



# APPG ON OSTEOPOROSIS AND BONE HEALTH



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# 1. FOREWORD FROM THE CO-CHAIRS

We re-launched the All-Party Parliamentary Group (APPG) on Osteoporosis and Bone Health because we saw the injustice of the current postcode lottery for care, and the major opportunities for the NHS and society if we get this right.

Osteoporosis is one of the most urgent challenges to people living well in later life. It affects half of women over the age of 50, and a fifth of men. The fractures it causes are no minor inconvenience- as many people die of fracture-related causes as from lung cancer and diabetes. For others, the condition leads to a loss of independence, broken connections with friends and family, and a sharp downturn in quality of life.

It doesn't need to be like this. The right therapies exist, and over time we hope research will lead to a pipeline of even better treatments. But, right now, tens of thousands of people are falling through the cracks due to cold spots of provision in the NHS which compound existing health inequalities. We are systematically failing to identify the people who desperately need a treatment plan for fracture prevention. The result is thousands of avoidable fractures, with all the pain, disability and spiralling costs for the NHS that they bring.

Last year, we launched a solutions-focused inquiry into how to resolve the postcode lottery for Fracture Liaison Services (FLS), the world standard for identifying people who have suffered a broken bone, assessing whether this is due to osteoporosis, and moving those needing care onto a treatment plan. The inquiry report was received formally by the Minister of Care. The next step for the APPG was obvious: a spotlight was needed on what's happening (or not happening) in primary care to cause the startling level of under-diagnosis and under-treatment of this condition.

Primary care, for most people, is the front door to the NHS. But levels of awareness of bone health amongst practitioners is low, routinely leading to missed opportunities for a timely diagnosis. Too often problems are left to escalate to crisis point, while early intervention could have helped people live well.

Osteoporosis has been a neglected cause for too long. We want to challenge the passivity and fatalism that has characterised the fight against this condition. If we have the will, we can beat it. Primary care has a crucial role to play. We want to thank everyone who has contributed evidence to this inquiry.

The recipe for making a decisive change - one that will benefit tens of thousands of people and our recovering NHS - is set out in the pages of this report. Now we need to make it happen.



# FOREWORD FROM ROYAL OSTEOPOROSIS SOCIETY

This report is the second major piece of policy output from the APPG on Osteoporosis and Bone Health. The Royal Osteoporosis Society (ROS) is incredibly proud to provide support to this dynamic, positive group of parliamentarians. All the members of the APPG are interested in answers and solutions. The group works across party lines to raise the level of public debate about bone health.

I'd like to thank - on behalf of the 3.5m people living with osteoporosis - the committed parliamentarians who sit on the APPG. We also owe an enormous debt of thanks to the people who contributed evidence to this inquiry. Over five hundred members of the public responded to the call for evidence - the scale of which took us aback (in a good way). It shows the level of energy and ambition for finding solutions to the ever-growing public health burden of osteoporosis and fractures. I'd also like to thank the witnesses who provided such compelling and insightful oral evidence.

We're clearly entering very difficult economic times with pressure on public spending. We know things are going to be very tough, but it's vital that we invest in and protect the services for people with osteoporosis. Missed opportunities to prevent fractures leads to even greater pressure on ambulances, acute hospital bed days and the elective care backlog. A modest pump-

priming of Fracture Liaison Services - just 27M per annum - will deliver £600M savings over 5 years, including 30,544 hip fractures prevented. If we front-load just 1.35% of the annual NHS hip fracture spend into fracture prevention, it will pay back 3:1 within a Parliament.

The days of osteoporosis being neglected in Westminster and the devolved legislatures are, thankfully, over. But we need to commit to making a reality of the blueprint provided in this report and our Fracture Liaison Service inquiry report from last year. As the population continues to age, the costs of inaction on osteoporosis will spiral. The answers are here. If we commit to them together we can make an enormous difference for the public and for our recovering NHS.

**Craig Jones Chief Executive** 



We heard compelling evidence for a national screening programme for people at high risk of fracture.

# 2. EXECUTIVE SUMMARY

In the UK the focus of osteoporosis care in the NHS has, to date, been on people who have sustained a fragility fracture as a result of their underlying condition. Rather less has been done with regard to preventing the first fracture, by promoting good bone health and proactively identifying people at higher risk.

GPs surgeries are the principal provider of care for people with osteoporosis. Primary care healthcare professionals can identify people at high risk of fracture, diagnose osteoporosis, prescribe treatment and monitor these individuals over the long term.

The APPG on Osteoporosis and Bone Health launched this inquiry into primary care provision for people with osteoporosis and those at high risk of fracture in March 2022 to establish the quality of care being offered to people at present. We heard directly from people with osteoporosis who responded to our survey, as well as from healthcare professionals trying to provide the best care to their patients. We also submitted a Freedom of Information (FOI) request to all CCGs, Health Boards and Health and Social Care Trusts, asking them about their responsibilities.

## Access to care

Despite national guidance outlining the responsibility on primary care to identify and manage people at high risk of fracture, we found that people were having to battle to access the care they needed. People struggled to access GP appointments, investigations, scans and specialist advice. Many reported having to go private to get the provision they expected from primary care.

# Identification, diagnosis and monitoring

The inquiry found primary care services that do not prioritise the identification and management of osteoporosis and high fracture risk. Patients reported poor experiences at diagnosis when the first critical conversation needs to take place between doctor and patient about the risks and benefits of treatment. Diagnosis represents the best opportunity to set people up to selfmanage their condition over the long term and ensure that they understand the critical importance of adhering to their agreed treatment. We heard about the ongoing problem of people not receiving good care and support, and consequently defaulting on treatment. Clinicians described

the global issue of the 'treatment gap' between those who need treatment and those who are on treatment, and the FOI data showed how this has widened as a result of COVID-19. Patients described feeling abandoned by their primary care team, with little or no monitoring or follow-up, and low recognition of osteoporosis as a serious long-term condition.

# Knowledge and skills

Many people told us that they wished their condition had been picked up earlier, and how, once it was, they found a lack of knowledge in primary care around osteoporosis. This was particularly marked among people with vertebral fractures who relied on primary care professionals to suspect a fracture when they presented with back pain. They needed their GP to refer them for imaging promptly, diagnose and treat the underlying osteoporosis and prevent further fractures. Healthcare professionals described how little training they had received on osteoporosis and how they need the support of specialist services to advise their patients better.

#### IT and digital tools

Healthcare professionals felt that the IT infrastructure and financial resources were currently inadequate to support the task of identifying and treating patients at high risk before the first fracture. They wanted to harness the opportunities offered by IT for identifying patients, with better integration of digital assessment tools.

#### Prioritisation of osteoporosis

Clinicians told the inquiry about the enduring problem of ownership of osteoporosis and fracture prevention due to it not being recognised as a medical specialty in its own right, its low priority within the NHS, lack of leadership, and the fact that osteoporosis is not officially recognised as a long-term condition within the NHS. This low prioritisation of osteoporosis and fracture prevention in primary care has resulted in an allocation of resources that is inadequate and not proportionate to the scale of the problem.



# Case-finding and screening

The inquiry heard about the opportunities offered by Integrated Care Systems in England for cost-effective population-based approaches to case-finding. In the context of the ongoing challenges of casefinding and the widening treatment gap we heard compelling evidence for a national screening programme for people at high risk of fracture.

## Attitudes to bone health

Finally, we learned from both individuals with osteoporosis and healthcare professionals about the need for a shift in public attitudes to bone health – from a complacency that tolerates hip fracture in old age, to one that promotes good bone health across the life course and takes seriously the responsibility to identify people at high risk of fracture at the earliest opportunity to prevent the devastating consequences of osteoporosis.

primary care services that do not prioritise the identification and management of osteoporosis and high fracture risk.

# 3. APPG INQUIRY SUMMARY RECOMMENDATIONS

# The case for screening

The National Screening Committee should reconsider the case for a targeted national screening programme to detect high fracture risk in 2023.

This recommendation is in line with Government's own focus on prevention in the NHS Long Term Plan. Targeted at the appropriate population, screening for fracture risk is both clinically and cost-effective. We believe that the appropriate conditions for an evidence-based screening measure have now been met.

# Raising public awareness

The Government should instigate a public health campaign to address the lack of awareness and complacency in the public about bone health.

To address the lack of awareness of bone health amongst the public, a campaign is needed to highlight the importance of supporting bone health across the life course. This should highlight the opportunity for individuals to assess their personal fracture risk, act on the results and avoid what could be life-altering fractures in the future.

# Osteoporosis, a long-term condition

Osteoporosis must be given parity with other long-term conditions, and defined as such within the NHS, to allow enhanced and equitable care and management.

The inquiry was pleased to hear that the Department of Health and Social Care's Women's Health Strategy has defined osteoporosis as a long-term condition. This must be reflected across all Government health guidance, strategy, funding and incentives.

# Access to care and barriers to referral

NHS England must outline plans to expand DXA services to deliver and exceed their recommended 4% increase in capacity in order to tackle the current backlog and future-proof services, – and improve access by including DXA in minimum specifications for Community Diagnostic Centres.

# Diagnosis, treatment and monitoring

Every individual who requires ongoing management or surveillance to reduce their fracture risk should have a personalised 'bone health management plan' with a specified timescale for reviews.

# Multi-disciplinary care for osteoporosis patients

ICSs should utilise the breadth of skills and expertise within the multi-disciplinary team to optimise and streamline local management pathways for people at high risk of fragility fracture.

Broadening the range of professionals who manage patients at high risk of fracture may include:

- Training to facilitate non-medical referral pathways for DXA.
- Opportunistic case-finding and risk assessment by nurses and allied health professionals during routine clinical encounters.
- Pharmacists monitoring treatment response and adherence.
- Use of non-medical prescribers.

# Ownership and leadership

Establish a new National Specialty Adviser for Fracture prevention and Osteoporosis within the NHS England and NHS Improvement clinical advisory structure, and equivalent in Scotland, Wales and Northern Ireland.

Osteoporosis care requires strong, visible leadership from a national specialty adviser, and for leadership to be embedded at all levels of health infrastructure, through the establishment of clinical networks.

Every patient should have access to a single point of contact for osteoporosis care.

This role would coordinate their care and address patients' queries and concerns. There is no need to define precisely who, or what professional group, should fulfil this role. It may or may not be a prescribing practitioner for example, as this would vary according to local clinical pathways.

# Raising knowledge and skills

The APPG recommends proportionate recognition of the importance of osteoporosis throughout healthcare education, with increased prominence in undergraduate and post-graduate healthcare professional training.

# Specialist support for primary care

Specialist services must support primary care colleagues to provide the best care to patients.

This should be achieved through:

- DXA reporting that includes comprehensive management advice and recommendations; and
- Access to specialist support given to primary care through the Advice & Guidance systems (or equivalent).

# Better vertebral fracture identification

All relevant national guidelines should be reviewed to better support imaging of the spine where there is a suspicion of vertebral fracture, particularly in patients with risk factors for osteoporosis. These include:

- Royal College of Radiology iRefer guidelines
- NICE guidelines

# **Funding**

NHS England must provide sufficient funding for ICSs to deliver against national quality standards and NICE clinical guidance.

Implementation of NHS England's Best MSK Health programme pathways requires resource at ICS level for workforce, training and service development.

# 4. INTRODUCTION

Osteoporosis is a common long-term condition that causes bones to lose strength, making them more susceptible to fracture. As a result, they may fracture during normal daily activities or after a minor bump or fall.

These fractures are known as 'fragility fractures' and are associated with substantial pain and suffering, disability and death. 1 in 4 people die within a year of suffering a hip fracture.1 Fractures caused by underlying osteoporosis incur substantial costs to health and social care - £4.5 billion per year in the UK.2 Hip fractures, which usually involve hospitalisation, surgery and considerable rehabilitation, account for £2 billion of this cost. We also know that every fracture of the spine (the most common fragility fracture) accounts for 14 additional GP visits in the first year after the break.3

## Current key statistics on fracture:

- At the age of 50 years, the lifetime probability of a major osteoporotic fracture is 22% in men and 46% in women.4
- In 2019, there were 527,000 new fragility fractures which equates to 1 per minute.5
- The annual number of fractures is rising due to an ageing population and is expected to increase by 138,000 to 665,000 by  $2034.^{2,5}$

### Fracture prevention

In the UK to date, osteoporosis spending has focused on care for people who have already had a fracture. In 2019, the cost of osteoporosis including treatments in the EU was estimated at €56.9 billion (1000 million), of which two thirds is spent on treatment of fractures, and only 3% on the cost of osteoporosis treatments.<sup>2</sup> There has been some progress in the UK in the last ten years in establishing hospital-based Fracture Liaison Services (FLS), though coverage is not universal and quality remains variable. FLS identify people aged 50 or older who have had a fragility fracture, assess them for osteoporosis and where appropriate provide treatment to prevent future fractures. This is known as 'secondary fracture prevention'.

The challenge remains however, to prevent the first fragility fracture, known as 'primary prevention'. Primary prevention involves public health initiatives promoting good bone health and a healthy lifestyle, together with targeted measures identifying people whose bone health is compromised, treating them appropriately and preventing fractures before they happen. This responsibility falls largely under primary care.

# Fractures caused by osteoporosis cost

# £4.5 BILLION EACH YEAR







# The role of primary care

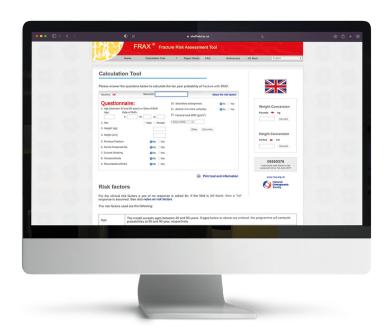
Primary care is the principal provider of medical care for people with osteoporosis. GPs are well placed to identify individuals at high risk of fragility fractures, before they sustain one, as they hold the relevant information about the patient's risk factors for fracture. They are able to obtain further information on a patient's bone density by referring them for a dual-energy X-ray absorptiometry (DXA) scan. They can then prescribe and monitor treatment. Only complex osteoporosis cases need to be referred to hospital services.

Once an individual has been identified as being at high fracture risk, a large proportion of fragility fractures are preventable. If a patient has risk factors their GP can establish their future risk of breaking a bone using an online fracture risk assessment tool. These tools are freely available and well-validated. The FRAX® tool in particular has achieved worldwide use in over 100 guidelines internationally.<sup>6</sup> Information regarding the patient's clinical risk factors are entered and the tool gives the patient a 10-year probability of both a hip fracture or a major osteoporotic fracture. Measurement of the patient's bone mineral density can be entered to fine-tune the fracture risk calculation. In the UK, the output from FRAX can be directly linked to the threshold for treatment shown on the National Osteoporosis Guideline Group (NOGG) website. NOGG guidelines are accredited by the National Institute for Health and Care Excellence (NICE) and were recently updated.<sup>7</sup>

Once identified, osteoporosis is treatable. Treatments for osteoporosis have been shown to be effective in increasing bone strength and substantially reducing fracture risk.<sup>8-13</sup> The first-line drugs most commonly used to treat osteoporosis are oral bisphosphonates which are very effective and affordable.

# Understanding the 'treatment gap'

Despite having effective fracture risk assessment tools and treatments, currently only a minority of people who need osteoporosis treatment are receiving it. This is called the 'treatment gap' and is well recognised. 14,15 In 2019, 66% of people in the UK who were at high risk of fracture had not received treatment. 2 This proportion has been increasing steadily since 2010. One of the main barriers is timely identification of people at risk of fractures. This inquiry intends to understand why patients are not being identified and what can be done about it.



In 2019, there were

527,000

new fragility fractures which equates to

1 PER MINUTE



Osteoporosis has been hampered by what is best described as an 'image problem' due to lack of awareness of its clinical significance and treatability amongst clinicians, policy-makers and the public.

