

AT2030

Championing community health literacy through mobile phones:

Insights from a pilot intervention with People with Disabilities in informal settlements in Freetown, Sierra Leone

January 2023

I. Gaskell, A. Kydd, J. Larrieta, R. Sinha, H. Bangura & J. Walker (2022)

Championing community health literacy using mobile phones: Insights from a pilot intervention with People with Disabilities in informal settlements in Freetown, Sierra Leone.

Report Produced for the Bartlett Development Planning Unit and Global Disability Innovation Hub AT2030 Sub-Programme 9, SHM Foundation, London



Funded by:



Conducted by:



COLLABORATION PARTNERS



The **Bartlett Development Planning Unit of University College London (DPU)** conducts world-leading research and postgraduate teaching that helps to build the capacity of national governments, local authorities, NGOs, aid agencies and businesses working towards socially just and sustainable development in the global south.



The **SHM Foundation** works globally to bring about positive social change through projects in health, education and the arts, by providing communities and individuals with the practical tools they need to develop innovative solutions to challenges they face. The SHM Foundation has over a decade of experience in developing and implementing digitally-enabled interventions through participatory co-design processes, such as the Zumbido Health model of mobile phone-based support groups.



The **Federation of Urban and Rural Poor (FEDURP)** is a grassroots organisation that seeks to empower poor communities to improve their social, economic, and environmental conditions by creating spaces and opportunities through collaborative actions to champion their own transformative and development agenda. FEDURP is a member of Slum Dwellers International (SDI) network, a social movement of the urban poor across 30 countries.



The **Sierra Leone Urban Research Centre (SLURC)** based in Freetown, is a globally connected research centre created through a partnership between the DPU and the Institute of Geography and Development Studies at Njala University. The centre builds capacity and undertakes research on the wellbeing of residents of informal settlements in cities across Sierra Leone.

EXECUTIVE SUMMARY

This report shares insights from a pilot intervention conducted with People with Disabilities, their carers, and assistive technology (AT) users living in informal settlements in Freetown, Sierra Leone, that used mobile phones and digital technology to support residents in accessing health information. The project was conducted as part of a sub-programme of AT2030, an international initiative led by Global Disability Innovation Hub, to improve access to life-changing Assistive Technology (AT) for all.

The pilot intervention highlights the need for access to primary health services for low income urban residents, particularly people with disabilities, and also suggests that the use of digital technologies accessible from basic smart-phones is a promising avenue for primary health strategies in contexts such as Sierra Leone.

The high level of uptake and engagement with this pilot intervention suggests that digital technologies, if used in accordance with participant priorities and capabilities, can be leveraged to support health information dissemination efforts and build health literacy among low income urban residents.

The results summarised in this report suggest that this intervention, if refined using the learnings gleaned from the pilot, has potential to be rolled out within this community, or replicated in similar settings, in partnership with key stakeholders.

CONTENTS

COLLABORATION PARTNERS	2
EXECUTIVE SUMMARY	2
INTRODUCTION	4
THE PILOT	6
RESULTS & INSIGHTS	9
CONCLUSION	18

INTRODUCTION

Health literacy is widely regarded as critical in managing personal and community health. The World Health Organisation defines health literacy as “the achievement of a level of knowledge, personal skills and confidence to take action to improve personal and community health by changing personal lifestyles and living conditions”¹. As such, the dissemination of accurate information to build health literacy has a central role to play in primary health care strategies.

People with disabilities commonly face barriers that make it harder for them both to access health services and build health literacy, particularly in low-resource settings. These can include attitudinal barriers, such as facing prejudice or discrimination from healthcare providers; physical barriers, such as health services being located far away, or having inaccessible entrances; communication barriers, such as a lack of sign language interpreters for people with hearing impairments, or health information being presented in complicated ways; and financial barriers, with more than half of people with disabilities in low-income countries unable to afford proper health care². As well as affecting access to treatment, these barriers can also make it difficult for people with disabilities to access accurate health information and build health literacy. In low-resource settings, the limited availability of health services can intensify these challenges.

This report shares insights from a pilot project conducted with people with disabilities, their carers, and assistive technology (AT) users living in informal settlements in Freetown, Sierra Leone that used mobile phones and digital technology to support residents in accessing health information.

Context of the pilot

AT2030, led by the Global Disability Hub, focuses on “Life Changing Assistive Technology for All”. Its aim is to reach over 3 million people, in particular, people with disabilities. The objective is to develop new approaches which can transform access to assistive technology (AT) such as wheelchairs, prosthetics, hearing aids, glasses and digital assistance (including smart phones and accessible software) by creating partnerships to build and shape markets, strengthen public infrastructure and support community participation.

The AT2030 sub-programme from which this report emerges is led by The Bartlett Development Planning Unit at UCL in partnership with Leonard Cheshire (UK), the Sierra Leone Urban Research Centre (Sierra Leone), and Yayasan Kota Kita Surakarta (Indonesia). The research question for the sub-programme was “How can collective and community-led responses enable disabled people to access better life outcomes, through increasing the relevance and uptake of assistive technologies?”.

Within this pilot project, the team worked with residents of Dwozark and Thompson Bay, two low income, informal settlements in Freetown, as well as members of the Federation of Urban and Rural Poor (FEDURP) and an organisation of slum-dwellers in Sierra Leone, affiliated to Slum Dwellers International (SDI), to design an intervention that would enable participants, all of whom were people with disabilities, carers, or AT users, to access health information on topics that were important to them; and to disseminate it within their communities.

¹ WHO (1998) Health Information Glossary. Accessed: <https://www.who.int/publications/i/item/WHO-HPR-HEP-98.1>

² WHO (2021) Disability and Health. Accessed: <https://www.who.int/news-room/fact-sheets/detail/disability-and-health>

INTRODUCTION

Context of the communities

Dwozark and Thompson Bay are low-income communities in Freetown, Sierra Leone.

