Health Seeking Behaviour in Kamrangirchar

RESEARCH PROTOCOL

Médecins Sans Frontières OCA

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The perceptions and experiences of health and health seeking behaviour for the community living in the slum areas of Kamrangirchar and Hazaribagh, Dhaka, Bangladesh: a qualitative study

Research Question: 'What are the perceptions on health and health seeking behaviour for the community living in Kamrangirchar and Hazaribagh, Dhaka, Bangladesh?

Study Sites: This study will take place in two sites that are part of the poorest urban extension to Dhaka, Bangladesh: Kamrangirchar and in the adjoining Hazaribagh.

Proposed start date of data collection for study: February 2016

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Acronyms

ACP	Annual Control Plan
CIPRB	Centre for Injury Prevention and Research Bangladesh
HAZ	Hazaribagh
icddr,b	International Centre for Diarrhoeal Disease Research, Bangladesh
KAM	Kamrangirchar
MOHFW	Ministry of Health and Family Welfare
MSF	Médecins Sans Frontières
NGO	Non-Government Organisations
OCA	Operational Centre Amsterdam
SRH	Sexual and Reproductive Health

1. Background

Rapid urbanisation in developing countries is becoming an increasing topic of concern.[1] The high influx of rural population creates a huge need for accommodation, and leads to growth of dense slum areas with poor living conditions.[2] Dhaka city is in this sense no different with urban inequality and poverty leading to uncontrolled growth of slums throughout the city,[3,4] with Kamrangirchar as the largest.[5] Overcrowding and bad housing are known to be associated with poor health. Such environments are detrimental to health, life chances and social behaviour.[2] Health indicators amongst slum residents are worse than their rural counterparts,[2,6] making slums an important risk for general public health.[1] Multiple studies indicate that health seeking behaviour amongst the poor of Dhaka's society is low,[7–9] despite the fact that in Bangladesh 90% of the urban population have access to a health facility available within 2km.[10,3] Concurrently, health seeking behaviour is a complex and multi-dimensional aspect of life, with utilisation dependent on many socio economic factor's, local political organisation of the health system and services,[11] and is determined by what has been termed demand and supply.[12]

On the supply side of health care, Ashraf, Chowdhury, & Streefland (1982)[13] conclude that there is a decreased use of 'traditional' medicine and an increase in the use of health services offering a biomedical model of care. However, this shift comes with an increasing number of unqualified practitioners of allopathic medicine in Bangladesh.[13,14] Multiple articles confirm that pharmacies are the most dominant healthcare source in both rural and urban settings.[8,12,15] Ahmed et. al. (2006)[16] conclude that there are multiple social and economic factors that influence this decision; distance and financial limitation are important, but also a lack of adequate services, absence of doctors and medication in the health facilities and corruption have an impact. Khan et. al. (2012)[8] emphasize the risk of unqualified practitioners and the need for control and education of the pharmacists.

On the demand side, a study by Ensor and Cooper suggest that the demand-side barriers might be equally important to supply barriers in health care utilization.[17] The literature shows a set of issues that prevent or put limits on health seeking behaviour, one of the most important is a lack of knowledge about common diseases and available services[18] which leads to normalisation of symptoms[19], meaning that symptoms are seen as normal in the functioning of the human body and not as an indicator of a disease. It is suggested that a lack of public information on health has an impact on this.[20] Besides that, there are important socio-cultural barriers that prevent adequate health seeking practice. The attitude of the health provider is seen as an important factor, a lack of respect towards the poor [16] or a lack of confidentiality [21] are mentioned as thresholds for patients. And it is also mentioned that patients measure the quality of the care given to them by the number of pills they receive.[16]

Several quantitative studies have been conducted on health utilisation, studying different population groups in Dhaka, for example; slum-dwellers,[22] street-dwellers,[23] and the urban poor.[24] These studies confirm that knowledge about common diseases and availability of services are important factors,[18] but do not address perceptions and behaviour of the care seeker. Few qualitative studies have been found that address health of the poor, for example; new-born care practices among slum dwellers, concluding that education plays an important preventive role. Furthermore, a study on poor and middle class childless women describes the complex relation between customary practice, religion and modern health care.[25] With a study on postpartum morbidity highlighting the political and cultural constraints that compromise women's health.[26] These studies highlight perceptions and behaviours, but are limited to the focus group of their studies.

