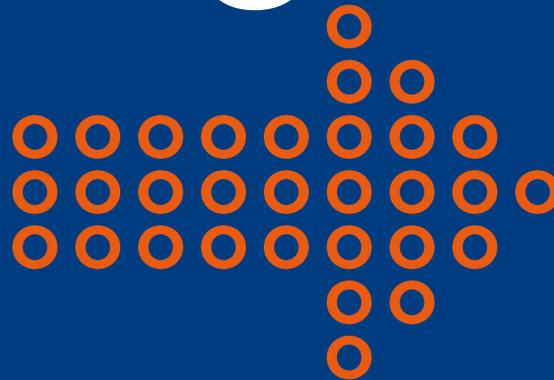




National  
Osteoporosis  
Society

# Strategic



# Plan

2013–2017

Building **stronger** bones

## Our vision

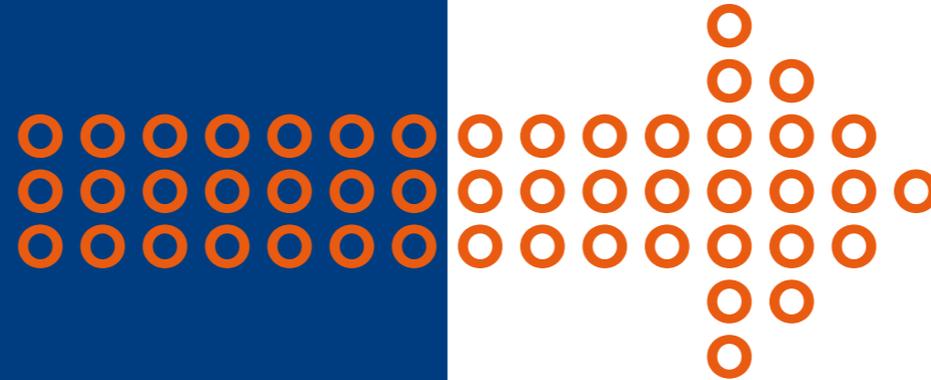
A future without fragility fractures.

## Our mission

Working together for a brighter future for people with or at risk of osteoporosis and fragility fractures across the UK, putting an end to preventable broken bones and helping people to live without pain and disability.

## Our values

We are caring, innovative, excellent, influential, ethical and passionate in all that we do.



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# Our impact

Our vision of a future without fragility fractures is an ambitious one. We have already come a long way since the charity was founded in 1986 and this plan will help us to take the next significant steps on our journey.

To realise our vision, we have set out a series of goals to undertake if we are to have a positive impact upon people with osteoporosis and fragility fractures. Our wide-ranging programmes of work aim to improve understanding, raise awareness, influence services and provide information and support.

The world in which we operate is very different from that of a few years ago. The economic and health environment is experiencing enormous change. The need for our work has never been greater: as the UK population ages and fragility fracture rates continue to increase, it is clear that more people than ever before are living with osteoporosis. To ensure that we continue to be the UK's leading authority on and charity for people with osteoporosis and fragility fractures, we will need to adapt and to be innovative and creative with all of the opportunities these changes and uncertainties present. The clear goals, objectives and actions we set out in this compelling plan will help us to meet the next stage of our journey to support and care for people with osteoporosis and fragility fractures.

We achieved a great deal during the lifespan of our previous plan. Every year 13,000 people have contacted our Helpline with their fears, concerns and questions about osteoporosis and fragility fractures. We have continued to improve public awareness of osteoporosis and the steps that can be taken to prevent fragility fractures. We have engaged with and influenced politicians and policy-makers across the UK to bring about improvements to services for people with osteoporosis and fragility fractures. With the help of our tenacious campaigning, osteoporosis has been included in the Quality and Outcomes Framework (QOF), meaning that GPs now have financial incentives to identify, diagnose and treat people with the condition. Although there is still a long way to go, there are now more NHS Fracture Liaison Services in place than ever before – an improvement we helped to drive through the relationships we have built with the UK's governments and the support we have offered to health professionals. The scientific research we have funded into why, how and when people develop osteoporosis has helped to bring us closer to the day when unnecessary fragility fractures are a thing of the past. We have provided first-class information, training and support to health professionals who prevent, diagnose, treat and care for people with osteoporosis and fragility fractures.

