CANCER

DIAGNOSTICS

HEART

LUNG

STROKE

# Innovation to implementation:
Stratified pathways of care for people living with or beyond cancer

# A 'how to guide'

**Innovation to implementation:** Stratifed pathways of care for people living with or beyond cancer
A 'how to guide'

# Contents

# Foreword

**Over the past few years NHS improvement, as a partner in the National Cancer Survivorship Initiative, has led the testing and prototyping of risk stratified pathways of care for those living with and beyond cancer to improve the quality and effectiveness of services for patients.**

I am delighted to support this document that provides local teams with a very practical 'how to' guide , based on the experience of the test sites, who with support from NHS Improvement, have developed and implemented the new model of care within their services.

Within the model of care, the implementation of stratified pathways tailored to individual needs offers huge benefits to patients and the service. It will improve the quality of life for people following treatment for cancer through addressing their needs, and help them to return to living their lives as positively, healthily and quickly as possible.

We are delighted that this work has now been recognised by professional associations and key charities.  There is great enthusiasm to change the way we manage follow-up, and this publication should provide the flexibility to guide you to implement this stratified model of care for those living with and beyond cancer.

**Gilmour Frew,** Director, NHS Improvement

**National Cancer Survivorship Initiative (NCSI):**

WE ARE MACMILLAN. CANCER SUPPORT

DH Department of Health

NHS Improvement

# Consensus statement

The National Cancer Survivorship Initiative (NCSI) through NHS Improvement has supported:

- **The implementation of Breast, Colorectal and Prostate stratified pathways in sites across the NHS**
- **The implementation of stratified pathways following treatment benefits patients, carers and the NHS.**

Patients have their needs met in a timely manner, are better informed about their disease, treatment and any longer term effects. With the focus on health and wellbeing, patients are supported to take back control of their lives as soon as they are able.

Reduction in unnecessary outpatient appointments for those who no longer require face to face appointment s releases capacity for those with complex needs and helps improve access for new referrals.

We believe that a supported self-management pathway with remote surveillance and with guaranteed re-access should now be offered as one standard practice in these tumour groups following treatment for cancer.

RCR The Royal College of Radiologists

Dr Jane Barrett
President

Royal College of Nursing

Dr Peter Carter
Chief Executive and
General Secretary

ABS ASSOCIATION OF BREAST SURGERY

Mr Dick Rainsbury
President

breast cancer care

Diana Jupp
Director of Services

Royal College of Physicians

Sir Richard Thompson
President

PROSTATE CANCER UK

Owen Sharp
Chief Executive

The Association of Coloproctology of Great Britain and Ireland

Mr Graham Williams
President

beating bowel cancer

Mark Flannagan
Chief Executive

# Introduction

NHS improvement has been working as part of the National Cancer Survivorship Initiative (NCSI) to improve the quality and effectiveness of care and support to those living with and beyond cancer. The NCSI was set up as a recommendation arising from 'The Cancer Reform Strategy (2007)', with more recent reference to the work in the 'Improving Outcomes: a Strategy for Cancer' (2011). The NCSI Vision was produced in 2010 and was recently updated to take work forward until 2015.

NHS Improvement has led the testing and development of a stratified model of care and support that accounts for holistic patient needs in addition to the needs of the disease or treatment received. The tumour pathways developed are for breast, colorectal, prostate and lung cancer. The lung cancer tumour pathway was pilot tested in two sites and was not taken forward to prototyping. The NHS Improvement team supporting this programme of work includes an improvement director, two national improvement leads and five national clinical advisors.

The generic pathway below identifies the key pathway components that need to be considered in commissioning and delivering care and support to cancer patients.
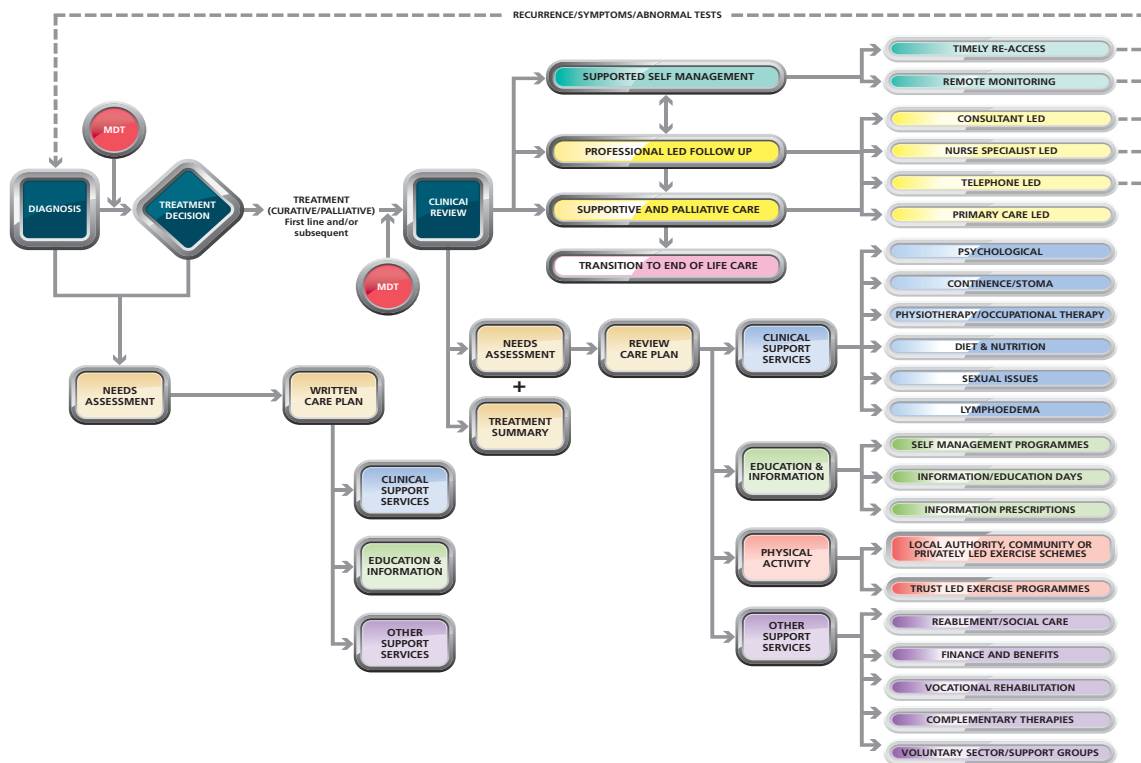
An interactive version of this pathway is available on the NHS Improvement website www.improvement.nhs.uk/cancer/survivorship/adult_survivorship_pathway and contains examples and content in the form of documents, video or audio clips.

During the testing of stratified pathways, NHS Improvement has supported, coached and facilitated pathway development and implementation in 14 test communities in England. The communities are based around cancer clinical teams where much of the learning has been obtained. Macmillan Cancer Support and other tumour specific charities including Beating Bowel Cancer, Prostate Cancer UK and Breast Cancer Care, have supported the sites in developing and implementing the new ways of working.

Since 2008 NHS Improvement has done a lot of work to better understand the needs of cancer patients and to improve their experience and outcomes of care. Their views of how the service can be improved have been at the heart of this improvement programme. The learning and evaluation of this programme NHS Improvement has produced several publications[2,3,4,5,6] outlining its work. This includes baseline evaluations[7,8] to understand the type of services patients need and the ability of the service to meet their needs.

1 Hull and East Yorkshire Hospitals NHS Trust
2 Salford Royal NHS Foundation Trust
3 Ipswich Hospital NHS Trust
4 Luton and Dunstable Hospital NHS Foundation Trust
5 North Bristol Hospital NHS Trust
6 Guy's & St Thomas' NHS Foundation Trust
7 Hillingdon Hospital NHS Trust
8 Brighton and Sussex University Hospitals NHS Trust
9 North West London NHS Trust
10 West Hertfordshire Hospital NHS Trust
11 The Royal Marsden NHS Foundation Trust
12 St George's Hospital NHS Trust
13 Royal United Hospital NHS Trust
14 Dorset County Hospital NHS Trust

**Using this guide**
The guide is intended as a flexible resource for you to refer to as you implement a package of care for those living with and beyond cancer. Documents, publications other items can be accessed via the links at the bottom of each page or on the USB stick accompanying hard copies of this guide. Teams can work together to assess the current position then select the order to implement the principles based on the needs of your community and the resources available. This is explained in greater detail in the section 'Getting started' on page 7 .

Although the sections on the principles are presented separately we recommend that you consider the whole programme timetable to ensure that all the elements are in place. Experience from testing has found that some components take much longer to deliver than others.

---
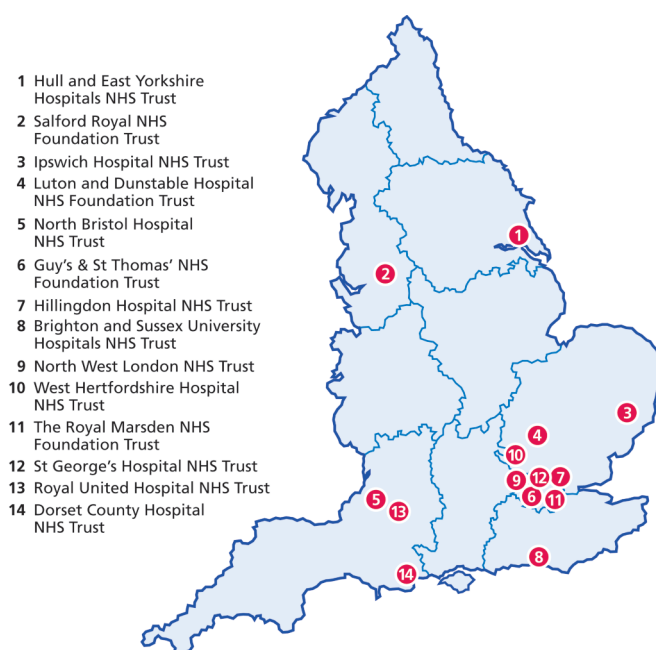
[1]Stratified pathway diagrams, Generic, breast, prostate, colorectal
[2]Rapid review of current service provision following cancer treatment. NHS Improvement (Sept 2010)
[3]Living with and beyond cancer: the improvement story so far (July 2010)
[4]Effective follow up: testing risk stratified pathways of care (May 2011)
[5]Sharing the learning through posters: The work of NCSI test sites ( March 2012)
[6]Stratified pathways of care: from concept to innovation. (May 2012)
[7]National Cancer Survivorship Initiative and Ipsos MORI Social Research Institute. Evaluation of Adult After - Care Cancer Service – Wave 1 Report October 2011
[8]National Cancer Survivorship Initiative and Ipsos MORI Social Research Institute. Evaluation of adult aftercare services. A qualitative analysis of care coordination (June 2012)

The following checklist will help you determine where you are with the introduction of stratified pathways and the components within the guide.

| Outcome | Implementation | | | Guide reference |
|---|---|---|---|---|
| | Yes | In progress | No | Go to page |
| Patients are stratified to the appropriate follow up pathway based on clinical and individual needs. | | | | |
| Assessment and care planning discussions are held at diagnosis, end of treatment and other key points in the pathway and all patients have a written care plan. | | | | |
| Treatment summaries are completed at the end of treatment and a copy provided to the patient and GP. | | | | |
| Information events and support programmes are available to all patients who need them. | | | | |
| Clinicians are aware of availability of clinical support services and how to refer e.g. psychological support. | | | | |
| Clinicians are aware of availability of non-clinical support services and how to refer e.g. physical activity schemes, benefits advice. | | | | |
| An IT system enables the specialist to schedule and monitor surveillance tests. | | | | |
| Systems to re-access the service are clear to patients, staff and commissioners and response to patients is timely. | | | | |

Once you have completed the above self-assessment you should read the section 'Getting started' on page 7 before you move onto implementing individual principles.

# → Getting started

# Getting started

This chapter provides information on how to get started with implementation and project management arrangements, together with advice on identifying your baseline position and on-going measures. In addition there is information on service improvement techniques that may be useful.

## Deciding the specialty focus

The Trust decision on which specialty is selected will depend on a variety of key factors including:

- senior medical and nurse specialist support and enthusiasm;
- executive and directorate management support;
- history of successful improvement work within the specialty;
- expected impact on quality of service for patients; and
- expected impact on efficiency and resources.

Other factors to consider are:

- IT support – access to IT time and skills is critical to the establishment of the self-managed pathway. Consider your Trust's IT strategy and where the development or introduction of a remote monitoring solution might fit into the annual programme; and
- project management support – progress is likely to be rapid and more successful if there is dedicated project management support.

Whilst we have divided the pathway into principles there are some elements that go hand in hand. For instance if you are planning to introduce a self-management pathway you need at a minimum to ensure that:

- you have an IT system that can schedule and record surveillance tests and functions independently of outpatient visits;
- you have an agreed protocol for managing patients on a self- managed pathway;
- patients have had their needs managed and they are informed and knowledgeable about their disease and follow up plan; and
- a system exists for re-accessing the service if required.

For those starting from scratch the following provides an indicative guide as to the order in which the principles should be addressed. The order reflects the time, importance and complexity of implementation.

| Component | Rationale |
|---|---|
| **Remote monitoring** | Without a robust safe system in place you should not transfer patients to a supported self- managed pathway. |
| **Needs Assessment and Care Planning** | Clinicians are more likely to refer to self-management once a safe system is in place. Setting up a system takes time and resource and needs to be started early. |
| **Stratification Criteria and Process** | May require approval for additional clinic time and review of job plans. |
| **Understanding** | Reaching consensus on how the system will work operationally may take time to agree between clinician's, managers and commissioners. |
| **Treatment summaries** | Completion can take longer than the traditional clinic letter. |
| **Information and education** | Information days and self-management programmes will take time to set up and deliver. |
| **Agree Systems to Re-access the Service** | Reaching agreement to ensure the process supports re-access for patients to the service when problems arise. |

### Planning for change

For a project to be successful it is important that time is spent on the preparatory work. This will be beneficial later on in the project and avoid duplication and surprises.

Preparatory work should include:

**1. getting the right team together;**
**2. obtaining executive and senior medical buy-in;**
**3. understanding the current pathway;**
**4. understanding what patients need;**
**5. identifying baseline data and on-going measures;**
**6. developing a programme plan; and**
**7. having a good communication plan.**

### 1. The right team

It is important to identify people with the right skills, abilities and enthusiasm to support implementation. The scope of the work will determine the management arrangements. Team members should be able to take decisions regarding the changes and improvements in their respective areas and be able to contribute ideas and information to the process.

Most organisations have an existing cancer programme board, improvement programme or similar steering group to which progress needs to be reported. This high level group should have a role in mandating improvement work and providing the resources required to deliver. The group should guide and monitor progress, unblock issues and provide strategic advice and support. It is useful if the group includes executive and senior clinical, commissioning representatives, patient representatives and other key stakeholders.

Assuming this high level steering group exists, a smaller implementation team will be required.

Suggested minimum members are:

- **specialty medical lead and clinical champion;**
- **oncology lead;**
- **specialty clinical nurse specialist;**
- **directorate manager lead; and**
- **implementation lead (separate role or designated to one of the above) with protected time.**

You may want to establish a separate sub group to progress the remote monitoring solution and where other individuals such as those from IT may need to be involved. Other sub groups may also be required to establish information days, assessment and care planning etc.

**Stakeholders**
Key stakeholders from across the pathway will be expected to provide managerial or strategic support but may not be a member of the implementation team. At the start of your work identify who your stakeholders are and decide the level of commitment needed for successful implementation of the project. The sample commitment scale below may be useful.

| | Stakeholder (people or groups) | | |
|---|---|---|---|
| **Level of commitment** | **A** | **B** | **C** |
| **Enthusiastic** Will work hard to make it happen | X | X | |
| **Helpful** Will lend appropriate support | | | X |
| **Hesitant** Holds some reservation: won't volunteer | | O | |
| **Indifferent** Won't help: won't hurt | | | O |
| **Uncooperative** Will have to be prodded | | | |
| **Opposed** Will openly state and act on opposition | O | | |
| **Hostile** Will block at all costs | | | |

**O – Indicates current level of commitment**
**X – Indicates level of commitment you require to deliver project**

**2. Senior level buy-in and support**

An executive sponsor should be sought to oversee the progress and support the team and help unblock issues as they arise. This would normally be an executive board member. They will help promote the work and ensure alignment with corporate objectives and improvement strategies.

This may involve presenting the work and the proposed benefits to boards, the multi-disciplinary team, clinical network groups etc[9].

**3. Understand the current pathway**

Understanding the cancer patient pathway is a key first step for the improvement team. The pathway should be fully understood from the point of referral through to the end of the follow up period. Mapping the journey for a typical patient should identify what happens 80% of the time. During testing this exercise proved valuable and revealed the complexity of follow up for some patients, with many followed up by several clinicians and often across multiple geographical sites.

The frequency and duration of follow up outpatient appointments and surveillance test regimes were found to differ between tests sites and even between clinicians within the same organisation. Reaching consensus on the follow up pathway and test regime may be one of the first actions for the group.

The mapping exercise should involve representatives from each stage of the pathway as well as patient representatives and other stakeholders. Once complete the pathway should be analysed and the quality improvements identified and discussed. At this point a future pathway may be helpful to identify to illustrate the proposed changes.

For further information on process mapping and other service improvement tools and techniques referred to in this guide go to page 17.

**4. Understand what patients need**

Many studies have been undertaken to determine the needs of patients following treatment for cancer. The generic pathway developed is in response to these needs with the emphasis on a more tailored approach to aftercare services, improved information and education and care closer to home where appropriate.

Local teams will need to engage with patients in supporting roll out of improvement work locally in order to ensure that the changes delivered really will improve their experience, are what they need, are coordinated and make it easier for them to manage their future health and wellbeing.

Involving cancer information teams, volunteers, audit and research teams and evaluation groups can also provide valuable insight into the service.

> **TOP TIP**
> Audit the case notes for a few patients who have completed the normal period of follow up to identify the actual time intervals between appointments and surveillance tests. Compare this with the local protocol to highlight issues or slippage.
>
> Whilst mapping the pathway, identify the documentation issued or generated for the patient and/or primary care at each point in the pathway. In consultation with patients and GPs there may be opportunities to improve or standardise.

[9]Introducing stratified pathways of care – Presentation slides to support start up

Some suggested methods for engaging patients are as follows:

- patient stories – real examples of what patients have experienced;
- discovery interviews – in depth understanding of experience  and outcome can help inform changes (further information see  http://www.improvement.nhs.uk/discoveryinterviews);
- surveys (local or national) - can highlight problem areas and provide a baseline for improvement;
- process mapping – ask patients and carers to participate and provide their insight to the process;
- complaints to identify trends or commonalities;
- PROMS 'patient reported outcome measures' provide comparisons on whether services do improve health and wellbeing; and
- focus groups – use existing groups, club, networks or set up for specific work.

Examples of where test sites have invited patients to input to the pathway changes include:

- development of a patient information leaflet on self-management pathway;
- evaluations following health and wellbeing information days;
- developing a care plan and documentation; and
- steering group representation.

**Project measures**
Data and measures are important features of all improvement work but should not dominate the project. All system changes need to be measured and recorded. Whether the change was a success or not, it is still useful to demonstrate its effect and learn from it.

Principles of monitoring for improvement:
1. Seek usefulness, not perfection in measurement ('good enough')
2. Use a balanced set of measures that reflect the goals and aims of the project. (quality, efficiency, cost, experience)
3. Keep measurements simple.
4. Write down operational definitions of measurements to avoid confusion over meanings and to ensure the context is understood.
5. Measure small representative samples.
6. Build measurement into daily work.

Data can be used to help:
1. Baseline current service to help understand the process and demands e.g. new referrals over time.
2. Monitor improvements over time - linked to the changes you are implementing, e.g., telephone calls to the clinical nurse specialist. Use run charts or statistical process control charts.
3. Measure sustainability - the long term impact of the changes, e.g. annual national patient surveys.

Establishing a true baseline is a key part of any improvement work as, without knowing what your position was at the start, it will be difficult to establish if your change has had an impact.

Do not start any changes to the pathway without first establishing:
1. what you want to improve;
2. how best to measure the improvement;
3. how will you use the data;
4. what patterns or relationship might you want to explore; and
5. does the data already exist (include any clinical audit data)?

The table on pages 13 and 14 identifies a range of measures that could be used to support pathway changes. It is not always easy to collect all the data you need and if it cannot be collected from existing systems local or manual systems may need to be set up for the period of the improvement project.

Sometimes snap shot data at key times is sufficient rather than collecting data for the duration of the project.

The frequency of data collection will depend on the measures selected. A few simple monthly measures to demonstrate impact as the project progresses will be helpful in maintaining momentum for the project.

**TOP TIP**

Junior medical staff are often keen to support local audits so seek volunteers to help collect and analyse local data to support your work.

Data may already be collected. Contact your local cancer information lead to discuss data requirements.

Also checkout medical audits – there are usually many being implemented.

