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Adoption of technology enabled care to support the management of children and teenagers in rheumatology services: a protocol for a mixed-methods systematic review

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ABSTRACT

Introduction COVID-19 catalysed a rapid move to provide care away from the hospital using online communication platforms. Technology enabled care (TEC) continues to be an important driver in progressing future healthcare services. Due to the complex and chronic nature of conditions seen within paediatric rheumatology, TEC may lead to better outcomes. Despite some growth in published literature into the adoption of TEC in paediatric rheumatology, there is limited synthesis. The aim of this review is to provide a comprehensive understanding and evaluation of the adoption of TEC by patients in paediatric rheumatology services, to establish best practices.

Methods and analysis This proposed mixed-methods systematic review will be conducted by searching a wide variety of healthcare databases, grey literature resources and associated charities and societies, for articles reported in English language. Data extraction will include population demographics, technology intervention, factors affecting adoption of intervention and consequent study outcomes. A parallel-results convergent synthesis design is planned, with independent syntheses of quantitative and qualitative data, followed by comparison of the findings of each synthesis using a narrative approach. Normalisation process theory will be used to identify, characterise and explain implementation factors. The quality of included articles will be assessed using the Mixed Methods Appraisal Tool for research papers and the Authority, Accuracy, Coverage, Objectivity, Date, Significance checklist for grey literature. Overall confidence in quality and strength of evidence will be assessed using the Confidence in the Evidence from Reviews of Qualitative Research tool.

Ethics and dissemination Ethical approval is not required due to the nature of this mixed-methods systematic review. The findings will be disseminated via a peer-reviewed journal, relevant conferences and any other methods (eg, via NHS Trust or NIHR YouTube channels) as advised by paediatric rheumatology patients.

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STRENGTHS AND LIMITATIONS OF THIS STUDY

⇒ A strength of this mixed-methods systematic review is the inclusion of a broad range of research methodologies, incorporating empirical research papers and relevant grey literature from a global perspective.
⇒ Including a previous patient as a coresearcher throughout the systematic review process will add an additional perspective and will assist in keeping the project aligned with patients' needs and priorities.
⇒ Factors affecting implementation will be identified, characterised and explained using normalisation process theory, complementing the open data coding process and strengthening awareness of implementation considerations.
⇒ Reviewed papers are anticipated to include diverse, heterogenous interventions and so meta-analysis may be limited.

INTRODUCTION

Context

Children and young people (CYP) cared for in paediatric rheumatology services experience inflammatory conditions, with up to two-thirds of CYP continuing with active disease into adulthood.[1 2] CYP experience inflammatory conditions such as juvenile idiopathic arthritis (JIA), and a range of non-inflammatory chronic musculoskeletal conditions. Consequently, CYP can have painful, stiff, swollen joints and reduced joint function, requiring continuous outpatient assessment and treatment. These chronic conditions cannot be cured and many CYP require long-term management with cytotoxic disease-modifying antirheumatic drugs. CYP with ongoing rheumatological conditions require multi-disciplinary specialist tertiary care, often necessitating long distances to travel,

affecting school attendance and parental time off work. Considering these challenges, one potential method of increasing service efficiencies and decreasing the burdensome effect for families within paediatric rheumatology may be to provide more services remotely by optimising the use of healthcare technologies.

Gap in knowledge

Although some clinical teams were providing remote services (eg, via telephone clinics) prior to COVID-19 alongside normal practice,[3] COVID-19 enforced a steep rise in remote monitoring.[4 5] During this time National Health Service (NHS) Trusts in the UK strived to reduce face-to-face appointments to 20%.[6] Furthermore, stipulations within NHS England and NHS Improvement (now NHS Impact) required healthcare providers to minimise routine visits, resulting in a rapid move to remote management with limited training for safe implementation.[7] Therefore, there has been considerable variability in technology enabled care (TEC) used to support such rapid changes,[8] with pre-COVID-19 evidence being criticised for not considering patients' and professionals' needs, or not being methodologically robust.[9]

