Treatment Webinar: Social Protection, Economic Empowerment, and ART Adherence among Adolescents Living with HIV

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Jennifer Pearson, JSI, AIDSFree: Greetings and welcome to today's webinar on social empowerment and ART adherence among adolescents living with HIV. My name is Jennifer Pearson and I am a Technical Adviser with the AIDSFree Project.

Before we begin today's presentation, I'd like to quickly review the Adobe Connect environment and set a few norms for today's webinar. Today's webinar has three presentations followed by a discussion period in which our speaker will address your questions. Within the webinar environment, please make use of the Q&A box on the bottom right side of your screen to share your thoughts, note your questions, or ask for help with sound during the presentation. Questions you ask are only visible to you, our presenters, and technical support. If you're experiencing difficulties, our technical support will respond to your question privately. We will collect your questions for our speaker, and will save them for the discussion period. It is great that we are able to connect so many people from so many places today, but your experience may vary based on your internet connection and computer equipment.

I will briefly go over a few troubleshooting steps if you have technology challenges today. A few troubleshooting tips: If you lose connectivity or cannot hear, close the webinar and reenter the meeting room in a browser other than Google Chrome by clicking on the webinar link provided. You can also use the Q and A box to ask AIDSFree tech for assistance. If these troubleshooting steps are not successful, please rest assured, the webinar is being recorded and the link to the recording will be posted to the AIDSFree website after today's event. Questions that don't get answered during the Q&A session will be compiled after the webinar, shared with our presenters, and responses will be shared with participants.

To get us started, I will now turn it over to our moderator Lorraine Sherr.

Lorraine Sherr, UCL: Hi. Good morning everybody, it's really wonderful to be here. I'd like to welcome and thank everyone for participating. I'm a professor of clinical and health psychology based at University College London and today's webinar was organized by AIDSFree, the collation of children affected by AIDS and 4 children. An amazing group who are all working in the interest of children.

We are gathered today in international four children's group to share some very preliminary and exciting results from studies in both South Africa and Uganda. Detailing different pathways that

uncover the connections between economic opportunities, cash plus care, which is becoming a really important concept; social protection, which we all know about; and HIV treatment outcomes for adolescents living with HIV.

Essentially I want to give you some very brief background and then introduce us to our wonderful speakers. As you all know adolescents are actually the lowest adherence group when we look at studies of all age groups, a very good review of this done by Hudelson and Cluver, it seems a group we really need to focus our attention on. Basically the idea that AIDS is actually the single greatest cause of adolescence death according to UNAIDS statistics, so this is a current and very demanding problem. Curiously, there is a really an absence of evidence based interventions. There's been three systematic reviews by Hudelson & Cluver, McPherson and an earlier one by Vreeman, none of which were able to show any rules for interventions.

Now what sort of ramifications, why does it matter? I think we need to understand what are the drivers, if we understand the drivers; maybe we'll have some better provisions and targeted interventions.

And what could they be?

So there are lots of drivers: structural drivers, behavioral, psychological, very practical, maybe they're medical drivers or something in the environment of adolescences. Stigma is a driver for adults and this is true of adolescents as well. Just the side effects of medication may be a driver, or fear; fear of taking the medication, fear of going to the clinic, a whole host of misunderstandings and miscommunications. Poor service, very common, and practical issues like drug stock out and clinic access.

With all of those many considerations adolescence non-adherence is really important. Why? Adolescents who do not adhere, the first problem is one of treatment failure. Their treatment for themselves will be affected and viral resistance may well develop. Now when an adolescent has found resistance, we have transmission risk to others. We know that early treatment and if viral load is undetectable, transmission rates really do go down. It's not only a risk to the adolescents themselves but for their partners.

Within the proper context, we know that second line treatment is extremely expensive and often not available. Cost escalation studies do show that it is much better to put many people on first line treatment, so we don't have to use second line and further treatment, especially in cost restrained environments. So the cost escalation is a real consideration and of course for the individual if treatment fails, if viral resistance occurs and if the HIV is not contained, illness and death are in the cards.

So with that kind of background, I think we're all keen to hear from our first speaker who is Professor Lucie Cluver. Lucie is based at Oxford University and joined the University of Cape Town and Lucie is going to discuss Cash and Care. Welcome to Lucie.

Lucie Cluver, University of Oxford: Thank you very much Lorraine and Lorraine may have to take over my talk, I've had a baby two weeks ago, and if you start hearing yelling the background, Lorraine will take over. Just to start by saying that this work that I'm presenting is actually a huge team effort and some of the team members are on this call but there are many others who are still slogging away in the townships on the Eastern Cape collecting data and can't be joining us today.

