International Centre for Evidence in Disability

Uptake of health and rehabilitation referrals for children in Malawi

Findings from field research in Malawi and current literature

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A copy of the full report is available at: http://disabilitycentre.lshtm.ac.uk

About the report

This report is made up of two parts:

Part A: Uptake of health and rehabilitation referrals for children in Malawi

In this section, using quantitative and qualitative methods, we explore i) uptake and ii) barriers to uptake of referrals for children identified through two projects using the Key Informant Method (KIM). The first KIM project ('Child disability KIM') identified children with disabling vision, hearing, physical, intellectual impairments and epilepsy. The second KIM project focused on children with hearing impairments ('Hearing KIM').

Part B: *Systematic review of interventions to increase access to health services for children in low and middle income countries*

In this section, we present a systematic literature review of interventions which aim to increase access to health services for children in low and middle income countries.

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Executive summary

Introduction

For many children with disabilities, being able to access health and rehabilitation interventions is important to maximise functioning and improve quality of life.[1, 2] The lack of available quality impairment-specific health and rehabilitation services is a significant challenge in many Low and Middle Income Countries (LMICs) such as Malawi.[3] However, even when services are available, evidence suggests that uptake of referrals to these services may remain low.[4, 5] Understanding the level of uptake and the reasons for non-uptake of health and rehabilitation services is important for planning and developing appropriate interventions to improve access.

Several studies have tested different interventions aimed at increasing access to health services for children in LMIC. There is a need to identify and review these studies in order to understand the evidence for the effectiveness for different types of interventions.

The aims of this project were to:

- Explore the uptake of and barriers to health and rehabilitation referrals among children in Malawi (PART A)
- Conduct a systematic review of interventions aimed at increasing uptake of health services for children in LMICs (PART B)

Part A: Uptake of referrals amongst children in Malawi

This study explored uptake of health and rehabilitation referrals among children who were identified through two previous projects using the Key Informant Method (KIM). The KIM approach involves training Key Informants (KIs) to identify children in the community who may have a disabling impairment. Identified children are invited to attend a screening camp where they are examined by relevant health professionals and referred to health and rehabilitation services as appropriate. The two KIM studies were:

- The 'Child Disability KIM' conducted in Thyolo and Ntcheu district which included children with vision, hearing, physical, intellectual impairments and epilepsy. Approximately 3000 children were referred to health and rehabilitation services as appropriate.
- The 'Hearing KIM' conducted in Thyolo district' which identified children with hearing impairments. In total 170 children were referred to ear and hearing services at Queen Elizabeth Central Hospital (QECH) in Blantyre.

We conducted a follow up of children from both of these KIM studies to address the following research questions:

- What proportion of children attended their referral?
- Among children who did not attend, what barriers were reported?
- Child Disability KIM only: Did uptake vary according to different socio-demographic characteristics of the child and caregiver (e.g. age, sex, socio-economic status)?

Methods

Quantitative Data collection: All 170 children from the Hearing KIM and a sample of approximately 10% of children from the Child Disability KIM were followed up. Using a structured questionnaire caregivers were asked whether they had attended their referral and, if not, what were the reasons for non-uptake. In addition, for the Child Disability KIM, data were collected on socio-demographic characteristics of the child and caregiver.

Qualitative data collection: In-depth interviews were conducted with i) a sub-sample of families of children who were referred during the KIM Hearing project but did not take up the referral (23 caregivers and 10 children) and ii) 15 key local stakeholders to explore barriers to uptake of ear and hearing services.

Key findings from the quantitative research

- Uptake of referral services was low: 56% of the children identified during the Child Disability KIM and only 3% from the Child Hearing KIM attended their referral

- The most common reasons given for non-uptake of referral were:
  - transport difficulties
  - lack of information or understanding regarding the referral
  - financial constraints

- In the Child Disability KIM study uptake was:
  - lower in Ntcheu (36%) than Thyolo (74%) district
  - lower among children from the poorest households
  - higher among children whose caregivers were divorced/separated
  - higher among children with epilepsy compared to those with other impairments

Key findings from the qualitative research

The in-depth interviews highlighted seven broad factors influencing the decision not to uptake referrals at QECH: location of the hospital, lack of transport, indirect costs (e.g. for transport, food and opportunity costs), fear and uncertainty regarding of the hospital, insufficient information about the referral, awareness and understanding of the child’s hearing loss and the lack of availability and visibility of ear and hearing services. For many families reasons for non-uptake were multiple and inter-related.

Part B: Systematic review on interventions to increase access to health services for children in low and middle income countries

Methods

A systematic review was conducted in January 2016. Four electronic databases were searched for studies that measured the effect of interventions that aimed to increase access to health services for children in low and middle-income countries. A narrative approach was used to synthesise results.

Results

In total, 66 studies were included in the systematic review. The majority (52%) were conducted in sub-Saharan Africa. Most studies were randomised controlled trials (n=51; 77%) with the remaining studies employing non-randomised designs. The quality of included studies was judged as variable. Studies evaluated a diverse range of interventions and various outcomes. Supply side interventions included: delivery of services at or closer to home and service level improvements (e.g. integration of services). Demand side interventions included: educational programmes, text messages, and financial or other incentives. Interventions that delivered services at or closer to home and text messages were in general associated with a significant improvement in relevant outcomes. A consistent pattern was not noted for the remaining studies.

Conclusion and recommendations

Uptake of referrals for health and rehabilitation services among children in these two districts in Malawi was low. Transport difficulties, lack of information regarding the referral and financial constraints were the most commonly reported reasons for non-uptake. Families referred to QECH for ear and hearing services experienced a range of multiple and interacting barriers. These included long distance to hospital, lack of transport, indirect costs, insufficient information about referral process given at the screening camps, fear/uncertainty of QECH and a lack of ear and hearing resources and staff.

The systematic review fills a gap in the literature by identifying the range and effectiveness of interventions that can be used to increase health care access for children in LMIC. It highlights some intervention areas that show encouraging trends which could address barriers to referral uptake identified in the studies in Malawi. Delivery of services at or close to home could be used to address distance, transportation issues and the lack of resources through task shifting to community health workers (e.g. Health Surveillance Assistants). Text message reminders have the potential to address communication challenges, fear and unfamiliarity of the hospital. Health worker training and educational interventions may be important to address the communication challenges about the referral process and the availability of ear and hear services.

Summary of recommendations

Potential strategies to overcome the barriers identified in this study, that need to be evaluated through robust research include:

- Increase health and rehabilitation services at community and district hospital levels, for example, by
    - Increasing outreach by staff at referral hospitals to remote communities
    - Developing the capacity of community health workers such as Health Surveillance Assistants in Malawi (of which there are >10,000 in the country) to deliver basic ear and hearing care at community level and to facilitate uptake of referrals
- Providing effective communication about the child's diagnosis and referral process. Further research is needed to develop and evaluate effective communication or counselling strategies as well as explore use and impact of text message information/reminders
- Providing group transport from rural communities to referral hospitals
- Raising awareness of staff at tertiary hospitals about the ENT services available

Given that reasons for non-uptake were often multiple and interacting, a combination of these strategies may be important to improve access.

Introduction

An estimated 5% of children - 150 million globally - are living with a disability, with 80% residing in low- and middle-income countries (LMICs).[1] Evidence suggests that children with disabilities experience poorer health and quality of life, higher mortality rates, lower rates of school participation and increased risk of poverty compared to their non-disabled peers.[1, 6, 7] Appropriate treatment and rehabilitation interventions - including rehabilitation medicine (e.g. club foot surgery), provision of assistive devices (e.g. hearing aids) and therapy interventions (e.g. education, counselling) could contribute to significant improvements in these domains for many children.[1, 2] Limited availability and awareness of such services is a challenge in many low resource settings.[3] However, even when services are available and children are referred to them, there is evidence that referral uptake can be low.[4, 5]

Barriers to access

Substantial barriers to accessing health services exist for children, in general, in LMICs. These include geographic barriers (e.g. distance), lack of health care availability, financial barriers and acceptability barriers.[8] Research shows that a range of interacting factors are likely to influence decisions about seeking care for children.[5, 9, 10] For children with disabilities there may be specific additional challenges, for example, related to cultural perceptions of disability or physical barriers to access. However, there is limited empirical research exploring uptake and barriers to referrals for impairment-specific health and rehabilitation services among children with disabilities in different LMICs.[4]

This report presents findings from two studies conducted in Malawi alongside evidence from the current literature on interventions to increase access to health services for children.

The two studies in Malawi explored uptake and barriers to referrals given to children as part of two different research projects using the Key Informant Method (KIM). This approach involves training Key Informants (KIs) to identify children in the community who may have a disabling impairment. Identified children are invited to attend a screening camp where they are examined by relevant health professionals and referred to health and rehabilitation services as appropriate. The first study ('Child Disability KIM') included children with vision, hearing, physical, intellectual impairments and epilepsy. The second KIM ('Hearing KIM') focused only on hearing impairments. In this report, we have explored the uptake of and barriers to referrals made during the screening camps of both of these KIM studies.

Interventions to improve access

Understanding patterns of referral uptake and barriers to attendance in different settings, is important for informing development context appropriate strategies to facilitate children to receive the services they could benefit from. Evidence is also needed on the effectiveness of the interventions for addressing these barriers. Empirical studies of interventions to improve uptake of specialist health/rehabilitation services specifically for children with disabilities are lacking. Therefore, we have conducted a systematic review of studies that have evaluated interventions aimed at increasing uptake of health services for children in LMIC.

Definitions used in this report

Disability and impairments: The World Health Organisation (WHO) International Classification of Functioning, Disability and Health (ICF) is a biopsychosocial model of disability that incorporates health conditions and functional impairments, activity limitations and participation as well as the environment. Using this framework, the United Nations Convention on the Rights of Persons with Disabilities[11] defines disability as "long-term physical, mental, intellectual or sensory impairments which, in interaction with various barriers, may hinder [a person's] full and effective participation in society on an equal basis with others".

The two KIM studies in this report focussed on the impairment component of disability, defined by the ICF as 'a loss or abnormality in body structure or physiological function'. Specifically, these two studies measured hearing, vision, physical and intellectual impairments as well as epilepsy (an often disabling health condition). In LMICs, where access to medical treatment, rehabilitation, education and other services are limited, people with impairments are often disabled[12], however, we did not specifically measure activities, participation or environmental components of disability in these studies.

Child: We define the child according to the United Nations Convention on the Rights of the Child as a person under 18 years of age.

Health and rehabilitation services: This report focuses on uptake of referrals for services specifically related to the child's impairment rather than, more broadly, on uptake of general health services such as primary care. The children in these studies were referred to a range of different interventions which, for simplicity, we refer to as 'health and rehabilitation' services in this report. Health services might include further examination and management of the referred children by an ENT doctor at the hospital. Rehabilitation services could include medical rehabilitation (e.g. clubfoot surgery), assistive devices (e.g. hearing aids) or therapy interventions (e.g. education)

Access to health care: Access is a complex concept and has a broad range of definitions. The Peter's framework of access to health care (2008) asserts that the following four dimensions are important in accessing health[8]:

- geographic accessibility (service location, user's location)
- availability of health care (health workers, drugs, equipment; demand for services)
- financial accessibility (costs, user's resources and willingness to pay)
- acceptability user's attitudes and expectations, service location).

Part A: Uptake of referrals amongst children identified through the Key Informant Method in Malawi

Overview

Using mixed methods, we conducted follow up studies to two different KIM projects in Malawi to explore uptake and barriers to referrals:

1) Quantitative research (Child disability KIM and Hearing KIM): we followed up children referred for services and using structured questionnaires assessed uptake and key reasons for non-uptake.
2) Qualitative research (Hearing KIM only): we conducted in-depth interviews with families of children identified referred to ear/hearing services as well as key stakeholders to explore the reasons for non-uptake of ear/hearing services in more depth this setting.

Study setting: Malawi

Malawi is a low-income country in sub-Saharan Africa with a population of approximately 17 million people.[13] The majority of the population live in rural areas and depend on agriculture for income. Over half (60%) of Malawians live below the international poverty line of 1.25 USD a day.[14] Malawi has a three tier health care delivery system: primary health care (including health centres, health posts), secondary health care (district hospitals), tertiary health care (central hospitals and specialist hospitals).[15] Following international calls for universal health coverage, the government of Malawi implemented full-cost coverage for an Essential Health Package. This includes coverage of over 50 interventions that are intended to reflect the health context of the country.

About the Child Disability KIM project

This KIM project was conducted in 2013-14 in two districts: Thyolo (Southern region) and Ntcheu (Central region).[16] In each district four of the eight traditional authorities were included.

A total of 500 KIs (community health workers) were trained to identify children with vision, hearing and physical impairments, intellectual impairments or epilepsy in the community. A total of 33 screening camps were held throughout the study districts. A detailed mapping of available service providers was undertaken prior to the project (e.g. CBR programmes, ophthalmic, orthopaedic and Ear Nose Throat facilities). At the screening camps children were examined by the relevant medical professional (see appendix 1 for details) and their caregivers were provided with a diagnosis and referred to appropriate available specialist health/rehabilitation services.

Approximately 3000 children with at least one of moderate/severe vision, hearing and physical impairments, intellectual impairments or epilepsy were identified and referred for treatment or other rehabilitation services as appropriate.

About the Hearing KIM Project

This project was conducted in 2015 in Thyolo district. The Key Informants were 29 community health workers known in Malawi as Health Surveillance Assistants (HSAs) from 5 randomly selected health centres in Thyolo district. The HSAs were trained in Primary Ear and Hearing Care (PEHC) using the WHO Basic and Intermediate training modules on PEHC.[17] Following the training, HSAs were asked to identify people (adults and children) with ear conditions and/or hearing loss in their communities.

All people identified and listed by HSAs as potentially having ear and hearing disorders were invited to attend screening camps at one of the selected health centres in Thyolo. These camps were conducted with an Ear Nose and Throat (ENT) Surgeon, ENT Clinical Officers and Audiology Officers from Queen Elizabeth Central Hospital (QECH). Examinations followed the WHO ear and hearing protocol which included testing hearing (using otacousitic emissions tests for <4 years and Pure Tone Audiometry for 4+ years) and examination of the ear using otoscopy. Participants were referred to ear and hearing services at the QECH as appropriate.

A total of 170 children were referred to QECH for ear and hearing services including further investigation, surgery and hearing aids.

Aims and Objectives

Aim: To explore uptake and reasons for non-uptake of referrals to specialist health and rehabilitation services among children in Malawi

The objectives of the quantitative component were:

- To assess the proportion of children referred for health/rehabilitation services during KIM screening camps who attended their referral
- To determine key barriers to referral uptake
- To explore whether socio-demographic factors or impairment type were associated with uptake of referral (Childhood disability KIM only)

The objective of the qualitative component was

- To explore in depth the reasons for non-uptake of ear and hearing referrals for children identified through the KIM.

Quantitative research methods

Study population

The follow up study for the Child Disability KIM was conducted in July-August 2015 in the eight traditional authorities included in the original KIM study. We randomly selected villages included in the KIM survey. All children in these selected villages who had been identified as having an impairment/epilepsy and given a service referral were invited to take part. In addition, to ensure sufficient numbers of children with vision impairment (the rarest impairment type) were included, any children with vision impairment (identified through the KIM project) who lived near the randomly selected villages were also included where possible. In total 200 children in each district were invited to take part.

The follow up for the Hearing KIM project was conducted in June 2016 and included all 170 children referred to ear and hearing services at QECH in the screening camps.

