



‘Stress & Health Study (Whitehall II Study)’ Participant Focus Group Report

Thursday 16 May 2024 by Zoom

Seven participants from the Stress & Health Study (Whitehall II Study), the Principal Investigator (Prof. Mika Kivimaki) and the Programme Manager (Mrs Isabelle Wilson) attended this online Focus Group.

Apologies: Prof. Archana Singh-Manoux

The day was divided into four separate topics focussing on:

1. Participant experience
2. i. Ongoing research ii. Research topics of interest to participants
3. The approach for future data collection
4. How to maximise the benefits of the study for public health

This report is a summary of the findings from the conversations held during the meeting conducted by the Programme manager; one of the operational members of the study team.

The group were welcomed and thanked for their valuable contribution to the study.

1. Participant experience

Each participant introduced themselves and outlined their experience of being in the study so far, and participants described some of the reasons for their involvement. These included:

- Altruism and the benefits of being part of the study for the wider good.
- Being grateful to contribute to something that will be of benefit to others.
- They considered the study as something of interest and observed that it was a good thing to be studying to work out how stress is related to people's long-term health.
- Participants also mentioned the opportunity to understand and gain knowledge of their own health as they age and
- described the practical benefits they perceived to get from participating in the medical reviews from time to time as these were not something which was usually available on the NHS (particularly in earlier/mid-life).
- They cited experiences of being in the Whitehall study, as ‘all positive’ and ‘well organised’, with clear instructions for data collection phases, and they mentioned that ‘it is also nice to meet old colleagues’.



- One participant described experiences of the testing as 'fun'.
- Participants described having a sense of pride when results come out, and a sense of camaraderie and of pride in contributing to something that's long lasting.

There was general agreement that the participants are pleased to contribute to a study which is widely used and that they have found it enjoyable and interesting: 'being part of the study has added to life'.

Of note,

- *'Fasting appointments were less desirable', and in one of the nine clinical waves 'there was some confusion over location of the clinic when the building was located on a mezzanine.'*

2. i Ongoing research

The Principal Investigator (PI) outlined the evidence to show that the study has been very beneficial for the wider health community. This included a summary of clinical guidelines and of public health policy documents which have used Whitehall II data. These include NICE guidelines, International Labour Organisation documents, EU guidelines, WHO policy documentations and commissioned publications in the Lancet which affect clinical practice nationally and internationally.

- The Whitehall data referenced in these guidelines and policy documents have mostly focused on the prevention of chronic diseases such as diabetes, coronary heart disease, stroke, Alzheimer disease, as well as on preclinical factors like obesity or prediabetes.
- More recently, these are also focused on old age conditions, such as frailty, disability, and on socio-inequalities, which is the topic which Prof. Michael Marmot, the founder of the Whitehall II study, is championing all over the world.
- Evidence from the Whitehall II study is valuable because of the length of follow up in this cohort. This makes it unique, as there are not so many of these studies worldwide.
- Three recent examples include a NICE guideline providing recommendations for cardiovascular disease prevention, a European guideline for the management of



- diabetes, and a report by Alzheimer Association on dementia risk factors, all of which used Whitehall data.
- The current Wellcome Trust funding for the study is for research into biomarkers for dementia, to try and identify new protein targets for drug development.
- To date dementia has been a disease for which finding a disease modifying drug has been frustratingly difficult. The Whitehall study, with its long follow up, is in a unique position to identify biomarkers that precede the onset of disease and determine whether these biomarkers are likely to be the cause or consequence of the pathology.
- We are also looking into biological vs chronological age of organs which affects multimorbidity.

In the discussion that followed, a question was raised about the relative importance of reducing a particular risk factor, such as the benefit of reducing the risk of heart attack by using statins, which themselves may present adverse side effects. The PI cited National Institute for Health and Clinical Excellence highlighting the benefits of starting treatment early. The goal is not only to increase life expectancy but also to increase the number of 'healthy years', and the PI emphasised that the side effects of treatment need to be balanced with the benefit.

It was stated that it had not been realised quite how amazing this longitudinal study is and recognised that the study team has been so careful in keeping all the donated bloods, and how valuable it is that they can be reused. It was confirmed that the study has a blood sample collection of 300,000 samples.

2. ii Research topics of interest to participants

Participants were asked what research topics are important to them.

- They cited that they thought the study team were on the right track by looking into **dementia**.
- They also vocalised that **mobility** was something that they thought would be a good area to focus on, noting how various conditions such as rheumatism and arthritis, and muscular and musculoskeletal issues all affect mobility. And

'if you can't move, then you can't keep fit, once you lose mobility there's many other things you lose along with it'.



- In light of the debate of age assisted dying it was suggested that information and medical back up on how ageing is actually going, might be especially useful.
- There was a discussion about the interest in not only living longer but also *how* to improve the quality of life and shorten the period of decline in old age. The focus was on what research can contribute to the quality of life for the older population, which now makes up a larger proportion of the UK population.

Other topics that were raised included:

- Cancer, cancer risk factors or cancer identification were brought up as another area of interest.
- Frailty which is in part related to mobility.
- Loneliness.
- Getting older and how that relates to how people relate to one another and the impact on mental health as well as physical health.
- Deafness, hearing loss, or sensory deprivation and how that affects quality of life, the ability to communicate and as that affects isolation, and disease progression. The discussion also explored alternative means of communication, such as British sign language, for older adults.
- It was asked what is coming out of the research that can benefit the younger generations and a suggestion made to a move to have health MOTs in our thirties so as to be able to intervene early on.