As a rule of thumb only collect the data you need and ensure what you collect is useful and meaningful. Make use of existing data that is collected and reported.

| Data description | Data source | To show | Comments |
|---|---|---|---|
| Reduction in outpatient attendances | Hospital episode statistics (HES) | Impact of self-management pathway. | Could also collect slots saved prospectively based on point stratified and current follow up regime.<br><br>May be feasible by specialty not cancer specific unless outpatient activity is coded. |
| Improved Patient Experience | NHS annual National Patient Experience Survey | Quality of experience across whole pathway. | Overall measure of quality. |
| Patient Reported Outcome Measures (PROMS) | National Quality of Life National PROM Survey | Improved management of clinical outcomes and impact on quality of life. | Tumour specific measure.  For patient specific PROMs local individual patient data collection will be required. Could be incorporated in remote monitoring systems. |
| Calls to helpline or clinical nurse specialist from patients post treatment | Helpline call log | Impact of improved information and support provision with associated reduction in enquiries. | Need to identify number and reason for calls and at what stage in the pathway the patient is, e.g. in treatment or post treatment. |
| Cancer waiting times | Trust  cancer information system | Reduction as follow up capacity is released. | As follow up attendances reduce, clinic templates should be adjusted to provide additional new slots. |
| Number/% of Patients with a Care Plan | Quality of Life National PROM Survey Local CQUIN | Care plans generated. | May also need to collect numbers offered a care plan. (NB Does not demonstrate usefulness of the care plan). |
| Number/% of Patients who receive a Treatment Summary within 6 weeks of end of treatment | Local electronic patient record system or snap shot review of case notes | Communication with primary care. | Undertake a random audit of case notes to determine %. Agree when patients who have no treatment or continuous treatment would expect a treatment summary. Could conduct a survey amongst GPs. |

| Data description | Data source | To show | Comments |
|---|---|---|---|
| Improved Level of Fitness and Wellbeing | BMI, BP, CV fitness plus self-reported measures such as fatigue and flexibility. | Impact on health and physical fitness. | See Bournemouth test community case study[10]. |
| Self-Assessment Scores | Self-Assessment Tool. | Change in patient needs and effectiveness of interventions over time. | Log distress score plus range of needs identified. |
| Number of patients enrolled to a Self-Managed Pathway | Remote Monitoring System. | Percentage of people suitable for self- managed pathway and when this occurs. | Include period since treatment ended. |
| Time to complete an Assessment and Care Plan | Local Collection. <br><br> Local Patient Interviews. | To determine resources required to support the service. | Include time to write up the care plan. <br> A short term measure at start then once established. <br> Identify time at each pathway point , e.g. at diagnosis, end of treatment or future review. |
| Patients Stories (Qualitative) | | Patient feedback on experience of an intervention, e.g., end of treatment review or perceptions of service | Those undertaking interviews need to be skilled and competent to do so. |

[10]Bournemouth test community case study 'Cancer survivors exercising their way back to health'.

### 5. Developing a programme plan

A project plan[11] is fundamental to the establishment of the project. It makes clear the reasons for undertaking the project, what it aims to achieve, how it will be delivered and the expected timescales for delivery.

The plan should identify why the improvement work is important to:
• patients;
• the organisation;
• commissioners; and
• staff.
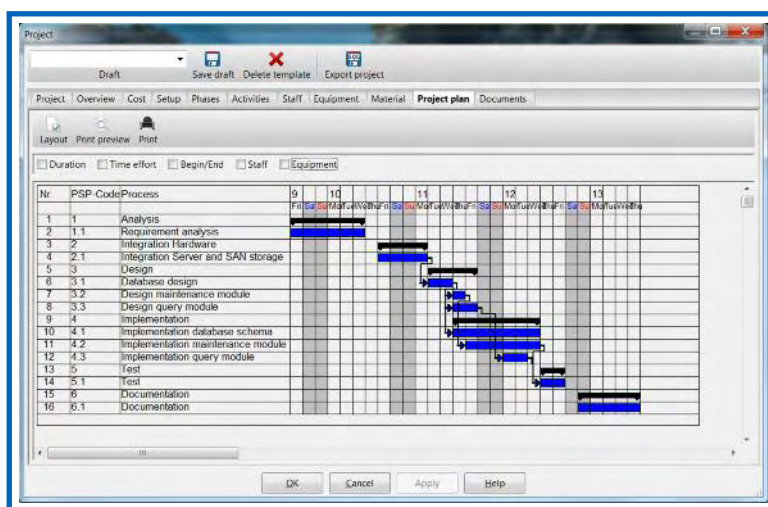
### 6. Communication plan

This needs to be developed as part of the programme plan in order to address the interests and concerns of key stakeholders, to ensure communications are timely and relevant and that people are kept appraised on the progress and outcomes of the work. A communication plan might typically cover the following:

| Deliverable | Target audience | Delivery method | Frequency | Person responsible |
|---|---|---|---|---|
| GP information leaflet | GPs | Via meetings email | Once only | Name and role |
| Article in trust or newsletter | Trust staff and primary care teams | Email | Quarterly | Communication lead |
| Posters for education events in clinics | Patients | Poster website | On-going | Cancer information team |

**Other general information to support project set up**

**Before starting**
- Identify local and national experts who may be able to help, advise or support such as other staff within the trust, strategic clinical networks, network specialty specific groups, charities, academic health science networks.
- Seek out relevant learning and publications, e.g., NHS Improvement interactive pathway, NCSI website, Macmillan Cancer Support and other charities).
- 'Go see' how pathway components work in other departments or organisations to adopt and adapt from the work of others rather than reinvent the wheel.
- Identify any local drivers such as:
  - Commissioning for Quality and Innovation payments (CQUINs);
  - Cost improvement or Quality, Innovation, Productivity and Prevention (QIPP) initiatives
  - Peer review recommendations; and
  - Performance on Patient Reported Outcome Measures (PROMs);
- Understand  Locally Enhanced Services (LES)  agreements, e.g., PSA monitoring in primary care
- Appraise the multidisciplinary team of planned project and invite active participation

**Current pathway and service demand**
- Be clear about current baseline activity, e.g., new and follow-ups per annum by tumour group.
- Process map current and planned future pathways.
- 'Go see' the process and review case notes to check process if necessary.
- Include process for referrals to specialist and tertiary centres.
- Assess capacity and demand in relation to anticipated workload changes e.g. impact of assessment and care planning on clinical nurse specialist capacity.
- Have knowledge of existing workforce capacity and relevant job plans.
- Understand process for collection of pathology specimens in the community.

**Cross boundary professional working**
- Contact local authority leads to identify availability of social and lifestyle support services.
- Contact colleagues where links to local authority services exist such as cardiac rehabilitation.
- Involve allied health professionals (AHPs), e.g., with physical activity initiatives.
- Involve multidisciplinary team coordinators, appointments and secretaries in pathway redesign.
- Engage local communication team to help promote the work and documentation changes.
- Where support services already exist use, e.g., Maggie Centres, cancer information centres

# Service improvement tools and techniques

# Service improvement tools and techniques

The following provides an overview of the common tools and techniques referenced within this guide.

### Process mapping

Process mapping is a technique used to identify all the interconnected steps and decisions in a process or pathway and converts these into a highly visible and easy to understand form. It can cover a short and simple sequence of actions by one person or it could be a complex set of activities involving many different people over time.

It provides an overview of the complete process from beginning to end, helping staff, often for the first time, understand how complicated the system can be for patients.

A mapping exercise also offers the chance to hear ideas from members who might not normally have the opportunity to contribute to service planning changes but who really know how things work. It is an interactive event that gets people involved, motivated and talking to each other.

Where possible, team members should also 'go see' what happens in practice and as it happens. This provides a further opportunity to understand some of the other issues that affect a process such as environmental, equipment or staffing issues.

### The model for improvement

The model for improvement was designed to provide a framework for developing, testing and implementing changes that lead to improvement. It uses 'plan, do, study, act' (PDSA) cycles to test out ideas on a small scale and to win commitment before implementing changes across whole departments, processes and systems.

The framework includes three key questions to ask before embarking on a change.



**Model for Improvement**

What are we trying to accomplish?

How will we know that a change is an improvement?

What changes can we make that will result in the improvements that we seek?

ACT | PLAN
STUDY | DO

**What are we trying to accomplish?**
- Clear and focused goals that focus on problems that cause concern for patients and staff.
- Consistent with local and national targets, plans and frameworks.
- Bold and aspirational with clear numerical targets.

**How will we know if a change is an improvement?**
- What can we measure that will change if the system is improved?
- How can we obtain this data? Is it available in existing information systems, or will we need to collect this manually?
- What is the best way to display the data we collect so that we can decide whether we are improving the system?
- Measure the baseline – how is the process performing before the change is made?

**What changes can we make that will result in improvement?**
- Many change ideas are generated at process mapping events.
- Use techniques of creative thinking and innovation to generate ideas and to sort them into those to be tested.
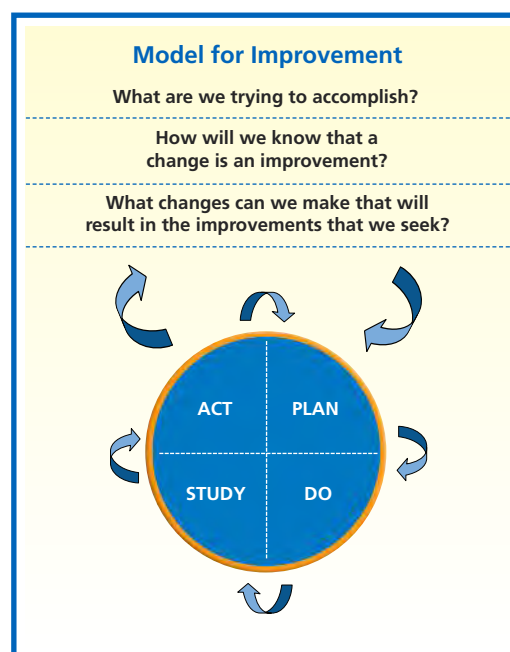
Before fully implementing any change use a PDSA cycle to test out ideas on a small scale.

**Plan**:    Agree the change to be tested or implemented.
**Do**:    Carry out the test or change and measure the impact.
**Study**:    Study data before and after the change and reflect on what was learnt.
**Act**:    Plan the next change cycle (amending the original idea if it was not successful) or plan implementation of successful ideas.

The NHS Institute for Innovation 'Improvement Leaders' Guide: Process mapping, analysis and redesign' can be ordered on line. The NHS Improvement PDSA template[12] may be helpful.

### Demand and capacity

This technique is used to measure the demand, capacity, backlog and activity at a bottleneck in the process and can be really useful in order to demonstrate where changes in practice should occur.

Demand is the requests and referrals coming in from all sources and capacity is the resources available to undertake the work. If there is disparity between demand and capacity, queues and bottlenecks will form.

Always measure the demand, capacity, backlog and activity in the same units for the same period of time. From this you can then establish a reasonably robust overview of the service in addition to understanding the dynamics and processes involved.

For further information see the NHS Institute for Innovation and Improvement: Improvement Leaders' Guide: Matching capacity and demand can be ordered on line.

### 1. Statistical process control (SPC)

Statistical process control (SPC) is a simple and visual way of observing variation in the system or process. It enables the team to understand what is 'different' and what is the 'norm' within a process. An SPC chart can help determine if an improvement project is actually improving a process and also to 'predict' statistically whether a process is 'capable' of meeting a set target.
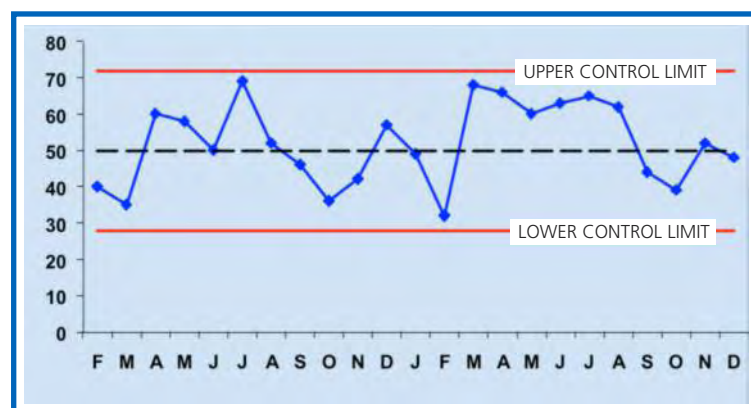


**Example SPC chart showing a process with a stable consistent pattern of variation.**

The inherent strength of these charts is that they provide a visual representation of the performance of a process by establishing data comparisons against calculated limits (known as the 'upper' and 'lower' control limits). These limits, which are a function of the data, give an indication via signals or chart interpretation rules as to whether the process exhibits either 'common cause' or 'special cause' variation.

For further information see NHS Improvement: A simple guide to improving services chapter 11[13] . An SPC chart generator is available on the NHS Improvement system www.improvement.nhs.uk/improvementsystem

---

[12]Plan, do, study, act template
[13]First steps towards quality improvement: A simple guide to improving services – chapter 11. NHS Improvement.

# → Stratified pathways

# PRINCIPLE 1: Pathway choice is a joint decision between the individual and the clinician

### What does this mean?

Adapted from a long term conditions model it is an approach to profiling patients' following treatment for cancer that is based on their clinical and individual needs. It is applied to all patients whether they have been treated with curative or palliative intent.
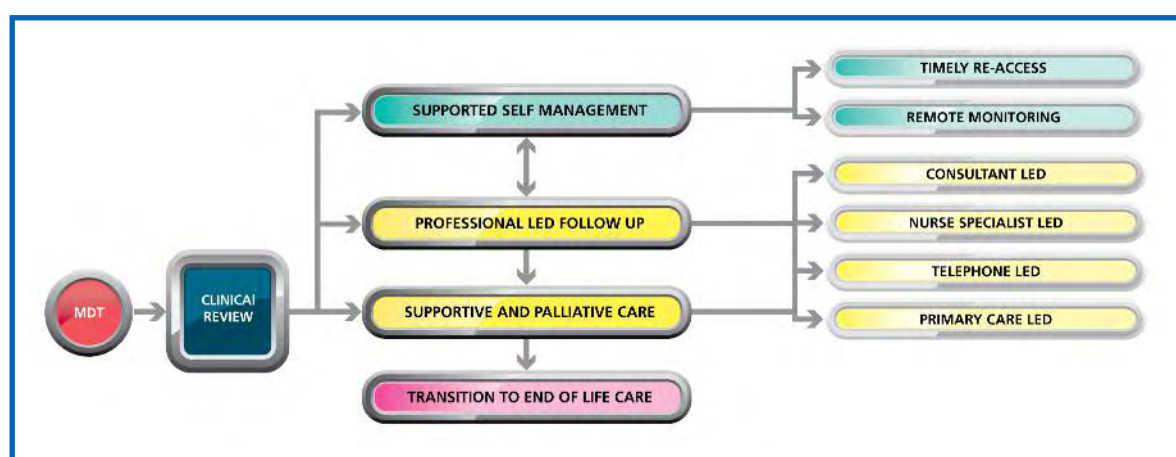


The self-management pathway is dependent upon the presence of other key components of the pathway. These include:

- a remote monitoring system to manage on-going surveillance tests;
- effective needs assessments that identify and address any outstanding needs and ensure the patient has the knowledge and confidence to self-manage;
- good communication between specialist and primary care teams; and
- a system that allows rapid re-access to the specialist team if needed.

### Why stratify?

- Many outpatient follow up appointments offer little value to the patient. Large proportions are scheduled simply to convey a test result.
- Demand is increasing by three per cent per year due to increased incidence and improved survival rates. Additional resources are not available to meet this increasing demand.
- Needs change as patients move along the pathway demanding a more tailored approach to care in place of the current 'one size fits all' approach.
- Released capacity enables resources to be redistributed to diagnosing more new patients and supporting those with metastatic and complex disease.
- The personal cost of follow-up can be significant for patients particularly those with other conditions and illnesses who need to attend other departments. Where the patient cost of care can be reduced it should be.
- Technology is offering many new alternatives to face-to-face follow up.
- Existing clinics are often overbooked and ensuring access times for new patients and urgent follow ups can be challenging.

**Expected impact**

Testing the stratification of patients within NHS Improvement test sites identified the following proportion of patients suitable for either a self-managed or professional led pathway (see also reference 6) It is expected that percentage of those on a self-managed pathway will increase as all key components of the stratified pathway are embedded and teams develop confidence in the new model of care.

| Tumour site | Professional- led pathway | Self-managed pathway |
|---|---|---|
| Breast | 25% | 75% |
| Prostate | 70% | 30% |
| Colorectal | 55% | 45% |

**The stratification process**

At the end of treatment the clinical team, in consultation with the patient, reviews the patient's condition against agreed criteria and considers which of the follow-up pathways would be most suitable to meet the patient's needs. This may include an additional review by the multi-disciplinary tea. The stratification decision depends on a number of elements including:

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

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

**How to implement pathway stratification**

**STEP 1 - Planning**

• **Discuss planned changes with key stakeholders**
• **Develop draft criteria for stratification**
• **Confirm processes to support pathway implementation**
• **Agree audit and baseline measures**

**STEP 2 - Testing and implementation**

• **Undertake a prospective audit to test criteria and identify likely impact**
• **Review criteria and agree operational protocol**
• **Plan transition to new pathway**
• **Prepare documentation to support launch**

**STEP 3 - Sustainability**

• **Include protocol within multi-disciplinary guidelines**
• **Embed the process**
• **Audit and PROMS**
• **Adjust outpatient clinic templates to address changing demand**

**STEP 1: PLANNING**

**Discuss planned changes with key stakeholders**
Ensure everyone within the team understands the current problems and why change is necessary. Share how other teams have implemented stratified pathways and how change will improve outcomes for patients.  Communication and engagement will build trust, develop a shared purpose and vision and win hearts and minds within the team.

Discussion should also take place outside the organisation. Local clinical networks, commissioners and GPs and primary care teams will all have an interest in the changes.

- develop draft criteria for stratification;
- confirm processes to support pathway  implementation;
- agree audit and baseline measures; and
- develop documentation to support implementation.

Information day events and user groups meetings can also be used to share the pathway change proposal, the rationale for this and the benefits stratified pathways offer. Several test sites took this approach and the response from patients, once they understood the process, was overwhelmingly positive.

**Develop draft criteria for stratification**
Team members will need to agree the inclusion and exclusion criteria to be applied to patients within each of the stratified pathways.  As confidence in the pathways grows and outcomes from evaluation are revealed the team may agree to include or exclude further patient groups to criteria.

Whilst a decision may be made initially to exclude those patients on clinical trials in time, the team may want to examine more closely what this consultation actually involves, whether an outpatient appointment is in fact necessary and whether these patients would also be suitable for a self-managed pathway.

Criteria[14] were developed during testing and adopted and adapted for local use within teams. Further examples are provided in the 'Concept to Innovation' publication (see reference 6).

**Confirm processes to support pathway implementation**
Consensus should be agreed with regard to scope, criteria of patients to be considered for each of the stratified pathways and the processes that will underpin implementation.

> **TOP TIP**
> When developing the criteria consider factors relating to the disease, the treatment (or the effects of treatment), and individual circumstances that may affect pathway selection.
>
> Identify time periods, e.g., the minimal time period between diagnosis and referral to a self-managed pathway.

Baseline process mapping enables the multidisciplinary team to understand the current patient journey and an opportunity to discuss how the pathway stratification process can be introduced.

[14]Criteria used for testing pathway stratification in colorectal cancer (December 2011). NHS Improvement

Develop and agree written protocols[15] within the team about how the stratified pathways will be managed operationally. Suggestions include:

- inclusion and exclusion criteria for each of the treatment options;
- processes to be followed;
- documentation;
- patient information; and
- audit.

**TOP TIP**
Document agreed criteria and patient selection process within local department operational guidelines.

In some NHS Improvement test sites the provisional follow up pathway is identified at the diagnostic multi-disciplinary team meeting and confirmed following completion of treatment. Informing patients of the likely pathway as soon as appropriate after diagnosis or treatment helps to manage expectations.

In a breast cancer test site the consultant uses the penultimate planned appointment to discuss the planned transfer to a self-management pathway. This works well and prepares the patient for the change.

In another breast unit, clinicians agreed an opt-out approach. All breast cancer patients are transferred to a self- managed pathway after completion of treatment unless exclusion criteria apply.

**Agree audit and baseline measures**
Establishing a baseline is critical to enabling measurement of improvements at a later date. Specific measures relating to pathway stratification include:

- the proportion of patients stratified to each follow up pathway;
- number of self-management pathway patients re-accessing the service with a recurrence;
- time from diagnosis to pathway stratification by treatment type; and
- National Patient Experience Survey and PROMs.

An audit would use the same measurements as those collected for the baseline which would then be used as a comparison and a measurement of change. The timing of when to audit should be included in the operational protocol. The audit could be included as one of constitutional audits for the annual peer review audit programme. PROMs could be collected by surveying patients and proxy PROMs could also be extrapolated from the trust's annual national cancer survey.

[15]Prostate cancer protocol and recall process – St Georges Hospital

## STEP 2: TESTING AND IMPLEMENTATION

### Undertake a prospective audit to test criteria and identify likely impact

Using the criteria suggested in Step 1 undertake a prospective audit to confirm criteria selection and to ascertain the likely impact on activity.

The data collection sheet below was used in one test site over four weeks to audit the proportion of prostate cancer patients that were suitable for each pathway. A sheet was attached to the case notes of all prostate cancer follow-up patients for clinicians to complete. It was completed for all those who had completed first line treatment (surgery, brachytherapy, radiotherapy or chemotherapy) and all patients who were on active surveillance, watchful waiting or hormone therapy. Excluded were those pre-diagnosis, newly diagnosed or in radical treatment.

| Patient label | Pathway | Tick | Months post treatment | Tick |
|---|---|---|---|---|
| | **Self-management (remote monitoring)**<br><br>• Curative patients at least one year post-treatment, with stable symptoms, who require annual PSA testing.<br>• Watchful wait patients.<br>• Metastatic patients with ≥ 90% fall in PSA who are asymptomatic.<br>• Hormone therapy patients with ≥ 90% fall in PSA who are asymptomatic. | | 0-3 | |
| | | | 3-6 | |
| | | | 6-12 | |
| | | | 12-24 | |
| | | | Greater than two years | |
| | **Consultant follow up**<br><br>• Patients who require other types of testing, e.g., biopsies.<br>• Patients with unstable PSA levels.<br>• Patients who are symptomatic.<br>• Patients on active monitoring. | | 0-3 | |
| | | | 3-6 | |
| | | | 6-12 | |
| | | | 12-24 | |
| | | | Greater than two years | |

Testing prospectively like this can help introduce the concept of alternative pathways amongst all members of the team and test the potential criteria without actually transferring a patient to any new pathway.

Some indicative data can be derived from this exercise to identify the impact on future follow-up activity. Note that the impact of any change may not be felt until the next follow-up is due, i.e., if an annual follow-up patient was seen today and enrolled, the first saved outpatient slot would be at the same time next year.

