

Participant engagement in longitudinal studies

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Please switch your mobile phones to silent

Participant engagement in longitudinal studies

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

Please switch your mobile phones to silent. Thank you

Knowledge
Exchange
Workshop



Communicating impact and research effectively

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Knowledge Exchange Workshop



UK Biobank: Engaged - but Will the Marriage Last? Thoughts on a Lasting Relationship

Presenter: Andrew Trehearne, Head of Communications, UK Biobank

Many scientists spend considerable effort finding and recruiting the perfect partners, only to discover the research relationship sours over time. UK Biobank has been following participants for ten years and will discuss some of the things that have helped keep research and participants together, and how we might sustain that relationship as the participants age.



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Developing content for feedback mailings: 1958 & 1970 cohorts

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flickr Gabriela Marques Vieira

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Objectives of a feedback mailing

1. Update contact information
2. Identify movers
3. Inform participants of updates from the study and how the information they give us is being used
4. Make participants feel like they're taking part in something interesting and important

Key components of annual feedback mailings

- Covering letter signed by study director
- 8-page A5 booklet of findings
- Change of contact details reply slip
- Birthday card
- All materials sent by post and made available on participant-facing websites



Choosing what to cover in a feedback mailing

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What we ask ourselves when looking for potential content

- What research has been done this year using the study?
- What research have we already written news items about?
- Has any research been covered in the media?
- What examples of impact have we uncovered?

A balancing act

We select 3-4 stories for the booklet that *together* provide a balance of:

- Different themes
- Positive and negative stories
- Findings and impact
- Research based on *longitudinal* analysis, and research that makes use of the *breadth* of data available

How to write something participants want to read

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General guidelines

- Limit articles to 250-300 words
- Write in plain English, using a journalistic style
- Include a 'What we asked you' section (not methods)
- Neutralise negative findings, or phrase them in the context of 'improving lives for others'
- Add relevant sidebars and boxes to articles
- Include simple graphs or infographics

Writing in plain English

- Passive sentences
- Nominalisations
- Shorter sentences, paragraphs and documents
- Jargon
- Readability stats

Selecting the right imagery

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flickr Tommy Hemmert Olesen



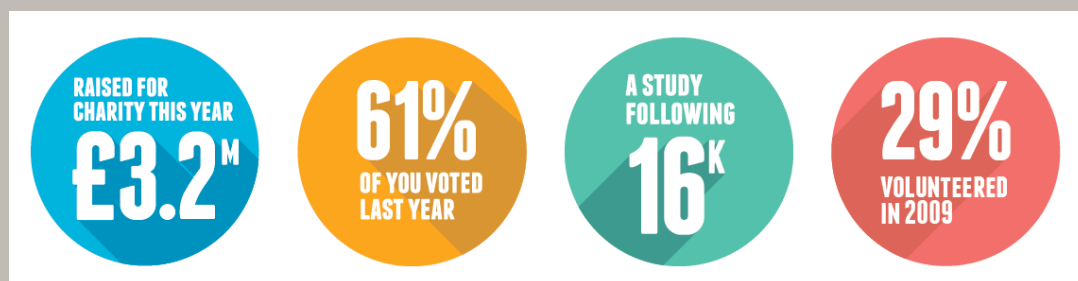
Challenges in selecting imagery

- Sourcing images is time consuming
- Stock photos largely American
- Stock photos limited for certain age groups & ethnicities
- High cheese factor
- Subjective feedback
- Non-photographic imagery is no quicker (but sometimes preferable)

Tips for choosing photographs

Do 	Don't 
<ul style="list-style-type: none">▪ Choose a photo relevant to the subject▪ Choose photos of people engaged in activity▪ Limit number of photos of people looking straight at the camera▪ Choose natural poses and smiles▪ Ensure a range of ethnicities for diverse studies▪ Ensure people are an appropriate age	<ul style="list-style-type: none">▪ Choose photos of people with model good looks▪ Choose photos that are clearly not set in the UK▪ Pick cheesy or obviously posed photos▪ Use only photos of faces

