

Development of patient-initiated follow-up resources for UK rheumatology departments: a co-design study with patient and clinician collaboration



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Summary

Background Patient-initiated follow-up (PIFU) is designed to give patients more control over their follow-up care in rheumatology and relies on patients coming forward to schedule appointments and understand how and when to contact their rheumatology team. Additionally, rheumatology teams need to establish suitable criteria and have systems in place to support PIFU. Resources to inform patients with rheumatic disease about PIFU or to support its implementation in rheumatology clinics is scarce. The aim of this study was to co-design resources with patients and clinicians to support the implementation of PIFU across the UK.

Methods This co-design study was done across four research centres in the UK: University of Oxford, University of Plymouth, King's College London, and the University of the West of England. The study was overseen by a steering group, who met on a monthly basis. Patients were invited through online advertisements disseminated via patient charities and clinicians were invited via email. Patients aged 18 years or older with a self-reported inflammatory arthritis and clinicians with and without experience in PIFU were included. Online patient-led and clinician-led workshops were conducted to discuss their views and experiences of PIFU, to identify the needs of both groups, and to develop PIFU resources to support its implementation.

Findings Between Oct 3, 2023, and April 30, 2024, ten online workshops were conducted (including seven patient-led [61 patients] and three clinician-led workshops [nine clinicians]). Based on discussions from these workshops several patient and clinician PIFU resources were designed. For patients, this included a PIFU video in English (with subtitles available in Welsh, Polish, Urdu, Punjabi, Romanian, and Cantonese), a frequently asked questions document, and an infographic with links to patient organisations. For clinicians, this included a handbook with case studies and a review letter template. Resources were made available on the British Society of Rheumatology and national patient organisations websites.

Interpretation Patients and clinicians were supportive of PIFU and willing to contribute to the co-design of resources. They focused on information to help patients access care in a timely way and suggestions for rheumatology teams in relation to organisation and planning, patient identification, and education. This study highlights the complexity of PIFU in practice, including the need to create resources that can be modified to meet the needs of diverse patients and rheumatology teams.

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Introduction

Patient-initiated follow-up (PIFU) is a model of care whereby people decide when they need access to health care rather than the traditional clinician-initiated appointments.^{1,2} PIFU aims to give patients more control over the timing of their follow-up care, empowering them to request a consultation when they require support as opposed to following a standardised schedule.³ PIFU has been used in several acute and long-term specialities,⁴ including trauma and orthopaedics, oncology, gastroenterology, respiratory medicine, and dermatology,⁵⁻⁷ with models and delivery methods varying across health conditions and National Health Service (NHS) Trusts.⁸ Criteria established by

specialty identifies those suitable for PIFU, generally stating that the patient must be at a low risk of immediate urgent follow-up, confident enough to manage their own supported self-management, comprehend what changes in health require a follow-up, and understand how to contact services delivering health information and care.⁹

Rheumatology focuses on the evaluation, diagnosis, and management of long-term musculoskeletal disorders or other immune-mediated inflammatory disorders, the most common of which are types of inflammatory arthritis, such as rheumatoid arthritis.^{10,11} Many of the conditions treated in rheumatology are complex, affect multiple body systems, and require a

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Research in context

Evidence before this study

The National Health Service (NHS) Long Term Plan highlighted the challenges in relation to traditional outpatient delivery models and the need for patients to have more control over their own health. Patient-initiated follow-up (PIFU) in rheumatology is a system where patients with stable rheumatological conditions take an active role in their care by initiating follow-up appointments only when they feel it is necessary, such as during a flare-up or if symptoms worsen, rather than attending routine, pre-scheduled clinic visits. A literature review was undertaken to identify existing evidence for PIFU in rheumatology and other medical specialties. Searches of PubMed on May 5, 2023, and supplementary sources identified seven randomised controlled trials of PIFU in rheumatology (n=1178), all restricted to patients with rheumatoid arthritis and all with methodological limitations and concerns regarding risk of bias. Most studies were small, conducted in single or two centres, and several pre-dated the widespread use of biological therapies or excluded patients receiving biologics. Importantly, none of the studies evaluated the content, quality, or effectiveness of educational resources designed to support patient self-management or appropriate use of PIFU. A review of existing Health Education England resources highlighted a gap in terms of training materials about PIFU. A recent discussion thread on NHS Futures has highlighted that some centres are using a “more targeted approach of contacting suitable patients en masse” and bulk transfer to PIFU with no mention of support, signposting relevant patient organisations or education. The British Society for Rheumatology Clinical Affairs Committee are also aware of this variability and called for assistance from clinicians across

