Designing, developing and testing a chatbot for parents and carers of children and young people with rheumatological conditions (the IMPACT study): Protocol for a co-designed proof of concept study

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Abstract

Background: Paediatric Rheumatology is a term that encompasses over 80 conditions affecting different
organs and systems. Children and young people with rheumatological chronic conditions are known to have high levels of mental health problems and therefore are at risk of poor health outcomes. Clinical psychologists can help children and young people manage the daily difficulties of living with one of these conditions, however, there are insufficient paediatric psychologists in the United Kingdom. We urgently need to consider other ways of providing early, essential support to improve current wellbeing. One such way of doing this would be to strengthen the networks around the child or young person and the people whom they look to everyday for support, their parents/carers.

Objective: The aim of this co-designed proof-of-concept study is to design, develop and test a chatbot intervention to support parents/carers of children and young people with rheumatological conditions.

Methods: This study will begin by exploring the needs and views of children and young people with rheumatological conditions, siblings and parents/carers of those with rheumatological conditions, and health care professionals working in paediatric rheumatology. We will ask approximately 100 participants in focus groups where they think the gaps are in current clinical care and what ideas they have for improving upon these. Creative Experience Based Co-Design (EBCD) workshops will then decide upon top priorities to develop further, whilst informing the appearance, functionality and practical delivery of a chatbot intervention. Upon completion of a minimum viable product, approximately 100 parents/carers will user-test the chatbot intervention in an iterative sprint methodology.

Results: We have full ethical approval for the study and enrolment began at the end of November 2023, with 42 currently enrolled into our focus groups. The anticipated completion of the study is April 2026. The primary outcome is to develop a product that is accessible and acceptable for parents/carers, to provide enhanced support compared to current clinical practice, with each parent/carer acting as their own control.

Conclusions: This study will provide evidence on the accessibility, acceptability and usability of a chatbot intervention for parents of children and young people with rheumatological conditions. If proven useful for parents/carers, it could lead to a future efficacy trial of one of the first chatbot interventions to provide targeted and user suggested support for parents/carers of children with chronic health conditions in healthcare services. This study is unique in that it will detail the needs and wants from children, young people, siblings, parents/carers in improving support given to families living with paediatric rheumatological conditions, conducted across the whole of the UK in all paediatric rheumatological conditions at all stages of disease trajectory.

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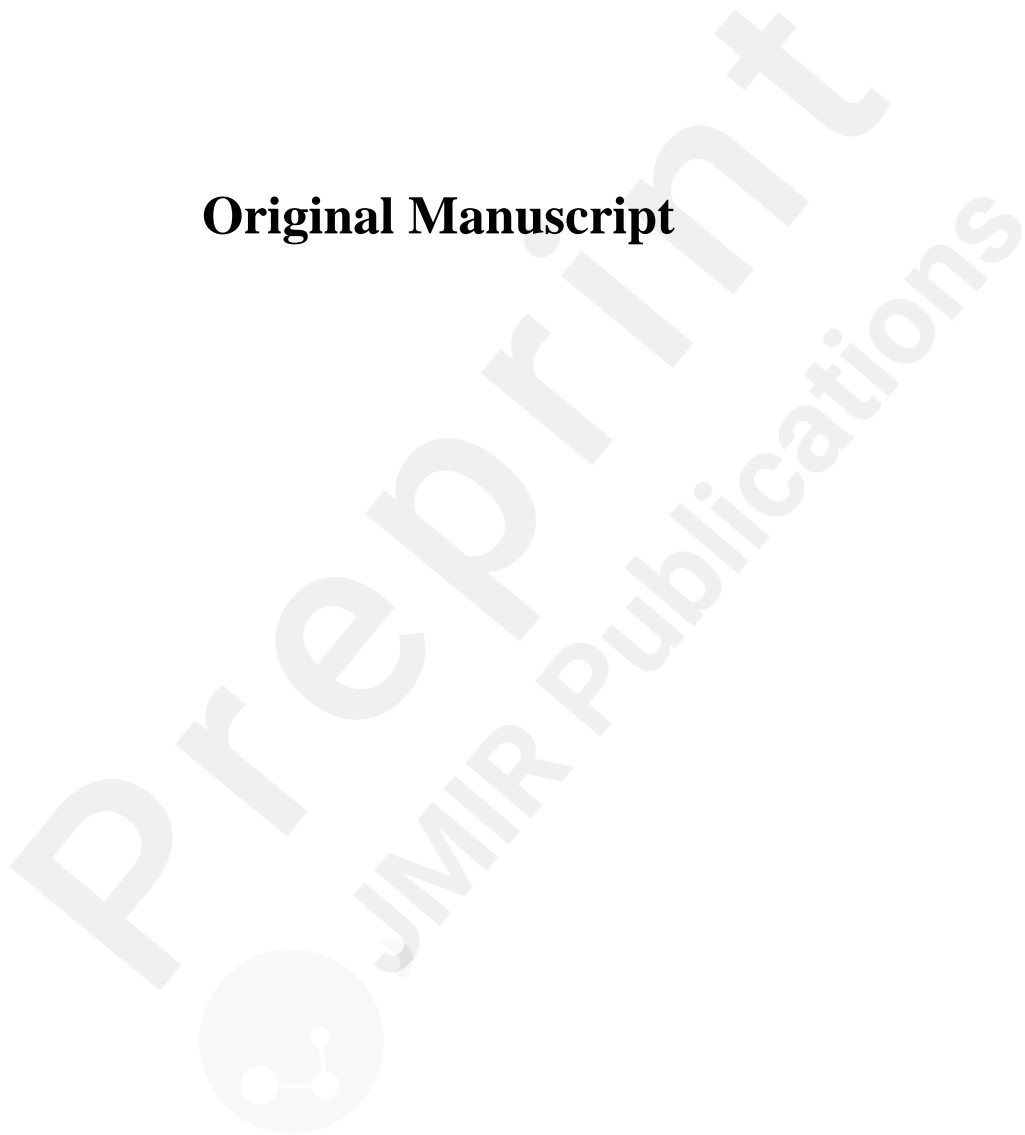
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Original Paper