Moving away from photography



Thank you

m.rainsberry@ioe.ac.uk

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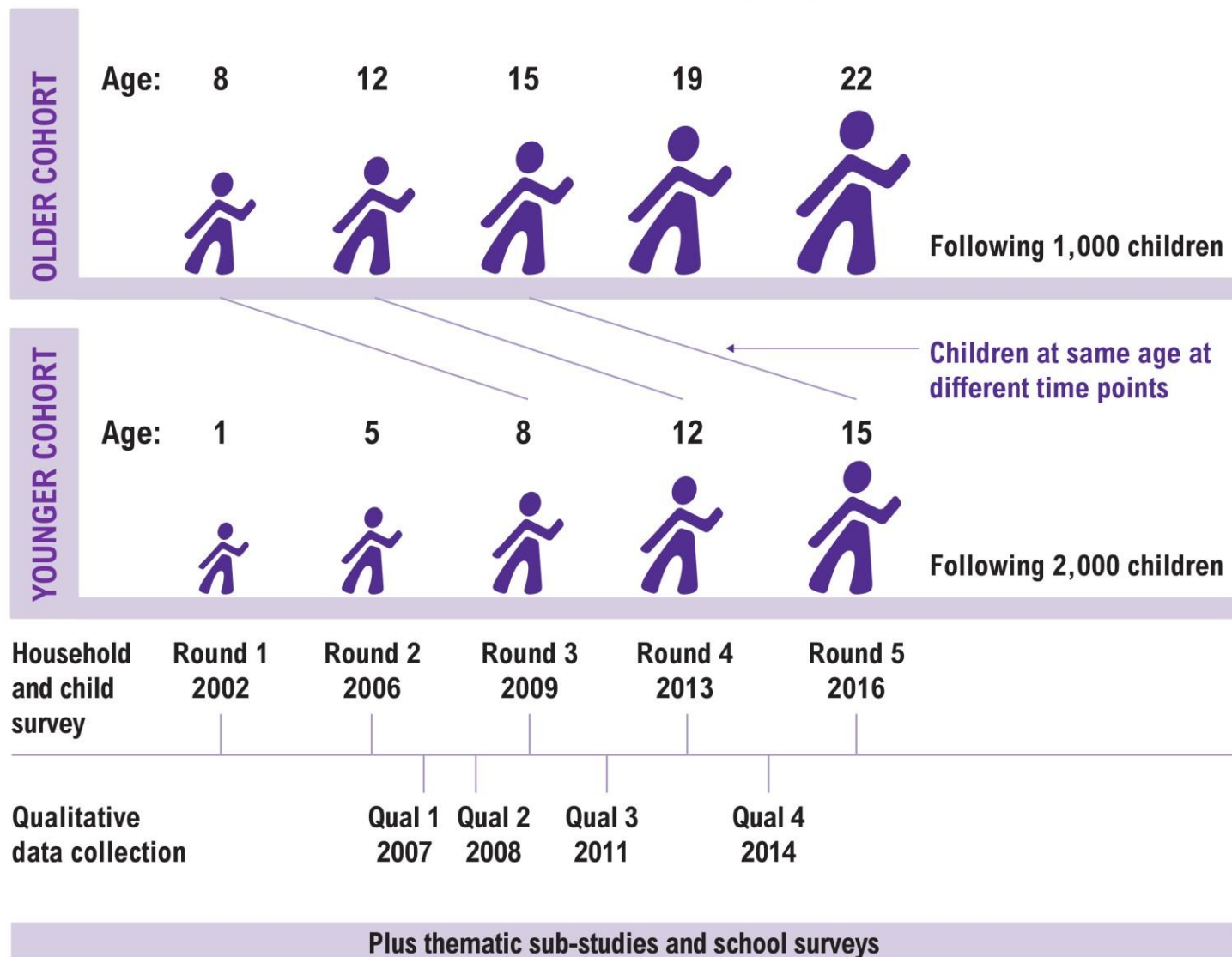
Communicating Findings and Impact to Young Lives Participants

Caroline Knowles,
Communications Manager

CLOSER Knowledge Exchange Workshop
on Participant Engagement in Longitudinal Studies,
29 Jan 2016

12,000 CHILDREN IN 4 COUNTRIES OVER 15 YEARS

Young Lives longitudinal data collected in 4 countries:
Ethiopia, India (Andhra Pradesh and Telangana), Peru, Vietnam



CONTEXT OF OUR COHORTS

- Sentinel site sampling - purposively over-sampled poor areas (40% urban / 60% rural)
- Random sampling of children within sites
- Survey = child, caregiver and community representatives
- Longitudinal qualitative research = child, peers, caregivers, community representatives (200 nested case studies)
- Logistics aren't always easy - poor infrastructure and services; low levels of education
- Attrition is low: YC 3.6%, OC 8.1%, Overall 5.0% (= careful tracking)

CONTEXT OF OUR COHORTS



Photos taken during piloting (not with Young Lives study children)

RESEARCH RECIPROCITY - RATIONALE

- Integral part of ethics approach/memorandum of understanding for fieldworkers
- Reciprocity in research implies an exchange (i.e. is not the same as giving info for informed consent)
- Important for maintaining trust and enabling respectful implementation of Young Lives
- Important for cohort maintenance (minimising attrition)
- Careful balance: how to 'compensate' and say thank you in a meaningful way - and how to feed back findings in a way that is easy to understand

RESEARCH RECIPROCITY - APPROACHES

- Led by country teams - different in each country
- Different levels - child, household, community and local/provincial officials = different objectives
 - Maintaining cohort
 - Maintaining government relationships
 - Updating on overall findings and impact
 - 'Feel-good factor'
- Includes feedback to families/communities - and 'incentives' (compensation for time spent)
- There are huge expectations (and confusion - i.e. we're not a programme intervention)
- And cultural issues about reciprocity

RESEARCH RECIPROCITY - 'ACTIVITIES'

Approaches have evolved over time - we're learning as we're going

Includes:

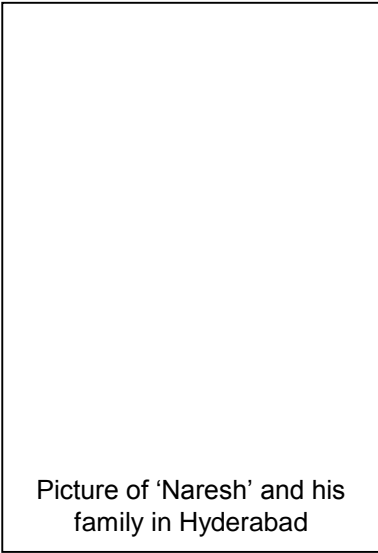
- Feedback to families, and community events
- Posters, calendars, leaflets and info sheets
- Participatory activities with children (with varying success)

Incentives - e.g.

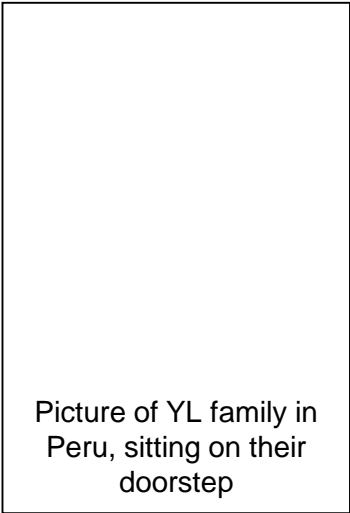
- Reimbursement for time
- Pens and books for children
- 'Gifts' for community - e.g. metal cupboard for school staff room

