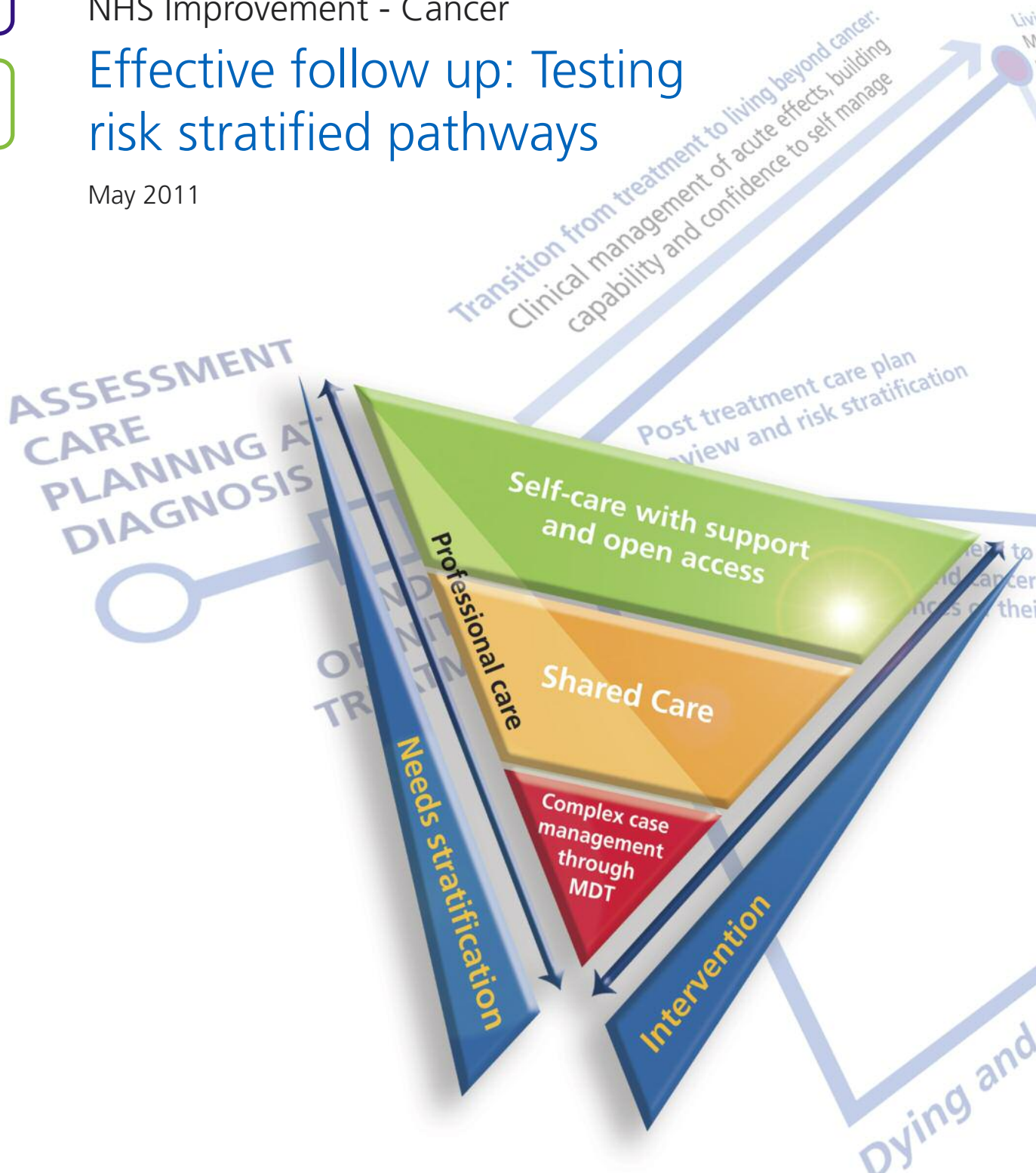




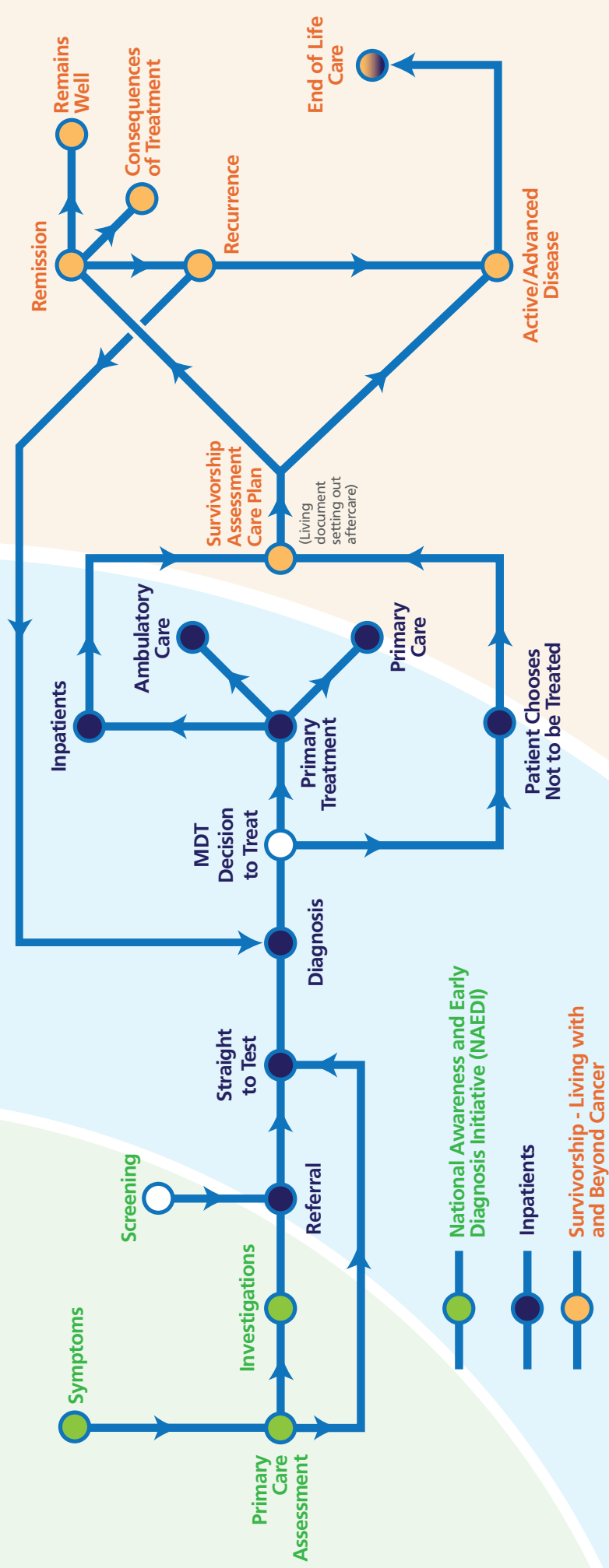
NHS Improvement - Cancer

Effective follow up: Testing risk stratified pathways

May 2011



Complete care pathway for a patient with a diagnosis of cancer



Effective follow up: Testing risk stratified pathways

Introduction

The purpose of this document is to highlight the work being led by NHS Improvement to support delivery of the National Cancer Survivorship Initiative (NCSI) Vision¹ for those living with and beyond cancer. This survivorship agenda is a priority which was outlined in the Cancer Reform Strategy² (2007) and Improving Outcomes; a Strategy for Cancer³ (2011).

As part of the NCSI, NHS Improvement is working in partnership with patients, clinical teams, Department of Health and voluntary agencies to improve the effectiveness and quality of service delivery for those living with and beyond cancer. A key aspect of this is ensuring effective pathway management across organisational boundaries, with the patient at the heart of the decision making process.

Traditionally, the focus of cancer service improvement has been on the referral to treatment pathway, with the emphasis post treatment on surveillance and monitoring for further disease. Primary care has, in the past, seen the management of cancer patients to be the province of the specialist cancer team until they have been discharged to the care of their GP.

There are estimated to be around 1.7 million (2008) people in England living following a diagnosis of cancer, with this number rising around 3.2% per annum.



Adam Glaser, Clinical Director,
National Cancer Survivorship
Initiative



Gilmour Frew, Director - NHS
Improvement

- **Risk stratified pathways of care** based on the tumour type, treatment and personal circumstances of the individual
- All patients will be offered a **personalised care plan** that focuses on their individual needs along with a **treatment summary** for the patient and those involved in their care
