This protocol has regard for the HRA guidance and order of content.

Exploring perspectives on Palliative and Supportive Care, to inform recommendations to help people live well with inflammatory arthritis throughout the disease course (ENRICH)

SHORT STUDY TITLE / ACRONYM Palliative and Supportive Care to help people with arthritis to live well (ENRICH)

PROTOCOL VERSION NUMBER Version 2.0
DATE 17th December 2025

RESEARCH REFERENCE NUMBERS

IRAS Number: 348144
SPONSORS Number: Dorothy House Hospice
FUNDERS Number: Arthritis UK 23281

SIGNATURE PAGE

The undersigned confirm that the following protocol has been agreed and accepted and that the Chief Investigator agrees to conduct the study in compliance with the approved protocol and will adhere to the principles outlined in the Declaration of Helsinki, the Sponsor's SOPs, and other regulatory requirement.

I agree to ensure that the confidential information contained in this document will not be used for any other purpose other than the evaluation or conduct of the investigation without the prior written consent of the Sponsor

I also confirm that I will make the findings of the study publicly available through publication or other dissemination tools without any unnecessary delay and that an honest accurate and transparent account of the study will be given; and that any discrepancies from the study as planned in this protocol will be explained.

For and on behalf of the Study Sponsor:

Signature: Date: 20th November 2025

.....

Name (please print): Wayne de Leeuw

Position: Chief Executive

Chief Investigator:

Signature:  Date: 19th November 2025

.....

Name: (please print): Professor Candy McCabe

LIST of CONTENTS

KEY STUDY CONTACTS

Chief Investigator	Professor Candy McCabe, Head of Education & Research, Dorothy House Hospice Care. Email: candy.mccabe@dorothyhouse-hospice.org.uk Phone: 01225 722988
Study Co-ordinator	Dr Sharon Grieve, Research Development and Delivery Lead Email: sharon.grieve@dorothyhouse-hospice.org.uk Phone: 01225 722988
Sponsor	Dorothy House Hospice Care, Winsley, Bradford on Avon, BA15 2LE Email: info@dorothyhouse-hospice.org.uk Phone: 01225 722988
Joint sponsor(s)/cosponsor(s)	None
Funder(s)	Arthritis UK Grant no. 23281
Key Protocol Contributors	Dr Sharon Grieve, Dorothy House Hospice, Winsley, Bradford on Avon, BA15 2LE, sharon.grieve@dorothyhouse-hospice.org.uk Professor Candy McCabe, Dorothy House Hospice, Winsley, Bradford on Avon, BA15 2LE, Candy.McCabe@dorothyhouse-hospice.org.uk Dr Alison Llewellyn University of the West of England Bristol Blackberry Road, Bristol, BS16 1DD Alison.Llewellyn@uwe.ac.uk Dr Mwidimi Ndosi University of the West of England Bristol Blackberry Road, Bristol, BS16 1DD Mwidimi.Ndosi@uwe.ac.uk

STUDY SUMMARY

Study Title	Exploring perspectives on Palliative and Supportive Care, to inform recommendations to help people live well with inflammatory arthritis throughout the disease course.
Internal ref. no. (or short title)	ENRICH
Study Design	Qualitative and quantitative
Study Participants	• People living with inflammatory arthritis • Healthcare practitioners working in Rheumatology, Palliative and End of Life Care (PEoLC), Primary Care and Community (GPs, district nurses, community therapists) • Representatives from relevant charities and organisations • Commissioners of health and social care services
Planned Size of Sample (if applicable)	Work-package 1: 15-30 participant interviews Work-package 2: minimum of 50 survey responses from healthcare practitioners.
Follow up duration (if applicable)	N/A
Planned Study Period	20 months

FUNDING AND SUPPORT IN KIND

FUNDER(S) (Names and contact details of ALL organisations providing funding and/or support in kind for this study)	**FINANCIAL AND NON FINANCIALSUPPORT GIVEN**
Arthritis UK	Financial support for the costs of conducting this project.

ROLE OF STUDY SPONSOR AND FUNDER

The sponsor, Dorothy House Hospice, has overall responsibility for the initiation and management of the study. This includes the development of the study design, conduct, data analysis and interpretation, any manuscript(s) and other dissemination arising, and any decisions regarding any of these aspects of the study.

The Funder's terms and conditions-please see Arthritis UK Contracts and Terms and Conditions

ROLES AND RESPONSIBILITIES OF STUDY MANAGEMENT COMMITEES/GROUPS & INDIVIDUALS

Prior to commencement of recruitment to the study, and beyond any required HRA/NHS ethical approvals, governance approvals will be required from the Bath Swindon and Wiltshire (BSW) Research Hub, Dorothy House Research Committee, Dorothy House Clinical Governance Committee and Dorothy House Chief Executive Officer.

Whilst some members of the study team sit on the Dorothy House Research Committee and the BSW Research Hub Executive, governance approvals will remain independent of the team members involved in the study.

The study team comprises patient and public representation and representatives from across the five collaborating organisations (Dorothy House Hospice; Royal United Hospitals NHS Foundation Trust; University of the West of England; University Hospitals Bristol and Weston NHS Foundation Trust; Elm Tree Surgery, Shrivenham).

Dorothy House regularly engages with Patient and Public Contributors via the Hospice User Group (HUG). The Research Committee also includes a lay member. We will include two patient and public contributors in the study team to provide ongoing input to the conduct of the study and to analysis, reporting and dissemination activities.

A Steering Committee will be formed and include patient and public representation, a methodologist relevant to the project design, and healthcare representation from Palliative and End of Life care, Rheumatology and Primary care.

