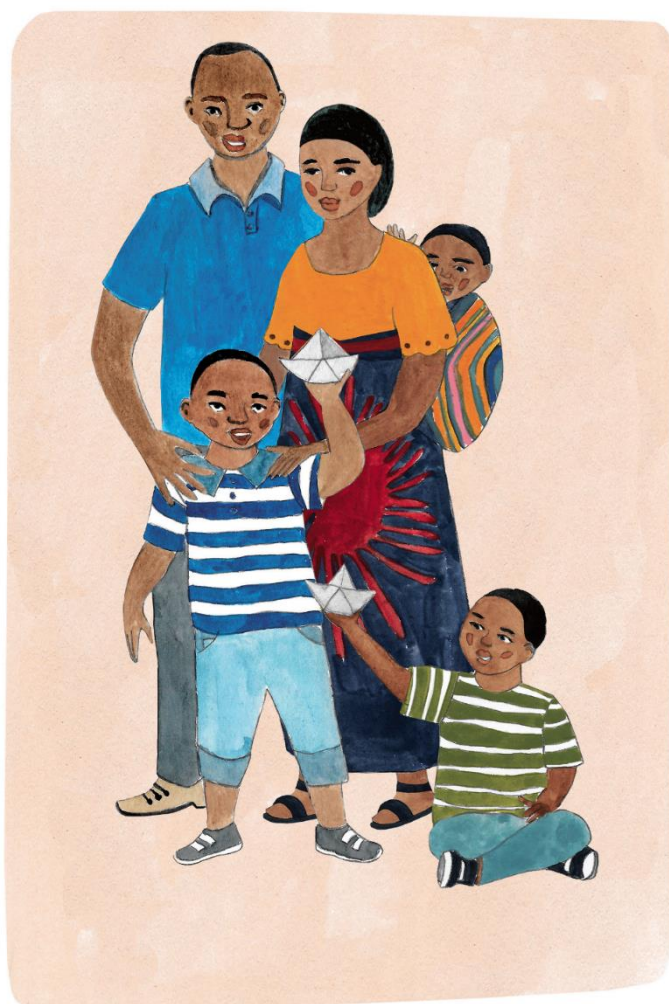


An intervention to improve uptake of referrals for children with ear disease or hearing loss in Thyolo District, Malawi: development and feasibility testing



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in Disability

STUDY DETAILS

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EXECUTIVE SUMMARY

STUDY BACKGROUND

The World Health Organization (WHO) estimates that 34 million children have disabling hearing loss worldwide.[1] The majority of these children live in low and middle income countries. In Sub-Saharan Africa, 1.9% of children are estimated to have hearing loss. In Malawi, the estimated prevalence in children is approximately 4.6 per 1000 population.[2] The impact of hearing loss can be profound, extending beyond the individual to the family and community. Childhood hearing loss can result in delayed speech and language and cognitive development. Evidence suggests that children with untreated HL have lower levels of literacy and poorer educational attainment compared to children with normal hearing.[3-6]

Early detection and provision of interventions such as hearing aids are important to limit the impact of hearing loss and maximise functioning. However, in many low and middle income countries, there is a substantial shortage of human resources and equipment to provide these services, particularly in rural settings. In Malawi, there are two trained Ear Nose and Throat (ENT) surgeons and three audiologists for a population of >17 million people.[7, 8]

To address the lack of ear and hearing services, outreach camps are regularly held in the districts surrounding Blantyre by ENT specialists from Queen Elizabeth Central Hospital (QECH). Although many conditions can be treated in outreach, some need further assessments or treatment at the central hospital. However, evidence suggests that very few children referred to specialist services take up this referral; a recent study found that <5% of children attended with key barriers including lack of information about the referral, fear about the hospital, and transportation problems. Delayed or of lack of access these services can have substantial long-term consequences for children and their families, including poorer health and quality of life, increased risk of mortality, lower rates of school participation and a greater risk of poverty.[18] There is therefore an urgent need to address this low uptake of referral. However, information is lacking on how best to improve uptake of referrals for ear and hearing services.

AIM

This study aimed to develop and test an intervention to improve uptake of referral for children with ear and hearing conditions in Thyolo district, Malawi.

METHODS

This study used the Behaviour Centred Design (BCD) approach to develop an intervention. This involves five steps – ABCDE: Assess, Build, Create, Design and Evaluate. The steps we took included those outlined in Figure 1 below.

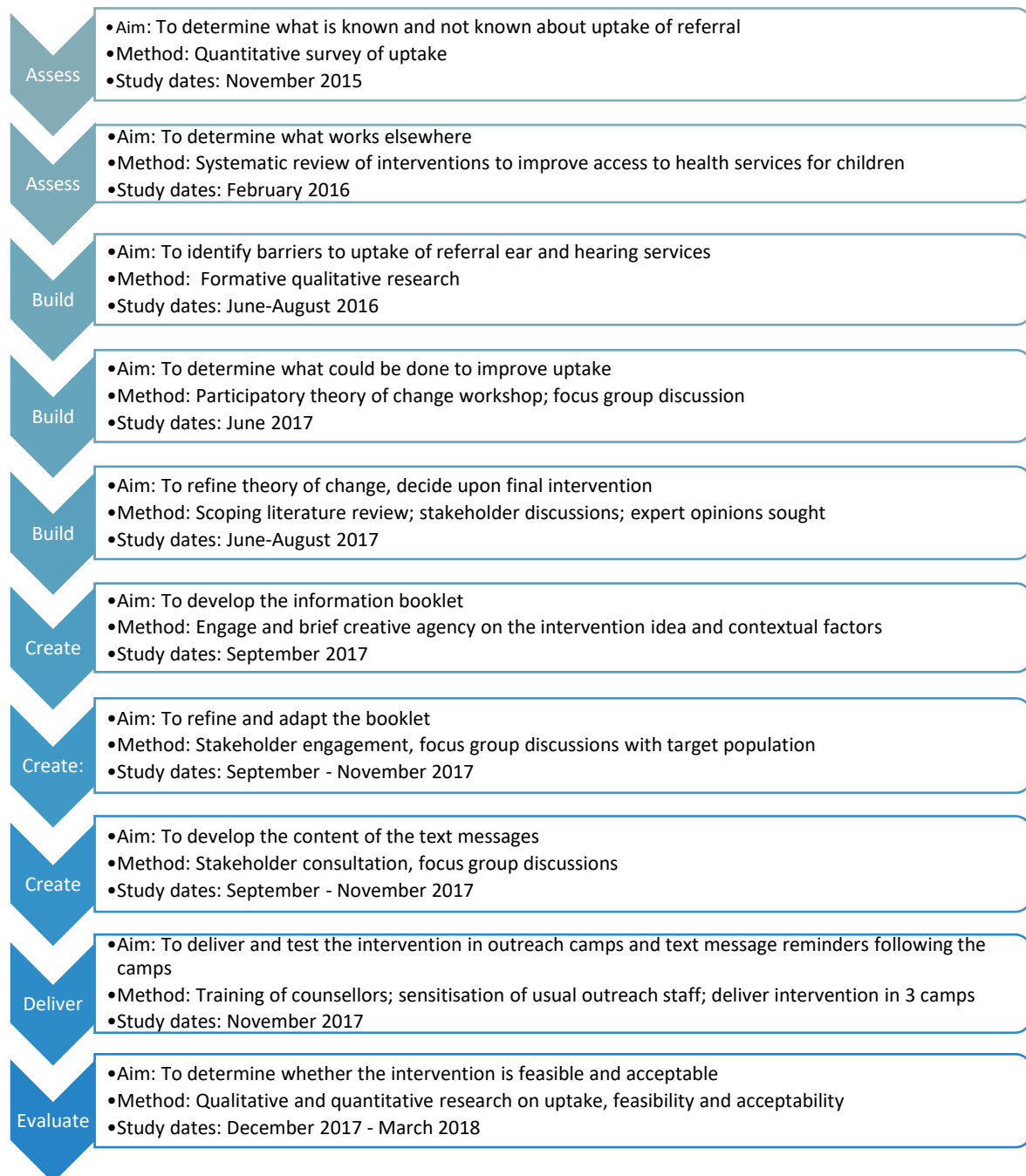


Figure 1: Steps taken to develop intervention

KEY FINDINGS

- Developing the intervention (assess, build and create: ABC):
 - The key barriers to referral uptake identified in previous research using qualitative interviews were: lack of information about the referral, fear about the hospital, and transportation problems.
 - Through a participatory theory of change workshop the following intervention approach was proposed: educational interventions to address the lack of understanding about the referral process and fear of the hospital.
 - Providing transport to the hospital was also discussed but considered to be unsustainable by stakeholders.
 - Based on the theory of change, and the available literature and stakeholder consultation, the final agreed intervention is shown in the Box below:

Final intervention
Information booklet: containing an illustrated story about a child attending QECH with their caregiver, a map providing photographs of key landmarks and directions to the ENT department, and a plan of action for attending the referral tailored to each caregiver
Counselling: by a trained expert mother and community health worker using the booklet
Text message reminder: to be sent 2 days before scheduled appointment, and 2 weeks after initial outreach if the appointment was not attended.

- An iterative process was used to develop the information booklet, whereby a creative agency was engaged to create an initial draft, which was adapted based on stakeholder and caregiver feedback.
- Feasibility and acceptability testing (evaluate: E):
 - Of 30 children who attended outreach camps and were referred to QECH and received the intervention, 16 attended (53%).
 - Caregivers provided positive feedback about the intervention and reported that the intervention assisted with decision-making. Caregivers found the illustrated storyline included in the booklet to be motivating. They also valued the counselling, particularly with the expert mother who had been through a similar process before.
 - Counselling with an information booklet was acceptable, and helped caregivers understand and discuss logistical requirements for uptake and how to prepare. In total 63% of caregivers received text messages. Text messages were perceived to be helpful for those who received them. Although the majority of caregivers had phones (93%), network and power issues may have prevented some caregivers from receiving the text message, limiting feasibility of this component
 - The intervention helped overcome some of the key barriers identified in the formative research (lack of information and fear of the hospital. However, for those who did not attend, transportation was still the major barrier. Families who did not attend experienced competing financial priorities at the time of referral which meant the cost of transportation was prohibitive.
 - The estimated cost to deliver the intervention in camps was £3.70 per person

RECOMMENDATIONS

Addressing poor uptake of referral is crucial to maximise the benefit of outreach camps. Compared to previous research, which showed that 5% attended, more than half of caregivers and their children attended after receiving the intervention which suggests that it may help to improve uptake.

Based on the findings of this research, the following recommendations are made:

- In future outreach camps, include patient education using the illustrated booklet, and counselling by an HSA and expert mother to assist in overcoming uncertainty about the referral and fear of the hospital
- Consider approaches to facilitate transport to hospital or expanding delivery of ear and hearing services in rural areas to address the transport barrier
- Given logistical challenges with text messages (e.g. power, network, and phone ownership), alternative approaches such as text messages to HSAs should be explored in future studies.
- Conduct a larger-scale controlled trial of the intervention to understand the effectiveness of the intervention
- Routinely assess patient follow-up following outreach camps to monitor referral uptake and follow up with patients who do not attend through increased communication between primary, secondary, and tertiary ear and hearing services.

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INTRODUCTION

HEARING LOSS IN MALAWI

The World Health Organization (WHO) estimates that, worldwide, 34 million children have disabling hearing loss.[1] The majority of these children live in low and middle income countries (LMICs). In sub-Saharan Africa 1.9% of children are estimated to have hearing loss. In Malawi, a study using the Key Informant Method estimated the prevalence of HL in children to be 4.6 per 1000 population.[2] The WHO have estimated that 60% of childhood hearing loss can be prevented, with the remaining treatable through effective interventions such as hearing aids and surgery.[9] Some of the main preventable causes are infectious diseases such as measles, mumps, rubella, otitis media, and birth complications.[9] Previous research in Malawi has found the prevalence of otitis media in children aged 4-6 years was 5.4%, with a prevalence of any middle ear condition of 47%.[10]

The impact of hearing loss can be profound, extending beyond the individual to the family and community.[11] Childhood hearing loss can limit speech and language development, which can in turn have substantial effects on cognitive development.[12] Evidence suggests that children with untreated HL have lower levels of literacy and poorer educational attainment compared to children with normal hearing.[3-6] In LMICs, children with hearing loss have limited access to educational services. For those with profound deafness, there are very few schools for the deaf – in sub Saharan Africa, a median of 6 schools for the deaf exist per country.[8] Poorer educational attainment can limit employment opportunities later in life. Through this pathway hearing loss is linked with poverty.[13] Children with hearing loss can also experience discrimination and stigma.[14]

Early detection and provision of interventions are important to limit the impact of hearing loss and facilitate maximum functioning. However, in many LMICs, there is a substantial shortage of human resources and equipment to provide these services. In Malawi, there are two trained Ear Nose and Throat (ENT) surgeons and three audiologists for a population of >17 million people.[7, 8]

ACCESS TO EAR AND HEARING SERVICES IN THYOLO DISTRICT, MALAWI

There are several initiatives to improve access to ear and hearing services in this highly underserved population including: i) task-sharing - training Health Surveillance Assistants (HSAs, Malawi's Community Health Workers) and a cadre of mid-cadre health workers including Ear Nose and Throat (ENT) Clinical Officers, and Audiology Officers; ii) outreach ear and hearing screening camps.

Task sharing

In previous research on task sharing, 29 HSAs, were trained by an ENT surgeon using the WHO Basic and Intermediate training modules on Primary Ear and Hearing Care in 2015.[7, 15] This training was found to be effective in improving the knowledge of HSAs in ear and hearing care.[7] This training formed part of a Key Informant Method (KIM) study in Thyolo district to assess the prevalence and causes of hearing impairment in the population (from here on referred to as KIM Hearing study). Following the training they received, the HSAs went back to their communities to identify people with ear and hearing conditions.

In addition, 27 ENT Clinical Officers and four audiology officers have been trained to deliver ear and hearing services at district and central hospitals to help improve access to services. These clinical officers receive 18 months of training, with the aim of increasing the ear and hearing healthcare workforce in a relatively short period.