RESEARCH RECIPROCITY - USING PHOTOS

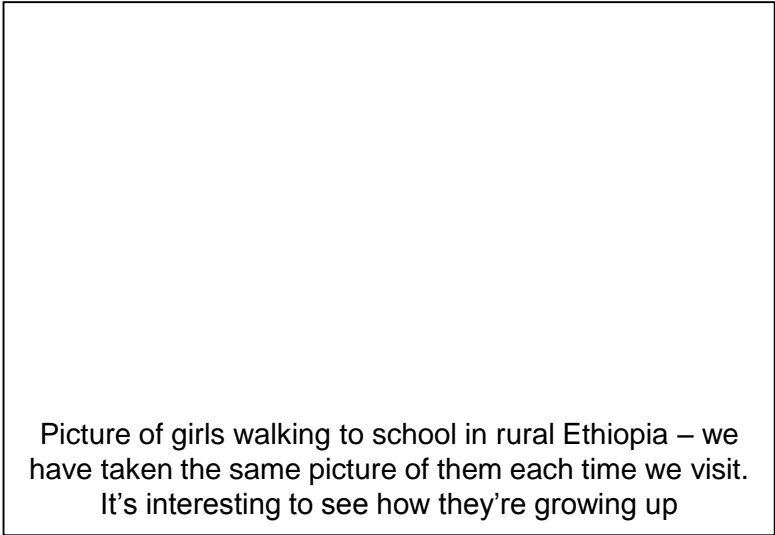
- One of the most valued things we do is to take a picture of the children and their family, in front of their home - each time we visit
- And photos of children doing their daily activities
- For 'Qual4' we made albums of these pictures



Picture of 'Naresh' and his family in Hyderabad



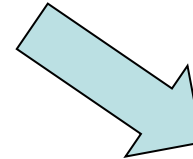
Picture of YL family in Peru, sitting on their doorstep



Picture of girls walking to school in rural Ethiopia – we have taken the same picture of them each time we visit. It's interesting to see how they're growing up

RELATIONSHIP BUILDING AND RECIPROCITY

- Participants enjoy seeing their image displayed on the screen of digital cameras
- This photograph was taken by the Young Lives team and given as a gift to the family who displayed the photograph in their home



Young Lives researcher Gina Crivello showing pictures to boys in Ethiopia



QUAL 4 PHOTO ALBUMS



One of the albums made by the Peru team



One of the Young Lives study girls in India laughing as she looks through her photo album

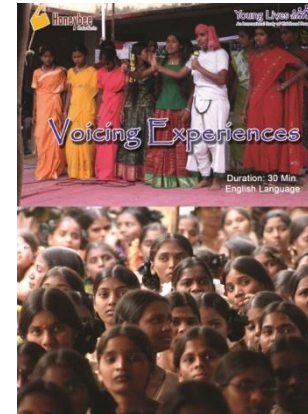
RESEARCH RECIPROCITY - ETHIOPIA

- Have tried various things... e.g. Photovoice
- Survey Round 4 we produced very simple leaflets of basic findings - in 3 languages (for 2 age groups)
- These are also highly valued by their parents



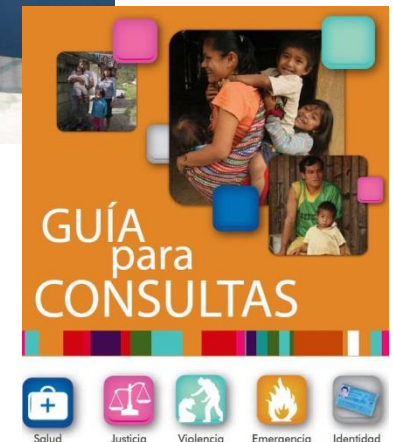
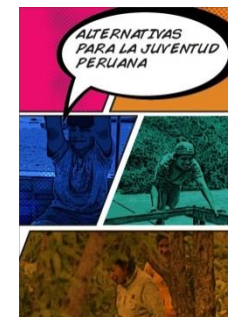
RESEARCH RECIPROCITY - INDIA

- Community meetings and posters for schools
- Participatory theatre (working through Save the Children)
- Survey Round 4 - organised very successful meetings with local officials, researchers and NGOs
- Few opportunities to engage with and reflect on implications of research for policy
- Local Collectors requested action - on nutrition/midday meal scheme and on child protection issues



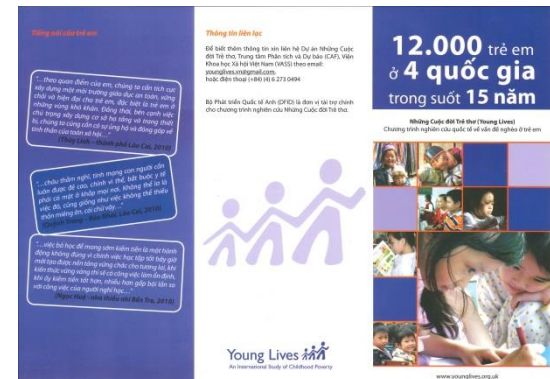
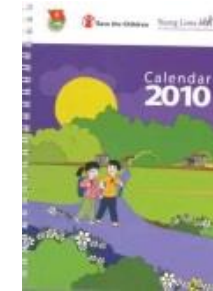
RESEARCH RECIPROCITY - PERU

- Feedback findings immediately to parents on nutrition and education - 'how well your child is doing'
- Fairs and fiestas - with activities for children and workshops for parents
- More recently: age-appropriate leaflets and guidance on accessing local services



RESEARCH RECIPROCITY - VIETNAM

- Importance of involving commune leaders/structures - e.g. Young Journalists Clubs
- Before research teams leave the community, they hold a meeting to 'report back' to parents and leaders
- They need to think carefully about how to pitch messages - so that they're meaningful and also protect confidentiality of children who have shared info
- Fieldworkers are sometimes asked to be 'ritual brothers' or 'godparents' - raises questions about boundaries and cultural issues about reciprocity

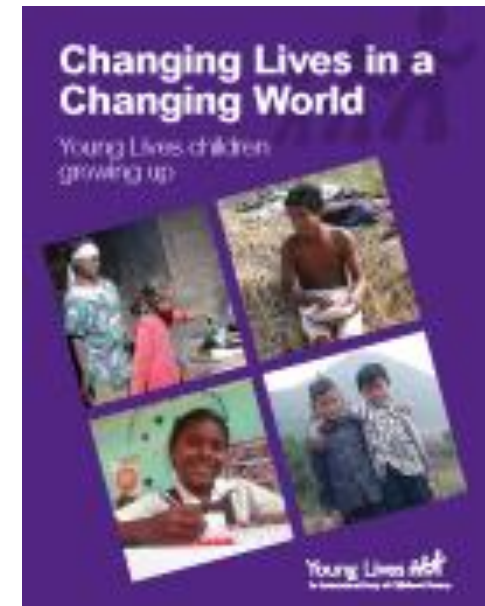


RESEARCH RECIPROCITY - PLANS FOR R5

- Currently consulting with teams - getting feedback from fieldworkers and Country Directors
- Will continue with photos
- And planning 'child-friendly version of child profiles
- And maybe do more video work?



