email for business communication. After all, any communication technologies that required writing skills were still considered challenging for these participants to use. A couple of years later, [van Pinxteren \(2012\)](#) found that Deaf people increasingly accepted the use of mobile phones in their daily lives. Short Message Services (SMS) and IM were used to widen their network with both Deaf and hearing people. However, functional literacy still troubled them in reading and writing messages.

This section provided profiles of the Deaf people in this research. Some understanding of the societal complexity started to form through the identifications of the three interrelated social barriers. This understanding continued to grow as the next section presents about Deaf people in the healthcare context.

3. Deaf people in the healthcare context of South Africa

This section reveals the healthcare system in South Africa, health professionals' awareness of Deafness, Deaf patients' journeys at health facilities, including their access to health information and health literacy. Continuing from the previous section narrating about Deaf people in South Africa, the social barriers that limit Deaf people's access to health information are described and visualized.

3.1 Healthcare system

The healthcare system in South Africa is decentralized into multiple levels: national, provincial, regional, and district-wise. The national Department of Health is responsible for setting mandates, user fees, schedules, and national legislation; it funds 40% of the total health expenditures in the governmental healthcare system. Such contribution allows free-of-charge health services for specific groups of patients, such as pregnant and breastfeeding women, children under the age of six, Human Immunodeficiency Virus/Acquired Immuno Deficiency Syndrome (HIV/AIDS) patients, tuberculosis (TB) patients, and unemployed patients. The provincial Departments of Health are in charge of maintaining operations, decision making on health services, and financing the hospitals and primary health centers. Health regions and districts are responsible for improving their services ([Chester, n.d.](#)); this is the health service-level that receives a vast amount of funding ([Ataguba & Akazilli, 2010](#)).

The healthcare system is organized around and adheres to a designated healthcare framework. Two frameworks for the Comprehensive Service Plan toward 2020 and 2030 to improve the quality of its health services were drafted and announced by the Department of Health Western Cape (DOHWC). The framework toward 2020 ([Western Cape Government, 2011](#)) has been a focus since this Ph.D. commenced. It emphasizes improving patients' experiences and quality of care and striving for further operational efficiencies. The health services are delivered through components of service platforms in the Western Cape, as illustrated in [Figure 5](#). Primary health services (the black areas of the pyramid) are assigned as the main components to deliver services to patients. Another component of service delivery is acute hospitals in secondary and tertiary levels of health services (the grey and the white areas of the pyramid). Along with these aforementioned components, four other components (in rectangular shapes) support comprehensive health services.

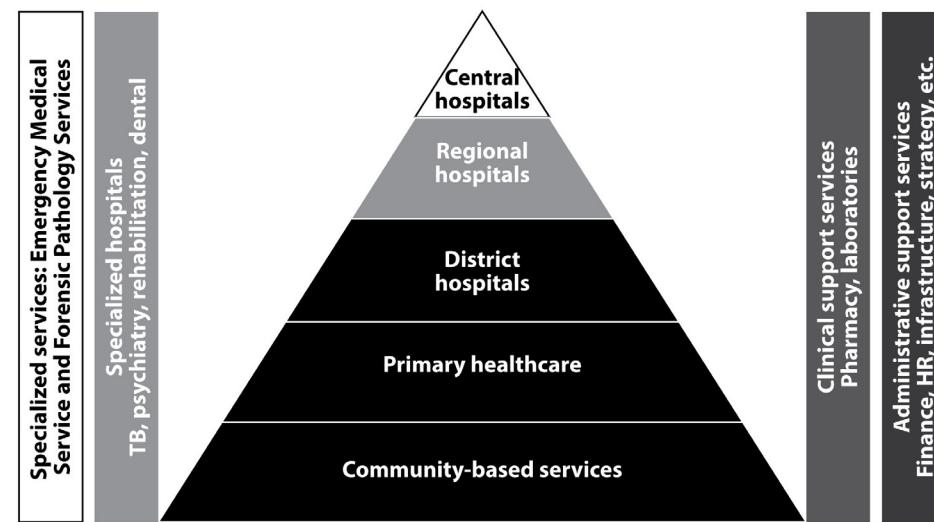


Figure 5. Components of the health service platform in Western Cape toward 2020.

During the writing of this thesis, the framework toward 2030 was drafted by DOHWC. The service components of the framework toward 2030 are aimed at delivering more integrated and comprehensive services than the framework toward 2020. It still focuses on person-centered quality care, but adds the provision of integrated health services, including continuity of care throughout the life course of the patient into the planning ([Western Cape Government, 2014](#)). The primary health services are to be further strengthened to cater comprehensive care (preventive, promotive and curative, and rehabilitative care). The framework community and technologies are to be involved in the care process. Paper-based documentation will be migrated to a digital version.

Concerning the use of languages in the healthcare context, the South African Health Act (61 of 2003) and Convention on the Rights of Persons with Disabilities 2006 enforce healthcare providers to provide understandable services to all patients. The first stated, “the health care provider concerned must, where possible, inform the user in a language that the user understands and in a manner which takes into account the user’s level of literacy” ([Government Gazette Republic of South Africa, 2004](#), p. 20), and the latter stated, “the purpose of the present Convention is to promote, protect and ensure the full and equal enjoyment of all human rights and fundamental freedoms by all persons with disabilities, and to promote respect for their inherent dignity” ([United Nations, 2008](#), p. 4). In line with these statements, Deaf people are entitled to have access to health information in SASL, similar to other patients who receive information in English, Afrikaans, isiXhosa, or

any of the official languages in South Africa. However, the use of the SASLIs to assist communication in health services for Deaf patients is low. None of the governments have taken any action to provide SASLIs readily available at health facilities ([Heap, 2013](#)).

There is an extreme shortage of the SASLIs who are specially trained for medical interpretation ([Heap, 2013](#)). Similar to a written or a spoken language, medical terminologies cannot be directly translated into a signed language. In fact, there are still not many signs developed for the terminologies related to medical conditions and diagnosis in SASL ([Kritzinger, 2011](#)). Therefore, the medical SASLIs need to be highly skilled in medical terminologies and adapt to different SASL dialects of their Deaf clients ([The complexities of being a sign language translator, 2015](#)). By recognizing this shortage, Health and Human Rights Programme (HHRP) of University of Cape Town has been piloting free-of-charge SASL interpreting services for health consultations within Cape Town metropole for Deaf patients ([Haricharan, Heap, Coomans & London, 2013; Heap, 2013](#)). Unfortunately, the current human resources of the medically trained SASLIs are not sufficient for the demands among Deaf patients.

This subsection introduces the health system of South Africa, the rights of Deaf patients in acquiring SASLI assistance at a health facility, and the shortage of the SASLIs trained specifically for medical interpretation. The next subsection, then, discusses how much health professionals in South Africa were aware of Deafness and Deaf patients’ communication needs.

3.2 Health professionals’ awareness of Deafness and Deaf patients’ communication needs

Limited literature has provided information concerning this topic. [Kenney \(2015\)](#) studied six health professionals in South Africa who were familiar with Deaf patients or who trained medical students about their awareness of Deaf patients’ communication needs. Two of these health professionals indicated that they had received training regarding Deaf awareness and Deaf culture from linguistic or signed language courses during their undergraduate degrees. All health professionals revealed that training on signed language and Deaf culture, including their exposure to Deaf communities, was necessary for their practice because they increased their awareness of Deafness. Still, five of these health professionals incorporated written and oral communication with some signing to communicate with their Deaf patients. Only one health professional reported preferring to use a professional SASLI to assist communication during a consultation. Another health professional optimized the use of a computer for video relay interpreting services or for typing out the communication. Some of these health professionals mentioned that visual tools could be useful during

health consultations with the Deaf patients. In a medical newsletter ([David, Khayelitsha Community Health Center \[CHC\] weekly newsletter circulated via email, November 11, 2013](#)), a doctor reflected on his clinical interaction with a Deaf patient who was escorted by a professional SASLI for the first time. This patient found this health consultation a breakthrough to understand her chronic diagnosed several years ago. Such incidence, made the doctor realized that some health professionals had inadvertently violated Deaf patients' human rights when failing to communicate efficiently with them, especially in the absence of SASLIs. Consequently, he urged his medical fellows to have SASLI at health facilities to deliver the rights to which all Deaf patients are entitled.

The stated literature demonstrates multiple health professionals' low awareness of Deafness and Deaf people's communication needs, which can be interpreted as a barrier. However, Deaf patients' experiences in their interactions with health professionals had to be reviewed before addressing it as another social barrier. Thus, the next subsection provides Deaf people's experiences on interactions with health professionals at health facilities.

3.3 Deaf people's patient journeys

Many Deaf people, who are of low economic status, use free-of-charge health services at public health facilities. They primarily receive health services at clinics, primary health centers, and district hospitals. Deaf people's common experiences in these health facilities are explained through a patient journey, starting in the waiting room and continuing until leaving the premises.

In the waiting room, nurses called the name or the queue number of each patient to notify them of their queues for history taking, consultation, medication collection, etc. Deaf patients revealed their anxiety during the wait. Some nurses in the waiting rooms reportedly ignored the word "DEAF" written on the front of the patient folders; they still shouted the name of Deaf patients for their presence in the queue ([Chinithorn, Glaser, Freudenthal, & Tucker, 2012](#)). This made Deaf patients who could lip-read continuously focus on the nurses' lip movements and made other Deaf patients who could not lip-read find other strategies to deal with such queue notification. Asking a hearing patient in the area to listen for the Deaf patients' names or befriending a staff member at those health facilities for smoother services are two examples of the strategies given by Deaf patients. However, with any strategy they tried, Deaf patients often found that they had already missed their queues ([Chinithorn, 2011; Kitzinger, 2011; Looijesteijn, 2009](#)).

In the consultation rooms, the consultations often took place without the presence of a SASLI. Some Deaf patients reported that their health

professionals scolded them for not bringing an interpreter ([Haricharan et al., 2013](#)). Once the provision of the SASLIs was pushed as if it were the responsibility of the Deaf patients, they felt obliged to take a friend, their partner, or a CODA as their interpreter instead of a professional SASLI whom they were unable to reach or afford ([Lotriet, 2011](#)). If none of these companions were available, the patients had to attend the consultation alone. Many Deaf patients tried to communicate with the doctors or the clinical nurses during such consultations via writing. Some patients indicated that they understood everything that the health professionals wrote, but they did not know the words to write a reply. Other Deaf patients admitted that they could not understand anything that the doctors wrote ([Haricharan et al., 2013; Kitzinger, 2011; Moola, 2010](#)). Whilst the Deaf patients who could lip-read would focus on the doctors' lip movements, many of them could only perceive 30-40% of the spoken words accurately ([Bauman, 2000](#)). Lip-reading skills became useless when the doctors wore a medical face mask while speaking because the mask obscured the patient's view of the mouth ([Looijesteijn, 2009](#)). When communication was broken entirely, many Deaf patients admitted that they just nodded their heads to "say yes" to everything the doctor explained. The nodding was to rush the consultation process to the end because the patients wanted to escape the confusing communication situation ([Kitzinger, 2011; Kitzinger, Schneider, Swartz, & Braathen, 2014](#)). In other cases, the patients did not know whether the consultation had ended. Frequently, doctors said goodbye while walking out the door, leaving the patients to wonder if their doctors would come back ([Looijesteijn, 2009](#)). Many Deaf patients left the consultation room without understanding the diagnosis, the relevant health information to improve their health, the treatment options, or the prescribed medication, including its purpose ([Chinithorn, 2011](#)).

At the hospital pharmacies, Deaf patients got stressed while waiting in their queues to collect the prescribed medications. They complained that pharmacists spent insufficient time, only two to six minutes, to explain the medication instructions. Due to limited functional literacy, many Deaf patients could not understand the prescribed medicines' name and the instructions as written on the label ([Chinithorn et al., 2012; Kitzinger, 2011](#)). The Deaf patients who could lip-read might have received some partial medication instructions from the pharmacists' explanations. However, the details regarding side-effects of medicines and symptoms of the medicine allergy were omitted. Deaf patients require that the name of the medicine, its purpose and use, instructions for taking it, the time for taking it, its dosage and recommendations, including side-effects, be made known to them ([Chinithorn, 2011; Haricharan et al., 2013](#)).

Before leaving the health facilities, an appointment for a follow-up visit should be made with the administrations. The hurdles repeated during the

appointment-making process due to the language barrier. ([Looijesteijn, 2009](#); [Kritzinger, 2011](#)).

Deaf people in South Africa have various experiences when reflecting on their accesses to health services. Those who had a SASLI escort to a consultation appreciated the full communication that they experienced. However, those who had a friend or a family member as their interpreter might not have received the complete medical information that they should have. These patients acknowledged that confidentiality about their health status could not be kept by these non-professional interpreters ([Haricharan et al., 2013](#)), whereas those who had to handle the communication barriers alone were unsatisfied with the quality of health services they received. As a result of communication barriers, Deaf patients indicated that they had to revisit health facilities more than they should have had ([Looijesteijn, 2009](#)). Some Deaf patients indicated that health professionals were arrogant towards them, laughing and rolling their eyes at the patient's writing during the attempt to communicate ([Chinithorn, 2011](#); [Haricharan et al., 2013](#)). A few other Deaf patients added that although the communication was confusing, some health professionals still treated them with respect ([Kritzinger, 2011](#)). [Haricharan et al. \(2013\)](#) pointed out that some rights to health services among Deaf people were violated when the communication was not in SASL. The health professionals' actions that pushed the provisions of SASLIs during a consultation as the responsibility of Deaf patients conflicts with the enforcement stated by the South African Health Act (61 of 2003) and the Convention on the Rights of Persons with Disabilities 2006.

The information in this section shows the contrast between the health professional's opinion on their effective methods for communicating with their Deaf patients and what Deaf patients experienced at health facilities. According to health professionals' low awareness of Deafness and Deaf patients' communication needs (refer to [this chapter, Subsection 3.2](#)) and Deaf people's troubled interaction with the health professionals at various health facilities ([this subsection](#)), non-Deaf friendly health services was identified as Social Barrier 4. [Figure 6](#) shows the influences which the formerly identified social barriers have on Social Barrier 4 (in blue). In agreement with [Heap \(2013\)](#), the government's and hearing people's low awareness of Deafness were found to result in Social Barrier 4. The scarce and expensive SASLIs also has some influence on the same social barrier. Due to their absence at health facilities, health services become inaccessible to many Deaf patients. The mismatched education for Deaf learners is, as well, accountable for Deaf patients' low functional literacy since the patients cannot understand the consultations that several health professionals choose to communicate with them via writing.

Health information available to the public

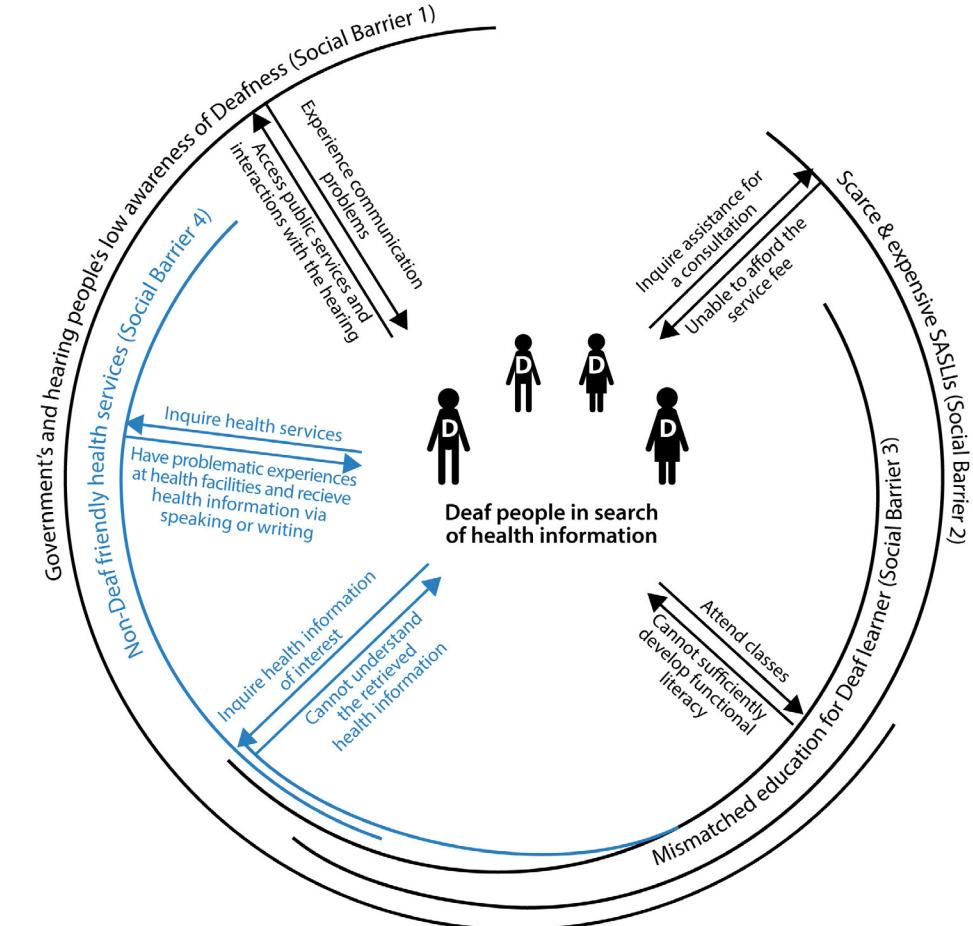


Figure 6. The four identified social barriers.

[Subsections 3.2 and 3.3](#) address the lack of SASLI assistance at primary health centers; they imply that Deaf people can rarely access health information from their health professionals. The next subsection, therefore, unveils Deaf people's alternative health information sources.

3.4 Deaf people's access to health information and their health literacy

This subsection provides how Deaf people in South Africa access health information through the different stages of their lives. How their health literacy has been affected is also touched upon.

In their childhood and youth, Deaf people in South Africa only learned about health at their schools, not from their families. Deaf children did not have a complete understanding of what their parents and family members, many of whom did not have signed language skills, taught them ([Mall & Swartz, 2012](#)). However, their access to health information at schools was not thorough either due to language barriers and mismatched education scheme ([Morgan, 2008](#)). As indicated by [Kritzinger \(2011\)](#) and [Nonkelela \(2013\)](#), not all medical conditions or diseases have a sign in SASL. This could be one reason that it is difficult for educators to teach health at an advanced level to Deaf learners. In the Life Orientation curriculum, which covers topics of health, health education was planned to be taught to the Deaf learners only during Grades 7 to 9. The teaching plans were centered around substance abuse, environmental health, and common diseases, such as TB, diabetes, epilepsy, obesity, anorexia, and HIV/AIDS ([Department of Basic Education, 2012](#)). These topics were in line with prevalent diseases and causes of death in South Africa, yet they were too limited and general.

In adulthood, access to health information among Deaf people in South Africa became even more limited. They may have an opportunity to access some health information during a health consultation regarding their health, but they generally missed this information when there was no SASLI assisting ([Haricharan, Heap, Hacking, & Lau, 2017](#)). When it comes to using alternative sources for delivery, such as electronic media like radio and television, Deaf people could not understand the health information ([Ismail, 2013](#); [Kritzinger, 2011](#)). Even if they were fortunate enough to access such information, it is mostly limited to HIV topics ([Mall & Swartz, 2012](#)). When the health information from these information sources was found inaccessible, Deaf people in adulthood commonly turned to their peers in their Deaf community for the needed information. [Kritzinger \(2011\)](#), [Ismail \(2013\)](#), and [Ismail and Henderson \(2014\)](#) discovered that health information was shared among different Deaf communities across the Western Cape via grapevines. [Kritzinger \(2011\)](#) elaborated further that many Deaf people tended to accept new information shared within a close-knit community readily. They might question its accuracy only when the information goes against their beliefs. [Ismail \(2013\)](#) added that most of the health information shared through the grapevine was obsolete and erroneous.

Access to health information is related to information seekers' health literacy. As such, information about health literacy among Deaf people in South Africa. The meaning of health literacy has expanded from just the individual ([Ratzan & Parker, 2000](#)) to embrace the community. [Dodson, Beauchamp, and Batterham \(2014\)](#) stated, "Health literacy refers to the personal characteristics and social resources needed for individuals and communities to access, understand, appraise, and use information and services to make decision

about health. Health literacy includes the capacity to communicate, assert, and enact these decisions" (p. 4).

[Glaser and Lorenzo \(2006\)](#) suggested that Deaf people's health literacy was low due to low functional literacy. [Kritzinger \(2011\)](#) found that Deaf participants knew only simple information, such as DOs and DONTs for HIV/AIDS prevention and the basic concept of health since no supportive reasons were taught in health education at schools for Deaf learners. The Deaf participants' address on health information needs beyond HIV/AIDS also indicated that the health topics taught at schools were limited; they needed information regarding coughs, sore throats, colds/flu, cancer, diabetes, and tuberculosis. [Ismail and Henderson \(2014\)](#) gave some examples of health misconceptions that Deaf people, from different areas of the Western Cape, hold due to their rare access to accurate health information. For instance: "If they put a slice of orange in the vagina and it turns red, then the person is HIV positive" (p. 43), and "if a man rapes a virgin, he may be cleansed of HIV infection" (p. 45). Beyond HIV/AIDS, [Haricharan et al.'s \(2017\)](#) survey revealed that all 41 of their Deaf respondents had heard of high blood pressure (hypertension). Eighty percent of the respondents knew what the disease was like, but they only understood the general concept of a healthy lifestyle, such as no smoking, no excessive alcohol drinking, weight control, eating a lot of vegetables and fruits, and regular exercise. Plus, only a few of them understood the appropriate self-management for controlling normalizing blood pressure.

At this step, three more social barriers were identified based on the aforementioned findings (see [Figure 7](#) for these newly identified social barriers in blue). The three barriers are limited health education for Deaf learners, family members who cannot sign, and health misconceptions among Deaf people. Limited health education causes insufficient foundations of health knowledge amongst Deaf learners; it affects their health maintenance and ability to judge the credibility of health-related information they receive. Therefore, it acts as a barrier when Deaf people are in search of health information. As it closely links to the mismatched education for Deaf learners, the two were eventually integrated as one social barrier (Social Barrier 3). Since most family members of Deaf people cannot communicate in signed language, their discussions during a gathering, which may contain some health topics, cannot be overheard by the Deaf member. As a result, Deaf people miss incidental learning about health from their family members. Due to this reason, family members who cannot sign are interpreted as Social Barrier 5.

Since Deaf people have had limited information sources, they often seek health information from their Deaf peers. The health information being

shared within a Deaf community is questionable for its accuracy. Oftentimes, inaccurate health-related information causes Deaf people to develop health misconceptions. Multiple researchers have considered health misconceptions among Deaf people as a difficult barrier that resists any correction to the inaccurate information. Likewise, health misconceptions were identified as Social Barrier 6.

Six social barriers that limit Deaf people's access to health information are identified step-by-step based on information about Deaf people in South Africa. All of the social barriers accumulated in [Figure 7](#).

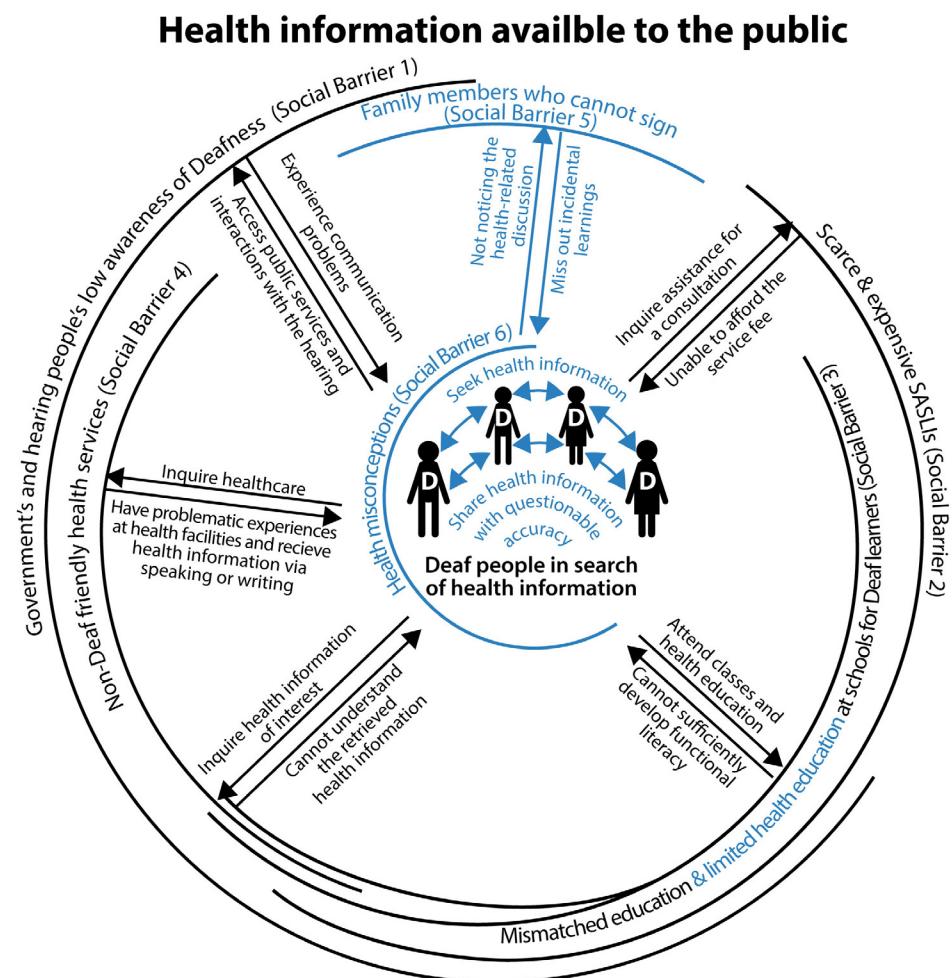


Figure 7. The six identified social barriers.

The next section summarizes the problem definition of this research context.

4. Problem definition and societal question

The six social barriers, including Deaf people's attempts in getting information access and experiences obstructed by these barriers, are summarized as shown in [Figure 8](#). Deaf people's limited access to accurate health information has been a persistent societal problem. The six social barriers have interrelated effects on each other. Their relationships can alter over time when some interventions will be implemented. Such interrelatedness and relationships denote complexity in providing health information accessibility to influence Deaf people's medication and treatment adherence.

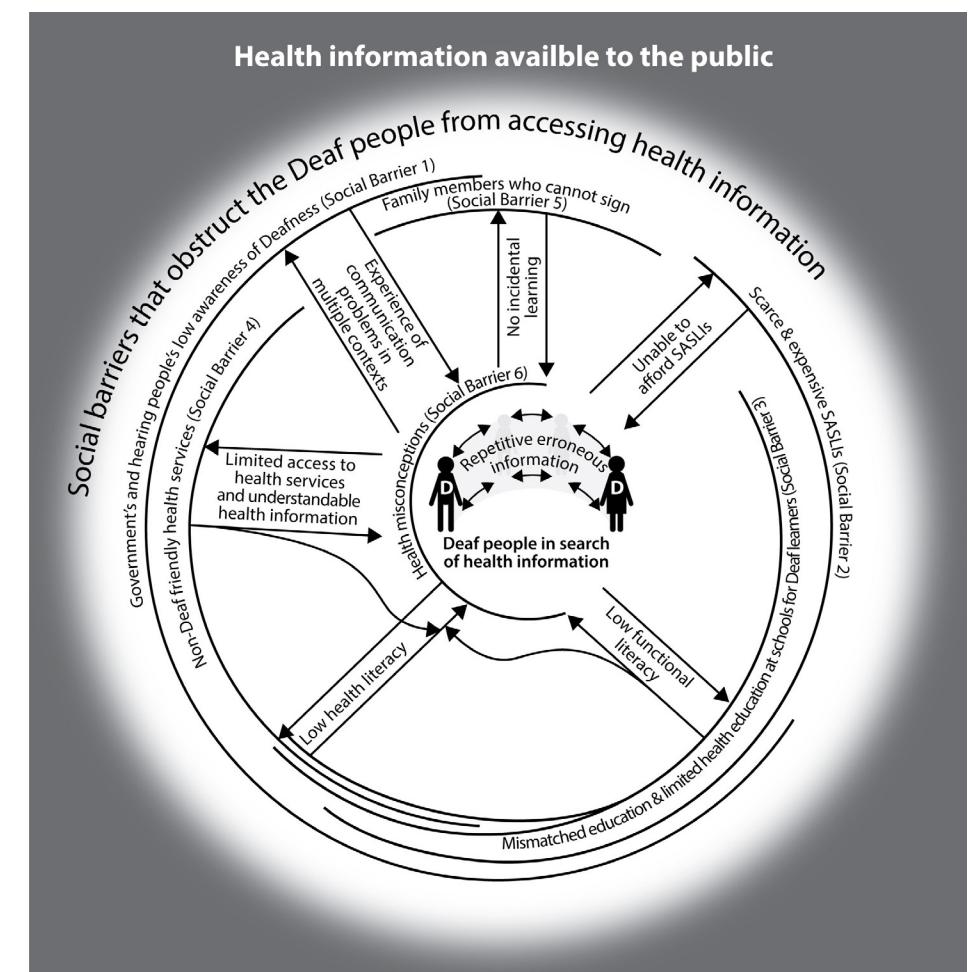


Figure 8. Social barriers that limit Deaf people's access to health information in the Western Cape.

Carefully dealing with this societal complexity might yield an interventions that meet Deaf people's, including relevant stakeholders,' needs and suit to the studied context. As such, a societal question was raised:

What contributions can be made to provide Deaf people access to accurate health information in Western Cape, South Africa?

According to the six social barriers, summarized in [Figure 8](#), there can be six potential contributions with details as follows:

- regarding Social Barrier 1, Government and hearing society's low awareness of Deafness: a platform for the government for creating understanding between Deaf and hearing people and overarch to other projects that provide Deaf people with access to information, such as health
- regarding Social Barrier 2, Scarce and expensive SASLIs: an alternative for affordable assistance from SASLIs for Deaf people
- regarding Social Barrier 3, Mismatched education and limited health education at schools for Deaf learners: educational materials to support Deaf youths' learning about health efficiently at schools
- regarding Social Barrier 4, Non-Deaf-friendly health services: a diagnosis and health information during a consultation accessible for Deaf patients, or make health information accessible for Deaf people who want to look up the information of interest
- regarding Social Barrier 5, Family members who cannot sign: a tool that a family member can refer to when sharing health information with their Deaf loved one, similar to the health education materials used at schools for Deaf learners
- regarding Social Barrier 6, Health misconceptions: a tool that Deaf people refer to before sharing accurate health information with each other.

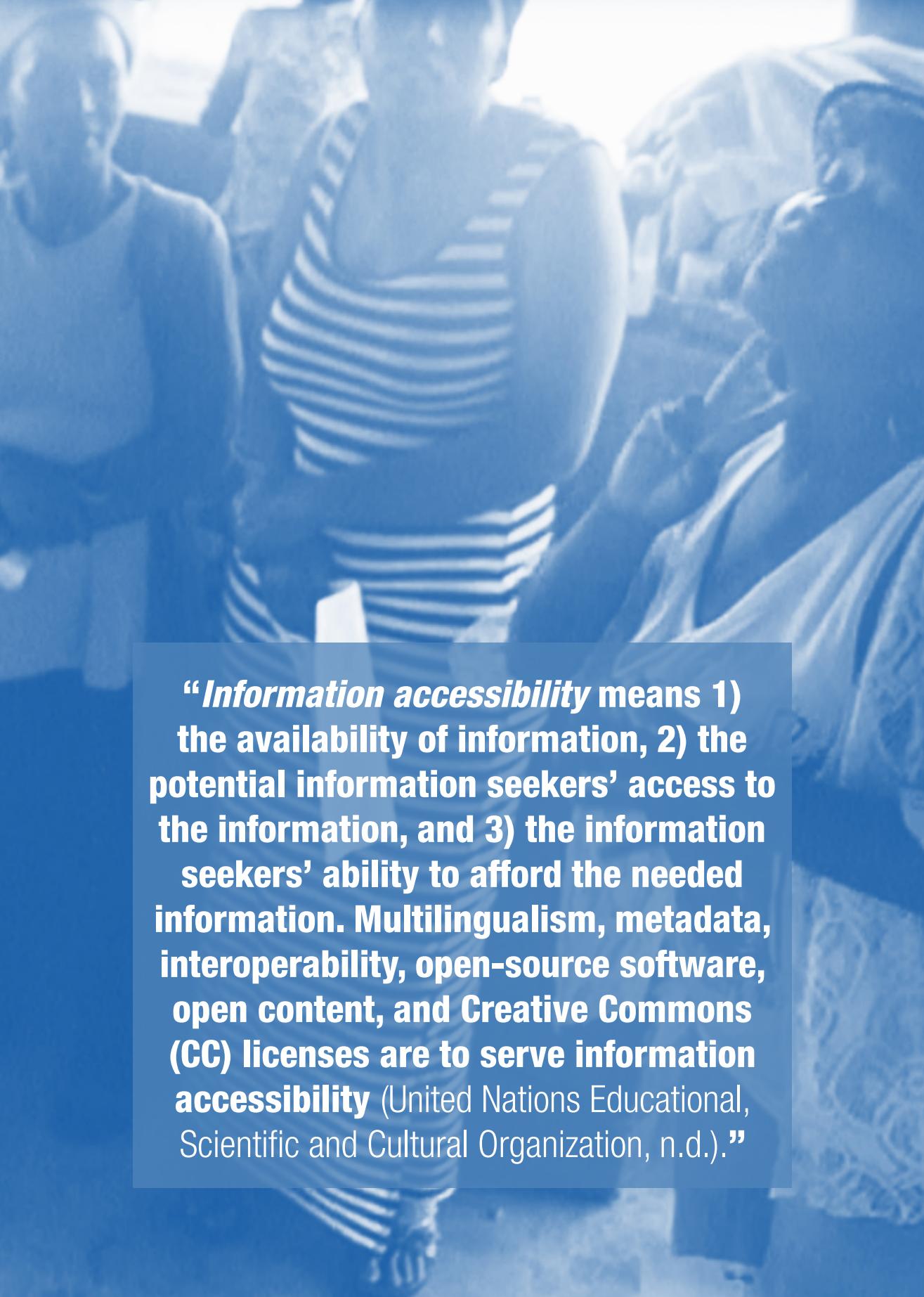
This [last section of Chapter 1](#) summarizes the six social barriers denoting societal complexity. A societal question urges all stakeholders, including Deaf communities, to find suitable interventions for solving this identified societal problem—Deaf people's limited access to accurate health information. Consequently, six potential contributions for designing and developing interventions associated with the stated social barriers are listed.

On account of the societal complexity, interventions retrieved from the limited literature about South Africa might be neither suitable nor sufficient to this research context. Thus, Deaf communities and relevant stakeholders in the Western Cape should be involved in an active design process of a suitable intervention. With such involvement, this research contains a characteristic of research through design (RTD) approach. In following this statement, the next chapter describes how the RTD approach was developed.

Chapter

2

Tackling societal complexity



“Information accessibility means 1) the availability of information, 2) the potential information seekers’ access to the information, and 3) the information seekers’ ability to afford the needed information. Multilingualism, metadata, interoperability, open-source software, open content, and Creative Commons (CC) licenses are to serve information accessibility (United Nations Educational, Scientific and Cultural Organization, n.d.).”

The previous chapter has addressed the societal complexity that requires an intervention to provide Deaf people with health information accessibility and mentioned the active involvement of a Deaf community and relevant stakeholders in a design process. The latter indicates the author’s necessity to follow guidelines for this unique involvement and application of a research-through-design (RTD) approach to tackle societal complexity. Thus, the main research question (MRQ) was formulated, as shown below, for the design of an intervention.

What intervention can be designed to provide Deaf people with health information for influencing medical and treatment adherence?

Desk research was conducted to gather knowledge that other researchers had contributed. The findings from this desk research primarily answered the MRQ with health information accessibility requirements for Deaf people and recommendations for interventions. Since there were some knowledge gaps and additional knowledge to be developed for an intervention suitable to the Western Cape context, empirical research had to be conducted. A design approach, like RTD, was reviewed. An RTD approach that involved Deaf community and stakeholders, together with a set of initial guidelines for actively involving participants in the process, was applied during the

empirical research. The results from the empirical research were expected to elicit knowledge for designing a suitable intervention and answer the MRQ.

Concerning the statement above, this chapter presents the desk research towards health information accessibility ([Section 1](#)), all sub-research questions (SRQs) ([Section 2](#)), and the approach to apply during the empirical research, including the initial set of the guidelines ([Section 3](#)).

1. Toward health information accessibility

[Subsection 1.1](#) presents the identification of the information accessibility requirements that led to elaborations by the recommendations from related works regarding information accessibility for Deaf people. [Subsection 1.2](#) discusses these recommendations and knowledge gaps the author had for designing an intervention.

1.1 Requirements of general information accessibility

The conceptual framework was developed based on definitions of *information*, *accessibility*, and *information accessibility*. As the definitions of these three words varied by the domain of study, their operationalized meaning was chosen from the definitions stated by the United Nations (UN)—a renowned organization that has been promoting information access for all of humanity.

According to the UN's Information for All Program (IFAP), information denotes “a message or data that was communicated concerning a specific issue” ([ICT for Information Accessibility in Learning](#), n.d., para.1). *Accessibility* refers to the appropriate requirements to ensure information seekers with 1) physical environment, 2) transportation, 3) information and communications, 4) technologies and systems for information and communications, and 5) other facilities and services made available to the public, both in urban and in rural areas ([United Nations Convention on the Rights of Person with Disability](#), 2006). *Information accessibility* means 1) the availability of information, 2) the potential information seekers' access to the information, and 3) the information seekers' ability to afford the needed information. Multilingualism, metadata, interoperability, open-source software, open content, and Creative Commons (CC) licenses are to serve information accessibility ([United Nations Educational, Scientific and Cultural Organization](#), n.d.).

Since “appropriate requirements” were stated as part of the definition of accessibility, theories and concepts concerning information accessibility were searched to define what these requirements could be. The work of two main contributors was found applicable. They also contributed to lists of the requirements. [Culnan \(1985\)](#) proposed a multidimensional concept of information accessibility. Culnan indicated that an information seeker's

experience with an information source, compared with other sources, influenced that seeker's perception and decision on the accessibility of that source. The perceptions of information accessibility have been classified into three dimensions: physical, interface, and informational.

The *physical dimension* refers to physical access that the information seeker has when reaching an information source. The *interface dimension* means the information seeker's ability to form a query and interact with the information source for the needed information. Lastly, the *informational dimension* denotes the information seeker's ability to retrieve relevant information and the understandings gained from the information. As [Culnan \(1985\)](#) did not visualize her multidimensional concept of information accessibility, the author modeled and deduced the requirements for each dimension (see [Figure 9](#)).

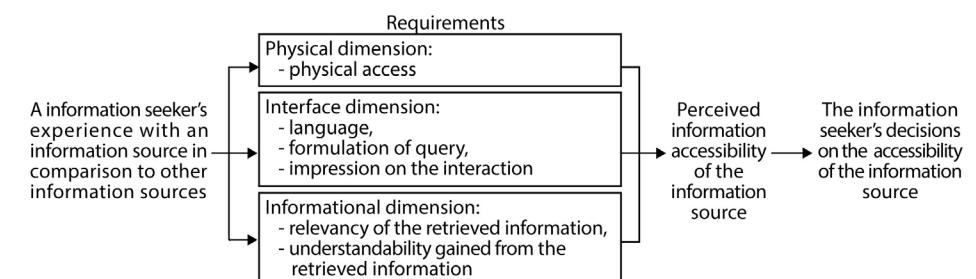


Figure 9. The requirements for information accessibility deduced from Culnan's (1985) multidimensional concept.

This multidimensional concept explains the phenomenon of how information seekers—Deaf people—in South Africa perceive their struggles to access health information. For instance, a Deaf patient who cannot afford a South African Sign Language Interpreter (SASLI) to give him physical access to information during a health consultation experiences a disrupted interaction with a doctor (refer to [Chapter 2, Section 3](#)). Although the doctor tries to write to communicate, the patient still finds many words difficult to understand. This patient is confused about his illness. This interaction feels inferior to a previous consultation when he was granted a free-of-charge SASLI as an escort to a health facility. As a result, the patient perceives and decides that health information delivered in the absence of a SASLI is and will be inaccessible.

The requirements derived from Culnan's concept are in line with two out of three definitions of information accessibility that [United Nations Educational, Scientific and Cultural Organization \(UNESCO\)](#) (n.d.) stated. The availability

of information and information seeker's ability to access that information is touched upon, but not the information seeker's ability to afford the information. The work of [Swanson \(1992\)](#) is also related to the three stated meanings, and it adds the information provider as a dimension of the phenomenon of accessing information. Without defining dimensions, his work proposed ten propositions in which information accessibility would increase:

1. The more and qualitatively better the sources,
2. The more and qualitatively better the channels,
3. The less occupied the sources and channels,
4. The more conveniently the user is situated relative to the sources and channels,
5. The more familiar the user is with the sources and channels,
6. The lower the prices if any charged by the sources and providers of the channels,
7. The lower the provision costs to the sources and providers of the channels,
8. The more recoverable the provision costs to the sources and providers of the channels,
9. The more the information need of the user is matched by the influence needs of the sources and providers of the channels,
10. The more the behavior of the informed user is anticipated to be consequential and consistent with the interests of the sources and providers of the channels from which the information may be obtained. (p. 195)

These propositions add additional requirements to Culnan's multidimensional concept. [Swanson's \(1992\)](#) Propositions 6, 7, and 8 are relevant to the affordability of information access. Propositions 1 to 4 show connections among information sources, channels, and users, similar to the requirements concerning a person's physical access (refer to [Figure 9](#)). [Swanson \(1992\)](#) additionally differentiates two types of information sources: direct and indirect sources. For example, a librarian (an indirect source) can locate a book (a direct source) for a library visitor's searching. These two types of information sources also expand the requirements regarding physical access. Proposition 5 is relevant to the requirements under Culnan's interface dimension since the information seeker's familiarity with an information source, or channel would increase one's impression of the interaction with that source or channel. Propositions 7 and 8 add the costs born by the information provider to provide information to the conceptual framework. Propositions 9 and 10 refer to influences on a person's selection of an information source.

All requirements defined through the work of [Culnan \(1985\)](#) and [Swanson \(1992\)](#) were rearranged and grouped to formulate the conceptual framework. The grouping was divided into 1) Suitability (related to both information provider and information seeker), 2) Experience (related to information seeker), and 3) Motivation (related to information seeker) (see [Figure 10](#)).

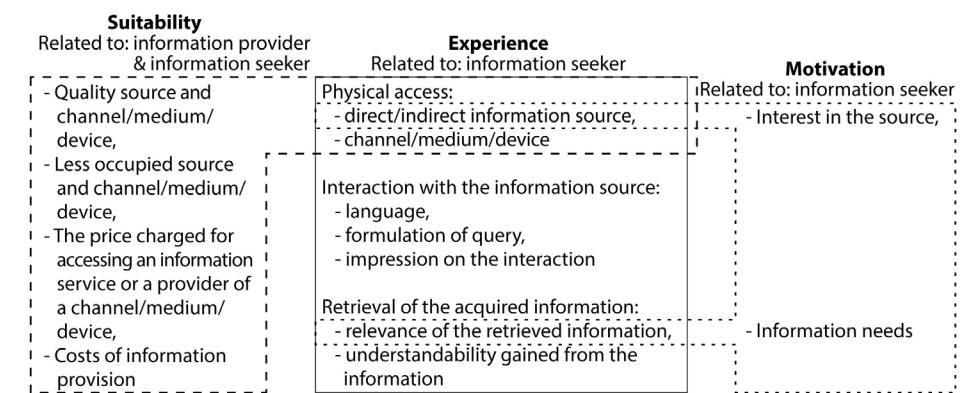


Figure 10. The conceptual framework of information accessibility.

The Experience Group consists of all requirements identified based on Culnan's multidimensional concept of information accessibility. The Suitability Group includes the requirements obtained from Swanson's Propositions 1 to 4 and 6 to 8. The Motivation Group comprises Swanson's Propositions 9 and 10. Several requirements across the groups are interrelated. Channel was conjoined with medium, including device since information seekers usually use a medium install on a device to access a channel; for example, an internet browser (medium) installed on a mobile phone (device) helps users access the Internet (channel). The solid border in [Figure 10](#) shows the Experience Group requirements. The dashed border refers to the relationship among the requirements under the Experience Group and the Suitability Group since an information seeker would find an information source, a channel, or a medium accessible when they are available with good quality, and their prices are affordable. Also, the information source would be accessible as long as its information provider could cover the information provision costs. The dotted border presents the relationship between the requirements under the Experience Group and the Motivation Group. The information seekers' interests lead them to access an information source and assess how much of the retrieved information is relevant to their needs.

The next subsection elaborates on the information accessibility requirements for Deaf people based on related works.

1.2 Elaborations on the requirements towards health information accessibility for Deaf people

The related works concerning health information for Deaf people was studied. Their recommendations elaborated on the information accessibility requirements, formulated in [Figure 10](#).

Health information + Deaf + sign language was the combination of the keywords searched in ScienceDirect and Google. Some gray literature was included as part of the review because it showed guidelines, frameworks, standards, and policies posted by governmental and non-governmental organizations. The search resulted in a large number of hits, but most of them were irrelevant to practices that avail health information particularly for Deaf people. However, there was a medical standard from the United Kingdom (UK) that mandates Deaf-inclusive health information. The search was broadened to include related works regarding general information access for Deaf people, and three more relevant results were retrieved. Due to the limited number of related work issues, the search was extended to information access for people with a language barrier and low functional literacy, with the combined keywords: *health information + low literacy*. As a result, a health informational guideline and a study, both from the United States of America (USA), were included as part of the literature review. These related works are associated with 1) Deaf-inclusive health information, 2) general information access specifically for Deaf people, and 3) health information access for people with the language barrier. Their details are as follows:

Deaf-inclusive health information

[The British Medication Association \(BMA\) \(2016\)](#) has set a standard in the UK mandating accessible healthcare for all service users, including Deaf patients. All health professionals under the provision of the National Health Services (NHS) are required to provide a British Sign Language Interpreter (BSLI) or to utilize speech-to-text-reporter (STTR) during a consultation. [Barnett \(1999\)](#) and [Barnett, McKee, Smith, and Pearson \(2011\)](#) have recommended health facilities providing American Sign Language Interpreters (ASLIs) for Deaf patients.

General information access specifically for Deaf people

[The World Association of Sign Language Interpreters and World Federation of Deaf \(WASLI & WFD\)'s \(2015\) guideline](#), [Office of Disability Employment Policy \(ODEP\)'s \(2012\) framework](#), and [Kirkpatrick, Connor, and Cooper's \(2018\) guidelines](#) are discussed regarding their interventions that avail multiple types of accessible information for Deaf people. [WASLI and WFD \(2015\)](#) provided guidelines on communication and information related to natural disasters and other mass emergencies for all countries. Emergency information should be

distributed free of charge to Deaf people and delivered via Short Message Services (SMS), app, teletypewriter (TTY), Internet-based relay services, and instant messaging (IM). Desktops or laptops with a webcam are the media that Deaf people used for extended communication. Information regarding emergency preparedness should be distributed via digital video disc (DVD), online video, workshops, and brochures. When possible, such information has to be provided in signed language with open captions for Deaf people in that designated area. Otherwise, text-based information should be in plain written language. With a similar attempt, [ODEP \(2012\)](#) suggested a framework to accommodate people with disabilities with access to information via Internet Communication Technology (ICT) at workplaces. Particularly for Deaf employees, TTY or an amplified sound system were recommended. In terms of information over the Internet, the Web Content Accessibility Guideline (WCAG) ([Kirkpatrick et al., 2018](#)) has recommended pre-recording content in a designated signed language so that website visitors who are Deaf can access the information.

Health information access for people with language barriers

[The Centers for Disease Control and Prevention \(CDC\)'s guidelines \(2009\)](#) and [Freimuth and Quinn's recommendations \(2004\)](#) are relevant to health information access for people with a language barrier. The [CDC \(2009\)](#) launched Simply Put, a set of guidelines to counsel health professionals across the USA in developing health information materials for diverse groups of patients. As nearly one-third of US adults have trouble reading and acting upon health-related information ([CDC, 2009](#)), a comprehensive list of health communication-planning guidelines regarding content, textual appearance, visuals, layout and design, cultural appropriateness, translations into languages spoken in the USA, and readability testing are specified in the resource. Likewise, [Freimuth and Quinn \(2004\)](#) studied health disparity in the USA context and proposed four health communication strategies to eliminate such disparities: 1) entertainment education, 2) media advocacy, 3) interactive health communication, and 4) interpersonal communication. This study indicated that only brief information broadcasted between TV programs could affect the audience and its friends and family when the information is being shared. Therefore, broadcast media is considered an excellent medium for alleviating health information disparity. Interactive health communication can increase health knowledge of some diseases, such as breast cancer and HIV/AIDS, among women with low literacy. Lastly, interpersonal communication between a doctor and a patient or from social support to the patient can reduce health disparity.

[Figure 11](#) presents the related works' recommendations in gray boxes with arrows to indicate which of the information accessibility requirements they elaborated. One requirement under the Suitability Group was elaborated;

an intervention to provide Deaf people with information accessibility should be free-of-charge, especially in emergency cases ([WASLI & WFD, 2015](#)). However, none of the related works' recommendations elaborated on the requirements about the quality and occupancy of the information source, channel, medium, and device, neither on the costs for providing the information.

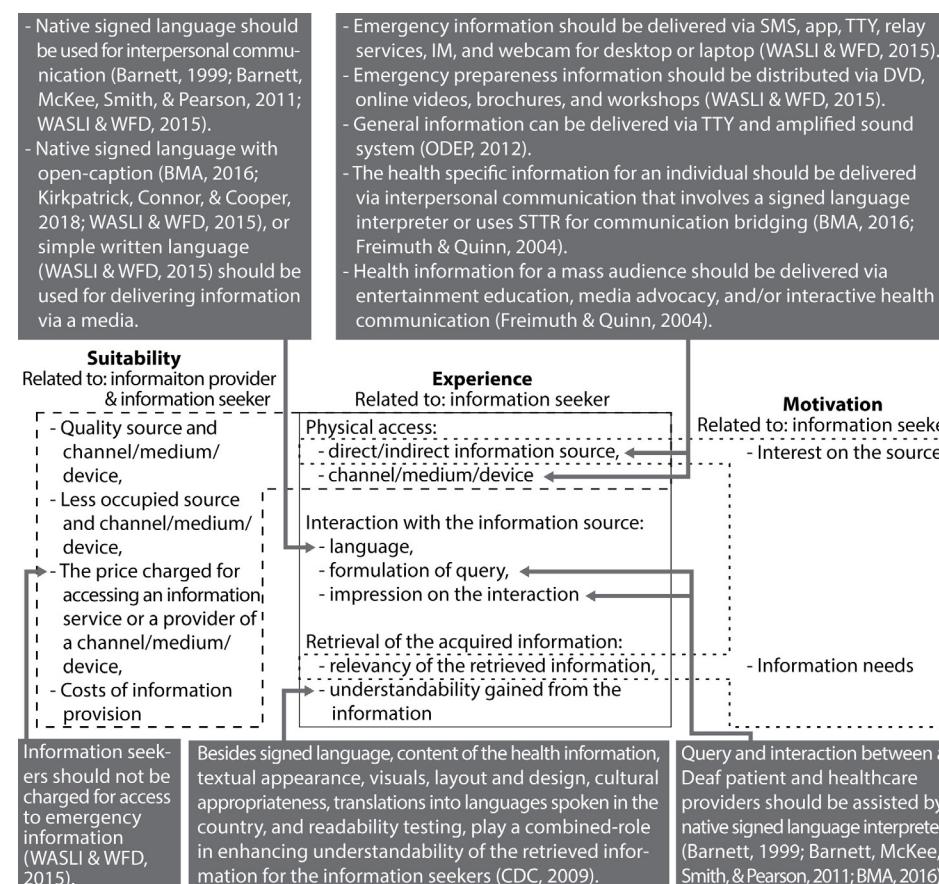


Figure 11. Elaborations on information accessibility requirements from desk research.

Most requirements under the Experience Group were elaborated, except the requirements regarding the relevancy of the retrieved information. The related works recommended channels, media, and devices that Deaf people could have physical access to different types of information, but did not indicate information sources responsible for such information distribution. Particularly about accessible health information for Deaf people, interpersonal communication was recommended as a channel to

deliver specific health information to Deaf individuals ([BMA, 2016; Freimuth & Quinn, 2004](#)); the entertainment education, TV programs, and interactive health communication were recommended as the channels to provide health information to a mass audience ([Freimuth & Quinn, 2004](#)). However, these recommendations had their limitation for not including the Deaf people's possible health-seeking behaviors through ICT channels. Nonetheless, the recommendations about the language used for the interaction between an information source and a Deaf person served multiple health-information seeking behaviors. Signed language was recommended for the interpersonal communication between an information source and a Deaf person ([Barnett, 1999; Barnett et al., 2011; WASLI & WFD, 2015](#)); signed language with open-caption ([BMA, 2016; Kirkpatrick et al., 2018; WASLI & WFD, 2015](#)), or else a simple written language should be used when interaction would be made via a medium ([WASLI & WFD, 2015](#)). A signed language interpreter ([Barnett, 1999; Barnett, et al., 2011](#)) or STTR ([BMA, 2016](#)) should be involved to assist the communication between an information source and a Deaf person. Understandability of the retrieved information was the only requirement elaborated, but such elaboration was formulated based on the related works regarding people with language barriers, not Deaf people. None of the requirements under the Motivation Group received any elaboration from these related works.

[Figure 11](#) illustrates that some knowledge was retrieved from the related works, and much more knowledge was still needed for designing an intervention suitable to the Western Cape context. Therefore, the empirical research had to be conducted to elicit such knowledge. To guide this empirical research, a set of SRQs was formulated with details provided in the next subsection.

2. Sub-research questions

Seven SRQs were formulated to elicit knowledge for designing an intervention for the Western Cape context. [Figure 12](#) presents these SRQs in connection with the conceptual framework of information accessibility. Each line pointing to an SRQ is numbered and explained.

As stated in [Chapter 1](#), the active involvement of Deaf community and relevant stakeholders was expected to yield an intervention suitable to the context. Line 1 indicates the need to develop guidelines for actively involving Deaf community (information seekers) and relevant stakeholders (information providers) during the empirical research. This SRQ is:

SRQ 1: What guidelines can help a designer and a researcher actively involve information seekers who are Deaf and information providers in a design and development process for an intervention?

