

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



Clara's story: Multimorbidity

NHS RightCare scenarios

This multimorbidity scenario is part of a [series](#) of NHS RightCare Long Term Conditions scenarios to support local health economies – including clinical, commissioning and finance colleagues – to think strategically about designing optimal care for people with long term conditions and their carers.

Each scenario is a discretionary resource that highlights potential improvement opportunities through a fictitious but representative patient story. They have been developed with experts in these areas and include prompts for commissioners to consider when using each product.

For this scenario on multimorbidity, commissioners, clinicians and providers responsible for long-term conditions care for their population should consider:

- Planning care models to address multimorbidity in addition to specific single conditions
- Systematically identifying individuals living with multimorbidity
- Providing tailored care to people with multimorbidity in line with NICE guidance, which considers, for example, treatment burden and sharing information to other professions and services.
- Using existing resources and data to identify opportunities to improve quality of care for people living with multimorbidity

Please contact your local [NHS RightCare Delivery Partner](#) if you would like to explore any of the scenarios further.

The story of Clara's experience of multimorbidity, and how it could be so much better

In this scenario – using a fictional patient, Clara – we examine a multimorbidity care pathway, comparing a sub-optimal but typical scenario to an optimal pathway. At each stage we have modelled the costs of care, both financially to the commissioner and personally and emotionally to Clara and her family.

This document is intended to help commissioners and providers understand the implications – both in terms of quality of life and resource costs – of shifting the care pathway of people living with multimorbidity from an approach focussed on individual conditions to a holistic approach that takes full account of a person's multiple conditions (a 'multimorbidity approach'). We have built the optimal pathway in line with the recommendations made in the [NICE guideline on multimorbidity, NG56](#), further resources are also available on the NICE [topic page](#).

This scenario shows how the NHS RightCare methodology can help clinicians and commissioners improve the value and outcomes of the care pathway as part of an overall approach to considering quality of care and commissioning.

Two summary slide packs are also included as appendices for optimal use by different audiences.

Introduction

Around one in four of people in England have two or more long-term conditions (LTCs), often known as ‘multimorbidity’, rising to two-thirds of those aged over 65 years old¹. Linked to this, around one million people in England live with frailty – a process associated with ageing in which multiple body systems gradually lose their inbuilt reserves, leading to reduced resilience and increased vulnerability to events such as minor illness or injury.

Both multimorbidity and frailty are associated with ageing and occur earlier in the life course for people in socially and economically deprived areas. They are closely linked; both have an adverse impact upon individual quality of life and are associated with higher mortality, adverse drug events and greater use of unplanned care. The scale of this increasing problem is highlighted in the 2016 report from the Government Office for Science, [Future of an ageing population](#). For example:

- The ‘oldest old’, who have a substantial risk of requiring long-term care, are the fastest growing age group in the UK
- Between a quarter and a half of people over 85 are estimated to be living with frailty
- Those living in the most deprived areas of England have nearly two more years of ‘not good health’ after 65 than those in the least deprived areas.

This is the story of Clara, a widow, mother and grandmother living with five long-term conditions and frailty. Clara and her story are fictional, but the events she experiences and her emotional responses are typical of those of many people living with multimorbidity.

¹ Barnett, K et al. 2012. Epidemiology of multimorbidity and implications for health care, research, and medical education: a cross-sectional study. *The Lancet* (Volume 380, No. 9836).

Introducing Clara



Clara was born in Jamaica in 1939, and along with her parents and older sister Ruth, became some of the first Caribbean immigrants to land in the UK after the Second World War. After immigrating, her family became heavily involved in their local church.

Clara first met her husband, Ray, at school, and they went on to marry in 1961, having three children and four grandchildren.

Ruth sadly passed away in 2010 and Ray in 2012 and, struggling to cope on her own, Clara moved into sheltered accommodation.