Another test site completed a similar audit and also captured the reasons cited by the professional for continuing face to face follow up. These included:

- Palliative /symptom management
- Co-morbidity issues
- High clinical risk
- Clinical examination required
- Anxious patient
- On-going adjuvant treatment
- Trial/research
- Training doctors

### Review criteria and agree operational protocol

Testing both the criteria and the process will inform the final version of the operational protocol prior to 'go live'. The operational protocol should be agreed by the clinical lead and ideally the multi-disciplinary team, prior to go live.
Approval of the clinical governance committees is not normally necessary.

### Plan transition to new pathway

Decide within the team the consultant and patient group that will be used initially to test the stratified pathways.

Agree when patients should be informed about the new pathways and prepare written information to support the discussion with patients. Put up posters in reception areas which could encourage patients to initiate discussions with clinicians.  This also may begin to engage any clinicians who are unsure of the new way of working.

> **TOP TIP**
> Information about stratification and self-managed pathways given when the patient is ready and at the beginning of a patient pathway sets the scene with regard to patient expectation and engages patients in the process.

Following a needs assessment and care planning discussion clinicians and patients should discuss and agree which of the stratified pathways is the most suitable for patients. Clinicians should ensure that all patients are able to recognise early signs and symptoms of recurring disease and effects of treatment.  However, it is particularly crucial for those patients stratified to the self-management pathway to be aware of what would precipitate re-access between surveillance tests as they will no longer be attending routine outpatient appointments.

Patients tell us that they are willing to be entered onto the self-managed pathway as long as they can see a specialist quickly if necessary. What is critical therefore in successfully engaging patients in the self-managed stratified pathway is the need to set up a fast-track re-access system to the specialist team as outlined in principle 4.

Patients can be transferred onto a self-managed pathway in advance of the remote monitoring system going live as long as a temporary system exists to record those enrolled, their diagnostic and treatment details, and test due dates. Ideally this should be a short-term temporary solution.

Set the date that you plan to start stratifying patients and communicate the launch date to the multi-disciplinary team and other stakeholders.

**Prepare documentation**
GPs and primary care teams will need to be briefed on the self-management pathway and how on-going surveillance tests will be managed[16]. The self-managed pathway should have no impact on primary care workload other than patients attending local health centres for blood tests to be taken.

The pathway will improve the information provided to patients through needs assessment and care planning, and the copying of treatment summaries will provide GPs with clear, concise information of the patient history, planned surveillance programme and any follow up actions for the GP and primary health care team.

A similar leaflet or information sheet should be available for patients to explain the self-management pathway. This can be given to patients when discussing follow up options.

For those enrolled on the self-managed pathway, provide an introductory letter[17] explaining how the pathway works, how tests will be arranged and results conveyed and on-going contact details for any worries or concerns. This letter would normally be copied to the GP.

Your patient reference group can help to develop this documentation.

## STEP 3: SUSTAINABILITY

**Include protocol within multidisciplinary clinical guidelines**
Review the clinical guidelines to include stratified follow-up pathways.
Ensure all team members acknowledge receipt of any updated protocol and are clear about their role and responsibilities.

**Embed processes**
Embed processes that support implementation of stratified follow-up pathways within clinical and administrative job plans and job descriptions.  Ensure sufficient supplies of new documentation supporting implementation are available and remove any old documentation from circulation.

Ensure written information on stratified pathways of care is included in staff handbooks and within induction programmes for new medical and nursing staff.  Include regular updates to the trust cancer board and commissioners. Profile the work with quality, transformational and communication teams within the trust.

**Audit and PROMs**
Include audit in the protocol, clinical guidelines and annual peer review work programme.  Audit outcomes should be fed back to the multidisciplinary team and to the wider locality tumour working group. Include measurement of quality of integrated care between primary and secondary care within the audit. Collect PROMs from all four levels of the model of care.

Audit the use of criteria to determine the pathway choice and adjust protocol if necessary.

**Adjust clinic templates to address changing demand**
As processes embed, the profile of clinics is likely to change. This will not happen immediately as the impact is likely to be felt a year or so after launch when annual follow-up attendances are due.

The team should adjust clinic templates to reflect new patient demand and the time required to see complex follow-up patients with multiple needs. The template should be regularly reviewed during the transition.
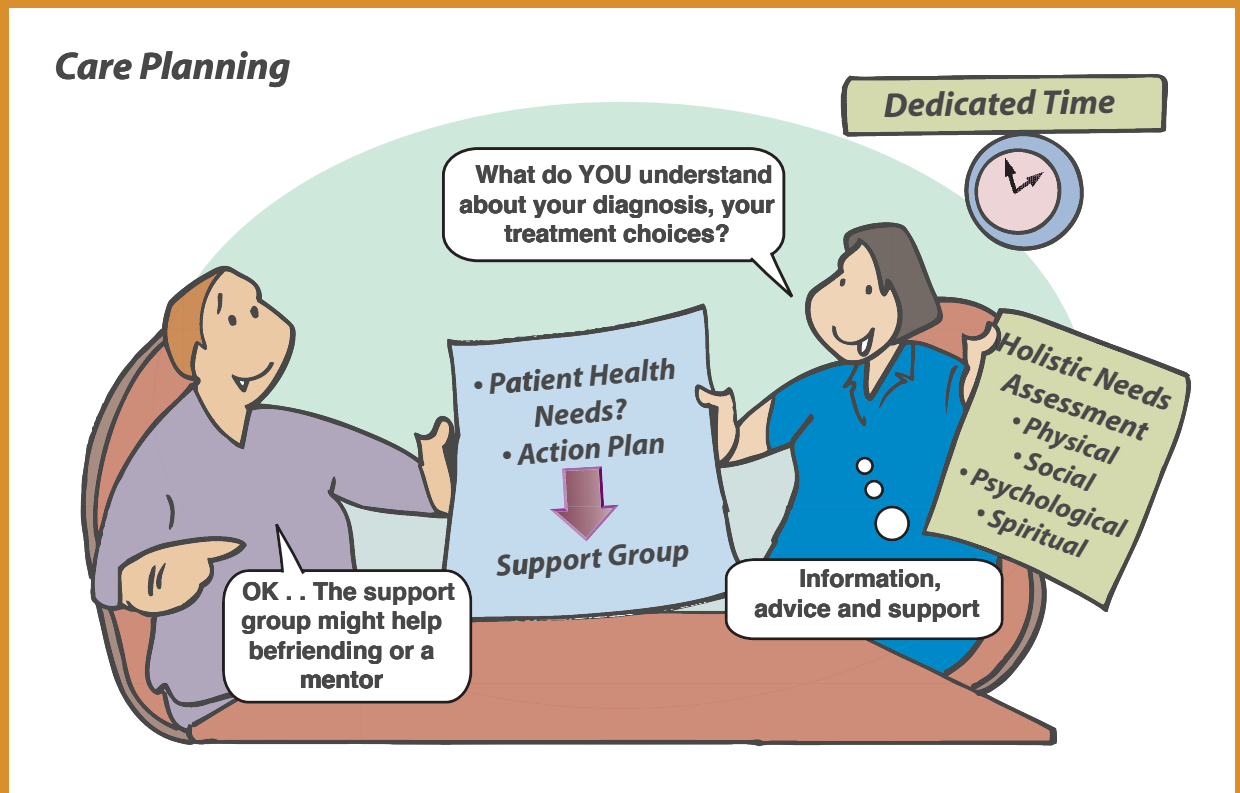
[16]Example GP information leaflet – St Georges Hospital Urology team
[17]Example patient introductory letter – Royal United Hospital Bath.

# ⊡ Needs assessment and care planning

# PRINCIPLE 2: Needs assessment and care plans should be offered at key points in the pathway

This chapter provides practical guidance on how to introduce effective needs assessments and care planning, which are key components of the cancer care pathway. It provides top tips reflecting the learning from NHS Improvement test sites.

Assessing patients' needs and subsequent care planning are important aspects of cancer care and whilst they are activities that professionals all undertake they may not always happen in a formal, structured or holistic way.

### What is a needs assessment and care plan?

A needs assessment is a process of identifying the needs of the patients by focussing on the whole person and their well-being (covering physical, emotional, spiritual, mental, social and environmental issues). The outcome of the needs assessment should result in a care plan which will be held by the patient. The professional role is to stimulate and encourage an assessment conversation and support, signpost or refer the individual to address any needs they may have.

### Why carry out a needs assessment?

Needs assessments and care plans will:
• identify people who need help;
• provide an opportunity for the person to think through their needs and together with the healthcare professional , make a plan about how to meet these needs;
• help people to self-manage their condition;
• help teams to target support and care efforts and work more efficiently;
• enable early intervention to address needs as they arise; and
• inform future service development needs and provision.

The rationale for comprehensively assessing need is evidence based. Armes et al (2010)[18] found that a third of cancer patients reported more than five 'moderate' or 'severe' needs during the first six months following treatment. These findings have been supported by National PROMs[19] findings.

Shorter lengths of inpatient stay coupled with a shift towards greater self-management during aftercare makes it even more important that patients have the opportunity to discuss worries or concerns and that these are addressed in a timely manner.

Care plans, when provided, are valued by patients. The baseline audit across NCSI test sites (see reference 7) found that of the 21% of patients who said they had a care plan, 84% found it useful.

Note: Assessment and care planning is becoming a standard feature of NICE guidelines and commissioning specifications, e.g., NICE Quality Standard 9 (Sept 2011) for early breast cancer states:

## "People having treatment for early breast cancer are offered personalised information and support, including a written follow-up care plan and details of how to contact a named healthcare professional".

---

[18]Armes J et al. "Patients supportive care needs beyond the end of cancer treatment; A prospective, longitudinal survey". Journal of Clinical Oncology Official Journal of the American Society of Clinical Oncology. Vol 27;No 36, pp.6172-6179, 2009

[19]Quality of Life of Cancer Survivors. Report on a pilot survey using patient reported outcome measures (PROMS). December 2012 Department of Health

**How to implement 'needs assessment and care planning'**

**STEP 1 - Planning**

- **Understand the pathway and how and when needs assessments will be undertaken in future**
- **Agree assessment tools and care plan documentation**
- **Identify resources (staff, IT, space)**
- **Agree competencies and identify any training needs**
- **Develop a local 'directory of services'**
- **Agree baseline data and how service will be measured**

**STEP 2 - Testing and implementation**

- **Set up clinics on PAS ( if required)**
- **Test assessments and processes to support these**
- **Scale up**

**STEP 3 - Sustainability**

- **Operational enablers**
- **Workforce and training**
- **Continuous evaluation**

## STEP 1: PLANNING

### Establish a team

The agreement to introduce a more structured assessment and care planning process should be endorsed by your local cancer programme board. Needs assessments and care planning may already be established elsewhere in your organisation and your chief nurse or cancer lead nurse will advise on current activity and any local policy guidelines.

At specialty level a small implementation team will be required. It would be beneficial to identify a lead.

Suggested team members are:
- clinical nurse specialist  - (surgical and oncology if separate)
- therapeutic radiographers
- specialist chemotherapy nurse
- palliative care lead (acute and/or community)
- patient representative
- cancer information team representative
- service manager

**Understand the pathway**

It is important to establish a common understanding around what a needs assessment is and its benefits.

Start by mapping the current patient pathway and include any assessments that are currently undertaken, what form they take and the documentation used. Then discuss with the specialty team ways in which the assessment and care planning process can be improved in the future. Those involved in the pathway should be invited to attend the session. This should include patient representatives.

**When should need assessments and care planning take place?**

The following diagram identifies the points in the pathway that a needs assessment and care planning discussion should be offered. Patients can also trigger a request for a review at any point that they feel it is needed.



TOP TIP

If a previous process mapping exercise has taken place, review and update the process with the team rather than reinventing the wheel.

If invitees are unable to attend, leave the map on the wall and invite comment on it as soon as possible afterwards.

Visit other departments or units with experience and resources to share.

# Needs assessment and care planning
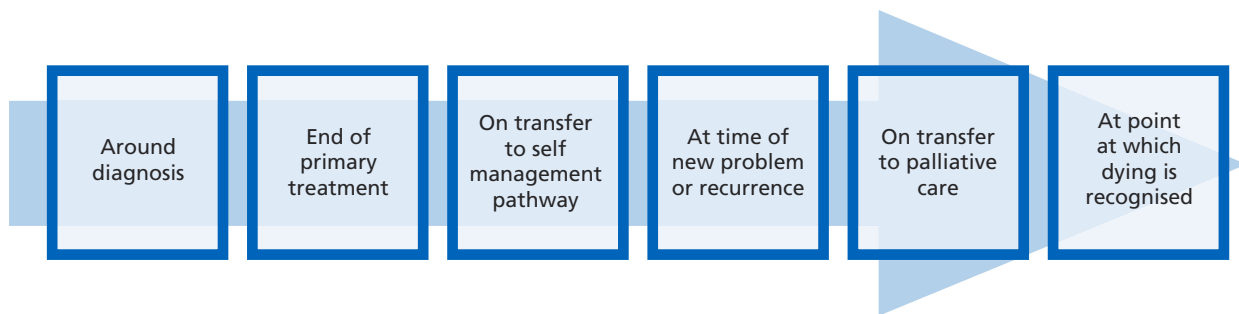


## Around diagnosis
Professionals will need to judge the best time to undertake the initial needs assessment. Most suggest that the appointment where diagnosis is confirmed is not an appropriate time for any structured need assessment. Probably an appointment is best arranged shortly afterwards when the impact of the diagnosis is better understood and the treatment plan is known. This may be days or even weeks after diagnosis and could form part of a pre-operative or treatment planning session. The discussion should include advice on keeping well during treatment, and referral to support services if needed.

## End of primary treatment
A separate appointment arranged usually three to four months after completion of treatment and the main side effects of treatment will have subsided. For many people the emphasis can now move from disease and treatment to recovery, health and wellbeing and getting back in control of their lives.

## On transfer to a self-managed pathway
This may be a relatively short discussion for those who have recently had an assessment at the end of treatment. Alternatively it could take place months or years after the end of treatment once their condition has stabilised. As well as addressing any remaining needs this appointment should focus on health and wellbeing, signs and symptoms to look out for in the future and how on-going surveillance tests will be organised. Key contact details will need to be reconfirmed.

## At a time of a new problem or recurrence
A new problem or diagnosis of reoccurrence is likely to trigger a new set of issues and concerns for the patient. It will be important to make available an opportunity for a further discussion relating to this change in circumstances.  NB. There are support groups specifically for those with secondary disease, e.g., Breast Cancer Care, The  Haven breast cancer support centres, Penny Brohn, Maggie Centres.

## On transfer to palliative care
The discussion at this point may also be referred to as 'advanced care planning' and enables a person to consider the impact of their future illness or disability and express wishes about their future health care in consultation with care providers and loved ones. Local agreement should be reached on responsibility for arranging this review. Previous needs assessments should help inform this discussion.

## At the point at which dying is recognised
All teams, irrespective of whether secondary or community based, should be aware of the needs of the dying patient. The 'Liverpool Care Pathway for the Dying Patient' is a model of care which enables healthcare professionals to focus on care in the last hours or days of life when a death is expected. It is tailored to the person's individual needs and includes consideration of their physical, social, spiritual and psychological needs. It requires senior clinical decision making, communication, a management plan and regular reassessment.

Ideally each assessment and care plan review should build on the previous assessment to reduce duplication and prevent patients being repeatedly asked similar questions. In some cases the above stages can follow in quick succession and therefore a common sense approach is required to avoid unnecessary appointments.

For those patients where no actual treatment is prescribed, for example prostate cancer patients on active surveillance, arrangements should be made to offer needs assessments at appropriate times.

It is recognised that issues may still be raised and addressed during the usual follow- up clinics, either with the medical team or the nurse specialist. Actions from these follow-up appointments should be documented in the case notes, however the care plan held by the patient may not be formally updated at this time.

A survey (see reference 7) of cancer survivors found that around 40 per cent of people with a diagnosis of breast, colorectal or prostate cancer also have a long term condition and a proportion of these are likely to have had a needs assessment and care planning discussion with the community team. It is good practice that secondary and primary care teams communicate with each other on care planning to avoid confusion and duplication. This will also enable patients to feel they are being supported by a team rather than dispirit individuals.

### Agree assessment tools and care plan documentation

Several NHS Improvement test sites established patient focus groups to discuss and agree the preferred documentation for use during an assessment and care planning discussion. This approach is highly recommended.

A variety of assessment tools exist. The most commonly used ones include:
• the Distress Thermometer;
• the Concerns Checklist;
• the SPARC tool
• the Pepsi Cola Aide memoir; and
• Hospital Anxiety and Depression Score (HADS) – often used as a secondary tool.

These and other examples can be downloaded via the cancer interactive pathway on the NHS Improvement website.

The Distress Thermometer has been validated in its current format for use in the NHS. As such Trusts are not permitted to change title or thermometer. For further information regarding copyright contact NCCN at www.nccn.org  or for advice contact **James Brennan** at: James.Brennan2@UHBristol.nhs.uk

Note: Testing found that some patients and staff were uncomfortable with the term 'distress' and preferred the term 'concerns' or 'problems'.

The National Cancer Survivorship Initiative is currently leading a project to test the usage of an electronic touchscreen device to carry out the needs assessment in hospital clinics. The choice of assessment tool within the device can be varied depending on the patient group and on local or personal preferences.  For more information on this project contact: nyoung@macmillan.org.uk

**The care plan**

The care plan should be developed in partnership with the patient. The purpose of a care plan is to document the main concerns and actions agreed. The outcomes of the discussion will vary.

1. Some concerns will be addressed simply through discussion with no further action.
2. Some concerns may require the patient to take action.
3. Some concerns may require follow-up by the clinical team, signposting or referral to another service.

A formal record of the discussion and agreed action helps reduce risk of misinformation or misunderstanding. The care plan is developed primarily for the patient but can also be shared (with the patient's consent) with other health professionals who may be supporting the patient, i.e., the GP. For those patients already being supported for other conditions, their community teams should also be informed.

The NCSI developed a simple care plan[20] used in conjunction with the concerns checklist[21]. A more detailed template[22] was developed and adapted for local use by teams who preferred a more comprehensive document.

The team should agree how and where care plans will be stored and decide if a new care plan will be issued on each occasion or whether simply updated along the pathway.

Some trusts supplement the content of the care plan with other information for the patient including:

**TOP TIP**
Electronic care plan templates with core dataset information imported automatically will make completion quicker and simpler. Speak to your IT department about this once the template has been tested and is agreed.

- diagnosis and treatment (planned or received) including dates started and finished;
- key contact details should problem or issues arise;
- potential long term effects of treatment and signs and symptoms to look out for; and
- planned surveillance tests and space to record results.

This should all form part of their personal care record.

**Identify resources**

In the current financial climate and with the rising demand facing all teams, finding resources to support set up can be extremely challenging. Whilst nurse specialists and others recognise that the support they provide to patients at the end of treatment is as important as the support they provide at diagnosis, the resources to meet this demand are not always immediately available.

If assessment and care planning is being rolled out in addition to stratifying patients to a self- managed pathway there may be opportunities to reallocate resources.

---

[20]NCSI Care plan – available as triplicate pads from www.be.macmillan.org.uk
[21]NCSI Concerns checklist – available as triplicate pads from www.be.macmillan.org.uk
[22]Care plan template example – NHS Improvement

National testing of stratified pathways found that 75% of breast patients, 45% of colorectal and 30% of prostate patients were suitable for a self-managed pathway. Once implemented, this will release significant capacity within outpatient clinics. Note: These percentages will change as confidence increases. Furthermore, the use of standard letters to convey results will reduce workload for secretarial and administrative staff.
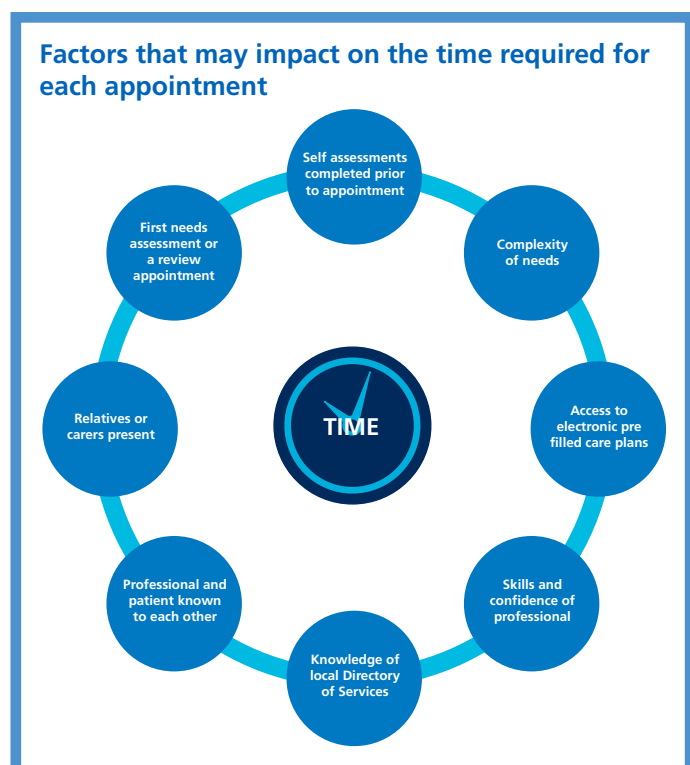
The new stratified pathway model should offer net savings to commissioners. The challenge is to pump prime qualitative improvements during transition from one model of care to another.

We do not have all the answers but the following suggestions may help.

1. Reallocate existing resources
- where nurse led follow-up clinics already exist, released clinic slots can be reallocated to undertake needs assessments; and
- where medical led follow-up clinics exist,  negotiate a transfer of resource from the medical to nursing staffing budget
2. Review the job plans of those undertaking assessment and care planning:
- is there duplication between oncology and surgical nurse specialists; and
- can some duties (chasing results or audits) be undertaken by others?
3. Review the referral pathway. - Many clinical nurse specialists struggle to cover all general clinics where a patient with a new diagnosis of cancer may be seen. This is made even more difficult where teams work across multiple sites. Streamlining the referral process to ensure that all suspected cancer patients are seen in a limited number of consultant clinics could free up clinical nurse specialist capacity elsewhere in the working week.
4. Get others involved. - It is beneficial if other staff members/colleagues are also able to undertake needs assessment as the patient moves through the pathway.
5. Finding space.  - Can your cancer information centre staff or volunteers support needs assessments and care planning at the end of treatment, for example access to non-clinical space to undertake the assessment?
6. Could primary care teams support needs assessments especially where patients require longer term care or on-going support?

