

Crossing Horizons: New avenues in research with longitudinal adolescent cohorts

A BRIEF REPORT



Introduction

On 5th November 2015, the Nuffield Foundation hosted a seminar on the theme “Crossing Horizons: New avenues in research with longitudinal adolescent cohorts” to discuss large-scale longitudinal cohort studies of youth in precarious social, economic and political circumstances. Longitudinal cohort studies present a unique opportunity to identify risk and protective factors, to trace behavioural and attitudinal patterns and changes among young people transitioning into adulthood, and to proffer stronger causal explanations.

The seminar involved investigators from leading cohort studies based in UK and Irish universities: Avon Longitudinal Study of Parents and Children, the BREATHER trial, the Community Care study, Collaborative HIV Paediatric Study (CHIPS), Next Steps, Young Lives, Mzantsi Wakho and the Cohort & Longitudinal Studies Enhancement Resources (CLOSER) programme. A full list of participants and cohort information is included in **Annex 1**.

The day began with an introductory address by Dr. Teresa Williams from the Nuffield Foundation. Dr. Williams highlighted the challenges routinely involved in studying and working with such hard to reach population groups. Dr. Williams outlined some of the questions that the day’s seminar hoped to address:

- a) What are the challenges that are routinely faced in longitudinal cohort studies? What are the best practices to deal with them?
- b) How can we recruit and retain participant in difficult-to-reach groups?
- c) How can we use longitudinal cohorts as platforms for intervention-based research?

The rest of this report includes a short summary of the presentations and discussions held.

Presentations by participating cohorts

Mzantsi Wakho

Dr. Franziska Meink, Ms. Elona Toska, Ms. Meaghan Thumath, Ms. Alexa Yakubovich, Mr. Craig Carty, Prof. Lucie Cluver,

The team of Mzantsi Wakho (MW) presented their ongoing longitudinal study of a cohort of over 1,500 HIV-positive adolescents and community controls, with community-tracing over three years (2014-2017), located in South Africa. The presentation provided an overview of the study and the current status of the project. Prof. Lucie Cluver noted that this was initially intended to be a cross-sectional study, but after recommendations from the Nuffield Trustees the project was implemented as a longitudinal cohort. Mzantsi Wakho currently employs three data collection methods: qualitative ethnography, quantitative longitudinal panel study, and teen workshops. These participant-based data are complemented by biomarkers (CD4 count and viral load data) and clinic-level profiles. Mzantsi Wakho’s ‘teen advisory group’ is a set of adolescents living with HIV that help research team develop the research questions for the questionnaire, helps in identifying risk and protective factors for ART adherence, improving access to sexual-reproductive healthcare services for teens etc. In this way, the teen advisory group serve as the “experts” and help develop better tools to support the well-being of children and adolescents in South Africa.

Challenges and Limitations

Touching upon the challenges faced in the course of implementation of this project, the importance of confidentiality and privacy of the HIV-positive research participants was highlighted. In order to avoid unintended disclosure of HIV status, Mzantsi Wakho uses animal names (such as ‘elephants’, ‘giraffe’ and ‘bear’) to refer to the HIV status of the research participants. The process of data-collection is also fraught with ethical entanglements and methodological problems. During data collection multiple accounts of child rape, child abuse, unintended HIV status disclosure surface. In the absence of community-level resources that such victims of child abuse could turn to, the question arises – how much should the field research teams get involved in order to support the victims? Furthermore, encountering such cases can be the cause of emotional vicarious trauma for the field staff. In order to mitigate this problem, MW team members are provided counselling services as and when needed.

Methodologically, one also needs to ascertain the degree to which the responses of the research participants (teens) can be relied upon. There is often a possibility that the data collected from the research participants is refracted by a ‘social desirability bias’ [i.e. respondents provide responses that they believe would be received favourably by the listener]. Further in the cohort of population that MW works with, the teen often exhibit symptoms of cognitive delays which poses further constraints on the collection and use of data. These problems are further compounded by a lack of validated measures in the research setting.

