doi: 10.1111/hex.12203

The development and initial validation of a questionnaire to measure help-seeking behaviour in patients with new onset rheumatoid arthritis

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Accepted for publication
2 April 2014

Keywords: delay in accessing health services, face validity, patient involvement, questionnaire development, rheumatoid arthritis, test–retest reliability

[1]Syndicate members are listed in Appendix 1.

Abstract

Background Early treatment for rheumatoid arthritis (RA) is vital. However, people often delay in seeking help at symptom onset. An assessment of the reasons behind patient delay is necessary to develop interventions to promote rapid consultation.

Objective Using a mixed methods design, we aimed to develop and test a questionnaire to assess the barriers to help seeking at RA onset.

Design Questionnaire items were extracted from previous qualitative studies. Fifteen people with a lived experience of arthritis participated in focus groups to enhance the questionnaire's face validity. The questionnaire was also reviewed by groups of multidisciplinary health-care professionals. A test–retest survey of 41 patients with newly presenting RA or unclassified arthritis assessed the questionnaire items' intraclass correlations.

Results During focus groups, participants rephrased questions, added questions and deleted items not relevant to the questionnaire's aims. Participants organized items into themes: early symptom experience, initial reactions to symptoms, self-management behaviours, causal beliefs, involvement of significant others, pre-diagnosis knowledge about RA, direct barriers to seeking help and relationship with GP. The test–retest survey identified seven

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items (out of 79) with low intraclass correlations which were removed from the final questionnaire.

Conclusion The involvement of people with a lived experience of arthritis and multidisciplinary health-care professionals in the preliminary validation of the DELAY (delays in evaluating arthritis early) questionnaire has enriched its development. Preliminary assessment established its reliability. The DELAY questionnaire provides a tool for researchers to evaluate individual, cultural and health service barriers to help-seeking behaviour at RA onset.

Background

Irreversible joint damage occurs during the early stages of rheumatoid arthritis (RA). The first 3 months following clinical disease onset represent a therapeutic window during which drug treatment is particularly effective at controlling synovitis and limiting subsequent damage to bone and cartilage.[1–4] Despite increased recognition of the benefits of early treatment, there remains considerable delay between symptom onset and the initiation of therapy.[5–7] Delays can occur at several levels including delay on the part of the patient in seeking medical advice at symptom onset, delay in obtaining an appointment with a primary health-care professional and delays in referral to a rheumatologist, diagnosis and commencement of disease modifying therapy.[8,9] The median delay between symptom onset and assessment by a rheumatologist in the UK has been reported to be 23 weeks, most of which was due to patient delay in seeking help (median 12 weeks).[7,10] Similar delays occur in many other European countries.[11,12] Many patients thus miss a potential therapeutic window because they delay in seeking help for their symptoms.

Qualitative studies and a meta-synthesis have identified barriers to help seeking at the onset of RA.[13–16] Barriers to early consultation included the insidious onset of symptoms which often characterize the onset of RA. Patients often normalized their symptoms and did not consider arthritis as a potential cause. Pre-existing ideas about RA, often termed prototypical illness beliefs (cultural understandings of an illness held by people without personal experience of the illness in question), led people to believe that RA was a mild condition that affected older people. These misperceptions made correct symptom interpretation unlikely. Prototypes for some illnesses are better formed than those of others, but generally they influence individuals' perspectives on an illness' likely duration, its symptomatology, severity and consequences and the need for treatment.[17,18] These prototypical models can be unhelpful if they are inaccurate and may mislead people into believing that the symptoms of conditions such as RA do not require them to seek medical attention.

In addition to symptom experience, the influence of advice from family and friends, a frequent desire to use alternative medicines, access to health services and attitudes towards health-care professionals, particularly general practitioners, are also important determinants of help-seeking behaviour.[15,19] Further research is needed to understand the importance of the range of barriers to seeking help identified through qualitative research and which barriers are relevant to different groups within the population. A method of systematically measuring barriers to seeking help at the onset of RA is thus required. A tool to measure barriers would allow the relationship between determinants and extents of delay in help seeking to be assessed. A cross-sectional survey using this tool would provide an evidence base from which tailored interventions to promote rapid help seeking could be developed.

Exploring the perspectives of people with a lived experience of RA has been instrumental

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in determining the research priorities for people with RA and the development of appropriate measurement tools used to assess RA.[20–23] Furthermore, involving patients in questionnaire development can ensure that the questions used were appropriate, relevant and comprehensible to the target population.[24,25] The use of qualitative methods to explore themes discussed in the questionnaire can help identify salient attitudes and norms, inform the content, format and layout of a measurement tool and provide information about user-friendliness.[26,27]

In this study, we describe the process of developing, validating and reliability testing the DELAY (delays in evaluating arthritis early) questionnaire, which was developed to assess the barriers to help seeking at RA onset. This research was undertaken in collaboration with two patient research partners who acted as co-facilitators during focus groups and were involved in the analysis and interpretation of qualitative data.

