

Participant Information Sheet FACETS Testimonial Survey [Ethics ID: 22757]

What is the purpose of the survey?

FACETS is a group-based fatigue management programme for people with multiple sclerosis. Findings from a consultation undertaken on behalf of the MS Society in 2017 recommended that further evaluation of the current FACETS programme should be performed to obtain more up-to-date information on the impact of the programme on people with multiple sclerosis.

Why have I been chosen?

As someone who has previously attended the FACETS programme, we are inviting you to participate in an online questionnaire.

Do I have to take part?

It's up to you to decide whether or not to complete the online survey. You can withdraw from participation at any time and without giving a reason, simply by closing the browser page. Please note once you have completed and submitted your survey responses, we are unable to remove your anonymised responses from the study.

How long will the online survey take to complete?

It will take between approximately 15-20 minutes to complete.

What are the advantages and possible disadvantages or risks of taking part?

The main disadvantage is the time it takes to complete the survey. However, you do not have to complete the survey in one go - by choosing a 'finish later' option your responses can be saved and you can return to the survey at a later time.

There will not be any immediate benefits to taking part. However, your survey responses will be of great value in helping us to find out more about the impact of the FACETS programme since its launch.

What type of information will be sought from me?

We are using an online survey to gather your views and experiences of attending the programme and whether it has made a difference to your management of fatigue.

Use of my information

Participation in this study is on the basis of consent: you do not have to complete the survey, and you can change your mind at any point before submitting the survey responses. Once we receive your survey responses, your personal information will processed in compliance with the data protection legislation. We will use your data on the basis that it is necessary for the conduct of research, which is an activity in the public interest.



Bournemouth University (BU) is a Data Controller of your information which means that we are responsible for looking after your information and using it appropriately. BU's Research Participant Privacy Notice sets out more information about how we fulfil our responsibilities as a data controller and about your rights as an individual under the data protection legislation. We ask you to read this <u>Notice</u> so that you can fully understand the basis on which we will process your information.

Once you have submitted your survey responses you may still be able to withdraw your data up to the point where the data are analysed.

Sharing and further use of your personal information

We will ask you if you are willing to be contacted by us in the future. If you answer 'yes' we'll ask you for your email address. These details will be saved separately from the information we collect from you. We'll not share your personal information with anyone outside the research team.

The information collected about you may be used in an anonymous form to support other research projects in the future and access to it in this form will not be restricted. It will not be possible for you to be identified from these data. Anonymised data will be added to BU's <u>Data Repository</u> (a central location where data is stored) and which will be publicly available.

Retention of your data

All personal data collected for the purposes of this study will be held for 5 years from the date of publication of the research.

Contact for further information

If you have any questions or would like further information, please contact

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If you have concerns about the study, please contact Dr Sarah Thomas, the project lead by email to <u>saraht@bournemouth.ac.uk</u>. If your concerns are not answered by Dr Thomas, you should contact the Deputy Dean of Research & Professional Practice at Bournemouth University, Professor Vanora Hundley by email to <u>researchgovernance@bournemouth.ac.uk</u>.