Towards universal coverage for preventive chemotherapy for Neglected Tropical Diseases: guidance for assessing
"who is being left behind and why"

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WORKING DRAFT FOR FURTHER PILOTING DURING 2018 – 2019

World Health Organization

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ABOUT THIS WORKING DRAFT

WHO and partners are advancing the mainstreaming project *Integrating a gender, equity and human rights focus into national programming on preventive chemotherapy and transmission (PCT) control for neglected tropical diseases (NTDs)* during 2016-2019. The long-term objective of the project is to build in-country capacity, as part of ongoing monitoring and evaluation of PCT, to collect and analyze additional quantitative and qualitative data, to show the differences in access to and impact of preventive chemotherapy treatment according to a person's sex, age and other social factors.

The project has three phases. WHO would like to thank Global Affairs Canada for their support for Phase 1. This work also benefitted from the support of the Bill and Melinda Gates Foundation to WHO on NTDs. Please see the "Acknowledgements" for additional partners.

	PHASE 1	**PHASE 2**	**PHASE 3**
Scope of work	Develop draft instruments for qualitative research, stratified quantitative analysis, and inputs for national PCT program reviews that enable an enhanced GER focus.	Following pre-piloting by partners in Kaduna State, Nigeria, revise the guide based on lessons learnt. (2017) Pilot the draft GER instruments in additional countries where there is ongoing WHO and partner support to national PCT program strengthening. (2018)	Based on lessons learnt from the pilots and after refinement of this guidance document, support integration of gender, equity and human rights issues in the forthcoming WHO guidance for reviewing/evaluating national NTD programs.
Timeframe	**Completed in 2016**	**2017-2018**	**2019**

The project is a WHO/HQ cross-departmental cooperation between the NTD's Preventive Chemotherapy and Transmission Control (PCT) unit and the Gender, Equity and Human Rights (GER) team, WHO/HQ. Partners interested in piloting this working draft of the guide, in part or in whole, or who have any suggestions for improvement of the guide, should contact: mbabazip@who.int, kollert@who.int.

ACKNOWLEDGEMENTS

TABLE OF CONTENTS

ACRONYMS

CDD   Community Drug Distributor

CST   Coverage Supervision Tool

DQA   Data Quality Assessment

EGR   Equity, Gender and human Rights

GER   Gender, Equity and human Rights

LF   Lymphatic Filariasis

M&E   Monitoring and Evaluation

MDA   Mass Drug Administration

MoH   Ministry of Health

NTDs   Neglected Tropical Diseases

PC   Preventive Chemotherapy

SDH   Social Determinants of Health

SDP   Service Delivery Point

STH   Soil-transmitted Helminthiasis

SDGs   Sustainable Development Goals

UHC   Universal Health Coverage

WHO   World Health Organization

INTRODUCTION

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1. 'Leaving no one behind': the NTD contribution to the 2030 SDG agenda and implications for monitoring of PC

Over 2 billion individuals are at risk for one or more neglected tropical diseases (NTDs), which cause substantial morbidity, and in some cases mortality, worldwide. Five of these diseases – lymphatic filariasis (LF), onchocerciasis, schistosomiasis, soil-transmitted helminthiases (STH), and blinding trachoma – can be prevented through preventive chemotherapy (PC).

PC aims to treat at-risk populations with safe and effective drugs once or twice a year through mass drug administration (MDA) to control, or prevent morbidity by NTDs or in some cases to eliminate the diseases (2). Preventive chemotherapy however is only one of the elements needed to overcome NTDs, with case detection and management, health education, vector control, veterinary public health, and improved sanitation and clean water supplies being equally important (3).

The burden of NTDs is not distributed equitably across or within countries – there are remediable differences in exposure, vulnerability, access to treatment and health outcomes (4–7). For example,

within countries the burden of NTDs is found among the poorest 40% of households, as well as those living in rural or peri-urban areas (8). There are differences between men and women: while they may be equally exposed, the health impacts and or consequences may be different for each sex. Pregnancy for example means that females with chronic helminth-infections are more vulnerable to develop severe helminth-associated anemia (5,9). Gender norms may also prevent women *and* men living in endemic areas from accessing PC, e.g. views about masculinity may mean that men refuse to take preventive medication, or social norms may define women's ability to accept drugs from a male community drug distributor[1] (CDD). Such norms often intersect with other factors e.g. poverty and occupation further affecting access and coverage. Discriminatory practices for people with disfiguration or disability from NTDs can lead to marginalization and these individuals may be excluded from MDA as a result.

1   CDDs includes teachers and individuals from communities who distribute PC drugs.

To be able to fulfill the commitments to leaving no one behind, as per the Sustainable Development Goals (SDGs) and related World Health Assembly resolutions (10,11), NTD program managers and partners must be better able to monitor differences between subpopulations within a country.

Countries are already required to routinely collect and report on PC coverage using (a) sex- and age-disaggregated data and (b) information about refusal of treatment (12). Forms for data collection and compilation at the subnational (peripheral and district) levels reflect this. Other sources of sex-disaggregated quantitative data for monitoring PC include: coverage evaluation surveys, data quality assessments and supervisor's coverage tool outcomes. These approaches can help identify if a more extensive review of PC coverage is needed at subnational level.

Surveys using **qualitative** methods (interviews, participant observation, self-administered questionnaires, focus groups) have been used in some countries to better explore gaps in PC coverage (6,13–16). The COUNTDOWN work on gender, poverty and other social factors, disability, community attitudes

and community drug distributors is also an important source (Cameroon, Ghana, Liberia, Nigeria). Limited routine collection of qualitative data however means that there is a gap in knowledge about community perspectives on how NTDs affect individuals and communities, what happens in practice with MDA and the selection of CDDs (17).

The guidance is therefore designed to (a) make better use of existing/routinely collected data and (b) broaden the available information on who is being missed and why in relation to PC at subnational and national levels.

The guidance can also be used to support other NTD M&E activities such as the Evaluation Framework for NTD programmes, which aims to: assess the achievements and progress towards the attainment of national goals, alignment with national health governance and health system strengthening efforts, and to inform future NTD programme policies, strategies and plans. The findings and follow up action from an equity, gender and rights review of PC coverage can be used to inform a program evaluation forming a key part of the evidence collected.

2. Overview of the guidance

The **primary audience(s)** for the guidance are: program managers for NTDs or communicable diseases (at national and subnational levels) for the five NTDs covered by PC and other partners providing support to national authorities for PC.

This guidance has two core objectives:
1. To build in-country capacity to collect and analyze existing and additional quantitative and qualitative data, to show the differences in access to and impact of preventive chemotherapy according to a person's sex, age, occupation, residence, income and other social factors, as well as identify barriers driving inequities and facilitators for coverage.
2. To catalyze integration of a focus on "who is being left behind and why" into ongoing country level monitoring and evaluation of PC to trigger remedial action as appropriate.

Figure 1 provides an overview of the guidance process highlighting how its relationship to the overall monitoring and evaluation cycle for PC.

The guidance is divided into the following modules:

Cross-cutting Module: Key terms and concepts - this is a cross-cutting module that provides a brief introduction to the key concepts used in the guidance, including universal health coverage and the framework for analysis of differences between groups in the population based on sex, socioeconomic status, place of residence and or ethnicity using an equity and gender lens. It includes linkages to other references and materials on equity, gender and human rights as well as references on monitoring and evaluation of NTDs. While it is for those who are not familiar with these concepts, it is recommended that all review teams read this module as a preparatory step.

Figure 1. Guidance on leaving no one behind in PC and overall M&E
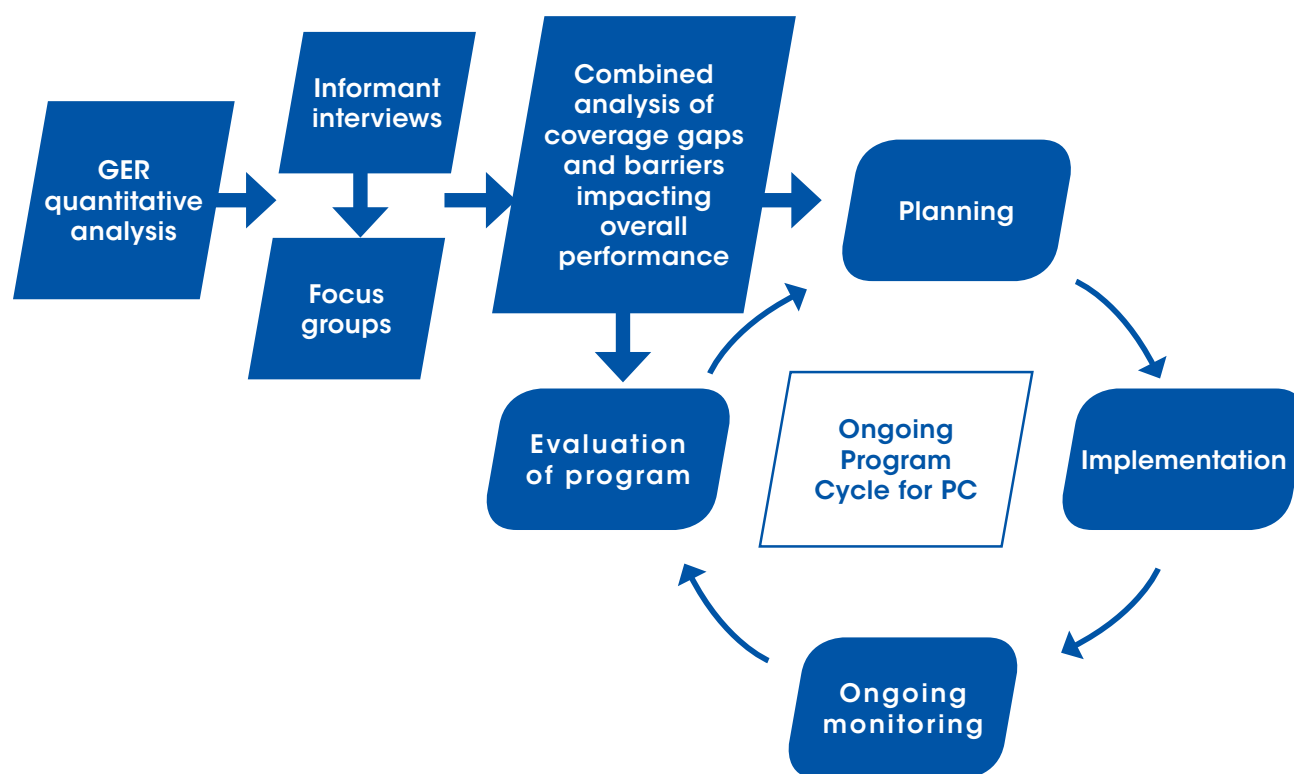
Module 1: Preparatory and scoping steps – these first steps need to be undertaken by the relevant program manager(s) in the NTD program at national level. Activity 1.2 involves undertaking a preliminary mapping of quantitative data on PC coverage disaggregated to district level linked with disaggregated data on equity, gender equality and other NTD measures.

Module 2: Quantitative data step using subnational data – this module includes guidance on undertaking detailed analysis of quantitative data on PC coverage at subnational level in at least two districts and 2-3 communities within each of these districts.

Module 3: Qualitative data step using national and subnational data – this module includes guidance on using existing qualitative data to look at barriers and facilitators for subpopulations in the country in PC coverage. It also includes guidance on undertaking additional qualitative data collection and analysis using key informant interview and focus group discussions (Activities 3.2 and 3.3).

Module 4: Reporting and making use of the findings – this module includes brief guidance on making use of the findings to: inform action to (a) prevent identified barriers and gaps in PC in future and (b) mitigate differential effects in existing coverage at sub-national and national levels; and develop an algorithm/process for integrating improved consideration of equity and gender issues in ongoing program monitoring and evaluation for PC at subnational and national levels to ensure no one is left behind.

If done in its entirety, the guidance enables program managers to broaden the available information to better identify how gender and other social factors specifically affect PC coverage. Tools are included for additional quantitative and qualitative data collection. However, resource constraints may mean that national authorities only wish to draw on parts of the guidance. For this reason, it uses a modular format (see **Figure 2**), allowing some parts to be undertaken as standalone exercises. However, it is suggested that some modules be undertaken for all reviews (see **Appendix 1**).

It is recommended that a full review - all 4 modules of the guidance – is undertaken every 3-4 years. However, an expected output of the review process is development of an algorithm/process for strengthening routine M&E to enable ongoing monitoring of changes and trends in effective PC coverage in endemic districts and agree on any remedial action (see Module 4). This would include updating and reviewing the routine PC data annually using some of the instruments in this guidance and to ensure no one is left behind. For a detailed overview of the activities within the modules, who is responsible for progressing, at what level, how often and linkages between the module see the Table at **Appendix 1**.

The national Ministry of Health may wish to contract aspects of this work out to national research institutes/academia or partners that can assist with the quantitative analysis, and who have experience in doing the qualitative work and in mixed methods, and who can process any ethics clearance/permissions. This is consistent with the research translation agenda for UHC and the call for greater cooperation between national authorities and the research community on coverage gaps and how to close them (18).

WHO wishes to underline that the modules and activities in this manual require adaptation to the country and programmatic context, and that the guidance here is in no way prescriptive. Adaptations to ensure appropriate use of existing data and engage/align with existing governance structures for health are encouraged.

Figure 2. Overview of modules in guidance

Cross-cutting Module: Key term and concepts

Module 1	Module 2	Module 3	Module 4
• National level Preparatory and scoping steps - with subnational imput	• Quantitative data step - using subnational data from 2 districts	• Qualitative step - using national and subnational data from 2 districts	• Reporting and making use of findings - national and subnational
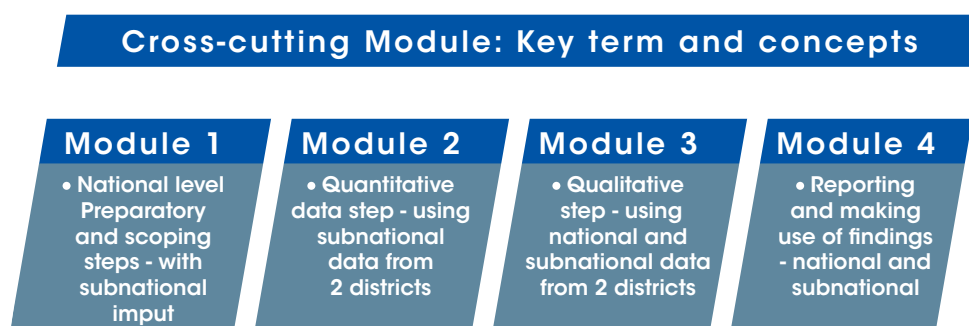
3. Limitations of the guidance

The guidance has been developed to support better consideration of equity, gender and human rights issues in monitoring of PC, and NTDs more widely consistent with the SDG approach to leaving no one behind. It is not designed to result in gold-standard research but verifiable findings (drawing on qualitative and quantitative work) to inform improvement to program design, delivery, and M&E to ensure everyone is reached.

 The follow up to the findings of the review however present an opportunity for more active involvement and engagement of communities in the re-design, delivery, and subsequent monitoring of the PC program and community coverage. Program managers wishing to initiate participatory action research should refer to other sources for this (including the participatory methods on the UK Institute of Development Studies website).

Participatory approaches

Participation, as a cross-cutting principle embodied in international human rights treaties, involves moving beyond information and or consultation with communities to increasing their engagement and capacity to be involved in key processes across the health programming cycle (19) (see Cross-cutting Module). The level and type of participation in a country will be determined by (a) governance, health—and wider social—systems structure and mechanisms for community participation within countries and (b) the strength of these mechanisms i.e. are they functioning. The level and type of community participation will determine the extent to which communities participate or are enabled and legitimized to participate.

Consultation with communities receiving MDA is a critical part of the review. In the current exercise, community or social participation is limited to consultation and feedback on the implementation of the PC program. This is because it is not feasible within this exercise (resources and timing) to initiate a process of co-design or review using participatory action research principles.

Inequities in exposure to risk factors for NTDs or in access to treatment once a person has an NTD

This guidance explicitly focuses on PC for NTDs. While it briefly touches on aspects of them, it does not explore issues related to inequities in exposure to risk factors for NTDs in any depth. Nor does it explore the differences in access to and outcomes of treatment once a person has an NTD. Table 1.2.1 is developed to provide an initial mapping of inequities; it provides for reporting of available data about morbidity, impairment or disability from NTDs. It includes numbers of people receiving surgery and/or the proportion of health facilities in endemic districts providing morbidity care. This data may serve as a proxy for inequities in PC coverage i.e. comparatively low levels of effective coverage but needs to be interpreted with caution (see Activity 1.3). Additional research would need to be done on these issues, in order to have a full understanding of inequities across the health and service continuum.

Introduction

CROSS-CUTTING MODULE: KEY TERMS AND CONCEPTS

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Cross-cutting Module: Key term and concepts

Module 1	Module 2	Module 3	Module 4
• National level Preparatory and scoping steps - with subnational imput	• Quantitative data step - using subnational data from 2 districts	• Qualitative step - using national and subnational data from 2 districts	• Reporting and making use of findings - national and subnational

This module should be undertaken at **national level** by relevant program managers (for NTDs, PC and or Communicable Diseases) in the Ministry of Health and other stakeholders (e.g. national consultant and review team).

The **aim** of the module is for those leading the review process to familiarize themselves with the key terms and framework of analysis used in the guidance.

The guidance draws from a set of related concepts and principles from the fields of health equity, gender, human rights and the social determinants of health (20).

Even where those leading the review are familiar with key terms and concepts, it is recommended that they read this module to ensure they are familiar with the specific framework of analysis used.

Beyond the average: pilot of guidance, Kaduna State, Nigeria

With a population of just over 170 million, Nigeria has the highest prevalence of NTDs in sub-Saharan Africa, representing 25% of Africa's total NTD burden. COUNTDOWN has been undertaking research in the country to explore how socio-economic factors such as poverty, age, gender, stigma and disability are accounted for within NTD programming and how they shape access to interventions. Health authorities in Kaduna State, Nigeria worked with partners, COUNTDOWN and Sightsavers Nigeria, to pilot this guidance. The pilot sought to identify potential barriers to services and incorporate a focus on equity, gender and human rights in the ongoing program monitoring and evaluation. Several barriers to PC were identified through the process. These were linked to sex and gender differences; seasonal timing of drug distribution and drug shortages; transportation issues; incompatibility of the service delivery modality with nomadic livelihoods; and inaccessibility of MDA to persons with physical disabilities, among others (21).

1. Why focus on equity, gender and human rights in PC coverage?

The universal health coverage (UHC) target of 80% essential health services coverage is broadly consistent with coverage targets for the prevention of NTDs (22). Furthermore, a precondition for reaching the UHC target of 100% financial protection by 2030 is that all NTD cases are financially protected (8).

NTDs are understood to be diseases of the poor, marginalized, voiceless and programs intended to focus on and benefit the poor. It is often assumed that PC and or NTD interventions are naturally equitable and meeting the needs of all groups in the population because efforts are already targeted at populations that are largely poor and rural. However, PC coverage is affected by a range of social, cultural and economic factors that impact on the good intentions of distribution of medicine at no-charge. These in turn can affect the effectiveness and equity of coverage.

Equity is the absence of avoidable, unfair, or remediable differences among groups of people, whether those groups are defined socially, economically, demographically or geographically. "Health equity" or "equity in health" implies that ideally everyone should have a fair opportunity to attain their full health potential and, more pragmatically, that no one should be disadvantaged from achieving this potential (23). **Health inequity** refers to a difference in health that is deemed to be avoidable, unfair or stemming from some form of injustice. Inequities in health status can be between groups of people within

countries and or between countries. Inequities are those differences in health that arise from avoidable differences in social, economic and environmental variables such as living and working conditions and including access to quality health care, disease prevention and health promotion services (24–26).

This guidance is based on a framework which assists in identifying the barriers and facilitators to effective coverage of an intervention (see **Figure 3**) – in this case preventive chemotherapy (20,27) and which might be leading to inequities in coverage i.e. differences that are avoidable, unfair and preventable. **Effective coverage** is defined as "people who need health services obtain them in a timely manner and at a level of quality necessary to obtain the desired effect and potential health gains" *(28)* and is important in considering universal health coverage *(20)*. In the case of PC, the service delivery goal for effective coverage will be at least 80% of the entire population living in endemic areas[2] and refers to treatment coverages that attain or surpass target thresholds set for the different diseases.

Barriers in this guidance are understood as those factors that obstruct the target population from appropriate use of an offered health service, therefore

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2   Coverage targets for preventive chemotherapy, are defined as 100% geographical coverage of endemic districts and between 65% and 80% disease-specific treatment coverage of eligible people requiring treatment within those districts, depending on which diseases are endemic.

Cross-cutting Module

reducing the effective coverage of the health or provision service, in this case effective coverage of PC delivered by MDA. The right to health draws attention to four types of barriers in access including physical, financial, information and discriminatory barriers. There may also be gender based barriers in access to and use of health services (20):pp.228-229) – e.g. reduced access for women and children when the CDD is male and the gender norms require that a male be present. The framework is used to assess the different factors that affect the health system's capacity to deliver effective drug coverage so that all the intended population benefit from MDA of PC.

Figure 3 illustrates *conceptually* how the percentage of the target population with effective coverage for health service delivery is affected by the coverage achieved in the different dimensions of availability, accessibility, acceptability, contact and lastly effectiveness. For example, if accessibility of preventive chemotherapy is reduced because the drugs do not reach some communities before the rainy season, then effective coverage will be reduced. These five dimensions are described in detail in the Glossary at **Appendix 2**, and in Module 3.

Assessment of the level of coverage achieved in these five dimensions is done by identifying barriers and facilitators.

The framework is useful for identifying the reasons why some subpopulations are benefiting from the intervention and others not. The first three coverage dimensions of the Tanahashi framework build on three of the essential elements of realizing the right to health (i.e., availability, accessibility and acceptability). The fourth element of the right to health is **quality** and calls for health facilities, goods and services to be scientifically and medically appropriate and of good quality. Quality is an issue relevant across the domains of the Tanahashi framework.

Figure 4 shows how the Tanahashi framework can be used to look at MDA to identify barriers and facilitators for effective coverage such as geographical barriers that prevent drugs reaching communities in time due to the rainy season or children going to school in non-endemic NTD areas. These barriers mean that some groups in the population are potentially being missed, due to factors that are avoidable, unfair, and remediable – inequities in health (see Glossary).