"It's not a very sexy subject. Do you know what I mean? It's just not... because it's 'old people', and 'decline and decrepitude, and 'not much can be done". GP

It is variously regarded by patients and clinicians alike as an inevitable part of ageing, a condition that 'only affects older women' and not a 'sexy' area of medicine.

"It's hard to think of another area where options for prevention, diagnosis and treatment are so often overlooked by clinicians and funding bodies - leading to much avoidable pain and suffering, and even death." **GP**<sup>16</sup>

"Treating the elderly has always had an image problem. It's not like cardiology, where you instantly save lives. It's about making people get worse more slowly, rather than making anyone better. It requires consummate communications skills, particularly with people with hearing difficulties, cognitive difficulties, mobility difficulties. It's not a condition that lends itself to being rewarding for the clinician." GP

Another significant component of the treatment gap is the problem of patients failing to stay on treatment. This is known as 'adherence', and is discussed in detail later in this report.

## **ROS Freedom of Information request 2022**

In 2022, the ROS completed a Freedom of Information (FOI) request on behalf of the APPG to all CCGs, Health Boards and Health and Social Care Trusts in the UK.

The FOI request revealed the low priority given to bone health by commissioners of primary care services. For example:

- 37% of respondents did not hold data on treatment spend for osteoporosis.
- 52% of respondents did not hold data on the spend on DXA scans.
- 74% of respondents did not know what proportion of GP practices had a systematic process (such as a regular data search) for identifying patients who may be at high risk of fracture.
- 90% did not know if there was an identified clinician with a special interest in osteoporosis in any of their

- practices. Of those that did, only one confirmed that 11% of their practices had such a healthcare professional.
- 97% of respondents did not hold information about 5-year reviews of osteoporosis treatments. Of the two respondents that did hold data, one confirmed that reviews did not take place, and the other stated that they took place in 1.7% of cases.

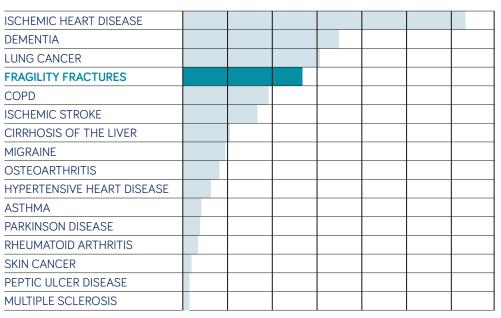
The results from those bodies which had access to the data showed that the treatment gap widened over the last three years:

- spending on bisphosphonates fell by 28% in the last three financial years.
- the average number of DXA scans fell by 45% during 2020/21. This recovered in 2022 to 1% above 2019/20 levels, but is insufficient to address the backlog.

## The burden of care compared to other conditions

The inquiry heard from clinicians that the main reason for the under-identification of osteoporosis and the growing treatment gap is that osteoporosis is not a priority in primary care health policy or practice.<sup>17,18</sup> This is despite the fact that the health burden from fragility fractures exceeds that of hypertensive heart disease and rheumatoid arthritis, and is outranked only by ischemic heart disease, dementia and lung cancer.<sup>19</sup>

DALYs by disease in EU6 in 17 selected non-communicable diseases13



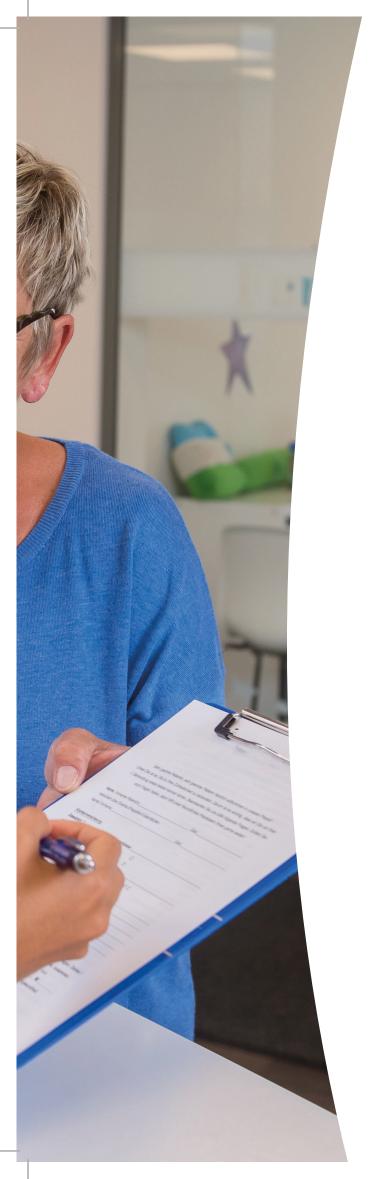
0 1,000 2,000 3,000 4,000 5,000 6,000 7,000 DALYs (000)

In order to raise the priority of osteoporosis and its associated fractures, data demonstrating the true scale of the problem needs to be collected and understood at a local level. The NHS Long Term Plan focus on prevention and addressing health inequalities using populationhealth based strategies presents an opportunity. Integrated Care Systems (ICSs) can focus on reducing the burden of osteoporosis and fractures by identifying people at risk of fragility fracture and closing the 'treatment gap' by providing them with assessment and treatment. NHS England's Best MSK Health programme has developed a toolkit to enable ICSs to coproduce local pathways of care using generic templates, and supported by ICS and Integrated Care Board-level clinical networks. These efforts can also be targeted for cost-effectiveness at populations known to have higher rates of osteoporosis (See case study: The Northern Bone Health Programme page 63).

# **OUR ANALYSIS**

The inquiry evidence, including the FOI request, demonstrates the low priority currently afforded to osteoporosis care and bone health by commissioners of primary care services. The inquiry aims to establish the causes and consequences of the low priority of osteoporosis in the planning of osteoporosis services.





# WHAT WE DID

- In February 2022, we launched our inquiry into the primary care provision for people with osteoporosis.
- In March, ROS published an online patient survey which received 545 responses.
- We submitted a Freedom of Information request to all CCGs, Health Boards and Health and Social Care boards in the UK asking for details on their primary care provision for osteoporosis.
- We also put out a call for evidence which received responses from individuals, clinicians and organisations.
- From April to September, we held three oral evidence sessions in Parliament where we heard directly from people living with osteoporosis, as well as leading clinicians and policy officials.
- From May to July, ROS conducted 20 interviews with a range of healthcare professionals (including GPs, clinical pharmacists, nurses, physiotherapists and first contact practitioners) to understand their experience of delivering primary care services to people with osteoporosis. Their contributions have been anonymised.
- We also conducted an external literature review to ensure our findings and recommendations were informed by the wider evidence and thinking in this area.

We are indebted to the 545 individuals with osteoporosis who responded to our inquiry survey and the 20 healthcare professionals who gave up their time to enhance our understanding.

# 5. WHAT IS THE CURRENT PATIENT EXPERIENCE OF PRIMARY CARE FOR **OSTEOPOROSIS?**

Given the central role of primary care in managing people with osteoporosis, the APPG inquiry conducted a survey to establish the nature of osteoporosis patients' experience. 554 patients gave evidence to the inquiry in this way.

The data were analysed and key themes derived. We also issued a call for written evidence to providers, patients and health professionals. A number of patients and clinicians submitted written evidence to the inquiry. This has been added to our survey analysis. The inquiry found that, apart from a few isolated examples of good care, primary care was not delivering the standard of care consistent with current clinical guidelines, and patients' experience was poor in many cases.

#### Access to care

A feature across all the responses to the inquiry survey was difficulty accessing care – whether that was due to problems for patients getting face-to-face appointments with their GP or having to convince their GP to refer them for diagnostic and follow-up scans, blood tests or to a bone specialist.

Only 12% (68/545) of the responses to the inquiry patient survey described receiving the care they expected or needed, from a GP who demonstrated awareness of risk factors, suspected osteoporosis, drove their diagnosis and monitored them regularly.

"My GP at the time was not happy that I had had a spinal fracture so easily and organised a DXA scan - I was 53 at the time and she felt that that was too young too - I am so grateful to her."

However, across their open responses, 27% (149/545) of respondents described having to instigate all aspects of their care. This raises the question of inequity of access to healthcare and the likelihood that patients of lower socioeconomic status (who experience higher rates of long-term conditions and multimorbidity) would be less likely to be proactive in their care than those with more social capital.<sup>20</sup>

"I've found that it's myself in charge of my osteoporosis care as I'm the one who either asks for or organises tests, reads about treatments and pushes for decisions. Generally I've found a lack of interest from most primary care providers...For other health conditions there is generally more help."

Respondents described being responsible for arranging follow-up care, and some were advised that it would be their responsibility to arrange all follow-up scans.

"I have had to ask for every DXA scan bar one. If I had not asked in the first place when I fractured my foot in 2007/8, I would not even know now that I have osteoporosis."

# ONLY 12%

# described receiving the care they expected or needed from a GP

## Access to GP appointments

#### What patients told us

Some respondents (11% or 62/545) referred to delays in accessing consultations with a clinician as well as appropriate investigations and treatment. Key examples included delays for DXA scans, delayed referrals to secondary care and difficulty getting appointments with their GP.

"I would normally expect the GP surgery to be in charge, but they show little concern. Current waiting time for a phone appointment is at least 1 month."

Accessing a face-to-face appointment (despite COVID restrictions) was particularly important to some respondents, especially at the point of diagnosis.

"I would like the GP to tell you in person that you have a disease of your bones and not via a letter. I would have appreciated the GP to have initiated a discussion regarding the medication and side effects."

Respondents were concerned that telephone consultations ran the risk of clinicians failing to make an accurate assessment of the patient. This was particularly pertinent for people with vertebral fractures.

"I think not being able to have a face-toface appointment with your GP is the wrong approach. If I had seen my doctor and he had examined my back I think he would have known it was a fracture on the spine."

Lack of face-to-face contact for those people who were struggling to manage their condition, left them feeling unsupported.

"I have been speaking with three different GPs at my practice in two and a half years and have never seen one face-to-face, therefore my anxiety builds up and keeps me isolating."

## What healthcare professionals told us

All the healthcare professionals expressed a preference for face-to-face consultation for people with musculoskeletal (MSK) conditions in particular where they felt that it was necessary for an accurate assessment. They had concerns about missing important clinical information over the phone. This included when a patient with multi-morbidities presents with one issue, but the doctor identifies a more pressing clinical concern.

"I think that in general patients don't present with osteoporosis. It's not normally something they come to see you about. So you have to have antennae around to pick it up, over and above what they present with."

They expressed unease about missing clinical signs and the non-verbal communication experienced when meeting in person. This ranged from a person's capacity or understanding of what has been discussed, how they appeared physically (frailty, BMI) or how they moved (indications of pain).

"You don't know what you're missing because you haven't seen it...I think we are still learning about how to do non - face-to-face consultations...I was taught to diagnose with my eyes. With MSK conditions in particular that is more difficult because I don't have the clues...you have to see and feel and touch and examine the patient." GP

"How they walk from the waiting room to the consultation room has huge clinical value...If you see they're thin and frail, you know... It starts making me think, [using] my soft identification skills for osteoporosis." GP

However, some healthcare professionals (particularly GPs) felt there were benefits to the increase in use of telephone appointments, particularly where the doctor had an established relationship with the patient. Benefits included:

The convenience for patients who for a variety of reasons will find it hard to get in for an appointment due to work, disability or caring responsibilities for example.

"You're saving them an awful lot of upheaval for something they can hear by phone." First contact practitioner/physiotherapist

The flexibility to check in with a patient a week or so after starting a new course of treatment for example or starting new exercises to check on them.

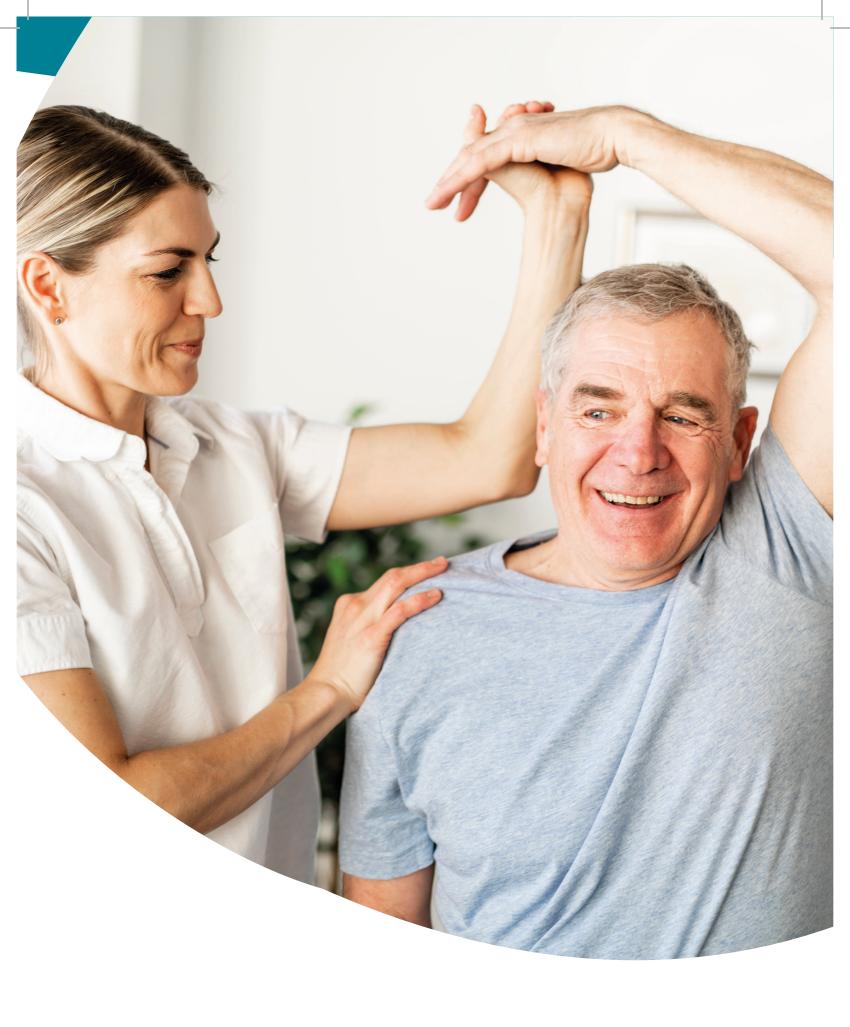
"I've found that phone calls have worked really nicely for follow-up and ongoing care for patients who I already knew. I knew what they understood about their health, they trusted me. It was actually really easy to decide what was manageable over the phone or when we needed to bring them in." GP

The efficiency of triaging more patients more quickly. This included referring them straight to physiotherapy or imaging without seeing them, saving valuable consultation time.

"I still feel comfortable triaging over the phone for the most part, unless there's an initial red flag. Then if there's no improvement it makes sense to get a face-to-face. So I'll have sort of an internal clinical pathway in my head." GP

Healthcare professionals preferred face-to-face consultation for people with musculoskeletal conditions







# **Impact of COVID-19**

COVID-19 was mentioned by a number of respondents in relation to accessing care due to its inevitable impact on waiting times for appointments. Most respondents described these delays as understandable, though some described how it left them unsupported.

"I'm currently waiting now for the test results and a date and treatment plan at the hospital. Due to the pandemic everything has been so protracted and the amount of suffering I've endured has at times been intolerable."

The patient experience during the pandemic is backed up by evidence from the FOI request which identified 27% and 45% falls in prescribing of osteoporosis treatments and DXA scans respectively over this period. Similarly, research has shown that use of the FRAX assessment tool in the UK fell by more than 50% over this period.<sup>21</sup>

While levels of prescribing have bounced back, they remain below pre-pandemic levels. The impact of the interruption in prescribing and delays in DXA is difficult to predict. However, the underserved group will include:

- patients who didn't attend appointments due to fear of being exposed to COVID-19
- patients who did not start treatment or remained unidentified
- patients who were not followed up due to the increased workload for healthcare professionals to provide care during the pandemic
- patients who failed to adhere to treatment
- patients who sustained a new fracture over that time period who would have benefitted from a review and new treatment plan.

