PRIME qualitative topic guide for formative study: key informants on district mental healthcare plans

As part of the PRIME formative phase, a qualitative study was carried out with key informants from the selected PRIME districts in Ethiopia, India, Nepal, South Africa and Uganda. The purpose of the qualitative study was to answer the following research questions:

1. What are the essential components of a district level mental health plan that will meet the needs of people with the priority mental, neurological and substance use disorders in the community?
2. How could the components of the mental health care plan be implemented in practice to achieve acceptable, feasible, equitable, sustainable and holistic mental health care for persons with selected priority disorders?

The qualitative study was designed to build on and develop the preliminary mental health care plans identified by our baseline syntheses of the evidence base, situation analyses, initial Theory of Change workshops and consultation with the PRIME Community Advisory Boards. The qualitative study findings then fed into further refinement of the mental health care plan.

A combination of in-depth interviews and focus group discussions was carried out with key informants from the community, primary healthcare setting and health service organisation level in the PRIME district.

The topic guide presented here includes both 'core' and 'optional' cross-country topics. The right-hand column indicates the core respondent group and modality of data collection (for example, "FGD-CO" for "Focus Group Discussion with Community key informant").

As in PRIME, anybody planning to use the topic guide will need to tailor the topics and probe questions to the particular country context. It is also advised that any qualitative work to inform implementation of scale-up of mental health care is nested in a broader situation analysis and process of community consultation, for example, following the methodology employed by PRIME.

Any queries about the approach can be directed to Charlotte Hanlon or Mark Tomlinson via the PRIME website.

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CORE Interview Questions

Introduction: Instructions for the PRIME country teams	**Core items ***	**Method**
- This is a collation of questions, not an interview schedule. The order of question and final selection of questions still needs to be done at country level. - Each country PI needs to develop the interview schedules for their country setting, ensuring that, at a minimum, core questions (indicated with *) from each of the sections below are covered. Per country setting any number of questions and themes can be added as is deemed relevant. The questions will need to be adapted according to: o 1) type of respondent o 2) the country context o 3) disorder, where relevant (- The categorization within themes is only to facilitate providing a structure for the collected question, but the label for the categories is <u>not</u> essential at this stage. - In the column on the far right we have indicated the method and respondent through which the core items are covered.		1. FGD N-HO 2. FGD D-HO 3. FGD HF 4. FGD CO 5. IV N-HO 6. IV D-HO 7. IV HF 8. IV CO IV=in-depth interview FGD= focus group discussion N-HO = national health organization level (Policy makers; MOU partners) D-HO= district health organization level (district health managers; district health co-ordinators) HF= health facility level (nurses; doctors/medical officers; specialists) CO= community level (community health workers; people with psycho-social disabilities;

			families; community key informants)
	Introduction 1 (policy-makers and planners) At the present time in ******, fewer than 1 in ** people with mental illness ever get the care they need. One of the main reasons is lack of access to mental health care due to a scarcity of specialised mental health professionals across the country. To overcome this problem, the WHO recommends integration of mental health care into primary health care. WHO has recently published up-to-date guidelines for PHC workers, called the mhGAP Intervention Guide. The aim of this study is to work with the Ministry of Health of ***** in order to develop an acceptable, feasible and sustainable mental health plan that can be implemented at the *district* level. After initial discussions with policy-makers and planners in ***** and consultation with the WHO, a model for components of a district mental health plan has been drafted. ***Show diagram of draft mental health plan and briefly talk through the components*** As a person with expertise and experience in the area of health service planning / delivery, we are interested to know about your views on the components of this draft *district* mental health plan, and how they could be implemented. Thank you for agreeing to participate and giving your time.		
	Introduction 2 (PHC / frontline workers) At the present time in ******, fewer than 1 in ** people with mental illness ever get the care they need. One of the main reasons is lack of access to mental health care due to a scarcity of specialised mental health professionals across the country. To overcome this problem, the WHO recommends integration of mental health care into primary health care. WHO has recently published up-to-date guidelines for PHC workers, called the mhGAP Intervention Guide.		

