Community Sensitization and Engagement: Experiences from the MITS Alliance

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MITS SURVEILLANCE ALLIANCE

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Acknowledgements

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Understanding the Importance of Formative Research in Community Sensitization

In many contexts and settings postmortem examination of any kind is a sensitive topic. Personal, religious, and cultural beliefs all influence perceptions of postmortem examination. Although hypothesized to be more acceptable than conventional diagnostic autopsy (CDA) by families, minimally invasive tissue sampling (MITS) is a relatively new technique, and the factors that influence its acceptability and feasibility are unique and specific to the context in which it is being introduced.

In this document we aim to share elements and tools for formative research and community engagement and sensitization activities related to MITS that have been conducted by social scientists across the MITS Alliance in low and middle-income countries. The information shared here comes from several sources including published literature and MITS Alliance Community of Practice discussions and presentations. It should be noted that the examples and tools that are documented here are described in brief and are not intended in any way to be prescriptive. Fundamental to this document is the fact that each project will need to adapt the frameworks, tools, experiences, and examples shared here to create unique community engagement and sensitization plans that are project and context specific. Experienced social scientists were responsible for both the design and implementation of the strategies and tools described here and the data analysis and interpretation. Social scientists are necessary for successful adaptation and analysis of formative research and community engagement strategies described in this document.

This may also be considered a "living document." The contents represent the collective knowledge and learning about community engagement and sensitization as they pertain to MITS that has occurred up until this point. However, as MITS projects continue to grow and evolve and engagement and sensitization efforts are evaluated, there is opportunity to refine and amend this document to address new information. Further, as the number of projects implementing MITS increases this document will also evolve to reflect the new cultural and religious contexts in which MITS is being implemented. The goal is to revise this document as necessary to reflect the growing body of knowledge related to MITS community engagement and sensitization. For questions or comments related to this document please e-mail mitsadmin@rti.org.

Formative Research

MITS Alliance projects have conducted formative research to inform MITS-related program strategies, materials, and tools that are culturally and geographically appropriate for a specific community. MITS Alliance projects have used the results of their formative research to identify the unique factors that will guide the development of a community engagement and sensitization strategy.

The scope and extent of formative research that has been conducted across the Alliance has ranged from extensive multiphase, multisite studies with large study populations aimed to inform the design and implementation of site-specific community engagement plans to smaller, more limited formative research that is largely focused on the pragmatics of MITS implementation. Regardless of the scope, at a minimum the primary rationale for conducting even limited formative research is to reduce the possibility that implementation of MITS would result in negative consequences or perceptions that could potentially put the project at risk.

MITS Alliance projects have used several approaches to conduct formative research, some of which are described below. And although general recommendations for key informants and focus group discussions are made, the specific participants will be modified to fit the overall objectives of the study. For example, although not included below, a study that focuses on child health would likely engage pediatricians as participants.

PICK-CHAMP

The CHAMPS network preceded the initiation of formative research by developing and implementing a community engagement curriculum, Participatory Inquiry into Community Knowledge of Child Health and Mortality Prevention or "PICK-CHAMP" (Appendix A). Designed to be an entry point for community engagement for the CHAMPs projects, this curriculum describes a participatory approach to train cadres of social and behavioral science workshop facilitators at each of its seven sites. These facilitators were then tasked with conducting workshops for community members and community leaders to gain an understanding of community perceptions of pregnancy, childhood health, illness, and death and how those perceptions aligned with CHAMPS activities including MITS. CHAMPS social scientists found that Exercise 6 was particularly useful in understanding community perceptions of CHAMPS-related activities. PICK-CHAMPS facilitators used the Alignment Tension Assessment Instrument (Appendix B) to assess the alignment between community perceptions, CHAMPS, and MITS. The CHAMPS network found this to be a crucial step in defining the framework, methods, and priorities for formative research at each site.

Key Informant Interviews

For many projects in the Alliance key informant interviews (KIIs) have been conducted as part of their formative research. KIIs can provide important information on how MITS might be perceived in a community or health care facility. Although the key informants will vary across contexts, MITS Alliance members have suggested that the following groups be included:

- Administrators and Government Leaders: Engaging these key informants lends legitimacy to the MITS project. These key informants may include local or regional health officials, health facility leaders, and Institutional Ethics Review Committees.
- Medical Personnel: Understanding physicians' and nurses' perspectives will help the MITS team learn about local perceptions, address misunderstandings, and begin to identify champions for postmortem examination and MITS. For hospital-based studies, engaging with medical personnel would also be useful in informing consent approaches as they understand the dynamics and processes within a hospital when a death occurs. In addition to hospital-based personnel, some projects have included community health care workers, who can serve as a link between the health facility and community.
- Pathologists: MITS being a relatively new procedure, pathologists offer a distinct perspective of current postmortem examination practices and help in the formulation of questions for additional social science data collection tools or approaches.
- Religious Leaders: Religious leaders can offer a MITS project deep understanding of religious beliefs around death and attitudes toward postmortem examination. Religious leaders can also give insight and information regarding standard burial practices.
- Village Leaders: Highly respected and in a position of authority, village leaders are typically in closest proximity to community members and where community members may first turn for

questions and concerns about MITS. These key informants will help to better understand community norms and may also be one of the first to become aware of any misinformation or rumors within the community.

- Informal Healthcare Providers: KIIs in this broad category can include traditional healers and traditional birth attendants. Although not necessarily members of the formal health care structure, these KIIs often interact within the community providing care in advance of or in parallel with more formal health care structures.

Although the exact number of interviews to be conducted with KIIs will depend on the richness of the data and when data saturation is achieved, some projects in the Alliance have found that by conducting one to two interviews with each of the key informant groups listed above, a trained social scientist can obtain sufficient information to inform the development of a community sensitization strategy. Appendix C offers some examples of KII interview guides shared by the Investigating Febriale Deaths in Tanzania (INDITe) project.

Focus Group Discussions

Most MITS Alliance projects have integrated at least a few (one to two) focus group discussions (FGDs) into their formative research. The data generated through FDGs not only emerge from the responses to the questions asked, but interactions between FDG participants can also generate new understandings. The sampling technique for FDG participants will depend on the focus and objective of the study. Examples of FGD participants include health care personnel (coroners, physicians, nurses, residents, support staff, and community health workers), patients and families (parents of live-born and deceased children), and community advisory boards. Although many Alliance member projects have conducted broad formative research on community beliefs about health, pregnancy, and death, other projects with shorter timelines and limited resources have been more specific and focused their inquiry on MITS. See the examples of focus group discussion guides shared by the Project to Understand and Research preterm Pregnancy Outcomes and Stillbirth-South Asia (PURPOSe) project in Appendix D.

Both FDGs and KIIs conducted as part of a formative research protocol have provided Alliance members with pragmatic information for the design and implementation of the MITS study and more specifically, the design of the community engagement and sensitization strategy. Further, some Alliance members have found that sharing the findings of the formative research with others such as health care personnel and community leaders has helped to build coalitions and increase support for MITS.

Ongoing In-Depth Interviews

In addition to conducting initial formative research to inform the design of the consent process, some Alliance projects have continued to monitor community perceptions after MITS has been initiated. For example, some projects conduct interviews with families and next of kin. In these interviews, social scientists interviewed both those who accepted MITS and those who refused. The benefit of the data gathered from families and next of kin who have experienced a death and have gone through the consent process is that results are based on real experiences rather than being hypothetical as is the case in KIIs and FDGs conducted with families that haven't experienced a recent death. As a result, the MITS team has gathered information such as why the families made the decision they did, their perceptions of the consent process, and assessment of the incentives. Projects have assessed their

activities on an ongoing basis and have adjusted their community engagement strategy accordingly. Interviews are conducted at a location that is most convenient for families, and findings across the MITS Alliance have consistently indicated that conducting these interviews relatively soon after the death, within the first 1-7 days, is preferable over waiting a longer period of time, because families found that waiting 2-4 weeks, for example, resurfaced family members' grief and was too painful. The optimal timeframe for a postmortem interview will vary and should be queried as part of formative research. Appendix E offers an in-depth interview guide created by the INDITe project.

Community Engagement and Sensitization

Community engagement and sensitization activities are developed based on the data gathered through formative assessment. The goal of conducting community engagement and sensitization activities is to ensure that MITS-related activities are initiated based on mutual trust established between the MITS project and community and are consistent with community priorities and interests. The cornerstone of MITS community engagement and sensitization strategies across the MITS Alliance has been ensuring transparency in communication and following through on commitments. Being transparent with communities regarding the objective and timing of the MITS procedure, the data to be collected, and how the findings will be used has facilitated MITS projects to establish trust with the community. Following through on commitments made to community leaders and members is fundamental to the integrity of the project. Being mindful of what is promised will ensure that once established, trust is not breached. Following the implementation of a sensitization strategy, projects across the Alliance have stressed the importance of ensuring ongoing opportunities for inquiry and questions from the community. This was accomplished by attending regularly scheduled community meetings and gatherings, inviting informal conversations with community members and leaders, and conducting ongoing KII with families following MITS.

The scope of MITS community sensitization and engagement strategies implemented across the Alliance has varied depending on project resources and objectives. Regardless, similar to the formative research that has been conducted, most Alliance projects have identified and engaged community members including village leaders, religious leaders, and medical personnel in sensitization strategies.

Community Advisory Boards

Social scientists from MITS Projects have both facilitated the convening of Community Advisory Boards (CABs) and engaged existing CABs to collaboratively support MITS implementation and dissemination of MITS information. Some MITS projects engaged CABs in a bilateral approach such as developing engagement strategies collaboratively and providing support and guidance to CABs to further disseminate MITS-related information in the community. Other groups used a more limited approach in CAB engagement by sharing relevant information and subsequently leaving the CAB to decide how to communicate and disseminate MITS-related information to the community. MITS social scientists have shared the findings from their formative research with CABs and then through different working groups, collaboratively developed strategies for community engagement. MITS Alliance social scientists have worked with CABs to determine how best to share MITS-related information with families. Ongoing regular meetings with the CAB working groups supported the implementation of those strategies. The engagement of CABs will be influenced by a number of factors including whether the MITS project is hospital based versus community based.

Tools for Community Engagement and Sensitization

Member projects of the MITS Alliance have developed some tools and resources to support the development and implementation of community engagement and sensitization plans. The tools below were developed based on the findings of formative research and are not designed to be universally applicable, but may be used to inform the development of site specific tools or adapted to suit other contexts.

Community Engagement Planning Site Visit

The CHAMPS network developed a planning tool to support sites to develop community engagement strategies (Appendix F). This tool identifies activities to be carried out when conducting a participatory community engagement planning site visit. In this document CHAMPS outlined a comprehensive approach for developing a robust community engagement strategy in collaboration with community representatives and leaders in addition to CHAMPS project and program staff. And although the scope and resources dedicated to planning community engagement will vary across projects and contexts, the framework, goals, and objectives outlined in this planning document will be applicable across a variety of MITS projects. The data gathered through the site visits was instrumental in the development of the CHAMPS Social and Behavioral Sciences Protocol (Appendix G).

Tools for Describing MITS

The method and manner in which MITS is described can be critical to MITS acceptance and an important component of a community sensitization plan. The approach to describing MITS to communities was largely informed by the objective of the study, the audience's role in the community, and the level of sophistication and cultural norms. In some projects MITS was described in comparison with CDA; in other projects, CDA was not referenced. The distinction was based on the role of CDA in the study and the current awareness and acceptability of CDA in the community. In addition to verbal description, some teams developed tools to describe MITS including drawings of the MITS procedure or pictures of some of the tools (needles) used to perform MITS or photos or drawings of what the MITS incision looks like once the procedure is completed. The INDITe team developed a flyer (Appendix H) describing postmortem examinations and the overall study that was shared with patients and families who consented to either CDA or MITS. Another Alliance member, the PURPOSe project developed talking points highlighting features of both CDA and MITS to discuss with family and community members (Appendix I). And the MITS in Malawi project developed a simple question and answer guide about MITS (Appendix J) that was used in sensitizing health care workers to MITS.

Summary

Formative research and community engagement strategies, including community sensitization, will vary across MITS Alliance projects. The objective of the MITS project and the context in which it is being implemented will be the driving forces in defining and implementing formative research and community engagement strategies. Social scientists in each MITS Alliance project have worked with their respective communities to conduct formative research and community engagement activities that are relevant to both the context and the project objective. And although there may be some common themes and strategies between projects, each project must develop its own strategy. This document contains some examples of formative research and community engagement activities across the Alliance with the aim of sharing tools and experiences that may support new Alliance projects in their own activities.

Appendix A: PICK-CHAMP Curriculum

CHAMPS

Child Health and Mortality Prevention Surveillance

PICK-CHAMP:

Participatory Inquiry into Community Knowledge of Child Health And Mortality Prevention

V.2: April 2016

Section 2. Overview of PICK-CHAMP

The PICK-CHAMP methodology adapts earlier methods of community health assets mapping known as PIRHANA (Participant Inquiry into Religious Health Assets, Networks, and Agency), PIRASH (Participant Inquiry into Religion and Adolescent Sexual Health, and PICHA (Participant Inquiry into Community Health Assets). PIRHANA was developed as a research instrument of the African Religious Health Assets Programme (ARHAP) – in a pilot research programme sponsored by the World Health Organisation (WHO) to map the religious health assets of selected sites in Zambia and Lesotho. PIRASH was an adaptation of PIRHANA specifically designed to understand the influence religious and cultural norms on adolescent sexuality in South Africa and the United States. PICHA adapted both of the two earlier methods to understand community perceptions related to HIV in informal settlements in Nairobi, Kenya.

The participatory approach to health assets mapping reflected in PICK-CHAMP is possible because of this earlier work. This manual is intended to be a practitioner's workbook for people trained to facilitate PICK-CHAMP workshops under the auspices of the Country Offices of the Child Health and Mortality Prevention Surveillance (CHAMPS) program. The information generated through the workshops will be used in at least two ways. It will be used to inform CHAMPS researchers on: 1) community perspectives on childhood deaths, and 2) the tensions and synergies between those perspectives and the goals/objectives/activities of the CHAMPS program.

This manual provides a basic overview of PICK-CHAMP (section 2), followed by background into the theoretical perspectives that ground the PICK-CHAMP methodology (sections 3 and 4). Following these sections that provide an overview and theoretical grounding, subsequent sections lay out the structure of the workshops (sections 5-8). Appendix I contains samples of the forms necessary to conduct PICK-CHAMP workshops including invitation letters and consent forms. Appendix II contains a comprehensive description of the materials necessary to complete the workshops (NOTE: The sections describing each of the modules for the three workshops also list the materials. Appendix II simply compiles those individual lists into a single, comprehensive list that simplifies the gathering of materials). Finally, Appendix III describes the title and responsibilities for each member of a PICK-CHAMP team.

Section 3: Behaviour and Attitudes in Participatory Research

There are five key elements that comprise the PICK-CHAMP acronym:

1. Participatory – Because this is an appreciative inquiry it is highly participatory; but this word also signals a link to the approach known as Participatory Rural Appraisal, or Participatory Learning and Action (PRA/PLA) –and therefore is rooted in the idea that participatory work means that local people drive the inquiry.
2. Inquiry. The task involves a desire to know more—to appraise, identify, analyse and map. The use of the term 'inquiry' is to make a specific link to the approach known as Appreciative Inquiry, and so the work must always seek to be empowering of communities and resist the temptation to extract information and resources from communities solely to drive the agenda of an external institution or authority.
3. Community Knowledge—We believe that every community possesses intrinsic wisdom and has developed complex assets for health that are already being mobilized "on the ground" within that community. Any effort on the part of funders, researchers, or service providers to work with communities to address various health issues should partner with members of those communities and recognize the often-overlooked resources that communities possess.

Because outsiders are often blind to those intrinsic assets, PICK-CHAMP facilitators must build partnerships with communities and develop processes in concert with communities if they want to identify and address the causes of childhood mortality.

4. Child Health—These workshops are designed to create partnerships between local communities and the CHAMPS program to improve childhood health. This, then, is the overall goal and focus of PICK-CHAMP and all CHAMPS activities: improved child health.
5. Mortality Prevention—The goal of improved child health will be achieved in two ways: 1) by maximizing existing resources that support health, and 2) by identifying the primary causes of childhood death and developing responses to prevent those causes. Therefore, mortality prevention is a key element of CHAMPS and it will also be a complementary element of PICK-CHAMPS.

Although PICK-CHAMP represents a modification of an existing methodology, in much of the work on Community Engagement we are entering an unknown field; and we are in that difficult situation where we know there is something that we are looking for, but we need to find it in order to know more precisely what it is! To this end, we need the help of local people who are the experts, and we need to find ways of opening up discussion and reflection so that we are helped, and in the process the participants feel stronger and motivated.

In these circumstances, Robert Chamber's reflection on Participatory Rural Appraisal is worth quoting in full:

> The core of good PRA is an awareness of our own behaviour and attitudes. Understanding those behaviours and attitudes is furthered by:
>
> - Being self-aware and self-critical
> - Embracing error
> - Sitting, listening, adapting
> - Using our own best judgement at all times
>
> So we can ask: Whose knowledge, analysis and priorities count? Ours? Theirs, as we think they should be? Or theirs as they freely express them?
>
> - Good PRA is empowering, not extractive
> - Good PRA makes mistakes, learns from them, and so is self-improving
> - Good PRA spreads and improves on its own

It is crucial then that when we engage in a PICK-CHAMP workshop we are conscious of our behaviour and attitudes, and while we are tasked with finding information for use by others, that we deliberately avoid an extractive research approach, and at all times to ensure that all knowledge and insights are 'owned' by the people who have offered them in the participatory setting.

Echoing these concerns, Chambers writes of the key principles of behaviour and attitudes in PRA:

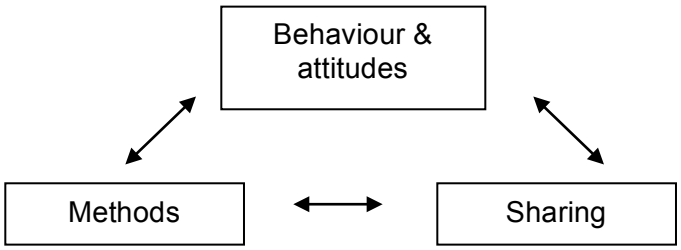
> Facilitating – they do it: facilitating investigation, analysis, presentation and learning by rural people themselves so that they present and own the outcomes, and also learn. This has been expressed as 'handing over the stick' (or pen or chalk). This often entails an outsider starting a process and then sitting back or walking away and not interviewing or interrupting.
>
> Self-critical awareness and responsibility: meaning that facilitators are continuously examining their behaviour, and trying to do better. This includes embracing error – welcoming error as an opportunity to learn to do better; and using one's own best judgement at all times, meaning, accepting personal responsibility rather than vesting it in a manual or a rigid set of rules.

Sharing of information and ideas between rural people, between them and facilitators, and between different facilitators, and sharing filed camps, training and experiences between different organisations.

Almost of all of us are outsiders. We are academics. We are comfortable with English. Some of us are anxious to perform, to meet deadlines, to drive a process. As an 'outside team' we radiate a presence and will need to be conscious of our large footprint in any process.

So START. Do not wait. Get on with it. Relax. Try things. Learn by doing. Fall forwards. Experiment. Ask – what went well? What went badly? What can we learn? How can we do better? How can we help others to do better?

Remember the three pillars:



4. Participatory inquiry with two groups

The PICK-CHAMP methodology consists of two workshops, one for community members-at-large and one for community leaders. The community members-at-large workshop is the primary opportunity to gather information and insights from community members themselves in regard to the objectives of the CHAMPS program. The workshop elicits community members' ideas, opinions, and perspectives related to death and dying, burial, autopsy, medical/clinical care, and antenatal care.

- There are three key purposes of the community members' workshop:
  1) build relationships with PICK-CHAMP participants over the course of CHAMPS activities,
  2) incorporate insights gathered from PICK-CHAMP on community perceptions beliefs, practices, and perceptions related to childhood death into the formative research and surveillance activities of CHAMPS, and
  3) establish structures for ongoing two-way communication so that community members' contributions influence CHAMPS activities and CHAMPS activities/findings are shared back in the community. PICK-CHAMP participants will be invited to stay in communication with the CHAMPS site in country so that findings from community participation and formative research activities can be shared and feedback elicited over the course of the program. In addition, participants will be invited to be part of regular community meetings to be held as part of the community participation activities over the course of the program.

The community leaders workshop endeavours to bring together a cross-section of leaders in the community: religious leaders, health leaders, educational leaders, tribal leaders, governmental leaders, etc. As key decision-makers within the community and as

gatekeepers to the community's resources, the perspectives of community leaders are important. The workshop has four key purposes:

1) to develop a social history of the community and to hear about the ways in which the community had successfully met earlier challenges,
2) to gauge community leaders' perceptions of the CHAMPS program, especially MITS procedures,
3) to identify common ground among community members, community leaders, and the CHAMPS objectives that could serve as the basis for community engagement and beginning the MITS and surveillance activities, and
4) to establish structures for ongoing two-way communication so that community members' contributions influence CHAMPS activities and CHAMPS activities/findings are shared back in the community. PICK-CHAMP participants will be invited to stay in communication with the CHAMPS site in country so that findings from community participation and formative research activities can be shared and feedback elicited over the course of the program. In addition, participants will be invited to be part of regular community meetings to be held as part of the community participation activities over the course of the program.

Section 5: Community Members Workshop: FACILITATOR GUIDE:

Facilitator's Notes:

As noted above, PICK-CHAMP will be used with two groups, namely, local community members and local community leadership. While it is not always possible to be exclusive in this process, attention is drawn to issues of power and domination when community leaders are present in gatherings with ordinary community members. Facilitators may realize that a participant in the community members workshop is, indeed, a community leader. If this occurs, then special care needs to be taken to limit possible domination or deference through skilful facilitation. By the same token, in certain contexts there is a power differential between men and women, and between elders and younger members of the community – and sensitivity will need to be exercised, such as providing different small groups for free discussion and participation.

Location.
This PICK-CHAMP needs to be undertaken in a local community setting such as a community centre, church or mosque, or health facility. If necessary, workshops can be held outside Chairs, shade, open floor space, and walls are important.

Participants
The workshop is most effective with between 20 and 25 people representing a good mix of gender, age, class, and religious perspectives. elders and youth, and different religious affiliation. While bias can never be fully avoided, it is crucial that the PICK-CHAMP facilitators work on the invitations to ensure broad-based participation and non-domination by a certain segment of the community.

Equipment.
The following equipment is necessary:

- Registration list: Form for people to fill in when they register
- Consent form: 1 form per person
- Marker pens: 25-30 (at least one per participant, in a range of colours)
- Newsprint: 50 sheets
- Masking tape: 2 rolls
- Index cards: 300 cards (102 x 152mm)
- Voice recorder: at least one with decent microphones to pick up discussion
- File box: A box to store the completed forms, as well as newsprint etc.

Translation
Working at local level means that English may not be the most

Facilitator's Notes:

familiar language for the participants. It is crucial therefore to work with a competent translator. He or she should have access in advance to the crucial research questions that are to be asked. It will be helpful to have these written out on newsprint for the various exercises so that they can be asked clearly and precisely.

Ethics and consent

PICK-CHAMP is research with human subjects. It is crucial that participants are informed about the meaning and implication of the research, and that they consent to being involved, to having their ideas used by others, and to having their photographs taken.

Agenda

The community member PICK-CHAMP unfolds as follows
(The exercises are described in detail in section 8)

8:30 Participants arrive and fill in the registration form
Refreshments provided

9:00 Welcome and Introductions: What Is CHAMPS?
Signing of consent form

9:15 Exercise 1: Describing CHAMPS Objectives to Reflect Community Priorities

10:00 Exercise 2: Perceptions of Pregnancy

10:40 Morning Tea

11:00 Exercise 3: Perceptions of Childhood Health and Illness

11:40 Exercise 4: Community Responses to Pregnancy

12:20 Exercise 5: Community Responses to Childhood Death

1:00 Lunch

2:00 Exercise 6: Participants' Perceptions of CHAMPS Activities

3:15 Afternoon Tea

3:30 Exercise 7: Valued Community Organizations That Could Support CHAMPS

4:15 Next Steps: Staying In Touch

4:30 Closure and thanks

Exercise 1: Describing CHAMPS Objectives to Reflect Community Priorities

Time: 45 minutes (9:15-10:00)

Equipment:

- 4 Index Cards per small group
- Markers for each participant
- Digital Voice Recorder

Moving naturally from introductions, the facilitator works with participants to describe CHAMPS objectives using the frameworks and contexts intrinsic to the community.

Objective: To identify the commonalities between community priorities and the objectives of the CHAMPS Program.

Break the group into small groups of 4-5 people each. The facilitator reads the following out loud to participants:

- *The purpose of CHAMPS is to understand how and why children get sick and why some of them die. The knowledge gained through CHAMPS will allow health officials to develop programs and services to address those causes—if these officials know what kills children or causes complications during pregnancy then they can do something about it.*

  We want your perspectives about these two priorities for CHAMPS:
  1) *To understand how and why children get sick and die.*
  2) *To use the information we find out to come up with programs that will cause less illness and fewer deaths in children. (HIGHLIGHT THIS OBJECTIVE)*

  (have these two priority items listed on two separate sheets of newsprint with both visible)

  Imagine that you have the task of explaining to the people in your own community why these two CHAMPS priorities are important. What would you say?

Step 1: Ask each small group to create a key message they would give to explain the importance of item #1 if they were that health official. First, all members in each small group should take 5-10 minutes to discuss this step and to create the messages through theat discussion. Second, one participant will write down **in a sentence or two** that key message on an index card provided. Encourage them to use messages that would resonate in their community by using cultural or religious ideas or stories. Each group may write up to two responses for item #1 (one per card).

Ask participants to do the same thing with item #2.

Facilitator's Notes:

*The facilitator instructs each small group to develop a set of key messages and then works with the entire group to decide on the **three most powerful key messages**.*

The facilitator should check with the note-taker for each small group to ensure that s/he understands her or his role.

The facilitator should be prepared to offer an example to help participants begin the discussion if needed

Facilitator's Notes:

When finished, each group should have 1 or 2 key messages that re-enforce the two CHAMPS priorities (a total of 2-4 key messages).

Step 2: The small groups gather back together in plenary. Cards are collected from each small group and then laid out one at a time on the floor, starting with the cards for item 1. When a card repeats what a previous card has said, it is laid down above its namesake.

Clearly the facilitator needs to group together words that express the same message even if they are different words.

In this way a 'bar graph' of the key messages that re-enforce the activities of item #1 is created.

The process is repeated with item #2.

Recorded discussion. The facilitator leads participants through a discussion of the messages that were written. What are participants' perceptions about the messages? Which are more powerful? Are there any disagreements? What makes these messages powerful?

Step 3. Flowing directly out of the discussion, the facilitator – in constant dialogue with the participants - draws together the key messages for item #1 to identify the **3 most powerful key messages** that support item #1. This process is repeated for item #2

Output:
A participant-driven list of messages based on community norms and language that re-enforce the objectives of CHAMPS with the three most powerful messages identified.

Exercise 2: Perceptions of Pregnancy

Time: 40 minutes (10:00-10:40)
Equipment:

- A marker pen for each participant
- 6 index cards for each small group
- 3 sheets of newsprint
- Tape recorder

Objective:
This exercise focuses on naming the community's perceptions about the things that contribute to healthy pregnancy. This exercise involves three clear steps.

Flowing naturally from the discussion in Exercise 1, the facilitator informs participants that one way CHAMPS will achieve the first objective listed in that exercise is to learn more about the things that help women deliver healthy children when they get pregnant.

Step 1: Participants move back into their same small groups. They are asked to discuss the answer to the question:

- *What do you consider to be the three most important factors that contribute to healthy pregnancies for women in your community?*

Each group discusses the question and develops three answers. A representative of the group writes down the group's answers on the three cards (one answer per card). The facilitator collects these cards and then lay them out in a place on the floor where all small group participants can observe. When a card repeats what a previous card has said, it is laid down above its namesake.

Clearly the facilitator needs to group together words that express the same factor even if they are different words (eg. nutrition = good food = healthy food = food; knowledge = education = understanding; etc.) In this way a 'bar graph' of the key factors that the participants believe cause healthy pregnancies is created, and the participants can see what they themselves believe to be the key factors. The cards are left on the floor for step 2.

Step 2. The first exercise is repeated, but the question is changed. Now as they work again in their small groups, participants are asked to write down the answer to the question:

- *What do you consider to be the three most important factors that cause complications during pregnancy for women in your community?*

A representative of the group writes down the group's answers on the three cards (one per card). These cards are collected and then laid out on the floor alongside the earlier set. When a card repeats what a previous card has said, it is laid down above its namesake.

Facilitator's Notes:

Note facilitator's leadership roles here:

- *Provide instructions (two topics)*
- *Process findings for each topic.*
- *Develop a list of 4-6* ***most important*** *factors that contribute to healthy pregnancies. This requires the facilitator to look for linkages between the two separate lists generated earlier in the exercise.*

Facilitator's Notes:

Again the facilitator will need to group 'ideas' rather than exact words together.

In this way a 'bar graph' of the key factors that the participants believe cause sickness is created, and the participants can see what they themselves believe to be the key factors.

Recorded discussion. Through probing questions participants are engaged in reflective discussion on the reasons that certain factors are more significant than others. This should be recorded by tape recorder for later transcription as it is likely to contain key insights.

Step 3. Flowing directly out of the discussion, the facilitator – in constant dialogue with the participants - draws together the key factors that affect healthy pregnancy – either positively or negatively. This requires some lateral thinking as for example the following list may be generated (votes in brackets):

Healthy Pregnancy	Complicated pregnancy
Good health care (9)	Sickness (9)
Nutrition (6)	Poverty (7)
Faith in God (5)	Pollution (6)
Good sanitation (5)	Bad nutrition (5)
Knowledge (3)	Ignorance (3)
Water (2)	No employment (1)
Medicine (2)	No health facilities close by (1)

Food is a clear factor for a healthy pregnancy and bad nutrition a factor in a complicated pregnancy – but clearly they express the same idea, and so only one word is chosen. Likewise, ignorance and knowledge express the same idea. Depending on how people understand pollution, it may be the flip-side of good sanitation. Thus, after some discussion, the participants agree on a combined set of five or six key factors contribute to healthy pregnancies in the community. In the above case these would probably be:

Nutrition
Knowledge
Against Poverty
Against Pollution
Medicine and health facilities

The facilitator should write these responses down on the newsprint.

Output:
A participant driven list of factors that impact pregnancy

Following the completion of this exercise, participants will break for morning tea until 11:00 AM

Exercise 3: Perceptions of Childhood Health and Illness

Time: 40 minutes (11:00-11:40)

Equipment:

- A marker pen for each participant
- 6 index cards for each small group
- 3 sheets of newsprint
- Tape recorder

Objective:
This exercise focuses on naming the community's perceptions about the things that affect children's health: the things that help children be healthy or the things that may make children sick. This exercise involves three clear steps and the process is identical to exercise 2 above with a different topic.

Step 1: Still in their same small groups, participants asked to write down the answer to the question:

- *What do you consider to be the three most important factors that contribute to the health of children in your community? Write down these factors (one per card) in a few words or a short phrase.*

Each group discusses the question and develops three answers. A representative of the group writes down the group's answers on the three cards. These cards are collected and then laid out in a place on the floor where all small group participants can observe. When a card repeats what a previous card has said, it is laid down above its namesake. Clearly the facilitator needs to group together words that express the same factor even if they are different words. In this way a 'bar graph' of the key factors that the participants believe cause good health is created, and the participants can see what they themselves believe to be the key factors. The cards are left on the floor for step 2.

Step 2. The first exercise is repeated, but the question is changed. Now as they work again in their small groups, participants are asked to write down the answer to the question:

- *What do you consider to be the two key factors that cause children to become ill or die in your community? Write down these factors (one per card) in a few words or a short phrase.*

A representative of the group writes down the group's answers on the three cards. These cards are collected and then laid out on the floor alongside the earlier set. When a card repeats what a previous card has said, it is laid down above its namesake. Again the facilitator will need to group 'ideas' rather than exact words together. In this way a 'bar graph' of the key factors that the participants believe cause sickness is created, and the participants can see what they themselves believe to be the key factors.

Recorded discussion. Through probing questions participants are

Facilitator's Notes:

This exercise will likely take less time than exercise 2 did because participants will be familiar with the process.

The process is quite similar.

Facilitator's Notes:

engaged in reflective discussion on the reasons that certain factors are more significant than others. This should be recorded by tape recorder for later transcription as it is likely to contain key insights.

Step 3. Flowing directly out of the discussion, the facilitator – in constant dialogue with the participants - draws together the key factors that contribute to childhood health – either positively or negatively. Thus, after some discussion, the participants agree on a combined set of five or six key factors that contribute to healthy children in the community. The list will be similar to the one generated in exercise 2. The facilitator should write these responses down on the newsprint.

Output:
A participant driven list of factors that impact childhood health, illness, and death.

Exercise 4: Community Responses to Pregnancy

Time: 40 minutes (11:40-12:20)

Equipment:
- 1 marker pen for each participant
- 5 index cards for each small group (25 cards total)
- 3 sheets of newsprint
- Tape recorder

Objective:
To create a participant-driven list of the most important things the community does when a woman becomes pregnant.

The facilitator leads participants through three steps:

Step 1: Ask each group to answer the following question:

- *What are the three most important things that happen in your community when a woman becomes pregnant? How does your community respond to the news of the pregnancy?*

Each group discusses the question and develops three answers. A representative of the group writes down the group's answers on the three cards (one response per card).

Step 2: Bring the small groups back together into plenary. Ask each group to read aloud and elaborate on the three most important things that happen in the community when a woman becomes pregnant. Have each group simply present their items; facilitators should allow questions for clarification but should not allow for any discussions about which items are most important until all groups have presented.

As each group reads their cards, the facilitator places them onto the floor one at a time without further comment. This continues until each group has completed naming their list. If there is a duplicate card among the groups, place it with the other like cards. If you think two cards are similar, ask the group to decide whether they represent the same thing; if so, place the cards to together and if not, leave them separate.

Step 3: After all small groups have named their three items, ask the large group to decide on the list of the *essential* things that are done when a woman becomes pregnant (as in earlier, this process should generate a list of 4-6 items). The facilitator should write these items on the newsprint. Once this list is generated, ask the group to discuss *why* these items are important.

Output:
A participant-driven list of important things done in the community with the key 4-6 things named in rank order.

Facilitator's Notes:

The facilitator instructs each small group to develop a list and then works with the entire group to decide on the most important things the community does when a woman becomes pregnant.

Exercise 5: Community Responses to Childhood Death

Facilitator's Notes:
The facilitator instructs each small group to develop a list and then works with the entire group to decide on the most important things the community does when a child dies.

Time: 40 minutes (12:20-1:00)

Equipment:

- 1 marker pen for each participant
- 15 index cards for each small group (25 cards total)
- 3 sheets of newsprint
- Tape recorder

Objective:
To create a participant-driven list of the most important things the community does when a child dies.

The facilitator leads participants through three steps:

Step 1: Ask each group to answer the following question:

- *What are the three most important things that happen in your community when a child dies? This would include children who die during the birth process, children who are stillborn, or any child who dies before their fifth birthday. How does your community respond to the news of the death?*

Each group discusses the question and develops three answers. A representative of the group writes down the group's answers on the three cards (one response per card).

Step 2: Bring the small groups back together into plenary. Ask each group to read aloud and elaborate on the three most important things that happen in the community when a child dies. Have each group simply present their items; facilitators should allow questions for clarification but should not allow for any discussions about which items are most important until all groups have presented.

As each group reads their cards, the facilitator places them onto the floor one at a time without further comment. This continues until each group has completed naming their list. If there is a duplicate card among the groups, place it with the other like cards. If you think two cards are similar, ask the group to decide whether they represent the same thing; if so, place the cards to together and if not, leave them separate.

Step 3: After all the small groups have named their three items, ask the large group to decide on the list of the *essential* things that are done when a woman becomes pregnant (as in earlier, this process should generate a list of 4-6 items). The facilitator should write these items on the newsprint. Once this list is generated, ask the group to discuss *why* these items are important.

After the exercise is complete, announce the lunch break. Before participants break, remind them to return in one hour. Inform participants that you will be available to talk during lunch if they would like to discuss any feelings that have arisen for them. Assess whether the cultural norm is to offer a blessing of the food or some other ritual such as handwashing prior to lunch. If a blessing is custom, ask for a volunteer from among the participants to lead the group in a blessing; if handwashing or other ritual is custom, provide the time to carry it out.

Output:
A participant-driven list of important things done in the community with the key 4-6 things named in rank order.

Facilitator's Notes:

Exercise 6: Participants' Perception of CHAMPS Activities

Facilitator's Notes:
Exercise 6 is complicated. Facilitators should go through the directions carefully to ensure participants understand and ask participants if they have any questions before beginning

Time: 75 minutes (2:00-3:15)

Objective:
To assess perceptions of the level of alignment or tension between CHAMPS activities and community priorities and perceptions.

This exercise has two parts. The first step identifies general alignment or tension between participants' perceptions and CHAMPS activities. The second step provides more specific contexts for determining alignments or tensions between CHAMPS activities and participants' perceptions.

PART ONE
Read the following aloud to participants:
We began the day by examining the objectives for CHAMPS. As a reminder, they are:

1) *To understand how and why children get sick and die.*
2) *To use the information we find out to come up with programs that will cause less illness and fewer deaths in children. (Highlight this objective)*

(have these two priority items listed on two separate sheets of newsprint with both visible)

*Now we want to discuss what needs **to be done** in order for the CHAMPS program to meet its objectives. In general, CHAMPS will need to carry out two activities in both hospital and community settings.*

For the first activity we will talk with women who are currently pregnant or have recently been pregnant. We will only talk with women who want to talk with us and will talk with them in both healthcare and community settings. We want to learn from women themselves the things that may have affected their pregnancy or the birth of their child. We want to hear about both things that helped and things that caused problems during pregnancy for all women. Finally, in the unfortunate case that the pregnancy results in a stillbirth, we want to learn about the kinds of health services will be helpful to mothers and will lead to positive birth outcomes.

For the second activity we will speak with some of the parents in your community who will have just experienced the death of their child. With their permission, we will gather small samples from the body of their child after the child's death. We will speak with parents either in hospital or at their home. Studying these samples will improve our accuracy in figuring out the things that cause children to die so that we help children live longer and healthier lives

Ask participants for if they have any questions for information or clarification. If they want to offer their opinions (instead of asking questions of fact) then assure them that the purpose of this exercise

Is to hear those opinions but ask them to wait a few moments until all questions are answered first. Once all questions have been answered, instruct participants to gather around the following two matrices taped to the wall:

CHAMPS Activity: Talking with women who are pregnant or who recently delivered a child.	How does this CHAMPS activity fit with our community's priorities?	
	It fits with our community	It does not fit with our community

	How does this CHAMPS activity fit with our community's priorities?	
CHAMPS Activity: With parents' consent, gather samples from the body of a child who recently died.	It fits with our community	It does not fit with our community

Step 1: If they don't have an opinion, they don't have to add the sticker. Participants will have a sheet of stickers in their participant folders (each sticker on that sheet will be pre-printed with each participant's unique ID). A participant will place her/his sticker in the box labelled "It fits with our community" if s/he believes that the CHAMPS activity aligns with community priorities and norms. If he or she believes that the CHAMPS activity is in tension with community priorities and norms the participant will place a sticker in the box labelled "It does not fit with our community." Participants should place one sticker on each matrix (in either of the two boxes of that matrix). They will place a total of two stickers on the matrices.

Step 2: After all participants have placed their two stickers, the facilitator should lead the participants in a discussion. In general, does the group believe that each CHAMP activity aligns with or is in tension with community priorities and norms? Why?

Output from part one:
A matrix showing alignment or tension between CHAMPS activities and community priorities.

PART TWO
The facilitator naturally moves the discussion from general perceptions of alignment and tension by telling participants that in part two will they will have an opportunity to give more specific information about alignment and tension. Prominently displayed on the walls are three signs:

Agree **Disagree** **Uncertain**

The participants are asked to respond to a series of 20 propositions (not questions), which are read out clearly by the facilitator, by

Facilitator's Notes:

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Be sure to look out for any surprising findings on the matriices. Pay special attention to squares on the matrix where participants identify high alignment between community activities and CHAMPS activities (especially look for any alignment with MITS)

moving, in silence, to stand beneath the sign that best represents

Facilitator's Notes:

their response to the statement. Three workshop team members will be stationed beside the three signs, one per sign. Each of those team members will have 20 sheets of paper with one proposition printed on each sheet. As each participant moves to a sign in response to their own opinion about the proposition that was read, they will place a sticker with their unique ID number on the team member's sheet for that particular proposition.

The numbers for each group (AGREE, DISAGREE, and UNCERTAIN) are calculated and written up on newsprint for each proposition AS THE EXERCISE IS CARRIED OUT. The participants remain under the sign while the next proposition is read out and then move.

This process should be done as silently as possible – the participants should not discuss their responses among each other.

