Quality and Productivity: Proven Case Study

Stratified cancer pathways:
redesigning services for those living with or beyond cancer
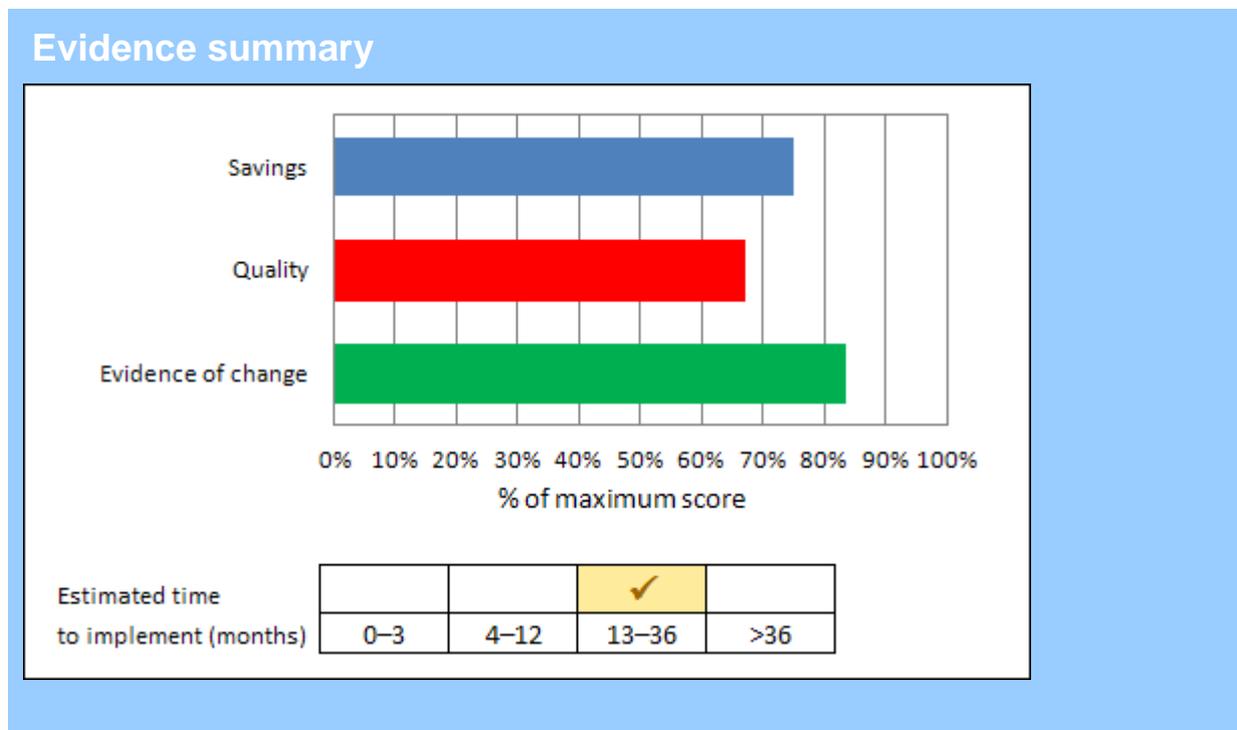
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Sharing QIPP practice: What are 'Proven Quality and Productivity' case studies?

The QIPP collection provides users with practical case studies that address the quality and productivity challenge in health and social care. All examples submitted are evaluated by NICE. This evaluation is based on the degree to which the initiative meets the QIPP criteria: savings, quality, evidence and implementability. The first three criteria are given a score which are then combined to give an overall score. The overall score is used to identify case studies that are designated as 'recommended' on NHS Evidence. The assessment of the degree to which this particular case study meets the criteria is represented in the summary graphic below.

Proven quality and productivity examples are case studies that show evidence of implementation and can demonstrate efficiency savings and improvements in quality.

Evidence summary

This document can be found online at:
http://www.evidence.nhs.uk/qipp

Details of initiative

Purpose	To improve aftercare services for those living with or beyond cancer, by matching the level of support to individual patients' needs and preferences.
Description (including scope)	This initiative focuses on redesigning follow-up pathways for people with breast, colorectal and prostate cancer. This includes the development of supported self-management pathways for those who have been treated with curative intent, whose treatment has been completed and in whom the acute effects of treatment have subsided.

