The retention of older people in longitudinal research studies

Key points
Longitudinal studies are facing serious problems of drop out (attrition) and are anxious to find ways of avoiding this. There are ways of minimising drop out and encouraging participants to continue taking part. We studied reasons for attrition in the Whitehall II study, surveyed the literature on attrition and gathered information from other organisers of longitudinal studies.

Why older people drop out of longitudinal studies
• The people who are most likely to drop out are older, have cognitive impairment and poor functioning, live alone, have lower socio economic status, and are women, unmarried, less educated and engage in fewer social activities;
• There are also practical reasons, including the study being too time consuming or contact too frequent, the questionnaires being too difficult, humiliating and/or repetitive. The journey may also be too difficult or there are problems with travelling;
• There are a number of issues to do with medical tests, which are sometimes felt to be tiring and where there is a dislike of certain things such as blood samples and cognitive tests. Some people felt that they were unnecessary as they were being seen elsewhere such as by their GP.

Why older people continue to take part in such studies
• One of the main reasons for staying in a study where there was a medical examination was to get the medical results and an explanation of them;
• The offer of home visits was popular;
• The prestige of the study/publicity featured;
• Some people felt that they were ‘giving something back to society’.

What might encourage them to continue participating?
• The medical tests and feedback on medical results were popular with the suggestion that a comparison of such results with others in the study and population as a whole would be useful. Indeed there were suggestions that other medical tests e.g. PSA could be introduced;
• Information e.g. newsletters, feedback on the study, personal response to queries, meetings, study website and personal gestures e.g. birthday cards, letters from the Principal Investigator;
• Emphasising the importance of the study e.g. media coverage;
• Incentives e.g. small gifts, monetary, fridge magnets;
• Practical issues e.g. the offer of home visits/local centres, use of headphones for deaf people;
• Making the experience as pleasant as possible e.g. comfortable surroundings, helpful staff, good refreshments;
• Questionnaires shorter, on-line;
• Use close relatives as proxies;
• Ask the participants themselves.

Conclusion and recommendation
Our research would indicate that it is worthwhile other studies concentrating on those most likely to drop out such as older, single women who are not well off and not well educated.

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Published May 2009
The aims of the study
The main aim of the research was to provide guidance to research teams planning or carrying out longitudinal studies about ways of increasing the retention of participants and reducing drop out rates.

Background
The importance of longitudinal studies for understanding what is happening over the life course to older people is increasingly being recognised as of great importance. They help us to understand the ageing process. However, the decline in participation rates is notable and this is particularly significant among older people. When this occurs the drop out (attrition) can cause the sample to become unrepresentative.

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 research reported here is of a number of pieces of evidence that might help address the problem. It synthesised existing evidence, drew together the experiences of researchers involved in longitudinal studies, and collected some new evidence about the views of survey participants.

Findings
The literature review
Attrition and methods of retention of older people (defined as 55 and over) were examined in the literature review in both current and completed (within the last 20 years) health-related longitudinal studies that have been conducted in Europe, North America and Australasia which included both men and women. Longitudinal studies were defined as running for a minimum of 10 years. The detailed results can be found in Bhamra et al, 2008.

There are three main reasons for attrition. These are refusal by the participant to continue in the study and the death or loss of contact with the participant. Our literature review found one systematic review of attrition in longitudinal studies but this was limited to 12 studies. This found that attrition was associated with being older, having poor functioning and cognitive impairment, living alone and not being married.

Our review found seven major factors where there is relatively clear evidence about the relationship with attrition. The first was being older where there were consistent findings from a large number of studies. The second was being cognitively impaired. The third was having lower socio-economic status which may lead to an under-representation of a vulnerable group when policies are made. The fourth was being less well educated, the fifth not having living children, the sixth was not being retired and the seventh was becoming less socially active. Factors where there seemed to be no clear evidence about the relationship with attrition were sex, marital status, having poor health/chronic disease and home ownership.

In the literature there were a number of reasons that people gave for dropping out of longitudinal studies. These included contact being too frequent or too time consuming, and dislike of the questionnaires which were seen to be difficult, intrusive or even humiliating. The next group of reasons related to medical tests which some people found tiring and in some cases (such as giving blood samples and taking cognitive tests) unpleasant.

The literature review showed that studies used a variety of methods to reduce drop out. These included personal gestures such as sending birthday cards or letters from the Principal Investigator. Giving feedback, both individual on medical results and about the study, were also methods used. Other ways included emphasising the importance of the study through, for example, media coverage, giving incentives such as small gifts or money, and addressing practical issues such as offering to provide transport to medicals or offering home visits.

The questionnaires to other researchers on longitudinal studies
Questionnaires were sent to 38 studies identified in the literature which met our criteria. Researchers from twenty studies responded. They were asked about methods they used (but had not necessarily published) of identifying, measuring and reducing attrition. There were recruitment variations in the studies which responded. Some studies had recruited across country, within communities, or within an organisation. All were aware that attrition was an issue that needed to be addressed although very few had collected reasons for attrition and fewer had published details. There were different ways of measuring attrition including comparing with baseline, between waves and annually. Moreover participation was described differently in most studies and terms used included full, partially active, partially withdrawn, withdrawn, active, temporary refusal and dead.

