

STUDY PROTOCOL

# PaEdiatric Rheumatology FramEworK for Technology enabled care (PeRFekT): A protocol for a consensus study

[version 1; peer review: awaiting peer review]

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## Open Peer Review

**Approval Status** *AWAITING PEER REVIEW*

Any reports and responses or comments on the article can be found at the end of the article.

## Abstract

### Background

Children and young people (CYP) cared for in rheumatology services are largely managed in the outpatient environment. Conditions such as Juvenile Idiopathic Arthritis are usually chronic and complex in nature, necessitating input from a range of multidisciplinary healthcare professionals. Technology Enabled Care (TEC) practices in paediatric rheumatology can be varied and may have the potential to better support families and clinical teams in managing rheumatological conditions. CYP people are known to be able users of technology but evidence-driven guidance to maximise the potential for technology enabled care remains limited. Drawing on previous PhD work package findings, the aim of this current project is to develop guidance through a modified Delphi consensus exercise.

### Methods

Findings from previous PhD work packages will be synthesised into a list of statements around the concept of technology enabled care. Following assembly of a Study Advisory Group, stakeholders will be approached to undertake two online modified Delphi technique rounds. For Round 1, stakeholders will indicate their level of perceived importance using a Likert scale, for each statement. Statements not

reaching consensus will be voted on again during a second Round. Stakeholders will then vote, in order of priority, on all statements reaching consensus. Descriptive quantitative analyses will be used to describe minimal stakeholder credentials and to demonstrate >75% consensus. The top 10-20 statements will be included in the final guidance.

### **Discussion**

All project risks and benefits have been considered, minimised, and presented as part of the Research Ethics Committee (REC) application to the School of Medicine at the University of Leeds (REC project reference 2550). Project dissemination is planned for traditional routes through appropriate academic journals and paediatric specialty-specific conferences. Further dissemination will take place following ongoing collaboration with Patient and Public representatives.

### **Trial registration**

Not applicable

### **Plain Language Summary**

Children and young people (CYP) with problems such as arthritis, are mainly cared for from the outpatient department. These CYP often need to be cared for by the multidisciplinary team (MDT) Eg. nurses, doctors, and physiotherapists etc. Technology Enabled Care (TEC) with these CYP can be very different. TEC may have the potential to better support CYP, parents and the MDT to manage CYP's care better. CYP are known to be able to use technology well, but research to best guide TEC is limited. This is the final part of a PhD. It describes the use of previous results to ask stakeholders (CYP, parents, MDT healthcare professionals, and others), to vote on which results are the most important to be included in future TEC guidance.

Previous PhD findings will be brought together into a list of TEC statements. A team representing each stakeholder as described above, will come together to agree which statements should be voted on. Next, a larger number of stakeholders will be asked to vote twice against each statement. For the first time, stakeholders will vote on how important each statement is using a number scale. Statements not reaching consensus will be voted on again for a second time. Finally stakeholders will vote on the priority of each statement that has reached consensus. Statistics will describe stakeholders and show the agreed consensus. The top 10-20 statements will make up the final guidance.

All project risks and benefits have been considered, minimised, and given the go-ahead by the School of Medicine Research Ethics Committee at the University of Leeds (SoMREC 2550). The project results will be written up in scientific journals and talked about at

conferences to share with colleagues. CYP will be asked how they would like the results to be shared.

### Keywords

Delphi, consensus, paediatric, paediatric rheumatology, rheumatology, healthcare technologies, technology enabled care, digital

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## Introduction

### Paediatric rheumatology context

Children and young people (CYP) cared for in paediatric rheumatology services often experience inflammatory conditions, with up to two-thirds of these CYP remaining in adult services<sup>1,2</sup>. Other CYP experience a range of non-inflammatory musculoskeletal conditions. Consequently, CYP can have varying, chronic, painful symptoms, requiring ongoing outpatient management. Often with no cure, many CYP need long-term management with cytotoxic disease-modifying antirheumatic drugs and multi-disciplinary specialist input. CYP's management can necessitate long travel distances and lead to reduced school and work attendance. One potential method of increasing service efficiencies and decreasing the burden for families within paediatric rheumatology may be to provide more services using technology enabled care (TEC).