Outreach camps

Outreach ear and hearing screening camps are commonly held by clinicians from QECH (also known as “Queens”). The clinicians who normally attend include: ENT specialists or ENT clinical officers, audiologists or audiology officers, and nurses. Some conditions can be treated and managed within the camp setting, whilst others need more specialist care. For those that need specialist care at QECH, referrals are made by ENT doctors verbally. Patients are given a date to attend QECH at this time. Referrals are typically made for surgery for chronic suppurative otitis media or dry perforations, further hearing assessment for children who cannot be tested in camps, and hearing aid fittings.

Outreach camps are important for reaching underserved populations in rural Malawi, where services are extremely limited. They also act as an awareness raising tool for communities about the services at the district and central hospitals. However, evidence suggests that uptake of referral is low following screening camps, which may limit the value of conducting this type of exercise. Following the KIM Hearing identification exercise, those identified by HSAs were invited to attend outreach camps in five health centres in Thyolo. Of 484 children who attended the camps, 170 were referred to ear and hearing services at QECH for further treatment or assessment. A follow-up survey found that only 3% took up the referral at QECH.[16]

Delayed or of lack of access to appropriate health and rehabilitation services can have substantial long-term consequences for children and their families, including poorer health and quality of life, increased risk of mortality, lower rates of school participation and a greater risk of poverty.[18] Given the ongoing outreach camps, and the evidence that uptake of referral is low, it is vital that this issue is addressed.

This report discusses the process of designing an intervention to address the poor uptake of referral in Thyolo district, Malawi. It also provides the results of a feasibility and acceptability study testing this intervention.

STUDY AIM

The aim of this study was to develop an intervention to address the poor uptake of referral for children with ear and hearing issues in Thyolo district Malawi.

APPROACHES TO DESIGNING NEW INTERVENTIONS

Several approaches exist for designing complex interventions to address public health issues. We drew on two key approaches in the development of our intervention: The Medical Research Council (MRC) framework for designing complex interventions and Behaviour Centred Design (BCD).[17, 18] These two approaches are complementary. This section provides a brief summary of each. For a more comprehensive overview, see the MRC and BCD guidance.[17, 18]

Medical Research Council (MRC) framework

The MRC framework suggests that first a systematic review should be carried out to understand what does or does not work (identifying the evidence base). Then, an appropriate theory for the intervention should be developed drawing on the existing evidence, and also supplementing this with additional research, for instance qualitative research with the target population to understand need [18]. Next, participatory workshops with key stakeholders are recommended to develop a Theory of Change (ToC) and potential solutions, which are then developed, pilot tested for feasibility and acceptability, and studied in a wider trial to understand impact. The ToC is a pragmatic framework which describes how an intervention is expected to influence change. It is usually developed in collaboration with key stakeholders and includes a series of hypothesised causes and effects which lead to the intended impact. Indicators of success are developed for each stage to measure progress.

Behaviour Centred Design (BCD)

Behaviour Centred Design (BCD) is a relatively new approach for designing interventions to change behaviour, developed at the London School of Hygiene & Tropical Medicine. The approach can be summarised in a single diagram which is shown in Figure 2. This approach has been used for a diverse range of public health issues including improving hand washing, reducing diarrhoea, and physical activity.[17]

BCD follows a similar stepwise process to the MRC framework, including analysing available literature on the topic, conducting formative research and developing a ToC, but it includes a greater focus on understanding the underlying drivers of behaviour [17].

The framework contains two main components i) a theory of change and ii) a process for designing interventions. Firstly, the ToC through the middle starts with an intervention, leads to a change in a “state of the world” via a causal chain.[17] The intervention aims to cause a change in the environment, which causes a change in the brain and/or body of an individual, resulting in re-evaluating the behaviour, which in turn leads to performance of the target behaviour. If many people engage in the behaviour, this results in a collective impact on the “state of the world” or in effect achieving a long term goal. This theory of change assists researchers and those involved in implementing programmes understand how an intervention will make change happen in the target population. Through specifying this mechanism, and the underlying assumptions, and indicators, the theory of change also allows improved evaluation of interventions and programmes.

At the core of BCD is developing a ‘surprising’ intervention that disrupts a behaviour setting¹. It is argued that without a surprise to “shake-up” the environment, everyday behaviour will continue along the same trajectory. The result of the surprise needs to lead to revaluation of the behaviour. Underpinning this revaluation are human motives. Aunger et al. (2015) describe motives as *“evolved psychological mechanisms*

¹ A behaviour settings are the situations where behaviour change happens. In behaviour settings, people have roles, adhere to social norms, and have expectations about how others behave. For example, education is a behaviour setting: the classroom is the stage, teachers and students are the actors, desks and chairs are props. People behave according to their roles in these environments. If we understand the behaviour setting well, can predict how people are going to behave.

that help us to choose the appropriate behavioural response to a situation – that is, the response most likely to lead to a satisfactory outcome in terms of the benefits accruing from that interaction with the environment (including other people)”. Some examples of human motives include:

- Nurture: desire to care for child
- Affiliate: desire to fit in socially
- Status: desire for recognition and title
- Curiosity: desire to learn and reduce gap in knowledge

Human motives can be used to change behaviour by highlighting the rewards that an individual may get from performing a certain behaviour. For example, a communication campaign has been tested in India which targeted emotional motivators to improve handwashing. One component of this campaign was the development of a character called “Super Amma” or super mother, who teaches her son good manners, including washing hands, to help him become successful. The target motive of this campaign was “nurture”. An evaluation of this programme found handwashing with soap was 31% more common in the intervention than control group after 6 months of exposure.[19]

The second part of the BCD approach is a process for developing interventions, shown by the blue arrows on Figure 2. This involves five steps – ABCDE: Assess, Build, Create, Design and Evaluate: assessing what is known about the target behaviour, building on this through formative research, using this knowledge to inform the creative design of an intervention, considering how the intervention will be delivered, and then evaluating the intervention.

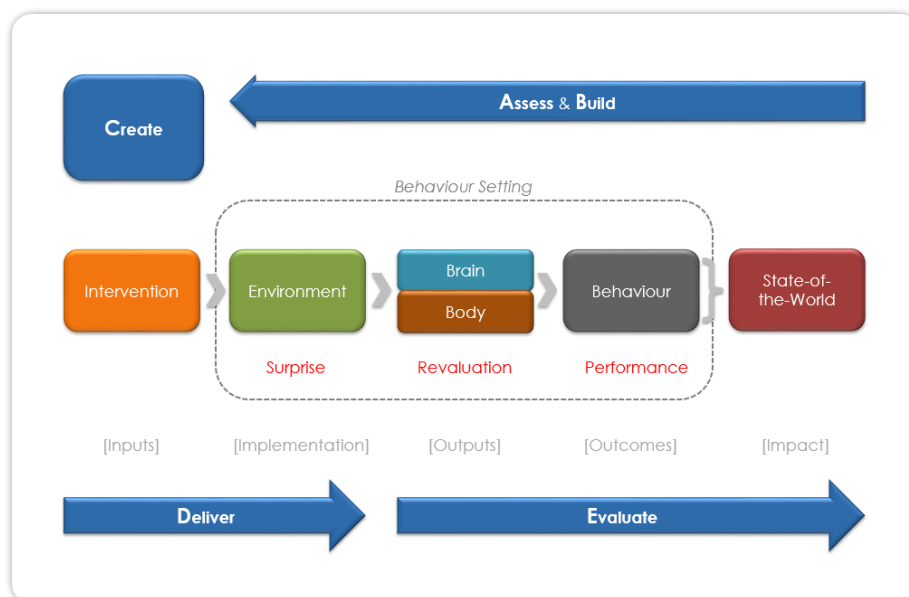


Figure 2: Behaviour centred design approach (from Aunger et al. (2016)) [17]

Although we drew on both the MRC and BDC approaches to intervention design, we have structured our process using the ABCDE process in this report for simplicity.

METHODS

For the process of designing and testing an intervention to address low uptake of referral a modified ABCDE approach from BCD was used. Figure 3 outlines the steps we went through for the ABCDE process, including the aim, method and study dates for each step. These steps are then discussed in the text below.

The research undertaken for the first three steps of the ABCDE have already been published and therefore will be briefly summarised in this report. The main focus of this report will be the on the steps – from build to evaluate.

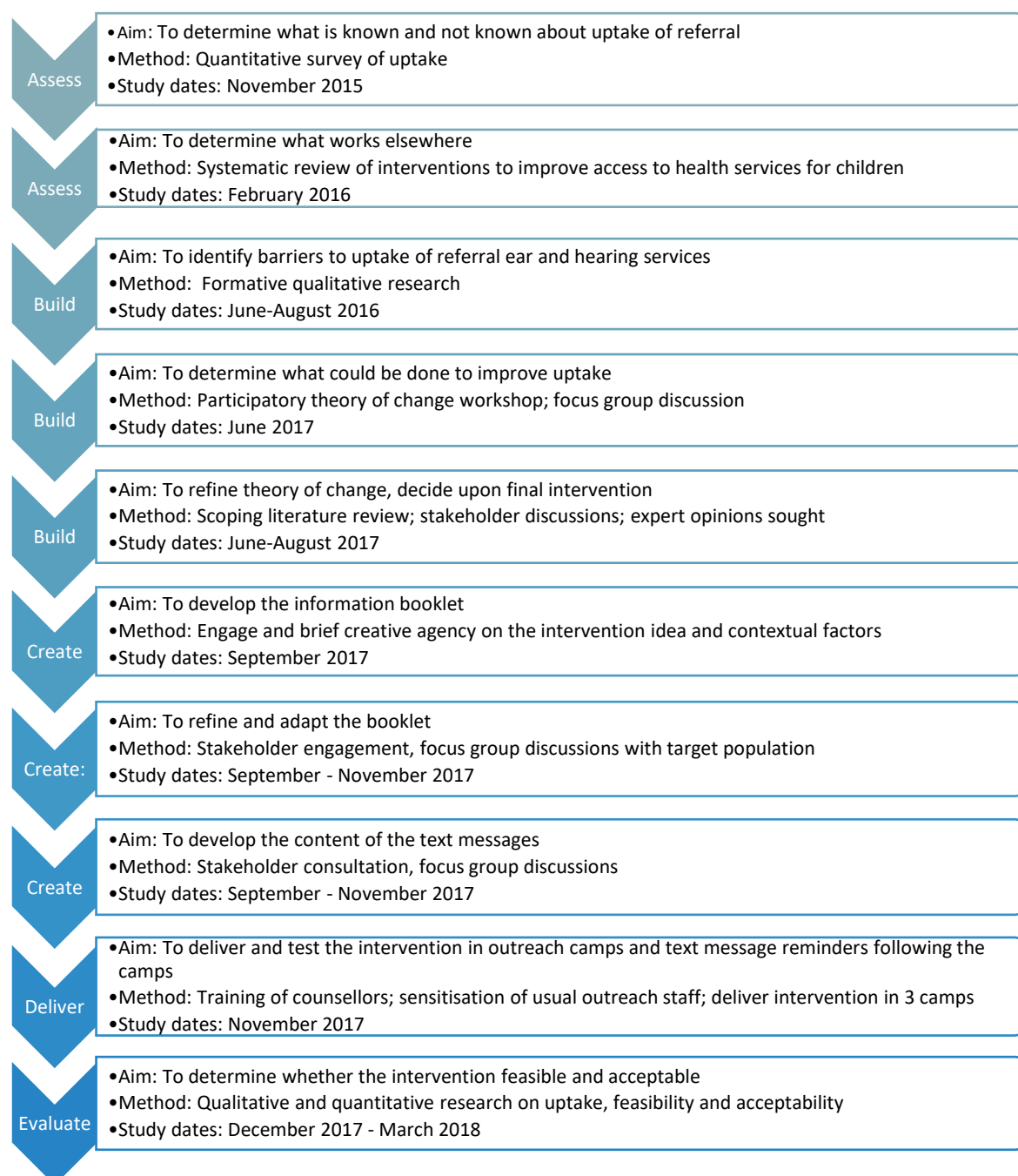


Figure 3: steps taken in ABCDE approach including month and year of each component.

1. ASSESS: DETERMINE WHAT IS KNOWN AND UNKNOWN ABOUT UPTAKE OF REFERRAL

To 'assess' what is known and not known about the problem, and the target behaviour, a quantitative survey was conducted which shown that referral uptake was poor. This survey identified that further research was needed to understand what the key barriers to uptake of referral were (see step 3 below).

2. ASSESS: DETERMINE WHAT WORKS ELSEWHERE

A systematic review was conducted to determine what works to improve access to health services for children in other LMICs. The results of the systematic review have been published previously.[20] In brief, this review identified delivery of services close to home, service level improvements, educational programmes, text message reminders, and incentives were the main intervention types. This review concluded that text message reminders and delivery of services close to home showed promising results. The findings for educational interventions were mixed, with some, but not all finding positive results. The review concluded further evidence was needed.

3. BUILD: IDENTIFYING THE BARRIERS TO UPTAKE OF EAR AND HEARING SERVICES

A mixed methods study was undertaken in June-August 2016 to assess uptake and explore barriers to uptake of ear and hearing referrals following the KIM Hearing study in Thyolo. This involved in-depth interviews and structured questionnaires with caregivers of children who did not attend QECH following referrals made in the KIM screening camps. The results have been published previously.[16] In brief, seven key interacting reasons for non-uptake of referral were identified:

1. Location of the hospital
2. Lack of and cost of transport
3. Fear and uncertainty about the referral hospital
4. Other indirect costs of seeking care
5. Procedural problems within the camps leading to lack of understanding about the referral
6. Awareness and understanding of hearing loss
7. Lack of visibility and availability of services

4. BUILD: TO DETERMINE WHAT COULD BE DO TO IMPROVE UPTAKE

The aim of this stage was to develop locally appropriate interventions to address barriers identified in stage 3. Two steps were taken to develop the intervention: i) Focus group discussion with caregivers of children with ear or hearing issue; ii) Participatory workshop with key stakeholders.

Focus group discussion

We held a dissemination meeting and focus group discussion with five caregivers who were participants of the KIM Hearing study who were purposively selected as having not attended Queens for the referral. The focus group discussion was held the day before the participatory stakeholder workshop. The results of the research were shared, feedback sought, and possible strategies to address the barriers were sought from participants. We wanted to ensure that the barriers identified related to what they experienced, and any additional barriers that had not emerged in the research were raised and fed into the workshop. We also wanted to discuss strategies with caregivers in a comfortable setting, to facilitate maximum participation and there concerns as many had never been to Blantyre or been part of a workshop with high-level government officials. Two of the caregivers from this focus group discussion attended the stakeholder workshop on the following day.