Methods

Integrated approaches were used to develop items for a questionnaire about help-seeking behaviour at the clinical onset of RA.[28] First, the research team identified potential items for inclusion from a synthesis of the literature regarding help-seeking behaviour in patients with RA.[15] Second, people with a lived experience of RA and joint problems participated in focus groups to discuss and further develop the questionnaire item pool and to explore item wording and questionnaire structure. During the third phase, focus groups were held with health-care professionals who reviewed the questionnaire for face validity. Finally, we undertook a test–retest study to assess the reliability and stability of responses to questionnaire items. NHS Research Ethics Committee approval was obtained for this study (reference: 10/H1207/98, issued 19/11/2010), and all participants gave written informed consent. Methods for each of these approaches are described below.

Initial questionnaire construction

Initially, 28 questionnaire items were derived from our group's qualitative interviews with people with RA.[13,14] Our systematic synthesis of the qualitative literature[15] regarding the barriers to help-seeking behaviour at RA onset increased the number of questionnaire items to 54. One or more statements were written to represent each concept identified from the existing literature. The questionnaire items were organized into themes, and a draft of the DELAY questionnaire was structured to allow respondents to indicate their agreement with each questionnaire item using a five-point Likert scale (ranging from strongly disagree to strongly agree).

Focus groups to discuss the relevance of potential questionnaire items

Twenty-three individuals were invited to participate in a series of focus groups to develop and validate the individual questionnaire items and the overall presentation of the DELAY questionnaire from the perspective of those with a lived experience of arthritis. Participants were recruited from local arthritis charities and patient support groups. Participants were 15 people diagnosed with RA, four with other arthritic conditions and four who were related to people with RA. RJS and two Patient Research Partners (IR and ST) co-facilitated the focus groups. Focus groups were guided by a topic guide developed by a multidisciplinary team (including IR, ST, RS, KR, RH, SHM and KS). The topic guide encouraged participants to share and reflect on experiences of help seeking at RA onset. The topic guide also addressed whether items should be rephrased, added or removed and to critically appraise the overall questionnaire in terms of structure and organization, comprehensibility, feasibility and acceptability.

Three focus groups with 19 health-care professionals (HCPs) including four consultant rheumatologists, two rheumatology trainees, three rheumatology nurse specialists, one practice nurse and nine general practitioners were

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conducted to offer insight into patient delay across a range of settings. HCPs were identified though advertisements in local rheumatology and academic centres.

The focus group discussions were digitally audio recorded and transcribed verbatim by RJS. Data were analysed using inductive thematic analysis methods.[29] Initial coding was used to generate analytical summaries of accounts. Blind independent initial coding of a sample of transcripts was undertaken by RJS and KR. The initial codes were grouped together into most noteworthy and frequently occurring categories, and related categories were linked together using qualitative data analysis software.[30] The themes were reviewed by RJS, KR (academics), ST and IR (patient research partners) who discussed changes to be made to the questionnaire and individual questions.

Test–retest study

The revised questionnaire was subject to a test–retest survey over two time points to establish item stability. Survey participants were patients aged 18 years or above and had RA (according to the 2010 ACR/EULAR criteria)[31] or unclassified arthritis (UA). Ninety-one patients with newly presenting RA or UA were approached by the assessing rheumatologist or nurse specialist in secondary care rheumatology clinics. Those who consented were asked to complete the DELAY questionnaire and return it using a freepost envelope.

Those who returned their first questionnaire were sent a follow-up copy of the DELAY questionnaire; the follow-up was sent approximately 2 weeks after the first questionnaire was returned. If the follow-up questionnaire was not returned within 1 week of it being sent to the participant, one postal reminder was sent. Answers given to questions at baseline and follow-up were compared using intraclass correlations. This statistic shows how strongly the scores given at each time point resemble one another. It was pre-specified that statements with correlations which were significant at the 1% level would be classified as having good test–retest reliability and the other statements would be considered to have poor test–retest reliability.

Findings

Focus groups with people with a lived experience of arthritis

The findings presented here are a summary of how the focus groups were used to inform the draft 54 item questionnaire developed from the existing qualitative literature. During the focus groups, additional items and concepts were proposed, and changes were made to the original items. Statements were organized into eight sections (which have been used as subheadings below): Experience of symptoms before seeing GP; Reactions to symptom onset; Initial self-management of symptoms; Beliefs about the cause of symptoms; Talking to others about symptoms; Knowledge about RA before diagnosis; Direct barriers to GP consultations (such as personal circumstances or environment); and Communication and relationship with GP. This process enhanced the questionnaire's face validity and increased the number of questionnaire items to 79. The findings are supported by quotations from focus group participants. The revised questionnaire items are presented in Table 1.

Section 1: symptom onset

Participants agreed that the core symptoms of pain, fatigue, swelling and stiffness were covered by the draft DELAY questionnaire, but suggested that the questionnaire should refer to 'symptoms' as an overarching descriptor, instead of referring to specific symptoms (see questions 1–7 Table 1). For many, fatigue stood out as a prominent symptom; therefore, item 8 was dedicated to this issue.

