



## Surveying Children in longitudinal studies

**EUCCONET International Workshop Thursday and Friday 5<sup>th</sup> & 6<sup>th</sup> May 2011  
Dublin, Ireland**

**Organisers:** James Williams, Director, Growing Up In Ireland (Economic and Social Research Institute, Dublin, Ireland)  
Kate Smith, Survey Manager, Millennium Cohort Study (Centre for Longitudinal Studies, Institute of Education, UK)

### **1. Summary**

This workshop focused on issues related to the ethical and practical issues surrounding best practice in surveying children aged 9-15. These ranged from ethical issues relating to recruitment and informed consent / assent to practical issues of consultation with children and parents in advance of implementation, as well as those associated with age appropriate modes of data collection in a longitudinal study.

There is much literature which focuses on the practical and ethical issues involved when carrying out research with children (e.g. Alderson & Morrow, 2004 & 2011; Tisdall et al, 2009) However much of this work is qualitative in nature and focuses on small-scale and once-off studies.

There is an increasing awareness that information should be taken directly from children, giving children a voice (the UN Convention on the Rights of the Child). However there is little evidence on the different approaches that large-scale longitudinal studies are taking as the children in these cohorts are growing up and become actors in their own right, but before they have reached legal adulthood.

These issues cover the areas of: data collection mode, what is the best way of engaging young people and what use can these studies make of new technologies?

With regards to the ethical and practical issues of surveying children, best practice highlights the importance of informed consent, however how is this practically implemented with a cohort of young people who have yet not reached the age of legal responsibility?

As these children grow, how do these studies ensure their cooperation and participation for the future?

The workshop brought together those running longitudinal studies around the world in order to share experiences and best practice in relation to these issues.

The programme for the two-day workshop included substantive presentations. The vast majority of the presentations were from child cohort studies based in Europe and one from the USA. There was also a presentation from a longitudinal study of school aged young people based in Europe. The rationale for the inclusion of this study as well as cohort studies is that they have already encountered many of the issues that the EUCCONET cohort studies will be experiencing and can share their knowledge.

This workshop offered a forum for different types of longitudinal studies from around the world to learn from each other.

## 2. Scientific Content and Discussion

In this section we present a summary of the scientific content of the contributions presented during the workshop. In broad terms these relate to two over-arching themes. The first focused on research with children in general terms including securing informed consent/assent and prior consultation with children to ensure that they had an appropriate voice in the research as set out under the UN Convention on the Rights of the Child. The second involved a consideration of age appropriate methods of recruiting and retaining children and young persons in longitudinal studies with a view to minimising attrition and maximising data quality and scientific rigour.

### 2.1 Over-arching issues in the ethics of research with children and ensuring child's voice is heard

The introduction (James Williams, *Growing Up in Ireland*, Economic and Social Research Institute) noted that although different approaches had been taken to recruiting children of varying ages into longitudinal child cohort studies the overarching concern is to ensure that Article 12 of the UN Convention on the Rights of the Child is implemented in a full and complete ethical manner. Article 12 notes that:

“Parties shall assure to the child who is capable of forming his/her own views the right to express those views freely in all matters affecting the child, the views of the child being given due weight in accordance with the age and maturity of the child.”

The Keynote address (Janet Boddy, Thomas Coram Research Unit, Institute of Education) developed this theme noting that in research with children there may often be a risk that we are “...less concerned with children's rights than with adults' freedoms” (Alderson 2007, p2273). When involving children in research specific consideration should be given to, *inter alia*:

- ❖ children's competencies, perceptions and frame of reference

- ❖ their potential vulnerability to exploration in interaction with adults
- ❖ the differential power relationships between adults and children
- ❖ the role of adult gatekeepers in mediating access to children

The role of parental involvement in the consent process was emphasised. This balance was summarised by Maguire (2005) who notes that “...at the ethical core of researching with children then are issues of equity, inclusion and exclusion and who gets to speak after all and whose voices are heard, recognised, or silenced’. Equally, it leads Powell and Smith (2006) to conclude that “overprotection contributes toward the structural vulnerability of children, which is not a biological reality but rather children’s lack of power and status within our societal structures” (p135). The question could be posed as to whether or not some groups of children are systematically being excluded from our studies and the need to avoid a “normalized absence” of some children’s voices was stressed. The balance between adult freedoms and children’s rights or protection and participation is a delicate one which must be addressed in the planning and design of Child Cohort studies.