In 2013 Médecins Sans Frontières (MSF) started an urban healthcare program with provision of an MSF core sexual reproductive health package[i] offered to females 10 -49 years, and occupational health, offering medical care to factory workers of all ages. There are a reported low status and low economic prioritization of women's health in poor households in Bangladesh,[2] resulting in significant morbidities and suffering. Several studies indicate that around 50% of women in Bangladesh fall victim to physical spousal violence,[27,28] and only 2% of them seek care or support for this.[28] This is compounded by limited access to medical and psychosocial care for survivors. For Occupational Health, a significant number of people living in Kamrangirchar and Hazaribagh have migrated from the rural areas of Bangladesh.[29] Many migrants make their living in the informal sector,[30] where a lack of information about occupational safety for factory owners and workers is known.[31] This creates the conundrum that poor and unsafe working conditions are both a cause and consequence of extreme poverty.[32]

1.1 Rationale for the study

No studies have been found that apply a qualitative methodology to understanding health perceptions and behaviours in Kamrangirchar and Hazaribagh. In the project, there is a need to gain an understanding of underlying social perceptions, opinions, and motivations towards health and health seeking behaviour. This study applies qualitative methods to allow an in-depth understanding of these issues, and in order to learn how and where to adapt the program to increase appropriateness, acceptability and so the effectiveness of health care for these communities. It is thought that the findings will add to existing data on health and life for such populations in similar settings.

1.2 Objectives

This study aims to provide a better understanding of community perceptions toward health and health services in order to inform programme strategies:

- Describe community and local-level perspectives and opinions on health care provision;
- Document gaps, barriers and influences that impact access and acceptance of health care;
- Contribute to best practice and development of health policy for this population

[i] Provision of MSF core SRH package includes: 1) provision of ante- and post-natal care; 2) provision of contraceptives; 3) management of reproductive tract and sexually transmitted infections; 4) provision of emergency contraception and termination of pregnancy; 5) provision of nutrition and counseling services for pregnant and lactating women; 6) referral service for institutional deliveries; 7) provision of routine immunisation services for newborns/tetanus toxoid vaccine for women; 8) conducting health and sexual health education in the clinic; 9) routine training and monitoring of staff and ensuring quality of care; 10) awareness raising in the community including schools through health promotion activities; 11) strengthening the access to quality sexual and reproductive health information and services; 12) working with community resources and services provided by other NGOs.

2. Methodology

2.1 Design

This qualitative study aims to explore perceptions that inform motivations and actions to seek solutions for poor health amongst community members of Kamrangirchar and Hazaribagh. Whilst the community as a whole is of general interest there will be a specific focus on the population utilising the main services in the project, those for sexual reproductive and occupational health. This study will use qualitative descriptive research techniques, to give a deeper understanding of the social and cultural perceptions that surround concepts of health. Qualitative methods are most suitable to conduct this type of studies as we aim to understand the social world through the eyes of the people that are studied.[33] Three approaches will be applied to optimise descriptive data for the topic being investigated:

a. Narrative/life history or storytelling method

For female participant groups, a narrative life history or storytelling method will be applied. This method focuses on describing the 'inner experience of individuals', of all ages in terms of how they interpret, anticipate, comprehend, and define the world around them.[33] This approach is particularly useful for understanding the past and present contextual influences on people's health perceptions and behaviours.[34] It allows us to uncover a variety of aspect of a participant's life, reflections and perceptions, but at the same time ensures thematic comparison of the data collected. For younger participants we will adapt this method as informal storytelling in the family setting. The parents will carefully briefed on the neutrality of their role and understand that they should not attempt to influence or interpret the responses of participants but can give their own opinion as part of the conversation. This method gives the possibility to supplement and contextualise participant data with data gathered from adults present. The narrative guide or questions used at beginning and end of narrative interview will piloted and adapted to ensure the younger person's responses are natural and to ensure technique is not overly complicated.

- Female participants 13 - 49 years of age (including family members for younger participants)

b. In-depth interviews

For the key informants of the community, participant-led in-depth interview will be carried out, using a topic list to guide the flow of conversation, allowing for deeper knowledge on specific topics to be extracted, at the same time ensuring comparability between cases and key informant groups.[33] Community groups are identified as:

- Factory workers
- Social workers, students, members of health Organisations (NGO's) and religious leaders

c. Observation and field notes

Detailed observations and field notes will be documented by the researcher during fieldwork, detailing insights and observations that develop over time and through repeated analysis of events, activities, behaviours, and interactions. This aims to complement the method design by enhancing understanding of data collected through life histories and in-depth interviews and increasing the validity of results through the verification and triangulation of data. It will also highlight any discrepancies from narratives gathered.

