

Knowledge
Exchange
Workshop



Participant engagement in longitudinal studies

Wi-Fi: Woburn House Conference Centre
Password: igitor

Please switch your mobile phones to silent



About CLOSER

- Consortium of 8 longitudinal studies, the British Library and the UK Data Service
- Funded by the ESRC and the Medical Research Council
- Areas of work: data harmonisation, data linkage, data search platform, research impact and training

Overarching objective

To maximise the use, value and impact
of the UK's longitudinal studies

The studies

- Hertfordshire Cohort Study
- MRC National Survey of Health and Development
- 1958 National Child Development Study
- 1970 British Cohort Study
- Avon Longitudinal Study of Parents and Children
- Southampton Women's Survey
- Millennium Cohort Study
- Understanding Society

CLOSER Longitudinal Communications Network

- Ryan Bradshaw, CLS
- Louise Cullen, ISER
- Janine Ford, USoc
- Tina Horsfall, SWS
- Dara O'Hare, ALSPAC
- Raj Patel, USoc
- Steph Pilling, MRC NSHD
- Meghan Rainsberry, CLS
- Emma Saville, CLS
- Shirley Simmons, HCS

Objectives for today

- Learn from each other
- Get new ideas
- Think about if and how we might share learning in the future
- Discuss, discuss, discuss

Programme (morning)

- 10:30 Housekeeping and opening remarks
- 10:45 Participant engagement: a review of current practice and what we know about effectiveness
Alison Park, CLOSER and Lisa Calderwood, CLS
- 11:30 Case study: Participant engagement in the Avon Longitudinal Study of Parents and Children
Makaela Jacobs-Pearson, Verity Katuszka and Dara O'Hare, University of Bristol
- 12:15 Exhibitions, networking and lunch

Programme (afternoon)

- 13:00 Concurrent discussion sessions 1
- 14:15 Break to get to your next session
- 14:20 Concurrent discussion sessions 2
- 15:35 Engaging different audiences (round table discussions)
- 16:45 Closing remarks and future work
- 17:00 End

Longitudinal studies and participant engagement: current practice and what we know about effectiveness

Alison Park, CLOSER, UCL Institute of Education

Lisa Calderwood, CLS, UCL Institute of Education

Content

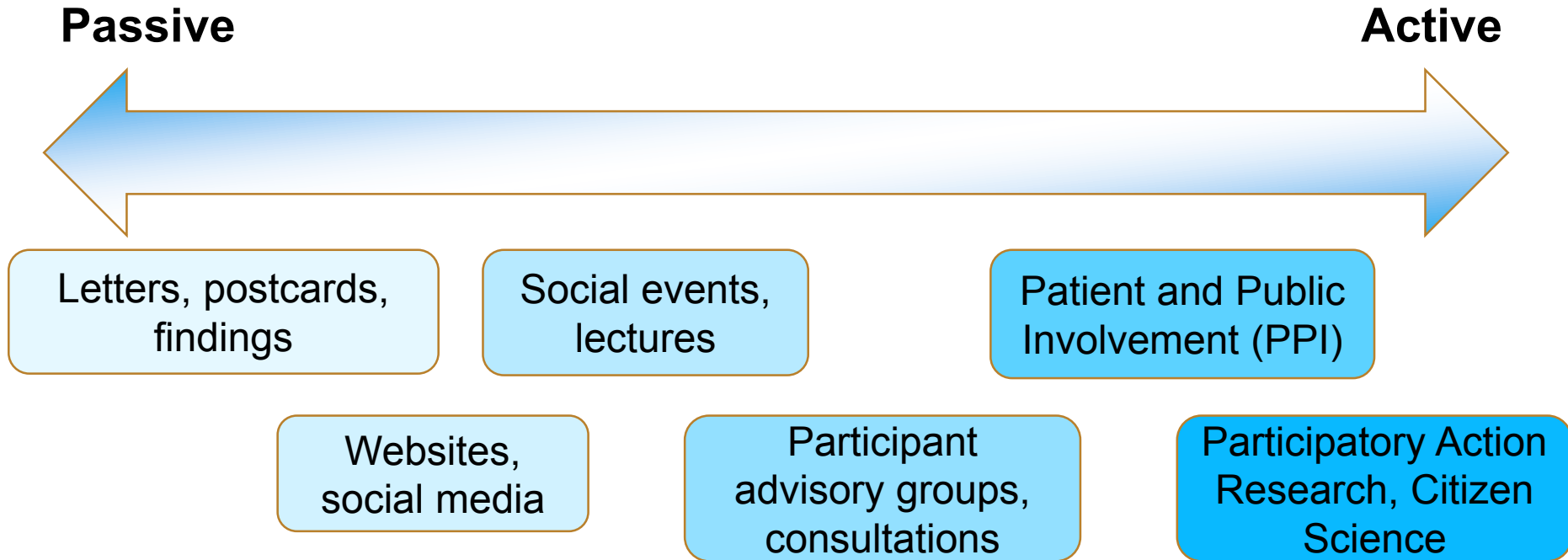
- What we mean by participant engagement, how it has changed over time
- Current participant engagement approaches among longitudinal studies
- Factors shaping engagement strategies
- What we know about effectiveness
- Concluding thoughts

Approaches to participant engagement

Participant engagement

- Range of ways in which studies engage with participants – from advance letters through to consultation and advisory groups
- Key constraints
 - Feasibility
 - Desirability
 - Effectiveness

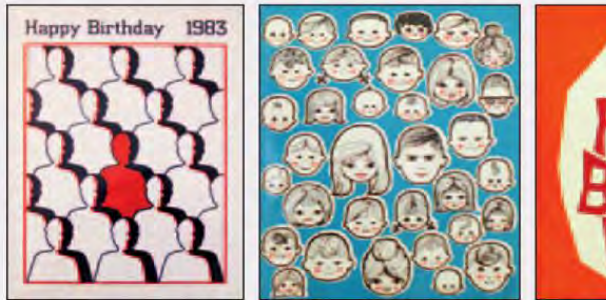
The engagement continuum



Evolving approaches: technology

NEWS FEATURE

H. PEARSON/M. DUNHAM/NATURE



The research team never forgets to send birthday cards

CARDS &

*How to keep a c
— for 65*

After tracking its subjects' health and well-being for longer than any other study, the 1946 British birth-cohort study has lessons to offer its



YOU WERE 14!



closer
Cohort & Longitudinal Studies
Enhancement Resources

Evolving approaches: participation



**Nothing
About Us
Without
Us!**

A screenshot of the INVOLVE website. The header includes the INVOLVE logo, the NHS National Institute for Health Research logo, and navigation links: Home, About INVOLVE, Find out more, Resources, News, InvoNET, Conference, and a search bar. A sidebar on the left lists links under "About INVOLVE": People at INVOLVE, Current work, How we work with others, INVOLVE documents, Terms of reference, INVOLVE jobs, and Keep in touch. The main content area is titled "About INVOLVE" and includes a "Go back" link. Below this is a paragraph about INVOLVE's establishment in 1996 and its role as a national advisory group. At the bottom, there are six boxes with links: "People at INVOLVE", "Current work", "How we work with others", "INVOLVE documents", "Terms of reference", and "INVOLVE jobs". A "Keep in touch" box is also present.

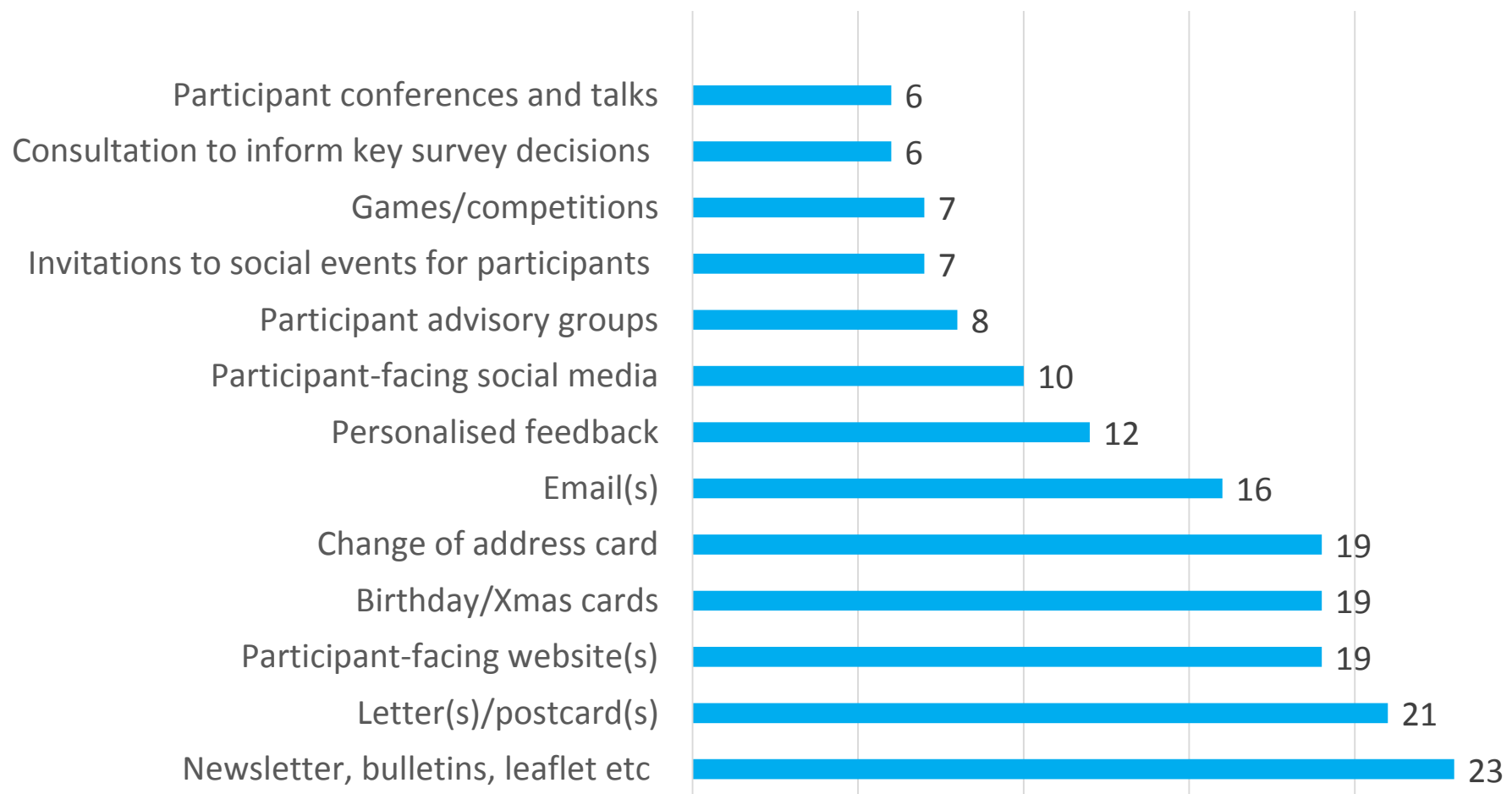
Current practice across longitudinal studies

CLOSER engagement survey

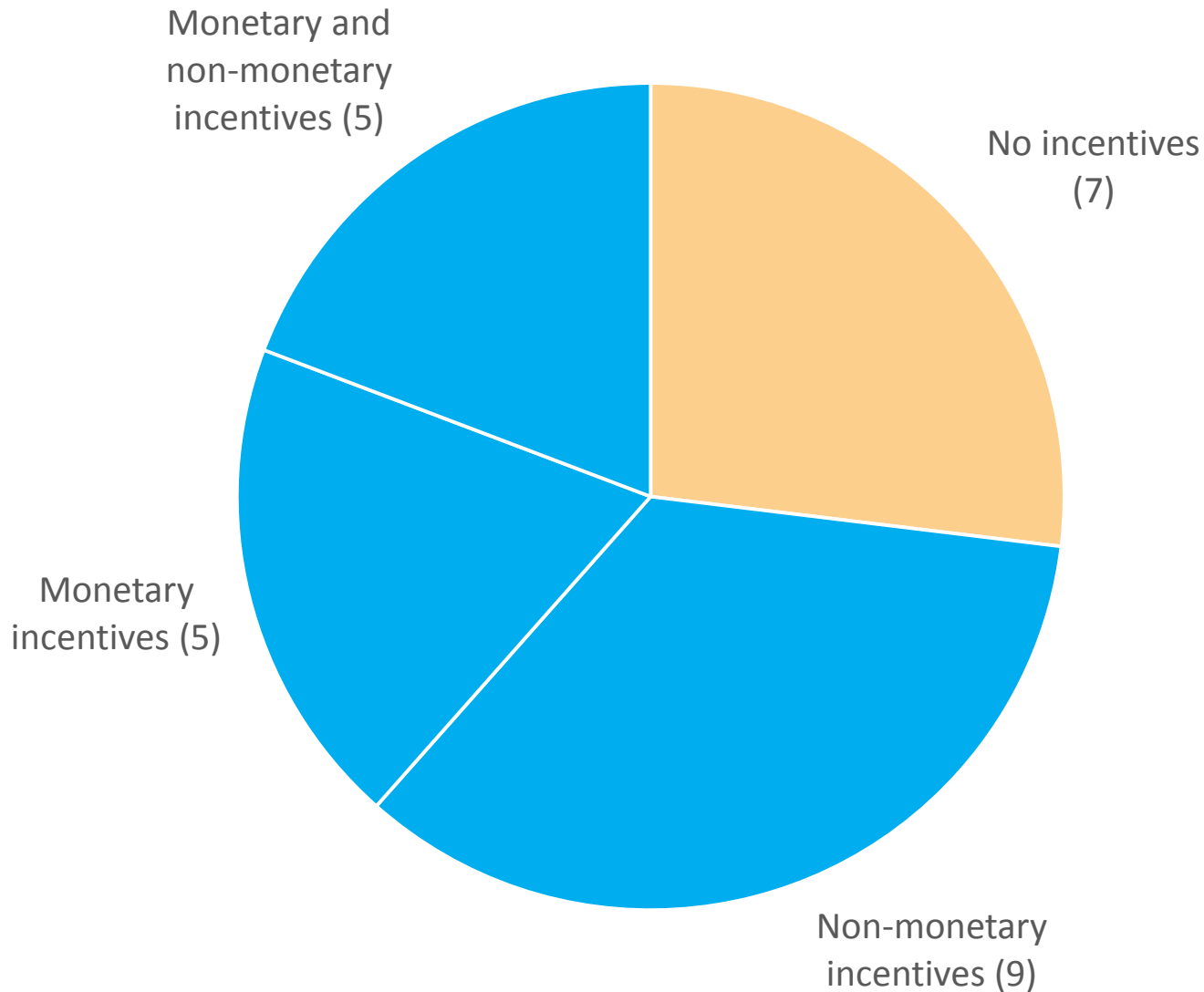
Survey carried out by CLOSER in 2015, 26 studies responded

- 14 UK studies
- 8 elsewhere in Europe
- 4 non-European studies

Types of participant engagement reported



Incentives



Factors influencing engagement strategies

Factors influencing engagement strategies

Background

- Social science vs biomedical traditions

Sample

- Homogeneity
- Life stage
- Size
- Location

Other practicalities

- Funding
- Interview mode

Factors influencing engagement strategies

Cultural context

- Public confidence and trust

Effectiveness

- Evaluation
- Awareness

Effectiveness

Advance notification (x-sectional)

- Positively associated with participation
- Length doesn't matter – little difference between letters and postcards
- Content doesn't have big impact either?
- Best practice design features widely used: sponsor, official letterhead, authority
- Appeal to reciprocity is effective

Advance notification (longitudinal)

- Impact on response rates/retention in longitudinal context?
- Targeted content may be effective at boosting response from sub-groups

Incentives (x-sectional)

- Effective at boosting response rates
- Unconditional incentives more effective than conditional incentives
- Cash incentives more effective than vouchers/payments in kind
- Higher value incentives are more effective than lower value incentives

Incentives (longitudinal)

- Unconditional incentives have larger long-term effect on reducing attrition than conditional incentives
- Higher value incentives reduce attrition at subsequent wave
- Reducing incentive amount at later waves (or even during the course of a single wave) doesn't seem to have a negative impact
- Cross-wave incentives?

