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# Community views on mass drug administration for filariasis: a qualitative evidence synthesis (Review)

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[Qualitative Review]

# Community views on mass drug administration for filariasis: a qualitative evidence synthesis

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## ABSTRACT

### Background

The World Health Organization (WHO) recommends mass drug administration (MDA), giving a drug at regular intervals to a whole population, as part of the strategy for several disease control programmes in low- and middle-income countries. MDA is currently WHO policy for areas endemic with lymphatic filariasis, which is a parasitic disease that can result in swollen limbs and disability. The success depends on communities adhering to the drugs given, and this will be influenced by the perception of the drug, the programme, and those delivering it.

### Objectives

To synthesize qualitative research evidence about community experience with, and understanding and perception of, MDA programmes for lymphatic filariasis.

To explore whether programme design and delivery influence the community experience identified in the analysis.

### Search methods

We searched CENTRAL, MEDLINE, Embase, and seven other databases up to 8 April 2021, together with reference checking, citation searching, and contact with study authors to identify additional studies.

### Selection criteria

This review synthesized qualitative research and mixed-methods studies when it was possible to extract qualitative data. Eligible studies explored community experiences, perceptions, or attitudes towards MDA programmes for lymphatic filariasis in any country, conducted between 2000 and 2019.

### Data collection and analysis

We extracted data on study design including: authors, aims, participants, methods, and qualitative data collection methods. We also described programme delivery factors including: country, urban or rural setting, endemicity, drug regimen, rounds of MDA received at

the time of the study, who delivered the drugs, how the drugs were delivered, use of health education, and sensitization and adherence monitoring.

We conducted a thematic analysis and developed codes inductively using ATLAS.ti software. We examined codes for underlying ideas, connections, and interpretations and, from this, generated analytical themes. We assessed the confidence in the findings using the GRADE-CERQual approach, and produced a conceptual model to display our findings.

**Main results**

From 902 results identified in the search, 29 studies met our inclusion criteria. The studies covered a broad range of countries in Africa, South-East Asia, and South America, and explored the views and experiences of community members and community drug distributors in low-income countries endemic for lymphatic filariasis. Four themes emerged.

**People weigh up benefits and harms before participating**. People understand the potential benefits in terms of relief of suffering, stigma, and avoiding costs (high confidence); however, these theoretical benefits do not always mesh with their experiences (high confidence). In particular, adverse effects are frightening and unwelcome (high confidence); and these effects are amplified through rumour and social media (moderate confidence).

**Many people are suspicious of MDA programmes.** When people lack a scientific explanation for the programme and their experiences of it, they often develop social explanations instead. These are largely shaped on the historical backdrop and level of trust people have in relevant authority figures (high confidence), although some have unwavering faith in their government and, by extension, the programme (moderate confidence).

**Programmes expect compliance, and this can become coercive and blaming.** Health workers and community members stigmatize non-compliance, which can become coercive (moderate confidence), so communities may appear to comply publicly, but privately reject treatment (moderate confidence).

**Community distributors are often not respected or valued.** They have little authority (moderate confidence), and the behaviour of some distributors damages the MDA programme's reputation (high confidence). Communities want information about programmes to help make decisions about participation, but drug distributors are not sufficiently informed, or skilled in this communication (high confidence).

We intended to assess whether programme designs influenced communities' perceptions of the programme and decision to adhere but were unable to do so as few studies adequately reported the design and implementation of the local programme.

We have moderate to high confidence in the evidence contributing to the review themes and subthemes.

**Authors' conclusions**

Adherence with MDA for filariasis is influenced by individual direct experience of benefit and harm; social influences in the community; political influences and their relationship to government; and historical influences. Fear of adverse effects was frequently described and this appears to be particularly important for communities. When views were negative, we were surprised by the strength of feeling expressed. Enthusiasm for these schemes as a strategy in global policy needs debate in the light of these findings.

## PLAIN LANGUAGE SUMMARY

**Community views on mass drug administration for filariasis: a qualitative evidence synthesis**

**What was studied in this synthesis?**

Mass drug administration (MDA) involves the regular delivery of treatment medicines to whole populations, regardless of whether an individual has the disease or not, and aims to prevent onward transmission (passing from one person to another). It is currently recommended for some disease control programmes in low- and middle-income countries, including the parasitic disease lymphatic filariasis, which can result in swollen limbs and disability. For governments and their health service this is a large logistical task requiring money and staff, and success depends on communities taking the medicines given.

In this review, we looked for studies that explored how people view and experience these programmes. We collected all relevant studies and included 29 in this synthesis.

**What was the aim of this synthesis?**

In this synthesis of qualitative research, we aimed to explore people's views on MDA programmes for treating lymphatic filariasis in low- and middle-income countries.

**Key messages**

People must weigh up a number of factors before deciding to take the medicines. Not everyone benefits from MDA and some may experience harms. The decision to adhere therefore, depends on a complex balance between their trust in the government distributing the medicines; their prior understanding of the disease and the knowledge they receive on the programme; their experience of harms; the influence of family, neighbours, and health staff; and their experience and perception of the people distributing the medicines.

**What were the main findings?**

We included 29 studies in our analysis. The studies covered a broad range of countries in Africa, South-East Asia, and South America, although most were conducted in India. These studies primarily explored the views and experiences of community members and those distributing the medicines in low-income countries where lymphatic filariasis is considered a problem. From the data, four themes emerged.

People weigh up benefits and harms before participating. People understand they can reduce the suffering, stigma and costs of developing the disease (high confidence); however, these benefits do not always mesh with their experiences (high confidence). In particular, side effects are frightening and unwelcome (high confidence); and these effects are amplified through rumour and social media (moderate confidence).

Many people are suspicious of MDA programmes. When people lack a detailed explanation for the programme and their experiences of it, they often develop explanations based on the historical backdrop and level of trust people have in relevant authority figures (high confidence), although some have unwavering faith in their government and by extension the programme (moderate confidence).

Programmes expect compliance, and this can become coercive and blaming. Health workers and community members stigmatize non-compliance, which can become coercive (moderate confidence), so communities may appear to comply publicly, but privately reject treatment (moderate confidence).

Community distributors are often not respected or valued. They have little authority (moderate confidence), and the behaviour of some damages the MDA programme's reputation (high confidence). Communities want information about programmes to help make decisions about participation, but drug distributors are not sufficiently informed, or skilled in this communication (high confidence).

We were unable to assess the impact of programme design on communities' perception of the programme and decision to adhere as these aspects were too similar across all studies.

**How up to date was this synthesis?**

We searched for studies published before 8 April 2021.

## SUMMARY OF FINDINGS

### Summary of findings 1. Summary of findings

| Theme | Subtheme | Studies with information giving rise to the evidence | CERQual rating | Explanation of CERQual rating |
|---|---|---|---|---|
| 1: people weigh up benefits and harms before adhering | 1.1: the perceived benefits relate to the relief of suffering, stigma, and costs of disease | Ahorlu 2018[a]; Amarillo 2008[b]; Babu 2008[c]; Banarjee 2019[c]; Cassidy 2016[c]; Gonzales 2019[d]; Kisoka 2016[e]; Kisoka 2017[e]; Krentel 2008[f]; Krentel 2021[c,f,g,h,i]; Manyeh 2020[a]; Manyeh 2021[a]; Parker 2013a[e]; Silumbwe 2019[k]; Wynd 2007[g] | High confidence | Coherence, adequacy, and relevance: no or very minor concerns<br>Methodological limitations: minor concerns |
| | 1.2: adverse effects are a frightening and unwelcome experience | Ahorlu 2018[a];Babu 2004a[c]; Babu 2004b[c]; Babu 2008[c]; Babu 2010[c]; Biritwum 2017[a]; Hussain 2014[c]; Kisoka 2016[e]; Krentel 2008[f]; Krentel 2021[c,f,g,h,i]; Manyeh 2020[a]; Manyeh 2021[a]; Parker 2013a[e]; Ramaiah 2000[c]; Silumbwe 2019[k]; Wynd 2007[g] | High confidence | Coherence, adequacy, and relevance: no or very minor concerns<br>Methodological limitations: minor concerns |
| | 1.3: news of adverse effects spreads rapidly and makes people fearful | Ahorlu 2018[a]; Babu 2004b[c]; Babu 2010[c]; Kisoka 2016[e]; Kusi 2020[j] | Moderate confidence | Relevance: no or very minor concerns<br>Coherence, adequacy, and methodological limitations: minor concerns |
| | 1.4: deciding to adhere draws on personal and shared experiences and is complex | Ahorlu 2018[a]; Babu 2004b[c]; Babu 2008[c]; Banarjee 2019[c]; Hussain 2014[c]; Kisoka 2016[e]; Krentel 2008[f]; Krentel 2021[c,f,g,h,i]; Manyeh 2021[a]; Njomo 2012a[j]; Parker 2013a[e]; Ramaiah 2000[c]; Silumbwe 2019[k]; Wodnik 2020[i]; Wynd 2007[g] | High confidence | Coherence, adequacy, and relevance: no or very minor concerns<br>Methodological limitations: minor concerns |
| 2: many people are suspicious of MDA programmes | 2.1: many people do not trust the programme and believe there is an ulterior motive | Babu 2004b[c]; Banarjee 2019[c]; Kisoka 2016[e]; Krentel 2008[f]; Kusi 2020[j]; Manyeh 2020[a]; Njomo 2020a[j]; Njomo 2020b[j]; Parker 2013a[e]; Wodnik 2020[i] | High confidence | Coherence, relevance, and adequacy: no or very minor concerns<br>Methodological limitations: minor concerns |
| | 2.2: some have an unquestioning attitude to government and a lack of agency, leading to unwavering faith in the programme | Krentel 2008[f] | Moderate confidence | Methodological limitations: no or minor concerns<br>Coherence, relevance and adequacy: moderate concerns |
| 3: programmes expect compliance: this can re- | 3.1: health workers may become au- | Banarjee 2019[c]; Kisoka 2017[e]; Krentel 2008[f] | Moderate confidence | Coherence: no or very minor concerns |

| | | | | |
|---|---|---|---|---|
| sult in coercive and blaming delivery | thoritarian to ensure compliance | | | Adequacy, relevance, and methodological limitations: minor concerns |
| | 3.2: community members may become coercive, and stigmatize non-compliance | Krentel 2008[f] | Moderate confidence | Coherence and methodological limitations: no or very minor concerns<br><br>Relevancy and adequacy: minor concerns |
| | 3.3: outward compliance, private rejection | Ahorlu 2018[a]; Biritwum 2017[a]; Krentel 2008[f]; Kusi 2020[j]; Manyeh 2020[a]; Njomo 2014[j]; Njomo 2020a[j] | Moderate confidence | Relevance: no or very minor concerns<br><br>Coherence, adequacy, and- methodological limitations: minor concerns |
| 4: distributor's status in the community is often low, and they are not well-equipped to answer the communities questions | 4.1: CDDs have limited authority | Banarjee 2019[c]; Kisoka 2016[e]; Kisoka 2017[e]; Krentel 2008[f]; Krentel 2021[c,f,g,h,i]; Kusi 2020[j]; Njomo 2020a[j]; Silumbwe 2019[k] | Moderate confidence | Adequacy and relevance: no or very minor concerns<br><br>Coherence and methodological limitations: minor concerns |
| | 4.2: people prefer CDDs that are well known to the community and have good behaviour | Ahorlu 2018[a]; Babu 2008[c]; Kisoka 2017[e]; Kusi 2020[j] | High confidence | Coherence, adequacy, and relevance: no or very minor concerns<br><br>Methodological limitations: minor concerns |
| | 4.3: people seek clarification and rationale, but do not always receive it | Ahorlu 2018[a]; Babu 2004a[c]; Banarjee 2019[c]; Biritwum 2017[a]; Kisoka 2016[e]; Kisoka 2017[e]; Krentel 2008[f]; Kusi 2020[j]; Manyeh 2020[a]; Manyeh 2021[a]; Njomo 2012a[j]; Njomo 2014[j]; Njomo 2020a[j]; Njomo 2020b[j]; Parker 2013a[e]; Ramaiah 2000[c] | High confidence | Coherence, adequacy, and relevance: no or very minor concerns<br><br>Methodological limitations: minor concerns |

CDD: community drug distributor.
[a]Ghana; [b]Philippines; [c]India; [d]Dominican Republic; [e]Tanzania; [f]Indonesia; [g]Papua New Guinea; [h]Fiji; [i]Haiti; [j]Kenya; [k]Zambia.

# BACKGROUND

## Description of the topic

Lymphatic filariasis (LF) causes ill health and disability in millions of people, particularly among the poor (Molyneux 2013). It is one of the neglected tropical diseases (NTDs), which are communicable diseases endemic to tropical and subtropical countries, and the World Health Organization (WHO) recommends mass drug administration (MDA) to eliminate the disease. Indeed, the WHO recommend MDA for all five of the most common NTDs: LF, onchocerciasis, soil-transmitted helminths, schistosomiasis, and trachoma (Webster 2014).

Symptomatic chronic filarial infection causes limb and genital swelling, peeling of the skin, and fevers. Without treatment, the infection persists, and without early treatment, some effects are irreversible and can cause substantive morbidity and disability in adults who are infected (WHO 2019).

LF occurs in clearly geographically defined areas of the tropics and is transmitted by a variety of mosquito species, mainly species of the genus *Anopheles* or *Culex*. Repeated exposure to the bite of infected mosquitoes is required to infect people; hence vector control is an important preventive measure (WHO 2019). A variety of highly effective drugs are available for treatment, including diethylcarbamazine (DEC), ivermectin, and albendazole (WHO 2019),

Apart from vector control, the main tool for eliminating transmission of the disease is treatment of the disease through suppression of microfilaraemia with drugs known to be effective as tablets, or sometimes with medicated salt (Adinarayanan 2007). This suppression is needed for the whole population over long periods of time, and MDA to treat the whole population every year is the approach used most often (WHO 2019).

The 2000 WHO Global Programme to Eliminate Lymphatic Filariasis (GPELF) has been important and continues; in addition, more integrative attempts are being made to treat multiple diseases through MDA programmes in which several drugs are given together to combat LF, soil-transmitted helminths, schistosomiasis, onchocerciasis, and trachoma (Webster 2014). Although it is clear that MDA if given as recommended helps to reduce transmission, some authors report difficulties in delivery at a local level (Parker 2013b). Parker and colleagues pointed out that the large financial inputs (valued at USD 2 billion and USD 3 billion annually; Webster 2014) may inadvertently create pressure to highlight programme success without acknowledging these difficulties (Parker 2013a). Indeed, by 2015, governments and donors had distributed over 6.7 billion tablets for treatment of LF alone (Specht 2019). However, to deliver medication on such a scale is a huge logistical task involving co-ordination between multiple sectors (Gyapong 2018). At the local level, village volunteers must identify, record, and inform the eligible population; this is followed by fixed day distribution (Allen 2011). Volunteers visit villages over a large geographical distance after completing a normal day's work. The work is unpaid and may have to be repeated if people are not at home for the first planned visit (Allen 2011). This can lead to shortcuts, with some distributors opting to give the tablets to one family member without ensuring that the entire family ingest them (Babu 2014).

Finally, regular delivery of medicines assumes that people adhere to treatment. Although providers have the intention of doing public good, this does not always mean that communities are willing to take the drugs (Allen 2011). Cross-sectional surveys conducted in India, Fiji, and Ghana estimate adherence levels between 67% and 96% (Bhue 2021; Dicko 2020; Kulkarni 2019; Rinamalo 2020). While this appears to be high, all four studies were conducted in areas of sustained LF transmission despite more than 10 years of MDA. The studies used health workers to interview community members about their participation in the most recent round of MDA, and it may be that people tend to over report their adherence in these situations. One retrospective study conducted in Ghana analyzed information from district health registers and found that compliance was much lower: 83% of the population missed at least one MDA in the previous three years, while 9.2% missed all three previous MDA (de Souza 2020). Despite the success of GPELF in eliminating LF in 17 countries to date, a further 48 remain endemic (WHO 2020). Therefore, it is important to understand the contexts in which MDA is not working to tailor implementation recommendations.

For example, It seems possible that the occurrence of adverse effects (AEs) may influence people's willingness to comply with MDA programmes (Cabral 2017). We know that among people with active infection, AEs are common with treatment. The death of filarial parasites can cause a local inflammatory response; therefore, when filarial load is high or worms are killed too rapidly, drug administration often leads to AEs (Kafle 2011). Mild reactions include fever and nausea, and serious AEs are those that lead to life-threatening or incapacitating conditions and hospitalizations (Lima 2012). With MDA, it is unclear whether these AEs are common as reporting and reporting accuracy are variable (Lima 2012; Wamae 2011; Weerasooriya 1998; WHO 2003). Although the uninfected population does not experience AEs, those who are infected may, and this could interfere with subsequent adherence to drug treatment (Mishra 2019).

## How the intervention might work

In terms of drug effects, LF is treated with either albendazole alone or in combination with ivermectin or DEC. These treatments reduce microfilarial levels in the infected individual, and in some cases completely clear infection (Ismail 2001). When given to whole populations repeatedly over several years, MDA can reduce filaria levels to the point where transmission can no longer be sustained (Gyapong 2018). For this reason, the WHO currently recommends that at least 65% of the population should receive MDA for at least five years to achieve elimination (WHO 2019).

In terms of delivery of the drug, MDA itself simply means giving the drug to whole populations, but this is a general term for a process that can take a variously organized and managed approach, with the various approaches themselves likely to influence the effectiveness of delivery. For example, MDA can be delivered by government health staff, by community health workers, or through schools; it can be provided through mobile camps or by door-to-door visiting; the procedure may include careful household mapping and adherence recording, or very little attempt may be made to monitor actual ingestion.

Delivery may take place alongside health education or sensitization initiatives such as media campaigns or public activities, whereby people are given information on the purpose of MDA along

with possible opportunities to raise concerns or queries. In addition, the whole process of planning MDA can vary from imposed programmes to full 'collaborative' projects between external agencies and the community (Table 1). These programmes can be organized into top-down, bottom-up, and collaborative approaches, whereby the latter two have equal or majority contribution and governance from the communities intended to benefit (Whitehead 2002). Community involvement in planning and implementing interventions is thought to generate respect, trust, and sustainable support for the programme (Liese 2010), thereby facilitating community participation and engagement (Annamalai 2016). In contrast, some point out that top-down approaches may be met with limited participation and missed opportunities to respond to problems arising at the local level (Silumbwe 2019; Sturmberg 2017), but these approaches may be simpler and more practical on a large scale. One analysis of top-down and bottom-up approaches to water, electricity, and sanitation initiatives suggested that in areas with weak economies, governance, and existing infrastructure, bottom-up approaches may be less effective and may require continued support from external actors (Annamalai 2016).