### Effects of Covid-19 on Technology Enabled Care (TEC)

Although some clinical teams were providing TEC Eg. remote services prior to COVID-19<sup>3</sup>, the pandemic forced a steep rise in using TEC for remote management<sup>4,5</sup>. National Health Service (NHS) Trusts in the UK strived to reduce face-to-face appointments to 20%<sup>6</sup>. Furthermore, stipulations within NHS England required healthcare providers to minimise routine visits, resulting in a rapid move to remote management with limited training for safe implementation using TEC<sup>7</sup>. Therefore, there has been considerable variability in TEC to support such rapid changes<sup>8</sup>.

### Learning from Covid-19 and continuation of Technology Enabled Care

There is a firm commitment in the UK to drive TEC<sup>9-12</sup>. UK national plans are outlined in the NHS Blueprint and built into the NHS Long Term Plan to ensure TEC is provided in a 'modern way' to retain what is argued to be valuable adaptations to NHS services for some patients during COVID-19. A change in UK government in 2024 continued to highlight the need for change in the NHS, by launching a 'rallying cry' for members of the public and NHS staff to share thoughts about the future of the NHS. This exercise was underpinned by three big shifts, of which 'analogue to digital' was one<sup>13</sup>, and was incorporated into the 10-year Health Plan for England<sup>14</sup>. Furthermore, an independent investigation of the NHS found that while there is great potential for TEC to transform NHS services, there is much more work to do to realise its full potential<sup>13</sup>. As highlighted by the NHS Federated Data Platform, there has been minimal change over the last two decades, specifically with CYP and how their care is co-managed with parents<sup>15</sup>. Looking further afield, there is a drive to lead, retain and streamline healthcare technology innovations across Europe<sup>16</sup> and to work together globally<sup>17</sup>.

### Potential for Technology Enabled Care in child health

CYP are known to be avid, proficient users of all things technology-related, seen by the increased use of smartphone technologies<sup>18</sup>. Examples of TEC in action may include wearable technologies, e-patient reported outcome questionnaires, web-based tools for peer support, or the use of various online

applications for provision of virtual clinics and medication reminders<sup>19</sup>. With these considerations in mind, it would therefore seem logical that TEC should be used routinely to support CYP, by empowering them to use their technological skills to develop self-management skills and to support their care decisions<sup>20</sup>. For the purposes of this study, Technology Enabled Care is used as a collective term and is defined here by Norwegian colleagues:

“Telecare, telehealth, telemedicine, mobile (m)-, digital- and electronic (e) health services<sup>21</sup>.”

There has been some empirical work published describing the changing landscape of TEC with CYP in cardiology<sup>22</sup>, those with complex needs<sup>23</sup>, and palliative care<sup>24</sup>. Focusing on paediatric rheumatology, one survey found face-to-face consultations more acceptable to parents<sup>25</sup>, with other findings reporting on financial cost-savings for patients but not necessarily for healthcare providers when using TEC for remote services<sup>26</sup>. Two systematic reviews have been published on the usability and effectiveness of electronic (e)-health<sup>27</sup> and mobile (m)-health<sup>28</sup> interventions for patients with juvenile idiopathic arthritis; these reviews were limited to studies only reporting on empirical research using quantitative methodologies.

### Previous PhD work packages

This protocol paper sets out the process for a consensus study, linked to a wider PhD-related project (PeRFekT study), where the overall focus is on providing evidence-based guidance for TEC in paediatric rheumatology. This present protocol is intended to fulfil the final work package of the wider PhD programme. Previous work packages entailed the following:

- WP1 – a mixed methods systematic review (PROSPERO number: CRD42023443058; published protocol: <https://bmjopen.bmj.com/content/14/2/e082515>)<sup>29</sup>.

Aim: To provide a comprehensive understanding and evaluation of the adoption of TEC by patients in paediatric rheumatology services, to establish best practices.

Status: Completed

- WP2 – an e-survey with industry partners.

Aim: To explore innovative technologies being developed for CYP's healthcare to support TEC across the UK.

Status: Completed

- WP3 – a mixed methods study with rheumatology healthcare professionals, CYP and parents.

Aim: To investigate what Technology Enabled Care practices are taking place and how Technology Enabled Care can be used to support and improve the management of Children and Young People across UK paediatric rheumatology departments.