Figure 3. Tanahashi conceptual framework illustrating how effective coverage is assessed* (20,27)
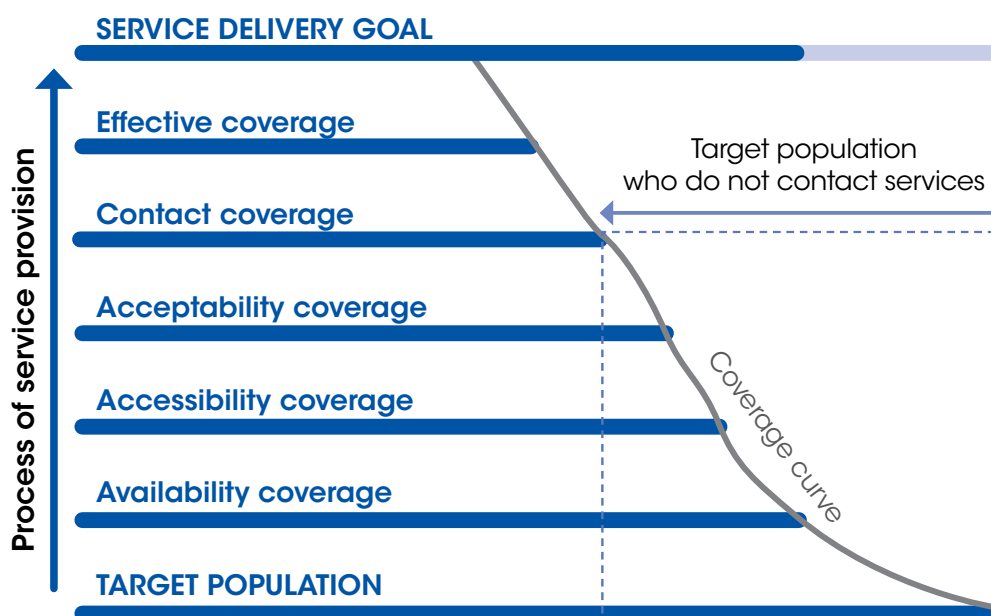
Note: *This figure should be understood as a conceptual model that is applied to assessing information for the relevant intervention and not as a representation of actual coverage for PC.*

Figure 4. Potential barriers and facilitating factors for MDA (examples only) (6,13–16)

Mass Drug Administration of PC in endemic areas by CDDs based on available data for communities needing PC

	Barriers	**Facilitators**
Availability	• Criteria for School Aged Children - preschool & children attending lower secondary school may be missed • Children going to school in non-endemic areas may be missed • Problems with drug supply chain – delayed delivery to communities	• A strategy and clear plan for treating nonenrolled school children • 100% availability in endemic areas • Drugs supplied free of charge to countries
Accessibility	• Physical – seasonality, remoteness and security challenges may affect CDDs opportunities to reach some communities and affect time required for drug distribution • Nomadic/travelling populations • Drugs not arriving in time or before the rainy season • Drugs provided when food shortage • CDDs' understanding about who should/should not receive the drugs • Community not aware CDD coming so not around to receive or take drugs e.g. men out at work	• Drugs provided free of charge • CDDs go to communities to distribute the drugs and teachers at schools • Mop-up sessions for absentee populations, and pregnant or lactating women who were missed where Albendazole was the drug administered • Village announcements about forthcoming MDA
Acceptability	• Gender norms that: prevent women and children receiving drugs from male CDDs where male member of household not present; and prevent men receiving drugs from a female CDD • Control of household head in decision of household to take medicine or not • Beliefs about PC medicine and need to take them, including potential harm and or belief that it is not necessary because no obvious health problems • Concern about side-effects • Acceptability of CDD i.e. community nominated, ethnicity	• Specific efforts to ensure recruitment of female CDDs • Strong community nomination processes for CDDs – increased acceptability • Strong community awareness and education programs about taking the drugs • Pharmocovigilance guidelines can mitigate against negative impacts on the programme
Effective coverage	• No strategy/plan for absentees and systematic follow-up of community members who are consistently refusing and or not taking the drugs.	• CDD directly distributes and observes taking/swallowing of tablets by community members • Planning for implementing mop-up activities • Clear plan for non-enrolled school children

2. Gender in health: making use of sex-disaggregated data to improve PC coverage for males and females

Gender refers to the socially constructed characteristics of women and men – such as norms, roles and relationships of and between groups of women and men. It varies from society to society and can be changed (29). The aim of looking at gender in health is to identify the roots of health-seeking behavior and to improve health outcomes for both female and male populations, regardless of age, ethnicity, religion and socioeconomic status. It cannot be assumed that health programs and policies affect men, women, boys and girls in the same way.

Specific vulnerabilities must be identified and addressed in health programs and policies in order to make progress towards health for all (30). This requires not only collecting but making use of sex-disaggregated data to better identify the reasons for differences between males and females in coverage, outcomes, and impacts, i.e., undertaking a gender analysis and concretely using it to improve the delivery of programs (17). Gender analysis in health examines how biological and sociocultural factors interact to influence health behavior, outcomes and services (30) (see the Glossary at Appendix 2 for further elaboration of gender and health).

Sex-disaggregated data in PC only gives an indication of the size of the difference between males and females. Therefore, the guidance focuses on using the sex-disaggregated data in PC coverage to examine if the differences in coverage between males and females reflect gendered differences in health-seeking behavior that can be changed and or strengthened to improve coverage and make it more equitable. It cannot be assumed that if males and females are equally covered by PC within a district with low coverage rates, that no gender analysis is required.

Analysis of the differences in coverage for both males and females is needed to identify the underlying factors. Different responses might be required. For example, the coverage rates for adult males may need to be improved because men are working outside the district in a non-endemic area and therefore missing out on treatment. Whereas women may be missing out if there are no female CDDs and women are not allowed to receive treatment from male CDDs.

3. Anchoring UHC (and PC coverage) in the right to health

NTDs have been identified as "litmus test" for UHC. Monitoring of UHC focuses on two discrete components of health system performance: levels of coverage with health services and financial protection, with a focus on equity/distribution of impact (31). In terms of NTDs and ensuring no one is left behind this means monitoring to ensure that:

1. financial risk protection for all NTD cases (8); and
2. gaps in coverage that arise from multiple types of discrimination (real and perceived) and may stem from factors outside the health system are identified and addressed (32).

The **right to health** refers to "the right to the highest attainable standard of health" and requires a set of social criteria that is conducive to the health of all people, including the availability of health services, safe working conditions, adequate housing and nutritious foods. Realization of the right to health is closely related to that of other human rights, including the right to food, housing, work, education and non-discrimination; equality; access to information; and participation (27).

The UN human rights-based approach to programming (HRBA) is a practical and concrete way for health and other sectors to fulfill their responsibility to realize human rights. This approach focuses attention and provides strategies and solutions to redress inequalities, discriminatory practices and unjust power relations as the underlying causes of health inequalities (20,33). This guidance draws on the HRBA by supporting monitoring of:

➔ **Non-discrimination:**
  • Health services, goods and facilities must be provided to all without discrimination (both real and perceived). The pilot of this guidance in Kaduna State Nigeria for example identified that people with physical disabilities may not access PC because they may not be able to come to the community meeting points where distribution can occur. As a result they are coordinating with State and Local government officials to re-design training tools to address people with disabilities and from nomadic communities (21). Additionally, the poles currently in use for determining treatment dosage by height do not make provision for measuring individuals with physical disabilities, nor is there clear guidance to CDDs on how to address the issue.
  • Where development programs cannot reach everybody at once, priority must be given to the most marginalized. This is the underlying approach with PC and MDA. However, there is still a responsibility to address the underlying and systemic causes of discrimination to improve equality e.g. prioritizing the improvement of water and sanitation facilities in endemic NTD areas to reduce exposure to the causes of NTDs.

➔ **Participation:** meaningful opportunities must exist for participation in all phases of the programming cycle. Consultation with communities receiving MDA is a critical part of the review, although it is limited to consultation and feedback on the implementation of the PC program due to limited resources and timing (see Introduction). Follow up to the findings of the review present an opportunity for more active involvement of communities at an earlier stage.

➔ **Accountability:** the right to health can be realized and monitored through accountability mechanisms, so long as they are accessible, transparent and effective. This standardized guidance supports improved accountability for ensuring no one is left behind in PC coverage by attention to non-discrimination and equality in addition to monitoring effective coverage using the Tanahashi framework (see Figures 3 and 4). (20,33)

Further resources and reading

For further information:
  • **Within country socioeconomic inequalities in NTDs** – see Houweling et al (2016) for a systematic review of within-country socioeconomic inequalities for nine of the NTDs in the London Declaration.
  • **Effective coverage and AAAQ** – see 'Step 4: Identifying the barriers and facilitating factors that subpopulations experience' – in the WHO *Innov8 Technical Handbook*.
  • On an **example of application of the Tanahashi framework** and how it can be useful in identifying subpopulations being missed and inequities to increase coverage and take a holistic approach to health and development – see 'Adolescent Sexual and Reproductive Health Programme to Address Equity, Social Determinants, Gender and Human Rights in Nepal. Report of the Pilot Project'
  • **Monitoring of inequalities/inequities in health** – see WHO website for the Handbook on health inequality monitoring with a special focus on low- and middle-income countries and PowerPoint lectures as well as the *Health inequality e-Learning module.*

Cross-cutting Module

Checklist for Cross-cutting Module

Now you have finished this module, review the checklist and identify if you are ready to undertake Module 1 and or any follow up action that needs to be taken:

Key issues	Yes/No/ Unknown	Comment including any follow up action
1. Have all potential members of the review team, including national MoH NTD stakeholders reviewed and discussed the key terms and concepts that underpin the equity, gender and rights review process?		
2. Is there a shared understanding of the key terms and concepts?		
3. Is it clear why equity, gender and rights are relevant to PC coverage and achieving NTD goals of leaving no one behind?		
4. Having reviewed the module, can you identify some of the potential barriers to effective coverage in your country?		
5. Is it clear how the review process is and or can be aligned with M&E for NTDs?		
6. If the guidance document needs adaptation to country context and or translation, has this been organized?		

MODULE 1: PREPARATORY AND SCOPING STEPS

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Cross-cutting Module: Key term and concepts

Module 1	Module 2	Module 3	Module 4
• National level Preparatory and scoping steps - with subnational imput	• Quantitative data step - using subnational data from 2 districts	• Qualitative step - using national and subnational data from 2 districts	• Reporting and making use of findings - national and subnational

Module 1 is undertaken at national level by relevant program managers (for NTDs, PC etc.) in the Ministry of Health, as preparation for undertaking a full review of how gender and other social factors affect PC coverage every 3-4 years.

Module 1 has three activities:

- **Activity 1.1:** Produce a draft review plan and hold a limited stakeholder meeting.
- **Activity 1.2:** Map inequities using available existing quantitative data (both about PC and socioeconomic factors within the country).
- **Activity 1.3:** Finalize the review plan and get ethics permission(s). This activity includes a stakeholder meeting.

When used in this guidance, **subnational** refers to the district and community/peripheral administrative units for information collection as part of routine monitoring of PC. They refer to the lowest level at which MDA is undertaken (community/peripheral) and then the next level up such as district which comprises all the communities. Usually this will be the second and third level administrative divisions within a country but this will vary. The following link provides an overview of administrative divisions by country to assist in identifying the level within a country that best matches the district and community/peripheral levels referred to in the guidance. The recommended data flow pathway for reporting preventive chemotherapy through these administrative levels is depicted in WHO manual on *Monitoring Drug Coverage for Preventive Chemotherapy* (Figure 2, page 8) (12).

ACTIVITY 1.1
PRODUCE A DRAFT REVIEW PLAN

This activity is conducted at national level, aligned with national programming cycles and—like all other activities—should be adapted to the national context and NTD program needs. The annual program review meetings provide an important entry point for beginning the review process.

The **outputs** of Activity 1.1 include:

- An initial scoping session and resulting draft "review plan", for discussion in subsequent steps including at the stakeholder meeting (see Activity 1.3).
- Agreement about who will undertake Activity 1.2 – the preliminary mapping of PC coverage and social determinants using subnational data.
- Agreement on timeframes for completing Activities 1.2-1.3.

Initial scoping session and draft plan for the review

This includes an initial meeting to plan the review. The **aims** of this meeting are to:

1. Agree on aims, objectives and outputs of the review, including how the findings will be used including timing of the review to align or feed into any annual NTD program review process.
2. Agree on any needed adaptations to the guidance for the country or programmatic context and operations.
3. Assess the potential resources available to support the review, including allocations from regular budget and program staff, and/or incorporation into joint work by or with partners. This would involve identification of a focal point for managing the review and budget source.
4. Agree on formal decision-making and clearance processes including ethics permission(s) (see Activity 1.3).
5. Identify and agree on other stakeholders to be invited to the process and at which stage, e.g. partners undertaking work on NTDs and linked academic institutions might provide support to Activity 1.3 if they are already working with the data.

Attendees of this meeting include those with overall responsibility for NTDs and PC in the country, e.g. the NTD Program Manager, and related stakeholders in the Ministries of Health and Education. The latter may comprise those responsible for:

- Other NTD interventions such as vector control, water and sanitation, veterinary public health and as appropriate to the country NTD program structure.
- PC medicine supply and distribution.
- Public health and or primary health care.
- Community health workers and or human resources at subnational levels.
- Social mobilization and community mobilization teams. Involving the manager/focal point from the team(s) is critical to identifying potential equity, gender and human rights issues from the beginning and the best ways to access communities.
- The country health information system and wider health system monitoring and evaluation. NB: involving the program manager/focal point from this section of the MoH is potentially critical to accessing data disaggregated by social and economic factors at sub national level. Consideration should be given to involving the health information area from the beginning of the review process.

This meeting will result in a draft "review plan", which will be used to undertake the subsequent steps and revised as appropriate/required with further inputs.

ACTIVITY 1.2
MAP INEQUITIES USING EXISTING QUANTITATIVE DATA

The **aim** of this module is to identify differences in PC coverage at subnational level using available data on PC and additional available data disaggregated by social and economic factors that operate to affect PC coverage – both disaggregated at district level wherever possible.

The **output** of this activity is a mapping of the potential gaps in PC coverage at subnational level linked to other social and economic factors. This mapping can then be used to identify 2 districts where a closer review of PC coverage might be undertaken because of what appear to be significant potential gaps at subnational level suggesting some groups in the population might be being left behind. In effect, these two districts are potentially proxies for inequities due to lower levels of coverage. This is similar to the NTD approach used for looking at potential drug resistance and selecting sentinel sites. However, the mapping of potential gaps, needs to be discussed with a wider group of stakeholders at the meeting in Activity 1.3 and from this the scope and parameters of the review will be finalized including the need for additional data collection (quantitative and qualitative).

Developing the map of potential gaps and identifying potential districts of focus

Table 1.2.1 provides the template for collation and review of routine and *additional* existing quantitative data to identify the 2 potential districts where more in-depth assessment will be taken using quantitative and qualitative data. The steps for completing the table are as follows:

➜ **Step 1** involves developing a *within country picture* of **differences in PC coverage** (population in need and covered or not covered, and overall coverage) at district level and using MoH coverage data and reports. Ideally the information should be shown using sex- **and** age-disaggregation at district level. For example, sex- and age-disaggregation by district for population in need of coverage and sex- and age-disaggregation for those treated and overall coverage. While the peripheral and district level forms provide for collection of sex- **and** age-disaggregated data (meaning the data is available in this format), the joint reporting form only provides for:
• Sex-disaggregated data by NTD;
• Age-disaggregated data by MDA and Treatment rounds.

Table 1.2.1 has therefore been developed to be completed as two worksheets within the same excel spreadsheet, and as follows:
a. numbers treated using sex-disaggregated data by specific NTD, and the overall coverage (%) against district level equity, gender and medicine supply factors; and
b. (%) covered using age-disaggregated data by MDA and or Treatment Round, against district level factors equity, gender and medicine supply factors.

The worked example of Table 1.2.1 at **Appendix 3** is only completed for sex-disaggregated data by NTD *at this stage*. It is also done as one worksheet for four of the five PC NTDs however, it may be easier to do one worksheet per NTD each linked to the equity, gender and health system data. If the data to be collated is significant then **priority should be given to working with the sex-disaggregated data initially** to gain insights into potential gender equality issues and given the age-disaggregated data links to treatment and broad age groups. Also, the calculation of population in need of coverage is done using aggregated rather than sex-disaggregated data. Therefore, demographic data sets are a pre-requisite of the information to be used in the review as some districts do have an uneven sex ratio which will affect the baseline. When reviewing the numbers

of males and females treated within a district, the sex ratio for the district should guide assessment of whether there is an inequality/differential in coverage based on the sex ratio. For example, it should not be assumed that coverage will be 50:50, males: females, it may need to be disproportionate i.e. more women covered than men if the sex ratio is 45:55 in the district (see the worked example at **Appendix 3**). Finally, the age- **and** sex-disaggregated data will be looked at as part of Module 2 where there is collation and review of subnational data for PC coverage.

➔ **Step 2** introduces an **equity lens** by collating and reviewing available data disaggregated by Gini co-efficient, urban/rural/remote and level of education or wealth quintile at district level. For example, do any or several of the districts with comparatively low PC coverage levels, also have low levels of primary school completion and or are largely in remote areas?

- **Existing sources for data** include the Demographic and Household Surveys (DHS), the Multiple Indicator Cluster Surveys (MICS) and country level data provided for the UNDP Human development country reports (HDI). DHS and or MICS reports are available for approximately 65% of the countries where PC is used for 1 or more of the NTDs, and are potentially the most easily accessible source to use. However, in some instances the data is quite old or reports are restricted or not available.

- For this step, the Gini co-efficient (as available in the DHS) disaggregated to subnational level is included to give an idea of the distribution of overall inequality within the country. Data on the urban/rural/remote characteristics of the district(s) should also be included in Table 1.2.1 together with information either about wealth quintile OR level of educational attainment. Where available, the median years of education for females and males should be used. In the worked example, it was not possible to use median years of schooling, given significant overall inequality within the country and so level of primary school completion for males and females was used to better differentiate between districts (see **Appendix 3**).

- Where DHS/MICS data are not available, the data for the inequality adjusted Human Development Index (HDI, see Glossary) in the latest country UNDP HDI report might be used. The data needs to be available disaggregated at subnational level. This may require liaison with the responsible government agency for statistics. Alternatives to using UNDP data include UNESCO – UIS and the World Bank Education Statistics - noting that these two sources tend to draw on DHS and MICS data.

- Where the data for the UNDP report is not available at subnational level, it is recommended that the most recent figure for inequality adjusted HDI at national level is presented. However, this only provides an indication of overall inequality at national level – see 'What to do if there is no or limited disaggregated data.'

- Finally, in some countries where there is extremely limited disaggregation for completion of Steps 2-4, there may be in-country studies including qualitative information that can be used to complete these steps e.g. COUNTDOWN data (see also Module 3).

➔ **Step 3** introduces a stronger focus on **gender equality**. It does this by including data drawn —where possible from the latest DHS and/or MICS reports—about women's empowerment on issues including: women's control over cash earnings; decisions on use of cash earnings; assets; participation in decision making; and attitudes towards wife-beating.

- The focus is on using the disaggregation at district level and looking at 1-2 indicators within a measure. For example, in the worked example (see **Appendix 3**) information on women's participation in decision-making using the specific indicator of women's own health care is used but in the notes consideration was also given to looking at the proportion of women in the district who do not have a say in any of the three decisions considered as part of the DHS (own health care, making household purchases, and visits to woman's family or relatives).

- Not all countries will have current DHS/MICS reports. Here the UNDP gender inequality index (GII) might be used (see Glossary). Ideally data will be available disaggregated at district level. It is recommended that one of the health measures used in the GII as available at district level is used. Where data for the GII is not available at disaggregated at district/ subnational level, it is recommended that the most recent figure for the GII at national level is presented. This provides an indication of the overall level of gender inequality in the country.

➡ **Step 4** introduces other NTD and/or health system measures to be considered including:

- **Supply of PC medicines for MDA** including (a) any delays in country level request for MDA; (b) any delays in distribution of medicines to any or all districts; and (c) number of tablets wasted due to expiry, poor storage conditions, etc., by district. This information should be available in the Inventory of PC medicines/ Joint reporting form for PC.

- The percentage of households with access to: improved drinking-water source; and improved sanitation. **Water and sanitation** or WASH conditions are critical to the effort to overcome NTDs and ensuring adequate access to sanitation is an important. WASH interventions, by lowering the basic reproductive number, can facilitate the ability of MDA to interrupt transmission (34).

  ° This information is likely to be available in DHS reports as well as the WHO/UNICEF – Joint Monitoring Program (JMP) for Water Supply and Sanitation – country reports and wealth quintiles - World Health Statistics for SDG Target 6.1, Drinking Water.

  ° While data may be available in disaggregated format, it may also be reported in terms of urban, rural, remote and or peri-urban differences rather than by district – this is the case in the DHS reports. For the worked example, however data was available from the website of the country statistical agency (see **Appendix 3**)

- **Morbidity or impairment or disability from NTDs** including hydrocele, lymphedema and blindness. This data is required for inclusion in national dossiers that are submitted for validation of elimination of lymphatic filariasis and trachoma as part of NTD program implementation (35,36). Therefore, district level data can be included for one or all of the following indicators depending on the NTD profile of the country:
  a. proportion of known hydrocele patients from LF who have received surgery (hydrocelectomy) – by default males;
  b. proportion of known lymphedema patients who have received health worker visitations and training on limb care - sex- and age-disaggregated;
  c. proportion of health facilities in endemic districts providing morbidity care services and
  d. number of people operated for trachomatous trichaiasis annually.

This information may not be easily available in all countries but may be located in MoH registries and some coverage surveys, particularly as reporting on these issues increases. Countries will need to select which if any morbidity indicator applies depending on their NTD profile.

What to do if there is no or limited disaggregated data

Where the level of disaggregation at subnational level is limited, then it is recommended that an overall national profile be developed that provides general information about the overall population and household characteristics within a country as far as possible. For example, a population pyramid using sex-disaggregated data and looking at differences between districts:

- in age and sex profile
- distribution and location of different subpopulations by various characteristics that may increase vulnerability to being left behind in PCT, e.g., people living in conflict areas, areas with higher proportions of agricultural workers who may be more exposed to risk factors due to their livelihoods, and nomadic communities who may miss out on treatment

Where it is necessary to use national level data from the UNDP HDI country report, then national data for the Inequality adjusted HDI and the Gender inequality index should be presented from the most recent year/report. This can provide information on an overall pattern of inequalities in the country. However, it is also recommended that the program manager for the national health information system be involved in the review process from the beginning and be engaged in addressing challenges with data disaggregation. For example, most countries have an inequality adjusted HDI and Gender inequality index score, that is updated annually. To calculate these scores, UNDP uses data disaggregated at sub national level i.e. the data exists but may not be easily available. The program manager for the national health information system may be able to follow this issue up with the relevant national statistics agency in the country.

