**Table 1.**Barriers identified from focus group and associated quotations

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| **Barriers** | **Selected illustrative quotations** |
| **Timing** | ‘*People have just not understood how to answer these because people often don’t have a diagnosis so they have been going to their GP for all these unexplained symptoms and naturally you’re going to be worried about what is wrong with you, you want to find out what is wrong with you. So there’s something odd about that, how you apply those questions at that time as well, when a diagnosis isn’t known yet.*’  ‘*When you finally find a place that you feel trusted and that you can trust and that you can believe and you find you finally feel like you’re getting somewhere, to suddenly have this, this questionnaire, it’s a little bit like a slap in the face. I feel it is quite… strongly worded as to make them think, yeah, their illness it’s saying that their illness might be in their mind, and that we actually maybe secretly do think that.*’  ‘*I think down the line with people there is value in identifying those people who are constantly symptom-focusing, I think that’s kind of important, but not at the point of assessment, perhaps that’s not the best stage?*’ |
| **Phrasing and language** | ‘*So just reading them out, I thought if I had to fill that in I’d find it more of a challenge. When you’re struggling with a lot of brain fog… I can see where people would struggle, just physically reading it, let alone the sort of thought process that it takes you down.*’  ‘*I think also there’s, whether this is capturing people’s anxiety in the way it presents in this cohort of people. I think the construct is different, being anxious about your health in the context of having a health condition compared to not, I think this isn’t the best tool to do it.*’  ‘*I wonder with the specific items, the wording of it, how many things you might endorse, just because you’ve got a health problem with multiple symptoms.*’  ‘*They feel ill, their felt experience is that they are very poorly so the idea that their GP telling them there is nothing wrong is never in a million years going to be reassuring.*’  ‘*well “lastingly relieved if my doctor tells me there is nothing wrong”, you know, it’s like you want them to find the thing that’s wrong with you from all these investigations, so that’s going to skew that answer as well… I’m not going to be relieved if my doctor tells me there is nothing wrong because I’m still ill, that’s why I’m here!*’  ‘*By the time they’ve got through the rest of the form, they’ve probably run out of energy and steam and mental ability and concentration to be able to cope with it and then they look at the words and just think “whoa, I can’t do it”.*’  ‘*I think people who haven’t filled it in, not because they’ve got a problem with it but just because they can’t be bothered, they see it as an extra thing, that looks hard, and when you start reading it, actually it does come across as quite challenging and “lastingly relieved”, that’s not a phrase that anybody would use!*’ |
| **Demand characteristics and response bias** | ‘*I wonder if there might be an element of wanting to feel in a quite extreme way to prove that they are struggling, as a diagnostic almost?*’  ‘*I think people are thinking what are we thinking… they see these boxes and they think that they are helping us by providing false information.*’  ‘*Maybe we’re not couching it enough in terms of actually, like with other conditions you can have like anxiety as well as other conditions, maybe we’re not doing enough around that because then it becomes either it’s this or it’s CFS.*’  ‘*Giving somebody a questionnaire working in CFS, I can imagine, there could be some resistance to it and people being quite guarded around what information they are giving you and if this will go as part of their diagnosis then they might be quite guarded about how they might achieve that. There could be, for some people, well not everybody but, could be some resistance to answering that or disclosing information.*’ |
| **Context** | ‘*I think that there is a particular culture around CFS/ME, more so than other health conditions around whether this is real. That is a real theme in our patient group and outpatient clinics.*’  ‘*Often I’ve done a bit of work about “yes it is separate to the other forms” and putting it in the context of “we are learning a lot about psychological help for people with all sorts of conditions like, cancer, Parkinson’s, MS, so, we’re exploring”, just trying to provide a bit more context within a wider medical background.*’  ‘*Patients could think “it’s all in my mind” especially if the question, the individual questions reinforce that.*’  ‘*Look, all we really need to say to people is “we know you’re ill – do you think you worry about it too much?” That’s really what we’re saying isn’t it? People can understand that!*’  ‘*I think also there’s, whether this is capturing people’s anxiety in the way it presents in this cohort of people. I think the construct is different, being anxious about your health in the context of having a health condition compared to not, I think this isn’t the best tool to do it.*’ |
| **Negative past experiences** | ‘*I think the language, even just being in hospitals and things is very anxiety provoking and I think we really take a lot of stuff about people’s journeys totally for granted and the jargon that people are suddenly faced with, as, you know, even with all the other forms, let alone this.*’  ‘*It depends on what their experience of having the illness is and the messages that they’ve been told, that they’ve been trying to fight against and if that’s not been good, to be suddenly confronted with something like this could be incredibly, well, it could be enough to make someone walk out I’d have thought.*’  ‘*Yeah, and I think the legitimacy issue, it just, is actually probably very different to a lot of other conditions.*’ |