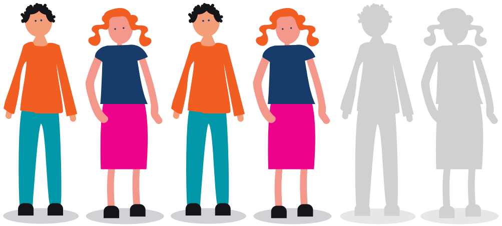
BREAKING THE SILENCE

Our Manifesto to Defeat Osteoporosis

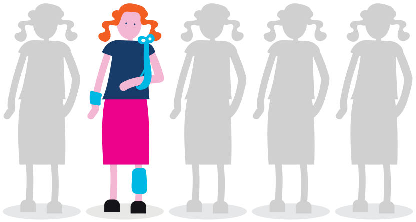
Royal
Osteoporosis
Society
Better bone health for everybody

Breaking the silence is vital



Two-thirds of spinal fracture patients in the UK – up to **2.2m people** – remain undiagnosed.

Untreated, spinal fracture patients are **three times more likely** to suffer a hip fracture.



A fifth of women who have broken a bone **break three or more** before even being diagnosed.

For every **£1** spent on Fracture Liaison Services, the taxpayer can expect **£3.28** back.

A Manifesto for a Future without Osteoporosis

Osteoporosis affects 3.5m people in the UK [1], but it's known as the 'silent disease', because of under-diagnosis, under-treatment and low public awareness. Yet fractures are linked to a similar number of deaths each year as lung cancer, diabetes or chronic lower respiratory diseases.[2]

Causing over half a million broken bones every year [1], osteoporosis has a devastating personal, societal and financial impact, with many thousands of people suffering alone and in silence – living with fear, severe pain, increasing isolation, loss of independence and unable to lead the life they want.

Osteoporosis has a devastating personal, societal and financial impact

Osteoporosis and fractures are preventable. Yet there's an ill-informed perception that osteoporosis and broken bones are an unavoidable consequence of getting older.

Fractures can follow minor injuries such as a simple fall. Even a cough, a sneeze or a hug from grand-children can trigger an acute, painful spinal (vertebral) fracture.

Hip and spinal fractures are particularly serious and devastating. A year after a hip fracture, up to 60% of people need help with activities including eating, dressing and taking care of their personal hygiene.[3] Tragically, around one in four dies within a year of their hip fracture.[4, 5]

Two-thirds of people with spinal fractures – up to 2.2m people – are undiagnosed.[6] Untreated, these people are around three times more likely to go on to suffer a hip fracture.[7]

A quarter of working age people with osteoporosis have to give up work, change their job or reduce their hours [8], with knock-on effects for the labour market.

GP care is patchy and opportunities to identify people with osteoporosis before their first fracture are often missed, resulting in failure to prevent life-changing pain and disability.

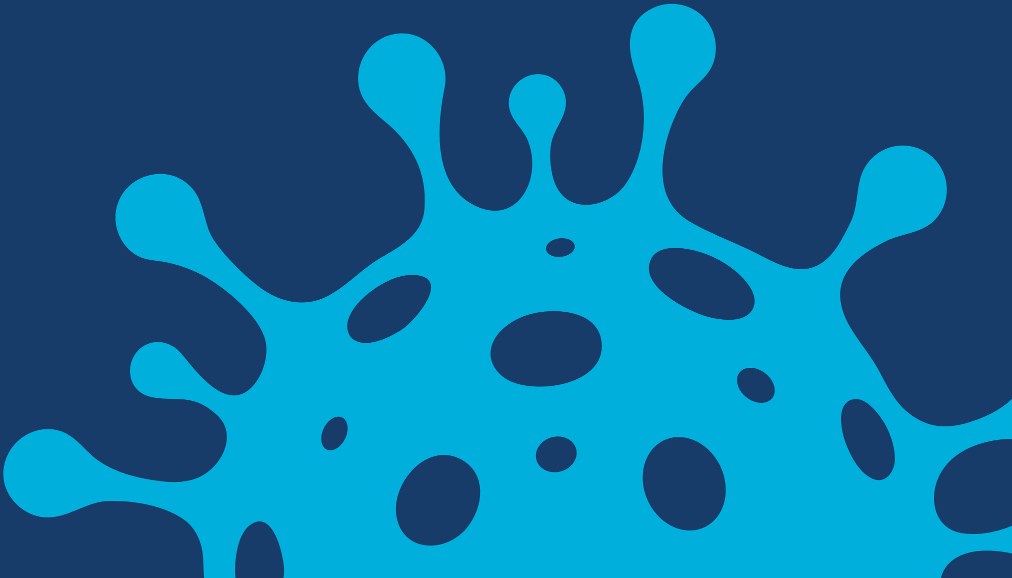
After the first fracture, there's a postcode lottery for high quality Fracture Liaison Services (FLSs), the world standard for secondary fracture prevention. There is evidence that the pandemic has worsened inequalities still further.[9]

With our ageing population, osteoporosis will put an increasing burden on the NHS – currently £4.5bn and projected to rise steeply.[2] Now is the time to break the personal, societal and financial costs spiral and take action to put an end to the dire consequences of fractures.