Status: Analysis almost complete

**What this study will bring**

This consensus study will bring together all previous work package findings, from which the consensus statements are currently being generated. The project is based upon the results of a large mixed methods systematic review. Although included papers in the review did not provide the opportunity to undertake a full quantitative analysis due to a lack of randomised controlled trials, a full narrative analysis has been performed inclusive of all types of paper. Furthermore, WP2 and 3 provide further robust evidence in generating consensus statements. Rather than relying solely on the literature, patients, parents, healthcare professionals or the lead author, this study will incorporate the views of a wide range of invested stakeholders for consensus input into a guidance framework.

The process to be used will follow similar principles to a recent clinical consensus format<sup>30</sup>. The current, consensus project aim, is to agree upon, by multi stakeholder consensus, the strongest 10–20 Technology Enabled Care statements for inclusion into the final framework for use as guidance in paediatric rheumatology services.

**Normalisation Process Theory (NPT)**

This study is the 4th and final PhD work package, and NPT has been used throughout. NPT is a middle-range, evidence-based, consistent framework used to explain implementation factors when considering the late stage of adoption of innovations in healthcare<sup>31</sup>. As part of the wider programme of work the statements will be mapped to NPT.

**Methods and analysis**

**Aim**

The current, consensus project aim, is to agree upon, by multi stakeholder consensus, the strongest 10–20 Technology Enabled Care statements for inclusion into the final framework for use as guidance in paediatric rheumatology services.

**Study design**

The study design takes a consensus-based approach, by undertaking an online modified Delphi study, with various stakeholders.

**Setting and sample**

**Characteristics of participants**

**Healthcare Professionals:**

Healthcare Professionals from the multidisciplinary team in paediatric rheumatology departments (including but not limited to: Clinical Nurse Specialists, Consultants, Registrars, Youth Workers, Research Nurses, Psychologists and Allied Healthcare Professionals).

**Families:**

CYP aged 11–17 years cared for within acute paediatric rheumatology services and their parents.

**Other Stakeholders:**

A range of other stakeholders: NHS Commissioners and Business Managers (working within general paediatric or paediatric

rheumatology services), charity workers and industry partners (working in the health tech or digital health space).

Previous Delphi studies have reported varying sample sizes from less than 20 and up to 80+<sup>32,33</sup>, often based on sparse robust evidence and dependent perhaps upon diversity of participants and the project undertaken<sup>34</sup>. Due to the lack of standardised approach, no formal sample size has been calculated. Drawing on previous PhD work packages and speaking with participants, as well as available literature, 16 participants from each of the above stakeholder groups (total 64) are anticipated to be recruited to allow for drop out between Rounds and to answer the research question.

**Eligibility criteria**

**Inclusion criteria**

**Healthcare Professionals:**

Multidisciplinary Team staff members who support the care of Children and Young People aged 11 – 17 years of age in paediatric rheumatology services in the UK.

**CYP and their parents/guardians:**

CYP aged 11 – 17 years inclusive who are cared for (regardless of diagnosis and length of time from diagnosis) in paediatric rheumatology services in the UK.

**Other stakeholders:**

NHS Commissioners and Business Managers, charity workers and industry partners.

All participants having the ability to read and understand the English language.

**Exclusion criteria**

There are no specific exclusion criteria, other than not being able to meet the above inclusion criteria.

**Recruitment**

Healthcare Professionals, CYP, parents/guardians and other stakeholders either taking part in the earlier stages of the PhD project or who have offered contact details to take part in further work, will be invited to take part during previous study interactions with the lead author. HCP participants will also be approached via national paediatric rheumatology professional groups, namely: Clinical Nurse Specialists, Clinical Psychology Network, Trainee Network, Allied Health Professionals Network, and the Barbara Ansell National Network for Adolescent Rheumatology (BANNAR). Recruitment materials will be sent to professionals (Eg. commissioners) to share across their networks.