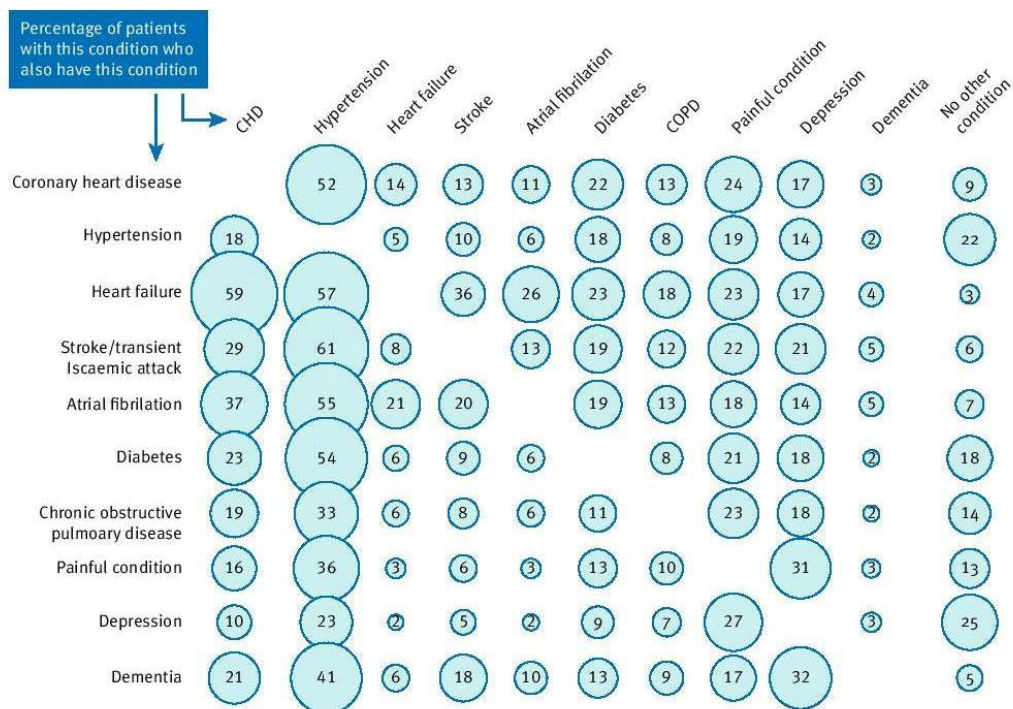
Clara's younger son and daughter now live over 100 miles away, but her elder son, Stephen, lives nearby. Stephen works long hours but is able to visit Clara in the evenings and at weekends.

Clara takes great joy from the companionship of her dog Bella. She also still tries to attend church and enjoys going to pensioners' clubs, although she sometimes struggles to get out because of her worsening health.

Clara has multiple long term conditions, including ischaemic heart disease, type 2 diabetes, osteoarthritis, hypertension and depression. She also has obesity, and feels lonely and isolated, despite living in sheltered accommodation and being surrounded by other residents. She suffers from persistent pain in her legs as a result of her osteoarthritis, and is living with increasing frailty.

A number of Clara's conditions commonly occur in combination in people living with multimorbidity. See Figure 1 on the following page for an overview of this.

Figure 1: People living with multimorbidity



Source: *BMJ* 2016;354:i4843.

Clara is prescribed around 10 medications, and has to take around 20 tablets a day. However, her memory is getting worse and she sometimes forgets to take some of them. She also has to attend around 30 medical appointments a year, provided she is able to get to them. These include regular GP check-ups and specialist appointments, including numerous appointments related to her diabetes – for example feet and vision appointments.

Clara's journey



Clara's journey starts on a Monday afternoon in September 2014, aged 75, when, after eating lunch, she started experiencing chest pain. The pain quickly became severe and so she called 999 and was taken to A&E by ambulance.

She was very anxious the whole time, fearing she was having a heart attack. However she was seen within just a few minutes in A&E and was diagnosed with

angina – a consequence of her ischaemic heart disease. Some of her existing medication was increased in dosage, and she was discharged home later the same night. The loneliness hit her as soon as she walked through the door.

The following night, when getting up to go to the toilet, Clara started to feel unwell again, this time feeling very light-headed, due to her blood pressure dropping. She tried getting to the phone to call her son but didn't make it, collapsing and banging her head on the wall. Fortunately, a neighbour heard the incident and a member of staff found Clara and raised the alarm. Clara was taken back to A&E where she was given a CT scan because of her head injury. The scan was all clear, but she was kept in hospital for a day as a precaution.

