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Measuring persistent somatic symptom related stigmatisation: Development of the Persistent Somatic Symptom Stigma scale for Healthcare Professionals (PSSS-HCP)

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ABSTRACT

Objective: Persistent somatic symptoms (PSS) describe recurrent or continuously occurring symptoms such as fatigue, dizziness, or pain that have persisted for at least several months. These include single symptoms such as chronic pain, combinations of symptoms, or functional disorders such as fibromyalgia or irritable bowel syndrome. While stigmatisation by healthcare professionals is regularly reported, there are limited measurement instruments demonstrating content validity. This study develops a new instrument to measure stigmatisation by healthcare professionals, the Persistent Somatic Symptom Stigma scale for Healthcare Professionals (PSSS-HCP).
Methods: Development was an iterative process consisting of research team review, item generation and cognitive interviewing. We generated a longlist of 60 items from previous reviews and qualitative research. We conducted 18 cognitive interviews with healthcare professionals in the United Kingdom (UK). We analysed the relevance, comprehensibility and comprehensiveness of items, including the potential for social desirability bias.
Results: After research team consensus and initial feedback, we retained 40 items for cognitive interviewing. After our first round of interviews ($n = 11$), we removed 20 items, added three items and amended five items. After our second round of interviews ($n = 7$), we removed four items and amended three items. No major problems with relevance, comprehensibility, comprehensiveness or social desirability were found in remaining items.
Conclusions: The provisional version of the PSSS-HCP contains 19 items across three domains (stereotypes, prejudice, discrimination), demonstrating sufficient content validity. Our next step will be to perform a validation study to finalise item selection and explore the structure of the PSSS-HCP.

1. Introduction

Persistent somatic symptoms (PSS) describe recurrent or continuously occurring symptoms such as fatigue, dizziness, or pain that have persisted for at least several months [1]. These include single symptoms such as chronic pain, combinations of symptoms, or syndromes meeting the criteria for functional disorders such as fibromyalgia or irritable bowel syndrome.

While symptoms have historically been distinguished as those with a clear biomedical pathophysiology or not, there is increasing evidence that all persistent symptoms share neuropsychological mechanisms [2]. We use the term PSS here also because it is the preferred umbrella term

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by people living with symptoms [3], although we acknowledge that other terms are used including functional disorders [4]. As well as causing distress and disruption to daily functioning [5], many people with PSS face stigmatisation which can delay help-seeking [6,7]. Perceived stigma by people with PSS is associated with decreased wellbeing [8], increased depression and anxiety [9], and treatment non-adherence [10].

Stigmatisation is a dynamic process where elements of labelling, stereotyping, separation, status loss, and discrimination occur in the context of power [11]. During clinical consultations, people with PSS have reported being dismissed, accused of faking or exaggerating symptoms, and having truthfulness in reporting symptoms questioned [12–16]. Healthcare professionals themselves report stigmatising attitudes towards people with PSS, questioning the legitimacy of symptoms and motivations for seeking treatment [17–19]. An important contributing factor to stigmatisation by healthcare professionals is incongruence between the severity and persistence of symptoms against biomedical expectation, or an absence of structural abnormalities [20]. This incongruence provides barriers to successful communication and explanations [21,22], and feelings of helplessness in the professional role [23].

There is increasing evidence that across stigmatised statuses, stigma can be considered a mediator that fundamentally shapes health outcomes and equalities [24]. In the context of PSS this link is correlational. A potential explanation for this is that when someone experiences a lack of validation about their symptoms, or an implication that their symptoms are illegitimate, this can cause psychological distress [6,9]. Further, stigmatised people may conceal their condition to protect themselves further from stigmatising experiences. In doing so they are less likely to seek care or more likely to delay care [9]. Through this connection to health outcomes and quality of life, reducing stigmatisation by healthcare professionals is a priority in both research and clinical practice.

Stigmatisation occurs at different, intersecting scales [25]. An influential model by Link and Phelan describes stigma as starting when a person is labelled based on particular characteristics, such as having PSS. They are then linked to undesirable characteristics (stereotypes) and devalued or excluded through status loss or discrimination. Throughout this process, emotional reactions can occur [11]. We wanted to focus more specifically on the role of the healthcare professional, where interventions can be focused and evaluated. Here, we conceptualise stigmatisation as a model of interacting stereotypes, prejudices and discrimination. Stereotypes are *"beliefs, or 'cognitive schemas' about the characteristics and behaviours of groups of individuals"*, characterised by their inaccuracy and negativity [26](p132). Prejudices are the negative "*emotional reaction or feelings that people have toward a group or member of a group"* [26](p132). These can include emotions of anger and hostility, but also fear or discomfort. Discrimination describes behaviours in the *"differential and disadvantaged treatment of the stigmatised"* [27](p93). These behaviours exist on a spectrum from subtle 'microaggressions', avoidance, maintaining social distance, to more explicit jokes, bullying or denial of opportunities.