### How this review might inform or supplement what is already known in this area

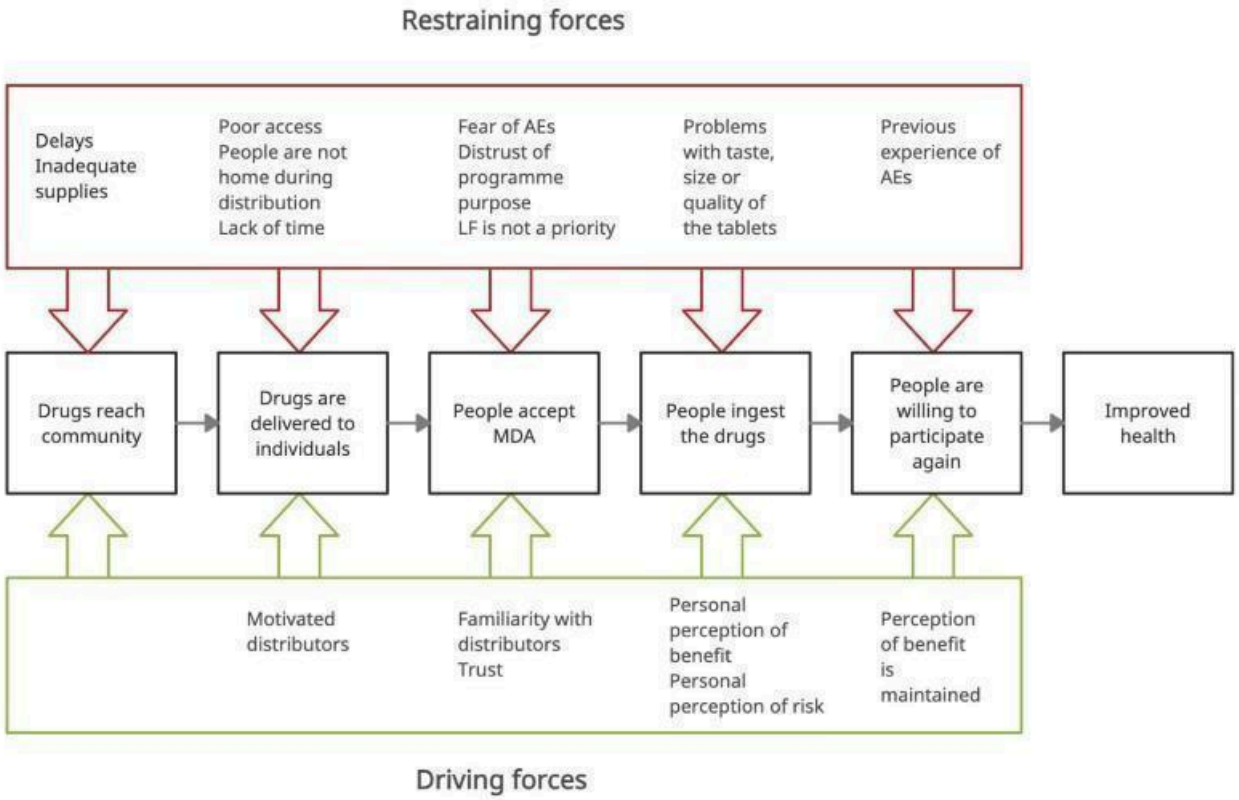
The *Cochrane Database of Systematic Reviews* includes two reviews regarding specific treatment regimens of MDA for LF. The first found that albendazole, given alone or in combination with other drugs, makes little difference (Macfarlane 2019); and the second found DEC salt effective but only with at least 90% coverage for over six months (Adinarayanan 2007). These disappointing findings raise the importance of investigating how people respond to MDA programmes for LP generally rather than specific drug regimens, and this is the focus of our review.

Before starting this review, we sought to examine the contributions of similar reviews that explored community views and responses to LF mass treatment programmes. We identified three systematic reviews and one rapid review (Table 2). One quantitative and two mixed-methods studies largely based their findings on quantitative study designs. These designs are useful for describing known barriers and facilitators to adherence but are limited in their ability to explore unknown phenomena, provide an in-depth understanding, and offer explanatory theory. One final study, a rapid qualitative review commissioned by the WHO (Ames 2019), was conducted in part by researchers who produced pieces of research advocating for MDA programmes (King 2011). Due to the nature of rapid reviews, limited time may have been provided to develop theories from the themes identified, and only one author was involved in the analysis.

Driving forces outlined in the above studies include training (Ames 2019; Silumbwe 2017), community awareness (Silumbwe 2017), management of AEs (Ames 2019; Krentel 2013; Silumbwe 2017), trust (Ames 2019; Krentel 2013), community involvement in planning and conducting the MDA (Ames 2019), and whether timing was convenient (Ames 2019). Restraining forces include fear of AEs (Babu 2014; Krentel 2013), lack of perception of benefit (Babu 2014; Krentel 2013), lack of information or understanding (Ames 2019; Babu 2014; Krentel 2013), delays in drug delivery (Krentel 2013; Silumbwe 2017), lack of motivation of distributors (Krentel 2013), and inadequate numbers of distributors (Ames 2019). Silumbwe 2017 noted some interesting contextual factors influencing compliance, including the belief that MDA transmits Ebola, and the thought that MDA is not a priority during other outbreaks. This may suggest that it is useful to consider findings in terms of country and context.

The conceptual model was developed from the findings of these reviews and represents the a priori understanding of the factors that influence adherence at the community level (Figure 1). Figure 1 aimed to help us delineate our thinking before conducting the review and to explore our own thoughts on the topic. The conceptual model was used as a guide in the initial analysis and was ultimately revised in light of the findings of this review.

**Figure 1. Conceptual model of the driving and restraining influences on MDA delivery and adherence. AE: adverse effect; LF: lymphatic filariasis; MDA: mass drug administration.**




## Why is it important to do this review?

Reviews conducted previously have helped by listing driving and restraining forces of adherence. Decisions to adhere to treatment are complicated, however, and often are related to multiple competing beliefs and values and the wider sociopolitical context. Therefore, we conducted a careful analysis using recent methods in qualitative evidence synthesis (QES) to:

- further examine the context in which these drugs are delivered in an effort to explain when sometimes adherence is not as high, as is desired by policy-makers, and
- delineate community views to provide feedback on programme design.

This approach provides the underpinning for this review, in which we aimed to synthesize the perceptions and experiences of those receiving MDA with the goal of attaining a broader understanding of the impact of programmes and consumers' openness towards them.

# OBJECTIVES

To synthesize qualitative research evidence about community experience with, and understanding and perception of, MDA programmes for LF.

To explore whether programme design and delivery influence the community experience identified in the analysis.

# METHODS

## Criteria for considering studies for this review

### Types of studies

#### *Inclusion criteria*

We included all qualitative research (including ethnographies, phenomenologies, qualitative process evaluations, and case studies). We defined qualitative research as studies that collected data using qualitative methods such as ethnographic observations, in-depth interviews, focus group discussions, and open-ended survey questions. Appropriate analysis methods included, for example, thematic analysis, narrative analysis, framework analysis, and grounded theory (Thomas 2008).

We included mixed-methods studies when it was possible to extract qualitative data.

We restricted included studies to those from 2000 to present day, as this marked the date of the introduction of the GPELF and the date that MDA activities were introduced and scaled up for filariasis (WHO 2019).

We included both published and unpublished studies.

#### *Exclusion criteria*

We excluded studies that included qualitative data collection methods but reported and analyzed all data quantitatively.

We excluded studies published in any language other than English.

#### Topics of interest

#### *Inclusion criteria*

**Phenomenon of interest:** community experiences, perceptions, or attitudes towards MDA programmes for LF.

**Setting:** any setting that provided MDA for filariasis, as the purpose of synthesis to inform decision-making was to yield theories that were more transferable and socially relevant over a broader range of contexts.

**Perspectives:** any community member eligible for the MDA programme and village leaders. Perceptions of lay healthcare workers (HCW; those without formal training or qualifications, including community health workers and drug distributors as defined by Lewin 2010) and government health workers may have been included to triangulate results if they were clearly separated from the perspectives of the general consumer population.

**Intervention:** delivery of MDA, which, for this review, was defined as administration of an anti-filarial drug to the entire at-risk population (irrespective of symptoms or infection) on a regular, often annual, basis. Eligible drug regimens included ivermectin, albendazole, and DEC alone or in combination. During scoping, we identified that most of the available research related to compliance in MDA programmes focused on LF specifically. Therefore, this review focused on community perceptions towards MDA programmes for LF.

#### *Exclusion criteria*

The literature on MDA policies and their implementation is extensive. This review was not concerned with understanding policies by those implementing them; therefore, we did not summarize the views of those affiliated with the programme design or with programme governance. When community or lay (or both) HCW voices could not be separated from programme staff, we excluded the study.

## Search methods for identification of studies

We developed the search strategy in consultation with Cochrane Infectious Diseases Group and Cochrane Effective Practice and Organisation of Care (EPOC) Information Specialists.

#### Electronic searches

We attempted to identify all relevant studies regardless of publication status (i.e. published, unpublished, in press, or in progress). The search was first conducted on 10 December 2019 and updated on 8 April 2021. We limited our searches from publication year 2000 onwards and to studies conducted in English. We searched the following databases using the search terms and strategy described in Appendix 1: Cochrane Central Register of Controlled Trials (CENTRAL), Issue 3, 2021, published in the Cochrane Library; MEDLINE (PubMed); Embase (OVID); Latin American and Caribbean Health Sciences Literature (LILACS, BIREME); Cumulative Index to Nursing and Allied Health Literature (CINAHL, EBSCOHost); Global Health (Web of Science); CAB Direct (Web of Science); and Science Citation Index – Expanded (Web of Science), ClinicalTrials.gov, and the WHO International Clinical Trials Registry Platform (ICTRP).

#### Searching other resources

The Cochrane Qualitative and Implementation Methods Group recommends supplementary searching activities due to the limited availability of qualitative research. To achieve this, we scanned reference lists and perform citation searches of included studies and existing reviews identified in the Background. We contacted experts in the field to ask what they knew about published and unpublished data.

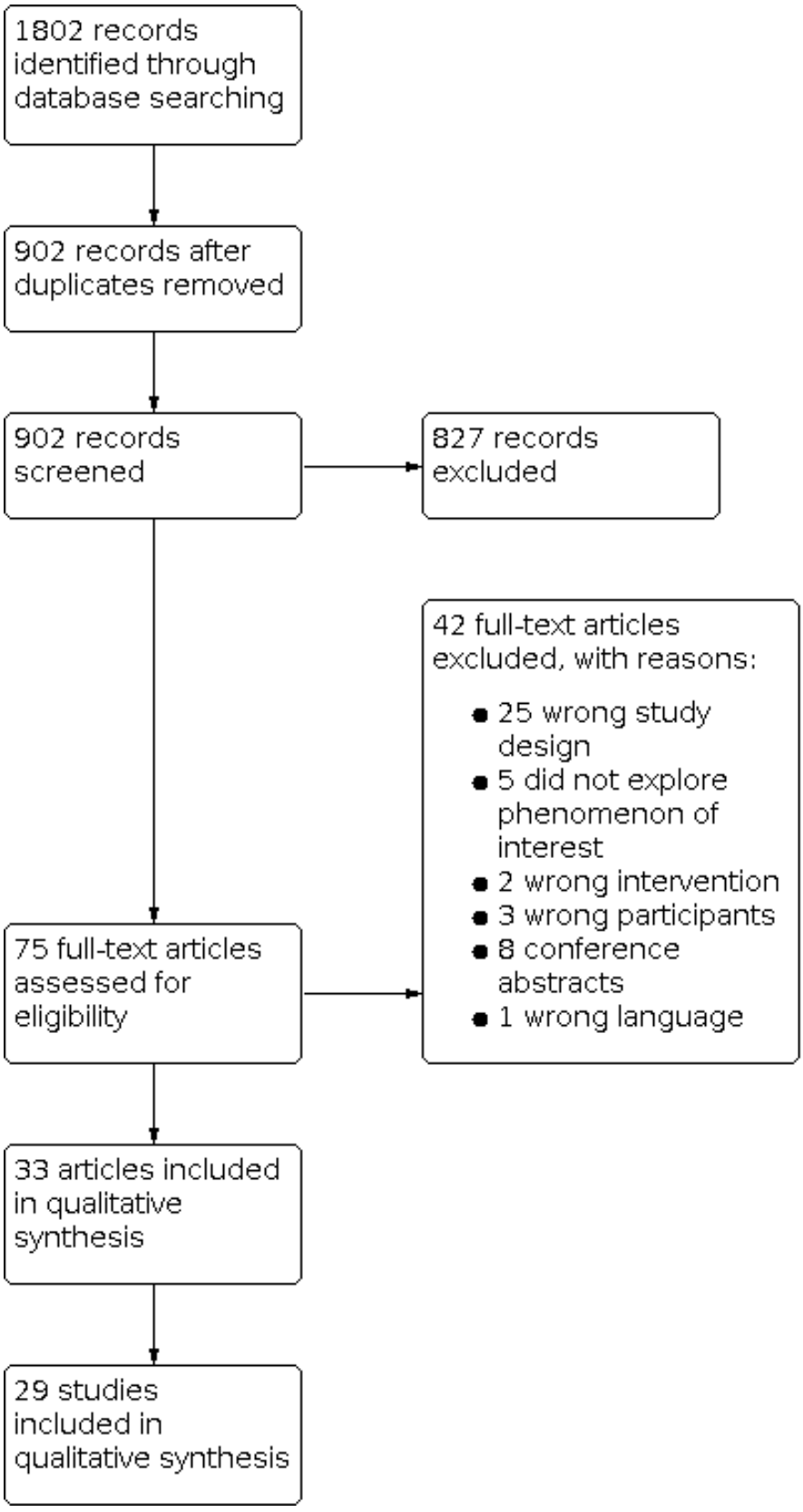
#### Grey literature

We searched OpenGrey to identify grey literature (www.opengrey.eu). Unpublished studies may be of lower quality and reliability than published studies. However, all grey literature results were subject to quality appraisal and, during this process, we did not identify any concerns.

## Selection of studies

We imported all search results into Covidence, and removed any duplicates (Covidence). Two review authors (MT and RT) independently screened retrieved search results against the inclusion criteria. This two-step process consisted of screening first titles/abstracts, then full text. Using two review authors to screen is valuable in providing opportunities to explore relevance and meaning of study findings (Soilemezi 2018). Studies were only included if both authors could reach a consensus decision and a third review author (PG) resolved any disagreements. We summarized this process in a PRISMA flow diagram detailing the numbers of studies removed and kept at each step (Figure 2). We noted the reasons for exclusion of full-text studies and present this information in the Characteristics of excluded studies table.

**Figure 2. Study flow diagram.**



### Language translation

Due to time and resource demands of translation, only studies available in English were eligible for inclusion.

### Sampling of studies

The search yielded only 29 eligible studies and so sampling was not deemed necessary.

### Data extraction and management

One review author (MT) independently extracted data on both the study design and programme delivery using a predefined data extraction form. This included the following information.

- Study design: author, aim, participants, methods, and qualitative data collection methods.
- Study context: country, urban or rural setting, endemicity, drug regimen, rounds of MDA received at the time of the study, who delivered the drugs, how the drugs were delivered, use of health education, and sensitization and adherence monitoring. We used this information to categorize each study using the seven delivery methods outlined in Whitehead 2002. Where information was unavailable, we sought other documents related to MDA policies in the country at the time to try to input some basic characteristics of the programme, and we noted which characteristics were secondarily derived from other sources. To find this information, we screened citations of the target study, then performed a Google search for other documents that referred to these programmes.

### Assessing the methodological limitations of included studies

We assessed the methodological limitations using a standardized set of criteria to impart some objective distance and to ensure consistency. We chose a modified version of the tool developed by the EPPI-Centre at University College London (UK) for its clear and straightforward approach and use in a similar QES investigating consumer perceptions and experiences of a health intervention (Appendix 2; Eshun-Wilson 2019). This tool assessed the following criteria: rigour in sampling, rigour in data collection, rigour in analysis, grounding of data, and breadth and depth of study findings. Each criterion offered several prompts to aid the user in making a judgement. For each category, studies received a score of (1) Yes, a fairly thorough attempt was made; (2) Yes, several steps were taken; (3) Yes, a few steps were taken; or (4) not stated/could not determine. Two review authors (MT and RT) independently conducted a methodological limitations' assessment of each paper before comparing findings and reaching a consensus.

We did not exclude studies based on our assessment of methodological limitations. However, we used this information to assess our confidence in the review findings.

### Data management, analysis, and synthesis

We used thematic synthesis as described in Thomas 2008 and informed by the Braun 2006 thematic analysis. Thematic synthesis assumes that knowledge of reality is mediated by perceptions and beliefs, thus making it an appropriate choice for a study investigating perceptions, experiences, and acceptability of a health intervention. This method also assumes that findings are reproducible and transferable, which aligns with the second objective of this review – to explore implications for programme delivery. We completed the following steps.

- Familiarizing with the data: two review authors (MT and RT) independently read relevant background literature and the full length of studies included in the review to become familiar with, and immersed in, the data, noting any initial thoughts.
- Generating initial codes: two review authors (MT and RT) independently began coding. Initially, we assigned codes deductively based on the findings outlined in the conceptual model (Figure 1). However, as we progressed through the studies, new findings and insights lead to the development of new codes and coding, therefore, took a more inductive approach. This included both first- and second-order data, with first-order data being the original quotations, and second-order data comprising study authors' interpretations. We attempted to retain accounts that differed from the emerging understanding of the situation. Review authors then compared individual codes on a study-by-study basis to reach consensus on the appropriateness and terminology of each code. The result of this process was the development of a shared coding framework that was applied to subsequent papers, which we refined and amended as new codes emerged.
- Searching for themes: working together, two review authors (MT and RT) grouped codes into potential themes, gathering all data relevant to each theme. Here, review authors interpreted the meaning behind the data and thought about the relationships between codes, themes, and hierarchies of themes. The wider team (MT, RT, SO, and OG) met regularly to reflect on emerging themes as a group.
- Reviewing themes: review authors ensured that the pattern of data within themes was coherent, and that there was a clear distinction between themes and subthemes. This involved breaking, merging, and removing themes with too little, too much, or disparate information, including subthemes that were graded 'low' certainty evidence for the coherence component of the CERQual assessment. We reviewed included studies a second time to capture any data missed for newly emerging themes.
- Producing the report: one review author (MT) produced a narrative of findings for each theme, integrating vivid illustrative quotes; this was then shared the wider team for feedback.

We then attempted to analyze findings specific to any geographical settings or contexts, such as settings also receiving MDA for other co-endemic diseases, poverty levels, and programme design (such as form of delivery, drug regimen, and rounds of MDA received at the time of the study).