Practical issues involved in adhering to best practice in protecting children in research was further considered by Anne Cleary, University College Dublin. She too stressed the need for an ever increasing focus on children as active social actors and participants in the research process and the need to embrace emerging understandings of children’s lives and experiences. Again, the balance between protection and participation was stressed, as were the tensions between the objectives of research; the recognition of children’s rights and well-being; and the responsibilities of parents. Minimizing the risk to children and protecting them in the research process may be achieved by clear risk assessment procedures; protocols to ensure compliance with ethical procedures and child protection frameworks; police vetting and assessment of the competency of interviewers; the training of interviewers and other staff involved in child cohort studies in the identification and reporting of potential child protection issues; and the need to have a fully developed protection protocol to deal with potential protection issues as they emerge.

Central to relevant protocols and procedures is the development of fully informed consent and assent procedures, which should be on-going at each round of a longitudinal study. This should involve a full explanation of confidentiality and anonymity, including potential limitations to both. Power relationships between adults and children in the consent/assent and interviewing processes must be specifically addressed. This will be assisted through appropriate interviewer training to ensure that children feel secure, protected, respected and that their views are accorded the importance they merit. Ethical protection is the key to minimizing harm and distress to children. Overprotection, however, should also be avoided. This is particularly relevant in the context of highly sensitive topics or questions which may be addressed without negative outcomes for children, particularly with the potential afforded by emerging technologies which may be



used as part of the toolkit of longitudinal surveyors. The need to align ethical and methodological perspectives emphasizes the ever increasing need for informational and cooperative loops between researchers and Research Ethics Committees. The primary concern in this work must be the protection of children in our research. Research methodologies must be developed to realistically, but sensitively, understand the lives and experiences of contemporary children.

Sheila Greene (*Growing Up in Ireland*, Trinity College Dublin) discussed in detail the consultation mechanisms within the Irish national Child Cohort study to ensure full involvement of children at all stages of the process and to provide a platform for children to meaningfully participate in the project and to inform the Study Team's decision making. The Children's Advisory Forum (CAF) is made up of 84 children selected from 12 schools nationally within Ireland. The Forum provided advice to the Study Team on issues such as assent and consent; information provided to both children and parents; questionnaire content and design (including pre-piloting of question wording and formats); implementation procedures (CASI / CAPI etc) and how best to balance child protection issues (including the presence of an adult in the room at the time for interview) with privacy considerations for the respondent children in completing their surveys; formats for feedback to the children and, in particular, child-friendly reports on the findings.

## 2.2 Recruiting, retaining and engaging children and young people in longitudinal cohorts.

A second major theme of the Workshop was the recruitment and retention of children in longitudinal cohort studies. Kate Jaeger (Fragile Families, Center for Research on Child Wellbeing, Princeton University) considered the strategies used to recruit, retain and interview children in a mobile and disadvantaged population. In particular, issues involved with introducing the role of genetics into social science research were considered, with the taking of saliva samples from respondents in Year 9 of the study. Parental consent and assent in the taking of the saliva sample using Oragene DNA self-collection kits were addressed. Issues including whether or not the samples could be used for specific or general research purposes; confidentiality and potential feedback were explored in discussion of consent/assent. Issues related to parental consent and contact information used for the teacher survey were also discussed. The presentation from Fragile Families also considered its strategies to reduce otherwise higher levels of attrition among a socially disadvantaged population, including use of previously recorded alternative contacts; paid locating databases; neighbourhood canvassing; internet and social network searches; respondent incentives and interviewer bonus schemes.

