

NHS RightCare scenario: The variation between sub-optimal and optimal pathways



The story of Susan's experience of an osteoporosis care pathway, and how it could be so much better

In this scenario – using a fictional patient, Susan – we examine an osteoporosis care pathway, comparing a sub-optimal but typical scenario against an ideal pathway. At each stage we have modelled the costs of care, both financial to the commissioner and also the impact on the person and their family's outcomes and experience.

This document is intended to help commissioners and providers understand the implications – both in terms of quality of life and costs – of shifting the care pathway of older people living with osteoporosis from a reactive approach (primarily based on an acute response) to a proactive approach, e.g. providing an integrated primary care and community-based response, with support from the voluntary sector.

It shows how the NHS RightCare methodology can help clinicians and commissioners improve the value and outcomes of the care pathway.

Two summary slide packs are also included as appendices.

Foreword

Osteoporosis is the fragile bone disease that puts people at risk of breaking bones from everyday activities, from reaching for a kitchen cupboard to hugging a grandchild. One in five women who have broken a bone break three or more before being diagnosed.¹

In the UK over 3 million people are estimated to have osteoporosis and there are estimated to be over 500,000 fragility fractures that occur in the UK each year.^{2 3}

Many of those fractures could be prevented with earlier identification and intervention. There are proven, cost-effective models for ensuring those at highest risk of a first or subsequent fracture are identified and given the best chance of avoiding further fractures. Currently 35% of local health services in England provide a Fracture Liaison Service (FLS) pathway but not all of these can demonstrate reliable assessment of all fracture patients.⁴

Fragility fractures are estimated to cost the UK around £4.4 billion each year.² Hip fractures alone account for 69,000 emergency admissions into English hospitals, adding up to 1.3 million bed days and a cost of £1.5 billion each year.^{5 6 7}

The cost to people can be much higher. This is the story of Susan: A wife, mother and grandmother living with osteoporosis. Susan and her story are fictional but the emotions and experiences are real; they are the product of many stories told to us by people living with osteoporosis.



Introducing Susan



58 year old Susan loves dancing. She met Robert (Bob), at a dance held at her local village hall back in 1980 and they have been dancing ever since. She treasures the memory of them tangoing into the Seville sunset on their honeymoon; they always promised they would return to relive the moment.

The couple have two children, David, who works in London and newly-wed Gillian, who still lives nearby. Susan enjoys working part time in the reception of the local primary school.

Susan's journey: 1 – First break

Susan's journey starts with Henry, her vacuum cleaner. Whilst cleaning the living room one Thursday afternoon, Susan became entangled in Henry's cable and lost her balance. Putting her hand out to break the fall, Susan felt pain shooting up her arm.

After a few hours waiting in A&E at her local hospital, the X-ray confirmed Susan had broken her wrist. The next few weeks were awkward, everyday tasks were problematic. Luckily Bob was great, helping her round the house and driving her to and from the fracture clinic.

After a few days of boredom at home, Susan was able to get a lift into school where she managed to work by typing with her good hand. With a few sessions of physiotherapy, life seemed to be back to normal.

Sadly it wouldn't stay that way for Susan. Like millions of other people across the UK, she has post-menopausal osteoporosis. Her age and low trauma fracture as a consequence of osteoporosis should have been enough to identify her as being at risk.

A facilities audit in 2016 found only 10 acute trusts across England, Wales and Northern Ireland that managed to identify at least 80% of their estimated fragility fracture caseload.⁸

If Susan had been given a bone health assessment at this point then the rest of her life would have turned out very differently.

Almost 40% of people with a diagnosis of osteoporosis had to prompt their own bone health assessment.⁹

Susan's journey: 2 – The music stops

A few years later, Susan was still dragging Bob along to dancing twice a week at the village hall. After waltzing around the floor for a few hours, the group would retire to the pub for a pint and a natter.

One evening, Bob and Susan drove home early; Susan had felt pain across her back straight after the final spin. When the pain didn't subside after a few days, she went to see her GP, who suggested it was probably some muscle pain and gave her some stretches to do. After following the doctor's recommendations for six weeks and a few more GP visits, the pain eventually did go away but Susan's vertebral fracture was never diagnosed.