Finally, we completely revised the conceptual model to reflect the new understanding. Our first conceptual framework was designed as a logic model for a programme focusing on the desired outcomes, taking into account barriers and facilitators that were either anticipated or confirmed in the literature. This was developed from earlier reviews that identified driving and restraining forces of adherence, but without sufficient in-depth analysis to examine how these factors inter-related. In conducting our QES, as our analysis found important links between individual behaviour and the wider community, and to policies and reputations of programmes and organizations, it was easier to visualize factors of influence being nested in an ecological model inspired by Bronfenbrenner's Ecological Systems Theory

(Bronfenbrenner 1989). This strengthens the explanations of why individuals choose to accept or avoid MDA. As with the thematic analysis process, the development of the conceptual model was inductive and subject to revision and discussion among the wider team.

### Assessing our confidence in review findings

Two review authors (MT and RT) used the GRADE-CERQual (Confidence in the Evidence from Reviews of Qualitative Research) approach to assess confidence in each finding (subtheme) (Lewin 2018). CERQual assesses confidence in the evidence based on the following four key components.

- Methodological limitations of included studies: the extent to which there were concerns about the design or conduct of the primary studies that contributed evidence to an individual review finding.
- Coherence of the review finding: how clear and cogent the fit was between data from the primary studies and a review finding that synthesized those data. By 'cogent', we meant well-supported or compelling.
- Adequacy of the data contributing to a review finding: the degree of richness and the quantity of data supporting a review finding.
- Relevance of included studies to the review question: how the body of evidence from the primary studies supported a review finding. This information was applicable to the context (perspective or population, phenomenon of interest, setting) specified in the review question.

After assessing each of the four components, we judged our overall confidence in the evidence supporting the review finding. We judged confidence as high, moderate, low, or very low. All findings started as high confidence and were then downgraded if there were important concerns regarding any of the CERQual components.

We chose to take an explanatory approach in this review with an emphasis on developing a cohesive conceptual model and theoretically generalizable findings. We consulted with a CERQual specialist during the preparation of this review and noted that the approach while useful, was mostly applicable to descriptive findings and had not been fully explored for use with explanatory findings. Therefore, we adapted their approach to fit the methodological assumptions of our review.

A full description of how we decided on the CERQual assessments is given in the Results and Appendix 3.

### Summary of qualitative findings table and evidence profile

We presented summaries of findings and our assessments of confidence in these findings in Summary of findings 1. We presented detailed descriptions of our confidence assessment in Appendix 3.

### Review author reflexivity

In qualitative research, we appreciate that the background and position of researchers will shape interpretation of results, and thus team positionality at the outset, through the process of analysis and synthesis. We state these broad positionality statements at the outset here. PG was the clinician organizing the delivery of MDA for LF as part of a research project in the Maprik Area of the West Sepik in the 1980s. During this time, he lived adjacent to the research village for several weeks. These populations were heavily infected with filariasis, and the DEC made people unwell, so he has seen AEs first-hand. As a public health professional, his values and principles include believing that health professionals take account of views of the public on clinical and public health policies. His research reflects these values. MT, RT, and SO have no personal experience regarding MDA programmes and hold differing perspectives on their value. RT is working on a project on human rights and guideline development and is sensitive to policies from a human rights perspective. SO is ambivalent about MDA programmes and views them from the standpoint of families rather than practitioners. The work will build on MT's thesis, which highlighted several consumer concerns about the programme. Before she conducted this research, MT's views on MDA were influenced by her academic tuition to date, which involved a provider-centred rhetoric that MDA is a highly effective and appropriate solution.

Analysis was conducted by two primary analysts (MT and RT), who additionally provided feedback on their findings and interpretations to the whole research team. This involved regular meetings with PG and occasional meetings with SO. As different researchers will approach the analysis from different perspectives, this collaborative effort should produce a richer, more nuanced understanding of a complex situation while generating opportunities to identify and contest any assumptions or beliefs held by individual review authors. To further increase reflexivity in our research design, we aimed to explore and explain any findings that appeared to contradict our understanding of the situation. Primary analysts kept memo notes during the initial stages of analysis to provide a transparent account of the interpretation process and the development of themes.

## RESULTS

### Search results

We included 29 studies described in 33 papers after screening 902 titles and abstracts and 75 full-texts (Figure 2). Krentel 2008 and Njomo 2012a were each described across three publications. Krentel 2008 was a PhD thesis and the remainder were published in peer-reviewed journals between 2000 and 2020. The full list of reasons for exclusion can be found in the Characteristics of excluded studies table.

### Description of included studies

#### Study methods

The full description of study methods can be found in the Characteristics of included studies table.

There was a mix of both qualitative studies (13; Ahorlu 2018; Babu 2004a; Babu 2010; Cassidy 2016; Gonzales 2019; Kisoka 2016; Kisoka 2017; Krentel 2008; Kusi 2020; Njomo 2020b; Silumbwe 2019; Wodnik 2020; Wynd 2007); and mixed-methods studies (16: Amarillo 2008; Babu 2003; Babu 2004b; Babu 2008; Banarjee 2019; Biritwum 2017; Hussain 2014; King 2011; Krentel 2021; Manyeh 2020; Manyeh 2021; Njomo 2012a; Njomo 2014; Njomo 2020a; Parker 2013a; Ramaiah 2000). These comprised a range of qualitative data collection methods including in-depth or semi-structured interviews (26: Ahorlu 2018; Amarillo 2008;

Babu 2003; Babu 2004a; Babu 2004b; Babu 2008; Babu 2010; Banarjee 2019; Biritwum 2017; Gonzales 2019; Hussain 2014; King 2011; Kisoka 2016; Kisoka 2017; Krentel 2008; Krentel 2021; Kusi 2020; Manyeh 2020; Njomo 2012a; Njomo 2014; Njomo 2020b; Parker 2013a; Ramaiah 2000; Silumbwe 2019; Wodnik 2020; Wynd 2007); observation (2: Kisoka 2017; Parker 2013a); and focus group discussions (22: Amarillo 2008; Babu 2003; Babu 2004a; Babu 2004b; Babu 2010; Biritwum 2017; Cassidy 2016; Gonzales 2019; King 2011; Kisoka 2016; Kisoka 2017; Krentel 2021; Kusi 2020; Njomo 2012a; Njomo 2014; Njomo 2020a; Njomo 2020b; Parker 2013a; Ramaiah 2000; Silumbwe 2019; Wodnik 2020; Wynd 2007).

Twenty-six studies included a mix of both community members, community or religious leaders and programme or health staff including: distributors, health workers, doctors, NGO staff, and medical officers (Ahorlu 2018; Amarillo 2008; Babu 2003; Babu 2004a; Babu 2004b; Babu 2008; Babu 2010; Biritwum 2017; Cassidy 2016; Gonzales 2019; Hussain 2014; King 2011; Kisoka 2016; Kisoka 2017; Krentel 2008; Krentel 2021; Kusi 2020; Manyeh 2020; Manyeh 2021; Njomo 2012a;. Njomo 2014; Njomo 2020b; Parker 2013a; Ramaiah 2000; Silumbwe 2019; Wodnik 2020). Three studies selected exclusively community members (Njomo 2020a; Wynd 2007; Banarjee 2019). Of which, one study purposely sampled non-compliers (Banarjee 2019).

### Study context

The full description of study context can be found in the Characteristics of included studies table and Table 3.

Studies were from 10 countries across India (10: Babu 2003; Babu 2004a; Babu 2004b; Babu 2008; Babu 2010; Banarjee 2019; Cassidy 2016; Hussain 2014; Krentel 2020; Ramaiah 2000); Indonesia (2: Krentel 2008; Krentel 2021); Philippines (1: Amarillo 2008); Papua New Guinea (2: Krentel 2021; Wynd 2007); Kenya (5: Kusi 2020; Njomo 2012a; Njomo 2014; Njomo 2020a; Njomo 2020b); Ghana (4: Ahorlu 2018; Biritwum 2017; Manyeh 2020; Manyeh 2021); Tanzania (3: Kisoka 2016; Kisoka 2017; Parker 2013a); Zambia (1: Silumbwe 2019); Dominican Republic (1: Gonzales 2019); Haiti (2: Krentel 2021; Wodnik 2020); American Samoa (1: King 2011); and Fiji (1: Krentel 2021).

Most studies described the setting as endemic for LF; while two studies included both endemic and non-endemic areas (Babu 2004b; Krentel 2008) and one described endemicity as 'low' (Wynd 2007). Most studies were conducted in mixed urban and rural settings, while three focused on urban areas (Banarjee 2019; Biritwum 2017; Gonzales 2019), and four on rural areas (Babu 2003; Manyeh 2021; Silumbwe 2019; Wynd 2007).

Participant populations had typically received a mean of two or three rounds of MDA at the time of the study. Although five studies, designed to investigate issues surrounding repeat non-compliance, were conducted after the seventh (Wodnik 2020), 10th (Manyeh 2021; Njomo 2020a), and 15th (Ahorlu 2018; Manyeh 2020) round of treatment.

Combined DEC and albendazole was the most common regimen (15: Amarillo 2008; Babu 2004a; Babu 2004b; Gonzales 2019; Hussain 2014; King 2011; Krentel 2008; Kusi 2020; Manyeh 2020; Manyeh 2021; Njomo 2012a; Njomo 2020a; Silumbwe 2019; Wynd 2007; Wodnik 2020), followed by DEC alone (5: Babu 2003; Babu 2008; Babu 2010; Cassidy 2016; Ramaiah 2000), combined ivermectin and albendazole (7: Ahorlu 2018; Biritwum 2017; Kisoka 2016; Kisoka 2017; Manyeh 2020; Manyeh 2021; Parker 2013a), and triple-therapy of albendazole, ivermectin, and DEC (3: Banarjee 2019; Krentel 2021; Njomo 2020b).

Community drug distributors (CDDs) supervised by government HCWs were responsible for the distribution in most studies. For Wynd 2007, the programme used a combination of CDDs alongside teachers. For the most part, distribution was conducted 'door-to-door' except for two studies where it was conducted at local gathering points such as schools (Kisoka 2016; Wodnik 2020), and one study that used a combination of door-to-door and local gathering points (Amarillo 2008).

Most studies provided education and sensitization as part of their implementation and two studies gave no information (Ahorlu 2018; Biritwum 2017).

Most studies were classified as 'top-down with limited community involvement', type V using the typology described by Whitehead 2002 (Table 1). One study was classified as "top-down with no community involvement" (type VI), as their distribution was via health staff (Ramaiah 2000).

Twelve studies reported directly observed treatment (DOT) (Amarillo 2008; Babu 2003; Babu 2004a; Babu 2004b; Babu 2008; Babu 2010; Banarjee 2019; Cassidy 2016; Gonzales 2019; Hussain 2014; King 2011; Ramaiah 2000), and the remaining 17 did not provide any details (Ahorlu 2018; Biritwum 2017; Kisoka 2016; Kisoka 2017; Krentel 2008; Krentel 2021; Kusi 2020; Manyeh 2020; Manyeh 2021; Njomo 2012a; Njomo 2014; Njomo 2020a; Njomo 2020b; Parker 2013a; Silumbwe 2019; Wodnik 2020; Wynd 2007).

## Assessment of methodological limitations

Table 4 shows a summary of judgements.

The reliability and trustworthiness of the studies was high in six studies (Kisoka 2016; Kisoka 2017; Krentel 2008; Krentel 2021; Kusi 2020; Njomo 2020b), medium in seven (Ahorlu 2018; Gonzales 2019; Manyeh 2020; Njomo 2014; Parker 2013a; Wynd 2007; Wodnik 2020), and low for 16 (Amarillo 2008; Babu 2003; Babu 2004a; Babu 2004b; Babu 2008; Babu 2010; Banarjee 2019; Biritwum 2017; Cassidy 2016; Hussain 2014; King 2011; Manyeh 2021; Njomo 2012a; Njomo 2020a; Ramaiah 2000; Silumbwe 2019). We based this judgement on: the rigour of sampling, which was of medium to high quality with at least several attempts made in nine studies (Kisoka 2016; Kisoka 2017; Krentel 2008; Krentel 2021; Manyeh 2020; Njomo 2020b; Parker 2013a; Wynd 2007; Wodnik 2020), a few steps taken to improve rigour in 17 studies (Amarillo 2008; Ahorlu 2018; Babu 2003; Babu 2004a; Babu 2008; Babu 2010; Biritwum 2017; Gonzales 2019; Cassidy 2016; Hussain 2014; King 2011; Kusi 2020; Manyeh 2021; Njomo 2012a; Njomo 2014; Ramaiah 2000; Silumbwe 2019), and three studies did not provide enough information to make a judgement (Babu 2004b; Banarjee 2019; Njomo 2020a). Rigour of data collection was medium to high quality with at least several attempts made in 12 studies (Cassidy 2016; Kisoka 2016; Kisoka 2017; Krentel 2008; Krentel 2021; Kusi 2020; Manyeh 2020; Njomo 2012a; Njomo 2014; Njomo 2020b; Parker 2013a; Wynd 2007), a few steps to preserve rigour in 10 (Amarillo 2008; Ahorlu 2018; Babu 2008; Babu 2010; Banarjee 2019; Hussain 2014; Gonzales 2019; Manyeh 2021; Njomo 2020a; Wodnik 2020), seven studies did not provide enough information to make a judgement (Babu

2003; Babu 2004a; Babu 2004b; Biritwum 2017; King 2011; Ramaiah 2000; Silumbwe 2019); and finally, the rigour of analysis, with only seven studies taking at least several steps to ensure rigour in the data analysis (Kisoka 2016; Kisoka 2017; Krentel 2008; Krentel 2021; Kusi 2020; Njomo 2020b; Wodnik 2020), and seven taking a few steps (Amarillo 2008; Ahorlu 2018; Banarjee 2019; Gonzales 2019; Manyeh 2020; Njomo 2014; King 2011). Fifteen studies provided insufficient information to make a judgement (Babu 2003; Babu 2004a; Babu 2004b; Babu 2008; Babu 2010; Biritwum 2017; Cassidy 2016; Hussain 2014; Manyeh 2021; Njomo 2012a; Njomo 2020a; Parker 2013a; Ramaiah 2000; Silumbwe 2019; Wynd 2007).

The weight in terms of usefulness of the findings for this review was low in 14 studies (Amarillo 2008; Babu 2003; Babu 2004a; Babu 2004b; Babu 2008; Babu 2010; Banarjee 2019; Biritwum 2017; Gonzales 2019; Hussain 2014; King 2011; Njomo 2012a; Njomo 2014; Ramaiah 2000), medium in eight studies (Cassidy 2016; Kusi 2020; Manyeh 2021; Manyeh 2020; Njomo 2020a; Silumbwe 2019; Wynd 2007; Wodnik 2020), and high in seven studies (Ahorlu 2018; Kisoka 2016; Kisoka 2017; Krentel 2008; Krentel 2021; Njomo 2020b; Parker 2013a). We based this judgement on: the grounding of the findings, which was 'good' in only eight studies (Ahorlu 2018; Cassidy 2016; Kisoka 2016; Krentel 2008; Krentel 2021; Kusi 2020; Njomo 2020b; Wodnik 2020), 'fair' in 10 (Banarjee 2019; Gonzales 2019; Kisoka 2017; Manyeh 2020; Manyeh 2021; Njomo 2014; Njomo 2020a; Parker 2013a; Silumbwe 2019; Wynd 2007), and 'limited' in 11 (Amarillo 2008; Babu 2003; Babu 2004a; Babu 2004b; Babu 2008; Babu 2010; Biritwum 2017; Hussain 2014; King 2011; Njomo 2012a; Ramaiah 2000); and the breadth and depth of findings, which were 'good' for both components for eight studies (Ahorlu 2018; Kisoka 2016; Kisoka 2017; Krentel 2008; Krentel 2021; Njomo 2020b; Parker 2013a; Wodnik 2020), 'fair' for three (Cassidy 2016; Manyeh 2020; Manyeh 2021), and 'limited' for 12 (Amarillo 2008; Babu 2003; Babu 2004a; Babu 2004b; Babu 2008; Babu 2010; Banarjee 2019; Biritwum 2017; Hussain 2014; King 2011; Njomo 2012a; Ramaiah 2000). A further six studies had good breadth but limited depth (Gonzales 2019; Kusi 2020; Njomo 2014; Njomo 2020a; Silumbwe 2019; Wynd 2007).

## Synthesis findings

We sought to describe how programme delivery factors impacted on community perceptions and the decisions to adhere. To do this we collected information on: drug regimen, mechanism of drug distribution, education and sensitization provided, and whether the programme was designed on a 'top-down' or 'bottom-up' approach. We briefly described the results of this in the 'study context' section. We found that few studies actually described the design and implementation of their local programme and as a result, most of the information we collected was based on national policy documents or related literature. The consequence of this is that these programme design influences appear nearly identical for most studies, preventing us from generating any meaningful comparisons.

A summary of the themes described below is presented in Summary of findings 1.

### Theme 1: people weigh up benefits and harms before adhering

Synthesis statement: there are many outcomes of taking the drugs, which can be both positive and negative. For community members, several of these may exist at once, and the decision to partake is a careful balance. Competing priorities and existing narratives of disease shape the perception of benefit. Any unpleasant associations, even if only experienced by a few people, rapidly become part of the narrative and spread rapidly through the community, and through social media.

#### *Subtheme 1.1: the perceived benefits relate to the relief of suffering, stigma, and costs of disease (high confidence)*

People recognize that MDA can both prevent LF and treat existing infections. When people describe the benefits, they often do so in terms of their felt experience, rather than listing information they have learnt as part of the programme education campaigns. People generally describe these benefits with a sense of relief and gratitude. Three main themes related to benefits emerged.

**Relief from suffering:** from a personal perspective, people were relieved that would not be at risk of developing the disease and becoming sick (India: Babu 2008; Krentel 2021; Indonesia: Krentel 2008; Philippines: Amarillo 2008; Papua New Guinea: Krentel 2021; Wynd 2007; Tanzania: Kisoka 2016; Kisoka 2017; Zambia: Silumbwe 2019; Ghana: Manyeh 2020; Manyeh 2021; Fiji: Krentel 2021). Some also found some relief in their current symptoms (Tanzania: Kisoka 2016). At a wider community level, people were motivated to participate in order to eliminate the disease from the area, they spoke of a greater good in ensuring the entire community was 'happy and healthy': "*I have to help my children, grandchildren and great-grandchildren by taking the drug to uproot the disease from our community*" (male opinion leader, Ghana; Ahorlu 2018) (Ghana: Ahorlu 2018; India: Cassidy 2016; Tanzania: Kisoka 2016; Indonesia: Krentel 2008; Dominican Republic: Gonzales 2019). Some remarked how there were fewer people in the community with LF since the start of the programme and this encouraged them to continue taking the drugs (Ghana: Ahorlu 2018; Tanzania: Kisoka 2016).

