

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



**Katie's story:
Advanced colorectal
cancer**

NHS RightCare scenarios

This colorectal cancer 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 advanced colorectal cancer, commissioners, clinicians and providers responsible for the care of people with advanced malignant disease in their population should consider

- Planning care models to address the range of supportive and palliative care needs, including access to specialist palliative care services
- Ensuring that an effective system is in place to identify people with palliative and life-limiting illness, so that they can be registered on their GP's supportive/palliative care register and, with their consent, up to date key information about their needs and preferences made accessible to professionals in and out of hours across organisational boundaries
- Ensuring personalised care for the individual which includes an emphasis on honest conversations and shared decision making about care, treatment and support
- Seeking local data around patient experience and outcomes for people with advanced malignant disease to identify and drive quality improvements

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

The story of Katie's experience of an advanced colorectal cancer journey, and how it could be so much better

In this scenario, using a fictional patient, Katie, and her family, we examine the advanced colorectal cancer pathway, comparing a suboptimal, but typical, scenario against an ideal pathway for an individual diagnosed with metastatic cancer who requires palliative care through to the end of life. 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 those with metastatic cancer, from a primarily reactive response to a proactive approach, e.g. providing integrated primary care and community-based responses, 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 journey of care as part of an overall approach to considering quality of care and commissioning.

The document will also support emerging Sustainability and Transformation Partnership (STP) areas, health and care leaders in the statutory and voluntary sector, and those developing and implementing digital health and care solutions.

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

Introduction

Colorectal cancer is the fourth most common cancer in the UK and it is the second most common cause of cancer death.¹ In the UK, 41,000 people are diagnosed with colorectal cancer each year; that is over 100 new cases each day.

Occurrence is strongly related to age, with almost three quarters of cases occurring in people aged 65 years or over.^{2,3} However, colorectal cancer can occur at any age.

There is some evidence to suggest that the incidence of colorectal cancer is beginning to fall in the UK.¹ This may be related to greater public awareness, screening programmes and removal of colonic adenomas at colonoscopy.⁴

Whilst colorectal cancer can be treatable, and in some cases curable, this outcome is dependent upon the diagnosis being made early, with survival rates dropping significantly as the disease develops. Survival depends on the stage of cancer at diagnosis (i.e. the size and whether it has spread), the type of cancer, and grade of the cancer cells (i.e. how abnormal the cells look under the microscope).¹

Although the results of treatment have shown a gradual improvement over the past 30 years, five-year survival is still only around 50% in the UK and it appears to be significantly lower than observed in other comparable countries.¹

Patients who are not cured of their disease will benefit from palliative care, aimed at improving their quality of life through early identification, assessment, and treatment of pain and other physical, psychosocial, and spiritual problems.

The *Ambitions for Palliative and End of Life Care: A national framework for local action 2015-2020* sets out what 'good' looks like from a whole system perspective (www.endoflifecareambitions.org.uk).

¹ Bowel Cancer Statistics, 2014, Cancer Research UK. <http://www.cancerresearchuk.org/health-professional/cancer-statistics/statistics-by-cancer-type/bowel-cancer#heading-Zero>

² National Bowel Cancer Audit, NHS Digital. <http://content.digital.nhs.uk/bowel>

³ Colorectal Cancer: Diagnosis and Management. NICE Guidance, 2014 [CG131]. <https://www.nice.org.uk/Guidance/cg131>

⁴ The UK National Bowel Cancer Screening Programme. <https://www.bowelcanceruk.org.uk/about-bowel-cancer/screening/>

***Ambitions for Palliative and End of Life Care: A national framework
for local action 2015-2020***

1. Each person is seen as an individual
2. Each person has fair access to care
3. Maximising comfort and wellbeing
4. Care is coordinated
5. Staff are prepared to care
6. Each community is prepared to help

www.endoflifecareambitions.org.uk

Furthermore, in 2016, the government published a [six point commitment](#) to people approaching the end of their lives, which enhances the person-centred approach which is the focus of the first ambition in particular. The six-point commitment is that people who are approaching the end of their lives will have opportunity and support to:

- have honest conversations about their needs and preferences
- make informed choices about their care based on clear and accessible information
- develop and document a personalised care plan
- share this plan with those involved in their care
- involve, to the extent they wish, their families and carers in developing and delivering their care
- know who to contact for help and advice at any time.

Katie's story illustrates how these commitments and the Ambitions Framework can be made a reality for her, and her family.

Introducing Katie



Katie is a 46-year-old retail worker. She lives with her husband, Isa, and two young children, Lucy aged 8 and James aged 5. She has no family living locally. Her elderly widowed mother lives almost three hours' drive away. Isa is originally from Lebanon and his parents still live there.

Katie was diagnosed with colorectal cancer at the age of 45. This was surgically removed, followed by adjuvant chemotherapy. She made a good recovery. One year on from completing her treatment, the family moved to a different county because of Isa's job. Prior to the move, her gastroenterologist carried out a surveillance CT scan. This showed no evidence of disease recurrence.

NICE guidance for follow-up after apparently curative resection of colorectal cancer

Offer follow up to all patients with primary colorectal cancer undergoing treatment with curative intent. Start follow up at a clinic visit four to six weeks after potentially curative treatment.

