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

**Friday 15<sup>th</sup> April 2016**

**Venue: School of Slavonic and East European Studies London**

**10.00am – 3.00pm**

**Report authored and compiled independently by Andrew Risner**

Eleven participants from the Stress & Health Study (Whitehall II Study) attended this specially convened Focus Group including key members of the study team who acted as observers. The day was divided into four separate topics focussing on:

1. Participant Experience
2. Operational Procedures
3. Data Quality
4. Future Participation

This report is an independent analysis of the findings from the table conversations held during the day conducted by Andrew Risner, an independent facilitator.

## Participant Experience:

It was quite evident that everyone involved without exception was happy to be taking part.

Many stated that it was a positive experience combined with many benefits.

Mention was made several times that participants felt that they were making a contribution to the nations health and were contributing to the study in a useful way. Some even said that they felt a sense of pride by taking part.

There was a feeling that due to receiving the reports after the tests that one was being looked after.

Participants feel that they are part of a well run study and get a sense of pride in being involved.

Many mentioned that it was an honour to take part.

*'Look forward to coming and have never gone away disappointed'.*

## Benefits:

The number one benefit most often discussed was the reassurance of regular health checks. This had often highlighted hitherto undiagnosed health issues. Reports from the study had uncovered:

- Irregular heart conditions
- Diabetes
- Glaucoma
- Vitamin D deficiency
- Overactive thyroid
- Narrowing of arteries

Many felt that it was reassuring to have a health check at regular intervals.

There were instances when as a result of testing participants were able to prevent future problems e.g. making a conscious decision to lose weight.

*'Nothing is as important as discovering an important health issue resulting in intervention'.*

*'I was 13.5 stone when diagnosed with diabetes and am now 9 stone. I changed my diet as a direct result'.*

Participants felt the benefit of knowing that they were provided with confirmation that they were healthy and used the study as a tool to manage their own ongoing health.

*'It reinforced my behaviour and re-assured me that I was doing the right sorts of things'.*

*'I'm 74 and I run, dance and belong to a choir, but with this I feel that I'm being kept on and now more active than when I was 54'.*

Participants mentioned several useful benefits from the study:

- Reduction of body weight
- Benefit of keeping a food diary creating an awareness of one's food intake
- Reassurance of cognitive testing
- Thirty years of regular health checks
- Feeling of connectedness with people who are running the study
- It was also a way of keeping in touch with past colleagues

## **Operational Procedures:**

### Communication from UCL

Consensus that communication was very efficient, polite and worked well with timely reminders sent in a variety of ways with clear instructions.

There would be some benefit in having a representative from the study at clinics in order to give feedback and provide useful information on how the study was progressing.

Mention was made of the usefulness of being provided with a synopsis of Professor Marmot's publication.

### Appointment system

Consensus that plenty of notice was given with some participants able to plan cheaper travel due to early notification.

Also the fact that people liked to use their freedom travel pass which was not always possible if having to travel before 9.30am.

### Access to venues

There was a preference for venues closer to participant's homes due to re- location outside of London, e.g. travelling to London from Bristol.

However, the general consensus was that everything worked well with regard to accessing the venues.

### Contact procedure

There was consensus that there were no issues around this topic.

### Exam procedure

This was found to be welcoming, simple, relaxed, efficient and well organised.

Participants commented on being seen on time and received clear explanations on the purpose of the exams.

There were individual cases of 'white coat syndrome' where blood pressure appeared to rise on seeing a clinician. However, this was dealt with in a sympathetic manner.

### Facilities and welfare needs

Consensus that facilities were good and participants felt welcomed and kept informed with regard to timings of examinations.

*'It's a nice day out'.*

There was some concern with regard to the issue of being provided with food that might be considered 'unhealthy' e.g. sandwiches.

There was a preference for a wider choice to include fruit and nuts.

### Results letter

Participants had noticed that the results letter had got better over time with more content now being provided.

It was beneficial to have a copy to pass on to their doctor and it would be even more useful if the results letter was more detailed and personalised.

One participant would find it useful to be provided with historical results.

There was a consensus that more information on how the studies have been used would be beneficial and of interest, e.g. access to published studies and articles in particular from Professor Marmot.

Some people would find it of use to have a list of the 'negatives' included within the results letter and would like to be told that there is nothing wrong if applicable, although there was agreement that this might be too much extra work.

## Data Quality:

### Meeting the researchers

Whilst not in the original agenda as a topic for discussion, participants found this impromptu session during lunch gave participants new insights into the Stress & Health Study (Whitehall II Study).

The most talked about finding from this opportunity was to meet a wider selection of the research team and that there was a dedicated website. And even though it is mentioned in letters and publications the majority of participants were not aware.

Other useful information reported by participants:

- An appreciation of the dedication from the Stress & Health Study (Whitehall II Study) team
- A lack of awareness regarding the fact that there are comments books at the clinics
- The investigation of alcohol consumption and its effects
- No more recruitment for new participants
- The amount of data mining and efficient analysis
- Low drop-out rates from participants
- The hair study was the largest study of its kind in the world

### How do you find the existing documentation and protocols?

There were no issues around the consent form.

Some participants did not see the need for any change.

Other participants commented that one's mood, emotional and mental state could affect the answers given.

The amount of time taken to complete the questionnaire varied between half an hour, two and a half hours and a couple of days.

Sometimes it was difficult to answer questions on diet and exercise as this changed over time.

