



City Research Online

City, University of London Institutional Repository

Citation: McBain, H. B., Shipley, M., Olaleye, A., Moore, S. & Newman, S. P. (2018). Experiences of a patient-initiated self-monitoring service in inflammatory arthritis: A qualitative exploration. *Musculoskeletal Care*, 16(2), pp. 278-286. doi: 10.1002/msc.1232

This is the accepted version of the paper.

This version of the publication may differ from the final published version.

Permanent repository link: <https://openaccess.city.ac.uk/id/eprint/18738/>

Link to published version: <https://doi.org/10.1002/msc.1232>

Copyright: City Research Online aims to make research outputs of City, University of London available to a wider audience. Copyright and Moral Rights remain with the author(s) and/or copyright holders. URLs from City Research Online may be freely distributed and linked to.

Reuse: Copies of full items can be used for personal research or study, educational, or not-for-profit purposes without prior permission or charge. Provided that the authors, title and full bibliographic details are credited, a hyperlink and/or URL is given for the original metadata page and the content is not changed in any way.

City Research Online:

<http://openaccess.city.ac.uk/>

publications@city.ac.uk

Abstract

Objectives

To explore patients' experience of a patient-initiated self-monitoring service for people with rheumatoid or psoriatic arthritis on methotrexate.

Methods

Qualitative semi-structured interviews, embedded within a randomized controlled trial. Twelve participants who were randomly assigned to the intervention arm were interviewed. Interviews were digitally recorded, transcribed verbatim and analysed using inductive thematic analysis. The study received full NHS ethics approval from Camden and Islington Community Local Research Ethics Committee (Ref. 09/H0722/91).

Results

Analysis revealed five key themes. Participants described usual care as burdensome and an inefficient use of time, particularly those in employment. Being able to self-monitor and initiate their own care increased patients' knowledge about their illness and its treatment, and enabled them to gain a sense of control and ownership over their arthritis. Patients appreciated the personalised nature of the new service, which allowed them to be seen at a time and by a method more appropriate to their needs. There was however some concern about fidelity to the service protocol, confusion about the lack of consistency between symptoms and laboratory results and anxiety about self-monitoring.

Conclusions

Overall, participants were positive about the new service, in comparison to usual care, valuing its tailored approach and empowering effects. Further work is needed to ensure adherence to the service protocol and address anxieties around self-monitoring prior to any widespread implementation of the service.

Experiences of a patient-initiated service

Keywords: qualitative research • patient experiences • arthritis • patient education • self-management

Introduction

As a result of increasing patient numbers the volume of follow-up cases in rheumatology outpatient services has soared (Kvalvik, Larsen, Aadland, & Høyeraal, 2007). As a consequence many healthcare trusts in the UK have been unable to offer patients with rheumatoid arthritis a timely follow-up appointment (National Audit Office, 2009). Various models of care have been developed and implemented in order to address the volume of outpatient appointments. The introduction of the nurse specialist to reduce the demand on rheumatologist-led services has been found to be as effective as rheumatologist-led clinics and also cost-effective (Ndosi, Vinall, Hale, Bird, & Hill, 2011; Ndosi et al., 2014).

Rather than simply redirecting care however, patients with arthritis can access their rheumatologist, much like in primary care, by initiating their own appointments rather than having regular pre-scheduled visits (Hewlett et al., 2000; Kirwan et al., 2003; Hewlett et al., 2005; Chattopadhyay & Hickey, 2008; Primdahl, Sørensen, Horn, Petersen, & Hørslev-Petersen, 2014; Primdahl, Wagner, Holst, & Hørslev-Petersen, 2012; Adams & Sands, 2009; Sands & Adams, 2009). These services, known as patient-initiated clinics (Whear et al., 2013), suggest that patients with arthritis are able to self-refer appropriately (Hewlett, Mitchell, & Kirwan, 1999). This has led to reductions in healthcare utilisation without compromising patients' clinical or psychological well-being (Hewlett et al., 2000; Kirwan et al., 2003; Hewlett et al., 2005; Chattopadhyay & Hickey, 2008; Primdahl, Sørensen, Horn, Petersen, & Hørslev-Petersen, 2014; Primdahl, Wagner, Holst & Hørslev-Petersen, 2012; Adams & Sands, 2009; Sands & Adams, 2009). Benefits have also been found in terms of improvements in self-efficacy, satisfaction with the service and confidence in the system (Hewlett et al., 2000; Kirwan et al., 2003; Hewlett et al., 2005). More recently, this model of care has been evaluated in the context of a nurse-led rheumatology service, and has been broadened to include patients not only monitoring their symptoms and side effects and using this information to initiate care from their

Experiences of a patient-initiated service

rheumatology team, but also self-monitoring their laboratory results (McBain, Shipley, Olaleye, Moore, & Newman, 2016). Quantitative evaluation of this service in an randomized controlled trial (RCT) revealed that patients can understand and interpret their blood test results appropriately. It also showed that this service leads to significant reductions in face-to-face nurse specialist outpatient visits which are more appropriately redirected to the nurse helpline, and reductions in arthritis-related GP appointments in comparison to usual practice, without having a negative impact on the clinical and psychosocial well-being of patients (McBain et al, 2016).