These phenomena have been observed in osteoporosis care internationally.<sup>22</sup> There is a concern among osteoporosis specialists that the move observed towards telemedicine and delayed DXA could erode the 'gold-standard' for assessment and treatment of patients.

Health professionals interviewed provided a detailed picture of how the service had coped during COVID-19, the long waiting times in its aftermath, and the pressure on them now from the need that was unmet during the pandemic.

Some expressed how preventative work had been hardest hit as clinicians ran to keep up with the new demand of increasingly complex patients.

"[During COVID] patients had good care, but we were seeing only those people that were really high need so all the good practice and all the things that we'd built up in our service - like our falls prevention work just stopped. I think it has changed people's mindsets a little bit. We're having to definitely start reminding people that actually, this preventative stuff that we do is the stuff that we need to be picking up. Reminding people that we aren't just that little reactive service that keeps people out of hospital." Physiotherapist

Some healthcare professionals felt that COVID had presented some beneficial opportunities for new ways of working which involved fewer

"The primary care/secondary care divide has been bad...But I'm feeling an appetite from all of us, you know, through crisis comes opportunity? To start building a much more informal peer-to-peer level [collaboration]." GP

# Barriers to referral and having to go private

In their responses to the inquiry survey 20% (109/545) of respondents described being refused referrals and investigations by their GP.

"I had months of extreme pain and visits to my GP, examinations and treatment for muscle pain...I asked for an x-ray several times and was told it would not show up...[At] my next visit to my GP I refused examination as I was in such pain and said I wished a referral for MRI scan at hospital. It took three nurses to help me undress and to support me on the scanner bed. The scan showed multiple compress spinal fractures, which took another 6 weeks to heal."

# CASE STUDY: KAY FROM SOUTH YORKSHIRE

Kay was enjoying a holiday in America with her husband when she fell and broke two vertebrae in her back.

We were cycling but I had stopped and was stood with a foot either side of the pedals. I'd only turned round to speak to my husband when I fell. At no point while I was being treated in America did anyone even raise the idea of osteoporosis.

When I saw my GP back in England, he didn't mention osteoporosis either. I asked to see a specialist about my fractures. He told me there would be a very long waiting list. So, I asked if he could recommend a private consultant. He did and referred me to a consultant neurosurgeon and spinal surgeon. He examined me, said my fractures had stabilised and no surgical intervention was needed. Again, there was no mention of the possibility of osteoporosis.

It was only a few weeks later, through a casual conversation with a family friend who is a GP, that the possibility of osteoporosis was first raised. Following that conversation, I then contacted my GP to arrange a bone density scan and to ask for a calcium supplement as a precaution. Without that conversation with a family friend, I'm not sure that osteoporosis would ever have been thought of.

I had to really push to get a DXA scan. Once I had it, I was informed by phone that I had osteoporosis and would be starting medication. There was no explanation or attempt to help me process the information. It wasn't until I spoke to a nurse at the ROS and they explained what the diagnosis meant and that I had the right to see my scans to better understand my situation.

Looking back and knowing what I know now about osteoporosis, it's hugely concerning that my GP appeared not to be alert to the indicators and risk factors. Post-menopausal fragility fractures should always be a cause worthy of investigation. I know that they are dealing with life and death illnesses on a daily basis but osteoporosis, whilst not immediately life threatening, is life changing and life limiting. The diagnosis of this condition could be handled much more sensitively and I could have known much more from the point of diagnosis that would have empowered me to make decisions about my treatment and how I managed the condition.

"It's hugely concerning that my GP appeared not to be alert to the indicators and risk factors."





"I have not been given anything by my GP because my GP said they are not interested in early diagnosis, screening, treatment as it would cost the NHS too much. I was advised to wait until I have several fractures, this is a GP surgery rated as good unfortunately by the CQC."

Some responses pointed to system barriers in the referrals system for DXA. GPs were reluctant to refer because they believed that the referral would not be accepted by the DXA scanning service.

"There's always pressure to not put people through to any form of imaging if you can, with the pressures we have on the system." **GP** 

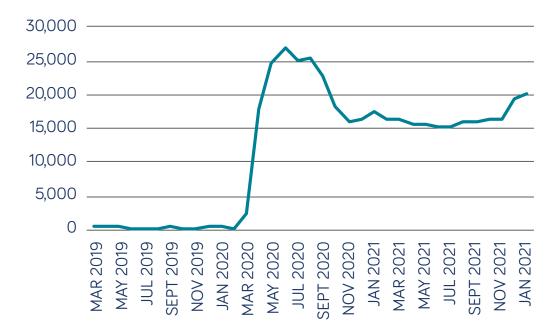
"As a medical professional when I request something [Imaging], I do truly believe it will help my diagnosis. But [the wording of the request] needs to be vetted by radiology consultants. There's so much bureaucracy involved...and I'm not sure why." **GP** 

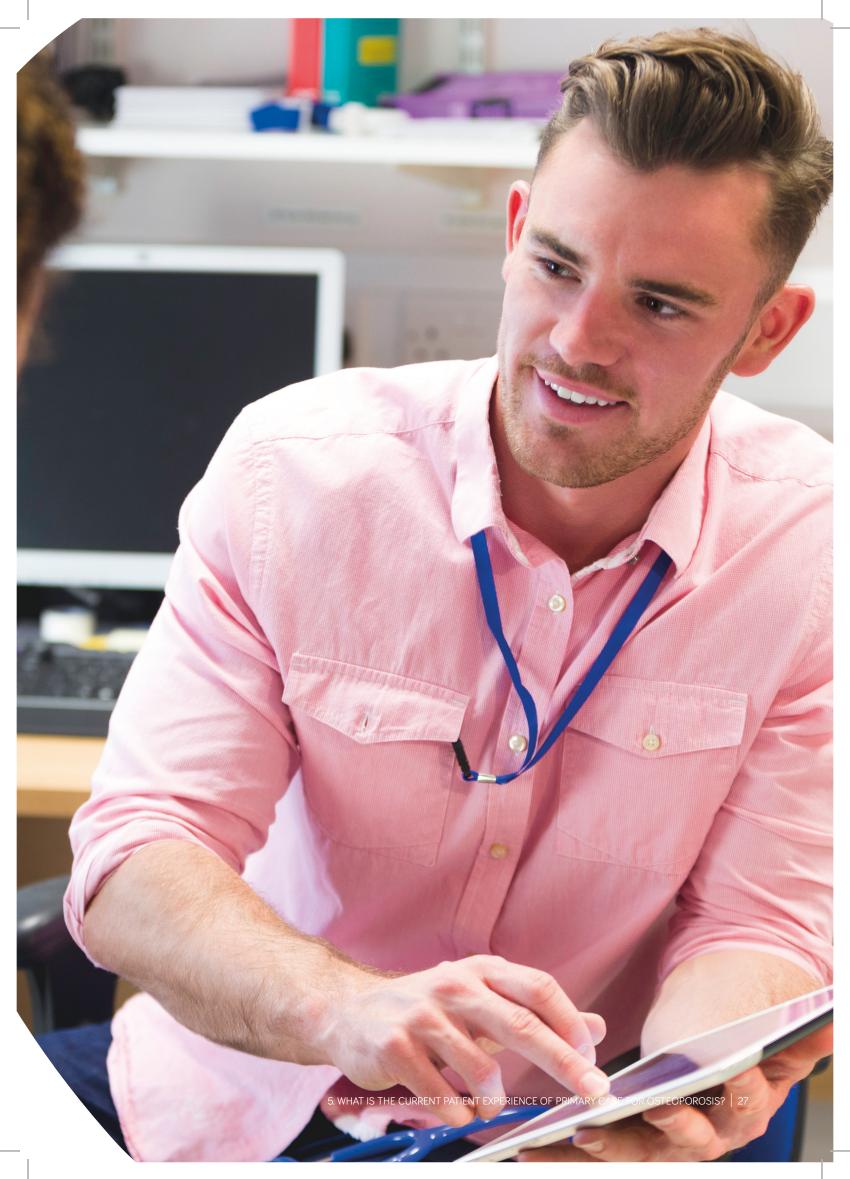
The backdrop of a national shortage of both scanners and radiographers was raised by a number of those who gave evidence to the inquiry – this shortage has resulted in restricted access to DXA services in some areas and variation in waiting times across the UK.523-25

In 2020, the NHSE – commissioned report by Prof. Sir Mike Richards recommended that DXA capacity was increased in line with the 4% annual growth rate in demand.<sup>25</sup> However, this recommendation may no longer be sufficient to support best practice care for people with high fracture risk. As a result of the COVID pandemic, waiting times for DXA have increased and remain high, presenting a barrier to timely scans and diagnosis.

Published NHS waiting times show that while 2295 patients were waiting for more than 6 weeks for their DXA appointment in March 2020, this had increased to 16,373 in March 2021, and over 20,000 by January 2022 – more than 8,000 of these had been waiting for more than 13 weeks.<sup>26</sup> The current DXA provision in England is inadequate to address the backlog of patients waiting, while also providing for new patients. This will be compounded as MSK programmes and new FLS services are commissioned.

Patient waiting 6+ weeks for a DXA appointment 26





In their oral evidence to the inquiry, one GP suggested that without ring-fenced funding for DXA scanning, GPs were deterred by the immediate cost.<sup>27</sup> There was also a push (through national guidance and CCG policies) to reduce the number of X-rays requested for back pain. This, combined with a lack of expertise, means that many vertebral fractures are not being identified promptly.

"She (GP) was very helpful but I did not meet the criteria to have a DXA scan on NHS. A few years later I saw a different GP. I still didn't meet the criteria and she suggested going private. I had one privately which confirmed osteoporosis. My GP was very apologetic and felt I had been let down by the NHS."

As a result, 11% (58/545) of respondents described having to go private to receive care including:

- Diagnostic blood tests
- DXA scans
- Consultations with a specialist consultant

"The same GP said I had no symptoms that warranted an MRI scan or X-ray. As pain was indescribably bad, I paid privately for an MRI scan to find there were multiple lumbar vertebral collapse and a newly fracture T11 vertebra."

"None of the NHS staff I saw identified my osteoporosis nor took it seriously once it was diagnosed. I have spent months in agony - it is truly awful. I work full time as a CEO and was only treated because I could afford private care. I prefer the NHS, but I spent 5 weeks with 2 breaks in my pubic rami, with no NHS X-ray, a diagnosis of arthritis...and a bottle of oral morphine (which the GP gave me without an X-ray!). I couldn't walk, I couldn't drive, manage stairs etc. When I got so desperate (as I couldn't function) I asked my [Private] rheumatologist to see me it took him 5 minutes to work out what it was. Quick X-ray and there it was - two breaks...it seems there is no way to get one of any kind or urgent care [in the NHS]."



# More than 1 in 10

# HAD TO GO PRIVATE

to receive care

# **OUR ANALYSIS**

Patients are experiencing a range of difficulties accessing the care they need. Fairness in access to healthcare is a founding principle of the NHS. However, the inquiry heard evidence that paints a picture of a system that currently only serves those who have the capacity and tenacity to persist in self-advocating for what they need – whether that be face-to-face appointments or referrals for scans, tests and specialist input.

Barriers to referral point to a need for increased awareness of and training in the risk factors for osteoporosis and the ways in which it presents. Patients being forced to go private to receive basic care highlights the health inequalities that persist in osteoporosis care.

The inquiry heard about difficulties experienced by patients in accessing DXA, due to a reluctance to refer by GPs in some cases and restricted access to DXA due to demand. We welcome the proposed Community Diagnostic Centres (as part of the Diagnostics Transformation programme) as an opportunity to support change and increase capacity to deliver DXA scans for patients at high risk of fracture. However, we were disappointed that despite a 4% annual growth in demand, DXA is not part of the minimum specification for Community Diagnostic Centres.

# **OUR RECOMMENDATIONS**

NHS England must outline plans to expand DXA services to deliver and exceed their recommended 4% increase in capacity in order to tackle the current backlog and future proof services, – and improve access by including DXA in minimum specifications for Community Diagnostic Centres.

# Diagnosis, Treatment and Monitoring

Long term adherence to treatment is essential to reduce fracture risk and thereby realise the costeffectiveness of treatment.<sup>28,29</sup> Current evidence however, shows that around 25% of patients will not even begin the bisphosphonate treatment they have been prescribed.<sup>30</sup> Of those that do start treatment, most will stop within the first few months, the average duration being only a few months. Less than 50% of people prescribed bisphosphonates continue taking them beyond one year.  $^{29,31}$  The 2021 Life with Osteoporosis report found that only 48% of people with osteoporosis were confident that they were on the right medication and more than half were worried about the potential side effects of their medication.<sup>32</sup> For this reason, follow-up and monitoring of osteoporosis patients is a critical part of osteoporosis care.

The reasons behind non-adherence are varied but include:

- Difficulty following complicated instructions about fasting and remaining upright when taking bisphosphonate tablets.
- Side effects or fear of them among patients and healthcare professionals alike (often due to misleading media coverage).
- The fact that patients do not experience symptomatic benefit from treatment.
- An overall lack of understanding of the benefit of long-term treatment in reducing their risk of fracture.

"The default that we have to appreciate is that people don't want to take osteoporosis medication. So sadly, unless they have the opportunity to ask guestions and receive reassurance that this is something that is going to be useful to them, they're unlikely to take

This is where GP surgeries can make the difference, by providing:

- 1. Effective support to patients at diagnosis.
- 2. The opportunity for shared decision-making about treatment including providing appropriate information on fracture risk, and the risks and benefits of treatment.
- 3. Regular monitoring of adherence to, and tolerance of, treatment.

Evidence to the inquiry from patients indicated that there were considerable problems in all three of these areas.

### 1. Supporting patients at diagnosis

Many patients gave evidence to the inquiry of a poor experience at diagnosis including their diagnosis being:

• Delivered by text, letter or phone call from a receptionist, in a manner which patients found insensitive.

"Just a phone call. No explanation or discussion. 'You have osteoporosis - the prescription is waiting at the pharmacy'. It was very bad."

• Mis-reported or not reported to them at all.

"I phoned the surgery to ask for the results and [was told that] there was nothing wrong. Four months later I was still in pain and having difficulty breathing. I went back to the GP and it was only then that he looked at the report and told me that I had osteoporosis."

# **OUR ANALYSIS**

The conversation at the time of diagnosis between doctor and patient is the most crucial opportunity to convey the purpose of treatment, the critical importance of adherence and that alternative treatments may be available if needed.

It allows clinicians to set expectations, allay fears, and equip patients with the confidence to manage their long-term condition until their medication requires a review, or to seek help if they are struggling with the treatment that has been prescribed. In 2021 an ROS report found that only 54% of people felt that the benefits and drawbacks of their medication had been fully explained to them.<sup>32</sup> The evidence heard by this inquiry suggests that many clinicians are unable to deliver a minimum standard of care around diagnosis, to the detriment of osteoporosis patients.

"When diagnosed [people need] an appointment longer than 15 minutes, [with someone] with full knowledge in the subject, should be provided together with information of how to handle the news, mental health, I had a massive breakdown when given the news."

# 2. Shared decision-making around treatment choice

43% (234/545) of those who responded to the inquiry survey described anxiety and frustration at the lack of opportunity to discuss treatment options with their GP or practice nurse.

"After that I had a phone call from the GP with the diagnosis and his suggestion of medication. There was no discussion as to how or why .... nor any discussion about choices of medication etc."

"I didn't take the prescription. I am unhappy about discussing osteoporosis with my GP practice as they don't appear confident to discuss options."

Many respondents felt that their GP was only concerned with the dispensing of medication (usually oral bisphosphonates) or was reluctant or unwilling to discuss alternatives (possibly due to lack of knowledge) if the patient felt that they were not tolerating them well. Some even described having care 'withdrawn' if they felt they could not take the recommended treatment or not being offered treatment at all.