*'Running to 47 pages and 157 questions can make it quite daunting.'*

There was a consensus that it was sometimes difficult to provide accurate answers with relation particularly to diet and exercise. This was due in some part to the ability to recall quantifiable figures.

It was suggested that it might be better if one could answer the questions based on the previous two weeks.

Participants were conscientious about wishing to be as accurate as possible

Examples of this were:

- Diet where it was sometimes problematic to remember what one ate.
- Exercise e.g. walking where time taken may not necessarily relate to distance. Answers may be influenced by recent maladies, e.g. knee operation.

*'If one was feeling depressed everything on the right would be filled in compared to if you're having a great time it will be on the left'.*

Suggestion for a way to give feedback on changes in one's lifestyle would be welcomed, e.g. diet and lifestyle.

*'I walk very slowly therefore this doesn't give an accurate picture of my exercise as I walk for a long time and don't go very far'*

*'If you're going to treat all questions seriously you're asking for a massive amount of time and effort and memory. I do wonder if it is sustainable'.*

There was mention that it would be useful to have space to write one's own health history and possible riders with regard to answers for questions that may deserve further explanation with regard to how they are answered.

It was pointed out that comments could be made on the back page of the questionnaire to give observations about previous answers.

There was mention that some questions were repeated in other forms within the questionnaire.

### Testing

More information on some of the individual tests would be welcomed, e.g. neuro-psychomotor testing.

### Fasting

This can be an issue if one has a late appointment on the day of testing and some participants made earlier appointments to prevent this happening.

There was some confusion around cortisol testing; however, this did not apply to everyone.

There were no problems regarding blood testing.

Clarity regarding permissible foods allowed before fasting would be welcomed by some whilst others found all the necessary information in the documentation

## **Future Participation:**

### What motivates you to continue?

There was a general consensus that it was an honour to take part in the study and the commitment every four or five years was not a big commitment.

It was felt to be valuable now and for the future. It was considered to be worthwhile and of benefit to future generations as well as taking responsibility for one's own health.

There was a sense of 'pioneer spirit' amongst some of the participants combined with a sense of pride and had flagged up conditions that otherwise might have gone undiagnosed.

It made participants more aware of their own health as well as making a contribution to social welfare and the health of the nation.

Being involved in the study was seen as being a civil servant and wishing to make a contribution to society.

There was some concern around future funding for the project and a possible cessation of the study.

Other people, i.e. friends are interested.

### What would you like to see happen in the future?

There was consensus on getting word out about the website which up until today was not known about by the majority of participants attending.

It was felt that the website could contain further information regarding subjects such as mental health, general health and diet.

It could also provide access to videos and findings from Professor Marmot and other researchers as well as how the study feeds into other projects.

Participants would welcome more contact with researchers especially after meeting some of them at lunchtime.

More information would be welcomed on how the project feeds into other health studies.

Participants commented on wanting the project to be more widely known about outside of the study. Examples given were:

- The listening project run by the British Library and broadcast on BBC Radio 4
- Articles in The Huffington Post
- More recognition for Professor Marmot
- Audio recordings by way of a complimentary source of material



Some participants would value a reminder of how the study began and an opportunity to feedback to UCL on their experiences together with news on how the study is progressing and how it has changed over the years.

Participants would welcome future 'get-togethers' for participants and researchers, maybe once a year. This could be of benefit to both parties. This was seen as being more social than formal. The result of attending the focus group had been beneficial by way of hearing about people's experiences as well as meeting with some of the research team.

#### What would make ongoing participation easier?

Due to the fact that one is dealing with an ageing cohort of participants who now live far and wide, some thought might need to be done with regard to people now living in the provinces by negating the need to travel to London by setting up clinics that are 'nearer to home'.

Suggestion was made with regard to the possibility of home based visits.

Allowing the choice of moving to web based questionnaires instead of paper for those who are internet proficient.

There was a consensus on one table that UCL already makes it easy to participate in the study.

## Summary

### Participant experience

All participants were highly satisfied with their participation in the Stress & Health Study (Whitehall II Study).

A common theme was that it was an honour to be taking part.

The main benefit was a continual and effective way of managing one's health and early diagnosis of potential health issues.

### Operational procedures

There was a consensus of opinion that the research team at UCL made every effort to communicate clearly and efficiently with regard to operational procedures and protocols.

The possibility of having clinics nearer to home was flagged up as a future consideration.

The clinical procedure was experienced as welcoming, relaxed, efficient and well organised.

Welfare was adequately taken care of whilst there was a request for more healthy choices of food at the clinics.

### Data quality

Whilst some participants found some of the existing documentation challenging, there was an understanding on why the amount of questions was necessary.

A desire for more information regarding how the Stress & Health Study (Whitehall II Study) was being implemented was requested.

Participants were conscientious regarding the completion of the documentation and wanted their answers to be as accurate as possible.

Space to feedback on changing lifestyles within the documentation would be welcomed.

### Future participation

There was an over-arching feeling that participants were pioneers and honoured to be taking part, all of which kept them motivated to continue with the Stress & Health Study (Whitehall II Study).

Participants were keen to have further opportunities to meet the study team in a more informal setting as well as social meet ups.

Better publicity with regard to the Stress & Health Study (Whitehall II Study) website would be useful as many participants were unaware of its existence.

Participation could be made easier in the future by way of more local testing as well as web based questionnaires.

Participants were keen to have further opportunities to meet the study team in a more informal setting as well as meeting other participants.