**FDG FOR 6 MOTHERS BELOW 30 YEARS FROM MULAGO HOSPITAL, LK**

**Moderator;** Now, you are very welcome our mothers, our six mothers as we are going to be discussing. As I mentioned my name earlier on, I am Lawrence Kakooza and I work with Doctor Phiona Ekyaruhanga and we have come today to discuss and know your thoughts about the reasons that you suspect as the causes for the mothers to delay to come to hospital or to hurry.

It is in two ways, there is delaying and hurrying. And in the same way, we would like to know according to you, the way your child was, what signs did you see and understand that made you know and conclude that the child might be having pneumonia. What signs? We are going to discuss this according to our numbers and see. We can either start from this side or that side. Let us start from number one. What signs did you see? You can even tell us that when I saw these signs, I did this till when I reached our main hospital, at Mulago.

**Respondent 1**; me on my child, the sign I saw, the child was not breathing well.

**Moderator;** was not breathing well..,

**Respondent** 1; The whole night, the child was not breathing well and had high body temperatures, that is why I decided to rush the child to the clinic. When I took the child to the clinic, they said it was pneumonia. They treated the child but it failed. We rushed to another hospital, a private hospital. Still, they treated the child for one week and that is when we ran to Mulago.

**Moderator;** Now, the day you saw when the child was not breathing well and had high body temperature, did you go to hospital immediately or to that clinic there and then at that very moment?

**Respondent 1**; I went like the next morning because the child started falling sick in the evening of the previous day at around 5pm, I went with the child and by morning I went to the hospital.

**Moderator;** so you went to the clinic…

**Respondent 1**; yes, I went to the clinic.

**Moderator**; how many days did you spend at the clinic?

**Respondent 1**; I spent there 3 days but still we were seeing no improvement, the child was still not breathing well, then the medical personnel gave us a recommendation to go to the hospital in Maganjo. When we went, the medical personnel had told us to go for a scan and when we went for the scan, they told us the child was badly off with pneumonia and infection. They still treated the child and it all failed and that is why we decided to come this way.

**Moderator;** how long did you stay in that other hospital at Maganjo?

**Respondent** 1; I spent there 7 days.

**Moderator;** okay! Okay!

**Moderator;** until you reached Mulago?

**Respondent 1**; yes

**Moderator;** okay, number 2

**Respondent 2**; just to say health worker, I did not know that the child had pneumonia. I saw the child breathing badly and breathing through the mouth, breathing with an open mouth. I wondered why the child was breathing from the mouth in addition to crying. When I would put the breast in his mouth, he was no longer breastfeeding and when he would sip drinks from a cup, he would sip but the drinks would not go in so well. That is when I said that may be what is causing him to breathe through the mouth might be cough that is making him not to want to feed and also the nostrils felt stuffy, he was not breathing well and would cry the whole night. I understood and decided to take him to hospital. On reaching to the hospital, he was injected, but on looking at him, I noticed he had a stuffy nose, with very thick mucus, the flu that you try to pull out and has formed a plug. To me that was so strange seeing that the child was not breathing well and the mucus was not flowing out of the nostrils. I decided to take the child to hospital. When I took the child to hospital, he was injected.

**(Dr. Phiona);** which hospital?

**Respondent 2**; It was a pharmacy. I will not lie to you that it was a hospital. It was a pharmacy. They injected him, I spent there the first and second day and saw like nothing was going on. I proceeded to another hospital called divine hospital and they are the ones that brought me here in their ambulance. At divine hospital, they also treated the child. They put him on oxygen. On oxygen alone that he may breathe well without injecting him with any medication. They gave him some medication for that flu to come out of the nostrils that he may breathe well. They also tried what they could and told me that you know what, we see that the child’s blood volume is reducing yet by the time you came here the blood volume was a bit okay but we see that now the blood volume is reducing. So now, the child may need to be transfused and yet, here we have no blood. You have to go to Mulago, such that the child stays on oxygen and gets transfused so that the blood volume does not reduce because we do not know why it is reducing. We then noticed that child’s heart was beating faster. He had no fever but the heart was still beating faster and yet the child’s body temperature was normal. The medic said that about the child’s heart beating faster, he may there but having a heart problem when we do not know. Yet when we go to Mulago, they put him under a scan, we can rule out the fact that the heart is okay and the problem is flu and cough that is causing him to breathe badly and the heart to beat faster because it was beating very fast. Then I brought him here.

**Moderator;** Now, at home, shortly after seeing the signs, how long did it take you to decide to seek medical care?

**Respondent 2**; As soon as I see it, naturally I hate seeing a child in pain. That is how God made me! Even when the child is not mine, I do not want to see a child in a hurting situation. I quickly do anything possible to see that that pain goes off him that he may return to normal.

**Moderator;** so, you went to hospital that very night?

**Respondent 2**; Yes, I went that very night. Because when I saw him, I hurried that he may get out of that situation because when someone breathes badly they are feeling unwell.

**Moderator;** when you try to count the days, how may days do you think they are, since the child fell sick up to now, how many days are they up to when you have reached Mulago?

**Respondent** **2**; a week. A week. No, When I add even the time I have been in Mulago, I have made a week

**Moderator;** so, you have made a week.

**(Dr. Phionah);** and how long have you been at Mulago

**Respondent** **2**; they brought me to Mulago yesterday. I have only spent a day here.

**Moderator;** Okay, thank you so much, number 3

**Moderator;** what signs did you see and you concluded that the child was sick?

**Respondent 3**; Health worker, I saw my child’s abdomen had become swollen, he was breathing badly with grunts and also had flu and cough. I took him to a clinic. I first took the child to a nearby pharmacy. They checked the child but he had no malaria. Then I told the medical personnel that the child had abdominal cramps as well and he gave the child a syrup to relieve the abdominal swelling but the swelling was not reducing. He was breathing very fast and on every breathe, an in-drawing would appear on his chest. The child was breathing badly. The medical personnel gave me a syrup and told me to give it to the child. I gave the child the syrup but still there was no improvement at all. The child’s condition just worsened. He was breathing badly with grunts.