Designing, developing and testing a chatbot for parents and carers of children and young people with rheumatological conditions (the IMPACT study): Protocol for a co-designed proof of concept study

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ABSTRACT

Background

Paediatric Rheumatology is a term that encompasses over 80 conditions affecting different organs and systems. Children and young people with rheumatological chronic conditions are known to have high levels of mental health problems and therefore are at risk of poor health outcomes. Clinical psychologists can help children and young people manage the daily difficulties of living with one of these conditions, however, there are insufficient paediatric psychologists in the United Kingdom (UK). We urgently need to consider other ways of providing early, essential support to improve current wellbeing. One way of doing this is to empower parents/carers to have more of the answers that their children and young people need to support them further between their hospital appointments.

Objectives
The objective of this co-designed proof-of-concept study is to design, develop and test a chatbot intervention to support parents/carers of children and young people with rheumatological conditions.

Methods and analysis
This study will explore the needs and views of children and young people with rheumatological conditions, their siblings and parents/carers of those with rheumatological conditions, and health care professionals working in paediatric rheumatology. We will ask approximately 100 participants in focus groups where they think the gaps are in current clinical care and what ideas they have for improving upon these. Creative Experience Based Co-Design (EBCD) workshops will then decide upon top priorities to develop further, whilst informing the appearance, functionality and practical delivery of a chatbot intervention. Upon completion of a minimum viable product, approximately 100 parents/carers will user-test the chatbot intervention in an iterative sprint methodology to determine its worth as a mechanism for support for parents.

Results
A total of 73 children, young people, parents/carers and health care professionals have so far been enrolled into the study which began in November 2023. The anticipated completion of the study is April 2026.

Conclusions
This study will provide evidence on the accessibility, acceptability and usability of a chatbot intervention for parents/carers of children and young people with rheumatological conditions. If proven useful, it could lead to a future efficacy trial of one of the first chatbot interventions to provide targeted and user suggested support for parents/carers of children with chronic health conditions in healthcare services. This study is unique in that it will detail the needs and wants from children, young people, siblings, parents/carers in improving current support given to families living with paediatric rheumatological conditions, conducted across the whole of the UK in all paediatric rheumatological conditions at all stages of disease trajectory.

