Osteoporosis & Bone Research Academy

Osteoporosis Research Roadmap

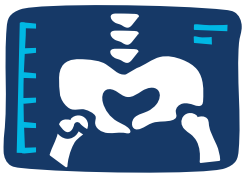
Working towards a cure

Royal Osteoporosis Society

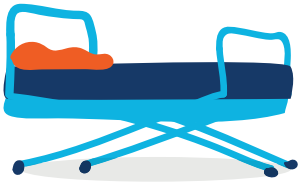
Better bone health for everybody

Contents

More than 3.5 million people in the UK are estimated to have osteoporosis



Over 500,000 fragility fractures per year in the UK



Older people with hip fractures occupy 4,000 NHS beds at any one time

Broken bones caused by osteoporosis cost the UK more than £4.5 billion every year

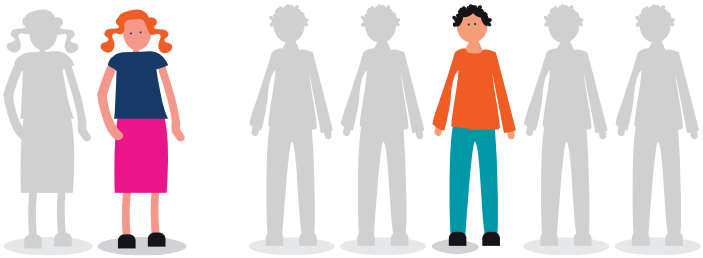
Osteoporosis is a devastating disease

Osteoporosis leads to easily broken bones from a trip or fall – termed 'fragility fractures'

Osteoporosis, literally "porous bones", is a common condition in which there is a decrease in the amount of bone and weakening of its structure, resulting in fragile bones that can break after a simple trip or fall.

These fractures not only cause severe pain and significant short-term impact on quality of life, but can result in life-changing, long-term disability and loss of independence.

There are 3.5 million people in the UK living with osteoporosis and this number is rising rapidly due to the ageing population. Despite significant advances in osteoporosis research that have led to real improvements in people's lives, there are still considerable challenges. Consequently, there is an urgent need to intensify the search for answers that can help us beat this cruel condition and prevent future generations from suffering the misery of broken bones.



One in two women and one in five men aged over 50 are expected to break a bone

One in three people with osteoporosis are in long-term pain described as 'severe' or 'unbearable'