COVID-19 impact on fracture risk

The order to "stay at home", and for the most vulnerable to shield, was taken very seriously by huge numbers of the frail and elderly, many of whom barely left their houses. The consequences for bone health are still being realised.

Lack of exercise and vitamin D, caused by prolonged lockdowns, is a potent recipe for a dramatic increase in falls and fractures – placing additional burden on our already overstretched NHS.



We’re calling on policy-makers to take action to:

1. End the postcode lottery for accessing quality-assured secondary fracture prevention
2. Incentivise GP surgeries to routinely use digital tools, which can assess risk and prevent the first fracture
3. Make osteoporosis core business across health and social care, joining the dots with a coherent pathway of care and prevention
4. Level up investment in research into musculoskeletal conditions, which is disproportionately low

1

End the postcode lottery for quality-assured secondary fracture prevention

Fracture Liaison Services (FLS) are the tried and tested model for systematically identifying and assessing people aged 50 and older who have had a fragility fracture, and delivering a personalised treatment plan to prevent further fractures.

The FLS model is a proven game-changer, reducing the risk of re-fracture by between 30-40%.[10] This success rate is why the FLS model has become the world-standard for secondary fracture prevention. It was pioneered in Glasgow, championed by the Royal Osteoporosis Society (ROS), and subsequently exported across the globe. So it's a bitter irony that FLSs are still inaccessible to so many people in this country. While everyone in Scotland and Northern Ireland has access to an FLS, only just under two thirds of the population in England is covered, and 72% in Wales. Even living the wrong side of a city can markedly increase a person's risk of re-fracturing, due to lack of access to an FLS.

Ensuring everyone over the age of 50 has access to a quality-assured FLS would prevent over 50,000 fractures across England and Wales over a five year period[10]. This would unlock a £287m net saving to the NHS over those five years[10]. The investment would free up 540,000 acute bed days and 114,000 rehabilitation bed days over the same period.[10]

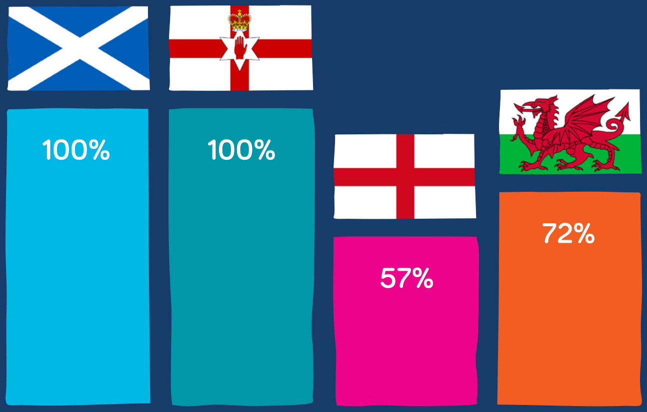
Having access to an FLS is not the whole solution. The effectiveness of the FLS model depends on the quality of the service provided and like coverage, this is also a postcode lottery. The ROS Clinical Standards for Fracture Liaison Services [11] set out the principles critical for an effective FLS. Over the years, the ROS has provided peer review, resources to raise standards, training for staff, and a Champions Network, but we need strong top-down direction to create system change.

Investing in universal coverage and achievement of these quality standards will pay for itself multiple times over: for every £1 spent on FLS, the taxpayer can expect £3.28 back.[11]

COVID-19 impact on clinical services

The COVID-19 pandemic has widened the treatment gap in hospitals still further. A major backlog in appointments for assessment, bone density scans (DXA) and treatment developed during the first lockdown as staff were redeployed to acute services. An ROS survey from July 2020 showed that around half of FLSs closed and DXA scanning was reduced by 80%. This survey was repeated in March 2021 and found that 15% of FLSs remained closed and 79% of DXA services still had capacity reduced by more than 50% in order to be COVID-safe.

