

# Information Sheet

## **1. Research title:**

The "I" in fibromyalgia - How does fibromyalgia shape the academic self?

## **2. Introduction:**

You are invited to take part in a research into fibromyalgia. In the following the key aspects of the research, its aim and the framework of participation as well as details about data storage, confidentiality and privacy are explained. Please, read this information carefully and in your own time before deciding whether you would like to take part or not.

## **3. Research aim:**

Fibromyalgia is characterised by symptoms of wide-spread pain as well as cognitive dysfunctions in addition to further secondary and related conditions such as chronic fatigue syndrome, irritable bowel syndrome, tension-type headaches and migraines amongst others.

The research explores how academics make sense of their experiences whilst dealing with fibromyalgia and its many symptoms. The research investigates how academics live with fibromyalgia, which coping strategies they employ, how these coping strategies may or not may not impact the private and public selves and how traditional fibromyalgia treatment routes are experienced. Finally, the research considers issues around disclosure/non-disclosure and stigma surrounding the invisible illness fibromyalgia.

## **4. Framework for participation:**

Your participation in this research is entirely voluntary and you may withdraw at any point without giving reasons should you wish to do so. The research question will be investigated through the use of creative methods, which will require you to participate in interviews, online discussions and creative and creating activities such as storytelling, music, photographs, drawing and painting or any other form.

The research will be carried out in four phases, and you are invited to participate in phases 2 and 3 or phases 2 and 4. To be eligible to take part in phases 2, 3 and 4, you must be an academic who has from fibromyalgia, even if you are not formally diagnosed. If you are unsure if you are eligible, but are willing to take part, provide the necessary agreement on the consent form and we will discuss your eligibility.

Phase 2: You will be asked to create two timelines and an identity box and to respond to questions about these. You will be asked to create one timeline about your academic life and one timeline in relation to your illness. These timelines can be created in written form or drawn or using photography and audiofiles.

The identity box activity means that in response to specific questions you will be asked to fill a shoebox with items. You will be asked to take photos of the boxes and explain the items you have placed in the box.

Phase 3: You will be asked to attend a virtual or face-to-face group meeting, during which you will be asked to collaborate with other research participants to create a representation of fibromyalgia. After the group meeting you will be asked to review your identity box and review your initial responses.

Phase 4: You will be asked to collect critical incidents and extracts from diaries. These materials will be the basis for interviews before you will be asked to take part in an online discussion. This will be the preparation for the final stage of the research, where you will be collaborating on a representation project, which will be produced in a virtual or face-to-face group meeting. Following the group meeting you will be asked to review your identity box and review your initial responses in a final interview.

For more information and resources about related to the research, see also: <http://www.nicole-brown.co.uk/category/071-ill-academics/>

## **5. Timeframe for the research:**

Phase 1 will run from September 2016 to December 2016, whereby you will be asked to participate in activities and tasks in your own time and in the comfort of your own home.

Phases 2 and 3 will run from January 2017 to September 2017, whereby you will be asked to participate in activities and tasks in your own time and in the comfort of your own home. You will be asked to attend one three-hour group meeting between April and July 2017.

Phases 2 and 4 will run from January 2017 to July 2018. You will be asked to participate in activities and tasks in your own time and in the comfort of your own home. You will be asked for an interview between September and November 2017, a three-hour group meeting in May 2018 and a final interview between May and July 2018.

## **6. Confidentiality, privacy and sensitive data:**

Due to the nature of the research into fibromyalgia, the data collection will include some sensitive information and data relating to your health issues. Primarily, the data will revolve around fibromyalgia, however, due to the nature of the illness and the typical experience of fibromyalgia

patients, some related diagnoses such as mental health issues or other physical diagnoses may be discussed, too. Personal data will also be collected in order to support the purposive sampling and ensuring a more representative selection of participants.

You will be asked to share whatever you feel comfortable sharing. You will be allowed to skip questions should you prefer not to answer them. You will also be asked to confirm your contributions and input to the research before direct quotes will be used.

All data will be anonymised and pseudonymised. This means that any data that may identify you will not be included in the final report and that your name will be replaced with an invented, made-up name. Throughout the research the identifiable, personal and sensitive information will only be accessed by the researcher, with anonymised and pseudonymised data being shared with the researcher's supervisors. As a research participant you will be able to access your personal data at all times.

All data will be stored on the researcher's PC and hard drive as well as in the cloud via Dropbox, which are all password protected. After the completion of the research all data will be encrypted and will be stored on a specifically dedicated external hard drive, which will be kept safely in a locked cabinet in the researcher's home for 10 years for review purposes and in order to be the basis for future research by the same researcher. Hard copies of data will also be kept safely and securely in a locked cabinet throughout the research and for ten years thereafter.

#### **7. Benefits of taking part in the research:**

There is no financial or material reward and there may not be any immediate benefit for the participants in this research. However, it is anticipated that the research will lead to better understanding of the process of making sense of and coming to terms with the fibromyalgia diagnosis and treatment. It is also hoped that as a result of this project fibromyalgia treatment options may be changed to reflect this process.

#### **8. Potential disadvantages of taking part in the research:**

Due to the nature of the research into your experiences with fibromyalgia you may at times feel uncomfortable reflecting on these feelings. You will not ever be asked to share anything that you do not feel comfortable sharing, and you can skip questions at all times without giving reasons. Throughout the research you will be involved in the meaning-making process in that any sections of analyses will be shared with you for clarification and information purposes. At this stage you may ask for any statements to be withdrawn or not used in the final write-up of the research.

## **9. Findings:**

Findings of this research will be shared at relevant conferences, in academic journals, in the final written doctoral thesis. Findings will also be shared with relevant policymakers, fibromyalgia treatment and pain management providers, and for information purposes with fibromyalgia support networks and the general public. A summarised preliminary report of the findings will be shared with all research participants.

## **10. Contact details:**

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