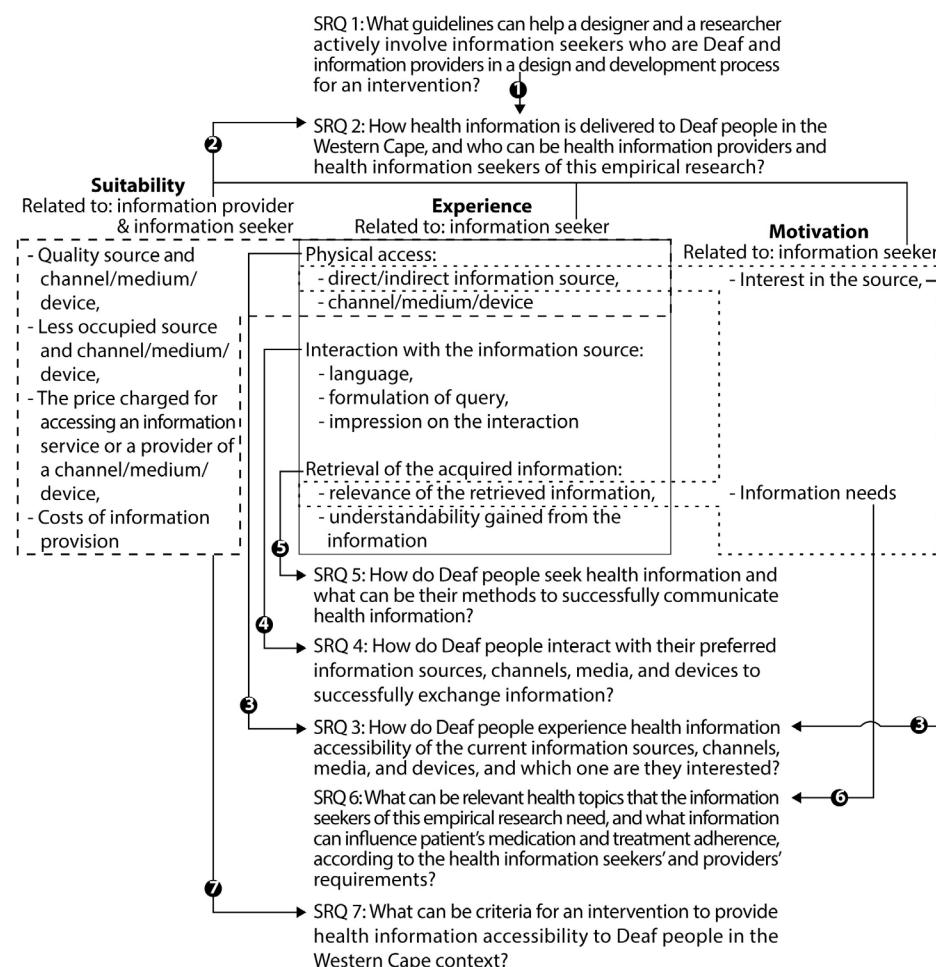


Figure 12. Overview of the SRQs.

Lines 2 requires an understanding of how health information delivered to Deaf people in the Western Cape and information providers and information seekers identification in this studied context. The SRQ in connection with Lines 2 is:

SRQ 2: How health information is delivered to Deaf people in the Western Cape, and who can be health information providers and health information seekers of this empirical research?

Lines 3 denote the requirements for health information sources, channels, media, and devices from which Deaf people in the Western Cape access health information. The SRQ in connection with Lines 3 is:

SRQ 3: How do Deaf people experience health information accessibility of the current information sources, channels, media, and devices, and which one are they interested?

Line 4 highlights the need to understand Deaf people's requirements regarding language, formulation of query related to health, and impressions on the interaction with the information sources, channels, media, and devices. SRQ 4 is:

SRQ 4: How do Deaf people interact with their preferred information sources, channels, media, and devices to successfully exchange information?

Line 5 indicates that the health information-seeking behaviors among Deaf people in the researched context and Deaf people's preferred methods for communicating health information needed to be identified. Thus, Line 5 leads to SRQ 5:

SRQ 5: How do Deaf people seek health information and what can be their methods to successfully communicate health information?

Line 6 concerns information needs among Deaf people. Providing content that matches an information seeker's needs positively affects their decision on the accessibility of the information source. This line led to SRQ 6:

SRQ 6: What can be relevant health topics that the information seekers of this empirical research need, and what information can influence patient's medication and treatment adherence, according to the health information seekers' and providers' requirements?

Line 7 marks the need for identifying the price charged for accessing an information service; the quality and the availability of a health information source, channel, and medium, device selected for the intervention of this research; and the costs of providing health information. This line led to SRQ 7:

SRQ 7: What can be criteria for an intervention to provide health information accessibility to Deaf people in the Western Cape context?

As this section explicates the formulation of all SRQs, the next section provides the approach applied during the empirical research.

3. The approach for empirical research

A community-based approach has been considered suitable for this empirical research since collectivism influences Deaf community members' decisions in multiple aspects (refer to [Chapter 1, Subsection 1.2](#)). As such, community-based research approaches were studied ([Subsection 3.1](#)) to identify benefits and challenges and which of these approaches had been applied to research with a Deaf community and relevant stakeholders. Based on this identification, community-based co-design (CBCD) has been outstanding for closely involving a Deaf community in designing communication bridging tools its members planned to adopt in daily lives ([Subsection 3.2](#)).

3.1 The study of community-based approaches

Deaf + Community-based research was the keyword for this literature search. Only one research group was found applying a community-based approach to co-design communication bridging tools with a Deaf community ([Blake, Tucker, Glaser, & Freudenthal, 2011](#)); the rest of the search results showed that researchers practiced a community-based approach with a hearing community ([Bluementhal, 2011](#); [Elovaara, Igira, & Mörberg, 2006](#); [Foster et al., 2010](#); [Groeneveld, Boess, & Freudenthal, 2013](#); [Hussain, Sanders, & Steinert, 2012](#); [Liu et al., 2011](#); [Puri, Byrne, Nhampossa, & Quraishi, 2004](#); [Tacchi & Watkins, 2007](#); [Wieland et al., 2012](#); [Winschiers & Fendler, 2007](#); [Winschiers-Theophilus, Bidwell, & Blake, 2012](#); [Winschiers-Theophilus, Chivuno-Kuria, Kapuire, Bidwell, & Blake, 2010](#)). These researchers who applied a community-based approach involved the community in their study to varying extents—some only involved the community during the exploration step, while others involved them from the start through the end of the creation of an intervention. However, they share two universal core principles: 1) ethical responses to the communities and 2) community empowerment. The benefits and challenges of applying a community-based approach could be categorized into three groups below: benefits for researchers, the participating community, and research progress.

Benefits for the researchers

Many studies were conducted across cultures, meaning the researchers were not members of the studied community. Thus, the cultural values, norms, socio-economics, politics, and knowledge system of the participating community might not be readily apparent to outsiders ([Hussain et al., 2012](#); [Liu et al., 2011](#); [Puri et al., 2004](#); [Tacchi & Watkins, 2007](#); [Winschiers & Fendler, 2007](#)). By using a community-based approach, the hidden values ([Blake et al., 2011](#); [Winschiers-Theophilus et al., 2010](#)) and beliefs and attitudes of the community members ([Foster et al., 2010](#)) could be revealed through researchers' multiple interactions with the community members.

Benefits for the participating community

The participating communities were empowered by training or workshops brought in by researchers who applied a community-based approach. The empowerments could be in the form of health improvement programs offered to studied communities in South Africa ([Puri et al., 2004](#)), China ([Liu et al., 2011](#)) and the USA ([Wieland et al., 2012](#)) or ICT literacy training that Bridging Application and Network Gaps (BANG) has been providing for Deaf Community of Cape Town (DCCT) ([Blake, 2010](#); [Blake et al., 2011](#)). These programs brought some positive changes within the community, for example, noticeable health improvement or confidence in selecting technology to solve communication problems.

Benefits for the research progress

As community members noticed that researchers listened to their problems and possible solutions, they felt being part of the team in steering the research trajectory. They knew that the project was meant for them ([Blake et al., 2011](#); [Groeneveld et al., 2013](#); [Puri et al., 2004](#)). Community-based approaches enabled the participating community to give their opinions and ideas freely toward solutions. Their requirements were made clear to all stakeholders, such as health professionals, governmental departments, and researchers. Explicit requirements from users helped researchers to quickly define the focus of the research ([Blake et al., 2011](#); [Hussain et al., 2012](#); [Groeneveld et al., 2013](#); [Puri et al., 2004](#)). The researchers' bias was also reduced when the community jointly decided on the design and development of the intervention ([Winschiers and Fendler, 2007](#); [Winschiers-Theophilus et al., 2012](#)).

Although there are multiple benefits, these community-based approaches were also found with several challenges as described below:

Challenge of finding availability of all participants

[Hussain et al. \(2012\)](#) and [Elovaara et al. \(2006\)](#) faced a challenge in organizing a research session that all participants could attend simultaneously. This situation frequently occurred when stakeholders were in the healthcare professions, in which there are shortages of human resources. These researchers stated that the scarce availability of some participants required a more flexible setup of the participatory process.

Challenge of financial constraints among the participants

[Hussain et al. \(2012\)](#) reflected that researchers had to take the participants' financial status into account. When requiring the participants who had a low income to commuting to a research venue, the researchers needed to plan for efficient and ethical compensation to retain the participants in the research session.

Challenge of planning a research session

Researchers found traditional participatory design requiring all participants—users, stakeholders, and designers/researchers—to gather at the same place and time impractical for researching in low-income countries ([Puri et al., 2004](#)). In dealing with this challenge, [Hussain et al. \(2012\)](#) suggested conducting participatory design with flexibility and in fragments. For example, a designer participated in a design session with the prospective users separately from the session with other stakeholders. Later, the users or the stakeholders could take turns leading subsequent participatory sessions. It is also possible to train the users and the stakeholders to work toward a co-creation.

[Winschiers-Theophilus et al. \(2010\)](#) and [Liu et al. \(2011\)](#) stated that researchers should recognize the shifting of roles and the complexity of the research context. During a research session, the participating community automatically takes the role of the local designer, while the researcher shifts to the role of a facilitator and observes the community's values, socio-cultural habits, and ethnic diversity.

Challenge regarding political interference in the decision making

Politics within the community may influence the outcome of decision making at any stage of the research. As such, [Puri et al. \(2004\)](#) suggested organizing multi-sectoral and multi-level meetings to achieve acceptable decision made by all stakeholders. [Blumenthal \(2011\)](#) added that community leaders or gatekeepers should be included in such meetings. In some cases, political interference appeared in the form of regulations. [Groeneveld et al. \(2013\)](#) recommended that the researchers study the regulations related to the determined intervention to avoid any drawbacks from its implementation.

Challenge of incorporating dialogues into a suitable solution

In the African context, decisions that would affect the community were made collectively during a community meeting through dialogue. With this traditional structure, the community members had dialogues to express their opinions or concerns; all contributions were respected without being judged. Thereafter, all members gave their decisions ([Winschiers-Theophilus et al., 2012](#)). A similar process was held to create new concepts or solutions jointly ([Winschiers-Theophilus et al., 2012](#)), then a decision was made to embark on any intervention that would affect the community ([Puri et al., 2004](#)). Researchers had to carefully listen, interpret, and manage the community's dialogues toward a solution.

Challenge of maintaining the research relationship

Maintaining a research relationship with a participating community is

not easy. [Liu et al. \(2011\)](#) stated that having a member who understands the language and culture of the participating community benefitted the research team. That member was responsible for establishing and maintaining trust with the community leaders.

Challenge of time management

Especially in the African context in which dialogue is essential, [Winschiers-Theophilus et al. \(2012\)](#) noted that the community-based approaches could be time-consuming because the process must be carried on until the community reached its consensus. Researchers had to acknowledge a possible delay in the progress of the community-based research and needed to have some backup plans to manage the project time span wisely.

Although these community-based approaches contained several challenges, the author perceived these approaches useful for this research context because of the benefits as stated. Thus, the CBCD approach was applied in this research. The next subsection presents the development of the CBCD approach to derive communication bridging tools together with a Deaf community.

3.2 Community-based Co-design

BANG, a research team in Western Cape, South Africa, has been refining its research approaches to achieve both positive scientific and societal outcomes. [Blake et al. \(2011\)](#) specified that the most suitable approach should guide the research team to identify design requirements effectively and bring about a communication tool that the participating Deaf community wants to adopt for their daily use. Before CBCD, BANG applied two other research approaches that yielded scientific knowledge but not societal outcomes. This was the starting point from which CBCD evolved based on the first two research approaches. BANG has had a long-term research relationship with DCCT since 2001. Three research approaches developed based on DCCT's feedback on the communication tools derived from research and BANG's reflections. The three phases (see [Figure 13](#)) can be described as follows:

Phase 1: Building a technology base

From 2001 to 2003, BANG consisted of the initial members from the Department of Computer Science, University of the Western Cape (UWC) and the Department of Computer Science, University of Cape Town (UCT). This research team applied an incremental software design approach in combination with user-centered design to build a technology base. Software incremental design ([Larman & Basili, 2003](#)) is an approach in which software developers break down software development into steps comprising user-

requirement analysis, function design, software coding, and system testing. The incremental cycle rapidly repeats until reaching the point where no software error is found. User-centered design ([Abras, Maloney-Krichmar, & Preece, 2004](#)) is an approach in which a professional team focuses on the needs of the potential users in order to create software or products for them. This combined research approach allowed BANG to take the lead in developing assistive communication tools for Deaf users. Communication tools were built based on text-to-speech conversion technologies to bridge deaf-and-hearing communications. An intermediary and a representative of DCCT took the roles of design testers in a laboratory setting.

The communication tools derived during Phase 1 were not moved to the next phase because the feedback from the design testers stated that there were multiple issues that would prevent DCCT Deaf members from integrating these tools into their daily lives. First, the tools could not always convert text-to-speech correctly; second, the telecommunications required for the tools were pricey at that time; and third, the majority of DCCT members were uncomfortable with texting with hearing people because of their low functional literacy. In addition, BANG realized that only researchers had been involved in the design processes, another possible issue that hindered the community's uptake of the communication tools. As a result, it was determined that the Deaf community needed more involvement in the design and development process. These reflections led to the second phase of the research collaboration in which Deaf people were empowered with skills training and technology exposure ([Blake et al., 2011](#)).

Phase 2: Community-based action research

During 2004 and 2007, action research was fused into a combined research approach in Phase 2. Action research was applied to let both Deaf people and researchers learn from each other about possible technologies for bridging communications between the Deaf and the hearing. ICT training and computer literacy courses were provided to empower the DCCT members. These Deaf people had chances to explore technologies and became more confident in expressing their requirements for communication tools to be designed and developed. Although there were increasing inputs from Deaf people, the research team still took the lead in designing. This newly combined research approach proceeded cyclically through four stages: *plan action, implement action, evaluation action, and reflection*.

During Plan Action Stage, Deaf people and researchers discussed and selected the communication problems and solution ideas. The research team took the lead in Implement Action Stage to code the agreed communication solution into a testable artifact for Evaluation Action Stage. At Reflection Stage, an intermediary, a representative of DCCT, including BANG, reflected

on the research approach and outputs. This cyclical research approach allowed for an iterative process. Feedback from the intermediary and the representative of DCCT determined if another round of the research cycle was needed.

Through exploring off-the-shelf communication technologies (such as MSN, Skype, and AIM), DCCT members could better define and express their communication needs. Due to the strong bonds within their close-knit community, DCCT members would rather adopt the tools that facilitated Deaf-to-Deaf communication than those that bridged Deaf-to-hearing communication. They preferred to stay connected with their Deaf peers via video calling instead of using text-based communication. As a result, they requested BANG to develop computer-based communication tools with video-call features, especially as they had low trust in the off-the-shelf options. Inputs from the Deaf members led to multiple transitions in the development of the communication tools of Phase 2.

The research collaboration on the Deaf-user side extended, for a short period, to Sign Language Education and Development (SLED)—another organization that promotes education in SASL. SLED shared their experience using Camfrog, an off-the-shelf communication tool, for their business purposes with DCCT. The tool was used for video-calling to coordinate two SLED offices located in different provinces of South Africa. After exploring the use of Camfrog, DCCT management adopted its use for social-activity promotions and networking with other local and international Deaf communities, who had already been using this video-calling tool. Deaf people still favored Camfrog, although its video quality was not as clear as what the communication tools derived from the research could provide. BANG analyzed this incident and understood that social considerations among Deaf people influenced their adoption of technologies more than the attributes of ICT itself. Thus, communication tools would be adopted by Deaf people if they meet the people's social-related needs ([Blake et al., 2011](#)).

Reflecting on their research approach applied during Phase 2, BANG still had not achieved the desired societal outcomes. The Deaf community still did not adopt these communication tools. BANG gradually learned the necessity of assertively engaging DCCT in research and saw the need to improve its research approach further.

Phase 3: community-based co-design

In 2008, Delft University of Technology (TU Delft) joined BANG; then, the team evolved CBCD based on the research approaches of Phases 1 and 2. There are some similarities and multiple differences between these

research approaches. Four stages of CBCD were divided by their main function. The first stage prompted a researcher and the participating Deaf community to explore communication problems, the researched context, and possible solutions together. In the second stage, the Deaf community and the researcher decided on problem-solving strategies, including the research trajectory. During the third stage, the Deaf community contributed details for the solution, and the researcher brought about a testable artifact. In the last stage, both the researcher and the community tested the usability of the artifacts. The differences between CBCD and the previous two approaches are that 1) CBCD's communication tool development started from the Deaf community's needs and their social context, not solely from the reflections of the design testers; 2) the Deaf community was engaged throughout the CBCD stages; 3) BANG transitioned from sole designer to design-facilitator and co-designer roles; and 4) the Deaf community members took on the roles of co-designers, instead of passive testers.

DCCT's active participation led to multiple positive changes to the research outcomes. While feature phones were becoming affordable to Deaf people, DCCT suggested BANG migrating the research focus from computer-based to mobile-phone based tools. Once again, it revived Deaf-and-hearing communication bridging projects. Deaf people anticipated using the intervention derived from the research ([Blake et al., 2011](#)). According to the reactions from the Deaf participants, the CBCD approach could potentially generate the Deaf community's uptake on the intervention.

Phase 1: building a technology base

Period: 2001 - 2003

Approach: combination of software engineering approach and user-centered design

BANG members: UWC and UCT

Deaf community: DCCT participated later

Roles of the participants: An intermediary of DCCT and a Deaf representative tested the tools.

Roles of the researchers: BANG selected technologies and designed the communication tools.

Communication tools: Telgo323, TelgoSIP, and Softbridge version 1 and 2

How the tools were tested: in a laboratory setting

Phase 2: community action research

Period: 2004 - 2007

Approach: combination of software engineering approach, user-centered design, and action research

BANG members: UWC and UCT

Deaf community: DCCT and SLED at later stage

Roles of the participants: The Deaf participants explored, selected their preferred technologies, then tested the tools.

Roles of the researchers: BANG empowered DCCT members with ICT and computer literacy training. They carried out the design and development of communication tools based on the participants' selected technologies.

Communication tools: SIMBA prototypes, Deaf Chat, Deaf Video Chat version 1

How the tools were tested: during real usages.

Phase 3: Community-based co-design

Period: as of 2008

Approach: Community-based co-design

BANG members: UWC, UCT, and TU Delft

Deaf community: DCCT and more

Roles of the participants: Deaf communities reveal their problems, opinions, attitudes, and values to researchers. They lead research with their ideas for solutions.

They take the role of research leaders and co-designers.

Roles of the researchers: BANG interacts with the participating Deaf community to gain insights. Researchers shift from the role of designer to facilitator.

Communication tools: Mobile Gestures, Deaf Video Chat version 2, SignSupport for a health consultation, and SignSupport for a medication dispensing process

How the tools were tested: Prototype or mock-up testing in simulated environments.

Figure 13. Overview of the development on the CBCD approach.

BANG's reflections show their trait in line with [Schön's \(1983\)](#) theory of reflective practitioners since they have continuously reflected on their research approaches and periodically changed their practices to be more effective. This reflective-practitioner trait has influenced the practice of the CBCD approach that allows researchers to reflect on their research methods and results periodically and formulate research methods to tackle the situation in the research context appropriately. As the Deaf community was closely involved in all four research stages, the CBCD approach could cultivate the participating Deaf-community members' readiness to adopt the tools that come from their contributions.

Due to the research and societal benefits of the community-based approach, the CBCD approach was applied in this empirical research. Such approach

could potentially yield the author—a researcher—and a participating Deaf community, including relevant stakeholders—participants—an intervention that would meet their requirements and suit the Western Cape context with societal complexity. The CBCD approach was also applied with caution upon the stated challenges. Consequently, a set of the initial guidelines for actively involving the participants in this CBCD approach was developed for the author to follow and reflect throughout the empirical research.

3.3 Initial guidelines

These initial guidelines were developed based on the universal core principles, the challenges of the community-based approaches (refer to [this chapter, Subsection 3.1](#)), and considerations about Deaf culture (refer to [Chapter 1, Subsections 1.2 and 2.3](#)). This was to define the guidelines for researchers to follow when collaborating with a Deaf community and relevant stakeholders to derive a determined intervention. These initial guidelines were clustered into nine topics. Under each topic, the general guideline for designers and researchers is first described, followed by how the author's adherence to the guideline during the empirical research.

Research ethics and ethics clearances

Guideline 1: A researcher should comply with the research regulations of each studied context before conducting empirical research with any human participants.

In South Africa, researchers are required to apply for an ethics clearance by one's institution of affiliation ([Human Sciences Research Council, 2018](#)). This clearance is to ensure the studied subjects and society that the subjects are safeguarded from any risks during the research sessions. The ethics clearance states the research rationale, the research objectives, the methodology to be used, the studied subjects' rights of participation, data analysis, and the dissemination of the research results. In addition, literature regarding research ethics related to the study field should be studied and brought to practice. The knowledge of research ethics can notably support researchers' social and moral values to treat their participants with respect and fairness.

This research has been granted ethics clearances by the Research Committee of the University of the Western Cape (registration numbers 14/9/46 and 15/7/231), including the Human Research Ethics Committee of Delft University of Technology (no registration number). These ethics clearances and the invitations were sent to the Deaf communities and health professionals. During the formulation of this empirical research, there was limited literature regarding the ethics related to the involvement of Deaf community in research. As such, literature about the research ethics for ICT

development with vulnerable communities and in developing countries, like the work of [Traxler \(2012\)](#) and [Dearden \(2013\)](#), was studied.

Pre-discussion and invitation sent to Deaf communities

Guideline 2: A researcher must discuss the research project with the leaders of the prospective Deaf community to gain approval for the project before reaching out to the community members.

This pre-discussion could be in writing format or a face-to-face meeting, depending on the community leader's preference. If the prospective community was a formal organization, the research inquiry should be brought to a discussion of their committee. Otherwise, if the community was an informal one, the researcher should ask permission from a contact person to attend its social gathering and introduce research to Deaf members. Once the committee of a formal Deaf community or the members of the informal Deaf community agreed to participate in the research, research activity could then begin.

The author followed this guideline when invited Deaf communities in the Western Cape to participate in the empirical research.

General criteria of the Deaf participants

Guideline 3: The main inclusion criteria for empirical research with the Deaf participants should be clearly defined in order to preliminarily approach the appropriate group of the participants.

The inclusion criteria of the Deaf participants for this study were as follows:

- The participants mainly use SASL for communication;
- The participants can have any degree of hearing loss;
- The participants are at least 18 years old or older because this research focuses on Deaf adults.

The author followed this guideline. Additional criteria of the participants in each research stage are delineated per research activity in [Chapters 4 to 7](#).

The languages used in this research

Guideline 4: A researcher must use SASL in the dialect that Deaf people prefer in order to collect data from them effectively. Language preference for research communication of other stakeholders should also be confirmed.

This guideline was applied to all research activities during the empirical research. As such, all communications with Deaf participants during the research sessions were in SASL, assisted by SASLIs. English was the language used with hearing stakeholders. All research-related documents

were written in simple English when submitted to Deaf community leaders. Given that many Deaf participants are not confident in reading and writing (refer to [Chapter 1, Subsection 2.4](#)), the informed consents were retrieved by recording the participants' hand raised in front of a video camera. With this consent retrieval technique, the Deaf participants were assured to be fully informed of the details of the research session, as stated in the ethics clearances. For hearing participants, informed consent was collected by either a signature on the consent forms or voice recording.

Criteria of SASLIs in this research

Guideline 5: For the most effective data retrieval, a researcher should ask the Deaf community about its preferred SASLIs. The selected SASLIs should also have a good command of the language that the researcher uses. The researcher must also respect the code of conduct of the SASLIs, as specified by [DeafSA \(2011\)](#).

Due to dialects in SASL, different Deaf communities prefer specific SASLIs to interpret for their members (see [Chapter 1, Subsections 2.2](#) and [2.3](#)). The SASLIs should be hired according to the recommendations of the Deaf communities. The SASLIs should be competent in English and know Deaf cultures. The SASLIs would, therefore, function to establish the understanding amongst the hearing researcher, the Deaf participants, and other hearing participants.

The author adhered to the code of conduct. The hired SASLIs were not required to interpret longer than 30 minutes continuously to maintain the quality of their interpretation. If there were technical terms used in research, materials for that specific research session were sent to the hired SASLI for preparation before the research day.

Planning for flexible research sessions

Guideline 6: A researcher should design a research session with flexibility to accommodate the arrivals and availability of the participants.

Flexible planning is necessary when multiple stakeholders will participate in research sessions. A researcher must be aware of the means of transportation that the participants would take, including any time limits the participants may have. Research methods and duration of any session involving health professionals, who usually have tight schedules, should be adjusted to fit the participants' availability. Flexibility should be allowed for a research session that would involve all key stakeholders at the same time.

This guideline was applied to all research activities during the empirical research. For example, many Deaf participants in this study took public

transportation to the research venue; these modes of public transportation in South Africa were often delayed. Therefore, some buffer time was added to the beginning of each research session, and a backup plan was included as part of the planning.

Adoption of Deaf culture into research practice

Guideline 7: A researcher should adopt Deaf culture into practice when interacting with Deaf people. This soft skill shall benefit the researcher in both research and social relationships with the Deaf community.

Given that Deaf people's culture links to the way they communicate (refer to [Chapter 1, Subsection 1.2](#)), specific characteristics of Deaf culture needs to be considered to organize Deaf-friendly research activities. As face-to-face meetings are important among Deaf people, research sessions should be organized accordingly. Deaf participants should be gathered at a designated venue to participate in a research session so that they could meet their Deaf peers and the researchers in person. Unless there are unforeseeable circumstances, interviews with Deaf people should be conducted via video calling.

During the research session, the research facilitator should be standing next to the SASLI and in a direction in which the Deaf participants can clearly see the interpretation ([DeafSA, 2011](#)). Since transparency is considered polite among Deaf people, all conversations during the research sessions should be interpreted to all participants. "Deaf" is the appropriate term for addressing all Deaf participants; this shows respect to their pride in Deafness. Also, name signs can be addressed. As part of the directness, the research facilitator should begin each research session by introducing the research brief point-by-point. Eye-contact with the Deaf participants should be maintained while speaking, not with the SASLI.

Since acknowledgment of physical appearance, intruding questions, and touching are common in the Deaf culture, the research facilitator should not take such interaction styles personally. In addition, Deaf people usually spend extended time for leave taking. Thus, another buffer time should be added for the end of the research session.

This guideline was applied to all research activities. For example, the author and Deaf participants met face-to-face for all research sessions. Each session was organized with two buffer times to accommodate the participants' greetings at the start and the end of the research session. The author stood next to the SASLI while speaking to the Deaf participants. Everything that the author or a research facilitator said had to be interpreted for transparency to all participants. Deaf participant or name sign was the term addressed to each Deaf participant. The author and other research facilitators introduced

each research session point-by-point while maintaining eye contact with the participants. The participants' acknowledgment of the author's or the research facilitator's appearance, intruding questions, and touches to gain attention were taken objectively.

Importance of learning SASL for researchers

Guideline 8: If possible, a Deaf person who can communicate in the language that the research team uses should be hired as part of the team. If such opportunity is not available, the researcher should learn SASL to maintain research and social relationships with the Deaf community.

The literature in [this chapter, Section 3.1](#) suggests that a research team should maintain a research relationship with the participating community by hiring a person who speaks the same language as the community. Furthermore, it is useful for those who will conduct research with a Deaf community to learn their signed language. A research facilitator who is equipped with SASL skills can make Deaf participants feel comfortable when arriving at the research venue. Besides the research relationships, friendships can also be cultivated between the research facilitator and Deaf individuals.

The author and two research fellows completed two courses of SASL. It empowered the research team in accommodating the Deaf participants with simple conversations during the research sessions.

Time management for the research timespan

Guideline 9: A researcher should be aware of possible research-related delays. Keeping track of the research timeframe and continuous discussions with the stakeholders involved in research are essential.

As discussed in [this chapter, Section 3.1](#), time management can be challenging when applying the CBCD approach. Thus, the author tried to prevent any delay during the empirical research by discussing the project timeline with the Deaf community, who were taking the leading role. Similar to the organization of a research session, some buffer period was added to the project planning.

These nine guidelines for conducting empirical research with Deaf communities were to be verified and reformulated after completing all CBCD's stages. How successful each guideline availed the author in organizing research sessions with the Deaf community and stakeholders was the criteria for the verification.

In conclusion, this chapter states the MRQ formulated to design an

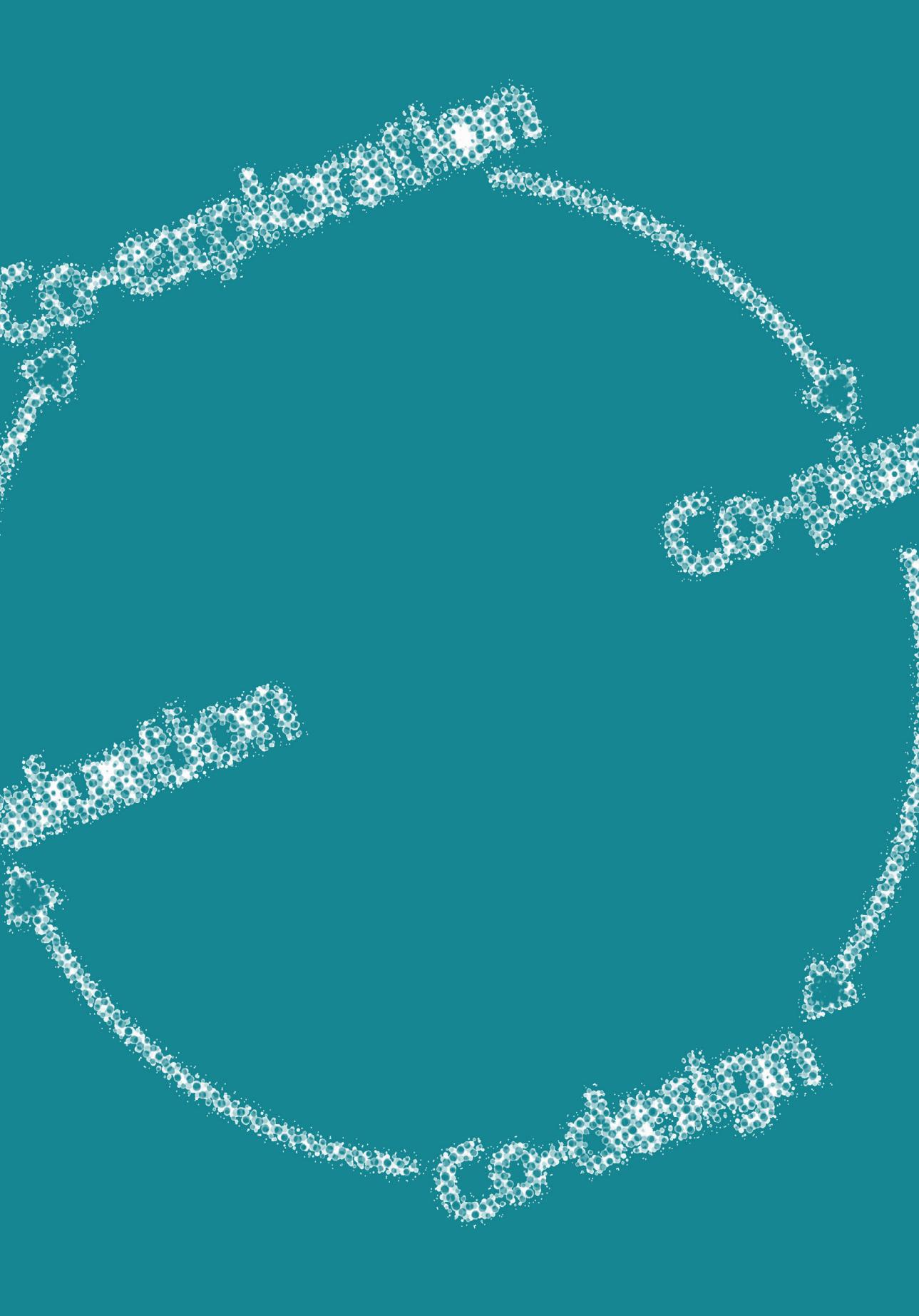
intervention that would provide health information accessibility to Deaf people and suit the Western Cape context with societal complexity. Desk research retrieved some knowledge contributed to a conceptual framework of information accessibility and recommendations on interventions to provide different types of information to Deaf people. This knowledge was considered applicable to designing an intervention that would provide health information accessibility to Deaf people and give the author opportunities to elicit additional knowledge for the design. CBCD, as an RTD approach, was perceived suitable for the active involvement of the participant during the empirical research. CBCD's suitability was gauged from the benefits that it could yield to researchers and the participants. The mentioned nine initial guidelines were to be verified during the author's empirical research whether they could yield positive results to researchers who would need to deal with challenges that the CBCD approach also incurred.

As this chapter has described the preparation for the empirical research, the next chapter presents the research design for the empirical research.

Chapter

3

Application of community-based co-design approach



The societal complexity has been identified in [Chapter 1](#). Research questions and their preliminary answers, the need to elicit knowledge for designing an intervention through the application of community-based co-design (CBCD)—a research-through-design (RTD) approach—and guidelines for active involvement of a Deaf community and relevant stakeholders have been stated in [Chapter 2](#). This chapter accordingly explains how the CBCD approach was applied within this empirical research. This explanation includes a decomposition of design tasks into six building blocks ([Section 1](#)) and the four stages of the applied CBCD approach ([Section 2](#)).

1. Building blocks

CBCD is a pragmatic approach that lets a Deaf community and researchers tackle a societal complexity by researching through a design process for an intervention ([Chapter 2, Subsection 3.2](#)). Participants and researchers attended several research and design sessions to carry out design tasks. The design tasks of this applied CBCD were decomposed into six building blocks (see [Table 1](#)). One building block corresponded to the application of the CBCD approach; the remaining building blocks were related to the sub-research questions (SRQs) (refer to [Figure 12](#)). Building Block 1 was to select a Deaf community to take the leading role; this corresponded to the continuous involvement of a Deaf community in the CBCD approach.

Building Block 2 defined relevant health topics of Deaf people's interest (related to SRQ 6). Building Block 3 chose Deaf users of an intervention that would be derived from this CBCD approach (SRQ 2). Building Block 4 determined the health-information providers who are also users of this intervention (also SRQs 2 and 3). Building Block 5 described the methods of communicating health information to Deaf people (SRQs 4 and 5). Lastly, Building Block 6 identified health information sources, channels, media, and devices to provide health information accessibility to Deaf people (also SRQs 3 and 7).

Findings for each building block should be derived at the first stage of this applied CBCD approach. The findings that matched the criteria stated in [Table 1](#) were considered as alternatives for each building block. They were later used to formulate a case study for this CBCD approach. The criteria of Building Block 1 were developed based on what a Deaf community had when attended BANG's CBCD approach. The remaining criteria were listed based on what each building block should contribute to the design of an intervention.

Table 1. Criteria for each building block in order to formulate a case study

Building blocks	The criteria for selecting an alternative for each building blocks
1. Leading Deaf community	<ul style="list-style-type: none"> • The community is willing to develop an intervention to provide accurate and accessible health information for Deaf people. • The community is fluent in SASL and acquainted with different SASL dialects. • The community leader reads and writes English the language used in this research. • The community consists of a large number of Deaf members. • The community has the skills to produce or distribute information to Deaf people.
2. Health topic of Deaf people's interest	<ul style="list-style-type: none"> • The health topic matches the interest of both Deaf members and the community's management to get their buy-in. • The topic is applicable to communicate health information about other diseases for Deaf people.
3. Intervention users who are Deaf	<ul style="list-style-type: none"> • The eligible Deaf users have an interest in the selected health topic. • They are familiar with significant others who have the disease selected as the health topic. • They are interested in designing an intervention.
4. Intervention users who are health-information providers	<ul style="list-style-type: none"> • The eligible users are involved in the promotion of health information or the treatment for the selected disease. • They are the information source that Deaf people preferred.
5. Method(s) of communicating accessible health information to Deaf people	<ul style="list-style-type: none"> • The methods are preferred by the Deaf people. • The methods match with information production or distribution skills of the leading Deaf community.
6. Sources, channels/media/devices to provide health information accessibility to Deaf people	<ul style="list-style-type: none"> • The media match with the interest of both Deaf members and the community leader. • Several Deaf people in Cape Town and the Western Cape should already have access to these media so that Deaf people can contribute ideas to optimize their usage.

One case was chosen over multiple case studies to allow the author, the leading Deaf community, and relevant stakeholders to spend sufficient time designing the case study's intervention. How and when these building blocks were operated during the CBCD approach are described in the next section.

2. The applied CBCD approach

The author was affiliated with Bridging Application and Network Gaps (BANG) because this research team developed the CBCD approach and practiced it in the Western Cape. This applied CBCD approach comprises four stages. Co-exploration, Co-planning, Co-design, and Co-evaluation were titled according to their function that BANG stated (refer to [Chapter 2, Subsection 3.2, Phase 3](#)) and envisaged to progress in one direction cyclical manner (see [Figure 14](#)). In addition to what BANG practiced, relevant stakeholders who have been engaged in health information delivery to Deaf people must also be actively involved in these stages.

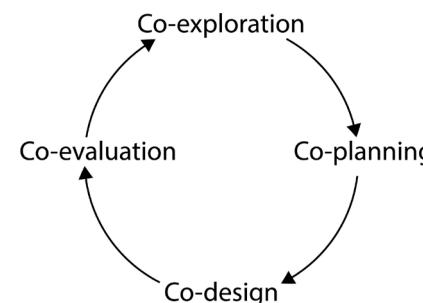


Figure 14. Four stages envisaged for this applied CBCD approach.

This chapter provides an overview of the four stages of this applied CBCD. Each stage is described with its objective, roles of the author, research fellows, and the participants, the expected results, and the relatedness of each stage.

Co-exploration ([Chapter 4](#)) was the first CBCD stage. The objective of this stage was to identify alternatives for the six building blocks. The author and a research fellow performed a combined researcher-facilitator role during research sessions. Deaf communities and stakeholders who have been engaged in health information distributed to Deaf people in the Western Cape took the role of context explorers. After all research sessions were conducted, the initial guidelines, as listed in [Chapter 2, Subsection 3.3](#), were verified for their suitability in guiding the research facilitators in organizing research sessions. At the end of this stage, the findings for each building block were brought to discuss with the selected Deaf community in the next CBCD stage. Preliminary answers for research questions were derived.

Co-planning ([Chapter 5](#)) was the second CBCD stage. The objective of this stage was to agree with a Deaf community that would take the leading role (Building Block 1) on the alternative for Building Blocks 2-6 in order to formulate a case study. Research questions had their answers refined based on the agreement with the leading Deaf community. Also, the initial guidelines were verified. The case study was brought to the next CBCD stage.

Co-design ([Chapter 6](#)) was the third stage. Its objective was to elicit the design of the intervention. The users who are Deaf and who are health-information providers took the role of co-designers; they presented ideas for the intervention. The author and research fellows performed design-facilitator roles to stimulate design ideas of the co-designers through research methods and instruments. Then, the author and research fellows took co-designer roles to compile the participants' ideas into a testable conceptual design—intervention mockup. The findings from this stage described the design of this intervention and refined answers to research questions. Similar to other research stages, the initial guidelines were verified.

Co-evaluation ([Chapter 7](#)) was the fourth CBCD stage. Its objective was to verify the design of the determined intervention. In this stage, the users who are Deaf and who are health-information providers, the author, and the research fellows co-evaluated the intervention mockup built based on the design retrieved from the co-design stage. The findings from this CBCD stage confirmed and updated details of the design. The guidelines on the active involvement of the participants in this CBCD approach were completely verified. The answers to all research questions were verified at this stage of research. Finally, the conceptual design for the intervention was further improved as a result of this research through design.

The answers to all research questions would also provide additional knowledge regarding the requirements of health information accessibility for Deaf people. As a result of this empirical research, the selected intervention would demonstrate how hearing designers and researchers could collaborate with a Deaf community, and relevant stakeholders tackled the stated societal complexity.

In conclusion, the research design for this empirical research is described with a design decomposition with six building blocks for formulating a case study and the envisaged four CBCD stages. The overview of the research design for co-exploration, co-planning, co-design, and co-evaluation are provided briefly with the intention to describe details of each CBCD stage in its chapter. The next chapter presents details of the first CBCD stage: co-exploration.

Chapter

4

Co-exploration



Deaf participant: **“I could understand some of the explanation from the doctor through writing. However, I lost some understanding or focus when the paper is transferred back and forth...” “We may ask for some information from Deaf friends if they have some advice for a simple disease, such as flu.”**

The first stage of the community-based co-design (CBCD) approach was Co-exploration. It was the stage that the participants—Deaf communities, relevant stakeholders engaged in health information distributions, including key informants—and researchers explored the context in which the health information inaccessibility to Deaf people took place. The activities for co-exploring the context were developed to derive needed information towards designing an intervention. Co-exploration Activity 1 was to identify alternatives for the six building blocks (refer to [Table 1, Chapter 3](#)). Co-exploration Activity 2 focused on the confirmation of the alternative for Building Block 6: sources, channels/media/devices to provide health information accessibility to Deaf people. [Figure 15](#) presents the overview of the Co-exploration Stage.

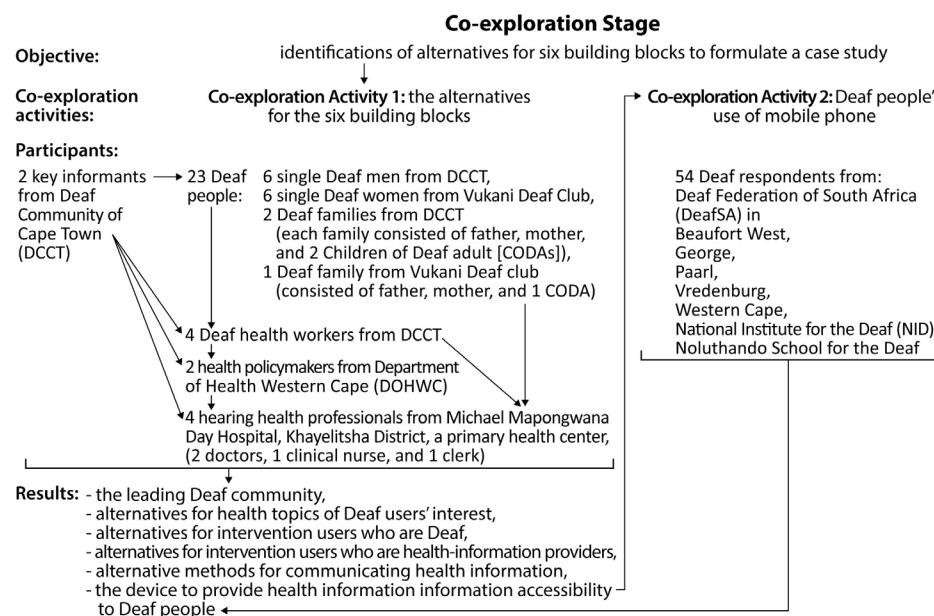


Figure 15. Overview of Co-exploration Stage.

This chapter is composed of four sections. The first section presents related works to this empirical research, describes the research process and findings of Co-exploration Activity 1, and concludes and discusses the findings. The same structure is provided in the second section about Co-exploration Activity 2. The third section verifies the initial guidelines practiced during Co-exploration Stage. The fourth section provides answers to research questions and a way forward for Co-planning Stage ([Chapter 5](#)).

1. Co-exploration Activity 1: the alternatives for six building blocks
[Section 1.1](#) presents the related works that influenced this co-exploration activity's research methods and suggested interventions from similar contexts. [Section 1.2](#) describes research objectives, criteria for selecting participants, research methods and instruments, data analysis, and limitation of this co-exploration activity. [Section 1.3](#) presents the findings. Lastly, [Section 1.4](#) concludes and discusses the findings of this co-exploration activity.

1.1 Related works

A literature study was conducted, and five studies were selected due to their relevance to Deaf people and their exploration of interventions for providing health information to Deaf people. Two of the five selected publications studied Deaf communities in the Western Cape, South Africa.

One of them focused on Deaf people's access to health information in general ([Kritzinger, 2011](#); [Kritzinger et al., 2014](#)), while the others focused on Deaf people and HIV/AIDS information in particular ([Ismail, 2013](#); [Ismail & Henderson, 2014](#)). In other countries, research on Deaf communities has focused on HIV/AIDS information. [Bat-Chava, Martin, and Kosciw \(2005\)](#) studied Deaf communities in the northeastern region of the United States. [Groce, Yousafzai, and van der Maas \(2007\)](#) compared Deaf and hearing people's access to health information in Nigeria. [Taegtmeyer et al. \(2009\)](#) studied a Deaf community in Kenya.

In terms of research methods, [Ismail and Henderson \(2014\)](#) and [Kritzinger et al. \(2014\)](#) involved key informants at the beginning of their research, applied semi-structured group interviews, and triangulated the data from the key informants and other participants. These two research teams stated that data from key informants let them preliminarily explore the research context, which helped them prepare for their upcoming data collection. Group interviewing with Deaf participants in the presence of a South African Sign Language Interpreter (SASLI) availed dynamic interactions between the Deaf participants and a hearing researcher. Semi-structured interviews allowed participants to express their views and experiences related to the interview topics. In addition, the two research teams were assured of the convergences of the findings obtained from different groups of participants after triangulation. [Bat-Chava et al. \(2005\)](#) applied group interviews but with structured questions and no key informants involved. Thematic analysis was used to identify the findings. In contrast, [Groce et al. \(2007\)](#) collected their data via online questionnaires interpreted in a signed language, while [Taegtmeyer et al. \(2009\)](#) compared the data that a health organization had gained without collecting primary data.

Based on these related works, similarities were identified concerning the health-information-seeking behaviors of Deaf people in different countries. During schooling, Deaf people received health information through educational programs. After schooling, they mostly sought health information from Deaf peers ([Bat-Chava et al., 2005](#); [Groce et al., 2007](#); [Ismail, 2013](#); [Ismail & Henderson, 2014](#); [Kritzinger et al., 2014](#)). [Groce et al. \(2007\)](#), [Ismail \(2013\)](#), [Ismail and Henderson \(2014\)](#), and [Kritzinger et al. \(2014\)](#) all found that health information was passed on through the grapevine within the close-knit Deaf community. Deaf people occasionally attended health-related workshops organized for them and considered these workshops a kind of health information source ([Ismail & Henderson, 2014](#); [Kritzinger et al., 2014](#)). Hospital ([Kritzinger et al., 2014](#)), TV ([Bat-Chava et al., 2005](#)), newspaper ([Bat-Chava et al., 2005](#)), books and magazines ([Bat-Chava et al., 2005](#)), and posters ([Taegtmeyer et al., 2009](#)) were alternate sources to get health information. Challenges in communication with health professionals through writing and

reading ([Bat-Chava et al., 2005](#); [Groce et al., 2007](#); [Ismail & Henderson, 2014](#); [Kritzinger et al., 2014](#)), including hearing or lip-reading ([Bat-Chava et al., 2005](#)), were the reasons that Deaf people did not find health information accessible at hospitals.

These related works made diverse recommendations. Training Deaf people or people with signed language skills to become health counselors was the most frequently recommended intervention for providing Deaf people with access to health information ([Bat-Chava et al., 2005](#); [Kritzinger et al., 2014](#); [Taegtmeyer et al., 2009](#)). Involving Deaf people in the design and development process of the interventions was recommended ([Groce et al., 2007](#); [Ismail & Henderson, 2014](#)). Other recommendations included a poster containing signs related to symptoms developed to aid health professionals in understanding explanations from Deaf patients, health information in a signed language broadcasted via TV programs, circulating health information via instant messaging (IM) on mobile phones ([Kritzinger et al., 2014](#)), development of health education materials in a signed language, optimizing the grapevine to pass on health information ([Ismail & Henderson, 2014](#)), using more pictures than text in printed materials ([Ismail & Henderson, 2014](#); [Taegtmeyer et al., 2009](#)), distributing videotapes containing health information to Deaf people, and making health information accessible to family members of Deaf people ([Bat-Chava et al., 2005](#)).

Although the related works suggested alternatives for some of the six building blocks, there was no assurance on their suitability to this research context. Thus, there was the need to conduct Co-exploration Activity 1. The research methods of the related works were referred to for the research design of Co-exploration Activity 1. The related works' and Co-exploration Activity 1's findings were later compared to preliminary define possible generalizability of the intervention of this CBCD approach.

1.2 Research process of Co-exploration Activity 1

This subsection describes the research that retrieved data from multiple stakeholders to identify alternatives for the six building blocks. Research objectives, criteria for selecting participants, research methods and instruments, data analysis, and a limitation of this co-exploration activity are included.

Research objectives

Two research objectives below were to answer SRQs 2 to 7:

- Research Objective 1: Identify relevant participants for this research.
- Research Objective 2: Identify the alternatives for the six building blocks (refer to [Table 1, Chapter 3](#)).

Criteria for selecting participants

Based on [Ismail and Henderson's \(2014\)](#) and [Kritzinger et al.'s \(2014\)](#) positive experiences with their applied research methods, key informants were firstly selected. With these key informants' inputs, other relevant participants were identified. Through this identification process, key informants, three groups of Deaf people, Deaf health workers, health policymakers, and health professionals working at primary health centers were chosen as the participants of Co-exploration Activity 1. The criteria for selecting the participants (refer to [Figure 15](#)) are as follows:

- Key informants must be experienced in the field of health information distributions to Deaf people in the Western Cape and fluent in SASL and English.
- Deaf participants must be at the age at least 18 years old (except the CODAs) since this study focused on Deaf adults. They can be with any functional and health literacy level and be fluent in SASL.
- Relevant health-information providers must be identified by the key hearing informants and Deaf participants, including their peers, as health-information providers involved in health information distribution to Deaf people in the Western Cape. They must be experienced in transferring health information to Deaf people.

The following subsection describes how these participants were selected and how they participated in different research sessions.

Research methods and instruments

Methods for selecting participants are described first, followed by the research methods and instruments used during Co-exploration Activity 1.

- Approach for identifying participants

A social worker working at DCCT at the time and a CODA working as a qualified SASLI in the Western Cape whose profiles matched the criteria for selecting key informants were approached. They agreed to participate in Co-exploration Activity 1; their inputs were used to identify the remaining participants. Based on the criteria for selecting Deaf participants, together with information from the key informants, three groups of Deaf people from DCCT and Vukani Deaf Club: Single Deaf men, single Deaf women, and Deaf families who have at least a CODA were involved in this co-exploration activity. Next, the inputs from the key informants and the Deaf groups were analyzed. As a result, DCCT Deaf health workers, whose profiles matched the relevant health-information providers' criteria, were selected. The inputs from the key informants, Deaf people, and DCCT Deaf health workers identified health policymakers from the Department of Health Western Cape (DOHWC) as relevant health-information providers also. Lastly, the

key informants' and the stated participants' inputs were used to select health professionals at Michael Mapongwana Day Hospital as another group of relevant health-information providers (see [Figure 15](#) that shows the sequence for identifying participants of Co-exploration Activity 1).

- Methods for interviewing Deaf groups and Deaf health workers

Information was gained from the participants towards designing an intervention. Frequency counting was also used to identify what alternatives could be for some of the building blocks. Group interview with semi-structured questions was applied in research sessions with all Deaf participants due to the positive effect that [Ismail and Henderson \(2014\)](#) and [Kritzinger et al. \(2014\)](#) experienced regarding the dynamic interaction between the participants and researchers. Three groups of Deaf people and DCCT Deaf health workers were asked two specific questions to explore health information distributions to Deaf people in the Western Cape. The other part of the interview was improvised to gain additional information from the participants. Following the advice of [Nielsen \(2000\)](#), six participants per group of single Deaf men and single Deaf women were recruited. Five participants were advised to identify response patterns sufficiently; the author added one more participant per group in case a participant might drop out. In each group interview session with Deaf family, only the father, the mother, and at least a CODA were involved in preserving the family's privacy in case that some particular information might be shared with researchers. All four DCCT Deaf health workers were invited to a group interview. One SASLI, who was recommended by the studied Deaf community (refer to the initial Guideline 5 in [Sub-section 3.3, Chapter 2](#)), was hired to assist with the communications in each group interview with Deaf participants. All participants were asked to take turns in answering each question to counteract groupthink—a participant's statements may influence other participants' opinions and contributions in each group interview.

- The interviews with hearing participants

The key informants, health policymakers, and health professionals working at a primary health center could choose to participate in a group or an individual interview since their availability was limited to attend a group interview at the same time. Such method justification followed Guideline 6: planning for a flexible research session (refer to [Subsection 3.3, Chapter 2](#)). The semi-structured questions were conducted similar to the interviews with the Deaf groups and DCCT Deaf health workers.

- Identifications of alternatives for the six building blocks

All Deaf groups were asked to name and rate three health topics that they thought all Deaf people and people similar to their particular group would be interested in learning. The purpose of these questions was to identify

alternatives for the health topics (Building Block 2) and who the target Deaf users would be (Building Block 3). DCCT Deaf health workers were only asked to recommend three health topics that all Deaf people needed to learn; their recommendations were used to support the selection of the alternatives for both Building Blocks 2 and 3 (see [Figure 16](#)).

All participants gave a list of health-information providers involved in distributing health information to Deaf people in the Western Cape. Only Deaf groups were additionally asked to rate their current information sources on an influence-map—a research instrument (see [Figure 17](#)), followed by the information sources from which they prefer seeking health information. The Deaf groups' inputs were prioritized for identifying intervention users who are health-information providers (Building Block 4). The health professionals' inputs were used in supporting the selection of the alternatives for Building Block 4.

Lastly, all participants were asked to reflect on health information distribution challenges, followed by good experiences. This course of reflections also prompted the participants to generate ideas about interventions suitable for the Western Cape. The methods chosen by health professionals for communicating health information to their Deaf patients and the methods Deaf participants preferred were categorized. The frequency was tabulated to identify alternatives for Building Block 5: methods for communicating health information. The participants were encouraged to draw ideas using the sensitizing toolset—another research instrument (see [Figure 18](#)). Their ideas were categorized and counted to identify alternatives for the channels, media, or devices for providing health information accessibility to Deaf people (Building Block 6).

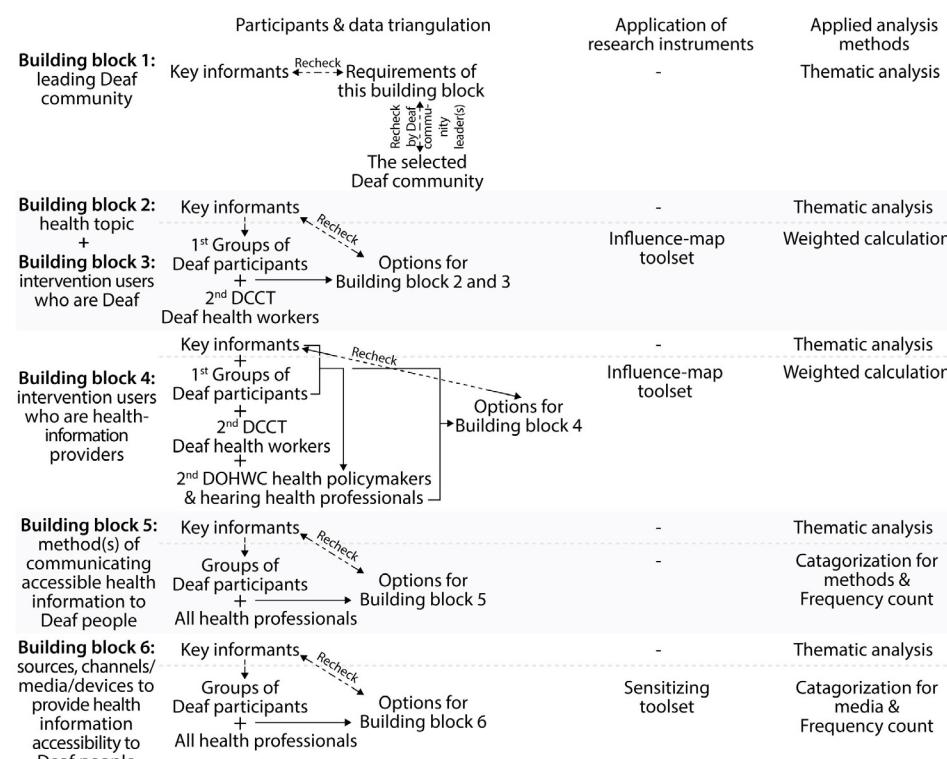


Figure 16. Overview of the methods for identifying alternatives for each building block.