We know that fulfilling our plan will bring us closer to our vision of **a future without fragility fractures**. We look forward to working together to achieve the goals set out in this plan and to continuing to build on our previous success.

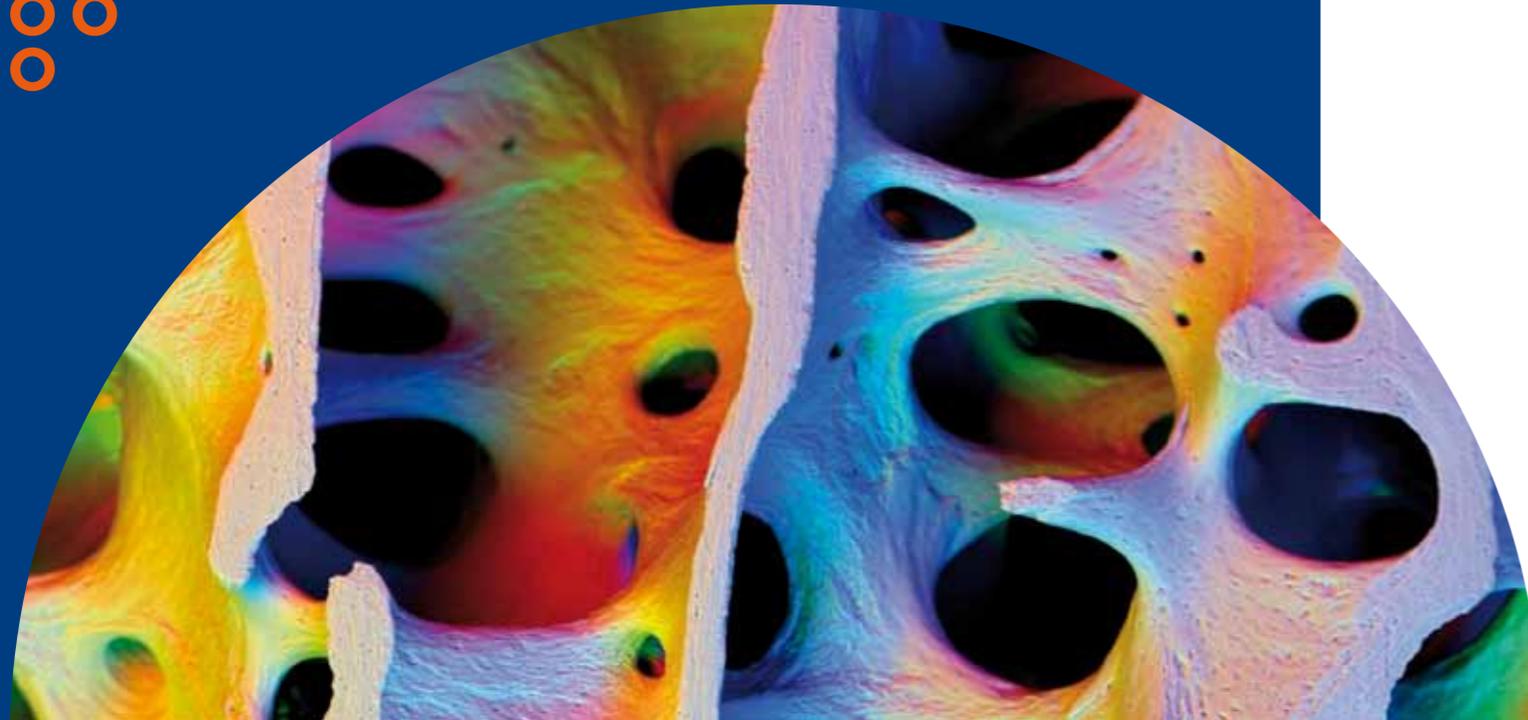
**Kate Tompkins**  
Chair, Board of Trustees

**Claire Severgnini**  
Chief Executive



# Osteoporosis

## and fragility fractures explained



Osteoporosis is a term we use to describe bones that are fragile and susceptible to fracture. These debilitating fractures are known as “fragility fractures”. They are often the result of low-impact bumps or falls – incidents that would not result in fractures for people with healthy bones – and usually happen from standing height or less. People with very fragile bones can suffer fractures while doing things as simple as turning over in bed. It is because of the impact that fragility fractures have on people that we seek to improve the way in which osteoporosis is prevented, diagnosed and treated.