Keywords:
Chatbot; Paediatric Rheumatology; Parents/Carers; Quality of life; proof-of-concept

Word count :
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INTRODUCTION

Background

Paediatric rheumatological illnesses are chronic inflammatory conditions which affect the musculoskeletal system [1,2]. Whilst some are rare, Juvenile Idiopathic Arthritis (JIA), the most common rheumatological disease of childhood, currently affects 10,000 children and young people in the United Kingdom (UK) [3]. JIA occurs as frequently as juvenile diabetes mellitus and ten times more frequently than acute lymphoblastic leukaemia [4]. Children and young people with rheumatological conditions are well known to experience high psychological burden, with decreased quality of life, increased pain and disease activity, physical disabilities, school absenteeism, suboptimal medication adherence and transition challenges [1,5]. Up to two thirds of young people continue with active disease into adulthood [6,7], with visible and invisible symptoms causing

marked psychological ramifications. High levels of mental health comorbidity and consequent risk for adverse health outcomes, are common in children and young people with rheumatological conditions [1,8]. The British Society of Paediatric and Adolescent Rheumatology (BSPAR) Standards of Care (2010) includes the recommendation that a paediatric clinical psychologist should be part of the core multi-disciplinary team [9]. However, a 2021 survey of 15 high volume paediatric rheumatology UK centres, highlighted that seven centres failed to achieve this [10]. In 2019, the British Society of Rheumatology (BSR) paediatric and adolescent State of Play report [11] highlighted poor access to psychology expertise and recommended increased psychology provision. Early identification of children and young people who are struggling is known to improve outcomes, but current systems fall short in providing adequate emotional and mental health support to those with rheumatological conditions [12].

A review examining the impact of living with a child with a long-term health condition revealed that parents perceive that they are not always supported in their quest for information and their ultimate responsibility for their child's health can be overwhelming [13]. Parents/carers described that when information is not available from health care professionals, they were compelled to search for it elsewhere [14] and feel the need to 'take charge', becoming an advocate for their child through 'tenacious information seeking' [15]. Patient and Public Involvement and Engagement (PPIE) activities revealed that available parental support is currently inequitably distributed and accessed. Charity access is inconsistent, with awareness dependent on clinical teams, other parents or through 'internet searching'. Education support offered at 'family weekends' is limited by geography and capacity. Social media closed groups are only available to those who know about them and due to unregulated content, parents were sceptical about the levels of support received.

Rheumatologists and nurse specialists in the UK identified lack of clinic time as one of the biggest limitations to asking about emotional and mental health support in appointments, followed by the absence of resources when concerns are raised [10]. While clinic time is limited, waiting lists are too long and the increase in number of psychologists is awaited, upskilling parents has the potential to improve their child's psychological wellbeing and prevent the need for latter mental health intervention. The James Lind Alliance also supports this in its 10 identified priority areas for mental health in children and young people specifically; what methods can parents/carers use to identify that their child's mental health is deteriorating and what are the most effective early intervention strategies for supporting them to improve mental resilience [16]. In 2023, five paediatric rheumatology UK charities were so worried about mental heath that they collaborated to develop and deliver a survey to understand the scale of the problem. The results from this work showed that out of 291 parents/carers completing the survey, 218 (82%) parents/carers reported their child's diagnosis, as impacting their own mental health. It also highlighted that 60% of children and young people have needed mental health support since diagnosis (had help/undergoing help/on a waiting list) and in relation to condition specific difficulties: 81% needed help with needle phobia; 80% are reluctant to take their rheumatology medicines and 78% are struggling with side effects from medications [17].

At the time of this study application, chatbots were being used as a means of providing useful information in a variety of settings [18]. Chatbots are typically cloud-based programmes that require internet-connected devices, and users interact with them in a number of ways including text and voice. In particular, chatbots, such as Vincent have proven to be useful to enhance mental health [19], iHelper provides guided self-assessment for stress, anxiety, depression and self-esteem, and Woebot, is a textbased conversational agent providing two-weeks of self-help, proven to significantly reduce depression [20]. Chatbots are beginning to be used in NHS services; 'Ask Olli' for parents at Alderhey [21] and the 'Oriel Assistant' for patients and staff at Moorfields [22] and evidence showed

that most internet users would be receptive to using health chatbots [23]. Since the funding for the study was awarded, chatbot interest has progressed rapidly with the launch of commercially available chatbots. Chatbots potential in healthcare is also growing, with research progressing in this area, for example ChatGPT and GPT-4 already show promise in translating radiology reports into plain language for families [24]. The exact deliverable for this study however is still work in progress, and will be decided by the co-design group, taking into account issues such as: digital-poverty; scalability; advantages/disadvantages of platforms; data security and outcome measures.