(See the list of propositions on the next page)

Once all propositions have been read and participants have responded to each with "AGREE," "DISAGREE," or "UNCERTAIN" the facilitator should lead the participants in a general discussion of the activity. Begin by de-briefing the activity. What were the participants' impressions? Are any of the group's responses striking or surprising? After thinking about these 20 propositions, did any participants change their mind about the acceptability of the CHAMPS surveillance activities? If so, why?

Output from part two:
A profile of participants' perceptions about CHAMPS activities across five categories:

1 Acceptability/Value
2 General acceptability of MITS even if there is personal discomfort
3 Beliefs about childhood death, burial, and MITS
4 Beliefs about pregnancy, childhood illness/death, & medical care
5 The value of surveillance and research

Following this exercise, inform participants that there will be a fifteen-minute break. Encourage them to speak with you if they want to talk about any aspect of this exercise.

	Acceptability/Value
	General acceptability of MITS even if there is personal discomfort
	Beliefs about childhood death, burial, and MITS
	Beliefs about pregnancy, childhood illness/death, and medical care
	The value of surveillance and research

Category	Proposition
	1. It is wrong to remove small samples of tissue from a child after she has died even if tests done on that tissue could tell you how she died.
	2. A woman should not be asked about what's happening during her pregnancy because that information is private.
	3. The information gained from tissue samples is worthwhile because this knowledge could help us improve child survival.
	4. If we know what happens to women during their pregnancy, we can figure out what to do to help women have safe pregnancies and give birth to healthy children.
	5. In my opinion, I don't think any parent should ever agree to let tissue samples be collected from the body of their child after that child has died.
	6. Our community owes a debt of gratitude to parents who consent to the removal of tissue from their child's bodies when they die because these parents are helping other children to live.
	7. Even if I didn't agree to have tissue samples collected from my child's body, I still think the knowledge we gain through this work is important for helping us fight childhood illness and death.
	8. Even if I might not want to answer questions about my own pregnancy (or wouldn't want my wife to), I am glad that other women in the community are doing so if it contributes to healthier pregnancies.
	9. Medicine and science may help us care for a child's body during life but care for a child's body at death is the work of faith and of God alone.
	10. I would not agree to any kind of procedure if it meant that I could not bury my child according to my faith or tradition.
	11. We can collect tissue samples and still be able to bury a child with love and respect.
	12. Collecting tissue samples shows a family's love for a child who has died and for all the children in our community because it gives us knowledge that could help children be healthier.
	13. All women in our community who are pregnant should be seen at a health centre to make sure there are no problems during their pregnancy.
	14. While medical care for pregnant mothers and children is important, it is not easy for them to get the care they need.
	15. I rely on a healer more than a healthcare provider to help me stay healthy.
	16. Healthcare providers and traditional healers both help me stay healthy. There should be no tension between the two.
	17. Knowing what causes children to get sick and what causes negative outcomes in pregnancy would allow us to do something about them.
	18. I am glad that this program is being carried out in our community. It will help improve our health in the long run.
	19. Researchers only care about the information they collect. They don't care about improving the health of our community.
	20. While CHAMPS activities focus on sickness and death, they are being carried out in order to improve our health and our living.

Exercise 7: Valued Community Organizations That Could Support CHAMPS

Time: 45 minutes (3:30-4:15)

Equipment:

- 25 index cards for each small group
- 1 pen or marker per participant
- Newsprint

Objective: Generate a list of valued community organizations and leaders in the community

Facilitator's Notes:

After break, participants gather back into their small groups. The facilitator directs participants to two matrices on the wall:

CHAMPS Activity: Talking with women who are pregnant or who recently delivered a child.	Who would be a Champion for this activity?

CHAMPS Activity: With parents' consent, gather samples from the body of a child who recently died.	Who would be a Champion for this activity?

Ask each group to write down the best community resources that might be a good partners to work with CHAMPS staff to carry out the CHAMPS activity that was named (up to five organizations/ individuals for each group). The group may name an organization or an individual. The facilitator then reads the list of organizations or individuals aloud, placing the cards on the floor as each one is read. Any duplicate cards are placed above the existing cards, creating a bar graph on the floor. After all the valued organizations have been named, record the top five on the newsprint along with the number of responses given for each organization.

Output: A participant driven list of local community organizations that are important resources for the community to respond to the death of a child that participants also identify as potentially supporting one or more CHAMPS activities.

Next Steps: Staying In Touch

Facilitator's Notes:
The workshop is completed. Before adjourning, the facilitator should invite participants to stay in touch with CHAMPS to receive updates on findings, future events, and community meetings.

Time: 15 minutes (4:15-4:30)

At this point the workshop is completed. Explain that this is one of the first activities being carried out by CHAMPS and that the CHAMPS team would like to stay in touch with the participants. Ask participants if they would like to continue to receive information about CHAMPS, including information of the findings, periodic newsletters, and invitations to future community meetings in which CHAMPS staff provide updates to the community. If so, have participants complete a "Stay In Touch" Card.

Adjourn the workshop with your thanks and gratitude and remain in the front of the room so that participants can speak with you individually if they would like.

Section 6: Community Members Workshop: SMALL GROUP SCRIBE GUIDE:

PICK-CHAMP is designed so that small groups develop thoughtful responses to exercises that elicit participants' perspectives on community norms, values, priorities, and beliefs. The small group responses will be examined through a large group process. The role of the small group scribe is to record the contributions of individual participants in each small group. Your role is essential because your input is the only way we can analyze responses given by individual participants and correlate those responses to the individual-level demographic information provided by each participant during the registration process. Therefore, quick, clear transcription of what is said in the group is essential along with a clear identification of the participants who spoke.

The following pages can be used to record participant responses for each exercise. A different form for each exercise has been developed for the scribe's convenience. Scribes should work closely with the facilitator to ensure that they are on the correct exercise and should turn in completed transcription pages to the workshop support team so they can begin to enter them into the database.

Exercise 1: Describing CHAMPS Objectives to Reflect Community Priorities

Time: 45 minutes (9:15-10:00)

Objective:
Participants in the small groups will use community norms and values to explain the importance of the two objectives of CHAMPS.

OBJECTIVE ONE: To understand how and why children get sick and die.

Participant #	Participant's Input

OBJECTIVE TWO: To use the information we find out to come up with programs that will cause less illness and fewer deaths in children.

Participant #	Participant's Input

Exercise 2: Perceptions of Pregnancy

Time: 40 minutes (10:00-10:40)

Objective:
Participants will describe the things that contribute to a healthy pregnancy or complicate pregnancies.

KEY QUESTION ONE: What are the most important factors that contribute to healthy pregnancies for women in your community?

Participant #	Participant's Input

KEY QUESTION TWO: What are the most important factors that cause complications during pregnancy for women in your community?

Participant #	Participant's Input

Exercise 3: Perceptions of Childhood Health and Illness

Objective:
Participants will describe the things that contribute to a healthy childhood or cause childhood illness.

KEY QUESTION ONE: What do you consider to be the three most important factors that contribute to the health of children in your community?

Participant #	Participant's Input

KEY QUESTION TWO: What do you consider to be the two key factors that cause children to become ill or die in your community?

Participant #	Participant's Input

Exercise 4: Community Responses to Pregnancy

Time: 40 minutes (11:40-12:20)

Objective:
Participants will describe the most important things the community does when a woman becomes pregnant.

KEY QUESTION: What are the three most important things that happen in your community when a woman becomes pregnant? How does your community respond to the news of the pregnancy?

Participant #	Participant's Input

Exercise 5: Community Responses to Childhood Death

Time: 40 minutes (12:20-1:00)

Objective:
Participants will describe the most important things the community does when a child dies.

KEY QUESTION: What are the three most important things that happen in your community when a child dies? This would include children who die during the birth process, children who are stillborn, or any child who dies before their fifth birthday. How does your community respond to the news of the death?

Participant #	Participant's Input

Exercise 6: Participants' Perception of CHAMPS Activities

This activity is completely carried out in large group. If individuals provide their opinions on the topic being discussed in the large group, scribes should try to take note of what was said and identify the participant # of the person who said it.

Participant #	Participant's Input

Exercise 7: Valued Community Organizations That Could Support CHAMPS

Time: 45 minutes (3:30-4:15)

Objective:
Participants will describe valued organizations and leaders in the community that could support CHAMPS.

KEY QUESTION ONE: Who would be a Champion for supporting CHAMPS in talking with women who are pregnant or who recently delivered a child?

Participant #	Participant's Input

KEY QUESTION TWO: Who would be a Champion for supporting CHAMPS to gather samples from the body of a child?

Participant #	Participant's Input

Section 7: Community Members Workshop: SUPPORT TEAM GUIDE

Support Team's Notes:

The support team places a crucial role in the success of PICK-CHAMP because you must attend to a number of administrative and logistical issues prior to and during the workshops. This section leads the support team through Pre-Workshop activities that need to be completed as well as the logistical elements of each exercise in the community members workshop.

Location: The PICK-CHAMP workshop needs to be offered in a local community setting such as a community centre, church or mosque, or health facility. Chairs, open floor space, and blank walls where newsprint can be hung are all important. Electricity is preferred and if electricity is not available, the team should ensure that any laptops (for registration or data entry) have sufficient battery life.

Participants: The workshop is most effective with between 20 and 25 people representing a good mix of gender, age, class, and religious perspectives. While bias can never be fully avoided, it is crucial that the PICK-CHAMP team works on the invitations to ensure broad-based participation and non-domination by a certain segment of the community.

Materials:

1. Registration list: Form for people to fill in when they register (may also be completed on a laptop using the Access program)
2. 30 consent form (1 form per person, plus extras as needed)
3. Ballpoint pens: 25-30 (one per participant plus some extras in case pens are lost)
4. Felt-tip marker pens: 10 (at least one per small group plus some extras for use by facilitators and support team during exercises)
5. Newsprint: 50 sheets
6. 30 pocket folders (one for each part. with extras as needed)
7. 60 pre-printed sheets for the propositions activity for exercise 6
8. Pre-printed sheet of labels (one sheet for each participant with their participant # printed on each label—the sheet should contain at least 22 labels)
9. 15 large, sealable manila envelopes. 7 of these should be pre-labeled for exercises 1-7. The remainder are extras as needed.
10. Masking tape: 2 rolls
11. Three large signs: "Agree," "Disagree," and "Uncertain."
12. A box of large rubber bands
13. Index cards: 200 cards (30 cards/group pre-labeled with the group number with blank extras available if needed)
14. Five pre-drawn matrices: 3 for exercise six, 2 for exercise seven.
15. Voice recorder: at least one with decent mic to pick up discussion
16. Extra batteries for the voice recorder.
17. File box: A box to store the completed forms, as well as newsprint etc.

Be sure to have all of the materials in this list on hand at the workshop.

Support Team's Notes:

Ethics and consent: PICK-CHAMP is research with human subjects. It is crucial that participants are informed about the meaning and implication of the research, and that they consent to being involved, to having their ideas used by others, and to having their photographs taken.

Agenda: The community member PICK-CHAMP unfolds as follows

8:30 Participants arrive and fill in the registration form
Refreshments provided

9:00 Welcome and Introductions: What Is CHAMPS?
Signing of consent form

9:15 Exercise 1: Describing CHAMPS Objectives to Reflect Community Priorities

10:00 Exercise 2: Perceptions of Pregnancy

10:40 Morning Tea

11:00 Exercise 3: Perceptions of Childhood Health and Illness

11:40 Exercise 4: Community Responses to Pregnancy

12:20 Exercise 5: Community Responses to Childhood Death

1:00 Lunch

2:00 Exercise 6: Participants' Perceptions of CHAMPS Activities

3:15 Afternoon Tea

3:30 Exercise 7: Valued Community Organizations That Could Support CHAMPS

4:15 Next Steps: Staying In Touch

4:30 Closure and thanks

Food: The Support Team should arrange any food to be served during the workshop. In general, PICK-CHAMP workshops provide a morning continental breakfast, a morning tea/coffee break, a mid-day lunch, and an afternoon tea/coffee break to participants. The workshop should be carried out in a facility that would allow for meal and break set up outside of the workshop meeting area so that food can be ready at designated times without disturbing participants during preparation.

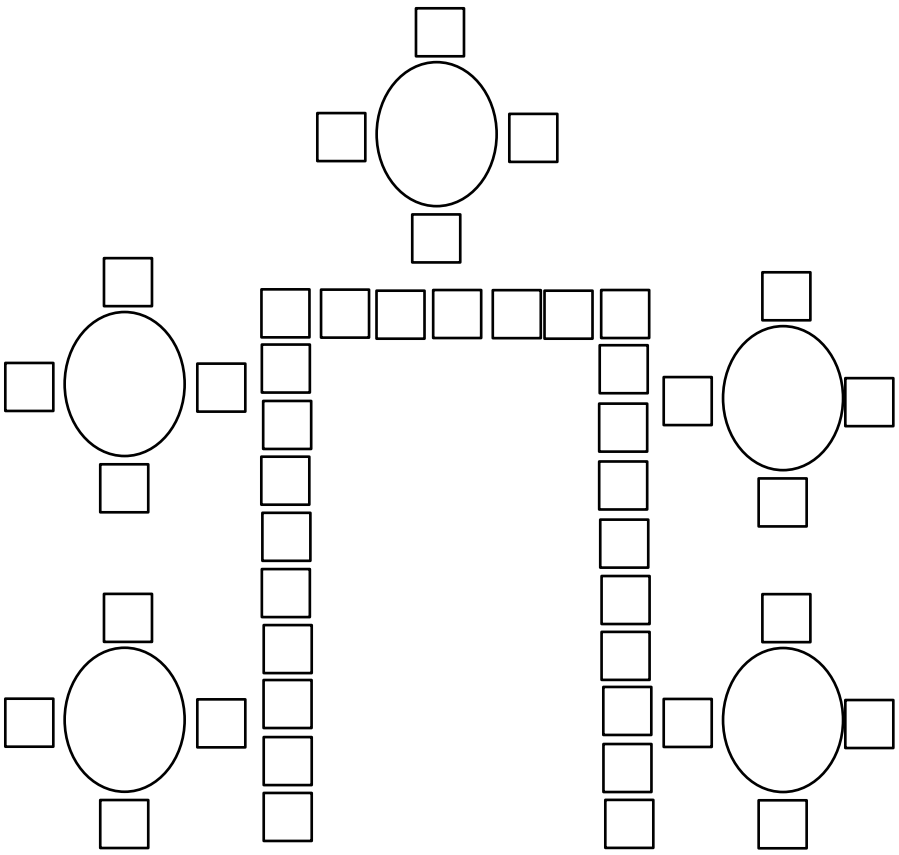
Registration
The support team should have registration tables by the entrance to

Support Team's Notes:

the workshop room. Participants will complete the registration process (either by filling out the paper registration form (see Appendix) or, preferably, by completing registration by having a support team member enter their information into the Access database. After completing the registration, a participant is given a nametag that has the participant's ID number printed on it and a pocket file folder that contains a sheet of preprinted laser labels along with a ballpoint pen. The support team must ENSURE that the number printed on the labels and on the nametag matches the participant's ID number from the registration form.

Room Set Up

The room should be set up to allow for an easy flow between small groups and a large group plenary. Each small group should be clustered together, ideally around a circular table and each small group should consist of 4-5 participants. With a maximum of 25 participants, each workshop should have no more than 5 small groups. Participants should be grouped together to reflect diversity in regard to age, gender, etc. There should be sufficient space in the room to allow participants to move back and forth between their small groups and a large group plenary area. The support team should decide on the optimal room set-up but, in general, it should have a design akin to this:



The workshop meeting room should have a set up similar to this

Support Team's Notes:

The Support Team should assign participants to small groups in such a way to ensure that one participant in each group has reading and writing proficiency to write the group's responses to the exercises on the index cards that are provided to each group.

A stack of 30 index cards should be provided to each group and each card in the group's stack should have the group's ID number pre-printed on it. In addition to the index cards, provide a felt-tip marker to the person who will be writing for the group.

Exercise 1: Describing CHAMPS Objectives to Reflect Community Priorities

Time: 45 minutes (9:15-10:00)

Equipment:

- Index Cards per small group
- Markers for each participant
- Digital Voice Recorder

Moving naturally from introductions, the facilitator works with participants to describe CHAMPS objectives using the frameworks and contexts intrinsic to the community.

Objective: To identify the commonalities between community priorities and the objectives of the CHAMPS Program.

Break the group into small groups of 4-5 people each. The facilitator reads the following out loud to participants:

- *The purpose of CHAMPS is to understand how and why children get sick and why some of them die. The knowledge gained through CHAMPS will allow health officials to develop programs and services to address those causes—if these officials know what kills children or causes complications during pregnancy then they can do something about it.*

  We want your perspectives about these two priorities for CHAMPS:
  1) *To understand how and why children get sick and die.*
  2) *To use the information we find out to come up with programs that will cause less illness and fewer deaths in children. (HIGHLIGHT THIS OBJECTIVE)*

  Imagine that you have the task of explaining to the people in your own community why these two CHAMPS priorities are important. What would you say?

Step 1: Ask each small group to create a key message they would give to explain the importance of item #1 if they were that health official. First, all members in each small group should take 5-10 minutes to discuss this step and to create the messages through theat discussion. Second, one participant will write down **in a sentence or two** that key message on an index card provided. Encourage them to use messages that would resonate in their community by using cultural or religious ideas or stories. Each group may write up to two responses for item #1 (one per card). Ask participants to do the same thing with item #2.

When finished, each group should have 1 or 2 key messages that re-enforce the two CHAMPS priorities (a total of 2-4 key messages).

Support Team's Notes:

This exercise begins in the small groups. After each small group has created up to 2 messages to support the 2 CHAMPS objectives, the participants will move into the large group.

Work with the facilitator to begin moving participants into the large group by 9:40.

Support Team's Notes:

The plenary discussion should be tape recorded so that any important perspectives were provided during the plenary discussion can be captured.

After the key messages are decided, the support team gathers all of the index cards laid out on the floor (each of these cards should have the number corresponding to the group that wrote the message pre-printed on the card). The team also gathers the six index cards that contain the most powerful key messages. All cards should be bundled together and placed into the manila envelop pre-labeled "Exercise 1." The envelope should be closed and sealed if data entry is to happen later offsite.

Step 2: The small groups gather back together in plenary. Cards are collected from each small group and then laid out one at a time on the floor, starting with the cards for item 1. When a card repeats what a previous card has said, it is laid down above its namesake.

Clearly the facilitator needs to group together words that express the same message even if they are different words.

In this way a 'bar graph' of the key messages that re-enforce the activities of item #1 is created.

The process is repeated with item #2.

Recorded discussion. The facilitator leads participants through a discussion of the messages that were written. What are participants' perceptions about the messages? Which are more powerful? Are there any disagreements? What makes these messages powerful?

Step 3. Flowing directly out of the discussion, the facilitator – in constant dialogue with the participants - draws together the key messages for item #1 to identify the **3 most powerful key messages** that support item #1. The facilitator should write down each of those messages, one per card, on index cards and label each card as Key Message to Support #1. This process is repeated for item #2 (the cards should be labelled Key Message to Support #2).

Output:
A participant-driven list of messages based on community norms and language that re-enforce the objectives of CHAMPS with the three most powerful messages identified.

Exercise 2: Perceptions of Pregnancy

Time: 40 minutes (10:00-10:40)

Equipment:

- Index cards for each small group
- 3 sheets of newsprint
- Tape recorder

Objective: This exercise focuses on naming the community's perceptions about the things that contribute to healthy pregnancy. This exercise involves three clear steps.

Flowing naturally from the discussion in Exercise 1, the facilitator informs participants that one way CHAMPS will achieve the first objective listed in that exercise is to learn more about the things that help women deliver healthy children when they get pregnant.

Step 1: Participants move back into their same small groups. They are asked to discuss the answer to the question:

- *What do you consider to be the three most important factors that contribute to healthy pregnancies for women in your community?*

Each group discusses the question and develops three answers. A representative of the group writes down the group's answers on the three cards (one answer per card). The facilitator collects these cards and then lay them out in a place on the floor where all small group participants can observe. When a card repeats what a previous card has said, it is laid down above its namesake.

Clearly the facilitator needs to group together words that express the same factor even if they are different words (eg. nutrition = good food = healthy food = food; knowledge = education = understanding; etc.) In this way a 'bar graph' of the key factors that the participants believe cause healthy pregnancies is created, and the participants can see what they themselves believe to be the key factors. The cards are left on the floor for step 2.

Step 2. The first exercise is repeated, but the question is changed. Now as they work again in their small groups, participants are asked to write down the answer to the question:

- *What do you consider to be the three most important factors that cause complications during pregnancy for women in your community?*

A representative of the group writes down the group's answers on the three cards (one per card). These cards are collected and then laid out on the floor alongside the earlier set. When a card repeats what a previous card has said, it is laid down above its namesake.

Support Team's Notes:

This exercise moves back and forth between the small groups and the plenary.

Work with the facilitator to begin moving participants into the final large group gathering by 10:25.

Support Team's Notes:

When the exercise is complete, the support team should gather all the cards generated for "factors that contribute to a healthy pregnancy" and bundle them together. Then, they should gather all the cards generated for "factors that cause complications in pregnancy" and bundle them together. Finally, they should gather the newsprint containing the "key factors" written by the facilitator. The three items should be placed in the manila envelope labelled exercise 2. The envelope should be closed and sealed if data entry is to happen later offsite.

Again the facilitator will need to group 'ideas' rather than exact words together.

In this way a 'bar graph' of the key factors that the participants believe cause sickness is created, and the participants can see what they themselves believe to be the key factors.

Recorded discussion. Through probing questions participants are engaged in reflective discussion on the reasons that certain factors are more significant than others. This should be recorded by tape recorder for later transcription as it is likely to contain key insights.

Step 3. Flowing directly out of the discussion, the facilitator – in constant dialogue with the participants - draws together the key factors that affect healthy pregnancy – either positively or negatively. This requires some lateral thinking as for example the following list may be generated (votes in brackets):

Healthy Pregnancy	Complicated pregnancy
Good health care (9)	Sickness (9)
Nutrition (6)	Poverty (7)
Faith in God (5)	Pollution (6)
Good sanitation (5)	Bad nutrition (5)
Knowledge (3)	Ignorance (3)
Water (2)	No employment (1)
Medicine (2)	No health facilities close by (1)

Food is a clear factor for a healthy pregnancy and bad nutrition a factor in a complicated pregnancy – but clearly they express the same idea, and so only one word is chosen. Likewise, ignorance and knowledge express the same idea. Depending on how people understand pollution, it may be the flip-side of good sanitation. Thus, after some discussion, the participants agree on a combined set of five or six key factors contribute to healthy pregnancies in the community. In the above case these would probably be:

Nutrition
Knowledge
Against Poverty
Against Pollution
Medicine and health facilities

The facilitator should write these responses down on the newsprint.

Output:
A participant driven list of factors that impact pregnancy

Following the completion of this exercise, participants will break for morning tea until 11:00 AM

Exercise 3: Perceptions of Childhood Health and Illness

Time: 40 minutes (11:00-11:40)

Equipment:

- A marker pen for each participant
- 6 index cards for each small group
- 3 sheets of newsprint
- Tape recorder

Objective:
This exercise focuses on naming the community's perceptions about the things that affect children's health: the things that help children be healthy or the things that may make children sick. This exercise involves three clear steps and the process is identical to exercise 2 above with a different topic.

Step 1: Still in their same small groups, participants asked to write down the answer to the question:

- *What do you consider to be the three most important factors that contribute to the health of children in your community? Write down these factors (one per card) in a few words or a short phrase.*

Each group discusses the question and develops three answers. A representative of the group writes down the group's answers on the three cards. These cards are collected and then laid out in a place on the floor where all small group participants can observe. When a card repeats what a previous card has said, it is laid down above its namesake.

Clearly the facilitator needs to group together words that express the same factor even if they are different words. In this way a 'bar graph' of the key factors that the participants believe cause good health is created, and the participants can see what they themselves believe to be the key factors. The cards are left on the floor for step 2.

Step 2. The first exercise is repeated, but the question is changed. Now as they work again in their small groups, participants are asked to write down the answer to the question:

- *What do you consider to be the two key factors that cause children to become ill or die in your community? Write down these factors (one per card) in a few words or a short phrase.*

A representative of the group writes down the group's answers on the three cards. These cards are collected and then laid out on the floor alongside the earlier set. When a card repeats what a previous card has said, it is laid down above its namesake. Again the facilitator will need to group 'ideas' rather than exact words together.

In this way a 'bar graph' of the key factors that the participants

Support Team's Notes:

This exercise moves back and forth between the small groups and the plenary.

Work with the facilitator to begin moving participants into the final large group gathering by 11:25.

Support Team's Notes:
When the exercise is complete, the support team should gather all the cards generated for "factors that contribute to the health of children" and bundle them together. Then, they should gather all the cards generated for "factors that cause children to become ill or die" and bundle them together. Finally, they should gather the newsprint containing the "key factors" written by the facilitator. The three items should be placed in the manila envelope labelled exercise 3. The envelope should be closed and sealed if data entry is to happen later offsite.

believe cause sickness is created, and the participants can see what they themselves believe to be the key factors.

Recorded discussion. Through probing questions participants are engaged in reflective discussion on the reasons that certain factors are more significant than others. This should be recorded by tape recorder for later transcription as it is likely to contain key insights.

Step 3. Flowing directly out of the discussion, the facilitator – in constant dialogue with the participants - draws together the key factors that contribute to childhood health – either positively or negatively. Thus, after some discussion, the participants agree on a combined set of five or six key factors that contribute to healthy children in the community. The list will be similar to the one generated in exercise 2. The facilitator should write these responses down on the newsprint.

Output:
A participant driven list of factors that impact childhood health, illness, and death.

Exercise 4: Community Responses to Pregnancy

Time: 40 minutes (11:40-12:20)

Equipment:

- Index cards for each small group
- Sheets of newsprint
- Tape recorder

Objective:
To create a participant-driven list of the most important things the community does when a woman becomes pregnant.

The facilitator leads participants through three steps:

Step 1: Ask each group to answer the following question:

- *What are the three most important things that happen in your community when a woman becomes pregnant? How does your community respond to the news of the pregnancy?*

Each group discusses the question and develops three answers. A representative of the group writes down the group's answers on the three cards (one response per card).

Step 2: Bring the small groups back together into plenary. Ask each group to read aloud and elaborate on the three most important things that happen in the community when a woman becomes pregnant. Have each group simply present their items; facilitators should allow questions for clarification but should not allow for any discussions about which items are most important until all groups have presented.

As each group reads their cards, the facilitator places them onto the floor one at a time without further comment. This continues until each group has completed naming their list. If there is a duplicate card among the groups, place it with the other like cards. If you think two cards are similar, ask the group to decide whether they represent the same thing; if so, place the cards to together and if not, leave them separate.

Step 3: After all small groups have named their three items, ask the large group to decide on the list of the *essential* things that are done when a woman becomes pregnant (as in earlier, this process should generate a list of 4-6 items). The facilitator should write these items on the newsprint. Once this list is generated, ask the group to discuss *why* these items are important.

Output:
A participant-driven list of important things done in the community with the key 4-6 things named in rank order.

Support Team's Notes:

This exercise begins in small groups and concludes in plenary. Participants move only once.

When the exercise is complete, the support team should gather all the cards generated in the small groups detailing the three most important things that happen in the community when a woman gets pregnant. They should also gather the newsprint containing the essential things done written by the facilitator. Both items should be placed in the manila envelope labelled exercise 4. The envelope should be closed and sealed if data entry is to happen later offsite.

Exercise 5: Community Responses to Childhood Death

Support Team's Notes:

This exercise begins in small groups and concludes in plenary. Participants move only once.

When the exercise is complete, the support team should gather all the cards generated in the small groups detailing the three most important things that happen in the community when a child gets dies. They should also gather the newsprint containing the essential things done written by the facilitator. Both items should be placed in the manila envelope labelled Exercise 5. The envelope should be closed and sealed if data entry is to happen later offsite.

Time: 40 minutes (12:20-1:00)

Equipment:

- Index cards for each small group
- Sheets of newsprint
- Tape recorder

Objective:
To create a participant-driven list of the most important things the community does when a child dies.

The facilitator leads participants through three steps:

Step 1: Ask each group to answer the following question:

- *What are the three most important things that happen in your community when a child dies? This would include children who die during the birth process, children who are stillborn, or any child who dies before their fifth birthday. How does your community respond to the news of the death?*

Each group discusses the question and develops three answers. A representative of the group writes down the group's answers on the three cards (one response per card).

Step 2: Bring the small groups back together into plenary. Ask each group to read aloud and elaborate on the three most important things that happen in the community when a child dies. Have each group simply present their items; facilitators should allow questions for clarification but should not allow for any discussions about which items are most important until all groups have presented.

As each group reads their cards, the facilitator places them onto the floor one at a time without further comment. This continues until each group has completed naming their list. If there is a duplicate card among the groups, place it with the other like cards. If you think two cards are similar, ask the group to decide whether they represent the same thing; if so, place the cards to together and if not, leave them separate.

Step 3: After all the small groups have named their three items, ask the large group to decide on the list of the *essential* things that are done when a woman becomes pregnant (as in earlier, this process should generate a list of 4-6 items). The facilitator should write these items on the newsprint. Once this list is generated, ask the group to discuss *why* these items are important.

After the exercise is complete, announce the lunch break. Before participants break, remind them to return in one hour. Inform participants that you will be available to talk during lunch if they would like to discuss any feelings that have arisen for them. Assess whether the cultural norm is to offer a blessing of the food or some other ritual such as handwashing prior to lunch. If a blessing is custom, ask for a volunteer from among the participants to lead the group in a blessing; if handwashing or other ritual is custom, provide the time to carry it out.

Output:
A participant-driven list of important things done in the community with the key 4-6 things named in rank order.

Support Team's Notes:

While the participants are at lunch, the support team should take time to hang the three matrices for exercise 6.

Exercise 6: Participants' Perception of CHAMPS Activities

Support Team's Notes: This exercise is different from all others and the support team's role is different.

Time: 75 minutes (2:00-3:15)

Equipment:

- Participants' labels (handed out at beginning of the day)
- 3 pre-printed matrices on newsprint

Objective:
To assess perceptions of the level of alignment or tension between CHAMPS activities and community priorities and perceptions.

This exercise has two parts. The first step identifies general alignment or tension between participants' perceptions and CHAMPS activities. The second step provides more specific contexts for determining alignments or tensions between CHAMPS activities and participants' perceptions.

PART ONE
Read the following aloud to participants:
We began the day by examining the objectives for CHAMPS. As a reminder, they are:

1) *To understand how and why children get sick and die.*
2) *To use the information we find out to come up with programs that will cause less illness and fewer deaths in children. (Highlight this objective)*

(have these two priority items listed on two separate sheets of newsprint with both visible)

*Now we want to discuss what needs **to be done** in order for the CHAMPS program to meet its objectives. In general, CHAMPS will need to carry out two activities in both hospital and community settings.*

For the first activity we will talk with women who are currently pregnant or have recently been pregnant. We will only talk with women who want to talk with us and will talk with them in both healthcare and community settings. We want to learn from women themselves the things that may have affected their pregnancy or the birth of their child. We want to hear about both things that helped and things that caused problems during pregnancy for all women. Finally, in the unfortunate case that the pregnancy results in a stillbirth, we want to learn about the kinds of health services will be helpful to mothers and will lead to positive birth outcomes.

For the second activity we will speak with some of the parents in your community who will have just experienced the death of their child. With their permission, we will gather small samples from the body of their child after the child's death. We will speak with parents either in hospital or at their home. Studying these samples will improve our accuracy in figuring out the things that cause children to

die so that we help children live longer and healthier lives

Ask participants for if they have any questions for information or clarification. If they want to offer their opinions (instead of asking questions of fact) then assure them that the purpose of this exercise is to hear those opinions but ask them to wait a few moments until all questions are answered first.

Once all questions have been answered, instruct participants to gather around the following two matrices taped to the wall:

CHAMPS Activity: Talking with women who are pregnant or who recently delivered a child.	How does this CHAMPS activity fit with our community's priorities?	
	It fits with our community	It does not fit with our community

	How does this CHAMPS activity fit with our community's priorities?	
CHAMPS Activity: With parents' consent, gather samples from the body of a child who recently died.	It fits with our community	It does not fit with our community

Step 1: If they don't have an opinion, they don't have to add the sticker. Participants will have a sheet of stickers in their participant folders (each sticker on that sheet will be pre-printed with each participant's unique ID). A participant will place her/his sticker in the box labelled "It fits with our community" if s/he believes that the CHAMPS activity aligns with community priorities and norms. If he or she believes that the CHAMPS activity is in tension with community priorities and norms the participant will place a sticker in the box labelled "It does not fit with our community." Participants should place one sticker on each matrix (in either of the two boxes of that matrix). They will place a total of two stickers on the matrices.

Step 2: After all participants have placed their two stickers, the facilitator should lead the participants in a discussion. In general, does the group believe that each CHAMP activity aligns with or is in tension with community priorities and norms? Why?

Output from part one:
A matrix showing alignment or tension between CHAMPS activities and community priorities.

PART TWO

Support Team's Notes:

The support team should have hung these two matrices up on the wall prior to the start of this exercise.

Support Team's Notes:
A support team member will be stationed under each sign, three people in all. The person under the "Agree" sign will have 20 sheets of paper. The first page will be labelled "Proposition 1: AGREE," the second labelled "Proposition 2: AGREE" and so on. The team members under the Disagree" and "Uncertain" signs will have a set of 20 sheets labelled similarly. As each proposition is read aloud, participants will place their sticker on the sheet corresponding to their answer. Support team members will need to make sure that they are displaying the sheet that corresponds to the current proposition as it is read. At the end of the proposition exercise, each support team member will have 20 sheets of paper filled with participants' stickers. Each set of papers should be bundled and the three bundled sets should be placed in a large manila envelope labelled "Exercise 6." In addition, the two matrices should be taken down off the wall, carefully folded and place in the envelope.

During the break, the support team should hang the two pre-printed matrices for exercise 7.

The facilitator naturally moves the discussion from general perceptions of alignment and tension by telling participants that in part two will they will have an opportunity to give more specific information about alignment and tension. Prominently displayed on the walls are three signs:

Agree **Disagree** **Uncertain**

The participants are asked to respond to a series of 20 propositions (not questions), which are read out clearly by the facilitator, by moving, in silence, to stand beneath the sign that best represents their response to the statement. Three workshop team members will be stationed beside the three signs, one per sign. Each of those team members will have 20 sheets of paper with one proposition printed on each sheet. As each participant moves to a sign in response to their own opinion about the proposition that was read, they will place a sticker with their unique ID number on the team member's sheet for that particular proposition.

The numbers for each group (AGREE, DISAGREE, and UNCERTAIN) are calculated and written up on newsprint for each proposition AS THE EXERCISE IS CARRIED OUT. The participants remain under the sign while the next proposition is read out and then move.

This process should be done as silently as possible – the participants should not discuss their responses among each other. **(See the list of propositions on the next page)**

Once all propositions have been read and participants have responded to each with "AGREE," "DISAGREE," or "UNCERTAIN" the facilitator should lead the participants in a general discussion of the activity. Begin by de-briefing the activity. What were the participants' impressions? Are any of the group's responses striking or surprising? After thinking about these 20 propositions, did any participants change their mind about the acceptability of the CHAMPS surveillance activities? If so, why?

Output from part two:
A profile of participants' perceptions about CHAMPS activities across five categories:

1. Acceptability/Value
2. General acceptability of MITS even if there is personal discomfort
3. Beliefs about childhood death, burial, and MITS
4. Beliefs about pregnancy, childhood illness/death, & medical care
5. The value of surveillance and research

Following this exercise, inform participants that there will be a fifteen-minute break. Encourage them to speak with you if they want to talk about any aspect of this exercise.

	Acceptability/Value
	General acceptability of MITS even if there is personal discomfort
	Beliefs about childhood death, burial, and MITS
	Beliefs about pregnancy, childhood illness/death, and medical care
	The value of surveillance and research

Category	Proposition
	2. It is wrong to remove small samples of tissue from a child after she has died even if tests done on that tissue could tell you how she died.
	4. A woman should not be asked about what's happening during her pregnancy because that information is private.
	6. The information gained from tissue samples is worthwhile because this knowledge could help us improve child survival.
	8. If we know what happens to women during their pregnancy, we can figure out what to do to help women have safe pregnancies and give birth to healthy children.
	10. In my opinion, I don't think any parent should ever agree to let tissue samples be collected from the body of their child after that child has died.
	12. Our community owes a debt of gratitude to parents who consent to the removal of tissue from their child's bodies when they die because these parents are helping other children to live.
	14. Even if I didn't agree to have tissue samples collected from my child's body, I still think the knowledge we gain through this work is important for helping us fight childhood illness and death.
	16. Even if I might not want to answer questions about my own pregnancy (or wouldn't want my wife to), I am glad that other women in the community are doing so if it contributes to healthier pregnancies.
	18. Medicine and science may help us care for a child's body during life but care for a child's body at death is the work of faith and of God alone.
	20. I would not agree to any kind of procedure if it meant that I could not bury my child according to my faith or tradition.
	22. We can collect tissue samples and still be able to bury a child with love and respect.
	24. Collecting tissue samples shows a family's love for a child who has died and for all the children in our community because it gives us knowledge that could help children be healthier.
	26. All women in our community who are pregnant should be seen at a health centre to make sure there are no problems during their pregnancy.
	28. While medical care for pregnant mothers and children is important, it is not easy for them to get the care they need.
	30. I rely on a healer more than a healthcare provider to help me stay healthy.
	32. Healthcare providers and traditional healers both help me stay healthy. There should be no tension between the two.
	34. Knowing what causes children to get sick and what causes negative outcomes in pregnancy would allow us to do something about them.
	36. I am glad that this program is being carried out in our community. It will help improve our health in the long run.
	38. Researchers only care about the information they collect. They don't care about improving the health of our community.
	40. While CHAMPS activities focus on sickness and death, they are being carried out in order to improve our health and our living.

Exercise 7: Valued Community Organizations That Could Support CHAMPS

Time: 45 minutes (3:30-4:15)

Equipment:

- Index cards for each small group
- Two pre-printed matrices on newsprint

Task 1: Generate a list of valued community organizations and leaders in the community

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After break, participants gather back into their small groups. The facilitator directs participants to two matrices on the wall:

CHAMPS Activity: Talking with women who are pregnant or who recently delivered a child.	Who would be a Champion for this activity?

CHAMPS Activity: With parents' consent, gather samples from the body of a child who recently died.	Who would be a Champion for this activity?

Ask each group to write down the best community resources that might be a good partners to work with CHAMPS staff to carry out the CHAMPS activity that was named (up to five organizations/ individuals for each group). The group may name an organization or an individual. The facilitator then reads the list of organizations or individuals aloud, placing the cards on the floor as each one is read. Any duplicate cards are placed above the existing cards, creating a bar graph on the floor. After all the valued organizations have been named, record the top five on the newsprint along with the number of responses given for each organization.

Output: A participant driven list of local community organizations that are important resources for the community to respond to the death of a child that participants also identify as potentially supporting one or more CHAMPS activities.

Support Team's Notes:

The support team should have created these matrices prior to the workshop.

After the exercise is complete, gather together the index cards that correspond to each matrix, bundle and label them. Place both sets of cards into a large manila folder labelled "Exercise 7." The envelope should be closed and sealed if data entry is to happen later offsite.

Next Steps: Staying In Touch

Support Team's Notes:
The workshop is completed. Before adjourning, the facilitator should invite participants to stay in touch with CHAMPS to receive updates on findings, future events, and community meetings.

Time: 15 minutes (4:15-4:30)

At this point the workshop is completed. Explain that this is one of the first activities being carried out by CHAMPS and that the CHAMPS team would like to stay in touch with the participants. Ask participants if they would like to continue to receive information about CHAMPS, including information of the findings, periodic newsletters, and invitations to future community meetings in which CHAMPS staff provide updates to the community. If so, have participants complete a "Stay In Touch" Card.

Adjourn the workshop with your thanks and gratitude and remain in the front of the room so that participants can speak with you individually if they would like.

Section 8: PICK-CHAMP: Community Leaders Workshop
FACILITATOR GUIDE

Facilitator's Notes:

This section provides a brief description of the groups who participate in PICK-CHAMP workshops and identifies the key purposes of the two PICK-CHAMP workshops.

As noted above, PICK-CHAMP will be used with two groups, namely, local community members and local community leadership. While it is not always possible to be exclusive in this process, attention is drawn to issues of power and domination when community leaders are present in gatherings with ordinary community members. Facilitators may realize that a participant in the community members workshop is, indeed, a community leader. If this occurs, then special care needs to be taken to limit possible domination or deference through skilful facilitation. By the same token, in certain contexts there is a power differential between men and women, and between elders and younger members of the community – and sensitivity will need to be exercised, such as providing different small groups for free discussion and participation.

Location.This PICK-CHAMP needs to be undertaken in a local community setting such as a community centre, church or mosque, or health facility. If necessary, workshops can be held outside Chairs, shade, open floor space, and walls are important.

