

Participant Information Leaflet: HSCP Focus Groups

Study Title	Parenting matters with inflammatory arthritis: a qualitative exploration of support needs and preferences
Research Site(s)	Discipline of Occupational Therapy, Trinity College Dublin
Principal Investigators and Co-Investigators (Study Team)	Ms Cathy White (TCD, PhD Student) whitec12@tcd.ie Dr Yvonne Codd (Trinity College Dublin, Primary Academic Supervisor) coddy@tcd.ie Prof Margaret McGrath (University College Cork, Academic Co-supervisor)
Data Controller	Trinity College Dublin
Data Protection Officer (Research Data)	Data Protection Officer Secretary's Office Trinity College Dublin Dublin 2



INTRODUCTION

We would like to invite you to take part in a research study that is being carried out by occupational therapy researchers at Trinity College Dublin.

If there is anything which is not clear, or if you would like more information, please ask the researchers. You should understand the benefits and any risks of taking part in this study so that you can make a decision that is right for you.

Do I have to take part?

No, you don't have to take part in this study. It is entirely voluntary and up to you. Don't feel rushed or under pressure to take part or to make a quick decision. You can change your mind and opt out at any time even if the study has started, without giving a reason, up until the point that your data have been analysed and reported.

This leaflet has six parts:

Part 1 - The Study

Part 2 - Data Protection

Part 3 - Approval, Organising and Funding

Part 4 - Further Information

Part 5 - Next s



PART 1 - THE STUDY

Why have I been invited to take part?

The overall aim of this project is to explore the support needs and preferences for parents with inflammatory arthritis to inform content and delivery of a parent-focused intervention.

The objectives of this phase of the study are:

- To explore the impact of inflammatory arthritis on parenting
- To explore recommendations regarding supports and interventions to be included in a parenting with arthritis programme.

We would value your perspectives on this topic as an experienced healthcare professional working with parents of children <21 years with inflammatory arthritis, specifically rheumatoid arthritis, spondyloarthritis (which includes ankylosing spondylitis, axial spondyloarthritis and psoriatic arthritis), JIA (juvenile idiopathic arthritis) and undifferentiated inflammatory arthritis.

We aim to recruit approximately 12-16 health professionals (doctors, nurses, occupational therapists and physiotherapists) for this phase of the study. Health professionals will be divided into focus groups of approximately 6 to 8 people. There may be a mix of different disciplines, or you may be allocated to a group comprised solely of professionals from your own discipline.

At the same time, we will be gathering the opinions of parents with inflammatory arthritis and arthritis service co-ordinators on the same topic. These stakeholders will take part in separate focus groups.



Why is this study being done?

This study forms part of a wider PhD research project at Trinity College Dublin which aims to develop a structured intervention (e.g., programme, course, or resource package) to support parents living with inflammatory arthritis.

We wish to record your observations and clinical experience regarding the parenting-related challenges faced by individuals with inflammatory arthritis and identify any gaps in service provision and areas where additional support may be beneficial.

Your professional insights will be considered alongside findings from separate parent and arthritis services co-ordinator focus groups.

What does taking part involve?

You are welcome to speak to a member of the research team to clarify any aspect of this information sheet. If you would like to arrange this, please email whitec12@tcd.ie to request a telephone call at a time convenient to you. Should you wish to proceed, you will need to virtually sign and return the study consent form. You will be invited to attend one online focus group via Microsoft Teams or in-person at a mutually convenient meeting place lasting approximately 60–90 minutes at a suitable time for all participants. With your consent, the discussion will be audio-recorded and auto-transcribed.

The focus group will be facilitated by PhD student Cathy White, supervised by Dr Yvonne Codd. Discussion topics are outlined in the focus group guide attached. A transcript of the discussion will be prepared, and you will have the opportunity to review your contributions for accuracy if you wish. All participants will be asked to agree to maintain the confidentiality of the discussion.

We ask all participants not to share what is said by others in the group outside the session.

If you have concerns about confidentiality at any point, please do not hesitate to contact a member of the research team



What are the possible benefits of taking part?

Taking part in this study may not bring direct benefits to you personally. However, your involvement is highly valuable. By helping us learn more about the experiences of parenting with inflammatory arthritis, you will contribute to the development of a well-designed support programme that could make a difference for rheumatology patients facing these challenges in the future.

Are there any possible disadvantages or risks from taking part?

This study follows Trinity College Dublin's Good Research Practice Policy. As part of this, we have put strong safeguards in place to protect your information, and the risk of any breach of confidentiality is considered low. However, no system is completely without risk, so we cannot guarantee that your personal data could never be compromised.

What will happen to the results of the study?

The information collected in this study will be used as part of a PhD research project being carried out by the group facilitator, Cathy White.

The results of the study will be reported in peer-reviewed healthcare research journals and disclosed at health/medical conferences.

Some direct quotations from the focus groups may be used in reports. However, no information which reveals your identity will be made public.



PART 2 - DATA PROTECTION

What information about me (personal data) will be used for this study

We will collect the following information about you:

- Your name
- Your profession
- Your title at work
- Your work setting e.g. acute hospital, rehabilitation service etc.
- How long you have been working in rheumatology services
- Your contact details (to arrange the focus groups)

We will also collect this research data, which will be anonymised and kept separately from the information above:

- The audio recording of the focus group you take part in and the final transcript

Your name and contact details will be stored separately from the rest of your information. This helps protect your privacy by reducing the chance that your personal details could be linked to you in the unlikely event of a data breach.