Osteoporosis is a long-term condition. The fragility fractures that result are most common in people over the age of 50. They are not, however, an inevitable part of growing old. A healthy lifestyle and bone-protecting treatments – prescribed when a person has been diagnosed with fragile bones – can reduce a person’s risk of suffering a fragility fracture by up to a half.

Currently, a diagnosis of osteoporosis is made based on the results of a bone density scan when the scan shows a reduced bone density at either the spine or hip (T-score of  $-2.5$ ). Having a low bone density however is only one of a number of significant risk factors for fragility fractures. So, although the diagnosis of osteoporosis on a scan does identify many people who are at risk of fragility fractures, it doesn’t identify everyone at risk.

Experts have therefore developed tools that take into account all the significant risk factors, including a bone density scan measurement, and give a risk of fragility fracture over a 10-year timeframe. This has been a vital step forward. The next step is for regulators to review how treatment decisions should be taken based on a person’s risk of fragility fracture rather than just their bone-density measurement. We support this as it will help doctors to better identify and treat people who are at high risk of fragility fracture.

When we use the term “osteoporosis” in this document we are using it in the broadest sense, to mean someone whose bones are fragile and susceptible to fracture.

## The impact of osteoporosis

A preventable tragedy is unfolding in the UK as the number of people with osteoporosis continues to grow. We are in the grip of an avoidable emergency that causes unnecessary pain and disability from 300,000 fragility fractures every year and leads to 1,150 needless deaths each month.

Osteoporosis can devastate lives – fragility fractures rob people of their independence, mobility and quality of life. Fragility fractures of the wrist, rib and spine can lead to people becoming housebound, isolated and depressed. Hip fractures too often lead to an early death. Without care, support and appropriate treatment, someone with osteoporosis can fracture a bone as a result of something as simple as coughing. As a result, a significant number of people with osteoporosis live in fear of falling and further fragility fractures.

Without early diagnosis and preventative action, osteoporosis puts people onto a pathway of multiple, disabling fragility fractures. A hip fracture is all too often the final destination of a 30-year journey of multiple fragility fractures, fuelled by decreasing bone strength and warning signs being ignored.

A worrying 40 per cent of people diagnosed with a fragility fracture in their spine (vertebral fracture) will experience constant pain and a majority will find daily activities difficult. Many suffer dramatic changes in body shape, leading to a range of problems that include loss of self-esteem and difficulty in finding clothes that fit. Ten per cent of those who have a hip fracture die within one month of their injury. Thirty per cent die within a year. Of those who survive, a majority will have difficulty with basic activities like eating, dressing, going to the toilet, shopping or climbing the stairs.

Osteoporosis and fragility fractures are a growing public health issue. For women, the lifetime risk of sustaining a hip fracture is greater than the risk of developing breast cancer. One in two women and one in five men over the age of 50 will break a bone, mainly due to poor bone health.

The number of people with osteoporosis and fragility fractures continues to grow dramatically in the UK, due to our ageing population, our lifestyle choices and the patchy access we have to Fracture Liaison Services. Without urgent action, hip fracture rates are set to rise by 57 per cent over the next 25 years. In addition to the impact on people, the cost to the NHS will spiral from £2.3 billion now to over £6 billion in 2036.

UK hip fracture rates are already among the highest in Europe. As the population of the UK gets older, we need to take steps now to drastically improve the prevention, diagnosis, treatment and care of people with osteoporosis and fragility fractures.

People with osteoporosis and fragility fractures may need different parts of the health and social care system at any one time – therefore, no one clinical or professional discipline has overall responsibility for people with the condition. Health professionals need our support to ensure they can provide the best possible treatment and care for people with osteoporosis and fragility fractures.

If we do not act now, the number of people affected by fragility fractures will continue to rise.



## Who we are here to help

The National Osteoporosis Society will support anybody in the UK who:

- has osteoporosis
- has suffered a fragility fracture
- is at risk of osteoporosis or fragility fractures
- works to support people with or at risk of osteoporosis and fragility fractures
- cares for or is a family member of somebody with osteoporosis or fragility fractures.