Clara began to worry more about her angina and about falling and as a result she became more reluctant to get out and about. However, looking after her dog Bella kept her going and she still took her for short walks in the local park. This helped keep her active and she also liked to see children playing and sometimes even talked to other passers-by. It came as a big shock to Clara the following January when Bella passed away. This was a huge blow to her, as she had spent fifteen years with Bella and she had been a great help in staving off the loneliness she experienced after Ray died.



Clara now fell further into depression. Her family felt powerless to help her, with only Stephen living nearby and unable to help during working hours.

Her GP put her on anti-depressants, but these made her nauseous, and, having so many tablets to take, she sometimes forgot to take them or simply didn't want to because she lacked the energy to get to the kitchen. However, she wasn't confident enough to approach the GP to ask for an alternative to the pills, as she had always thought that the 'doctors know best' and that she just needed to put up with any unpleasant side-effects of drugs.

Over a few months, Clara lost a lot of weight, going from 83kg to 62kg, due to her low mood, advancing frailty and a lack of appetite caused by all of the medication she was taking. To add to this, she began to experience problems with the diabetes medication that she had been on for a number of years. Her treatment could have been reduced as she had lost weight and her blood sugars had become much lower, but nobody realised this because she missed one or two of her routine blood tests and when she did go to her doctor to complain that she was feeling excessively tired

and even dizzy at times, these symptoms were thought to be due to her heart disease and depression.

In June 2015, aged 76, Clara had another fall at home, hurting her hip, and was taken to A&E by ambulance. Although no damage was shown to her hip other than bruising, she was still finding it more difficult to walk due to the pain from her osteoarthritis. The A&E doctors noted that she was already prescribed simple painkillers from her own GP and so added in opiate painkillers to try and help improve control of the pain from her osteoarthritis. What they didn't realise was that Clara had not been taking the simple painkillers regularly and so might not have really needed the stronger tablets. After being discharged the following day, Clara proceeded to take the new tablets regularly four times a day, not realising that she could reduce the dose if her pain settled down.

Clara became very constipated as a result of taking the new tablets. This was very distressing for her but she was too embarrassed to tell her GP about it, and so one afternoon she tried to walk to the local pharmacy to get something to deal with the constipation. On her way she became very dizzy and collapsed on the pavement.

She was taken to A&E once more and was found to have a fractured wrist. Because she'd been brought in from the street, the doctors didn't have any information about her, her conditions, or what medication she was taking. Because of her nausea and constipation she hadn't had anything to eat or drink since the morning. It was a particularly busy day in A&E, and she became very confused and agitated, so much so that she was referred to the psychiatry team. The team felt her mental state was too unstable and her mobility was too poor to be sent home, and she was kept in hospital.

Whilst on the ward, Clara remained confused at times, fell again, and was sometimes incontinent of urine and faeces. This only served to distress her further, and although her son was able to visit and put her at ease some evenings, the isolation of being in hospital hit her hard.

Over the three weeks she was in hospital, Clara felt increasingly lonely and her mental state deteriorated to the worst it had ever been. At the time she was discharged, she was noted as having ongoing cognitive impairment.

Once out of hospital, Clara required 24 hour care in a care home to meet the needs associated with her frailty and cognitive impairment. Although she found the carers very helpful, and appreciated their company, she still felt very lonely, despite them being constantly around. She struggled to be taken out at all, even into the garden of the care home, and relied on visits from her children and grandchildren to lift her spirits.

After three months in the care home, Clara deteriorated quickly with an acute chest infection and associated acute kidney failure, and was admitted to hospital. She remained there for the next ten days, where she declined and sadly passed away on the ward.

Questions for GPs and commissioners to consider

At the CCG population level, there are likely to be thousands of people living with multimorbidity. In the local population, who has overall responsibility for:

- Promoting interventions aimed at treating multimorbidity?
- Systematically identifying individuals living with multimorbidity?
- Planning care models to address multimorbidity, which focus on a multimorbidity approach rather than on specific single conditions?
- Coordinating and delivering care to specifically address multimorbidity for individuals?
- Identifying and reporting on measurable positive and negative multimorbidity associated outcomes?
- Quality assurance and value for money of multimorbidity care?
- Has any engagement activity taken place with patients with regards to multimorbidity care?
- Do you already have valuable local data around patient experience and outcomes for multimorbidity care in your area?
- How could this local data be used to identify and drive improvements?