Dwozark is a hillside settlement located 5km from Freetown city centre that has been populated since the 1940s and now contains 5,236 households³. There is no connection to the main city water pipeline and poor drainage. The settlement includes one health centre, one market, 12 schools, 12 public toilets and 20 public water points. The characteristics and location of the settlement make it prone to fires, floods, rock falls, and outbreaks of waterborne diseases⁴ and the topography of the settlement makes accessibility and mobility a serious challenge, especially for people with disabilities and older people.

Thompson Bay is a seaside settlement approximately 10km from Freetown city centre, populated since the late 1990s and now containing 1,624 households.⁵ It has a food market, school and a mosque. Located in a shoreline wetland, the settlement is prone to flooding, has poor sanitation and limited access to safe drinking water, and consequently high risk of waterborne diseases.

⁶ Across both settlements, approximately one in five residents (or 20.6%) have a disability - and there is

very low availability of assistive products, such as spectacles, wheelchairs, crutches and hearing aids.⁷ This is a high prevalence of disability compared to estimated disability prevalence rates of 15.6% globally, and 18% in lower income countries.⁸

Dwozark and Thompson Bay each have a single formal health centre whose services are primarily focused on maternal and antenatal health, and administering vaccinations. Other health services are normally accessed from hospitals outside the settlements, for a fee. As a result, residents have limited access both to health services and accurate health information as a primary/ preventative health resource.

For people with disabilities in these communities, accessing health services and information are even harder for the reasons outlined above, not least because the health centres are difficult to reach for people with mobility-related disabilities. What's more, the voices of residents with disabilities are rarely taken into account in the planning and delivery of health services - an issue that is prevalent globally, in both health and development⁹ - though grassroots organisations are working to change this.

³ CODOSAPA and FEDURP (2011). Community-Led Enumeration and Profiling: The State of 11 Coastal Slums in Freetown, Sierra Leone.

⁵ CODOSAPA and FEDURP (2011)

⁶ Ossul-Vermehren et al (2022)

⁸ WHO and The World Bank (2011). World Report on Disability

⁴ Ossul-Vermehren, I., Carew, M.T. and Walker, J. (2022). Assistive Technology in urban low-income communities in Sierra Leone and Indonesia: Rapid Assistive Technology Assessment (rATA) survey results. Bartlett Development Planning Unit - Global Disability Innovation Hub, London.

⁷ Ossul-Vermehren et al (2022)

⁹ Groce, N., Kett, M., (2013) The Disability and Development Gap. Leonard Cheshire Disability and Inclusive Development Centre working paper series no. 21. London: LCDIDC.

THE PILOT

In November-December 2021, a five-week intervention was piloted as a collaboration between DPU, SLURC, FEDURP and the SHM Foundation in the informal settlements of Dwozark and Thompson Bay. The focus of this project responded to a priority for Accessible and Affordable Health Care which had been expressed as a shared aspiration by participants in Phase 1 of the AT2030 Project in Sierra Leone between 2019 and 2020. In Phase 1 of the project we had worked with a core group of 60 research participants (a group of 30 from each community, primarily AT users and persons with disabilities but also including around a quarter who were non-disabled community residents) to understand residents' aspirations and the role that access to AT played in these, using methods such as photo diaries, shadowing and workshops.

A range of aspirations were expressed across the two communities which were validated by participants in the communities in Jan/Feb 2021, to ensure that we had accurately captured people's needs and the challenges that they experienced in their day to day life in the settlements. We then held a series of workshops in the two communities to identify a shared aspiration which was both transformative (having a potentially big impact on the lives of people with disabilities and AT users) and inclusive (linking the priorities of People with disabilities and AT users to those of other community members) which would act as the focus of a pilot intervention. The final selected aspiration for the two communities was Accessible and Affordable Health Care.

Co-design process

The model for the pilot project was co-designed through a series of participatory workshops with residents of the communities, and drew on previous research conducted as part of AT2030. Through this work, key priorities and considerations emerged that shaped the design of the model:

People with disabilities-led: People with disabilities should be at the centre of the intervention

Community-oriented: The participants wanted to access information on health topics that were priorities for them and their community.

Appropriate: The information needed to be shared in simple and accessible ways by an expert with knowledge of the context.

Safe: There needed to be an ongoing process of monitoring and moderating the text message discussions, in order to spot and address potential safeguarding issues.

Model:

Design & implementation

Stakeholders



HEALTH CHAMPION

16 people with disabilities and carers were nominated by FEDURP to take part in the project. Each was given a mobile phone charged with data, and an anonymous username to access rocket.chat, a secure digital platform for group messaging.