Between-wave mailings

- Overall effectiveness
- Inclusion of newsletters
- Targeted content

Branding/design of survey materials

- Evidence that professionally designed materials can boost participation (particularly for certain sub-groups)

Emails

- Evidence that can boost response rates in a web-survey context (along with other reminders/contacts)
- Literature on timing of emails
- Little evidence of their effectiveness in longitudinal context e.g. as part of between-wave engagement strategy

Evidence on effectiveness of other strategies?

- Web/social media?
- Games/Competitions?
- Personalised feedback?
- Participant advisory groups?
- Events/conferences?

Summary

Current state of play

- Array of approaches to participant engagement, but most common at more passive end of spectrum
- Shaped by combination of feasibility, desirability and perceived effectiveness
- Some areas well researched – but little evidence about others

The future

- **Future challenges**
 - Increasing non-response
 - Widening range of engagement methods
 - (Even) tighter budgets
- **Vital we know and share what works**
- **Rationale behind today's event**

References

Advance notification

De Leuw, E., Callegaro, M., Hox, J. Korendijk, E., and Lensvelt-Mulders, G. (2007). The Influence of Advance Letters in Telephone Surveys. *Public Opinion Quarterly*, 71(3), pp.413-443. DOI: 10.1093/poq/nfm014

Lynn, P. (2014) Targeted initial letters to longitudinal survey sample members: effects on response rates, response speed, and sample composition. ***Understanding Society Working Paper Series No. 2014 – 08***

Incentives

Church, A. H. (1993). Estimating the effect of incentives on mail survey response rates: a meta-analysis. *Public Opinion Quarterly*, 57, pp.62-79. DOI: 10.1086/269355

Singer, E., Hoewyk, J. V., Gebler, N., Raghunathan, T. and McGonagle, K. (1999). The effects of incentives on response rates in interviewer-mediated surveys. *Journal of Official Statistics*, 15(2), pp. 217-230. DOI: **10.4135/9781446262269**

Singer, E. (2002). The Use of Incentives to Reduce Nonresponse in Household Surveys. In Groves, R.M., Dillman, D.A., Eltinge, J.L., and Little, R.J.A. (eds.). *Survey Nonresponse*, New York: John Wiley and Sons.

Jackle, A. and Lynn, P. (2008). Respondent incentives in a multi-mode panel survey: cumulative effects on non-response and bias. *Survey Methodology*, Vol. 34, No. 1, pp105-117.

Rodgers, W. (2002). Size of Incentive Effects in a Longitudinal Study, *American Association for Public Research: Strengthening Our Community – Section on Survey Research Methods*.

Between-wave mailings

McGonagle, K.A., Couper, M.P., and Schoeni, R.F. (2011). Keeping Track of Panel Members: An Experimental Test of a Between-Wave Contact Strategy. *Journal of Official Statistics*, 27(2), 319-338

McGonagle, K.A., Schoeni, R.F., and Couper, M.P. (2013). The Effects of a Between-Wave Incentive Experiment on Contact Update and Production Outcomes in a Panel Study. *Journal of Official Statistics*, 29(2), 261-276.

References

Between-wave mailings (cont'd)

Fumagalli, L., Laurie, H. and Lynn, P. (2013). Experiments with Methods to Reduce Attrition in Longitudinal Surveys. *Journal of the Royal Statistical Society Series A*, 176(2), pp.499-519. DOI: 10.1111/j.1467-985X.2012.01051.x

Calderwood, L. (2014). Improving between-wave mailings on longitudinal surveys: a randomised experiment on the UK Millennium Cohort Study. *Survey Research Methods*. 8 (2), pp. 99-108.

Branded/designed materials

Boyd, A., Tilling, K., Cornish, R., Davies, A., Humphries, K and Macleod, J. (2015). Professionally designed information materials and telephone reminders improved response rates: evidence from an RCT nested within a cohort study. *Journal of Clinical Epidemiology* 68 (877-887)

See also Fumagalli et al. (2013)

Taylor, M. (2013). *Better communication with participants*. Presentation to International Workshop on Household Survey Non-Response, London.

Children of the 90s (ALSPAC): a warts-and-all account of participant engagement

Dara O'Hare and Makaela Jacobs-Pearson



Avon Longitudinal Study
of Parents and Children

Supported by
wellcometrust



Hello!

We are:

Makaela Jacobs-Pearson, participation worker

Dara O'Hare, communications and participation manager

Our talk will cover:

- Events
- Focus groups and advisory panels
- Social media

ALSPAC jargon buster:

ALSPAC = Avon Longitudinal Study of Parents and Children = Children of the 90s

COCO90s = Children of the Children of the 90s

YPs = Young people = original cohort participants

TAP = Teenage Advisory Panel

OCAP = Original Cohort Advisory Panel



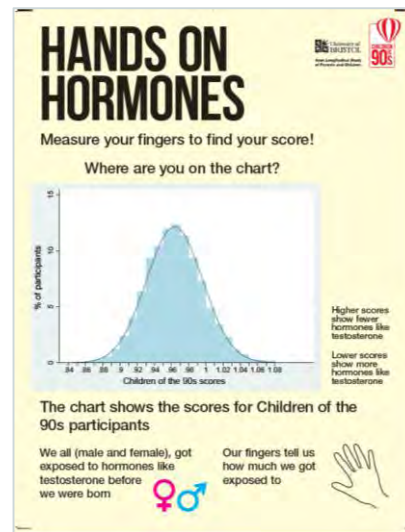
ResearchFest

- A conference for participants showcasing CO90s research as part of year-long events programme
- Held in Colston Hall Bristol on a Sunday
- Brought together researchers, participants and staff (academic and admin) in the planning and delivery
- Provided participants with 'Plain English' training to equip them with skills to work with our researchers and collaborators to deliver high-quality lay posters
- Mix of scientific talks and hands-on activities
- Aimed to develop an understanding of epidemiology and how CO90s fits in to the bigger picture
- Aimed to encourage participation in future CO90s data-collection exercises



ResearchFest

- Talks (genes, obesity, cannabis)
- Question Time
- Demos and displays
- Information tables
- Feedback points
- Lay posters
- Roaming researchers
- A participant-made film



- Resource intensive
- High cost per attender
- Big project to coordinate
- Mainly local, engaged participants who attended



Research Fest

- Great success in terms of depth and breadth of engagement
- Participants like this type of event and said it was long overdue
- Felt pride after gaining a better understanding
- Reached wider audience by making footage and resources available online
- <http://www.bristol.ac.uk/alspac/events/researchfest2012/>

Pleased to see the results of our (collective) efforts. Thanks for doing this, keep up the good work

Very interesting day. All the speakers were enthusiastic and engaging. Puts the research into a much bigger perspective & highlights its importance

I have had a great day and learnt a lot! I can't wait to take part as a sibling! Hope an event like this happens again soon!

Thank you, a really interesting and fascinating day

Today has made me proud to be part of this study. So many important findings

Would like to see more events like this! It's nice to get some info back having given data all my life!

Thought it was a great idea for the people in the study to find out what their information has gone on to do and become. The day was really nice and the people and staff are really friendly! Thank you very much

Really interesting day – Thanks for acknowledging us and the time spent early on. It has been so interesting to be involved.

Summer School 2014

- Six talks throughout the summer
- Invitations via newsletter, website and social media
- Booking via Eventbrite
- Mid-week evenings
- In-house event
- Self-catered and staffed
- Variety of topics to appeal to different cohort groups
 - The early years
 - The teenage years
 - Women's health
 - The role of genetics
 - Data linkage
 - What is next?
- Lab tours



Summer School 2014

- 158 participants attended the six talks
- Women's health (menopause) talk was the most popular
- Data linkage talk was the least popular
- Overall, successful and very good value for money
- Still biased towards local, engaged participants
- Attendees dwindled towards the end of the summer



Children of the Children of the 90s (COCO90s) party at Bristol Zoo



COCO90s coffee mornings

- Opportunity to meet other similar aged mums
- First Monday of the month
- Held at Children of the 90s
- Low cost
- Low staff burden

COCO90s Coffee Morning



When: First Monday of the month

Time: 10.30am – 12pm

Where: Oakfield House, Oakfield Grove,
Clifton, BS8 2BN

We hope that this event will allow you to meet other COCO90s parents and children. Refreshments will be provided but feel free to bring along extras. We are unable to provide childcare but there will be plenty of toys and books to help keep the little ones entertained. Due to the space numbers are limited so please let us know if you would like to attend as places, along with parking spaces, will be allocated on a first come first served basis. Please take a flier or ask a member of the team for more details.

We hope you can make it!

Email: info@childrenofthe90s.ac.uk

Phone: 0117 331 0039

COCO90s seasonal coffee mornings

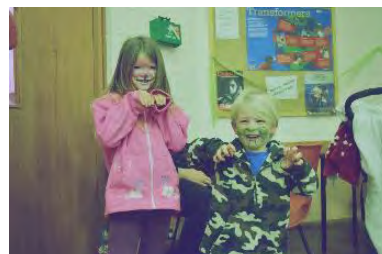
- Held quarterly
- Local hall
- Free parking available
- Safe space for children
- Good bank of CO90s toys – bubble machine, ball pit, tunnels, tents, beach balls, books, building blocks etc.
- Own catering
- Engaging content for social media and website



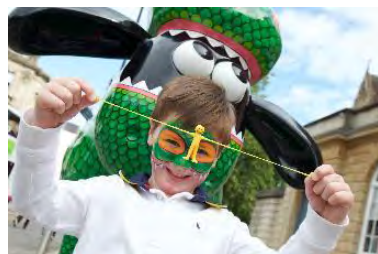
COCO90s Christmas parties



COCO90s Easter party



COCO90s summer party



Creative workshops for study mothers

- Professor Debbie Lawlor is researching women's health as they go through the menopause
- Holistic approach – physical, mental and emotional health
- 'Time of Our Lives' qualitative research project, Isabel de Salis and Ian Beesley
- Building on this with creative workshops led by poet Ian McMillan, cartoonist Tony Husband and photographer Ian Beesley to explore themes of 'empty nest' and 'kinship'



Professor Debbie Lawlor

Creative workshops for study mothers



'His dad can't stand football, so I took him to his first football match: City vs Rovers (Bristol) – he has been a fan ever since.'

*'I sobbed, I sobbed all the way back
(from taking her to university)
And I was seriously depressed for three or four weeks.
And now it's like, almost like a love affair ...
because I think oh I'm going to see her
And then all day I get really, really excited.'*



Creative workshops for study mothers

Challenges

- External partners made it difficult to coordinate
- Lack of information in advance – artists used to improvising
- Artists unfamiliar with ethics process
- Practical issues on the night, e.g. consenting; partners needing tea!

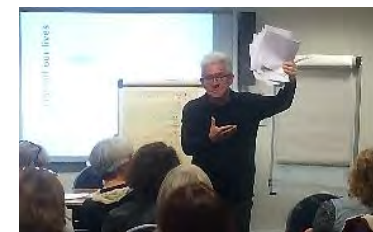
Benefits

- Low-budget (in-house, self catered)
- Able to turn qual research into novel engagement activity
- Great feedback
- Unwillingness to leave!
- Concrete outputs
 - ‘chapbook’ and cartoon
- Visual aspect great for social media

‘Lively, thought-provoking, clever, participative.’

‘Haven’t laughed so much in ages. Poetic delivery was amazingly brilliant.’

‘Fast-moving, humorous and vibrant! All inclusive without feeling pressure to contribute, really good methods!’



Teenage Advisory Panel (TAP)

- Children of the 90s first set up a participant advisory panel in 2006 (TAP)
- Members have been asked to advise on study documentation, data collection proposals and study design
- Members sit on the study's ethics committee and frequently share their opinions about the future of Children of the 90s

'We aim to represent the total cohort in our opinions and as participants our input is valuable to how the study is conducted. It's great to be more involved in the study & to contribute to its successes.'



Original Cohort Advisory Panel (OCAP)

- New name to reflect that the members are no longer teenagers
- Annual re-enrolment and recruitment
- Introduction of role description
- Update of Terms of Reference
- Introduction of OCAP committee
- Formalised schedule alongside our ethics and internal meetings
- Given ownership to the group
- Opportunities outside of OCAP

HEALTH SERVICES AND DELIVERY RESEARCH

VOLUME 2 ISSUE 36 OCTOBER 2014
ISSN 2050-4349

Public involvement in research: assessing impact through a realist evaluation

David Evans, Jane Coad, Kiera Cottrell, Jane Dalrymple, Rosemary Davies, Christine Donald, Vito Laterza, Amy Long, Amanda Longley, Pam Moule, Katherine Pollard, Jane Powell, Anna Puddicombe, Cathy Rice and Ruth Sayers



Other focus groups

Online Parents
Advisory Forum

Smoking Study
Feedback Group

Family
Newsletter
Focus Group

Breast Tissue
sub study Focus
Group

Male Fertility
Focus Group

Mums
Questionnaire
pilot

COCO90s
Focus Group

Dads Focus
Group – F1

21st birthday book

- Book to give to each participant as a Christmas present in 2012
- Wanted to involve participants from the outset
- Wrote a 'job description' detailing commitment required and compensation
- Participants involved every step of the way, including remotely (Ireland and Switzerland)
- Participants interviewed (grilled!) the design teams
- Advised on content
- Contributed ideas, art and photography



21st birthday book

They said...

Don't make it
too light-hearted

The design
shouldn't date

Listen!

Think about
accessibility for people
with dyslexia, visual
impairments

Each example should
have some kind of impact
–'wow'/smile/laugh

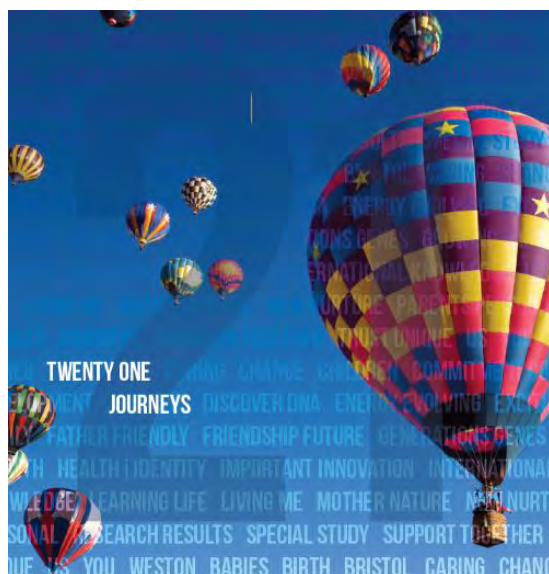
Elegant/treasure

Celebration
and thank you

Make the science
accessible without
patronising people

21st birthday book

We listened...