In addition to these day-to-day challenges, the MW field team has had to tackle major challenges during the course of data collection. In the past, there have been attempts at hijacking of project vehicles, and there are multiple cases of violent crimes in the neighbouring towns in Eastern Cape. Political unrest manifests itself in frequent political rallies and riots during which data collections cannot be carried out. The field team regularly deals with multiple logistical problems and technical failures, such as: theft of data tablets, data server crashes, intermittent power failures, load shedding and erratic Internet and mobile connectivity. Notwithstanding these challenges, ongoing analysis of the data continues to provide valuable insights on factors and predictors of ART adherence.

Encouraging Results

In an early analysis of predictors of non-adherence (n=861), medication side-effects, hunger, abuse, domestic violence, cognitive delays, behaviour problems and stigma predicted non-adherence. MW’s findings also confirm the WHO disclosure guidelines which suggests that adolescents who know their HIV-positive status have doubled odds of past-week ART adherence. The MW longitudinal cohort also provides interesting perspectives on matters of sexual and reproductive health (SRH) concerning teens in the Eastern Cape. Preliminary analysis indicate that knowing one’s status is linked to higher odds of condom use at last sex, while disclosing one’s status to one’s partners or knowing of one’s partner status does not seem to make a difference. Qualitative findings highlight the complex power and gender inequalities that may compromise the ability of HIV-positive adolescents to negotiate safe sex. The study also reveals multiple myths surrounding contraception and a lack of basic education pertaining to reproductive cycle and sexual health. Most teenage girls use injection hormonal contraception; with adherence to the contraceptive pills being patchy. There is a persistently high demand for

contraception and accurate SRH information at schools. The MW cohort study shows that, for the teens, the fear of pregnancy is far greater than the fear of contracting HIV.

The MW research findings problematize the received understanding of the causes behind non-adherence. Often the question on non-adherence is posed as one of certain prejudiced knowledge and attitudes towards HIV and medication. In practice, however, the decisions leading to non-adherence are more circumstantial – such as food insecurity – and sometimes tactical. Distinguishing between these types of non-adherence and factors that influence each will be crucial to identifying appropriate adherence-promoting interventions.

MW's experience shows that qualitative research can be an asset to longitudinal studies. Insights emerging from qualitative data collection helps the research team to improve the design and development of the questionnaire, helps investigate harder to reach groups (such as, HIV-positive pregnant teenagers) and facilitates collaborative analysis. In particular, ethnography serves as an important tool for working with teens and families over a long period of time. Such an approach serves to complement longitudinal cohort studies.

One persistent feature of the sample of research participants that MW works with is an extremely high rate of TB. This brings into relief the simultaneous burden of communicable diseases witnessed in the region. 75% of new cases of Tuberculosis-HIV co-infection are in Sub-Saharan Africa out of which South Africa shoulders one of the greatest burdens. MW also seeks to understand the risk factors for TB among HIV-positive adolescents and community controls and the extent to which the HIV care system in the country can help address this problem. The current findings reveal that up to 1/3rd of HIV-positive teens with symptoms of severe TB have not undergone a TB test.

Another element of MW's research analyses issues of mental health emerging out of stigma against HIV-positive teens. The MW team works on identifying the risk, protective factors, mediators, and moderators of poor mental health in the longitudinal cohort. The MW team is also working on developing and validating an HIV-stigma scale. On-going research is interrogating whether additional characteristics such as poverty, school dropout, parenting, abuse, and bullying contribute to internalized HIV stigma. The MW team has used a quasi-experimental evaluation model to study the link between social protection schemes and adolescent adherence. Preliminary findings suggest that free school meals, parental monitoring, presence of a parent supportive of ART, presence of a boy/girlfriend supportive of ART, and high social support were found to be statistically significant in ensuring adolescent adherence.

Future Steps – Intervention Development: Testing an App for HIV-positive teens

In an innovative approach to improving the access and delivery of medical services for teenagers, MW is proposing an interactive mobile intervention that disrupts the traditional clinic model and changes how health care is delivered. The intervention involves gamification of the clinical interaction whereby kids who refuse to go to the clinic are provided support through the mobile application. In addition, a ward based outreach team can be deployed to respond to any medication-based side effects that may be involved.