> This should be major problem not just problem. I have fallen to sleep while driving and I can fall to sleep while talking to people, it's like a switch, a wave of exhaustion. You should change the question. (Participant with RA: Focus group four).

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Table 1 DELAY patient questionnaire items including results of intraclass correlation analysis (deleted items are in bold italics)

	N valid cases	Mean	SD	Intraclass correlations	Sig
Section 1: These questions ask about your experiences of symptoms before you first went to see your GP					
1. My arthritis symptoms began very quickly, coming on over a few days	38	3.16	1.393	0.775	0.000
2. Initially, my joint symptoms seemed like the usual aches and pains that I had occasionally had before	40	3.58	1.222	0.494	0.001
3. My arthritis affected my day to day activities within the first few weeks	40	3.70	1.280	0.542	0.000
4. My arthritis symptoms began very quickly, coming on over a few hours	39	2.63	1.402	0.455	0.001
5. The symptoms of my arthritis came on very slowly	39	2.83	1.251	0.858	0.000
6. It is difficult for me to remember the exact day or even week that my symptoms first began	39	3.29	1.190	0.612	0.000
7. For a long time my symptoms would repeatedly come and go	40	3.02	1.293	0.715	0.000
8. Initially fatigue and weakness were major problems for me	38	3.10	1.296	0.608	0.000
Section 2: These questions ask about how you reacted to your symptoms before you went to see you GP					
9. At first I ignored my symptoms hoping that they would go away	39	3.63	1.485	0.850	0.000
10. At the beginning I tried to pretend that I did not really have a problem with my joints	39	2.93	1.313	0.717	0.000
11. At first I thought that these symptoms were normal for someone like me (for example, someone of my age, gender etc)	41	2.92	1.369	0.774	0.000
12. When I first developed my symptoms, they frightened me	39	2.80	1.286	0.695	0.000
13. When I first developed my symptoms I understood what the cause was	38	2.17	1.092	0.591	0.004
14. When I first developed my symptoms they caused me to panic	38	2.15	1.201	0.771	0.000
15. I have so many other medical problems that I didn't have time to worry about my joints symptoms when they began	39	1.87	1.103	0.790	0.000
Section 3: These questions ask about the actions you may have taken to manage your symptoms before you first saw your GP					
16. Initially I tried to control my arthritis symptoms myself with tablets I bought from the chemist	41	3.25	1.468	0.787	0.000
17. I went to a health shop to buy products to control my symptoms.	40	2.19	1.266	0.617	0.002
18. I spoke to a pharmacist about my symptoms before I went to see the GP	37	2.07	1.219	0.832	0.000
19. Initially I tried to control my symptoms with an ice pack or a heat pack placed on my joint	41	3.22	1.391	0.851	0.000
20. *I spoke to another type of healthcare professional (such as a physiotherapist, chiropractor, osteopath, or a chiropodist) before I went to see the GP about my symptoms*	**39**	**1.91**	**1.261**	**0.487**	**0.021**
21. Initially I tried to control my arthritis symptoms myself with alternative medicines before I went to see the GP	39	2.17	1.300	0.619	0.002
22. Initially I tried to control my arthritis symptoms myself by altering my diet before I went to see the GP	39	2.07	1.137	0.635	0.001
23. *When my symptoms first began I tried to exercise and keep moving*	**40**	**3.53**	**1.081**	**0.448**	**0.033**
24. Initially I used prayer or sought spiritual or religious guidance to help me manage my symptoms	39	1.81	1.152	0.852	0.000
25. *Initially I tried to control my symptoms by limiting how much I moved*	**38**	**2.61**	**1.264**	**0.524**	**0.014**
26. Initially I bought things to support my joints, like splints or tubi-grips etc	38	2.69	1.477	0.813	0.000
27. Initially I took baths to relieve my joint symptoms	38	2.98	1.479	0.743	0.000
Section 4: These questions ask what you thought may have been causing your symptoms before your first saw your GP					
28. At first I thought that my joint symptoms may have been caused by something I had been doing (for example at work, during sports, while playing games or around the house)	38	3.60	1.400	0.883	0.000

