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Patient expectations and experiences of current and new gout management

Submission date
06/05/2025

Recruitment status
No longer recruiting

Registration date
27/05/2025

Overall study status
Completed

Last Edited
28/09/2026

Condition category
Musculoskeletal Diseases

[X] Prospectively registered
[X] Protocol
[_] Statistical analysis plan
[_] Results
[_] Individual participant data
[X] Record updated in last year

Plain English summary of protocol
Background and study aims
Medication for long-term prevention of gout is widely available, but research shows that less than 40% of people with gout are on these medications. New strategies for helping manage gout, such as mobile apps and medication reminders, have been trialled in research. This study aims to further understand what people think about gout and its management by interviewing people with lived experience of gout. Furthermore, preliminary remission criteria for gout have been made by doctors, and the research will explore what people with gout think of remission for their condition, and whether this aligns with the criteria made by doctors. People interested in taking part in this study will take part in filling out a baseline questionnaire involving demographics and information about their gout, followed by a qualitative interview involving open discussion about gout, its management and gout remission. The study expects to recruit participants from all over the UK.

Who can participate?
Adult (aged 18 years or older) patients with a diagnosis of gout.

What does the study involve?
Participants will receive a participant information sheet, either as a paper copy or in an online format, allowing them time to review the study details and consider their involvement. Before formal enrolment, participants will be asked a series of screening questions to assess eligibility. Those who meet the eligibility criteria will be invited to provide written informed consent, confirming their agreement to participate in the study. Following the provision of informed consent, participants will be contacted to complete a baseline questionnaire at their own pace. This questionnaire collects information on gout history, current gout medications, comorbid conditions, and overall quality of life. These data provide context for subsequent interviews.

Instructions within the questionnaire will guide participants on how to respond. Assistance will be available either in person or via email for those completing the questionnaire online. Upon completion of the baseline questionnaire, participants will be invited to take part in a voluntary, audio-recorded interview. The interview will explore participants' understanding of gout, its management, and remission. Participants may decline or withdraw from the interview at any time.

Interviews will be scheduled at a time convenient for the participant. For in-person interviews, a private room at the research site will be used, and verbal consent will be reconfirmed before recording. For online interviews, a Microsoft Teams link will be provided via email. The baseline questionnaire is expected to take approximately 20 minutes to complete.

What are the possible benefits and risks of participating?
There are no direct benefits to participants for taking part in this study. However, the findings may contribute to improved understanding and management of gout, potentially benefiting future patients. Reasonable travel expenses incurred for attending the study site will be reimbursed.

There are no anticipated risks or disadvantages associated with participation. Involvement in the study will not affect the healthcare participants receive. Participation will require a time commitment to complete the baseline questionnaire and attend an interview.

Where is the study run from?
The study will run from a single-centre, at one of the University of Edinburgh sites - The Institute of Genetics and Cancer. However, the study is designed to enable participation in the full study online.

When is the study starting and how long is it expected to run for?
April 2026 to November 2026

Who is funding the study?
The study is sponsored by ACCORD. The Academic and Clinical Central Office for Research and Development (ACCORD) is a partnership between the University of Edinburgh and NHS Lothian Health Board.

Who is the main contact?
Miss Rowan Hart, r.e.hart@sms.ed.ac.uk

Contact information

Type(s)
Public, Principal investigator

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Additional identifiers

Integrated Research Application System (IRAS)
352392

Protocol serial number
AC25083

Study information

Scientific Title
Patient Expectations and experiences of Current And Novel (PECAN) management of gout: a qualitative study

Acronym
PECAN

Study objectives
What are patient perceptions, experiences and expectations of current and novel gout management, in relation to their experiences of gout?

Ethics approval required
Ethics approval required

Ethics approval(s)
Approved 05/06/2025, Wales REC 7 (Health and Care Research Wales, Castlebridge 4, 15-19 Cowbridge Road East, Cardiff, CF11 9AB, United Kingdom; +44 (0)2922 940968; Wales.REC7@wales.nhs.uk), ref: 25/WA/0179

Primary study design
Interventional

Study design
Single-centre interventional mixed-methods study

Study type(s)
Quality of life, Other

Health condition(s) or problem(s) studied
Adults (aged 18 or older) with gout

Interventions
Participants will be recruited in a 1:1 ratio of those using a novel supported self-management (SSM) strategy for gout, and those who are not. People who are using a SSM will be recruited from an adjacent clinical trial (Clinicaltrials.gov identifier NCT05507723). Participants taking part in this study will fill in a short baseline questionnaire that asks for details about their gout and any gout medication. Further questions include what other medical conditions participants have, and questions about quality of life. After this, participants will take part in one recorded interview which will ask them more in-depth about experiences and expectations of current and novel management for gout, as well as questions about gout remission. Those in the SSM arm will be asked specific questions around the intervention, whereas the other arm will be asked hypothetical questions about using this intervention. All other questions will be the same between the two arms. A thematic analysis of transcripts from the interviews will be undertaken, using a grounded theory approach. Participants in the SSM arm will need to have experienced the intervention for at least one month prior to interview.

Intervention Type
Other

Primary outcome(s)
Patient experiences and expectations of current and novel gout management using qualitative interviews analysed using a grounded theory approach

Key secondary outcome(s)
There are no secondary outcome measures

Completion date
01/11/2026

Eligibility

Key inclusion criteria
1. Evidence of a personally signed and dated informed consent document indicating that the participant has been informed of all aspects of the study.
2. Adult aged ≥18 years with gout based on full ACR/EULAR gout classification criteria, those with a physician diagnosis of gout, or those with a likely diagnosis of gout based on symptom questions from ACR/EULAR gout classification criteria.

Participant type(s)
Patient

Healthy volunteers allowed
No

Age group
Mixed

Lower age limit
18 Years

Upper age limit
120 Years

Sex
All

Total final enrolment
0

Key exclusion criteria
1. Participant is unable to consent
2. Participant has limited English language capabilities

Date of first enrolment
21/04/2026

Date of final enrolment
24/09/2026

Locations

Countries of recruitment
United Kingdom

Scotland

Study participating centre
Institute of Genetics and Cancer
The University of Edinburgh
Crewe Road
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Sponsor information

Organisation
Accord (United Kingdom)

ROR
https://ror.org/01x6s1m65

Funder(s)

Funder type
Other

Funder Name
Investigator initiated and funded

Results and Publications

Individual participant data (IPD) sharing plan
The transcripts generated during the study are not expected to be made available. Though full transcripts will be pseudonymised and identifiable information generalised, the potential depth and detail of qualitative interview transcripts may have enough information to identify others, even with changed names or places. Furthermore triangulation of data between questionnaire and interview data may increase the likelihood of data being identifiable.

The questionnaire data generated during the study will be made available upon request from the chief investigator of the study, Rowan Hart (r.e.hart@sms.ed.ac.uk).

IPD sharing plan summary
Available on request

Study outputs

Output type	Details	Date created	Date added	Peer reviewed?	Patient-facing?
Participant information sheet	version 1.0	28/03/2025	20/05/2025	No	Yes
Protocol file	version 1.0	28/03/2025	20/05/2025	No	No