

Knowledge
Exchange
Workshop



Participant engagement in longitudinal studies

Wi-Fi: Woburn House Conference Centre
Password: igitor

Please switch your mobile phones to silent



Participant engagement in longitudinal studies

Wi-Fi: Woburn House Conference Centre. **Password:** igitor

Please **tweet** positively & responsibly
using **#CLOSERKEW**, and do not
include any costs

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Knowledge
Exchange
Workshop



Consent

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Securing informed consent from children and young people in a home setting: learning from the Millennium Cohort Study

CENTRE FOR
LONGITUDINAL
STUDIES



Importance of consent in social research with children

- UN Convention on the Rights of the Child gives children rights of protection and participation.
- In the context of social research, this means protecting their freedom to participate, while ensuring their wellbeing throughout
- Role of parents as gatekeepers to approach child as under 16
- Precise approach = study specific
 - Depends on complexity of content + age/capacity of children + nature of the study

Millennium Cohort Study: approach to consent

- Fully informed for parents and young people
- Formalised consent process for parents and also young people since Age 11
- Consent forms for parents and young people
- Written consent from parents to approach the young person
- Verbal consent from YP for overall participation and for each element
 - questionnaire
 - cognitive assessments
 - physical measurements
 - saliva sample (Age 14)

Developing the MCS Approach

Informed by:

- Ethics committee (MREC approval required)
- Best practice
- Literature
- Requirements of study type (longitudinal): ensuring not only most comfortable experience at any one data collection point but securing participation for the future
- Need to standardise process as much as possible for interviewers in home environment
- Qualitative research with children & parents at ages 11 & 14

Age 11 findings:

- 11 year olds focused on immediate research experience – what it would be like to take part
- Less likely to interest in the purpose of research and what data would be used for
- Conclusion: they understood enough to be able to consent to their own participation BUT parents should still be involved

Age 14 findings:

- Young people felt that they would still like their parent(s) to be involved in decisions around participation – many still look to their parents for advice, support and guidance.
- Young people said they would like to receive their own post with all of the survey information in it – letters = ‘novelty’
- Young people have a strong awareness of privacy issues.
- Young people wanted a sense of control over the research by being informed.
- Young people felt signing consent could make the process overly formal & daunting.

Securing voluntary informed consent in practice for MCS

Parent (Ages 11 and 14)

- Full written information sent in advance
- Written consent secured by the interviewer on the day:
 - participation in their elements
 - to approach the cohort member
- Interviewer to ensure parents understand/happy with all key points including how data will be used

Securing voluntary informed consent in practice for MCS

Children

- Age 11:
 - Advance leaflet (4 pages) with summary information - sent to the parents
 - Interviewer played key role in explaining detail tailored to child's understanding on the day using written consent form as a guide
 - Verbal consent from child + interviewer sign confirmation
 - Stress right to choose, stop at any time & confidentiality
 - Regular reminders throughout so consent was on going

Answer some questions about my life. 30 minutes

The interviewer will give you a booklet of questions to fill in on your own. You can ask the interviewer for help if you find it difficult to do it on your own. You can also use headphones and have the questions read out to you. You do not have to show the interviewer or anyone else your answers.

The questions are about lots of different things. These things include your family and friends, school, the things you do outside school, the area you live in and how you feel. If there are any questions you don't want to answer, that is OK. You can just skip them. The booklet isn't a test. We just want to know what you think about things.



Be measured to find out how I am growing. 10 minutes

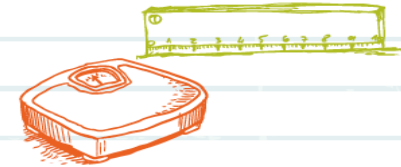
The interviewer will measure how tall you are. They will also see how much you weigh and how much of your body is made of fat. To do this they will use special scales. The interviewer will give you a copy of your measurements if you want. They will not tell anyone else your measurements.



What if I have questions? What will I have to do?

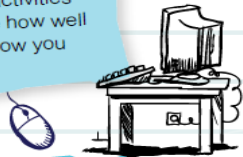
The interviewer will tell you more about these activities when they come to see you. They will ask you if you have any questions. They will also make sure you understand what you have to do before you start.

The interviewer will ask you to do some different things. You can decide whether or not you want to do each one.



Do three activities to find out how I think. 25 minutes

The interviewer will ask you to tell them how some words go together. They will also ask you to do two fun activities on a computer. The first computer activity will see how well you can remember things. The second is about how you make up your mind.



Do I have to do these things?

You don't have to help us by doing these things if you don't want to. The interviewer will ask you about them one at a time and you can say yes or no to each. You can stop at any time.

Will I get anything for doing it?

The interviewer will give you a small thank you present. We will also send you a special certificate to show that you have taken part. It will show that you have helped us to make lives better for children in the future.



What is it?

Child of the New Century is an important survey of 19,000 children. As you know, you are one of those special children who have been chosen out of all of the children in the country of your age. We have visited the Children of the New Century when they were babies and when they were 3, 5 and 7 years old. We want to find out what your life is like now.

What's it for?

It's to find out what it's like to be growing up in England, Scotland, Wales and Northern Ireland today. By taking part in Child of the New Century you have already told us a lot about how to make children's lives better. By taking part again, you will help to make things better for all children in the future.

What will happen to the information about me?

The interviewer will send your answers and measurements back to the company doing the survey. They will not have your name and address on, so no-one who looks at them will know whose they are. They will be put together with the answers and measurements collected from the other children. You do not have to tell anyone your answers. It is up to you whether you want to tell your parents your answers.

Securing voluntary informed consent in practice for MCS

Young People

- Age 14:
 - Advance letter & 12 page leaflet with full information, addressed to both parents & YP - equal weight given to parents & CMs
 - Written consent from parents to approach YP
 - Verbal consent from YP + interviewer sign confirmation
 - Stress right to choose, stop at any time & confidentiality – from parents as well as interviewer
 - Regular reminders throughout so consent on going
 - Specially designed text through YP qaire – locking answers; hiding screen; sensitivity & honesty text reminders of confidentiality

TAKING PART AT AGE 14

WHY SHOULD I TAKE PART?

Child of the New Century is an important study of your generation. As you know, you are one of the young people who have been chosen out of all of the people in the country of your age. The study covers many different parts of young people's lives, including their health, education and what they do for fun, which helps us to see how everything fits together. Your unique contribution is incredibly valuable so we do hope that you will take part.

WHAT'S SO IMPORTANT ABOUT AGE 14?

Age 14 is a very important age - you are growing up and changing, and making some really important decisions about your future. In school you are likely to be choosing the subjects that you want to study for the next two years. You will also be experiencing new things, making new friends and thinking about what you want to do when you finish school.

Because this is such an important age, we want to record how you think, what you do, and how you feel, so we can see how you've changed since you were younger.

DO I HAVE TO TAKE PART?

It's crucial that all different kinds of young people continue to take part in the study - we need to make sure we are representing all of the different voices of your generation.

Most young people enjoy the different parts of the survey, but it's up to you whether you would like to take part. You can always choose to do some things and not others.