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Table 1 Continued

	N valid cases	Mean	SD	Intraclass correlations	Sig
29. I suffer with osteoarthritis and though that that was the cause of my worsening joint symptoms	40	2.23	1.371	0.866	0.000
30. At first I thought my symptoms were stress related	38	1.95	0.955	0.804	0.000
31. At first I thought my symptoms were due to an injury (such as a knock, or a sprain)	39	2.66	1.358	0.775	0.000
32. At first I thought my symptoms were caused by a particular traumatic event in my life.	38	1.93	1.137	0.797	0.000
33. At first I thought my symptoms were related to hormonal changes	39	1.97	1.017	0.770	0.000
34. At first I thought that my symptoms were caused by my lifestyle (for example drinking, smoking or diet)	39	1.85	1.031	0.849	0.000
35. At first I thought that I my symptoms were caused by another serious condition other than arthritis (such as cancer)	38	1.93	1.100	0.856	0.000
36. At first I thought my symptoms were a natural part of the aging process (like getting older)	40	2.97	1.339	0.730	0.000
37. When my arthritis began I thought I had developed the flu	39	1.97	1.033	0.580	0.004
Section 5: These questions ask about other people you many have spoken to about your symptoms before your first saw your GP					
38. When I first developed my symptoms I did not want to discuss them with my family or friends	38	2.42	1.221	0.705	0.000
39. It was someone I know well who really persuaded me to go to see my GP with my joint symptoms	37	2.69	1.453	0.780	0.000
40. *I got advice from a friend or relative who knows a lot about health or medicine*	**38**	**2.17**	**1.142**	**0.539**	**0.010**
41. *I spoke to other people about my symptoms but no one told me that I should see my GP*	**37**	**1.98**	**1.017**	**0.415**	**0.056**
42. When I spoke to other people about my symptoms they suggested alternatives (such as exercise, prayer, herbal remedies and alternative therapies)	38	2.07	1.057	0.615	0.002
43. Before seeing the GP, I tried to find out more about my symptoms (either on the internet, in books or by asking other people)	38	2.67	1.316	0.736	0.000
44. Before seeing the GP it was obvious to family and friends that there was something seriously wrong with me.	38	2.42	1.221	0.730	0.000
Section 6: These statements are about what you may have known about arthritis before you first saw your GP					
45. I had heard about rheumatoid arthritis at the time when I first developed my symptoms	37	3.37	1.272	0.637	0.002
46. *When I first developed my symptoms I knew that rheumatoid arthritis was a serious condition*	**37**	**3.15**	**1.186**	**0.545**	**0.010**
47. When I first developed my symptoms I knew that there were good treatments that could be used for rheumatoid arthritis	37	2.72	1.056	0.793	0.000
48. When I first developed my symptoms I thought that I was too young to get arthritis	37	2.88	1.297	0.750	0.000
49. When my joint symptoms first began I was worried that I might have developed rheumatoid arthritis	37	2.66	1.124	0.906	0.000
50. I didn't realise that it was important to seek help early for the symptoms of rheumatoid arthritis	38	3.32	1.121	0.817	0.000
51. When I first developed my symptoms I knew there was something wrong with my joints	38	3.51	1.074	0.671	0.001

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Table 1 Continued

	N valid cases	Mean	SD	Intraclass correlations	Sig
52. When I first developed my symptoms I didn't think that joint pains could be a sign of something serious	38	3.24	1.150	0.670	0.001
53. In the past I'd not taken much of an interest in my health	37	2.14	1.008	0.892	0.000
54. Before diagnosis, I knew there were many different type of arthritis (such as Rheumatoid arthritis and Osteoarthritis)	38	3.53	1.049	0.634	0.001
Section 7: These statements are about your reasons for seeing the GP about your arthritis symptoms and your reasons for waiting before you went to see the GP					
55. I went to the GP because it got to the stage that I was unable to do normal every day things (such as climbing the stairs, turning on the taps or getting dressed)	38	3.68	1.265	0.705	0.000
56. I went to the GP because my pain was very severe	39	4.13	0.785	0.623	0.002
57. I went to the GP because the stiffness in my joints was severe	38	4.13	0.785	0.659	0.001
58. I went to the GP because the swelling around my joints was severe	39	4.14	0.880	0.676	0.001
59. The main reason I went to my GP was to get some treatment to make my joint symptoms better	39	4.14	0.880	0.559	0.001
60. I only went to see my GP when I found that I could not control my symptoms myself	38	3.15	1.257	0.646	0.001
61. *The main reason I went to my GP was to find out what was causing my joint symptoms*	**39**	**4.32**	**0.725**	**0.532**	**0.010**
62. I didn't go to the GP at first because I didn't have the time	37	1.91	0.923	0.826	0.000
63. When I first developed my symptoms I did not think that there would be much that my GP would be able to do for me	37	2.51	1.023	0.848	0.000
64. When I first developed my symptoms I didn't want to see my GP in case they said that my symptoms were my fault (i.e. were due to my diet, weight or lifestyle)	36	1.98	0.991	0.807	0.000
65. I went to my GP because I was actually worried that I may have had another serious condition (such as cancer)	37	2.19	1.008	0.803	0.000
66. I didn't want to see my GP because I was worried they would say I had something seriously wrong	37	2.09	0.978	0.680	0.000
Section 8: These statements are about your relationship with your GP					
67. In the past I have been pleased with the level of service that my GP has given me	37	3.92	0.915	0.841	0.000
68. I don't like to see my GP about symptoms if I think I can control them myself	36	3.54	1.095	0.846	0.000
69. When I make an appointment to see my GP I worry that I am using a valuable appointment that someone else might need more	35	2.88	1.226	0.855	0.000
70. On the whole I get on well with my GP	37	4.12	0.781	0.884	0.000
71. As a rule I always go to see the GP when I am not well	37	2.78	1.161	0.793	0.000
72. Most times that I go to the GP I don't see the same person	36	3.30	1.295	0.836	0.000
73. I have other illnesses which my GP helps me to manage	34	3.19	1.344	0.891	0.000
74. I feel confident that my GP knows what she/he is doing	37	4.02	0.827	0.843	0.000
75. I usually understand what the doctor is saying to me when I visit	36	4.19	0.545	0.797	0.000
76. I find it difficult to get to see the GP when I want to	36	2.91	1.254	0.750	0.000
77. Usually I just wait for my symptoms to go away on their own before making an appointment to see the GP	36	3.21	1.333	0.852	0.000
78. When I go to see the GP I feel rushed (as though the GP is short of time)	36	2.29	1.107	0.683	0.001
79. I sometimes find it difficult to tell the GP what I want	34	2.27	1.044	0.894	0.000