Supporting patients to self-manage their own health and wellbeing can meet unmet needs and reduce demand on services, where appropriate. This can be done in the following ways:

- Stratifying patients to an appropriate pathway based on clinical and individual needs.
- Organising needs assessments and care plan reviews at key points in the pathway – for example, at the end of treatment or when problems arise.
- Providing a treatment summary that is a succinct record of diagnosis, treatments, potential side effects of treatment, contact details and other key information.
- Improving access to clinical and non-clinical support services.
- Offering advice on health and wellbeing, and signposting to local support services – for example, walking groups, support groups, stop smoking groups, etc.
- Ensuring that, for those suitable for a self-management pathway at the end of treatment, surveillance tests will continue to be scheduled and monitored by the specialist team and, according to NICE standards, remote monitoring systems continue to be used with results sent by post without the need for face-to-face follow-up appointments.

'Stratified' means that the clinical team and the person living with cancer make a decision about the best form of aftercare based on their knowledge of the disease (the type of cancer and what is likely to happen next), the treatment (what the effects or consequences may be both in the short and long term) and the person (whether they have other illnesses or conditions, and how much support they feel they need). The 3 forms of aftercare are:

- Supported self-management – when patients are given information about self-management support programmes or other types of available support, clinical signs and symptoms to look out for and whom to contact if they notice any, scheduled tests they may need (such as annual

mammograms), and how to contact relevant professionals if they have any concerns.

- Shared care – when patients continue to have face-to-face, phone or email contact with professionals as part of continuing follow-up.
- Complex case management – when patients are given intensive support to manage their cancer and/or other conditions.

The resulting release of resources allows those with complex needs to have more contact with their specialist team and those experiencing problems to re-access help more quickly.

This change in approach has been broadly welcomed by clinicians and patient groups alike who are enthusiastic in taking the initiative forward and developing similar pathways for other types of cancer.

Topic	Long-term conditions, productive care, right care for patients – shared decision-making, and safe care.
Other information	There is growing demand for cancer aftercare services as a result of increasing incidence and better survival rates. Together with feedback from patients that they continue to have many unmet needs at the end of treatment, this prompted a radical review of the way aftercare services were delivered and how quality and productivity could be improved.
	Routine 1 to 5-year follow-up of cancer survivors within the NHS costs in the region of £250 million per year out of a £6 billion per year budget. This is currently delivered through a mainly medical model using consultant outpatient appointments and associated diagnostic tests. The case for routine follow-up as an effective method to pick up early recurrence or disease progression is not strong.
	For lower-risk patients, a stronger emphasis on holistic care planning to sustain recovery, manage the consequences of treatment and reduce the risk of recurrence should be affordable without compromising early recurrence detection; indeed it may even improve this.

Savings delivered

Amount of savings delivered	The estimated net saving in England is £90 million over 5 years, equivalent to an annual saving of £44,592 per 100,000 population. These savings are based on the data in the table overleaf.

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Tumour group	Total population (5-year survival)	% patients eligible for supported self-management	Appointments saved per patient over 5 years	Savings per patient over 5 years
Breast	200,000	77%	4	£336
Colorectal	138,418	45%	6	£432
Prostate	85,624	36%	4	£384

Additional costs per patient	
Remote monitoring	£161
Self-management programme	£45
End of treatment review, including care planning	£72

Testing of stratified pathways found that breast, colorectal and prostate cancer patients were suitable for supported self-management, but that lung cancer patients were generally not suitable, or only for short periods. This is because 70% of lung cancer patients present with advanced or incurable disease that is highly symptomatic, and the vast majority require some form of professional management. Therefore they have not been included in the table above. Lung cancer patients can still be stratified into shared care or complex case management, but there are fewer savings associated with this.

Please note that the savings above will be reduced by subsequent re-investment of resources to support those patients with more complex needs, or to absorb future demand. Data are not yet available on how this was done at the test sites.

Type of saving	A mixture of cash savings and improved productivity. Productivity is improved through the release of outpatient resources. The cash saving is from the commissioner's point of view, due to the reduced number of appointments.
Any costs required to achieve the savings	Change can be achieved with minimal additional resources if adequate IT systems are in place to schedule and monitor tests, issue standard results letters, trigger defaults in the case of missed appointments and record outcomes. If these systems are not in place, investment will be required, depending on the shortcomings identified. Costs associated with setting up a remote monitoring system will differ significantly between organisations. Trusts should consider and cost the options carefully at the start of their change programme.

The on-going costs of running the self-management programme are included in the analysis of savings delivered. |
| **Programme budget** | Cancers and tumours. |
| **Supporting evidence** | Testing of stratified pathways at 14 sites confirmed the percentage of |

patients suitable for supported self-management and the resulting release of outpatient resources.