"My GP did not offer any alternative, he said I should be prepared to "put up with" side effects."

"I asked my GP what treatment was available and she said 'Nothing. Just come back when your bones start breaking.' I was appalled disgusted and really upset."

Written evidence from clinicians highlighted research that found that patients needed support from clinicians to integrate medication-taking into their daily routines, to enhance their feeling of control over their health and their ability to adhere to treatment.<sup>17,18</sup> Good communication is essential to achieve the best outcome in this regard. The inquiry heard evidence from a clinician about how, though they may be focused on treatment, GPs must bridge the gap between their clinical focus on treatment and the priorities of the patient. The patient is often more focused than the clinician on their risk of having another fracture, their symptoms and how they are feeling.<sup>34</sup>

The healthcare professionals interviewed described their responsibility of gauging how to share decision-making

"It has to be a bit tailored. We need to appreciate what would work for that individual. [For some patients] I would

lose them if I overwhelmed them with information." GP

"There's definitely some of those, particularly where it's starting medication, where we'd be much better off doing them as face-to-face appointments." GP

Research evidence has indicated that lack of expertise may underlie a reluctance to share decision-making with patients. For example, both clinicians and patients have been shown to have doubts about the effectiveness of bisphosphonates and a range of expectations about what they offer (including strengthening bone, preventing worsening of osteoporosis, maintaining bone density and/or total fracture prevention).<sup>17</sup> GPs also want more support around how to explain the pros and cons of certain medications, through videos for example.<sup>35</sup>

## **OUR ANALYSIS**

NICE has already issued guidance on shared decision-making for all healthcare settings, and with regard to osteoporosis treatment specifically states that "The choice of treatment should be made on an individual basis after discussion between the responsible clinician and the patient... about the advantages and disadvantages of the treatments available."36,37 Without shared decisionmaking between patient and clinician and a person-centred approach, adherence to treatment is jeopardised and cost-benefit will not be realised. The evidence presented to the inquiry suggests that while GPs appreciate the need for shared decision-making, pressures on clinician time, lack of expertise and lack of support for decisionmaking means that expected standards are not being met.

"I did not feel that the GP was interested in listening to why I was concerned about what medication I was going to be prescribed. They just wanted me to agree to take what they suggested."



# **ONLY 48%**

of people with osteoporosis were confident that they were on the right medication



### 3. Follow-up and monitoring adherence

Despite the well-recognised problem around adherence to treatment, 54% (294/545) of respondents to the inquiry survey said that they did not receive ongoing support from primary care to manage their osteoporosis over the long term. Only 7% (39/545) described having good support.

"[Since 2019] I have had little or no contact with my surgery although I have this last month had an 'over 70s' health check. My osteoporosis wasn't mentioned."

"I was sent back to my GP, the [hospital] doctor suggesting that the GP monitor my condition. I had no further help from my GP about my osteoporosis until I had more fractures in 2021."

A number of patients described having either no review of their medication, or a review that was inadequate in their view:

"I have never been reviewed even after telling my doctor I wasn't taking tablets anymore. She said I could start them again and gave me a prescription. I never took them."

When given the opportunity, several respondents told the inquiry that they would like an annual review of their condition to discuss medication, any side effects, their personal fracture risk and other issues.

"I have yearly reviews for my asthma so why not a yearly review of osteoporosis at my own GP practice?"

The inquiry heard evidence about how patients commonly want proof of the effectiveness of treatment, through structured monitoring, to support adherence. The survey respondents also indicated the importance to them of tracking the progression of their disease through their bone density score (via DXA).

"Osteoporosis is a silent illness, we do not know if what we are recommended to take makes any difference, we should be regularly monitored on our progress by the primary care and osteoporosis specialists."

A 2021 ROS report found that only 40% of people with osteoporosis thought that their medication was effective.<sup>32</sup> Lack of evidence of effectiveness is known to act as a disincentive for patients to continue treatment. 17

Some factors for effective monitoring identified in evidence to the inquiry:

- Specialist services' support for primary care clinicians led to better patient outcomes and improved adherence.
- Shared decision-making led to improved adherence to treatment.
- Use of tests such as bone turnover markers in the early stages of treatment can show patients that their treatment is working, encouraging adherence. However, these are not available in many parts of the UK.
- Targeting follow-up to those who most need it could be clinically and cost-effective.
- Interventions (e.g. texts) that remind and support patients to integrate medicationtaking into their daily routines.
- Not using administrative staff for monitoring treatment (to promote adherence) as clinical knowledge was required.
- Not relying on what patients self-report as this does not correlate with their actual adherence.38

## What healthcare professionals told us

Healthcare professionals interviewed were very familiar with patients' reluctance to adhere to osteoporosis treatments. Clinicians described how the lack of symptom change when on treatment of osteoporosis acted as a disincentive to adhering to treatment over a long period of time. Patients do not 'feel better' when being treated, and therefore do not perceive a benefit to treatment.

"Well, I've done XY and Z for my osteoporosis, but I'm still getting this pain'. Having that discussion with them, explaining that it's not a necessarily a symptomatic management - that's quite a difficult and challenging conversation with a lot of people." First contact practitioner/physiotherapist

"The biggest reason [for nonadherence is the lack of symptom change...and the education behind that." First contact practitioner/ physiotherapist

A number of healthcare professionals interviewed described how particularly older patients with poor appetites and who drank very little were very reluctant to take bisphosphonate pills that require a full glass of tap water to be drunk on administration.

"You have to take it half an hour an hour before your other medications. It's got to be, sit up straight, it's going to be at this time, and make sure they have a glass of water. 'But that's a big glass of water. I can't drink a big glass of water!' You know, especially when they get older, it's sips throughout the day." GP

"...sometimes people don't see the importance of [treatment] either, which is very short sighted because often if you have broken hip, you're never the same again afterwards. ...I suppose it's not giving it enough importance. People think it's more important to take their heart medications." Occupational therapist

Similarly, because patients do not feel the consequences of missing a dose, it was easier to fail to take it.

"You know, trying to get people to take [medication] when they don't feel the consequences of it is much more difficult compared to when, if you missed your dose, you feel it." GP A number of clinicians expressed their preference for patients to receive annual infusions or six-monthly injections to by-pass the difficulties around oral medication regimens.

"One of the advantages of having intravenous treatment is, it's every year, so once you've had it, compliance isn't an issue. You don't have to keep taking the tablets." GP

Encouraging adherence required skilled healthcare professionals, rapport with the patient, and a very personalised approach.

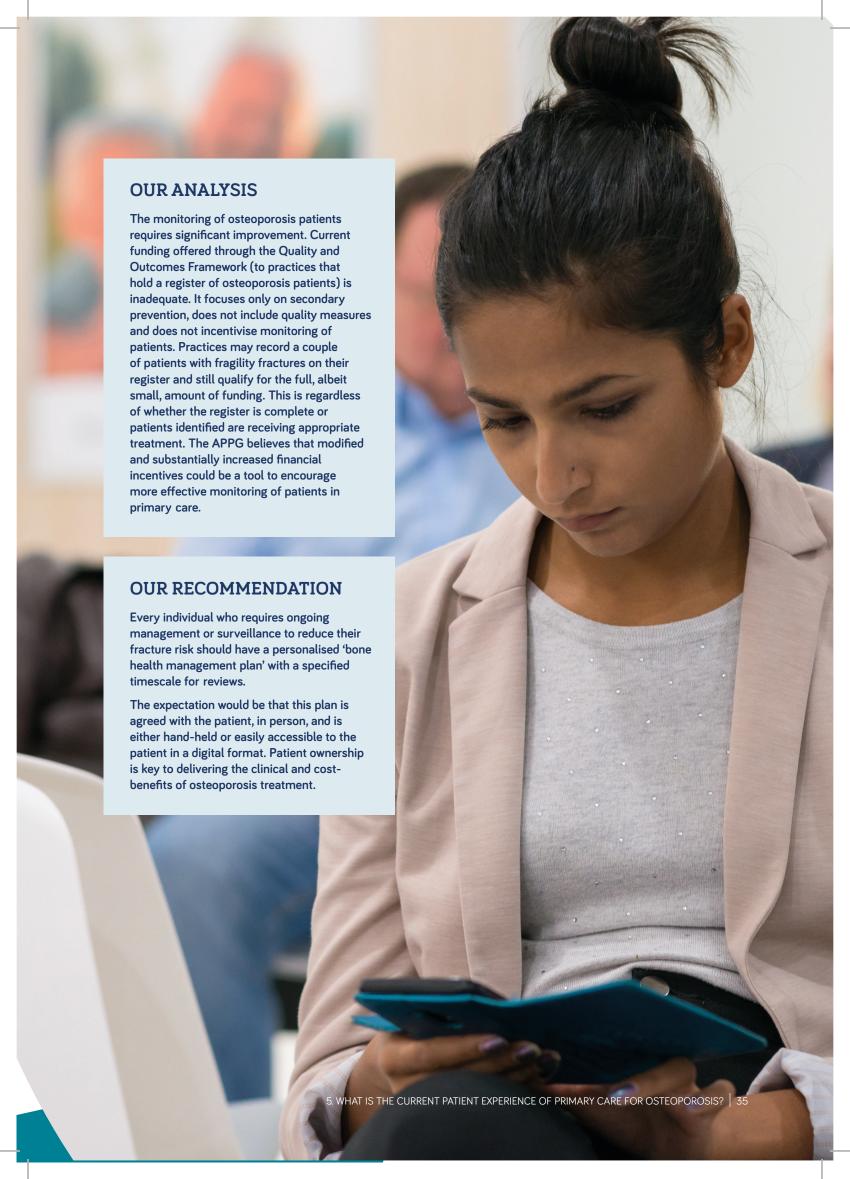
> "When it comes to adherence to medication or understanding of the importance of a condition, if you're not explaining it, if you're not meeting the patient where they are in their life, if you're not able to put it in the context of their life and what's important to them. You know, I'm thinking of a 70-year-old chap whose life is golf, and you say 'Look, if there's a risk of a fracture, you might not be able to play golf again.' Suddenly [they are listening to advice] 'Oh my goodness, tell me doctor about how I can make sure that I can keep playing golf." GP

Healthcare professionals told us that the monitoring role could be undertaken by a range of professionals.

"Certainly in bigger practices now with pharmacists there, it can easily be a role for the pharmacist to review the medication at those particular times. It takes lot of pressure off the GP." **GP** 

'Healthcare professionals also described the financial disincentives for more proactive management of osteoporosis in primary care.

"My practice this year is getting £14,000 for diabetes, £10,000 for asthma and £622 for the management of osteoporosis. The practice can't do anything with this." **GP** 39



# Lack of support and information

40% (217/545) of respondents to the inquiry survey described a lack of support, understanding and empathy from primary care. Many people felt afraid, abandoned, or worried about their future with osteoporosis. There was a widespread feeling that healthcare professionals in primary care needed to listen more, appreciate the impact of the diagnosis, and provide psychological support.

"No support was offered at all. Incredibly frightening and lonely experience."

"[What we need is] taking the time to discuss the results with you to ensure you have an understanding. Even having empathy for how life changing this is for the patient. The information was delivered like I had a minor ailment."

There were some examples of primary care professionals offering good information, advice, and signposting to patients.

"My GP has given me 5 exercises to do for my back which I do daily – it only takes 10 minutes."

However, 44% (240/545) of respondents to the inquiry survey described not having been given enough information about osteoporosis or information about how to self-manage their condition – including advice about diet, safe movements, exercise, and supplements.

"When I was diagnosed there was no real explanation or guidance on what to do other than take the meds." "[I would have liked] advice on how to cope with pain, home adaptations, psychological impact, how to talk to family. Ongoing support as is currently provided for asthma."

"GPs need to understand the diagnosis of severe osteoporosis is a total shock to someone who is fit and active and didn't suspect they had anything wrong until they fractured something. Need more info on drugs and treatment's and changing lifestyle and advice on eating and vitamins to take. Had to do all the research myself and call the ROS several times – they are amazing."

Many of the healthcare professionals interviewed acknowledged that providing information on bone health was not a strength. There was a concern about overwhelming patients, and a perception of the need to drip feed over time. This concern was not reflected in the patient survey. Some GPs made reference to the value of other healthcare professionals from other disciplines in their team supporting patients on topics such as exercise and safe movement. Physiotherapists were highlighted in this regard.

"With some of the language you can push people to the point where they're afraid to move, so they don't want to do exercise because they think they're both just going to fall apart...I think as physios, we're better at having those conversations with people." **Physiotherapist** 

44%

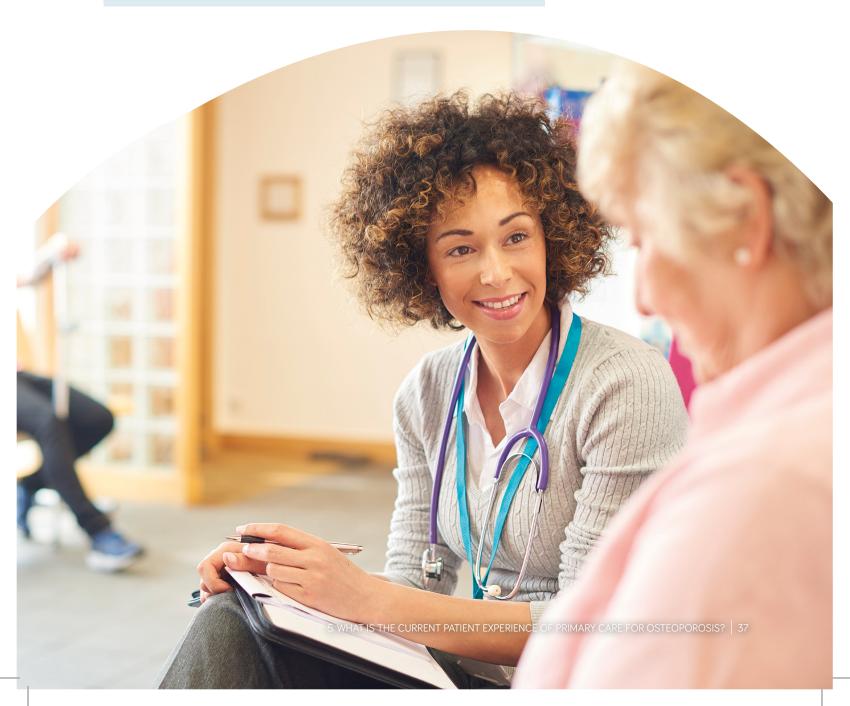
of people felt that they had not been given enough information about osteoporosis



### **OUR ANALYSIS**

People with osteoporosis who responded to the inquiry survey showed high levels of motivation to manage their long-term condition themselves. This aligns well with the NHS Long Term Plan's ambition to achieve personalised care through supported self-management. Individuals demonstrated in their responses to the inquiry survey that they wanted to do whatever they could to build their bone density. However, they struggled to get the support and information for this from primary care.

The reasons behind this lack of support need to be addressed through a range of innovative solutions including expanding the range of professionals involved with osteoporosis patients to take pressure off GPs while giving patients a single point of contact (see single point of contact page 43), giving patients shared ownership of their osteoporosis management plan (see bone health management plan page 35), addressing issues around expertise (see knowledge and skills page 44-49), technological solutions (see case-finding page 59-61) and giving osteoporosis the priority it needs given the burden it places on the NHS.



### 6. WHO IS BEST PLACED TO **IDENTIFY, MANAGE AND FOLLOW-UP PATIENTS WITH OSTEOPOROSIS?**

While most clinical decisions and much prescribing are still largely dealt with by GPs, the inquiry heard evidence of the need for more patient management to be undertaken by a range of healthcare professionals across various disciplines - including other prescribing colleagues, first contact practitioners, physiotherapists, nurses and clinical pharmacists.<sup>16</sup>

The NHS Long Term Plan outlined a vision, supported by new NHS bodies (ICS and PCNs) for multi-disciplinary and integrated services in primary care.