Where it is not possible to complete Steps 2-4 of Table 1.2.1 due to limited or no data disaggregated below national level, it is recommended that Step 1 be completed using available sex- and age-disaggregated PC Coverage data at district level together with the following information for each district:

- if the district is largely or entirely urban, rural and or remote;
- any other key sociodemographic information such as district located in a conflict zone, has a large nomadic population or a significant proportion of adults who are migratory workers.

This information might be available through studies by other agencies.

The inequity map should then be discussed in detail as part of Activity 1.3 at the meeting with the wider range of stakeholders and in finalizing the districts to be included in the review including limitations of the available data at subnational level.

Table 1.2.1

These tables will be provided in Excel format to assist in completion and inclusion of all required information. It is likely that the data for Step 1A in Template A will be collected in a separate sheet for each NTD (for which the country is endemic) and shown against the data collected in Steps 2-4.

A: Template for collation of quantitative data to identify the potential gaps in PC and districts for review – using sex-disaggregated data by PC NTD

D	Step 1: PC coverage x district (epidemiological coverage)																						Step 2 – Equity Lens			Step 3 – Gender	Step 4 – Medicine Supply & NTDs			
	Step 1A: PC coverage of population in need by sex																													
	Population treated for LF				Population treated for Onchocerciasis				Population treated for Soil-transmitted helminthiasis				Population treated for Schistosomiasis				Population treated for Trachoma				Gini co-efficient	Urban/ Rural/ Remote	Educational attainment - % primary education complete		Gender Equality*	PC Drugs	WASH		NTD Morbidity or Health care measure
	Total (#) Popn in Need	M(#)	F(#)	Total (%) treated in need of PC	Total (#) Popn in Need	M(#)	F(#)	Total (%) treated in need of PC	Total (#) Popn in Need	M(#)	F(#)	Total (%) treated in need of PC	Total (#) Popn in Need	M(#)	F(#)	Total (%) treated in need of PC	Total (#) Popn in Need	M(#)	F(#)	Total (%) treated in need of PC			M	F		*	Safe Drinking Water	Sanitn	*
1																														
2																														
3																														
4																														
5																														
6																														
7																														
8																														
9																														
10																														

D = districts/subnational level
* Indicators Used: * Indicate which measure used.
Comments/Notes NTD situation in country:
Comments/Notes data quality:
Sources and dates: Joint reporting forms; DHS survey for country and date; any other reports or websites.

B: Template for collation of quantitative data to identify the potential gaps in PC and districts for review – using age-disaggregated data by MDA and treatment rounds (to be completed if required)

D	Step 1: PC coverage x district (Epidemiological coverage) — 1B: PC Coverage by age (%)*																	Step 2 – Equity Lens				Step 3 – Gender	Step 4 – Medicine Supply & NTDs			
	MDA 1		MDA 2			MDA 3		T1		T2			T3- R1 and 2					Gini co-efficient	Urban/Rural/Remote	Educational attainment - % primary education complete		Gender Equality*	PC Drugs	WASH		NTD Morbidity or Health care measure
	SAC	Adult	Pre-SAC	SAC	Adult	SAC	Adult	SAC	Adult	Pre-SAC	SAC	Adult	Pre-SAC	SAC	Adult					M	F		*	Safe Drinking Water	Sanitn	*
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D = districts/subnational level
* Indicators Used: * Indicate which measure used.
Comments/Notes data quality:

Sources and dates: Joint reporting forms; DHS survey for country and date; any other reports or websites.

Reviewing and interpreting the mapping to identify potential districts to include in the review plan

In order to identify the two districts to be included in a full review the following is a suggested process for reviewing the data at Table 1.2.1:

Differences in PC coverage by district: looking at the data on Population in Need (PIN) who are Not Covered are there clear differences in the country between districts? For example, is it only a few districts who have much lower levels of coverage? Or does there appear to be an overall lower level of coverage for most-all districts in the country? See the worked example (Appendix 3) which shows wide variation between districts depending on the PC NTDs treated.

The worked example also shows that **treatment for LF was interrupted** in 6 districts. In other districts **PC drugs were given for Onchocerciasis and STH in districts where there was no identified population in need** and or to communities within districts that were not included in the total population in need of treatment. This highlights a range of potential issues including data quality and the original baseline figures (see **Appendix 3**).

If there is an **overall lower level of coverage in most to all districts** in the country, then the other data collected in Table 1.2.1 needs to be closely reviewed to identify the districts where the data indicates:

- Differences in **sex** and (where included as part of Table 1.2.1) **age characteristics** of populations covered and not-covered by PC in the district? Is there a notable difference between males and females not covered and covered? Also, is there a notable difference between age groups? Higher numbers of men missing coverage may be due to work practices including working outside the district.
  - ➔ NB: as indicated differences between males and females treated requires attention to the population breakdown i.e. is it a 50:50 breakdown between males and females so therefore you would expect to see roughly equal coverage?
- **Higher levels of inequality within the district** in terms of the Gini co-efficient and compared to other districts.

- Higher potential disadvantage for coverage due to geography e.g. largely rural and or remote. What is the **geography of the district** – largely urban, or largely rural with several remote areas? The more remote and inaccessible a district, the more likely there will be challenges with supply of medicines and access to communities for MDA at certain times of year. Are mop-up exercises or use of nomadic CDDs already in place?
- Lower positive scores for **schooling** (lower median years of schooling, lower median years of schooling for girls) within the district. Districts with lower median years of schooling may indicate additional barriers related to literacy and health service use.
- Lower potential levels of **gender equality** including a lower percentage of women in the district who participate in decision making about their own health care and or other decisions.
- Any or more **delays with PC medicine requests and supply,** and greater numbers of tablets wasted due to expiry, poor storage and related factors.
- A lower percentage of households with access to **improved drinking-water** source and improved sanitation.
- Higher numbers of people receiving **surgery** (hydrocelectomy and trachomatous trichaiasis) annually.
- Lower proportions of patients and **health services** for morbidity care of NTDs.
  - ➔ NB: make a note of where data is missing/ unknown/more than 5-years out of date.

This should help narrow the selection of districts for consideration as part of the review from several to a few so that the districts that are most potentially disadvantaged can be better identified.

Where **clear differences between districts can be identified from the PC coverage data** then the data in Table 1.2.1 should be reviewed as outlined above for **those districts with lower levels of coverage** to (a) potentially narrow down the districts to be included in a full review and or (b) develop a more specific map of potential inequalities e.g. location and education.

Consideration also needs to be given to the gaps in and quality of the data used as part of this reviewing step including:

- See **earlier comments** about additional numbers of people treated for Onchocerciasis and STH who are not included in the baseline figures of population in need for the district. This could be a data problem and or a problem with MDA.
- **Data availability and gaps** – What is missing? What can be filled? What needs to be noted as a gap? Which gaps can be addressed immediately and which at the stakeholder meeting (see Activity 1.3)? For example, data in Table 1.2.1 disaggregated to subnational levels on other social factors? This might be something that can be progressed with a wider group of stakeholders as part of Activity 1.3.
- **Quality of the data** – the last four indicators for the mapping relating to health services and management of morbidity for NTDs should be interpreted with caution as the data may be relatively new and there may be under-reporting of the provision of health services. In addition, higher levels of surgery may reflect a substantive effort to improve care for people requiring surgery and so may not reflect current inequalities in PC coverage but previous inequalities.

Next Steps

The next step is Activity 1.3 which includes discussion and agreement about which two districts are to be included in the review.

ACTIVITY 1.3
FINALIZE THE REVIEW PLAN AND GET ETHICS PERMISSIONS

The **aims** of this activity are:

- Review the mapping of inequities (output of activity 1.2) in PC coverage to better understand potential subpopulations that are being left behind in coverage;
- Confirm the two districts to be included in the in-depth review of coverage at subnational level (for Modules 2-3);
- Identify potential communities within the two districts to be included;
- Identify specific potential key informants (national and subnational levels) and types of focus group participants dependent on mapping of subpopulations;
- Get ethics committee permissions; and
- Finalize the scoping and parameters for the review, updating the draft review plan done in activity 1.1.

The **outputs** of this activity are:

1. Finalization of the document on the review plan, which outlines the scope of the review (aims, objectives, outputs), terms of reference, timeframe, resources and ethics clearances required.
2. List of agreed key informants (national and subnational levels).
3. List of agreed focus group participant profiles/ characteristics for the work in the two districts.

4. Identification and provision of any additional data to supplement any gaps in mapping.
5. Ethics committee permissions.

This activity is largely focused on holding a meeting with a wider group of stakeholders to finalize the scoping and parameters of the review, using the mapping undertaken in Activity 1.2 as the basis. However, it is recommended that the national NTD program manager discuss the findings from Activity 1.2 with the program managers/focal points for PC from the two potential districts to be included in the in-depth review, before the stakeholder meeting, to:

- Share and test the findings from the mapping with them.
- Identify any gaps e.g. subpopulations that might not have been identified in the mapping e.g. people with a disability, nomadic population.
- Identify potential key informants at district level and community level (as appropriate).
- Identify 2-3 potential communities for inclusion in the review.
- Finalize the timeframe for the review. Ideally, the timeframe should provide for the draft report on the findings to be developed within 4-6 weeks of completion of Module 3 (see Module 4.1).

Stakeholder meeting to finalize review plan

This meeting should aim to get the necessary inputs for finalizing the review plan (see Activity 1.1). Hence, it is a way to get feedback and ownership for the scope of the review (aims, objectives, outputs), terms of reference, timeframe, resources and ethics approvals required.

Participants to the stakeholder meeting should include those involved in the initial meeting for scoping the review (see Activity 1.1). In addition, process organizers may wish to invite stakeholders from:

- other relevant parts of the health sector who have not initially been involved;

- any relevant academic and donor partners working on NTDs (if they have not already been involved);
- other government sectors (as appropriate given country and NTD context) including environment or public works for WASH concerns, education, women's affairs; and
- other agencies including non-government and civil society organizations, as well as any other donor or partner agencies for NTDs.

Consideration should be given to **how best to involve other agencies** and at what level (e.g. national and or district). For example, at national level the

agency responsible for WASH conditions might just be involved in a referral or advisory capacity, with direct participation by the district/local WASH agency. The stakeholder meeting provides an opportunity to identify other resources that might be used to support the review (financial and human resources, as well as access to data).

A key focus of the stakeholder meeting should be to review the findings from the mapping and identification of potential subpopulations who may be left behind. Activity 1.2 includes guidance on reviewing the data in Table 1.2.1 to identify the potential subpopulations who may be being left behind.

Decisions about additional data collection

The presentation of the data from Activity 1.2 should indicate data gaps and seek to test the findings about potential inequalities in PC coverage with stakeholders.

The guidance is designed to make best use of existing data on PC coverage and where available existing qualitative information. However, there is limited qualitative information about MDA/PC in many countries. **Equity and gender issues raised by stakeholders at the meeting** and **not identified through the mapping** of quantitative data (Activity 1.2) should be given specific attention as they may reflect gaps/limitations in the data and need further exploration as part of a qualitative exercise e.g. people with a disability due to NTD morbidity or areas with persistently low treatment coverage trends.

Where countries prefer to use an existing qualitative dataset and not collect additional qualitative data, then this dataset should be reviewed using the guidance at Module 3.1. Limited qualitative information may affect the specificity and or accuracy of knowledge about barriers in coverage and therefore the efficacy of any responses developed to address barriers. Therefore it is recommended that countries undertake some additional qualitative data collection every 3-4 years even where existing qualitative data is available (6,13–16) (17). Existing qualitative datasets/ studies might also be used to inform the mapping done at Activity 1.2.

The value of collecting additional information: pilot of guidance, Kaduna State, Nigeria

The COUNTDOWN work on gender, poverty and other social factors, disability, community attitudes and CDDs in Cameroon, Ghana, Liberia and Nigeria provides pre-existing source of important information about how such social factors shape access to PC. Despite this, the pilot of this guidance in Kaduna State, Nigeria included additional information through key informant interviews and focus groups (Module 3). Among the barriers identified, the additional information enabled researchers to identify that women were sometimes not receiving MDA if the community drug distributor was male; social norms made it difficult for a woman to accept MDA if the man of the household was not present at the time to engage with the male CDD. The research found that the selection process of CDDs influenced lack of access to PC because men were often in the role of selecting CDDs. Men often selected other men as community drug distributors because of gender bias, including the common perception that women were too weak to take on this task. Likewise, the research found that men who who were away from home working may also miss out on MDA. This additional research not only helped give greater specificity to knowledge of the barriers to PC in Nigeria but also begins to address an identified gap in knowledge about what happens in practice in countries with selection of CDDs and whether gender and power processes shape selection processes (17,21).

To **inform the decision about additional qualitative data collection at subnational level**, the existing qualitative data set should be reviewed in relation to Table 1.2.1 to identify:

- The **age of the data** i.e. when was the qualitative information collected? Have there been any major changes to the NTD program (nationally or within districts) and or within the health system since the qualitative information was collected?

- Is the existing qualitative information drawn from the same two districts as those proposed to be included in the full review? If not, **how different are the districts** in the current review from those included in the existing qualitative information/study? For example, differing overall years of schooling, rural compared to remote, no nomadic communities? If the districts are vastly different, then consideration should be given to undertaking some supplementary qualitative data collection in the 3-4 yearly review.

- **Is there enough information in the study to better explore any barriers** being experienced by potential subpopulations, and or how MDA works in practice including nomination of CDDs? If yes, can it be supplemented by analysis of the existing qualitative data? If no, consideration should be given to supplementing through either additional key informant interviews (particularly at district and community level) and or by 1-2 focus groups.

- **Will any additional ethical permissions** be required to use the data differently?

It is important to review the existing qualitative data at this stage in order to include any additional qualitative data collection activities to be included in the review plan, particularly where this has resource and or ethics implications.

Sensitization exercise

As indicated in the Cross-cutting Module, the assumption that MDA is equitable in design and hence in outcome and impact, needs to be explored through an assessment of the barriers and facilitators to ensure no one is being left behind for reasons that are unfair and avoidable. However the need for such a review is not always well accepted (28). This means that at the stakeholder meeting, some constituencies may ask why this review is being undertaken given that they assume the program is already equity- and gender-responsive. The meeting is an opportunity to increase awareness of the kinds of barriers that some subpopulations may face in accessing services and to clarify what key concepts such as gender equity mean. It is recommended that, to do this, organizers may wish to give a presentation highlighting the evidence base on types of barriers that can inhibit access to PC services (see Figure 4), as well as share case studies of the findings of these types of reviews in other contexts (case studies are forthcoming). The Cross-cutting Module could be used as the basis for developing the sensitization exercise with country adaptation to potential groups who might be experiencing barriers in access to PC. Alternatively Figure 4 which highlights potential barriers and facilitators that affect effective coverage of PC could be used as basis to stimulate discussion. It is also recommended that the review team involve the social and community mobilization team(s) from the Ministries of Health and Education (as appropriate) in designing this exercise and in the stakeholder meeting.

Ethical considerations

Ethical permissions/clearance must be obtained from the relevant government, partners and university bodies. It is recommended that the following standards are followed, in addition to others that may be mandated by national ethics review bodies:

- Ensuring compliance with cultural, community and administrative systems for engaging districts and communities/villages. For example, this will usually involve meeting with the relevant district authorities and following traditional administrative authority such as engaging village or community leaders to introduce and explain the pilot and processes involved (37). This will vary from country to country.

- Ensuring that all owners of the data/findings agree to its use for the purpose of reviewing effective coverage. For example, the quantitative step entails the use of existing data from routine monitoring for PC. In some situations, such as those with Indigenous communities, the data may be jointly owned by the government and Indigenous communities. This is likely to require a different and additional approval.

- Prior to all individual interviews and or focus group discussions, the purpose of the data collection, the process to be followed and how the data will be used must be explained to all potential participants. Field teams should give consideration to using both written and oral materials in providing this explanation. Also, the voluntary nature of participation should be stressed including the freedom to refuse to answer any question and or withdraw consent to participation at any time during the process.

- In order to protect participants from stigmatization and/or adverse consequences as a result of engagement in the process, information about the process should make it clear that all information will be de-identified. That is, no identifiable individual level-data will be shown and that all information will be treated confidentially and securely stored (physically and electronically).

- Verbal consents must be obtained from the interviewees and participants prior to interviews or focus groups.

- All key informant interviewee and focus group participants must participate on a voluntary basis. This needs to be re-stated prior to the interview or focus group.

- If interviews and or focus groups are to be recorded, photographed and or videoed, written consent must be obtained from all participants and data must be safely stored (taking into account the need for de-identification).

It is also recommended that the review process allow for feedback to participants in the qualitative research component, in particular to focus group participants, key informants and or local communities who are not part of the project stakeholder/advisory group. Most partners and academic institutions will have processes for ensuring feedback loops. This will be a requirement of ethics permissions, should be incorporated into the scoping of the review.

Checklist for Module 1

Now you have finished Module 1, review the checklist and identify if you are ready to undertake Module 2 and or any follow up action that needs to be taken:

Key issues	Yes/No/ Unknown	Comment including any follow up action
1. Have Activities 1.1-1.3 been completed?		
2. Is the review aligned and set up to inform ongoing M&E and the annual review process for NTDs in the country, including any planned evaluations of the program?		
3. Any gaps in available data disaggregated to subnational level for completing Table 1.2.1? If 'yes', have these gaps been addressed e.g. via Key Informant interviews or additional data from the national statistics agency and or is there a plan to address these gaps?		
4. Have two districts/sub national administrative units been identified for a more detailed review of effective coverage? Is there an agreed focal point in each district for the review process and have they been involved in Module 1, particularly in Activities 1.2-1.3?		
5. Did the stakeholder meeting (Activity 1.3) involve all relevant stakeholders including other sectors, civil society organizations and partners?		
6. Is there an agreed plan for the review including clear roles and responsibilities, timeframes, resources (financial and human) to be allocated and agreement about any ethical permissions required? Is there a single focal point for the review process e.g. PM for NTDs? Does the plan include resources for sub national meetings to discuss the findings and their implications, and enable community participation at these meetings?		
7. Will the review include collection and review of any qualitative data? If 'no', how will information on CDDs sub national and community perspectives be collected and reviewed?		

MODULE 2: SUBNATIONAL QUANTITATIVE DATA STEP

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Cross-cutting Module: Key term and concepts

Module 1	Module 2	Module 3	Module 4
• National level Preparatory and scoping steps - with subnational imput	• Quantitative data step - using subnational data from 2 districts	• Qualitative step - using national and subnational data from 2 districts	• Reporting and making use of findings - national and subnational

Following the work done at national level, the review plan can include subnational work in two or more locations as proxies. The **aim** of this step is to undertake collation and review of routinely collected quantitative data for PC in the two districts and related communities to better identify within district differences and subpopulations who may be being left behind.

It involves:

1. **Activity 2.1** – Subnational quantitative data collation

2. **Activity 2.2** – Review and analysis of subnational quantitative data

ACTIVITY 2.1
SUBNATIONAL QUANTITATIVE DATA COLLATION

This activity comprises collating sex- and age-disaggregated data from routine PC monitoring in the 2 or more districts/LGAs to better identify potential availability, accessibility, acceptability and coverage issues requiring more in-depth analysis using the Tanahashi framework for effective coverage outlined at **Figure 3** (see Introduction). It builds on the outputs of Module 1, and seeks to advance the inequity profile developed as part of Activity 1.2.

The **output(s)** from this activity are completed **Tables 2.1.1-2.1.2** which provide the template for recording the existing quantitative data aligned with the effective coverage framework (see **Figure 3**) at district and peripheral levels. The template also indicates the potential equity issue(s) to be considered and available sources of data.

- Table 2.1.1 is to be completed for the two districts where PC coverage is to be reviewed and includes district numbers and averages. It would be completed twice where two districts are the focus of the review; and

- Table 2.1.2 is to be completed for each of the 2-3 communities within the selected district where focus groups may be held, if this is part of the exercise. It would be completed 4-6 times depending on how many communities in each district are to be reviewed.

Both templates are to be completed as a desk-based exercise with some follow up through (a) Ministry of Health, districts and partners and or (b) KI interviews and or focus group discussions (if undertaken as part of Module 3), where data appears to be missing or incomplete (if the additional qualitative data collection step is being undertaken).

Table 2.1.1 For collation of district level quantitative data on effective coverage

A separate form needs to be completed for each district.

Indicator	Source(s)	Potential GER issues to explore in the qualitative work	Data – if not available and or of variable quality indicate why
Availability			
Total number of people (age and sex disaggregated[3]) in the district requiring treatment – taking numbers from the community **and or** school enrolled populations depending on the NTDs.	Register and or district/national annual work plan.	This is descriptive information that will help to contextualize the 2-3 communities being reviewed in relation to the rest of the district i.e. do these communities form a large percentage of the treatment population within the district.	
Total numbers (age and sex disaggregated) of CDDs (including teachers who are CDDs) available to the community and or school enrolled populations within the district. This includes looking at the ratio of trained teachers who are CDDs to number of children to be treated (where appropriate).		This is descriptive information that helps contextualize the CDD numbers for the 2 districts being reviewed. For example, if one district has more numbers of CDDs compared to the other district being reviewed and yet has the same population requiring treatment, then this might need attention or highlight a challenge with availability.	
Estimated level of funding per CDD for the district including financial as well as non-financial remuneration e.g. provision of a motorcycle to reach some communities or a small payment to cover costs.	*This information may only be available from KI interviews.*	This should be explored as part of the qualitative component in terms of (i) whether CDDs are actually receiving the allocated funding and (ii) whether it is a fair distribution if they have to serve a population spread over a larger geographic area than CDDs serving other communities. It may also require capturing in-kind support such as provision of bicycles and or mobile phone card credits rather than funding.	
Number of tablets received at district level	Inventory of PC medicines in the country see Joint reporting form for PC at country level	This is descriptive information that helps to provide a picture of whether there are challenges with the supply-side of medicine distribution that need to be explored in the KI interviews - both national and district level – and in the focus group with CDDs.	
Number of tablets distributed to 2-3 communities being reviewed			
Number of tablets reported to be used in treatment rounds for 2-3 communities being reviewed			
Number of tablets wasted due to expiry, poor storage conditions etc.			