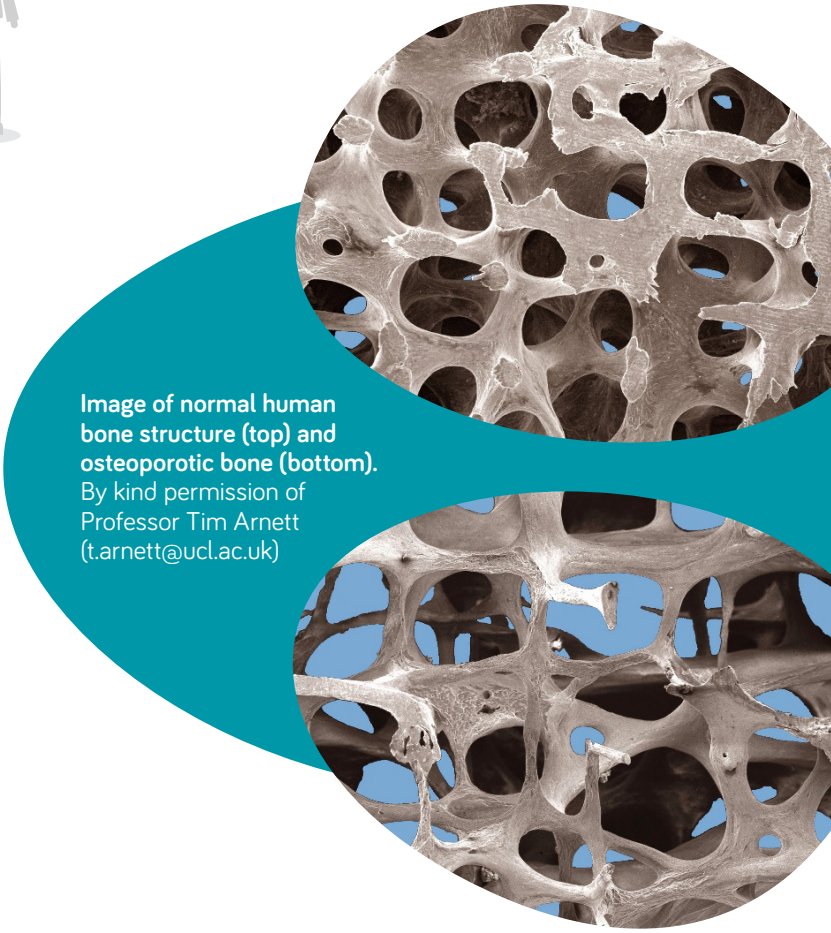


Image of normal human bone structure (top) and osteoporotic bone (bottom).
By kind permission of Professor Tim Arnett (t.arnett@ucl.ac.uk)

Royal Osteoporosis Society
a future without osteoporosis

Our vision of a future without osteoporosis will be achieved through work to:

- improve the bone health of our nation and prevent osteoporosis;
- influence healthcare providers and professionals to deliver high quality care so that all people at high risk of fragility fractures are assessed and treated appropriately;
- influence policy makers so that osteoporosis gets the priority and funding that it deserves;
- provide the best information, support and services to help people with osteoporosis live well;
- drive the research and development of new treatments and preventative strategies that will ultimately cure osteoporosis.

Osteoporosis and Bone Research Academy
putting cure centre stage

Our Osteoporosis and Bone Research Academy was launched in February 2019 by ROS President, Her Royal Highness the Duchess of Cornwall. It brings together leading national and international expertise with patient advocates.

The Academy has undertaken evidence reviews to identify gaps in osteoporosis research and patient care, and has generated a comprehensive programme of projects to address the resulting key priorities.

The Academy's mission is to achieve a cure for osteoporosis through the development of novel strategies to optimise bone health across the whole lifecourse, and to implement new practices to ensure that every person at increased risk of fracture is identified, assessed and treated appropriately.

ROS President, Her Royal Highness the Duchess of Cornwall

Osteoporosis Research Roadmap
working towards a cure

The Research Roadmap represents the culmination of the first phase of the Academy workplan, setting out the identified knowledge gaps and the planned research projects.

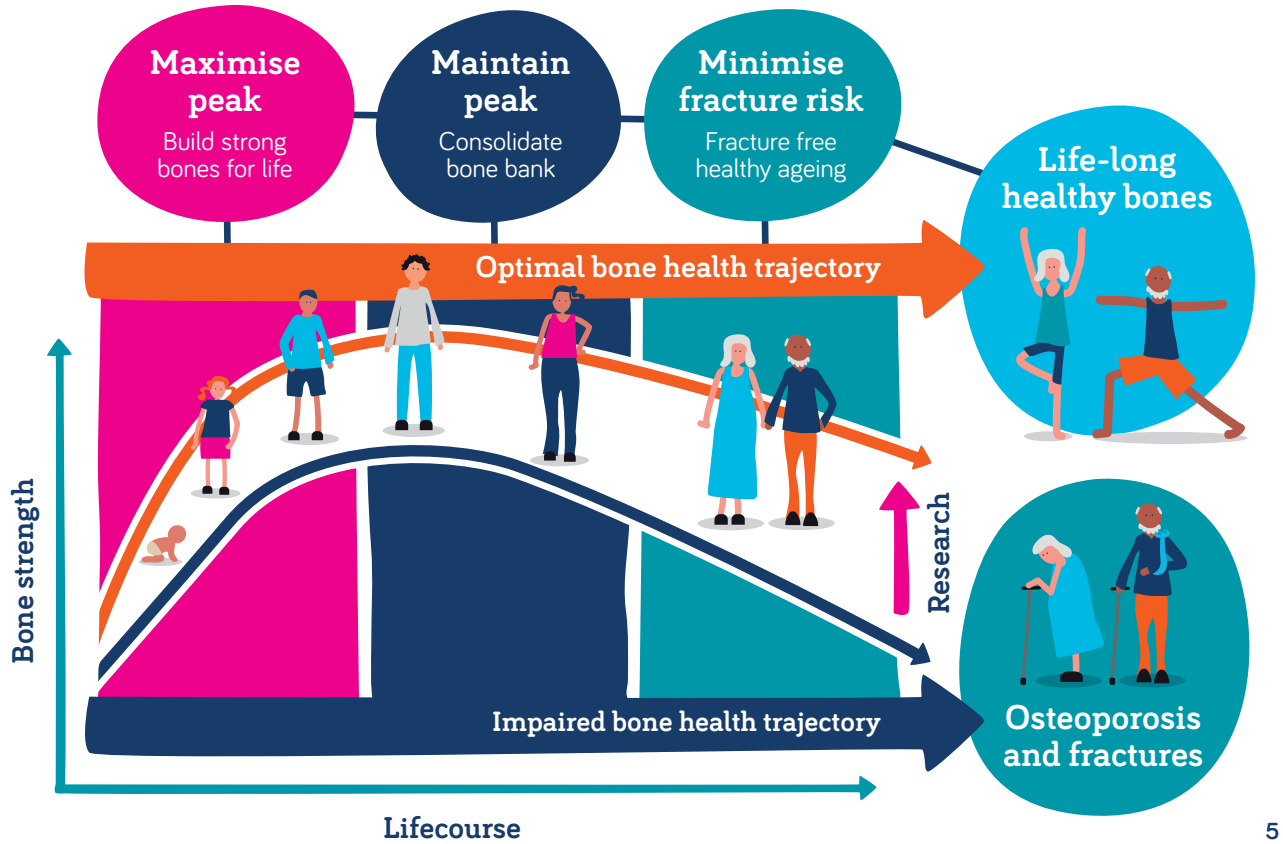
Our Osteoporosis and Bone Research Academy