"The doctor used to be like the kingpin, at the top of the pyramid and all the rest of it. But we are now much more of a team player in a ring, and everybody's holding that ring for the benefit of the patient who's in the middle. We're all trying to make things better. I think we're realizing that there's a wider population health job that we need to do." GP

The inquiry heard evidence from clinicians who felt that more needed to be done in primary care to accelerate the development of this new way of working and expand the range of professionals involved in the care of people with osteoporosis. This discussion must be set against a realistic backdrop of the current unprecedented shortages of clinicians (GPs and nurses in particular), and equally difficult issues around staff retention due to professional 'burnout' post-pandemic.40

"I was taking increasing shortcuts to get through the workload...I was doing triage, not even via talking to the patient because I know once I do that that's going to be at least 15 minutes. I started recognizing how much I was doing that...This is actually pretty damn risky. I started getting that gut feeling in my stomach that it's going to blow up...I just wasn't sleeping anymore and then needed to sort of take a step back." GP

A number of healthcare professionals interviewed who worked with GPs expressed frustration that current patient pathways did not allow them to take on more responsibility for patients - including for example, being allowed to instigate imaging investigations.

"I just don't think he [GP] thought that at our level of training we should be doing things like FRAX assessment...But now the problem is that if patients don't have access to a GP, I think it's even more important that we're asking the relevant questions because they're not really getting seen." Occupational therapist

#### **GPs**

Patient survey responses indicated that GPs are still having the lion's share of contact with patients with osteoporosis. They are best placed to identify the condition, arrange appropriate investigations and critically, communicate the results. Patients most commonly described treatment decisions and prescribing as being dealt with by their GP.

#### Nurses

Nurses in primary care should be well placed to manage patients with osteoporosis. However, satisfaction rates with nurses' expertise elicited in the inquiry survey demonstrated a lack of involvement between practice nurses and patients with osteoporosis - 60% of respondents felt that the question was nonapplicable. Only 8% were satisfied with their care, and 21% were dissatisfied with the care offered. In their written evidence to the inquiry, a group of clinicians highlighted research that indicated that nurses lack the skills to conduct FRAX®, communicate risk to patients, and take action on FRAX® scores without additional training.41

#### **Pharmacists**

The inquiry heard evidence about how the expertise of both clinical and community pharmacists could be used effectively in osteoporosis care. A pharmacist interviewed by the inquiry described frustration at local procedures that did not entitle her to act as a non-medical referrer to DXA.

"Unfortunately it needs to go through the GP. Previously, I was referring people for DXA, and a load bounced back. Because it's classed as an X-ray, pharmacists aren't allowed to refer in directly. So essentially I will check that they fulfil the criteria for the DXA scan, print out the form, fill in all the details and then the GPs looks it over and then it gets sent in." Clinical pharmacist

Clinical and community pharmacists are involved in the monitoring and review of patients in some areas, but may require specific skills training to ensure shared decision making takes place.<sup>18</sup> GPs gave evidence to the inquiry, cautioning the likely limitations of pharmacist

input - such as in a practice which has 50% of the time of a clinical pharmacist, affords them 450 medication reviews per year (which take 30 minutes to complete) across all patient conditions.<sup>42</sup> However, pharmacists can be involved in other ways at ICS level. For example, in the Northern Bone Health Programme, casefinding was undertaken centrally by clinical pharmacists (see case study: The Northern Bone Health Programme Insert page no. p.63).

### Care coordinators and administrative staff

While a care coordinator cannot make clinical decisions, they could be well placed to arrange the appointments and care patients need. Administrative staff can also make a valuable contribution to the potentially laborious task of case-finding.

### Physiotherapists and first contact practitioners (FCP)

Several respondents to the inquiry survey described very good experiences of care from physiotherapists. Where the physiotherapist had the right expertise, they could support patients very effectively – improving their understanding of how to self-manage their condition and improve the bone health through weightbearing exercise. This group of staff are also well positioned to identify those who may be at risk of fragility fracture or who have already sustained a vertebral fracture.

"I asked if I could be referred to a physiotherapist as I was anxious about starting exercise again. He did this and although I only had two sessions with him, it was helpful in rebuilding some confidence about exercising."

"I did ask GP at original diagnosis what I could do to help, and he said, don't fall over. It was the physio who invited me to her exercise group for people with osteoporosis. She was brilliant, and so knowledgeable."

Several respondents described having to pay to access physiotherapy expertise.

"The only help I have had was when I paid for an appointment with a private physiotherapist who was extremely helpful, but I can't afford any more appointments."

There were, however, an almost equal number of reports of physio input that had at best not been useful, and at worst, had been positively harmful - most notably among those with vertebral fractures in which these physiotherapists did not have the appropriate expertise.

"I was not diagnosed with osteoporosis for 6+ months after first fracture and only after NHS physio caused a second fracture through spinal manipulation."

FCPs are physiotherapists professionally qualified to treat patients without a referral from a GP or other healthcare professional. This new model of care helps to address the national shortage of GPs, pressure on GP appointments, and the needs of an increasing elderly population. For the patient it can expedite treatment and recovery.

"There's a kind of push for [FCPs] being able to prescribe as well, so that we can support GPs as much as possible. It's fair to say that it's a developing role.

There seems to be an awareness that a GP is exactly that, a general practitioner. The opportunity to see a specialist [physiotherapist] right at the start of the journey is a godsend for a lot of patients." Advanced physiotherapist/first contact practitioner

Pressures on GP time and declining GP numbers mean it is essential to exploit what other clinical and non-clinical roles have to offer. This in turn, requires a shift in mindset of both clinicians and patients, away from the traditional one-to-one patient doctor dynamic to a teambased approach.

Our interviews with physiotherapists indicated that this shift in approach was something that was still evolving, and continued to present challenges.

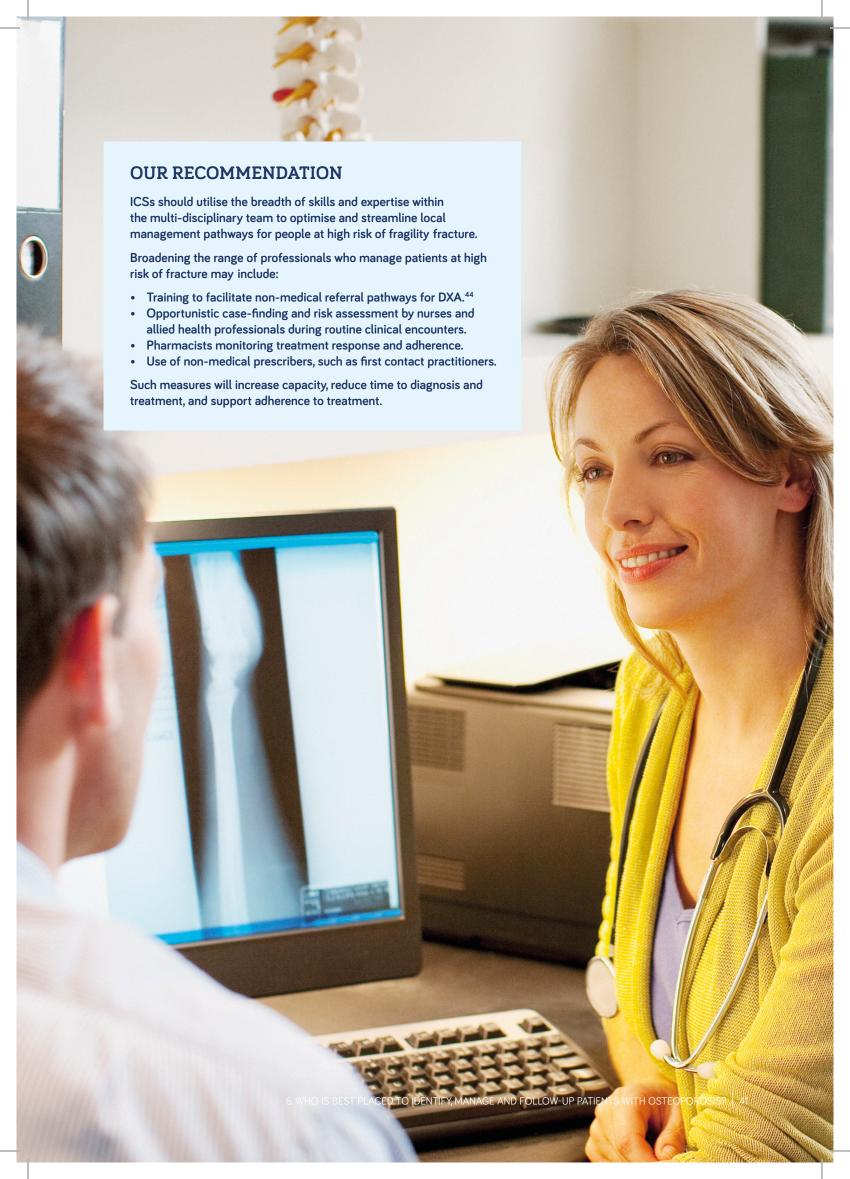
"A lot of GP practices aren't quite sure of what the scope of the role actually is, because they're new. So the role itself hasn't been fully defined or isn't fully understood." First contact practitioner/ physiotherapist

"From a clinical point of view...the pandemic actually encouraged us to expand our roles...By chipping in, improving, we can do a lot more than maybe you first thought we were capable of. We've proven that we can actually be very beneficial within primary care." First contact practitioner/physiotherapist

### **OUR ANALYSIS**

Several different professionals should have a role (in collaboration with each other) in the ongoing management of patients with osteoporosis. The current picture suggests that the primary care workforce need time and resources (including specialist training) to deliver effective multidisciplinary care for patients with osteoporosis.

Through Primary Care Networks (PCNs), larger multi-disciplinary teams of staff including GPs, nurses, pharmacists, care coordinators and FCPs can offer team-based services to their population at scale but still close to where they live. This ambition has yet to be fully realised for reasons that are outside of the scope of this inquiry.<sup>43</sup> New roles are being supported by the Additional Roles Reimbursement Scheme (ARRS) but have yet to be fully embraced and exploited by the current primary care culture.



### Conflicts of responsibility

One of the challenges in multi-disciplinary osteoporosis care remains the issue of ownership. This is due in part to the number of specialties under which osteoporosis falls. The inquiry heard oral evidence from a GP that due to the lack of ownership, osteoporosis is often overlooked.

"Osteoporosis always becomes someone else's problem." GP 16

This was reflected in patient responses to the inquiry survey. When asked who was in charge of their care only 55% described a clinician as in charge of their care – a vocal minority (15% or 59/383) said that no one was in charge or referenced a conflict of perceived responsibilities for osteoporosis patients. This was often accompanied by a sense of abandonment or being let down.

"No one is in charge of my osteoporosis!! Diagnosed age 50 following early menopause. Battled with GP for years to get HRT whilst I was osteopenic. Never been referred to specialist or given any advice or guidance from a healthcare professional. Did my own research and joined some support groups took control of my own health and started HRT two months ago. Totally let down by NHS."

Conflicting views in primary and secondary care about who is responsible for osteoporosis patients were highlighted in evidence to the inquiry. For example, the inquiry heard that GPs hold differing opinions about whether fracture risk assessment is the role of primary or secondary care. 18,41 Further evidence showed that some GPs believe secondary care to be responsible for patients that they have prescribed treatments that may reduce their bone density, such as patients prescribed longterm corticosteroids.34

"I'm thinking here of people who are on steroids...They will normally be started in secondary care who are notoriously bad at thinking about bone protection. They just run them straight on it for their inflammatory bowel or psoriasis or eczema or their asthma. We're on the picking up end of that. But that's a bit hit and miss. It depends on the GP spotting it." GP

Healthcare professionals interviewed could see the benefit of establishing leadership for osteoporosis at practice level and above.

"One of the concepts which I kept talking about was having a bone health lead in the practice, which could be a pharmacist or could be the GP." GP

### **OUR ANALYSIS**

Leadership and responsibility for osteoporosis needs to be established at national level and throughout the infrastructure across all four nations. as well as across healthcare provider or commissioning bodies in order to achieve clarity around respective responsibilities for osteoporosis patients. This will allow for development of clear local pathways and guidance to deliver improvements in care for people with osteoporosis.

### OUR RECOMMENDATION

Establish a new National Specialty Adviser for Fracture prevention and Osteoporosis within the NHS England and NHS Improvement clinical advisory structure, and equivalent in Scotland, Wales and Northern Ireland.

Osteoporosis care requires strong, visible leadership from a national specialty adviser, and for leadership to be embedded at all levels of health infrastructure, through the establishment of clinical networks.

### Only

## 55%

## felt that a clinician was in charge of their care

### A single point of contact

In the absence of effective monitoring of osteoporosis patients and clear responsibility for their care, the one suggestion that came through very strongly in responses was the need for patient access to a single point of contact in primary care.

"Perhaps every GP cluster (not necessarily every practice) should have a point of contact with the knowledge needed to address concerns and be able to offer guidance."

Some respondents to the survey had experience of this kind of continuity of care, from a specialist osteoporosis nurse through hospitalbased services. This was highly valued by patients and highlights an effective model of care that meets their needs.

"I was referred to a specialist nurse and felt very grateful that all of this was in place. The specialist nurse was excellent, knowledgeable and caring and I was able to build up a very good relationship with her over 7 years."

### **OUR ANALYSIS**

Osteoporosis care is currently compromised by a lack of ownership and fragmentation of care that is confusing for patients. This is exacerbated by the lack of a shared understanding of the responsibility for osteoporosis between secondary and primary care. To navigate this, patients with osteoporosis need to have a single point of contact for their osteoporosis care.

### **OUR RECOMMENDATION**

Every patient should have access to a single point of contact for osteoporosis care.

This role would coordinate their care and address patients' queries and concerns. There is no need to define precisely who or what professional group, should fulfil this role. It may or may not be a prescribing practitioner for example, as this would vary according to local clinical pathways.

## 7. WHAT SUPPORT DO PRIMARY CARE PROFESSIONALS **NEED TO PROVIDE QUALITY SUPPORT TO ALL** OSTEOPOROSIS PATIENTS?

### Raising levels of expertise, knowledge and skills

The inquiry patient survey found 50% of patients were dissatisfied with the expertise of their GP. Only 18% of respondents were fairly or very satisfied.

"The GP who informed me was pretty hopeless and induced huge worry on my part as he had little idea of my prognosis and wasn't at all reassuring or helpful."

Lack of expertise was cited in all areas including:

- identification of osteoporosis
  - "...it should set alarm bells ringing, about the standard of training and diagnosis in primary care, if a 63-year-old woman, presents to her GP with fragility fractures from a minor fall and one of the first checks isn't, could this possibly be osteoporosis?"
- understanding of osteoporosis risk factors
- interpretation of DXA scan results
- knowledge of treatment options

"The GPs in my local surgery seem to know less about osteoporosis and the treatments than I do."

- osteoporosis in men and younger women
  - "My GP does not have enough knowledge and initially responded to me as though I was 80, which isn't helpful when I am still working and active."
- appropriate lifestyle modifications including exercise.

"My GP did not really understand what this meant for me, in my mid-50s, active and fit. I was told to not lift anything, to not walk on grass, and to be very careful on uneven pavements. I was told to stop cycling and practicing yoga... I had a very anxious wait of three months [to see a consultant rheumatologist], during which I was afraid of doing anything physical. My GP told me I had the bones of an 80-year-old and would fracture."

## CASE STUDY: LINDA IS 60 YEARS OLD AND LIVES IN BIRMINGHAM

I've always been fit and full of energy and imagined I would always be. Then, while visiting an aunt in hospital in December 2019, I slipped on a wet grass verge as I got out of the car.

I knew immediately I'd done something to my left arm as the pain was awful. It turned out I'd broken my wrist in three places. I was surprised how bad the break was as I hadn't fallen from a height — I'm only 4ft 10in — and the grass was quite soft.

Both of my sisters-in-law had broken bones in the past few years and, afterwards, were offered a bone density scan — known as a DXA scan — to see how strong your bones are.