Data Collection

The primary caregivers of the selected children were interviewed using a structured questionnaire. Questionnaires were administered by trained interviewers, in private, at a central location in the village (e.g. a health post or school). Interviewees were asked whether or not they had attended the referral(s) given during the KIM screening camp. For children who had not attended, the reasons why were sought. An open question was asked with pre-coded response options developed based on previous research, discussions with stakeholders and pilot testing.

In the Child Disability KIM, data were also collected on socio-demographic characteristics of the child (age, sex and education) and caregiver (age, sex and marital status), and socio-economic indicators (family monthly income and ownership of household assets).

Data Analysis

The data were analysed to address the following questions:

- Among children referred to services, what proportion attended that referral?
- Among children who did not attend, what barriers were reported?
- Was there any difference in uptake of services by child’s sex (e.g. were boys or girls more likely to attend?), age, whether attending school, impairment type, household socio-economic status, or literacy or marital status of the caregiver (Child Disability KIM only)

Socio-economic status (SES) was measured using a composite score created from data collected on household ownership of 11 assets (e.g. tables, TV, vehicle). We used multivariate logistic regression to assess the relationship between attendance and socio-demographic/impairment characteristics.

Qualitative Research Methods

Study setting

The qualitative study was conducted in the five health centres in Thyolo district that were included in the KIM hearing project: Bvumbwe, Changata, Gombe, Chimaliro, and Chisoka.

Participants and recruitment

Purposive sampling was used to select a sub-sample of 30 children from all the children (<18 years) and who did not take up their referral given at the screening camps. The sample was selected to ensure representation from different health centres, child age, sex, and severity of hearing loss.

Health surveillance assistants (HSAs) visited the selected participants at their home to explain the study and arrange an appropriate time for interview. Caregivers were invited to attend an interview at the health centre on a specified day with the child who had been seen in the camps. Families were compensated for their transportation to the health centre. Children who were 10 years or older and able to communicate were also interviewed, in the presence of their caregiver if requested.

A total of 23 caregivers and 10 children were interviewed. For six selected children, the HSAs were unable to locate the families. We did not select additional families for interview, because theoretic saturation was reached (i.e. no new information was emerging from the interviews). Table 1 shows the characteristics of the children included in the sample. Of the children of school going age, the majority (83%) attended school. However, 93% of these children were in a lower than age appropriate grade.

Table 1: Characteristics of children in sample

	N	**%**
Age group		
0-4 years	5	22
5-10 years	8	35
11 years+	10	43
Sex		
Male	10	43
Female	13	57
Diagnosis		
Normal hearing with ear disorders	5	22
Mild hearing loss	3	13
Moderate hearing loss	5	22
Severe hearing loss	3	13
Profound/probable profound hearing loss	4	17
Fail OAE (one or both ears)	3	13
Referral		
Surgery	9	39
Hearing aids	7	30
Unknown	7	30
School attendance		
Yes	15	83*
No	3	17*
N/A (<6 years)	5	-
Repeated grade^		
Yes	14	93
No	1	7
* % of those eligible for school (n=18) ^ % of those attending school (n=15)		

In addition, 15 key stakeholders within Thyolo and Blantyre districts were interviewed. These stakeholders were chosen based on their involvement in ear and hearing care and the screening camps. At least one key stakeholder from each health centre was interviewed as well as staff at the district hospital in Thyolo and Queen Elizabeth Central Hospital (QECH) in Blantyre. A table of key stakeholders is provided below (Table 2).

Table 2: Key stakeholders interviewed

Stakeholder role	Number
Health Surveillance Assistant supervisor	1
Health Surveillance Assistant	4
MA	5
Ear Nose & Throat clinical officer	2
Audiologist	1
Malawi Council for the Handicapped (MACOHA) staff member	1
Chief clinical officer	1
Total	15

Data collection

Interviews were carried out in July and August in 2016 by two researchers (one each from Malawi and UK). All interviews with caregivers and children were conducted in Chichewa. Interviews were recorded, transcribed and translated into English. Interviews were conducted in a private room within the health centres and lasted approximately ones hour. Except in one case, the primary caregiver was interviewed with the child present. Most children were interviewed with the caregiver present, except when they expressed that they felt more comfortable being interviewed alone. In-depth interviews were conducted using topic guides, which were informed by the findings of the quantitative studies. The guides included open-ended questions with probes about the following: family background, experience of the hearing screen camp, reasons for not attending the referral, and factors which might facilitate attending the referral. For children, we asked about their experiences at the screening camp and the impact of hearing loss on their lives (e.g. education, home life, community and socially).

Stakeholder interviews covered the following: background about role and responsibilities of stakeholder, barriers to ear and hearing service uptake at the family and community level, barriers at the screening camp, barriers at the hospital level, barriers at the national level, and recommendations for improving uptake.

Topic guides piloted and reviewed accordingly during the research period in light of the findings. This flexibility in the interviews and iterative approach ensured that relevant questions and probes were asked to the study participants.

Data analysis

Transcripts were analysed using nVivo (Version 11) by two research assistants who coded separately. A thematic analysis approach was used. Themes were identified through sorting of data, and labelling ideas and phenomena as they appeared using nVivo. Emerging trends were critically analysed and discussed between the two researchers.

Ethical Considerations

For both studies Ethical approval was obtained from the College of Medicine Research Ethics Committee Malawi (COMREC) and the London School of Hygiene and Tropical Medicine. Informed consent by signature or thumbprint was obtained from all participants.

Findings from the quantitative research

Study population

Child disability KIM: A total of 358 out of the 400 eligible participants in the selected villages were interviewed (89%). The majority of interviewees were female (93%) and the child's primary caregiver (91%) and 77% were mothers of the selected child. The mean age of the children included in the study was 10.9 years, 55% of the children were male and 61% were attending school.

The socio-demographic characteristics of the sample were broadly similar to that of the larger study population of children identified through the KIM Malawi project (Table 3).

Hearing KIM: Out of the 170 families included, 150 were traced (88%) and 20 could not be found (12%). All caregivers interviewed were female. The mean age of the children included in the study was 7.2 years and the majority of the children (74%) were female (Table 3).

Table 3: Characteristics of the study populations

	KIM Malawi follow up study population		KIM hearing follow up study population	
	N	%	N	%
District				
Thyolo	189	52%	145	100%
Ntcheu	176	48%	-	-
Child characteristics				
Age (years)				
0-4	38	10%	24	17%
5-9	109	30%	42	29%
10-14	128	35%	55	38%
15-18	90	25%	22	15%
Sex*				
Males	158	54%	53	36%
Females	133	46%	92	74%
Currently attending school**				
No	131	38%		
Yes	202	61%		
Impairment type***				
Physical	121	33%		
Hearing	115	31%	145	100%
Vision	38	10%		
Intellectual	94	26%		
Epilepsy	70	19%		
Cerebral Palsy****	43	11%		
Multiple	81	22%		
Caregiver/household characteristics				
Primary caregiver age (years)				
15-29	91	26%		
30-44	183	52%		
45+	81	23%		
Marital status of primary caregiver				
Married	250	71%		
Widowed	39	11%		
Divorced	64	18%		
Both biological parents living with child	129	37%		
No	222	63%	**	
Yes				
Literacy of primary caregiver				
Illiterate	195	55%	1,039	40%
Can read/write	158	45%	1586	60%
Socio-economic status				
1 (poorest)	98	27%		
2	88	24%		
3	92	25%		
4 (least poor)	90	25%		

* Data were missing for original study. **restricted to children of school going age ***some children had more than one impairment type and therefore for totals equal more than 100% **** We included cerebral palsy as a separate impairment category because it was the most common underlying health cause of disability in the original study sample.

Uptake of referral

Child disability KIM: Overall, 56% of children were reported to have attended the referral they were given during the KIM screening camp. For those who attended, journey times were reported to be more than 2 hours for 42% people in Thyolo district and 25% for Ntcheu residents.

Hearing KIM: Only five out of the 150 children (3%) had taken up their referral to QECH.

Reasons for non-uptake of referral

Across both studies the most commonly reported barriers were transport difficulties (Child disability KIM 23%, Child hearing KIM 40%, Table 4) and lack of information or understanding about the child's condition or referral process (17% and 60% respectively). Both these barriers were more commonly reported among the Hearing KIM population compared to the Child Disability KIM.

In terms of lack of information/understanding, insufficient information given by the health professionals at the screening about the referral was the most common reason and was reported by nearly half of caregivers in the Hearing KIM study.

Other common reasons mentioned Child Disability KIM in Ntcheu (18%) and Hearing KIM (39%) was that they had been told they would receive a follow up visit (from relevant service provider e.g. and HSA or CBR worker) but this did not happen. In Ntcheu 11% forgot their appointment.

In Thyolo district, for the Child Disability KIM) and KIM Hearing studies, 27% and 39% respectively reported financial barriers, most commonly with transport (24% and 31%) and food needed for the visit to the service provider (6% and 22%). Child/family illness (18%) and fear (12%) were also frequently reported in Thyolo. Few people reported cost of service as a barrier because health care is free at the point of access in this setting.

Table 4: Reported reasons for not attending referral services by district

	Kim Malawi			Kim Hearing (n=145)
	Ntcheu (n=106) %	**Thyolo (n=51) %**	**Combined (n=157) %**	
Transport difficulties [a]	23%	24%	23%	40%
Lack of information/understanding				
Not enough information about referral	11%	16%	13%	46%
Location referral wasn't specified	3%	0%	2%	13%
Family didn't communicate information from camp	4%	4%	4%	0%
Unclear if service would cost money	0%	2%	1%	3%
Total	**16%**	**18%**	**17%**	**60%**
Financial				
Not enough money for transport	0%	24%	8%	31%
Not enough money for the service	0%	4%	1%	4%
Not enough money for food needed	0%	6%	2%	22%
Total	**0%**	**27%**	**9%**	**35%**
Told someone [b] would visit family but did not happen	**18%**	**0%**	**12%**	**39%**
Illness child/other family member				
Child not well	0%	8%	3%	0%
Other family members unwell	6%	14%	9%	0%
Total	**6%**	**18%**	**10%**	**0%**
Forgot appointment	11%	4%	9%	2%
Afraid	1%	12%	5%	10%
Attended but denied appointment /no medication available	6%	0%	4%	0%
Family members did not agree	2%	2%	2%	0%

a Practical/geographic challenges, not including cost [b] e.g. health or CBR worker

Factors associated with referral uptake

Table 5 shows the odds of attending referral by different socio-economic and impairment characteristics among children identified by the Child Disability KIM project. These data are presented for the two districts separately and combined. Referral uptake was significantly higher in Thyolo (74%) than Ntcheu (36%) district.

For the two districts combined, attendance was significantly higher for children with epilepsy (74%) compared to those without, but did not differ significantly for the other impairments. Attendance was also higher for children whose caregiver was divorced or separated (62%) compared to married (53%). There was a strong association with SES: children from the wealthiest households (76%) were much more likely to attend their referral compared to the poorest households (40%). Age, sex or school attendance of the child were not associated with uptake.

In Ntcheu district alone the child having epilepsy, caregiver being divorced/separated and older (>45 years) and wealthier household SES were all associated with being more likely to uptake the referral.

In Thyolo, children from wealthier households and those with a caregiver who was divorced/separated were more likely to attend their referral.

Table 5: Relationship between service uptake, sociodemographic, and clinical factors for the Child Disability KIM

	Combined districts		Ntcheu District		Thyolo District	
	Uptake N (%)	Age, sex, SES adjusted OR	Uptake N (%)	Age, sex, SES adjusted OR	Uptake N (%)	Age, sex, SES adjusted OR
District						
Ntcheu	60 (36%)	1.0				
Thyolo	140 (74%)	3.7 (2.1-6.8)*				
Child variables						
Sex						
Male	89 (58%)	1.0	31 (41%)	1.0	58 (75%)	1.0
Female	68 (53%)	0.9 (0.5-1.6)	19 (31%)	0.6 (0.3-1.4)	49 (72%)	0.9 (0.4-2.0)
Age (years)						
1-5	33 (61%)	1.0	7 (37%)	1.0	26 (75%)	1.0
6-10	77 (62%)	1.0 (0.4-2.3)	21 (40%)	1.0 (0.2-3.2)	56 (77%)	1.7 (0.5-5.1)
11-15	59 (53%)	0.7 (0.3-1.8)	16 (32%)	0.9 (0.3-4.5)	43 (71%)	1.1 (0.4-3.2)
16+	30 (47%)	1.0 (0.3-1.7)	16 (36%)	1.2 (0.3-4.5)	14 (74%)	1.1 (0.2-4.7)
Attends school						
No	73 (58%)		28 (42%)	1.0	45 (78%)	1.0
Yes	108 (54%)		30 (35%)	1.1 (0.5-2.4)	78 (70%)	0.6 (0.2-1.5)
Impairment type						
Physical impairment	72 (61%)	1.3 (0.8-2.0)	20 (44%)	1.6 (0.7-3.7)	52 (72%)	0.9 (0.4-2.1)
Hearing impairment	57 (51%)	0.7 (0.4-1.3)	17 (30%)	0.9 (0.4-2.1)	40 (73%)	0.8 (0.3-1.8)
Vision impairment	15 (39%)	0.5 (0.2-1.2)	5 (23%)	0.5 (0.2-1.9)	10 (59%)	0.5 (0.1-1.8)
Intellectual impairment	49 (55%)	1.0 (0.6-1.8)	13 (30%)	0.6 (0.2-1.4)	36 (80%)	1.6 (0.6-4.1)
Epilepsy*	50 (74%)	2.8 (1.4-5.2)*	16 (59%)	4.6 (1.6-13.2)*	127 (74%)	1.3 (0.5-3.7)
Cerebral palsy	22 (54%)	0.8 (0.4-1.8)	9 (38%)	0.6 (0.2-1.8)	33 (83%)	1.6 (0.4-6.6)
No. of impairments						
One	155 (56%)	1.0	48 (37%)	1.0		1.0
Multiple	45 (58%)	1.0 (0.7-1.3)	12 (32%)	1.0 (0.4-2.6)		1.8 (0.6-4.9)

Caregiver Variables						
Age (years)						
15-29	47 (53%)	1.0	7 (19%)	1.0	40 (76%)	1.0
30-44	100 (57%)	1.3 (0.7-2.4)	32 (38%)	4.3 (1.3-14.0)	68 (74%)	0.9 (0.3-2.5)
45+	48 (60%)	1.5 (0.7-3.0)	19 (46%)	6.2 (1.6-24.5)*	29 (75%)	1.1 (0.3-3.6)
Marital status						
Married	130 (53%)	1.0	43 (36%)	1.0	87 (71%)	1.0
Widowed	19 (49%)	1.0 (0.5-2.4)	6 (30%)	0.8 (0.2-2.7)	13 (68%)	0.8 (0.2-3.1)
Divorced/separated	44 (62%)	3.8 (1.7-8.3)*	10 (42%)	3.3 (1.0-11.3)	34 (87%)	3.5 (1.0-11.9)
Caregiver literacy						
Illiterate	89 (57%)	1.0	25 (32%)	1.0	54 (76%)	
Can read/write	106 (55%)	0.9 (0.5-1.4)	35 (42%)	0.9 (0.4-1.9)	80 (72%)	
Both parents live with child						
No	73 (58%)	1.0	23 (37%)	1.0	49 (79%)	1.0
Yes	122 (56%)	0.7 (0.4-1.3)	36 (37%)	0.9 (0.4-1.9)	86 (72%)	0.6 (0.2-1.5)
Household variables						
Income group						
0-7 USD	103 (54%)	1.0	19 (28%)	1.0	84 (69%)	1.0
7-14 USD	81 (62%)	1.3 (0.7-2.2)	32 (45%)	1.5 (0.6-6.6)	49 (81%)	1.8 (0.8-4.0)
>14 USD	14 (42%)	0.9 (0.3-2.2)	9 (33%)	1.2 (0.4-3.7)	5 (83%)	2.6 (0.324.6)
SES						
1 (Poorest)	38 (40%)	1.0	13 (25%)	1.0	25 (61%)	1.0
2	44 (52%)	2.5 (1.2-5.0)*	17 (35%)	2.1 (0.8-5.7)*	27 (77%)	3.7 (1.1-12.2)*
3	51 (57%)	3.3 (1.7-6.7)*	13 (36%)	2.2 (0.8-6.2)*	38 (72%)	3.6 (1.2-10.5)*
4 (least poor)	67 (76%)	7.6 (3.6-16.0)*	17 (60%)	6.6 (2.2-19.7)*	50 (83%)	6.5 (2.1-20.5)*

* Significant (p<0.05); SES = Socio-economic status

Key findings from the quantitative research

- Uptake of referral services was low:
    - Just over half (56%) of the children identified during the Child Disability KIM and only 3% from Child Hearing Kim had taken up their referral
- The most common reasons given for not attending referral were transport difficulties, lack of information or understanding regarding the referral, and financial constraints
- In the Child Disability KIM study:
    - Uptake was higher in Thyolo (74%) than Ntcheu (36%)
    - Children from poorer households were less likely to attend their referral
    - Attendance was higher among children whose caregivers were divorced or separated
    - Children with epilepsy were more likely to have taken up their referral compared to children without epilepsy

Findings from the qualitative research

Seven thematic reasons related to non-uptake of referral emerged from the interviews with stakeholders and caregivers.

