



**Institute
of Gerontology**

KING'S
College
LONDON

The experience of being a participant in research

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Outline of presentation

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2. The four studies I am a participant in
3. The importance of longitudinal studies
4. Recent relevant research
5. Why do older people agree to participate?
6. Why do older people drop out?
7. Who drops out?
8. Some conclusions
9. Summing up



1. Background

The focus is on:

- My personal experience as a participant
- Relevant research undertaken both by me and by others
- Older people
- Mainly on longitudinal studies (i.e. not in one off studies)
- My role as Chair of the King's College Research Ethics
2001 – 2011 – this has coloured my views



2. The four studies I am a participant in

- The UK collaborative Trial of Ovarian Cancer Screening (randomly selected for the control group and subsequently randomly for symptoms questionnaire)
- The Office for National Statistics Household Assets Survey (randomly selected and now completed 2 interviews)



2. The four studies I am a participant in (ctd)

- A comparison of TOMsynthesis with Digital Mammography in the UK Breast Screening Programme (the TOMMY Trial) (asked to participate after mammography)
- The Whitehall II study



The Whitehall 11 study

- All non-industrial civil servants aged 35-55 in 20 departments in Central London were chosen for this study in 1985 (10,308 participated – 73%)
- The original focus was on stress at work but this has now widened to a longitudinal study of health, retirement, work, diet etc
- It examines the influence of health on circumstances at work, at home and in the wider community



The phases of the Whitehall 11 study

Started with Phase 1 with self completion questionnaire and medical screening

- Now completed phase 9 in 2009
- We have all undertaken regular health screening and some have had other tests e.g. MRI scans, ultrasound on neck for signs of cardiovascular disease.



My involvement in the Whitehall study

- Have taken part in all the stages
- Kept a diary
- Written 2 articles
- Presented the view of the participant at the launch of the publication in 2004 and at subsequent conferences
- Done a double act with the PI, Professor Sir Michael Marmot at an RSM conference on patients as partners
- Obtained a grant for a more extensive study (the Retention one – see later)



3. The importance of longitudinal studies

- To understand what is happening over the life course and the ageing process
- However the decline in participation rates is notable and this is particularly significant among older people



4. Recent relevant research

‘The retention of older people in longitudinal research studies’ A Tinker, G Mein, S Bhamra, R Ashcroft, C Seale and the late J Askham (May 2009)

- Funded by Atlantic Philanthropies for 1 year in 2008



The retention study

Rationale and research question

The research question was ‘What factors encourage older people to remain as participants, or discourages them from continuing to participate in health related longitudinal or panel studies?’



The retention study

Aims

The main aim of the research was to provide guidance to research teams planning or carrying out surveys about ways of increasing retention of older participants and reducing drop out rates



The retention study

- Literature search
- Questionnaires to other researchers of longitudinal studies
- The Whitehall II study
 - quantitative secondary analysis of data
 - qualitative secondary analysis of data (people's views)
 - collection of new data from focus groups and telephone interviews



The retention study

Literature search

- 45 studies met our criteria
- Few studies mentioned attrition in publications



The retention study

Questionnaires to researchers in 38 longitudinal studies

identified from the literature survey . 20 responded

- All were aware of attrition but very few had collected reasons for dropout. Few had published details.
- Attrition was measured in a variety of ways e.g. comparison with baseline, between waves, annually



The retention study

The Whitehall II study

- quantitative secondary analysis of data

A comparison of those who have stated that they do not wish to take any further part in the study (excluding people who withdrew for other reasons e.g. death) with those who have continued to participate



The retention study

The Whitehall II study

Ethical issues:

- All the participants had given consent to being followed up.
The process for contacting them, interviews etc were approved by the UCL research ethics committee
- The PI (AT) did not have access to the data of her fellow participants except in an anonymised manner (this was declared to the ethics committee)



The retention study

The Whitehall II study

- *qualitative secondary analysis of data* (people's views)

An analysis of the Whitehall II data base of comments from the views of participants who have dropped out of the study and their reasons for doing so



The retention study

The Whitehall II study

- *collection of new data from focus groups and telephone interviews*
- 100 invitations were given to participants attending the medical examination
- 35 responded
- 5 refused
- 30 agreed to take part in a focus group or telephone interview and 19 did take part



5. Why do older people agree to participate?

a. From the *literature*:

- Altruism – giving something back to society
- Wanting to be part of a prestigious study
- To advance knowledge
- To obtain medical results



5. Why do older people agree to participate?

b. On a *personal* level

- Being part of an increasingly important study
- Our views are asked for which helps us feel part of the study
- We get the results of medical tests
- Interesting to be 'on the other side of the fence'



5. Why do older people agree to participate?

c. From the Whitehall II study

- The most important factor was having a medical examination
- Liked the prestige of being recognised as part of an important study
- 'Giving something back'



6. Why do older people drop out (from the literature and personal)

- It is time consuming
- It is not always pleasant e.g. some of the medical tests, such as giving blood, fasting, MRI scan, memory tests



6. Why do older people drop out (from the literature and personal) (ctd)

- The results of the tests are sometimes very slow in reaching the participants
- There is not a great deal of involvement by participants in the research process



6. Why do older people drop out (from the Whitehall II study)

- Too busy/study takes up too much time
- Chronic ill health
- Really disliked the questionnaire
- Memory questions made them feel 'stupid'
- Lack of understanding for some of the tests
- Relocation or travelling



7. Who drops out?

- From the literature people who are older, have cognitive impairment, live alone, have lower socio economic status and are women, unmarried, less educated
- From the Whitehall II study multivariate analysis being older and those in lower socio economic groups were more likely to drop out



8. Some conclusions

- Clear explanations about what is going to happen are invaluable
- The assurance of confidentiality is vital
- Consent needs careful explanation
- Participants need feedback on the study so that they will want to co-operate next time
- More tests? People seem to like free tests



8. Some conclusions (ctd)

- Can questionnaires be shortened?
- The importance of thanking people
- Participants need to feel valued – and it is often the small things that make a difference
- How realistic is it for participants to be more involved – I would like more and think this would help the problems of drop out



9. Summing up

As someone who has seen both sides of the picture (see A.Tinker 'The other side of the fence', BMJ, 22.11.97. 315,1385-1386) being a participant has shown the value of research but it has also helped me to understand how participants feel.



References

Summary of the findings of the Whitehall 11 study from
www.pcs.org.uk in pdf format

Summary of the Retention study on KCL Gerontology
website