In the end, the Mzantsi Wakho team posed three questions to the attendees of the seminar and invited recommendations on the same:

1. Should MW follow their cohorts into adulthood?
2. Should MW turn its cohorts into intervention trials?
3. How can qualitative research contribute most usefully to quantitative research?

Suggestions from the audience:

- It could be interesting to explore how involvement in a clinical trial can influence and change the understanding of the research participants about HIV. There could be an additional question that explores the impact of being previously involved in a research study.
- Including parents in the research study could be beneficial since many family members are vertically infected and thus, what happens in the family is crucial. Thus, instead of longitudinal expansion, MW could consider horizontal expansion to other family members (parents and siblings) in the future.
 - In ALSPAC, the study starts with the baby and then extend the survey to the entire family. At the 15 year follow up, the response rate plummeted, so beware of this as the cohort grows older.
- Did you use different researchers for parents versus the kids?
 - In some settings, MW did. However, the logistics of transporting multiple interviews to the households made matters difficult. MW involves parents for practical considerations such as scheduling meetings, clearing ethical obligations, and obtaining consent.
- There was a suggestion to combine datasets across all the researcher cohorts present. Example: the CIPHER and FACTS cohort of 450 HIV-positive youths and 250 HIV-negative controls.
- Suggestion to harmonize research instruments so that different cohorts can compare experience between Lower-Middle Income Countries and UK/Europe.
- Regarding the MW data on the rate of condom use after disclosure of HIV status, it was suggested that the data be disaggregated by gender.

The presentation slides may be downloaded [here](#). For more information on the Mzantsi Wakho study please contact Prof. Lucie Cluver, lucie.cluver@spi.ox.ac.uk.

Young Lives

Ginny Morrow, Oxford Department of International Development

Young Lives is a multi-disciplinary study that aims to improve understanding of childhood poverty and provide evidence to improve policies and practice. The study comprises 12,000 children in 4 countries: Ethiopia, India, Peru and Vietnam over the course of 15 years. The sample is pro-poor, and mostly based in rural areas. The study has undertaken 4 rounds of survey and 4 waves of qualitative research and is undertaking the fifth and final survey round in this year/in 2016. Young Lives has dedicated field teams working in each of the 4 countries. Fieldworkers travel by car, bus, boat, on foot and even donkey carts to research the research participants. The rate of attrition in the Young Lives cohort has been impressively low, and we think this is for a number of reasons:

- Young Lives fieldwork teams undertake tracking between survey rounds, to check where people are/who has moved from the communities. This has the following benefits:
- It becomes easier to maintain contact with young people who are frequently on the move (especially as they have grown up over time).
- It allows the opportunity to offer research reciprocity through sharing findings with communities and families.
- Fieldworkers have built relationships with the families and children over many years, and keeping in touch regularly helps nurture these relationships.

Key Points from the discussion on ethics

- Careful attention must be paid to informed consent processes. In poverty contexts, research participants often think that the research teams are from an NGO and can provide them with assistance.
- **Informed consent** is an ongoing process and is renegotiated at each visit.
- **Understanding the contexts** in which the research is conducted has been crucial to understanding how ethics operate in practice. While shared ethics principles are important, these need to be applied with some flexibility.
- **Child protection** concerns are dealt with by teams on a case-by-case basis in each country. The coordinating team in Oxford provides guidance and support. Young Lives follows Save the Children child protection/safety guidelines in the field.
- **Compensation** is paid for people's time in some, but not all, countries. Care is taken that this remuneration not seen as an incentive to participate.
- **There** are ongoing ethics questions to be thought through at every stage of the study, not least how to **say goodbye** to participants at the end of the current phase, and possibly inviting them to continue to be involved in research.

Young Lives qualitative longitudinal research has additional benefits:

- It has allowed Young Lives to capture the children's experience and understandings more holistically. It prioritizes children's own points of view.
- It helps explain divergent experiences and trajectories across the four countries.

- It helps the researchers understand how multiple deprivations overlap and affect children's well-being and trajectories.