And really what we're going to talk about is some of the potential for social protection and adolescence adherence. This is a study which was developed with a whole range of partners and funders and here are many of the really key ones and you can see that the South African government has been particularly, strongly involved as well as colleagues at USAID, PEPFAR and UKAID.

Really the two key points to think about, because Lorraine and I were sharing very similar data and literature background was that there is a huge number of HIV positive adolescents in southern Africa. And although at the moment it's around 70% prenatally infected and 30% postnatally infected, that is shifting over time and we will be seeing more postnatally infected adolescents as infection rates rise and as PMTCT hopefully starts to take more and more effect.

But really what we want to try and understand was whether social protections, specifically cash plus care, could help reduce the worryingly high rates of non-adherence that we're seeing amongst adolescents. And really at the point of starting to test, we didn't have a strong sense, there was no literature, no evidence to suggest whether this might work apart from some really interesting work which has been done in Ethiopia with USAID and colleagues at the World Food Programme, which was showing the provision of food and financial support to adults with HIV was increasing rates of adherence and that's really encouraging, that we may see the same with adolescents.

So this is a new study, we've just finished collecting the first year of data collection, it's a three year study and we're in the midst of the second year. And really it's in two parts. The first part is an in-depth qualitative part led by Dr. Rebecca Hodes at UCT and she and her team have spent around 2,000 hours following, observing and spending time with positive adolescents and observing what happens when they're in their life and in clinics.

What I'm going to talk more about this morning is a longitudinal panel study which is alongside that which interviewed just over a 1,500 adolescents, of whom a thousand were HIV positive and five hundred were neighbor adolescents. Essentially when we interviewed an adolescent, we would interview the kid next door or another kid at home. Really as a stigma prevention

measure but this has also really given us an interesting control group of negative adolescents. And essentially what we tried to do which was a bit different than most studies will interview teenagers which are in the clinics and who come into the clinics, because we're interested particularly in non-adherence and drop out, we started with the clinic and in 53 clinics, every clinic in a health district in the Eastern Cape, which is one of South Africa's poorest, most deprived provinces. We found, we went to every clinic, we went through the big file rooms, we found every file of every adolescent who had ever initiated ART and then went to their homes to try and find them. We will be following them over three years.

We developed with teenagers, with our teen adversary group of positive adolescents, cool designs on tablet based programs and questionnaires. We hope this will help them feel more comfortable and happy to talk about very stigmatized things like non-adherence. You can see on the right, the crucial question of who's your favorite sports player.

And the question is how did we do in terms of sample representatively. How much like the sample initiated adolescents did we get? Well, due to a tremendous amount of hard work by our field team, 90% adolescents were found and interviewed. You can see that there were small numbers that we didn't manage to reach. As we go back in the second year, we are going back to the ones who refused and the ones who we were unable to trace to see if we can find them again. But 90% seems pretty good.

When we look at who our sample are, you can see by the red lines are the HIV positive and the blue lines are the HIV negative. We can see high rates of maternal and paternal orphaning, around 45% in the positive group. Very high rates of poverty in both groups but not statistically important different and in our HIV positive group around 65% knew their own HIV status, so particularly many of the younger ones hadn't yet been told that they were HIV positive.

When we looked at rates of self-reported non adherence we start seeing some very worrying patterns. So in the past week, 36% of adolescents report they've been non-adherent, in the past weekend alone that was 25% and in the past year 23%. When we look at detectable viral load, which is biomedical marker often used to look at non adherence, we see around 60% have a detectable viral load, a very high rate.

And I suppose the real question that we asked ourselves is how reliable is self-reported non adherence and this is something I'm sure Fred will talk about as well. It's a tricky questions because viral road is also potential unreliable, it could be due to other reasons. So what we did was we did two things. The first was that we really worked with adolescents and piloted to improve the way we really talked about non-adherence with them. So for example if you say to a teenager, did you not take your meds last week, they will of course lie to you and say yes I did take my meds. But if we try, we tried to make it a sort of story about adolescents who wanted to take their meds but had struggled to do so. That seemed to increase the willingness of

teenagers to talk about this. But we also wanted to statistically check if it was reliable or now. So what we did was we compared associations with biomarkers of opportunistic infections like TB and oral thrush and then also looked at reliability against detectable viral load and controlled as you can see below in the left for a whole range of demographic potential confounders. And what we found was very high correlation.

So it looks like self-reporting non-adherence is very strongly associated with biomarkers. And we hope then that is should be a relatively valid measure. So we start to think first about what might be some of the structural drivers of non-adherence and really this is very initial data and I hope you'll all bear with it because over the next six months we hope to get much more detailed data. But even when we just start to look at missing appointments and missing pickups of medication, controlling for socio-demographic and illness co variates, we start seeing some structural factors which suggest social protection may be important. When we looked at the range of predictors and non-access, we see that lack of travel money and attending the clinics on your own, not having a caregiver come with you to attend clinic, were both strong predictors of missing medication pickups and missing appointments.