Location of hospital

The distance to QECH was perceived by most caregivers to be vast and a significant obstacle to taking up the referral. For instance, caregivers explained that Gombe is 100km from Blantyre and because of the challenging terrain the journey is at least 2.5 hours. It also required walking or cycling up steep hills to reach public transportation which parents felt was too difficult. Several parents felt that the journey was therefore out of the realms of possibility for them and particularly so for their children. For example, one caregiver described the challenges of making this journey particularly in the context of concerns that they would not be seen on the same day:

> *It's a long journey, imagine from here to Goliati you will ride a bike and in the hills you will be walking on foot. At Goliati we board another [minibus] to Limbe and then another to Queens. Its long journey and you might not be assisted the same day when you go.* [Caregiver]

Lack of transport

Several caregivers and stakeholders asserted that there was no transport available to get Blantyre. Some reported that ambulance services at the health centre and district hospital level, in theory, can transport patients to the next level referral facility (i.e. from the health centre to district and district to QECH). However, there was a consensus that this service was unreliable or was only used for priority services such as maternity care. Some caregivers reported unsuccessful attempts to use the service due to lack of availability of the ambulance.

> *We tried that time to get an ambulance but failed because every time we came to ask about the ambulance, we were told that it had already left.* [Caregiver]

Further, stakeholders reported that the ambulance service to QECH was one-way only and once patients were in Blantyre they faced the additional challenge of finding a way back to their villages.

> *The other challenge is when they are discharged, because coming here is easy because they have an ambulance. When everything has been done here and they have been helped or they have been assisted, they still need an ambulance to take them back, so we don't have a ready ambulance to pick them up.* [Stakeholder]

Indirect costs

Although most health care in Malawi is free at the point of delivery, parents raised concerns about indirect costs of seeking care associated with travel and time spent at QECH. Most caregivers gave the high cost of transport as a reason for not attending services. Some reported that, because of the long distance, from their village to QECH it would cost around 1500 Kwacha, a price which is prohibitive for rural farming families.

> *I had no money to pay for travels to go to Queens so I just stayed [at home].* [Caregiver]

A few caregivers mentioned that if they requested an ambulance, they were told to buy fuel for the ambulance to take them, which they could not afford.

In addition, there were also difficulties with paying for food needed for both the journeys and time spent at the hospital.

> *Some things might be needed, [to travel to and wait at QECH] such as flour, firewood and relish and some other things like porridge flour, sugar and others.* [Caregiver]

Most caregivers mentioned that their income depends on seasonal activities; at certain times of year they are not engaged in income generating activities making it difficult for them to meet the additional costs involved in care seeking. Many also felt concerned that seeking care would be a lengthy process resulting in several days where they could not be engaged in work on their farms. Further, some of the parents reported that there would be nobody to care for their other children if they travelled to QECH for several days. These interacting challenges were summarised by one caregiver:

> *From here [Chisoka] to Queens there is a need for proper transportation as you know this place is far. And when you arrive there you know these days [outside harvesting season], people don't harvest enough and it is possible that we might not be treated same day, maybe we may spend some days. So [money for] food would and transport would be a problem.* [Caregiver]

Fear and uncertainty of the hospital

Several factors relating to the referral hospital (QECH) were mentioned by caregivers and stakeholders as potential barriers to the referral uptake.

Many caregivers and stakeholders expressed fear and unfamiliarity of QECH as a reason for not attending. Most parents had never previously been to QECH. QECH was perceived to be a "big hospital", with several parents asserting a fear that they "would not know where to go" once they arrived at the hospital.

Some caregivers explained that they were not sure if they would find the ENT clinic at QECH and so they were afraid of being stranded. Further, fear of long waiting time at the hospital was raised as a concern by some parents.

> *Some people think that Queens is a very big hospital, you can spend the whole day without being helped.* [Caregiver]

> *It is just fear, some have never been to Queens so referring them to Queens… and you give them directions. They may have money but for them to go, maybe it is fear.* [Stakeholder]

Insufficient information about the referral

The interviews revealed a number of issues with communication at the screening camps that influenced uptake of referral. The protocol for children who needed referrals was to verbally advise caregivers to attend QECH as well as writing this in their health passport. HSAs were instructed to follow up with patients to check attendance to QECH and ensure they adhere to treatment or instructions. However, it was evident that many caregivers were confused about the referral process. Many parents reported that either they were not aware that they had been given a referral at all or that they were waiting to receive more information about when to attend QECH. Where possible, we examined health passports for the referral and found referral notes were lacking on several occasions.

> *I: So the only thing they did was to put some medication that's all? Didn't they say; no, we will need this child again for another consultation, they didn't say anything?*
> *P: From here?*
> *I: From here, whether another place or from Queens or wherever?*
> *P: No, they didn't say that*
> [Caregiver]

> *I was not told that we needed to go. We were just waiting for information on the day to go to Queens.* [Caregiver]

Screening camps were reported to be very busy and many caregivers described long waiting times to be seen by the clinicians. The majority of caregivers asserted that the doctors within the camp did not explain the results of the tests or provide information about the diagnosis. As a result, caregivers expressed an uncertainty about what would happen at QECH. Some caregivers mentioned that they were just told that the problem was "big". In addition, caregivers were not given information on how to manage their children while waiting to go for referral. Stakeholders highlighted the lack of information given to caregivers as a substantial shortcoming of the camps. A stakeholder involved in camps explained:

> *Of course giving them advice, advising them on what to do with the conditions, because they needed counselling for them to understand the problem, if the problem could be treated, or how can they be assisted with their problem. We didn't have that time, and we just said no, just go to*

> *Queens and you will be treated or come to Thyolo you will be treated in such a way.* [Stakeholder]

Awareness and understanding of hearing loss

The majority of stakeholders felt that limited knowledge of ear and hearing health for most people living in the rural areas of Malawi was a substantial barrier to uptake of referrals, and some also indicated that disabled children may be neglected by the their families.

> *The most important issue which is like a barrier for them to access the services it is; themselves, because sometimes they don't even know, even understand what is going on, so at the end of the day they don't give them [the child] a second chance. They just declare that this is the way things are. Maybe you've heard somewhere that these kinds of children, or the disabled, people would just dump their house and just sit there.* [Stakeholder]

Interviews with caregivers suggested that specific knowledge regarding the causes and available treatments for their child's ear and hearing loss was limited, despite attendance at the KIM screening camps. Some caregivers also described seeking alternative or home-based treatments for their child, which are likely to exacerbate ear conditions. For instance, distilling cooking oil or traditional medicines in to the ear canal. However, many acknowledged that no improvements were seen post-treatment.

> *Yes, my grandmother looked for traditional medicine once, when we applied once, it looked as if they made her have another problem. The hearing loss became severe now and in the morning I stopped her from applying any more traditional medicine.* [Caregiver]

However, many of the caregivers did display an awareness of their child's hearing loss. Most were able to recall when their child's hearing loss or ear condition started, even if it was delayed and several described, in a compassionate way, the impact on their child. For example:

> *We can say that the problem started at birth but then for us to realise her difficulty in hearing was when she was 4 years old. That's when we realised that the child does not hear properly because when spoken at if she was not looking at you then she was acting in way like she hasn't heard you while if she is looking at you, she was able to hear.* [Caregiver]

In contrast to the stakeholder perceptions, caregivers also showed a motivation for seeking care for their child. They attended KIM camps and the majority of caregivers interviewed had also previously sought care from health centres.

Lack of availability and visibility of ear and hearing services

As well as the specific challenges to uptake of referral to QECH, the interviews raised more broadly the lack of resources at health facilities as a serious problem limiting access to ear and hearing services. Several stakeholders highlighted the lack of visibility of the ear and hearing services at QECH and Thyolo district hospital as a barrier to patients receiving appropriate care. They felt that because other staff at the hospitals were not always aware of the ear and hearing services, patients do not always actually reach the ENT department. It was asserted that patients may be sent from department to department without ever finding the appropriate provider. Other patients may be seen but only by a generalist doctor rather than an ENT specialist and therefore may not receive the appropriate care.

> *What is working well is; at least there is somebody who is deals with these issues like the ENT clinician, where it doesn't work well is; these other people who are not ENT clinicians, they don't know what to do and they may send back some of the children when they are not supposed to be sent back.* [Stakeholder]

Some stakeholders felt that these experiences would make people reluctant to seek care again. This was supported by some caregivers who suggested that the risk of not receiving assistance at the hospital discourages them from spending the money to get there:

> *We might go there and may not find the doctor. We only have money for one day [so] we may be stranded.* [Caregiver]

Limited availability of the ENT personnel, in general, at health facilities was raised as an issue by both caregivers and stakeholders. For example, some caregivers reported previously attending the district hospital, which often involved a day of travel, but finding that the ENT clinical officer was not available and therefore no care was received. Stakeholders attributed this to lack of ENT personnel: there is only one ENT clinical officer who is the sole mid-cadre ear and hearing professional in the district, highlighting the significant lack of human resources for dealing with the demand for services.

> *They think of transport issues, and how they will reach there if they will be admitted or how they will meet the ENT person since its only one person. Sometimes he is not there, he goes to the meetings, and there is no one to help them on the issues of hearing problems.* [Stakeholder]

Several caregivers also asserted that health facilities were not able to provide treatment for ear problems because they did not have drugs and once they had experienced this, they did not feel it was worthwhile to seek ear and hearing services again. A caregiver described the challenges of obtaining medication for their child's at the health centre levels:

> *She [relative of caregiver] came with him [to the health centre] but she was told that the medication was scarce and she should continue looking for the medication elsewhere. So she looked for the medicine but she failed.* [Caregiver]

The lack adequate medication, equipment and human resources to enable diagnosis and appropriate treatment for children with ear and hearing problems was raised by several stakeholders. For example, health centre staff described the challenges of managing ear conditions due to limited resources:

> *Sometimes we just prescribe medication because we know that this is Otitis Media and Chronic and maybe Acute. We don't know, but we just prescribe medication, but if we may have equipment and are able to see that the problem is huge, we shouldn't delay but quickly rush. But also sometimes we delay because we assume that the problem is small because we did not look into the ear.* [Stakeholder]

> *We don't look into the ear, we just see if the child is discharging, we look at how the pus looks like and give them a cotton to wipe with but we don't look inside because we don't have the equipment to use.* [Stakeholder]

Perceptions of the camps

In addition to reasons for non-uptake, stakeholders and caregivers were asked about their perceptions of the KIM screening camps. Most stakeholders considered that the camps were worthwhile and should be repeated regularly as they provided children with ear and hearing issues long-awaited medical care close to home. Staff at the health centres also mentioned that the camps were important for raising visibility and advocating for the needs of children with ear/hearing difficulties. For example one person said camps provide with "good data on children who have this problem". Another explained they were important for "*unmask[ing] most of the children who are in the rural areas, who were kept and labelled useless."*

> *There are so many benefits that come with these camps. Because it is easier for the parents to come and access those services near to them instead of them travelling long distance. When you conduct those services close to the places where they are found, then you can see many of them coming there. So I can say attendance becomes good, becomes high, because they can access them. That is the major benefit that am seeing organizing camps.* [Stakeholder]

Caregivers also positively expressed that the camps were geographically accessible and had given them opportunity to consult the doctor and receive help for their child. However, some expressed that they were expecting to receive treatment at the camp.

> I*: When you found out they [the doctors] were coming from Queens, how did you feel?*

> *P: I really felt good*
> *I: You felt good?*
> *P: We wanted to believe that perhaps they were going to give us medication which will make this problem better*
> [Caregiver]

Key findings from the qualitative research

The in-depth interviews highlighted six broad factors influencing the decision not to uptake referrals for children identified at the hearing screening camp including:

- Location of the hospital
- Lack of transport
- Indirect costs (e.g. for transport, food and opportunity costs)
- Fear and uncertainty regarding the referral hospital
- Insufficient information about the referral
- Awareness and understanding regarding hearing loss
- Lack of availability and visibility of ear and hearing services

Despite challenges with uptake, the screening camps were in general perceived to be a positive activity.

Table 6 below show how these factors align with the four dimensions of the Peter's framework of health access.

Table 6: Relationship between barriers to uptake/access and dimensions of access to health

	Dimension of access			
Factor	**Geographic accessibility**	**Availability**	**Affordability**	**Acceptability**
Location of hospital	X		X	
Lack of transport	X	X	X	
Indirect costs	X		X	
Fear and uncertainty regarding the referral hospital				X
Insufficient information about the referral		X		X
Lack of visibility and availability of ear and hearing services at referral hospital		X		X
Levels of awareness and understanding of hearing loss				X
Lack of resources at health facilities	X	X	X	X

Part B: Systematic review on interventions to increase access to health services for children in low and middle income countries

Overview

There is strong evidence that, in LMIC, substantial barriers exist to accessing health services for children and children with disabilities may experience additional specific barriers. However, evidence on the effectiveness of interventions to overcome these barriers, and increase access to services, is less well documented. Studies of interventions specifically addressing access to health/rehabilitation services for children with disabilities are lacking. Thus, we conducted a systematic review to identify studies that have evaluated interventions aimed at increasing uptake for children.

Defining access

Access is a complex concept and has a broad range of definitions. For the purposes of this review, we defined access according to a framework from Peters et al (2008). This framework suggests access has four main components as shown in Box 1.