Theory of change workshop

We held a one-day participatory stakeholders workshop at QECH to present research findings from stage 1 and 2 (above) and to develop (“build”) ideas on how to address the barriers identified and improve uptake. The workshop involved developing a ToC. ToC models can guide the design, development and evaluation of interventions. The resulting TOC should be testable through clearly defined indicators to measure intervention implementation, receipt and uptake.[21, 22]

Participants

In total, 19 stakeholders working in, or with an interest in ear and hearing care in Malawi attended the workshop. This included: ear and hearing health professionals and administrative staff/project co-ordinators from QECH, HSAs from Thyolo, a Ministry of Health official, a representative from Malawi Counsel for the Handicapped (MACOHA), a representative from Malawi National Association for the Deaf (MANAD), other disabled persons organisations (DPOs), and two caregivers who were referred in the KIM Hearing study.

Workshop process

For the workshop participants were divided in to three groups, ensuring a balance between different sectors, whilst also ensuring that group members could all communicate well (some participants did not speak English/Chichewa).

Three experienced facilitators ran the workshop (TB, WM, RT). First the research on uptake and barriers to referral services was presented. Following this, the key processes to develop the ToC included:

- i) developing a long term goal for the project;
- ii) backwards mapping from the long term goal to outcomes;
- iii) discussing possible activities to achieve the prioritised outcomes;
- iv) prioritisation of suggested activities in terms of cost and sustainability.

To develop outcomes, each of the barriers identified in step 3 were reversed in to outcomes e.g. “lack of transport” became “transport is available”. Thus, we started with 7 key outcomes related to the 7 barriers identified in the research (see step 2 above). The long term goal for this project (determined in the meeting) – and the behaviour we were hoping to change was *improved uptake of ear and hearing referrals for children*. As attending QECH is often not a one-off event, with most people needing additional appointments beyond the initial referral, our ultimate goal was that attendance at follow-up appointments was also sustained, resulting in improved ear and hearing health.



Figure 4: Theory of Change Workshop

Results

Proposed interventions

Table 1 shows the six outcomes (addressing each barrier) and the interventions that were proposed to achieve these. Members of the focus group and ToC workshop particularly emphasised that learning from peers who had been through the experience of attending QECH would be encouraging for caregivers.

Table 1: Outcomes of theory of change workshop

	Outcome	Proposed interventions
1	Reduced fear about hospital	<ul style="list-style-type: none">• peer counselling• information about hospital procedures communicated effectively during outreach
2	Sufficient information about referral	<ul style="list-style-type: none">• peer support/counselling• village health committees• videos about the referral process• text message reminders
3	Improved awareness and understanding about ear and hearing health	<ul style="list-style-type: none">• ear/hearing day advocacy event• education of gatekeepers in the community
4	Service available closer to the community	<ul style="list-style-type: none">• expand outreach camps in the community
5	Transport is available	<ul style="list-style-type: none">• group transport provided with community escort

Prioritising interventions

A prioritisation task was held whereby each member of the group voted on their top three interventions – with consideration to costs, feasibility, acceptability, and sustainability. Through this task a consensus was reached to focus on 1-3 in Table 1 (interventions to address fear about the hospital, awareness and understanding about ear and hearing health, and information about the referral).

Provision of transportation was not considered to be a sustainable option by both members of the focus group, and TOC workshop, despite transportation being a key barrier. This was due to the suspected high long-term costs involved.

5. BUILD: REFINING THE THEORY OF CHANGE AND DECIDING UPON FINAL INTERVENTION

The next step of intervention development, building on the recommendations from the workshop and evidence obtained from the systematic review, included consultation with experts in educational interventions as well as other stakeholders in Malawi. Through this, the following intervention package was proposed:

- A photograph booklet providing information about the referral and process of going to QECH
- Counsellors trained to deliver information booklet in camp settings, including one “expert” mother who would provide peer support and a community health worker
- Text message reminders sent to caregivers who had been referred to Queens

The final ToC for this intervention can be found in Figure 5 and a narrative summary for this is provided as Appendix 5. A multiple component intervention was proposed to address the multiple barriers raised in the formative research and to facilitate prompts/reminders to attend after the camp, once the families were at home. Table 2 shows the rationale behind each component of the intervention, drawing on the theories including the BCD as well as the behaviour change wheel.[17, 23]

Table 2: Rationale for each component of the intervention

Intervention component	Behaviour change technique	Hypothesised mechanism
Booklet	Instruction on how to perform behaviour (uptake of referral)	Providing directions and creating a tailored plan of action demonstrates to caregivers what needed to be done to attend, and familiarises them with the process to help overcome lack of understanding about the referral.
	Social comparison	The storyline shows other people going through the process of taking up referral and therefore caregivers compare themselves to the family in the booklet. This addresses fear of the hospital.
	Demonstration of behaviour	Photographs/images help caregivers overcome fear, through becoming familiar with Queens.
Counselling	Prompt/cue	The booklet will be used as a tool for decision making about attending the referral, with the idea that it would be shared with caregivers/family members who did not attend the camp.
	Social support	Counsellors provide opportunity for two-way dialogue with people who understood the process. The expert mother has had a similar experience to those being referred and thus is able to share her personal experience.
	Information on health consequences	Counsellors discuss with caregivers the consequences of not attending the referral and answer key questions posed by caregivers.
Text message reminders	Prompt/cue	Text message reminders act as a prompt or cue for caregivers to remember to attend the referral once they had returned home from the screening camps.

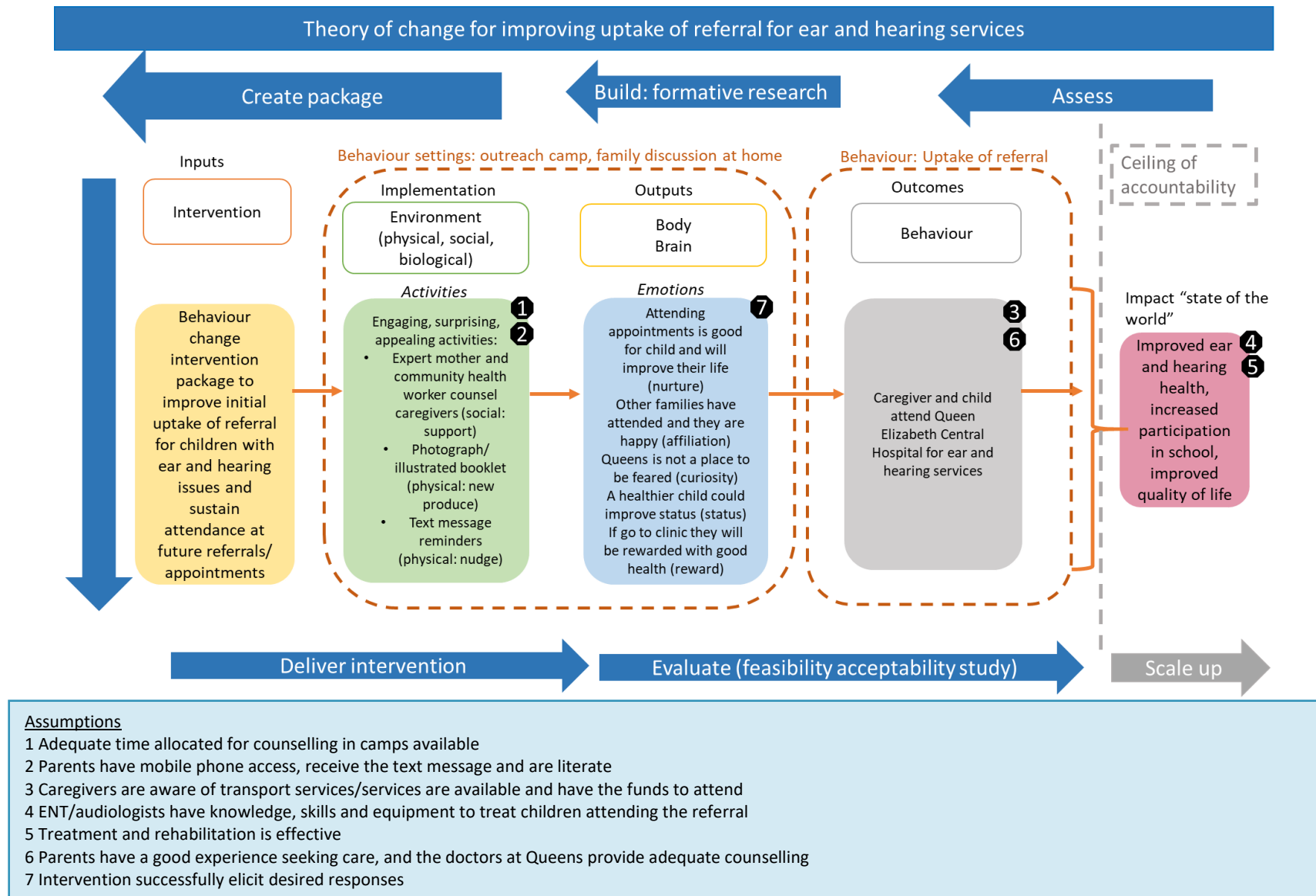


Figure 5: Final theory of change

6. CREATE: DEVELOPING THE BOOKLET

A London-based creative agency called *RE-UP* was engaged to create the information booklet. The agency have previous experience working with London School of Hygiene & Tropical Medicine on hand-washing interventions. We briefed them on the background of the project, the Malawi context, and the intervention idea. The design brief for the project can be found in Appendix 2. The task of the agency was to create a booklet to address poor uptake using the information from the creative brief. The key components we wanted to include were: a story of a child going to Queens with their caregiver, directions to the hospital and department, and a plan of action (for attending the appointment) for counsellors to discuss and formulate with each caregiver. Whilst one booklet was proposed, two storylines were required to suit the two main referral types – one for children who needed surgery and one for children who needed hearing aids.

7. CREATE: REFINING THE BOOKLET

To develop the three sections of the booklet (storylines, map/directions, action planning; see Box 1), an iterative process was used.

Development of story: To tell the story of a family attending QECH, interviews were conducted with two caregivers of children from Thyolo who had previously attended QECH – one for their child's ear surgery and one for hearing aid fitting. These caregivers were sampled from QECH registries. Details were gathered about their child, the referral process, the journey and their experiences at the hospital. Alongside these interviews, photographs of the caregivers were taken by a local photographer in addition to photographs of: a typical village in Thyolo, the hospital, ear and hearing health professionals, and landmarks that would be important for caregivers to recognise on their journey. These stories and photographs were used to draft the first version of the booklet. The creative agency suggested that a storyline would work well with illustrations based on the families interviewed, rather than use photographs themselves to introduce an element of 'surprise' which is recommended in the BCD approach to ensure people will pay attention to it and assist engagement in the behaviour change process. Figure 6 shows an illustration of the family based on photographs taken.



Figure 6: Photograph of one of the families that was interviewed for the development of the booklet and the first version of the illustration on the right.

An iterative process of consultation and adaptation of the booklet was undertaken, with recommended changes incorporated by RE-UP between each of the following consultation stages:

- Draft 1 and 2 reviewed by LSHTM researchers
- Draft 3 reviewed by eight stakeholders from Malawi (six from original TOC workshop)

- Draft 4 reviewed by target population through a focus group discussion with eight caregivers of children with ear diseases/hearing impairment from Thyolo). Caregivers were asked to reflect on suitability of the images, comprehensibility of the text, and usefulness of the components of the booklet.

Changes were made to the booklet content, format and photographs after each feedback round. Examples of some of these changes are shown in Figures 7 and 8.

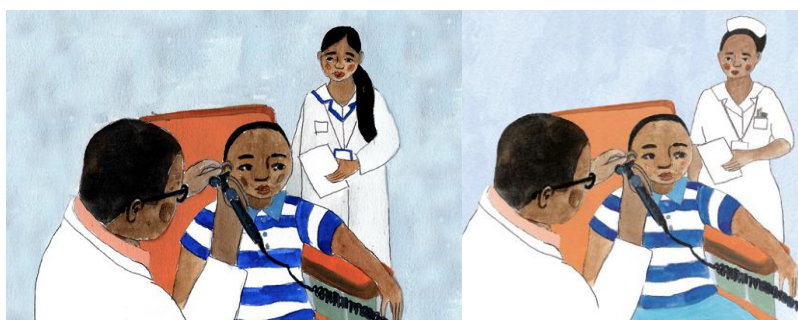


Figure 7: Left: prior to focus group discussion. Right: After feedback which suggested the nurse looked like a foreigner with long hair and needed to be wearing a cap to be more locally applicable.



Figure 8: Left: prior to focus group discussion with target population and consultation with stakeholders. Right: After revisions made – participants felt that more children should be included in the family as is more common in Malawi and the mother's clothing, particularly the shoes needed to be more appropriate to what is worn in the villages.



Figure 9: The final booklet

Final booklet components:

The final booklet is shown in Appendix 1 and Figure 9. It folds down to A6 size for easy of carrying and storage and opens out to A3. It includes the following components:

- **Section 1:** Story of Mr and Mrs Banda and their child Chimemwe who has an ear or hearing problem who go through the process of attending Queens from Thyolo district. Two versions were included – one where the child received hearing aids and the other surgery. This enabled the information and counselling given to be tailored to the type of referral.
- **Section 2:** Directions to Queens from the village, with photographs showing landmarks from the bus stop at Queens to the ENT department and the people that caregivers will meet once they arrive at the hospital
- **Section 3:** Action plan which is tailored to the caregiver including: how they will get there, who will go, what they need to take, phone numbers of key contacts, costs of the treatment, how long they are expected to stay at the hospital etc.

8. CREATE: DEVELOP CONTENT OF TEXT MESSAGES

The following steps were used to develop the text message component:

- Development of text message content
- Gather feedback about content in focus group discussions and stakeholder interviews and discussion about timing and frequency of messages

Based on these steps the following approach was proposed:

- **First text message reminder:** send sent two days before the scheduled appointment at 12:30pm. This time was felt to be appropriate as caregivers would be home from working in the field for lunch.
- **Second text message reminder:** if they did not attend on the scheduled date, a second text message would be sent 2 weeks after the initial outreach camp.