Despite the evidence, healthcare professionals have identified a number of challenges to implementing patient-initiated clinics into secondary care, including a lack of understanding of the concept of patient-initiated services, concerns about clinical safety, pressures on work-load, financial concerns and the inability of leaders to make decisions about implementation (Kieft, Day, Byng, McArdle, & Goodwin, 2017). Along with understanding healthcare professional's perspectives on the barriers to implementing alternative models of care, it is important to establish the experiences of patients who are subjected to such services. Recent qualitative evaluation of direct access to a rheumatologist for adults with rheumatoid arthritis found that implementation could be aided by increasing patient confidence in the response of the system, and ensuring the systems incorporate regular disease monitoring and are in a convenient setting for patients and staff (Child, Goodwin, Perry, Gericke, & Byng, 2015).

The aim of this study was to explore the experience of patients who were part of a patient-initiated self-monitoring service, in order to understand acceptability from the patient perspective. The service included a brief group-based education session to explain the service and teach patients how to self-monitor, a nurse specialist-led telephone help-line to review any abnormalities in symptoms or laboratory results and when required quick access to a face-to-face appointment with a rheumatology nurse specialist. The potential value of conducting qualitative research at this stage is

to add relevance and interpretation to the findings of the RCT and in this way aid the possible implementation of this complex intervention (O'Cathain, Thomas, Drabble, Rudolph, & Hewison, 2013).

Patients and Methods

Study design

This study was a qualitative enquiry, from a realistic phenomenological perspective, utilising semi-structured interviews, embedded within an RCT conducted in the UK. The RCT aimed to compare a patient-initiated DMARD self-monitoring service with standard care.

Intervention

Intervention group had taken part in a group based training session to provide them with the knowledge, skills and resources required to self-monitor and initiate their own care. Participants self-monitored markers of inflammation (CRP and ESR), haemoglobin, white blood cell count, liver function tests (ALP and ALT), platelets and neutrophils. Participants continued to receive routine care from their rheumatologist, defined as outpatient appointments every 6 months; had access to the emergency nurse helpline if necessary and continued with routine blood monitoring every 4-6 weeks depending on their dose of methotrexate.

Following each blood test, participants were sent a copy of their results either via email or post, depending on the patient's preference. Included were the patient's previous blood test results, to enable calculation of change scores by the participant. Criteria for a significant change or out-of-range blood test were developed and agreed by the clinical team and shared with the patient (Table 1).

Participants also recorded, using a 17-item checklist developed by the authors, the side effects and symptoms they had experienced since their last blood test, indicating if they were any new or

Experiences of a patient-initiated service

continuing symptoms. For continuing symptoms participants indicated if the symptom had become worse, better or remained the same since their last blood test. The criteria for seeking a telephone consultation with the CNS was a blood test that was outside of the normal range, a blood test that had changed significantly or the appearance of a new symptoms since their last blood test, or a continuing symptoms or side effects that had become worse since their last blood test.

Blood test frequency and visits to the rheumatologist remained as per usual care. Usual care typically consisted of blood tests every 4-6 weeks and optimally outpatient appointments with their rheumatologist every 6 months. Advice was also freely available via the emergency nurse helpline when requested. Full details of the trial and the service can be found elsewhere (McBain et al., 2016).

Ethical Approval

The study received full NHS ethics approval from Camden and Islington Community Local Research Ethics Committee (Ref. 09/H0722/91).

Participants and recruitment

All 52 intervention group participants who took part in the RCT were eligible to participate and were asked on entry into the trial whether they would be willing to be contacted about participating in a qualitative intervention at the end of the trial period. Inclusion criteria for entry into the RCT were those with diagnosed RA or PsA whose treatment was classified as stable. This was defined as treatment with methotrexate for at least 6 months, plus a further 3 months if the patient were receiving one of two self-injecting anti-TNF agents; adalimumab or etanercept. As participants completed the trial those who did agree were contacted by the researcher and additional written consent was obtained. All interviews were conducted by HM, digitally recorded with the participant's permission and transcribed verbatim, with any identifiable data removed.

Data collection

The interview schedule was semi-structured (Appendix 1), and was designed to obtain detailed accounts of the experience of participants. A draft of the interview schedule was produced by the lead author, focusing on each of the key areas of the intervention, and developed further in collaboration with the research team. Questions covered the participants' decision to take part in the trial, the training and information received in the education session, the tasks involved and their reflections on the experience of standard care and the value they placed on the new service.

Prompts and probes were used if further details were needed.

Sample size and analysis

The study aimed to recruit an initial sample of 10 participants from the intervention group with a stopping criterion of up to a further three interviews to confirm that data saturation had been achieved (Francis et al., 2010). Data were analysed by HM using inductive thematic analysis (Braun & Clarke, 2006), a 6 step method for identifying, analysing and reporting patterns within data (Table 2).