Osteoporosis evidence review → **Identification of knowledge gaps** → **New projects** Causes Technology Effectiveness → **New knowledge** Dissemination Implementation → **Optimised prevention, assessment and treatment**

Cure: a world without fragility fractures

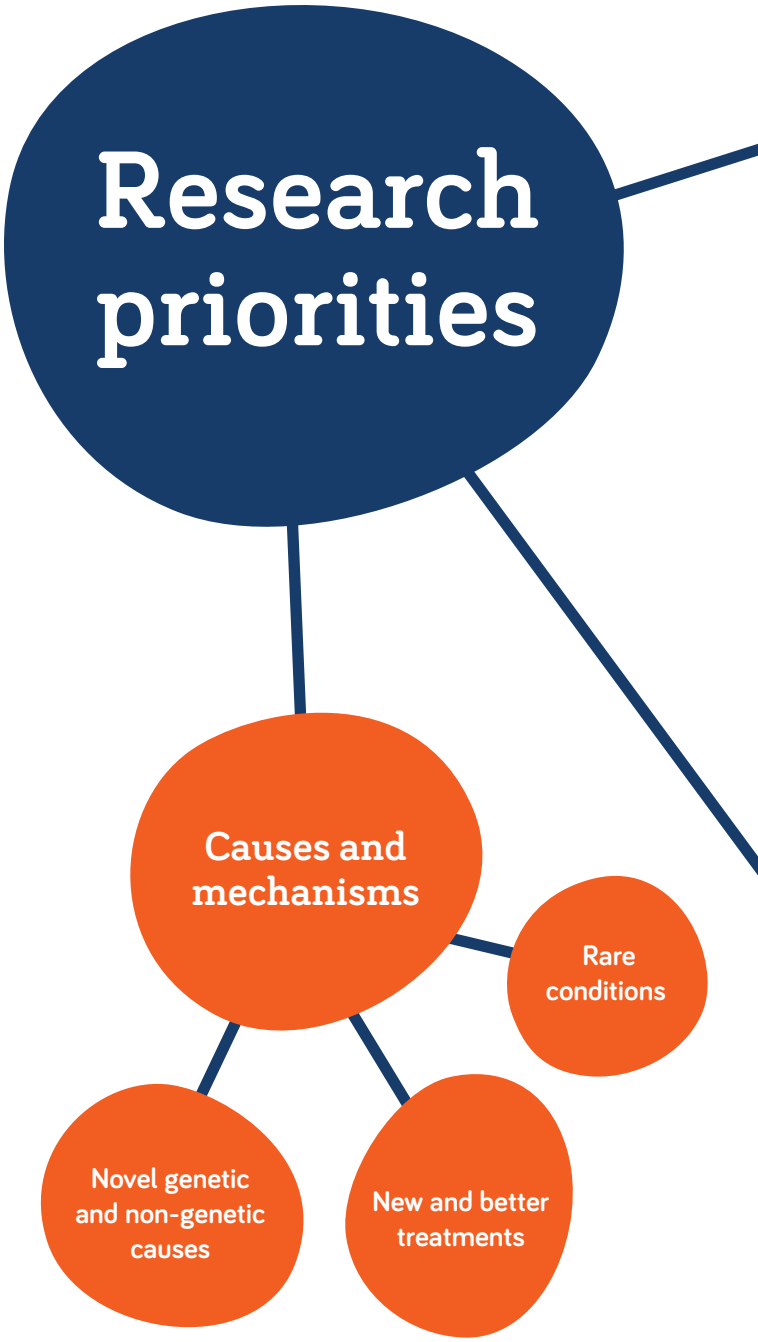
The Academy has identified key gaps in research and clinical care across three phases of the lifecourse: early growth through development in the womb and during childhood until peak bone mass is achieved in young adulthood; maintenance of bone mass through adulthood; and minimisation of bone loss and fracture risk in older age. The overarching aim is to ensure that bone development, growth and maintenance are optimised and bone loss and fracture risk are minimised (represented as the orange curve in the diagram below). This results in healthy bone ageing and ensures that all individuals avoid the impaired bone health trajectory (lower blue curve) that results in osteoporosis and fractures.