THANK YOU!



Optional discussion questions

1. How valuable are findings in keeping your participants engaged? Are they more/less important than other methods?
2. How can we communicate how our research has made a difference (impact)?
3. Writing in plain English is a skill. Do you feel your team has sufficient training in this area?

14:15 Break

Please head to your next session

Please fill in your Evaluation forms

Involving participants in study design & management

Please switch your mobile phones to silent

Knowledge Exchange Workshop



ALSPAC: The Benefits, Challenges and Impact of Involving Participants

Presenter: Makaela Jacobs-Pearson, Participation Worker, University of Bristol

In this session, we will outline some of our current work involving participants in study management and design. We will use two case studies to discuss the benefits, challenges and impact of involving participants: 1) focus group of male participants looking at acceptability and feasibility of a male fertility sub study 2) our long-standing participant panel.





Involving young people in longitudinal research

More than glitter and post-it notes

Dr Lorna Fern

National Cancer Research Institute Teenage
and Young Adult Clinical Studies Group

Acknowledgements



The Core Consumer Group, 2008-2012

James Ashton
Katie Brooman
Tom Grew
Hannah Millington
Carol Starkey

The YAPPERS, 2013



The YAPPERS, 2014



The YAPPERS, 2015





BRIGHTLIGHT

- BRIGHTLIGHT is an NIHR funded programme grant (ref: RP-PG-1209-10013)
- Aim is to evaluate teenage and young adult cancer services in England through a series of inter-connected studies
- Central to BRIGHTLIGHT is the 2012 TYA Cancer Cohort Study
 - Evaluation of care according to patient experience



Do specialist cancer services for teenagers and young adults add value?



Challenges

- What study design?
 - Ideally randomised controlled trial, BUT
 - Services are already in place
 - Unethical to randomise to specialist care vs. not
 - Variation in services across country
- What sample?
 - Too much variability to be single centre
 - National cohort, BUT
 - How do you identify ALL young people?
 - How do you recruit ALL young people?
- What outcomes?

The Art of Age-Appropriate Care

Adolescent
Cancer care
Coping behav
Peers support
Survivors
Young adult

Background: In cancer care, teenagers and young adults with cancer merit age-appropriate specialist care. However, outcomes associated with such specialist care are not defined. Patient experience and patient-reported outcomes such as quality of life are gaining importance. Nevertheless, there is a lack of theoretical basis and patient involvement in experience surveys for young people.

Objective: We previously proposed a conceptual model of the lived experience of cancer. We aimed to refine this model adding to areas that were lacking or underexplored. The proposed conceptual framework will inform a bespoke patient experience survey for young people. **Methods:** Using participatory methods, 11 young people aged 13 to 26 years of diverse backgrounds participated in a workshop consisting of semi-structured interviews.

Results: Four themes emerged; impact of cancer on daily life, role of health professionals, support services and social aspects of living with cancer. **Conclusion:** This study has provided a conceptual framework for a longitudinal

"Your Place or Mine?" Priorities for a Specialist Teenage and Young Adult (TYA) Cancer Unit: Disparity Between Adult and Professional Perceptions

Purpose: To identify key components of a specialist breast and young adult (YA) cancer unit from the perspective of young people and health professionals. **Methods:** Interviews were conducted in a theoretical framework with participants from both target audiences. Interviews were identified in a literature search of English and non-English journals and conducted in a survey of a patient conference. Data were analysed using grounded theory and content analysis. **Results:** Young people and health professionals wanted to be consulted and to be involved in the survey. Young people felt the unit with the best facilities and staff would be the most likely to attract them. Health professionals suggested the unit should be located in the community, have a dedicated staff, and be able to offer a range of services. Young people and health professionals wanted to be consulted with and to be involved in the survey. Young people felt the unit with the best facilities and staff would be the most likely to attract them. Health professionals suggested the unit should be located in the community, have a dedicated staff, and be able to offer a range of services. **Conclusion:** The findings of this study will be used to inform the development of a specialist breast and young adult (YA) cancer unit. **Keywords:** breast cancer, young people, health professionals, consultation, survey, grounded theory, content analysis, patient conference, theoretical framework, grounded theory, content analysis, patient conference, theoretical framework.

SOME OF THE RESEARCHERS ARE FROM THE UNITED STATES (TVA HAS OFFICES IN MEMPHIS AND CHATTANOOGA) AND THE NATIONAL INSTITUTE OF ENVIRONMENTAL HEALTH AND SAFETY (NIEHS) HAS A RESEARCH CENTER IN CHATTANOOGA. THE STUDY IS BEING CONDUCTED IN PART BY THE UNIVERSITY OF TENNESSEE AT CHATTANOOGA, WHICH IS ONE OF THE PUBLIC SCHOOLS IN THE GREAT NORTHEASTERN REGION OF THE UNITED STATES. THE STUDY IS BEING CONDUCTED IN PART BY THE UNIVERSITY OF TENNESSEE AT CHATTANOOGA, WHICH IS ONE OF THE PUBLIC SCHOOLS IN THE GREAT NORTHEASTERN REGION OF THE UNITED STATES. THE STUDY IS BEING CONDUCTED IN PART BY THE UNIVERSITY OF TENNESSEE AT CHATTANOOGA, WHICH IS ONE OF THE PUBLIC SCHOOLS IN THE GREAT NORTHEASTERN REGION OF THE UNITED STATES.

