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A qualitative study of patients' experiences of screening for psoriatic arthritis

Dear Editor,

Psoriatic arthritis (PsA) is a chronic inflammatory arthritis which can cause pain, fatigue, swelling and stiffness in the joints, and result in limited physical function and a high psychosocial burden[1]. Patients with psoriasis are at greater risk of developing PsA than those without[2].

There is no definitive test for PsA. Diagnosis is made by rheumatologists after referral from primary care, based on the patient's medical history, a physical examination, blood tests, MRI scan and X-rays. Delays can be due to patient-related factors (e.g., reluctance to seek medical help) and clinician-related factors (e.g., the lack of autoimmune diagnostic markers). Even a 6-month delay from symptom onset can result in worse long-term physical function[3].

The PROMPT programme (NIHR grant: RP-PG-1212-20007) is investigating clinical and cost benefits of early detection of PsA. The main study is a two-arm parallel-group cluster randomized controlled trial (RCT) of screening (known as TUDOR), using enhanced surveillance for PsA in primary care *vs* standard care. Screening included an examination of participants' skin, joints, hands, feet, scalp, physical tests (e.g., touching toes), height and weight measurement, blood tests, X-rays, MRI scans and questionnaires. An important aspect of TUDOR is understanding whether screening would be acceptable to patients with psoriasis, some of whom will be diagnosed with PsA as a result and some of whom will not. The aim of this study was to understand the experience of screening from the perspective of participants with psoriasis recruited to the enhanced surveillance arm in the TUDOR RCT.

The study was approved by the Proportionate Review Sub-committee of the North East – Newcastle & North Tyneside 1 Ethics Committee (reference 16/NE/0393) and the Health and Applied Sciences Faculty Research Ethics Committee of the University of the West of England (reference: HAS.17.03.129). A qualitative design was used. Data were collected in one-to-one, semi-structured, telephone interviews and analysed using Framework Analysis[4]. Twenty-four participants were recruited from two sites in the TUDOR RCT (Table 1). Three main themes represent the data.

Theme 1 reports participants' views on screening as part of healthcare. Participants described a range of feelings from apprehension and mild anxiety through to excitement and optimism. Overall, screening was a well conducted, positive and reassuring experience. Participants appreciated the thoroughness of the examination and the time to talk with specialists, including about the impact of their condition on their mental health. This was the case both for participants who screened positive for PsA and for those who did not. Some felt that if it were not for the screening, they would still be suffering pain and fatigue and living with undiagnosed PsA. For some participants screening resulted in other conditions being diagnosed (e.g., osteoarthritis, Crohn's disease) and they were able to receive advice and help for these.

This article has been accepted for publication and undergone full peer review but has not been through the copyediting, typesetting, pagination and proofreading process which may lead to differences between this version and the Version of Record. Please cite this article as doi: 10.1111/bjd.21825

Theme 2 reports participants' thoughts on how screening enhanced a sense of control over their health. Participants who screened positive for PsA valued the help they were given in treating their condition, while those who screened negative gained an awareness of symptoms to watch out for and the need to seek advice quickly and get started on treatment if necessary. For some, diagnosis was a 'lightbulb moment' where the reason for their stiff, achy joints became clear. Participants referred to having made changes beneficial to their health following screening, for example to diet and exercise, and adapting the way they did things and talked to others (including employers) about their PsA.

Theme 3 reports views on optimising screening. Suggested improvements include using case studies, signposting to support groups and information provision. Participants mentioned barriers to attending screening, including location, parking and time of appointments. Other potential barriers included embarrassment (especially if clothing needs to be removed) and concerns about what to expect.

These findings showed that screening was acceptable to participants whether diagnosed with PsA or not. This supports a systematic review and thematic synthesis of qualitative studies which found that participants felt empowered when they understood the link between psoriasis and PsA[5]. In addition to possible diagnosis, screening appointments provided an environment to support participants' self-management by communicating advice about the nature and treatment of PsA, addressing negative illness beliefs and unhelpful coping strategies that participants may have developed to deal with their psoriasis, and by encouraging participants' ownership of their health condition[6,7]. This contrasts with participants' experiences of being diagnosed with PsA in the current health-care context, where those who had experienced disbelief and misdiagnoses could arrive in rheumatology already anxious, in pain and distrustful of healthcare providers[8].

This qualitative study indicates that screening is acceptable and a potentially valuable method to increase the early detection of PsA in patients with psoriasis and improve their clinical outcomes.

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Funding: This report is independent research funded by the National Institute for Health Research, Programme Grants for Applied Research [Early detection to improve outcome in patients with undiagnosed PsA ('PROMPT'), RP-PG-1212-20007].

This report presents independent research commissioned by the National Institute for Health Research (NIHR). The views and opinions expressed by authors in this publication are those of the authors and do not necessarily reflect those of the NHS, the NIHR, NETSCC, the Programme Grants for Applied Research programme or the Department of Health. The views and opinions expressed by the interviewees in this publication are those of the interviewees and do not necessarily reflect those of the authors, those of the NHS, the NIHR, MRC, CCF, NETSCC, the Programme Grants for Applied Research programme or the Department of Health.

Conflicts of interest: The authors declare no conflicts of interest.

Data availability: The data that support the findings of this study are available from the corresponding author upon reasonable request.

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Table 1: participant data

Diagnosis	Male/ female	Age in years	Time with psoriasis	Heard of PsA	Site	Interview date
PsA	M	71	54 years	No	1	11/11/19
PsA	F	39	22 years	No	1	15/11/19
PsA	F	70	60 years	Yes	1	20/11/19
OA	F	58	6 years	No	1	22/11/19
PsA	M	40	30 years	No	1	25/11/19
None	F	59	15 years	No	1	02/12/19
OA	F	73	50 years	Yes	1	06/12/19
PsA	M	39	12 years	No	2	11/12/19
None	F	70	30 years	Yes	2	12/12/19
PsA	M	49	24 years	No	2	12/12/19
PsA	M	58	57 years	Yes	1	13/12/19
None	F	72	30 years	No	1	10/01/20
None	F	56	51 years	No	2	15/01/20
OA	F	66	38 years	Yes	1	15/01/20
PsA	M	43	22 years	No	1	24/01/20
None	M	62	43 years	Yes	2	02/03/20
None	F	40	24 years	No	1	03/03/20
None	F	56	38 years	No	2	05/03/20
Crohn's	F	71	20 years	Yes	1	06/03/20
PsA	M	72	7 years	No	2	15/05/20
*None	F	56	38 years	Yes	2	15/05/20
PsA	F	61	55 years	Yes	2	18/05/20
PsA	M	55	20 years	Yes	2	18/05/20
None	F	35	18 years	Yes	2	21/05/20

**Awaiting diagnosis at time of interview*
OA – osteoarthritis