How participants would like to be kept informed of results

Participants mentioned that it was a little hard to find the website which is under the name 'Whitehall II' whereas participants know the study as the 'Stress and health study'.

Participants requested to be kept informed by email and by hard copy and requested a mixed mode approach e.g. for the newsletter to sent by hard copy and electronically. And a request also to keep the website.



3. The approach for future data collection

The requirements for section 251 under the NHS act 2006 for ongoing data linkage were summarised. The participants were reminded that this information on the use of section 251 had previously been circulated in the 2023 Newsletter and that the information is available on the Study website under the participants area.

This was re-presented (by zoom) to the focus group to remind the group how participants have been informed of this information to date. The group was reminded that this information is also provided at each data collection phase, where participants initial their understanding of continued data linkage.

The group were asked if they were comfortable with ongoing future data linkage under section 251 in the absence of informed consent and participants were reminded that informed consent will be requested at the next data collection phase for participants who attend.

- All participants responded that they were supportive of ongoing data linkage so long as data was not shared with insurance companies or prospective employers, which the Programme manager confirmed it would not be.
- Participants reported that it was acceptable to continue to collect data in this way, as they felt that their data was being put to good use.
- There were no issues or concerns raised.
- A query was raised about how long the study would continue to link to records. The response given was that this would continue as long as there remains even a single participant in the study.

Participants were asked for their opinion on attending clinic versus home visits.

- Some participants reported attending home visits rather than clinics due to covid-19 but stated that their preference was still to be invited to attend a clinic so long as it wasn't too far away and they were able-bodied so that the study team could conduct the full set of tests (rather than the reduced number of tests it was perceived are conducted at home visits).
- Home visits were reported as being efficiently conducted but participants also reported how nice it was to bump into old colleagues when attending clinics.
- As with other appointments, it was suggested to offer home visits to those who are unable to attend in person, while expecting those who can attend the clinic to do so. There was consensus from participants on this approach.



Participants were asked for their opinion on electronic versus paper data collection.

Participants brought up the barrier to electronic data collection and issues logging into password protected portals, and potential Mac/ Microsoft issues but reported completing a lot of surveys online and that these can be a bit frustrating but considered that it might make data analysis easier. It was suggested that the study team could ask participants about their priorities at the next data collection phase.

4. How to maximise the benefits of the study for public health

- The participants noted that the study already has diagnostic benefit for participants, the results are publicised widely (Michael Marmot's work was mentioned) and information coming directly out of the study is widely available.
- A lot of the benefit seems to come when the study data is **combined** with the work of others that appears to be very valuable – it was mentioned that it is important to find a way to retain credit when the work is combined with others.
- The most benefit appears when information solidifies into practical advice about things that people can do.
An example was given of a Radio 4 programme e.g. do one thing to make your life better. This kind of information which is translated into short, 15-minute bytes which explains the background and might tell you something which will actually help, and make an impact and would have real value in terms of the public as this will be accessible to the ordinary member of the public, rather than papers which are written for researchers. That is, it is important to think how people will digest information and in increasingly short bursts, as attention spans get shorter.
- To maximise benefit to the public good it was suggested to take huge research papers and distil them into something useful such as short (not long) articles e.g. 2 punchy paragraphs and a conclusion
- Recognise the need for commercialisation.

A question was asked whether the population of Whitehall is representative of the population of the wider population in the UK and whether this would have an impact.



The Whitehall cohort is an occupational cohort which makes it a healthier group compared to the general population. The general population also includes the unemployed population so the study is not representative of the population as it is quite selective. Although the prevalence of a particular disease cannot be generalised to the UK population, we do observe similar risk factor-disease associations as seen in population-based studies. Therefore, Whitehall is very useful, especially for identifying new risk factors and protective factors. The longitudinal nature is key, offering an incredible opportunity to look back in time rather than needing to collect new prospective data and wait 20-40 years for results. For example, when examining mobility difficulties in later life we can immediately use existing data to identify protective factors in midlife and old age.

- A suggestion was made to focus on the interests of the funders by addressing prominent public health questions. It was recommended to use the Whitehall study to answer relevant questions, concentrating on current policy concerns and maintaining an outward-looking approach. Not looking at the data and asking what can we do with it? But looking instead at the concerns out there and asking how can our data and research inform and answer that in a particular way.
- Also informing other researchers work not to go in a particular direction, publishing the positive findings but also the less successful results and, this way, direct and influence other work in a more fruitful direction.
- *Making yourselves available as a long term modifier to short term studies*
- Encourage more people to pick up various lifestyle choices early, annual MOTs, modify eating habits.

Participants were asked what motivates them to continue

Participants responded that the study was '*clearly valuable*' and '*no great burden*' and '*a good experience*'. They reported that it was potentially diagnostic for the participants, and that the personal benefit from regular reviews was a motivation in itself to continue, but also that the study was helpful to a lot of research and that they would like to continue to support that, noting that this work was important and that the public good can now clearly be demonstrated. Other mentions included learning something you didn't know before, meeting ex-colleagues and that it was interesting, relaxed and enjoyable.

'It's a good thing, I would love to go on doing it'



Closing remarks, request for feedback and thanks for participation from both the Programme Manager and the Principal Investigator.