Good afternoon, your child [name] was recently referred to Queen Elizabeth central hospital in Blantyre because of a problem with their ears or hearing. We want to remind you to attend your appointment on [day, date]. If you have any questions please call: [phone number]

Figure 10: Text message reminder

Whether or not the person attended, and thus whether a second message was necessary, would be ascertained from the clinic records to be checked daily by the research assistant. Figure 10 shows the final agreed text to be used in the text message. Participants felt it was important to include the child's name as well as the agreed date of the appointment as caregiver's would take greater notice of the message.

Box 1 shows the final intervention component after the development phase.

Final intervention
Information booklet: containing an illustrated story about a child attending QECH with their caregiver, a map providing images of key landmarks and directions to the ENT department, and a plan of action for attending the referral tailored to each caregiver
Counselling: by a trained expert mother and community health worker using the booklet
Text message reminder: to be sent 2 days before scheduled appointment, and 2 weeks after initial outreach if the appointment was not attended.

9. DELIVER: IDENTIFICATION AND TRAINING OF COMMUNITY HEALTH WORKER AND EXPERT MOTHER

Once the booklet and text message were finalised, the next step was to identify and train two counsellors from Thyolo district: one HSA and one "expert mother" who had been to QECH. The HSA was selected from those who had been involved in the KIM Hearing study so that they had some knowledge of ear and hearing health, and could counsel based on their expertise in the area. The mother was selected by reviewing clinic records for patients (<18 years) who had attended QECH from Thyolo, either for a hearing aid fitting or surgery.

The HSA and expert mother were trained for 1.5 days. The training covered results from the previous studies and purpose of the project, background to ear and hearing in Malawi including service availability, introduction to ear and hearing disorders and the possible treatments, the booklet, types of questions that caregivers might ask, and the study procedures. The counsellors were trained to tailor their counselling based on the type of referral that was made – either for surgical services or rehabilitation (hearing aids). In addition, the expert mother was trained to share her own experiences of having a child with hearing loss, with a focus on the benefits of the treatment, and her experiences attending QECH. The counsellors received lunch and were reimbursed for their transport costs to attend QECH.



Figure 10: HSA (left) and expert mother (middle) practicing counselling with the booklet with trainer (right)

10. DELIVER: DELIVERING THE INTERVENTION IN OUTREACH CAMPS IN THYOLO AND SENDING TEXT MESSAGE REMINDERS

The intervention was implemented within three outreach camps held in Thyolo district during November 2017.

A typical outreach camp includes 3 stations: registration, ear examination, and hearing testing. To deliver the intervention, a fourth station was set up for counselling (see Figure 11). Text message reminders were sent as planned and described in step 8.



Figure 11: Photo showing counselling being delivered in the outreach camps using the booklet

11. EVALUATE: FEASIBILITY AND ACCEPTABILITY STUDY

The aim of this step was to evaluate the feasibility and acceptability of the intervention. The methods are outlined below.

11.1. STUDY POPULATION

The intervention was tested in three ear and hearing outreach camps in Thyolo. The expectation was that three camps would identify approximately 30 families of children (<18 years) with hearing loss to receive the counselling intervention. This sample size was considered sufficient for pilot testing based on recommendations from the literature.[24] The eligibility criteria was children < 18 years, referred to QECH for hearing loss requiring hearing aids or surgery.

11.2. DATA COLLECTION

After receiving counselling, caregivers were interviewed using a structured questionnaire by a trained local research assistant (MP). Data were collected on baseline demographic information about the child and family, the results of their ear and hearing screening assessments, and caregiver reflections on the counselling intervention. Data was collected electronically on tablets using Open Data Kit (ODK) and mobile tablets.

After 4 weeks, caregivers were revisited in their homes and interviewed using a structured questionnaire (which included pre-coded and open text responses) about attendance at referral, reasons for going, reasons

for not going, and feedback on the counselling, booklet and text messages. In addition, qualitative interviews were undertaken with a sub-sample of participants who were selected purposively according to age, gender and whether or not they attended QECH. We aimed to interview 10 caregivers who attended and 10 who did not. Topic guides were developed for these interviews and covered: history of hearing health, previous care seeking, experiences at the outreach camp, decision making process for attending queens, experience attending queens, and general feedback about the intervention (Appendix 2). Interviews were conducted in Chichewa and audio-recorded.

We also conducted qualitative interviews with the counsellors, and clinicians who were involved in the outreach camps to gain their perspectives about the intervention. The topic guide for these interviews is included as Appendix 3. These interviews were conducted at QECH, Thyolo District Hospital, or in the participant's home. The intention of interviewing these stakeholders was to find out about fidelity of the intervention – or whether it was delivered as we intended, as well as to get general feedback and suggestions about the intervention.

Data were also collected on the costs of the intervention including: costs of developing booklet, printing costs, costs of training counsellors, costs of sending text messages, and time taken to counsel each caregiver.

11.3. DATA ANALYSIS

All qualitative interviews were transcribed and translated and analysed by two experienced qualitative researchers (TB and AB), using a thematic analysis approach. The first stage involved reading transcripts and field notes for data familiarisation. Open coding was used to code transcripts according to emerging patterns in the data. Themes were derived from open coding.

11.4. TRAINING OF RESEARCH TEAM

A local research assistant received training by an experienced researcher who was involved in all steps of the ABCDE approach (TB). TB attended the first two outreach camps to supervise data collection. As part of training, the topic guides for the qualitative research were pilot tested, adjustments made to the questions, and feedback given on questioning style. A protocol and checklist was developed for the baseline and followup study which was followed closely by the local research assistant.

11.5. ETHICAL CONSIDERATIONS

Informed consent was obtained from all participants before the intervention was received. An information sheet was given to the participants which outlined the purposes of the study. This was also summarised verbally before consent was obtained. Participants agreed to have their photographs taken as part of this research. Ethical approval was obtained from London School of Hygiene & Tropical Medicine ethics board and the College of Medicine Research Ethics Committee (COMREC) in Malawi.

11.6. RESULTS

11.6.1. CHARACTERISTICS OF THE SAMPLE

In total, from the three outreach camps in Thyolo, 30 children were recruited to the study from 28 families (2 sets of siblings). Table 3 provides a description of the sample. The mean age of children in the sample was 10.5 years (range 4-16 years) and 57% were female. All caregivers reported that children had difficulty hearing, with 60% reporting a lot of difficulty. The vast majority (60%) reported difficulties for between 1-5 years. All

children of school age attended mainstream schools, however over half (59%; n=16) were in a lower grade than other children their age. The vast majority (n=22; 73%) of caregivers had previously sought care for their child's ear or hearing condition, with most seeking care at the district hospital (n=14; 64%). In terms of type of referral given at the outreach camp, the majority (63%; n=19) were referred for surgery with the remaining (37%; n=11) referred for hearing assessment/hearing aids due to suspected permanent hearing loss.

Table 3: Characteristics of the sample

Child characteristics		N (%)
Mean age (range) (years)		10.5 (4-16)
Sex		
	Male	13 (43%)
	Female	17 (57%)
Duration of hearing difficulty		
	<1 year	7 (23%)
	Between 1-5 years	18 (60%)
	>5 years	4 (13%)
	Don't know	1 (3%)
Attend school (among those of school age)		25 (100%)
Grade		
	Same year as other children	10 (37%)
	Lower grade than other children their age	16 (59%)
	Higher grade than other children their age	1 (3%)
Referral type		
	Hearing assessment/hearing aids	11 (37%)
	Surgery	19 (63%)
Caregiver characteristics**		
Sex		
	Male	6 (20%)
	Female	24 (80%)
Age group (years)		
	19-29	9 (30%)
	30-39	14 (47%)
	40-49	7 (23%)
Mean age (range) (years)		34.0 (19-49)
Primary caregiver		
	Yes	26 (87%)
	No	4 (13%)
Relationship to child		
	Mother	19 (63%)
	Father	5 (17%)
	Grandparent	1 (3%)
	Other	5 (17%)
Father lives in same household		
	Yes	16 (53%)
	No	14 (47%)
Father contact in last 6 months		
	Daily	16 (53%)
	Monthly	3 (10%)
	Once every 6 months	2 (7%)
	Don't know	6 (20%)
Literate		25 (83%)
Currently Working		
	Yes full time	8 (26%)
	Part time	4 (13%)
	No	18 (60%)
** for two caregivers, two children were referred (i.e. total number of caregivers was 28)		

All 30 children were followed up after 4 weeks, and all completed the quantitative questionnaire. Of these, 26 caregivers of 23 children were interviewed in-depth for the qualitative study. In five cases, two caregivers were interviewed, one who had been to the camp and one who had attended QECH. This was done so that we could gain different perspectives about the referral (at the camps) and the uptake of the referral (at Queens). Of those interviewed qualitatively, 12 did not attend, and 11 attended the referral at QECH. In addition, seven key stakeholders were interviewed. The results are discussed below in terms of factors that influenced the decision to uptake of referral and acceptability of the intervention.

11.6.2. REFERRAL UPTAKE

Overall, over half (53%; n=16) of children took up the referral at QECH with a caregiver. Of those that took up the referral, the treatment received included: surgery (n=2), hearing aid fitting (n=2), diagnostic hearing test (n=7), medication (n=4), and wax removal (n=1). Those that received medication were referred for surgery, however required treatment prior to surgery (e.g. to dry discharging ears).

11.6.3. ACCEPTABILITY OF THE INTERVENTION

This section discusses the intervention in terms of its acceptability amongst caregivers and stakeholders interviewed. Firstly, the booklet and counselling component, and secondly the text message reminders.

1. BOOKLET AND COUNSELLING COMPONENT OF THE INTERVENTION

ENABLING TWO-WAY CONVERSATION

The counselling allowed an opportunity for a two-way conversation and a setting in which caregivers could feel at ease about asking questions. Stakeholders interviewed reported that some of the benefits of counselling included: the counsellors explained the benefits of attending QECH and consequences of not attending; counselling was tailored to the individual; and caregivers now have greater understanding about the processes. Out of the 16 who attended QECH, two reported that having their questions answered during outreach was the most important factor in helping them to attend. It was noted by some stakeholders that clinicians do not have time to counsel in depth, so this extra time spent by the counsellors with those referred was beneficial. From the caregiver's perspective, 75% of reported that they were very satisfied with the counselling. One caregiver explains how asking questions was important for them:

It [the counselling] was wonderful since we were being encouraged, the doctor can explain to you, yes, but you might have questions, but we were able to have a discussion with them. [Caregiver who attended QECH, 316]

The way caregivers spoke about their experience of counselling also highlighted that parents were motivated to get assistance for their child. In particular, conversations with the expert mother in the counselling seemed to provide motivation to attend. This was reported by both caregivers who did and did not attend.

The [counsellor] said that their child also had a similar problem, had hearing loss, and when they went to QECH, they were assisted. And now things are okay. [Caregiver who went to QECH 105]

Because her [the counsellor's] child had hearing problem and could not speak, but when they went to the hospital, was given hearing aids, and now can hear and that is helpful. [Caregiver who did not attend, 309]

Despite this finding, the interviews suggested that there was variation in how counselling was delivered. Several caregivers who were referred for surgery did not know that the expert mother had a child with hearing

loss, but noted that this would have been helpful should she have shared it. From the expert mother's perspective, she reported that she did share this information with everyone, but went in to greater detail for children who needed hearing aids. Given her child wears hearing aids, it is not surprising that she could provide greater support for some individuals compared to others. The training provided to counsellors prior to the camps covered the range of questions that caregivers might ask, and how these could be answered. This was done to ensure that counsellors were prepared for the two-way conversations with caregivers. The counsellors reported that they were able to answer most of the questions posed by caregivers, but occasionally needed to clarify things with the clinicians in the camps.

DISPELLING MISCONCEPTIONS AND FEAR

Caregivers reported that the knowledge gained from the booklet and counselling alleviated their fears and uncertainties about attending Queens, and gave them confidence to attend. One caregiver explained the benefits of counselling:

It was good since they made us to be free to see that Queens is not a dangerous place but where one can get assistance. [Caregiver who attended QECH, 104]

However, some caregivers still expressed uncertainty about attending suggesting that this barrier was not overcome in all cases:

The worries were there, that what will be treatment at QECH, and what are we going to meet there, being a big hospital that everyone else go [Caregiver who did not attend QECH, 310]

MOTIVATION FROM STORYLINE

Out of 16 who attended, seven caregivers reported that the most important factor in making the decision to go was the Banda Family Story and the possibility that their child could get better, like the child in the booklet. One caregiver explained:

The first thing that I got from this is booklet was the story of Mr Banda and when I heard about it, I was interested and I said 'I will do the same, maybe it is possible that my child might become better'. [Caregiver who went to QECH 106]

The story that I liked in the book is the parents followed the counselling and their child's hearing was restored. And the child was happy when he started hearing. [Caregiver who went to QECH 315]

Both caregivers who did and did not attend spoke about the storyline as providing them with a good example of what to do. They compared their own situation to that of the family in the booklet. Caregivers suggested they were motivated to follow the instructions like Mr and Mrs Banda had in the story:

Some of the things we discussed with the HSAs were about the booklet, they gave an example of Mr and Mrs Banda's family. Their child had hearing loss like my child, and they explained it very well that Mrs Banda followed the instructions very well until their child got assisted. [Caregiver who attended, 311]

What I liked most was that when Mr and Mrs Banda followed instructions about their child, the child got well, the ear problem ended and the child started doing well in class. [Caregiver who did not attend, 310]

FACILITATING PLANNING

Detailed information and instructions about the journey, including the map, cost of transport and the photographs of the doctors in the ENT and audiology departments, was widely valued by caregivers. Of those that did go to QECH, the majority reported that the map section of the booklet was helpful in finding the correct department (81%). Some caregivers reported that they needed additional assistance from passer's by or hospital staff to find the correct location. Even those that did not go to QECH reported that the map was helpful:

The part I liked so much was the part of map since they gave me a good way even though I have never been at QECH but I would have gone there without problems as the maps showed. [Caregiver who did not attend QECH, 101]

One caregiver explains using the booklet to reach the ENT department, showing that the booklet improved their care-seeking experience:

I did not find it very difficult because I had the book, which I was given, which had the map to the hospital. Apart from that when I reach at the gate I just asked for directions. After that, I followed what was written in the book so I did not have any difficulties. [Caregiver who attended QECH, 304]

Caregivers were also encouraged to learn that the treatment they would receive at Queens was free (including the possibility of free hearing aids available through a "pay-what-you-can" system), and knowledge that accommodation was available if they needed to stay overnight. This knowledge was gained from the counselling in the camps and action planning within the booklet. This seemed to positively influence decision-making. One caregiver explains:

We asked that the trip to QECH from here is a long trip and if can happen that one cannot receive the treatment the same day and may need a place to sleep. And how would one find a place to sleep? And they told us that there is free place, and on the issue of food and beddings they told us to prepare on our own but the place is going to be there. And we also ask if we are going to pay money for the treatment and they said it is free. [Caregiver who went to QECH, 104]

This quote also demonstrates the importance of being able to ask questions to counsellors in a comfortable environment.