The Interventions to improve Mental health supPort in families with children And young people with Chronic rheumaTological conditions (IMPACT) proof-of-concept study, aims to design, develop and test a chatbot intervention for parents/carers of children and young people with rheumatic conditions. It is hoped that through empowering parents/carers we will strengthen the support around children and young people, prevent anxieties and uncertainties from escalating and improve other aspects of paediatric rheumatological care, such as adherence to therapies. This intervention is not to replace human contact, but to be an adjunct when human contact is limited, for example between appointments and whilst on holiday.

Study set up

The research team is led by the Principal Investigator (PL) who is a Senior Paediatric Rheumatology Nurse and Research Facilitator (KK) who has a psychology degree and background in paediatric rheumatology research. This study proposal was submitted for a personal post-doctoral National Institute for Health and Social Care Research (NIHR) Advanced Clinical Academic Fellowship (ACAF) (NIHR 302864), awarded in 2023 to PL, the first and currently (at time of writing) only ACAF award given to a nurse in the UK. The study timeline is from April 2023 – April 2026.

Patient and Public Involvement and Engagement (PPIE)

A strong and engaged UK wide steering group of children, young people, parents/carers and health professionals, is pivotal to the success of this study. The group is composed of four children and young people, four parents/carers and three health care professionals (a clinical psychologist in paediatric rheumatology, a senior paediatric nurse who is working in rheumatology research and a clinical informatics expert).). The working group currently includes over 30 children and young people, parents/carers, health professionals and key charity stakeholders who have all been involved in the study proposal since idea conception.

PPIE activities began over two years ago helped to shape the current study detailed here today. Initially children, young people, parents/carers and health professionals were asked whether they need more support in living with a chronic paediatric rheumatological condition. As conversations proved there was a need to increase support to improve psychosocial wellbeing, discussions moved over time to consider what this may look like. Initially, the intervention was expected to be tailored towards children and young people, however as conversations continued, parents/carers were open about their need for further support for themselves. A digital intervention was suggested which could help to; better prepare their child through their 'firsts' (first joint injection/first blood test/first scan), to know the right questions to ask in appointments; how to have conversations with school; how to encourage medication adherence; how to talk about distorted body image due to corticosteroid therapy; how to encourage home exercises; how to identify red flags in their child's mental health and where to go for help. During brainstorming activities, the idea of a 'chatbot' was presented by a

parent and unanimously selected as a potential targeted intervention. Parents/carers particularly liked the anonymity of chatbots and their constant availability.

Regular meetings, both virtual and face-to-face have ensured key decisions have been agreed upon as a group, for example such as whether two participants from the same family could be included in the focus groups. Key documentation have been reviewed by both the steering and working groups, and they will continue to be involved from beginning to end of the study. The methodology used for this study ensures that the study is directed by children, young people and parents/carers, ultimately for children, young people and parents/carers.

METHODS

Methodological underpinnings

This research study utilises Experience-Based Co-Design (EBCD) methodology to guide the project, underpinned by the MRC-NIHR Complex Intervention Research Framework [25]. EBCD is a form of participatory research, combining user-centered design, learning theory and delivered through a six stage collaborative process [26,27], see Box 1. These stages will be embedded throughout the study maximising the potential to use creativity and ideation to generate wide ranging ideas and maximise opportunities for innovation as recommended in the recently updated research framework [25].

A 'trigger film' (short film) is integral to the EBCD methodology and highlights 'touchpoints' which elicit shared reflections. For this study the focus groups and planned exercises during the workshops will be video recorded, then edited to produce the trigger film. This film is useful to understand some of the key decisions made throughout the study and can be a useful aide for dissemination. Using EBCD methodology is compliant with the NIHR Participant in Research Experience survey that recommends 'technology provided to participants should be tested for reliability and ease of use and co-designed with the intended users' [28].

Aim
This proof-of-concept study aims to design, develop and test a chatbot intervention to provide enhanced support compared to current clinical practice that is accessible, acceptable and useable for parents/carers.

Inclusion and Exclusion Criteria
Children and young people over the age of eight years with a rheumatological condition diagnosed before 17 years of age and their siblings will be invited to join focus groups. Parents/carers of those with rheumatological conditions will also be invited to parent specific focus groups. Health professionals who care for paediatric and adolescent rheumatological patients will also be invited to join health care specific focus groups. Those without rheumatological conditions as a child or young person, siblings or parents of these, will not be included. Members of our steering group are also excluded from partaking as a research participant in the focus groups, although welcomed as a facilitator.