Social media (X – formerly Twitter, Facebook and LinkedIn) will be used to maximise awareness, with the study link to the Participant Information Sheet and Consent Statement being made available via the study link. CYP in the Patient and Public Involvement group ‘Your Rheum’<sup>35</sup> will be approached by the group’s coordinator. Three charities have agreed to share the study on their social media channels +/- approach via official

charity emails (Children’s Chronic Arthritis Association – CCAA<sup>36</sup>, National Rheumatoid Arthritis Society – NRAS<sup>37</sup>, and Lupus UK<sup>38</sup>).

A purposive sampling approach<sup>39</sup> will be used to target a range of participants Eg. in terms of professional background, age of CYP, CYP diagnosis, location and whether participants have taken part in previous PhD work packages (a mixture of both

will be targeted). Please see Table 1–Table 4 for the Sampling Frameworks.

**Consent**

All potential participants will first be asked to assess their eligibility within Online Surveys (a web-based platform to distribute electronic questionnaires). Next, study documents will include a participant-specific Participant Information

**Table 1. Sampling Framework for 16 Healthcare Professionals.**

Main sampling Category			
1. Role: MDT	Doctor	Nurse	Other
2. Gender	Female	Male	Other
3. Centre type	Tertiary	District General Hospital	
4. Ethnicity	White	Ethnic minority background	
5. Participated in previous PhD work package	Yes	No	

**Table 2. Sampling Framework for 16 Children and Young People.**

Main sampling Category			
1. Gender	Female	Male	Other
2. Age	<13 years	14–15 years	16–17 years
3. Travel distance	<10 miles (<1/2 hour)	10–29 miles (1/2 hour – 1 hour)	>30 miles (>1 hour)
4. Ethnicity	White	Ethnic minority background	
5. Centre type	Tertiary	District General	
6. Exposure to TEC	Undertaken virtual clinic	Not undertaken virtual clinic	
7. Participated in previous PhD work package	Yes	No	

**Table 3. Sampling Framework for 16 Parents.**

Main sampling Category			
1. Gender	Female	Male	Other
2. Ethnicity	White	Ethnic minority background	
3. Participated in previous PhD work package	Yes	No	

**Table 4. Sampling Framework for 16 ‘other’ Stakeholders.**

Main sampling Category			
1. Professional background	Business Manager	Healthcare tech industry partner	Commissioner
2. Participated in previous PhD work packages	Yes	No	

Sheet (PIS) and a Consent Statement (CS) and will be available within Online Surveys for all participants to read. Once the PIS and CS have been read, participants will enter their name and date, indicating their informed, digital consent to take part and providing contact details for the lead author to follow up with them. The lead author's contact details will be provided within the study documents if any participants would like to discuss the study directly with a member of the research team.

All CYP aged 16 years and over will provide informed consent for themselves following the above method and using separate PIS's and CS's. Parents of CYP less than 16 years will provide consent on behalf of their child following the above method and using separate PIS's and CS's. As is best practice, CYP less than 16 years will also be required to provide assent, or their agreement to take part, again following the above method and using separate PIS's and CS's.

If electronic consent +/- assent is difficult for a participant or would result in them being excluded in taking part, then every effort will be made to accommodate individual requirements (Eg. by collecting a wet ink signature via paid postage of the appropriate documents).

All consent discussions, recruitment etc will be carried out according to Good Clinical Practice principles. CYP and parents taking part in the study will be provided with a £20 voucher per completion of each of the online modified Delphi rounds (£40 total) to thank them for their time and providing their perspectives. CYP will also receive a certificate.

The Study Advisory Group and Participant Flow chart are included as [Figure number 1](#).

### Data collection

Data collection will take place using an online modified Delphi technique<sup>40</sup>. The format of the Delphi Rounds will follow a similar method used recently by the Study Advisory Group's methodologist, Adam Galloway (AG)<sup>30</sup>.

### Study Advisory Group

A Study advisory group (SAG) has been convened, consisting of the lead author, the academic supervisory team, 2 PPI representatives (1 young person and 1 parent) and an experienced appropriate methodologist (AG). The SAG will meet to organise and streamline all TEC implementation factors and previous PhD work package findings prior to undertaking the consensus exercise. The streamlined statements/factors will be piloted on Online Surveys to check accessibility and formatting.

The SAG will meet again following Round 1 of the online modified Delphi exercise (see below) to discuss the outcomes of Round 1, incorporate any additional comments (by agreement with the SAG), and plan for Round 2.