The interviewer will ask you about one activity at a time and you can say yes or no to each. You can stop at any time if you decide you don't want to do it anymore.



WHO DECIDES IF I CAN TAKE PART?

The interviewer will ask your parent first if it's okay for us to ask you to take part, but it's up to you to decide whether you want to or not.

Even if your parent agrees you can take part in these activities, you don't have to do them if you don't want to.

We will ask your parents' permission for you to give a saliva sample. We are required to get your parents' permission for this because of its special nature, and because you are not yet an adult. **Even if your parent says yes, it's still up to you whether you want to give the sample.**

WILL ANYONE ELSE IN MY FAMILY TAKE PART?

We would like to ask your parent(s) who live with you to answer some questions, do a word activity and give a saliva sample.

WHAT WILL I GET FOR TAKING PART?

As a thank you for your time, you will be given a small gift by the interviewer.

You're unique and the picture isn't complete without you. If you choose not to take part, we can't replace you with anyone else.



ANSWER SOME QUESTIONS ABOUT YOUR LIFE

(40 MINUTES)

We would like you to answer some questions yourself on the interviewer's tablet.

WHY?

These questions help us learn about different aspects of your life, like your family, friends, school, and what you do for fun.

HOW?

THE QUESTIONS ARE ABOUT DIFFERENT THINGS INCLUDING:

- ☆ How you spend your free time
- ☆ What you think about different issues
- ☆ How you feel about school and your future
- ☆ Your identity
- ☆ Your friends, family and relationships
- ☆ Things you might have experienced, like bullying
- ☆ Your body, health and feelings
- ☆ Your personality



It is not a test so there are no right or wrong answers. If you don't want to answer a question that's ok, you can skip it.

Some questions are about things that not all people your age will have done. We're just as interested in what people have done as well as what they haven't. It's important that you answer honestly.

Take as much time as you need. If you make a mistake or change your mind you can go back and change your answer.

The interviewer won't show or tell your answers to anyone.

LONGITUDINAL
STUDIES

WHAT WOULD WE LIKE YOUR CHILD TO DO?

ANSWER SOME QUESTIONS ABOUT THEIR LIFE

(40 MINUTES)

We would like to ask your child to answer some questions on their own on the interviewer's tablet computer.

WHY IS THIS USEFUL?

Asking young people about their experiences and interests is important as it gives them the opportunity to talk about their lives. The information helps us to understand how different aspects of young people's lives - such as home, school, and social elements - affect their general wellbeing, emotional development, and educational progress. The information can also be compared to similar data collected from previous generations of young people around the same age, to understand how lifestyles have changed over time.

WHAT WILL WE BE ASKING YOUNG PEOPLE?

THE QUESTIONS ARE ABOUT A LOT OF DIFFERENT THINGS INCLUDING:

- ☆ How they spend their free time
- ☆ What they think about different issues
- ☆ How they feel about school and their future
- ☆ Their identity
- ☆ Their friends, family and relationships
- ☆ Their body, health and feelings
- ☆ Things they might have experienced, such as bullying
- ☆ Their personality

Most young people find the questions interesting and enjoyable to answer. They have been designed to reflect their lives and interests.

There are no right or wrong answers and if there are questions they don't want to answer they can skip them. It is important that young people answer the questions privately so we get their own answers.

Most questions will be relevant to all young people of their age. Some of the questions are about things that not all young people of this age will have done.

It is still important that all young people answer them so we know how many young people of this age have done these things.

If you would like to know more about what we will be asking your child, please ask the interviewer when they visit

**YOUNG PERSON
(TO BE COMPLETED BY INTERVIEWER)**

Name of young person (print)

INTERVIEWER: You must make sure that the young person understands and agrees to the following points before you start the first young person element (refer to the advance booklet: "What would we like you to do?")

- a) **READ OUT:** Child of the New Century is an important study of your generation. As you know, you are one of the young people who have been chosen out of all of the people in the country of your age. It provides information on young people's health, education and what they do for fun.
- b) **READ OUT:** I will ask you to fill in some questions and do some different activities. I will also ask your parent(s) if they live with you to answer some questions and give us a saliva sample.
- c) **READ OUT:** It's up to you whether you want to take part in the survey. It's ok to do some things and not others. You can stop at any time.
- d) **READ OUT:** Do you have any questions about the study?

INTERVIEWER CHECK: You must make sure that the young person has read and understood the information in the booklets "What would we like you to do?" and if applicable, "Wearing an activity monitor and completing a time-use record". The headings below show which section of the booklets should be read and understood by the young person before asking consent.

For each, ensure that the young person has asked any questions they want to.

Questionnaire ("Answer some questions about your life" in "What would we like you to do?")

READ OUT: I'd like you to answer some questions on my tablet. You can stop at any time. It is not a test so there are no right and wrong answers. If you don't want to answer a question that's ok, you can skip it. It usually takes about 40 minutes.

READ OUT: Are you OK to answer some questions about your life?

| | | |
|--------------------------|--------------------------|-------------------------------|
| Yes | No | N/A - No parent consent given |
| <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |

Young person's contact details ("More information about the survey" in "What would we like you to do?")

READ OUT: Would you be willing to give us your mobile phone number so that we can keep in touch with you about the study? It will only be used for Child of the New Century.

IF YES RECORD IN CAPI.

| | | |
|--------------------------|--------------------------|-------------------------------|
| Yes | No | N/A - No parent consent given |
| <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |

READ OUT: Would you be willing to give us your email address so that we can keep in touch with you about the study? It will only be used for Child of the New Century.

IF YES RECORD IN CAPI.

| | | |
|--------------------------|--------------------------|-------------------------------|
| Yes | No | N/A - No parent consent given |
| <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |

Activities ("Do some activities to understand how you think" in "What would we like you to do?")

READ OUT: I'd like to ask you to do two activities on my tablet. The word activity looks at how you understand the meaning of words. The decision-making activity looks at how you make decisions. I will show you what to do. You can stop at any time. These usually take about 20 minutes in total. Are you OK to complete the...

Word activity?

| | | |
|--------------------------|--------------------------|-------------------------------|
| Yes | No | N/A - No parent consent given |
| <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |

Decision-making activity?

| | | |
|--------------------------|--------------------------|--------------------------|
| <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
|--------------------------|--------------------------|--------------------------|

Measurements ("Be measured to understand how you grow" in "What would we like you to do?")

READ OUT: I would like to measure how tall you are, how much you weigh and your body fat percentage. It is ok if you only want some of the measurements taken or if you don't want any taken. You can change your mind once you've started. I won't show or tell anyone (including your parent(s)) your measurements. This will take about 10 minutes in total. Are you OK for me to measure your...