- **Information and education** that enables choice and confidence to self manage will be provided at the right time to meet the patient's individual needs
- **Remote monitoring** which provides safe and effective monitoring at a distance with timely intervention if required
- **Care coordination** as a function that ensures that the needs of the individual are met seamlessly across organisational and clinical service boundaries. All patients will have **appropriate timely access** to the right service, first time, when problems arise
- The patient is the only constant through their journey of care. **A hand held record** could enhance communication across providers of care or in an emergency.

Key emerging principles for future care and support for those living with and beyond cancer:

As the incidence and prevalence continues to rise, the current traditional approach to managing patients is:

- Not always meeting the individual's needs
- Based on a medical (illness) model rather than a self management (wellness) model⁴

To get to where we are today we have undertaken scoping work to inform us about perceptions, preferences and models of current care delivery across England:

- In 2007, a survey of 3,000 patients and professionals involved in providing cancer care in hospital and primary care was undertaken. The purpose of the survey was to identify perceptions and preferences for follow up care. There was consensus as to why follow up happens, though there were differences in the relative importance of the responses. With regard to preferences, patients preferred what they have experienced⁵.
- In March 2008, a meeting of nearly 200 patients in partnership with Macmillan Cancer Support⁶ was held to explore follow up options for the future. The conclusion at the end of the day was that patients were not adverse to alternative approaches to follow up so long as they have:
 - Good quality, pertinent information
 - Rapid access to specialist care as needed
 - A care plan which is agreed by all those providing care and is owned by them.

