

Royal
Osteoporosis
Society

Better bone health for everybody



BREAKING THE SILENCE

Strategy
2022-2026





Osteoporosis is one of the most urgent public health crises of the modern era

Fractures (broken bones) caused by the condition are one of the most serious threats to living well in later life. Left untreated, osteoporosis threatens our freedom, dignity, quality of life and independence.

Put simply, we want to transform the experience of later life in this country



Join us...

Osteoporosis is an invisible disease that silently weakens people's bones, leaving them vulnerable to fractures following simple injuries. Just a fall from standing height, a cough, even a hug from grandchildren, is enough to cause a painful, life-altering fracture.

Half of women over the age of 50 will suffer a fracture due to osteoporosis, and one fifth of men¹. For most people, the first sign they have osteoporosis is their first fracture. That's why it's called 'the silent condition', characterised by under-diagnosis, under-treatment and low public awareness.

Every minute in the UK, someone breaks a bone because of osteoporosis. Sadly, as many people die from fracture-related causes as from lung cancer and diabetes².

It doesn't need to be like this. Osteoporosis is treatable and fractures preventable. With an early diagnosis and the right treatment plan, people with osteoporosis can live very well, thanks to safe, effective medication that is highly affordable for the NHS.

But missed opportunities for diagnosis and early intervention mean that tens of thousands of people every year are missing out on the medication they need.

There are missed opportunities for prevention too. Too few of us give the same thought to our bones that we give to our weight, heart and skin. If we did, we could take action to reduce our risk of fractures and keep our bones strong for as long as possible.

We're committed to our public mission to raise awareness and inspire action among the public and policy-makers, demanding change for the 3.5 million people who live with osteoporosis. We want to seize the moment and beat this condition together.

If we get this right, we can prevent hundreds of thousands of avoidable fractures, extend quality of life for millions of people, and make a game-changing difference for our NHS.

Our strategy on a page

Our vision

Strong and healthy bones for life

Our purpose

We transform lives and society by leading the effort to improve bone health and defeat osteoporosis.

Our goals

To drive fracture prevention amongst people who are at high risk.

Quicker diagnosis and better ongoing care, wherever people live.

To support more people to live well with osteoporosis.

Our values

We're Bold

We fearlessly stand up for and give a voice to people who need us.

We're Focused

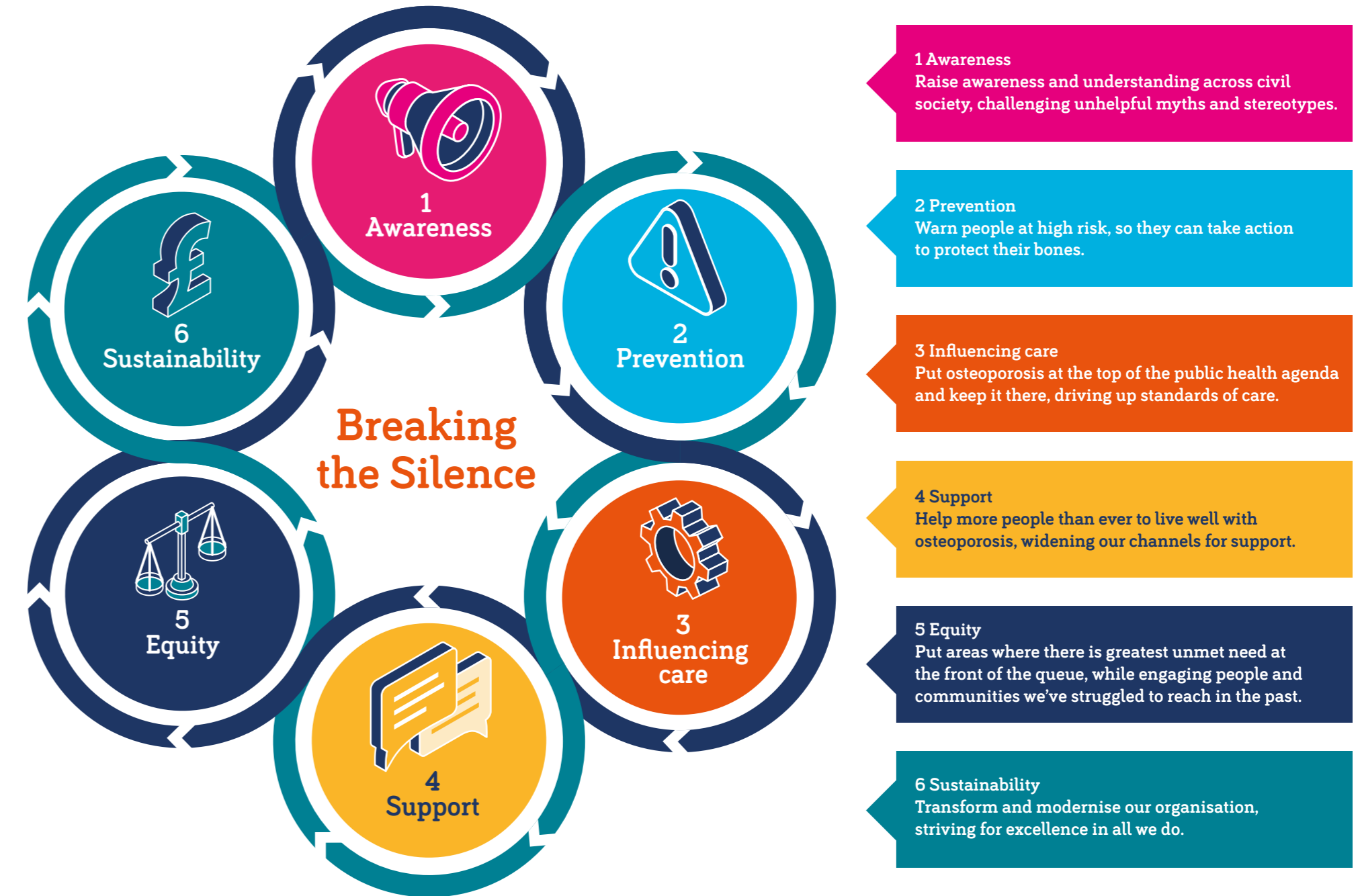
We concentrate on where we can make the biggest difference.