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	INTRODUCTION 3 (community) At the present time in ******, many people who suffer from mental disorders or problems with alcohol can't get treatment because there aren't enough specialists to deliver the care. In this study we are working with ******'s Ministry of Health to try to improve this situation. The community will be very important in helping with this effort. We are, therefore, interested to hear about your opinions on how people with mental disorders and alcohol problems can best be helped. Thank you for agreeing to participate and giving your time		
	When we talk about people with mental disorder, we are thinking about the following kind of problems: (1) psychosis (2) depression (3) alcohol problems (4) (epilepsy)		

	Presentation of case-vignettes as examples **(If needed to orientate respondents)** (Use the WHO vignettes – see appendix)		
I.	**DEMAND/ACCESS**		
1.	Many people with mental disorders do not seek help from health care facilities. What strategies do you think could be used to increase demand for services? Specify for: • Psychosis • Depression • Alcohol problems • (Epilepsy)		FGD HF FGD CO IV N-HO IV D-HO IV HF IV CO
2.	Would it be helpful to try to raise awareness? What would be the best way to do this? Who would do the awareness-raising?		IV N-HO IV D-HO IV HF IV CO
	Detection/ identification		

3.	Many people who suffer from mental disorders / alcohol problems never get identified.
	What do you think is the reason for this?
	• How could detection of mental disorders be improved in the community?
	• Who could help to improve detection?
	  ○ Community health workers? Traditional healers? Religious leaders / healers?
	  ○ Do you think people in the community can be trained to help in the identification of people with mental illness?
	  ○ What non-health sector stakeholders could be involved?
	  ○ How could they integrate identification and detection work within their day-to-day activities and responsibilities?
	  ○ Is it the same for psychosis? For depression? For alcohol problems? For epilepsy?
	• How could detection of mental disorders be improved in the PHC setting?
	  ○ Is it the same for psychosis? For depression? For alcohol problems? For epilepsy?
	• Do you think detection could be more difficult for some groups? For example, women? Those who are very poor? In what way? How could this be overcome?
		*	IV N-HO
			IV D-HO
			IV HF

	Access to care		
4.	What do you think could be the main barriers for people with mental disorders to come to PHC for treatment? • Ask specifically about distance, cost, lack of relatives, differing cultural beliefs, concern about quality of care in PHC / availability of medications? Anything else? • What about access by women? By the very poorest in society? • Do you think this will be more of a problem for some disorders than others? What about AUD? What about depression? What about psychosis? What about epilepsy? If so, why?		FGD CO IV D-HO IV HF IV CO
5.	What could be done to improve access to mental health care in PHC to overcome these barriers? • What could the community do to help? • What could be done by PHC workers?	*	FGD CO IV D-HO IV HF IV CO
6.	How do we ensure that the most disadvantaged are able to access mental health care? • What can be done to make mental health services easier to access for women in the community? • What can be done to make mental health services easier to access for the poorest people in the community?	*	FGD CO IV D-HO IV HF IV CO
	Pathways to care		
7	Consider someone with who has a mental illness/depression/alcohol misuse who has sought help for this problem? • Who did they seek help from? • Do you know how they knew where to seek help from? • What was the nature of the help they received? • What other kinds of help/care are available in your community? • Do you know how long it took to get help once identified as having a mental health problem? • Would you advise other community members to seek help for depression/alcohol misuse/serious mental illness from this source again? o If yes – Why? o If no – Why not?	*	FGD CO IV HF IV CO
8.	Some people with mental illness may not know that they can receive help. What do you think		FGD CO

	would be the best way of informing them and helping them to get the care that they need?		IV HF IV CO
II	**DELIVERY**		
9.	What do you think about community health workers being trained to perform tasks that are currently/ usually being performed by mental health specialists? • Do you think it can work in practice? • What parts of mental health care would be the most difficult for the PHC worker to do? • Are there some kinds of mental illness that would be easier/more difficult? • What would be necessary to make it work? • How acceptable would it be to PHC workers? • How acceptable would it be to people with mental disorders? • What limitations does this approach have? • Is there an alternative?	*	IV N-HO FGD HF FGD CO IV D-HO IV HF
10.	How feasible would it be in the current health care system? • Specify for different tasks: o Detection o Diagnose mental illness? o Prescribe medications for mental health problems? o Medication continuation? o Provide psychosocial interventions? o Monitoring of condition?	*	IV N-HO FGD HF FGD CO IV D-HO IV HF
11.	Who do you think can provide these mental health services? • Which primary health care worker should be trained to deliver mental health services? • Specify for different tasks: o Detection o Diagnose mental illness? o Prescribe medications for mental health problems? o Medication continuation? o Provide psychosocial interventions? o Monitoring of condition?	*	IV N-HO FGD HF FGD CO IV D-HO IV HF
12.	What training do you think PHC workers would need before they could deliver mental health care?	*	FGD HF