## How long should a needs assessment and care planning discussion take?

Testing has identified that the appointment at the end of primary treatment takes between 30 minutes and one hour allowing time for discussion and completion of the care plan. The care plan should be completed at the time of the appointment or sent to the patient within the next two working days. No discussion should exceed one hour on a single occasion. If required, a separate further discussion should be arranged on another occasion (which can take place over the phone).

**Factors that may impact on the time required for each appointment**

- Self assessments completed prior to appointment
- Complexity of needs
- Access to electronic pre filled care plans
- Skills and confidence of professional
- Knowledge of local Directory of Services
- Professional and patient known to each other
- Relatives or carers present
- First needs assessment or a review appointment

TIME

For those with complex needs or pre-existing long term conditions additional time may be required to liaise with relevant community teams who will be coordinating care for the patient in the community. The exchange of written information is important but it is even better if this written information is supported by a telephone discussion. Nothing beats personal contact.

**Competencies and training needs**
Any health care professional can undertake a needs assessment as long as they are skilled and competent to do so. Some organisations have developed performance criteria and expectations about knowledge and understanding to support implementation.

At diagnosis and at the end of treatment the CNS usually undertakes the assessment although other professionals including doctors, allied health professionals (AHPs), community nurses or social care professionals may be well placed to undertake part or all of the assessment depending on the patients' needs.

Effective assessment hinges on the provision of appropriate education and training for health care staff though the skills involved in conducting a useful and sensitive assessment are not new for most experienced professionals.

> **TOP TIP**
> Staff members that have experience in conducting needs assessments and care planning in your organisation or elsewhere may offer the opportunity to shadow.

The Holistic Needs Assessment for People with Cancer – A Practical Guide (NCAT)[23] provides practical advice on all aspects of the assessment and care planning process including the 'assessment conversation'.

Professionals conducting assessments need to have knowledge and understanding of legislation and governance, clinical knowledge of the disease, treatments available and potential complications and knowledge of the services that are available to support patients.

Within Yorkshire cancer network a set performance criteria and competencies[24] for Holistic Assessment have been adapted from the Skills for Health PSL5 'Undertake an assessment or re-assessment of a patient' competencies.

Motivational interviewing is a tool for helping patients feel engaged and in control of their health and care. It aims to engage people's intrinsic motivation to change their behaviour that uses questions and support to help people set their own goals, see discrepancies between where they are and where they would like to be and develop strategies to move forward.

The approach focuses on what triggers change. The techniques used may include seeking to understand a person through reflective listening, expressing acceptance, recognising the patient's degree of readiness to change, eliciting and reinforcing the patient's own self motivational statements and affirming the patient's freedom of choice and self- direction. This technique is particularly applicable to cancer patients who are recovering and moving on from their disease.

Staff involved in undertaking needs assessments may wish to self-assess their level of competence as well as identify any training needs.

---

[23]'The holistic needs assessment for people with cancer – a practical guide'. National Patient Access Team 2010
[24]Competencies for undertaking holistic assessments. Yorkshire Cancer Network

The self-assessment could demonstrate that the staff member:

1. has no knowledge or experience of assessment and care planning; has awareness and knowledge but no practical experience;
2. is competent to undertake needs assessments alone; and
3. is confident in knowledge and experience to train others.

**Evaluating the service - agree baseline data and how improvement will be measured**

There are a number of ways in which the team can assess the effectiveness of the service.

In broad terms you will want to measure:

- whether assessments are being undertaken; and
- what affects they have had

Whilst these national surveys do not always provide results to Trust specialty level the questions could be useful for local surveys.

**TRAINING OPPORTUNITIES**
- Assessing distress - Trust psychology team or Kate Jenkins, Consultant Psychologist - Salisbury NHS Trust. Contact: kate.jenkins@salisbury.nhs.uk
- Motivational interviewing - Information on external suppliers available through the internet
- Macmillan Learn zone - video example available summer 2013
- Advanced communication skills – https://www.connectedonlinebookings.co.uk

**TOP TIP**
Set realistic achievable objectives. For instance, 'within 12 weeks of the end of treatment 50 per cent of colorectal cancer patients will have had a needs assessment and a care plan that addresses their needs'.

Completion of care plans may be included as a CQUIN requirement so agreement may have been reached with commissioners on what this means and how it will be measured.

As well as immediate feedback from patients there are ways that teams can measure the efficiency and effectiveness of the needs assessment service. Here are some suggestions.

| Measure | Data source | Comment |
|---|---|---|
| The number of formal needs assessments completed versus those planned | PAS clinic attendees | If not set up on PAS, an alternative way to record activity should be agreed. Also record assessments offered but refused. |
| Telephone calls to helplines | Helpline log book | As the quality and depth of information provided increase the calls to the helpline should reduce. Some trusts have agreed a tariff cost for telephone advice. |
| Type and volume of referrals to support services | Care plans | As needs are identified referrals may increase |
| % saying they received information about self-help groups | National Cancer Patient Experience Survey | Annual survey results available at trust level (note 1) |
| % saying they received information about financial advice or benefits | National Cancer Patient Experience Survey | |
| Sufficiency of emotional support | National Cancer Patient Experience Survey | |
| Perception of services and support across teams feeling 'joined up' | National Cancer Patient Experience Survey | |
| Staff competencies to undertake assessments – self assessment | Self-assessment skills audit - health care professionals | On-going |
| Patient reported outcome measures, e.g., trouble with sleeping, anxiety and depression etc. | Quality of Life of Cancer Survivors (PROMS)[25] | Include in performance development plans |
| Complaints | Trust complaints team | Annual survey – NB report is not trust specific |
| Clinical measures pre and post referral for physical activity | Case notes | Identify common issues that could be addressed through the needs assessment process |
| E.g. BMI, Blood pressure, self-efficacy | Assessment records | See Bournemouth case study (reference 10) |

Note 1: link to trust level reports www.quality-health.co.uk/surveys/2011-2012-cancer-survey-trust-level-reports

[25]PROMS patient questionnaire. Colorectal Cancer 2011

## STEP 2 - TESTING AND IMPLEMENTATION

### Set up clinics on patient administration system (PAS)

Following mapping, additional clinic session may be required to support needs assessment and care planning. Agreement should be reached on the frequency of the clinic, clinic lead (i.e. nurse led, AHP, medic-,) the number of appointment available and whether assessments will be face-to-face or by telephone. This information will help inform the tariff for this activity.

In many provider organisations new clinics require approval internally within the Trust and from commissioners. Seek advice from your service manager if unclear.

Environmental issues also need to be considered such as:

- a quiet room that can be used where discussions will not be disturbed;
- access to a computer and printer for information that may be needed during the conversation; and
- whether refreshments are available.

Further tips on preparing for an assessment can be found within the Holistic Needs Assessment -A practical guide for health professionals' (see reference 26).

### Test the process

As with all improvement activity use a 'plan do study act' (PDSA) approach to test the assessment process.
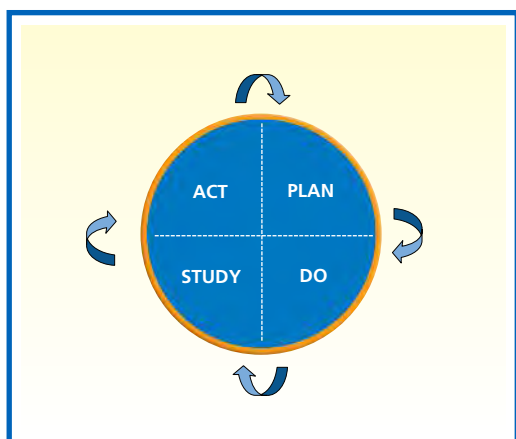
> **TOP TIP**
> Find out if there are any unused clinic sessions within specialty that could be reallocated for end of treatment assessment and care planning clinics. You may find several clinics are set up on PAS but are not used.
>
> Avoid running new clinics in parallel with consultant clinics. This will reduce the risk of disruption.
>
> Confirm with commissioners the process for referrals to clinical support services, e.g. sexual dysfunction, or counselling. Avoid the need for re-referral via the GP.



- Test first on a small scale – one clinic, two or three patients, one day – this minimises the risk of time and money and is safer and less disruptive for patients and staff and builds confidence.
- Increase the numbers booked to the clinic as the process is refined and competence and confidence increases.
- Test with people who are willing and happy to participate.
- Only implement fully when you are confident that you have considered and tested all the possible ways of achieving the change.
- Check and recheck that the process works (see reference 13 for PDSA template).

**In evaluating the process ask yourselves …..**
- Is the process clear for identifying patients for an assessment?
- Were the patients prepared for the assessment and were they given sufficient information before the appointment about what to expect?
- Was it made clear whether relatives and carers should be present during the assessment?
- Were there practical issues identified such as transport issues, interpreters, room layout?
- How long did the assessment take? (NB. As confidence increases the time should reduce).
- Did you have all the information in order to conduct the assessment effectively, e.g., case notes, copies of any previous assessments, directory of services and stationary items.

A summary of the findings[26] identified through testing and 'Holistic Needs Assessment and Care Planning – Sharing Good Practice'[27] provide further information.

**Prepare to scale up**

At this stage you will need to ensure that the whole team are signed up to this process, understand its importance and their role in supporting any change in practice. In particularly you will need to ensure that administrative and clerical staff are aware of the clinic and how patients should be booked. This includes reception staff who may be meeting patients on arrival.

> **TOP TIP**
> Have a senior clinician/manager send out a 'launch email' which will ensure all clinical staff in the department are aware of what is being implemented and when.

Before scaling up, complete the following check-list for readiness

| | Yes | In progress | No |
|---|---|---|---|
| The future patient pathway is agreed | ☐ | ☐ | ☐ |
| Assessment referral process confirmed with the multidisciplinary team | ☐ | ☐ | ☐ |
| Clinics (if required) are set up on PAS | ☐ | ☐ | ☐ |
| Assessment tools confirmed | ☐ | ☐ | ☐ |
| Care plan documentation agreed | ☐ | ☐ | ☐ |
| Staff are trained and competent to carry out assessments | ☐ | ☐ | ☐ |
| Demand and capacity exercise complete and resources identified | ☐ | ☐ | ☐ |
| Directory of support services available to staff | ☐ | ☐ | ☐ |
| The team have been appraised of the assessment process and their roles in supporting this | ☐ | ☐ | ☐ |
| A suitable space has been found to undertake the assessments | ☐ | ☐ | ☐ |
| Measures have been agreed and base-lined and data collection methods agreed | ☐ | ☐ | ☐ |

The team will need to closely monitor the process over the first months and proactively address issues to ensure that slippage to the old system does not occur.

[26]Assessment and care planning: Lessons learnt from testing.NCSI (December 2010)
[27]Holistic needs assessment and care planning – sharing good practice (Winter 2012)

### STEP 3 - SUSTAINABILITY

Once the service is established it may take time to realise the benefits in terms of patient experience, clinical outcomes or efficiency.

Along with the collection of a few measures there are other things that should be considered to support sustainability.

#### Operational enablers
- **Governance** - Develop an operational protocol to support needs assessments and care planning. The protocol should reflect roles and responsibilities and governance arrangements where necessary. It should be part of new staff induction.
- **Publicity** - Place posters and leaflets[28] in waiting rooms[29] to inform patients they can ask for an assessment and care plan. Ensure publicity and good practice is shared locally within networks and nationally through conference events, poster submissions, and award nominations and so on.
- **Electronic templates** - Once templates for care plans have been tested and agreed arrangements should be made to install electronically and prefilled with patient data sets and other existing information where appropriate. Ideally this should record the assessment outcomes within the electronic patient record and will enable rapid transfer of the information (with the patient consent) to the primary care team.

#### Workforce and training
- Manpower – The service should not be dependent on one member of staff.  Resources should be available to cover annual leave and sickness
- Include assessment and care planning in all relevant job plans and job descriptions and person specifications
- Ensure training is available for new staff as they join the organisation and especially where this is a core requirement of their role. Joint learning programmes for primary and secondary care teams will enhance team working.  Record training needs in annual appraisal reviews.

#### Continual review
- Schedule periodic reviews of the process and effectiveness of needs assessments with patient groups, with the specialist team and between specialist teams. Sharing the learning will support continuous improvement. Present any measures and outcomes that are available showing the improvement to quality, experience and effectiveness.
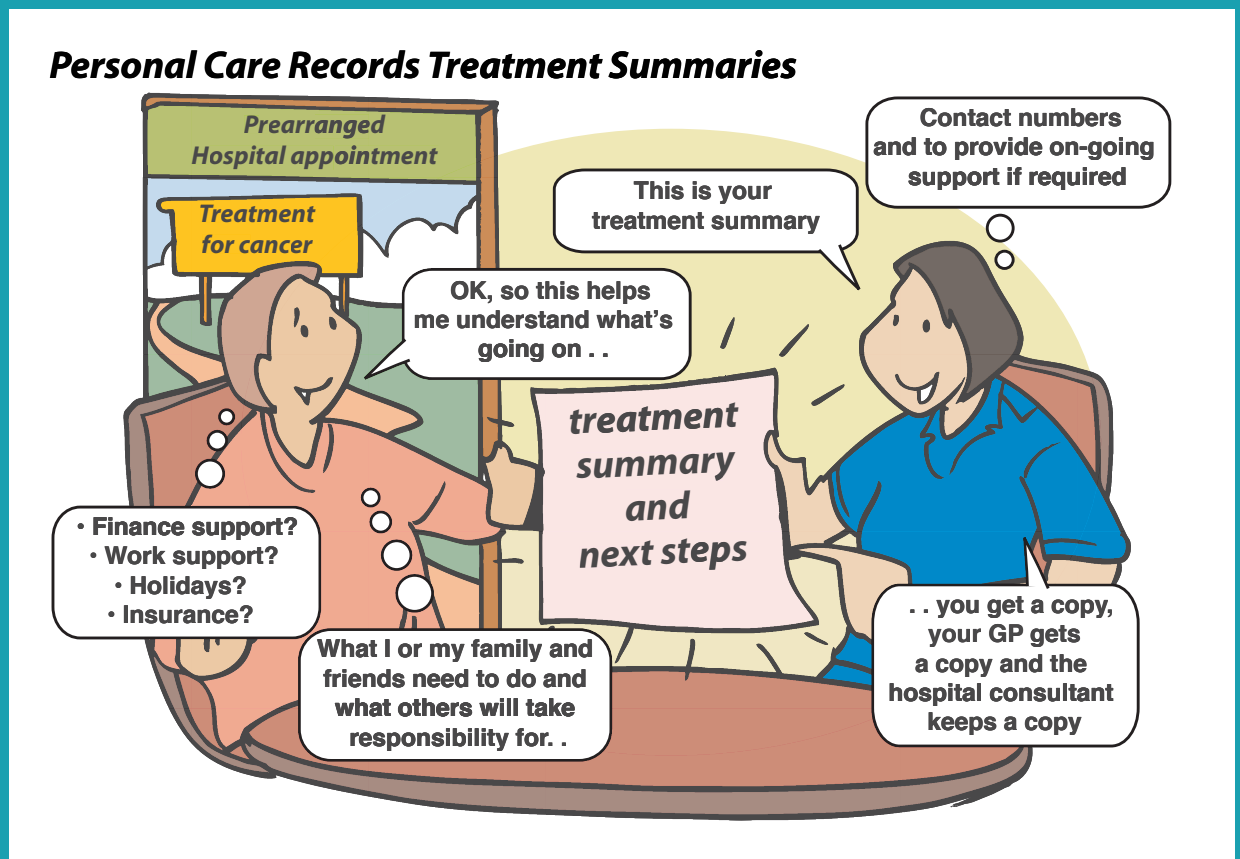
---

[28]Assessment and care planning patient leaflet. Macmillan cancer support.
[29]Assessment and care planning poster -  Pan-Birmingham Cancer Network

# → Personal care records and treatment summaries



**Personal Care Records Treatment Summaries**

# PRINCIPLE 3: Individuals should have a personal care record that includes a treatment summary

### What is a personal care record?

A personal care record is patient held and contains information provided to the patient during all stages of care and treatment. This might include:

- treatment plan;
- self–assessment and care plan;
- treatment summary;
- clinic letters; and
- key contact details.

Supporting information may also be included for example:
- Tumour specific information and fact sheets
- Decision tools on treatment options
- Local directory of support services

A folder or document wallet is provided by many Trusts at or around the time of diagnosis. The 'Macmillan Organiser' is available for those that do not have Trust versions available. Breast Cancer Care and Prostate Cancer UK have similar organisers.

Note. This differs to the NHS 'Summary care record' being introduced across all GP practices in England. This is an electronic record of important information about patients including allergies, previous bad reactions to medicines and current medications. The summary care record will only be available to health-care staff and will help to ensure the right people have the right information at the right time particularly in an emergency situation.

The treatment summary is a document produced by the specialist team at the end of treatment for cancer and at other subsequent trigger points. It is developed for the patient copied to their GP and provides information on diagnosis and treatment the patient has had, the short and longer term side effects, and the signs and symptoms of recurrence. It also provides key contact details should there be any future worries or concerns.

Initially designed for use in cancer it could be adapted for use within other disease groups.

### Why provide a treatment summary?

Patients value summary information on their diagnosis, treatment and follow-up plan. It helps them to inform health care professionals they may come into contact with and for other practical uses such as returning to work or for travel insurance purposes.

Young people, for whom treatment may have started when they were children, find them particularly useful and the summary can play an important part in their transition to adulthood and to accessing adult services.

The treatment summary can also help to improve the communication between specialist and primary care teams and to assist GPs to better support patients and carers in the community. A scoping exercise by the NCSI in 2010 found that whilst GPs received lots of information from the specialist over the course of a patient's cancer treatment, what was missing was a summary of diagnosis, treatment and a management plan to enable patients to be better managed in the community and avoid unnecessary referral back to the specialist team.

**How to introduce treatment summaries**

**STEP 1 - Planning**

- **Discuss and agree proposal with Trust cancer lead and stakeholders**
- **Agree scope**
- **Understand the process**
- **Agree how patients will be indentified**
- **Agree who will complete the Treatment Summary**
- **Agree format and storage including management of READ codes**
- **Agree measures for improvement**
- **Communicate plans with other members of the multidisciplinary team**

**STEP 2 - Testing and implementation**

- **Complete checklist of readiness**
- **Test**
- **Scale up and continually review**

**STEP 3 - Sustainability**

- **Develop electronic solutions**
- **Commissioning specifications**
- **Audit effectiveness**

### STEP 1: PLANNING

#### 1. Discuss and agree proposal with trust cancer lead and key stakeholders

Discuss the proposal and the benefits of treatment summary with the trust lead cancer nurse and cancer clinical lead. This quality improvement component of the pathway will require a change in practice for clinical and secretarial teams and their support and enthusiasm in progressing this will be invaluable.

A similar discussion is required with the lead clinician for the tumour group and the identification of a lead to help develop and implement this change.

One of the main beneficiaries of the treatment summary is the GP. Early discussion with the Clinical Commissioning Group (CCG) about providing these is important.

The Macmillan GP advisors have driven the introduction of this initiative and can provide support to you during implementation. To find out who is your local Macmillan GP advisor contact macmillan_primary_care@macmillan.org.uk .

Other stakeholders will include patient representatives, secretarial staff, outpatient nurses, clinic booking clerks, MDT co-ordinators and cancer information leads.
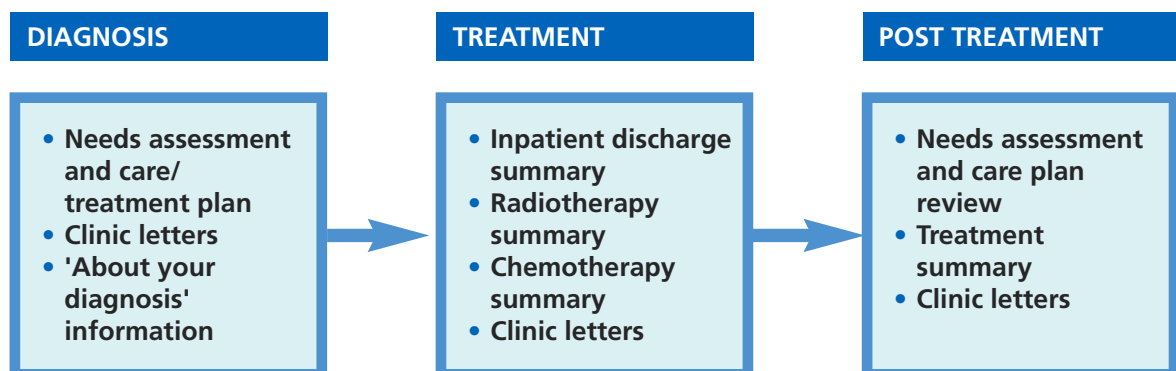
**2. Agree scope**
Questions to ask:

1. In which tumour groups do you want to introduce the treatment summary? For example, in urology will it apply to prostate cancer or all urology cancers?
2. Are there any types of patients that will be excluded, e.g., those on long term hormone therapy, active surveillance etc?
3. Who will complete summaries for those attending tertiary centres?
4. What level of detail is required on treatment delivered?
5. Who will receive a copy of the treatment summary?
6. What is the likely demand for treatment summaries at the end of treatment and other points in the pathway? What can reasonably be delivered?
7. Can the treatment summary replace any existing documentation?

**3. Understand the process**
Undertaking a simple process mapping exercise will help identify the points at which components of the personal care record should be produced. A more detailed mapping exercise may be required to clarify details.

**Personal care record - document flow**

| DIAGNOSIS | TREATMENT | POST TREATMENT |
|---|---|---|
| • **Needs assessment and care/ treatment plan**<br>• **Clinic letters**<br>• **'About your diagnosis' information** | • **Inpatient discharge summary**<br>• **Radiotherapy summary**<br>• **Chemotherapy summary**<br>• **Clinic letters** | • **Needs assessment and care plan review**<br>• **Treatment summary**<br>• **Clinic letters** |

Map the process to confirm the point at which the treatment summary will be generated.   The first treatment summary should be completed within four to six weeks of the end of treatment once it is confirmed that no further treatment is required.