To achieve our vision and have an impact on the rate at which people suffer fragility fractures, we support health professionals to assist them in the delivery of their essential services. We also engage with health professionals working within the social care and public health services, national and local officials and politicians in all of the UK's countries and regions.

A majority of fragility fractures in older people are caused by a combination of osteoporosis and a fall. We recognise this and welcome the fact that falls, osteoporosis and fragility fractures are often considered part of the same problem by the UK's governments, the NHS and the media.

However, we also recognise that a significant number of fragility fractures suffered by people with osteoporosis are not connected to a fall – many vertebral fractures, for example, occur spontaneously. At present, no other UK-wide charity exists to speak up on behalf of these people. We will work to ensure that people who suffer fragility fractures without falling receive the same level of care and support as those who suffer falls-related fragility fractures.



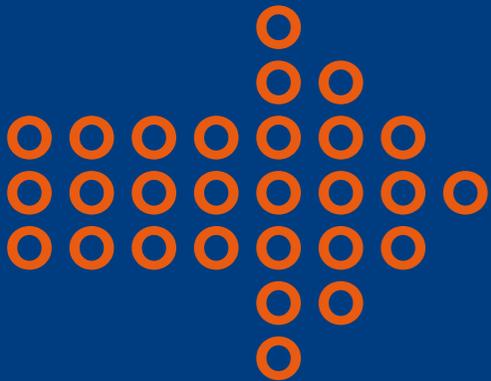
## Our next five years

In developing this plan, the people we seek to help, our advisers, our employees and our volunteers have helped us in better understanding the many challenges and opportunities we will face during the period 2013–2017. We will mitigate, adapt to and take advantage of these by:

1. Continuing to improve our understanding of our beneficiaries by seeking the views of people with osteoporosis and fragility fractures and undertaking research.
2. Being aware of emerging drug treatments, diagnostics and ways of managing the condition and how best to translate them into practice.
3. Navigating our way through the volatile economic landscape by making the most of every pound we raise and by demonstrating the value for money we provide.
4. Being bold about our priorities, helping everybody in the UK with osteoporosis and fragility fractures, and bringing into sharper focus fragility fractures that are not the result of a fall.
5. Working in collaboration with others, as appropriate, to achieve our goals.
6. Staying abreast of and reacting to political changes, for example alterations to the UK's constitution and to the way in which NHS and social care services are organised and provided.
7. Being dynamic, innovative and open to new opportunities.



# Our strategic plan

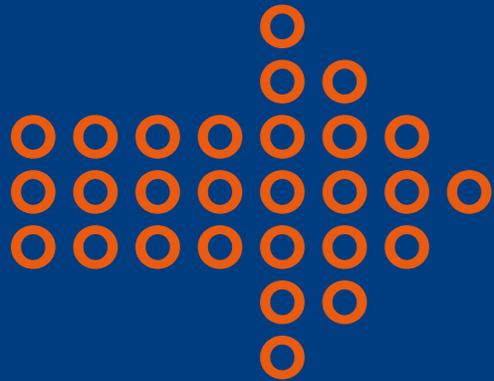


To achieve a positive impact for people with osteoporosis and fragility fractures, we have set out under our strategic framework, eight goals that will advance our mission. Sitting under each goal are one or more objectives, which we will use to monitor our achievements and progress.

Our strategic framework describes five key areas of work:

- Understanding
- Awareness
- Influence
- Information and support
- Effective organisation

Our goals have been set in partnership with the people we seek to help, our advisers, our employees and our volunteers. The achievement of some of our goals will be dependent upon the work undertaken directly by the charity. However, others will depend upon our ability to influence the behaviour and decisions of organisations and people outside the charity – particularly those which involve statutory funding or providing NHS and social care services.



# Our strategic framework

## Understanding

**Goal 1:** Improve our understanding of the prevalence and impact of fragility fractures in the UK

**Objective**

We will know how many people are affected by fragility fractures and the impact they have.

**Goal 2:** Add to the knowledge base on osteoporosis and fragility fractures

**Objective**

Our research activities will be built around the needs of people with or at risk of fragility fractures and the charity's ability to work on their behalf.

## Awareness

**Goal 3:** Raise awareness and understanding of osteoporosis and fragility fractures and the leading role the National Osteoporosis Society plays

**Objectives**

More people will know what osteoporosis and a fragility fracture is.

