



Parenting Matters with Arthritis Participant Information Leaflet: Parent 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 (research data)
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.

Before you decide whether or not you wish to take part, please take time to read this information leaflet carefully and discuss it with your family, friends or rheumatology team if you wish.

If there is anything that 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 steps



PART 1 - THE STUDY

Why have I been invited to take part?

We are interested in understanding experiences of parents with inflammatory arthritis. You are being invited to participate in this study because you have responded to our recruitment campaign seeking parents with a diagnosis of one of the following forms of inflammatory arthritis:

- Rheumatoid arthritis
- Spondyloarthritis (includes ankylosing spondylitis, axial spondyloarthritis and psoriatic arthritis)
- Juvenile idiopathic arthritis
- Undifferentiated inflammatory arthritis

For the purposes of this study “parent” is defined as a primary caregiver for a child/children and/or young adults from birth- 21 years.

We may have up to 24 parents participating in the study. The parents will be divided into focus groups of approximately 6 to 8 people. Should you decide to take part, you will be assigned to one of these focus groups.

At the same time, we will be gathering the opinions of healthcare professionals and service co-ordinators on the same topic. These professionals will take part in separate focus groups.



Why is this study being done?

This study is part of a larger project that aims to develop an intervention (such as a course, programme or set of resources) for parents living with inflammatory arthritis. By taking part in a focus group, you will help us understand two key things.

First, we want to learn about the parenting challenges individuals with inflammatory arthritis face in everyday life, and the approaches they use to manage these challenges.

Second, the information shared in the groups will guide the design of the parent support itself. This includes identifying what topics parents would find most helpful, as well as understanding what practical arrangements, such as timing and format would suit parents best.

What does taking part involve?

If you decide to take part, you are welcome to request that a member of the research team telephones you to discuss this information leaflet and consent form with you. Once you have returned the consent form, you will be given a copy for your records and this leaflet to keep. Each member of the focus group will also be asked to sign a confidentiality statement.

You will be invited to take part in an online (Microsoft® teams) focus group meeting with other parents with inflammatory arthritis. The meeting will be scheduled for a mutually convenient time for participants, and it will last between 60 and 90 minutes. With your permission, the interviews will be audio recorded and auto transcribed.

The meeting will be facilitated by a PhD student (Cathy White). The primary research supervisor, Dr Yvonne Codd will also be in attendance. During the focus group you and the other participants will be asked questions about your experience of being a parent with arthritis and what supports could help you in that role. Further information about what type of questions to expect are attached in the focus group guide.

We will transcribe (write out) the recording. You will have an opportunity to check this transcript, and we can edit the text if necessary.



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 parents facing similar 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.

There is a possibility that you may become upset during interview. Talking about your diagnosis, treatment, and life as a parent in this context may be a sensitive subject to talk about. If you do become upset, you are reminded that you can stop the interview at any time. All participants are reminded that they can access support services such as Arthritis Ireland should they wish to seek any support services.

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 rheumatology diagnosis
- How long it has been since you received this diagnosis
- Your identity as a parent e.g. mother, father
- Your ethnic identity (your cultural or ethnic background)
- Who lives in your house and supports you with your parenting role
- How many children or young adults for whom you are a primary caregiver
- The age range of these children or young adults
- Your contact details (to arrange the focus groups)

Collecting this data will allow us to describe the group of people who took part in the study. This information will be reported in an anonymised form and will not identify any individual participant. Collecting these details helps readers understand who is represented in the research and the context in which participants' views and experiences should be interpreted.

We will also collect this research data, which will be pseudonymised (this means your information will be given a pseudonym or "fake name" so that you cannot be identified), 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). Another member of the research team, Professor Margaret McGrath at University College, Cork will have access to the coded data. 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.

You may have heard about this study through Arthritis Ireland or another support group for people with arthritis. However, 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 (before the end of 2026). 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 your contact details to recruit participants for 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 8th May 2026. 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.

Should you change your mind and withdraw from the study at any point, 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 on 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

Thank you for taking the time to read this participant information leaflet.

You will be given a copy of this leaflet and the signed consent form to keep. Please retain these in case they are needed for future reference.



Trinity College Dublin

Coláiste na Tríonóide, Baile Átha Cliath

The University of Dublin