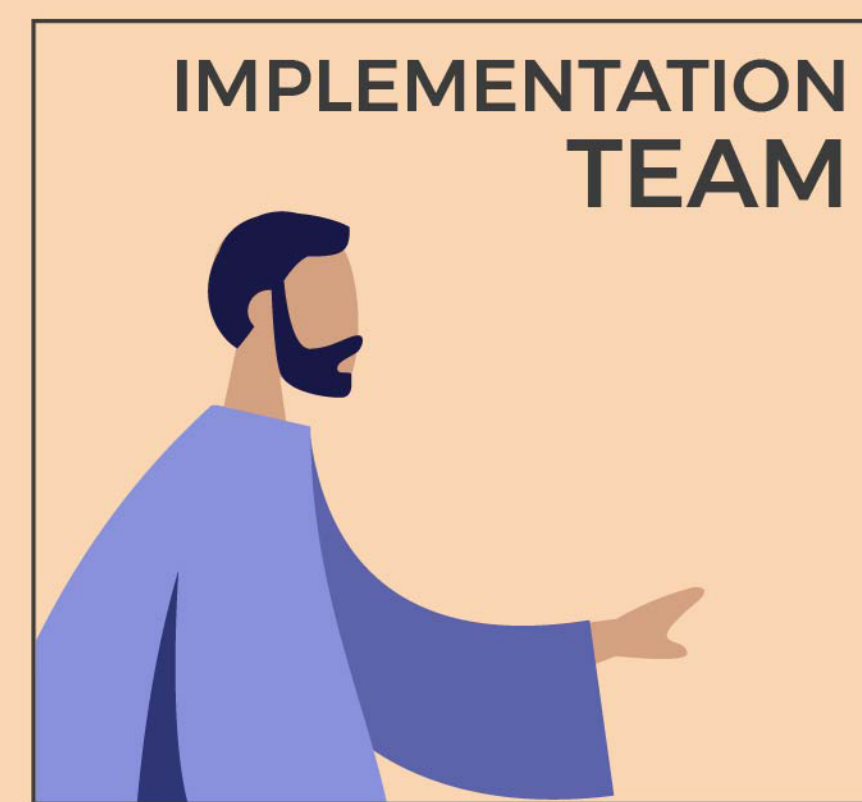
FACILITATOR

4 FEDURP members who received mobile phones, data and digital facilitation training. They monitored and facilitated discussion, set "challenges" to gather questions ahead of guest speaker sessions, and encouraged Health Champions through the project



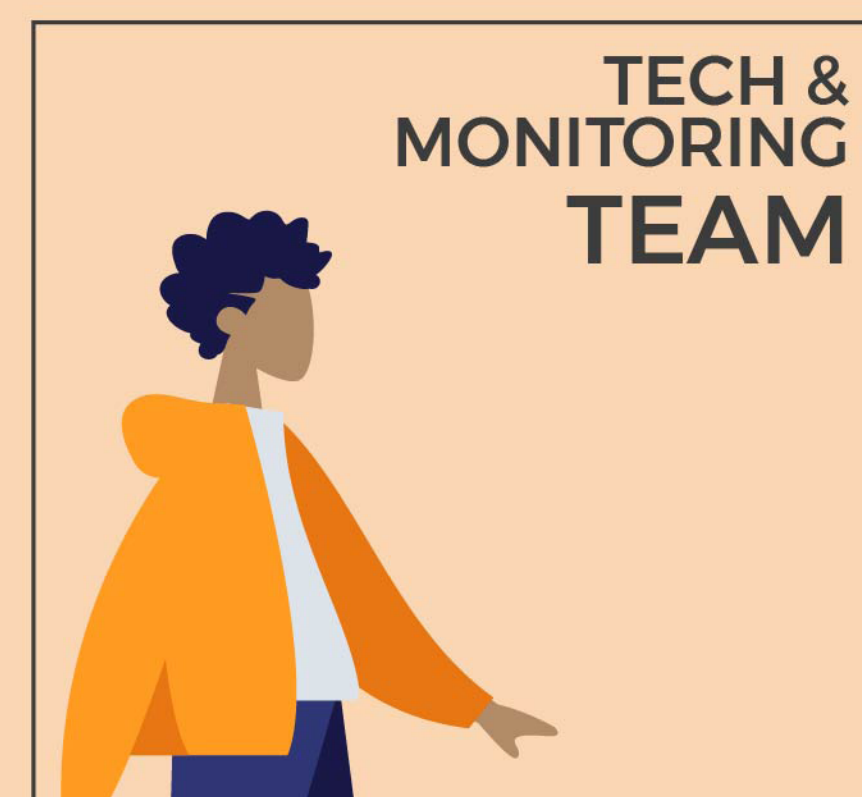
GUEST SPEAKER DOCTOR

A Sierra Leonean doctor was engaged to act as a "guest speaker" in the rocket.chat groups, hosting a weekly question and answer session via text message



IMPLEMENTATION TEAM

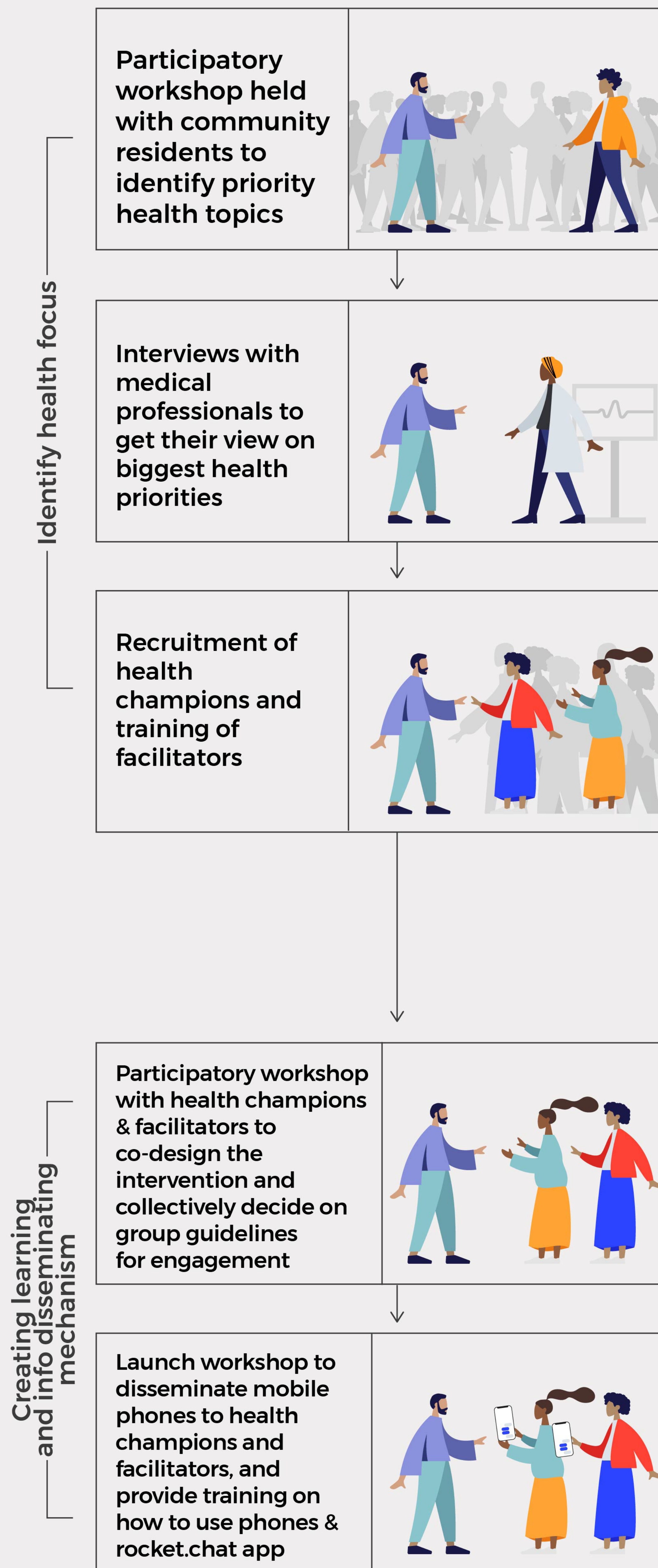
SLURC team handled the practical support for implementing the project, training facilitators and participants in how to use the digital technology, set up rocket.chat and charge the phones with data