More people will know what steps they can take to improve their bone health.

More people will know who we are and what we do.

More people aged 50 and above without a prior fracture will consider their personal risk.

## Influence

**Goal 4:** Ensure that the National Osteoporosis Society is the authority on and the voice of people with osteoporosis and fragility fractures

**Objective**

Others will regard us as:

- a key stakeholder and consultee in the UK and devolved governments' policy- development processes.
- the first "port of call" for clinical and scientific expertise.
- the partner of choice.

**Goal 5:** Ensure access to and provision of quality health and social care services and treatments

**Objective**

We will analyse and use evidence of agreed indicators to monitor the performance of the NHS.

## Information and support

**Goal 6:** Empower people to make choices and manage their condition in ways that best meet their own needs

**Objectives**

More people will have the opportunity to discuss their diagnosis with health professionals or the charity to better understand their condition.

More people will access our information and support and feel empowered to take steps to manage their condition and improve their bone health.

**Goal 7:** Support health professionals in providing care for people with osteoporosis and fragility fractures

**Objective**

We will better understand the needs of health professionals working in the field and will provide useful support that meets their needs.

## Effective organisation

**Goal 8:** Raise funds to deliver the work of the charity

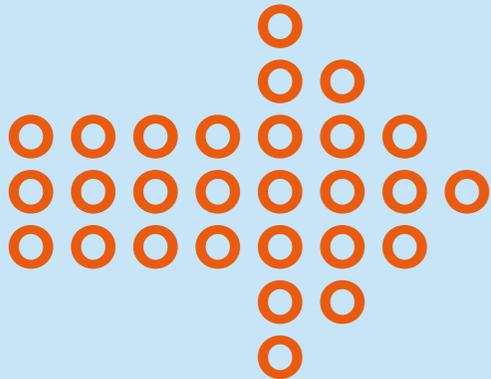
**Objectives**

We will operate a balanced portfolio of sustainable income-generating activities.

People will be inspired to help us achieve our vision and know how to support us.

# Understanding

Continuing to better understand the impact that osteoporosis and fragility fractures are having on people in the UK will help us to improve the day-to-day lives of those who suffer from them. Knowing more about the physical, psychological and economic effects of fragility fractures will mean that we can improve the care and support we offer to people with osteoporosis and fragility fractures. It will also mean that our campaigns can be tailored to bring about meaningful change to the health and wellbeing of these people. We start from a strong base – we now have access to more data about osteoporosis and fragility fractures than ever before: national audits measure the quality of care provided to people who suffer fragility fractures; helpful online tools demonstrate the cost savings that the NHS can achieve if people with osteoporosis are identified, assessed and treated; and we can also now show how hip fracture rates vary between local areas across the UK.



**Goal 1:** Improve our understanding of the prevalence and impact of fragility fractures in the UK

**Objective**

We will know how many people are affected by fragility fractures and the impact they have.

**Why this is important**

We need to learn more about the burden and impact that fragility fractures are having – in terms of the pain, discomfort and concern they cause people and communities – and the time and costs they incur for the NHS.

**We will**

Undertake a comprehensive analysis of the burden and impact of fragility fractures and fragility fracture risk in the UK.

Gain a better understanding of the interplay between osteoporosis, bone strength and fragility fractures.



## **Goal 2:** Add to the knowledge base on osteoporosis and fragility fractures

### **Objective**

Our research activities will be built around the needs of people with or at risk of fragility fractures and the charity's ability to work on their behalf.

### **Why this is important**

Osteoporosis and fragility fractures are under-resourced areas of medical research, despite the fact that more people are living with osteoporosis than ever before. There are many more things about bone that we desperately need to understand. Further research is required to transform the lives of people with osteoporosis and fragility fractures and help health professionals to improve prevention, treatment, diagnosis and care. We rely on our partners to fund the majority of the research that is central to the hopes of people with osteoporosis and those who care for them. We must engage with our partners to ensure that all research into osteoporosis and fragility fractures is focussed on the needs of those with the condition.

### **We will**

Make the most of our own research findings by ensuring that they translate into our wider work and into benefits for people with or at risk of fragility fractures.

Work with other organisations funding studies into osteoporosis and bone health.