Identify research area

Design the research study

Publish research results

Life changing impact of diagnosis

Provision of information

Place of care

Role of health professionals

Psychological support

Life after cancer

Analyse research results

The Essence Echo

...enter guidance

Message from the Editor

Reporter guidelines

Message from the Editor

Today's breaking news story is about a group of experienced cancer researchers who want to conduct research which is relevant and meaningful to young people who have experienced cancer. They have recruited nine young people to help them. We have decided to run a series of articles on this, during which we will interview young people who have had cancer and also the professionals who cared for them.

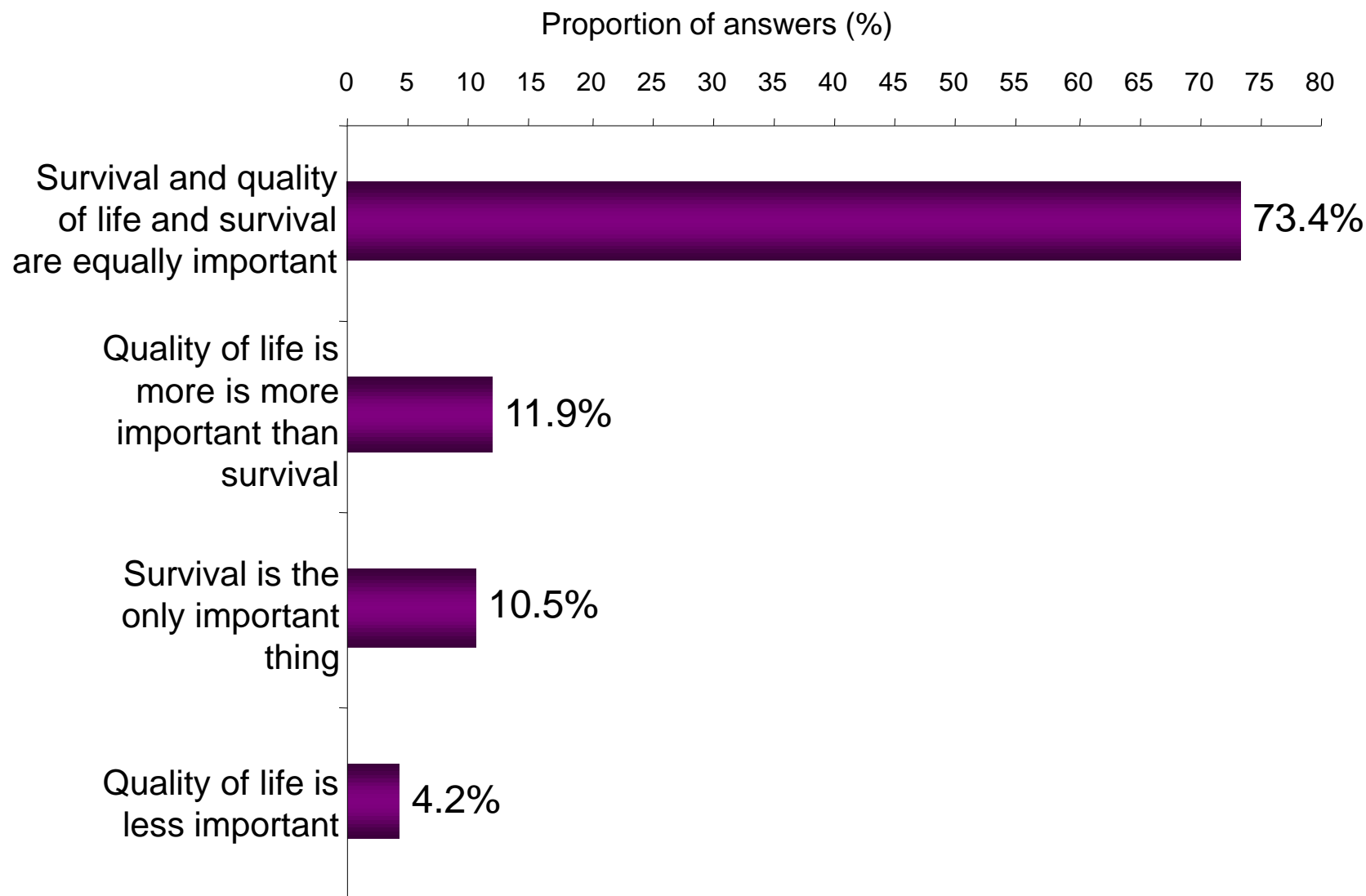
Read out what it was like to be treated for cancer when you are a young person who has experienced cancer, recovery and the things you would like to make a difference. What is the real difference between childhood and beyond cancer?

Today's breaking news is that researchers who have experienced cancer as young people who have lived with cancer when you are a young person. We have decided to run a series of interviews with young people who have had cancer and the professionals who cared for them.

What you need to find out what it was like to be treated for cancer when you are a young person and what is required to improve cancer care, recovery and the quality of life for people living with and beyond cancer.

[illegible]

Thinking back to the '*place of care project*'. How important do you think 'quality of life' is? (n=149)