Height?

| | | |
|--------------------------|--------------------------|-------------------------------|
| Yes | No | N/A - No parent consent given |
| <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |

Weight?

| | | |
|--------------------------|--------------------------|--------------------------|
| <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
|--------------------------|--------------------------|--------------------------|

Body fat percentage?

| | | |
|--------------------------|--------------------------|--------------------------|
| <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
|--------------------------|--------------------------|--------------------------|

Interviewer use only:

YP BARCODE

13-025042-02/CF01



Approach to consent for children and young people in MCS: key similarities & differences

| Age 11 | Age 14 |
|---|--|
| Advance letter & information booklet sent to parents | Advance letter & information booklet addressed to cohort members |
| 4 page CM booklet | 12 page CM booklet |
| Age appropriate basic information | Age appropriate fuller information |
| Verbal consent with written confirmation by interviewer | Verbal consent with written confirmation by interviewer |

Thank you.

k.smith@ioe.ac.uk

CENTRE FOR
LONGITUDINAL
STUDIES



Growing Up in Ireland – *the national longitudinal study of children*

Informed Consent

Participant engagement in longitudinal studies

Closer Knowledge Exchange Workshop

James Williams

Economic and Social Research Institute (ESRI), Dublin

29th January 2016

❖ Longitudinal two-cohort design

“CHILD Cohort” - recruited at 9 years of age

“INFANT Cohort” - recruited at 9 months of age

❖ Main participants/respondents:

Principals/
Teachers

Other Sig.
Caregivers

Parents/
Guardians

Children/
Young People

❖ Signed informed Consenting (or Assenting) process at each round of interviewing

Child Cohort

Phase 1:

(2007/08) **9 years** – 8,500 children

(2011/12) **13 years of age**

Phase 2:

(2015/16) **17 years of age**

(2018) **20 years of age**

Infant Cohort

Phase 1:

(2008/09) **9 mths**–11,100 children

(2010/11) **3 years of age**

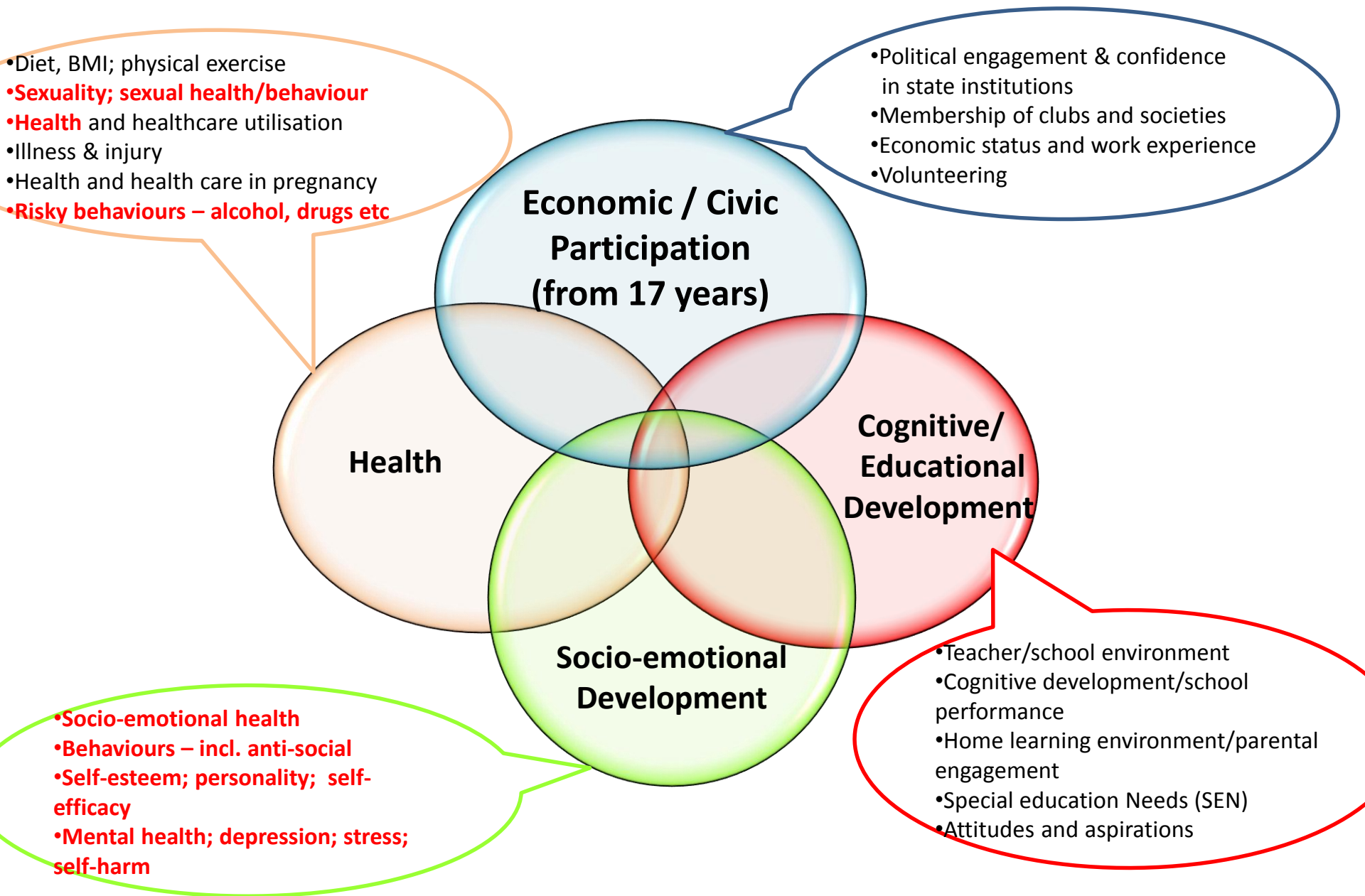
(2013) **5 year of ages**

Phase 2:

(2015/16) **7 years of age (postal)**

(2017/2018) **9 years of age**

Domains, themes and topics



- ❖ Confidentiality guaranteed in law - study is being conducted under the **Statistics Act 1993**
 - data may be used only for statistical purposes
 - identify of respondents may not be disclosed
- ❖ Balance between:
 - rights of the child and child's voice (*article 12, UNCRC*)
 - child protection
 - legalities of recording data – incl. Data Protection legislation
 - recording good quality statistical data
- ❖ All Child Welfare and Protection concerns processed through the Study's Child Welfare and Protection Protocol.

Consent in younger Infant Cohort - at 9 months, 3 years, 5 years

- ❖ Signed, informed parental consent
 - information sheet
 - general consent
 - data linkage
 - to approach the teacher (at 5 years)

- ❖ No Assent by children at these early ages

Consent in the older Child Cohort – 9 & 13 years

- ❖ **Signed Parental consent**
 - information sheet
 - general consent
 - data linkage
 - to approach the teacher

- ❖ **Signed Child Assent**

- ❖ *at 13 years:* **Separate Parental Consent for Child's 'Sensitive Questionnaire'**
 - alcohol, smoking and some anti-social behaviours

- ❖ Blank copy of Child's 'Sensitive Questionnaire' shown to parent before signing consent form

Consent in older Child Cohort at 17 years of age

- ❖ Details on very sensitive info. recorded from 17-year-old
 - alcohol and drug consumption
 - sexual orientation, health and behaviours
 - mental health
 - anti-social behaviours – some of which are illegal

- ❖ **Signed Parental Consent**

- ❖ **Signed 17-year-old Assent**

PARENT/GUARDIAN at 17 years

Summary of some key points



PARENT/GUARDIAN CONSENT FORM – (Young Person less than 18 years)