SHARING BOOKLET WITH SOCIAL NETWORKS

As hypothesised, caregivers reported that they discussed the referral with family members and neighbours once they reached their homes. Part of the intention with creating a booklet, was so that something tangible could be taken home to share with caregivers who did not attend QECH (see Table 2). Most caregivers (97%) reported that they shared the booklet with a relative, and reported that it was useful in making the decision to go to Queens. Decisions to seek care in Malawi appear to be typically made through family or community discussions. Through these discussions, caregivers reported that they were encouraged to attend by others who saw the referral as important:

I: You discussed with your in law about the child?

P: Yes, and [she] is the one who encouraged me very much to say as it is this is very helpful, don't just leave it, you need to do something and go there with the child [Caregiver who went to QECH, 106]

In some situations, despite encouragement from family or friends, some caregivers still found it difficult to attend. The following quote demonstrates this:

I: After explaining to the parents that you have been told to go with the child to QECH, how did they receive the news? What did they say?

P: They were happy and said that they will go with her [Caregiver who did not attend, 310]

Two caregivers explained that sharing this booklet with family members, helped provide knowledge and reassurance for them to attend:

They took it and look[ed] at it and said that it was good that the booklet has provided directions and it will be easy to travel since it was showing where we were going and doctors who will receive us. [Caregiver who attended QECH, 105]

On the booklet, their views [the family at home] were that this is a good example, and they felt that this was the good time maybe God was answering in that way. And that we should source money so that the child should go. [Caregiver who did not attend QECH, 308]

The counselling received in the camps and the booklet appeared to play an important role in enabling conversations within households and the community the about how they could borrow money to attend. The third component of the booklet focussed on action planning, which involved a conversation about the amount of money required to attend QECH. One person describes how this section played an influencing role in communication with their neighbours about the amount required to take up the referral:

I was refusing since I didn't have money for transport; if am not able to find soap in my house, and salt too; and to find 10 thousand kwacha for transport for two people I wouldn't make it. And that's when another woman [neighbour] said "can you bring your booklet, and let me look at it". And they read the letter and they told me that no matter what I should do what I can and find money for transport and go with the child. [Caregiver who attended QECH, 104]

This demonstrates the importance the booklet and counselling played in motivating caregivers and their support networks to attend Queens and get treatment for their child.

SUGGESTIONS FOR IMPROVEMENT

Caregivers were happy with the content of the booklet in general. Stakeholders also expressed similar sentiments, however some thought that some components could be improved. One felt that the booklet should be tailored more specifically to the type of referral made – either surgery or hearing aids (i.e. have two separate booklets). One felt that photographs would work better than the illustrations of the Banda family. This opinion was not shared by the majority of people interviewed. In general, caregivers felt that the Banda Story was the most useful and liked part of the booklet, with very positive feedback on this section.

2. TEXT MESSAGE REMINDER COMPONENT OF THE INTERVENTION

The text message reminder was also reported to be a contributing factor to referral uptake, by some caregivers. One caregiver who attended the referral explains the benefits of the text message:

It helped us to remember that we have a trip to QECH and we shouldn't forget the dates that we agreed. [Caregiver who attended QECH, 104]

The positive, respectful, welcoming tone of the message and the number to call for questions were both considered helpful. The significance of delivering this challenging call to action in an encouraging manner was explained by the expert mother:

What was good about the messages is that [caregivers] were greeted happily and we were not forcing them. The message said they wanted to remind the parents about the trip to the hospital with the child because of their ear problem. And if you didn't understand you could call the same number to ask. [Expert mother]

Despite this reported benefit, only 19 (63%) caregivers actually received the message. This is discussed further in the next section in terms of the feasibility of this component of the intervention.

Yes, I did not receive...maybe the reason can be that the phone was off. [Caregiver who did not attend QECH, 110]

Overall, the text message was most acceptable when received by caregivers who were ready to attend the referral. For those who were not yet ready, continued support, in the form of reminders, helped keep caregivers focused on their goal.

3. RESIDUAL BARRIERS

Although there were largely positive reflections on the intervention from caregivers, some were still unable to attend, suggesting that residual barriers exist which were not addressed by this intervention.

COSTS OF SEEKING CARE

Accessing specialist healthcare in the city incurs significant extra costs. Undertaking the long journey to, and from, the hospital in Blantyre requires substantial funds for transport and food, and obtaining these funds is challenging in the context of an economy based on subsistence farming. None of the caregivers were able to afford transport to Queens on their own so the cost of transport had to be shouldered communally. Those who managed to attend the referral were able to borrow money from family or friends, which enabled them to make the journey to Queens. The booklet and counselling played important roles in initiating conversations with networks about money, and motivating caregivers to take up referral. One caregiver describes how this was possible with contribution from several family members:

My grandmother and my younger sister are the ones who contributed [the money for transport]. And the other part I had myself and when we combined we were able to start our journey. [Caregiver who attended QECH, 105]

In contrast, all caregivers who did not attend reported difficulties with finding funding for transport and were unable to borrow from family or members of the wider community. This was the main reason they did not attend despite suggesting they were otherwise motivated to attend after receiving the intervention. The following quotes demonstrate two caregivers' attempts at obtaining the funds after the camps. Despite being unsuccessful, these stories highlight the caregiver's motivation to attend:

From the groups where they pledged to lend me from my village, they said that if I don't pay back in time, then they will come and remove my house iron sheet from one side of the home, and I saw that it was not good. I should just wait since I have seen that the pus stopped coming out [of my child's ears], and I should first of all wait. When I harvest my crops, selling them I will find transport and go to QECH. [Caregiver who did not attend QECH, 108]

I received the news [...] and [thought] that I can go to QECH since I was thinking that I will [contact] people in Johannesburg to send me money but when I called them to tell them that there is this problem, they told me that they didn't receive pay and it was difficult, now I am worried because I am not working. [Caregiver who did not attend QECH, 308]

For those who did take the journey, the majority (56%) travelled 3-4 hours to get to Queens, however 25% travelled >5 hours. The time of the return journey was between 1-8 hours with equal proportions travelling 3-4 hours (38%) and >5 hours (38%). The majority of caregivers who attended did not report difficulties with the journey (75%). In terms of the costs – 44% (n=7) spent between 2000-3999 Malawian Kwacha (MK) (approx. £2-4) on travel to and from QECH, 44% (n=7) spent between 4000-5999 MK (approx. £4-6), and the remaining 4 spent over 6000 MK (approx. £6). Affordability of transportation was a major factor influencing referral uptake, aligning with findings from the formative research on reason for low referral uptake.

COMPETING PRIORITIES

In some situations, family emergencies arose which required the caregivers to spend their money on other things. One caregiver explains that because the child's grandmother was sick, they had no money left to go to QECH:

There is no problem. Whatever happened here, everyone home accepted it and there was nothing to make us fail, we were just waiting. That's when the sickness came in and when time came close, we lost the money for transport.[Caregiver who did not attend QECH, 101]

UNFAMILIARITY

A small minority of caregivers had been to Blantyre, and even to QECH, and the journey was perceived to be so long and expensive. Lack of experience travelling to QECH reflected a broader inexperience and unfamiliarity with the culture of hospitals and biomedicine, which raised some concerns despite the intervention's attempts to overcome the fear of hospital raised in the formative stages of the research. Fears ranged from the consequences of a being on a tight budget, such as being caught in Blantyre longer than expected without accommodation or money for food, to fears that the child's ear would be cut off in surgery.

11.6.4. FEASIBILITY OF THE INTERVENTION

TIME TAKEN

In terms of feasibility, the main drawback of personal counselling was that it was time consuming and extended the duration of the outreach camps. Counsellors reported that a few people complained about waiting, although none of the caregivers mentioned it in the interviews. One of the counsellors claimed that at least one caregiver had left the camp after a long wait because she was fed up with waiting for counselling. To reduce waiting times in the future, counsellors suggested training more counsellors for outreach camps or counselling should be given as a group. The clinicians reported finishing their work prior to the counsellors and having to wait before returning to QECH. The stakeholders describe the issue of timing:

Problems cannot fail to be there [...], but the kind of problems were not big. But, time was an issue because we were counselling one person at a time, everyone on their own, the parent and their child, the parent and their child. There was enough time, people got tired they waited and got tired.[Stakeholder who delivered counselling]

Mmmh, I feel maybe the counselling, maybe because it was their first time to do the counselling, I think maybe they are taking too much time. Because looking at the time that we spent at the [health centre] where we had almost twelve clients, we spent a lot of time. So it could be maybe because it was a new thing to the counsellors as well. But maybe with time they will improve. At the same time [you do not want to] compromise the quality and content of the counselling.[Stakeholder involved in the camp]

LITERACY

One uncertainty about the booklet prior to the feasibility study was the level of literacy amongst caregivers. A small number of stakeholders interviewed also expressed concerns that literacy might be an issue for some people to understand the benefits of the booklet. However, only a small number of caregivers reported that they could not read the booklet on their own due to problems with vision or literacy, those that reported this asked for assistance to read the booklet from relatives. This again demonstrated that the booklet was shared at home as intended. Text-based information and education were perceived as helpful; most of the sample (83%) were literate and those who could not read tended to ask for help and receive it. A counsellor explained:

The good thing is that there are people who can read and others who cannot. Nowadays those who cannot read are few and if there is someone who can't read, they always ask what is written. That means someone will read for them and they can keep the message that they have been told. [Expert mother]

SCALE UP

Stakeholders involved in the intervention delivery greatly appreciated the counselling and booklet and wanted to develop the intervention further. They suggested incorporating the booklet and counselling into local health centres to increase familiarity with QECH more broadly within Thyolo communities. For instance, a counsellor emphasised the value of the booklet in educating the community, beyond those who attend camps:

More HSAs should be trained so that this message can reach the villages. If the people get the message in their homes and villages, maybe they can do something about it. Most people do not know that an ear problem is a problem [that can be treated]. They just keep the children at home. But if they receive the message from us, some people would go on their own to QECH because the booklet has a map. It explains the directions very well. And it also explains the money – how much you will spend - so the person can understand, even be enlightened, about money. One can decide on their own that “this child of mine, I should do this to take her to the hospital, I should not wait for the camp”. [Counsellor]

Stakeholders also felt that this intervention could be used for adults as well as children who are referred to QECH as adults too make up a large proportion of those who attend outreach camps.

MOBILE PHONE COVERAGE AND NETWORK

In terms of the text message, 19 caregivers (63%) of those who attended the camps received the text message. 13% did not receive because they did not have a phone, and 23% had a phone but did not receive the text message. Of those who received the message, all reported that they or a family member could read the message and found that the message was easy to understand. Stakeholders felt that implementation of this component of the intervention would be difficult if it was rolled out on a wider scale due to power supply, network issues, and mobile phone coverage. One stakeholder explains:

Maybe the phone can be off and because of electricity problems. And maybe they didn’t charge it, and for them to notice that a message came in the phone, it will be past 3 days or 1 week without charging it waiting for electricity. And it can be found that the message didn’t deliver because it was off. [Stakeholder involved in camps]

Several caregivers suggested that the radio might be a better medium of communication:

The message was great, but it was something coming direct on the phone. And if the phone was not on due to electricity problems we having nowadays, that mean someone might not see it. That is why I said, some of the messages should go through the radio, you can put names of the people according to the program of going to QECH. To get them prepare for the trip, there are a lot of people who listen to the radio and since they buy batteries. [Caregiver who attended QECH, 104]

11.6.5. COSTS OF INTERVENTION

Table 4 shows a breakdown of the costs of developing and delivering the intervention. The cost per person for the whole intervention package including the development costs was £110. Considering the delivery costs only (i.e. removing the capital costs), the cost per camp was £3.70. If the text messages are excluded, the cost per camp was £3.30.

Table 4: Cost of intervention

Item	Cost Malawian Kwacha	Cost GBP (using exchange rate from November 2017)
Development costs (capital)		
Developer costs	3,152,000	3000
Costs of photographs (photographer, transport, food)	115,000	110
Focus group discussions and interviews with stakeholders	45,000	43
Training cost (transport reimbursement, lunch)	27,000	26
<i>Subtotal</i>	3,455,000	3179
Delivery costs		
Printing booklet	30,000	29
Salary and transport for intervention delivery (HSA and expert mother)	75,000	71
Cost of text message reminders and follow-up calls (24 caregivers who had phones)	11,000	11
<i>Subtotal</i>	116,000	111
Grand total	3,339,000	3290
Cost per person for delivery + development	246,786	110
Cost per person for delivery	8,286	3.70
Cost per camp for delivery of booklet + counselling (not text messages)	7500	3.30

DISCUSSION

REVIEW OF FINDINGS

This report describes the process of designing an intervention to address poor uptake of referral to specialist ear and hearing services in Thyolo district Malawi. We used the MRC framework and BCD approach to tackle this issue. The steps we took included Assess, Build, Create, Deliver, and Evaluate (ABCDE). Evidence suggested that referral uptake was very low following outreach camps in Thyolo (assess stage). Formative research was carried out to understand the barriers to referral for caregivers (build stage). A ToC workshop with key stakeholders, including members of the target population, was held to clarify long-term goals, and possible pathways to reach these goals through a range of intervention options (build stage). With further consideration from the literature and expert consultation, the final agreed intervention was: an information booklet delivered with counselling by a trained “expert mother” and HSA, alongside text message reminders about the referral (Box 1). A creative process was taken to develop the information booklet, working with a London based creative agency (create stage). Following this, the intervention was delivered in three outreach camps in Thyolo district (deliver stage). The intervention was evaluated in a feasibility and acceptability study (evaluate stage).

