Core protocol for assessment of patient experience and service provision culture

A Guide to Clinic Ethnography

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1. Introduction

Clinic ethnography is a qualitative approach based on ethnographic methods. Ethnography is a methodology popular in anthropological research, as well across the social sciences, designed to systematically study people and cultures. An ethnographic methodological approach is in-depth, flexible, iterative, participatory and focuses on understanding meaning in context. It is built on the premise of the researcher immersing him or herself into the social world of the participants in order to build trust, rapport and an 'emic', or insider's, perspective of their lives.

Applying ethnographic methods to a health or clinic setting can be a valuable tool for health researchers. Herdt (1999) states that "what distinguishes clinical ethnography from anthropological ethnography in general is (a) the application of disciplined clinical training to ethnographic problems and (b) developmental concern with desires and meanings as they are distributed culturally within groups and across the course of life". Researchers are able to immerse themselves to a degree, allowing for richer understanding of the social and power dynamics of a clinic, provider behaviours, patient perceptions and experiences of health care. This can be important for assessing issues such as: access to care, quality of care, continuity of care, and other barriers to care including indirect costs (e.g. transportation) and lack of trust in health care providers.

Long (2008) explains the value of using ethnographic methods in a hospital, providing opportunities to explore not only the organisational and structural characteristics of an institutional system, but also a space where new identities are forged: "for many people, hospitals are places in which their previous identities as a healthy person, as a mobile person, as an immobile person, are stripped bare. New identities, such as a cancer survivor, a more mobile person with a new hip, a rehabilitated person with one less limb are forged". Patients, health providers and a range of staff members and visitors (including researchers) move about these spaces, bringing with them multiple roles and skillsets, which have an impact on the way illness and treatment, are experienced. Gordon (2004) usefully describes clinic ethnography as: "the attempt to situate clinical cases within a cultural framework, one that is based on *both* the specialized expertise of the clinician and the broad-based grasp of cultural issues that characterizes the ethnographer".

Undertaking clinic ethnography involves a range of participatory and non-participatory data collection methods, including semi-structured interviews, observations using "thick" description, and reviews of routine data sources (e.g. treatment register, patient records, clinic guidelines and protocols). These are used to develop patient case studies, clinic mapping, infrastructural assessment, tracking patient pathways, time-motion studies for different cadres of health workers. Additional participatory techniques (e.g. action research, photo-voice, Participant Ethnographic Evaluation Research) may be used to support the collection and collation of detailed field notes. Specifically, the methods outlined in this manual will allow you to capture issues relating to space, infrastructure (e.g. building design equipment, and technology), consumables (e.g. medicines and medical devices), as well as movement and flow of patients and health workers, and ideas and values about health, risk, illness, and health-related behaviours; all issues which are pertinent to settings where NCD and MHPSS care is provided.

The guidelines provided below are general and intended as a starting point. We offer some steps, tips and suggestions, along with references to further resources that you will be able to use to develop and refine your study. Examples of instruments used and data collection experiences are provided throughout this manual for reference purposes. As each project is context specific, the instruments provided should not be used without further adapting to the specific objectives of each project.

2. Aims and objectives

Before commencing your study, researchers must have a clear understanding of the aims and objectives of applying ethnographic methods to each specific health setting. For research conducted under the support of the NIHR Research Unit on Health in Fragility, this principally involves building understanding of patients' and health providers' experiences of non-communicable diseases (NCDs) and mental health and psychosocial support (MHPSS) services in primary health care (PHC) facilities, noting that in PHC facilities, continuity of care and encouragement to return is a key goal. The methods outlined in this manual are designed to provide preliminary evidence in support of assessing patient trajectories to care, patient treatment adherence issues and staff experiences as providers of care. This includes understanding patient knowledge about their risk of illness, illness experience and/or treatment and staff communications and interactions during care.

3. Research questions

Research questions serve to define the focus of your study and should therefore be adapted to each specific study and setting. The questions should explicitly relate to the topic and stages or pathways of care you are investigating. Questions can be descriptive or more analytical. Descriptive questions aim to provide a comprehensive and detailed account or narrative of the phenomena under observation, while an analytical question usually seeks to examine the influence of one or more factors on a particular outcome.

Example 1: Descriptive questions

General descriptive questions might, for example, include:

- What is the structure and organisation of services for X diseases in this clinic?
- What is the process of registering patients in primary care facilities?
- What is the trajectory of care for patients with X condition presenting to the primary care facility?
- How often, when, and where do staff involved in care for X condition communicate directly with each other?

Example 2: Analytical questions

Analytical questions might, for example, include:

- How does the spatial layout of the clinic influence pathways to care for X condition?
- Does gender (or age) influence patients' trajectory of care?
- How do power dynamics among staff in the clinic influence the organisation of care for X condition?
- How do working conditions in the clinic influence health providers' motivation and the delivery of care?
- How do patient-provider interactions influence patients' experience of care/adherence to x treatment regimen?

Example 3 : Questions specific to different perspectives of key figures in your study

It may also be helpful to develop questions specific to the different perspectives of key figures in your study (e.g. patients, health providers, managers). For instance, questions focused on patients' perspectives might include:

- What are patients' experiences of care pre-diagnosis? During treatment? Post-diagnosis?
- What is the role of X [specific cadre of health worker] in the care of patients with condition Y?
- When and how do clinic managers collate and make use of clinic data on condition X?
- How do managers support health workers in clinic X?

Example 4: Questions for studies evaluating particular interventions or strategies

If the study is evaluating implementation of particular interventions or strategies, questions might include:

- What has the intervention or strategy affected work roles, responsibilities and routines in the clinic?
- What are health providers perceptions of the value of the intervention/strategy? How do they perceive it will change processes and/or outcomes of care?
- How have health providers/patients responded to the interventions? What are their experiences of implementing the new strategy?
- What are the challenges to and enablers of implementation of the strategy?