When we looked at a range of predictors of non-adherence, passive non adherence, we find that three types of violence very strongly predicted non-adherence that was physical abuse in the home, abuse by a teacher at school and exposure to domestic violence within the home. And this is going to be presented at the international AIDS Conference and at the Children and AIDS pre conference, the Coalition for Children pre-conference in July.

We see when we look at marginal effects, the way of testing either cumulative impact of social drivers that may be affecting non-adherence. Just looking at violence we see very clear effects. So for example an adolescent with no violence at all has around 30% non-adherence, whereas an adolescent who is being physically abused at home, has violence at school and is exposed to domestic violence has a 66% chance, more than double chance of non-adherence.

So the next thing that we looked at and this is a paper that is going to be published in the International AIDS Conference special edition, equity edition, of AIDS Care journal. We asked ourselves, what other potential social protection factors that might be improving this problem of non-adherence and we looked at a whole range of cash on the left and care on the right variables. So in cash we looked at government cash transfers, food security, school access, school feeding and access to clothing. And in care we looked to see if the adolescent was accessing an HIV support group, a sports group, a choir/arts group, whether they were receiving positive parenting, warmth and praise and whether they were receiving good parental supervision. That's like monitoring the adolescent, knowing who their friends are, having time to get home in the evening. And underneath you can see that we controlled for basically anything you could imagine for to really robustly check and we put all of these factors in together to check if they were functioning independently of each other.

Unfortunately or fortunately, because South Africa has done so well in the government cash transfer rollouts and school feeding, the numbers were very high and we had to exclude those because they weren't statistically viable. Too many kids were getting them so I think that's a good thing over all.

So what did we find? You can see that the factors in red are the ones that came out independently significant with everything else. We can see that what came out significant predictors of adherence to ART was food security for at least two meals a day regularly in the past week, accessing an HIV support group, which only 13% of adolescents were, and having good parental supervision. Positive parenting, warmth and praise, unfortunately didn't seem to make a difference but good monitoring and supervision did.

We then asked the same questions as we did with the predictors of poor adherence. We said if we join them together do we get better affects? Really excitingly we do. So if you look to the left, you can see adolescents who have neither a support group nor food security nor good parental monitoring, 54% of them had been non-adhering to ART in the past week. If we look to the far right we can see that adolescents with all three of the social protection factors, reduced to only 18% of them had been non-adherent in the last week. And that seems a really promising effect of social protection.

And just very briefly before I finish I wanted to mention some addition analyses that Elena Toska, working with Rebecca Hodes have been doing, which is really thinking if social protection does help reduce unsafe sex for HIV positive adolescents. Now Elena asked about the last time that the adolescent had had sex and whether it was protected or unprotected and worryingly 28% of adolescents, HIV positive girls, have reported having unprotected sex at their last time of intercourse. And if you look at the qualitative evidence, you see a real range of things that adolescents talk about, predicting why they struggle to disclose to their partner and why having safe sex is a really difficult and complex social issue for them.

But Elena really wanted to also ask about social protection and whether that really did make a difference. And what we see here again is a really encouraging set of predictors which suggest that we really can do something with social protection. Now these predictors were slightly different than the ones for adherence. Good parental supervision came out strongly again but access to school, and attending either a free school or one that they could afford, also came out very strongly. And so did getting positive and respectful care within the clinic, within the central health clinic. And we can see if we look to the left, an adolescent girl that gets none of those, 50% of them had unprotected sex the last time they had intercourse whereas adolescent girls who had good parental supervision, school access and respectful clinic care had only 8% had unprotected sex the last time they had intercourse.

So really do watch this space for more analyses like this and we would really value any suggestion further things that we should be or could be looking at that could be useful for practitioners and policy makers and programmers.

And I'd like to end by saying this has been an enormous team effort, you'll see just some of the incredibly hard working teams' names here and our incredibly hard working 4x4 vehicle, one of which is stuck very firmly in the mud.

Thanks very much everyone, I look forward to your questions. Bye bye.

Lorraine Sherr, UCL: Thank you Lucie, that was really very interesting. Please everybody could you continue adding your questions for Lucie in the Q and A box for our discussion at the end. And now I'm going to move over to the next presentation, which is from Professor Fred Ssewamala and Professor Laura Gauer Bermundez from Columbia University.

Fred M. Ssewamala, Columbia University: Thank you so much Lorraine and thank you so much to everyone who is joining in. Thanks Lucie for that lead presentation. Our presentation is going to be co-presented between me, Fred Ssewamala; I'm a professor here at Columbia University in the School of Social Work and Laura, who is our doctoral student here at the school of social work.