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.

What could have happened differently?

Clara's optimal care pathway

The story of Clara's optimal pathway starts two years earlier, in August 2012, aged 73, when her GP surgery identified her as having moderate frailty using the electronic Frailty Index (eFI) and multimorbidity. She was identified as likely to benefit from the tailored approach to care identified in the NICE NG56 guideline.

Clara's practice allocated her a dedicated care co-ordinator, Sarah, who knew all about her different conditions and personal circumstances. Sarah enjoyed working with Clara and found it fascinating hearing about her life experiences. Clara felt at ease with her and always felt that she was interested in her and not just her medical problems. She knew she could contact her if she was worried about anything to do with her conditions and she would be able to advise her who the best person would be to help. She was able to support the self-management of her individual conditions but also helped her to understand they were all interrelated.

Largely through Sarah's relationship with Clara, the practice understood that Clara had a number of different problems, and that they were all connected, and arranged for her to come in for regular check-ups.

They started offering her extended appointments so that she could have holistic reviews every six months. During these appointments, Clara had the opportunity to explain what was important to her and how her conditions, and the treatment that she needed for them, were affecting her life. Her son was able to attend some of them, enabling him to discuss how he could best support his mother.



The sessions helped Clara understand what her different medications were for and to think about other things that she could do to help herself keep healthy, well and independent.

They also went through important aspects of her care and support such as signposting to financial entitlements, advice on arranging Lasting Powers of Attorney for Property and Affairs and for personal welfare and even thinking about what kind of care Clara would like if she developed a serious illness.

Clara also expressed how much she cherished her relationship with her dog Bella, but how she was struggling to keep up with looking after her. The practice put her in contact with a local charity, which gave Clara support and advice on how to look after Bella, and a local voluntary organisation that took Bella out for walks most days.

Comfortable in approaching her GP surgery, Clara explained to her care co-ordinator that she was struggling to keep up with all of her medication, and so the care co-ordinator arranged for her to be given an automatic pill dispenser by her pharmacist. This divided up all of the medication she needed every day, removing the risk of her forgetting or becoming confused by what she needed to take. Being a regular user of her mobile phone, she was also set up with a telehealth system to aid in the management of her diabetes.

Because of her issues with memory and the distress this was causing her, Clara's GP referred her to a memory clinic for an assessment. Fortunately, this showed only mild cognitive impairment, and it presented a valuable opportunity to alert Clara and her family to the higher risk of delirium in acute illness, and to plan for this eventuality. Clara was very relieved that she had not been diagnosed with dementia and became a bit more confident again. The GP also referred her for check-ups for vision, dental and hearing, to make sure there were no issues in these areas.

Clara's GP practice also recognised that, as a person living with moderate frailty, she might be at risk of falls. When this was discussed at one of her review appointments, she admitted that she had fallen at home three or four times in the last 12 months. They suggested to Clara that it might help her if a falls risk assessment was carried out for her at home and she agreed, because she realised that she could fall again at home and would need to seek help quickly. They arranged for this to be carried out by the Council. As a result, the Council put in place a movement sensor and a care call, recognising the risk that Clara could fall and would need a way of calling for help.



The GP practice also suggested to Clara that it might help her to reduce her risk of falling if she went along to a strength and balance class. She found this very helpful, not only helping her to build up her physical strength but also giving her additional confidence to stay active.

She also enjoyed the social aspect of the classes, making friends with others in a similar position to her.

One evening Clara began experiencing chest pain and, recognising that this could be a consequence of her ischaemic heart disease from her conversations with her care co-ordinator, called an ambulance and was taken to A&E. The team in A&E did a number of investigations that ruled out a heart attack and she was diagnosed with angina.

Through their assessment, the A&E team realised Clara's symptoms were probably largely related to stress and discussed with her how they might be able to help her. They reassured her that there was no sign of a heart attack and that her regular medicines were doing a good job. They suggested referring her back to see the cardiologist in clinic, but she said that it was quite difficult for her to get to out-patients and so if possible she would prefer to go back to discuss this with her own GP rather than come back to the hospital. They reassured her that was a reasonable plan and reassured her that the GP would have a letter from them by the next day to let them know that she had been to A&E, what tests had been done and what treatment they had given.