The presentation slides may be downloaded [here](#).

The Community Care Study

Prof. Lorraine Sherr, University College London

The Community Care Cohort Study follows nearly 2,000 children being served by diverse community-based programs. Currently, the study is near completion of its baseline and collecting data about the children and the type of program they attend. The same data will be collected 12-18 months later, providing a snapshot of psychosocial changes in children correlated with the features of programs they attend. The study looks at different domains of child functioning: health, education, and emotional well-being.

For data collection, the study employs mobile phone technology that enables the principal investigator to track data collection in real time and also allows for a speedy follow up with the field team when any irregularities are spotted. Reflecting upon the learning process during the period of data collection, Prof. Sherr highlighted the discrepancies involved in recording the age and date of birth of the participants. At the time of birth, an infant may be treated as either 1 year old by his/her parents or as 0 years old. As a result, a simple difference in the custom of tracking the age of an infant can be recorded in two equally valid ways and may distort the data. Prof. Sherr also recognized the emotional burden that the process of data collection can pose for the research assistants, and the need to provide support and debriefing was emphasized. It was noted that many projects give very little support to prepare researchers for the field and how mindfulness training and regular counselling services via telephone can be helpful in such scenarios. However, Prof Sherr noted, provision of such support services remains difficult since counselling for research staff is often not supported by the funders. On the need to train data collectors better, the need to balance passion with precision was highlighted. Prof Sherr shared an anecdote from another study wherein an overzealous data collector, who was supposed to randomize and interview only targeted children, ended up interviewing everyone.

The Community Care Study also provided some of the more hands-on suggestions emanating from their experience in the field, such as: the relative benefits of hiring a project car than buying one, acquainting oneself with days when the research participants will be indisposed for data collection, staying safe in the field and avoiding car hijackers, and how they fast-tracked request for referrals through the use of UCL letterheads.

The presentation slides may be downloaded [here](#).

Children of the 90s/ Avon Longitudinal Study of Parents and Children (ALSPAC)

Ms. Lynn Molloy, University of Bristol

Avon Longitudinal Study of Parents and Children (ALSPAC) is a birth cohort study based in Bristol involving 14,500 pregnant women, 10,000 children and 400 grandchildren. ALSPAC works with a biomedical model of research and uses genetic, biological, psychological, social and environmental data.

One of the major challenge faced by ALSPAC has been the variability of the response rates and attrition during follow-up. It was noted that fewer boys wanted to take part in the clinical assessment and that this trend worsens as they get older. To deal with such problems, the engagement strategy for the adolescents was modified. Instead of focusing on just the parents, a dedicated team, with members who were experienced in dealing with teenagers, was employed and easier and innovative data collection methods were used (for example, an online questionnaire). Data collection was carried out at specific sites such as schools and shopping centres, and participants were offered incentives/rewards for the use of their time. Two-way communication between the researcher and the adolescents was maintained through the use of social media. In addition, ALSPAC developed policies to deal with the disclosure of sensitive data such as information pertaining to suicidal thoughts, self-harm, psychosis, and criminal activities.

ALSPAC also uses a “participant advisory panel” that is chaired and run by participants of the research study. Member of this panel assist with data collection, planning engagement events, and provide insights on policy design and ethical considerations involved in the research. Reflecting upon the lessons learned from the research process, Ms. Lynn Molloy noted that the transition phase for the cohort was difficult and needed careful planning. It was found that it was difficult to keep adolescent boys involved in the research. To this end, special strategies were employed, such as use of male fieldworkers. The presence of fieldworkers who had sufficient public relations experience and who enjoyed working with teens made the research process easier. Similarly, participant involvement at the stage of planning and organization, and using age appropriate form of communications tools proved to be key. In the future, ALSPAC hopes to use randomized control trials nested in their research cohort.

The presentation slides may be downloaded [here](#).