Overall, 16 out of 30 children attended QECH (53% uptake). This is much higher than uptake following the KIM ear and hearing study carried out in 2015 in which only 5% children examined at outreach camp attended their referral to queens. This is an encouraging finding. However, further evidence is required to understand the effectiveness of the intervention.

In terms of acceptability, the counselling enabled a **two-way conversation** about the referral between health workers and caregivers, and helped to **dispel misconceptions and fear**. The booklet provided **motivation to attend**, particularly through the illustrated storyline, and instructions on how to attend. It also allowed information about the referral to be **shared with social networks**, initiating conversations about raising funds about attending. Overall, the interviews highlighted the importance of education about the referral, and the ability to discuss it with counsellors and ask questions, particularly a counsellor who had been through this process before (expert mother). By **increasing the acceptability of referral**, this study suggests that individual counselling by an expert mother and HSA was an important factor in motivating caregivers to take up the referral. Since primary caregivers could not afford to take up the referral on their own, they had to be able to mobilise support from the other caregivers and paid workers in the child’s family or close social network. All caregivers became encouraged and took responsibility to try to mobilise social support, showing their motivation to seek care. Sharing the booklet helped to **initiate conversations** about borrowing money to attend. However, despite this motivation, **costs of transport** to the hospital, and **competing priorities** remained **prohibitive** for some families. Some caregivers expressed **uncertainty** about attending Queens, despite efforts to dispel these. The counselling was feasible to deliver within camps, however there were some concerns from implementers on the **time taken** to discuss the referral in individual counselling, and **literacy** of caregivers. Stakeholders also provided positive feedback about the counselling and booklet intervention, however noted that the counselling added time to the outreach camps. To overcome this, they suggested training more counsellors to be involved in future outreach camps. The feasibility of this needs to be investigated.

The text message reminder was also found to be a **valued prompt** for caregivers. However, despite fairly high phone coverage amongst caregivers (93%), only 63% of caregivers actually received the message. Problems with **network** and **electricity** were the thought to be the reason for this. This suggests the use of text messages may be challenging, and further investigation in to alternative reminder mechanism is warranted. For instance, through engagement with community health workers (HSAs) working in the communities where outreach is held to remind families following the camps.

In terms of the costs of the intervention, the delivery per person was very low at £3.70 per person. Including the development costs this increases to £110 per person, however these development costs are one off and further implementation will not require substantial costly changes.

OVERCOMING BARRIERS

In the formative research, the following barriers were identified [16]:

- Location of the hospital
- Lack of and cost of transport
- Other indirect costs of seeking care
- Fear and uncertainty about the referral hospital
- Procedural problems within the camps leading to lack of understanding about the referral
- Awareness and understanding of hearing loss
- Lack of visibility and availability of services

When comparing the results of the formative research and feasibility study, the vast majority of caregivers in the feasibility study did not express fear or uncertainty about attending QECH. Further, there did not appear to be any procedural problems within the camps even amongst those who did not attend; caregivers were certain that they had been referred and knew when to attend. Caregivers also showed understanding of the referral process (i.e. when and where to go, why they were being referred), and showed greater understanding about their child's condition than caregivers in the KIM Hearing study. Overall, the findings suggest the intervention may have **helped to overcome some of the key barriers** that were identified in the formative research.

Affordability of transport (or ability to find funding) is essential to take up the referral and was the key barrier reported for those who did not go. For some people, the booklet and counselling helped caregivers initiate and engage in conversations with family members and other members of the community about borrowing money to attend. Through this support system, those who attended were able to overcome the financial barrier to uptake. However, other caregivers were not able to borrow money, or had other emergency financial commitments that took priority over attending QECH.

The determinants of access described by Peters et al. (2008) are: financial accessibility (affordability), acceptability, availability, geographic accessibility (Figure 12).[25] Acceptability refers to the i) user's knowledge, attitudes and expectations about the service and the ii) characteristics of the health services. Affordability refers to the costs and price of services and the user's resources and willingness to pay. Geographic accessibility refers to the location of the service in comparison to the user. Finally, availability refers to whether health workers are available, and the overall demand for services.

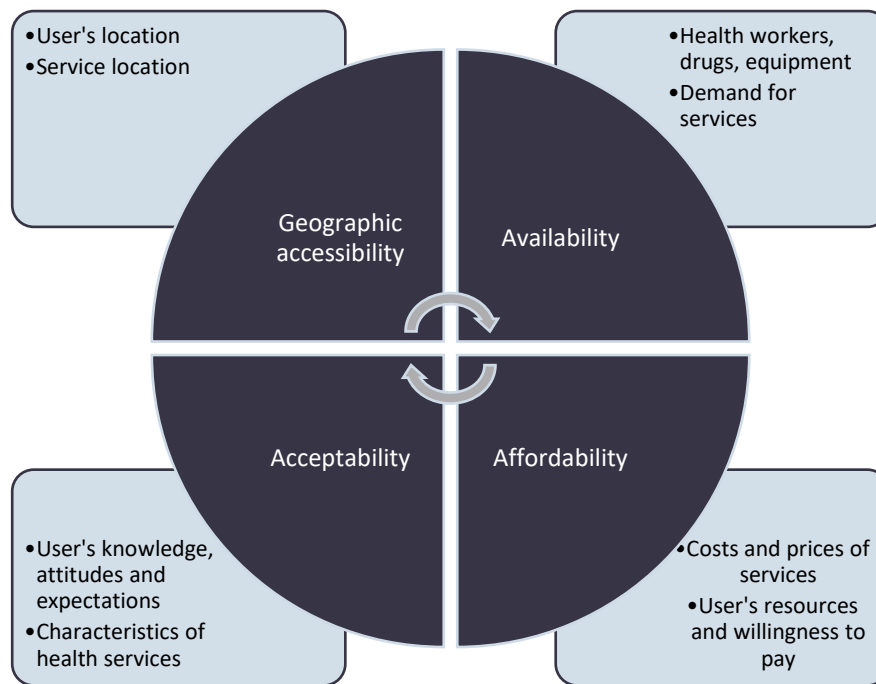


Figure 11: Dimensions of access (adapted from Peters et al. 2008)[25]

In the build stage of the research, stakeholders prioritised addressing: fear and uncertainty about the referral hospital, lack of information about the referral, and awareness and understanding of hearing loss. As a result of this, our intervention relates to the acceptability components of access, without addressing the availability of services, geographical accessibility, and affordability. Although caregivers showed motivation to attend, and the counselling and booklet helped to overcome some of the barriers, without transportation funds caregivers will continue to find it difficult to take up the referral. Our research has highlighted **the importance of overcoming the multitude of barriers to access**, across the four dimensions shown in Figure 11. Addressing availability of services and geographic accessibility requires greater resources to address the paucity of services in rural areas. This is vital in the medium to long term. In recent years, the number of ear and hearing health care professionals in Malawi has increased, particularly with the introduction of mid-cadre health workers such as ENT clinical officers, however the current number is still inadequate to meet the population need.[8] Outreach camps are intended to overcome barriers geographic accessibility, by bringing services closer to rural communities. The majority of camp attendees present with relatively minor conditions that can be treated within the camps, such as wax impaction. However, in the three camps we attended 27%, 35%, and 16% of people were referred (including adults). Those that are referred are those with more serious conditions that cannot be treated in the community. The potential benefit of attending QECH of these people is significant. Thus, it is important to increase efforts to ensure those referred attend. To address affordability of transportation, investigation into the **feasibility of transport provision or reimbursement is warranted**. Although it was deemed to be an unsustainable option amongst stakeholders in the ToC workshop, it could be considered as an option in the short-term. There is a lack of evidence of the effectiveness of this type of strategy, and thus further research is needed into locally appropriate options (e.g. reimbursement, community transportation).

LIMITATIONS

This study has some limitations that need to be taken in to account when interpreting the results. The small sample size in this study means that we are unable to assess effectiveness of the intervention. To assess effectiveness a larger scale cluster randomised control trial is needed. This stage of the research has allowed

us to understand whether the intervention is acceptable amongst the target population, and which components need to be adapted before a full trial is carried out.

Two of the outreach camps where the intervention was delivered were relatively small. This may have influenced the way that the intervention was delivered. In smaller camps, with fewer people referred, counsellors were able to counsel each family in a similar amount of time (approx. 15 minutes). In larger camps, this might not be possible due to increased work pressure. Despite this, the third camp had over 100 attendees, and counselling time did not change dramatically.

Between the KIM Hearing camp in 2015, and the evaluation camps in 2017 several outreach camps have been held. The uptake of referral from these camps is not known, however clinicians involved in the camps understand it is typically very low. We do know that 53% uptake found in this study is much greater than the 5% found in the KIM study. Once again, a controlled trial would need to be undertaken to understand the true effect of the intervention.

RECOMMENDATIONS

Addressing poor uptake of referral is crucial, especially if outreach camps continue and a significant proportion of those who are seen will be referred. Compared to previous research, which showed that 5% attended, more than half of caregivers and their children attended after receiving the intervention, which suggests that it may help to improve uptake.

Based on the findings of this research, the following recommendations are made:

- In future outreach camps, **include patient education using the illustrated booklet**, and counselling by an HSA and expert mother to assist in overcoming uncertainty about the referral and fear of the hospital
- **Consider approaches to facilitate transport to hospital** or expanding delivery of ear and hearing services in rural areas to address the transport barrier
- Given logistical challenges with text messages (e.g. power, network, and phone ownership). **alternative approaches such as text messages to HSAs should be explored** in future studies.
- Conduct a larger-scale controlled **trial of the intervention to understand the effectiveness** of the intervention
- Routinely assess patient follow-up following outreach camps to **monitor referral uptake** and follow up with patients who do not attend through increased communication between primary, secondary, and tertiary ear and hearing services.

CONCLUSIONS

This research study describes the process of designing an intervention to improve uptake of referral for ear and hearing services for children in Thyolo, Malawi. It also provides the results of a feasibility and acceptability study. The final multi-component intervention aimed to address barriers to uptake that were identified through formative research. An illustrated booklet was developed, which was delivered by a trained community health worker and expert mother, and a text message reminder was sent following the referral. Out of 30 children referred to QECH for specialist services in this study, over half took up the referral. The counselling and illustrated booklet were acceptable among both caregivers and stakeholders. These components of the intervention appeared to help families understand the referral process, and improve their confidence about attending. Families who could not go were motivated to attend, however were unable to fund the journey to the hospital. However, transportation availability and costs is still a major barrier that needs to be addressed. The text message reminder was also found to be a valued prompt for caregivers. Challenges to feasibility included low network and phone coverage, time needed to implement the

intervention and the residual financial barriers for some families. As regular ear and hearing outreach camps are held in Malawi, future camps should consider including the counselling and booklet as part of regular camp activities, however they must also consider whether transport could be provided to assist families without adequate means.

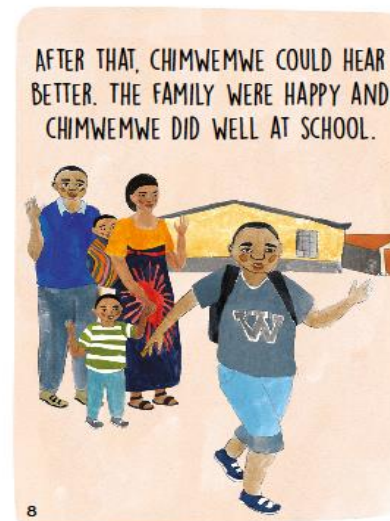
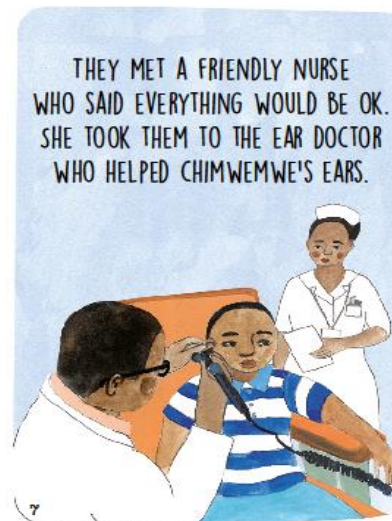
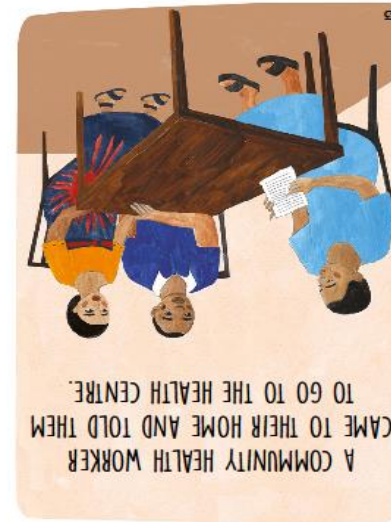
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12. APPENDICES

APPENDIX 1: FINAL ENGLISH VERSION OF THE BOOKLET



HOW TO GET THERE



1 Bus stop for Queens - get off when you see the blue flyover. Then walk and ask for Queens.

2 QECH main gate - walk straight along main road. Image above is the Main reception, where you can ask for directions.

3 Junction 1 - when you walk up to the first junction, take the left road.

4 Junction 2 - then when you come to the second junction, take a right.



5 Eye clinic - the Qech eye clinic is approx 50 metres away from the KNT clinic. When at the eye clinic, you will be guided to the KNT.



6 John Hopkins Centre - this is what you will pass by, when you're on your way to the KNT clinic.



7 Entrance to KNT/Mercy James - turn left here when you see Mercy James Centre - it's a large building.



8 KNT Clinic - here is where you will meet the doctor who will treat your child. The Audiology Clinic is also next door.

PEOPLE YOU WILL MEET



THE NURSE

You can ask a nurse at the hospital to help you find the KNT department.



THE ENT CLINICIAN

They will be the person who will deal with your child's hearing problem.



THE HEARING SPECIALIST

They will check your child's ears and take you to the KNT doctor.

THINGS TO KNOW

TODAY YOUR CHILD WAS FOUND TO HAVE:

- ☐ A problem with their ears that might be helped with surgery.
- ☐ A problem with their hearing that might be helped with hearing aids.



YOU NEED TO GO TO QUEENS FOR FURTHER TREATMENT OR TESTS. YOU CAN GO BETWEEN MONDAY AND FRIDAY.