**(Dr. Phiona);** was that at the pharmacy?

**Respondent 3**; Yes, at the pharmacy.

**Respondent 3**; the child was grunting, and we made 2 days so, yesterday was the third day when I had taken the child back to the pharmacy. So I told the child’s father not to take the child back to the pharmacy because me I had decided not to go back and most people were telling me to go to Kawempe hospital where I delivered them from, that it is where I should take them because it is them that can handle because I delivered them as pre-matures. Now, I was telling their father that we should go and he was saying that we should first inquire but the child was breathing so badly. So we took the child there. While there, the medical personnel put a cannula on the child to pass the medicine but the child’s condition just worsened. The child was restless and persistently crying without stopping! The grunting increased and the he even got a fever which he did not have before. I stayed there for a moment because I did not have the money to take me to Kawempe at that moment and yet the fever had increased that even some one seated at a distance would hear that the child was grunting. Then my neighbor told me that we should take the child to a certain hospital nearby where they are good at understanding children’s conditions. When we reached, they first injected the child to lower the body temperature because the child’s body temperature was so high.

**Moderator;** which hospital was it?

**Respondent 3**; it is called Rajjib something .I do not remember very well. (laughs )

**Moderator;** Ooh! The hospital?

**Respondent 3**; yes

**Moderator;** so when you reached..?

**Respondent 3**; when I reached, they injected the child to lower the body temperature. The temperature then reduced and he stopped grunting. Then I carried him and after that, the medical personnel wrote for me a letter and told me to go to Kawempe because he was not going to be able to manage the child. At least this one was able to admit that he was not able to manage the child unlike the first one who did not tell me anything but was just giving me syrups and did not tell me that actually he was not going to be able to treat the child and yet the abdomen would just continue to swell. We first went to Kisenyi hospital because the child would not make it to here given his worsening condition. The eyes had started rolling upwards, so we went to Kisenyi. At Kisenyi hospital, they gave him some medication and they wrote for us the medicine and told us to buy it and also put him on oxygen

**Moderator;** so they put him on oxygen. Okay! Okay, so, when you count the days, like how many days are they?

**Respondent 3;** to do what? When they are sick?

**Moderator;** the days in Mulago.

**Respondent 3;** we had made 3 days, now today is the fourth day.

**Moderator;** today is the fourth day? Okay, thank you very much! Number 4

**Moderator;** what signs did you see?

**Respondent 4**; me, the signs I saw, I saw them on Sunday, when he had a cough. He started with a cough and was coughing. After that he got flu. When he got flu, he was not breathing well. The cough was un-productive even after coughing a lot. Then on Monday morning, I took the child to a clinic called’ Yesu Awonya’. I took him there that morning. When we reached that morning, they administered some medication through a cannula that they put on him. When they administered that medicine, they said the treatment was to be for 3 days. We were there admitted from Monday up to Wednesday. On Wednesday when it came to morning, the child’s condition worsened and the medical personnel told me that I should take the child to Mulago because she was not going to be able to manage the child being that the child’s condition was worsening. Then I asked the medical personnel why she did not tell me from the start that she was not going to be able to manage the child. She answered that she thought that she would be able to treat the child but now she can no longer manage and that I should take the child.

**Moderator**; is it the medical personnel that told you that?

**Respondent** **4**; yes, she is the one who told me.

**Respondent** **4**; and I stayed even the next day, on Thursday I stayed there, she gave me a certain syrup to give the child then on Friday it worsened and that is when I came to hospital.

**Moderator;** you came to Mulago…

**Respondent** **4**; I came to Mulago

**Moderator;** okay, number 5.

**Respondent** **5**; me when I had just seen the signs I did not understand it because I thought maybe it was fever but the child was not breathing badly and was not showing any signs of either flu or cough. I brought the child, it was a Monday when she had had a high body temperature throughout the whole night. I brought the child to Mulago, up there. They took off blood from her and prescribed some medication for her that she had no malaria in her blood. They discharged us and told me to go and buy the medication. When we reached home, the moment I gave the child the medicine, she worsened and the flu started to come out then. When the flu came out, the child started not breathing. I bought nasal drops and applied them on her but still there was no change. She even refused to breast feed for about 2 days without breastfeeding at all and was also not drinking. Then on Wednesday at around 2pm, I said to myself that I should go back to Mulago and explain to them. I reached at about 2:30pm. They worked on the child and then they told me that the child is sick, we are going to admit her. By then, I had not understood that the child had pneumonia. Again they took off blood for malaria and she was still negative. They put a cannula on her and administered some medication. I then told them that maybe I should go back home now, it being not far from here, I will come back tomorrow early morning. When I reached home, the child just worsened. I then told myself to be strong, that I would go back to hospital the next morning. I came back to hospital the next morning but the child was not breathing and it is yesterday that the child resumed breast feeding after being off oxygen.

**Moderator;** When you mentioned that’ I will go back to Mulago and explain to them,’ had you been to Mulago or like a few days before?