ParticipantsThe workshop is most effective with between 20 and 25 people representing a good mix of gender, age, class, and religious perspectives. While bias can never be fully avoided, it is crucial that the PICK-CHAMP facilitators work on the invitations to ensure broad-based participation and non-domination by a certain segment of the community.

Materials:

1. Registration list: Form for people to fill in when they register (may also be completed on a laptop using the Access program)
2. 30 consent forms (1 form per person, plus extras as needed)
3. Ballpoint pens: 25-30 (one per participant plus some extras in case pens are lost)
4. Felt-tip marker pens: 10 (at least one per small group plus some extras for use by facilitators and support team during exercises)
5. Newsprint: 50 sheets
6. 30 pocket folders (one for each participant with extras as needed)
7. 15 large, sealable manila envelopes. Six of these should be pre-labeled for exercises 1-6. The remainder are extras as needed.
8. Masking tape: 2 rolls
9. A box of large rubber bands
10. 20 index cards/participant, pre-labeled with participant ID
11. Voice recorder: at least one with decent microphones to pick

Facilitator's Notes:

up discussion
12. Large Post-It Notes (approximately 10/participant)
13. Extra batteries for the voice recorder.
14. File box: A box to store the completed forms, as well as newsprint etc.

Ethics and consent

PICK-CHAMP is research with human subjects. It is crucial that participants are informed about the meaning and implication of the research, and that they consent to being involved, to having their ideas used by others, and to having their photographs taken.

Agenda

The community leader PICK-CHAMP unfolds as follows

8:30 Participants arrive and fill in the registration form
Continental breakfast provided

9:00 Welcome and Introduction
Signing of consent form

9:15 Exercise 1: Commonalities Between CHAMPS Objectives and Community Priorities

10:00 Exercise 2: Perceptions of Pregnancy

10:45 Morning Tea

11:00 Exercise 3: Perceptions of Childhood Health and Illness

11:45 Exercise 4: What are the Roles of Community Leaders in Response to Pregnancy and Childhood Death

12:30 Lunch

1:30 Exercise 5: Leaders' Perceptions of CHAMPS Activities

2:30 Afternoon Tea

2:45 Exercise 6: Building Support for CHAMPS

3:45 Next Steps: Staying In Touch

4:00 Closure and thanks

Exercise 1: Describing CHAMPS Objectives to Reflect Community Priorities

Time: 45 minutes (9:15-10:00)

Equipment:

- 4 Index Cards per participant
- Markers for each participant
- Digital Voice Recorder

Moving naturally from introductions, the facilitator works with participants to describe CHAMPS objectives using the frameworks and contexts intrinsic to the community.

Objective:
To identify the commonalities between community priorities and the objectives of the CHAMPS Program.

Break the group into small groups of 4-5 people each. The facilitator reads the following out loud to participants:

- *The purpose of CHAMPS is to understand how and why children get sick and why some of them die. The knowledge gained through CHAMPS will allow health officials to develop programs and services to address those causes—if these officials know what kills children or causes complications during pregnancy then they can do something about it.*

  We want your perspectives about these two priorities for CHAMPS:
  1) *To understand how and why children get sick and die.*
  2) *To use the information we find out to come up with programs that will cause less illness and fewer deaths in children. (HIGHLIGHT THIS OBJECTIVE)*

  (have these two priority items listed on two separate sheets of newsprint with both visible)

  As a community leader, imagine that you have the task of explaining to the people in your own community why these two CHAMPS priorities are important. What would you say?

Step 1: Ask each participant to craft a message they would give to communicate the importance of priority one as a community leader. Ask participants to do the same thing with item #2.

When finished, each participant should have at least 2 key messages that re-enforce the two CHAMPS priorities.

Facilitator's Notes:

The facilitator instructs each small group to develop a set of key messages and then works with the entire group to decide on the ***three most powerful key messages****.*

The facilitator should check with the note-taker for each small group to ensure that s/he understands her or his role.

The facilitator should be prepared to offer an example to help participants begin the discussion if needed

Facilitator's Notes:

Step 2: Cards are collected from each small group and then laid out one at a time on the floor, starting with the cards for item 1. When a card repeats what a previous card has said, it is laid down above its namesake.

Clearly the facilitator needs to group together words that express the same message even if they are different words.

In this way a 'bar graph' of the key messages that re-enforce the activities of item #1 is created.

The process is repeated with item #2.

Recorded discussion. The facilitator leads participants through a discussion of the messages that were written. What are participants' perceptions about the messages? Which are more powerful? Are there any disagreements? What makes these messages powerful?

Step 3. Flowing directly out of the discussion, the facilitator – in constant dialogue with the participants - draws together the key messages for item #1 to identify the **3 most powerful key messages** that support item #1. This process is repeated for item #2

Output:
A participant-driven list of messages based on community norms and language that re-enforce the objectives of CHAMPS with the three most powerful messages identified.

Exercise 2: Perceptions of Pregnancy

Time: 45 minutes (10:00-10:45)

Equipment:

- A marker pen for each participant
- 6 index cards for each participant
- 3 sheets of newsprint
- Tape recorder

Objective:
This exercise focuses on naming the community's perceptions about the things that contribute to healthy pregnancy. This exercise involves three clear steps.

Flowing naturally from the discussion in Exercise 1, the facilitator informs participants that one way CHAMPS will achieve the first objective listed in that exercise is to learn more about the things that help women deliver healthy children when they get pregnant.

Step 1: Participants move back into their same small groups. They are asked to discuss the answer to the question:

- *What do you consider to be the three most important factors that contribute to healthy pregnancies for women in your community?*

Each group discusses the question and develops three answers. A representative of the group writes down the group's answers on the three cards (one answer per card). The facilitator collects these cards and then lay them out in a place on the floor where all small group participants can observe. When a card repeats what a previous card has said, it is laid down above its namesake.

Clearly the facilitator needs to group together words that express the same factor even if they are different words (eg. nutrition = good food = healthy food = food; knowledge = education = understanding; etc.). In this way a 'bar graph' of the key factors that the participants believe cause healthy pregnancies is created, and the participants can see what they themselves believe to be the key factors. The cards are left on the floor for step 2.

Step 2. The first exercise is repeated, but the question is changed. Now as they work again in their small groups, participants are asked to write down the answer to the question:

- *What do you consider to be the three most important factors that cause complications during pregnancy for women in your community?*

A representative of the group writes down the group's answers on the three cards (one per card). These cards are collected and then laid out on the floor alongside the earlier set. When a card repeats what a previous card has said, it is laid down above its namesake.

Facilitator's Notes:

Note facilitator's leadership roles here:

- *Provide instructions (two topics)*
- *Process findings for each topic.*
- *Develop a list of 4-6* ***most important*** *factors that contribute to healthy pregnancies. This requires the facilitator to look for linkages between the two separate lists generated earlier in the exercise.*

Facilitator's Notes:

Again the facilitator will need to group 'ideas' rather than exact words together.

In this way a 'bar graph' of the key factors that the participants believe cause sickness is created, and the participants can see what they themselves believe to be the key factors.

Recorded discussion. Through probing questions participants are engaged in reflective discussion on the reasons that certain factors are more significant than others. This should be recorded by tape recorder for later transcription as it is likely to contain key insights.

Step 3. Flowing directly out of the discussion, the facilitator – in constant dialogue with the participants - draws together the key factors that affect healthy pregnancy – either positively or negatively. This requires some lateral thinking as for example the following list may be generated (votes in brackets):

Healthy Pregnancy	Complicated pregnancy
Good health care (9)	Sickness (9)
Nutrition (6)	Poverty (7)
Faith in God (5)	Pollution (6)
Good sanitation (5)	Bad nutrition (5)
Knowledge (3)	Ignorance (3)
Water (2)	No employment (1)
Medicine (2)	No health facilities close by (1)

Food is a clear factor for a healthy pregnancy and bad nutrition a factor in a complicated pregnancy – but clearly they express the same idea, and so only one word is chosen. Likewise, ignorance and knowledge express the same idea. Depending on how people understand pollution, it may be the flip-side of good sanitation. Thus, after some discussion, the participants agree on a combined set of five or six key factors contribute to healthy pregnancies in the community. In the above case these would probably be:

Nutrition
Knowledge
Against Poverty
Against Pollution
Medicine and health facilities

The facilitator should write these responses down on the newsprint for use in exercise 4. Write largely as that exercise will require participants to place cards next to these factors.

Output:
A participant driven list of factors that impact pregnancy

Following the completion of this exercise, participants will break for morning tea until 11:00 AM

Exercise 3: Perceptions of Childhood Health and Illness

Time: 45 minutes (11:00-11:45)

Equipment:

- A marker pen for each participant
- 6 index cards for each small group
- 3 sheets of newsprint
- Tape recorder

Objective:
This exercise focuses on naming the community's perceptions about the things that affect children's health: the things that help children be healthy or the things that may make children sick. This exercise involves three clear steps and the process is identical to exercise 2 above with a different topic.

Step 1: Participants are asked to write down the answer to the question:

- *What do you consider to be the three most important factors that contribute to the health of children in your community? Write down these factors (one per card) in a few words or a short phrase.*

These cards are collected and then laid out in a place on the floor where all participants can observe. When a card repeats what a previous card has said, it is laid down above its namesake.

Clearly the facilitator needs to group together words that express the same factor even if they are different words. In this way a 'bar graph' of the key factors that the participants believe cause good health is created, and the participants can see what they themselves believe to be the key factors. The cards are left on the floor for step 2.

Step 2. The first exercise is repeated, but the question is changed. Now participants are asked to write down the answer to the question:

- *What do you consider to be the two key factors that cause children to become ill or die in your community? Write down these factors (one per card) in a few words or a short phrase.*

These cards are collected and then laid out on the floor alongside the earlier set. When a card repeats what a previous card has said, it is laid down above its namesake. Again the facilitator will need to group 'ideas' rather than exact words together.

In this way a 'bar graph' of the key factors that the participants believe cause sickness is created, and the participants can see what they themselves believe to be the key factors.

Recorded discussion. Through probing questions participants are

Facilitator's Notes:

This exercise will likely take less time than exercise 2 did because participants will be familiar with the process.

The process is quite similar.

Facilitator's Notes:

engaged in reflective discussion on the reasons that certain factors are more significant than others. This should be recorded by tape recorder for possible transcription as it is may contain key insights.

Step 3. Flowing directly out of the discussion, the facilitator – in constant dialogue with the participants - draws together the key factors that contribute to childhood health – either positively or negatively. Thus, after some discussion, the participants agree on a combined set of five or six key factors that contribute to healthy children in the community. The list will be similar to the one generated in exercise 2. The facilitator should write these responses down on the newsprint for use in exercise 4. Write largely as that exercise will require participants to place cards next to these factors.

Output:
A participant driven list of factors that impact childhood health, illness, and death.

Exercise 4: What are the Roles of Community Leaders in Response to Pregnancy and Childhood Death?

Time: 45 minutes (11:45-12:30)

Equipment:

- A marker pen for each participant
- 6 index cards for each small group
- Tape recorder

Objective: This exercise asks participants to identify their roles and responsibilities as leaders in addressing the factors that impact pregnancy and childhood health/illness (named in exercises 2 and 3)

Step 1: The facilitator shows to the participants the two sheets of newsprint from exercises 2 and 3 that list the key factors that impact pregnancy and childhood health/illness. After going through the list of key factors, the two sheets are laid out on the floor side by side. Participants are asked to write down the answer to the question:

- *As a community leader, what do you do (or what **could** you do) in addressing these factors? If the factor contributes to health, what is your role in making it available to the community? If the factor worsens health, what is your role in minimizing it?*

Participants write down three responses to the question, one response per card. After writing their three responses, participants place them on top of the newsprint sheets beside the factor their response addresses. The facilitator leads participants in a discussion of the roles identified, noting any overlaps among responses. The cards are left on the floor for step 2.

Step 2. The facilitator then asks participants:

- *How can CHAMPS support you in carrying out the roles you have just named?*

Participants write down three responses to this question, one response per cared. The cards are collected and then laid out on the floor. When a card repeats what a previous card has said, it is laid down above its namesake. Again the facilitator will need to group 'ideas' rather than exact words together. In this way a 'bar graph' of the support that CHAMPS can provide is created.

Recorded discussion. After all the cards are laid down, the facilitator leads the participants in a discussion on the items written on the cards. As part of that discussion, the facilitator should ask participants specifically about their interest in working with CHAMPS to determine next steps for CHAMPS to their suggestions.

Output:
A participant driven list of 1) leaders' role in addressing the factors that impact pregnancy and childhood health/illness, and 2) the ways that CHAMPS could support leaders in carrying out those roles.

Following this exercise, participants break for lunch until 1:30 PM.

Facilitator's Notes:

Exercise 5: Leaders' Perceptions of CHAMPS Activities

Facilitator's Notes:

NOTE: This is the most complicated and time-consuming exercise.

Time: 60 minutes (1:30-2:30)

Equipment:

- 1 pen per participant
- 6 index cards for participants
- Two Matrices created on newsprint that can be laid out on the floor (see example below)

Objective*:* To assess the level of alignment or tension between CHAMPS activities and community perceptions.

The facilitator reads the following aloud to participants:

- *We began the day by asking you to write down important messages that re-enforce the importance of the objectives of the CHAMPS program—to figure out what causes children to die and to do something about it. Now we want to discuss what needs* ***to be done*** *in order for the CHAMPS program to meet those objectives. CHAMPS would like to work with the community to gather information on the issues that arise during women's pregnancies and to gather information about what causes the death of children. We propose some specific ways to gather this information but we also realize that the community already does important things to celebrate pregnancy and to mourn the death of a child. We want to find ways to work with you to carry out our activities while being respectful and appreciative of the things that the community already does.*

Step 1: Ask participants the following question:

- *What happens in your community when a woman finds out she is pregnant? What happens in the family? What happens in the broader community?*

Participants are instructed to write down three responses to this question, one response per card. They should keep the cards with their written responses for this exercise. Allow time for all participants to write down their responses.

The facilitator then says to participants:

In order to help women who are pregnant get good healthcare and have services to help address problems during pregnancy when they arise, CHAMPS staff will talk with women who are currently pregnant or have recently been pregnant. We will only talk with women who want to talk with us and will talk with them in both healthcare and community settings. We want to learn from women themselves the things that are affecting their pregnancy or affected the birth of their child. We want to hear about both things that helped and things that caused problems. We want to know from you as community leaders whether our effort.

to talk with these women will be in tension with what the community does to support women during pregnancy

Step Two: Introduce participants to the following matrix, which will be laid out on the floor.

	Things our community does when to celebrate a woman's pregnancy
Talking with women who are pregnant or who recently delivered a child.	HIGH LEVEL OF TENSION
	TWO DIFFERENT ACTIVITIES/ NO TENSION BUT NO ALIGNMENT
	HIGH LEVEL OF ALIGNMENT

Have participants take their cards spread out on the floor and place them one at a time onto the matrix. When all cards have been placed on the matrix, de-brief with the participants on the process of reaching consensus. After the de-briefing is completed, the facilitator moves immediately to Exercise 4.

Step Three: The facilitator informs participants that they will now focus on CHAMPS activities related to childhood illness and death. The facilitator then reads the following aloud to participants:

> *We want to find out what causes children to die so that something can be done about those things. This will mean that fewer children would die because things could be done to prevent those deaths. We also know that there are things that are done in your community when a child dies. Those things are very important. We want to find ways to work with you to carry out our activities while being respectful and appreciative of the things that the community does.*

The facilitator then asks participants the following question:

- *What happens in your community when a child dies? What happens in the family? What happens in the broader community?*

Participants are instructed to write down three responses to this question, one response per card. They should keep the cards with their written responses for this exercise. Allow time for all participants to write down their responses.

The facilitator then says to participants:

> *In order to figure out the things that cause children to die CHAMPS staff would like to speak with some of the parents*

Facilitator's Notes:

Be sure to look out for any surprising findings on the matrix. Pay special attention to squares on the matrix where participants identify high alignment between community activities and CHAMPS activities.

Facilitator's Notes:

Be sure to look out for any surprising findings on the matrix. Pay special attention to squares on the matrix where participants identify high alignment between community activities and CHAMPS activities.

in your community who will have just experienced the death of their child. With their permission, we will gather small amounts of tissue and blood from the body of their child within 12 hours after the child's death. We will speak with parents either in hospital or at their home. Studying this tissue and blood is the only way we can accurately figure out the things that cause children to die so that we can do something to help other children.

Step Four: Introduce participants to the second matrix, which will be laid out on the floor.

	Things our community does when to when a child dies
With parents' consent, gather blood and tissue from the body of a child who recently died.	HIGH LEVEL OF TENSION
	TWO DIFFERENT ACTIVITIES/ NO TENSION BUT NO ALIGNMENT
	HIGH LEVEL OF ALIGNMENT

Have the participants take the cards with their responses and place them one at a time onto the matrix.

When all cards have been placed on the matrix, de-brief with the participants. After the de-briefing is completed, the facilitator says:

Outputs: 1) A participant-driven list of community activities carried out when a woman is pregnant ranked by the level of alignment/tension to CHAMPS pregnancy surveillance activities, and 2) a participant-driven list of community activities carried out when a child dies ranked by the level of alignment/tension to CHAMPS mortality surveillance activities.

Following this exercise, participants will break for tea until 2:45 PM

Exercise 6: Building Support for CHAMPS

Time: 1 hour (2:45-3:45)

Equipment:

- Coded index cards for participants
- 1 pen or marker per participant
- Newsprint

Objective: Use the six messages related to CHAMPS objectives to create/strengthen alignment between community activities and CHAMPS activities.

Step 1: Refer participants to the key messages that were identified in exercise 1.

Starting with a community activity from exercise 5 that is in tension with CHAMPS activities, discuss with participants how the key messages crafted in exercise 1 could be used to lower tension and increase alignment. Following the discussion, ask participants to write down on a card, **one specific, concrete action step** that they could take that would use these messages to help create some level of alignment between the community and CHAMPS activities. On that same card, ask them if they could identify someone in the community (it could even be the participant herself or himself) who might be the champion of this activity.

Step 2: Continue this process with all community activities that are in tension with CHAMPS activities.

Outcome: A participant driven list of action steps (and champions) that align with community messages that could be undertaken to build support for CHAMPS.

Facilitator's Notes:

Work to ensure that participants identify **specific concrete action steps that THEY can undertake.**

Next Steps: Staying In Touch

Facilitator's Notes:

The workshop is completed. Before adjourning, the facilitator should invite participants to stay in touch with CHAMPS to receive updates on findings, future events, and community meetings.

At this point the workshop is completed. Explain that this is one of the first activities being carried out by CHAMPS and that the CHAMPS team would like to stay in touch with the participants. Ask participants if they would like to continue to receive information about CHAMPS, including information of the findings, periodic newsletters, and invitations to future community meetings in which CHAMPS staff provide updates to the community. If so, have participants complete a "Stay In Touch" Card.

Section 8: PICK-CHAMP: Community Leaders Workshop
SUPPORT TEAM GUIDE

Support Team's Notes:

As noted above, PICK-CHAMP will be used with two groups, namely, local community members and local community leadership. While it is not always possible to be exclusive in this process, attention is drawn to issues of power and domination when community leaders are present in gatherings with ordinary community members. Facilitators may realize that a participant in the community members workshop is, indeed, a community leader. If this occurs, then special care needs to be taken to limit possible domination or deference through skilful facilitation. By the same token, in certain contexts there is a power differential between men and women, and between elders and younger members of the community – and sensitivity will need to be exercised, such as providing different small groups for free discussion and participation.

This section provides a brief description of the groups who participate in PICK-CHAMP workshops and identifies the key purposes of the two PICK-CHAMP workshops.

Location.
This PICK-CHAMP needs to be undertaken in a local community setting such as a community centre, church or mosque, or health facility. If necessary, workshops can be held outside Chairs, shade, open floor space, and walls are important.

Participants
The workshop is most effective with between 20 and 25 people representing a good mix of gender, age, class, and religious perspectives. While bias can never be fully avoided, it is crucial that the PICK-CHAMP facilitators work on the invitations to ensure broad-based participation and non-domination by a certain segment of the community.

Materials:

1. Registration list: Form for people to fill in when they register (may also be completed on a laptop using the Access program)
2. 30 consent forms (1 form per person, plus extras as needed)
3. Ballpoint pens: 25-30 (one per participant plus some extras in case pens are lost)
4. Felt-tip marker pens: 10 (at least one per small group plus some extras for use by facilitators and support team during exercises)
5. Newsprint: 50 sheets
6. 30 pocket folders (one for each part. with extras as needed)
7. 15 large, sealable manila envelopes. Six of these should be pre-labeled for exercises 1-6. The remainder are extras as needed.
8. Masking tape: 2 rolls
9. A box of large rubber bands
10. 20 index cards/participant, pre-labeled with participant ID
11. Voice recorder: at least one with decent mic to pick

Be sure to have all the materials listed here available at the workshop.

Support Team's Notes:

up discussion
12. Large Post-It Notes (approximately 10/participant)
13. Extra batteries for the voice recorder.
14. File box: A box to store the completed forms, as well as newsprint etc.

Ethics and consent

PICK-CHAMP is research with human subjects. It is crucial that participants are informed about the meaning and implication of the research, and that they consent to being involved, to having their ideas used by others, and to having their photographs taken.

Agenda

The community leader PICK-CHAMP unfolds as follows

8:30 Participants arrive and fill in the registration form
Continental breakfast provided

9:00 Welcome and Introduction
Signing of consent form

9:15 Exercise 1: Commonalities Between CHAMPS Objectives and Community Priorities

10:00 Exercise 2: Perceptions of Pregnancy

10:45 Morning Tea

11:00 Exercise 3: Perceptions of Childhood Health and Illness

11:45 Exercise 4: What are the Roles of Community Leaders in Response to Pregnancy and Childhood Death

12:30 Lunch

1:30 Exercise 5: Leaders' Perceptions of CHAMPS Activities

2:30 Afternoon Tea

2:45 Exercise 6: Building Support for CHAMPS

3:45 Next Steps: Staying In Touch

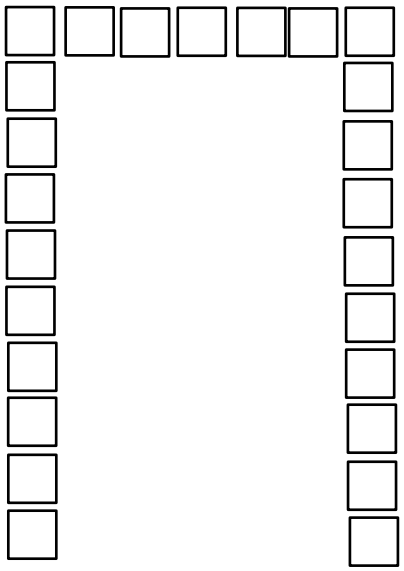
3:45 Closure and thanks

Food

The Support Team should arrange any food to be served during the workshop. In general, PICK-CHAMP workshops provide a morning continental breakfast, a morning tea/coffee break, a mid-day lunch, and an afternoon tea/coffee break to participants. The workshop should be carried out in a facility that would allow for meal and break set up outside of the workshop meeting area so that food can be ready at designated times without disturbing participants.

Registration
The support team should have registration tables by the entrance to the workshop room. Participants will complete the registration process (either by filling out the paper registration form (see Appendix) or, preferably, by completing registration by having a support team member enter their information into the Access database. After completing the registration, a participant is given a nametag that has the participant's ID number printed on it and a pocket file folder that contains a sheet of preprinted laser labels along with a ballpoint pen. The support team must ENSURE that the number printed on the labels and on the nametag matches the participant's ID number from the registration form.

Room Set Up
The room should be set up to allow for an easy flow between small groups and a large group plenary. Each small group should be clustered together, ideally around a circular table and each small group should consist of 4-5 participants. With a maximum of 25 participants, each workshop should have no more than 5 small groups. Participants should be grouped together to reflect diversity in regard to age, gender, etc. There should be sufficient space in the room to allow participants to move back and forth between their small groups and a large group plenary area. The support team should decide on the optimal room set-up but, in general, it should have a design akin to this:



Exercise 1: Describing CHAMPS Objectives to Reflect Community Priorities

Time: 45 minutes (9:15-10:00)

Equipment:

- 4 Index Cards per participant
- Markers for each participant
- Digital Voice Recorder

Moving naturally from introductions, the facilitator works with participants to describe CHAMPS objectives using the frameworks and contexts intrinsic to the community.

Objective:
To identify the commonalities between community priorities and the objectives of the CHAMPS Program.

Break the group into small groups of 4-5 people each. The facilitator reads the following out loud to participants:

- *The purpose of CHAMPS is to understand how and why children get sick and why some of them die. The knowledge gained through CHAMPS will allow health officials to develop programs and services to address those causes—if these officials know what kills children or causes complications during pregnancy then they can do something about it.*

  We want your perspectives about these two priorities for CHAMPS:
  3) *To understand how and why children get sick and die.*
  4) *To use the information we find out to come up with programs that will cause less illness and fewer deaths in children. (HIGHLIGHT THIS OBJECTIVE)*

  (have these two priority items listed on two separate sheets of newsprint with both visible)

  As a community leader, imagine that you have the task of explaining to the people in your own community why these two CHAMPS priorities are important. What would you say?

Step 1: Ask each participant to craft a message they would give to communicate the importance of priority one as a community leader. Ask participants to do the same thing with item #2.

When finished, each participant should have at least 2 key messages that re-enforce the two CHAMPS priorities.

Step 2: Cards are collected from each small group and then laid out one at a time on the floor, starting with the cards for item 1. When a

Support Team's Notes:

Support Team's Notes:

After the exercise, the support should gather all the participants' completed cards containing the messages, bundle them together, and place them in an envelope labelled, "Exercise #1

card repeats what a previous card has said, it is laid down above its namesake.

Clearly the facilitator needs to group together words that express the same message even if they are different words. In this way a 'bar graph' of the key messages that re-enforce the activities of item #1 is created.

The process is repeated with item #2.

Recorded discussion. The facilitator leads participants through a discussion of the messages that were written. What are participants' perceptions about the messages? Which are more powerful? Are there any disagreements? What makes these messages powerful?

Step 3. Flowing directly out of the discussion, the facilitator – in constant dialogue with the participants - draws together the key messages for item #1 to identify the **3 most powerful key messages** that support item #1. This process is repeated for item #2

Output:
A participant-driven list of messages based on community norms and language that re-enforce the objectives of CHAMPS with the three most powerful messages identified.

Exercise 2: Perceptions of Pregnancy

Support Team's Notes:

Time: 45 minutes (10:00-10:45)

Equipment:

- A marker pen for each participant
- 6 index cards for each participant
- 3 sheets of newsprint
- Tape recorder

Objective:
This exercise focuses on naming the community's perceptions about the things that contribute to healthy pregnancy. This exercise involves three clear steps.

Flowing naturally from the discussion in Exercise 1, the facilitator informs participants that one way CHAMPS will achieve the first objective listed in that exercise is to learn more about the things that help women deliver healthy children when they get pregnant.

Step 1: Participants move back into their same small groups. They are asked to discuss the answer to the question:

- *What do you consider to be the three most important factors that contribute to healthy pregnancies for women in your community?*

Each group discusses the question and develops three answers. A representative of the group writes down the group's answers on the three cards (one answer per card). The facilitator collects these cards and then lay them out in a place on the floor where all small group participants can observe. When a card repeats what a previous card has said, it is laid down above its namesake.

Clearly the facilitator needs to group together words that express the same factor even if they are different words (eg. nutrition = good food = healthy food = food; knowledge = education = understanding; etc.)

In this way a 'bar graph' of the key factors that the participants believe cause healthy pregnancies is created, and the participants can see what they themselves believe to be the key factors. The cards are left on the floor for step 2.

Step 2. The first exercise is repeated, but the question is changed. Now as they work again in their small groups, participants are asked to write down the answer to the question:

- *What do you consider to be the three most important factors that cause complications during pregnancy for women in your community?*

A representative of the group writes down the group's answers on the three cards (one per card). These cards are collected and the

Support Team's Notes:

When the exercise is complete, the support team should gather all the cards generated for "factors that contribute to a healthy pregnancy" and bundle them together. Then, they should gather all the cards generated for "factors that cause complications in pregnancy" and bundle them together. These items should be placed in the manila envelope labelled exercise 2. The envelope should be closed and sealed if data entry is to happen later offsite

laid out on the floor alongside the earlier set. When a card repeats what a previous card has said, it is laid down above its namesake.

Again the facilitator will need to group 'ideas' rather than exact words together.

In this way a 'bar graph' of the key factors that the participants believe cause sickness is created, and the participants can see what they themselves believe to be the key factors.

Recorded discussion. Through probing questions participants are engaged in reflective discussion on the reasons that certain factors are more significant than others. This should be recorded by tape recorder for later transcription as it is likely to contain key insights.

Step 3. Flowing directly out of the discussion, the facilitator – in constant dialogue with the participants - draws together the key factors that affect healthy pregnancy – either positively or negatively. This requires some lateral thinking as for example the following list may be generated (votes in brackets):

Healthy Pregnancy	Complicated pregnancy
Good health care (9)	Sickness (9)
Nutrition (6)	Poverty (7)
Faith in God (5)	Pollution (6)
Good sanitation (5)	Bad nutrition (5)
Knowledge (3)	Ignorance (3)
Water (2)	No employment (1)
Medicine (2)	No health facilities close by (1)

Food is a clear factor for a healthy pregnancy and bad nutrition a factor in a complicated pregnancy – but clearly they express the same idea, and so only one word is chosen. Likewise, ignorance and knowledge express the same idea. Depending on how people understand pollution, it may be the flip-side of good sanitation. Thus, after some discussion, the participants agree on a combined set of five or six key factors contribute to healthy pregnancies in the community. In the above case these would probably be:

Nutrition
Knowledge
Against Poverty
Against Pollution
Medicine and health facilities

The facilitator should write these responses down on the newsprint for use in exercise 4. Write largely as that exercise will require participants to place cards next to these factors.

Output:
A participant driven list of factors that impact pregnancy

Following the completion of this exercise, participants will break for morning tea until 11:00 AM

Exercise 3: Perceptions of Childhood Health and Illness

Time: 45 minutes (11:00-11:45)

Equipment:

- A marker pen for each participant
- 6 index cards for each small group
- 3 sheets of newsprint
- Tape recorder

Objective:
This exercise focuses on naming the community's perceptions about the things that affect children's health: the things that help children be healthy or the things that may make children sick. This exercise involves three clear steps and the process is identical to exercise 2 above with a different topic.

Step 1: Participants are asked to write down the answer to the question:

- *What do you consider to be the three most important factors that contribute to the health of children in your community? Write down these factors (one per card) in a few words or a short phrase.*

These cards are collected and then laid out in a place on the floor where all participants can observe. When a card repeats what a previous card has said, it is laid down above its namesake.

Clearly the facilitator needs to group together words that express the same factor even if they are different words. In this way a 'bar graph' of the key factors that the participants believe cause good health is created, and the participants can see what they themselves believe to be the key factors. The cards are left on the floor for step 2.

Step 2. The first exercise is repeated, but the question is changed. Now participants are asked to write down the answer to the question:

- *What do you consider to be the two key factors that cause children to become ill or die in your community? Write down these factors (one per card) in a few words or a short phrase.*

These cards are collected and then laid out on the floor alongside the earlier set. When a card repeats what a previous card has said, it is laid down above its namesake. Again the facilitator will need to group 'ideas' rather than exact words together.

In this way a 'bar graph' of the key factors that the participants believe cause sickness is created, and the participants can see what they themselves believe to be the key factors.

Recorded discussion. Through probing questions participants are

Support Team's Notes:

This exercise will likely take less time than exercise 2 did because participants will be familiar with the process.

The process is quite similar.

Support Team's Notes:

When the exercise is complete, the support team should gather all the cards generated for "factors that contribute to the health of children" and bundle them together. Then, they should gather all the cards generated for "factors that cause children to become ill or die" and bundle them together. These items should be placed in the manila envelope labelled exercise 3. The envelope should be closed and sealed if data entry is to happen later offsite.

engaged in reflective discussion on the reasons that certain factors are more significant than others. This should be recorded by tape recorder for possible transcription as it is may contain key insights.

Step 3. Flowing directly out of the discussion, the facilitator – in constant dialogue with the participants - draws together the key factors that contribute to childhood health – either positively or negatively. Thus, after some discussion, the participants agree on a combined set of five or six key factors that contribute to healthy children in the community. The list will be similar to the one generated in exercise 2. The facilitator should write these responses down on the newsprint for use in exercise 4. Write largely as that exercise will require participants to place cards next to these factors.

Output:
A participant driven list of factors that impact childhood health, illness, and death.

Exercise 4: What are the Roles of Community Leaders in Response to Pregnancy and Childhood Death?

Time: 45 minutes (11:45-12:30)
Equipment:

- A marker pen for each participant
- 6 index cards for each small group
- Tape recorder

Objective:
This exercise asks participants to identify their roles and responsibilities as leaders in addressing the factors that impact pregnancy and childhood health/illness (named in exercises 2 and 3)

Step 1: The facilitator shows to the participants the two sheets of newsprint from exercises 2 and 3 that list the key factors that impact pregnancy and childhood health/illness. After going through the list of key factors, the two sheets are laid out on the floor side by side. Participants are asked to write down the answer to the question:

- *As a community leader, what do you do (or what **could** you do) in addressing these factors? If the factor contributes to health, what is your role in making it available to the community? If the factor worsens health, what is your role in minimizing it?*

Participants write down three responses to the question, one response per card. After writing their three responses, participants place them on top of the newsprint sheets beside the factor their response addresses. The facilitator leads participants in a discussion of the roles identified, noting any overlaps among responses. The cards are left on the floor for step 2.

Step 2. The facilitator then asks participants:

- *How can CHAMPS support you in carrying out the roles you have just named?*

Participants write down three responses to this question, one response per cared. The cards are collected and then laid out on the floor. When a card repeats what a previous card has said, it is laid down above its namesake. Again the facilitator will need to group 'ideas' rather than exact words together. In this way a 'bar graph' of the support that CHAMPS can provide is created.

Recorded discussion. After all the cards are laid down, the facilitator leads the participants in a discussion. As part of that discussion, the facilitator should ask participants specifically about their interest in working with CHAMPS to determine next steps for CHAMPS to respond to the items identified.

Output:
A participant driven list of 1) leaders' role in addressing the factors that impact pregnancy and childhood health/illness, and 2) the ways that CHAMPS could support leaders in carrying out those roles.

Following this exercise, participants break for lunch until 1:30 PM.

Support Team's Notes:

When the exercise is complete, the support team should take photographs of the newsprint sheets with the cards placed on alongside each of the identified key factors. Then the team should gather all the cards generated for step 1 and bundle them together, the cards genderated for step 2 and bundle them together, and then carefully fold the two newsprint sheets. All of the three items should be placed in the manila envelope labelled exercise 4. The envelope should be closed and sealed if data entry is to happen later offsite.

Exercise 5: Leaders' Perceptions of CHAMPS Activities

Support Team's Notes:

NOTE: This is the most complicated and time-consuming exercise.

Time: 60 minutes (1:30-2:30)

Equipment:

- 1 pen per participant
- 6 index cards for participants
- Two Matrices created on newsprint that can be laid out on the floor (see example below)

Objective*:* To assess the level of alignment or tension between CHAMPS activities and community perceptions.

The facilitator reads the following aloud to participants:

- *We began the day by asking you to write down important messages that re-enforce the importance of the objectives of the CHAMPS program—to figure out what causes children to die and to do something about it. Now we want to discuss what needs **to be done** in order for the CHAMPS program to meet those objectives. CHAMPS would like to work with the community to gather information on the issues that arise during women's pregnancies and to gather information about what causes the death of children. We propose some specific ways to gather this information but we also realize that the community already does important things to celebrate pregnancy and to mourn the death of a child. We want to find ways to work with you to carry out our activities while being respectful and appreciative of the things that the community already does.*

Step 1: Ask participants the following question:

- *What happens in your community when a woman finds out she is pregnant? What happens in the family? What happens in the broader community?*

Participants are instructed to write down three responses to this question, one response per card. They should keep the cards with their written responses for this exercise. Allow time for all participants to write down their responses.

The facilitator then says to participants:

In order to help women who are pregnant get good healthcare and have services to help address problems during pregnancy when they arise, CHAMPS staff will talk with women who are currently pregnant or have recently been pregnant. We will only talk with women who want to talk with us and will talk with them in both healthcare and community settings. We want to learn from women themselves the things that are affecting their pregnancy or affected the birth of their child. We want to hear about both things that helped and things that caused problems. We want to know from you as community leaders whether our efforts.

Support Team's Notes:

to talk with these women will be in tension with what the community does to support women during pregnancy

Step Two: Introduce participants to the following matrix, which will be laid out on the floor.

	Things our community does when to celebrate a woman's pregnancy
Talking with women who are pregnant or who recently delivered a child.	HIGH LEVEL OF TENSION
	TWO DIFFERENT ACTIVITIES/ NO TENSION BUT NO ALIGNMENT
	HIGH LEVEL OF ALIGNMENT

Have participants take their cards spread out on the floor and place them one at a time onto the matrix. When all cards have been placed on the matrix, de-brief with the participants on the process of reaching consensus. After the de-briefing is completed, the facilitator moves immediately to Exercise 4.

Step Three: The facilitator informs participants that they will now focus on CHAMPS activities related to childhood illness and death. The facilitator then reads the following aloud to participants:

> *We want to find out what causes children to die so that something can be done about those things. This will mean that fewer children would die because things could be done to prevent those deaths. We also know that there are things that are done in your community when a child dies. Those things are very important. We want to find ways to work with you to carry out our activities while being respectful and appreciative of the things that the community does.*

The facilitator then asks participants the following question:

- *What happens in your community when a child dies? What happens in the family? What happens in the broader community?*

Participants are instructed to write down three responses to this question, one response per card. They should keep the cards with their written responses for this exercise. Allow time for all participants to write down their responses.

The facilitator then says to participants:

> *In order to figure out the things that cause children to die CHAMPS staff would like to speak with some of the parents in your community who will have just experienced the death of their child. With their permission, we will gather small amounts of tissue and blood from the body of their child*

Support Team's Notes:

When the exercise is finished, the support team should take numerous photographs of the two matrices BUT DO NOT REMOVE AND BUNDLE THE CARDS AS THEY WILL BE NEEDED FOR THE NEXT EXERCISE.

within 12 hours after the child's death. We will speak with parents either in hospital or at their home. Studying this tissue and blood is the only way we can accurately figure out the things that cause children to die so that we can do something to help other children.

Step Four: Introduce participants to the second matrix, which will be laid out on the floor.

	Things our community does when to when a child dies
With parents' consent, gather blood and tissue from the body of a child who recently died.	HIGH LEVEL OF TENSION
	TWO DIFFERENT ACTIVITIES/ NO TENSION BUT NO ALIGNMENT
	HIGH LEVEL OF ALIGNMENT

Have the participants take the cards with their responses and place them one at a time onto the matrix.

When all cards have been placed on the matrix, de-brief with the participants. After the de-briefing is completed, the facilitator says:

Outputs: 1) A participant-driven list of community activities carried out when a woman is pregnant ranked by the level of alignment/tension to CHAMPS pregnancy surveillance activities, and 2) a participant-driven list of community activities carried out when a child dies ranked by the level of alignment/tension to CHAMPS mortality surveillance activities.

Following this exercise, participants will break for tea until 2:45 PM

Exercise 6: Building Support for CHAMPS

Time: 1 hour (2:45-3:45)

Equipment:

- Coded index cards for participants
- 1 pen or marker per participant
- Newsprint

Objective: Use the six messages related to CHAMPS objectives to create/strengthen alignment between community activities and CHAMPS activities.

Step 1: Refer participants to the key messages that were identified in exercise 1.

Starting with a community activity from exercise 5 that is in tension with CHAMPS activities, discuss with participants how the key messages crafted in exercise 1 could be used to lower tension and increase alignment. Following the discussion, ask participants to write down on a card, **one specific, concrete action step** that they could take that would use these messages to help create some level of alignment between the community and CHAMPS activities. On that same card, ask them if they could identify someone in the community (it could even be the participant herself or himself) who might be the champion of this activity.

Step 2: Continue this process with all community activities that are in tension with CHAMPS activities.

Outcome: A participant driven list of action steps (and champions) that align with community messages that could be undertaken to build support for CHAMPS.

Support Team's Notes:

When the exercise is complete, the support team should gather all the cards that describe action steps and individuals who could undertake those action steps. These cards should be bundled and placed in a large manila envelope labelled Exercise 6. The envelope should be closed and sealed if data entry is to happen later offsite.

The team should also gather the cards on the two matrices (from exercise 5). These cards should be bundled and placed in a large manila envelope labelled Exercise 5. The envelope should be closed and sealed if data entry is to happen later offsite.

Next Steps: Staying In Touch

Facilitator's Notes:

The workshop is completed. Before adjourning, the facilitator should invite participants to stay in touch with CHAMPS to receive updates on findings, future events, and community meetings.

