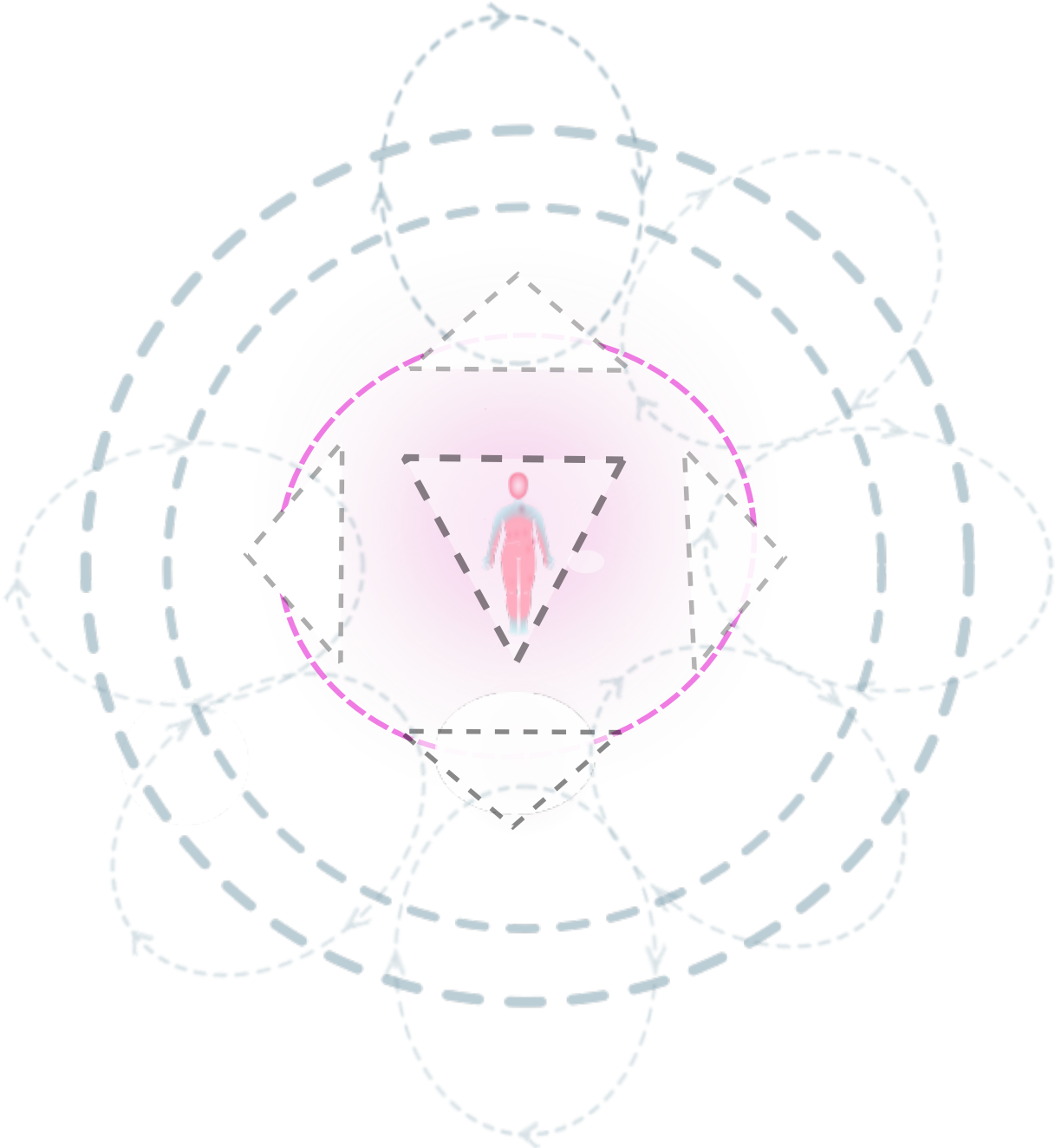
Therapeutic explanations

CO-DESIGNING A RESOURCE FOR SHARED UNDERSTANDINGS OF FUNCTIONAL SOMATIC SYMPTOMS



Chloe Hope Saunders

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Contents

Contents (continued)

Abbreviations

CBT	Cognitive Behavioural Therapy
CFS/ME	Chronic Fatigue Syndrome/Myalgic Encephalitis
ETUDE	Encompassing Training in Functional Disorders across Europe
EURONET-SOMA	European Research Network on Somatic Symptom Disorders
FD	Functional Disorder
FND	Functional Neurological Disorder
FSS	Functional Somatic Symptoms
GP / GPs	General Practitioner(s)
HCP / HCPs	Health-Care Professional(s)
IBS	Irritable Bowel Syndrome
MCS	Multiple Chemical Sensitivity
MUS	Medically Unexplained Symptoms
NVivo 12 Pro	Qualitative analysis software
OSF	Open Science Framework
PD	Participatory Design
PEM	Patient Education Material
PPI	Patient and Public Involvement
PPS	Persistent Physical Symptoms
RCT	Randomised Controlled Trial
REDcap	Research Electronic Data Capture
SOLK	*Somatisch Onvoldoende verklaarde Lichamelijke Klachten*
STATA	Statistical software

List of tables and figures

Preface

> **'medicine's ontological politics:** a politics that has to do with the way in which problems are framed, bodies are shaped, and lives are pushed and pulled into one shape or another.'
>
> Annemarie Mol (Annemarie Mol 2002)

Setting for the thesis

The project is situated within a contested space in contemporary healthcare. Its methods seek to bring into dialogue diverse perspectives on what constitutes therapeutic explanation for Functional Somatic Symptoms (FSS).

This thesis follows the development of a public-facing explanatory framework designed to communicate transdiagnostic mechanisms underlying FSS. The project was based at the Research Clinic for Functional Disorders and Psychosomatic Medicine, Aarhus University Hospital, Denmark, and funded by the European Horizon ITN ETUDE (Rosmalen et al. 2021).

The original aim of the PhD programme was to create a cross-European eHealth programme as an accessible first-step intervention for functional disorders. It became clear as the project progressed that there was an urgent need for online resources that communicate integrative explanations for symptoms directly to the public and could harmonise understandings of FSS across countries and groups of practice. This thesis follows our response to this challenge. The outcome was *bodysymptoms.org* a participatory-designed website built around a novel explanatory framework for FSS, designed with younger adults experiencing multi-system symptoms in mind, and translated into 7 European languages.

A note on terminology

The term *Functional Somatic Symptoms* (FSS) is used throughout this thesis to describe the family of symptoms under focus.

Functional Somatic Symptoms (FSS) is an umbrella term describing common and often disabling bodily symptoms that affect multiple physiological systems (See figure 1) (Burton et al. 2020). Conditions characterised by FSS typically lack reliable biomarkers at the group level and challenge conventional biomedical diagnostic paradigms (Eriksen et al. 2013), which has led to a proliferation of partially overlapping terms, whose acceptability and usage continue to evolve (Greco 2012).

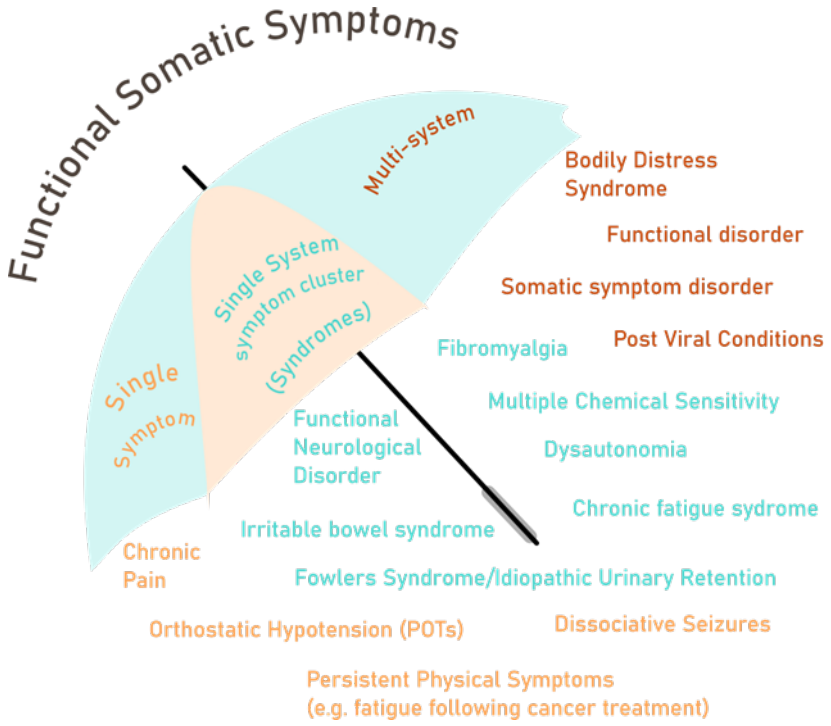

Figure 1: Conditions considered to be under the umbrella of FSS

In **Study I**, we defined FSS as any persistent or recurrent somatic (bodily) symptom(s) lasting longer than three months, for which appropriate medical investigation has not identified an alternative biomedical disease sufficient to explain the symptom(s) (Saunders et al. 2023). At the outset of the participatory design phase of the project, terminology was discussed again in depth. The term FSS was considered both relevant and acceptable by participants, and was therefore kept as the main term used to describe the family of symptoms under focus in this project (Saunders et al. 2024).

We consider the term **Functional** to be helpful, in that it invites us to consider that symptoms can be a product of dynamic neuro-physiological processes. The term Functional does not necessarily imply that symptoms are unexplained, psychogenic, or serve an unconscious purpose. Rather, it refers to disruptions in the dynamic functioning of body-mind systems. **Somatic** focuses attention on symptoms experienced and interpreted through the body and its physiological processes, as distinct from symptoms primarily understood as 'mental'. **Symptoms** are sensations or limitations interpreted as signals of ill health—they are either unpleasant or restrictive in themselves or considered threatening in relation to the person's future health (Ahlzén, 2017).

However, the boundary between functional and disease specific ('structural') mechanisms, as well as the boundaries between somatic and mental symptom experiences, are porous (Chesterfield et al. 2024). Dysfunctional physiological processes may, over time, give rise to structural changes, just as symptoms stemming from injury or disease inevitably involve functional disturbance as chronicity develops. As this PhD has progressed, there has been increasing adoption of the term **Persistent Physical (or Somatic) Symptoms (PPS**) within the field (Löwe, Toussaint, et al. 2024). This reflects a recognition of the difficulty of distinguishing functional and structural symptoms in practice (Löwe, Zipfel, et al. 2024), and aligns with the transdiagnostic stance adopted in the Bodysymptoms project. Consequently, some later documents use the term PPS. Nonetheless, for the sake of consistency, this thesis continues to use FSS to denote persistent physical symptoms that are most helpfully understood through functional, or dynamic bio-psycho-social, mechanisms.

We also use the terms functional disorder, and functional somatic syndromes. **Functional Disorder (FD)** refers to an established condition in which FSS evolve into illnesses that significantly affect daily life (Burton et al. 2020). The use of this term indicates a role for specialised treatment. **Functional somatic syndromes** is used as shorthand for the group of FD diagnoses based on common FSS clusters (Barsky A.J. and Borus J.F. 1999). Functional somatic syndromes include Fibromyalgia, IBS, CFS/ME and MCS, amongst others. A full list of terms that we

understand to describe conditions characterised by FSS is included in Appendix A.

Throughout the thesis, I use the pronouns *we* and *our* when referring to my own reflections and ideas. This choice maintains consistency with the four embedded studies, which are all written in a collaborative voice.

The term **Bodysymptoms** refers to the overall research programme, while **bodysymptoms.org** denotes the digital presentation of the explanatory model developed as part of this work.

Outline of the thesis

This thesis follows the natural development of the Bodysymptoms project, beginning with conceptual foundations, describing the research-in-action project at the centre of this thesis, and concluding with an evaluation and reflections.

Chapter 1 introduces functional somatic symptoms and functional disorders, situating them within lived, clinical, and historical contexts. **Chapter 2** explores the concept of medical explanation, outlining theoretical, clinical, and social dimensions. **Chapter 3** presents a review of explanatory approaches to FSS, as outlined in the academic literature and sets out the problem the thesis responds to.

Chapter 4 then turns to the studies that comprise the thesis, introducing the rationale and aims of the studies included as articles in **Chapter 5-8**

Chapter 9 connects the papers, tracing the methodological approaches and synthesising the main contributions **Chapter 10** discusses the strengths and limitations of the methods. **Chapter 11** outlines a conceptualisation of therapeutic explanation, relating this to learnings that emerged through the Bodysymptoms project, suggests implications of the work and future directions for research. **Chapter 12** provides English and Danish summaries.

The thesis is based on the following articles:

Chapter 5: Study I

Saunders, C., Treufeldt, H., Rask, M. T., Pedersen, H. F., Rask, C., Burton, C., & Frostholm, L. (2023). Explanations for functional somatic symptoms across European treatment settings: A mixed methods study. *Journal of Psychosomatic Research*, 111155. https://doi.org/10.1016/j.jpsychores.2023.111155

Chapter 6: Study II

Saunders, C., Gordon, M., Righini, C., Pedersen, H. F., Rask, C. U., Burton, C., & Frostholm, L. (2024). Participatory design of bodysymptoms. org: An interactive web resource to explain multisystem functional somatic symptoms. *Journal of Psychosomatic Research*, *183*, 111827. https://doi.org/10.1016/j.jpsychores.2024.111827

Chapter 7: Study III

Saunders, C., Pedersen, H. F., Rask, C. U., Greco, M., & Frostholm, L. (2025). Embodied wisdom: towards acceptable and helpful explanations for functional somatic symptoms. *Medical Humanities (online first)*. https://doi.org/10.1136/medhum-2025-013380

Chapter 8: Study IV

Saunders, C., Pedersen, H. F., Rask, C., & Frostholm, L. (2025). bodysymptoms. org: Postlaunch evaluation and update. *Journal of Psychosomatic Research,* 112445 https://doi.org/10.1016/j.jpsychores.2025.112445

Thank you for reading, I hope you come across some interesting new perspectives.

Chloe Saunders

Aarhus, Denmark

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Löwe, B., Zipfel, S., van den Bergh, O. and Henningsen, P. (2024) Reconsidering Persistent Somatic Symptoms: A Transdiagnostic and Transsymptomatic Approach. *Psychotherapy and Psychosomatics* 94 (1), 20–25.

Rosmalen, J., Burton, C., Carson, A., Cosci, F., Frostholm, L., Lehnen, N., Olde Hartman, T., Rask, C., Rymaszewska, J., Stone, J., Tak, L.M., Witthöft, M. and Löwe, B. (2021) The European Training Network ETUDE (Encompassing Training in fUnctional Disorders across Europe): a new research and training program of the EURONET-SOMA network recruiting 15 early stage researchers. *Journal of psychosomatic research* 141, J Psychosom Res.

Chapter 1: Functional somatic symptoms

1.1 Epidemiology

On a population level, approximately 30% of adults experience multi-system symptoms characteristic of FSS (Smakowski et al. 2025), and around 1 in 10 meet criteria for a functional disorder (Rometsch et al. 2024). FSS are associated with various demographic, psychosocial, and biological factors. They occur more frequently among women (Ballering et al. 2022) and marginalised groups, including migrants (Vermeir et al. 2021), and are often comorbid with neurodiversity (Vickers et al. 2025), anxiety and depression (Kohlmann et al. 2016). Vulnerability is associated with traits such as high neuroticism (Atasoy et al. 2022), low self-efficacy (Petersen et al. 2023) as well as with developmental experiences (Münker et al. 2023), trauma (Afari et al. 2014; Jacobsen et al. 2023) and other stressful life events (Ludwig et al. 2018). Functional symptoms often arise during acute illness—including infections such as Epstein–Barr virus, gastrointestinal pathogens, Borealis or SARS-CoV-2—suggesting that inflammatory processes may act as triggers in predisposed individuals (Schovsbo et al. 2022; Choutka et al. 2022).

Conditions characterised by FSS frequently overlap within individuals (Petersen et al. 2020), and longitudinal data suggest that symptom patterns often fluctuate, with one syndrome evolving into another (Schovsbo et al. 2024). The epidemiology of FSS points to complex, dynamic interactions between bodily, psychological, socio-cultural, and care-related factors, highlighting the need for personalised and integrative explanatory approaches (van der Meulen et al. 2024). However debate persists about how these interactions should be conceptualised and where explanatory or therapeutic emphasis should lie (Hunt 2024).

1.2 Experiences with FSS

> 'The uncertainty and moral ambiguity associated with the lack of a diagnosis and explanation can leave sufferers in a state of embodied doubt and permanent narrative chaos'
>
> (Greco 2017)

When symptoms cannot be readily controlled, explained, or normalized, they provoke a search for meaning and mastery (Kirmayer and Gómez-Carrillo 2019). Unlike conditions with clear biological markers, Functional Somatic Symptoms (FSS) exist in a space of ontological ambiguity. This defines several features of the typical patient experience.

Experiences with healthcare

Health professionals often lack training in the management of FSS (Finset 2018). As a result patients typically only find part of their illness addressed, or they receive multiple diagnoses with little knowledge of how their problems are connected, without a coherent explanatory framework or management plan (Frølund Pedersen et al. 2019). In addition to this problem of shared conceptual resources, the legitimacy of the sufferer's experience is frequently questioned, and patients may come up across experiences of disbelief, humiliation, stigmatization, and marginalization (Treufeldt and Burton 2024). Navigating healthcare while experiencing FSS can thus be fragmenting and deeply challenging (Barends et al. 2022).