We're Collaborative

We work as one team and embrace partners to change society together.

We have Integrity

You can trust us to do what we say we will.



How we'll change

From our launch in 1986 we have a proud history as the UK's only national charity for people living with osteoporosis, acting as a champion and lifeline. Much of the framework of clinical standards around osteoporosis in the UK is thanks to the determination of the clinicians and activists who founded us.

We'll build on their legacy by modernising and making ourselves relevant and accessible to a wider audience. The tone of our content will become more informal, warmer and more relatable.

Most visibly, we'll put more resources into bone health and prevention, intervening earlier to transform lives and help people to age well.

This next phase in our story will be unrelentingly outward-looking. It'll look and feel different – more challenging to the system and less satisfied with

the status quo. It'll be marked by a step change in campaigning, public engagement and advocacy.

ROS only has just over £1 to spend on every person living with osteoporosis. This means we need to be more focused than in the past, concentrating our limited resources on areas where we can drive the most impact and change. This strategy will be clear about what we won't do, as well as what we will.

The scale of our mission is vast, so we need to think in terms of networks and a movement. We won't feel the need to 'own' everything ourselves, instead becoming more collaborative, better at partnership working and stronger at holding others to account.

Finally, the last decade has seen society, technology and politics change at a dizzying pace. Strategic thinking has never been more important, but we also need to stay agile and flexible. Strategy shouldn't be something we return to only once every five years, but instead will be 'always on', always adapting.



Context

BREAKING POINT

This strategy reorientates ROS to meet the needs of society following the COVID-19 pandemic.

Even before the pandemic, the treatment gap for osteoporosis was startlingly wide, with around two-thirds of people missing out on the treatment they need³. NHS backlogs have widened that treatment gap still further.

Action is now beyond the point of urgency.

For the lifetime of this strategy, we'll focus on closing the treatment gap through our advocacy, while reducing demand on the NHS through prevention and support.

Demand for our support services has reached record levels as we've filled in for NHS services. We know the NHS's recovery will take time, so we'll continue to step up for everyone who needs help. This puts a premium on the need to invest in, widen access to, and improve our direct support services.

On a local and national level, we'll influence the NHS to change, holding decision-makers to account to ensure fairer and more equitable care across all parts of the UK.

This strategy is also about inspiring a revolution in prevention. We want greater awareness amongst people in high-risk groups, and a 'nudge' to action to prevent avoidable fractures. Early intervention is the golden ticket to beating osteoporosis and fractures, while safeguarding our NHS.