Results

Sample characteristics

All 52 participants who were randomised to the intervention arm agreed to be approached to take part in an interview. The first 41 trial participants were invited to an interview, 12 (27.91%) of these consented, at which point no new themes were emerging and no further participants were approached. All participants had completed the trial and had experienced of the service for an average of 34 weeks (SD = 8.52). The interviews lasted between 20 and 38 minutes, and took place within the University. Participant characteristics can be found in Table 3.

Themes

The analysis revealed five key themes (i) burden of usual care, (ii) the self-management process, (iii) conflict, (iv) anxiety and (v) a tailored service. Four of the five themes also contained between 2 and 3 subthemes, as indicated below.

Theme one – burden of usual care

Sub-theme – Stop wasting my time

All participants reported that their rheumatology outpatient appointments were often an inefficient use of their time and that of the clinical team. Many participants described situations in which they had made the journey to hospital, waited in delayed clinics and were then seen by their nurse for a matter of minutes. These appointments often consisted of discussions around what patients felt were minor symptoms or were used to obtain blood tests forms; activities which they felt could have been dealt with via other methods of communication, such as email or telephone. These appointments often led to no changes in treatment, which patients found extremely frustrating.

“...today I mean [the nurse] was running half an hour late, my appointment was at 11.15 and it was in fact at 11.45 but I was out of [the nurse’s] office by 11.50 for a 15 minute appointment, basically we don’t have anything to say, there aren’t any issues and really the whole purpose was for me to get some more blood test forms.” – Participant 10, Male, PsA, 60years

Sub-theme – “A much larger cost”

For those participants who were in employment, attending outpatient appointments along with juggling the demands of their arthritis was a challenge, and was a driver to participating in the trial. Regular reviews with the nurse were described as “*coming at a cost*”, both in terms of time and financially, for the participant and health service.

Experiences of a patient-initiated service

“You know, and I’ve spend 45 minutes in the waiting room and you know, it comes at a time cost, particularly when you’re paid by the hour it can come at a much larger cost” Participant 1, Male, PsA, 35years

Theme two – the self-management process

Sub-theme - Knowledge is power

All participants felt that the training they received as part of the new service increased their knowledge of arthritis, their treatment, the reasons for regular testing and the meaning of test results. This knowledge allowed participants to feel involved in the consultation process, which in turn enabled them to ask more relevant questions of their clinical team and be an active participant in the treatment process.

“But yes I was probably more knowledgeable and I was able to ask him more relevant questions.”

Participant 4, Female, PsA, 58 years

Sub-theme - Control

A sense of control was identified as important for all participants and was nurtured as a result of the new service, both in terms of general health and their arthritis. This allowed them to take “ownership” of their illness and treatment.

“I thought it was important to own your illness, you know what I mean to take responsibility for it by looking at the data” – Participant 10, Male, PsA, 60years

Sub-theme – Behavioural adjustment

A number of participants felt that self-monitoring allowed them to make a connection between their behaviour, including taking their medication and making changes to their lifestyle, and their

Experiences of a patient-initiated service

laboratory results, and provided them with the opportunity to understand how their condition was changing over time.

“...seeing my results has enabled me to understand my body and its reactions to the disease and to methotrexate.” – Participant 11, Female, RA, 76 years

Being able to monitor the impact of alcohol, diet and smoking on symptoms and laboratory results led some participants to consider changing their lifestyle. For example, one participant considered whether changes in his alcohol consumption, either by drinking less or by drinking more water after consuming alcohol, would alter his liver function tests.

Theme three - conflict

Sub-theme – Conflict between laboratory tests and symptoms

Patients expressed confusion about the disparities between their laboratory tests and their experience of symptoms. In some interviews participants reported excruciating pain and swelling, but this was not reflected in their inflammatory markers. Participants found this confusing and in some cases led to patients questioning their diagnosis.

“I get confused because sometimes the results would tell me the opposite of what I’m feeling and sometimes, like you are low, you go for a test and you got low inflammatory factors but your hands are puffed up and you’re in pain” – Participant 3, Male, RA, 50 years

For others when congruence between symptoms and laboratory results occurred this reassured them, helped provide an explanation for their symptoms and validated their experience.

Experiences of a patient-initiated service

Sub-theme – Conflict between study guidelines and practice

Participants felt that fidelity to the study protocol was important and this was identified as an area for future improvement. This was a result of less stringent criteria being implemented by the nurse specialist. Although a majority of participants sought help appropriately, even when there were only small deviations in their laboratory results, a number of participants struggled to decide whether they needed to contact their nurse. Some felt they knew the outcome of the consultation or did not fully recognise the importance of any abnormalities; despite this they more often than not contacted their clinical team.

“You know you follow them accordingly and I guess sometimes, you would see that your figure was just outside the range or just moved by a certain amount and you think that’s probably no big deal, but I knew what to do” Participant 1, Male, PsA, 35years

Theme four – anxiety

Increased anxiety made some participants extra diligent in checking their laboratory results against the pre-defined criteria. There was also some concern about the “*risk*” of allowing patients to take full responsibility for their monitoring. These participants felt that it would be important to have additional safety nets in place to ensure that any serious abnormalities were also flagged to the clinical team.