James Williams (*Growing Up in Ireland*, Economic and Social Research Institute, Dublin) discussed recruitment and consent among the 9 and 13-year-olds in Ireland's national longitudinal study of children. The two-staged sample design was based on schools, with consent first being secured for the cooperation of a nationally representative sample of schools. This was then used as a vehicle for securing consent and assent from the children and their families who participated in the study. The school was pivotal in securing consent/assent. Information packs on the project were sent to parents by the school. These included a multilingual letter of introduction; Children's and Parent's information leaflets; Consent and Assent forms (with duplicates of each for respondents to retain for their own records). The information leaflets included details on the background to the Study; its objectives; funders; how the sample had been selected; what was involved in participation; a flavour of the questions asked; the longitudinal nature of the study (involving repeat visits to the homes) and contact details of the Study Team.

Feedback to the children, retention and panel maintenance were also considered by Kate Smith (Millennium Cohort Study, Institute of Education, London) who discussed recruitment and consent/assent in the Age 11 Dress Rehearsal which was being carried out in the summer 2011 (with a view to main stage fieldwork in January 2012). In particular, she considered the consent/assent issues involved, especially around the new saliva sampling component of the project, which is being introduced at age 11<sup>1</sup>. The acceptability of saliva sampling for both children and their parents was considered. Throughout the consenting process in the

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<sup>1</sup> Saliva had been collected to test for a specific hygiene hypothesis at age 3. The collection at age 11 is for more broadly-based research.



Millennium Cohort Study power rests with the child, with child assent taking priority over parental consent. Feedback to the children was also an important consideration discussed in the presentation.

Larisa Duffy (ALSPAC, University of Bristol) discussed issues of enrolment of 14,541 pregnant women in this longstanding study. Initial recruitment was through media coverage; approaches at routine scans in hospital after birth; through community midwives. Children, mothers, their spouses/partners, siblings and offspring were all recruited into the study. Given the nature of the ALSPAC project biometrics and related issues of consent/assent were clearly an important aspect of this study. Maintenance in the early years of the study (until the children were five years of age) relied on such approaches as accessing child health records; GP records; change of address cards; birthday and Christmas cards; hotline numbers; participant newsletters; prize draws and branded gifts containing the Study logo.

In the middle years retention and follow-up relied heavily on linkage through administrative databases; alternative contact details; school records and mobile phones. Linkage to NHS address data was also used as were social networking sites; email; outreach clinics through local health and community centres as well as Summer festivals where study participants might congregate.

As ALSPAC has matured and its primary respondents (usually children) got older the focus for tracing, consent and recording of information changed from the parent to the growing child. Children are increasingly encouraged to attend at ALSPAC clinics by themselves. One aspect of this shift is the Teenage Advisory Panel which was recruited in 2006. Thirty young people met monthly to assist with study planning and to advise on ways of engaging with participants. The Teenage Advisory Panel became members of the ALSPAC Law & Ethics Committee. This panel in ALSPAC appears to be very similar in structure and function to the Children's Advisory Forum (made up of slightly younger children) in the *Growing Up in Ireland Study* and discussed in the course of the workshop by Sheila Greene from Dublin.

Rob Taal (Generation R Study, Erasmus MC Centre, Rotterdam) discussed recruitment retention as well as future plans for Generation R. The sample of 10,000 parents and children for this study was recruited pre-natally between 2001 - 2006. The Study aims to identify biological, environmental and social determinants of normal and abnormal growth, development and health. Biometrics including collection of cord blood, DXA scans, heart ultrasounds, tooth pictures, abdominal fat and urine samples all form an important component of this study. Retention strategies include newsletters; parent groups; feedback to participants; on-going website updates; multilanguage documentation. Generation R is also examining the possibility of using social media sites and smartphones to assist both in retention and also in implementation at future rounds. Given high levels of mobile phone ownership among 9-14-year-olds (approximately 75 per cent) the feasibility of using phone apps. for questionnaire completion is being actively examined as is the option of web-based interviewing.