4. Selecting the project site

It is important to first define the clinic/facility under study and have a clear understanding of which aspects of the clinical setting will form the crux of your research. It may be that your study will include a combination of primary, secondary, tertiary, diagnostic, treatment, in-patient or outpatient services. For instance, if the study is focusing on a particular NCD, you may decide to conduct the clinic ethnography in the specific ward or outpatient treatment facility, while also reaching out to relevant community or social support services (i.e. those that the patient or would-be care seeker is in contact with in relation to their care). A cancer patient may, for instance, be in contact with a community support network or organisation alongside their medical treatment.

5. Study population and sampling

Depending on the above factors, the study population may consist of patients and staff members (including any auxiliary staff and/or staff from referring departments and institutions if relevant) of the clinic/facility under study. Selection criteria may include:

- All patients beginning treatment during the period of study
- Staff members (including auxiliary and referral staff) who are involved in patient care during this same period

In some countries/contexts, it may be more common for care to be provided at the community level, perhaps through informal care. When appropriate, these settings can also be incorporated into the study by including the relevant care providers (e.g. informal carers, community health providers) working in this sphere as part of the study population.

Your method of recruiting participants will depend on the aims of your project. Once your target group and eligibility criteria are identified, purposive sampling can be used to recruit participants that share the specific set of characteristics relevant to your study. Snowball sampling can then be applied if there is a large number of potential participants that are not easily identifiable.

Theoretical sampling is a sampling technique commonly used in grounded theory but also appropriate to ethnographic research. A form of purposive sampling, this strategy allows you to locate participants on

the basis of identifying people and information that specifically pertain to conceptual questions and theoretical development (Miles and Huberman 1994). In a health setting, this may refer to recruiting participants who can help you answer specific questions about common themes and patterns of patients' or providers' experiences in the health facility, as demonstrated by the data you have already been collecting. For instance, you may find that patterns in your data indicate differences in how participants understand their own role as either patient or provider, or the role of the clinic in which they work or are visiting. Using theoretical sampling to develop the concept of how these roles might differ in alternate care settings (e.g. informal care received in the home or social support received by a community health network) may lead you to additional research sites with a new subset of potential participants.

Example 5: Theoretical sampling of maternal health service providers in rural Andean communities of Peru

In a study of community health workers (CHWs) providing maternal health care in Peru, participants were initially sought on the basis of their direct involvement with CHWs and rural maternal health services (e.g. women receiving pre-/post-natal care from CHWs, CHWs themselves, formal care providers visiting rural health posts). During analysis of CHW and health provider interviews, patterns of discrimination in the workplace began to emerge, specifically amongst lower level care providers who had previously been based in or received training from district level health facilities. A theoretical sample was then selected consisting of multiple cadres of health providers from the district level and not limited to maternal health care. Subsequent interviews were then held to explore emerging conceptualisations of discrimination as it was experienced between different cadres of health providers including CHWs, as well as between health providers and health seekers in district level health facilities (Vidal 2015).

6. Ethical considerations

Prior to collecting data, it is important to consider the ethical issues you may encounter during qualitative research (Iphofen and Tolich 2018). General principles of ethical research should be applied throughout the study. This includes following agreed upon procedures for obtaining informed consent and ensuring participant confidentiality and anonymity. Researchers must respect the dignity and values of their research participants. This requires being cognizant of cultural similarities and differences without passing judgement. Working in a clinical setting means the researcher may be privy to confidential or sensitive patient information. Some individuals may also have experienced, or currently experience, hardships or other forms of vulnerability. Therefore, researchers must clearly articulate to the research participants the aims of the study, the reasons they have been asked to participate, and any potential benefits or risks (or lack thereof) to their involvement. Participants should be provided with an information sheet and consent form (see Appendices 1 and 2) which clearly outline these and further details of the study and the participants' rights (e.g. that their participation is voluntary, that they have the right to withdraw at any time).

7. Data collection

In a clinic ethnography, data can be collected using a combination of any of the following methods:

- Interviews
- Observation
- Patient case studies
- Clinic mapping
- Infrastructural assessment
- Tracking patient pathways
- Time-motion studies
- Participatory techniques
- Collecting field notes

7.1 Interviews

Interviews are one of the main methods of conducting qualitative research and are useful for understanding the issues from the participant's point of view. In a clinical setting, you will have a chance to interact with staff members and patients, both of whom will have very different perspectives of the issues at hand.

There are several types of interviews that can vary in degree of structure. The two main types of interview are unstructured and semi-structured. **Unstructured** interviews may follow the format of a conversation. Though you may have a broad theme in mind during this type of interview, you will be open to pursue other themes depending on what the interviewee says. **Semi-structured interviews** include the use of a loosely structured topic guide made up of both closed and open-ended questions. This type of interview allows you to approach the interviewee with specific themes and questions in mind, also making use of probes to follow up on topics of interest pertinent to your research objectives. Note that the interview guide should not be used as a 'questionnaire'; rather, it is a tool that gives you the freedom to adapt or probe on other topics as they come up.

Interviewing staff members allows insight into aspects of health care provision and delivery. This includes individuals who belong to different cadres of care. All staff involved in patient care and support, such as medical, nursing and administrative staff, as well as any auxiliary staff and/or staff from referring departments and institutions if relevant, can be interviewed using a semi-structured topic guide (see Appendix 3). The focus of these interviews can range from exploring staff interactions and communication practices with patients to their perceptions on the challenges and barriers to service delivery and patient continuity of care.

Example 6: Conducting staff interviews at an outpatient tuberculosis (TB) clinic in Latvia

In a study conducted in 2017, Kielmann and colleagues (2018) used semi-structured interviews to investigate tuberculosis treatment adherence in Riga, Latvia. A total of 14 staff members were interviewed over two rounds. Staff members included in the first round of interviews were selected on

the basis of their involvement with TB patient care and support (medical, nursing, administrative, and auxiliary) at the designated outpatient clinic as well as at three relevant referring departments and affiliated institutions. Six of these staff members were interviewed during a follow-up round. Their involvement in follow-up interviews was determined on the basis of their awareness and role in supporting the intervention related to the study. Follow-up interviews were not conducted with staff who were not directly involved, or had very limited roles in direct communication and care of patients initiated onto treatment during the intervention period.