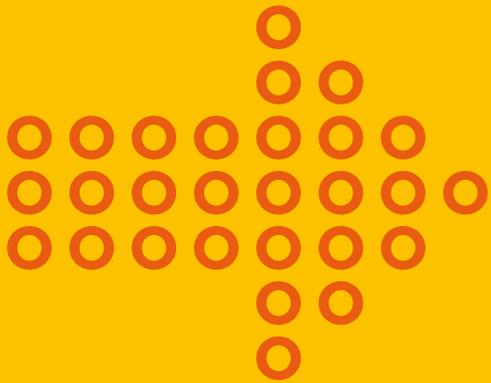
Share our new findings as widely as possible.



# Awareness

Our UK-wide surveys prove that awareness of osteoporosis and fragility fractures and the steps we can take to keep our bones strong into later life is low. This leaves people at risk of avoidable broken bones, disability and early death.

If the growing number of fragility fractures in the UK is to be reduced, it is absolutely vital that people learn about the link between their lifestyle and their future bone health.



**Goal 3:** Raise awareness and understanding of osteoporosis and fragility fractures and the leading role the National Osteoporosis Society plays

## Objectives

More people will know what osteoporosis and fragility fractures are.

More people will know what steps they can take to improve their bone health.

More people will know who we are and what we do.

More people aged 50 and above without a prior fracture will consider their personal risk.

## Why this is important

When somebody suffers a fragility fracture, it shows that they are likely to have another in the future. Half of all people who suffer a broken hip have had a previous fragility fracture. A first fragility fracture should be the trigger for assessing, treating and offering lifestyle advice to reduce a person's risk of further broken bones. There are also other signs, such as a parental history of fragility fractures, that suggest that a person could be at risk before they suffer a broken bone. Yet many of the people who come to us for support have suffered numerous fragility fractures before being diagnosed. We need to inspire more people to take action and, at the same time, raise the profile of osteoporosis, fragility fractures and the work we do.

## We will

Define our audiences and establish baselines to enable us to measure awareness.

Raise awareness of risk factors for fragility fractures and encourage people to consider their personal risk.

Promote the primary prevention of fragility fractures among people over the age of 50 (primary prevention means action to reduce the risk of suffering a first fragility fracture).

# Influence

The UK's governments, NHS and local councils have a big part to play in ensuring that people with osteoporosis and fragility fractures are identified, assessed, treated and cared for. Despite some pockets of excellent practice, the reality of service provision is unacceptable and patchy. Many opportunities to prevent unnecessary pain and disability are being missed. In some cases, people die prematurely because of not receiving appropriate care. Health providers should be offering Fracture Liaison Services, recommended in official guidelines, as part of which dedicated nurses identify people with fragility fractures and organise their assessment and treatment where necessary. Treatment options also need to be improved. Bone-protecting drugs are being restricted to certain groups because no official guidance exists to inform health professionals about the bigger picture. Men, for example, can miss out on treatment that could cut the number of fragility fractures they experience, as can those who have rarer risk factors for fragility fractures.

## Goal 4: Ensure that the National Osteoporosis Society is the authority on and the voice of people with osteoporosis and fragility fractures

### Objective

Others will regard us as:

- a key stakeholder and consultee in the UK and devolved governments' policy-development processes.
- the first "port of call" for clinical and scientific expertise.
- the partner of choice.

### Why this is important

We need to work to ensure that public policy and health and social care services meet the requirements of people with or at risk of fragility fractures, and to engage politicians and policy-makers in key areas of our work. We must continue to be the authority on osteoporosis and fragility fractures in the UK. Our policies must be underpinned by the expertise of our clinical and scientific advisory network and the views of people affected by fragility fractures. We need to ensure that these groups are at the forefront of our campaigns and have opportunities to engage directly with key decision-makers. In England, we must engage with the new health, social care and public health structures, which now include clinical commissioning groups and local councils.

### We will

Ensure that our policy development is informed by the people we represent and by clinical and scientific expertise.

Continue our influencing programme throughout the UK.

Build alliances with a range of other organisations to maximise our impact on public policy.