**Relief from stigma:** the physical signs of the disease (i.e. hydrocoele and elephantiasis) is highly stigmatized in the community (Ghana: Manyeh 2020). People described how they would feel ashamed if they got LF and would anticipate social exclusion (Indonesia: Krentel 2008; Philippines: Amarillo 2008). In one study, simply being shown pictures of swollen limbs was enough to shock people into compliance (Dominican Republic: Gonzales 2019). As well as personal shame, people spoke of the wider reputation of the area. One man described how "*He and his family would feel ashamed and uncomfortable if outsiders saw [their] people with big legs*" (young community member, Indonesia; Krentel 2008). He connected this statement to feeling embarrassed seeing "*someone's enlarged genitals on a large film screen in public*" referring to sensitization campaigns, and did not want himself or his neighbours to be made an example of.

**Relief from costs:** falling sick with LF costs money. People worried about being able to afford operations to manage the morbidity and about how they would support their family if they are unable to work (Indonesia: Krentel 2008; Philippines: Amarillo 2008): "*the risk of getting LF if he did not take the treatment was too costly for him in economic terms; who would pay for his operation? He also felt responsible for the economic livelihood of his household so if he was sick with LF, then he would not be able to provide for his family*" (community member, Indonesia; Krentel 2008).

***Subtheme 1.2: adverse effects are a frightening and unwelcome experience (high confidence)***

When community members talked about AEs, they used words such as 'frightened' or 'afraid'. Many gave vivid accounts of the suffering they experienced and observed from others and explained that for this reason, they were unwilling to adhere (Ghana: Ahorlu 2018; Biritwum 2017; Manyeh 2020; India: Babu 2004a; Babu 2004b; Babu 2008; Babu 2010; Banarjee 2019; Hussain 2014; Tanzania: Kisoka 2016; Parker 2013a; Indonesia: Krentel 2008; Kenya Njomo 2012a; Njomo 2020b; Papua New Guinea: Krentel 2021; Wynd 2007; Zambia: Silumbwe 2019). One woman from Indonesia described "*going to sleep and not waking until the next morning (saying they were unconscious)*" (community member, Indonesia; Krentel 2008). One explained why he had never adhered: "*I was afraid of the side effects, I don't want to become weak after taking it or to develop rashes and itches on my body*" (CDD, Ghana; Ahorlu 2018). For some, AEs were not only feared, but they could interrupt people's lives and could prevent them from being able to attend work (Ghana: Ahorlu 2018; Indonesia: Krentel 2008). In one study, people found AEs so upsetting that they attacked the CDDs; "*They usually complain and sometimes attack me … because of the reactions or side effects they have after taking the drug*" (CDD, Ghana; Manyeh 2020). In contrast, some experience the AEs and find them tolerable but still chose not to adhere, suggesting that they were either unaware of the benefits or did not believe they were worth feeling ill for: "*I feel really fine and not taking it is also okay. Rather that, than take it too and am dizzy, sleeping, like taking ecstasy, it is better not to bother with it*" (community member, Indonesia; Krentel 2008). Despite AEs being a serious concern for community members, the experiences were sometimes dismissed by health staff and their impact on adherence undervalued: "*[the community] say they were vomiting, and feeling dizzy … but we have not recorded any serious side effects that should scare somebody enough not to take the drug*" (Health worker, Ghana; Manyeh 2020).

It is already a frightening experience to fall seriously ill after taking an unfamiliar drug. This is heightened when people realize they need urgent medical attention and are unable to access it. Community members may find that MDA staff have left and there is no one around to help (Hussain 2014): "*I would have died if I was not admitted to the head-quarter hospital during the night after consuming the tablets. There was no one to look after me. After the [health care] worker gave me the medicine, I could not find him again. There was no one in our nearby hospital when I arrived there*" (female community member, India; Hussain 2014). Those that did find a health worker were sometimes asked to pay for treatment (Ghana: Ahorlu 2018). People living in poor communities may have been unable to afford this treatment and may have decided it is not worth the risk of adherence. When AEs were prewarned and after-care and monitoring were provided, health staff reported improvements in participation and community members described an increased level of trust in the programme (Ghana: Manyeh 2021; Haiti: Krentel 2021; India: Babu 2004b; Papua New Guinea: Krentel 2021).

***Subtheme 1.3: news of adverse effects spreads rapidly and makes people fearful (moderate confidence)***

Refusing to adhere to treatment due to AEs was a common finding and further, several studies presented quotes that suggested whole communities, or at least large groups were collectively rejecting treatment: "*People are afraid to take these medicines. Something may happen after eating these medicines. So we are not willing to swallow*" (male community member, India (Babu 2004b)) (Ghana: Ahorlu 2018; India: Babu 2004b; Babu 2010). Any occurrence of AEs appeared to become swiftly part of the community narrative of the MDA programme. This meant that people who had never taken the treatment before, or had never personally experienced AEs may not have been willing to take the treatment either. This collective fear of treatment often arose because of rumours and stories that rapidly propagated through media and social networks, causing mass panic. "*I remember very well that somewhere in 2008, several children were given the drug and they had serious side effects including rashes, dizziness and swollen faces and legs …, some became very sick. Since then, the news had spread like wildfire, and as a result of that, many people in many communities do not want to take the drug again*" (opinion leader, Ghana; Ahorlu 2018) (Ghana: Ahorlu 2018; India: Babu 2004b; Babu 2010; Indonesia: Krentel 2008; Tanzania: Parker 2013a). If not warned AEs could happen, their occurrence may have strengthened the perception that MDA was harmful and reinforced the distrust people had in the programme.

***Subtheme 1.4: deciding to adhere draws on personal and shared experiences and is complex (high confidence)***

Not every individual experienced benefits, and some may have experienced harms. As a result, the community adhered based on their personal and shared experiences, rather than what was viewed from the global policy level. Further, benefits were interpreted in the context of what people experienced so far. Especially in places where the disease had been around a long time, as people had their own narratives of how the disease was transmitted and what it looked like.

A common belief was that only people with symptoms were infected, and so did not believe that LF was a problem in the area or that they were at risk. They may have recognized some benefits and accepted that the programme was useful to others, but not to them personally: "*filariasis does not occur to me, so I have not swallowed. Those who are suffering from filariasis should swallow … why should we swallow?*" (male community member, India: Babu 2004b) and "*There isn't a filarial patient in our house, so it is not going to spread in our home. Two filaria patients in our village are from the same family and as they are residing at the extreme end of the village, the infection will not attack us*" (community member, India; Hussain 2014) (Ghana: Ahorlu 2018; India: Babu 2004a; Babu 2004b; Banarjee 2019; Ramaiah 2005; Krentel 2021; Indonesia: Krentel 2008; Tanzania: Kisoka 2016; Parker 2013a; Kenya: Njomo 2020b; Papua New Guinea: Wynd 2007; Haiti: Wodnik 2020). Similarly, in the context of their lives, some did not perceive LF as a problem when compared to malaria, fever, and diarrhoea (India: Ramaiah 2005; Tanzania: Parker 2013b).

People with late-stage LF were those with the physical conditions of hydrocoele and elephantiasis, they suffered the most from the disease and yet did not benefit from the treatment; "*you can't do anything for it when the leg is already big*" (community member, Indonesia; Krentel 2008). Moreover, the symptoms were what many people tended to associate with 'having LF'. As a result, the community's perception of the effects was influenced by the poor correlation between taking the drug and disease: "*Some people don't see any effect in their sickness after taking the drugs. They don't improve and are still sick, even in the leg*" (28-

year-old male farmer, Indonesia; Krentel 2008) (Tanzania: Parker 2013b; Indonesia: Krentel 2008; Zambia: Silumbwe 2019).

However, their perception of harm was influenced when previously 'healthy' people went on to develop symptoms after being treated. The drugs could induce hydrocoele and elephantiasis in previously asymptomatic people and this led some to think the drugs actually caused LF rather than prevented it (Tanzania: Parker 2013b; Indonesia: Krentel 2008; Haiti: Krentel 2021).

People's understanding of the programme purpose was influenced by their previous experience of similar public health programmes. Some believed the drugs worked like a vaccine, making them immune "*they will never get sick with filariasis again in times to come*" (community member, Papua New Guinea; Wynd 2007). As a result, they may have falsely believed they were no longer at risk, and thus refuse subsequent rounds of treatment or question the efficacy when they did go on to develop LF (Papua New Guinea: Wynd 2007; Tanzania: Parker 2013b).

Some people had not seen benefits despite years of treatment, LF was still ongoing in the community and they were experiencing treatment fatigue: "*The treatment has a hard time killing the worms and healing [LF]. The researchers have to keep taking blood. I don't understand the point of the treatment, there has been treatment since the 80s and there is no change*" (41-year-old male farmer and community leader, Indonesia; Krentel 2008) (Tanzania: Parker 2013b; Indonesia: Krentel 2008).

**Theme 2: many people are suspicious of MDA programmes**

Synthesis statement: history shapes community attitudes and narratives and fosters this suspicion, although a few in poor communities have complete faith in government.

***Subtheme 2.1: many people do not trust the programme and believe there is an ulterior motive (high confidence)***

Many people do not trust the programme and believe there must be an ulterior motive: "*People believe that these drugs have a hidden agenda*" (community member, Indonesia; Krentel 2008) (India: Babu 2004b; Banarjee 2019; Indonesia: Krentel 2008; Ghana: Biritwum 2017; Manyeh 2020; Tanzania: Kisoka 2016; Kisoka 2017; Parker 2013a; Kenya: Kusi 2020; Njomo 2020b; Haiti: Wodnik 2020). Some suspect the true purpose was to collect blood to sell (Indonesia: Krentel 2008); or that the drugs were contraceptives (Indonesia: Krentel 2008; Tanzania: Kisoka 2016; Kisoka 2017; Parker 2013b; Kenya: Kusi 2020; Njomo 2020b; Ghana: Manyeh 2020; Haiti: Wodnik 2020); or even, in the extreme, that the drugs had been brought to kill them: "*Free drugs are brought to kill us. People are afraid to use even the free bed nets provided*" (community member, Indonesia; Krentel 2008) (Tanzania: Kisoka 2016; Indonesia: Krentel 2008). MDA campaigns are implemented into complex historical and political contexts that ultimately shape how they are received. Without an adequate understanding of why the drugs were distributed, people may have inferred motivation from this sociopolitical context instead. As a result, the trust people have in the programme was often an extension of the trust they had in their government: "*you have to trust in the government to swallow the tablets … trust matters a lot. If you don't trust them, you can't swallow the drug*" (Tanzania: Parker 2013b).

As a result, negative experiences and perceptions of government can harm the credibility of the programme. In one study, people described how their needs had been ignored by the government in the past; they questioned the sudden intent to help, when they were still without anti-malarials and clean water; "*There is something strange going on. If the government want to help us, they should distribute malaria drugs for free, not [elephantiasis and hydrocele]*" (young male community member, Tanzania; Parker 2013a). Others may recall traumatic events. PKI (the Indonesian Communist Party) had distributed free goods as part of their campaign in 1965 and all those in receipt of such items were found guilty by association and murdered. As a result, people are fearful of free gifts: "*many have suffered trauma from [outsiders], lots of trauma. If someone comes with a free distribution, they [community] ask me if they are associated with PKI [Indonesian Community Party]. PKI gave free goods, and in the end, we have family who died as a result, they were murdered*" (community leader, Indonesia; Krentel 2008).

For some people, these fears could be attributed to colonial legacies. Some community members were aware of the role of western donors in the programme and in some cases, this fuelled their suspicions (Tanzania: Parker 2013b). For example, some believed the drugs were contraceptives because they know that "*white people were fed up giving us help every day*" (male community member, Tanzania; Parker 2013b) and that "*We know women in Europe have two children and their intention is to make Africans like Europeans. They think we can't manage so many children, that we can't provide proper education, health care and home environment*" (community member, Tanzania; Parker 2013b).

***Subtheme 2.2: some have an unquestioning attitude to government and a lack of agency, leading to unwavering faith in the programme (moderate confidence)***

Some community members describe themselves, as 'simple uneducated people', who automatically accept their governments' advice as they believe they know what is best for them: "*We don't know – we are little people here so if they give us services, then we accept it; if not, then we sit quietly like this … they know more about the situation in this country, how to advance this country. They know how far the capability is. We, the little people, don't know. They know*" (community member, Indonesia; Krentel 2008). They may have felt grateful to be noticed and helped by their government. They may also have felt a responsibility to make government programmes work and perhaps to be seen as compliant citizens: "*So if he doesn't drink, we will direct or persuade him so that he will also take it so that this government programme will have results in 2010*" (community member, Indonesia; Krentel 2008).

**Theme 3: programmes expect compliance: this can result in coercion and blame**

Synthesis statement: government HCWs, CDDs, and community members can become coercive and blaming as a response to the programme's imperative for compliance.

***Subtheme 3.1: health workers may become authoritarian to ensure compliance (moderate confidence)***

HCWs and CDDs are responsible for the delivery of MDA and perhaps, under pressure to meet programme targets could become demanding (Kisoka 2017). For example, in one study, when people spoke about HCW or CDD attitudes, they sometimes

described them as "angry" or "shouting" to take the drugs, and to take them quickly (India: Banarjee 2019; Tanzania: Kisoka 2016; Indonesia: Krentel 2008). A few were afraid that if they did not take the drugs, HCWs would blame them for falling sick with LF and deny them further treatment: "*They will say – the doctor has already come and now you're sick! It's your own fault! You take your own risks. They will not help you if you get sick, you will go to the hospital alone*" (female community member, Indonesia; Krentel 2008)). The husband of one HCW stated that their authoritarian approach was justified "*force is necessary, so people will understand*" (community member, Indonesia; Krentel 2008). It is possible that this directive approach was normalized and the health workers believed it was the obvious solution to the challenge of low compliance in communities.

***Subtheme 3.2: community members may become coercive, and stigmatize non-compliance (moderate confidence)***

In one study, some members of the community also dealt with non-compliance from neighbours similarly: perhaps taking their lead from the behaviour displayed by HCWs and CDDs. While HCWs and CDDs were likely under pressure to meet compliance demands, coercive behaviour by community members appeared to be fuelled by genuine fears of LF persisting in the community and putting others at risk, or the financial and physical burden of having to take care of a sick neighbour or family member: "*If she's sick, everyone has to think about helping her. Everyone's burdened. If she doesn't want to take the drug, what can we do? Force? If there is someone who refuses, and they get sick, the neighbours can come and yell and force her to take it*" (male community member, Indonesia; Krentel 2008) (Indonesia: Krentel 2008). In contrast to subtheme 3.1, people were not only blamed for falling sick but for harming everyone else and so people justified coercion in order to protect themselves and their families. This may have been in the form of aggression as described above; shaming: "*all will ridicule her at the time*"; or by shunning them from the rest of the community: "*she can be fenced in, not allowed to live with family, she would be expelled so that this disease could not breed*" (community leader, Indonesia; Krentel 2008) (Indonesia: Krentel 2008).

When people were asked how they would react to a non-complier, there were cases insisting that the decision was up to the individual and they would not be forced. It may have been that the coercion and stigmatization of non-adherence observed varied between communities and countries. However, in one example, the respondent simultaneously described how they did not use force, but then went on to explain how they *would* pressure the woman to concede: "*We won't force her, but if we show her the right way again and again, for sure she will think, ya, I want to follow too*" (female community member, Indonesia; Krentel 2008,) suggesting that perhaps coercive behaviour is so normalized during distribution that people did not even realize they were doing it.

***Subtheme 3.3: outward compliance, private rejection (moderate confidence)***

While the 'official' public narrative is high rates of adherence to the drugs, there were instances where people appeared to comply, and privately reject (Ghana: Ahorlu 2018; Manyeh 2020; Indonesia: Krentel 2008)*:* "*Many people she knew hid the medication when asked to take it in front of the health official, drinking water only instead of swallowing the medication, which they threw away later*" (female community member, Indonesia; Krentel 2008. People may have pretended to be pregnant or breastfeeding to be exempt from treatment (Ghana: Ahorlu 2018). These examples represent a strong rejection of both the treatment and the authority promoting it, and may have further eroded the trust between programme and participants. CDDs also had a role in this facade as "*some of [them] will throw some of the medicine away and then mark people in the register as having received the medicine just to show that [they] are hardworking*" (female distributor, Ghana; Ahorlu 2018) (Ghana: Ahorlu 2018; Indonesia: Krentel 2008; Kenya: Njomo 2020b). Some people described how the CDD "*will give you the drug and it is left to you to take it or refuse*" (female opinion leader, Ghana; Ahorlu 2018) (Ghana: Ahorlu 2018; Manyeh 2020). This evades the social pressure of adherence described above and allows families to make a personal decision: "*the choice of taking drugs will remain to be of the household head and even the community members want it that way because they think that is what is best*" (village elder, Kenya; Njomo 2014).

**Theme 4: distributor's status in the community is often low, and they are not well-equipped to answer the communities' questions**

Synthesis statement: they have little authority, and the behaviour of some damages the MDA programme's reputation. Communities want information about programmes to help make decisions about participation, but drug distributors are not sufficiently informed, or skilled in this communication.

***Subtheme 4.1: community drug distributors have limited authority (moderate confidence)***

CDDs hold no formal qualifications or titles and so are not perceived as part of the health system. Yet, they are placed in a position to demand people take treatment and are expected to answer complex health questions. As a result, they have a muddled role in the distribution that leads people reject their involvement. Their lack of formal qualifications or status means people did not trust that they were being given correct advice: "*He disapproved of the community health worker … claiming that she was too poorly educated to be credible*" (community member, Indonesia; Krentel 2008) (Tanzania: Kisoka 2016; Kisoka 2017; Indonesia: Krentel 2008; India: Babu 2004a; Ramaiah 2000; Ramaiah 2005; Krentel 2021). In addition, some people argued that if the drugs were so important, their doctor would have already informed them (India: Banarjee 2019; Kenya: Kusi 2020). As a result, some people rejected treatment, while others refused to engage until their doctor had given them permission (Tanzania: Kisoka 2016; Indonesia: Krentel 2008; India: Banarjee 2019; Krentel 2021; Ramaiah 2000; Ramaiah 2005; Kenya: Kusi 2020). Further, the limited authority that community members did have could sometimes have the opposite effect; people were sometimes offended that CDDs were 'acting like health workers', in effect, above their station and: "*they come to order all of us about as if they are our doctors. I think that the doctors should have a meeting with us and tell them in our presence that they are under us for us to supervise them*" (male community leader, Ghana; Ahorlu 2018) (Ghana: Ahorlu 2018).