At this point the workshop is completed. Explain that this is one of the first activities being carried out by CHAMPS and that the CHAMPS team would like to stay in touch with the participants. Ask participants if they would like to continue to receive information about CHAMPS, including information of the findings, periodic newsletters, and invitations to future community meetings in which CHAMPS staff provide updates to the community. If so, have participants complete a "Stay In Touch" Card.

Appendix B: CHAMPS Alignment Tension Assessment Tool

This instrument is to be used to assess the degree of alignment/tension between community perspectives and CHAMPS activities, particularly MITS, in light of findings from the PICK-CHAMP community engagement workshops.. The instrument should be completed by the facilitator(s) of the PICK-CHAMP workshops carried out in the local community.

Community Members Workshop

Exercise 1: Describing CHAMPS Objectives to Reflect Community Priorities

This exercise reframes two primary CHAMPS objectives using the language and norms of the local community. Those objectives are:

1) *To understand how and why children get sick and die.*
2) *To use the information we find out to come up with programs that will cause less illness and fewer deaths in children.*

Output: A participant-driven list of messages based on community norms and language that re-enforce the objectives of CHAMPS with the three most powerful messages identified.

Scoring: (NOTE: This exercise does not generate a "Tension" score)
How many total ***different*** messages were created by participants?

<6	Alignment: 0
6	Alignment: 2
7-9	Alignment: 4
10-12	Alignment: 6
>12	Alignment: 8

Exercise 2: Perceptions of Pregnancy

Participants name factors that contribute to a health pregnancy and factors that contribute to complications during pregnancy.

Output: A participant driven list of factors that impact pregnancy.

Scoring: (NOTE: This exercise does not generate a "Tension" score)
Examine all of the factors named (not only the final key factors). Using your own judgment, identify the percentage of all factors named that are regularly addressed by medical/clinical/public health interventions vs. those that reflect a social/cultural issue not regularly addressed by medical/clinical/public health.

What percentage of all factors is regularly addressed by medical/clinical/public health interventions? _____

<10%	Alignment: 0
10-33%	Alignment: 1
34-57%	Alignment: 2
58-80%	Alignment: 3
>80%	Alignment: 4

Exercise 3: Perceptions of Childhood Health and Illness

Participants name factors that contribute to childhood health and factors that contribute to childhood illness or death.

Output: A participant driven list of factors that impact childhood health and illness.

Scoring: (NOTE: This exercise does not generate a "Tension" score)

Examine all of the factors named (not only the final key factors). Using your own judgment, identify the percentage of all factors named that are regularly addressed by medical/clinical/public health interventions vs. those that reflect a social/cultural issue not regularly addressed by medical/clinical/public health.

What percentage of all factors is regularly addressed by medical/clinical/public health interventions? _____

<10%	Alignment: 0
10-33%	Alignment: 2
34-57%	Alignment: 4
58-80%	Alignment: 6
>80%	Alignment: 8

[NOTE: Exercises 4 and 5 do not measure alignment or tension with CHAMPS activities]

Exercise 6: Participants' Perception of CHAMPS Activities

This exercise assesses perceptions of the level of alignment or tension between CHAMPS activities and community priorities and perceptions.

Outputs: 1) A matrix showing alignment or tension between CHAMPS activities and community priorities, and 2) a profile of participants' perceptions about CHAMPS activities based on a set of propositions.

Scoring

This exercise will generate four scores

1) perception of alignment/tension for pregnancy surveillance
2) perception of alignment/tension for MITS
3) support for pregnancy surveillance
4) support for MITS

To generate the score for perception of alignment/tension for pregnancy surveillance:

1) Looking only at the matrix that asks about perceptions of the CHAMPS activity "talking with women who are pregnant or who recently delivered a child" count the number of stickers placed in the box labeled "It fits with our community."

   Enter that number here: _____

2) Count the total number of stickers placed in either box on that same matrix.

   Enter that number here: _____

3) Divide the number from step 1 by the number from step 2 and enter it here as a percentage: _____

   The percentage entered in step 3 generates the following alignment and tension scores:

<10%, then	Alignment: 0	Tension: 4
10-36%	Alignment: 1	Tension: 3
37-53%	Alignment: 2	Tension: 2
54-90%	Alignment: 3	Tension: 1
>90%	Alignment: 4	Tension: 0

To generate the score for perception of alignment/tension for MITS:

1) Looking only at the matrix that asks about perceptions of the CHAMPS activity "with parents' consent, gather samples from the body of a child who recently died." count the number of stickers placed in the box labeled "It fits with our community."

   Enter that number here: _____

2) Count the total number of stickers placed in either box on that same matrix.

   Enter that number here: _____

3) Divide the number from step 1 by the number from step 2 and enter it here as a percentage: _____

   The percentage entered in step 3 generates the following alignment and tension scores:

<10%, then	Alignment: 0	Tension: 8
10-36%	Alignment: 2	Tension: 6
37-53%	Alignment: 4	Tension: 4
54-90%	Alignment: 6	Tension: 2
>90%	Alignment: 8	Tension: 0

To generate the score for support for pregnancy surveillance:

1) Calculate the total number of "Agree" "Disagree" and "Uncertain" responses for the following propositions (NOTE: Be sure to enter the "Agree" and "Disagree" responses in the correct column)

#2	A woman should not be asked about what's happening during her pregnancy because that information is private.	DISAGREE _____	AGREE _____	UNCERTAIN _____	
#4	If we know what happens to women during their pregnancy, we can figure out what to do to help women have safe pregnancies and give birth to healthy children.	AGREE _____	DISAGREE _____	UNCERTAIN _____	
#8	Even if I might not want to answer questions about my own pregnancy (or wouldn't want my wife to), I am glad that other women in the community are doing so if it contributes to healthier pregnancies.	AGREE _____	DISAGREE _____	UNCERTAIN _____	
#13	All women in our community who are pregnant should be seen at a health centre to make sure there are no problems during their pregnancy.	AGREE _____	DISAGREE _____	UNCERTAIN _____	
Add the numbers in each column. Then add the number of responses for "ALIGNMENT", "TENSION," and "UNCERTAIN" and record the sum in the "TOTAL" box		ALIGNMENT _____	TENSION _____	UNCERTAIN _____	TOTAL _____

2) Divide the number of UNCERTAIN responses by the TOTAL number of responses. If the result is greater than .3, place an "X" in the "Alignement" and "Tension" boxes on this row on the score sheet and check the line "High degree of uncertainty."
3) If the result from step 2 is <.3, then divide the number of ALIGNMENT responses by the TOTAL number of responses

Enter it here as a percentage: _____

The percentage entered in step 3 generates the following alignment and tension scores:

<10%, then	Alignment: 0	Tension: 4
10-36%	Alignment: 1	Tension: 3
37-53%	Alignment: 2	Tension: 2
54-90%	Alignment: 3	Tension: 1
>90%	Alignment: 4	Tension: 0

To generate the score for support for MITS:

1) Calculate the total number of "Agree" "Disagree" and "Uncertain" responses for the following propositions (NOTE: Be sure to enter the "Agree" and "Disagree" responses in the correct column)

#1	It is wrong to remove small samples of tissue from a child after she has died even if tests done on that tissue could tell you how she died.	DISAGREE _____	AGREE _____	UNCERTAIN _____
#3	The information gained from tissue samples is worthwhile because this knowledge could help us improve child survival.	AGREE _____	DISAGREE _____	UNCERTAIN _____
#5	In my opinion, I don't think any parent should ever agree to let tissue samples be collected from the body of their child after that child has died.	DISAGREE _____	AGREE _____	UNCERTAIN _____
#6	Our community owes a debt of gratitude to parents who consent to the removal of tissue from their child's bodies when they die because these parents are helping other children to live.	AGREE _____	DISAGREE _____	UNCERTAIN _____
#7	Even if I didn't agree to have tissue samples collected from my child's body, I still think the knowledge we gain through this work is important for helping us fight childhood illness and death.	AGREE _____	DISAGREE _____	UNCERTAIN _____
#9	Medicine and science may help us care for a child's body during life but care for a child's body at death is the work of faith and of God alone.	DISAGREE _____	AGREE _____	UNCERTAIN _____
#10	I would not agree to any kind of procedure if it meant that I could not bury my child according to my faith or tradition.	DISAGREE _____	AGREE _____	UNCERTAIN _____
#11	We can collect tissue samples and still be able to bury a child with love and respect.	AGREE _____	DISAGREE _____	UNCERTAIN _____

Add the numbers in each column. Then add the number of responses for "ALIGNMENT", "TENSION," and "UNCERTAIN" and record the sum in the "TOTAL" box	ALIGNMENT _____	TENSION _____	UNCERTAIN _____	TOTAL _____

2) Divide the number of UNCERTAIN responses by the TOTAL number of responses. If the result is greater than .3, place an "X" in the "Alignement"

and “Tension” boxes on this row on the score sheet and check the line “High degree of uncertainty.”

3) If the result from step 2 is <.3, then divide the number of ALIGNMENT responses by the TOTAL number of responses

   Enter it here as a percentage: _____

   The percentage entered in step 3 generates the following alignment and tension scores:

<10%, then	Alignment: 0	Tension: 8
10-36%	Alignment: 2	Tension: 6
37-53%	Alignment: 4	Tension: 4
54-90%	Alignment: 6	Tension: 2
>90%	Alignment: 8	Tension: 0

[Note: Exercise 7 does not measure alignment or tension with CHAMPS activities.]

COMMUNITY LEADERS WORKSHOP

Exercise 1: Describing CHAMPS Objectives to Reflect Community Priorities

This exercise reframes two primary CHAMPS objectives using the language and norms of the local community. Those objectives are:

1) *To understand how and why children get sick and die.*
2) *To use the information we find out to come up with programs that will cause less illness and fewer deaths in children.*

Output: A participant-driven list of messages based on community norms and language that re-enforce the objectives of CHAMPS with the three most powerful messages identified.

Scoring: (NOTE: This exercise does not generate a “Tension” score)
How many total ***different*** messages were created by participants?

<6	Alignment: 0
6	Alignment: 4
7-9	Alignment: 8
10-12	Alignment: 12
>12	Alignment: 16

Exercise 2: Perceptions of Pregnancy

Participants name factors that contribute to a health pregnancy and factors that contribute to complications during pregnancy.

Output: A participant driven list of factors that impact pregnancy.

Scoring: (NOTE: This exercise does not generate a “Tension” score)
Examine all of the factors named (not only the final key factors). Using your own judgment, identify the percentage of all factors named that are regularly addressed by medical/clinical/public health interventions vs. those that reflect a social/cultural issue not regularly addressed by medical/clinical/public health.

What percentage of all factors is regularly addressed by medical/clinical/public health interventions? _____

<10%	Alignment: 0
10-33%	Alignment: 4
34-57%	Alignment: 8

58-80% Alignment: 12
>80% Alignment: 16

Exercise 3: Perceptions of Childhood Health and Illness

Participants name factors that contribute to childhood health and factors that contribute to childhood illness or death.

Output: A participant driven list of factors that impact childhood health and illness.

Scoring: (NOTE: This exercise does not generate a "Tension" score)
Examine all of the factors named (not only the final key factors). Using your own judgment, identify the percentage of all factors named that are regularly addressed by medical/clinical/public health interventions vs. those that reflect a social/cultural issue not regularly addressed by medical/clinical/public health.

What percentage of all factors is regularly addressed by medical/clinical/public health interventions? _____

<10% Alignment: 0
10-33% Alignment: 4
34-57% Alignment: 8
58-80% Alignment: 12
>80% Alignment: 16

Exercise 4: What are the Roles of Community Leaders in Response to Pregnancy and and Childhood Death?

Participants identify the things that they could do as community leaders to address factors that impact pregnancy outcomes and childhood health as well as the ways that CHAMPS could support them in addressing those factors.

Output: A participant driven list of 1) leaders' role in addressing the factors that impact pregnancy and childhood health/illness, and 2) the ways that CHAMPS could support leaders in carrying out those roles.

Scoring: Working with the CHAMPS country office leadership, identify which of the identified ways that CHAMPS could support community leaders are feasible for CHAMPS to actually support.

What percentage of identified ways that CHAMPS could support community leaders are actually feasible? _____

<10% Alignment: 0 Tension: 16
10-33% Alignment: 4 Tension: 12
34-57% Alignment: 8 Tension: 8
58-80% Alignment: 12 Tension: 4
>80% Alignment: 16 Tension: 0

5. Leaders' Perceptions About CHAMPS Activities

Outputs: 1) A participant-driven list of community activities carried out when a woman is pregnant ranked by the level of alignment/tension to CHAMPS pregnancy surveillance activities, and 2) a participant-driven list of community activities carried out when a child dies ranked by the level of alignment/tension to CHAMPS mortality surveillance activities.

Scoring: [Note: This exercise generates two different alignment/tension scores—one for mortality surveillance and one for pregnancy surveillance.]

1. Looking only at the matrix entitled, "Things our community does to celebrate a woman's pregnancy," count the number of cards placed in the area of the matrix called "HIGH LEVEL

OF TENSION" and divide that number by the total number of cards placed on the entire matrix. Enter that number here as a percentage: _____

<10%	Alignment: 0	Tension: 8
10-33%	Alignment: 2	Tension: 6
34-57%	Alignment: 4	Tension: 4
58-80%	Alignment: 6	Tension: 2
>80%	Alignment: 8	Tension: 0

2. Looking only at the matrix entitled, "Things our community does when a child dies," count the number of cards placed in the area of the matrix called "HIGH LEVEL OF TENSION" and divide that number by the total number of cards placed on the entire matrix. Enter that number here as a percentage: _____

<10%	Alignment: 0	Tension: 16
10-33%	Alignment: 4	Tension: 12
34-57%	Alignment: 8	Tension: 8
58-80%	Alignment: 12	Tension: 4
>80%	Alignment: 16	Tension: 0

SCORING SHEET			Alignment	Tension
COMMUNITY MEMBERS WORKSHOP				
1. Describing CHAMPS Objectives to Reflect Community Priorities				
	How many total ***different*** messages were created by participants?		Range: 0-8	No Response
2. Perceptions of Pregnancy				
	What percentage of all factors is regularly addressed by medical/clinical/public health interventions?		Range: 0-4	No Response
3. Perceptions of Childhood Health and Illness				
	What percentage of all factors is regularly addressed by medical/clinical/public health interventions?		Range: 0-8	No Response
6. Participants' Perceptions of CHAMPS Activities				
a	Perception of alignment/tension for pregnancy surveillance		Range: 0-4	Range: 0-4
b	Perception of alignment/tension for MITS		Range: 0-8	Range: 0-8
c	Support for pregnancy surveillance	High degree of uncertainty ____ (if checked, place an X in the "Alignment" and "Tension" boxes to the right)	Range: 0-8 unless X	Range: 0-8 unless X
d	Support for MITS	High degree of uncertainty ____ (if checked, place an X in the "Alignment" and "Tension" boxes to the right)	Range: 0-8 unless X	Range: 0-8 unless X

Scoring for Community Members Workshop			
	1. Add the numerical responses for each box in the "Alignment" column and place that number in the "Alignment Total" box. Add the numerical responses for each box in the "Tension" column and place that number in the "Tension Total" box.	Alignment Total Range: 0-48	Tension Total Range: 0-28
	2. Count the number of boxes in the "Alignment" column that contained a number and enter the result in the "# of Alignment Responses" box. Count the number of boxes in the "Tension" column that contained a number and enter the result in the "# of Tension Responses" box.	# of Alignment Responses Range: 5-7	# of Tension Responses Range: 2-4
	3. Divide the number in the "Alignment Total" box by the number in the "# of Alignment Responses" box, round to the nearest whole number, and place the result in the "CM Alignment Score" box. Divide the number in the "Tension Total" box by the number in the "# of Tension Responses" box, round to the nearest whole number, and place the result in the "CM Tension Score" box.	CM Alignment Score Range: 0-7	CM Tension Score Range: 0-7

COMMUNITY LEADERS WORKSHOP			
1. Describing CHAMPS Objectives to Reflect Community Priorities			
	How many total ***different*** messages were created by participants?	Range: 0-16	No Response
2. Perceptions of Pregnancy			
	What percentage of all factors is regularly addressed by medical/clinical/public health interventions?	Range: 0-8	No Response
3. Perceptions of Childhood Health and Illness			
	What percentage of all factors is regularly addressed by medical/clinical/public health interventions?	Range: 0-16	No Response
4. What are the Roles of Community Leaders in Response to Pregnancy and Childhood Death?			
	What percentage of identified ways that CHAMPS could support community leaders are actually feasible?	Range: 0-16	Range: 0-16
5. Leaders' Perceptions of CHAMPS Activities			
a	Things our community does to celebrate a woman's pregnancy	Range: 0-16	Range: 0-8
b	Things our community does when a child dies	Range: 0-16	Range: 0-16

Scoring for Community Leaders Workshop			
	1. Add the numerical responses for each box in the “Alignment” column and place that number in the “Alignment Total” box. Add the numerical responses for each box in the “Tension” column and place that number in the “Tension Total” box.	Alignment Total Range: 0-88	Tension Total Range: 0-40
	2. Count the number of boxes in the “Alignment” column that contained a number and enter the result in the “# of Alignment Responses” box. Count the number of boxes in the “Tension” column that contained a number, and enter the result in the “# of Tension Responses” box.	# of Alignment Responses 6	# of Tension Responses 3
	3. Divide the number in the “Alignment Total” box by the number in the “# of Alignment Responses” box, round it to the nearest whole number and place the result in the “CL Alignment Score” box. Divide the number in the “Tension Total” box by the number in the “# of Tension Responses” box, round it to the nearest whole number, and place the result in the “CL Tension Score” box.	CL Alignment Score Range: 0-15	CL Tension Score Range: 0-13

	CM Alignment Score (Range: 0-7)	
	CL Alignment Score (Range: 0-15)	
	COMPOSITE ALIGNMENT SCORE (CM+CL) (Range: 0-22)	
	CM Tension Score (Range: 0-7)	
	CL Tension Score (Range: 0-13)	
	COMPOSITE TENSION SCORE (CM+CL) (Range: 0-20)	

Composite Alignment Score (Range: 0-22)		Composite Tension Score (Range: 0-20)	
<6	CRITICALLY LOW ALIGNMENT	<=5	VERY LOW TENSION
6-11	LOW ALIGNMENT	6-10	LOW TENSION
12-16	MEDIUM ALIGNMENT	11-15	MEDIUM TENSION
17-22	HIGH ALIGNMENT	16-20	HIGH TENSION

	ALIGNMENT	TENSION	
If	CRITICALLY LOW	HIGH	then delay pending consultation with PO
If	CRITICALLY LOW	all others	then delay until add’l community engagement (CE) completed
If	LOW	HIGH/MEDIUM	then delay until additional CE completed
If	LOW	LOW/VERY LOW	then consider implementing with CE focus on increasing support
If	MEDIUM	HIGH	then delay until additional CE completed
If	MEDIUM	MEDIUM	then implement with CE focus on support/addressing concerns
If	MEDIUM	LOW/VERYLOW	then implement with CE focused on support
If	HIGH	HIGH	then delay until additional CE completed
If	HIGH	MEDIUM	then consider implementing with CE focused on concerns
If	HIGH	LOW/VERY LOW	then implement and continue CE activities.

Appendix C: Key Informant Interview Guides (INDITe)

Key Informant Guide—Medical Personnel

We are working to understand more about the causes of infectious diseases in the area. During our investigations, we will be asking family members of recently deceased whether they will accept that we carry out an autopsy or take small tissue samples using minimally invasive procedures. These procedures will allow us to determine the cause of the disease that killed the person. In the future this information can be used to assist clinicians in selecting appropriate therapy and to prevent disease occurring in other people.

As part of this investigation, we would also like to collect information on local perceptions of disease and cultural and religious practices related to death and burial. We will also want to learn about how people in this community view examinations or procedures carried out post-mortem, and how decisions are made as to whether to accept or refuse certain medical procedures after a family member has died.

I would like to start the interview by collecting some background information. (Go to structured guide)

Perceptions of disease causality, age at death, and predestination

- Where do most patients on your ward come from?
- What are some of the most common causes of death on your ward?
- What are local beliefs and perceptions related to the cause of death?
    - Is the cause of death talked about by family members? If not, what are some of the reasons for not talking about the cause?
    - Do perceptions of the cause vary according to age (children vs. adults) or sex of the deceased?
- To what extent do spiritual causes play a role?
    - How does this vary according to the type of illness or age of the person who died?
- What are local perceptions of illness associated with fever?
    - If the illness associated with fever leads to death, what might people assume is the main cause?
- What are local beliefs related to things happening including death that are associated with God's will or destiny?
    - Does this vary according to ethnicity and religion?
    - Does this vary according to urban vs. rural dwellers?
- To what extent do you think people in this area would like to learn more about the cause of deceased family members?
    - Why or why not might they want to know about the cause of death?

  - For their personal family interest?
  - For the broader community or society?

- How might the desire to learn about the cause vary according to the age of the deceased?
    - Are there any other factors that may affect their desire to learn about the cause of death?

Knowledge about post-mortem examinations

- What are local perceptions regarding sampling of blood or organs?
    - Do people coming to the hospital have prior experience with taking blood or organ samples?
    - What are local perceptions regarding why blood or organs are sampled?
    - Are there beliefs associated with particular organs that may make community members more reluctant to accept the procedures?
- To what extent are people in this area familiar with postmortem?
    - What are local perceptions of postmortem?
    - Is there a local term for autopsy?
    - Is there a local term for postmortem?
    - What do people think is done during a postmortem?
    - Why do people think that postmortem is done?
    - Under what circumstances might postmortem be carried out?
    - What type of information is needed to encourage a person to accept postmortem?
- Have you had patients that have accepted postmortem
    - Please explain the circumstances
- Are there any local practices that occur after death that are at all similar to what is done during a medical postmortem?

Attitudes, norms and acceptability of examinations conducted at hospital

- In your experience, how would you describe the relationship between community members and trained health providers working in the hospital?
    - What type of health providers (biomedical vs. traditional) do people trust more?
    - Do they trust less?
- Under what circumstances do people generally seek care with biomedical providers?

- Do you think that family members or community leaders would accept to have an autopsy done on family or community members?
    - Why might people refuse
    - Why might people accept?
- What information might family members need to know about the procedure to make a decision?
    - What aspects of the procedure, if any, might be perceived to be objectionable?
    - What aspects of the procedure, if any, might be perceived to be beneficial?
- Can you describe the decision making process family members follow related to how to treat a body post-mortem?
    - Who in the family might be involved?
    - Is there somebody in particular who typically takes charge?
    - How might decision making vary according to the age of the deceased and how the person died?
    - What other community members might be consulted when families make their decision?
- If the deceased person had fever, how might this affect decision making?
- If autopsy is not acceptable, do you think that people in this community might be willing to accept a different, less invasive procedure involving collecting a small piece of a organs (e.g. brain, lung, liver) from someone who died with fever? Probe for why or why not.
- What information might community members need to know about the procedure to make a decision?
    - What aspects of the procedure, if any, might be perceived to be objectionable?
    - What aspects of the procedure, if any, might be perceived to be beneficial?
- In what situations might this procedure be acceptable? Probe for when it would or would not be acceptable.
- If a family came to you for advice about making a decision like this (for either type of procedure), what would you say to them?
- How should information on these procedures be shared with community members?
- Who should be involved in introducing the procedures and gaining trust with community members?

Obtaining consent

- What are your suggestions regarding how to approach families for carrying out post-mortem or needle biopsy specimens?
    - What family members should be approached?
    - Who should approach them?
    - How should they be approached?
    - Who should first be approached?
    - When should families be approached?
    - What type of information should be shared?
    - Are there any words or terms that may be particularly sensitive and should be avoided
- Do you think that more people would accept autopsy if we told them that the cause of death is frequently misdiagnosed? If we share this information, might there be negative ramifications related to perceptions of the capabilities of the medical staff in the hospital?
- Do you think that it would be helpful to have somebody else present (e.g. health providers, religious or other influential leaders) while explaining the procedures and obtaining consent?
- Do you think that it would be helpful to the family to present sketches or illustrations of the corpse after the procedures?
- Do you feel that some sort of assistance should be offered to families who agree to an autopsy or to have their deceased family member undergo a needle biopsy to collect tissue? If so, what type of assistance may be appropriate
    - Probe for transport to the home, payment for preservation of the body, daily fees for the morgue, or payment for the coffin
- If we want to go back to families to ask them some questions about why they accepted or refused autopsy, when would be the most appropriate time to go back?
- If we want to go back to families to ask some more detailed questions (may take about an hour) about what occurred prior to the death, when would be the most appropriate time to go back?

Key Informant Guide—Village/Street Leaders

We are working to understand more about the causes of infectious diseases in the area. During our investigations, we will be asking family members of recently deceased whether they will accept that we carry out an autopsy or take small tissue samples using minimally invasive procedures. These procedures will allow us to determine the cause of the disease that killed the person. In the future this information can be used to assist clinicians in selecting appropriate therapy and to prevent disease occurring in other people.

As part of this investigation, we would also like to collect information on local perceptions of disease and cultural and religious practices related to death and burial. We will also want to learn about how people in this community view examinations or procedures carried out post-mortem, and how decisions are made as to whether to accept or refuse certain medical procedures after a family member has died.

I would like to start the interview by collecting some background information. (Go to structured guide).

I would like to start by asking you some questions about the burial ceremony and practices followed by people of your religious faith.

Burial practices and rituals

- Can you please describe the burial ceremony in your community. Please describe it from start to finish, giving as many details as possible. Probe for
    - Who is in charge of decisions related to preparing the body and the burial? (Probe for involvement of religious representatives, as well as family members)
    - How are bodies prepared for burial? Does this vary in any way according to ethnic differences or backgrounds?
- Please describe what occurs during the actual burial in the community. How do practices vary according to ethnicity, age or the person who died (children vs. adults)?
    - What is the timing of the burial and how does this vary according to
        - Cultural backgrounds
    - What condition/state does the body need to be in for burial?
- What are attitudes regarding the physical status of the corpse (making the body presentable, pure) prior to burial?
- What are attitudes towards changing/altering the body postmortem?
- What are perceptions of spirits/spiritual retribution if the body is changed in any way?
- What are local concepts related to death and the supernatural?

Perceptions of disease causality, age at death, and predestination

- What are local beliefs and perceptions related to the cause of death?
    - Is the cause of death talked about by family members? If not, what are some of the reasons for not talking about the cause?
    - Do perceptions of the cause vary according to age (children vs. adults) or sex of the deceased?
- To what extent do spiritual causes play a role?
    - How does this vary according to the type of illness or age of the person who died?
- What are local perceptions of illness associated with fever?

  - If the illness associated with fever leads to death, what might people assume is the main cause?

- What are local beliefs related to things happening according God's will or destiny?
  - Does this vary according to ethnicity and religion?
- To what extent do you think people in this area would like to learn more about the cause of death in family members?
  - Why or why not might they want to know about the cause of death?
    - For their personal family interests?
    - For the broader community or society?
  - How might the desire to learn about the cause vary according to the age of the deceased?
  - Are there any other factors that may affect their desire to learn about the cause of death?
  - Do you think that they would like to learn about the cause if they knew that the cause is often misdiagnosed?

Knowledge about post-mortem examinations

- What are local perceptions regarding sampling of blood or organs?
  - Do communities have prior experience with taking blood or organ samples?
  - What are local perceptions regarding why blood or organs are sampled?
  - Are there beliefs associated with particular organs that may make community members more reluctant to accept the procedures?
- To what extent are people in this area familiar with postmortem?
  - What are local perceptions of postmortem?
  - Is there a local term for postmortem?
  - Why do people think that postmortem is done?
  - Under what circumstances might postmortem be carried out?
  - Have you know of community members who have accepted to have a family member undergo postmortem?
    - If so, please explain the circumstances.
  - Where in the area are autopsies done?
- Are there any local practices that occur after death that are at all similar to what is done during a medical postmortem?

Attitudes, norms and acceptability of post-mortem examinations conducted at hospital

- How would you describe the relationship between community members and trained health providers?
    - What type of health providers (biomedical vs. traditional) do people trust more?
    - Do they trust less?
- Do you think that family members or community leaders would accept to have a full autopsy done?
    - Why might people refuse?
    - Why might people accept?
- What information might community members need to know about the procedure to make a decision?
    - What aspects, if any, might be perceived to be objectionable?
    - What aspects, if any, might be perceived to be beneficial?
- Can you describe the decision making process of family members related to how to treat a body post-mortem?
    - Who in the family is generally involved?
    - Is there somebody in particular who typically takes charge?
    - How might decision making vary according to the age of the deceased and how the person died?
    - What other community members might be consulted when families make their decision?
    - Do you think that families will want to request a religious representative to be part of the process? Why or why not?
    - Do you think that families will want to request a community representative/leader to be part of the process? Why or why not?
- If the deceased person had fever, how might this affect decision making?
- If autopsy is not acceptable, do you think that people in this community might be willing to accept a different, less invasive procedure involving collecting a small piece of an organ (e.g., brain, lung, liver) from someone who died with fever? Probe for why or why not.
- What information might community members need to know about the procedure to make a decision?
    - What aspects, if any, might be perceived to be objectionable?
    - What aspects, if any, might be perceived to be beneficial?

- In what situations might this procedure be acceptable? Probe for when it would or would not be acceptable.
- If a family came to you for advice about making a decision relate to having a postmortem procedure done on a family member, what would you say to them?

Communication

- Who in the community should be informed about these procedures in the hospital setting?
- How should information on these procedures be shared with community members?
- Who in the community should be involved in introducing the procedures and gaining trust with community members?
- What would be the best approach used to gain trust with community members regarding the procedures?
- Would it be helpful to share visual representations of what the deceased looks like after the procedures are completed?
- What are the challenges that might be associated with the procedures once they are introduced to ward residents?
    - What might happen if negative rumors start circulating about the procedures?
    - What would be the best approach to try to stop the negative rumors?

Returning to families

- If we want to go back to families to ask them some questions about why they accepted or refused autopsy, when would be the most appropriate time to go back?
- If we want to go back to families to ask some more detailed questions (may take about an hour) about what occurred prior to the death, when would be the most appropriate time to go back?

Key Informant Guide—Medical Administrators

We are working to understand more about the causes of infectious diseases in the area. During our investigations, we will be asking family members of recently deceased whether they will accept that we carry out an autopsy or take small tissue samples using minimally invasive procedures. These procedures will allow us to determine the cause of the disease that killed the person. In the future this information can be used to assist clinicians in selecting appropriate therapy and to prevent disease occurring in other people.

As part of this investigation, we would also like to collect information on local perceptions of disease and cultural and religious practices related to death and burial. We will also want to learn about how people in this community view examinations or procedures carried out post-mortem, and how decisions are made as to whether to accept or refuse certain medical procedures after a family member has died.

I would like to start the interview by collecting some background information. (Go to structured questionnaire).

Now I would like to start the interview.

Perceptions of disease causality, age at death, and predestination

- What are some of the most common causes of death in your region or district?
    - For children?
    - For adults?
- What are local beliefs and perceptions related to the cause of death?
    - Is the cause of death talked about by family members? If not, what are some of the reasons for not talking about the cause?
    - Do perceptions of the cause vary according to age (children vs. adults) or sex of the deceased?
- To what extent do spiritual causes play a role?
    - How does this vary according to the type of illness or age of the person who died?
- What are local perceptions of illness associated with fever?
    - If the illness associated with fever leads to death, what might people assume is the main cause?
- What are local beliefs related to death occurring because of God's will or destiny?
    - Does this vary according to ethnicity religion?
    - Does this vary according to urban vs. rural dwellers?

Knowledge about post-mortem examinations

- What are local perceptions regarding sampling of blood or organs?
    - Do communities have prior experience with taking blood or organ samples?
    - What are local perceptions regarding why blood or organs are sampled?
    - Are there beliefs associated with particular organs that may make community members more reluctant to accept the procedures?
- To what extent are people in this area familiar with postmortem?
    - What are local perceptions of postmortem?
    - What do people think is done during a postmortem?
    - Why do people think that postmortems are done?
    - Under what circumstances do they think that a postmortem might be carried out?

Attitudes, norms and acceptability of post-mortem examinations conducted at hospital

- In your experience, how would you describe the relationship between community members and trained health providers working in the hospital?
    - What type of trained providers (biomedical vs. traditional) do people trust more?
    - Do they trust less?
- To what extent do you think people in this area would like to learn more about the cause of deceased family members?
    - Why or why not might they want to know about the cause of death?

  - How might the desire to learn about the cause vary according to the age of the deceased?
  - Are there any other factors that may affect their desire to learn about the cause of death?

- To learn more about the cause, do you think that families would accept to have an autopsy to remove small pieces of tissue from specific organs on family members?
  - Why or why not?

- What information might community members need to know about the procedure to make a decision?
  - What aspects, if any, might be perceived to be objectionable?
  - What aspects, if any, might be perceived to be beneficial?

- Can you describe the decision making process of family members related to how to treat a body post-mortem?
  - Who in the family/community might be involved?
  - Is there somebody in particular who would typically take charge?
  - How might decision making vary according to the age of the deceased and how the person died?
  - What other community members might be consulted when families make their decision?

- If the deceased person had fever, how might this affect decision making?
- If autopsy is not acceptable, do you think that people in this community might be willing to accept a different, less invasive procedure involving collecting a small piece of an organ (e.g., brain, lung, liver) from someone who died with fever? Probe for why or why not.
- What information might community members need to know about the procedure to make a decision?
  - What aspects, if any, might be perceived to be objectionable?
  - What aspects, if any, might be perceived to be beneficial?

- In what situations might this procedure be acceptable? Probe for when it would or would not be acceptable.
- If a family came to you for advice about making a decision about autopsy or minimally invasive procedures, what would you say to them?

Obtaining consent

- What are your suggestions regarding how to approach families for carrying postmortem or needle biopsy specimens?

  - What family members should be approached?
  - Who should approach them?
  - How should they be approached?
  - Who should first be approached?
  - When should families be approached?
  - What type of information should be shared?
  - Are there any words or terms that may be particularly sensitive and should be avoided?

- Do you think that families would be more willing to accept if they knew that the cause of death is frequently misdiagnosed?
- Do you think that it would be helpful to have somebody else present (e.g. health providers, religious or other influential leaders) while explaining the procedures and obtaining consent?
- Do you think that it would be helpful to the family to present sketches or illustrations of the corpse after the procedures?
- Do you feel that some sort of assistance should be offered to families who agree to an autopsy or to have their deceased family member undergo a needle biopsy to collect tissue? If so, what type of assistance may be appropriate
  - Probe for transport of the body to the home, payment for preservation of the body, daily morgue fees, or payment for the coffin

Communication

- Who in your district or region should be informed about the autopsy procedures being offered in the hospital setting?
- Who in the district or region should be involved in introducing the procedures and gaining trust with community members?
- How should information on these procedures be shared with community members?
- What would be the best approach used to gain trust with community members regarding the procedures?
- What are the challenges that might be associated with the procedures once they are introduced to ward residents?
  - What might happen if negative rumors start circulating about the procedures?
  - What would be the best approach to try to stop the negative rumors?

Returning to families

- If we want to go back to families to ask them some questions about why they accepted or refused autopsy, when would be the most appropriate time to go back?

- If we want to go back to families to ask some more detailed questions (may take about an hour) about what occurred prior to the death, when would be the most appropriate time to go back?

Key informant Guide—Political leaders

We are working to understand more about the causes of infectious diseases in the area. During our investigations, we will be asking family members of recently deceased whether they will accept that we carry out an autopsy or take small tissue samples using minimally invasive procedures. These procedures will allow us to determine the cause of the disease that killed the person. In the future this information can be used to assist clinicians in selecting appropriate therapy and to prevent disease occurring in other people.

As part of this investigation, we would also like to collect information on local perceptions of disease and cultural and religious practices related to death and burial. We will also want to learn about how people in this community view examinations or procedures carried out post-mortem, and how decisions are made as to whether to accept or refuse certain medical procedures after a family member has died.

I would like to start the interview by collecting some background information. (Go to structured guide).

I would like to start by asking you some questions about acceptance of these procedures by community members living in your ward.

Attitudes, norms and acceptability of post-mortem examinations conducted at hospital

- How would you describe the relationship between community members and trained health providers?
    - What type of health providers (biomedical vs. traditional) do people trust more?
    - Do they trust less?
- To what extent do you think people in this area would like to learn more about the cause of death in family members?
    - Why or why not might they want to know about the cause of death?
    - Probe for learning how the family member died, learning more about what is killing people in the community, using the information to prevent and control illness in the future, etc.
- Do you think that they would be more interested to get information on the cause of death if they knew the cause is often misdiagnosed?

Full autopsy

I'd like to ask you some questions about the autopsy procedure

- How do you think that people in your ward would regard the autopsy procedure?
    - What aspects, if any, might be perceived to be objectionable?
    - What aspects, if any, might be perceived to be beneficial?

- What in your view would be the best way to introduce the procedures to family members?
- Who would need to be involved in introducing the procedures?
- What information would community members need to know about the procedure to make a decision?
- In your view, in what situations might this procedure be acceptable to people in your ward?
    - Probe for when it would or would not be acceptable
    - Probe for whether the age of the deceased may affect decision making
    - Probe for whether the perceive cause of the disease may affect decision making
- If a family came to you for advice about making a decision like this, what would you say to them?
- Do you think that families would accept to have an autopsy done on a family member who died of fever?
    - Why or why not?

Minimally invasive autopsy

I'd now like to talk about a different, less invasive procedure involving collecting a small piece of an organ (e.g., brain, lung, liver) from a family member who died with fever. After the procedure, a small mark is left on the body.

- If autopsy is not acceptable, do you think that people in this ward might be willing to accept a different, less invasive procedure involving collecting a small piece of an organ (e.g., brain, lung, liver) from a family member who died with fever? Probe for why or why not.
- How do you think that people in your ward would regard the less invasive autopsy procedure?
    - What aspects, if any, might be perceived to be objectionable?
    - What aspects, if any, might be perceived to be beneficial?
- What in your view would be the best way to introduce the procedure to family members?
- Who might need to be involved in introducing the procedures?
- What information might community members need to know about the procedure to make a decision?
- In what situations might this procedure be acceptable?
    - Probe for when it would or would not be acceptable.
    - Probe for whether the age of the deceased may affect decision making
    - Probe for whether the perceive cause of the disease may affect decision making

- If a family came to you for advice about making a decision like this, what would you say to them?
- Do you think that families would accept to have an autopsy done on a family member who died of fever? Why or why not?

What might be the concerns about offering these procedures in your ward?

What might be the perceived benefits in offering these procedures in your ward?

Communication

- Who in the ward should be informed about the introduction of these procedures in the hospital setting?
- How should information on these procedures be shared with community members?
- Who in the ward should be involved in introducing the procedures and gaining trust with community members?
- What would be the best approach used to gain trust with community members regarding the procedures?
- What are the challenges that might be associated with the procedures once they are introduced to ward residents?
    - What might happen if negative rumors start circulating about the procedures?
    - What would be the best approach to try to stop the negative rumors?

Key informant Guide—Religious leaders

We are working to understand more about the causes of infectious diseases in the area. During our investigations, we will be asking family members of recently deceased whether they will accept that we carry out an autopsy or take small tissue samples using minimally invasive procedures. These procedures will allow us to determine the cause of the disease that killed the person. In the future this information can be used to assist clinicians in selecting appropriate therapy and to prevent disease occurring in other people.

As part of this investigation, we would also like to collect information on local perceptions of disease and cultural and religious practices related to death and burial. We will also want to learn about how people in this community view examinations or procedures carried out post-mortem, and how decisions are made as to whether to accept or refuse certain medical procedures after a family member has died.

We would like to focus on your congregation, but if you would like to share any differences with other religions, we would like to learn about those differences.

I would like to start the interview by collecting some background information. (Go to structured questionnaire)

I would like to start by asking you some questions about the burial ceremony and practices followed by people of your religious faith.

Burial practices and rituals

- Can you please describe the burial ceremony once the body has left the hospital. Please describe it from start to finish, giving as many details as possible. Probe for
    - Who is in charge of decisions related to preparing the body and the burial? (Probe for involvement of religious representatives, as well as family members)
    - How are bodies prepared for burial? Does this vary in any way according to ethnic differences or backgrounds?
- Please describe what occurs during the actual burial in the community.
- How do practices vary according to ethnicity, age or the person who died (children vs. adults)?
- How do practices vary in more urban compared to community settings?
    - What is the timing of the burial and how does this vary according to
        - Cultural backgrounds?
        - Urban or community settings
    - What condition/state does the body need to be in for burial?
- What are attitudes regarding the physical status of the corpse (making the body presentable, pure) prior to burial?
- What are attitudes towards changing/altering the body postmortem?
- What are perceptions of spirits/spiritual retribution if the body is changed in any way?
- What are local concepts related to death and the supernatural?