While there are many reported examples of stigmatisation by healthcare professionals, there is a lack of validated measurement instruments. Methods used to measure PSS related stigmatisation include explicit measures (e.g. questionnaires, interviews) [17,28–31], and implicit measures (e.g. response latency tests [32] or response priming studies [33]). While multiple methods are needed, we focused on developing a self-reported questionnaire that could primarily be used as an outcome measurement for stigma reduction interventions. In a recent systematic review [34], we found that there was no candidate instrument with sufficient content validity. Assessed constructs were rarely defined and development lacked involvement of healthcare professionals or pilot testing. Among identified instruments, the HC-PAIRS was the most established [35], used most frequently among our included studies. However, this largely explored beliefs about the ability of patients to function rather than stigmatising attitudes about these patients. While a couple of instruments demonstrated sufficient relevance (>85% of items) based on face validity (the Chronic Fatigue Syndrome Attitudes Test [30] and the Medical Condition Regard Scale [29], we felt that some items were not relevant in this context. Further, we felt that these scales were not comprehensive relating to stigma (sufficiently exploring each component of stereotypes, prejudices and discrimination). Therefore, we decided to develop a new instrument to measure PSS related stigmatisation by healthcare professionals, the Persistent Somatic Symptom Stigma scale for Healthcare Professionals (PSSS-HCP).

2. Methods

The development of the PSSS-HCP was an iterative process consisting of research team review, item generation and cognitive interviewing. This study was pre-registered on Open Science Framework (https://osf.io/7jtr4). The research was approved by the University of Edinburgh and the South Central - Oxford C Research Ethics Committee (22/SC/0473). The current study is part of the innovative training network ETUDE (Encompassing Training in fUnctional Disorders across Europe) [36].

2.1. Taxonomy of measurement properties

The taxonomy of measurement properties developed by the COnsesus-based Standards for the selection of health Measurement INstruments (COSMIN) group was used [37,38]. While COSMIN guidelines are primarily designed for outcome measurements in patients, the process can simply be adapted by applying the criteria to healthcare professionals.

2.2. Regular review by research team

Feedback was regularly reviewed by a research team which consisted of a medical anthropologist/ sociologist, consultation-liaison psychiatrist, general practitioners, psychologist, epidemiologist, neurologist and social scientist with expertise in stigma. During the item generation phase, we also received feedback on face validity from other healthcare professionals including two general practitioners, an internal medicine specialist, and two people with lived experience of PSS.

2.3. Item generation

We generated an initial longlist of 60 items from: 1) adapting the most relevant examples by face validity from a previous systematic review of PSS related stigma instruments [34]; 2) adapting items from stigma instruments relating to other health conditions; and 3) adapting items from a recent scoping review on stigmatisation during clinical consultation [15]. We grouped each item according to stereotypes, prejudices and discrimination. Response categories were created in a five-point Likert scale. A five-point scale was chosen due to its familiarity and ease of administration. From collective feedback, items were removed or amended resulting in a 40 item scale for cognitive interviewing. The rationale for 40 items at this stage was pragmatic, based on a proportion of reduction similar to other developed stigma instruments [39] while allowing for each remaining item to be suitably tested during interviewing.

2.4. Cognitive interviewing

Cognitive interviewing aimed to evaluate and improve the content validity of items. Cognitive interviewing is a qualitative technique that evaluates how a participant responds to a questionnaire [40,41]. Response processes include comprehension, the retrieval of necessary information from memory, evaluation of retrieved information, and the

selection of a response [40,42]. Related to this is the measurement property of content validity: the "degree to which the content of an instrument is an adequate reflection of the construct to be measured" [38]. Within content validity, there are components of relevance (items must be relevant to the construct, target population and context of use, including appropriate response categories), comprehensiveness (ensuring no key concepts are missing), and comprehensibility (ensuring that items and response options are understood as intended) [43].