Quality outcomes delivered

Impact on quality of care or population health

Benefits of the self-management pathway include the following.

1. Patients with complex needs have more contact with their specialist team.

2. Release of outpatient resources improves access times for new cancer referrals and enables rapid access back into the system for existing patients with problems.

3. Providing time for a needs assessment and care planning discussion with patients at key points in the pathway helps to detect and manage cancer-related psychosocial morbidity that might not be identified in a typical outpatient appointment.

4. Continuity of care is enhanced because the clinician monitoring surveillance tests remotely is more likely to be a person who is familiar with a patient's history.

5. Further development of patients' knowledge and understanding of their condition and situation, through needs assessments and information events, should enable earlier self-detection of recurrence. Demand for helplines and unplanned admissions decreases. Patient confidence to self-manage their health and wellbeing increases.

6. An open access approach encourages patients to contact a service earlier with any worries or concerns. In a survey to identify the personal cost of follow-up to patients, 24% of participants reported having new symptoms that they did not report until their next outpatient appointment.

7. Dedicated helplines run by suitably trained staff offer more responsive access to specialist teams if problems occur.

8. A standardised monitoring system for surveillance tests that meets NICE quality standards and is tailored to individual tolerances provides a safer system to monitor patients in remission and reduce the numbers 'lost to follow-up'.

9. Treatment summaries for patients provide a succinct record of diagnosis and treatment, and prompt primary care teams to undertake cancer care reviews and alert patients to potential effects that may occur many years after treatment. A baseline evaluation of clinic letters found there to be insufficient information for GPs to enable patients to be managed in primary care leading to a higher likelihood of people being referred back to specialist teams if problems arise.

10. Discussion of healthy lifestyle advice is a key component of any needs assessment and care planning. For some patients,

	lifestyle changes will reduce the risk of disease recurrence, lower the impact of comorbid disease and improve quality of life.
	These benefits have been demonstrated in the short term but, given the long-term nature of cancer, the sustainability of the benefits of the initiative has not yet been proven.
Impact on patients, people who use services and/or population safety	Safety is improved to a slight extent as better patient knowledge and understanding results in more rapid identification of problems in self-management, and more resources are available to enable new patients to be seen sooner.
Impact on patients, people who use services, carers, public and/or population experience	There are significant improvements to the patient experience because they are given support to manage the condition themselves and do not have to attend unnecessary appointments to obtain negative test results.
Supporting evidence	A survey commissioned by NHS Improvement provides evidence that the patient experience is improved, but conclusive data on aspects of quality and safety are not yet available, given the long-term nature of cancer.
	An evaluation of treatment summaries at the test sites was undertaken by Tribal in 2010. The treatment summary was positively received in both primary and secondary care. Eighty per cent of GPs found them 'useful' or 'very useful'. The majority of hospital clinicians recognised the value of recording what could be months of treatment and holistic care into a concise summary.

Evidence of effectiveness

Evidence base for case study	The National Cancer Survivorship Initiative Vision Document (Department of Health 2012) sets changes required in the care of people living with and beyond cancer, including a greater focus on life after treatment, self-management and tailored support. This initiative helps to address those goals. 'Evidence to inform the Cancer Reform Strategy: the clinical effectiveness and cost-effectiveness of follow-up services after treatment for cancer.' (Centre for Reviews and Dissemination 2007) examined the clinical and cost effectiveness of cancer follow-up services.
Evidence of deliverables from implementation	Stratification was tested on the breast, prostate and colorectal pathways during 2011 and 2012. The results confirmed the proportion of patients eligible for supported management and hence the amount of resources that would be released to deal with more complex cases or to absorb future demand increases. Please see 'Degree to which the actual benefits matched

assumptions' below.