“what I would like to be able to do, is feel certain at the back of my mind that if the things aren’t going well it isn’t entirely left me to decide find that’s all.” – Participant 11, Female, RA, 76 years

Whilst some expressed concern others acknowledged the seriousness of interpreting their blood tests, but weren’t worried about the additional responsibility.

Experiences of a patient-initiated service

Theme five – a tailored service

Sub-theme - Right time

Participants described usual care as being a “*snap shot*” in the disease course. Significant changes in their disease status often occurred between outpatient visits, but were not known or acknowledged by the clinical team.

“Because the things were so snap-shotty, it’s impossible for people, for three months you could be really ill but the whole care is based on how you were there and then. That's frustrating.” –

Participant 3, Male, RA, 50 years

Being seen by a member of the clinical team when they were unwell was an important part of validating their experiences. As a result of this lack of alignment between ill health and delivery of care all participants valued the tailored and timely nature of the new service, which allowed them to access care when they felt they needed it. Self-monitoring and initiating their own reviews was recognised as important, both when they were well and their disease was stable so that they could avoid unnecessary visits, but also when their condition deteriorated as they were able to make contact with their clinical team and be seen as a matter of urgency. At which point they felt regular face-to-face contact with their nurse was more appropriate.

“...saying that my psoriatic arthritis is relatively under control, now if mine wasn’t under control I think I might not be saying that. I think I would like, if things weren’t under control and I was in pain all the time, related to the arthritis I think I would feel more comfortable seeing someone on a more regular basis”. – Participant 10, Male, PsA, 60years

Experiences of a patient-initiated service

Participants acknowledged that the new service could also benefit newly diagnosed patients and established patients who were unwell by freeing clinic time, which they felt was hugely beneficial and important.

“I mean I think this idea for freeing up specialist nurse’s time to see people who really need to be seen just seems to be to be incredible important and I think you should press ahead with that” –

Participant 12, Female, RA, 47 years

Sub-theme - Right method

All participants spoke about the benefits of having direct access to the nurse by telephone, as this provided the opportunity to seek help immediately. Despite not seeing the nurse face-to-face, telephone contact was considered an acceptable method of accessing urgent care and for follow-up consultations.

“I knew that if I had a problem that if I felt unwell, really unwell then I would phone [the nurse] anyways and I knew I could always speak to her. So I did not feel I was just put in the study and shipped out and left on my own to deal with it I felt there was support there in place for me if I needed it.” – Participants 6, Female, RA, 44 years

Discussion

The aim of this study was to explore participants’ experiences of a patient-initiated DMARD self-monitoring service, using qualitative interviews. The overall narrative suggested participants held a positive view of the new service, valuing its efficiency and tailored approach. Empowering patients to self-monitor and initiate their own care provided them with an opportunity to increase their knowledge and sense of control; however, some participants did express concerns about the responsibility of self-monitoring and initiating their own care along with intervention fidelity.

Participants weighed the advantages of self-monitoring and initiating their own appointments against usual care. As reported elsewhere in the literature (Primdahl, Wagner, & Hørslev-Petersen, 2011; Child, Goodwin, Perry, Gericke, & Byng, 2015) on the whole usual care was considered an inefficient use of their time, and that of the nurse specialist. This was frustrating and was further compounded by long waiting times and appointments that led to little or no change in treatment, a view shared by many rheumatologists (Mitchell, 2000; Hehir et al., 2001). This was particularly salient for people with work commitments, and may explain why people with arthritis are more likely to prefer an evening or weekend appointment if they are employed (Douglas et al., 2005). The difficulties participants reported in terms of attending appointments and monitoring their arthritis, alongside their work commitments, may be an additional reason why patients with arthritis experience occasional loss of work hours (Gignac, Cao, Lacaille, Anis, & Badley, 2008). Work disability not only constitutes a financial burden for patients and an economic burden for society, but also has a negative impact on self-esteem (MacKinnon & Miller, 2003) and quality of life (Chorus, Miedema, Boonen, & van der Linden, 2003). The findings from this qualitative study and other research (Gignac, Cao, Lacaille, Anis & Badley, 2008), suggests that it is not only a complete inability to work that may be detrimental, but also frequent interruptions to work life as a consequence of continual monitoring and appointments.

The knowledge gained in the training session, in combination with self-monitoring and being able to initiate their own care allowed patients to feel greater control over their illness and its treatment, reflecting outcomes from other patient-initiated services in arthritis (Sands & Adams, 2009; Child et al., 2015). This enabled patients to be more active participants in the consultation process and gain ownership of their condition. Having access to test results and explanatory information about relevant laboratory and disease markers, as well as arranging their own appointments has also been found to promote illness ownership in other chronic conditions (Winkelman, Leonard, & Rossos,

2005). As there appears to be significant disparity between the level of involvement patients with arthritis would like in relation to decisions around their treatment and care (Neame, Hammond, & Deighton, 2005; Renzi, Di, & Tabolli, 2011) and the level of involvement patients actually achieve (Cunha-Miranda, Costa, & Ribeiro, 2010; Brekke, Hjortdahl, & Kvien, 2001; Lim, Ellis, Brooksby, & Gaffney, 2007; Kjekken et al., 2006; Leung et al., 2009), this alternative model of care could be a way of bridging this gap.