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3   For age-disaggregation for PCT that is not limited to SAC, please use the three age groups in the Manual for Monitoring of PCT: 0-4 years, 5-14 years and >15 years.

Indicator	Source(s)	Potential GER issues to explore in the qualitative work	Data – if not available and or of variable quality indicate why
Accessibility			
District average for individuals requiring treatment (disaggregated by age and sex) in the endemic community who received: • at least 1 treatment of PC; or • for all diseases targeted for treatment in that community/area/enrolled school population.	Treatment registers National NTD Coordinators District NTD Coordinators	This shows if there are differences between the district average for individuals requiring and receiving treatment when compared to the 2-3 communities within the district being reviewed. Issues to look at are differences in: overall numbers for the treatment; males and females; and different age groups. For example, do any of the communities being reviewed have lower numbers requiring and receiving treatment compared to the district average, is it very different for men or for women and or do adolescents appear to be missing treatment? This simply serves as a proxy for further exploration in the qualitative component.	
District average of individuals requiring treatment (disaggregated by age and sex) in the endemic community who **did not** receive MDA/PC for all reasons other than refusal of treatment.	Data summaries – national and or district National NTD Coordinators District NTD Coordinators	This includes all individuals coded as non-treatment (pregnancy, lactation, sickness, under age/height, absent or other) **but excludes** those who were coded as refusing treatment (these numbers are included under acceptability). The district averages for non-treatment (excluding refusal) should be compared to the numbers for the people in the 2-3 communities being reviewed. How are the communities the same or different e.g. higher rates of men not present for treatment, and or greater numbers of women who are pregnant? This then needs to be explored as part of the qualitative component, particularly in the focus groups.	
District average of individuals requiring treatment (disaggregated by age and sex) who **did not** receive MDA/PC shown by all reason(s) except for refusal.		Apart from refusal (see acceptability) this will provide a **breakdown by reason for non-treatment** and an indicative idea of why people in the district are not usually receiving MDA. This can then be compared to the data for the 2-3 communities to be reviewed to see how similar or different the reasons are, and then specific issues explored in the focus groups. For example, are there higher numbers of people in the 2-3 communities being reviewed who are sick and under age/height and so unable to receive treatment compared to the district average? Or are there more people absent or many categorized as other? This then needs to be explored as part of the qualitative component, particularly in the focus groups.	

MODULE 2

Indicator	Source(s)	Potential GER issues to explore in the qualitative work	Data – if not available and or of variable quality indicate why
Distance from main treatment or distribution points for the district: • Communities • Schools • Health clinic	May need to be generated by national or district level health authorities. Also for follow up in KI interviews.	This information should be used to look at whether the CDDs in the 2-3 communities being reviewed have to travel longer distances than others within a district e.g. from their own community to obtain the medicine, and or to deliver PC etc. Differences with other communities then need to be explored through the qualitative component particularly the KI interviews at district level in terms of how the program supports CDDs to get around their community, and in the focus groups) particularly the ones for CDDs.	
Number of nomadic communities within the district and if considered part of the treatment population in the 2-3 communities being reviewed.	Census and DHS Coverage data	This information should also be used to look at whether the CDDs in the 2-3 communities being reviewed have to travel longer distances than others within a district in order to reach nomadic communities and or if arrangements are in place to support CDDs to obtain the medicine and distribute it to nomadic communities. While it is important to look at 2 treatment rounds, what is more important is to find whether the nomadic communities receive the full PC package as per the endemicity of that district. Some districts require 1/year treatment, others 2/year treatment. NB: this information may not be available quantitatively but have to be explored in Module 3. However, where it is available: Where nomadic communities are part of the treatment population, this information should be used to look at whether the CDDs in the 2-3 communities being reviewed then this issue needs to be explored in the qualitative component in terms of (i) how it affects workforce capacity to provide treatment and (ii) accessibility for nomadic communities who may be missing out. It also flags the need to include nomadic communities in the focus group discussions.	

Indicator	Source(s)	Potential GER issues to explore in the qualitative work	Data – if not available and or of variable quality indicate why
Acceptability			
Total numbers (age and sex disaggregated) of CDDs available to the community/school enrolled population.	Coverage data	The age, sex and origin of the CDD may affect acceptability e.g. if there is a preference for female CDDs for female patients in some communities but the CDDs are mainly males, this may affect the acceptability and hence uptake of treatment i.e. females may not be willing or allowed to receive treatment from male CDDs.	Collected as part of availability – see above.
District average of individuals requiring treatment (disaggregated by age and sex) in the endemic community/area who were present and **not treated** but only including those whose non-treatment was coded as **refusing** MDA/PC.		This includes only the totals for individuals coded as non-treatment because they **refused treatment** (other reasons for non-treatment are included under accessibility – see above). The district average for refusing treatment should be compared to the numbers for the people in the 2-3 communities being reviewed. How are the communities the same or different e.g. higher rates of men refusing treatment or higher overall numbers of people refusing? This then needs to be explored as part of the qualitative component, particularly in the focus groups. This will show age and sex related differences in relation to those refusing receiving treatment and begin to provide an indication of potential equity issues to be explored about the acceptability of PC among some members of the community.	
Effective coverage			
District average for individuals requiring treatment (disaggregated by age and sex) in the endemic community/area/school enrolled population who received and swallowed the medicine.		Effective coverage shows difference between expected coverage and actual/effective coverage. Here the district average should be compared to the 2-3 communities being reviewed to see if there are higher or lower numbers for effective coverage. Issues to look at are differences in: overall numbers for receiving treatment; males and females; and different age groups.	

MODULE 2

Table 2.1.2 For collation of peripheral/community level quantitative data on effective coverage

A separate form is to be completed for each community being reviewed.

Indicator	Source(s)	Potential GER issues to explore in the qualitative work	Data – if not available and or of variable quality indicate why
Availability			
Total number of people (age and sex disaggregated) in the community/area and or schools requiring PC treatment.	Register and or district/ national annual work plan.	This is descriptive information that helps contextualize the 2-3 communities being reviewed in relation to the rest of the district i.e. do these communities form a large percentage of the treatment population.	
Total numbers (age and sex disaggregated) of CDDs (including teachers) available to deliver PC in the community/ area and or schools.		This is descriptive information that helps contextualize the CDD numbers for the 2-3 communities being reviewed compared to the district figures.	
Number of tablets reported to be received at community level for the most recent MDA.	District NTD Coordinator Store inventory/ Stores officer	This is descriptive information that helps to provide a picture of whether there are challenges with the supply-side of medicine distribution (at national, district and or community levels) that need to be explored in the KI interviews - both national and district level – and in the focus group with CDDs. At the community level, it might be that deferral of a treatment round results in the medicines having to be stored and or going past their expiry date.	
Number of tablets reported to be distributed in treatment rounds at community level.			
Number of tablets reported by CDDs wasted due to expiry, poor storage conditions etc.,			

Indicator	Source(s)	Potential GER issues to explore in the qualitative work	Data – if not available and or of variable quality indicate why
Accessibility			
Total number of individuals requiring treatment (disaggregated by age and sex) in the endemic community who received: • at least 1 treatment of PC; or • for all diseases targeted for treatment in that community/area/school population	Treatment registers National NTD Coordinators District NTD Coordinators	This simply shows if there are differences between males and females for different age groups e.g. higher numbers of adult males receiving treatment than adult women. It simply serves as a proxy.	
Total number of individuals requiring treatment (disaggregated by age and sex) in the endemic community/area/school who **did not** receive MDA/PC for all reasons other than refusal of treatment.	Data summaries – national and or district National NTD Coordinators District NTD Coordinators	This includes all individuals coded as non-treatment (pregnancy, lactation, sickness, under age/height, absent or other) **but excludes** those who were coded as refusing treatment (these numbers are included under acceptability). This will show age and sex related differences in not receiving treatment and begin to provide an indication of potential equity differences between communities and the district average.	
Total number of individuals requiring treatment (disaggregated by age and sex) in the endemic community/area/school who **did not** receive MDA/PC shown by all reason(s) except for refusal.		Apart from refusal (see acceptability) this will provide **breakdown by reason for non-treatment** and an indicative idea of why people in the 2-3 communities being reviewed are not receiving MDA. These can then be further explored particularly in the focus groups. It will be particularly important to explore reasons for receiving but not taking the tablets including because of concerns about side-effects, and or that the medicine cannot be taken during pregnancy.	

Indicator	Source(s)	Potential GER issues to explore in the qualitative work	Data – if not available and or of variable quality indicate why
Acceptability			
Total numbers (age and sex disaggregated) of CDDs available to the community/school enrolled population.	Coverage data	The age, sex and origin of the CDD may affect acceptability e.g. if there is a preference for women CDDs for female patients in some communities but the CDDs are mainly men, this may affect the acceptability and hence uptake of treatment i.e. women may not be willing or allowed to receive treatment from male CDDs.	Collected as part of availability – see above.
Total number of individuals requiring treatment (disaggregated by age and sex) in the endemic community/area/school who were present and **not treated** but only those where non-treatment was coded as **refusing** MDA/PC.		This includes only the totals for individuals coded as non-treatment because they **refused treatment** (other reasons for non-treatment are included under accessibility – see above). This then needs to be compared to the district average and the other communities being reviewed and explored as part of the qualitative component, particularly in the focus groups. For example, teasing out is it because of health values and beliefs, concerns about side-effects of the medication etc.	
Effective coverage			
Total number of individuals requiring treatment (disaggregated by age and sex) in the endemic community/area/school who received and swallowed the medicine.		Effective coverage shows difference between expected coverage and actual/effective coverage. This will need to be compared to the district average and the other communities being reviewed. Issues to look at are differences in effective coverage by: overall numbers for receiving treatment; males and females; and different age groups.	

ACTIVITY 2.2   REVIEW AND ANALYSIS OF SUBNATIONAL QUANTITATIVE DATA

This step might be undertaken by the review team including district focal points and relevant stakeholders or as part of a wider stakeholder meeting. All data should be collated and summarized using templates/forms at 2.1.1-2.1.2 as well as the initial mapping of inequalities (Table 1.2.1). This meeting needs to be held before any qualitative data collation or additional qualitative data collection (key informant interviews and or focus groups) begins and used to:

a. review/confirm the potential list of key informants to be interviewed, particularly at district and or community level and identifying if any other type of key informant needs to be included;

b. review/confirm the communities within the district that might serve best to explore equity and gender issues affecting PC coverage including the types of participants based on the subpopulations that might be left behind (nomadic communities, people with a disability) and composition of focus groups; and

c. to revise the qualitative tools (interview and focus group questions) to better these findings.

The data in Tables 2.1.1-2.1.2 should be reviewed for each district and their related communities with attention to:

1. Within district **differences between the communities reviewed and the district average or numbers:**
   ° Those who were present but not receiving MDA for all reasons other than **refusal of treatment** (age and sex disaggregated) and broken down by reasons for non-treatment.
   ° Those who were present but whose non-treatment was coded as **refusing MDA** (age and sex disaggregated).
   ° Population who received and swallowed the medicine (age and sex disaggregated)
   ° CDDs (age and sex disaggregated) available to the community/school enrolled population
   ° Number of tablets wasted due to expiry or poor storage conditions.

2. Any notable differences within the district **between the communities** reviewed including:
   ° wider gaps in coverage – non-treatment and or refusals
   ° greater differences between males and females or age-groups
   ° drug wastage
   ° availability of CDDs

3. Other questions/issues to consider include:
   ° Are any of the communities more remote/inaccessible than others?
   ° Nomadic communities – do any or all of the communities have nomadic populations?
   ° Gaps in the data for Tables 2.1.1-2.1.2

This data should also be compared to the preliminary mapping of inequalities (see Table 1.2.1) to identify if it is consistent with the earlier findings including:

- lower levels of coverage within the district and
- potential sub-populations who may be disadvantaged e.g. nomadic communities

The review of the data should then be considered in terms of implications for the proposed approach to qualitative data at subnational level (see Module 3) including whether:

- additional data collection is required, particularly where the intention is to use an existing qualitative data set
- the selection of key informants and or composition of focus groups needs revision?

This may mean that the review plan needs revising, particularly where there are resource requirements e.g. decision to include some KI interviews where originally no additional qualitative data collection was planned.

Checklist for Module 2

Now you have finished Module 2, review the checklist and identify if you are ready to undertake Module 3 and or any follow up action that needs to be taken:

Key issues	Yes/No/ Unknown	Comment including any follow up action
1. Have Activities 2.1-2.2 been completed?		
2. Are there any gaps in the data at sub national level in either district and or related communities in completing Tables 2.1.1-2.1.2? Can these gaps be addressed through follow up quantitative data collection or through KI interviews and or focus group discussions (Module 3)?		
3. Have the findings as per Tables 2.1.1-2.1.2 been reviewed by relevant stakeholders in terms of: gaps in the data; differences between communities; comparison to the inequality profile (Table 1.2.1); and any additional issues that need to be considered as part of qualitative data collection e.g. other sub population groups identified that are experiencing barriers? Did the review involve the focal points from the two districts? If there has been no review of the findings by the group, will this take place before any qualitative data collection begins?		
4. Are all arrangements in place for qualitative data collection including any administrative arrangements, checking of suitability for travel to area, and or ethical permissions/clearances, and or any additional resources due to changes to Module 3?		

MODULE 3: SUBNATIONAL QUALITATIVE STEP

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Cross-cutting Module: Key term and concepts

Module 1	Module 2	Module 3	Module 4
• National level Preparatory and scoping steps - with subnational imput	• Quantitative data step - using subnational data from 2 districts	• Qualitative step - using national and subnational data from 2 districts	• Reporting and making use of findings - national and subnational

The **aim** of this module is to support collation/collection and analysis of (existing or new) qualitative data in order to:

1. Identify the barriers and facilitating factors to effective coverage with preventive chemotherapy perceived by different subpopulations (poorer or more rural populations, men or women, older people, people with a disability) or communities, and characterize these in relation to availability, accessibility, acceptability, contact and effective coverage using the Tanahashi framework.

2. Identify the perceptions of district health managers, providers and community drug/medicine distributors regarding why some subpopulations and communities may have lower rates of coverage for PC, considering both the ways in which the program is delivered (supply-side issues) and demand-side issues.

3. Highlight opportunities to improve equity and gender equity in the delivery of PC in the district for improved coverage for all groups in the intended population.

The **output** from this step is collation of this data/ information using the framework for effective coverage to:

- review delivery and implementation of PC at district and community levels with a view to redesign where necessary for improved coverage within the district; and
- integrate consideration of equity, gender and human rights issues into national programming for PC (as part of the wider NTDs response) for improved coverage nationally – ensuring no one is left behind.

This module is comprised of:

- **Activity 3.1** Using existing Subnational Qualitative Data
- **Activity 3.2** Additional Subnational Qualitative Data – Key Informant Interviews
- **Activity 3.3** Additional Subnational Qualitative Data – Focus Groups
- **Activity 3.4** Compiling the results from the subnational qualitative assessments

ACTIVITY 3.1
USING EXISTING SUBNATIONAL QUALITATIVE DATA

Existing qualitative data about barriers to PC coverage

Some countries have **existing qualitative data about PC coverage** that they may elect to use to review effective coverage together with the quantitative data.

Example themes arising from existing identified qualitative studies of PC are featured in the below box.

Examples of findings from existing qualitative studies on PC related to barriers

- **Supply chain issues** – treatment rounds might be delayed or missed due to delays or challenges with production, shipping, customs clearance and or miscellaneous in-country issues in getting the drugs distributed such as the weather, in-country transport issues and or lack of resources or coordination and or there may be problems with the quality of the medicines (14,38,39).

- **Implementation issues** including communities being skeptical about the manner in which MDA is implemented e.g. limited attempts by implementers to share information and mobilize residents and or that CDDs are not trained health professionals (16).

- **Different priorities** – communities are not always convinced that MDA is a priority health issue, particularly where: there are low levels of severe morbidity in the community; they only associate severe morbidity with certain conditions e.g. elephantitis; or where they consider they have more pressing health problems e.g. malaria, diarrhea. There is also concern that medicine is only part of the solution when improved WASH facilities would make a significant difference also (13,15,40).

- **Inequalities in coverage due to occupation** and or timing of CDD visits e.g. people are either at work in the fields or fishing and or working their gardens. Therefore they may not be close to the distribution point when the CDD visits (40). This may affect men more than women if they are away from home due to occupational roles which extend for long periods, and males may be more distrustful of treatment (6,13,40).

- **Inequalities in coverage of pregnant or lactating women** due to two reasons. First, CDDs may be unaware of which medicines are safe for pregnant and breastfeeding women, and so may not administer drugs which can be given in some circumstances. Second and linked to this, some women may several rounds of MDA because at the next round they are breastfeeding or pregnant. In some countries, this issue is addressed through mop-ups. It highlights however a need for community-level training in drug distribution to include gender-specific issues/guidelines for treating pregnant and breastfeeding women. Programs may also be missing young women who are not in school and therefore not receiving PC as part of school based programs (6).

Table 3.1.1 is for the collation and analysis of qualitative data based on the five dimensions of the Tanahashi framework for effective coverage, specifically availability, accessibility, acceptability and contact and effective coverage. Examples of the types of barriers and facilitating factors for MDA for PC are included to assist the team in reviewing data. It can be used to review existing qualitative data on MDA and PC if appropriate. In the case that existing qualitative data is used, the below steps can be undertaken to incorporate it into the review. However, the **existing qualitative data** should have been reviewed previously (see Activity 1.3) to ensure it is recent, comparable (i.e. the same districts or those with a similar profile) and detailed enough to generate useful information about barriers and facilitators in effective coverage at subnational level.

➔ **Step 1:** review and an analyze the findings from Activities 1.2, 2.1-2.2 (see completed Tables 1.2.1 and 2.1.1-2.1.2) to identify whether:

- The findings about subpopulations who may be being left behind largely consistent with the existing qualitative information about barriers and subpopulations?

- Identify if any gaps in the existing information about vulnerable subpopulations, and or how MDA works in practice including nomination of CDDs can be supplemented by analysis of the existing qualitative data? If no, consideration should be given to supplementing through either additional key informant interviews (particularly at district and community level) and or by 1-2 focus groups.

➔ **Step 2:** review the existing qualitative data set (and any supplementary qualitative data collected) and use **Table 3.1.1** (see below) to collate findings for analysis.

Table 3.1.1 Dimensions to be explored to identify barriers and facilitating factors to effective coverage for preventive chemotherapy

Dimension	Types of barriers and facilitating factors – key areas for preventive chemotherapy or MDA
Availability	Resources are available for delivering the medicines needed for preventive chemotherapy and are sufficient, including: • Availability of medicines (drugs) that are safe and of high quality i.e. meets the pharmacopoeial quality specifications, within date and at the right time i.e. arrive and are available before the treatment round is due to begin. • Availability of suitable drugs e.g. PZQ syrup for children who are unable to swallow tablets. • Availability of resources for medicines to reach all districts and communities e.g. resources for in-country land transport. • Availability of resources to support CDDs to reach all communities effectively e.g. transport for CDDs to get around their communities.
Accessibility	*Geographic:* • CDDs have to travel long-distances within the communities they serve to reach all groups and have limited means of transport as well as specific time periods (before rainy season starts) when transport is feasible to some locations. There may also be security challenges which affect when CDDs can reach communities and how often. • Children have to walk a long way to school and in bad weather do not attend when a treatment round may be scheduled. • People with a disability or impairment (due to NTD condition or otherwise) might not be able to get to treatment and their own and or other's perceptions might mean that their participation is not prioritized. *Financial:* • Indirect costs to community members of lost time at work e.g. having to be at home when the medicine is distributed, having to have food available to take with the medicine and or lost time at work due to reaction to the medicine e.g. vomiting, diarrhea etc. • Direct costs to CDDs in coordinating with community members and getting to the points of distribution e.g. transport costs, mobile phone costs, this may limit the times that medicines are distributed. • Indirect costs to CDDs in distributing the medicines including time away from home, this may limit the times that medicines are distributed. *Organizational and informational:* • Insufficient information, mobilization and community engagement in advance of treatment rounds. • Attention schedules/opening times for treatment rounds that mean some subpopulations are more able to access than others. • Systems to schedule treatment rounds with communities including – out of working hours and or during the harvest season so that food is available. • Scheduling visits for medicine distribution to places where people work including their gardens and including nomadic communities • Appropriate information delivered in appropriate formats about the medicines, their purpose, possible side effects etc.

Dimension	Types of barriers and facilitating factors – key areas for preventive chemotherapy or MDA
Acceptability	• Selection process for CDDs – ideally, they should be selected from and by the community but in some instances, they might be nominated by a health professional. or come from outside the selected community where it is not possible to find a CDD with high enough literacy from within the community. • Cultural and other beliefs e.g. acceptability of taking medicine without a diagnosis of need for this specific medicine and or the process for assessing dosage and or who requires the medicine e.g. people with lymphedema might not be seen to benefit and therefore excluded from MDA either by CDD or the community or the individual themselves. • Gender norms, roles, and relations and gender-responsiveness of services (including same-sex CDDs where culturally appropriate). • Age-appropriateness of services (e.g., adolescent-friendly). • Perceptions of priority of the need for PC compared to other health priorities in the community e.g. more pressing health needs and the morbidity from NTDs not obvious e.g. few people with lymphedema or hydrocele. • Perceptions about the benefits of medicine compared to vector control e.g. insecticide treated mosquito nets and or provision of improved water and sanitation. • Concern about side effects and or adverse events. • Perceptions about who needs to be treated e.g. people with an impairment or disability may not be able to get to treatment and or it may be seen that treatment is not necessary if they already have morbidity from an NTD. • Lack of trust in the health services, services that are funded from outside the country particularly with the aim of distributing medicines e.g. communities linking MDA to birth control medicines. • Perceptions of service quality e.g. administration and delivery by community members rather than health professionals. • Discrimination by providers (e.g., based on community social hierarchies, ethnicity, marital status, religion, caste, sexual orientation). • Gender-linked consequences for female CDDs e.g. where they have to work during the evenings and or are away from their home for a long period of time (e.g., reprimands by husband or mother in law for time away from household/caretaking roles, exposure to abuse).
Contact	• Actual contact between the CDDs and individuals in the communities, similar to "utilization".
Effective coverage	• Barriers in ***treatment* adherence** (due to unclear instructions particularly for pregnant and lactating women, unsuitability of drug format e.g. children who are unable to swallow tablets, poor patient-provider relationship, adverse social conditions and gender roles/relations preventing follow-up by the patient e.g. head of household won't let household members take the tablets). • Barriers in ***provider compliance*** which can be related to: low levels of training e.g. in understanding which medicines pregnant and lactating women can be given; lack of supportive system requirements including lack of resources to meet direct costs incurred by CDDs in getting to the points of distribution e.g. transport and phone costs, this may limit the times that medicines are distributed; indirect costs to CDDs in distributing the medicines including time away from home, this may limit the times that medicines are distributed; accountability issues in terms of monitoring and evaluation due to weak support and or lack of clarity about the CDDs role i.e. the enumerator for the census believes they should be delivering the medicines not the CDD and do not turn up or provide the correct information for the CDD to accurately record treatment figures; and or lack of support from health professionals within the community and or wider district. • Barriers in ***diagnostic accuracy*** e.g. the poles used for determining treatment dosage by height do not make provision for measuring individuals with physical disabilities, nor is there clear guidance to CDDs on how to address the issue. This can affects the accuracy of dosage and hence effectiveness. • Barriers in ***quality of drugs*** e.g. where counterfeit medicines have found their way into legitimate distribution channels and there have been adverse events creating concerns around safety and acceptability of the drugs in the communities with affected individuals.