A PATIENT'S VIEW

Huge advances have been made in cancer treatment over past years, and survivorship rates are increasing all the time. However, a by-product of this success is that cancer patients typically need supporting for many years beyond the end of their primary treatment. The care planning needs include not only monitoring for possible recurrence of the original illness but also a whole range of unrelated conditions that can arise because of the long term effects of the original cancer treatment. Patients may go for many years leading normal lives, requiring only occasional surveillance, but if more serious medical issues do arise it is very important that they can easily access the specialist medical attention they need. Clear and flexible recording of medical history has an important role to play here. If patients are in a different part of the country from the location of their initial cancer treatment, or if they need to see specialists in a different medical area because of the late effects of treatment, the doctors and nurses need easy access to the patient's medical history so that they can readily understand the context of new symptoms or conditions.

The NHS Cancer Improvement Programme seeks to address all these issues. As a patient who has lived with the effects of cancer over many years, I am hugely encouraged to see the progress being made. I am also very pleased to have the chance to contribute as a patient representative, and work with the excellent team of professionals taking the work forward under Gilmour Frew's leadership.



Michael Prior, Cancer Patient

- During summer 2009, a rapid review of follow up⁷ care and support was undertaken across England using a questionnaire for clinical teams across three tumour types; breast, colorectal and prostate. The findings of the review showed a predominantly medical model of follow up care with 'one size fits all' the norm. For many patients follow up care was managed by clinical nurse specialists through consultant protocols. There were pockets of innovative practice where individuals were self managing with open access if required.
- Over a period of 15 months in 2009/10, 28 pilot sites across England tested elements of survivorship care. Eleven of these sites were testing approaches to assessment and care planning and use of the Treatment Summary. In practice, for the majority of test sites, there was a separation between survivorship support services and clinical follow up. The work in the pilot sites was captured in *The Improvement Story So Far*⁸, Picker testing elements of care evaluation⁹, a summary of the testing of assessment and care planning¹⁰ and Treatment Record Summaries¹¹

A UNIQUE PERSPECTIVE...

Many of you will know me from my work as a project manager for the National Cancer Survivorship Initiative (NCSI), however, what you may not know is that I am a survivor of ovarian cancer (10 years now). I have also been a carer for my daughter who was diagnosed with ovarian cancer nearly 11 years ago (at the age of 19) and who is also a survivor and now a very active and busy young lady. An unbelievable coincidence but even more so because I was the gynae-oncology specialist nurse in the team that treated my daughter. This unique situation has given me a different perspective on cancer and the impact it has on patients and their families. In learning how to manage cancer in my own life, I realised that there was a lot more we could do to support those who were living with the disease and I have been fortunate to have had the opportunity to contribute to these developments that can make a real change. I believe that by identifying peoples' needs by careful assessment and care planning and with the right support in place, we can make risk stratification work to improve the quality of survivorship. Better patient information and education for survivorship will give people the opportunity to take control of their lives again. It has been a privilege for me to be able to work with NHS Improvement and the NCSI to make living with and beyond cancer an active and fulfilling experience for those who are fortunate enough to survive.



Noëline Young, Project Manager – NCSI

- In the summer of 2010 clinical consensus meetings were held to develop risk stratified pathways of care for six tumours; breast, colorectal, lung, prostate, head and neck and myeloma. The prototype summary pathways are contained within this document in each of the tumour sections.
- In the autumn of 2010, an economic evaluation to determine the cost of five years of follow up after treatment for the service and the patient was undertaken for breast, colorectal, lung, prostate and myeloma patients.

The outcomes from these pieces of work have provided the scope for further testing. This work will consist of the testing of risk stratified pathways of care and two critical enabling projects; remote monitoring and care coordination. It needs to be remembered that the care and support of individuals following their cancer treatment does not happen in isolation but is part of the seamless provision of care from experiencing symptoms until the end of their life. This ongoing testing work will be the focus of the remainder of this document.



Vanessa Brown, National Improvement Lead, NHS Improvement



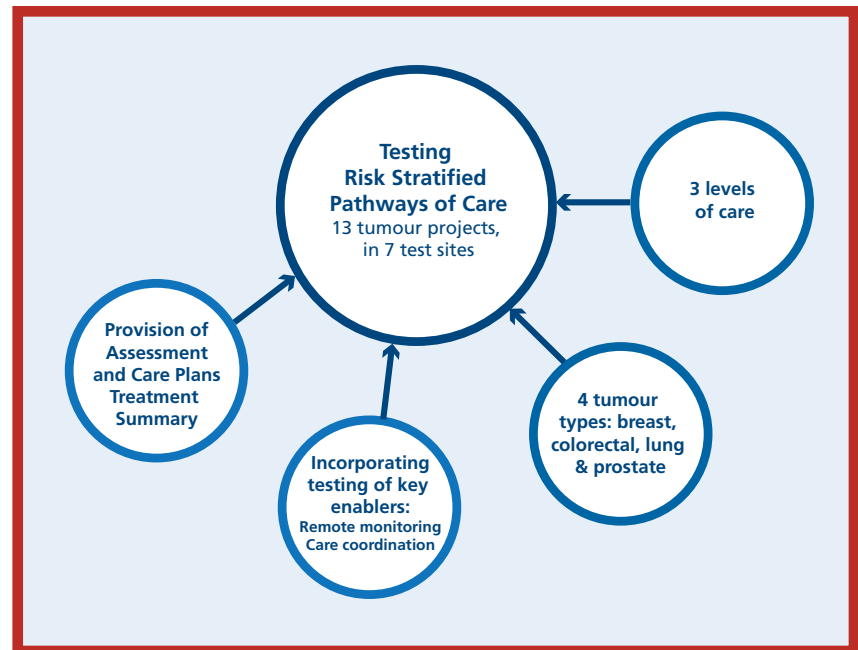
Anne Wilkinson, National Improvement Lead, NHS Improvement