The new service also highlighted the impact that taking medication and making changes to lifestyle had on the results of laboratory tests and experience of symptoms. Participants were able to see how their behaviour was affecting their blood test results. This included the link between taking their methotrexate and improvements in their inflammatory markers. As well as making a connection between their lifestyle such as alcohol consumption, diet and weight and their clinical well-being. The findings suggest that patients may also adjust their behaviour based on their laboratory results. The creation of a link between laboratory findings and behaviour is an important incentive to make healthier lifestyle choices.

Frustration and confusion were reported when there was conflict between laboratory tests and participants' experience of symptoms, for example the presence of intense pain and swelling in the absence of elevated inflammatory markers. Research has demonstrated discordance between objective and subjective measures of function in arthritis (van den Ende, Hazes, Le Cessie, Breedveld, & Dijkmans, 1995; O'Connor et al., 1999) and it is now well established that the association between subjective reports of pain with radiographic damage are modest at best (Sarzi-Puttini et al., 2002). This discordance has been linked to both psychological and social determinants of the illness experience, reflected in the development of the bio-psychosocial model of chronic illness. The confusion and frustration reported by patients however, suggests that the imperfect relationship between markers and experience have not been adequately communicated to patients. Similar

frustrations have been reported in other chronic conditions (Winkelman et al., 2005), leading to patients losing trust and value in their laboratory tests and consultant reports, as reported in this study. The legitimization and validation of the fluctuating nature of arthritis was important to participants. This was achieved when there was consistency between symptoms and laboratory tests, but also when patients were seen by a healthcare professional during these periods.

Legitimization of symptoms is an important part of the diagnosis of arthritis (Undeland & Malterud, 2007; Brand, Claydon-Platt, McColl, & Bucknall, 2010), but has not been explored in patients with established arthritis. One of the main reasons patients seeking help in primary care is legitimization of symptoms and in order to maximise the effectiveness of the consultation it has been argued that this should be acknowledged from the outset (Main, Buchbinder, Porcheret, & Foster, 2010).

Validation of pain in particular, appears to be important to psychological well-being (Linton, Boersma, Vangronsveld, & Fruzzetti, 2012) and is, therefore, key to our understanding of arthritis since this is the most frequently reported symptom (Carr et al., 2003). By providing a service which allows patients to access care in times of perceived need, as in this study, this shifts control back to the patient and provides them with the opportunity to receive the validation they require.

The inefficiency of 'usual care' and the need for legitimization is characterised by the need for personalised care from the rheumatology team, a narrative present across all of the interviews. It was important to participants that they were able to not only see their clinical team at the right time, but also access their nurse by the most convenient method. A majority felt that telephone consultations were an acceptable model of care, enabling them to seek help at the appropriate time and quickly. High levels of patient satisfaction with nurse-led rheumatology telephone follow-up clinics has been reported elsewhere in the literature (Pal, 1998; Hennell, Spark, Wood, & George, 2005). The advantages of saving time and money, less stress for the patient and greater convenience are reported to outweigh the disadvantages of not meeting face-to-face and should be considered more widely as an alternative method of consultations.

Although the quantitative results of the RCT suggested a decrease in levels of generalised anxiety in the intervention arm and an increase in the control arm (McBain et al., 2016), the current qualitative study found that a number of participants were worried about the responsibility of monitoring and initiating their own care. Whilst this has been attributed to a lack of understanding about abnormal readings in other long-term conditions (van der Vaart, Drossaert, Taal, & van de Laar, 2013; Peel, Parry, Douglas, & Lawton, 2004), it could also reflect a clear understanding and genuine concern about the underlying disease progression or concern that someone may not contact the service as reported in other qualitative explorations of patient-initiated clinics {Child, 2015 5369 /id}. As a consequence participants in this study were particularly vigilant about checking their results.

Issues of power between the researcher and participant can be particularly problematic in qualitative research. This study contains potential bias as the interviewer also delivered elements of the service. Participants may have therefore felt pressured to report socially acceptable responses. It is also possible that the researcher encouraged dialogue that evoked a more positive response to the intervention. The fact that the analysis reports both positive and negative views of the service suggests that these bias may have been limited. As opposed to quantitative research which aims to quantify opinions or beliefs, qualitative research is about the richness of the data and hence sample size calculations are not conducted in the same way (Kuzel, 1992). The sample size could however be criticised as being too small, although saturation of themes was achieved and the sample was diverse in age, disease duration and length of treatment. Barriers and facilitators to implementing a patient-initiated service can be experienced by both healthcare professionals and patients. The perspective of healthcare professionals would have brought an additional perspective to aid our understanding of the barriers and facilitators to implementing the service, but were not collected as part of this study.

Experiences of a patient-initiated service

The overall narrative indicated that participants were positive about the new service, valuing its efficiency and tailored approach. The service allowed patients to gain new knowledge and use this information along with their newly acquired skills to take control of their arthritis. For some participants, however, there were feelings of conflict and anxiety, which caused concern and would need to be addressed prior to any widespread implementation of the service.