➡ **Step 3:** when the findings using qualitative data have been collated using Table 3.1.1 go to Module 3.4 for guidance on next steps.

ACTIVITY 3.2   ADDITIONAL SUBNATIONAL QUALITATIVE DATA COLLECTION - KEY INFORMANT INTERVIEWS

This activity provides guidance for collection of additional qualitative data using **key informant interviews** including the composition, organizational details, the program and questions/script.

The **aim** of this step is to support collection and analysis of data from the interviews to:

1. Identify the barriers and facilitating factors to effective coverage in PC.
2. Identify the perceptions of district health managers, providers and community drug/medicine distributors about different levels of coverage.

3. Highlight opportunities to improve equity and gender equity in the delivery of PC in the district for improved coverage for all groups in the intended population.

The **output** from this step is completion of Table 3.1.1 to collate and report the findings. **No qualitative work should commence until ethics clearance has been given** (see Activity 1.3). Most importantly all data must be de-identified so that first and foremost nobody can be identified from the findings.

Key informants

It is recommended that interviews are conducted at national and district levels including program managers/focal points/those responsible for:

- PC or MDA and/or the NTDs covered by PC;
- health facility and public health or primary care (i.e. the person responsible for providing care at the first level of entry in the health system) including anyone responsible for working with other sectors such as WASH;
- drug supply and distribution;
- human resources for health;
- other sectors specifically education, water and sanitation, the ministry for women and social affairs, and others as relevant e.g. environment, agriculture;
- community drug distributors (teachers and community members);
- a donor agency for MDA; and
- a relevant and active NGO for MDA.

The list of key informants to be interviewed is as follows:

National Level
- One program manager from the MoH responsible for either Mass Drug Administration and or each of the program managers for the NTDs covered in the country, depending on the structure (1-5 people potentially).

- WHO Representative of the concerned WHO Country Office given their responsibility for processing the Joint Request for Selected PC Medicines, submission of the Joint Reporting Form and Epidemiological data reporting form, all of which constitute the Joint Application Package (JAP).
- One program manager responsible for the joint request for selected PC medicines from the MoH.
- One program manager responsible for human resources for health including management of the community health workers and or community drug distributors from the MoH. This might be the program manager for primary care.
- One program manager responsible for public health and or wider environmental health issues from the MoH.
- One donor representative (as relevant).
- One NGO (e.g. Helen Kelleher International).

District Level
- One district program manager for MDA/PC/NTDs.
- Two health facility managers for the district in a part of the district that has worse coverage for PC and/or higher overarching rates of prevalence of NTDs.
- One public health manager for the district (whoever is responsible for wider environmental health issues including WASH).

- One representative responsible for handling drug distribution/medicines management across the district.
- One representative from the Ministry of Education (MoE) at district level who is involved in school health related activities, in particular for PC.
- One representative from the district level government agency responsible for water and sanitation.
- One representative from the district level agency responsible for women's affairs.
- One-six community drug distributors (1 x female CDD from rural/remote/ disadvantaged areas and or peripheral urban settlement communities and 1 x male CDD from rural/remote/ disadvantaged areas and or peripheral urban settlement communities). NB: where facility based MDA is used, then suggest that only 2-3 CDDs for household distribution are interviewed and the remaining 2-3 CDDs are those who distribute to a facility based setting.

- One-three teachers at schools where MDA is delivered (rural/remote and or urban communities, with attention given to disadvantaged areas and/or areas with highest coverage gaps and disease prevalence).

➡ **Step 1:** This list may require adaptation to country context in terms of the structure of administrative units, how the NTD program is designed and delivered within a country, and how government agencies are structured. Where funds are limited, the suggested list provides a guide to ensuring inputs from a minimum level of stakeholders relevant to assessing effective coverage in PC. Use the findings from completed Modules 1 and 2 (see Activities 1.2-3 and 2.2) to inform any adaptation. It should be noted that any adaptations should still adhere to the ethics-related principles and approaches adopted for the review (see Activity 1.3).

Key Informant Interview Script and questions

➡ **Step 2:** Review and adapt script and questions to the country context as appropriate. When adapting or changing specific questions consideration needs to be given to whether changes make the question more closed, too leading and or too negative.

➡ **Step 3:** Undertake the KI interviews including recording the interviews as possible.

Thank you for agreeing to talk with me, and for your participation in this project. I anticipate the interview will last about 60 minutes, and appreciate any information you can provide. This interview is important for the success of this assessment, and it will serve to enhance our understanding of as well as your perception of the effectiveness of coverage of preventive chemotherapy in your country/district/community. Your answers are completely confidential and will be coded and recorded without names. Although your responses will only be reported as part of a group, it is helpful for accuracy to record your responses. Is it okay if I tape record this interview?

I understand that you work in (PROVIDED BY … FOR EACH KEY INFORMANT). Please consider your particular institution and level of coverage of your work (national, district, community/peripheral) when answering the interview questions.

a. What is your role in serving the health needs of the population in this area? How does this relate to the NTD program?

b. How would you rate the overall access to quality health care in your country/ district/community and program/geographical area of responsibility? Would you say excellent, good, fair or poor? Why?

Questions ONLY for national level KIs and district level MoH KIs. To be asked after questions (a) and (b). For ALL other KIs continue onto question (h) – next box

c. What are the main factors (barriers and or facilitators) affecting the availability of medicines for treatment rounds of preventive chemotherapy? (Probes: the Joint Request process, in-country factors such as weather and transport, lack of effective communication, mobilization issues)?

d. What material resources are available for the distribution of medicines for preventive chemotherapy in your country/district/community? (Probe for: transport of the medicines to districts, sufficiency of resources.)

e. What are the financial resources available for the distribution of medicines for preventive chemotherapy in your country/district/community? (Probe for: funds for CDDs to deliver, sufficiency of resources.)

f. What suggestions would you have to improve the **availability** of medicines for treatment rounds of preventive chemotherapy, specifically for those subpopulations and communities at district level who might be missing out? (Probe for: timing and seasonal variations that affect MDA, nomadic communities, people with disabilities who cannot make it to MDA due to transport issues?

g. What issues are there in ensuring PC is linked with other components of the NTDs response (e.g. vector control, WASH), so as to ensure an integrated approach to NTDs prevention and control in a way that it is most effective in reducing prevalence and in reducing inequities?

For ALL KIs

h. How are community drug distributors/teachers identified, appointed, and trained in your country/district/local area? (Probe for: the process of selection including community involvement, who selects (fairness), gender consideration/preferences in relation to performance, CDD availability considerations and turn out rate of CDDs)

i. What kinds of support do these community drug distributors/teachers get? (Probe for: training, transport, incentives, and supervision)

j. What are the reasons CDDs leave the program? (Probe for: gender issues, lack of recognition and recompense for what is required, other opportunities)

MODULE 3

k. What do you believe are the main barriers and facilitating factors to access to: (a) preventive chemotherapy in your country/district/community/school; and (b) health services more generally? What are the main reasons people/some groups of people don't receive or accept preventive chemotherapy? (Probe for: medicine supply issues, limited resources for CDDs, the sex of the CDD, limited use of health communication and mobilization efforts to get communities engaged). NB: This question might need to be modified for KIs who are CDDs or teachers as CDDs as they may use different terminology i.e. stick medicine rather than preventive chemotherapy.

l. What are the specific gender or cultural norms, roles and relations that would influence who is able to access PC and who does not? For example, men are away working when the CDDs come, women have to ask permission from men to accept the PC, and or women with high fertility rates (no spacing between births)?

m. Which groups in the community do you think are not covered - which people in which communities don't get access to preventive chemotherapy? (Probe for: males or females specific age-groups i.e. adolescent boys, the poor, people with certain occupations, people with lower levels of education, children not in school, people living in rural or remote areas, ethnic minorities).

n. Why do you think these groups might not be covered? (Probe for: the times and or seasons when the treatment round is held, distance from the treatment points for some people, because they are ill and don't want to take the medicine, women who are pregnant or lactating and so the CDDs do not provide the medicines to them).

o. Are there people in this community who refuse treatment during MDA/MAM rounds? Which people in the community refuse treatment during MDA/MAM rounds? (Probe for: males or females, specific age-groups i.e. adolescent boys, economic status, people with lower levels of education, ethnic minorities, distrust, ethnic background of CDDs, illness as an excuse)

p. Why do people in these groups refuse treatment? (Probe for: traditional beliefs, cultural beliefs, concern about harm from taking the medication, religious beliefs, belief that there is no need because everybody looks healthy, they don't agree with the approach used for delivery of the medicine, lack of trust in the health system?

Reporting on the key informant interviews

➜ **Step 4:** It is recommended that **Table 3.1.1** (see Activity 3.1) be used for collation and reporting of data from the KI interviews as it is aligned with the framework for effective coverage. As indicated previously, all data should be de-identified, so that no individual can be identified from the interview transcripts and or findings.

ACTIVITY 3.3   ADDITIONAL SUBNATIONAL QUALITATIVE DATA COLLECTION – FOCUS GROUP DISCUSSIONS

This module provides guidance for collection of additional qualitative data using **focus group discussions** including the composition, organizational details, the program and questions/script.

The **aim** of this step is to support collection and analysis of data from the interviews to:

1. Identify the barriers and facilitating factors to effective coverage in PC.
2. Identify the perceptions of communities and CDDs about PC.
3. Highlight opportunities to improve equity and gender equity in the delivery of PC in the district for improved coverage for all groups in the intended population.

The **output** from this step is completion of Table 3.3.1 – one for the focus groups with CDDs and one for focus groups with community members. **No qualitative work should commence until ethics clearance has been given** (see Activity 1.3).

Most importantly all data must be de-identified so that first and foremost nobody can be identified from the findings. Where there is participation by people with an intellectual impairment, consent forms need to be adapted to meet their needs.

Timing: Ideally the focus groups should be held after the completion of the quantitative analysis and any key informant interviews. This is because certain issues will arise during the quantitative analysis and KI interviews that will lead to refinement of the composition of the groups and types of issues to be covered. As with the KI interviews, the guidance on the focus groups will need to be adapted to country context and the inequalities profile. Does religion for example play an important part in health practices and so should local religious leaders be included in one group? Or do traditional healers need to be included? Are inequalities linked to occupation, education, ethnicity, having a disability and or nomadic communities? Are these subpopulations well represented?

Overview of focus groups

Two separate types of focus groups need to be undertaken:

1. with communities who have received at least one round of but preferably 2 treatment rounds of preventive chemotherapy treatment, and
2. with community drug distributors (both those from communities and teachers where MDA is delivered in school-based settings).

The focus groups are to be conducted with members of the target communities/ subpopulations with lower PC coverage and which the earlier analysis (see Activities 1.2-3 and 2.2) suggests may face barriers in accessing treatment. Due attention to differences between males and females, based on gender norms need to be considered in the criteria for composition of both groups.

Separate focus groups with CDDs are essential given the critical role of CDDs in ensuring distribution of medicines and hence effective coverage – how they do the job is important. While it is recommended that 1-3 CDDs are interviewed as part of the KI interviews, it is also important to generate more detailed information about their experiences and perceptions as providers of MDA using a focus group rather than interview format and with other CDDs. As indicated for the KI interviews, school teachers who are involved in MDA for schistosomiasis and STH should be included in FGDs either separately or with other CDDs. In deciding whether to have teachers and community based drug distributors in the same FGD, consideration should be given to country and local social hierarchy where for example teachers might be viewed as more authoritative. The composition of the two types of focus groups is outlined in detail here.

Focus groups with communities

Focus groups should be held in a minimum of 2 communities/areas/school enrolled populations with more than 2 treatment rounds within each district **and the same 2-3 communities** reviewed in Module 2, (Table 2.1.2). Depending on the composition of the district this should be 1 rural and 1 remote community and or 1 urban/peri-urban and 1 rural/remote community. However, this will depend on which communities were identified as having lower levels of coverage in Modules 1 and 2. The communities/areas/school enrolled populations should also have lower than expected coverage rates in the district and where there are several, from among these, it is suggested to select the communities/areas known to be more disadvantaged.

Up to five focus groups will be convened within each community comprised as follows:

- One group of adult women only
- One group of adult men only
- One mixed group of adults (men and women) and or different community actors
- One mixed group of adolescents **OR** one group of adolescent females and one group of adolescent males where it is indicated as necessary for religious or cultural reasons to have a separate group for adolescents.

Within each focus group there should be **no more than 10 people.**

The rationale for 4-5 groups is that:

a. it is important to provide separate as well as mixed focus groups to allow for gender norms and values, and enable women and or men to speak more freely. Having a mixed group of adults (men and women, and or different community actors) also enables an open exchange but may not be possible in some contexts;

b. having age-disaggregated groups e.g. one for adolescents responds to issues identified previously about male adolescents not seeing the necessity for medicines and wanting CDDs who were closer to their own age. It also allows adolescents to speak more freely. Where there is a limited adolescent population in the communities, then consideration can be given to either only holding a mixed group and

or ensuring inclusion of adolescents in the adult group; and

c. place of residence is an important determinant of accessibility. Some districts will only be rural. Therefore, it will be necessary to differentiate between the rural and more remote areas. Where there is not significant urban/rural/remote distinction within a district, communities with lower than expected coverage rates should be priorities for inclusion.

Suggested composition within focus groups with community members:

- Participation in treatment round – at least 50% of participants should have been exposed to the most recent treatment round, at least 40% of participants should either NOT have taken part in the most recent treatment round and or refused to take the medicine.
- Education – 50% with only primary school completion or less.
- Gender:
  ° Mixed group at least 40% men
  ° Women/female only group – at least 2-3 who were pregnant and lactating during the most recent treatment round of MDA
  ° Women and mixed group – at least 2-3 with pre-school aged children who should be receiving preventive chemotherapy as part of other treatment programs or in alignment with e.g. Vitamin A.
- Adolescents – 30-50% not attending school at all or regularly and or where relevant adolescents who go to school in another treatment area
- Age – to mirror the population profile of the country and district
- Morbidity (or impairment or disability) from NTDs addressed by preventive chemotherapy – 2 adult participants with morbidity from NTDs e.g. blindness, impaired vision, hydrocele or lymphedema
- Carers of people with morbidity/impairment/disability from NTDs in women and mixed groups – 2 adolescent or adult participants who are caring for someone with severe morbidity from NTDs
- Disability, impairment or chronic illness – 1 participant. NB: inclusion of one person with a disability needs to be handled sensitively and

with attention to potential discrimination or stigma if the participant is the only person in the FGD. Here an individual interview might be required and or a separate focus group.

- Occupation – at least 50% of participants have some kind of occupational exposure that increases their risk for the NTDs such as agriculture or fishing.

Disability, impairment or chronic illness

Disability and or impairment often intersect with social determinants due to stigma and marginalization within communities, meaning that people with a disability or impairment (not necessarily NTD related e.g. a person with intellectual impairment due to stunting) are likely to be poorer, less educated and overlooked or 'left behind' for PC. Other community members might decide that it is not necessary. Alternatively, the height for age of a person with a disability might mean that they are not considered as needing PC. Consideration should also be given to exploring whether people with a chronic illness such as mental illness (diagnosed or undiagnosed) are also being excluded from MDA due to beliefs about the impact of medication and or whether it is necessary.

➡ **Step 1:** Review the suggested composition of the focus groups with communities. It provides a guide to ensuring inputs from a minimum level of stakeholders relevant to assessing effective coverage in PC. However, it may need adaptation to country/district/community context and to ensure inclusion of identified subpopulations who are potentially being left behind, as per the earlier quantitative findings and any feedback from stakeholders. For example, is there need for an all adult male focus group because a high proportion are away from communities for their work for extended periods of time? Use the findings from completed Modules 1 and 2 (see Activities 1.2-1.3 and 2.2). As indicated, it is essential to include people who are being missed and where they have a disability, the FGD composition needs to be done so that it does not lead to discrimination and stigma, such as smaller focus groups and or individual interviews.

➡ **Step 2:** Ensure ethics permissions obtained (see Activity 1.3) and all relevant consent forms available for conducting the focus groups.

➡ **Step 3:** Review and adapt script and questions to the community context as appropriate. When adapting or changing specific questions consideration needs to be given to whether changes make the question more closed, too leading and or too negative.

➡ **Step 4:** Undertake the focus groups including recording the interviews as possible, and where not possible some notations should be made to indicate if people become uncomfortable talking about certain issues.

MODULE 3

Proposed agenda and questions for focus groups with community members

Agenda and script

a. The moderator starts off by introducing him/herself, and explaining why the focus group has been gathered. The moderator should give a brief outline of how the focus group will be run. The explanation should read as follows:

"We are meeting to discuss your experiences as CDDs for distribution of medicines in your community/school for preventing [Lymphatic Filariasis, Schistosomiasis, Onchocerciasis, and or Soil-transmitted Helminthiasis]. What we discuss here will remain confidential (that is, no names will be associated with the data gathered nor will your name appear in any report of study findings). I will start by asking you to describe very briefly an experience you have had in delivering a treatment round. We will then go on to discuss some of your experiences in more detail. The entire session will probably take about 1 and a half hours. During this time, we will provide you with something to drink. We will tape the sessions but nothing you say on tape will be linked to you. We are taping the sessions because we need to have an accurate record of the discussions. The work we are doing today is part of a large study."

b. The moderator goes on to introduce the team.

c. The moderator invites the members of the focus group to introduce themselves and say a short word on: who they are, what is their working or occupational background, and how long they and or their family have lived in the community, and what motivated them to become a CDD.

d. The moderator then starts the discussion with the following opening sentence:

"Now, very briefly, would each of you please describe your most recent experience with undertaking a treatment round in your community? Who would like to start?" (expected time: about 20 minutes)

The moderator needs to make short notes on each story as they go through, to help him/her decide who will be selected for the more detailed story-telling.

e. After everyone has completed their stories, indicate that you would like to focus on a few more stories in more detail. The moderator will need to select about 5 stories to focus on. The selection of stories should be made according to the following principles: the stories should be diverse with respect to highlighting the different factors that act as barriers or facilitators to coverage, focusing on accessibility, acceptability and treatment adherence (see **Table 3.3.1** below). This part of the focus group is the longest part and should take about an hour.

"The stories that you have told are very interesting. I would now like us to focus on the details of a few of these stories. I would like to start with X's story. X, could you please describe your experience again in a little more detail. While X is describing the experience, I would like everyone else in the group to think about what happened to X and how they would have felt in X's situation. After X has retold the story, I will ask some questions for clarification. I would then like to open up the discussion for the whole group to ask questions and make any comments on their reaction to X's experience. Once we have finished discussing X's experience, we will go on to discuss another story. I would like us to cover four to five of the stories told here today in a similar way. Now, X, would you please start". We are interested in exploring in the following issues:

i. what you know about the purpose of mass drug administration/PC? (Probe for: what do you know in advance of the distribution? What are you told? Who tells you e.g. mother in law, traditional healer? How are you told e.g. at coffee, at a women's meeting, or by the village broadcaster?;

ii. about any stories where mass distribution of medicines has been delayed? What causes these delays e.g. lack of or delays in supplies/medicines reaching the community? Who is missed or misses the MDA because of these delays?;

iii. if you can tell us any stories about people who do not participate in mass distribution of medicines? What are the reason you or other people don't participate? (Probe for: being away due to work/livelihoods, opportunity costs of going, not being able to attend because the CDD is not a woman etc.;

iv. what you think the benefits or not are of taking the medication? (Probe for: concerns about side-effects or that there is no need because people don't seem to be that sick or that they are uncertain about taking medicine that is known to be donated) Can you describe the positive impacts that you have seen because of people taking the medication (Prompt for: they saw the worms when their children passed stools and or among older adults they are seeing a difference in reduced severe morbidity in the community e.g. fewer people with lymphedema, blindness etc.);

v. if anyone in the focus group has someone in their family who has severe morbidity from one of the NTDs (e.g. blind, has lymphedema)? What it is like to care for someone with severe morbidity from an NTD? (Probe for: the possible impacts that this caring role has had on the participant, their family or the community) What are the available health and social services?;

vi. what as a community, do you see as your primary health needs? (Probe for: malaria, other health conditions and or expressed sentiments about also needing structural change such as improved WASH conditions);

vii. what you think about the CDDs in your community? How knowledgeable and skillful are they? What activities have the CDDs conducted to engage or mobilize the community? What roles have the basic care/front line health facility played in the engagement of the CDDs? Have you been involved in your CDDs are selected? Or are you aware of the process?;

viii. can you tell us about the way in which CDDs distribute the drugs? (Prompt for: when the CDDs come i.e. only at certain times, how and if they follow up people who are absent due to working, or they come outside of mealtimes or seasons when food is scarce so it is difficult to find something to eat with the medicines); and or

ix. whether people take the medication and or refuse it, and if they refuse it are they willing to explain why; and if they take the medication are there any experiences about noticing a difference, and if so for them to describe.

After completion of the first story the moderator should prompt the respondent for more information using the following questions, **if necessary and not covered** by the respondent:

"Please tell me more about:

- how the distribution of medicine could have been done differently; or
- how you or your community might be better involved or prefer to be involved in this in future e.g. community meetings prior the MDA or community meetings to discuss health needs and priorities; or
- how taking the medicines is making a difference to you, your family and or community e.g. what are the differences in health that you notice e.g. children growing better, fewer people with severe morbidity who need someone to stay at home and care for them etc.".

The moderator then needs to open the discussion to the rest of the group by saying:

"Now, please would the rest of the group like to discuss their reaction to X's story".

The moderator should move on to the next story, once no more comments are forthcoming from the group.