Children of the 90s created a poll.

31 July 2012 · 🌐

So you may have heard that we are creating a book to celebrate 21 years of Children of the 90s.... We now need your help with the title. Vote for your favourite from the options below.

<input type="radio"/>	21 Years: Our Journey	+25
<input type="radio"/>	21: Our Journey	+4
<input type="radio"/>	Our Journey to 21	+3

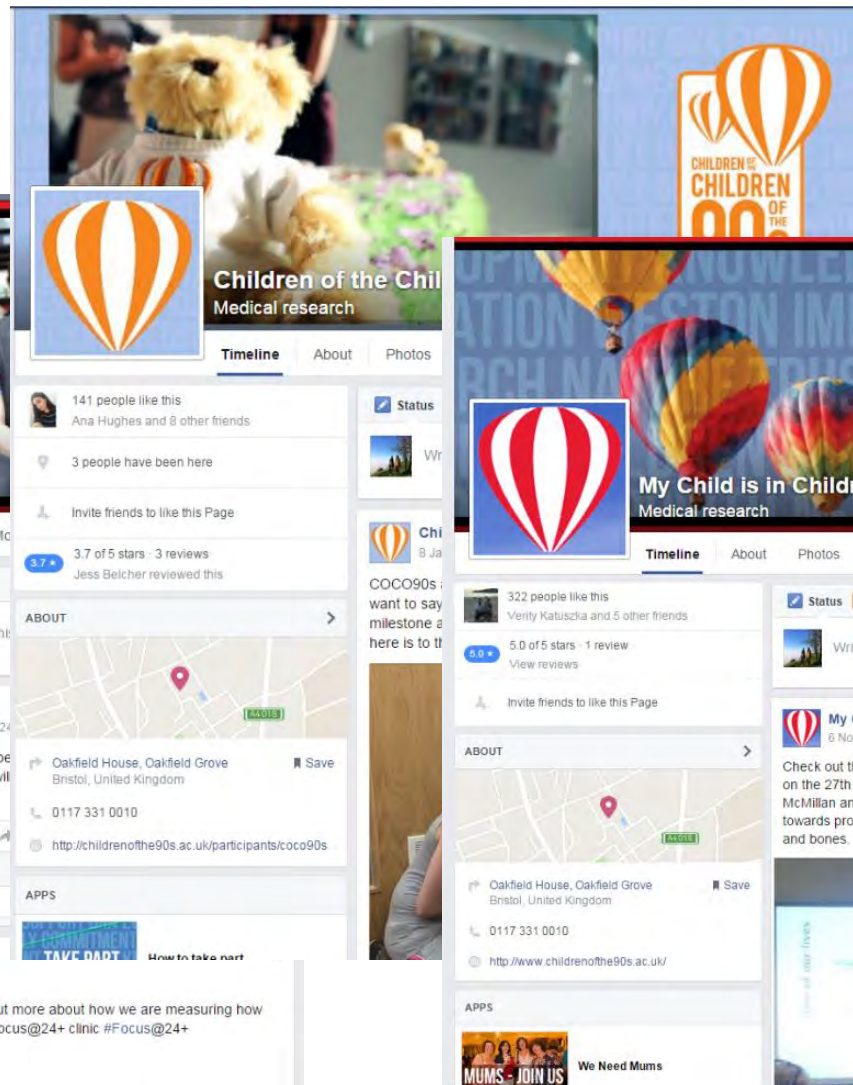
In absolute awe about the fantastic findings that have come from CO90s!

After reading results of @CO90s longitudinal study published in '21 yrs' milestone book I feel so lucky to be part of such a worthy cause :)

Facebook



Facebook profile for **Children of the 90s Medical research**. The cover photo shows a group of women and a child. The profile picture is a red and white hot air balloon logo. The page has 3,140 likes and 213 people have been here. A recent status update from Chris Raistrick says "We are off until 2016 - we hope and a Happy New Year We will". The page also has a map location for Oakfield House, Oakfield Grove, Clifton, Bristol, United Kingdom, and a link to <http://www.childrenofthe90s.ac.uk/>.



Facebook profile for **Children of the 90s Medical research**. The cover photo shows a teddy bear and a hot air balloon logo. The profile picture is a red and white hot air balloon logo. The page has 141 likes and 3 people have been here. A recent status update from Jess Belcher says "COCO90s: want to say milestone here is to t". The page also has a map location for Oakfield House, Oakfield Grove, Bristol, United Kingdom, and a link to <http://childrenofthe90s.ac.uk/participants/coco90s>.



Facebook profile for **My Child is in Children of the 90s Medical research**. The cover photo shows several colorful hot air balloons and a red and white hot air balloon logo. The profile picture is a red and white hot air balloon logo. The page has 322 likes and 5.0 stars. A recent status update from Verity Katuszka says "My Child is in Children of the 90s added 4 new photos". The page also has a map location for Oakfield House, Oakfield Grove, Bristol, United Kingdom, and a link to <http://www.childrenofthe90s.ac.uk/>. A photo of a man presenting at a workshop is also visible.

Facebook – what's going on at CO90s

 **Children of the 90s** added 4 new photos.
Published by ChildrenOfTheNineties [?] · 5 November 2015 · 🌐

Earlier this week the BBC Points West team came to Focus@24+ to chat to our participants and researchers about the clinic. Check out the pictures of presenter Charlotte Callen interviewing some of our researchers and participants and keep an eye out for us tomorrow on BBC1 at 6.30pm!




993 people reached


Boost Unavailable

16 Likes · 1 Share



 **Children of the Children of the 90s**
Published by Makaela CO90s [?] · 8 January at 16:06 · 🌐


COCO90s are celebrating our 1000th visit today with Lance and Zoe. We want to say a HUGE thank you to everyone who has helped us reach this milestone and we look forward to seeing you all at some point this year - here is to the next 1000!




254 people reached

Boost Unavailable

16 Likes




Facebook – share our research

**Children of the 90s**
Published by Makaela CO90s (?) · 28 August 2015 · 🌐


**** New research published today - Goth teens could be more vulnerable to depression and self-harm ****




We've discovered that young goths might be at increased risk of depression and self-harm – not because being a goth causes depression or self-harm, rather that some goths are more vulnerable to developing these conditions. We found that teenagers who identified very strongly with being a goth when they were 15 were three times more likely to be clinically depressed and five ... [See More](#)



Being a goth 'not all dark and gloomy' - BBC News
Stacey Elder, a self-identifying goth who has dealt with depression, says it is "not all dark and gloomy".
BBC.CO.UK

2,875 people reached Boost Unavailable

22 Likes · 2 Comments · 1 Share 


 Like  Comment  Share

2,875 People Reached

35 Likes, Comments & Shares

27 Likes	22 On Post	5 On Shares
2 Comments	2 On Post	0 On Shares
6 Shares	1 On Post	5 On Shares


316 Post Clicks

0 Photo views	54 Link clicks	262 Other Clicks 
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NEGATIVE FEEDBACK


0 Hide Post	2 Hide All Posts
0 Report as Spam	1 Unlike Page

Facebook – involve our participants

**My Child is in Children of the 90s**
Published by Makaela CQ90s [?] · 18 January at 14:13 · 🌐

The Museum of Life.

As part of our 25th celebrations each fortnight we'll showcase an item from our past in our online 'Museum of Life'. Thank you so much to everyone who took part in naming our online archive. Just follow the link below to check out the first item.






Bristol University | Avon Longitudinal Study of Parents and Children | 25 Years
Children of the 90s is 25 years old this year! To celebrate our anniversary we are collecting 25...
BRISTOL.AC.UK

1,205 people reached


Boost Unavailable

11 Likes 1 Comment 2 Shares

 Like  Comment  Share

1,205 People Reached**32** Likes, Comments & Shares**104** Post Clicks**NEGATIVE FEEDBACK**

Facebook – invitations


Children of the Children of the 90s
 Published by ChildrenOfTheNineties [?] · 13 March 2015 ·

*** COCO90s would like to invite you to a party! ***


* When :Monday 30th March, 10.30am - 12pm
 * Where: Tyndale Baptist Church Hall, Whiteladies Road, BS8 2QG.

We would love for you to join us for a drink and some cake followed by morning of spring craft activities, games and an Easter egg hunt as well as a chance for you to meet the other COCO90s parents and parents-to-be.


Due to the hall size numbers are limited so please let us know if you would like to attend and how many adults and children you will be bringing as places, along with parking spaces, will be allocated on a first come first served basis. Please see the map for directions.

Please RSVP ASAP and let us know how many adults/children you will be bringing with you - you can do this by commenting below, sending us an email at info@childrenofthe90s.ac.uk or phoning us on 0117 331 0039.

We hope to see you there!!



208 people reached
 Boost Unavailable

5 Likes · 6 Comments
 

Like · Comment · Share

208 People Reached

20 Likes, Comments & Shares


6 Likes	5 On Post	1 On Shares
12 Comments	10 On Post	2 On Shares
2 Shares	0 On Post	2 On Shares

48 Post Clicks


16 Photo Views	0 Link clicks	32 Other Clicks
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NEGATIVE FEEDBACK

0 Hide Post	0 Hide All Posts
0 Report as Spam	0 Unlike Page



Children of the Children of the 90s shared their album.
 Published by Makaela CO90s [?] · 4 December 2015 ·

It's beginning to look a lot like Christmas... Thank you so much to everyone who came and made our COCO90s Christmas Party so much fun. We hope you all had a wonderful time!







71 people reached
 Boost Unavailable

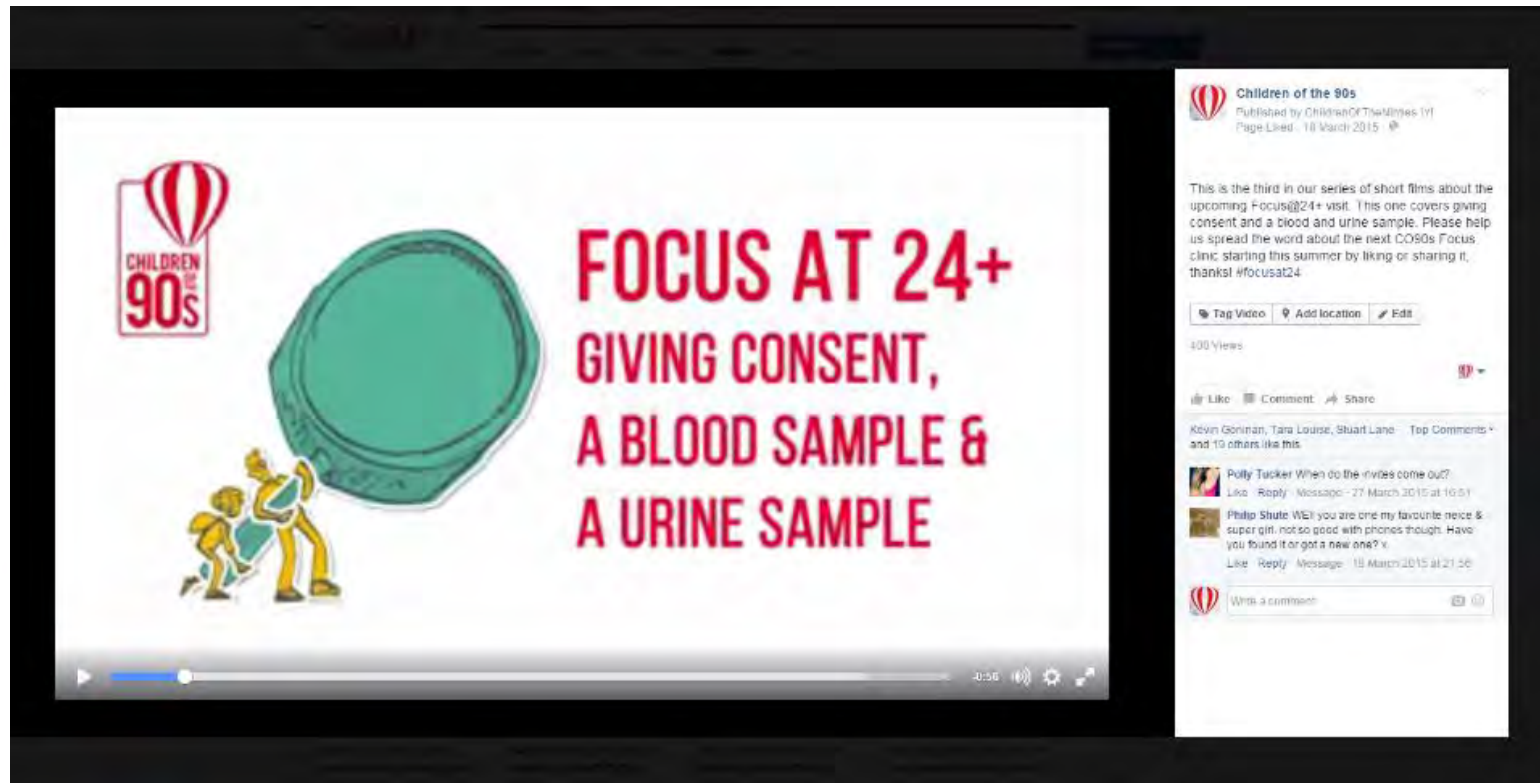


Like · Comment · Share

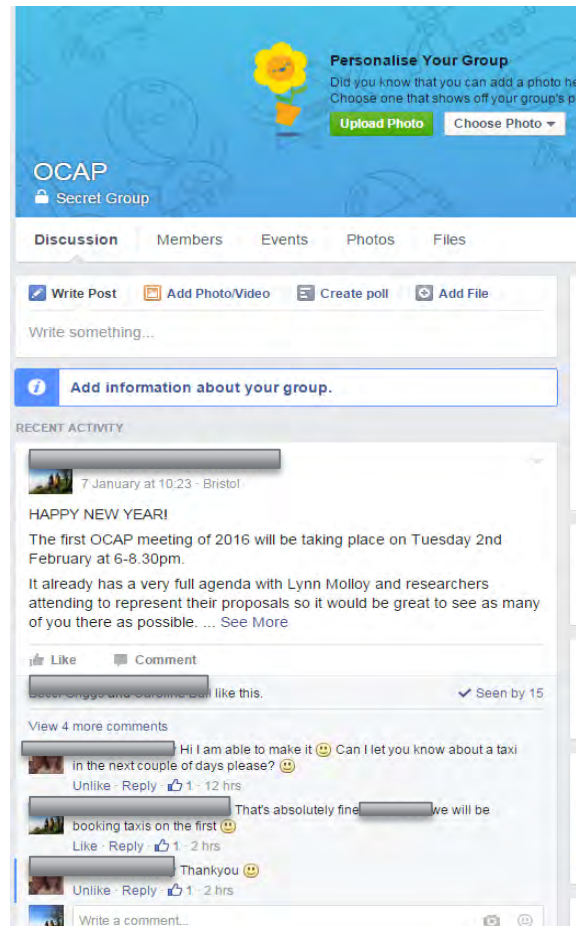

Children of the Children of the 90s added 24 new photos to the album: COCO90s Christmas Party 2015.
 Published by Makaela CO90s [?] · 4 December 2015 ·