- Research instruments

Two research instruments were used to retrieve in-depth information. The influence-map toolset (see [Figure 17](#)) comprised sticky notes, writing utensils, and an A0-sized map. It was used to notify the Deaf participants about rated the influence of health-information providers through concise text and graphical information accessible to them.

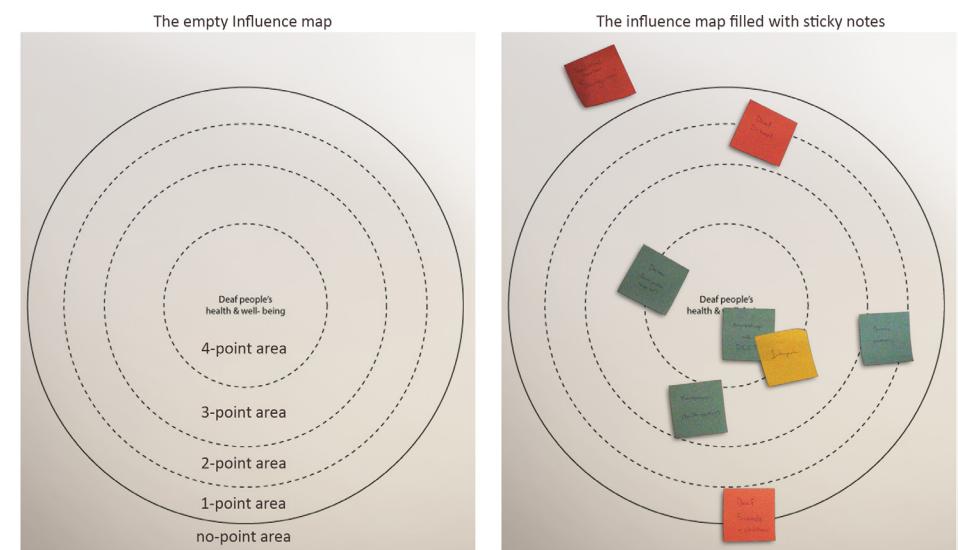


Figure 17. The influence-map toolset.

The participants had to discuss and reflect on each health-information provider's influence on the health and well-being of Deaf people. Simultaneously, the researcher wrote down each health-information source that the participants stated onto a sticky note for the participants to place on the influence map. The map was composed of five concentric circles. The circle in the middle, valued at four points, was corresponded to health-information sources that highly influenced Deaf people's health and well-being. The other circles ranged outward from this central area, valued from three points down to one point, and denoted the sources with lower influence. The area outside the circles was used for sources considered to have no influence on Deaf people and was valued at zero.

The sensitizing toolset (see [Figure 18](#)) consisted of blank A4 paper, colored markers, and stickers in different shapes and colors. The participants could use these tools to draw their ideas for providing accessible health information to Deaf people in the Western Cape.



Figure 18. Sensitizing toolset at a data collection.

Before data collection, the interviews and research instruments were piloted with an expert affiliated with BANG. [Figure 19](#) illustrates the procedures used during the interviews with the participants who are Deaf and hearing.



Figure 19. Procedure of Co-exploration Activity 1.

Informed consent was obtained from the participants who are Deaf via raising their hand in assent in front of a recording video camera, in accordance with their language preferences (refer to the initial Guideline 4 in [Chapter 2, Sub-section 3.3](#)). Informed consent from hearing participants was retrieved via either a voice recording or a signature on a consent form. SASLIs assisted communication between Deaf participants and the researcher, and DCCT Deaf health workers and the researcher. No translator was involved in the interviews with the hearing participants since they had a good command of English.

These methods were piloted among the research fellow before deploying to data collection.

Data analysis

Voice and video records of all interviews were transcribed manually. The timing was added to the end of each sentence for traceback. Facial expressions and body language were observed and annotated in the transcriptions for additional analysis. The leading Deaf community was derived from the statements of the key informants and relevant sources in comparison with the requirements of Building Block 1. Alternatives for the health topics (Building Block 2) were derived from weighted calculations based primarily on the Deaf groups' rating and secondarily on the DCCT Deaf health workers' recommendations. Health topics ranked first were weighted three-fold, and those ranked in second and third place were weighted doubly and singly, respectively. The recommendations from the DCCT Deaf health workers added one score to each of the health topics. The three health topics that earned the highest summed scores were selected as the alternatives for Building Block 2.

Subsequently, the intervention users who are Deaf (Building Block 3) related to the health topics were selected. Alternatives for the intervention users who are health-information providers were also identified through weighted calculations. Each of the health information sources that the three Deaf groups placed in the influence map was weighted accordingly. Their scores were summed to indicate which of the sources had a higher influence on Deaf people's health and well-being. The health-information sources with the highest scores were selected as the alternatives for intervention users who are health-information providers (Building Block 4). Alternatives for Building Block 5 were gained from frequency counts of the methods that DCCT Deaf health workers and hearing health professionals chose to communicate health information to their Deaf patients, including the frequency counts of the preferred communication methods that Deaf participants stated. Alternatives for the medium (Building Block 6) were obtained from a classification of the ideas that all participants stated. For this analysis, access <https://doi.org/10.5281/zenodo.4093712>.

Data from different groups of the participants were triangulated with the key informants' information, as presented in [Figure 16](#).

Limitation of this exploration

The findings of this co-exploration activity which were retrieved from two Deaf communities: DCCT and Vukani Deaf Club might resemble interventions and requirements on health information accessibility of Deaf communities in the same area. Before designing an intervention with other

Deaf communities from other areas, these requirements will have to be rechecked with their members.

1.3 Findings from Co-exploration Activity 1

This subsection presents the alternatives for Building Blocks 1 to 6. Building Block 1: the leading Deaf community of choice

Findings about Deaf communities in the Western Cape are provided, followed by a potential Deaf community to take the leading role in this CBCD approach. Four main Deaf communities in the Western Cape: DCCT, the Deaf Federation of South Africa (DeafSA), Vukani Deaf Club, and the National Institute for the Deaf (NID) were mentioned by the key hearing informants.

DCCT is a Deaf community whose office is located in Cape Town, the capital city of the Western Cape province. It is a Deaf run and non-profit organization that serves Deaf people across the province with programs that reduce Deaf people's social issues. Health information inaccessibility is considered a social issue. Therefore, DCCT offers an HIV/AIDS lay counseling program for Deaf individuals and a related workshop for a large group of Deaf audiences. This is the only Deaf community equipped with health workers who are Deaf, trained, and certified for lay counseling. DeafSA is a larger Deaf run and non-profit organization in comparison to DCCT. There are several DeafSA headquarters in South Africa. Its Western Cape headquarter is located in Cape Town, with four minor communities scattered in rural areas (i.e., Vredenburg, Paarl, Beaufort West, George). DeafSA's services involve advocacy on the importance of SASL, Deaf-awareness promotion to the hearing society, and jobs and life-skills support. Social workers who are Deaf work with all DeafSA's communities. Vukani Deaf Club is an informal Deaf community in Khayelitsha district, near Cape Town. It does not offer any service to reduce Deaf people's social issues, but purpose for fellowship. Its members gather every Sunday at Noluthando School for the Deaf. NID is a Deaf college-based community that accommodates Deaf learners from various areas in South Africa and neighboring countries. It is a non-profit organization founded by the Dutch Reform Church. NID focuses on education and occupation skills provided by Deaf people, including deaf and hearing people who are related to Deaf people. It capacitates in producing Deaf-accessible multimedia and dictionary of the standardized SASL.

All the mentioned non-profit organizations, except Vukani Deaf Club, are with a profile that matched the criteria of a Deaf community eligible to take the leading Deaf community role. However, the key hearing informant's statements seemed to indicate DCCT more suitable than other Deaf

communities for the following reasons. DCCT matched three out of five requirements for an eligible Deaf community to take the leading role in this CBCD research (see [Table 1, Chapter 3](#) for the criteria). DCCT is a large Deaf community with members of a broad age range:

"Deaf people who become DCCT members know DCCT by word-of-mouth and through programs... Deaf people access DCCT when reaching the age of 18 or finishing school because they want to access job or continue their training. Deaf children also know DCCT from HIV program at Deaf schools." This Deaf community is skilled in producing and distributing health information to Deaf people. It is the only Deaf community in the Western Cape equipped with DOHWC-accredited Deaf health workers trained to promote health service and information, especially HIV/AIDS. DCCT Deaf health workers serve Deaf communities in Cape Town and occasionally outreach areas, such as Vredenburg, Paarl, Beaufort West, George, Robertson, and Khayelitsha. One key hearing informant described the program's services as:

"DCCT services entire Cape Town. HIV program is limited in Cape Town, but more [programs] extended to seven focused outreach areas... the team created a DVD in signed language which is accessible for Deaf people. The team does dramas from area to area. Deaf-friendly pamphlets and posters have been provided with more pictures and signs with simple texts. The outreach programs, on the World's AIDS day, also invite Deaf people from various areas to the central area to do activities with different methods to teach via dramas and music, and there are a lot of participatory activities for Deaf people."

In addition, the DCCT staff is fluent in SASL and familiar with dialects. They have promoted health information across the Western Cape.

The proficiency in SASL and English and the community's willingness to participate in an intervention design were the other two requirements that DCCT matched for becoming the Deaf community to take the leading role. The DCCT management is strong at SASL and English, and their Deaf members are fluent in SASL. DCCT's research history showed the plausibility that it would be willing to design an intervention during this CBCD approach again.

DCCT was chosen over other Deaf communities to take the leading role based on the findings and reasons stated above. Other communities with experiences in promoting information to Deaf people were considered as alternatives.

Building Blocks 2 and 3: alternatives for health topic and intervention users who are Deaf

The key informants' statements that led to the inclusion of single Deaf men, single Deaf women, and Deaf families with at least one CODA in this research activity are elaborated. Then, Deaf people's health-information-seeking behaviors that helped identify the alternatives for these two building blocks are described.

The key informants' statements urged the author's attention to health information needs and seeking behaviors of the three Deaf groups:

"There are a lot of sad stories. Prostate cancer is common in men. Deaf people thought it is normal to have lumps and bumps, but it turned out to be cancer. And then they entered the hospital when it passed the stage where they could have been saved...., 'If you place a slice of orange in your vagina and it turns red, then you have HIV!..' DCCT also asks for volunteers from hearing children of Deaf parents [to perform the health drama] because they know how to communicate with Deaf people..."

Interviewing these three groups of Deaf participants could result in various health topics and the relevant intervention users who are Deaf. Thereafter, one group of Deaf men, one group of Deaf women, and three Deaf families were interviewed. Several Deaf participants disclosed that they mostly sought health information when they suffered from a disease. They consulted a doctor when they fell sick, yet experienced communication problems at health facilities. A Deaf family stated that "when there is a health problem, doctor is the first information source that we [dad and mom] turn to." Deaf women expressed: "I get health information from the hospital. However, it is difficult to understand information by lip-reading from the doctor who cannot sign."

Low writing and reading skills have hindered them from accessing health information from other sources. As a result, they have rarely been exposed to accessible information and have low health literacy, and Deaf friends have become immediate providers for simple advice. Example statements of the Deaf women group were:

"I could understand some of the explanation from the doctor through writing. However, I lost some understanding or focus when the paper is transferred back and forth..." "We may ask for some information from Deaf friends if they have some advice for a simple disease, such as flu."

Information from the key informants and the Deaf men and women groups demonstrated that many Deaf people quickly trusted information shared by

their Deaf friends without questioning its accuracy. They did not realize that their peers were similarly exposed to limited information. The Deaf family groups had health-information-seeking behaviors that were slightly different from other Deaf groups'. The Deaf parents often relied on their CODAs for bridging communication at health facilities or interpreting health information retrieved from other sources, while the participants of other Deaf groups did not have such assistance.

When discussing alternatives for the health topics, all Deaf participants addressed the health topics that Deaf people and their peers particularly needed. [Table 2](#) presents the top three interests in ranked order. While focusing on the Deaf participant groups, the Deaf men showed a steady interest in sexual health; they suggested that both Deaf men and all Deaf people should similarly learn about it. The Deaf women discussed more of the ailments that the participants in their group were suffering from and diseases that were frequently reported in the news during that period. The Deaf families expressed health information needs regarding the chronic diseases that they and other Deaf people in the same generation have been developing. Also, they addressed that Deaf families needed to understand health topics concerning the health of their children.

Table 2. Deaf participants' health topics of interest

Categories	Health information by ranking		
	1 st	2 nd	3 rd
Single Deaf men group's opinion on the health topics that all Deaf people need in general	HIV	Hypertension	Heart attack/ Epilepsy
Single Deaf men group's opinion on the health topics that single Deaf men need in particular	Sex education	Penis care	Sterile circumcision
Single Deaf women group's opinion on the health topics that all Deaf people need in general	Swine flu	Cancer	Arthritis
Single Deaf women group's opinion on the health topics that single Deaf females need in particular	Women's cancer	Depression	Problems with feet
Deaf families' opinion on the health topics that all Deaf people need in general	Diabetes	Cancer	Hypertension
Deaf families' opinion on the health topics that Deaf families need in particular	Chickenpox/ Diabetes	Diseases related to muscles	Allergies

Furthermore, Deaf health workers recommended cancer, diabetes, and hypertension as health topics that all Deaf people should learn. This recommendation was made based on their casework revealing Deaf clients' confusion about these three diseases. With reference to the findings above, cancer (weighted summed scores = 8), diabetes (weighted summed scores = 7), and hypertension (weighted summed scores = 4) were considered as alternatives for a health topic (Building Block 2). By following these alternatives, any Deaf person who was interested in information about the topic could become one of the intervention users who are Deaf (Building Block 3). Refer to <https://doi.org/10.5281/zenodo.4093712> for this analysis. These options were later discussed with DCCT leaders to select a topic that matched their Deaf health workers' expertise and were convergent to roll out health information delivery for other health topics.

Building Block 4: alternatives for intervention users who are health-information providers

The information from the key informants was for tracing the relevant health-information providers involved in health information distributed to Deaf people in the Western Cape. The findings that led to the selected alternatives for this building block are described.

[Figure 20](#) provides an overview of how health information is distributed to Deaf people in the Western Cape. The national Department of Health standardizes health information and cooperates with provincial Departments of Health in scheduling health programs and health promotions. DOHWC partners with health facilities and Deaf communities to deliver health information to the Deaf population. These organizations are the primary stakeholders from whom Deaf people frequently seek health services and information. One of these partners is the DCCT, equipped with Deaf health workers who deliver HIV/AIDS health information and its comorbid diseases to Deaf people. They promote health information through health workshops to big groups of Deaf people and one-to-one counseling for individual Deaf patients. They do not encounter language barriers when communicating with Deaf people. Another partnership is with primary health centers, which are generally staffed with hearing health professionals. The majority of their health services and information are delivered through face-to-face consultations with individual patients. They often struggle to communicate with their Deaf patients when there is no assistance from a SASLI.

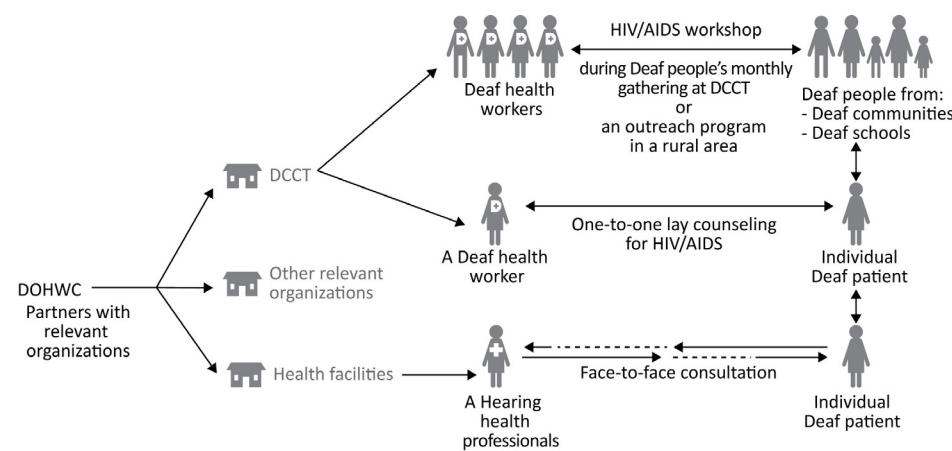


Figure 20. Overview of health information distribution to Deaf people in the Western Cape.

The findings regarding Deaf participants' preferred health-information providers are presented in Figure 21. The column on the left presents the list of the health-information sources to which Deaf participants currently have access. The column on the right is an extended list containing preferred providers. The bidirectional arrow in Figure 21 highlights consultation with a doctor in the absence of a SASLI—the current information source that Deaf people approached the most for health information when fell sick—was not the most preferred by Deaf participant. This was due to the language barrier. Since there has been a shortage of qualified and medically-trained SASLIs in the Western Cape, the possibility that a Deaf patient would attend a health consultation in the presence of a SASLIs would be dimmed. These findings indicate that communication between a health professional and a Deaf patient should be bridged by an intervention in order to avail health information accessibility to Deaf people. Doctors or health professionals working at primary health centers were considered as intervention users who are health-information providers.

The list of the current health information sources	
Ranking	number of mentions (point)
1 Consultation with a doctor in the absence of a SASLI	9
2 DCCT's workshop and lay counseling	5
3 Newspaper	3
4 Parents of the Deaf participants	3
5 Deaf friends	3
6 Hearing friends	2
7 TV program without SASL interpreting rendered	1
8 Events held by DeafSA	1
9 Traditional healer	1
10 Deaf school in childhood	1
11 Pamphlets from health facilities	1
12 Magazine	1
13 Internet	1
14 HHRP's SMSes and presentations	1

The extended list of the preferred health information sources	
Ranking	Summed scores (point)
1 Consultation with a doctor in the presence of a SASLI	20
2 DCCT's workshop and lay counseling	19
3 Deaf friends	13
4 Newspaper	11.5
5 HHRP's SMSes and presentations	11
6 Consultation with a doctor in the absence of a SASLI	6
7 Parents of the Deaf participants	5
8 School of children of the Deaf participant	5
9 DeafSA's health event	4
10 Partners of the Deaf participant	4
11 The Internet	4
12 SASLI	4
13 SignSupport	4
14 TV programs with SASL interpreting rendered	4
15 TV programs without SASL interpreting rendered	3.5
16 Pamphlets from health facilities	3
17 Magazines	3
18 Deaf schools in childhood	1
19 Radio	1

Figure 21. A comparison of the current and extended lists of preferred health-information sources.

The participants from the three Deaf groups also elaborated on the extended list of the preferred health-information sources, which can be accessed from <https://doi.org/10.5281/zenodo.4559837>.

Building Block 5: alternative methods for communicating accessible health information to Deaf people

These findings were derived from communication methods that the key informants gave an opinion about, Deaf health workers' and hearing health professionals' challenges for communicating health information to Deaf people and the communication methods they were using, and how the Deaf participants' preferred interacting with their health-information providers.

- The key informants' opinion about communication methods
- The key informants perceived the lay counseling and the workshop that DCCT Deaf health workers have effectively communicated to Deaf people. The increase in Deaf people's understanding of HIV/AIDS manifested their effectiveness. Lay counseling for HIV-infected Deaf individuals comprised three elements: 1) relationship-building to earn trust from the patient, 2) escorting the HIV-positive Deaf patients to a health facility, and 3) explaining health information both in SASL and with pictures regarding medication adherence to the patient. HIV/AIDS workshops for large groups of Deaf

attendants were conducted during Deaf people's monthly gathering at DCCT (on the third Sunday of each month) or for outreach programs at Deaf communities in rural areas. The presentation consisted of three combined methods: 1) a health-related roleplay in SASL, 2) a short presentation with pictures, and 3) an open platform for questions and answers (Q&A). The Deaf health workers mostly performed the roleplays themselves. The workshop's content was adjusted to suit the situation and the understandability of prospective attendants from different age groups and literacy levels.

- Deaf health workers' communication methods

The Deaf health workers describe the methods in alignment with the key informants' opinion. They added that Deaf people knew this health-related roleplay as drama. Through the application of both lay counseling and workshops, these Deaf health workers noticed signs of success in multiple instances. For example, many of the HIV-positive Deaf people understood how to take the prescribed medication and adhere to the treatment; the Deaf audience became comfortable with clarifying their own doubts by referring to the problems that the characters in the roleplay had because they did not have to disclose their issues; and an increasing number of the Deaf people understood comorbid diseases of HIV/AIDS.

- Hearing health professionals' communication methods

Hearing health professionals working at a primary health center discussed three challenges in delivering health information and treatment to Deaf patients: 1) language barriers, 2) rechecking of the patient's understanding, and 3) the patients' background knowledge. In interactions with patients, the language barrier was the biggest challenge that these health professionals faced. Even in the presence of a SASLI, they felt that they could not recheck the patients' understanding of the diagnosis or the explained information effectively. Through years of experience, these health professionals found that patients' background knowledge—including low functional and health literacies, lack of biology knowledge, preconceived understandings of diseases, and religious beliefs—deprived them of understanding the diagnoses. However, these hearing health professionals had contradicting views about coping with these challenges. The team of health professionals from the TB clinic came up with a set of four methods: 1) avoiding communicating with their Deaf patients with the signs that the staff invented themselves to prevent any miscommunication, 2) writing to communicate with the patients, 3) delivering only the essential information: what is wrong (the name of the disease), what to do to get better, and when the patient would feel better, and 4) reminding the patients to bring along their caregiver to the follow-up appointment. They chose to omit other relevant health information to avoid confusing the Deaf patients. However, the doctor from the HIV/AID and diabetes clinic believed some supporting information was crucial for

a patient to understand the diagnosis. He demonstrated an analogy that could be applicable to explaining a pathology to a Deaf patient, as follows:

"HIV is the virus that you can't see, but it presents in [your] blood [and] your body secretions. If it gets in your body, it kills the soldiers of your body's blood. The soldiers are the army that protects you from other things that can come [in]to your body. So the HIV virus kills your soldiers. When you take medications to stop HIV from spreading in the body, the soldiers will come back to your body. So your body will become healthy again."

- Health policymakers' suggestions

Health policymakers perceived two challenges in distributing health information to Deaf people in the Western Cape: 1) the language barrier and 2) limited long-term funding for interventions to improve access to health information. An intervention implementable in South Africa's health system should enable health professionals to communicate and recheck Deaf patients' understandings of the information that was just explained. Health policymakers elaborated further that any new intervention development should follow the health funding trends that link to the burden of diseases in the country. The higher priority the disease is, the longer term the government allocates funding. Funding makes an intervention sustainable in the healthcare system.

- Deaf participants' preferred methods

The Deaf participants reflected on the preferred interactions with the health-information providers they had stated (see [Figure 21](#)). Any interaction with a provider that required reading and writing skills was considered inaccessible. All groups of Deaf participants emphasized SASL as the crucial language for communicating health information to Deaf people. The assistance of SASLIs made their interactions with any health-information provider preferable, especially during health consultations. However, they were aware of the scarcity of SASLIs. Thus, they need interventions to enable a successful interaction between a Deaf patient and an information provider.

In addition, Deaf men and a Deaf family stated that a lengthy presentation without pictures was boring. Deaf women affirmed that pictures accompanying the explained content enhanced Deaf people's understanding. They suggested that health information could be distributed through a small group of Deaf people who would likely share accurate information with their peers. Also, all health information should be available for Deaf people to seek at their convenience.

The communication methods that the health professionals used were

compared with Deaf participants' preferred methods. The Deaf health workers' combined methods for the HIV/AIDS workshop distinguished with fourfold: 1) SASL was used to convey the health content; 2) drama was accessible for a Deaf audience of any age group and literacy level; 3) pictures helped enhance the audience's understanding on the explained topic; and 4) the open platform for Q&A allowed the audience to clarify doubts reluctantly. The last fold was in line with the health policymakers' statement for allowing the Deaf health workers to recheck their audience's understanding. Due to the multi-fold distinction, DCCT's combined methods became the potential methods for communicating health information to Deaf people.

Building Block 6: the device to provide accessible health information accessibility to Deaf people

These findings were garnered from all participants' ideas for the solutions and triangulated with the recommendations from key informants. The key informants gave several recommendations: 1) pieces of health information should be repeated for Deaf people to understand and remember, 2) each piece of health information should not be longer than 20 minutes to keep the Deaf audiences' attention, 3) intervention developers should adopt the combined methods that the Deaf health workers have developed, and 4) health dramas should be distributed to Deaf people on DVDs as many people in the province owned a DVD player. The key informant addressed that technological solutions can be of use. However, they cannot replace the essential roles of human-to-human interactions: "Technology is not all in all but how we work together [and] how we integrate technology with the human factor[s]."

Forty-five ideas were retrieved from the participants. These ideas were clustered in three categories: 21 about the use of ICT, 18 regarding the human-to-human interaction, and 11 on the use of mass media (see [Figure 22](#)) (Chinithorn, Diehl, Glaser, & Tucker, 2015).

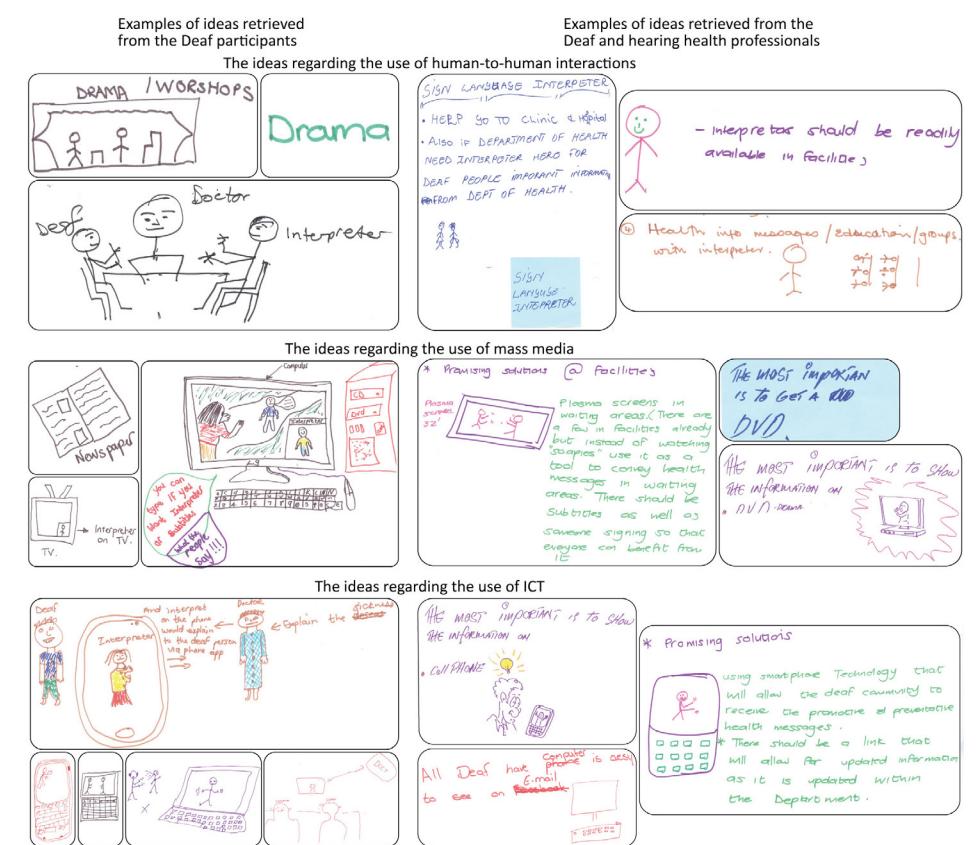


Figure 22. Examples of ideas from participants clustered in three categories.

In the leading category, the use of ICT, 12 ideas were related to the optimization of mobile phones. This finding indicated that mobile phones would be the medium that could best provide accessible health information to Deaf people. However, this indication contradicted key informants' recommendations of using DVDs for health information delivery. Although some Deaf participants and health professionals presented the ideas related to DVDs, the frequency was much lower than ideas regarding mobile phones. As a result, mobile phones were selected as the devices to provide health information accessibility to Deaf people.

This subsection has presented the findings of Co-exploration Activity 1 that resulted in the alternatives for the six building blocks. Mobile phones, as potential devices, were explored further to ascertain that these devices would be accepted by various Deaf people in the Western Cape. Before approaching Co-exploration Activity 2, the next subsection concludes and

discusses the findings of this Co-exploration Activity.

1.4 Conclusion and discussions of Co-exploration Activity 1

This subsection concludes the findings that achieved this co-exploration activity's research objectives and discusses the similarities and one difference between these findings and the related works' findings.

In conclusion, Co-exploration Activity 1 achieved its research objectives. Relevant participants were successfully identified by garnering information from the key informants, then triangulated with the information retrieved from the three Deaf groups, the Deaf health workers, the health policymakers, and the hearing health professionals working at primary health centers. These relevant participants were interviewed, and the alternatives for each building block were systematically identified. DCCT was selected as the potential Deaf community to take the leading role during this CBCD approach (Building Block 1). Its profile matched with the criteria for selecting the Deaf community. Cancer, diabetes, and hypertension were the alternatives for the health topic (Building Block 2) for the interested Deaf people (Building Block 3). Hearing health professionals working at primary health centers were identified as the health-information providers who use an intervention to deliver health information to their Deaf patients (Building Block 4). This was due to the fact that these health professionals were the most popular source that Deaf people approached when they fell sick, but they and Deaf people have struggled the most to exchange health information. Both the health professionals, relevant to one of the health topics, and Deaf patients, who needed information of such health topic, required an intervention to enable their interactions at the primary health centers. The DCCT's combined methods: health drama in SASL, a short presentation with accompanying pictures, and an opened platform for Q&A could be the methods for communicating health to Deaf people (Building Block 5). Lastly, mobile phones were defined as the devices to provide health information accessibility to Deaf people (Building Block 6).

Findings from Co-exploration Activity 1 had four similarities and one difference with the related works' findings. The first similarity was that Deaf participants of Co-exploration Activity 1 showed health-information-seeking behaviors that corresponded to those found from related works. They sought health information when they fell sick. The second similarity was that the Deaf participants in this study used similar sources of health information as found from related works. Deaf schools are a source of health information for those of schooling age, and Deaf peers are the alternative for those in adulthood. Third, any interactions with health-information sources that required reading and writing skills were inaccessible among Deaf people. As such, health information delivered during health consultations in

the absence of a SASLI was inaccessible to Deaf people due to language barriers. The fourth similarity was that signed language with pictures accompanying the explanation was one of the methods for communicating accessible information. The only difference found was the media for providing accessible health information. This difference can be explained by technological advancements in different researched contexts. The rest of this co-exploration activity's findings contributed insight related to the research objectives that the related works did not touch upon.

As mentioned before, mobile phones were further explored to confirm whether Deaf people from multiple Deaf communities across the Western Cape would accept them as devices to provide health information accessibility. The next section provides the details of Co-exploration Activity 2.

2. Co-exploration Activity 2: Deaf people's use of mobile phone

This section reports co-exploration on mobile phones as communication devices, conducted together with Deaf communities across the Western Cape. The verification for their acceptability was determined by Deaf people's physical access to the devices. The structure of this section is similar to [Section 1 of this chapter](#).

2.1 Related works

Due to the scarcity of relevant studies specific to South Africa found in online scientific databases, the work of researchers in connection with BANG was studied. Deaf people's ownership and use of mobile phones have continually changed over the years. In 2009, each Deaf participant from DCCT in [Looijesteijn's study \(2009\)](#) owned a feature phone—a mobile phone with a small screen and tiny physical buttons. In 2011, feature phones were still in use among Deaf members at DCCT. However, several of them had migrated to smartphones with the BlackBerry Operating System (OS) for its free chat app. Smartphones with big screens were seen among a few members ([Chininthorn, 2011](#)).

In terms of mobile telecommunication package subscriptions, most Deaf people used a prepaid SIM ([Chininthorn, 2011](#)). [Chininthorn \(2011\)](#) and [van Pinxteren \(2012\)](#) similarly found that some DCCT Deaf members shared a mobile phone because they could not afford a phone or airtime—mobile telecommunication credit. Deaf people's use of the mobile telecommunications has also changed over time. While feature phones were still popular, Deaf people at DCCT ([Looijesteijn, 2009](#)) and in Worcester ([Liebenberg & Lotriet, 2010](#)) used expensive SMSes to accomplish many communication purposes, except for chatting. These Deaf people regularly messaged their peers but rarely messaged hearing people due to functional literacy. Deaf people who could afford mobile data used their phone for

more entertainment purposes; Mxit, Mobile Chat, and BB gradually became popular IM apps among the Deaf ([Chinithorn, 2011](#)). Participants browsed different kinds of information and vocabulary and shared them via the IM app ([Chinithorn, 2011](#)). In addition, Bluetooth was optimized for sharing information within close range to save on data charges. In 2012, Deaf people reconnected with specific groups of hearing people via mobile phones. Hearing family members, friends, and SASLIs were contacted for legal advice, business affairs, an escort when visiting a hospital, or seeking health information ([van Pinxteren, 2012](#)).

Several variables seemed to differentiate Deaf people's use of mobile phones. Deaf men appeared to be much more experienced in using mobile phone features than their female counterparts ([Chinithorn, 2011](#)). Deaf people who were younger than 40 years old used the features on their phones, such as alarms and reminders, more than older Deaf people ([Chinithorn, 2011](#)); younger users also discarded old communication technologies more frequently than the older users ([Liebenberg & Lotriet, 2010](#)). People with a severe degree of hearing loss and the onset of hearing loss during their pre-lingual phase (before two years of age) relied on text messaging more than other Deaf people ([Liebenberg & Lotriet, 2010](#)). Voice calls were a service that hard-of-hearing (HOH) people used, even though they often struggled to follow the conversation. Deaf people who preferred signed language were more likely to use video-chat than other telecommunications ([Liebenberg & Lotriet, 2010](#)). Those with college degree used more telecommunications than their lower-educated counterparts. The participants with a college degree used SMS, IM, and email for both business and social connection purposes ([Liebenberg & Lotriet, 2010](#)). In agreement with these findings, gender, age group, achieved education, and employment status were considered as variables that could differentiate Deaf people's use of mobile phones. The degree of hearing loss was discarded from the variable list, but the onset of hearing loss remained. In addition, the Deafness status was added as one of the variables. These decisions were made by following the sociocultural perspective of Deafness (refer to [Sub-section 1.1, Chapter 1](#)), which focuses on the people's language identity and culture instead of the hearing inability. These variables resulted in the design of the questionnaire, as described in [Subsection 2.2 of this chapter](#).

Based on the learnings above, Deaf people's use of mobile phones may have changed further in 2017—the year in which this exploration was conducted. The next part of this subsection presents the findings from Co-exploration Activity 2.

2.2 Research process of Co-exploration Activity 2

This research activity focused on whether the identified devices,

mobile phones, would be acceptable to the larger number of Deaf people in the Western Cape as the primary means for accessing health information. The findings from this co-exploration activity were aimed at refining the answers for sub-research question (SRQ) 4 (Deaf people's preferred medium), SRQ 5 (health-information-seeking behaviors through the use of a mobile phone), and SRQ 7 (criteria of mobile phones as devices).

Research objectives

Three research objectives were formulated to serve the focus of this activity:

- Research Objective 1: Confirm whether mobile phones would be the devices Deaf people in the Western Cape would accept by exploring the number of those who already own and have access to a mobile phone and the number of those who regularly sought and shared health information via mobile phone.
- Research Objective 2: Describe Deaf people's requirements on mobile phones that suit their needs.
- Research Objective 3: Account for the demographic could effect mobile phone usage among Deaf people.

Criteria for Deaf respondents and sampling technique

Being at least 18 years old was the only criterion required for the respondents since this research focused on Deaf adults. People at this age can legally purchase a Subscriber Identity Module (SIM) by themselves. The respondents were recruited via convenience sampling since Deaf individuals across the Western Cape could rarely be reached by a hearing researcher solely. Assistance from the management of each Deaf community in the respondent recruitment was essential.

Research methods and instrument

The approach to recruiting the respondents and a questionnaire for exploring Deaf people's use of mobile devices are explained.

- An approach to recruit the respondents

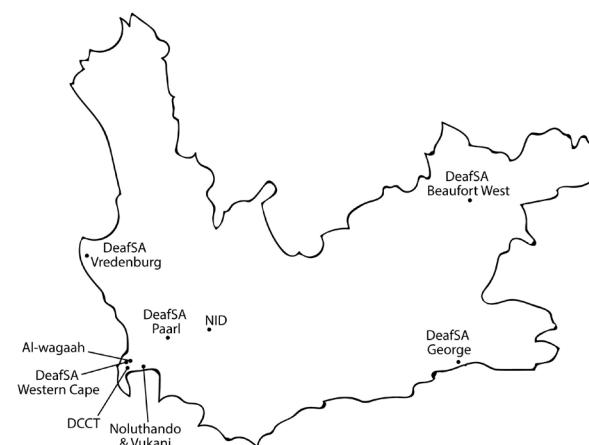


Figure 23. A map of studied sites in the Western Cape.

Deaf SA Western Cape and its branches in Vredenburg, Paarl, Beaufort West, and George were approached because their members were of a wide age range, and included a variety of genders, education levels, and employment statuses. Al-wagaah Islamic Institute for the Deaf was also approached for a similar reason, including its location near the city of Cape Town. NID and Noluthando School for the Deaf were approached because of young-age-range respondents and locations in different parts of the province. Altogether, eight research sites (see Figure 23) agreed to take part in this exploration.

Ten respondents were requested from each of the research sites. Sixty-eight people agreed to fill in the mobile questionnaire, but 54 of the completed questionnaire made to data analysis. The reduced number of respondents was due to a SASL-dialect issue, the missing respondents, and the underage respondents (see Figure 24). The remaining respondents' demographic profiles are in Table 3.

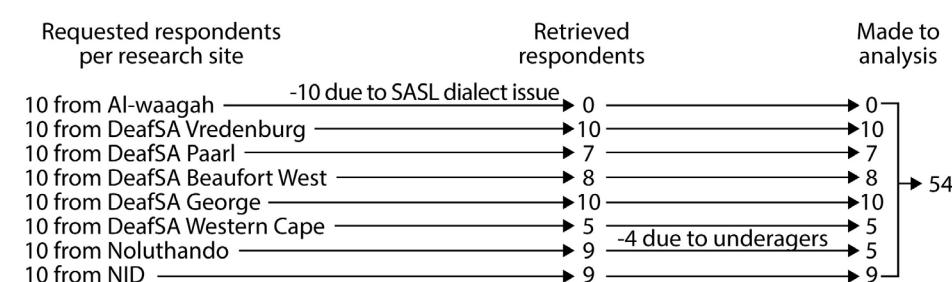


Figure 24. The respondents of Co-exploration Activity 2.

Table 3. Demographics of the Deaf respondents

	Categories	Frequency
Genders	Male	14
	Female	40
Age groups	The younger group aged between 18 and 47 years old	40
	The older group aged between 48 and 77 years old	14
Deafness status	Identified themselves as Deaf	47
	Identified themselves as HOH	7
The onsets of hearing loss	Born Deaf	28
	During their pre-lingual phase (younger than two years)	5
	During the post-lingual	9
The achieved levels of education	No schooling	3
	Foundation level (Grade 1-4)	1
	Intermediate level (Grade 5-8)	2
	Senior phase (Grade 7-9)	17
	Further Education and Training (FET) (Grade 10-12)/college	12
	Higher education	2
Employment status	Some form of occupational training	3
	Unemployed	29
	Employed	25

The respondents ranged from 18 to 76 years old, with a mean age of 37 years old.

- Questionnaire to explore Deaf people's use of mobile devices
- Questionnaire was selected as a method for collecting data from various Deaf people at the same time. Four question groups (see Figure 25) were created based on the literature in order to achieve the stated research objectives.

Question group 1 Demographics:	Question group 2 Ownership of mobile device:
- gender, - age, - Deafness status, - the onset of the hearing loss, - the completed education, - employment status, - location	- if the respondents have/have no mobile device, - if the respondents share/share no mobile device, - the mobile device that the respondents use, - the type of SIM the respondents have
Question group 3 Deaf people's use of social network and standard features on the mobile phone:	Question group 4 Deaf people's behavior of health information seeking via the use of mobile phone:
- if they use social media: -> the social media they use, - if they take photos with their mobile device: -> number of photos taken in the past 7 days, - if they share photos with others: -> the means they share the photos, - if they record videos with their mobile device: -> number of videos recorded in the past 7 days, - if they share videos with others: -> the means they share the videos, - if they play music with their mobile device: -> duration (minutes) they play music, - if they use their mobile device as a clock or an alarm, - if they use their mobile device as an agenda planner, - if they use their mobile device for emailing, - if they use their mobile device for video calling: -> the app they use	- if they use their mobile device for health-information seeking: -> from who they sought and shared health information with, - if they use their mobile device for browsing Internet: -> the subjects they normally seek, -> how they normally connected to the Internet

Figure 25. The question groups for exploring Deaf people's mobile phone usage.

Question Group 1 served Research Objective 3 for collecting demographic profiles of the respondents. Question Group 2 was in line with Research Objective 1 to gather the number of mobile phone owners and those who had access to the medium. Question Groups 3 to 4 were in accordance with Research Objective 2 for retrieving data about the phone properties that met Deaf people's needs. All question groups contained close-ended and open-ended questions.

- A research instrument

A mobile questionnaire—a questionnaire on a mobile phone—was a research instrument developed to meet Deaf people's communication requirements and researchers' data-collection needs. An app developer, a SASLI who was also a CODA, two Deaf reviewers, the author, and a research fellow designed and developed this mobile questionnaire ([Henny & Chininthorn, 2021](#); [Chininthorn, 2016](#)). A SASL dialect that was expected to be understood by various Deaf people in the Western Cape was used. The mobile questionnaire was installed on mid-range Android smartphones whose screen size and resolution availed clear visibility of interpretations and whose battery was longlasting. Thus, it allowed Deaf respondents to view the questions and give answers in SASL and aided the researchers in collecting data in any areas of the Western Cape with electricity and Internet inconsistency. Surveys completed by Deaf respondents were locally stored on the research phones and uploaded to the research server when researchers returned to the office.

Each research site recommended the local SASLI whom they preferred. The local SASLI was asked to review whether the dialect used for the mobile questionnaire was understandable for the potential Deaf respondents in the area. Relay interpretations were performed by the local SASLI whenever the interpretations in the questionnaire were confusing for the respondents. The procedures for data collection are shown in [Figure 26](#). The Deaf community leaders suggested budgets of 30 South African Rand (R) for lunch and R50 for transportation as compensation for each respondent.

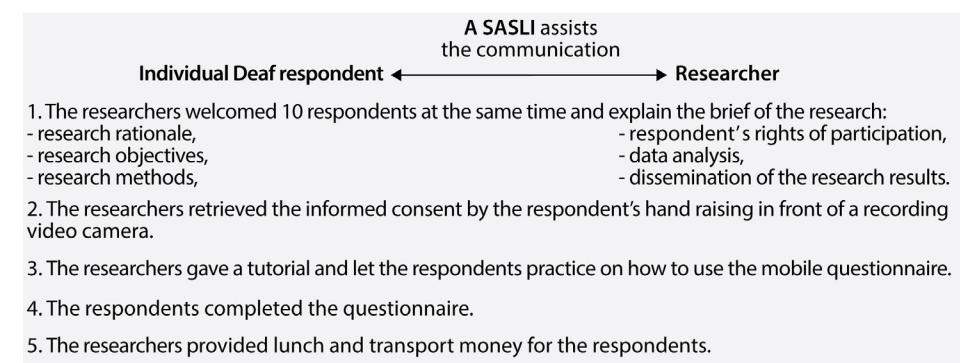


Figure 26. Procedure for Co-exploration Activity 2.

Data analysis

The data retrieved from the respondents were analyzed in two ways. The answers to the open-ended questions were thematically analyzed. Coding themes were both pre-set and derived along the coding process; frequency was counted for analyses. Descriptive analysis was utilized to analyze the closed-ended questions, and comparisons of trends between variables were conducted. Results from these analyses allowed for a comparison of trends and patterns for some key variables. Access <https://doi.org/10.5281/zenodo.4559835> for the coding themes and data analyses.

Limitation of this exploration

This exploration was conducted with a limited number of Deaf people in the Western Cape. Its findings may not represent all Deaf population, but it is possible to infer their mobile phone usage.

2.3 Findings from Co-exploration Activity 2

The findings from Co-exploration Activity 2 are presented in line with the question groups. The data retrieved from Question Groups 2, 3, and 4 described the respondents' ownership of mobile devices, use of social networks and standard features on mobile phones, and health-information-seeking behaviors via mobile devices. The demographic information

retrieved from Question Group 1 was used for analyzing whether they could affect the Deaf respondents' mobile phone usage.

Ownership of mobile devices

These findings cover how Deaf people owned and had access to a mobile device, the types of mobile devices to which they had access, brands of the devices, the local mobile-network providers they chose, and the types of SIM they subscribe. See [Figure 27](#) for an overview.

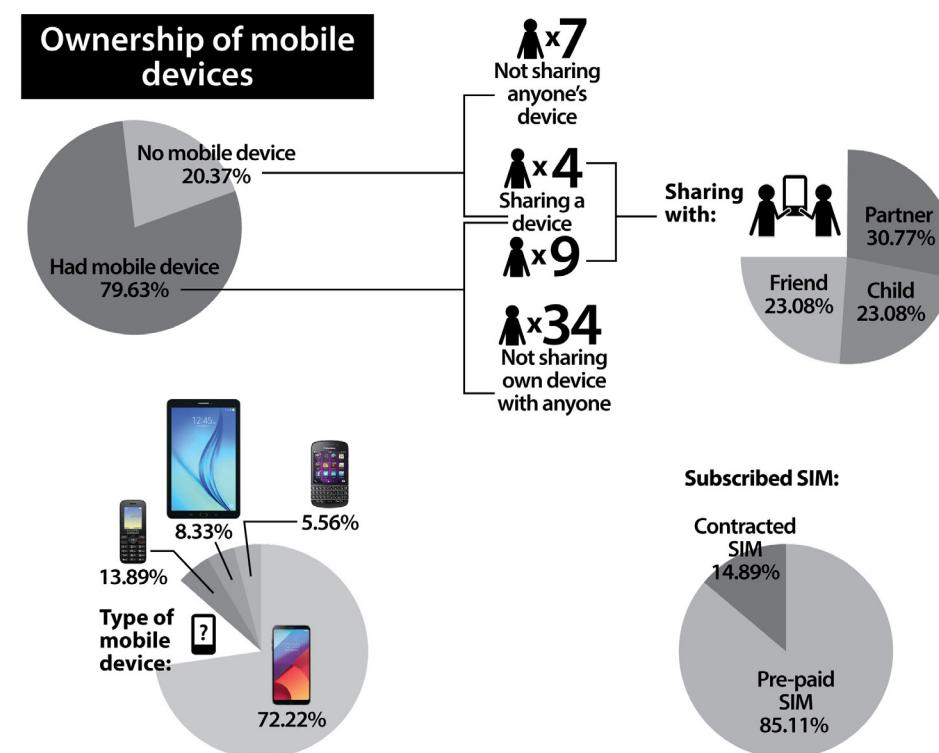


Figure 27. Deaf respondent's mobile device ownership.

Forty-three respondents had mobile devices: 41 respondents who owned one device and two respondents each of whom had two devices. Nine respondents let their Deaf friends, family members, or partner share their device. Among the respondents who had no mobile device, four of them shared a mobile device belonging to their partner, child, or friend. In total, 47 respondents had access to mobile devices. Seven respondents had no access to a mobile device. Smartphones were mostly used, followed by feature phones, one tablet, and one BlackBerry phone with a physical

keyboard. Samsung was the most popular, followed by other brands. The majority of respondents subscribed to a prepaid SIM.

Use of social network and standard features on mobile devices

Forty respondents in this exploration used a mobile device to access their social networks. Forty-one respondents used mobile devices to take photos, with an average of 25 photos taken per day. Twenty-two respondents shared photos to their fellows via their mobile device. Twenty-eight respondents recorded videos with their mobile devices, with an average of five videos per day. Twenty-three respondents used their device to send videos to their friends and family.

The rankings of the channels that Deaf people used for sending their videos were similar to the rankings for sending photos. Furthermore, the respondents used multiple standard features on their mobile device. [Figure 28](#) summarizes the participants' usages of social networks and standard features on the device.

Thirty-five respondents from the younger age group (those between 18 and 47 years old) and 12 respondents from the older age group (participants between 48 and 77 years old) had access to a mobile device. Analyses showed that the respondents of the younger age groups were exposed to more varieties of the social network; they used more channels to share information than the older age group. The older age group tended to use Whatsapp and Facebook mainly. Deafness status, the onset of hearing loss, and the achieved education level did not differentiate the respondents' use of the social network. There was also an indication that the respondents who achieved a higher education level would send and receive emails via their mobile device more than the respondents with lower education levels.

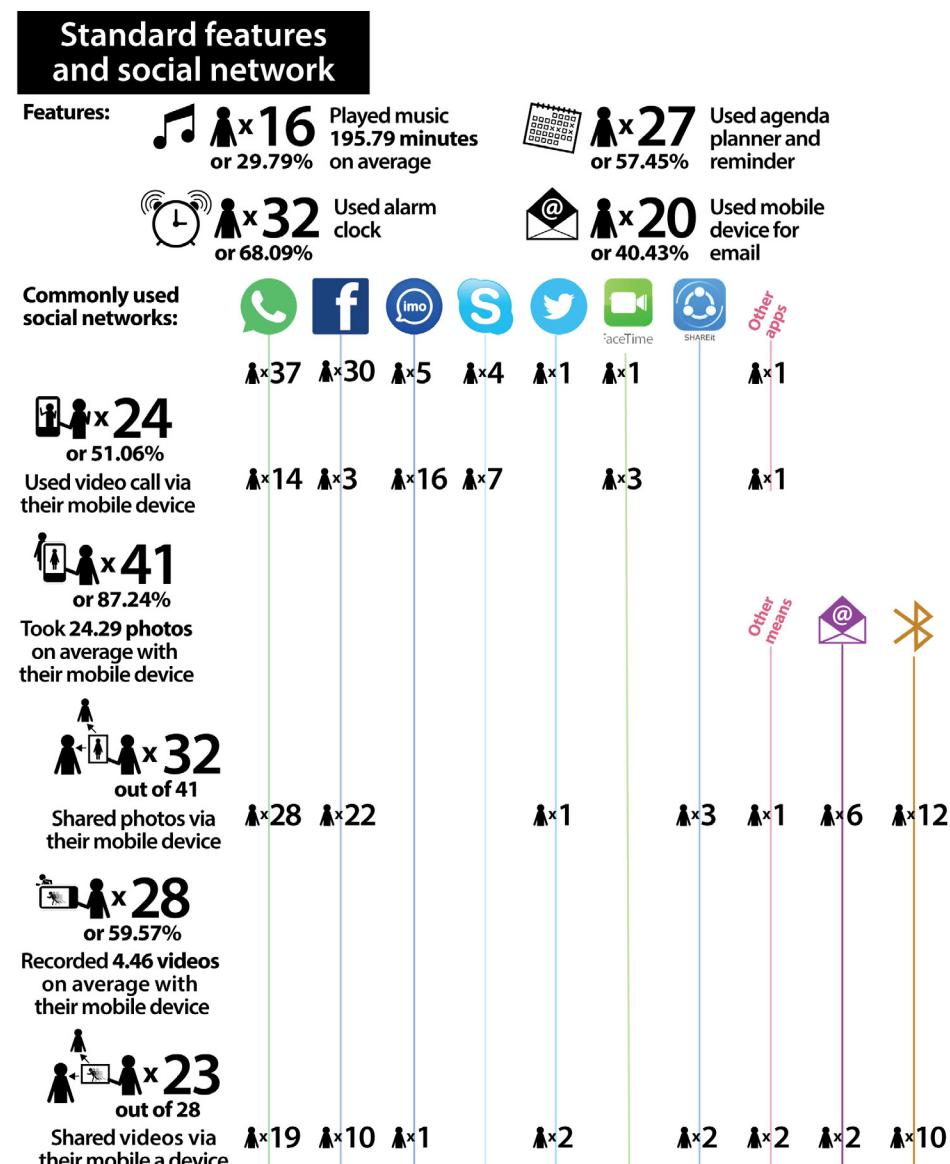


Figure 28. Deaf respondents' usage of social networks and standard features of their mobile device.

Health-information-seeking behaviors via mobile device

Health-information-seeking behaviors via the use of mobile device did exist among these respondents. Of the respondents who had access to a mobile device, 19 of 47 sought and shared health information via this medium. The top three sources of health information were ranked as follows: 1) family members and friends (each, n = 4), 2) doctors (n = 3), and 3) the partner and the child of the respondents (each, n = 2).

The next subsection concludes and discusses whether these devices would be accepted for Deaf people in the Western Cape.

2.4 Conclusion and discussions of Co-exploration Activity 2

This section starts with the conclusion that Co-exploration Activity 2 achieved its research objectives. Next, it discusses a comparison between these findings and the related works' findings.

The findings demonstrated that 47 of 54 respondents had access to mobile devices. Android smartphones would be accepted by Deaf people in the Western Cape as communication devices since they were popularly used by the respondents. Deaf people had already used mobile devices to seek and share health information via their phone (as part of Research Objective 1). The mobile phones that met Deaf people's needs (in line with Research Objective 2) should be equipped with quality front and back-facing cameras because 22 respondents took 25 photos and 28 respondents recorded five videos per day. They also shared pictures and videos with their families and friends through multiple social networks on their phones. WhatsApp, Facebook, imo, sky were the four popular apps that Deaf people used for sharing photos and videos. Health information sought and shared could be part of this communication. For the standard features on the phone, more than half of the respondents used their phone as an alarm clock and an agenda planner/a reminder. Fewer respondents used mobile phone for emailing and playing music to feel the beats. The respondents' achieved education levels and age groups were the variables that affected their usage of mobile phones (achieved Research Objective 3). The respondents with higher achieved education levels used their mobile phone for emailing more than their peers with lower education levels. Also, the respondents of the younger age groups (between 18 and 47 years old) used more varieties of social networks than those of the older age group (between 48 and 77 years old).

Since the Deaf majority in Co-exploration Activity 2 has access to a mobile device, it could be interpreted that many Deaf people in the Western Cape are acquainted with the use of this medium. The sharing of a mobile device implied that some Deaf people need to use it in their daily lives. If they could afford it, they would have owned one. The popularity of Android

smartphones in the findings suggested that this type of mobile phone should be the specified medium for Building Block 6. Also, the intervention of this CBCD approach should be designed to accommodate users who will be sharing a smartphone with their significant others.

The findings from Co-exploration Activity 2 shared two similarities with the related works. Firstly, many Deaf people owning a mobile device were found similar to the related works' findings. Secondly, some Deaf people still shared a mobile device with their trusted one, similar to findings in 2011-2012 from [Chinithorn's study \(2011\)](#) and [van Pinxteren's study \(2012\)](#). One difference from the related works' finding was the phone usage varieties that the Deaf respondents of Co-exploration Activity 2 had. The more advance the technology is, the more varieties of the phone's features and social networks that Deaf use.