It is a good idea to include multiple cadres of staff in your participant group, while also differentiating between community-led, primary, secondary or tertiary care practitioners. This way you will be able to capture the experiences and opinions of people working within or with the designated clinic setting who are involved in patient care. For example, a medical receptionist at a primary care facility in charge of greeting and registering patients might have a very different yet equally valid account than a treating physician or a mental health nurse working in an inpatient facility.

Interviews with patients can be conducted using a semi-structured topic guide (see Appendix 4) that covers aspects of their experience seeking and/or receiving care at the clinic/facility. This may include treatment initiation, care and support, communication with providers at each stage of treatment, as well as the broader familial and social context of their medicine/taking (or other aspects of care seeking) behaviour. A patient who is undergoing treatment for hypertension, for example, may be following a strict diet and exercise regime along with taking prescribed medication. Their treatment in this case extends into their home life where lifestyle factors may be related to or influenced by their family or broader environment.

Depending on the design and length of your study, you may choose to conduct more than one interview with each participant at different points in time. The first interview may for instance be at the start of the study, with a second interview occurring at the mid or end points. Iterative probing can be useful for collecting baseline data which you can then use to compare with data collected at later stages.

7.2 Observations

Observations should be conducted at relevant points of the patients' trajectory of care with a purposively selected set of staff and patients who have sought or initiated treatment during the study period (dependent on selection criteria). In qualitative research, observations can be structured, unstructured or falling somewhere in between. Unstructured observations may involve deciding on the setting of observation and taking detailed notes of everything you see. This can be useful during the formative stages of a study or if the topic of study is unfamiliar. Structured observations on the other hand, follow a pre-defined checklist of items. In clinical settings, both semi-structured and structured observations can be useful for assessing aspects of the quality of health services (Kielmann et al. 2011).

A semi-structured observation guide (Appendix 5), for instance, can be used to identify communication style, informational content and other aspects of patient and provider interactions (Wind 2008). In a health setting, this would normally include at least the following points: reception, initial meeting with a clinician or nurse, and consultation regarding treatment regime if applicable. Depending on the particular patient trajectory, other points of patient contact might include additional referring

departments, outreach services or other home-based visits. Wind (2008) discusses some limitations and possibilities of observation in specialised healthcare settings.

Example 7: Selecting observation points at an outpatient TB clinic in Latvia

For their study, Kielmann et al. (2018) conducted brief observation sessions of 20 to 30 minutes in the DOT (direct observation treatment) room of the ambulatory clinic and the physician's office where patients would go following their first diagnosis with TB. These points along the patient trajectory were selected according to relevant staff members' availability to minimise disruption to clinic functions. There were two researchers present during each session who were then able to collate observation notes. During the second round of data collection, the researchers were invited to observe an outpatient DOT clinic for a period of two hours. These observations provided the researchers with an in-depth understanding of the use of clinic space, the implementation of direct observation as a care practice, and the interactions between DOT nurses and patients on treatment.

The observations should be recorded through notes that may include descriptive notes (providing rich detail on *what is* happening), analytical notes (beginning to interpret what you see by providing meaning and context) and reflective notes (providing insights on one's own experience and feelings associated with ones presence in the field, and the process of data collection).

7.3 Patient case studies

You may wish to develop short narrative case studies where possible, for a select number of patients. These case studies can be used to document comprehensive information on their experience of treatment which can be triangulated from different sources including interviews, observations, review of patient records, and quantitative data collected over the course of study.

Example 8: Short narrative developed from patient case study in Riga, Latvia (Kielmann et al. 2018)**.**

The following narrative was written using data collected through semi-structured interviews, observations and a review of demographic information gathered from patient records. Names were changed to protect confidentiality.

"Kaspars started treatment in mid-October 2016. When we interviewed him in November 2016, he expressed anger and frustration with the experience of hospitalisation and delays in establishing a diagnosis. The head ambulatory nurse recalled her first meeting with him as tense; he appeared to be paranoid, and have some "*mental problems*"; she described his mistrust of doctors, negative

attitude and nervous mannerisms. However, after gaining trust and support not only for himself but his girlfriend who was also being treated for TB, he came regularly, asked questions, and appreciated the care he received. At the time of our second visit in March 2017, he had not missed any doses to date. Kaspars' case illustrates the influence of previous experience with the health system on treatment readiness. Here, a change in his treatment literacy and responsiveness can be linked to his experience of care at [the outpatient clinic] as being '*humane*' and reassuring after his time at the hospital which he described as a '*factory*'".

Example 8: Short narrative developed from patient case study in El Salvador (de Vos et al.)

The following narrative was written using data collected through patient illness narratives gathered in El Salvador with the aim of describing the different pathways of support in people living with non- communicable diseases. Names were changed to protect confidentiality.

Margarita is 45 years old; her father was killed when she was two years old. Her mother, sister and sister's daughter currently live in the United States. She lives with 3 of her 6 children and works at home. She was diagnosed with diabetes mellitus in 2012 at the public hospital of Santa Rosa following a complication of her illness. She has never attended a clinic; instead she has been monitoring her illness using primary care services, however, not regularly. She went once to a private clinic because her partner recommended she do so. Fifteen days prior to the interview she underwent a leg amputation due to her illness.

7.4 Clinic mapping

Ethnographic mapping consists of drawing a map of the local community or the setting in question to locate key features, landmarks, social services and other important information. This activity is usually carried out by the researchers, and sometime with the help of members of the local population. In a health setting, mapping can be useful to locate clinics, doctors' offices, hospitals and other important health or social service facilities which make up the 'territory' of the study population (Pelto 2016).