AWARENESS

The challenge

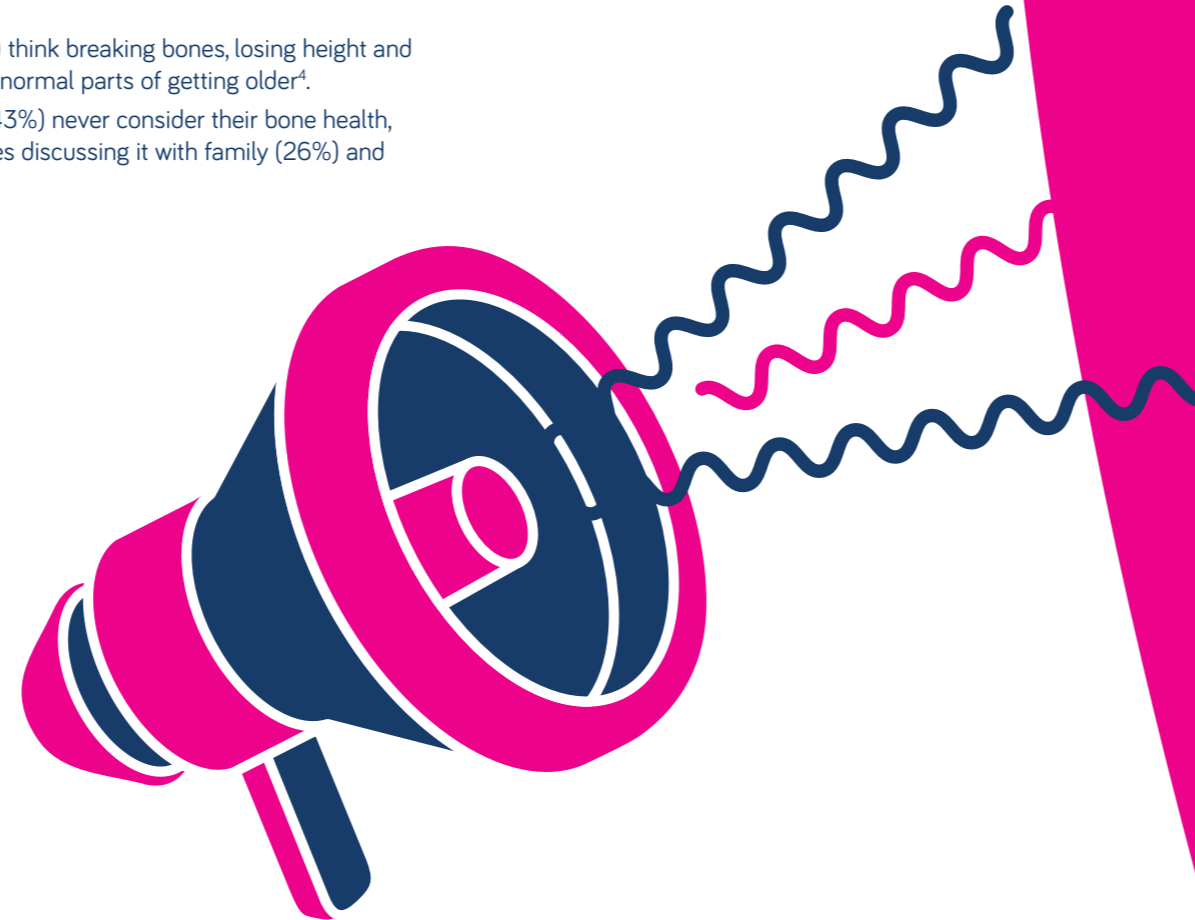
The silent condition has long been characterised by low levels of awareness. Harmful stereotypes about ageing are getting in the way of a timely diagnosis of osteoporosis. Further misconceptions that the condition only affects older people and women are preventing thousands from taking notice and acting.

The same applies to bone health. Low awareness is the first barrier to overcome if we're to inspire a revolution in prevention amongst people who may be at higher risk.

The evidence

- Four in ten people (41%) think breaking bones, losing height and being hunched over are normal parts of getting older⁴.
- Almost half of people (43%) never consider their bone health, with only small minorities discussing it with family (26%) and friends (12%).⁵

We want to transform the culture around osteoporosis from passivity and defeatism to one of optimism and determination



The change we'll make

Strategic objective: Raise the level and tone of discussion about osteoporosis and bone health across civil society

We'll influence commentators, charities, public authorities, businesses and political leaders to tell the real story about osteoporosis in the UK, drawing on people's experience as well as the latest statistics and research. We'll change the image of osteoporosis by challenging unhelpful myths and stereotypes.