**TOP TIP**
Consider whether the treatment summary could replace the standard clinic letter on this occasion.

**4. Agree how patients will be identified**

In preparation for outpatient clinics it can be difficult in advance to identify which patients will require a treatment summary to be completed. The outcome of pathology tests or post treatment scans may not be known or treatment may be incomplete.

> **TOP TIP**
>
> Ask radiotherapy and chemotherapy teams to copy summaries of treatment to the clinical nurse specialist to make them aware that a phase of treatment is complete.
>
> Ask outpatient clinic nurses to identify post treatment patients by adding treatment summery sheets or a sticker to front of case notes.
>
> Ask secretarial staff who normally type up the standard clinic letter, to trigger completion of the treatment summary.

In some specialties, the multi-disciplinary team reviews each patient once treatment is complete and, should no further treatment be required, recommends the proposed follow up pathway. The health care professional managing the patient should discuss the proposed follow up pathway with the patient at their next visit and complete the treatment summary.

**5. Agree who will complete the Treatment Summary**

The treatment summary was designed for completion by the consultant with overall responsibility for management of the patient in consultation with other members of the multidisciplinary team involved in the care of the patient. Local agreement should be reached between clinicians on who holds responsibility for issuing the treatment summary and who has responsibility for coordinating its completion if more than one person is involved.

Ideally once treatment has completed, one clinician should manage the patients during follow up. In some circumstances, such as in colorectal cancer, this responsibility may transfer to a nurse specialist immediately following discharge from hospital after surgery.

Some trusts have opted to combine the care plan and treatment summary as one document that is completed by the nurse specialist at the end of treatment. This can work well though there may be instances where the patient is happy for the GP to receive factual information regarding treatment but would prefer not to share information about specific care needs identified during the assessment process.

Agreement on who completes the treatment summary should be documented within the operational protocol.

> **TOP TIP**
>
> Oncology teams are required to complete a treatment summary following completion of each phase of treatment. It provides information to the GP on drug therapy used, specific side effects to be aware of etc. These should not be confused with the overall treatment summary to which this section refers. You may wish to rename the modality specific summaries to avoid confusion.

## 6. Agree format and storage of treatment summaries including the management of READ codes

The example design[30] of the treatment summary has been developed by clinicians and Macmillan GP advisors over the past few years. A user guide[31] has also been developed to support implementation.

Three different formats for the treatment summary are provided in the guidance.

- Standard treatment summary template
- Structured letter template
- Electronic solution (see also sustainment section)

There are no copyright issues so any of the templates can be adapted to suit local community or IT systems.

### READ codes

The sample treatment summary contains a list of the common 'READ' codes for the two IT systems used in primary care. It is the GPs responsibility to assign the correct READ code not the specialist teams. GP READ codes are similar to healthcare resource group (HRG) codes and are used to identify diagnosis, tests and treatment. They are included in the template purely to remind GPs to code their patients correctly and thereby improve patient safety in terms of future surveillance (e.g. cardiac), disease tracking and audit.

### 7. Agree measures for improvement

At the planning stage you should consider how you will measure the process and effectiveness of the treatment summary

Suggested measures might include:

**TOP TIP**

The list of common codes can be sent to each local practice for them to use as an aide memoir rather than send out the list with each treatment summary issued

For other cancer codes not included in the core sample contact your Macmillan GP advisor.

| Measure | Data source | Methodology |
|---|---|---|
| The % of patients who have a treatment summary in their case notes at six months or more after completion of treatment | Medical case notes and cancer registry | Review of 20 sets of case notes on people who completed treatment six months previously |
| Usefulness of treatment summary within primary care | Local Survey | Use questionnaire developed for original testing[32] |

[32]GP Questionnaire on Treatment Summaries

### 8. Communication

The multidisciplinary team will need to be kept up to date on the progress of the plan to implement the use of the treatment summary. Clinicians involved in the care of patients will wish to be kept involved and participate. There may be some resistance to its introduction given that the standard clinic letter is generated quickly using a dictaphone and completion of treatment summary may take longer to complete. The project lead will need to spend time with the team to agree the simplest way to introduce this new document.

The patient voice will be a key lever in supporting implementation. Patients value these summary documents and their backing will encourage the team to identify a way to ensure the summaries are produced.

### STEP 2 –TESTING AND IMPLEMENTATION

### 1. Complete checklist of readiness

| Action | Yes | In progress | No |
|---|---|---|---|
| Has the proposal been agreed with the lead cancer nurse and cancer clinical lead | ☐ | ☐ | ☐ |
| Has the process for completion been agreed by the team | ☐ | ☐ | ☐ |
| Has format and storage of the treatment summary been agreed | ☐ | ☐ | ☐ |
| Have key stakeholders been consulted | ☐ | ☐ | ☐ |
| Is the solution available electronically | ☐ | ☐ | ☐ |
| Have measures for effectiveness been agreed | ☐ | ☐ | ☐ |
| Have plans been communicated with the team | ☐ | ☐ | ☐ |

**2. Test**

Use a PDSA approach to first test on a really small scale, for example for one or two patients who have recently completed treatment.

Identify a clinician who is willing to complete the summary. Ensure the case notes are available and time how long the summary takes to complete and then repeat the process for the next patient. This can be tested by any member of the clinic team such as the consultant, registrar, nurse specialist.

Test the feasibility of storing the treatment summary on the Trust EPR system and how others involved in supporting patients such as physiotherapists, nurse specialists can contribute to its completion.

**TOP TIP**

Start with the obvious patients first. You will not identify all patients first time around due to the complexity of cancer treatment and multiple site locations

Enlist the support of specialist registrars or other members of the medical team who may have more time available to support testing.

Treatment summaries may not be appropriate for every patient e.g., prostate cancer patients on 'watchful waiting'. In such cases a simple clinic letter may suffice.

As well as testing the completion of the summary itself, teams should also review the process to identify patients who have reached the end of treatment. Consider the role of the multidisciplinary co-ordinator, radiology and chemotherapy teams, out-patient staff and how they can help.

Gradually increase the use the summary across all members of the clinical team. Awareness training may be required for secretarial staff. The template can be installed as a standard template on the shared server until an electronic and automated solution is available.

**STEP 3 - SUSTAINABILITY**

### 1. Develop electronic solutions

Simplicity and ease of access will help to support continued use. Electronic template versions of the template can be automatically populated from cancer information systems provided by the Somerset Cancer Register[33] and InfoFlex CIMS Ltd. This can then be added to the patient's electronic record, making it quicker and easier for the clinician to complete at the end of treatment.

Both these examples are tailored to organisations to include standard letter heads and contact details and include drop down lists to select the normal signs and symptoms of recurrence for this type of cancer patient as well as the common actions required of GPs. They are very quick to complete.

If you already use either of these cancer information systems contact your system provider for more details.

Somerset – Stella Davies CancerReg@SomersetHIS.nhs.uk
InfoFlex – Phillip Brown
www.infoflex-cims.co.uk/cims/contact

> **TOP TIP**
> If opting to use Somerset or InfoFlex, ensure that the professionals planning to generate the summaries have access to these systems. Note. There may be license implications with the InfoFlex system.

If you use an in-house cancer information management system and would like advice about adding the treatment summary template please contact your local IT lead or email: nyoung@macmillan.org.uk.

### 2. Commissioner specifications

There are some commissioners who have developed CQUINS to support the implementation of treatment summaries. This has the benefit of attracting additional funding to support implementation of electronic solutions.

Note: The use of treatment summaries may be included in the future peer review process.
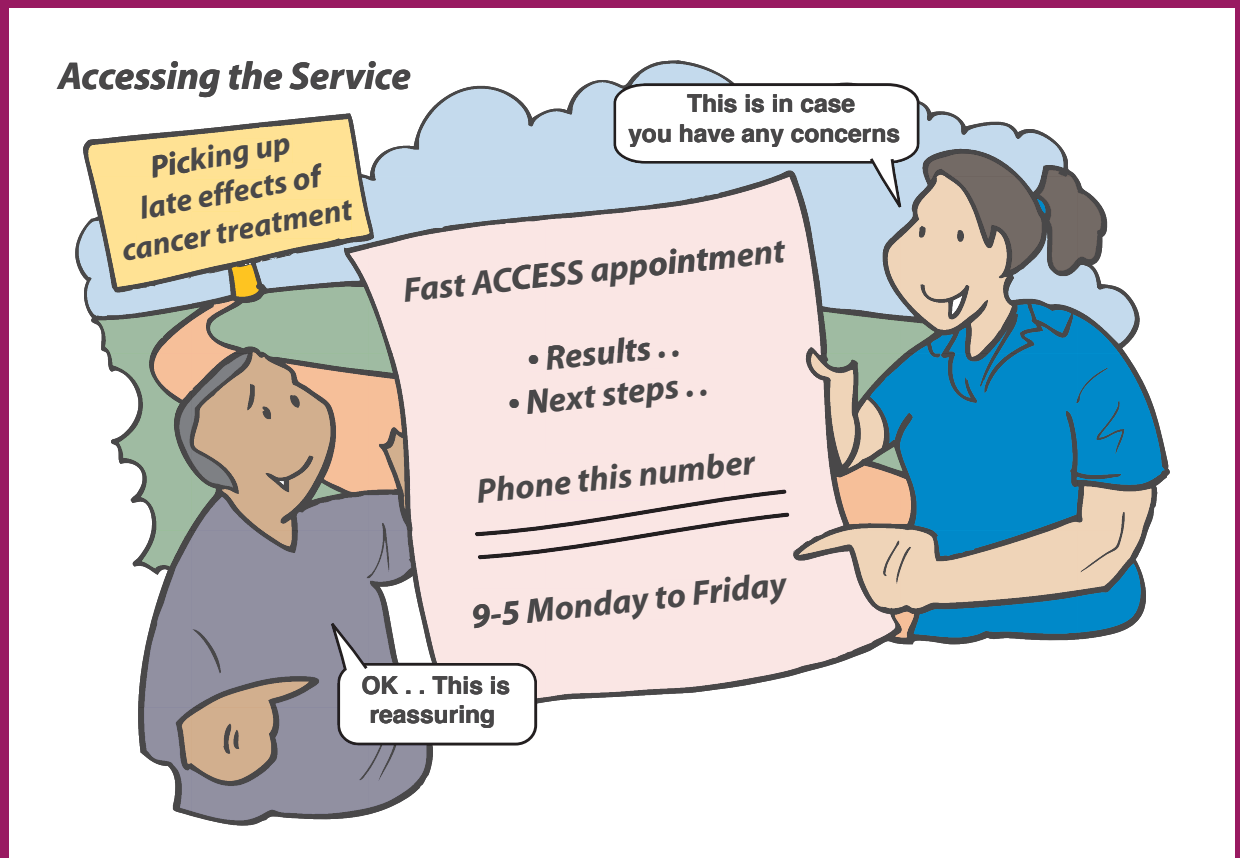
### 3. Audit effectiveness

Periodic reviews of the benefits and impact of the treatment summary should be scheduled. Patients, GPs and secondary care clinicians should be consulted on ease of use and content and any adjustments to the content or lay out of the summary addressed.

[33]Treatment summary - Somerset Cancer Registry

# PRINCIPLE 4:
# → Assessing the service

# PRINCIPLE 4: Timely re-access to appropriate professionals should be guaranteed

## What does this principle mean?

All patients under the clinical supervision of the specialist team should have rapid access back to a professional, if required. This applies to any patient on any pathway either self-referred or referred via their GP and whether needs are clinical or non-clinical in nature.

Re-access may be prompted by:
- the patient or carer;
- the GP;
- the specialist team;
- cancer information centre; and
- third sector organisations, e.g. a charity helpline

Responses should be timely. Patients leaving telephone messages should receive a response within one working day. If there is suspicion of recurrence, the patient should wait no longer than two weeks to see the specialist.

All patients should be provided with up to date key contact details. These should be reconfirmed in writing at all key points in the pathway.

## Why is this principle important?

Treatment for cancer and subsequent recovery will affect people in different ways and at different times. Whilst there is now a good understanding of the likely effects that most patients experience these do not occur with every individual and not necessarily at the time they would normally be expected to do so.

It is imperative that patients (particularly those on a self-management pathway) carers, GPs and those supporting in the community can access advice, support and interventions quickly and responsively and avoid unnecessary delays.

Professionals responding to contacts should be proactive in helping to resolve queries, taking responsibility for coordinating follow up actions on behalf of the patient where possible to do so.

## Protocol for handling enquiries

Organisations need to consider:

- How telephone enquiries are managed and recorded;
- The process of referral for further investigations and specialist advice; and
- The process for referral to other clinical and non-clinical support services.

All units should have an agreed protocol for the handling of enquiries from patients, carers, GPs and other professionals. The protocol should include the standard for response times, clarification of roles and responsibilities, triggers and the process for urgent referrals.

Answerphone messages should be clear and give information on when the message will be picked up and responded to. Out of hours the message should include who to contact should the problem or enquiry not wait until the next working day. These might include numbers for one or more of the following:

- The oncology ward or on call team;
- Hospice number;
- Community palliative care team;
- GP out of hours service; and
- Tumour specific charity helplines. Note. Macmillan Cancer Support offer an extended weekday service Monday to Friday from 9am-8pm. Prostate Cancer UK offer a late service on Wednesdays till 9pm and an email enquiry service for those patients wishing to communicate electronically rather than by phone.

A single helpline service could be established to cover several patient groups

A few units provide patients with individual staff contact details (telephone, bleep or mobile) but this can raise expectations and may delay response times for instance when staff are on annual leave.

### Process for re-calling patients

All team members should be aware of referral criteria and routes back to the specialist team or to support services for patients if required.

The nurse specialist should, where possible, have authorisation to arrange further tests and or urgent appointments with the specialist should concerns raised by the patient or their GP suggest recurrence of the cancer.

The process for re-accessing the service should support the needs of the patient. Process requirements to support funding payments should be secondary considerations. In principle, all support services relating to cancer treatment or the effects of treatment, should be accessible directly without recourse to primary care.

> **TOP TIP**
> Some support services may be more accessible or appropriate via community services. This might include counselling, sexual dysfunction, continence services. Find out what services are available locally and agree as part of a local service specification.

Any suspicion of a new cancer or a recurrence normally prompts a series of repeat investigations, a discussion at the MDT, a new patient consultation where further treatment options or management are discussed. Recall to any specialist clinic should be funded at the higher 'new' patient tariff rather than a 'follow up' tariff to reflect the additional expenses incurred.

> **TOP TIP**
> Consider with commissioners a process that avoids unnecessary steps for the patient. For example if a patient contacts the specialist team reporting symptoms of a possible recurrence the referral back in to the team should not necessitate a GP visit to arrange this. The team could simply notify the patients' GP and request an urgent referral under the two week wait rule. This ensures the patient receives a speedy uncomplicated referral and that care is coordinated and funded appropriately.

**Measures - activity and effectiveness**
Organisations should audit and measure the effectiveness of their help-line service to:

• monitor response times
• dentify number and reason for contact with the service

Teams should identify the measures that will support improvements and continually seek ways to improve the service to patients

Investment in personalised information, effective needs assessments care planning, education and good written information and treatment summaries should result in fewer calls to the specialist team. Patients should be better informed and know who and when to call for advice and support.

**Supporting documentation**
All patients should be provided with information and education relating to re-accessing the system. The needs assessment and care plan at the end of treatment provides an excellent opportunity to reinforce these.

Professionals have a responsibility to ensure that patients understand and are aware of what signs and symptoms they need to look out for in the future, what to do about these and who to contact.

It is not uncommon for patients to have several 'key workers' during their care and it is important that written contact details are confirmed at each point in the pathway to avoid confusion and misunderstanding. The team should agree roles and responsibilities for informing the patient when details change. This also applies to tertiary centres where patients may be referred for specialist surgery or treatment before returning to the host centre for on-going follow-up.

**Training**
All staff handling calls from patients and carers as well as other professionals should ensure enquiries are handled sensitively and effectively.

Staff must be able to handle confidential patient data in a sensitive and discrete fashion in compliance with Trust policy and procedure guidance.

Staff should be confident in approaching team members for advice and support and communicate any short falls in the service identified by callers that require action and escalation.

Training needs should be identified within job descriptions and person specifications and training needs addressed within annual performance reviews.

**Establishing a helpline**

Identify a dedicated direct dial telephone line with answerphone. (A new phone line may be required). Lines should be located in an area where sensitive conversations can be undertaken in private and without undue background noise. Ideally the line should be located close to the specialist nurse base.

Agree the date that the help-line is to be launched and ensure publicity material is available within patient information documents, posters in waiting areas and the local cancer information centre. You may wish to add details to the Trust website.

All calls to the service should be logged and monitored and include:
- Date and time of call;
- Patient name and NHS number;
- Contact telephone number;
- Status – pre treatment, in treatment, post treatment;
- Reason for call; and
- Outcome of call.
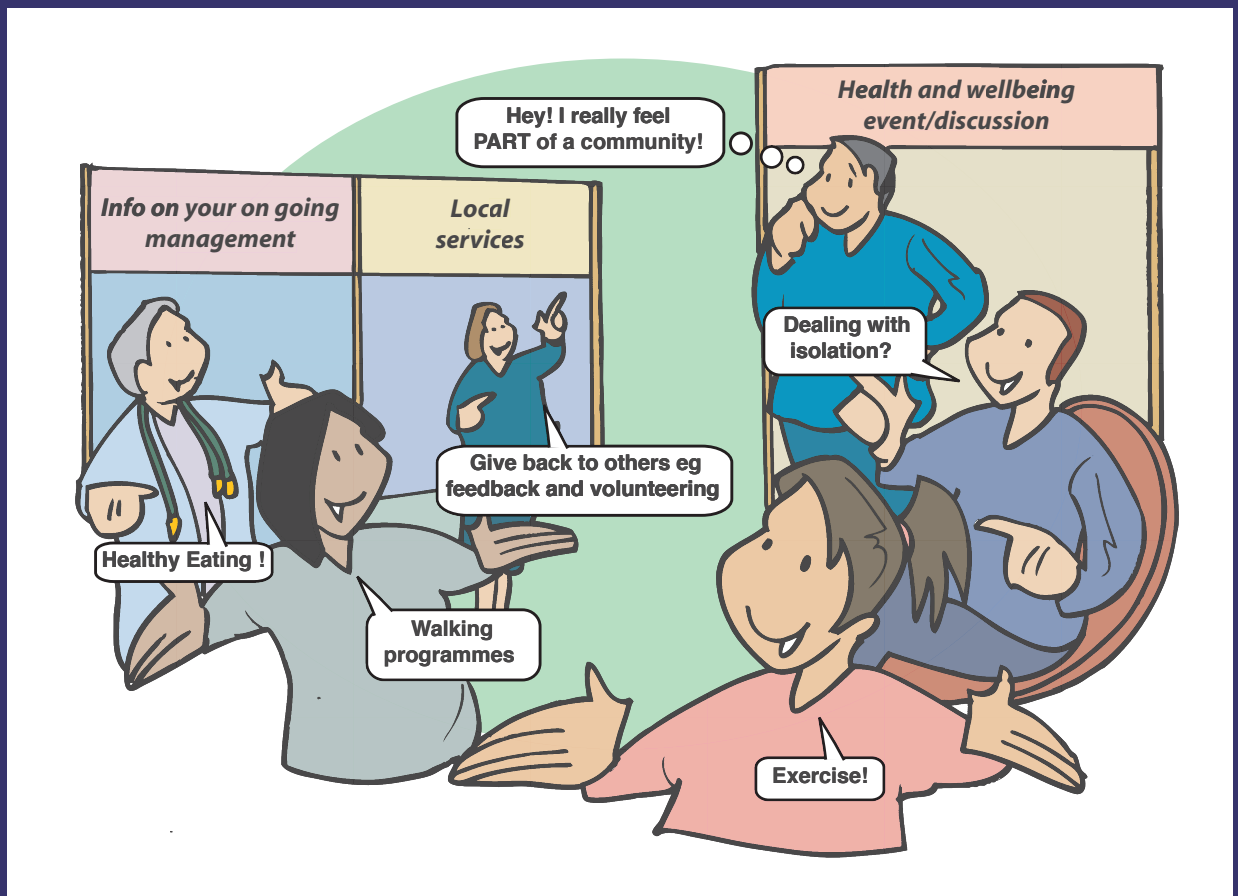
Any on-going clinical or referral details should be recorded in the patient health record or on the surveillance monitoring system.

TOP TIP
Agree a reliable messaging system for enquiries requiring action by staff. Avoid post it notes.

# PRINCIPLE 5:
# ➡ Information and education

# PRINCIPLE 5: Information, advice and support should be tailored to individual needs

An informed patient is better placed to make decisions about their care and well-being, and manage changes in their health status. Information gives people the autonomy and confidence to become partners in their care. It helps them to regain a sense of control over their lives and can reduce the fear and loneliness that the diagnosis of cancer or a long-term condition can bring.

There is good evidence that patients who are given and supported to use information to make decisions about their care:
• are able to manage their condition more effectively;
• use NHS services less often than patients who have not been given
• information;
• choose less invasive (and less expensive) treatment options;
• have fewer repeat consultations with health professionals;
• have fewer unscheduled admissions to hospital, and lower rates of readmission; and
• comply better with medicines regimes, leading to fewer wasted drugs.

### What do we mean by tailored information, advice and support?
**Tailored information**
It is important that information is provided to meet the individual's needs and choice is offered as to how the information is delivered. This may be a combination of generic and tailored information and may include sign-posting to appropriate services arising from the assessment and care planning process. Information can be presented in a number of formats from written leaflets and booklets, electronic media such as CD-ROM or DVD and interactive education and information through websites.

Information prescriptions is a national initiative which aims to co-ordinate a package of information tailored to the individual.