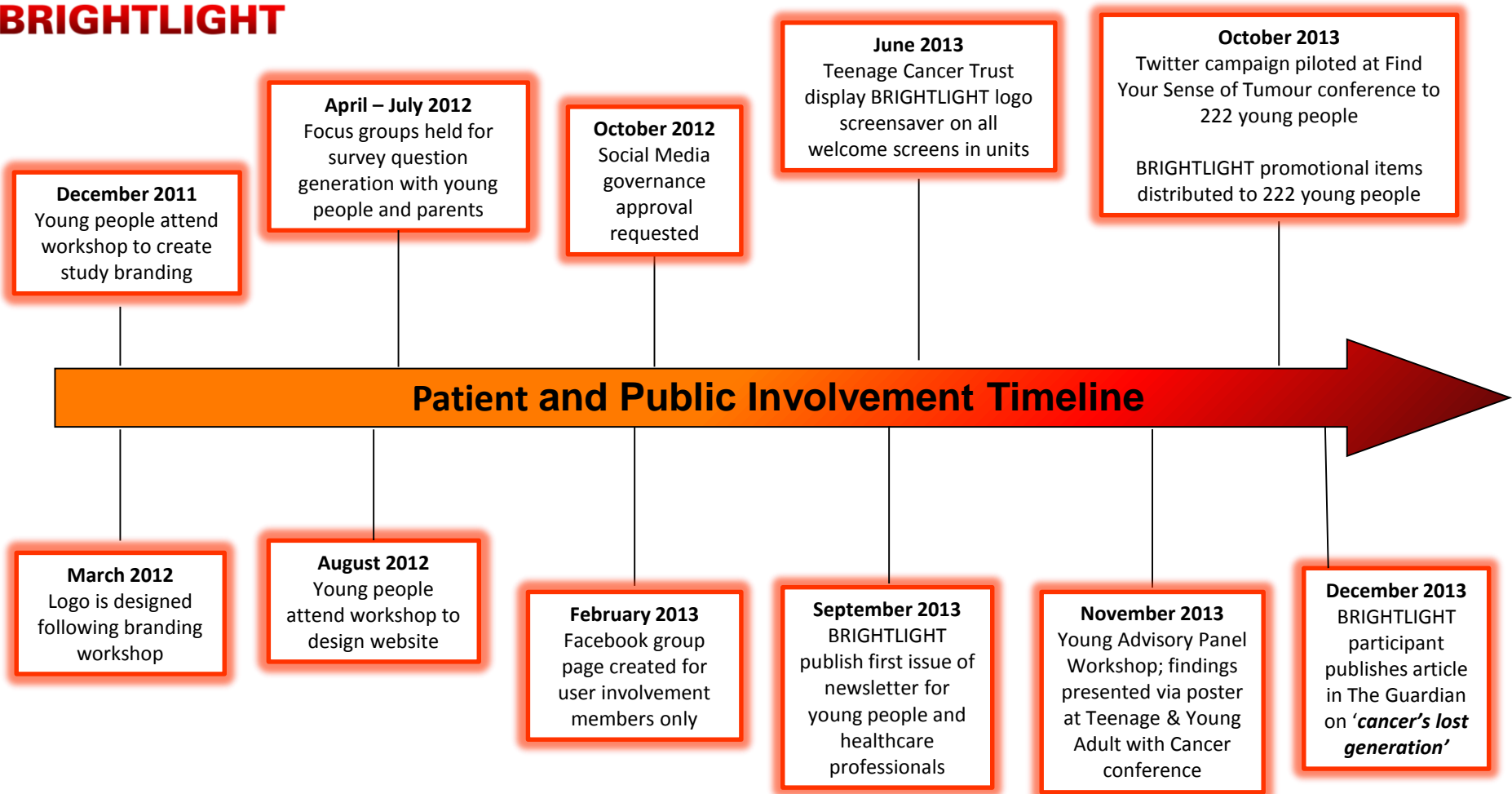


The Influence of TYA Cancer Care



BRIGHTLIGHT

Do specialist services for TYA with cancer add value?





May 2014
Young Advisory Panel and
BRIGHTLIGHT study team record
patient information videos with JTV
Cancer Support

Aug 2014
BRIGHTLIGHT publish second
issue of newsletter for young
people

March 2014
Young Advisory Panel
member takes part in
BBC5 Live Radio
interview at- Teenage
Cancer Trust Royal
Albert Hall concert

July 2014
University College London Hospital
Research Day
showcased study to members of the
public- prize won for best stall

Oct 2014
National Cancer Research
Institute feature BRIGHTLIGHT
in their newsletter distributed
at annual conference

January 2014
BRIGHTLIGHT
participant publishes
article in The
Guardian on the
'Need of support into
education and
employment'

Patient and Public Involvement Timeline

Feb 2014
BBC Breakfast News
Chief Investigator
takes part in
interview about
Teenage & Young
Adult specialist care

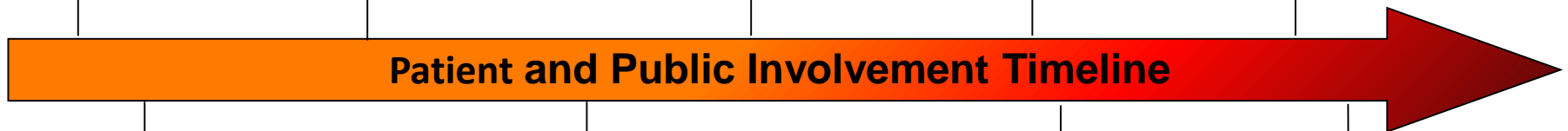
April 2014
Workshop branding paper
submitted for publication

June 2014
Young Advisory Panel Workshop;
findings presented via poster at
National Cancer Intelligence
Network conference – prize won for
best 'patient choice' poster

Sep 2014
Young Advisory Panel
workshop held to explore
methods of retaining study
participants

Results following young person
workshop fed back to
attendees

Nov 2014
Find Your Sense of
Tumour Conference:
Two Young Advisory
Panel members present
early findings and
stressed importance of
retention



January 2015
BRIGHTLIGHT is featured in the INVOLVE winter newsletter

April 2015
Poster on the challenges of PPI presented at the Royal College of Nursing International Research annual conference

June 2015
Paper reporting the YAPs work on improving access to research reported in the European Journal of Oncology Nursing

September 2015
YAP workshop to develop hypotheses to guide secondary data analysis

November 2015
Poster on recruiting to BRIGHTLIGHT presented at the National Cancer Research Institute annual conference

February 2015
YAP help develop 'fast facts' to feed results back to the Cohort

May 2015
Paper reporting the branding of BRIGHTLIGHT published in BMC Medical Research Methodology

September 2015
YAP workshop exploring body image, relationships and sexuality with Brian Lobel