We conducted cognitive interviews with healthcare professionals within the United Kingdom (UK) over two rounds, with recommendations made after each round. Participants were recruited using a purposive sampling method. We aimed to recruit from each of the following disciplines: general practitioners, internal medicine specialists, neurologists, psychologists, nurses, and physiotherapists. We also aimed to maximise variation in the sample by recruiting healthcare professionals with varying years of experience of working with people with PSS and varying attitudes towards people with PSS. Inclusion criteria were as follows: 1) participant was willing and able to give informed consent; 2) over 18 years of age; 3) completion of basic healthcare professional training (but not necessarily specialisation); 4) some experience of interacting with people with PSS in their healthcare role (thought this contact did not have to be regular or recent); 5) they were fluent in English (language of interviewer). Healthcare professionals were initially recruited through two sources: NHS Lothian (Scotland, UK) and contacts of the research group based in the UK. These contacts were asked to share our advertisement of the research. Potential participants gave verbal consent to be contacted by the lead researcher (BMF), who waited at least 24 h before contacting the potential participant to discuss the study and arrange a meeting time for consent and interview. All participants were offered a £25 high street voucher to compensate them for their time and input.

Each participant was interviewed one time, lasting between 45 and 90 min. Cognitive interviews were conducted by an experienced qualitative researcher (BMF). We adopted a hybrid approach of the 'think aloud' method and verbal probing [40,42]. Within the think aloud method, participants think out aloud while answering, or recall thoughts after completing an item. Verbal probing occurs where the interviewer administers specific probe questions. These can be anticipated probes, designed to search for potential problems (for example comprehension of a particular phrase) or they may be reactive probes to the response of the participant [40,42]. We explored relevance and comprehensibility for each item, and included a specific prompt for comprehensiveness at the end of the interview. We also explored understanding of the umbrella term 'persistent somatic symptoms' and related terms. Finally, we discussed if participants felt pressured to respond to items in a particular way (social desirability). Our topic guide is shown in **Appendix 1**. Interviews were audio recorded following informed consent and transcribed verbatim.

Interview transcripts were analysed using a codebook developed from examples in cognitive interviewing research [42,44] and content validity components. Analysis was conducted using MaxQDA 2022. All interviews were coded by the interviewer (BMF). A sample of interviews ($n = 4$) was independently coded by a consultation-liaison psychiatrist (CM) and coding compared. Coding was further discussed with a general practitioner experienced in qualitative research (PL). Where there were differences in coding, these were discussed until consensus was reached. We used these discussions to update the codebook. To assess comprehensiveness, saturation of item generation was evaluated across each round of interviews. Each component of content validity and social desirability was assessed, with recommendations made for each item. Removal or amendment of items were made following consensus of the research group. This process was repeated until only a few minor problems could be identified.

3. Results

The development process of the PSSS-HCP is summarised in Fig. 1**.** A five-point Likert scale is used and ranges from 1 = Strongly disagree, to 5 = Strongly agree.

3.1. Item generation

We generated 60 initial items, grouped into domains of stereotypes, prejudices and discrimination as defined in the introduction. After research team consensus and initial feedback, this was reduced to a shortlist of 40 items for cognitive interviewing. Reasons for removal included similarity and overlap with other items ($n = 6$), lack of comprehensibility (n = 6), lack of relevance ($n = 5$), and potential social desirability bias ($n = 3$). Indicative examples of removed items are presented in Table 1. The full list of generated items including original sources is provided in **Appendix 2.**

3.2. Cognitive interviewing

We conducted 18 cognitive interviews with healthcare professionals, including four general practitioners, three nurses, two internal medicine specialists, two physiotherapists, two neurologists, a psychologist, a speech and language therapist, and a doctor in the NHS Foundation Programme (training for newly qualified doctors preceding specialisation). Participant characteristics were missing for two participants. Participant characteristics are summarised in Table 2. Interviews were done in two rounds ($n = 11$, $n = 7$), with amendments made after each round. Interviews were coded to identify potential problems with relevance, comprehensibility, comprehensiveness, social desirability and response options (our codebook is available in **Appendix 3).** A summary of recommendations at each round is available in **Appendix 4.**

After our first round of interviews, we removed 20 items (14 removed for lack of relevance, four removed for lack of comprehensibility and two removed for perceived social desirability). We added three items from suggestions of the research group (two items were variants of existing concepts and one item explored a new concept, diagnostic overshadowing). We amended five items that were perceived as relevant but comprehensibility was slightly inconsistent. The second version of the PSSS-HCP for pilot testing included 23 items. After our second round of interviews, we removed four items (three for lack of relevance and one for lack of comprehensibility) and amended three items. Remaining items are presented in Table 3.