The team in A&E had access to an electronic shared record for Clara, which showed which medicines were issued when, and that she was living with frailty, and so initiated a comprehensive geriatric assessment.

Clara was kept in the clinical decision unit for observation overnight. A further review of her medication was undertaken. Some medications were stopped as they were now deemed unnecessary but she was also given some additional medication for her angina, with full explanation of side effects. She was discharged home the next day and referred back to her GP for follow up as discussed the previous evening.

Unfortunately, a few days later, Clara began to feel dizzy when she stood up. She recognised that this could be a side effect of the new medication, as it was explained to her in the hospital that it might cause her blood pressure to drop, and she went to visit her GP, who was aware of her recent visit to the hospital, and made further adjustments to her medication.

Over time, Clara became more anxious at home, finding it more and more difficult to manage simple tasks, and was fearful of falling. She was also hit with a big blow when her dog Bella died, and she became more depressed. Recognising these problems, her GP referred her for appropriate psychological support through the local 'Talking Mental Health' service. At first she had one to one treatment and then as she got a bit better she was encouraged to join a local support group, which she found a great help. She said: "Being able to talk to people in a similar position was a great encouragement, and showed me that I am not alone."

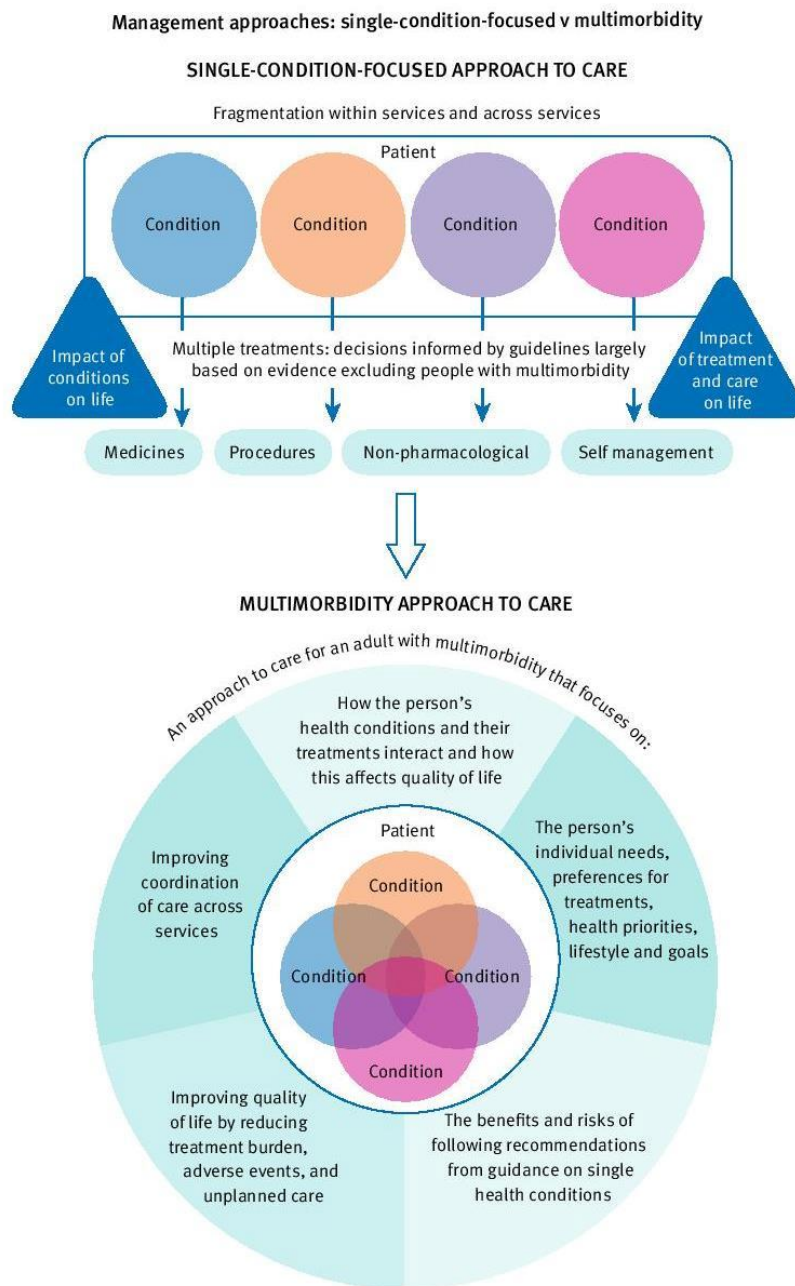
Clara began to lose weight quickly due to her increasing frailty. She was given a further holistic review, referred for assessment for additional support, and was given a care package that included twice-daily support at home to carry out basic tasks such as dressing, bathing and toileting.