PROTOCOL CONTRIBUTORS

Professor Candy McCabe, Head of Education and Research, Dorothy House Hospice, Winsley, Bradford on Avon, BA15 2LE

Dr Sharon Grieve, Research Development and Delivery Lead, Dorothy House Hospice, Winsley, Bradford on Avon, BA15 2LE

Dr Alison Llewellyn, Associate Professor - Clinical Research. University of the West of England, Blackberry Road, Bristol, BS16 1DD

Dr Mwidimi Ndosi, Associate Professor in Rheumatology Nursing, University of the West of England, Blackberry Road, Bristol, BS16 1DD

KEY WORDS: Inflammatory arthritis; palliative care; end of life care; supportive care

STUDY TIMELINE

The study described below will run from January 2026-April 2027. Please see Gantt chart for details (Appendix 1)

STUDY PROTOCOL

Exploring perspectives on Palliative and Supportive Care, to inform recommendations to help people live well with inflammatory arthritis throughout the disease course.

1 BACKGROUND & RATIONALE

Palliative Care helps people with life-limiting illnesses live as well as possible. It focuses on improving quality of life, not just for patients, but also for their families. This care looks at the whole person, including physical comfort, emotional wellbeing, and spiritual needs.[1,2] Palliative care is about helping people live fully, even as they approach the end of life.[2] It is delivered by a multi-disciplinary team of healthcare professionals across many settings like hospitals, care homes, hospices, and a person's home.

The recently updated NHS England Ambitions for Palliative and End of Life Care Framework specifies high quality palliative and end of life care should be available to anyone with a life limiting illnesses, regardless of their diagnosis.[3] Despite this, it is most commonly offered to people with cancer, heart disease, lung conditions, and AIDS. Inequalities of access are known to exist particularly for people with non-malignant conditions.[4-7] This is especially true for those with multiple long-term illnesses, including those with an Inflammatory Arthritis such as: rheumatoid arthritis (RA), psoriatic arthritis (PsA), juvenile idiopathic arthritis (JIA), or axial spondyloarthritis (axSpA). The high incidence of rheumatic and musculoskeletal diseases,[8] and associated chronic pain, mean these conditions often comprise one or more of the multimorbidity conditions an individual may be living with.

Palliative care can begin as soon as someone is diagnosed with a life-limiting illness, and some hospices provide care from the last 1,000 days of life,[9] but in cancer care, for example, a broader approach called Palliative and Supportive Care (PSC) is now used, with 'Supportive Care' being provided much earlier in a person's disease course.[10]

Palliative and Supportive Care

PSC aims to support people and those close to them throughout the illness, meeting a wide range of needs: physical, emotional, social, spiritual, and cultural.[11] Recent research has recommended a more inclusive definition of PSC, which would apply to anyone with a serious or chronic illness, and not just people with a cancer diagnosis.[11] For example, PSC is now widely adopted in non-cancer conditions, such as cardiac, renal, and neurological diseases. Starting PSC early has been shown to improve quality of life, extend survival, and reduce the need for aggressive treatments at the end of life.[12-14] This approach could also help people with inflammatory arthritis live better, more comfortable lives.

Inflammatory Arthritis

These conditions can cause long-term pain, stiffness, fatigue, and disability.[15] They may also affect other parts of the body, like the lungs, skin, eyes, and bowel.[16-19] These secondary complications, and the side effects of medications used to help

slow the progression of the disease or improve symptoms, can shorten life expectancy, for example, people with Rheumatoid Arthritis and associated lung disease may live only 3–7 years after diagnosis.[20,21] Fatigue, depression, and anxiety are common and can deeply affect daily life, work, and relationships.[22,23,24] Managing medications and unpredictable flare-ups of the condition adds to the emotional strain.[25] Having a chronic inflammatory condition treated with glucocorticoids, immunosuppressants and biological medications can also increase the risk of secondary co-morbidities including cardiovascular disease, diabetes, hypertension, risk of infections and malignancies.[26-28]

Experts suggest that even outside of end-of-life care, people with arthritis could benefit from support that combines Rheumatology and Palliative Care.[29] However, current guidelines for healthcare professionals does not include arthritis when helping doctors identify who might need end-of-life care.[30] No guidelines currently exist for Palliative Care teams on how to support people with arthritis, which can leave patients feeling their arthritis is overlooked or misunderstood.

Inflammatory arthritis and the potential need for palliative and supportive care. care.

In preparation for this study, we conducted focus groups with people living with an inflammatory arthritis, all of whom had experience of palliative and end of life care through their life experiences (n=11). They told us they often do not mention arthritis symptoms when receiving palliative and end of life care in a hospice setting, because they assume healthcare professionals already understand the impact of their arthritis, or they are used to living with the pain and believe it is more important to tell hospice staff about the pain related to their palliative diagnosis. Palliative care professionals confirmed this, saying their focus tends to be on the most life-threatening condition. Furthermore, they described having limited knowledge about inflammatory arthritis and its impact on the individual.

In conversations with people living with inflammatory arthritis, many said they had faced moments when extra help would have made a big difference. When they learnt more about PSC, they thought this type of care would be of significant help to them. One woman described how her arthritis symptoms were so severe early on in her diagnosis that her children had to help her with basic tasks like dressing and eating. Focus group participants also spoke about future challenges they might face, especially near the end of life. They worried about pain from being unable to move, side effects from medications, and wanted to have conversations in advance about treatment options and comfort care.