Where implemented	Draft stratified pathways were tested in 14 tumour specific teams during 2011 and 2012 in the following organisations:

- Brighton and Sussex University Hospitals NHS Trust
- North Bristol NHS Trust
- Guy's and St Thomas NHS Foundation Trust
- The Hillingdon Hospital NHS Trust
- Hull and East Yorkshire Hospitals NHS Trust
- Ipswich Hospital NHS Trust
- Luton and Dunstable NHS Foundation Trust
- Salford Royal NHS Foundation Trust

Degree to which the actual benefits matched assumptions

Assumptions made on the proportion of patients that would be suitable for self-management were largely accurate, with the exception of lung cancer patients, as shown below:

Tumour	Assumed % suitable for self-management	% suitable based on testing
Lung	15%	0%
Breast	70%	75–80%
Colorectal	40%	46%
Prostate	40%	27–44%

Unplanned admissions for people with a known diagnosis of cancer following completion of treatment were predicted to fall by 10%. Testing identified no significant change within breast, colorectal or prostate cancer. However, in lung cancer both teams identified a reduction in unplanned admissions of between 6% and 8%. In one of these sites, length of stay also reduced from 11 to 9 days compared with the local control site where length of stay and unplanned admissions had increased. The provision of a more proactive approach to symptom management and an outpatient service more flexible to patients' needs seems to have created this impact.

If initiative has been replicated how frequently/widely has it been replicated

The stratified cancer pathways approach has been widely tested and is now being implemented at the following additional organisations:

- Dorset County Hospital NHS Foundation Trust
- Imperial College Health Care NHS Trust
- North West London NHS Trust
- The Royal Marsden
- Royal United Hospital NHS Trust
- St Georges Hospital NHS Trust
- West Hertfordshire Hospital NHS Trust

Supporting evidence

Evidence of effectiveness comes from testing the initiative at the 14 sites identified above. Data are not yet available for patient

outcomes, but qualitative evidence indicates a positive patient experience.

Details of implementation

Implementation details

The initiative was tested for 4 pathways: breast, colorectal, lung and prostate cancer, across 14 sites. Some sites tested more than 1 pathway.

For each pathway
With the support of NHS Improvement, current pathways were mapped to identify the different routes patients may take from diagnosis and treatment decisions to specialist support and aftercare. Baseline data were gathered around referral numbers and patient flow through the pathways.

A patient experience survey was undertaken to identify the main issues for patients, in order to improve the information and support offered to different groups. For breast cancer patients the main issues identified were fatigue, fear of recurrence and recognising signs and symptoms of recurrence; for colorectal cancer they were bowel and urinary problems, erectile dysfunction and sexual issues, and signs and symptoms of recurrence; for lung cancer they were weight loss, fatigue and breathlessness, and financial problems; and for prostate cancer they were the signs and symptoms of recurrence, erectile dysfunction and continence management.

Patient education events or wellbeing clinics were established for patients in all pathways. The format varied according to local needs and resources, but all aimed to provide patients with more information based on the issues previously identified.

Charities specific to the tumour groups were engaged from the start of the programme and there are examples of joint initiatives arising from this work – for example, the Beating Bowel Cancer: Moving On survivorship booklet and input to the video clips on FAQs on their website. Leading charity representatives attended workshop events to work with and advise teams.

For all pathways holistic needs assessments were implemented. These built on previous assessments and focused on a patient's medical, psychological, social, spiritual, financial and information needs following treatment.

Patients and clinicians then jointly developed care plans and treatment summaries based on the patients' identified needs. This informed the process of stratification, in which patients were stratified into supported self-management, shared care or complex case management, corresponding to low, medium and high levels of specialist support.

The stratification decision depended on a number of elements

including:

- level of risk associated with cancer type
- short- and long-term effects of treatment
- other comorbidities
- patient's ability to manage
- level of professional involvement required.

Patients can move between the different levels of care as their needs and the degree of dependency change.

The test work established that for lung cancer all patients required some form of professional-led care but several could self-manage for periods of the pathway and could be supported by telephone assessment during this period.

The treatment summary provides a useful tool for patients and GPs to understand the disease stage, what treatment the patient received, the management plan and what to look out for in the future.

At each test site
Following recruitment, each test site participated in briefings and launch workshop events run by NHS Improvement, explaining the aims and objectives of the initiative and clarifying the expectations and deliverables over the course of the project. Risks were identified at this stage and advice was provided.

Each team established a project steering group with stakeholder representation to agree plans. The most successful teams featured strong clinical champions supported by enthusiastic nurses and an executive team.

Pathway mapping and baseline data collection were scheduled and facilitated by NHS Improvement at each test site. Data on the number of new referrals per annum, outpatient activity and unplanned admissions were confirmed and trajectories identified over the course of the test period. Progress and data were reported monthly to NHS Improvement.

Several national workshop events were held for each phase of the programme. These sought to share learning, solve problems and enable networking with colleagues.

Patient involvement groups were held locally as well as by the national team. Patients were encouraged to attend national workshop events with their local teams.