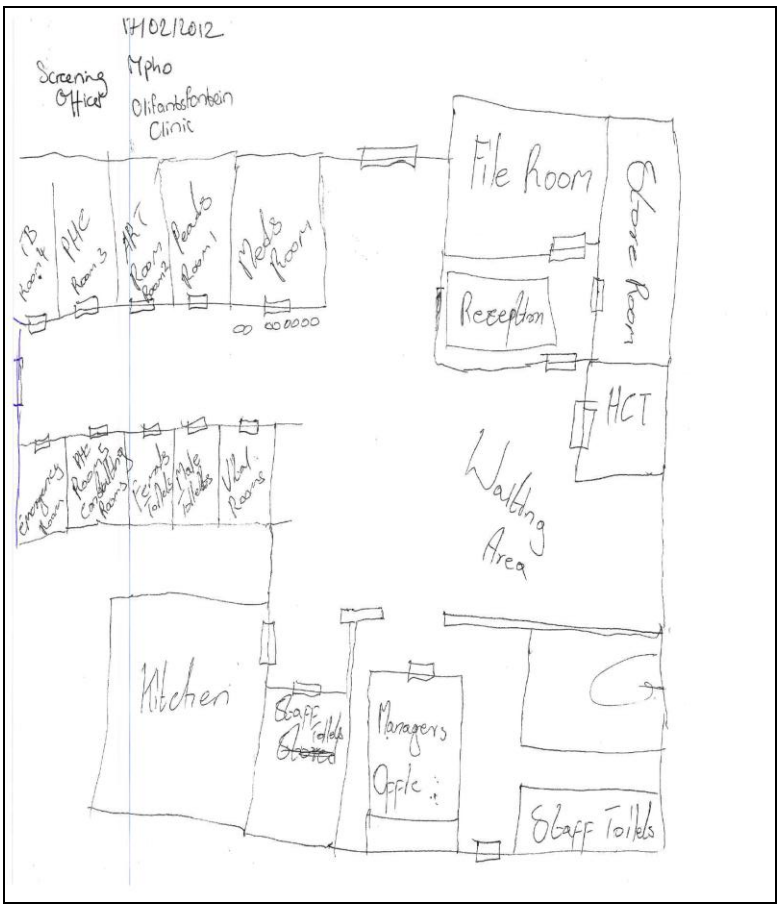
Example 9: Clinic map of TB and HIV services in South Africa

In the MERGE trial (Kufa et al. 2014), researchers sought to understand how TB and HIV services might be better integrated in South African primary care clinics. Researchers asked health workers to draw clinic maps in order to

visualise the spaces where TB and HIV care were being delivered, and the pathways that patients undertook to navigate these services (See

Figure 1)

Figure 1: Clinic map



7.5 Infrastructural assessment

Infrastructural assessment can be a valuable tool relevant to health care systems management. This approach views the role of health care facility infrastructure as a major component of the health care system. Full or rapid assessment is therefore conducted to measure the quality of all infrastructural components in health facilities. This assessment is dependent on the condition you are investigating. For instance, infrastructural assessments of TB services will be different from those of other illness services such as HIV or cancer care. See for example WHO (2008), which provides a useful operations manual of infrastructure considerations for health centres providing HIV services. Sholz et al. (2015) also provides a useful summary of different forms of assessment tools available in developing countries that consider

facility infrastructure including 'Service Availability and Readiness Assessment' (SARA) and the 'Health Center Assessment Handbook' (Federal Ministry of Health, Ethiopia 2008).

7.6 Tracking patient pathways

The patient pathway is the route a patient takes from their first point of contact with a health provider, leading to diagnosis, potential referral and completion of their treatment. Tracking patient pathways allows you to map the expected route of a patient's care within a specified timeframe and setting (O'Brien et al. 2007). This can be approached through a review of patient records or other routinely collected data about the patients' service usage.

7.7 Time-motion studies

Time-motion studies can be used to capture information about time allocation and productivity. Since its development in the early 20th century within the industrial engineering field, the approach has been broadly adapted by biomedical researchers often focusing on clinical workflow related factors. There is however methodological variability in how previous studies have reported data and findings. Lopetegui et al. (2014) provide a detailed description of the distinct methods used in articles referencing time-motion studies. In a clinic ethnography, this approach can, for example, be applied to understand how different cadres of health workers use their time.

Example 10: Time-motion studies in Tanzania (Tani et al. 2016)

This study investigates this issue for paid community health agents trained for nine months in primary health care service delivery and deployed to villages as subjects of a randomized trial of their impact on childhood survival in three rural districts of Tanzania. To capture information about time allocation, 30 community health workers were observed during conventional working hours by research assistants for 5 days each over a period of 4 weeks. Results were presented in terms of percentage time allocation for direct client treatment, documentation activities, health education, health promotion non-work-related activities and personal activities.

7.8 Participatory techniques

In contrast to the methods described thus far, participatory techniques aim to involve the participant as much as possible in the research process. By consulting and involving citizens over the course of developing and implementing studies, these techniques hope to improve quality, transparency, and accountability of research and its use in local communities. As Cornwall et al. (1995) state: "breaking the linear mould of conventional research, participatory research focuses on a process of sequential reflection and action, carried out with and by local people rather than on them…the key difference between participatory and conventional methodologies lies in the location of power in the research process".

Participatory research has also been used with varying levels of success in ethnographic research. For example, action research, which uses new understandings of situations to develop new activities, can be used to link research back to a project's plans (Tacchi et al. 2003). Photo-voice, a form of action research, is typically used to give 'voice' to marginalised populations by analysing photographs they take as part of a study (Burris and Wang 1997, Sutton-Brown 2014). Participant Ethnographic Evaluation and Research (PEER) is another strategy that has been used in situations where participants may not have established, or had time to establish, trust or rapport with the researchers, as may be a case in fragile or conflict-affected settings or other situations of vulnerability.

Example 11: Using PEER in South Sudan

Elmusharaf et al. (2017) address how contextualized data can be collected in a short time and under conditions in which participants in conflict-affected zones might not trust external researchers. Through their use of PEER, they overcome a problem common to many ethnographic or participatory approaches: extended time and resources needed to develop trusting relationships with the community to understand the local context and the social networks they form. In their study, they trained South Sudanese marginalized women as PEER researchers to design research instruments, and collect and analyse qualitative data to assess barriers to maternal health care.