3. Reflections on the initial guidelines

The reflections of Guidelines 2, 4, 5, 6, 7, and 8 (refer to [Chapter 2, Subsection 3.3](#)) are discussed. Guideline 1 is not discussed because all researchers have to comply with the research ethics outlined by the Human Sciences Research Council. Guidelines 3 and 9 are discussed at the end of the Co-evaluation Stage (see [Chapter 7, Section 5](#)).

The pre-discussion and invitation sent to Deaf communities (Guideline 2) were experienced as an initial step that was appropriate to approach Deaf communities. The DCCT management and the contact person, including Deaf members of the Vukani Deaf Club, were informed of the research purposes. Because of research benefits that would be contributing to their community, they were willing to participate in this empirical research. The initial guidelines regarding language use (Guideline 4) and the involvement of the SASLI, whom each Deaf community recommended (Guideline 5), were verified. Applying them for group interviews with participants who are Deaf and the use of the mobile questionnaire for data collections proved that using the SASL dialect that matched the preference of each Deaf community was vital. Through observations, some Deaf participants in Co-exploration Activity 1 and Deaf respondents in Co-exploration Activity 2 showed confusion while processing interpretations in a different SASL dialect. Flexible planning (Guideline 6) was useful for the conduct of this empirical research. Health professionals with tight schedules were separately interviewed at their own time and place, without affecting the quality of the interviews. Including one buffer time before the start of a research session and another one at the end of the session as part of organizations for research sessions was helpful. These buffers accommodated the participants' delayed arrivals, often caused by malfunctioning public transportsations (also Guideline 6), and the long leave-taking behaviors (Guideline 7), respectively. The adoption of Deaf

culture in research practice (also Guideline 7) and SASL learning (Guideline 8) were two other helpful guidelines because they enabled researchers to properly treat Deaf participants and respondents.

4. Answers to research questions and a way forward to the next research stage

The findings from Co-exploration Activities 1 and 2 answered SRQs 2 to 7. The SRQ 1 regarding the guidelines for actively involving a Deaf community and relevant stakeholders are going to be answered in [Chapter 7](#)—after completing the Co-evaluation Stage.

SRQ 2: How health information is delivered to Deaf people in the Western Cape, and who can be health information providers and health information seekers of this empirical research?

Answer: The information seekers in this research context are any Deaf people who are interested in information about the health topic(s) of their interest. Multiple stakeholders have engaged in health information distribution to Deaf people in the Western Cape. As such, there can be several health information providers. DOHWC partners with DCCT, other relevant organizations, and health facilities to deliver health information to Deaf people. DCCT's Deaf-health-worker team delivers information about HIV/AIDS by two channels. They have organized workshops for a mass group of audience at DCCT monthly gathering or Deaf communities that joined DCCT's outreach program. Also, they have provided one-to-one lay counseling for HIV-infected Deaf individuals. The hearing health professionals have provided health information for Deaf patients who came for consultation.

SRQ 3: How do Deaf people experience health information accessibility of the current information sources, channels, media, and devices, and which one are they interested?

Answer: Deaf participants had access to multiple health information sources. However, they experienced that most of these sources did not provide adequate health information accessibility when the information was not in SASL. A health consultation with a doctor in the presence of a SASLI was their most interesting channel due to the successful health information accessibility.

SRQ 4: How do Deaf people interact with their preferred information sources, channels, media, and devices to successfully exchange information?

Answer: Doctor at primary health centers, in the presence of a SASLI, was

Deaf people's most ideal information source. However, in reality with the societal complexity, consultation with a doctor in the absence of a SASLI and DCCT's health workshop and lay counseling were the channels that Deaf people accessed the most. Deaf participants preferred using mobile phones as media to seek and receive health information.

SRQ 5: How do Deaf people seek health information and what can be their methods to successfully communicate health information?

Answer: Deaf participants in the Western Cape did not regularly seek health information unless they suffered from a disease. They consulted a doctor when fell sick. They sometimes sought and received health information from their Deaf fellows when meeting face-to-face or via the use of mobile phone. 19 of 47 Deaf people who had access to a mobile phone sought and shared health information via it. Facebook and Whatsapp were used for multiple purposes, including health-information seeking. These Deaf people sought and shared health information with family members ($n = 4$), friends ($n = 4$), doctors ($n = 3$), their partner ($n = 2$), and their child ($n = 2$).

SRQ 6: What can be relevant health topics that the information seekers of this empirical research need, and what information can influence patient's medication and treatment adherence, according to the health information seekers' and providers' requirements?

Answer: Different groups of Deaf participants had various interests in the information of different diseases.

- Deaf men were interested in sex education, penis care, and sterile circumcision.
- Deaf women were interested in women's cancer, depression, and feet problems.
- Deaf families were interested in chickenpox/diabetes, diseases related to muscles, and allergies.
- Deaf participants of all groups were interested in cancer, diabetes, and hypertension.

SRQ 7: What can be criteria for an intervention to provide health information accessibility to Deaf people in the Western Cape context?

Answer: Mobile phones were the selected devices since they were Deaf participants' most popular ideas ($n = 12$). The Deaf respondent majority (47 out of 54) had access to them. Android smartphones were popular among these Deaf respondents (26 out of 47). As such, an Android app to provide health information to Deaf people during a health consultation at a primary

health center could be a suitable and accessible intervention in this research context. The app should be available to Deaf users free-of-charge since the Deaf majority are unemployed.

If possible, a smartphone with the specifications that met the potential Deaf users' requirements should be subsidized. A suitable phone should contain Deaf people's often used standard features: a music player, agenda planner and reminder, alarm clock, and already installed apps for email. The phone should be equipped with a battery that lasts for the prospective users may play music for three hours per day; have sufficient memory capacity to accommodate user-created data for long periods without backup.

Besides the answers to the SRQs, the Co-exploration Stage's findings contributed to alternatives, presented in [Table 4](#), for the six building blocks to formulate a case study.

Table 4. Proposals on the formulation of a case study brought to discussions with DCCT management

The building blocks for a case study	Proposals
1. The leading Deaf community in this CBCD approach	DCCT
2. Health topics of interest among Deaf people	Cancer
	Diabetes
	Hypertension
3. Intervention users who are Deaf	Any Deaf people
4. Intervention users who are health-information providers	Health professionals from primary health centers
5. Methods for communicating accessible health information to Deaf people	Drama in SASLI, a short presentation with pictures, and a platform for Q&A
6. Medium and device to provide accurate and accessible health information to Deaf people	App (medium) for Android smartphones (a type of device)

The next chapter (Co-planning Stage) provides details of the discussions and the joint decision making on the alternatives for these six building blocks with the leaders of the potential Deaf community.

Chapter

5

Co-planning



Deaf participant: “It’s important for the doctor to explain by means of interpreter. So that there is no breakdown of communication... I want to know what can I do to be healthy.”

Co-planning was the second stage of the applied community-based co-design (CBCD) approach. At this stage, the researcher and the Deaf community leaders discussed the findings from the co-exploration stage, then decided upon the alternatives for the six building blocks (as proposed in [Chapter 4, Table 4](#)) to formulate a case study. The management—the leaders—of the Deaf Community of Cape Town (DCCT) (a potential leading Deaf community) were invited to discuss the Co-exploration Stage’s findings and decide on the alternatives for the other five building blocks. The DCCT management decided that the community would not take the role of the leading Deaf community due to research validity and fatigue. Consequently, another Deaf community, with a profile that matched the criteria of a leading Deaf community, was approached. The National Institute for the Deaf (NID) stepped in as the new leading Deaf community for this CBCD approach. The findings of the co-exploration were introduced to the NID committee. The six building blocks and an additional study to get to know their Deaf members were proposed. The committee endorsed the additional study and awaited the outcomes to decide on the complete proposal. [Figure 29](#) presents the overview of the Co-planning Stage.

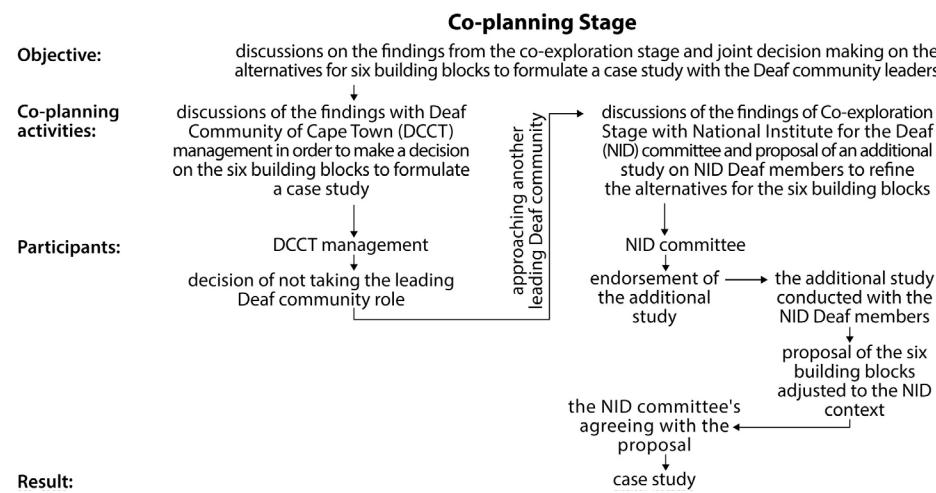


Figure 29. Overview of the Co-planning Stage.

This chapter comprises five sections. The first section provides the author's discussions with DCCT management and their reactions. The second section delineates the discussion with the NID committee regarding the alternatives for specific building blocks and a proposal on an additional study to understand Deaf members' understanding of diabetes, health information needs, and preferred methods for communicating health information. The third section provides the process and findings of the additional study. The fourth section provides validation on the initial guidelines for involving a Deaf community and relevant stakeholders in designing an intervention. Lastly, the fifth section refines answers to sub-research questions (SRQs) 4, 5, and 6 and formulates the case study for this CBCD approach.

1. Discussions with DCCT management

The discussions about the Co-exploration Stage's findings were facilitated through two modes of communication. First, an executive report summarizing the findings and proposing the building blocks to formulate a case study (refer to [Chapter 4, Table 4](#)) was emailed to the DCCT management. Second, a face-to-face meeting was arranged. The management mainly responded to the building blocks regarding health topics. They acknowledged Deaf people's interests in health topics beyond HIV/AIDS. They were interested in incorporating the Deaf men's information needs regarding sex education, penis care, and sterile circumcision as part of DCCT's HIV/AIDS programs. However, the management did not see how DCCT Deaf health workers' expertise could serve Deaf people's interests in the information about cancer, diabetes, and hypertension. Also, there were restrictions on their funding and workforce. These Deaf health workers have been contracted to deliver

healthcare services, especially for HIV/AIDS. Based on these arguments, the management and the author realized the mismatch about the health topics that would potentially affect this CBCD approach's validity. In addition, they had research fatigue since joining several research cycles with Bridging Application and Network Gaps (BANG). Thus, the management rescinded DCCT's active participation and recommended the author to identify a new leading Deaf community and include more relevant health organizations.

2. Shifting to NID—the leading Deaf community

The author and BANG had a roadshow about this CBCD approach for designing an intervention to other Deaf communities across the Western Cape. NID, a Deaf community with a profile (refer to [Chapter 4, Subsection 1.3](#)) that matched the criteria of a leading Deaf community (see [Table 1, Chapter 3](#)), agreed to take the role. This community was willing to design an intervention to provide health information accessibility to Deaf people. NID is a large Deaf community that accommodates Deaf learners from various areas in South Africa and neighboring countries. Their members are fluent in SASL and learn different dialects from each other. The community committee is fluent in English, and the members can read and write English. Furthermore, their staff is experienced in producing Deaf-accessible multimedia ([NID, 2017](#)). This Deaf community would be able to positively contribute to the intervention design, development, and dissemination. The following in this subsection provides the discussions the author had with the committee and staff.

According to one of the health promoters at NID, Deaf members of this community had limited health literacy. The provincial health-promotion curriculum that NID complied with covered a limited number of diseases within the educational periods. HIV/AIDS and TB information was mainly distributed to NID students as ranking in the Western Cape's health priority at the time. Although NID Deaf members were college students who could read and write relatively better than other Deaf people, their access to health information was as limited as many others' ([H. Visser, personal communication, March 29, 2016](#)).

The Co-exploration Stage's findings were introduced to the committee of NID—the new leading Deaf community as part of Building Block 1. The proposal on five other building blocks was adjusted to suit the NID context. This adjustment included additional studies with NID Deaf members, as recapped in [Table 5](#). The proposal for Building Blocks 2 to 6 is detailed below.

Building Block 2: proposed health topics

Sexual health information that Deaf men from Co-exploration Activity 1 were interested in was discarded to avoid any future conflict based on

cultural sensitivity. Deaf men from this church-founded community (refer to [Chapter 4, Subsection 1.3](#)) might not feel comfortable discussing information needs on this health topic with a female researcher, like the author.

Co-exploration Activity 1 highlighted that cancer and diabetes were the top two health topics of interest among Deaf participants in general. Diabetes was chosen over cancer for multiple reasons. Since cancer is a disease with a vast spectrum of appearances, selecting it for a case study might not be feasible for the timeframe of this research. Diabetes is widespread, strongly influences one's daily life, and requires complex treatments with active inputs from both the patient and health professionals. In terms of scientific contribution, diabetes' sophisticated treatments could benefit design sophistication for the intervention. At the same time, it would benefit Deaf people who would seek diabetes facts and learn how to self-manage diabetic lifestyle toward positive changes.

Since diabetes was chosen, type 2 diabetes was proposed specifically as the health topic due to its prevalence. This disease's ranking has moved up as a severe cause of death in South Africa, from fifth place in 2013 ([Statistics South Africa 2014, 2014](#)) to second place in 2016 ([Statistics South Africa 2016, 2017; Statistics South Africa 2017, 2018](#)). The Centre for Diabetes and Endocrinology (CDE) in Johannesburg predicted that the South African majority has type 2 diabetes without being diagnosed ([Otterman, 2012](#)). With this significance in health priority, the intervention that deals with type 2 diabetes would likely get long-term funding from the government.

Building Block 3: proposed intervention users who are Deaf and an additional study on Deaf NID members

According to a discussion with a health educator (H. Visser, personal communication, March 29, 2016), no NID student had been diagnosed with type 2 diabetes, and many of them might have a limited understanding of diabetes. Thus, the users for Building Block 3 could be any Deaf people who were interested in diabetes information. Although this group of Deaf users seemed to be too general, they could advantage this research for apparent measurements between their understanding and the knowledge they would gain after interacting with an intervention of the CBCD approach.

Thus, an additional study on NID Deaf members' understanding of diabetes and relevant health information needs was proposed to the NID committee. This study was meant to verify the selected users for Building Block 3, plus elaborate on the proposal of Building Block 2 (health content).

Building Block 4: proposed intervention users who are health-information providers

Hearing health professionals engaged in diabetes treatments at primary health centers were proposed as the target users of this building block. Health professionals from the health facilities that NID Deaf members usually visited were to be invited to the next CBCD stages.

Building Block 5: an additional study of NID members' preferred methods for communicating accessible health information

NID members' preferred methods for communicating health information might differ from the DCCT Deaf participants'. Consequently, the author proposed to study NID Deaf members' preferences before completing the details for this building block.

Building Block 6: the proposed medium and device

Android app (the medium) installed on an Android smartphone (Deaf people's preferred device) remained in the proposal.

The table below recaps the proposal on specific building blocks and the additional study.

Table 5. A proposal to formulate a case study discussed with NID

The building blocks for a case study	Proposals
1. The leading Deaf community	NID
2. The proposed health topic	Type 2 Diabetes
3. The proposed intervention users who are Deaf	Any Deaf people who are interested in the diabetes information Additional study: NID Deaf members' baseline understandings of diabetes and information needs regarding type 2 diabetes
4. The proposed intervention users who are health-information providers	Hearing health professionals who were engaged in diabetes treatments at primary health centers
5. The proposed methods for communicating health information to Deaf people	Additional study: NID Deaf members' preferred method
6. The proposed medium and device to provide accurate and accessible health information to Deaf people	App (medium) for Android smartphones (type of device)

The NID committee complied with the proposed building blocks and endorsed the two additional studies. The next section describes the additional study.

3. Additional study to get to know Deaf members of the leading Deaf community

This section includes the work related to Deaf people's understandings of different diseases, research methods and instruments, findings of this additional study, and conclusion and discussions.

3.1 Related works

The keyword non-diabetic Deaf people's understandings of diabetes within South Africa was searched in scientific and Google databases. The search results showed no study on Deaf people's understanding of diabetes in South Africa, including similar contexts. However, two studies came close and were worthed mentioning for their coherent findings. One was a study regarding the assessment of Deaf people's knowledge of hypertension in Cape Town ([Haricharan, Heap, Hacking, & Lau, 2017](#)), and the other was a study of diabetic Deaf people's knowledge about the disease in the United Kingdom (UK) ([The Deaf Health Charity, 2014](#)). [Haricharan et al. \(2017\)](#) surveyed Deaf people's baseline understanding using questionnaires. [The Deaf Health Charity \(2014\)](#) launched its questionnaire for Deaf people to complete over the Internet. Both related works showed that Deaf people understood common practices for a healthy lifestyle. However, they had a limited understanding of the diseases and were unaware of the necessity for early pathology detection.

3.2 Research process of the additional study

Research objectives, a criterion for selecting the respondents and sampling technique, research methods and instruments, and data analysis are provided.

Research objectives

Two research objectives were set. Research Objective 1 verified Building Block 2 and refine answers for SRQ 6 (Deaf people's health information of interest). Research Objective 2 verified Building Block 5 and update the answers for SRQ 5 (Deaf people's preferred methods for communicating health information), including for SRQ 4 (Deaf people's interaction with their preferred information sources).

- Research Objective 1: Identify NID Deaf members' understanding of diabetes and information needs regarding diabetes.
- Research Objective 2: Understand their preferred methods for communicating health information.

A criterion of the respondents and sampling technique

Being students of NID college was the only criterion for selecting these respondents. There was no requirement on their health literacy, health condition, or gender. [Table 6](#) presents the demographic profiles of the respondents in this study.

Table 6. Demographics of the Deaf respondents

	Categories	Frequency
Genders	Male	18
	Female	9
Study programs	Professional Cookery	9
	Upholstery	3
	Project Management	5
	Construction	7
	Dual program of choice	3
Current medication use	Not on any medication	21
	Regularly on a medication	3
	Occasionally on medication	3
Assistance to the significant other for medication taking	Often assisted their significant other with taking their medication	9
	Sometimes reminded their significant others to take their medication	6
	Helped no one	12
Visited health facilities	Government hospitals only	9
	Private doctors only	7
	Governmental primary health centers only	4
	Governmental primary health centers alternated with governmental hospitals	3
	Private doctors alternated with pharmacies	1
Locations of the visited health facilities	Worcester only	5
	Worcester alternated with another area	2
	Eastern Cape province only	4
	Durban province only	3
	Cape Town only	3
	Others and combined areas	8
	Not visiting any health facility	2

The group of students comprised five distinctive study programs: 1) Professional Cookery, 2) Upholstery, 3) Project Management, 4) Construction, and 5) dual programs of choice. Each of these study programs might affect the respondents' understanding of diabetes to different extents. For example, Professional Cookery students might be exposed more frequently to health-related subjects than their counterparts from other study programs. By following [Nielson's advice \(2000\)](#) on data collection from people of distinct groups, at least three respondents from each stated study program were specified to sufficiently identify patterns from their answers. A request for the respondents was submitted to the NID designated staff for scheduling the interview time slots.

Research methods and instrument

A literature search was conducted to find instruments for assessing diabetes knowledge of people who have never been diagnosed with type 2 diabetes. However, the instruments found in the literature were meant for those who already have diabetes. As such, research methods and instruments were developed in consultation with Diabetes South Africa (Diabetes SA).

Diabetes SA is a reputable health organization recommended by health policymakers from DOHWC. With contributions from health professionals, it has been distributing information about the most common types of diabetes—type 1, type 2, and gestational—and consultations for self-management via their website (www.diabetessa.org.za), Diabetes Focus eMagazine, and a booklet titled Diabetes and You.

- Interview methods

Individual interviews with structured questions were applied so that each Deaf respondent could answer questions to demonstrate their understanding of various topics about diabetes without other respondents' influence. The interviews were conducted in SASL and made similar to a hearing-Deaf discussion in the presence of a SASLI. This discussion-like interview was to avoid Deaf individuals' feeling like they were being assessed. Each interview was expected to last between 15 and 20 minutes for adequate data collection. All interviews were video recorded for analysis purposes. Four groups of questions were set to obtain findings in line with the research objectives (see [Figure 30](#)).

Question group 1 Demographics: - Gender, - Age, - Field of studying at NID, - Current use of medication, - The respondent's experiences in assisting a significant other for self-management, - The health facility that the respondent frequently visit	Question group 2 Baseline understanding on diabetes: - What the disease is - Common types of diabetes, - Symptoms of the disease, - Risk factors of becoming diabetic, - Actions to take to reduce the risks, - The action to take when suspecting of having diabetes, - Health complications while having diabetes, - Self-management action
Question group 3 Deaf people's requirements on health information regarding diabetes and its care: - Types of the needed information, - The methods to explain health information	Question group 4 Retain the participants for the co-design stage

Figure 30. Question groups for the additional study with NID.

Question Group 1 was related to the Deaf respondents' demographics that could affect their understanding of diabetes. Question Group 2 determined respondents' understanding. Question Group 3 identified the respondents' health information needs regarding diabetes and their preferred methods to communicate health information. Lastly, Question Group 4 intended to retain the respondents for the next CBCD stages.

Suppose a respondent stated not knowing what diabetes was. In that case, the questions in Group 2 about the common types of diabetes, symptoms of the disease, risk factors, and actions to reduce the risk could be skipped, in agreement with that particular respondent. The remaining questions in Group 2 were to continue in case the respondents might know the answers. For Question Group 3, animations, photographs, or illustrations accompanying the content, and simplification of health information in the form of an analogy, as suggested by the participants during Co-exploration Activity 1, were examples given to generate discussions with each respondent. With this process, NID Deaf members' preferences on the method(s) to communicate health contents were expected to be revealed.

- Research instrument

A diabetes-fact template containing checklists of accurate information about diabetes was developed to analyze the respondents' answers. Access <https://doi.org/10.5281/zenodo.4559833> for this template. Diabetes and You booklet was the reference for the checklists regarding what diabetes is ([Diabetes SA, n.d., p. 6](#)), symptoms of low and high blood glucose ([Diabetes SA, n.d., p. 11](#)), and lifestyle modifications ([Diabetes SA, n.d., p. 7-13](#)). The Diabetes SA website was used as a reference for the checklists concerning common types of diabetes ([Diabetes SA, 2018a](#)), risk factors ([Diabetes SA, 2018b](#)), comorbid diseases of diabetes ([Diabetes SA, 2018a](#)), and the action to take when one suspects they have diabetes. A Diabetes SA representative was the reference for the checklist about actions to take for reducing the risks of becoming type 2 diabetic.

- Involvement of South African Sign Language Interpreters

Two South African Sign Language Interpreters (SASLIs) recommended by NID were hired to take turns for interpretations. One SASLI was responsible for each interview. Before the data collection day, the research brief was interpreted and recorded in SASL and back-translated to recheck the interpretation accuracy. This research brief was displayed for individual respondents before each of them was asked to give consent to participate in the interview. The procedure for each interview is represented in [Figure 31](#).

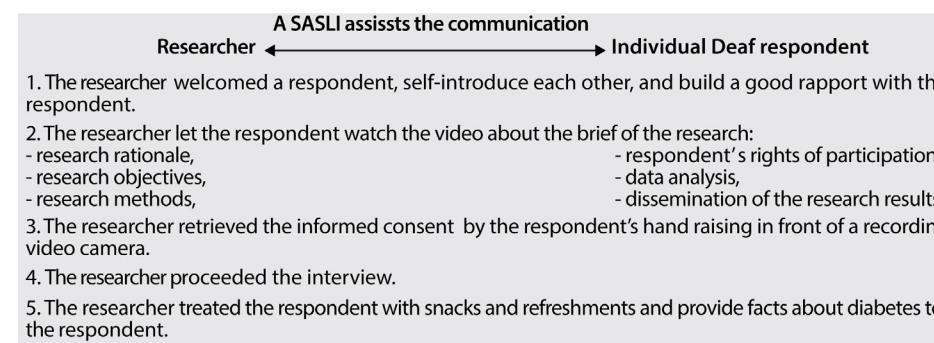


Figure 31. Procedure for individual interviews with Deaf respondents.

Data analysis

All interviews were transcribed manually. The answers for Question Groups 1, 3, and 4 were categorized and counted for frequency. The analysis of the answers to Question Group 2 was conducted in two steps: 1) classification for the correctness of the answers, and 2) thematic analysis of the incorrect answers.

At Step 1, each respondent's answer to a particular question was compared with the diabetes fact template and classified as either correct or incorrect using color-coding. Correct answers were marked in green, while incorrect answers were colored red. This analysis step was conducted to establish Deaf respondents' baseline understanding of diabetes and which misconceptions needed to be debunked. Access <https://doi.org/10.5281/zenodo.4765655> for the analysis for Step 1.

At Step 2, all classified answers were broken into short statements per question. Incorrect statements that were thematically related to each other were grouped. A table was created as part of this analysis. Its first cluster of columns collected the correct statements. The second cluster of columns contained the incorrect statements and their themes. The same process was

repeated for all questions in Group 2. Through these codings, the correct statements presented the baseline understanding of various topics about diabetes. The incorrect statements addressed the health misconceptions that an intervention of this research needed to debunk. [These tables can be accessed from https://doi.org/10.5281/zenodo.4765659](https://doi.org/10.5281/zenodo.4765659). At different periods, these analyses were checked twice by the author for the consistent findings.

Limitation of this additional study

This study was conducted to learn NID Deaf members' baseline understanding of diabetes, relevant information needs, and preferred methods for communicating health information. The results of this data might apply to some Deaf communities in the Western Cape, but they might not represent understanding about the disease and needs of all Deaf people.

3.3 Findings from the additional study

Twenty-eight students signed up for interviews; however, one person refused to participate after viewing the research brief. These findings were consequently analyzed based on completed interviews with 27 respondents.

Deaf people's baseline understanding of diabetes

[Table 7](#) presents the frequencies of correct and incorrect answers per question in Group 2. Thereafter, the findings from the analysis in Step 2 are elaborated.

Table 7. The answers retrieved for questions in Group 2

Questions	Correct answers	Incorrect answers	Skipped answers
What is diabetes?	0	16	11
What are the common types of diabetes?	0	7	20
What are the common symptoms found among diabetic people?	2	9	16
What are the risk factors for a person to become a (type 2) diabetic?	1	10	16
What are the actions to take to reduce the risk of becoming diabetic?	3	10	14
What is the action to take when you suspect you have diabetes?	23	4	0
What are the health complications that come with diabetes?	2	8	17
What are the actions to improve health conditions and prevent health complications (self-management)?	15	5	7

- What diabetes is

No respondent could provide an entirely correct answer. One respondent nearly gave a completely correct answer by touching upon high blood glucose levels but not the other three descriptions of what diabetes is. Seven themes of error statements were identified: 1) a disease caused by sugar, 2) a disease transmitted via coughing only, 3) a disease that always needs medication, 4) a disease transferred via blood only, 5) a disease transferred via mosquitos, 6) a disease with a digestive problem, and 7) a disease that is the same as high blood pressure. For Theme 1, the respondents associated diabetes with excessive sugary-food intake. Themes 2, 4, and 5 showed that several respondents mistook diabetes as a transmitted disease. Their answers implied that the preconceived understanding about other diseases influenced their (mis)understanding of diabetes. Concerning Themes 3 and 7, these respondents seemed to develop such understanding through accidental learning from their diabetic family members.

These findings indicated that the intervention of this CBCD approach should contain health content that would provide Deaf people with a basic understanding of how the human body converts eaten food into energy and describes the occurrence of diabetes when that process goes awry. These

two topics were expected to expose Deaf people to some diabetes facts and help them address their preconceptions.

- The common types of diabetes

None of the respondents could provide the totally correct answer. Twenty-five respondents did not know that there are multiple types of diabetes. Seven respondents did not skip this question and gave incorrect answers. Two respondents mentioned type 1 and type 2, but elaborated on details with errors. Two themes of error statements were identified from the respondents' elaborations for type 1 diabetes and three themes for type 2. Each of these error themes received only one mention. None of these respondents knew about gestational diabetes.

These findings suggested that the intervention of this CBCD research should provide Deaf people with understanding of the common types of diabetes.

- Common symptoms of diabetes

Two respondents gave entirely correct answers. Extreme fatigue or lack of energy, blurred vision, and unusual weight loss were the top three mentioned symptoms. However, many respondents who answered this question barely knew the six other common symptoms. While analyzing the error statements, six themes were found. Each of these themes gained one or two mentions. These findings showed that Deaf people have a limited understanding of the symptoms.

Therefore, it is necessary to make information accessible regarding the common symptoms of diabetes for Deaf people so they will be able to observe their own or significant others' health.

- Risk factors of becoming diabetic

One respondent could give an entirely correct answer. Three out of seven risk factors of becoming diabetic: having a family history of diabetes, cholesterol in the blood, and high blood pressure or heart disease were mentioned by the respondent who gave a completely correct answer and those who gave incorrect answers. Thirteen themes of error statements were derived. Too much sugar intake earned the most mentions, followed by medicine or drug abuse, being contaminated by diabetic people, and being sprayed by somebody's cough. The remaining error themes received one mention each. An association was found between the answers regarding the risk factors and the answers about the understanding of diabetes. Most of the respondents who believed diabetes was a disease related to sugar stated that excessive eating of sugary foods was a risk factor of becoming diabetic. A similar association was found from the respondents who considered diabetes a transmitted disease and stated the relevant errors in the risk factors.

These findings indicate that the risk factors of becoming diabetic should be described to Deaf people point by point after the basic information about diabetes is provided to them. With this information, Deaf people will be exposed twice to the health content that could help them replace misconceptions with facts.

- Actions to take to reduce the risks of becoming diabetic

Three respondents gave completely correct answers about the action to take. Healthy diet, exercise, and no smoking were mentioned as the actions to reduce the risks of becoming diabetic. None of them thought of weight control and reduction in stress as correct actions. Seven themes were identified from the error statements. The top three were taking medication to prevent diabetes, avoid touching diabetic people, and not sharing clothes and utensils with the diabetic person in the family. The rest of the error themes received one mention each.

Based on these findings, part of the content delivered through the intervention of this CBBCD research should emphasize lifestyle modifications as an essential practice for reducing the risks of becoming diabetic. Also, the content should repeat that diabetes is not contagious and that medication cannot protect anyone from having diabetes.

- The action to take when suspecting of having diabetes

Twenty-three respondents gave a correct answer about the action to take. Consulting a doctor is the correct action that Diabetes SA recommends to anyone who suspects having diabetes. As opposed to the majority, one respondent insisted on not consulting any doctors due to her fear of problematic communication.

- Health complications that come with diabetes

Two respondents gave a correct answer concerning health complications. High blood pressure and high blood glucose were mentioned by the respondents who provided the completely correct answers and those who gave incorrect answers. These respondents did not state blindness, stroke, kidney failure, impotence, sexual dysfunction, and amputation. The incorrect answers fell into five themes, including no health complications, becoming a carrier of a contagious disease, and three other themes that each of them was only mentioned once by the respondents.

These findings showed that the information available through the intervention must address health complications that a person who ignores improving one's diabetic condition will have. Emphasis on diabetes as a non-transmitted disease has to be repeated.

- Actions to improve health conditions and prevent health complications
- Fifteen respondents gave a correct answer concerning health complications. Healthy eating, regular exercise, and taking medication as prescribed ranked the respondents' top three mentions. However, foot care and blood glucose testing as part of the checklist were unknown to them. Each of the five themes of error statements was found with one mention. Based on these findings, all five practices to improve the health conditions and prevent health complications should be made known to Deaf people to provide long-term benefits.

The demographic profiles that might affect the respondents' understanding of diabetes were observed (refer to [Table 6](#)). The respondents who were studying Professional Cookery and Project Management could better elaborate on their understanding than their counterparts from the other two programs. The respondents' current medication use or assistance to their significant other with taking medication seemed not to contribute to their knowledge of diabetes. Nonetheless, exposures to a diabetic family member affected their understanding of diabetes, symptoms, and actions to reduce the risks.

Diabetes information needs and communication methods

This subsection comprises the answers regarding the respondents' information needs and their preferred methods to communicate health contents.

- Deaf people's health information needs if diagnosed with diabetes
- Eighteen topics regarding the respondents' needed health information are categorized in [Table 8](#).

Table 8. Diabetes content needed by Deaf respondents

The required health topics regarding diabetes	Frequency
Actions to take to improve the health condition	18
Causes of diabetes	12
Medication instructions	12
Preventing diabetes	10
Diet for people with diabetes	8
How diabetes takes place in the body	7
Dos and Don'ts	7
Consequences in life after becoming diabetic	6
Treatment options	6
Comorbid diseases	4
Assistive tools which sound an alarm before a diabetes attack	3
Purposes of injection	2
Frequency of blood glucose testing	2
Types of diabetes	1
Importance of follow-up appointments	1
Prognosis after being diagnosed	1
Duration of bed days at health facilities	1
Information for a caregiver of the diabetic person	1

Next, the respondents discussed the methods they preferred a health professional to use for communicating health information to them in the absence of a SASLI.

- Deaf people's preferred method for receiving health information

Receiving health information in SASL was the ideal situation for all respondents. Twenty respondents said that photographs to accompany health information would help them locate internal organs in the body. However, seven respondents argued that photographs of organs could be unclear or scary, and that illustrations of internal organs could be a better presentation. Twenty-one respondents expressed that animation could help them understand the progression of the disease in the body. These respondents recommended rendering SASL interpretation next to the animation and inserting subtitles at the bottom. They would glance at the subtitles when some signs used by the SASLI were not understood. A

respondent suggested that the font-size of the subtitles should be readable if they were being displayed on mobile phones. Several respondents preferred a straightforward explanation and thought an analogy that a doctor might use for explaining health information was difficult to understand.

Four respondents shared that their doctor used an X-ray film or a scanned image to accompany explanations in some of their previous consultations. These two materials helped them better understand their sickness. They presumed that an X-ray film or scanned image could help in the explanation about diabetes. A respondent added that hand-drawn sketches could sometimes enhance his understanding during a consultation with a doctor, so he expected it to also enhance his understanding of diabetes. In addition, presentation slides, a diagram, and an explanation in writing were also suggested by a few respondents. None of these 27 respondents mentioned the combined methods that DCCT applied in health information delivery since they were rarely exposed to the DCCT's outreach program.

In summary, animation to accompany the explanation received the highest number of mentions. Photographs to accompany the explanation got the second highest, and illustrations received the least number of mentions.

Retaining participants

Twenty-one respondents were interested in participating in the next stage of this research. One respondent declined, and five respondents were unsure.

3.4 Conclusion and discussions of the additional study

This section concludes DCCT's and NID's decisions on taking the leading Deaf community role in this CBCD approach and the findings from the additional studies conducted with NID Deaf members. Similarities between this additional study's findings and related works' are discussed. Two Deaf communities participated in discussions to select each option for the six building blocks to formulate a case study. DCCT was the first Deaf community that participated and refused to take the role of the leading Deaf community due to research validity and fatigue. NID consequently took this role and endorsed an additional study. The results from this study refined a list of relevant health content that met Deaf people's needs (Building Block 2), verified Deaf users of the intervention (Building Block 3), and updated methods for communicating health information to Deaf people (Building Block 5).

NID Deaf respondents' understanding of diabetes was limited. Preconceived knowledge and previous experiences with health services seem to cause the respondents' misconceptions in multiple diabetes topics. These

respondents constructed their understanding of the disease based on what they knew about HIV/AIDS and TB—the two health topics frequently distributed at NID. Further evidence of respondents associating their past experiences with the treatment of other diseases included faulty inquiring about the prognosis for a diabetes diagnosis and recommending X-ray films as an accompaniment to the explanation about diabetes. These findings show two similarities with what the related works found. Many Deaf people knew how to live a healthy lifestyle, but only a few people were aware of the necessity to detect a disease.

4. Reflections of the initial guideline

Guidelines 2, 4, 5, 6, 7, and 8 were applied and observed whether they could help the author in closely involving a Deaf community toward designing an intervention, like what reflected in [Chapter 4, Section 3](#). Pre-discussion with Deaf communities' leaders (Guideline 2) was a verified guideline since it helped the author establish research relationships with Deaf communities in the Western Cape appropriately. Specifically for the NID committee, they were informed of this CBCD approach's purposes. Upon diabetes health information that Deaf people would be exposed to, they were willing to let NID members participate in the remaining CBCD stages. The initial guidelines regarding languages used during this CBCD stage (Guideline 4) and the involvement of the SASLIs whom the Deaf community recommended (Guideline 5) were verified. Employing the SASLIs who used the dialect that matched the preference of NID Deaf members was vital. Each Deaf respondent and the author needed to understand each other while continuing a discussion. Adoption of Deaf culture into research practice (Guideline 7), especially about the communication requirements, was used the most to engage Deaf respondents in the discussions. SASL learning (Guideline 8) was another practical guideline for comforting Deaf respondents whom a hearing researcher interviewed. Each respondent became relaxed after seeing that the author could greet and understand each other's self-introduction in SASL.

Through these reflections, these six initial guidelines were verified for aiding the author in establishing new research relationships with Deaf communities and conducted interviews that were appropriate to the Deaf culture and Deaf people's communication requirements.

5. Answers to research questions and a way forward to the next CBCD stage

This section presents the refined answers to SRQs 4, 5, and 6, then formulates the case study of this CBCD approach. The answer to SRQ 4 was rephrased to emphasize NID Deaf members' health information sources, channels, media, and devices. Photographs and illustrations for

enhancing Deaf people's understanding of the location of the internal organs, animation for explaining the disease's progression in the body, and SASL interpretation with subtitles rendered in the video were new methods refined for SRQ 5. The respondents' information needs when being diagnosed with (type 2) diabetes contributed answers to SRQ 6. How to improve their health condition, the causes of the disease, and medication instructions were the first three pieces of health content they most needed, followed by an extended list.

SRQ 4: How do Deaf people interact with their preferred information sources, channels, media, and devices to successfully exchange information?

Answer: Doctors were NID Deaf members' preferred health information sources. Health consultations at primary health centers were their main channel to access health information. In addition, NID members agreed that mobile phones could be the devices to provide them with access to health information in the absence of a SASLI.

SRQ 5: How do Deaf people seek health information and what can be their methods to successfully communicate health information?

Answer: Deaf people in different locations had different preferences for methods to communicate health information. NID Deaf members preferred methods involving a combination of SASL, visual materials, and subtitles for communicating health information. As for the visual materials, photographs and illustrations were recommended for describing the body organs, and animation was for explaining the progression of diseases.

SRQ 6: What can be relevant health topics that the information seekers of this empirical research need, and what information can influence patient's medication and treatment adherence, according to the health information seekers' and providers' requirements?

Answer: Diabetes was chosen over other diseases and target any Deaf people interested in the disease's information. NID Deaf people who put themselves in the shoes of a patient diagnosed with diabetes for the first time expressed the top 3 health contents they would need 1) how to improve their health condition, 2) cause of the disease, and 3) medication instructions.

The details in [Table 9](#) were collected based on the findings from this additional study and brought to another discussion with the NID committee.

Table 9. The final selection for the building blocks of the case study

The building blocks	Details
1. The leading Deaf community in this CBCD approach	NID
2. Health topic of interest among Deaf people	Type 2 diabetes Basic understanding regarding type 2 diabetes for Deaf people and diabetic Deaf patients Health information should comply with medical standards and include at least the following: 1) how to improve their health condition, 2) the causes of the disease, 3) medication instructions as NID Deaf members require.
3. The target users who are Deaf	Any Deaf people who have an interest in the information
4. The target users who are health-information providers	Hearing health professionals who were engaged in diabetes treatments at primary health centers in Worcester
5. Methods for communicating accessible health information to Deaf people	Photographs and illustrations to enhance Deaf people's understanding of the location of the internal organs Animation to accompany the explanation on how the disease progresses in the body SASL interpretation rendered in the video
6. Medium and device to provide accurate and accessible health information to Deaf people	App for Android smartphones

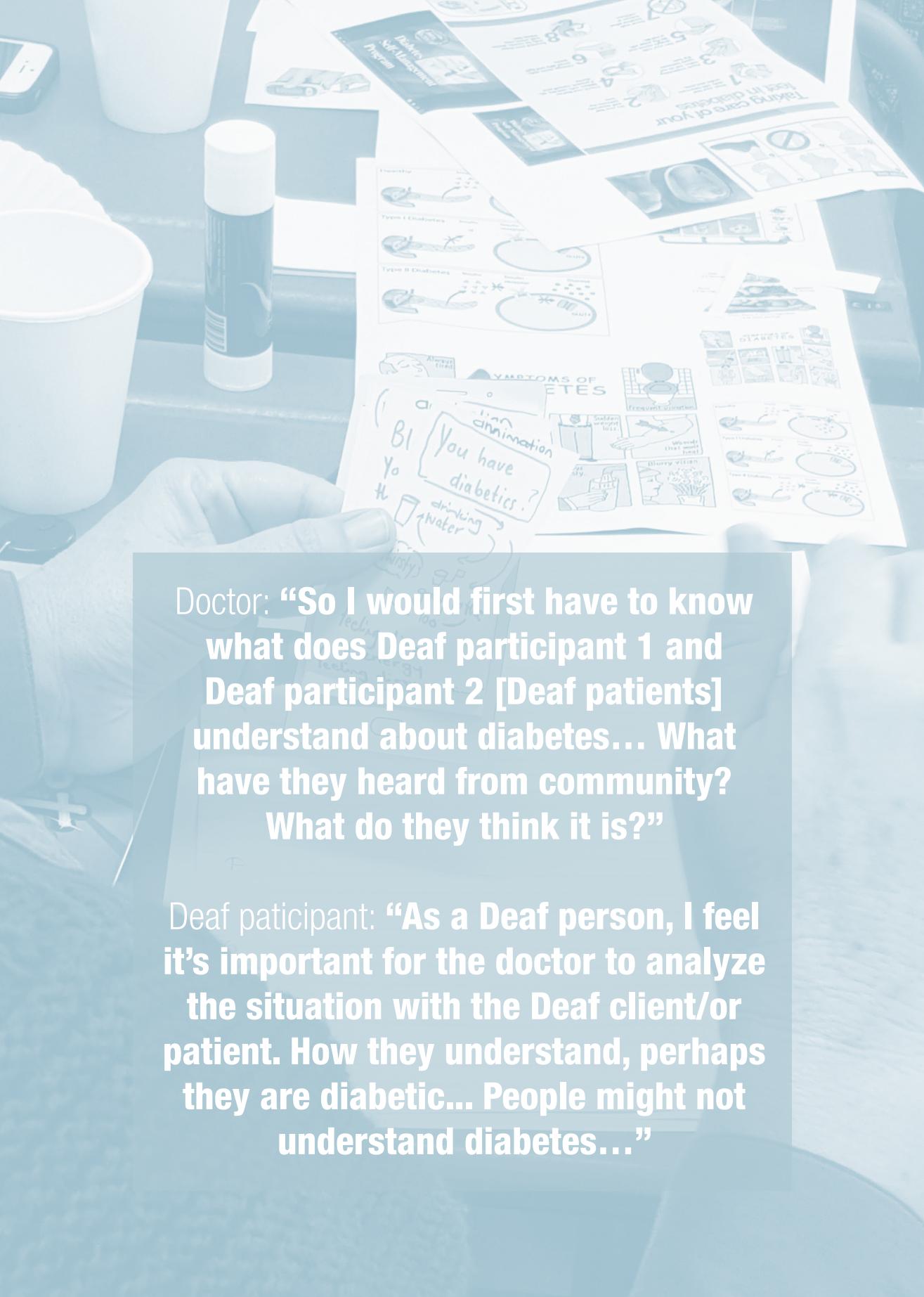
The committee agreed with the details and formulated a case study for this CBCD approach. The case study directed a preparation toward the co-design stage. The intervention of this research has been specified as an Android app (resulting from Building Block 6) that bridges communication between a Deaf patient (resulting from Building Block 3) and a health professional engaged in Type 2 diabetes treatment at a primary health center (resulting from Building Blocks 2 and 4) in order to deliver accessible health information regarding diabetes (resulting from Building Block 2). Health content should be presented via a combination of SASL, visual materials, and subtitles (resulting from Building Block 5) in a video format through the app.

Refer to [Table 9](#), some requirements (e.g., methods for communicating health information) for designing an intervention were retrieved. Their details, including other requirements, still had to be identified and elaborated. [The next chapter](#) explains the identifications of the design requirements during the co-design stage.

Chapter

6

Co-design



Doctor: "So I would first have to know what does Deaf participant 1 and Deaf participant 2 [Deaf patients] understand about diabetes... What have they heard from community? What do they think it is?"

Deaf participant: "As a Deaf person, I feel it's important for the doctor to analyze the situation with the Deaf client/or patient. How they understand, perhaps they are diabetic... People might not understand diabetes..."

Co-design was the third stage of the community-based co-design (CBCD) approach. In this stage, researchers and participants collaborated to elicit knowledge for designing an app—the intervention identified through the Co-exploration and the Co-planning Stages. This knowledge included a way to 1) design an app for bridging communication between a Deaf patient and hearing health professionals and 2) design accessible health content for Deaf patients. Deaf people, health professionals, and Deaf experts took the role of local designers; researchers shifted between the roles of design facilitators and co-designers. Three co-design activities were formulated (see [Figure 32](#)).

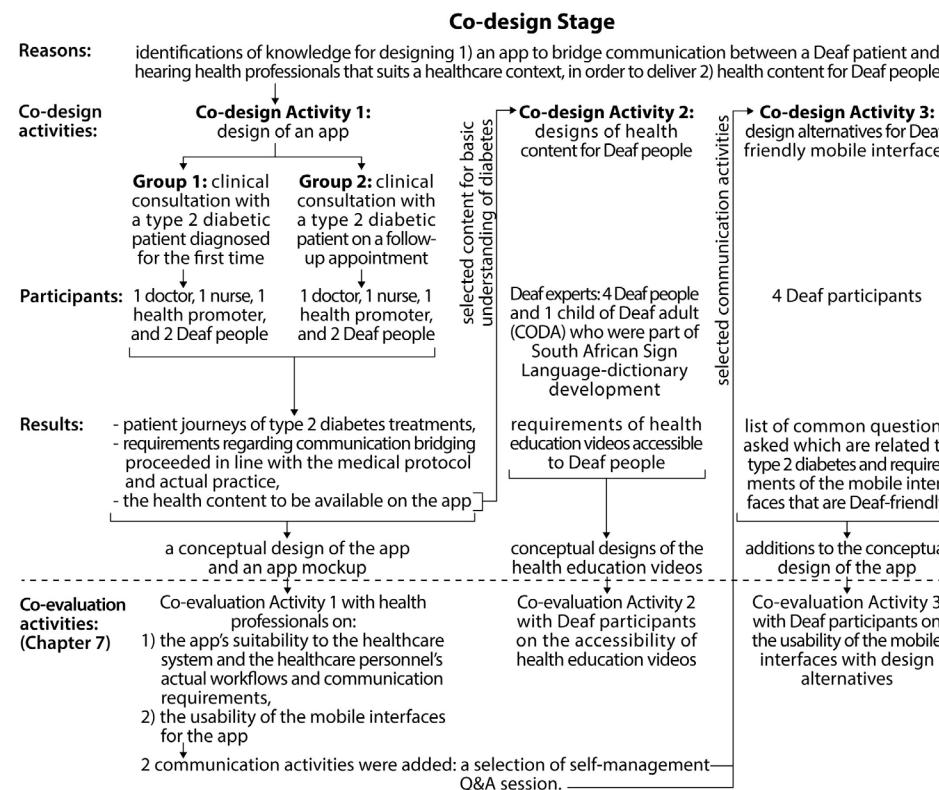


Figure 32. Overview of the Co-design Stage.

Co-design Activity 1 ([Section 1](#)) was conducted to identify requirements for an app to bridge communication and deliver health information between a Deaf patient and healthcare personnel during type 2 diabetes treatments. Deaf people and health professionals were involved in this co-design activity to contribute to 1) patient journeys of type 2 diabetes treatments, 2) requirements regarding communication bridging in line with the medical protocol and actual practice, and 3) the health content available on the app.

The third outcome of Co-design Activity 1 was further iterated upon during Co-design Activity 2 ([Section 2](#)). A group of Deaf experts, consisting of Deaf people and a CODA who have had experiences developing and producing educational materials and a SASL dictionary, were involved in this second co-design activity. The results of Co-design Activity 2 were 1) the scripts and narrations in South African Sign Language (SASL) for the selected the health content regarding diabetes, 2) visual materials for content that needed visual enhancement, and 3) presentation of all elements: SASL narrations, visual materials, subtitles, and voice-overs.

Co-design Activity 1's results were compiled into a conceptual design and an app mockup for health professionals to test during Co-evaluation Activity 1 ([Chapter 7, Section 1](#)). Consequently, improvement points were listed for this app's design to comply with health-service guidelines and cater to actual practices at primary health centers. Based on Co-evaluation Activity 1's improvement points, Co-design Activity 3 ([Section 3](#)) obtained design alternatives from Deaf participants toward Deaf-friendly mobile interfaces.

This chapter is composed of five sections. [Sections 1 to 3](#) present details of Co-design Activities 1 to 3. [Section 4](#) reflects on the initial guidelines for actively involving a Deaf community and health professionals in this CBCD approach. Lastly, [Section 5](#) refines answers to the SRQs and addresses the way forward to the co-evaluation stage ([Chapter 7](#)).

1. Co-design Activity 1: design of an app

This section includes related works, research and design process, findings from the participants' inputs for the app design, a conceptual design of the app, and conclusion and discussion.

1.1 Related works

Two types of related works were studied: 1) health-service guidelines for type 2 diabetes treatments and 2) mobile-interface design guidelines to design an app during this co-design activity.

Health-services guidelines were studied since this app needed to suit the healthcare system in Cape Winelands District (CWD)—where the National Institute for the Deaf (NID) is located. The 2012 Society for Endocrinology, Metabolism, and Diabetes of South Africa (SEMDSA) Journal ([Amod et al., 2012](#)) and Primary Care 101 (PAC 101) Guideline 2013/14 ([University of Cape Town Lung Institute for the National Department of Health, 2014](#)) implemented in the CWD were consequently selected. Based on these two health-service guidelines, patient journeys were developed and split into two routes: 1) journey of a type 2 diabetic patient who is diagnosed for the first time and 2) journey of a type 2 diabetic patient who is on a follow-up appointment. These health-service guidelines described, in particular, the roles of health professionals, such as nurses and doctors. However, the roles of the auxiliary staff with whom the patients also interact were barely mentioned. Thus, there was a need to identify the auxiliary staff and health professionals and detail their communication activities and health content delivered to patients.

As this app had to be easy to use for both healthcare personnel (health professionals and auxiliary staff) and Deaf patients, guidelines for designing an app were studied. *Mobile interface design* guidelines was the keyword

searched in the Google database to derive the guidelines that designers popularly referenced. Selecting popular related works on design guidelines could ensure that this app's mobile interfaces would likely be easy to use. Two guidelines regarding information architecture ([McVicar, 2012](#)) and user patterns together with Graphic User Interface (GUI) elements ([Hoober & Berkman, 2011](#)) were selected. The first recommended an organization of information for a user's smooth navigation through the app. The latter guided a designer to implement consistent user patterns and GUI elements for a user's information access, input, control, and output, including confirmation of information input.

1.2 Research and design process of Co-design Activity 1

This section describes the research objectives, criteria for selecting participants, research methods and instruments, data analysis, and limitations of Co-design Activity 1.

Research objectives

Four research objectives were formulated to obtain requirements for designing an app to bridge communication between a Deaf patient and healthcare personnel for delivering health information during type 2 diabetes treatments. These findings were to refine the answers to sub-research questions (SRQ) 2 (listing of healthcare personnel who provides health information to diabetic patients), SRQ 4 (interactions between a patient and a health professional), SRQ 5 (methods for communicating health information), SRQ 6 (relevant health content), and the main research (MRQ) question (an intervention to influence Deaf people's medical and treatment adherence).

- Research Objective 1: Develop patient journeys for type 2 diabetes treatments at primary health centers.
- Research Objective 2: Identify communication activities between a Deaf patient and healthcare personnel during the patient journeys.
- Research Objective 3: Determine listings of health content available on the app to meet health-service guidelines for type 2 diabetes treatment, health professionals' requirements, and Deaf patients' needs.
- Research Objective 4: Describe mobile interfaces designed based on health professionals' and Deaf participants' ideas.

Criteria for selecting the participants

The criteria for selecting health professionals and Deaf participants were:

- Health professionals must be expertized in type 2 diabetes treatments, have some experience in delivering health information to Deaf people,

and being interested in designing an intervention.

- Deaf participants should be the respondents from the additional study during the Co-planning Stage who indicated in the questionnaire that they are interested in diabetes information and co-designing an intervention.

Research and design methods and instruments

These methods are about a process for identifying relevant participants, research and design methods, including the research instruments used during the co-design sessions.

- Process for identifying participants

Descriptions of patient journeys according to the related works ([Amod et al., 2012](#); [University of Cape Town Lung Institute for the National Department of Health, 2014](#)), retention of Deaf people from the Co-planning Stage (refer to [Chapter 5, Subsection 3.3](#)), and realization of the communication challenges between Deaf and hearing people (refer to [Chapter 1, Subsections 3.2 to 3.3](#)) were referred to for identifying the relevant participants.

Doctors and clinical nurses were the health professionals delivering health information to Deaf people the most. As such, they were identified as relevant participants. The doctors and nurses, who have been engaged in type 2 diabetes treatment and had some experience interacting with Deaf patients, were invited from health facilities frequently visited by NID members. This was to recruit health professionals aware of Deafness and Deaf people's communication needs for this co-design activity.

Since Deaf and hearing people (i.e., doctors, clinical nurses, and researchers) were to co-design an intervention, communication challenges could occur and affect their dialogues. To overcome these challenges, Deaf participants with specific characteristics and additional participants to intervene and prevent undesirable effects were recruited. Deaf participants with a better understanding of diabetes than other NID members and Deaf participants who were outspoken were paired to stimulate the dynamic dialogues between Deaf participants and health professionals. Additionally, health promoters who had some experience working with Deaf people and coaching diabetic patients to adhere to the prescribed medication and treatments were involved in this co-design activity. They were to moderate the requirements for the app's design to fit both health-service guidelines and Deaf patients' needs. One health promotor was working at NID as a health educator, and the other has been the Diabetes South Africa (Diabetes SA) representative. In summary, doctors, nurses, Deaf people who had higher diabetes knowledge than the Deaf average, outspoken Deaf people, and health promoters were invited to participate in Co-design Activity 1. Their profiles

are described in [Table 10](#).

- Research and design methods

Group training about diabetes for Deaf participants, focus groups, storytelling, and involvement of South African Sign Language Interpreters (SASLs) were applied as the methods to this research and design. Deaf participants were required to attend a 30-minute-long group training on common types of diabetes. This was to prepare them with basic knowledge about type 2 diabetes for co-designing an app. With assistance from a SASLI, the Diabetes SA representative introduced the group to basic knowledge on diabetes through a presentation with many illustrations for enhancing the participants' understanding. They were followed by a question and answer (Q&A) session to clarify their doubts.