Despite also not having medical training, community or religious leaders do possess authority in their communities and their instruction is perhaps trusted more than that of CDDs (Indonesia: Krentel 2008; Kenya: Kusi 2020; Zambia: Silumbwe 2019). One man explained how "*an American missionary pastor*

*told him that when he was sick, he should take traditional medicine and since then, he had followed his advice*" (older male community member, Indonesia; Krentel 2008). As a result, CDDs that are chosen by or endorsed by community leaders may elicit greater trust and co-operation (Ghana: Ahorlu 2018; Manyeh 2020: Kenya: Kusi 2020; Indonesia: Krentel 2008).

#### *Subtheme 4.2: people prefer community drug distributors that are well known to the community and have good behaviour (high confidence)*

As explored in theme 2 (many people are suspicious of MDA programmes), people can be suspicious of interventions imposed on them from external agents. Therefore, some reported they were motivated to adhere when their CDDs were known by them and came from the same community. Some explained that they participated in MDA specifically because of their relationship to their distributor (India: Babu 2008; Tanzania: Kisoka 2017; Kenya: Kusi 2020; Njomo 2020b; Zambia: Silumbwe 2019). In contrast, some reported various instances of CDDs behaving inappropriately (examples included demanding money or gifts, drinking too much alcohol, or arguing about politics) and that they refused the drugs on this basis (Ghana: Ahorlu 2018). "*Personally, I don't take the medicine every year because I just don't like the distributor in this community*" (male opinion leader, Ghana; Ahorlu 2018). In all, this demonstrates how integral the perception of CDDs is on the success of the programme.

#### *Subtheme 4.3: people seek clarification and rationale, but do not always receive it (high confidence)*

Communities with long-standing LF often have their own well-established narratives about the disease, which means any rationale for MDA needs to be compatible with this. People could and did choose to incorporate public health information into their traditional narratives and participate in the programme (India: Babu 2008; Ghana: Ahorlu 2018; Indonesia: Krentel 2008). However, as one man explained how "*for him, traditional medicine and LF medicine had the same use—to prevent disease and keep him healthy. He planned to continue using traditional medicine so that he would not get sick from LF*" (community member, Indonesia; Krentel 2008). This man accepted the public health knowledge given to him as it reflected his own reason for taking traditional treatment. But the rationale given for MDA did not make sense in the context of his own experience – he already had an effective treatment. The different community knowledge on LF, the varying quality of education campaigns, and the problems communities had in integrating their own knowledge with what was being said to them meant people had questions (Kenya: Njomo 2012a; Njomo 2014; India: Banarjee 2019; Tanzania: Biritwum 2017; Parker 2013a; Indonesia: Krentel 2008). Krentel 2008 provided a list of questions commonly asked during their study and we found that they typically reflected community concerns explored in earlier themes. For example, some people were confused why they needed to take the drugs even though they felt well; and were concerned why people went on to develop symptoms of elephantiasis and hydrocoele after treatment (subtheme 1.4: the decision to adhere is complex and based on personal and shared experiences so far). Others questioned why "E*uropeans [are] manufacturing tablets for [elephantiasis and hydrocoele] when they do not suffer from these diseases?* (community member, Indonesia; Krentel 2008) (theme 2: many people are suspicious of MDA programmes).

CDDs possessed mainly procedural knowledge on the rules of programme delivery, but were sometimes unable to explain things to the community. "*I took the medications for about three times and stopped because the distributors were not telling us why we should continue to take the medicine*" (male opinion leader, Ghana; Ahorlu 2018). In one study, despite having received training on the causes of LF, distributors had a varied understanding of transmission, for example: "*From what I learned in school, it is transmitted by mosquitoes, but we were not told so in this MDA*" (community member, Tanzania; Kisoka 2016) and "*Elephantiasis is a disease which a person gets from worms that are found in the water. The person gets the disease by entering into the water and being bitten by insects living in the water with worm*" (CDD, Tanzania; Kisoka 2016). This may have reflected inadequate training and communication between programme implementers and an important group of stakeholders. CDDs were the main interface between programme and community, any distortion at this level was bound to result in misunderstandings and lack of appropriate knowledge. Furthermore, in one study, the community leader intentionally withheld biomedical explanations from the villagers as he assumed they would not understand (Indonesia: Krentel 2008). In all, this lack of common understanding led to frustration at the community level as they did not have enough details to make an informed decision (Ghana: Ahorlu 2018; Manyeh 2020; India: Banarjee 2019; Ramaiah 2005; Tanzania: Biritwum 2017; Kisoka 2016; Kisoka 2017; Parker 2013b; Indonesia: Krentel 2008; Kenya: Kusi 2020; Njomo 2012a; Njomo 2014; Njomo 2020b). In one study in Ghana, social mobilization and education resulted in increased willingness to participate in future campaigns (Manyeh 2021).

### Confidence in the findings

Based on the CERQual assessment, we graded six subthemes as high confidence and six subthemes as moderate confidence. Summary of findings 1 shows a summary of the CERQual assessment and the full assessment including individual justifications is detailed in Appendix 3. We found the process of considering coherence, including describing and explaining divergent cases, made for stronger theory and two subthemes were dissolved and merged as a result of this.

## DISCUSSION

### Summary of findings

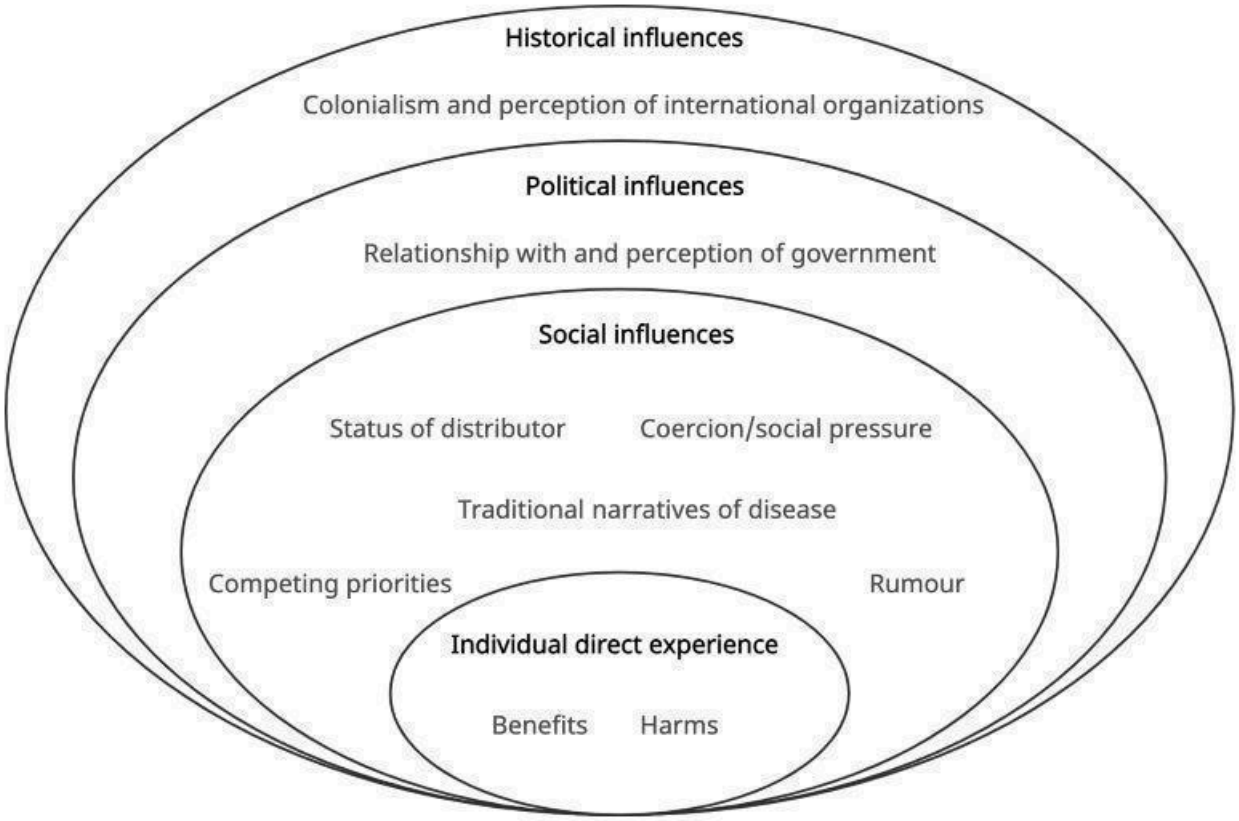
This review sought the views and experiences of community members, which is often absent from the analysis of vertical programmes. We conducted a QES using thematic analysis and generated four themes:

- people weigh up benefits and harms before adhering;
- many people are suspicious of MDA programmes;
- programmes expect compliance: this can result in coercion and blame; and
- distributor's status in the community is often low, and they are not well-equipped to answer the communities' questions.

The conceptual model below summarizes the findings of this review (Figure 3). Our analysis found important links between individual behaviour and the wider community, and to policies and reputations of programmes and organizations, it was easier to visualize factors of influence being nested in an ecological model inspired by Bronfenbrenner's Ecological Systems Theory

(Bronfenbrenner 1989). This model builds on the conceptual framework developed in the protocol (Taylor 2020), and included in the Background (Figure 1) to demonstrate how several additional factors such as historical and political contexts, competing narratives of disease, social pressures, and sufficiency of information and education impact adherence. It also demonstrates how interventions are not implemented into naive populations and instead interact with pre-existing multi-layered narratives and challenges that policymakers could consider when designing and implementing these programmes.

**Figure 3. Updated conceptual model demonstrating the wider social, historical, and political influences that shape the experience of the programme and ultimately the decision to adhere.**




The review authors were careful to draw out examples of positive perspectives associated with the programme, yet found the overall narrative in the primary research to be predominantly negative. The qualitative literature summarized here foregrounds community views and experiences that are currently missing from policy documents and decisions and could be used to inform programme design and delivery. We are not evaluating the public health effectiveness of programmes and the stated successes in achieving elimination and reduced transmission in many countries to date. However, despite the claims of success from donors, it may be a good time to pause and reflect on lessons to learn from the 48 countries that remain endemic and the communities that continue to be affected by LF despite more than 10 years of treatment (WHO 2020); well beyond the five years recommended by the WHO. The effectiveness of MDA programmes is a contested area and debates in recent years have questioned the international rhetoric of success compared to the apparent failures at community level (Parker 2014; Reisz 2013).

We had intended to analyze the findings in accordance with aspects of programme design and delivery, to see what components influenced community views and in what way. However, there was too little detail in the information we collected to allow for any meaningful comparison.

AE were the most frequently mentioned topic. With LF, this is not an intrinsic effect of the drug, but the result of the drug killing microfilaraemia causing fever, headaches, malaise, and muscle pain as a result of the antigen release. We know AEs may be relatively uncommon in MDA programmes as much of the population is uninfected, but even small rates of AEs result in enough cases to generate fear in communities and refusal of treatment. Furthermore, 'mild' AEs (such as fever and nausea; Lima 2012) may still prevent individuals from being able to work or go about their daily lives and this is more important to them than any perceived benefit. The findings of this review indicate that policymakers may wish to consider that communities are informed about these AEs prior to distribution and to ensure that appropriate after-care is provided. This helps foster more trust in the programmes.

### Overall completeness and applicability of the evidence

The studies encompassed a wide range of countries and were predominantly based on community members of both genders, in both urban and rural settings.

Krentel 2008 contributed substantially to the coded quotations. This is a PhD thesis conducted in Indonesia. Most of the other studies were conducted in India. However, the studies conducted in Africa were consistent with the broad themes identified, indicating the themes documented by Krentel 2008 and others in South-East Asia about this global programme are applicable in the main regions covered by the global elimination programme.

The findings are based on studies conducted in areas of known low compliance and five studies were conducted in areas that had received seven, 10, or 15 rounds of MDA. As a result, the views described may not reflect those of communities with high levels of compliance. However, given how widespread compliance challenges are, the findings of this review make a valid contribution to understanding how some communities perceive MDA programmes.

The number of studies meeting the inclusion criteria has increased over 2019 to 2021; we identified 16 studies prior to 2019 and eight studies after 2019. This reflects an increased interest and importance placed on successful MDA campaigns since 2000 with the implementation of GPELF. We conducted a search update in April 2021 as more than one year had passed since we conducted the original search. The findings that emerged from this additional data set broadly supported the findings we had originally, and there were no new themes. We did note however that, for some more-recent studies (Krentel 2021), community knowledge and acceptance was increased, and the primary study authors related this to education and sensitization initiatives and provision of AE after-care.

The PhD thesis we included was detailed (Krentel 2008). Although not published in peer-reviewed publications, the quality assessment on this study scored high. In addition, two studies have been published using data originally reported by the thesis, and so we had no concerns about the inclusion of this study in our analysis.

### Agreements and disagreements with other studies

The current global guideline for LF states that MDA is an acceptable intervention (WHO 2017). However, our findings indicate that for many people, this is not the case.

This review found that communities are often suspicious of MDA programmes and may believe the drugs have been brought to kill them or to act as contraceptives. This was supported by two reviews on MDA for LF by Krentel 2013 and Ames 2019. Similar suspicions have also been described for MDA programmes for schistosomiasis and soil-transmitted helminths (Hastings 2016; Legge 2020; Parker 2011). Poor perceptions and experiences of government and international involvement may fuel these assumptions. Parker 2011 reported this in their findings and a study by Lowes 2018 described how those in with a greater historical exposure to French-colonial campaigns to prevent sleeping sickness were more likely to refuse a free, non-invasive blood test.

Perception of benefit, need, or risk as a motivator towards adherence is well-supported in the literature (Ames 2019; Krentel 2013; Legge 2020; Shuford 2016). This study noted that MDA may not be as prioritized as other concerns such as malaria or access to clean water. Hastings 2016, Silumbwe 2017, and Bhullar 2010 all remarked that worm infections are to some 'just part of life', and that communities describe a sense of bewilderment that LF control is given at the expense of interventions for diseases such as malaria and cholera, which cause high mortality, particularly for their children. This review found that many people do not adhere to treatment because they are afraid of the potential AEs. These findings are supported by several reviews who described AEs as one of the main reasons for non-compliance (Ames 2019; Babu 2014; Krentel 2013; Shuford 2016; Silumbwe 2019). These concerns have also been reported in control programmes for onchocerciasis (Shuford 2016), soil-transmitted helminths (Legge 2020; Parker 2011), and schistosomiasis (Parker 2011).

Ames 2019 briefly noted that health workers may 'exert some pressure' on people who refused to adhere. However, the use of coercion by health workers and community members is not discussed in detail or elsewhere in the literature relating to MDA programmes.

The review identified problems regarding perception of distributors and sufficiency of information provided to the community. Ames 2019, Liese 2010, and Silumbwe 2017 also described how inadequate training, motivation, and knowledge of distributors negatively impacted adherence. Krentel 2013 noted how familiarity with distributors establishes trust and improves adherence. However, Ames 2019 noted that while this may work in small communities, it does not work in larger ones because the likelihood of knowing the distributor is reduced.

## AUTHORS' CONCLUSIONS

### Implications for practice

Despite the reported benefits and success of mass drug administration (MDA) programmes in the global literature, this review describes some fundamental community concerns and suspicions, including beliefs of harmful ulterior motives and fears surrounding adverse effects of treatment. These concerns likely provide substantive barriers to the effective delivery of MDA.

We are not convinced that these problems can be fixed by simply training health workers better (for example). The current problems with adherence must give rise to questions over the assumptions in the current MDA model. Is MDA acceptable to recipient communities? While we were unable to identify any particular components of programme design and delivery that influenced the views of community members, our findings do suggest some important considerations for future practice.

- Policymakers and providers need to ensure distribution targets do not create an atmosphere in which non-adherence is stigmatized, as this may further erode the trust and co-operation on which the programme depends.
- Improved education and sensitization is desired by recipient communities and may help to address the fears and misinformation, but needs to be sensitive and responsive to the local experiences and context.

- Communities need to be informed about adverse effects in advance, what they represent, and how they should manage them. In addition, after-care may be provided, whereby a doctor is present at the distribution and for some time afterwards to manage any serious adverse effects.
- Community drug distributors require improved training and status in the community so that their instruction is both trusted and valued.
- Pre-existing experiences and narratives shape the interpretation of both benefits and harms. Greater involvement of the community in planning and implementation may help here

It is likely these findings are relevant to other MDA programmes in low- to middle-income countries, including MDA for soil-transmitted helminths, schistosomiasis, onchocerciasis, or malaria.

### Implications for research

Most of our findings are well-supported in the literature, both for MDA programmes for filariasis and also for other parasitic infections such as schistosomiasis and soil-transmitted helminths. However, Theme 3 (Programmes expect compliance: this can result in coercion and blame) of our review is currently graded as moderate-confidence evidence for all subthemes. While it fits in with some other findings, we would encourage more careful research across a range of settings to explore if this is a common finding and increase our confidence that this is true and occurs more generally.

In addition, we found that study reporting was often poor and recommend the following areas for improvement.

- Most studies were graded as low reliability due to the lack of reporting of data collection and analysis. In particular, few studies included a reflexivity statement.
- Future research should describe aspects of the local programme delivery in the study setting, as this will allow for analysis of how these factors impact community views and decisions to adhere.

Further operational research at a local level may help highlight and alleviate some barriers identified here, although the very substantive range of problems suggest the impact of such modifications may be limited.

Further research with other MDA programmes and vertical disease programmes in general is urgently required and seems likely to be higher on the agenda as decolonization is discussed more widely in global health.