3.2.1. Relevance

3.2.1.1. Terminology. While the umbrella term PSS was not always spontaneously recognised, all participants were able to clearly distinguish people with these symptoms after being provided with a definition and examples. There was a split in familiar terminology according to treatment setting. Participants in primary care settings were more familiar with PSS, though the term PSS was sometimes used interchangeably with 'persistent physical symptoms' or 'medically unexplained symptoms' in education settings. Participants in secondary care settings were typically more familiar with specific PSS such as chronic pain, or functional disorders such as functional neurological disorder or irritable bowel syndrome. Most participants did not express a preference for terms, but some noted the need to highlight examples and relevant diagnostic terms. We adjusted our definition of PSS to include examples at the symptom, syndrome and disorder level **(Appendix 5).**

3.2.1.2. Relevance to stigma. Items focused on causal attribution (for example: "Persistent somatic symptoms are primarily a psychological disorder") were initially viewed as relevant, with participants noting that psychological attributions of symptoms were often perceived as

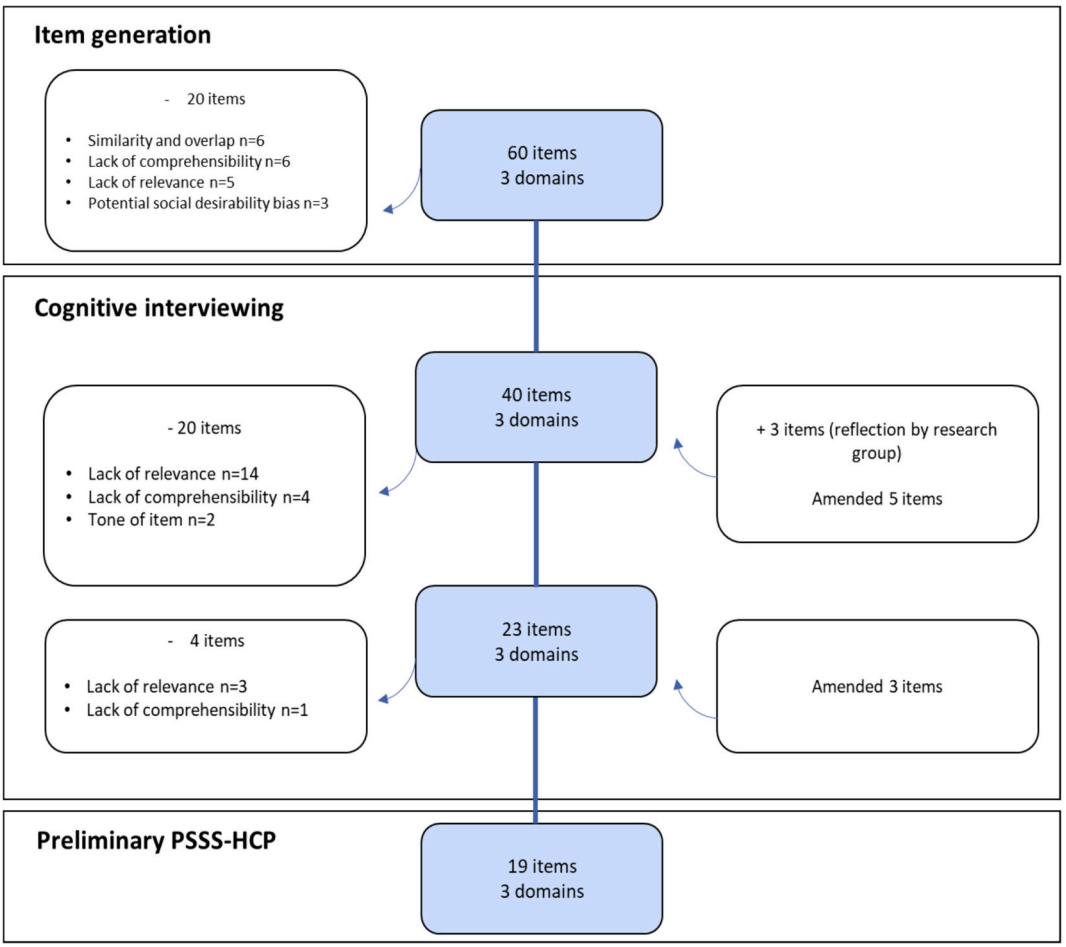

Fig. 1. Development process of the PSSS-HCP.

