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Participant Information Sheet

Study Title: Sjögren's in the Community: A Baseline Awareness Survey for Primary Healthcare Professionals

Researcher: Dr Nikki Dunne, Programme Manager & Research Fellow, School of Pharmacy and Biomolecular Sciences, RCSI. nikkidunne@rcsi.com

Principal Investigator (Project Lead): Prof Michelle Flood, Associate Professor, School of Pharmacy and Biomolecular Sciences, RCSI **Contact:** michelleflood@rcsi.ie phone number: +353-1-4022385

Co-investigators:

Prof Frank Moriarty, Associate Professor, RCSI; Dr James Larkin, postdoctoral researcher, Department of General Practice., RCSI; Dr Eoghan McCarthy, Clinical Lead, Consultant Rheumatologist, RCSI & Beaumont Hospital

RCSI Data Controllers' Identity: RCSI University of Medicine and Health Sciences

Data Controllers' Contact Details: 123 St Stephen's Green, Dublin 2, 01-4022100

Data Protection Officer: Dónall King

Data Protection Officer's Contact Details: dataprotection@rcsi.ie

You are being invited to take part in a research study to be carried out by Prof. Michelle Flood, School of Pharmacy and Biomolecular Sciences, RCSI.

Before you decide whether or not you wish to take part, you should read the information provided below carefully and take time to think about the information and ask any questions.

You do not have to take part in this research. If you decide not to take part, it will not affect you in any way and you do not have to give a reason.

Why is this study being done?

This survey is part of an ongoing effort to enhance the understanding and management of Sjögren's among healthcare professionals currently working in primary care. The survey aims to explore the current level of awareness and experience of Sjögren's amongst primary healthcare professionals (GPs, community pharmacists, dentists, opticians and physiotherapists). This group of healthcare professionals have been selected as they may come into contact with Sjögren's patients in their clinical practice. The findings from the survey will help us identify knowledge gaps and inform the development of targeted educational interventions to improve diagnosis, treatment, and patient care.

Who is organising and funding this study?

This study is being conducted by a team of researchers, who are working together on a five-year project called SYNERG-IE, that is aiming to understand and improve healthcare for people living with Sjögren's in Ireland. This study is funded by the Health Research Board under grant HRB-APRO-028 and will take between 12-18 months to fully complete.

The research will be carried out by Dr Nikki Dunne, Programme Manager and Research Fellow. Prof Michelle Flood, Programme Lead and Associate Professor will provide ongoing oversight and supervision.

Why am I being asked to take part?

You are invited to participate in this survey because you are a healthcare professional currently working in primary care in the Republic of Ireland and because you may encounter patients with Sjögren's in your practice. Specifically, the survey is looking to the following groups of healthcare professionals currently working in the Republic of Ireland:

- GPs
- Community pharmacists
- Dentists
- Optometrists
- Physiotherapists



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Your insights into your current knowledge and the challenges you face in recognising, diagnosing or treating Sjögren's are crucial for the success of this study.

How will the study be carried out?

The survey will open in January 2025. You will receive a link to an online survey which contains questions about your familiarity with the symptoms, diagnosis and treatment of Sjögren's. You can also go directly to the SYNERG-IE website <https://sjogrens-synergie.eu/> The survey will direct you to questions that are most relevant to your specialty and will take about 15-20 minutes to complete.

We will combine all the responses to better understand the knowledge and understanding of Sjögren's amongst healthcare professionals currently working in primary care in Ireland. Our aim is to use this information to identify knowledge gaps and inform the development of targeted educational interventions to improve diagnosis, treatment, and patient care.

What will happen to me if I agree to take part?

If you choose to take part, you will be asked to participate in a 15-20 minute online survey. The survey will have a number of questions in relation to your understanding and knowledge of the symptoms, diagnosis and care of Sjögren's patients. The survey will have a number of questions in relation to your current role, your age category, and the sector you are employed in. These questions help us to make sure that we collect responses from a variety of people with different backgrounds. It is important to collect responses from different backgrounds to ensure that the survey results are a reflection of the opinions of the identified healthcare professionals working in primary care in Ireland

This is a once-off survey. All information collected will be kept in the strictest confidence and combined, anonymous results will be reported only. It will not be possible to identify any particular individual in the results and no information that could identify you will be published or provided to anyone.