Next Steps

Dr. Lisa Calderwood, Institute of Education, University of London

Next Steps is a study of 16,000 adolescents in England born between 1989 and 1990. The study began in 2004 when the research participants were 13-14 years old and were recruited through schools. The participants were surveyed annually until 2010 when they were 19-20 years old. In this way, Next Steps studies the “missing” cohort of young people born in the early 1990s (this is the demographic section that wasn’t included in the other social policy research). It also the only major longitudinal study that focuses on the transition through the teenage years into adulthood. Next Steps has had an impact on different policy areas ranging from bullying to access to education and vocational training. It collects data through sequential mixed mode design using the internet-based, telephonic and face-to-face data collection. Adequate participant engagement is ensured through branding techniques, use of social media, participant packs, etc.

In order to maximize response rate on part of the participants, Next Steps traces participants through administrative data and by Centre for Longitudinal Studies’ data maintenance team, and participants are offered differential incentives if they reply sooner after they have been contacted. Reflecting upon the challenges involved in the research process, it was noted that a recall period between 5 and 10 years was too long since it was

nearly impossible to get the housing histories of the research participants. In order to collect data on sensitive questions, Next Steps piloted data collection through Interactive Voice Response (IVR) technology but had limited success. This was followed by using web-based methods, but it too offered little improvement. In the end, face-to-face data collection was deemed to be the most appropriate method for data collection.

The presentation slides may be downloaded [here](#).

CHIPS, AALPHI and EPICCC studies

Dr. Ali Judd, University College London

Ms. Marthe Le Prevost

The need to track the transition of HIV-positive adolescents into adulthood is necessitated by the fact that the health outcomes for many chronic conditions worsen during the transition into adulthood. For HIV in particular, neurocognitive and mental health issues, stigma and discrimination, HIV disclosure etc. are issues that need to be tackled during the transition into adulthood. **Ali Judd and Marthe Le Prevost** from UCL discussed some of the cohort studies that analyse this period of transition in detail.

- a) Collaborative HIV Paediatric Study (CHIPS) is a follow up study of HIV-infected children under care in the UK and Ireland. CHIPS aims to enhance the exchange of information and expertise between clinics in order to promote standardised high quality paediatrician-led care of all HIV-infected children in the UK and Ireland. Its objectives are to describe clinical, laboratory and treatment information in HIV infected children under care in the UK and Ireland, and to describe the use of paediatric HIV services. The National Study of HIV in Pregnancy and Childhood notifies CHIPS of any children with confirmed HIV infection, and for each of these children a baseline CHIPS questionnaire is sent to the respective clinic for completion. Thus, the study does not require the researchers to obtain consent directly from the patients. Discussing the follow-up stage of the research, the need to secure future funding was highlighted.
- b) Adolescents and Adults Living with Perinatal HIV (AALPHI) cohort works with perinatally-infected HIV-positive and HIV-negative participants living with an HIV-positive family member, and collects data through face-to-face interviews. Till now, it has analysed the neurocognitive functions, psychosocial health, and sexual and reproductive health challenges faced by pre HIV-positive patients. It was noted that the recruitment of HIV-negative participants has been a challenge, and the use of web-based data collection was being considered to potentially minimize the cost of research.
- c) European Pregnancy and Paediatric HIV Cohort Collaboration (EPICCC) is a network of cohort studies involving nearly 8,000 perinatally-infected HIV-positive patients in HIV cohorts in the countries of European Union/European Economic Area. The study works on HIV-infected pregnant women, children and children perinatally-exposed to HIV with a programme of work encompassing individual patient data meta-analyses, pharmacovigilance projects and other observational studies. A persistent challenge for the research has been the lack easy comparability across cohorts. Some of the cohorts have a relatively large proportion of research

participants that come from lower middle income countries. Similarly, not all cohorts allow for the possibility to follow participants as they transition into adulthood.

- d) Healthy Adolescents and Young Adults (HAYA) is a partnership between the Centre for Maternal, Adolescent, Reproductive and Child Health (MARCH) at the London School of Hygiene & Tropical Medicine and the Africa Centre for Population Health. It is being funded by the ViiV Positive Action Programme, which supports communities affected by HIV and AIDS. The Unit will work collaboratively with other research groups, developing academic partnerships nationally, regionally and internationally. The initiative will also provide a focus for training and building capacity in research and adolescent healthcare in sub-Saharan Africa.
- e) Global Cohort Collaboration CIPHER is the largest paediatric cohort collaboration till date and includes more than 250,000 infants, children and adolescents. Noting that the data merger has taken over a year to finish, it was highlighted that the variability in the different variables collected across cohorts and the limited follow-up times has been challenging for the project.