The pain returned just two years later, when Susan was stretching for something in a kitchen cupboard. Her GP initially suggested she take painkillers and see how she felt – after all, the pain had gone away last time. After two months and more GP visits, she was referred to physiotherapy classes. The physiotherapist helped for a time but the pain never went away. Eventually, Susan stopped going back to GP – she didn't want to be a burden.

More than half of people with vertebral fractures report being in long-term pain ... 60% of those people describe their pain as severe of unbearable – Life with Osteoporosis Survey, 2014.¹⁰

Susan tried to continue dancing but her back hurt too much. She felt frustrated and angry about her sudden transition from twirling around the dance floor to wincing when climbing into the bath.



Dancing was such a big part of her life that Susan felt like she'd lost a part of herself. Her second grandchild was born a few months later and although Susan loved looking after both of them, it hurt to find that her pain prevented her from playing with baby Emily as actively as she had with her brother George.

One in two people who have experienced fractures have given up sport or exercise or reduced what they do – Life with Osteoporosis Survey, 2014.¹⁰

Susan's journey: 3 – Waiting for the phone to ring

Working at the local primary school was a rewarding job for Susan. The highlight of her day was the happy children always remembering to wave goodbye to her from reception as they headed home. In school, she was still at the heart of things.

One evening, after a day at the school, Susan lost her balance climbing out of her living room chair, breaking her other wrist.

She waited to be seen in A&E, accompanied by her husband, where she was told she would need wrist plate surgery. After a couple of days in hospital, Susan returned home and began 1-1 physiotherapy.

Sadly a few months later Susan had still not regained the full function in her hand.

Between her stiff wrist and constant back pain, Susan realised she could no longer cope with work. The children and staff gave her a lovely farewell, showering her with presents and praise, describing 'Mrs A' as the 'lifeblood of the school' but weeks later, she found herself missing the smiles and the waving children.

*"I feel I have lost my purpose" – Life with Osteoporosis Survey, 2014*¹⁰

Susan missed the sense of purpose. She'd always cooked a big Sunday lunch for the grandkids and Gillian but just couldn't manage it anymore.

Gradually Susan and Bob started to see less and less of their dance friends. Initially they would still join them in the pub but Susan soon began to feel like an outsider. Instead of being in the midst of the conversation, the 'in-jokes' were passing her by.



- Life with Osteoporosis Survey, 2014.¹⁰

The majority of people who have fractured have experienced height loss or a change in their body shape – Life with Osteoporosis Survey, 2014.¹⁰

Susan was also embarrassed eating in public. The undiagnosed vertebral fractures had caused her spine to curve, leaving her with digestive difficulties and feeling like an old lady amidst attractive couples. She tried to not let it bother her but still felt uncomfortable. In the end it was easier to hide away. Eventually the phone stopped ringing.

"It was a case of my friends not asking me to go anywhere anymore because the things we used to do together were quite active. Eventually they stopped even ringing me to see how I was doing" – Life with Osteoporosis Survey, 2014. ¹⁰

Susan's journey: 4 – No last dance

A third undiagnosed vertebral fracture brought Susan further pain and discomfort. The increased curvature of her spine made her breathless and exacerbated her digestive problems.

One in three people with at least one vertebral fracture have experienced breathlessness – Life with Osteoporosis Survey, 2014. ¹⁰

Following more GP appointments Susan was referred to a local pain clinic. The techniques she learned were a big help but she was still finding life difficult.

Travelling long distances in the car become so painful that Susan and Bob stopped visiting their son David in London, instead waiting for when he could visit them.

The weekend meals with her daughter that had replaced her Sunday roast were also cancelled; the embarrassment and discomfort of sitting hunched over in a restaurant was just too much to bear.

One in three people with at least one vertebral fracture have digestive difficulties – Life with Osteoporosis Survey, 2014.¹⁰

Susan felt an overwhelming guilt for shrinking her husband's life. She was holding him back from doing interesting things and visiting friends and family.

"I'm ruining my husband's life. He has to care for me when we should be enjoying our retirement" – Life with Osteoporosis Survey, 2014. ¹⁰



Susan had always dreamed about returning to Seville for their 50th wedding anniversary to relive their dance by the river but found she just wasn't up for the trip. Bob passed away the following year; they never had their last dance.

"We haven't danced for years now and we both really miss it" – Life with Osteoporosis Survey, 2014. ¹⁰

Susan's journey: 5 – Never returning home

Susan was devastated about Bob. Her children and family visited when they could, but between football tournaments, tennis matches and other commitments the visits were infrequent. The family couldn't always be there. Without the distraction of friends, family or activities, the loss of Bob was unavoidable and the loneliness was unbearable.