Angela Thompson and Emma Wallace (of IPSOS MORI) discussed a qualitative study undertaken to inform the collection of sensitive information from 11-year-olds in the fifth round of the Millennium Cohort Study. This was carried out to ensure that sensitive information on issues such as alcohol, tobacco and drugs; anti-social behaviour; bullying; puberty; relationships within the family etc. could be recorded from children in an ethically appropriate way whilst simultaneously ensuring that refusals were minimised, that disengagement with the study was avoided and that data quality was maintained. In addition, the research also investigated the acceptability to children and their parents of collecting saliva using Oragene self-collection kits. The study was based on 12 in-home interviews with parents and children (separately and privately) as well as 10 in-school friendship cells. The work illustrated the need to appropriately plan for the collection of such information in a technically robust and ethically acceptable way, ensuring that its collection is wholly informed by the voice and views of the children who will ultimately be the centre of the research.

Jutta Von Maurice (German National Educational Panel Survey, University of Bamberg, Germany) provided an overview of the NEPS study. This ambitious study, incorporating a multicohort sequential design based on eight stages (or ages), is investigating how education is acquired by children at all stages of the education system in Germany and seeks to analyse the major educational processes and trajectories across the lifespan. The study is collecting longitudinal data on the development of competencies, learning environments, effects of social inequality and migration as well as returns to education throughout the entire life span. The presentation provided a particular focus on the recruitment procedures used on the first wave of the 9<sup>th</sup> grade starting cohort, as well as the instruments used with these children. This included securing general permission to collect data in more than 500 schools in the first instance with subsequent recruitment of students and parents in the 9<sup>th</sup> Grade cohort through the participating schools. The consent processes involved in securing this information was discussed in full.

Nick Howat (TNS-BMRB,UK) discussed the Longitudinal Study of Young Persons in England (LSYPE). This study charts changes in educational development of children from 13 years to 19 years (2004 to 2010). The presentation focused on consent issues and the changing focus of consent over the life of the study, particularly from parental consent to one based on respondents being viewed as “young people” not “children”. This represented a move away from strategies aimed at maximizing parental “buy-in” to ones aimed at respondent/young person “buy-in”. The survey also experienced a major change in mode of implementation from face to face in Wave One to Four to a sequential mixed mode design in Wave Five onwards. This latter was based on web, telephone and face-to-face interviewing. Notwithstanding the change to a sequential mixed mode approach the Study Team maintained very high response rates (low levels of attrition) and data quality appeared not to be compromised.

Inger Kristine Meder (The Danish National Birth Cohort, University of Copenhagen) described the 11-year follow-up of this longitudinal birth cohort. Data collection

methods were highly innovative, based on web-based questionnaires for both parents and children. At age 11 the mother was still the gatekeeper with an introductory letter addressed to her. In the same envelope was a separate letter addressed to the Study Child. By adopting this approach the Study Team was able to balance the ‘protective role’ of the parent with the right to participation of the child, with the mother as initial gatekeeper.

The innovative website developed for the 11-year-olds included the so-called ‘Club 11’ for participating children. This was very child oriented and aimed at fully engaging the child in ways with which s/he might be familiar from playing computer games. The ‘Club 11’ website included 3 items: the professor’s laboratory; the questionnaire; Avatars. The innovative and highly progressive IT solution encountered some problems. These included: participation rates which were somewhat lower than anticipated; login procedures which seemed complicated to respondents, along with some IT problems; moderate success with the Avatar scenarios; concern by mothers about the content of some of the child sensitive questions; fathers feeling left out of the process and handicapped children being unable to participate and hence not having a voice in the study.



### 3. Assessment of results and impact of the workshop

It is felt that this Workshop was very successful in focusing on its stated objectives viz ethical issues related to recruitment and informed consent as well as aspects of retention and new modes of data collection in longitudinal studies of children.