Box 1: Dimensions of access (Peter's)

Geographical accessibility	Relates to the physical distance and/or travel time from the health service to the user. If services are concentrated in particular areas and inadequate provision is available in others (e.g. in poor, rural areas) this imposes a geographic barrier.[18]
Availability of health care	Relates to the ability to access the right care at the right time. This element includes factors such as the hours of operation of a service, the availability of specialist staff, and waiting times that meet the user's demand for services.
Financial accessibility	Refers to affordability to access a service that depends on costs and prices of services, and user's resources and willingness to pay. This also includes the indirect costs such as opportunity costs of time of both the patient and those accompanying them.
Acceptability	Depends on the characteristics and structure of health services matching the needs and expectations of the users as well as individual user's knowledge and attitudes

These dimensions are not mutually exclusive and may interact with each other. Strategies to improve health care can therefore be simple, targeting just one dimension of access (e.g. improving local availability of health services) or complex, incorporating multiple interacting components (e.g. health education of the community and health systems strengthening). Further to this framework, Jacob's et al (2012), suggested that interventions may target the demand or supply side.[19] These concepts are used to delineate the results of the review and discuss the barriers to access that they may target.

Methods

Search strategy

We conducted a systematic review of effectiveness of interventions aimed at increasing access to health services for children in LMIC. In total, four databases (EMBASE, Global Health, MEDLINE, and PSYCINFO) were searched in January 2016.

Search terms were developed using MeSH (see Appendix 4 for search strategy). No limits were placed on language. Reference lists of included studies were inspected in order to further identify relevant studies. Furthermore, studies included in any relevant systematic reviews were reviewed for relevance. Finally, if any study protocols were identified, a search was made to determine whether the results of the study had been published.

Inclusion/exclusion criteria

For this review, we focussed on articles that tested interventions aimed at increasing access to health care for children under 18 years of age, according to the United National Convention on the Rights of the Child.

Using Peter's definition of access, a wide range of intervention types and outcome measures were possible. We focussed on three broad outcome types based on previous reviews on access to health: health care utilisation; immunisation uptake; and compliance with medication/referrals. Example of outcome measures in these categories include:

- **Health care utilisation:** e.g. proportion of children taken to health facility in event of illness, uptake of early infant diagnosis of Human Immunodeficiency Virus (HIV)
- **Immunisation uptake:** e.g. coverage of Diphtheria, Pertussis, and Tetanus (DPT) vaccination, measles vaccination
- **Compliance with medication/referrals** e.g. intermittent preventative treatment for malaria, adherence to antiretroviral therapy (ART)

In terms of study design, randomised controlled trials (RCT) and non-randomised controlled study (NRS) designs were included in the review.

Study selection

Three review authors (TB, SP, and HK) independently examined the titles, abstracts, and keywords of electronic records according to the eligibility criteria. One author examined all titles and abstracts (TB), whilst the remaining records were divided between two authors (SP, HK) for double screening. Results of the initial screening were compared and full-text records obtained for all potentially relevant studies. Two review authors (TB and SP) screened the full texts using eligibility criteria for final inclusion in the systematic review. Any disagreements in the selection of the full text for inclusion were resolved by discussion with a third author (HK).

Data extraction and synthesis

The following data were extracted from the final included articles:

- Publication details: author, year and journal.
- Methods: study design and duration.
- Study location: including country and setting (urban/rural).
- Participants: age, sex and sample size.
- Interventions: details on the intervention and its comparator.
- Outcomes: type of outcome(s), measurement instruments, and time points measured.
- Results: including relevant measure of effect (odds ratio, risk ratio, p values).

A narrative approach was used to synthesise results in line with the recommendations for systematic reviews of complex interventions.[20] We did not conduct a meta-analysis due to the variation in included study designs, intervention types and outcomes. Given the broad range of interventions expected in the review, we used the Jacob's and Peter's conceptual frameworks to classify our intervention types and allow synthesis of results.[8, 19] The framework suggests that interventions to increase access to health care can target the supply or demand side and can be financial or non-financial.

Risk of bias

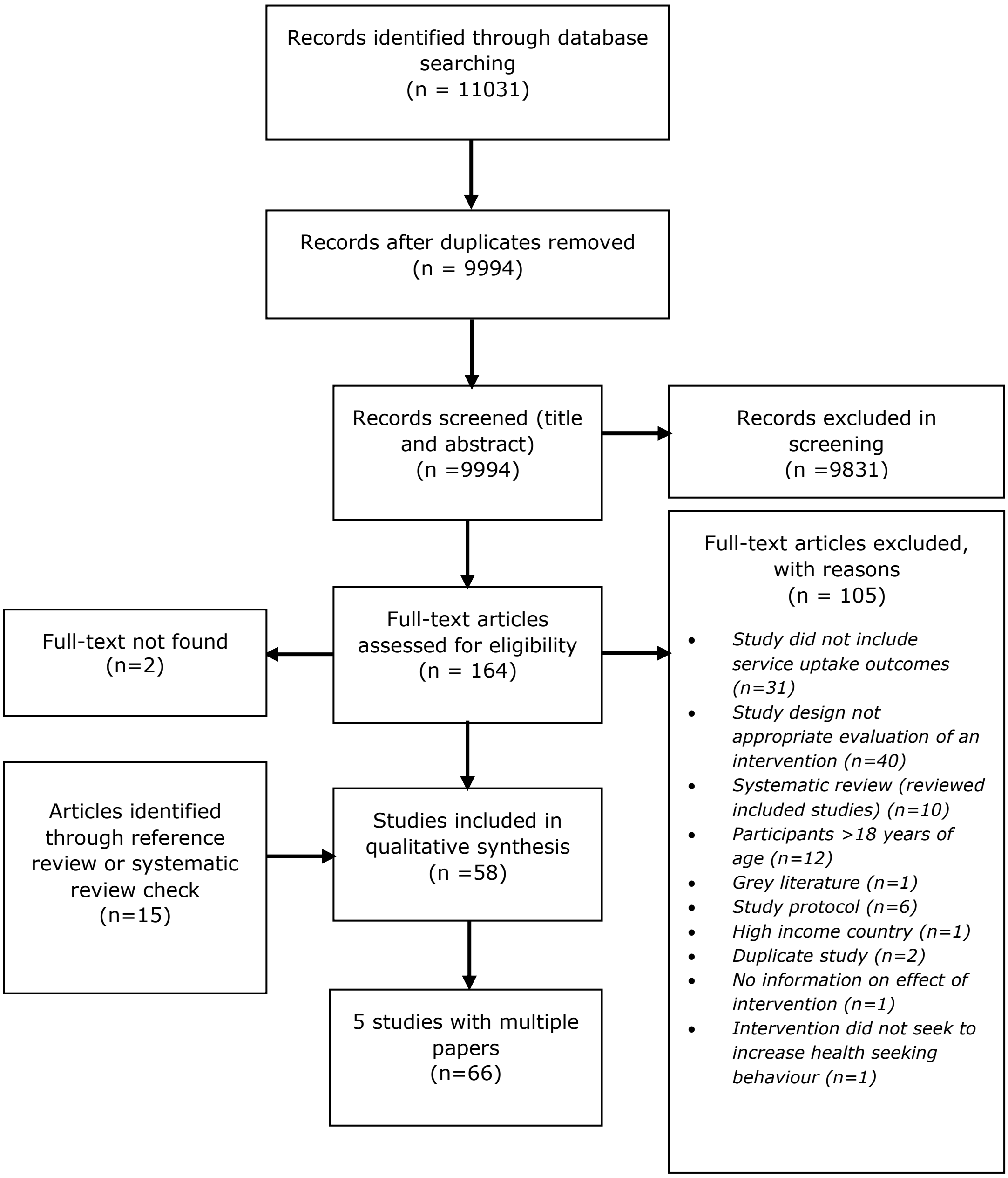
Two authors (TB, SP) independently assessed the methodological quality of the selected studies. Disagreements were resolved through discussion. For randomised control trials, we used the Cochrane 'Risk of Bias' tool.[21] For non-randomised studies, we used the Effective Public Health Practice Project (EPHPP) quality assessment tool for quantitative studies. [22]

Results

Selection of final sample

A total of 11,031 records were initially identified by the electronic searches, of which 1037 were duplicates and removed. A further 9,882 records were excluded during the initial screening yielding 164 potentially eligible studies for which full text reports were sought. Following the full text review, 105 studies were excluded and the full text could not be located for 2 articles.[23, 24] An additional 15 studies were identified through screening reference lists of the included publications, yielding a total of 73 publications eligible for inclusion in the review. Five of these were duplicate publications on the same study and these were grouped together leaving a total of 66 included studies (see Figure 1).

Figure 1: Flow chart of search results



Overview of study characteristics

A summary of the study characteristics of the 66 included studies is shown in table 6. Studies were published between 1994 and 2015 (Figure 2). The majority of studies were published from 2010 onwards (n=48; 73%). Study duration ranged from 3 months to 6 years.

Table 6: Characteristics of 66 included studies

Variable	**Number**	**%**
Location		
Urban or periurban	17	26
Rural or semi rural	34	52
Mixed	15	23
Decade of publication		
1990	2	3
2000	16	24
2010	48	73
Study design		
RCT	51	77
Non-RCT	2	3
Controlled before-after study	10	15
Historical controlled study	2	3
Interrupted time series	1	2
Region		
Latin America/Caribbean	6	7
East Asia/Pacific	4	5
Sub-Saharan Africa	34	49
South Asia	20	37
Middle East/North Africa	1	2
Europe/Central Asia	1	2
Outcome category		
Immunisation	19	29
Health care utilisation	34	52
Compliance	5	8
Combination	8	12
Intervention category		
Delivery of services closer to or at home	9	14
Health promotion/education programme	25	38
Service level improvements	11	17
Reminders	7	11
Financial or other incentives	14	21

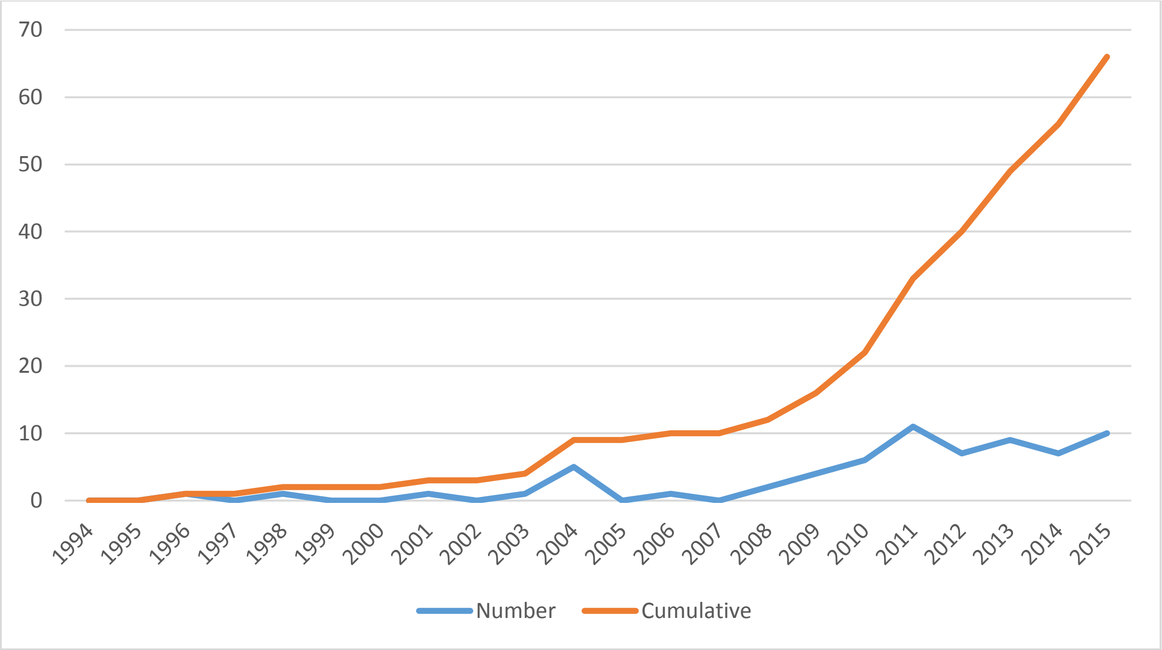


Figure 2: *Year of publication of included studies*

Just over half of the studies (n=48, 52%) were conducted in Sub-Saharan Africa, 20 (30%) in South Asia, six (9%) in Latin America/Caribbean, four (6%) in East Asia/Pacific, one (2%) in the Middle East/North Africa, and one (2%) in Europe/Central Asia. More than half of the studies (n=34, 52%) were conducted in rural or semi-rural locations, 17 (26%) were carried out in urban or peri-urban centres and 15 (23%) were carried out in a combination of settings (e.g. urban and rural).

The majority of studies (n=51; 77%) were RCTs. The remaining studies employed the following NRS study designs; non-RCTs (n=2; 3%); historical controlled study (n=2; 3%); controlled before-after study (n=10; 15%) and interrupted time series analysis (n=1; 1%).

Of the 66 included studies; 34 (52%) reported health care utilisation outcomes, 19 (29%) reported on immunisation, 5 (8%) studies reported compliance outcomes and 8 (12%) studies reported on multiple outcomes (e.g. health service utilisation and compliance). Appendix 5 highlights the specific outcomes measured for each study.

Considering the target group for the intervention, the vast majority of studies (n=57; 86%) focussed on children under 5 years of age. The remaining studies focussed on adolescents (n=9; 14%).

The interventions identified in this review were grouped into broadly similar categories and into supply-side or demand-side and non-monetary and financial categories according to Jacobs' framework [25]. These groups are shown in table 7.

Table 7: Intervention types in included studies

	Examples of intervention	**Number of studies**	**Reference**
Supply side: non-financial			
Delivery of services at or closer to home	Delivery of immunisation, medication/treatment, and referrals by health care professionals, community health workers (CHW), school-based programmes, and immunisation camps	8	26-32
Service level improvements	Health worker training, scaling up services, and integration of services	9	33-41
Supply side: financial			
Service level improvements	Contracting in or out of services, and pay for performance	2	42, 43
Demand side: non-financial			
Health promotion/education programmes	Delivery of health promotion by varying personnel including health workers, CHW, peers, and participatory women's groups	27	44-67
Text messages	Text message reminders, and promotion of service	6	68-72
Demand side: financial			
Financial or other incentives	Cash transfers, vouchers, fee exemptions and food incentives	14	73-86

Some studies evaluated interventions with multiple components ('intervention packages') and but were allocated to one of the above categories according to their primary component for simplicity. A summary description of all the interventions in the included studies is provided in Tables 8 and 9.

Risk of bias

A total of 51 studies used a RCT design (either cluster RCT or RCT). The majority of studies (n=29; 57%) were judged as having an unclear risk of bias in at least one of the six Cochrane domains (sequence generation, allocation concealment, blinding of outcome assessment, incomplete outcome data, selective reporting and other bias). The remaining studies, 21 (41%) were judged as having a high risk of bias. The domains most commonly contributing to high bias risk were lack of blinding of outcome assessors, incomplete outcome data and 'other' biases such as recall bias and use of self-reported data to ascertain vaccination status or health care utilisation. Most of the 15 non-randomised studies were assessed to be of moderate quality (i.e. weak in one domain) (n=9), and strong quality (n=2), and the remaining 4 were judged as weak using the EPHPP tool. The main sources of bias in NRS studies were study design, presence of confounders, and withdrawals or dropouts.

Overview of study outcomes

In order to determine which interventions showed an improved impact on access for children, the outcomes of interest were classified in terms of the effectiveness of the interventions. The following classification system was used:

- **Positive:** if there was a statistically significant improvement in the outcome(s) of interest (health care utilisation, immunisation uptake and/or compliance outcomes) in the intervention group relative to the comparison group.
- **Negative:** if a statistically significant decrease in the outcome(s) relative to the comparison group was found.
- **Null:** if there was no statistically significant change in the outcome of interest
- **Mixed positive:** if there was a significant improvement in at least one outcome and no significant change in other outcomes (for studies measuring more than one outcome).
- **Mixed negative:** if findings were a mix of negative and null (for studies measuring more than one outcome).