For each of the two patient journeys (see [Subsection 1.1 of this chapter](#)), a focus group session was planned. These two focus groups were conducted simultaneously, within two and a half hours, to suit the participants' limited availability. Each focus group was composed of the paired Deaf participants, one doctor, one nurse, and one health promoter. One main research facilitator to facilitate the co-designing, one assisting facilitator to video-record and photograph the session, and one assisting facilitator to supply stationery and cater a break were assigned to each group.

As suggested by [Johansson \(2014\)](#), storytelling was used as a method to stimulate dialogues and creative thinking. The story for this co-design activity was crafted to depict the struggles and frustrations that a Deaf patient and a doctor experienced at a primary health center. This story encouraged all participants to contribute to designing an app and health content that should be delivered to a diabetic patient.

Table 10. Profiles of the participants and composition of the two focus groups (part 1)

Focus Group 1: Clinical consultation with a type 2 diabetes Deaf patient diagnosed for the first time	
Participants and their profiles	Reasons for assigning
Deaf Participant 1 had a higher understanding of diabetes than others.	The combination of both types of Deaf participants should stimulate the dynamics in the dialogues amongst Deaf and health professional participants.
Deaf Participant 2 was outspoken and liked to advocate Deaf people's rights.	
Doctor 1 has been a doctor from the Comprehensive Health Program who had some experience serving Deaf patients at the NID clinic in the past.	The doctor's research on chronic diseases and experiences in serving Deaf people could contribute to details of communication activities during a clinical consultation and a selection of health content necessary for diabetes consultations.
Nurse 1 has been a policymaker for chronic diseases and nursing.	The nurse's involvement in the implementation of a health-service guideline at primary health centers in CWD could help refine communication activities throughout the patient journeys.
Health Promoter 1 was a health educator teaching Deaf students at NID.	The health promoter's experiences should contribute to both the app's design to bridge clinical communication and an appropriate sequence of health information to promote understanding of diabetes for Deaf people.

Table 10. Profiles of the participants and composition of the two focus groups (part 2)

Focus Group 2: Clinical consultation for a Type 2 diabetic patient on a follow-up appointment	
Participants and their profiles	Reasons for assigning
Deaf Participant 3 had a higher understanding of diabetes than others.	The same reason as presented in Focus Group 1
Deaf Participant 4 was outspoken and liked to advocate Deaf people's rights.	
Doctor 2 has been specialized in chronic care at a primary health center.	The doctor's interest in the care for chronic diseases could contribute to communication activities that help diabetic Deaf patients understand how to self-manage their health.
Nurse 2 was a staff nurse working at a nursing home for Deaf adults.	The nurse's experiences working with Deaf people could contribute to details of communication activities and an appropriate sequence of health information for promoting self-management to Deaf patients.
Health Promoter 2 has been representative from Diabetes SA who had been coaching diabetic people with low literacies.	The health promoter's experiences should contribute to the selection and appropriate sequencing of health content necessary for self-management.

SASLIs recommended by the NID contact person and who also have high English proficiency were employed. This was to overcome language barriers that could obstruct the dialogues between the Deaf and hearing participants, including research facilitators.

- Research instruments

A diagram of the patient journeys in type 2 diabetes treatments (see Figure 33) and a sensitizing toolset (see Figure 34) were used as research instruments. The diagram, in Figure 33, was constructed based on information retrieved from health-service guidelines (Amod et al., 2012; University of Cape Town Lung Institute for the National Department of Health, 2014). The diagram was printed on an A4 sheet for the doctor and the nurse of each focus group to identify the healthcare personnel and explicate the communication activities

during the patient journeys. The participants could redraw or write changes in the communication activities onto the diagram.

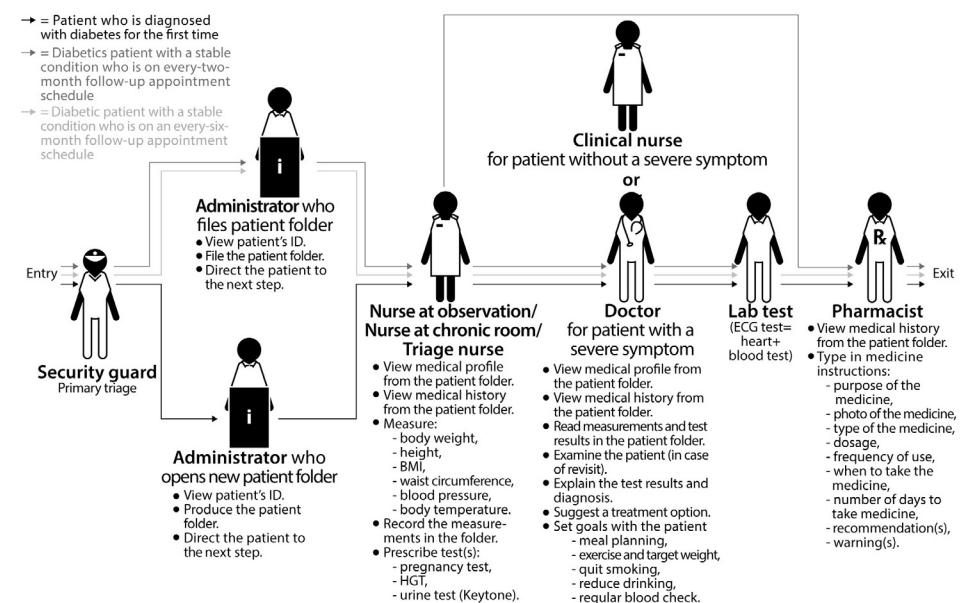


Figure 33. Diagram of the patient journeys.

According to Chinithorn (2011) and Looijesteijn (2009), sensitizing toolsets could help participants manifest their ideas to other participants. Each participant was provided with a sensitizing toolset to draw ideas on how a mobile app should bridge communication and transfer health information between a health professional to a Deaf patient. The drawings were to make the "verbal" explanations explicit. The sensitizing toolset comprised a booklet in the shape and size of a smartphone, colored stationery, an eraser, a pair of scissors, and pictures related to diabetes and its self-management (Figure 34).



Figure 34. Sensitizing toolset for Co-design Activity 1.

The two co-design groups were proceeded as described in [Figure 35](#).



Figure 35. Procedure for Co-design Activity 1.

First, data in line with Research Objective 3 was retrieved by asking the participants to discuss the matching between Deaf patients' needed health information and the content that the health professionals had to deliver. Next, the participants' ideas for the app were gathered as part of Research Objective 4. Lastly, the checking on the patient journeys, as part of Research Objectives 1 and 2, was conducted. Prior to the sessions, these procedures were piloted with research fellows, and minor adjustments were made.

Data analysis

Videos recorded during Focus Groups 1 and 2 were manually transcribed. To achieve Research Objectives 1 and 2, the health professionals' feedback about the listing of the healthcare personnel engaged in type 2 diabetes treatments and communication activities in the diagram was analyzed. The feedback that led to changes was accepted since they reflected health professionals' actual workflows at health facilities. These changes were marked in blue in the diagram. Access <https://doi.org/10.5281/zenodo.4765679> for this analysis.

As part of Research Objective 3, the participants' statements regarding the health content to be available on the app were analyzed and categorized. Next, comparisons were discursively made among Deaf people's information needs during the co-planning stage, SEMDSA's list of health content ([Amod et al., 2012](#)), and the health content stated by all participants during this co-design activity. Health content targeting diabetic pregnant women, children, and elderly were discarded as they were not the focus of this research. The commonly stated health content was selected to be available on the conceptual design of the app. Access this analysis from <https://doi.org/10.5281/zenodo.4765684>.

All participants' ideas were accepted to respect all opinions (see the dialogue characteristic of the CBCD approach in [Chapter 2, Subsection 3.1](#)). In achieving Research Objective 4, the participants' statements were analyzed and categorized, and their drawings were interpreted. By combining the mobile-interface design guidelines of [Hoover and Berkman \(2011\)](#) and [McVicar \(2012\)](#), a table was created to categorize the participants' statements about designs of the app in three aspects: 1) page layout, 2) visual information used in mobile interfaces, and 3) users' interactions with the app. [Figure 36](#) presents each coding theme with a bullet point under the three aspects of the mobile interface design. The analysis of the design requirements of the app for communication bridging can be accessed from <https://doi.org/10.5281/zenodo.4765691>.

Page layout	Visual information used in these mobile interfaces	Users' interactions with the app
Page orientations: portrait or landscape	Use patterns for information access: - mobile information architecture, - lateral access (tab, peel away, simulated 3D effects, pagination, and location within), - top-down approach (link, button, indicator, icon, stack of items, and annotation)	Use patterns for information input: - text and character input (keyboards and keypads, pen input, mode switches, input method indicator, or autocomplete and prediction), - area and selection (input area, form selection, mechanical style, and clear entry), - entry of information (directional entry, other hardware keys, accesskeys, dialer, on-screen gestures, kinesthetic gestures, and remote gestures)
Wayfinding: - lateral access, - top-down approach	Use patterns for information control: - zoom and scale, - location jump, - search within, - sort and filter	Confirmation on the input of information: - delayed input, - statuses of icon
Page size: up to the technology	Information output: - tones, - voice input, - voice readback, - voice notifications, - haptic outputs	
Grid design: - masthead, - alerts, - locator, - content, - footer		

Figure 36. Three aspects to analyze requirements for designing mobile interfaces.

Limitation of this co-designing

This co-design activity was conducted within a limited time. Thus, the retrieved requirements for this app's mobile interfaces could be restricted. Also, details of the healthcare personnel engaged in type 2 diabetes treatments and communication activities retrieved from health professionals of one health district might differ from those in other health districts.

1.3 Findings from Co-design Activity 1

The findings are presented in line with the research objectives. Patient journeys for type 2 diabetes treatments and the participants' requirements for communication bridging were aligned with Research Objectives 1 and 2. Health content to be available on the app was associated with Research Objective 3.

Patient journeys in type 2 diabetes treatments

The patient journeys were composed of 1) the healthcare personnel with whom a patient needed to interact, starting from entering until exiting a primary health center, and 2) the communication activities of the healthcare

personnel (see Figure 37). Access enlargeable patient journeys from <https://doi.org/10.5281/zenodo.4120866>.

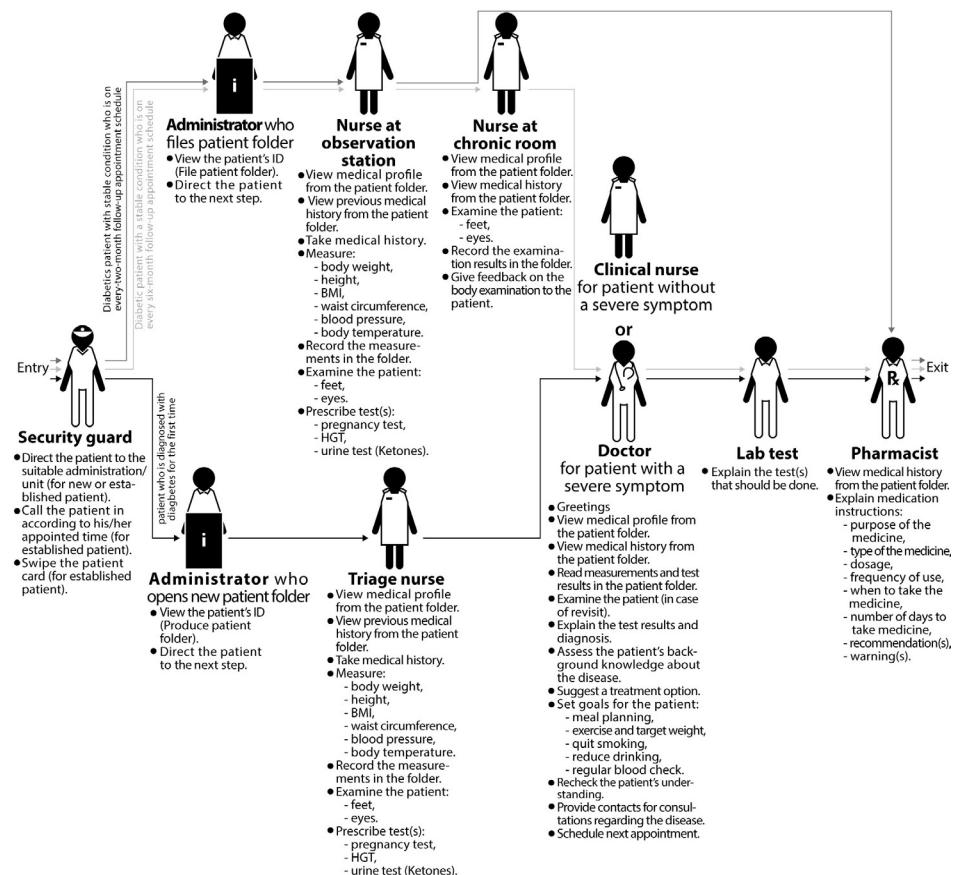


Figure 37. Patient journeys in type 2 diabetes treatments..

The identified healthcare personnel comprised auxiliary staff (i.e., security guard and administrators) and health professionals (i.e., triage nurse, nurse at the observation station, nurse in the chronic room, clinical nurse, doctor, staff at the lab, and pharmacist). The security guard played the role of directing a patient to the appropriate administrator. The route on the bottom line illustrates a new patient being diagnosed with type 2 diabetes for the first time. Alternatively, a patient diagnosed with type 2 diabetes would interact with the healthcare personnel along the upper route. The healthcare personnel's communication activities with a diabetic patient had to be bridged.

The participants' requirements of communication bridging

The participants' inputs regarding 1) communication activities bridging between a doctor or a clinical nurse and a Deaf patient and 2) use patterns and GUI elements were derived from the participants' drawings. These communication activities are intended to transfer health content during the clinical consultation, starting with greetings and ending with scheduling a follow-up appointment.

The building of a good rapport at the start of a clinical consultation was addressed as crucial. A good rapport in clinical consultation refers to an establishment of a relationship between a health professional and a patient towards an effective diagnosis. Understanding the patient's emotions, feelings, and symptoms, including providing the patient with a welcoming ambiance, are part of the communication activities that any health professional needs to achieve. As such, Doctor 1 drew an example of a mobile interface to build a good rapport with the patient. "Hello!" was positioned at the top of the page to welcome the patient before requesting the patient to select feelings and symptoms from the available choices (see [Figure 38](#)).

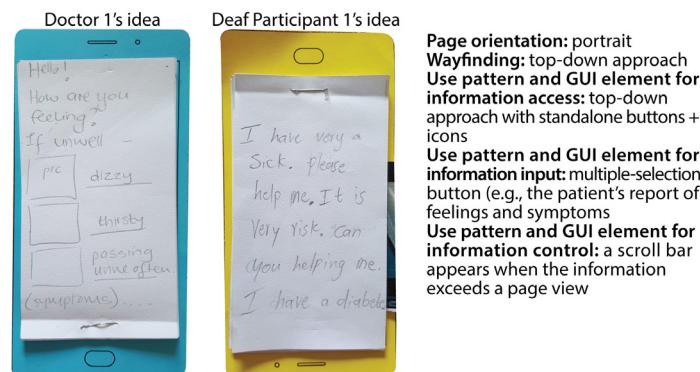
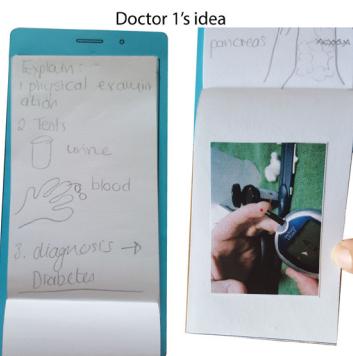


Figure 38. Ideas for building a good rapport.

Deaf Participants 1 and 2, who represented the role of patients, coherently expressed that the app had to assist them in explaining their feelings and symptoms and summarize their inputs in text for a doctor or clinical nurse to read (also [Figure 38](#)). Health Promoter 1 verbally suggested that the app should also gather information about the patient's lifestyle, such as usual food and meals, prior to diagnosis from a doctor or clinical nurse.

After establishing a good rapport with the patient, Doctor 1 needed the app to provide options for planning communication activities or input information to continue the consultation with the Deaf patient. Her drawing in [Figure 39](#) illustrates a combination of use patterns and GUI elements.



- Page orientation:** portrait
- Wayfinding:** top-down approach
- Use pattern and GUI element for information access:** top-down approach with standalone buttons + icons
- Use patterns and GUI elements for information input:**
 - keypads for text and number input (e.g., name of the diagnosed disease)
 - type-in box (e.g., for typing in the diagnosed disease)
 - multiple-selection button (e.g., medical tests done to the patient)
- Use pattern and GUI element for information control:** standalone button + icon only (e.g., arrow as an icon to move on to the next page)

Figure 39. An idea about communication planning during a clinical consultation.

Doctors 1 and 2, Health Promoters 1 and 2, and Deaf Participant 4 had a similar requirement that the patient's knowledge of the diagnosed disease should be assessed at every consultation for newly diagnosed and already diagnosed patients. Health Promoter 1 also suggested that the app should help a doctor or clinical nurse ask the patient if one had heard of diabetes beforehand.

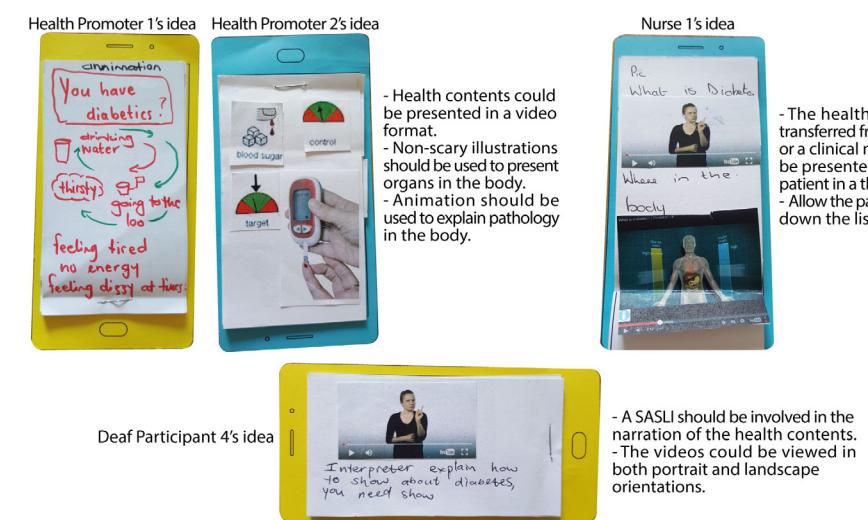


Figure 40. Ideas regarding methods to communicate health contents.

All participants showed coherent ideas about accompanying each content with visuals—mostly with animations or illustrations—to enhance the patient's understanding (see [Figure 40](#)). Voice-overs should be added to the content since some Deaf patients had a residual hearing, and their caretaker might also need to understand it. The Deaf participants emphasized the need

to see narrations in SASL, in combination with subtitles, to back up their understanding of some signs that they were unfamiliar with. Both portrait and landscape orientations are acceptable for watching health content.

All participants required an option in the app to recheck the patient's understanding of the diagnosis and the explained information. Two participants described their ideas verbally and through signing. Doctor 1 wanted the app to provide options for a doctor or clinical nurse to ask open-ended questions. The questions could be orchestrated to the patient in SASL and could allow the patient to give answers via signing or selecting pictures. Deaf Participant 1 suggested a similar idea about providing answers in SASL.

Health Promoter 2 needed the app to assist a doctor or clinical nurse in setting self-management goals for the patient. She reasoned that the patient had to rely on the app to modify their lifestyle gradually.



Figure 41. Ideas for presenting examples of self-management.

Deaf Participant 4 addressed the need for exact instructions on how to conduct proper self-management. The instructions had to show food ingredients and exercises that diabetic patients should eat and do (see [Figure 41](#)).

Health Promoter 2 and Doctor 2 agreed that health content, including the contact details (such as email and phone number) of diabetic peers and organizations, should be transferred to the Deaf patient and the caregiver in order to support the patient's effective self-management. Doctor 2 also stated that some primary health centers authorized doctors and clinical nurses to schedule appointments with their patients for a follow-up visit. Thus, the app should assist a health professional in achieving the task of making an appointment.

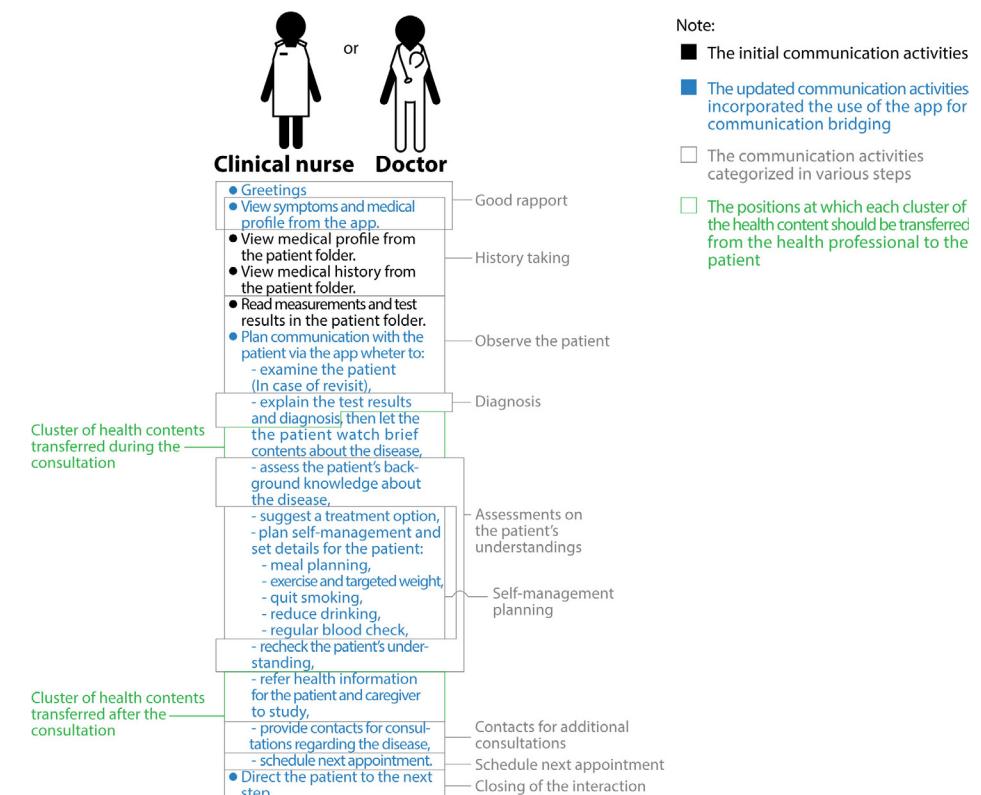


Figure 42. Communication activities that incorporated the use of the app during a clinical consultation.

The aforementioned requirements were implemented to bridge communication between a Deaf patient and a doctor or clinical nurse. [Figure 42](#) illustrates the initial communication activities in black, the app's use for communication bridging and health information delivering in blue, categorizing of communication activities in gray, and the positions where each cluster of health content would be transferred from the health professional to the patient in green.

The use patterns and GUI elements shown in [Figures 38](#) to [41](#) were categorized into the three aspects for designing mobile interfaces of the app (see [Figure 43](#)). Details related to page layout, visual information, and the users' interactions with the app marked with N/A denoted that the participants did not provide clear input for that particular topic. During the design conceptualization, the author selected specifications from online Android-mobile-interface-design resources to replace these N/As.

Page layout	Visual information used in the mobile interfaces	Users' interactions with the app
Page orientations: <ul style="list-style-type: none">- portrait = while communication bridging is in process,- landscape or portrait = while the patient is viewing a health content	Use pattern and GUI element for information access: top-down approach via buttons	Use patterns and GUI elements for information input: <ul style="list-style-type: none">- type-in box (e.g., for typing in the diagnosed disease name),- text and number inputs requiring qwerty and number keypads,- multiple-selection buttons (e.g., for the patient to report feelings and symptoms)
The theme colors: N/A	Use patterns and GUI elements for information control: <ul style="list-style-type: none">- scroll bar for information that exceeds a page view,- standalone buttons + icons only (e.g., for moving on to the next page),- video control bar	Use pattern and GUI element to confirm the input of information: Symbol and a color code for the watched and unwatched health educational videos,
Texture: N/A	Use pattern and GUI element for information output: N/A	Use pattern and GUI element for information output: N/A
FONTs: <ul style="list-style-type: none">- family: N/A,- sizes: N/A		

Figure 43. The participants' choices for use patterns and GUI elements for an app.

Health content to be available on the app

The health professionals tended to transfer more health content than what the Deaf patients needed at that time. Deaf Participant 4 and other Deaf participants were concerned that many patients could be in shock when being diagnosed with a disease or worsening health condition. They might only be able to absorb limited information during the consultation. Consequently, all participants discussed information transfer and agreed to transfer the health content into two clusters for watching on the app during and after a clinical consultation. The content for watching during the consultation should be concise, while the remaining content should be transferred to the patients after the consultation to spend time learning the content.

Listings of health content to be available on the app were derived from a comparison of NID respondents' health information needs during the Co-planning Stage, SEMDSA's (Amod et al., 2012) advice on health content for diabetic people, and health content to meet the needs of health professionals and Deaf participants gathered during Co-design Activity 1. Figure 44 presents two clusters of the health content proposed to be available on the app.

Cluster 1: contents watched during a consultation	Cluster 2: contents watched after a consultation
- Brief information of diabetes,	- Fundamental knowledge of how our body gets energy,
- Brief information about treatment and self-management	- Relationship of insulin, blood glucose, and body cells,
	- Types of diabetes,
	- Risk factors of becoming diabetic,
	- How the disease progresses and causes complications,
	- Signs and symptoms of diabetes,
	- Importance of medicine and self-management,
	- Treatment options,
	- Healthy eating and meal adjustment,
	- Regular exercises and weight loss,
	- Quit smoking and reduce alcohol drinking,
	- Regular blood tests,
	- Alerts: N/A,
	- List of DOs and DONTs,
	- Foot care,
	- Importance of adhering to medical appointments,
	- Myths about diabetes and self-management,
	- Stories of diabetic people who successfully control their diabetes

Figure 44. Health content divided into during and after a consultation.

The findings of Co-design Activity 1 emphasized the importance of bridging communication throughout the identified patient journeys in order to provide information accessibility to Deaf patients. It was necessary to incorporate the participants' mobile interface designs for such communication bridging to meet their usages. Also, it was vital to present health content to a Deaf patient in an appropriate amount to meet their information needs, yet cover all information that the health-service guidelines required the health professionals to deliver to their type 2 diabetic patients. A conceptual design of the app should, therefore, be compiled with the essentials stated above.

1.4 Conceptual design of the app

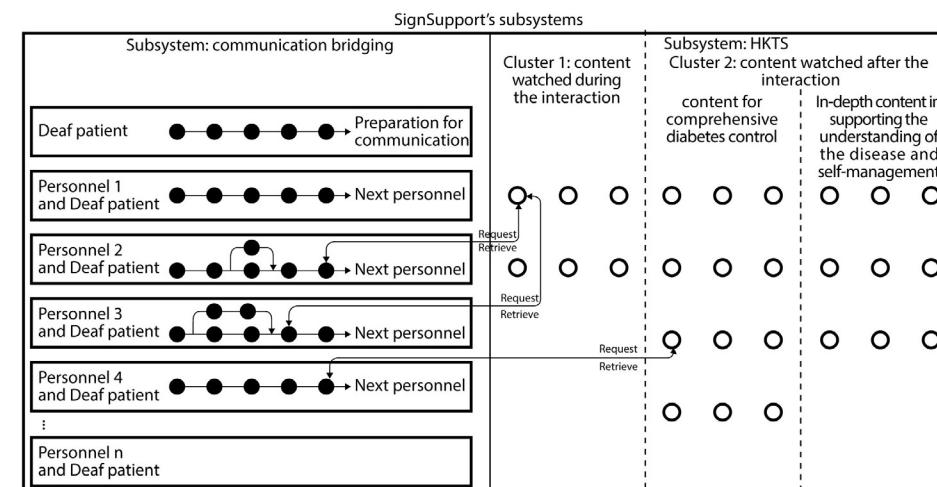
In line with Research Objective 4, these conceptual design descriptions were composed of mobile information architecture, the design of the mobile interfaces, and an overview of how a Deaf patient uses the app to communicate with healthcare personnel at a primary health center.

Mobile information architecture

The information architecture was applied to organize information within this app for the users' understanding and easy access. Information architecture's basis comprising of 1) context, 2) users, and 3) content (Rosenfeld, Morville, & Arango, 2015) were referred to during conceptualization. Based on the participant's inputs aligned with users and content, this app was composed of two subsystems for 1) communication bridging between healthcare personnel and a Deaf patient and 2) storing health content (database). Both subsystems formulated information independently and work seamlessly. The communication bridging subsystem was designed with multiple communication modules. One module prompted the Deaf patient to input patient profiles and medical history, complying with South Africa's health-service guidelines, before initiating any communication with healthcare personnel at a primary health center. Other modules were

each healthcare personnel's communication activities with whom the patient interacts (refer to [Figure 37](#), based on the participants' inputs). This subsystem with a modular design allowed flexibility in both app usability and maintenance. The modular design did not restrict the order of the healthcare personnel engaged in diabetes treatments. In terms of usage, auxiliary staff or a health professional could direct a patient to the next treatment step autonomously. Concerning system maintenance, the number and the order of the healthcare personnel could be updated without affecting this subsystem.

Communication activities in each healthcare-personnel module had to be classified with steps and positioned where relevant health content should be transferred to the patient, in line with the communication activities during a clinical consultation (refer to [Figure 42](#), based on the participants' inputs). At the positions to transfer health content, a list appears for a health professional to select (see [Figure 45](#)). The subsystem storing health contents is called the Health Knowledge Transfer System (HKTS). The health contents in HKTS were divided into two clusters: 1) content for the patient to watch during the interaction with a health professional and 2) content for watching after the interaction to meet Deaf patients' information needs. The latter is subdivided into two subclusters: 1) content for comprehensive diabetes control and 2) in-depth content for supporting the understanding of the disease and for self-management. These divisions were for health professionals' efficient usage; each content in the first cluster is tagged with recommendations for the next relevant content within the same subcluster or across subclusters. By doing so, they could go through a shorter list while transferring health content for the patient to watch after the consultation.



[Figure 45. Overview of the information architecture for the app](#)

Listings of health content presented in [Figure 46](#) were made based on the initial listing in [Figure 44](#) and the related works' advice.

HKTS		
Cluster 1: content watched during the interaction	Cluster 2: content watched after the interaction	Cluster 2: content watched after the interaction
V1.1 Brief information about diabetes	V2.1 Fundamental knowledge of how our body gets energy <also suggest to watch V2.2> V2.2 Relationship of insulin, blood glucose, and body cells <also suggest to watch V2.3 and V3.2> V2.3 Types of diabetes <also suggest to watch V2.4> V2.4 Risk factors of becoming diabetic <also suggest to watch V2.5> V2.5 How the disease progresses and causes complications <also suggest to watch V2.6> V2.6 Signs and symptoms of diabetes <also suggest to watch V2.7 and V3.3-V3.5>	In-depth content to support the understanding of the disease and self-management V3.1 Meal examples and meal spacing <also suggest to watch V3.2> V3.2 Why are you tired, hungry, and losing weight even though you are eating? <also suggest to watch V3.3> V3.3 Why do you have tingling/numbness and unhealing wounds? <also suggest to watch V3.4> V3.4 Why do you frequently urinate and why are you thirsty? <also suggest to watch V3.5> V3.5 Why do you have genital thrush and blurred vision? <also suggest to watch V3.6> V3.6 Reasons why one should quit smoking <also suggest to watch V3.7> V3.7 Diseases that smoking can cause <also suggest to watch V3.8> V3.8 Poisons in tobacco smoke <also suggest to watch V3.9> V3.9 Benefit of quitting smoking <also suggest to watch V3.10> V3.10 How to deal with worries when quitting smoking <also suggest to watch V3.11> V3.11 Steps to take to quit smoking <also suggest to watch V3.12-V16> V2.12 Regular blood tests <also suggest to watch V2.13-V2.17> V2.13 List of DOs and DONTs <also suggest to watch V2.16-17> V2.14 Foot care <also suggest to watch V3.3> V2.15 Importance of adhering to medical appointments <also suggest to watch V2.16> V2.16 Myths about diabetes and self-management <also suggest to watch V2.17> V2.17 Stories of diabetic people who successfully control their diabetes <also suggest to watch V3.1-V3.16>
V1.2 Brief information about treatment and self-management	V2.7 Importance of medicine and self-management <also suggest to watch V2.8> V2.8 Treatment options <also suggest to watch V2.9> V2.9 Healthy eating and meal adjustment <also suggest to watch V3.1-V3.2> V2.10 Regular exercises and weight loss <also suggest to watch V3.2> V2.11 Quit smoking and reduce alcohol drinking <also suggest to watch V2.13 and V3.6-V3.16> V2.12 Regular blood tests <also suggest to watch V2.13-V2.17>	V3.9 Benefit of quitting smoking <also suggest to watch V3.10> V3.10 How to deal with worries when quitting smoking <also suggest to watch V3.11> V3.11 Steps to take to quit smoking <also suggest to watch V3.12-V16> V3.12 Story of a guy who successfully quit smoking <also suggest to watch V3.14> V3.13 Story of a lady who successfully quit smoking <also suggest to watch V3.15> V3.14 Limit alcohol drinking for male <also suggest to watch V3.16> V3.15 Limit alcohol drinking for female <also suggest to watch V3.16> V3.16 Drink alcohol along with food <also suggest to watch V2.13>
V1.3 Pregnancy test V1.4 RPG test V1.5 Urine test (Keytone) V1.6 Foot examination V1.7 Eye examination		

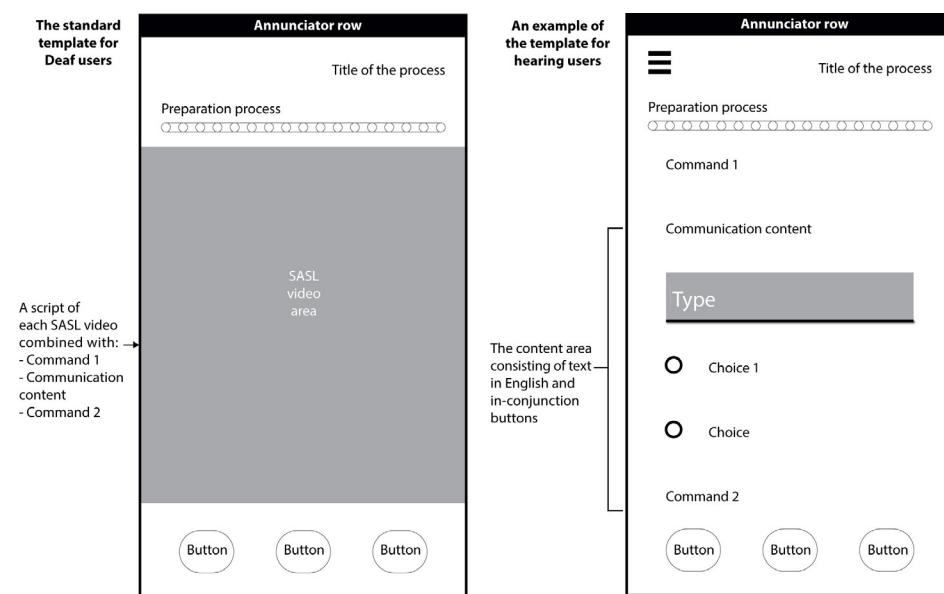
[Figure 46. Listings of health content in clusters in HKTS subsystem](#)

The listing in the left column included SEMDSA's ([Amod et al., 2012](#)) content for diabetic patients. The middle column was the list of the health content for the patient to watch after a consultation. The listing in the right column contained health content regarding meal spacing, alcohol consumption reduction, and smoking cessation retrieved from SEMDSA ([Amod et al., 2012](#)) and [van Zyl-Smit et al. \(2013\)](#). Each health content is numbered. A blueprint of the app, which can be accessed from <https://doi.org/10.5281/zenodo.4765711>, depicts how the two subsystems worked together in detail. The green bi-directional arrows denote the request and retrieval of health content during communication bridging.

Design of the app interfaces

The participants' inputs with regard to the mobile interfaces, including specifications (e.g., area size for responsive design, color pallets, Android annunciator theme, button sizes) referenced from the Internet to fulfill the incomplete details (N/A)s in [Figure 43](#), were used for designing the mobile interfaces of the app. The overview of the selected details for the app's mobile interfaces and reasons for choosing them can be found at <https://doi.org/10.5281/zenodo.4133610>.

Five grids: 1) annunciator row, 2) locator area (title of the process), 3) interstitial area (preparation process), 4) content area (in either SASL for the patient or concise text for healthcare personnel), and 5) fix-button area were applied to all mobile interfaces (see [Figure 47](#)). The default alignments for all mobile interfaces were specified. The page title was aligned right, the progress bar in the center, information in the content area on the left to provide space for a scroll bar, and the fixed-button area in the center.



[Figure 47. Templates for Deaf patients and healthcare personnel.](#)

For Deaf patient's mobile interfaces (the left in [Figure 47](#)), the communication content area displays a combination of Command 1, communication content, and Command 2 in a SASL video. The fixed button area appears with icon(s) or simple wording(s) to suit Deaf people's low functional literacy. [Figure 48](#) shows icons and wording included as part of button details for these mobile interfaces ([Chininthorn, 2011](#)). Their interfaces were consistent and simple.

What Deaf participants understood: Yes No OK

What Deaf participants did not understand: Confirm

[Figure 48. Wordings and icons which many Deaf people could and could not understand.](#)

As illustrated on the right in [Figure 47](#), the mobile interfaces for the healthcare personnel were more complex since they were familiar with intricate use patterns and GUI elements from other mobile apps. Therefore, their templates for mobile interfaces consisted of one communication content area filled with written English and multiple types of in-conjunction buttons, e.g., multiple-selection, single-selection, and search within buttons.

Overview of the app

Details of this conceptual design could be illustrated through patient journeys of a Deaf patient named Prang (see [Figure 49](#)). This Deaf person attended a workshop on an app called SignSupport that was held in her Deaf community. Prang learned that this app could assist her in communicating with health professionals at primary health centers when no SASLI could escort her. This app had been installed on her smartphone.

It was the first time that she was going to use this app. After tapping on the SignSupport icon (see the leftmost section of [Figure 49](#)), an interstitial page flashed for five seconds before leading her to the home page (Homepage 001). Four standalone buttons appeared on the home page.

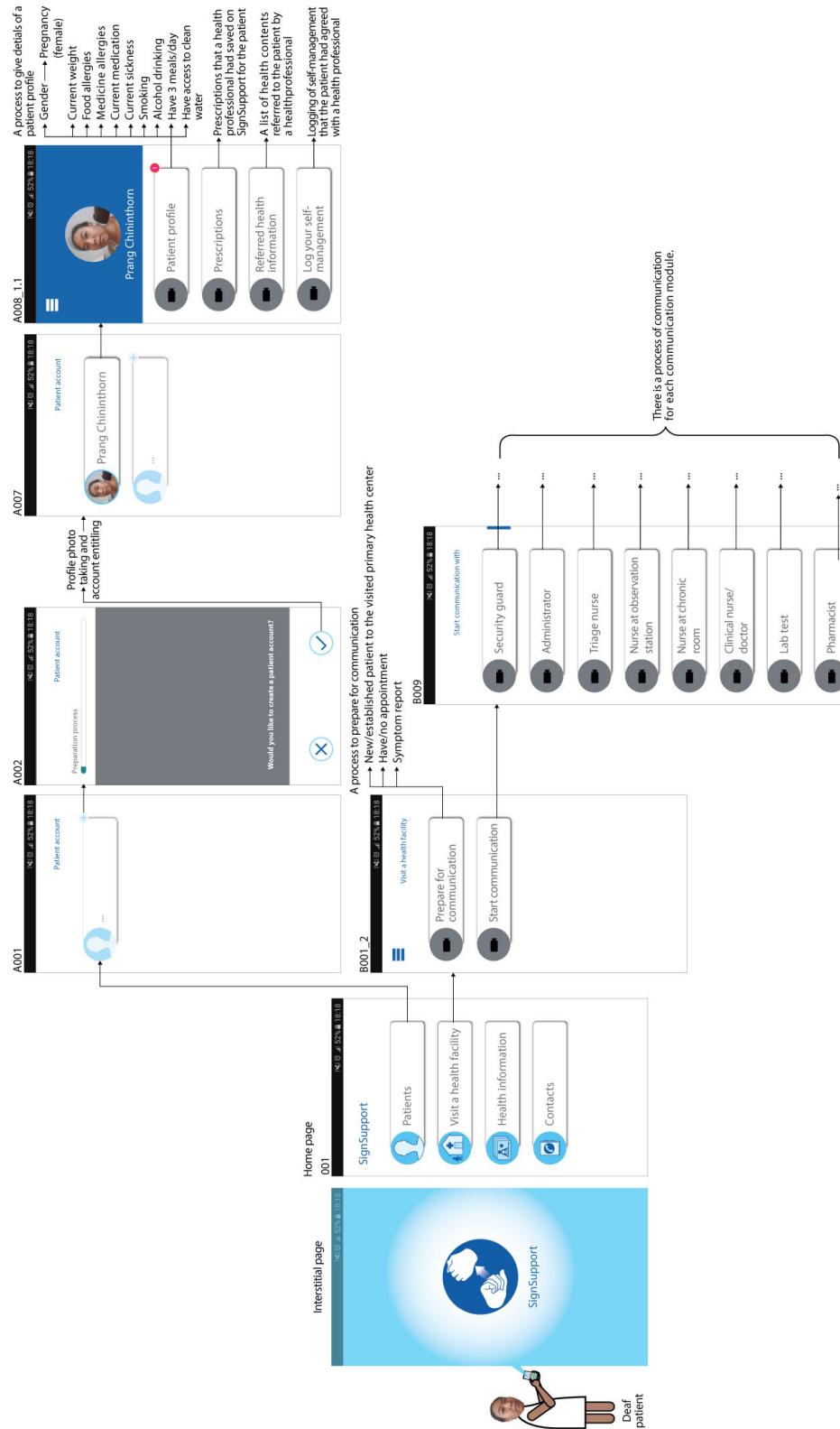


Figure 49. The overview of the conceptual design of the app.

The Patient button would lead Prang to create a patient account or select the already created patient account. The Visit a health facility button would prompt her to prepare for the communication, which would take place at the visited primary health center. Details of whether the patient was a new patient to this health facility, whether the patient already had an appointment, and the patient's reporting of the symptom(s) were part of this preparation. This button would also lead to communication activities between the patient and an auxiliary staff member or a healthcare professional engaged in the diabetes-treatment process. The Health information button would provide Prang with access to the health content available on the app. The Contacts button would lead her to a list of contacts of the relevant consultations that a health professional would save on the app for Prang.

On the home page, Prang selected the Patient button to create her Patient account. Once the account was created (A007) and selected, a notification showed at the Patient profile button (A008_1.1), calling Prang's attention to input details which an administrator and health professionals will acquire. For the other buttons in A008_1.1, the Prescription button would lead Prang to medication that would be prescribed by doctors. The referred Health information button would lead her to the health content that a health professional would transfer for her to watch. The Log your self-management button would lead to self-management logs, which would be activated after the patient discusses a self-management plan with her doctor or clinical nurse.

Access <https://doi.org/10.5281/zenodo.4133662> for the enlargeable overview of how this app would bridge communication between a Deaf patient and healthcare personnel at a health facility. For Prang's preparation before going to a primary health center, access a description and full wireframe of a patient account creation and fill-ins of details at <https://doi.org/10.5281/zenodo.4133664> and the wireframe for reporting patient's status and symptoms at <https://doi.org/10.5281/zenodo.4134909>. As journeying through the route of a patient diagnosed with type 2 diabetes for the first time, the description of Prang's interactions with a security guard, an administrator, and a triage nurse, together with a wireframe for bridging communication, can be accessed from <https://doi.org/10.5281/zenodo.4137080>. How she used the app during a clinical consultation can be accessed from <https://doi.org/10.5281/zenodo.4137016>. Since the doctor had prescribed this patient some tests, she used the app to bridge communication with staff at the lab; see the description of how the app was used and the wireframe of this communication bridging process from <https://doi.org/10.5281/zenodo.4137122>. Once receiving medication and a follow-up appointment, the patient left the health facility. At home, she logged self-management as agreed with the doctor; the description and

wireframe for self-management at <https://doi.org/10.5281/zenodo.4137138>. Two months after the initial visit, Prang visited the primary health center for her follow-up appointment and journeyed through the route for a diabetic patient who was on a follow-up appointment. She prepared for communication, then interacted with the security guard, who directed her to the administrator who filed folders of the established patients. Next, she was directed to consult a nurse at the observation station. This nurse had the same communication activities as the triage nurse. Access the wireframe of communication bridging with the nurse at the observation station through <https://doi.org/10.5281/zenodo.4137168>. Prang's patient journey continued with the pharmacist at this health facility to refill her medication, and the journey should end at the administrator to schedule an appointment for the next 6-month visit.

Six months after the second visit, Prang revisited the same health facility and started her patient journey similarly to the previous 2-month appointment. After consulting the nurse in the observation room, she interacted with a nurse in the chronic room. This nurse had similar communication activities as the nurse at the observation station, but one difference was that she could not prescribe a medical test for the patient. This nurse completed the task that the nurse at the observation had not done, then she directed Prang to consult a doctor since her health condition did not improve. Access the wireframe of communication bridging with the nurse in the chronic room at <https://doi.org/10.5281/zenodo.4137168>. The app was used to bridge communication during the clinical consultation. This time, the nurse could see a summary of Prang's self-management logs. This summary (see B028A in the wireframe of self-management logging, which could be accessed from <https://doi.org/10.5281/zenodo.4137138>) helped the patient and the health professional collaborate towards effective treatment.

1.5 Conclusion and discussions of Co-design Activity 1

The participants' inputs during Co-design Activity 1 resulted in two patient journeys filled with additional healthcare personnel engaged in type 2 diabetes treatments (Research Objective 1) and communication activities that suit the healthcare personnel's practices at primary health centers (Research Objective 2). Listings of health content available on the app (Research Objective 3) were identified with a cluster for a patient to watch during a consultation and a cluster for watching afterward. This was to provide health information that matched a Deaf patient's needs and assisted the health professional to deliver the content that complied with the health-service guidelines implemented in the context. The participants' ideas about mobile interfaces described how they wanted to use this app for bridging communication and transferring relevant health content; they also contributed to the use patterns and GUI elements that could be used in

this app's design (Research Objective 4). All participants' contributions were compiled into a conceptual design of the app by the author. As a result, this app was conceptually designed to bridge communication activities along the patient journeys and provide health content at the designated times.

There are differences between the findings of Co-design Activity 1 and the related works. The listings of the healthcare personnel engaged in type 2 diabetes were similar to the descriptions of SEMDSA Journal ([Amod et al., 2012](#)) and PAC 101 Guideline 2013/14 ([University of Cape Town Lung Institute for the National Department of Health, 2014](#)). However, the healthcare personnel positioned during the patient journeys and its communication activities identified from this co-design activity were more extended than what the two health-service guidelines advised. Doctors and nurses from the two focus groups provided health information aligned with the health-service guidelines' advice to support diabetic patients' medication adherence and self-management. Nonetheless, the patients only want to understand the name of the disease, how, and when to get better during a health consultation. They would like to learn the remaining health information at their convenience. Although the drawings and ideas from all participants did not thoroughly explain the app's mobile-interface designs, some consistent use patterns and GUI elements could be detected. The design of the mobile interfaces for Deaf users contributed knowledge to the design field, which serves the Deaf majority.

2. Co-design Activity 2: designs of health content for Deaf people

The structure of Co-design Activity 2 is similar to the preceding section.

2.1 Related works

The health content had to be narrated in SASL—Deaf people's preferred language and a spoken language (for Deaf people with a residual hearing and their caretaker), accompanied with visual materials to enhance their understanding, and displayed via a smartphone screen (refer to the participants' requirements in [Subsection 1.3](#)). Consequently, the health content can be characterized as multimedia. As such, the literature studies about characteristics of SASL and how to design multimedia that could match Deaf people's needs were studied. Therefore, the work of [Wehrmeyer \(2013\)](#)—a doctoral thesis that provided the characteristics of SASL based on the work of other researchers, Deaf Cognition for Deaf Learners ([Marschark & Hauser, 2008](#))—a book collected research fellows' studies on Deaf cognitions, and the theory of multimedia learning ([Mayer, 2002](#))—a theory described how different elements in multimedia videos could affect its viewers' learning were selected as related works to this co-design activity. [Wehrmeyer's thesis \(2013\)](#) was included as a related work since it provided SASL's eight characteristics crucial for narrating content accessible to Deaf

people. [Marschark and Hauser's book \(2008\)](#) was chosen because it analyzed the cognitions Deaf people used for processing as perceiving information and its visuals. Six characteristics of educational content that would suit Deaf cognition were identified for arranging messages of each health content, the use of sign language for narrations, incorporations of visual information with narrations, and the use of multimodal information for Deaf learners. The theory of multimedia learning ([Mayer, 2002](#)) was found as another related work as it described how nine characteristics could advantage and impede multimedia learners. Although this theory was not formulated based on studies with Deaf people, several of its characteristics emphasize several elements that could enhance any learners' understanding of a topic introduced to them. [Figure 50](#) summarizes characteristics of accessible educational content for Deaf people derived from these related works.

Characteristics of SASL	Characteristics of educational contents that suit Deaf cognition	Characteristics of multimedia learning (Mayer, 2002)
1) Phonology = rules of hand and body movements (Fromkin & Rodman, 1998) handshape, palm and finger orientation, location, movement, and non-manual features (Akach, 1997; Johnston & Schembri, 2007; Koizumi, Sagawa, & Takeuchi, 2002; Prinsloo, 2003) to form words,	1) Signed language is an effective language for Deaf education (Marschark & Hauser, 2008).	1) Multimedia = Information transfers better when a message contains words and pictures.
2) Morphology = compound of phonology to describe a word in spoken language (Humphrey & Alcorn, 1996),	2) Pieces of information should be chunked to suit Deaf people's span of short-term or working memory (Marschark & Mayer, 1998).	2) Spatial contiguity = Information transfers better when words are placed near the picture.
3) Lexicon = the signs developed based on the established signs and sense-making on the context influenced by spoken language (Leeson & Saeed, 2012)	3) Visual modality is important (Marschark & Wauters, 2008).	3) Temporary contiguity = Information transfers better when corresponding narration and animation are presented simultaneously.
4) Other signed languages (Leeson & Saeed, 2012),	4) Dynamic visual displays are helpful in accompanying verbal descriptions about processes (Iding, 2000).	4) Coherence = Information transfers better when irrelevant words, pictures, and sounds are excluded.
5) Invented iconic signs based on the visual world (Brennan, 2005; Koizumi et al., 2002; Leeson & Saeed, 2012; Metzger, Fleetwood, & Collins, 2006),	5) and detection of motion in the periphery (Corina, Kritchevsky, & Bellugi, 1992; Swisher, 1993).	5) Modality = Information transfers better from animation and narration than from animation and on-screen text.
6) Fingerspelling for terminology (Napier, 2002),	6) Multimodal information is advantageous for Deaf people's cognition process. However, consecutively alternating Deaf people's cognition process with multimodal information might impede their learning (Johnson, 1991).	6) Redundancy = Information transfers better from animation and narration than from animation, narration, and on-screen text.
7) Discourse structure (Wehrmeyer, 2013),		7) Pretraining = Information transfers better when proceeded by training on component.
8) Syntax structure (Wehrmeyer, 2013),		8) Signaling = Information transfers better when the narration is signaled.
		9) Personalization principle = Information transfers better when words are in conversational style.

[Figure 50. Characteristics of possibly accessible educational content for Deaf people.](#)

The three aspects in [Figure 50](#) encompassed how the research and design of Co-design Activity 2 was processed.

2.2 Research and design process of Co-design Activity 2

Requirements for the health content accessible to Deaf people were identified from the inputs of Deaf experts—those who are Deaf and are experienced in producing educational materials for Deaf learners—and categorized in line with the characteristics for accessible educational content. This section describes the research objectives, criteria for selecting the Deaf experts, research methods and instruments, data analysis, and limitation of this co-design activity.

Research objectives

Three research objectives were formulated to identify the requirements to design health education for Deaf patients who were diagnosed with type 2 diabetes. The results from Co-design Activity 2 were aimed to refine the answers to SRQ 5 (methods for communicating health content).

- Research Objective 1: Describe how to narrate the selected health content in SASL.
- Research Objective 2: Identify visual materials to accompany the narrations for enhancing Deaf patients' understanding.
- Research Objective 3: Develop representations of all elements needed for the health content accessible for Deaf patients.

Criteria for selecting the Deaf experts

The Deaf experts were required to be fluent in SASL and knowing multiple SASL dialects used in the Western Cape, skilled in producing accessible content for Deaf people, and understand written English.

In consultation with the NID committee, their educational material production team was selected since their profile met the criteria. These Deaf experts consisted of four Deaf members and one CODA; most of them had been part of the NID's SASL-dictionary development and educators for Deaf learners. Research method and instruments

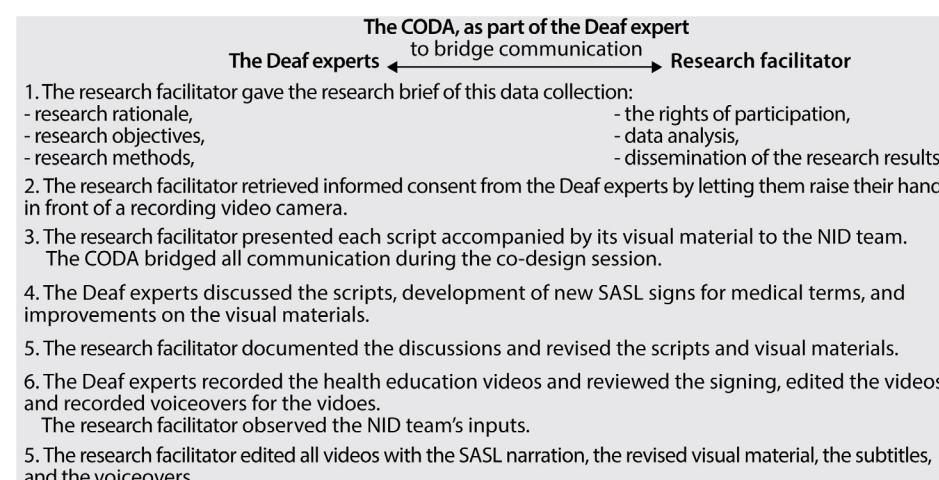
Focus group was the method applied to identify the requirements for designing health educational videos with the Deaf experts. The research instruments included the selected health content and their scripts, storyboards, and visual materials.

- Methods to research and design

The focus group was conducted at NID; research instruments were used to generate discussions during the focus group. The Deaf experts and one research facilitator participated in designing each of the selected health content, starting from revising the selected health content's scripts and the accompanying visual materials. Next, SASL narrations were video recorded.

Each health educational video was edited to include all elements.

Tasks were divided among all participants of this co-design activity. The CODA took the role of a linguist and a SASLI, a cameraman, and a video editor. Other Deaf experts took the lead in simplifying the scripts for videos, reviewing the signing for the health educational videos' narrations, developing new SASL signs for medical terms, and giving input on the visual materials. The research facilitator took the roles of an illustrator revising visual materials and a video co-editor (see [Figure 51](#) for the procedure). This co-design activity lasted for one month, taking into account the Deaf experts' availability. The discussions were documented in a booklet, and drawings were photographed for analysis.