Designing : Experience Based Co-Design Focus groups

The 'core elements' of the revised MRC-NIHR Framework [25] state that it is imperative to understand key uncertainties, consider the context, and engage stakeholders. Therefore, the aim is to understand, from the perspective of children, young people, siblings, parents/carers and health professionals, what support they think would be useful and whether they think this could be delivered within a chatbot intervention. Focus groups will be used to yield rich qualitative data from a range of individuals from across the UK. A minimum of eight focus groups are planned, with approximately six-twelve participants in each group. The parent/carer groups will outnumber the child/young person, sibling and health care professional groups as the intervention is ultimately for parents/carers. However, we are also interested to ask participants with rheumatic conditions what they would have found helpful for their parents/carers to have known, ask siblings for their perspectives and for health professionals to discuss where they see more support could be offered. Groups will be undertaken virtually or face-to-face depending on requests of the majority of participants (in line with NIHR PPIE survey findings) [29].

Parents/carers, siblings, children and young people will be recruited using consecutive sampling. Participants will learn about the study through study advertisement flyers in clinical settings or being given a flyer. Ethical approval has been granted for local paediatric and adolescent rheumatology centres to display and distribute flyers, and in conjunction with paediatric rheumatology charity social media channels and email lists, this should increase the opportunities for inclusivity across all four nations of the UK. A study specific website has been developed which encourages interested children, young people or parents/carers to contact the study team to find out more or if unable to access technology, their local team can contact the IMPACT research team on their behalf. Language specific study documentation and interviews will be offered for those who English is not their first language. Staff will be recruited through seeing the study flyers and contacting the study team. A sampling matrix will ensure representation from professional groups and centres.

Consent will be sought for audio and visually recording, the former to guide data analysis, whilst the video recording will form the trigger film. Thematic analysis (TA) [30] will be conducted by two members of the research team and discussed with the steering group to identify themes critical to shape the chatbot development using NVIVO software. The final themes will help develop the chatbot.

Developing : Experience Based Co-Design (EBCD) workshops

The working group will meet in two face-to-face workshops to discuss the themes and help identify the core components of the chatbot intervention. The workshops will use personas and scenarios developed from the focus group discussion to help inform the chatbot development process. Such creative and participatory methods will allow the shared experiences of the members of the working group to shape the intervention development process. The workshop will be video recorded as recommended in EBCD methodology and excerpts of the film used later in the trigger film.

Over the last years as chatbot technology has developed at an alarming rate with large language models now leading the way, their popularity has increased [31]. Whilst it Is not possible to be specific regarding the content of the chatbot until the focus groups have been completed and analysed, a content management system will be developed to inform the chatbot development. It is anticipated that the chatbot may include such functions as: 1. Frequently asked questions, 2. Rheumatology specific information, 3. Information about managing 'firsts', 4. Parental red-flag identification and signposting and 5. Persuasive argument roleplay. Using agile principles, the exact technologies and approaches used may change as the team learn more about the user requirements.

Development of the chatbot will occur within existing recommendations such as the NICE Evidence Standards Framework for Digital Health Technologies (DHT) [32], NHS Digital guidance for Cloud security [33] and the Department of Health guidelines for 'Putting data, digital and tech at the heart of transforming the NHS' [34].

Testing : Agile sprint methodology user testing

Chatbots can potentially lead to frustration, anger, dissatisfaction and at worst, disengagement with the technology, if not designed and developed with key-stakeholders [35,36]. This is not new technology, however, using it for this purpose, for parents/carers of children and young people with rheumatological conditions is new. Therefore, the crucial step before a larger study, must be to determine accessibility, acceptability and usability through user-testing.

User-testing will occur through an iterative methodology with short product development cycles and deployment of the prototype to groups of parents/carers. This will ensure user feedback directs incremental iterative software development. This process of 'agile development' runs in a cycle of design, develop, test, refine (termed a 'sprint'). Every 3-month cycle, we will user-test, analyse and develop. At least 25 parent/carers will be recruited for each cycle, anticipated to be up to 4 cycles in total. Whilst the majority of participants will be naïve to each cycle, some may be invited back to 'test' new modifications in the next cycle. Parent/carers will be requested to use the chatbot on a number of occasions for a defined frequency of time.