Sue O'Neil, PA - NHS Improvement - Adult Survivorship

The hypothesis - testing risk stratified pathways of care

This phase of testing is taking a whole system approach looking to redesign the pathways of care in four tumour sites with the focus on risk stratification. The resulting model of care, when tested, should provide early evidence on the benefits of this approach compared to the current widespread traditional model of care. This is in keeping with current policy of care closer to home and increasing the proportion of self managed care for those living with and beyond cancer. Given the nature of cancer survivorship, evidence will accrue over time and, this current phase of testing will require data collection to continue in the longer term to ensure the full impact of risk stratified pathways is captured.



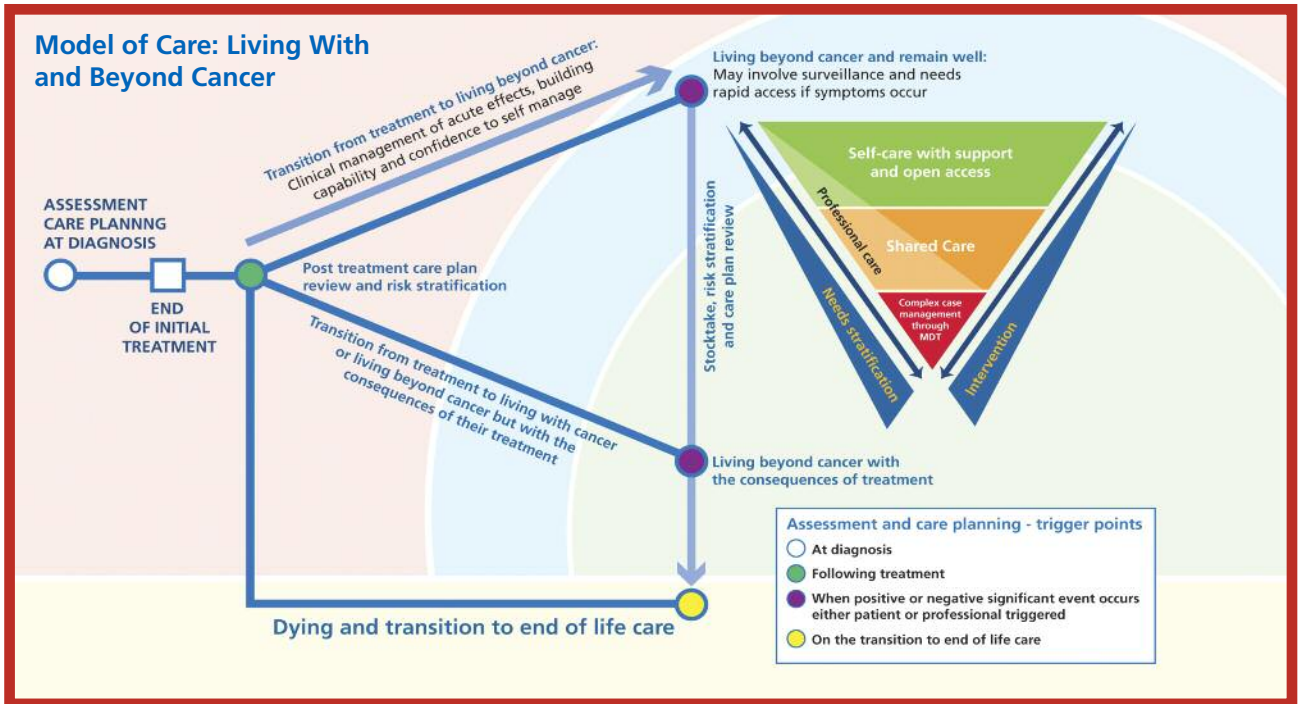
The overall direction of the work is led by an NHS Improvement Director and National Clinical Lead, supported by a National Improvement Team and National Clinical Advisers. The mandate for this work is through the National Cancer Survivorship Initiative (NCSI) Steering Group, Cancer Programme Board and NHS Improvement Executive Team.

Regardless of whether individuals have been treated with curative or palliative intent, the same model should apply with risk stratification into an appropriate level of care. This should take account of the

disease process, the treatment received and the individual's personal circumstances. There are two essential underpinning enablers without which the model may not achieve the full potential. The key enablers are remote surveillance which ensures patient safety at a distance, and care coordination which should ensure services and communication channels function across organisations and appears seamless to the individual.