You will not be asked to give money at hospital but you will need to pay for transport. The counsellor will discuss with you how much money you need.

You may be asked to pay what you want for hearing aids (as much as you can afford).

WE WANT TO HELP YOU TO PLAN YOUR JOURNEY TO QUEENS SO THAT YOUR CHILD CAN ALSO GET THE HELP THEY NEED.

How are you going to get there? _____

How much money will I need? _____

Who will stay at home with the other kids when you go to Queens? _____

Who will go with you? _____

How are you going to get home? _____

How long to wait? _____

What you need to take? _____

When are you going to go? _____

DO YOU HAVE ANY QUESTIONS?

If you still have any questions here are some useful contacts:

QECH Audiology clinic: 0995471446 or 0881379864.

QECH ENT clinic: 0998683716.

Mwanaisha Phiri: 0993667583.

APPENDIX 2: TOPIC GUIDES FOR CAREGIVERS

Topic guide for caregivers

Uptake of ear and hearing service referrals for children in Malawi

Semi- structured interview guide – with Primary Caregiver (or caregiver who attended camps with child)

NB: for pilot – questions slightly different, and are **highlighted in red** – this is because we do not yet have quantitative (survey) data on these individuals. In the follow-up, the qualitative interviews will come after the survey questions, so you can build upon the answers from the questionnaire and explore these in more depth in the qualitative interviews.

[In pilot (we will introduce ourselves before quantitative in the 4 week followup): Introduction: Good morning and thank you for your time. I am _____ from am here today to as part of the research study we discussed before and which you kindly agreed to take part in. Remind parents of the full information sheet that they received about the study. Remind them of the issue of confidentiality which is fully explained in the info sheet. You can stop me at any time if something is unclear. If there us anything that you do not want to answer, then you do not need to.]

THIS TABLE IS NOT FOR QUESTIONNING PARTICIPANT – IT SHOULD BE USED IN YOUR OBSERVATIONAL NOTES – FILL BEFORE OR AFTER INTEVIEW

Subject ID	
Interview Date and Time:	
Interview Venue and Location:	
Interviewer:	
Interviewee:	
Relationship to Child:	
Gender:	<input type="checkbox"/> Male <input type="checkbox"/> Female
Child in School:	<input type="checkbox"/> YES <input type="checkbox"/> NO
Type of School:	<input type="checkbox"/> Primary <input type="checkbox"/> Lower Secondary <input type="checkbox"/> Upper Secondary <input type="checkbox"/> Special School
General Observations: (Interview location, who present, anything which might impact how the interview is conducted, e.g. other present.)	

Your child was recently referred to Queen Elizabeth Central Hospital after being screened at [Zoa/Thekarani/Thyolo DH] health centre for ear and hearing concerns.

- Can you tell me a little bit about your family – who lives in the household? Who works?
- Can you tell me a little bit about your son/daughter/the child who has had their hearing screened? Age? School attendance?
- Can you tell me about his/her hearing (or ear condition)? When did it start?
- Have you ever sought care for the problem before?
- Was this the first time that you got a referral to go to Queens for your child's hearing/ear problem?

Screening and referral

- **In pilot: Do you remember the recent camp held at the health centre/DH?**
- Can you explain to me what happened there?
- What were your expectations about the camp? Were you expecting to be referred to Queens? If not, what did you expect?
- What did you understand about what the doctors told you before you received the counseling? Note: if identified difficulties, pick up on these
- Were you told a day to go to Queens? Did this help to make the decision?
- If went to Queens (based on quantitative interview) –
 - When did you go to Queens?
 - How did you get there? (Describe the journey, cost)
 - Can you explain what happened when you got there?
 - How did you find the department?
 - How long did you wait?
 - What did the doctors say?
 - What was the treatment?
 - Who made the decision to go to Queens? Did you discuss this with anyone? Who? What did other people in the household think?
 - **What things helped you in taking up that referral?** (prompt: was it the booklet? Was it the text messages? Anything else?)
- If did not go to Queens
 - You mentioned that the reason you did not go to Queens was **XXXX** – can you explain a little more about this?
 - E.g. if transport was an issue – what was it about transport exactly? Cost? Time? Availability of transport?
 - How did you feel when you were told to go to Queens?
 - How did other family members feel about the referral? Did this play a role in making the decision about whether or not to go to Queens?
 - Have you been to Queens before for any reason?
 - If so, what for? What was it like when you went there?
 - If not, what did you think when you were told to go there for your child?
 - Were there any other challenges stopped that you (and your family) attending the referral at Queens that you have not yet mentioned? (probe further to get a good understanding based on the responses)
 - Note: If there are a number of reasons: You mentioned several challenges in attending Queens, what would you say is the main challenge for you?
 - Is there anything that would help you go?

Now I am going to ask you a few questions about the counseling you received in the camps and the booklet you received:

- **[In pilot: show booklet – do you remember being given one of these? Can you show me?]**
- How did you feel about the time spent with the counselors? Did you feel comfortable? If not, why not?
- What do you remember about the conversation with the counselors?

- Can you share your thoughts about the booklet? What did you like about it?
- Was there anything you disliked about the booklet?
- Is there anything that could be improved about the booklet? (prompt: talk about each section of the booklet – get feedback)
- Were you able to read the booklet? If not, did the pictures help? Did somebody help you read it at home?
- Following the counseling session, were the counselors able to answer any questions that you had? Was this helpful? In what way? Why not? What questions did you ask? Was there anything that you wanted to ask, but didn't?
- Did you know that one of the counselors had a child with hearing loss and was using a hearing aid? If yes, was this helpful to talk to her? How was it useful? If not, why was it not useful?
- What did you like/dislike about having an HSA to talk to in the camps?
- Is there anyone else you would have preferred to speak to (other than HSA/mother)?
- How do you think the counseling be improved?
- After the counseling did you still feel uncertain about the referral?
- When you went to Queens, did you use the map that is in the booklet to help you find Queens?
- If they reported sharing the booklet with others (in quantitative): What did other family members think when you shared it? [In pilot: did you show the booklet with anyone when you got home from the camps? If so who? If not why not?]
- Is counseling required? Or is giving the booklet enough?
- Would you recommend this counseling service to others who were told their child needed hearing care? Why/why not?

We also sent text message reminders to people referred, reminding them about the appointment

Text message received

- You mentioned that you received the text message reminder - was this helpful?
 - If so, why was it helpful?
 - If not, why was it not helpful?
 - Could you read the text message?

[In pilot: did you receive a text message reminder about going to Queens? was this helpful? If so, why was it helpful? If not, why was it not helpful?]
- What did you do after you got the message?
- Is there anything that could be improved about the text message reminders? (prompts: enough information, too much information, too long, difficult to understand)?
- Was the text message helpful in making your decision to go to Queens?

Text message not received

- You mentioned that you did not receive the text message reminder – do you have a phone? Or could there be another reason that you did not receive it? [in pilot: If texts not received was this because you do not have a phone or is there another reason that it might not have been received?]

Both

- We sent one text message reminder? Do you think this is enough? If not, how often would you like to receive text messages?
- What time of day is best for receiving text messages?

Can you make any other suggestions about what would be helpful for you to attend Queens? Anything else you would like to add?

Thank you for your time. We will be providing feedback once we've had time to look at all the information from the parents and clinicians.

APPENDIX 3: TOPIC GUIDES FOR STAKEHOLDERS

Uptake of ear and hearing service referrals for children in Malawi

Semi- structured interview guide – with Implementers

TABLE: TO WRITE THE FOLLOWING DETAILS IN YOUR OBSERVATION NOTEBOOK BEFORE OR AFTER THE INTERVIEW
– NOT QUESTIONS FOR THE RESPONDENT

Subject ID	
Interview Date and Time:	
Interview Venue and Location:	
Interviewer:	
Interviewee:	
Role in intervention delivery:	
Gender:	<input type="checkbox"/> Male <input type="checkbox"/> Female
General Observations: (Interview location, who present, anything which might impact how the interview is conducted, e.g. other present.)	

Good morning and thank you for your time. I am _____ from I am here today to as part of the research study we discussed before and which you kindly agreed to take part in. Remind participants of the full information sheet that they received about the study. Remind them of the issue of confidentiality which is fully explained in the info sheet.

You can stop me at any time if something is unclear. If there is anything that you do not want to answer, then you do not need to.

Icebreaker questions:

- Introduce yourself (role, how long have been working at queens, other experience)
- How were you involved in the recent outreach camps?
- Have you been involved in camps previously?
- In comparison to other camps, were the camps held with counseling similar in size? If not, why do you think that might be?

Now I want to ask you about the booklet with HSA/expert mother counseling that was provided in the recent camps in Zoa and Thekarani:

- Firstly, what do you think worked well about the counseling with the information booklet? What was useful?
- Was there anything that did not work well?
- How can the counseling with the booklet be improved? (probe: what do you think of the story, what about the map, what about the action plan)
- How realistic do you think this could be in future camp settings? Do you think it is a sustainable option?
- Is there any other method of delivery that would work well or better than the one we have tried - we tried one to one counseling, could it also work as group counseling?
- What do you think about the location of counseling - is a camp setting the most appropriate? Is there another way it could work?

- How useful do you think it is in helping caregivers make the decision to go to queens? What other things do you think will be important in decision-making? (probe here)
- Do you think that this type of intervention could also be used for adults who also need to go to queens? Or would a different approach be more suitable? If so, what do you suggest?
- For clinicians (including nurse) only: how did you find the logistics of the additional station? Did you change anything about your usual outreach practice to accommodate the counseling?
- For counselors only:
 - Do you think the counseling and booklet were accepted by parents? Why/why not?
 - Did you face any challenges with implementations? (prompts: time, enough information/knowledge about referral processes)
 - What type of questions did parents ask you in the camps?
 - Do you feel that children were also engaged in the counseling? If not, why not? Do you think this is important?
 - Can you describe how counseling varied from one patient to the next? (prompts: did some people need more time, explanation than others?)
 - Anything that could be improved about the training? Did you feel that the training prepared you well for the intervention delivery? If not, why not?
- For expert mother only: did you find that people were interested in your experience as a person who has gone through this process before? What type of unique questions did you get? Do you think parents found this useful? Is there anything you would like to change about the counseling delivery?
- Thank you for your thoughts about the booklet and counselling – is there anything else you would like to comment on before we talk about the text messages?

Now I would like to ask a few questions about the text message reminders. We sent the following message (show them), two days before the appointment. And if they do not come we will send another reminder 2 weeks after the camps

- What do you think would work well about the text message reminders?
- Do you expect that there would be anything that won't work well?
- How can this be improved?
 - prompts:
 - challenges
 - usefulness
 - acceptability amongst caregivers
 - literacy
 - sustainability
- What do you think about the timing of the text messages? Should they be sent more or less regularly? How many text message reminders should they receive
- Do you have any other comments about the text messages?

Further comments

- Do you have any other suggestions, for how uptake of referral could be improved?
- Are there any other issues which I haven't covered which you would like to comment on that will be useful for us to address in relation to uptake of ear and hearing services for children?

Thank you for your time. We will be providing feedback once the document is ready.

Developing an intervention to improve uptake of referral for ear and hearing services for children in Malawi

1. Stakeholders

Project stakeholders are: Ear Nose and Throat Department (Queen Elizabeth Central Hospital), Audiology Department (Queen Elizabeth Central Hospital) College of Medicine Malawi. Research, intervention design and pilot testing is led by International Centre for Evidence in Disability (London School of Hygiene & Tropical Medicine)

2. What is the problem?

An estimated 32 million children are living with a disabling hearing loss and the vast majority live in low and middle-income countries (LMICs). The impact of childhood hearing loss is well established. Hearing loss can affect speech and language development, social and cognitive development, and school performance. Poor educational attainment can lead to limited employment opportunities later in life. Many children with hearing impairment experience reduced functioning unnecessarily because of lack of uptake of treatment (e.g. surgery) or rehabilitation (e.g. provision of hearing aids). In many LMIC, there is a severe shortage of quality ear and hearing services, Even when services are available, there is evidence that utilisation remains low.

Malawi is a low-income country in Southern Africa with a population of approximately 17.2 million people. As of 2017, there were two Ear Nose and Throat surgeons (ENT) and three audiologists to serve this population. To date, no population-based surveys of hearing impairment in Malawi have been conducted. In sub-Saharan Africa, the prevalence of hearing impairment has been estimated at 1.9% for children aged 5-14 years.

In a recent study we conducted using the Key Informant Method (KIM)¹, children with hearing impairment in Thyolo district Malawi were identified by community health workers. Approximately 150 children were examined by an ENT and referred to the Government hospital in Blantyre (Queen Elizabeth Central Hospital or Queens) for treatment or further assessment. However, fewer than 5% of these children attended their referral. Qualitative interviews with caregivers who did not attend showed that the most common barriers to uptake of ear and hearing services were: i) poor understanding or insufficient information regarding the child's condition or the referral process; ii) fear of the hospital and iii) transportation difficulties. These barriers are potentially amenable to intervention.

3. Stakeholder consultation

Following the study to understand the barriers to uptake, we held a focus group discussion and a Theory of Change (ToC) workshop with key stakeholders (June 2017). The focus group discussion was held in Thyolo with four caregivers who took part in the qualitative interviews. We provided

¹The Key Informant Method uses trained community members (usually community health workers, teachers) to identify and list children with disabilities (including hearing impairment) living in their communities. Screening camps are then held to confirm diagnoses and refer individuals for further treatment.

feedback about the main barriers identified in the research and tried to understand from caregivers what could be done to help them attend. In addition, a participatory ToC workshop was held in Blantyre. The workshop was held with key local stakeholders including caregivers of children with hearing impairment, Disabled Persons Organisations, Community Based Rehabilitation workers, community leaders, health-workers. The identified barriers to uptake of referrals were presented, and were used as a platform to discuss mechanisms/possible activities to address the barriers and the resources required to do so.

Stakeholders in the both the ToC workshop and focus group discussion prioritised education/communication interventions to address the lack of understanding about the referral process and fear about the hospital. Specific suggestions included: development of educational materials, text message reminders, follow-up of children referred by community health workers (CHW), and peer support by expert families who have previously attended Queen Elizabeth Central Hospital either in person, through a video or other means. Group transport or financial reimbursement for travel were not prioritised, as they were not seen as sustainable options. The resulting theory is provided as Appendix 1.