Experiences with diagnosis

Despite the prevalence of FSS, they are poorly represented in diagnostic classifications, often relegated to residual categories. As a result, formal FD diagnoses are often delayed and typically given only in more severe cases (Murray et al. 2016). Receiving a label can initially provide relief, but in FSS, such diagnoses rarely live up to their promise of delivering a satisfactory explanation or effective

treatment (Tattan et al. 2025). Consequently, fear, hopelessness, and the social stigma of having an "unexplained" illness often remain (Bakken et al. 2023).

Experiences in society

What occurs during interactions with healthcare providers is only part of the picture. People with FSS typically find the legitimacy of their suffering questioned across social contexts, including when seeking social, or welfare support (Rogers 2022), and within their close relationships (Schone 2019). The internet has fundamentally reshaped this process. For many, it is now the primary site for interpreting suffering, developing illness understandings, researching symptom management strategies, and forming connections with others who share similar experiences (Kingod et al. 2017). Although online communities can offer support, the legitimacy of conditions associated with FSS is often questioned in prominent online discourse (McLoughlin et al. 2025) and people seeking information about FSS online often face misrecognition and stigma (Groenevelt 2022).

Experiences of self

For individuals experiencing FSS, the persistent mismatch between their lived reality and the understandings recognized by dominant biomedical paradigms can result in profound sense of alienation from their bodies and their self-knowledge (Burbaum et al. 2010). Discourses around the legitimacy of symptoms without objective biomarkers often becomes internalized, fostering self-doubt and self-blame (Cheston 2022) and recursive debility (Rogers 2022).

1.3 A socio-historical perspective

These challenges, while pressing today, are deeply rooted in the history of medical approaches to FSS. Although conditions resembling modern functional disorders have been described since antiquity (Ackerknecht 1982), a shift came with the transformation in medical knowledge that accompanied the rise of anatomo-clinical medicine in 18th-century Europe (Foucault 2002). During this time, physician-scientists began to look for clinical symptom patterns that correlated with objective disease markers, often from post-mortem examination.

By the 20th century, the importance of a causal relationship between disease and symptoms had become a dominant epistemic foundation underpinning western evidence based medicine (Svenaeus 2000). Within this paradigm, the body came to be seen as a complex anatomical machine, fragmented into organ systems and cells (Bellacasa 2010).

This biomedical approach provided powerful explanations for many diseases and paved the way for new technologies and treatments. Yet not all symptoms revealed their causes under the microscope. Some symptom patterns showed no clear anatomical or pathological correlate. In the 19th century, physicians paid particular attention to neurological symptoms that could not be explained by emerging neuroanatomical knowledge. Charcot's studies of 'hysterical epilepsy', dramatized through public demonstration, captured both medical and public imagination. After Charcot's death, his students Janet and Freud continued his work on hysteria but developed divergent approaches: Janet advanced neuro-cognitive theories of dissociation, while Freud emphasized psychogenic mechanisms that spurred the development of various psychological and behavioural therapies in the 20th century (Leaviss et al. 2020; Liu et al. 2019). The influence of psychoanalysis persisted and likely contributed to a tendency among doctors and psychologists to attribute unexplained symptoms to psychogenic (somatisation) processes (Kirmayer 1988).

However, this psychological approach opened up an epistemic gap between professional explanatory models and patients who predominantly experience symptoms in the light of dominant biomedical paradigms. This epistemic gap is especially important in healthcare systems where psychiatric diagnoses may carry social stigma, reduced access to care, or lower insurance coverage (Dumit 2006). As a result, explanations for disorders characterised by FSS remain highly contested—not only on scientific or clinical grounds, but also on socio-political and ethical ones (White et al. 2023). At stake are questions of legitimacy, access to care, and the right to be understood as a credible witness to one's own bodily experience.

1.4 Assessment and Treatment

Addressing FSS invites a polemic about the appropriate role of modern medicine in supporting health. On one side are proponents of a strictly biomedical model, who view the physician primarily as providing technical expertise while remaining distant from psychological, social or existential concerns. On the other side are advocates of bio-psycho-social approaches—variously described as integrative, holistic, or person-centred medicine—which emphasise the interplay of biological, psychological, and social/ecological factors in both illness and recovery. Caught between these perspectives, patients with FSS often encounter fragmented care, or even 'socially organised neglect' (Cupit et al. 2025). However, some current directions in the assessment and treatment of FSS are outlined below.

Stepped care models

Improving primary care for FSS makes sense, as timely support holds the potential to prevent maladaptation to illness and reduce the risk of long-term disability (Berezowski et al. 2022). FSS account for around half of presentations to primary care, however the majority of symptoms resolve with simple measures and are no longer reported a year later (Chaabouni et al. 2023). Stepped care models are increasingly emphasised, beginning with supportive interventions in primary care and escalating to more specialised services when needed (olde Hartman et al. 2017). Ideally, general practitioners are equipped with the training and resources to enable patients to better understand, manage, and live with their symptoms. In practice, however, such resources are often lacking, and patients are more likely to experience disjointed care, characterised by multiple referrals to organ-specific specialists who rule out disease within their domain but fail to address the broader picture (Barends et al. 2022).

Collaborative care

Collaborative care networks have emerged as a response to the fragmentation of services for people with FSS (Röhricht et al. 2024). These models aim to build partnership between GPs and other professionals involved in the patients care with the aim to support and empower the individual. Regular coordination

between professionals promotes consistent messaging and reduces repeated consultations and diagnostic uncertainty and helps to support integrative approaches to management (Mamo et al. 2024).

Specialist Multi-disciplinary Treatment

When it comes to specialised treatment for established FD, multidisciplinary approaches are regarded as best practice but remain inconsistently available (Henningsen 2018; Löwe et al. 2024). Where established, multidisciplinary treatment centres bring together medical specialists, psychologists, physiotherapists and other disciplines, such as psychomotor therapists, occupational therapists and social workers, to provide coherent and whole-person care (Saunders et al. 2024). There is a broad range in the therapies one might receive in such services, but in essence, rather than applying symptom targeted treatments in isolation, they target interventions towards mechanisms that appear to be important for maintaining symptoms in an individual's condition (Mamo et al. 2025). Interventions are applied concurrently on multiple levels, hence the need for a multi-disciplinary clinical team, and supportive environment.

Digital health interventions

Alongside face-to-face assessment and treatment, digital and internet-delivered interventions have emerged as both effective and scalable. Interventions range from structured self-help programmes to advanced digital health solutions that incorporate real-time monitoring and feedback (Liu et al. 2025). Evidence indicates that these approaches can expand access, facilitate early intervention, and deliver meaningful outcomes across diverse patient groups, including populations traditionally underserved by conventional healthcare systems (Wanless et al. 2024). Various e-health programmes have been developed to support treatment of FSS within clinical settings (Frumer et al. 2024; Pedersen et al. 2023), or as self-help interventions (Rask et al. 2024).

Explanation as treatment

Patient activation—defined as 'having the knowledge, skill, and confidence to manage one's health' (Hibbard et al. 2007) often begins with explanation. The

recognition that expectations play a particularly significant role in FSS has led several authors to propose that explanation itself may constitute a form of treatment (Stone et al. 2016). From this perspective, explanation is not merely an adjunct to care but an intervention capable of influencing illness experiences and behavioural responses.

Recent RCT evaluations of explanatory interventions lend empirical support to this view. In the REAL study (Burton et al. 2024), participating GPs received training in 'symptom science' and were taught to identify individually relevant causal pathways collaboratively with the patient and were given different examples of how they might then integrate them into a model of symptom perception (Fryer et al. 2025). A comparable, though briefer, intervention was evaluated in the Norwegian ICIT trial, where a structured, CBT-informed communication tool based on stress-system explanations significantly improved function, quality of life, and work participation compared with usual care (Abrahamsen et al. 2023). These studies invite reflection on what constitutes a therapeutic explanation, illustrating that the act of explaining, in the context of adequate clinician training and time, can be treated as an intervention with observable effects on patient outcomes.

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Chapter 2: Explanation in medicine

Explanation can be understood as the activity of bringing together information to shed light on a given phenomenon. It is a way for individuals and groups to make the world more intelligible (Wright and Bechtel, 2007). The word "explanation" is used in a wide variety of ways in medicine (Sheredos, 2016). There are scientific explanations, which include both causal and mechanistic explanations (Lange, 2016). We also use the word 'explanation' within clinical communication, for example a physician might explain a set of symptoms by assigning a label or diagnosis. A physiotherapist might explain how to do a breathing exercise. A doctor might explain why they made a diagnosis in relation to a particular patient's history, and so on. These examples show that explanation is not only foundational to scientific reasoning, but also to communication in clinical care.

Although the form and complexity of an explanation will differ depending on the context, typically, explanations are prompted by a question, require an answer that can be grasped, and incorporate relevant information as evidence (Campaner, 2022). In this chapter, we outline the relevant theoretical frameworks and terminology in order to clarify, and distinguish, what is meant by *therapeutic explanation* within the context of this thesis.

2.1 Adequate explanation

Medicine, as a relational practice, depends on shared epistemic norms that frame whether an explanation is considered adequate or not. Differing expectations for what is an appropriate focus and form of explanation are held within different contexts and epistemic communities (communities of practice or interest groups) (Akrich, 2010). One general epistemic norm for explanations used in medicine, is that, although explanations may be expressed in scientific terms, they are rarely expected to be complete or objectively literal. Medical explanations often employ metaphor, or schematic visuals to aid understanding (Kirmayer *et al.*, 2023). Different specialisms, for example molecular biology, epidemiology, internal

medicine, and psychiatry may all endeavour to explain the same symptom, but explanations may focus in on different systems (i.e. different perspectives of scale or composition) (Eronen, 2015). Another pragmatic epistemic norm in medical explanation is that the relevance of the details from which the mechanism is built is prioritized over sheer volume of detail (Craver and Kaplan, 2020). A focus is selected because it has explanatory relevance, for example in justifying an intervention provided by that discipline. In this way, explanations in medicine are not complete fixed truths, but selected representations grounded in both epistemic norms and pragmatic goals (Fagan, 2019).

The Role of Explanation in Clinical Care

In the clinic, explanations serve both relational and practical purposes. This practice of making sense of the history of an illness is in part a relational act, helping the patient to feel understood, and their suffering recognised and validated. Associated with the diagnostic process, explanations offer a language and framework through which patients can begin to understand their own bodily experience (Balint, 1965). By addressing biographical questions like *"Why me?"* explanation shapes narrative meaning making: making symptoms understandable by offering a plausible causal chain (Kirmayer, 2023). These types of 'why-me' explanations act as scaffolding for identity, a theme which will be explored in greater detail in section 2.3. As well as pointing to a historical causal chain, explanations also have a role demystifying the future (Kleinman, 1980). Understanding things on the level of 'what's actually going on in the body' clarifies routes to symptom management (Kozlowska, 2013). In this role explanations can empower autonomous behaviour change as well as setting positive expectations for treatment (Greco, 2017).

Ontic constraints

While it is useful to view explanation as a relational activity, this 'making sense of' is not divorced from its object. In one sense, explanations exist independently of our conceptualising minds: they must mirror an underlying reality in the structure and organisation of nature (Craver, 2014). Therefore, explanations in medicine are constrained, on the one hand, by the requirement to reflect causal–physical

relations with sufficient accuracy, and on the other, by the need to be understandable, actionable, and aligned with the patient's needs and narratives (Kirmayer, 2023). These ontic and epistemic constraints may pull explanations in different directions (Illari, Phyllis., 2013). In practice, compromises are inevitable, with different balances struck between accuracy and intelligibility depending on pragmatic aims.

How ontic constraints operate depends on the stage of development of the science underpinning an explanation. An explanation may 'rest on science' that is currently 'good enough', provided it fulfils social, political, or therapeutic purposes (Dumit, 2000). This should be seen as part of a dynamic process: the science behind an explanation may may begin as a well-reasoned possibility, become increasingly probable as evidence accumulates, and eventually stabilise as reflecting established theory (Campaner, 2016).

The role of mechanism

This thesis primarily focuses on mechanistic explanations. A useful way to distinguish between types of explanations lies in the questions they address: *"Why"* questions typically seek causal or identity-based accounts, whereas *"How"* questions aim to uncover mechanisms—the processes and interactions that underlie and shape phenomena (Dammann, 2020). Mechanisms describe the dynamic activities of a system, understood as occurring within a broader dynamic context (Salmon, 1984). Defining the boundaries of the system that a mechanism describes requires epistemic decisions, influenced by factors such as the research context, the question being asked, and disciplinary traditions. Consequently, mechanistic explanations are inherently partial and perspectival, reflecting the situated nature of scientific inquiry (Lee and Dewhurst, 2021). It has been argued that mechanistic explanations are crucial to medical understanding (Varga, 2024).

Therapeutic explanation

We use the term *therapeutic explanation* to refer to an adequate response to the question: *"What do I need to understand in order to better manage my symptoms or recover?"* To distinguish it from clinical explanation, a therapeutic explanation may be constructed outside of the clinical environment, for example through positive interactions with wider (including online) communities and culture. Crucially, a therapeutic explanation should motivate constructive emotional responses, empower individuals with knowledge of where they might have agency or options for healing, and foster bodily, interpersonal and socio-technological dynamics conducive to healing.

2.2 Explanation and the social context

Philosophy of science has often focussed on co-production of explanation and consensus reaching, within the social worlds of scientists (Miller, 2024). Yet medical explanations differ in that they circulate beyond professional boundaries: they are shaped by cultural and informational environments, carry socio-political significance, and are increasingly generated outside established institutions of expertise (Wagner, Polak and Świątkiewicz-Mośny, 2019).

Socio-political function

As well as the role of explanation in clinical communication, explanations have an important social role. They are used to communicate to friends, family and co-workers, as a way to establish legitimacy for the person's suffering, and are used as a tool in negotiating the shape of the sick role the sufferer expects to inhabit (Nettleton, 2006). Explanations in the social domain might be valued for their ability to provide medical legitimacy within societal structures that guard the sick role. For example, an immunological causal explanation for fatigue, can be yielded to gain access to services or institutions that provide access to financial or medical support during illness (Rogers, 2024).

Cultural and informational environment

Prevailing cultural models of the body, personhood, health, and illness shape what explanations are considered relevant and acceptable (Wolfe, 2009; Wilcox, 2010). The informational context the healthcare-professional and patient are exposed to supplies the discursive framework through which meaning-making in the clinic is possible (Kirmayer and Sartorius, 2007). For example, the doctor's informational context is usually formed around their training, identity and practice as healthcare professionals(Francisconi *et al.*, 2016). The patient's informational context is increasingly shaped in online spaces (Nettleton, 2004).

Explanations online

The internet brings with it many benefits: including support, access to expertise and practical know how (Barrett, Ortmann and Larson, 2022). However, the internet is not a universally comfortable, or beneficial, mediator of illness experience. There are concerns about the quality and accuracy of the information circulating (Treadgold *et al.*, 2025): a patient's informational context is increasingly subject to the whims and tendencies of algorithms (Sendra Toset, Torkkola and Parviainen, 2023). Algorithms shape what content is visible and to whom, often reinforcing existing beliefs and identities (Pollock, 2024). Unfortunately, current algorithms do not appear to be well suited to amplifying nuanced information about health (Amico-Korby, Harrell and Danks, 2025). Search engine users engage more with results that mention serious illness, potentially shaping algorithms to prefer more alarming content (White and Horvitz, 2009), and there have been concerns raised about undue influence of unqualified 'health-influencers' and conspiratorial narratives in online health spaces (Kisa and Kisa, 2025).

Conditions associated with FSS are often at the centre of emotionally charged online discourse, particularly around questions of aetiology, treatment approaches, and diagnostic legitimacy (Groenevelt and de Boer, 2023; McLoughlin *et al.*, 2025). This complicates the process of forming therapeutic explanations: the uncovering of a contested area of knowledge can erode trust in scientific research, medical professionals, and mainstream healthcare approaches

(Sendra Toset, Torkkola and Parviainen, 2023). Algorithmic mediation of epistemic bubbles may widen existing health inequalities by constraining interpretative resources and limiting exposure to new perspectives in unequal, and often invisible, ways (Origgi and Ciranna, 2017).

Explanation and health social movements

Online peer support groups often serve as key sites for people looking to understand their symptoms, offering recognition, solidarity, and explanatory frameworks. Within these communities, illness understanding emerges as a dynamic and situated process—one that involves weaving together medical explanation, personal experience, and the shared meanings offered by peers (Brown *et al.*, 2004). The case of long COVID exemplifies these dynamics (Callard and Perego, 2021). In the aftermath of the pandemic, online peer support groups filled critical gaps left by unprepared health services. They offered members recognition, solidarity, and practical strategies for symptom management, often becoming 'ahead of the medical information' through the circulation of lived expertise (Day, 2022).

Health-social movements are groups that therefore also have an interest in the development of medical explanation, often shaped by socio-political concerns (Wagner, Polak and Świątkiewicz-Mośny, 2019). By emphasizing the validity of lived experience, members of these movements seek to redraw the boundary between professional and experiential knowledge. A key feature of such movements is their ability to challenge dominant medical narratives. For example they offer a challenge to evidence based medicine, to broaden its concepts around how evidence is evaluated and institutionalised (Faulkner, 2017). They continue to offer a criticism around the limitations and misuse of bio-psycho-social models of illness, for example by pointing out how system-structural factors are often missed as part of an integrative approach (Hunt, 2024).