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Participants were keen for the questionnaire to capture the different types of symptom onset and represent the different intensities of symptoms experienced by people at disease onset. Questions 1, 4, 5, 6 and 7 were modified from existing statements to create items representing the different types of symptom onset.

> Severity is one of the problems, the onset of the problem, so if the onset is insidious or slow and you may ignore it. Obviously if it's very severe and it interfering with their activities of daily living or employment then..... they may need to access some sort of health professional as soon as they can suppose. (Participant with RA: focus group five).

It was highlighted that the proposed methodology was to administer this questionnaire to patients at their initial presentation in secondary care. It was also noted that there was often considerable delay between initial presentation to the GP and assessment in secondary care; therefore, it was felt important to emphasize that the time period being asked about in the questionnaire was that prior to presentation to the GP. Participants suggested that some questions could be subject to misinterpretation, because some items asked about symptoms that for many people with RA would be on-going problems and that responses may reflect current symptoms rather than symptoms prior to initial consultation with a health-care provider.

> I suppose if you're asking someone if that was something that affected them straight away, you might be able to put it in a better way. You could say 'did fatigue affect you straight away'. Because people will get confused, they will think – I've still got fatigue now.... So word that differently, so you know, it's looking for them to say that it was only initially. (Participant with RA: focus group three).

Questions were thus changed to emphasize that they were focussed on symptom onset, by including words such as 'initially' and 'first began' (see item 1, 2, 3, 4, 6 and 8). Participants also advised that the questionnaire should be introduced by the statement 'we would like to ask you about your thoughts and feelings at around the time you developed your arthritis'. In addition, they suggested that the headings to each section should make clear the timeframe that the questions related to. As a result, the following statement was added to the introduction to section 1: 'These questions ask about your experience of symptoms before you first went to see your GP', and similar headings were added to subsequent sections as appropriate.

Section 2: reactions to symptom onset

Psychological reactions to the presence of RA symptoms included ignoring symptoms, normalizing symptoms, carrying on as usual and a 'wait and see' approach. Participants believed that reactions like these caused people to delay for longer and should be a strong feature of the items in section 2.

> My equivalent is the computer at work and I'd think of my shoulders and it happens to so many people....you think oh I have been spending too long on the computer, I ought to do my exercises, I will take some more painkillers so you are normalising it. (Participant with RA: focus group four).

Section 3: initial self-management of symptoms

Participants suggested that self-management strategies caused people to delay for longer and should feature in the questionnaire, particularly as they may offer symptomatic relief but would not be of benefit to long-term disease outcomes.

> I don't know if you could add this, but some people try to keep moving, or try to sit better at their desk. So.... I certainly tried to do things for myself which involved trying to change my behaviour. (Participant with RA: focus group one).

The range of self-management strategies described during the focus groups was broad and varied.

> The usual things are 'oh I'll take some paracetamol', I'll try an ice pack or a hot pack.

> Oh heat pack is another thing that we can put on there.

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> Yeah like lavender.
>
> Oh yeah those bean bags that you can put in the microwave.
>
> I think a lot of people take cod liver oil, while it's good it's not going to do anything for something this major. (Participants with RA: focus group three).

Items related to the use of over the counter medications, exercise, diet, seeking advice from pharmacists, complementary therapists, other types of health-care professional and seeking spiritual or religious help were discussed. Participants highlighted that the items included in this section of the questionnaire should cover a range of possibilities including using pharmacies (items 16 & 18), alternative medicines (item 21) and baths (item 27).

Section 4: beliefs about the causes of symptoms

Participants discussed the causes they had attributed the early symptoms of RA to or had heard that other people had attributed the initial symptoms of RA to. The causes selected for the draft DELAY questionnaire related to beliefs about the causes of symptoms which may have influenced help-seeking behaviour. Some participants suggested that the questionnaire should contain questions which related to the menopause; however, the group felt that this was a gender-specific issue and concluded that statement which related to '*hormone changes*' would be preferable (item 33).

> RP 7: Say whether it would be too much of a leading question, should there be a question on the menopause?
>
> PRP 3: I mean you could say, well not to natural causes, but to the menopause, or just generally getting old.
>
> PRP 4: Or hormone levels changing. (Participant with RA: focus group two).