So Lucie gave us a very good kind of lead to a quote I want to begin with. And you can see from this quote, it's from a teenager living with HIV/AIDS in Rakai, one of the participants who worked with when we were beginning this study.

The study I'm going to present is funded by NIH and ICHAD but the views are specific to those of us who are researchers. This participant said and I quote, "When I first started taking ARVS, I learned I had to take them with food else I'd become nauseous. They also made my appetite too high. I felt hungry all the time. I tried to eat more than usual, but the hunger I felt during that time was too much. I just didn't have enough food to satisfy my hunger, so I stopped taking my ARVs."

This is extremely important, especially in light of the free ARTs now being given out to all young people in Uganda as long as you are below the age of 16.

So the question always was are young people not adhering because they don't have access to ARTs or are there other reasons. So with free ARTs, why are so many young people not adhering and so our such question, the question that guides us, in light now of access, free access, do economic factors still influences adherence to medication among these young people who is living with HIV.

The data that we are using today comes from a study called SUUBI+ Adherence, it's in the six district in Uganda studying impact in 39 clinics and we have two study conditions. We have one

study where participant and their families are given economic empowerment opportunities which constitute a savings account, management training and access to microenterprise training. And then the other group receives information about adhere; we use cartoons and that sort of stuff. So we have these two arms, the impediment has 20 clinics and the control arm has 19 clinics, and these are all marked at baseline. Our inclusion criteria was the person had to be HIV positive, living within their family and they have to be prescribed ART and enrolled at one of the clinics we are partnering with.

So the slide next really just gives you the distribution. We are 356 young people in the 20 health centers that meet the treatment conditions and 344 in the control conditions. The randomization was done at the clinic level. All the people, within the clinic, received the same interventions so we have a total of 702 young people.

So without going into detail about the numbers what I wanted to highlight here is the fact that the area where we are working has a slightly higher prevalence rate than the rest of the country. This is the high Muasaka region with 9.8% prevalence rate of HIV.

So we used different measures for us to be able to measure adherence which is really very common because like Lucie clearly pointed out, the question always is "are self-reporting as accurate as biomarkers compared to things like Wisepill?" In this study we are using a wide range of measures and the slide that I'm showing right now, we're seeing that at baseline over 75% of participants report perfect adherence when we look at their self-reports and the 64% report perfect adherence when we use the Wisepill. The Wisepill device is a device which is like a memory, it registers an opening each time the participant opens the device and we assume each time the patient opens the device that they are taking the medication, they open and close and we are able to track that. And then we also drew blood from viral load and only 59% of the participants were perfect adhering.

I want now to move on now to the findings and these will be presented by Laura.

Laura Gauer Bermudez, Columbia University and International Center for Child Health and Asset Development: Thank you so much Fred for giving us a great overall picture of the broader SUUBI+ adherence study. What I'll be talking about now is the examination of the pre-intervention baseline data that we did to look at equity and adherence based on social and economic factors.

In this particular paper, our dependent variable, our primarily outcome analysis was self-reporting adherence based on the number of days a respondent had missed at least one dose of medication in the last month. And our independent variables fall into three different categories. We categorized them as assets and employment, which looks at variables such as material assets, financial inclusion and caregiver employment. Also food security, which as it

sounds is about food security, and then social equity which covered things such as school enrollment, distance to community resources, and social support.

The analysis we used for this paper is using logistic regression and we looked at bivariate comparisons, meaning we looked at each of the individual variables in isolation to see what their impact was on adherence. And then we also looked at composite measures, we made these composites of food security and social equity to see what the cumulative effect of what food security and social equity would be on adherence.

So this is a table of our results and I'll just let you know how to look at this. Using logistic regression, the second vertical column down called OR is the odds reached. Basically in the way that we set up the variables anything over 1 means that for adolescence that have higher values in the variables in the left were more likely to self-report perfect adherence. Anything under one had an inverse relationship, which means that adolescents that had higher values for these variables were actually less likely to adhere, and this is a little bit counterintuitive, we have a couple of leads so we'll talk about that.

The other thing to talk about is that those results that are bolded and with a star mean that they are statistically significant at an additional .05 value. Those with the little cross mark fell between .05 and .1 which is sort of the statistical grey area. Some people reported, others don't, we basically listed it as something of interest.

So as you look at the results, you'll see that more assets by the family was statistically related to adherence, so those that had more assets were more likely to adhere by factor of 1.69, where alternatively if a child's caregiver was in the formal labor market, they were more actually less likely to adhere. This is one that falls in the statistical grey area but something that's a bit interesting and something we could talk about during the Q and A.