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### Editorial and peer-reviewer contributions

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The following people conducted the editorial process for this article:

- Contact Editor: Dr Ingrid Eshun-Wilson. We are also grateful to CIDG Editor Dr Hellen Gelband for her input as Editor Advisor.
- Sign-off Editor (final editorial decision): Professor Lisa Bero, Cochrane Senior Editor.
- Managing Editor (selected peer reviewers, collated peer-reviewer comments, provided editorial guidance to authors, edited the article): Dr Deirdre Walshe, CIDG.
- Copy Editor (copy editing and production): Anne Lawson, Cochrane Copy Edit Support.
- Peer-reviewers (provided comments and recommended an editorial decision):
  - protocol stage: Ms Meike-Kathrin Zuske, Swiss Tropical and Public Health Institute, Basel, Switzerland;
  - protocol and review stage: Professor Ruth Garside, University of Exeter;
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* Indicates the major publication for the study

## CHARACTERISTICS OF STUDIES

### Characteristics of included studies *[ordered by study ID]*

#### Ahorlu 2018

| ***Study characteristics*** | |
|---|---|
| Country | Ghana |
| Setting | Mixed urban/rural; endemic |
| Aim | "To determine the community members' participation and ingestion of the intervention drugs and generate appropriate information from community perspectives to inform promotional strategies to rekindle participation and promote the ingestion of the intervention drugs in hotspot communities". |
| Drug regimen | IVM + ALB[a] |
| Participants | Village chiefs, queen-mothers, drug distributors, and opinion leaders<br>n = 72 |
| Study methods | Qualitative |
| Data collection methods | In-depth interviews |
| Notes | |

#### Amarillo 2008

| ***Study characteristics*** | |
|---|---|
| Country | Philippines |
| Setting | Rural |
| Aim | "To determine the MDA acceptance rate among a population endemic for LF, and the factors associated with MDA acceptance". |
| Drug regimen | DEC + ALB |
| Participants | Local health officers, field health personnel, and community leaders |
| Study methods | Mixed-methods |
| Data collection methods | In-depth interviews and focus group discussions |
| Notes | |

#### Babu 2003

| ***Study characteristics*** | |
|---|---|
| Country | India |

**Babu 2003** *(Continued)*

| | |
|---|---|
| Setting | Rural; endemic |
| Aim | "To identify factors responsible for coverage and compliance of treatment". |
| Drug regimen | DEC |
| Participants | Community members, key-informants interviews, health workers, medical officers, and CDDs<br>n = 64; 27 groups |
| Study methods | Mixed-methods |
| Data collection methods | Semi-structured interview and focus group discussions |
| Notes | |

**Babu 2004a**

| ***Study characteristics*** | |
|---|---|
| Country | India |
| Setting | Mixed urban/rural; endemic |
| Aim | "To explore the attitudes and perceptions of the community members, medical officers, peripheral health workers, private medical practitioners, and non-governmental organizations (NGO) involved in the MDA for LF control in four endemic districts (Khurda, Puri, Balasore and Ganjam) of Orissa state". |
| Drug regimen | DEC + ALB |
| Participants | Community members, key informants, medical officers, private practitioners, health workers, and NGO personnel<br>n = 218 |
| Study methods | Qualitative |
| Data collection methods | Semi-structured interview and focus group discussions |
| Notes | |

**Babu 2004b**

| ***Study characteristics*** | |
|---|---|
| Country | India |
| Setting | Mixed urban/rural; mixed endemicities |
| Aim | "To report coverage and treatment compliance in Orissa and discuss other operational issues of the programme that influence the coverage and compliance of the MDA". |
| Drug regimen | DEC + ALB |

**Babu 2004b** *(Continued)*

| | |
|---|---|
| Participants | Community members, health workers, key informants, people with LF, NGO staff, private practitioners, and medical and district health officers<br><br>n = 113; 20 groups |
| Study methods | Mixed-methods |
| Data collection methods | Semi-structured interview and focus group discussions |
| Notes | |

**Babu 2008**

| ***Study characteristics*** | |
|---|---|
| Country | India |
| Setting | Mixed urban/rural; endemic |
| Aim | "To identify the factors responsible for compliance and non-compliance during MDA from the community's perspective in the state of Orissa, India". |
| Drug regimen | DEC |
| Participants | Head of household<br><br>n = 240 |
| Study methods | Mixed-methods |
| Data collection methods | Semi-structured interview |
| Notes | |

**Babu 2010**

| ***Study characteristics*** | |
|---|---|
| Country | India |
| Setting | Mixed urban/rural; endemic |
| Aim | "To describe the perceptions of community members and programme partners regarding severity, management and impact of adverse reactions on MDA compliance". |
| Drug regimen | DEC |
| Participants | Community members, key informants, drug distributors and their supervisors, and programme partners including doctors<br><br>n = 96; 15 groups |
| Study methods | Qualitative |

**Babu 2010** *(Continued)*

| | |
|---|---|
| Data collection methods | Semi-structured interview and focus group discussions |
| Notes | |

**Banarjee 2019**

| ***Study characteristics*** | |
|---|---|
| Country | India |
| Setting | Mixed urban/rural; endemic |
| Aim | "To assess the coverage and compliance with MDA of filariasis as well as exploring perspective of beneficiaries for `non-consumption` in selected slum area of Nagpur city". |
| Drug regimen | ALB + DEC + IVM |
| Participants | Community members who chose not to adhere<br>n = 12 |
| Study methods | Mixed-methods |
| Data collection methods | In-depth interview |
| Notes | |

**Biritwum 2017**

| ***Study characteristics*** | |
|---|---|
| Country | Ghana |
| Setting | Urban; endemic |
| Aim | "To identify the opportunities and barriers for implementing MDA in urban settings, and to develop appropriate strategies for MDA in these settings". |
| Drug regimen | IVM + ALB[a] |
| Participants | Community and religious leaders, community members, CDDs, health workers, and NGO staff<br>n = 40 + 4 focus group discussions with 6–8 members |
| Study methods | Mixed-methods |
| Data collection methods | In-depth interviews and focus group discussions |
| Notes | |

### Cassidy 2016

| ***Study characteristics*** | |
|---|---|
| Country | India |
| Setting | Mixed urban/rural; endemic |
| Aim | "To assess perceptions of lymphedema and retrospectively evaluate the impact of this program on patients, family members, program volunteers, and community members". |
| Drug regimen | DEC |
| Participants | People with lymphoedema, their families, programme volunteers, and community members.<br>n = 211 |
| Study methods | Qualitative |
| Data collection methods | Focus group discussions |
| Notes | |

### Gonzales 2019

| ***Study characteristics*** | |
|---|---|
| Country | Dominican Republic |
| Setting | Urban; endemic |
| Aim | "To present a qualitative analysis of this 'positive deviant' [areas with high coverage] and increase our understanding of what can be successful in urban settings". |
| Drug regimen | DEC + ALB |
| Participants | Community members, CDDs, community leaders, LF programme staff and managers, and NGO programme managers<br>n = 85 |
| Study methods | Qualitative |
| Data collection methods | Semi-structured in-depth interviews and focus group discussions |
| Notes | |

### Hussain 2014

| ***Study characteristics*** | |
|---|---|
| Country | India |
| Setting | Mixed urban/rural; endemic |

**Hussain 2014** *(Continued)*

| | |
|---|---|
| Aim | "To assess: the filariasis knowledge in the community, the coverage and compliance of MDA from the community perspective, and factors affecting compliance, as well as the operational issues involved in carrying out MDA activities from the drug distributor's perspective". |
| Drug regimen | DEC + ALB |
| Participants | Community members, drug distributors, healthcare workers, and medical officers<br>n = 713 |
| Study methods | Mixed-methods |
| Data collection methods | Semi-structured interview |
| Notes | |

**King 2011**

| ***Study characteristics*** | |
|---|---|
| Country | American Samoa |
| Setting | Mixed |
| Aim | "To describe the formative research methods used, opportunities identified, changes made in the campaign strategies and the impact on community compliance in MDA". |
| Drug regimen | DEC + ALB |
| Participants | Religious leaders, nurses, programme directors, health assistants, and volunteers who served as drug distributors |
| Study methods | Mixed-methods |
| Data collection methods | Focus group discussions and structured interviews |
| Notes | |

**Kisoka 2016**

| ***Study characteristics*** | |
|---|---|
| Country | Tanzania |
| Setting | Mixed urban/rural; endemic |
| Aim | "To gain an understanding of community experiences with, and perceptions of, the MDA campaign implemented in 2011 by the National Lymphatic Filariasis Elimination Programme". |
| Drug regimen | IVM + ALB |
| Participants | Community members and drug distributors |

**Kisoka 2016** *(Continued)*

| | |
|---|---|
| | n = 21; 18 groups |
| Study methods | Qualitative |
| Data collection methods | In-depth Interviews and focus group discussions |
| Notes | |

**Kisoka 2017**

| ***Study characteristics*** | |
|---|---|
| Country | Tanzania |
| Setting | Mixed urban/rural; endemic |
| Aim | "To understand the different forms of involvement in the campaign and the experiences of stakeholders concerning their part in the community-directed distribution of medicines". |
| Drug regimen | IVM + ALB |
| Participants | Community members, community and religious leaders, health workers, and CDDs<br>n = 156 |
| Study methods | Qualitative |
| Data collection methods | Participant observation, focus group discussions, and semi-structured interviews. |
| Notes | |

**Krentel 2008**

| ***Study characteristics*** | |
|---|---|
| Country | Indonesia |
| Setting | Mixed urban/rural; mixed endemicities |
| Aim | "To describe the reasons people comply with treatment within the context of Alor district". |
| Drug regimen | DEC + ALB |
| Participants | Community members, community and religious leaders, health workers, and CDDs<br>n = 43 |
| Study methods | Qualitative |
| Data collection methods | In-depth interview |
| Notes | |

### Krentel 2021

| ***Study characteristics*** | |
|---|---|
| Country | Fiji, Haiti, India, Indonesia, and Papua New Guinea |
| Setting | Mixed urban/rural; endemic |
| Aim | "To assess the acceptability of ivermectin, DEC and albendazole (IDA). This paper presents aggregated results from a five-country acceptability study that informed development of new guidelines for use of IDA in the global LF elimination program". |
| Drug regimen | IVM + DEC + ALB |
| Participants | Community members, community leaders, community health workers, and CDDs<br>n = 42; 27 groups |
| Study methods | Mixed-methods |
| Data collection methods | In-depth interviews and semi-structured interviews |
| Notes | |

### Kusi 2020

| ***Study characteristics*** | |
|---|---|
| Country | Kenya |
| Setting | Mixed urban/rural; endemic |
| Aim | "To explore and describe perceptions of CDDs during MDA for LF in Mvita sub-county in Mombasa county and Kaloleni sub-county in Kilifi county, Kenya; and provide recommendations for the effective engagement of communities and CDDs in low-resource settings". |
| Drug regimen | DEC + ALB |
| Participants | Community members, community health workers, community leaders, NTD, and LF programme officials<br>n = 64 |
| Study methods | Qualitative |
| Data collection methods | Focus group discussions and semi-structured interviews |
| Notes | |

### Manyeh 2020

| ***Study characteristics*** | |
|---|---|

**Manyeh 2020** *(Continued)*

| | |
|---|---|
| Country | Ghana |
| Setting | Not stated; endemic |
| Aim | "To help design and implement a quality improvement strategy for more effective MDA by way of learning from a district that interrupted the transmission of LF, as well as to understand factors contributing to the persistent transmission of LF in a hotspot district". |
| Drug regimen | DEC + ALB or IVM + ALB |
| Participants | Community members, community health workers, and CDDs<br>n = 36 |
| Study methods | Mixed-methods |
| Data collection methods | In-depth interviews |
| Notes | |

**Manyeh 2021**

| | |
|---|---|
| ***Study characteristics*** | |
| Country | Ghana |
| Setting | Rural; endemic |
| Aim | "To use the RE-AIM framework to evaluate CEQI intervention's effect on the implementation of LF MDA in the Bole District of Northern Ghana". |
| Drug regimen | DEC + ALB or IVM + ALB |
| Participants | Community leaders, CDD, and health workers<br>n = 42 |
| Study methods | Mixed methods |
| Data collection methods | In-depth interviews |
| Notes | |

**Njomo 2012a**

| | |
|---|---|
| ***Study characteristics*** | |
| Country | Kenya |
| Setting | Mixed urban/rural; endemic |

**Njomo 2012a** *(Continued)*

| | |
|---|---|
| Aim | "To establish the role of social mobilization in MDA uptake during the National Programme to Eliminate Lymphatic Filariasis in Kenya". |
| Drug regimen | DEC + ALB |
| Participants | People with LF, opinion leaders, community members, drug distributors, healthcare workers, and programme co-ordinators<br>n = 185; 16 groups |
| Study methods | Mixed-methods |
| Data collection methods | In-depth interview, semi-structured interviews, and focus group discussions |
| Notes | |

**Njomo 2014**

| ***Study characteristics*** | |
|---|---|
| Country | Kenya |
| Setting | Mixed urban/rural; endemic |
| Aim | "To identify, design and test strategies that could be used to develop guidelines for achieving high treatment coverage in an urban setting and to identify possible pitfalls that could be a hindrance to achieving high treatment coverage in such urban settings". |
| Drug regimen | Not stated |
| Participants | Opinion leaders, community members, and distributors<br>n = 40; 15 groups |
| Study methods | Mixed-methods |
| Data collection methods | In-depth interview and focus group discussions |
| Notes | |

**Njomo 2020a**

| ***Study characteristics*** | |
|---|---|
| Country | Kenya |
| Setting | Mixed urban/rural; endemic |
| Aim | "To identify barriers of community participation and access to MDA, develop and test strategies to be recommended for improved uptake". |
| Drug regimen | DEC + ALB |

**Njomo 2020a** *(Continued)*

| | |
|---|---|
| Participants | Community members<br>16 groups with 8–12 participants |
| Study methods | Mixed-methods |
| Data collection methods | Focus group discussions |
| Notes | |

**Njomo 2020b**

| | |
|---|---|
| ***Study characteristics*** | |
| Country | Kenya |
| Setting | Mixed urban/rural; endemic |
| Aim | "To identify some of the implementation challenges and opportunities for improved MDA uptake from the perspectives and experiences of the CDDs". |
| Drug regimen | DEC + ALB + IVM |
| Participants | Community leaders, drug distributors, and health workers<br>n = 45; 8 groups |
| Study methods | Qualitative |
| Data collection methods | In-depth interviews and focus group discussions |
| Notes | |

**Parker 2013a**

| | |
|---|---|
| ***Study characteristics*** | |
| Country | Tanzania |
| Setting | Mixed urban/rural; endemic |
| Aim | "To document understandings and responses to MDA for the treatment and prevention of lymphatic filariasis among adults and children in northern coastal Tanzania from 2004 to 2011". |
| Drug regimen | IVM + ALB |
| Participants | Community members, local healers, healthcare providers, and village elders<br>n = 628 |
| Study methods | Mixed-methods |
| Data collection methods | In-depth interviews, observation, and semi-structured interviews |

**Parker 2013a** *(Continued)*

| |
|---|
| Notes |

**Ramaiah 2000**

| ***Study characteristics*** | |
|---|---|
| Country | India |
| Setting | Mixed urban/rural; endemic |
| Aim | "To study the pattern of DEC distribution and compliance achieved in Tamil Nadu's annual single-dose DEC mass treatment programme". |
| Drug regimen | DEC |
| Participants | Key informants, medical officers, health workers, and CDDs<br>n = 9 + 5 focus group discussions |
| Study methods | Mixed-methods |
| Data collection methods | In-depth interviews and focus group discussions |
| Notes | |

**Silumbwe 2019**

| ***Study characteristics*** | |
|---|---|
| Country | Zambia |
| Setting | Rural; endemic |
| Aim | "To document the community engagement processes and how they shaped participation in the first and second round of MDA for LF in Luangwa District of Zambia (2016–2017), with a view of proposing an effective community engagement strategy". |
| Drug regimen | DEC + ALB |
| Participants | Community members, health workers, facility in-charges, and programme co-ordinators<br>n = 82 |
| Study methods | Qualitative |
| Data collection methods | In-depth interviews and focus group discussions |
| Notes | |

**Wodnik 2020**

| ***Study characteristics*** | |
|---|---|
| Country | Haiti |
| Setting | Urban; endemic |
| Aim | "To identify potential contributing factors to the low MDA coverage for LF in metro Port-au-Prince". |
| Drug regimen | DEC + ALB |
| Participants | Community members, community leaders, and CDDs |
| Study methods | Qualitative |
| Data collection methods | In-depth interviews and street microphone interviews |
| Notes | |

**Wynd 2007**

| ***Study characteristics*** | |
|---|---|
| Country | Papua New Guinea |
| Setting | Rural; 'low' endemicity |
| Aim | "To investigate Misima community members knowledge and attitudes about lymphatic filariasis and the elimination programme". |
| Drug regimen | DEC + ALB |
| Participants | Community members and prominent village members<br>n = 150 |
| Study methods | Qualitative |
| Data collection methods | In-depth interview and focus group discussions |
| Notes | |

ALB: albendazole; CDD: community drug distributor; DEC: diethylcarbamazine; IVM: ivermectin; LF: lymphatic filariasis; MDA: mass drug administration; n: number of participants; NTD: neglected tropical disease; NGO: non-governmental organization.
[a]Biritwum 2019.

## Characteristics of excluded studies *[ordered by study ID]*

| Study | Reason for exclusion |
|---|---|
| Adekeye 2020 | Wrong intervention |
| Babu 2004 | Wrong study design |

| Study | Reason for exclusion |
|---|---|
| Baker 2007 | Wrong participants |
| Banarjee 2018 | Wrong study design |
| Benjamin 2018 | Conference abstract |
| Bhullar 2010 | Wrong study design |
| Bogus 2016 | Wrong study design |
| Cabral 2017 | Wrong study design |
| Coulibaly 2014 | Conference abstract |
| Da-Costa Vroom 2014 | Not phenomenon of interest |
| Da-Costa Vroom 2015 | Wrong study design |
| Das 2005 | Wrong study design |
| Derua 2018 | Wrong study design |
| Ikawati 2018 | Not phenomenon of interest |
| Ipa 2018 | Unable to supply |
| Karki 2018 | Wrong intervention |
| Kouassi 2018 | Did not explore phenomenon of interest |
| Krentel 2015 | Conference abstract |
| Krentel 2016 | Wrong study design |
| Krentel 2018 | Conference abstract |
| Krentel 2019 | Conference abstract |
| Krentel 2020 | Wrong study design |
| Kyelem 2008 | Wrong study design |
| Lahariya 2008 | Wrong study design |
| Laveglia 2017 | Conference abstract |
| Malecela 2009 | Wrong study design |
| Manyeh 2019 | Wrong participants |
| Meyrowitsch 2013 | Conference abstract |
| Mukhopadhyay 2008 | Wrong study design |
| Mwakitalu 2013 | Wrong study design |

| Study | Reason for exclusion |
|---|---|
| Nair 2013 | Conference abstract |
| Njomo 2010 | Wrong study design |
| Njomo 2012b | Wrong study design |
| Nuwaha 2004 | Wrong study design |
| Pataduk 2018 | Wrong language |
| Ramaiah 2005 | Wrong participants |
| Rath 2006 | Wrong intervention |
| Rudra 2012 | Wrong study design |
| Showkath 2008 | Did not explore the phenomenon of interest |
| Silumbe 2015 | Did not explore the phenomenon of interest |
| Widjanarko 2018 | Wrong study design |
| Wodnik 2019 | Conference abstract |

## ADDITIONAL TABLES

**Table 1. Types of delivery in mass drug administration (MDA) programmes**

| Form of delivery | Definition | Approach |
|---|---|---|
| Type I | "Programs in which individuals or groups/organizations indigenous to the community to be served by a program (target community) initiate, without any external (to that community) support". | Bottom-up |
| Type II | "Programs in which individuals or community groups/organizations groups/organizations indigenous to the community initiate, and recruit external, technical (expertise) support". | Bottom-up |
| Type III | "Programs in which individuals or community-based community based organizations (CBOs) pursue external fiscal support or funding". | Bottom-up |
| Type IV | "Programs in which individuals or CBOs indigenous to the target community initiate and recruit external technical and fiscal support". | Bottom-up |
| Type V | "Programs which are initiated by external change agencies (public or private organization, university, a corporation, a foundation or some other philanthropic group, and so on) within a target community, but [are done] does it without any input from individual residents or organizations of that community, except as program recipients". | Top-down |
| Type VI | "Programs which are planned and initiated by external change agencies, and community members are eventually invited to participate on community advi- | Top-down |

**Table 1. Types of delivery in mass drug administration (MDA) programmes** *(Continued)*

| | | |
|---|---|---|
| | sory committees, or as lower-level lower level project staff such as 'community "community outreach workers', workers", or as volunteers". | |
| Type VII | "Programs which are planned and implemented as an equitable partnership by CBOs and an external change agent or technical organization". | Collaborative |

Amended from Whitehead 2002.