**Respondent** **5**; I came. It was a Monday because when she gets sick, like she normally gets flu, each time she falls sick I come up there, there is a place where children are worked on from. So I went there, they worked on her but the flu was not showing any signs. I then went back home. They had written for me medication. I bought it and gave it to her but I was seeing no improvement.

**(Dr. Phionah);** up where? Is it at assessment?

**Respondent** **5**; yes

**Moderator;** up where they used to immunize the children from?

**Respondent** **5**; I do not know whether they immunize children from there.

**Moderator;** okay, thank you! Then number 6

**Respondent** **6**; for me health worker the child started with abdominal pain. The abdomen was paining him so much. Then in the evening I went to a clinic and bought some pain killers and gave him, but the pain persisted and he spent the whole night crying. He started having high body temperature. In the morning I took him to Dr. Mukasa’s clinic near home

**Moderator;** Dr. Mukasa?

**Respondent** **6**; yes, and he told me that the fevers were so high. He injected the child and gave us some syrup and told me that the child will get better. The child was not improving and the abdomen was just increasing to swell. Doctor then told me that I had to take back the child to the clinic. When I took the child back to the clinic, the Doctor told me that now, let me write for you a letter and you go to the hospital in Mityana. We went to Mityana hospital, they treated the child but still there was no improvement and was breathing badly at a faster rate. We were there for some days and then we were discharged.

**Moderator;** when you count, how many days do you think were they?

**Respondent** **6**; we have made a week

**Moderator;** so when did you come to Mulago?

**Respondent** **6**; we came on Monday

**Moderator;** Monday, okay!

**Moderator;** Thank you so much because everyone has been able to tell us what they went through.

**Moderator;** now, in Uganda you find that in most cases the care takers do not come to hospital within the first 24 hours after the child has gotten cough or even difficulty in breathing. Have you ever heard of the saying that once a child gets pneumonia they need to come to hospital before the first 24 hours elapse? Have you heard of it before or does anyone of you know it?

Nobody knows it?

Now, when a child catches pneumonia they need to get urgent medical help at least within the first 24 hours. That a side, do you know any advantages of seeking medical care before it is too late? What do you think we benefit from going to hospital early to get medical help?

**Respondent** **2**; now when you hurry to go to hospital for medical help, the illness may not affect you or the child so much.

**Moderator**; thank you so much.

**Moderator**; she has told us as you have heard. Another one…

**Respondent** **1**; you save the child’s life.

**Moderator;** you save the child’s life. Another one. Do we have any other person with a different reason from what these ones have mentioned?

**Respondent** **3**; health worker, if I had hurried, my child would not have reached to this point. Over staying in clinics is what caused all this because I almost lost my child.

**(Dr. Phionah);** what do you mean in all this?

**Respondent** **2**; a child being on oxygen is not life health worker!

**Respondent** **1**; I wish the moment I got to know that the child was sick I came here, my child would have recovered there and then. But first going to the other side (the clinic), and they don’t tell you that the child has pneumonia…

**Moderator;** okay, thank you number 3 and number 2 for adding.

**Moderator;** is there any reason that we might have left out apart from that of number 1, 2 and 3? Is there any?

**Respondent 2**; now health worker, when you come late to hospital each time you fall sick, even the body parts that were initially not sick become sick because of the delay. Yet when you come early to hospital, for instance, if pneumonia was at a lower level initially, it increases with time but if you come early to hospital the disease will be captured when it is still at a lower level where it started from. It means by the time we come to hospital, pneumonia has already spread for example by the time I brought my child, the bacteria had already spread in the whole body and yet if I had hurried to come, the bacteria would not have spread throughout the whole body

**Moderator;** thank you very much for your supplement.

**Moderator;** now you find that where we stay or the areas where we stay, some of the care takers come to hospital as soon as they see that the child has a cough or difficulty in breathing. In your thinking, what reasons do you think lead to this, to be that some people hurry to come to hospital? What reasons do you think they have that make them to hurry?

**Respondent** **2**; health worker, may be they have ever seen a person suffering from that disease, or maybe like how I have come to hospital today and I see the various conditions that children suffering from pneumonia be in. Now, also me when am there I will hurry for the fear of my child being like one of those children I once saw in hospital. Then I hurry to come to hospital.

**Moderator;** so that is what causes hurrying, what do you think could be causing….okay lets first leave it at that.

**Moderator;** okay. Fine. Apart from number 2, does anyone else have any other reasons that cause the caretakers to go to the hospital quickly?

**Respondent** **2**; you may fear that your child may die

**Moderator;** your child may die….thank you! So, apart from number 1 and 2, because they have given their suggestions. I request that you tell me about some of the few reasons that you think make the caretakers to come to hospital before it is too late apart from having witnessed and fear that the child may die, what else do you suspect?

**(Dr. Phionah);** that which enables them

**Moderator;** it may even be away from the signs and we consider looking at collective things like where we live, the way we move, our mindset and thinking, the poverty we are living in at the moment, you find that you may look at reasons but considering such.

**Respondent** **1**; Health worker, I think it is due to where I stay, because where I stay is a very cold environment. It is possible to have been the cause of my child’s illness. The house I stay in is very cold.

**Moderator;** now, leaving the reasons that cause us to hurry aside, you find that most of the care takers take long to come to hospital. In your own thinking, what reasons do you think cause the caretakers to delay to come to hospital? This time, we are going to have number 2 and 1’s submissions last. I request that you give us some of the reasons, number 6, that might be leading to the delay to come to hospital. You may not consider only the signs but also look at all the things surrounding us. Everything like transport, where we stay and the situation at hand.

**Respondent** **3**; health worker the medical personnel in clinics tell us that the children will get better. They give us medication, and you stay there thinking that the child will recover.