If you look at available cash savings, participation in a formal banking institution or material housing value, all of these are over one, showing that adolescents with greater values or greater advantages were more likely to adhere however this is not statistically significant.

When you look at food security, it's the same, all over one. Adolescents with greater food security are more likely to adhere but the only ones reaching statistical significance or close by was number of meals per day. And then when you look at social equity variables, the first looking at school enrollment, this is not statistically significant but if it were, it had an inverse relationship, which was rather interesting. Children enrolled in school were actually less likely to report perfect adherence. As you go down you'll see proximity to community resources all over one, all showing that the closer you are to the resources, the more likely you are to adhere. However the only one that was statistically significant was the proximity to the health clinic.

Electricity in the home was at one, which is neutral, it means that adolescents were no more and no less likely to adhere based on availability of electricity. And social support for adherence, again over one, more likely to adhere if having social support but not statistically significant.

These results are just the results in the text form so I'll bypass them since we looked at this chart. Then we when look at the Multivariate regression which is our composite indices with our control.

I'll start first with the controls. While these were primarily just meant as control factors, there was one that turned out to be statistically significant and its influence on adherence and that was gender. Females in this age group of 10-16 were actually more likely to adhere by a factor of 1.73 and that's something interesting we'll talk about in the discussion as well.

When we come to our composite indices, assets and employment were statistically significant when associated with adherence. Cumulatively, those with greater advantage in material assets, financial inclusion, etc. were more likely to adhere.

Food security not statistically significant but if it were had a bit of an inverse relationship, it was less than one. So those with more food security were less likely to adhere, it's a bit counterintuitive but we have some thoughts on that for the discussion. And then social equity, also greater than one, more likely to adhere if had greater advantage in the social realm cumulatively but not quite statistically significant.

So that brings us to the discussion, we have some implications for policy and practice. We believe that economic and social determinants of adherence should be given due priority when designing and developing programs targeting youth with HIV, even in context where ARV rollout is free. We believe there are certain factors that are preventing uptake of ARV medication.

So when we're looking at our study and the results, we feel that interventions that aim to improve financial assets, foster financial inclusion or provide geographically improved access to treatment services are ones that may offer promising returns to greater uptake of ARV among adolescent population.

Then when we talk about our implications for research. So this paper was done purely quantitatively, we were just crunching numbers. It would be very interesting qualitatively how adolescents interpret their sense of advantage or disadvantage in economic or social realm.

Also looking at gender, girls were reported to have more optimal adherence than boys. How does this change when you age out of the statistics teen age group. As females marry and have familial responsibilities, does their adherence change? And what are we doing to target adolescent boys? Does this need to be more targeted for better uptake by this group?

Looking at food security, again it wasn't statistically significant but it did show that those with greater food security were less likely to adhere which was very interesting as it is counterintuitive. We thought that this could be illustrative of a family having a limited set of resources and having to decide whether or not to buy food or to have money for transportation to a clinic to pick up their medication. Perhaps in this instance, they chose to buy food, which would show if they're filling a survey that they are food secure because they have food at the time but are not adherent. So that is our thought on that.

Also to notice that we were using measures that were available measures of food security from prior SUUBI questionnaires, they were food security questions kind of tossed in to a multi-dimensional poverty assessment. It wasn't a very detailed or long validated scale of food security so that is another thing to note.

Looking at school enrollment and stigma that was one that also had an inverse relationship. Could school enrollment participation have, does this have an inverse effect on adherence and is this because children have a fear of status and social ostracism, that's something to think about moving forward.

And then just lastly, when we talk about this concept of equity, it's a hot term, very exciting, but there are not really standard core measures of what it means to achieve equity, particularly not in this area of adherence. If it's possible for the community to come together, to develop a core set of equity measures, is this something that we can put into multi-dimensional screening tools for use to determine those that may have predictable challenges to adherence moving forward and then strategically plan our programs to reach the most vulnerable youths.

And just lastly, that wraps up our paper but we wanted to give you a little sneak peek about what we're doing with the larger SUUBI adherence study. We do have some data coming in from Wave 2, thanks to our colleagues at the Raki health services program, Dr. Nusi and others, we have viral load comparisons and Wisepill comparisons and while the data is mixed, the trends are basically showing that those involved in our treatment group who received a financial inclusion aspect intervention are becoming more likely to adhere after two years than those in the control.

So these are our acknowledgements, we've worked with such a great group of people, so we'd love to acknowledge all of them, it couldn't happen without everyone's hard work. Thank you very much.