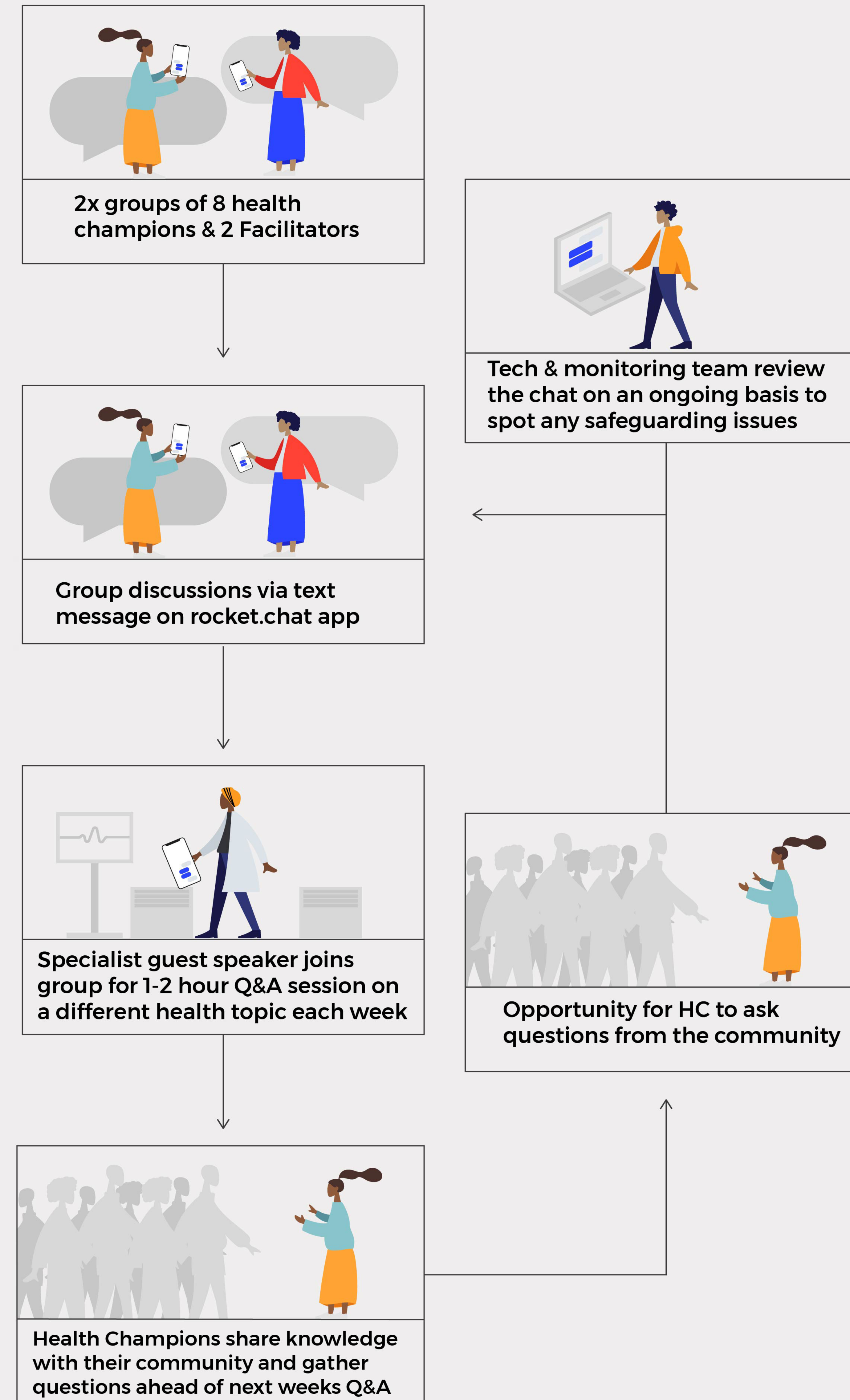
TECH & MONITORING TEAM

SHM Foundation set up the digital infrastructure for the rocket.chat groups, and monitored the groups for safeguarding purposes

1 Design Process



2 Knowledge sharing in action



3 Graduation



THE PILOT



Data collection

A mixed methods approach was used to gather data to assess the acceptability and feasibility of the pilot intervention, and identify how the project design could be strengthened for future implementation. Additionally, we wanted to glean insights into health-related knowledge, attitudes, behaviours, and challenges of the participants which could be useful for other community health interventions and research with this population, or in similar contexts. Informed consent was given by all participants for the collection of this data, and ethics was approved

Pre and post intervention interviews

Participants engaged in a pre- and post-intervention semi-structured interview, delivered by the FEDURP team. The interview explored themes related to their expectations and experiences of the intervention, including the digital technology, health topics and content, and experiences of disseminating information to the wider community; as well as themes of perceived stigma related to disability.