The authors list a number of steps required in the use of the PEER methodology, including the following:

1. Recruitment of PEER researchers,
2. Training of the PEER researchers,
3. Development of data collection instruments,
4. Data Collection,
5. De-briefing,
6. Insider interpretation,
7. Thematic data analysis.

7.9 Collecting field notes

Taking field notes throughout data collection is recommended as it can help capture your thoughts and experiences about what is happening. This can be a good opportunity to reflect on anything that you find new, interesting or noteworthy, which you can later use to complement or expand upon data collected elsewhere (Kielmann et al. 2011). It is very important to train yourself and your research

assistants and make a habit of taking notes from an early stage on in the project. Note-taking is not intuitive, but can be developed as a skill alongside using observation techniques to more fully describe the clinic and other settings one is immersed in.

8. Data management and analysis

In accordance with the ethical guidelines of your study's institutional review board, all data involving participants will likely need to be anonymised at the start of data collection. Interviews should be recorded, transcribed and translated if necessary. After interviews have been transcribed, audio files should be permanently deleted. All remaining data (i.e. transcriptions, observation notes, case studies, maps etc.) should be stored electronically using password protected files. To assist with quality assurance, data can be reviewed by other members of the research team who were present during data collection to check accuracy and to fill in any missing pieces of information (with the information sheet provided to participants at the outset of the study having signalled that only members of the research team would have this access).

An option for analysing data in a clinic ethnography is to use a deductive approach to develop a thematic framework and coding system based on the content and context of patient/provider interactions, working practices and patient/provider experiences of care (See Kielmann et al. 2011 for details and tips on analysing qualitative data). Table 1 below provides a useful list developed by Braun and Clarke (2006) of the steps of thematic analysis. They note that these steps should not be viewed in a linear manner. Analysis is instead iterative, repeating steps as necessary.

Table 1: Phases of thematic analysis (Braun and Clarke 2006, p.87)

Phase	Description of the process	
1	Familiarizing yourself with your data:	Transcribing data (if necessary), reading and re-reading the data, noting down initial ideas.
2	Generating initial codes:	Coding interesting features of the data in a systematic fashion across the entire data set, collating data relevant to each code.
3	Searching for themes:	Collating codes into potential themes, gathering all data relevant to each potential theme.
4	Reviewing themes:	Checking if the themes work in relation to the coded extracts (Level 1) and the entire data set (Level 2), generating a thematic 'map' of the analysis.
5	Defining and naming themes:	Ongoing analysis to refine the specifics of each theme, and the overall story the analysis tells, generating clear definitions and names for each theme.
6	Producing the report:	The final opportunity for analysis. Selection of vivid, compelling extract examples, final analysis of selected extracts, relating back of the analysis to the research question and literature, producing a scholarly report of the analysis.

'Thick description' will be helpful throughout your analysis. 'Thick description' refers to using detailed interpretive descriptions to explain not only behaviour, but more importantly the underlying context of behaviour (Geertz 1973). The aim is to specify as many details, conceptual structures and meanings, rather than just noting down descriptive observations.

The field notes that you have taken throughout data collection allow you to take a closer look at the cultural context and meaning participants (and researchers) place on their actions and experiences. While sifting through your data, consider the following questions:

- Who are the specific people involved?
- What clues signify people's status' or roles?
- What explicit structures, rules or norms govern the situation?

Coding is an important step in the analysis process. You will need to set up a coding system which generally involves assigning labels to text that relate to a thematic idea. See, for example, Kielmann et al. (2011) for details on how to code data.

The codes that you develop should aim to *show* the events that are occurring rather than simply describing them (2006). One option as Glaser (1978) helpfully suggests is to use 'gerunds', or action words, to achieve this aim; however, the coding strategy you use will depend on the objectives of your project.

Example 12: Coding using action words to move beyond descriptions

In the study of community health workers providing maternal health services by Vidal (2015), the interview line "…the community members know to come to *me* when there is a problem…" (CHW 1) reflects how this participant viewed her role as a CHW.

A descriptive code, such as *"community members visiting community health workers"* would do well to describe the situation but could result in missing important culturally specific meanings hidden in the data. In this case the participant was expressing the feeling that the community members know to visit CHWs (rather than hospital workers or other health professionals) if they need advice. This excerpt was then coded as: *"acting as a community representative".*

Note that if the study is conducted over more than one point in time, the thematic framework can be developed for analytical comparison between each point, focusing on the context, mechanisms, and processes of change in communication and care practices (e.g. extracted from staff interviews) and how they are experienced by patients (e.g. extracted from patient interviews, observation notes).

9. Reporting findings and disseminating results

The content of ethnographic reporting varies, but most include narrative vignettes, which can be used to take the reader through your study from the participants' points of view. As with any study, you will

want to make sure you provide details of your data collection and analysis methods. Describe not only what you have observed but also provide interpretive accounts of the themes and patterns developed from your data, addressing also their theoretical relevance to your study problem.

Of particular relevance to the work of the NIHR Research Unit of Health in Situations of Fragility, the methodology outlined in this manual has potential to contribute to the development of NCD and MHPSS interventions or strategies. It can enable understanding of participants' awareness and engagement with relevant NCD and MHPSS services. Given the participatory nature of some of the techniques provided, it is critical to disseminate the results to not only key health systems management stakeholders, academics and wider audiences, but also to the participants themselves.

10. Conclusion

This manual has described the theoretical and practical aspects of conducting ethnography in a health setting. The approach is a form of ethnographic research which encompasses a range of qualitative data collection methods, including participatory techniques. The manual provided here is a starting point which can be used to develop and refine your study.

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APPENDIX 1: SAMPLE PARTICIPANT INFORMATION SHEET & CONSENT FORM: STAFF

My name is “xxxxx” and I am a researcher from “xxxx” in “xxxx”. I am a part of an international research team undertaking a research project titled: “xxxx”

You are being invited to take part in a research study. Before you decide whether or not to take part, it is important for you to understand why the research is being done and what it will involve. Please take time to read the following information carefully. Talk to others about the study if you wish. Contact us if there is anything that is not clear or if you would like more information. Take time to decide whether or not you wish to take part.