The moderator should close the session by thanking everyone for their participation in the focus group: for example, "Your stories have been very insightful and interesting. I would like to thank you all for participation".

The 1-and-a-half-hour time limit should be not followed strictly. If the moderator sees that participants are enjoying the discussion, she/he can let it run for longer. In closing, the moderator should also ask if the group were satisfied with the way the discussion ran and if everyone felt that they were able to say what they had wanted, noting that an hour and a half is a lot of time.

Reporting on the focus group discussions

➔ **Step 5:** It is recommended that Table 3.3.1 be used for collation and reporting of data from the focus group discussions with both community members and CDDs. The text shaded in grey relates to the additional aspects to be explored with CDDs only. As indicated previously, all data should be de-identified, so that no individual can be identified from the interview transcripts and or findings.

Table 3.3.1   Dimensions to be explored to identify barriers and facilitating factors to effective coverage for preventive chemotherapy in focus groups

Dimension	Types of barriers and facilitating factors – key areas for preventive chemotherapy or MDA
Availability	Resources are available for delivering the medicines needed for preventive chemotherapy and are sufficient, including: • Availability of medicines (drugs) that are safe and of high quality i.e. meets the pharmacopoeial quality specifications, within date and at the right time i.e. arrive and are available before the treatment round is due to begin. • Availability of suitable drugs e.g. PZQ syrup for children who are unable to swallow tablets (question for CDD focus groups). • Availability of resources for medicines to reach all districts and communities e.g. resources for in-country land transport • Availability of resources to support CDDs to reach all communities effectively e.g. transport for CDDs to get around their communities
Accessibility	*Geographic:* • CDDs have to travel long-distances within the communities they serve to reach all groups and have limited means of transport. • Children have to walk a long way to school and in bad weather do not attend when a treatment round may be scheduled. *Financial:* • Indirect costs to community members of lost time at work e.g. having to be at home when the medicine is distributed, having to have food available to take with the medicine and or lost time at work due to reaction to the medicine e.g. vomiting, diarrhea. • Direct costs to CDDs in coordinating with community members and getting to the points of distribution e.g. transport costs, mobile phone costs, this may limit the times that medicines are distributed • Indirect costs to CDDs in distributing the medicines including time away from home, this may limit the times that medicines are distributed. *Organizational and informational:* • Insufficient information, mobilization and community engagement in advance of treatment rounds. • Attention schedules/opening times for treatment rounds that mean some subpopulations are more able to access than others. • Systems to schedule treatment rounds with communities including – out of working hours and or during the harvest season so that food is available. • Scheduling visits for medicine distribution to places where people work including their gardens. • Appropriate information delivered in appropriate formats about the medicines, their purpose, possible side effects.
Acceptability	• Selection process for CDDs – ideally, they should be selected from and by the community but in some instances, they might be nominated by a health professional. • Cultural and other beliefs e.g. acceptability of taking medicine without a diagnosis of need for this specific medicine and or the process for assessing dosage. • Gender norms, roles, and relations and gender-responsiveness of services (including same-sex CDDs where culturally appropriate). • Age-appropriateness of services (e.g., adolescent-friendly). • Perceptions of priority of the need for PC compared to other health priorities in the community e.g. more pressing health needs and the morbidity from NTDs not obvious e.g. few people with lymphedema or hydrocele. • Perceptions about the benefits of medicine compared to vector control e.g. insecticide treated mosquito nets and or provision of improved water and sanitation. • Lack of trust in the health services, services that are funded from outside the country particularly with the aim of distributing medicines. • Perceptions of service quality e.g. administration and delivery by community members rather than health professionals. • Discrimination by providers (e.g., based on community social hierarchies, ethnicity, marital status, religion, caste, sexual orientation). • Gender-linked consequences for female CDDs e.g. where they have to work during the evenings and or are away from their home for a long period of time (e.g., reprimands by husband or mother in law for time away from household/caretaking roles, exposure to abuse).

MODULE 3

Dimension	Types of barriers and facilitating factors – key areas for preventive chemotherapy or MDA
Contact	• Actual contact between the CDDs and individuals in the communities, similar to "utilization".
Effective coverage	• Barriers in *treatment* **adherence** (due to unclear instructions particularly for pregnant and lactating women, poor patient-provider relationship, adverse social conditions and gender roles/relations preventing follow-up by the patient). • Barriers in *provider compliance* which can be related to: low levels of training e.g. in understanding which medicines pregnant and lactating women can be given; lack of supportive system requirements including lack of resources to meet direct costs incurred by CDDs in getting to the points of distribution e.g. transport and phone costs, this may limit the times that medicines are distributed; indirect costs to CDDs in distributing the medicines including time away from home, this may limit the times that medicines are distributed; accountability issues in terms of monitoring and evaluation due to weak support and or lack of clarity about the CDDs role i.e. the enumerator for the census believes they should be delivering the medicines not the CDD and do not turn up or provide the correct information for the CDD to accurately record treatment figures; and or lack of support from health professionals within the community and or wider district.

Focus groups with community drug distributors

A focus group with CDDs is essential given their critical role in the MDA strategy and their experience in distributing medicines within their own community. This includes any knowledge of barriers they experience and or see the community experiencing. However, as they are providers it is not appropriate that they participate in focus groups with community members but separately. This also provides an opportunity for them to speak in more detail about their experience in terms of motivation, any barriers or difficulties they might experience, and the quality of training and support that they get from the health system to be able to undertake the task effectively.

Depending on the NTD profile in the country and or communities, two focus groups should be held with community drug distributors from the different communities and as follows:

- One group with CDDs who distribute to households within communities
- One group with teachers who distribute and administer within the school setting and or including CDDs who distribute to communities in a facility based setting (where this is appropriate)

Within each focus group there should be **no more than 10 people.**

The two focus groups should be roughly 50:50 for the two communities from which they are drawn. However, if one community comprises a much larger population than the other, then there should be greater representation from that community than the other.

Suggested composition within focus groups with CDDs:
- CDDs should have participated in at least 2 treatment rounds, and have received some form of training but having a mix of CDDs who are fairly new to the task and those who have been doing it for a while
- CDDs who are also community health workers in other areas
- Education – even mix of primary school only, secondary and post-secondary education
- Gender – 40-50% female as far as possible
- Age – even distribution across the focus group
- Employment – mix of formal and informal employment including those who work outside of the home and those who work at home only

➔ **Step 1:** Review the suggested composition of the focus groups with CDDs. It provides a guide to ensuring inputs from a minimum level of stakeholders relevant to assessing effective coverage in PC. However, it may need adaptation to country/district/community context. For example, how to hear from female CDDs if they distributors in both communities are predominantly male? Use the findings from completed Modules 1 and 2.

➔ **Step 2:** Ensure ethics clearance obtained (see Activity 1.3) and all relevant consent forms available for conducting the focus groups.

Proposed agenda and questions for focus groups with community drug distributors

➔ **Step 3:** Review and adapt script and questions to the community context as appropriate. When adapting or changing specific questions consideration needs to be given to whether changes make the question more closed, too leading and or too negative.

➔ **Step 4:** Undertake the focus groups including recording the interviews as possible, and where not possible some notations should be made to indicate if people become uncomfortable talking about certain issues.

Agenda and script

The moderator starts off by introducing him/herself, and explaining why the focus group has been gathered. The moderator should give a brief outline of how the focus group will be run. The explanation should read as follows:

"We are meeting to discuss your experiences as CDDs for distribution of medicines in your community/school for preventing [Lymphatic Filariasis, Schistosomiasis, Onchocerciasis, and or Soil-transmitted Helminthiasis]. What we discuss here will remain confidential (that is, no names will be associated with the data gathered nor will your name appear in any report of study findings). I will start by asking you to describe very briefly an experience you have had in delivering a treatment round. We will then go on to discuss some of your experiences in more detail. The entire session will probably take about 1 and a half hours. During this time, we will provide you with something to drink. We will tape the sessions but nothing you say on tape will be linked to you. We are taping the sessions because we need to have an accurate record of the discussions. The work we are doing today is part of a large study."

a. The moderator goes on to introduce the team.

b. The moderator invites the members of the focus group to introduce themselves and say a short word on: who they are, what is their working or occupational background, and how long they and or their family have lived in the community, and what motivated them to become a CDD.

c. The moderator then starts the discussion with the following opening sentence:

"Now, very briefly, would each of you please describe your most recent experience with undertaking a treatment round in your community? Who would like to start?" (expected time: about 20 minutes)

The moderator needs to make short notes on each story as they go through, to help him/her decide who will be selected for the more detailed story-telling.

d. After everyone has completed their stories, indicate that you would like to focus on a few more stories in more detail. The moderator will need to select about 5 stories to focus on. The selection of stories should be made according to the following principles: the stories should be diverse with respect to highlighting the different factors that act as barriers or facilitators to CDDs doing their work effectively and realizing effective coverage (see **Table 3.3.1** above). This part of the focus group is the longest part and should take about an hour.

"The stories that you have told are very interesting. I would now like us to focus on the details of a few of these stories. I would like to start with X's story. X, could you please describe your experience again in a little more detail. While X is describing the experience, I would like everyone else in the group to think about what happened to X and how they would have felt in X's situation. After X has retold the story, I will ask some questions for clarification. I would then like to open up the discussion for the whole group to ask questions and make any comments on their reaction to X's experience. Once we have finished discussing X's experience, we will go on to discuss another story. I would like us to cover four to five of the stories told here today in a similar way. Now, X, would you please start". We are interested in exploring in the following issues:

i. How you came to be a CDD? (Probe for: what motivated them, what continues to motivate them, the impact on their lives e.g. time away from home, and or what is frustrating and difficult about the task including dealing with hostility from other community members, friends and or family or spouses e.g. husbands abusive because of the time taken away from home to deliver a treatment round and in following up community members);

ii. If there are times when you have had to delay or cancel a treatment round because of lack of supplies or delays in medicines reaching the community? How this was handled? How were you involved? How did you feel about it? How did the community react to the delay or cancellation?;

iii. Are people or specific groups in the population groups being missed in MDA rounds? (Probe for: specific groups based on the equity profiles as well as obvious such as adolescent males, pregnant or lactating women from season to season, nomadic communities.) Why do you think they are being missed? How do you look for and record people that may be missing?;

iv. Can you describe your experience in trying to convince people about the importance of PC and or taking the medicines? (Probe for: the main challenges the CDD faces, whether there are specific types of individuals who are missing out including people with a disability, specific ethnic or religious groups, males or females – adolescents, adults, etc. and based on inequity profile). What do you do to overcome challenges in reaching these groups;

v. Can you give any examples of particularly difficult situations e.g. aggressive refusals of medication by one or more community members? What did you do to manage this situation? What could have made a difference?

vi. What level of training and support do you get as CDDs? What resources and or incentives (financial, in-kind etc.) are you provided with for undertaking the task? What recognition do you receive from community members, the community, your family and other health professionals for undertaking this task? What motivates/demotivates you?;

vii. Can you describe your experiences in working with other volunteers in MDA such as enumerators? How have these been positive and or negative? How this facilitated the treatment round and or impacted on collection of data about treatment numbers and the accuracy? NB: this question may not be applicable to all settings.;

viii. Can you tell us how you think the location of the distribution points and timing influences treatment i.e. if the setting and timing for delivery of medication seems to make a difference? (Probe for: are mothers more inclined to accept treatment if CDDs are distributing from a health or education based facility, seasonality). What do you think the reasons are for this?; and

ix. Gender norms related question i.e. do you face challenges in being able to do this type of volunteering and how has this impacted their ability to engage the community. NB: for women, this question should seek to explore norms about women staying at home, any potential affect that their volunteering has on doing work at home, being available to their family etc. It should also be explored with male CDDs as it may be that there are fewer male community volunteers because of perceptions that taking care of the health of the family and community is a woman's role. This needs to be explored further because it stops males taking responsibility for their own health, that of their families and their wider communities.

Please see **Table 3.3.1** for the dimensions to be explored to identify barriers and facilitating factors to effective coverage for preventive chemotherapy for CDDs. Additional questions specific to the focus groups for CDDs are shaded in grey.

After completion of the first story the moderator should prompt the respondent for more information using the following questions, if necessary and not covered by the respondent:

"Please tell me more about:

- how the distribution of medicine could have been done differently;
- access issues re getting to communities and how this could be improved e.g. providing CDDs with transport to get around communities easily during bad weather, and also to reach community members at work, and or to provide food with the medicine etc.;
- knowledge, skills, training and support by MoH and how this could be improved including dealing with community concerns that this is not a priority health issue either compared to other health issues; or because it is preventive and the morbidity is not obvious; or because people don't trust the government; or concerns that the medicine makes them sick or infertile etc.;
- better support to CDDs for routine data collection and monitoring;
- other barriers to uptake and adherence of medicines among the community;
- enablers/facilitating factors – where you think it is working and why."
- ideas for other delivery channels (beyond schools and outreach to people at homes) that could be beneficial means for distribution, and ideas on ways to mobilize communities for this;

The moderator then needs to open the discussion to the rest of the group by saying:

"Now, please would the rest of the group like to discuss their reaction to X's story".

The moderator should move on to the next story, once no more comments are forthcoming from the group.

The moderator should close the session by thanking everyone for their participation in the focus group: for example, "Your stories have been very insightful and interesting. I would like to thank you all for participation".

The 1-and-a-half-hour time limit should be not followed strictly. If the moderator sees that participants are enjoying the discussion, she/he can let it run for longer. In closing, the moderator should also ask if the group were satisfied with the way the discussion ran and if everyone felt that they were able to say what they had wanted, noting that an hour and a half is a lot of time.

➡ **Step 5:** It is recommended that **Table 3.3.1** be used for collation and reporting of data from the focus group discussions with both community members and CDDs. The text shaded in grey relates to the additional aspects to be explored with CDDs only. As indicated previously, all data should be de-identified, so that no individual can be identified from the interview transcripts and or findings.

ACTIVITY 3.4   COMPILING THE RESULTS FROM THE SUBNATIONAL QUALITATIVE ASSESSMENTS

The results from the qualitative module(s) – review of existing qualitative data, and or KI interviews and or focus group discussions - should be compiled and analyzed separately, and then together.

The following is a **suggested outline** for compiling the results from the qualitative finding(s):

Existing findings Module 3.1	KI Interviews Module 3.2	Focus Groups Module 3.3
Summary of study methodology, how the data was collected, and key characteristics of study participants e.g. males and females, age groups, types of conditions.	Summary of characteristics of key informants or focus group participants e.g. x district level personnel, x national level personal, government and composition of focus groups. This should not include any identifying information e.g. name of the person, position and location, whether they are male or female.	
	Data collection process and context. This should include a description of how long the interviews took, whether any were shorter than others or very different and with an indication of why. This section should include information that highlights anything to do with the context of the interviews that may affect the results e.g. some KIs cut short the interviews, or the interviewers ran out of time and or the KI turned out not to be able to answer the questions. Again, this information must be de-identified.	A summary about the data collection process and context of focus groups. This should include a description of how the focus groups worked, whether people seemed comfortable discussing certain issues and if any of the focus groups were not well-attended and potential reasons why. This information does not need to be extensive but as for the KI interviews it is to assist in identifying any limitations with the method which may bias and or affect the findings. Also, this summary must not include identifying information about focus group participants.
Findings can be presented using Table 3.1.1 which follows the 5 dimensions from the effective coverage framework – availability, accessibility, acceptability, contact and effective coverage, including other for any other issues identified.		Findings can be presented using Table 3.3.1 – one for the discussions with CDDs and the other with communities. The table follows the 5 dimensions from the effective coverage framework – availability, accessibility, acceptability, contact and effective coverage, including other for any other issues identified.

The review team should meet to discuss the summary reports from (a) Activity 3.1 (existing qualitative data analyzed as subnational level) or (b) Activities 3.2 and or 3.1 (the KI interviews at national and subnational levels and focus group discussions) and from this: identify key themes; and develop a summary report from both processes drawing out key findings. This includes **triangulating for both differences and similarities** in results from the different sources. Where differences are identified, they should be noted and included for discussion at the review team meeting to be held to discuss and develop the final report. No aggregation of any divergent data/findings should be done at this stage - the divergence should simply be noted. Where the qualitative work is undertaken by only some of the review team, all documents must be made available to the review team as required.

ACTIVITY 3.5
DEVELOPING A DRAFT SUMMARY REPORT

Between completing the qualitative exercise and undertaking the activities in Module 4, it is recommended that the review team meet to develop a draft summary report of the key findings. The summary is to inform discussions at the sub-national and national meetings to be undertaken as follow up to the review (see Activities 4.1 and 4.2). Suggested format for the summary report:

1. Scope and purpose of the review
2. Methods
3. Findings:
   a. Inequalities profile and district(s) selected
   b. Review of sub national data in 2 districts and linked communities
   c. Qualitative data – national and sub national

4. Discussion:
   a. Key barriers and facilitators to effective coverage
   b. Recommended follow up actions for addressing inequalities at sub national levels
   c. Recommended follow up actions for addressing inequalities at national level
   d. Implications for ongoing monitoring and evaluation of effective coverage for PC
5. Limitations

It should be a brief report and can even be a PowerPoint presentation that can be sent to all relevant stakeholders in advance of the meetings at national and sub national level.

MODULE 3

Checklist for Module 3

Now you have finished Module 3, review the checklist and identify if you are ready to undertake Module 4 and or any follow up action that needs to be taken:

Module 3 Key issues	Yes/No/ Unknown	Comment including any follow up action
1. Has all planned qualitative data collection, and analysis for Module 3 been completed? Have the findings been collated as per Activity 3.4 and summary reports developed?		
2. Are there any major gaps in the data collected at national or sub national levels? Is there any mechanism for addressing these gaps within the existing plan (time and resources)?		
3. Have the summary reports from the qualitative assessments been discussed by the review team with a focus on drawing out key findings?		
4. Has a draft summary report based on the findings from activities in Modules 1-3 been compiled to inform meetings at sub national and national level and as part of Module 4? See Activities 4.1 and 4.2.		

MODULE 4: REPORTING AND MAKING USE OF FINDINGS

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Cross-cutting Module: Key term and concepts

Module 1	Module 2	Module 3	Module 4
• National level Preparatory and scoping steps - with subnational imput	• Quantitative data step - using subnational data from 2 districts	• Qualitative step - using national and subnational data from 2 districts	• Reporting and making use of findings - national and subnational

The **objectives** of this Module are to **use the findings** about effective coverage to:

a. subnationally, address barriers in the districts where the tools have been applied, as well as consider implications for long term M&E approaches at district level
b. nationally, to learn from the pilots to consider ways to improve the ongoing M&E plan and approaches.

Module 4 has three activities:

- **Activity 4.1**: At the **subnational level** the two districts involved in the review will each hold a meeting will all key stakeholders and develop a plan: (a) of action to address gaps and barriers to PC coverage at district and community levels; and (b) for enhancing the focus on equity, gender and human rights in routine monitoring and evaluation of effective PC coverage at peripheral and district level.

- **Activity 4.2: Nationally** the Ministry of Health will hold a stakeholder meeting to: (a) review the learnings from both subnational assessments, considering their recommendations made to the national level that could help them overcome barriers and make a draft plan for addressing them; and (b) review the M&E plan revisions produced by both subnational sites and consider implications for integrating equity and gender considerations into routine monitoring and evaluation and programming for NTDs at a national level including follow-up actions

- **Activity 4.3:** The research team takes findings from Modules 1-4 and consolidates them in a final report.

It is anticipated that these activities are undertaken or aligned to inform the annual program review process for NTDs in a country. 'Module 6: Monitoring and Evaluation' in the WHO *Program Managers' Training Course for NTDs Targeted for Control or Elimination by Preventive Chemotherapy Interventions* forms a key resource for this module, particularly in terms of (a) when to hold the stakeholder meetings for Activity 4.2 or 4.3 and (b) which monitoring and evaluation tools might be strengthened to better incorporate a focus on equity, gender and human rights.

ACTIVITY 4.1 REVIEW OF FINDINGS AT SUBNATIONAL LEVEL AND DEVELOPING A PLAN OF ACTION

This activity is conducted at subnational level in the two districts where a detailed review of PC coverage data was undertaken. Ideally the timing of the activity is aligned with the national programming cycle – although this will be dependent on the review process itself (see Module 1).

The **aims** of this activity are for each district to have the opportunity to review the findings in relation to their district with all relevant stakeholders at subnational level, and: develop a plan of action to address gaps and barriers in PC coverage at district and community levels; and develop a plan for enhancing the focus on equity, gender and human rights in routine M&E of effective PC coverage at peripheral and district levels.

The **outputs** of Activity 4.1 include:

- An action plan to address gaps and barriers to PC coverage at district and community levels,

indicating objectives, activities, partners, resources required and a timeline for moving forth, as well as how these activities will become part of the main PC approach at district level so as to ensure sustainability.

- Inclusion in the action plan of any national level action e.g. medicine supply and distribution to support changes at district level, and proposing this to national authorities to address in Activity 4.2.

- A plan for enhancing the focus on equity, gender and human rights in routine monitoring and evaluation of effective PC coverage at peripheral and district levels including ensuring collection, reporting and use of sex- and age-disaggregated data at all levels.

- As agreed, making proposals for continued use of qualitative sources as part of subnational routine monitoring and evaluation of effective PC.

Developing a subnational action plan to address gaps and barriers to PC coverage and improve ongoing M&E of equity, gender and rights in routine M&E efforts

As per Activities 2.2 and 3.4, a summary of quantitative and qualitative findings should be collated and presented using the Tanahashi framework for effective coverage. This might be prepared and organized by the research review team (depending on the review process), and needs to be provided to participants in advance of the stakeholder meeting, and potentially in different formats e.g. an oral summary as well as a written report.

The report on the findings should be reviewed with regard to:
- Key findings about gaps, barriers and facilitators specific to subnational level and verifying/testing them with all stakeholders.
- Where does action need to be taken – at national and or subnational level. For example, whether there is a barrier in the joint medicine supply process at national level with subnational impact

i.e. drugs getting to communities at the start of the rainy season.
- How generalizable the information about gaps, barriers and facilitators is across the district depending on the size and geographical terrain of the district i.e. is it geographically large and including many remote as well as some urban areas which are endemic for NTDs? For example, if one of the barriers has been low coverage of males due to many working outside of their communities when MDA is delivered, how common is this in other communities?
- In terms of the subnational action plan for addressing existing gaps and barriers what actions need to be taken:
  - In the immediate, medium and longer term e.g. mop ups, changed reporting, introduction of nomadic CDDs, increased training and capacity building, improving the drug distribution process;

- ° By whom and at what level i.e. national or district or community level;
- ° With communities – how can community engagement be strengthened to increase their involvement in design, implementation and ongoing M&E of changes;
- ° With other sectors or with other parts of the health sector;
- ° What resources are needed (human and financial); and
- ° What is already in place/available that can be made better use of e.g. existing training and capacity building events, online modules and or other surveys?
- ° What is the timeline for activities?
- What else might be affecting lower than expected coverage which has not been identified e.g. possibility of drug resistance?
- Are any of the gaps, due to gaps in knowledge and as a result of poor data collection and reporting e.g. forms incorrectly completed or not completed. Is this common across the district for all communities? Is greater training and capacity building needed? Or is there also a problem at national level with using the tools and systems for NTD reporting and evaluation?