the UK. Co-design approaches, such as workshops, have been shown to improve efficiency, quality of care, and clinical outcomes. This is achieved through a better understanding of the needs of knowledge users, including patients and clinicians. We applied a co-design approach with extensive patient and public involvement to generate PIFU resources for patients and clinicians.

Added value of this study

We have produced freely available resources about PIFU in rheumatology for both patients and clinicians. The interactive workshop methods and extensive patient and public involvement in this study mean that these resources are based on patients' views and lived experiences and clinical practice. The resources for patients involve written, spoken, and visual information to enhance their accessibility. The resources for clinicians are adaptable, in recognition of the variation in how PIFU might be set up and delivered across different sites.

Implications of all the available evidence

The co-designed PIFU resources can help patients to understand what PIFU is and how it works, while also supporting clinicians and rheumatology teams to implement this model of care. These resources recognise the complexity of PIFU in practice and are adaptable to meet the needs of different patient groups and clinical contexts. The PIFU resources developed in this study are currently supporting an ongoing trial investigating the clinical and cost-effectiveness of PIFU in patients with inflammatory arthritis in the UK (TAILOR [NIHR156922], a trial of patient-initiated care leading to improved outcomes in rheumatology).

multidisciplinary approach to care.¹² Pharmacological treatment can include rescue drugs such as non-steroidal anti-inflammatory drugs and glucocorticoids, and long-term immunosuppressive disease-modifying antirheumatic drugs. Non-pharmacological treatments can include physiotherapy, occupational therapy, psychology, and podiatry. Inflammatory arthritides are associated with common comorbidities such as hypertension, cardiovascular disease, stroke, diabetes, chronic kidney disease, heart failure, lung disease, and obesity.^{13,14}

Before the COVID-19 pandemic restrictions, most rheumatology consultations were in person. Since then, rheumatology teams have adapted their models of care, including more remote consultations and remote monitoring.¹⁵ Initially, this was to reduce risk of infection transmission, to enable remote working, and to free up capacity in acute hospitals.¹⁶ However, many health-care systems have continued to embrace the potential of new models of care, including those supported by digital technologies and remote delivery.¹⁷ The NHS Long Term Plan¹⁸ highlighted the challenges, and frustrations, for

both patients and clinicians, in relation to traditional outpatient delivery models. It argued for people to have more control over their own health and more personalised care when they need it, which has further contributed to the implementation of PIFU.

To promote the safe, effective, and equitable implementation and uptake of PIFU, it is important to support both patients and rheumatology teams. PIFU is reliant on the patient coming forward. Therefore, it is crucial to provide accessible resources and guides for patients on how and when to contact the rheumatology team for help. It is also important that the criteria and processes surrounding PIFU are clear for rheumatology teams, including guidance about which patients might benefit and how to ensure quality and equity of care. There is very little information available to inform rheumatology patients about PIFU as a model of care; or to support rheumatology health professionals set up and implement PIFU in their service. The aim of this study was to use a co-design methodology via patient and clinician collaboration to design PIFU resources to help support both a national randomised controlled trial of

PIFU (NIHR156922) and the wider implementation of PIFU in rheumatology clinics across the UK.