[Figure 51. Procedure of Co-design Activity 2.](#)

- **Research instruments**

Seven health topics (see [Figure 52](#)) were selected from [Figure 46](#) (derived from Co-design Activity 1) since they did not require extensive knowledge from Deaf people to understand them. With forward-thinking to the next CBCD stage, these health topics would benefit Co-evaluation Activity 2 twofold: 1) the health content accessibility could be explicitly measured since several variables were discarded from affecting the participants' understanding, and 2) the participants' change in understanding about diabetes before and after watching this set of health educational videos could be observed.

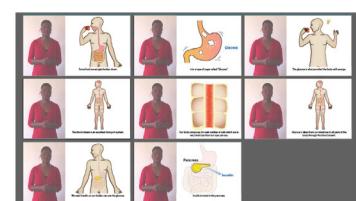
Content 1: Brief information about diabetes
 Content 2: Fundamental knowledge of how our body gets energy
 Content 3: Relationship of insulin, blood glucose, and body cells
 Content 4: Signs and symptoms of diabetes
 Content 5: How the disease progresses and causes complications
 Content 6: Risk factors of becoming diabetics
 Content 7: Brief information about treatment and self-management

[Figure 52. The seven health topics selected for Co-design Activity 2.](#)

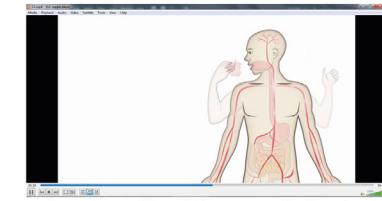
Storyboards and visual materials were prepared as research instruments to facilitate the co-designing with the Deaf experts (see [Figure 53](#)). The storyboards for simple content—Contents 1 and 7, were presented without visual material. In these cases, the SASL narrator was placed in the middle of the screen layout. English subtitles were overlaid at the bottom of the area, with a voice-over that was rendered synchronously. As for the storyboards for more complex health content that required visual material to enhance Deaf people's understanding, the SASL narrator shared half of the screen layout with the selected visual material. The English subtitles, with voice-overs, were overlaid on the visual area. The visual material was displayed directly after the SASL narrator paused signing to avoid overloading a Deaf person's attention.



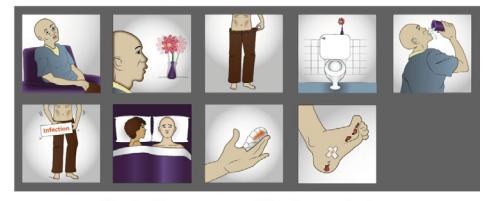
Scripts of the selected health contents



A storyboard for a health content



A screen caption of the prepared animation



Illustrations prepared for the co-design



An example with 2 screen captions for interactive video for a health content

[Figure 53. Research instruments for Co-design Activity 2.](#)

Presentations of SASL narrations, English subtitles, and English voice-overs were to accommodate potential Deaf, and even hearing, viewers of these health educational videos. The scripts for Contents 1 to 7 were written based on information borrowed from Diabetes SA's website ([Diabetes SA, 2018a](#)) and the Diabetes and You booklet ([Diabetes SA, n.d.](#)) as these were the diabetes information sources that the DOHWC health policymakers recommended.

The types of visual materials proposed for each health educational video were selected from the NID Deaf respondents' preferred methods (refer to [Chapter 5, Subsection 3.3](#)). Animations were proposed for Contents 2, 3, and 5 since the NID Deaf respondents preferred to see them accompany the explanation of biological processes in the body. Illustrations were chosen for Content 4 to avoid scary photographs of the internal body organs or the disease's symptoms. In Content 6, interactive health communication, as suggested by one of the best practices in [Chapter 2, Subsection 1.2](#), was proposed for a trial to determine whether or not it could raise Deaf people's awareness of diabetes. Access <https://doi.org/10.5281/zenodo.4120431> for these scripts and visual materials.

Data analysis

The Deaf experts' inputs regarding the rearrangements in the scripts and signing for narrations were compared with the characteristics of SASL, educational content that suit Deaf cognition, and multimedia learning (all three columns in [Figure 50](#)); this was to describe their formulation for the scripts and narrations in SASL. Next, the Deaf experts' inputs concerning the animations and illustrations were solely compared with the characteristics of educational content that suit Deaf cognition (the middle column in [Figure 50](#)). This was to identify the requirements on the visual materials that would enhance information accessibility for Deaf people. Lastly, the Deaf experts' inputs were compared with the characteristics of educational content that suit Deaf cognition and multimedia learning (the second and third columns in [Figure 50](#)). This was to develop presentations of all elements in each video. Access <https://doi.org/10.5281/zenodo.4121982> for the analyses.

Limitation of this co-designing

These findings could apply to those who would provide information accessibility to Deaf people through health educational videos. It might be limited to diabetes information. Those who will replicate these requirements for designing content about other diseases or other information beyond health should test if the same set of requirements would yield similar accessibility to Deaf people before implementation.

2.3 Findings from Co-design Activity 2

The Deaf experts' inputs regarding the requirements of scripts and narrations in SASL, visual materials, and presentation of elements for the health education videos are provided.

Scripts and narrations in SASL

The Deaf experts' decisions concerning the scripts and narrations were delineated in four aspects: 1) the combining and rearranging of the health contents and the scripts, 2) the simplifications and elaborations added to the scripts, 3) the selected dialect for narrations, and 4) the development of new signs. The Deaf experts reviewed the scripts—the research instruments—and decided to combine and rearrange some of them (see [Figure 54](#)) to avoid redundancy and avail understanding. The list was reduced from seven to five scripts. This decision was in line with one characteristic of Deaf cognition, the chunking of information.

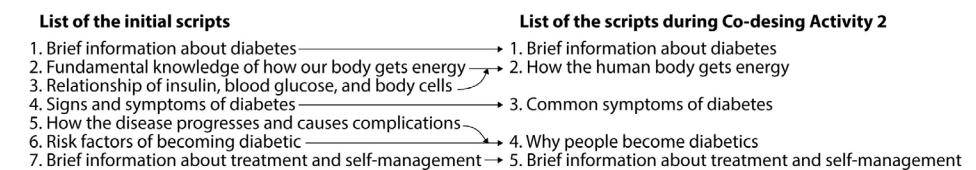


Figure 54. Combining of the scripts during Co-design Activity 2.

Although the information borrowed from Diabetes SA already targeted people with low literacy, the Deaf experts still identified the need to further simplify and elaborate on several messages. This was because the Deaf majority did not know biology, and there is a lack of SASL signs developed for all spoken or written words. The simplifications were to overcome the limited signs in SASL that newly developed signs could not convey the intended meanings. For example, there was no sign in SASL for risk factors of becoming diabetic. Instead of coming up with a new sign, the Deaf experts chose to sign a phrase: "why people become diabetic" to convey the meaning. The elaborations were devised for three purposes: 1) to introduce the content of each video, 2) to support Deaf viewers' understanding by providing the context, and 3) to emphasize the takeaway message. The first purpose was in line with the signaling characteristic of multimedia learning. As an example, one of the introductions was: "The signs you are going to see now is about glucose, insulin, and energy for the body, to enable you to run. How does your body get energy?" The second purpose applied to explaining complex medical terms. For example, "Some pregnant women can have insulin resistance which causes their body cells unable to absorb

glucose. Once glucose is not absorbed, it goes through the placenta, and the baby gets excessive glucose. Excessive glucose is stored as fat. That is why the baby weighs more." This message was added to the script for elaborating "gestational diabetes," a cause of some women developing type 2 diabetes later on in life. This decision slightly contradicted a characteristic of multimedia learning regarding coherence. Although no irrelevant words, pictures, or sounds were added, the extensive details might be distracting to some Deaf viewers. The Diabetes SA representative approved the accuracy of the new scripts before video recordings. **For the simplifications and elaborations conducted for the script of each health education video, access <https://doi.org/10.5281/zenodo.4121982>.**

The Deaf experts agreed to narrate all health content in SASL with a selective dialect, adhere to the SASL syntax structure, and use personalization style. These decisions were aligned with two characteristics of SASL (i.e., discourse and syntax structure), one characteristic of Deaf cognition (signed language as an effective language for the Deaf education), and one characteristic of multimedia learning (the personalization principle). The dialect used at NID was selected for the narrations since it was blended from several other dialects in South Africa. Thus, it was expected to be comprehensible for Deaf people from other communities as well. Personalization, such as signing with "you" and "your," was used since it is part of SASL. Mouthing in any South African's spoken languages, not mouth shapes as part of non-manual features in SASL, was avoided to accommodate Deaf viewers who grew up in other language environments. Each Deaf expert demonstrated how to sign all of the health content. Four Deaf experts, except the CODA, took a turn to narrate each script in SASL, reviewed each other's narration, and selected the most accessible one for the video recording.

Eleven medical terms that are diabetes, glucose, energy/power, pancreas, cell, insulin, insulin injection, cholesterol, kidney, blood pressure, and heart disease do not have official signs in SASL. The Deaf experts discussed this issue and decided to develop each new sign based on a widely used lexicon among Deaf people in South Africa, other sign languages, and fingerspelling. These decisions were aligned with all characteristics of SASL. When there was no popular lexicon that the Deaf could experts refer to, they visited www.spreadthesign.com and www.youtube.com to look up other signed languages for the specific medical term. Fingerspelling was used in two cases: 1) when other signed languages also did not have a sign for that specific term, and 2) when the developed signs tended not to convey the intended meaning to Deaf people in South Africa. Illustrations were created to accompany the finger spellings to enhance the viewer's understanding. **Table 11** classifies the developments of the new signs for the stated medical terms.

Table 11. Characteristics of SASL for the newly developed signs

Invented iconic signs + phonology	Lexicon + morphology	Fingerspelling + picture
Glucose Insulin Insulin injection Cholesterol	Diabetes Cell Energy Blood pressure Heart disease	Pancreas Kidney

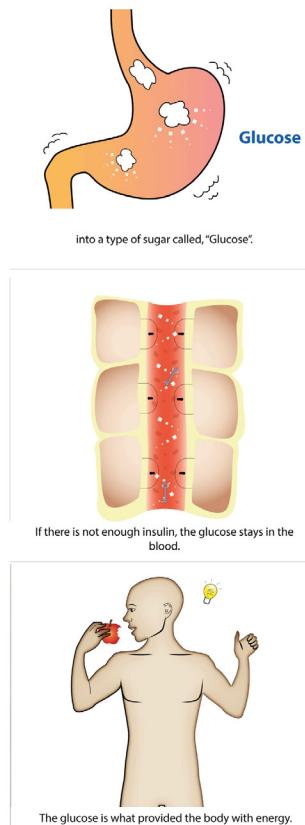
A SASL glossary of these newly developed signs for medical terms was also produced in a video format to back up Deaf viewers' understanding. **Access <https://doi.org/10.5281/zenodo.4126938>** for visuals of these newly developed signs and the glossary.

Visual materials

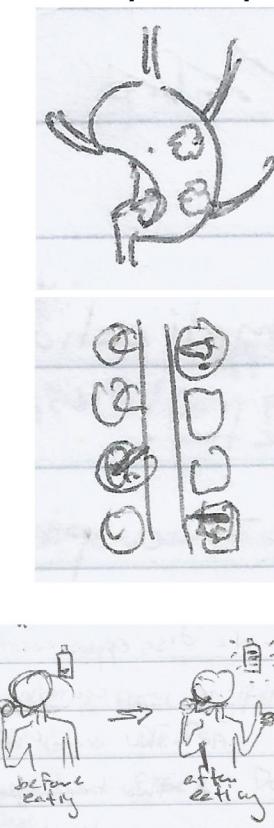
For the combined health content (refer to the column on the right in [Figure 54](#)), the Deaf experts' inputs on the visual materials are identified in two parts: 1) the use of visual modality in accompanying narrations, and 2) the use of animation specifically. The Deaf experts found the visual materials—the research instruments—were already accessible to Deaf people. In the past, they had seen that animation has a positive effect on Deaf people's learning of the processes. The Deaf experts decided to use animation to accompany the narrations for Content 2, explaining how the human body gains energy and the pathology of type 2 diabetes. Illustrations were found to be useful, but they could not explain a process as adequately as animation. Thus, they were used to accompany some non-complex content—Content 3. However, visual materials were not always required for simple health content—Contents 1 and 5. Agreeing with the research instrument regarding an interactive video, the Deaf experts expected it to raise the Deaf people's awareness of the risk factors of becoming diabetics.

In addition, the Deaf experts recommended revisions on the visual materials for them to better convey semantic meanings for Deaf people in the Western Cape (see [Figure 55](#)). Two recommendations were made about nutrients being absorbed in the stomach and glucose getting into cells, and they were added to the animation. The other recommendation was replacing one symbol that better conveys a semantic meaning of energy to suit Deaf people's familiarity. These revised visuals were implemented in the animation to accompany Content 2.

Visuals prepared for the co-design activity



Sketches based on the Deaf experts' inputs

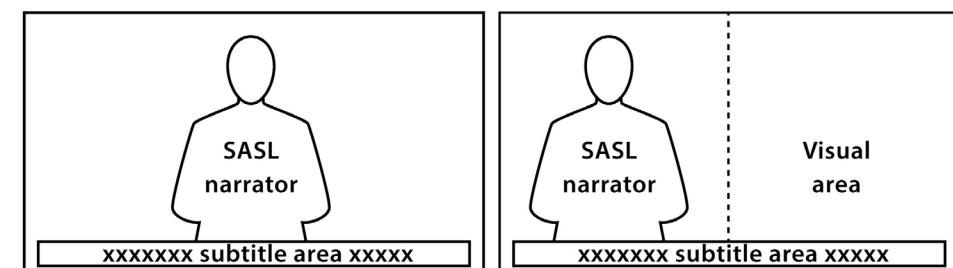


Add veins in the scene. Show that nutrients are absorbed through the stomach wall, then flow along the veins.

Add details for how glucose enters the cells.

Replace a light bulb with a battery to represent energy that a person feels after eating. Flat battery = "before eating" Full battery = "after eating."

left of the video layout, and the area for the visual material was at the right (see the right of [Figure 56](#). When the visual material faded out, the SASL narrator would shift back to the center. One SASL narrator was responsible for signaling the core message of the videos, and another one presented the details. The Deaf experts disagreed with the author on pausing narration, subtitles, and voice-overs to display visual material. They insisted that Deaf people were good at shifting attention between the SASL, subtitles, and visual material. Diverting attention between multimodal information does not drastically impede Deaf people's learning. Thus, for all health content, SASL narrations, the visual material (if there was any), subtitles, and voice-overs were displayed simultaneously for Contents 2, 3, and 4.



[Figure 56. Layouts of the video without visual material \(left\) and with visual material \(right\).](#)

The Deaf experts agreed to render subtitles at the bottom of the video area, which was not far from the presented visual material. All elements (i.e., SASL narrations, visual material, subtitles, and voice-overs) should be synchronized as much as possible, even though these narrations were based on the art of interpretation, not translation. Dissimilar to the subtitles that appeared in the storyboards (see [Figure 53](#)), these subtitles were to overlay across the whole width of the video layout for a better reading flow (see [Figure 56](#)).

[Figure 57](#) summarizes the Deaf experts' inputs in three aspects: scripts and narrations in SASL, visual materials, and presentations of all elements. In comparison to the characteristics of educational content that is accessible to Deaf people that the related works suggested, “” in [Figure 57](#) refers to the corresponding inputs, “” denotes the contradicted inputs, and “!” means the partially contradicted inputs of the Deaf experts.

Health content that was deemed simple to be understood by Deaf people did not need any accompanying visual material—SASL narration alone was sufficient. One SASL narrator was assigned for this type of content and appeared in the center of the video layout (see the left of [Figure 56](#)). These elements were implemented in Contents 1 and 5. For health content that required visual material, the SASL narrator occupied an area at the

Scripts and narration in SASL	Visual materials	Presentations of all elements
- SASL for narration with its syntax structure and a selective dialect was selected for narrations. (✓ Characteristics of SASL: 7) discourse structure and 8) syntax structure ✓ Deaf cognition: 1) signed language ✓ Multimedia learning: 9) personalization principle)	- An animation communicates the pathology of the disease. (✓ Deaf cognition: 4) dynamic visual displays) - Illustrations communicate symptoms of the disease or appearance of the organs in human body. (✓ Deaf cognition: 3) visual modality) - An interactive video communicates and raising awareness on the risk factors of becoming diabetic. - No visual material is needed for simple health contents.	Health contents that do not require visual material: - One SASL narrator communicates the content. - The SASL narrator appears in the center of the video layout. Health contents that require visual material: - The area for SASL narrator occupies the left side, and the area for visual material occupies the right side of the video layout. - Visual material fades in from the right side of the video layout, while the SASL narrator shifts to the left half of the layout. - One SASL narrator signals the core messages. Another narrator carries out the rest of the messages. - The visual material and the SASL narrator display simultaneously. For all health contents: - The SASL narrator, visual material (if any), subtitles, and voiceover should be presented simultaneously. They all should be synchronized as much as possible. (✓ Deaf cognition: 5) Deaf people are strong at shifting visual attention and detection of motion in the periphery, and 6) Multimodal information is advantageous; however, consecutively alternating Deaf people's cognition process ! Multimedia learning: 1) multimedia x Multimedia learning: 4) redundancy ✓ Multimedia learning: 3) Temporary contiguity, 4) Coherence, and 5) Modality) - Subtitles are placed at the bottom of the screen and near the visual material. (✓ Multimedia learning: 2) Spatial contiguity)
- Relevant health contents could be combined and presented in a particular sequence to help Deaf viewers form knowledge. (✓ Deaf cognition: Pieces of information should be chunked) - Messages could be simplified to accommodate the viewers' understanding when developing a new sign would cause confusion, and elaborated to: - introduce contents of each video, - provide context for the viewers, - emphasize the take-away message. (✓ Multimedia learning: 8) signaling ! Multimedia learning: 4) coherence) - A guide on how to interact with the interactive video should be provided to the Deaf viewer. (✓ Multimedia learning: 7) pretraining) - New signs could be developed based on: - invented iconic signs combined with phonology, - lexicon combined with morphology, - or fingerspelling with an accompanying picture. (✓ Characteristics of SASL: 1) phonology, 2) morphology, 3) lexicon, 4) other signed languages, 5) invented iconic signs based on the visual world, and 6) fingerspelling for terminology)		

Figure 57. The requirements on the design of the health educational videos.

2.4 Conceptual designs of the health educational videos

The Deaf experts' inputs were implemented in the conceptual design of five health educational videos. This subsection provides screenshots as previews for these health educational videos. First, a screenshot representing the simple content—Videos 1 and 5—is provided, following by screenshots portraying Videos 2 and 3 that needed accompanying visual materials. Lastly, the design for the interactive Video 4 is presented. The full videos are available at <https://doi.org/10.5281/zenodo.4137875>.

Video 1: Brief information about diabetes and Video 5: Brief information about treatment and self-management (see Figure 58) were the videos with simple content. No visual material was required to accompany these narrations. Only one narrator conveyed the messages, and he appeared in the middle of the video.



Figure 58. Screenshot of simple videos.

Video 2: How the human body gets energy was a video accompanied by an animation and Video 3: Common symptoms of diabetes was a video with several illustrations accompanying its narration. Both videos shared the same presentation that had two SASL narrators signed the content of these videos. Both videos started with one SASL narrator responsible for signaling the core message (see the left of Figure 59), and another one presented the details. The latter narrator was placed at the left in the video layout, while visual material was displayed on the right (see the right of Figure 59). Alternatively, he was placed at the center when the visual material faded out.



The sign we are going to see now

So you are eating food

Figure 59. Screenshots of videos that needed a type of accompanying visual material.

Video 4: Why people develop diabetes was an interactive video. Buttons allowed a Deaf person to identify if one would be at risk of becoming diabetic. Another SASL narrator conveyed the messages regarding the risk factors (see the left of Figure 60). A walking mannequin hinted how far or

how close the person could develop diabetes; its movements were due to the selected risk factors—the rectangular buttons on the top right of the video layout. One SASL narrator signed the introduction and the guide on how to interact with the buttons (see the right of [Figure 60](#)).

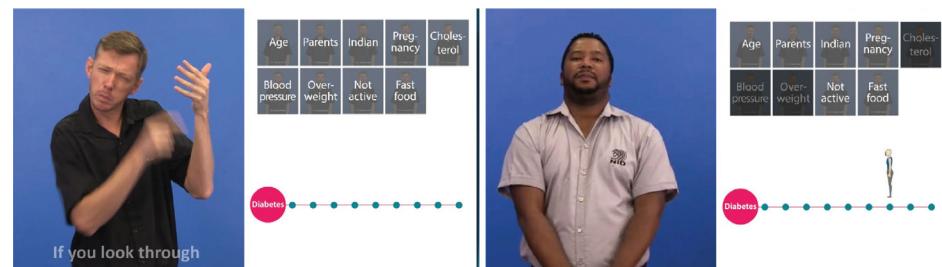


Figure 60. Screenshots of interactive Video 4.

2.5 Conclusion and discussions of Co-design Activity 2

The contributions of all participants made this co-design activity achieved its research objectives. To achieve describing the narration of health content accessible for Deaf people (Research Objective 1), seven pieces of the health content selected from the results of Co-design Activity 1 were combined and rearranged into five pieces by the Deaf experts. This was to help Deaf people who have low health literacy understand the health content. Next, the messages of each script were reviewed, simplified, and elaborated on to support Deaf people's understanding. NID's SASL dialect was selected for the narrations because it is the dialect that blends multiple dialects in South Africa. New sign developments were conducted for eleven words (e.g., diabetes, pancreas, insulin, etc.) that their meanings could not be conveyed effectively by simplifying and elaborating the scripts. Through a process of identifying a suitable type of visual material for each health content (Research Objective 2), simple health content did not need an accompanying visual material. For more complex content, an animation was selected to accompany a description of a pathological process, illustrations for the content explaining non-procedural content, and an interactive feature for the content that raises awareness of the person. Regarding the presentations of all elements (Research Objective 3), SASL narrations, a type of visual material, subtitles, and voice-overs were implemented in the health educational videos that conveyed sophisticated content. For the videos that provided simple content to Deaf people, a similar set of elements, except visual material, was implemented.

The Deaf experts' inputs, presented in [Figure 55](#), are discussed with regard to the related works' contributions. Their inputs concerning narrations in SASL were in line with all characteristics of SASL. As for visual materials,

the use of animation to accompany an explanation about a pathology process matched with the dynamic-visual-display characteristic of Deaf cognition. The application of illustrations enhanced the explanations about the symptoms of diabetes and the appearance of the internal body organs. The use of interactive videos to promote Deaf people's awareness of the risk factors of becoming diabetic was the only Deaf experts' input that did not fit any related work's characteristics about Deaf cognition. Their inputs to presentations of all elements went in line with two characteristics about the Deaf cognition: 1) Deaf people's strength in shifting visual attention and motion in the periphery, and 2) the presentation of the multimodal information. Such inputs also corresponded with four characteristics about multimedia learning: 1) temporary contiguity, 2) coherence, 3) modality, and 4) spatial contiguity. However, one input contradicted the redundancy characteristic of the multimedia. The Deaf experts decided that rendering health educational videos with narrations in SASL, subtitles, and voice-overs was essential for Deaf people, including hearing caretakers.

3. Co-design Activity 3: design of Deaf-friendly mobile interfaces

The outcome of Co-design Activity 1, a mockup of the app, was evaluated by health professionals (see [Chapter 7, Section 1](#)). It was concluded that the design of the app could suit the healthcare system, but some parts of it needed further improvements. There was the need to identify the use pattern and the GUI elements that would be Deaf-friendly to serve both users: health professionals and Deaf patients. Two additional communication activities: Deaf patient-led self-management and a Q&A session, as part of the improvement points (visit [Table 17, Chapter 7](#)), were used for the research and design during Co-design Activity 3. Besides aiming to gain knowledge regarding Deaf-friendly mobile interfaces, this co-design activity also extended an objective to find whether the design of this app could be generalized to other resource-constrained countries, such as India. This section is structured similarly to the two preceding co-design activities.

3.1 Related works

A junior researcher from India, based in the Netherlands, joined the research team for this specific Co-design Activity. She was required to study literature regarding the design of mobile interfaces for Deaf people and common questions concerning type 2 diabetes and self-management. Due to limited literature about the design of mobile interfaces for Deaf people, the literature study also included web-based interfaces for Deaf people. Three publications: [Chinithorn's \(2011\)](#) mobile interface design, [Chinithorn, Glaser, Tucker, and Diehl's \(2016\)](#) design of the mobile questionnaire, and [Fajardo, Cañas, Salmerón, and Abascal's \(2006\)](#) findings on the use of graphical hypertexts in providing website navigations for Deaf visitors were found as related works. Specific symbols and simple wording that the Deaf

majority understood ([Chinithorn, 2011](#)) and a large-screen-covering video area for displaying mobile-interface-interaction guides in SASL ([Chinithorn et al., 2016](#)) were taken as the starting point for identifying Deaf-friendly mobile interfaces. [Fajardo, Cañas, Salmerón, and Abascal's \(2006\)](#) suggested graphical hypertexts and short pathways being helpful in providing website accessibility to Deaf visitors. Deaf people performed well while navigating websites containing graphical (symbol and picture) buttons, and short pathways required them less cognitive load.

Next, common questions related to type 2 diabetes asked by South Africans and Indians were studied. These questions were gathered from [www.healthrenewal.co.za](#) and [www.health24.com](#), two popular sources of health information for South Africans and [www.intolife.in](#) one popular source for Indians. The common questions were categorized into three groups: 1) the causes of the disease, 2) mediation and treatments, and 3) self-management.

The knowledge gained from these related works encompassed how this co-design activity was processed.

3.2 Research and design process of Co-design Activity 3

The author planned this co-design activity together with the junior researcher from India. India shares similarities in education and health services with South Africa's.

Research objectives

Two research objectives were formulated to refine the answers for SRQ 4 (interaction between a Deaf patient and a health professional), SRQ 6 (relevant health content), and the MRQ.

- Research Objective 1: Identify questions that would match diabetic Deaf people's information needs for designing a Q&A session.
- Research Objective 2: Propose design alternatives to improve the use patterns and GUI elements for Deaf users' interactions with the app by taking the patient-led self-management and a Q&A session as scenarios.
- Research Objective 3: Observe this app's generalizability to a country similar to South Africa.

Criteria for selecting the junior researcher and the participants

The criteria for selecting a Deaf community and a junior researcher were as follows:

- A Deaf community in a country with education and healthcare contexts similar to South Africa was approached. Its members should have higher education levels in comparison to the Deaf majority in that country.

- One junior researcher from the same country studied in the design field and was interested in co-designing an app with Deaf people.

Research and design methods and instruments

The approach to identify a relevant junior researcher and Deaf participants, the research and design methods, research instruments, data analysis, and limitation of Co-design Activity 3 are provided.

- Identification of a relevant junior researcher

A call for an M.Sc. graduation project was posted on Delft University of Technology's portal to attract a relevant junior researcher. A graduating student with Indian Nationality was chosen. There are similarities between South Africa's and India's education ([NationMaster, 2020a](#)) and healthcare ([NationMaster, 2020b](#)) contexts. Thus, it was expected to observe the generalizability of the app's design when applied to the Indian context.

In response to Research Objective 1, the junior researcher was assigned to take the role of a research facilitator who identified the questions from a Deaf community and compiled questions that people in India and South Africa commonly asked. The junior researcher had to co-design with a Deaf community in India to accomplish Research Objective 2. The results should propose Deaf-friendly mobile interfaces while the app was bridging communications between a doctor and a Deaf patient during a Deaf-led self-management and a Q&A session. As for Research Objective 3, the author would observe Co-design Activity 3's results and reflect on the generalizability of the app design.

- Identification of a Deaf community

The Association of People with Disability (APD) in Bangalore, India, was approached since it is located at a school; its Deaf members are educated. APD is run by a hearing social worker who understands Indian Sign Language. The research brief and the ethic clearance were presented to the social worker, and she agreed to recruit Deaf participants for Co-design Activity 3.

- Methods to research and design

A focus group and a roleplay were the methods applied. Five participants were invited to contribute sufficient information, as advised by [Nielsen \(2000\)](#). The focus group started with the first part of the semi-structured questions to stimulate dynamic dialogues between the Deaf participants and the researcher. The questions stimulated the participants to think of their past experiences while consulting a doctor upon their illness. Next, a roleplay was proceeded to put the participants in a situation that they were diagnosed with type 2 diabetes for the first time and prompted to

ask questions by the end of the consultation. The research facilitator took a doctor role, and the participants acted as patients who needed health information during a clinical consultation. This part of the focus group was proceeded toward achieving Research Objective 1. The focus group was closed with the second part of the semi-structured questions that stimulated the participants to draw their ideas onto a piece of paper about how a mobile app could be used to retrieve health information to achieve Research Objective 2.



Figure 61. Roleplaying and drawing during Co-design Activity 3.
From [Tambay \(2018\)](#).

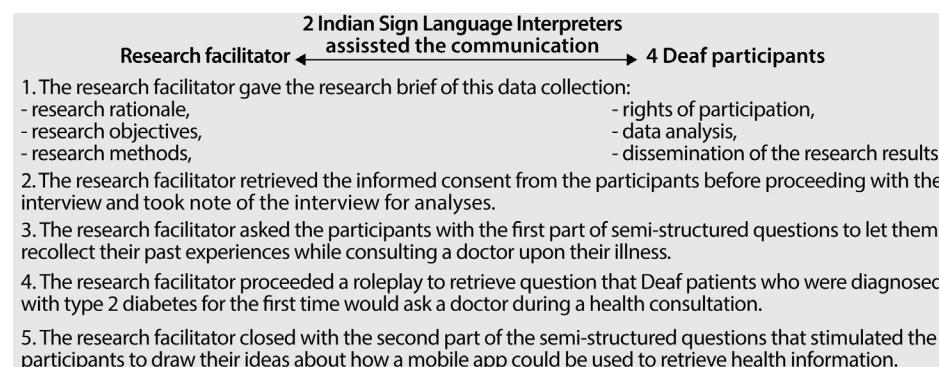


Figure 62. Procedure of Co-design Activity 3.

After the focus group, the researcher took the role of a co-designer to 1) review the author's conceptual design of the app, 2) propose design alternatives to improve the GUI elements of the mobile interfaces designed for Deaf-patient-led self-management and a Q&A session based on the participants' inputs, and 3) incorporate the derived questions in the alternative designs. This procedure was piloted with the author, and minor adjustments, such as the sequence of the questions, were implemented before the data

collection in India. The process of Co-design Activity 3 is recapped in [Figure 62](#). The focus group was video recorded and manually noted in the junior researcher's booklet for analysis. Two Indian Sign Language interpreters recommended by the social worker assisted all communications during the co-design session.

Data analysis

To achieve Research Objective 1, the questions to be included as part of the design for the Q&A session were accumulated from three sources: 1) the focus group, 2) the three selected websites, and 3) the findings of the additional study (see [Chapter 5, Subsection 3.3](#)). A table with four columns was created to organize these questions. The first three columns listed the findings from the three stated sources, and the last column indicated the questions obtained from Co-design Activity 3 (the design of a Q&A session). This table can be accessed from <https://doi.org/10.5281/zenodo.4765721>. The junior researcher discussed her derived questions with the author before including them as part of the design of the app.

For Research Objective 2, the junior researcher reviewed the use patterns and GUI elements that the author selected for the app in <https://doi.org/10.5281/zenodo.4765736>. The participants' drawings and explanations of their wishes to use the app for retrieving health information were analyzed. Next, the design alternatives aimed to improve the app's mobile interfaces were proposed.

For Research Objective 3, the author observed the extent of generalizability of the design of the app design by checking similarities and differences between the requirements on communication bridging and the designs derived from the participants in South Africa and India.

Limitation of this co-designing

The findings from this Co-design Activity 3 were retrieved from a Deaf community in India which might represent only some questions Indian Deaf people would ask to clarify their doubts about type 2 diabetes, treatments, and self-management. In addition, the participants' drawn ideas could limitedly contribute to design alternatives for improving the app's mobile interface to be Deaf-friendly.

3.3 Findings from Co-design Activity 3

The findings are reported according to the research objectives: a list of questions included as part of the Q&A session in the app, the proposed design alternatives for Deaf-friendly mobile interfaces, and the author's observation on the generalizability.

A Q&A session

Sixteen commonly asked questions regarding type 2 diabetes, were derived (see [Figure 63](#)).

- Should I take medicine before or after food?
- What is the injection for?
- How can I check my blood sugar level?
- Is my diabetes really bad when insulin injection is prescribed?
- Can I eat chocolate and sweets?
- Can I eat out at restaurants?
- How many times should I drink water?
- What should I avoid eating?
- Does eating too much sugar cause diabetes?
- Do I have to follow a special diet?
- Is it true that I cannot eat carbohydrate when I have diabetes?
- Should I avoid certain fruits when I have diabetes?
- Is snacking and drinking bad for me?
- How can I take better care of my health?
- How long will leave?
- Do only fat people get diabetes?

Figure 63. The list of 16 common questions about type 2 diabetes.

They were later categorized into 1) medication-related, 2) food-related, and 3) lifestyle-related questions and implemented into a conceptual design for bridging communication of a Deaf patient and a doctor during a Deaf-led self-management and a Q&A session.

The proposed design alternatives

Ten design alternatives to improve the use patterns and the GUI were interpreted from the Deaf participants' drawings and explanations ([Tambay, 2018](#)), in combination with what was suggested by the related works ([Chinithorn, 2011](#); [Chinithorn et al., 2016](#); [Fajardo, Cañas, Salmerón, & Abascal, 2006](#)). The junior researcher continued dedicating a large area for video in SASL to guide the Deaf patient in interacting with the app and the doctor. She proposed using 1) icons to accompany wording on buttons that showed communication activities to the patient and 2) food ingredient pictures to accompanying wording on the buttons that the doctor could recommend the patient to eat. Carousel was the pattern proposed for the patient to navigate the self-management options in a looping view. Colors were proposed for multiple usages. Additional shades of blue were introduced to the theme colors for a fresher look and feel of the app. Color codes accompanied the guides in SASL that indicated which of the in-conjunction buttons the patient need to input information, including haptic feedback, to confirm the patient when the information was inputted. Selecting list was the pattern for the patient to navigate a question list to proceed with a Q&A session. For example, if the patient selects Food as a topic for the Q&A session, a listing of food questions will appear for the patient to select and ask the doctor to clarify one's doubts upon the selected question. The details were implemented in her conceptual design (see [Figures 64 and 65](#)).

Possible generalizability

The Deaf participants in India encountered communication problems during a health consultation with a doctor, similar to Deaf people's experience in South Africa. Their questions were similar to the listings from

the related works and what NID Deaf members asked. Their drawn ideas and explanations about how a mobile phone could be used to retrieve the needed health information from the doctor. These findings showed a possibility that the design of this app, which was initially designed with Deaf people in South Africa, could be generalizable to a healthcare context in India. However, the generalizability still had to be observed until the CBCD approach would be completed.

3.4 Conceptual design for a Q&A session and a Deaf-led self-management

[Figures 64 and 65](#) present the ten proposed design alternatives and their purposes. Designs 1 to 4 are illustrated by comparing with the designs that the author had designed during Co-design Activity 1. Designs 5 to 10 were the new additions that the junior researcher proposed.

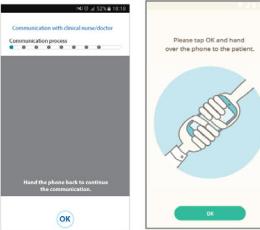
In a scenario in which a Deaf patient was just diagnosed with type 2 diabetes, the app was used to complete the health consultation with a doctor. The communication proceeded to the point that the doctor asked the patient to choose which of the options to start self-management.

The patient pressed a button on the side of the screen to navigate such options (see Design 9, [Figure 65](#)). The chosen option(s) would require the patient to input additional information, such as the amount of alcohol intake per day (see Design 6, [Figure 65](#)) and the current and target weights (see Design 7, [Figure 65](#)). By reviewing the additional information, the doctor helped plan self-management, such as meal spacing and the food ingredients, for the patient to reach the goal (see Designs 4 and 5, [Figure 64](#)). The planned self-management was recorded on the phone; the chosen self-management should be logged by the patient later on.

If the patient was in doubt, it could select relevant questions available on the app to ask the doctor. The questions presented in SASL for the patient to preview were listed under the groups of food, medication, and lifestyle (see Design 10, [Figure 65](#)). The answers to each question were pre-recorded for the doctor to select to clarify the patient's doubt.

Chapter 6

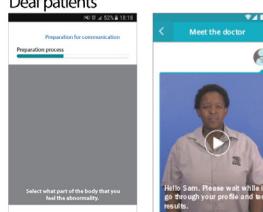
Design 1: Phone handling via animation
Purpose: To examine whether animation could effectively prompt Deaf patients to hand the phone to the doctor without watching a guide in SASL



The initial design with SASL to prompt the phone handling

Alternative design with animation to prompt the phone handling

Design 2: Provision for the feeling of direct interaction with a health professional
Purpose: To examine whether a speech bubble could provide feelings of directly interacting with a health professional for Deaf patients



The initial design with an interaction guide in SASL

Alternative design with an interaction guide in SASL and speech bubble

Design 3: Icons in accompany with sophisticated wording for standalone buttons

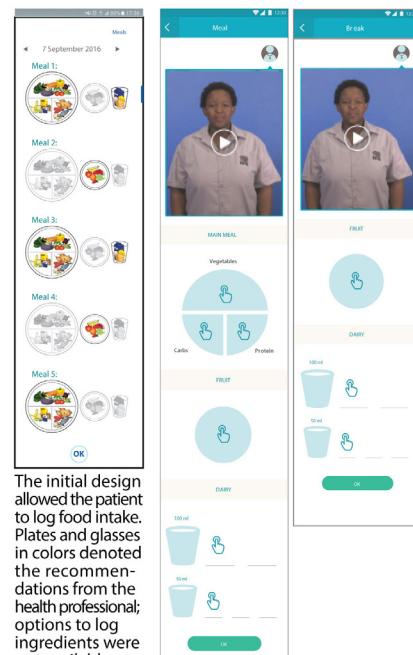
Purpose: To examine whether these icons could convey the functions of buttons with sophisticated wordings as accurate as tooltips



The initial design with standalone buttons with tooltips in SASL

Alternative design with standalone buttons with icons

Design 4: Icons in accompany standalone buttons without wording
Purpose: To examine whether the icon could convey semantic meanings of buttons without wordings



The initial design allowed the patient to log food intake. Plates and glasses in colors denoted the recommendations from the health professional; options to log ingredients were not available.

Alternative design allowed the patient to log ingredients intake. Pictures of the ingredients recommended by the doctor will appear in the plate or glass areas.

Figure 64. Design Alternatives 1 to 5 (part 1).
 From [Tambay \(2018\)](#).

Design 6: in-conjunction button that requires the user to multitask while inputting information

Purpose: to examine whether this in-conjunction button that required multitasking were easy to understand and use for Deaf patients



No comparable design from the initial design since different method was used

Alternative design for in-conjunction button for inputting number of cigarettes smoked per day

Design 7: color codes for double in-conjunction buttons which requires the user to consecutively input information

Purpose: to examine whether color codes could notify the patients about where to input each type of information in a page with multiple in-conjunction buttons

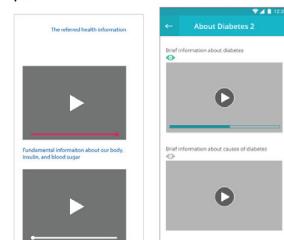


No comparable design from the initial design since this was an additional communication activity

Alternative design using double in-conjunction button in a page

Design 8: notification for the watched and unwatched referred health contents

Purpose: to examine whether the eye icons and color codes could adequately notify Deaf patients for which video was watched or unwatched

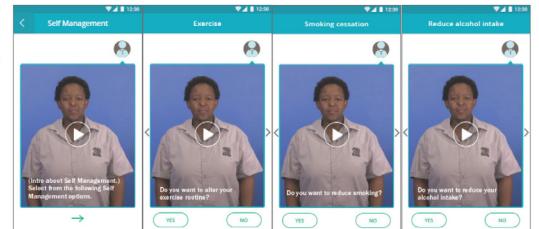


The initial design with a video bar and color codes to indicate what is watched and unwatched

Alternative design with a video bar, an eye icon, plus color codes to indicate the watched video

Design 9: wayfinding with carousel pattern for self-management options

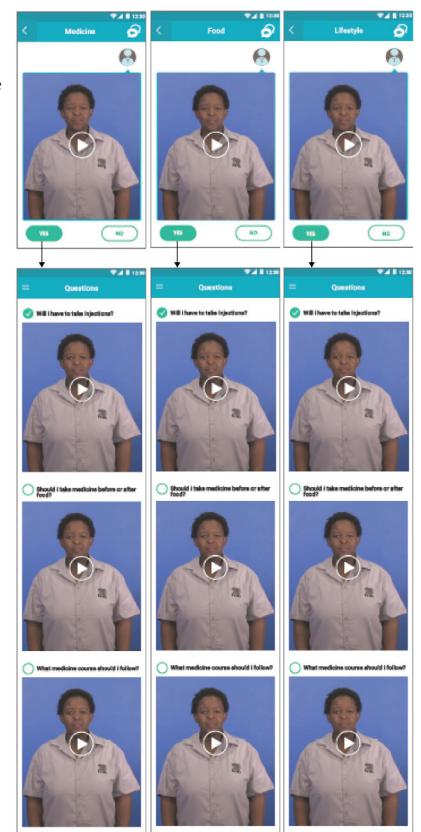
Purpose: to examine whether the carousel pattern could effectively prompt the patients to access the listing of self-management contents and select the type(s) of self-management that they wanted to modify their lifestyle



Alternative design for wayfinding with carousel pattern

Design 10: wayfinding with select-listing pattern for Q&A session

Purpose: to examine whether the select-listing pattern could prompt the patients with access through a Q&A session



Alternative design for wayfinding with "select list" pattern

Figure 65. Design Alternatives 6 to 10 (part 2).
 From [Tambay \(2018\)](#).

3.5 Conclusion and discussions of Co-design Activity 3

Questions regarding type 2 diabetes were listed and categorized for a Deaf patient to select and proceed a Q&A session to clarify one's doubt with a doctor during a health consultation (achieved Research Objective 1). Ten design alternatives were described. They were derived from the Deaf participants' inputs and the junior researcher analysis for improving toward Deaf-friendly mobile interfaces (in line with Research Objective 2). The similarities about mobile phone usage for retrieving health information and questions to clarify doubts about the disease were found between the Deaf participants in India and South Africa. As such, there would be a possibility that this app's design could be applicable to both groups of Deaf people (aligned with Research Objective 3).

When comparing the findings of this co-design activity and the related works, both corresponded with each other. The questions people asked to understand diabetes, the food one should eat and avoid eating, how to take the prescribed medication, and lifestyle modifications were commonly asked. Besides, the junior researcher's proposed design alternatives were aligned with what the related works suggested. Nevertheless, it was necessary to let Deaf people test them before this CBCD approach could provide design recommendations.

4. Reflections on the initial research guidelines

Reflections were made based on the author's experiences during Co-design Activities 1 and 2 and the junior researcher's practice during Co-design Activity 3. Guideline 1 concerning research ethics and ethic clearances, together with Guideline 2 regarding pre-discussions with the community leader, helped the junior researcher built a new research relationship with a Deaf community in India. This was because the community leader understood the research objectives and assured that Co-design Activity 3 would be conducted ethically. Guideline 4 about language use and Guideline 5 regarding the involvement of the signed language interpreters who the Deaf communities recommended helped the author and the junior researcher collect data effectively. Guideline 6 concerning planning for a flexible research session was not clearly practiced by the junior researcher since the Deaf community leader booked the participants' time slot for attending the co-designing. However, it was followed and found helpful for the author to meet the availability of all stakeholders. The author and the junior researcher practiced Guideline 7 by adopting the Deaf culture; it positively affected all three co-design activities in meeting the participants' communication requirements and showing them respect. Guideline 3 about general criteria of the Deaf participants and Guideline 8 concerning learning the signed language of that country were inapplicable for the junior researcher as she approached a Deaf community in India and had too limited time to learn

a few signs before approaching the community. Nonetheless, the author followed them and found desirable interactions from the Deaf participants. Guideline 9 about time management for the research time span is reflected in [Chapter 7](#) when all CBCD stages would be completed.

5. Answers to research questions and a way forward to the next research stage

The findings from the Co-design Stage refined answers to SRQs 2, 4, 5, and 6 and contributed the answer to the MRQ. See the details below.

SRQ 2: How health information is delivered to Deaf people in the Western Cape, and who can be health information providers and health information seekers of this empirical research?

Answer: The information seekers in this research context are any Deaf people or diabetic patients interested in information about type 2 diabetes. At primary health centers, doctors and clinical nurses were the health professionals who provide health information to diabetic patients the most. As such, these two health professionals were the health information providers for this case study.

SRQ 4: How do Deaf people interact with their preferred information sources, channels, media, and devices to successfully exchange information?

Answer: Doctors were NID Deaf members' preferred health information sources. Health consultations at primary health centers were their main channel to access health information. In addition, NID members agreed that mobile phones could be the devices to provide them with access to health information in the absence of a SASLI. An app which would be installed on Deaf patients' smartphones should allow individual Deaf patient to see mobile interfaces that bridge one's communication with healthcare personnel, including the app, in signed language.

SRQ 5: How do Deaf people seek health information and what can be their methods to successfully communicate health information?

Answer: NID Deaf members and Deaf experts chose methods involving a combination of SASL, visual material, and subtitles for communicating health information. However, visual material was not always required. Simple health contents could be communicated via a combination of SASL and subtitles, without visual material. An animation, illustrations, and an interactive feature were chosen for sophisticated health content that needed visual materials to enhance Deaf people's understanding. An animation was used to accompany the explanation of biological processes in the body, such as how the human

body gains energy and pathology of type 2 diabetes. Illustrations were used to accompany some of the content did not show a process, such as common symptoms of diabetes. An interactive feature was selected for a trial on whether it could raise Deaf people's awareness of diabetes.

SRQ 6: What can be relevant health topics that the information seekers of this empirical research need, and what information can influence patient's medication and treatment adherence, according to the health information seekers' and providers' requirements?

Answer: Diabetes was chosen over other diseases, and this study targeted any Deaf people who were interested in information about the disease.

Deaf patients usually needed much less health information during a consultation than what a health professional wanted them to understand. Consequently, Deaf participants and the health professionals agreed that there should be two health information clusters for the patient to view. This was to meet the patient's information needs and induce their medication and treatment adherence. The first cluster is the health contents to be viewed by the patient during the interaction with a health professional. The second cluster is the health contents for the patient, including one's caregiver, to study at a convenient time. In addition, the second cluster should be designed in two subclusters for agile user experience and effective management of the health contents. The first subcluster contains the contents for comprehensive diabetes control, and the second subcluster consists of the contents in supporting the understanding of the disease and self-management. The answers to questions people commonly asked about type 2 diabetes were considered listed as health content in the second subcluster for the patient to view and review after the health consultation.

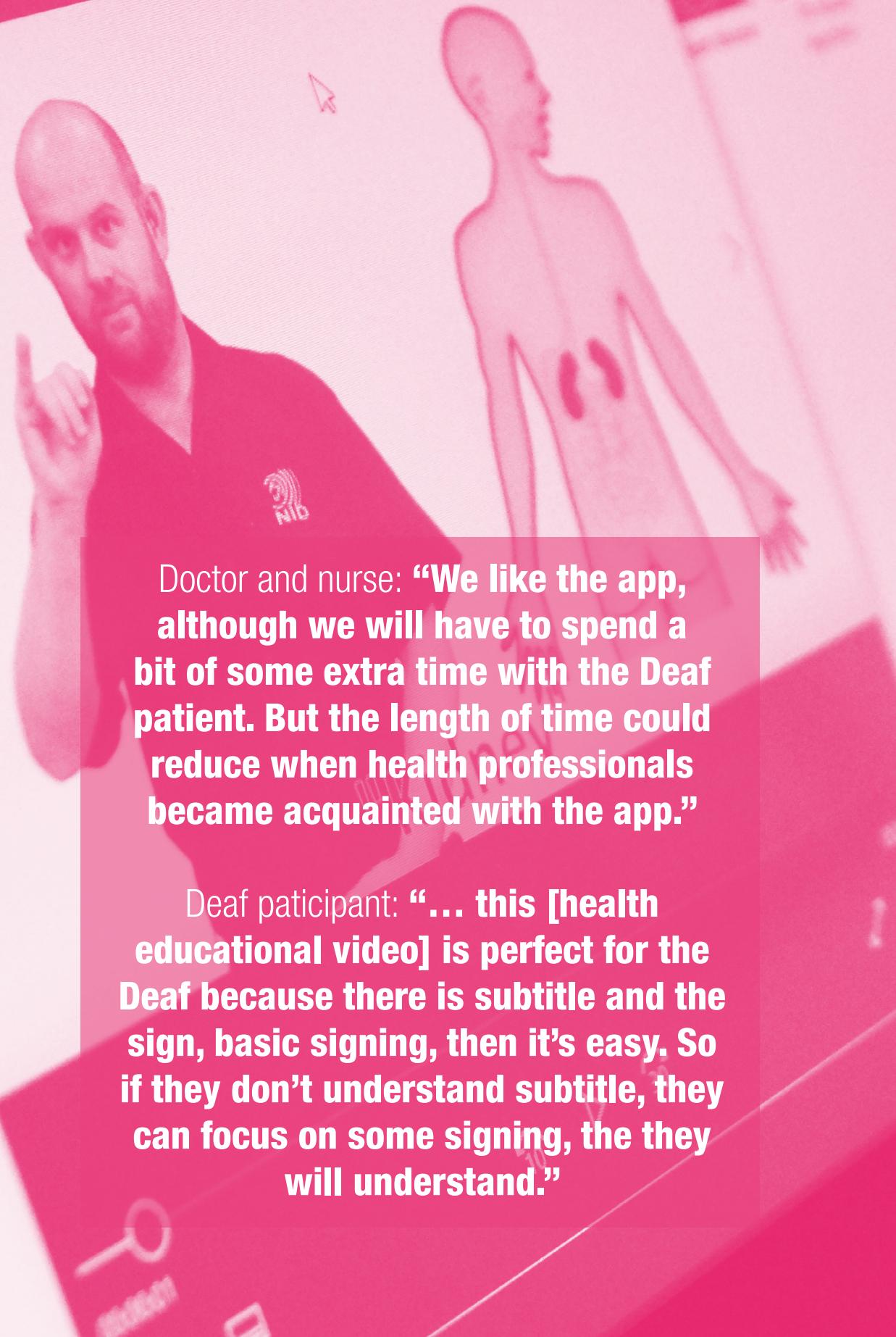
MRQ: What intervention can be designed to provide Deaf people with health information for influencing medical and treatment adherence?

Answer: An Android mobile app for Deaf patients to install on their mobile phone. This app could be designed by organizing complex and extensive information according to the information architecture in [Figure 45](#). The mobile-interface design could follow the requirements shown in <https://doi.org/10.5281/zenodo.4765736>. Health content orchestrated on the app had to be designed, starting from adjusting and rearranging the messages to accommodate the understanding of Deaf patients who could have low health literacy, followed by designing a suitable type of visual materials and presentation of all elements: narrations in SASL, subtitles, visual materials, and voice-overs. How to design health content accessible to Deaf people could be followed in [Figure 57](#).

Chapter

7

Co-evaluation



Doctor and nurse: “**We like the app, although we will have to spend a bit of some extra time with the Deaf patient. But the length of time could reduce when health professionals became acquainted with the app.**”

Deaf participant: “**... this [health educational video] is perfect for the Deaf because there is subtitle and the sign, basic signing, then it's easy. So if they don't understand subtitle, they can focus on some signing, the they will understand.**”

Co-evaluation was the fourth and final stage of the community-based co-design (CBCD) approach. The stage in which researchers and the participants—health professionals and Deaf people—co-evaluated the conceptual designs derived from all co-design activities. [Figure 66](#) illustrates the research activities of the Co-evaluation Stage.

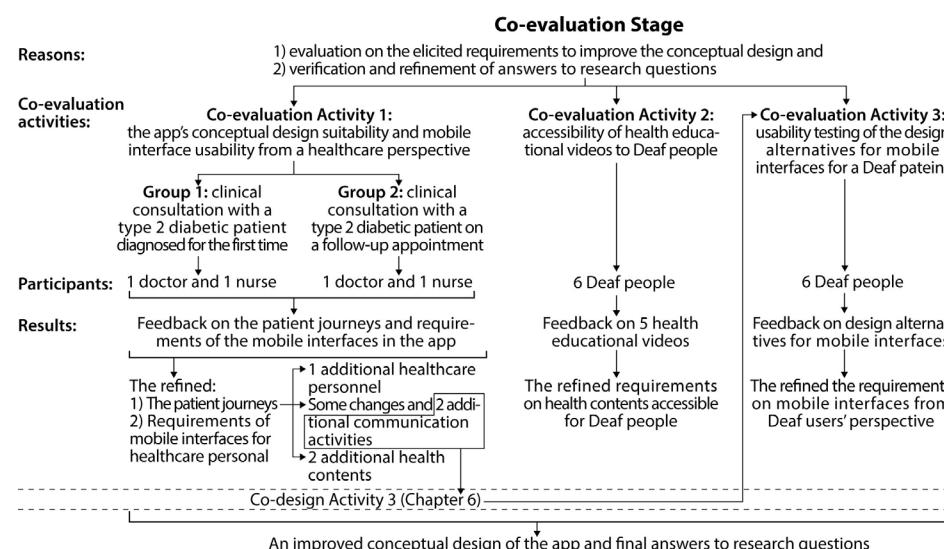


Figure 66. Overview of the Co-evaluation Stage.

Co-evaluation Activity 1 ([Section 1](#)) verified whether the app's conceptual design was suitable for the healthcare system and whether the mobile interfaces were easy to use and helped the health professionals to complete their communication activities. Co-evaluation Activity 2 ([Section 2](#)) studied whether the South African Sign Language (SASL) narrations, the selected visual materials, and the presentations of all elements for the health educational videos could provide health information accessibility to Deaf people. Co-evaluation Activity 3 ([Section 3](#)) had Deaf participants tested whether the design alternatives proposed for the mobile interfaces of the two additional communication activities could be Deaf-friendly.

This chapter is composed of six sections. [Sections 1 to 3](#) provide details of Co-evaluation Activities 1 to 3. [Section 4](#) addresses the improved design for the app and the health educational videos. [Section 5](#) reflects on all initial guidelines for actively involving a Deaf community and health professionals in this CBCD approach. Lastly, [Section 6](#) presents the refined answers to research questions.

1. Co-evaluation Activity 1: the app's conceptual design suitability and mobile interface usability from a healthcare perspective

This co-evaluation involved health professionals who had participated in Co-design Activity 1 to evaluate the requirements for designing an app they had contributed. This was to maintain the essential characteristic of the CBCD approach that continuously involves the target users for deriving an

intervention they would be ready to adopt in their daily lives (refer to [Chapter 2, Subsection 3.2](#)). The app's suitability to a healthcare system and the app's mobile interface usability to healthcare personnel were focused. This section includes the research processes, the health professionals' feedback on the app and mobile interfaces, and conclusion and discussions.

Research objectives

Two research objectives were formulated to verify the answers to the answers to sub-research questions (SRQ) 4 (interactions between a patient and a health professional), SRQ 6 (health content relevant to type 2 diabetes), and the main research question (MRQ) (an intervention to influence Deaf people's adherence to type 2 diabetes medication and treatments).