The stakeholder meeting also needs to develop a plan for enhancing the focus on equity, gender and human rights in routine monitoring and evaluation of effective PC coverage at peripheral and district levels including ensuring collection, reporting and use of sex- and age-disaggregated data at all levels. The information about gaps in data/knowledge found as part of the review can inform this as well as thinking through the processes for collection and collation of data at peripheral and district levels including:

- Where are the challenges i.e. incomplete recording of age- and sex-disaggregated data and or refusals for treatment?
- Aggregation of disaggregated data at district level making it difficult to see where there may be gaps?
- The need for opportunities for reviewing routine M&E data including gaps in coverage at community and district levels to ensure quicker action?
- The need for strengthened capacity building?
- Improving peripheral to district to national level communication and exchange?

A draft of both plans should be shared with the national MoH focal points in advance of the national meeting on the review findings (see Activity 4.2) to inform discussion at the national level meeting.

Process for the district stakeholder meeting

Before the meeting the following information will be sent to participants: the scope and purpose of the meeting; a provisional agenda for the meeting; and a summary of the key findings from the review including recommendations.

It is recommended that the meeting(s) is **externally facilitated** e.g. a member from academic institution that was part of the team for the assessment of effective coverage or even independent from the process.

In addition to the NTD program managers or focal points (at national and subnational levels) it is recommended that the **following other stakeholders at subnational level** are invited to participate in this meeting including but not limited to:

- Other program managers from within the district health authority/service including those responsible for medicines, public health including any responsible officer for WASH, primary health, health education/promotion/social mobilization;
- Stakeholders from other sectors such as the agency responsible for sanitation, education, women's affairs and or social protection;
- Partners working in the NTD field and civil society organizations;
- CDDs; and,
- Community members and or representatives of the community depending on traditional administrative structures e.g. village leader or council members.

A suggested draft agenda/program for a one-day stakeholder meeting is at Appendix 4, for both subnational and national meetings.

ACTIVITY 4.2 REVIEW OF FINDINGS AT NATIONAL LEVEL - DEVELOPING A PLAN OF ACTION AND AN ALGORITHM FOR ONGOING MONITORING AND EVALUATION OF EFFECTIVE COVERAGE

This activity is conducted at national level involving participation from all relevant districts (i.e. endemic for NTDs) in the country. Ideally the timing of the activity is aligned with the national programming cycle – although this will be dependent on the review process itself (see Module 1).

The **aims** of this activity are for all stakeholders to have the opportunity to review the findings at national level, looking across the country as well as the outputs from the two districts as part of Activity 4.1 and: develop a plan of action to address gaps and barriers in PC coverage where action is required at national level and/or action has implications for other districts; and develop a plan for enhancing the focus on equity, gender and human rights in routine M&E of effective PC coverage at peripheral, district and national levels.

The **outputs** of Activity 4.2 are:

1. An action plan to address gaps and barriers to PC coverage at national and subnational levels.
2. An algorithm/agreed process for improved routine monitoring and evaluation of subnational differences in PC coverage to ensure no one is left behind.

Developing a national action plan to address gaps and barriers to PC coverage

As per Activity 4.1, the meeting of national stakeholders together with all districts where there is an NTD program, should be used to:

- Review the findings at subnational level, considering the both subnational sites' recommendations made to the national level to help them overcome barriers as well as overall findings from the review process about the NTD program. Make a draft plan for addressing them. Consider if any of the recommendations will require operations research to test feasibility before scaling up.

- Review the M&E plan revisions produced by both subnational sites and consider implications for integrating equity and gender considerations into routine monitoring and evaluation and programming for NTDs at a national level.

- Develop an algorithm/process for improved routine monitoring and evaluation of subnational differences in PC coverage to ensure no one is left behind.

The report on the findings should be reviewed using the same approach as in Activity 4.1 as well as considering:

- The recommendations from the two subnational sites about actions required at national level to address gaps and barriers to PC coverage.
- How generalizable the information about gaps, barriers and facilitators are to other districts. For example, is one of the barriers common to several districts e.g. strengthening the cultural and health literacy of CDDs. In this case is national level action required to support subnational action to address the gaps or barriers such as a program of training for CDDs?
- Are any of the gaps, due to gaps in knowledge and as a result of poor data collection and reporting e.g. forms incorrectly completed or not completed. Is this common across all districts? Is greater training and capacity building needed? Or is there also a problem at national level with using the tools and systems for NTD reporting and evaluation?

Using the findings to strengthen routine monitoring and evaluation to ensure no one is left behind

As indicated in the Introduction, this guidance has been developed with the aim of strengthening NTD program capacity to better monitor differences in PC coverage at subnational level and between subpopulations to support realization of the SDG of leaving no one behind. This guidance therefore builds on existing available data as well as broadening the available information on who is being missed and why in relation to PC. Part of this process includes (a) identifying if there are areas in the collection and reporting of existing data that need to be improved and (b) incorporating some additional key information to broaden the equity and gender equity focus, as part of routine monitoring and evaluation (see Figure 5). This may involve developing a new or revised algorithm and or process that feeds into ongoing and regular program review process.

At this point in the process, consideration needs to be given to the NTD profile within a country and or whether there is an integrated program for NTDs. Issues to consider include:

- Would Activity 1.2 (Table 1.2.1) serve as a useful mechanism for updating and reviewing equity, gender and rights issues in PC coverage on an annual basis? The Table uses routine existing data that is collected and reported annually using the Joint Reporting Form. Therefore, the Table could be updated annually with this data, as well as looking to update any of the equity, gender and health system components (as updated data is available e.g. a new DHS report).

- Could the Joint Application Process (undertaken annually) be used as an entry point for annual review of MDA with regard to leaving no one behind? How is it currently undertaken? Could it be strengthened to take a broader evaluative approach to MDA within the country? Or is the Annual work planning a better opportunity?

- Can the Demography form for the country in the Integrated NTD database be updated to include additional demographic and equity information relevant to the equity profile (see Table 1.2.1)?

- The Integrated NTD Database offers opportunities for WHO/Partner reports, Standard reports and custom reports. Reflecting on the review experience, what gaps exist in the data for the WHO/Partner and Standard reports that appear to have affected data collation. Can these be strengthened through improved capacity building and training? Can the inequity profile (as per Table 1.2.1) be entered into the database in the longer term to make it easier to undertake annual reviews?

- Whether the recommended pathway for collection and compilation of PC data (12) can be improved to enable better collection and utilization of sex- and age-disaggregated data across all levels – from peripheral to sub-district to district to national levels. What needs to change to strengthen this process? For example, ensuring disaggregation of sex- and age-disaggregated data continues up through all levels of reporting to national level instead of getting aggregated?

- Depending on the NTD profile and stage of MDA (i.e. scaling up or down), can the existing algorithms/M&E processes for specific NTDs be used to structure a revised algorithm/process for consideration of equity and gender issues? What needs to happen to ensure consistency with existing data flow for PC?

Process for the stakeholder meeting

Before the meeting the following information will be sent to participants: the scope and purpose of the meeting; a provisional agenda for the meeting; and a summary of the key findings from the review including recommendations (see Module 4.1).

It is recommended that the meeting(s) is externally facilitated e.g. a member from academic institution that was part of the team for the assessment of effective coverage or even independent from the process.

In addition to NTD program managers or focal points (at national and subnational levels) it is recommended that the **following other stakeholders** are invited to participate in this meeting including but not limited to:

- Other program managers from the Ministry of Health including those responsible for medicines, public health including any responsible officer for WASH, primary health, health education/promotion/social mobilization;
- Stakeholders from other sectors such as the agency responsible for sanitation, education, women's affairs and or social protection; and
- Partners working in the NTD field and civil society organizations.

A suggested **draft agenda/program** for a one-day stakeholder meeting is at Appendix 4, for both subnational and national meetings.

MODULE 4

ACTIVITY 4.3
REPORTING ON THE REVIEW FINDINGS

This activity is conducted by the research team using the findings from Modules 1-4 and including the outputs from Activities 4.1 and 4.1.

The **aim** and **output** of this activity is a final report on the review including the agreed follow up actions (at national and subnational level) and the algorithm. The final report might be integrated into a wider report on PC or the integrated NTD program in the country or produced as a standalone report.

This guidance does not provide a specific format for the report on the assessment of effective coverage, beyond following the general template used for scientific reporting. The summary of quantitative and qualitative findings presented at the stakeholder meetings as part of Activities 4.1 and 4.2 will use the Tanahashi framework for effective coverage. The WHO Health inequality monitoring eLearning module provides information on reporting on inequalities including considerations for value judgements (in particular see Lecture 6 -Reporting Inequalities I, Lecture 7 - Reporting Inequalities II and Lecture 8 - Cumulative Example at http://www.who.int/gho/health_equity/handbook/en/).

The review team might want review reports by other countries who have undertaken a review using the Tanahashi framework. This provides examples of the different ways the findings can be presented, including but not limited to the following:

- Barriers and facilitating factors in access to health services in the Republic of Moldova (WHO, 2012)
- Review and reorientation of the Serbian national program for early detection of cervical cancer towards greater health equity (WHO, 2015)

It may however be more useful for the review team to use the reporting structure for evaluation of integrated NTD programs, see examples from country plans for integrated NTD programs.

Regardless of the format used, a final draft of the full report including proposed recommendations for action should be developed and provided to stakeholders within 3 weeks of completion of Activities 4.1 and 4.2. This ensures timeliness of the information collected and also maintains the momentum of the review process. All stakeholders (those at subnational sites and national level) should be given 2 weeks to comment on the final version, and then 1 week to finalize the full report.

Checklist for Module 4

Now you have finished Module 4, review the checklist and identify if the review process is complete and or any follow up action that needs to be taken, particularly to act on the findings:

Key issues	Yes/No/ Unknown	Comment including any follow up action
1. Have all Activities in Module 4 been completed including the two sub national meetings and a national meeting to discuss the findings from the review process?		
2. **Activity 4.1:** did CDDs, and local communities participate in the meetings held in the two districts? Was a summary of the findings made available to participants in advance? Was an action plan for addressing existing gaps in coverage developed for both districts? What is the process for implementation and follow up? Did districts develop a proposal for national level action as required and was this shared as part of the national meeting?		
3. **Activity 4.2:** did all relevant stakeholders participate in the national meeting to discuss findings from the review process? Was a summary of the findings made available in advance together with the proposals from the two districts about any national level action to address gaps in coverage?		
4. Has an algorithm/process been developed to enable improved routine M&E of sub national differences in PC coverage to ensure no one is being left behind? Where is this documented? How is it being implemented including any resourcing?		
5. **Activity 4.3:** Is the final report complete and easily available e.g. electronic and on MoH website? Was a draft shared with all stakeholders (national and sub national) with an opportunity for feedback? How has it been disseminated?		

MODULE 4

CONCLUDING REMARKS AND NEXT STEPS

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This document provides guidance on undertaking a full review of effective coverage of PC every 3-4 years. As indicated, however, this guidance has been developed with the aim of strengthening NTD program capacity to **better routinely monitor and evaluate** differences in PC coverage at subnational level and between subpopulations to support realization of the SDG of leaving no one behind. This guidance therefore builds on existing available data as well as broadening the available information on who is being missed and why in relation to PC.

A key output of Activity 4.2 is an algorithm/process to ensure strengthened routine monitoring and evaluation of equity, gender and human rights considerations as part of PC coverage.

It is recommended that the annual/regular review process for the NTD program is used as an opportunity to also review effective coverage and monitor progress of action taken to address barriers and gaps from year to year – both in terms of implementation (process) and impact (e.g. increased coverage). This needs to be lead and coordinated at national level from the Ministry of Health with subnational participation (NTD program managers/focal points from endemic districts) and those from the education sector depending on the NTD profile within the country. Any annual review however will be determined by the agreed algorithm/process for ensuring improved monitoring of equity and gender issues in routine surveillance for PC.

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APPENDICES AND AIDS

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Appendix 1: Overview of modules and activities in this guidance

Module and Activity	How often?	Level of data / information collected	Meeting and type	Sources	By whom	Links between modules
CROSS-CUTTING MODULE:						
All	Every 3-4 years	No data collected	NA	NA	MOH at national level - program managers (for NTDs, PC and or Communicable Diseases) and other stakeholders (e.g. national consultant and review team).	Feeds into Module 1, and can also be used as a sensitization exercise at the stakeholders meeting in Activity 1.3
MODULE 1: PREPARATORY AND SCOPING STEPS						
Activity 1.1	Every 3-4 years	National and sub-national	MoH meeting limited to NTD-related persons from health and education.	Routine M&E data on PC coverage	MoH at national level to lead with subnational participation as required	Feeds into Module 2 and forms basis of review including selection of 2 districts to be the focus of subnational data collection.
Activity 1.2	Every 3-4 years – potentially updated annually	National and sub-national		Routine PC data and existing available data on social determinants and factors (e.g. WASH, rural/urban) disaggregated to subnational level.	By review team using national and sub-national data	
Activity 1.3	Every 3-4 years; potentially updated annually	National and sub-national	Wider stakeholder meeting with health and other sectors plus NGOs to review results from Activity 1.2 and finalize plan for full review.	Routine existing national and sub-national data on PC and other social determinants.	MoH at national level to lead with subnational participation as required	
MODULE 2: QUANTITATIVE STEP						
Activity 2.1	Every 3-4 years	Sub-national data from two districts	None	Routine PC coverage data at subnational level from: data summaries, register or annual work plan, inventory of medicines, coverage data and census or DHS data.	Review team	Builds on Activities 1.2-3 and links to Module 3 - qualitative data step.
Activity 2.2			Review team or wider stakeholder meeting to identify implications for qualitative data step			
MODULE 3: QUALITATIVE STEP						
Activity 3.1	Every 3-4 years	National and subnational	Review team only, unless otherwise indicated	Existing in-country qualitative data/study(ies)	Review team unless otherwise indicated.	Builds on Activities in Modules 1-2. Feeds into Activity 3.4 and then Module 4.
Activity 3.2		National and subnational		New data collected via key informant interviews (national and sub-national levels)		Builds on Activities in Modules 1-2. Feeds into Activities 3.3 and 3.4, and then Module 4.
Activity 3.3		Subnational		New data collected via focus groups with communities in 2 districts being reviewed (sub-national level)		Builds on Activities in Modules 1-2 and Activity 3.3. Feeds into Activity 3.4, and Module 4.
Activity 3.4		National and subnational	Review team with others as appropriate to prepare for activities in Module 4	Qualitative data – existing and or new depending on agreed review process.		Builds on previous Activities in Modules 1-3 and feeds into Module 4.
Activity 3.5		National and subnational	Review team with others as appropriate to prepare for activities in Module 4	Completed activities and data from Modules 1-3	Review team with others as appropriate	Supports and informs Activities 4.1 and 4.2
MODULE 4: REPORTING AND MAKING USE OF THE FINDINGS STEP						
Activity 4.1	Every 3-4 years	Sub-national level	Stakeholder meeting in both subnational sites with all local stakeholders to review the summary findings and develop related action plans and proposals.	Summary report of findings from Modules 1-3.	Subnational sites with national input and review team.	Feeds into Activities 4.2 and 4.3.
Activity 4.2		National and subnational	Stakeholder meeting with all national level stakeholders, and all NTD subnational sites to review the summary findings and develop: follow up action plan; and algorithm for routine M&E of effective PC coverage to ensure no one is left behind.	Summary report of findings from Modules 1-3.	National MOH and subnational NTD program managers	Feeds into Activity 4.3.
Activity 4.3		National and sub-national	Development of final report on findings from full review.	Summary report from Modules 1-3 and outputs from Activities 4.1 and 4.2.	National MoH and review team with input from subnational sites as appropriate.	Completion of review – Modules 1-4.

Appendix 2: Glossary

AAAQ: Acronym for the human rights based approach principles of 'Availability, Accessibility, Acceptability and Quality'. See the individual terms for their definitions and brief descriptions.

Acceptability: Even if resources are available and accessible, they may not be used if the population does not accept them. Acceptability includes factors such as culture, beliefs, religion, gender-sensitiveness and age-appropriateness of services, and confidentiality. Acceptability cove rage is influenced by people's perceptions, expectations for health services, and personal beliefs. Often, it is based on previous experiences and interactions with health personnel. Discriminative attitudes of health personnel, soliciting of informal payments (or inappropriate use of public services for private gain) by health personnel, and perceptions of low quality services (including safety concerns) can create systemic barriers to acceptability coverage.

Accessibility: Even if the service is available, it must be located within reasonable reach of the people who should benefit from it. The capacity of the service is limited by the number of people who can reach and use it and thereby access it (Tanahashi, 1978). There are two main dimensions of accessibility: physical access and financial accessibility. These are described below.

- *Physical accessibility.* Distance from a health service provider is a strong accessibility factor. Another factor closely related to distance and transport is time. The travel time[4] to a health facility to access services and the waiting time to see a health professional are associated with the patients' perception of accessibility of services. However, the value of time (the opportunity cost of time) is different for different groups of people and consequently its impact as an access barrier will also vary.
- *Financial accessibility.* User fees and transport costs have been shown to negatively impact access to health services, rendering health services less accessible to poor and vulnerable households. Uncertainty of costs and expectations of high out-of-pocket costs (formal or informal) can also obstruct access.

Availability: The ratio between availability of resources – such as human power, facilities, drugs – and the size of the target population gives the measurement of availability coverage (Tanahashi, 1978). Availability coverage considers the resources available for delivering an intervention and their sufficiency, namely the number or density of health facilities and personnel or the availability of necessary inputs (e.g., drugs, equipment). Availability coverage measures the capacity of a health system in relation to the size of the target population or ideally for the population in need.

Barriers: in this guidance, consistent with the Tanahashi framework, barriers are understood as those factors that obstruct the target population from appropriate use of an offered health service, therefore reducing the effective coverage of the health or provision service, in this case effective coverage of PC delivered by MDA. The right to health draws attention to four types of barriers in access including physical, financial, information and discriminatory barriers. There may also be gender based barriers in access to and use of health services (20):pp.228-229) – e.g. reduced access for women and children when the CDD is male and the gender norms require that a male be present.

Community Medicine/Drug Distributors: NTD control programs rely on volunteers who distribute preventive chemotherapy drug packages through community and school-based platforms (using mass drug administration). They are now known as community drug distributors (CDDs) and previously community drug distributors. They may or may not receive financial and or non-financial incentives e.g. provision of a motorcycle to visit communities for drug distribution.

Differentials: simply refers to differences between groups e.g. differences between men and women, younger and older people without any analysis as to the causes of these differences.

Disability and health: "The International Classification of Functioning, Disability and Health (ICF) defines disability as an umbrella term for impairments, activity limitations and participation restrictions. Disability is the interaction between individuals with a health condition (e.g. cerebral palsy, Down syndrome and depression) and personal

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4   Travel time may be more relevant than distance, as lack of all-weather roads in some forested, tribal areas can lead to difficulties in access during monsoon and rains. Mountainous terrain can also prolong travel times, hence creating an access barrier.

and environmental factors (e.g. negative attitudes, inaccessible transportation and public buildings, and limited social supports). The rates of disability are increasing in part due to ageing populations and an increase in chronic health conditions. Disability is extremely diverse: some health conditions associated with disability result in poor health and extensive health care needs, others do not. All people with disabilities have the same general health care needs as everyone else, and therefore need access to mainstream health care services. Article 25 of the UN Convention on the Rights of Persons with Disabilities (CRPD) reinforces the right of persons with disabilities to attain the highest standard of health care, without discrimination."(41)

Gender: refers to the socially constructed characteristics of women and men – such as norms, roles and relationships of and between groups of women and men. It varies from society to society and can be changed. While most people are born either male or female, they are taught appropriate norms and behaviors – including how they should interact with others of the same or opposite sex within households, communities and work places. Gender norms, roles and relations influence people's susceptibility to different health conditions and diseases and affect their enjoyment of good mental, physical health and wellbeing. They also have a bearing on people's access to and uptake of health services and on the health outcomes they experience throughout the life-course (29).

Gender analysis in health: examines how biological and sociocultural factors interact to influence health behavior, outcomes and services. It also uncovers how gender inequality affects health and well-being of both men and women (30).

Gender inequality index (GII): This is a composite measure that reflects gender-based inequalities in the 3 areas of reproductive health, empowerment, and economic activity. The GII can be interpreted as the loss in human development due to inequality between female and male achievements in the three GII dimensions. High gender inequalities can affect PC coverage adversely e.g. limited education and health literacy among women about the importance of taking medication for prevention.

Gender norms: refer to beliefs about women and men, boys and girls that are passed from generation to generation through the process of socialization.

They change over time and differ in different cultures, contexts and populations. Gender norms can shape inequality if they reinforce: a) mistreatment or oppression of one group or sex over the other; or b) differences in power and opportunities (42).

Gender roles: refers to what males and females are expected to do (in the household, community and workplace) in a given society(42).

Gender relations: refers to social relations between and among women and men based on gender norms and roles. Gender relations often create hierarchies between and among groups of men and women that can lead to unequal power relations, disadvantaging some groups over others – e.g. women who are socially excluded because of poverty, low education etc. Socio-political and economic systems and processes such as racism, sexism, homophobia (e.g., discriminatory policies, etc.) shape gender and gendered experiences, contributing to inequities in gender relations (42).

Gender in health: looks at the roots of health-seeking behavior. It aims to improve health outcomes for both female and male populations, regardless of age, ethnicity, religion and socioeconomic status. It cannot be assumed that health programs and policies affect men, women, boys and girls in the same way. Differences and specific vulnerabilities must be identified and addressed in health programs and policies in order to make progress towards health for all (30).

Gender equity in health: Gender equity refers to fairness and justice in the distribution of benefits, power, resources and responsibilities between women and men to allow them to attain their full health potential. The concept recognizes that women and men have different needs and opportunities that impact on their health status, their access to services and their contributions to the health workforce. It acknowledges that these differences should be identified and addressed in a manner that rectifies the imbalance between the sexes (Adapted from (42,43).

