Malawi-Liverpool-Wellcome Trust (MLW)

Report for a Entry Exercise in Chikwawa (ADAPT, CAPs, IST & ADJUST studies)

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1. Introduction & Background

Malawi Liverpool Wellcome Trust has been conducting research in Chikwawa since 2002. With the main studies being **SEVANNA**, **IPTpd** and **ACTia** the organization has established a platform with communities within the areas where recruitment is done. Some of the activities that have been carried out in the district included establishing Community Advisory Groups (CAGs), briefing meetings with community leaders, District Health Management Committee (DHMT), Health surveillance Assistants (HSAs) and many community sensitization meetings that aimed at engaging community members on the studies. Following the phasing out of ACTia study, new studies are yet to be conducted in Chikwawa and this justified the fact that another main community engagement had to be carried out so as to establish an entry point of studies into the respective communities. These new studies are **IST, ADAPT, ADJUST** and **CAPs**.

2.0 Planning for the community engagement exercise

Being the first time to conduct such an exercise which involved four studies altogether much of the time was committed to planning; this involved meetings with the Principal Investigators (PIs), reviewing budget(s), consultations with the field team in Chikwawa, placing orders for incentives and liaising with study representatives on the mode of study briefing. As mentioned earlier, putting all the logistics in place demanded more time than expected as a result the dates for commencing the exercise were changed several times eventually on 2nd September the first meeting was conducted.

The exercise was planned in a way that the first meeting was to brief Chikwawa District Health Management Committee (DHMT) and then following meetings with both Chiefs and CAGs in separate sessions. The rest of nine days was committed to conducting community meetings in various zones of the catchment area.

2.1 Targeted catchment area for the exercise

On the ground about 54 villages were targeted for the exercise, the baseline came about because of the difference in the defined catchment areas for respective studies, for instance CAPs will be recruiting from all the 54 villages while ADJUST will have selectable villages within a 30 minutes drive from Chikwawa District Hospital .

2.2 Contributions for the exercise

Considering that four studies had to conduct a community engagement simultaneously among other things the nature of these studies was used in terms of contributions towards the exercise. It should also be pointed out that IST study upon realizing the plan for the exercise, the PI decided to contribute about 10% of the total budget. The remaining amount was sourced from the three other studies as follows; CAPs contributed 50%, while ADJUST contributed 25% and ADAPT 25%. For more information please refer to the budget and other documents that accompanied this report.

2.3 Carrying out the exercise

It is the responsibility of Science communication department to take a lead in conducting and coordinating all community engagement activities for MLW however representatives from respective studies are also supposed to be involved, such is the case because other studies are more technical that further clarification from nurses or clinicians is required. Therefore apart from Science communication team (Elvis Moyo ,Tamara Chipasula and Kelvin Makina) this exercise also involved the following MLW staff; Evelyn Udedi (Chikwawa Acting Site In charge), Chifundo Ndalama (CAPs), Phyllis Mzanga (ADJUST/ IST), Andrew Naunje (CAPs), Milness Mangani (ADAPT/ IST), Frank Mbalume (CAPs, Emma Nyirenda (CAPs) and Aonenji Manyika (CAPs)

Before the actual community engagement exercise study representatives were thoroughly taken through the content of the information that was relevant to be shared to the audience which included the DHMT, the Chiefs, CAGs and the communities at large. A quick guide line was drafted and was circulated to the whole team. Some of the areas which were highlighted were;

- Sponsors/ Funders of the study
- Brief background of the problem/area of focus of the study
- Objective(s) of the study
- Inclusion and exclusion criteria of the study
- Flow of the procedures that will be involved in the study
- Possible risks that may be experienced by a study participant
- Benefits that the participants would have while in the study
- Duration of the study
- The importance of consenting and privacy in the study

3.0 Summary outcome of the meetings

Being a community entry point for all the four studies, the first briefing meeting was with Chikwawa District Health Management Committee, so far the team comprised of 10 representatives from various departments at the hospital. Using a projector, power point presentations for all the four studies were shared using the flow above. Some of the questions that were captured during the meeting are outlined below;

ADJUST study

- The hospital staff from clinical department wanted to know if there will be a possibility of sharing the ECG machine once the study start and in response it was mentioned that the possibility is very narrow but the PI will be consulted on the matter.