The presentation slides may be downloaded [here](#).

Mater Hospital PEDS HIV Project

Dr. Jack Lambert & Mr. Craig Carty

This research project is based in the Buffalo City Municipality of Eastern Cape, South Africa. Many HIV+ positive children in this region are now entering the period of young adulthood during which there are multiple medical, psychological, social and others forms of stigma that they experience. It has been noted that the highest risk of mortality from HIV remains in the young adult population. A significant feature in this region has been the lack of information on the number of paediatric cases of HIV. As a result, a project was undertaken to digitize all paper-based record for future migration into an electronic medical record (eMR).

The Pediatric ART Data Management Tool offers an easy to access and intuitive interface to access a patient records. The use of this eMR interface offers a number of benefits:

- It allows for prospective collection of information for clinical and research use.
- It offer the opportunity to link with adult clinics and in the presence of adequate identifiers, it may allow us to track the patients through their transition into adulthood.
- It can allow us to establish guidelines for best practices that are derived directly from the data.

The eMR also includes data on caregiver's relationship to the patient, the age of newly enrolled patients can be disaggregated by the year of admission, and the information of the year of ARV initiation can be obtained.

Based on initial analysis, an intervention is being planned which may either be common for all HIV-positive adolescents globally, or may differ from country to country, or may

be specific to an adolescent's specific circumstances. Future analysis on the mental health issues faced by the cohort is also being planned and funders are being sought.

The presentation slides may be downloaded [here](#).

The CLOSER Programme

Prof. Alison Park, UCL Department of Education

The CLOSER programme (Cohort & Longitudinal Studies Enhancement Resources) brings together nine leading studies, the British Library and the UK Data Service, CLOSER works to stimulate interdisciplinary research, develop shared resources, provide training, and share expertise. CLOSER helps to build a body of knowledge on how life in the UK is changing – both across generations and in comparison to the rest of the world. CLOSER's key activities include:

- Retrospective data harmonization to highlight the advantage of comparing different cohorts.
- Linking survey data to administrative data.
- Creating resources for others through training on data harmonization, creating search platforms to view survey data and questionnaires within CLOSER's cohorts.

CLOSER seeks to organize capacity building events and next January it will run a workshop on how to keep participants engaged during the period of research.

BREATHHER Trial

Dr. Sara Papparini, University College London

The overall aim of the BREATHHER trial is to evaluate the role of Short-Cycle Therapy (SCT) in the management of HIV-infected young people who have responded well to antiretroviral therapy (ART) and to determine whether young people with chronic HIV infection undergoing Short-Cycle Therapy of five days on ART and two days off maintain the same level of viral load suppression as those on continuous therapy, over 48 weeks.

Reflecting upon the challenges of the research project, Dr. Papparini highlighted the difficulties with recruitment in the UK (as opposed to in Uganda). It was also noted that the use of mixed methods can mean that findings obtained from qualitative and quantitative methods contradict each other. Other challenges include:

- The need to ensure informed consent is sought continually – often carers don't understand what they are consenting to. We need to ensure that young people understand their opting-out capabilities.
- Social desirability bias in interviews
- Once relationship of trust develops between fieldworkers and the research participants, it becomes difficult for the fieldworkers to take action and divulge the information that the youth is not adhering to ART.
- Different cross-cultural understanding of what is meant by "abuse". In multiple country studies, there will be different meanings of what constitutes "abuse".

Taking this discussion forward Dr. Papparini offered her insights from the Millennium Cohort Study. It was also highlighted how the qualitative element of the research can be used to improve questionnaires. It was noted that ethics committees need to realize that if the consent forms are too long and detailed, the research participants may refuse to read them altogether. The MW team, drawing upon their experience, shared that they conduct qualitative research before quantitative research. The qualitative stage of the research allows the MW team to experiment different ways in which questions about adherence can be raised.