Perceptions of disease causality, age at death, and predestination

- What are local beliefs and perceptions related to the cause of death?
    - Is the cause of death talked about by family members? If not, what are some of the reasons for not talking about the cause?
    - Do perceptions of the cause vary according to age (children vs. adults) or sex of the deceased?
- To what extent do spiritual causes play a role?
    - How does this vary according to the type of illness or age of the person who died?
- What are local perceptions of illness associated with fever?
    - If the illness associated with fever leads to death, what might people assume is the main cause?
- What are local beliefs related to things happening including death that are associated with God's will or destiny

  - Does this vary according to ethnicity and religion?
  - Does this vary according to urban vs. rural dwellers?
- To what extent do you think people in this area would like to learn more about the cause of deceased family members?
  - Why or why not might they want to know about the cause of death?
    - For their personal family interest?
    - For the broader community or society?
  - How might the desire to learn about the cause vary according to the age of the deceased?
  - Are there any other factors that may affect their desire to learn about the cause of death?

Knowledge about post-mortem examinations

- What are local perceptions regarding sampling of blood or organs?
  - Do communities have prior experience with taking blood or organ samples?
  - What are local perceptions regarding why blood or organs are sampled?
  - Are there beliefs associated with particular organs that may make community members more reluctant to accept the procedures?
- Has somebody in your congregation experienced autopsy?
  - Why was the autopsy carried out?
  - What did you think about it?
- To what extent are people in this area familiar with postmortem?
  - What are local perceptions of postmortem?
  - Is there a local term for autopsy?
  - Is there a local term for postmortem?
  - What do people think is done during a postmortem?
  - Why do people think that postmortem is done?
  - Under what circumstances might postmortem be carried out?
  - What type of information is needed to encourage a person to accept postmortem?
- Are there any local practices that occur after death that are at all similar to what is done during a medical postmortem?

Attitudes, norms and acceptability of post-mortem examinations conducted at hospital

- What are your congregation members' experiences with the trained health providers working in the hospital?
    - What type of trained providers do they trust more? Do they trust less?
- Do you think that family members or community leaders would accept to have an autopsy done on family or community members?
    - Why might people refuse?
    - Why might people accept?
- What information might community members need to know about the procedure to make a decision?
    - What aspects of the procedure, if any, might be perceived to be objectionable?
    - What aspects of the procedure, if any, might be perceived to be beneficial?
- Can you describe the decision making process family members follow related to how to treat a body post-mortem?
    - Who in the family is generally involved?
    - Is there somebody in particular who typically takes charge?
    - How might decision making vary according to the age of the deceased and how the person died?
    - What other community members might be consulted when families make their decision?
    - Do you think that families will want to request a religious representative to be part of the process? Why or why not?
- If the deceased person had fever, how might this affect decision making?
- If autopsy is not acceptable, do you think that people in this community might be willing to accept a different, less invasive procedure involving collecting a small piece of an organ (e.g., brain, lung, liver) from someone who died with fever? Probe for why or why not.
- What information might community members need to know about the procedure to make a decision?
    - What aspects of the procedure, if any, might be perceived to be objectionable?
    - What aspects of the procedure, if any, might be perceived to be beneficial?
- In what situations might this procedure be acceptable? Probe for when it would or would not be acceptable.

- If a family came to you for advice about making a decision like this (for either type of procedure), what would you say to them?
- How should information on these procedures be shared with community members?
- Who in this community should be involved in introducing the procedures and gaining trust with community members?

Obtaining consent

- What are your suggestions regarding how to approach families for carrying out post-mortem or needle biopsy specimens?
    - What family members should be approached?
    - Who should approach them?
    - How should they be approached?
    - Who should first be approached?
    - When should families be approached?
    - What type of information should be shared?
    - Are there any words or terms that may be particularly sensitive and should be avoided (get copy of consent and share with respondent)
- Do you think that more people would accept autopsy if we told them that the cause of death is frequently misdiagnosed? If we share this information, might there be negative ramifications related to perceptions of the capabilities of the medical staff in the hospital?
- Do you think that it would be helpful to have somebody else present (e.g. health providers, religious or other influential leaders) while explaining the procedures and obtaining consent?
- Do you think that it would be helpful to the family to present sketches or illustrations of the corpse after the procedures?
- Do you feel that some sort of assistance should be offered to families who agree to an autopsy or to have their deceased family member undergo a needle biopsy to collect tissue? If so, what type of assistance may be appropriate
    - Probe for transport to the home, payment for preservation of the body, daily fees for the morgue, or payment for the coffin
- If we want to go back to families to ask them some questions about why they accepted or refused autopsy, when would be the most appropriate time to go back?
- If we want to go back to families to ask some more detailed questions (may take about an hour) about what occurred prior to the death, when would be the most appropriate time to go back?

Appendix D: Focus Group Discussion Guide (PURPOSe)

Appendix A: Semi-Structures Interview Guide for Key-informant interviews

کلیدی معلوماتی انٹرویو کے لئے نیم منظم انٹرویو ائیڈ

Note: Key-informants will include medical director-NICH, healthcare providers (doctors, nurses, midwives), religious leader, secretory health, Public health expert, obstetrician, neonatologist, member of Bioethics committee and professionals involved in proceedings related to death and dying to explore their understanding and perceptions regarding autopsies and MITs on neonates.

نوٹ: ان انٹرویوز میں وہ افراد حصہ لیں گے جن کا تعلق (این آئی سی ایچ) سے ہے جن میں ڈاکٹرز، نرس اور مڈوائف شامل ہیں۔ مذہبی رہنما، صحت کے ماہرین ، نیو نٹولوجسٹ، بائیو اتھکس کمیٹی کے ممبران اور وہ ماہرین شامل ہیں جو موت اور آٹوپسی طریقہ کار کا بچوں پر عمل درآمد ہونے کی وجہ جاننے کی کوشش کررہے ہیں۔

Eligibility Criteria: اہلیت کا معیار

1. Healthcare professionals from a range of clinical backgrounds who are in regular contact with death and who get involved in discussions with parents and families about autopsy procedure (Medical director- NICH, obstetrician, neonatologist)

ایسے ماہرین جو والدین اور رشتہ داروں سے براہِ راست رابطے میں رہتے ہیں اور (ایم آئی ٹی ایس) طریقہ کار کے بارے میں بات کرتے رہتے ہیں۔

2. Someone who has the privilege to know the local community, and/or can influence the decisions of community (religious leader, community leader)

کوئی ایسا شخص جو برادری کے فیصلے پر اثر انداز ہوسکتا ہے اور ان کو اچھی طرح سمجھتا ہو،

3.*Other powerful entities such as policy makers and governmental authorizes (Secretary Health)*

بعض ایسے ادارے جو حکومت سے تعلق رکھتے ہوں ۔ جیسے پالیسی بنانے والے یا حکومتی حکام۔

4. Health care providers who are in regular contact with death situation, especially at the time of death (doctors, nurses, midwives)

صحت کے وہ ماہرین جیسے (ڈاکٹرز، نرس یا مڈوائف)

5. Experts from the field of public health and bioethics

عوامی صحت کے ماہرین اور بائیو اتھکس شعبے کے ماہرین

6. Professionals involved in proceedings related to death and dying (Body washers)

موت اور مرنے سے تعلق رکھنے والی کاروائی یعنی (غسل وکفن) دینے والے افراد۔

Explanation of full autopsy and MITS procedure:

Full autopsy - Most comprehensive and complete method to estimate cause of death - Rarely undertaken in such resource-poor environments due to cultural, financial, religious, and physical barriers - Very extensive examination of internal organs begins with the creation of a Y or U- shaped incision from both shoulders joining over the sternum and continuing down to the pubic bone
MITS procedure - Involves imaging - Examination of internal organs and tissue sampling is carried out using laparoscopic or 'keyhole surgery' approach. - Requires a small incision (around 10-20mm) to the central diaphragm. - Following the procedure the cut is closed with sutures - There are minimal cosmetic consequences compared to a full autopsy.

ICE Breaker: What is the respondent role _____ جواب دہند گان کا کیا کردار ہے۔

1. Pregnancy and Birth (perceptions) حمل اور پیدائش کا احساس

1.1 In your opinion what helps a woman to be healthy during her pregnancy?
آپ کی رائے میں عورتوں کو ان کے حمل کے دوران صحت مند رہنے کے لئے کون سے عوامل یا چیزیں ہیں جو مدد کرتی ہیں۔

Probes:
- Nutritional Practices غذائی دیکھ بھال (کھانے میں صحت مند اشیاء کا استعمال)
- Antenatal visits ڈاکٹرز کے باقاعدہ دورہ کرنا

1.2 In your opinion what are the causes (pregnancy-related) which result in premature birth or a stillbirth?
آپ کی رائے میں کونسی ایسی وجوہات ہوسکتی ہیں جس کے نتیجےمیں بچوں کی وقت سے پہلے پیدائش ہوجاتی ہے یا مردہ بچوں کی پیدائش ہوتی ہے۔

Probes:
- Common beliefs and practices around early pregnancy loss, stillbirth, or neonatal death?
لوگوں کے عام خیالات کیا ہیں جیسے ابتدائی درد یا نوزائیدہ اموات۔

1.3 What are the barriers to seeking care?
ڈاکٹرز تک رسائی یا حمل کی دیکھ بھال میں کیا رکاوٹیں ہوسکتی ہیں۔

Probes:
- Financial limitations مالی حالات بہتر نہ ہونا
- Poor access to health facilities صحت کے مراکز تک مشکل رسائی

2. Neonate Death/Stillbirth and related practices **نوزائیدہ اموات یا ان سے متعلق عمل**

2.1 Please describe what happens when a premature or mature baby (stillbirth/ neonatal death) dies:
وضاحت کریں جب ایک بالغ بچہ یا وقت سے پہلے پیدا ہوا بچہ مرجاتا ہے ۔

Probes:
- Chronology of events واقعات کی تحریر
- Parents/families interacting with the body والدین/ خاندان کا بچے سے تعلق
- Burial and mourning Process دفنانے کا طریقہ
- Cultural practices and rituals – different ethnic and religious groups. Why are those things (cultural practices) done? What happens if they're not done?
ثقافتی طریقوں کو دوسرے مذہبی اور نسلی فرقوں کو مختلف فرقوں کے ساتھ کیوں کیا جاتاہے ۔ اگر ہم یہ کام نہ کریں تو کیا ہوگا
- Cultural and religious beliefs around death
موت کے اردگرد مذہبی اور ثقافتی عقائد

3. Cause of Child Death **بچے کی موت کا سبب**

3.1 Do you think it is important to inquire in to the cause of child death?
کیا آپ سمجھتے ہیں کہ بچے کی موت کی وجہ جاننی چاہئے۔

Probes:
- If yes why? If no why? اگر ہاں تو کیوں، اگر نہیں تو کیوں نہیں۔
- How the cause of death can be determined? Do you know about any such procedure?
موت ہونے کی وجہ کو کس طرح معلوم کیا جاسکتا ہے۔

3.2 To find out the cause of child death (still birth/ neonatal death), various lab tests and samples (fluids) from the body (tissues) are taken within 24 hours after a child dies. Do you thing such procedures are important?
بچے کی موت کے 24 گھنٹوں کے اندر بچے کے جسم سے کچھ نمونے لئے لیب ٹیسٹ کے لئے جاتے ہیں۔ کیا آپ سمجھتے ہے کہ یہ ضروری ہے۔

Probes:

- Do you think finding out this information would be valuable? کیا آپ کو لگتا ہے کہ یہ معلومات قیمتی ہوگی
- If it's valuable, why? If not, why not? اگر یہ اہم ہیں تو کس لیے اور اگر اہم نہیں تو کیوں نہیں
- How much or what information would be valued? ان معلومات کی کتنی اور کیا اہمیت ہے

3.3 In your opinion, would it be acceptable to perform MITS procedure on a recently deceased child?
کیا آپ سمجتے ہیں کہ حال ہی میں مرنے والے بچے پر (ایم آئی ٹی ایس) طریقے کار کا استعمال قابل قبول ہے ۔

Probes:

- If yes why? If no why? اگر ہاں تو کیوں، اگر نہیں تو کیوں نہیں

4. Perceived advantages, facilitators and barriers related for the implementation of minimal invasive tissue sampling procedure

(ایم آئی ٹی ایس) طریقہ کار کی سہولت، رکاوٹیں اور عمل درآمد سے متعلق آپ کیا سمجھتے ہیں۔

4.1 What are the perceived (foreseen) advantages for the implementation of MITS procedure?
(ایم آئی ٹی ایس) طریقہ کار کو عمل درآمد کرنے کے لئے فائدہ مند طریقہ کیا ہوتا ہے۔

Probes:

- To understand the cause of death in stillbirth/deceased neonate نوزائیدہ اموات کی وجہ معلوم کرنا
- To prevent further deaths مزید اموات سےبچاؤ
- Greater diagnostic accuracy تشخیص کی درستگی
- Involves tissue analysis (to identify if it's an infection) ٹشو کے نمونے کا تجربہ
- Comparatively shorter procedure (accelerate turnaround times) مختصر طریقہ کار
- Procedure more palatable (pleasant) مزیدصاف طریقہ کار

4.2 What are the concerns for the use of MITS procedure in a deceased neonate/stillbirth?
مردہ بچوں میں (ایم آئی ٹی ایس) طریقہ کار کے کیا تعلقات ہیں۔

Probes:

- Concerns related to body/soul جسم اور روح کا تعلق
- Concerns with timing of ceremonies and burial دفنانے کی تقریبات
- Religious beliefs مذہبی عقائد
- Traditional beliefs روایتی عقائد
- Fear of breach of confidentiality (in relation to the disease carrying stigma e.g. HIV) رازداری کی خلاف ورزی کا خوف
- Perceived inappropriateness (in cases when clinical diagnosis is clear) ڈاکٹری تشخیص کو نا مناسب سمجھنا

- Not reaching same level of certainty ایک طرح کے فیصلے پر مکمل طور پر نہیں پہنچتے
- Complex decision making process مشکل فیصلہ کرنے کا عمل
- MITS procedure costs for the family طریقہ کار کی (ایم آئی ٹی ایس) خاندان کے لئے قیمت
- State of mind around the death موت کے قریب ذہنی کیفیت

4.3 What are the perceived facilitators for the implementation of MITS procedure?
(ایم آئی ٹی ایس) طریقہ کار کے عمل کے لئے سہولت فراہم کرنے کے لئے کیا خیال کرنا چاہئے۔

Probes:

- Carrying out the procedure ASAP to facilitate timely body release, burial and related ceremonies
جلد از جلد جسم کو دفنانے اور اس سے متعلقہ عمل کو مکمل کرنا
- Body preservation جسم کی حفاظت
- Community involvement (support from leaders, health professionals)کمیونٹی کا شامل ہونا
- Information and transparency (clear information about the procedure) و طریقہ کار کے بارے میں ضاحت
- Cost reduction (waiving the cost of MITS procedure) قیمت میں کمی

5. Suggestions to improve awareness about MITS procedure (ایم آئی ٹی ایس) طریقہ کار کے بارے میں بہترمعلومات کیسے فراہم کریں

5.1 What do you think would be the best method of educating the community about MITS?
آپ کو کیا لگتا ہے (ایم آئی ٹی ایس) کے بارے میں کمیونٹی کو تعلیم دینے کا بہترین طریقہ کیا ہوسکتا ہے۔

Probes:

- Community discussions کمیونٹی سے بات چیت
- Counseling of parents/families والدین کو سمجھانا یا ان کی ر ہنمائی کرنا
-

6. Requirements for the health system for MITS procedure (Questions only for health system and public health experts) (ایم آئی ٹی ایس) طریقہ کار کے لئے صحت کے نظام کی کیا ضروریا ت ہیں۔

6.1 What are some of the requirements for the health system (i.e. medical facilities) to conduct MITS procedures? صحت کے نظام میں (ایم آئی ٹی ایس) طریقہ کار کی کیا ضروریات ہیں

Probes:

- Level of current knowledge (about MITS) among health care workers.
صحت کی دیکھ بھال کرنے والوں کے درمیان علمی قابلیت
- Acceptability of MITS among health care workers. (ایم آئی ٹی ایس) صحت کے دیکھ بھال کرنے والوں کے درمیان طریقہ کار کو قبول کرنا
- Availability of experts to conduct MITS/personnel (ایم آئی ٹی ایس) کو چلانے کے لئے ماہرین کی موجودگی
- Equipment سامان
- Healthcare facilities – good reputation of the facilities performing MITS
صحت کےمراکز کی اچھی کار کردگی

- Health professionals attitude and preparedness صحت کے ماہرین سے متعلق پیشہ ورانہ رویہ اور تیاری
- Integration of MITS within the existing health system (ایم آئی ٹی ایس) موجودہ صحت کے نظام کے اندر کا تعلق

6.2 Having named those requirements, which of them are in place in your health system?
آپ کی صحت کے نظام میں کیا چیزیں ضروری ہیں۔

Probes:

- What would need to be put in place in regard to facilities? Equipment? Personnel?
سہولت فراہم کرنے کے لئے کیا ضروری ہے۔
- Is the health system prepared? کیا اس چیز کے لئےصحت کا نطام تیار ہے

- Unprepared health system (lack of equipment, financial limitations) غیر صحت مند نظام

6.3 What role could your health system play in carrying out MITS?
صحت کا نظام (ایم آئی ٹی ایس) طریقہ کار کو استعمال کرنے میں کیامدد کرسکتا ہے

Probes:

- Could MITS be carried out in your health facilities?
کیا (ایم آئی ٹی ایس) طریقہ کار کا استعمال صحت کے مراکز میں استعمال کرسکتے ہیں
- Could your healthcare workers go out into the community to carry out MITS?
کیا صحت کے کارکن اس طریقہ کو کمیونٹی میں استعمال کرسکتے ہیں

6.4 What are the perceived implementation issues relating to the MITS procedure?
(ایم آئی ٹی ایس) طریقہ کار کو استعمال کرنے میں کیا مسائل ہوسکتے ہیں

Probes:

- Lack of skills and training مہارت اور تربیت میں کمی
- Logistics لاجسٹکس
- Cost implications قیمت کا اثرا
- Equity concerns – access مساوات تک رسائی
- Acceptance and governance گورنمنٹ کی قبولیت
- Reluctance from healthcare professionals (increased workload) صحت کے ماہرین کے پیشہ ور افراد سے نا پسندی

7. Role of Government (questions only for government authorities) حکومت کا کردار – (سوالات صرف سرکاری حکام کے لئے)

7.1 What is the role of the government, if any, when a child dies?
کسی بچے کی موت پر حکومت کا کیا کردار ہوسکتا ہے۔

Probes:

- What are the reporting requirements? اطلاعات کی ضروریات کیا ہیں
- Are there any investigations conducted (i.e. if there is suspicion of intentional injury causing the death)? کیا کوئی تحقیق کی جاتی ہے

7.2 What government stakeholders think about MITS procedure?
حکومتی اسٹیک ہولڈرز (ایم آئی ٹی ایس) طریقہ کار کے بارے میں کیا رائے رکھتے ہیں

Probes:

- Is it acceptable and feasible? کیا یہ قابل قبول اور ممکن ہے
- Can be supported by government? حکومت کی طرف سے حمایت

Appendix B: Semi-Structures Interview Guide for FGDs (Parents and relatives at OPDs and well-baby clinics of NICH hospital) نیم ساختہ انٹرویوز کے لئے ر ہنمائی (والدین اور رشتہ داروں کے لئے)

Eligibility Criteria: اہلیت کا معیار

- *Parents and relatives of newborns who are visiting outpatient department (OPD) and well-baby clinics of National Institute of Child Health (NICH) hospital for regular post-natal check-ups.*
  والدین اور نوزائیدہ بچوں کے رشتہ دار جو باقاعدگی سے (او پی ڈی) اور (این آئی سی ایچ) میں علاج کے لئے آتے ہیں ۔
- *Considering the cultural and ethical sensitivity, this qualitative research will not interview parents and relatives of admitted newborns who are waiting at the in-patient areas.*

ثقافتی اور اخلاقی حساسیت کو مدِ نظر رکھتے ہوئے یہ تحقیق ان والدین اور رشتہ داروں سے نہیں کی جائے گی جن کے بچے ہسپتال میں داخل ہونے کے منتظر ہوں۔

Explanation of full autopsy and MITS procedure: مکمل آٹو پسی اور (ایم آئی ٹی ایس) طریقہ کار کی وضاحت

Full autopsy مکمل آٹو پسی - Most comprehensive and complete method to estimate cause of death موت کی وجہ کا اندازہ کرنے کے لئے مکمل اور جامع طریقہ - Rarely undertaken in such resource-poor environments due to cultural, financial, religious, and physical barriers ثقافتی ، مالی ، مذہبی اور جسمانی رکاوٹوں کی وجہ سے اس طرح کے وسائل میں نا قابل یقین حد تک غریب ماحول میں آغاز کیا گیا - Very extensive examination of internal organs begins with the creation of a Y or U- shaped incision from both shoulders joining over the sternum and continuing down to the pubic bone اندرونی اعضاء کا وسیع جائزہ جو (وائے) اور (یو) کے ذریعے دونوں کندھوں سے مل کر عوامی ہڈی کو جاری رکھے
MITS procedure (ایم آئی ٹی ایس) کا طریقہ کار : - Involves imaging امیجنگ شامل ہے - Examination of internal organs and tissue sampling is carried out using laparoscopic or 'keyhole surgery' approach. اندرونی اعضاء اور ٹشو کے نمونے کا امتحان لیپو سکوپی یا کی ہول سرجری کے نقطہ نظر کا استعمال کرتے ہوئے کیا جاتا ہے - Requires a small incision (around 10-20mm) to the central diaphragm. مرکزی ڈایا فرام سے 10-20 ملی میٹر کے ارد گرد ایک چھوٹا سا انضمام کی ضرورت ہوتی ہے - Following the procedure the cut is closed with sutures عمل کے بعد زخم کو سوت سے بند کیا جاتا ہے - There are minimal cosmetic consequences compared to a full autopsy. سوت کے مقابلے میں کم سے کم کاسمیٹک نتائج موجود ہے

ICE Breaker: What is the respondent role in the process (around death)? _____
موت کے اردگرد عمل میں جواب دہندگان کا کیا کردار ہے

1. Health status of Pregnant women حاملہ خواتین کی صحت کا معیار

1.1 In your opinion what helps a woman to be healthy during her pregnancy?
آپ کی رائے میں عورتوں کو ان کے حمل کے دوران صحت مند رہنے کے لئے کیا چیزیں یا عوامل مدد گار ثابت ہوتے ہیں۔

Probes:

- Nutritional Practices(غذائی دیکھ بھال (کھانے میں صحت مند اشیاء کا استعمال
- Antenatal visitsڈاکٹرز کے باقاعدہ دورہ کرنا

1.2 In your opinion what are the causes (pregnancy-related) which result in premature birth or a stillbirth?
آپ کی رائے میں کونسی ایسی وجوہات ہوسکتی ہیں جس کے نتیجے میں وقت سے پہلے بچوں کی پیدائش ہوجاتی ہے یا مردہ بچوں کی پیدائش ہوتی ہے۔

Probes:

- Common beliefs and practices around early pregnancy loss, stillbirth, or neonatal death?
عام خیالات کیا ہوسکتے ہیں ۔ نوزائیدہ اموات، حمل کا ضائع ہوجانا

2. Neonate Death/Stillbirth and related practices **نوزائیدہ بچوں کی اموات**

2.1 Please describe what happens when a premature or mature baby (stillbirth/ neonatal death) dies:
وضاحت کریں جب ایک وقت سے پہلے پیدا ہوا بچہ یا کوئی بالغ بچہ مرجاتا ہے تو کیا ہوتا ہے ۔

Probes:

- Chronology of events واقعات کی تحریر
- Parents/families interacting with the body والدین/ خاندان بچے کے ساتھ بات چیت
- Burial and mourning Process دفنانے کا عمل
- Cultural practices and rituals – different ethnic and religious groups. Why are those things (cultural practices) done? What happens if they're not done?
ثقافتی طریقوں کو دوسرے مذہبی اور نسلی فرقوں کو مختلف فرقوں کے ساتھ کیوں نہیں کیا جاتا ۔ کیا ہوگا اگر یہ نا ہوں تو ؟
- Cultural and religious beliefs around death موت کے ارد گرد ثقافتی اور مذہبی عقائد
- How does the family tell the community that the child has died? When do they tell?
ایک خاندان اپنے رشتہ داروں یا کمیونٹی کو کس طرح بتاتا ہے کہ بچہ مرگیا ہے۔
- Is anything done long after the child has died (e.g., at the anniversary of the child's death)
جب بچہ مرجاتا ہے تو اس کے لئے کوئی برسی وغیرہ رکھتے ہیں

3. Cause of Child Death بچے کی موت کا سبب

3.1 Do you think it is important to inquire the cause of child's death?
کیا آپ سمجھتے ہیں بچے کی موت کا سبب جاننا چاہئے؟

Probes:

- If yes why? If no why? اگر ہاں تو کیوں، اگر نہیں تو کیوں نہیں
- How the cause of death can be determined? Do you know about any such procedure?
موت کا سبب کیسے پتہ کیا جاسکتا ہے ۔ آپ ایسے کسی بھی طریقے کو جانتے ہیں ؟

3.2 To find out the cause of child's death (still birth/ neonatal detah), various lab tests and samples (fluids) from the body (tissues) are taken within 24 hours after a child dies. Do you thing such procedures are important? بچے کی موت کے 24 گھنٹوں کے اندر بچے کے جسم سے کچھ نمونے لئے جاتے ہیں لیب ٹیسٹ کے لئے کیا آپ سمجھے ہیں یہ ضروری ہے

Probes:

- Do you think finding out this information would be valuable? کیا آپ سوچتے ہیں کہ یہ معلومات قیمتی ہوگی
- If it's valuable, why? If not, why not? اگر یہ قابل قدر ہیں تو کیوں ہے ۔ اگر نہیں تو کیوں نہیں
- How much or what information would be valued? ان معلومات کی کتنی اور کیا قدر ہے
- Would you accept the cause which is given by the doctor or nurse as such and feel satisfied? Or would you like to know more to satisfy you

کیا آپ ڈاکٹر یا نرس کی طرف سے دی گئی وجہ قبول کریں گے اور مطمئن ہیں یا اپنے آپ کو مطمئن کرنے کے لئے اور جاننا چاہیں گے

3.3 Would it be acceptable to perform MITS procedure to the recently deceased child?
حال ہی میں مقتول بچے پر (ایم آئی ٹی ایس) طریقہ کار کا استعمال قابلِ قبول ہے ۔

Probes:

- If yes why? If no why? اگر ہاں تو کیوں، اگر نہیں تو کیوں نہیں
- How would the parents/ immediate family feel about this being done?
- اگر (ایم آئی ٹی ایس) طریقہ کار کا ستعمال مقتول بچے پر کیا جائے تو قریبی رشتہ دار اور ماں باپ کیسا محسوس کریں گے ۔
- How would your community feel about this being done? آپ کی کمیونٹی اس کے بارے میں کیا سوچے گی
- How would MITS be named in your community? آپ کی کمیونٹی میں اس طریقہ کار کو کیا نام دیا جائے گا
- What kinds of rumors might start in the community? Do you have any suggestions about ways we could work in your community to address those rumors if they started?
آپ کی کمیونٹی میں کن افواہوں کا خدشہ ہے۔ کیا آپ ہمیں کوئی رائے دے سکتے ہیں جس سے ہم ان افواہوں کو روک سیکیں

4. Perceived advantages, facilitators and barriers related to the implementation of minimal invasive tissue sampling procedure (ایم آئی ٹی ایس) طریقہ کار کی سہولت، رکاوٹیں اور عمل درآمد میں آپ کیا سمجھتے ہیں

4.1 What are the perceived (foreseen) advantages for the implementation of MITS procedure?
(ایم آئی ٹی ایس) کے طریقہ کار کے عمل کے لئے مفید فوائد کیا ہیں

Probes:

- To understand the cause of death in stillbirth/deceased neonate نوزائیدہ بچے کی موت کے سبب کو جاننا
- To prevent further deaths مزید اموات کی روک تھام

4.2 What are the concerns for the use of MITS procedure in a deceased neonate/stillbirth?
مردہ بچوں میں (ایم آئی ٹی ایس) طریقہ کار کے استعمال کے کیا خدشات ہیں

Probes:

- Concerns related to body/soul جسم اور روح سے متعلق خدشات
- Concerns with timing of ceremonies and burial تقریبات اور دفن کے وقت کے ساتھ خدشات
- Religious beliefs مذہبی عقائد
- Traditional beliefs روایتی عقائد
- Fear of breach of confidentiality (in relation to the disease carrying stigma e.g. HIV)
رازداری کی خلاف ورزی کا خوف
- Perceived inappropriateness (in cases when clinical diagnosis is clear)
نامناسب سمجھنا (مقدمات میں کلینکل تشخیص واضح ہے)

- Complex decision making process پیچیدہ فیصلہ سازی کا عمل
- MITS procedure costs for the family خاندان کے لئے (ایم آئی ٹی ایس) طریقہ کار کی لاگت
- State of mind around the death موت کے اردگرد دماغ کی حالت
- Mistrust on the heath facility/health professionals/new procedures (MITS) صحت کی سہولت، ڈاکٹرز یا (ایم آئی ٹی ایس) طریقہ کار سے نا مطمئن

4.3 What are the perceived facilitators for the implementation of MITS procedure?
(ایم آئی ٹی ایس) طریقہ کار کے عمل کے لئے سہولت سازوں کے لئے کیا خیال کرنا چاہئے؟

Probes:

- Carrying out the procedure ASAP to facilitate timely body release, burial and related ceremonies جلد از جلد جسم کو دفنانے اور اس سے متعلقہ عمل کے لئے طریقہ استعمال کرنا چاہئے
- Body preservation جسم کی حفاظت
- Community involvement (support from leaders, health professionals) کمیونٹی کی شمولیت (ڈاکٹرز اور رہنماؤں سے)
- Information and transparency (clear information about the procedure) طریقہ کار کے بارے میں واضح معلومات
- Cost reduction (waiving the cost of MITS procedure) قیمت میں کمی
- What are the best ways for us to work with the community? What are the best ways to share what we find? کمیونٹی کے ساتھ کام کرنے کے لئے ہمارا بہترین طریقہ کیا ہے جو کچھ ہم تلاش کرتے ہیں اسکو بانٹنے کا بہترین طریقہ کیا ہے

5. Relatives of families who have experienced a recent neonatal death

والدین /خاندان جن کے یہاں ایسی کوئی نوزائیدہ موت ہوئی ہو۔ کیا آپ کسی ایسے خاندان کو جانتے ہیں جن کے یہاں ایسا کچھ ہوا ہو۔

Note: Questions are only for those who have experienced a prior loss/ families who know someone affected by the recent neonatal death

یہ سوالات صرف ان کے لئے ہیں جنہوں نے ایسا نقصان برداشت کیا ہویا وہ کسی خاندان کو جانتے ہوں

5.1 Did anyone approach you for permission to carry out the autopsy/MITS procedure of your deceased child?
کیا کبھی آپ سے کسی نے آٹوپسی طریقہ کار کو استعمال کرنے کی اجازت طلب کی۔

Probes:

- Who approached you? آپ سے کس نے رابطہ کیا
- When, where and how did they approach you? کب، کہاں اور کیسے
- How did you react? آپ نے کیسا برتاؤ کیا

5.2 If autopsy was carried out, was it full autopsy or MITS? اگر اس طریقہ کو استعمال کیا تو کیا وہ مکمل آٹوپسی کا عمل تھا یا ٹشو کے نمونے لئے گئے

5.3 Can you describe how you came to decide whether to have the autopsy/MITS
کیا آپ بتاسکتے ہیں کہ "آپ نے اس طریقہ کے استعمال کا فیصلہ کیسے کیا۔

Probes:

- Was there somebody to influence you? How did they influence you?
کیا وہاں آپکو کسی شخص نے زور دیا/ کس نے

- At the time of decision making, who was with you from the family? Alone/with partner/Family Member/Friend/Medical Staff/Religious beliefs/Other – directly or indirectly
  جب آپ فیصلہ کر رہے تھے/ دوست/ کوئی طبی اسٹاف/ یا آپکے مذہبی عقائد دیگر
- How difficult it was it to make a decision آپ کے لئے فیصلہ کرنا کتنا مشکل تھا

5.4 Looking back, what kind of things do you think the medical team could have done at that time?
پچھلی باتوں اور عمل کو سوچتے ہوئے آپ کو کیا لگتا ہے طبی عملے کو کیا کرنا چاہئے تھا

Probes:

- Expert should provide more understanding – clarity on the procedure
  کیا ماہرین کو اس طریقہ کار پر مزید وضاحت اور سمجھنے کی ضرورت ہے
- Respect – care and ethics اخلاقیات اور احترام کی دیکھ بھال کی ضرورت ہے۔

Appendix E: In-depth Interview Guide (INDITe)

Focused Group Discussion Guide- Community Members

Now I would like us to start our discussion by looking at **perceptions of disease causality**

Beliefs and perceptions about the cause of death

- What are the local beliefs and perceptions related to the cause of death?
- Is the cause of death talked about by family members? If not, what are some of the reasons for not talking about the cause?
- Do perceptions of the cause vary according to the age (children vs. adults) or sex of the deceased?
- To what extent do people associate death with God's will or destiny? Does this vary according to ethnicity or religion?
- To what extent do spiritual causes plays a role?
    - How does this vary according to the type of illness or age of the person who died?
- What are local perceptions of the illness associated with fever? If the illness associated with fever leads to death, what might people assume is the main cause?
- To what extent do you think people in this area would like to learn more about the cause of death when family members die? Why or why not they might want to know about the cause of death?
- Do you think that they would be more interested to get information of the cause of death if they knew the cause is often misdiagnosed?
- Are there any others factors that might affect their desire to learn about the cause of death?

Knowledge about postmortem

- How would you describe the relationship between community members and trained heath providers working in the hospital?
- Do you as community members have prior experience with having blood or organs sampled?
- What are local perceptions regarding why blood or organs are sampled?
- To what extent are people in this area familiar with post-mortem?
- What are local perceptions of post-mortem?
- Is there a local term for post-mortem?
- Why in your view are postmortems done?
- Under what circumstances post-mortem might be carried out?

- Do you know community members who have accepted to have family members undergo post-mortem?
- If so, what did you think about the fact that they accepted post-mortem procedures?

Full autopsy

- Do you think that family members/community leaders would accept to have a post-mortem done?
    - What aspect, if any, might be perceived to be objectionable?
    - What aspect, if any, might be perceived to be beneficial?
- What information might community members need to know about the procedure to make a decision?
- Are there beliefs which are associated with particular organs that may make community members more reluctant to accept the procedures?
- Why might people refuse or why might people accept post-mortem procedures?
- Do you think that families would accept to have postmortem done on the family members who died of fever? Why or why not

Minimally invasive tissue sampling

- If full postmortem is not acceptable, do you think that people in this community might be willing to accept a different, less invasive procedure involving collecting a small piece of an organ (brain, lung, liver) from someone who died? Why or why not?
- How do you think that people in your community would regard the less invasive post-mortem procedure?
    - What aspect, if any, might be perceived to be objectionable
    - What aspect, if any, might be perceived to be beneficial?

Family Decision Making

- Can you describe the decision making process of the family members related to how to treat a body post-mortem?
- Who in the family might be involved? Is there somebody in particular who would typically take charge?
- How might decision-making vary according to the age of the deceased and how the person died?
- What other community members might be consulted when families make their decision?
- How should we approach family members about the post-mortem procedures? How much detail should be given to the family about the procedures?

- Who do you recommend is involved in approaching family members and carrying out the consent process?
- Would it be helpful to offer some sort of assistance (give examples of the type of assistance we are talking about) to families accepting the procedure? If so, what?
- Do you think that family members would like to have the opportunity to witness the procedure? Please explain
- When would be the best time to follow up with families who accepted or refused post-mortem to ask them a few additional questions about their perceptions of the procedures and why they did or did not accept?

Communication

We are now planning on how best to share post-mortem procedures with community members. We would like to get your input on community leader engagement and communication efforts.

- When introducing post-mortem procedures, we feel that it is first very important to gain trust with communities. How could efforts to gain trust with community members be best carried out?
- Who specifically should be involved and what should their role be?
- How should information on these procedures be shared with community members?
    - Probe: How to share the information, what venue should be used
- What information about the procedures should be shared? How much detail should be shared?
- Who should be the target audience when sharing the procedures?
- What if negative rumors start circulating in the community regarding the procedures? How would you recommend dealing with negative rumors?

Conclusion

- Overall, what are your feelings regarding acceptance of post-mortem? Do you think that people in your community will accept? If not, why not? If so, why?
- What might be some of your concerns about having post-mortem procedures carried out regularly in the hospital?
- What in your view might be some of the benefits of post-mortem procedures?

Appendix F: CHAMPS Community Engagement Strategic Planning Site Visit Document

Title: Assessment of community perceptions and the feasibility of conducting child mortality and pregnancy surveillance

Child Health and Mortality Prevention Surveillance (CHAMPS) Network

Investigators:

Principal Investigator

- Rob Breiman, MD, MPH, Emory Global Health Institute

  Dr. Breiman will serve as principal investigator for the study. He will be responsible for oversight and final approval of study design, instruments and procedures.

Co-investigators

- Emory University
  - John Blevins, PhD

- Centers for Disease Control and Prevention (CDC)
  - Elizabeth O'Mara Sage, PhD, MPH, MS (SEV 14926)
  - Pratima Raghunathan, PhD, MPH (SEV 4389)
  - Allan Taylor, MD, MPH (SEV 11832)

  CDC Co-investigators will provide technical assistance in tool development, study design, staff training, data analysis and report writing.

- Manhiça Health Research Centre in Mozambique (CISM)
  - Khatia Mungwambe, PhD
  - Inacio Mandomando, MD
- Chris Hani Baragwanath Academic Hospital
  - Shabir Madhi, MD
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Background and Significance

Although progress has been made to reduce childhood mortality worldwide, approximately six million children under the age of five (16,000/day) still die every year (World Health Organization [WHO], 2015). Neonatal deaths, in particular, constitute 45% of under-five mortality with rates of stillbirths being almost equal to the number of neonatal deaths (UNICEF et al, 2015; Cousens et al., 2011). Most of these deaths are caused by diseases that are preventable through cost-effective and basic quality-delivered interventions (March of Dimes, PMNCH, Save the Children & WHO, 2012). Understanding global child health and mortality is severely limited by inadequate methods and measurement. Less than 20% of the world's 192 countries have high-quality death registration data, and more than one-third have no cause-specific mortality data at all (Mathers et al., 2005). Tracking under-five mortality is at the forefront of public health, and improving our knowledge of the causes of death will have an impact worldwide.

In low-income countries throughout the world, children often die without being seen by qualified medical personnel; they die without a documented medical history and are often buried before a cause of death determination (CoD) has been conducted. Furthermore, in low-resource countries, deaths that occur in the community are often different from those that occur in the facility and may not be tracked or identified quickly enough for autopsy or postmortem examination. Even for those who die in a health facility setting, the CoD is often difficult to assess, not only due to the fact that post-mortem examinations are seldom performed, but also due to multiple coexisting illnesses, which may lead to diagnostic discrepancies between post-mortem findings and clinical diagnoses (Mushtag & Ritchie, 2005; Gupta et al., 2014). The inability to obtain CoD in health facilities and/or in the community often results in uncertainties in global disease estimations (Lishimpi et al., 2001; Ugiagbe & Osifo, 2012). Uncertainty about the true causes of child death limits the effectiveness of public health programs and often leaves public health policy makers misinformed about the most beneficial allocations of resources and interventions.

Complete diagnostic autopsies (CDA) are recognized as the most comprehensive method to estimate CoD (Fligner et al., 2011). A number of issues make CDAs difficult to execute, however, especially in low-income countries. These include cultural and religious beliefs, financial limitations, and constraints related to public health infrastructure (Turner et al., 2012; Cox et al., 2011; Oluwasola et al., 2009). To this end, the World Health Organization (WHO) recommends the use of verbal autopsy (VA) as a non-invasive alternative (Butler, 2010; Byass, 2014; Gareene, 2014; Jha, 2014). VA involves structured interviews with individuals close to the deceased, through which a CoD is derived. The VA alone as a method to determine CoD, however, is often inaccurate due to lack of diagnostic information, time between death and interview, and diseases with similar clinical presentation (Snow et al., 1992; Soleman et al., 2006). The weakness of VAs in attributing CoD is especially apparent in neonatal deaths, which are often associated with non-specific signs or symptoms.

The imperfections inherent in VA methodology, the impracticality of CDAs in resource-poor settings, and the inaccuracy of clinician ascribed CoD highlight the critical need for an alternative method to better address the causes of death and reduce under five mortality. To this end, the minimally invasive tissue sampling (MITS) procedure was developed to reduce uncertainties regarding causes of death in developing countries (Bassat et al., 2013). The MITS procedure involves extracting tissue specimens from a predefined set of organs and undertaking histopathologic examination. MITS are potentially quicker, less expensive, more acceptable and markedly less invasive than CDAs, and may therefore increase community uptake and participation (Vogel, 2012; Ben-Sasi et al., 2013).