2.2 Setting

The study will take place in Kamrangirchar and Hazaribagh, both areas are situated in the south west corner of the city and are well known as a highly polluted and poverty stricken. Kamrangirchar is the biggest slum of Dhaka located on a peninsula of the Buriganga river. At least 400.000 people live in this area of only 3.68 km,[35] although the exact number is unknown, this figure is widely accepted. On the north eastern border of Kamrangirchar, encapsulated by the city, lays Hazaribagh, an area of 3.94 km2 where estimated 185.000 people live[36]. This area accommodates 95% of the countries leather processing factories.[37] The exact number of tanneries is unknown due to rapid changes, however, studies show that there are around 250 to 300 tanneries.[38] This area is the fifth most densely polluted location in the world.[39] Workers are exposed to dangerous and hazardous situations on a daily basis impacting their health. The inability to process the waste produced by community and industry, and the high rural influx[30], into this area, result in a densely populated and highly polluted environment.[35]

2.3 Sampling and recruitment

This study will rely on purposive sampling, allowing for the researcher to select key informants who will have a useful perspective on health and solutions for ill health. Participant selection will be based on the groups outlined above and will be recruited through the project using outreach teams and project liaison. Whilst the final number of participants will only be known once data saturation occurs,[36] in this instance at least 12 participants will be approached per key informant group, so we estimate the total sample size to be approximately 36 participants. Guest (2006) validates that saturation occurs for such research design 'within the first twelve interviews, although basic elements for meta-themes were present as early as six interviews'.[40]

To enhance the credibility of this sampling, a maximum variation sample will be used to ensure the consideration of key demographic variables likely to have an impact on participant's views, for example, gender, age, ethnicity, and occupation. This aims to ensure that the sample within the selected groups is both diverse and representative of the communities in question, and so maximise a fair share of perspectives and views.

Interviews will be organised and conducted in a designated place to optimise privacy and confidentiality. Appropriate venues will be identified during the planning phase of the study as a neutral space and will be selected in collaboration with the MSF team. During the pilot the appropriateness of the venue(s) will also be assessed. Interviews are completely voluntary, and participants may withdraw from this study at any moment. For participants under the age of 18 years, parental or guardian consent will be sought as per legal requirement.[36] The narrative methodology for this group will include storytelling by the younger participants in a family setting.

a) Inclusion criteria
   - Factory workers
   - Female participants 13 - 49 years of age (including family members for younger participants)
   - Social workers, students, members of health organisations and religious leaders.

b) Exclusion criteria
   - Individuals that do not give consent or decide to withdraw their participation during or after the interview
   - Individuals considered to be too unwell to participate (by MSF team; gatekeeper; researcher or participant themself). This will not exclude those with chronic conditions but those for whom participation would cause

increased pain or discomfort; aggravate an existing health condition or potentially jeopardise recovery. If there are any concerns in this regard an MSF medical team member will be consulted.

2.4 Data collection and analysis

Both narrative accounts and in-depth interviews will be recorded and transcribed into English. These will include careful contextual translation of idioms, metaphors, and other local expressions. Translators will be closely supervised, and the quality of their work monitored by checking and back-translation of a subset of each translator's work by a second translator. Debriefings will also be held with translators/transcribers to ensure any concerns are addressed and resolved in a clear and consistent manner.

Interviews will be carried out considering sensitivities to gender. This will include recruiting translators of an appropriate gender (e.g. female translators for female participants) and ensuring thorough briefing of international researchers on cultural and gender issues and norms appropriate in the context (including appropriated dress etc.). Gender issues will also be included in the training, planning and ongoing team debriefings to ensure this is incorporated throughout the research process. Field notes will be taken throughout the period.

Data will be coded and then rigorously and continuously reviewed and categorised. Emerging patterns, themes and relationships will be identified and labelled. To enhance reliability, a subset of data will be coded and analysed by a second researcher. Data will then be triangulated in order to maximise validity, and cases that do not fit with conclusions will be re-analysed in order to test emerging theory and ensure that examples are not selected purely to reiterate desirable conclusions.[41] In addition, certain narratives or case studies will be drawn out to ensure the individual 'stories' are not lost and to explore how the themes interrelate in particular cases.

2.5 Interview language

All interviews will be conducted in Bengali with a translator and transcribed from Bengali to English verbatim.

2.6 Data validation

Cross checking of data and constant comparison as well as negative cases will also be examined in detail and explained in order to strengthen the analysis. Self-reflexivity – documenting the researcher's biases and assumptions, and how his/her position and perspectives have changed throughout the study will be accessible through field notes. Audit trails – tracing the conceptual development of the project from raw data through data reduction, analysis and reconstruction is built into the research.

The following methods will also be used to ensure a reflexive research process:

a) Including multiple researchers, translators and local co-investigators in the study to ensure multiple perspectives are included in the ongoing data collection and analysis. Practically this will include regular debriefings with the research team and a feedback session with local co-investigators and MSF team upon conclusion of data collection and prior to analysis.

b) Ensuring ongoing supervision and peer debriefing, including oversight by an impartial researcher who will examine the transcripts, final report and general methodology and provide sparring and feedback in order to enhance credibility and ensure validity.

c) Keeping rigorous field notes or a research diary will provide 'a form through which the interaction of subjective and objective aspects of doing research can be openly acknowledged and brought into a productive relationship.'(Watt, 2007) Whilst there are no rules over what should or should not be included in a research diary, it will include both descriptive and reflective content and cover subjects such as: thoughts and reflections; a record of reading (with comments/summaries/quotes); a record of phone calls and meetings; notes on methodology; observations; unresolved problems, issues or questions; plans for action; keywords and visual material (as appropriate). These will be used to inform analysis and act as the basis for discussions within the research team. However, the ethical issues involved in keeping a diary will be kept in mind and the confidentiality of both for the researcher and the characters that appear in the research story will be considered.