Supply side non-financial

Delivery of services at or close to home

Delivery of services at or close to home through home visits or outreach was evaluated in eight of the included studies. These interventions included service delivery at home by community health workers (CHWs)[28-30, 32, 87, 88] or health professionals[31, 89] or in the community through immunisation camps [90](Table 8). The majority of studies in this category found a positive or mixed positive impact on the measured outcomes of access (n=7; 88%). The remaining study found no significant improvements. No clear trends were seen in the effectiveness of interventions between delivery modes.

Service level improvements

Service level improvements such as health worker training[33, 36, 37, 91], scaling up of services[38], and service integration[34, 35, 39, 41, 92] were evaluated in nine of the studies. In total, three of these studies found a significant improvement (positive result), two studies had mixed-positive findings, and two found null effect (Table 8). Some variation in effectiveness was found between the intervention approaches: health worker training was in general associated with positive findings (1 positive, 1 mixed positive). Two of three studies evaluating service integration found positive results, whilst the remaining found null effect. Scaling up of immunisation services found no significant impact on immunisation coverage.

Supply-side; financial

Service level improvements

Service level improvements with a financial component were investigated in two studies. Pay for performance for health care workers showed a significant improvement on health care utilisation, but no significant impact on immunisation coverage (mixed-positive result).[93] A study evaluating delivery of primary health services by a contractor found unclear results (Table 8).[43]

Demand side; non-financial

Health promotion/education

Health promotion/education programmes were the most frequently evaluated intervention in this review (n=27). Education interventions were delivered by a variety of professionals including: health professionals (nurses, doctors) [47, 51, 65, 66, 94](n=5), community health workers[46, 48, 50, 55, 57, 59, 63, 67, 95-98] (n=11), women's participatory learning groups (n=5)[45, 52, 54, 58, 60, 64], and other members of the community (e.g. Teacher or peer) [44, 61, 99-102](n=6) (Table 9). Education focussed on a range of topics such as immunisation, childhood infections, and newborn care, antenatal care.

Overall, 37% of the educational interventions found evidence for a positive impact on access (n=10) and 26% found mixed positive significance (n=7). The remaining 37% found null effect (n=10). Considering mode of delivery, health worker delivered educational interventions were in general positive or mixed positive (60% positive; 20% mixed positive; 20% null). Delivery by CHWs, teachers, peers or counsellors had more varied results. None of the five studies evaluating women's groups as a standalone intervention found a significant improvement in outcomes of interest. However, one study combined women's groups with health systems strengthening and staff training and found a positive results.

Of eight studies that evaluated health education delivered by a CHW, the majority found null effect (n=4; 50%), one (13%) was positive and three (37%) were mixed-positive. A further three studies combined health education delivered by a CHW with other components. Positive results were seen when CHW education was combined with either: health systems strengthening, or community development.[46, 95] When CHW education was combined with both strengthening of health systems and women's groups, no effect was seen.[59]

Text message reminders

A total of six studies evaluated text message reminders[69, 70, 103-105] (n=5) or promotion of a health care service [71](n=1) (Table 9). Text message reminders were for early infant diagnosis of HIV, HIV care, and vaccination services. The health promotional text messages were for HIV. A total of 5 studies (83%) showed positive results and the remaining study had mixed positive results.

Demand-side; financial

Financial or other incentives

Financial interventions were the second most common intervention category identified in this review (n=14). A range of interventions were tested:

unconditional or conditional cash transfers [74, 78, 80, 82, 83, 86, 106], fee exemptions [73, 75, 76, 84, 85], and food incentive schemes [79, 81, 107] (Table 8).

Six of studies in this group were positive (43%), four found mixed-positive results (29%) and four showed null effect (29%). Specifically, studies evaluating food incentive schemes all found a positive impact (n=3). Studies evaluating removal of user fees alone were varied (1 positive, 1 mixed, 1 null). Fee exemptions in combination with social mobilisation, education, and strengthening of services, resulted in a positive impact was found on health care utilisation.[108]

Results from cash transfer interventions (1 positive, 4 null, 2 mixed) were more varied. When conditional cash transfers were combined with health services strengthening and a community based nutrition programme, positive mixed positive results were seen.

Table 8: Summary of intervention types and results on the supply side (P=positive; MP=mixed positive; N=null; U=unclear)

	Non-financial	**Effectiveness**	**Reference**	**Financial**	**Effectiveness**	**Reference**
Supply	**Delivery of services close to home**			**Service level improvements**		
	Home visits by nurse or other health worker			Pay for performance for health care workers	MP	93
	Home visits by nurse to provide immunisation to those who did not attend appointments	P	28	Contractor delivery of primary health services (contracting-out vs contracting-in)	U	43
	Home visits by weighing agent who flagged abnormalities with GP and those in need provided with free consultations	P	31			
	CHW					
	Diarrhoea (ORS)	P	32			
	Malaria (IPTc)	P	87			
		MP	30			
		N	88			
	School based					
	School based schistosomaisis control programme (adolescents)	MP	90			
	Immunisation camps					
	Well publicised immunisation camps and food incentives	P	89			
	Service level improvements					
	Health worker training					
	Health worker training	P	37			
		MP	36			
	Scaling up of services					
	Strengthening of routine vaccination programme function	N	38			
	Integration of services					
	Integration of intermittent preventive treatment for children alongside EPI vaccines	P	34			
	Integration of HIV services with immunisation/ANC	P	35			
		N	39, 41			
	Combined interventions (Primary component service level improvement)					
	Health worker training, health systems improvements, family and community activities (e.g. formation of village health workers)	N	33			
	Integration of HIV and immunisation services, operational support, training for staff, counselling of caregivers, community awareness campaigns	N	92			
	Health worker training in youth friendly health services, outreach services, school based education, community mobilisation (adolescents)	N	91			

Table 9: Summary of intervention types and results on the demand side (P=positive; MP=mixed positive; N=null)

	Non-financial	**Result**	**Ref**	**Financial**	**Result**	**Ref**
Demand	**Health promotion/education programmes**			**Financial or other incentives**		
	Health worker			***Cash transfers***		
	Redesigned immunisation card, centre based education delivered by health worker	P	65, 66	Cash transfers (conditional or unconditional)	MP	74, 82
	Structured educational programme on childhood infections for mothers delivered by health worker	P	51		N	77, 78, 109
	Post-partum home visits by registered midwives to provide information, educate and support women	N	47	***Fee exemptions*** User fee exemption	P	73
	Vaccination recommendation by social paediatrician alongside phone call reminders (adolescents)	N	94		MP	75
	CHW			***Incentive schemes***		
	CHW home visits for pregnant women to promote newborn care, refer sick newborns	N	55	Food/medicine coupon incentive at each immunisation visit	P	79
		MP	50	Supplementary nutrition as monthly take home for children attending paediatric HIV/AIDS clinic	P	81
	Package of essential newborn care for pregnant women delivered by CHW	N	96	Pre-treatment snack, educational messages (adolescents)	N	107
	Postnatal educational programme delivered by CHW	N	48	***Combined interventions (primary component financial)***		
				Fee exemption, social mobilisation, education, improvement of service quality, financial monitoring	P	108
	Educational programme for mothers using pictorial cards about vaccinations delivered by CHW	P	97	Conditional cash transfer, strengthening of services	N	80
	Antenatal and postnatal home visits for pregnant women by CHWs to provide health messages	MP	57, 63, 98	Conditional cash vouchers, health service strengthening and community based nutrition programme	MP	83
	Antenatal and postnatal home visits for pregnant women by CHWs to provide health messages, assist with birth in absence of skilled care, manage illness where referral not available (sepsis, pneumonia), health facility strengthening	N	67			
	Other member of the community (teacher, volunteer, lay counsellor)					
	Educational programme on:					
	Newborn care	N	101			
	Vaccines	MP	44			
		N	61			
	HIV (adolescents)	P	99, 100			
	Reproductive health awareness campaigns, training peer educators in counselling and education, training of health providers (adolescents)	N	102			
	Women's groups					
	Women's groups with participatory models of communication, identification of problems, development, implementation and monitoring of strategies to improve maternal and neonatal problems	N	52, 54, 58, 60, 64			
	Combined interventions (Primary component education)					
	Women's groups, health systems strengthening, training of staff	P	45			
	Health promotion delivered by CHW, illness management, reporting, community development	P	95			
	Health education of families, identification of sick newborns in the community by CHW, health systems strengthening and strengthening of referral systems (including provision of free care and referrals)	P	46			
	Home visits by CHWs, training in improved case management of sick children, women's groups, strengthening of health systems	N	59			

Table 1: Summary of intervention types and results on the demand side (P=positive; MP=mixed positive; N=null)

	Non-financial	**Result**	**Ref**	**Financial**	**Result**	**Ref**
Demand	**Text messages**					
	Early infant diagnosis appointment reminders	P	70			
	HIV appointment reminders	P	69			
	Vaccination appointment reminders	P	103			
		MP	105			
	Cataract follow-up appointment reminders (adolescents)	P	104			
	Text messages providing health promotion for HIV	P	71			

Summary of findings from the literature review

The review was large, with 73 peer-reviewed articles from 66 studies. The review identified six broad groups of interventions that aim to increase access to health services for children in LMIC including:

- Supply side; non-financial
    - Delivery of services close to home
    - Service level improvements
- Supply side; financial
    - Service level improvements
- Demand side; non-financial
    - Health promotion/education
    - Text message reminders
- Demand side; financial
    - Financial or other incentives

The interventions identified in this review target different dimensions of health care access, as characterised by the Peters framework, both on the supply and demand side. On the supply side, delivery of services at or closer to home (by nurses, CHWs, school programmes or camps) target both geographical barriers and financial barriers by reducing the travel and opportunity costs associated with attending health services. Interventions designed to improve health services tackle issues of acceptability and availability aiming to increase quality services that meet the needs and expectations of users.

On the demand side, the most common interventions identified in this review was health promotion/educational programmes via different delivery modes addressing acceptability (i.e. aiming to influence user’s knowledge and attitudes), as well as geographical accessibility barriers (i.e. providing health promotion within the home or community). Text message reminders or health promotion target the acceptability dimension of access through the improving user’s knowledge and attitudes about the service. Finally, a group of interventions target the financial accessibility of services through providing financial assistance, for example cash transfers, vouchers and fee exception, or food incentives conditional on certain health seeking behaviours.

Evidence on the effectiveness of the interventions included in this review were mixed, even within the different intervention types. The two intervention types most consistently associated with a positive improvement in the uptake of health services for children were the use of text messages and the delivery of services closer to home.

Overall, few studies in the review were judged as having a high quality. This the review has highlighted a need for more rigorous research from a range of low and middle-income countries.

Discussion

The uptake of referral services by children identified in the KIMs was low, particularly for the children referred to hear and hearing services at QECH. Failure to receive appropriate treatment and management of impairments can have long-term consequences for children with disabilities and their families, including: poorer health and quality of life, higher mortality rates, lower rates of school participation and increased risk of poverty.[2, 8]

In the Child Disability KIM, Children from families with poorer socio-economic status were less likely to take up their referral compared to those from wealthier households. This supports previous findings, including a study of referral uptake from a KIM in Bangladesh and of access to health care in Malawi.[5, 110] Children with epilepsy were more likely to attend their referral, which also aligns with the Bangladesh KIM study.[5] However, this tells us only about uptake of the initial referral and not sustained use of appropriate epilepsy medication which is recognised as considerable challenge in different LMIC settings.[111, 112]. Uptake was much higher in Thyolo district than in Ntcheu. The reasons for this are unclear and requires further exploration, particularly in light of the low uptake from the Hearing Kim which took place in Thyolo.

Despite the differences in the study populations of the two KIM studies in terms of impairment types, the major reasons for non-uptake in the quantitative surveys were consistent: transport difficulties, lack of information about referral and financial barriers. The qualitative study, allowed us to explore these barriers in more depth.

Contrary to perceptions by some stakeholders who suggested reasons for non-uptake included a lack of awareness of the need for ear/hearing care and neglect of the child, the interviews with caregivers indicated they were motivated to seek help for their child. They had attended the screening camps and most had previously sought health services for their child's ear/hearing difficulties, indicating an underlying motivation to seek care. However, they experienced a range of barriers – distance, transport, costs, fear of hospital - which contributed to non-uptake. These findings echo previous research about barriers to accessing health care.[4, 8, 19] In addition, it was evident that many caregivers were confused about the referral process or were under the impression that they would receive a follow up visit from a health worker, which did not happen. This indicates limitations in the referral procedures at the KIM camps, which are likely related to the fact that they were extremely busy. This must be addressed in future KIM studies and community outreach screening activities. For many families reasons were multiple and inter-related. For example, in the context of severe financial constraints, lengthy, expensive travel to an unfamiliar setting coupled with lack of detailed information about what they were expected to do on arrival, prevented them making the journey to QECH.

These findings have identified several key areas that may be amenable to interventions to increase uptake of health and rehabilitation services. The systematic review has allowed us to summarise the available evidence on interventions that have been tested to improve health care access for children. In the next section, we discuss further the main barriers identified in the Malawian context, together possible strategies to tackle the barriers according to the findings of the systematic review (in boxes).

Location of hospital and lack of transport

The long distance over difficult terrain to the hospital and the lack of available transport presented significant challenges to accessing services in this largely rural, remote district of Malawi. Other studies have also highlighted geographical barriers to accessing health care.[4, 19] While ambulances are supposed to be provided at health centres for referrals to the hospital, in reality, because of limited resources, certain condition (e.g. maternal care) are prioritised and thus this was not option for people interviewed this study.

Indirect costs

Even in a context where most government health care is free at the point of care, the study has shown that financial insecurity was a significant reason for non-uptake of services.[113] In the quantitative survey of uptake from the Child Disability KIM, children living in poorer households were much less likely to attend their referral. In the qualitative interviews, many families were unable to pay the cost of travel to Blantyre by public transportation. Costs of food and loss of earnings due to taken the child to get to the hospital were also prohibitive

Box 2: Interventions to address transport and indirect costs

Location of service and lack of transport are related to the *geographic* and *financial accessibility* dimensions of access according to Peter's framework (see Box 1).

The systematic review identified several interventions that aimed tackle these barriers such as *delivery of services close to home* (supply side; non-financial). Interventions tested in this group were in general found to be effective. Services were delivered by a range of health personnel including community health workers and health professionals, both showing promising results.

Access to specialist health/rehabilitation services might therefore be increased by upgrading services at community and district hospital levels, either by increasing skills and competences of CHWs in remote communities to perform effective health promotion and basic treatment, or by increasing the frequency of outreach visits by referral hospital staff to remote communities.

In Malawi, there is a well-established system of community health workers (HSAs) who play an important role in service delivery. In the Hearing KIM, they were trained to identify people with ear and hearing issue. Therefore, one strategy that deserves attention in this context is increasing the capacity of HSAs to deliver, for example, basic ear and hearing services and facilitate referral uptake. This would need to be done with consideration to the already multiple responsibilities of HSA's in Malawi to ensure that other programmes they work on were not negatively impacted.[114, 115]

No interventions providing or facilitating transport to health services were identified in the review. This may deserve further attention, particularly in the context of outreach activities (e.g. KIM camps) where several people in a community are referred: provision of group transport may reduce costs and also provide a sense of "safety in numbers" and help to address the fear/uncertainties regarding the hospital.