2.3 Explanation as mediator of illness experience

It has been established that the way individuals perceive their symptoms can significantly influence health behaviours, treatment adherence, and overall illness trajectory (Frostholm *et al.*, 2005). In this sense, explanations for symptoms can be understood as *looping kinds* (Kirmayer and Gómez-Carrillo, 2019): they are shaped by the symptoms they seek to explain, yet simultaneously influence how those symptoms are perceived and thereby experienced. In particular, a strong tendency to attribute symptoms to disease, and to view symptoms as chronic, has been associated with greater fatigue, disability, psychological distress, and increased healthcare utilisation (Frostholm *et al.*, 2014; De Gucht, V., F. K. *et al.*, 2017; De Raaij *et al.*, 2018). Moreover, changes in how an illness is understood appear to mediate treatment success (Christensen *et al.*, 2015), and such shifts in understanding often feature centrally in patients' own recovery narratives (Bakken *et al.*, 2023). Fostering a sense of coherence and agency over symptoms emerges as a key mechanism in effective patient education interventions (Frølund Pedersen *et al.*, 2019).

One pathway through which symptom explanations may shape illness course is via internal shifts in self-concept or identity. There is a growing literature on illness identities, much of which explores how individuals with chronic illness or physical disability adapt to the disruption brought about by impairment (Charmaz, 1995). The adoption of an illness identity has been linked to increased agency in managing health and may therefore be beneficial, particularly in the context of chronic illness (Moons, 2018). In conditions marked by FSS, some of these same benefits are likely to apply (Barker, 2002). However, there are also some ethical concerns (Charland, 2015).

As people typically research their symptoms online well in advance of attending a doctor, explanations for illness or identities based on 'self-diagnosis' may well be established early in the trajectory of a symptom experience, and there-in begin to shape the information environment a person finds themselves in (Hiaeshutter-Rice et al., 2024). While online communities formed around diagnosis based identities can provide validation and empowerment, there are also routes to dysfunctional

forms of empowerment (Petrič, Atanasova and Kamin, 2017). For example experiences shared within them typically represent the most severe and chronic cases (Arigo, Suls and Smyth, 2014). Illness identities are not inert: they reinforce *response expectancies*—for example, "I have/am X, therefore Y will now occur" which can impact both the symptom perception and actions taken in response to symptoms (Pagnini, 2019). Chronicity narratives can shape individuals' expectations and complicate their engagement with medical care (Cupit *et al.*, 2025). People seeking to understand their symptoms online may too easily come to view themselves as victims of a disabling biological process—one perceived as lacking a clear cause, prognosis, or cure (Bakken *et al.*, 2023).

It has been suggested that an individual's identity-shaped digital information environment should now be recognized as a major social determinant of health (Palmer and Gorman, 2025). Knowledge of placebo and nocebo mechanisms re-enforce how meaning and expectation can profoundly influence health outcomes (Tracey, 2010). This raises important ethical and relational challenges for healthcare professionals (Saunders, 2023). When clinicians endorse particular illness identities or explanatory models, they may inadvertently limit patients' openness to alternative possibilities and close off potential therapeutic avenues (Greco, 2017). Although recent literature has suggested healthcare professionals routinely ask a patient about their experiences with health information online (Winters *et al.*, 2025), this issue often remains unaddressed. Patients may experience a mismatch between their illness identity and the healthcare system's responses as invalidating (Gask *et al.*, 2011), and many describe feeling "gaslighted"—a disorienting experience of having one's perspective or lived experience undermined (Plastina, 2025).

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Chapter 3. Explanatory Approaches in FSS

In this chapter we review what academic literature tells us about explanatory approaches to conditions characterised by FSS.

3.1 Aetiological approaches

Medical research often seeks to map causal and aetiological pathways. In the case of functional disorders (FD), it is frequently claimed that their aetiology remains poorly understood or under-researched. However, the reality is more complex. A recent review sought to synthesise existing evidence regarding the main functional somatic syndromes—irritable bowel syndrome (IBS), fibromyalgia, and chronic fatigue syndrome (CFS)—as well as their diagnostic analogues (Kleinstäuber et al. 2023). This review identified numerous studies that have investigated a wide range of aetiological factors, spanning biological, psychological, social, and ecological domains. The review identified moderate-quality evidence for a wide range of aetiological factors at the group level, but with each individual factor only responsible for a small effect.

While such findings underscore the need for methodological improvements—particularly greater consistency in factor selection, clearer reporting, and more transdiagnostic research—they also point to a deeper issue: the limitations of conventional aetiological research in explaining FSS. Firstly, it appears that multiple, interacting aetiological factors are likely at play, with any single factor contributing only minimally to the illness experience of an individual. Research methodologies that are typically used to statistically prove causality, are ill-suited to capturing the complex, dynamic interactions that give rise to or maintain FSS (Eriksen et al. 2013).

3.2 Mechanistic approaches

Beyond the difficulties inherent in identifying objective reliable causes of FSS, it has been argued that one might know the cause of an illness, without understanding that illness. Understanding requires the ‘grasping’ of how

symptoms come about, or mechanistic explanation (Varga 2024). Such explanations help map opportunities for intervention at different levels, and are therefore valued and utilised in clinical settings (Morton et al. 2017). The dominant integrative mechanistic research paradigm in the field of FSS posits that symptoms arise not directly from sensory inputs, but from an ongoing, dynamic interaction between top-down predictions by the brain and bottom-up sensory data about the state of the body and the environment, modulated by affective, attentional, and experiential factors (Van den Bergh et al. 2017). The 'symptom-as-inference' model accommodates the high variability between bodily signals and conscious symptom experience and applies irrespective of whether an identifiable disease is present or absent. In line with increasing adoption of this model in professional groups, the clinically orientated literature recommends that integrative, mechanistic explanations for FSS are communicated to the public (Löwe et al. 2024).

3.3 Clinical approaches

The following section reviews what the existing literature can tell us about explanation for FSS and FD within clinical settings and patient education. Building on a protocol established by Kohlman and Weigel (unpublished), a literature search was conducted to ensure comprehensive coverage of explanatory models for Persistent Physical Symptoms (PPS) and to provide a transparent foundation for the present work. Searches were carried out in PubMed, PsycINFO, and EMBASE, covering publications from 1990 to October 2022, using predefined search strategies (Appendix B). Eligible studies included peer-reviewed full-text articles in English that described, evaluated, or provided principles for developing or communicating explanatory models for PPS or related diagnostic categories. Exclusion criteria were studies that mentioned causative factors, or mechanisms without translating these into explanatory models understandable to patients. All records were screened in a two-stage process—first by title and abstract, then by full text—by at least two reviewers, with disagreements resolved by discussion. Key results are summarised narratively in the text below. A PRISMA-style flow diagram illustrating the selection process is provided as Appendix C.

Group 1: Principles in the development and presentation of clinical explanations

The search strategy returned ten studies describing conceptual and practical principles for developing and communicating explanatory models of PPS (Morriss and Gask 2008; Stone 2011; Stone et al. 2016; Morton et al. 2017; Cathébras 2021; Kirmayer and Sartorius 2007; Roenneberg et al. 2019; Francisconi et al. 2016; Burton et al. 2015; Frølund Pedersen et al. 2019). Collectively, they emphasised that providing an explanation is a bridging step between diagnosis and management. Effective explanations should be negotiated with the patient, grounded in their lived experience, and presented in clear, relatable language (Cathébras 2021). Cultural aspects were noted as influential in shaping explanatory preferences and clinician–patient communication (Kirmayer and Sartorius 2007; Francisconi et al. 2016). The importance of written and online resources to support explanations was highlighted (Stone et al. 2016)

The reviewed studies emphasised that explanations for symptoms should begin with validation of the patient's experience (Stone et al. 2016). Patients are more likely to engage when their symptoms are acknowledged as real and meaningful (Stone 2011). Effective explanatory models should be developed through collaboration between clinician and patient, allowing individual beliefs and narratives to shape how information is presented (Morriss and Gask 2008). Importantly, explanations should not remain abstract or purely psychological; Clinical explanations should aim to help patients with multiple FSS conditions understand the connection between their diagnoses (Frølund Pedersen et al. 2019); they should link symptoms to understandable bodily mechanisms and outline clear pathways for management and treatment (Burton et al. 2015).

Morton and colleagues applied linguistic analysis to GP consultations addressing various MUS. They classified three types of explanations—rational adaptive, automatic adaptive, and complex—as well as three explanation components: facts, mechanisms, and causes. Of these, mechanisms were most commonly invoked, appearing in 94% of consultations. The authors identified seven types of mechanisms: somatic, sensitisation, exhaustion, dissociation, alarm, attention, and

avoidance, illustrating the range of explanatory narratives employed by GP (Morton et al. 2017).

Group 2: Explanatory Models with Lay Translation

A qualitative review from 2010 summarized clinically useful explanatory models, i.e. etiological models that have been presented in patient appropriate language, for MUS (van Ravenzwaaij et al. 2010). They identified nine different models as well as one model that comprised aspects of all other models. The identified explanatory models were related to somatosensory amplification, sensitization, sensitivity, immune system sensitization, endocrine dysregulation, signal filter model, illness behavior model, dysfunction or dysregulation of the autonomous nervous system.

11 papers contained a full explanatory model with an example of how this might be communicated in lay language. Four of these covered Central Sensitization in various pain conditions (Namerow et al. 2016; Nijs et al. 2011; van Ittersum et al. 2014; van Wilgen and Keizer 2012). Two papers gave full explanations with examples for a Multisystem Stress Model (Kozlowska 2013; Lucini and Pagani 2012). Two papers gave integrated models of Body-brain dysfunction (Brown 2013; Hungin A.P.S. et al. 2015). Full explanations with examples were also available for Dissociation (Mellers 2005), Embodied experience (Kozlowska 2016), and the Illness-Perception-Behavior model (Brazier D.K. and Venning H.E. 1997).

While these models draw on distinct theoretical traditions, they share a focus on reversibility, bio-psycho-social integration, and promoting agency through mechanistic understanding.

Group 3: Empirical Investigations of Explanatory Models

Twelve studies evaluated explanatory interventions using heterogeneous methods. Studies carried out in the United Kingdom concluded that attempts to normalize symptoms without an explanation, or 'reattributing' symptoms to psychosocial events are ineffective (Dowrick et al. 2004; Morriss R. et al. 2010). A further qualitative study suggested co-constructed explanations lead to the best outcomes (den Boeft et al. 2017). Randomised trials of structured explanatory

interventions (e.g., pain neuroscience education) demonstrated moderate improvements in health outcomes for conditions such as fibromyalgia and functional seizures (Van Oosterwijck et al. 2013; Aiarzaguena J.M. et al. 2007; Aiarzaguena et al. 2013; Barrenengoa-Cuadra et al. 2021). Written information alone was less effective than face-to-face explanations (van Ittersum et al. 2014). Overall, empirical evidence supports the therapeutic potential of providing clear, body-centred explanations but remains limited by small sample sizes, variable quality, and inconsistent outcome measures.

3.4 Summary of the background and problem definition

Explanations play a central role in the experience of illness: they shape how symptoms are interpreted, how illness identities are formed, and how people engage with healthcare. Yet explanations for FSS remain fragmented and contested. Functional disorders (FD) are frequently said to be poorly understood or lacking a definitive cause. Yet such claims obscure a more nuanced reality: contemporary culture still lacks a shared language to articulate multiple levels of causality and mind-body integration in ways that are meaningful for both patients and healthcare professionals. At the same time, the informational environment surrounding illness has shifted dramatically. Online, health-related knowledge circulates within algorithmically governed ecosystems that amplify emotive, identity-organised, and polarising narratives. These socio-technological conditions shape how people make sense of bodily experiences long before they encounter healthcare professionals.

Therefore, although more recently developed mechanistic models offer new conceptual bridges across mind–body dualisms, their translation into accessible public-facing resources, that can capture attention within digital information environments remains limited. The *Bodysymptoms* studies introduced in the following chapters describe our exploration of and attempted response to this predicament.

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Chapter 4. Overview of study aims and rationale

This chapter presents the four studies that comprise the thesis. Although Studies II and III address different aspects of the same process—the development of *bodysymptoms.org*—the rationale and aims of each study are introduced separately. Connections between the studies and broader methodological reflections are discussed in Chapter 10.

Study I: Explanatory Models in European Healthcare Settings

This PhD was initially proposed as a project to develop an early intervention digital health resource for FD that could be relevant across European treatment settings. At the outset, it was unclear whether approaches to FSS described in the literature are relevant across different treatment and cultural contexts. The first study sought to map how healthcare professionals explain FSS and what patient education resources they rely upon in practice. The aim was to identify both existing explanatory practices and resource gaps across European healthcare contexts.

Study II: Developing bodysymptoms.org: a focus on Participatory Design processes.

Shared explanations are essential in addressing the stigma, lack of healthcare resource and scientific neglect experienced by both patients and professionals seeking to understand and manage FSS. However trustworthy and integrative explanations for FSS are largely absent in the public domain. In response, we aimed to develop a therapeutically relevant and broadly acceptable public facing explanatory resource. Study II focuses on the participatory processes employed in the co-design of *bodysymptoms.org*, a website that communicates how FSS arise, persist, and may be alleviated. The overarching aim was to explore whether meaningful participation can result in the co-design a novel explanatory resource.

Study III: Conceptual development of a Therapeutic Explanatory Framework

Study III describes the conceptual development of the bodysymptoms explanatory framework and reflects on the epistemic and ethical considerations that arose

during this process. The overarching aim was to produce a therapeutic explanatory framework for multi-system FSS that is acceptable and helpful across relevant epistemic communities (I.e. coherent with views from research, healthcare and lived experience) through iterative stages of dialogue and reflection.

Study IV: Post-Launch Evaluation

The final study comprising the thesis is a short report evaluating the public-facing bodysymptoms.org website following its launch. This study explored the acceptability, usability, and relevance of the resource in real-world contexts, and reports on how feedback contributed from visitors to the website was formative in guiding the updated version of bodysymptoms.org that was launched in September 2025.

In this digital document, chapters 5-8 which reproduce published journal articles have been removed. Open access versions of the articles can be found via the following links:

Study I: https://doi.org/10.1016/j.jpsychores.2023.111155
Study II: https://doi.org/10.1016/j.jpsychores.2024.111827
Study III: https://doi.org/10.1136/medhum-2025-013380
Study IV: https://doi.org/10.1016/j.jpsychores.2025.112445

Chapter 9: Summary of main results

This chapter synthesises the central findings of the thesis and reflects on the methodological trajectory of the Bodysymptoms project, examining how its four constituent studies are connected. Together, the four studies trace a coherent methodological arc—from mapping existing explanatory practices for functional somatic symptoms (FSS), through the participatory design and conceptual development of *bodysymptoms.org*, a digital explanatory resource, to the formative evaluation of the website following its launch. Each study informed the next, and generated insights that build toward our conceptualisation of therapeutic explanation as applied to a contested and complex area of healthcare.

Study I employed a mixed-methods approach to map how explanations for FSS are formulated and communicated in clinical practice across Europe (Saunders et al. 2023). It identified some building blocks for a generalised explanatory framework alongside key epistemic and communicative challenges faced by clinicians as they try to provide biopsychosocial explanations for FSS. In particular it drew attention to the international lack of accessible, high-quality online resources to support integrative explanations. These findings established the rationale for adopting a research-in-action methodology: a solvable, practice-based problem called for a pragmatic response capable of generating immediate value for the affected communities (Gubrium et al. 2016).

In response, **Study II** adopted a participatory design-based approach to explore how explanations might be co-created and communicated. The study describes and evaluates the participatory processes that led to the launch of *bodysymptoms.org* in January 2024 (Saunders et al. 2024). This methodology enabled the project to unfold as an applied investigation of how explanatory models can be embedded in metaphor, visual imagery, and digital usability (UX) design. By creating dialogic space between different forms of expertise, and different ways of knowing (Cowley, N. 2013) , Bodysymptoms aimed not only to

produce a digital resource but also to generate new insights into what constitutes therapeutic explanation.

Study III reflects on the conceptual and ethical underpinnings of the *bodysymptoms.org* explanatory framework(Saunders et al. 2025). Providing information in areas of contested and stigmatised illness is an ethical endeavour that requires careful attention to how knowledge is created, curated, and communicated (Buchanan 2020). Alongside describing the development of the Bodysymptoms explanatory framework, Study III articulated the epistemic and ethical reflections that emerged as the project engaged diverse methods to capture and synthesise multiple modes of knowing.

Finally, **Study IV** presents a formative evaluation of the perceived relevance, usability, and acceptability of *bodysymptoms.org* following its public launch. This evaluation can be seen as a further iterative phase in the participatory design process, extending participation to a broader public beyond the initial project group. Despite limitations to the generalisability, feedback indicated potential acceptability and perceived usefulness of the resource, while also generating suggestions for refinement that were incorporated in an update to the website in September 2025, as well as for future research directions (see Chapter 12).

Taken together, these studies demonstrate a clear methodological progression—from exploration and conceptualisation to participatory co-creation and evaluation—anchored in reflexivity, interdisciplinarity, and iterative learning.