I thought I'd ask for one after the cast came off just in case there was some underlying problem. I was concerned because I'd been through the menopause in my early 40s, which is a risk factor for osteoporosis, a condition that weakens bones and makes them more likely to break.

When I asked my GP, he said that a scan was unnecessary and that when we get older we tend to do a bit more damage when we fall. I wasn't happy and kept pressing for the DXA scan. In the end I was finally given a DXA in July 2020, seven months after my fall.

A doctor then called me and told me that I had moderate to severe osteoporosis. Hearing this, I felt utterly let down. I'd been made to feel like a clumsy woman who was 'getting on a bit' when they should have checked there wasn't some underlying reason for such a bad break.

Since my diagnosis, my GP practice have not offered me any support or advice on lifestyle and diet changes. No one is in charge of my care. At no point have I been monitored, and I currently have no idea how my bones are, in terms of their brittleness. I am certain that I will have to request that my GP look into this.

50%

of patients were dissatisfied with the knowledge and skills of their GP



### Clinical confidence

The inquiry heard that lack of staff with the skills and confidence to calculate and communicate fracture risk to patients was a barrier to improving care. 34,42,45 This aligned with what patients told the inquiry about GPs being unable to decipher the results of their DXA scans.

"My latest scan result printout puzzled my GP. I interpreted the information for her."

It also aligned with the findings of the interviews with healthcare professionals across a range of disciplines who had different levels of confidence in using the tool and differing levels of trust from clinicians to use it appropriately.

"I feel having a direct pathway there would be far more efficient. [rather than having to refer back to GP or Rheumatologist]" First contact practitioner/physiotherapist

The inquiry heard how confidence was improved when Imaging departments gave thorough and explicit guidance to GPs regarding DXA results, further investigations and appropriate treatment. 42,46 This practice varies across the UK however. The inquiry evidence highlighted Sheffield as an area of good practice.

### CASE STUDY: OSTEOPOROSIS SERVICE, METABOLIC BONE CENTRE, SHEFFIELD

The underlying ethos of the Sheffield osteoporosis service is to support GPs to deliver specialist-led care to all people presenting at risk of fracture instead of focusing expertise only on the small number of people who can be accommodated in the secondary care clinics.

A key component is a comprehensive one-stop fracture risk assessment service. All referrals to the service have DXA scans and complete a risk factor questionnaire. Many also have more specialised tests at the same visit including scans to look for vertebral fractures and blood tests to investigate for underlying causes of osteoporosis. Tests are tailored to each patient's individual profile by trained DXA technicians and each assessment is reported by a medical practitioner with expertise in osteoporosis.

We found that a crucial part of the system's success is that the report received by the GPs includes not only the test results but also a clear interpretation and concise recommendations on next steps. This clarity enables GPs to deliver timely care with confidence and is supported by other initiatives designed to optimise and streamline management in the community.

GPs in Sheffield have access to blood tests used to monitor response to osteoporosis treatments. These can identify a response within the first months of treatment, much sooner than can be picked up from follow-up DXA scans, which are also more expensive. Patients found to have poor response or side-effects and needing intravenous bisphosphonates can be referred directly to the specialist nurse-led treatment facility.

Crucially, this has all been achieved without additional cost to commissioners as the extra tests in the one-stop assessment and the option to refer patients directly for IV treatment mean that fewer patients need to be seen in the specialist clinics (~5% of referrals compared to 15% previously).

"GPs in Sheffield have access to blood tests used to monitor response to osteoporosis treatments."

"We get a lovely comprehensive report talking all about [the bone density] and all that. But then at the bottom there's a paragraph that says, 'Dear Doctor, just do this.'" GP

"It is complicated because it talks about T-scores and Z-scores... maybe something which GP is not terribly familiar with. We're very lucky in Highland where the FLS advanced nurse practitioner will put the interpretation of the test on the recommendations. I think that's what GP's need...that extra confidence and they feel reassured. Ultimately it is better for the patient."

The inquiry heard evidence of the lack of under - and post-graduate training for doctors in osteoporosis, including in the general practice curriculum.<sup>42</sup> It was not felt that this could instil sufficient clinical confidence in osteoporosis care, leading to sub-standard care for patients. None of the healthcare professionals interviewed could recall anything other than scant coverage of osteoporosis in their medical training.

"My GP was honest and told me she did not understand how to read the scoring system on the bone scan report so therefore I feel this is another area where GPs would benefit from education."

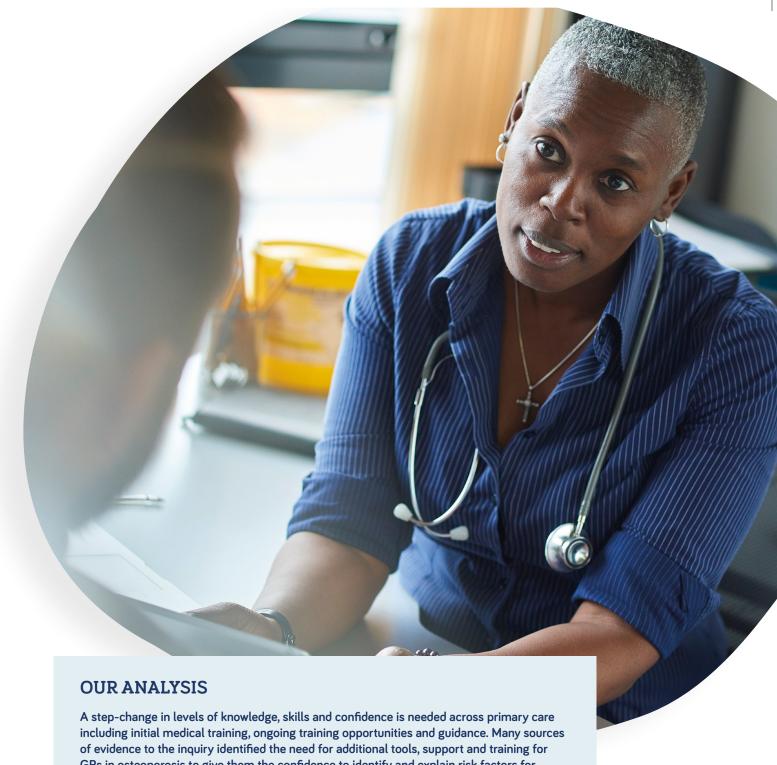
"I don't remember anything on osteoporosis when I trained as a medical student, and I don't remember anything on osteoporosis when I did my GP training." GP

"It's not really going to be on your radar particularly unless you've got a personal interest in it. So I think it'd be better If there was more training and undergraduate training around it and even postgraduate training. Bone health should be everyone's business." Occupational therapist

Clinicians suggested that improvements in primary care provision could be achieved with the following:

- Clarity over local pathways (to avoid patients being referred inappropriately)
- Pathways that allow qualified colleagues, other than GPs, (advanced nurse practitioners, physiotherapists and clinical pharmacists for example) to refer patients
- A clear summary of current guidelines (one side of A4), and
- Clear standardised guidance on who should be referred from primary to secondary services.
- Support from Imaging services by directing GPs in their interpretation of DXA scans, including a full clinical report and management advice AND flagging the need to GPs to code to the patient record the fact that they have had a fragility fracture.

"This is a good example of change that could be done without huge investment. If we can establish what is good practice [such as. when to refer back to specialist care] we can find ways to do things better by making simple changes."39



GPs in osteoporosis to give them the confidence to identify and explain risk factors for osteoporosis to patients and refer patients appropriately.

### **OUR RECOMMENDATION**

The APPG recommends proportionate recognition of the importance of osteoporosis throughout healthcare education, with increased prominence in undergraduate and postgraduate healthcare professional training.

### Specialist support for primary care

Several healthcare professionals interviewed referenced their need for support from secondary care services. Sheffield's metabolic bone service for example was highlighted as offering primary care professionals exceptional support. In this case, the cost of this support has been offset by the reduction in the number of patients needing to be seen in specialist clinics. Primary care professionals with this support expressed greater confidence and enjoyment in the care they could offer osteoporosis patients.

"If you feel [with support from secondary care] as though it is the appropriate drug and that in fact it's leading-edge treatment, it gives you a bit of a buzz. So instead of being a bit sort of worried about it, you feel quite confident." GP

"We feel supported [by the Bone and Metabolic hospital service] in primary care to be able to offer quite a comprehensive service" GP

One development during the pandemic which facilitates the provision of support by secondary care specialists for primary care clinicians was highlighted by a GP. The Advice & Guidance system allowed GPs to consult with secondary colleagues digitally and in real time rather than wait for written advice or for a referral to be accepted

"There was one thing that came out of the pandemic which I said, please God, let this continue. Suddenly we had access to secondary care specialists on a rapid basis for advice or collaboration. So anything that you wanted advice and guidance about before COVID, was - you dictate a letter, it gets written up, it's sent by post, takes three to four weeks, and then maybe you get one letter back, right? That's it.

Suddenly...I could fire off an e-mail quickly about a patient by, you know, nhs.net mails, get a response back within 48 hours and then because

what would happen is I would find out almost the e-mail of the consultant and see if they would take on the care of the patient...instead of a big formal referral process" GP

A number of survey responses suggested that mechanisms for support from secondary services for primary care would be useful in the absence of sufficient expertise.

"I was struck by the apparent total lack of awareness, either that I might be at risk (no HRT), or that I might have a genuine problem, not just ageing aches...Once diagnosed, what to expect and how to deal with it. Again this is an observation not a criticism - they can't be experts in everything. Perhaps some specialists are needed at primary care level, or is that a contradiction?"

Notable among the survey responses, more proactive care was described in Scotland where there is more comprehensive coverage of Fracture Liaison Services. This could possibly be attributed to the leadership and specialist input by FLS for primary care clinicians.

### OUR RECOMMENDATION

Specialist services must support primary care colleagues to provide the best care to patients.

This should be achieved through:

- DXA reporting that includes comprehensive management advice and recommendations46; and
- Access to specialist support given to primary care through the Advice & Guidance systems (or equivalent)

#### Vertebral fracture Identification

Vertebral fractures are the most common fragility fracture, yet the majority (70%-80%) do not come to medical attention.<sup>47,48</sup> While there are examples of good practice, identification of vertebral fractures challenges many primary care clinicians.<sup>49</sup> Typically, a patient with a new vertebral fracture will go to their GP with sudden-onset back pain. The most alarming accounts from the inquiry survey were from patients with vertebral fractures whose GP did not suspect a vertebral fracture or osteoporosis during that first appointment. The degree to which this was clinically appropriate is impossible to determine. It may be accounted for by national guidance on avoiding imaging investigations for lower back pain and the sometimes non-specific nature of vertebral fracture presentation.<sup>50</sup> However, ultimately many patients reported going back several times over a prolonged period of time before their symptoms were investigated.

Respondents included those who had reported back pain to their GP but were refused investigations. Their pain was attributed to other causes (usually muscular strain, old age, or arthritis) and they were prescribed painkillers and/or physiotherapy instead of further investigation.

"My GP did not listen or take me seriously even although I pleaded for help with the pain. He kept saying that it was a flare up of fibromyalgia...After my fall in 2019 I knew that there was something causing my pain but my GP definitely did nothing to help." [Two vertebral fractures were eventually identified following intervention by a physiotherapist]

"It took three months of endless visits to the GP and local hospital before the 8 spinal fractures were diagnosed, unfortunately when asking the then GP shouldn't I have X-rays and scans as could this be an osteoporotic fracture, he said I wasn't yet 60 and this sort of thing happened to 80-year-olds."

Clinicians who gave evidence to the inquiry described pressure from CCGs not to refer people with back pain for X-ray, and the general move away from requesting imaging in cases of sudden onset back pain in clinical guidance.<sup>42</sup>

### **OUR ANALYSIS**

Identification of vertebral fractures in primary care stands out as an area of immediate concern. Current referral guidance appears to have discouraged GPs from referring people with spinal pain for x-ray unless there are significant concerns regarding a vertebral fracture. This latter caveat appears to be overlooked and referrals are not being made. This trend needs to be reversed through greater awareness in primary care of the clinical presentation of a vertebral fracture, especially in older patients and those with risk factors for osteoporosis. GPs need to know when to suspect that pain is due to a vertebral fracture rather than simply mechanical and when to refer patients for imaging.

### **OUR RECOMMENDATION**

All relevant national guidelines should be reviewed to better support imaging of the spine where there is a suspicion of vertebral fracture, particularly in patients with risk factors for osteoporosis. These include:

- Royal College of Radiology iRefer guidelines<sup>51</sup>
- NICE guidelines<sup>50</sup>

### **CASE STUDY: STEPHEN IS 64 YEARS OLD AND** LIVES IN NORTHALLERTON

Two years ago I would not have given much thought to osteoporosis. I thought it was something that women were prone to after the menopause, and certainly did not realise it could affect men.

l started to suffer back pain in November 2016. Nothing serious, just a niggle. However, it slowly got worse. I was starting to have difficulty lifting things at work so went to see my GP in January. I was told that it was caused by wear and tear on my back as I was 64 and did a lot of lifting at work. I was advised to undertake only light duties for a couple of weeks and take paracetamol.

I followed this advice but the pain got worse over the next 3 months, during which I made several more visits to my GP. I took time off work and the sick notes were mounting up. By April, my GP referred me to the local back clinic. At the appointment I asked about an MRI scan. I was unhappy that the pain was becoming unbearable and I was taking painkillers every day. I was refused and told that it wouldn't show anything because the pain was just muscular. They suggested stronger pain killers.

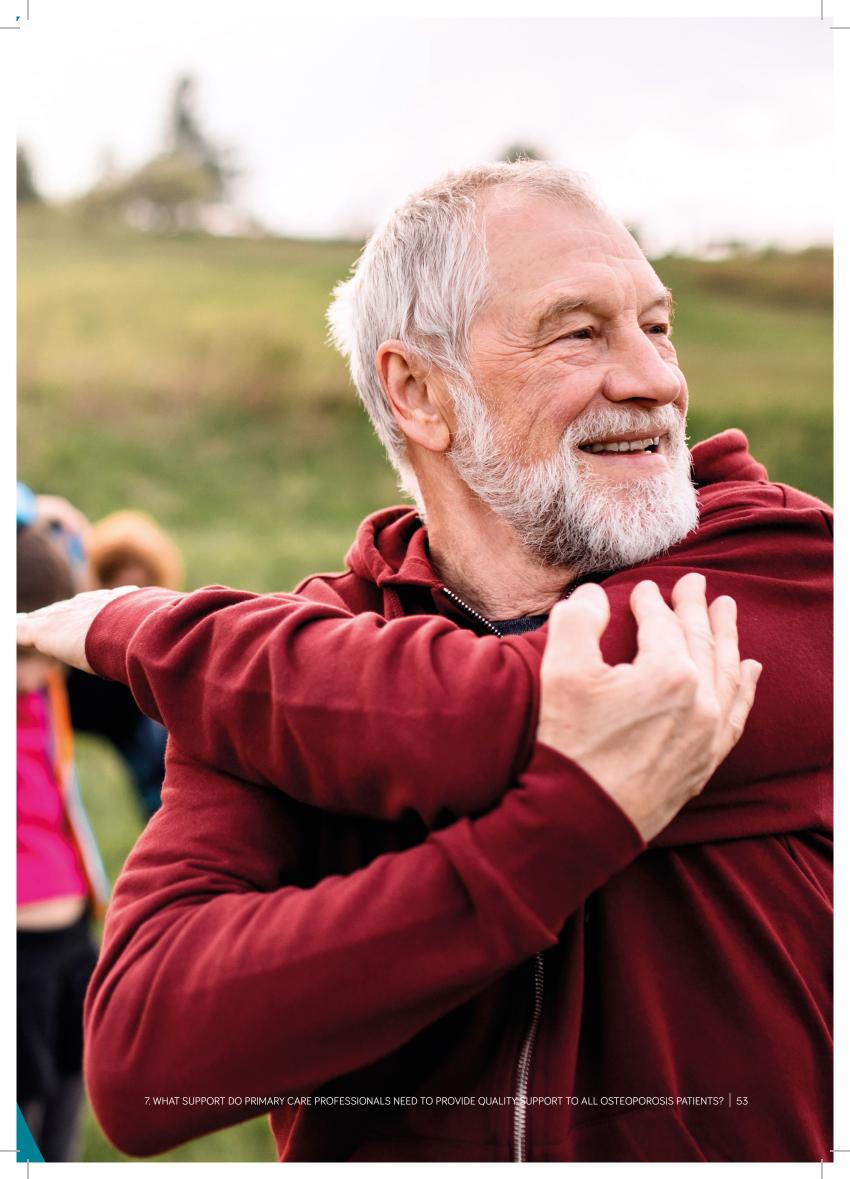
Two weeks later I was walking into the kitchen to make a cup of tea, sneezed and collapsed to the floor in agony. At that moment, it was obvious that my problem was more than 'just muscular'. My family were really concerned, so they paid for an MRI at a private hospital in the middle of May 2017, followed by a full spinal scan one week later. I was unable to walk on my own by this point.