December 2015
Launch of the new website developed with the YAP



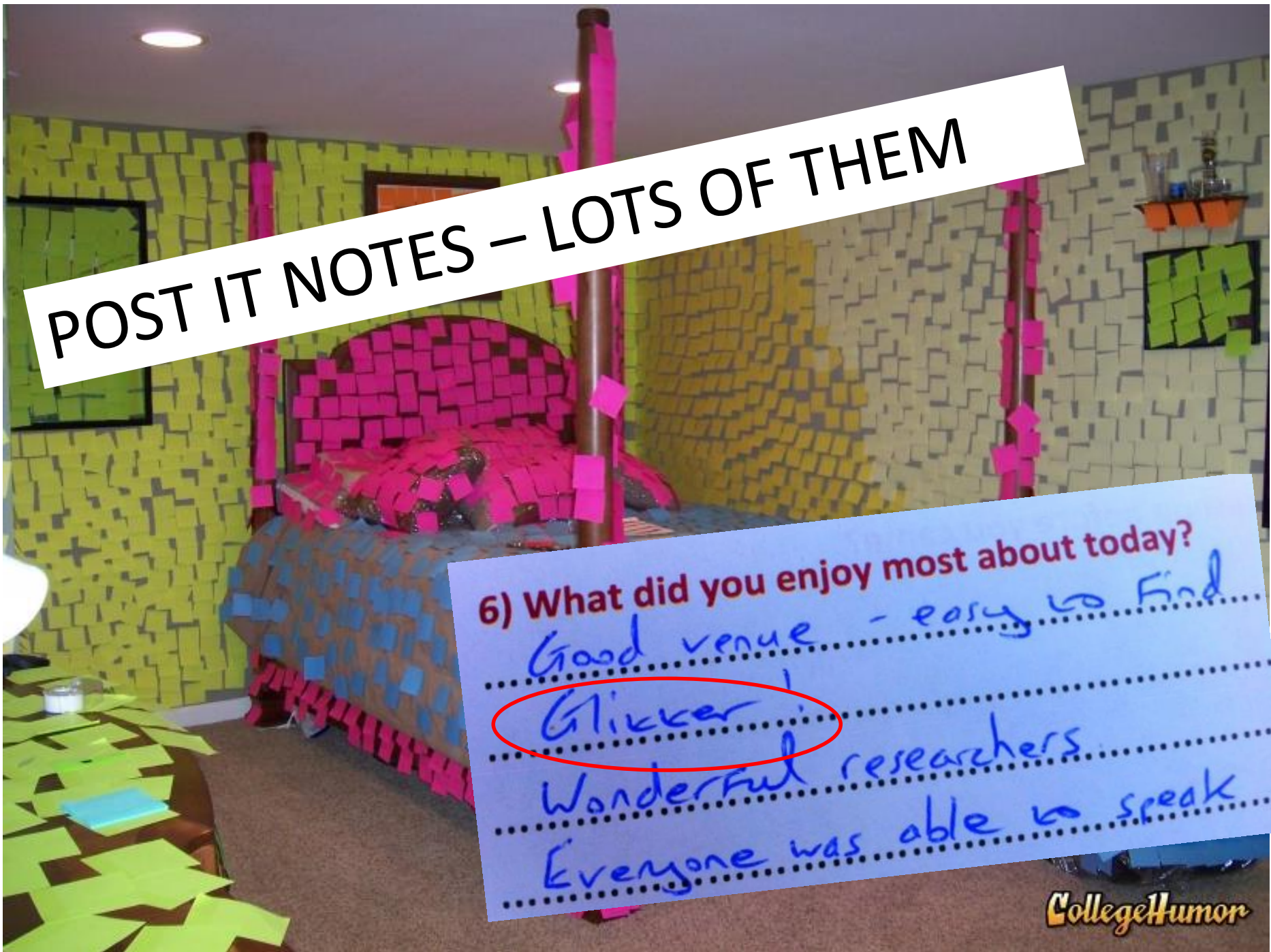
Benefits

- Higher than expected uptake
- Higher than anticipated retention
- Patient insight into recruitment processes
- Interpretation of data so results are meaningful to young people
- Integral to dissemination of data



The six P's

- Passionate people!
- Preparation
- Perseverance
- Practice
- Pounds



POST IT NOTES – LOTS OF THEM

6) What did you enjoy most about today?
Good venue - easy to find
Glicker!
Wonderful researchers
Everyone was able to speak



Thank you for your time

This presentation presents independent research funded by the National Institute for Health Research (NIHR) under its Programme Grants for Applied Research Programme (Grant Reference Number RP-PG-1209-10013). The views expressed are those of the author(s) and not necessarily those of the NHS, the NIHR or the Department of Health.

Email: brightlight@uclh.nhs.uk

Website: www.brightlightstudy.com

Phone: 0741 555 7668

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Participant perspectives on study design in the Millennium Cohort Study

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Overview

- Challenge: managing the transition from childhood to adulthood, and in particular between age 11 and age 14
 - Need to retain cohort members for the Age 14 Survey and into the future
 - Need to adapt survey processes as cohort members have a greater independent role in the participation decision
- Solution: quantitative and qualitative research with MCS cohort members and parents

Aims of the research

- To explore what has driven or prevented involvement so far
- To explore the dynamics of family decision making about participation
- To investigate experiences of taking part
- To gather views of respondent communications, and preferences for the future

What did the research involve?

- Research was carried out by the National Children's Bureau (NCB) and Ipsos MORI with cohort members and their families.
- Survey:
 - 123 cohort members
 - 159 main carers
 - 58 partners
- Depth interviews
 - 14 families
- This research was supplemented by other research with non-cohort members to address other aspects of the survey design.

Who was included?

- Cohort members were aged 12/13 at the time of the research.
- Survey: stratified random sample (intended to achieve responses from a wide range of types of families).
- Depth interviews: families chosen to be representative.

What did the research show?

Understanding of the study and importance of individual participation

- Not all families were aware of how important their continued participation was.
- They understood that it was an important study, but didn't know specifically what difference it had made
- Although families understood that the study was following their children over time, some weren't sure how long it would continue for.