Methods

Study design and participants

This co-design study was done across four research centres affiliated with academic institutions including University of Oxford, University of Plymouth, King's College London, and the University of the West of England. The study was overseen by a steering group, chaired by a clinical academic (LCC) with input from clinicians (MGP and JG), researchers with expertise in qualitative research and co-design (AEJ and ED), and patient and public involvement advocates and experts with lived experience of rheumatological conditions (AB, MB, HL, and JE).

As a co-design study, both clinicians (rheumatologists) and patients were invited to take part. Clinicians were contacted via email and included clinicians with different degrees of experience with PIFU. Patients were recruited if they were aged 18 years or older and had a self-reported inflammatory arthritis. Patients did not have to be on a PIFU pathway or familiar with the model of care to participate in the study. Patients were recruited via an online advertisement disseminated through patient charities, the National Rheumatoid Arthritis Society and the National Axial Spondyloarthritis Society, as well as through Psoriatic Arthritis HQ, a support group and resource hub hosted by a co-author (MB). Co-design is an intentionally applied process, used as a creative way of understanding experiences and improving services through the adoption of a range of design methods and tools that are often described as human-centred.¹⁹ The co-design methods used to produce the PIFU resources in this study are classified at the collaborate level according to the International Association of Public Participation framework.²⁰ A fundamental feature of this approach is working with knowledge users, such as patients and clinicians, to understand their experiences of service design, service provision, and quality of care. Using co-design methods to produce the resources aligns with a human-centred approach and reflects the central role of patients as active collaborators in their own health care.²¹ As such, we collaborated with both patients and clinicians to gain insight into the current processes, barriers and enablers surrounding PIFU in rheumatology and to identify the support needs that we could address through producing new PIFU resources for patients and adapted resources for clinicians.²² As the focus was on creating, adapting, and improving the design of resources rather than providing data to answer research questions, this study was classed as patient and public involvement by the research ethics committee at the University of the West of England where AEJ and ED are based, and therefore did not require ethical approval. In accordance with National Institute for Health Research (NIHR) guidance,^{23,24} workshops were audio

recorded with previous verbal consent provided by participants as a memory aid but not for transcription or formal analysis.

Procedures and outcomes

The design and production of the PIFU resources were overseen by the steering group. Online steering group meetings were held via Microsoft Teams at least every month throughout the co-design process. Several online knowledge user workshops were hosted by AEJ and ED to identify key concerns and information needs, and to develop ideas for resources that address these needs. The workshops were separated into those for rheumatology patients and those for clinicians. For each workshop, topic guides were developed by the steering group and flexibility was allowed to prompt discussions surrounding PIFU and to understand the types of PIFU resources needed for each group. Discussions included consideration of the social, economic, policy, health care, and organisational barriers and facilitators that might shape knowledge users' access to and uptake of PIFU. Types of resources were not pre-determined but developed with input from the steering group and knowledge user workshops. At the start of each workshop, it was explained that discussions would be audio recorded through Microsoft Teams and that these audio recordings would be used to collate anonymised information to inform the co-design process. When running the workshops, AEJ and ED spent time at the beginning making introductions and inviting people to ask questions and interact with each other. During the workshops, individuals could discuss their ideas verbally or through the Microsoft Teams chat function. The researcher hosting the groups made sure to hold space for each person present to ensure every voice was heard.

The purpose of the patient-led workshops was to discover patients' concerns and informational needs regarding PIFU and to generate ideas about the style and content of resources to meet these concerns and needs. The purpose of later workshops was to generate statements as the basis for a storyboard script for a patient-facing PIFU video and to create a patient-facing frequently asked questions (FAQs) document. Patients interested in taking part in the study emailed the research team to confirm availability and were then sent a list of workshop dates to choose from. Once they confirmed their intention to attend, a Microsoft Teams link was sent via email. Workshop places were allocated on a first come first served basis. When workshops reached their full capacity (maximum ten people), any patients interested after that point were put on a waitlist and contacted if spaces became available. After taking part, patients were reimbursed for their time with vouchers, in line with NIHR recommended rates²⁵ as this was the easiest compensation method for patients. Patients were also sent a survey before the workshops to collect patient demographics (ie, age, sex, and ethnicity).