Offer patients regular surveillance with:

- a minimum of two CTs of the chest, abdomen, and pelvis in the first three years

AND

- regular serum carcinoembryonic antigen tests (at least every six months in the first three years).

Offer a surveillance colonoscopy at one year after initial treatment. If this investigation is normal consider further colonoscopic follow up after five years, and thereafter as determined by cancer networks.

Start reinvestigation if there is any clinical, radiological or biochemical suspicion of recurrent disease.

Stop regular follow up:

- when the patient and the healthcare professional have discussed and agreed that the likely benefits no longer outweigh the risks of further tests, or
- when the patient cannot tolerate further treatments.

Katie and her family moved into their new home in January. Once she had settled in the children, Katie registered with her new GP who noted her cancer history in her medical records. She remained well throughout that year.

In January, a year after moving into their new home, Katie started experiencing abdominal pain. Initially intermittent, this became more persistent and severe over the next four weeks. She found herself calling in sick to work quite frequently as she was struggling with the pain. This put a financial strain on Katie and her family as she wasn't entitled to sick pay.

In February, as the pain hadn't improved, Katie decided to see her GP. She rang the surgery and was given an appointment for a fortnight later as this did not classify as an emergency. On the day of the appointment, the pain didn't seem too bad. Katie was rushing to collect her children from school, so she did not discuss the details of her problem with her GP. She was advised to take simple painkillers and to return if the pain didn't settle.

In March, Katie returned to see her GP as the pain persisted and the painkillers did not seem to be doing the trick. Her GP gave her a prescription for stronger painkillers and ordered blood tests and an abdominal ultrasound. The blood tests were taken the following week which was the earliest Katie could see the practice nurse. She received an appointment for an outpatient ultrasound scan which was to take place at her local hospital in two months' time.

By that weekend, despite attempts to manage with the stronger painkillers she had been prescribed, Katie's pain seemed much worse. She called the out-of-hours GP who visited, and advised her to increase the dose of her painkillers.



Katie struggled on. By the following Friday evening, now in April, the pain had become so severe that her husband, Isa, panicked and called an ambulance. Katie was taken to their local Accident and Emergency (A&E) Department.

She described how her abdominal pain had been getting worse over the past three months and that she had experienced nausea and vomiting more recently. Physical examination revealed a significantly enlarged liver. Katie was admitted and blood tests carried out. She was started on intravenous fluids as she had been struggling to hold down liquids and was becoming dehydrated. An urgent chest x-ray and abdominal ultrasound were undertaken while she was in hospital.

Whilst Katie was in hospital, Isa had to take sole care of their children. He began to get a hard time at work as he was frequently late and was finding it hard to concentrate. He was given a number of warnings, but eventually lost his job.

Carer support

The quality of life of a person with colorectal cancer and their family is deeply affected by the diagnosis, as a result of both the physical and psychological impact it has.

Family and friends often act as unpaid carers, providing support which can be physically, emotionally, socially and financially demanding, and often result in the neglect of their own needs.

One in five carers (20%) who are providing 50 hours or more of care each week are receiving no practical support with their caring role. They are twice as likely to be in bad health as those not providing care. A quarter of carers (26%) report that they have been, or are currently, in debt as a result of their caring role.⁵

Recognising the needs of carers is extremely important, both for them and the person for whom they care, and has been shown to have positive effects on quality of life and quality of care.

Information available for carers:

- www.carersuk.org
- www.carers.org
- www.macmillan.org.uk/information-and-support/audience/looking-after-someone-with-cancer.html

Back to Katie's journey

Katie had daily blood tests and a CT scan was performed as an inpatient. An unsuccessful attempt was made to track down Katie's previous notes, so her GP was contacted to provide an update on her history.

Sadly Katie's CT scan revealed that she had developed widespread metastatic disease. Katie's situation was discussed at the hospital cancer multi-disciplinary team (MDT) meeting. It was decided that the metastases were not operable. A liver biopsy would help to guide further management.

Katie was informed of the CT scan results on the ward round. Unfortunately, she was on her own at the time, so she was the one who had to tell Isa later when he came to visit. They were devastated, but decided not to say anything to the children at this stage as they were reacting badly to their mother's absence from home. At this point Katie's GP had not yet been informed.

⁵ UK State of Caring 2016, Carers UK. <https://www.carersuk.org/for-professionals/policy/policy-library/state-of-caring-2016>

Katie underwent a liver biopsy during the second week of her admission. The results were discussed at the MDT meeting the following week. It was decided that Katie should be referred to the oncologists to discuss further treatment options. This could take place as an outpatient.

By now, Katie had been in hospital for three weeks. She was discharged home and it was only when her GP received her discharge summary that she knew of Katie's CT scan and biopsy results, and the plans for the next steps.

The following week, by now early May, Katie met and discussed her treatment options in the oncology clinic. It was decided that she could have palliative chemotherapy. The first treatment was scheduled for later that week. This took place in a nurse-led clinic, where Katie was given both intravenous and oral treatment.