Some participants questioned whether the questionnaire was relevant to younger people in its current form and whether it reflected the activities that younger people typically engage in.

> Would you consider doing a section for younger people, I mean when you're younger you don't really do that much house work, so you can't really attribute it to getting down on the floor and scrubbing the carpet because you're a teenager and you don't really do that sort of thing. So I guess I would have attributed my symptoms to that, I would have attributed it to sport or something like that – if I was a sporty person. So there needs to be something along those lines for younger people. So that younger people feel involved in the questions and that (Participant with RA: focus group three).

In response to this, careful consideration was given to the relevance of items to all age groups. Some items were changed for example playing games was included in the following question, 'At first I thought that my joint symptoms may have been caused by something I had been doing (for example at work, during sports, while playing games or around the house)' (item 28).

Figure 1 illustrates the impact of participant involvement on saturating one section of the questionnaire with a range of perspectives on causal beliefs and how they may influence patient delay.

Section 5: speaking to other people and seeking information

Participants highlighted the positive and negative consequences of speaking to other people about symptoms. In some cases, interactions were felt to delay help-seeking behaviour.

> And, so probably it had been 2 or 3 weeks like that I had spoken to a friend and they said 'Oh yes. . ...you expect to get stiffness and aches and pains'. And my ankles my feet were a bit. ... were painful. (Participant with RA: focus group four)

In addition, it was felt that the internet was also used to find information about symptoms, diagnoses and treatment. Therefore, the internet was seen as an alternative to asking other people for information before seeking help. The group highlighted that information obtained, for example via the internet or by speaking with others, could lead a person to seek help or could cause them to delay for

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(a)

Section 4	These questions ask what you thought may have been causing your symptoms when they first began				
	Strongly disagree	**Disagree**	**Uncertain**	**Agree**	**Strongly agree**
At first I thought that my joint symptoms may have been caused by something I had been doing (for example at work or around the house).	☐	☐	☐	☐	☐
I suffer with osteoarthritis and thought that it was the cause of my worsening joint symptoms.	☐	☐	☐	☐	☐
At first I thought my symptoms were stress related.	☐	☐	☐	☐	☐
At first I thought my symptoms were due to an injury (such as a knock, or a sprain)	☐	☐	☐	☐	☐

(b)

Section 4					
These questions ask what you thought may have been causing your symptoms **before you first saw your GP.**	**Strongly disagree**	**Disagree**	**Uncertain**	**Agree**	**Strongly agree**
At first I thought that my joint symptoms may have been caused by something I had been doing (for example at work, during sports, while playing games or around the house).	☐	☐	☐	☐	☐
I suffer with osteoarthritis and thought that it was the cause of my worsening joint symptoms.	☐	☐	☐	☐	☐
At first I thought my symptoms were stress related.	☐	☐	☐	☐	☐
At first I thought my symptoms were due to an injury (such as a knock, or a sprain).	☐	☐	☐	☐	☐
At first I thought my symptoms were caused by a particular traumatic event in my life.	☐	☐	☐	☐	☐
At first I thought my symptoms were related to hormonal changes.	☐	☐	☐	☐	☐
At first I thought that my symptoms were caused by my lifestyle (for example drinking, smoking or diet).	☐	☐	☐	☐	☐
At first I thought that I my symptoms were caused by another serious condition other than arthritis (such as cancer).	☐	☐	☐	☐	☐
At first I thought my symptoms were a natural part of the aging process (like getting older).	☐	☐	☐	☐	☐
When my arthritis began I thought I had developed the flu.	☐	☐	☐	☐	☐

Figure 1 Section 4 before (a) and after (b) input from Research Partners.

longer and that questionnaire items should reflect both circumstances (see items 41 & 42).

> So it is another tool that they use, but it can have a negative impact. So an important question maybe if they search for information on the internet did it stop them going to see their GP. Because they may have pulled up methotrexate and thought, 'oh I ain't going'. If that's what I've got, then I not going..... going down that path. (Participant with RA: focus group three).

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Section 6: knowledge

Participants highlighted that many people were unaware that there was more than one type of arthritis and may never have heard of RA.

> There are people in my family that have or had osteoarthritis but some might have RA. In clinic I was asked if there was a family history and I said no but looking back there probably were people in my family with RA. (Participant with RA: focus group five).

Additional items were added to the questionnaire to explore the knowledge that participants felt the public had about RA, and the type of knowledge that may help a member of the public to be aware of RA and seek prompt help at the onset of symptoms.

Section 7: direct barriers and drivers of help seeking

Participants were encouraged to reflect on additional questions and items to be added to the questionnaire. Not being able to carry out everyday activities and the increasing severity of symptoms were thought to encourage help seeking.

> I think some of them do keep trying to go [to the GP], and it affects them quite severely, and there may be a reason for them presenting. Because they couldn't go to the gym and couldn't do the five a side football. Or whatever. (Participant with RA: focus group five).

A question was added about not being able to perform daily activities (item 55). In addition to this, three questions were added about the severity of pain (item 56), stiffness (item 57) and swelling (item 58).