**Advice and support**
Advice and support can be provided through:
• help lines which are provided by the NHS and cancer charities;
• patient groups which may be facilitated by clinical nurse specialists;
• clinical teams in hospital and primary care through a key worker; and
• a local directory of services where patients can be signposted to help meet their needs.
• cancer information centres

### Approach and current service provision
The team should consider current information provision and whether it currently meets patient needs at each point in the pathway.

In deciding the approach a variety of options may be required. Trusts should be mindful that not one size fits all and that those patients who are socially isolated and have low confidence are likely to require more support to be able to self-manage than others.

Equally the receptiveness of patients to accept information advice and support will vary. Some will wish to move on from their illness as soon as possible and not 'dwell on things' whilst others will benefit from the opportunity to learn more and share their experiences with others.

It is also worth undertaking an analysis of local stakeholders who could potentially support interventions or improvements including charities, public health colleagues, local authority services such as gyms and leisure clubs. Seek out and discuss opportunities to link with other referral schemes such as courses supporting cardiac rehabilitation or long term conditions such as diabetes.

**Information events and programmes**

Education can be delivered one to one, as single day events or programmes spanning several days or weeks. The day events or programmes can be targeted at specific cancer types or generic across different cancer types. The aim is to help people to improve their quality of life and the ability to self-manage their condition.

The single day events offer a one stop approach which brings together a range of professionals covering clinical and non-clinical support and information. Most education events are aimed at those recovering from primary disease and treatment though charities and some organisations also run events specifically for those with a recurrence of cancer or active and advanced disease.

Educational programmes running over several weeks are offered to those who need more in depth information and support. The programmes are generally aimed at building confidence, managing anxiety to build resilience and using goal setting to achieve behavioural change.

Testing within NHS Improvement test sites, Macmillan cancer support pilot sites and elsewhere have demonstrated that both options have been well received amongst patients, carers and professionals.

All types of events should include an evaluation process to learn and improve for future events. This should include a post event briefing with both professionals and volunteers involved in leading the events.

**Organising an event or programme**

Initial things to consider:
- generic or specialty based event;
- planned frequency;
- eligibility – all patients, patients at certain stage in the pathway, carers?;
- how it will be publicised; and
- available resources.

These factors will guide the scope of presentations and venue selection.
- **Venue** - consider, room size; ambiance; seating; kitchen facilities; storage (especially if this going to be a regular venue); disabled access; break out areas; space for stands; parking; and public transport connections.
- **Identifying patients to invite** - a systematic approach to tracking patients through invitation and attendance should help to ensure that all patients who can benefit attending an event have the opportunity to do so. Open invitations through posters or through local media should request that people phone to book a place. This way you will know the numbers planning to attend.
- **Format** - there is no prescriptive model and teams should experiment and innovate to tailor events to the intended audience. The model of presentations accompanied by a series of market stalls appear to provide the most effective support and seems to work well.

> **TOP TIP**
>
> If an outside venue is required consider locations that may attract the patient group such as the local rugby club for prostate cancer patients. For on-site venues consider using post graduate centres late afternoon or early evening when less busy and when parking is easier.
>
> Avoid sitting people in rows – for small groups a horseshoe arrangement is more relaxed and encourages discussion. For larger groups arrange in cabaret style.
>
> Hospital transport may not be available for getting people to events especially if off site venues are used so consider public transport connections or seek help through your local volunteer driver service.

- **Content**

Suggested core elements of education events should include:
  - diet – healthy eating and nutrition;
  - physical activity - benefits and local opportunities available;
  - emotional health – managing anxieties, worries and fears;
  - relationships, sexuality, body image;
  - returning to work, benefits and finance;
  - managing common symptoms e.g. fatigue;
  - patient personal story; and
  - question and answer session.

A variety of information stands and 'taster' opportunities could include:
  - complementary therapies;
  - relaxation sessions;
  - support groups;
  - stoma therapy and continence advice;
  - charity stalls – Macmillan, tumour specific;
  - physical activity options and an opportunity to sign up to activities;
  - Macmillan benefits advisors;
  - local colleges and libraries to promote short courses available
  - hospice; and
  - travel insurance advice.
- **Timing** - events are generally aimed at those who have recently completed treatment. An event at three to six months after the end of treatment seems to work well for most patients. The tumour type may determine to some extent the timing and format of the event. For some patients a group event may not appeal for some time after treatment has ended. Others may wish to attend on one or more occasion. A flexible approach is required wherever possible.In lung cancer, events are usually planned soon after diagnosis for those not receiving treatment with curative intent.
- **Staffing** - the type, content and scale of the event will determine the health care professionals required on the day. At a minimum this should include the clinical nurse specialist, allied health professionals and a consultant.

An administrative or coordinator will be required. This may be part of an existing role or a function of a key worker. The role can be undertaken by trained volunteers. Their role includes arranging the date, venue, refreshments and administer invitations, booking and liaising with patients.

Note: As the scale of traditional follow up for 'well' patients reduces consultants have welcomed the opportunity of attending the information days to keep in touch with those who have recovered and are doing well.

**TOP TIP**

Allow time for introduction and getting to know each other and allow reasonable time for lunch if the day is mostly presentations as people do like the opportunity to talk and meet each other.

Arrange for someone to 'meet and greet' as people arrive and provide refreshments. Ask volunteers to help support this.

Consider providing an opportunity to ask questions anonymously that may be of benefit to the wider group i.e., 'The question you want to raise but were afraid to ask'. This works well for questions relating to sexuality, body image etc. It also provides control in dealing with inappropriate questions or managing people who dominate discussions.

**TOP TIP**

Ensure information day events are confirmed in staff diaries before events are publicised and consider contingency cover in the event of an emergency.

## CASE STUDIES

**North Bristol NHS Trust**[34] offer: A rolling programme of 'Living Well' tumour specific events run as half or full day events with talks by a range of health care professionals. The focus is on health and wellbeing, recovery and rehabilitation and education in self- management. Talks cover, signs and symptoms of recurrence; reducing risk factors; managing the side effects of disease and treatment; managing anxieties; and stress management. A self-care plan completed at the end of the event encourages patients to summarise what they plan to do regularly to look after themselves and to stay healthy. For information contact: 0117 3232 6283.

**Ipswich Hospital NHS Trust** offer: Twice yearly cancer information days which are publicised in the hospital, GP waiting rooms, local newspapers and local radio stations. The last event attracted 150 attendees. Funding for the venue and refreshments is from trust charitable funds. Speakers and 'market stall' holders offer their time free of charge. Contact: louise.m.smith@ipswichhospital.nhs.uk

### Information programmes

Similar to information days, information programmes offer more structured support and the opportunity to address issues in more depth. These can be arranged in house or run by charities and other providers. Programmes and generally run as smaller groups of say 10-12 people and comprise shorter sessions of 2-3 hours with one or two topics covered per session.

Meeting others regularly over several weeks helps to build trust and forges friendships, encouraging peer support in the longer term.

## CASE STUDIES

A two day course at **Mount Vernon Hospital** for head and neck cancer patients once their primary treatment is complete. Led by the clinical nurse specialist, the course focuses particularly on diet and speech as well as the longer term consequences of treatment, e.g. dry mouth due to radiotherapy damage to the salivary glands.

**'Moving forward'** - this Breast Cancer Care Charity led four week programme is held in association with **Guys and St Thomas'** and **Kings College Hospital**. It focuses on issues that may affect patients and information and provides professional guidance on topics such as, lymphoedema; exercise; diet; breast awareness; coping with anxiety; stress; intimacy; and relationship issues.

The **'HOPE'** course (Helping to overcome problems effectively) at **Ipswich Hospital NHS Trust** uses trained facilitators to lead small groups. It focuses on problem solving and action planning to promote healthy lifestyles and recovery as well as helping to cope with uncertainty, anxiety and decision making. The emphasis is on self-management and finding solutions to problems. (This is a Macmillan sponsored programme)

Self-management programmes at **North Bristol NHS Trust** – these are six week group-based courses to address, managing fatigue; condition specific problems; stress management; and combating depressive reactions. They are led by clinical psychologists, nurse specialists and patient tutors and run regularly throughout the year.

[34] Cancer Living Well Programme – North Bristol NHS Trust

**Funding**
Funding requirements will vary widely. The greatest expense usually involves venues so if a suitable in house solution can be found so much the better.

A report by the University of East Anglia[35] evaluated four self- management programmes including; New Perspectives; 'HOPE'; 'Mi@wellbeing'; and 'Moving On' exploring both the benefits and cost effectiveness of each. Financially, no one programme came out as a clear winner and the report concluded that a composite course built on the better elements of the four options would help minimise costs whilst achieving greatest benefits.

See also chapter on commissioning and funding (page 81) and also www.ncsi.org.uk/what-we-are-doing/health-and-wellbeing-clinics for the reports from pilot testing.

**Information prescriptions**
Information prescriptions are available to both professionals and the public. Information prescriptions allow health care professionals to tailor the type and amount of information given to patients based on an assessment of their needs and personal requests.

The Information Prescription Service brings together into one place a wealth of information from NHS Choices and charity partners. Local information can be added against particular topics, e.g., local support groups. Most of the information on the system has been accredited by the Department of Health's Information Standard to ensure that all information produced is reliable, trustworthy and up to date.

The health care professional can generate the on-line information prescriptions by highlighting the condition for which the prescription is needed and selecting the type of information required. Personal comments can be added to highlight key items that staff may want to bring to the patient's attention, or to summarise what has been discussed during a consultation. The information can be printed for the patient at the time or emailed to them to view at home.

Most NHS trusts in England have received training in issuing information prescriptions. For more information go to www.nhs.uk/ips

**Developing a directory of services**
Knowing what resources are available to patients and how to access them is important for all those involved. The key support services identified to support the care pathways can be found on the tumour specific pathways (see reference 1).

As a general rule these should include advice on:
• benefits;
• social care;
• employment;
• rehabilitation services;
• lymphoedema;
• physical activity schemes;
• diet and nutrition;
• financial advice;
• psychological support;
• sexual dysfunction;
• continence services;
• complementary therapies;
• support groups; and
• support programmes and information days.

**TOP TIP**
Seek help from your cancer information centre to help compile the directory and ensure contact details are kept up to date.

Seek advice from patient support groups on local information and contacts they think should also be included in the directory.

Contact the local authority who are required to keep a list of the local authority services available. This may save you a lot of time.

[35] Supported self-management – Final report. University of East Anglia (August 2012)

The directory should be readily available to all those involved in assessing and supporting patient needs. Patients should be provided with details of the services that they can access direct.

**Physical activity and cancer**

The evidence[36] is growing to support the role of physical activity during and after cancer treatment. Physical activity can help recover physical function, reduce the risk of recurrence and mortality and can reduce the risk of developing other long term conditions.

Health care professionals have a key role in promoting physical activity at all stages of the pathway. Evidence shows that if a recommended activity is carefully tailored to the individual it is likely to have a positive effect on the patient.

There are no formal physical activity guidelines for people living with and beyond cancer. However evidence suggests that guidelines for the general public are appropriate when advising and supporting otherwise healthy cancer survivors to gradually build up to health related physical activity.

There are many physical activity initiatives now being made available to patients. Examples include:
• exercise referral schemes - currently available through GPs for those with long term conditions;
• physiotherapist led programmes run within hospital or community centres;
• local authority or private sector schemes. These might include walking groups, Nordic walking groups etc; and
• others initiatives such as swimming, gardening or cycling groups led by volunteers.

Fitness instructors are required to hold Level 3 to support the GP referral schemes and further training to level 4 is required to manage patients who have experienced cancer. Several test site teams have helped train fitness instructors by providing an overview of cancer types, treatments, medications and side effects as well as sharing the evidence based benefits of physical activity and current guidelines on physical activity and exercise management during and after cancer treatment. See the following links for more information on the training available. www.hfigroup.com or www.fitnessindustryeducation.com. Referral processes should be agreed between the trust and providers to ensure safety and minimise risk.

The Department of Health 'Let's get moving' campaign provides other resources. www.dh.gov.uk/health/2012/03/lets-get-moving

---

[36] The Importance of physical activity for people living with and beyond cancer – a concise evidence review
Macmillan Cancer Support (June 2012)

## CASE STUDIES

**North Bristol NHS Trust** in partnership with **Bristol City Council**, run an 'Energise Programme'. It is a community-based project led by the physiotherapy team and follows a structured exercise programme in order to restore physical fitness, self-confidence and knowledge.

**Royal Bournemouth and Christchurch Hospital**, in conjunction with **Littledown Centre**, have a subsidised exercise referral scheme. Suitable and willing patients are assessed by an exercise therapist to assess fitness, goals and motivation. A 12- week programme of activity is agreed. Patients are supported throughout and reassessed on completion of the course.

**Ipswich Hospital** – an exercise referral scheme set up in partnership with six local gyms. It offers a subsidised membership for patients and carers for the first three months and one to one support. Fitness instructors are supported to undertake GP referral scheme and level 4 cancer awareness training.  Additional twice yearly education days cover topics such as lymphoedema, motivational interviewing and communication skills. There is also a swimming group for patients and carers run by volunteers.

Luton - a joint initiative between **Luton and Dunstable Hospital, Active Luton and community nursing teams**. Patients are assessed in order to develop a tailored personal fitness programme with a wide range of choice available. The assessment is repeated on completion. Fitness instructors and clinicians attended a joint training session on motivational interviewing to help patients to set their own goals. This also helped build relationships between staff prior to the launch of the referral scheme.

Information and education
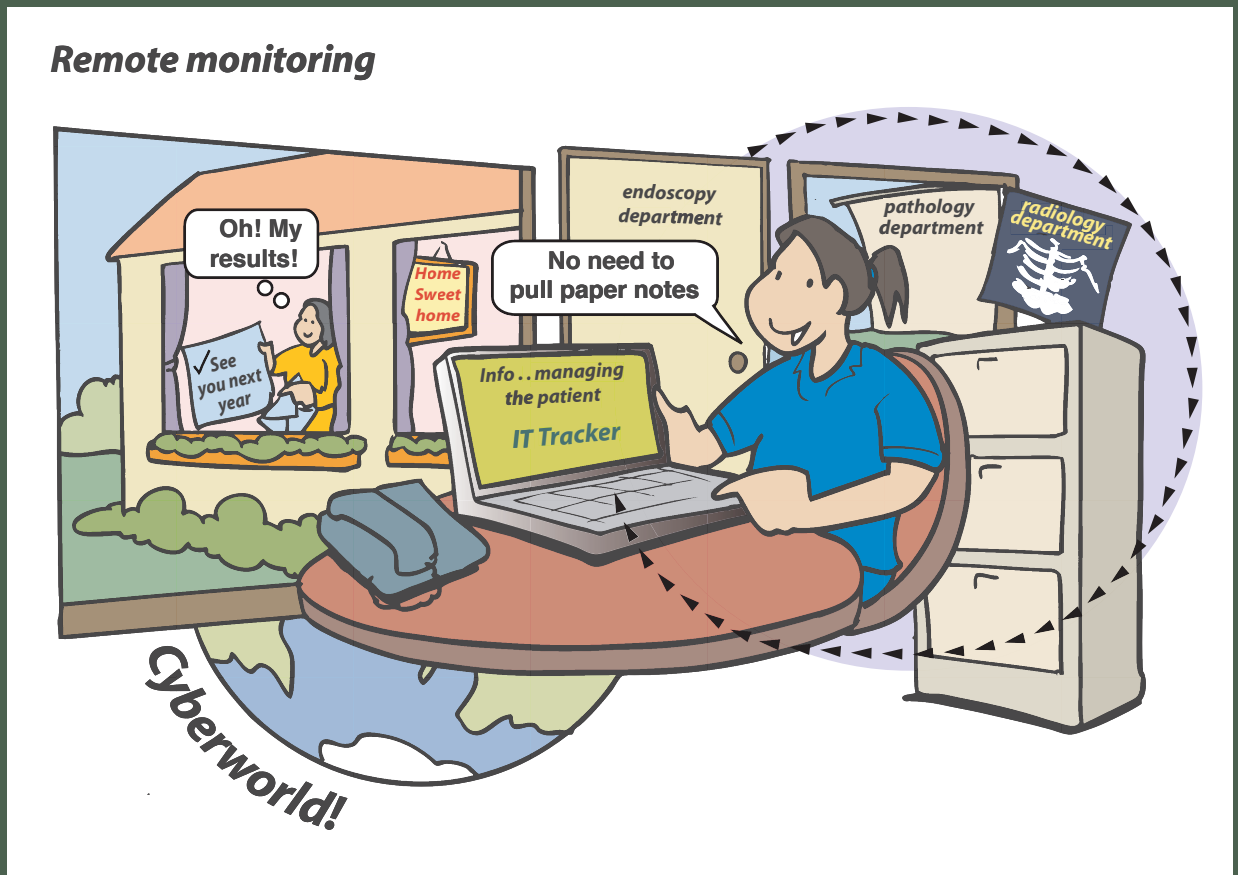
# → Remote monitoring

# PRINCIPLE 6: IT systems should allow for surveillance tests to be monitored remotely

**Remote monitoring – what does this mean?**
Remote monitoring is a term used to describe how the specialist can schedule and monitor surveillance tests for patients who have completed treatment for cancer, without the need for a face to face outpatient appointment to convey the result.

Its primary role is to support low risk patients treated with curative intent that is suitable for a supported self-managed pathway.

Remote monitoring systems should hold sufficient information to enable the clinician to manage the patient without the need to access case notes.

This chapter focuses on a secondary care led solution, however it could be adapted for use in primary care.

**Why do it?**
The traditional method of face to face follow-up is unnecessary for a large proportion of patients who attend outpatients simply to receive the result of surveillance tests. Remote monitoring, as part of a support package for patients, offers an alternative model of care delivered closer to home.

The risk of being 'lost to follow up' in primary or secondary care is reduced. A robust IT solution ensures all patients suitable for a self-managed pathway who require surveillance tests, are monitored safely and appropriately for as long as necessary.

It enables the release of outpatient capacity and reduces demand on clinical and secretarial resources.

It has the potential for use in other specialties and other disciplines.

**How to implement remote monitoring?**

**STEP 1 - Agree project brief (allow up to 2 months)**

- **Confirm project scope.**
- **Evaluate the IT options and agree preferred option.**
- **Consider resource implications to deliver project and sustain long term.**
- **Agree business case (if required).**

**STEP 2 - Implementation (allow 2-4 months)**

- **Establish project team.**
- **Agree project plan.**
- **Confirm functional requirements.**
- **Establish IT infrastructure.**
- **Write system interfaces.**
- **Agree standard documentation and letters.**
- **Agree 'out of area'issues.**
- **Confirm phlebotomy service provision.**
- **Agree operational guidelines and governance arrangements.**
- **Agree outcome measures and ongoing data collection.**
- **Confirm activity tariff with commissioners.**

**STEP 3 - Testing and 'go Live' (allow 2 months)**

- **Test with operational teams.**
- **Training.**
- **'Go live' launch and publicity.**

**STEP 4 - Sustainment**

- **System support and development.**
- **Staff training.**
- **Audit and effectiveness.**
- **Project closure.**

**STEP 1 – AGREE PROJECT BRIEF**

**1. Confirm project scope**
Things to consider include:
• which disease groups will the solution support? Each condition will have a different range of surveillance tests and differing data sources;
• is this a stand-alone solution or do you intend it to have the capability to roll out to other tumour types or specialties outside cancer? Within cancer, remote monitoring has been successfully implemented for breast, prostate and colorectal follow-up, but consideration could be given to extending this out to other suitable tumour types, such as bladder cancer and certain haematological cancers;
• the approach and model of care preferred by commissioners. This will avoid unnecessary work should they wish to manage a patient group in a different way. Consider if some patient groups, for example prostate patients on intermittent hormone therapy, offer greater benefits in terms of quality and cost savings if managed by the specialist rather than the GP.

**2. Evaluate the IT options and agree preferred solution**
There are four approaches currently available for remote monitoring. Consider each carefully, liaising with contacts provided if necessary.  A different solution may be required for different tumour groups.

**Option 1 – Use functionality within existing IT systems**
Many IT systems have scheduling and monitoring systems available within them and may only require small adjustments to accommodate the needs for remote monitoring. IT leads or system providers will be able to provide advice on the local system capability. For example, CIMS (Clinical Information Management Systems) who supply InfoFlex have developed remote monitoring capability within their system.

NB. Breast mammography scheduling is feasible using trust radiology information systems.

**Pros**
• Existing familiarity of use with staff.
• Fewer interface requirements than other options.
• On-going support through existing service contracts.
• Send and receive data capability.
• Flexibility to suits local needs, e.g. audit.
• Speed of implementation.
• Less likely to require business case approval.

**Cons**
• May require additional licences.
• System provider consultancy costs to support implementation.

**Option 2 – Develop a bespoke remote monitoring solution**
This suits organisations where there is local IT development team skill and capacity or local restrictions on use of external software.

**Pros**
• Local ownership and development.
• Fit with existing IT architecture.
• No external maintenance costs.

**Cons**
• Long lead in time for development (allow three months from approval and three months to test and implement).
• Existing IT workload can delay development and implementation.

### Option 3 – National Cancer Survivorship Initiative (NCSI) solution

NHS Improvement, North Bristol NHS Trust (NBT), Royal United Hospital Bath and national clinical advisors have developed a remote monitoring solution to support prostate and colorectal cancer. Both modules are designed to interface with the local cancer registry and diagnostic systems such as pathology, radiology and endoscopy systems.

Within each module the specialist can view all their patients with a diagnosis of prostate or colorectal cancer. Once selected for enrolment to a self-managed pathway, the specialist enters diagnostic details, treatment and relevant drug therapy, comorbidity and any other relevant information. Test results are automatically drawn into the modules and displayed numerically, graphically or as text. Standard outcome letter templates are generated from the system to send to the patient and the GP.

Maintenance and development of the NCSI system is available to sites through a service level agreement (currently £5,000 per annum) with North Bristol NHS Trust. Assistance with local installation is also available on request.

**Pros**
- Available to any NHS organisation.
- Capable of interface with any IT system.
- No license issues.
- Remote installation of system including any future upgrades.
- Recent upgrade (March 2013).