Unfortunately, throughout the Saturday night following her treatment, Katie had increasing abdominal pain. She phoned NHS 111 in the early hours of Sunday morning and was advised that, as she was on chemotherapy, she must attend A&E immediately. She made her way to the A&E department where she spent the entire day waiting for on-call oncology advice. Eventually she was told to increase the dosage for her painkillers and discharged home by taxi. It was after 10pm by the time she got home, the children were in bed and she was exhausted.

The following week, Katie developed constipation, which exacerbated her abdominal pain. She called an out-of-hours GP who offered an emergency face to face appointment. The GP prescribed a laxative to help with the constipation.

Katie coped for a further week and made it to her next chemotherapy session. By now, it was June. She explained to the nurse that she was still having abdominal pain and had started to vomit from time to time. Her chemotherapy was deferred and she was admitted from the clinic to the medical assessment unit (MAU). Katie had bloods taken and started on intravenous fluids to rehydrate her. An ultrasound scan was ordered and the oncologists contacted for advice. It was advised that Katie should be given anti-sickness medication by injection whilst awaiting her results.

Katie remained an inpatient for nine days. During this time she was sent to the oncology clinic from the general medical ward. Given that her pain and vomiting had settled, her oncologist decided that she should go ahead with her second cycle of chemotherapy then. Katie was discharged home later that week with an outpatient CT scan scheduled for 10 days later.

Four days after she got home, Katie again developed abdominal pain. She was unable to open her bowels and started vomiting. She was readmitted to hospital via the A&E department and ended up being admitted to the MAU, where she remained an inpatient for a further five days. She had her scheduled CT scan whilst in hospital. Her scan revealed no response to the chemotherapy and her blood tests showed deteriorating liver function tests; on these grounds the oncologists decided that Katie should stop her chemotherapy as it was clearly not having the desired effect. Katie was referred to the hospital palliative care team on the day of her discharge. They

were able to give advice regarding symptom control and to refer Katie to the community palliative care team, but there wasn't time for them to do much else before she went home.



By July, things were becoming increasingly difficult for Katie and her family at home. Isa was struggling to cope, having lost his job, and with no prospect for another job or other income whilst Katie was so ill. Isa was becoming increasingly concerned about the impact that this was having on their children and decided to contact the school to discuss the situation.

Katie was contacted by the community palliative care team two weeks after she got home. They tried to arrange a visit, but as Katie was still struggling to come to terms with what was happening, she declined the visit. She felt it would be 'giving in' to do so.

When Katie's GP received the discharge letter outlining the outcome of her recent admission, she asked the district nurses to visit Katie and her family at home. During the visit, the district nurse discussed with Katie and Isa her care needs. Katie was still reluctant to let the community palliative care team visit. However, she agreed to have a carer coming in once a day, allowing Isa to take the children to school in the morning. The district nurse put in an application for the care package through continuing healthcare (CHC) but unfortunately Katie's clinical condition deteriorated prior to this care being put in place.

The week after seeing the district nurse, Katie fell at home, whilst trying to get from her bedroom to the toilet. She did not tell her husband about this. She continued to deteriorate. By Sunday of that week, she was vomiting constantly. Isa contacted the out-of-hours service, who asked Katie to attend the out-of-hours GP surgery, as she was reluctant to go to A&E. Isa felt that she was too unwell to travel so he tried to call the community palliative care team for advice instead. Unfortunately, the palliative care team did not provide a weekend service and the automated message advised him to contact the out-of-hours service. By now it was getting late and, not knowing what to do, Katie and Isa decided to hold off till the morning.

First thing on Monday morning, Isa rang Katie's GP to ask for an urgent review, as she had continued to vomit overnight and fallen again. Her GP visited her at home. Katie was clinically dehydrated and still vomiting so her GP felt the situation could not be managed at home. She called for an ambulance to take Katie to A&E.

The doctors at A&E suspected that Katie had developed bowel obstruction. Bloods were taken and intravenous fluids started to rehydrate her. Morphine was given by injection to help with the pain and a nasogastric (NG) tube placed to reduce vomiting. Chest and abdominal x-rays were arranged and Katie was seen by the on-call surgical team. They advised her that she would need nutritional support by means of a feeding tube inserted through the stomach wall. Katie was frightened and refused the procedure. So her NG tube was left in place instead and she was told to avoid taking any food or fluid by mouth to minimise her vomiting.

Bowel obstruction is not uncommon in colorectal cancer. The symptoms of abdominal pain, vomiting and constipation should have rung alarm bells, and Katie could have been advised to seek medical advice more promptly.

Katie remained an inpatient on the medical assessment unit for the rest of the week. During this time, Isa asked to see the medical team. However, this didn't happen as the team was very busy and their availability did not coincide with Isa's visits. The nurses explained to Isa that as Katie was *'terminally ill...nothing can be done.'* Isa was advised to *'take her home to die.'*

On the Friday following her admission, the ward team looking after Katie realised that she had been referred to the hospital palliative care team previously. They contacted the team to inform them that Katie's condition was deteriorating. It was thought that she might benefit from an admission to the local hospice but there was no bed available at that time. Katie told the ward team that she was frightened and overwhelmed by all that had happened over the last seven months. She was told that a referral had been made to the community palliative care team again and was encouraged to see them this time.

