

THE MILLION WOMEN STUDY

A national survey of women's health

The Million Women Study Participant Panel

Terms of reference

Purpose and role:

To act as a consultative forum to provide a participant perspective on the research carried out using data from the Million Women Study and to give feedback on participant facing materials.

Panel membership:

The panel consists of 6-8 Million Women Study participants and 2 members of the Million Women Study team who act as panel administrator and panel facilitator.

Initial Panel recruitment:

Million Women Study participants volunteered in response to a message sent with the paper questionnaire in 2018/19 and a message on the Million Women Study website. Panel members were selected using stratified random sampling and remaining interested participants placed on a waiting list.

Membership guidelines:

Membership is voluntary and panel members are recruited for a 2-year term. There may be the option of renewal of membership for a further 2 years. Non-attendance or non-response on 3 consecutive occasions without apologies will result in the member being withdrawn. A panel member may withdraw at any time by writing to the panel facilitator.

Panel meetings:

A panel meeting is held in Oxford once a year (or online via video conference if needed), with further contact by email on an ad hoc basis. The face to face meeting lasts 2 hours including lunch, with reasonable travel expenses reimbursed. Occasionally, individual members may be co-opted to provide specific advice, as appropriate.

Accountability:

Minutes of the meetings are kept by the panel administrator and agreed by attendees. These minutes are sent to the study Principal Investigators. Summaries of opinions may also be included in ethics and funding applications.

Confidentiality:

Documents shared at the meetings and by email should be treated as confidential by panel members. Panel members will be made aware of our [Privacy Notice](#) which describes how we collect and use personal data and will be asked for their permission for the use of any photographs, to record meetings and to store their

contact details for the purpose of participation in the participant panel. The Million Women Study is coordinated through the Nuffield Department of Population Health at the University of Oxford and data are collected and used in accordance with the Department's [Privacy Notice](#).

Fees and expenses

As a member of the public involved in work undertaken by researchers at the University of Oxford, panel members will be offered a fee when asked to undertake a specific task, such as attending a group meeting or reviewing documents. These fees are honorarium payments, a form of reward and recognition offered for the contribution that panel members make to our work. This does not mean they have a contract of employment with the University of Oxford.

We follow the NDPH public participation payment policy. The fees offered will be in line with those recommended by the National Institute for Health Research's Centre for Engagement and Dissemination. For example, currently this is £12.50 for half an hour's activity (eg reviewing a summary and providing feedback). Members are not obliged to accept a fee that is offered. If they would prefer not to receive it, or to be offered a lower amount, they can tell the panel facilitator. Please note that receiving any form of payment may affect a state benefit claim and we recommend seeking expert advice from a benefits advisor or from Jobcentre Plus.

The fee is in addition to the reimbursement of all other reasonable expenses associated with the panel member's involvement, such as the costs of travelling to a meeting.

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