The Workshop raised an awareness internationally of the need to ensure that child cohort studies must be undertaken with children and for children with a view to benefiting children and enhancing child outcomes. This requires us to set our longitudinal child cohort studies within the parameters of rights, responsibilities and protection, set out in the UN Convention on the Rights of the Child. Securing and listening to the child's voice is fundamental to the implementation of child cohort studies (Article 12 on Children's Opinion and Article 13 on Freedom of Expression). The balance between child rights and parental responsibilities in terms of child protection is a delicate one. Raising its profile among researchers at meetings such as the EUCCONET workshop can substantially assist in ensuring that such considerations are incorporated into the work of researchers in developing child cohort studies.

Related to the right to participation among children are issues associated with children's advisory forums and advisory panels adopted by several of the child cohorts which presented at the Workshop. These provide an important input to formats for securing informed consent and assent by parents and children respectively. Sharing of information on the ways in which informed assent/consent may be secured can only assist and improve the work we do.

Equally, sharing of information on retention and attrition minimization strategies can also help to ensure best practice procedures are adhered to with a view to improving data quality and consistency across surveys within ethically acceptable parameters. An aspect of this is the use of new technologies, particularly web and internet based, phone apps. and so on in the implementation of child cohort studies.

In terms of future directions, the workshop underlined the need for clear thinking on the ethical issues involved in child cohort studies and an international convergence to what might be agreed as ethical best practice in terms of balancing rights and responsibilities of all parties involved - the children, their parents/guardians and researchers. A harmonized approach to ethical procedures would ensure not only enhanced protection of children but would also allow international benchmarking of child cohort studies in this area. Such benchmarking could involve comparison of each cohort in terms of the extent to which consent/assent can be truly considered to be informed; the extent to which children are actively engaged in the research process and the degree to which data collection, recruitment and retention methods are age appropriate and consistent with best ethical practice. The ideal outcome would involve such ethical



benchmarking exercises becoming standard in comparing the rigor of child cohort studies in the same way as response rates are currently used to assess their technical robustness.

## Final Programme

### Programme

#### Thursday 5<sup>th</sup> May

- 11:00 - 11:30      **Registration; Tea/coffee**
- 11:30 - 11:40      Welcome and introduction  
*James Williams (Economic and Social Research Institute, Ireland)*
- 11:40 - 12:20      The State of *Fragile Families* in the States: Retaining and Interviewing Children in a US Birth Cohort Study.  
*Kate Jaeger (Center for Research on Child Wellbeing, US)*
- 12:20 - 13:00      Children and longitudinal studies. Experiences from the Generation R Study.  
*Rob Taal (Erasmus Medical Centre, Netherlands)*
- 13:00 - 13:40      Lunch**
- 13:40 - 14:20      Growing Up in Ireland - the work of the Children's Advisory Forum and the Qualitative Component  
*Sheila Greene (Trinity College, Dublin, Ireland)*
- 14:20 - 15:00      Millennium Cohort Study - The design and approach to interviewing children in the Age 11 survey  
*Kate Smith (Institute of Education, UK)*
- 15:00 - 15:20      **Tea/coffee**
- 15:20 - 16:00      ALSPAC: The story so far  
*Larisa Duffy and Kate Angel (University of Bristol, UK)*
- 16:00 - 16:40      The 11-year follow-up in the Danish National Birth Cohort  
*Inger Kristine Meder and Pernille Stemann Larsen (Statens Serum Institut, Denmark)*
- 16.40 - 17.20      Discussion and Close
- 19.00                  Dinner**