**Respondent** **2**; they give you syrups…that take! The child will be fine!

**Respondent 3**; they even inject them…

**Respondent** **3**; and you see now health worker

**Moderator,** thank you number 3, yes number 5

**Respondent** **5**; you see now health worker you may find that, like now, the disease just comes abruptly. There is a time when the child just gets normal flu and is not pneumonia. Now, as a parent, when she sees that the child has flu, she is used that each time the child gets flu, she normally treats that child herself without even first going to hospital when she knows the treatment for flu and that may also result in delay to go to hospital

**Moderator;** she has told has her reason. Thank you very much number 5

**Respondent** **4**; now health worker, what makes any person to delay to bring the child to hospital is that you may be having a child, and he/she gets sick and you take them to a clinic. When you take the child the clinic, they tell you that le us give the child this syrup or let us establish a cannula and administer medicine and the child will be okay. So, you also maintain that, that the child will be okay since it is the medical personnel that told me. By the time you remember that the sickness has worsened, it is already too late. That is what makes us to delay to come to hospital.

**Moderator**; all your inputs are correct! Thank you all! Number 4 thank you so much. Does anyone else have any other reason for the delay?

**Respondent** **2**; health worker, I have mine

**Moderator;** okay

**Respondent** **2**; I may come to a hospital, like now here the way we are. When we come and then you ask for money from us. In other words the prices are too high. So when I am discharged and go back home, I start getting worried about where I will get the money for Mulago from.so, I decide to first try in a clinic because the money you asked from me the last time I came was a lot. At times you resort to using herbal medicine due to the fear of hospital bills So, there is also such a scenario

**Moderator;** does that happen to you each time you come here?

**Respondent** **2**; yes. It happens.so each time the child falls sick, you relate to your last experience and get worried about having no money and wonder what you are going to do! That also happens. So you delay trying to manage the child with herbal remedies in fear of hospital bills

Another reason is the distance from the health facility. You may find that the clinic near home will not give you the desired results and yet the better hospital is for instance Mulago where they will tell you that the child has pneumonia. Like where we started from, they tested the child and they were just telling us that the child had no fever. The tests revealed nothing but the swelling of the abdomen was increasing. When we went to the main hospital that is when they told us that the child had pneumonia.

**Moderator;** okay. I think this has somehow confused you because, thank you. You have understood and have discussed well but I think we can we try to categorize our reasons in order of causes for delay to decide to seek care, delay to walk to the health facility and delay to receive care while at the facility because they are different. There may be something that causes you to delay to take the child to hospital, and the after you deciding to take the child to hospital and after reaching hospital there is what delays you to receive medical care

**Respondent** **2**; when I had just brought the child the first time, the health worker I found at the reception made me hate the hospital. She made me hate the hospital! Because I came in ambulance up to here with my auntie and they told me to take the child to the reception where they start from. The health worker barked at me saying,’ why have you brought the child here without weighing him first!!’ I told her health worker, we have come in an ambulance and they told us that since the child was on oxygen, he needs oxygen urgently.

‘Now, sit there! If you cannot wait for the queue! Sit there, if you cannot wait for these in the queue to get worked, sit there! Whether he does not have oxygen, be it so! , as she barked at me.

That situation really discouraged me a lot because I had hopes of being helped quickly when I get to hospital, but when she baked at me, I was so discouraged! So discouraged! Now, I may have the child fall sick again and I fear for who I am going to meet at the reception.

**Moderator;** so, that means that your delay was after you reaching hospital.

**Respondent** **2**; yes, I spent much time there as she was tossing me. I really spent much time there it being that I had to urgently get the child back on oxygen and yet she was still tossing me here and there! Yet by the time I brought the child, it was indicated that he had to first be put on oxygen. I was really disturbed so, if am discharged, the next time the child falls sick I may not want to go through the same disturbance and being barked at by the nurse at the reception the second time. So, all those are challenges of the hospital.

**Moderator;** now, thank you number 2. Number 4, you said that in most cases the delay is due to first going to the clinic. Apart from those reasons that the medical personnel at the clinic has told you that she/he will treat the child to recovery. Is there any other reason that you left might have left behind that may lead you to delay to decide to go to hospital or to walk or now that you reached to the hospital? Did you leave any reason out?

**Respondent** **4**; health worker, another reason that causes the delay or what caused my delay was the issue of money. I did not really have money to come to Mulago and when I reached here, they first told me to give them 20,000shillings to first test the child’s blood yet I had not come with any money. Actually the medical personnel told me to sit aside and that I would only be worked on when I get the money. It was until I got the money, gave it to her and then she worked on me.

**Respondent** **2**; another thing health worker like me when am discharged and as I have told you earlier on, it is me who will discourage others about coming to Mulago. The negative reports we give to other people are what discourages them from coming to Mulago, we ourselves! The report I carry home on discharge, the rumor! We go with reports like when you reach there it is like this and this. The very people you work one, we take reports to others. So now if my neighbor’s child falls sick, she may not want to come because I told her what I went through while in Mulago. Now when it is her time to come to Mulago, she is hesitant because she is now afraid that I told her then she goes to where she will not be helped from. So, health worker if you create a hospitable environment, we can quickly come!

**Moderator;** now that means for most of us the delay was at the hospital.

**Moderator;** now, number 2

**Respondent** **2**; it is us who take negative information on discharge to where we come from

**Respondent** **4**; I would not have a problem. You see that night I came, I came and they took off blood. The health worker told my husband you know what, but he did not have money, not even a single coin. The medic told him you know what, I want 30, 000 shillings we go and test blood (I do not how she exactly said it). When we reached home, remember we had requested to first go back home, my husband told me you know what, do not go back! I do not have money, that 30, 000 shillings.