Rheumatologists and palliative care teams told us they had limited knowledge about each other's specialities, which could lead to uncertainty about the optimum care for people with an inflammatory arthritis towards the end of life. For example, should arthritis medications be stopped or continued near the end of life? When should conversations about end-of-life care begin in Rheumatology practice? Despite these challenges, rheumatology and palliative care have a similar approach to care, that it is holistic, person centred and aimed at maximising quality of life. Rheumatology and Palliative Care healthcare professionals told us our work could encourage closer working between the two Specialities, as well as improve care for those with inflammatory arthritis. For example, "there's a lot of overlap of those symptoms (pain, breathlessness), and sometimes we might be treating things we know well rather

than looking a bit wider to the things we don't know so well" (Palliative Care Clinician).
General Practitioners and Community healthcare professionals told us it was important for us to also include them in our work as they care for many people towards the end of life. They would welcome guidance on inflammatory arthritis and PSC, especially on the management of medications.

Current evidence
We conducted a rapid literature review at the outset of this study (parameters: English language; 2014-present; 'arthritis'; 'spondylitis'; 'ankylosing'; 'ankylosing spondylitis'; 'Palliative Care') looking for any study design that described the interaction between Rheumatology and Palliative Care, patient and/or health care professionals' perspectives on potential Palliative Care need. Only three relevant papers were identified.[29,31,32] One was an opinion piece[32] and two explored routine clinical data,[29,31] which demonstrated symptoms in rheumatology patients that could be met by palliative care services. No qualitative research was identified, and nothing that described the patients' or healthcare professionals' perspectives in either Speciality. Of note, in 2008, the dearth of literature in this area was highlighted in the Journal of Palliative Care with the authors concluding that rheumatologists, palliative and primary care physicians should become more aware of patients with rheumatic diseases to offer them the care they need.[33]

Focus and study population
As described, we have consulted widely with people with inflammatory arthritis, rheumatology, palliative care, primary and community healthcare professionals. They confirmed this is an important topic to investigate. They encouraged us to explore the potential value of Supportive Care, in addition to Palliative Care, as although not widely available outside of cancer services, the similarities in personal health and emotional challenges for Rheumatology patients may mean it is highly appropriate.
This study focuses on four common types of inflammatory arthritis:
- Rheumatoid Arthritis (RA)
- Psoriatic Arthritis (PsA)
- Juvenile Idiopathic Arthritis (JIA)
- Axial Spondyloarthritis (axSpa)

These conditions often involve similar symptoms, treatments, and related health issues. While there are other rare, life-threatening rheumatic diseases,[34-37] this study concentrates on the more common ones to better understand how Supportive and Palliative Care could help throughout a person's life.

2 THEORETICAL FRAMEWORK

This project comprises three discrete and iterative work-packages (WP). Qualitative methods have been selected for work-package 1 (WP1) which explores with people living with an inflammatory arthritis, what their understanding and perspectives are of PSC, and how PSC may support them to live well. Semi-structured interviews are the optimal method to explore a topic where little prior knowledge exists, and in the context of the lived experience.[38] Semi-structured interviews allow for core topics to be raised for discussion but give scope for participants to raise unanticipated issues; the use of a topic guide facilitates the discussion but the precise wording and order of questions is contextual and responsive to the participant's account.[38]

Work-package 2 (WP2) aims to explore (1) Rheumatology, General Practice and Community healthcare professionals' (HCP) views on PSC, and (2) Palliative Care HCPs' views on Inflammatory Arthritis and Supportive Care, how they currently collaborate, and how PSC may help people with Inflammatory arthritis to live well. As this work seeks to capture a large volume of data from a range of different populations at a single time point, then a survey format is appropriate. The majority of the survey data will be quantitative to ensure forced choice responses for clarity of data, and ease of data analysis.

The final work-package (WP3) will take a qualitative approach as it aims to explore the views of stakeholders, where no prior expectations have been set. Focus groups provide an opportunity for exploration of a topic, facilitated by a topic guide, to elicit the range of opinions and recommendations within the group. They can also enable group consensus on a topic where this is required[39].

3 STUDY AIMS, OBJECTIVES, RESEARCH QUESTIONS & OUTCOMES

3.1 Aims:

- To explore the potential role of PSC for people with inflammatory arthritis.
- Describe any unmet patient need.
- Develop clinical and research recommendations to help people with inflammatory arthritis to live well over the course of their disease.

3.2 Objectives

- Create 3 short videos for use within our WPs, to aid understanding and ensure consistent messaging in our project.
- Conduct semi-structured online or telephone interviews with people living with an inflammatory arthritis to understand their views of PSC, and how PSC may support them to live well throughout the course of their disease (WP1).
- Conduct an e-survey with healthcare professionals working in Rheumatology, Palliative Care, Primary Care and Community services to determine current provision of PSC for people with inflammatory arthritis and understand views about the potential value of PSC support (WP2).
- In collaboration with Public Contributors, assimilate data from WPs1 and 2 into a 'key findings' summary document and presentation, to be shared with expert stakeholders. Repeat previous rapid literature review and include any new findings in the summary document and presentation (WP3).
- Conduct four online stakeholder focus groups to agree: a) the nature and scope of 'unmet need' as described in our data; b) recommendations for future clinical practice and research, and patient identified areas of importance, which should be measured.
- Disseminate study findings.

3.3 Research questions:

1. What are the views of people with inflammatory arthritis of PSC and how PSC may support them to live well?
2. How do Rheumatology, PC, Primary Care and Community services healthcare professionals currently collaborate, and what do they perceive as the potential future value of PSC to support people with inflammatory arthritis to live well?
3. What is the nature/scope of patients' unmet need?
4. What are expert stakeholders' recommendations for future clinical practice and research to help people live well with inflammatory arthritis via PSC throughout the disease course?