Synthesis

The work consists of four interconnected studies that together identify and address a gap in therapeutic explanation for FSS, positioning this problem—and its proposed solution—within the digital information ecosystem. Collectively, these studies advance the field by exploring how therapeutic explanation can be conceptualised, and how a resource that aims to support therapeutic explanation can be developed, and communicated to the public. Table 6 (below) summarises the contribution of each study and how they advance the overall arguments of this thesis

Study / Paper	Core Question	Methods & Data	Principal Findings	Contribution to Thesis Argument
Study I – Explanations for FSS across European treatment settings (Saunders et al. 2023)	How do European clinicians currently explain FSS, and what explanatory models are available to patients?	Mixed methods: cross-national survey (n = 186), thematic analysis of patient-education materials (n=72); semi-structured interviews (n=14).	Identified five dominant explanatory approaches; Revealed inadequacy of online resources to support clinical explanatory practices and lack of a shared explanatory framework.	Identifies the core problem: lack of a coherent, shared explanatory language with legitimate online visibility, highlighting the need for a unifying and accessible therapeutic framework situated in the digital information ecosystem.
Study II – Participatory Design of bodysymptoms.org (Saunders et al. 2024)	Can a digital resource presenting therapeutically relevant and broadly acceptable explanations for FSS be developed through meaningful participatory processes?	Participatory-design workshops with young adults with multisystem FSS; iterative prototyping.	Develops bodysymptoms.org as a sustainable and evolving resource for supporting integrative shared understandings of FSS Successfully demonstrates a participatory approach to development of an explanatory resource for FSS.	Provides insights into principles that can improve acceptability, relevance and helpfulness of explanations.
Study III – Conceptual Development of Explanatory Framework (Saunders et al. 2025)	What constitutes an adequate explanatory framework for FSS?	Reflective analysis, narrative approaches, embodied writing workshops, iterative development.	Describes a new explanatory framework for FSS structured around 28 interacting mechanisms.	Provides the conceptual foundation for therapeutic explanation as an epistemic and ethical practice.
Study IV– Post-launch evaluation of bodysymptoms.org (Submitted)	How is the online resource received in real-world contexts? How can the prototype be improved in terms of acceptability, relevance and usability?	Web analytics, user feedback, think aloud interviews. Consists of one iterative feedback loop in the broader design process.	Provides initial validation through early indications of acceptability, relevance and usability; moderate visitor numbers highlighted need for creative dissemination strategies.	Highlights need for further personalisation to streamline routes through content. Raises the question of how health information might be ethically created, curated and communicated in digital environments.

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Chapter 10: Discussion of methods

This chapter reflects on the methodological logic that guided the research design within the Bodysymptoms project. It begins by outlining how our assumptions and positioning shaped the project's commitments to participation and perspectivism. The chapter then considers the strengths and limitations of the research approaches.

11.1 Reflections on Assumptions and Positioning

Several intellectual commitments guided the project from the outset and became increasingly explicit as the work unfolded.

Ontological assumptions

Firstly, the project was grounded in an understanding of FSS as complex and emergent phenomena. It assumed that symptoms cannot be reduced to discrete causal pathways but arise from dynamic, multi-level interactions between bodily, cognitive, emotional, and social processes. This view, shaped from the outset by our academic and institutional positioning, was also reflected in the perspectives of healthcare professionals surveyed in Study I. However, these assumptions are not universal, and they carried direct methodological implications.

Adopting this integrative stance influenced how research questions were formulated, how participants were recruited, and how the explanatory framework ultimately evolved. It also shaped the approach taken in *bodysymptoms.org*, where a trans-diagnostic mechanistic model of explanation was prioritised over condition-specific narratives. While this was an innovative and conceptually coherent feature of the resource, it may also have limited its accessibility and reach for visitors looking for information framed through familiar symptom or diagnostic categories. In this sense, the project's theoretical commitments both enabled conceptual innovation and introduced systematic bias by limiting its

resonance among those who favour disease-mirroring approaches to symptom explanation.

Epistemological stance

Our research approach was underpinned by an epistemic commitment to perspectivism (Fagan 2019), informed by feminist standpoint epistemology (Harding 1991). It assumed that no single perspective—scientific, clinical, or experiential—could claim epistemic authority over understanding FSS; rather, meaning emerges through dialogue among these distinct forms of knowing (Wagner et al. 2019). Traditional biomedical epistemologies have tended to privilege scientific reasoning over lived experience. The *Bodysymptoms* project deliberately resisted this hierarchy by creating spaces where new meanings could surface through interaction. Iterative, dialogic methods—such as workshopping, think-aloud interviews, and collaborative prototyping—were employed not only as participatory tools but as epistemic interventions, designed to foster conditions in which novel and integrative insights could emerge (Pot 2022). Nevertheless, the range of perspectives included inevitably shaped the epistemic boundaries of the knowledge produced.

Participatory action research

The Bodysymptoms project exemplified the principles of research-in-action, characterised by iterative refinement of methods and outputs in response to feedback and emerging insights. Rather than proceeding linearly, the project unfolded as a dynamic cycle of inquiry, design, reflection, and adaptation. The research-in-action approach enabled responsiveness to emergent insights (Gubrium et al. 2016). However, the emphasis on developing a resource with immediate, practical benefit for affected communities necessarily shaped what was possible in terms of evaluation. Making bodysymptoms.org freely available to the public—without log-ins or other barriers to access—meant that formal assessment of its effects through methods such as randomised controlled trials was not feasible.

10.2 Strengths and limitations

The following section discusses the methodological strengths and limitations of the project in relation to mixed methods, inclusivity of perspectives, evaluation design, and broader methodological contributions.

Mixed methods: Study 1

By combining analysis of materials, interviews, and survey data, the mixed methods design of Study I allowed us both breadth and depth of insight into patient education practices across European treatment settings. Analysis of patient education material enabled direct view of explanatory materials patients receive, the survey mapped a broad picture across multiple countries and professional groups, and interviews deepened analysis through including HCPs own reflections on their explanatory practices.

Alternative methods could have been employed to address the research question. Direct observation of patient–practitioner encounters could have captured explanatory practices in their natural setting, revealing not only what was said but also how explanations were delivered, negotiated, and received. However, this would have required extensive resources, raised ethical concerns, and been more difficult to standardise across countries. A structured consensus-building method such as the Delphi technique could have been used to identify areas of agreement and divergence among experts in FSS care. This would have highlighted professional priorities and facilitated dialogue across disciplines, though results might reflect ideals even further from the explanations used in day–to–day practice. Focussing on a larger-scale survey could have produced more generalisable data on explanatory models used across Europe. However, such an approach would have sacrificed the richness of insights gained from qualitative interviews and materials analysis, and would likely have provided a less nuanced understanding of the relational and cultural dynamics of explanation.

Inclusivity of Perspectives

Participatory methods were chosen in recognition that knowledge of illness arises not from any singular locus of expertise but from relational encounters between a

person, their body, healthcare, and technologies (Liu et al. 2025). This approach enacted a modest democratisation of epistemic authority (Buchanan 2020), positioning people with lived experience as credible knowers rather than passive recipients of professional expertise (Carel and Kidd 2014) and reflects a wider 'participatory turn' in healthcare policy and research, which increasingly emphasise patient-centredness, participation, and empowerment (Wehling et al. 2015).

However, as has been previously argued, participatory design (PD) inevitably operates within power-laden and bounded contexts (Kensing and Blomberg 1998). Despite efforts to create inclusive processes, bounded openness characterised the project: it welcomed multiple perspectives but remained constrained by its institutional setting and recruitment routes (Zahlsen et al. 2022). The recruitment of participants to the Bodysymptoms project via clinicians, though ensuring diagnostic relevance and safe participation, may have biased participation toward individuals predisposed to engage constructively with healthcare rather than be uncomfortably critically of it (Faber 2024). Individuals with higher digital literacy and health literacy were more likely to participate and provide feedback across the studies, while it is likely views aligned with reductionist or biomedical frameworks were underrepresented. The project thus risked reproducing epistemic bubbles, even as it sought to expand them (Pollock 2024).

Use of digital technologies for project activities likewise simultaneously enabled and limited inclusion. Online workshops facilitated transnational participation and accommodated fluctuating health, yet they also excluded individuals without digital access or confidence in spoken English. A broader inclusion of socio-technologically disadvantaged and 'non-institutional' voices could have increased the projects relevance to a wider population of potential end users (Faber 2024).

Within these constraints, the project experimented with ways of giving form to knowledge often excluded from evidence-based medicine (Faulkner 2017). Narrative workshops (Anderson 2002, 2020) provided opportunities to translate tacit, embodied, and pre-linguistic experience into shareable concepts. Yet, even

these creative methods may have privileged participants able to articulate their experiences narratively or metaphorically, introducing another potential source of bias in terms of whose perspectives were represented, and which perspectives were systematically excluded.

Evaluating the Project

The evaluation of the project was designed as a formative process, (Eldridge et al. 2016), guided by considerations for evaluating complex public health interventions (Glasgow et al. 1999). Our analysis plan included an evaluation of feasibility under the headings: Process, Resource, Management, and Output (Orsmond and Cohn 2015). The Process evaluation is written up within Study II, and the Output evaluation, which focuses on the perceived acceptability and relevance of the website to inform an update, as Study IV. For a synthesis of the other areas of evaluation please see Appendix F. This choice reflects the limitations of- applying RCT-style designs to publicly available web-resources, where exposure and control cannot easily be managed (Eysenbach 2002).

Taking this approach prioritised a focus on process over demonstrating effectiveness. Choosing not to orientate the project towards a randomised trial introduced specific limitations to the inferences that can be drawn regarding usability and engagement. An RCT focused feasability would have required that we kept bodysymptoms.org behind a log-in barrier, reducing its initial value for effected communities, but might have delivered a clearer rationale for scaling by generating effectiveness data more readily recognised within conventional evidence based medicine hierarchies. The pragmatic, participatory trajectory adopted here prioritised relevance and responsiveness over rigour in the positivist sense. While this choice aligns with our epistemological stance, and our funders open-access values, it also restricts generalisability and limits the project's capacity to make comparative claims about impact, reflecting the tension between PD's situated, processual nature and the scientific preference for systematic evaluation (Nguyen 2022).

The dual role of project members as designers and evaluators risked confirmation bias: interpretive proximity that enhanced reflexivity might also have compromised objectivity. When it came to making use of web-analytics, our commitment to visitor privacy restricted the collection of fine-grained data on user trajectories or behavioural outcomes. Thus, while triangulation of public feedback, web-use analytics, and team reflection enhanced the credibility of the findings, the evaluation remained reliant on selective engagement and self-reporting biases. These factors limit the generalisability of the results and constrain conclusions about the website's broader impact on the population affected by FSS.

Methodological Contributions

The participatory design and implementation of *bodysymptoms.org* demonstrate an ethical approach to the creation, curation, and communication of health information in digital environments (Kyakulumbye et al. 2019). The project synthesised principles from PD and PPI to facilitate multi-perspectival knowledge exchange and exemplified how bodily limitations can be attended to within co-design processes (See representative study documents included as Appendices I–M). This commitment to psychological safety and working with fluctuating symptoms, enabled sustained engagement and models a successful approach to meaningful participatory research within a contested field of health.

Beyond conditions characterised by FSS, these methods have transferable value for other areas of medicine characterised by epistemic uncertainty, stigma, or competing explanatory paradigms. The project demonstrates that participatory, reflexive, and transdiagnostic approaches can produce frameworks that are not only scientifically coherent but also experientially resonant and socially legitimate.

10.3 Summary

Across all studies, the methodological design of the Bodysymptoms project integrated scientific, clinical, and experiential perspectives through reflexive and dialogical practice. Its perspectival epistemology and participatory ethos enabled

the project to remain responsive to complexity and to the lived realities of those affected by FSS. Participatory methodologies functioned not simply as inclusive procedures but as tools for knowledge creation, producing epistemic spaces where novel understandings of symptom meaning and management could develop.

Overall, the Bodysymptoms project demonstrates the methodological value of interdisciplinary approaches to advance both the theory and practice of explanation in medicine. At the same time, it is important to acknowledge that a participatory ethos does not eliminate bias. PD's emancipatory promise can obscure whose voices are still excluded and how design decisions stabilise particular worldviews (Nguyen 2022; Zahlsen et al. 2022). Recruitment strategies and the institutional context which Bodysymptoms was situated in, inevitably shaped which voices were included, and delineated the project's epistemic boundaries.

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Chapter 11: Discussion of results

One way to understand the Bodysymptoms project is as a process of collective learning: as we engaged with perspectives (texts, experiences, narratives, metaphors, feedback) that sometimes sat uncomfortably along-side each other, attention to the surprising elements, or frictions, allowed a new understandings to emerge (Hasse 2015). In this chapter we outline a conceptualisation of therapeutic explanation, that emerged through this learning process. We will then discuss the value and limitations of bodysymptoms.org as a resource for supporting therapeutic explanation before suggesting clinical implications and future research directions.

11.1 Towards therapeutic explanation

Throughout this thesis, explanations have been explored as both epistemic and pragmatic tools—means through which illness and recovery are experienced and enacted. Previous philosophical accounts of explanation in medicine have tended to emphasise scientific reasoning, or focus on the clinician's epistemic endeavour (Varga 2024). By contrast, we advance a conceptualisation of therapeutic explanation that centres the epistemic endeavour of the person seeking to make sense of their symptoms.

We suggest that therapeutic explanation:

- is co-constituted between the individual and the technologies, socio-cultural worlds, and healthcare systems they engage with
- provides a coherent account of reality that resonates meaningfully across epistemic communities allowing shared understandings to develop in key therapeutic relationships (e.g. between HCPs and patients)
- invites hope and (self-)compassion while softening blame and shame
- enables an embodied form of understanding that opens up, rather than forecloses, future possibilities.

This conceptualisation builds upon and extends previous work on explanation in the field of FSS. Greco's description of 'pragmatic explanation' reconfigures explanation for symptoms as a creative and ethical wager—its truth grounded not in representational accuracy but in its capacity to generate salutary effects in practice (Greco 2017). Kirmayer has emphasized the metaphorical, embodied and enacted dimensions through which individuals make sense of and transform their suffering (Kirmayer 2023). The work of Sanders et al. on biographical repair further demonstrates that explanation can have reparative effects on narrative coherence and identity (Sanders et al. 2024). Research focussing on clinical communication has identified the importance of mechanistic explanation that can be presented as understandable adaptations to circumstances (Morton et al. 2017), while Kozlowska highlights the importance of co-construction of mechanistic explanations that bring focus to areas where interventions hold potential to shift the mind-body systems back to health (Kozlowska 2013). The present thesis brings together these related ideas by proposing that therapeutic explanation brings about three linked domains of understanding:

1. **Mechanistic understanding** involves grasping how a symptom is constituted so that opportunities for intervention become clear (Morton et al. 2017; Kozlowska 2013).
2. **Narrative understanding** lends meaning to symptoms, orienting illness identity in therapeutic directions. When explanations resonate narratively, they restore coherence and meaning where these have been lost (Sanders et al. 2024), opening imaginative space for new forms of self-care and recovery (Greco 2017).
3. **Embodied understanding** represents a tacit *know-how* integrated through bodily experience—a practical understanding through which symptoms become manageable (Kirmayer and Gómez-Carrillo 2019).

Our concept advances these ideas by placing the person experiencing symptoms at the centre of an inherently individual, dynamic, and relational process of sense making unfolding through ongoing interactions within a broader lifeworld (figure

7).