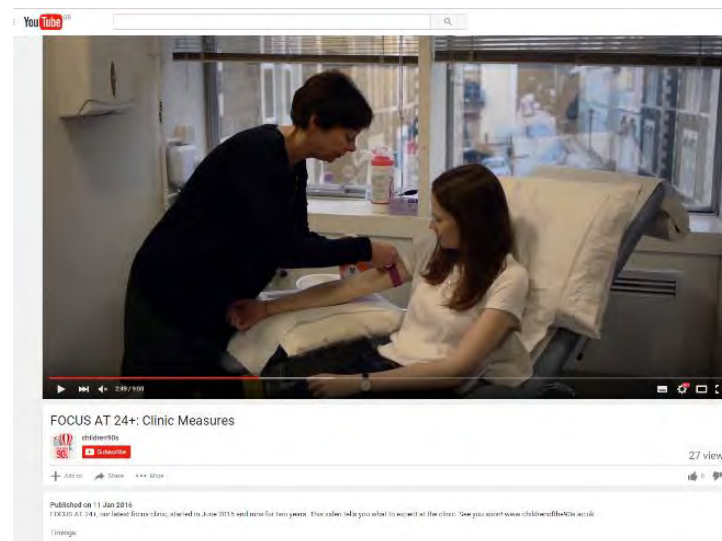
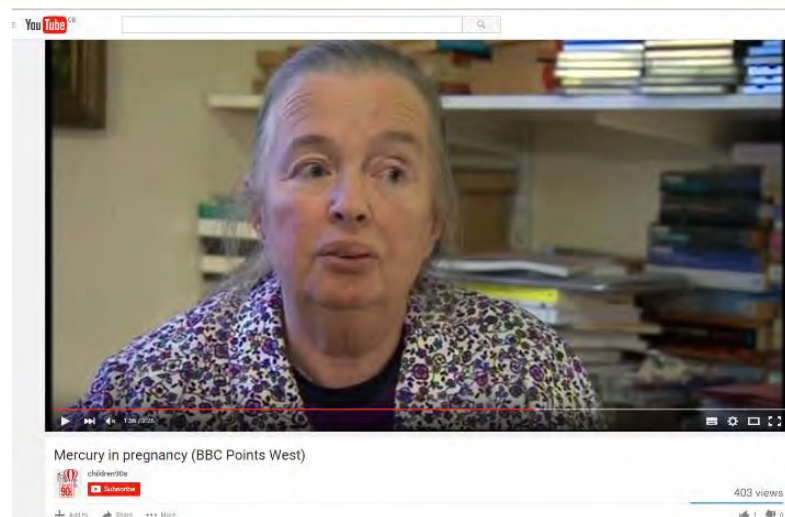
Facebook – what to expect



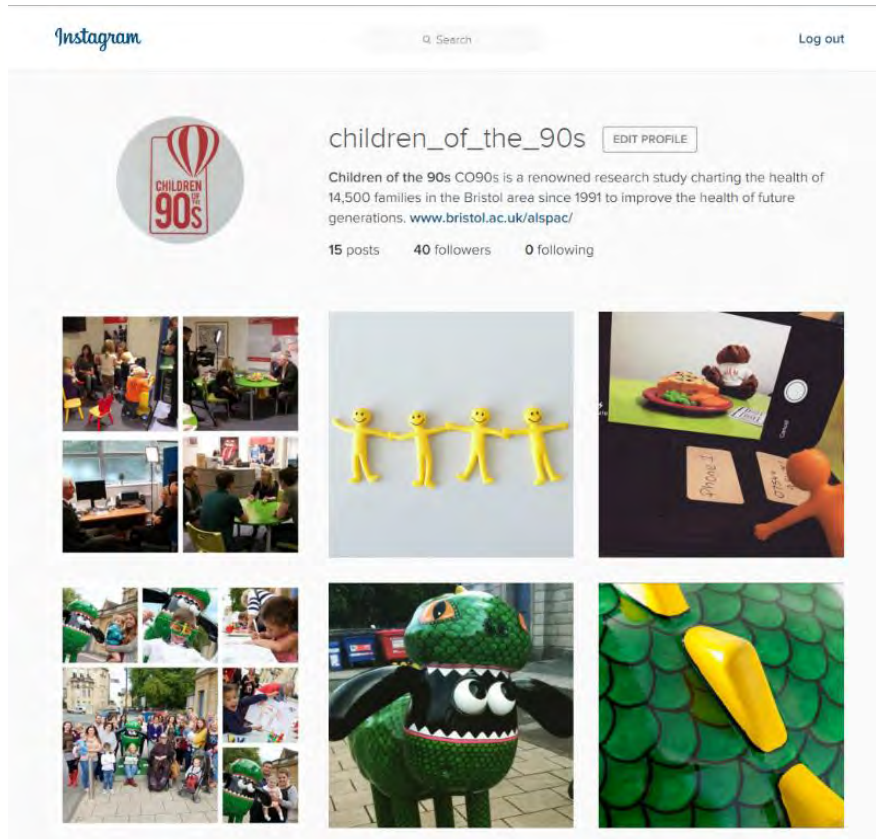
Facebook – communication with participants



Youtube



Instagram



Twitter

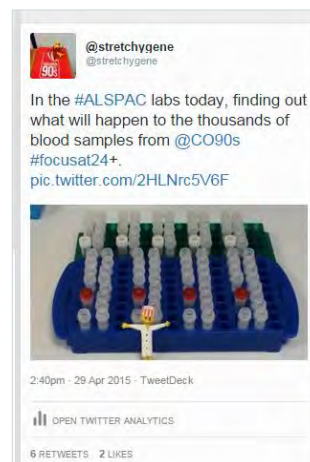
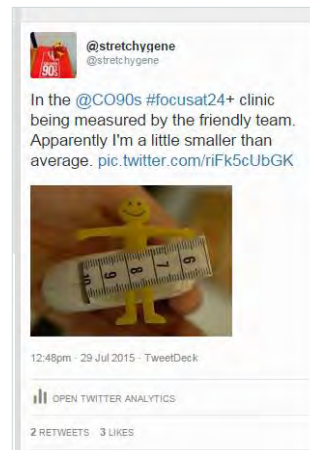
- @CO90s
- Audience primarily science community
- Increased from 7 to 1,400+
- Key influencers include Dr Adam Rutherford, 28K followers:
 - *‘An epidemiologist’s dream: a terribly important longitudinal study, ALSPAC. 14k kids followed since 1991.’*
 - *‘The Avon Longitudinal Study of Parents and Children, the gold standard of transgenerational research.’*
- Followed by some participants who send us updates and comment on research, clinics and questionnaires



Twitter



- @stretchygene
- Aimed at participants
- Small (62) but exclusive following!
- Effective way to communicate what goes on behind the scenes in a light-hearted way
- Fast, free and fun



Social media guidelines

INVOLVE


National Institute for
Health Research

Guidance on the use of social media
to actively involve people in research

INVOLVE


National Institute for
Health Research

Example 6: Children of the 90s

Using Facebook and Skype to involve young people in a long-term research project

<http://www.invo.org.uk/wp-content/uploads/2014/11/9982-Social-Media-Guide-WEB.pdf>

<http://www.invo.org.uk/wp-content/uploads/2014/11/Social-media-guidance-example6.pdf>

Want to know more?

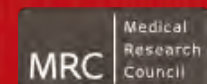
- Come along to Makaela's 14.20 session
 - *'Involving participants in study design and management'*
- Talk to us in the breaks
- Contact us:
 - Makaela Jacobs-Pearson
 - makaela.jacobs-pearson@bristol.ac.uk
 - Dara O'Hare
 - dara.ohare@bristol.ac.uk
 - www.bristol.ac.uk/alspac
 - www.facebook.com/childrenofthe90s
 - @CO90s
 - [@stretchygene](https://www.instagram.com/stretchygene)
 - www.instagram.com/children_of_the_90s/

THANK YOU



Avon Longitudinal Study
of Parents and Children

Supported by
wellcometrust

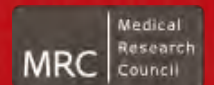


ANY QUESTIONS?



Avon Longitudinal Study
of Parents and Children

Supported by
wellcometrust



Knowledge
Exchange
Workshop



12:15 - 13:00 Lunch

Please head downstairs to the Tavistock Room

Please fill in your evaluation form. Thank you.



Knowledge
Exchange
Workshop



Innovative methods of engagement 1

Please switch your mobile phones to silent



CHAP BOOKS, TWINS AND MOBILE PHONES



Ann Barratt
Family Liaison Officer

Liz Andrews*
Senior Research Fellow
www.borninbradford.nhs.uk

CLOSER Knowledge Exchange Workshop
Participant engagement in longitudinal studies
Woburn House Conference Centre, London
Friday 29th January 2016

Study Launch December 2005



Fathers and babies



Fathers and babies



First Birthday Card



Eighth Birthday Card



New Years Day Baby Grows Up



New Years Day Baby Grows Up



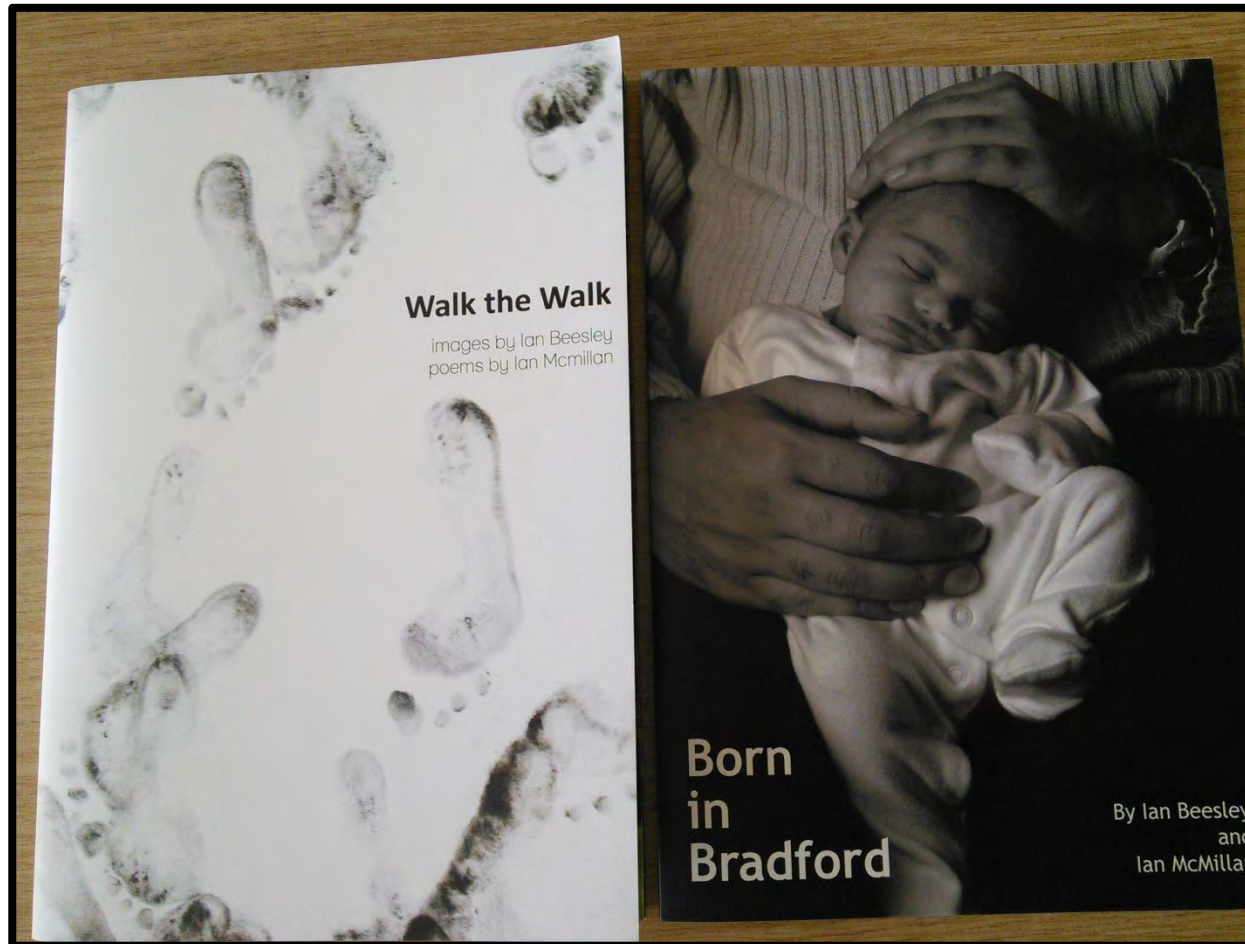
Twins Growing Up



Twins Growing Up



Chap Books



Mobile Phones for Research



Children's photos of their meals at home



2014 Family Festival



BiB and the First World War



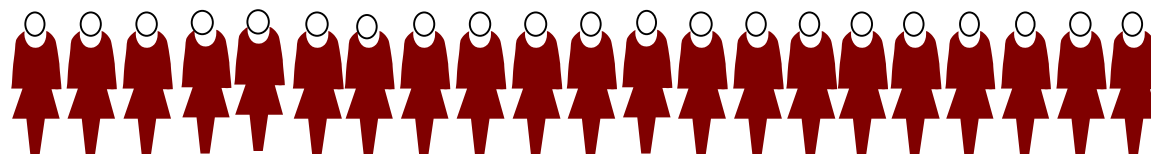
Southampton Women's Survey: supporting interventions and vice versa

Hazel Inskip

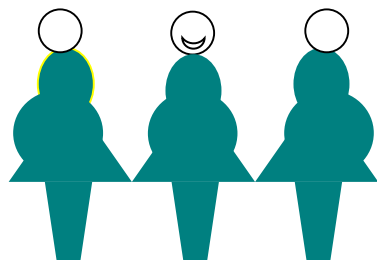
MRC Lifecourse Epidemiology Unit,
University of Southampton.

January 29th 2016

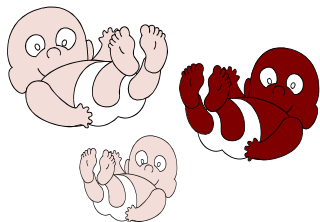
The Southampton Women's Survey



12,583 non-pregnant Southampton women aged 20-34 years interviewed between 1998 and 2002.



Subsequent pregnancies studied, ultrasound scans and interviews.



3158 births



Children followed-up at 6, 12, 24 and 36 months. Samples seen at 4, 6-7, 8-9 and 11-13 yrs.

