



Altruism and participation in longitudinal health research? Insights from the Whitehall II Study

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ABSTRACT

Research that follows people over a period of time (longitudinal or panel studies) is important in understanding the ageing process and changes over time in the lives of older people. Older people may choose to leave studies due to frailty, or illness and this may diminish the value of the study. However, people also drop out of studies for other reasons and understanding the motivation behind participation or drop out may prevent further loss of valuable longitudinal information and assist the continuation of longitudinal studies.

This paper examines qualitative data from interviews and focus groups in 2003/2008 with participants of the Whitehall II Study (based at UCL), and investigates reasons participants give for participating in longitudinal health studies, and recommendations they give for encouraging continued participation as they grow older.

A total of 28 participants and 14 staff were interviewed, and 17 participants took part in focus groups. Our findings are discussed in the light of the debate between of altruism and reciprocity. Rather than being wholly motivated by altruism, as research staff had assumed, participants were motivated by the benefits they perceived, particularly the information and care received during the medical examinations and the sense of loyalty and membership associated with being part of the study. Our findings support the view that far from being primarily motivated by altruism, research participation in studies such as this may also involve a degree of implicit and explicit reciprocity. However, participants disliked the obligation to complete the study questionnaires – which may have influenced the expectation of payment or reciprocation, as participation was not wholly pleasing. To try and maintain participation in longitudinal health studies this project recommended gathering information from exit interviews as a way of preventing further withdrawals and closer involvement of participants through a user panel.

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Introduction

Research that follows people over a period of time (longitudinal or panel studies) is important in understanding the ageing process and changes over time in the lives of older people as they age. If people drop out of studies – which older people are more likely to do – the value of the study diminishes because the

remaining participants are less typical of the population they represent (Chatfield, Brayne, & Matthews, 2005). Identification of factors and explanations for attrition has focussed on describing the characteristics of older participants and non-participants and reasons for dropping out (Chatfield et al., 2005; Von Strauss, Fratiglioni, Jorm, Viitanen, & Winblad, 1998). A review by Bhamra, Tinker, Mein, Ashcroft, and Askham (2008) found a wide range of factors associated with attrition from longitudinal studies of older people including, educational, cognitive, and marital status, together with participation in social activities, but with no common pattern.

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Attrition bias, the perceived benefits of participation in health research and altruism

It is common for research staff to be concerned about whether those who participate in studies are significantly different from the population they are there to represent. In longitudinal research, or 'panel studies', this problem is magnified because even if the original sample is representative, those who drop out of a study over time are likely to be different from those who remain (Patel, Doku, & Tennakoon, 2003), resulting in a selection bias. Ribisl et al. (1996) reviewed the research into attrition and found this to be dominated by studies providing statistical profiles of dropouts, in an attempt to identify groups at increased risk (for example, older participants (Chatfield et al., 2005)).

A systematic review of the literature (Chatfield et al., 2005) suggested researchers should incorporate a rationale for why people participate in panel studies as this will assist in designing appropriate incentives for participation and ensure that studies are acceptable, convenient and rewarding for participants. Felt, Bister, Strassnig, and Wagner (2009) found participation in medical research was reliant upon predetermined information behind informed consent and if people understood that biomedical research is a "public good" they were more likely to participate. For participants to continue to participate they need to feel their effort or time is being rewarded or appreciated. This is often manifested by a feeling of personal benefit or perceived benefit for another party. The benefit of participating in research is not always apparent or tangible, and because of the nature of research, the results of the research at the time of participation are frequently unknown. Scott, Valery, Boyle, and Bain (2002) suggest that balancing the benefits and risks associated with participating in research is not a straightforward matter.

To take part in health research, people must give up their time, experience, knowledge and sometimes samples, hence it is reasonable to regard participation as being equivalent to the act of gift-giving, and therefore in some cases altruistic. Gift giving has been the subject of considerable anthropological and sociological study (Mauss, 1954; Titmuss, 1970). Mauss (1954) suggested that the idea of a "pure" unreciprocated gift is not possible; he believed that all gifts are reciprocated in some way. The recipient may be those other than the participant, including family, fellow sufferers of a condition, or an identified group.

There is current debate as to whether altruism or true selflessness actually exists. Altruism is said by Badcock (1986) to involve "unconditional and reciprocal acts of giving", however, the term altruism has been developed to include a number of variations to the original concept. Opinions vary as to whether the term should be used if there is any consideration of personal benefit (McCann, Campbell, & Entwistle, 2010). Batson and Shaw (1991) argued that all acts of supposed altruism involve a degree of reciprocity whereby the giver and the receiver both benefit.

Rationale for the study

This study seeks to examine the motivation of older participants for continued participation in a longitudinal study and to identify factors which may encourage continued future participation.

Aims and objectives

Participation in health research has implications for the uptake of health information, and preventive healthcare elsewhere. The aim of this analysis was to examine why participants participate and what would maintain participation as they grow older. The Whitehall II Study provides an ideal opportunity to explore these

issues, since the study includes both a medical examination and questionnaires. In depth interviews aimed to provide insight into the experiences of participants who took part in these medical examinations and determine how they made sense of the measurements taken, what role(s) they adopted, and why they were prepared to participate. Focus groups aimed to examine what participants liked and disliked about participating in the study, and what might encourage them to continue future participation.

This study uses qualitative data from the longitudinal Whitehall II Study (Marmot & Brunner, 2005) to understand how both staff and participants of the study population comprehend their participation. This in turn has implications for understanding how to improve retention in studies of older people.

Setting

The Whitehall II Study

The Whitehall II Study (Marmot et al., 1991) based at University College London (UCL) began in 1985 to study the effect of social gradients on health. The Whitehall II Study cohort originally comprised 10,308 people all aged between 35 and 55 years recruited from the London offices of twenty civil service departments. Over the period of the study the Civil Service has been decentralised and privatised and the study has increasingly focused on the effects of stress on health and ageing, expanding the remit of the earlier Whitehall study.

Since the first medical examination in 1985, participants have completed a detailed health questionnaire every two years and have attended a medical examination every five years. These collections of data have become known as "phases". When the Whitehall II Study began participants were all working for the Civil Service and medical examinations were conducted by research staff within the participants' workplaces. In later phases uniformed research nurses have carried out the increased number of medical tests which the medical examination came to include in a dedicated examination venue known by staff and participants alike as the "the Clinic". Over the years most participants have retired and some have moved away from London. Since phase 5 participants have been offered a choice of having the medical examination in central London or in their own home.

At the medical examination a variety of procedures related to health measurements are involved including:

- Blood samples – for biochemical and genetic analyses
- Blood pressure – recorded after a 5 min rest
- General mobility – assessed using a walking test
- Lung-function – measured using a spirometer
- Anthropometry – involving weight, height and body shape measurements
- Heart function – monitored using an Electro Cardiogram (ECG) and Heart Rate Variability (HRV) equipment
- Cognitive functioning – tested through a "General Knowledge" questionnaire and a Mini-Mental State Examination (MMSE)

The time required for the medical examination has lengthened with the increasing number of measures introduced since the Whitehall II Study began. In the early phases of data collection the examinations took just under 1 h, whereas most participants now spend over 3 h at the medical examination.

For a few of the measures, such as spirometry and HRV, participants are informed that they will not receive any feedback. For the other measures, participants are given some results on the day while others are mailed to them (with a copy for their GP) within two months.

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