In terms of financial accessibility, interventions that targeted this dimension included cash transfers, fee exceptions and food incentive schemes. The results from these studies were varied. Food incentives interventions that showed promise however, there were only two studies so further research is necessary. Malawian health services are already free at the point of care for items in the Essential Health Package, thus user fee exemption as an intervention is not relevant for this setting.

Cash transfers have been an area of interest in many Latin American countries and is gaining traction in sub-Saharan Africa. The results of our review found limited evidence of a positive impact on health care utilisation and immunisation uptake for children. Our findings contrast somewhat to a systematic review by Lagarde et al (2007) which concluded that these programmes are effective in increasing the use of preventive services.[116] However, the authors confirmed the dearth of evidence on the topic and many of the studies included were from grey literature sources or used study designs that did not meet our inclusion criteria. In addition, the previous review did not have a specific focus on children. Thus, further investigation in to whether cash transfers could assist with uptake of referral in Malawi is warranted.

Fear and uncertainty regarding the hospital

Given the challenges of transportation outlined above, it is not surprising that many caregivers had never been to Blantyre let alone to QECH. Many caregivers were unfamiliar with the hospital, perceived it as a big place and were concerned they would easily lose their way. Caregivers expressed concern about waiting times and availability of appropriate staff at QECH based on previous experiences seeking care.

Insufficient information about the referral

Lack of information on referral at the screening camp was a significant factor in the non-uptake. Many caregivers were uncertain about the referral process including where and when to attend. This is likely to have contributed to the fear and uncertainty they felt regarding the hospital. This suggests that insufficient time, perhaps due to the busy camps, was spent with families explaining about the child's diagnosis and the referral process.

This study focusses on uptake of referral from camps conducted as part of KIM research projects, however, the negative impact of poor communication on uptake is noted across different health care settings.[117] Disability-inclusive communication and fair treatment by health workers are identified by the World Report on Disability as key areas of development required for overcoming barriers to access.[1]

This study has highlighted a critical need for more effective communication to convey key messages to caregivers about the child's health condition, treatment options and referral process. Adequate time must be spent on counselling families and the information needs to be provided in a clear and accessible way. As the KIM screening camps are usually crowded, this will likely require employing additional staff dedicated to this task or the support. KIs or HSAs could play this role and also facilitate subsequent uptake of referrals.

Box 3 Interventions to address lack of information and fear/uncertainty of the hospital

Lack of information about the referral and fear/uncertainty of the hospital relate to the *acceptability* (caregiver knowledge and attitudes) and *availability* aspects of access. The systematic review identified some interventions that tackle these dimensions. For example 27 studies evaluated educational interventions. However, the evidence for these was very mixed. Service level improvements, through health worker training in general found a positive impact on access to services. However, there were few studies in this group and thus further investigation is required.

Studies evaluating text message reminders in general found positive effects on access to outcomes. With evolving mobile phone technology and rapidly increasing numbers of mobile phone users in LMIC, there is increased interest in the use of this relatively low cost technology within health services.

There is a need to identify and evaluate the most effective methods for communication of information for children identified in the community as needing referral to impairment specific health and rehabilitation services. Counselling could be undertaken for example by trained health workers, HSAs or peer educators. The use of text message as additional means of communication reminder also deserves attention.

Lack of availability and visibility of ear and hearing services

The limited availability of ENT personnel as well as the lack of visibility of ear and hearing services at the hospital were raised as challenges to accessing appropriate ear and hearing care. There was concern among caregivers, sometimes based on previous experience at the health centre, that even if they travelled the hospital they may not be seen. This was supported by stakeholders, who felt that the presence of audiology and ENT services at QECH was not common knowledge amongst staff from other departments. As a result, patients may not reach the services they need and this may deter patients from attending.

Box 4: Interventions to address availability and visibility of ear and hearing services

The systematic review identified some interventions that tackle the dimensions of *acceptability* (caregiver attitudes about the hospital, aspects of service delivery) and *availability* (health workers at the hospital) dimensions of access. Service level improvements, through health worker training in general found a positive impact on access to services and this should be investigated further. Other service level improvement interventions were more varied (integration of services, scaling up of services).

The specific concerns regarding visibility of ear and hearing services suggest a need to raise awareness of all staff at QECH about service availability, as well providing hospital maps/directions. The lack of ENT personal and equipment throughout the health system is more a complex challenge in this resource-constrained setting. As described above, the training of HSAs at community level, to deliver basic ear and hearing care and facilitate referral described above, is one strategy that deserves attention.

Strengths and limitations

Strengths

The quantitative follow up surveys had high response rates and allowed us to explore uptake and barriers to uptake in two different study populations using comparable methods. The qualitative interviews enabled us to explore reasons for non-uptake in more depth. The similarity in findings on the major reported barriers between the two quantitative surveys as well as between the quantitative and qualitative data, lends weight to the reliability of the findings.

The review is the first comprehensive systematic review of interventions to increase access to health care with a specific focus on children in LMIC. The review was large, including 66 studies. We used a systematic approach to searching, screening, appraising and extracting data checked by two reviewers. We attempted to minimise citation bias through reviewing references of included studies and relevant systematic reviews.

Limitations

In the Child Disability KIM, children were referred to a range of different services, provided in different ways, which may have influenced uptake, but was not well captured in this study. Further, we did not assess severity of the impairment, which may also have influenced uptake. In-depth interviews were conducted at health centres due to logistical constraints. Although the response rate was reasonable, it is possible that this will have resulted in under-representation from families with children with more severe impairments who could not reach the centre. Qualitative interviews for hearing KIM were also conducted in health centres, rather than the participant's home for pragmatic reasons and thus caregivers may have responded differently to if they were interviewed in a familiar environment. However, we made efforts to limit this risk by ensuring the interview room was always private and experienced researchers familiar with qualitative interview techniques conducted the interviewers.

There were some limitations to the systematic review that should be taken into account when interpreting the findings of the review. Although we did not restrict our search in terms of language, we only used English search terms and few French or Spanish citations were retrieved. Therefore, relevant evidence from francophone Africa and Latin America may have been missed. While the broad nature of our review question was effective in highlighting the range of different intervention approaches it precluded a detailed analysis of each intervention type and potential mechanisms to be theorised and this deserves further attention.

We included only peer-reviewed studies that employed RCT, non-RCT, controlled before after study, historically controlled study and interrupted time series designs to reduce risk of important biases. However, interventions addressing health care access are often complex and challenging to evaluate using a trial design. We may therefore have missed interventions of interest evaluated using other study designs or published in grey literature.

This review did not explore the quality of the interventions that were delivered or the impact on equity and thus warrants further investigation. Finally, the vast majority of studies included in this review did not assess cost-effectiveness of the interventions. Further attention is needed to understand this aspect of these interventions.

Conclusion and recommendations

Uptake of referrals for health and rehabilitation services for children in these two districts in Malawi was low. Transport difficulties, lack of information regarding the referral and financial constraints were most commonly reported as reasons for non-uptake. Families referred to QECH for ear and hearing services experienced a range of interacting barriers which contributed to non-uptake - distance, transport, costs, lack of information about referral process, fear/uncertainty of QECH and a lack of ear and hearing resources and staff. The systematic review fills a gap in the literature by identifying the range and effectiveness of interventions that can be used to increase health care access for children in LMIC. It highlights some intervention areas that show encouraging trends to address some of the barriers to referral uptake. Delivery of services at or close to home could be used to address distance, transportation issues and the lack of resources through task shifting to community health workers (HSAs). Text message reminders have the potential to address communication challenges, fear and unfamiliarity of the hospital. Further evidence is also required on health worker training to address communication challenges, and improve aspects of the referral hospital. Evidence on educational interventions in the review was more varied. Further investigation of this is urgently needed considering that lack of information and understanding about the referral process was such a significant factor in non-uptake in our studies. It is recommended that increased efforts to further evaluate these interventions are conducted in LMIC. In the review, no studies were identified that focussed on children with disabilities, and thus it is important to evaluate how effective these interventions are amongst this group.

Summary of recommendations

Potential strategies to overcome the barriers identified in this study, that need evaluating through robust research, include:

- Increase health and rehabilitation services at community and district hospital levels, for example, by:
    - Increasing outreach by staff at referral hospitals to remote communities
    - Developing the capacity of community health workers such as Health Surveillance Assistants in Malawi (of which there are >10,000 in the country) to deliver basic ear and hearing care at community level and to facilitate uptake of referrals
- Providing effective communication about the child's diagnosis and referral process. Further research is needed to develop and evaluate effective communication or counselling strategies as well as explore use and impact of text message information/reminders
- Providing group transport from rural communities to referral hospitals
- Raising awareness of staff at tertiary hospitals about the ENT services available

Given that reasons for non-uptake were often multiple and interacting, a combination of these strategies may be important to improve access.

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Appendices

Appendix 1 Clinician responsible for examination of children in the Child Disability KIM Screening camp

Impairment/health condition	**Staff**
Epilepsy	Nurse
Intellectual impairment	Nurse
Moderate/severe physical impairment	Orthopaedic clinical officer
Moderate/severe vision impairment	Ophthalmic clinical officer
Moderate/severe hearing impairment	ENT clinical officer and Audiologist

Appendix 2: Semi-structured interview guide for stakeholders (Part B)

Icebreaker

Can you tell me about your role?

Prompts:

- How long have they been in that role?
- What is their main responsibility?
- How many staff are they responsible for?
- What geographic area they cover (national or regional/local remit).
- How does your work relate to children with hearing loss?
- What are the common issues you see at the health clinic with ears and hearing? What is the main reason parents usually bring their child?
- How are people referred to you?
- How old are the children that normally come?
- What is done to manage ear and hearing issues at this level? What services are available for people with hearing loss?
- How are you connected with QECH?

So you have been in your role for XXX years, and have a wealth of experience from which we can learn from. It will be great to hear more about this.

We would like to explore the main facilitators and barriers to the uptake of ear and hearing services for children in this setting. Let us start with what you think might be helping people come for services starting with at the family level.

At a family and community level

- What do you think the main challenges which families face in accessing health services generally and specifically for children with hearing impairments (prompts: transport, finances, attitudes, perceptions of priority, lack of knowledge, past experiences of health services)?
- What do you think are the enablers for attending services? (currently)
- What do you think are the main attitudes towards children with hearing impairments and their access to health services?
- Are there any cultural beliefs about hearing impairment?
- What are the attitudes towards children with hearing impairments and their access to health services?
- Are children with hearing impairment included in education, other services? Excluded? Other health services?

At screening camp (provide description for those who were not involved)

- What do you think are the benefits/shortcomings of using this approach for referring children with hearing impairment?
- What improvements do you think could be made?
- How do you think families generally understand the need for services for their child after referrals are made at the camps?
- For HSAs
    - How did you go about identifying children in the community for the camps? What did you usually say when you were informing them about the camps?

    - Were you aware of how the referral process would work? Or How did you understand the referral process would work?

At hospital

- Once children/families arrive at the hospital, what do you think are the barriers in place at this level?
- Do you think there are any issues which affect inclusion of children in health and rehabilitation services (prompts: accessibility, communication difficulties, waiting times, staff attitudes)?

At a national policy level

- Get an overall picture of who is responsible for treatment and rehabilitation provision for children with hearing impairment at the district level? Which ministerial offices responsible for what? How is government policy impacting upon access to these services? What's working well, less well, change as a result of any new policies.
- How does your role fit in to the national picture? How do you connect with other health workers in the system- at other levels?
- Prompts: disability legislation, policy Issues related to the policy environment, implementation of the policy, budgetary allocation, ministerial roles and responsibilities for children with disabilities, training of health staff

Recommendations

- Recommendations to address some of the issues above (refer back to specific issues) to improve uptake of ear and hearing services for children with hearing impairment
- What improvements do you suggest in your health centre? At the family level? At the national level? At the hospital level? At the screening camps
- Eg. You mentioned that there were problems with XXXX, how do you think this could be overcome?

Other

- Are there any other important 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 through the XXX. This will be in 2-3 months' time, once we've had time to look at all the information from the parents and children.

Appendix 3: Semi-structured interview guide for caregivers and children (Part B)

Introduction:

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 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.

Information about child to be extracted from database (before interview)

- Age
- Name
- Diagnosis
- Recommendations
- Barriers reported in quantitative study

About your Family (Icebreaker)

Please tell me about your family

a) Prompts: Who lives in the house? Number of children living in the household? (age, sex) Are all the school-age children going to school? If not, why not? What grade are they in at school? Is this age appropriate grade? Who is working in the house? What kind of work?
b) Who is involved in caring for the child?

About the child's ear or hearing issues

a) *Understanding of hearing loss and causes*

Please tell me about your son/daughter who was seen at the camps in (Jan)

- *Get a sense of understanding of child's hearing difficulties or troubles with ears (check diagnosis, if conductive/chronic middle ear issues questions might be slightly different)*
    - How is [name's] hearing?
    - When did you first notice it? Did you seek care at the time? Why/why not? Who first noticed the issue? Was it noticed at home or at school?
        - *If problems with middle ear:* How many times has he/she had this issue? When was the first time? What usually happens when he/she has the issue?
    - Diagnosed prior to the camps?
        - If yes, when?
        - Where?
        - Who went with the child?
        - What happened?
        - What were you told?
        - Did the child receive any treatment?
            - If so, what was that treatment?
        - Did it make a difference for the child?

            - If the treatment stopped or child stopped using the device, why was this?
            - If treatment was surgery or medication, explore if the issue recurred (eg. recurring ear infections, perforations, discharge). Any complications from the surgery?
            - If problem has happened more than once, how often did it happen? did you seek care each time?
        - What do you think caused the condition?
        - Why do you think the child has the condition?
        - What do your family/husband think?
        - Do you know anybody else with this condition? Other family members? Did you know about the condition before your child experienced it?
            - Note: some children in sample have family history, might be worth checking if anyone else in the family has any problems with their hearing and how it affected them.
            - Did they seek care for the sibling? Or other family member?
    - Has the child ever seen a traditional healer because of the ear/hearing problem?

a) Impacts of hearing loss
    - Does hearing loss have an impact on [name's] life? (*Note: If no, move on. If yes, explore what that impact might look like.)*
        - Pick up on any issues noted. Eg. unable to speak, explore how that affects family/child.
    - What things does she/he find more difficult or not possible for your child to do, that other children of the same age can do? Please tell me about his/her day – does she go to school/is able to help around the house (kind of assistance needed)
    - If child goes to school, how is he/she going? Any difficulties? Any support from the teacher
    - What is she/he able to do?
    - How does it impact parent's life/other family members?
    - How do other family members treat your child?
    - Communication difficulties?
    - How do you try to overcome the communication difficulties?

b) Interviewer note: any other observable health conditions hearing loss?
    - We have talked a lot about [name's] hearing, are there any other concerns you have about their health? (*Separate this question from hearing unless it comes up naturally)*
    - If yes, ask about care seeking for that condition? Eg. Do you have to go to the health centre for this and how often?