In response to the limitations of currently available data, the Child Health and Mortality Prevention Surveillance (CHAMPS) Network aims to develop a long-term network of sites that collect robust and standardized primary data aimed at understanding and tracking the preventable causes of childhood deaths globally. Timely and accurate data generated by the initiative will inform efforts to address the deaths of children carried out by funding agencies, ministries of health, national public health institutes, scientists, clinicians, government leaders, journalists and the public. The overall CHAMPS Network, when fully realized, has the goal of establishing the scientific evidence needed to dramatically reduce early childhood death and disability, including the factors that may underlie the progression from severe illness to death (malnutrition, electrolyte imbalance, poor access to health care among others).

RATIONALE

Because of its primary emphasis on documenting CoD, CHAMPS Network objectives differ from those of typical surveillance programs and studies focusing on disease etiology. The scope of CHAMPS mortality surveillance[1] is also broad, aiming to capture both perinatal causes of deaths and deaths in infants and children under five years, and deaths caused by both infectious and noninfectious etiologies. MITS methods and advanced laboratory techniques, methods rarely used in settings with high child mortality rates, will be used to attribute cause of death as accurately as possible. In addition, pregnancy surveillance will facilitate identification of stillbirths and neonatal deaths to assist in understanding the causes of these deaths, which are often unaccounted for. The MITS methodology offers the possibility for gathering critical missing data to determine the causes of under-five mortality; however, because the procedure is carried out on the body of a recently deceased child, a wide-range of complex religious, cultural, and ethical questions inevitably arise. Widespread acceptability of child mortality surveillance incorporating MITS will require a profound understanding of cultural and religious norms and practices to determine the feasibility and understand the perceptions of MITS and pregnancy surveillance prior to implementation. For example, beliefs about death and the afterlife, opposition to and concerns about body disfigurement, difficulties in obtaining consent from grieving families, inadequate involvement/endorsement of community leaders, lack of community awareness, suspicion of researchers, and burial practices are some of the factors underlying autopsy refusal. Understanding these kinds of cultural norms and practices will be essential to the acceptability and sustainability of CHAMPS activities[2] in relation to both child mortality and pregnancy surveillance.

JUSTIFICATION FOR THIS FORMATIVE RESEARCH

In order to assess the feasibility of child mortality surveillance and pregnancy surveillance that uses MITS, formative research is necessary to understand specific cultural, religious and socio-behavioral factors that may increase or decrease acceptability of MITS on children under five, and the factors that may influence care-seeking behaviors during pregnancy, labor and delivery, and in the newborn period. These data will ultimately help determine the overall feasibility of MITS in the context of child mortality and pregnancy surveillance as well as to determine the nature and scope of behavior/belief modification efforts through community engagement, and communication with religious, traditional, thought/opinion, and political leaders.

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[1] Child mortality surveillance refers to the process of identifying and reporting the death of a child under the age of five years in the catchment community; this includes CHAMPS activities and procedures such as consent, clinical procedures (MITS, laboratory diagnostic procedures, etc.), incentives, family and community feedback, etc.

[2] CHAMPS activities involve socio-behavioral sciences (formative research and community engagement) and surveillance programs focusing on mortality, pregnancy, demographics and possibly severe diseases in children under 5 years old.

Formative research will also be employed to assess the contexts in which families grieve, to identify how and which family members participate in pregnancy and postpartum processes (including rituals), to determine which family member(s) and how members should be approached when introducing the MITS procedure, and to identify other community members (e.g. religious leaders, healthcare providers) who could act as positive influences when deciding whether to accept child mortality surveillance and MITS. In addition, formative research will help determine whether and in what context incentives, such as assistance with funeral costs or recognition of the family's participation, would be ethically feasible, effective or appropriate for encouraging MITS acceptance and participation. Finally, formative research will complement and guide community engagement activities and help to assess the effectiveness of these activities and how they should be modified to optimize acceptance of child mortality surveillance including the MITS procedure and other CHAMPS activities.

HYPOTHESIS (narrative)

It is anticipated that this formative research will help identify, specifically: (1) the *facilitators and barriers* for undertaking child mortality surveillance, including conducting MITS when patients die within healthcare facilities and at home or elsewhere within communities; (2) the *facilitators and barriers* to care-seeking, access to care and perceptions of pregnancy, labor/birth, and the postnatal period; and, (3) what incentives, if any, would be ethically feasible, effective and appropriate for encouraging participation in child mortality surveillance with MITS.

EXISTING FACTORS TO BE CONSIDERED IN THE FORMATIVE RESEARCH

Formative research will examine and assess key factors related to the feasibility and perceptions of CHAMPS surveillance procedures. These factors include: 1) religious beliefs, 2) cultural norms, 3) political conditions, 4) economic conditions, 5) disease prevalence/incidence, and 6) environmental factors. Any examination of these factors will require intentional, ongoing, respectful partnerships with community members and community leaders, including religious and traditional leaders. Such partnerships are essential for establishing the conditions on which trust can be built and strengthened over time. Methods for community assessment and engagement with community members and leaders are spelled out in subsequent sections of this document.

Religious beliefs about death and related practices that demonstrate faithful care for the body of a deceased loved one will undoubtedly impact community perceptions and beliefs about MITS. Studies on the perceptions of autopsies in low and middle income countries name religious beliefs as the most frequent cause of suspicion of and refusal to consent to either autopsies or post-mortem examinations (Gurley et al., 2009; Lishimpi et al., 2001). Religious beliefs on these issues vary tremendously across and within traditions because they are often blended with other cultural factors that affect beliefs and practices within the local context; moreover, religious practice is rarely a simple expression of a singular belief system, but is itself a hybrid mixture of various traditions (Bhabha, 1994). For some people of faith, the invasive nature of MITS may pose a fundamental challenge to beliefs about the nature of the body, God's providence, respect for the deceased, one's own place in the family and community, and the afterlife. As such, suspicion of MITS protocols may be quite high. At the same time, religious traditions may support participation in child mortality surveillance activities if they are understood to generate knowledge that could eventually be used to treat the causes of death of children. The formative research of the CHAMPS network will assess religious beliefs and practices, recognizing that such assessments must be adapted to disparate cultural and geographic contexts. Such assessments will aid in framing the design of the formative research and other activities carried out across the network in ways meaningful to community stakeholders. Demonstrating respectful appreciation of religious beliefs

will in turn help foster trust to find common ground and better understand the ethical issues involved in community buy-in and individual consent.

Cultural norms beyond religion may also influence perceptions of child mortality, pregnancy and neonatal surveillance and care for and burial of young children. For example, expectations and experiences of parenthood are embedded within longstanding and powerful cultural frameworks which are gendered, creating different expectations for men and women as to their appropriate parental roles and responsibilities. Traditional beliefs surrounding pregnancy may also affect when a women discloses pregnancy, care seeking during pregnancy, and how and where a women delivers. In addition, cultural beliefs related to the child's age at death, disease causality and fatalism are likely to influence perceptions of the relative meaning or value of CHAMPS protocols involving child mortality and pregnancy surveillance. In particular, similar to the earlier mentioned crucial role of religion, cultural norms will be key determinants of community perceptions and beliefs about MITS. Formative research examining cultural norms will allow the in-country CHAMPS teams the opportunity to develop surveillance activities in ways that align with local norms and to address key ethical tensions between cultural values and CHAMPS procedures that could not be ascertained through the laboratory and clinical protocols alone.

Political conditions affect the social relations across communities and among community members. They may contribute to an ethos of cooperation and trust among members of a community despite cultural, religious, ethnic, class, or economic differences or they may exacerbate those differences, leading to tension or violence. Community perceptions of political leaders and governmental alliances and programs (at both the local and national levels) will influence perceptions of the CHAMPS activities, especially in relation to the role of the Ministry of Health in each specific country. Finally, perceptions of global political issues may impact perceptions about the involvement of international researchers associated with CHAMPS. By assessing these political conditions (both historical and current), the formative research protocol aims to gain insights into the influence of these broader political forces on acceptability of CHAMPS activities.

Economic conditions are a primary social determinant of poor health and health inequity (WHO 2008). Formative research that assesses the economic conditions among stakeholder communities will be instrumental in understanding the connections between this social-structural factor and the causes of under-five mortality. In resource-poor settings, economic conditions may impact food security and lessen the availability of and access to health facilities and services. These inter-related issues could in turn influence perceptions of CHAMPS surveillance activities, particularly if residents in these settings believe that services for their children were lacking when they were alive, but that CHAMPS personnel are eager to carry out MITS protocols after their child has died. In addition, information on economic circumstances in communities can help to gauge the possibility of an undue influence of incentives for participation in CHAMPS activities. Similarly environmental factors can impact childhood morbidity and mortality. Assessing environmental conditions at the stage of formative research will be useful in understanding how these factors contribute to food availability, air quality and nutritional sustainability for children.

EXISTING STUDIES AND LIMITATIONS

MITS was first proposed in the literature in 1995 by Avrahami et al. These initial papers were focused on the use of laparoscopy and thoracoscopy as an alternative to conventional autopsy, which were found to be accurate and easy to perform and highly sensitive for victims of trauma. Since then, multiple studies have explored the use of MITS to understand its clinical value and its potential for replacing conventional

autopsy. While most studies have focused on developed countries and non-infectious causes of death, e.g. birth defects (Sebire et al., 2012; Fan et al., 2010; Breeze et al., 2011; Weustink et al., 2009), several recent projects are working to validate the technique in developing countries (Bassat et al., 2013).

Globally, neonatal deaths constitute 45% of under 5 mortality (UNICEF, WHO, World Bank, UN Population Division, 2015) and stillbirths are nearly equal to the number of neonatal deaths (Cousens et al, 201). Trends in both neonatal mortality and stillbirth rate reduction lag behind progress being made in reducing under-five deaths (Cousens et al., 2011; UNICEF et al., 2015). Pregnancy surveillance is an essential element needed for identification of perinatal and infant deaths. Identification of perinatal deaths, however, is highly dependent on cultural practices. For example, cultural norms can influence the timing of when and with whom a woman communicates that she is pregnant, is in labor and gives birth, or has a pregnancy or neonatal loss. Understanding the norms around these critical life events is fundamental to designing and implementing a pregnancy surveillance system that captures complete birth outcomes and perinatal deaths. Finally, it is only through a pregnancy surveillance system that pregnancy outcomes can be successfully tracked and stillbirths and neonatal deaths can be accurately identified and counted.

Due to the limitations of the current CoD methodologies, there is a pressing need for additional research to determine the best method to determine CoD in developing countries, especially among children under five. Today, the global health community lacks consistent, accurate, and timely infectious disease epidemiology and surveillance data to inform strategy and enable critical decisions for reducing childhood mortality. A lack of quality primary data across key geographies has led to large gaps in knowledge and has prompted an over-reliance on modeling. Data that are available are gathered through non-standardized processes into siloed systems, limiting stakeholders' ability to integrate, analyze, compare, make inferences and take timely actions. Furthermore, available data offer limited insight into etiology in high mortality countries. Finally, the availability of primary data is often delayed for years due to misaligned incentives among stakeholders, resulting in a lagging view of evolving epidemiology. This combination of factors restricts the ability of global stakeholders as well as national leaders to make evidence-based decisions such as prioritizing product development, targeting interventions appropriately, measuring the impact of interventions, and refining strategies to address changing epidemiology.

Goals/Aims

GOALS

The overall goal of the CHAMPS Network is to provide accurate, timely and reliable data on the causes of death for children under age five. A unique aspect of CHAMPS will be the collection of tissue samples, by pathologists, from recently deceased children. While this is a sensitive topic, it is crucial to determining causes of child mortality to inform policy and program decisions aimed at reducing child deaths. **To this end, this formative research will aim to evaluate the feasibility (i.e. acceptability, practicality and implementation) and ethical considerations of child mortality surveillance in different cultural, social, religious and geographical contexts.**

Another important and overlapping goal of the CHAMPS Network is to conduct pregnancy surveillance to help support complete identification of birth outcomes, stillbirths and neonatal deaths in communities by monitoring live births up to 2 months after delivery. **As a secondary objective, this formative research will also aim to explore perceptions of pregnancy, birth and the postpartum period to inform the development and implementation of pregnancy surveillance systems aimed to identify**

stillbirths and neonatal deaths, as well as to understand acceptability of pregnancy surveillance among those who would be participating.

PRIMARY OBJECTIVES

- To describe cultural, social, and religious norms, rituals and practices involving the death of a child (stillbirth, newborn, infant and child)
- To examine the role of socio-cultural attitudes and traditions on communities' views on child mortality surveillance
- To examine facilitators and barriers related to consent for MITS
- To determine factors affecting acceptability of child mortality surveillance, including motivators and barriers, by the relatives of the deceased child, community leaders and other community members involved
- To identify factors motivating the acceptance and refusal to perform child mortality surveillance both theoretically and in actuality
- To inform tools and approaches for ongoing CHAMPS activities and to adapt approaches as community awareness and perceptions evolve and relationships with communities are strengthened
- To assess the success of community engagement efforts and identify approaches aimed to increase both general acceptability of MITS, and acceptance by parents who are requested to allow a MITS to be performed on a deceased son or daughter.

SECONDARY OBJECTIVES

- To examine the role of socio-cultural attitudes and traditions on communities' views on pregnancy, birth, postpartum and newborn care and pregnancy loss
- To document the facilitators and barriers of identifying stillbirth and neonatal deaths

SPECIFIC AIMS

Specific Aim 1: Examine and assess factors associated with the overall feasibility (acceptability, practicality and implementation) of child mortality surveillance on patients (deceased) identified in facilities and in the community with a focus on the following factors:

a. Beliefs about child death and corpse, religions and traditions, confidentiality, family issues, perceived need and appropriateness, etc.
b. Desire/willingness to consent and gain knowledge of the cause of death
c. Relevant cultural practices
d. Rituals and grieving (age, gender and community)
e. Stigma associated with stillbirths and neonatal deaths
f. Beliefs about the incentives that may play a role in CHAMPS activities (i.e. child mortality and pregnancy surveillance), history of incentives in target communities
g. Beliefs about early pregnancy loss, still birth and neonatal death (i.e. religious and traditional beliefs, confidentiality, family issues, MITS being unnecessary and inappropriate)
h. Requirements for health systems to accept and participate in child mortality surveillance utilizing MITS, including reluctance and competing priorities
i. Collaborations and relationships with MOHs and other relevant government and non-government agencies
j. Community understanding and acceptance of public health initiatives such as CHAMPS including a general history of public health interventions in the target communities

k. Training needs for those involved in CHAMPS activities (i.e. community engagement leaders, epidemiologists, clinicians, etc.)

Specific Aim 2: Identify and respond to known and unanticipated perceptions, concerns, barriers and opportunities that will/could arise through CHAMPS activities:

a. Incentives
    i. Influence on acceptance of child mortality surveillance incorporating MITS
    ii. Effect on participants' perceptions of the cultural and ethical issues involved
    iii. Knowledge of incentives on community perceptions of participants
    iv. Perceptions of the individual, community, and social benefits of child mortality surveillance
    v. Influence on participation in pregnancy surveillance
b. Legal considerations
    i. Issues that impact CHAMPS activities in the countries where the surveillance activities will be implemented
        a. Reporting requirements for deaths involving trauma or violence, reportable disease requirements, partner notification requirements
    ii. Role of governmental authorities (e.g., Ministries of Health) in CHAMPS activities
c. Researcher concerns
    i. Researcher communication about the value of child mortality surveillance and MITS without inappropriately influencing pre-existing perceptions during formative data gathering
d. Health care worker concerns
    i. Clinicians may feel threatened by results from MITS if the message given to parents is different than what they transmitted or if the message suggest that there was an error in clinical decision-making and actions that missed opportunities to prevent (or hastened) death
    ii. Alternatively, clinicians might view MOITS as a way to improve clinical management and raise concerns about the limited geographical or age-based scope of CHAMPS

Specific Aim 3: Examine and assess community entry and engagement approaches and requirements with focus on the following:

a. Approaches for identifying the key community stakeholders that should be involved in examining community entry
b. Approaches/methodologies to researching the barriers, facilitators, gaps and needs of community engagement
c. Methodologies for assessing and developing approaches for community sensitization of pregnancy and child mortality surveillance
d. Methodologies for identifying the benefits of CHAMPS activities on the existing clinical and laboratory infrastructure/services in the community as a value-added outcome
e. How to conduct monitoring of acceptability and address rumor control
f. Approaches for involving the community during CHAMPS implementation
g. Awareness of rituals and grieving (variable by age, gender or community) and the appropriate ways to address them in community engagement

Specific Aim 4: Explore the perceptions involving pregnancy, birth, postpartum and newborn care practices that facilitate or impede notification of births, stillbirths and neonatal deaths.

a. Patterns associated with pregnancy notification, care-seeking behaviors, delivery planning including location of delivery and desired birth attendants, birth notification, and postpartum practices
b. Barriers associated with access to care involving ANC, health facility delivery and newborn care, and postnatal care,
c. Community perceptions about the capacity and quality of ANC and delivery
d. Facility capacities in pregnancy dating, skilled birth attendant coverage and postpartum and newborn exams
e. Provider perceptions regarding ANC policies, preferences, and improvements related to ANC and postnatal and newborn care

Formative Research Design

The CHAMPS social behavioral component will employ a qualitative design based on sociological and anthropological approaches, namely ethnography and phenomenology. The core qualitative approach will be ethnography, which is an iterative, cumulative process resulting in the scientific description and interpretation of cultural behavior. Over an extended time period, the socio-behavioral science team interacts directly with members of the local communities in their own natural and daily environment (Hammersley et al., 1983). This approach will first allow members of the site socio-behavioral science[3] team to explore the cultural and social phenomena (i.e., "death") in its broader context. This approach will also lend to understand local meaning before looking more deeply into the specific research questions (i.e., *acceptability of child mortality surveillance including MITS* and *perceptions of pregnancy in relation to notification of births and deaths*). In addition, an ethnographic approach will help strengthen relations between the members of the CHAMPS site socio-behavioral science teams and community members and leaders, which may facilitate the trust needed to optimize acceptability of child mortality surveillance. Phenomenology is an approach to understand first-hand experiences of those involved in a phenomenon of interest to the research question (i.e., being pregnant, caring for a child with severe illness, or losing a child) (Starks, 2007). This approach will enable the team to move from the more theoretical leanings on potential factors influencing the acceptability of the CHAMPS program into understanding how these factors play in actuality. It will also contribute, in real time, to the achievement of the aim of assessing the success of community engagement efforts and identifying approaches for making them more effective towards acceptance of MITS in principle, and when parents are requested to allow a MITS to be performed.

The methods for this formative research will involve a combined phased approach of semi-structured interviews (SSIs), key informant in-depth interviews, focus group discussions (FGDs) and participant observations. This multi-method approach will facilitate data triangulation needed to validate information collected across different data sources regarding the feasibility and perceptions of CHAMPS activities. This procedure assumes that different data collection approaches enhance the nature and integrity of inferences drawn from diverse data. By Please refer to Appendix G for an example timeframe reflective of the formative research process.

[3] Members of the CHAMPS site socio-behavioral science team include a lead socio-behavioral scientist and other socio-behavioral researchers (and assistants) to assist with data collection, analysis and community engagement activities. These individuals may also be referred to as "interviewers" in this protocol and will be responsible for data collection.

FORMATIVE RESEARCH SETTINGS

Formative research will take place at potential CHAMPS surveillance sites selected by the CHAMPS Program Office. Initially, the sites will include Manhiça District, Mozambique; Bamako, Mali; and Soweto Township within Johannesburg, South Africa. Additional sites will be included as the CHAMPS Network expands.

Manhiça District is a rural area located 80 km north of Maputo (Mozambique's capital) with a population of about 165.000. The Manhiça Health Research Centre (CISM) manages a Health Demographic Surveillance System that has progressively expanded to cover most of the population since 1996. Life expectancy at birth is 57.1 years and child mortality rate is 76.1/1000 live births. The district is served by a district hospital and 14 rural health centers. Shangaans constitute the dominant ethnic group, with very strong patriarchal social structures and cultural aspects that are similar to other ethnic groups within the Southern region of Africa. Christianity and different forms of animism are the main belief systems in this area, and a minority of the population is Muslim (Manhiça HDSS 2015).

In Johannesburg, the capital of South Africa, formative research will be conducted in Soweto, a township with peri-urban characteristics, inhabited predominantly by a low-income community of 1.4 million people, of whom 125 000 are under-5 years of age. The main ethnic groups are the Zulus, Xhosas and Sothos (STATS-SA 2012). The community is severely affected by HIV, with a prevalence of HIV infection in women attending antenatal clinics in Soweto that has stabilized at 30% since 2005 (The 2012 National Antenatal Sentinel HIV & Herpes Simplex Tissue Type-2 Prevalence Survey in South Africa). However, vertical mother-to-child transmission (MTCT) of HIV has declined from 8-12% in 2007 to less than 2% by 2010 (Barron et al., 2013).

Bamako, the capital of Mali, has a population of approximately 2 million inhabitants. The Centre for Vaccine Development (CVD) in Mali established a HDSS. According to The World Factbook, life expectancy at birth is 55 years and child mortality is 102 deaths/1000 live births (2013-14). Based on DHS 2013 data, during the past five years, of 1000 births, 56 die before reaching their first birthday. Of 1,000 children a year, 41 do not reach their fifth birthday. Overall, the risk of dying between birth and the fifth birthday is 95 to 1,000 live births (DSH, 2012-13). Hôpital Gabriel Touré is the main tertiary level teaching hospital in Bamako. Within the DSS, 3 Centres de Santé Communautaire (CSComm) or health centers provide the health care services in the area. Among the 10 existing main ethnic groups, the Bambara, the Sonrais, the Fulani and the Soninke predominate. The main religion is Islam (94.8% of the population), and 2.4% of the population adheres to Christian beliefs. Traditional spiritual beliefs are also common among adherents of both Islam and Christianity.

FORMATIVE RESEARCH PARTICIPANTS

A combination of nomination and snowball sampling techniques will be used to identify potential respondents. It is important that broad representations of the different segments and sectors of the communities involved in the program be approached and invited to take part in the formative research. To this end, each site must carefully consider the views, interests, needs, priorities, expectations and concerns of individuals and communities when identifying participants. In addition, sites must assess any potential negative impact on certain individuals and/or communities caused by social, cultural, economic, political and/or environmental circumstances. Each site will define study respondents and the participant inclusion and exclusion criterion in accordance with local norms and relevance to the formative research objectives.

Examples of community and health members or representatives with the following characteristics could be considered to participate in interviews (sites to include additional categories/subcategories as appropriate). Data collection approaches and sample sizes are also suggested (see following sections for detailed information on recruitment and field data collection approaches).

Table 1: Examples of community representatives, methods and sample sizes

Community Representatives	Data Collection Approach	Expected Participant Range
Knowledgeable leaders in the community (notables, elders, matrons)	key informant in-depth interviews Focus groups (2)	3-6 10-16 (total participants)
Community level health care providers (public, private, and traditional, including traditional healers and birth attendants)	key informant in-depth interviews Focus groups (2)	3-6 10-16 (total participants)
Professionals involved in proceedings related to death and dying (e.g., mortuary attendants, body preparers, burial/cemetery workers)	Key informant in-depth interviews	2-5
Religious leaders (including representatives of world religious traditions and indigenous religions)	Key informant in-depth interviews	6-10
Local community members representing the potential participants in CHAMPS, including parents and/or next of kin	Semi-structured interviews	8-10
Participants in vigil, burial, or cremation ceremonies, and other grieving or mourning rituals	Key informant in-depth interviews	2-5
Political representatives	Semi-structured interviews	4-6
Village chiefs or other traditional authorities	Key informant in-depth interviews	6-10
Health/Policy Representatives	**Data Collection Approach**	**Sample Range**
Policy makers from the health, legal, vital registration, etc.	Key informant in-depth interviews	3-6
Public health practitioners (staff from governmental health programs, MCH specialists, representatives of key international NGOs/FBOs, etc.)	Focus groups (2)	10-16 (total participants)
Representatives of clinical and medical professional organizations	Semi-structured interviews	3-6
Clinicians (pediatricians, pathologists, medical officers) (outside of the community)	Semi-structured interviews	6-8
Researchers (demographers, biomedical researchers, epidemiologists, etc.)	Semi-structured interviews	3-6

RECRUITMENT

The formative research will be an iterative process, whereby recruitment will start from central level institutions down to local level institutions, less formal organizations and individuals.

At the level of institutions (government, the private sector, research institutions, health facilities), a list of the departments and sectors within the institutions will be requested, from which the senior-most and at least one executive or practitioner within the sector will be purposively selected. A meeting between the appropriate member of the site socio-behavioral science team and the potential participant will be requested in person in order to invite the potential participant to take part. Snowball recruitment will also take place. In other words, participants being interviewed may refer to other people who, in their opinion, would be better suited to discuss particular issues with the research team. Those newly nominated people will also be invited to participate.

At the community level, meetings with Community Advisory Boards (CAB), local Health Committees (HC) and community representatives will serve to produce the key sampling frame. During the meetings, the different interest groups will be mapped, and a list of contacts for the participants will be generated. One to two individuals representing each interest will then be purposively selected and contacted to be interviewed. Snowball sampling may also occur until it is felt that sufficient data has been collected to meet the desired objectives of this protocol.

During the interviews with community representatives, the community level health care providers, entities involved in proceedings related to death, and the knowledgeable people will be mapped out. As much as possible, information about where to find those entities will be obtained from those conducting the interviews. The site socio-behavioral science team will purposively select at least two representatives from each group, stratified by geographical area, and approach them for inclusion in this formative research. Because MITS will occur both in clinical and community settings, parents and relatives of children who have experienced severe illness must be recruited from both contexts in order to ascertain their perceptions.

The procedure for recruitment from clinical settings will be carried out as follows: children (from 0-5 years of age) who experienced severe illness in the previous 30 days, or those children who have died, will be listed from health facility records; and, parents and relatives of these children will be identified with the aid of the health facility records and data from the Health Demographic Surveillance System (HDSS) in place in each site. If no HDSS is in place, identification will be through health facility records alone. The CHAMPS protocol will identify specific criteria for defining severe illness. A list of children along with their respective parents or relatives will be generated and a subset will be will be randomly selected and visited at home for inclusion.

The procedure for recruitment from community settings will vary depending on existing systems in each country. The Social Behavioral Science (SBS) lead in each country with work with the CHAMPS Program Office SBS team to develop a protocol for community recruitment after assessing those systems. Some examples for possible recruitment would include: using HDSS to determine children who died at home and visiting their parents (feasible only in countries with active an HDSS); interviewing community health workers to identify families in the local community that have had a child experience severe illness and visiting those families regarding possible inclusion in the study (may not be feasible in light of confidentiality laws); and working with traditional healers and religious leaders to identify families that have had a child experience severe illness and visiting those families.

COMMUNITY PARTICIPATION

The formative research component will be implemented with a community entry and engagement strategy. The two approaches will use mutual feedback since the successful implementation of formative research requires that community representatives (and the community they represent) be adequately informed. Community engagement at the start of the formative research will be essential for reaching consensus with key community stakeholders on the proposed objectives and approaches of the formative research. In addition, formative research results will inform on-going community engagement activities to help establish trust between CHAMPS staff and the community as a whole. Such trust provides a basis for creating sustainable, shared commitments that align and further CHAMPS objectives and the communities´ views, interests, needs, desires, priorities, expectations and concerns.

A dedicated on-site Community Liaison Officer (CLO) will act as the interface between the research team, the community members, and the community representatives and will be responsible for the mutual feedback between research findings and the community as a whole in order to improve the community entry and engagement strategy.

Community participation will focus on eliciting feedback from community members-at-large and from representative community leaders.

Community members-at-large

The CHAMPS community participation strategy for community members-at-large is based on established qualitative methodologies in community-based participatory research and action (CBPR/A). The method, Participatory Inquiry into Community Health Assets (PICK-CHAMP) (Blevins et al., 2012), employs an asset-based framework adapted from the model of Participatory Rural Appraisal (PRA) developed by Robert Chambers (Chambers, 1998). PICK-CHAMP was named as a best practice model for community engagement for activities carried out under the US President's Emergency Plan for AIDS Relief (PEPFAR) (Jaskiewicz, et. al., 2009). PICK-CHAMP brings together community members to participate in workshops designed to describe community members' perspectives and priorities on a selected topic. Therefore, the community entry dialogue and additional community engagement opportunities will help promote and provide context to the topics to be explored in the specific aims (see previous section).

PICK-CHAMP will serve three purposes: 1) it will serve as the first community participation activity, setting the stage for building relationships with PICK-CHAMP participants over the course of CHAMPS activities, 2) qualitative data from PICK-CHAMP on community perceptions beliefs, practices, and perceptions related to childhood death will be incorporated into KI and FGD interview guides, and 3) the same qualitative data will provide feedback on possible modifications to child mortality surveillance, MITS procedures and protocols. PICK-CHAMP participants will be invited to stay in communication with the CHAMPS site in country so that findings can be shared and feedback elicited over the course of the CHAMPS surveillance initiative. In addition, participants will be invited to be part of regular community meetings to be held as part of the community participation activities over the course of the CHAMPS program. Appendix F contains the PICK-CHAMP curriculum that will be used.

Community leaders

In sites where Community Advisory Boards (CABs) or local Health Committees (HCs) (or their equivalent)

are in place, these structures will constitute key entry points for this aspect of this formative research. Through meetings between site socio-behavioral science teams and CAB or HC, this protocol and objectives will be discussed and suggestions from board or committee members will be incorporated into the formative research Standard Operational Procedures. Additionally, individual or group meetings (where appropriate) will be held with community-level religious, cultural, political/ administrative representatives as well as local-level health and/or psycho-social service professionals from the public, private, faith-based, and traditional sectors. Findings from the community members-at-large workshops will be shared with community members to begin discussion on community perceptions and priorities. The discussions in the meetings center on the following issues:

- What are the suitable characteristics and appropriate conduct of research team members when approaching and interacting with community members
- How CHAMPS activities can align with and support the existing clinical and public health infrastructure
- How to enter the locations where proceedings related to death take place
- How to best approach and invite family members to participate in formative research (and ultimately CHAMPS surveillance)
- How to recognize family members´ contribution to the formative research (and ultimately CHAMPS surveillance)
- What are the best channels and approaches to feed back the information gleaned from the community assessments for CHAMPS activities to community members

Regarding feedback of the results, the same channels used for community entry will be used to share the outcomes of the formative research and discuss implications. In addition, during the data collection process, a specific question on how each participant would like to learn about the results of the formative research will feature as a topic for discussion. The dissemination approach and channels used will be based on the suggestions of the CAB, community representatives and individual participants.

FIELD DATA COLLECTION METHODS

Qualitative data will be collected through semi-structured interviews, key informant in-depth interviews, focus group discussions and observations, which are detailed below.

Semi-structured interviews (SSI)

The SSI is a qualitative method of oral inquiry which allows a verbal interchange between an interviewer and the respondent based on a written interview guide consisting of pre-determined open questions (see Appendix B for an example SSI guide). The questions are presented in a predetermined format and sequence, but allowing some flexibility in the way the topics are addressed by both interviewer and respondent. Specifically, despite having some degree of structure, the respondent is encouraged to develop his/her ideas, rather than giving “yes” or “no” type of answers (Longhurst, 2010).

This method will be used to obtain and register information on the views, concerns and expectations of individuals representing entities or institutions that implement or use mortality surveillance with MITS (policy makers, public health patricians, researchers, clinicians, community-level health care providers, etc.). SSIs will also be carried out among parents of children who have experienced severe illness or have died and pregnant women. For planning purposes, minimal sample sizes for each target group

were anticipated (as seen in table 1), based on experiences from past studies. However, a reduced or additional number or participants per target groups may be recruited depending on the saturation point. Although indicative minimal sample size has been provided (table 1), participants should be recruited until theoretical saturation for each research question is reached, which is the point when no new insights are generated through the data (McLafferty, 2004; Onwuegbuzie et al., 2009). However, it will be necessary to continue collecting and analyzing data after the initial formative research analysis to readdress certain community perceptions and potential changes in methods. Data collection and analysis will be performed in a cyclical way in order to monitor theoretical saturation.

These interviews will be conducted individually, face-to-face and will be audio recorded with the permission of the participant (respondent). Each SSI will take approximately 45 to 60 minutes and will be audio-recorded according to the comfort and permission of the participant. Interviews will also be translated from local language to English, French or Portuguese and transcribed. The interviewer will take notes during the interviews which will later be translated and entered into a spreadsheet. Data will be entered in NVivo, a qualitative text-organizing software.

Key informant in-depth interviews

Key informant interviews are qualitative in-depth interviews with those who have firsthand knowledge of the community. Key informant interviews are typically less structured, open-ended sets of verbal questions based on an interview topic guide that orients the interviewer on the overall issues to be discussed. The topics are very broad and within each topic, the format, order, and depth of each question is formulated by the interviewer (Longurst, 2010) (see Appendix C for an example IDI guide).

Key informant interviews will include, for example: political, religious, traditional authorities, notables, elders, matrons and others especially those involved in proceedings related to severe disease avoidance, notification and treatment. In addition, key informants may also involve those involved in events around a death in order to gain an in-depth understanding of cultural, social and religious norms. Key informant interviews will also be conducted to explore informants' roles in the local processes surrounding death, their opinions about performing MITS to deceased children and the best way to proceed if MITS were to be offered at the health facility and in the community. Others areas of key informant interviews may also focus on pregnancy and severe illness as related to CHAMPS. Participants should be recruited until theoretical saturation for each research question is reached, which is the point when no new insights are generated through the data (McLafferty, 2004; Onwuegbuzie et al., 2009). However, it may be necessary to continue collecting and analyzing data after the initial formative research analysis to readdress certain community perceptions and potential changes in methods. Data collection and analysis will be performed in a cyclical way in order to monitor theoretical saturation.

Each key informant interview will take approximately 1 hour. The interviews will be audio-recorded according to the comfort and permission of the participant and translated from local language to English, French or Portuguese and transcribed. The interviewer will take notes during the interviews which will later be translated and entered into a spreadsheet. Data will be entered in NVivo, a qualitative text-organizing software.

Focus group discussions (FGDs)

FGDs are semi-structured forms of verbal exchange between the researcher and the respondents, who are convened to take part in a group interview (Longhurst, 2010). When required and/or appropriate, the above information will be collected through focus group discussion because there may be instances when participants may be more comfortable discussing the topic in a group and/or where a more

productive and robust conversation occurs due to group dynamics. Each FGD will take no longer than 1.5 hours. All contents of the FGD will be audio-recorded with permission from participants (see Appendix D for an example FGD guide). Two note-takers will take notes during each FGD which will later be translated and entered in NVivo for data coding.

Sample and sample size: Focus group discussions (interviews) will include, for example: knowledgeable leaders in a community including religious, traditional authorities, notables, elders, matrons and others especially those involved in proceedings related to severe disease avoidance, notification and treatment. Discussions may also be compromised of those involved in events around a death in order to gain an in-depth understanding of cultural, social and religious norms. Focus group discussions will also be conducted to explore community healthcare and public health provider perceptions regarding the local processes surrounding death, their opinions about performing MITS to deceased children and the best way to proceed if MITS were to be offered at the health facility and in the community. Focus group discussions may also emphasize pregnancy and severe illness as related to CHAMPS.

Each focus group discussion will take approximately 1 hour. The discussions will be audio-recorded according to the comfort and permission of the participant and translated from local language to English, French or Portuguese and transcribed. The discussions will be facilitated by a member of the site social behavioral science team and a minimum of two additional transcribers will take notes during the discussions (which will later be translated). Data will be entered in NVivo, a qualitative text-organizing software.

Observations

Designated members of the site social sciences team will contact and ask permission to community leaders to accompany the procedures, rituals, customs and traditions around death at the community (health centers, funeral homes, religion services, funerals, etc.). Community leaders will intercede with the family and the community in order to allow the research team to explore attitudes, behaviors and relationships in this context and to understand the local norms and practices around death. This approach will help to elucidate appropriate ways of enrolling and involving potential participants.

Once MITS are introduced in the health facility and after they have been introduced in the community, it will be important to gain direct insights of interactions between health workers and family members of the deceased. In addition, it is important to understand family members' attitudes and coping strategies when facing the task of asking/ giving consent to perform MITS; a skilled social scientist will be present to observe the entire informed consent process. There will be no direct interaction between the social scientist and the health worker or with the family members in order to minimize interference with the decision-making process.

Hospital- and community-based health professionals performing MITS will be under observation while performing their routine activities in order to determine which procedures are acceptable by them and which strategies and approaches are the most appropriate for a future implementation of MITS techniques. The observation sessions will take as long as the procedure being observed lasts. Field notes will be the main source of recording the information. Appendix E provides a template for field notes; using this template will help ensure consistency in what is collected across sites.

INFORMED CONSENT PROCEDURES

When recruited individuals arrive for a semi-structured interview, a key informant in-depth interview or a focus group, the interviewer will read a verbal consent script (see Appendices A, B and C respectively).

Each potential participant will be informed about the purpose of the formative research, the procedures to be followed, risks and benefits anticipated, their rights as a participant, and that participation is voluntary. Informed consent will be adapted according to site-specific requirements. Potential participants will be informed that:

1) The interview is audio recorded to best capture an accurate record of his/her perspective and experiences; the interviewer will begin by conducting a short test of the recording capacity to screen out ambient noise. If recording is not feasible because of such noise or because of mechanical failure of the recording device, the interviewer will take notes as the interview proceeds;
2) The participant may refuse to answer any question, or may stop the interview at any time; if the participant stops the interview, s/he will be asked if the recording of the unfinished interview might be used for analysis. If not, it will be destroyed as per the participant's request;
3) The audio recordings will be transcribed in-country, and saved to a cloud-based storage system until data analysis is completed as reference. This system will be encrypted and password-protected to ensure security of data.
4) Their decision to participate in the interview (or not) and their decision to answer specific questions (or not) will not impact their ability to receive health care services in the future.

Any questions will be answered and verbal consent for participation will be sought, but signature documentation will not be requested.

Justification for Waiver of Documentation of Informed Consent

A waiver of documentation of informed consent is being requested as allowed under US CFR 45.46.117, which states that the requirement for the investigator to obtain a signed consent form for some of all or the subjects may be waived under the following conditions:

1) The only record linking the subject and the research would be the consent document and the principal risk would be potential harm resulting from a breach of confidentiality; and,
2) The research presents no more than minimal risk of harm to subjects and involves no procedures for which written consent is normally required outside of the research context.

Both of the above conditions are met in this formative research. Therefore, no written documentation of informed consent will be sought. An unsigned copy of the verbal consent script will be provided to all participants. Separate verbal consent scripts for participation in individual interviews (both SSIs and IDIs) and FGDs are included in Appendices A, B and C respectively.

For those who are not able to read or read with difficulty, an independent individual with reading skills will be asked to read out the participant information sheet. After this, time will be allowed for questions, which will be answered by the site socio-behavioral science team members. Participants who still have doubts will be allowed time to consult others (i.e., family members). Participation in the formative research will be voluntary, and confidentiality will be preserved in accordance with the national legislation regarding data protection, or in the absence of this, in accordance with the GCP ICH norms.

Protection of Privacy and Confidentiality

All interviews will be conducted in private locations. If any names happen to be used in the focus groups and interviews, they will later be stripped from transcripts and replaced by generic distinguishing codes

that correspond to the focus group discussion number and the gender of the participant.

Only socio-behavioral science team members will have access to data collected. All forms will be stored in locked cabinets in site socio-behavioral science team offices. All databases and computers will be password-protected and maintained in secure buildings.

Potential Risks

Participation in this formative research is not anticipated to expose participants to substantial risk or harm. We will collect no identifying information at any time, and the formative research involves only minimal or no risk to participants. We will therefore apply for exemption from the requirements for full IRB review set forth in 45CFR 46 (United States Code of Federal Regulations) and will apply for a similar exemption from the IRBs or ethics oversight committees of participating sites as required.

The members of the socio-behavioral science team and focus group discussion assistants must consider risk and harm throughout individual and/or focus group interactions. For example, a mother may impart traditional (cultural) preterm care practices that could potentially be harmful to the baby. Careful consideration of how to react to this type of ethical dilemma will be discussed among the researcher and assistants prior to the focus group sessions.

Risks
Risks from participation in this formative research are limited to possible embarrassment at some sensitive questions and at voluntary disclosure of sensitive information to other participants in focus group discussions.

Protection against risks
These risks will be minimized by the voluntary nature of participation. In addition, it will be made clear to participants that they may decline to answer any question or divulge any information at any time.

Participant names will not be recorded, either at the time of recruitment or during the conduct of focus groups or interviews. During the focus groups and interviews, participants will be instructed to refrain from mentioning any specific names (their own or other people's). In our experience, some individuals will choose to use their true first name despite such instruction. Therefore, as added protection against inadvertent disclosure, any potential identifiers in the interview data will be eliminated during the transcription process by replacing specific names of people, places, or organizations, with general terms or pseudonyms. Participants will be distinguished from one another by arbitrary, generic codes in transcripts, which will be assigned in such a way that participants' comments may be distinguished from one another but that participants cannot be otherwise identified. We will keep all data confidential. All information pertaining to the formative research will be stored in locked filing cabinets in office of the local collaborating institution, and all electronic files will be encrypted. Audio recordings will be destroyed after accuracy of transcription is verified and after the corresponding digital files have been securely stored.