## Goal 5: Ensure access to and provision of quality health and social care services and treatments

### Objectives

We will analyse and use evidence of the following indicators to monitor the performance of the NHS:

- More people with fragility fractures will be identified, assessed and treated (where appropriate) within 12 months.
- Fewer people will suffer more than one fragility fracture before diagnosis and treatment.
- The rise in the age-standardised rate of fragility fractures among older people will be halted or the rate will fall.
- More people will be able to move back to their place of residence following a hip fracture after (a) 6 months and (b) 12 months.

### Why this is important

Access to Fracture Liaison Services is patchy, yet they are proven to save the NHS money while keeping people with fragility fractures free from pain and disability. People should be identified, assessed and treated promptly. Where fragility fractures cannot be prevented, services should work together to help the people who suffer from fragility fractures back to their prior quality of life.

Success in achieving these objectives will be largely dependent on our ability to influence the UK's governments, the NHS and local authorities. We cannot ourselves deliver the services that are essential to those we support. The objectives we set out for this goal will be measured using NHS and local council data.

### We will

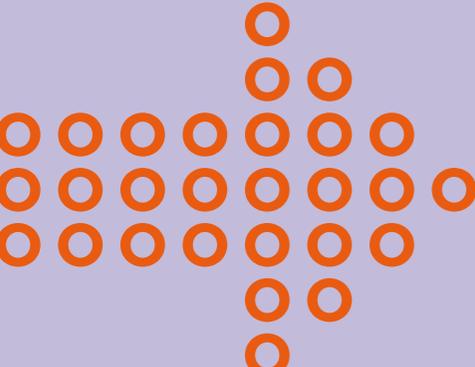
Influence, engage with and support decision-makers and health and social care commissioners and providers.

Collaborate with other organisations to press for a charter to be put in place that clearly sets out what people with or at risk of fragility fractures should expect from their health and social care services.

Champion the perspectives and experiences of people with or at risk of fragility fractures.



# Information and support



Finding out that you have osteoporosis can be distressing. Fragility fractures can rob people of their independence, mobility and quality of life. When people are told they have osteoporosis, they can face fear, uncertainty and the emotional toll of not knowing how the condition will affect their lives. The majority of people diagnosed with osteoporosis often do not have sufficient time with an NHS doctor or nurse to help them fully understand their condition. People contact the charity at the end of their tether – concerned and worried and with nowhere else to turn. Health professionals need us too, to support them in managing people with or at risk of fragility fractures.



**Goal 6:** Empower people to make choices and manage their condition in ways that best meet their own needs

## Objectives

More people will have the opportunity to discuss their diagnosis with health professionals or the charity to better understand their condition.

More people will access our information and support and feel empowered to take steps to manage their condition and improve their bone health.

## Why this is important

People who are newly diagnosed with osteoporosis need opportunities to ask questions and learn about their condition, and we will facilitate this through engaging with and supporting health professionals.

People with osteoporosis and fragility fractures, concerned relatives and those with questions about their bone health rely on the life-changing information and support we provide. We must continue to offer relevant, high-quality publications and our nurse-led Helpline which gives people the caring support and essential information they need, as well as our activities in local communities around the UK.

## We will

Support people who are newly diagnosed through our partnerships with health professionals.

Provide information through our publications and our website.

Provide a nurse-led Helpline, answering queries from people across the UK.

Provide support in local communities, through our groups and events.

## **Goal 7:** Support health professionals in providing care for people with osteoporosis and fragility fractures

### **Objectives**

We will better understand the needs of health professionals working in the field and will provide useful support that meets their needs.

### **Why this is important**

As those responsible for identifying, assessing, treating and caring for people with osteoporosis and fragility fractures, health professionals are the front line in achieving our vision. Yet understanding of osteoporosis differs among health professionals and clinical practice varies between localities, resulting in varying standards of care and missed opportunities to prevent fragility fractures. Health professionals are working in a challenging environment and we need to be responsive to their changing needs and provide a range of support, from our information, resources and training to providing networks to facilitate the sharing of best practice. These activities will help those working in a variety of clinical disciplines to raise the standard of care for people with osteoporosis and fragility fractures. We must ensure that our activities are based on recognised standards of best practice and are developed in partnership with our expert advisers and those professionals whom we seek to benefit.