3.4 Outcomes

The primary outcomes for this research will be:

- A description of the nature and scope of unmet patient need,
- Clinical and research recommendations, informed by expert opinion and the 'six pillars' framework of the British Society of Lifestyle Medicine[40], which describe the potential role of PSC for people with inflammatory arthritis throughout the disease course. We will particularly consider Supportive Care, within the 'six pillars' framework, as this includes improving a person's general physical and mental health.[41] These recommendations will be shared with people with inflammatory arthritis, clinicians, academics and service commissioners. Future work will explore how to implement the recommendations into practice to improve the lives of people with inflammatory arthritis.
- Patient identified areas of importance which should be measured in future work.

4 STUDY DESIGN /SAMPLE/ METHODS/ ANALYSIS

4.1 Overview of study

This exploratory study comprises three sequential work-packages (WP1-3), which build on each other and include qualitative and quantitative data collection.

4.2 WP1 (months 4-9)
Explore with people living with an Inflammatory arthritis, what their understanding and perspectives are of Palliative and Supportive Care, and how Palliative and Supportive Care may support them to live well.

4.2.1 Inclusion and exclusion criteria

Inclusion criteria: Adults (> 18 years) with a diagnosis of arthritis (Rheumatoid, Psoriatic or Juvenile Idiopathic) or Axial Spondyloarthritis; able to understand and communicate in verbal and written English (or via an interpreter nominated by the participant or provided via an agency by the research team); in receipt, or not in receipt of Palliative Care services; access to Microsoft Teams or a telephone; and consent to sharing preferred contact details. **Exclusion criteria**: Cognitive

impairment that impedes communication; non-English speaker (should an interpreter not be available).

4.2.2 Sample size: 20 to 30 participants will be sought. 15-30 participants is considered sufficient to capture rich, focused data, and to identify patterns or tendencies.[38]

4.2.3 Patient recruitment will purposefully seek an adult heterogenous sample (range of ages, in receipt or not of palliative care, and from across the disease course) from Bath and Bristol Rheumatology clinics; Bristol Bone and Joint Health Integration Team; Bath Institute for Rheumatic Diseases; Dorothy House Hospice and wider national hospice network who have agreed to be Participant Identification Centres (PIC) sites. As an NIHR portfolio study, an advertisement will be shared via NIHR networks e.g. RDN Residential Settings Network and NIHR Be Part of Research. Advertising via social media platforms (e.g. Facebook, 'X', LinkedIn) will be considered dependent on response in the previous groups. We will seek to include diverse representation by working with organisations who serve ethnically diverse communities e.g. Sawubona (We See You) and Bath and Bristol Research Engagement Networks. Potential participants will not be approached directly by the research team ensuring participation is entirely voluntary and self-selecting.

An interpreter will be engaged via an agency for those people who do not speak English at a fluency which would enable them to participate. On expression of interest, the relevant study documents will be translated (e.g. Participant Information Sheet, consent form, data privacy notice and video). We cannot guarantee an interpreter will be available for all languages, and this may impact recruitment.

4.2.4 Recruitment materials will be co-designed with Public Contributors and include contact details (email, telephone) of the Research Fellow (RF) for more information. On receipt of an expression of interest, the RF will email or telephone to confirm eligibility and share the Participant Information Sheet, consent form, and data privacy notice via email or post. Communications and documentation will be translated where applicable. The RF will email or telephone to follow-up and will arrange an agreed interview date. Only two attempts to contact will be made at each time point.

4.2.5 Data collection will be via semi-structured individual interviews conducted online via Microsoft Teams. Guidance on Microsoft Teams will be provided as needed. Communication via MS Teams can be via computer or telephone (without the need for a camera). Our participant information documents will recommend conducting the interview in a private area, or at a time when privacy can be provided, and the researcher will offer flexibility in appointment times. An interpreter will be provided for the duration of the interview, if required and available.

A topic guide will be co-designed with Public Contributors and informed from: existing literature, research objectives, and pre-application focus group feedback from people with Inflammatory arthritis. An embedded pilot of the interview schedule will be conducted with two participants.

Following provision of responses to any questions about the study and receipt of **verbal participant consent,** interviews will be recorded using an embedded audio recording function or via Dictaphone if any technical challenges are encountered. Participants will be asked for their understanding and perspectives on PSC before being shown a brief video[42] describing PSC and the support these services can offer. Subsequent questions will explore if the video has changed participants' views, which circumstances Palliative and/or Supportive Care may have been helpful to the participant in the past, or envisaged future benefit. As the topic area has potential to cause distress, an a priori distress protocol[43] for interviews will guide the RF's response and actions throughout the interview (see supporting documents).

Limited personal data will be collected during the interviews (age, sex, ethnicity and geographical location), for the purposes of describing the sample in dissemination activities and to assist with efforts to ensure inclusion as per NIHR INCLUDE guidelines.[44]

Data will be transcribed verbatim using the transcribe function within Microsoft 365, checked for accuracy by the RF, and thematically analysed following Braun and Clarke.[38] Transcripts will be psuedonymised via usage of unique ID numbers. No participant will be identifiable from any reports or dissemination activities undertaken.

Participants' contact details will be retained if they wish to receive a summary of study findings or contribute to stakeholder focus groups (WP3).

4.3 WP2 (months 8-12)
Explore Rheumatology, General practice and Community healthcare professionals' (HCP) views on Palliative and Supportive Care, and Palliative Care HCPs' views on Inflammatory Arthritis and Supportive Care, and how Palliative Care and Supportive Care may help people with Inflammatory arthritis to live well.

4.3.1 Inclusion and exclusion criteria

Inclusion criteria: Registered HCPs working in Rheumatology; registered and non-registered HCPs in Palliative Care; Primary Care (GPs); Community teams (district nurses, therapists). Non-registered staff are key personnel in Palliative Care.
Exclusion criteria: Living and working outside UK.