Eligible parents/carers will be those of a child or young person diagnosed before the age of 17 years with a chronic paediatric rheumatological condition who agrees to complete the user metrics throughout the testing period. Flyers in local hospitals will again advertise this part of the study to parents/carers, who will then contact the study team for further information. If families are identified who do not have access to technology, individual conversations will occur to investigate whether a device may be loaned. All parents/carers will be sent an information pack and provide written consent. Of note, the chatbot technology can integrate 'Google Translate' and as such, families who do not have English as a first language will be able to participate.

Usability outcome measures and qualitative experiences will be sought in order to understand the acceptability of the chatbot for progression to a future study. Outcome measure selection will be informed through exploring what success would look like to families. These may include such measures as 1) Attrition of participants; 2) Engagement and duration of conversations; 3) User satisfaction measures (such as the System Usability Scale (SUS) [37,38]; User Experience Questionnaire (UEQ) [39] and Net Promoter Score (NPS) [40,41] and 4) Semi-structured interviews with the final group of 'sprint' participants.

Ethical considerations
The study will be conducted in accordance with the Principles of Good Clinical Practice and the Declaration of Helsinki. Ethical approval from the Health Research Authority (HRA) has been received for the study (approval received on 31st August 2023 from the Yorkshire & The Humber – Leeds West Research Ethics Committee IRAS ID: 329476. REC Reference:23/YH/0172). All participants are asked to provide informed written consent or assent (for those under 16 years of age, paired with parental/carer consent) prior to being enrolled onto the study. Consent and assent is requested to audio and video record the focus groups and workshops to enable data analysis and the production of the trigger film, whilst also requesting to use anonymised quotes and pictures of physical creations in dissemination.

RESULTS

The study is ongoing. As of the 28th of February 2024 we have enrolled 73 children, young people, parents/carers and health professionals in 12 focus groups so far. We have had over 280 children, young people, siblings and parents/carers reach out to be included in focus groups and therefore an ethics amendment has been sought to increase our recruitment target. This huge interest validates the need for the study and already interesting ideas are emerging. Preliminary results will be published from the focus groups by the end of 2024 and from the user testing by the beginning of 2026.

DISCUSSION

Rheumatological conditions of childhood affect the whole family. Children and young people have been shown to suffer with their emotional and mental health as they cope with the implications of a chronic health condition. Parents/carers and siblings of the child, have also been shown to experience difficulties as they too navigate the new normal family lifestyle and the implications of the health condition on their own life. Parents/carers report that for conditions such as JIA there is a wealth of information available on the internet, however, it is not always clear how robust and trustworthy this information is, whilst for rarer paediatric rheumatological conditions, there is much less available information and searching for what little there is, can be upsetting and often futile. Providing information and support in the style of a chatbot has many advantages, including physician ratified and endorsed information, anonymity, being accessible throughout the day and night and the ability to integrate new novel functions, such as the ability to practice difficult conversations with the chatbot enacting as their child or young person. Therefore the aim of this study, is to investigate whether a chatbot intervention could provide additional support to families between appointments, without the need for human resource.

If the chatbot proves to be a success, then such an intervention may be useful in other diseases and with other populations. If the chatbot shows that parents/carers do not find it useful and its function is limited, this is useful learning during the current rapidly advancing technology climate and further intervention development may be commissioned. If the intervention is deemed to be acceptable, then to make conclusions regarding the effectiveness of the intervention, a further study would be required. Discussions will begin early to scope options for embedding the chatbot into NHS services in order to enhance the transition from research to service delivery following further assessment. Links to research outputs will be made available on the IMPACT study website at www.theimpactstudy.co.uk [42].

This study has several limitations, primarily as a proof-of-concept study it will be difficult to generalise findings. Coping with a chronic health condition varies on a daily basis depending on disease severity, treatments and their side effects, social support and daily mood fluctuations. Therefore, the chatbot may prove useful to families for the short duration of this study, but as there is no external control group, analysing all variables and drawing sound conclusions, could be challenging. Also, due to the technological nature of a chatbot intervention, families who do not have easy access to technology may be disadvantaged, however, we are in the process of scoping local technology resources which can be loaned out if required. We also set a lower age limit for child participation as eight years and over, this was to be mindful that the questions we are asking children about what else they would have liked support with, would be difficult for most under eight's to answer. However, we are aware in some instances, parents/carers feel their younger child may have liked the opportunity to take part.