One day, a friend had taken her out to a lunch club at church, Clara fell and hurt her hip. She was taken to A&E and given x-rays that showed nothing serious. Her up-to-date shared record showed that she was already on analgesics for her osteoarthritis, and so the doctors decided she didn't require any further medication. They referred her to an intermediate care team to support her at home after discharge, and she returned home the next day.

As Clara's health declined, her GP practice made sure that they had a discussion with her about her wishes for end of life. Her care package was increased to four visits daily, and although there were times when Clara might have been rushed to hospital, she was kept at home in line with her wishes, where she died peacefully surrounded by her family.

There are different approaches to managing care for a single condition versus multimorbidities. Many aspects of these are illustrated in Clara's story. See Figure 2 on the following page for an illustration.

Figure 2: The differences between a single condition approach to care and a multimorbidity one



Source: *BMJ* 2016;354:i4843.

The 'bills' and how they compare

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 day². We have included the wider social 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 Clara and family.

This scenario is using a fictional patient, Clara. 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 multimorbidities 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.

Table 1: Analysis by provider

Analysis by provider	Sub-optimal	Optimal	Optimal %
Third sector	£0	£510	N/A
Acute	£14,570	£1,028	7%
Ambulance service	£932	£466	50%
Community teams	£75	£1,717	2276%
Mental health provider	£0	£1,655	N/A
Primary care	£657	£1,140	174%
Social services	£10,227	£9,024	88%
Dentist / Optician	£0	£40	N/A
Grand total	£26,462	£15,581	58.9%

As can be seen from Table 1 (above) secondary care expenditure in the two scenarios is radically different. Acute costs in the optimal case represent only 7% of the original sub-optimal case (94% reduction in bed days from 35 days in the suboptimal case to two days in the optimal case) equating to a reduction of £13.2k.

² £400 has been used as a proxy measure to calculate the approximate costs of a single day's treatment in a ward in a hospital setting. This value has been derived from 2015/16 SUS data using the weighted bed-day cost with Market Forces Factor applied for age ranges between 40-74. This age range is typical for the suite of Long Term Conditions scenarios produced.

Edbrooke and colleagues estimated the average cost per patient day in 11 ICUs was £1,000 www.ics.ac.uk/EasySiteWeb/GatewayLink.aspx?allid=441. Reference costs applied are at 2015/16 prices. The excel spreadsheet designed to cost these scenarios includes full details of cost data sources and is available upon request. Please contact NHS RightCare at rightcare@nhs.net if you would like further details about the methodology.

Mental health and primary care teams offer a great deal more support in the optimal scenario as the optimal case needs to invest in these areas to ensure Clara's care and support is as good as possible given this complex case. Note this also raises the importance of improved strategic budgeting across the wider health economy.

Not only is Clara's quality of care so much better in the optimal scenario, but the cost savings are also significant at £10.8k (41.1%). As stated above, the financial costs are calculated on a cost per patient basis and local decisions would need to take a population view of costs and improvement.

Table 2: Analysis by cost category

Analysis by cost category	Sub-optimal	Optimal	Optimal %
Primary care management	£627	£1,090	174%
Urgent and emergency care	£1,160	£694	60%
Secondary care management	£14,342	£2,455	17%
Prevention and public health	£30	£885	2,941%
Community care	£75	£8,740	11,584%
Nursing home care	£10,277	£0	0%
Intermediate care	£0	£1,717	N/A
Grand total	£26,462	£15,581	58.9%

This is a scenario that clearly highlights that proactive planning and correct signposting to well trained (and equipped) teams is important - there is a significant impact on patient experience, quality of care and finance. Care can be improved by investigating the root cause of sub-optimal care and working with clinicians to design an improved evidence-based pathway.