As different patients attended each of the workshops, the researchers hosting each workshop began with a brief presentation to introduce themselves, provide an explanation of PIFU, and clarify the purpose of the co-design study. Patients were then asked whether they were currently on a PIFU pathway. In the initial workshops, patients discussed their informational needs in relation to PIFU, drawing on their own rheumatology experience. Other topics included patients' views on rolling PIFU out to more patients, potential benefits, concerns, specific PIFU-related education and support needs, the importance of health checks for common comorbidities, and the duration of time that they would be willing to go without contact from their rheumatology team. Following these initial workshops, statements and questions were generated surrounding PIFU. These were reviewed by the steering group and drafted as a video script and FAQs. The final patient-led workshops critiqued the video script, animation ideas, and the FAQs, and provided feedback on the wording and content of each point.

The purpose of clinician-led workshops was to explore the barriers and enablers to implementing PIFU in practice, drawing on experiences and insights from clinicians working in different settings. The intention was to learn from those clinicians with practical experience of PIFU and from those who had no direct experience, but who were considering how PIFU could work in their service. Workshop discussions focused on clinicians' views on PIFU as a model of care generally and the pros and cons of PIFU in practice. Summaries of the workshops were shared with the steering group and informed the development of resources for rheumatology teams.

The steering group worked iteratively with an animation producer (RL) to draft, revise and refine a range of patient-facing and clinician resources, based on the outcomes of the knowledge user workshops. Discussions focused on accessibility and creating a style that could be used consistently across resources. They are expected to be helpful because they include visual, written and audio information and formats, they

	Purpose	Participants	Number of participants	Date	Outcomes
Workshop 1	Identify information needs and generate ideas for patient-facing resources	Patient-led	18	October, 2023	Insights into patients' concerns, motivations and informational needs in relation to PIFU; initial ideas on how to meet these needs.
Workshop 2	Identify information needs and generate ideas for patient-facing resources	Patient-led	8	October, 2023	Insights into patients' concerns, motivations and informational needs in relation to PIFU; developing initial ideas for resources from workshop 1 and the steering group, including content and type of media.
Workshop 3	Identify information needs and generate ideas for patient-facing resources	Patient-led	8	October, 2023	Insights into patients' concerns, motivations and informational needs in relation to PIFU; defining and refining ideas from workshop 2 and the steering group, such as the use of animation in the video and the need for a FAQs document.
Workshop 4	Identify information needs and generate ideas for patient-facing resources	Patient-led	9	October, 2023	Consolidation of insights into patients' concerns, motivations and informational needs in relation to PIFU drawing on previous workshops and the steering group; decisions about content and style of resources, ready for prototyping.
Workshop 5	Collate views and diverse experiences of PIFU in practice and identify unmet needs and how best to meet them	Clinician-led	3	November, 2023	Insights into the differences between services and the whole systems challenges of implementing PIFU; understanding the nature and type of adaptations required by different services to offer PIFU in practice.
Workshop 6	Collate views and diverse experiences of PIFU in practice and identify unmet needs and how best to meet them	Clinician-led	3	January, 2024	Insights into the differences between services and the whole systems challenges of implementing PIFU; understanding the nature and type of adaptations required by different services to offer PIFU in practice.
Workshop 7	Reviewing and refining draft storyboards, video statements, FAQs content, and wording generated in earlier workshops and steering group meetings	Patient-led	5	January, 2024	Knowledge-user informed, co-designed patient-facing PIFU video and FAQs resources reviewed.
Workshop 8	Reviewing and refining draft storyboards, video statements, FAQs content, and wording generated in earlier workshops and steering group meetings	Patient-led	5	February, 2024	Resources agreed by patients in workshop 7 and the steering group, further discussed and reviewed; final version of the video agreed and ready for dissemination; FAQs required further input.
Workshop 9	Collaborate with early adopters of PIFU to understand what works and why, and how to support implementation	Clinician-led	3	February, 2024	Provision of standard operating procedures, protocols and template letters to be adapted by the clinician collaborators and the steering group (in response to workshops 5 and 6); ideas for the format of a clinician handbook.
Workshop 10	Refine and finalise FAQs content and language	Patient-led	8	April, 2024	Final version of the co-designed FAQs document ready for dissemination.