During the lockdown, 51% of callers to the ROS Specialist Nurse Helpline said they had nowhere else to go.



Access to FLS by country

2 Incentivise GP surgeries to routinely use digital tools, which can assess risk and prevent the first fracture

The majority of osteoporosis management is delivered in primary care. But many GPs and other healthcare professionals lack confidence in managing osteoporosis, missing opportunities to identify people at risk early and prevent their first fracture. A recent study showed that 65% of older women seen in primary care who were at high risk of fractures were not given the medication they needed, due in part to a failure to diagnose osteoporosis.[12]

40% of people were either ambivalent or dissatisfied with the advice of their GP

Our evidence shows that 40% of people were either ambivalent or dissatisfied with the advice of their GP. We also know that 39% of people diagnosed with osteoporosis prompted their own bone health assessment.[8] Experience tells us that people living in areas of deprivation, people who speak limited English, and people with cognitive impairment are less likely to step forward.

A fifth of women who have broken a bone, break three or more before even being diagnosed.[13]

These stark figures show how much harm could be prevented if we put prevention at the heart of primary care. Frustratingly, accessible digital solutions already exist, but they're not integrated properly into IT systems in GP surgeries.

These IT solutions can identify people with risk factors for osteoporosis before the first fracture. A ten-year fracture probability assessment (FRAX)[14] can be carried out to quantify the risk, alongside a falls risk assessment. Patients who are found to be at higher risk can be offered anti-osteoporosis treatment pro-actively, with a personalised management plan, comprising medication, lifestyle advice, vitamin D supplementation and falls prevention strategies including balance and stability sessions.

Provided we support GPs with education and training on bone health, this vision for early intervention becomes a reality.

> *“I do wonder whether, if I had been referred for a scan six years ago, my osteoporosis might not have been given the opportunity to advance as far as it has.”*
>
> Janet

3

Make osteoporosis core business across health and social care, joining the dots with a coherent pathway of care and prevention

A crucial tenet of the NHS Long Term Plan is to treat avoidable illnesses early on. *Getting it Right First Time* (GIRFT) principles show the importance of making sure the whole pathway is effective and joined-up and that best practice is identified and replicated to reduce variability within and between services. Yet far too many people fail to get the timely support they need. Even amongst those who do, more than half stop taking their treatment within the first year and are not followed up and offered an alternative.[15]

To change this picture, osteoporosis needs to be treated as core business for all healthcare professionals, in the same way that cholesterol, blood pressure and blood sugar are routinely monitored, and proactive action taken. Wherever a risk for osteoporotic fracture presents, whether this is a person starting steroid treatment with their GP, someone taken to A&E with a fracture, or an elderly care home resident having frequent falls, this should trigger a personalised pathway of care to manage their risk.

Clear guidance will be needed to achieve this step change. Current UK guidance on osteoporosis is piecemeal, some is out-of-date and some is contradictory. The National Institute for Health and Care Excellence (NICE) strategy gives us a chance to totally reboot the standard of care. So we're calling on NICE to issue a new, up-to-date, comprehensive and authoritative guideline for the management of osteoporosis – defining a new joined-up pathway that works right across Integrated Care Systems (ICS).

New NICE guidance has the potential, and authority, to reduce inequalities and drive up standards in the management of osteoporosis – from case identification, risk stratification and DXA scanning, to drug sequencing, monitoring and lifestyle advice. As part of this jigsaw, the ROS Specialist Nurse Helpline can provide nationwide direct support to everyone who needs it, as long as there's sustainable funding.

“ *I really do believe that if the fracture I suffered in my spine had been spotted earlier than it was, I would have been spared a great deal of pain and suffering. Believe me when I say, living with these fractures is a nightmare that never goes away.* ”

Christine

“ *When I was at my worst with my spinal fractures, the discomfort from feeling like I was being squashed was just absolutely unbearable.* ”