"I'm unable to visit family. I have to depend on them to visit me, as I cannot travel for any length of time" – Life with Osteoporosis Survey, 2014. ¹⁰

She spent her time pottering around the garden Bob and she had created. But without his help it was so difficult to maintain. One day Susan slipped on the patio, breaking her hip. Her neighbour came to her rescue after hearing her cries.

The ambulance rushed her to hospital and she was in surgery within 48 hours. She was kept comfortable in the local acute and then community hospitals and was looked after well, but never regained her mobility and was unable to return home.

Only around half of people admitted from their home have successfully returned home a month after a hip fracture. ¹¹

Susan would never see her family home again.

With her children unable to look after her, Susan was moved into a nursing home where she would receive the daily care that she needed. David and Gillian visited as often as they could, but with the grandchildren at university and David still in the London area, she often spent her days gazing out of the window picturing the sunset dance with Bob.

Surrounded by strangers and with few visitors, Susan became more isolated and less active as the weeks passed. Three months later, she died following a chest infection.

1 in 4 people die within a year

of suffering a hip fracture.



Graphic reference. ¹²

Questions for GPs and commissioners to consider

At the CCG population level, there are likely to be thousands of people living with osteoporosis-related issues, many of whose symptoms will not have been identified formally to the care system.

In the local population, who has overall responsibility for:

- Promoting osteoporosis as a condition for which targeted interventions must be planned and delivered?
- Identifying individuals living with osteoporosis?
- Planning care to address management of osteoporosis?
- Identifying and reporting on measurable osteoporosis associated outcomes?
- Quality assurance and value for money of osteoporosis care?
- Getting best value for money from the investment?
- Identifying how we do the right thing for the patient and at the same time recognise that costs shift from health to social care?
- Reviewing <u>NHS RightCare data</u> to understand musculo-skeletal care and outcomes in your CCG?
- Building the strategy and work-plan to reduce the number of fragility fractures in your population?
- Building a strategy for effective musculo-skeletal care including osteoporosis in your CCG?
- Providing a fracture liaison service (FLS)? Is this integrated with your falls prevention initiatives?
- Reviewing the fracture liaison service, to make sure that it meets the published standards? ¹³
- Ensuring that a plan is in place to make sure that your local FLS will be able to meet the published standards?

And patient engagement is very important too:

- ✓ Has any engagement activity taken place with patients with regards to osteoporosis care?
- Do you already have valuable local data around patient experience and outcomes for osteoporosis care in your area?
- ✓ How could this local data be used to identify and drive improvements?¹

The above questions are vital in understanding who manages which components of a whole system. Most importantly, it is impossible to effect optimal improvement if the system is not aware of the answers.

If you need any help with any of these issues please contact the National Osteoporosis Society's service delivery team, who will be able to give practical advice and support. Call 01761 473 112 or email <u>fls@nos.org.uk</u>.

¹ If you require advice and resources around engagement please contact The Involvement Hub through this link: <u>https://www.england.nhs.uk/participation/</u>

It didn't have to be that way...

Susan's optimal care pathway 1: Stopped at one

As before, Susan's journey starts when she trips and falls whilst vacuum cleaning. She visits her local A&E, has her wrist fracture confirmed by X-ray and attends the fracture clinic a week later.

This time, however, Susan's local area has a Fracture Liaison Service (FLS) which spots that her break may well have been a fragility fracture.

The FLS administrator finds Susan during their daily trawl of the fracture clinic records and invites her for a meeting with Julie, an FLS Nurse.

FLS Standard 1: All patients aged 50 years and over with a new fragility fracture or a newly reported vertebral fracture will be systematically and proactively identified – Clinical Standards for Fracture Liaison Services.¹³

Julie asks Susan a few questions about her fall and any past breaks to help complete a fracture risk assessment before sending her for a DXA scan to measure her bone density.

When the results come back confirming osteoporosis, Susan is initially scared but Julie is a great help; she explains what osteoporosis means, what she can do to keep her bones healthy and how bone protection medication could help reduce her risk of breaking more bones.