Improving the bone health lifecourse through research



Academy research priorities

The three Academy working groups (Causes, Effectiveness and Technology) have generated an integrated workplan addressing three synergistic and closely interlinked research areas: Causes and mechanisms; Novel technology for skeletal assessment; Optimising effectiveness of assessment and treatment.



Causes and mechanisms

There are many factors that influence bone health and many routes to sub-optimal peak bone mass and osteoporosis. This journey starts as early as during development in the womb.

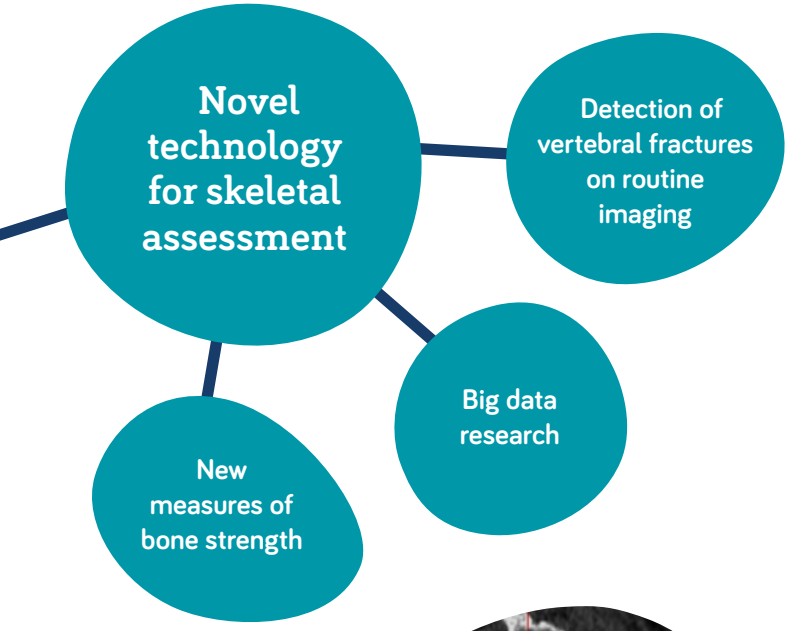
The causes and mechanisms work stream will establish novel genetic and non-genetic causes, in particular:

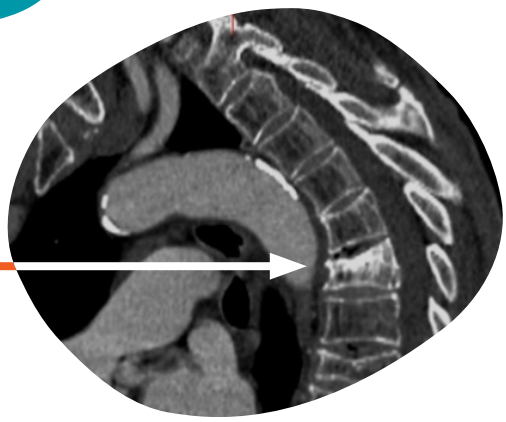
- interrogating existing genome-wide association (genetic) data to develop new and better treatments;
- exploring mechanisms linking diet and the gut microbiome (the microorganisms in our bowel) to bone health;
- studying rare disorders, such as pregnancy and lactation associated osteoporosis, to understand mechanisms that may be applicable to osteoporosis more generally, and to improve the assessment and care of people suffering from these devastating conditions.

Whilst there is already an impressive array of treatments for osteoporosis, greater understanding of underlying mechanisms will generate new and more effective preventive and therapeutic strategies, dramatically changing the outlook for patients.

Pregnancy and lactation associated osteoporosis is a rare condition when bones break (fracture) easily around the time a woman is giving birth. These fractures usually happen in the spine or sometimes the hip, and cause pain and disability.

Scanning electron micrograph of activated osteoclast and resorption pits. By kind permission of Professor Tim Arnett (t.arnett@ucl.ac.uk)





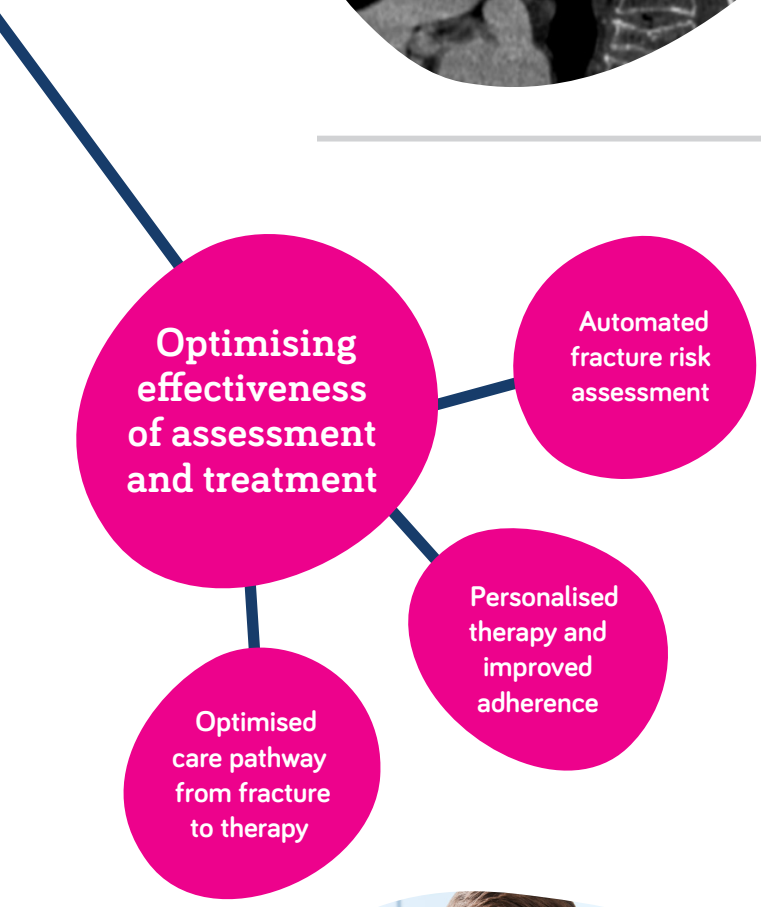
Vertebral fracture detected on a routine CT scan.

Novel technology for skeletal assessment

New technologies are the particular focus here, bringing together cutting-edge advances:

- to facilitate opportunistic detection of vertebral fractures on routine hospital imaging;
- to use big data resources such as NHS clinical records and UK Biobank to identify novel risk factors;
- to derive new measures of bone strength, for example by applying machine learning algorithms to images obtained from diagnostic scans.

Optimal use of state-of-the-art technology will lead to improved algorithms for risk assessment, enable the diagnosis of previously undetected spinal fractures and provide more accurate estimation of bone strength. Such advances will result in a step change in the ability to assess fracture risk and identify those who will benefit from osteoporosis treatments.