**Cons**
- Importing external solutions may not align with local IT strategy.
- Requires server capacity.
- 'Virtual clinics' are still required on PAS to capture activity data.

For more information contact: Simeon.Barron@nbt.nhs.uk  IT development Lead, North Bristol NHS Trust.

**Option 4 – Primary care solution**

Examples exist of primary care based IT systems for monitoring surveillance tests. Whilst these have not been tested by the NCSI there are systems available as an option for those considering a primary care based solution.

**Pros**
• Care transferred closer to home.
• Potential reduction in cost to commissioners.
• Releases maximum capacity within secondary care.

**Cons**
• Not viable by individual practice due to the small patient numbers. A clinical commissioning group option might be feasible.
• Professional education required to establish and maintain disease knowledge base.
• Reaching GP consensus to manage surveillance tests.
• Less immediate access to specialist for advice on abnormal or equivocal results.
• Manual entry of enrolment data.
• IT and project management resources in the community to support set up.

---

**CASE STUDY**

In **Derby**, the urology team have developed an 'expert' system for use in primary care to monitor PSA results for stable prostate cancer patients. The software makes management suggestions based on the test result and the patient history rather than simply relaying information that then requires interpretation by a specialist. The system is registered as a medical device under European Legislation and can be managed by an eNurse specialist (currently AfC Band 5) based in either secondary or primary care.

Contact: **Mr Mike Henley**, Consultant Urologist, Derby Royal Hospital or visit www.iqudos.com

---

**Option 5 – National breast screening system (NBSS) – mammography only**

Set up a parallel recall system for breast cancer patients who require annual mammograms. This is the same as, but separate to, the national breast screening programme and mirrors the model set up for managing high risk familial patients who require annual rather than three yearly mammograms.

**Pros**
• Excellent clinical governance.
• Very low risk of patients being missed as processes, system and staff involved are the same as those delivering the national breast screening service.

**Cons**
• Limited use as does not link to radiology information systems.
• Set up and licence costs.
• Implementation more difficult for non- screening sites.
• System cannot be adapted without NBSS approval.
• Unsuitable for use through mobile units.

Contact: David Soloman at Temenos for further information on this option dsolomon@temenos. Temenos are the IT suppliers for the national breast screening system.

### 3. Consider resource implications

The following provides an indicative guide to the potential resource implications you may need to consider during set up. Each will vary according to the solution selected.

| | Time | Main role |
|---|---|---|
| Project manager | 2 days a week | Coordination and project delivery for a minimum four month period. |
| Trust IT time for system development* | 2-3 days a week | To design and test solution with users. Allow three months. |
| Trust IT time for installation | 10-15 days | Meetings, writing interface files, installation, testing, trouble shooting. |
| Lead clinician | 5 days | Meetings, standard letters, testing, sign off, operational guidelines, communication with multidisciplinary team. |
| Clinical nurse specialist | 5 days | Meetings, testing, operational guideline, training, communication with team. |
| Patient representative | 3 days | Patient information and standard letters, meetings. |
| Diagnostic interfacing** | 2 days | To write data extract file. NB. can cost up to £6K per extract if system provider commissioned to undertake work. |

\* For in house development option only.

** The ability to extract pathology and other diagnostic data will vary by trust and system provider.

Remote monitoring systems take time to implement to ensure safety, training and operational compliance. When planning the project realistic timescales should be agreed with the clinical and project lead to align with the planned launch of the new model of care. With strong project management, committed clinical leadership and enthusiasm and dedicated IT support, the system (once available) can be operational within three to four months.

**TOP TIP**
If timescales are critical and resources unavailable consider bringing in external project management and IT support.

**TOP TIP**
When planning clinical trials consider whether remote monitoring could be used to manage the patient group. If so, there may be funding opportunities. Contact your local clinical research and development team for information.

It is feasible to commence patients on a self-management pathway in advance of the remote monitoring solution being fully in place, however this does carry risks in terms of patient safety and data management and as such should only be considered as a short term measure.

**Ongoing revenue costs**
This is a good time to consider the expected demand on resources to support the patient group once the system is fully implemented. Demand is based on the number of new referrals and expected proportion suitable for self-management in the speciality. The example below assumes the clinical nurse specialist is managing patients who have been enrolled on the self-management pathway. A planned weekly session is better than trying to undertake on an ad-hoc basis. It will ensure that patients receive results promptly and reduce unnecessary telephone calls and patient anxiety.

## Example - colorectal cancer

200 new patients per year x 74% survival at one year     = 148 patients
Of which say 45% are suitable for self- management     = 67 patients
Multiply by five years follow up divided by 12 months     = 28* patients/month
*Maximum number - survival rates reduce to around 53% after five years
Allowing ten minutes per patient review     = 4 hours 40 minutes/ month

Revenue costs need to reflect health care professional time to review test results and generate result letters and chase defaults. The time allowed may require adjustment as the process embeds.

For some solutions there may be on-going costs associated with maintenance and development of the IT system.

Resources to support patients on remote monitoring should be available within directorate budgets but may need some reallocation between clinical teams. See chapter on commissioning and funding (page 87).

**4. Agree business case (if required)**
Business case approval may be required to support any new investment.  The focus of any business case should be on the service that it will help deliver rather than the IT investment alone. In other words, the investment in IT and associated qualitative initiatives will enable a proportion of patients to self-manage and thereby release outpatient capacity and consequent savings. The scope of qualitative initiatives will differ between organisations with some elements considered essential and others desirable. The full package of care needs to be included. An example business case[37] is provided.

Note: In future the costs associated with any remote monitoring system plus other quality components of the cancer survivorship pathway may be captured within a 'care package' tariff.

[37] Example business case: Implementing self-management pathways

### STEP 2 – IMPLEMENTATION

**1. Establish project team**

This is a significant project and requires a robust project management approach. A separate subgroup may be required.

The role of the project manager is to coordinate the development and implementation of the remote monitoring system. This will include liaison between IT leads, diagnostic teams, system suppliers and operational teams to ensure that when the solution is installed, it is fit for purpose and is a success operationally.

Suggested project team members include:
- Senior IT lead to lead on IT infrastructure, installation, inter-face needs;
- Senior manager to lead operationally, liaise with commissioners;
- Clinical lead to provide clinical advice, sign off solution, prepare multidisciplinary team;
- Clinical nurse specialist to input on operational use, training system users;
- Pathology lead to advise on diagnostic issues; and
- Patient representative to advise on patient needs, patient documentation.

Other representatives may be enlisted from oncology, radiology, endoscopy or commissioning.

Ensure responsibilities are made explicit and actions are delegated.

**2. Agree project plan**

A project plan should be agreed by the executive sponsor. This should cover:
- the purpose and rationale for the project;
- scope;
- project management and governance arrangements;
- team members and their responsibilities;
- stakeholder assessment;
- how the project will be delivered;
- project timetable;
- quality and control measures;
- funding agreements;
- risk management; and
- communication plan.

**Potential issues and risks to be aware of are:**
- consultant and nurse specialist workload and availability to input to project;
- cost implications for interface with diagnostic systems;
- managing out of area pathology results;
- phlebotomy  – not all GPs fund phlebotomy services for secondary care requests;
- access to IT resources for development work and support during installation; and
- data quality within cancer registries to feed remote monitoring solutions.

A sample IT project plan[39] is provided to provide insight into the specific actions required of the IT lead to install the NCSI solution.

[39] NCSI option - sample IT project plan

### 3. Confirm functionality requirements

Teams opting to develop or adapt in-house solutions should identify the functional requirements for the required IT solution. It will be helpful for any IT developer to understand how the system will work operationally, e.g., who will be reviewing test results, how will results be sent, where will access to the system be required etc.?

The specification should reflect the information required in order for clinicians to make a clinical decision on the outcome of a test. All systems should allow patients to be managed using this system alone and without the need to access case notes.

Pathology test results are needed numerically and graphically to show changes over time. The full text of radiology and endoscopy reports will be required unless a conclusive statement of 'normal', 'abnormal' or 'equivocal' is recorded by radiology and endoscopy teams.

The functional specification[39] developed to inform the development of the NCSI remote monitoring solution may be useful.

Teams may wish to consider collecting patient specific feed-back on quality of life and/or patient reported outcome measures. Questionnaires with stamped addressed envelopes could be issued with test requests or result letters and results recorded onto the system. Problems arising, despite a normal test result, may be picked up and addressed sooner if such a system existed. In the longer term, patient portals (that allow on-line patient access to results and the personal health record) may offer an electronic solution for collecting outcome data.

Consider also whether you wish the solution to hold a record of any telephone contact, outcomes or advice provided.

### 4. Establish IT infrastructure

The solution selected will determine the infrastructure required. For some solutions, the trust may need to purchase additional server capacity to store the data.

If you use an existing system supplier, for example InfoFlex, consider the additional licences that may be required. Some trusts have trust-wide licence agreements, others 'spot buy' additional licences as required. If the latter, take time to consider who needs to have access to this data when fully operational and at what level, i.e., to edit or to view.

Depending on where staff will be based when using the system, additional computers and printers may be required. Any printer generating patient information must comply with Caldicott standards to ensure confidentiality.

> **TOP TIP**
> It may be possible to forward a series of letters generated during a session for dispatch in bulk rather than printing individually.

[39] Functional requirements for NCSI remote monitoring solution.

**5. Write system interfaces**

To enable patients to be monitored remotely, information will need to be drawn from existing IT systems. For example when monitoring a patient with prostate cancer the clinician will need to see:

- patient general data set;
- GP name, practice code, address;
- patients who have died or been suspended from self-management pathway;
- diagnosis and treatment details;
- recent contacts, e.g., helpline concerns; and
- PSA data – history, unique identifier, date of test and value.

It is the responsibility of the IT team to write the file format that allows this key information to be viewed.

The implementation plan[40] to support the NCSI option (see page 64), provides guidance on the field format requirements for interfacing with the various IT systems.

> **TOP TIP**
> You may need to purchase an extract file from your pathology IT supplier if access is restricted or if skills are not available to undertake the work in-house.

**6. Agree standard documentation and letters**

The use of standard letters is common to all solutions and should be agreed by the clinical lead for the project on behalf of the specialist team and after consultation with patient representatives. Note. Some trusts require trust communication lead approval for new patient letters and information sheets.

Patient and GP contact details along with the test result and date of next test should be generated automatically within standard template letters.

**As a general guide the standard letter templates should include:**

- patient enrolment letter – explains process and arrangements for first test;
- normal results;
- re-test request letter – i.e. slightly abnormal so a further test required;
- abnormal result and recall – usually preceded by phone call to patient;
- default letter – to those who have not had test when asked to do so;
- end of surveillance and discharge to GP;
- GP information leaflet (optional); and
- patient information leaflet (optional).

Some example letters[41] are provided.

> **TOP TIP**
> - Understand the process and how tests will be ordered. This will need to be reflected in the letters.
> - Agree and sign letters on behalf of the team to avoid consultant specific letters.
> - Combine patient and GP letters as one document as this saves time.
> - Consider whether the test value should be included in result letters.
> - Re-enforce signs and symptoms to look out for within each satisfactory result letter.
> - With each test result, send the date for next test along with the request form. The system will alert for defaults if dates are forgotten.
> - Annual tests that coincide with month of diagnosis are easier for patients to remember.

[40] NCSI Implementation plan version 3 0 0 for remote monitoring solution.
[41] Example standard letters for remote monitoring system

### 7. Address out of area issues

Patients transferring between trusts that require on-going surveillance tests will need to be registered on the local cancer information system to ensure their details (GP, diagnosis and treatment information) are available through the remote monitoring solution. Check with your cancer information team or multidisciplinary coordinator the arrangement for this.

For patients living on the periphery of the pathology catchment area, or who have been referred in as tertiary referrals, alternative arrangements may need to be made for the taking and processing of blood samples.

Where possible samples should always be processed by the same laboratory as machine calibration does differ between laboratories.

> **TOP TIP**
> For out of area patients consider sending the patient the request form, the blood bottles and a stamped addressed envelope to ensure the samples reach the correct laboratory. Discuss feasibility with your pathology lead.

### 8. Confirm phlebotomy service provision

A clear aim of this model of care is that services should be provided closer to home with as little inconvenience to the patient as possible. For many, the hospital is a distance from home and a more local phlebotomy service is more appropriate.

> **TOP TIP**
> To avoid confusion provide patients with a list of locations (including access times) where blood tests can be taken to ensure the sample will be transferred to the correct laboratory for processing.

All GPs offer a phlebotomy service to cover requests generated by primary care and some, but not all, provide phlebotomy services for requests generated by secondary care. Trusts are advised to check arrangements with the local commissioning teams.

### 9. Agree operational guideline and governance arrangements

A system administrator will need to be appointed to manage and agree local access to the remote monitoring system. This should conform to local data protection policies. Levels of access should be agreed by the clinical lead.

An operational guideline should be developed and agreed by the multidisciplinary team that states how patients on the self-managed pathway will be managed.

It should cover topics including:
• patient criteria for self-management pathway;
• exclusions;
• process for managing tests remotely;
• triggers for recall;
• any delegated responsibilities – who will be doing what;
• management of abnormal tests; and
• audit.

An example protocol[42] is provided for reference.

---

[42] Remote monitoring operational protocol example.

**10. Agree outcome measures and on-going data collection**
The collection of outcome and performance measures is key for continuous improvement. Measures might include:
• number of patients enrolled to remote monitoring per month;
• number of test defaults per month;
• turnaround time from receipt of result to result letter sent; and
• re-calls for suspected recurrence.

**11. Confirm activity tariff with commissioners**
The implementation of remote monitoring will enable the introduction of the self- management pathway and the consequent release of outpatient activity. Savings associated with saved appointments need to be off set against the time that the specialist team will still need to interpret results and inform the patient and the GP of the results.

Before launching this pathway a discussion should take place with commissioners to agree an appropriate tariff for the service and how activity will be recorded. Note. The non-mandatory price tariff for a non face to face appointment is £23 (2013/14 prices) though given that tests and interpretation of results are involved a higher local negotiated tariff may be more appropriate.

**STEP 3:  TESTING AND 'GO LIVE'**

**1. Testing with operational teams**
Once the solution has been installed and/or developed by the IT team the solution needs to be tested to ensure all the functions operate satisfactorily.

**2. Training**
Training will be required for any of the solutions. This should be provided in-house where possible. Where appropriate, system suppliers can provide training.. Trusts may wish to consider having one or two 'super users' who can cascade training to team members and ensure they are competent. The 'super users' would be the first point of contact for user queries.

> **TOP TIP**
> Teams should allow sufficient time to complete this testing process and to resolve any 'bugs' in the system. This should continue after the system is live as nuances and problems may only become apparent when real data is used.

Training may also be required for local IT support staff on the functionality of the system and simple troubleshooting measures.

> **TOP TIP**
> • Start with new patients first and build up as your confidence increases.
> • Enrol those in current follow-up over the course of the year. As they present in outpatients, explain the new care model and offer a choice to transfer. Some patients may prefer to continue face to face appointments.
> • Run a parallel system for an agreed period until you are 100% assured that the new system works.
> • Ensure cover for leave and sickness.
> • Maintain regular contact between operational and IT teams during the initial 'go live' period, keeping a log of queries and issues identified.

### 3. 'Go live' launch and publicity

Once testing is complete the solution should be signed off by the project team and clinical lead as fit for purpose and safe to use.

Whilst the launch date may have been included in the original project plan the final date should be re-advertised and publicised widely and certainly within the multidisciplinary team. Patient endorsement of the proposed change will be beneficial and support roll out.

### STEP 4: SUSTAINABILITY

### 1. System support and development

Instructions should be provided to users on the process to access support should problems arise using the system. Day to day first line support should be through local IT support teams and second line support, if applicable, through the system provider. Note. For the NCSI solution, North Bristol NHS Trust provide second line support and development as part of a service level agreement.

Provision for on- going development will also be required as needs change and further opportunities for expanding the scope and functionality arise.

### 2. Staff training

Training should be available for new IT, operational and clinical staff. Ideally the trust should have at least one 'super user' who can cascade training to new staff on induction.
All new medical and nursing staff should be made aware of how the system works (and should provide a demonstration if possible) so even if they are not direct users they understand what the system can offer, who it is for, and can respond to questions about it from patients.
Consideration should be given to including responsibility for remote monitoring in future job descriptions.

### 3. Audit and effectiveness

On-going activity and quality data on patients who are remotely monitored should be audited with results presented at local audit meetings and operational team meetings. This will help ensure the system remains active, especially in the early stages, and that a mechanism exists for formally reviewing effectiveness and safety.
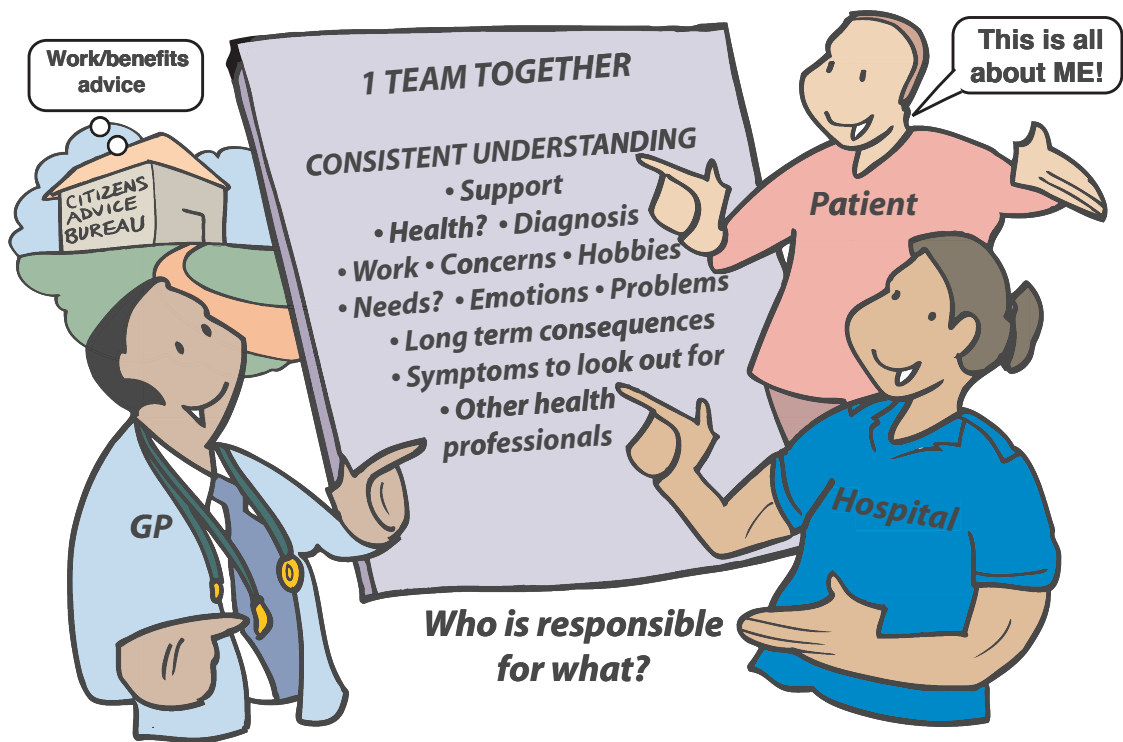
### 4. Project closure

At the formal close of the project a short report identifying lessons learnt and any follow up actions should be completed by the project manager.

Remote monitoring

# ▣ Care co-ordination

# PRINCIPLE 7: Organisations should work together to provide seamless coordinated care

## What is care coordination mean?

A consensus definition of care coordination has not fully evolved as it means different things to different people. However there are common elements which can be put together to form a working definition:

**'Care coordination is a relationship between two or more people, including the patient, resulting in the appropriate organisation and provision of services to meet patient needs and preferences. This supports delivery of high quality care, improving the individual's quality of life and experience'.**

Three main perspectives contribute to the success or failure of care coordination:
• the patient/carer/family perspective;
• the professional perspective; and
• the system perspective.

When all of the different perspectives are working to a common purpose, and key components such as health needs assessment and timely re-access systems to specialist teams are in place, care coordination is likely to be successful.

Care coordination is dynamic and a number of activities need to happen in unison to deliver high quality and effectively coordinated service delivery. At its heart an up-to-date and cohesive care plan that, following assessment, is jointly owned by the patient and the professionals caring for them. This common thread helps ensure care is timely, consistent, safe and seamless as patients move along the care pathway and cross organisational and professional boundaries.

As part of a qualitative study (see reference 8) patients identified the following words to describe a well co-ordinated service.



75

# Care co-ordination

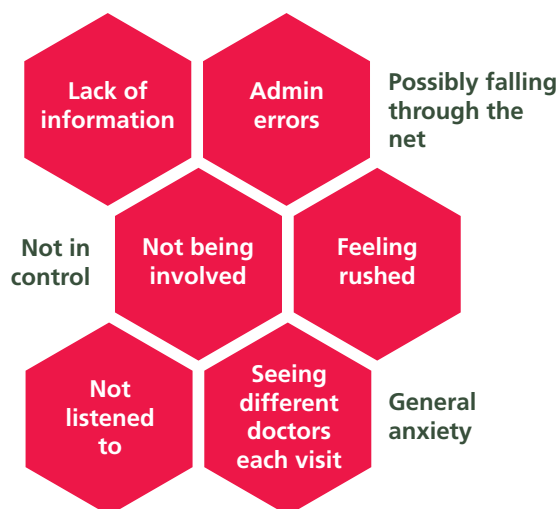They also identified words to describe poor care co-ordination.

**How to improve care coordination**

Identify key stakeholders to develop a shared vision. Stakeholders will be many and varied and include secondary and primary care professionals, public health colleagues, and local authorities and in particular, social care professionals and voluntary organisations. Not forgetting of course patients who need to be central to the planning and delivery of care coordinated services.

Consider how the other components within this guide dovetail together to provide seamless care and transition for patients across the pathway. Care coordination will be the gel that brings together all of the other components.

Select measures to support the process of continuous improvement and evidence the impact of service changes. Although this is an area where there are few existing measures, localities need to look creatively at what are the most appropriate indicators and how they can be collected for their population.