Table 1
Indicative examples of removed items in item generation stage.

Reason for removal	Example item
Similarity or overlap to other items	• If I had persistent somatic symptoms, I would never admit this to my family
Lack of relevance	• I feel powerless when working with people with persistent somatic symptoms
Lack of comprehensibility	• I tend to ignore people with persistent somatic symptoms
Potential influence of social desirability bias	• I am able to avoid stigmatising comments towards people with persistent somatic symptoms

more stigmatising. This fed into discussions about mind and body dualisms within medicine, with some preferring not to engage with a mutually exclusive concept. Some participants felt unable to answer causal attribution questions due to a perceived lack of knowledge. We reflected that causal attribution was less related to stigma than illness perception, so we removed these items.

Some items exploring personal prejudices were reflected as healthcare systems challenges rather than stigma. This included items such as people with PSS being 'difficult to manage', being 'demanding' or feeling 'frustrated' as a healthcare professional. Participants reflected that these emotions were more a reflection of fragmentation of healthcare, lack of guidance and challenging interactions:

> *"By the time they come to see me as a patient, they have been run around the houses quite a bit… it sometimes feels like hard work because you're having to unpick some of that."* (P12, physiotherapist).

Table 2
Participant characteristics.

Variable		n	% (from 16 participants)
Age (years)	18–25	1	6.25
	26–44	7	43.75
	45–64	7	43.75
	≥ 65	1	6.25
Gender	Woman	9	56.25
	Man	7	43.75
Type of healthcare professional	General practitioner	4	25
	Nurse	3	18.75
	Internal medicine specialist	2	12.5
	Physiotherapist	2	12.5
	Neurologist	2	12.5
	Psychologist	1	6.25
	Speech and language therapist	1	6.25
	NHS Foundation Programme	1	6.25
Years of experience working with people with PSS	0–1	1	6.25
	1–2	2	12.5
	2–5	3	18.75
	5–10	1	6.25
	≥ 10 years	9	56.25

We amended two items to focus more on specific prejudices explored in interviews, including 'feeling uncomfortable'.

Items relating to social distance were generally not perceived as relevant, with participants noting that other factors would influence

Table 3
Preliminary version of the PSSS-HCP.

#	Item (* = reverse score)	Domain	Sub-domain/ concept
1	Anybody could develop persistent somatic symptoms under the right circumstances.*	Stereotype	Beliefs about people with PSS
2	Most people with persistent somatic symptoms don't try hard enough to get better.	Stereotype	Beliefs about people with PSS
3	There is little I can do to help people with persistent somatic symptoms.	Stereotype	Beliefs about people with PSS
4	I find that people with persistent somatic symptoms often exaggerate their symptoms.	Stereotype	Beliefs about people with PSS
5	It is important to encourage hope for improved quality of life for people with persistent somatic symptoms.*	Stereotype	Responsibility of healthcare professional
6	I feel as comfortable talking to a person with persistent somatic symptoms as I do other people.*	Prejudice	Emotions about people with PSS
7	I find it satisfying to support people with persistent somatic symptoms.*	Prejudice	Emotions about people with PSS
8	People with persistent somatic symptoms evoke negative feelings in me, such as aversion, stress or impatience.	Prejudice	Emotions about people with PSS
9	I secretly hope that people with persistent somatic symptoms will not return.	Prejudice	Emotions about people with PSS
10	I often feel uncomfortable about providing care to people with persistent somatic symptoms.	Prejudice	Emotions about people with PSS
11	I struggle to feel compassion for people with persistent somatic symptoms.	Prejudice	Emotions about people with PSS
12	Sometimes I lose patience with people with persistent somatic symptoms.	Discrimination	Responsibility of healthcare professional
13	If I had a choice, I would rather not care for people with persistent somatic symptoms.	Discrimination	Responsibility of healthcare professional
14	When someone with persistent somatic symptoms presents a new symptom or complaint, I am less likely to pay attention to other diseases than in other people.	Discrimination	Diagnostic overshadowing
15	If a colleague told me they had persistent somatic symptoms, this would not change how willing I was to work with them.*	Discrimination	Social distance
16	Employers should hire a person with persistent somatic symptoms if they are the best person for the job.*	Discrimination	Social distance
17	If I developed persistent somatic symptoms, I would be reluctant to tell my friends.	Discrimination	Disclosure and help-seeking
18	If I were under treatment for persistent somatic symptoms, I would try not to disclose this to any of my colleagues.	Discrimination	Disclosure and help-seeking
19	I would be reluctant to seek help if I knew I had persistent somatic symptoms.	Discrimination	Disclosure and help-seeking