(All mothers laugh)

‘The child just has flu. We can treat with Panadol and a syrup for flu. 30,000 shillings is a lot! Remember you are going back, they prescribe for you medicine and yet I could top up on that and buy medication’, said my husband.

**Respondent** **4**; Now me myself when I saw the child’s condition, I said no, money is not the main issue! Let me go. So we came

**Moderator;** apart from that situation, was there no other issue that challenged you say at home, and made you decide to take the child to hospital?

**Respondent** **4**; there is none, because if I see that it is normal flu, like he usually suffered from flu, I would buy syrups and give him but when I see that it has worsened, like it had reached a time when the child would have high body temperature and even when you would give Panadol, it would only work for a few minutes and after short while and the temperature raises again because they had also given me that Panadol to insert in his anus (In the buttocks) , but still it would take a short while and the temperature raises again. Then I said no! This has never happened!

**Moderator;** it was not the usual one

**Respondent** **4**; but still you would notice that when the temperature reduced he would resort to playing without any problem.

**Respondent** **2**; and you yourselves (the medical personnel) cause us trouble when we go back, you cause us chaos at home because the husband now thinks your cheating from him because you are asking for money. When we go back home there is chaos. The husband starts quarrelling that ‘’when you were at hospital you used to call me asking for money! 100 000, 200 0000 do you think that when you go to hospital we are here making money?’’ because when you are in hospital you call him saying now health worker has said that we need 100,000, 200,000 there!

**Respondent** **2**; he starts telling you never to go back to that hospital because they ask for a lot of money! So, when the child falls sick, you become hesitant because the last time you were there you spent. All that is trouble in a home arising from the hospital.

**(Dr. Phionah);** it is as if I have understood something. Do fathers at times stop you from bringing to hospital?

**Respondent** **2**; yes, because of money! Each time you call and tell him that now they have asked for such an amount of money to do a chest x-ray, he starts asking you that it being a government facility, how come they are asking for money? So the next time you have a sick child he stops you from coming to hospital in fear of asking for money from him. He then tells you to go to the clinic, buy some tablets and start the child on them then you be in such a situation yet the child is weakening the disease that has been at a lower level increases to a higher level. By the time you decide to bring the child to hospital, it is already late and the illness has already spread throughout the whole body. Yet it is the situation that causes that because we come to hospital in great fear. We really come to the hospital in great fear!

**Moderator;** what about the situation at hand these days? The situation these days. Say you have decided that I am now going. I am going to move and your husband had decided that the money is here to pay at the hospital.

**(Dr. Phionah);** what may hinder you?

**Moderator;** what reason can lead to the delay to reach Mulago? Mama from Mityana, what reason do you think might have led to your delay to reach Mulago Hospital?

**Respondent** **6**; Health worker, we had no money for the ambulance

**Moderator;** money for the ambulance

**Respondent** **6**; in fact, we had to first look for the money,

**Respondent** **2**; but they also over charge us

**Respondent** **6**; people had to contribute for us to come. Yet the child was in great pain.

**Respondent** **2**; me they got me from Nansana at 60,000 shillings and yet a boda boda can transport you for only 3000 shillings but they charged me 60000 shillings

**Moderator;** okay

**Respondent** **2**; yes, they charged me 60000

**Moderator;** have we left any reason behind, that might have caused the child to delay to get medication, as we have categorized them? You may have left one behind. That may be, for me, in making my decision may be something happened and no one has talked about it yet.

**Respondent** **6;** Health worker, last time they took off blood from this child and they told me that I should take it to the lab down. When I reached there they told me that I should give them 60000 shillings. They told me that if I don’t have the money, they will not work on the sample and up to now am still waiting.

**Respondent** **2**; that means the child has not yet received the right treatment!

**Moderator;** here in Mulago?

Yes.

**Respondent** **4**; Health worker, the problem I got is a medical personnel coming and intimidating me. Instead of comforting me, he started saying that the child has downs syndrome. That such a child has eyes, a weird face and that the nose and he has 3 of these small things (undescribed).

(Mothers laugh)

It confused me! They said that such a child becomes crippled, sometimes they never talk, and yet mine walks, you see!? And even talking he can say Wangi, daddy, like that. He told me that if you have any challenge with that, go on to Google (mothers laugh) you watch and understand it properly. There I got some bit of trouble. Then I wondered that of all the medics that checked the child, how come that this one has now come to tell me such a word!

**Moderator;** were you affected by that in any way?

**Respondent** **4**; it really affected me so much!

**Respondent** **2**; it also affected me because they told me the same thing and I have always been on that doctors case inquiring about my future with my child

**Respondent** **4**; actually, I got annoyed and marked that young Doctor’s face .Even if I see him! I even said that God should help me so that my child grows and talks such that I will take the child to him to see.