The adoption (integration and use of a new technology in a workplace[10]) of caring for patients using TEC is likely to continue.[11] It has been argued that despite having made advances in TEC there is a risk that outpatient services may default back to traditional face-to-face appointments for *all* outpatient appointments for *all* patients, rather than capitalising on what COVID-19 taught us in terms of TEC.[12] However, there is a firm commitment in the UK, demonstrated by various governmental publications, to drive technology-based service provision.[13–16] UK national plans are outlined in the NHS Blueprint and have been built on the NHS Long Term Plan to ensure TEC is provided in a 'modern way' to retain what has been argued to be valuable adaptations to NHS services for some patients during COVID-19. Most recently the importance of exploring and implementing technological advances and treatments has been set out as a priority area for the strategic direction of travel in the UK in retaining our NHS workforce and promoting digital literacy for nurses as the largest profession within the workforce.[17 18] Furthermore, there is a drive to lead, retain and streamline healthcare technology innovations across Europe[19] and to work together globally.[20]

There has been some empirical work published describing the changing landscape of remote care. Areas of paediatric focus have been within cardiology,[21] children with complex needs[22] and palliative care.[23] Focusing on paediatric rheumatology, one survey found face-to-face consults more acceptable to parents,[24] with other findings reporting on financial cost-savings for patients but not necessarily for healthcare providers when moving to remote services using TEC.[25] Two international surveys investigating the changes in practice brought by COVID-19 found clinicians reported that patients became more accepting of using smartphones for telemedicine appointments over time and most centres surveyed in the USA (16/18) were using telemedicine for 75%–100% of visits at the height of the pandemic.[26 27]

Objectives

Although two systematic reviews have been published on the usability and effectiveness of electronic (e)-health[28] and mobile (m)-health[29] interventions for patients with juvenile idiopathic arthritis, these reviews were limited to studies only reporting on empirical research using quantitative methodologies. To our knowledge, this will be the first mixed-methods systematic review inclusive of all conditions seen within paediatric rheumatology services, all research methodologies, opinion, reviews and grey literature, into the adoption of TEC in the paediatric rheumatology setting. Our review will synthesise all types of papers and reports on the implementation factors.

Aim and research questions

The overall aim is to provide a comprehensive understanding and evaluation of key factors affecting the adoption of healthcare technologies by children and teenagers in rheumatology services by answering the following research questions:

- Are healthcare technologies being used to support TEC?
- If so, how are healthcare technologies being used within TEC?

METHODS AND ANALYSIS

Study design

A mixed-methods systematic review incorporating quantitative, qualitative, mixed methods and grey literature will be conducted. The protocol has been developed in accordance with the Preferred Reporting Items for Systematic Review and Meta-Analysis Protocols (PRISMA-P) checklist (see online supplemental material 1).[30 31] In using a parallel-results convergent synthesis design, studies reporting on quantitative and qualitative data will be analysed separately and in parallel (ie, the results of one type of methodological approach will not inform the other).[32] Findings of each synthesis will be compared using a narrative approach. See figure 1 for design process. Significant amendments to the protocol will be updated in PROSPERO and within published review findings. This review will be used to inform future work packages of a doctoral programme of study. The broad definition of 'Technology Enabled Care' has been purposefully used at this early stage to shape and focus prospective, related projects. The definition used for the completion of this review, as described by Norwegian colleagues for a systematic review into patient experiences with TEC across healthcare settings at the beginning of the COVID-19 pandemic, will be:

> Telecare, telehealth, telemedicine, mobile (m)-, digital- and electronic (e)-health services.[33] (p779)