- Research Objective 1: Verify the app's conceptual design suitability via checking throughout the patient journeys whether all relevant 1) healthcare personnel engaged in type 2 diabetes treatments, 2) the communication activities between the healthcare personnel and the Deaf patient, and 3) health content were included as part of the app mockup.
- Research Objective 2: Test the mobile interface usability whether they were easy to use and helped the healthcare personnel to accomplish one's communication activities.

The criterion for selecting the participants

The selected health professionals had to participate in Co-design Activity 1. Thus, Doctors 1 and 2 and Nurses 1 and 2 (refer [Table 10, Chapter 6](#)) were invited to co-evaluate the app's conceptual design derived from their previous inputs.

Research methods and instruments

Focus group, roleplays, and think-aloud were the research methods applied. The diagram of patient journeys, derived from Co-design Activity 1, and an interactive app mockup were used as research instruments.

- Research methods

This co-evaluation activity was conducted with the health professionals solely to let them spend sufficient time and give full attention to providing feedback on the app's conceptual design. Focus groups were applied to let a doctor and a nurse help each other give feedback regarding the patient journeys and the app mockup. The doctors and nurses were assigned to the same focus groups they participated in during Co-design Activity 1. In Focus Group 1, Doctor 1 and Nurse 1 co-evaluated the app's conceptual design for bridging communication throughout the journey that a type 2 diabetic patient diagnosed for the first time had to go through. In Focus Group 2,

Doctor 2 and Nurse 2 co-evaluated the app's conceptual design for the journey that a type 2 diabetic patient attending a follow-up appointment had to undergo. As part of roleplay, they were required to perform the roles of all healthcare personnel in their assigned patient journey (see [Figure 37, Chapter 6](#)); the researcher acted as a Deaf patient, then continuing a reflective practitioner role (refer to [Chapter 2, Subsection 3.2](#)). The think-aloud method allowed these health professionals to give feedback on the healthcare personnel and communication activities while reviewing the patient journeys and interacting with the app mockup's mobile interfaces immediately. They stated what was seen on the mobile interfaces, followed by their feedback, including suggestions for changes as finding anything unsuitable to the healthcare system and their usability.

- **Research instruments**

The diagram of the patient journeys (refer to [Figure 37, Chapter 6](#)), printed on an A4 sheet of paper, was used for retrieving the health professionals' feedback regarding the healthcare personnel and communication activities (as part of Research Objective 1).

The interactive app mockup, representing the conceptual design of the app (refer to [Chapter 6, Subsection 1.4](#)), was used for obtaining the health professionals' feedback on health content available on the app mockup (as part of Research Objective 1) and the usability of the mobile interfaces designed for each healthcare personnel (in line with Research Objective 2). This mockup was created using PowerPoint since this software does not require additional programming skills. The app mockup was presented on a touchscreen laptop to provide the health professionals with an experience close to their interaction with an app on a smartphone.

At the end of each co-evaluation session, the participants were asked to reflect on their satisfaction, preferences, and concerns about the app's conceptual design. Satisfaction meant that the health professionals needed no change in the app's conceptual design. Preferences referred to what they wished to be implemented in the design. Concerns denoted what could obstruct the app suitability and mobile interface usability. Criteria were set to verify the suggestions for changes, preferences, and concerns (see [Table 12](#)) before including them as part of the improvement points.

Each focus group was conducted at the time and the health facility that the health professionals selected to fit their availability. A session of one hour was with six steps, as described in [Figure 67](#). The first five steps were the same for the two focus groups. Step 6 of Focus Groups 1 and 2 differed by the healthcare personnel a Deaf patient had to interact with on that particular patient journey (refer to [Figure 37, Chapter 6](#)). Since all four

health professionals preferred participating in the co-evaluation sessions at their offices in the health facilities, all of these co-evaluation sessions were voice recorded in order to follow the health facilities' rule prohibiting video recording and photographing.

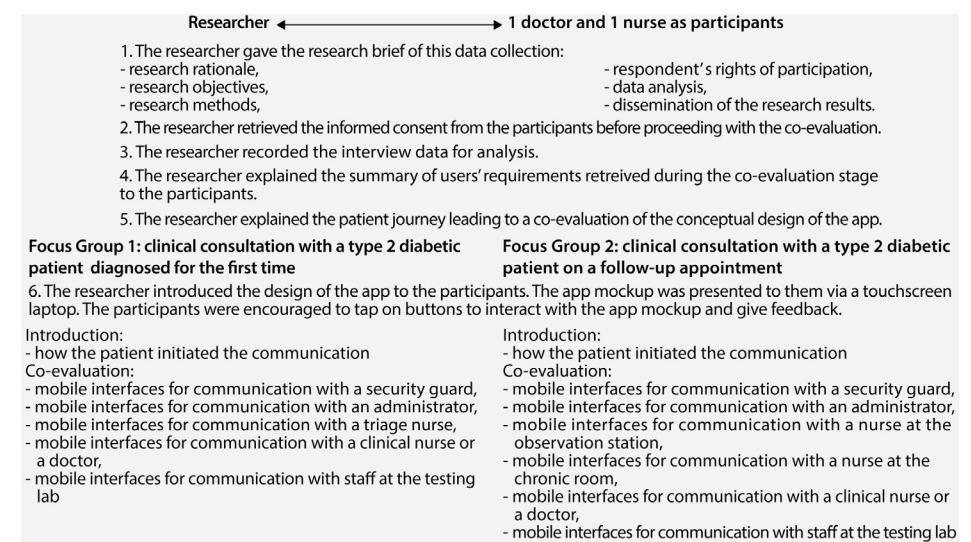


Figure 67. Procedures for Co-evaluation Activity 1.

Data analysis

For each focus group, the participants' feedback was transcribed and categorized into a table to derive 1) satisfaction, 2) suggestions for changes, 3) preferences, and 4) concerns regarding healthcare personnel in the patient journeys, communication activities, health content available on the app, and mobile interfaces. These analyses of this feedback can be accessed from <https://doi.org/10.5281/zenodo.4139717>. Such categorized feedback was verified with the criteria in [Table 12](#) before accumulating them as improvement points for the app's conceptual design.

Table 12. The criteria set for validating the improvement points of the app

Topics	Criteria
Any statement that would change the healthcare personnel and the communication activities	No contradiction to the health-services guidelines
Any statement that would change the health information content	- no contradiction to the health-services guidelines, - agreed by a Diabetes South Africa (Diabetes SA) representative in the aspect supporting the patients' effective self-management
Any statement that would change the mobile interfaces	- being in line with other participants' feedback, - minimizing the use patterns and GUI elements for the mobile interfaces previously elicited in Chapter 6

These criteria were formulated based on the two health-service guidelines: the 2012 Society for Endocrinology, Metabolism, and Diabetes of South Africa (SEMDSA) Journal ([Amod et al., 2012](#)) and Primary Care 101 (PAC 101) Guideline 2013/14 ([University of Cape Town Lung Institute for the National Department of Health, 2014](#)) implemented in the Cape Winelands District (CWD)—this studied context.

Limitation of this co-evaluation

The feedback from these health professionals was to refine their inputs regarding the requirements for designing an app. These requirements should be confirmed with app users again before implementing them in a different time span or context.

1.1 Findings from Co-evaluation Activity 1

The findings are divided into two topics about the app's conceptual design suitability and the mobile interface usability.

The app's conceptual design suitability for a healthcare system

The participants' satisfaction is presented first to show the app's suitability to the CWD healthcare system. Next, the participants' suggestions for changes, preferences, and concerns upon 1) the healthcare personnel engaged in type 2 diabetes treatments, 2) the communication activities between the healthcare personnel and the Deaf patient, and 3) the health content are provided.

During the roleplay, Doctor 1 and Nurse 1 gave feedback on behalf of the healthcare personnel engaged in the patient journey for a diabetic patient who was diagnosed for the first time. They were satisfied with the summaries of the patient's status and symptoms; they understood the Deaf patient's conditions even in the absence of a SASLI. (B010 for security guard, B013 for administrator, and B018 for triage nurse in <https://doi.org/10.5281/zenodo.4137080>, B045 for clinical nurse and doctor in <https://doi.org/10.5281/zenodo.4137016>, B083 for staff at lab test in <https://doi.org/10.5281/zenodo.4137122>). They also found the explanation of the prescribed test helpful for the patient to know what would take place in the patient's body (B022.1 for triage nurse in <https://doi.org/10.5281/zenodo.4137080>). A concern was raised regarding nurses with little experience in using smartphones. The nurses at observations and the triage nurses whom the app required inputting various types of information (e.g., values measured from the patient's body) might feel overwhelmed. Thereby, Doctor 1 and Nurse 1 suggested improving the app's conceptual design by prompting a clinical nurse or a doctor to input such values instead. Referring to the health-service guidelines, these health professionals must explain such values and meanings to patients. In terms of health content, Doctor 1 and Nurse 1 suggested making content about signs and symptoms of low and high blood sugar available on the app. Doctor 2 and Nurse 2 found the app's conceptual design suitable to their practices at primary health centers. They stated that they would still use this app in providing accessible health services and information for Deaf patients, although it prolonged the doctor-patient interaction. They reasoned that the app helped bridge communication and availed constructive self-management that led to the patient's medication and treatment adherence (for example, wireframes for bridging communication activities during a clinical consultation in <https://doi.org/10.5281/zenodo.4137080> and wireframes for self-management logging in <https://doi.org/10.5281/zenodo.4137138>).

With some improvements based on the participants' suggestions for changes, the app's conceptual design should suit the CWD healthcare system. [Table 13](#) summarizes the communication activities to add and remove and health content to include for supporting the patients' understanding of diabetes and their self-management (refer to [Figure 46, Chapter 6](#)). Accessed <https://doi.org/10.5281/zenodo.4139717> for this feedback in detail.

Table 13. Summary of the feedback on healthcare personnel, communication activities, and health content (part 1)

At which position in the patient journeys	Feedback		Suggested by
All healthcare personnel		(+) A message to prompt each healthcare personnel on how to interact with a Deaf patient appropriately, e.g., tapping on the patient's shoulder to notify for a queue, as the app introducing the patient to that healthcare personnel.	Nurse 2
Administrator	who opens new patient folders	(+) Seventeen details of the patient profile in line with the medical protocol in Western Cape	Doctor 1
		(+) Options for the administrator to require the patient's 1) Identity Document (ID), 2) address, and 3) proof of unemployment (if relevant).	Doctor 2
	who files existing patient folders	(+) Options for the administrator to require the patient's 1) patient card and 2) patient folder number	Doctor 3
Triage nurse	(+) Four options for medical test prescriptions: 1) body weight, 2) blood pressure, 3) urine test, and 4) finger prick (known as HGT) (-) The patient's body examination		Doctor 1 and Nurse 1
	(!) Inputting all measured values from the patient's body		Doctor 1 and Nurse 1
Nurse at the observation station	(!)	Inputting Body Mass Index (BMI)	Doctor 1 and Nurse 1
		Remove BMI because it can be calculated from weight and height.	Doctor 2 and Nurse 2
		(+) Three additional questions for medical history: 1) How many days have you experienced this symptom? 2) Has the symptom affected your daily activities? 3) Is the symptom relieved after taking medication?	Doctors 1 and 2 and Nurses 1 and 2

Table 13. Summary of the feedback on healthcare personnel, communication activities, and health content (part 2)

Clinical nurse/doctor		
	(+) Options for the health professionals to provide options for the health professional to explain the process of body examination, for example, "sit on the examination bed," and "remove your shoes and socks for a foot examination."	Doctor 1
	(+) Three additional questions that these health professionals commonly ask for assessing the patient's knowledge: 1) Have any of your parents been diagnosed with diabetes? 2) Have you heard of diabetes before? 3) Were you diagnosed with diabetes during your pregnancy?	Doctor 1 and Nurse 1
	(!) Inputting all measured values from the patient's body and explaining their meaning	Doctor 1 and Nurse 1
	(-) Prompting these health professionals to select types of self-management and setting goals for the patient (+) Prompting the Deaf patient to lead in choosing the types of self-management before the health professionals help to set the goals	Doctors 1 and 2 and Nurses 1 and 2
	(+) Requiring the patient to provide mealtimes before the health professionals can help in spacing the meals	Doctor 2
	(!) A Q&A session for the patient to clarify doubts before receiving brief information about diabetes	Doctor 1 and Nurse 1
	A Q&A session for the patient to clarify doubts after the planning for self-management	Doctor 2 and Nurse 2

Table 13. Summary of the feedback on healthcare personnel, communication activities, and health content (part 3)

Clinical nurse/doctor	(+) Example of the question for the Q&A session: “Why was a diabetic patient’s leg amputated?”	Doctor 2 and Nurse 2
	(-) Replacing the word “refer” by “direct” in relation to health information to the patient	Doctor 2
	(+) Directing the same health information to the patient’s caregiver as well	Nurse 2
	(+) Providing a directory of help-lines for the health professionals to search	Doctors 1 and 2
	(+) Stating at the closing of the consultation for the patient to bring next of kin for the follow-up appointment	Doctor 1
	(-) Changing the time span in the summary of self-management logs from one month to a two-or-six-month span, according to the blood-glucose testing that many patients have access to during a follow-up appointment	Doctor 2 and Nurse 1
	(+) Options: good, bad, and not so good for the patient to assess one’s performance for self-management	Doctor 1
	(+) Including foot care and signs and symptoms of low and high blood sugar as part of the health content on the app	Doctor 2 and Nurse 1
	(+) Similar communication activities, except body examination, giving a diagnosis, assessment of the patient’s background knowledge regarding diabetes, medication prescribing, and appointment making	Doctors 1 and 2 and Nurses 1 and 2

Note: (+) = add, (-) = remove, and (!) = with contradiction

The feedback that did not contradict the selected health-service guidelines would be included in the improvement points for the app’s conceptual design. The four feedback marked with (!) in Table 13, including the feedback concerning the mobile interfaces, were verified before improving the app’s conceptual design.

The mobile interface usability from health professionals’ perspective

This feedback comprises the health professionals’ satisfaction with the mobile interfaces, two additions they wished and two concerns about the mobile interfaces. These health professionals found the mobile interfaces easy to use and helped them accomplish communication activities with a Deaf patient. Doctor 1 and Nurse 1 wished that the app would give two notifications: 1) the doctor’s or the clinical nurse’s possible aloud-reading of what shown within the app to the patient during the clinical consultation, and 2) the take-home messages that the doctor or the clinical nurse might give to the patient. Doctor 1 and Nurse 1 were also concerned about font sizes and colors. They suggested a zoomable feature for readability and vibrant color, such as orange, for the summaries of the patient’s symptoms.

Access <https://doi.org/10.5281/zenodo.4139717> for detailing feedback retrieved from these health professionals.

1.2 Conclusion and discussions of Co-evaluation Activity 1

The health professionals’ feedback helped this co-evaluation activity achieved its research objectives. They found the possibility that this app’s conceptual design would suit the CWD healthcare system (in line with Research Objective 1) if the listing summarized in Table 13 could be implemented. These health professionals found the mobile interfaces easy to use; they allowed these health professionals to accomplish their communication activities effectively (achieved Research Objective 2). Still, they mentioned the font sizes and colors that could improve these mobile interfaces’ usability.

2. Co-evaluation Activity 2: health educational video accessibility for Deaf people

This research activity co-evaluated whether the health educational videos derived from Co-design Activity 2 were accessible to Deaf people with different SASL dialect backgrounds and could provide them with a basic understanding of diabetes. The accessibility of each video was verified from Deaf participants’ increased understanding of the selected topics about type 2 diabetes, intelligibility on SASL narrations, the use of visual materials in enhancing Deaf participants’ understanding of that health content, and the presentation of all elements (i.e., the narrations, subtitles, visual materials, and voice-overs). The findings from this co-evaluation activity were to

improve the requirements for designing the health educational videos (see [Figure 57, Chapter 6](#)).

2.1 Related work

Intelligibility, in this context, refers to the complex capacity that a Deaf person has in understanding the meaning of a sign by recognizing expressions and contextual information in which that sign is communicated. The modified Record Text Testing (RTT) retelling ([Parks & Parks, 2010](#)) was taken as a related work for the research methods of this co-evaluation activity. The RTT retelling was selected since it determined how much a Deaf participant understood the entire signed content, not just a single sign or word.

The standard RTT retelling method ([Casad, 1974](#)) was developed to test a short text intelligibility of a language. [Parks and Parks \(2010\)](#) modified it for assessing the intelligibility of a video conveyed across two signed languages for two Deaf participants. They divided the video content into message blocks and gave one score to every correctly retold message that matched a block. The scores were summed, and a percentage was calculated. The higher the percentage of matched blocks found, the better performance the SASL narration was considered to be. This related work was used to design the research of this co-evaluation activity.

2.2 Research process for Co-evaluation Activity 2

The research objectives, the criteria for selecting the participants, research methods and instruments, data analysis, and the limitation are described.

Research objectives

Four research objectives were formulated to verify the answers to SRQ 5 (methods for communicating health content). They were as follows:

- Research Objective 1: Verify whether these health educational videos could provide Deaf people with a basic understanding of diabetes.
- Research Objective 2: Assess the intelligibility of the narrations in the selected SASL dialect for Deaf people.
- Research Objective 3: Evaluate whether the visual material accompanying the health educational videos could enhance Deaf people's understanding.
- Research Objective 4: Test the presentations of all elements being the SASL narrations, selected visual material, subtitles, and voice-overs to ensure that intended content was conveyed to Deaf people.

Criteria for selecting the participants

All the Deaf participants were required to be fluent in SASL and can be fair in English to evaluate the narrations and the subtitles. Three Deaf students and three Deaf staff from NID were invited to have these health educational videos evaluated by Deaf people of different backgrounds—literacies and SASL dialects. However, one Deaf staff was unable to participate in this co-evaluation activity due to illness. The profiles of the remaining five Deaf participants are summarized in [Table 14](#).

Table 14. Profiles of the participants who participated in Co-evaluation Activity 2

Participants	Profiles				
	Age	Deafness status	Area of origin	Studying program/profession	Exposure to SASL
1	22	Deaf	An area in Durban	End-User Computing	Four years old
2	22	Deaf	Cape Town, Worcester, and Johannesburg,	End-User Computing	Sixteen years old
3	27	Deaf	Johannesburg	End-User Computing	Five years old
4	32	Deaf	Worcester	The production team of assistive learning materials for Deaf learners	Six years old
5	40	Deaf but wearing hearing aids and being a trilingual	Worcester	Technical support	Around five or six years old

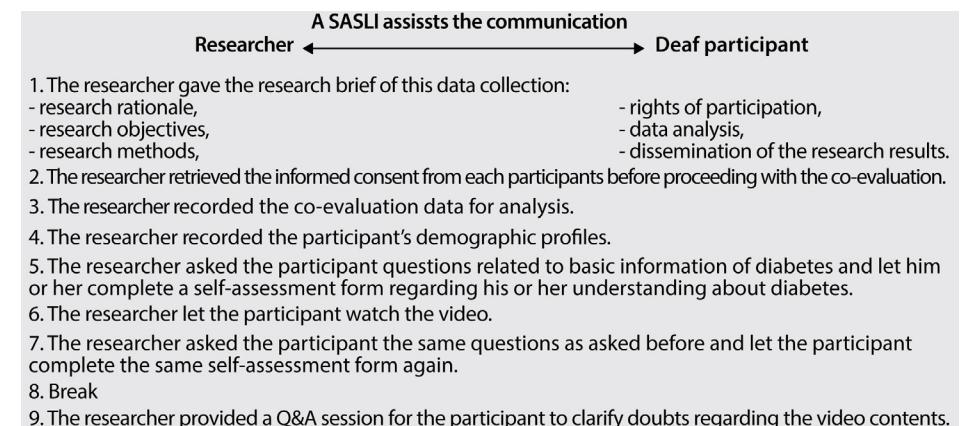
Research methods and instruments

The research methods were self-assessments on the participant's understanding of diabetes with ten-point Likert scales, the modified RTT retelling ([Parks & Parks, 2010](#)) adapted for Co-evaluation Activity 2, reflections on the SASL narrations, and reflections presentation of all elements. Two research instruments: One self-management form and five health educational videos were employed.

- Research methods

Six participants were invited to this co-evaluation activity in case one participant would not be able to join. This number of the participants was decided by following Nielsen's (2000) suggestion stating that five participants in a design testing could yield patterns of feedback and problems helpful in improving the app. One participant at a time was asked to join a co-evaluation session to provide feedback without interference from other participants. Five demographic data: 1) age, 2) Deafness status, 3) area of origin, 4) studying program, and 5) exposure to SASL were collected from each participant to understand what might affect each participant's understanding of the videos.

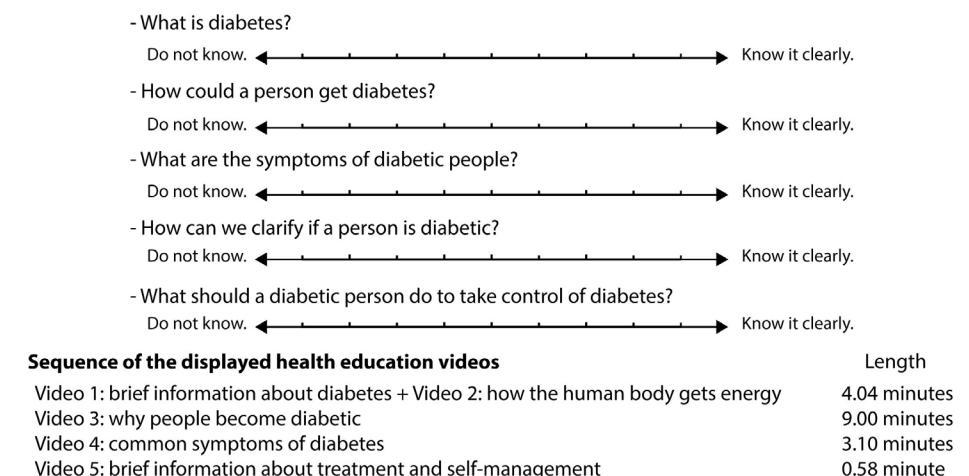
Questions to retrieve answers from each participant's understanding of five topics about type 2 diabetes, a SASLI, and a self-assessment form were involved in accomplishing Research Objective 1. Each participant was required to answer five questions regarding diabetes; a SASLI interpreted the questions and the participant's answers. Next, the participant self-assessed the understanding of each diabetes topic by circling within Likert scales on the self-assessment form (see [Figure 69](#)) before watching the health educational videos. After watching all videos sequenced in [Figure 69](#), the SASLI interpreted the same questions and the participant's answers again; the participant also self-assessed the gained understanding by marking a cross onto the same five Likert scales. The retrieved answers, coupled with participant's self-assessments, were for validating one's understanding increased after watching these health educational videos. For achieving Research Objective 2, the modified RTT retelling method ([Parks & Parks, 2010](#)) was adapted. Each participant watched a full video and could repeat it as often as needed until readily retelling the content. Video 1 that was very short and related to Video 2 were presented consecutively. The remaining videos were displayed individually. After watching each video, the participant retold the messages according to one's understanding. In line with Research Objectives 3 and 4, the participant reflected on the visual material and presentation of all elements after watching each health educational video. Before closing a session, glossary videos of the newly developed signs for medical terms and a question and answer (Q&A) session were provided to prevent each participant from leaving the research venue with diabetes misconceptions. [Figure 68](#) summarizes this procedure.



[Figure 68. Procedure of Co-evaluation Activity 2.](#)

- Research instruments

The self-assessment form was composed of the Likert scales, divided into ten points, ranging from do not know (valued 0%) to know it clearly (valued 100%) (see [Figure 69](#)).



[Figure 69. Self-assessment form and the sequence of the video presentations.](#)

Each of the health educational videos was overlaid with a frame in the shape of a smartphone. It was on a 1:1 scale of a phone on a touchscreen laptop (see [Figure 70](#)) for the participant could have a similar experience to watching videos on a smartphone. The participant could also tap on the screen while responding to an interactive video. These videos were not displayed on an actual smartphone during the co-evaluation to avoid having the participant interact with the phone so that one could focus on the videos solely.



[Figure 70. A health educational video presented to a Deaf participant during co-evaluation.](#)

Data analysis

The video recording of each co-evaluation session was transcribed manually. In achieving Research Objective 1, the participants' self-assessments rated before and after watching videos were compared. The increase in understanding was used to verify if this set of health educational videos could provide a basic understanding of diabetes to Deaf people. [For the participants' self-assessments, access <https://doi.org/10.5281/zenodo.4146723>.](#)

To achieve Research Objective 2, the script of each health educational video was divided into message blocks. Each block contained a core message. A table for analysis was created for each health educational video. There were six message blocks for Video 1, 16 message blocks for Video 2, 20 message

blocks for Video 3, 17 message blocks for Video 4, and nine message blocks for Video 5. Each participant received one score per retold message that matched a message block. Subsequently, the percentage of the matched blocks for each participant on each video was calculated. Access <https://doi.org/10.5281/zenodo.4140365> for this analysis. The obtained percentages determined the SASL narrations' intelligibility in conveying health content to Deaf people with different SASL-dialect backgrounds.

In line with Research Objectives 3 and 4, the participants' reflections on the visual materials and the presentations of all elements were categorized into 1) satisfaction and 2) suggestions for changes. The analyses for both research objectives were conducted from the same document. Access <https://doi.org/10.5281/zenodo.4140363> for the participants' reflections. The suggestions for changes in the designs of health educational videos were brought to a discussion with the Deaf experts who had participated in Co-design Activity 2. If the experts accepted such suggestions, that particular video would be rescripted and rerecorded.

Limitation of this co-evaluation

Those who plan to replicate these requirements for designing health educational videos to their context should test if the NID' SASL dialect could provide information accessibility to the target Deaf people. However, the knowledge about the visual materials and presentation of all elements might be applicable to videos for diverse topics.

2.3 Findings from Co-evaluation Activity 2

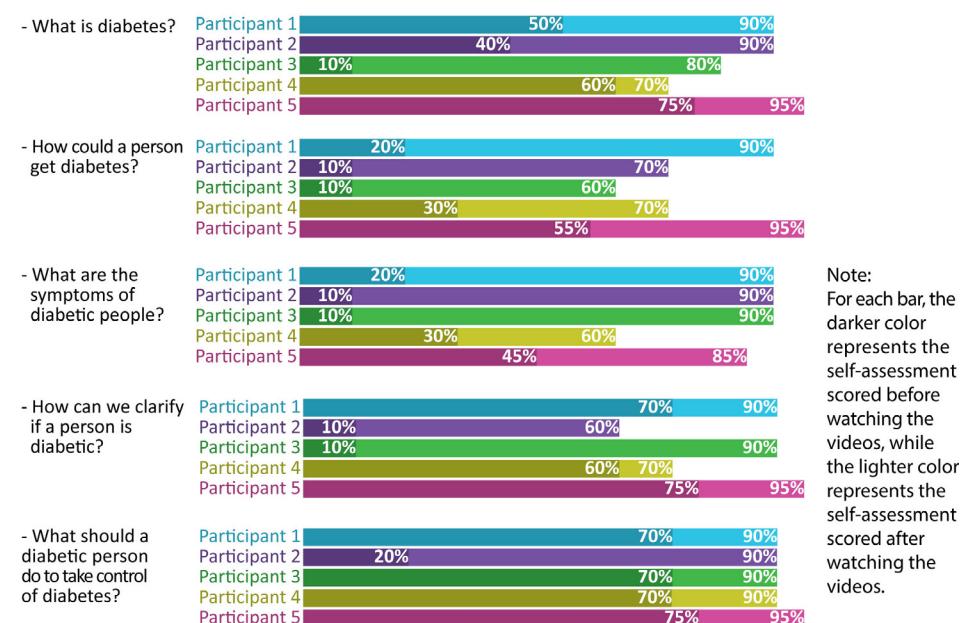
The findings are provided in two topics. The first is the participants' increased understanding of the five topics regarding diabetes and feedback on the narration intelligibility. The second is the feedback on the visual materials, the subtitles, and voice-overs.

The increased understanding and the feedback on SASL narration intelligibility

Before watching these videos, Participants 1 and 3 stated that they were not familiar with the word "diabetes." A slight difference was that Participant 1 had seen other people discuss sugar or blood level, fever, and getting fat. Participant 2 was familiar with some information about diabetes. Participant 4 learned about diabetes from her diabetic grandfather. Participant 5 was exposed to health information through his mother, who worked as a nurse. His diabetes understanding seemed to be much more in-depth than the basic information provided through these health educational videos. Participants 1, 2, and 4 had a similar opinion that diabetes was a disease that afflicted people who had consumed excessive sugar and were overweight. As such, diabetic people had to cut down on sugary food to

improve their health. Participants 4 and 5 knew finger pricking as regular blood testing from their significant others. However, only Participant 5 knew some diabetes remedies, e.g., diabetic people with low blood sugar should eat a piece of chocolate to relieve symptoms. All of the participants had learned from school that healthy eating was essential to maintain good health, and that sick people needed treatment from a doctor.

After watching the videos, all participants self-assessed that they had an increased understanding of all five topics about diabetes (See [Figure 71](#)). From watching Videos 1 and 2, they understood the relationships of the pancreas, insulin, blood sugar, the body cells, and energy. They stopped associating diabetes with excessive sugar intake and restated that the disease was triggered by the pancreas not being able to produce enough insulin or the body not being able to use insulin to open the body cells (i.e., when glucose in the bloodstream cannot enter the cells, the body cannot gain energy).



Note:
For each bar, the darker color represents the self-assessment scored before watching the videos, while the lighter color represents the self-assessment scored after watching the videos.

Figure 71. The increase in the participants' understanding of diabetes.

For Video 3, all participants increased their understanding of how people could develop diabetes. After watching Video 4, their understanding regarding common symptoms of diabetic people was increased. While Participant 4 felt that the content of Video 5 was too general, other participants gained much in-depth information. Participants 1, 2, 3, and 5 were able to give a list to control diabetes through consulting a doctor when feeling sick, regular exercise, and having a healthy lifestyle.

The SASL narration intelligibility was assessed by the percentages that the participants had after watching the health educational videos (see [Table 15](#)). Access <https://doi.org/10.5281/zenodo.4140365> for the details of the analysis.

Table 15. Summary on the percentages of the SASL narration intelligibility per video

Videos	Percentages (%) of intelligibility per participant				
	1	2	3	4	5
Video 1: How our body gets energy (16 message blocks)	6	25	44	N/A	13
Video 2: Brief information about diabetes (6 message blocks)	50	33	17	N/A	0
Remark for Videos 1 and 2	All participants gained an understanding of the relationship between insulin, blood glucose, and body cells.				
Video 3: Why people become diabetic (20 message blocks)	25	20	35	20	40
Remark	1) They recalled the first couple of risk factors of becoming diabetic. 2) They recalled the intriguing risk factors. 3) They recalled the risk factors that matched their preconceived knowledge about health in general.				
Video 4: Common symptoms (17 message blocks)	29	35	N/A	29	29
Remark	They tended to remember the first and last symptoms.				
Video5: Brief information about treatment and self-management (9 message blocks)	33	56	N/A	11	33
Remark	-				

Note: N/A = no data retrieved due to video error (researcher's notetaking was used to back up the analysis)

100% = the participant retold the messages that matched all message blocks

Most of these participants watched Videos 1 and 5 only one time before retelling the messages due to the simple content. Some of the complex videos—Videos 2, 3, and 4—were watched twice before retelling. All participants stated that they understood the narrations. Their retold messages were their overall understanding—self-defined core content of each video. Several details might be missing based on the retold messages since the content could be difficult for those who might have low health literacy and just watching these videos for the first few times. After all, nearly every participant could score the highest percentage for retelling the messages of each video.

Based on these findings: Participants' self-assessments on the increased understanding, statements regarding the clarity of the SASL narrations, and the percentage results, the SASL narrations of all health educational videos showed that they could convey the health content to NID Deaf members. These findings also infer that Deaf people from any SASL-dialect background would understand the NID's SASL dialect selected for the video's narrations.

Feedback on the visual materials, the subtitles, and the voice-overs

This feedback was combined from the Deaf participants' reflections on the visual materials implemented in Videos 2, 3, and 4 ([access <https://doi.org/10.5281/zenodo.4140363> for details](https://doi.org/10.5281/zenodo.4140363)) and reflections on the presentations of all elements for the health educational videos ([access <https://doi.org/10.5281/zenodo.4140363> also for details](https://doi.org/10.5281/zenodo.4140363)). This feedback is summarized in [Table 16](#). These participants agreed with the Deaf experts' decision on the designs for Videos 1 and 5 that simple health content did not always need a visual material accompaniment to provide information accessibility to Deaf people. The participants also elaborated on how they recalled health content. All participants relied on SASL and subtitles to recall the core messages of Videos 1 and 5 that had no visual material accompanying the narrations. For the videos that included visual materials to accompany the narrations, most participants relied on some visual material to recall the content. An apple, as part of the animation, in Video 2 helped all participants recall how the human body digested food, although "apple" was not signed for the narrations. In addition, Participants 3 and 5 stated that the elaboration that signaled the content of Video 1 helped them recall the core messages. As for Video 3, the participants relied on the SASL narrations and the subtitles to recall the risk factors of becoming diabetics instead of the interactive feature. The participants depended on various combinations of the elements to recall the content of Video 4. Participants 2 and 5 relied on the combination of SASL and subtitles. Participant 3 recalled the content from the combination of SASL, subtitles, including illustrations without particular order. Participant 1 thought of SASL before illustrations.

Participant 4 firstly depended on subtitles, secondly SASL, and thirdly illustrations. These participants' elaborations suggested that the SASL narrations and subtitles were the elements Deaf people rely on the most while recalling health content.

Table 16. Summary of the feedback of the visual material, the subtitles, and the voice-overs

Elements	Feedback	
Visual materials	Animation for Video 2	Participants 1 and 3 found the animation helped them understand clearly how the body functions.
	Interactive feature for Video 3	Participants 1, 2, and 3 understood Video 3 as an interactive video. However, these Deaf participants did not find most of the provided risk factors applicable to themselves.
	Illustrations for Video 4	Participants 1, 4, and 5 found illustrations enhanced their understanding of the symptoms of diabetes.
Subtitles	<p>For Video 3, Participants 1 and 5 found that the subtitles' speed was too quick for their reading. Therefore, Participant 5 suggested presenting the subtitles in two lines; let the first line fade out before the second line.</p> <p>For Video 4, Participant 4 found the fonts' colors and contrast for the subtitles difficult to read when rendered over different background colors.</p>	
Voice-overs	Only Participant 5, who wore a hearing aid, suggested increasing the voice-over volume for Video 3. He found the volume in other videos acceptable.	

2.4 Conclusion and discussions of Co-evaluation Activity 2

The participants' increased understanding of the five topics about diabetes and their statements about the clear signing showed that this co-evaluation activity achieved Research Objectives 1 and 2. Although Deaf participants did not reach 100% for retelling the messages, they touched upon some core messages of the new information learned during the first few times of video watching. This means the narrations were intelligible so that they could retell the messages based on their own understanding. These health educational videos increased Deaf participants' understanding by manifesting through their restatements on different topics about

diabetes. Nonetheless, if the participants were emphasized to review each video several more times, they might have scored higher. Diabetic patients in reality should also be encouraged to review relevant health information to support their understanding and effective self-management.

These participants found the animation for Video 2 and illustrations for Video 4 enhance their understanding of the health content (accomplished Research Objective 3). The interactive feature of Video 3 was understood, but it did not help the participants understand the health content. As for the presentation of all elements (in line with Research Objective 4), apart from the satisfying signing, the participants suggested improving the subtitles by 1) slowing down their speed, 2) presenting them in two lines, and 3) using a contrast color and increasing volume of the voice-overs for Deaf people with residual hearing and their hearing caretakers. The participants mainly relied on SASL and subtitles to recall the health content. If animation, not illustration, accompanied the narrations, the participants relied on it alternatively to recall some of the content.

3. Co-evaluation Activity 3: usability testing of Deaf-friendly mobile interfaces

Ten design alternatives of the mobile interfaces (refer to [Figures 64 and 65](#), [Chapter 6](#)) derived from Co-design Activity 3 were brought to the NID Deaf members for testing the usability of the mobile interfaces. The same junior researcher who conducted Co-design Activity 3 was assigned to take a researcher-facilitator role.

3.1 Research process for Co-evaluation Activity 3

The research objectives, the criteria for selecting the participants, research methods and instruments, data analysis, and the limitation are described.

Research objective

The research objective for Co-evaluation Activity 3 was to verify whether any of the ten design alternatives could improve mobile interfaces for Deaf patients and contribute to answer the MRQ (an intervention to influence Deaf people's adherence to type 2 diabetes medication and treatments).

Criteria for selecting the participants

Three novices and three experienced mobile-phone users who were Deaf were invited. They were required to be fluent in SASL and have English skills to interact with the app mockup.

Research methods and instrument

The recruitment of Deaf participants, the research methods and instruments, data analysis, and limitation of Co-evaluation Activity 3 are provided.

- Recruitment of Deaf participants

The participants with the profile that matched the criteria above were recruited through the contact person whom the NID committee assigned. Their time slot was booked to participate in this co-evaluation activity.

- Research methods

Storytelling, roleplay, and think-aloud were applied as the research methods. An interactive app mockup was a research instrument used for this co-evaluation activity. Similar to the preceding activities, [Nielsen's \(2000\)](#) suggestion on the involvement of five participants for sufficient data collection was followed. Six NID Deaf members were invited to participate in this co-evaluation in case a participant would be absent. One participant at a time provided feedback without interference from other participants.

Storytelling was used for putting each participant in the shoes of a Deaf patient who communicated with a health professional. The story was about a Deaf person, Sam, who fell sick and was using an app called SignSupport to bridge communication during a consultation with a doctor at a primary health center. The story consisted of communication activities regarding Deaf patient-led self-management and a Q&A session that the participant who acted as Sam had to accomplish by interacting with the design alternatives for the mobile interfaces. The roleplay simulated a clinical interaction between Sam and a doctor, with the research facilitator taking the doctor's role. The Deaf participant was required to think aloud about all interactions with the mobile interfaces.

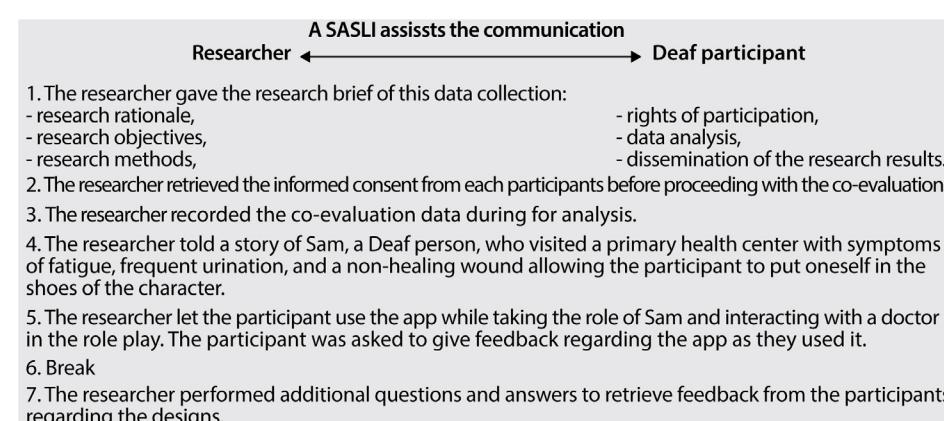


Figure 72. Procedure of Co-evaluation Activity 3.

Each Deaf participant's interactions with the mobile interfaces and feedback were video recorded. Their body language and facial expressions were annotated to verify their feedback. [Figure 72](#) illustrates seven steps that were followed during Co-evaluation Activity 3. This procedure was piloted with research fellows before execution.

- Research instrument

The app mockup was created with Proto.io, a software developed for user experience design, and installed on an Android smartphone for the participant to interact with a device in hand.

Data analysis

Video records were transcribed manually. The participants' feedback on each of the ten design alternatives was analyzed by listing in one table. Each design alternative's usability in prompting Deaf participants to accomplish a communication activity and the participants' suggestions on making that particular design alternative easier to use for Deaf people were written in the table. The usability categorized as Effectual denoted the design alternative understood by the participants for its meaning or function, or else as ineffectual. These analyses were checked twice by two researchers at different times to ensure consistent results. Access <https://doi.org/10.5281/zenodo.4146856> for the analysis of the ten design alternatives. The effectual design alternatives were checked using patterns and the GUI elements initially elicited during the co-design stage (access <https://doi.org/10.5281/zenodo.4133610>). The effectual design alternatives that minimized the number of the use patterns and GUI elements employed for the mobile interfaces would be included in the improvement points for the app.

Limitation of this co-evaluation

This retrieved feedback sufficed for the scenario in which the app was used to bridge communication for Deaf-led self-management and a Q&A session. It would possibly be applicable to the mobile interfaces for other communication bridgings within this app. However, a thorough usability testing of these mobile interfaces should be conducted before deploying this app in a real-life situation.

3.2 Findings from Co-evaluation Activity 3

The feedback from the six Deaf participants regarding the ten design alternatives are summarized in [Table 16](#). The feedback with details can be accessed from <https://doi.org/10.5281/zenodo.4146856>.

Table 17. Summary of feedback on design alternatives and suggestions for improvement

Design Alternatives		Participants					
		1	2	3	4	5	6
Design 1: phone handling via animation		✓	✓	✓	✓	✗	✓
Suggestions	Prefer seeing a guide in SASL more than an animation						
Design 2: provision for the feeling of direct interaction with a health professional		✗	✗	✓	✗	✗	✗
Suggestions	1) Let subtitles appear in two lines. 2) Icon of the doctor should be larger.						
Design 3: icons to be accompanied by sophisti- cated wording for standalone buttons	Medical history	✗	✗	✗	✗	✗	✗
	Symptoms	✓	✓	✓	✗	✓	✓
	Test results	✓	✓	✓	✗	✗	✗
	Diagnosis	✗	✗	✗	✗	✗	✗
	Treatment	✓	✓	✓	✓	✓	✓
	Self-manage- ment	✓	✗	✗	✗	✗	✗
Suggestions	Participants 1 and 4: use icon with wording Participant 2: use a tooltip in place of icon Participant 6: use icon of the hand-shapes (signing)						
Design 4: icon to accompany standalone buttons without wording		✓	✓	✓	✓	✓	✓
Design 5: icon to be accompanied with simple wording for standalone buttons		✓	✓	✓	✓	✓	✓
Design 6: in-conjunction button that requires the user to multi-task in inputting information		✗	✓	✓	✗	✓	✗
Design 7: color codes for double in-conjunction buttons which required the user to consecutively input information		✓	✓	✓	✗	✗	✓

Design 8: notification for the watched and unwatched health content	✗	✗	✗	✗	✗	✗
Design 9: wayfinding and presentation of self-management options	✗	✓	✗	✗	✗	✗
Design 10: wayfinding and presentation for Q&A session	✓	✓	✓	✓	✓	✓

Note: ✓ = effectual and ✗ = ineffectual

The effectual design alternatives and the Deaf participants' suggestions were checked with the previously elicited design requirements of the app before including the ones that reduced the number of the use patterns and GUI elements in the improvement points for the app.

3.3 Conclusion and discussions of Co-evaluation Activity 3

The ten design alternatives were evaluated could improve mobile interfaces for Deaf patients. Design 4: Icon to accompany standalone buttons without wording, Design 5: Icon to be accompanied with simple wording for standalone buttons, Design 10: Wayfinding and presentation for Q&A session were understood by all participants. Design 8: Notification for the watched and unwatched health content and part of Design 3: Two of the icons accompanying sophisticated wording for standalone buttons were not understood by any participant. These participants partly understood the remaining design alternatives.

The understood design alternatives were checked with the initial use patterns and the GUI elements before including as part of the improvement points for the app's conceptual design.

4. The improved conceptual design

[Subsection 4.1](#) gives a list of the improvement points for the app's conceptual design. Next, [Subsection 4.2](#) provides the points of improvement for the videos. Researchers and design practitioners can refer to these lists of requirements when designing a mobile app for providing health information accessibility to Deaf people in a similar context.

4.1 Improvement in app design

These improvement points start with communication bridging, combined with the health content available on the app, and followed by the improvement for the mobile interfaces.

Communication bridging and health content

The improvement points for communication bridging were chosen from the health professionals' feedback summarized in [Table 13](#) and consulted the health-service guidelines implemented in the CWD. These improvement points and reasons for selecting them are outlined in [Table 18](#), described by communication modules to be improved.

Table 18. Summary of improvement points for the communication bridging

Improvement points per interlocutor's communication module		Reference to which findings	Reasons or criteria for the decision making
Deaf patient	As part of the Patient profile: Cover 17 details for opening a patient folder.	Health professionals' feedback in Subsection 1.1 of this chapter	This information is required to adhere to the medical protocol for the paper-based patient folder used in the Western Cape
	As part of Symptom report: Cover four questions and answers regarding medication-history taking.		To serve the information needs of the triage nurse and the nurse at the observation station
All healthcare personnel: Introduce to the healthcare personnel that the patient was Deaf and that tapping on the patient's shoulder is appropriate to gain the Deaf patient's attention.		Health professionals' feedback in Subsection 1.1 of this chapter	To prompt the healthcare personnel to proceed with Deaf-friendly communication
Administrator	who opens new patient folders	- View patient profile with 17 details. - View proof of unemployment.	The author's inputs to make the design of the app for communication bridging in line with the health professionals' feedback
	who files existing patient folders	- View patient card. - Ask for the patient folder number.	To serve the information needs of each type of administrator for their administration work

Triage nurse: Remove body examination from communication activity.	Health professionals' feedback in Subsection 1.1 of this chapter	No contradiction to the health-service guidelines since it is a medical task of the nurse at the observation station, the nurse in the chronic room, and the clinical nurse/doctor
Clinical nurse/doctor: - Add additional questions for assessing the patient's knowledge about the diagnosed disease. - Let the health professional watch the patient's answers to the assessment questions. - Let Deaf patient plan self-management and the health professional help in setting a goal for the patient's selected type of self-management. - Provide a Q&A session for the patient to clarify doubts regarding treatments and self-management. - Direct health information for both the patient and the caregiver.	Health professionals' feedback in Subsection 1.1 of this chapter	No contradiction to the health-service guidelines
Dietician: - The communication activities are similar to those of the clinical nurse/doctor, except for 1) body examination, 2) giving a diagnosis, 3) assessing the patient's knowledge of the diagnosed disease, 4) medication prescribing, and 5) appointment making.	Health professionals' feedback in Subsection 1.1 of this chapter	No contradiction to the health-service guidelines

The improvement points in [Table 18](#) resulted in adding the details requiring the patient to input, the dietician and its communication activities, and other healthcare personnel's communication activities in the finalized diagram of the patient journeys (see <https://doi.org/10.5281/zenodo.4151680>, text in blue indicating the improvement points).

The improvement points were selected from the health professionals' feedback in [Table 13](#) and the 16 questions for the Q&A session (see [Figure 63, Chapter 6](#)). They were verified by the health-service guidelines implemented in CWD and the Diabetes SA representative. These improvement points and the reasons for selecting them are summarized in [Table 19](#).

Table 19. Summary of points of improvement for health content

Improvement points	Reference to which findings	Reasons or criteria for the decision making
Signs of low blood sugar and immediate actions to take	Health professionals' feedback in Table 13 of this chapter	Agreed by Diabetes SA representative
Signs of high blood sugar and immediate actions to take		
16 videos related to the Q&A session	Deaf participant's 16 questions for the Q&A session, in Figure 63, Chapter 6	No contradiction to the health-service guidelines

These improvement points were added as part of the subcluster that stored the in-depth content to support the understanding of the disease and self-management. V2.15 Myths about diabetes and self-management that was part of the listings of the health contents (refer to in [Figure 46, Chapter 6](#)) was removed since the other 16 videos have covered this. As a consequence, the following health contents were renumbered. The newly added health contents are numbered with V3.17-V3.34.

The compilation of the improvement in the listing of the healthcare personnel, communication activities of all interlocutors, and the health content to be available on the app resulted in an improved mobile-information architecture shown via <https://doi.org/10.5281/zenodo.4153040>.

Mobile interfaces

The health professionals' feedback on the app mockup's mobile interfaces (refer to [this chapter, section 1.1](#)) and Deaf participants' feedback on the design alternatives toward Deaf-friendly mobile interfaces (see [Table 17](#)) were selected through the criteria stated in [Table 12](#). [Table 20](#) summarizes the selected improvement points for the mobile interfaces and reasoning.

Table 20. Summary of improvement points for the app's mobile interfaces (part 1)

Improvement points	Reference to which findings	Reasons or criteria for the decision making
Zoom as a GUI element is used for the health professionals to zoom in on the textual information if they find the font sizes too small to read.	Health professionals' feedback, as part of Subsection 1.1	Using the same use pattern and GUI element with the symptom report = not increasing new use patterns and GUI elements
Each mobile interface for the Deaf patient is equipped with a guide in SASL.	Deaf participants' feedback on Designs 1 and 2, as part of Subsection 3.2	Meeting Deaf people's language preference
Tooltips to accompany standalone buttons with sophisticated and simple wording.	Deaf participants' feedback on Designs 3, 4 and 5, as part of Subsection 3.2	Minimizing the use patterns and GUI elements
An icon showing a hand with a finger pointing is used to accompany buttons for logging food intake, but the text: <i>tap to add ingredients</i> is still present to prevent any miscommunication in terms of the semantic meaning.	Deaf participants' feedback on Design 4's effectual usability, as part of Subsection 3.2	Making the mobile interfaces easy to use for the Deaf patient
Color codes are applied for a mobile interface that requires a Deaf patient to input information in double in-conjunction buttons with the same page.	Deaf participants' feedback on Design 7's effectual performance, as part of Subsection 3.2	Making the mobile interfaces easy to use for the Deaf patient when being required to multitask within the same page

Table 20. Summary of improvement points for the app's mobile interfaces (part 2)

Color codes and symbols are applied as part of the notifications to indicate which health educational video is watched or unwatched or how far it has been watched.	Deaf participants' feedback on Design 8's effectual performance, as part of Subsection 3.2	Making the mobile interfaces for the health educational videos easy to use for the Deaf patient
The selecting-list pattern is used for any list that requires a Deaf user to select an option.	Deaf participants' feedback on Design 10's effectual performance, as part of Subsection 3.2	Making the use patterns regarding information access consistent across the mobile interfaces

The improvement points in [Table 20](#) were for improving the requirements for designing this app, shown in blue texts in [Figure 73](#). These improved requirements were used to finalize the conceptual design of this app that bridges communication to provide accessible health information related to type 2 diabetes to Deaf people. Access <https://doi.org/10.5281/zenodo.4153622> for the finalized conceptual design of the app.

Page layout	Visual information used in the mobile interfaces	Users' interactions with the app
Page orientations: <ul style="list-style-type: none"> - portrait = while communication bridging is in process, - landscape or portrait = while the patient is viewing a health content Wayfinding: <ul style="list-style-type: none"> top-down approach Page size: <ul style="list-style-type: none"> 1920 x 1080 Pixel (px) Grid design: <ul style="list-style-type: none"> - annunciator row (in-line with alerts), - locator area (in-line with locator), - interstitial area (in-line with alerts), - content area (in-line with content), or framed with a speech bubble: <ul style="list-style-type: none"> - for Deaf patient, the content area = SASL video area conveying Command 1, communication content, and Command 2 - for healthcare personnel, the content area = 1) Command 1, 2) communication content, and 3) Command 2, - fixed-button area (in-line with footer) 	The theme colors: <ul style="list-style-type: none"> - generic gradients  <ul style="list-style-type: none"> for buttons, icons, progress bar, text in the communication content area. Contrast colors  <ul style="list-style-type: none"> for notifications Texture: <ul style="list-style-type: none"> matte Fonts: <ul style="list-style-type: none"> - family: sans-serif, - size: <ul style="list-style-type: none"> - 48 or 11 Point(pt) of visible size for the title of the communication process and communication content, - 72 or 16 pt of visible size for Commands 1 and 2 	Use patterns and GUI elements for information access: <ul style="list-style-type: none"> - the hierarchy structure for the organization of complex contents in the app, - the main page = the center in accessing other subpages, - top-down approach via buttons, - buttons + tooltips in SASL + simple/sophisticated wordings = options on both main page and subpages which present options for the user to select, - the press and hold gesture at the tooltip symbol = activate a display of the explanation in SASL of the wording on the button, - SASL guides on interactions = for Deaf users, - concise-text guides on interactions = for hearing users Use patterns and GUI elements for information input: <ul style="list-style-type: none"> - standalone buttons (buttons for an immediate action without a user's additional input): <ul style="list-style-type: none"> - standalone buttons + icons only = for the patient to create a new <i>Patient account</i>, <i>fill in the patient profile</i>, <i>prepare for communication</i>, and <i>respond to questions during interaction</i>, - standalone buttons +icon + simple wordings = for food ingredients, - standalone buttons + tooltips in SASL + sophisticated wordings = for the patient to input detail for <i>Patient profile</i> and report symptoms, - in-conjunction buttons (buttons for input and control for further action): <ul style="list-style-type: none"> - multiple-selection buttons with concise text = for healthcare personnel to plan communication with the patient, to select questions to assess the patient's knowledge of the diagnosed disease, to plan self-management for the patient, and to recommend smoking cessation tips, - multiple-selection buttons with tooltips in SASL = for the patient to select the type of self-management and questions for a Q&A session, - single-selection buttons with concise text = for healthcare personnel to direct the patient to the next healthcare personnel and to explain the medical test results to the patient, and for a clinical nurse/doctor to introduce one's name, - type-in boxes for search within an infinite list = for healthcare personnel selects a mannequin body to examine, a medical test to prescribe, and a disease name for giving a diagnosis, - regular type-in box = for a clinical nurse/doctor to type in one's name for self-introduction, values to explain the medical test results, and other values related to self-management, - multiple in-conjunction buttons that appear on the same page for Deaf patients are to be guided in SASL and color codes for interactions, Keypads: <ul style="list-style-type: none"> - qwerty keypads = for text inputs (e.g., name of a clinical nurse/doctor, entitling the <i>Patient account</i>, a body part to examine, a medical test to prescribe, a suggested contact name and email, etc.), - number keypads = for numeric inputs (e.g., medical test results, the patient's lifestyle regarding meals/day, the target weight, etc.), - directional entry = slide bars = for the patient's logging of weight and blood sugar tests in a day, - input areas = for the patient to select a body part to report a symptom and the scheduling of a follow-up appointment between a clinical nurse/doctor and the patient Use patterns and GUI elements for information control: <ul style="list-style-type: none"> - scroll bar = for information that exceeds a page, - hamburger button = a shortcut to the home page, - hard key = the button for returning to the previous page, - zoom and scale = for the use during a symptom report GUI elements to confirm the input of information: <ul style="list-style-type: none"> - delayed input <ul style="list-style-type: none"> - question tags = to prevent an overwriting of the existing information (i.e., before creating a patient account, update the profile in the <i>Patient account</i>, and prepare for communication). - exit guards = to prevent an accidental exit from a process (i.e., at the end of inputting the patient profile), - pop-up notifications = get attention from a user to take an action (i.e., a pop-up notification requiring the patient to input profile in the created Patient account), - symbol and a color code = status of the selected button(s) (i.e., check mark and color change for the selected multiple and single selection, color change for all types of the selected standalone buttons and pressed keypads) GUI element for information output: <ul style="list-style-type: none"> - interstitial bar = the progress of a communication process

Figure 73. The improved requirements for designing an app.

4.2 Improvement in health educational video design

Based on the feedback from the Deaf participants during Co-evaluation Activity 2, two improvement points were selected in agreement with Deaf experts from NID. These improvement points and reasoning for selecting them are summarized in [Table 21](#).