Methods used by these studies to reduce attrition were similar to the ones identified in the literature. They included giving information, keeping contact which involved newsletters as well as personal responses, meetings, reminder telephone calls, giving feedback both about the study and about personal results and having a study website. Incentives included fridge magnets, pens, money and calendars. Efforts to reduce attrition also included tracing participants, completing questionnaires on-line and having local medical examinations. Using close relatives as proxies was also a method.
The Whitehall II study
In 1985 civil servants aged between 35-55 years from 20 London based departments were invited to participate in the Whitehall II study. The purpose was to investigate the social gradients in health found in the original Whitehall I study. It has particularly looked at the relationship between stress, health and occupational grade. Of those originally invited 10,308 participated giving a response rate of 73%. Participants self complete questionnaires every two years and undergo medical examinations every five years. There have been a number of other sub studies such as an MRI scan and vascular study. All the active study (both the medical and questionnaire elements), participants who had chosen to leave feedback. These comments indicate a number of reasons which were similar to those found in the literature. The most common reasons given were that the study took up too much time and they were too busy, the journey was too long and difficult, participants suffered chronic ill health, or were being seen elsewhere (such as their GP) for medical tests, they were no longer interested in the study, they had retired and/or they had moved/relocated.

Collection of new data from focus groups and telephone interviews
Using the Whitehall II study participants a small qualitative study was undertaken to gather data about people’s experiences of, and views about, participating in longitudinal studies. This project took place whilst the Phase 9 medical examinations of the study were operating. Invitations to take part in a focus group or telephone interview were given out to all participants attending the medical examinations until 100 had been distributed. Thirty five responded and five refused. Thirty agreed to take part in focus groups or telephone interviews and nineteen did take part.

The transcriptions from the focus groups were coded and themes were identified. They were put into categories of good and bad experiences of the study (both the medical and questionnaire elements), motivating factors for continuing in the study and suggestions to make future participation easier.

There were many benefits which were identified by members of the focus groups. There was support for the medical examination and the explanation about some of the tests. For example one man said:

‘Asked if I would like a repeat – it was so enjoyable I could not refuse’

However, there is an issue about whether the participants think that they are getting the complete range of health tests when this is clearly not the case.

Other things that were identified as valuable included participants being impressed with the offer of home visits, liking the flexible appointment system, enjoying meeting ex-colleagues and appreciating the use of headphones for people who have difficulty hearing.

There were a number of bad things about the study which came out of the focus groups and telephone interviews. There was a strong dislike of the memory questions given during the medical examinations which were described as making the participants feel ‘stupid’ and ‘humiliated’. There was a real dislike of the questionnaire which was 49 pages containing 110 questions (and many sub questions within that) in the last phase.

One man said:

‘Oh basically ‘cause it is such a slog, I’m racking my brains as to how to answer the questions’.

People also found that the questions were repetitive and they did not like having to choose between boxes for the answers. There was a lack of understanding about the reasons for doing some of the tests in some focus group participants and also a feeling that there was insufficient information about the study.

There were a variety of reasons why participants were motivated to continue with the study. The most
important factor was having the medical examination. Other factors included liking the prestige of the study and enjoying talking to old friends and colleagues at the examination. There was also the view that by participating they were ‘giving something back to society’.

When asked about making future participation easier, a variety of suggestions were identified. These included continuing being flexible about support of travel needs, shortening the questionnaires and asking participants what would help them to continue participating (as they had been). Some participants would also like more medical tests pertinent to ageing, such as the PSA (Prostate Specific Antigen), and hearing and eyesight tests. Some would like more information on their results including how these related to the population at large. Most wanted to continue with the comfortable surroundings and good refreshments that had been provided latterly by the study organisers. An exit interview to record reasons for withdrawal was also suggested.

**Conclusions**

Our major conclusion is that longitudinal studies are facing serious problems of drop out and investigators are anxious to find ways of avoiding this. Our contacts with investigators on studies, including the Whitehall II study, indicate their willingness to consider ways of retaining participants.

**About the project**

The research was funded by The Atlantic Philanthropies for nine months from 1st March 2008 (extended until 30.12.08). The investigators (the authors of this article) came from multidisciplinary backgrounds which included social policy, sociology, nursing, philosophy, and biomedical ethics.

The methods chosen were:

- A literature review;
- A questionnaire to other researchers on longitudinal studies;
- The Whitehall II study:
  - Quantitative secondary analysis of existing data from the Whitehall II study based on 8,471 participants;
  - Qualitative secondary analysis of existing data from the Whitehall II study based on 1,521 responses;
  - Collection of new data from focus groups and telephone interviews with Whitehall II participants

**References**


**Acknowledgements**

We acknowledge with gratitude the grant from The Atlantic Philanthropies which enabled us to undertake this research. We also thank the Whitehall II study for allowing us access to their data (in an anonymised form). We also owe a great debt of gratitude to the late Professor Janet Askham who was a co investigator but who died unexpectedly half way through the project.

**Ethical issues**

The research was scrutinised by the appropriate Research Ethics Committees. A declaration was also made that the Principal Investigator was a participant in the Whitehall II study and that she would only have access to anonymised data.