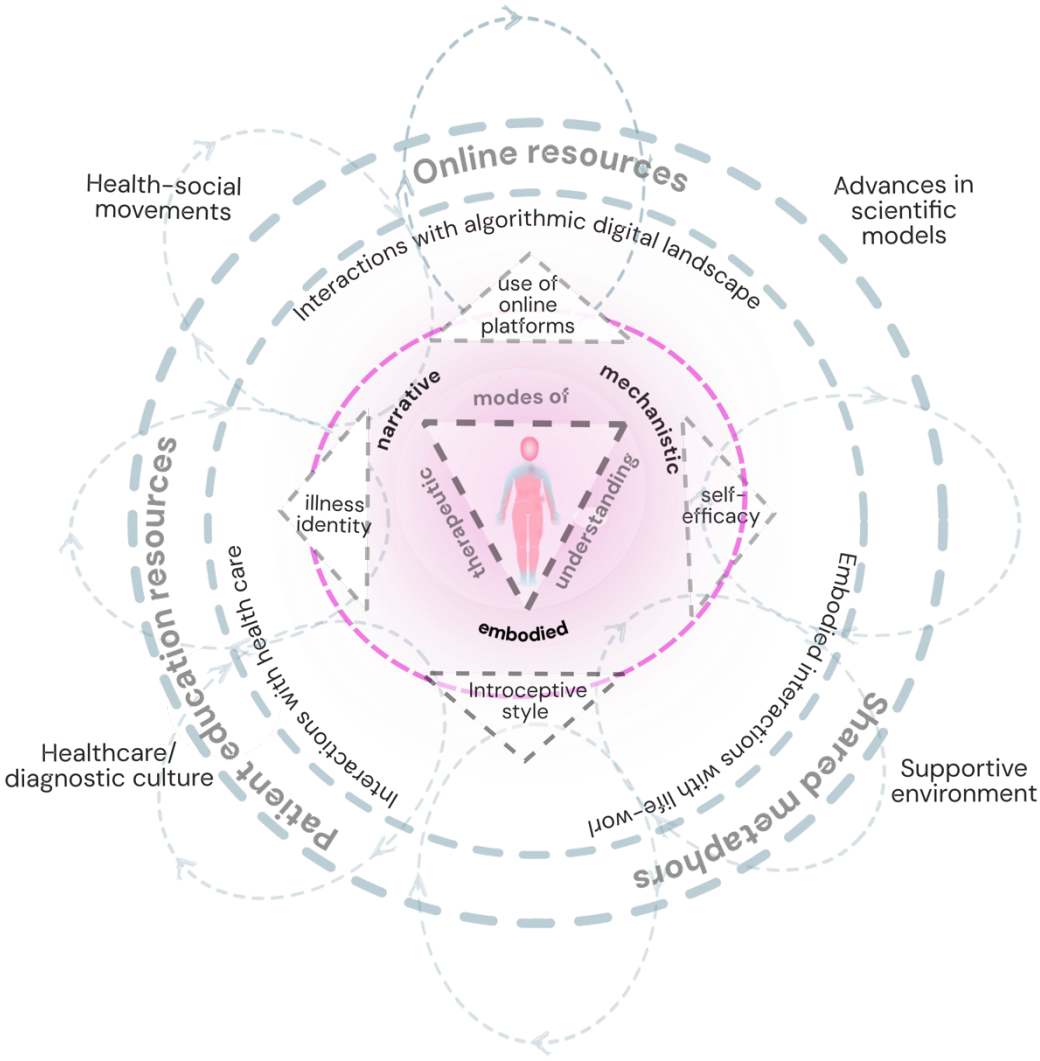

Figure 10 Co-constitution of therapeutic explanation

An illustrative case: Terence

Terence joined the Bodysymptoms project after developing persistent symptoms related to Covid-19. He describes a shift that came about in his health when the old metaphor he was holding to explain his symptoms was replaced by a new one:

> *"The first thing I assumed—as many do—was that my immune system was weakened.* (I discovered).. *In fact, it may be on high alert. That was a new concept for me and those I mentioned it to."*

As a martial artist, the idea of weakness had triggered a drive to push harder to strengthen himself. Understanding his immune system as overactive, however, led him to adopt a radically different approach:

> *"Instead of working to strengthen my immune system, I focused on relaxing my body to let it do its job. Very quickly, I noticed an improvement in my symptoms."*

This example illustrates succinctly how the three forms of understanding invoked by a therapeutic explanation inter-relate. There was a shift in mechanistic understanding, articulated in metaphorical terms: Terence had assumed his fluctuating symptoms were maintained by a weak immune system, letting frequent infections take hold; however he came to understand the immune system as 'on high alert', with symptoms generated by overprotective immune defences. He could integrate this new metaphor in his biography: given his previous health and athleticism, it made sense to Terence that his immune system was overactive, rather than weak. This new narrative understanding allowed him to repair his self-concept as a vigorous, healthy person. The embodied understanding then came as he applied himself to relax the body 'to let it do its job', leading to a noticeable improvement in symptoms.

These themes align with findings from Bakken *et al.*'s study of common threads in the narratives of people who have recovered from CFS/ME. They conclude a shift in illness understanding is pivotal in recovery when it opens up new ways to interpret sensations and increases the degrees of freedom imagined for self-regulation (Bakken *et al*. 2023). However, such a shift in understanding is relatively hard to come by. Terence only came to his therapeutic explanation several years into his illness, despite seeking advice from the healthcare system, carrying out extensive online research, and being active in several online support groups. Other participants described even more complicated processes.

In the following section, we draw on concepts from postphenomenology to outline key constituents and relational structures that may underlie therapeutic

explanation as it unfolds through an individual's interrelations with their lifeworld (Verbeek 2015).

Mediation of therapeutic explanation

In Study I, healthcare professionals (HCPs) noted that patients' pre-existing understandings, along with the online resources available to them, were key factors shaping whether a clinical explanation could be accepted and made use of. This observation highlights several elements that mediate the development of therapeutic explanation. These encompass both individual dispositions (e.g. illness identity) and external structures (e.g. the algorithmic systems that determine which information is made visible to an individual based on the categorisation of their 'digital double') (See figure 10).

However, therapeutic explanation does not arise from a simple interaction between disposition and external structures. Rather, it is co-constituted through dynamically related 'looping effects' (Kudina 2023), in which persons and technologies continually shape one another. For example, the relationship between illness identity and algorithmic information exposure is recursive: identity-based searches influence how individuals engage with algorithms (Hiaeshutter-Rice et al. 2024), while in turn, illness identity is scaffolded by the heuristic resources that algorithms render visible and shape (Chevalier 2024).

Moral aspects

One central question raised by this thesis, is where responsibility for therapeutic explanation lies, if it is not clearly situated within the clinical or scientific domains. Our conceptualisation of therapeutic explanation as a continual negotiation of knowledge, identity, and action, advanced by the individual, but shaped by the resources and relationships available to them suggests a distributed responsibility across people with symptoms, healthcare systems, scientific communities, health-social movements, cultural influencers and networked technologies. Within this ecology of knowledge, there is a shared responsibility for determining which explanatory resources are available and made visible to shape the possibilities for symptom management or recovery.

11.2 The value and limitations of bodysymptoms.org as a resource to support therapeutic explanation

Bodysymptoms.org represents an attempt to create a digital resource capable of supporting the development of therapeutic explanations for FSS. Its value lies in the guarantee that its curated metaphors, narratives, and framings have been iteratively refined incorporating feedback from various perspectives. In this sense bodysymptoms.org can be said to offer relevant explanations for symptoms that have been 'tested out' for acceptability across multiple epistemic communities.

However, several limitations temper this potential. Firstly, the challenge of personalisation proved substantial. Therapeutic explanations are individual: they must resonate across heterogenous conditions and contexts. Yet as a public facing resource, *bodysymptoms.org* necessarily presents generalised content. Although various steps were taken to facilitate personalisation of the bodysymptoms explanatory framework (Saunders et al. 2024), it was clear from Study IV that these attempts did not go far enough to mitigate for individual differences both in symptomatology, health literacy, attention and motivation.

Second, the transdiagnostic scope constrained digital reach. By avoiding syndrome-specific terminology, the approach was conceptually innovative, but lost algorithmic visibility in search environments dominated by diagnostic keywords (Lee et al. 2021). This limits both discoverability and immediate relevance for users orientating their search for information on the basis of specific symptoms or diagnostic labels.

This highlights the broader challenge of digital visibility in contemporary health knowledge ecosystems (Liu et al. 2025). Explanations increasingly circulate within algorithmically mediated spaces where visibility and hence credibility are shaped by emotional salience (Zhang and Centola 2019). Within this landscape, *bodysymptoms.org* offers an important epistemic alternative—prioritising integrative, balanced, and compassionate framings over alarmist or polarised narratives—but its influence is necessarily constrained by the infrastructures that govern online attention. Sustaining the resource as a living site of therapeutic

explanation will therefore require ongoing engagement with dissemination strategies and search engine optimisation (SEO) to ensure that reflective and humane understandings of bodily experience remain accessible within the broader digital information environment (Jafar et al. 2023).

11.4 Clinical Implications

Developing integrative understandings of persistent physical symptoms—and improving both public and professional literacy around the mechanisms that maintain them—has been identified as a central challenge for European healthcare (Toussaint et al. 2025). This thesis contributes to that agenda through both its conceptualisation of therapeutic explanation and the participatory development of bodysymptoms.org, which together suggest new directions for clinical practice.

Good explanations for FSS have been recognised not merely as adjuncts to treatment but as therapeutic interventions in their own right (Stone et al. 2016). Yet training of healthcare professionals in supporting therapeutic explanation remains underdeveloped (Salmon 2007; Nagel et al. 2024). This thesis provides a framework for integrating support for therapeutic explanation more deliberately into clinical practice. By centring the person seeking to make sense of their symptoms—and acknowledging that this process unfolds within a digitally mediated information ecosystem—it reframes the clinician's role as information provider (Winters et al. 2025). Recognising that shifts in understanding can take time, the clinician's task becomes one of supporting the patient in the grasping, integration or embodiment of new metaphors that hold potential to resonate on personal levels and shift the bodily condition from illness back to health.

Clinicians can draw on the metaphors and framings developed through *bodysymptoms.org* as conversational tools, or direct patients to the site as a trusted resource that complements in-person dialogue (McLoughlin et al. 2025). Beyond this, our concept of therapeutic explanation could also equip clinicians to recognise the individual factors—such as illness identity, digital information environment, interoceptive style or self-efficacy that may be obstacles to

therapeutic understanding for an individual, and to target their support accordingly. Importantly, recognising that therapeutic explanation is that which is grasped and integrated by the patient, often fairly independently of healthcare, challenges traditional knowledge hierarchies (Erikainen et al. 2019). It asks clinicians to share epistemic authority and to acknowledge patients—even when they bring "uncomfortable knowledge" (Sendra Toset et al. 2023) as the central constructor of meaning. Such a reorientation is in line with a broader movement towards person-centred medicine (Cathébras 2021), but further responds to the reality of the digital information ecosystem as an increasingly important mediator of illness identity and health outcomes (Zenone et al. 2022).

11.5 Future directions

Personalised explanation

Future studies could build on *bodysymptoms.org's* ontological framework to develop a personalised and adaptive explanatory tool (Quinn et al. 2014). Effective personalisation of our mechanistic modular framework could be achieved through a reasoning engine that links user input (for example questions on the phenomenology of symptoms, level of information sought) with tailored explanatory content. Machine learning could refine these rules, enabling the system to infer which explanatory modules best match an individual's needs and context. Such a system would mirror expert clinical reasoning—constructing flexible, context-sensitive explanations that help people make sense of their unique experiences, without burdening or overwhelming them with irrelevant information. Developing personalised approaches to explanation is a necessary step toward precision medicine in this field (Gómez-Carrillo et al. 2023).

Evaluation of therapeutic explanation as a mediator of illness experience

This thesis assumes that explanations can themselves act as preventive or therapeutic interventions: structures of meaning that lay the foundation for adaptive responses to the experience of symptoms. The development of

bodysymptoms.org offers one instantiation of a resource that aims to support therapeutic explanation, but the broader framework invites examination of the therapeutic effects of explanation, across diverse online and offline settings. Methodologies need to consider the necessarily individual and dynamic nature of therapeutic explanation. We suggest that qualitative methods (e.g. narrative analysis (Bakken et al. 2023)) are suitable and appropriate forms of enquiry. When it comes to quantitative approaches, *n=1* and other idiographic methodologies will be essential for tracing individual experiential trajectories over time (Burton 2025), and measures of self-efficacy, illness perceptions, or empowerment could be fruitful outcomes to investigate (McAllister et al. 2012).

Exploration of the role of technology as mediator of illness experience

We have suggested that explanations are co-constituted, with the digital information environment centrally important in the development of therapeutic explanations. However this proposal would benefit from further research. Ethnographic, sociological, and philosophical approaches can illuminate how illness explanations and identities are co-constituted within algorithmised medicine (Liu et al. 2025). Postphenomenological approaches may be particularly valuable for examining how engagement with technology shapes evolving illness identities—either reinforcing anxiety and chronicity or promoting agency, dignity, and wellbeing, and help further clarify how moral responsibility for un-therapeutic explanations might be shared by networked technologies (Verbeek 2024).

11.6 Conclusion

In conclusion, this thesis offers a pragmatic response to the predicament faced by many people with persistent symptoms: the absence of adequate and helpful explanations within both healthcare and wider information environments. This problem is deeply intertwined with the complex and contested nature of conditions characterised by FSS, which often fall outside conventional disease categories.

Existing theories of explanation in medicine largely centre on scientific or clinical sense-making and communication. However, these frameworks tend to overlook how explanations are shaped by those seeking to understand their own symptoms, particularly as this meaning-making increasingly unfolds within digitally networked spaces. This thesis introduces the concept of *therapeutic explanation*: a person-centred cognitive process through which an answer to the question, *"What do I need to understand in order to better manage my symptoms or recover?"* is grasped, integrated, and embodied. This concept extends existing accounts by foregrounding the socio-technical and embodied dimensions through which such questions are posed and answers sought in contemporary, "e-scaped" medicine (Nettleton 2004).

Within this landscape, *bodysymptoms.org* provides an open-access repository of metaphors, narratives, and framings that bring clinical insight and emotional nuance into a shared digital space. Rather than competing with diagnosis-oriented medical websites, it aims to communicate transdiagnostic, integrative explanations that bridge mind and body through non-reductive language. In developing this framework, we navigated the tension between the need for personalised, person-centred explanation and the value of generalisable models that can be shared across clinical, research, and cultural domains. Yet the reach and influence of such a resource are inevitably shaped by the digital infrastructures through which people seek understanding.

To sustain bodysymptoms.org as a resource that can support therapeutic explanation on a wider scale, future work must remain attuned to the sociotechnical conditions through which explanations emerge. This entails sustained attention to digital visibility, the development of adaptive personalisation tools, and inclusion of diverse perspectives. Above all, *bodysymptoms.org* must evolve alongside shifting forms of illness identity, networked knowledge, and artificial intelligence, remaining visible and meaningful within the algorithmic logics that shape the digital age.

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Chapter 12: English Summary

This thesis addresses a persistent challenge in contemporary healthcare: how to explain symptoms that are not directly caused by structural disease or injury. Such symptoms are common and can lead to distress, disability, and difficulties navigating healthcare. The terminology used to describe them is varied and contested; here, the term Functional Somatic Symptoms (FSS) is adopted as an umbrella category. Although experiences of FSS are highly individual, many people encounter diagnostic uncertainty, stigma, and fragmented care.

Explanations of bodily symptoms are central to how patients understand, manage, and recover from illness. Therapeutic explanations—those that enable constructive sense-making and guide effective symptom management—form the conceptual focus of this thesis. In an era where online information increasingly shapes health beliefs, the lack of accessible, evidence-based explanations for common FSS in many European languages, coupled with algorithmic biases toward alarming content, creates an information void that can exacerbate anxiety and hinder recovery.

The project explored how therapeutic explanations can be collaboratively developed and made publicly accessible through participatory methodologies. Four interlinked studies were conducted to map current explanatory practices, co-design an integrative explanatory framework, and evaluate its usability and acceptability.

Study I maps explanatory practices for FSS across European healthcare systems using mixed methods, revealing the absence of shared, integrative frameworks to communicate models of symptom causation.

Study II describes the participatory development of bodysymptoms.org, an open-access website offering integrative, evidence-based explanations for multi-system FSS.

Study III articulates an explanatory framework comprising 28 interacting mechanisms, translated through metaphor, narrative, and actionable advice, and develops the conceptual foundation of therapeutic explanation.

Study IV evaluates the digital resource's relevance, usability, and acceptability following its public launch.

Across the project participatory research-in-action approaches were combined with mixed methods and reflective inquiry, demonstrating that co-design can produce an explanatory framework for symptoms that is acceptable and relevant across different end user groups, within a contested area of healthcare.

The thesis proposes the concept of therapeutic explanation as a framework for understanding the experiences of people with FSS as they come to make sense of their symptoms within the current socio-technological landscape in ways that can restore meaning, support embodied understanding and expand possibilities for shared understandings and symptom mastery.

Future work should focus on developing adaptive, personalised explanatory tools, understanding how therapeutic explanations are co-constituted between individuals and their social, technological, and healthcare contexts, and continue to broaden inclusion of perspectives.

Chapter 13: Dansk resumé

Denne afhandling omhandler en vedvarende udfordring i det moderne sundhedsvæsen: hvordan man kan forklare symptomer, der ikke direkte skyldes en strukturel sygdom eller skade. Sådanne symptomer er almindelige og kan føre til betydelig belastning, funktionsnedsættelse og vanskeligheder med at navigere i sundhedssystemet. Terminologien, der anvendes til at beskrive dem, er mangfoldig og omstridt; her bruges betegnelsen *funktionelle somatiske symptomer* (FSS) som en overordnet kategori. Selvom oplevelsen af FSS er individuel, møder mange mennesker diagnostisk usikkerhed, stigmatisering og fragmenteret behandling.

Forklaringer på kropslige symptomer er afgørende for, hvordan patienter forstår, håndterer og kommer sig over sygdom. *Terapeutiske forklaringer* – forstået som forklaringer, der understøtter meningsskabelse og fremmer effektiv symptomhåndtering – udgør afhandlingens konceptuelle fokus. I en tid, hvor onlineinformation i stigende grad former sundhedsopfattelser, bidrager manglen på tilgængelige, evidensbaserede forklaringer om almindelige FSS på mange europæiske sprog, sammen med algoritmisk bias mod alarmerende indhold, til et informationstomrum, der kan forstærke angst og vanskeliggøre bedring.

Projektet undersøgte, hvordan terapeutiske forklaringer kan udvikles i fællesskab og gøres offentligt tilgængelige gennem deltagelsesbaserede metoder. Fire indbyrdes forbundne studier blev gennemført for at kortlægge eksisterende forklaringspraksisser, co-designe en integrativ forklaringsramme og evaluere dens anvendelighed og relevans.

Studie I kortlagde forklaringspraksisser for FSS på tværs af europæiske sundhedssystemer ved hjælp af blandede metoder og viste, at der mangler fælles og integrerende modeller til at kommunikere symptomårsager.