willingness to interact with people before PSS would play a role. Some participants noted that disruption to daily functioning from symptoms may limit possibilities for interaction, but this was distinct from willingness to engage. Items assessing social distance in the workplace and during clinical consultation were generally perceived as more relevant than items relating to friendship or more personal interaction. We removed items on prospective friendship, instead focusing on relationships in the work context.

3.2.1.3. Relevance to healthcare professionals. One item about treatment was considered not relevant to all healthcare professionals. Treatment was considered only applicable to clinicians, with some nursing participants suggesting that in their role they didn't personally treat people. We rephrased this item from 'treating' to 'supporting'.

3.2.1.4. Relevance of response categories. No problems emerged with the proposed response categories. Two participants expressed a desire for more response categories (such as a seven-point Likert scale), with more explicit 'slightly agree' or 'slightly disagree' options. Two participants expressed a desire for open questions, to provide further qualification or context for responses. In a recent analysis comparing different numbers of response categories (three, five and seven point Likert scales), the authors reported that using a five point response category provided no disadvantage compared to a seven point response, while offering more ease of responding [45]. Therefore, we decided to retain the simpler five-point Likert scale and provide an optional open question in future testing.

3.2.1.5. Responsiveness to change. While examples of stigmatisation by other healthcare professionals were regularly discussed, we reflected that items exploring perceived stigmatisation by others were not relevant. Since we aimed to evaluate stigmatisation by individual healthcare professionals, the score on these items would not necessarily be responsive to change. We removed these items.

3.2.1.6. Recall. No problems with the recall and retrieval of relevant information from memory were found. Some participants reflected that their amount of experience affected their responses. One participant reflected that their answers would have been a lot more negative during an early stage of their career, without the years of experience, support, or successful communication strategies that they would later rely on.

3.2.2. Comprehensibility

For items focusing on control, participants questioned if they referred to voluntary control and motivation for secondary gain (stigmatising), or successful management of symptoms and improved functioning (not stigmatising):

> *"Control is a difficult one… it has connotations with almost choice… some people can modify some of their symptoms, but it's not straightforward or consistently effective… the other side of [control] is the notion that you can through processes of education and understanding… you can help people to live with their symptoms and potentially manage them more effectively."* (P02, general practitioner).

There was also doubt if control referred to initial onset of symptoms, or how a person could modify symptoms once presenting. Because of this inconsistency we removed this item. We adjusted an item about motivation to be more explicitly a stereotype: we re-phrased [people with PSS would] 'get better if they really wanted to be healthy' with 'don't try hard enough to get better'.

An item about recovery was also interpreted inconsistently. Some participants interpreted recovery in a biomedical model, referring to complete alleviation of symptoms or a return to baseline condition. For others, recovery could refer to improved functioning and achieving personal goals. We amended this to more explicitly ask about the role of the healthcare professional in encouraging a better quality of life. An item about potential health seeking was also seen as unclear, with 'If I thought I had PSS, I would seek help'. Participants noted that seeking clarity about symptoms is an important motivation for help-seeking. We amended this item to 'knew', where it was clearer that an explanation had previously been provided.

3.2.3. Comprehensiveness

Comprehensiveness was discussed in every interview, with item

generation coded both to spontaneous suggestions and to a specific prompt at the end of the interview. Participants commented that they felt the breadth of the items was sufficient: *"it covers most aspects you know… everything comes to mind*" (P16, internal medicine specialist). When asked to generate new ideas: a typical response was *"[I] can't think of anything specific"* (P17, psychologist). In our first round of interviews, we coded four quotes relating to item generation. In our second round, we coded two quotes for idea generation, both of which had been considered in the item generation stage. Therefore we consider it likely that saturation was reached.

