

# NHS RightCare scenario: **The variation between standard and optimal pathways**



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

Appendix 1: Summary slide pack

January 2018

# Katie's story

This is the story of Katie's experience of an advanced colorectal cancer care pathway, and how it could be so much better

In this scenario we examine a colorectal cancer care pathway, comparing a sub-optimal but not atypical scenario against an ideal pathway.

**1**

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.

**2**

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

**4**

**3**

This document is intended to help commissioners and providers to understand the implications – both in terms of quality of life and costs – of shifting the care pathway

# Katie and the sub-optimal pathway (1)

- Katie is a 46-year-old retail worker. She lives with her husband, Isa and two young children
- Katie had **surgery and adjuvant chemotherapy** for colorectal cancer when she was 45. Scans clear at one year and the family moved county for husband's job
- Katie developed **right upper quadrant pain** – persisted and became more severe over a month
- Waited **two weeks for GP appointment** – saw GP twice and out of hours GP once over next two weeks
- Pain intensified – **ambulance took her to A&E** where enlarged liver noted
- Admitted to surgical ward – **inpatient for three weeks**. CT scan showed metastatic disease and she had liver biopsy. Katie was told the news on the ward whilst she was on her own, and **had to break the news to Isa herself**
- During this time, Isa took over childcare and was struggling, eventually **getting sacked from his job**
- Katie was referred to oncologist as outpatient: Palliative chemotherapy planned

## Katie and the sub-optimal pathway (2)

- After first cycle of chemotherapy, **struggled with pain and constipation**: Visits to A&E and out of hours GP
- After further chemotherapy and inpatient acute care, follow up CT scan showed **no response to chemotherapy** and her liver function deteriorating: Chemotherapy discontinued
- The district nurse put in an application for the care package through continuing healthcare (CHC) but **Katie's clinical condition deteriorated** prior to this care being put in place
- Further admission to acute setting with bowel obstruction: Isa was told by the nurses that as Katie was '**terminally ill... nothing can be done.**' Isa was told he should 'take her home to die.'
- Katie said she did not want to die at home. Her preference was for a hospice if a side room was available. She did not want to discuss Advance Care Plans or decisions about Cardiopulmonary Resuscitation, or see the community palliative care team – **still struggling with situation**
- Katie **died at home** in the end and the family situation was stressful and distressing in the extreme

# Katie and the sub-optimal pathway

## Slow diagnosis

- Healthcare communication & patient education could be improved

Reactive rather than proactive

## Care integration

- Traditional treatment
- Pathway flow not optimised
- Lack of patient choice

Inappropriate care

## Too late

- Too much reliance on acute care
- Devastating consequences

Insufficient community care support

# Questions for GPs and commissioners

In the local population, who has overall responsibility for:

**1**

Leading the Ambitions Framework and realising the DH Choice Commitment for the local system?

**2**

Ensuring the identification and registration of people with life-limiting illness on a locality register and multi-disciplinary meetings to optimise holistic care?

**3**

Ensuring discussion, shared decision making & documentation of care plans?

**4**

Implementing digital solutions including electronic palliative care coordination systems?

**5**

Ensuring that care is personalised for the individual, including the offer of personal health budgets for people who might benefit from one?

**6**

Ensuring commissioners utilise the suite of contemporary tools and guidance available aimed at reducing unwarranted variation and improving experience

**7**

Involving patients in planning improvements in the care provided for people with advanced colorectal cancer and palliative care needs?

# Katie and the optimal pathway (1)

- Katie and her family moved to their new home in January, having **finished her chemotherapy** for colorectal cancer a year earlier
- When registered, her new **GP promptly referred her** to a local nurse-led colorectal cancer follow-up clinic and forwarded her notes and images
- When she developed persistent abdominal pain a year later, Katie rang the **colorectal nurse specialist** directly – this triggered the locally agreed pathway and a CT scan and bloods were organised
- **MDT discussion** took place following results of CT scan and then of liver biopsy.
- On each occasion, Katie was **offered appointment at results clinic** and opportunity to bring somebody with her
- Katie was given a **double appointment in her GP surgery** to allow time for questions and discussion. A personalised care and support plan was documented using the enhanced section of summary care records

# Katie and the optimal pathway (2)

- Katie was seen by the **enhanced supportive care service** in hospital and palliative nature of the treatment plan and symptom management discussed. Community palliative care team and local hospice family support team supported Katie and her family at home
- Katie's pain settled so she was **able to return to work** part-time, undergoing two cycles of chemotherapy
- Follow up **CT scan results** showed that her cancer was not responding - Katie decided to stop chemotherapy
- Katie was introduced to the concept of a **personal health budget** and later used it to pay her neighbour to help with her care
- Towards the end (two months later than the suboptimal scenario), although Katie's care was not perfect (as a hospice side room was not available when she needed it), she and her family were **well prepared and well supported**
- Katie was able to **die peacefully in hospital** (importantly not at home) and the whole process was well managed, including the provision of family bereavement support



# Katie and the optimal pathway

## Right first time focus

- Proactive education and communication
- Third sector engagement

Proactive  
and great  
communication

## Efficient processes

- Strong co-ordination between primary and secondary care
- MDT working
- Patient choice
- Shared decision making

Great holistic  
care

## Appropriate

- Support mechanisms in place
- Trusted system
- Happier and healthier experience

Great  
community  
care

# Caregiver 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.

Caregivers often provide uncompensated care, which is physically, emotionally, socially and financially demanding and results in the neglect of their own needs.

It has been demonstrated that the psychological health of caregivers is often negatively affected, with reports of increased prevalence of both anxiety and depression.

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](http://www.carersuk.org)
- [www.macmillan.org.uk/information-and-support/audience/looking-after-someone-with-cancer.html](http://www.macmillan.org.uk/information-and-support/audience/looking-after-someone-with-cancer.html)

# Financial information

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%
<b>Grand total</b>	<b>£19,626</b>	<b>£11,726</b>	<b>59.7%</b>

- 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 very difficult case. NB This also raises the importance of improved strategic budgeting across the wider health economy.

# Financial information

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%
<b>Grand total</b>	<b>£19,626</b>	<b>£11,726</b>	<b>59.7%</b>

Not only is Katie's quality of care so much better in the optimal scenario, but the cost savings are also significant at £7.9k (40%). **NB** 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. Plus chemotherapy costs (including drug costs) are the same in both scenarios. This is not a distinguishing variable in this study.

# Financial information



# Further information

For more information about Katie's journey, NHS RightCare or long term conditions you can:

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