ADAPT & IST study

- The presenter was requested to highlight if food will be provided to participants upon admission and further clarification on the matter was provided

- Another issue that took time to discuss was about a Memorandum of Understanding (MOU) that was between ISTP study and Chikwawa District Hospital. The MOU stated that ISTP study was expected to

construct structures such as an extension of a laboratory and additional wards attached to it, all this came up because during ADAPT's presentation it was also mentioned that other additional wards will be constructed as one way of ensuring that recruitment is not delayed. At the end of the discussion acting site in charge who was also in attendance responded that the situation was in control because with ADAPT study the DHO was aware however later after the meeting these two issues were discussed further with other representatives from the DHO who approached the acting site in charge to probe more. (Further clarification can be obtained from Evelyn Udedi, the acting site in charge for Chikwawa field Site)

- CAPs presentation did not invite many questions from the audience apart from the general ones such as the commencement of the study and minor ones.

3.1 Meetings with Chiefs and CAGs

After briefing the DHMT the exercise preceded with meeting chiefs and CAGs separately, the former meeting invited 53 chiefs which comprised of Group Village Heads (GVHs) and Village Heads while the later meeting invited about 64 community Advisory Group members from the villages within the catchment area. The content of the study information was almost similar to the one that was shared with the DHMT except that with such meetings other technical terms are simplified further. In addition, presenters usually use a local language other than English and PowerPoint presentations become ineffective.

Under normal circumstances such meetings are not expected to last more than one hour 30 minutes but due to this exercise, four studies had to be shared to the audience, eventually they lasted for almost two hours 30 minutes. Some of the questions which were captured from the audience included these listed below;

CAPs study

- Who will be the custodian of the stoves when the family is divorced?
- What is the durability of the cook stove considering a Malawian setting?
- Are cook stoves temporarily provided to the participants?
- What will be criteria for a house to be enrolled into the study?
- With the solar that will be provided, will the family be allowed to use them for other purposes such as charging phones and other usages?

ADJUST study

- The presenter was requested to shed more light on the exclusion criteria for those children who will be diagnosed with heart problems
- The amount of blood that will be collected as a sample and also if the participant (s) will be provided with transport
- Will it not be good for the study to involve anemic children so as to help them?

ADAPT study

- What will be the radius of the villages from where enrolled participants will be coming from?
- With the new types of ARVs being introduced, will there be any change in the design of the study?
- What is the duration of the study?

From the two meetings, both CAGs and chiefs requested information about the studies in form of leaflets or pamphlets; this was mentioned after the audience got overwhelmed with the information that was shared. They described it as helpful and confessed that it would be not possible to remember all of it. Science communication took up the matter and ensured them that their request will be acted upon as soon as possible. Mean while at the end of these meetings CAGs and chiefs were assured of the efforts put in place by the new studies in provision of incentives. It was reported t that t-shirts were to be provided soon after the whole exercise and cell phones will possibly follow.

3.2 Community briefings

With community briefings, the setting is always different from the meetings with chiefs, CAGs and the DHMT. Usually a Public Addressing system is used as one way of drawing the attention of the entire community. In this exercise it was planned that about 18 separate meetings should be conducted and this was achieved, two meetings were conducted in a day, in every meeting the attendance of community members was really impressive, the range was from 200 to 500. Some of the questions that were frequently asked about the studies included the following;

CAPS

- Can you use the cook stove to prepare maize thus raw maize?
- What is the difference between this cook stove and the normal one which is commonly known as Mbaula?
- Can people go relocate to their farms with the cook stove?
- How will you ensure that the doctors attend to participants faster just as it used to be in the previous studies?
- How will you help a person if you discover that their lungs are infected with bad air which you will be measuring?
- Can you only use wood for the cook stoves or alternatively use charcoal?
- How are you going to address the problem is ethanol which contaminates air here in Chikwawa because that may have an effect in your findings of this study?
- You mentioned that you will make sure medication for pneumonia is available, will this be accessed by everyone?
- Many families are extended families, are you going to bring bigger cook stoves which will cater for cooking for such big families?
- What's the use of the battery inside of the cook stove?

- It seems like the focus is on women and children, what about men? Don't men cook or suffer from pneumonia? What about old people too?
- Can 2 kids in the study be considered as a household?
- What will happen in times of divorce? Is it that the husband and the wife will have to divide the cook stoves?
- Will you take the cook stoves back when you are done with the study thus after two years of your study?
- How will you ensure people are using the stoves because others may opt not to use them and use their old system of cooking thus using logs?
- Are there no other problems with the study apart from the ones mentioned?
- Can't people buy the cook stoves if they have money? In addition, what will be the sustainability of these cook stoves once the study gets to its completion? Say for instance someone's battery no longer saves power, where will that person get to buy and replace the battery?
- What about when it's raining? How do you charge the stoves? Furthermore will this cook stove not have any effect if it is used in locked doors because with our local cook stove(Mbaula) we are told not to use in while windows and door are closed