We want to transform the culture around osteoporosis from passivity and defeatism to one of optimism and determination. This strand is about mobilising like-minded organisations across the UK to create an environment where it's easier to talk about osteoporosis, and where positive action to improve bone health is role-modelled and celebrated.

Strategic objective: Advise, accredit and hold to account the organisations that provide services for people with osteoporosis

We know that people living with osteoporosis rely on a range of products and services from businesses, charities and the public sector. We'll use expert clinical guidance, advice, accreditation and publicity to make sure those products and services are as good as they should be.

How we'll measure our impact

We'll increase our media coverage and grow our network of commentators. We'll show strong examples of how we've supported, influenced and challenged other organisations for the better.



PREVENTION

The challenge

We want to identify people who are at risk of breaking bones and make sure treatment is offered to prevent the first fracture. We need to warn people who have already had a fracture that this may be due to osteoporosis and that it's never too late to prevent the second and subsequent fractures. We know prevention is the key to helping people live well – and that to make a generational difference we need to act now.

The evidence

- A fifth of women with osteoporosis suffer three or more fractures before getting a diagnosis.⁶
- Over a third (38%) of people had to wait over a year after their first broken bone to get diagnosed; almost one in five (17%) had to wait more than five years.⁷

We'll launch the most ambitious public outreach effort in our history

The change we'll make

Early in the life of this strategy, we'll launch the most ambitious public outreach effort in our history. An early warning can help get people into the system, tackling under-diagnosis and sparing them the pain of avoidable fractures.

Strategic objective: Launch an ambitious campaign to influence people at higher risk of osteoporosis to take action for their bones

We'll concentrate on reaching people who are at high risk of osteoporosis. As a small organisation, we need to be targeted if we want to cut through. We'll start with those in urgent need: people who've had a fracture, but no checks for osteoporosis, which leaves them at risk of further broken bones.

A self-assessment tool will help people understand their risk of fracture, with a 'nudge' to action for those who are at higher risk. When the advice is to contact their GP, we'll make sure that there's guidance for the GP about what to do next.

Another top-priority group is people who live with health issues that increase their risk of osteoporosis, for example inflammatory conditions, steroid treatment, menopause and some cancer therapies. We can reach them through joint work with the charities and organisations that support and represent them. We need to do more of this type of collaboration and get better at it.

Strategic objective: Create a bone health platform that makes us relevant to people who don't have osteoporosis but may have a higher risk of developing it in future

We'll develop a bone health campaign to make our message relevant to people who don't have osteoporosis. This second phase will extend our campaign to raise awareness of bone health amongst women and men over 45. This age coincides with when people are invited for five-yearly health checks, and also the perimenopause in women when the risk of osteoporosis spikes.

We'll concentrate on the prevention messages that set us apart – including weight-bearing exercise, vitamin D supplementation and a calcium-rich diet. For generic messages around diet, smoking cessation and alcohol reduction, we'll work in partnership with public authorities and other health charities, rather than acting alone.

To keep our efforts focused we won't engage younger groups during this strategy, but if we're successful we'll scale the campaign up in future.

How we'll measure our impact

As a proxy for fracture prevention, we'll set ambitious targets for use of the self-assessment tool showing how people took action for their bones based on its recommendations.