Subsequent SAG meeting(s) will remain flexible and essentially used for discussion and agreement regarding any outliers or cases of uncertainty.

### Study introduction video

All participants will be asked to view a short (10–15 mins) recorded introduction video made by the lead author. The video will introduce all previous related work to date and explain what is expected from participants during the online modified Delphi rounds and prioritisation ratings undertaken via email.

### Online modified Delphi rounds

There will be 2 Rounds of online modified Delphi consensus exercises for all recruited and consented participants. Both Rounds will be conducted using Online Surveys. Round 1 is planned to take place during November/December 2025 and Round 2 at the start of 2026.

#### Round 1 Online modified Delphi consensus exercise

All participants will be asked to undertake an online consensus exercise. All streamlined statements agreed by the SAG will be listed within Online Surveys and participants will indicate their level of perceived importance using a 5-point Likert scale (1=very important – 5=very unimportant). A free text space will be available for each statement to suggest new statements/clarification. All statements reaching >75% level of consensus will be removed prior to Round 2 to reduce the burden on participants during Round 2. The exercise will remain open online for up to a month afterwards for pragmatic reasons, to give more opportunity for participants to complete it on their own.

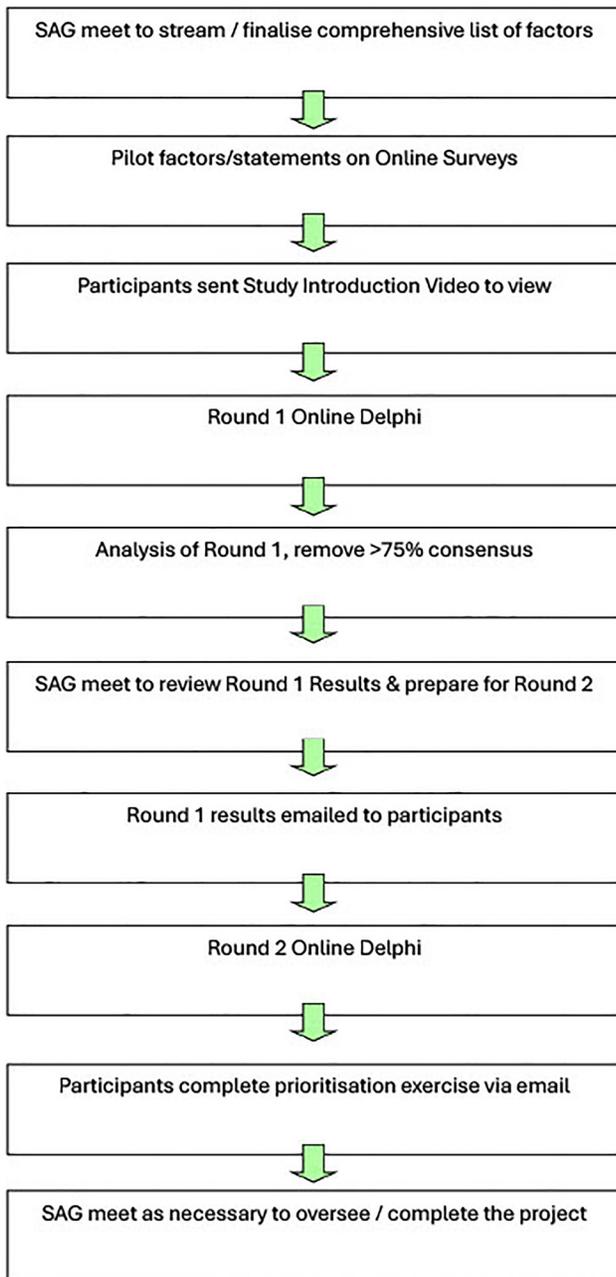
#### Round 2 Online modified Delphi consensus exercise

All participants will be sent a summary of the Round 1 results prior to the Round 2 exercise. Only those statements not meeting consensus, plus any new considerations suggested by participants from Round 1, will be included in Round 2. There will be no free text options during Round 2 and the same Likert scale (1–5) will be used again. Otherwise, the exercise will follow the same format as Round 1.

All factors rated as 'Important' or 'Very important' by at least 75% of all respondents in Round 1 & Round 2 will be included in a prioritisation exercise.