Remote monitoring
Remote monitoring means the scheduling and monitoring of ongoing surveillance tests without the need for a face-to-face outpatient appointment. Remote monitoring is a critical component of the self-managed pathway. Suitable patients are low risk, stable patients in terms of their disease, their treatment and its effects, and their psychological or social support needs.

The system must provide a robust method of tracking patients and ensuring that patients are tested as per the local follow-up schedule and that defaults in attendance are managed appropriately. The systems draw data from local cancer information systems, pathology and other diagnostic systems to enable the healthcare professional (usually a clinical nurse specialist working under protocol) to review the test results, take the appropriate action and arrange the next test. The monitoring solution can be individualised to include details of staging, diagnosis and treatment, and upper limits that would trigger recall. The systems hold a range of standard letters for informing patients and their GPs of the results, with reinforcement of information on signs and symptoms to look out for and key contact details for worries or concerns. Abnormal or equivocal results usually trigger review at the next multidisciplinary team meeting when a management plan is agreed.

The 3 general choices of system will be to use existing IT system functionality, develop a bespoke solution or select an externally developed solution. An example of the latter is the IT solution sponsored by NHS Improvement that can be interfaced with cancer and other diagnostic systems in any NHS organisation. This is available to trusts via North Bristol NHS Trust who host, support and develop the system. It is funded through a service-level agreement (£5000 per annum) covering support and maintenance with each participating organisation. A similar solution is available via other system suppliers such as Chameleon Information Management Services who own the InfoFlex system. This is available free to InfoFlex users although some trusts have required consultancy support from InfoFlex for set-up and interface work. The purchase of additional user licences may also be required.

All solutions require IT and project management resources for set-up to ensure that both the technical and operational arrangements are fit for purpose. Ongoing costs associated with managing patients remotely in place of face-to-face follow-up are negotiated locally with commissioners. A return on investment based on released outpatient resources would normally be expected within 1 to 2 years, but this would depend on the system used and the scope of patients selected for the pathway.

Time taken to implement	The initiative involves significant changes to multiple care pathways and may take between 1 and 3 years to plan, test and implement the changes.
Ease of implementation	Implementing stratified pathways is a large-scale change involving multiple NHS organisations across a health economy.
Level of support and commitment	The initiative is likely to achieve good buy-in from key influencers.

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Barriers to implementation	The initiative rebalances demand in the pathways away from follow-up appointments and toward assessments and planning. This requires moving resources or changing the focus of some roles.
Risks	In any large-scale reorganisation there is the risk that patients can get 'lost' in the system, that care is not joined up effectively, and that demand may exceed capacity at certain stages. Careful mapping of existing pathways including observation of numbers and flow of patients at different points and ensuring all areas affected are represented in planning can mitigate these risks. It is vital that those who maintain contact with patients throughout the pathway such as clinical nurse specialists are engaged as stakeholders. Trialling stratification in 1 or 2 areas initially helps to minimise risk and allows further development before wider roll-out. Talking to other organisations that have implemented similar initiatives is very helpful.
	There is the risk that IT systems will not be able to cope with increased demand or will fail to function as expected. To minimise these risks, it is essential that systems are thoroughly tested before they go live, even in smaller trials.
Supporting evidence	Evidence of implementation comes from testing at the 14 sites identified in the section 'Where implemented'.

Further evidence

Dependencies	Systems need to be in place to allow the safe remote monitoring of patients. This means the ability to book, monitor and record the results of tests, and issue results by post where appropriate. If this capability does not already exist, it will need to be developed or bought in.
	Some scheduling and monitoring systems are available within existing IT systems; others can be developed in house; some healthcare professionals may opt to use the system developed by NHS Improvement for this purpose. All solutions should consider server and licence costs, interface costs, IT time (10–15 days), team, maintenance and development costs.

Contacts and resources

Contacts and resources	Centre for Reviews and Dissemination (2007) Evidence to inform the Cancer Reform Strategy: The clinical effectiveness and cost-effectiveness of follow-up services after treatment for cancer.
	Department of Health (2012) National Cancer Survivorship

This document can be found online at:
http://www.evidence.nhs.uk/qipp

Initiative Vision Document.

NHS Improvement (2012) Stratified pathways of care... from concept to innovation.

NHS Improvement (2012) Children and young people cancer survivorship initiative: Improving quality and the patient experience.

If you require any further information please email: qipp@nice.org.uk and we will forward your enquiry and contact details to the provider of this case study. Please quote QIPP reference 12/0020 in your email.

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