We believe this study can have significant future applications and implications, such as learning from families perspectives of how we can improve upon current rheumatological clinical care, providing a responsive and tailored intervention to help support families better and an understanding of how such technology could be embedded into the wider healthcare system. This is particularly relevant in today's current climate of limited staffing resources and an interest in delivering care differently. This study also offers an insight into how a chatbot could be used for families who live at a distance from their healthcare site, thus offering advantages over face-to-face support appointments and providing a resource for families, which may in turn lessen the need to contact the local team for support and thus free up valuable resources. The interest in the study so far at over 280 families who have reached out in just over three months, over double the planned recruitment for the focus groups, is clear evidence that we need to do more to listen to, engage with and support families further.

Acknowledgements

Data Availability

The anonymised data sets analyzed during this study will be available from the corresponding author upon reasonable request.

Authors Contributions

PL substantially contributed to the conception and design of the protocol and write up of the protocol.

KK contributed to the design of the study and has been involved in revising the manuscript. She has approved the submitted version and agreed to be personally accountable for her own contributions and ensured that any accuracy and integrity if they appear in the future will be appropriately investigated and resolved.

LW contributed to the conception of the study and has been involved in revising the manuscript. She has approved the submitted version and agreed to be personally accountable for his own contributions and ensured that any accuracy and integrity if they appear in the future will be appropriately investigated and resolved.

AK contributed to the design and conception of the study and has been involved in revising the

manuscript. She has approved the submitted version and agreed to be personally accountable for her own contributions and ensured that any accuracy and integrity if they appear in the future will be appropriately investigated and resolved.

LS contributed to the design and conception of the study and has been involved in revising the manuscript. She has approved the submitted version and agreed to be personally accountable for her own contributions and ensured that any accuracy and integrity if they appear in the future will be appropriately investigated and resolved.

RS contributed to the design and conception of the study and has been involved in revising the manuscript. She has approved the submitted version and agreed to be personally accountable for her own contributions and ensured that any accuracy and integrity if they appear in the future will be appropriately investigated and resolved.

GR contributed to the design and conception of the study and has been involved in revising the manuscript. He has approved the submitted version and agreed to be personally accountable for his own contributions and ensured that any accuracy and integrity if they appear in the future will be appropriately investigated and resolved.

NS contributed to the design and conception of the study and has been involved in revising the manuscript and approved the submitted version and agreed to be personally accountable for the authors own contributions and ensured that any accuracy and integrity if they appear in the future will be appropriately investigated and resolved.

FG contributed to the design and conception of the study and has been involved in revising the manuscript. She has approved the submitted version and agreed to be personally accountable for her own contributions and ensured that any accuracy and integrity if they appear in the future will be appropriately investigated and resolved.

IMPACT Steering Group contributed to the design and conception of the study, have reviewed the manuscript and approved the submitted version. The steering group comprises; Eire Byrne, Natalia Kasaru, Morgan Pawlett, Cameron Papantoniou, Emily Earle, Nathanael Bourns, Rachel Pulfree-Blythe, Eunice Kasaru, Emma Piepenstock, Gemma Molyneux and Heather Rostron. Please see www.theimpactstudy.co.uk for further information.

Conflicts of interests
PL is currently receiving a personal fellowship award from the National Institute for Health and Care Research (NIHR) fellowship for non-medical heath care professionals (ACAF reference number 302864) and as PPIE co-lead for the NIHR GOSH BRC, she receives some salary support from the NIHR Biomedical Research Centre at GOSH. PL is also a Senior Centre Affiliate at The Centre for Adolescent Rheumatology Versus Arthritis at UCL UCLH and GOSH which is supported by Versus Arthritis (21593). LRW s contribution was underpinned by grants from the Medical Research Council (MRC) [MR/R013926/1] Versus Arthritis [22084, 21593], Great Ormond Street Hospital