**Respondent** **2**; because even the child he told me about sits, and can as well look for his play items. He was the first person to tell me such. The same way this one (number 4) was also told. He told me that it causes the child to fail to sit, failure to learn well in class,

**Respondent** **4**; that a child becomes like a mongle.

**Respondent** **2**; such bad news scares us

**Respondent** **4**; Instead of comforting me that it is like this.

**Moderator;** okay, we are very thankful that we have been able to discuss the reasons that cause the delays and those that make us hurry. Now, in this research, we continue to try to understand if there is any, among all the traditional methods or if there are things we do in our daily lives and they can cause you to decide to go hospital once you see that the child is suffering from pneumonia? Do you think there are any traditional ways that may cause you to either delay or hurry to seek medical help? Our traditional remedies, that when I do this, this happens

**Respondent** **2**; health worker, one time back then my friend once told me that if it is pneumonia, you boil ‘‘ mwambala butonnya,’’ that those things of the Mulago hospital are burdening you for nothing and you will conclude by coming back to the traditional remedies but I also told her that you know what, let me first take the child to the medical professionals and once they are done with their medication , I will come and we try the herbal medicine too , but I did not discourage her

**Moderator;** did this affect you in any way?

**Respondent** **2**; no! Not in any way. I told her that let me fist do to the medical professionals, because even with them if it is pneumonia, they can know it and they also have their western medicine. Herbal and western medicine do not make overdose. I hope when I alternate from western medicine to herbal treatment there is no over dose. When they give the child western medicine and then I give him herbal no one will tell me that since you gave the child a lot of medication that is; the western medicine and the herbal remedy then that is why pneumonia failed to be cured. No! So when they give the child the western medicine, I will supplement it with the herbal remedy.

**Moderator;** now, about number 2’s opinion as she has discussed, that someone has told you that when you give the child boiled ‘’mwambala butonnya’’ pneumonia will get cured. Does any of us have any reason that resembles that of number 2, that may be some told you to first give the child a certain herbal remedy like number 2?

**Respondent** **1**; it is the same as mine because when I was the other side and they were treating infection, and yet the abdomen was swelling then my auntie told me that I should take the child away from hospital to her.. The child will die in your sight. Then I told her that the child was on oxygen and I could not get it off him.

**Respondent** **2**; they told me pneumonia does not get cured.

**Respondent** **1**; Then I told her that let me first rush the child to Mulago being that he is on oxygen and when he gets off oxygen, I will bring him to you. Personally I do not know those things.

**Moderator;** now number 1; when she told you did you feel in any way? Didn’t you take the child there?

**Respondent** **1**; I did not take the child to her. I just got some fear thinking maybe it is what will work. I also did not know that among the signs of pneumonia the abdomen swells and was just suspecting that may be the child ate something. I was just suspecting and I told God to show me the way because I do not know what to do!

**Moderator;** but you said that you were going to first get the child off oxygen and then take him. Are you going to take him?

**Respondent** **1**; now when I brought the child here, I see that even the abdomen has reduced in size, the child is breathing well and everything went back to normal.

Mo**derator;** that means you are not going to take him to your auntie

**Respondent** **1**; I cannot! I cannot

**Moderator;** does anyone else have any reason concerning the traditional methods we use or do?

Me, they told me that my child has false teeth. (Laughs). A woman told me to go and see, that my child has false teeth and that they kill

‘’then what do you do for them?’’(Murmurs from some mothers)

**Respondent** **2**; the Baganda scrub them off

Moderator; does anyone else have any other reason that made them to delay to decide for instance like this one who has told us that someone has told you to use certain herbal medicine and you end up saying that let me first use this remedy because I over trust the person that has told me and you go to hospital after it failing?.

**Moderator;** number 5

**Moderator,** any other reason that made you delay to seek medical care?

**Respondent** **5**; my brother called me yesterday, and I told him that we have been admitted, the child has Pneumonia. He asked why I took the child to hospital yet he has pneumonia? He also asked why the child has been put on oxygen. He then told me that I should go, get ‘matugunda leaves’, squeeze juice out of them and give the child to drink. The child will be okay. He even would not have been put on oxygen if you had told me early enough and I tell you what to do. I then told him that right now I no longer have what to do because now the child is breathing well compared to how I brought him

**Moderator;** How did it make you feel? Did you feel like taking the child to get the matugunda leaves?

**Respondent** **5**; no

**Respondent** **2**; and another thing health worker, they once told me that whites (western medicine) do not treat and don’t cure pneumonia. They had discouraged me.

**Respondent** **1**;That is true

**Respondent** **2**; but when I reached here the health worker told us the children with pneumonia are treated and get cured. Then I got so clingy on her and asked her that health worker is it treated to full recovery? She replied with a yes

**Moderator;** thank you so much number 2

**Moderator;** number 5 you were saying something?

**Respondent** **5**; me, according to how the say it, they say that pneumonia has no medical cure. That you can even spend 5 months of admission in Mulago without leaving because of pneumonia! That if you are discharged to go back home and the child gets exposed to coldness, it worsens and never gets cured until the child is fully grown up.

**(Dr. Phiona);** so what solution do they give? Does it mean that since it does not get cure you should not bother to take the child to hospital or?

**Respondent** **2**; yes! That western medicine has never cured it and for its cure you need to look for herbal remedy.

**Moderator**; herbal, so, have you ever taken to herbal

**Respondent** **2**; you try on every thing

**Respondent** **1**; me even to come here, I first gave the child herbal treatment and would give him whatever I was directed.

**Moderator;** did that reduce your time of coming in any way and you said may be since I have given the child herbal treatment let me be patient?

**Respondent** **1**; and yet things just worsened because they were not working.

**Respondent** **2**; health worker remember now in herbal there is no oxygen that is required at the moment. The traditional healer will give you the herbal treatment but the child will not be able to swallow it. Even the oxygen required for the lungs to get well is not there. That is why I insist and tell them that let me first take the child, they put him on oxygen then I come back and we see plan B, when the child can breathe rather than telling me to go there when even the child cannot breathe and eventually he will die. That is why we want to bring the child here for oxygen therapy such that the lungs can be normal again, they give him whatever western medicine they can or even cure it if they can, then I resort to the herbal medicine that cures it. That is the point.