What is the purpose of this study?
The purpose of this project is to [aims of study]. This will involve [example: identifying staff communication practices with patients and the perceptions of patients about the service and quality of care received at this clinic]. The questions we will ask you today are focused on [example: the care you provide for patients]. If you agree to take part in this small study we will use your views and the information you share with us to assess [adapt to individual study].

Why have I been asked to take part?
You have been selected as a representative [clinic/facility name] as a regular provider of services delivered at this facility, and thus as an expert of the main challenges you have experienced and still face in providing [MHPSS/NCD] care among [population group].

Do I have to take part?
It is up to you to decide whether to join the study. We will describe the study and go through this information sheet. If you agree to take part, we will then ask you to sign a consent form. You will be free to withdraw at any time, without giving a reason.

What will happen if I take part?
If you agree, we would like to conduct [one or two] face-to-face interview[s] with you. Each interview will take about one hour, and we could arrange the time that most suits you. Additionally, you may also be requested to: 1) permit the researchers to conduct semi-structured observations of your interactions with patients whilst providing [service], and 2) permit the researchers to review patient files whose care you may have been involved in. You will be free to decline these requests at any time, without giving a reason.

What are the possible benefits of taking part?
The study will probably not help you directly, but the information we get should help us to understand [adapt to individual study].

What are the possible disadvantages of taking part?

There [are/are no] risks identified in relation to this project. If any question makes you feel uncomfortable during the interview, you will not be required to answer and if you are very uncomfortable or upset you should feel free to end the interview.

Will my taking part in the study be kept confidential?
Yes. The information being sought is strictly for study purposes and will not be revealed to anyone except members of the study team. In reporting our findings, no names will be disclosed; instead pseudonyms will be used where care will be taken to mask your identity.

What will happen to the results of the study?
The information we gather from the interviews will be used to evaluate [aims of study]. We will use this to inform the writing and publication of research articles in scientific journals as well as materials that can be of use for [key stakeholders: health service professionals, policy makers, etc] such as [policy briefs and/or presentations].

What happens when this study is finished?
The anonymised raw data collected during the study will be shared, stored and looked at by individuals based at Queen Margaret University, UK, [other institutions]. With your consent, this information will be stored in a repository for [up to 5 years at "xxxx"-adapt according to individual study] in an anonymised format for future research purposes only. If the results of this study are published in scientific journals or presented in scientific events, your name or any information that could disclose your identity will have been deleted or replaced by a code to protect your right to confidentiality.

Who is organising the research and why?
This research project is part of the NIHR Research Unit on Health in Fragility managed by partners from Queen Margaret University, UK and [additional partners].

Who has reviewed the study?
This study has been reviewed and approved by the research ethics committees of Queen Margaret University, UK and [additional partners].

What if something goes wrong or if I would like to speak to someone after my interview?
If you have a concern about any aspect of this study, you can speak to a person independent of your participation who will do their best to answer your questions:

[Name and contact information]

If you remain unhappy and wish to complain formally, you can do this through the principal investigator:

[Name and contact information]

If you have any questions, feel free to ask now or at the end of the interview. If you have read and understood this information sheet, any questions you had have been answered, and you would like to be a participant in the study, please now see the consent form.

Contact details of the researcher(s) conducting your interview:

[Name of researcher(s), address, email, telephone]

Participant Consent form – Staff[1]

Study Title:	
Principal Investigator:	**Study Site:**

	Please initial box
1. I confirm I have read and understood the information sheet dated "xxxx" for the above study. I have had the opportunity to consider the information, ask questions and have had these answered satisfactorily.	
2. I understand that participation in this study is voluntary and I am free to withdraw consent at any time, without giving a reason, without any penalties.	
3. I understand that data collected during the study, may be shared and looked at by the individuals from the research team who are employed by: Queen Margaret University, (UK) and [additional partners] I give permission for these individuals to have access to the information I have provided.	
4. I understand that the researchers will be conducting observations of staff and patient interactions in the clinic which may include written note-taking.	
5. I agree for the research team to have access to selected patient records whose care I may have been involved in and that information gathered from the review of selected patient records may be used to develop patient case studies.	
6. I agree for my interview to be recorded for the purpose of note taking.	
7. I agree to take part in the above study.	

Signing this declaration does not affect your right to decline to take part in any future study.

[1] Note that in lower literacy settings a simplified version of this form may be appropriate, with the participant providing a single signature or ark, or the researcher signing to confirm receipt of verbal consent by the participant.

Name of participant Date Signature

Name of person taking Consent Date Signature

APPENDIX 2: SAMPLE PARTICIPANT INFORMATION SHEET AND CONSENT FORM: PATIENTS

My name is “xxxxx” and I am a researcher from “xxxx” in “xxxx”. I am a part of an international research team undertaking a research project titled: “xxxx”

You are being invited to take part in a research study. Before you decide whether or not to take part, it is important for you to understand why the research is being done and what it will involve. Please take time to read the following information carefully. Talk to others about the study if you wish. Contact us if there is anything that is not clear or if you would like more information. Take time to decide whether or not you wish to take part.

What is the purpose of this study?
The purpose of this project is to [aims of study]. This will involve [example: identifying the clinical, social and financial factors that influence the health-seeking, and treatment behaviours of patients, as well as the perceptions of patients about the service and quality of care received at this clinic]. The questions we will ask you today are focused on [example: the care you receive, with particular emphasis on your experiences with communication and interactions with clinic staff]. If you agree to take part in this small study we will use your views and the information you share with us to assess [adapt to individual study].

Why have I been asked to take part?
You have been selected as a representative of the patients that use the services delivered at [clinic/facility name, and thus as an expert of the main challenges you have experienced and still face in accessing [MHPSS/NCD] care.