Risk/benefit ratio
The risk/benefit ratio for this formative research is appropriate. There is little risk involved with participating in this formative research. There are also no more than minimal benefits to participants. What we learn will be used to help implement more effective strategies for communicating and

implementing CHAMPS activities directly in the communities from which participants come. Therefore, participants and their communities will benefit indirectly.

Benefits

There are no direct benefits to the participants. This is in accordance with the US Code of Federal Regulations for studies with minimal risk. The participants may feel a sense of pride or purpose in knowing that their participation may indirectly benefit their community in the future. For example, the information gained around the concepts of health seeking behavior, cultural practices, and perceived barriers to care has the potential to inform programmatic decision-making by national and sub-national ministry of health and non-governmental organization staff. This may ultimately improve access to and quality of maternal and newborn health services. Moreover, this formative research will provide crucial information about the feasibility of CHAMPS surveillance activities in the formative research site settings which will inform the implementation of these activities using culturally acceptable methods.

Compensation

Participants will not be financially compensated for their time and effort in order to avoid the perception of coercion. A small item, such as a bar of soap or sack of flour, may be provided as a token of appreciation to all subjects who are offered participation in the formative research based on the acceptability of this practice as determined by each site. Participants may also be compensated for transportation costs by reimbursing each participant for the median cost for in-town public transportation. Some type of refreshment (i.e., soda, juice) will be provided for each participant when culturally appropriate.

Data Analysis

Only members of the CHAMPS site and Program Office socio-behavioral science team will have access to data collected. All forms will be stored in locked cabinets in the offices of socio-behavioral science members. All databases and computers will be password-protected and maintained in secure buildings. Members of the site socio-behavioral science teams will be trained on data management, security, collection, standard coding and data analysis prior to data collection.

Each member of the socio-behavioral science team will complete data summary sheets on a daily basis to document main themes derived from the discussions and/or observations. If required, members of the site socio-behavioral science teams will recourse to the audio recordings to complete the information. By the end of each week, data collectors will be required to complete a spreadsheet based on data from the summary sheets. This spreadsheet will summarize socio-demographic characteristics of participants involved in the formative research and the main themes emerging from the discussions (content analysis). This spreadsheet will provide the capacity to monitor the saturation point. Additionally, a descriptive analysis will be performed for quantitative indicators (ex: quantifiable variables from the semi-structured interviews) by frequency distribution.

All data collected (i.e. key informant in-depth interviews, semi-structured interviews, focus group discussions) will be digitally recorded and later transcribed. Audio contents of interviews and focus group discussions of pregnant women and next-of-kin experiences will be transcribed verbatim into MS Word by dedicated trained transcriptionists. If conducted in local language, transcripts will be locally translated by the same transcriptionists to a formally written language (i.e., Portuguese, English or

French, depending on the site). Supervisors at sites will perform quality checks of transcripts by listening to 25% of the audio recordings against the respective transcripts. Field notes taken during interviews and observations will also be transcribed. Roughly 30% of transcripts in Portuguese and French will be translated into English for subsequent analysis by team members from the CHAMPS Program Office for the purposes of quality control. Data analysis will therefore be performed by the CHAMPS site research team in-county. Analysis training and trouble-shooting will be consistently monitored through technical assistance provided by Socio-Behavioral Scientists located in the CHAMPS Program Office.

After all quality checks have been completed, Word documents will be imported into NVivo, version 10; a software that facilitates the management and coding of large sets of qualitative data. Transcripts, observation reports and field notes will be coded locally by the research team, which will work collaboratively across the sites to develop the coding frame. A generic outline of nodes and codes will be developed (coding tree) which will have the flexibility of including emerging themes from specific sites (grounded theory). As the emerging themes are incorporated, they will be shared with the investigators of the 3 sites and in that way the coding tree will be continuously updated. Coded text will be translated and shared with the other sites for multisite analysis.

Plans for Monitoring the Formative Research for Safety

All audio files will be securely stored with password protection and kept for 5 years beyond the end-date of data collection. After that period, data will be destroyed. Transcripts will be kept securely in the same manner, but they will be kept in electronic format as source documents for at least 10 years beyond the end-date of analysis. NVivo project containing all the transcripts will be kept in the server and can be used in the future for training and academic purposes.

All data collected in the formative research including audio files, transcripts, and interview notes will be digitized and downloaded into a formative research database on a password protected computer at each formative research site. A copy of each digital file will be sent by encrypted electronic mail to the site socio-behavioral science lead. Hard copies and original files on audio devices will be erased or destroyed immediately after the site socio-behavioral science lead confirms receipt of the files. The formative research database will be kept on both the computers of the site socio-behavioral science lead and those responsible for data collection and transcriptions, which will be password-protected and located in a 24-hour security-controlled building. A back-up copy of the database will be kept on an external, encrypted hard-drive in a locked file cabinet of the site socio-behavioral science lead, which is also in a 24-hour security-controlled building. The CHAMPS Program Office and site socio-behavioral science team will be the only people to have direct access to the data. Limited and segmented access to the data files will be granted to data analysis technicians, as needed.

Confidentiality

Actions will be taken to maintain privacy and confidentiality throughout the data collection and analysis phases of the formative research. Individual and focus group discussion interviews will be conducted in private settings that minimize the ability and likelihood of non-participants overhearing or viewing the conversations. Subjects will not be identified personally, nor will personal information about subjects be collected beyond age, gender, and category (e.g., pregnant women). For protection of subjects, verbal consent will be collected as opposed to a written consent form. Furthermore, all formative research

facilitators and note-takers will receive training on maintaining confidentiality and will be required to sign a confidentiality agreement form prior to conducting interviews. Following consent procedures at the onset of focus group discussions, the importance of confidentiality will be discussed with participants. A verbal agreement not to discuss information shared with others outside the group will be required prior to participation.

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Appendix A: Consent

Verbal Consent

Date (dd/mm/yyyy): __ __ /__ __/__ __ __ __

Introduction

Thank you for participating in this interview. I am _____ from _____.

What is this interview?

This is an interview we are asking members of your community to participate in. This is part of a bigger effort to better understand what members of your community do when: 1) a woman becomes pregnant, 2) she experiences problems during her pregnancy, or 3) when a child dies. The results of the interview will help us better understand the causes of child deaths so that we can help to reduce preventable deaths in the future. Your participation is voluntary (your choice). If you do not want to participate in the interview, it will not affect your job, your ability to access health care, or your participation in CHAMPS activities, now or in the future.

What are the possible risks and benefits?

You will be asked to give at most 1.5 hours of your time and you can choose to stop at any time even if the interview is not complete. We will also give you a form you can send in later if you change your mind and want us to remove your information from our records. We will not record your name, but we will record some simple information about you such as your gender, age, and the country you live in. The only foreseeable risk to you is a potential loss of privacy. However your privacy is very important to us and we will be very careful with your information. The only people who will have access to the information shared in the interview will be the members of the CHAMPS socio-behavioral science team and they will not share individual results with anyone else for any reason. When the CHAMPS social-behavioral science team shares findings from these interviews, all information that could identify any individual who was interviewed will be removed before the findings are shared.

There will be no direct benefit to you or your family members from participating in this interview. However, the information that you provide may ultimately help us to improve the health of babies and children in your country in the future.

If you have any further questions about this interview or your participation in this study, please ask now or contact the following individual: [Name of site lead Socio-Behavioral Scientist]. We can send you a copy of this information, if you would like.

Contact Information

If, at any time, you have questions about this screening process, your rights as a research participant, or if you have questions, you may contact the Emory University Institutional Review Board at +01 404-712-0720 or toll-free at +01 877-503-9797 or by email at irb@emory.edu

Consent

Do you have any questions about anything I just said? Were there any parts that seemed unclear?

Do you agree to take part in the study?

Participant agrees to participate: Yes No

If Yes:

_____

Name of Participant

_____

Name of Legally-Authorized Representative (if non-treatment study, must be parent/legal guardian of minor, or have Power of Attorney for Research)

_____

Relationship of Legally-Authorized Representative to Participant

_____

Signature of Person Conducting Informed Consent Discussion Date Time

_____

Name of Person Conducting Informed Consent Discussion

Appendix B: Semi-Structures Interview Guide (example)

Please note that the purpose of this guide is to provide examples for semi-structured interview consent and questions reflective of the specific aims listed in the protocol. These should be modified to satisfy the cultural norms, timing and sensitivities in each site accordingly. Interviewing strategies involving question sequencing, probing structure, timing and transition should also be designed based on each site's current methodologies. It is anticipated that 8 to 10 questions will take approximately 1 hour using a semi-structured method.

Example Types of Interview Questions

Demographic information

Topic 1: Death and related practices (feasibility)

Example questions for the general sample population:

1. Please describe what happens when a child dies in [name of community].
   Probes:
   - Ask about cultural practices and rituals
   - What happens to the corpse?
2. When a child dies, what happens to the child's spirit and what does the family or the community do to help this happen?
   Probes:
   - Why are those things done? What happens if they're not done?
   - Are there specific things done in the family? Are they done in private? How does the family tell the community that the child has died? When do they tell?
3. What helps a woman to be healthy during her pregnancy? What causes her to lose her child during pregnancy? Are the common beliefs and practices around early pregnancy loss, stillbirth, or neonatal death?
   Probes:
   - If she loses her child, what does she do?
   - What does the community do?
   - Are there specific things done in the family? Are they done in private? How does the family tell the community that the child has died? When do they tell?
4. People are often sad when a child dies. How do people in your community show their sadness?
   Probes:
   - Does a family member do anything specifically? Does the mother?
   - How does the community support the family?
   - Is anything done long after the child has died (e.g., at the anniversary of the child's death)?
   - What things are done to show sadness when a mother loses her child during pregnancy?
5. Do you feel there is value in knowing the cause of death?
   Probes:
   - Explore the desire/willingness to consent.

- How much or what information would be valued?

Example questions for community health care providers, public health practitioners, clinicians, policy and political representatives, researchers, etc. (can be used with conjunction with general questions):

1. What are some of the requirements for the health system (i.e. medical facilities) to conduct MITS procedures?
   Probes:
   - What might be the level of current knowledge (about MITS and/or other CHAMPS activities)?
   - Explore the acceptability of MITS among health care workers.

Example questions for next of kin and/or parents (can be used with conjunction with general questions):

1. Do you feel there is value in knowing the cause of death of your [child, niece, nephew, grandchild, etc.]?
   Probes:
   - Explore the desire/willingness to consent.
   - How much information would be valued?

Topic 2: Ethical Considerations

Example questions for the general sample population:

1. Do you think people should be offered something for taking part in a health-related activity?
   Probes:
   - Have you had any past experiences with receiving food or money by participating in [example health activity] (receiving incentives)?
   - If something were offered to members of your community when they take part in this activity, how would people respond?
2. We want to find out what causes children to die so that we can do something about those things and have fewer deaths of children. Do you think finding out this information would be valuable?
   Probes:
   - If it's valuable, why? If not, why not?
3. [Follow-on to question #2] To find out this information, we have to gather some tissue and fluids from the body of the child after they die so they we can know what caused the child to die. We need to do that within 24 hours after a child dies. We would only do it if the child's parents agreed. How would your community feel about this being done?
   Probes:
   - Explore any concerns from the perspective of the community.
   - Explore any concerns from the perspective of the family.
   - Is there anyone in your community
4. Should women in the community talk with our project staff so that the staff can find out about the things that women face when they're pregnant and learn about the things that can make pregnancy difficult? Doing this would only involve us talking with women and we would only talk with them with their permission.
   Probes:
   - If yes, why? If no, why not?
   - Do you think that families in your community would be willing for the wife/mother to do this?

Example questions for community health care providers, public health practitioners, clinicians, policy and political representatives, researchers, etc. (can be used with conjunction with general questions):

1. What is the role of the government, if any, when a child dies?
   Probes:
   - What are the reporting requirements?
   - Are there any investigations conducted (i.e. if there is suspicion of intentional injury causing the death)?
2. What is the process for reporting deaths in [facility name or community]?
   Probes:
   - Do clinicians feel threatened by results of MITS if different from their diagnosis?
   - Would others (i.e. clinical personnel) see MITS as helpful?

Topic 3: Community Entry and Engagement

Example questions for the general sample population:

1. What places do people go to most often for healthcare?
   Probes:
   - Which facilities in your community are most often used?
   - Which facilities or health providers are most trusted?
   - Outside of health facilities, who do people see for their health (e.g., a faith healer, a traditional healer)?
2. We want to find out what causes children to die so that we can do something about those things and have fewer deaths of children. Do you think finding out this information would be valuable?
   Probes:
   - If it's valuable, why? If not, why not?
3. [Follow-on to question #2] To find out this information, we have to gather some tissue and fluids from the body of the child after they die so they we can know what caused the child to die. We need to do that within 24 hours after a child dies. We would only do it if the child's parents agreed. How would your community feel about this being done?
   Probes:
   - Explore any concerns from the perspective of the community.
   - Explore any concerns from the perspective of the family.
   - Is there anyone in your community
4. If tissue and fluids from the body of a child who dies were to be collected with the parents' permission, what kinds of rumors might start in the community?
   Probes:
   - Do you have any suggestions about ways we could work in your community to address those rumors if they started?
5. People are often sad when a child dies. How do people in your community show their sadness?
   Probes:
   - Does a family member do anything specifically? Does the mother?
   - How does the community support the family?
   - Is anything done long after the child has died (e.g., at the anniversary of the child's death)?
   - What things are done to show sadness when a mother loses her child during pregnancy?

Example questions for community health care providers, public health practitioners, clinicians, policy and political representatives, researchers, etc. (can be used with conjunction with general questions)

1. Who are the most important people that need to be involved in activities related to community entry [describe community entry]?
   Probes:
   - Religious leader?
   - Village chiefs?
2. What do you think would be the best method of educating the community about MITS?
   Probes:
   - Explore facility and community discussions.
3. What are some of the best ways to speak with and involve community leaders in CHAMPS activities [describe CHAMPS activities]?
   Probes:
   - Explore rituals and traditional practices.

Topic 4: Pregnancy and Birth (perceptions)

Example questions for the general sample population:

1. Please describe how pregnant women receive care during their pregnancy.
   Probes:
   - How do women share the news of their pregnancy? When does this usually occur?
   - Do women typically go to an antenatal care facility or receive care at home?
   - Who provides the care for pregnant women (at home and/or in a facility)?
   - Where do women go to deliver? Who provides the care during delivery?
2. What are some barriers to seeking care?

Example questions for community health care providers, public health practitioners, clinicians, policy and political representatives, researchers, etc. (can be used with conjunction with general questions)

1. What are the current capacities in this [facility or community] to date pregnancies and postpartum and newborn exams?
   Probes:
   - Explore types of care and quality of care.
2. Can you describe any policies related to antenatal care?
   Probes:
   - Explore strengths and weaknesses of antenatal care.

Appendix C: Key Informant In-Depth Interview Guide (example)

Please note that the purpose of this guide is to provide examples for key informant in-depth interview consent and questions reflective of the specific aims listed in the protocol. These should be modified to satisfy the cultural norms, timing and sensitivities in each site accordingly. Interviewing strategies involving question sequencing, probing structure, timing and transition should also be designed based on each site's current methodologies.

Example Types of Interview Questions

Topic 1: Death and related practices (feasibility)

Example questions for the general sample population:

1. Please describe what happens when a child dies in [name of community].
   Probes:
   - Ask about cultural practices and rituals
   - What happens to the corpse?
2. When a child dies, what happens to the child's spirit and what does the family or the community do to help this happen?
   Probes:
   - Why are those things done? What happens if they're not done?
   - Are there specific things done in the family? Are they done in private? How does the family tell the community that the child has died? When do they tell?
3. Who are the people who take the lead in doing these things in your community
   Probes:
   - What do religious or spiritual leaders do? Is there more than one type of religious leader in your community?
   - What do healthcare workers do?
   - What do women do? What do men do? What do children do?
4. Can you tell me what happens to the body of a child who dies?
   Probes:
   - How is the body cared for after death?
   - How is the body buried?
   - Who prepares the body?
   - Is there a religious service or some activity the community does together when the child's body is buried? If so, who leads it?
5. Are these things always done for everybody or do people decide that some things don't have to be done?
   Probes:
   - How important is it to carry out these activities?
   - Imagine that these activities weren't carried out. What would happen?
6. What helps a woman to be healthy during her pregnancy? What causes her to lose her child during pregnancy?
   Probes:
   - If she loses her child, what does she do?
   - What does the community do?

- Are there specific things done in the family? Are they done in private? How does the family tell the community that the child has died? When do they tell?

7. Is someone or something to blame for the death of a child or the loss of a child during pregnancy?
   Probes:
   - If so, who is it? What is it?
   - What does the community do in response?
8. People are often sad when a child dies. How do people in your community show their sadness?
   Probes:
   - Does a family member do anything specifically? Does the mother?
   - How does the community support the family?
   - Is anything done long after the child has died (e.g., at the anniversary of the child's death)?
   - What things are done to show sadness when a mother loses her child during pregnancy?
9. Do you feel there is value in knowing what caused a child to die?
   Probes:
   - Why would this be valuable?
   - Explore the desire/willingness to consent.
   - How much or what information would be valued?
10. Our project wants to work collaboratively and respectfully with your community? Do you have any suggestions for helping us to do that?
    Probes:
    - How can we be mindful and respectful of mothers' and families' needs after the death of a child?
    - How can we be mindful and respectful of the community's needs after the death of a child?

Example questions for community health care providers, public health practitioners, clinicians, policy and political representatives, researchers, etc. (can be used with conjunction with general questions):

1. What are some of the requirements for the health system (i.e. medical facilities) to conduct MITS procedures?
   Probes:
   - What might be the level of current knowledge (about MITS and/or other CHAMPS activities)?
   - Explore the acceptability of MITS among health care workers.
2. Having named those requirements, which of them are in place in your health system?
   Probes:
   - What would need to be put in place in regard to facilities? Equipment? Personnel?
3. What role could your health system play in carrying out MITS?
   Probes:
   - Could MITS be carried out in your health facilities?
   - Could your healthcare workers go out into the community to carry out MITS?
4. What role could your health system play in carrying out pregnancy surveillance?
   Probes:
   - Could pregnancy surveillance be carried out in your health facilities?

- Could your healthcare workers go out into the community to carry out pregnancy surveillance?
- Do you have access to an existing disease surveillance database that could provide data for pregnancy surveillance

5. How can CHAMPS activities work with the existing health priorities and activities in the community?

   Probes:

   - How can CHAMPS activities integrate with and/or support the activities of your health system?
   - How can CHAMPS contribute to the public health infrastructure of your community?

Example questions for next of kin and/or parents (can be used with conjunction with general questions):

1. Do you feel there is value in knowing the cause of death of your [child, niece, nephew, grandchild, etc.]?

   Probes:

   - Explore the desire/willingness to consent.
   - How much information would be valued?

2. What is most important for us to do in showing our respect to your family during this difficult time?

Topic 2: Ethical Considerations

Example questions for the general sample population:

1. Do you think people should be offered something for taking part in a health-related activity?

   Probes:

   - Have you had any past experiences with receiving food or money by participating in [example health activity] (receiving incentives)?
   - If something were offered to members of your community when they take part in this activity, how would people respond?

2. We want to find out what causes children to die so that we can do something about those things and have fewer deaths of children. Do you think finding out this information would be valuable?

   Probes:

   - If it's valuable, why? If not, why not?

3. [Follow-on to question #2] To find out this information, we have to gather some tissue and fluids from the body of the child after they die so they we can know what caused the child to die. We need to do that within 24 hours after a child dies. We would only do it if the child's parents agreed. How would your community feel about this being done?

   Probes:

   - Explore any concerns from the perspective of the community.
   - Explore any concerns from the perspective of the family.
   - Is there anyone in your community who would need to give their approval to allow community members to take part in CHAMPS?

4. Should women in the community talk with our project staff so that the staff can find out about the things that women face when they're pregnant and learn about the things that can make pregnancy difficult? Doing this would only involve us talking with women and we would only talk with them with their permission.

   Probes:

- If yes, why? If no, why not?
- Do you think that families in your community would be willing for the wife/mother to do this?

5. You described for us things that are important in the community to do when a child dies. We've described for you the importance for CHAMPS of identifying the things that cause children to die so that we can do something about those things. How important are each of these things to your community?
   Probes:
   - If community activities are more important, why?
   - If CHAMPS objective is more important, why?
6. Do you think that it's possible to do the things that are important in the community when a child dies **AND** to gather the tissue and fluid samples from the child's body?
   Probes:
   - If no, please describe the reasons why both aren't possible in your opinion
   - If yes, please describe the ways that both can be done
7. How can CHAMPS be respectful of and build the trust of community members?
   Probes:
   - Can you think of anything we might do accidentally that would be offensive to the community?
   - What are the best ways for us to work with the community? What are the best ways to share what we find?

Example questions for community health care providers, public health practitioners, clinicians, policy and political representatives, researchers, etc. (can be used with conjunction with general questions):

1. What is the role of the government, if any, when a child dies?
   Probes:
   - What are the reporting requirements?
   - Are there any investigations conducted (i.e. if there is suspicion of intentional injury causing the death)?
2. What is the process for reporting deaths in [facility name or community]?
   Probes:
   - Do clinicians feel threatened by results of MITS if different from their diagnosis?
   - Would others (i.e. clinical personnel) see MITS as helpful?

Topic 3: Community Entry and Engagement

Example questions for the general sample population:

1. What places do people go to most often for healthcare?
   Probes:
   - Which facilities in your community are most often used?
   - Which facilities or health providers are most trusted?
   - Outside of health facilities, who do people see for their health (e.g., a faith healer, a traditional healer)?
2. We want to find out what causes children to die so that we can do something about those things and have fewer deaths of children. Do you think finding out this information would be valuable?
   Probes:
   - If it's valuable, why? If not, why not?

3. [Follow-on to question #2] To find out this information, we have to gather some tissue and fluids from the body of the child after they die so they we can know what caused the child to die. We need to do that within 24 hours after a child dies. We would only do it if the child's parents agreed. How would your community feel about this being done?
   Probes:
   - Explore any concerns from the perspective of the community.
   - Explore any concerns from the perspective of the family.
   - Is there anyone in your community

4. If tissue and fluids from the body of a child who dies were to be collected with the parents' permission, what kinds of rumors might start in the community?
   Probes:
   - Do you have any suggestions about ways we could work in your community to address those rumors if they started?
5. People are often sad when a child dies. How do people in your community show their sadness?
   Probes:
   - Does a family member do anything specifically? Does the mother?
   - How does the community support the family?
   - Is anything done long after the child has died (e.g., at the anniversary of the child's death)?
   - What things are done to show sadness when a mother loses her child during pregnancy?
6. How can CHAMPS be respectful of and build the trust of community members?
   Probes:
   - Can you think of anything we might do accidentally that would be offensive to the community?
   - What are the best ways for us to work with the community? What are the best ways to share what we find?

Example questions for community health care providers, public health practitioners, clinicians, policy and political representatives, researchers, etc. (can be used with conjunction with general questions)

1. Who are the most important people that need to be involved in activities related to community entry [describe community entry]?
   Probes:
   - Religious leader?
   - Village chiefs?
   - Others?
2. What do you think would be the best method of educating the community about MITS?
   Probes:
   - Explore facility and community discussions
3. What are some of the best ways to speak with and involve community leaders in CHAMPS activities [describe CHAMPS activities]?
   Probes:
   - Explore rituals and traditional practices.

Topic 4: Pregnancy and Birth (perceptions)

Example questions for the general sample population:

1. Please describe how pregnant women receive care during their pregnancy.
   Probes:
   - How do women share the news of their pregnancy? When does this usually occur?
   - Do women typically go to an antenatal care facility or receive care at home?
   - Who provides the care for pregnant women (at home and/or in a facility)?
   - Where do women go to deliver? Who provides the care during delivery?
3. What are some barriers to seeking care?

2. What are some barriers to care for women who are pregnant?

3. What do people in the community do when they find out a woman is pregnant?
   Probes:
   - What happens among women when they find out another woman is pregnant?
   - What happens among men when they find out a man's wife is pregnant
   - What happens in the family when the mother finds out she's pregnant?
   - What happens in your faith communities when the members find out that a woman in the community is pregnant?

Example questions for community health care providers, public health practitioners, clinicians, policy and political representatives, researchers, etc. (can be used with conjunction with general questions)

1. What are the current capacities in this [facility or community] to date pregnancies and postpartum and newborn exams?
   Probes:
   - Explore types of care and quality of care.
2. Can you describe any policies related to antenatal care?
   Probes:
   - Explore strengths and weaknesses of antenatal care.
3. How could CHAMPS activities be aligned with and complement your current antenatal and postpartum services?

Appendix D: Focus Group Discussion Guide (example)

Please note that the purpose of this guide is to provide examples for focus group consent and questions reflective of the specific aims listed in the protocol. These should be modified to satisfy the cultural norms, timing and sensitivities in each site accordingly. Interviewing strategies involving question sequencing, probing structure, timing and transition should also be designed based on each site's current methodologies.

Example Types of Focus Group Discussion Questions

Topic 1: Death and related practices (feasibility)

Example questions for the general sample population (i.e. community health care leaders and providers, public health practitioners, clinicians, etc.)

1. Please describe what happens when a child dies in [name of community].
   Probes:
   - Ask about cultural practices and rituals
   - What happens to the corpse?
2. Can you tell me what happens to the body of a child who dies?
   Probes:
   - How is the body cared for after death?
   - How is the body buried?
   - Who prepares the body?
   - Is there a religious service or some activity the community does together when the child's body is buried? If so, who leads it?
3. Are these things always done for everybody or do people decide that some things don't have to be done?
   Probes:
   - How important is it to carry out these activities?
   - Imagine that these activities weren't carried out. What would happen?
4. What helps a woman to be healthy during her pregnancy? What causes her to lose her child during pregnancy?
   Probes:
   - If she loses her child, what does she do?
   - What does the community do?
   - Are there specific things done in the family? Are they done in private? How does the family tell the community that the child has died? When do they tell?
5. Our project wants to work collaboratively and respectfully with your community? Do you have any suggestions for helping us to do that?
   Probes:
   - How can we be mindful and respectful of mothers' and families' needs after the death of a child?
   - How can we be mindful and respectful of the community's needs after the death of a child?
6. What are some of the requirements for the health system (i.e. medical facilities) to conduct MITS procedures?
   Probes:

- What might be the level of current knowledge (about MITS and/or other CHAMPS activities)?
- Explore the acceptability of MITS among health care workers.

7. Having named those requirements, which of them are in place in your health system?
   Probes:
   - What would need to be put in place in regard to facilities? Equipment? Personnel?
8. What role could your health system play in carrying out MITS?
   Probes:
   - Could MITS be carried out in your health facilities?
   - Could your healthcare workers go out into the community to carry out MITS?
9. What role could your health system play in carrying out pregnancy surveillance?
   Probes:
   - Could pregnancy surveillance be carried out in your health facilities?
   - Could your healthcare workers go out into the community to carry out pregnancy surveillance?
   - Do you have access to an existing disease surveillance database that could provide data for pregnancy surveillance
10. How can CHAMPS activities work with the existing health priorities and activities in the community?
    Probes:
    - How can CHAMPS activities integrate with and/or support the activities of your health system?
    - How can CHAMPS contribute to the public health infrastructure of your community?

Topic 2: Ethical Considerations

Example questions for the general sample population (i.e. community health care leaders and providers, public health practitioners, clinicians, etc.):

1. Do you think people should be offered something for taking part in a health-related activity?
   Probes:
   - Have you had any past experiences with receiving food or money by participating in [example health activity] (receiving incentives)?
   - If something were offered to members of your community when they take part in this activity, how would people respond?
2. Should women in the community talk with our project staff so that the staff can find out about the things that women face when they're pregnant and learn about the things that can make pregnancy difficult? Doing this would only involve us talking with women and we would only talk with them with their permission.
   Probes:
   - If yes, why? If no, why not?
   - Do you think that families in your community would be willing for the wife/mother to do this?
3. Do you think that it's possible to do the things that are important in the community when a child dies **AND** to gather the tissue and fluid samples from the child's body?
   Probes:
   - If no, please describe the reasons why both aren't possible in your opinion
   - If yes, please describe the ways that both can be done
4. How can CHAMPS be respectful of and build the trust of community members?

Probes:

- Can you think of anything we might do accidentally that would be offensive to the community?
- What are the best ways for us to work with the community? What are the best ways to share what we find?

3. What is the role of the government, if any, when a child dies?
   Probes:
   - What are the reporting requirements?
   - Are there any investigations conducted (i.e. if there is suspicion of intentional injury causing the death)?
4. What is the process for reporting deaths in [facility name or community]?
   Probes:
   - Do clinicians feel threatened by results of MITS if different from their diagnosis?
   - Would others (i.e. clinical personnel) see MITS as helpful?

Topic 3: Community Entry and Engagement

Example questions for the general sample population (i.e. community health care leaders and providers, public health practitioners, clinicians, etc.):

1. What places do people go to most often for healthcare?
   Probes:
   - Which facilities in your community are most often used?
   - Which facilities or health providers are most trusted?
   - Outside of health facilities, who do people see for their health (e.g., a faith healer, a traditional healer)?
2. If tissue and fluids from the body of a child who dies were to be collected with the parents' permission, what kinds of rumors might start in the community?
   Probes:
   - Do you have any suggestions about ways we could work in your community to address those rumors if they started?
3. People are often sad when a child dies. How do people in your community show their sadness?
   Probes:
   - Does a family member do anything specifically? Does the mother?
   - How does the community support the family?
   - Is anything done long after the child has died (e.g., at the anniversary of the child's death)?
   - What things are done to show sadness when a mother loses her child during pregnancy?
4. How can CHAMPS be respectful of and build the trust of community members?
   Probes:
   - Can you think of anything we might do accidentally that would be offensive to the community?
   - What are the best ways for us to work with the community? What are the best ways to share what we find?
5. Who are the most important people that need to be involved in activities related to community entry [describe community entry]?
   Probes:
   - Religious leader?

- Village chiefs?
- Others?

6. What do you think would be the best method of educating the community about MITS?
   Probes:
   - Explore facility and community discussions
7. What are some of the best ways to speak with and involve community leaders in CHAMPS activities [describe CHAMPS activities]?
   Probes:
   - Explore rituals and traditional practices.

Topic 4: Pregnancy and Birth (perceptions)

Example questions for the general sample population (i.e. community health care leaders and providers, public health practitioners, clinicians, etc.):

1. Please describe how pregnant women receive care during their pregnancy.
   Probes:
   - How do women share the news of their pregnancy? When does this usually occur?
   - Do women typically go to an antenatal care facility or receive care at home?
   - Who provides the care for pregnant women (at home and/or in a facility)?
   - Where do women go to deliver? Who provides the care during delivery?
2. What are some barriers to care for women who are pregnant?
3. What do people in the community do when they find out a woman is pregnant?
   Probes:
   - What happens among women when they find out another woman is pregnant?
   - What happens among men when they find out a man's wife is pregnant
   - What happens in the family when the mother finds out she's pregnant?
   - What happens in your faith communities when the members find out that a woman in the community is pregnant?
4. What are the current capacities in this [facility or community] to date pregnancies and postpartum and newborn exams?
   Probes:
   - Explore types of care and quality of care.
5. Can you describe any policies related to antenatal care?
   Probes:
   - Explore strengths and weaknesses of antenatal care.
6. How could CHAMPS activities be aligned with and complement your current antenatal and postpartum services?

Appendix E: Field Notes Template for Observation Data

Please note that the purpose of this guide is to provide examples for observation opportunities reflective of the specific aims listed in the protocol. These should be modified to satisfy the cultural norms, timing and sensitivities in each site accordingly.

1. **As best you can, provide a brief description of the ritual**
    - Source of this information: (e.g., subjective impression, discussion with someone present)

2. **What does the ritual signify?**
    - Source of this information: (e.g., subjective impression, discussion with someone present)

3. **Where is the ritual being held?**
    - What is the significance of the site, if any?
        - Source of this information: (e.g., subjective impression, discussion with someone present)

4. **Who is present for the ritual?**
    - What are the various roles of those present?
    - Who is the leader/leaders?
    - Are there any variations in roles based on characteristics such as gender, age, relationship to person who died?
    - Is anyone absent?
        - Source of this information: (e.g., subjective impression, discussion with someone present)

5. **What are the elements of the ritual? What activities are performed?**
    - Do the various activities signify anything in particular?
        - Source of this information: (e.g., subjective impression, discussion with someone present)

6. **When is the ritual carried out?**
    - What time of day?
    - How long after the death of the child?
    - What events occur before or after these events?
    - Is timing important?
        - Source of this information: (e.g., subjective impression, discussion with someone present)

Template for Observation of Discussion with Family for Possible Participation in MITS

1. **What CHAMPS team member(s) spoke with the family?**
    - Who did they speak to? Primarily the husband? Primarily the wife? Both? Did they acknowledge all family members?

2. **What was said?**
    - Did the CHAMPS team member say anything before discussing MITS? If so, what did s/he say? (be detailed here. If necessary, continue this on the back of the sheet)
    - How did the CHAMPS team member broach the subject of the family consenting to MITS? What did s/he say (again, be as detailed as possible)
    - Was there any form of non-verbal communication? (e.g., eye contact, a touch on a family member's hand, etc)

3. **What was the family's response?**
    - What did they say specifically?
    - What questions did they ask?
    - What were the responses back from the CHAMPS team member?
    - Did the family display emotion? If so, what emotion was displayed?

4. **Did the family consent**
    - If so, what elements of the conversation were most important for eliciting their consent, in your opinion?

Appendix F: PICK-CHAMP Workshop Curriculums

Community Members Workshop

- Exercise 1: Perceptions of Pregnancy
    - Task: Identify community members' perspectives of the things that cause problems in pregnancy and the things that contribute to a healthy pregnancy
    - Output: A participant driven list of factors that impact pregnancy

- Exercise 2: Perceptions of Childhood Health and Illness
    - Task: Identify community members' perspectives of the things that contribute to healthy children and the things that cause childhood illness and death.
    - Output: A participant driven list of factors that impact childhood health, illness, and death.

- Exercise 3: Participants' Perception of the Death of a Child
    - Task: Participants develop a list of community activities undertaken when a child dies.
    - Output: A list of most important things done in the community when a child dies generated by each individual participant.

- Exercise 4: Community Responses to Childhood Death
    - Task: Participants decide upon the most important things done in their community when a child dies.
    - Output: A ranked list of things done in the community with the most important 4-6 listed.

- Exercise 5: Commonalities Between CHAMPS Objectives and Community Priorities
    - Task: Identify commonalities between community priorities and norms and the objectives of CHAMPS
    - Output: A participant-driven list of messages based on community norms and language that re-enforce the objectives of CHAMPS with the three most powerful messages identified.

- Exercise 6: Relationship Between Community Responses to Childhood Death and CHAMPS Activities
    - Task: Assess the level of alignment or tension between CHAMPS activities and community responses to childhood death.
    - Output: A ranked matrix of alignment and tension between CHAMPS activities and community activities.

- Exercise 7: Community Organizations That Could Support CHAMPS Activities
    - Task: Generate a list of valued community organizations and leaders in the community that could support CHAMPS.
    - Output: A participant driven list of local community organizations that are important resources for the community to respond to the death of a child that participants also identify as potentially supporting one or more CHAMPS activities.

Community Leaders Workshop

- Exercise 1: A History of Our Community
    - Task: Develop a timeline of key social, political and health events in the local community over the last 50 years.
    - Output: A timelines that reflects important historical events and show historical trends that have shaped the current health, social, and political environments.

- Exercise 2: Commonalities Between CHAMPS Objectives and Community Priorities
    - Task: Identify commonalities between community priorities and norms and the objectives of CHAMPS
    - Output: A participant-driven list of messages based on community norms and language that re-enforce the objectives of CHAMPS with the three most powerful messages identified.

- Exercise 3: Perceptions About CHAMPS Activities
    - Task: Assess the level of alignment or tension between CHAMPS activities and community responses to childhood death.
    - Output: A matrix of alignment and tension between CHAMPS activities and community activities.

- Exercise 4: Building Support for CHAMPS
    - Task: Use the key messages created in exercise 2 to create/strengthen alignment between community activities and CHAMPS activities
    - Output: A participant driven list of action steps (and champions) that align with community messages that could be undertaken to build support for CHAMPS

- Exercise 5: Creating a Spiderweb
    - Task: Identify the relationships among key organizations that could support CHAMPS as identified in the community members workshop.
    - Output: A participant developed social network map and contact information for potential community partners of CHAMPS.

Appendix G: Example Timeline for Year 1 (for site consideration)

Activities	Jan	Feb	Mar	April	May	June	July	Aug	Sept	Oct	Nov	Dec
Protocol Adaption (at site)												
Review all materials and forward implementation plan for review												
Finalize protocol and implementation requirements												
Finalize all training materials												
IRB Approvals												
IRB approval												
Submit amendments as required												
Community Entry and Engagement Workshops (PICK-CHAMP)												
Set dates for the workshop												
Recruit participants												
Conduct workshops												
Semi-Structured Interviews (SSIs)												
Train research assistants												
Identify incentives and participant transportation												
Identify participants												
Refine interview questions												
Conduct interview pre-test (pilot)												
Refine interview questions again												
Conduct interviews												
Key Informant In-Depth Interviews												
Identify participants												
Refine interview questions												
Conduct interview pre-test (pilot)												
Refine interview questions again												
Conduct interviews												
Focus Group Discussions (FDGs)												
Identify and arrange site locations for focus groups												
Identify participants												
Register participants												
Develop focus groups questions												
Conduct focus group in [insert area]												
Conduct focus group in [insert area]												
Analysis												
Analyze data for SSIs and key informant in-depth interviews												
Analyze data for FGDs												

Draft preliminary reports												
Post activities												
Conduct evaluation												
Finalize reports and continue to inform community engagement and CHAMPS activities												

Appendix G: CHAMPS Social and Behavioral Sciences Protocol

CHAMPS
Child Health and Mortality Prevention Surveillance

Community Engagement Planning Site Visit

April 2017

This document provides guidance to Country Sites in the Child Health and Mortality Prevention Surveillance (CHAMPS) network on the activities carried out in a community engagement planning site visit. Through the site visit, Country Sites will develop a community engagement approach in collaboration with the CHAMPS Program Office as they carry out CHAMPS activities in local communities. This document will allow Country Site staff to prepare for a strategic planning site visit to develop their community engagement approach.

Table of Contents

I. SITE VISIT AGENDA

Subject to modification

DAY ONE

1. Introduction: The CHAMPS Approach to Community Engagement
    - The Importance of Community Engagement in the Success of CHAMPS
    - The Goals, Objectives, and Outputs of Community Engagement
        - Descriptions
        - Rationale
        - CHAMPS Community Engagement Logic Model
2. The Site's History of Community Engagement
    - Building on existing relationships
        - Existing organizations/bodies
        - History of community engagement
        - Self-assessment of strengths/weaknesses
    - Additional elements that CHAMPS should build on (the unique context of CHAMPS)
3. Activities to Achieve Community Engagement Objectives
    - Current activities
    - Findings from PICK-CHAMP/Formative Research informing the two objectives and related ouputs
    - Community Engagement Activities (initial draft) and their place in the logic model

DAY TWO

Community Visits and Meetings: *The specific agenda will be developed in conjunction with the site prior to the visit. The objectives of these meetings are to:*

1. Introduce the community to community engagement objectives and plans
2. Present findings from the PICK-CHAMP workshops and relevant formative research
3. Discuss challenges and opportunities in the community for implementing and sustaining CHAMPS in light of those findings and CHAMPS objectives
4. Gather community input on implementing community engagement

DAY THREE

1. Developing the site's community engagement plan
    - Modifying the day one draft based on community input from day two
    - Creating and defining activities and approaches
2. Identifying and addressing Logistics
    - Budget
    - Staffing
    - Community partners
    - Timelines
    - Activity planning

DAY FOUR

1. Identifying and addressing logistics (continued)
2. Community feedback
    - Present complete draft plan to community representatives (e.g., the site's Community Advisory Board)
        - Address concerns and adapt as needed
3. Adopt final plan

II. INTRODUCTION

The purpose of the strategic planning site visit is to develop a site-specific community engagement approach to demonstrate to the communities where CHAMPS is being carried out that the Country Site is committed to collaboration, transparency, open communication, and a focus on community priorities. Through the strategic planning site visit, staff from the Country Site and the Program Office will determine the activities to be carried out in local communities in order to achieve the goal and objectives of the CHAMPS community engagement approach:

Section 2.01 Goals, Objectives, and Outputs

While each Country Site will develop its own specific community engagement activities, community engagement across the CHAMPS network is guided by a common goal and two common objectives.