Vitamin D in pregnancy

Vitamin D status in pregnancy

- linked to bone density at birth and through childhood
- linked to femur shape (akin to rickets) in utero



Leading to MAVIDOS

(MAternal Vitamin D in Osteoporosis Trial)

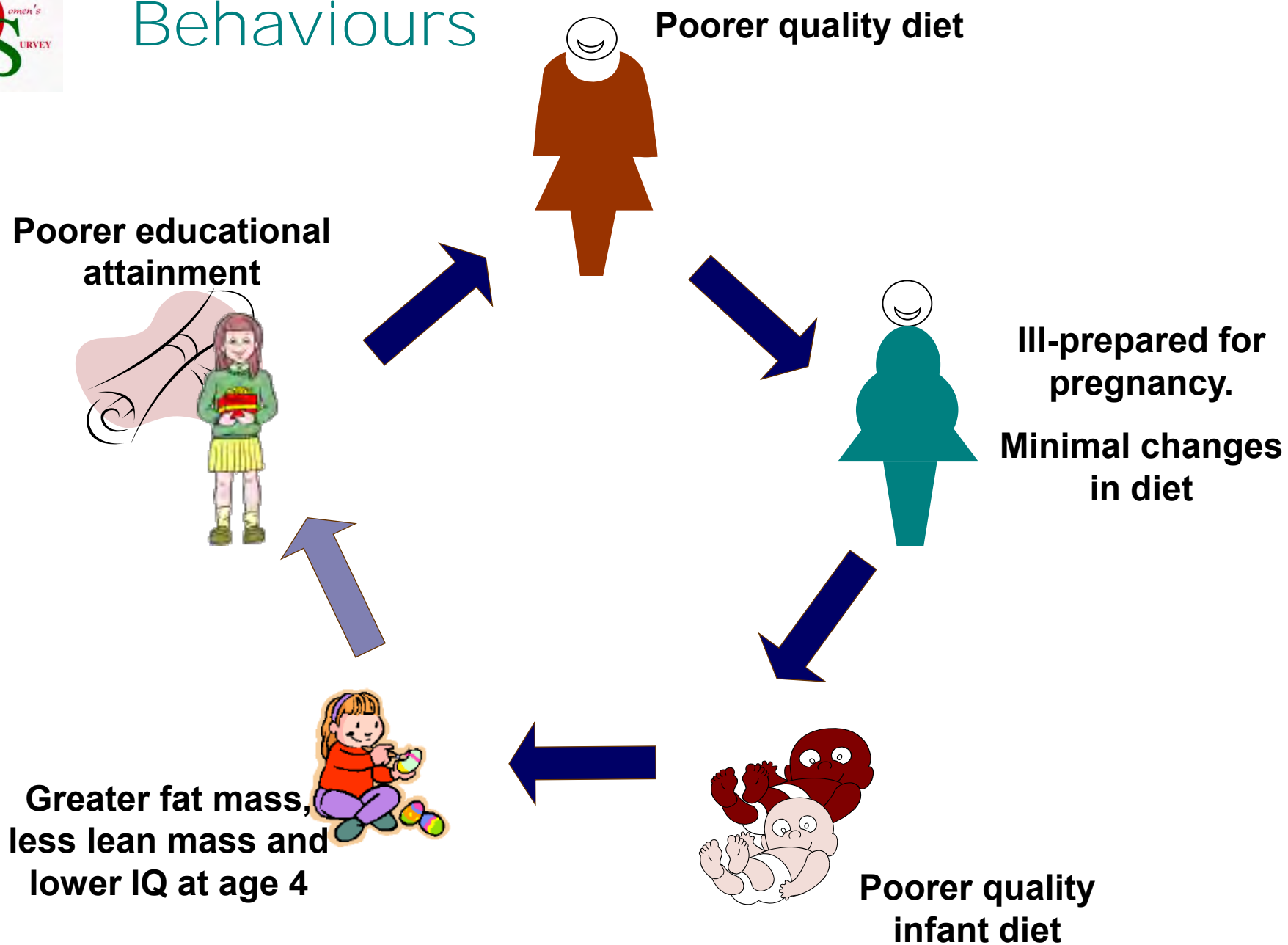
Some participants in MAVIDOS were in SWS

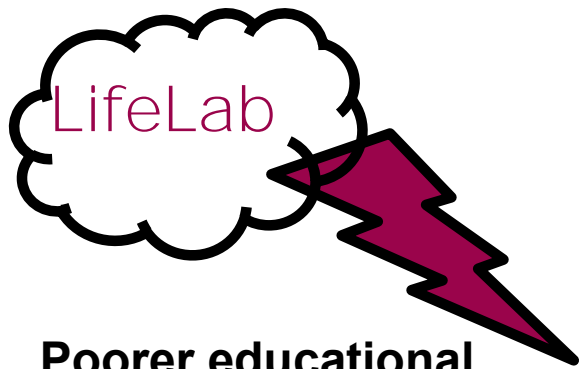
Enthusiasm for SWS helped MAVIDOS recruitment



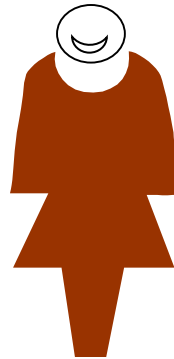
Extra attention in MAVIDOS reinforced enthusiasm for continuing with SWS

Behaviours

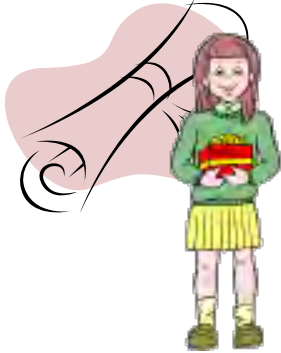




Poorer quality diet



Poorer educational attainment



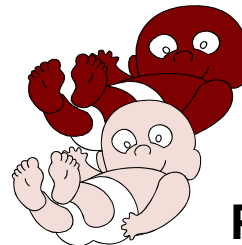
**Greater fat mass,
less lean mass and
lower IQ at age 4**



**Ill-prepared for pregnancy.
Minimal changes
in diet**



**Poorer quality
infant diet**



LifeLab Southampton



'Me, My Health and My Children's Health'

Engaging 13-14 year olds in

- the importance of their diet and lifestyle:
 - for their own health and
 - their future children
- inspiring them to take in interest in science

Evaluated in a cluster randomised trial funded by British Heart Foundation



Educational intervention based on research evidence:

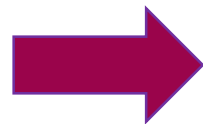
- **Education:**

Pupils need to understand the science behind health issues to make informed judgements about their health

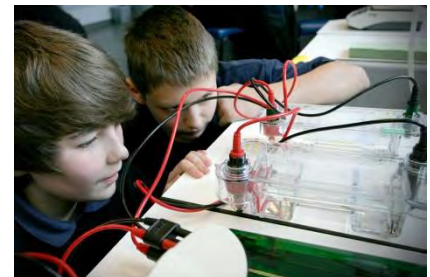


- **Medical:**

A healthy lifestyle in early life



Better health in later life and for future generations



LifeLab aims to provide school students with opportunities to:

- Learn how they can improve their health and the health of their future children through increased health and science literacy
- Become enthusiastic about science, and consider further study and careers in scientific disciplines



LifeLab and SWS

- LifeLab materials draw on SWS findings
- SWS participants and/or their siblings are now attending LifeLab
- SWS is seen to be of value
- Enhanced enthusiasm for SWS
- Spreads the word about LifeLab in the peer group



Summary and acknowledgments

- Cohort studies can lead to interventions
- When conducted in the same target population they can enhance each other
- Generating support for research generally and making links between studies can assist in raising enthusiasm for research projects

With thanks to the
SWS, MAVIDOS and
LifeLab participants and
research teams.



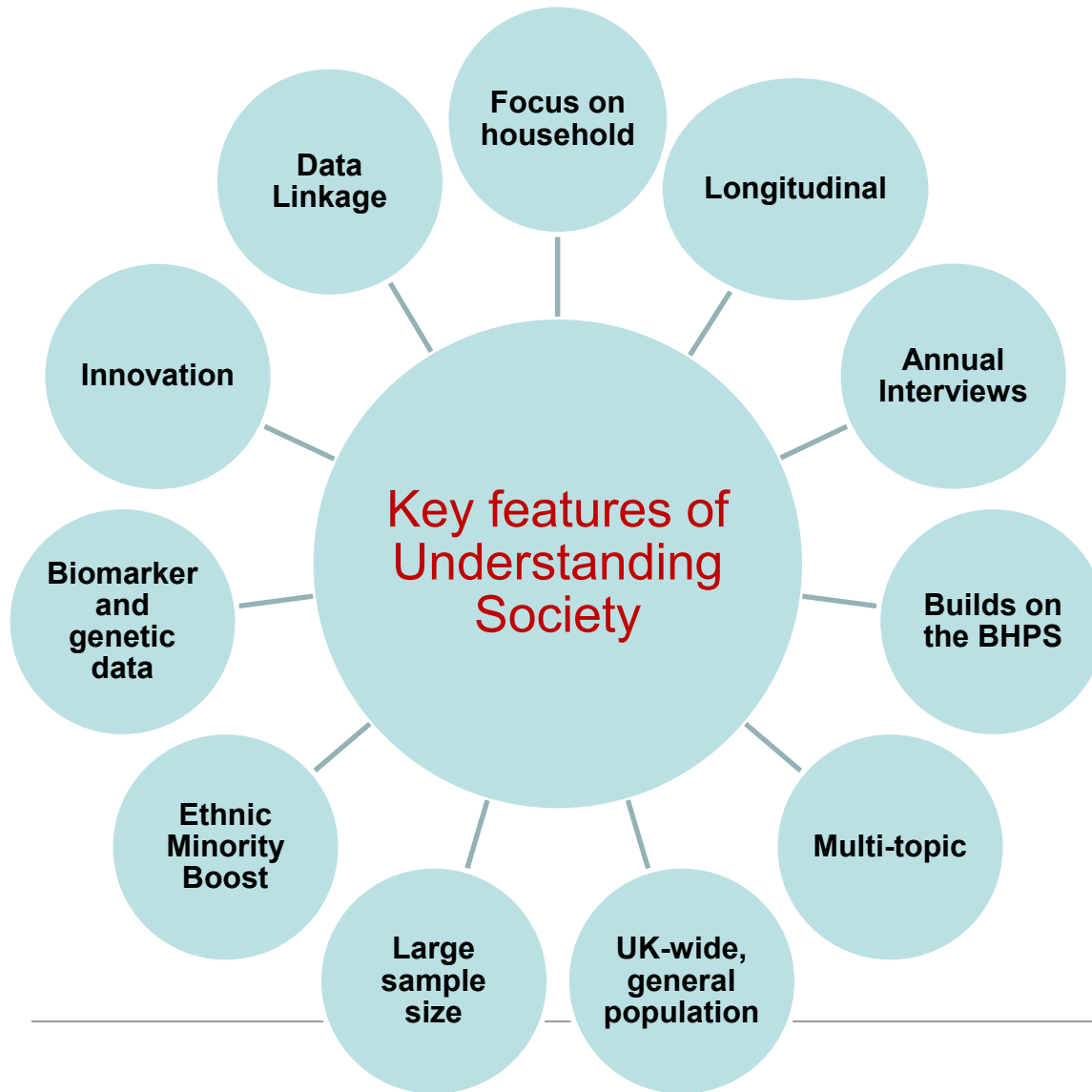


Understanding Society

The continuous cycle of engagement

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

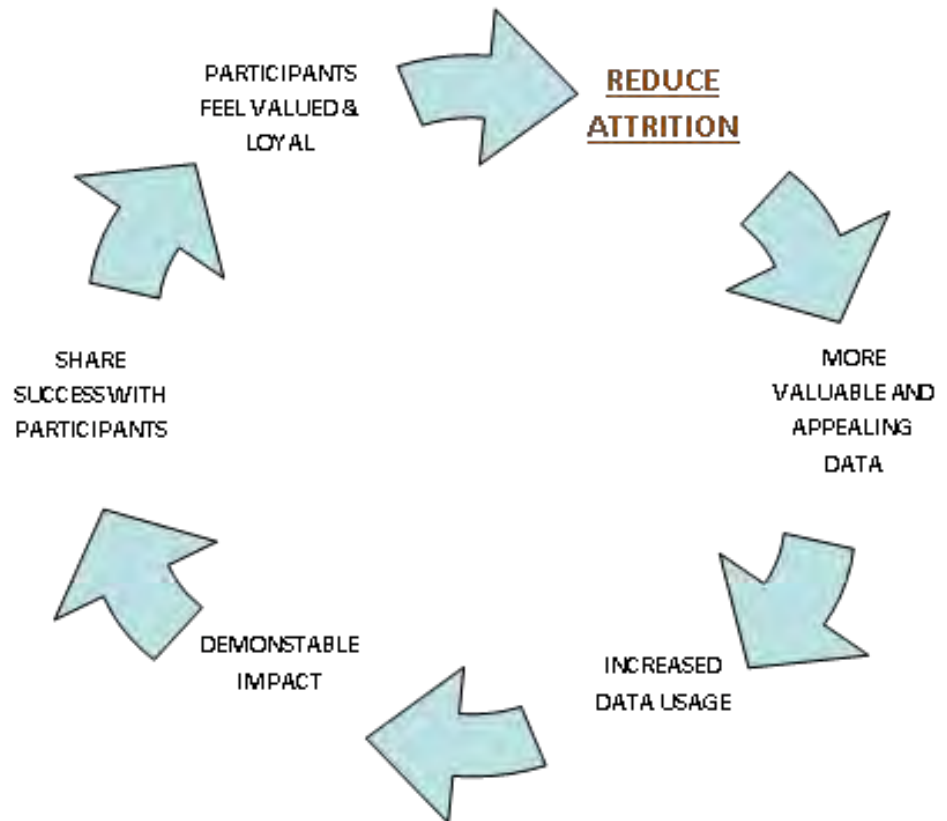


We interview
the same
people each
year to build a
picture of
change over
time in the UK

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



Aim of engagement



Motivate **sample members** to

- Respond
- Keep in contact with us

How?

- Make them feel valued by us
- They cannot be replaced
- What they are doing has an impact on society

Motivate **interviewers** to

- Make additional efforts
- Be more effective at persuading sample members to become participants

How?

- Make them feel valued
 - What they are doing has an impact on society
-

The interview is the core – but engagement is continual

- The point of highest contact is the annual interview
- But to get to that, we have to maintain a continual effort to engage
 - Before the interviewer calls
 - During the interview
 - After the interviewer leaves

Before the interviewer calls...



Sample member

- Tailored advance letter/email
 - Incentive
 - COA card
 - URL of website
 - Our contact details
 - Social media info
-



Logo – on all communications

<resp_name>
<FF_Address1_fin>
<FF_Address2_fin>
<FF_Address3_fin>
<FF_Address4_fin>
<FF_Address5_fin>
<FF_PostCode_fin>

Key messages in right column

<Date>

Dear <NAME>,

You are an important part of the Understanding Society Study and we thank you for your continuing support. By taking part, you are representing thousands of other people like you.

Your £10 voucher

We've enclosed a £10 voucher to say thank you for your help and let you know we value your contribution.

What happens next?

An interviewer will be in touch with you soon to arrange a convenient time for an interview.

Over 60,000 participants take part in this study every year but only a small number in this area and so each and every person matters to us. Your participation is crucial to the success of the study, its value to researchers and accuracy of their research findings. If we lose you, we can't replace you.

At the bottom of this letter is a change of address card. Please let us know if you change any of your contact details, either by using this card or using the "Contact us" details below. If you have any questions about the study, please don't hesitate to get in touch with Colette Lo from our Participant Helpline.