By now it was August. On Saturday, as she had stopped vomiting, the weekend on-call team decided that Katie could go home with painkillers and her NG tube in place. The ward nurse left a message asking the district nurses to visit Katie after the weekend. Katie was transferred home late that evening in a non-emergency ambulance.

On Monday morning, Isa decided to contact the community palliative care team himself. The children were becoming distressed and Katie wasn't showing any signs of improvement. They agreed that the team would visit on Wednesday that week.

Having picked up the message from the ward sister, the district nurse visited Katie on Monday afternoon. She noted Katie's marked deterioration and alerted the community palliative care team to expedite their visit; they agreed to come the next morning. The district nurse put in an urgent request for a hospital bed and commode and asked for a care package to be started as a matter of urgency with carers coming three times a day.

Katie was restless that night. She became confused and Isa noticed that her breathing had become a bit erratic.

The palliative care nurse visited Katie the following morning and discussed with her and Isa what they wanted to do next, trying to establish what mattered most to Katie. Katie said that she wanted to go into a hospice as she didn't want to die at home. Katie did not want to discuss Advance Care Plans (ACP) or decisions about Cardiopulmonary Resuscitation (CPR). There were no beds available in a side room in the hospice, which was Katie's preference, so the palliative care nurse put Katie on the waiting list and promised to visit her again the next day. She arranged for night sitters but explained to Katie and Isa that this wouldn't be available until the following evening.

Katie's palliative care nurse contacted her GP and asked her to arrange for a subcutaneous infusion via a syringe driver to be set up as Katie was not reliably holding down her oral medications. She suggested that the current dose of Katie's medications should be adjusted to address her vomiting, pain and anxiety. The district nurse visited Katie that Tuesday afternoon and set up the syringe driver for her.

In the early hours of Wednesday morning, Isa noticed that Katie's breathing pattern had changed markedly and he was unable to wake her. In panic, he called for an ambulance. Katie died shortly before the paramedics arrived. They found Isa in a state of shock and distress. James, their 5 year old son, had woken up and wandered into the bedroom; he began wailing when neither parent responded to him. The paramedics contacted the GP to certify the death.

On Wednesday afternoon, the hospital bed turned up and the hospice called to offer Katie a bed, neither having been informed about Katie's death. This caused Isa further distress and anger. He later put in a complaint about the poor communication that they had experienced in the hospital, stating that they had not been prepared for the imminence of Katie's death, and the confusion in the community the day she died. He was traumatised by Katie's death and struggled to look after their two young children who were extremely bewildered and distressed.

The community palliative care team visited but it was a difficult visit because they hadn't had a chance to develop a relationship with the family. Isa was angry as his impression was that they had failed to do anything for Katie on the one day they met her.

Questions for GPs and commissioners to consider

In the local population, who has overall responsibility for:

- Enabling systematic follow up and direct access following a previous cancer diagnosis?
- Ensuring that people with palliative and life-limiting illness are identified and registered on a supportive care register and that, with their consent, up to date key information about their needs and preferences are accessible to professionals in and out of hours across organisational boundaries?
- Ensuring that multidisciplinary meetings to optimise holistic care and support for the person and those close to them, including any children or vulnerable adults involved, take place on a regular basis?
- Ensuring personalised care for the individual which includes an emphasis on shared decision making about care, treatment and support?
- Involving people with palliative and life-limiting illness in planning improvements in the care provided for people in their situation?
- Seeking local data around patient experience and outcomes, and considering how this valuable data is used to drive improvements?
- Leading the implementation of the Ambitions Framework for Palliative and End of Life Care across the local system, including promoting the 6-point commitment to the individual approaching the end of their lives?

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.

Planning and commissioning palliative and end of life care (and life-limiting illness in children) can be complex and complicated as it involves multiple health and care agencies - statutory and voluntary.

A national Resource Hub (<http://endoflifecareambitions.org.uk/resources/>) holds many helpful tools and guidance developed with and for commissioners that can help. The site also groups new and historic information by 'Ambition' (<http://endoflifecareambitions.org.uk/>) for quick reference for those working across the whole health and care system.

The NHS England website (<https://www.england.nhs.uk/resources/resources-for-ccgs/>) links to some of these documents, and offers a helpful overview on specialist level palliative care, summarised through this [link](#).

Specialist Level Palliative Care: Information for Commissioners

The NHS has responded with energy and enthusiasm since the publication of the Five Year Forward View (2014), with local and national bodies coming together to lay the foundations for its vision for 2020 and start delivering it. For End of Life Care, September 2015 saw the publication of the [Ambitions for Palliative and End of Life Care: A National Framework for Local Action 2015-2020](#), published by 27 national partners, including NHS England.

To support the work being undertaken to realise the Ambitions, NHS England has published [Specialist Level Palliative Care: Information for commissioners](#). The aim of this publication is to help commissioners understand the characteristics and benefits of Specialist Level Palliative Care (SLPC) for adults, and to explain how SLPC fits within the different components of end of life care (EoLC) provision in any care setting.

The guidance encourages commissioners to take a collaborative approach to system leadership, as advocated by the [Five Year Forward View \(FYFV\)](#). It acknowledges that single providers alone will not always be able to meet all the specified criteria, and supports commissioners to take a whole-system, whole-population view.