Participants recognized that in some cases, people sought help for very different reasons. Participants felt that in some cases, people may have been motivated to see the GP for an explanation of symptoms, while others may have been driven by the desire for symptom relief. Therefore, items 59 to 62 reflected the different reasons participants felt would drive someone at the onset of symptoms to help-seeking behaviour.

> Because you know that there is something really wrong. (Interviewer: 'Was that more important than getting treatment?'). 'Yeah, because you fearing what it's going to lead to, I mean am I going to be a cripple for the rest of my life?' (Participant with RA: focus group three).

Participants suggested that people with busy lives would be less likely to seek help; therefore, a direct barrier to seeking help was a lack of time. This theme was reflected in item 62.

> I think an overriding factor is that people don't have the time. People who are employed are running round like, not headless chickens, but the last thing that they worry about is their health because they are more interested in earning a living to feed the children and run the car and so on and so I think the time factor is the enemy of you getting information across to people. (Participant relative of person with RA: focus group one).

Section 8: communicating with health-care professionals

Participants described how some patients did not like visiting their GP; reasons were varied including finding it difficult to communicate with the GP and not wanting to waste the GP's time.

> But I think a lot depends on the relationship with the GP. The patient's belief in their GP. So, some patients may be aware that they are viewed as a malingerer, and this may impact on their future help-seeking behaviour. (Participant with RA: focus group four)

In addition, it was highlighted that primary care was seen by some as a pressured emergency service not appropriate for musculoskeletal complaints. In contrast, it was recognized that some individuals were 'demanding' in their approach to health-care and were thus more likely to seek help quickly.

> Getting back to the doctors, if it's not in your nature to be demanding, you know, it's finding the right words to say to them. (Participant with RA: focus group three).

It was generally felt that some people had a dislike of doctors and thus did not like to visit their GP, while other people did not want to bother or inconvenience the doctor.

> I mean question two 'I won't go to see the doctor if I think I can control it myself'. I think

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> 90% of people would rather do it themselves rather than trouble the doctor. (Participant with RA: focus group five).

Focus groups with Health-care professionals

Health-care professionals were asked to reflect on their experiences of patients consulting with the early symptoms of RA and consider how their experiences mapped on to questionnaire items. The quotations below are examples of the experiences health-care professionals recalled.

> One of my patients recently, a new RA he had it for about 3 or 4 months and he got it in his feet. And what he would do every morning is he'd wake up extra early and take is dog out for a walk, an extra along walk and the walk got longer and longer and longer, because he said that when he walked his feet felt better. So he just carried on and you know. (Consultant rheumatologist)

> The last one I had, had a mother with Rheumatoid. But she had delayed coming because she had a lot of other co-morbidities. She had depression. And she had family troubles. (Rheumatology specialist nurse)

Health-care professionals confirmed that the items in the questionnaire were representative of their experiences. They also confirmed and discussed the organization of items into sections and felt that these sections represented core and overarching drivers of patient delay.

> You've got a section on lay sources of information, the internet, the Daily Mail and sources like that. Definitely the internet. Like the health columns in the newspaper. (Practice nurse)

In addition, health-care professionals recommended three items to be added to the pool generated during the previous focus groups with patients and relatives (see items, 25, 30 and 50).

> Just general relaxation, mild exercises and just try to take it easy, but it's not really captured, we could write a question about yoga, massage or relaxation people talk about Pilates. (Consultant rheumatologist)

> I will add another one, 'I think that my condition is stress related'. I see patients that think it's work related here's another one for you. (Practice nurse)

> The question would be if you think there is a magic cure for something called RA, would you have come earlier. As you have said, most people don't realise that there is a magic cure out there- ……..Maybe you could say….'I didn't think that there was treatment available'. Or a treatment that needed to be given early. (General practitioner)

Finally, health-care professionals commented upon the language used in the questionnaire. Health-care professional was concerned that some items may be difficult for patients to understand and therefore prone to misinterpretation. Item 11 was changed, and the word 'circumstance' was replaced with 'etc' following the statement below.

> It's just language I mean the first page someone of my age, gender and circumstances. I mean age everyone understands, gender - does everyone know what that means?, well… circumstance what does that mean? To some people that make sense but to our patients it wouldn't make sense. (Nurse consultant)

Test–retest findings

A total of 91 patients were approached to participate, of whom 69 consented and completed baseline questionnaires. Forty-one of these patients completed the follow-up questionnaire. The characteristics of responders are shown in Table 2.

Intraclass correlations indicated that the majority of questionnaire items showed good reliability over time. Table 1 shows the intraclass correlations and significance level of each item. Seven questionnaire items (20, 23, 25, 40, 41, 46 and 61) were deleted due to weak intraclass correlations which did not reach a predetermined level of significance of < 0.01.