Acknowledgements

The authors thank the trial participants, University College London Hospital Charity who funded the study, and the reviewers for their advice and comments.

Conflicts of interest

The study was part funded by the Shipley-Rudge Fund via UCLH charities for which MS is a principal donor. No other authors have any conflicts of interest.

References

- Adams, N. & Sands, A. (2009). Patient versus practitioner-initiated follow-up for rheumatoid arthritis. *European Journal of Pain*, 13, S132.
- Brand, C., Claydon-Platt, K., McColl, G., & Bucknall, T. (2010). Meeting the needs of people diagnosed with rheumatoid arthritis: an analysis of patient-reported experience. *Journal of Nursing and Healthcare of Chronic Illness*, 2, 75-83.
- Braun, V. & Clarke, V. (2006). Using thematic analysis in psychology. *Qualitative Research in Psychology*, 3, 77-101.
- Brekke, M., Hjortdahl, P., & Kvien, T. K. (2001). Involvement and satisfaction: a Norwegian study of health care among 1,024 patients with rheumatoid arthritis and 1,509 patients with chronic non-inflammatory musculoskeletal pain. *Arthritis Care & Research*, 45, 8-15.
- Carr, A., Hewlett, S., Hughes, R., Mitchell, H., Ryan, S., Carr, M. & Kirwan, J. (2003). Rheumatology outcomes: the patient's perspective. *Journal of Rheumatology*, 30, 880-883.
- Chattopadhyay, C. & Hickey, P. (2008). Are Routine Appointments Cost-Effective in Modern Rheumatology Practice? A Comparative Outcome Audit of Routine Follow-ups and Patient Initiated Consultations. *Arthritis & Rheumatism*, 58, S885.
- Child, S., Goodwin, V. A., Perry, M. G., Gericke, C. A., & Byng, R. (2015). Implementing a patient-initiated review system in rheumatoid arthritis: a qualitative evaluation. *BMC Health Services Research*, 15, 157.
- Chorus, A. M. J., Miedema, H. S., Boonen, A., & van der Linden, S. (2003). Quality of life and work in patients with rheumatoid arthritis and ankylosing spondylitis of working age. *Annals of the Rheumatic Diseases*, 62, 1178-1184.
- Cunha-Miranda, L., Costa, L., & Ribeiro, J. S. (2010). Near study: Needs and expectations in rheumatoid arthritis - Do we know our patient's needs? *Acta Reumatologica Portuguesa*, 35, 314-323.
- Douglas, K. M., Potter, T., Treharne, G. J., Obrenovic, K., Hale, E. D., Pace, A., Mitton, D., Erb, N., Whallett, A., Delamere, J.P. & Kitas, G.D. (2005). Rheumatology patient preferences for timing and location of out-patient clinics. *Rheumatology*, 44, 80-82.
- Francis, J. J., Johnston, M., Robertson, C., Glidewell, L., Entwistle, V., Eccles, M. P. & Grimshaw, J. (2010). What is an adequate sample size? Operationalising data saturation for theory-based interview studies. *Psychology & Health*, 25, 1229-1245.
- Gignac, M. A. M., Cao, X., Lacaille, D., Anis, A. H., & Badley, E. M. (2008). Arthritis-related work transitions: A prospective analysis of reported productivity losses, work changes, and leaving the labor force. *Arthritis Care & Research*, 59, 1805-1813.
- Hehir, M., Mitchell, K., Hewlett, S., Kirwan, J., Memel, D., & Pollack, J. (2001). What happens in rheumatoid arthritis out-patient clinics? *Rheumatology*, 40, 146.
- Hennell, S., Spark, E., Wood, B., & George, E. (2005). An evaluation of nurse-led rheumatology telephone clinics. *Musculoskeletal Care*, 3, 233-240.
- Hewlett, S., Mitchell, K., & Kirwan, J. (1999). Patients who access or don't access open review: Reasonable decisions? *Arthritis & Rheumatism*, 42, S221.
- Hewlett, S., Mitchell, K., Haynes, J., Paine, T., Korendowych, E., & Kirwan, J. R. (2000). Patient-initiated hospital follow-up for rheumatoid arthritis. *Rheumatology*, 39, 990-997.
- Hewlett, S., Kirwan, J., Pollock, J., Mitchell, K., Hehir, M., Blair, P. S. & Perry, M.G. (2005). Patient initiated outpatient follow up in rheumatoid arthritis: six year randomised controlled trial. *British Medical Journal*, 330, 171.
- Kieft, E., Day, J., Byng, R., McArdle, P., & Goodwin, V. A. (2017). Bridging the second gap in translation: a case study of barriers and facilitators to implementing Patient-initiated Clinics into secondary care. *European Journal for Person Centered Healthcare*, 5, 129-137.