Treatment-seeking behaviour – understanding of diagnosis and referral

(Interviewer Note: This is NOT about checking up on them for not going – emphasise about learning from their experience)

Check what they recall about the screening camp and understanding of diagnosis/referral:

a) Do your remember the 'camp' – held at XX (camp location) - which you attended with your child in Jan/Feb this year. We would like to learn more about your experience from this camp.
   - How did you hear about the camp?
   - What did you think might happen at the camp?
   - What happened at the camp? How long did you wait? How far did you travel? How did you travel?
   - What were you told about your child's ear/hearing? Did the doctor explain the results to you?
   - What were you told about possible services available to help your child?
   - Did you understand what the doctor told you?
   - (*Note: if required hearing aid:* Did they tell you that you needed a small gadget to help your child hear? Do you know what a hearing aid is? *Show picture of a child wearing hearing aid.* Do you know how much this hearing aid might cost?
   - Note: If surgery required: did caregiver understand what that surgery would involve? How much it would cost?)
   - Do you remember being given any referral form, notes written in health passport or advice?
   - Can you show me what you received?
     - If yes – what did you do?
   - What did you understand would happen at the follow-up appointment?
   - Do you think your child's ear/hearing problem can be improved (or cured). If yes, how?
   - Note: if they say they were waiting for information: did the health surveillance assistant talk to you about going to Queens?

b) Past experiences
   - Also ask about past experiences of services that may inform their decision to attend/not attend a new referral (positive/negative experiences). What kind of treatment do you like?
     - When someone is ill, what do you do?
     - Something here about serious illnesses, would they go to QECH? Priorities?
     - Where is the nearest clinic?

Barriers to attending referral

(Explore main reasons for not attending referrals - aim to get concrete examples where possible rather than generalisations)

- What did you understand about the referral? *(Note: if identified difficulties, pick up on these)* What was the referral?
- What are the main reasons are for your child not going to the hospital for their hearing problem? What might be some of the challenges you or your

child face in accessing help for hearing? Prompt more, ask specific questions about each barrier that is arising.
    - *Note: Prompt if necessary: eg. a lot of caregivers have said that [cost, knowledge of cost, transport, availability of information on service, stigma, lack of time, family members] was the reason why they did not go to hospital. Explore these topics further. Eg. If transport is a problem, why? What are the distances – how long to get there, cost of transport, does someone have to accompany the mother and child, time off work etc, caregivers for other childen? If cost is perceived as an issue: how much do services cost? Is it difficult for you to pay for services?*
    - *If there are a number of reasons, ask parents to rank the main reasons and explain why they have ranked them in that way (A small ranking exercise here on card)*
- What do you think would happen at the hospital if you attended with your child? Were multiple followups required?
- Did you know what was going to be offered when you attended the appointment at the hospital?
- Would you like to followup on your referral? If no, why not?

Enablers to attending hospital

- What might be useful for overcoming some of the challenges that you mentioned? Are there any suggestions you have for improving uptake of services? Is there anything that you think would help your child to attend their hospital referral. What support would you like to attend the referral?
- If the parent was told the child needed a hearing aid, do they think that is worth investing in?

Summarise main points of interview back to participant, to check understanding. Is there anything else that we haven't covered about that you would like to add? Is there anything else you would like to tell me about your situation?

Thank you for your time. We will be providing feedback through the XXX. This will be in 2-3 months time , once we've had time to look at all the information from the parents and children.

Appendix 3: Semi- structured interview guide – with Child (> 8 years)

Introduction:

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 participant 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.

We would like to ask you a few questions about yourself and your experiences:

- Icebreaker: How old are you? Do you go to school?

- If go to school: what grade are you in? Do you enjoy school? What do you enjoy about it? Do you have any difficulties? How do you feel most of the time when you are at school? Where do you sit in the classroom? Can you hear the teacher?
- Tell me about your hearing? Any problems? When did you first notice it?
- Any difficulties experienced at home? School? Community? Playground? Friends?
- Tell me about your experience at the screening camp? Referral? Understanding of diagnosis? Treatment? (*Older children ask directly, could use photographs for the younger children)*
- What would you like to do in the future?

Thankyou

Appendix 4: Search strategy

	Concept	**Number of hits**
A	**Population**	
1	child/	1529952
2	infant/	588992
3	exp paediatrics/	95214
4	(child* or infant* or p?ediatric*).ti,ab	1934384
5	exp handicapped child/	8130
6	("children with disabilit*" or "people with disabilit*" or pwd or "persons with disabilit*" or "individuals with disabilit").ab,ti.	6255
7	exp adolescent/	1328092
8	"adolescen*".ti, ab.	258384
9	1 or 2 or 3 or 4 or 5 or 6 or 7 or 8	3306882
B	**Intervention - Setting**	
10	exp health program/	98631
11	exp health service/	4080400
12	exp health promotion/	76003
13	exp rehabilitation/	291352
14	exp immunization/	257019
15	exp health care/	3838165
16	("health adj5 access" or "community hospital" or "health care" or "health services" or "rehabilitat*" or therap* or treatment).ab,ti.	6644190
17	10 or 11 or 12 or 13 or 14 or 15 or 16	9451205
C	**Intervention - Strategies**	
18	(barrier* or facilitator* or uptake or usage or intake or access* or adherence or compliance or complian* or adher* or promot* or increas* OR prevent* or reduc* or program* or educat* or campaign* or predict* or determin* or behavio#r*).ab,ti.	12511153
19	((barrier* or facilitator* or uptake or usage or intake or access* or adherence or compliance or complian* or adher* or promot* or increas* OR prevent* or reduc* or program* or educat* or campaign* or predict* or determin* or behavio#r*) adj3 (health* or ill or illness or ills or well or wellbeing or wellness or poorly or unwell or sick* or disease*)).ab,ti.	576682
20	18 or 19	1251153
D	**Study design**	
21	Clinical trial/	859727
22	exp controlled clinical trial/	530729
23	exp experimental design/	12337

24	exp experiment/	2254758
25	exp feasibility study/	61100
26	"clinical trial".ab,ti.	129856
27	"controlled clinical trial".ab,ti.	12879
28	"randomi#ed controlled trial".ab,ti.	70586
29	randomi#ed.ab,ti.	588698
30	(trial or rct).ab,ti.	582657
31	"intervention study".ab,ti.	8364
32	"quasi randomi#ed".ab,ti.	3127
33	((clin* or control* or compar* or evaluat* or prospectiv*) adj3 (trial* or studi* or study)).ab,ti.	2116839
34	21 or 22 or 23 or 24 or 25 or 26 or 27 or 28 or 29 or 30 or 31 or 32 or 33	5055412
E	**Country**	
35	exp Developing Country/	83201
36	(asia or africa or "south america" or "developing count*" or "low middle income countr*").ti.	55505
37	35 or 36	125953
	A + B + C + D + E	
38	9 and 17 and 20 and 34 and 37	1961

Appendix 5: Data extraction from systematic review

Appendix 5a: Delivery of services close to home (supply side; non-financial)

	Author (Year)	Country and setting	Design and population	Intervention (Int) and control (Con)	Main outcome of interest (HCU= health care utilisation; I=immunisation; C=compliance)	Result summary	Targeted barrier (according to Peter's framework)
CHWs							
1	Patouillard (2011)[118]; Kweku (2009)[29]	Ghana, rural	cRCT; Children aged 3-59 months; n=1,456	Int: Community based delivery of IPTc by CHW Cont: Facility based delivery of IPTc	C: Proportion of children who received all for courses of IPTc	Null	Geographic: service location
2	Seidenburg (2012)[30]	Zambia, rural	cRCT; Women aged 14-45 years who had at least one child; n=440	Int: CHW taught to perform rapid diagnostic tests and administer malaria medication or antibiotics Con: CHW supplied with malaria medication for treatment of suspected malaria and referred non severe malaria cases to health centre	HCU: First source of care for any illness	Mixed positive	Geographic: service location Availability: health workers, drugs
3	Tin (2014)[32]	Myanmar, rural	cRCT; Children <5 years; n=104 village tracts	Int: Delivery of ORS and zinc by CHW Con: Usual services	HCU: Use of ORS plus zinc for diarrhoea	Positive	Geographic: service location Availability: health workers, drugs
4	Bojang (1998)[27]	The Gambia, rural	cRCT; Children <6 years; n=12,326	Int: Delivery of IPTc by CHW	C: coverage of 3 IPTc treatment courses	Positive	Geographic: service location

				Con: Delivery of IPTc by RCH trekking teams			Availability: health workers, drugs
5	Brugha (1996)[28]	Ghana, rural	cRCT; Children aged 12-18 months; n=419	Int: Home visits to perform immunisation for children who did not attend appointments C: No home visits	I: Complete vaccination (BCG, polio, DPT3, measles)	Positive	Geographic: service location Availability: health workers, drugs
Health professional							
7	Banjeree (2010)[26]	India, rural	cRCT; Children 1-3 years, n=2,188	Int: Well publicised immunisation camps plus/minus food incentive Con: Usual services	I: Probability of completing the EPI	Positive	Geographic: service location Availability: demand for services Acceptability
8	Simonyan (2013)[31]	Mali, urban	CBA; Children aged 0-72 months; n=180	Int: Home visits for children by health worker who flagged abnormalities with GP and those in need provided with free consultations Con: Usual care	HCU: Medical consultations for children with reported disease episodes	Positive	Geographic: service location Financial: cost and prices of services
Other							
9	Favre (2015)[90]	Brazil, mixed	RCT; Children aged 6-15 years; n=3,092	Int: School based schistosomiasis control programme	C: Treatment compliance	Mixed positive	Geographic: service location

				Con: Community based schistosomaisis control programme			

Appendix 5b: Service level improvements (supply side; non-financial)

	Author (Year)	Country and setting	Design and population	Intervention (Int) and control (Con)	Main outcome of interest (HCU= health care utilisation; I=immunisation; C=compliance)	Result summary	Targeted barrier (according to Peter's framework)
Health worker training							
1	Mohan (2004)[36]	India, rural	cRCT; mothers of children < 5 years; n=2,460	Int: Training for doctors in counselling, communication, clinical skills Con: Training for doctors in clinical skills alone	HCU: Care seeking behaviour for sick children	Mixed positive	Availability: Health workers Acceptability: characteristics of health services
2	Robinson (2001)[37]	Indonesia, mixed	CBA; Children age 12-23 months; 12 participating health centres	Int: Immuniser training immuniser peer training programme Con: No training	I: Number of age appropriate doses DPT1, polio and measles	Positive	Availability: Health workers
3	Aninyana (2015)[119]	Ghana, mixed	cRCT; Adolescents aged 10-24 years; n=2,664	Int: Health worker training in youth friendly health services, school based sex education, peer outreach, community mobilisation Con: Health worker training and community mobilisation only	HCU: STI management service usage; HIV testing and councelling service usage	Mixed positive	Acceptability: user's attitudes, knowledge and expectations Availability: health workers health workers Geographic: service location
Scaling up of services							

4	Ryman (2011)[38]	India, rural	CBA; Children 12-23 months, n= 3,681	Int: Strengthening routine vaccination programme functions Con: Usual services	I: Proportion children fully vaccinated (BCG, DPT, polio, measles)	Null	Acceptability: characteristics of health services; user's attitudes and expectations. Geographic: service location. Availability: health workers, systems improvements.
Integration of services							
5	Dicko (2011)[34]	Mali, rural	cRCT; Children aged 0-23 months; n=1,050	Int: Integration of intermittent preventive treatment for children alongside EPI vaccines Con: Usual services	I: Proportion of children completely vaccinated (BCG, DPT, polio, measles, yellow fever)	Positive	Acceptability: characteristics of health services Availability: drugs
6	McCollum (2012)[35]	Malawi, urban	CBA; Children offered HIV testing at immunisation or under 5 clinics; n=1,757	Int: Integration of early infant diagnosis into immunisation clinics Con: Early infant diagnosis at under 5 clinic	HCU: Uptake of provider initiated counselling and testing; uptake of PCR testing	Positive	Availability: health workers, drugs, equipment; systems improvements; demand for services
7	Turan (2015)[39]; Washington (2015)[41]	Kenya, rural	cRCT; Pregnant HIV positive women >18 years; n=1,172	Int: Integrated antenatal care, PMTCT and HIV care services	HCU: infant HIV testing by 3 and 9 months of age	Mixed negative	Availability: health workers, drugs, equipment; systems

				Con: Routine services	C: Infant’s ARV use		improvements; demand for services
Combined interventions (primary component service level improvement)							
8	Arifeen (2009)[33]	Bangladesh, rural	cRCT; Families utilising government health facilities; n=20 catchment areas	Int: Health worker training, health systems improvements, family and community activities (eg. Training village health workers) Con: Usual services	HCU: Proportion of children ill in the last 2 weeks taken to appropriate provider; referral completion I: Measles vaccination coverage for children aged 12-23 months	Mixed positive	Availability: health workers, systems improvements. Geographic: service location. Acceptability: characteristics of health services
9	Wang (2015)[40]	Zambia, rural	cRCT; Children attending under 5 clinic; n=40 facilities	Int: Integration of HIV testing and immunisation services, operational support, training for staff, counselling of caregivers, community awareness campaigns Con: Usual care	HCU: Average number of DBS tests I: Average number of DPT1 doses	Null	Availability: health workers; systems improvements; demand for services. Acceptability: user's attitudes, knowledge and expectations

Appendix 5c: Service level improvements (supply side; financial)

	Author (Year)	Country and setting	Design and population	Intervention (Int) and control (Con)	Main outcome of interest (HCU= health care utilisation; I=immunisation; C=compliance)	Result summary	Targeted barrier (according to Peter's framework)
1	Schwartz (2004)[43]	Cambodia, rural	Non-randomised trial; Children aged 12-23 months; n=1,825	Int: Contracting in or contracting out health service delivery Con: Traditional government model	I: Percent children fully immunised (BCG, DPT, polio, measles)	Unclear	Availability: Service level improvements
2	Basinga (2011)[42]	Rwanda, mixed	cRCT; Children < 6 years' n=166 health facilities	Int: Pay for performance scheme for health workers Con: Standard service	HCU: Younger than 23 months' preventive visit; 24-59 months' preventive visit in previous 4 weeks I: Aged 12-23 months fully immunised according to national schedule	Mixed positive	Availability: Service level improvements

Appendix 5d: Health promotion/**e**ducation (demand side; non-financial)

	Author (Year)	**Country and setting**	**Design and population**	**Intervention (Int) and control (Con)**	**Main outcome of interest (HCU= health care utilisation; I=immunisation; C=compliance)**	**Result summary**	**Targeted barrier (according to Peter's framework)**
Health workers							
1	Fatugase (2013)[51]	Nigeria, rural	Non randomised trial; mothers or caregivers of children < 5 years; n=400	Int: Structured educational programme on childhood infections for mothers delivered by health worker Con: No educational programme	HCU: Source of information on infection and treatment; proportion commencing treatment after symptom recognition	Positive	Acceptability: user's attitudes, knowledge and expectations
2	Usman (2009)[65]	Pakistan, urban	RCT; Children visiting EPI centres for DPT1; n=1,506	Int: Redesigned immunisation card, centre-based education or both Con: Standard care	I: DPT3 immunisation completed during 90 days followup	Positive	Acceptability: user's attitudes, knowledge and expectations
3	Usman (2011)[66]	Pakistan, rural	RCT; Children visiting EPI centres for DPT1; n=1,500	Int: Redesigned immunisation card, centre-based education or both Con: Standard care	I: DPT3 immunisation completed during 90 days followup	Positive	Acceptability: user's attitudes, knowledge and expectations
4	Bashour (2008)[47]	Syria, urban	RCT; women who delivered healthy newborn; n=876	Int: postpartum home visits by registered midwives to provide information, educate and support women	I: Immunisation status at 3 months (according to the national schedule)	Null	Geographic: Location of provider.