Discussion

We have adopted a mixed approach to the development of the DELAY questionnaire, a

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Table 2 demographic characteristics of patients consenting to participate in the test–retest study

	Baseline ($N = 69$)	Follow-up ($N = 41$)
Age (years)	Mean: 53.8 SD: 14.6	Mean: 51.1 SD: 15.2
Female; *n* (%)	50 (72.5)	29 (70.7)
Ethnic origin; *n* (%)		
White British	60 (87.0)	37 (90.2)
South Asian or South Asian British	6 (8.7)	3 (7.3)
Black British	3 (4.3)	1 (2.4)
Time from symptom onset to initial contact with health-care professional*	Median: 49 days IQR: 2–153 days	Median: 41 days IQR: 7–153 days
Fulfilment of 2010 ACR/ EULAR classification criteria for RA; *n* (%)	40 (58.0)	29 (70.7)
Disease activity score 28	Mean: 4.7 SD: 1.4	Mean: 4.3 SD: 0.9

*Median reported due to data not being normally distributed.

tool to assess the drivers of and barriers to patient consultation at the onset of RA. This study, like others, has demonstrated that people with RA, relatives and carers have a valuable role to play in the development of research instruments.[27,32] We have described aspects of face and content validity and test–retest reliability and how these were assessed through qualitative methods and statistical testing. Participants (including people with the lived experience of RA and health-care professionals) have impacted on questionnaire design by adding questions to the item pool, modifying phraseology, determining item relevance and organizing statements for the questionnaire into eight sections, thus directly influencing questionnaire format. Fatigue has previously been recognized by patients as a key attribute for patient reported outcome measures for RA.[20] Our study adds to this by suggesting that fatigue is an important determinant of help-seeking behaviour – the use of this questionnaire in prospective studies will assess the extent to which this is so.

The aim of the questionnaire development process was to generate a large pool of potential reasons for patient delay at the onset of RA, and the next phase of this research is to attempt to quantify the occurrence of these reasons for delay in a large cohort of people with a new onset of RA symptoms. Our current research is using the DELAY questionnaire in a cross-sectional sample of people with RA and unclassified arthritis. This questionnaire is used alongside a questionnaire completed by a health-care professional in secondary care (rheumatologist or nurse specialist) during the initial contact with the patient. The health-care professional questionnaire captures data on a range of demographic, socioeconomic and disease-related variables as well as the extent of delay at different time points in the patient's journey from symptom onset to rheumatology assessment. In particular, delays from the onset of symptoms of inflammatory arthritis and from the onset of persistent joint swelling are captured, in line with recent recommendations from the EULAR study group for risk factors for RA.[33] Relationships between patients' perspectives on their disease and their responses to statements reflecting reasons why they may present quickly or slowly will be related to the extents of delay in seeking help to understand in detail the correlates of rapid and delayed help seeking.

The DELAY study is on-going, and exploratory factor analysis is planned to identify clusters of items which may explain different types of help-seeking behaviour and validation and testing in other languages. This is particularly pertinent, as recent data indicate that people from South Asian communities delay for longer in seeking help at the onset of RA.[13] Translations of this tool, if validated and reliability tested using the methodology presented in this study, can be used to understand the barriers specific to other communities. In some countries including the UK, only half of patients present to a health-care professional

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within 12 weeks of the onset of symptoms attributable to their RA.[11] However, in other countries including Austria, Germany and the Netherlands, delay on the part of the patient is shorter.[2,11] The DELAY questionnaire with validation for use in other countries could be used to explore such international differences in reasons for patient delay.

Lengthy patient delays in seeking help are seen in many other musculoskeletal diseases besides RA, and in some situations (e.g. patients with ankylosing spondylitis), it is much longer than in RA.[34] As in RA, long patient delays can lead to poor patient outcomes.[35] The DELAY questionnaire provides a template which can be adapted to better understand patient delay in other musculoskeletal conditions, where early intervention is beneficial to patients.

Conclusion

In collaboration with patients, relatives and a multidisciplinary team of health-care professionals, we have developed and tested a questionnaire to explore patient delay in help seeking for RA. Involvement of people with the lived experience of arthritis in the development of this research tool has led to a more patient oriented measure which includes items of most relevance to RA patients' experiences and in a format that is acceptable for completion. After statistical testing and further feedback from patients, the DELAY questionnaire is now being administered in a cross-sectional study to investigate the causes of delay and drivers of help seeking in different demographic groups. Data from this study will inform the development of tailored health promotion interventions targeted at reducing delay in help seeking for patients with new onset RA.

Acknowledgements

We would like to acknowledge the DELAY study service user panel and all of the patients and health-care professionals who continue to support the study. We would also like to thank Birmingham Arthritis Resource Centre and the Early Rheumatoid Arthritis Network, for their on-going support and partnership. Finally, this multicentre study has benefited from the support of the Research and Development department at Sandwell and West Birmingham NHS trust.

Funding

This article presents independent research funded by the National Institute for Health Research (NIHR) under the Research for Patient Benefit Programme (funder's reference PB-PG-1208-18114). The views expressed in this publication are those of the authors and not necessarily those of the NHS, the NIHR or the Department of Health.

Conflicts of interest

None.

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Appendix 1: DELAY Pilot Study Syndicate

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