INTERVIEWER: COMPLETE THIS CONSENT FORM BEFORE THE YOUNG PERSON'S CONSENT FORM

Name of Young Person: _____ Young Person's Date of Birth: _____
(BLOCK CAPITALS PLEASE) (DD/MM/YYYY)

- I have read and understand the information sheet provided. I understand that I can ask any questions I may have about the *Growing Up in Ireland* study.
- I consent to participating in the *Growing Up in Ireland* study on the terms set out below.
- I consent to my 17-year-old participating in the *Growing Up in Ireland* study.
- I understand that my child's other parent, my spouse or partner (where different) will also be asked to take part in the study
- I understand that the protocol for interviewing my 17-year-old allows the interviewer to be alone in a room with my 17-year-old to administer the questionnaire, provided the door of the room is open and someone aged 18 years or more is also in the accommodation throughout the interview.
- I understand that the questionnaire completed by my 17-year-old contains information on sensitive topics including the following: smoking; drinking alcohol; drug-taking; sexuality, sexual behaviour and sexual activity; self-esteem; mental health; self-harm and anti-social behaviour (some of which may be illegal).
- I understand that none of the information recorded in the survey may be given to any person, government body or agency in a way which could be identified with my child or my family and that no information collected in the study could be used for any purpose other than statistical analysis. This includes the answers to questions on anti-social behaviour (some of which may be illegal).
- I have been asked by the interviewer if I want to see a blank copy of the questionnaire containing these sensitive questions, before my 17-year-old completes it.
- I understand that the names, address and other identifying information relating to my family will be removed from the details provided by me and my family in the course of our interviews. The survey information (without identifying details) will then be stored on a computer so that it will be available to researchers. The information can be used only for research purposes. It would be an offence to use it for any other reason.
- I understand that, although I will have access to the information given by me on the questionnaire which I complete, I will not have access to the information given on the questionnaires completed by my 17-year-old; by my spouse/partner (if relevant); or by my 17-year-old's other parent (where different).
- I understand that, as with all other parts of the *Growing Up in Ireland* study, neither I nor anyone else will receive any feedback or be told about the answers given by my 17-year-old to the questions which the interviewer asks him/her or which he/she gives in the self-completion questionnaire, regardless of what those answers might be.
- I understand, however, that if the interviewer observes something or is told something other than in answer to direct survey questions, which causes him/her or the people running the study to have serious concerns for the welfare of my 17-year-old, or any other vulnerable person, they may have to tell the appropriate authorities.
- I understand that I may choose not to answer any individual or sets of questions which I am not comfortable with, and still do the rest of the interview.
- I understand that some information on the characteristics of the school which my son/daughter attends (or most recently attended) may be added to the information which I provide in the survey interview.
- I understand that because this study looks at the development of Young People over time, I and my 17-year-old will be asked to participate in a follow-up study in a few years time.

Name of Parent/Guardian: (BLOCK CAPITALS PLEASE) _____

Address of Parent/Guardian: _____

Signature of Parent/Guardian: _____ Date: _____ Phone: _____

If relevant: Name of Parent/Guardian not resident in your household: _____
(BLOCK CAPITALS PLEASE)

Address of Parent/Guardian not resident in your household: _____

Signature of Parent/Guardian not resident in household: _____ Date: _____ Phone: _____

AREA HHOLD YP No. Int No Int Name: _____

- ..I consent to my 17-yr-old participating
- .. int. may be alone with 17-yr-old in communal room, with door open
- ..sensitive topics: drink; drugs; sexuality & behaviour; self-esteem; mental health; self-harm; anti-social behaviours (some illegal)
- ..no info. from study given to govt. body etc. and used only for statistical purposes
- ..asked by the int. if I want to see a blank copy of the YP Sensitive Questionnaire
- ..no access to info recorded from other family members
- ..no feedback
- ..if int. observes or is told something to cause concern for 17-yr-old's welfare they may have to tell someone who can help

YOUNG PERSON'S CONSENT FORM – (Young Person less than 18 years)

Name: _____

(BLOCK CAPITALS PLEASE)

Date of Birth: _____

- I have read and understand the information sheet provided. I understand that I can ask any questions I may have at any time before or during the *Growing Up in Ireland* study.
- I consent to participating in the *Growing Up in Ireland* study on the terms set out below.
- I understand that my parent(s) / guardian(s) will also be asked to take part in the study and to be interviewed, about themselves and me.
- I understand that my parent/guardian has already signed a consent form regarding my participation in the *Growing Up in Ireland* study, as this is a legal requirement for anyone under 18 years of age.
- I understand that the protocol for interviewing 17-year-olds allows the interviewer to be alone in a room with me to administer the questionnaire, provided the door of the room is open and someone aged 18 years or more is also in the accommodation throughout the interview.
- I understand that the questionnaire completed by me contains information on sensitive topics including the following: smoking; drinking alcohol; drug-taking; sexuality, sexual behaviour and sexual activity; self-esteem; mental health; self-harm and anti-social behaviour (some of which may be illegal).
- I understand that none of the information recorded in the survey may be given to any person, government body or agency in a way which could be identified with me or my family and that no information collected in the study could be used for any purpose other than statistical analysis. This includes the answers to questions on anti-social behaviour (some of which may be illegal).
- I understand that the names, address and other identifying information on my family will be removed from the details provided by me and my family in the course of our interviews. The survey information (without identifying details) will then be stored on a computer so that it will be available to researchers. The information can be used only for statistical analysis and research purposes. It would be an offence to use it for any other reason.
- I understand that, although I will have access to the information given by me on the questionnaires which I complete, I will not have access to the information given on the questionnaires completed by my parent(s) / guardian(s).
- I understand that, as with all other parts of the *Growing Up in Ireland* study, neither I nor anyone else will receive any feedback or be told about the answers given by me or anyone else in the questionnaires, regardless of what those answers might be.
- I understand, however, that if the interviewer observes something or is told something, outside the answers given to the direct survey questions, which causes him/her or the people running the study to have serious concerns for my welfare, or the welfare of any other person, they may have to tell someone who can help.
- I understand that I may choose not to answer any individual or sets of questions which I am not comfortable with, and still do the rest of the interview.
- I understand that some information on the characteristics of the school which I attend (or most recently attended) may be added to the information which I provide in the survey interview.
- I understand that, because this study looks at the development of young people over time, I will be asked to participate in a follow-up study in a few years time.