PIFU=patient-initiated follow-up. FAQs=frequently asked questions.

Table: Knowledge-user workshop groups

consider multiple viewpoints, and they can be adapted to suit local systems. The steering group collaborated with national patient organisations and professional bodies, such as the British Society of Rheumatology, to disseminate the co-designed resources.

Role of the funding source

The funder of the study had no role in study design, data collection, data analysis, data interpretation, or writing of the report.

Results

Between Oct 3, 2023, and April 30, 2024, 10 knowledge user workshops were conducted (including seven patient-led and three clinician-led workshops), generating results using the first three stages of a human-centred design approach (table; figure). Collectively, 61 patients with a rheumatic disease were included across the seven patient workshops (table). To try and broaden the sample, recruitment was targeted towards specific groups which were under-represented (eg, Asian women). The patient-led workshops comprised a mix of sex, age groups, and ethnicities. In total, 38 (62%) of 61 patients were female, 23 (38%) were male, and 33 (54%) identified as White English, Welsh, Scottish, Northern Irish, or British. Overall, 25 (41%) of 61 patients were aged 18–35 years, 22 (36%) were aged 33–54 years, and 14 (23%) were aged 55 years or older. Nine rheumatology clinicians were included across the three clinician-led workshops.

Each patient-led workshop lasted between 50–85 min. Informational needs identified in the early patient-led workshops that needed to be addressed in the patient-facing PIFU video included what PIFU stands for, the rationale for the model of care, criteria for being invited and accepted onto PIFU, the outcomes of PIFU, what patients should do when moving onto PIFU, what support they can access on the PIFU pathway, and whether they can go back to usual care if desired (table). These informational needs were made into statements in the early workshops and by the steering group and shown to patients for feedback and refinement in later patient-led workshops. Discussions led to removing or re-wording phrases that patients thought were unsuitable or vague and focusing on making the language clear and concise. The findings were given to RL, who produced a storyboard based on content and stylistic ideas generated by those in the patient-led workshops.

Patients said that they would like the video to include animated characters showing an individual's journey of joining PIFU. As well as an overview, they also wanted information to be available in smaller chunks. They preferred multiple and diverse characters to feature in the video to make it relatable to as many people as possible. For this reason, patients preferred having a cartoon as opposed to a humanoid or real-life figure. Generally, it was agreed that a single voice over

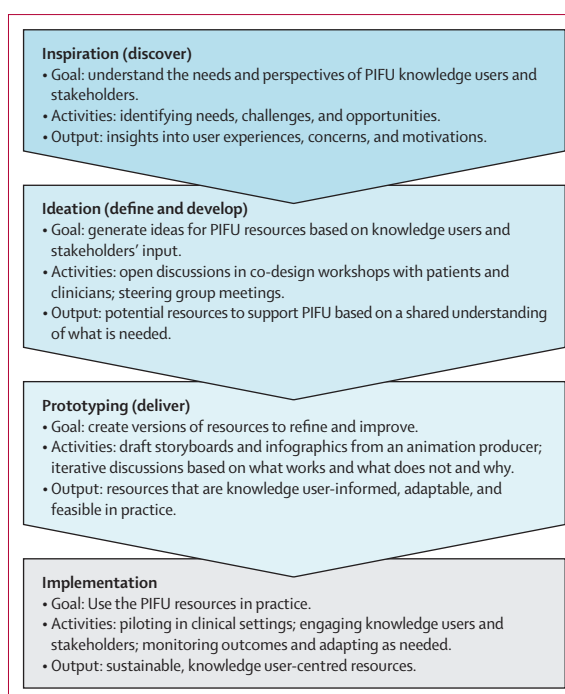


Figure: Phases of human-centred design

This study focused on the first three (inspiration, ideation, and prototyping) phases of human-centred design. PIFU=patient-initiated follow-up.