**Moderator;** okay

**Respondent** **3**; they also told me it that does not get cured.

**Moderator;** but everyone is like ‘’they told me! They told me!’ I don’t know who says

**Moderator;** let me ask number 3, who is that person that told you?

**Respondent** **3**; health worker you see, pneumonia cures because I have my first born, a baby girl. She suffered from pneumonia and really disturbed me until she made 9 months, but as I speak now, she has no pneumonia.

**Moderator;** now you see!?

**Respondent** **2**; it means that we have to stick to the medical workers, they give us medication and we leave alone those people that tell us that pneumonia has no cure.

**Moderator;** okay, fine. We are grateful for this moment and for everything. Have we left anything out? Everyone is saying,’ they told us’ It seems you do not want to tell me who told you. At least the other one told us it was the brother.

**Respondent** **2**; now health worker you can leave this place and meet someone when they ask you of the child’s illness and you tell them that it is pneumonia, they tell you that you are dead! It has no cure!

**Respondent** **4**; for me they laughed at me that I never covered the child and exposed him to coldness now see!

**Respondent** **2**; some other person will tell you that you are dead! Are you not going to spend 5 months in Mulago seated, pneumonia!? You also start to fear because if someone tells you about those 5 ; there is the cost for eating, drinking and sleeping in Mulago then you think of where to get the money from . They have even told you 5 months stay in Mulago, then you fear and stay at home.

**Respondent** **2**; you stay at home and don’t come to hospital because they have told you about the 5 months and that it does not cure. Then you wonder about who will feed you for that long remember you have the child but you are not with the child’s father. When you call him he will think you are cheating him of his money. In that way, you fear to bring the child because you have heard the words.

**Moderator;** words

**Respondent** **2**; yes

**Moderator;** I think,

**Respondent** **2**; health worker you have to convince us again that it can be cured so that we may stay and get cured very well that we may take a positive report to other people that our children were admitted with pneumonia but now they recovered. Also handle us well and treat us well such that we do not come to you in fear. You make us say things in fear. I come to you, you ask for 60,000shillings from me and you make me say null things because of fear. I speak to you in a shaky way because I fear you.

**Moderator;** thank you very much I think number 2 has concluded this reason and I think we have discussed a bit

**Moderator;** in what ways or how do you think we can tell people and they will cause them to quickly decide to seek medical care in case they have a child with cough or difficulty in breathing? You may say that for all the people to come (in future), if they are told this and this, it will help them to come quickly to hospital. Like we told you that we want to see how we can improve and to know that people get medical help in a quick and easy way. According to you, what ways do you think we would be telling to people, basing on what you have gone through, what would you tell that person in the village about peumonia?

**Respondent** **2**, I am suggesting that mothers with children suffering from pneumonia should be handled well that they may take back positive reports to their home villages. When we take back good reports, people will quickly come to hospital to treat the children. When we take back negative reports, people will stay in the villages and not bring their children. Yet if they learn of the fact that mama Sarah took her child who was suffering from pneumonia to hospital, the child was treated and in just a week the child fully recovered, no longer falls sick and is now okay.

**Respondent** **2**; that is the report I will take and if I find one with a sick child I will tell them that recently mine had pneumonia, I took him to Mulago and returned home when the child was okay. So, because of that good report I have taken, it will be spread.

**(Dr. Phionah);** I want to the bad things done in hospitals that inhibit you. What exactly do you want to have improved?

**Respondent** **2**; if I come here with a patient and I tell you that I have brought a sick person and tell you about the illness, do not be rude to me. Handle me gently and tell me that may be you go and weigh the child. you ask me how the child is, then, I may even tell you that the child is not in good condition depending on where I have brought the child from, he has been on oxygen, then you put the child on the bed check him quickly such that I can quickly move to get treatment without having to first suffer so much.

**Respondent** **2**; yes

**Respondent** **2**; if I do not suffer so much, I can even tell my neighbor that when you reach there, they make things easy for you, you reach quickly and the child gets well real quick. But the more I suffer, walking to look for medication here and there and that is what gives the people we leave at home a hard time. You understand? Because each time they call you, you tell them how you are just there and have not gotten any treatment, the treatment is to be bought and the like. So if the person I left home calls me and I tell her such, they will not bring their child if they are sick, but will just go through a short cut to a clinic. She will say that if mama Sarah is still suffering in Mulago and the child is not yet well, should I also go there? No! And then she does not come.

**Respondent** **2**; yet if I tell her that were are okay, the child is being worked in and treated then, she will be prompted to bring her child as well.

**Moderator;** thank you very much number 2

**Respondent** **2**; that is what I see at hand.

**Moderator**; now, in what other ways or how else can we help other care takers to quickly bring the children to hospital?

**Respondent** **1**; telling them that you can also treat pneumonia because most people out there know that pneumonia does not get cured and cannot be treated. Just telling them that and assuring them.

**Respondent** **2**; you see now, good news spreads something faster

**Respondent** **1**; may be you can do gatherings, meetings and you tell them that once your child gets pneumonia, do not take him to the herbalists or traditional healers. Bring them to hospital from where we shall treat them and they will get cured.

**Respondent** **2** ; now ,health worker, take it this way, in case you wake up one morning and start up a school, and all the students get first grades . How many students do you get the following year? The same way you should consider this disease. The more you give good results about something, from your side that you are good, you take care of us and we get well, even if you do not make gatherings. We ourselves, the people that have brought children in that thing, the news we take back is enough. Like I told you that when you make a school and you get first grades, with all the students having passed, it means that if you had 100 students, the following year you will get 500 students. That is the best way

**Moderator;** okay. Now, number 3, 4, 5 and 6, can you please tells us some of the ways? We have heard from number 1 and 2, does anyone of you have a differing reason from what these two have said? You can say that maybe mine is this.