"If it wasn't for the FLS service I would never have known that I have osteoporosis" – Patient in Portsmouth

Susan is relieved to hear that she won't have to give up dancing; in fact Julie explains that weight-bearing exercise is good for keeping her bones strong, though she might want to avoid the Argentine Tango.

Julie arranges for Susan to have four weeks' worth of bone protection medication whilst a long-term care plan is agreed with Susan and her GP. Susan is copied into all the FLS letters, so she knows what is going on.

The most common bone protection medication costs the NHS 24 pence per week.¹⁴

After logging on to the National Osteoporosis Society website for a bit of information about calcium and vitamin D, Susan spots that her local support group is holding a newly diagnosed session.

It is nice to meet some other people in the same boat and hear about some of the changes they have made around the house to make them less worried about slipping and breaking something.

After four and then twelve months following the fracture, Susan receives calls from Julie to discuss how she is getting on with her medication.

Susan's optimal care pathway 2: The song continues

A few years later, Susan and Bob were enjoying themselves, attending dance classes, seeing the family and going for dinner parties with their friends.

Five years after her incident with her vacuum cleaner, Susan visited her GP for a treatment review. After a three year pause in treatment (the normal procedure for oral bisphosphonates) Susan began her medication again, remembering what Julie the nurse said about the importance of taking it according to the instructions.

Nights spent twirling across the dance floor have made Susan's balance and mobility better than most. So when, one evening, she tripped she was able to twist and avoid the worst of the fall. A trip to her GP confirmed that her bone strength had stabilised enough to avoid another broken wrist.

Therapies and interventions approved by the National Institute for Health and Care Excellence (NICE) significantly reduce the risk of re-fracture by 20–70% depending on the fracture site. ¹⁵

Upon turning 70, Susan decided it was time to spend more quality time with her husband. The school made a big fuss for her in a special leaving assembly, presenting her with a rose plant and a set of engraved gardening tools. Susan would smile in the years to come as she pottered round the garden with 'Mrs A's Magic Trowel'.



With more time on her hands, Susan and Bob spent more precious moments with their grandchildren, playing in the garden and cheering from the side-lines at their football matches. Susan couldn't help but burst with pride watching her granddaughter Emily follow in 'Nan's' footsteps with her first dance recital.

Susan and Bob slowly started reducing their dance classes. Luckily, their friends were doing the same. As the time approached for them to all pack up their dancing shoes, the group began day trips, continuing to meet up regularly.

"As I'm aware that many women have it without knowing, I feel happy that my condition is being managed effectively and that I've been lucky that I have suffered no fractures and little limitation on my lifestyle" – Life with Osteoporosis Survey 2014.¹⁰

Susan's optimal care pathway 3: Last dance

With their 50th anniversary upon them, the couple decided to make the trip back to their beloved honeymoon destination of Seville.

Despite their best dancing days behind them, they waltzed by the river, reminiscing about the best moments of their life and how much they were enjoying their retirement together.

When Bob died the following year, Susan was still distraught. But with a firm friendship group and close-knit family, everyone rallied around to support her through the tough times.

Susan's ex-dancing friends invited her to join the University of the Third Age with them, where joking about how their 'Granny trips' could distract her from Bob's absence.



In her spare time Susan tended the garden she and Bob had grown together. Ably keeping their roses immaculate, she remembered Bob as the partner who danced through the ages with her; rather than the man whose last years of life were spent nursing her.

Susan's optimal care pathway 4: 20 years saved

After 20 years free from back pain, Susan experienced her first vertebral facture while stretching for something in a kitchen cupboard.

Susan visited her GP, who knowing her diagnosis, sent her for an X-ray.

The X-ray alerted the FLS who invited Susan back to see a new nurse, Karen.

Karen explained the vertebral fracture to Susan, prescribed her a different treatment and gave her a few tips on how to avoid further fractures.

Susan's children were quick to act on Karen's advice, helping make adjustments to the kitchen so handles were within reach, allowing Susan to stay in her marital home.

The Glasgow FLS saw reductions in hip fractures of 7.3% in the 10 years after it was set up, compared to a 17% rise in England for that time.¹⁶



The physiotherapist and postural stability instructor at her local strength and balance classes helped keep Susan active and able to visit her grandchildren. A little while later Susan watched her grandson George graduate from university, three years after she would have died in the care home.

The 'bills' and how they compare

What is the cost of Susan's journey to the local health and social care economy?