presenting the information in the third person was the clearest, most inclusive option. The video also needed to emphasise the shared decision-making aspect of PIFU and signpost patients to available charities for further guidance and information.

Draft versions of the video were refined with the steering group and made into a resource that can be embedded on relevant webpages, including national charities. The video was broken down into four smaller edits to enhance accessibility and dissemination: PIFU introduction; what happens in PIFU; where you can get more information and support about PIFU; and agreeing to PIFU—the next step (video).

Informational needs identified in the early patient-led workshops that needed to be addressed in the patient-facing PIFU FAQs were like those for the video. However, the intention was to produce a generic resource that individual rheumatology teams could amend to explain an aspect of PIFU specific to their service. Later patient-led workshops considered the content and wording of potential questions and answers; for example, whether they should be in the first or third person. Like the development of the video, patients generated, reviewed, and refined the FAQs and drew attention to wording that they did not like or found unclear, suggesting alternatives. Patients wanted an additional question about blood monitoring and how this would work in a PIFU pathway. They also had queries about shared decision making, when and how to

See Online for video

contact their rheumatology team, general practitioner versus rheumatology care, the role of digital monitoring and minimum and maximum times between rheumatology health reviews.

After the steering group agreed on a final version, the FAQs document was made into a PDF file with some set standard text and some editable boxes to allow hospital sites to add their details. RL created two versions of the FAQs document; a coloured version for sharing and online use, and a black and white version that would be NHS printer friendly.

The steering group decided that a patient-facing PIFU infographic could provide an overview of PIFU, without the level of detail in the video and FAQs, and offer an additional, accessible resource. Information in the infographic overlaps with the PIFU video and FAQs and has been designed in the same visual style that those in the patient-led workshops advocated; for example, the cartoon characters and colours. The infographic contains QR codes that link to relevant charities and helplines and there is also a section that allows relevant webpage links to be inserted by organisations.

Each clinician-led workshop lasted for 30–60 min (table). Two of the three workshops comprised allied health professionals and consultants, some of whom had clinical experience of PIFU. The discussions within these workshops focused on the drivers and reasoning for implementing PIFU, criteria for patient eligibility to be on a PIFU pathway, resources that teams would find useful, and concerns regarding patients' self-monitoring and access to support when they needed it, for example IT requirements, team preparedness, and ensuring uptake and sustained engagement. Generally, clinicians' experiences were positive; however, there was an example of top-down implementation in one service, where patients were moved onto a PIFU pathway without any consultation or shared decision making. How to present PIFU to patients was a key topic of discussion. Clinicians stated that education should include patients' friends, family, and support networks, especially in situations where patients might require extra help (eg, due to cognitive decline). In practical terms, patients should be given time to think about whether to go on PIFU, rather than being invited at an appointment and being expected to give an immediate response. Patients should be able to initiate the move onto a PIFU pathway if the option is available in the service. Once a patient is on a PIFU pathway, reviews should be ongoing, and patients should be able to reverse the decision if they wish to.

The other clinician-led workshop comprised rheumatology consultants who all had extensive practical experience of PIFU. Discussions confirmed that PIFU pathway set-up and delivery varied across services; examples included patients attending education and self-management programmes as a pre-requisite to moving onto PIFU, the use of remote monitoring

between consultations and differences in which allied health professionals could be accessed on the PIFU pathway. The clinicians shared experiences of their current resources, what did and did not work well in their service and any amendments they would make to enhance PIFU. They also shared their standard operating procedures and protocols for PIFU with the steering group. However, even when standard operating procedures were used, it was acknowledged that soft judgements remained around selection of patients for PIFU, for example, if a patient calls the team's rheumatology advice or help line frequently, PIFU might not be suitable.