**Measures could include the following:**

| Possible measure | Related outcome |
|---|---|
| Care coordination checklist | Patients in the local area are supported by health, social care and charity organisations to meet their holistic needs. |
| Number of patients with an up to date personal care record<br><br>Patient's experience of using the personal care record including how they have used it.<br><br>Health and social care professional experience of using personal care record | Patients have the opportunity, information, choice and control to coordinate their care. |
| Carers experience of care coordination/ personal care record<br><br>Confidence to manage own health<br><br>Reduction in unplanned admissions to secondary care | Carers have access to information to enable them to assist the person they care for to coordinate their care following a diagnosis of cancer |
| The number and reason for patients to contact the specialist team to see if personal care record changes pattern | People living with and beyond cancer have the information and knowledge to manage their own care and make appropriate use of the services available to them |

Lack of information

Admin errors

Possibly falling through the net

Not in control

Not being involved

Feeling rushed

Not listened to

Seeing different doctors each visit

General anxiety

For commissioning to be effective, commissioners will need to know the likely uptake of services and costs that make up the 'bundle of care'. Health professionals who are working with patients and undertaking care planning need to be monitoring what services they are referring patients to, where patients are being signposted to and if there are gaps in service provision. Those providing services need to be providing information on uptake.

A directory of services as outlined on page 57 should be developed and service providers contacted in order to start to build relationships that foster good care coordination for patients.

Build relationships to discuss and resolve issues that impede good care coordination. You should be sharing information and patient outcomes data about the services you are delivering with other providers within the survivorship pathway as indeed they should be communicating with you about their services. This two way flow of communication will help ensure good care coordination and identify gaps and issues in service provision and potential areas to improve quality of care.

Good care coordination will take time to embed and become 'business as usual'. Points to consider that will support sustainability include:

- Audit beyond numbers to include quality of care plans, attainment of patient goals and effectiveness of inter-agency working. Ensure patient's views inform standards and consider setting joint quality standards audit across services. Audit outcomes should be fed back to all services, practitioners and managers involved in care coordination.
- Where possible deliver joint training to primary, secondary and third sector service health professionals involved in the care pathway. Ensure training to new staff members across all stakeholder services is part of the on-going training programme. Foster an understanding and respect for each other's roles.
- Sharing good practice and learning locally will enhance continuous improvement as will shared protocols, information and good communication.

Care co-ordination

**PRINCIPLE 8:**

# → Self-management

# PRINCIPLE 8: Where able, individuals should take responsibility for optimising future health and well-being

### What do we mean?

Supporting self-management is about helping people help themselves though taking action to maximise their recovery and helping them to sustain that recovery. It aims to give people confidence and capability to move on from their cancer diagnosis and treatment and get on with living their lives.

This does not mean they will be on their own, for many they will be monitored from a distance and have timely access to support services when they need it. By its very nature, this section of the guide draws on all other sections in this guide.  If you look at care coordination being about how the system work together to support patients, self-management is about empowering the individual to make choices and take control of living their lives albeit within the limitations place upon them by their disease and its treatment.

### Who benefits

Through being supported to self-manage, the individual following the cancer treatment will have the information, advice and support to enable them to adapt to their condition and move on with their lives either living with or beyond cancer. They should also be better informed about the choices they make to have a positive impact on their future health and wellbeing. Chronic problems can arise through unmet needs and providing support to meet their needs early on could reduce the risk of recurrence and morbidity associated with the disease or its treatment, or developing comorbidities that could impact on the individual's ability to live the lives they would want to. Reducing follow-up appointments that add no value, means less personal cost to the individual and may reduce anxiety associated with attending outpatient appointments.
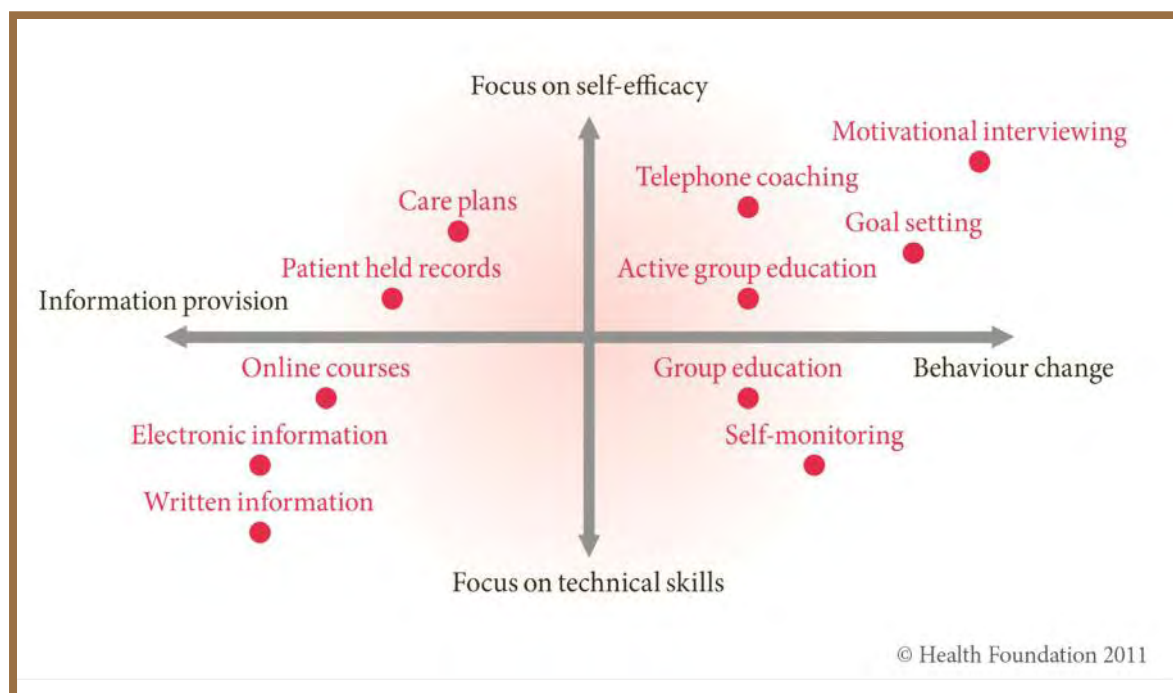
For the NHS this is about investing to save; though skilling up patients to be more resilient, being better informed and supported when things go wrong, helps the individual better adapt to their new circumstances. This in turn reduces the burden on the NHS as people become better able to cope and more confident in looking after themselves day to day. By reducing follow-up that adds no value, through the introduction of remote monitoring systems, you can release capacity in the system for those who need it.

### What types of support work?

The Health Foundation document 'Helping people help themselves'[43] published in May 2011, found that "Initiatives can be categorised along a continuum with passive information provision about peoples condition and technical skills at one end of the scale and initiatives that more actively seek to support behaviour change and increase self- efficacy at the other end of the continuum". Several examples within figure 1 on the following page are discussed in more detail elsewhere in this guide.

No single initiative is sufficient and many if not all, may be needed to ensure people are able to self-manage effectively.

---

[43] The Health Foundation. Evidence: Helping people help themselves. May 2011.

Focus on self-efficacy

Motivational interviewing

Telephone coaching

Care plans

Goal setting

Patient held records

Active group education

Information provision

Behaviour change

Online courses

Group education

Electronic information

Self-monitoring

Written information

Focus on technical skills

© Health Foundation 2011

**How to do it**
A variety of approaches will be needed. Some are more suited to some cancer types or patient groups and others may require an alternative approach.

The principles outlined in this guide provide further information on many of the components highlighted above. If done well these will ensure that supportive self-management is a success.

Please refer to the following principles for further information:

**Principle 1: Risk stratification**
**Principle 2: Assessment and care planning**
**Principle 3: Personal care record**
**Principle 4: Re-accessing the system**
**Principle 5: Information and education**
**Principle 6: Remote monitoring**

You will know whether you have got it right by measuring the outcomes in terms of costs, unplanned activity and patient experience and reported outcomes.

# → Commissioning and funding

# Commissioning and funding

The aim should be to commission and deliver a package of care that supports the implementation of stratified pathways and improves the quality and effectiveness of care for those living with and beyond cancer.

This chapter provides information on current costs associated with cancer aftercare services and where funding opportunities may exist to support implementation of the pathways.

**Background**
From 1 April 2013, GP led CCGs will commission cancer follow-up services, based on assessing the needs of the local population, securing services that meet those needs and monitoring the quality of care provided.

Each CCG will negotiate with provider units (acute trusts) a service specification and agree the outcomes required. At present most CCGs pay for cancer follow-up through a national tariff structure that varies according to appointment type, volume and specialty (see table below). Outpatient attendances are generally paid for under a block contract rather than on an individual basis and are not cancer specific.

|  | Breast surgery | Colorectal surgery | Urology | Oncology (clinical or medical) |
|---|---|---|---|---|
| **First appointment (new patient)** | | | | |
| Single professional | 150 | 120 | 129 | 213 |
| Multi professional | 150 | 120 | 157 | 223 |
| **Follow up appointment** | | | | |
| Single professional | 86 | 72 | 71 | 92 |
| Multi professional | 99 | 110 | 108 | 105 |
| Non face to face (irrespective who leads) | 23 | 23 | 23 | 23 |

2013/14 National tariff costs.

Currently there are no specific tariffs for managing tests remotely, nurse led clinics, information events or physical activity initiatives although there are emerging examples of 'packages' of care being commissioned that reflect outpatient attendances as well as some of these qualitative initiatives.

Savings to commissioners through released outpatient attendance could be significant. For example a breast cancer patient who would normally have nine appointments over five years (year 1 x 4, year 2 x 2, years 3 - 5 x 1) after completion of treatment, may in future only require two appointments. The cost savings need to be offset against the cost of quality improvements, e.g., assessment and care planning.

A CQUIN may be attached to a service specification. This is a temporary incentive scheme which forms part of the contract agreed between a commissioner and a provider and links the successful delivery of specific outcomes, e.g., needs assessments.

**Surveillance tests**

The table below provides indicative cost to the service of surveillance testing (NB. These will vary based on local surveillance regimes).

| Test | No:/5yrs (excluding diagnosis) | Cost per test | Cost per patient/5 years | Cost sources) | Comments |
|---|---|---|---|---|---|
| Breast - mammogram | 5 | £150 | £750 | DH economic appraisal | |
| Breast -dexa scan | 2 | £74 | £148 | National tariff 2013/14 | Frequency may vary. |
| Colorectal -CEA | 8 | £10 | £80 | DH economic appraisal | Includes report cost |
| Colorectal -CT (2 areas with no contrast) | 2 | £109 | £218 | National tariff 2013/14 | Tumour marker |
| Colorectal -MRI scan (3 areas no contrast) | 2 | £177 | £354 | National tariff 2013/14 | Includes report cost |
| Colorectal -diagnostic colonoscopy | 2 | £452 | £904 | National tariff 2013/14 | Includes report cost |
| Prostate -PSA | 9 | £10.00 | £90 | DH economic appraisal | Tumour marker |

Organisations are encouraged to discuss the implication of future service changes with their commissioners and agree a local tariff to reflect quality improvements. This applies particularly to patients who will be managed remotely. Be aware of timescales for negotiating local tariffs that may not come into effect until the next financial year.

**The cost of aftercare initiatives**

Quality initiatives will vary depending on local resources (people, space, kit) but potentially could include the following:

- Remote monitoring;
  - licences, maintenance and development costs;
  - professional time to review test results; and
  - administrative support.
- Needs assessments and care planning - nurse led clinics;
- Helplines;
- Physical exercise schemes;
- Support services; and
- Information days/programmes – venue, hospitality, administrative support, staff costs.

The following sections provide further guidance and cost estimates for each component.

### 1. Remote monitoring

This describes the system used by the specialist team to manage surveillance without the need for face to face follow up appointments.

Revenue costs will vary depending on specialty and remote monitoring solution. In breast cancer for instance there may be no costs involved if mammograms are booked and reported using existing radiology PACS and CRIS systems. However for colorectal cancer, using the NCSI remote monitoring system (see Principle 6) with results overseen by the specialist nurse the following costs may be incurred.

**Example:**
- Assuming 200 new colorectal patients per annum over five years with 45% expected to be suitable for a self-management pathway.

  | | |
  |---|---|
  | 200 x 5 x 45% | **= 450 on system at any one time** |
  | 38 per month x say 10 minutes per review | **= 6hrs 30 minutes/month** |
  | CNS Band 7 midpoint | **= £1,400 p.a.** plus on costs |

- NCSI remote monitoring system

  | | |
  |---|---|
  | support and maintenance | **= £5,000 p.a.** plus on costs |

- Admin support (chasing defaults, processing letters, follow up)

  | | |
  |---|---|
  | Band 3 midpoint two hours per week | **= £880 p.a.** |

### 2. Needs assessments and care planning

Testing has identified that a formal needs assessment and care plans take between 30 and 60 minutes to complete.

- 200 new patients per annum would generate demand for 17 HNAs at end of treatment per month. Assuming 80% take up = say 3-4 per week.

  One three hour session per week for 52 weeks (4 assessments/session) based on a Band 7 midpoint = £2,850 p.a. plus on costs and cover for annual leave

NB: Additional resource may be required to cover patients returning with recurrence and or other triggers that require a formalised review of the care plan

### 3. Treatment summaries

These should be completed by the healthcare professional (preferably consultant) at the end of treatment and at other key trigger points in the pathway. These can be completed in clinic or soon after using prefilled templates for example within InfoFlex or Somerset systems.

- Assuming say 150 patients require a summary per year:

  | | |
  |---|---|
  | Clinician time (10 minutes per patient) | = 25 hrs per annum |
  | Secretarial time (5 minutes per patient) | = 12 hrs per annum |

### 4. Helpline support

This assumes an administrative role to triage calls from patients. Allow one hour per weekday for call handling, logging calls and follow up actions.

Band 3 midpoint for approximately 5 hours per week = **£2,400 p.a.** plus on costs

### 5. Information days and support programmes

There is a wide variation in the content, structure and consequent costs of information days and support programmes. Here are some examples.

### Macmillan Cancer Support

- Case study 1 – Lincolnshire CNS and volunteer led. Market stall with optional one to one sessions. Off site venue. Eight clinics held with average seven patients per clinic
  **£1,200 per clinic** (£171 per patient)

- Case Study 2- Milton Keynes – Nurse, Information manager, volunteers. Market stalls plus assessment clinic. On- site venue. Three clinics – average nine patients  per clinic
  **£2,507 per clinic** (£278 per patient)

- Case Study 3 – Velindre. Consultant led with AHP plus volunteers. Off site venue. Seven clinics with average of five patients per clinic.
  **£4,219 per clinic** (£843 per patient).

(See http://www.ncsi.org.uk/what-we-are-doing/health-and-wellbeing-clinics/ for the full economic assessment on health and wellbeing events -Aug 2011).

### NHS Improvement Test sites (2011)

(Indicative costs only)

- Guys and St Thomas – CNS and AHP led session. Presentations and market place. On site venue. Two clinics held with an average 12 patients per session
  **£1047 per clinic** (£87 per patient)

- Salford – Consultant, CNS, and AHP led events over 2 days. Presentations and market stall. Off site venue.  30 patients per clinic. 3 planned per annum.
  **£3,440 per clinic** (£114 per patient) Could be reduced if only 1 day.

- Ipswich – CNS, AHP and volunteer led. Presentations and market stalls. Off site venue. 150 patients and carers invited via clinics, local media. Funded through charitable funds
  **£500 per event** (£3 per attendee)

### Self- management courses

A report (see reference 38) commissioned by the Anglia cancer network identified the costs and benefits from four support programmes.

- 'Moving on' Programme (Ipswich) over 4 weeks with 2.5 hours per week, max 12 per session. 8 courses per year. Includes completion of care plan in week 4. CNS and volunteer led with visiting speakers.

  £97 per patient

- Hope Programme – similar to the Moving on programme it runs over several weeks with about 8-10 per course. Higher costs reflects trainer expenses during the pilot

  £272 per patient

### 3. Physical activity programmes

Local authorities will advise on the level of subsidy they can offer to NHS patients. It is worth investigating whether other referral schemes already exist e.g., cardiac rehabilitation

**Cost examples:**
- Bournemouth – 12 week activity and exercise programme for people following treatment for cancer. Assessment and support from lifestyle coaches.

  £200 per patient per 12 week course

- Ipswich
  - Swimming club - £4 per swim ( patient self-funded)
  - Exercise programme – subsidised for three months at £15 per month.

    Note: £500 to provide level 4 training to leisure centre staff)

### 4. Support services (will vary depending on tumour type)

The following services should be available to patients where a need is identified:

- diet and nutritional advice;
- physiotherapy;
- occupational therapy;
- psychological (Level 3 counselling and Level 4 psychological);
- stomatherapy;
- continence advice;
- sexual dysfunction (male and female);
- lymphoedema;
- social care;
- finance and benefits;
- vocational rehabilitation;
- menopause;
- gastroenterology  (for late effects of treatment);
- physical activity initiatives; and
- support groups and peer support programmes;

Implementation of the new pathways may place increasing demand on support services and may necessitate a review of access and service provision.  Where needs are identified as a direct consequence of a person's diagnosis and treatment for cancer the above should be directly accessible without recourse to primary care.

**Managing the released capacity**

Release of capacity through a reduction in unnecessary outpatient appointments may provide a range of opportunities such as:

• additional new patient outpatient slots to improve access for new referrals;
• extended consultation time for remaining follow up patients to improve quality;
• redirection of resources to other areas of service, e.g., reallocate medical resources freed up through fewer outpatient slots to nursing budget to support quality initiatives, e.g., needs assessment and care planning, information events; and
• reallocation of redundant clinics to other higher priority services.

Solutions will need to be agreed locally and in consultation with local commissioners.

**Funding options**

Implementing stratified pathways is likely to be an 'invest to save' project and you may identify that additional short term funding is required to support the setup of these new pathways. In the long term implementing a choice of follow up pathways should offer both quality improvements and net cost savings to the local health economy.

Suggested options to explore for short term funding:

• Hospital/cancer trust fund;
• Local research and development committees;
• Macmillan Cancer Support;
• Tumour specific Charities; and
• CCG transformation funding.

# ⇥ References and acknowledgements

# References

USB sticks containing all the reference documents included in this guide accompany hard copies of this guide. The guide is available on line with documents available through the appropriate links.
References

1. Stratified pathways of care. Generic, breast, prostate and colorectal.
2. Rapid review of current service provision following cancer treatment – NHS Improvement (September 2010)
3. Living with and beyond cancer: the improvement story so far ( July 2010)
4. Effective follow up: testing risk stratified pathways of care (May 2011)
5. Sharing the learning through posters; The work of the NCSI tests sites (March 2012)
6. Stratified pathways of care: from concept to innovation. (May 2012)
7. National Cancer Survivorship Initiative and Ipsos MORI Social Research Institute. Evaluation of adult aftercare service – Wave 1 report (October 2011)
8. National Cancer Survivorship Initiative and Ipsos MORI Social Research Institute. Evaluation of adult aftercare service – A qualitative analysis of care co-ordination (June 2012)
9. Introducing stratified pathways of care – presentation slides to support set up
10. Bournemouth test community case study 'Cancer survivors exercising their way back to health'
11. Project plan template and guide notes
12. Plan, do, study, act template.
13. First steps towards quality improvement: A simple guide to improving services.
14. Criteria used for testing pathway stratification in colorectal cancer (Dec 2011). NHS Improvement
15. Prostate cancer protocol and recall process – St Georges Hospital
16. Example GP information leaflet – St Georges Hospital urology team
17. Example patient introductory letter – Royal United Hospital Bath
18. Armes J et al. "Patients supportive care needs beyond the end of cancer treatment; a prospective, longitudinal survey." Journal of Clinical Oncology. Vol 27; No 36, pp 6172-6179, 2009
19. Quality of life of cancer survivors: report on a pilot survey using patient reported outcome measures (PROMS). December 2012. Department of Health.
20. NCSI Care plan - available as triplicate pads from www.be.macmillan.org.uk
21. NCSI Concerns checklist - available as triplicate pads from www.be.macmillan.org.uk
22. Care plan template example – NHS Improvement
23. The holistic needs assessment for people with cancer – a practical guide. National Cancer Action Team (2010).
24. Competencies for undertaking holistic assessments. Yorkshire Cancer Network.
25. PROMS patient questionnaire - colorectal cancer 2011
26. Assessment and care planning: lessons learnt from testing. NCSI (Dec 2011)
27. Holistic needs assessment and care planning: sharing good practice (Macmillan - winter 2012 edition)
28. Assessment and care planning – patient leaflet. Macmillan cancer support
29. Assessment and care planning poster - Pan Birmingham cancer network.
30. NCSI treatment summary template
31. NCSI treatment summary user guide (updated December 2012)
32. GP questionnaire on treatment summaries
33. Treatment summary – Somerset cancer registry
34. Cancer Living Well Programme – North Bristol NHS Trust.
35. Supported self –management – Final report. University of East Anglia (August 2012)

# References

36. The importance of physical activity for people living with and beyond cancer – a concise evidence review. Macmillan Cancer Support (June 2012)
37. Example business case: Implementing a self-management pathway
38. NCSI option – sample IT project plan
39. Functional requirements for NCSI remote monitoring solution
40. NCSI option. Implementation plan version 3 0 0 for remote monitoring set up
41. Example standard letters for remote monitoring system
42. Remote monitoring operational protocol example
43. Evidence: helping people help themselves. The Health Foundation (May 2011)
44. British Society of Gastroenterology. Information and resources to assist local adoption of the practice guidance on the management of acute and chronic GI problems arising as a result of treatment for cancer (January 2013)

# Acknowledgements

We are grateful to all the test sites for their commitment and hard work in developing, testing and implementing stratified pathways of care and quality improvement initiatives for patients who are living with and beyond their diagnosis of cancer.

The test site expertise and enthusiasm combined with support from clinical leaders, clinical networks, charities and patient representatives has given us a wealth of experience, knowledge and skill to share. We thank you all again for your contribution.

**NHS Improvement - Adult Cancer Survivorship Team**

# Acknowledgements