Table 21. Summary of points of improvement for the health educational videos

Improvement points		Reference to which findings	Reasons or criteria for the decision making
Redo font style, colors, and the display of subtitles	Zoom as a GUI element is used for the health professionals to zoom in on the textual information if they find the font sizes too small to read.	Health professionals' feedback, as part of Subsection 1.1	Using the same use pattern and GUI element with the symptom report = not increasing new use patterns and GUI elements
	Each mobile interface for the Deaf patient is equipped with a guide in SASL.	Deaf participants' feedback on Designs 1 and 2, as part of Subsection 3.2	Meeting Deaf people's language preference
	Tooltips to accompany stand-alone buttons with sophisticated and simple wording.	Deaf participants' feedback on Designs 3, 4 and 5, as part of Subsection 3.2	Minimizing the use patterns and GUI elements

Scripts and narration in SASL	Visual materials	Presentations of all elements
<ul style="list-style-type: none"> - SASL for narration with its syntax structure and a selective dialect is selected for narrations. - Relevant health contents can be combined and presented in a particular sequence to help Deaf viewers form knowledge. - Messages can be simplified to accommodate the viewers' understanding when developing a new sign will cause confusion, and elaborated to: <ul style="list-style-type: none"> - introduce contents of each video, - provide context for the viewers, - emphasize the take-away message. - A guide on how to interact with the interactive video should be provided to the Deaf viewer. - New signs can be developed based on: <ul style="list-style-type: none"> - invented iconic signs combined with phonology, - lexicon combined with morphology, - or fingerspelling with an accompanying picture. 	<ul style="list-style-type: none"> - An animation communicates the pathology of the disease. - Illustrations communicate symptoms of the disease or appearance of the organs in human body. - An interactive video communicates and raising awareness on the risk factors of becoming diabetic. - No visual material is needed for simple health contents. 	<p>Health contents that do not require visual material:</p> <ul style="list-style-type: none"> - One SASL narrator communicates the content. - The SASL narrator appears in the center of the video layout. <p>Health contents that require visual material:</p> <ul style="list-style-type: none"> - The area for SASL narrator occupies the left side, and the area for a visual material occupies the right side of the video layout. - Visual material fades in from the right side of the video layout, while the SASL narrator shifts to the left half of the layout. - One SASL narrator signals the core messages. Another narrator carries out the rest of the messages. - The visual material and the SASL narrator display simultaneously. <p>For all health contents:</p> <ul style="list-style-type: none"> - The SASL narrator, a visual material (if any), subtitles, and voiceover should be presented simultaneously. They all should be synchronized as much as possible. - Subtitles are placed at the bottom of the screen and near a visual material. They are presented in both one line and two lines depending on the flows of the signing.

Figure 74. The improved design requirements of the health educational videos.

The two improvement points in [Table 21](#) resulted in the improvement in the requirements for designing health educational videos. [Figure 74](#) presents the update in blue, while the details of the interactive video are removed. The five health educational videos were edited in line with these improved requirements. [These finalized health educational videos can be accessed from \[https://www.youtube.com/watch?v=Y4ZHYN3YJ4&list=PL_34qO4qYjUiahweEDdwPt1eaRb49kcPF\]\(https://www.youtube.com/watch?v=Y4ZHYN3YJ4&list=PL_34qO4qYjUiahweEDdwPt1eaRb49kcPF\)](#).

5. Reflections on all initial guidelines

All of the initial guidelines for actively involving a Deaf community and health professionals (refer to [Chapter 2, Subsection 3.3](#)) are reflected upon since all CBCD stages were completed.

Guideline 1: A researcher should comply with the research regulations of the studied context made the author and the junior researcher conduct this field research ethically and keep all stakeholders primarily informed. By doing so, the local research ethics committee, the leading Deaf community, and the relevant health professionals were informed about the research objectives and procedures. They were ensured that the participants' rights were not violated; the participants were provided fair compensations for participating in a research session; and there was a protocol to safeguard the Deaf participants from leaving a research session with diabetes misconception.

Guideline 2: A researcher must discuss the research project with the leaders of the prospective Deaf community to gain approval for the project before reaching out to the community members was perceived sequential from Guideline 1. The leaders took care of the community's interests and performed a gatekeeper role. Discussing the research project to obtaining their approval before approaching the community members showed respect and established a research relationship appropriately with the involved Deaf community.

Guideline 3: The main inclusion criteria for empirical research with the Deaf participants should be clearly defined was experienced as an essential step. It framed the author and junior researcher to focus on the appropriate Deaf participants rather than compromising their scarcity during the recruitment.

Guideline 4: A researcher must use SASL in the dialect that Deaf people prefer in order to collect data from them effectively, and Guideline 5: a researcher should ask the Deaf community about its preferred SASLIs and respect the SASLIs' code of conduct were found relevant with each other and could be merged as one guideline. Multiple incidences during this CBCD approach showed that the Deaf participants could not understand the SASLIs who used a SASL dialect differed from theirs; the communication during data collections broke down. The language for communicating with the hearing health professionals also needed to be confirmed while organizing a research session to yield effective data collection.

Guideline 6: A researcher should design a research session with flexibility to accommodate the arrivals and availability of the participants was necessary for involving Deaf participants and health professionals in this CBCD approach. This was because the Deaf participants were college learners who could attend a research session while having no class, and the health professionals were busy.

Guideline 7: A researcher should adopt Deaf culture into practice when interacting with Deaf people, and Guideline 8: A researcher should learn SASL stimulated the author and the junior researcher to develop soft skills. These guidelines were related to each other because the signed language was part of the Deaf culture. These guidelines enabled researchers to maintain research relationships and cultivate social relationships with the Deaf community.

In relevance to Guideline 6, *Guideline 9: Being aware of possible research-related delays* was reflected as essential to researchers who practiced the CBCD approach. Having to follow the participants' availability made the author and the junior researcher have less control over the project. Planning

adjustments were periodically required to complete the project within the timeframe.

6. Answers to research questions

The findings from the Co-evaluation stage refined the answers to SRQs 2, 4, 5, and 6 and the MRQ.

SRQ 2: How health information is delivered to Deaf people in the Western Cape, and who can be health information providers and health information seekers of this empirical research?

Answer: The information seekers in this research context are any Deaf people or diabetic patients interested in information about type 2 diabetes. At primary health centers, doctors and clinical nurses, and dietitians were the health information providers for diabetic patients

SRQ 4: How do Deaf people interact with their preferred information sources, channels, media, and devices to successfully exchange information?

Answer: Doctors were NID Deaf members' preferred health information sources. Health consultations at primary health centers were their main channel to access health information, but the available SASLIs were scarce. The NID members agreed that mobile phones could be the devices to provide them with access to health information in the absence of a SASLI. An app which would be installed on Deaf patients' smartphones should allow individual Deaf patient to see mobile interfaces that bridge one's communication with healthcare personnel, including the app, in signed language.

SRQ 5: How do Deaf people seek health information and what can be their methods to successfully communicate health information?

Answer: NID Deaf members and Deaf experts chose methods involving a combination of SASL, visual material, and subtitles for communicating health information. However, visual material was not always required. Simple health contents could be communicated via a combination of SASL and subtitles, without visual material. Animation and illustrations were chosen for sophisticated health content that needed visual materials to enhance Deaf people's understanding. The animation was used to accompany the explanation of biological processes in the body, such as how the human body gains energy and pathology of type 2 diabetes. Illustrations were used to accompany some of the content that did not show a process, e.g., common symptoms of diabetes. An interactive feature for a health educational video did not help raise Deaf people's awareness of the risk factors for developing

diabetes like the author's and the Deaf experts' expectations. Clear SASL narrations and the subtitles at a readable speed were the most critical elements Deaf people rely on the most when recalling the health content.

SRQ 6: What can be relevant health topics that the information seekers of this empirical research need, and what information can influence patient's medication and treatment adherence, according to the health information seekers' and providers' requirements?

Answer: Diabetes was chosen over other diseases, and this study targeted any Deaf people interested in information about the disease.

Deaf patients usually needed much less health information during a consultation than what a health professional wanted them to understand. Consequently, Deaf participants and the health professionals agreed that there should be two health information clusters for the patient to view. This was to meet the patient's information needs and induce their medication and treatment adherence. The first cluster is the health contents to be viewed by the patient during the interaction with a health professional. The second cluster is the health contents for the patient, including one's caretaker, to study at a convenient time. In addition, the second cluster should be designed in two subclusters for agile user experience and effective management of the health contents. The first subcluster contains the contents for comprehensive diabetes control, and the second subcluster consists of the contents in supporting the understanding of the disease and self-management. The answers to questions people commonly asked about type 2 diabetes should be listed as part of the health content in the second subcluster so that the patient can view to support ones' self-management.

MRQ: What intervention can be designed to provide Deaf people with health information for influencing medical and treatment adherence?

Answer: An Android mobile app for Deaf patients to install on their mobile phone. This app could be designed by organizing complex and extensive information according to the information architecture in [Figure 45](#). The mobile –interface design could follow the requirements shown in [Figure 73](#). Health content orchestrated on the app had to be designed, starting from adjusting and rearranging the messages to accommodate the understanding of Deaf patients who could have low health literacy, followed by designing a suitable type of visual materials and presentation of all elements: SASL narrations, subtitles, visual materials, and voice-overs. How to design health content accessible to Deaf people could be followed in [Figure 74](#).

The last stage of the CBCD approach ends with this chapter. The next

chapter of this thesis concludes the research objectives, relationships, and results of all CBCD's four stages. Also, the envisaged versus the practiced CBCD approach was discussed. Lastly, the finalized answers to all research questions, including 1) the guidelines for a designer and a researcher to actively involve a Deaf community and relevant health professionals in a design and development process for an intervention and 2) requirements for designing an app to provide health information accessibility to Deaf people are addressed.

Chapter

8

Conclusion and discussions



The community-based co-design (CBCD) approach was the key to identifying the requirements for designing a mobile app to provide health information accessibility to Deaf people that the desk research could not yield for this study sufficiently. This last chapter concludes this thesis with the objectives and relationships of the CBCD's four stages and answers all research questions. Next, it discusses multiple topics regarding the application of the CBCD approach, the author's reflections upon this research approach and findings, this research's scientific and societal contributions, the generalizability of this research's results, and future work.

1. Conclusion

This study is concluded with CBCD's four stages ([Subsection 1.1](#)) and the reformulated answers to all research questions ([Subsection 1.2](#)).

1.1 The four stages of the CBCD approach

The research objectives, research activities, results, and relationships of co-exploration, co-planning, co-design, and co-evaluation are concluded in [Figure 75](#). The co-exploration was the first CBCD stage conducted to explore the context and identify relevant participants and alternatives for all six building blocks purposed toward formulating a case study. Two Co-exploration activities were proceeded. Co-exploration Activity 1 identified

the relevant participants: three groups of Deaf participants and Deaf and hearing health professionals and derived the alternatives for the six building blocks. Co-exploration Activity 2 confirmed whether mobile phones, an alternative for Building Block 6, were physically accessible to people from Deaf communities in the Western Cape and elaborated on the requirements for the phones that met Deaf people's needs.

Co-planning was the second CBCD stage during which the alternatives for the six building blocks, obtained from the Co-exploration Stage, were jointly selected by the author and the Deaf community leaders: Deaf Community of Cape Town (DCCT), and later the National Institute of the Deaf (NID), to formulate a case study. The DCCT management rescinded the community from taking the leading role due to the mismatch between its Deaf health workers' expertise and Deaf people's health topics of interest that could affect the research validity. Research fatigue was another reason for their rescission due to the fact that they had been participating in Bridging Application and Network Gaps (BANG)'s CBCD approach. Next, the NID committee agreed for its community to take that leading role. They also reviewed and agreed with the proposed alternatives of Building Blocks 2, 3, 4, and 6 (see Figure 75), including the alternative of Building Block 5 obtained from an additional study on the NID Deaf members. The additional study was about the Deaf members' understanding of diabetes and information needs (to elaborate details on the option of Building Block 2) and preferred methods for communicating health information (to refine the option of Building block 5). Consequently, a case study was jointly formulated for the CBCD approach's trajectory (refer to Chapter 5, Section 5).

Co-design, as the third CBCD stage, was designed with three activities. Co-design Activity 1 purposed four objectives: 1) development of patient journeys for type 2 diabetes treatments, 2) identification of the communication activities between a Deaf patient and healthcare personnel, 3) determining the listings of health content available on the app, and 4) description of requirements for designing an app based on the health professionals' and Deaf participants' inputs. Co-design Activity 2 was to 1) describe how to narrate the selected health content in SASL, 2) the visual materials to accompany the narrations, and 3) the presentations of all elements for the selected health content.

Co-evaluation was the fourth CBCD stage designed to evaluate the results of the co-design activities. Co-evaluation Activity 1 verified the requirements from Co-design Activity 1 from a healthcare perspective. Part of this verification was brought to Co-design Activity 3 as an opportunity to derive Deaf-friendly mobile interfaces. Consequently, the results of Co-design Activity 3 were verified before improving the requirements for designing

the app and the conceptual design of the app. Co-evaluation Activity 2 straightforwardly verified the requirements for designing health content derived from Co-design Activity 2. Its results contributed to the improved health educational videos to be displayed within the app.



Figure 75. Conclusion on the four stages of the empirical research.

Since the Co-exploration Stage, the requirements for designing an app and health information accessible to Deaf people were verified step-by-step. These stated processes showed how consistent these findings were.

1.2 Findings to research questions

In Chapters 4 to 7, answers to research questions were found and verified step-by-step (refer to [Chapter 4, Section 4](#); [Chapter 5, Section 5](#); [Chapter 6, Section 5](#); [Chapter 7, Section 6](#)). Those answers are presented as the findings of this study to the main research question (MRQ) and the sub-research questions (SRQs).

MRQ: What intervention can be designed to provide Deaf people with health information for influencing medical and treatment adherence?

Finding: The Deaf community and health professionals relevant to the case study identified an app for Android smartphones as an intervention to provide health information to Deaf people in the Western Cape context. An app installed on individual Deaf patients' smartphones. The app's information architecture should be designed to organize complex and extensive information (refer to [Figure 45, Chapter 6](#)). The mobile-interface design should follow the requirements in three aspects: page layout, visual information used in the mobile interfaces, and user's interactions with the app, as shown with extended details in [Figure 73, Chapter 7](#). Health content orchestrated on the app should be designed by adjusting and arranging messages to accommodate the understanding of Deaf patients who may have low health literacy, using a suitable type of visual materials, presentation all elements (i.e., narrations in signed language, subtitles, visual materials, and voice-overs) (summarized in [Figure 74, Chapter 7](#)).

The requirements for designing the app were accumulated from the findings to the SRQs below.

SRQ 1: What guidelines can help a designer and a researcher actively involve information seekers who are Deaf and information providers in a design and development process for an intervention?

Finding: Seven guidelines were formulated based on the author's and research fellows' reflections upon the initial guidelines retrieved from other researchers who had practiced community-based research. The initial guidelines were practiced and reflected throughout the CBCD's four stages (refer to [Chapter 4, Section 3](#); [Chapter 5, Section 4](#); [Chapter 6, Section 4](#); [Chapter 7, Section 5](#)). As such, they are hands-on for those who plan to actively involve information seekers who are Deaf and information providers in designing an intervention to provide information accessibility to Deaf

people. Details of these seven guidelines are as follows.

Guideline 1: Comply with the research and ethics regulations of the studied context by clearly stating the research objectives and methodology, protecting the participants' rights, and safeguarding the participants from health misconceptions caused by the studied topics.

Guideline 2: Show respect and establish a research relationship appropriately with the prospective Deaf community that would take a leading role throughout the CBCD approach by discussing the research project with the Deaf community leaders before reaching out to the community members.

Guideline 3: Define the main inclusion criteria for selecting Deaf participants and focus on the appropriate Deaf participants rather than compromising their scarcity. More criteria for selecting the participants can be specified when needed for each research session.

Guideline 4: Use a signed language with the dialect and the signed language interpreters the Deaf community recommends, including the language that the hearing participants prefer to collect data effectively.

Guideline 5: Design a research session with flexibility to accommodate the availability of the participants.

Guideline 6: Adopt Deaf culture into practice while interacting with the Deaf community and learn their signed language to maintain research relationships, including growing social relationships with the Deaf community.

Guideline 7: Periodically adjust the research planning to handle possible research-related delays due to the research sessions organized by following the participants' availability.

SRQ 2: How health information is delivered to Deaf people in the Western Cape, and who can be health information providers and health information seekers of this empirical research?

Finding: Multiple stakeholders have engaged in health information distribution to Deaf people in the Western Cape. There can be several health information providers (refer to [Figure 21, Chapter 4](#)). This empirical research took the delivery of health information regarding type 2 diabetes as a case study (see [Table 9, Chapter 5](#)). Thus, information seekers were Deaf people interested in information about type 2 diabetes, such as diabetic Deaf patients, and information providers were health professionals working at primary health centers. Doctors, clinical nurses, and dietitians were identified as the health

professionals who would provide relevant health information to the patients the most during health consultation to influence medication and treatment adherence and effective self-management (see <https://doi.org/10.5281/zendodo.4151680>, text in blue indicating the improvement points).

SRQ 3: How do Deaf people experience health information accessibility of the current information sources, channels, media, and devices, and which one are they interested?

Finding: Deaf people had access to multiple health information sources, such as those illustrated in [Figure 21, Chapter 4](#). Health consultations with a doctor, including a clinical nurse and a dietitian, in the absence of a South African Sign Language Interpreter (SASLI), ranked first place as the current health information channel to Deaf people. However, such channels did not provide adequate health information accessibility when the information was not in South African Sign Language (SASL). Deaf people were interested in and preferred accessing health information from health consultations in the presence of a SASLI instead. Such interest and preference resulted from their past experiences with successful health information accessibility when the information was in SASL.

SRQ 4: How do Deaf people interact with their preferred information sources, channels, media, and devices to successfully exchange information?

Finding: Deaf people preferred doctors—health information sources—who provided information during health consultations—channels—in the presence of a SASLI, who were scarce and expensive to Deaf people. Deaf members from NID (refer to [Chapter 6, Subsection 1.3](#)), including Deaf Community of Cape Town DCCT and Vukani Deaf Club (refer to [Figure 22, Chapter 4](#)), agreed with using mobile phones—devices—to intervene in the situation for providing health information accessibility to Deaf people. An app—a medium—can be installed on an individual Deaf patient's smartphone to bridge communication with healthcare personnel (auxiliary staff and health professionals) engaged in type 2 diabetes treatments. A patient should be prompted in SASL to interact with mobile interfaces and communicate with the healthcare personnel to seek health information.

SRQ 5: How do Deaf people seek health information and what can be their methods to successfully communicate health information?

Finding: The studies with Deaf communities in the Western Cape showed that Deaf people sought health information when they fell sick. NID Deaf members and Deaf experts chose methods involving a combination of SASL, visual materials, subtitles, and voice-overs for communicating health

information (refer to [Chapter 6, Subsection 1.3](#)). However, visual materials were not always required for simple health content, which could be communicated via a combination of SASL and subtitles. For sophisticated health content, animation or illustrations can be used to enhance Deaf people's understanding. An animation was effective for accompanying an explanation of biological processes in the body, such as how the human body gains energy and the pathology of type 2 diabetes. Illustrations effectively accompanied the content that explicates the appearance of things without scaring their viewers, such as unhealing wounds—a common symptom of diabetes. Deaf people majorly rely on both SASL and subtitles to recall the content; both have to synchronize as much as possible while still maintaining the arts of interpretation. The narrations in SASL for both simple and sophisticated health content had to be in the dialect that the target Deaf viewers were familiar with. The subtitles had to be at a readable speed. Voice-overs were for Deaf people who had residual hearing and Deaf patients' caretakers.

SRQ 6: What can be relevant health topics that the information seekers of this empirical research need, and what information can influence patient's medication and treatment adherence, according to the health information seekers' and providers' requirements?

Finding: Deaf patients usually needed much less health information during a consultation than what a health professional wanted them to understand (Refer to [Table 8, Chapter 5](#); [Chapter 6, Subsection 1.3](#)). Consequently, Deaf participants and the health professionals agreed that there should be two health information clusters for the patient to view in order to meet the patient's information needs and induce their medication and treatment adherence. The first cluster is the health content to be viewed by the patient during the interaction with a health professional. The content for the first cluster was brief information about the diagnosed disease and how to improve such health conditions to meet the patient's readiness in absorbing health information about their sickness. The second cluster contained the health content for the patient, including one's caregiver, to study at a convenient time. The second cluster should be divided into two subclusters for agile user experience and effective management of the health content. The first subcluster contains the contents for comprehensive diabetes control. The second subcluster consists of the contents—reasoning of self-management and frequently asked questions—supporting the understanding of the disease and self-management.

SRQ 7: What can be criteria for an intervention to provide health information accessibility to Deaf people in the Western Cape context?

Finding: Literature and findings from the CBCD's four stages contributed to six criteria for designing an intervention with the following details:

Criterion 1: Deaf people have physical access to the selected intervention.

[Calnan \(1985\)](#) and [Swanson \(1992\)](#) suggested that information would become accessible when information seekers had physical access to it. The findings from Co-exploration Activities 1 and 2 inferred that an app installed on a Deaf individual's Android smartphone would provide the person with physical access to health information available within it. Mobile phones were the selected devices since they were Deaf participants' most popular ideas ($n = 12$) (refer to [Chapter 4, Section 1.3](#)); and the Deaf respondent majority (47 out of 54) had access to such devices; Android smartphones were popular among these Deaf respondents (26 out of 47) (refer to [Figure 27, Chapter 4](#)).

Criterion 2: Health information access should be free of charge for Deaf people.

Vital information should be available to Deaf people free of charge since the Deaf majority are unemployed ([WASLI, 2013](#); [WASLI & WFD, 2015](#); [Zulu, 2014](#)). As such, the app should be available free of charge. If possible, a smartphone with the specifications that meet Deaf people's needs should be subsidized. A suitable phone should contain Deaf people's often used standard features: a music player, agenda planner and reminder, alarm clock, and already installed apps for email. The phone should be equipped with a battery that lasts for the prospective users who may play music for three hours per day; have sufficient memory capacity to accommodate user-created data for long periods without backup (refer to [Chapter 4, Subsection 2.3](#)). Without smartphones, no access to an app could be possible; without an app, only limited health information accessibility Deaf people experienced within this studied context.

Criterion 3: The target users' preferred language should be confirmed.

Deaf people preferred communicating and retrieving health information in signed language (refer to [Chapter 1, Subsection 3.4](#)); Deaf people in this studied context preferred SASL (refer to [Chapter 4, Subsection 1.3](#); [Chapter 5, Subsection 3.3](#); [Chapter 6, Subsections 1.3, 2.3, and 3.3](#); [Chapter 7, Subsections 2.3 and 3.2](#)) when interacting with the app and healthcare personnel. As for the health professionals' preferred language, English was primarily used for this case study. Their preferred language(s) should be confirmed before implementing it or applying this app in a comparable context.

Criterion 4: The selected intervention should handle a considerable amount of information.

[United Nations Educational, Scientific and Cultural Organization \(n.d.\)](#) recommended that an intervention providing information accessibility for all in any country should be able to handle metadata. The improved conceptual design of the app (refer to [Chapter 7, Subsections 4.1](#)) showed that the app accommodated a considerable amount of information—the patient's profile, SASL guides for prompting a Deaf patient's interactions with the app, and healthcare personnel, and health content.

Criterion 5: The health content available within the selected intervention must match with Deaf people's health information needs.

[Calnan's \(1985\)](#) and [Swanson's \(1992\)](#) work inferred that an information seeker would find an intervention accessible when the information retrieved from it matched with their needs. The findings from [Chapter 6, Section 1.3](#) showed that Deaf patients needed a limited amount of health information compared to what health professionals aimed to deliver. As such, clustering of health content to let a Deaf patient watch during and after a health consultation was necessary. The health content should be reviewable to support their effective self-management (refer to [Chapter 7, Subsection 4.1](#)).

Criterion 6: The selected intervention should suit the target healthcare system.

[United Nations Educational, Scientific and Cultural Organization \(n.d.\)](#) recommended the selected intervention providing information accessibility for all to be interoperable with a relevant system. For this case study, the app complied with the healthcare framework toward 2020 ([Western Cape Government, 2011](#)) and the healthcare framework toward 2030 ([Western Cape Government, 2014](#)). Specifically for type 2 diabetes treatments, the app also complied with the 2012 Society for Endocrinology, Metabolism, and Diabetes of South Africa (SEMDSA) Journal ([Amod et al., 2012](#)) and Primary Care 101 (PAC 101) Guideline 2013/14 ([University of Cape Town Lung Institute for the National Department of Health, 2014](#)). The app catered to preventive, promotive, curative, and rehabilitative care—comprehensive care—through features, such as search and review health educational videos and self-management logs.

2. Discussions

This section discusses the practiced CBCD approach and reflections upon the findings retrieved from it ([Subsection 2.1](#)), the benefits and challenges when applying such approach ([Subsection 2.2](#)), the similarities with and

modification for a co-creation ([Subsection 2.3](#)), this study's scientific and societal contributions ([Subsection 2.4](#)), the generalizability of this research's results ([Subsection 2.5](#)), and future work ([Subsection 2.6](#))

2.1 The practiced CBCD approach and reflections upon the findings

In [Chapter 3, Subsection 2](#), the CBCD was initially envisaged as a one-directionally cyclical approach that involved only one Deaf community from the beginning until the end of the research cycle. However, researching the real-life system could rarely be perfect and proceeded with one directionally cyclical CBCD approach. Breaking down each CBCD's stage into multiple research activities and designing a couple of them to reiterate were needed for identifying comprehensive results.

The CBCD approach has shown how robust it has been since the Co-exploration Stage ([Chapter 4](#)). Minor methodological details could be modified to handle research-related change and obtain much in-depth information without altering the main objectives of the CBCD's stage (see [Figure 76](#)).

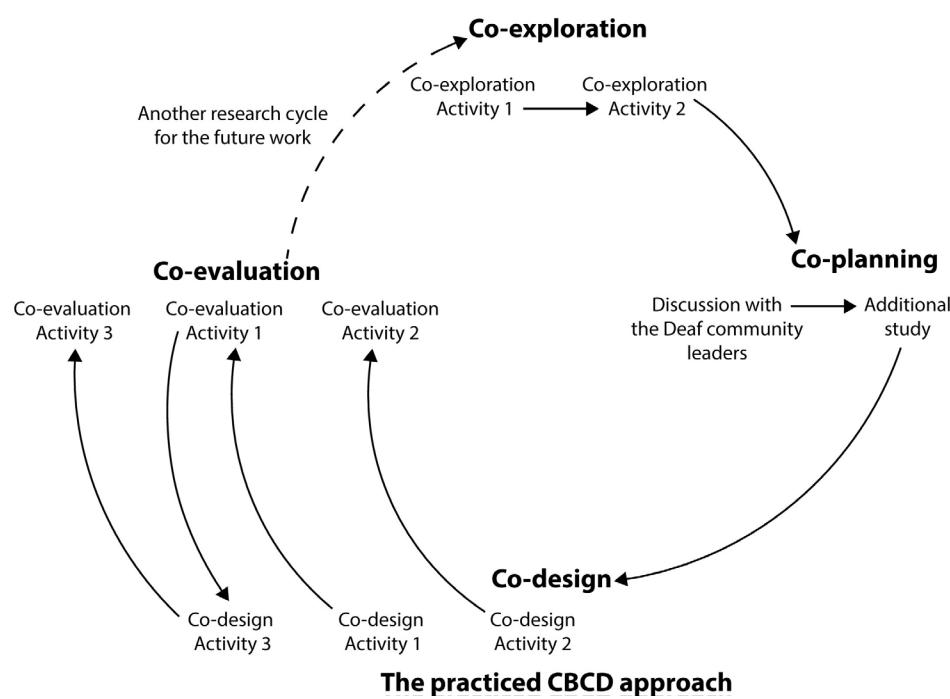


Figure 76. The practiced CBCD approach.

Shifting from DCCT to NID that took the leading Deaf community was the major research-related change. The community shifting resulted in establishing new research relationships with a new Deaf community and an additional study during the Co-planning stage to gain new insights before jointly formulating the research trajectory. Plus, the Co-design Stage and the Co-evaluation Stage broken down into three activities and iteratively proceeded allowed verifications of comprehensive requirements for designing the app.

A reflection on how the CBCD approach safeguarded this research progress was made. The rescindment of DCCT was felt as if a (research) partner called for a break in a long-term (research) relationship. If the CBCD approach was not applied, this empirical research would have to restart by involving a new Deaf community. However, the CBCD approach allowed methodological modification for researchers to proceed with research activities in modules, refer, and reuse information retrieved from a previous CBCD's stage to design an intervention in a real-life system. It took the four—the suitable research approach, the interested and competent Deaf community, the relevant stakeholders, and the determinant researchers—to accomplish this kind of study. Thus, researchers who will apply the CBCD approach in their empirical research should be aware of what can be encountered. The benefits and challenges that the author and the research fellows experienced by applying the CBCD approach are provided in the next subsection.

2.2 Benefits and challenges when applying the CBCD approach

The benefits and the challenges for 1) the researchers and the designers, 2) the participating Deaf community, and 3) the research progress were reflected after applying the CBCD approach. These reflections' narrative is formulated similarly to what other researchers who had practiced community-based research provided in [Chapter 2, Subsection 3.1](#).

Three benefits for researchers and designers

- *Empathy development for Deaf people and increasing understanding of their culture, norms, and values:* Literature could help a researcher develop some empathy for Deaf people, but frequent interactions with Deaf people provided opportunities for the author and research fellows to empathize with the Deaf culture, norms, and values even more.
- *Enabling the organization of research sessions that are Deaf friendly:* The understanding above skilled the author and research fellows in organizing practical research sessions by adopting Deaf culture (e.g., organizing a group session more than individual sessions, addressing the participants appropriately as "Deaf" or with their name sign, accepting their straightforward comments and intrusive questions, accepting their shoulder touching to gain attention, and long leave-taking) and met

their communication requirements (e.g., consulting the Deaf community leaders before hiring a suitable SASLI with the dialect and interpretation style, setting up a barrier-free environment for effective communication, specifying the positions for where the SALI and the research facilitator(s) should stand in the research venue, giving a direct speech while communicating with the Deaf participants, and ensure the participants that all information said was interpreted for transparency).

- *Retrieval of in-depth information toward the intervention that Deaf people plan to adopt in their daily lives:* As a result of the Deaf-friendly research sessions, the Deaf participants were comfortable and became more responsive to the research facilitator(s). They tended to reveal in-depth information about their needed intervention.

Three challenges for researchers and designers

- *Planning a research session involving participants with limited availability:* Research sessions conducted with Deaf participants that had to involve their preferred SASLI were challenging since the SASLI usually had limited availability. Research sessions conducted with health professionals were challenging since they were most of the time busy. Consequently, the planning could be even more challenging when Deaf participants, SASLIs, health professionals were involved in the same research session (Co-design Activity 1).
- *Deaf participants' limited budget for commuting to the research venue:* Several Deaf people were unemployed. They had difficulties commuting to a research venue. As such, transportation fares and food and beverage had to be budgeted as compensation.
- *Minor contradictions between regulations and what stakeholders practice in reality:* Some health professionals at primary health centers sometimes contradicted the health-service guidelines. These minor contradictions could make a researcher hesitate to follow either the health-service guidelines or the feedback from the health professionals to derive a suitable app.

Two benefits for the leading Deaf community

- *Increasing opportunities to be exposed to health information beyond HIV/AIDS and TB:* Deaf communities across the Western Cape were enthusiastic about participating in this CBCD research since they saw opportunities to gain health information in SASL. After the research sessions of the Co-planning, Co-design, and Co-evaluation stages, Deaf participants expressed appreciation of every piece of health information that aided their understanding of diabetes.
- *Being empowered and listened since their ideas are taken toward a solution:* Deaf communities were satisfied when their ideas were taken for designing an app. They were motivated to move the design of the

app forward. Their satisfaction and courage evidenced the sense of empowerment when being listened.

One challenge for the former leading Deaf community

Political interference on decision making in multiple forms: The political interference was found in two forms: 1) a participant in the higher hierarchy than other participants in the same group interviews, and 2) the funding that restricts diverse health information promotions. An example for the first form of political interference was found at a Deaf-family level during a group interview; the Deaf father imposed his opinion on the Deaf mother to change her rating on their family's health information sources. The second form of political interference was found at the managerial level when the DCCT management rejected diabetes as the health topic for a case study due to the funding for their Deaf health workers restricted to HIV/AIDs health promotion.

Two benefits for the research progress

- *Quickly defining the research focus because of the target users' explicit requirements:* The Deaf participants' and the health professionals' communication requirements and ideas for interventions were identified at the first stage of the CBCD approach.
- *Hampering researchers' and designers' bias on selecting the design details due to the participants' explicit ideas:* The ideas for the intervention drawn by the Deaf participants and health professionals described the use patterns and GUI elements that the author should compile for the conceptual design of the app. As such, their explicit ideas hampered the author's bias in selecting any details that might not meet their user experience with the apps.

Two challenges for the research progress

- *Managing research relationship while proceeding with the CBCD approach:* The Deaf community should be continuously updated on the research progress, especially when the author or the research fellows did not present at the Deaf community for a period. This was to ensure them that the community's inputs were being processed. Otherwise, the community could feel the lack of communication and felt used for the researchers' benefits.
- *Managing time for both research-session level and the overall research time frame:* This was the most difficult challenge to handle since multiple stakeholders were involved in this research. The author had to deal with unforeseeable circumstances, such as nationwide protests that obstructed the empirical research; changes of planning were discussed with the NID committee and relevant health professionals to achieve the mutual objectives. The duration of individual research sessions and

the overall length of the study had to be discussed with stakeholders to complete the empirical research within the planned timeframe.

These reflections contained challenges, but they were manageable. The CBCD approach was and will still be worthed practicing by those who will aim to bring an intervention to reality. Such approach did yield in-depth information that other research approaches might not avail. the reflections upon 1) the relatedness between CBCD and co-creation and 2) what the co-creation community can apply from the CBCD research.

2.3 The similarities with and modification for a co-creation

Since the benefits and the challenges in applying the CBCD approach are reflected, some readers may find that this approach is related to the broad group of co-creation methods. The author agrees with that opinion. In general, the CBCD approach can be perceived as a member of the co-creation practice by which a researcher or a designer co-creates with a community and relevant stakeholders, from exploring a context to evaluating their co-creation, and perhaps, reiterating the process towards an improved version of the co-creation.

More specifically, CBCD can be perceived as leaning towards co-creation methodology in terms of 1) empathy development among the stakeholders involved in a design and development for an intervention, 2) the skills that the involved stakeholders learned from each other, 3) the empowerment for the prospective users when their ideas are taken toward the making of the intervention, and 4) the derivation of the intervention that all stakeholders contributed and the prospective users were ready to adopt.

Besides all these similarities, the CBCD approach is also distinctive in particular perspectives. The close involvement of a community is the key—no community, no CBCD. A community exists long before the design effort is planned. As such, the community is rather distinctive from a group of meticulously selected people. The community is close-knitted as its members being relatives or know each other very well. Noticeably, the CBCD approach has been frequently applied by those who worked with communities in rural areas of low-to-middle-income countries. Those practitioners aim to both identify an intervention with the community members and transfer knowledge to sustain such intervention in the context it will be serving.

Due to the relatedness stated above, co-creative practitioners who plan to involve a community in their research or design can apply or modify the guidelines—the findings of Sub-research Question 1—presented in [this chapter, Subsection 1.2](#). These guidelines can be modified by replacing keywords of a determined context. The words: “Deaf community,” “Deaf

culture,” and “signed language” can be replaced respectively with the community name that the practitioners will be engaging and that community’s culture and language. By following the modified guidelines, the co-creative practitioners can practice working with their community, including relevant stakeholders, and may excel in their co-creation without reinventing the wheel.

2.4 Scientific and societal contributions

The findings of this research made a scientific contribution through the formulation of the conceptual model of health information accessibility for Deaf people in a context with complexity. The conceptual model was also examined to described different phenomena when different interventions were designed to provide health information accessibility to Deaf people. As well, the findings for the MRQ made a societal contribution via describing requirements for designing a suitable intervention for such context.

Scientific contribution

The findings from the CBCD approach contributed to the changes in the requirements of generic information accessibility, as illustrated in [Figure 11, Chapter 2](#). Such changes to the requirements under the Experience and Motivation Groups are discussed together to describe the relationship between information source, channel, medium, and device in the context of health information accessibility. Next, the changes to the requirements under the Suitability Group are described. Lastly, the conceptual model of health information accessibility for Deaf people in the context with complexity is presented.

[Figure 77](#) illustrates the narratives of 13 changes. The model on the left is the conceptual framework of information accessibility formulated based on the work of [Culnan \(1985\)](#) and [Swanson \(1992\)](#), as stated in [Chapter 2](#). Their conceptual framework described the accessibility of generic information, but not particularly on the vital health information and the information accessibility that embraces complexity in a real-life system. The model on the right comprises the changed requirements. Texts in blue represent the changes made to the requirements of generic information accessibility. These narratives start from the roles of the stakeholders involved in the provision and the acquirement of health information.

In this CBCD research cycle, the roles of all stakeholders are defined as follows:

- *Information providers:* Diabetes South Africa (Diabetes SA), NID educational-material-production team, and BANG (that the author is part of the team) collaborated as the information providers for this study. Diabetes SA is an accredited organization that Department of Health

Western Cape (DOHWC) accredited in promoting health information to support effective diabetes self-management. The author and NID borrowed health content from Diabetes SA to provide health education videos for information seekers.

- *Information seeker:* a Deaf patient or a Deaf person
- *Indirect information source:* Health professionals working at primary health centers are defined with the role of the indirect information source since they used the app to deliver health information to the Deaf patient.
- *Direct information source:* The app functions as the direct information source containing health education videos that the health professionals can select for a Deaf patient to watch.

Since both the information seeker and the indirect information source are the users of the direct information source, the indirect information source becomes another relevant of the Experience Group. Thus, this is the first change made to the conceptual model of generic information accessibility. Next, the second change made to the requirements regarding the physical access (Experience Group) elaborates on the types of information sources. The information seeker has physical access to both direct and indirect information sources; the indirect information source has physical access to the direct information source.

The third change is made to a requirement under Motivation Group. Since health information source, channel, media, and device are identified from Deaf participants' interests and preferences, thus the requirement about the information seeker's interest in the source is rephrased as interest in the information source, channel, medium, and device. The fourth change is simultaneously implemented by extending the relationship of the third change to cover channel, medium, and device to which the information seeker and the indirect information source have physical access.

The fifth change is made to the requirements regarding the information seeker's and the indirect information source's language, formulation of the query, and the impression on the interaction. The languages used for the interaction have to be the ones the information seeker and the indirect information source are fluent in or familiar with. The results of the CBCD approach suggested that SASL, concise texts, and icons are for the information seeker while interacting with the app, and written English and icons are for the indirect information source.

For the sixth change, the formulation of a query of the information seeker and the indirect information source should be prompted by the interfaces of the direct information source for them to achieve their communication goal. The requirements verified through this CBCD approach suggest

prompting the information seeker with the guides in SASL and the Deaf-friendly use patterns and GUI elements while one is interacting with both the app and the indirect information source. The prompting in the concise text is applied to the indirect information source's interactions with the app and the information seeker. As such, the seventh change is the clear guides, consistent use patterns, and easy-to-use interfaces to provide both the information seeker and the indirect information source with positive impressions on the interaction with the app and the interaction with each other.

Under the requirement concerning the retrieval of the acquired information, the eighth and the ninth changes are made. The eighth change is the relevance of information defined by how much it matches the information seeker's readiness in learning new information. This change is supported by the requirements that suggest clustering the health content within the app into 1) the content the information seeker watches during a health consultation and 2) the content watched afterward. The ninth change is the phrase: *intelligibility of the retrieved information for replacing "understandability gained from the information."* The new term implies the sophisticated capacity—SASL skills to understand the narrations in the health educational videos, the attention shifting between the narrations and the subtitles, and the processing of the accompanying visual materials—that the information seeker possesses more than just understanding the retrieved information.

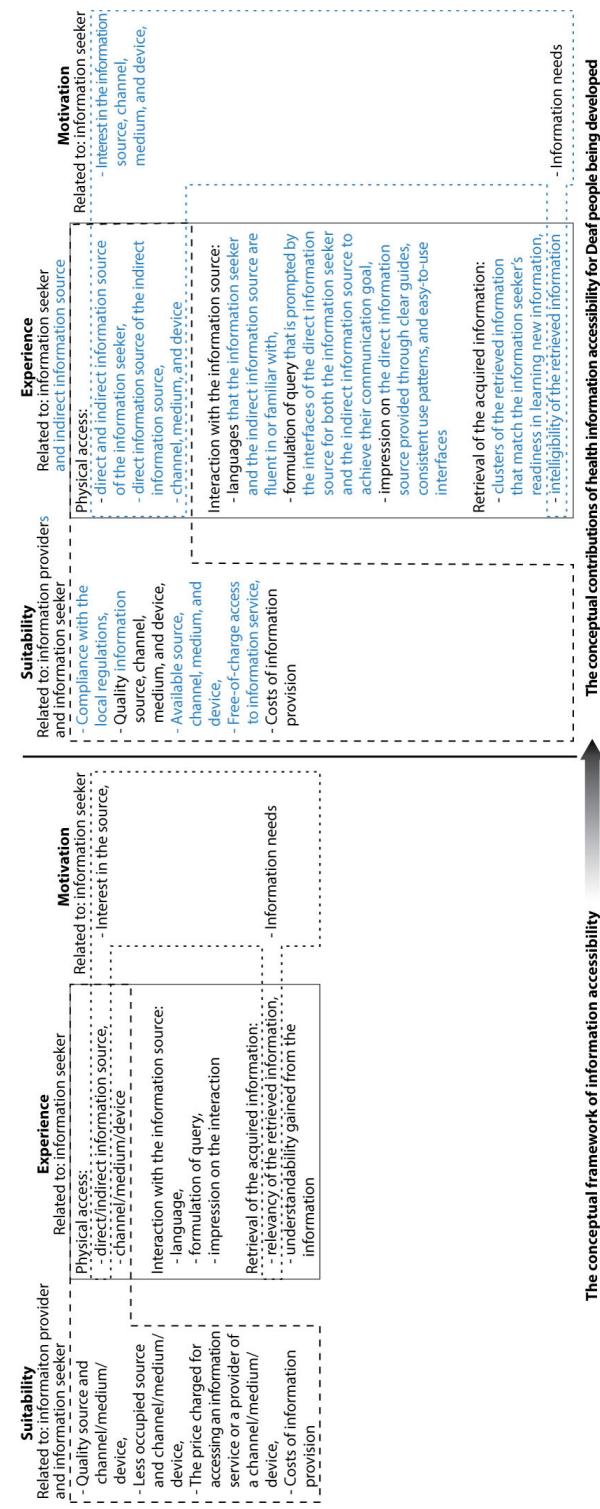


Figure 77. Development of the conceptual model of health information accessibility for Deaf people.

Four requirements under the Suitability Group of the generic information accessibility are changed based on the findings from the CBCD approach. The tenth is an additional requirement. The intervention should be designed in compliance with the local regulations. In a healthcare context, health policies and health-service guidelines should be followed. The 11th change is a matter of rephrasing: *quality information source, channel, medium, and device* for clarity. The 12th change is replacing “the less occupied source, channel, medium, and device” with *available occupied source, channel, medium, and device* for better comprehension. The 13th change relates to the requirement of the price charged for accessing an information service; it is changed to *free-of-charge access to an information service* since the Deaf majority in this studied context are unemployed and needed free access to health information. The requirement of cost of information provision is not elaborated since it has to be calculated per production for health education videos and guides for interaction in SASL, including the coding for the app.

These changes were used to formulate a conceptual model of health information accessibility for Deaf people, as illustrated on the right of Figure 77. The model was examined whether it could explain phenomena when other potential interventions (identified in Chapter 1, Section 4) would be designed to provide health information accessibility for Deaf people. This examination verified most of the requirements within the conceptual model and showed that not all interventions would be used by an indirect information source. For example, an online platform that would provide health information to Deaf people through affordable SASL-interpretation service (resolving Social Barrier 4), and health content on Youtube that would provide family members health information to be referred to a Deaf person in the household (Social Barrier 5) would not be used by an indirect information source. An online platform with the SASLI as the medium, a health consultation is a channel, and a doctor can simultaneously perform as the information provider and the direct information source for a Deaf patient—the information seeker—to access health information. There is no indirect information source in this phenomenon. An internet connectable device is a medium, Youtube is the channel, DOHWC can be the information provider, and a family member is the information seeker. The family member seeks health information to make the Deaf person understand his or her diagnosed disease. As such, the Deaf person is a passive recipient of the information, and there is no indirect information source functioning in this phenomenon. The stated examination resulted in the finalized conceptual model of health information accessibility for Deaf people in order to explain phenomena whether there would be an indirect information source in the context or not (see Figure 78).

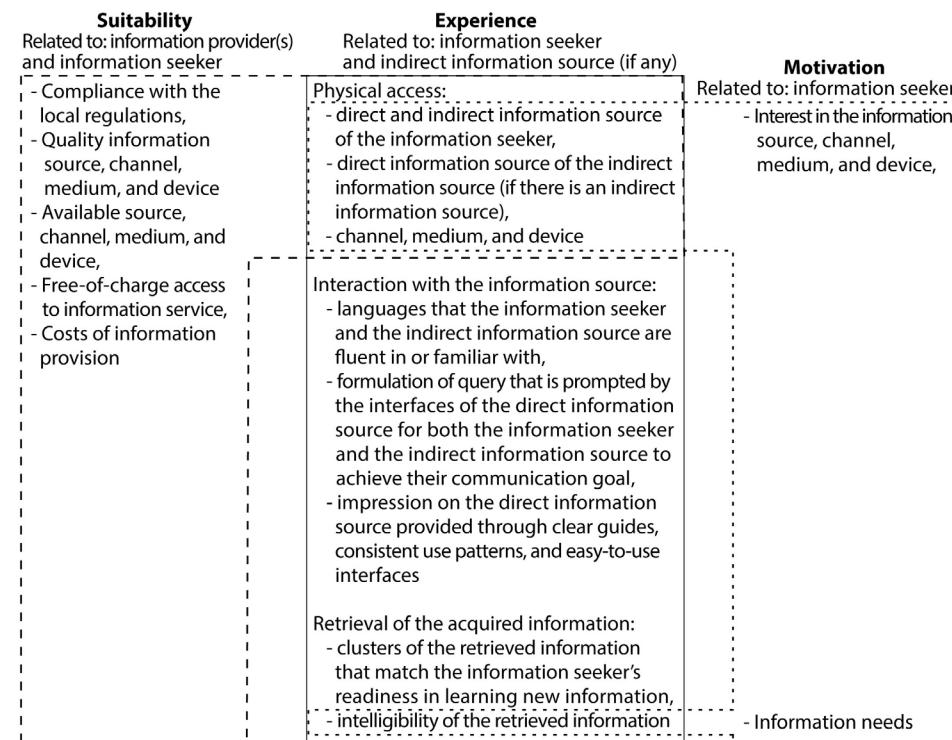


Figure 78. The conceptual model of health information accessibility for Deaf people.

Societal contribution

In response to the societal question of this research (refer to [Chapter 1, Section 4](#)), a digital booklet of comprehensive guides was made for those who desire to provide Deaf people access to accurate health information to induce their medication and treatment adherence. This digital booklet is composed of 1) the guidelines for actively involving a Deaf community and relevant stakeholders in designing an intervention (answers to SRQ 1) and recommendations in [this Chapter, Subsection 2.4](#), and 2) the guidelines for designing an app for communication bridging between a Deaf patient and healthcare personnel and health educational videos displayed within the app (finding to the MRQ). These guidelines were made to be hands-on. Researchers and designers can follow the first part when involving the aforementioned participants. If their identified intervention becomes an app, they can also use the second part of the guidelines as related work to test their design. Accessed <https://doi.org/10.5281/zenodo.5559705> for the booklet.

2.5 Generalizability

The generalizability is discussed regarding 1) the app design that serves *information accessibility for all*, 2) socioeconomics, and 3) different health topics in the context of the Western Cape.

The app design serving information accessibility for all

This app was designed and envisaged with multilingualism, metadata, interoperability, open-source software, open content, and CC license serving *information accessibility for all* defined by the UN [United Nations Educational, Scientific and Cultural Organization, n.d.](#)). In correspondence with multilingualism, this version of the app bridges SASL-English communication between a Deaf patient and healthcare personnel. This app can be replicated for communication bridging of SASL and other official languages used in the Western Cape within the same health-topic context. The app was designed to be flexible for updates and maintenance. Therefore, it is designed to be capable of upscaling. This app system could handle communication and health content related to type 2 diabetes only in its current stage. When the app's design is upscaled to include the health content of other common types of diabetes (i.e., type 1 diabetes and gestational diabetes) or other chronic diseases, the system will become a platform securing metadata. This app will interoperate with the healthcare system in the Western Cape as its design adheres to the health-services guidelines implemented in the context and matches the workflow of health professionals at the frontline of primary healthcare. The app is envisaged as open-source software that Deaf communities with the competencies to produce accurate health content in collaboration with DOHWC's accredited health organizations. As for the CC license, BANG is in the process of discussion with NID—the Deaf community took the leading role of this CBCD approach.

The conceptual design of the app was designed with a mobile information architecture that organized modular communication activities and sectorial health content. Such organization was meant to be flexible when healthcare personnel and their communication activities will be rearranged and when the health content will be updated without affecting the whole app system.

Socioeconomics

This app can be applied to other countries with similar low-to-medium socioeconomics as South Africa's. Geographics does not play an important role in affecting this intervention's applicability since its design was derived from South Africa and India. Although this study has not been conducted in other socioeconomic contexts, this app may serve the health information needs of Deaf people in higher socioeconomics, who have also encountered problems in accessing health information, such as the USA and the UK (refer to [Chapter 2, Subsection 1.2](#)). However, the app's applicability

might be hampered by other socioeconomic factors.

Smartphones as the medium and mobile-network coverage as the channel to provide accessible information are discussed in the aspect of mobile technologies. As long as Deaf people have physical access to smartphones in the determined contexts, the app can be used to access accurate health information in signed language contributed by accredited information providers. Since this app is designed to be installed on Deaf people's smartphones and workable offline, mobile-network coverage is not the main concern in this aspect.

Different health topics

This app can be applied to bridge communication and transfer the health contents of diseases beyond type 2 diabetes. Since this app was designed with functions that avail the patient's logging of self-management, it can be extended to cater to the communication and health information delivering of other chronic diseases, such as common types of diabetes, cardiovascular diseases, and cancer spectrum that the Deaf participants of the CBCD approach were highly interested (refer to [Chapter 4, Subsection 2.3](#)).

2.6 Future work

Three topics: app's suitability to the healthcare system, language use, and updates on Deaf-friendly mobile interfaces are discussed concerning future work.

App's suitability to the healthcare system

Linked with the next selected health topic, extensive studies will have to be conducted with health professionals and Deaf people relevant to that health topic to identify the patient journeys: the engaged healthcare personnel, communication activities, and health content to be available within the app. The information architecture of the app will change, and Graphic User Interface (GUI) elements for mobile interfaces may be elaborated. Health-service guideline(s) implemented in the context must be consulted to assure the app's suitability to the healthcare system in that specific context.

Language use

The design of this app avails communication bridging between a signed language with a dialect of choice and another official language of the studied context. As such, when applying this app to another context using a different signed language or dialect, new videos that guide a Deaf user to interact with the app and another interlocutor will need to be recorded with that signed language. Also, if the app will be applied in a context with

a different official language, the guides prompting the healthcare personnel interactions with the app and all textual information in mobile interfaces; subtitles of all health educational videos should be translated and rewritten.

Updates on Deaf-friendly mobile interfaces and phone sharing

The current mobile interfaces for a Deaf patient were replicated from the results of Co-evaluation Activity 3, a scenario the patient used the app to proceed, and a Deaf-led self-management and a question and answers with a doctor. Therefore, there can be multiple areas, along with other communication activities, for future researchers and designers to contribute to better Deaf-friendly mobile interfaces. Given that new apps for communication and socializing are launched frequently, Deaf people's familiarity with such apps might take place. Their user experience with mobile apps could become sophisticated than the findings of this study. As such, it is recommended for future researchers and designers to explore Deaf people's mobile app usage in order to update Deaf-friendly mobile interfaces.

Although the finalized conceptual design of the app (refer to <https://doi.org/10.5281/zenodo.4153622>) cater the usage of Deaf people's mobile phone sharing behaviors, there are still rooms to improve such design. This particular design is related to the design for Deaf-friendly mobile interfaces.

Here is the end of my journey with the CBCD approach practiced in the Western Cape. I cannot let you flip to the last page without letting you see this personal message: “Thank you for staying tuned this far. I thank you for being interested in what people in a society can do to help Deaf communities having access to health information which many of us hearing do.”

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Curriculum vitae

Prangnat Chininthorn, or Prang to family, friends, and research fellows, was born on January 4th, 1984, in Bangkok, Thailand. A toddler Prang watched a documentary about surgery and found surgeons surrounded an operating table were cool people. She jumped in front of her grandma and repeatedly shouted: "I want to be a surgeon!" Later in Grade 2, she became more passionate

about becoming a designer. She excelled in biology and arts through middle school. In September 2008, Prang received a Bachelor of Architecture, majored in Industrial Design, from King Mongkut's Institute of Ladkrabang, Thailand. She worked as a designer for Blooming Ground—a kids furniture company, a researcher at the Golden Jubilee Goldsmith School, and a junior lecture at the Faculty of Architecture, Rajamangala University of Technology Thanyaburi, Thailand.

However, the medical-related passion still lingers within a grown-up Prang. As planning to pursue her further education, Medisign program offered by Delft University of Technology (TU Delft), the Netherlands, drew Prang's attention for enrolment. Her childhood passion met with her design and research profession. Although not completing the Medisign program, Prang completed her graduation project related to a design of an app to bridge communication between a Deaf patient and a pharmacist in the South Africa context and received her Master of Science in September 2011.

This graduation project was funded by South Africa Netherlands Research Programme on Alternative in Development (SANPAD). Such project allowed Prang to learn South African Sign Language and grew compassion for Deaf people's challenges in accessing accurate information amid the hearing society. She also found the community-based co-design (CBCD) approach helpful for a design researcher to derive a communication tool. Involving Deaf people and the person they needed to communicate throughout a design process for a communication tool cultivated their anticipation of adopting the tool for daily lives because they jointly designed it.

After her Master's, she was employed as a researcher at Bridging Application and Network Gaps (BANG), University of the Western Cape, South Africa,



to develop the app together with a Master's student in the field of Computer Science and a Ph.D. student in the field of pharmacy. The project was succeeded with the app's trial at an actual hospital pharmacy, and it showed opportunities to scale up the app usability, including other interventions. As seeking funding to continue research through a doctoral study, Prang took a break from academia by practicing management skills at Hyva (Thailand) Ltd.

The doctoral study was made possible by funding from the Faculty of Architecture, Rajamangala University of Technology Thanyaburi, Thailand, for education and multiple funders (Technology and Human Resources for Industry Programme, South Africa's National Research Foundation, Cisco Systems, Aria Technologies, and Telkom) for research activities. The latter fundings were received through Prang's affiliation with BANG. This doctoral degree was commenced at TU Delft.

Prang plans to research with Deaf people in Thailand and learn Thai Sign Language. She also hopes to practice the CBCD approach in any research field where possible.

Publications and poster presentations

Henney, A., & Chininthorn, P. (2021). A mobile survey for collecting data from Deaf people who use sign language for communication. In D. Heukelman (Ed.) *Information Communications Technology and Society Conference* (pp.79-84). doi: 10.1109/ICTAS50802.2021.9394973.

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