#### Friday 6<sup>th</sup> May

- 09.15 - 09:30      **Tea and coffee**



- 09:30 - 09:40      Welcome and introduction  
*Kate Smith (Institute of Education, UK)*
- 09.40 - 10.20      Keynote Address: Ethical decision-making across the research process? Participation, protection and other issues.  
*Janet Boddy (Institute of Education, UK)*
- 10.20 - 11.00      Growing Up in Ireland -recruiting, retaining and interviewing nine-year-olds in Ireland's child cohort study  
*James Williams (Economic and Social Research Institute, Ireland)*
- 11:00 - 11:20      **Tea and coffee**
- 11:20 - 12:00      The German National Educational Panel Study: Need, main features, research potential  
*Jutta Von Maurice (University of Banberg, Germany)*
- 12:00 - 12:40      Qualitative Research to inform the collection of sensitive data among 11-year-olds on the fifth wave of the Millennium Cohort Study.  
*Angela Thompson (Ipsos MORI,) and Emma Wallace (Ipsos MORI, UK)*
- 12:40 - 13:20      **Lunch**
- 13:20 - 14:00      Merging ethical concerns and innovative research practice  
*Anne Cleary (University College, Dublin, Chair Research Ethics Committee, Growing Up in Ireland)*
- 14.00 - 14.40      LSYPE - An Education Journey  
*Nick Howat, Carrie Harding (TNS-BMRB, UK) and Helen Wood (Department of Education, UK)*
- 14.40 - 15.20      Discussion and close

## List of Speakers and Participants

<b>Speakers</b>	
<b>Name</b>	<b>Study</b>
Angie Thompson	Millennium Cohort Study
Carrie Harding	Longitudinal Study of Young People in England
Emma Wallace	Millennium Cohort Study
Helen Wood	Longitudinal Study of Young People in England (LSYPE)
Inger Kristine Meder (speaker)	Danish National Birth Cohort
Janet Boddy	Institute of Education
Jutta von Maurice (speaker)*	National Educational Panel Study
Kate Jaeger	Fragile Families and Child Wellbeing Study
Kate Smith	Millennium Cohort Study
Larisa Duffly	Millennium Cohort Study
Nicholas Howat	Longitudinal Study of Young People in England
Pernille Stemann Larsen (speaker)	Danish National Birth Cohort
Rob Taal	The Generation R Study
Kate Angel	Children of the 90s
Anne Cleary	University College Dublin
James Williams	Growing Up in Ireland
Sheila Greene	Growing Up in Ireland
<b>Participants</b>	
Aakash Shrivastava	Lifeways Cross Generation Cohort Study
Anne-Kristine Molholt	Children and Young People in Denmark
Asta Danilevičiūtė	KANC newborns cohort
Jet Smit	PIAMA birth cohort
Joachim Heinrich	GINI and LISA
Joan Forn's Guzmán	INMA (Childhood and Environment) birth cohort
Judith Mabelis	Growing up in Scotland
Julie Pagis	Etude Longitudinale Française depuis l'Enfance
Karien Viljoen	Lifeways Cross-Generation Study
Lisa Calderwood	Millennium Cohort Study
Lucinda Platt	Millennium Cohort Study

Mireia Gascon Merlas	INMA (Childhood and Environment) birth cohort
Muriel Ferrer Vergés	INMA (Childhood and Environment) birth cohort
Patricia Schruder	Norwegian Mother and Child Cohort Study
Regina Grazuleviciene	KANC newborns cohort
Renee Liang	Growing Up in New Zealand
SC Noah Uhrig	Understanding Society
Sofie Stage	Children and Young People in Denmark
Sosthenes Ketende	Millennium Cohort Study
Amanda Quail	Growing Up in Ireland
Cathal McCrory	Growing Up in Ireland
Maeve Thornton	Growing Up in Ireland
Aisling Murray	Growing Up in Ireland
Brian Merriman	Growing Up in Ireland
Sinead McNally	Growing Up in Ireland
David O'Neill	Growing Up in Ireland
Emer Smyth	Growing Up in Ireland
Paula Mayock	Growing Up in Ireland
Anne-Marie Brooks	Department of Health and Children
Sinead Hanafin	Department of Health and Children
Jillian Heffernan	Growing Up in Ireland
Claire Delaney	Growing Up in Ireland