Annexes

Annex 1 – Information on speakers and participating cohorts

Cohort/ Study Name	Speaker	Institution	Description
	Prof. Alison Park	CLOSER programme	<p>Prof. Park is director of the CLOSER programme (Cohort & Longitudinal Studies Enhancement Resources). The programme aims to maximise their use, value and impact both at home and abroad. Bringing together nine leading studies, the British Library and the UK Data Service, CLOSER works to stimulate interdisciplinary research, develop shared resources, provide training, and share expertise. In this way CLOSER is helping to build the body of knowledge on how life in the UK is changing – both across generations and in comparison to the rest of the world.</p> <p>http://www.closer.ac.uk/about/</p>
The Community Care Study	Prof. Lorraine Sherr	UCL	<p>Prof Lorraine Sherr is a Clinical Psychologist and head of the Health Psychology Unit. Prof Sherr has worked at National and International levels on HIV, mental health, treatment adherence, switching, gender, pregnancy, families, children, parenting, palliative care, discrimination and HIV infection. Prof Lorraine Sherr is editor of three International Journals; AIDS Care (in its 23rd year of publication under her editorship), Psychology Health and Medicine and Vulnerable Children and Youth Studies. She is one of the organisers of the AIDSImpact conferences which delve into the detailed psychosocial aspects of HIV. She has wide spread policy work such as serving on the WHO Strategic Advisory Committee (STAC), chairing the WHO Disclosure guidelines group and providing input for Governments, USAID, Save the Children, UNICEF, PEPFAR, REPSSI, French ANRS, British Psychological Society, British HIV Association, IAS and USA Congressional initiatives.</p> <p>Together with Prof. Mark Tomlinson, Prof. Sherr runs the Community Care study. The study is following nearly 2,000 children being served by diverse community-based programs. Near completion of its baseline, the study is gathering data about the children and the type of program they attend. The same data will be collected 12-18 months later, providing a snapshot of psychosocial changes in children correlated with the features of programs they attend.</p> <p>http://www.ccaba.org/our-projects/research/the-ucl-stellenbosch-childrens-cohort-study/</p>

Cohort/ Study Name	Speaker	Institution	Description
Avon Longitudinal Study of Children and Parents	Ms. Lynn Molloy	University of Bristol	<p>Based at the University of Bristol, the Avon Longitudinal Study of Parents and Children (ALSPAC), also known as Children of the 90s, is a world-leading birth cohort study. Between April 1991 and December 1992, the study recruited more than 14,000 pregnant women into the study and these women (some of whom had two pregnancies or multiple births during the recruitment period), the children arising from the pregnancy, and their partners have been followed up intensively over two decades. Children of the 90s is the most detailed study of its kind in the world and it provides the international research community with a rich resource for the study of the environmental and genetic factors that affect a person's health and development.</p> <p>http://www.bristol.ac.uk/alspac/</p>
BREATHER/ ARROW trials	Dr. Sara Papparini	London School of Hygiene and Tropical Medicine	<p>The overall aim of the BREATHER trial is to evaluate the role of Short-Cycle Therapy (SCT) in the management of HIV-infected young people who have responded well to antiretroviral therapy (ART) and to determine whether young people with chronic HIV infection undergoing Short-Cycle Therapy of five days on ART and two days off maintain the same level of viral load suppression as those on continuous therapy, over 48 weeks.</p> <p>To assess the advantages and disadvantages of the strategy, the incidence of toxicities, immunological control, resistance mutations, acceptability, quality of life and adherence to the randomised strategy will also be compared. Importantly, because of insufficient data on short-term viral load rebound after stopping ART in this population, the trial will incorporate an initial pilot phase in selected centres, to assess the safety of the SCT strategy by evaluating detailed HIV-1 RNA profiles of participants on the SCT strategy.</p> <p>http://www.ctu.mrc.ac.uk/news/2015/social_science_arrow_breather_09072015</p> <p>http://penta-id.org/hiv/penta-trials/penta-trials-publications/112-penta-16-breather.html</p>
CHIPS UK	Dr. Ali Judd	University College London (UCL)	<p>CHIPS is a follow up study of HIV-infected children under care in the UK and Ireland. CHIPS aims to enhance the exchange of information and expertise between clinics in order to promote standardised high quality paediatrician-led care of all HIV-infected children in the UK and Ireland. Its objectives are to describe clinical, laboratory and treatment information in HIV infected children under care in the UK and Ireland, and to describe the use of paediatric HIV services. This information is fed back to the reporting paediatricians in order to inform and improve care provision. The National Study of HIV in Pregnancy and Childhood, at the Institute of Child</p>