Frequency and method of communications

- Cohort members felt that they wanted to receive information from the study more than once a year, although parents generally felt happy about the annual mailing.
- Cohort members and parents both liked receiving communication from the study by post.
- Cohort members in wanted to access information via the website and through social media, such as Facebook and Twitter.

The Age 14 Survey

- Cohort members felt that age 14, they would still like their parent(s) to be involved in decisions around participation.
- Some young people said they would like to receive their own post at age 14 with all of the survey information in it.
- Parents were generally happy for young people to receive their own communications at 14, but felt that as parents they should also know what their child was receiving.

What about the name – Child of the New Century?

- Cohort members were happy with the name of the study, and generally felt it described the study well.

“It makes perfect sense, it does what you want.”

“It does what it says on the tin.”

- Parents thought the name of the study was appropriate, and would continue to be so as the young people grew older.

How have the findings informed practice?

We kept the name!

- As a result of consulting with cohort members, we kept the name...
- ... but gave the study a new brand!

**CHILD OF THE
NEW CENTURY** 

A re-launch mailing

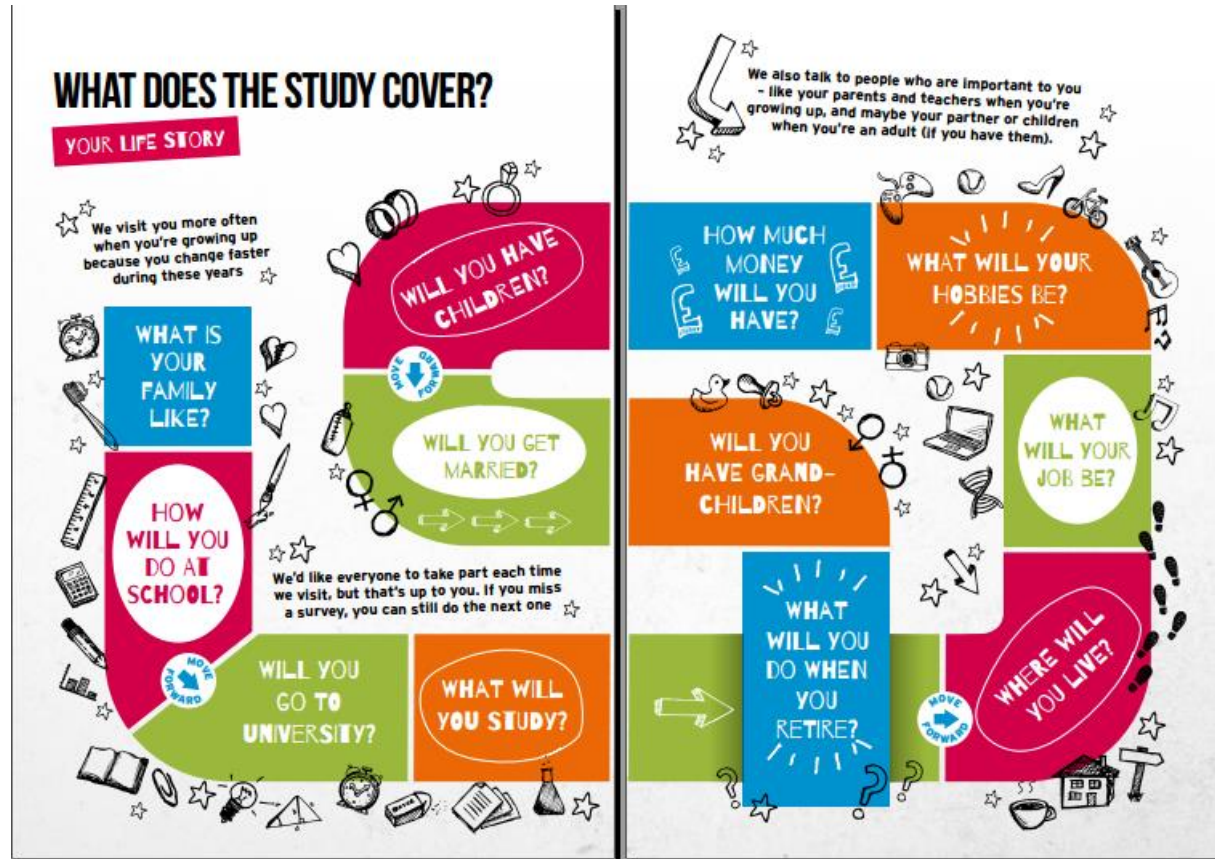
- In 2014, we sent all cohort members a 're-launch mailing' in the post. It contained:
 - A letter
 - A booklet providing information about the study, highlighting the importance of the study keeping in touch with each family, and information on how findings have been used.
 - Some small gifts – a keyring, travel-card holder and notebook and pen
- The mailing was sent to cohort members directly, rather than through their parents.

Key messages

- What MCS does: building a picture of your generation.
- Why each cohort member is important: your life story – you're irreplaceable.
- The impact of MCS - you make a difference by participating.
- MCS in the future - the nature of a longitudinal study.



‘Game of life’ from the re-launch booklet



A new website, and social media profiles

- The website was revamped, to include more information about the study, about each survey and findings.
- A Facebook page and Twitter account were set up for cohort members (and their families).

An approach to the Age 14 Survey

- Joint mailing for cohort members and parents
- Young people and parents had their own letters and leaflets, each in a separate envelope.
- Two envelopes contained in a larger envelope and jointly addressed to the cohort member and their parent(s).

Going forward

- We are continually reviewing how and when we communicate with cohort members.
- Considering utilising email to contact cohort members more regularly (with findings etc.).

Reflections on gaining participant perspectives

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Reflections on gaining participant perspectives

- Informed important design decisions at this key transitional point
- Cohort members have a unique perspective
- What are the design issues on which it is essential to seek views of participants - and what can other families usefully contribute?
- Should we seek or encourage feedback from participants more generally?

Thank you!

I.calderwood@ioe.ac.uk

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Optional discussion questions

1. How does your study involve participants in study design and management?
2. What are the main barriers to participant involvement in longitudinal studies?
3. Are participants who choose to be more involved in studies really representative of their peers?

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 forms