Lorraine Sherr, UCL: Right wonderful thank you everybody. Those are really two excellent and thought provoking talks. Now I'd like to look at the time we have for discussion, which is really quite good. So could everyone please type questions into the Q and A box? We already have a whole load, so I'm going to try and get to as many questions as we can in the time remaining.

Right, so the first question that I would like to raise was one where somebody has asked Lucie how you got to your response rate and is this something that they can learn for their research.

Lucie Cluver, University of Oxford: That's a great question and thank you. I think the answer is sheer determination of the field team. Essentially what we did, it was all quite difficult because many people did not provide a full name or address and there are high levels of migration and movement but essentially we went to villages and townships and traipsed around trying to find the kids. We had to be quite vague on what the study was about…. Inaudible… we couldn't mention that they had HIV because we didn't want to stigmatize them.

They literally sat around, they asked people, they went to schools, they went to churches. They just kept going until they found almost every child. And if you're determined enough, you really can find people.

Lorraine Sherr, UCL: Great, now we had another question that's come in from Jason, which is, if we think social protections, particularly cash transfers, are an important ingredient to support adherence and the South African child coverage is so high that it is possible, why do we think non-adherence is an issue? I'm going to ask Lucie to comment on this in terms of South Africa and maybe Fred can comment on cash transfers for further north.

Lucie Cluver, University of Oxford: Thank you; I was actually going to ask Lorraine for her thoughts on this. When Jason asks a question, my heart always races because I don't think I'll be able to answer it. And the truth is…. Inaudible…. One thing is thing is that you know when you look at the findings and also at the study in Ethiopia, we saw that having enough money to get to the clinic and enough money to pay for food seems to be very basic social protection requirements.

At the South Africa child support is 200 rand per month for the whole family and that wouldn't be enough to pay for those two basics. So it could be that all those who are on it may not be enough. Lorraine, what do you think?

Lorraine Sherr, UCL: well for a start, it isn't even perfect in rich countries. So clearly it's not the magic bullet. I think it's necessary but not sufficient and that's the answer. Just looking at Fred and Laura's data, such drastic poverty must be the background taken into context. Clearly cash transfers are a great big step but my view would be that it's a great step but it's not sufficient.

Laura? Fred? What are your thoughts?

Fred M. Ssewamala, Columbia University: Could you repeat the question?

Lorraine Sherr, UCL: I believe the question, which is really quite a challenging one, is "are cash transfers an important ingredient and South Africa's childcare coverage really is so high now,

why do we think adherence is such an issue?" So, really, is cash transfers going to solve all the problems?

Fred M. Ssewamala, Columbia University: Actually that's a fair question. Look at our presentation indicated one factor, it's a combination of….inaudible… I don't know whether Laura agrees.

Laura Gauer Bermudez: I would agree, I mean also look at economic strengthening. Fred said cash transfers and economic child support. I mean to build more long term aspects and cash transfers serve as the immediate stop measure at the time….inaudible… have an eye on the long-term financial inclusion. Inaudible.

Lorraine Sherr, UCL: Let's try and pack in some more questions. We have one where somebody asked was there any opportunity to look at effects if other economic variables beyond overall poverty, access to conditional cash based transfers affects adherence. So this person asks about things like employment or job training, does anyone manage to look at those?

Lucie Cluver, University of Oxford: This came from Michael didn't it? Michael, it's a great question and the answer is no we haven't looked yet because our kids were too young. Very low rates of employment in that age group, we only went up to 19 in this first year but we will be looking at it in the coming years. But I think it would be great for Fred to be able to answer that as well because Fred's SUUBI study is really, which you're familiar with, is creating this sort of exciting economic empowerment program and it would be great to hear a little bit about that. So Fred or Laura, I would love to hear about that.

Fred M. Ssewamala, Columbia University: Thank you Lucie, our kids are probably younger than Lucie's, so we haven't looked at that. Our kids are 10-16 year olds at baseline and hopefully, this is a five year study and hopefully by year 5 we are able to address that question. So Michael it's a great question but at this stage we haven't addressed the question because the kids are young. The oldest is sixteen years old; in fact the sixteen age group is even smaller. We have a bigger number if you look at the distribution in the 10-13 year olds.

Lorraine Sherr, UCL: Ok, thanks. Heidi asks that if she understood correctly the first presentation said there was a correlation social support and adherence but the second seemed to show no significant effect. Has she understood that correctly? And if so, can you both comment on that?

Lucie Cluver, University of Oxford: Shall I answer first? Heidi it's a great question. You know what, we haven't looked at social support more generally, we've looked at being in an HIV support group, which you know, they said they had to attend at least monthly. We did try and look at kids that attended weekly the support group but only something like 3% of kids attended weekly and about 13% attended monthly. And that did improve adherence but general

levels of social support is a really good idea, I don't know why we haven't looked at it yet but we should have and we will. From my recollection, when we looked at it briefly and initially, it was predictable of adherence. Fred, what did you find?