2.7 Limitations of the study

This is a qualitative study, and therefore only concepts can be generalised and shared for other settings. It is acknowledged that the role of the researcher as part of the project team may influence responses, which will be reduced through research profile as separate from operational responsibility. Care to choose communities that will not have been burdened by other surveys or assessments will be taken by cross-referencing with existing/on-going research in the area.

Translators or local language speaking third parties conducting the interview might have a lesser understanding of the topic resulting in phrasing or translating questions and responses incorrectly. They will be carefully selected to ensure compatible characteristics (e.g. female translators for female participant groups) as well as technical translation skills, 'soft skills' such as empathy, tact and communication skills, and motivation to work with MSF on this specific study. This process will involve an open recruitment process supported by the mission HR Department. They will then be thoroughly trained on the study objectives and methodology, with a specific focus on objective translation and confidentiality. Transcribers will be recruited and trained in the same way. Both translators and transcribers will be closely supervised including regular debriefings and quality checks.

Whilst competing interests or biases may affect translation, in addition to the above steps the following mechanisms will be put in place to mitigate this: transcribers will quality check translations when listening to audio recordings of interviews and raise and questions or concerns with the PI and a subset of each transcriber's transcriptions will be checked and back translated by another transcriber, and again any discrepancies discussed with the PI.

3. Ethical considerations

3.1 Potential benefits of the study

Social value of this study: an opportunity for participants to express their views and better understand how to manage their health as a consequence of this study.

Project level benefits: There are no known studies available looking at the communities' perspectives on health or health seeking behaviour of the population concerned. By providing new insights with regard to this topic, it is hoped that recommendations will inform future activities for effective programming and better health outcomes. In addition, it is an opportunity to share within MSF, the value of urban health focus programmes.

Community level benefits: This study could help to improve understanding barriers or opportunities for good health care. The largest benefit being for future patients as barriers are reduced and enablers are optimised to provide dignified and effective treatment. A two-way more acceptable and accessible pathway to care is envisaged as a result.

National level benefits: With a better understanding of community perceptions and experiences, it is hoped that this study will provide a valuable insight and influence on the national health policy for this population's health needs.

International level benefits: Concepts drawn from this study could also be comparatively analysed with neighbouring countries with communities coping with similar living conditions. In this sense, findings can contribute to the ongoing global policy and best practice linked to urban health.

3.2 Potential risk of the study

Current security restrictions and movement limitations may impact recruitment and response rate, remuneration for participants is anticipated and will be as per MSF standard. It is not foreseen that respondents will receive financial compensation in exchange for participation. However, non-monetary tokens such as a soap kit or equivalent and transport fees will be included. Under extenuating circumstances work time would be recompensed per hour of work losses. Extenuating circumstances to be defined as when the participant has no other time available to participate within the study timeframe and there was a low uptake of volunteers for the research.

Informed consent will be obtained, and participant privacy and confidentiality respected at all times. In the case interviews are conducted with participants under the age of 18 years, permission will be obtained by the individual in question and through their parental or legal guardian as per local law requirement. The natural power imbalance between adult interviewer and younger participant will be minimised by creating a relaxed atmosphere prior to embarking on the data collection by having an informal chat at the beginning reassuring that the conversation is not a 'test' in any sense, and that all responses are equally acceptable, valid and welcomed. As a check topic guides will be piloted prior to use.

The main burden to interviewees will be the time taken for the interview. We have communicated with relevant authorities from the outset to ensure correct permission, courtesy, and access to the population. The research team will be especially mindful of anonymity of specific areas/neighbourhoods as well as participants.

There is a risk that participants may feel distressed by talking about any difficult or sensitive experiences during the interview. For this, we aim to link with existing project support teams should any specific needs or psychosocial support be needed. Equally requests for medical support will be diverted to the existing services. There is also a risk that participants may disclose information that implicates poor health and safety, or risks taken contrary to local law

(occupational).[36] This will be dealt with prior to the interview by stating that any disclosures that pose a significant individual or public medical risk will be managed on a case-by-case basis, in line with standard MSF protocol and where appropriate seeking expert advice.

To undertake the study should not substantially interfere with routine programmatic activities although it will require the support of the project team in terms of the time of selected health workers for an interview, input into participant selection, and ensuring confidential space for the interviews.