Focus group discussion

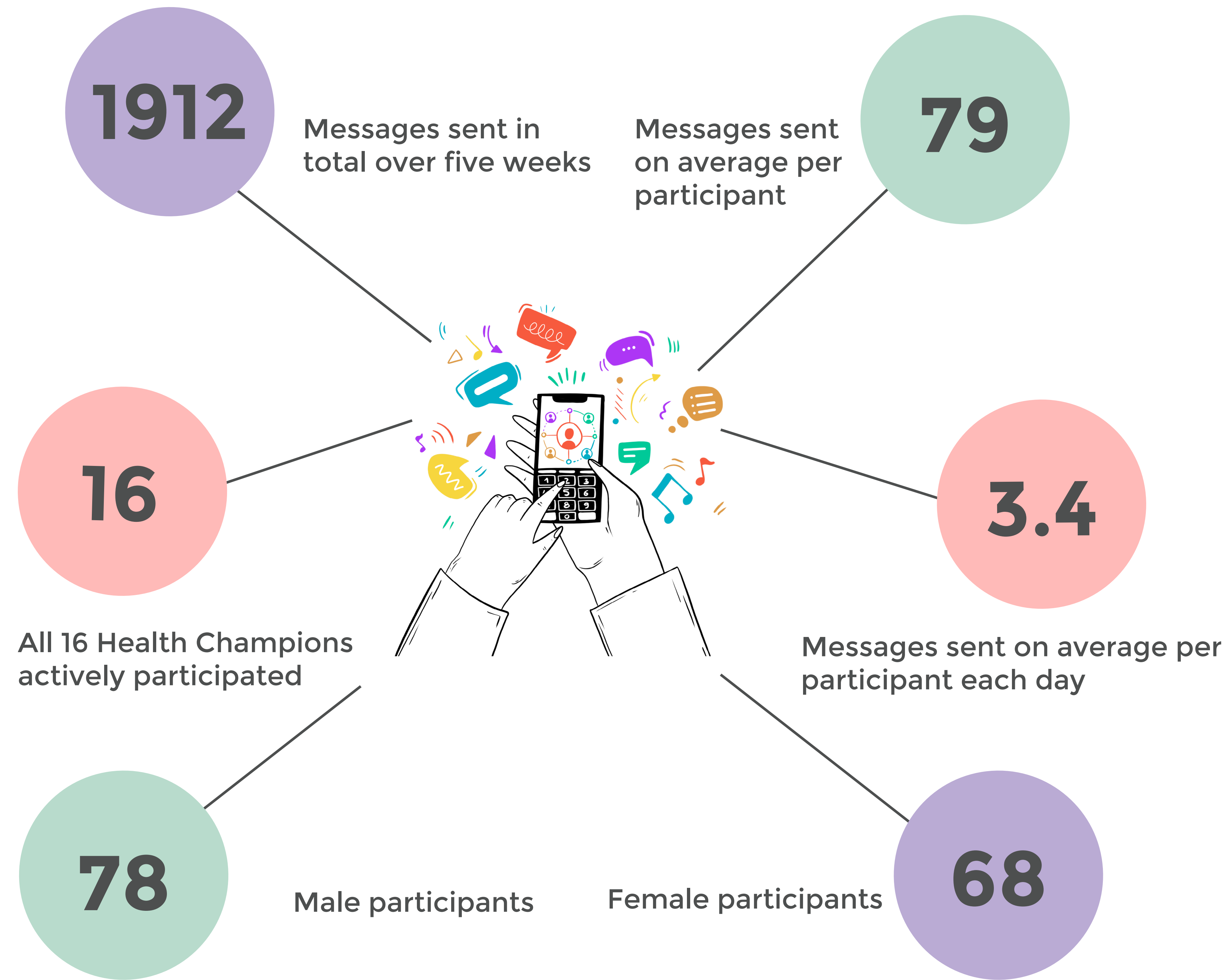
A focus group discussion was conducted by the research team during the closing event with 13 participants. Key quotes from the focus group discussion transcript were isolated by the research team. The focus group explored similar themes to those above, as well as what participants learned from the intervention, what they found valuable about the intervention, what could have been better, and a more in-depth discussion of where and who they shared information with in their community.

Text message data

The research team was able to collect core analytics and text message data from the technology platform, Rocket.Chat.

RESULTS & INSIGHTS

Engagement & participation



The Health Champions took their role seriously, encouraging one another to participate, reminding one another of the code of conduct they decided on at the launch, and calling on each other to engage when they noticed that someone seemed absent from the discussion.

We have promised our self to always make this group interactive and educative.

We have promised our self to always make this group interactive Emojis is against our principle, remember we all agreed to this. thanks to draw our attention to it. Area_Boy please [...] don't use emojis sticker please type full for us to understand

RESULTS & INSIGHTS

A wide range of health topics and conditions were raised over the course of the intervention, the most prominent being water, sanitation and hygiene, headaches, colds, malaria, pregnancy, nutrition and sexually transmitted diseases, particularly HIV/AIDS, chlamydia, gonorrrhea and syphilis.

The Health Champions not only engaged in the group discussions, they took their role of cascading learnings to others in the community seriously.