Laura Gauer Bermudez: Hi, this is Laura, that's an excellent question and she is correct. In our particular presentation we had social support which was one particular variable under the larger social equity composite. For social support the way we looked at it, the question to adolescents was do they have access to social support for adherence specifically. And in our findings, while the results were over one and did show that those with higher levels of social support for adherence were more likely to adhere it was not quite statistically significant. So that is the way that our results showed up.

Lorraine Sherr, UCL: Ok, inaudbile asks if you could very briefly summarize the findings of the financial education savings interventions and its effect on adherence.

Fred M. Ssewamala, Columbia University: we did that in the last slide but we can go over it again. I think the implications am I right? The implications…

Laura Gauer Bermudez: I think what she is asking is what are some of the preliminary findings of our treatments, the effect of our treatments, in ways too and maybe this question can be provided by the last slide but there are some details in the last slide that show that those who are adolescents that are participating in the treatment group, who are receiving a financial intervention, are showing prevalence towards greater adherence after two years. Thank you for pulling this up, thanks so much.

This will be a five year study so we'll have more data moving on, these are just preliminary results and it will be very interesting to see how this trend continues.

Fred M. Ssewamala, Columbia University: Hello?

Lorraine Sherr, UCL: Great, we have loads of questions pouring in, so somebody's asked if you could if you could tell them a little bit about how the cash transfers work in South Africa. It's an enormous question but maybe if you could just give them a little clue.

Lucie Cluver, University of Oxford: Absolutely and once again I'm going to ask Lorraine for her inputs on this. Really South Africa is leading the way in Africa with cash transfers to the poor. And the child support grant, the vast majority of the cash transfers that are delivered here is around 200 rands per month. Generally shared out among the whole family, it goes to the main caregiver of the child and that's almost always a woman. It just to be mainly coming in cash but now primarily delivered into a bank account by the social security agency of South Africa. And I would recommend if you're interested in this to look at Michael Sampson's work and Unicef has done some really excellent work on the child support grants and if you just google that, you can

find a whole lot of really valuable information, particularly on some of the health benefits on children.

Lorraine is there anything else I've forgotten? Lorraine and I did all these analysis together so I rely on her.

Lorraine Sherr, UCL: I think that covers it very easily. South Africa has just started. In some countries it's still in the research environments, both conditional and unconditional. I think that unconditional makes life very much easier to reach the most vulnerable.

We had a series of questions which were all on the same thing. Which are really about the clinic visits? Maybe both teams could answer the question, several people have asked it. Basically, what can the clinic do, the clinic issues seem to be an issue here. Would you suggest more frequent visits or better quality visits, what could you do?

Lucie Cluver, University of Oxford: Fred, do you want to have a go at answering first, I'm happy to-

Fred M. Ssewamala, Columbia University: No, that's fine. One of the measures that we have in our study is the use of what we call clinic records. In Uganda, in the area that we are working in the 6 district, there are adolescent days. Adolescents come in for their medication on specific days so our research team goes in on those days and tries to interact with the youth during that time. It also allows us to get to know which youths are there, which youths didn't show up and why. So that's in terms of our financial assistance being in the clinics. And also what that does it allows us to find out which youths are consistently not turning up and when they need to go and visit them at their homes. Our team has done such a good job that they know every child of the 700 kids they have reached at their home to give out the Wisepill devices and so the question of clinic visits, I don't know whether it's about the process but they do it in Uganda in the 6th district where we work, we rely mainly on those adolescent days. But we also do unannounced visits to the young people themselves, to their homes, where we can do counts without telling them that we're there. We have combined clinic visits with research statistics when they go to the clinics and we have reached out to the participants. I'm not sure if that answers your question in regards to clinic visits.

Laura Gauer Bermudez: I can add as well. I think from the study shows the statistically significant finding was that those had closer proximity to the health clinic was more likely to adhere. So we do feel that distance is an issue and that there has been a lot of success with mobile clinics in testing and counseling. If that sort of emphasis is also placed on adherence for this particular population with the use of mobile clinics perhaps that would also be plausible.

Lucie Cluver, University of Oxford: I just wanted to say that is such an important question. Elena Toska's work has shown that in regards to sexual health it was hugely important the sort

of clinics that came from clinic staff. We are actually in the middle of doing a really quite complicated analyses where were looking at a whole range of clinic level factors ranging from what kind of clinic, whether it's a pediatric clinic or a main hospital clinic. Also looking at how the staff treats the adolescents. What kind of staff they see, whether they see a doctor or a pharmacist or a nurse or a counselor and what's the availability, whether there are stock outs. It's a big question, a complicated question and we should have the finding within the next month or so. Could I ask, if it's something that really interests you, please do drop me in an email in about a month's time where we should really clarify those results? We're not certain enough of them to report them yet.