What are the benefits of taking part?

There are no direct benefits of taking part in this study. However, studies like this can make an important contribution to our understanding of Sjögren's care. If you decide to take part, your answers will help us develop educational resources for healthcare professionals about Sjögren's with the aim to improve patient care.

What are the risks?

We do not see any risks to taking part in this survey. The survey requires your commitment to a 15-20 minute online survey at a time that suits you. We have taken the necessary steps to ensure your personal information is protected. Further information can be found in the following section 'Is this survey confidential?'

Is the study confidential?

Yes. All information collected will be kept in the strictest confidence. The survey will be answered on RCSI's survey tool procured from Microsoft. This is an online survey tool which has been approved for use by RCSI. This is an anonymous survey therefore no personal information will be used as part of this study. You will not be asked to include any information in your responses that could identify you. It will not be possible to identify any particular individual in the survey results, and combined responses of participants will be reported on only. In the event that a survey participant includes identifying information in their answers, this will be permanently deleted as soon as it is identified. Survey answers will be stored in the RCSI survey tool while the survey is open to respondents. All data in the survey tool will be stored and processed in the EU. It will be subject to the GDPR.

Once the survey is closed, the researcher will download the responses from the survey tool to RCSI's own server and permanently delete the information from the survey tool. Access to survey answers will be restricted to selected individuals in the research team.



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Anonymous survey data may be published in peer-reviewed journals and reports or presented at conferences. It will not be possible to identify any particular individual in the results and no information that could identify you will be published or provided to anyone.

If you would like additional information on the survey, please contact us with your query at the email or phone number noted below.

Data Protection

Records

- We will not be collecting personal data in this study.
- We will be analysing anonymised survey data.
- We will follow the General Data Protection Regulation 2016 at all times during this study.
- Only the investigators named on this information leaflet will have access to the research information.
- The research data, will be stored securely on the RCSI OneDrive for 7 years, after which it will be deleted in accordance with the Data Protection Guidelines.
- As the research participant, you have a right to withdraw consent. Our survey invitation will include information about the study and the option to consent. You do not have to consent and complete the survey.
- Participants can withdraw from the research for whatever reason up to the point that they submit their survey responses. After you submit your survey, you will be unable to review, edit, or delete the survey responses as your answers are anonymised and we cannot link your responses back to you.
- All data subjects have a right to lodge a complaint with the Data Protection Commissioner.
- We are not collecting personal data, all study participants will be able to request a copy of the research findings.
- We will not be sharing the research data with any third party.
- We will not be collecting any personal data for profiling from the study participants.

Results

- It will not be possible to identify you in the results as no participant or identifiable pieces of information will be used.
- If you wish to read the completed study results the lead researcher can send you a copy once it has been finalised. Please contact the researcher requesting a copy of results.
- An article arising from the study will be submitted to an appropriate journal for publication. Findings may also be reported in reports, at conferences and using innovative visual outputs such as infographics. It will not be possible to identify you in any of these publications.

Personal Data that we Process / Purposes of Processing and Legal Basis

We will not be collecting personal data in connection in this study.

Consent to Future Uses

If you choose to take part, we would also like to ask your permission to use your responses for other research that will be part of the broader SYNERG-IE programme. There will be no additional request from us to you to do anything if you say yes, and saying no will not affect your participation in this research.

The reason for this request is that it is likely that the information you share will also help inform some of our next steps for example, informing the design of training materials for healthcare professionals or we may identify something important that we want to look at in the future and may wish to revisit the information provided by participants to see if they said anything about that.

If we decide to do that in future, we will put in a formal request to the RCSI Research Ethics Committee who have approved this study, and they will make a decision as to whether what we propose is acceptable to them. If that approval is granted, your anonymised information will be kept securely and looked at it again. Data will be destroyed after 7 years.



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If you consent to future re-use of your data and subsequently change your mind after submitting your responses, we will not be able to remove your data from future analysis or use in future studies as we cannot link your responses back to you.

To any questions about this process, please contact Dr Nikki Dunne at nikkidunne@rcsi.ie/086 8208536.

Where can I get further information?

If you have any further questions about the study, please contact Dr Nikki Dunne (nikkidunne@rcsi.ie or +353 868208536 who will be happy to answer any questions you have.

Thank you for reading this and for taking the time to consider participating.