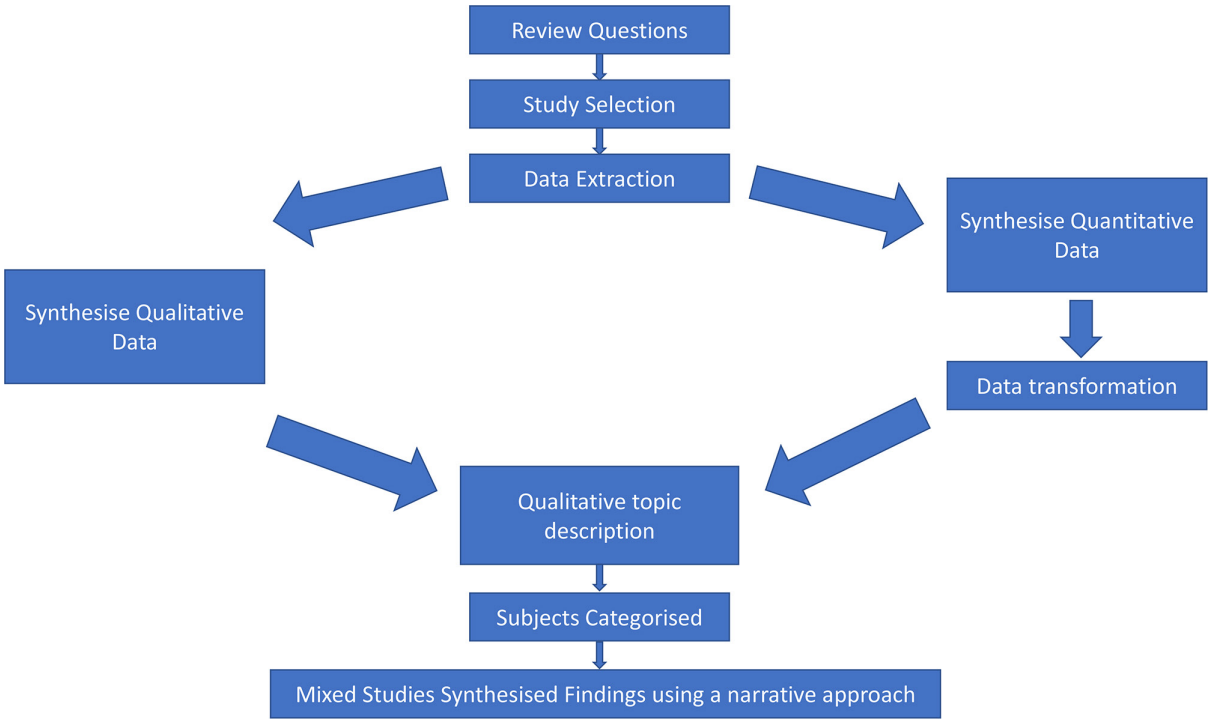

Figure 1 Review design process. Figure provides a visual overview of the proposed sequence of events in relation to this protocol paper, particularly to illustrate how the extracted data will be synthesised.

Eligibility criteria

Studies meeting all inclusion criteria will be included in the review. Inclusion criteria are presented here.

Population

To be included, studies must provide data or information related to children and teenagers aged 11–17 years inclusive, who are cared for within paediatric rheumatology services.

Intervention

All interventions need to be patient facing healthcare technologies that come under the defined TEC umbrella (definition provided by Leonardsen *et al* in the methodology section). Examples include:

- Personal digital assistants such as mobile phones or wearable devices.
- Innovative technologies being brought into the clinical environment (eg, patient-reported outcome instruments used to monitor symptoms).
- Digital technologies being used or discussed within clinical consultations (eg, digital pedometers).
- Examples of TEC interventions that would be excluded are those used by healthcare professionals only (eg, digital imaging) and those that can only be used within the physical hospital setting (eg, specialist equipment used for capillaroscopy). Articles will also be excluded if TEC refers only to the method of gathering data (eg, telephone interviews or electronic diaries used as a data capture method and not as part of the overall study aims/objectives).

Control

All eligible papers will be included regardless of whether they have a control or comparison group.

Outcomes

For inclusion into the review, study outcomes need to report on *at least one* of the main outcomes in relation to TEC:

- Health-related quality of life.
- Patient satisfaction with paediatric rheumatology services.
- Adoption of TEC in paediatric rheumatology services.