**Table 2. Characteristics of review studies**

| Author | Aims | Methods | Inclusion criteria | Number of studies |
|---|---|---|---|---|
| Babu 2014 | "To systematically review published studies on the coverage of and compliance with MDA under the Programme for the Elimination of Lymphatic Filariasis (PELF) in India". | Quantitative | • Up to 2013<br>• India<br>• Quantitative studies and quantitative data that can be extracted from mixed-methods studies<br>• "Community based studies that evaluated MDA coverage and compliance conducted by the health services. Data were excluded if governmental, non-governmental or research organizations intervened to improve compliance. However, papers that reported such studies were considered and data on control MDAs were included". | 36 |
| Silumbwe 2017 | "To systematically document the barriers and facilitators to implementation of MDA for LF in Sub-Saharan Africa". | Mixed-methods:<br><br>qualitative (3 studies); quantitative (4 studies); mixed methods (4 studies); programme reports (6 studies); evaluation (1 study) | • 2000–2016<br>• Sub-Saharan Africa<br>• Studies that assessed the following outcomes: "(i) treatment coverage/compliance, (ii) program sustainability, (iii) successful implementation referring to perceptions among implementation stakeholders (both provider and community) that a given treatment, service, practice, or innovation is agreeable, palatable, or satisfactory with their needs, and (iv) community participation, defined as the involvement of the community in programme design implementation and evaluation". | 18 |
| Krentel 2013 | "To attempt to identify factors and patterns that are associated with compliance with MDA that apply across countries and cultures". | Mixed-methods: proportion of qualitative and quantitative studies unclear | • 2000–2012<br>• Global<br>• "Studies that: (i) reviewed the literature on compliance with MDA for LF; (ii) described or assessed factors associated with compliance with MDA for LF; (iii) analysed, observed, or documented compliance rates with MDA and/or provided an explanation or discussion of the rates; and (iv) were identified from reference lists of primary papers". | 79 |
| Ames 2019 | "To rapidly review the existing qualitative literature to identi- | Qualitative | • 2002–2017<br>• Global | 14 |

**Table 2. Characteristics of review studies** *(Continued)*

| | | |
|---|---|---|
| | fy perspectives from the community and drug distributors. We focused on factors influencing feasibility of planning and carrying out campaigns and acceptability of MDA within community settings". | • Qualitative studies and qualitative data that can be extracted from mixed-methods studies<br>• Studies that "discussed community and/or drug distributor perceptions of and experiences with any form of MDA for LF elimination. Community encompasses people receiving treatment as well as those around them. A drug distributor can be anyone distributing medicines". |

LF: lymphatic filariasis; MDA: mass drug administration.

**Table 3. Programme design and delivery for included studies**

| Author | Rounds of MDA | Programme organization | Community engagement | Who delivers | How delivered | Adherence monitoring |
|---|---|---|---|---|---|---|
| Ahorlu 2018 | 15 | 6 | None mentioned | CDDs[a] | Door-to-door | None mentioned |
| Amarillo 2008 | 2 | 6 | Yes | CDDs and health staff | Door-to-door | Yes |
| Babu 2003 | 1 | 6 | Yes | CDDs | Door-to-door | Yes[b] |
| Babu 2004a | 2 | 6 | Yes | CDDs | Door-to-door[c] | Yes[b] |
| Babu 2004b | 2 | 6 | Yes | CDDs | Door-to-door | Yes[b] |
| Babu 2008 | 2 | 6 | Yes | CDDs | Door-to-door | Yes[b] |
| Babu 2010 | 4 | 6 | Yes | CDDs | Door-to-door | Yes[b] |
| Banarjee 2019 | 5 | 6 | Yes | CDDs | Door-to-door | Yes[b] |
| Biritwum 2017 | 0–1 | 6 | None mentioned | CDDs[a] | Not mentioned | None mentioned |
| Cassidy 2016 | 3 | 6 | Yes[c] | CDDs[c] | Door-to-door[c] | Yes[c] |
| Gonzales 2019 | 3 | 6 | Yes | CDDs | Door-to-door | Yes |
| Hussain 2014 | Not mentioned | 6 | Yes | CDDs | Door-to-door | Yes[c] |
| King 2011 | 3 | 6 | Yes | CDDs and health staff | Door-to-door and "drug distribution booths set up at major work locations and the central market". | Yes |

**Table 3. Programme design and delivery for included studies** *(Continued)*

| | | | | | | |
|---|---|---|---|---|---|---|
| Kisoka 2016 | Not mentioned | 6 | Yes | CDDs | Door-to-door and "sometimes public places such as markets in urban areas". | None mentioned |
| Kisoka 2017 | Not mentioned | 6 | Yes | CDDs | Door -to-door | None mentioned |
| Krentel 2008 | 4 | 6 | Yes | CDDs | Not mentioned | None mentioned |
| Krentel 2021 | MDA-naïve regions (Papua New Guinea, Indonesia) to 3 sites with multiple years of MDA rounds (India, Haiti, and Fiji) | 6 | Yes | CDDs | Door-to-door | None mentioned |
| Kusi 2020 | 2 | 6 | Yes[c] | CDDs | Door-to-door[c] | None mentioned |
| Manyeh 2020 | 15 | 6 | Yes | CDDs | Door-to-door[a] | None mentioned |
| Manyeh 2021 | 10 | 6 | Yes | CDDs | Door-to-door[a] | None mentioned |
| Njomo 2012a | 3 | 6 | Yes | CDDs | Door-to-door | None mentioned |
| Njomo 2014 | 3 | 6 | Yes | CDDs | Door-to-door | None mentioned |
| Njomo 2020a | 10 | 6 | Yes[b] | CDDs | Door-to-door | None mentioned |
| Njomo 2020b | 3 | 6 | Yes | CDDs | Door-to-door | None mentioned |
| Parker 2013a | 3 | 6 | Yes[d] | CDDs | Door-to-door | None mentioned |
| Ramaiah 2000 | 3 | 5 | Yes[c] | "PHC network in rural areas and various categories of health staff in urban areas" | Door-to-door | Yes |
| Silumbwe 2019 | 2 | 6 | Yes | CDDs | Door-to-door | None mentioned |

**Table 3. Programme design and delivery for included studies** *(Continued)*

| | | | | | | |
|---|---|---|---|---|---|---|
| Wodnik 2020 | 7 | 6 | Yes[e] | CDDs | Distribution posts including: schools, markets, health facilities, churches, and local gathering places[c] | None mention |
| Wynd 2007 | 5 | 6 | Yes | "Village birth attendants, community based health workers, and teachers in drug distribution" | Not mention | None mentioned |

CDD: community drug distributor; MDA: mass drug administration; PHC: primary Health Centre.
For some studies, further information was provided by a: Biritwum 2019; b: Njomo 2012a; c: NVBDCP 2018; d: Kisoka 2016; e: Oscar 2014.

**Table 4. Methodological limitations appraisal**

| Author | Were steps taken to increase rigour in the sampling? | Were steps taken to increase rigour in the data collected? | Were steps taken to increase rigour in the analysis of the data? | Were the findings of the study grounded in/ supported by the data? | Please rate the findings of the study in terms of their breadth and depth | Overall, what weight would you assign to this study in terms of the reliability/trustworthiness of its findings? | What weight would you assign to this study in terms of the usefulness of its findings for this review? |
|---|---|---|---|---|---|---|---|
| Ahorlu 2018 | Yes, a few steps taken | Yes, a few steps taken | Yes, a few steps taken | Good grounding | Good breadth and depth | Medium | High |
| Amarillo 2008 | Yes, a few steps taken | Yes, a few steps taken | Yes, a few steps taken | Limited grounding | Limited breadth and depth | Low | Low |
| Babu 2003 | Yes, a few steps taken | Not stated/can't tell | Not stated/can't tell | Limited grounding | Limited breadth and depth | Low | Low |
| Babu 2004a | Yes, a few steps taken | Not stated/can't tell | Not stated/can't tell | Limited grounding | Limited breadth and depth | Low | Low |
| Babu 2004b | Not stated/can't tell | Not stated/can't tell | Not stated/can't tell | Limited grounding | Limited breadth and depth | Low | Low |
| Babu 2008 | Yes, a few steps taken | Yes, a few steps taken | Not stated/can't tell | Limited grounding | Limited breadth and depth | Low | Low |
| Babu 2010 | Yes, a few steps taken | Yes, a few steps taken | Not stated/can't tell | Limited grounding | Limited breadth and depth | Low | Low |
| Banarjee 2019 | Not stated/can't tell | Yes, a few steps taken | Yes, a few steps taken | Fair grounding | Limited breadth and depth | Low | Low |
| Biritwum 2017 | Yes, a few steps taken | Not stated/can't tell | Not stated/can't tell | Limited grounding | Limited breadth and depth | Low | Low |
| Cassidy 2016 | Yes, a few steps taken | Yes, several steps were taken | Not stated/can't tell | Good grounding | Fair breadth and depth | Low | Medium |
| Gonzales 2019 | Yes, a few steps taken | Yes, a few steps taken | Yes, a few steps taken | Fair grounding | Good breadth but limited depth | Medium | Low |

**Table 4. Methodological limitations appraisal** *(Continued)*

| | | | | | | | |
|---|---|---|---|---|---|---|---|
| Hussain 2014 | Yes, a few steps taken | Yes, a few steps taken | Not stated/can't tell | Limited grounding | Limited breadth and depth | Low | Low |
| King 2011 | Yes, a few steps taken | Not stated/ can't tell | Yes, a few steps taken | Limited grounding | Limited breadth and depth | Low | Low |
| Kisoka 2016 | Yes, several steps were taken | Yes, several steps were taken | Yes, several steps were taken | Good grounding | Good depth and breadth | High | High |
| Kisoka 2017 | Yes, several steps were taken | Yes, several steps were taken | Yes, several steps were taken | Fair grounding | Good breadth and depth | High | High |
| Krentel 2008 | Yes, a fairly thorough attempt was made | Yes, a fairly thorough attempt was made | Yes, a fairly thorough attempt was made | Good grounding | Good breadth and depth | High | High |
| Krentel 2021 | Yes, a fairly thorough attempt was made | Yes, a fairly thorough attempt was made | Yes, a fairly thorough attempt was made | Good grounding | Good breadth and depth | High | High |
| Kusi 2020 | Yes, a few steps were taken | Yes, several steps were taken | Yes, a fairly thorough attempt was made | Good grounding | Good breadth but limited depth | High | Medium |
| Manyeh 2020 | Yes, several steps were taken | Yes, several steps were taken | Yes, a few steps were taken | Fair grounding | Fair breadth and depth | Medium | Medium |
| Manyeh 2021 | Yes, a few steps were taken | Yes, a few steps were taken | Not stated/can't tell | Fair grounding | Fair breadth and depth | Low | Medium |
| Njomo 2012a | Yes, a few steps were taken | Yes, several steps were taken | Not stated/can't tell | Limited grounding | Limited breadth and depth | Low | Low |
| Njomo 2014 | Yes, a few steps were taken | Yes, several steps were taken | Yes, a few steps were taken | Fair grounding | Good breadth but limited depth | Medium | Low |
| Njomo 2020a | Not stated/can't tell | Yes, a few steps were taken | Not stated/can't tell | Fair grounding | Good breadth but limited depth | Low | Medium |
| Njomo 2020b | Yes, several steps were taken | Yes, a fairly thorough attempt was made | Yes, a fairly thorough attempt was made | Good grounding | Good breadth and depth | High | High |
| Parker 2013a | Yes, several steps were taken | Yes, several steps were taken | Not stated/can't tell | Fair grounding | Good breadth and depth | Medium | High |

**Table 4. Methodological limitations appraisal** *(Continued)*

| | | | | | | | |
|---|---|---|---|---|---|---|---|
| Ramaiah 2000 | Yes, a few steps were taken | Not stated/can't tell | Not stated/can't tell | Limited grounding | Limited breadth and depth | Low | Low |
| Silumbwe 2019 | Yes, a few steps were taken | Not stated/ can't tell | Not stated/can't tell | Fair grounding | Good breadth but limited depth | Low | Medium |
| Wodnik 2020 | Yes, several steps were taken | Yes, a few steps were taken | Yes, a fairly thorough attempt was made | Good grounding | Good breadth and depth | Medium | Medium |
| Wynd 2007 | Yes, several steps were taken | Yes, a fairly thorough attempt was made | Not stated/can't tell | Fair grounding | Good breadth but limited depth | Medium | Medium |

# APPENDICES

## Appendix 1. Detailed search strategies

Cochrane Central Register of Controlled Trials (CENTRAL)

Issue 3 of 12, March 2021

#116 MeSH descriptor: [Filariasis] explode all trees

#117 MeSH descriptor: [Elephantiasis, Filarial] explode all trees

#118 lymphedema or lymphoedema

#119 wuchereria or brugia

#120 #116 or #117 or #118 or #119

#121 "mass drug administration"

#122 MeSH descriptor: [Mass Drug Administration] explode all trees

#123 "coordinated administration" or "mass treatment" or "mass distribution"

#124 #121 or #122 or #123

#125 #120 and #124

#126 MeSH descriptor: [Qualitative Research] explode all trees

#127 "focus group*" or "grounded theory" or "narrative analys*" or "lived experience*" or "life experience*" or "theoretical sampl*" or purposive

#128 semi-structured OR semistructured OR "structured categor*" OR "unstructured categor*" OR "action research" OR (audiorecord* OR tape recorded *or videorecord* OR videotap*) OR (audio OR tape OR video*) OR interview* OR quasi-experiment* OR "case stud*"

#129 qualitative or ethno* or emic or etic or phenomenology* or hermeneutic*

#130 collaborat* or consultat* or experience or involve* or narrative* or opinion* or participat* or partner* or perspective* or story or stories

#131 MeSH descriptor: [Interview] explode all trees

#132 MeSH descriptor: [Focus Groups] explode all trees

#133 MeSH descriptor: [Surveys and Questionnaires] explode all trees

#134 MeSH descriptor: [Self Report] explode all trees

#135 MeSH descriptor: [Anthropology, Cultural] explode all trees

#136 #126 or #127 or #128 or #129 or #130 or #131 or #132 or #133 or #134 or #135

#137 #136 and #125

PubMed (MEDLINE)

Search query

#1 Search filaria* Field: Title/Abstract

#2 Search "Elephantiasis, Filarial"[Mesh]

#3 Search "Filariasis"[Mesh]

#4 Search lymphedema Field: Title/Abstract

#5 Search lymphoedema Field: Title/Abstract

#6 Search "Wuchereria bancrofti"[Mesh] OR "Brugia malayi"[Mesh]

#7 Search (((((#6) OR #5) OR #4) OR #3) OR #2) OR #1

#8 Search mass drug administration Field: Title/Abstract

#9 Search "Mass Drug Administration"[Mesh]

#10 Search "mass administration" Field: Title/Abstract

#11 Search "coordinated administration" Field: Title/Abstract

#12 Search "mass treatment " Field: Title/Abstract

#13 Search "mass distribution" Field: Title/Abstract

#14 Search "coordinated distribution" Field: Title/Abstract

#15 Search ((((((#14) OR #13) OR #12) OR #11) OR #10) OR 9) OR #8

#16 Search (#15) AND #7

#17 Search "Qualitative Research"[Mesh]

#18 Search "focus group*" or "grounded theory" or "narrative analys*" or "lived experience*" or "life experience*" or "theoretical sampl*" or purposive Field: Title/Abstract

#19 Search semi-structured OR semistructured OR "structured categor*" OR "unstructured categor*" OR "action research" OR (audiorecord* OR tape recorded *or videorecord* OR videotap*) OR (audio OR tape OR video*) OR interview* OR quasi-experiment* OR "case stud*" Field: Title/Abstract

#20 Search "Interviews as Topic"[Mesh] OR "Interview" [Publication Type]

#21 Search "Focus Groups"[Mesh]

#22 Search qualitative or ethno* or emic or etic or phenomenology* or hermeneutic* Field: Title/Abstract

#21 Search "Surveys and Questionnaires"[Mesh]

#22 Search "Self Report"[Mesh]

#23 Search "Anthropology, Cultural"[Mesh]

#24 Search collaborat* or consultat* or experience or involve* or narrative* or opinion* or participat* or partner* or perspective* or story or stories Field: Title/Abstract

#25 Search (((((((((#24) OR #23) OR #22) OR #21) OR #20) OR #19) OR #18) OR #17

#26 Search (#25) AND #16 Filters: Publication date from 2000/01/01

Database: Embase 1947 to present, updated daily

Search strategy:

---

1 filaria*.tw.

2 exp lymphatic filariasis/

3 exp filariasis/

4 (lymphedema or lymphoedema).tw.

5 Bancroftian filariasis/

6 Brugian filariasis/

7 1 or 2 or 3 or 4 or 5 or 6

8 "mass drug administration".tw.

9 Mass Drug Administration/

10 "mass administration".mp.

11 "coordinated administration".mp.

12 ("mass treatment" or "mass distribution").tw.

13 "coordinated distribution".tw.

14 8 or 9 or 10 or 11 or 12 or 13

15 7 and 14

16 exp qualitative research/

17 ("focus group*" or "grounded theory" or "narrative analys*" or "lived experience*" or "life experience*" or "theoretical sampl*" or purposive).tw.

18 (semi-structured or semistructured or "structured categor*" or "unstructured categor*" or "action research" or (audiorecord* or tape recorded * or videorecord* or videotap*) or (audio or tape or video*) or interview* or quasi-experiment* or "case stud*").tw.