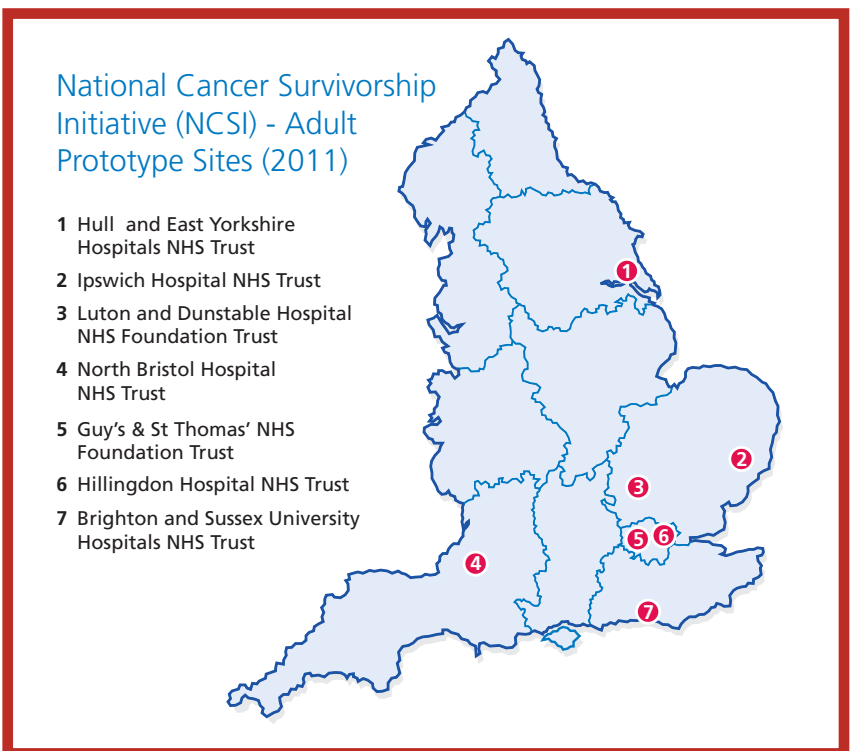
The testing hypothesis is that through risk stratifying into appropriate level(s) of care there will be:

- An improvement in the experience and patient reported outcomes of care from baseline
- A 50% reduction in outpatient attendances from the traditional model
- A 10% reduction in unplanned admissions from baseline.



The national test sites

There are seven national test sites working on 13 adult tumour projects. The testing will be completed by December 2011. The report on this phase of testing, including the evaluation, will be completed by April 2012. There will be, as previously mentioned, a need for ongoing measurement to evidence the longer term benefits of this risk stratified model of care.



Risk stratification

As a result of the pilot phase of the testing and consensus meetings to agree the prototype pathways in each of the tumours the difference in risk stratification for each tumour became apparent. The percentages in the table opposite were agreed as the hypothesis for the proportion of patients likely to be risk stratified to each pathway. During the testing, clinical teams will be identifying the criteria for stratifying into the different levels of care and whether the suggested proportions are applicable in practice.

Key assessment/reassessment triggers

There is an assumption that all patients will be offered a care plan updated when reassessment takes place, have a timely treatment record summary updated and communicated appropriately after each phase of treatment. With the patient's consent this should be shared with those providing or supporting care delivery. It is recommended that every patient diagnosed with cancer is provided with a hand held record, either in paper or electronic format, which contains information pertinent to their ongoing management - whether this is self or professionally managed.

The key trigger points for assessment or reassessment along the pathway of care will depend on the disease process, the treatment and the individual patient circumstances.

Risk stratification proportions table

	Self Management	Shared Care	Complex Care
Breast Cancer	70%	10%	20%
Prostate Cancer	40%	25%	35%
Lung Cancer	15%	60%	25%
Colorectal Cancer	40%	30%	30%

Treatment summary

The treatment summary should summarise the current state and also the signs and symptoms that both the individual and professionals providing care should be looking out for. Information and education should be tailored to the individual through the assessment process and be part of their care plan. Education and support will also be required across the clinical community. Good communication in a timely manner is critical between professionals and with the individual who is living with or beyond cancer. This is therefore about a package of care for the individual which is seamless across organisational boundaries, with the right care, at the right time, first time.

Relationship between cancer and other diseases/conditions

There will be elements of the pathways which are unique to individual tumour types and also to individuals living following a

cancer diagnosis e.g. spinal cord compression following radiotherapy and there will be elements which are generalisable e.g. physiotherapy or dietetics, across the different tumour types and also to non cancer conditions and diseases.

Key elements to support self management

- Information and education appropriate to the individuals needs
- Key contacts for care/support in and out of hours for cancer and non cancer related problems
- Appropriate timely access if the condition changes
- Effective care coordination
- Effective remote monitoring as appropriate.

Measures

Various measures will be collected locally and nationally:

- The number of prospective outpatient follow up slots saved, based on point of pathway where patients risk stratified to no further routine follow-up care
- The number and percentage of patients risk stratified to each of the levels of care within each tumour type
- The number of unplanned admissions for patients with a known diagnosis of cancer
- The number of referrals to care and support services (internal and external)
- Ipsos MORI is working in partnership with national and local teams to undertake a Patient Reported Outcome and Experience Measure survey as a baseline prior to testing of risk stratified pathways and repeated for a cohort of patients stratified into the new pathways in January/February 2012
- Evaluation of care coordination and remote monitoring is currently under discussion.

Evaluation

The evaluation of this programme of work will come from the Ipsos MORI experience/ patient reported outcome of care surveys, the evaluation of each of the enabling projects, care coordination and remote monitoring, local audits, experiences and improvement work being undertaken in each of the test sites and their reported learning and results. The national

HES data will provide a retrospective picture of changes over time. It is recognised that there will be a need for further evaluation of this work over the

next few years and beyond in order to measure and assess the ongoing impact and full extent of the savings associated with this model of care.