CM

4

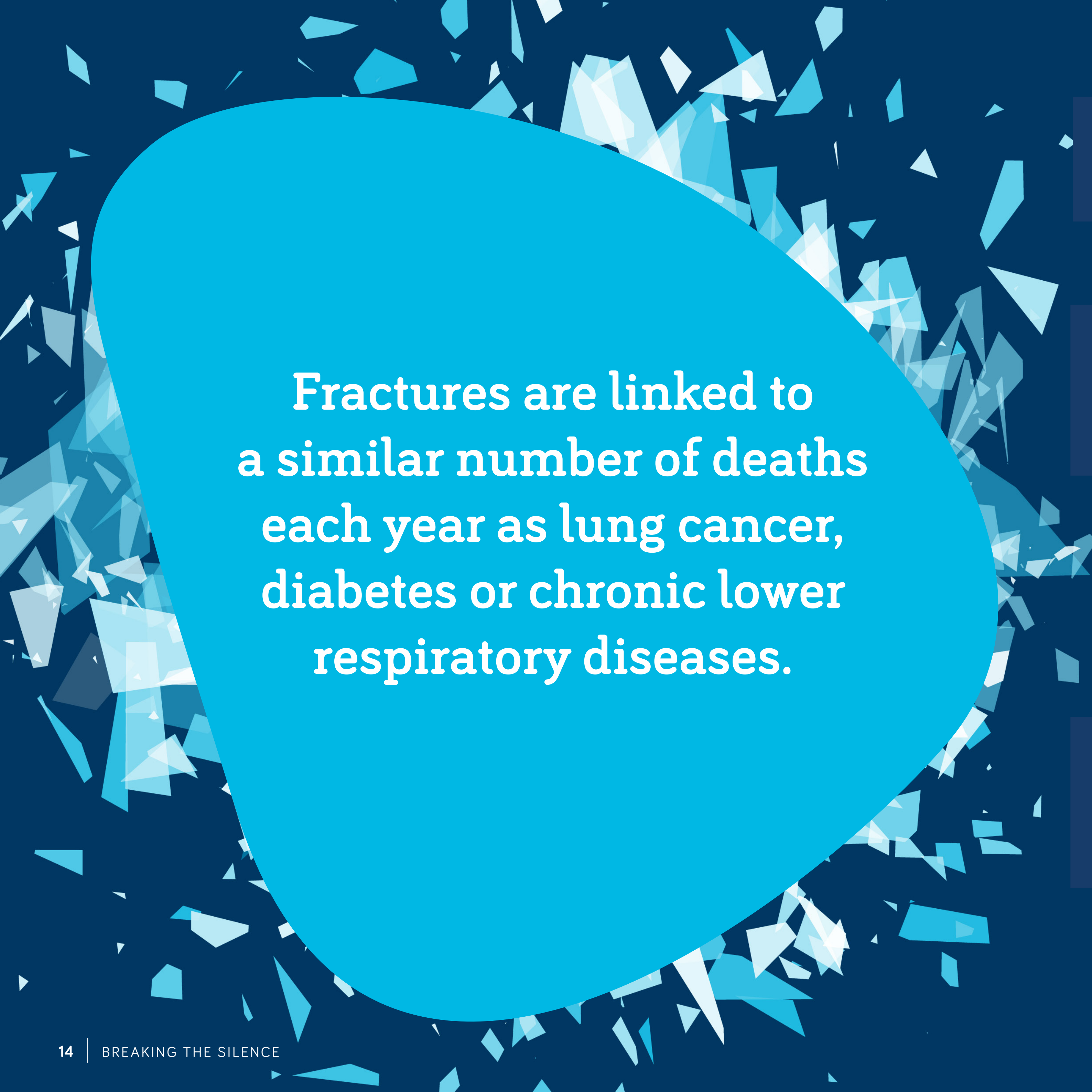
A fair share of research investment

During the pandemic, the benefits of collaborative research couldn't have been made clearer. The speed of vaccine development shows what can be achieved when clinicians, academia, government and the private sector join forces in the public interest. These developments inspire hope that other conditions can be eased, or even better defeated, through coordinated research.

The Royal Osteoporosis Society (ROS) is leading research on osteoporosis. Our Research Roadmap aims to bridge the gaps in knowledge and focus research priorities. Essential research is required to address the significant undertreatment of osteoporosis and introduce new methods of identifying and treating people who are at higher risk.

But we can't do it alone. We ask Government to match-fund our research investment, as part of a much-needed rebalancing of research investment towards musculoskeletal (MSK) conditions, which account for 9% of the health burden but a mere 3% of research spend.[16] Together, we can defeat osteoporosis.

MSK conditions account for 9% of the health burden but a mere 3% of research spend



Fractures are linked to a similar number of deaths each year as lung cancer, diabetes or chronic lower respiratory diseases.

About us

The Royal Osteoporosis Society is the UK's only national charity dedicated to bone health and osteoporosis. We work to improve the bone health of the nation and support everyone with osteoporosis to live well through our support services and advice.

We influence and shape policy and practice at every level through our work with healthcare professionals and policy-makers. We're driving research and the development of new treatments, working towards defeating osteoporosis.

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President: HRH The Duchess of Cornwall

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