Studie II beskriver den deltagende udvikling af *bodysymptoms.org*, en åbent tilgængelig hjemmeside, der tilbyder integrerende og evidensbaserede forklaringer på multisystemiske FSS.

Studie III præsenterer en forklaringsramme bestående af 28 sammenhængende mekanismer, formidlet gennem metaforer, fortællinger og handlingsanvisende råd, og udvikler det konceptuelle grundlag for *terapeutisk forklaring*.

Studie IV evaluerer den digitale ressources relevans, anvendelighed og acceptabilitet efter offentlig lancering.

På tværs af projektet blev deltagende *research-in-action*-tilgange kombineret med blandede metoder og refleksiv analyse. Resultaterne viser, at co-design kan frembringe forklaringsrammer for symptomer, der opleves som meningsfulde og anvendelige af forskellige slutbrugergrupper inden for et komplekst og omstridt sundhedsområde.

Afhandlingen introducerer begrebet *terapeutisk forklaring* som en ramme til at forstå, hvordan mennesker med FSS forsøger at skabe mening i deres symptomer i et moderne socioteknisk landskab. Sådanne forklaringer kan genskabe mening, styrke kropslig forståelse og udvide mulighederne for fælles forståelse og symptommestring.

Fremtidigt arbejde bør fokusere på at udvikle adaptive, personaliserede forklaringsværktøjer, undersøge hvordan terapeutiske forklaringer samskabes mellem individer og deres sociale, teknologiske og sundhedsmæssige kontekster, samt styrke inddragelsen af mangfoldige perspektiver.

Appendices

Appendix A: List of terms describing conditions considered to be primarily characterized by FSS.

Please note that some of the terms are contentious, and some are outdated*.

However, as they are all still used in some contexts, we include them for reference.

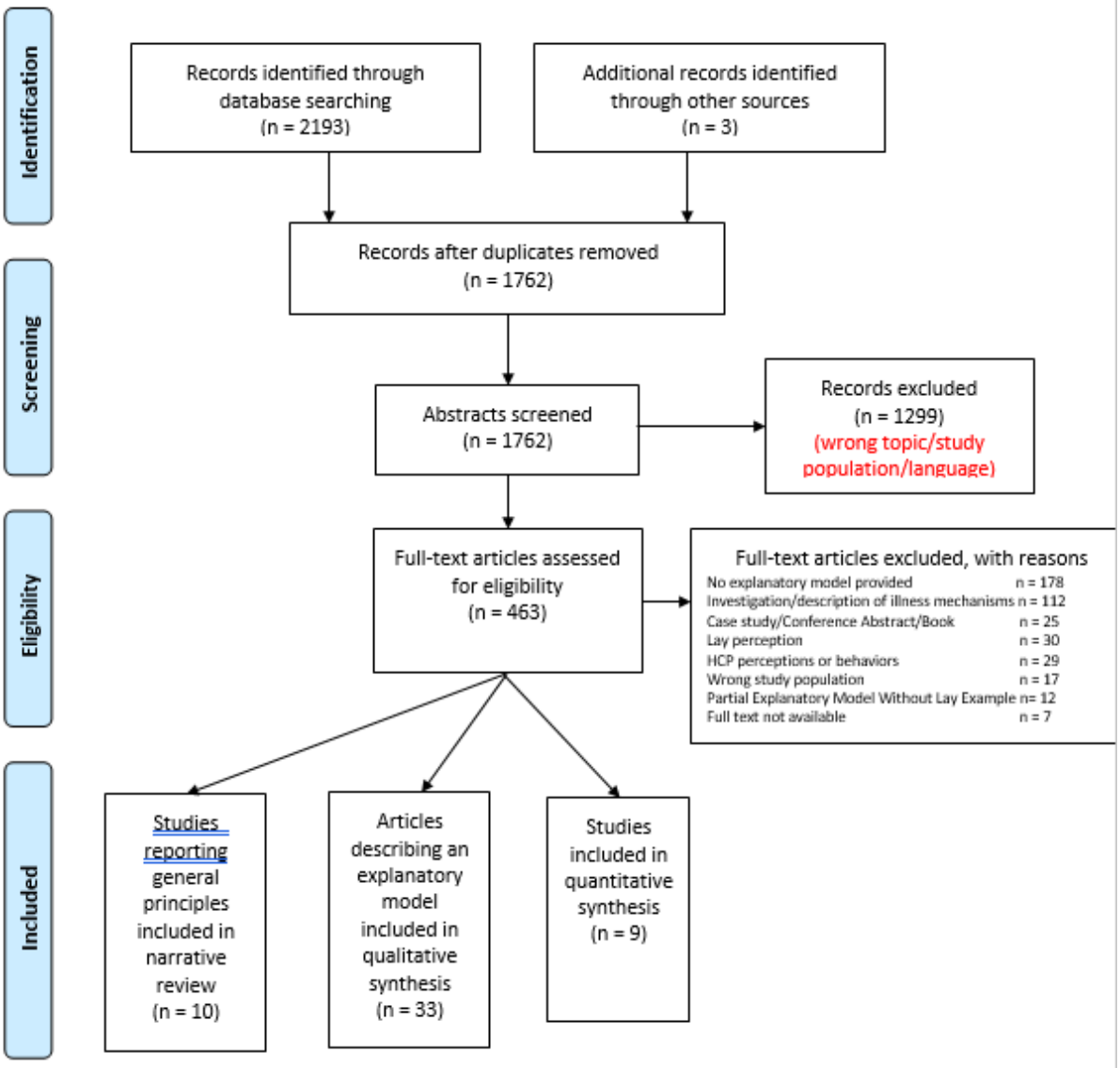
Terms used to describe symptoms	**Functional** symptom e.g. 'functional bloating'
	Persistent symptom e.g. 'persistent dizziness'
	Non-organic e.g. 'non-epileptic attacks'*
	Psychogenic symptom, e.g. 'psychogenic palpitations'*
	Subjective symptom, e.g. 'Subjective shortness of breath'
	Chronic symptom e.g. 'Chronic widespread pain'
	Intolerance e.g. 'Systemic exertion intolerance'
	Sensitivity/hypersensitivity e.g. 'Reflux hypersensitivity'
	Dysfunction e.g. 'Dysfunctional breathing' or 'Temporo-mandibular dysfunction'
	Disorder e.g. Functional neurological disorder
	Dissociative symptom, e.g. 'Dissociative amnesia'
	Psychosomatic
	Centrally mediated e.g. 'Centrally mediated abdominal pain'
	Medically unexplained*
	Idiopathic e.g. 'idiopathic overactive bladder'
	Nonspecific symptom e.g. 'Nonspecific chest-pain'
Functional somatic syndromes (Refers to defined clusters of symptoms, usually by organ system)	**Chronic fatigue syndrome** (ME/CFS)
	Irritable Bowel Syndrome (IBS)
	Fibromyalgia (FM/FMS)
	Multiple chemical sensitivity (MCS)
Related to trigger	**Post-'**disease/treatment' symptom, e.g. Post-chemotherapy fatigue; post-viral fatigue; Post-concussion syndrome; Post-traumatic complaint
	Chronic- 'name of infection or infury' e.g. Chronic Lyme/ Chronic Epstein Barr; Chronic Whiplash
	Repetitive **strain/overuse** injury
	Stress-related symptoms e.g. stress headache
Related to mechanism	Dissociative disorder

	Conversion disorder*
	Bodily stress
	(Disorders of) central sensitisation
	Disorder of brain-gut interaction
	Myofascial pain
	Microvascular, e.g. 'Microvascular Angina'
	Hyperventilation syndrome
Miscellaneous	
Gastro-intestinal	Globus sensation; Cyclic vomiting syndrome; Proctalgia fugax; Levator ani syndrome
Urological	Irritable bladder; Urethral syndrome; Shy-bladder; Interstitial cystitis; Fowler's syndrome; Hinman Syndrome
Neurological	Allodynia; Stroke mimic; Tension type headache; Dysautonomia
ENT (Ear, nose and throat)	Glossalgia; burning mouth; bruxism; Persistent postural perceptual dizziness; tinnitus, globus
Cardiology/Respiratory	Orthostatic hypotension (POTS); Hyperventilation syndrome
Psychiatry	Bodily Distress Disorder (ICD-11); Somatic Symptom Disorder (DSM-5); Somatoform* (ICD-10), Somatisation* (Primarily used by psychologists)
Endocrinology/general	Adrenal fatigue, burn-out, pre-menstrual tension; Neurasthenia/neuromyasthenia*; Circadian rhythm disorders; Sleep-wake cycle disorders.

Appendix B: Search term used in literature review (Section 3.3)

Search (((((explanatory model*[Title/Abstract]) OR "psycho education"[Title/Abstract]) OR psychoeducation[Title/Abstract]) OR explanation[Title/Abstract])) AND ((functional somatic syndrome*) OR functional somatic symptom*) OR functional syndrome*) OR functional disorder*) OR functional disease*) OR "Somatoform Disorders"[Mesh:NoExp]) OR "somatoform") OR "somatization") OR "somatisation") OR "Briquet's syndrome") OR somatic symptom disorder*) OR "Fibromyalgia"[Mesh]) OR Fibromyalgia*) OR "muscular rheumatism") OR "fibrositis") OR Fibrositide*) OR diffuse myofascial pain syndrome*) OR "fibromyositis-fibromyalgia") OR "chronic widespread pain") OR chronic benign pain syndrome*) OR chronic benign pain disorder*) OR "Fatigue Syndrome, Chronic"[Mesh]) OR CFS) OR "myalgic encephalomyelitis") OR "royal free disease") OR post viral fatigue syndrome*) OR "chronic fatigue") OR "fatigue syndrome") OR "Neurasthenia"[Mesh]) OR "neurasthenia") OR "Irritable Bowel Syndrome"[Mesh]) OR "IBS") OR Irritable Bowel Syndrome*) OR "irritable colon") OR "recurrent abdominal pain") OR "functional abdominal pain") OR functional gastrointestinal disorder*) OR "BDS") OR bodily distress syndrome*) OR "central sensitivity syndrome") Filters: Publication date from 1990/01/01 to 2022/01/31; English

Appendix C: Prisma flow diagram of search results



From: Moher D, Liberati A, Tetzlaff J, Altman DG, The PRISMA Group (2009). *Preferred Reporting Items for Systematic Reviews and Meta-Analyses: The PRISMA Statement.* PLoS Med 6(7): e1000097. doi:10.1371/journal.pmed1000097

Appendix D: Descriptions of A-priori Explanatory components (Study 1)

Individual Vulnerability: Factors predispose an individual to develop FD. This vulnerability can be based on combined genetic, epigenetic, personality traits, or neurodevelopmental factors.

Embodied Trauma: Traumatic events including adverse childhood experiences play an important role in the development of FD through dissociative mechanisms.

Stress triggers: Physiological and/or social stresses are important precipitating factors for bodily distress (in predisposed individuals).

Conditioned Sensitization: Enhanced somatic response to sensations as a result of former repeated experiences of symptoms which can lead to memory traces at a neuronal level which increase sensitivity for future stimulation.

Abnormal Interoception: People with FD may demonstrate more sensitive perception of sensations occurring in their body.

Abnormal Proprioception: People with FD may have reduced ability to notice information about the position of the body and respond to them appropriately, for example by adjusting posture.

Signal Filter Model: 'Faulty filtering' leads to impaired ability to differentiate sensory information from normal physiological processes. Therefore, the number of concerning or alarming physical sensations experienced is increased.

Predictive Coding Model: Perception is determined as much by expectations or predictions as by peripheral sensory input. Based on a model of the brain constantly "constructing" its environment, including bodily states. Disorders of perception can arise as failures of inference due to mis-calibrated prediction/sensation processes

Autonomic Nervous System Dysregulation: ANS dysfunction is a potential mechanism connecting psychosocial stress to functional symptoms. Dysregulation of sympathetic/parasympathetic nervous system resulting in a long-lasting in chronic stress burden. May be referred to as 'stress' and 'sooth' systems or 'fight flight/rest digest'.

Immune System Sensitization: Chronic immune activation influences psycho-physiological responses to threats or stressors through the brain cytokine system.

Endocrine Dysregulation: Dysregulation of the body's response to acute and chronic stress through the HPA axis and cortisol levels. May be related to concepts of 'adrenal fatigue'.

Gastrointestinal Dysbiosis: Altered gut conditions (e.g. after GI infection) may cause symptoms through several mechanisms, including through lack of absorption of nutritional factors, effects of low-level inflammatory responses in response to abnormal gut flora, and/or impacts on serotonin signalling.

Under-expressed Emotion (Alexithymia): Symptoms may be caused, worsened by or otherwise linked to feelings that are not expressed, or are 'bottled up'. This may also be related to alexithymia (difficulties an individual has identifying and naming their own emotional states)

Illness Perception-Behaviour Model: Patients' beliefs or anxiety about symptoms influence their behaviour. Adapted behaviour can in turn affect physiology and symptoms, resulting in a vicious circle and maintaining symptoms.

Somatosensory Amplification: A physical sensation arises and patients focus their attention on the sensation. They develop further cognitions and attributions which further amplify the perception of these physical signals. This amplification results in a 'vicious circle' in a way that symptoms are re-enforced by patient's thoughts and concerns.

Interpersonal or Systemic Models of Role formation: The role of the ill individual has a function within their social structures and through interpersonal relationships, maintained by power and/or emotional dynamics within these systems.

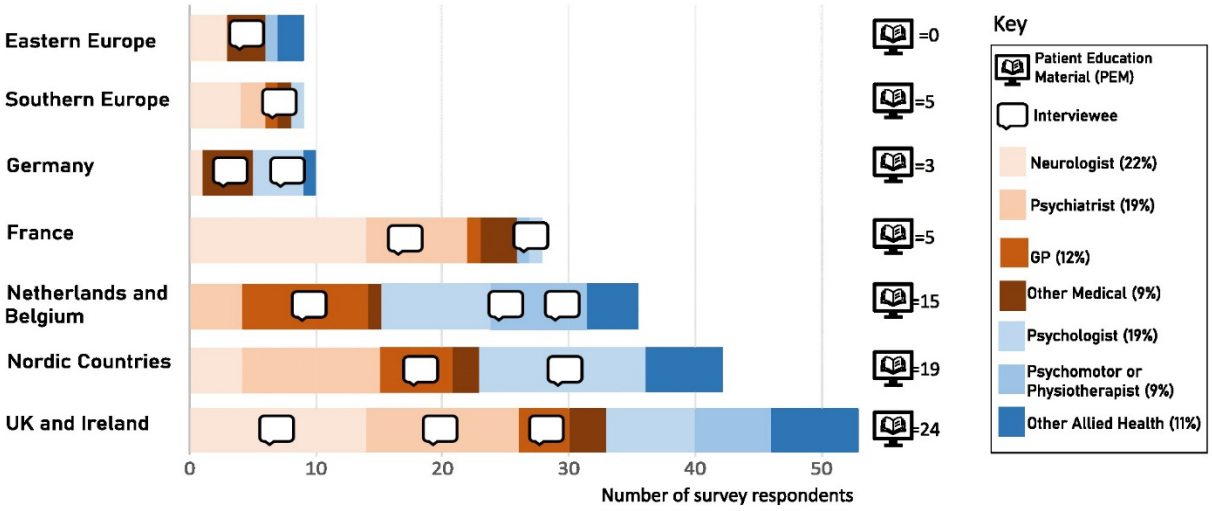
Iatrogenicity: Healthcare and social care systems focus on and validate biomedical causality of symptoms which forces patients into a sick role unresolved until an adequate biomedical cause is identified and treated. Patients are (unintentionally) neglected and forced into illness behaviours by these systems which both create and maintain morbidity.

Bio-psycho-social: Functional symptoms are always caused and maintained by complex interaction of multiple factors which can be best conceptualized on Biological, Psychological and Social domains.

Non-Explanation: Functional symptoms do not yet have an adequate explanation; it is important to recognize this and focus on the need to manage uncertainty.

Appendix E Professional groups and country of work of the survey respondents, interviewees, and PEM (Study 1)

Survey Respondents (n=186) Interviewees (n= 14) and Patient Education Material Represented by Geographical Area and Profession.