4.3.2 Sample size: As this is an exploratory study, sample size calculations are not necessary. We aim to recruit a minimum of 50 participants to draw meaningful preliminary conclusions.[45]

4.3.3 Recruitment: As a Research Delivery Network (RDN) Portfolio study, recruitment to the e-survey will be via the RDN. Additional advertising will be via an e-link to the survey on professional organisational networks, websites, and social media platforms (e.g. Facebook, 'X', LinkedIn).

4.3.4 Data collection will be via e-survey using the Qualtrics platform, to determine current provision, and understanding of the value, and potential value of PSC for people with an Inflammatory arthritis. Survey items will be informed by WP1 data, and Speciality expertise within the research project team, and piloted with five HCPs

prior to being finalised. The survey platform will include the participant information sheet and informed **consent** prior to presentation of open and closed questions to collect data including clinical role, level of education, experience since qualification, experience in current specialty, personal experience (self or close relative) and geographical location. It will comprise multiple-choice and Likert scale items[46] with limited open-text options about participants' understanding of PSC (Rheumatology, Primary Care and Community professionals), or Inflammatory arthritis and Supportive Care (Palliative Care professionals), and participants' current practice. Videos[42] will be embedded in the survey about PSC services or Inflammatory arthritis, as appropriate. Subsequent items will ask how PSC services may support people with Inflammatory arthritis to live well, and in what circumstances (e.g. symptom profile, stage of disease, stage of life). We anticipate the survey will be "live" for 60 days and take up to 15 minutes to complete. To protect participant anonymity, IP addresses and location data will not be collected. Respondents will be invited to add their email address if they wish to contribute to Stakeholder Focus Groups (WP3). This identifiable information will be shared with the research team at DHHC and this transfer of information between UWE and DHHC will be made explicit in the PIS.

Downloaded data (quantitative and qualitative) will be analysed descriptively without between-groups comparisons or associations between variables. Content analysis will be applied to responses to open questions. [47]

4.4 WP3 (months 13-17)

Establish the views of expert stakeholders on 1. nature and scope of 'unmet need' as described in our data; 2. key points for Rheumatology, Palliative Care, Primary Care, and Community services future clinical practice and research; 3. barriers and facilitators to implementing this expert opinion.

4.4.1 Inclusion and exclusion criteria

Inclusion criteria: Four population groups will be included in this WP who represent the key demographics best placed to have knowledge, experience and views on this topic to inform next steps.

a) People who meet inclusion and exclusion criteria for WP1
b) HCPs who meet inclusion/exclusion criteria for WP2
c) Representatives from key charities and national organisations (e.g. Arthritis UK, National Rheumatoid Arthritis Society, National Axial Spondyloarthritis Society, Hospice UK).
d) Commissioners of services in Integrated Care Boards.

Exclusion criteria: Unable to access Microsoft teams; non-English speaker without access to a nominated interpreter (should an interpreter not be available).

4.4.2 Sample size: Guest et.al.[48] recommend three focus groups as sufficient to capture the most prevalent themes in a topic area. Due to the diversity and number of HCPs, in terms of Specialty and Setting, we will conduct four stakeholder focus groups to ensure we capture a representative breadth of views. Each group will comprise a minimum of two and maximum of four representatives from populations a) and b), and a minimum of one representative from population c). It is hoped at

least one focus group will include representation from population d) but practicalities may require 1:1 consultation with this group (n=2).

4.4.3 Recruitment: Participants who have volunteered in WPs1 and 2 to participate, will be contacted again to confirm interest. Email invitations will be sent to identified key charities and national organisations, and to Integrated Care Board Medical and Commissioning leads for Bristol and Bath regions.

4.4.4. Data collection Data from WP1 and 2 will be assimilated into a 'key findings' presentation to be shared with expert stakeholders. Pre-application rapid literature review will be repeated and any new findings included in this presentation. A summary of the project's findings, and links to the three videos used, will be sent to participants prior to the online event/s to optimise the potential for reflective and deep discussion.[49] This summary will be used as a topic guide to steer the discussion to key questions. Focus groups will be conducted face to face (x2) and online (x2) via Microsoft Teams at a date and time convenient to participants, and following **participant consent,** recorded using embedded audio recording function**.** Each focus group will run for a maximum of 120 mins. Discussion will broadly focus on:

- What would 'good' look like for people with Inflammatory arthritis to live well with support from PSC services?
- How would this be measured?
- What is the current unmet need?
- What could reduce/address this unmet need in Rheumatology and Palliative care services?
- What are the challenges and barriers?
- What further clinical and/or research work is required?

After each event, the discussion will be summarised by the lead facilitator (Fry or McCabe) and confirmed by members of the group. An iterative approach will be taken across these events so the final summary is representative of the discussion from all Stakeholder events. For example, in groups 2 and 3, following initial discussion and agreement of draft recommendations, the views of the previous Stakeholder group/s will be shared and added to or refined. Using transcribe function within Microsoft 365, audio data will be transcribed verbatim and analysed using inductive qualitative content analysis.[49,50]

4.5 Data analysis

4.5.1 WP1 Qualitative interviews

Interview data will be analysed by the Research Fellow (RF), supported by Qualitative co-applicant lead Llewellyn, following Braun and Clarke's six stage process for reflexive thematic analysis (TA).[38] An inductive orientation will ensure the analysis is driven by data, rather than by existing theoretical constructs. Lumivero NVivo qualitative data analysis software will be used for data management and analysis.