- Kirwan, J. R., Mitchell, K., Hewlett, S., Hehir, M., Pollock, J., Memel, D. & Bennett, B. (2003). Clinical and psychological outcome from a randomized controlled trial of patient-initiated direct-access hospital follow-up for rheumatoid arthritis extended to 4 years. *Rheumatology*, 42, 422-426.
- Kjeken, I., Dagfinrud, H., Mowinckel, P., Uhlig, T., Kvien, T. K., & Finset, A. (2006). Rheumatology care: Involvement in medical decisions, received information, satisfaction with care, and unmet health care needs in patients with rheumatoid arthritis and ankylosing spondylitis. *Arthritis Care & Research*, 55, 394-401.
- Kuzel, A. J. (1992). Sampling in qualitative inquiry. In B. Crab & M. Miller (Eds.), *Doing qualitative research. Research methods for primary care.* (pp. 31-44). Thousand Oaks, CA, US: SAGE Publications, Inc.
- Kvalvik, A. G., Larsen, S., Aadland, H. A., & Høyeraal, H. M. (2007). Changing structure and resources in a rheumatology combined unit during 1977–1999. *Scandinavian Journal of Rheumatology*, 36, 125-135.
- Leung, Y.-Y., Tam, L. S., Lee, K. W., Leung, M. H., Kun, E. W., & Li, E. K. (2009). Involvement, satisfaction and unmet health care needs in patients with psoriatic arthritis. *Rheumatology*, 48, 53-56.
- Lim, A. Y., Ellis, C., Brooksby, A., & Gaffney, K. (2007). Patient satisfaction with rheumatology practitioner clinics: can we achieve concordance by meeting patients' information needs and encouraging participatory decision making? *Annals of the Academy of Medicine*, 36, 110-114.
- Linton, S. J., Boersma, K., Vangronsveld, K., & Fruzzetti, A. (2012). Painfully reassuring? The effects of validation on emotions and adherence in a pain test. *European Journal of Pain*, 16, 592-599.
- MacKinnon, J. R. & Miller, W. C. (2003). Rheumatoid arthritis and self esteem: the impact of quality occupation. *Journal of Occupational Science*, 10, 90-98.
- Main, C. J., Buchbinder, R., Porcheret, M., & Foster, N. (2010). Addressing patient beliefs and expectations in the consultation. *Best Practice & Research Clinical Rheumatology*, 24, 219-225.
- McBain, H., Shipley, M., Olaleye, A., Moore, S., & Newman, S. (2016). A patient-initiated DMARD self-monitoring service for people with rheumatoid or psoriatic arthritis on methotrexate: a randomised controlled trial. *Annals of the Rheumatic Diseases*, 75, 1343-1349.
- Mitchell, K. (2000). Shared care-the way forward for patient-orientated follow-up care in rheumatoid arthritis. *Rheumatology*, 39, 457-458.
- National Audit Office (2009). *Services for people with rheumatoid arthritis: census findings* London: The Stationart Office.
- Ndosi, M., Lewis, M., Hale, C., Quinn, H., Ryan, S., Emery, P., Bird, H. & Hill, J. (2014). The outcome and cost-effectiveness of nurse-led care in people with rheumatoid arthritis: a multicentre randomised controlled trial. *Annals of the Rheumatic Diseases*, 73, 1975-1982.
- Ndosi, M., Vinall, K., Hale, C., Bird, H., & Hill, J. (2011). The effectiveness of nurse-led care in people with rheumatoid arthritis: A systematic review. *International journal of nursing studies*, 48, 642-654.
- Neame, R., Hammond, A., & Deighton, C. (2005). Need for information and for involvement in decision making among patients with rheumatoid arthritis: a questionnaire survey. *Arthritis & Rheumatism*, 53, 249-255.
- O'Cathain, A., Thomas, K. J., Drabble, S. J., Rudolph, A., & Hewison, J. (2013). What can qualitative research do for randomised controlled trials? A systematic mapping review. *BMJ Open*, 3, e002889.
- O'Connor, D., Kortman, B., Smith, A., Ahern, M., Smith, M., & Krishnan, J. (1999). Correlation between objective and subjective measures of hand function in patients with rheumatoid arthritis. *Journal of Hand Therapy*, 12, 323-329.
- Pal, B. (1998). Following up outpatients by telephone: pilot study. *British Medical Journal*, 316, 1647.
- Peel, E., Parry, O., Douglas, M., & Lawton, J. (2004). Blood glucose self-monitoring in non-insulin-treated type 2 diabetes: a qualitative study of patients' perspectives. *British Journal of General Practice*, 54, 183-188.
- Primdahl, J., Sørensen, J., Horn, H. C., Petersen, R., & Hørslev-Petersen, K. (2014). Shared care or nursing consultations as an alternative to rheumatologist follow-up for rheumatoid arthritis