The clinician handbook and resources needed to be generic or adaptable to meet the requirements of different rheumatology teams' approaches and systems.²⁶ In addition to the clinician workshops, the steering group contacted rheumatology colleagues for examples of PIFU in practice. These were collated into a series of case studies, highlighting the different ways that PIFU can be undertaken. A concern for both patients and clinicians was that patients could get lost in a PIFU system and spend long periods without assessment or monitoring of their inflammatory arthritis. Therefore, a template review letter for patients on a PIFU pathway from their clinical team was adapted by AEJ, based on one that had been kindly shared by an early adopter of PIFU. The adapted template outlined what PIFU was, gave patients a timeframe for their rheumatology review, explained what patients could expect from the review, clarified how to contact the rheumatology team if patients needed help, and how to contact their general practitioner on advice about comorbidities. It also included links to additional support. An important message was that the patient was still on the PIFU pathway and under the care of the rheumatology team.

Finalised versions of the resources were generated in English. Unfortunately, funding limitations required the steering group to prioritise which resources would be translated into multiple languages. The PIFU video was chosen, as the visual aspect made it one of the more accessible ways of obtaining health information, compared with written text. Therefore, subtitled versions were created and made available in Welsh, Polish, Urdu, Punjabi, Romanian, and Cantonese. These languages were chosen based on census data and a national survey of rheumatology units asking which languages would be most helpful for the patients that they see.

All the co-designed resources were compiled and sent to the project funder, the British Society of Rheumatology, who made them available on their website and downloadable as PDFs.²⁷ The PIFU video and the other resources were uploaded to patient organisation websites to facilitate sharing, including the National Rheumatoid Arthritis Society, National Axial Spondyloarthritis Society, and Psoriatic Arthritis HQ. The steering group launched the resources in a co-ordinated approach on

World Arthritis Day in October, 2024, to disseminate the resources via patient and professional organisations.

Discussion

This study successfully developed resources to support the implementation of PIFU in rheumatology services using a co-design approach. Patients and clinicians' high level of willingness to participate in this time-consuming process suggests that PIFU is seen as important. The workshop discussions captured the complexity of undertaking PIFU in practice and the need for a nuanced approach. The study contributes to a growing body of co-design work in rheumatology health services; for example, in relation to group consultations, supported self-management, remote monitoring, and digital health apps. It also supports qualitative research showing that patients welcome the flexibility of PIFU, but they need relevant information to act adequately in this new patient role.^{28–30}

The information provided in the co-designed PIFU resources included the perspectives of patients with rheumatic disease and clinicians and aligned with the latest guidance for NHS services initiating a PIFU approach for inflammatory arthritis. This triangulation of perspectives was central to creating resources for use in practice. In addition to being available for rheumatology teams across the UK, the resources are included in an ongoing trial investigating the clinical and cost-effectiveness of PIFU in patients with rheumatic disease across the UK (TaILOR [NIHR156922], a trial of patient-initiated care leading to improved outcomes in rheumatology). The qualitative sub-study in the trial will provide an opportunity for NHS patients and clinicians across the UK to use the new and adapted resources and feedback on them, if relevant to their experience. This study focused on people with inflammatory arthritis as the current NHS England guidance is specific to these conditions; however, similar approaches could be undertaken for other conditions in rheumatology in the future.