It is intended to assist commissioning discussions, at a local system level alongside the newly refreshed toolkit [Commissioning person-centred end of life care](#), to inform discussions between commissioners and local SLPC providers. The toolkit provides a valuable supporting resource for the commissioning process and an interactive directory of current guidance.

For more detailed information please visit the blog: [Realising ambitions: improving palliative and end of life care for all in three steps](#).

Public Health England has published a new tool and report [Cost-effective commissioning of end of life care: Understanding the health economics of palliative and end of life care](#) (PHE, 2017). This document includes an explanation on the work and progress of 'currencies for palliative care for both children and adults'. PHE also maintains a set of End of Life Care Profiles as part of its Fingertips series.

Each Clinical Commissioning Group (CCG) has access to NHS RightCare data for its population. Overviews are available in Long Term Condition packs published in December 2016 and Where to Look packs published in January 2017. Other supporting information is available on the [NHS RightCare website](#).

What could have happened differently? Katie's optimal journey



Katie is a 46-year-old retail worker. She lives with her husband, Isa, and two young children, Lucy aged 8 and James aged 5. She has no family living locally. Her elderly widowed mother lives almost three hours' drive away. Isa is originally from Lebanon and his parents still live there.

Katie was diagnosed with colorectal cancer at the age of 45. This was surgically removed, followed by adjuvant chemotherapy. She made a good recovery. One year on from completing her treatment, the family moved to a different county because of Isa's job. Prior to the move, her gastroenterologist carried out a surveillance CT scan. This showed no evidence of disease recurrence.

Katie and her family moved to their new home in January. Once Katie had settled in the children, she registered with her new GP. She had been given detailed notes and copies of her scans, which she handed over to the GP. She referred Katie to a local nurse-led colorectal cancer follow-up clinic and forwarded her notes and scans. Within three months, Katie had been reviewed in the Band 7 nurse-led colorectal cancer clinic and given a range of advice relating to her health and wellbeing. There were clear written and verbal communications between the clinic and the GP.

In January, a year after Katie had moved, she started experiencing abdominal pain. Initially intermittent, this became more persistent and severe over the next four weeks. She had to be off sick from work on and off, which had financial consequences as she did not get sick pay. However, she saw a welfare rights officer at the local Citizen's Advice Bureau, as mentioned by the colorectal clinic, and got some help.

By early February, as the pain had not improved, Katie phoned the nurse-led colorectal clinic directly. She could do that as she had been registered and seen by them already. She discussed the recent onset of her pain and her growing anxieties about it. She was assessed over the phone by a nurse specialist, the locally agreed pathway was triggered, and a CT scan and blood tests were ordered. Katie said that she would prefer to come into the clinic for her results; she did not want to get this over the phone. She was seen in the clinic later that week and examined by the nurse specialist, who then contacted her GP to request a prescription for painkillers and to discuss her care pathway. The GP phoned Katie to offer support and discussed the prescription with her. Blood tests, including tumour markers, were

done on Thursday of that same week, and a CT scan was performed as an outpatient the following day. The nurse specialist spoke to the surgeon and they agreed to add Katie on to the following week's Cancer MDT list, pending the CT scan results.

At the MDT meeting the following Thursday, Katie's scan was reviewed, confirming metastatic disease, and her situation discussed. The hepato-biliary surgeon, who was present at that meeting, agreed that a liver biopsy would be the next step. An appointment was booked for this. The nurse specialist phoned Katie and offered her an appointment at the results clinic, suggesting that she might like to bring somebody along with her.

Katie attended the nurse-led clinic during school hours. Katie's friend accompanied her to the clinic, at her request, as she did not want her husband, Isa, to have to miss work in case this caused problems for him. She was told that there appeared to be secondary cancer in her liver, and that a team of experts (MDT) had reviewed all of her recent test results and agreed that this was probably inoperable. It was explained that this meant that the disease was now incurable. More detailed information was offered and a plan was discussed. The nurse who was breaking the news had previously undergone specialist training in advanced communication, and had the skills and confidence to discuss this in a clear and sensitive manner. Katie was referred to the cancer centre's enhanced supportive care service, where she was seen by a consultant, who reviewed her painkillers and offered further opportunity to discuss the news she had so recently received. At the end of that week, her friend accompanied her to have a liver biopsy to confirm the histology. There was a further MDT discussion the following week, with the results of the liver biopsy, and an oncology appointment was arranged.

The following Tuesday, by now the first week in March, Katie and Isa both attended the results clinic. It was confirmed to them that surgical resection was not an option. The GP was updated about the results and plans for a palliative approach by telephone. The following week, Katie was seen in her GP surgery where a double appointment had been booked to allow opportunity for questions and discussion. This led to a personalised care and support plan being documented using the enhanced section of the summary care records. Katie's current concerns and priorities were noted. Fast track access to her own named GP was established for her if she needed it in the future, and a sick leave certificate for work was arranged.

The GP also added Katie's name to the practice's Quality and Outcomes Framework (QOF) palliative care register to make sure she was kept under review.

Care coordination and Shared electronic records

Identification and registration of people with a 'palliative diagnosis' and who are approaching end of life is crucial to ensure that care is coordinated across the system, and that the choices and advance care plans of each individual are elicited, captured and shared. It also has the potential to improve shared decision making between patient and clinician by triggering these discussions and facilitating documentation of decisions.