The analysis phases will be:

1. Familiarisation with the data
2. Generation of initial codes to identify data items which represent units of meaning relevant to the research questions
3. Generation of candidate themes representing conceptually similar codes
4. Review and reorganisation of themes to reflect the most significant patterns in the data
5. Naming and refinement of themes in relation to core concepts
6. Reporting.

Prior to the writing and dissemination of the final summary report, themes will be presented for review by our Public Contributors to gain their interpretation and inform dissemination of findings. To ensure rigour, oversight will be provided by the research team throughout the analysis process.

4.5.2 WP2 Healthcare professional e-survey

As this is an exploratory study, sample size calculations are not necessary, but we will aim to recruit a minimum of 50 participants to draw preliminary conclusions.[51] Survey response data in Qualtrics will be downloaded as an SPSS file onto a secure UWE Bristol OneDrive folder. Anonymised data will be securely transferred from UWE to Dorothy House and only members of the research team will have access to this information. Data will be analysed by the RF, supported by Quantitative co-applicant lead Ndosi. Free text responses will be analysed using content analysis.[50] Quantitative responses will be analysed using descriptive statistics, with categorical variables summarised as frequencies (%) and continuous variables summarised as medians (interquartile ranges).

4.5.3 WP3 Stakeholder Focus Groups

Transcribed data will be uploaded onto NVivo, and analysed by RF, supported by project lead McCabe, using inductive qualitative content analysis in a three-phase process.[50,51]

1. Preparation phase: collecting suitable data, making sense of the data and selecting the unit of analysis. Each focus group transcript will be considered a single ‘unit of analysis’ as large enough to be considered whole but small enough to be kept in mind during the analysis process.[49] Transcribed text will be categorised into content areas (approximately 6), or NVivo ‘parent nodes’, that reflect the questions asked in the stakeholder focus groups.

2. Organisation phase: open coding, creating categories and abstraction. Headings will be attributed to the text, and categories freely generated (open coding). Categories will be compared and grouped into higher order categories, where text appears to ‘belong together’. During abstraction, categories will be re-compared and re-grouped and put into a hierarchical model of closeness to distance from the text.[51]

3. Reporting phase: The content of the categories will be described and reported in detail to our Public Contributors and the research team to

increase trustworthiness of findings, prior to publication. The findings will be presented as clinical and research recommendations for PSC, to help people with inflammatory arthritis to live well over the course of their disease. We will particularly consider Supportive Care, within the 'six pillars' framework[40], as this includes improving a person's general physical and mental health.[41.]

5. STUDY SETTING

The majority of this study collects data online (WP1, WP2 and 2 focus groups in WP3). The two face to face focus groups in WP3 will be conducted at Dorothy House Hospice.

6.STUDY RECRUITMENT AND WITHDRAWAL

6.1 Work-package 1

We have allocated four months for recruitment and the conduct of interviews. We have deliberately sought agreement from a large number of organisations (Bath and Bristol Rheumatology clinics; Bristol Bone and Joint Health Integration Team; Bath Institute for Rheumatic Diseases; Dorothy House Hospice and wider national hospice network; Sawubona (We See You) and Bath and Bristol Research Engagement Networks). We do not anticipate any problems in recruiting a minimum of 6 people per month, for example, the Bristol and Bath Rheumatology services see approximately 500 people with inflammatory arthritis per month, and Dorothy House Hospice, has had, on average, 10 people with inflammatory arthritis referred every month for the past two years. We will monitor recruitment rate closely and if any concerns arise that we may not hit our recruitment timeline, then we will advertise on social media.

Interview participants will not be paid or incentivised to take part.

6.2 Work-package 2

We have allocated three months for the e-survey to be 'live' to recruitment, and to reach a minimum of 50 participants. We consider this to be realistic based on similar surveys our research team have conducted in the past two years. For example, a recent national, online survey of healthcare professionals recruited 77 participants over a three-month period via professional networks and social media. The project timelines have flexibility within them for us to extend the survey for a further month if required.

6.3 Work-package 3

The majority of participants in our four stakeholder focus groups will be volunteers from WP1 and 2. If at the end of those work-packages we have any concerns about the number of volunteers then we will actively seek additional participants via our established patient and public collaborators, and professional networks.

Focus group participants will be given a £25 voucher as a 'thank you'.

6.4 Withdrawal from the study

WP1: Participants will be advised during data collection that they can pause or stop the interview at any time if they wish to do so. Each participant also has the right to withdraw from the study for up to two weeks after their interview. This means that any recording and transcription related to them will be deleted at that point, and they will not be contacted further. However, it will not be possible to exclude their data if they request to withdraw after two weeks, as their data may already be included in the analysis. Participants will be made aware of this via the participant information sheet.

WP2: Completion and submission of the survey is voluntary. Once a participant submits their survey, it will not be possible to withdraw their data. Participants will be made aware of this via the participant information sheet.

WP3: Participation in the focus groups is voluntary. Participants can withdraw at any time during the event. It will not be possible to remove a participant's individual contribution in the recording of these focus groups. Participants will be informed that these focus groups will be recorded in the participant information sheet and again at the start of workshop. At the end of the focus group all participants will be reminded that the focus group was recorded and data will be anonymised. If a participant has a particular response they would like to withdraw, then a note will be made of this and that part of their contribution will not be included in the final data set.

7 ETHICAL AND REGULATORY CONSIDERATIONS

7.1. Assessment and management of risk

At the onset of the project, a full risk assessment and data protection impact assessment will be conducted, and issues identified, and mitigations found.

Training needs of research staff or our Public Contributors will be identified and training completed, this will be supported by our local RDN as they have a suite of research delivery training for research staff and the public.