English language articles (inclusive of conference papers, abstracts, posters, theses) or those with English translation, will be included. All countries will be considered.

Search strategy

Searches were planned to find published and unpublished studies and reports in the following bibliographic databases: Medline (Ovid), Embase (Ovid), CINAHL (EbscoHost), Core Collection (Web of Science), Epistemonikos, PsycInfo (Ovid), HMIC (Ovid). The aim of including grey (unpublished) literature resources is to reduce the risk of publication bias and for inclusion of anticipated small projects or patient involvement work.[34] Although included grey literature is unlikely to be as robust as empirical research papers, the approach taken for the overall project is to be as inclusive as possible and to capture all related projects. For grey literature, the following resources will be searched: E-Theses Online

Service (EThOS), Social Care Online, Google Scholar, UK Child Health Technology Conference, NIHR Children and Young People MedTech, International Clinical Trials Registry Platform, in addition to associated paediatric rheumatology charity websites: Lupus UK, Versus Arthritis (VA), National Rheumatoid Arthritis Society, Childrens Chronic Arthritis Association, Juvenile Arthritis Research, Scottish National Arthritis for Children, Olivia's Vision, Arthur's Place, Myositis UK. Finally, the British Society of Rheumatology (BSR) and Barbara Ansell National Network for Adolescent Rheumatology will also be searched.

The searches will include index terms, synonyms and alternative phrases for the following search concepts: 'paediatric rheumatology', 'aged 11–17 years inclusive', and 'technology enabled care interventions'. See online supplemental material 2 for the search strategy.

Reference lists of eligible studies and review articles will be scrutinised and key global researchers in the field will be contacted for any clarifications as required. The search strategy is not restricted by language, year of publication or geographic location. The searching process took place from June 2023 to September 2023 and the screening of titles and abstracts during October 2023. The planned end date for the study is April 2024.

Screening and data extraction

All studies retrieved from the search will be downloaded into EndNote (https://endnote.com/) to store and organise references. Following duplicate removal, papers will be exported to Covidence online systematic review software (https://www.covidence.org/) for screening of titles and abstracts. HR will independently undertake screening of all papers (titles and abstracts). PL, BD, and AWG will independently screen a selection (approximately a third each) of the papers (titles and abstracts) to ensure that every paper has been independently screened by two authors. In the case of >20% disagreement then review criteria will be discussed between all authors and refined until the consensus threshold is reached. All papers requiring further information to assess criteria will be included.

Qualifying papers will be included for full text review. HR and PL will each independently review half of the full text papers. In cases of conflict, HR and PL will meet to discuss and in cases of uncertainty and if in disagreement, discussion will also take place with BD and AWG. Included study authors will be contacted if necessary if further clarification is required.

Covidence software will be used to undertake data extraction using a bespoke form within Covidence software. HR and one co-author will together pilot the bespoke data extraction form for the first 10% of studies and agree on data items. Thereon, HR and one co-author who is trained and experienced in extracting and coding data for systematic reviews, will complete the remaining extraction of data (50% each). Authors of individual studies will be contacted via email or ResearchGate (https://www.researchgate.net/) for further information if necessary. In cases of uncertainty around data inclusion, the wider authorship team will be consulted for further direction.

The Preferred Reporting Items for Systematic Reviews and Meta-Analyses flow diagram will be used to display the search results.[35]

Anticipated data to be extracted where available:

- Study/paper background details (author, title, journal, year of publication, data collection date, setting details).
- Population (age, gender, condition, socioeconomic status, ethnicity).
- Study aim(s) and design.
- Intervention details (type, aim of use, duration).
- Factors affecting use/adoptions of intervention.
- Outcome measures employed.
- Outcomes and main findings.