3.2.4. Influence of social desirability

When asked about the use of a confidential online survey to answer questions, participants raised no concerns about social desirability. A typical response was *"… if somebody's gonna commit to doing it, I think you'll get honest answers"* (P05, nurse). Some participants commented on the value of reflecting on experiences as a healthcare professional and acknowledging difficult feelings:

> *"I think that sort makes you think… how you portray a group of patients and how we feel about them and get that out a little bit… I think it's helpful. You know these people desperately need something and if our mission is here to help somehow, how can we help rather than just hoping they go away and not come back"* (P08, nurse).

However, for two items we noted that there was hesitance to answer the question if they found the tone negative. For example, we tested an item about personality traits of people with PSS, which one participant described as *"not liking the concept"* (P02, general practitioner). Similarly, an item about manipulation was described as being a *"judgmental statement"* (P04, general practitioner). We removed these items and reflected that early items were predominately negative formulations. We amended the order to include reverse-scored items higher in the item order.

4. Discussion

Perceived stigmatisation is associated with poorer health outcomes and quality of life for people with PSS. While there is increasing need to evaluate the effectiveness of stigma reduction interventions, there are limited stigma measurement instruments that explain their development process or demonstrate content validity. In this study we developed a measurement instrument to assess PSS related stigmatisation by healthcare professionals, the PSSS-HCP. The preliminary version of the PSSS-HCP contains 19 items within three domains (stereotype, prejudice, discrimination). The total sum of scores can range from 19 to 95 and a lower score indicates less stigma. Items 1, 5, 6, 7, 15, 16 are reverse-scored. This has been developed in the context of healthcare professionals working in the UK, requiring further evaluation of validity and reliability before we can consider the scale complete.

We found that responses of healthcare professionals were influenced by perceived structural factors. The importance of structural factors such as policy, legislation and media are well reported in stigma literature [25], as well as in the context of PSS clinical consultations [15]. Participants cited structural factors including lack of knowledge and guidelines [46], lack of support from senior healthcare professionals [47], and fragmented healthcare systems [48,49]. All of these factors are highly likely to influence stigmatisation, for example through factors such as perceived confidence and competence. However, we took care in the development process to remove items that were solely considered in the context of healthcare systems factors.

Many of our items exploring social distance were not perceived as relevant. The relevance of social distance might be attributable to dimensions of stigmatised conditions. These dimensions include concealability (the extent to which the visibility of the condition is controllable), aesthetics (how repellant or upsetting the condition is perceived as) or peril (how dangerous the condition is perceived as) [50,51]. Studies regularly using measures of social distance include conditions with perceived risks of infection such as HIV or leprosy, or conditions with stereotypes about danger, unpredictability or violence (such as mental health stigma) [52]. It could be that desired social distance as operationalised in other stigma instruments are less of a contributing factor to stigmatisation in PSS, or that health conditions with particular dimensions (such as higher perceived peril and lower perceived aesthetics) are better suited to explore questions of social distance than PSS. Therefore, we focused on social distance questions that were perceived as more relevant to participants.

In this study we found evidence that self-report questionnaires can offer reflection for professionals about their own experiences. In a review of outcome measurement instruments, it was similarly reported that self-reported questionnaires are not a neutral act of information retrieval. Rather, self-reporting can influence communication in a clinical setting [53]. Questionnaires like the PSSS-HCP may similarly offer a starting point for self-reflection and improved clinical communication. Indeed, there are some specific PSS educational interventions that focus on self-reflection, for example through the use of group supervision [54]. This supports the notion that both explicit and implicit measurement instruments are needed to explore complex social processes such as stigma, with triangulation made between them. While demand characteristics pose a threat to the validity of the instrument, these could also apply to implicit measurement instruments [55] or study designs when evaluating stigma reduction interventions [56]. Therefore, we believe in the utility of self-reported instruments while also emphasising the importance of assessing the influence of demand characteristics where possible.

While we have used a well-recognised conceptualisation of stigma during this development, it is important to acknowledge that there are multiple possible conceptualisations. For example, recent interventions against mental health stigma have conceptualised stigma as a problem of knowledge, attitudes and behaviour [57]. This was based on the work of Thornicroft et al., who described stigma as a problem of ignorance (knowledge), attitudes (prejudices), and behaviour (discrimination) [58]. There is typically convergence between these conceptualisations, with items broadly covering cognitive, affective and behavioural components of stigma from the perspective of a potential stigmatiser. However, points of divergence might include the approach in which items are asked. For example, while we proposed to measure the extent of agreement with stereotypes, another conceptualisation of stigma may lead to items that test knowledge more prescriptively (with correct or incorrect responses). Similarly, while there is recently some critique about the role of emotional reaction as a necessary part of the stigma conceptualisation [59], this critique is aimed at the perspective of someone who is stigmatised rather than the perspective of a potential stigmatiser. In the context of PSS, we know that the emotional reactions experienced by healthcare professionals are particularly relevant, so we developed items to specifically explore this. Therefore, while conceptualisation of stigma will undoubtedly affect the operationalisation of items, these approaches are not necessarily exclusive of each other.