Health Champions reported sharing what they learned with relatives, neighbours, friends, and community residents in a variety of ways including by telephone, at their or other people's homes, and in conversation with community members at the water collection point, the market, the mosque and the church

The information they most commonly shared was related to how to treat headaches and colds; how to prevent malaria; how to maintain good personal and household hygiene and sanitation; what to eat during pregnancy and common problems to look out for; how to prevent transmission of sexually transmitted infections

215
Questions

The doctor answered a total of 215 questions over the four guest speaker sessions, though approximately twice this number of questions were asked

190
Messages

An average of 190 messages were sent per guest speaker session

40%
of messages

40% of the messages sent over the course of the five week intervention were sent during the six hours-worth of guest speaker sessions

The Health Champions expressed a desire to receive summaries of the guest speaker sessions, so the team created infographics highlighting the key questions and answers, and shared physical copies with them.

RESULTS & INSIGHTS

Insights yielded

The group discussions and the engagement with the guest speaker yielded interesting insights about the participants' knowledge, attitudes, and experiences.



Learning

Opportunities to engage with and ask questions of a health professional were strongly welcomed as other avenues for accessing health information were reported to be limited.

The guest speaker session on “general health” topics, covering headaches, colds, water, sanitation and hygiene, generated some of the highest engagement in the intervention. Common questions included how to treat and prevent headaches and colds, how poor hygiene impacts health, what are good hygiene practices, and when to use medications such as ibuprofen and paracetamol.

The high appetite to engage with the health professional during the guest speaker sessions was demonstrated by the high volume of questions asked. On average, 102 questions were asked during each 1.5 hour guest speaker session.

I learn so many information today I give thanks to all champion health workers in this wonderful forum

Taking part in this project has helped me get an understanding of some health issues and their treatment. For e.g. I never knew how to treat cold but now, I know what to do

Yesterday session was amazing actually, and Dr B makes me learn something new. Thankyou Dr B for the opportunity to ask so many things

RESULTS & INSIGHTS

Misinformation

Inferences from questions participants asked the doctor during guest speaker sessions suggested the presence of misinformation on some health subjects.

Key areas where health myths were brought up or referred to occurred on the topics of:

Malaria

Participants raised questions on the topic of malaria that suggested misinformation on a) what malaria is and how it differs from other diseases, and b) how malaria is transmitted, specifically whether malaria can be transmitted through contact with the sweat of an infected person, or by eating certain fruits.

Sweat can transfer malaria

Is malaria different from typhoid because i have heard some people say i have typhoid, i have malaria

Some of us don't believe it epilepsy, as long as we see the saliva we will say it the attack by a Jin(devil)

Epilepsy

Participants referred to the association of fits and seizures with supernatural possession. It was clear that some participants were referencing this as a belief held by other community members, while other participants held that view themselves.

Vaccines

Some questions raised by participants suggested potential worries that vaccinations can cause illness.

Why something some nurse or doctors give injection and later affected the sick person.

Diabetes

A small number of participants raised questions that may have suggested a belief that diabetes can be transmitted person-to-person.

Is it good to share drinking cup, spoon, clothes, and eating with diabetic person?

RESULTS & INSIGHTS

Community activism

Participants used the groups as spaces for advocacy and citizenship.

Beyond the topic of health and specific activities of the project, participants used the groups to discuss bigger issues facing their community, whether as people with disabilities or as residents of informal settlements:

In my own view, lacking access to safe drinking water and sanitation and poor implementation of policy are serving as the most challenging issues in our community.

It had been enshrined in our constitution which was enacted in 2011 that all disabled people must be entitled to free medical treatment in this country, but as we speak it has not took effect up to now.

Given that all Health Champions were people with disabilities or carers, the groups also offered spaces for them to reflect on their ability to participate in community action:

This is the first time I have be given a chance to participate in the development of my community.

Health services

Access to health services is limited, and participants reported that additional barriers of physical distance and cost make it especially challenging for people with disabilities to get care.

The physical distance to the nearest hospital and lack of transportation presents major challenges when seeking emergency care:

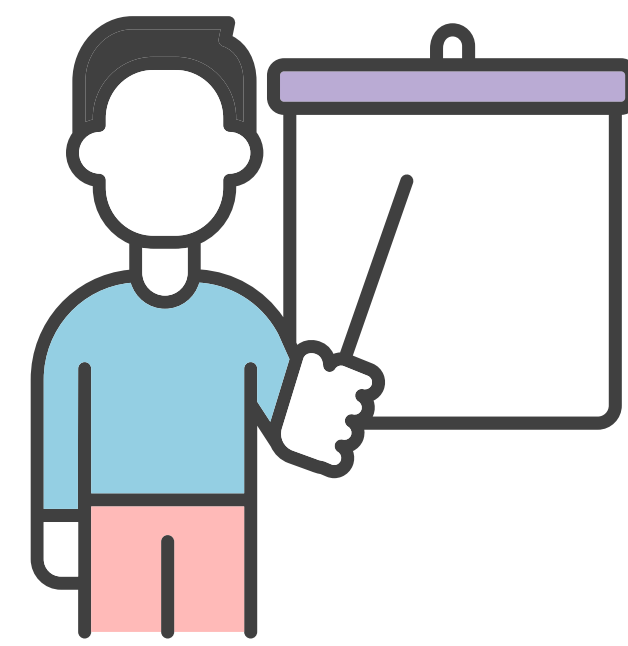
Most disabled people can't afford treatment in hospitals because of lack of funds, accessibility, and discrimination

A young pregnant lady was rushed to the hospital this evening after she complained of pain in her stomach. It was a little bit challenging to take her to the hospital because there was no vehicle available at that time. Few people had to volunteer to grab her on their shoulder onto the Calton Community Field where she was able to get an "Okada" or motorcycle to take her to the nearest hospital

