Patient and Public Involvement and Engagement Information Sheet

November 2025

Early Identification of Poor Bone Health

Contact details

For questions or if you wish to withdraw your participation, please contact:

Jessica Davis

(Chief Nurse Research Fellow, St George's University Hospitals NHS Foundation Trust)

Email: Jessica.davis@stgeorges.nhs.uk

You have access to an impartial contact should you have any concerns about the way the project is being conducted. Please contact:

Victoria Mummery

(Lead Emergency Practitioner, St George's University Hospitals NHS Foundation Trust; project supervisor)

Email: Victoria.mummery@stgeorges.nhs.uk

Invitation

You are being invited to take part in a project as part of patient and public engagement (PPIE). Before you decide whether or not to take part, it is important for you to understand why the activity is being conducted and what it will involve. Please take time to read the following information carefully.

I am keen to understand the factors that make it more likely for someone to experience lower bone density and/or experience a low-energy fracture at a young age. This is because current research focuses on older adults (usually over the age of 50) and most often on women. However, newer research demonstrates that younger adult women and men also experience poor bone density or problems with how strong their bones are (a.k.a. their bone microarchitecture). Current screening tools only allow screening from age 30 or older, so this limits assessment in younger adults aged 18-30. By identifying how known risk factors and potentially new risk factors affect bone health in a younger population, we may be able to develop a new screening tool that can better predict fracture risk from a younger age.

As part of the development of a research idea and research proposal, I am seeking feedback from patients and/or their carers with lived experience of poor bone health. This may have presented as:

- A ‘low-energy fracture’, where you sustained a break in a bone from standing or a low height.
- A diagnosis of ‘osteopenia’, where your bone density is lower than it should be for your age, but not at the stage of ‘osteoporosis’.
- A diagnosis of ‘osteoporosis’, where your bone density is poor; some people call this ‘brittle bones’.

I am particularly interested in gaining feedback from members from communities that are currently under-represented in health research, including: younger adults (18-30 years old), Black, African, Asian, and Caribbean communities, LGBTQ+ communities, and people with disabilities or long-term conditions.

You will be contributing your views in a personal capacity to support the lead researcher (Jessica Davis) make the research more relevant to diverse communities by providing help with appropriate wording and research design. Your contribution is completely voluntary and, as such, no reimbursement will be provided at this time.

General information about the project and collected data

- The purpose of the project is to get feedback from patients and the public around the initial research idea, research aims and objectives, and proposed research methods.
- The project is being run by Jessica Davis as part of a Chief Nurse Research Fellowship, in preparation for applications for further research funding to complete doctoral studies.
- Your opinions (data) will be collected by an online survey which will take between 5-10 minutes to complete.
- This project will run for 6 weeks but you are only asked to complete a single survey.
- This project conforms to and complies with the City St George's University of London Research Ethics Committee's conditions for exemption from formal review. This is because sensitive patient data is not being collected nor are outcomes being published and this project is being completed as part of funding development/co-design.
- This project may create intellectual property (IP), where ideas from the research proposal will generate new information and/or healthcare tools. This IP will wholly belong to the University.

What will I be asked to do if I agree to take part?

- If you choose to take part, you will be asked to complete a single online survey, which should take no more than 10 minutes to complete.
- It is up to you to decide whether or not to take part in all or some of the activities included in the survey. If you do decide to take part you will be given this information sheet to keep and be asked to provide evidence of your consent.
- The only compulsory part of the survey is the consent form, which you will be asked to complete prior to gaining access to the survey.
- While there may not be a direct benefit to yourself after completing this project, your contribution will help shape a research project which will help further our understanding of poor bone health in younger adults and may lead to the development of new screening tools for this under-diagnosed population.
- A possible disadvantage of taking part in this project is that it is an unpaid contribution. While the contribution time is expected to be minimal (10 minutes), some may see this as a time burden. We do not expect any psychological, emotional, social, or professional impact from participation. However, if you feel you have been affected in this way, please reach out to the project lead (Jessica Davis) for support.

If you are affected by poor bone health and feel you do not have adequate information about ways to manage it, the following resources may be of interest:

Osteoporosis information and support | Royal Osteoporosis Society.

While much of this information is aimed at patients with 'osteoporosis', those with 'osteopenia' and/or those who are younger and have experienced a low-energy fracture may still find it useful.

Please note that during your involvement, you may encounter or be given access to confidential information and you are asked not share details outside of the project team.

How will the data I provide be used?

- In line with the City St George's University of London data management policy, your opinions (data) will be stored on a secure server, at a minimum, for the expected duration of research planning through to doctoral study completion (July 2029). Where the project may generate a new screening tool and require a patent application, this data will be held for and additional 10 years.
- No personally identifying information will be required on the survey. Consent confirms that public contributors who want to be contacted

for future patient/public engagement related to this project can provide their email address and that legal requirements limit the extent to which confidentiality can be preserved.

- Signed consent forms and email addresses will be collected virtually in the online survey. Where you decide you may want to be contacted in future, your name and email address will be extracted onto a password-protected excel sheet which will be stored on a secure data base which is accessed only through personal log-in through the University system. This information will be stored for, at a minimum, the duration of the doctoral project (June 2029), but up to 10 additional years if IP has been produced from the project.
- Your opinions (data) will shape a research proposal. Where you have agreed for this to be shared with you, the final research proposal will be shared via the email address you provide. Your participation and how this project was conducted will also be shared with the National Institute of Health Research (NIHR) as part of a funding application for a Doctoral Award. No patient-identifiable information will be shared in the research proposal or associated funding applications.

Your right to withdraw from the project

You are engaging with this project on a voluntary basis and have the right to withdraw from the project at any time without needing to give a reason.

If you wish your survey responses to be excluded, you may do this up until the time all data have been aggregated for analysis, which is expected to be 12 December 2025. You may do this by:

- Clicking on the ‘withdraw survey’ button

You have the right to ask for your data to be removed after your participation in the project. You may do this by:

- Emailing Jessica Davis to advise you wish your name and email address be removed from the follow-up list

How do I agree to take part?

You can 'opt in' for the project by completing the PPIE consent form at the start of the online survey.

Thank you

Thank you for taking time to read this information, even if you do not want to participate.

Data protection

- City St George's University of London and St George's University Hospitals Foundation NHS Trust are the joint Data Controllers for the personal data that you provide.
- For research-related activities, the lawful reason for processing your data will be that conducting academic research is part of City St George's University of London and St George's University Hospitals Foundation NHS Trust public task. The consent we request from you relates to ethical considerations.
- Where you have provided consent, the information you have given to us will only be used to disseminate project findings to you and/or invite you for further PPIE engagement tasks related to this project.
- The Doctoral award research project may take place at a university different to City St George's University of London. In this event, your information may be transferred to an external university. The lawful reason for these transfers is that it is part of our public task to conduct academic research. They will only be given personal data in order to carry out a specific activity, and we have contractual arrangements to safeguard their use of your personal data.
- You have a number of rights as a data subject:
    - To request a copy of the personal data we have about you.
    - To rectify any personal data which is inaccurate or incomplete.

- Restrict the processing of your data.
- To receive a copy of your data in an easily transferrable format (if relevant).
- To erase your data.
- To object to us processing your data.

If you are concerned about the way we have processed your personal information, you can contact the Information Commissioner's Office (ICO). Please visit the ICO's website for further details.