Quality assessment

The Mixed Methods Appraisal Tool (MMAT) will be used to assess risk of bias and quality for individual papers.[36] The MMAT will be effective as guidance for assessing all five types of study approaches (qualitative, quantitative randomised controlled trials, quantitative non-randomised, quantitative descriptive and mixed methods). MMAT is comprised of two parts following two screening questions used to assess whether papers are empirical work. The first part is a checklist and the second, a helpful explanation of all criteria used to inform checklist answers (part 1). Both parts are divided into five sections (ie, for each of the five study methodological approaches) and each subsection allows the reviewer to rate the paper as 'yes', 'no' or 'cannot tell' in regard to each methodological criterion. The checklist criteria will be applied to all included papers independently by two authors. Any disputes will be discussed together and with a member of the PhD supervisory team if there is no consensus.

Grey literature (ie, those papers failing the screening section within MMAT) will be assessed using the Authority, Accuracy, Coverage, Objectivity, Date, Significance (ACCODS) checklist as an evaluation and critical appraisal tool for use with grey literature.[37] ACCODS uses five criteria (Authority, Accuracy, Coverage, Objectivity, Date, Significance) for reviewers to assess the quality of grey literature. The same method will be used in terms of reviewer roles as for the MMAT.

Evidence synthesis

A parallel-results convergent synthesis design is planned, with independent syntheses of quantitative and qualitative data, followed by comparison of the findings of each synthesis using a narrative approach.[32] This narrative interpretation of the relationship between the two sets of evidence will be reported in the discussion section of the final report, with reference to the main research questions.[38] See figure 1 for an overview of the review design process.

Quantitative synthesis

For quantitative data, homogenous studies (minimum of two) reporting on comparable aspects of TEC outcomes (eg, quality of life, satisfaction with the service) will be considered for meta-analysis and standardised mean differences using the RevMan systematic review and meta-analysis tool (https://revman.cochrane.org/info). If there are insufficient comparable studies, the 'synthesis without meta-analysis' method will be used to guide the quantitative synthesis without meta-analysis.[39] Next, the synthesised data from included quantitative papers will be coded into qualitative categories in accordance with normalisation process theory prior to narrative comparison with qualitative data to report the overall review findings.[40]

Qualitative synthesis

NVivo data analysis software (https://lumivero.com/products/nvivo/) will be used to facilitate organisation and coding of qualitative data using thematic synthesis, for example, data relating to CYP's attitudes towards TEC, how technologies have changed or affected their care in rheumatology services.[41] Included data will be extracted from the results, discussion and conclusion sections of relevant articles and on which we will develop themes. Although open, inductive coding will be undertaken initially, data relating to normalisation process theory will also be collected to identify implementation issues and enablers for both qualitative data and qualitatively coded quantitative categories.[40] All coding will be undertaken on the extracted data.

Subgroup analyses

There are many different diagnoses cared for within paediatric rheumatology services, many of which are very rare. Subgroup analyses are planned for different diagnoses seen within the services as diagnosis may affect different experiences of TEC.

Examples of specific research questions include:

- Is the adoption of TEC different according to patient diagnosis?
- If so, what are these differences?
- Do demographic factors impact access to TEC (eg, socioeconomic background or ethnicity)?
- Is TEC accessible to patients who are visually impaired (eg, patients diagnosed with uveitis or cryopyrin-associated periodic syndromes) or those with hearing loss?

Subgroup analyses are also planned according to gender and country in which the original paper recruited participants from. An additional sensitivity analysis will be undertaken exclusive of studies at high risk of bias, where available data will allow.

Assessing confidence in cumulative evidence

The Confidence in the Evidence from Reviews of Qualitative Research (CERQual) tool will be used to assess confidence in qualitative evidence synthesis.[42] Using CERQual will provide a transparent and systematic assessment of qualitative evidence synthesis. HR and one co-author will independently judge on four CERQual components: methodological limitations of included studies, coherence of the review finding, adequacy of data leading to a review finding and relevance of included studies in respect to the study aims and objectives.