RESULTS & INSIGHTS

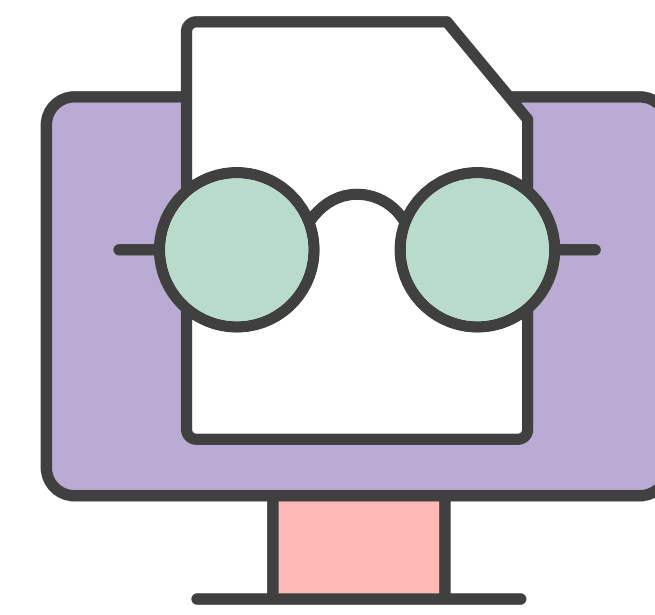
What worked well in the project?

The participants found the project valuable in four key ways:



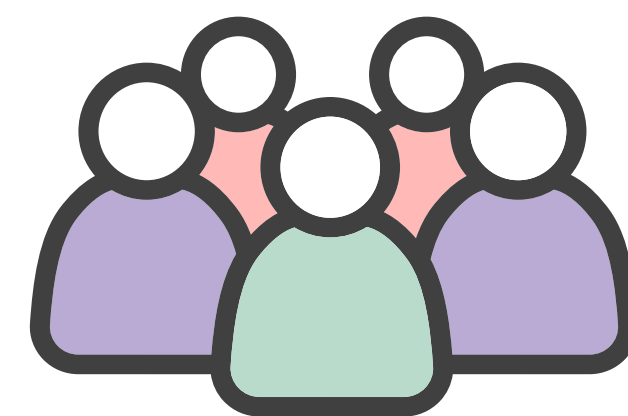
Learning

Enabling them to learn about health topics that mattered to them



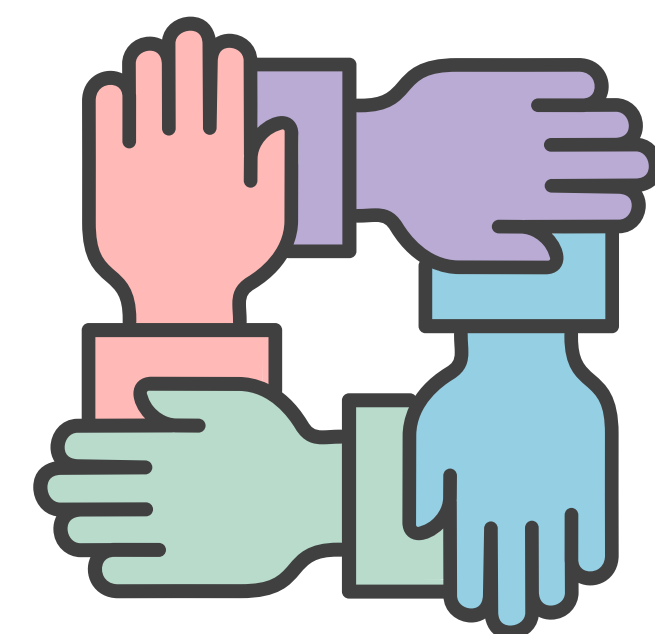
Digital literacy

Increasing their digital literacy skills



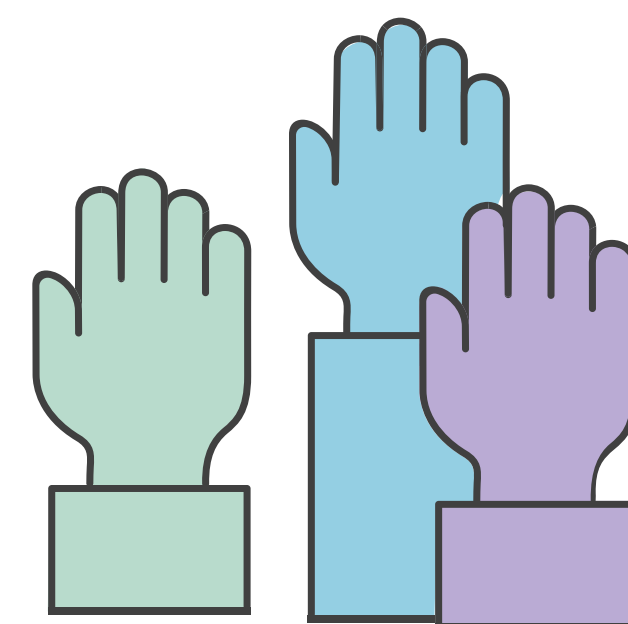
Connection

Enabling them to connect with other people who had shared experiences



Support

Providing an opportunity to play a role in supporting their communities, from which they often felt excluded. They consequently reported feeling that the project boosted their social standing and inner confidence



Advocacy

Providing a space for advocacy and citizenship

Taking part in this project has helped me get an understanding of some health issues and their treatment. [...] I also do not know how to use a smart phone like this way the project made us used it. I valued the skills this project gave.

This is the first time I have been given a chance to participate in the development of my community.

The chance it gives to disabled people to participate. It has helped us to take the lead, to feel belong and it brings inclusiveness to PWDs.

RESULTS & INSIGHTS

Most participants found the digital technology easy to use, having received training in how to use the mobile phone and rocket chat application.

This was due in part to the previous research conducted with participants that mapped their attitudes, knowledge and use of mobile phones and other ICTs¹⁰. With this understanding, the team were able to design the project around the existing capabilities and knowledge gaps of the participants:

The network in my community made it a bit challenging in the 1st few days when we started. But the App and the phone were both easy for me to operate.

The Health Champions' process of cascading learnings onto others in the community was generally very positively received, with high levels of engagement from other residents.