When I saw the private consultant a few days later, he told me that I had severe osteoporosis and ten compression fractures in my spine. I was advised not to expect to be able to return to work and retirement was the best option.

As my treatment had already cost £3,000 I asked the consultant to send his findings to my GP so that I could receive treatment through the NHS. My GP then referred me for a DXA scan which took another 10 weeks. I was chair-bound and having to sleep in the chair as I was unable to lie down. The pain was too severe even with all the painkillers. I was finally referred to and saw a Rheumatology consultant in October 2017, 10 months after my first GP visit, after which I started a course of Forsteo injections.

I am happy to report that a year after starting treatment things are a lot better. I am mobile again and can live with the pain levels without painkillers. However, I have retired, lost four and a half inches loss of height and need help getting things off the top shelf at Tesco's. I was very fortunate to have had financial backing of my family to go private. Without this, I shudder to think how much longer I would have had to suffer.

"I was very fortunate to have had financial backing of my family to go private. Without this, I shudder to think how much longer I would have had to suffer."





# 70-80%

of vertebral fractures do not come to medical attention

#### Shared care

Shared care for patients is required in some instances where a patient is under secondary specialist care but would benefit from receiving their treatment closer to home. This is most commonly seen in provision of Denosumab, an injectable drug and infusion treatments (such as IV zolendronate). These are highly effective and provide an alternative to oral bisphosphonates where these are not well tolerated. NICE guidance state that "denosumab is likely to be provided as part of general medical services in primary care. The Committee concluded that while treatment with denosumab may be started in secondary care, it would be subsequently delivered almost exclusively in primary care." Though approved by NICE, shared care was often difficult to obtain for many patients and varied by postcode. Respondents to the inquiry survey described difficulties getting primary care clinicians to agree to shared care.

"I have been prescribed Denosumab by the hospital consultant, for reasons I am unaware of my surgery will not administer the drug, so I need to go up to the hospital twice a year for it to be administered...This incurs extra expense for the NHS as I am admitted to the medical day unit for a 30 second procedure!"

"I am a Clinical Nurse Specialist and have real issues trying to engage primary care in agreeing to shared care for Denosumab." Clinical Nurse specialist

GPs with a special interest in osteoporosis expressed frustration to the inquiry at not being able to offer more specialised treatments in some areas.<sup>27</sup> Other clinicians interviewed felt that passing responsibilities which used to be held in secondary care to GPs and nurses in the community was unfair without additional funding for this.

"That's a bit of a contentious area because this is now moving from what was used to be specialist Care to primary care, with the pressures we're facing. It's not really followed by funding with it, for the time it's using for our nurses and HCA's to do this. This is more of a commissioning issue. [We are] is feeling a lot of pressure out in the community when it comes to these sorts of things." GP

Most healthcare professionals interviewed expressed a desire to collaborate with secondary care clinicians in the face of increasingly complex patients being treated for multiple long-term conditions.

"I think a lot of us we recognize the reality of us taking on quite complex cases. But then we also want to be able to collaborate around this. not like it's in your court/it's in my court, if we're actually going to have interdisciplinary or multidisciplinary care around what are increasingly complex care needs for our patients, multiple long-term conditions, polypharmacy." GP

Healthcare professionals from the Sheffield area who were interviewed described how shared care was working effectively in their area as a result of the leadership of the metabolic bone service.

"We worked with the Community Nursing service and the Consultant Rheumatologist... we've got a protocol so that if the patient is housebound, the district nursing team are confident to go and check their calcium level and if it's satisfactory, then to be able to give denosumab." GP

### **OUR ANALYSIS**

In line with the ambitions of the NHS Long Term Plan to provide care closer to home, barriers to shared care for patients with osteoporosis need to be removed. A fully integrated model of care is needed which blends both primary and secondary care expertise to provide holistic and personalised care for people with long-term conditions, including osteoporosis. This will require leadership from secondary care, and ultimately, at ICS level to achieve. Harnessing the development of regional and local ICS MSK leads could support action in this regard.

### 8. WHAT ACTION CAN BE TAKEN IN PRIMARY CARE TO IMPROVE PROVISION FOR PATIENTS WITH OSTEOPOROSIS?

### What patients told us

Respondents to the inquiry patient survey wanted to see proactive primary prevention of osteoporosis and associated fragility fractures. Patients want intervention before fractures, rather than wait for them to fracture first.

"I think post-menopausal patients should all be assessed for risk...It's a national disgrace that there is not screening programme similar to the one for males for aortic aneurysm... Women should not have to wait for a fracture for this cruel disease to be identified."

Respondents wanted primary care to do more to promote better bone health by providing more information on nutrition, physical activity and risk factor reduction. Patients wished they had known more, at the right time, about preventative steps they could have taken, such as bone-preserving HRT.

"I think osteoporosis should feature in health reviews at 50 and 60 to raise the profile of bone health and outline the positive steps people can take to prevent a fracture. Postmenopausal women should have their risks assessed to prevent fracture as opposed to the current practice of intervention after a fracture. I have managed to improve my bone density and I think there should be a greater focus on maintaining bone health."

### Targeted risk assessment

As described, patients wanted to receive more general and timely advice on bone health. However, many respondents felt that they should have been screened for osteoporosis due to their known risk factors (including fragility fracture, long term use of steroid medications and early menopause):

"It would have been good to have been part of an osteoporosis screening system, just to take some of the pressure off trying to get GP appointments and sometimes feeling that you were one of the 'worried well'."

"Despite sustaining two fractures after the age of 50 and the information that my mother had osteoporosis no one suggested a DXA scan."

Fracture risk assessment for patients in primary care with significant risk factors is already expected under current clinical guidance. NICE outlines the need to assess the fracture risk and bone mineral density of patients with any of the three major risk factors for osteoporosis, including:

- current or frequent use of oral or systemic glucocorticoids
- untreated premature menopause, and
- previous fragility fracture.<sup>52</sup>

Furthermore, NICE guidance also advises assessment of all women over 65 and all men over 75.

However, the inquiry heard evidence that this is not taking place:18

# 61%

## with a major risk factor did not receive a bone health assessment

- 61% of those with one of the three major risk factors for a bone health assessment had not received one, and men were less likely than women to receive a bone health assessment if they had.<sup>53</sup>
- A study of 16 million patient records found that, despite NICE guidance, only 13% of those on steroids had been prescribed bone protection.54

Patients told the inquiry about how they had to initiate the assessment and, in some cases, to 'fight' to be assessed.

"Asked GP for referral for DXA scan on a number of occasions because of family history and personal use of oral steroids. This was refused both by my GP and after my GP consulting with the local NHS osteoporosis service... They blocked my diagnosis."

"I initiated a GP appointment despite having no symptoms as my mother had osteoporosis and I had had an early menopause...I wonder how many people like me have it asymptotically so require treatment. Shouldn't primary care be checking this out?"



Men are less likely than women to have a bone health assessment if they need one

### What health professionals told us

Many of the healthcare professionals interviewed expressed regret that they did not focus on primary prevention and were instead part of the problematic 'fracture first' culture.

"It always seems a shame when they have an innocuous fall, they have a fracture, and that's the first we know about it. If that happened with a heart attack. We would be like, why haven't we checked their blood, they're 75? Why didn't they have a blood pressure check? Why has no one asked them about smoking? Or check whether they're diabetic. We could have prevented this." **GP** 

"If you think about osteoporosis specifically for population health, it's massive. And if you look at the cost to the health service if it's done badly, that's massive. So we should really have something built in to stop that happening because it's a big avalanche and it's all going in the wrong direction at the minute." **GP** 

However, some clinicians interviewed also took a different view of the imperative to identify osteoporosis, particularly in older patients with multi-morbidities. There was a sense of the clinician acting as gatekeeper (rightly or wrongly) to identification and treatment where they felt the benefit would be outweighed by more immediate considerations for the patient. Reference was also made to unrealistic expectation that GPs should be responsible for health promotion and prevention, given the time constraints of a consultation.

"I decided not to go into treating their osteoporosis because there just wasn't time to do it. It may be that the patient comes back and I will treat her at that point." **GP** 

"If the view is that when someone comes to see the GP for an unrelated issue they should be screening or advising on bone health – you've got to think if you want them to do that. What else would you want them not to do?" **GP** 

### **OUR ANALYSIS**

Patients made a case for proactive identification of people at risk of osteoporosis. How to address this in practical terms was described by a range of clinicians who gave evidence to the inquiry.



# **ONLY 20%**

of NHS organisations are digitally mature, and only some ICSs have shared patient records

### Case-finding

The inquiry heard from clinicians that the easiest gains to be made in osteoporosis care are, in the first instance, in restoring osteoporosis patients already known to the practice to followup, followed by more systematic case-finding and identification of patients at risk of fracture.

Several GPs with a special interest in osteoporosis gave evidence to the inquiry. They described how they undertook relatively simple data searches of patients in their practice. These searches identified patients with osteoporosis or people who were at high risk of fracture. These patients could then be assessed and treated if necessary.

Of the healthcare professionals interviewed, one GP described efforts to identify target groups for screening in their practice, starting with patients with vertebral fractures who are over 75. This GP was working in the Sheffield area where noteworthy leadership from a secondary care service has resulted in greater awareness in primary care, and the prospect of better identification and care for osteoporosis patients.

"We've done some recent teaching on osteoporosis and are thinking about how we can start to identify target groups pragmatically. Because we're just not at the moment, which isn't great." **GP** 

Several clinicians described their experience of case-finding, the tools available to them and the barriers they faced.

### Primary care IT and coding systems

One healthcare professional interviewed described how their practice had attempted to make coding of patient records as systematic as possible, despite the time-consuming nature of the activity.

"We've got into that groove now so that if we get a discharge summary from the hospital about a fracture, first thing we'll look for is are they over 75? Did it look like it was probably a fragility fracture? You know, fall from a standing height and have they been put on bone protection? ... We can put that on the computer, and [if they've been

treated in hospital] as long as they've got some sort of calcium vitamin D as well, we are happy.

Sometimes it's not guite as clear as that and you start digging...ask the relatives. What was the situation? Did they say you've got to go back? ...This client group are elderly, frail, deaf, dementia, you know, you name it, they've got it. So you have to do a bit of digging to get it right." GP

However, a GP who gave oral evidence to the inquiry explained how the current NHS IT infrastructure is 'not up to the job.' He also described how difficult it was to search for patients with risk factors for osteoporosis compared to searching for other conditions such as diabetes.42

Similarly, a number of those giving evidence highlighted how the quality of a patient record was only as good as the data inputted. It relies on the expertise of administrative staff to code records appropriately. The inquiry heard from a number of sources how simple data inputting oversights and errors in coding often thwarted attempts at screening or case-finding patients and made it hard to recall patients for annual review for example.34,55

"If data is poorly inputted, then healthcare professionals won't pick up patients at risk or monitor them properly...Some GP practices are poor at entering diagnoses from hospital letters. How can they be encouraged to do better? Can CQC inspections have data input as a quality marker?". GP 55

"We don't have a great way of recording family history of fractures, so that is just invisible. Possibly partly because we don't ask." GP

One GP gave evidence about how many GPs do not have access to local hospital notes and rely on letters - many of which take months to arrive or do not arrive at all.<sup>27</sup> These then need to be inputted correctly to the patient record. The introduction of shared patient records by 2025 to unify patient data from secondary and primary care will go some way to achieving more coordinated care for osteoporosis

patients.<sup>56</sup> However, as the Department of Health and Social Care admits, only 20% of NHS organisations are digitally mature, and only some ICSs have achieved a shared patient records to date.56

"Whatever the GP prescribes, we can see...as long as they are using SystmOne. I think we've got two GPs in the district that don't use SystmOne. They're the only ones that we can't see." Physiotherapist

#### Automated fracture risk alerts

The inquiry heard from clinicians about research evidence for use of a system to alert GPs to a patient's increased risk of osteoporosis to help increase the number of patients identified with osteoporosis who are risk of major fracture. Alerts improved GP guideline-consistent behaviour towards bone mineral density testing and prescribing of osteoporosis treatments.<sup>57</sup>

"Use IT systems on the electronic health record to identify risk factors for insufficiency fractures and automatically alert the GP. This is already done to remind GPs to consider issuing steroid cards for those on steroids and to consider malignancy in those with back pain and a history of malignancy. It should be straightforward to apply the same technology to read coded entries conferring a risk of insufficiency fracture." GP 55

Data sharing between secondary and primary care could allow automatic alerts to GPs to be triggered by acute services when a patient has suffered a low-trauma fragility fracture recommending that the GP instigate further investigations.

### Integrating fracture risk assessment tools

Several clinicians gave evidence to the inquiry on the need for full integration of the FRAX® risk assessment tool and the linked National Osteoporosis Guideline Group (NOGG) intervention thresholds into all general practice IT systems.<sup>12,41</sup> Currently GPs are required to log into a separate web-browser on their computer to access and input data to the

FRAX platform to assess the risk of a patients fracture. If this were to be embedded into the GPs own clinical consultation IT system it could be auto-populated with the data required and updated automatically as things change - such as patients' recorded weight changes, if they are prescribed oral glucocorticoids or record a new fragility fracture. The resulting FRAX scores could then also automatically be embedded into the patients GP record.