In the sub-optimal pathway Clara's care was over-reliant on secondary care and was not sufficiently managed in primary care or at home. Improved management had a dramatic impact on her and her family. Such costs are difficult to quantify, but are very real. In addition, a saving of 41% is material to any health economy.

Think change, Think NHS RightCare

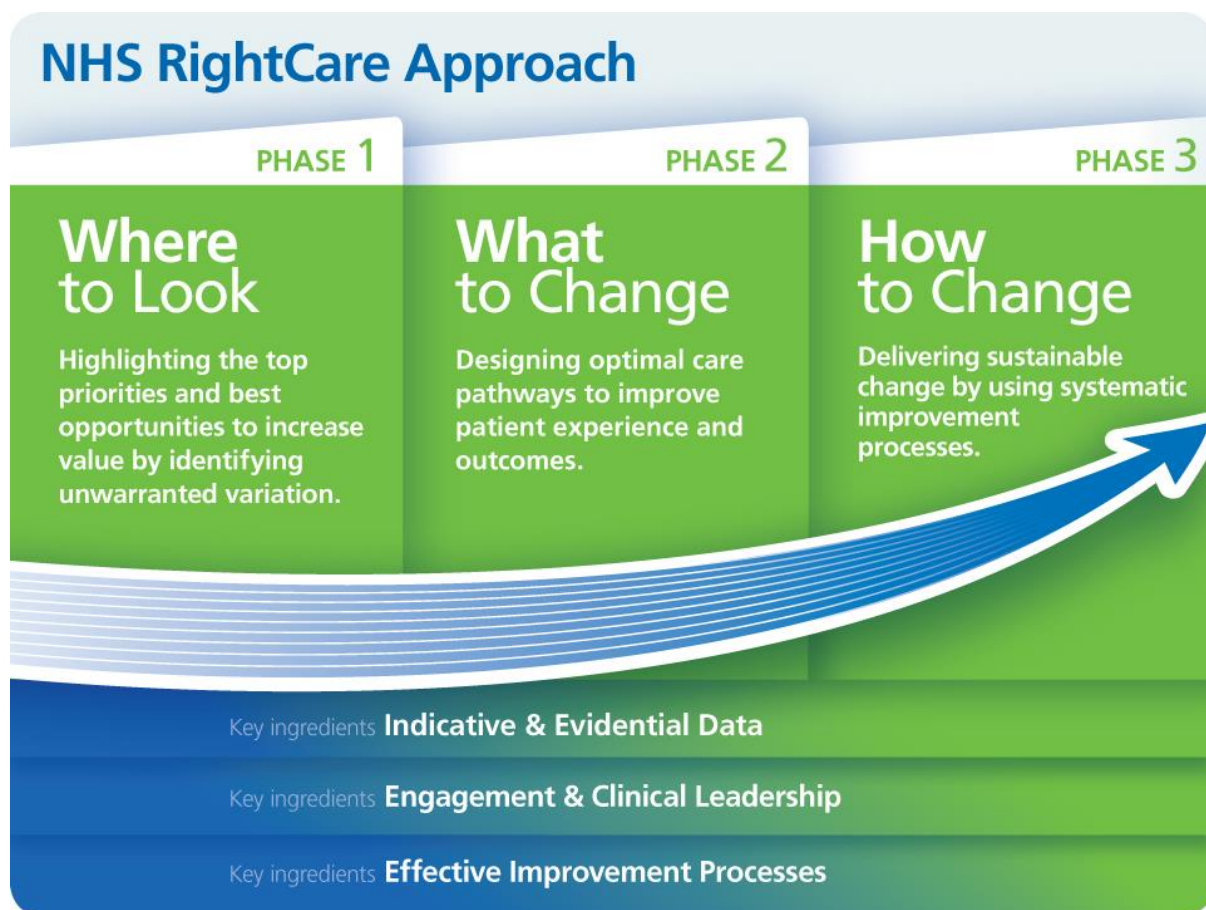
This optimal pathway was understood, tested and created using the proven NHS RightCare approach.

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 below.

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 [publications](#) and for more details about our programme visit www.england.nhs.uk/rightcare.

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



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

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 england.contactus@nhs.net