# 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.
- 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.

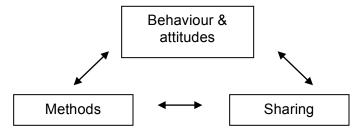
Self-critical awareness and responsibility: meaning that facilitators are continuously examining their behaviour, and trying to do better. This includes embracing error – welcoming error as an opportunity to learn to do better; and using one's own best judgement at all times, meaning, accepting personal 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,
  - 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.

#### <u>Agenda</u>

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).

<u>Step</u> 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 <u>complications during pregnancy</u> 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)

Nutrition (6)

Faith in God (5)

Good sanitation (5)

Knowledge (3)

Water (2)

Sickness (9)

Poverty (7)

Pollution (6)

Bad nutrition (5)

Ignorance (3)

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 <u>health of children</u> 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 <u>children to become ill or die</u> 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).

<u>Step 2</u>: 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.

<u>Step</u> 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.

Facilitator's Notes:

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.

## 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	How does this CHAMPS activity fit with our community's priorities?		
women who are pregnant or who recently delivered a child.	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.

<u>Step 2</u>: 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	Uncertair
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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)

#### **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.
- 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.
- 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) Facilitator's Notes:

#### 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

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.

<u>Output</u>: 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**

Objective:		

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

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 <u>healthy pregnancies</u> for women in your community?

Participant #	Participant's Input

KEY QUESTION TWO: What are the most important factors that cause <u>complications during</u> <u>pregnancy</u> 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 <u>health of children</u> 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**

Could Support CHAIMPS	
<i>Time:</i> 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

i articipant #	Farticipant's input
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# Section 7: Community Members Workshop: SUPPORT TEAM GUIDE

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.

<u>Participants</u>: 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 broadbased 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 prelabeled 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.

**Support Team's Notes:** 

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

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

<u>Food</u>: 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 midday 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.

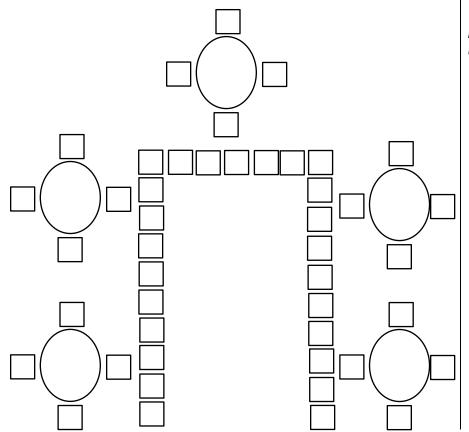
### Registration

The support team should have registration tables by the entrance to

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

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.

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 prelabeled "Exercise 1." The envelope should be closed and sealed if data entry is to happen later offsite.

<u>Step</u> 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 <u>complications during pregnancy</u> 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.

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 Poverty (7) (6)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 <u>health of children</u> 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 <u>children to become ill or die</u> 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.

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.

<u>Step 3</u>: 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:

<u>Step</u> 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).

<u>Step 2</u>: 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.

<u>Step</u> 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:	How does this CHAMPS activity fit with our community's priorities?	
Talking with women who are pregnant or who recently delivered a child.	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.

<u>Step 2</u>: 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.

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:

> Uncertain Agree Disagree

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	
	<ol><li>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.</li></ol>
	4. A woman should not be asked about what's happening during her pregnancy because that information is private.
	<ol> <li>The information gained from tissue samples is worthwhile because this knowledge could help us improve child survival.</li> </ol>
	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

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?

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

Support Team's Notes:

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.

<u>Output</u>: 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.

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

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.

<u>Location.</u> 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.

<u>Participants</u> 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 broadbased participation and non-domination by a certain segment of the community.

### Materials:

- 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:

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.

### 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?

<u>Step</u> 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:

<u>Step 2</u>: 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 <u>complications during pregnancy</u> 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)

Nutrition (6)

Faith in God (5)

Good sanitation (5)

Knowledge (3)

Water (2)

Sickness (9)

Poverty (7)

Pollution (6)

Bad nutrition (5)

Ignorance (3)

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 <u>health of children</u> 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 <u>children to become ill or die</u> 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)

**Facilitator's Notes:** 

### 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 iust 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.

## **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

<u>Step Two</u>: 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	HIGH LEVEL OF TENSION
	TWO DIFFERENT ACTIVITIES/ NO TENSION BUT NO ALIGNMENT
a child.	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.

<u>Step Four</u>: 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	HIGH LEVEL OF TENSION
	TWO DIFFERENT ACTIVITIES/ NO TENSION BUT NO ALIGNMENT
recently died.	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.

<u>Step 1</u>: 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.

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

<u>Outcome</u>: 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

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. While bias can never be fully avoided, it is crucial that the PICK-CHAMP facilitators work on the invitations to ensure broadbased participation and non-domination by a certain segment of the community.

### Materials:

- 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

### Support Team'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.

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

- 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

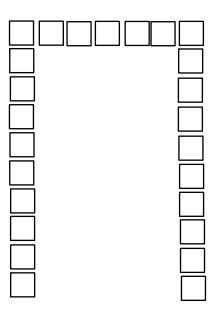
The Support Team should arrange any food to be served during the workshop. In general, PICK-CHAMP workshops provide a morning continental breakfast, a morning tea/coffee break, a mid-day lunch, and an afternoon tea/coffee break to participants. The workshop should be carried out in a facility that would 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)

### Support Team's Notes:

### 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?

<u>Step</u> 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.

<u>Step 2</u>: 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

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 <u>complications during pregnancy</u> 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

When the exercise is

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):

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

Healthy Pregnancy
Good health care (9)

Nutrition (6)

Faith in God (5)

Good sanitation (5)

Knowledge (3)

Water (2)

Complicated pregnancy
Sickness (9)

Poverty (7)

Pollution (6)

Bad nutrition (5)

Ignorance (3)

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 <u>health of children</u> 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 <u>children to become ill or die</u> 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.

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.

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

<u>Step Two</u>: 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.

<u>Step Three</u>: 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

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.

<u>Step Four</u>: 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.

<u>Step 1</u>: 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.

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

<u>Outcome</u>: 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.