'Shared records' is a building block for care being coordinated in the Ambitions Framework. "Care records for all people living with a long term condition must encompass their needs and their preferences even as they approach the end of life. With the person's consent, these records should be shared with all those involved in their care"

<http://endoflifecareambitions.org.uk/>. The ability to share personalised care plans is also part of the Government's six-point commitment to people who are approaching the end of their lives.

There are a number of digital solutions, including electronic palliative care coordination systems and the enhanced Summary Care Record. All must comply with nationally set standards.

Quality and Outcomes Framework (QOF) driven primary care locality registers hold information about all patients in need of palliative care/support irrespective of age. Registered patients should be discussed at least three-monthly at multi-disciplinary case review meetings.

Records that are flagged as 'end of life care' can help to alert urgent and emergency care services to this situation and the existence of further information about the person's needs and preferences, to inform their decisions and actions.

The following week she was seen in the oncology clinic by the consultant and nurse specialist, where the histology was confirmed as a recurrent colorectal adenocarcinoma and chemotherapy was proposed. The following week, Katie's situation was discussed at the primary care MDT meeting so that the team were aware of her situation.

At the beginning of April, Katie went to the nurse led chemotherapy clinic for her first cycle of intravenous and oral chemotherapy. She had a review with the enhanced supportive care service, and the palliative nature of the treatment plan was discussed in addition to opening up a discussion about advance care planning. Finances remained a problem for Katie and Isa but the nurse specialist completed a DS1500 form for her, and pointed her towards the local Maggie's Centre, where she had help to undergo a full finance assessment and ensure that she could access all the benefits for which she was eligible.

DS1500 is a form, completed by a GP, consultant, hospital doctor or nurse specialist, which enables someone who is terminally ill to claim Disability Living Allowance or Attendance Allowance under special rules, i.e. that the patient's death may 'reasonably be expected' within the next 6 months. This means that they will automatically receive the higher rate of Attendance Allowance (for those aged 65 years or over) or the high rate care component of Disability Living Allowance (if under 65 years).

During the second week in April, Katie saw her GP for a further discussion about planning her future care, as she was keen to make things as easy as possible for Isa and the children. Her GP updated the system, with Katie's consent, to share information on the local electronic shared records system for care coordination purposes. Katie was offered, and accepted, a palliative care team referral. Katie's pain had settled so she was able to return to work part-time. A nurse specialist from the community palliative care team visited Katie, and Isa took annual leave to be present for the meeting. Katie was then referred to the family support team at the hospice, who discussed with her and Isa, what was available in terms of social care support.

Mixed funding streams in palliative care

The hospice community is an example of where most services have mixed funding streams from the NHS and charitable donations (to varying proportions) though the services are free at the point of use, regardless of funding source. Some voluntary sector organisations 'pump-prime' posts and support staff, fully or partially, even if they are employed by the NHS or another voluntary sector organisation. Voluntary and advocacy organisations are important and significant contributors to the wider services that support individuals with a palliative or life-limiting diagnosis, in care delivery, support and advocacy. The jointly owned and system-wide approach of the Ambitions Framework encourages and facilitates organisations within localities to work collaboratively, in a way that focuses upon each individual and those who are important to them, regardless of how staff or services are funded.

Isa was encouraged to be open with his employers about the current situation. He found them to be sympathetic and supportive. Katie's situation was discussed again at the locality MDT, and the occupational therapists and district nurses were made aware of her. Katie continued her part-time work, in part because the extra household income was important to their family, but also because, as for many other people, maintaining some 'normal' activities, being around other people and contributing to society is an important part of living with a palliative diagnosis and helped Katie to retain a sense of meaning in life.

At the end of April, Katie returned to the nurse-led oncology clinic, where she had her second cycle of chemotherapy, the electronic shared records system was updated, and the enhanced supportive care team saw her in clinic. A follow up CT scan was carried out during the second week of May. Katie was accompanied by her friend. The family support team also met with Katie and Isa later that week.



With Katie and Isa's permission, the family support team met the children, then contacted the children's school and arranged some psychological support for them. In this locality, art therapy was available, and Katie and Isa liked the sound of that option.

Isa found that he could discuss his own concerns on the phone with the community specialist palliative care nurse, something he found really helpful.

The community palliative care team nurse specialist arranged to see Katie and Isa at home in the third week of May to discuss 'what if' the CT scan results showed that her cancer was not responding to treatment. Katie was introduced to the concept of a personal health budget during that appointment and she liked the idea of being able to pay her neighbour to help with her care if needed.

A personal health budget (PHB) is an amount of money to support a person's identified health and wellbeing needs, planned and agreed between the person and their local NHS team. NHS England has been testing the use of PHBs in end of life care to support increased personalisation and choice. Anybody who is eligible for fast track NHS Continuing Healthcare is legally entitled to request a PHB instead. Early feedback shows that there can be cost savings, in addition to improved patient choice and experience.