Signature: _____ (Young Person) Date: _____

Summary

- ❖ Signed parental consent in each round of the study
- ❖ Signed Child / Young Person Assent from 9 years
- ❖ Statistics Act, 1993 provides legal basis for guarantees of confidentiality
- ❖ No feedback to respondents or anyone else on any information recorded
- ❖ Investigation and reporting of potential Child Welfare and Protection issues observed by interviewer



**Thank you.
Questions?**

<http://www.growingup.ie>



NTNU

Innovation and Creativity

Participant engagement in the HUNT study – involving the public in consent-issues

Maria Stuiifbergen, PhD
Adviser HUNT Research Centre

The Nord-Trøndelag Health Study (HUNT)



- Norway: ca. 5 million inhabitants
- Nord-Trøndelag: 135.000
- The HUNT Study:
 - 1984-1986: 74.500 (88%)
 - 1995-1997: 70.000 (70%)
 - 2006-2008: 50.800 (54%)*
 - **2017!**
- 120.000 participants
- 80.000 with samples

* Krokstad et al, Int. J. Epidemiol. (2013) 42 (4): 968-977:
<http://ije.oxfordjournals.org/content/42/4/968.long>

Consent in The HUNT Study

- HUNT1 (1984): no consent – meeting up for the study was considered consent
- HUNT2 (1995): broad consent.
 - Data treatment, results to physician, possibility for additional studies, connect with other registries, research on samples. If necessary: new consent
 - 2002: Revision because of possibilities of genetic research
- HUNT3 (2006): broad consent
 - As 1995, but DNA and genetics mentioned
 - 2012: new “negative” consent because of genetic data sharing abroad
- No consent to be recontacted – actively avoided in the management of HUNT study

Background for involving public

A wish to get a better understanding for what our participants think of number of topics, because of:

- Ethical and practical discussions around consent model
 - Ethical debate around dynamic consent
 - Possibility for feedback of individual results
 - Have participants co-decide on how to conduct research?
- Research purposes
 - Researchers' wish to recontact participants –
 - Targeted
 - Cheaper methods with IT technology
- Communication purposes
 - What kind of communication do participants wish?
 - Meetings as part of communication strategy itself

Background for involving public

- Ethical and practical discussions around consent model
 - Ethical debate around dynamic consent
 - Empowering participants: continuous choice, easy to look up what one consented to, alter choices, consent to new studies.
 - Better information to participants: individual communication channel about (general) results from HUNT
 - Potential for feedback of results of analyses – desirability heavily debated, weighing advantages and disadvantages, and possibilities to law opens for.

Open Discussion Meeting - Why?

- Timely
- Curiosity
- Call for change

HUNT4 og DEG:
Engangsmøte eller livslangt forhold?

ÅPENT MØTE

Vi trenger dine tanker og mening om hvordan du vil involveres i verdens største helseundersøkelse!

Dato: Mandag 21. september
Tid: kl. 17:00-19:00
Sted: HUNT-Forskningscenter (Levanger)
Mat: Pizza med mer



Utlodning av gavekort fra G-Sport Levanger

I 2017 vil Helseundersøkelsen i Nord-Trøndelag samle inn data og blodprøver (HUNT4). Flere mener at du som deltaker bør være bedre informert om og mer involvert i det som skjer med dine blodprøver og helseopplysninger. Men her strides de lærde...

Nå er tiden kommet for at DU kan spille inn hva du tenker om spørsmål som dette i forkant av HUNT4:

- Ditt forhold til HUNT → aktivt eller passivt?
- Samtykke → kun ved oppmøte eller hele tiden?
- Forskningsinformasjon på e-post → mas eller must?
- Innsyn i egen forskningsdeltakelse → viktig eller unødvendig?
- Tilbakemelding av forskningsresultater → bra eller belastende?

Du kan være med, uansett om du har vært med på HUNT tidligere eller ei.

- Les mer på <http://ntnu.blog.medisin.ntnu.no/samtykke-oppdvalgning-og-datainnsyn/>
- Har du spørsmål ring 74075180, spør etter Maria Stulbergren

PÅMELDING:
Sjarest og senest søndag 20. september.
Send en e-post til hunt@medisin.ntnu.no skriv "HUNT4ogDEG" i emnefeltet.

Hjertelig velkommen!

NTNU
HUNT forskningscenter

Forskningsdagene

creativity

How to get people to attend your workshop?

“HUNT and YOU A one-time meeting or a life long relationship?”

Pizza, Research Week, professors announced:

- Website
- Facebook
- E-mails to network
- Radio talk

.....7 participants

District newspaper.....



“Few wish to visit Steinar” ...

- 42 participants!



Who attended the meeting?

- Age/Gender
- Background
- Selected
- No dissidents



Open Meeting at HUNT

Content & Format

- Topics:
 - Return of individual research results
 - Information /Involvement
 - Consent



Open Meeting at HUNT

Content & Format

- Format
 - Brief introduction to each topic
 - Questions for discussion in small groups
 - Poll questions
 - Plenary discussions
- Timeframe 1,5 hrs



Impressions

- Engaged!
- Spectrum of ideas
- Reciprocity



Impressions



- Note:
 - No novel ideas
 - Not there to educate
 - We did not draw up the depth & width of the discussions

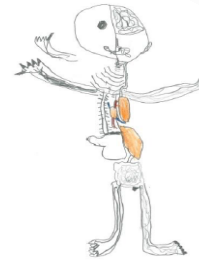
Return of individual results:

- Genetic testing
 - YES!!
 - BUT...



Information/Involvement

- How it is done today is good enough
- Engage me a little more
- Do not bother me
- No civic duty



Tegning: Håvard Brønson

Foreldre påvirker ungdommers alkoholbruk i stor grad

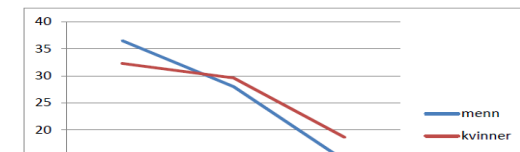
Barn som vokser opp med foreldre som misbruker alkohol er mer sårbare for selv å utvikle skadelige alkoholvaner. Men også «mer alminnelig fyll og festing» blant voksne utgjør en risiko. Det å vise seg beruset for barna øker sjansen for at barna selv utvikler et mer risikofyllt drikkemønster opp gjennom tenårene, viser Siri Håvas Haugland i doktoravhandlingen sin.

I materiale fra voksen-HUNT og Ung-HUNT fant hun at alkoholbruken til gutter var mest relatert til farens alkoholvaner, mens blant jenter var alkoholbruken relatert til både

Helseundersøkelse Trøndelag fylte

Siden 1984 har HUNT gått fra en (tenkt) engangsundersøkelse med fokus på blodtrykk, diabetes og livskvalitet til en helhetlig oppfølgingsstudie med mange tema som er tatt i bruk av forskergrupper over hele Norge og internasjonalt. Siden HUNT2 er det også samlet inn blodprøver og annet biologisk materiale – noe som viser seg å være svært verdifullt i dag. I dette nyhetsbrevet finner du et lite utvalg av forskning med HUNT. Jubileet ble feiret med faglige seminarer og publikumsrettede aktiviteter i oktober måned.

Røyking i Nord-Trøndelag



Information/Involvement

- Access on my terms!
- «MyPage»
 - Very good idea!



Consent

- And we asked...



How do you think is the best way to consent?

- a) Once and for all is good enough!
- b) I want to consent to all projects that use my data!
- c) It is best if one can choose the way one wants to consent!
- d) I do not really see the point of (written) consent. If I participate I use my free will!

How do you think is the best way to consent?