3.3 Respect for recruited participants and communities

Feedback mechanisms ensuring accessibility to younger participants will be used to ensure participants are aware of the findings and outcomes of the study. Respondents can choose to opt in or out of this feedback process prior to interview commencement. Summary findings of the study will also be made available to all participants. As part of the consent form participants will be asked if they would like to receive feedback on the study findings. If they state they would, they will select their preferred contact mechanism (see updated consent form in Annex 1). These details will be stored confidentially and securely (password protected) and used only for the purpose intended. They will be destroyed once this dissemination has occurred.

3.4 Informed consent and confidentiality

Prior to their involvement, all participants will be given detailed information about the objectives and methods of the study. The consent process will ensure participants are aware that participation is voluntary, and they can change their mind about participating and/or terminating the interview at any point. It will also explicitly clarify that participation is in no way linked to receiving (or not receiving) services or other benefits. Consent will be briefly outlined verbally to ensure respondent comprehension, with voluntary written consent, thumbprint or another local alternative then being obtained. In the case of younger participants under the age of 18 years, permission of the parents or legal guardians will be sought as per local law on legal age of consent. Alongside parental consent, assent from the young person will be included as part of the consent, meaning there is a signal that the young person is willing to take part. Refusal to take part or withdrawal from discussion or interview involves no penalty or loss of services. All data will be anonymized, and care will be taken to ensure any quotes presented in the final report cannot be linked to individuals or places other than the study area itself.

Translators will be thoroughly trained on confidentiality, including the implications of not respecting it, and these messages will be reinforced during the data collection period. Translators and transcribers will also be asked to sign a specific confidentiality agreement (developed in collaboration with the mission HR department).

3.5 Data management and protection

We will ensure that all the data collected (digital files, survey forms, paper notes, audio recordings, transcriptions) is managed respectfully and confidential and will exclusively be used for the purpose of this study and the project. Paper documents will be kept in a locked drawer and digital files will be stored in a password-protected format. Each participant will be assigned a code that relates to his or her identity and time & place of the interview. Data will be shared with others, presented or published only with the discretion of the Medical Director, MSF Operational Centre, Amsterdam (OCA).

Details of participants recorded with their express consent to ensure feedback of findings will be stored confidentially and securely (password protected) and used only for the purpose intended. They will be destroyed once this feedback process has occurred. Recordings, notes and consent forms will be destroyed will be destroyed after five years and/or

two years post publication. Electronic data will be deleted from the hard drive and paper documents will be shredded by the MSF UK Programmes Unit.

3.6 Independent review

The study protocol will be submitted to the Research Ethics Committee of Centre for Injury Prevention and Research Bangladesh (CIPRB) and the MSF Ethical Review Board, for full ethical review prior to study commencement.

4. Study implementation

4.1 Collaborative partnerships

This study represents collaboration between the Ministry of Health and family welfare of Bangladesh, Médecins Sans Frontières, Centre for Reproductive Health International Centre for Diarrhoeal Disease and Research, Bangladesh (icddr,b) and Centre for Injury Prevention and Research Bangladesh (CIPRB). Within MSF, the primary investigator is based in Dhaka, Bangladesh, and the co-investigators in the coordination office in Dhaka, MSF Operational Centre in Amsterdam (The Netherlands), and Qualitative research support team, MSF UK in London. The co-investigator Nell Gray will participate in the data collection in the field for female participants.

Co-investigators will be considered also as co-authors of the manuscript developed from this study. The roles of those involved are outlined below:

Principal Investigator (PI):

Jeroen van der Heijden (MSF OCA): leads study including developing protocol, methodology and research tools, and conducting preparation and data collection, analysis and write-up.

Co-investigators:

Beverley Stringer (Health Policy and Research Advisor, MSF UK): supervises study process ensuring quality and best practice, including support in development of protocol, methodology and research tools, and overseeing data collection, analysis and write-up.

Nell Gray (Qualitative Research Officer, MSF UK): provides direct support to PI during the study, including participating in preparation and data collection in Bangladesh (particularly activities involving female participants), co-analysing data and contributing to write-up.

Dr. Stobdan Kalon (Medical Coordinator, MSF OCA Bangladesh): supports study process in Bangladesh, contributing to development of protocol, facilitating data collection and reviewing manuscript.

Dr. Animesh Bishwash (Senior Scientist, Centre for Injury Prevention and Research Bangladesh (CIPRB): reviews and contributes to the protocol and draft manuscript, supports national ethical review process.

Dr. Aminur Shaheen (Deputy Project Coordinator Centre for Reproductive Health International Centre for Diarrheal Disease Research, Bangladesh (icddr,b)): reviews and contributes to the protocol and draft manuscript.

Sadika Akhter: (Deputy Project Coordinator Centre for Reproductive Health International Centre for Diarrheal Disease Research, Bangladesh (icddr,b): reviews the draft manuscript.