Health worker, mine is similar to hers (number 2).

**Moderator;** that may be when you can put this right

When I came yesterday, the nurse barked at me yet my child was dying. She first told me to put the child to the weighing scale yet the child was dying! I told her that health worker, my child is dying! Then she told me to first give her money for the bed liner. I told her first wait I take the child on a bed at least and she told me to be careful with her! Then I undressed the child.

**Respondent** **2**; there where we start from. And remember health worker each time you go somewhere but when the starting point was not easy, it means you will not make it to the end! Health worker do you know that you can tell me to do something when I have just come at the reception and I turn and take my child away? Do you know that I can take the child outside? I just go without even taking the child to where they have told me to but just go to kill the child because of what you have showed me here at the start. If the starting point is not okay it means where am heading to is the worst.

**Respondent** **2**; that means I should expect the worst if they tell me to go to ward 18 because if where I start from is terrible, that means I just have to take the child back home and go to a clinic because am afraid.

**Moderator;** Number 4; what do you think we have left out?

**Respondent** **4**; now, health worker yesterday when I reached here, I reached at 8am in the morning. The nurse first checked and examined the child and the child was okay. She first told me to go for Covid testing before she touches my child (sighs)

**Respondent** **2**; now what would the child be on?

**Respondent** **4**; I told her that I have no problem with testing for Covid but the child is breathing badly.

**Respondent** **2**; now you see how your child can die!

**Respondent** **4**; then she asked me why I delayed yet I saw that the child was breathing badly. She told me to first go for Covid testing.

**Moderator;** you have talked about the issue of Covid. You see the times we are in, do you think covid-19 has contributed to the delays in receiving medical help in anyway? Apart from that, you have talked about Covid because no one had talked about it.

**Respondent** **2**; we bear with the situation because we do not want to suffer from Covid. When they tell us in that manner we become patient and accept to do that reason being we also want to take care of our children without becoming sick of Covid. So when they tell you about Covid then you say that what if I fall sick and die leaving a baby behind! Then you run and go back to where they have told you because you also fear and also you see and hear about people dying from Covid at Mulago.

**Moderator;** so number 4 that means the cause of the delay is Covid testing? So, what do you think we can do to see that Covid testing is done quickly since you need it as well and the child is worked on at the same time?

**Respondent** **4**; health worker, personally I had no problem with it but I had to first slope, only to find a long queue.

**Respondent** **2**; bring Covid testing services in here such that one moves in a sequence and fast enough to get the medication as well . Instead of telling me to first go out of the ward and go back, then it becomes hard.

**Moderator;** it means, you have said that Covid testing should be done from within the wards

**Respondent** **4**;Yes, when the services are a bit near the ward but I had to first slope down, then I came back and that is when they worked on my child. By the time I came back, I found people there who I had to wait for and by the time they put the child on oxygen it was already 1pm yet I came at 8am in the morning.

**Respondent** **2**; even us when we came, they chased us and they told us that we had to first go for Covid testing. So we had to drive to the Covid center, still in the ambulance. They tested us and then we had to drive back to the ward. Even the ambulance driver did not know where they test Covid from, we kept asking for directions all through the way.

**Moderator;** the reason number 4 is giving for the delay is,

**Respondent** **4**; what made me delay was going for Covid testing, at a place far away from the ward and with a very a long queue.

**Moderator;** so, it means if Covid testing was faster,

**Respondent** **4**; if it were near, it would have been easy for me.

**Moderator;** number 5, what do you think that if corrected can help the caretakers to get medical help quickly?

**Respondent** **5**; the reasons that have been given can help

**Moderator;** number 6, as we wind up number 6

**Respondent** **6**; they are the same health worker

**Moderator;** the same? Okay.

Moderator; we are so grateful for this time and all the good thoughts that we have been able to discuss and I thank everyone for the genuine submissions. Like I said whatever we have collected here has nothing, and you have noted that I did not ask for your names as we were discussing. Are we together? On that matter therefore, I would like to thank you for bringing the children to hospital. We have also heard the good opinions that you have given us and another thing, always tell people to come to hospital.

**Respondent** **2**; the obligation is yours health worker to see that you treat us to full recovery and that at discharge when we reach home alive, people look at us as live examples that you treat pneumonia.

**(Dr. Phiona);** how about what you would want the government to do for you that you may come early to hospital?

**Respondent** **2**; the government should really give us drugs because when they give us we do not suffer that much. Children with pneumonia should be given a separate room and they get their treatment from there.

**Respondent** **4**; COVID testing services should be near. They should integrate covid-19 testing services into normal routine care and on the same ward

**Respondent** **2**; a machine for testing pneumonia can be put in place as well such that the children suffering from pneumonia are tested for COVID from a particular place.

**Moderator;** thank you very much

Moderator; unless there is anything that cannot be left out

**Respondent** **2**; me I don’t leave anything out! Even at home I am like that! I tell my husband whatever is at heart. I don’t leave anything out if you get annoyed, so be it!

**Moderator;** thank you number 2, thank you for your thoughts. I think it has not just been a discussion but it has also helped us to learn things pertaining to our children because it is the main reason that brings us together. Our child who had gotten a problem.

Thank you, I remain health worker Lawrence Kakooza and Doctor Phiona.

**(Dr. Phiona);** Even me Dr. Phiona, now what I am requesting you……