- a) **Once and for all is good enough!**
- b) I want to consent to all projects that use my data!
- c) It is best if one can choose consent form oneself!
- d) I do not really see the point of written consent. I am using my free will when I participate!

Outcomes

Recommendations

Road ahead

- Return of individual research results
- MyPage
- Consent

Questions



- Are such outreach activities worth while?
- How to handle the gap between scholarly discussions and the public understanding?
- Are we making things unnecessary complicated?
- Are we creating needs?
- Whose needs do we need to meet?

HUNT and YOU

A one-time meeting or a
life long relationship?

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THANKS TO MY COLLEAGUES:

Kristin Solum Steinsbekk

Berge Solberg

John-Arne Skolbekken

Lars Ursin

Optional discussion questions

1. How has your study used engagement materials to help with the process of gaining informed consent?
2. What are the particular challenges your study faces when it comes to issues of consent?

Knowledge
Exchange
Workshop



14:15 Break

Please head to your next session

Please fill in your Evaluation form



Knowledge
Exchange
Workshop



Incentives

Please switch your mobile phones to silent





Understanding Society

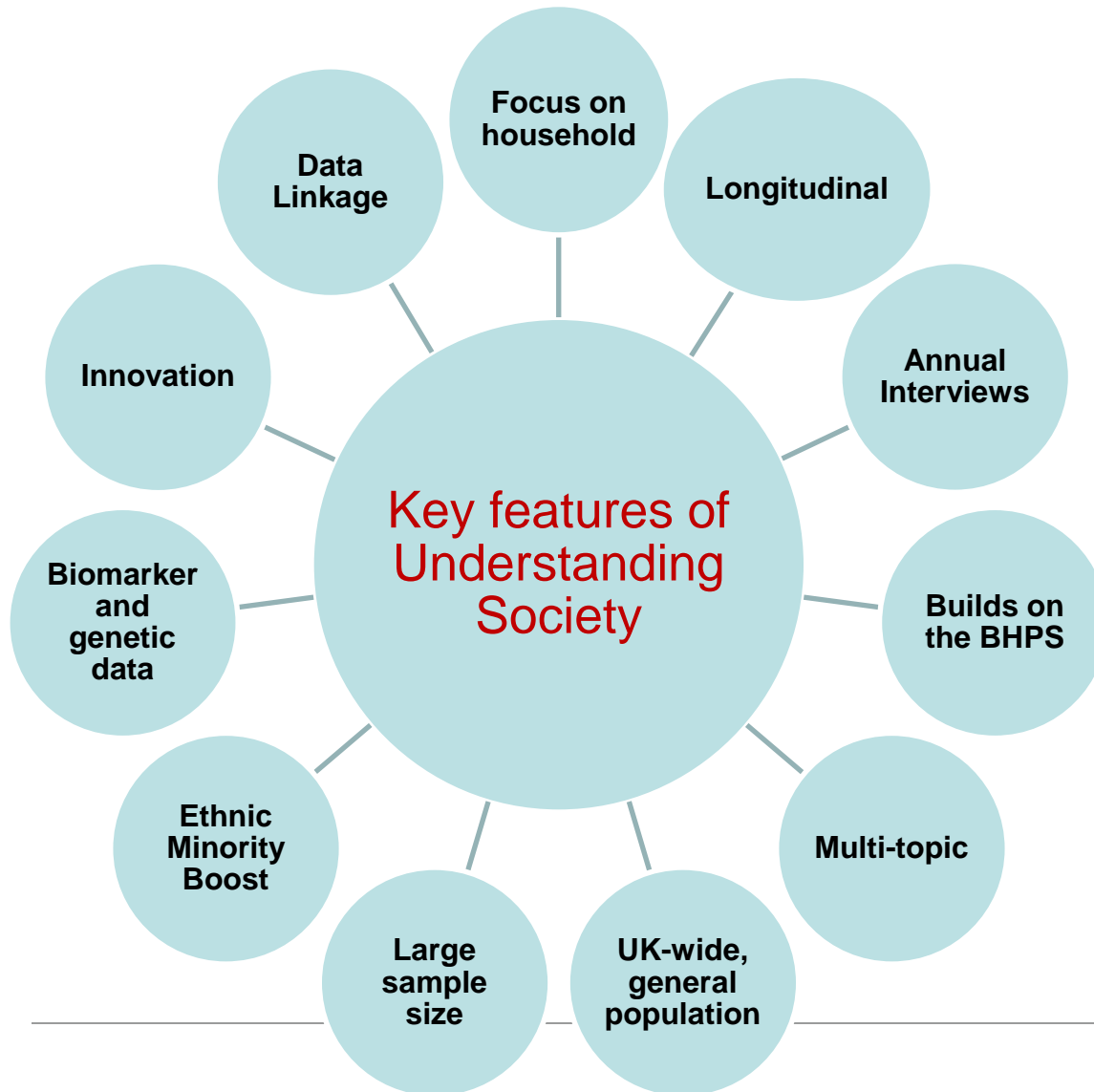
THE UK HOUSEHOLD LONGITUDINAL STUDY

Understanding Society

**Traditional and novel
ways to keep participants
loyal**

An initiative by the Economic and Social Research Council, with scientific leadership by the Institute for Social and Economic Research, University of Essex, and survey delivery by the National Centre for Social Research.

Overview of the study

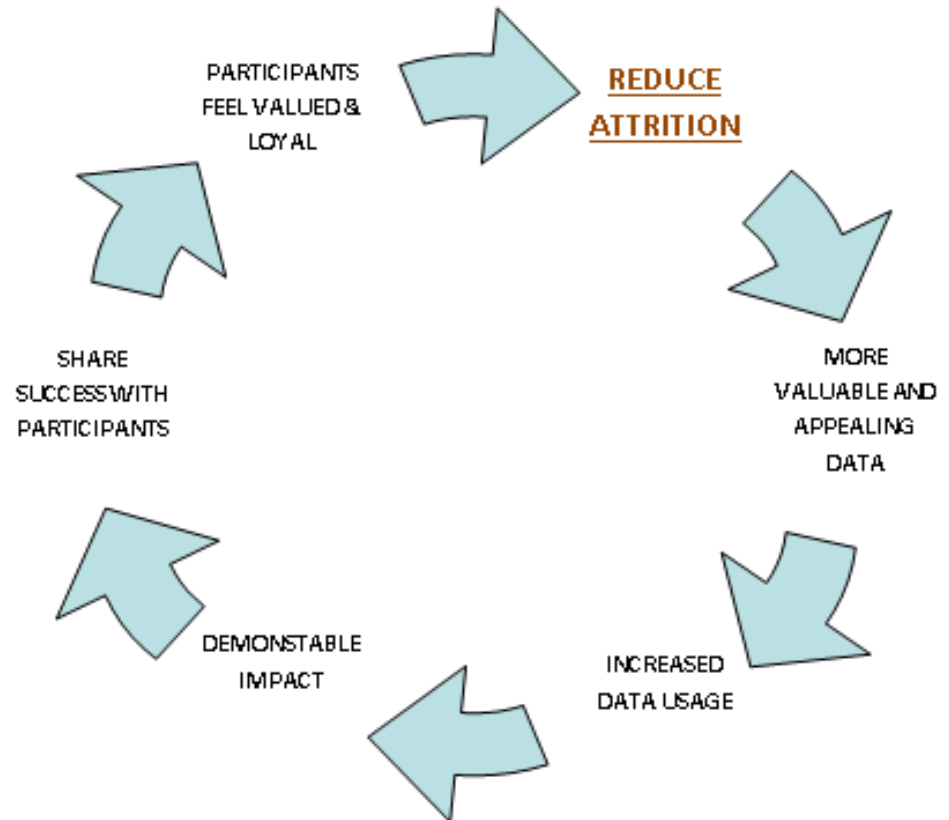


We interview
the same
people each
year to build a
picture of
change over
time in the UK