A social care referral was requested and agreed. Katie felt more able to discuss advance care planning now. She considered appointing a lasting power of attorney, but wanted to be assured that she could still make her own decisions. It was explained to her that the information and decisions she recorded in the advance care plan would only be used if she did not have capacity to participate in decision-making herself. Whilst she had capacity to make her own decision, her views at that time would always trump whatever she had decided in advance. The information discussed on the advance care plan was communicated to the team via the shared electronic records system by extending the existing personalised care and support plan. She was offered a day hospice placement for complementary therapy, which she planned to attend weekly. She continued to work part time, out of personal choice.

On the Saturday in the third week of May, Katie developed increasing abdominal pain. She phoned NHS 111 and, as her record had been flagged, she was immediately connected to the clinical assessment service. The clinician who took the call sought advice from the palliative care nurse specialist within the integrated urgent care system. Katie's painkillers were increased and she was prescribed a laxative. Her electronic notes were immediately updated.

Katie's scan results were discussed in the colorectal MDT and it was noted that there had been minimal response. The oncologists were willing to try more chemotherapy, though they noted her weight loss and deterioration in her liver function tests. The nurse specialist discussed the results of the CT scan and blood tests with Katie and Isa. Katie was in part prepared for this news, but wanted time to consider her options about further chemotherapy.

Katie's GP rang and offered to visit her at home that week. Together they discussed her views about further chemotherapy, and Katie continued the discussion with the palliative care team as part of the shared decision-making process.

Shared Decision Making is a process in which patients, when they reach a decision crossroads in their health care, can review all the treatment options available to them and participate actively with their healthcare professional in making that decision. Using current clinical information, relevant to their particular condition and situation, about all the options available to them, patients are helped to work through any questions they may have, explore the options available and a treatment route (or not) which best suits their needs and preferences.

By June, Katie was still working part-time. She rang the clinic to say that she had decided that she did not want further chemotherapy. Katie's GP and the palliative care nurse specialist visited her at home. They discussed how her medicines could be optimised and increased the dose of her steroids. Katie's advance care plan was updated. They discussed the need for symptom management support in the future, which included additional medication, possible syringe driver and hospice admission. Katie was able to state that she did not wish to die at home for her children's sake, but she wanted assurance about being pain free. She decided that she did not want to be resuscitated in the event of a cardiopulmonary resuscitation, so a 'Do Not Attempt Cardiopulmonary Resuscitation' (DNACPR) order was completed, the form signed and left with the Katie. The district nurses were alerted through the locality MDT. A referral was made to the occupational therapist. The family support team art therapist was invited to run a session in the school with Katie's children. The information on all these was updated on the electronic system, and the personalised care and support plan was also updated in the enhanced section of the NHS Summary Care Record. Katie continued to attend day therapy for complementary therapy.

Towards the end of that month, Katie was seen by the occupational therapist. No equipment was needed at this stage but advice was given and Katie and Isa were encouraged to contact the team directly should her needs or wishes change.

In the second week of July, Katie's situation was discussed at the locality MDT. The following week, it was noted that she was starting to struggle a bit with personal care. She started to use her personal health budget to pay her friend to help for an hour each morning, which included doing some housework and shopping for meals for the family. The occupational therapist reviewed Katie again and ordered a standard package of equipment and a commode.

During the last week of July, Katie decided that it was time to tell her own mother what was happening. She was able to talk to her palliative care nurse specialist and rehearse what she was going to say. She contacted her mother by telephone with support from Isa. Her mother asked to come and visit.

In August, Isa phoned the family support team, as he was struggling to cope. They asked for increased family support and there was ongoing support from the community palliative care team. The electronic notes were updated.

In September, Katie's pain recurred, despite having been under good control recently. She also started vomiting on the Saturday. She phoned NHS 111 where she was put through to the clinical assessment service immediately, as her record had been flagged. The nurse confirmed her history and arranged for a specialist palliative care physician to visit at home. Bowel obstruction was diagnosed and admission to the hospice was arranged, where she remained for five days until her symptoms settled. She was discharged with a syringe driver containing painkillers and anti-sickness medication. The district nurse visited daily to reload the syringe driver. The locality MDT was updated. The community palliative care team continued to visit to monitor symptoms, and they liaised with the GP and district nurse. The vomiting settled and, ten days after discharge from the hospice, Katie was able to resume oral medication and the syringe driver could be discontinued. However, she was becoming noticeably weaker and the review of her care needs indicated that she now needed twice daily care. She continued to use her personal health budget to control who provided her care.

In October, her pain increased again and she was becoming weaker. The GP and community palliative care nurse specialist made a joint visit and consulted her palliative care consultant by phone for advice. They discussed Katie's rapid deterioration with her. She was psychologically part-prepared for this discussion, and had had time to think about her wishes and discuss them with Isa. Her advance care plan was revisited and updated. She remained adamant that she did not want to die at home because of the children, preferring a side room in the hospice. If this was not available, she said that she would prefer to die in hospital. Her GP suggested that she contacted other family members to update them. She was now having night sitters twice a week. She was managing sips of fluid and was able to enjoy ice lollies, which her children enjoyed too. Isa was able to spend time discussing his fears and what to expect as Katie deteriorated with the palliative care nurse specialist. He was able to discuss help for the children. He contacted his parents, who flew over to provide support. He and Katie arranged for Katie's mum to visit.