With many thanks

Michaela Benzeval

Professor Michaela Benzeval
Director, Understanding Society
Institute for Social and Economic Research
University of Essex

We need your help



We'll arrange a time



Complete the survey



Here's £10



Find out more



Contact us:

Participant helpline
(Colette):

0800 252 853

Web:

understandingsociety.ac.uk

Email:

contact@understandingsociety.ac.uk

You can also follow us on

Twitter @usociety.

Colour text to indicate key actions

Emphasise importance of person

Contact details on all communications

Back of letter – more information

Why are you important to us?

You make the survey more complete and useful. Without you, the study is less complete.

You have been specially selected to help us make sure that Understanding Society accurately represents experiences of all types of people. This way, we can see how factors such as the economy or housing affect lives across the whole of the UK.

Your participation is crucial to the success of the study, its value to researchers and accuracy of their research findings. If we lose you, we can't replace you.



What is the study about?



Understanding Society is a long-term study that helps us find out about the issues that matter to everyone. How is the recession affecting you? Are you happy with your local services and facilities? Are your health care requirements being met?

The information we collect is used by academics and researchers to inform policy debates on issues that matter to you.

Why do you interview young people?

Young people's opinions matter to us, too. If there are young people aged 10-15 in your household, we hope that they can complete their part of the survey. We'll ask them about their hobbies, friends, school life and hopes for the future. Each child that takes part will receive a £5 voucher.



Before the interviewer calls...

Sample member

- Tailored advance letter/email
 - Incentive
 - COA card
 - URL of website
 - Our contact details
 - Social media info

Interviewer

- Briefing
 - Researchers present their work
 - Examples of research, impact and media coverage
 - Use of videos of heads of ISER/agencies thanking them



During the interview: Face-to-face engagement

Interviewers *and* sample members

- Well-trained, experienced, professional interviewers
 - Information leaflets about the study (new entrants)
 - Case-studies of research
-

Case study example (double-sided card)

Understanding
Society

How is my information used?

We asked 10-15 year olds about their wellbeing



The research

The Office for National Statistics used this data to report on children's wellbeing, relating to their relationships, health and education.

What the research found

- 79% of boys and 68% of girls reported being relatively happy with their looks.
- The proportion of children in England aged 2 to 15 who were overweight, including obese, was 28% in 2012.
- 12% of children reported being frequently bullied physically, in other ways, or both.

Newspaper headlines

- **Children 'satisfied, yet fear of bullying remains'** BBC News 8th October 2014
- **Want your children to be happy? Try talking to them...** Daily Mail 8th October 2014
- **Girls twice as likely to worry about their appearance as boys** The Telegraph 8th October 2014

Why is this research important?

- This sort of research can help local authorities improve children's services including social care, education and public health.



During the interview: Face-to-face engagement

Interviewers *and* sample members

- Well-trained, experienced, professional interviewers
 - Information leaflets about the study (new entrants)
 - Case-studies of research
 - Long fieldwork period – allows greater flexibility to fit in with needs of participants
 - Thank-you leaflet
-



After the interview: We need to keep engaged

Sample members *and* interviewers

- Inter-wave mailing reports, with COA

WHAT'S CHANGED IN 25 YEARS?

How have our lives changed since the 1990s? Do we care more or less about big issues like politics, religion and education?

It has been 25 years since the British Household Panel Study (BHPS) first started collecting data in 1991. By comparing BHPS with more recent Understanding Society data, we can see how much people's attitudes and behaviour have changed.

How do you think the UK has changed in the last 25 years? Test yourself to see if your guesses match our research findings...

- 1** In 1994, young people said they wanted to get married at 21, what is the average age now?
 - A. 23 years old
 - B. 26 years old
 - C. 30 years old
- 2** In 1994, young people said they wanted to start a family at 23 years old, this has increased to...?
 - A. 24 years old
 - B. 27 years old
 - C. 35 years old
- 3** In 1991, 20% of people thought that the household cooking should be shared. How many think that now?
 - A. 25%
 - B. 35%
 - C. 45%
- 4** In 1991, 50% of people thought that pre-school children suffer if their mother works. How many think that now?
 - A. 20%
 - B. 30%
 - C. 40%

- 5** In 1991, 55% of people said both partners should contribute to the household income. This has risen to what percentage?
 - A. 60%
 - B. 70%
 - C. 80%
- 6** In 1991, 25% of UK couples shared the household cleaning. How many share the load now?
 - A. 30%
 - B. 40%
 - C. 50%
- 7** In 1991, 32% of people were satisfied with our jobs. How many of us are happy at work nowadays?
 - A. 7%
 - B. 17%
 - C. 27%
- 8** In 1991, 54% of us said we were managing our finances well, what percentage is it now?
 - A. 55%
 - B. 65%
 - C. 75%

- 9** In 1991, 51% of people said that they were interested in politics. Since then our interest has dropped - what was it in 2014?
 - A. 23%
 - B. 33%
 - C. 43%
- 10** In 1991, 62% of the UK belonged to a religious group. How many people do now?
 - A. 30%
 - B. 40%
 - C. 50%
- 11** In 1992, 13% of people lived together out of wedlock. What proportion of residents now cohabits?
 - A. 24%
 - B. 44%
 - C. 64%
- 12** In 1991, 90% of people said they like living in their neighbourhood. How many of us get on with our neighbours now?
 - A. 34%
 - B. 64%
 - C. 94%

Turn to see how well you did...





After the interview: We need to keep engaged

Sample members *and* interviewers

- Inter-wave mailing reports, with COA
 - Emailed “Participant Updates” quarterly
 - Covering recent research, media coverage, links to stories about interviewers/participants
 - Social media
 - Facebook / Twitter / Instagram...
-



Understanding
Society

UnderstandingSociety

@usociety FOLLOWS YOU

Longitudinal survey following 40,000 UK households annually. Unprecedented research opportunities. Tweets/RTs on the survey and things longitudinal.

Colchester, UK

understandingsociety.ac.uk

Joined June 2009

Tweet to

Message

TWEETS
4,324

FOLLOWING
2,165

FOLLOWERS
6,844

LIKES
372

LISTS
9

Tweets

Tweets & replies

Photos & videos



UnderstandingSociety Retweeted



UKDataService @UKDataService 7h

@usociety Interested in data on Information and Communication Technologies? Book for @UKDataService webinar bit.ly/1Ob1FcJ #ICT



UnderstandingSociety Retweeted



Omar Khan @omaromalleykhan 23h

@nspmartin @usociety thanks! Wrote short piece w/ Alita: repository.essex.ac.uk/10705/ Remittances kind of savings but perhaps less than expected?

Understanding Society constraints

- Confidentiality of sample members very important
- Cannot risk 'contamination' and disclosure of identities



After the interview: We need to keep engaged

Sample members *and* interviewers

- Inter-wave mailing reports, with COA
 - Emailed “Participant Updates” quarterly
 - Covering recent research, media coverage, links to stories about interviewers/participants
 - Social media
 - Facebook / Twitter / Instagram...
 - Web-site
-

Web-site a key tool for engagement



- Allows sample members to contact us
 - Ask questions
 - Inform us of a change of address
 - News about the study
 - Research findings and publications, including full version of “Insights”
 - Examples of “impact”
 - Stories from participants and interviewers
 - FAQs
 - Copies of past inter-wave mailings
-

Challenges



- How do we maintain sample member engagement and motivation over the coming years?
 - Dealing with increased competition for time
 - Moving to a mixed-mode approach, losing the face-to-face contact
 - How to give sample members a voice and consult with them
 - Within the constraints of privacy and confidentiality
 - Social media not (currently) suitable
 - Anonymous online forum?
 - Decreasing resources – how to maintain, or do more, for less?
-

The participant engagement team

Dr Jon Burton, Senior Research Fellow jburton@essex.ac.uk

Janine Ford Communications Manager- jlford@essex.ac.uk

Louise Miles, Content Editor lkiles@essex.ac.uk

Dr Violetta Parutis, Senior Survey Officer vparutis@essex.ac.uk

www.understandingsociety.ac.uk

Twitter: @usociety

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

Optional discussion questions

1. What stifles innovation in participant engagement in your study? What facilitates it?
2. How do we know what works? How have you evaluated new or innovative methods of engagement?
3. Can you be innovative on a shoe-string budget?

14:15 Break

Please head to your next session

Please fill in your evaluation form. Thank you.

Innovative methods of engagement 2

Please switch your mobile phones to silent



5 Ways to help your participants know
how special they really are...

Dr Robin Morton, KE Manager



THE UNIVERSITY
of EDINBURGH

Centre for Cognitive Ageing
and Cognitive Epidemiology

THE SCOTTISH COUNCIL FOR
RESEARCH IN EDUCATION

1932
*MENTAL SURVEY
TEST*

*SUITABLE FOR PUPILS OF
TEN AND ELEVEN YEARS OF AGE*

MENTAL SURVEY TEST, 8 pp., 4d.

PRELIMINARY PRACTICE TEST, 2 pp., 1d.

*INSTRUCTIONS FOR ADMINISTRATION,
8 pp., 4d.*

SPECIMEN SET - 9d., post free

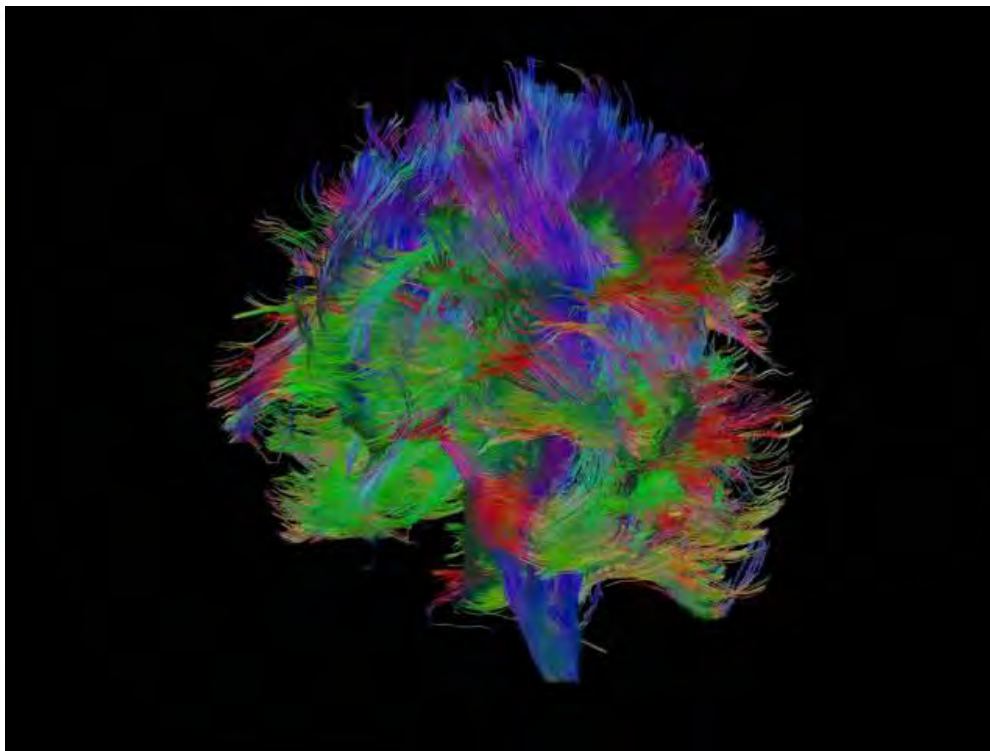
UNIVERSITY OF LONDON PRESS LTD.

WAR-TIME ADDRESS:

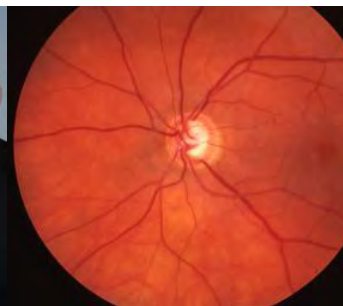
ST HUGH'S SCHOOL, BICKLEY, KENT



©2006, Illumina Inc. All rights reserved.



A
D F
H Z P
T X U D
Z A D N H
P N T U H X
U A Z N F D T
N P H T A F X U
X D P H T Z A N
F A C T O R H U P Z



Scottish Collaborative Group Food Frequency Questionnaire version 7.0

Diet questionnaire for adults
© University of Aberdeen, 2005

Thank-you for agreeing to complete this questionnaire, which should take around 20 minutes to complete.

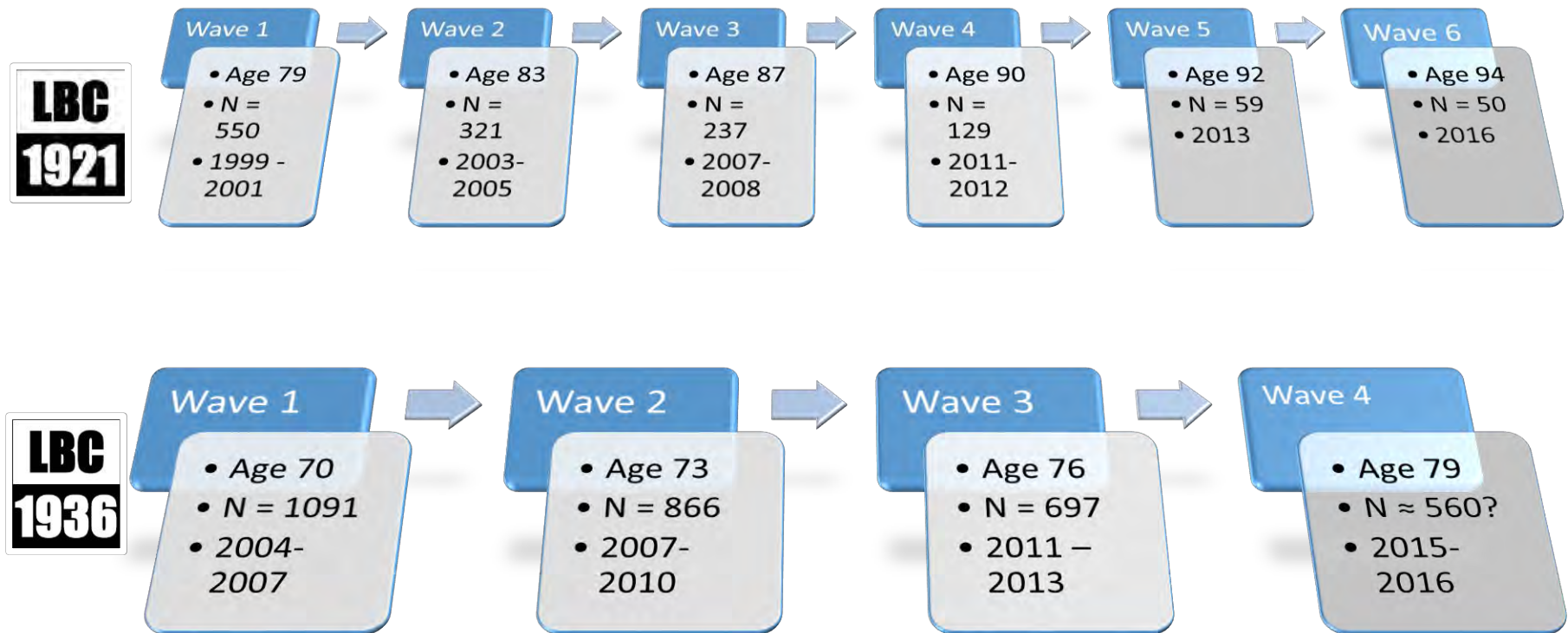
Please take a few minutes to read the instructions carefully.