Optimising effectiveness of assessment and treatment

The effectiveness work stream will develop an integrated approach to the automated assessment of fracture risk, selection of appropriate therapy and optimisation of treatment adherence. This will provide:

- universal access to automatic fracture risk assessment in primary care;
- personalisation of therapy targeted to the individual level of fracture risk;
- achievement of an automated care pathway in people who fracture, including assessment, treatment and monitoring.

The undertreatment of osteoporosis remains a key care gap, and successfully ensuring that every person at high fracture risk receives appropriate assessment and treatment for osteoporosis will result in a major advance in the care of these vulnerable patients.

Patient Advocacy Framework

Patients' perspectives and inputs are key to the ongoing success of this work. Academy patient advocates sit on the Advisory Committee and expert Working Groups as equal partners and have been fully involved in setting the research priorities.

A critical element in the development of the Research Roadmap is the contribution of wider patient insight, to ensure that patients' priorities and expectations are comprehensively represented and incorporated. Patients' views on proposed research topics were received from 2,000 ROS members. All the research priorities were rated as either 'extremely' or 'very' important by at least 80% of respondents.

Endorsement of the Research Priorities by patients or carers of people with osteoporosis is essential if the Academy work plan is to achieve a real-world impact on the lives of people living with osteoporosis.

"I really welcome the Royal Osteoporosis Society's commitment to involving patients and the public in all areas of their work. I hope that by being part of a team of patient advocates in the Academy, we can help to share our insights from a patient perspective - contributing to the relevance and effectiveness of research."

Mary Bishop, Academy Advisory Committee Patient Advocate.

ROS staff with some of the Academy's Patient Advocates.

ROS Aspiring Leaders Initiative supporting the next generation of clinical and research leaders

If the ROS Academy's mission is to succeed, there is an urgent need to support the next generation of clinical and research leaders in osteoporosis and metabolic bone health.

The Aspiring Leaders initiative, in collaboration with the Faculty of Medical Leadership and Management, presents an innovative, forward-looking and exciting leadership course covering themes such as: personal effectiveness; leading through complexity; high performance team working; and influencing government policy. The course takes on 12 outstanding academics/ clinicians each year with application through initial nomination by a senior colleague.

"Only by nurturing the best and brightest minds in osteoporosis can we create a pipeline of leaders capable of finding a cure."

Lauren Wiggins, Director, Osteoporosis and Bone Research Academy

"I believe the Aspiring Leaders Programme has been an invaluable experience for me and has significantly enhanced both my academic and clinical work. I feel more empowered to 'step up' to more challenging managerial and leadership roles which previously I would have found daunting."

Michael Clynes, Clinical Lecturer in Rheumatology, University of Southampton.

ROS Aspiring Leadership candidates at Westminster, January 2019.

The Research Roadmap sets out the route to a world without osteoporosis and fragility fractures. The mission of the Academy is to work towards a cure for osteoporosis, addressing gaps in clinical research and translating the results of this work into clinical practice.

The Academy is also committed to providing support and training for the next generation of healthcare professionals and academics to ensure its continuing success. Bringing national and international experts together with the patient voice creates an exciting opportunity to optimise bone health across the population and to ensure that every individual at high fracture risk is optimally identified, assessed and treated. For more details visit **theros.org.uk/academy**

To achieve our aims we need your support. We are asking you to get behind ROS and the Osteoporosis and Bone Research Academy. You can do this in a number of ways including:

- Joining the ROS, visit **theros.org.uk/membership**
- Engaging directly in our research, via our events and by following us on Twitter and LinkedIn;
- Supporting our work through a donation.

The development of the Research Roadmap has been led by Professor Juliet Compston (Academy Chair) and Professor Nick Harvey (Academy Vice-Chair) in conjunction with the Academy Advisory Committee and Working Groups. For more details visit **theros.org.uk/research-roadmap**

Funding and support for researchers

We aim to support the best researchers at all stages of their career via a diverse portfolio of funding schemes. Building on our previous successes, we continue to implement a research grants programme in order to fund high-quality research. For more details visit **theros.org.uk/researchfunding**

Royal Osteoporosis Society
Camerton, Bath BA2 0PJ
theros.org.uk

Telephone: 01761 471771
Email: info@theros.org.uk
Nurse Helpline: 0808 800 0035

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