INFLUENCING CARE

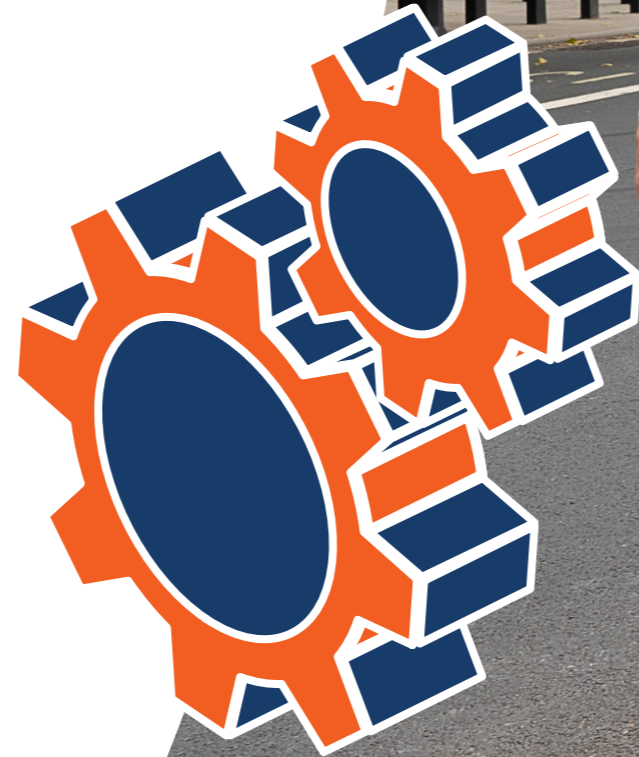
The challenge

Tackling osteoporosis is the key to making sure our ageing society can live well. Without action, a longer life won't be a better life. Without change, our public services face an impossible level of demand. But so far, the silent condition has punched way below its weight in public policy and the NHS.

ROS has long championed the blueprint for timely diagnosis and care: Fracture Liaison Services (FLS). But health inequalities run deep across the four nations, with a postcode lottery for quality care. Our healthcare professional networks have the insight and experience to shape the change needed. We need to get their voices heard at all levels in the NHS.

The evidence

- 2.2 million people have undiagnosed spinal fractures – these are alarm bells for future hip fractures, which alone cost the NHS £2bn per year, but around 70% never come to medical attention.⁸
- Almost a third of people (29%) had to prompt their own health assessment.⁹
- Less than a third of people (32%) are satisfied with the level of monitoring and review they're getting.¹⁰
- Only one in ten (13%) thinks the NHS gives osteoporosis the attention it deserves.¹¹



The change we'll make

Strategic objective: Put osteoporosis and bone health at the top of the public health agenda and keep it there

We'll be a bold, campaigning charity that makes the strongest case for reform in the NHS, social care system and other public services. We want to galvanise our members, volunteers and supporters into a movement for change.

We'll make the case for osteoporosis care and treatment to be a top priority for all four UK health systems, with national plans and investment in place across each. And we'll fight hard to make sure that everyone can get the timely diagnosis, treatment and care they need, wherever they live.

We'll be a bold, campaigning charity that makes the strongest case for reform in the NHS, social care system and other public services.

Devolution has fostered game-changing health innovations, from the smoking ban to the organ donation opt-out. That's why we'll make sure we're as influential in the Senedd, Holyrood and Stormont as we are in Whitehall.

There are more platforms for us to shape public policy than ever before: the Long Term Plan's focus on ageing well and prevention, Best MSK Health, Integrated Care Systems (ICS), the One Wales Plan, the Women's Health Strategies in England and Scotland, and unprecedented interest in the menopause. We'll put osteoporosis at the heart of all these reforms.

Strategic objective: Shape and drive up NHS standards and improve care

Getting the right treatment can depend on where you live and how well-informed healthcare professionals are about the best ways of treating osteoporosis. So we'll continue to foster NHS service improvement across the whole UK, spreading best practice and raising standards. But to truly serve the whole country, we'll be more strategic and facilitative than in the past, using our standards and convening power to empower strong local voices to do the delivery.

Our policy arguments are only as strong as our insights from frontline practice. We'll continue to build our active network of healthcare professionals from different specialties and disciplines to come together and learn from each other. We'll educate and train healthcare professionals on osteoporosis where we're best placed to do so, while influencing the Royal Colleges and others to do it at scale. We need to improve our connections with GPs, pharmacists and other professionals. And we'll work with our clinical members to define what best practice looks like and champion this standard in our engagement with public authorities.

Strategic objective: Foster world-class research, focusing our grants programme on pioneering studies which can help close the treatment gap

Research has always been a top priority for our members. They want the pipeline of new treatments and diagnostic methods to be as strong as possible for the benefit of people now and in the future. That's why we launched the Osteoporosis and Bone Research Academy as our research network, and it's why we've invested record amounts in research in the years since. Our strength is putting the voice of people living with osteoporosis at the heart of every study we fund.

In view of the scale and urgency of the treatment gap we'll focus our grants on studies that can improve care and lead to quicker and more accurate diagnosis. When this strategy is complete, we'll return to the other parts of our Research Roadmap, including the important causes and genetics agenda.