Quality, Innovation, Productivity and Prevention (QIPP)

The QIPP agenda is a national priority and this programme of work is aligned to those priorities. Improving the quality of patient care is at the heart of the NCSI agenda, empowering patients to live with and beyond cancer. The traditional model of cancer after care does not encourage patients to exercise choice and control in their journey. Also there is little evidence to support the current traditional ‘one size fits all’ model of follow up offered to many cancer patients around the country.

Quality: The introduction of risk stratified pathways of care will result in more effective, efficient service delivery which should enhance patient experience and reported outcomes of care. This will also encourage supportive self management rather than a paternalistic model of care.

Innovation: The pathways and their constituent parts are innovative in that, as far as we are aware, there are no clinical

teams nationally or internationally who have pulled together elements of care into a ‘total’ package driven by effective risk stratified pathways of care for those living with and beyond cancer. This is a significant cultural shift for individuals who have had a diagnosis of cancer and for the clinical teams supporting them.

Productivity: Through delivering risk stratified pathways the reduction in unnecessary appointments will release resources to help meet access targets and provide capacity to support patients in greater need. Better coordinated and informed care and support will contribute to a reduction in unplanned admissions.

Prevention: The emphasis will be on secondary prevention through having an effective pathway that is personalised to the individual and encourages a healthy lifestyle through exercise and healthy living.

National Cancer Survivorship Initiative Support Projects

The NCSI goal for the prototype sites is to provide evidence based, best practice integrated care pathways for breast, colorectal, prostate and lung cancer patients which can be rolled out across the NHS. There is an offer of support to the prototype sites incorporating one or more of the following within their testing work:

Benefits made clear¹² - A Macmillan interactive online tool offering benefits advice and information for patients, full support to use the tool and supporting materials are available.

Health and Well Being Clinics - Health and Well Being Clinics are one off events, a group programme delivered by a mix of professional staff supported by trained and inspired volunteers. The clinics offer expert advice on health and wellbeing, access to support groups, reliable information, financial benefits and support and give people the confidence and skills to manage their condition themselves as far as possible.

Supported self management - To enable supported self management to take place changes need to be made in skills development programmes for professionals, self management support options for patients/survivors and institutional support for service redesign.

Supported self management demands a cultural shift that views the person with cancer as an expert in themselves and the health care professional as experts in cancer care both working together in partnership to achieve the best outcome for the person with cancer. A number of voluntary sector partners in care can offer support to establish a range of self management opportunities, including training of facilitators, support for professionals to develop confidence in engaging patients within a more collaborative approach to care.

Physical activity - There is robust evidence of the effectiveness of physical activity for those living with and beyond cancer. It can have a positive effect on the side effects of radiation, chemotherapy, immunotherapy hormone therapy and steroid therapy. Additional support for prototype sites is available to integrate evidence based physical activity promotion and services into standard patient care, at appropriate points across the patient care pathway, and champion the promotion of physical activity across oncology and primary care for cancer patients.

Vocational Rehabilitation (VR) -

The VR project provides services and information to help people with cancer remain in or return to work. The NCSI Vocational Rehabilitation Project has developed a four level model of Vocational Rehabilitation which provides early information and support at Levels 1 and 2 and a Vocational Rehabilitation Case Manager at Levels 3 and 4 with referrals to specialist services such as physiotherapy and self management programmes eg fatigue and pain management. Macmillan can offer support to establish vocational rehabilitation services within the prototype sites, provide advice and access to e-learning programmes and information, both printed and on line and provide peer support from an established network of VR pilots.

Many of the above projects within NCSI are coordinated with Macmillan Cancer Support. This testing will contribute to the best practice evidence base, and to the overall aim of the NCSI to ensure that all cancer survivors receive the help and support that they need. For further information about Macmillan and other tumour specific voluntary organisations involved in providing support to the test sites please see the resource page in the tumour sections and at the end of this document.

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Care coordination is a function
not an individual.”

Enabling projects: Care coordination

Care coordination is not one person's role, job or responsibility. It is the joining up of services, coordination, information and communication between care givers, treatment providers, those living with and beyond cancer and their families that creates a seamless experience of care.

There are models for care coordination in other policy areas: The single assessment process for older people¹³, person-centred planning for people with learning difficulties¹⁴ and The Care Programme Approach¹⁵ (CPA) for people with a mental illness. All of these referred to the importance of assessment, care planning, care coordination, review and the importance of joint working across health and social care within their specialist areas which resonates with our hypothesis and prototype pathways.

As good care coordination will provide the best opportunity for patients to be confident to self manage their lives with and beyond cancer, it is important for all tumour teams that care coordination is addressed whilst testing the new risk stratified pathways. Building relationships and networks is crucial to improving care coordination - not just within the NHS, but beyond to social care, charities, community care providers and other agencies that meet the needs of individuals.



This will help to facilitate efficient transfers of care throughout the pathway, wherever they occur, whether to vocational rehabilitation, physiotherapy, voluntary services, social care, or end of life care.