Overview of participants

- W1 = **61,920**
- W5 = **41,041**
- Aged from **10 to 102**
- **UK-wide** locations and **variety of backgrounds**
- Motivations vary: incentives, altruism, belonging/loyalty
- Changing & busy lives: health, travel, university, family ...
- Communications challenges =
LARGE SAMPLE SIZE
DIVERSITY & IN FLUX
PRIVACY

Engagement objectives



How much is enough?

- First, flat incentive
 - £10/adult
 - £5/child (10-15)
- In later waves, differential incentives:
 - £10/adult in last-wave responding households
 - £20/ adult in last-wave non-responding households (last chance to convert)
 - In the following wave, if the household is converted, the incentive reverts back to £10

Conditional or unconditional?

- First, all incentives unconditional, sent with advance mailing
 - In later waves, conditional incentives
 - for those individuals who haven't received advance mailing (new entrants, movers)
 - last-wave non-contact households (£20)
 - last-wave non-responding individuals in responding households (£10) (from Wave 8)
 - Interviewers prefer conditional incentives
 - Unconditional:
 - Issued adults in last-wave responding households
 - Last-wave refusal households (£20)
 - Youth (10-15)
-

If not cash then what?

- Paper Love2Shop vouchers (unconditional)
 - easy to administer
 - expensive
 - can't be used in local corner shops
 - Love2Shop gift cards (conditional)
 - need to be activated (takes a few days),
 - accuracy of entering 16-digit card number by interviewers
 - respondent can't check the amount on it but can spend it
 - can't be used in local corner shops
 - In the past, Post Office vouchers
 - cash equivalent but need to go to the Post Office
 - requires collaboration with Post Office
-

Additional incentives

- Ad hoc incentives for additional tasks
 - e.g. completing a time diary or a qualitative interview as part of an associated study
 - £5 for returning CoA card
 - Prizes for winners of IWM competitions
 - iPad draws for Rising-16s
 - Loyalty bonus for BHPS respondents? (future)
-

The participant engagement team

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Twitter: @usociety

Facebook: /Understanding-Society-UK-Household-Longitudinal-Study

The Cork BASELINE Birth Cohort Study – An overview of retention methods

Emma Cobbe

Mairead Kiely^{2,3}, Louise Kenny², Alan Irvine⁴, Jonathan Hourihane^{1,2}
and Deirdre Murray^{1,2}

¹Department of Paediatrics and Child Health, University College Cork

²The Irish Centre for Fetal and Neonatal Translational Research (INFANT), University College Cork

³Cork Centre for Vitamin D and Nutrition Research, School of Food and Nutritional Sciences, University College Cork

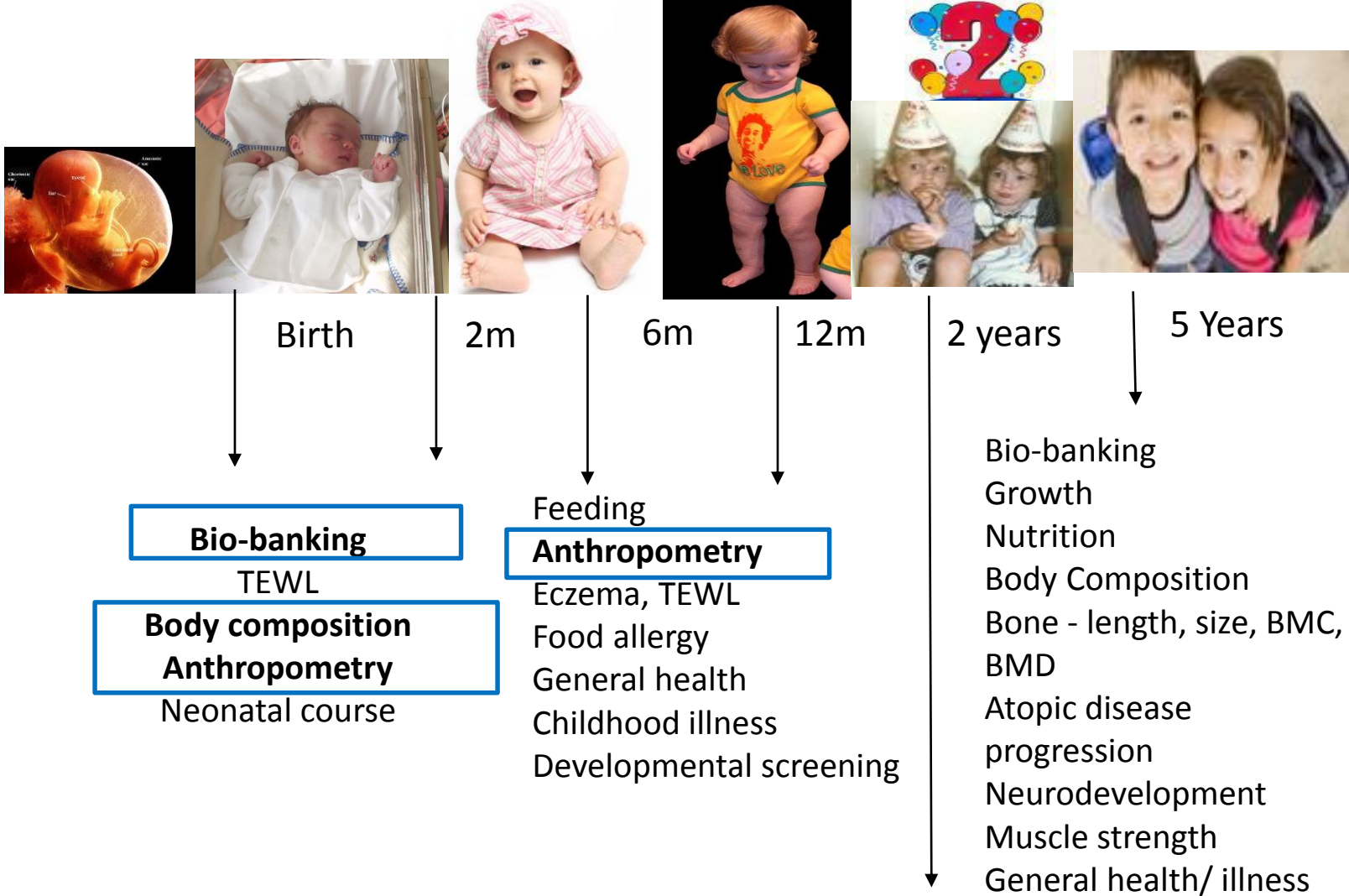
⁴Department of Paediatric Dermatology, Our Lady's Children's Hospital, Dublin, Ireland.