The project involves interviews, a survey, and stakeholder focus groups with human participants who are either healthcare professionals, or recipients of healthcare services, including from the NHS and hospices. NHS Ethical and HRA approvals will be sought prior to the commencement of participant recruitment.

We will have a process for adverse events. A distress protocol will be compiled and adhered to in the event of any emotional issues arising amongst participants and a list of sources of support will be available.

A Steering group will monitor progress of the project and ensure all issues are considered in a timely way, and we will benefit from a range of expertise from members. Membership will include: at least one Public Contributor; experts in the project's methods; clinical academic expertise in Rheumatology and Palliative Care, and ICB representation.

BSW Research Hub will also help with all aspects of research governance and sponsor support, as our local R&D office. This includes helping with and ensuring all relevant regulatory and ethical approvals are in place before the study commences.

7.2 Research Ethics Committee (REC), other Regulatory review & compliance and amendments

The Chief Investigator will ensure this study is conducted in accordance with the principles of the Declaration of Helsinki and with relevant regulations and with Good Clinical Practice.

The protocol, participant information sheet, and consent form will be submitted for HRA and NHS Ethical Approval by a member of the study team. Further approvals will be sought from the UWE ethics committee, BSW Research Hub and via the internal DHHC research governance process. Formal approval will be obtained from recruitment centres via Participant Identification Centre documentation. Participant recruitment will not commence until these approvals have been gained.

The Chief Investigator will review any requests to amend the protocol and will decide whether an amendment is substantial or non-substantial. The Chief Investigator will ensure that any required study amendments are submitted to the appropriate body for approval, including substantial amendments that require review by NHS REC. Amendments will be communicated to relevant stakeholders and will not be implemented until all required approvals have been received. Amendments will be recorded in the study data file and will be reflected with revision of the study protocol, tracked using version numbers.

All correspondence with the REC will be retained and reporting completed as requested including notification to the REC of the end of the study. Annual progress reporting will be the responsibility of the Chief Investigator.

7.3 Patient and Public Involvement

People with lived experience of inflammatory arthritis have been central to developing our proposal. They will remain integral to our project, and work alongside our research team providing insights, challenges and advice.

Two public contributors with inflammatory arthritis have developed this project alongside us (Fry and James). With appropriate training, they will lead our public involvement activities supported by two public engagement facilitators in Palliative Care and Rheumatology services. Fry will also co-lead Study 3 with McCabe. Input from Fry and James into this application reflects our aim to ensure meaningful public engagement is included in our research. Acting as co-applicants and members of the Project team they bring a wealth of lived experience of inflammatory arthritis.

We plan to engage with more public contributors at key stages in the project. Those people who contributed to our project preparation focus group and 1:1 meetings, have agreed to remain involved with the project and to be consulted as it progresses. We also have agreed access to Bristol Rheumatology Patient Group and Bath Institute for Rheumatic Diseases membership. We will seek the views of people from

these groups at key time points in the application, in addition to the contributions from Fry and James:

- The co-creation of explanatory videos on PSC and inflammatory arthritis with Leon! Animations[42]
- Content and design of recruitment materials
- Interview topic guide
- Review of Study 1 draft qualitative themes to inform dissemination of findings and Study 2 survey items
- Summary of key findings for stakeholder focus groups
- Dissemination strategy

Public contributors will be paid for their time and expertise according to NIHR payment guidance[52].

7.4 Identifiable information

The study team will ensure that participants anonymity is maintained throughout the research lifecycle.

WP1 & WP3**:** All personally identifiable information will be redacted from transcripts, and pseudonyms will be used in all subsequent analysis and reporting to prevent re-identification

WP2: In accordance with data minimisation principles, the Qualtrics survey settings will be configured to ensure that IP addresses and geolocation data are not collected. Respondents will be invited to provide an email address only if they voluntarily wish to contribute to Stakeholder Focus Groups (WP3). These contact details will be stored separately from the survey dataset

All participants will be identified only by a unique participant ID number or pseudonym on all project documents and databases. The study will comply with the UK General Data Protection Regulation (UK GDPR) and the Data Protection Act 2018, which requires data to be anonymised as soon as it is practical to do so. All documents will be stored securely and will only be accessible to the study team or to authorised personnel solely for regulatory purposes, and with approval from the Chief Investigator.

7.5 Data protection and patient confidentiality

Dorothy House

DHHC will act as data controller and all data will be stored in accordance with its data management policies. A DHHC data protection impact assessment will be completed and approved by the DHHC Head of Governance prior to the start of data collection.

Participant identifiable details will be securely stored at DHHC for the duration of the project. Written documents will be secured in a locked filing cabinet within the Research Team office, and electronic documents will be stored in a secure folder on the DHHC server, accessible only to members of the study team. All documents containing participant identifiable details will be deleted on completion of the study.

The only exception will be if study participants have given express permission during consent for the study team to contact them again in relation to future research or education projects. If this permission is revoked all identifiable details in relation to that individual will be deleted.

If a Dictaphone is used in the study, it will remain in the possession of the study team at all times when not stored in a locked cabinet at DHHC. Audio recordings from the Dictaphone or MS Teams will be uploaded to a folder (accessible only to members of the study team) on the DHHC secure server as soon as is practicable and deleted from the audio device (Dictaphone or Microsoft Teams recording) immediately thereafter.

All audio recordings, wherever held, will be erased once analysis of the data is complete.

A single electronic document linking unique identification numbers with participants' personal information will be password protected and securely stored on the DHHC server. This will be accessible only to the study team and will be deleted on completion of the project.

WP1 anonymised interview data files will be stored in a secure folder on the DHHC server. These files will be shared with the WP1 lead at UWE via a secure encrypted folder on the DHHC server.