4. Vision for intervention

Based on the ToC, together with consideration of evidence from the literature, and further consultation with key stakeholders, we want to develop a low-cost and sustainable educational “package” to be delivered during camp/outreach settings for children identified as needing referral for ear and hearing services at Queens in Blantyre. The package will centre around counselling by a trained person (e.g. Community Health Worker or expert mother) in screening camps for children/caregivers referred, together with text message reminders sent 2 weeks after referral. We envisage that the counselling will be delivered using a photograph booklet developed with your assistance.

We want the photograph booklet to include the following components:

- 1) Information about the referral – where is the hospital, which department, number of contact (for questions), which days they can go (Monday-Friday), what time is best (morning), picture of friendly face (doctor)
- 2) Simple information about the diagnosis – what the doctors found in the camps
- 3) Plan of action for attending referral – how are they going to get there, how much will it cost, what do they need to take, when will they go, who will go, how will they get home etc
- 4) Case study/story of one or two families going through the referral process – from village (transport taken, duration of travel etc), arriving at Queens, what happened when they got there, speaking to doctor, outcome of appointment, returning home, impact of surgery/hearing aids on children’s life (e.g. school and family life). We want this story to show a successful outcome and show the benefits of attending. We would like two different stories showing one child who needs surgery and one who needs hearing aids (see further details below).

We think these components of the booklet (delivered with counselling) will play a vital role in overcoming the barriers identified in previous research (lack of information about the referral, lack

of knowledge about treatment/lack of prioritisation of hearing loss, and fear of Queens) and alongside text message reminders result in increased uptake of referral.

We plan to interview families who have been through the referral process and tell their story through the booklet. We want the photographs to be as informative as possible as literacy levels are low in Malawi. We are hoping to rely on visual information! We really value your input on how our approach could have the intended impact of increasing uptake of referral so that children receive the needed treatment.

Once a draft booklet is developed, we aim to get feedback from the target population and other stakeholders. We hope to pilot test the final intervention in screening camps in Thyolo district in early November 2017 with a small group of child-caregiver pairs who need referral (approx. 30). We hope this type of intervention could be scaled up for use at a wider scale, and for different population groups.

5. What else do you need to know?

- a. Hearing loss in children in Thyolo: The magnitude and impact of hearing loss in Thyolo is not well understood. However, we know that hearing loss in childhood can negatively impact speech and language development, educational attainment, social integration, and employment opportunities later in life. Children interviewed as part of our qualitative study were often delayed in school. Teachers in mainstream schools Thyolo have very little knowledge about education of children with hearing impairments. The only adjustment that are made are placing the child at the front of the classroom.
- b. Types of ear and hearing issues we need to educate about in booklet: In screening camps, there are two main conditions where referrals are made – Chronic Suppurative Otitis Media (CSOM) and permanent hearing loss.

CSOM involves prolonged discharge from ears and a hearing loss of varying severity – which can be reversed through treatment. If left untreated it can cause breakdown of various parts of the middle ear, with resulting permanent hearing loss and sometimes more serious life- threatening complications such as meningitis. These children are referred to Queens from the camps for possible surgery.

Permanent hearing loss involves treatment with hearing aids. A child with hearing loss identified in the camps will need further hearing tests and counselling about hearing aids at Queens.

- c. Role of fathers: Children are typically accompanied by their primary caregiver when attending camps, which is usually their mother. However, decisions to seek care (or take up referrals) are usually made within the household through discussion with fathers and other family members. Fathers are often neglected from health care interventions for children. We would like the booklet to include a positive male role model as part of the story.
- d. Thyolo District: Thyolo district where the intervention will be piloted is located in the

Southern Province of Malawi. The closest part of Thyolo is 30 kms from Blantyre; however, some villages (e.g. Gombe) are more than 50km away on rough terrain. It is a very poor predominantly rural district. The population is approx. 600,000. Like the rest of Malawi, most people in Thyolo rely on subsistence farming. Thyolo area is known for its tea plantations (Fig.1) . There is a high prevalence of HIV in the area. Fig. 2 shows a map of the area.



e.

Fig. 1 Tea plantations in Thyolo

Google maps link to Thyolo: <https://www.google.co.uk/maps/place/Thyolo,+Malawi/@-16.1274109,34.9767503,11z/data=!3m1!4m5!3m4!1s0x18d82ea4fca6da95:0xd61cc0a9ee598a44!8m2!3d-16.1299177!4d35.1268781>

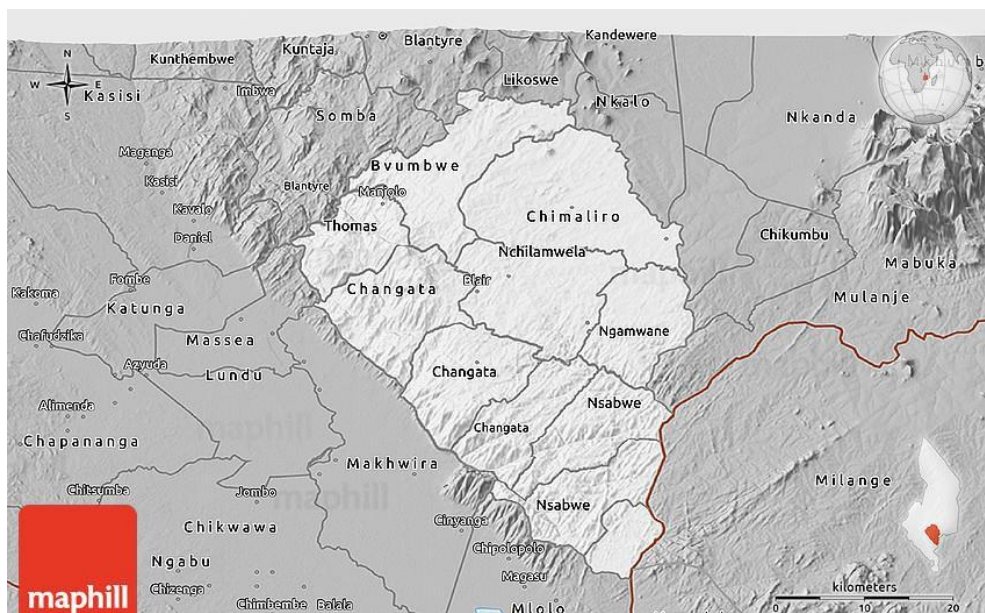


Fig. 2 Map showing Thyolo district showing topography

Thyolo district has 33 health centres, 1 district hospital, and about 450 Community Health Workers (see Fig. 3-5). 29 community health workers have been trained in identification of children with ear and hearing issues. They are involved in finding the cases to be screened in the outreach camp, alongside teachers.



Fig. 3 Typical Malawian Health Centre (image credit: GIZ)



Fig. 4 People waiting to receive treatment at Thyolo District Hospital (image credit: MSF)



Fig 5. Typical rural area of Thyolo (image credit: MSF)

- f. About Queen Elizabeth Central Hospital: Queen Elizabeth Central Hospital is one of the few hospitals in Malawi that provide ear and hearing services (Fig. 6). There is

one Ear Nose and Throat (ENT) surgeon, and three audiologists serving here. In addition, there are seven audiology and ENT clinical officers. These professionals work in the ENT department and audiology department within Queens. Patients attending Queens come from all over Malawi and often wait to be seen as there is no appointment system.



Fig. 6 People waiting at entrance to Queen Elizabeth Central Hospital (image credit: Open Arms Malawi)



Fig. 7 More recent photographs of main entrance to Queens (June 2017)



Fig. 8 ENT department at Queens (June 2017)



Fig. 9 Audiology department Queens (June 2017)

6. Agency deliverables

- Development of photograph booklet for pilot testing including
 - Development of first draft
 - Revisions based on initial feedback from LSHTM researchers
 - Revisions based on feedback from focus group discussion and ad- hoc consultations with key stakeholders
- Guidance on printing document for in-country printing

7. Timeline for booklet development

- Mid-late September: Photographs and interviews completed
- Mid-October: first draft of booklet complete for use in focus group (including translation into Chichewa)
- End-October: final draft of booklet ready for printing in Malawi

APPENDIX 5: NARRATIVE SUMMARY FOR THEORY OF CHANGE

Improving access to ear and hearing care for children in Thyolo District, Malawi

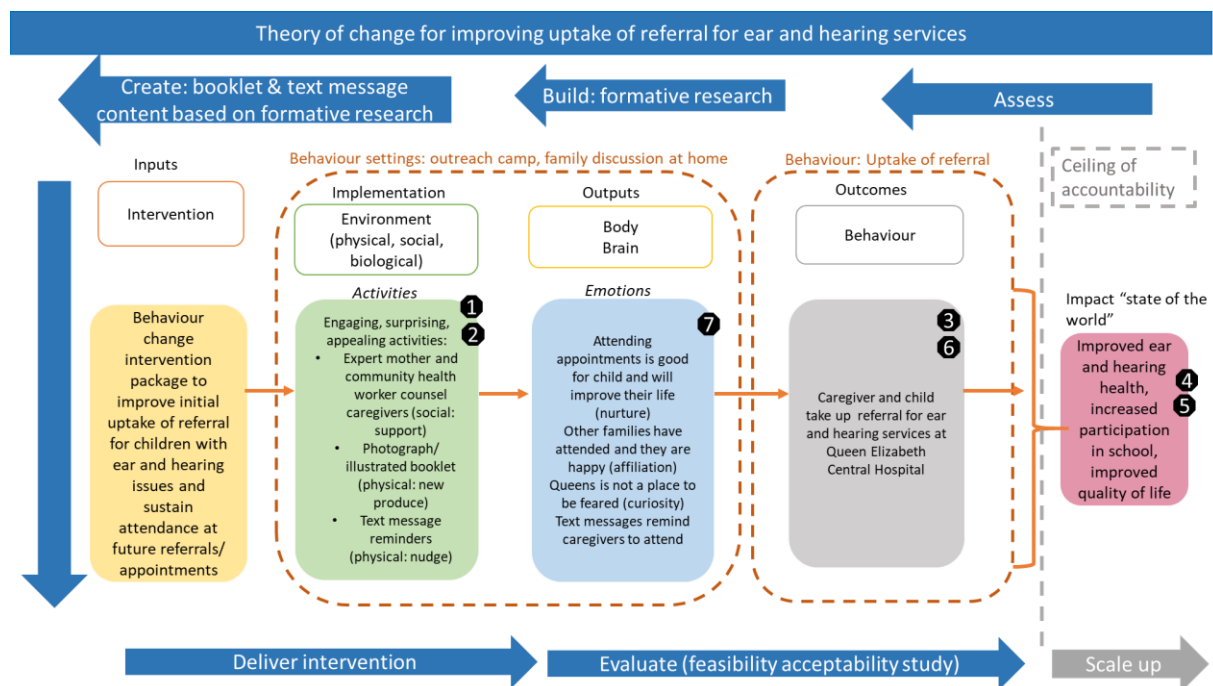
Impact “state of the world”: Ultimately, we want children with ear and hearing issues to have improved ear and hearing health, which would result in: increased participation in school, family and social life; increased educational attainment; increased productivity through greater employment opportunities later in life; and poverty alleviation through gainful employment. These improvements in participation in these aspects of life have positive impacts on the child and family’s quality of life. In addition, improved access to care ultimately leads to reduced burden of ear and hearing issues.

Behaviour (outcome): We want more caregivers and their children to take up their referral at Queen Elizabeth Central Hospital (QECH), receive treatment or rehabilitation and thus improve the child’s ear and hearing health. This improved ear and hearing health leads to improved knowledge amongst caregivers, and recognition of when to seek care, improved care seeking behaviour, and again children receive treatment and their ear health is improved (positive reinforcement).

Pathways to reaching the goal (inputs, implementation and outputs): Semi-structured interviews with caregivers revealed multiple overlapping barriers to taking up referral at QECH including: insufficient information about the referral process, fear of the referral hospital, awareness and understanding of hearing impairment, lack of and cost of transportation, and lack of availability/visibility of hearing services. Thus, there are possible several activities to reach the long-term goal. Participants at the theory of change workshop prioritised increased awareness and understanding of hearing impairment, providing sufficient information about the referral, and reducing fear of the hospital as key outcomes. The final agreed intervention was counselling by an expert mother and health surveillance assistant (HSA) delivered in the camps alongside an illustrated booklet, followed by text message reminders about the appointment. How the intervention results in behaviour change is described below:

- Firstly, healthcare workers and expert mother (experienced with seeking care at Queens for child with ear or hearing issue) within outreach or screening programmes in the community are trained to provide counselling about the diagnosis, referral process, treatment, and come up with a tailored action plan for caregivers to attend Queen Elizabeth Central Hospital. The counsellors are trained to give counselling which is tailored to the type of referral that the caregivers receive (surgery, hearing aids, other). After the training, they are able to provide the counselling in the outreach camps. The counselling targets underlying motives: nurture (desire to care for child), desire to fit in socially (affiliation), and desire to learn or find things out (curiosity). Through this, the counselling and booklet also try to familiarise caregivers with the hospital, alleviating fears expressed about attending previously. The booklet also acts as a nudge because it is available at the outreach camp, but the caregiver takes it away and discusses the referral at home with other people involved in caring for the child. This leads to behaviour change to take up the referral. This activity assumes that health care workers have adequate time to provide the information to caregivers, which was a challenge in previous camp situations.
- Text message/phone call reminders act as a nudge to attend once the caregiver arrives home. Once received and understood by caregivers, this reinforces counselling intervention and prompts further discussion about the appointment amongst caregivers. The text messages nudges caregivers to reevaluate and perform the behaviour change task (take up referral). This activity assumes that caregivers own mobile phones and are literate.

Behaviour settings: The settings where behaviour change are expected to happen for this intervention are within the outreach camp – when receiving the referral – and within the home, when making the decision with other family members about whether or not to seek care.



Assumptions

- 1 Adequate time allocated for counselling in camps available
- 2 Parents have mobile phone access
- 3 Caregivers are aware of transport services/services are available and have the funds to attend
- 4 ENT/audiologists have knowledge, skills and equipment to treat children attending the referral
- 5 Treatment and rehabilitation is effective
- 6 Parents have a good experience seeking care, and the doctors at Queens provide adequate counselling
- 7 Intervention successfully elicit desired responses