Do I have to take part?
It is up to you to decide whether to join the study. We will describe the study and go through this information sheet. If you agree to take part, we will then ask you to sign a consent form. You will be free to withdraw at any time, without giving a reason.

What will happen if I take part?
If you agree, we would like to conduct [one or two] face-to-face interview[s] with you. Each interview will take about one hour, and we could arrange the time that most suits you. Additionally, you may also be requested to: 1) permit the researchers to conduct semi-structured observations of staff and patient interactions during provision of care, and 2) permit the researchers to review your patient file. You will be free to decline these requests at any time, without giving a reason.

What are the possible benefits of taking part?
The study will probably not help you directly, but the information we get should help us to understand [adapt to individual study].

What are the possible disadvantages of taking part?
There [are/are no] risks identified in relation to this project. If any question makes you feel uncomfortable during the interview, you will not be required to answer and if you are very uncomfortable or upset you should feel free to end the interview.

Will my taking part in the study be kept confidential?
Yes. The information being sought is strictly for study purposes and will not be revealed to anyone except members of the study team. In reporting our findings, no names will be disclosed; instead pseudonyms will be used where care will be taken to mask your identity.

What will happen to the results of the study?
The information we gather from the interviews will be used to evaluate [aims of study]. We will use this to inform the writing and publication of research articles in scientific journals as well as materials that can be of use for [key stakeholders: health service professionals, policy makers, etc] such as [policy briefs and/or presentations].

What happens when this study is finished?
The anonymised raw data collected during the study will be shared, stored and looked at by individuals based at Queen Margaret University, UK, [other institutions]. With your consent, this information will be stored in a repository for [up to 5 years at "xxxx"-adapt according to individual study] in an anonymised format for future research purposes only. If the results of this study are published in scientific journals or presented in scientific events, your name or any information that could disclose your identity will have been deleted or replaced by a code to protect your right to confidentiality.

Who is organising the research and why?
This research project is part of the NIHR Research Unit on Health in Fragility managed by partners from Queen Margaret University, UK and [additional partners].

Who has reviewed the study?
This study has been reviewed and approved by the research ethics committees of Queen Margaret University, UK and [additional partners].

What if something goes wrong or if I would like to speak to someone after my interview?
If you have a concern about any aspect of this study, you can speak to a person independent of your participation who will do their best to answer your questions:

[Name and contact information]

If you remain unhappy and wish to complain formally, you can do this through the principal investigator:

[Name and contact information]

If you have any questions, feel free to ask now or at the end of the interview. If you have read and understood this information sheet, any questions you had have been answered, and you would like to be a participant in the study, please now see the consent form.

Contact details of the researcher(s) conducting your interview:

[Name of researcher(s), address, email, telephone]

Participant Consent form - Patients[2]

Study Title:	
Principal Investigator:	**Study Site:**

	Please initial box
1. I confirm I have read and understood the information sheet dated "xxxx" for the above study. I have had the opportunity to consider the information, ask questions and have had these answered satisfactorily.	
2. I understand that participation in this study is voluntary and I am free to withdraw consent at any time, without giving a reason, without any penalties.	
3. I understand that data collected during the study, may be shared and looked at by the individuals from the research team who are employed by: Queen Margaret University, (UK) and [additional partners] I give permission for these individuals to have access to the information I have provided.	
4. I understand that the researchers will be conducting observations of staff and patient interactions in the clinic, which may include written note-taking.	
5. I agree for the research team to have access to selected patient records (which may include my own) and that information gathered from the review of selected patient records may be used to develop patient case studies.	
6. I agree for my interview to be recorded for the purpose of note taking.	
7. I agree to take part in this study.	

Signing this declaration does not affect your right to decline to take part in any future study.

[2] Note that in lower literacy settings a simplified version of this form may be appropriate, with the participant providing a single signature or ark, or the researcher signing to confirm receipt of verbal consent by the participant.

Name of participant Date Signature

Name of person taking Consent Date Signature

APPENDIX 3: SAMPLE INTERVIEW GUIDE – STAFF

The below interview guide was used in the study by Kielmann et al. investigating TB treatment adherence at an outpatient clinic in Riga, Latvia.

Section 1: Profile of participant and role in TB service delivery

- Brief profile of participant (background, training, history of involvement at CTLD)
- His/her current role in TB care

Section 2: Understanding patient trajectories to care

- [*dependent on who is being interviewed*]: Please describe your involvement with TB patients in terms of the communication and activities you fulfil at different stages of their care-seeking process (e.g. at reception, patient registration, risk assessment, follow-up clinical, DOT and patient counselling visits)
- What are the main challenges you face in fulfilling your role (e.g. when it comes to screening, diagnosis, treatment follow-up, patient social and environmental conditions)?
- What strategies do you use to respond to these challenges (probe on patient follow-up methods, frequency of follow-up attempts, referral to other staff or external support services)

Section 3: Communication practices and patterns

- Returning to a patient's trajectory through the clinic as described, can you tell me more about your communication with the patient at different stages of care? (probe on when communication is required, by whom, length of time, what is the content of communication to patients during each stage? What is its purpose?)
- What sorts of issues or challenges, if any, arise at any/each of these stages? (probe on communication challenges such as language barriers, patient health literacy, patient behavioural cues, content that may be "lost in translation" during staff/patient communication). How do you handle these situations?
- At what stage(s) do you think it is most important to reach out to patients who might be at risk for non-adherence? Why?
- Did the training you received in August make a difference to how you communicate with patients likely to struggle with adherence? If yes, in what ways?
- What are some strategies you have used, or seen others use to ensure the patient shows clear understanding of the importance of continuing uninterrupted treatment? (probe on style, method and content of communication, perceived importance of communication, what makes it effective, what do you think would be most effective in helping them with adherence issues?)
- Can you provide some examples of instances where you felt a patient was more receptive to the information you were providing them? Less receptive? Why do you think this is? (probe on perceptions on patients' communication toward staff)

- Can you think of any examples where someone has had to adjust their communication style or language according to patient circumstances? (probe with whether or how often they have to repeat themselves or use other strategies to communicate such as translation/back translation, third-party). Describe how you handled this.
- Please recount any experiences you may have had, if any, with patients who you feel expressed disinterest/disengagement in their treatment or with the medical advice they are given (probe on body language, communication strategies as above). Describe how you handled this.
- What do you recommend as ways of communicating with this person to help improve their adherence?