We're not an academic think-tank or research institute; we generate and apply evidence to real-life settings. We'll make sure breakthroughs are quickly put into practice, so that advances in research rapidly make a difference. When we find solutions, our advocacy work will make the case to Government and NHS leaders for the changes needed to put theory into practice.

How we'll measure our impact

To track our progress in improving care we'll monitor the number of fractures identified using the FLS Database, as well as the number of people given the medication they need.

We'll maintain our recent record investment in research. There'll be examples of improved diagnosis and treatment methods as a result of studies we've funded.



SUPPORT

The challenge

We want to dramatically transform people's and carers' experience of osteoporosis. Every year, our support services help tens of thousands of people to live well with the condition. But we know we're reaching only the tip of the iceberg. There are millions of people in need of our help who we don't reach at all.

Our support services continue to be in record demand following the pandemic. To play our full role we need to modernise our services, reach more people and ensure no one feels excluded from the help we offer.

We'll expand our support offer through digital, one-to-many channels that will reach more people than ever before

The evidence

- A quarter of people (26%) are living in long-term pain; a third of those (36%) say the pain is severe or unbearable.¹²
- Half of people (48%) say osteoporosis has affected their emotional health, mainly because of pain and having to stop activities they enjoy. 70% say that fear of fractures has had a significant impact on what they do.¹³
- Only half (53%) of people feel the benefits and drawbacks of their medication were properly explained.¹⁴
- Osteoporosis has one of the lowest rates of treatment adherence of any condition.
- Only half of people (54%) feel confident about managing their osteoporosis.¹⁵



The change we'll make

Strategic objective: Significantly widen the reach of our specialist support and information services to help more people live well

Over the next four years, we'll expand our support offer through digital, one-to-many channels that will reach more people than ever before. Our target will be to provide a million pieces of support and information per year by the end of 2025. We'll concentrate on the themes people have told us are most important for them: support with medication, exercise, preventing fractures and healthy eating to strengthen bones. We'll put a special emphasis on supporting people who are newly diagnosed. And our impressive network of volunteers will be at the centre of our effort to design new services.

An early priority will be to refresh our membership offer to provide long-term support, including to people who are less comfortable online, while finding new ways to connect our members across different parts of the UK.

We know osteoporosis can be tough on carers, family and friends, so we'll provide the best quality information to support them too.

Underpinning all this will be an ambitious refresh of our website, so we can give people better content, a more usable platform and a modern, more informal look and feel.

Finally, we'll raise our profile with healthcare professionals so they routinely direct all patients to our information and support.

Strategic objective: Prioritise helping more people feel empowered with their treatment plan and care

An osteoporosis medication plan can be complicated to follow, which isn't helped by a lack of review and systematic follow-up in many areas of the country. We'll prioritise helping people to become more confident with their medication plan through our digital and telephone support.

Support with navigating public services is important too. We'll empower people to know what excellent care looks like, and how to discuss any concerns with their healthcare team. We'll give people the knowledge and confidence to ask questions, interpret advice, and make informed choices about their care.

How we'll measure our impact

We'll show year-on-year rises in the number of people getting support from ROS directly, helping them feel more confident about managing the impact of osteoporosis in their lives.

Cross-cutting strand

EQUITY

The challenge

Osteoporosis isn't experienced by everyone the same way. There are stubborn health inequalities around the UK, which cause unmet need that is even more urgent to address.

The evidence

- People from lower-income households have a 25% higher risk of fractures¹⁶ and a higher mortality rate following hip fractures¹⁷.
- People from lower-income households typically experience more severe pain from fractures, feel more isolated, are more physically impacted, and less satisfied with the information available to them.

We'll put the areas with the deepest health inequalities at the front of the queue for our awareness-raising, prevention, influencing and support work



The change we'll make

Strategic objective: Focus our activities on the areas where there is greatest need, while making our support services more accessible for the people who need them most

We'll put the areas with the deepest health inequalities at the front of the queue for our awareness-raising, prevention, influencing and support work.

We'll understand better the reach of our information and support into different communities of people and make sure we're relevant to their specific experiences. Most urgently, we'll make sure people from lower-income households get the support they need.

Our member research shows we also have work to do in reaching men and people from ethnic minorities, so we'll pay special attention to improving our engagement here too.

To succeed, we need to role-model openness and inclusion, so we'll work hard to improve diversity in our workforce at all levels.