The Cork Babies After Scope: Evaluating the Longitudinal Impact Using Neurological and Nutritional Endpoints (BASELINE) Birth Cohort study is the first birth cohort study in Ireland.

2137 born between Aug 2008 and Oct 2011.



2137



The CORK
BASELINE
Birth Cohort

Bio-banking
Anthropometry
Skin prick testing (allergy)
Neurodevelopment assessment
Nutritional assessment

Progress to date

Born into the study 2137 at completion of recruitment

- 2 months - 1954 complete - 9% dropout
- 6 months - 1817 complete - 7% dropout
- 12 months - 1706 complete -6% dropout
- 24 months - 1604 complete -6% dropout

5 year assessments: 720 complete (to date) -20% dropout

Incentives

- No monetary incentives(including car parking)
- Allergy testing and follow up
- Neurodevelopment with follow up
- Healthcare advice (eczema, weight gain, feeding)

Retention

- Flexible with appointments
- Low turnover of staff
- Good rapport with staff
- Parents Information evening
- Information booklet on findings
- Higher education levels of parents
- Website – sharing publications

Lessons learned for the future





**Special thank you to all participating families, the
SCOPE and BASELINE research teams
and to our funding agencies**



Incentives in the Panel Study of Income Dynamics

Narayan Sastry

University of Michigan

PSID Overview

- Panel study begun in 1968 in U.S.
- World's longest-running national household panel survey, includes 10,000 families
- Interviews by telephone every other year
- Several major supplements:
 - Child Development Supplement
 - Transition into Adulthood Supplement
 - Disability and Use of Time
 - Web supplements (child retrospective, wellbeing)

Overview of Incentives in PSID

- Long-standing PSID plan to provide incentives to Rs
 - Payment is approximately \$1 per interview minute
 - Uniform incentives over fieldwork period and across sample members; modest increases across waves
- Several additional incentives offered
 - A small payment for returning an address update postcard
 - Reimbursed \$10 for use of cell phone minutes
 - Provided child care/meal reimbursement for CDS
- Payments by check, mailed to Rs
 - Obtain accurate addresses
 - Cash for small number of face-to-face interviews
- All incentives reviewed/approved by IRB (ethics board)

Changes in PSID Incentives

Recently have begun using incentives more strategically

- Lower response among certain subgroups
 - Targeted incentives (new Rs, “recontacts”)
- Periods of low productivity
 - Time delimited incentives (holiday incentive)
- Lagging or more burdensome study components
 - Separate incentives for specific components (e.g., time diaries, saliva samples for genetic analysis)
- High-cost activities where R cooperation is essential
 - Additional incentive for keeping appointment for in-person visits in remote areas
- Challenges in achieving response rate goals
 - This year offered end-of-study incentive for first time that doubled incentives in final month (\$75 to \$150)

Key Considerations with Incentives

- Concern with long-run effects of incentives
 - Negative effects of incentives that are withdrawn (e.g., “early bird” incentives)
- Equity—related families are interviewed, some may receive larger incentives than others
 - Have always matched incentives when asked
- Generally avoided incentives that reward “bad” behavior
 - Missed appointment bonus (HRS: \$50 extra for keeping 4th appointment)
 - “End-game” incentives
- Interviewer discretion in offering “optional” incentives
 - Implicitly allowing differential incentives
- Have begun using small prepaid incentives
 - \$5 gift with holiday card; effectiveness not studied yet
- Targeted incentives have appeal, especially for one-time events
- Essentially no *interviewer* incentives
- Worry about Rs reaching payment threshold triggering tax forms

PSID Transition into Adulthood Supplement Incentives, 2015

Baseline, for all Rs

- \$60 baseline
- \$10 reimbursement of cell phone use

Targeted incentives

- \$30 one-time “welcome” special
- \$30 one-time “welcome back” special

Other incentives

- \$5 cash in New Year’s greeting card

End-game incentives

- TBD—based on how close we are to achieving RR goals

CDS 2014 Respondent Incentive Reference Card

Interview Incentives

| | |
|------------------|------|
| PCG: | \$60 |
| Child age 12-17: | \$20 |
| Child age 8-11: | \$10 |

Saliva Incentives

| | |
|-----------------|------|
| PCG: | \$10 |
| Child age 5-17: | \$10 |

Time Diary Incentive

| | |
|--------|---|
| PCG: | \$10 per each child for whom we receive a completed weekday/weekend time diary pair |
| Child: | \$0 |

Cell Phone Reimbursement: You are authorized to offer a cell phone reimbursement if the respondent indicates that the expense of cell phone minutes would prevent him/her from completing the interview.

| | |
|------------------|------|
| PCG: | \$10 |
| Child age 12-17: | \$10 |

Childcare/M meal Reimbursements: You are authorized to offer a childcare reimbursement **OR** a meal reimbursement to PCGs based upon the following guidelines:

Childcare Reimbursement: If a PCG indicates that the need for childcare during the interview makes it difficult to participate or if you have difficulty scheduling an appointment and suspect that childcare may be an issue, you may do the following:

- Ask the PCG whether they might be able to obtain childcare for the duration of the interview if we could help cover the cost.
- If so, inquire about the approximate cost.
- Indicate that you're able to provide payment of the cost in full (if under \$40) or to defray the cost by an additional payment of \$40.
- Do not arrange for the childcare yourself. Do not pay the sitter directly.

Meal Reimbursement: If a PCG indicates that the need to prepare meals makes it difficult to participate or if you have difficulty scheduling an appointment and suspect that offering a meal payment will encourage the R to allow you to schedule through a mealtime, you may do the following:

- Ask the PCG whether it would be easier for him/her/the children to participate if we could provide them with an extra payment to cover the cost of a carry-out (or delivered) meal.
- If so, suggest an amount up to \$40 that that you feel is reasonable given the size of the family.
- Indicate that you're able to provide a meal payment up to that amount to either cover or defray the cost of the meal and make it easier for the family to participate.
- Do not order the meal yourself. Do not pay for the meal directly.

Note: Meal payments must be made to the PCG even if the meal purchased by the family is to enable a child or teen's participation.

Conclusions

- Incentives an essential component of PSID
 - Especially for large oversample of poor families
 - Devote considerable PSID resources to incentives
- Incentives should evolve and adapt over time
- Evaluations of incentive experiments valuable

PSID

A national study of socioeconomics and health
over lifetimes and across generations

-- END --

Optional discussion questions

1. What approach does your study take to incentives and why?
2. What are the pros and cons of non-monetary incentives?
3. Can/should we vary the incentives offered to different groups?

Knowledge Exchange Workshop



15.35-16.45 Engaging different audience types [Main Hall]
(round table discussions with refreshments)

Please note that you will hear 'please change' at 15-minute intervals. You may then switch tables, or stay at the same table for the entire 70 minutes if you wish.

Please fill in your Evaluation form