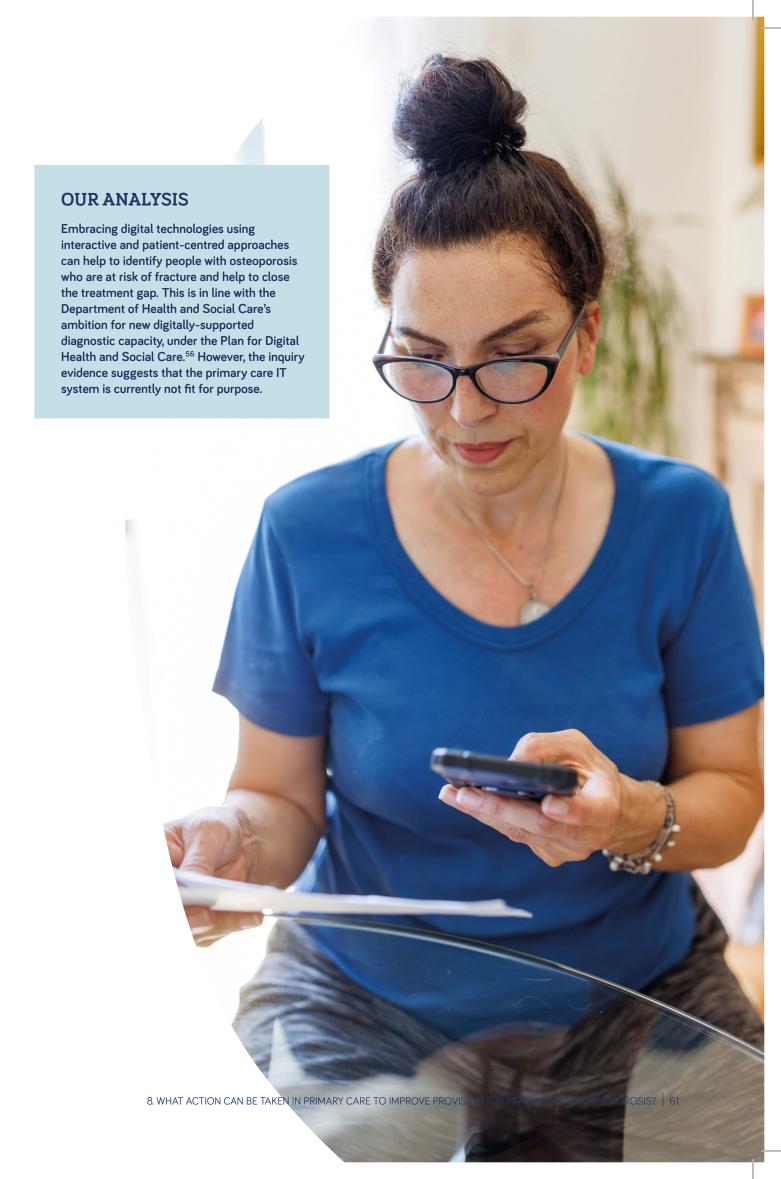
"FRAX needs to be embedded in the computer system. The requirement for the extremely timepressured primary care clinician to manually input data externally to the health record is a big ask and a huge impediment to fracture risk assessment." GP 55

The majority of healthcare professionals interviewed described the lack of integration as a barrier to using the tool.

"[I have] frustrations with the FRAX tool, that it still doesn't embed really nicely in SystmOne. It's GP workload. Although it's only minutes maybe... flicking from screen to screen. 'What's their BMI?', 'Have they had a fracture?', 'Oh, I can't remember whether they're on steroids. How many courses have they had?' It's not the most straightforward and intuitive. It's a pain in the \*\*\*\*. And I think that puts some of my GP colleagues off. It's not the notion of it...we can all see that it's valuable." GP

### Other digital tools

The inquiry heard evidence of practices that use digital communication tools such as AccurX (www.accurx.com). This tool is used by 98% of GP surgeries for a range of purposes and could be used to send patients a fracture assessment survey with simple structured responses, allowing practices to screen or monitor patients.<sup>58</sup> All replies are coded and saved to the medical record and could be used to generate a personalised fracture risk score.



### 9. WHAT BENEFITS WOULD RESULT FROM SYSTEMATIC **IDENTIFICATION OF PATIENTS** WITH RISK FACTORS FOR FRACTURE IN PRIMARY CARE?

### Using data for population health management

The inquiry heard that strategic and targeted initiatives to improve care for people with osteoporosis within practices or PCNs are currently only ad hoc. They are impeded by lack of awareness of the significance of osteoporotic fractures among clinicians and patients alike, and the perception that patients would be averse to being 'screened' for osteoporosis if they are already experiencing other significant illnesses and treatment.<sup>41</sup> The patient survey identified no examples of a patient having been proactively approached by their practice and referred for a scan following any kind of screening for osteoporosis risk factors.

"In our experience [systematic identification] is very variable and depends on the interest in the practice to proactively search patient lists for risk assessments."18

Similarly, our interviews with healthcare professionals found that they were not using FRAX assessment to proactively screen or casefind patients who had yet to come to clinical attention. Rather they were using the FRAX assessment tool in situations where they already suspected a high risk, to give weight to their request for further investigation and imaging.

"I very rarely check a FRAX score where actually it comes out... all green, plain sailing. I guess that's probably because they're not the patients that we're thinking to check it in" GP

The advent of ICSs affords the opportunity to use data to address osteoporosis as part of population health management to address health inequalities. While still exceptional, the inquiry heard about some areas where this has taken place. The inquiry heard about the Frimley ICS, where populations known to have a lowerthan-expected prevalence of osteoporosis were targeted in a data-led strategy.<sup>59</sup> These were commonly areas with significant ethnic minority populations and areas of social deprivation. Dr. Hayter GP and National Clinical Director for Older People and Integrated Person-Centred Care at NHSE&I described how case-finding could be targeted. For example, targeting patients over 50, with a fracture but not coded as having osteoporosis, with some form of assessment. He described to the inquiry the anticipatory model of care in Frimley which proactively targeted frail patients who had no GP contact in the last six months. While there has been a 7.1% reduction in achievement of QOF targets nationally since 2019 (i.e. pre-pandemic), areas that adopted a broader strategic approach have bucked this trend, even during the COVID-19 pandemic.

### **OUR ANALYSIS**

Data and digital technology have the potential to transform primary care to meet previously unmet need in communities in a time - and costefficient manner. However, there is currently wide variation in digital maturity, leadership and the right expertise across ICSs and PCNs to use data analytics to target vulnerable populations and improve services.43

### CASE STUDY: THE NORTHERN BONE **HEALTH PROGRAMME**<sup>3</sup>

Dr. Sunil Nedungayil GP gave evidence to the inquiry regarding another primary care-based project which ran from April 2020 to July 2021. It adopted a population health approach to primary and secondary prevention of fragility fractures and osteoporosis using FRAX assessment. 59 GP practices participated.

Electronic patient records were analysed using bespoke computerised software algorithms to identify cohorts of patients with or at risk of fragility fractures and osteoporosis. Fracture risk assessment was done using the FRAX® fracture probability tool without bone mineral density values. The project was undertaken centrally by clinical pharmacists.

27.8% (153,206) of the population were identified for targeted risk assessment as per NICE guidance. 17.8% of these (27,202) were identified as at high risk of fracture and requiring intervention. Of these:

- 9.4% (14,499) were high risk and had not been assessed or treated before.
- 26% (7096) were recommended for treatment without further investigations.
- 22% (5,944) were recommended for further investigation (eg DXA).

### As a result of the project:

- 12,719 patients with osteoporosis were identified - of which 53% were not on current treatment.
- 3,478 new prescriptions of bone-sparing medications were recommended.
- 524 treatment holidays (pause in treatment) were recommended after review.
- Participating practices reported increased awareness of osteoporosis and are putting in place systems to improve bone health management in primary care.

551,550 Patient records analysed

153,206 Identified for FRAX assessment

27,202 At high risk of fracture

"...when I call patients, they seem to be very happy that we are being proactive about their care and preventing future fractures." Clinical feedback

# The case for a national screening programme – systematic assessment of fracture risk in primary care

"We urgently need a change in policy in order to ensure that we don't persist with 70% of individuals at high fracture risk not treated."60

The APPG wanted to explore the case for a cost-effective screening programme to identify those most at risk of debilitating fractures. Given the barriers that currently exist to systematic identification of people at risk of fracture and osteoporosis in primary care, there seems to be good cause for consideration of a public health strategy of this nature. Without this, the current complacency of both clinicians and the public towards bone health due to its 'image problem' (as an unappealing area of medicine and an inevitable part of ageing) will continue to pose a significant barrier to progress in osteoporosis care.

### A proposed screening programme for the UK

The Falls and Fragility Fracture Audit Programme has already demonstrated the efficacy of a national approach to clinical improvement in osteoporosis. Establishment of the National Hip Fracture Database has transformed outcomes following hip fracture and the Fracture Liaison Service Database Audit demonstrates that high-quality fracture liaison services deliver effective secondary fracture prevention. This inquiry highlights the need to take a national approach to the prevention of the first fracture.

One solution to this would be to implement a programme of systematic case finding, or "screening", as has already been implemented in other areas such as breast cancer. The ideal programme would use a validated risk assessment tool with additional targeted investigation using DXA to identify individuals at high fracture risk for treatment. In 2019 the UK National Screening Committee concluded there was insufficient justification for a screening programme across all postmenopausal women. Current evidence suggests a more targeted approach should be considered.

The UK primary care-based MRC-SCOOP (Screening for Osteoporosis in Older People) Trial examined a systematic approach to identifying older women for fracture prevention. 61-65 Around 12,500 older women were randomised to either risk stratification using FRAX to estimate hip fracture probability and target use of anti-osteoporosis treatment, or to usual care. The intervention led to a 28% reduction in hip fracture risk and was found to be cost-saving (reducing cost by £286 per patient). 66 The intervention also increased adherence to treatment.

The prevention of hip fractures observed in SCOOP was supported by the findings of two further studies, the Danish Risk Stratified Osteoporosis Strategy Evaluation (ROSE) study, and the SALT Osteoporosis study from the Netherlands.<sup>67,68</sup> In 2021, a metaanalysis demonstrated a convincing benefit for a screening intervention to prevent fragility fractures and most recently, the International Osteoporosis Foundation conducted a comprehensive review of the evidence that concluded that they key conditions required by the UK National Screening Committee had now been met.<sup>4,69</sup> If national screening were implemented, it would lead to a step change in hip fracture prevention. The data indicate that at least 8000 hip fractures could be prevented annually, resulting in a huge reduction in the burden on our hard-pressed NHS.

### How would screening work?

A risk factor questionnaire based on the FRAX® risk assessment tool would be completed, in paper form or electronically, by women aged 70 years or older through self-completion or completion assisted by a family member or caregiver. The questionnaire data would then be utilized centrally to calculate the 10-year major osteoporotic fracture probability and the 10-year hip fracture probability. Those with a low risk of hip fracture would receive a letter of reassurance with general lifestyle advice, while the remainder would have a DXA scan. The bone density result would then be incorporated in an updated FRAX calculation. People who are found to be at high risk of hip fracture would then be recommended for treatment. The recommendation would be communicated to both the individual and their GP. Targeting screening at women over 70 ensures that the programme would have good clinical and cost effectiveness.4 Such an approach might be incorporated into an automated system based on primary care computer systems, as described earlier in this report, and which is currently the subject of active research funded by the ROS.



### **OUR RECOMMENDATION**

The National Screening Committee should reconsider the case for a targeted national screening programme to detect high fracture risk in 2023.

This recommendation is in line with Government's own focus on prevention in the NHS Long Term Plan. Targeted at the appropriate population, screening for fracture risk is both clinically and cost-effective. We believe that the appropriate conditions for an evidencebased screening measure have been met.

Screening led to a 28% reduction in hip fracture risk

## 10. WHAT ACTIONS SHOULD **GOVERNMENT, POLICY** MAKERS AND HEALTH CARE BODIES TAKE TO IMPROVE PROVISION FOR OSTEOPOROSIS IN PRIMARY CARE?

In the UK, the number of fracture-related deaths is comparable to, or exceeds those from lung cancer, diabetes and chronic lower respiratory diseases.<sup>5</sup> Similarly, the disability-adjusted life year loss related to osteoporosis is higher than that for chronic obstructive pulmonary disease.<sup>70</sup> However, osteoporosis does not currently receive the same recognition or funding by the NHS as a long-term condition.

"We need professionals to take it seriously, this needs the government to spend money on NHS. They force people to go private for care and information."

53% of people with osteoporosis don't think that the NHS gives osteoporosis the level of attention it deserves.<sup>32</sup> Almost all contributors to this inquiry agreed that the most significant barrier to the identification and effective treatment of people with osteoporosis was the lack of priority the condition is currently afforded within the NHS.

"Primary care has never been motivated to make osteoporosis a priority and I blame the NHS strategy over many years for this."39

It was universally agreed that osteoporosis must be recognised as a long-term condition within the NHS in order to drive improvements in care and to begin to address the burden fragility fractures place on the health service.

"We would pick up and think about whether [a patient] needed a bone health assessment, but I think it wasn't an embedded part of a normal long-term condition consultation. Some of our nurses take the lead in long term condition management but it wasn't an embedded part of that. I think embedding stuff in the long-term condition appointment (in terms of identifying people who we need to think about) isn't too much extra work." GP

### **OUR RECOMMENDATION**

Osteoporosis must be given parity with other long-term conditions, and defined as such within the NHS, to allow enhanced and equitable care and management.

The inquiry was pleased to hear that the Department of Health and Social Care's Women's Health Strategy has defined osteoporosis as a long-term condition.71 This must be reflected across all Government health guidance, strategy, funding and incentives.

53%

of people with osteoporosis feel that it doesn't get the level of attention it deserves in the NHS

In 2021, NHS England launched the Best MSK Health Collaborative programme. The osteoporosis workstream has since developed pathway templates and KPIs to support osteoporosis management within ICSs.72 These templates were created with the intention that they should be used to be further developed and implemented at ICS level to meet local needs.

Many contributors to the inquiry agreed that additional responsibility or expectations in primary care for osteoporosis prevention had to be accompanied by ringfenced funding to support healthcare professionals to achieve it.

"If they don't have the resources and time, it's unfair to give someone the responsibility to do it. If the NHS wants osteoporosis to be picked up in the general practice consultation system, they need to provide the resources to do that." GP

### **OUR RECOMMENDATION**

NHS England must provide sufficient funding for ICSs to deliver against national quality standards and NICE clinical guidance.

Implementation of NHS England's Best MSK Health programme pathways requires resource at ICS level for workforce, training and service development.



Fracture related deaths exceed or are comparable to deaths from lung cancer diabetes and chronic lower respiratory diseases

### Bone health across the lifecourse

Several of those who gave evidence to the inquiry felt that one of the most effective drivers for change in services was demand from informed patients. Evidence heard by the inquiry however, suggests that a shift in awareness of the importance of bone health across the life course is required in clinicians and the general population alike, who by and large take their bone health for granted.<sup>73</sup>

Good musculoskeletal health underpins independent living and healthy ageing. While genes determine to some extent the size and strength of a person's skeleton, there is a lot of scope for individuals, across a life course, to support their bones to stay strong and healthy. This includes eating the right foods, being active, ensuring adequate intake of vitamin D, avoiding smoking, limiting alcohol and maintaining good balance and stability as they enter old age. Several of the respondents to the inquiry survey felt strongly that more needed to be done to raise awareness and find a proactive response to the challenge of declining bone health after the age of 35, after which bone density and strength begins to decrease.

"Through my research and reading online in the last five weeks since my recent bone breaks I have come to realise just how many women are affected. This is an epidemic. It certainly needs addressing...Prevention would be far better."

"My diagnosis could have been avoided and I feel angry that my GP surgery who I've been with for 25 years did not give me the right information."

Health professionals interviewed felt that their patients knew very little about osteoporosis, and that because osteoporosis is mostly not symptomatic it did not command attention. They described a complacency around bone health that is culturally ingrained among clinicians and the public.

"It's because it's accepted as something that doesn't have a treatment almost like 'Oh yeah, Mabel broke her hip'. No one guestions "Oh? Had she not had her bone density assessment?" GP

"People just think if you get older, you fracture your hip because they know their neighbour fractured their hip. But they don't really understand the reasons behind it, and they certainly don't understand the lifetime input that they could be doing to prevent that or to mitigate that risk." GP

One healthcare professional interviewed felt that increased patient awareness was essential given the direction of travel within the NHS towards a population health approach.

"I think the way the NHS funding is going...it's not medical and tablets, it's population health. That's really where we need to be [but] I don't think the public really have got the message about osteoporosis." GP

The inquiry heard evidence regarding the research currently underway to find ways of optimising bone health across the lifecourse, starting in pregnancy, in order to reduce the risk of fracture across the population rather than only addressing it in those at high risk of fracture.<sup>60</sup>

"It is vital to consider both the lifecourse approach and addressing the bone health of those at high risk of fracture, in order to reduce the number of osteoporotic fractures."60

### **OUR RECOMMENDATION**

The Government should instigate a public health campaign to address the lack of awareness and complacency in the public about bone health.

To address the lack of awareness of bone health amongst the public, a campaign is needed to highlight the importance of supporting bone health across the lifecourse. This should highlight the opportunity for individuals to assess their personal fracture risk, act on the results and avoid what could be life-altering fractures in the future.

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