Although the co-design process was based on in-depth collaboration with knowledge users and input and oversight from a steering group with lived experience and clinical expertise from the outset, there were limitations. We did not include formal qualitative research in the process, as recommended by co-design approaches such as the Experience-Based Co-Design toolkit.¹⁹ This was due to time constraints and our focus on collaborative working that can be challenging to maintain in a researcher–participant dynamic. The patient-led workshop contributors were invited to take part through patient organisations. Some of those taking part confirmed that they had previous experience of research. It is possible that these patients were more informed and proactive in relation to their rheumatic health condition compared with the general rheumatology patient population. The workshops were

conducted online, which was efficient in several ways (for example, time and cost for the contributors and the project team) and allowed for patients and clinicians from any geographical location to participate. However, it meant that patients who took part were familiar with online communication and confident enough to contact the project team via email and join an online group. These methods would have disadvantaged patients who were less confident or had limited access to digital resources. Although the patient-facing PIFU video is available with subtitles in several languages, the workshops that informed the content and style were done in English. Over time, it would be important to evaluate the co-designed resources with patients with wide ranging and diverse clinical and sociodemographic characteristics, including those who are digitally excluded, those with limited health literacy, those with disabilities such as cognitive impairment and their carers, and those who do not speak English.

When patients registered their intention to join one of the workshops, they were emailed a meeting link individually, to avoid sharing email addresses. However, the link was easily copied and some of the original recipients shared it with other people who had not been in contact with the project team and thus might not have seen the original advert highlighting what was needed of them. As such, the first patient-led workshop included contributors who were not expected to join, and the group was larger than anticipated ($n=18$). This might have contributed to some patients keeping their cameras off and not engaging with the main discussion or using the Microsoft Teams chat box facility. The increase in popularity of online qualitative data collection has led to concerns around imposter participants and the need to ensure that people taking part meet the project criteria and intend to actively contribute.^{31,32} This first workshop was a learning opportunity and with the subsequent workshops, it was specified that the meeting link should not be shared and that if patients wished to participate, they would have to contact the project team directly. Thereafter, workshops had smaller groups and were more interactive with more in-depth discussion.

The co-designed resources use the term PIFU to refer to a system in which patients initiate access to health care. However, other terms exist that refer to the same model of care, such as direct access. To optimise their usefulness, future versions of the patient-facing resources need to be fully amendable so that the language can align with whatever term the individual rheumatology team uses.

In conclusion, this study used a co-design approach to identify PIFU informational needs, create resources to support rheumatology teams using PIFU for patients with inflammatory arthritis and help patients living with a inflammatory arthritis understand PIFU as a potential pathway to managing their condition.

Contributors

AEJ: data collection, project administration, resource co-design, writing (original draft). AB: project administration, methodology, resource co-design, writing (review and editing), dissemination. MB: project administration, methodology, resource co-design, writing (review and editing), dissemination. JE: project administration, methodology, resource co-design. JG: methodology, writing (review and editing). MGP: methodology, resource co-design, writing (review and editing). HL: methodology, resource co-design, writing (review and editing), dissemination. RL: resource co-design, software, visualisation. LLC: project conceptualisation, funding acquisition, methodology, resource co-design, project leadership, writing (review and editing). ED: data collection, methodology, resource co-design, supervision, writing (original draft). ED and AJ had full access to all the data in the study. ED and AJ directly accessed and verified the underlying data reported in the manuscript. All authors had final responsibility for the decision to submit for publication.

Declaration of interests

LLC reports grants from AbbVie, Amgen, Janssen, and UCB; consulting fees from AbbVie, Amgen, Bristol Myers Squibb, Eli Lilly, Enliven, Janssen, Moonlake, Novartis, Pfizer, Takeda, and UCB; payment or honoraria from AbbVie, Amgen, Eli Lilly, Janssen, Novartis, Pfizer, and UCB; support for attending meetings from Novartis and UCB; and is a member of BritPACT and GRAPPA committees. JG reports speaking fees from AbbVie, Alfasigma, Eli Lilly, Janssen, Novartis, Pfizer, and UCB. All other authors declare no competing interests.

Data sharing

For participant confidentiality, original recordings of meetings are not retained and so no data sharing is possible in this study.

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