Hard to reach populations: can refer to people who are geographically or physically isolated and hard to reach. Populations who for example live in very remote areas and or areas very difficult to reach by land or usual transportation, such as people living in remote and or insecure areas of north-eastern Nigeria

who are urgently in need of care and displacement by the 8-year conflict. Here medical teams supported by WHO are in place to set up mobile clinics and provide humanitarian assistance. It can also refer to where actions or services are targeted to the mainstream/universal in application but not accessible, acceptable or relevant to some sub-groups in the population. For example, nomadic communities and MDA. In these instances, the strategies used for increasing engagement and uptake include: tailoring of the action or service by providing information and services in other languages, making it more sensitive to cultural and religious beliefs including gender norms e.g. provision of services to women by female health providers; developing networks and partnerships with populations about the services; and ensuring providers are recruited from hard-to-reach communities e.g. peer mediators, CDDs who are female and community nominated (44).

Health equity (and equity in health): Equity is the absence of avoidable, unfair, or remediable differences among groups of people, whether those groups are defined socially, economically, demographically or geographically. "Health equity" or "equity in health" implies that ideally everyone should have a fair opportunity to attain their full health potential and, more pragmatically, that no one should be disadvantaged from achieving this potential (23).

Health inequality: The term means a difference in health status between individuals or groups, as measured by, for example, life expectancy, mortality or disease. Health inequalities are the differences, variations and disparities in the health achievements of individuals and groups of people. Some differences are due to biological or other unavoidable factors such as age; others, however, are avoidable (24).

Health inequity: Health inequity refers to a difference or inequality in health that is deemed to be avoidable, unfair or stemming from some form of injustice. Inequities in health status can be between groups of people within countries and or between countries. Health inequities arise from differences within and between societies and the distribution of resources and power. Inequities are those differences in health that arise not from chance or from the decision of the individual but from avoidable differences in social, economic and environmental variables (such as living and working conditions, education, occupation, income and access

to quality health care, disease prevention and health promotion services) that are largely beyond individual control and that can be addressed by public policy. It should be noted that the terms health inequalities and health inequities are often used interchangeably, while in most languages other than English there is only one term to describe such differences. Thus, the term health inequalities is also used to refer to those differences in health that are deemed to be avoidable and unfair and that are strongly influenced by the actions of governments, stakeholders and communities, and that can be addressed by public policy. Therefore the terms health inequality and health inequity are commonly used to refer to those health differences that are unfair and avoidable (24–26).

Inequality adjusted Human Development Index: The Human Development Index (HDI) is a summary measure assessing long-term progress in 3 dimensions of human development: a long and healthy life, access to knowledge and a decent standard of living. A lower level of human development for some districts within the country may adversely affect preventive chemotherapy coverage. The Inequality-adjusted HDI, allows inequality in the 3 dimensions by 'discounting' each dimension's average value according to its level of inequality. The 'loss' in human development due to inequality is expressed as a percentage. As the inequality in a country increases, the loss in human development also increases. High inequalities can affect preventive chemotherapy coverage adversely e.g. different education and health literacy levels among different groups within a district may affect uptake of PC and coverage levels.

Neglected tropical diseases: are a diverse group of communicable diseases that prevail in tropical and subtropical conditions in 149 countries – affect more than one billion people and cost developing economies billions of dollars every year. Populations living in poverty, without adequate sanitation and in close contact with infectious vectors and domestic animals and livestock are those worst affected.

Nomadic: The term *nomadic* is used when mobility is high and in irregular patterns; *transhumant* when there are regular back-and-forth movements between relatively fixed locations; and *sedentary* for the rest. Pastoralists are people who live mostly in dry, remote areas. Pastoralists are people who derive more than 50 per cent of their incomes from livestock and

livestock products, while agropastoralists are people who derive less than 50 per cent of their incomes from livestock and livestock products, and most of the remaining income from cultivation. Pastoralists' livelihoods depend on their intimate knowledge of the surrounding ecosystem and on the well-being of their livestock. Pastoral systems take many forms and are adapted to particular natural, political and economic environments. Mobility is a key feature qualifying pastoralism (45).

Preventive chemotherapy transmission and control: is the large-scale delivery of free and safe, single-dose, quality-assured medicines, either alone or in combination, at regular intervals to treat selected neglected tropical diseases including: cysticercosis, dracunculiasis (guinea-worm disease), foodborne trematode infections, **lymphatic filariasis, onchocerciasis, schistosomiasis** and **soil-transmitted helminthiasis**. Blinding **trachoma** control through the SAFE strategy – combining drug treatment with hygiene and environmental management – can be linked to helminth control interventions to improve the overall health of affected communities.

The **right to health:** refers to "the right to the highest attainable standard of health" and requires a set of social criteria that is conducive to the health of all people, including the availability of health services, safe working conditions, adequate housing and nutritious foods. Realization of the right to health is closely related to that of other human rights, including the right to food, housing, work, education and non-discrimination; equality; access to information; and participation. The right to health comprises both freedoms and entitlements. Freedoms include the right to control one's health and body (e.g. sexual and reproductive rights) and to be free from interference (e.g. free from torture and from non-consensual medical treatment and experimentation). Entitlements include the right to a system of health protection that gives everyone an equal opportunity to enjoy the highest attainable level of health. Health policies and programs have the ability to either promote or violate human rights, including the right to health, depending on the way they are designed or implemented. Taking steps to respect and protect human rights upholds the health sector's responsibility to address everyone's health (46).

Social determinants of health: The social determinants of health are the conditions in which people are born, grow, live, work and age, including the health system. These circumstances are shaped by the distribution of money, power and resources at global, national and local levels, which are themselves influenced by policy choices. The social determinants of health are mostly responsible for health inequities – the unfair and avoidable differences in health status seen within and between countries (25).

Universal health coverage (UHC): is defined by WHO as "ensuring that all people can use the promotive, preventive, curative, rehabilitative and palliative health services they need, of sufficient quality to be effective, while also ensuring that the use of these services does not expose the user to financial hardship." (http://www.who.int/health_financing/en/). The three dimensions of the so-called "UHC cube" are: (i) extending coverage to individuals who previously were not covered; (ii) extending coverage to services that previously were not covered; or (iii) reducing direct payments needed for each service.

Appendix 3: Worked example of Table 1.2.1 using sex-disaggregated data for 4 of 5 PC NTDs

D	Step 1: PC coverage x district (epidemiological coverage)																	Step 2 – Equity Lens				Step 3 – Gender	Step 4 – Medicine Supply & NTDs			
	Step 1A: PC coverage of population in need by sex																									
	Population treated for LF				Population treated for Onchocerciasis				Population treated for Soil-transmitted helminthiasis				Population treated for Schistosomiasis				Gini co-efficient	Urban/ Rural/ Remote*	Educational attainment - % primary education complete		Gender Equality*	PC Drugs	WASH*		NTD Morbidity or Health care measure*
	Total (#) Popn in Need	M(#)	F(#)	Total (%) treated in need of PC	Total (#) Popn in Need	M(#)	F(#)	Total (%) treated in need of PC	Total (#) Popn in Need	M(#)	F(#)	Total (%) treated in need of PC	Total (#) Popn in Need	M(#)	F(#)	Total (%) treated in need of PC			M	F		*	Safe Drinking Water	Sanitn	*
1					725 390	202 404	230 670	59.7	316 375	100 111	87 679	59.36					28.7	70+% rural	2,00	3.3	64.1		80.5	4.0	
2					766 306	234 528	252 501	63.56	221 874	65 865	51 134	52.06					32.4	60% rural	5.7	1.8	54.8		71.1	3.3	
3	459 235	120 870	125 927	53.74	29 482	16 324	16 039	14.04	102 760	19 294	14 902	33.28	208 998	39 095	30 697	33,.9	36.4	Rural+urban	8.7	4.8	69		68.2	23.5	
4	281 896	57 956	59 793	41.77	1 332 784	394 332	411 864	60.49	332 136	100 111	87 679	52.72	576 672	158 603	137 554	51.05	31.2	Rural+urban	3.3	4,00	55.1		73.6	12.00	
5					794 461	222 117	246 126	58.94	354 207	98 806	88 402	52.26	87 781	43 123	40 510	94.74	21.4	70+% rural	8,00	4,00	53.8		93.2	4.2	
6					962 481	307 303	316 950	65	190 185	49 291	50 499	52.47	107 012	53 858	45 743	91.11	14	75% rural	2.00	1.5	46.7		61.9	2.0	
7					178 143	23 078	24 959	26.97	91 000	21 486	19 687	45.24					38.8	Rural+urban	7.6	5.4	59.1		67.9	12.5	
8	923 821	243 572	260 885	53.61	49 260	8 461	9 187	35.83					117 523	15 082	12 095	23.12	27.7	60+% urban	9.8	5.5	71.3		72.2	24.7	
9					601 596	150 131	142 135	48.58	136 472	39 268	33 841	53.57	155 280	39 268	33 841	44.65	22.7	60% rural	3.6	3.4	58.5		63.2	5.7	
10	518 491	149 038	171 394	61.8	302 070	102 720	106 386	69.22	77 359	20 453	18 320	50.12	101 911	37 446	33 568	64.78	30.5	Rural+urban	4.7	3.2	67.7		87.1	6.5	
11	806 946	235 712	261 417	61.6	699 361	204 893	222 828	61.16					120 612	55 864	48 540	86	29.3	65% rural	3.4	3.2	68.8		64.00	8.6	

D – refers to the District e.g. 1 = District 1

Indicators Used: To look at differences in **educational attainment** across districts and between males and females, % of primary school completion (completing 6 classes of primary education) was used in this instance because median years of schooling not readily available; to look at differences in **gender equality** between districts women's participation in decision making as measured by making specific decisions about their own health care was used (%); to look at differences between districts in terms of **WASH** the percentage of districts with the percentage of households with access to safe drinking water and modern toilets was used. **Rural/urban** descriptions had to be taken from percentage of population classified as living in rural or urban areas as it was not readily available from statistics agency. This needs to be reviewed in the stakeholder meeting.

Comments/Notes NTD situation in country and data quality:
- Not all districts are endemic for any or all four of the five PC NTDs.
- Within districts not all areas are endemic for all or any of the NTDs e.g. no PIN identified for LF for District 9.
- **Treatment for LF was interrupted in 6 districts.**

- In some areas **treatment appears to have been given where there is not an indicated population in need either within the district or to communities not identified as in need in the district:**
  - For **Onchocerciasis** the following Districts treated people from communities in the District that were not included in the total PIN as follows: in District 3, 246,800 in addition to the identified total PIN; District 8, where 473,000 people were treated from communities not included in total PIN, and 13,800 were treated from the identified PIN communities but not included in the sex-disaggregated figures or total count; District 10 where 219,000 people were treated from communities not included in total PIN; and District 11 where 133,000 people were treated when no PIN was identified for this district.
  - For **Soil Transmitted Helminthiasis**, in Districts 8 and 11 treatment has been given for STH where there was no indicated population in need. District 3 treated 247,000+ people from communities not identified in need; District 4 treated 117,700+ people from communities not identified in need; and District 10 treated 320,000+ people from communities not identified in need.

Comments/Notes data quality: in some districts data is listed for treatment that appears to have been given even though there is not an indicated population in need; some potential errors in reporting?

Sources: Joint reporting forms; DHS survey for country (data is pre-2013); Country Statistical agency website.

Dates of data: Educational and gender equality data is from 2011-2012; Water and Sanitation data by District is from 2010;

Observations:

- **Differences between Districts in terms of PC coverage:** District 3 was one of two districts with a low/lowest score for three out of the four PC NTDs treated; District 10 scored highest for 2 of the PC NTDs treated but third lowest for STH; District. 8 has a very low coverage score for Schisto. However, within Districts there may be steep differences in coverage between areas e.g. District 3 for LF where one area has a coverage rate far lower than the rest of the districts. Therefore, when Table 1.2.1 is being reviewed, it may be necessary to look within districts to highlight outliers for the more detailed subnational data review/exercise.

- **Lymphatic filariasis:** data is missing for 5 districts because treatment was interrupted. This requires further exploration – for example was treatment interrupted because drugs arrived after the rainy season and CDDs could not make it to communities?

- **Onchocerciasis and STH figures - data quality and populations being treated where not included in the PIN figures:** See the comments above for Onchocerciasis and STH where the coverage figures do not reflect the number of people listed as treated because people were being treated from communities not identified as in need. This may be a recording and data quality issue but it may also reflect a misunderstanding about distribution of drugs leading to lower levels of coverage within districts among the communities identified as in need. It may also reflect a problem with baseline data about communities in need within the district or in the district at all. Are there for example, nomadic communities within these districts that have not been counted or school children from communities endemic for STH attending school in non-endemic communities and receiving treatment nonetheless?

- **Differences between males and females treated:** Note that the data represents the numbers treated and the % of men in need of PC coverage and who receive it is higher or lower than women. This is because the calculations of the population in need are not sex-disaggregated. In some districts and for some PC NTDs the numbers of men treated is higher than the numbers of women – see for example District 9 for Oncho, STH and Schisto. In other departments, the numbers of women treated is higher than the numbers of men – see for example District 6 for 2 of the 3 PC NTDs. In others, it varies for the PC NTD see District 3. These differences may reflect the population distribution in the department e.g. more men than women or vice-versa and or the related PC NTD and potential exposure. It is recommended that countries check against the sex-disaggregation of populations within departments and between districts. For this exercise, available sex-disaggregated data from 2013 was reviewed which showed that in most departments the disaggregation by sex in the population was largely 50:50 in all districts included.

- **Inequality:**
  - ° Gini co-efficient – there is a high level of inequality throughout the country, with departments that have been classified as equally rural and urban as being more unequal than others.
  - ° Urban/rural/remote differences – none of the districts classified as largely rural have the lowest coverage rates, seemingly reflecting the average coverage for the PC NTD. District 6 which is classified as largely rural also has the second highest coverage for Schisto at 91,11%, with the lowest score within the district being 64% and remaining districts above 90% and one district with 100% coverage.
  - ° Education – median years of schooling by department and sex disaggregated was not especially useful for showing in-country inequalities as there is an overall high level of inequality within the country. The percentage of completed primary education was used, and even then, both males and females have quite low rates throughout the country. There are however some notable differences within some Districts including Districts 2, 3, 5 and 8 where the percentage of males completing primary education is 2-3 times that of females.

- **Gender Equality:** as measured by the percentage of women who participate in decisions about their own health care shows that Districts 2, 4, 5 and 6 score lower than the other Districts. Districts 2 and 5 are also those where the percentage of males completing primary education is 2-3 times that of females. The same four departments have a higher percentage of women who do not participate in decisions (about their own health care, making household purchases and visits to her family or relatives) (not shown here).

- **PC Drugs:** Not available – needs follow up in KI interviews at national level. In addition, the significant number of people being treated from communities who are not included in the PIN figures suggests that there may be problems with PC drugs and so the figures require attention.

- **Water and Sanitation:** the proportion of households with access to safe drinking water ranges from 62% (District 6) to 93% (District 5); and District 6 has the lowest percentage of households with access to modern toilets (2%) and District 8 the highest (24.7%).

- **NTD Morbidity or health care:** Not available – needs follow up at district level during KI interviews

Appendix 4: Example of a draft agenda for stakeholder meetings (Activities 4.1 and 4.2) for acting on findings from the review at subnational and national level

Agenda Item	Activity 4.1 – subnational meeting	Activity 4.2 – national meeting
Introduction		
Welcome and participant introductions	This might include a welcome not only from the head of the district health service but also the village/community leaders from the 2-3 communities reviewed	Welcome from MoH, other sectors such as Education and or key partners.
Meeting objectives	Recap of objectives of the meeting, process for agreeing on the action plan and expected outputs/outcomes. This is to reinforce that it is about developing consensus for the key areas for action and shared ownership for monitoring and evaluation of equity and gender issues in the future.	Recap of objectives of the meeting, process for agreeing on the action plan and expected outputs/outcomes. This is to reinforce that it is about developing consensus for the key areas for action and shared ownership for monitoring and evaluation of equity and gender issues in the future.
Findings from review of effective coverage		
Presentation about the key findings from the review of effective coverage for PC.	Suggest that the presentation of the key findings is given by the member of the assessment team most familiar with the findings with a commentator from the district – ideally a CDD and the district NTD focal point.	Adaptation of the presentation to begin with national findings, drilling down to two districts reviewed as proxies and including findings from national and subnational qualitative work. Suggest this presentation is given by the review team, the national PM or focal point for NTDs and the two district NTD focal points to speak to district findings.
Discussion and questions about key findings	Plenary discussion and review as per Activity 4.1 including: • Consensus on key findings about gaps, barriers and facilitators in the district • Generalizability of the information across the district e.g. how heterogeneous is the district • What else might be affecting lower than expected coverage and has not been identified e.g. possibility of drug resistance • Limitations of the review and any gaps in knowledge	Plenary discussion and review as per Activity 4.1 as well as considering: • Generalizability of findings from two districts • Recommendations from two districts about actions required at national level • Limitations of the review and any gaps in knowledge
Presentation on how the program is currently addressing coverage gaps (or not)	Presentation on current efforts to enhance MDA and address potential gaps. For example, mop-ups, improved social and community mobilization activities, and coverage supervision tool exercises. This could be supported by input from the national NTD program manager about 'good' or 'promising' practices from other countries in closing coverage gaps.	Presentation on current efforts to enhance MDA and ensure country is on track to reaching 2020 targets. Also include examples of what other countries have done to close coverage gaps i.e. drawing on 'good' or 'promising practices' as a basis for discussion. This can draw on both NTD specific examples to address inequities in coverage as well as examples from other programs such as TB to ensure no one is left behind.

Agenda Item	Activity 4.1 – subnational meeting	Activity 4.2 – national meeting
Developing an action plan to address barriers to PC coverage		
Agreed areas for action and working groups.	Plenary discussion to agree on key areas for action to address gaps and barriers in PC coverage in the district. Two-three working groups to develop feasible an action plan/recommendations to address gaps at district level including both district and national level action, indicating key actors responsible and a suggested timeframe (see bullet points in Activity 4.1). The working groups can be mixed i.e. health facility and other government sectors, with CDDs and community members or 2-3 separate groups of only government sectors, CDDs and of community members. To ensure the action plan is feasible, prioritization might be needed. Suggested approach/criteria for prioritizing are having a balance between: • remedial and preventive action • short, medium and longer-term action • action by the health sector alone, and intersectoral or whole of society action • district and national level action • actions that call for new resources (people and funds) and those that can build on existing efforts including reorienting approaches.	Plenary discussion to agree on key areas for action to address gaps and barriers in PC coverage that need to be addressed at national level. This can include barriers that districts think exist in most or all districts and therefore need national level action or support. The plenary discussion should be informed by the proposals from the two districts about follow up action that is needed at national level to redress gaps. Two-three working groups to develop feasible recommendations for addressing the agreed areas for action based on the findings about specific barriers to effective coverage for PC at national level, and indicating key actors responsible and a suggested timeframe (see bullet points in Activity 4.1). As with the subnational meeting, working groups should give consideration to prioritizing actions by ensuring a balance of types of action – see suggested criteria for district action plans in previous column.
Feedback from working group session	Presentation of working group recommendations.	Presentation of working group recommendations.
Facilitated plenary discussion	Facilitated plenary discussion/ exchange with district NTD focal point about: • next steps for taking this forward as an action plan, and agree on timeframe; and • local working group to support implementation and follow up.	Facilitated plenary discussion/ exchange with national NTD PM about: • next steps for taking this forward as an action plan, and agree on timeframe; and • national working group to support implementation and follow-up.
Developing an algorithm/process for integrating EGR considerations into routine monitoring and evaluation of PC		
Presentation on current monitoring and evaluation for PC coverage and the program review process	Joint presentation by national and district level focal point for NTDs on what currently happens as part of routine M&E, the program review process and areas for improvement based on the findings from the assessment of effective coverage e.g. gaps identified in how data is collected at peripheral levels and existing sources of qualitative knowledge.	Joint presentation by national NTD PM/focal point together with the NTD focal points from the two districts and key partners on: • what currently happens as part of routine M&E • the program review process and areas for improvement based on the findings from the assessment of effective coverage e.g. gaps identified in how data is collected at district levels • availability or not of other data disaggregated by social and economic factors to district level • availability and existing sources of qualitative knowledge e.g. existing COUNTDOWN • the proposed M&E plans from the two districts • possibilities for algorithm/process to integrate EGR into routine M&E of PC (see list in Activity 4.2).

Agenda Item	Activity 4.1 – subnational meeting	Activity 4.2 – national meeting
Implications for ongoing M&E of PC coverage: how can communities, districts and national stakeholders better integrate equity, gender and rights considerations into their PC program implementation	Suggested approach is 2-3 working groups as follows: • A district and community level participant working group • A CDDs working group • A community/area participant working group Working groups to discuss the gaps in data/knowledge found as part of the review and think through processes for collection and collation of data at peripheral and district levels in terms of challenges such as incomplete recording of age- and sex-disaggregated data, need for increased opportunities for reviewing data as a community more often, the need for capacity building (see points in Activity 4.1). Consideration should be given to identifying: • District and national level actions • Actions that build on existing M&E efforts • What support is needed and what is already in place to support change/enhanced EGR focus • Timeframe • 2-3 actions that can be taken and implemented within the next 18 months Feedback from working groups.	Suggested approach is facilitated plenary discussion based on the options from the presentation in the previous session including whether: • Table 1.2.1 serves as a useful basis for updating and reviewing EGR issues on an annual basis • Joint application process as an entry point • Updating the demography form in the integrated NTD database to include additional demographic and equity information • Other opportunities in the integrated NTD database • Ensuring recommended pathway for reporting on PC uses sex- and age-disaggregated data in reports at all levels i.e. national level • Can existing algorithms/M&E processes in the country for specific NTDs be used to better consider equity and gender issues?
M&E implications for effective coverage for PC – what needs to change	Facilitated plenary discussion with district NTD focal point and national NTD PM on next steps for taking this forward including the proposal to be put to the national working group and support by the local implementation group.	Facilitated plenary discussion by national NTD PM on next steps for taking this forward including how this will be supported by the national implementation working group.
Agreed next steps	Facilitator to sum up next steps including responsibilities of all participants, and seek consensus on these as next steps.	Facilitator to sum up next steps including responsibilities of all participants, and seek consensus on these as next steps.
Close	Session close with a milestone date for follow up agreed.	Session close with a milestone date for follow up agreed.