				Con: No home visits			Availability: health workers
5	Camurden (2015)[94]	Turkey, urban	CBA; Children with diabetes under 20 years; n=231	Int: Vaccination recommendation by social paediatrician and up to 2 phone call reminders Con: One phone call reminder. Hospital controls.	I: Vaccination status (Hep A, Hep B, measles, mumps, varicella, mumps, PCV, Td)	Mixed positive	Acceptability: user's attitudes, knowledge and expectations
Community health workers							
6	Bolam (1998)[48]	Nepal, urban	RCT; pregnant women; n=540	Int: Postnatal health education programme for mothers delivered by CHW Con: No health education	I: Uptake of immunisation at 6 months (DPT, polio, BCG)	Null	Acceptability: user's attitudes, knowledge and expectations
7	Darmstadt (2010)[50]	Bangladesh, rural	cRCT; women aged 15-49 years; n=10,700 pregnancy outcomes	Int: CHW home visits for pregnant women to promote birth and newborn care, refer sick neonates, facilitate compliance Con: Standard care	HCU: Number of neonates with 1 or more of 10 complications receiving any treatment; or qualified provider	Mixed positive	Geographic: service location Availability: health workers Acceptability: user's attitudes, knowledge and expectations
8	Kirkwood (2013)[55]	Ghana, rural	cRCT; pregnancies that ended in livebirth; n=16,329 births	Int: CHW home visits for pregnant women to promote newborn care, assess newborns and refer sick neonates	HCU: Care seeking (sick babies taken to hospital or clinic)	Positive	Geographic: service location

				Con: Standard care			Availability: health workers Acceptability: user's attitudes, knowledge and expectations
9	Kumar (2008)[56]	India, rural	cRCT; pregnant women in the study area; n=3,890	Int: Package of essential newborn care for pregnant women delivered by CHW Con: Standard care	HCU: Care seeking providers used for infant; percentage regular clinic visit	Mixed positive	Geographic: service location Availability: health workers, equipment Acceptability: user's attitudes, knowledge and expectations
10	Le Roux (2013) [57]; Rotheram-Borus (2014)[63]	South Africa, urban	cRCT; pregnant women; n=1,238	Int: Antenatal and postnatal home visits for pregnant women by CHWs to provide health messages Con: Standard care	HCU: Infant HIV PCR testing at 6 weeks I: Number of 6 and 18 month immunisations C: Infant NVP, AZT post birth	Mixed positive	Availability: health workers Acceptability: user's attitudes, knowledge and expectations
11	Owais (2011)[62]	Pakistan, urban	cRCT; children < 6 weeks; n=366	Int: Educational programme for mothers using pictorial cards about vaccinations delivered by CHW	I: DPT3/Hep B immunisation rates at 4 months after enrolment	Positive	Acceptability: user's attitudes, knowledge and expectations

				Con: Verbal receipt of health promotional messages delivered by CHWs			
12	Tomlinson (2014)[120]	South Africa, urban	cRCT; pregnant women aged 17 and older; n=3,494	Int: Antenatal and postnatal home visits for pregnant women by CHWs to provide health messages Con: CHWs provided information on accessing social welfare grants and conducted home visits	HCU: proportion of exposed infants having HIV test at 6 weeks; clinic visit in first week of life; uptake of cotrimoxazole	Mixed positive	Availability: health workers Acceptability: user's attitudes, knowledge and expectations
13	Waiswa (2015)[67]	Uganda, rural	cRCT; pregnant women and their newborns; n=395	Int: Antenatal and postnatal home visits for pregnant women by CHWs to provide health messages, assist with birth in absence of skilled care, manage illness where referral not available (sepsis, pneumonia), health facility strengthening Con: Standard care, facility strengthening	HCU: Care seeking outside home for infants with a danger sign	Null	Geographic: service location Availability: health workers Acceptability: user's attitudes, knowledge and expectations
14	Tomlinson (2014)[120]	South Africa, urban	cRCT; pregnant women aged 17 and older; n=3,494	Int: Antenatal and postnatal home visits for pregnant women by CHWs to provide health messages Con: CHWs provided information on accessing social welfare grants and conducted home visits	HCU: proportion of exposed infants having HIV test at 6 weeks; clinic visit in first week of life; uptake of cotrimoxazole	Mixed positive	Geographic: service location Availability: health workers Acceptability: user's attitudes, knowledge and expectations

Other community member							
15	Andersson (2009)[44]	Pakistan, rural	cRCT; Children < 5 years; n=1,867	Int: Informed structured discussions with community members on vaccine costs and benefits Con: No structured discussions	I: Measles vaccination uptake; full DPT vaccination	Mixed positive	Acceptability: user's knowledge, attitudes and expectations
16	Hanson (2015)[53]	Tanzania, rural	cRCT; women of aged 13-49 years; n=1,060	Int: Home based counselling strategy delivered by female volunteers promoting birth and neonatal care Con: Standard facility based care	HCU: Referral to hospital for very small babies	Null	Acceptability: user's attitudes, knowledge and expectations Geographic: service location
17	Oche (2011)[61]	Nigeria, urban	CBA; Children < 2 years; n=358	Int: Health education about immunisation delivered by community volunteer Con: Standard care	I: Proportion immunised (DPT3)	Null	Acceptability: user's attitudes, knowledge and expectations
18	Bhana (2014)[99]	South Africa, mixed	RCT; Children 10-14 years enrolled in HIV care; n=65	Int: Collaborative HIV prevention and adolescent mental health family programme delivered by lay counsellor Con: No educational programme	C: Youth adherence to ART	Positive	Acceptability: user's attitudes, knowledge and expectations

19	Burnett (2011)[100]	Swaziland, urban	RCT; students in grades 9 and 11; n=135	Int: Educational programme delivered by teacher including: Life skills for HIV, awareness and prevention, computer technology, job readiness, community outreach Con: No intervention	HCU: Ever had HIV test	Positive	Acceptability: user's attitudes, knowledge and expectations
Women's groups							
20	Fottrell (2013)[52]	Bangladesh, rural	cRCT; Women aged 15-49; n=25,321 births	Int: Women's groups to improve maternal and neonatal health Con: Standard care	HCU: Infant received check up in the first 6 weeks by formal provider	Null	Acceptability: user's attitudes, knowledge and expectations
21	Houweling (2013);[54] Tripathy (2010)[121]	India, rural	cRCT; Women aged 15-49 years; n=18,775 births	Int: Women's groups to improve maternal and neonatal health Con: Standard care	HCU: Care seeking behaviour in the event of infant illness; post-natal check-up for baby at medical facility	Null	Acceptability: user's attitudes, knowledge and expectations Availability: system improvements; demand for services
22	Manandhar (2004)[58]	Nepal, rural	cRCT; Women aged 15-49 years; n=6,275 births	Int: Women's groups to improve maternal and neonatal health, strengthening of health services, training of healthcare workers, CHWs, and TBAs	HCU: Proportion of infants taken to health facility in event of illness	Positive	Acceptability: user's attitudes, knowledge and expectations Availability: system improvements

				Con: Standard care			
23	More (2012)[60]	India, rural	cRCT; Women who joined groups; n=18,197 births	Int: Women’s groups to improve maternal and neonatal health Con: No women’s groups	HCU: Clinic care for specified newborn illness within the first 24 hours I: Infant BCG vaccine	Null	Acceptability: user's attitudes, knowledge and expectations
Combined interventions (primary component education)							
24	Azad (2010)[45]	Bangladesh, rural	cRCT; Women aged 15-49 years; n=30,952 births	Int: Women’s groups to improve maternal and neonatal health outcomes, health services strengthening Con: No women’s groups, health services strengthening	HCU: Health care seeking behaviour in the event of an illness	Null	Acceptability: user's attitudes, knowledge and expectations Availability: system improvements; demand for services
25	Bari (2006)[46]	Bangladesh, rural	cRCT; Infants and caregivers; n=4,343	Int: Health education of families, identification of sick newborns in the community by CHW, health systems strengthening and strengthening of referral systems (including provision of free care and referrals) Int: Usual services	HCU: Care seeking from qualified providers; care seeking from hospital	Positive	Geographic: service location Acceptability: user's knowledge, attitudes and perceptions Financial: cost and prices of services
26	Brenner (2011)[49]	Uganda, rural	CBA; Children < 5 years; n=1,118	Int: Health promotion for children delivered by CHW, illness	I: Measles vaccination coverage	Positive	Geographic: service location

				management, community development Con: Usual services			Availability: health workers Acceptability: user's attitudes, knowledge and expectations
27	Mazumder (2014)[59]	India, mixed	cRCT; infants; n=29,667 births	Int: Home visits by CHWs, training in improved case management of sick children, women’s groups, strengthening of health systems Con: Standard care	HCU: Clinic care for severe newborn illness within the first 24 hours I: Infant BCG vaccine	Null	Geographic: service location Availability: systems improvements Acceptability: user's attitudes and expectations

Appendix 5e: Text messages (demand side; non-financial)

	Author (Year)	Country and setting	Design and population	Intervention (Int) and control (Con)	Main outcome of interest (HCU= health care utilisation; I=immunisation; C=compliance)	Result summary	Targeted barrier (according to Peter's framework)
1	Bangure (2015)[68]	Zimbabwe, mixed	RCT; mother or caregiver; n=304	Int: SMS vaccine appointment reminders and health education at 6, 10 and 14 weeks of age Con: Routine health education only	I: Receipt of scheduled vaccines at 6,10, 14 weeks	Positive	Acceptability: user's attitudes, knowledge and expectations
2	Bigna (2014)[69]	Cameroon, mixed	RCT; caregivers of children who are infected/exposed to HIV; n=242	Int: HIV appointment reminders by i) SMS ii) Phone call iii) Both Con: No reminder	HCU: Proportion of patients attending the previously scheduled appointment	Positive	Acceptability: user's attitudes, knowledge and expectations
3	Finocchano-Kessler (2014)[70]	Kenya, urban	Historically controlled study; mother infant pairs presenting to EID; n=843	Int: Early infant diagnosis for HIV SMS reminders to mothers for results, treatment, routine testing due Con: Historical controls	HCU: Retention in EID care at 9 months	Positive	Acceptability: user's attitudes, knowledge and expectations
4	Odeny (2014)[71]	Kenya, urban	RCT; HIV positive women attending ANC; n=388	Int: SMS health promotional messages during pregnancy for HIV positive women	HCU: Infant HIV testing uptake	Positive	Acceptability: user's attitudes, knowledge and expectations

5	Schlumberger (2015)[72]	Burkina Faso, urban	RCT; mothers attending first EPI appointment; n=521 mothers	Int: SMS appointment reminders for EPI vaccinations Con: Standard care	I: Uptake of vaccinations (BCG, DPT, HiB, Hep B, pneumococcal, antirotovirus, polio, rubella, yellow fever)	Mixed positive	Geographic: service location Availability: health workers Acceptability: user's attitudes, knowledge and expectations
6	Lin (2012)[104]	China, urban	RCT; pre and post-operative cataract patients aged <18 years; n=258	Int: SMS appointment reminders for children with cataract Con: No reminders	HCU: Number of followup appointments attended	Positive	Acceptability: user's attitudes, knowledge and expectations

Appendix 5f: Financial or other incentive (demand side; financial)

	Author (Year)	**Country and setting**	**Design and population**	**Intervention (Int) and control (Con)**	**Main outcome of interest (HCU= health care utilisation; I=immunisation; C=compliance)**	**Result summary**	**Targeted barrier (according to Peter's framework)**
Cash transfers							
1	Akresh (2012)[74]	Burkina Faso, rural	cRCT; Children<15 years; n=2,559	Int: Conditional or unconditional cash transfers made to mother or father Con: No cash transfer	HCU: Routine preventative health clinic visits	Mixed positive	Financial: recipient resources; willingness to pay
2	Beck (2015)[78]	India, rural	cRCT; Villages; n=2,034 households per village	Int: Unconditional cash transfer Con: No cash transfer	I: Proportion children fully vaccinated (BCG, polio, DPT, MMR)	Null	Financial: recipient resources; willingness to pay
3	Barham (2009)[77]	Nicaragua, rural	cRCT; Children aged 0-35 months; n=2,229	Int: Conditional cash transfer to mother (*Red de Proteccion Social*) Con: No cash transfer	I: Proportion children fully vaccinated for all 4 vaccines (BCG, measles, polio, DPT)	Null	Financial: recipient resources; willingness to pay
4	Robertson (2013)[86]	Zimbabwe, mixed	cRCT; Children<18 years; n=2,507	Int: Conditional or unconditional cash transfers Con: No cash transfer	I: Proportion of children with up to date vaccinations (measles, BCG, polio, DPT)	Null	Financial: recipient resources; willingness to pay

5	Macours (2012)[82]	Nicuragua, rural	cRCT; poor households; n=4,021 households	Int: Conditional cash transfer (Atencion a Crisis) Con: No transfer	HCU: Use of preventive health services	Mixed positive	Financial: recipient resources; willingness to pay
6	Levy (2010)[106]	Jamaica, mixed	CBA; Children <17 years; n=2,500 households	Int: Conditional cash transfer (*Programme of Advancement through Health and Education*) Con: No transfer	HCU: Health clinic attendance for preventive care	Positive	Financial: recipient resources; willingness to pay
Fee exemptions							
7	Abdu (2004)[73]	Sudan, urban and rural	cRCT; Children<3 years and pregnant women; n=8 health centres	Int: Health centre user fee exemptions Con: No exemption	HCU: Number of children with malaria seen at health centre	Positive	Financial: cost of services
8	Ansah (2009)[75]; Ansah (2013)[76]; Powell- Jackson (2013)[84]	Ghana, rural	cRCT; Children aged 6-59 months; n=4,765	Int: Removal of user fees Con: Paid user fees	HCU: Number of clinic visits per year	Mixed positive	Financial: cost of services
Incentive schemes							
9	Chandir (2010)[79]	Pakistan, urban	CBA; Infants 0-6 months; n=4,545	Int: Food/medicine incentive at each immunisation visit	I: DPT3 immunisation at 18 weeks	Positive	Financial: Recipient resources and

				Con: No incentive			willingness to pay
10	Kundu (2012)[81]	India, urban	Historically controlled study; Children 2-12 years, n=180	Int: Provision of supplementary nutrition for children attending HIV/AIDS clinic Con: No supplementary nutrition	HCU: Percentage regular clinic visits	Positive	Financial: Recipient resources and willingness to pay
11	Muhumuza (2013)[107]	Uganda, mixed	cRCT, Primary school children; n=1,284	Int: Pre schistosomaisis treatment snack, educational messages Con: Educational messages only	HCU: Uptake of treatment	Positive	Availability: demand for services Acceptability: user's attitudes knowledge and expectations
Combined interventions (primary component financial)							
12	Ridde (2013)[85]	Burkina Faso, rural	ITS, Children <5 years; n=112,724 observations	Int: Fee exemption for curative care, health education, strengthening of services Con: No fee exemption, standard care	HCU: Health centre utilisation	Positive	Financial: cost of services Availability: strengthening of services
13	Galasso (2011)[80]	Chile, rural	CBA; poor households; n=12,900 households	Int: Conditional cash transfer, strengthening of services (*Chile Solidario*) Con: No cash transfer, standard services	HCU: Children under 6 with regular check ups	Null	Financial: recipient resources; willingness to pay Availability: strengthening of services

14	Morris (2004)[83]	Honduras, rural	cRCT; Children <3 years and pregnant women, n=70 municipalities	Int: Conditional cash transfer, strengthening of services (*Programe de asignacion familiar)* Con: No cash transfer, standard services	HCU: Proportion of children take to health centre in last 30 days I: Measles, DPT1 coverage	Mixed positive	Financial: recipient resources; willingness to pay Availability: strengthening of services