We would like you to describe your typical diet over the last 2-3 months. This should include your main meals, snacks and all drinks apart from water which you have at home or away from home e.g. at work, at restaurants or cafes and with friends and family.

The questionnaire lists 175 foods and drinks, and for each one a measure is listed to help you estimate how much you usually have. The photograph below gives examples of some of these measures.

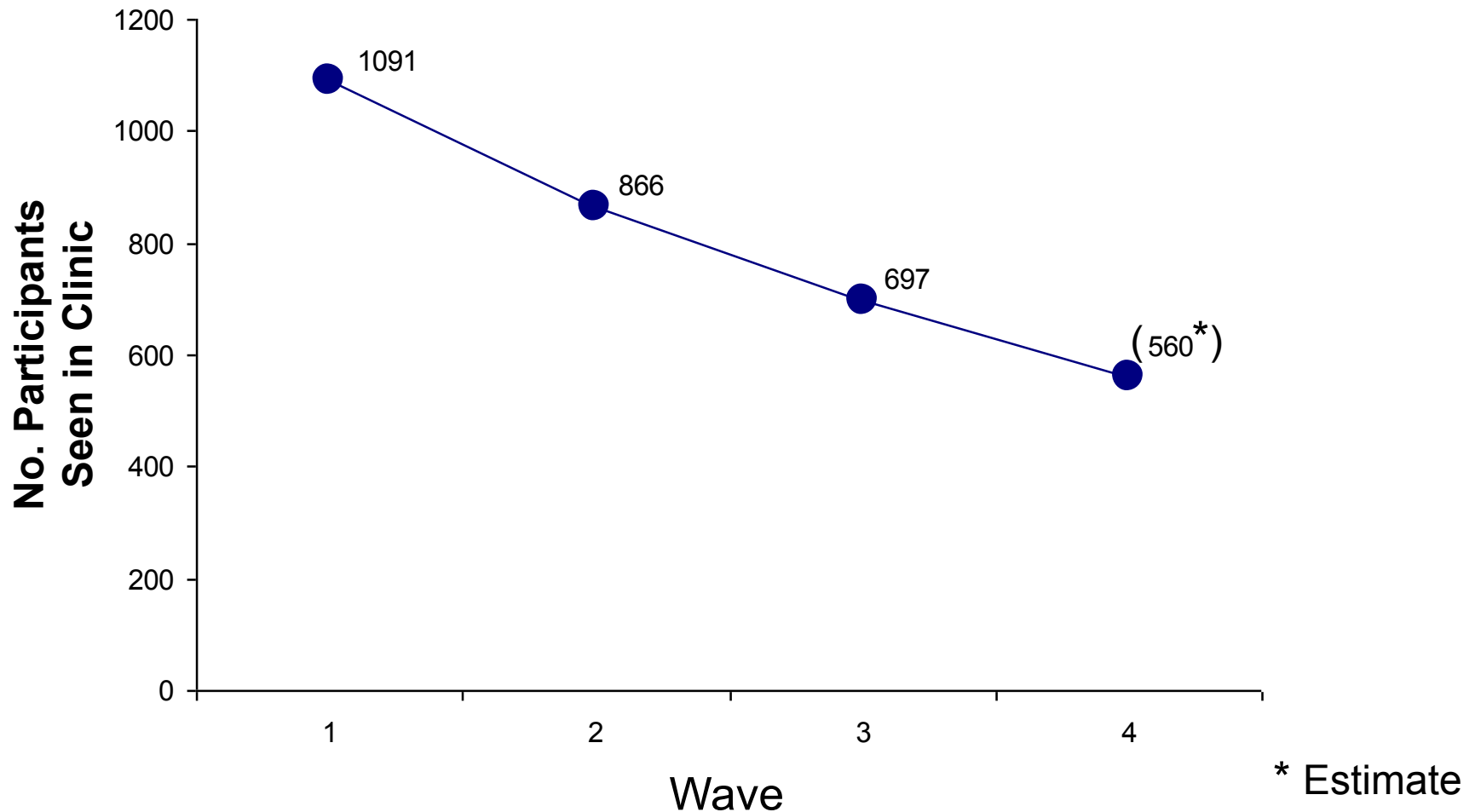
1 small bowl	1 wine glass
1 slice	1 medium glass
a thin layer (e.g. margarine)	1 tablespoon
1 teaspoon	1 ounce (28g)
1/2 plate	2 tablespoons

Participants in the Lothian Birth Cohort



Inter-wave retention rates from
c.55-80%

Participants in the Lothian Birth Cohort 1936



1. Congratulate them!



Best wishes on your 80th birthday
from the Lothian Birth Cohort 1936
study team

to be sent in December

Happy Birthday

A birthday card with a blue header and footer. The number '80' is prominently displayed in the center, filled with a collage of many small photos of people. To the left of the card is a table with an index of names and initials. To the right is a table with dates and checkboxes for card delivery.

Index No.	DOB	Card Sent
1	01/01/36	✓
2	01/01/36	✓
3	03/01/36	✓
4	04/01/36	✓
5	05/01/36	✓
6	05/01/36	✓
7	06/01/36	✓
8	07/01/36	✓
9	07/01/36	✓
10	09/01/36	✓
11	10/01/36	✓
12	10/01/36	✓
13	10/01/36	✓
14	11/01/36	✓
15	12/01/36	✓
16	12/01/36	✓
17	12/01/36	✓
18	14/01/36	✓
19	14/01/36	✓
20	14/01/36	✓
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	27/01/36	✓
	28/01/36	✓
	28/01/36	✓
	29/01/36	✓
	29/01/36	✓
	29/01/36	✓
	29/01/36	✓
	31/01/36	✓
	31/01/36	✓

LBC 1936

Best wishes on your 80th birthday
from the Lothian Birth Cohort 1936
study team

2. Ask them
out to tea



2. Ask them out to tea

whole genome for genetic
and wellbeing in old age

DISCUSSION

LBC1921 and LBC1936 have joined many
other, large-scale, genetic meta-analytical
studies to improve the power of detecting genetic
traits related to wellbeing (Table 1).

	Consortium	Sample
	*CAGES	~3,500
	CHARGE	~20,000
	COGENT	~9,000
	*CHIC	~8,000
	GERAD	~50,000
	ENIGMA & CHARGE	~16,000
	VU University Amsterdam	~17,000
	MRC-HGU Edinburgh	~10,000
	International Handedness	~59,000
	Consortium	~49,000
	Boston University	~91,000
	SpiroMeta-CHARGE	~30,000
	HomGen	~30,000
	ICBP-GWAS	~124,000
	HaemGen	~40,000
	CHARGE haemostasis	~2,700
	CHARGE haemostasis	~12,700
	CHARGE haemostasis	~18,000
	CHARGE haemostasis	~70,000
	CHARGE	~45,000
	CHARGE	~25,000

collaborations.

Sample size includes both
approximate.

analysis and other
currently



Project Partners

- CF and the companies. Developing a model study agreement based on the UK model contract for non-commercial trials
- CF and the CF Centres
- CF and Imperial College Research Agreement

Benefits of Program

- Enhancements made to the additional data collection needs
- Opportunity to reimburse Specialist contribution properly acknowledged
- Opportunity to further develop College statisticians
- Increased sustainability of UK CF Register
- Opportunity to improve the quality of R
- Leverage for improved access to BMA/Pharmal - in line with CF Trust
- UK - seen as 'leading' in programme/model - US and interested and wishing to
- Projects for research interactions

4

The Disconnected Mind

Unlocking secrets of healthy mental ageing

Principal Investigators – Ian J. Deary, John M. Starr and Joanna Wardlaw, University of Edinburgh.
Funded by Age UK

Extraordinary beginnings

On 4 June 1947, 70,000 11-year-old school children in Scotland took an intelligence test as part of the Scottish Mental Survey. Today, in their 70s, many are taking part in a unique research project on cognitive ageing.

A 21st-century health challenge

Losing thinking skills is one of the greatest fears about ageing. It's the main reason why older people lose their independence.

1 million

people in the UK over 65 have cognitive impairment and the number is growing.

We need solutions, but don't fully understand why cognitive functions decline with age, or why marked differences in these changes are seen between individuals across the life-course. Without this knowledge, we are powerless to act.



Key questions

The Disconnected Mind is examining cognitive ageing by addressing two key questions:

- What factors affect how well or poorly people's thinking skills change as they age?
- How do changes in the brain's white matter – its wiring network – contribute to age-related cognitive decline?

Centre for Cognitive Ageing and Cognitive Epidemiology

The heart of the project

To find the answers, The Disconnected Mind is studying 1,091 people who took the Scottish Mental Survey test. Known as the Lothian Birth Cohort 1936 (LBC1936), they were recruited at age 70. They re-took the 1947 test and gave exhaustive information about their life course. Every three years, they complete comprehensive testing, including:

- cognitive testing
- socio-economic and lifestyle questionnaires
- personality and mood
- medical and
- blood samples
- brain scans

Testing at 70 and 73 completely new progress gets rich

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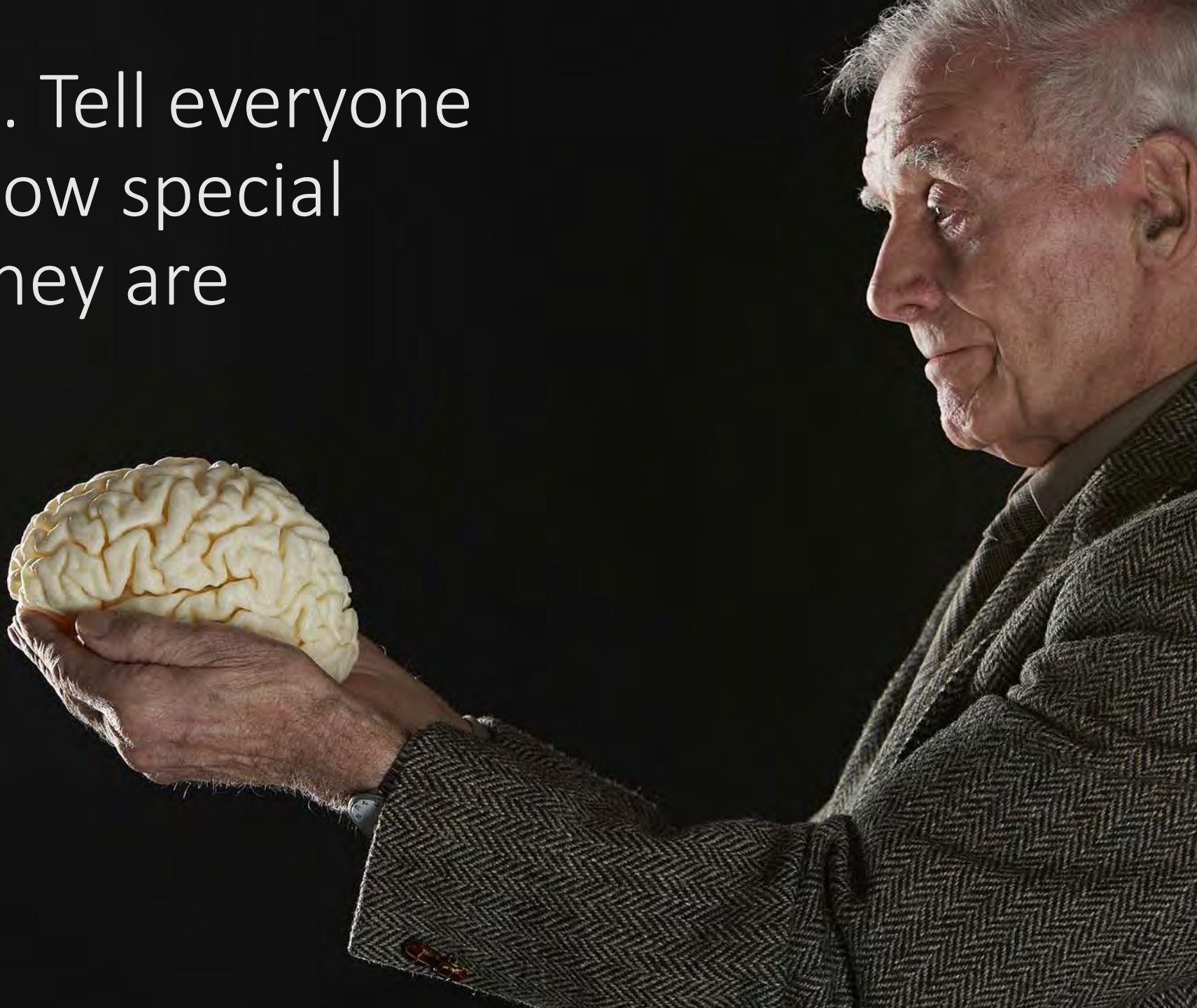


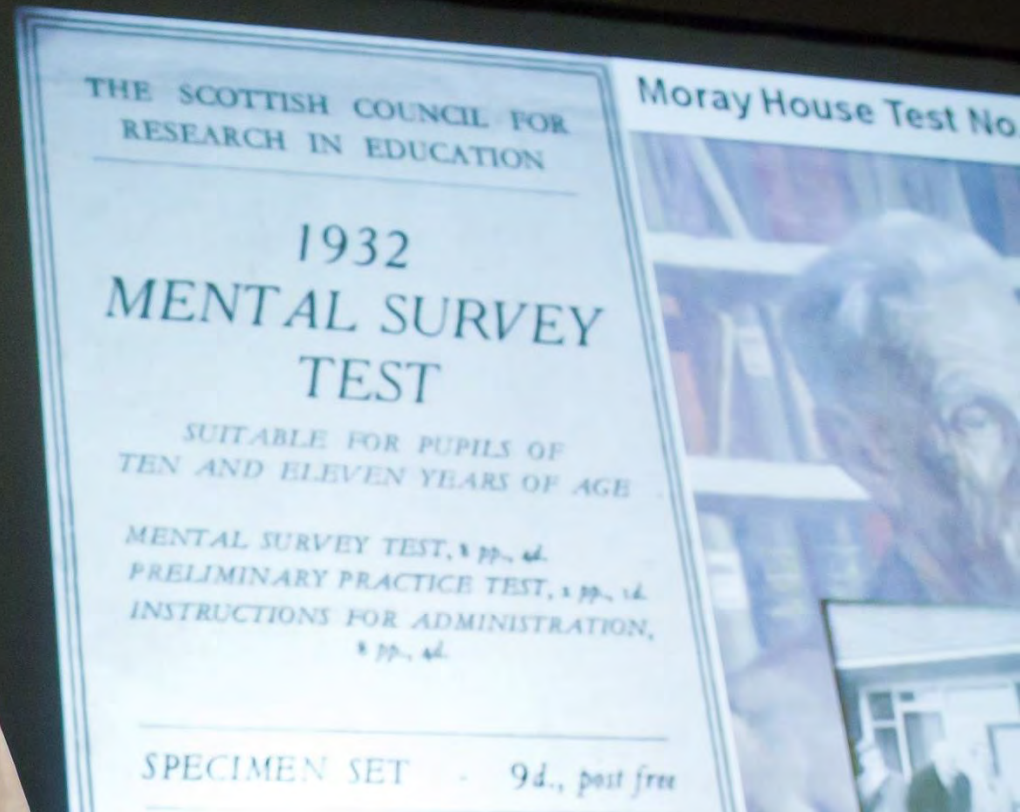
3. Work with them



3. Work with them

4. Tell everyone
how special
they are





4. Tell everyone
how special
they are



Chris van Tulleken 
@DoctorChrisVT



Following

In 1947 these people took a test at school that [@ccace](#) and [@The_MRC](#) are now using to tell us how the brain ages



RETWEETS

4

FAVORITES

6



1:00 PM - 29 Oct 2015



I was able to spend a day with Deary and his team of exceptional scientists. The enthusiasm was palpable... I can think of no more urgent and important project for every one of us.