Martins Dada (Health Advisor, MSF OCA, the Netherlands): oversees study; reviews and contributes to protocol and manuscript.

4.2 Timeline

The study will be conducted in a 4-month period, (comprising of approximately 1.5 month preparation, 1.5 month data collection in Bangladesh (end-Feb to end-March) and 1 month data analysis and write-up). Dissemination is aimed to take place in May 2016.

4.3 Dissemination plan

An internal briefing paper will be produced, highlighting the key findings of the study, including any recommendation that can be given. These findings will be distributed to MSF, the MSF field team in Kamrangirchar and the Coordination office

in Dhaka. A summary of study findings will also be made available to participants, ensuring easy accessibility to younger participants, through field team members and/or the principle investigator. A meeting will be held with participants to discuss the emergent findings and to gain their feedback and thoughts on these. A study manuscript will be produced and submitted for publication in a peer-reviewed journal. Discussions will be held with the MoHFW where policy is implicated and, MSF field contacts and coordination teams regarding the implementation of study findings to future programme activities.

4.4 Budget and resources.

The cost for this study is factored into the standard budget lines of the project. A breakdown of the actual has been agreed upon in the Autumn Control and Planning (ACP) of November 2015, for the budget year 2016. The total cost of the study will amount to approximately € 1300.

Additional logistics support will be required from the MSF field team in terms of transportation and essential materials: voice recorders etc.

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Annex 1: Information sheet and consent form

Consent form participant Médecins Sans Frontières MSF- Operational Centre Amsterdam

INFORMATION SHEET FOR PARTICIPANTS

REC Reference Number: MSF_ 2016

We would like to invite you to participate in this research project. You should only participate if you want to; choosing not to take part will not disadvantage you in any way. Before you decide whether you want to take part it is important for you to understand why the research is being done and what your participation will involve. Please take the time to read or listen to the following information carefully and discuss it with others if you wish. Ask if there is anything that is not clear or if you would like more information.

Who is MSF?
This project is being led by researchers from Médecins Sans Frontières (MSF). MSF is an international non-governmental humanitarian organization that aims to help people worldwide where the need is greatest, delivering emergency medical aid to people affected by conflict, epidemics, disasters or exclusion from healthcare. Active in Bangladesh since 1985, where we provide healthcare in Kamrangirchar and Hazaribagh and in Cox's bazaar.

Who is collaborating in this Study?
Médecins Sans Frontières is conducting this research, the primary investigator is anthropologist Jeroen van der Heijden, co-investigators are Nell Gray and Beverley Stringer (MSF UK), Dr. Animesh Bishwash (Centre for Injury Prevention and Research Bangladesh), Dr. Stobdan Kalon (MSF, Bangladesh), Dr. Aminur Shaheen (International Centre for Diarrheal Disease Research), Martins Dada (MSF, the Netherlands) Sadika Akhter (International Centre for Diarrheal Disease Research).

What is the aim of this research project?
The aim of this study is to provide more information on people's perception of health and their related health seeking behaviours in Kamrangirchar and Hazaribagh. We aim at answering questions like: How are health and sickness perceived? And what actions are taken and why? By gathering this information, we hope to improve our understanding of the community and use this knowledge to improve our services.

Who can take part?
The community as a whole with a special interest in the project population of factory workers and women of childbearing age (13 – 49 years), we interview people who are related to these groups, for example family members, community members, managers, etc.

What will the study involve?
We will conduct a 45 – 60 minutes interview in which we will ask about your life, vision and opinion in relation to health. There is no wrong or right answer. We only ask you to be open and honest. We want to learn how we can strengthen our program in the community and therefore wish to have a better understanding of perceptions of health. This study will result in a report with findings and recommendations. A summary of our findings will be made available to all participants; you may choose if you would like to receive this feedback or not, before the interview. Basic conditions of participation in this research are:

- If you decide to take part, you are still free to withdraw at any time and without giving a reason.

- Alongside parental consent, we ensure that adolescent participants under the age of 18 have given a positive signal that they are willing to take part in the study.
- Your answers and information will be kept private and confidential. Any comments we use will be done so anonymously and not linked to you.

- We will record interviews and take notes, but these will not be used for any other purposes or be available to any other parties and will be destroyed at the end of the project.

What are the risks and benefits of participating?

The main benefit of participating is the opportunity to help to improve the services that MSF provides, this can directly (factory workers or adolescent women) or indirectly (family members or social circles) result in benefit to the participant on the longer term. We aim to speak with all levels in the community and don't foresee any stigma being associated with participation to this study. However, there is a risk that participants may feel distressed by talking about difficult or sad experiences during the interview. For this, we aim to link with existing support teams should any specific needs for psychosocial support arise. We will treat interviews anonymous and confidential and hope that people will feel free to talk openly about their experiences and opinions.