Who will access my personal data?

Only the PhD student (Cathy White) and the primary academic supervisor (Dr Yvonne Codd) will be able to identify you. They will keep the master file which links your identity to the research data.

The PhD student will remove your name from all research data and replace it with a code. The key to reidentify participants will be kept confidential and separate to the research data and deleted as soon as all data has been gathered and checked (before the end of 2026). The coded information will be analysed, and it will form the basis of the study findings which will be shared in academic journals and at conferences. Another member of the research team, Professor Margaret McGrath at University College Cork will have access to the coded data.

You may have heard about this study through a professional representative group such as the IRHPS, ISR or equivalent. Only the research team will have access to your data; these organisations will not be able to view or access it.



How is the information kept confidential and secure?

Your data will be stored on a restricted server hosted by Trinity College Dublin (SharePoint), with password protection, with access restricted to the two members of the research team listed previously.

All researchers involved with this project are governed by a professional code of ethics to maintain your confidentiality. They have all completed training in data protection law and practice has been provided to those individuals involved in carrying out the research.

A Data Protection Impact Assessment has been carried out to provide an indication of the level of risk identified.

Confidentiality may be breached in circumstances in which the research team has a strong belief or evidence exists that there is a serious risk of harm or danger to you or another individual. Disclosure may also be required as part of a professional code, legal process, or Garda investigation. In such instances, information may be disclosed to significant others or appropriate third parties without permission from you being sought. Where possible, a full explanation will be given to you regarding the necessary procedures and the intended actions that may need to be taken.



How long will my personal data be needed?

The audio recording of the focus groups will be retained until it has been transcribed and the content verified. It will then be permanently deleted.

Your name and contact details will be retained until the next phase of the study takes place, as we will be recruiting a smaller group to gain a consensus or collective decision on what could best support parents with inflammatory arthritis. Once recruitment to the next phase of the study is completed, your name and contact details will be permanently deleted.

All other information about you that is collected, along with the answers you provide in the focus groups will be Pseudonymised. This data will be kept by Trinity College for three years after the umbrella project on parenting with arthritis has been completed, in line with TCD's data retention policy. At that point, the anonymised data will be permanently deleted.

What is the lawful (legal) basis to use my personal data?

We will only use your personal data for this research project, and if you consent, future research which will refine the development of the parenting support programme. We will also ask for your consent as a requirement of Irish law (Health Research Regulations), but we do not rely on this as our legal basis under GDPR (Article 6(1)(e) and Article 9(2)(j)).

What are my rights under Data Protection law?

As a participant in this research study, you are entitled to the following rights:

- object to our use of your personal data or any further use;
- request access to your personal data and to receive a copy of it;
- request inaccurate personal data be corrected or deleted;
- request restriction of our use of your personal data;
- request deletion of your personal data.

By law you can exercise the above rights in relation to your personal data up until a certain point in the research process unless the request would make it impossible or very difficult to



conduct the research. For example, if the study is about to be published then we may not be able to delete data as it would impact on the results.

You can exercise these rights by contacting the researcher: Cathy White, Discipline of Occupational Therapy, School of Medicine, Trinity College Dublin whitec12@tcd.ie or the Trinity College Data Protection Officer, Secretary's Office, Trinity College Dublin, Dublin 2, Ireland. Email: dataprotection@tcd.ie. Website: <https://www.tcd.ie/dataprotection/>

PART 3 - APPROVAL, ORGANISING AND FUNDING

Has this study been approved by a research ethics committee?

Yes, this study has been approved by Trinity College Dublin Research Ethics Committee (REC). Approval was granted on [INSERT DATE]. An annual report will be provided to the REC and on completion of the study.

Who is organising and funding this study?

This study is being undertaken by Cathy White as part of PhD studies. It is being funded by Trinity College Dublin.

Will I be paid for taking part?

No, we are not paying you to take part in the study.

PART 4 - FURTHER INFORMATION

What happens if I change my mind?

Your participation in this study is entirely voluntary, and you can change your mind even if the study has started.

You do not have to give a reason for changing your mind.



If you would like to withdraw from the study, please contact Cathy White who can organise this for you.

We will check if you are happy for us to continue to use information about you which has already been collected. If you do not consent to your personal data being retained for this study, we will delete any information that could identify you.

Please note that we will not be able to remove personal data which has been shared or pooled for use in publication before your request for deletion.

We will not contact you again.

Who should I contact for information or concerns?

If you have any concerns or questions, you can contact:

Cathy White or Yvonne Codd (contact details of page 1 of this leaflet)

If you have any questions in relation to your rights under data protection law, you can contact the Data Protection Officer, Trinity College Dublin: Data Protection Officer, Secretary's Office, Trinity College Dublin, Dublin 2, Ireland. Email: dataprotection@tcd.ie. Website: <https://www.tcd.ie/dataprotection/> (remove if site DPO is contact point).

Under GDPR, if you are not satisfied with how your data is being processed, you have the right to raise a concern with the Office of the Data Protection Commission, 21 Fitzwilliam Square South, Dublin 2, Ireland. Website: www.dataprotection.ie

PART 5 - NEXT STEPS

Will I be contacted again?

We will contact you in seven (7) days' time, to give you time to consider your participation in the study. If we do not hear back from you, we will contact you on one further occasion and if we do not hear from you after that, we will not contact you again.

Thank you for taking the time to read this Participant Information Leaflet.