The terminology used to describe persistent somatic symptoms continues to be debated [1,4,60,61]. We explored comprehensibility of PSS as part of this study and updated our definitions through testing. A broad spectrum of recognised terms was expected, reflecting both available training to healthcare professionals and familiarity with relevant diagnostic criteria. We found no consensus on preferred terminology, and no significant problems with understanding or coherence when definitions and examples were provided. So long as appropriate definitions are provided, we consider it likely that the term persistent somatic symptoms in the scale could be substituted for related terms such as functional disorders, or syndromes including irritable bowel syndrome or fibromyalgia in future versions of the scale without compromising content validity.

4.1. Strengths and limitations

The most important strength of this study is the use of robust methodology throughout development. We have followed COSMIN guidance throughout development and reporting, offering transparency about analysis and decision-making. We involved healthcare professionals throughout the process, evaluating the instrument and individual items for their content validity.

A further strength of this study is the consideration of the influence of social desirability bias. We discussed the potential influence of social desirability on individual item responses as well as overall responses by distribution format. We also explored factors that might influence the likelihood of giving socially desirable answers. This included removing items that were perceived to be too negative in tone.

This study also has limitations. While the PSSS-HCP is developed for healthcare professionals, our involvement of people with PSS is limited. We gained feedback from people with lived experience of PSS in early stages of development through a convenience sample, but there is scope to include perspectives more formally. We mitigated the impact of this by adapting items from a recent scoping review exploring patient perspectives of stigmatisation in the clinical consultation [15] and an ongoing interview study exploring patient perspectives of stigmatisation during diagnosis of functional neurological disorder [16]. Therefore, we do not believe that any important domains are missing. However, additional research may be warranted to expand the item pool.

Another limitation is that there may be a risk of bias in our sample of healthcare professionals. Participants were self-selecting and therefore more likely to have an interest or willing to discuss their experiences working with people with PSS. This is reflected in the high proportion of participants with extensive experience of working with people with PSS. Therefore, these participants may not represent the full spectrum of beliefs and attitudes of healthcare professionals in the UK. However, since the aim of the study was to assess the content validity of items rather than measure stigmatisation outright, we think the likely impact is negligible. The effect of recruitment bias was further limited with the use of a detailed topic guide.

Our next step will be to perform a validation study of healthcare professionals in the UK to finalise item selection, explore the structure of the PSSS-HCP, and assess the validity and reliability of the scale (preregistration: https://osf.io/7jtr4). Only through both studies can we consider the development complete. However, we believe that this initial study represents an important step in the development of the scale and in the measurement of PSS related stigma.

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Ethics approval

The research was approved by the University of Edinburgh and the South Central - Oxford C Research Ethics Committee (22/SC/0473).

Consent to participate and publish

Informed consent was obtained from all individual participants included in the study.

CRediT authorship contribution statement

Brodie McGhie-Fraser: Writing – review & editing, Writing – original draft, Project administration, Methodology, Formal analysis, Conceptualization. **Caoimhe McLoughlin:** Writing – review & editing, Methodology, Formal analysis, Conceptualization. **Peter Lucassen:** Writing – review & editing, Supervision, Methodology, Formal analysis, Conceptualization. **Aranka Ballering:** Writing – review & editing, Conceptualization. **Sandra van Dulmen:** Writing – review & editing, Supervision, Methodology, Conceptualization. **Evelien Brouwers:** Writing – review & editing, Supervision, Methodology, Conceptualization. **Jon Stone:** Writing – review & editing, Conceptualization. **Tim Olde Hartman:** Writing – review & editing, Supervision, Methodology, Conceptualization.

Declaration of competing interest

The authors have no relevant financial or non-financial interests to disclose.

Data availability

The project file for this study can be found on the Open Science Framework (https://osf.io/7jtr4). Data of this study are available upon reasonable request by the corresponding author.

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Appendix A. Supplementary data

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