What are the next steps?

If you would like to take part, please inform Jeroen van der Heijden. We will then arrange a convenient time for the interview. Prior to the interview, we will explain the research project in more detail, discuss any questions you have, and ask you to complete a consent form.

CONSENT FORM FOR PARTICIPANTS IN RESEARCH STUDIES over 18 years

Please complete this form after you have read the Information Sheet and/or listened to an explanation about the research.

Title of Study: The perceptions and experiences of health and health seeking behaviour for the community living in the slum areas of Kamrangirchar and Hazaribagh, Dhaka, Bangladesh: a qualitative study

Ethics Committee Ref: _____

Thank you for considering taking part in this research. The person organizing the research must explain the project to you before you agree to take part. If you have any questions arising from the Information Sheet or explanation already given to you, please ask the researcher before you decide whether to join in. You will be given a copy of this Consent Form to keep and refer to at any time. Please tick or initial:

☐ I have read the information sheet and/or had a full explanation of the research study and what my participation means.

☐ I have had the opportunity to ask questions and discuss the study

☐ I understand that I may withdraw from the study at any time without giving a reason and without personal consequence. I understand that I will be able to withdraw my data up to the point of publication *[OR insert date if stated on Information Sheet].*

☐ I understand that the information I give may form part of a published report and that I can choose to receive a summary copy.

☐ In understand that confidentiality and anonymity will be maintained, and it will not be possible to identify me from any publications.

☐ I agree that the research team may use my anonymised data for future analysis which may lead to further publications; all conditions above would be respected.

☐ I consent to my interview being recorded.

<u>Feedback of study findings</u>

☐ I would like to receive a summary of the study findings and agree for my contact details to be maintained for that purpose. I would like to be contacted on:
Telephone number……
☐ I would like to receive a summary of the study findings and undertake to collect them from the MSF Clinic
☐ I do not need to receive a summary of the study findings.

Participant information
Name :
Date : Signature :

CONSENT & ASSENT FORM IN RESEARCH STUDIES FOR PARENTS/CAREGIVERS OF PARTICPANTS between 13 and 18 years

Please complete these forms after you have read the Information Sheet and/or listened to an explanation about the research.

Title of Study: The perceptions and experiences of health and health seeking behaviour for the community living in the slum areas of Kamrangirchar and Hazaribagh, Dhaka, Bangladesh: a qualitative study

Ethics Committee Ref: _____

PARENT/ CARE GIVER CONSENT FORM

- ☐ I have read the information sheet and/or had a full explanation of the research study and what my child's participation means.

- ☐ I have had the opportunity to ask questions and discuss the study

- ☐ I understand my child may withdraw from the study at any time without giving a reason and without personal consequence. I understand that I will be able to withdraw my data up to the point of publication *[OR insert date if stated on Information Sheet].*

- ☐ I understand that the information my child gives may form part of a published report and that I can claim a summary copy at MSF main clinic.

- ☐ In understand that confidentiality and anonymity will be maintained, and it will not be possible to for my child to be identified in any publications.

- ☐ I agree that the research team may use my child's anonymised data for future analysis which may lead to further publications; all conditions above would be respected.

- ☐ I consent to my child's interview being recorded.

<u>Parent/care giver information</u>

Name:

Date: Signature:

INFORMED ASSENT FORM

- ☐ I have checked with the child and they understand that participation is voluntary
- ☐ I have checked with the child and they understand the information and have had a full explanation of the research study and what participation means.
- ☐ I have checked with the child and they have had the opportunity to ask questions and discuss the study
- ☐ I have checked with the child and they understand they may withdraw from the study at any time without giving a reason and without personal consequence.
- ☐ I have checked with the child and they understand that the information given may form part of a published report and that a summary copy can be claimed at the MSF main clinic.
- ☐ In have checked with the child and they understand that confidentiality and anonymity will be maintained and it will not be possible to be identified in any publications.
- ☐ I have checked with the child and they agree that the research team may use anonymized data for future analysis which may lead to further publications ; all conditions above would be respected.
- ☐ I have checked with the child and they understand the interview is being recorded.

Feedback of study findings

- ☐ I have checked with the child and they would like to receive a summary of the study findings and undertake to collect them from the MSF Clinic located at …….
- ☐ I have checked with the child and they do not need to receive a summary of the study findings.

Participant information (13 y or older)

Name:

Date: Signature:

Researchers Signature

I have fully explained the research study described in this form. I have answered the participant and/or parent/guardians questions and will answer any future questions to the best of my ability.