Individual interviewees are represented by a speech bubble icon 🗨 within the portion of the bar representing their profession and location. Percentages in legend represent proportion of total survey respondents by profession. X axis: number of survey respondents from each geographical area. Abbreviations: UK = United Kingdom, GP= General Practitioner (Primary Care Physician)

Appendix F: Feasibility synthesis

Table summarising key feasibility indicators (Process–Resources–Management–Scientific) and "stop/continue/modify" judgments

Area	Description (key feasibility indicators)	Comments
Process • Did the project met personal and group aims and objectives. • Views of participants on how empowerment and participation were conducted. See Saunders et.al 2024[9] for an in depth analysis of the process.	Our objective was to develop an online resource to share acceptable, relevant and usable information about how FSS come about, become persistent, and how these processes can be reversed. We sought meaningful involvement for all who participated in the project. 7 individuals with lived experience of multisystem functional somatic symptoms (FSS) were engaged from start to finish. Measures of meaningful engagement were reliably rated highly, with participants rating all measures 'MOSTLY' to 'STRONGLY AGREE' at all time points. In addition, personal aims for being involved in the project were also MOSTLY to STRONGLY fulfilled at the final time point. Participant's written and verbal feedback confirmed satisfaction with the process. At launch, 19 out of 20 essential requirements were met in the project output, which met pre-defined success criteria.	Overall, the process was successful in meeting aims and objectives. In general the aims of develop an online resource which met our cocreated essential requirements was successful, and the PPI embedded participatory design process by which this was done proved to be feasible. There was one requirement that was met (by consensus): linked social media was not created. It was generally agreed that this requirement was unrealistic due to the challenges of moderating suh a space. Instead the decision was made to link to existing patient organisations via the resources page. This decision might have impacted on the numbers of visitors to the website in the period of this early evaluation.
Resources • Resources required to manage and implement the study • The sustainability of the project.	The total budget required to manage and implement the bodysymptoms project was Euro 26,153. Breakdown: Webdevelopment 21,265 Translation 1876.75 Domain purchase and hosting 327.56 Graphics/formatting 1381.09 Expenses to lived experience participants 1302.56 Environmental impact was minimised throughout the design process. The web-hosting platform was selected on criteria of environmental impact, and lazy loading was implemented throughout the site, with elements	The ongoing sustainability of the project looks promising, with international interest in the platform, an international steering group will be formed. Ongoing ground costs for the hosting of the website are low, approximately 135 euros/year. Basic updates can be made easily through wordpress back-end. Additional improvements are planned, including new translations. These will be paid for by the translating teams, or through raising further grant money.

	floating into view as the user scrolls, and simplified graphics.	
Management • Review and reflections on the project management journal. • Feasibility of procedures, • Obstacles faced, ethical considerations and reflections on the methodological choices that were made.	A Participatory design approach was integrated within a PPI-framework. Lived Experience (LE) recruitment was smooth, and workshops were well-attended. There were some difficulties communicating aesthetic preferences with design contractors and content development proved slower than expected, requiring more time and energy investment. The translation strategy was also more time consuming than expected, and feedback suggested that in some languages, they did not lead to an appropriate quality of translation. Obstacles to evaluating the impact of the project related to the ethical dimensions of collecting data on a resource intended for the public domain. The decision was taken to maximise sustainability and user privacy over collecting large amounts of web analytics data for evaluation. Another obstacle was encountered was that search engine optimisation was not planned into the project from the start. Lastly, the project lead took a parental leave so active dissemination was paused shortly after launch.	On reflection, the project was set up to enable participation in some areas of the project, but limit it in others. Early collaborative workshops were focussed on establishing essential requirements, shared aims, prototypes and design. However the conceptual framing of the explanatory model itself would have benefited from earlier input from multiple perspectives. Overall, decisions made that meant less data for post-launch evaluation was available were justified. Despite lower survey numbers than anticipated we achieved a rich enough set of feedback to implement the next stage of development of bodysymptoms.org, and an improved iteration of the website can be implemented. However it was an oversite that SEO and a structured communication plan was not budgeted for (either in time or finances). This will be part of future projects, but means impact will be delayed while funding is sought for this.
Scientific • Evaluating the early impact of the website bodysymptoms.org, and its acceptability and perceived relevance to visitors.	In the first month after launch 1167 there were individual visitors to bodysymptoms.org with a low bounce rate of 5%. Think-aloud interviews (n = 6) and survey responses (n = 8) revlealed few problems with usability, with users finding the exploratory navigation structure and contextualizing pages helpful. 75% of respondents found the information personally helpful and 87% would recommend the site to others. The majority of respondents found the tone, structure, and content of the website accessible, trustworthy, and supportive. Concerns about acceptability were focussed on a perceived emphasis on psychological mechanisms, or the evidence base of mechanisms. Concerns on the usability were focussed on complexity of the information, and quality of translations.	Our initial evaluation indicates usability and content relevance. Acceptability across end users was generally high, but with some outliers which reflected the ideologically contested domain the resource sits in. Areas for ongoing improvement, such as improved translation, clearer routes through the sites related to specific symptom presentation, clearer contextualisation and greater personalisation were highlighted. Early evaluation suggests the feasibility of bodysymptoms.org as a resource to support public understanding of Persistant Physical Symptoms and suggests the relevance of further development of the with additional investment in SEO and communications.

Appendix G: Post launch survey questions

Consent and Permissions

Please let us know how we can use your responses.
(Link to Information Sheet: "Survey to Evaluate Bodysymptoms.org.pdf")

Demographics

What is your age?
What is your gender?
What is your profession?
What is your education level?

Website Usage and Experience

What was the main reason that you visited bodysymptoms.org?
What language did you use on bodysymptoms.org?
What device did you access bodysymptoms.org on?
What is your relationship with technology?
Did you experience any technical issues with the website?
If yes, are you able to describe the technical issue?

Health Context *(Conditional logic> IF answered visited bodysymptoms to understand own symptoms better)*

Can you tell us a bit more about why you visited bodysymptoms.org?
What symptoms were you trying to understand?
How long have you had these symptoms?
Have you seen a doctor about the symptoms that you have?
Is there a diagnosis that you feel explains your symptoms (whether or not a doctor has given you this diagnosis)?
What are the diagnoses you identify with? *(Check all that apply)*
What other diagnoses do you identify with?
Has a doctor confirmed this diagnosis?

Content Evaluation

Was any of the information new to you?
Please tell us more about what information was new to you.
Was the information on bodysymptoms.org helpful?
Please tell us more about what information you found helpful.
Would this information have been helpful to you at an earlier point in your life?
Please tell us more about what information you would have found helpful.

Feedback and Further Participation

Would you recommend the website to others?
Please give us any other feedback that can help us improve the site for other users.
Would you be able to take part in a 20-minute online interview to help us improve this resource?
If yes, please provide your email so we can contact you about this.

Appendix H: Think aloud interview Protocol

Initial Contact

Once individuals have been identified who are willing to take part in the walk through protocol, they will be sent an information sheet, consent form, and basic instructions for the walk through protocol (how to share screen etc).

Orientating conversation (5 minutes)

The researcher will establish a connection with the participant. Greet them, thank them for their engagement

Check participant's understanding of the protocol.

Establish shared screen.

Check consent to record and to utilise the data for evaluating and developing the website.

Open browser and navigate to bodysymptoms.org.

Walk through protocol (15 minutes)

Researcher starts recording (of the Zoom meeting) This is time stamp 0.00

Prompts

If the participant is silent for a long time, the researcher can prompt: 'Can you tell me what you are thinking at the moment'. Or 'What is your impression as you read this page'. *The researcher might want to observe the expression on the face of the participant, i.e. whether they seem frustrated, or absorbed in reading.

To close

At the end of the walk through protocol (either if the participant seems to be bored OR at 20 minutes) the researcher says. 'Thankyou, that is the end of the test today. At this point, you have been using the website for 20 minutes. What are your overall impressions of the website?' The researcher might ask 1-2 follow up questions to show interest and clarify what the participant means.

Following this the researcher thanks the participant for their time and reminds them to complete the post-test survey.

Output and data processing

Several different types of data will be generated: video and audio files and observation notes from the thinking aloud session. In addition, there will be the results from the post test survey. The audio/video file are re-played. Transcripts of comments are made and marked with timestamps of what happened on the screenshare for example:

[F1]: "*And, I would like to return to the home page #Click the back button in the browser window*".

Survey data will be used to allow contextualisation of participant's responses. For example, comparison by age, education level, language or technical ability.

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

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

ROLE DESCRIPTION: PARTNER WITH LIVED EXPERIENCE

WHAT IS THE TIME COMMITMENT?

The project will run **over 1 year**, from October 2022 to October 2023.

We expect that the time commitment will be approximately **10 hours** which includes attendance at **3x2 hour workshops**. The dates of these will be arranged to suit everyone's schedule.

All project activities and workshops will take place virtually (i.e. via Zoom)

You will be compensated €250 for the time you contribute to this project.

AM I RIGHT FOR THIS PROJECT?

You may be right for the project if:

- You are above 18 years old.
- You have experienced persistent physical symptoms for at least 3 months. Your symptoms might be current or mostly in the past.
- You may have received a diagnosis of a functional somatic syndrome such as fibromyalgia or functional neurological disorder, or your symptoms might remain unexplained.
- You can attend meetings via Zoom.
- You understand and speak English.
- You are able to see the benefit of an integrative approach to persistent physical symptoms including but not limited to physical therapies, social and psychological approaches.

If you chose to get involved, you will not be asked to share lots of details about your own life. It is more important you can share what you have learnt through your experience in a way that can benefit others.

IS THE PROJECT RIGHT FOR ME?

When you are thinking about giving your valuable time, it is important that you contribute to a project that aligns your values. To help you get a sense of this, here is a summary of our approach:

- This project is grounded in the value of **care**. It is being conducted from a desire to take practical steps where possible to relieve unnecessary suffering.
- We have a value of **inclusion**, and think it is important that knowledge, in line with the most up to date research, is accessible and can benefit people across our societies broadly.
- The project is **open to change**. The perspective brought by partners and collaborators will be valued and as far as possible used to directly influence the course of the project.
- We aim for clarity and **transparency** when communicating with you. Especially about the nature of involvement and potential for influence.
- We recognise the value to the project in engaging a diverse group of people with **different experiences** and from different communities, including those who take critical perspectives of traditional healthcare models.
- We recognise the importance of providing adequate **support** to people volunteering their lived experience, including compensation of time and expenses and clear protocol to ensure the emotional wellbeing of people involved.
- We are interested in making **an Impact**

WHAT DOES THE ROLE INVOLVE?

PROPOSED SCHEDULE OF PROJECT ACTIVITIES

An **initial meeting (1 hour)** to allow roles, and shared goals to be agreed, and to allow for mutual decisions to be made about whether the collaboration/partnership is a good fit.

End of October 2022- **Group Workshop 1 (2 hours Via Zoom)**

This will be arranged at a time that works for the majority of participants

December 2022- **Group Workshop 2 (2 Hours via Zoom)**

February 2023- **Group Workshop 3 (2 Hours via Zoom)**

At the end of the project, you will be invited to an individual exit meeting where shared goals will be reviewed and satisfaction with the process can be discussed.

You will be invited to contribute by email between workshops, for example being asked to review and comment on mock-ups of website content. Whether you wish to contribute outside of workshops will depend on your availability and is considered an optional part of involvement.

EXTRA-ROLES

To help you get out what you would like from the project, all role descriptions and schedules presented are considered flexible and can be adapted based on your skills and interests. For example, you might be interested in other parts of the research process such as co-authoring scientific publications, or disseminating the output of the project. Your ideas about how you would like to be involved in the project can be discussed at the beginning of your involvement and can be reviewed at any stage.

LIMITATIONS OF ROLE

As far as possible, all aspects of the project remain flexible and open to change. However there are some limitations to how far the influence of partners and collaborators can steer decisions. The basic description and timeline of the project is not open to change, due to limitations of funding, university and ethics regulators. In addition, it is important that content and tone of the website is in keeping with the evidence-base available and aligns with guidelines for treating persistent physical symptoms and functional disorders where these exist across Europe.

The process of how decisions are made will be discussed and agreed collaboratively by all research partners at the beginning of the process. A clear purpose and values statement will be drawn up developed in line with discussions with the lived-experience partners, and reviewed with all stakeholders at regular intervals.

More detail is described in the project protocol and other documents available via this link: https://osf.io/tncbu/

WHO WILL I BE WORKING WITH?

The project team will involve collaborating healthcare-professionals with expertise in functional disorders and 3-4 other people with lived experience of functional symptoms from across Europe.

The project lead is Chloe Saunders, a Doctor from the UK with an interest in functional illnesses. They are working full time on this project as part of a PhD programme and is happy to be contacted with any questions
chloe.saunders@clin.au.dk

Lisbeth Frostholm, lead psychologist at Department of Functional Disorders based in Aarhus University Hospital, Denmark, is the senior project supervisor. Her research focuses on persistent physical symptoms, functional disorders and health anxiety with a specific interest in psychological interventions, eHealth, and epidemiological studies. You can find out more about the clinic's work here: https://funktionellelidelser.dk/

Chloe Saunders, Project Lead

Lisbeth Frostholm, Main Project Supervisor

This study is part of a wider EU funded network of PhD researchers working on functional disorders:

https://etude-itn.eu/our-team/#early-stage-researchers

WHAT CAN I EXPECT IF I TAKE PART?

We will follow the approach to meaningful patient or public involvement outlined in the European Patient Forum Value+ Handbook https://www.eu-patient.eu/globalassets/projects/valueplus/doc_epf_handbook.pdf

SUPPORT

To support you to get what you want from the project, you will be invited to individual meetings at the beginning and end of the project. During the initial meeting, you will be given the opportunity to share information about your current needs to help the research team discuss with you how best to support you through the process. Of course it is your decision if you would prefer not to disclose information, but all information you do share will be treated as confidential.

COMPENSATION

The expectation is that participation as lived experience partner in this project will require around 10 hours of time over the course of 1 year, including attendance at the three workshops.

Compensation for this time will be automatically assigned to the value of €250 for each partner after the third workshop. If you leave the project early then you will be compensated according to the length of your involvement proportional to the full year.

You will not be considered an employee of Aarhus University or any other associated institutions. It is possible to compensate you via bank transfer or by means of a voucher for a business of your choice. Your preference for receiving compensation will be discussed during the initial meeting.

Additional compensation for taking on extra-roles can also be discussed on a case-by-case basis.

CONFIDENTIALITY

Basic demographic data may be collected to ensure accurate reporting of the study in terms of allowing those evaluating this project to understand to what degree partners are representative of the target population. All personal data collected from Research Partners or Collaborators will be collected and stored on Aarhus University GDPR compliant systems.

When it comes to sharing results of the project, anonymity might be a concern. You will be consulted before any action which makes identifying information, publicly available, such as acknowledgment or authorship in a scientific publication or conference presentation.

NOT SURE WHETHER THIS PROJECT IS RIGHT FOR YOU?

I would be very happy to have a phone call or zoom meeting to get to know each other a bit and discuss any questions you might have.

Please email me at chloe.saunders@clin.au.dk. I will get back to you quickly to arrange a time to speak.

NEXT STEPS TO GET INVOLVED

You will be contacted by Chloe, project lead, and invited to a meeting to discuss involvement further.

Thank you for your interest in this project.

We look forward to meeting you.

Collaboration Agreement: bodysymptoms project

This document outlines the conditions and expectations for working together on the bodysymptoms project. This collaboration agreement is expected by the university and our project funders and will help guide us if any disputes or difficulties arise regarding the topics outlined below.

1. Roles, Responsibilities and Decision making

Collaborators with lived experience are expected to have (at minimum) a consultative role in the bodysymptoms project. The time commitment will be approximately 10 hours over the course of 1 year which includes attendance at 3x2 hour Workshops. The dates of these will be arranged to suit everyone's schedule. All project activities and workshops will take place virtually (i.e. via Zoom). Collaborators will be invited to contribute by email between workshops, for example being asked to review and comment on mock-ups of website content. Whether collaborators wish to contribute outside of workshops will depend on their availability and interests and is considered an optional part of involvement.

The research team withhold the right to be able to select their approach and procedures, and have ultimate responsibility for responsible conduct of the project, distribution of research funds and making final decisions. However, the project is open to change and the perspective brought by partners and collaborators will be valued and as far as possible used to directly influence the course of the project. The research team will aim for clarity and transparency in all communications and must always be able to provide information to collaborators about why decisions have been made and should be able to defend their choice of method.

2. Health and Wellbeing

The research team endeavor to hold a safe, healthy, and accessible space for all those involved in the project. **Collaborators** are invited to inform the research team of any particular needs or difficulties that arise during involvement with the bodysymptoms project so that specific needs can be accommodated, and necessary adjustments made. However **the research team** do not hold any responsibility for the healthcare or treatment of collaborators. **Collaborators** should continue to seek advice for any health concerns from their local medical teams throughout the project.

3. Conflicts of Interest

Conflicts of interest are situations in which researchers or collaborators have financial or other interests that may compromise or influence their research findings. The integrity and impartiality of researchers and collaborators must be beyond question. In order to preserve transparency, we ask all collaborators to declare any conflicts of interest prior to partaking in the project. These include, but are not limited to, financial interests in the outcome of the project.

4. Principles for Responsible conduct of research

The research team are bound by the Danish Code of Conduct for Research Integrity is based on three fundamental principles (Honesty, Transparency and Responsibility). These principles should pervade all phases of the project, and collaborators are expected to conduct themselves in relation to the bodysymptoms project in accordance with these principles.

The project is also required to follow open science principles, meaning that results and other documents from the project are transparent and made freely available to the public. An Open Science Environment for the project has been created at:
https://osf.io/tncbu/?view_only=5caa9a61418f4265a2101fbd5233fc77

5. Funding and Affiliation

The current study 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.

6. Data Collection and Storage

Data are defined as all material collected systematically for research purposes, including electronic data, for example from registers, surveys or interviews, notes, texts, literature and images. Personal data of collaborators, such as contact details, video recordings of the workshops and basic demographic data will be collected and stored to ensure accurate reporting of the study in terms of allowing those evaluating this project. All personal data collected from Research Partners or Collaborators will be collected and stored on Aarhus University and Aarhus University Hospital's password protected GDPR compliant IT servers and all data will be pseudoanonymized prior to dissemination so that individual collaborators are not identifiable.

7. Dissemination of scientific results and Authorship

Any scientific papers that arise from this project will be published in peer review, open access journals. Collaborators can be cited as authors on scientific publications in accordance with Aarhus University's definition of authorship. A contributor is defined as an author if they have made a significant contribution to the publication in question, if the contribution has been acknowledged by all other authors, and if the contribution at a minimum comprises:

- Substantial contributions to research idea or design, data collection, analysis or interpretation of data
- Substantial contributions to the drafting of the publication.