### Prioritisation

Ten to twenty statements are planned to be included in the final framework. Regardless of how many statements meet the >75% inclusion threshold, all participants will be asked to complete a prioritisation exercise. The exercise will indicate priority to implement statements into practice, based on importance, level of agreement, and perceived priority. The prioritisation exercise will be completed via email after Round 2. The top 10–20 prioritised statements will be included in the final framework guidance. The timescale for completing the prioritisation exercise is January 2026.



**Figure Number 1.** Study advisory group and participant flow chart.

**Data analysis**

**Data analysis**

Free text responses offered during Round 1 of the online modified Delphi exercise will be analysed using content analysis<sup>41</sup> and added to the comprehensive list of statements (if agreed by the SAG) either as a new statement in its own right or as a sub-factor within a broader theme.

Quantitative analysis will be used to describe minimal non-identifiable participant details and for Round 1 to report the

level of consensus, to remove those factors >75% consensus from the Round 2 exercise. Quantitative analysis will then be used for Round 2 to identify >75% consensus, then all those factors reaching >75% consensus from both Round 1 and Round 2 will be included for the prioritisation exercise, again using quantitative analysis.

**Normalisation Process Theory**

As alluded to in the introduction, NPT is a sociological theory that can be used flexibly to explain implementation factors when integrating innovative interventions into healthcare settings<sup>31</sup>. It provides a framework as a tool using the domains ‘Coherence (understanding), Cognitive Participation (relational work that builds a community of practice around an intervention), Collective Action (operational work that people need to do to make an intervention successful), and Reflexive Monitoring (appraisal work). NPT also considers the context of implementation and outcomes.

**Patient and Public Involvement**

Patients and the public have been involved with the PhD at numerous stages, including overall design, data collection, and previous publication<sup>29</sup>. For this specific sub-project, eligible PPI contributors will be invited to take part as participants in order for their views and opinions to be taken into account when providing guidance on TEC.

**Dates of study**

Study design and concept April 2024-January 2025; REC approval received April 2025; Participant approaches and consents received from June 2025 (ongoing); Data collection planned from October-February 2025/26; Data analysis planned for February 2026; Dissemination planned for submission March 2026.

**Discussion**

**Strengths and limitations of this study**

- The range of different participants, inclusive of patients and parents, is viewed as a strength of the study
- Consensus statements are based upon comprehensive evidence-based PhD project findings
- Involvement of patients and the public throughout the project and earlier PhD findings has increased relevancy of the outcomes
- Consensus is limited at the outset to two adapted Delphi rounds to incorporate a pragmatic approach, which may be seen as a study limitation

**List of abbreviations**

BANNAR: Barbara Ansell National Network for Adolescent Rheumatology

CCAA: Children’s Chronic Arthritis Association

CS: Consent Statement

CYP: Children and Young People

PeRFekT: PaEdiatric Rheumatology FramEworK for Technology enabled care

PIS: Participant Information Sheet

PPI: Patient and Public Involvement

NHS: National Health Service

NPT: Normalisation Process Theory

NRAS: National Rheumatoid Arthritis Society

REC: Research Ethics Committee

SAG: Study Advisory Group

TEC: Technology Enabled Care

WP: Work Package

## Declarations

### Ethics approval and consent to participate

This consensus project has received ethical approval from the University of Leeds (School of Medicine ethical approval number 2550), with full consideration of ethical and safety implications outlined within the REC application. All participants will provide digitally recorded consent to take part. A full

outcome report will be produced and published in a leading journal in this field. The review report will also be submitted to the British Society for Rheumatology conference and/or Paediatric Rheumatology European Society conference. Members of Your Rheum and Barbara Ansell National Network for Adolescent Rheumatology (BANNAR) will be invited to share their creative dissemination ideas. This consensus paper and overall PhD results are part of a wider programme of work aiming to create guidelines for implementing future TEC approaches.

## Consent for publication

Not applicable.

## Data availability

Repository name: Figshare

Persistent Identifier: <https://www.doi.org/10.6084/m9.figshare.30862478>

Description: The dataset contains all Participant Information Sheets and Consent Statements for the project

Licence: Creative Commons Attribution 4.0 International (CC-BY 4.0)

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