ADAPT study

- If a person is admitted, will you give them food?
- Why will the person be admitted for 3 days if he would manage to take the medication at home?
- Why is this study only in Chikwawa and QECH and not any other areas?
- How will you know those on ARVs? Why can't pregnant women participate?
- What if you recruit someone and then they develop side effects. Will you change their medication?
- What age can someone be allowed to get into the study?
- Are you going to give the same amount of transport to all participants in the study?
- What is the total number of people needed in the study?
- Are you going to find people at the hospital or the community?
- What will happen to those who will be admitted for the whole of 3 days and yet they are bread winners, their families may starve while they are in the hospital.

IST study

- Can a person who is out of the catchment area be allowed to be enrolled in the study if he has a strong interest?

- What if someone transfers and goes out of the catchment area, will the person child still be followed up until the completion of the study?
- On the means of assessment of a child's thinking capacity, sometimes children will not do certain things because they are simply following rules, how will you know in that case that a child is not thinking clearly?
- Why will the study provide all the incentives mentioned such as soap, napkins and transport?
- Why has the study decided to only consider those who were already in the previous study? What about those other women who may have interest to join now?

ADJUST study

- Will participants get transport after visiting the clinic on follow up visits?
- How much blood sample will a child be taken and how more often will that be? Another follow up question on the number of finger pricks was paused.
- Why excluding those children who will be found with a heart problem in the study?
- What will happen to those children who will be found with complication while already in the study?
- It was mentioned that DHA PPQ was tried already in other studies, why are we still using LA? And why did you only do research on children and yet you are saying it works for adults too?
- What will the the arrangements of transport to and from the hospital?

3.3 Other general questions

- Where are the results of previous studies like Pregact? Don't we need to wait before starting new studies?
- Which type of mosquito give malaria?
- Why do others get bitten with the mosquito but they don't suffer from Malaria?
- Last year we had people coming to spray yet we still get malaria, how do you explain such a scenario?

3.4 Lesson(s) learnt

- Both communities and their leaders are now in a proper channel of understanding research though this is somehow attached to incentives. For instance during this whole exercise as one of keeping the audience attentive quiz questions were asked after a briefing of every two studies, those who got the questions collect were given a hardcover as a prize. A total about 200 hard covers which were charged to science communication department were given

- Most communities in Chikwawa were thought not to have a culture of reading but this was proved wrong when they requested for handouts after all the presentation, this entails that there need to thoroughly develop leaflets containing study specific information in readiness of community engagement exercise in the district.

- Communities need to be provided feedback on the progress of at least each and every study being conducted in the area. This was cited considering that most communities were interested to know the progress of Pregact study. Another similar issue that came up during two community meetings was concerning other studies which are not under MLW but are being conducted in the same villages; these are supposed to at least brief communities on the objectives because whenever something goes out of hand in the communities, most people think it's a study under Malawi Liverpool Wellcome Trust.

- Another critical area that was learnt is on incentives for specific studies, it is highly recommended that Principal Investigators in the steering committee for Chikwawa try as much as possible to provide incentives which are not very different from other studies. This has been observed in a number of questions that came up during the meetings, for instance on transport reimbursement; it is important that studies have a well document chat which will guide them on how much money will be reimbursed to participants from the same village though participating in separate studies.

4. Acknowledgement

Cooperation and commitment from all the four Principal Investigators (Dr Anja Terlouw, Associate Professor Victor Mwapasa, Dr. Kelvin Mortimer and Dr. Mwayi Madanitsa), this is in both technical support and financial support. Am sure this will continue throughout the period of recruitment. Tremendous support from all study representatives need to be mentioned, they worked tirelessly with Science Communication department from the commencement date up to the end. The acting site in charge together with CAPs consultant are acknowledged for their commitment which ensured that most of the logistics on the ground were put in place and also their involvement in a series of these meetings.

5. Conclusion

Basing on the outcome of the meeting so far communities are really interested to be updated on the progress of studies being conducted in their area, it is therefore important that MLW as an organization gets committed to sustain its efforts to have the engagement process done as it is ongoing in nature, in addition this will pave way to have a reduced number of defaulters in the studies. Communities have now placed their trust in research work though this should not taken for granted hence the need of having that will help their concerns addressed and simultaneously get updated on the progress. Meanwhile incentives which were initially planned to be provided to the CAGs and Chiefs have been issued, the process of purchasing cell phones for both CAGs and Chiefs has started and update will be provide in due course