Section 4: Experiences with intervention components (risk screening tool and enhanced support) [to be asked only of staff using risk screening tool and providing enhanced support]

- Tell me about your experiences with the screening tool. What are you finding most useful in using this tool? Least? (probe on thoughts on how helpful the tool is for identifying "at risk" patients, potential benefits/disadvantages)
- What did you find most challenging in using this tool? Least? (probe on practical aspects such as extra time/paperwork)
- Can you think of any examples where using the tool helped or hindered your interaction assessment of the patients' status? (probe on patient perceptions/reactions to the tool, perceptions of whether they feel its use makes a difference in the services being provide, patient/staff rapport, and/or patient treatment adherence)
- Tell me about your experience providing enhanced support for at risk patients? Please give me a recent example and how the patient was followed up, what were the concrete issues addressed?
- How feasible is it to provide enhanced support to patients who need it? (probe on practical aspects, feasibility, views on sustainability)
- How do you feel patients are responding to the enhanced support package (probe on patient attitudes, motivation)? Any challenges?
- Can you think of any issues that patients receiving enhanced support raise most frequently with you? Do you notice any differences between these and your other patients? (probe on differences in dialogue, health literacy, treatment support, other social and economic issues)
- Have you noticed any differences in the ways patients and staff interact with each other since this intervention started? (probe on changes to content, frequency or style of communication between staff and patients such as verbal or body language, patients' attitudes or behaviour towards treatment

APPENDIX 4: SAMPLE INTERVIEW GUIDE – PATIENTS

The below interview guide was used in the study by Kielmann et al. investigating TB treatment adherence at an outpatient clinic in Riga, Latvia.

Section 1: Background and profile of informant

A. Patient profile

- Please tell me a little bit about yourself and your situation?
- Do you have any family here? Can you tell me a bit about them?
- How is your health at the moment? What kinds of health issues have you faced in the past? How about your family?
- What has been your experience of seeking health care in this city? What, if anything, have you found positive during with this experience? What, if anything, have you found negative? (probe on access, transport, ease of finding services)

B. Pathways to TB treatment and care

- Tell me about when you first started feeling symptoms that led you to seek care? OR
- When were you first screened for TB? Can you recall the experience? (tell me more about it, what were the circumstances?)
- What happened next? How were you diagnosed?
- Did you talk to family or friends about this diagnosis?
- Tell me about when you started coming to this clinic for your treatment (probe for original impressions, ease of access, general feelings at the time)
- Is there a typical time of day you prefer to visit the clinic? How long does it take you to travel here? How long are you normally in the clinic? (probe on how much time out of the day is required to receive treatment)

Section 2: Treatment adherence issues

A. TB knowledge

- How knowledgeable about TB do you feel you were before your diagnosis?
- Going back to when you were diagnosed, tell me more about how you were informed. (probe on who did this, in which facility, how long did they take to explain the diagnosis and treatment?)
- What is your understanding of how the treatment works now? Can you think of anything more that you would have liked to know or would have been helpful to have been explained to you when you were diagnosed?
- How have you felt on this treatment? How easy/difficult is it for you to take these medicines regularly? What makes it easy/difficult? (probe on social/environmental challenges)

B. Staff communication and interactions during care

- Tell me more about your daily visits for treatment. How many staff members would you say you come in contact with each time? For how long with each?
- Do you ever feel you need more/less time with clinic staff?
- How do you feel you are treated when you come in (probe on whether it is a personable or welcoming experience? (probe on patient/staff rapport if any)
- Can you give me any examples of a situation that would make it difficult for you to visit the clinic for your treatment (traffic, work, illness)? What would you do in this case? (probe on whether they inform the clinic or if clinic contacts them first)
- In what ways does the clinic support your treatment currently? What are they doing to help you stay on treatment? Can you think of anything that could be done differently to help you stay on treatment?
- What are your perceptions of the ways staff interact with you or other patients? Do you feel there is strong communication? Do you feel sufficiently supported? (probe on communication content, language issues, staff communication style, is it sufficient, easy to reach out to staff members if necessary)
- Can you recall any instances where you felt that the clinic staff was unavailable to you? How important do you think it is to be in regular contact with your treatment team?

APPENDIX 5: SAMPLE SEMI-STRUCTURED OBSERVATION CHECKLIST

The below observation checklist was used in the study by Kielmann et al. investigating TB treatment adherence at an outpatient clinic in Riga, Latvia

Preliminary observations on context

- At what stage of the patient pathway is the observation being conducted: (e.g. patient registration, risk assessment consultation)
- Where is the observation being conducted?
- Who is present?
- Brief description of individuals present
- What is the purpose of the communication?
- How are the individuals present positioned in relation to each other? [*if useful, provide small diagram*]
- How far apart/close are the individuals present to each other? [*approximate*]
- Any analytical notes regarding appearance, voice, eye contact, expressions, body language.

Observation notes on communication [*use scripted format*]

- How does the staff member greet the patient and/or introduce him/herself [*if first* meeting]?
- How does the staff member communicate with the patient?
    - What is the tone of voice used?
    - What is the communication style? [*e.g. directive, assertive, associative etc*]
    - What gestures, if any, are used?
    - What aids, if any, are used to support the communication?
- Rough descriptive notes [*if possible*] on content, duration of each persons' intervention
- How does the patient engage with the provider? what interjections if any does he/she make and to what purpose?
- Analytical notes on dynamics of communication, any indications of how the staff member and patient engage with each other [*keep these in separate font/colour when typing up*]
- Does anyone else enter/interrupt the communication and how is this treated?
- How is the communication concluded?
  How is the communication documented by the provider?

Find out more about the RUHF here: http://www.qmu.ac.uk/ruhf

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