A working group consisting of clinicians, patients and service managers are guiding and advising the direction of this enabling project. The group has developed the guiding principles for delivering good care coordination as detailed below:

Guiding principles

- Good communication and professional relationships, formal and informal, between the patient, their carer/family and the care or support team

- Proactive and prompt access and intervention when needed
- Appropriate provision of correct information to enable individual choice and control
- Proactive monitoring as necessary (remote monitoring where possible)
- Transition of care along the pathway should appear seamless to the person receiving the care
- Provision of correct information for healthcare professionals to support effective patient management in the event of care delivery away from their usual care team e.g. hand held record with the components listed:

Hand held record components

- The treatment summary gives information on diagnosis, treatment, the clinical management plan and includes signs and symptoms to look out for. (The care plan may be integrated into the document or may be a separate document)
- A care plan, where it is not incorporated within the treatment summary, should be available for all patients and should outline needs identified, who is taking action to meet those needs and timescales
- Contact numbers for support services appropriate to their needs
- Telephone numbers to contact if patients have cancer related or non-cancer related symptoms, in or out of office hours
- A self assessment should be available for completion, should patients feel their condition or needs change (This should be sent to the appropriate contact)
- A section for recording any issues the patient is experiencing, what they have done about it and whether it resolved the problem. This information will be useful where the individual's care crosses organisational or professional boundaries.

Testing

Care coordination will be tested as part of the overall flow of the pathway. Any issues may also be the cause of unplanned admissions or contacts with the health care team which will be monitored throughout the testing. There will also be a care coordination audit tool for teams to use locally to consider their local stakeholders, geography, facilities and services outside health, efficiency in interagency communication and patient information and feedback. It is hoped that this approach will also prompt other agencies to think about their own communication and coordination. This will be reviewed after testing to identify where things have improved and areas for further work.

Evaluation

The evaluation of care coordination will centre on clearly defined questions set in focus groups led by external facilitators. This will include the usefulness and effectiveness of the Hand Held Record from both the patient and staff perspective. With consent from participants we will use selected quotes and detailed thematic analysis to produce clear findings in separate patient focus groups and health, social and care staff focus groups

The audit tool results will form part of the evaluation. There will be various national and local measures collected regarding the effectiveness of care coordination.

- **Good communication and professional relationships**
- **Proactive and prompt access to appropriate service**
- **Timely information provision and support**
- **Seamless care transition across services and providers**
- **Hand held record with 'Then, Now and When'**
- **Proactive monitoring, remotely where appropriate.**

Guiding principles for delivering good care coordination

Enabling projects: Remote monitoring

Background

During meetings to seek agreement on the new prototype pathways of care, it became apparent that access to a safe reliable system that enables clinicians to monitor large numbers of stable patients in the community without the need for a face to face follow up appointment was a key enabler for testing risk stratified pathways of care. Such systems were considered appropriate for breast, prostate and colorectal specialties where routine standard tests applied and where interpretation of results could take place remotely.

Responding to the opportunity this offered, a small working group comprising test site clinicians and IT representatives was established and the key requirements for the system identified. We are indebted to Mr Jon McFarlane, Consultant Urologist at the Royal United Hospital, Bath and his team who helped inform the development of the solution for prostate cancer and on which the colorectal solution will also be based.

REQUIRED FUNCTIONALITY OF REMOTE MONITORING:

1. To pull patient data set information from PAS via the local cancer information system
2. To pull test results from local diagnostic IT systems
3. To store key diagnostic and key patient history data
4. To log any relevant treatment history during monitoring period including a log of patient contacts
5. To set individual patient range/tolerances for specific tests
6. To schedule tests based on user definable follow up schedules
7. To hold a range of template letters to enable communication of results to patients and GPs by post or electronically
8. To include an alert system that identifies test results for review, due dates exceeded or test result that exceed tolerance
9. To provide a summary history and treatment page with test results shown numerically and graphically
10. To record the outcome of any event or test
11. To provide standard and ad hoc reporting and routine monitoring function and be amenable to clinical audit
12. To be NHS and HL7 compliant with secure access
13. To use a common file format for all data export to be able to import the data into local IT systems if required.

Prostate cancer

The main indicator for prostate cancer is the prostate specific antigen test (PSA). Whilst not the only indicator of recurrent disease, it is the test used routinely to monitor patients in the follow up period for a minimum period of five years and often for life. The PSA tolerance level is based on the treatment received.

From a clinical perspective the system needs to provide data that demonstrates PSA results numerically and graphically over time as a gradual increase in PSA levels, even if levels are within tolerance, can indicate disease recurrence.

Colorectal cancer

Surveillance tests following treatment for colorectal cancer comprise regular carcinoembryonic antigen (CEA) tests, CT scans and colonoscopy or sigmoidoscopy procedures depending on the site of the tumour. The exact frequency of tests is determined locally and re-investigation prompted if there is any clinical, radiological or biochemical suspicion of recurrent disease.

The remote monitoring solution for colorectal will need to access a variety of test results from various sources to inform the decision making process.

Breast cancer

For patients following treatment for breast cancer annual mammography should be offered to patients for five years or until they reach screening age (in England this is 47 years). We know that many patients continue to attend outpatient clinics simply to receive the results of their mammogram test.