Katie had a visit from the spiritual leader for their community. She was very tearful. She did not want to die and was very sad about leaving Isa and her children. The family support worker and a volunteer held a session at home with Katie, Isa and both children where they made memory jars. This was a hugely significant time for Katie and her family.

Support for children whose parents have cancer

A parent being diagnosed with cancer can be a difficult time for children, especially if the prognosis is not good. How this information is communicated will depend on children's age and understanding. It is important to be open and honest with children. There is information on Macmillan cancer's website about talking to children <http://www.macmillan.org.uk/information-and-support/coping/talking-about-cancer/talking-to-children>

There is also bereavement support available for children through Cruse Bereavement Care: <http://www.cruse.org.uk/children> and Child Bereavement UK <http://childbereavementuk.org/>

Maggie's also runs kids and teens days at some of their centres and runs the RipRap website which contains discussion fora, and information about local support. <http://www.riprap.org.uk/>

In addition, many palliative care teams are able to offer bereavement support. *Child Bereavement UK; CRUSE Bereavement Care; RipRap; Maggie's*

Two days later, in the third week of October, Katie deteriorated. She could no longer stand up. She felt frightened and overwhelmed with increasing pain and breathlessness. She began to feel unsafe at home. As a side room in the hospice was not available at the time, Katie asked to be admitted to hospital as she did not want to be at home when she died. Her GP arranged admission via non-emergency ambulance, directly to a general medical ward. The hospital palliative care team had already been alerted about her admission by the community palliative care team. They rapidly reviewed her in hospital to make sure that symptom management plans were in place. Her DNACPR status and advance care plan were known to the ward staff. Unfortunately, no single room was available in the hospital either, but the staff was able to arrange a bed beside the large bay window, which offered Katie some privacy. The ward relaxed their visiting rules to allow Katie's children to spend more time with her. Katie's in-laws arrived from overseas and they helped with the children and were able to offer support. They also helped with Katie's mum, who was elderly and disabled.

In the last week in October, Katie became semi-conscious and it was clear that death was imminent. A side room in the hospice became available and was offered.

The palliative care nurse specialist re-assessed Katie. With Isa's agreement, it was decided that Katie was too ill to be transferred to the hospice, as ambulance transfer would be required. Moreover, Isa and the children had got to know the ward staff well. A side room in the hospital became available and the ward staff moved Katie there to allow greater privacy for the family and freedom of movement. Katie died four days later with Isa at her side. The children had had an opportunity to say goodbye and their grandparents looked after them. The GP and district nurse were informed of Katie's death that day.

The GP phoned Isa the day after Katie's death to see how he was and promised to contact him again in a month's time when his parents and Katie's mum had gone home. Family bereavement support was offered by the specialist palliative care team.

Some hospitals and organisations take part in quality improvement initiatives, including **reviewing the experience of care after death**. Examples of this initiative include bereavement surveys, clinical and psychological supervision and Schwartz Rounds. These focus on continuous improvement cycles and help to ensure that staff are able to reflect and maintain emotional resilience, so that they can continue to provide compassionate care.

What was the cost of Katie's journey to the NHS and the wider social and economic impacts?

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 day⁶. 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 Katie and Isa, and their children.

This scenario is using a fictional patient, Katie. 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 people living with advanced colorectal cancer from a reactive to a proactive approach. The financial costs are indicative and

⁶ £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 (please note that you will need to register to view the link). 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.

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	£1,379	n/a
Acute	£18,467	£4,978	27%
Ambulance service	£536	£0	n/a
Carer	£0	£1,152	n/a
Community teams	£321	£3,732	1164%
Patient	£0	£10	n/a
Primary care	£302	£459	152%
Grand total	£19,626	£11,726	59.7%

Secondary care expenditure in the two scenarios is radically different. Acute costs in the optimal case represent only 27% of the original sub-optimal case (90% reduction in bed days) – equating to a reduction of £13.5k.

Community teams offer a great deal more support and a personal carer is also necessarily higher in the optimal scenario as the optimal case needs to invest in these areas to ensure Katie’s care and support is as good as possible given this difficult case. **NB** This also raises the importance of improved strategic budgeting across the wider health economy.

Not only is Katie’s quality of care so much better in the optimal scenario, irrespective of her place of death, but the cost savings are also significant at £7.9k (40%). (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.)

NB Chemotherapy costs (including drug costs) are the same in both scenarios. This is not a distinguishing variable in this study).

Table 2: Analysis by cost category

Analysis by cost category	Sub-optimal	Optimal	Optimal %
Community care	£125	£2,907	2333%
Elective admissions	£0	£1,000	n/a
Palliative and End of Life	£156	£4,002	2558.1%
Prescribing and Meds Optimisation	£88	£491	559.5%
Primary care management	£117	£384	329.4%
Secondary care management	£17,719	£2,902	16.4%
Self care	£0	£20	n/a
Urgent and emergency care	£1,421	£20	1.4%
Grand total	£19,626	£11,726	59.7%

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 Katie's care was over-reliant on secondary care and was not sufficiently managed in the community or at home. This had a dramatic impact on her, her husband and her young family. Such costs are difficult to quantify, but are very real (the primary point) and the secondary point is that a saving of 40% 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 (email) england.longtermconditions@nhs.net.

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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