Patient and public involvement

Patient and public involvement (PPI) is defined as research being carried out 'with' or 'by' members of the public rather than 'to', 'about' or 'for' them.[43] Rather than being about research participants taking part in a study, PPI is about patients with relevant experience of a condition advising or working alongside researchers to influence the design, conduct or dissemination of a project. Well-conducted PPI adds unique insights from those with a lived experience of the condition under investigation, thereby improving the quality and relevance of research projects, resulting in better recruitment and retention rates.[44] PPI has been and will continue to be an important thread within the review; BD is co-author of this paper, and PPI lead for this review and for the wider PhD project. BD is a patient and young person who was diagnosed with JIA and has been cared for under paediatric rheumatology services for several years. As PPI lead for this review, BD's role has been to actively contribute to designing and reviewing the protocol by meeting with co-authors regularly to discuss and influence important decisions, for example, in defining intervention and inclusion criteria. Other aspects of BD's role will be to screen papers, meet with co-authors as required regarding any disagreements over article inclusion, and input into dissemination of results as co-author via journal and/or conference presentation. BD's involvement will ensure that the study will be employed with a patient perspective at every stage and not just the ideas and wishes of the researchers.

Additionally, on 4 May 2023, the lead author (HR) consulted with 'YourRheum': a national Young Person's Advisory Group supported by Versus Arthritis (https://yourrheum.org/). Eight YourRheum members aged 12–24 years who have lived experience of having a rheumatological condition attended. HR presented the wider PhD project and more specifically, the present protocol ideas. YourRheum members reported that they felt TEC was an important topic to research. They had strong feelings that the project, 'should not just be about JIA, as everything is always just about JIA', which led to the project being designed with all patients seen within paediatric rheumatology services in mind. Another aspect they felt was important to them, was that the project should seek to understand where and how TEC was happening. Hence, the systematic review was designed as a mixed methods protocol. Feedback was received regarding which review search terms members thought should be used and general thoughts about the wider, prospective PhD project. Beyond the present protocol, YourRheum

members will be supporting the development of survey questions, topic guides and interview questions for future related projects, to ensure the project's focus remains aligned with what matters to patients.

Protocol validity and registration

In accordance with the guidelines, our mixed-methods systematic review protocol is reported according to the PRISMA-P guidelines[30 31] and registered with the International Prospective Register of Systematic Review (PROSPERO) on 11 July 2023 and was last updated on 17 July 2023 (https://www.crd.york.ac.uk/prospero/display_record.php?ID=CRD42023443058).

ETHICS AND DISSEMINATION

This mixed-methods systematic review of academic papers and grey literature is exempt from ethical approval because there will be no direct contact with patients or participants.

A full report will be produced, and the outcome published in a leading journal in this field (eg, *BMJ Open* or *Health and Technology*). The review report will also be submitted to the British Society for Rheumatology conference and/or Paediatric Rheumatology European Society conference. Members of YourRheum will be asked for their creative ideas regarding dissemination. This protocol paper and subsequent review results are part of a wider programme of work that will combine with expert consensus to create guidelines for implementing future TEC approaches.

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Contributors HR is the PhD student, guarantor and chief investigator for the project, led PPI meetings to inform the planning and design of the review, and drafted the manuscript. JMW is an information specialist and co-led the development of the search strategy, article selection criteria and the risk of bias assessment strategy with HR. AWG contributed with HR, to the data extraction criteria, technology considerations and planning in the use of normalisation process theory. PL developed the methods for screening of articles and data synthesis. BD is a patient author and PPI lead for the project, provided a patient perspective into the planning, proposed conduct of the project, prioritisation and interpretation of technology enabled care, in writing this protocol. PL and BD provided expertise into paediatric rheumatology specific knowledge. SP and ACR guided the conception, design of the current manuscript and provided broader PhD oversight. AWG, PL, SP and ACR supervise the overall PhD programme. All authors read, provided feedback and approved the final manuscript. If the authors need to amend this protocol, they will give the date of each amendment, describe the change and give the rationale in the review findings publication. Changes will not be incorporated into the protocol. HR will be responsible for approving, documenting and implementing all amendments.

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Competing interests None declared.

Patient and public involvement Patients and/or the public were involved in the design, conduct, reporting, and dissemination plans of this paper. Refer to the Methods section for further details.

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