Cohort/ Study Name	Speaker	Institution	Description
			<p>Health, notifies CHIPS of any children with confirmed HIV infection, and for each of these children a baseline CHIPS questionnaire is sent to the respective clinic for completion. Thereafter, a follow-up questionnaire is sent to the clinic annually.</p> <p>http://www.ctu.mrc.ac.uk/our_research/research_areas/hiv/studies/chips/</p>
Next Steps	Dr. Lisa Calderwood	Institute of Education, University of London	<p>Next Steps, formerly known as the Longitudinal Study of Young People in England (LSYPE), follows the lives of around 16,000 people born in 1989-90. The study began in 2004, when the cohort members were aged 13-14, and has collected information about their education and employment, economic circumstances, family life, physical and emotional health and wellbeing, social participation and attitudes. The Next Steps data has also been linked to National Pupil Database (NPD) records, which include the cohort members' individual scores at Key Stage 2, 3 and 4.</p> <p>Next Steps is managed by CLS and funded by the Economic and Social Research Council. The study was previously managed and funded by the Department for Education (2004-2012). The initial Next Steps survey was in 2004 and included all young people in Year 9 who attended state and independent schools in England. Following the initial survey at age 13-14, the cohort members were visited every year until 2010, when they were age 19-20. The next survey is currently taking place in 2015/16, when the cohort members are 25 years old.</p> <p>http://www.cls.ioe.ac.uk/page.aspx?&sitesectionid=1246&sitesectiontitle=Welcome+to+Next+Steps+(LSYPE)</p>
Mater Hospital Paediatric HIV Studies	Prof. Jack Lambert	Mater Hospital, Dublin	<p>The Mater Hospital in collaboration with the East London Hospitals Resource Centre, the Frere and Cecilia Makiwane Hospitals is working on two projects: (1) Paediatric ART Clinic Software Development & Audit Study (PASDP) and (2) Passages Project. PASDP has a dataset of over 50,000 visit records from 2 500 paediatric patients. The data is being analysed to allow clinics and researchers to further understand the nuances of managing children living with HIV. For the past two years, PASDP has been working on digitising these medical records. Data from both the first and the second stage of the project is stored in the Eastern Cape Department of Health. The tool also supports multivariate analysis of both biological and social indicators that are critical for the management of young HIV patients. The PASDP program is a project which has been developed by the Eastern</p>

Cohort/ Study Name	Speaker	Institution	Description
			<p>Cape Health's Paediatric Outpatient Department and Paediatric Software Development and Audit Project in partnership with Chiva South Africa, ViiV Healthcare.</p> <p>The Passages Project is a ViiV Healthcare-funded, multi-country cohort starting with qualitative interviews of multiple groups: yet to transition, transitioned, and lost-to-follow-up adolescents. The study involves paediatric patients, health care providers, and carers. Preliminary findings will be presented at AIDS 2016 in Durban.</p>
Young Lives	Prof. Virginia Morrow	University of Oxford	<p>Young Lives is an international study of childhood poverty, involving 12,000 children in 4 countries over 15 years. It is led by a team in the Department of International Development at the University of Oxford in association with research and policy partners in the 4 study countries: Ethiopia, India, Peru and Vietnam. Through researching different aspects of children's lives, Young Lives seeks to improve policies and programmes for children.</p> <p>http://www.younglives.org.uk/</p>