

BODYSYMPTOMS: PROJECT DESCRIPTION

The narratives we have access to about our bodies and health are important. It is difficult to find integrative explanatory models about how symptoms are generated and persist in online spaces. This disempowers those experiencing symptoms from understanding all the dimensions that might be relevant when seeking improved health or treatment. It is also a stumbling block in the campaign for better clinical services for functional disorders within healthcare systems. We want to co-create space for a better discourse about bodily symptoms.

The aim of the bodysymptoms project is to make a website about how functional symptoms come about, become persistent and how these processes can be reversed. We will combine perspectives drawn from up-to-date research, from healthcare-professionals who specialise in treating these symptoms, and from people with direct experience of living with symptoms.

WHAT DO YOU MEAN BY 'FUNCTIONAL SYMPTOMS'?

Functional Symptoms is used as an umbrella term which incorporates common persistent physical symptoms such as fatigue/dyspepsia/dizziness as well as symptoms that are attributed to defined functional somatic syndromes such as IBS, Fibromyalgia or Functional Neurological Disorder.

The focus of this project is where multiple symptoms are experienced in a pattern that suggests dysregulation of complex interacting experiential and physiological processes, where such processes are not well understood or treated through narrow biomedical paradigms. It is perhaps easiest to think of the project as relevant to the understanding of any bodily complaint where an integrative approach to rehabilitation and recovery is indicated, regardless of whether a pathologically-defined disease was part of the causation.

WHY IS THIS IMPORTANT?

Navigating health-care, self-concept and the demands of life when you have functional symptoms can be a fragmenting and difficult experience. It is often difficult for health professionals to explain functional symptoms within the restraints of a typical healthcare appointment. Different diagnostic labels are given, depending on the country you live or what medical specialism you consult. All this confusion can be anxiety provoking, and can exacerbate unwellness.

Good online information is increasingly important in helping people navigate support and recovery when they have health problems. However, in many countries there is a lack of accessible evidence-based online resources about functional symptoms. It needs to be clearer and easier to understand and talk about these symptoms and share knowledge about treatments and other ways to return to health.

We think it is only fair that people who are ill in these specific ways have access to the best information to maximize their chances for recovery and engage most effectively with healthcare. More broadly we hope this project will improve awareness and understanding of functional illnesses.

HOW WILL THE WEBSITE DESIGN AND CONTENT BE DECIDED

The website will be developed during a participatory design process which will build on the perspectives of people from different backgrounds and experience. This includes partners with lived

bodysymptoms project

experience of functional symptoms, researchers and healthcare professionals treating people with these symptoms, from multiple European Countries.

The brief is to offer an integrative evidence-based approach to understanding functional symptoms, navigating the healthcare system, and support and advice for planning recuperation and rehabilitation. It is important that the website is accessible, and that the explanatory models presented are relatable and helpful to those experiencing symptoms.

All information will be aligned with the research literature, clinical expertise and guidelines and the best existing examples of educational material from across Europe. We aim to offer the website in 5 languages.

WHO IS ORGANISING THIS PROJECT AND HOW IS THIS PROJECT FUNDED

This project has been initiated by researchers and healthcare professionals who are dedicated to working towards the conditions needed for better care for people with persistent physical symptoms, bodily distress and functional disorders. We are based in Denmark and the UK.

The current project is part of the innovative training network ETUDE (Encompassing Training in fUnctional Disorders across Europe; <https://etude-itn.eu/>), ultimately aiming to improve the understanding of mechanisms, diagnosis, treatment and stigmatization of Functional Disorders. This project has received funding from the European Union's Horizon 2020 research and innovation programme under the Marie Skłodowska-Curie grant agreement No 956673.

TO READ MORE ABOUT THIS PARTICIPATORY DESIGN PROJECT:

https://osf.io/tncbu/?view_only=5caa9a61418f4265a2101fbd5233fc77