The good news is the South Africa department of health is working rather closely with us on that and are very determined to make changes in their clinic visions based on these findings. So that's really encouraging.

Lorraine Sherr, UCL: this is an easy question, they want you to clarify the age and how you define adolescents. I think that was mentioned in some of the talk but anyways if we could just have that clarified.

Lucie Cluver, University of Oxford: Sorry we should have said! 10-19 we started with but of course as we keep following the, they'll get older.

Laura Gauer Bermudez: and in our particular study, our cohort was 10-16.

Lorraine Sherr, UCL: Great and I think that's really reassuring because we see a lot of research which really has a loose definition of adolescent and I think really clouds the picture. I've seen studies where groups go up to 24 and the worst is when I've seen a study written where it's gone up to 35 and I think that if we are interested in the particularities of adolescents, it think sticking with the Unicef definition of ages 18 or younger is really going to help researchers in this area. So that was a really great question and I think we all need to work on that.

We've got loads and we're running close out of time but I'm going to try and pack them in. Sarah has asked are you looking at the impact of the more frequent quality clinic visits and if when the clinic is structured in a certain way to support people's needs, does that impact on adherence. So that really builds on your comments about the clinics, what's your point of view on frequency?

Lucie Cluver, University of Oxford: great question, we actually hadn't looked at it but we will. I think that we need to distinguish whether they're being asked to come more frequently or whether they're going more frequently because they're two different things. Yes, you're right; we should put it on our list of things to look at. Thank you.

Lorraine Sherr, UCL: Helena asks to the first group do you have a challenge with consensual parents of the participants. And if you did, how did you deal with it?

Lucie Cluver, University of Oxford: That's a great question. Shall I answer first and then Fred and you can answer? We had very, very high rates of consent, we only had 4% in the whole sample who didn't consent but you're right, most of them were parents and not adolescents. And often the parents who didn't consent was often because they were very scared of, feeling very stigmatized, very worried and very scared that anything would be identified. And once we interviewed some other kids in the street that often went away. The other reason that we sometimes do get parental non-consent is when the parent is abusing the child or when there is something going on at home that they don't want people to be finding out about, particularly if they're dealing drugs or doing something illegal. So that's also quite difficult to deal with. The other reason of when we had non-consent was when people had really large dogs and our interviewers were too scared in case of being bitten by the dogs and I have no idea how to deal with that. Any advice would be gratefully received.

Fred M. Ssewamala, Columbia University: so just to go back on the clinic question, I may have misunderstood so thanks to Laura for clarifying. So in regards to the consent, I mean this is research, so we do get consent from the parents but in terms of the numbers our inclusion criteria is that a kid must be aware of why they are taking ARTs and what we found is that over 100 families who came with their kids, they had not, while they had given consent for their kids to participate in the study, they had not disclosed to the kids why they were taking medication. And so they wanted our team to be the ones to disclose to the kid so that the kid could enroll in the study. And as you all know disclosure takes time, you have to prepare the child, you cannot disclose at the time of the interview. So I don't recall if we had any parent who said they did not want to be part of the study, the parents and kids that were not included was purely because of non-disclosure. Most of the kids that were not included and on ARTs had been quote on quote lied to by being told you are taking medication because of a constant headache or because you have ulcers and so these kids didn't know they were HIV positive and it wasn't the responsibility of our team to disclose, so we asked to be the ones to tell them and take time with their kids and eventually disclose to the kids and then after that they could be enrolled in our study. So the short answer is that all the parents that were invited consented but many were not included because the kids didn't know why they were taking the medication and because that was part of our inclusion criteria, we couldn't enroll them.

Lorraine Sherr, UCL: thank you for that, that's really an interesting issue, particularly on those who didn't know. Fascinating and in Lucie's, they also had a group who didn't know their status. Sadly we've come to the end of the hour and I had to use the scale bar to read all the questions. I know everyone will try and answer them so before we wrap up, I'd like to again thank all the participants for giving their time. We had over 100 attendees from all over the world and our expertise today from our three speakers.

In the next three days you will receive a link to today's recording and before we close the room, I really want to encourage you to take a moment and fill out the poll questions below as that

really helps us to plan future webinars and from my point of view I really want to thank the people who made this possible, the AIDSFree group has been amazing, the Coalition and 4 Children. This is just such a vital type of dialogue and I'm sure everyone would agree upon how important these webinars are. Thank you everybody.

Lucie Cluver, University of Oxford: Thank you everyone, bye bye.