How we'll measure our impact

Each year we'll show how our priority programmes have directly addressed the needs of people and communities identified in this strand

Cross-cutting strand

SUSTAINABILITY

We'll only succeed in our mission if we run a resilient, sustainable organisation. That means spending every pound that's donated to us wisely, prizing financial responsibility.

People rely on us to change and improve lives, so we'll build a high-performance culture that's committed to excellence. Crucially, this means being a good employer and investing in our people – who are our greatest asset. We'll bring out the full range of their talents, making sure we're a great place to work.

We'll prize the input of volunteers. And we'll work in partnership with organisations that share our vision, pooling resources and avoiding costly duplication.

People's health outcomes are intrinsically linked with the need for a clean environment, so we won't waste any opportunities to reduce our carbon impact.

How we'll measure our impact

We'll raise our employee engagement rating, while continuing to make record investment in professional development. We'll grow and diversify our income, while keeping within the limits of our new, stricter reserves policy



The catalysts that will speed up our progress

To grow our capacity to deliver the change people need, we'll:



Reflect people's lived experience in everything we do



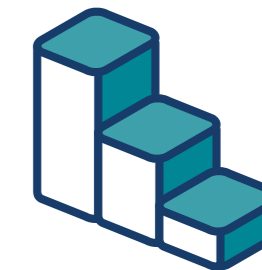
Grow and diversify our income



Foster innovative research collaborations



Make the most of digital, data and tech



Measure our progress, learn from ourselves and others, and adjust our priorities and plans accordingly

People rely on us to change and improve lives, so we'll build a high-performance culture that's committed to excellence

How we designed this strategy

We put the voice of people living with osteoporosis at the heart of this new strategy.

Our detailed *Life with Osteoporosis 2021* survey was completed by over 3,200 people. The findings gave us the richest set of insights for many years into the realities of living with the condition.

We collected further insights from our public and healthcare professional members, who helped us understand their priorities. We're fortunate to have the input of over 70 Volunteer Advocates, who represent the 3.5 million people with osteoporosis, and many of them brought their lived experience to this strategy. We also gathered insight on the public's views of bone health.

No charity succeeds in bringing about social change in isolation, so we conducted in-depth interviews with the full range of our partners and stakeholders. This included Parliamentarians, NHS leaders, funders, clinical leaders, and domestic and international sister charities.

We tested the final strategy with our Members and Volunteers Committee and Volunteer Advocate community to make sure our new strategic direction reflects their hopes, ambitions and priorities. We'll now check in with them regularly on how we're translating words into action.



Citations

1 International Osteoporosis Foundation. 'Broken Bones, Broken Lives: A Roadmap to Solve the Fragility Fracture Crisis in the United Kingdom', 2018

2 C Willers, N Norton, NC Harvey, T Jacobson · H Johansson, M Lorentzon, EV McCloskey, F Borgström, JA Kanis. *Epidemiology and Economic Burden of Osteoporosis in the United Kingdom*, International Osteoporosis Foundation and Royal Osteoporosis Society

3 *Epidemiology and Economic Burden of Osteoporosis in the United Kingdom* · C Willers · N Norton · NC Harvey · T Jacobson · H Johansson · M Lorentzon · EV McCloskey · F Borgström · JA Kanis

4 *Research conducted for ROS by YouGov (2021)*

5 *Research conducted for ROS by YouGov (2021)*

6 *ROS Stop at One survey (2013)*

7 *ROS Life with Osteoporosis report (2021)*

8 *ROS State of the Nation report on vertebral fractures (2021)*

9, 10, 11 *ROS Life with Osteoporosis report (2021)*

12, 13, 14, 15 *ROS Life with Osteoporosis report (2021)*

16 Valentin et al, *Socio-economic inequalities in fragility fracture incidence: a systematic review and meta-analysis of 61 observational studies*

17 Valentin et al, *Socio-economic inequalities in fragility fracture outcomes: a systematic review and meta-analysis of prognostic observational studies.*



Join us...

theros.org.uk

info@theros.org.uk

   @RoyalOsteoSoc

Helpline

0808 800 0035

nurses@theros.org.uk

President: HRH The Duchess of Cornwall

Royal Osteoporosis Society is a registered charity no. 1102712 in England and Wales, no. SC039755 in Scotland, and no. 1284 in Isle of Man.
Registered as a company limited by guarantee in England and Wales no. 4995013, and foreign company no. 006188F in Isle of Man.

Published February 2022