	• How much training, how long? • What methods of training? • How could we assess whether they have the necessary skills? • Who should provide the training? • What resources and methods are required to sustain the training?		IV HF IV D-HO IV HF
13.	After the training, what kind of support or supervision would the provider need to be able to deliver the interventions? • Would they need any support from a mental health specialist? • How could this work? (explore, eg how often should the supervision/support sessions happen?, who should provide the supervision?) • Would they need ongoing supervision? • Are there similar existing models for other disorders? • Would they need ongoing in-service training? • How often? Is this feasible in practice?	*	FGD HF IV HF IV D-HO IV HF
14.	What are the existing health supervision structures? Is it adequate? What additional supervision structure and skills need to be implemented? • How to ensure quality of supervision?? • How can that be made sustainable?		FGD HF IV HF IV D-HO IV HF
	Provide a brief introduction on the mhGAP Intervention Package • Key treatment components for o Depression: diagnosis → provide psycho-education → address psychosocial stressors → reactivate social networks → consider anti depressants → consider psychotherapy (Cognitive Behavioural Therapy, Interpersonal Therapy, Behaviour Activation) o Psychoses: diagnosis → provide psycho-education → begin anti-psychotic medications → provide psychological interventions (family therapy, social skills training) → facilitate rehabilitation o Alcohol Use Disorder: diagnosis → provide brief interventions to reduce harmful drinking → enrol self help groups → support families and carers -→ relapse prevention (including psychotropic medications)		
15.	How do you think that the key treatment components (as per mhGAP package, SEE ABOVE) fit	*	IV N-HO

	with the existing work of the primary health care staff? • How can these treatment components be best delivered within a non-specialist setting? • Are there parts of the treatment components that you think will be difficult to implement? Why do you think? And how could these difficulties be overcome?		FGD HF IV D-HO IV HF
16.	How feasible will it be to provide medications that are not on the essential drugs list? • What is needed to get these medicines made available? • What are the barriers to medication procurement? • How can a continuous supply of medication be ensured? • What should we do if these medications are not available?		IV N-HO FGD HF IV D-HO IV HF
17.	Organizational structures within the health service will need to support the delivery of mental health care. What do you think are the key system requirements? • Would a coordinator be required / feasible? • At what level would they operate? • Would they be a mental health professional? • (For health service managers): what information would you need to monitor mental health care on an ongoing basis?	*	IV N-HO FGD HF IV D-HO IV HF
III	**RECOVERY**		
18.	The treatment of some mental disorders often requires long-term / ongoing care and rehabilitation. How could this be achieved? • If people with mental illness drop out of care, what are the ways of detecting this and supporting them to get the care they need? • Any models of outreach from the health facility? • How can they be supported to take medication over a long period of time? • Are there existing models that could help e.g. in the field of HIV? • What support could be given to the family?	*	IV N-HO FGD CO IV D-HO IV HF
19.	Some people with mental illness may be more likely to drop out of care (eg people who don't have access to transport, or don't have money for transport). How can we make sure that ongoing mental health care is provided equitably?	*	IV N-HO FGD CO IV D-HO IV HF
20.	Who are the key persons in the community in regard to rehabilitation / reintegration? • How can we work with them for people with mental disorders? • Are there existing models for engaging with traditional / religious healers?	*	IV N-HO FGD CO IV HF