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Abbreviations
ACAF Advanced Clinical Academic Fellowship
BRC Biomedical Research Centre
BSPAR British Society of Paediatric and Adolescent Rheumatology
BSR British Society of Rheumatology
CCAA Childrens Chronic Arthritis Association
DHT Digital Health Technologies
EBCD Experience Based Co-Design
HRA Health Research Authority
JIA Juvenile Idiopathic Arthritis
NPS Net Promoter Score
NIHR National Institute for Health and Care Research
NRAS National Rheumatoid Arthritis Society
PPIE Patient and Public Involvement and Engagement
SNAC Scottish Network for Arthritis in Children
SUS System Usability Scale
TA Thematic Analysis
UK United Kingdom
UEQ User Experience Questionnaire
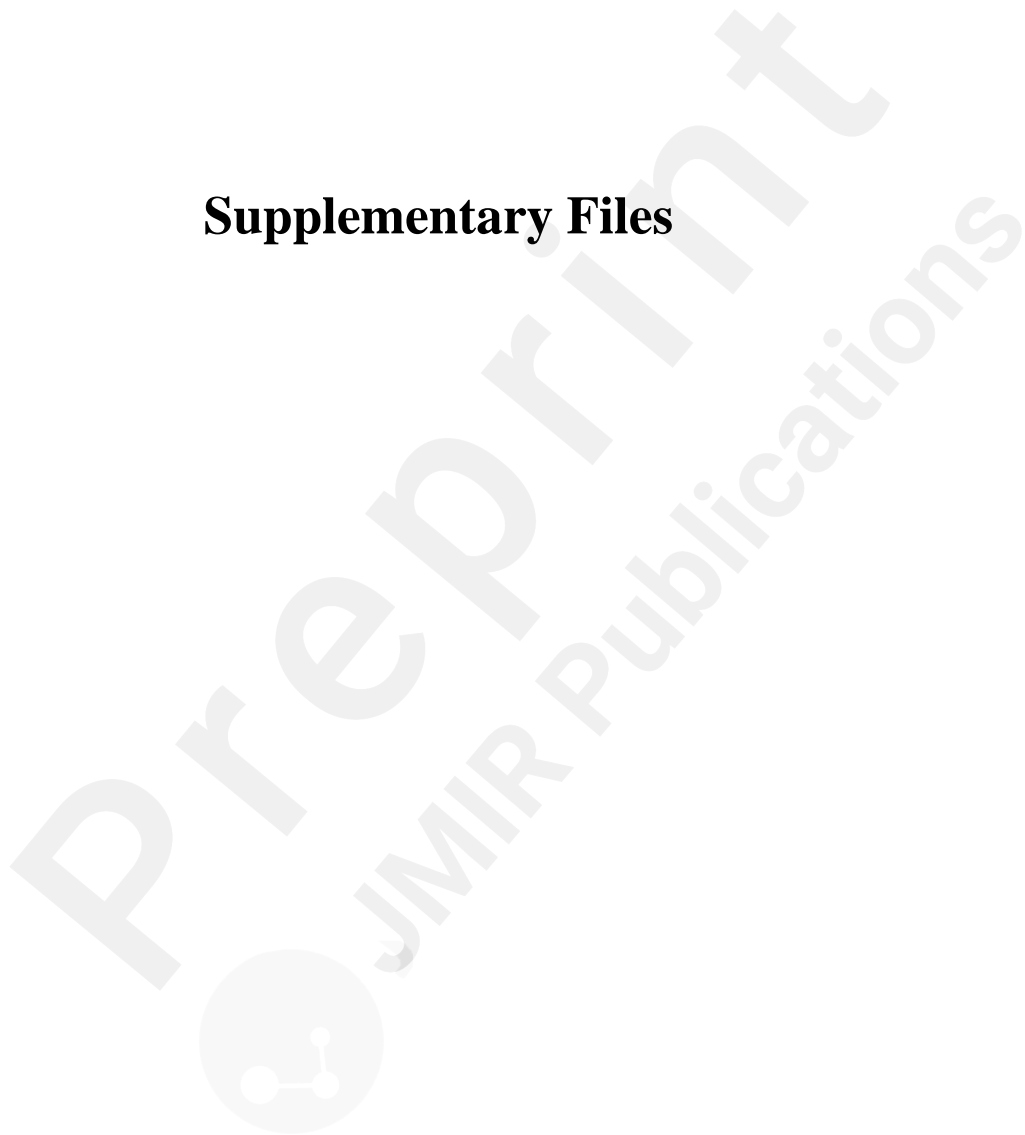**VA** Versus Arthritis

Box 1 - Six stages of EBCD

1) Project set-up 2) Staff Experiences 3) Patient/carer experience 4) Feedback and co-design 5) Co-design teams 6) Celebration event

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Supplementary Files

Multimedia Appendixes

Reviewer comments.
URL: http://asset.jmir.pub/assets/2d305d00bebf96a14f8a0b3634a59ff6.pdf