If collaborators do not wish to contribute as author in publications that arise from this project, they will be acknowledged in relevant publications with their consent.

8. Ownership of data and project outputs

At the end of the project Collaborators will not be able to claim any ownership of intellectual property resulting from the project. The project output (website) will be made freely available to the public in keeping with open science principles but rights to use the web domain bodysymptoms.org,

intellectual property and data from the project will be retained within the research team according to previous agreements between the university and grant holders.

9. Compensation of collaborators

The expectation is that participation as lived experience partner in this project will require around 10 hours of time over the course of 1 year, including attendance at the three workshops. Compensation for this time will be automatically assigned to the value of €250 for each partner after the third workshop, by bank transfer or via vouchers (depending on the collaborator's preference and individual situation). Collaborators will not be considered an employee of Aarhus University or any other associated institutions and will retain personal responsibility for reporting the compensation to any relevant tax authorities. Collaborators leaving the project early will be offered compensation according to the length of their involvement proportional to the full year.

I confirm that I agree to the terms described in the above document (Collaboration Agreement: bodysymptoms project). In particular I confirm that I have declared any potential conflict of interest, and that I consent to video recording of project activities and storage of my personal data as described above:

Name of Collaborator:

Signature:

Date:

Project lead, Chloe Saunders

Signature:

Date:

Appendix L: Agenda for Workshops

A list of ground rules for the workshop shared at the beginning of each workshop:

- Be kind
- Critique ideas, not people
- Share your perspective
- Speak honestly
- Share the airtime—no one dominate
- Choose to be present
- Respect other points of view
- Keep confidential issues inside the room
- Everyone take responsibility for following and upholding the ground rules
- We will end on time.

Workshop 1 3/11/2022- 'Scoping'

The focus of the first workshop was on creating a space of mutuality in which participants are able to explore and rehearse potential futures together and develop consensus around the direction the project shall take..

10:00	**Welcome and Introductions**
10:10	Review goal hierachy
10:15	Group exercise: Requirements boards- content and design
10:30	Review of Values
10:35	Group exercise: Purpose statement
10:40	**Break**
10:45	Prototype 1 Demonstration and discussion
10:55	Prototype 2 Demonstration and discussion
11:05	Prototype 3 Demonstration and discussion
11:15	Group exercise: Reviewing the requirements boards
11:35	**Break**
11:40	Discussion: how to evaluate the success of the project
11:50	Recap, Questions, and Next Steps

Workshop 2 27/1/2023 'Developing'

This workshop was focused on working through the processes involved in developing and organizing content, attuned to the production of new digital health cultures in the context of Functional Somatic Symptoms.

10:00	**Welcome and Introductions**
10:10	Prototype Review and feedback
10:15	Content overview
10:40	Break
10:45	Discussion and feedback on content.
11:15	Discussion about Stories/Multimedia content/Writing Workshops
11:30	Break
11:35	Discussion and feedback on content.
11:50	Next Steps

Between workshop 2 and 3, embodied writing workshops were held.

Workshop 3 8/9/2023 'Scaling'

This workshop focused on opportunities for sustaining and scaling the project, how to engage with the larger online community and with other stakeholders.

16:00	Welcome and Introductions
16:10	Prototype update
16:15	Content overview with some questions
16:40	**Break**
16:45	Discussion about social media and dissemination
17:15	Evaluation Plan
17:30	**Break**
17:35	Discussion about evaluation plan
17:45	Closing and finishing admin

The following questions were asked to participants in the post-workshop surveys.

Measuring success The final questions are about how we evaluate and measure the success of the process we are on together.

The first questions are measures of success taken from the European handbook of Public Involvement in research, which is one way in which we will monitor the participatory design process. Please answer honestly, as this will show us areas we can improve.

1) There has been an induction and adequate training/support for me to understand my role and participate
2) I feel like my specific needs and requirements have been taken into account so I have been supported to participate in the project
3) I feel like my input is meaningful and will have an impact on the direction of the project
4) I understand who the other partners are in the project, and their roles
5) Communication about the Project and Workshop has been good
6) I understand how to communicate with others in the project and feel the communication strategy fits my needs
7) It is clear how decisions will be made in the bodysymptoms project
8) I feel there are opportunities to build meaningful working relationships within the bodysymptoms project
9) I enjoyed the workshop
10) At the workshop, I felt able to speak and share my views

Appendix M: Embodied writing workshops planning documents

Background: Bodysymptoms.org is a co-created project aiming to shape the ontological politics of medicine and the body. Our goal is to create a new empowering explanatory model of functional somatic symptoms, based on perspectives drawn from different knowledge domains. Lived experience and creativity are two of the knowledge domains that the project draws from. Writing workshops will be held as a space for lived experience participants and other guests to write and sharing their personal stories about symptoms and recovery. We will work together on creative writing exercises with prompts to write about the body, symptoms, illness and recovery. We will have a chance to read our stories aloud and give each other feedback.

At the end of the process, participants will be invited to contribute their stories for the website we are co-creating

Benefits of writing: Having unexplained or functional symptoms can be a fragmenting experience. Storytelling is an integrative process. The experience of writing, telling, and hearing stories enhances our connection to the body. The process of writing helps us in remembering and assembling pieces to create a whole. A good story engages interest, response to feelings, and connects to memory and personal involvement. Writing our personal stories brings us to the moment not as observer, but as participant. It also helps us summarize our experience in a way that makes sense to others. Our stories can be powerful to inspire and help others reflect on their own experience.

When we write, we draw on all the experiences we have known. Experiences of family, of birth and death, of intimacy and place. Writing also invites into space experiences we have never known, tapping our collective imagination. In the process of writing, we engage a willingness to be recreated as we create; if we already know what we will say before we write, why begin? Part of creative work is the practice of becoming comfortable with not knowing. As we allow our curiosity to guide our experience, writing becomes a process of discovery.

Writing our body stories allows us to go part by part through our structure, noting the memories and associations which emerge. As we listen to our bodies, each person has stories to write and to tell.

4 workshops were held between January and March 2023. All lived experience participants in the bodysymptoms project were invited. Attendance was compensated at 25 Euros an hour.

General Structure:

Each 1 hour writing workshop will be set around a single writing exercise.

1. We will start every workshop with freeform writing in response to a chosen prompt (10 mins).
2. We will then utilize a rewriting exercises, for example the following drawn from ACT therapy (15 mins)
3. We will read our work aloud to the group (15 mins)
4. We will provide feedback to each other on what we have written (15 mins)

Prompts

(Adapted from Olsen A. Bodystories: A guide to experiential anatomy. UPNE; 2004.)

Thinking body

Write the entire story of a symptom. Start with its origins, and write about how it evolved, and all the things that have impacted it along the way.

Write about how illness is treated and managed in your family culture.

Write about the different things that you have been told, or understood about your symptoms. How has your understanding changed over time?

Moving Body

Write about your earliest movement memory (earliest kinesthetic sensation you can remember. Examples: being rocked, learning to swim, bouncing on your parent's knee, falling from a tree, riding a bicycle)

Write about an experience of training your body (e.g. sports, dance, musical instruments, a skill learnt in recovery)

Write about your experiences of intentional and instinctive movements. What movement patterns come easily, which feel inhibited.

Feeling body

Write about your relationship to body weight, strength or flexibility.

Write about areas of blockage, numbness or pain in your body. How do these feelings evolve.

Write about your own attitudes towards sensuality, sexuality and gender. How does your body make you aware of these things?

Protective body

Write about an experience of illness, what does it feel like to be ill? How does the world change for you in illness?

Write about protective habits or patterns. How does your body try to keep itself safe?

Rhythmic body

Write about the rhythms that you notice in your body or with your symptoms

Write about how a rhythm has enhanced or caused challenges in your recovery.

Regulating body

Write about how your experiences of control and loosing control with your body.

Write about your body's experience of slowing down, rest and relaxation.

Connected body

Write about the origin of your life, focusing on the story of your birth. What types of things was your mother doing when you were in her womb. What happened to your body during the process of being born.

Write about an environment where you have lived (How did that place affect how you move, how you perceive. If relevant link this to symptoms that emerged in a particular time and place)

Re-writing Exercise

(Adapted from Hayes SC. Get out of your mind and into your life: The new acceptance and commitment therapy. New Harbinger Publications; 2005)

Underline, color or highlight all words in your story that are reactions. Reactions might be thoughts, feelings, memories, sensations, urges, or things you did. Don't circle explanations for why you reacted: just the reaction itself.

Read a second time through the story and in a different colour, underline or highlight every external situation or fact.

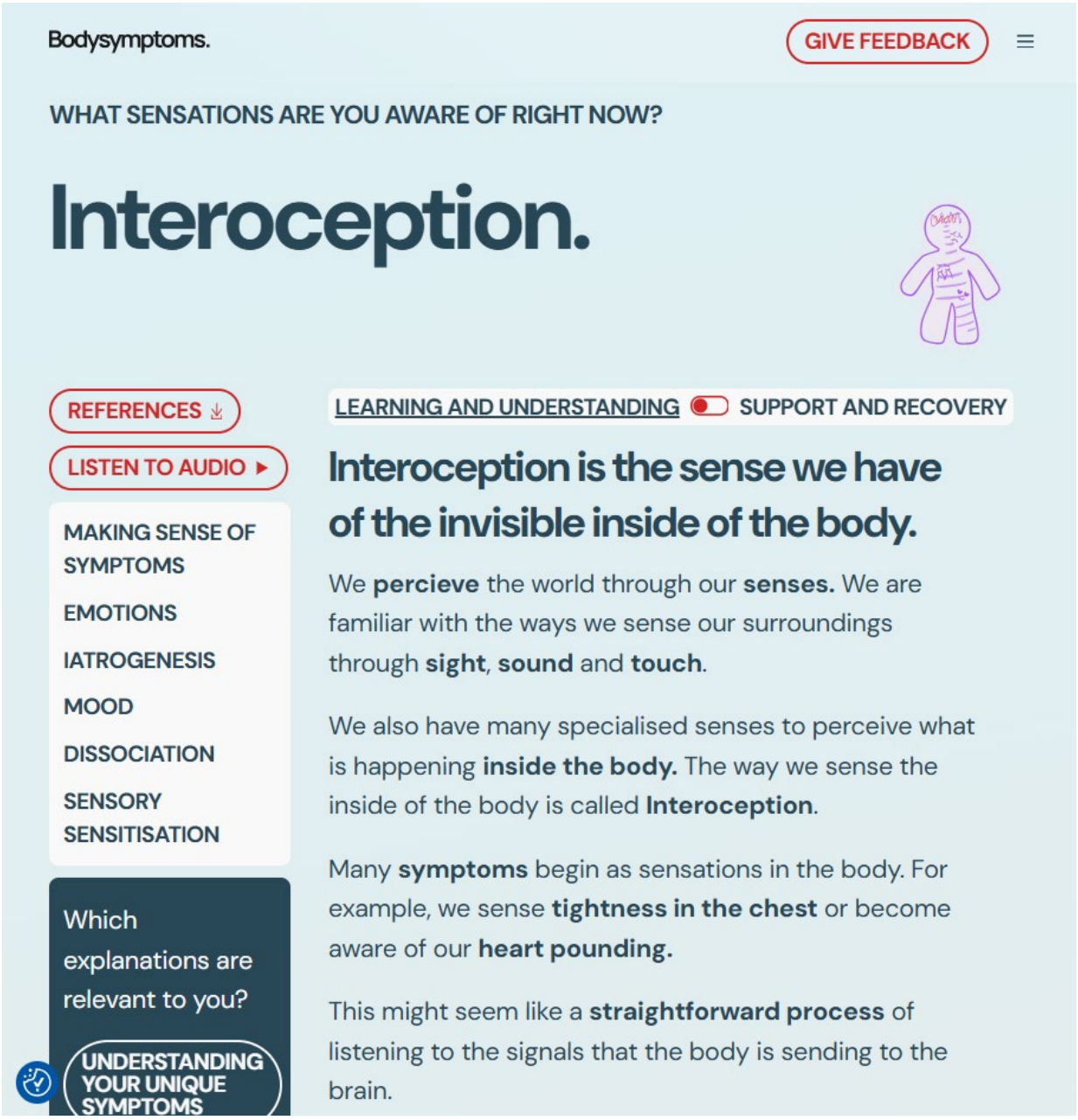
Copy and paste all the underlined or highlighted parts of the story to a new page.

Now comes the challenge: re-write what you have just written so that the theme, meaning, outcome, or direction is totally different, but every item that is circled or underlined is included in your new story. It is not important to write a better story, or a happier one, or a truer one. The only criteria is that it makes sense, to fit well with the underlined and highlighted material.

Advice for participants:

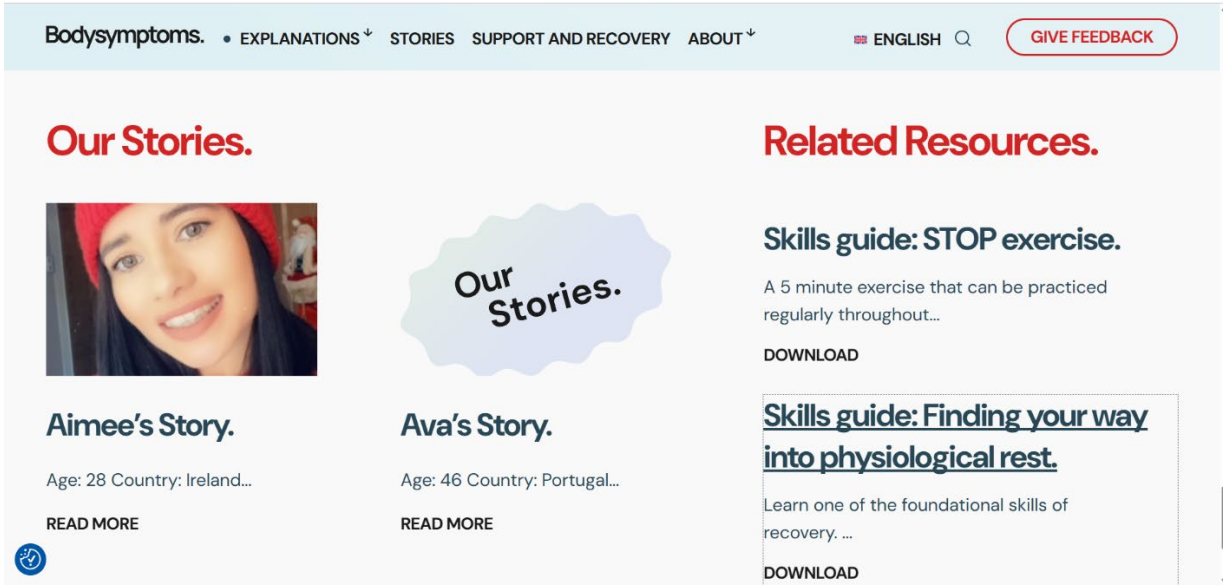
1. Write from the whole body; try to keep your pen moving; maintain a supportive, non-judgmental attitude; resist editing or censoring your words. The task is to let your body write you - i.e., to become a vehicle through which your own stories emerge.
2. When you choose a prompt the task is to write a brief story about yourself. Start with a couple of hundred words about one thing – something that perhaps you struggle with or has a bit of a history to it. Don't write about everything, choose one thing.
3. When reading your writing aloud, both hear and feel the language. Often the experience of reading is very different from that of writing. As we read our work to others, work on cultivating a supportive non-judgmental sides of yourself. If emotions come, it is okay to continue reading with the feelings.
4. When giving feedback to others in a group, comment on what stands out to you, what moves you. Maintain your non-judgmental but discerning awareness as listener. Each person's stories emerge as they are met by receptive ears

Appendix M (Screenshots of Example page from bodysymptoms.org)



https://bodysymptoms.org/mechanism/interoception/

https://bodysymptoms.org/zoe-story/



Bodysymptoms. EXPLANATIONS STORIES SUPPORT AND RECOVERY ABOUT ENGLISH GIVE FEEDBACK

What causes symptoms

Symptoms can be caused by different things, but it's usually a combination of many factors.

In western societies we usually distinguish between symptoms we experience in the **mind** and symptoms we experience in the **body.**

In reality there is not such a clear divide. Instead, **the systems of the mind, body and environment all continuously interact.**

They cannot be seperated

Many symptoms, even those experienced as coming from the body, are not caused in a simple way by damage that we can see on a blood test or scan.

We get further if we understand these symptoms as products of the **dynamic functioning of the body-mind in its environment.**

If the functioning in one part of the system is pushed out off balance, it can have knock-on effects in other, seemingly unrelated, places. **New dynamics are set up that can maintain symptoms.**

We call these Functional Mechanisms

FAQ: WHAT DOES 'FUNCTIONAL' MEAN

https://bodysymptoms.org/symptoms/

Amendments. The following amendments have been made in this digital version of the thesis (February 2026), compared with the version submitted to Aarhus University for assessment (October 2025):

P viii -bodily mind- changed to body-mind
P88- spelling of 'understanding' corrected. Minor formatting corrections including: Font and font size standardized. Curve of text 'Embodied' on figure 10. formatted.

Chapters 5-8 have been removed. These are all available as articles open aand hyperlin