- outpatients with low disease activity - patient outcomes from a 2-year, randomised controlled trial. *Annals of the Rheumatic Diseases*, 73, 357-364.
- Primdahl, J., Wagner, L., Holst, R., & Hørslev-Petersen, K. (2012). The impact on self-efficacy of different types of follow-up care and disease status in patients with rheumatoid arthritis - A randomized trial. *Patient education and counseling*, 88, 121-128.
- Primdahl, J., Wagner, L., & Hørslev-Petersen, K. (2011). Being an outpatient with rheumatoid arthritis - a focus group study on patients' self-efficacy and experiences from participation in a short course and one of three different outpatient settings. *Scandinavian Journal of Caring Sciences*, 25, 394-403.
- Renzi, C., Di, P. C., & Tabolli, S. (2011). Participation, satisfaction and knowledge level of patients with cutaneous psoriasis or psoriatic arthritis. *Clinical & Experimental Rheumatology*, 36, 885-888.
- Sands, A. & Adams, N. (2009). A comparison of patient-initiated versus conventional follow-up for rheumatoid arthritis. *Rheumatology*, 48, i157-i158.
- Sarzi-Puttini, P., Fiorini, T., Panni, B., Turiel, M., Cazzola, M., & Atzeni, F. (2002). Correlation of the score for subjective pain with physical disability, clinical and radiographic scores in recent onset rheumatoid arthritis. *BMC Musculoskeletal Disorders*, 3, 18.
- Undeland, M. & Malterud, K. (2007). The fibromyalgia diagnosis-hardly helpful for the patients? A qualitative focus group study. *Scandinavian journal of primary health care*, 25, 250-255.
- van den Ende, C. H. M., Hazes, J., Le Cessie, S., Breedveld, F. C., & Dijkmans, B. A. C. (1995). Discordance between objective and subjective assessment of functional ability of patients with rheumatoid arthritis. *Rheumatology*, 34, 951-955.
- van der Vaart, R., Drossaert, C., Taal, E., & van de Laar, M. (2013). Giving rheumatology patients online home access to their electronic medical record (EMR): advantages, drawbacks and preconditions according to care providers. *Rheumatology International*, 33, 2405-2410.
- Whear, R., Abdul-Rahman, A. K., Boddy, K., Thompson-Coon, J., Perry, M., & Stein, K. (2013). The Clinical Effectiveness of Patient Initiated Clinics for Patients with Chronic or Recurrent Conditions Managed in Secondary Care: A Systematic Review. *PloS one*, 8, e74774.
- Winkelman, W. J., Leonard, K. J., & Rossos, P. G. (2005). Patient-perceived usefulness of online electronic medical records: employing grounded theory in the development of information and communication technologies for use by patients living with chronic illness. *Journal of the American Medical Informatics Association*, 12, 306-314.

Experiences of a patient-initiated service

Table 1. Normative ranges by blood test

Test	Normal Range	Definition of significant change
Haemoglobin	12.0 - 17.0 g/dl	Fall of more than 1.0
WBC	3.0 - 10.0 x10 ⁹ /L	A fall of more than 2
Neutrophils	2.0 - 7.5 x10 ⁹ /L	Two readings in a row each with a fall of more than 1.0
Platelets	150 - 400 x10 ⁹ /L	Two readings in a row with falls of more than 50
ALP	40 - 129 IU/L	A result which doubles from the previous blood test or rises 208
ALT	10 - 50 IU/L	A results which doubles from the previous blood test or rises above 70
ESR	0 - 20 mm/h	A rise of more than 20 from the previous blood test results
CRP	0 - 5 mg/dL	A rise of more than 20 from the previous blood test results

WBC - White Blood Count; ALP - Alkaline Phosphatase; ALT - Alanine Transaminase; ESR - Erythrocyte Sedimentation Rate; CRP - C-Reactive Protein

Table 2. Process of thematic analysis

Step	Description
1. Familiarizing yourself with your data.	The transcripts were read and re-read and initial themes and patterns were noted.
2. Generating initial codes	Interesting features of the data were coded systematically across the entire data set.
3. Searching for themes	Codes were collated into potential themes.
4. Reviewing themes	The themes were then checked to ensure that they worked in relation to the coded extracts (Level 1) and the entire data set (Level 2). This also involved generating a thematic 'map' of the analysis.
5. Defining and naming themes	The specific aspects of each theme were then refined, including generating clear definitions and names for each theme.
6. Producing the report	Quotes were selected to represent themes and subthemes.

Adapted from Braun and Clarke (2006)

Table 3. Participant characteristics

Participant no.	Gender	Age	Condition	Disease duration (years)	MTX duration (years)	MTX dose (mg) [†]	DAS28 [†]	PsARC physician [†]	PsARC patient [†]	PsARC tender [†]
11	Female	76	RA	26	1	12.5	6.13	-	-	-
9	Male	49	RA	8	5	10	3.46	-	-	-
6	Female	44	RA	7	5	7.5	4.20	-	-	-
12	Female	47	RA	22	17	22.5	3.76	-	-	-
3	Male	50	RA	10	5	15	3.42	-	-	-
8	Female	64	RA	22	5	15	5.67	-	-	-
4	Female	58	PsA	3	1	10	-	2	2	3
10	Male	60	PsA	11	10	20	-	2	1	17
1	Male	35	PsA	4	2	15	-	2	2	14
5	Male	27	PsA	6	4	17.5	-	2	1	0
7	Male	66	PsA	31	16	15	-	2	2	21
2	Male	76	RA	7	6	7.5	1.72	-	-	-

ID – Identification Number; MTX – Methotrexate; DAS28 – 28-item Disease Activity Score; PsARC – Psoriatic Arthritis Response Criteria; RA – Rheumatoid Arthritis; PsA – Psoriatic Arthritis; † - at baseline