Simon Callow, *The Times*, 15 February 2010.

5. Tell their stories



Transformations LIFE PORTRAITS

THE TIMES | Saturday April 24 2010 EST EDT

News

A healthy lifestyle tip from the 1950s: carry on dancing

A new exhibition links art, science and history through the lives of a group now in their 70s. **Mike Wade** reports

When May McBride was a young woman growing up in Glasgow in the 1950s, nothing could match an evening's dancing. Three hours a night, twice a week, she glided around St Andrew's Hall, to the sound of Ken Mackintosh and his big band. May was just 15. That happy time may have been the closest she came to a smile before McBride's fate yesterday as she attended a special showing of an art project in Edinburgh. Along with the golden memory, she was given proof that her physical fitness, a legacy of those dancehall years, was helping her to a healthier life in older age.

May and her husband Robert (they met at a dance hall) were two of the subjects of *Life Portraits*, a sequence of photographs featuring four 73-year-olds, cut together to a soundtrack of the music of Billie Holiday. Taking its cue from the latest research into cognitive ageing, the exhibition focused on the key role of physical fitness in maintaining mental well-being.

Linda Kosciwicz-Fleming, the artist behind the show, said she had been struck by the obvious truth of the adage: a healthy body makes a healthy mind. Not only were Mrs McBride and



The Times City Chambers

Art of Ageing

600 video views



5. Tell their stories



Fiona Connell

Fiona Connell 14



5. Tell their stories



LIFETIMES

Ann Lingard

THE LIVING BRAIN



5. Tell their stories



LIFETIMES

Ann Lingard



Still Life Dreaming, Edinburgh Festival Fringe

The BBC arts editor Will Gompertz explores the rash of older performers at this year's Fringe, who prove it's not just a festival for those starting out in their

"The play reveals some of the results and explores the subject of cognitive aging. Which is interesting. But the human stories are better. The tales that emerged from the individuals who had taken the test back in 1947 are now re-told"

WILL GOMPERTZ' WEEK: STILL LIFE DREAMING



Still Life Dreaming is a Wellcome Trust/Spare Tyre co-production and is part of the

>700 saw play

The Times

Friday Night
Review Show

4 * review



5 Ways to help your participants know how special they really are...

1. Congratulate them
2. Ask them out to tea
3. Work with them
4. Tell everyone how special they are
5. Tell their stories



THE UNIVERSITY
of EDINBURGH

Centre for Cognitive Ageing
and Cognitive Epidemiology

LBC

1936

Thanks to all the LBC Participants and staff



"They make you feel important. They take the time and trouble to do that... I will support it as much as I possibly can for as long as I possibly can"



how important they are.



MRC National Survey of Health and Development (NSHD): Engaging Participants

Presenter: Marcus Richards, Programme Leader, MRC Unit for Lifelong Health and Ageing at UCL

NSHD has historically high response rates due to a culture of commitment, possibly established early through a sense of civic responsibility and in response to study impact (e.g. policy changes in anaesthetic administration in childbirth; paediatric ward facilities; educational reform). This is maintained today by birthday card with lay summaries of research, study member website, study member events for 65th and 70th birthday, responses to personal enquiries, duty of care for medical and psychological problems. However, concern over possible future increased attrition as the cohort ages; in this context we are reviewing new modes of data capture such as wearables, diaries, mobile phones. We held two focus groups for the neuroscience sub-study, and are considering holding more to tackle the issues addressed above. We have also developed a management strategy for study members who wish to engage with the media about their experiences with the study.



A happy respondent is a participating respondent

Best practices in the LISS panel

Josette Janssen

January 29, 2016
Knowledge Exchange Workshop
London



CentERdata
Institute for data collection and research



LISS panel

4,600 households, comprising 7,000 persons,
aged 16+

Online panel

Probability sample drawn from address
sampling frame of Statistics Netherlands

Contacted by CATI/CAPI interview and
includes households without internet
access who are provided a simPC and/or
internet connection



Fieldwork

- Every month (30 minutes)
- Invitation by email
- Two reminder emails if not participated 1.5 weeks and 3 days before end of fieldwork period

Survey topics: health, economic situation, social relationships (family/friends), religion, work, schooling, politics, culture, mobility, leisure **time et cetera...**

Also methodological: vignettes, mixed-mode



Panel management system

Overzicht

Panel manager

Veldwerk planning

Exports

In bruikleen

Betalingen

Statistieken

Website

Nabellen

Accelerometers

TBO

Mobiliteitsonderzoek

Mobile Web Survey

Weegonderzoek

Smartphones

Uitloggen

v. 1.3.2

Josette Jansen

Recent

222601

202592

208933

204855

204627

Berichten

Tickets

E-mails

Brieven & Kaartjes

Nieuwe SIM

Naam

Bericht

van Kjod, Iklioh ritiop
(m)

Vanaf 15 januari 2016 maakt mijn dochter Ka
naar Groningen.

van Joeerk, Innezus
(v)

Geachte heer, mevrouw,

Ik woon sinds 2 weken op een nieuwe adres. M
1200-1200 1200 1200 12 Amsterdam.

Met vriendelijke groet,
(Signature van [Name])

van der Friw, Lirek (m)

Een woning kopen (ca. 5 min.)
Uw opleiding (ca. 4 min.)

[Signature]



Sleepers (dormant Rs)

LISS definition:

A panel member who did not complete a Q for a period of three months.

But... action taken after 2 months...
and 3 months (... and longer if need be)

After all: sleeping leads to attrition!

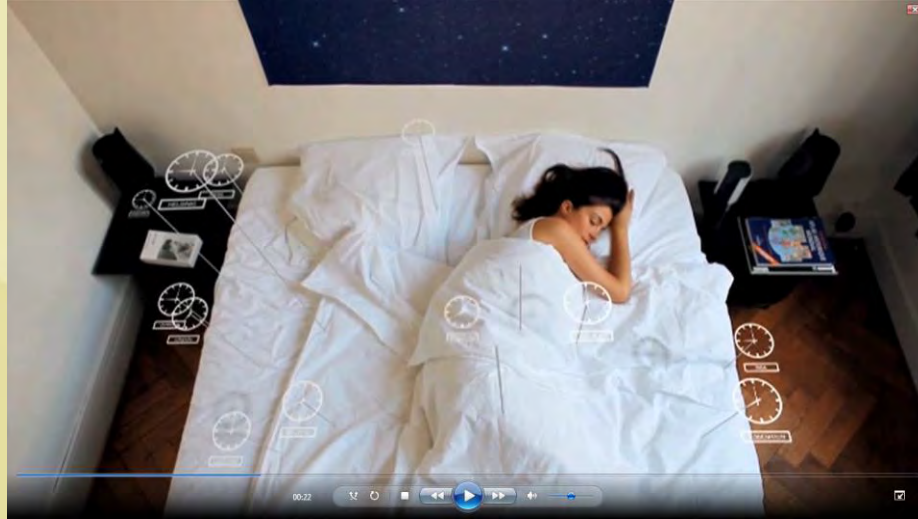


Sleepers (dormant Rs) (2)

214052	[REDACTED]	2	Zal met vragenlijst starten (06-03-2015 13:41)
221950	[REDACTED]	2	Huisgenoot gesproken (10-03-2015 17:44)
221120	[REDACTED]	2	Zal met vragenlijst starten (17-03-2015 15:56)
203217	[REDACTED]	2	Zal met vragenlijst starten (10-03-2015 17:52)
203169	[REDACTED]	2	Neemt de telefoon niet op (26-03-2015 15:43)
219579	[REDACTED]	2	Geen telefoonnummer (10-03-2015 17:54)
200328	[REDACTED]	2	Huisgenoot gesproken (17-03-2015 16:06)
216514	[REDACTED]	2	Zal met vragenlijst starten (10-03-2015 18:21)
221239	[REDACTED]	2	Zal met vragenlijst starten (10-03-2015 18:19)
221852	[REDACTED]	2	Neemt de telefoon niet op (26-03-2015 15:48)
203476	[REDACTED]	2	Wil later teruggebeld worden (10-03-2015 18:26)
222315	[REDACTED]	2	Zal met vragenlijst starten (10-03-2015 18:27)
219688	[REDACTED]	2	Neemt de telefoon niet op (26-03-2015 15:48)
208535	[REDACTED]	2	Pakket A: ADSL only Zal met vragenlijst starten (10-03-2015 18:34)
217123	[REDACTED]	2	Zal met vragenlijst starten (10-03-2015 18:35)
202055	[REDACTED]	2	Neemt de telefoon niet op (26-03-2015 16:18)
203690	[REDACTED]	2	Geen telefoonnummer (10-03-2015 18:39)
207782	[REDACTED]	2	Huisgenoot gesproken (10-03-2015 18:41)
207593	[REDACTED]	2	Geen telefoonnummer (10-03-2015 18:44)
207647	[REDACTED]	2	Zal met vragenlijst starten (10-03-2015 18:54)
207524	[REDACTED]	2	Zal met vragenlijst starten (10-03-2015 18:54)
219815	[REDACTED]	2	Huisgenoot gesproken (10-03-2015 19:00)
222383	[REDACTED]	2	Zal met vragenlijst starten (10-03-2015 19:03)
222362	[REDACTED]	2	Neemt de telefoon niet op (26-03-2015 16:20)
215981	[REDACTED]	2	Neemt de telefoon niet op (26-03-2015 16:13)
217350	[REDACTED]	2	Huisgenoot gesproken (10-03-2015 19:44)



Sleepers (dormant Rs) (3)



Short interview with 3 Qs:

- Main reason you have not participated for a while?
- Why did you decide to participate as a panel member?
- What do you think about the length of the Qs?



Screening comments/remarks

Rs comment at end of Q on all sorts of things.

Every comment is screened by panel management.

.



Work flow Time Use Research

	210259 210960 217880	214264 216760	214989 217363 218450	216019 217232 217604		207704 209733 210035 210225 210505 210587 212475 214204 214899 214989 217232 217363 217604 217880	210259 210960 211168 211534 213929 214264 216019 216760 217672 217816 218446 218450		216760			
Niet begonnen	(4x) 209709 210940 212679 218586	(3x) 211832 213244 215173	(4x) 211714 214322 214717 216442	(4x) 207734 208186 215508 216171	(3x) 211552 213415 214043	(10x) 203559 207734 210202 210772 212065 213244 213972 215173 216171 218323	(12x) 202034 204534 207606 208186 211832 212298 212679 213415 215508 216442 216527 217335	(1x) 210940	(1x) 213244	(0x)	(2x) 207734 215508	(1x) 213415
Begonnen	(5x) 210113 210880 212065 212111 213972	(2x) 217259 217451	(2x) 203559 209514	(3x) 205575 210141 217611	(10x) 204534 212261 212298 212688 212701 215220 215336 216527 218422 218841	(2x) 210940 217259	(10x) 211552 211714 212261 212688 212701 212702 214656 215220 215336 217029	(0x)	(0x)	(0x)	(0x)	(1x) 211552
Afgerond	(18x) 204734 205541 207606 208329 210266 211190 212068 212132 212535 212702 212704 213112	(23x) 203749 206930 209244 210504 210772 210781 211595 211636 212520 212967 213400 214533	(21x) 200506 201361 204347 204424 204426 204599 206017 208102 208803 209784 210202 211167	(20x) 201728 204173 204417 205406 206105 207184 207536 210224 211152 211655 213309 213943	(18x) 201345 202034 208320 208332 210336 211197 212909 213671 214209 214656 214898 215082	(57x) 200506 201361 204424 204426 204599 205406 205575 206017 206105 206930 207536 208102	(49x) 201345 201728 203749 204173 204347 205406 204734 205541 207184 208320 208332 209514	(1x) 218586	(2x) 209709 212679	(4x) 211714 214322 214717 216442	(0x)	(1x) 214043



Work flow SHARE/LISS

Selecteer welke module niet afgerond: Lijst 4: CV + module 1 ingevuld, module 2 niet af

Pnmr	Panellid	Leeftijd (±)	#	Q	M1	M2	M3	M4	M5	Actie
504964	[redacted]	76	8							Zal met vragenlijst starten (203)
603552	[redacted]	71	5							Zal met vragenlijst starten (203)
500191	[redacted]	66	6							Zal met vragenlijst starten (203)
604433	[redacted]	63	1							Zal met vragenlijst starten (203)
502740	[redacted]	63	4							Zal met vragenlijst starten (203)
601552	[redacted]	60	4							Zal met vragenlijst starten (203)
506820	[redacted]	60	5							Zal met vragenlijst starten (203)
506617	[redacted]	58	6							Zal met vragenlijst starten (203)
603686	[redacted]	57	3							Zal met vragenlijst starten (203)
506607	[redacted]	55	9							Zal met vragenlijst starten (203)



How to make/keep R happy...

- Monetary incentive of 15 euro per hour
- Newsletter with results of studies
- Participation in innovative projects such as accelerometer, smartphone (time use research/mobility), bathroom scale
- (Instruction) Videos for special occasions
- Free internet access and computer on loan (if need be)
- Website for Rs with FAQ, contact info, results, videos by researchers



Helpdesk

- ❖ Telephone: every weekday, 3 evenings, and on Saturday & Sunday
- ❖ Technical support (by phone, **Teamviewer, or at R's home**), even for non-survey/non-panel related problems
- ❖ Secondary technical support by supplier of simPC/internet
- ❖ Contact also by email and through message on Q screen



Happy?

In the LISS panel we try to make every R feel valued and heard, by our actions and by the information given to them.

Rs are not treated as just **a 'panel member number'**.

Every contact is registered and the panel management can look at every **R's** contact history. Rs do not need to explain things twice, even if someone else from panel mgt. is on the phone.



What did not work well...

- Information in folder with FAQ, how to start etc.
- Electronic greeting cards to be sent to friends and family
- Set of (paper) greeting cards



Thank you

More information about the LISS panel:
www.lissdata.nl

Email: jjanssen@uvt.nl



CentERdata
Institute for data collection and research



Optional discussion questions

1. How is innovation different for studies that cannot reveal their participants' identities (even to each other)?
2. What does innovation look like when participants enter old age?
3. What stifles innovation in participant engagement in your study? What facilitates it?

Knowledge Exchange Workshop



15.35-16.45 Engaging different audience types
(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. Thank you.



Knowledge Exchange Workshop



16:45 Closing remarks and discussion on future participant engagement training or events

17:00 End



Knowledge
Exchange
Workshop



Participant engagement in longitudinal studies

Wi-Fi: Woburn House Conference Centre
Password: igitor

Please fill in your evaluation form. Thank you.