Printed name of researcher obtaining parental permission/ consent

Signature of researcher obtaining parental permission/consent

Annex 2: Topic guides

TOPIC LIST FOR PARTICIPANT LED IN-DEPTH INTERVIEWS
Kamrangirchar & Hazaribagh 2016

Introduction (5 mins max)

- Thank the participant for agreeing to take part in this research
- Introduce yourself
- Offer the participant something to drink when this is possible

- Tell each participant:

"I (We) would like to talk to you about the topics of "health" and "sickness" and your experience and outlook on this. This interview will contribute to a better understanding of how people living in Kamrangirchar and Hazaribagh experience and behaviours, to be able to improve the services that are given to the community by Médecins Sans Frontières."

The interview will take approximately 45 - 60 minutes and can be stopped by you at any time without any consequences.

This conversation will be held in full confidentiality, and your anonymity will be preserved at all times in this study. Meaning that any quotations or information used in this study will never lead back to the individual. Any disclosures that pose a significant medical risk will be managed on a case-by-case basis and in-line with standard MSF protocol.

- Make sure the participant has filled in the consent form for participants in research studies

- NOTE: Turn on the recorder and test it is recording (avoid placing cell phones close to recorder!)

Reiterate that there is no obligation to participate and that the participant can redraw from the interview at any given time. And tell the participant that you will now start with the interview.
Keywords: Illness / sickness / health / perceptions / thoughts / believes / experiences / Healing / Choices / Lifestyle / solutions

Topic 1: life and migration history

- Grand opening questions: Can you tell me about yourself, your life and family, how did you come to be here? Let's start at the place you lived before you moved to here (probe: What did it look like, with whom did you live in what kind of environment? What did you do for a living? When did you decide to come here? What was the reason to come?)
- Tell me about your life here in KAM /HAZ, your work/study, your friends and social life?
- What is important to you and why? How do you feel about life in KAM/HAZ?
- What is important to you in your life and where does health come into this? (probe: How would you rank the importance of health in your life?)
- How do you see your future? (probe: Where do you see yourself 5 years from now? What are your ambitions/expectations for the future?)

Topic 2: Experience of a 'healthy community'

- What does it mean to be healthy, do you perceive yourself as healthy and how do you know that you are healthy?
- What indicates health or sickness for you elaborate on how you feel in general day to day, healthy non-healthy? (probe: How do you know you are healthy or sick?)

- When do you choose to go to an (external) practitioner? (probe: At what point do you decide you need help in relation to your health, and how do you come to that conclusion?)
- Can you tell me about the health in your household/ family? (probe: Are there many cases of illness in your family/household and are they curable or chronic)
- Can you tell me something about how you see the healthcare system and how are what type of practitioners perceived in the community, and why do you think this is? (probe: How does the community perceive biomedical caretakers, and what about traditional practitioners, what others are used and why is this?)

Topic 3: The patient-practitioner relationship

- To what type of practitioner do you choose to go to and why do you go there? (probe: When are you satisfied with the care you have received; how do you measure this?)
- Can you tell me what is important for you in the healthcare you receive, what makes it good health care in your opinion? (probe: How do you rate the quality of the provided care? What makes you feel satisfied with the care that you received, for example; time spent; medication prescribed; respectful behaviour of practitioner)
- Can you tell me about the last time you had received medical care… and the time before, what happened? (probe: Can you describe the process from the moment you walked in until the moment you left? What was your feeling afterwards about the visit?)

Topic 4: Self-care and responsibility

- Tell me if all your medical needs are covered by the care you seek/receive? (Probe: Are all the medical problems, physical or mental covered by the care you seek or are there other aspects that you would like help with)
- Are there any problems you experience in getting the care that you need, and what these difficulties are? (Probe: economic limitations; physical limitations; socio-cultural and religious limitations?)
- Are there any actions you take besides seeing a practitioner to help yourself to get better, what are those actions and why do you think they are helpful? (Probe: Are there any practical things you do like take rest or vitamins or anything else?)
- how do you feel better and what do you think is the most important reason you get better (Probe: Is it a feeling, or do you go for a follow-up medication / belief / self-healing)?

Topic 5: Concluding the interview

Interviewer summarizes the interview and highlights the core of the discussion

- Is there anything you would like to add to this discussion, or anything that we missed?
- Do you have any questions you would like to ask me?
- Is there anything else

Thank the participant for his/her participation. Tell them their participation is highly appreciated and a valuable contribution to the study and to the improvements of the services provided by MSF.

* Stop the recording and lock the file on the device

LIST FOR STORIES

Narrative topics: techniques used to encourage participant to tell their story or use illustrations or pictures to tell their story (age related or preference)

Probe narratives on:

- How participants create and make sense of the rules, roles and norms of the social world in which they live;
- Dynamics of power between different groups within a society, and within the different institutions they belong to: family, marriage, schools, clubs, health centers, religious centers
- Few key topics
- Their life journey so far
- Health in the home
- Health outside the home
- How they stay healthy
- Life, wellbeing, health and death- what they experience, think and feel