GOAL: Work in partnership local communities to develop and implement activities that help align the CHAMPS site with community values, priorities and interests in relation to CHAMPS activities with a long-term impact on improving maternal and child heatlh.

OBJECTIVES: To accomplish this goal, the CHAMPS community engagement approach focuses on ***two objectives***, one of which is responsive and the other proactive***:***

1. Objective 1: Increase the feasibility of carrying out CHAMPS mortality and pregnancy surveillance in the community.

   This objective will be accomplished through *responsive* activities to address community concerns that arise in response to any CHAMPS activities at the site. Outputs to further this objective will reflect the metrics for measuring feasibility in the SBS formative research:
   a. Increase *acceptability* of CHAMPS surveillance activities in the community.
   b. Improve *practicality* of CHAMPS surveillance activities.
   c. Support *implementation* of CHAMPS surveillance activities.

2. Objective 2: Develop and sustain activities that demonstrate respect for the community and reflect the communities' priorities in relation to maternal and child health.

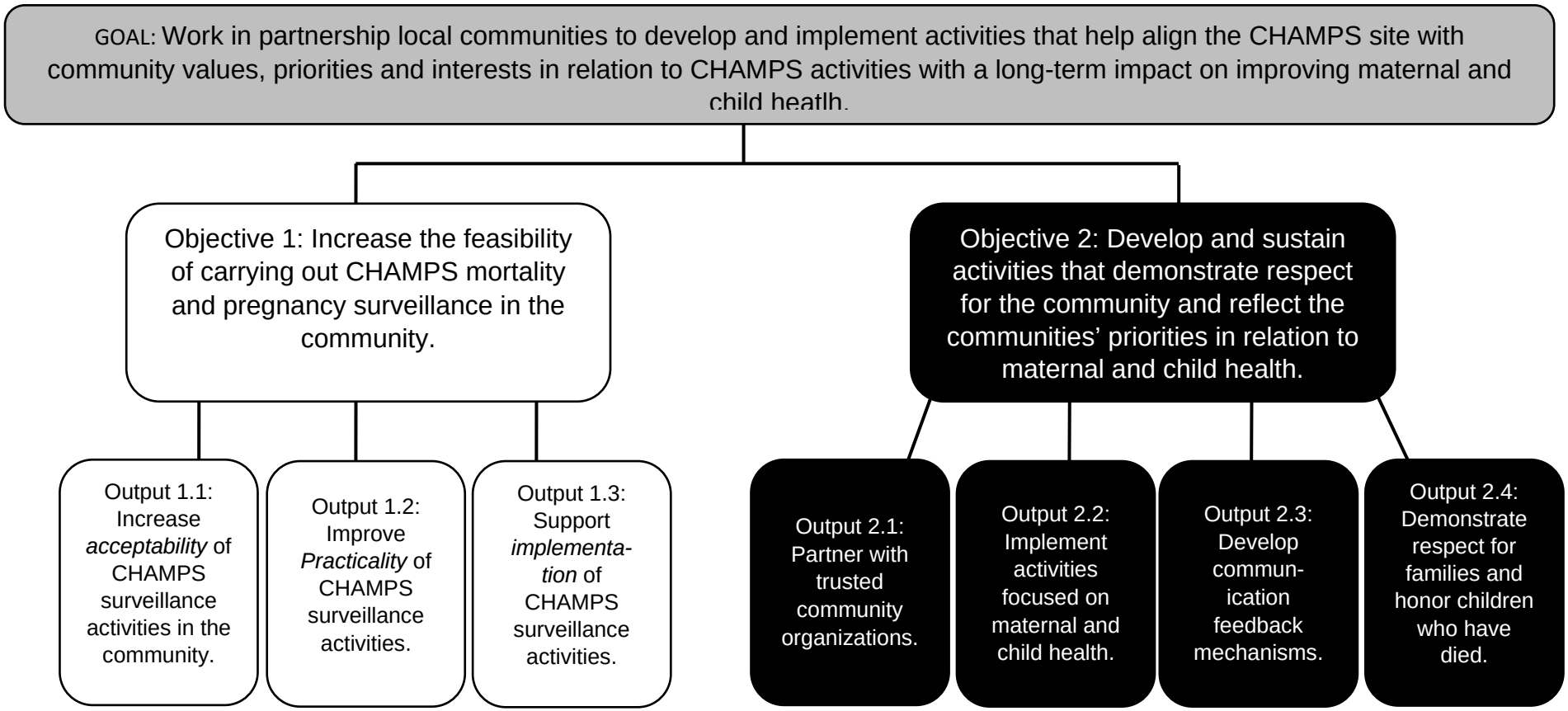
   This objective will be accomplished through *proactive* activities. Four outputs will further this objective:
   a. Build partnerships with existing, trusted community organizations and key leaders already at work to improve maternal and child health.
   b. Implement activities focused on maternal and child health with input from the community in collaboration with existing, trusted community organizations and key leaders.
   c. Develop communication feedback mechanisms in which insights from the community inform CHAMPS surveillance efforts and data from those efforts are shared back to the community.

d. Demonstrate respect for all families who have lost children through culturally appropriate religious and community rituals that honor children in the community who have died.

Through the site visit the Program Office will work with Country Sites to formulate their community engagement approaches to reflect the objectives and outputs of the CHAMPS community engagement approach. The Social-Behavioral Sciences (SBS) staff in the Country Sites will be familiar with these objectives since they are discussed as part of the initial activities of social-behavioral sciences, especially in relation to the community entry activity known as Participatory Inquiry into Community Knowledge of Child Health and Mortality Prevention (PICK-CHAMP). The site visit will occur following the PICK-CHAMP workshops and the completion of the first wave of formative research activities. The site visit will involve not only the SBS staff but representatives from other science teams as well as leadership from the site. In addition, Program Office and Country Site staff will participate in community meetings and work with community representatives and leaders to create the community engagement approach. Once each site's specific community engagement approach is determined, the site staff will begin to implement community engagement activities, which will be carried out in tandem with ongoing formative research activities over the duration of the program. Of course, community engagement approaches and activities can and will be modified over the life of the CHAMPS program; nonetheless, the initial plan for community engagement developed through this process will be crucial for creating strong community partnerships that will be essential for support and sustainability of CHAMPS.

Section 2.02 Project objectives and outputs and logic model

The following pages provide a graphic of the relationships between objectives and outputs as well as logic model for the CHAMPS community engagement approach



Notes: Specific activities related to the outputs named above will be developed with each Country Site. Activities will be culturally and contextually relevant to communities where the CHAMPS personnel in the Country Site work. The outputs for objective 1 reflect the research variables in the SBS conceptual framework for formative research across the CHAMPS network. Specific Country Sites have added site-specific variable to their conceptual frameworks. In such cases, sites are encouraged to develop additional outputs (e.g., activities) related to any site-specific variables. In such instances, those activities will be developed during the site visit.

GOALS AND OBJECTIVES	INPUTS	OUTPUTS		OUTCOMES		
		Activities	Participation	Short Term	Medium Term	Long Term
1. Increase the feasibility of carrying out CHAMPS mortality and pregnancy surveillance in the community.	CHAMPS Personnel Community members Partner community organizations Community leaders Community members PICK-CHAMP findings Formative Research findings Surveillance SOPs Grant deliverables CHAMPS objectives Budget Materials/logistics	1. Increase *acceptability* of CHAMPS surveillance activities in the community. 2. Improve *Practicality* of CHAMPS surveillance activities. 3. Support *implementation* of CHAMPS surveillance activities.	CHAMPS Personnel, with leadership from SBS Community members Community leaders Community organizations Governmental organizations Faith-based organizations (both service providers and faith communities)	Short Term Supportive community leaders engaged Specific elements of CHAMPS surveillance that are in tension with community identified Needed resources identified	Medium Term Increased acceptance of surveillance Stronger partnerships in the community	Long Term Improved maternal and child health in the community
2. Develop and sustain activities that demonstrate respect for the community and reflect the communities' priorities in relation	CHAMPS Personnel Community members Partner community organizations Community leaders	1. Build partnerships with existing, trusted community organizations.	CHAMPS Personnel, with leadership from SBS Community members	Short Term Community-focused MCH activities initiated	Medium Term Increased trust CHAMPS activities and data informed	Long Term Improved maternal and child health

	Community members PICK-CHAMP findings Formative Research findings Identified community priorities Budget Materials/logistics	2. Implement activities focused on maternal and child health. 3. Develop communication feedback mechanisms. 4. Demonstrate respect for families and honor children who have died.	Community leaders Community organizations Governmental organizations Faith-based organizations (both service providers and faith communities)		by community contributions	

NOTE: During the site visit, specific activities that reflect the outputs named above will be identified. In addition, additional outputs that reflect site-specific variables in the SBS conceptual framework will be developed. Finally, site-specific outcomes will be identified and defined. These activities and outcomes will then be placed in the logic model.

Section 2.03 *Rationales for the Outputs*

This section will describe the rationale the outputs related to each objective.

(a) Objective 1

Increase the feasibility of carrying out CHAMPS mortality and pregnancy surveillance in the community.

(i) Output 1.1:

Increase *acceptability* of CHAMPS surveillance activities in the community.

- **Rationale:** In order to accomplish this output, the CHAMPS Country Site will *respond* to the following questions:
  Are CHAMPS activities (pregnancy surveillance, mortality surveillance, demographic surveillance, verbal autopsy, and MITS) acceptable in the communities within the catchment area? Why or why not?
  [Note: For further elaboration on the activities across the SBS team that will be carried out to answer these questions, see the SBS Protocol for the Country Site]

  Community engagement activities will contribute to knowledge on ways to increase acceptability in addition to SBS formative research. The specific nature of these activities will be determined by the site visit.

(ii) Output 1.2:

Improve *practicality* of CHAMPS surveillance activities.

- **Rationale:** In order to accomplish this output, the CHAMPS Country Site will *respond* to the following question:
  If acceptable, can surveillance activities practically be carried out?

  Practicality is assessed in light of two focuses: 1) the overall community infrastructure that must be in place to support surveillance and 2) the community activities that occur when a child dies when must be respected when carrying out surveillance activities.
  [Note: For further elaboration on the activities across the SBS team that will be carried out to answer this question, see the SBS Protocol for the Country Site]

  Community engagement activities will contribute to knowledge on ways to improve practicality in addition to SBS formative research. The specific nature of these activities will be determined by the site visit.

(iii) Output 1.3:

Support *implementation* of CHAMPS surveillance activities.

- **Rationale:** In order to accomplish this output, the CHAMPS Country Site will *respond* to the following question:

What capacities will the CHAMPS Country Site and the community need to carry out these activities?
While the Program Office will work with the Country Site to assess implementation in relation to the infrastructure capacities and needs of the CHAMPS site (e.g., personnel, equipment), the SBS team will support assessment of implementation needs by identifying the key leaders, resources, and organizations which can support surveillance activities in the local community.

Community engagement activities will contribute to knowledge on ways to support implementation in addition to SBS formative research. The specific nature of these activities will be determined by the site visit.

(b) Objective 2

Develop and sustain activities that demonstrate respect for the community and reflect the communities' priorities in relation to maternal and child health.

(i) Output 2.1:

Build partnerships with existing, trusted community organizations and key leaders already at work to improve maternal and child health.

- **Rationale:** In order to accomplish this output, the CHAMPS Country Site will develop *proactive* activities that
  - *Strengthen existing community programs while building support for CHAMPS.* Because CHAMPS has such a strong community engagement model and will conduct ongoing mixed-method research in the social behavioral sciences, the program can offer some resources to local CBOs/NGOs to further their reach and to integrate activities. At the same time, partnerships with trusted organizations and leaders will be essential to CHAMPS in order to build trust by demonstrating that we support and endeavor to strengthen the resources already at work in the community.

  - *Build trust.* As an initiative coming in from the outside, CHAMPS may well be perceived with suspicion initially. When communities find out that CHAMPS will be conducting minimally invasive tissue sampling (MITS) on the bodies of children who have died, that suspicion may well increase. CHAMPS cannot simply ask the community to work with us; we must earn the community's trust by developing relationships in the community. We will work to develop numerous relationships through a variety of activities but establishing relationship with those CBOs/NGOs and leaders who are already trusted.

  - *Increase support for CHAMPS among the community*. Initial findings from follow-up family interviews from MITS pilots have revealed that parents most often cite finding out the cause of their child's death as the primary reason for consenting to the procedure. In community meetings with some local CBOs working on child health, staff

expressed puzzlement as to why they should work with CHAMPS if this is the primary benefit. The possibility that findings from CHAMPS could lead to more effective, more targeted initiatives that could lower mortality was positive but the long time before the implementation of surveillance and findings informing such initiatives served to minimize support and increase perceptions that CHAMPS was simply a research project.

If CHAMPS sites could build partnerships with existing, trusted organizations and leaders the difficulties in describing the benefits of CHAMPS to the community could be lessened.

- *Ease worries of established programs that CHAMPS will be a competitor.* In an era of limited resources, we hope that existing programs will be glad to know that CHAMPS is not entering in to the community as another children's health service organization but as a project whose work can eventually strengthen existing children's health services. If CHAMPS demonstrates its commitment to partnership, the existing organizations and leaders working in this area can be important resources for referral, education, and community health activities (see objective 2).

- *Establish a stronger presence in the community's social networks*. Country Sites are not service providers. Even those sites with well-established community advisory boards (CABs) or other community structures may not be known or trusted entities in the communities where CHAMPS will be carried out. By building partnerships with trusted organizations/individuals, CHAMPS will have opportunities to work across the intrinsic social networks already existing in the community and to eventually become a part of them.

(ii) Output 2.2

Implement activities focused on maternal and child health with input from the community in collaboration with existing, trusted community organizations and key leaders.

- **Rationale:** In order to accomplish this output, the CHAMPS Country Site will develop *proactive* activities that
  - *Align CHAMPS with community priorities for maternal and child health.* Mortality surveillance is a CHAMP program priority; CHAMPS is not primarily a program that provides services to improve maternal and child health. While public health research and practice will be strengthened by CHAMPS and targeted, more effective maternal and child health programs will be developed because of CHAMPS, community members themselves are not likely to see surveillance per se as a priority. Maternal and child health activities will help in aligning CHAMPS with the communities' priorities and encourage trusting relationships to develop.

- *Strengthen partnerships with existing, trusted community organizations (see Objective 1).* Joint activities that further the reach of community partners and leaders will contribute to objective 1 of the community engagement approach outlined above.

- *Build perceptions that CHAMPS is focused on maternal and child health and not limited only to mortality surveillance.* PICK-CHAMP findings already demonstrate that CHAMPS may likely be perceived as a project that focuses on childhood death (participants in various countries have described CHAMPS as a death project). These activities, sponsored by CHAMPS and carrying CHAMPS logos and messaging, will re-enforce a perspective that CHAMPS is committed to maternal and child health and honors that commitment through by supporting specific activities.

- *Develop mechanisms for reporting childhood deaths or complications to pregnancy as quickly as possible.* In some countries where CHAMPS works, the time between the death of a child and her or his burial may be as little as 4 hours. In all countries where CHAMPS works, the Country Site is committed to minimizing delays in the burial processes that will be carried out when a child died. Honoring this commitment requires that CHAMPS Country Sites be notified of a death as quickly as possible. By working proactively with local leaders and organizations to carry out activities, CHAMPS Country Sites will build trust and good will over time. With proper organization, that can translate into improved systems for reporting childhood deaths in the community. Given the very tight timeframe required for carrying out mortality surveillance, such systems will be essential.

(iii) Output 2.3

Develop communication feedback mechanisms in which insights from the community inform CHAMPS surveillance efforts and data from those efforts are shared back to the community.

- **Rationale:** In order to accomplish this output, the CHAMPS Country Site will develop *proactive* activities that
  - *Help ensure that the communities' perspectives inform CHAMPS activities.* Mortality and pregnancy surveillance are both essential to CHAMPS but both may face some level of resistance and be perceived negatively by the community. The CHAMPS Country Site has opportunities to mitigate against these possibilities by adapting surveillance activities to align with the communities' perspectives. While formative research will inform these efforts initially, including specific communications platforms in the community engagement strategy will help the Country Site to adapt accordingly over time and not only in the initial implementation stages.

  - *Provide opportunities for the CHAMPS Country Site to share data from the project with communities.* The CHAMPS network prioritizes

transparent and rapid sharing of data. This is true not only for research and public health leaders but also for communities where CHAMPS will carry out activities. At this point, we are not sure what kinds of data will be most meaningful to communities; this is something to be learned through community engagement, with subsequent platforms to be developed based on what we find. CHAMPS must not be perceived as a research project that merely extracts data from a community; it must be seen as responsive to communities' recommendations. Community engagement activities centered on communications platforms demonstrate such responsiveness. Further, such platforms can provide opportunities for communities to communicate their own points of view related to CHAMPS.

- *Inform data-to-action activities as a follow-on to surveillance activities.* CHAMPS will evolve beyond the surveillance to provide a foundation for targeted initiatives to improve maternal and child health outcomes. Communication platforms will be a valuable tool through these transitions from surveillance to intervention, offering mechanisms to share intervention plans with communities and involve them in creating community-focused, sustainable models.

(iv) Output 2.4

Demonstrate respect for the children who have died in the community and appreciation for the families who participate in CHAMPS activities in culturally appropriate ways.

- **Rationale:** In order to accomplish this output, the CHAMPS Country Site will develop *proactive* activities that
  - *Create culturally appropriate activities that remember children who have died.* These activities, or rituals, will be developed in collaboration with community leaders and members in order to reflect and respect cultural and religious norms. In some countries where CHAMPS works, such rituals might be communal whereas communal rituals around childhood death would not be appropriate in other countries and more individual or familial rituals would be expected.
  - *Ensure that the bodies of children on whom MITS procedures are carried out are treated respectfully.* The surveillance protocols dictates that a series of procedures be carried out on the children's bodies soon after death. CHAMPS staff must ensure that the bodies of children are handled with utmost care and respect during those procedures and that the bodies of children are returned to families in ways that demonstrate our respect.
  - *Express appreciation for families who participate in CHAMPS.* In collaboration with community leaders and members, the Country Site will identify appropriate activities to thank families and to demonstrate respect for their contributions to CHAMPS. These activities should be ongoing to the extent that families wish because they should be based on a commitment to building trustworthy relationships with these families.

- *Create tangible reminders of the importance of children to the life of the community* (e.g., a community garden, mural, or trees planted). In reference to objective 2 above, CHAMPS cannot be seen only as a program that focuses on maternal and child death. By creating and maintaining community reminders of the valuable role of children in the community, CHAMPS will communicate and re-enforce to the community that its long-term goal is the improvement child health even as many of its current activities focus on mortality surveillance.

III. Preparing for the Community Strategic Planning Site Visit

The SBS team (specifically the Community Engagement Lead) is asked to prepare presentations on the following topics and be prepared to present these on Day One of the site visit: 1) Community structures and partnerships, 2) Community activities, and 3) Data from PICK-CHAMP and formative research.

In addition, the County Site team is asked to prepare for community visits/meetings on Day Two of the site visit by 1) identifying relevant participants, 2) coordinating visits to important organizations, and 3) creating an agenda

Section 3.01 Community structures and partnerships

The SBS team should prepare a presentation on this topic, with specific information on the following:

(a) Existing community structures

Please provide an overview of the structures that the CHAMPS site already has in place in the community. Name and briefly describe:

1. Existing structures (e.g., community advisory board),
2. The purposes of the structures
3. Individuals who are part of those structures and their functional roles, and
4. Key personnel in the CHAMPS site who relate to the community structures and their functional roles.

(b) Existing community partnerships

Beyond the community structures that the CHAMPS site already has in place, does your site also have existing partnerships with organizations in the community such as non-governmental organizations (NGOs), local community-based organizations (CBOs), or governmental programs/offices. Name and briefly describe:

1. Organizations in the community with whom you have an existing partnership,
2. The purpose of the partnership. What activities are carried out?
3. Key personnel in each organization who relate to the CHAMPS staff and their functional roles related to the partnership, and
4. Key personnel in the CHAMPS site who relate to the organizations and their function roles related to the partnership

(c) History of community engagement

Aside from currently community structures and partnerships, what history (if any) of community engagement does the CHAMPS site have? Briefly describe:

1. Previous instances of community engagement from the CHAMPS site,
2. Examples of successful community engagement in the past a brief assessment of the reasons for such success, and any ongoing benefits enjoyed by this successful history,
3. Examples of unsuccessful community engagement in the past, a brief assessment of the reasons for such challenges, and any ongoing challenges/barriers as a result of previous unsuccessful engagement.

Section 3.02 Community Activities

The SBS team should prepare a presentation on this topic, with specific information on the following:

(a) Existing activities

Please provide an overview of current activities in the community carried out by the CHAMPS site (even if the site is carrying out those activities with funding from other sources). Name and briefly describe:

1. Community activities,
2. Number and type of participants/beneficiaries,
3. Partnering organizations (if any),
4. Evaluation data (if any) on outcomes or impact, and
5. Extent to which existing activities have any connection to CHAMPS community engagement objectives. Could these activities be expanded to support those objectives?

(b) New activities under CHAMPS

You do not need to prepare a presentation on this topic. A key activity in the site visit will be to develop an initial draft of community engagement activities under CHAMPS and adapting/refining that draft in collaboration with community stakeholders to finalize the site's community engagement approach.

Section 3.03 Data from PICK-CHAMP and formative research

(a) PICK-CHAMP Workshops

Please present on the ways in which outputs from PICK-CHAMP can inform CHAMPS staff about community perceptions in relation to community engagement objectives and activities. The table below summarizes the ways in which the exercises in PICK-CHAMP community leaders and community members workshops may be relevant to community engagement activities. In preparing your overview, feel free to highlight PICK-CHAMP outputs that are relevant to the ftwo community engagement objectives and seven community engagement ouputs described in **Part II** above even if that relevance is not specifically named in the table below.

	EXERCISE	OBJECTIVE	OUTPUT	RELEVANCE TO OBJECTIVES AND OUTPUTS
Community Leaders	Exercise 1: Describing CHAMPS Objectives to Reflect Community Priorities	To identify the commonalities between community priorities and the objectives of the CHAMPS Program.	A participant-driven list of messages based on community norms and language that re-enforce the objectives of CHAMPS with the three most powerful messages identified.	**Objective 1:**The key messages from this exercise can be used to increase acceptability (*Output 1.1*). **Objective 2:** The key messages from this exercise can be used to "make the case" of the importance of CHAMPS to current and potential partners (*Output 2.1*) and respectfully communicate the importance of families' and community members' participation in CHAMPS (*Output 2.4*) in ways that mirror community perspectives.
	Exercise 2: Perceptions of Pregnancy	To identify the community's perceptions about the things that contribute to healthy pregnancy.	A participant driven list of factors that impact pregnancy	**Objective 1:** Understanding community perceptions of pregnancies helps CHAMPS team address negative perceptions and increase acceptability (*Output 1.1*). Once acceptability is increased, understanding these perceptions can guide the CHAMPS team in adapting SOPs to address any issues related to practicality. **Objective 2:** Understanding community perceptions of pregnancies can inform the kinds of MCH activities (*Output 2.2*) that will mirror community norms and assist the CHAMPS staff in communicating more effectively back to the community (*Output 2.3*).

	EXERCISE	OBJECTIVE	OUTPUT	RELEVANCE TO OBJECTIVES AND OUTPUTS
	Exercise 3: Perceptions of Childhood Health and Illness	To identify the community's perceptions about the things that affect children's health: the things that help children be healthy or the things that may make children sick.	A participant driven list of factors that impact childhood health, illness, and death.	**Objective 1:** Understanding community perceptions of childhood illness helps CHAMPS team address negative perceptions and increase acceptability (*Output 1.1*). Once acceptability is increased, understanding these perceptions can guide the CHAMPS team in adapting SOPs to address any issues related to practicality. **Objective 2:** Understanding community perceptions of childhood illness can inform the kinds of MCH activities (*Ouput 2.1)* that will mirror community norms, assist the CHAMPS staff in communicating more effectively back to the community (*Output 2.3*), and support the CHAMPS staff in demonstrating respect to families and the community (*Output 2.4*) in ways that reflect community perceptions.
	Exercise 4: What are the Roles of Community Leaders in Response to Pregnancy and Childhood Death?	To identify participants' roles and responsibilities as leaders in addressing the factors that impact pregnancy and childhood health/illness (named in exercises 2 and 3)	A participant driven list of 1) leaders' role in addressing the factors that impact pregnancy and childhood health/illness, and 2) the ways that CHAMPS could support leaders in carrying out those roles.	**Objective 1:** Understanding community leaders' roles and responsibilities in supporting healthy pregnancies and addressing childhood illness and death can increase acceptability (*Output 1.1*) if CHAMPS builds partnerships with leaders that support both CHAMPS surveillance activities and leaders' roles. As trust is built through these partnerships, the social capital of leaders can be an important resource for addressing issues of practicality (*Output 1.2*) and identifying/mobilizing community resources to support implementation (*Output 1.3*). **Objective 2:** Understanding community leaders' roles and responsibilities in supporting healthy pregnancies and addressing childhood illness and death can assist in identifying key partners (*Output 2.1*) at both individual and organizational levels, build partnerships with leaders to support their efforts through shared activities (*Output 2.2*), creating social networks through which communication efforts can be carried out (*Output 2.3*), and demonstrating respectful engagement with families and the community-at-large (*Output 2.4*).

	EXERCISE	OBJECTIVE	OUTPUT	RELEVANCE TO OBJECTIVES AND OUTPUTS
	Exercise 5: Leaders' Perceptions of CHAMPS Activities	To assess the level of alignment or tension between CHAMPS activities and community perceptions.	1) A participant-driven list of community activities carried out when a woman is pregnant ranked by the level of alignment/tension to CHAMPS pregnancy surveillance activities, and 2) a participant-driven list of community activities carried out when a child dies ranked by the level of alignment/tension to CHAMPS mortality surveillance activities.	**Objective 1:** Understanding the alignment or tension between community activities and CHAMPS activities in relation to pregnancy and childhood death will be essential for increasing acceptability (*Output 1.1*) and addressing questions of practicality *(Output 1.2*). **Objective 2:** Understanding the alignment or tension between community activities and CHAMPS activities in relation to pregnancy and childhood death can provide insight for CHAMPS staff on ways to communicate with the community and topics to address in communication activities (*Output 2.3*).
	Exercise 6: Building Support for CHAMPS	Use the six messages related to CHAMPS objectives to create/strengthen alignment between community activities and CHAMPS activities.	A participant driven list of action steps (and champions) that align with community messages that could be undertaken to build support for CHAMPS.	**Objective 1:** The action steps identified in this exercise represent community-initiated activities which can increase acceptability (*Output 1.1*) and address any identified issues of practicality (*Output 1.2*). **Objective 2:** When community leaders and organizations support CHAMPS in its efforts they provide a platform from which the CHAMPS staff can build partnerships with existing organizations and leaders (*Output 2.1*), collaborate on activities that further the mission of CHAMPS and partner organizations (*Output 2.2*), create social networks through which CHAMPS staff can communicate back to the community (*Output 2.3*), and work through those social networks to carry out activities in the community that demonstrate respect (*Output 2.4*).

	EXERCISE	OBJECTIVE	OUTPUT	RELEVANCE TO OBJECTIVES AND OUTPUTS
Community Members	Exercise 1: Describing CHAMPS Objectives to Reflect Community Priorities	To identify the commonalities between community priorities and the objectives of the CHAMPS Program.	A participant-driven list of messages based on community norms and language that re-enforce the objectives of CHAMPS with the three most powerful messages identified.	**Objective 1:**The key messages from this exercise can be used to increase acceptability (*Output 1.1*). **Objective 2:** The key messages from this exercise can be used to "make the case" of the importance of CHAMPS to current and potential partners (*Output 2.1*) and respectfully communicate the importance of families' and community members' participation in CHAMPS (*Output 2.4*) in ways that mirror community perspectives.
	Exercise 2: Perceptions of Pregnancy	This exercise focuses on naming the community's perceptions about the things that contribute to healthy pregnancy.	A participant driven list of factors that impact pregnancy	**Objective 1:** Understanding community perceptions of pregnancies helps CHAMPS team address negative perceptions and increase acceptability (*Output 1.1*). Once acceptability is increased, understanding these perceptions can guide the CHAMPS team in adapting SOPs to address any issues related to practicality. **Objective 2:** Understanding community perceptions of pregnancies can inform the kinds of MCH activities (*Output 2.2*) that will mirror community norms and assist the CHAMPS staff in communicating more effectively back to the community (*Output 2.3*).
	Exercise 3: Perceptions of Childhood Health and Illness	This exercise focuses on naming the community's perceptions about the things that affect children's health: the things that help children be healthy or the things that may make children sick.	A participant driven list of factors that impact childhood health, illness, and death.	**Objective 1:** Understanding community perceptions of childhood illness helps CHAMPS team address negative perceptions and increase acceptability (*Output 1.1*). Once acceptability is increased, understanding these perceptions can guide the CHAMPS team in adapting SOPs to address any issues related to practicality. **Objective 2:** Understanding community perceptions of childhood illness can inform the kinds of MCH activities (*Ouput 2.1)* that will mirror community norms, assist the CHAMPS staff in communicating more effectively back to the community (*Output 2.3*), and support the CHAMPS staff in demonstrating respect to families and the community (*Output 2.4*) in ways that reflect community perceptions.

	EXERCISE	OBJECTIVE	OUTPUT	RELEVANCE TO OBJECTIVES AND OUTPUTS
	Exercise 4: Community Responses to Pregnancy	To create a participant-driven list of the most important things the community does when a woman becomes pregnant.	A participant-driven list of important things done in the community when a woman finds out she is pregnant.	**Objective 1:** Even if support of pregnancy surveillance exists in the community, CHAMPS must work to ensure that any disruptions to important community/family activities through such surveillance are minimized. Findings from this exercise will help in these efforts, thereby addressing issues of practicality that might arise (*Objective 1.2*). **Objective 2:** Understanding the things that happen in the community when a woman becomes pregnant can aid the CHAMPS staff in developing relevant and timely MCH activities (*Output 2.2*) and identifying the appropriate contexts for effectively communicating to women in the community on findings from pregnancy surveillance activities (*Output 2.3*).
	Exercise 5: Community Responses to Childhood Death	To create a participant-driven list of the most important things the community does when a child dies.	A participant-driven list of important things done in the community when a child dies.	**Objective 1:** Even if support of mortality surveillance exists in the community, CHAMPS must work to ensure that any disruptions to important community/family activities through such surveillance are minimized. Findings from this exercise will help in these efforts, thereby addressing issues of practicality that might arise (*Objective 1.2*). Understanding the things that happen in the community when a child dies can aid the CHAMPS staff in developing relevant MCH activities (**Objective 2**), identifying the appropriate contexts for effectively communicating to members in the community on findings from mortality surveillance activities (**Objective 3**), and demonstrating respect to families and the community-at-large.

	EXERCISE	OBJECTIVE	OUTPUT	RELEVANCE TO OBJECTIVES AND OUTPUTS
	Exercise 6: Participants' Perception of CHAMPS Activities	To assess perceptions of the level of alignment or tension between CHAMPS activities and community priorities and perceptions.	*From Part One:* A matrix showing alignment or tension between CHAMPS activities and community priorities. *From Part Two:* A profile of participants' perceptions about CHAMPS activities across five categories: 1 Acceptability/Value 2 General acceptability of MITS even if there is personal discomfort 3 Beliefs about childhood death, burial, and MITS 4 Beliefs about pregnancy, childhood illness/death, & medical care 5 The value of surveillance and research	**Objective 1:** Understanding the alignment or tension between community activities and CHAMPS activities in relation to pregnancy and childhood death will be essential for increasing acceptability (*Output 1.1*) and addressing questions of practicality *(Output 1.2*). Because the propositions exercise asks participants about detailed, contextual issues related to alignment or tension, an analysis of participants' responses to the propositions can be useful in developing specific community activities to respond to named tensions. **Objective 2:** Understanding the alignment or tension between community activities and CHAMPS activities in relation to pregnancy and childhood death can provide insight for CHAMPS staff on ways to communicate with the community and topics to address in communication activities (*Output 2.3*).
	Exercise 7: Valued Community Organizations That Could Support CHAMPS	Generate a list of valued community organizations and leaders in the community.	A participant driven list of local community organizations that are important resources for the community to respond to the death of a child that participants also identify as potentially supporting one or more CHAMPS activities.	**Objective 1:** Partnerships with the organizations and/or leaders identified in this exercise can increase acceptability (*Output 1.1*) and address any identified issues of practicality (*Output 1.2*). **Objective 2:** Partnerships with named community leaders and organizations can support CHAMPS in its efforts (*Ouput 2.1*). Such partnerships provide a foundation for developing activities that further the mission of CHAMPS and partner organizations (*Output 2.2*), creating social networks through which CHAMPS staff can communicate back to the community (*Output 2.3*), and working through those social networks to carry out activities in the community that demonstrate respect (*Output 2.4*).

(b) Formative Research

Please present on any relevant findings from formative research that relate to the community engagement objectives and outputs. The presentation should:

1. Summarize stage one formative research activities,
2. Name the types of participants (referencing the sampling strategy for phase one), and
3. Name and describe any themes that emerged through narrative analysis of transcripts which are relevant to community engagement activities. *[For example: name and describe themes that reflect interviewees' perceptions of factors that contribute to maternal and child health and then discuss the ways in which those factors could be addressed through activities carried out under objective 2.]*

Section 3.04 Community Input

This section details planning elements for community meetings and for a small group of community representatives to work with the SBS team and the Program Office staff on Day Four of the site visit.

(a) Site visit

During the site visit the SBS team will host a day of community meetings with community members/leaders and organizations. In planning for these meetings, the SBS team need not develop a presentation (the Program Office will provide a general template for any presentations with the SBS team in the Country Site providing site-specific content), but please address the following:

1. Participants
   a. What community leaders should be included? Have all participants from the PICK-CHAMP community leaders workshops been invited? Are there additional leaders (e.g., as key stakeholders) to invite?
   b. What community members should be included? Have participants from the PICK-CHAMP community members workshops been invited? Are there additional members (e.g., as representatives of key groups) to invite?
2. Organizations
   a. What organizations should be invited?
   b. Should there be additional site visits to particular organizations or is it sufficient to invite organization representatives to a larger meeting?
3. Logistics
   a. What types of events will be scheduled? Will there be larger meetings for the community as a whole? Site visits to certain organizations? One-on-one meetings with key leaders?
   b. Where will meetings be held?
4. Agenda

   Keeping in mind the elements from section 1, 2, and 3 above, please develop a day-long agenda for the community meetings and share it with the Program Office prior to the site visit.

(b) Community Representatives for Day Four

A small group that can represent community perspectives will meet with the SBS team and Program Office staff on the last day of the site visit. On this day, the draft community engagement approach will be shared and representatives will offer input and feedback. In preparation for this meeting, please identify 3-5 participants, keeping mind who would be the most effective and trusted stakeholders who could participate.

IV. SITE VISIT PREPARATION CHECKLIST

The following checklist may be helpful for the SBS team to keep track of items for which it is responsible in preparation for the site visit:

The CHAMPS SBS team will be responsible for presenting on:

- Community Structure and Partnerships (see Section 3.01 above for further description)
- Community Activities (see Section 3.02 above for further description)
- Data from PICK-CHAMP and formative research (see Section 3.03 above for further description)

The CHAMPS SBS team will be responsible for planning community meetings on day two of the site visit and for identifying a small group of community representatives for a second meeting on Day Four of the site visit. In planning for these events, the team should:

- Determine Participants for meetings
- Identify Organizations that should be represented and whether a site visit to that particular organizations should be scheduled
- Address Logistics including types of meetings and meeting locations
- Develop an agenda and share it with the Program Office
- Identify 3-5 key stakeholders to represent the communities' perspectives on Day Four of the site visit.

See Section 3.04 above for further description of all of these elements.

V. Site/Program Office Communication

Well before the site visit, the Program Office will contact the SBS team to set up a call to discuss site visit logistics. The SBS team should feel free to contact John Blevins in the Program Office with any questions related to site visit planning (see contact information below).

LOGISTICS

- ☐ Program Office personnel travel itineraries shared
- ☐ Lodging and transport logistics arranged
- ☐ Meeting locations secured
- ☐ Meeting times with CHAMPS staff (including non-SBS staff) set
- ☐ Other items specific by the Country Site:

  _____

  _____

  _____

  _____

The Program Office looks forward to working with the SBS team to develop community engagement approaches and support the activities that follow! Thank you all for your hard work. We look forward to the upcoming site visit.

John Blevins
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Appendix H: INDITe Patient Education Flyer

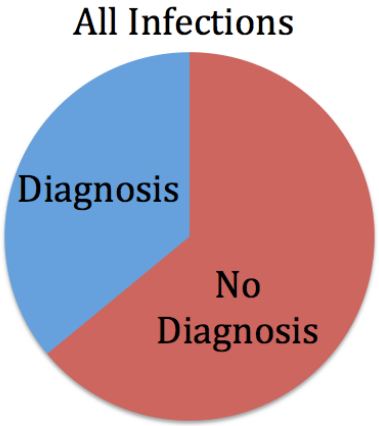
Post-Mortem Examination: General Information

WHAT is a post-mortem examination?

A post-mortem is a procedure done on the body to help **determine the cause of death**

WHY are you doing a post-mortem?

The cause of death is often not known. A post-mortem is the **most effective method** for understanding the cause of death.



What you need to know about post-mortems

WHO

Post-mortem examinations are done by **specialists** in diagnosing the cause of death.

WHERE

The post-mortem will be done at KCMC, in an area reserved for examinations.

WHEN

Immediately after death and will last 1-4 hours.

PARTICIPATION

We are asking families of all patients who die at KCMC and Mawenzi Hospital medicine and pediatric wards to participate.

Frequently Asked Questions

What will happen to the body?

The pathologist will examine organs and will take very small samples to examine further. To do this procedure, the specialist will have to make two openings, one on the chest and one on the back of the head.

Can there still be a viewing?

Yes. There is no procedure done on the face.

Can the body still be washed and wrapped?

Yes. The openings will and closed so that the body can be buried normally.

Will any organs be removed?

No. All organs will remain inside the body at the end of the procedure.

Will organs be used for transplants or medicines?

Absolutely not. Organs are not used to make aspirin or paracetamol.

ORGANS

How much will the procedure cost?

Nothing. The research team will pay for the procedure and up to one week of morgue fees.

How will I learn about the results?

Results are shared with families within two months.

How will the results be used?

Knowing the cause of death from infection can help your family and community protect themselves from a similar illness. The knowledge will also help improve healthcare in Tanzania.

Appendix I: PURPOSe MITS Description Talking Points

Full autopsy - Most comprehensive and complete method to estimate CoD - Rarely undertaken in such resource-poor environments due to cultural, financial, religious, and physical barriers - Very extensive examination of internal organs begins with the creation of a Y or U- shaped incision from both shoulders joining over the sternum and continuing down to the pubic bone
MITS - The MITS procedure involves body inspection and recording of basic anthropometric data; body weight, height/length, mid-upper arm circumference, head circumference, lower leg length and foot length - The procedure involves body palpation by a MITS specialist. - The procedure involves imaging/photography by a MITS technician - The procedure uses biopsy needles to obtain samples of lung, brain, liver and other organs for histopathologic and microbiologic examination to help determine COD

Appendix J: MITS in Malawi Briefing

How to communicate about MITS…

What is MITS?

MITS is an abbreviation for Minimal Invasive Tissue Sampling, a novel and dignified post-mortem that involves no cutting of the body yet is effective at establishing cause of death

Why MITS in Children?

A record number of children are dying despite them being provided with adequate care in hospitals. Doctors believe that there might be underlying causes of death which, when properly understood, can be addressed and the number of children dying can be heavily reduced. The only way through which this underlying cause can be established is through a post-mortem. MITS, therefore, becomes a viable alternative.

What will the procedure involve?

The procedure will involve getting tissues from the body as is done in living people/children. These will then be examined to establish the cause of death.

Will there be any marks left on the body?

There might be small marks in the places where needles were inserted to access the tissue samples. These marks are as small as pencil tip. In Some circumstances, there are no marks visible at all.

How long will this procedure take?

The MITS procedure will usually take 2 hours. However, to properly take care of the body so that it is released to the family in a dignified state, the body will be released to the family within 8 hours.

Will MITS affect burial ceremonies?

MITS will not have a huge impact on the burial ceremony. If the body has to be washed by the family or religious leaders after a death, it can be washed; if there is a need for body viewing before burial, the body can be viewed by the family or community.

Concerns on privacy: who will have access to the samples?

Doctors and pathologists working on the study are the only people with access to the tissue samples. These have been trained in confidentiality and are bound ***not to disclose*** *any details to any person who is not a part of the study.*

How long after the procedure will the results of MITS be released to the family?

The results will be given to the family between 4 to 6 weeks after the procedure. This will be given to the family at the place they will have agreed.

Unanswered questions, whom to contact?

If there are questions or concerns on the study, please feel free to contact Dr Cornelius Huwa (0999 374 103), Dennis Chasweka (0991 492 070/0888 735 851) or Dave Namusanya (0999 697 873)

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