For the financial evaluation we performed detailed analysis through mapping the lifecycle of the pathways. Through this process we were able to identify the cost drivers that would be incurred in primary, community and hospital care, using NHS reference costs and, where there is a hospital stay, average cost per bed day. We have included the wider social impacts and economic impacts but we have not attempted to cost financially outside of the health remit or the social, emotional, physical and financial costs to Susan herself.

This scenario features a fictional patient, Susan. It is intended to help commissioners and providers understand the implications (both in terms of quality of life and financial costs) of shifting the care pathway of older people living with osteoporosis from a reactive to a proactive approach. The financial costs are indicative and calculated on a cost per patient basis. Local decisions to transform care pathways would need to take a population view of costs and improvement.

The tables below represent the different impacts of the two pen portrait journeys from a financial perspective:

Table 1: Analysis by cost category:

Analysis by cost category	Sub-optimal	Optimal			
Community care	£549	£565			
Elective outpatient care	£475	£77			
Palliative & End of Life	£10,589	£0			
Secondary care prevention	£0	£99			
Primary care management	£567	£744			
Self care	£0	£8			
Urgent & emergency care	£16,691	£1,195			
Grand total	£ 28,871	£ 2,688			

Table 2: Analysis by provider:

Analysis by provider	Sub-optimal	Optimal			
Acute	£11,227	£933			
Ambulance service	£233	£0			
Care home	£10,589	£0			
Community hospital	£5,706	£0			
Community teams	£549	£511			
Fracture Liaison Service (secondary care based)	£0	£438			
Patient	£0	£62			
Primary care	£567 £744				
Grand total	£ 28,871	£ 2,688			

In the sub-optimal pathway Susan receives very little / inappropriate support during the early years of her osteoporosis symptoms. Initially, there are only the health costs associated with the first broken wrist but the time-bomb is ticking loudly without the appropriate diagnosis and treatment. Strategically, these early years are the most important to Susan's long-term health.

As shown in the optimal scenario, preventative care has a huge impact and the later complications are then largely avoided / delayed.

Not only is Susan's (and her husband's) health and quality of life significantly better in the optimal scenario, but the costs to the health economy are reduced by 91%. The impact is significant on outcomes, quality and finance.

Think change, Think NHS RightCare

This optimal pathway was understood, tested and created using the proven NHS RightCare approach.

NHS RightCare is a methodology that focuses relentlessly on increasing value in healthcare and tackling unwarranted variation. It is underpinned by intelligence and robust evidence, showing commissioners and local health economies 'Where to Look' i.e. where variation and low value exists. The approach then goes on to support health economies through 'what to change' and 'how to change'. The diagram showing all three key phases is shown on the next page.

NHS RightCare offers facilitation and support to all CCGs and their health economies in implementing the RightCare approach and the developmental thinking, tools and data that enhance population healthcare improvement.

NHS RightCare is a proven approach that delivers better outcomes and frees up funds for further innovation. Please explore our latest <u>Commissioning for Value</u> <u>publications</u> and for more details about our programme visit <u>www.england.nhs.uk/rightcare</u>

You can also contact the NHS RightCare team via email at rightcare@nhs.net

The NHS RightCare System:

Objective	Maximise Value								
Principles	Get everyone talking about same stuff	Talk about fix and future		t	Demonstrat viability		ate	Isolate reasons for non-delivery	
Phases	Where to Look What to Change			to e	How to Change				
Ingredients	(1) Clinical leadership	2 Indicativ data	e	3 Engage	ement	(4) Evid data) lential a		5 Effective processes

For a toolkit for general practice in supporting older people and achieving the requirements of the Unplanned Admissions Enhanced Service please visit: http://www.nhsig.nhs.uk/media/2630779/toolkit_for_general_practice_in_supporting_older_people.pdf

For more information about the Long Term Conditions work at NHS England please contact england.longtermconditions@nhs.net

For more information about the National Osteoporosis Society visit https://nos.org.uk/

You can download the NHS RightCare musculo-skeletal (MSK) focus packs at https://www.england.nhs.uk/rightcare/intel/cfv/data-packs/

Two slide packs to summarise this scenario – a full length pack and a short summary pack summary – are included as appendices.

This information can be made available in alternative formats, such as easy read or large print, and may be available in alternative languages, upon request. Please contact 0300 311 22 33 or email <u>england.contactus@nhs.net</u>

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