



Institute
of Gerontology

KING'S
College
LONDON

Whitehall II Study 30th Anniversary Celebration Event
25.11.15

The perspective of participants

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The views of participants

Outline of presentation

1. A personal view
2. Research evidence (from own research)



1. A personal view: background
 - A participant in the study from the start
 - Not missed any stage
 - Kept a diary of the visits
 - Spoken at a previous conference on this topic
 - Communicated with the PI



1. A personal view: background
 - Given other academic presentations
 - Written 2 articles based on this experience (BMJ 22.11.97 and Generations Review)
 - Obtained a research grant on the retention of participants in longitudinal studies (see part 2 – research evidence)



1. A personal view: Advantages – what I have got out of it
 - The health data (e.g. blood pressure, cholesterol etc.)
 - Feeling of contributing to an important study



1. A personal view: Advantages – what I have got out of it (ctd.)
 - Interest in the topic:
 - Gerontology
 - Ethics (chaired the KCL Ethics Committee for 10 years and this was a valuable personal experience)
 - Research methodology (especially longitudinal studies)
 - Funding for another research grant



1. A personal view: Disadvantages – what I have disliked
 - The health data – problems of getting blood
 - Fasting
 - The memory tests (mini mental and others). See the film 'Like Alice'
 - The Geneactiv sensor which had to be worn on the wrist for 9 days in Phase 11. This monitors rest and activity and is very irritating to the wrist and intrusive



1. A personal view: What is key
 - Caring attitudes of the staff –greatly improved
 - The little things that count such as standard of refreshments and especially being offered something after the blood tests
 - Being able to get into the place where the tests are carried out – clear instructions



2. Research evidence (from own research)



The research project: 'The retention of older people in longitudinal research studies'

- Funded by Atlantic Philanthropies
- For 9 months from 1st March 2008 (extended until 30.12.08)
- Investigators from multidisciplinary backgrounds (disciplines include social policy, sociology, philosophy, nursing, social sciences, biomedical ethics)



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The research project investigators

Anthea Tinker, KCL, Gill Mein, St George's University of London, Richard Ashcroft and Clive Seale, QMC and the late Janet Askham, KCL



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?”



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

Methods

1

- Literature review
- Questionnaires to other researchers

2

- Secondary analysis of existing data
- Quantitative and qualitative

3

- Collection of new data
- Focus groups and telephone interviews



The Whitehall study: Ethical issues

The PI is a participant in the Whitehall II study, she did not have access to the data of her fellow participants except in an anonymised manner (this was declared to the relevant ethics committees)



Summary of statistical findings

Secondary analysis of existing quantitative data

Using multivariate analysis we found attrition in the Whitehall II study is associated with:

- Having a lower occupational grade (those from a lower grade at baseline were more than twice as likely to drop out than those from other grades)
- Being older (with each additional year increasing the odds of withdrawal by a factor of 1.042)



The Whitehall study: Secondary analysis of existing data

Qualitative Analysis

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



Qualitative Analysis of existing written material

Data - results

For those who withdrew from the study and left comments, the most frequent reasons for dropping out were:

- Too busy/study takes up too much time
- Journey is too long/difficult
- Chronic ill health
- Being seen elsewhere e.g. GP
- No longer interested in study
- Retirement
- Relocation or travelling



The collection of new quantitative data

- Using the Whitehall II study participants, a small qualitative study to gather data about people's experiences of, and views about, participating in longitudinal research.
- Data was collected through 3 focus groups and telephone interviews.



Focus groups - results

The transcriptions from the focus groups were coded and themes were identified and were put into categories of:

- Good and bad experiences of the study
(medical and questionnaire)
- Motivating factors for continuing in the study
- Suggestions to make future participation easier



Focus group results – good things

- Liked having a medical examination
- Liked explanation of some of the tests
- Impressed with the offer of home visits
- Liked flexible appointment system
- Enjoyed meeting ex-colleagues
- Appreciated use of headphones for people who cannot hear



Focus group results - bad things

The memory questions in the medical examination made participants feel “stupid” “humiliated”

- Lack of understanding of reasons for doing measures
- Really disliked the questionnaire
- Found the questions repetitive, did not like having to choose between boxes to answer
- Lack of information about study



Focus group results – motivation for continuing with the study

- The most important factor was having a medical examination
- Loved the prestige of being recognised as part of the study, publicity, the media
- Giving something back
- Enjoyed talking to friends/old colleagues after medical examination – boosted confidence as all the same



Conclusions

An important well conducted study which should continue and be used by other researchers.

Personally I would welcome more involvement of the participants