All laptops/PCs used in the collection and analysis of data are password protected as is access to electronic files held on the DHHC server. A study log will be used to maintain detailed records of data collection and research activities.

Anonymised electronic data will be securely held for 10 years following the study end date, then deleted.

University of the West of England

UWE Bristol will act as the data controller, and all personal data will be processed in accordance with the General Data Protection Regulation (GDPR) and the Data Protection Act 2018.

WP2 data collection, including informed consent, will be conducted via Qualtrics, the University's authorised survey tool to ensure legislative compliance. Participants must affirmatively agree to the electronic consent statement before accessing the survey. In adherence to data minimisation principles, identifiable data collection will be restricted to what is strictly necessary.

Upon completion of WP2 data collection, both the electronic consent records and the survey dataset will be downloaded directly to a secure, encrypted project folder on UWE Bristol's password-protected OneDrive server, accessible only to authorised researchers (which includes the DHHC research team). Immediately following successful transfer and verification, all data held on the Qualtrics platform will be permanently deleted.

Personal data will be retained only for the period justified in the participant consent form and Research Data Management Plan (RDMP). Upon completion of the research or at the end of the agreed retention period, personal data will be securely

destroyed in line with UWE's disposal standards. Anonymised data, from which individuals cannot be re-identified, may be archived for future research use. All researchers involved will adhere to the principle of "data protection by design and default" throughout the project lifecycle.

7.6 Indemnity

DHHC has appropriate insurance to meet the potential legal liability of the sponsor/employer and of the study investigators, for harm to participants arising from the conduct and management of the research.

7.7 Access to the final study dataset

Access to raw data (demographic characteristics, audio-recordings and transcripts) from all WP's will only be granted to members of the study team in line with the provisions of section 7.4 above. Due to the nature of the qualitative data, the dataset will not be shared beyond the study team. Anonymised data may be used for reporting, informing future research, and for secondary analysis. This will be made explicit in the participant information sheet and in the consent form.

8 DISSEMINATION POLICY

8.1 Dissemination policy

DHHC will own the data arising from the study. Data reporting will contain non-identifiable data only.

Working with our public contributors we will draft a dissemination strategy at the start of the project and review and update it as the project progresses. We anticipate the following outputs:

- Project summary reports will be emailed to those research participants in Study 1 who have accepted this offer
- Podcast of our research findings in collaboration with the Bath Institute for Rheumatic Diseases (BIRD). Since 2020, BIRD have been producing podcasts for people living with a rheumatology condition (see letter of support, and podcase examples[53])
- Text on the Bristol Bone and Joint Health Integration Team website, and in email alerts to the membership, which includes people living with arthritis (see letter of support and website[54])
- We would like articles in national charity newsletters, for example, Arthritis UK, National Rheumatoid Arthritis Society and National Axial Spondylarthritis Society.

8.2 Authorship eligibility

Authorship of the final study report will be limited to members of the study team.

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10. APPENDICES

10.1 Appendix 1: Gantt chart

Appendix 1

Palliative and Supportive Care to help people with arthritis to live well (ENRICH)

Exploring perspectives on Palliative and Supportive Care, to inform recommendations to help people live well with inflammatory arthritis throughout the disease course. (ENRICH)			**Year 1:** 26th August 2025 - 31st July 2026												**Year 2**: 1 August 2026 - 27th April 2027							
			Aug	Sept	Oct	Nov	Dec	Jan	Feb	Mar	Apr	May	Jun	Jul	Aug	Sept	Oct	Noc	Dec	Jan	Feb	Mar	Apr
Task schedule		Month		1	2	3	4	5	6	7	8	9	10	11	12	13	14	15	16	17	18	19	20
CM= Candy McCabe, JF = Julie Fry, JJ = Julie James AL= Alison Llewellyn, MN= Mwidimi Ndosi PSG = Project steering group PMG = Project management group	Mgt Lead	Resource																					
Project management	**CM**																						
Project governance (commences pre-study)		CM & Research Manager																					
PSG meetings-Steering Group members to be appointed by start of project and will include expertise in research methods, PPI, Rheumatology and Palliative Care		CM, Research Manager, Steering Group members																					
PMG meetings		All applicants, Research Manager, Research Nurse, Research Fellow & PPI Administrator																					
PMG teleconferences (ad hoc as required, estimate shown)		CM, Research Manager, Research Nurse & Research Fellow																					
HRA & University ethics, Dorothy House organsiational approval (commences pre-study)		CM, Research Manager, Research Fellow																					
PPI	**CM, JF,JJ**																						
PPI co-applicant training		CM, JF, JJ & PPI administrator																					
PPI input (in addition to PMG & PSG meetings)		CM, JF, JJ & PPI administrator																					
Development of videos	**CM**																						
Co-design of content with Leon! Animations		CM, PMG																					
WP 1: Qualitative interviews	**AL**																						
Interview document and preparation		AL, Research Nurse & Research Fellow																					
Recruitment & conduct of Interviews		Research Fellow, PPI Administrator																					
Data analysis and draft publication		AL, Research Nurse & Research Fellow																					
WP 2: E-survey	**MW**																						
Survey preparation and item development		MN, Research Manager & Research Fellow																					
Data collection		MN & Research Fellow																					
Data analysis and draft publication		MN, Research Manager & Research Fellow																					
WP 3: Stakeholder Focus groups	**CM &JF**																						
Preparation of data summary report		CM, JF, JJ & Research fellow																					
Delivery of focus groups		CM, JF & Research fellow																					
Data analysis and draft publication		CM, JF & Research fellow																					
Project report, publications and dissemination	**CM**																						
Completion of publications		**All**																					
Final report & dissemination		**All**																					

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