19 interview/

20 "Focus Groups".tw.

21 (qualitative or ethno* or emic or etic or phenomenology* or hermeneutic*).tw.

22 questionnaire/

23 self report/

24 cultural anthropology/

25 (collaborat* or consultat* or experience or involve* or narrative* or opinion* or participat* or partner* or perspective* or story or stories).tw.

26 16 or 17 or 18 or 19 or 20 or 21 or 22 or 23 or 24 or 25

27 15 and 26

Global Health; CAB Direct; Science Citation Index – Expanded (all in the Web of Science)

#7 #6 AND #3

#6 #5 OR #4

# 5 TOPIC: (survey* or questionnaire* or "focus group" or interview*) OR TOPIC: (experience* or satisfaction or narrative)

# 4 TOPIC: ("qualitative research")

# 3 #2 AND #1

# 2 TOPIC: ("mass drug administration" or MDA or "mass treatment")

# 1 TOPIC: (filaria* or elephantiasis or lymphedema or brugia or wuchereria)

Database :

LILACS

Search on :

filaria$ or wuchereria or brugia [Words] and  administration [Words]

CINAHL (EBSCOHost)

S5

S3 AND S4

S4

TX qualitative research OR TX ( "focus group*" or "grounded theory" or "narrative analys*" or "lived experience*" or "life experience*" or "theoretical sampl*" or purposive ) OR TX ( survey or questionnaire or interview or surveys or questionnaires or interviews )

S3

S1 AND S2

S2

AB mass drug administration OR MH mass drug administration OR TX ( mass treatment or mass distribution )

S1

filariasis OR MH filaria OR TX ( lymphedema or brugia or wuchereria )

Clinicaltrials.gov, WHO ICTRP:  = Filariasis, Elephantiasis, Wuchereria Bancrofti infection

And “mass drug administration”

## Appendix 2. EPPI-Centre quality assessment tool

| | |
|---|---|
| 1. Were steps taken to increase rigour in the sampling? Consider whether:<br>• the sampling strategy was appropriate to the questions posed in the study (e.g. was the strategy well-reasoned and justified?);<br>• attempts were made to obtain a diverse sample of the population in question (think about who might have been excluded; who may have had a different perspective to offer);<br>• characteristics of the sample critical to the understanding of the study context and findings were presented (i.e. do we know who the participants were in terms of, for example, basic sociodemographics, characteristics relevant to the context of the study, etc.). | Yes, a fairly thorough attempt was made.<br>Yes, several steps were taken.<br>Yes, a few steps were taken.<br><br>No, not at all/not stated/can't tell |

*(Continued)*

| | |
|---|---|
| 2. Were steps taken to increase rigour in the data collected? Consider whether:<br>• data collection tools were piloted/(and if quantitative) validated;<br>• (if qualitative) data collection was comprehensive, flexible and/or sensitive enough to provide a complete and/or vivid and rich description of people's perspectives and experiences (e.g. did the researchers spend sufficient time at the site/with participants? Did they keep 'following up'? Was more than one method of data collection used?);<br>• steps were taken to ensure that all participants were able and willing to contribute (e.g. processes for consent, language barriers, power relations between adults and children/young people). | Yes, a fairly thorough attempt was made.<br>Yes, several steps were taken.<br>Yes, minimal/few steps were taken.<br>No, not at all/not stated/can't tell |
| 3. Were steps taken to increase rigour in the analysis of the data? Consider whether:<br>• data analysis methods were systematic (e.g. was a method described/can a method be discerned?);<br>• diversity in perspective was explored;<br>• (if qualitative) the analysis was balanced in the extent to which it was guided by preconceptions or by the data;<br>• the analysis sought to rule out alternative explanations for findings (in qualitative research, this could be done by, for example, searching for negative cases/exceptions, feeding back preliminary results to participants, asking a colleague to review the data, or reflexivity; in quantitative research, this may be done by, for example, significance testing). | Yes, a fairly thorough attempt was made.<br>Yes, several steps were taken.<br>Yes, minimal/few steps were taken.<br>No, not at all/not stated/can't tell |
| 4. Were the findings of the study grounded in/supported by the data? Consider whether:<br>• enough data are presented to show how the authors arrived at their findings;<br>• the data presented fit the interpretation/support claims about patterns in data; *the data presented illuminate/illustrate the findings;<br>• (for qualitative studies) quotes are numbered or otherwise identified and the reader can see that they don't just come from one or two people. | Good grounding/support.<br>Fair grounding/support.<br>Limited grounding/support |
| 5. Please rate the findings of the study in terms of their breadth and depth. Consider whether (NB: it may be helpful to consider 'breadth' as the extent of description and 'depth' as the extent to which data have been transformed/analysed):<br>• a range of issues are covered;<br>• the perspectives of participants are fully explored in terms of breadth (contrast of two or more perspectives) and depth (insight into a single perspective);<br>• richness and complexity have been portrayed (e.g. variation explained, meanings illuminated);<br>• there has been theoretical/conceptual development | Limited breadth or depth.<br>Good/fair breadth but very little depth.<br>Good/fair depth but very little breadth.<br>Good/fair breadth and depth. |
| 6. To what extent does the study privilege the perspectives and experiences of children? Consider:<br>• whether there was a balance between open-ended and fixed response options;<br>• whether children were involved in designing the research;<br>• whether there was a balance between the use of an a priori coding framework and induction in the analysis;<br>• the position of the researchers (did they consider it important to listen to the perspectives of children?);<br>• whether steps were taken to assure confidentiality and put young people at ease. | Not at all.<br>A little.<br>Somewhat.<br>A lot. |
| 7. Overall, what weight would you assign to this study in terms of the reliability/trustworthiness of its findings? Guidance: think (mainly) about the answers you have given to questions 1 to 4 above. | Low.<br>Medium.<br>High. |
| 8. What weight would you assign to this study in terms of the usefulness of its findings for this review? Guidance: think (mainly) about the answers you have given to questions 5 and 6 above, and consider: | Low.<br>Medium.<br>High. |

*(Continued)*

- the match between the study aims and findings and the aims and purpose of the synthesis;
- its conceptual depth/explanatory power.

## Appendix 3. Evidence profile

| Theme | Subtheme | Studies with information giving rise to the evidence | limitations | Coherence | Adequacy | Relevance | CERQual rating |
|---|---|---|---|---|---|---|---|
| 1: people weigh up benefits and harms before adhering | 1.1: the perceived benefits relate to the relief of suffering, stigma, and costs of disease | Ahorlu 2018[a]<br>Amarillo 2008[b]<br>Babu 2008[c]<br>Banarjee 2019[c]<br>Cassidy 2016[c]<br>Gonzales 2019[d]<br>Kisoka 2016[e]<br>Kisoka 2017[e]<br>Krentel 2008[f]<br>Krentel 2021[c,f,g,h,i]<br>Manyeh 2020[a]<br>Manyeh 2021[a]<br>Parker 2013a[e]<br>Silumbwe 2019[j]<br>Wynd 2007[g] | Minor concerns: the findings emerged from mainly high-quality studies and low-quality studies concurred with this finding. | No or very minor concerns. No concerns with internal consistency and any discordant findings explained within theme or elsewhere in review. | No or very minor concerns. Sufficient volume of studies, participants, and richness of content. | No or very minor concerns. Findings emerged from several countries and regions. | High confidence |
| | 1.2: adverse effects are a frightening and unwelcome experience | Ahorlu 2018[a]<br>Babu 2004a[c]<br>Babu 2004b[c]<br>Babu 2008[c]<br>Babu 2010[c]<br>Biritwum 2017[a] | Minor concerns. The findings emerged from mainly high-quality studies and low-quality studies concurred with this finding. | No or very minor concerns. No concerns with internal consistency and any discordant findings explained within theme or elsewhere in review. | No or very minor concerns. Sufficient volume of studies, participants, and richness of content. | No or very minor concerns. Findings emerged from several countries and regions. | High confidence |

*(Continued)*

| | | | | | | |
|---|---|---|---|---|---|---|
| | Hussain 2014[c]<br>Kisoka 2016[e]<br>Krentel 2008[f]<br>Krentel 2021[c,f,g,h,i]<br>Manyeh 2020[a]<br>Manyeh 2021[a]<br>Parker 2013a[e]<br>Ramaiah 2000[c]<br>Silumbwe 2019[j]<br>Wynd 2007[g] | | | | | |
| 1.3: news of adverse effects spreads rapidly and makes people fearful | Ahorlu 2018[a]<br>Babu 2004b[c]<br>Babu 2010[c]<br>Kisoka 2016[e]<br>Kusi 2020[k] | Minor concerns. The findings emerged from mainly high-quality studies and low-quality studies concurred with this finding. | Minor concerns. Some community members were unbothered by adverse effects and it was not clear what contexts led to mass fear and rumour. However, where this occurred, accounts were compelling. | Minor concerns. Small number of studies but sufficient thickness and number of participants. | No or very minor concerns. Findings emerged from several countries and regions. | Moderate confidence |
| 1.4: deciding to adhere draws on personal and shared experiences and is complex | Ahorlu 2018[a]<br>Babu 2004b[c]<br>Babu 2008[c]<br>Banarjee 2019[c]<br>Hussain 2014[c]<br>Kisoka 2016[e]<br>Krentel 2008[f]<br>Krentel 2021[c,f,g,h,i]<br>Manyeh 2021[a] | Minor concerns. The findings emerged from mainly high-quality studies and low-quality studies concurred with this finding. | No or very minor concerns. No concerns with internal consistency and any discordant findings explained within theme or elsewhere in review. | No or very minor concerns. Sufficient volume of studies, participants, and richness of content. | No or very minor concerns. Findings emerged from several countries and regions. | High confidence |

(Continued)

| | | | | | | | |
|---|---|---|---|---|---|---|---|
| | | Njomo 2012a[a]<br>Parker 2013a[e]<br>Ramaiah 2000[c]<br>Silumbwe 2019[j]<br>Wodnik 2020[i]<br>Wynd 2007[g] | | | | | |
| 2: many people are suspicious of MDA programmes | 2.1: many people do not trust the programme and believe there is an ulterior motive | Babu 2004b[c]<br>Banarjee 2019[c]<br>Kisoka 2016[e]<br>Krentel 2008[f]<br>Kusi 2020[k]<br>Manyeh 2020[a]<br>Njomo 2020a[k]<br>Njomo 2020b[k]<br>Parker 2013a[e]<br>Wodnik 2020[i] | Minor concerns. The finding emerged from mainly high-quality studies and low-quality studies concurred with this finding. | No or very minor concerns. No concerns with internal consistency and any discordant findings explained within theme or elsewhere in review. | No or very minor concerns. Sufficient volume of studies, participants, and richness of content. | No or very minor concerns. Finding emerged from several countries and regions. | High confidence |
| | 2.2: some have an unquestioning attitude to government and a lack of agency, leading to unwavering faith in the programme | Krentel 2008[f] | No or very minor concerns. Finding emerged from high-quality studies only. | Moderate concerns. It is unclear why similar historical and political contexts lead some people to have unwavering faith in contrast to suspicion. | Moderate concerns. The finding emerged from only 1 study; however, there was substantial volume and richness of the data. | Moderate concerns. The finding emerged from only 1 country; however, we believe the finding may be broadly transferable to other low- to middle-income countries. | Moderate confidence |
| 3: programmes expect compli- | 3.1: health workers may become au- | Banarjee 2019[c]<br>Kisoka 2017[e] | Minor concerns. The finding emerged from | No or very minor concerns. No concerns with internal consistency and any dis- | Minor concerns. Small number of studies but suffi- | Minor concerns. The finding emerged from | Moderate confidence |

(Continued)

| | | | | | | | |
|---|---|---|---|---|---|---|---|
| ance: this can result in coercion and blame | thoritarian to ensure compliance | Krentel 2008[f] | mainly high-quality studies and low-quality studies concur with this finding. | cordant findings explained within theme or elsewhere in review. | cient thickness and number of participants. | only 1 region; however, we believe the finding may be broadly transferable to other low- to middle-income regions. | |
| | 3.2: community members may become coercive, and stigmatize non-compliance | Krentel 2008[f] | No or very minor concerns. Finding emerged from high-quality studies only. | Moderate concerns. It was unclear if people do become coercive towards others or only report that they would in a hypothetical situation. | Moderate concerns. The finding emerged from only 1 study; however, there was substantial volume and richness of the data. | Moderate concerns. The finding emerged from only 1 country; however, we believe the finding may be broadly transferable to other low- to middle-income countries. | Moderate confidence |
| | 3.3: outward compliance, private rejection | Ahorlu 2018[a]<br>Biritwum 2017[a]<br>Krentel 2008[f]<br>Kusi 2020[k]<br>Manyeh 2020[a]<br>Njomo 2014[k]<br>Njomo 2020a[k] | Minor concerns. The finding emerged from mainly high-quality studies and low-quality studies concurred with this finding. | No or very minor concerns. No concerns with internal consistency and any discordant findings explained within theme or elsewhere in review. | Minor concerns. Although there were several studies that contributed to this finding, data were often few. | No or very minor concerns. Finding emerged from several countries and regions. | Moderate confidence |
| 4: distributor's status in the community is often low, and they are not well equipped to answer the communities questions | 4.1: CDDs have limited authority | Banarjee 2019[c]<br>Kisoka 2016[e]<br>Kisoka 2017[e]<br>Krentel 2008[f]<br>Krentel 2021[c,f,g,h,i]<br>Kusi 2020[k] | Minor concerns. The finding emerged from mainly high-quality studies and low-quality studies concurred with this finding. | Minor concerns. some inconsistency with sub-theme 4.2. i.e. people with few qualifications may still be respected by the community if they are familiar to them. | No or very minor concerns. Sufficient volume of studies, participants, and richness of content. | No or very minor concerns. Finding emerged from several countries and regions. | Moderate confidence |

(Continued)

| | | | | | | |
|---|---|---|---|---|---|---|
| | Njomo 2020a[k]<br>Silumbwe 2019[j] | | | | | |
| 4.2: people prefer CDDs that are well known to the community and have good behaviour | Ahorlu 2018[a]<br>Babu 2008[c]<br>Kisoka 2017[e]<br>Kusi 2020[k] | Minor concerns. The finding emerged from mainly high-quality studies and low-quality studies concurred with this finding. | No or very minor concerns. No concerns with internal consistency and any discordant findings explained within theme or elsewhere in review. | No or very minor concerns. Sufficient volume of studies, participants, and richness of content. | No or very minor concerns. Finding emerged from several countries and regions. | High confidence |
| 4.3: people seek clarification and rationale, but do not always receive it | Ahorlu 2018[a]<br>Babu 2004a[c]<br>Banarjee 2019[c]<br>Biritwum 2017[a]<br>Kisoka 2016[e]<br>Kisoka 2017[e]<br>Krentel 2008[f]<br>Kusi 2020[k]<br>Manyeh 2020[a]<br>Manyeh 2021[a]<br>Njomo 2012a[k]<br>Njomo 2014[k]<br>Njomo 2020a[k]<br>Njomo 2020b[k]<br>Parker 2013a[e]<br>Ramaiah 2000[c] | Minor concerns. The finding emerged from mainly high-quality studies and low-quality studies concur with this finding. | No or very minor concerns. No concerns with internal consistency and any discordant findings explained within theme or elsewhere in review. | No or very minor concerns. Sufficient volume of studies, participants, and richness of content. | No or very minor concerns. Finding emerged from several countries and regions. | High confidence |

CDD: community drug distributor.

(Continued)

[a]Ghana; [b]Philippines; [c]India; [d]Dominican Republic; [e]Tanzania; [f]Indonesia; [g]Papua New Guinea; [h]Fiji; [i]Haiti; [j]Zambia; [k]Kenya

## WHAT'S NEW

| Date | Event | Description |
|---|---|---|
| 27 January 2023 | Amended | Licence type corrected on copyright line in the review, from Cochrane Collaboration copyright to author copyright |

## HISTORY

Protocol first published: Issue 6, 2020
Review first published: Issue 2, 2022

| Date | Event | Description |
|---|---|---|
| 21 February 2022 | Amended | Minor edit to Abstract, placing three sentences in bold text |

## CONTRIBUTIONS OF AUTHORS

MT developed the protocol, screened studies, conducted analyses, and wrote up findings.

RT screened studies, conducted analyses, and commented on the final version of the review.

SO contributed to 'background' and 'methods' section, commented on findings in wider team discussions, commented on and edited final version of review.

PG contributed to 'background' and 'methods' section, commented on findings in wider team discussions, commented on and edited final version of review.

All review authors approved the final version of the review.

## DECLARATIONS OF INTEREST

MT is employed by the Liverpool School of Tropical Medicine (LSTM). She is a CIDG Research Assistant and was not involved in the editorial process of this review. LSTM is a world leader in promoting mass drug administration (MDA) for filariasis through its previous Director, Professor David Molyneux. LSTM continues to receive grants from a variety of sources to help implement MDA programmes in filariasis, including COUNTDOWN, which is committed to development of trials and mass treatment programmes related to neglected tropical diseases (NTDs), valued at GBP 7 million from 2014 onwards.

RT was employed by LSTM as a CIDG Clinical Research Associate, and was not involved in the editorial process of this review. LSTM is a world leader in promoting MDA for filariasis through its previous Director, Professor David Molyneux. LSTM continues to receive grants from a variety of sources to help implement MDA programmes in filariasis, including COUNTDOWN, which is committed to development of trials and mass treatment programmes related to NTDs, valued at GBP 7 million from 2014 onwards.

SO has no known conflicts of interest.

PG is the Cochrane Infectious Diseases Group (CIDG) Co-ordinating Editor, and was not involved in the editorial process of this review. He is employed by LSTM. LSTM is a world leader in promoting MDA for filariasis through its previous Director, Professor David Molyneux. LSTM continues to receive grants from a variety of sources to help implement MDA programmes in filariasis, including COUNTDOWN, which is committed to development of trials and mass treatment programmes related to NTDs, valued at GBP 7 million from 2014 onwards. From 2014 to 2017, PG received salary support from the COUNTDOWN Research Consortium.

## SOURCES OF SUPPORT

### Internal sources

- Liverpool School of Tropical Medicine, UK

### External sources

- Foreign, Commonwealth, and Development Office (FCDO), UK

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## DIFFERENCES BETWEEN PROTOCOL AND REVIEW

Rebecca Thomas joined the author team at review stage.

We amended the title from 'Mass drug administration for filariasis: community views and programme design influences – a qualitative evidence synthesis' (Taylor 2020), to 'Community views on mass drug administration for filariasis: a qualitative evidence synthesis'.

## INDEX TERMS

### Medical Subject Headings (MeSH)

Communication; *Filariasis; Health Personnel; *Mass Drug Administration; Qualitative Research

### MeSH check words

Humans