Participants made use of a wide array of community spaces and interactions to share health information from the guest speaker doctor, from the mosque to the water collection point, the market to the neighbour's house.

Some participants reported that having the "backing" of a community leader facilitated greater willingness from other community members to hear what they had to say:

It was easy because the mosque leader gave me the strong backing I needed.

The written materials created after the guest speaker sessions and shared with Health Champions were a valuable and welcome resource in cascading the information onto the wider community.

These materials were created based on the most commonly asked questions from each of the guest speaker sessions, and reflected the language used by participants and the doctor.

The participants reported that they found the materials a useful reminder, simple to understand and would continue using them beyond the timeframe of the project.

¹⁰Gaskell et al (2022) Characterising mobile phone inclusion among assistive technology users. Report Produced for the Bartlett Development Planning Unit and Global Disability Innovation Hub AT2030 Sub-Programme 9, SHM Foundation, London

RESULTS & INSIGHTS

What were the key challenges?

Approximately half of the questions asked during guest speaker sessions were left unanswered, though some of these were repeated questions.

The high level of engagement from participants during the guest speaker sessions, who asked a high volume of questions very quickly, the limitations of the technology and time considerations meant that it was not possible for the doctor to answer every question asked.

Participants expressed a desire to have more time in which to ask questions, whether through longer or more frequent guest speaker sessions.

The Health Champions sometimes encountered resistance or negative responses when sharing their learnings with other community members.

Some Health Champions reported encountering disability-related stigma.

Occasionally, Health Champions reported that community residents interpreted their information-sharing as a personal criticism, for instance of their hygiene.

Connectivity issues, breakages and data shortages occasionally impeded participants from engaging in the groups.

It was critical to have local facilitators and team members available to support participants with data top-ups and resolve technical issues when these occurred.

Some people accepted. But other misunderstood me that I am judging them because their compounds are dirty.

Those people who did not like disabled people were not interested in what I shared.

The Health Champions were sometimes expected by other community members to provide more than information.

It was important throughout the intervention for facilitators and Health Champions to reiterate the boundaries of their role. Some residents asked participants to provide treatment and diagnosis.

But [I told them] mind you I am not a medical practitioner, meaning my knowledge in health is limited. After reading out the questions and answers I told them for more clarification please try to see a medical doctor for assistance

It was hard because some residents asked for medical and financial support.

RESULTS & INSIGHTS

Considerations for replication

Should this intervention be replicated in these or other communities, the following elements would need to be considered to ensure the sustainability of the project:

Participatory co-design process

To ensure uptake and engagement, potential participants should be engaged as part of a co-design process to adapt the intervention to their priorities and needs.

This is particularly important given the central use of digital technology within this intervention, so this process should involve gaining and understanding of participants' capabilities and attitudes relating to mobile phones so as to anticipate and address any challenges.

Facilitation

Facilitators played an important role in this pilot intervention in leading and moderating the digital group discussions, sharing key information with participants, and alerting the wider team to issues, such as a participant's malfunctioning phone.

Identifying facilitators who have lived knowledge of the community and/or issues the project is focused on is critical for its smooth implementation.

These facilitators need to receive some training in digital facilitation and in the use of the specific hardware and software used in the intervention.

Provision of data and mobile phones

Mobile data is expensive in Sierra Leone, and not all participants in this pilot had mobile devices of their own that they could use.

For people in low-income communities, having to provide or pay for their own data for a project like this would be a huge barrier to participation.

It would therefore be important for data and mobile devices to be provided to participants, or at the very least heavily subsidised, to ensure accessibility.



Safeguarding mechanisms

To ensure the digital groups remain safe spaces, it's important to have a process for monitoring and moderating the discussion, with a protocol for addressing and potential safeguarding issues should they occur.

CONCLUSION

Key takeaways

Sierra Leone has a strategy for rolling out primary healthcare, in particular to populations with limited access to health services and facilities. A key thrust of this has been a focus on supporting, and training a cadre of Community Health Workers (CHW), as set out in the SL Community Health Workers Policy of 2012 ¹¹ and the National Community Health Workers Policy 2016-2020, led by the SL Ministry of Health and Sanitation.

The CHW initiative in Sierra Leone is based on evidence that CHWs play an important role in the implementation of preventive and curative, and often life-saving interventions at community and household level.

It is guided by the principle of equity and access rooted in the Right to Health, with an emphasis on reaching marginalised communities and individuals with the poorest access to health care. However, in its current form the CHW scheme in Sierra Leone focuses primarily on rural communities, despite the poor access of residents of low income urban communities to health services, and does not engage with the specific challenges faced by persons with disabilities in accessing health services and information.

This pilot intervention highlights the need for access to primary health services for low income urban residents, including people with disabilities, and also suggests that the use of digital technologies accessible from basic smart-phones is a promising avenue for primary health strategies in contexts such as Sierra Leone. **The high level of uptake and engagement with this pilot intervention suggests that digital technologies, if used in accordance with participant priorities and capabilities, can be leveraged to support health information dissemination efforts and build health literacy among low income urban residents.**

The results summarised in this report suggest that this intervention, if refined using the learnings gleaned from the pilot, has potential to be rolled out within this community, or replicated in similar settings, in partnership with key stakeholders.

It is guided by the principle of equity and access rooted in the Right to Health, with an emphasis on reaching marginalised communities and individuals with the poorest access to health care. However, in its current form the CHW scheme in Sierra Leone focuses primarily on rural communities, despite the poor access of residents of low income urban communities to health services, and does not engage with the specific challenges faced by persons with disabilities in accessing health services and information.

¹¹ Government of Sierra Leone, Ministry of Health and Sanitation (2012) Policy for Community Health Workers in Sierra Leone. Accessed: <https://chwcentral.org/wp-content/uploads/2015/01/CHW-Policy-Sierra-Leone.pdf>