	• Are there existing models for engaging with non-health sector? • How could people with mental illness be supported with their livelihood? To develop skills?		IV CO
21.	(*Stigma*) People with mental disorders can sometimes experience negative attitudes from other people. • What could be done to tackle this? • Who could help? • Would awareness-raising be helpful?	*	IV N-HO FGD HF FGD CO IV HF IV CO
22.	(*Discrimination*) People with mental disorders can sometimes be excluded from social gatherings, prevented from working with others, prevented from taking certain positions, even after they have recovered from their illness • What could be done to tackle this? • Who could help? • Would awareness-raising be helpful?	*	IV N-HO FGD HF FGD CO IV HF IV CO
23.	(*Abuse*) People with mental disorders can sometimes be victims of violence or chained up • What could be done to tackle this? • Who could help? • Would awareness-raising be helpful?	*	IV N-HO FGD HF FGD CO IV HF IV CO
IV	**ACCOUNTABILITY**		
24.	How to ensure adequate quality of care? • How is this best monitored / improved? • By whom? • Does the wider community have a potential role?	*	IV N-HO IV D-HO FGD HF
25.	How can implementation of mental health services best be monitored? What would have to be adapted to improve the current system?		IV N-HO IV D-HO
V	**STAKEHOLDER VIEWS ON MENTAL HEALTH AND RESEARCH UPTAKE**		

26.	How do you think mental health care can be given more priority? • Which key decision makers need to be influenced? • What methods of communication should be used? • What type of knowledge/evidence may be useful to improve the priority status?		IV N-HO FGD HF IV D-HO IV HF IV CO FGD CO
27.	Which groups do you think are important to speak to in the district for improving mental health care?		IV N-HO FGD HF IV D-HO IV HF IV CO FGD CO
28.	Research Uptake and Communications • How can we ensure that the results of our research are useful to you? • What are the best ways in which we can share our research with you (e.g. articles, policy briefs, brochures?		IV N-HO FGD HF IV D-HO IV HF IV CO FGD CO
29.	How to create political buy-in for the integration of mental health in primary health care? • At district and national level?		IV N-HO IV D-HO FGD HF

Appendix 1

Case vignette of psychosis

A previously normal person has changed over the past 1-2 weeks. He or she has become extremely restless, looking frightened, and trying to do unreasonable or dangerous things - starting a fire, smashing objects, undressing, tearing clothes, or even attempting to harm people for no reason. Sometimes such a person may behave as if hearing voices that no one else can hear, or seeing things which are not real. Such a person may be very difficult to stop or talk to, but may say that he/she is receiving orders from God, or is communicating with spirits. Usually this sort of state lasts for days or a couple of weeks after which the person either returns to normal, or continues to say strange things and look about strangely but is no longer excited and difficult to manage.

Case vignette for depression

Someone in periods, lasting for weeks or a couple of months, has been looking very sad, miserable and unable to cope with everyday activities, and is slow in speech and movements. If spoken to, such a person may say that he/she is very ill, and describe various apparent or presumed illnesses; that life if not worth living; that he/she would never get better; that the family would starve; or that he/she is a sinful or worthless person. Nothing seems to be capable of cheering him/her up. Such a person usually does not eat well, cannot sleep at night and may lie in bed for days without doing anything. Sometimes a person with such problems may look very tense and afraid, as if something terrible is going to happen, and be unable to stay still, pacing up and down nervously. Such a person may attempt suicide.

Case vignette for alcohol problems

*Someone drinks alcohol frequently. When they drink alcohol, they often drink the strongest alcoholic drinks (e.g. **, **)) and often become intoxicated. On many occasions after drinking alcohol they become argumentative and get into fights with other people, on two occasions resulting in them being arrested. This person would rather drink alcohol than work and the drinking is causing problems within the family. The person sometimes shakes in the mornings.*

Case vignette for epilepsy

Someone from time to time has fits in which he/ she suddenly falls to the ground with a scream, the body becomes very stiff for a short while, and then violent jerky movements of the limbs begin. The person having a fit may get frothy at the mouth, usually turns blue in the face, and may pass urine without being aware of it. During the fit he/she is unconscious, does not respond to questions, and is insensitive to touch. The jerks of the body last for a couple of minutes and gradually stop, after which the person may go off into sleep, or stand up looking dazed, be slow in replying to questions, and unable to remember what had just happened. Between fits such persons look normal, but some of them may be known for their difficult character.