### **We will**

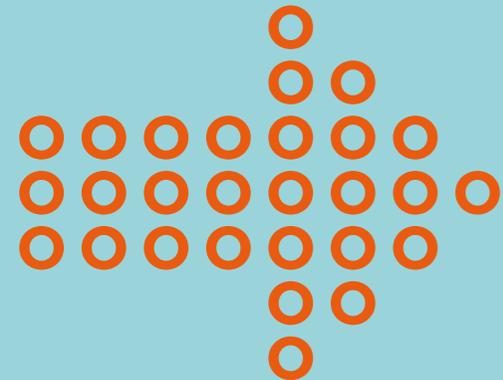
Review the needs of health professionals and how we can best meet their needs.

Continue to develop and provide relevant and accessible information, resources, training and networks.

Pro-actively engage and support health professionals across the UK.



# Effective organisation



The resources we call upon to support people with or at risk of osteoporosis and fragility fractures and those who care for them are dependent on the generosity of our supporters as we receive no statutory income. In the uncertain economic environment in which we will operate, we will make the most of every pound we raise. Effective organisation will be integral to achieving this. We will be efficient and professional in all we do, recruiting and developing employees and volunteers who share our values. We will make the most of the information technology available to us.



## Goal 8: Raise funds to deliver the work of the charity

### Objectives

We will operate a balanced portfolio of sustainable income-generating activities.

People will be inspired to help us achieve our vision and know how to support us.

### Why this is important

As the only UK-wide organisation working to support people with osteoporosis and fragility fractures, it is vital that we continue to understand how and why supporters enable us to bring about a brighter future for people with osteoporosis and fragility fractures.

We need to grow the National Osteoporosis Society's financial resources, seeking new sources of sustainable income. To retain and develop existing support as well as inspire and engage new support, we must demonstrate our impact and be transparent in all we do. Importantly, in the competitive UK funding climate we must demonstrate the value we place on our supporters by responding to their needs and providing relevant and timely information so they know how they have made a difference.

### We will

Diversify our income streams and focus on income-generating activities that provide a strong return on investment.

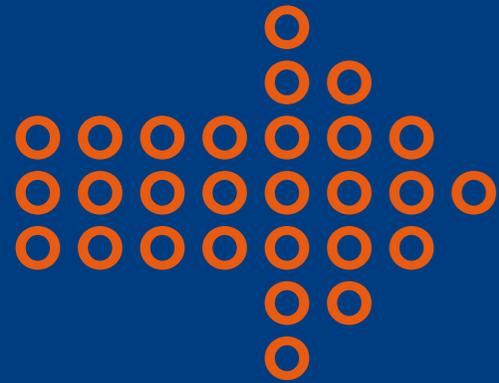
Explore new opportunities for generating non-fundraised income.

Increase the number of people and organisations who support us and inspire everyone who contacts us to support the charity.

Develop impact-measurement methods to ensure transparency and supporter understanding.

Grow and maximise our supporter base.

# Delivering our plan



People are central to everything we have achieved since 1986 – thousands support the work of the National Osteoporosis Society in many different ways. It is thanks to the hard work of our supporters, our employees, our advisers and our volunteers that we have made life better for people with osteoporosis and fragility fractures. Our values underpin everything we do.

As we deliver this plan, we will establish baseline measurements for the goals and objectives we have set out. This will enable us to clearly measure the impact that we are having on the lives of the people we seek to help at various points during the period 2013–2017.

We also recognise that we can bring many more benefits to people with osteoporosis than those that can be quantified and measured. We will not lose sight of this as we deliver our plan.

We understand that we cannot work alone to achieve our vision. We will continue to collaborate with other organisations that have a stake in supporting people with osteoporosis and fragility fractures and those who care for them. This will help us to create a stronger voice and make the most of every pound we raise. We will identify initiatives that will benefit from collaboration and will work with our partners, underpinning our spirit of co-production.

Our plan has been developed to build on our strengths and take full advantage of our opportunities, to further advance our vision of **a future without fragility fractures.**



National  
**Osteoporosis**  
Society



**0845 450 0230 (Helpline)**



**0845 130 3076 (General Enquiries)**



**[www.nos.org.uk](http://www.nos.org.uk)**



**[info@nos.org.uk](mailto:info@nos.org.uk)**



**Camerton, Bath BA2 0PJ**

Building **stronger** bones

President: HRH The Duchess of Cornwall

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