Given that some good systems already exist for breast mammography a decision was made by the working group to use existing systems where possible rather than reinvent the wheel and develop a specific module within the new IT solution. The two models for mammography surveillance that have been identified are:

Model 1 - On site Breast Screening Unit (BSU) - Patients are recalled for annual mammography with appointments booked on standard PAS clinic booking system (paper mammography clinic) with the reports generated by screening radiologists on standard radiology reporting system (CRIS). The BSU send results of the mammogram to the patient, GP and surgeon. Abnormal results referred to the MDT and recalled to the BSU for further investigations if required

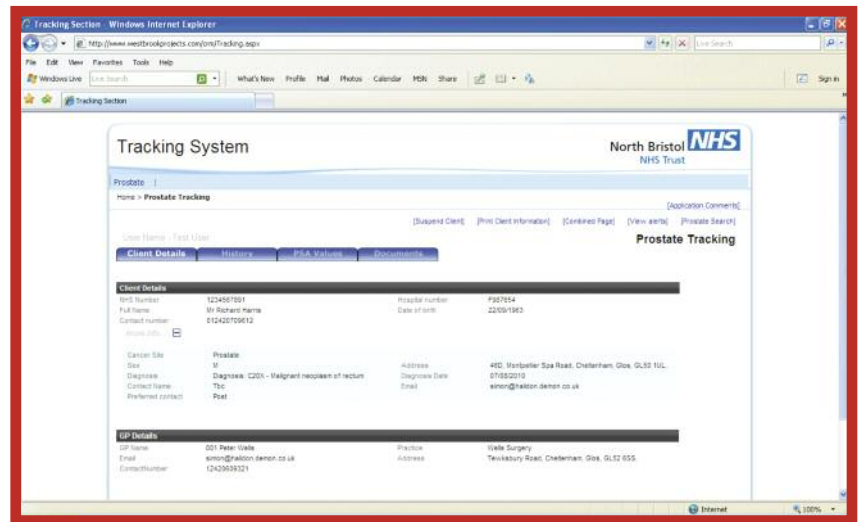
Model 2 - Off site Breast Screening Unit - Patients are referred for annual mammogram to the National Breast Screening Service and managed through the NBSS System using an identical NBSS system to that for high risk patients with familial disease. Results are sent by letter to patients and copied to the GP. Abnormal results are referred to surgeon to arrange recall and further investigations. Server and licence costs approximately £5,000.

The IT solution being tested
The IT developer in partnership with colleagues at North Bristol

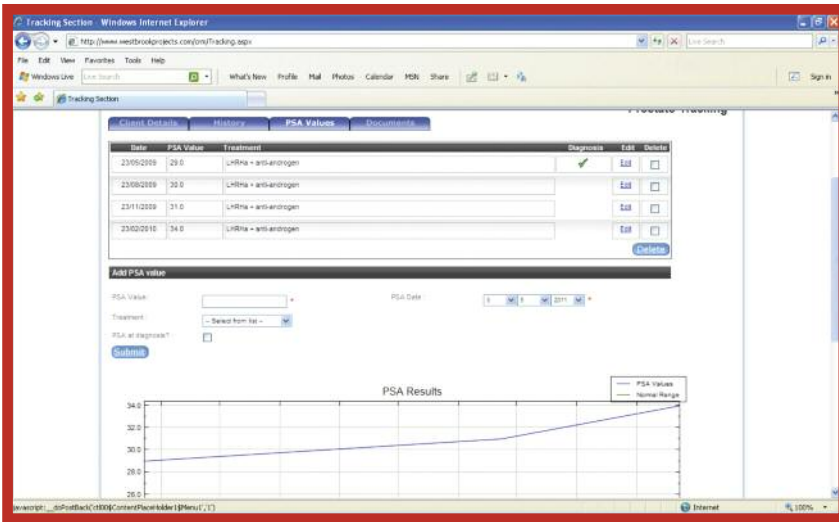
NHS Trust, The Royal United Hospital in Bath and prototype test sites have been testing the proposed solution for PSA monitoring over recent weeks.

Once this and the testing of the interface connectivity are complete the solution for prostate cancer PSA monitoring will roll out to the prototype sites for use from early July. The modifications for colorectal cancer will be developed during June with rollout anticipated from August.

The following screenshots provide examples pages from the proposed solution using fictitious data.



Screenshot 1: The system automatically draws patient dataset and GP details from the Trust Patient Administration System (PAS). This ensures data is always accurate and up to date.



An evaluation of the prostate and colorectal modules will take place in early 2012 following the initial six months of use along with other locally developed systems where Trusts have used or developed their own solutions for this purpose.

Screenshot 2: The PSA tracking page automatically draws PSA test results from the Trust pathology systems and plots on a graph below for easy interpretation.

The screenshot shows the 'Alert' page of the PSA tracking system. It features a table with columns for Client Name, NHS Number, Hospital Number, DOB, Range, Due Date, and Alert. The table lists several patients with their respective alert details. The header includes 'Tracking System' and 'North Bristol NHS Trust'.

Client Name	NHS Number	Hospital Number	DOB	Range	Due Date	Alert
Richard Smith	70948123	158753456	12/01/1967	8	02/02/2011	19/04/2011 Open task due
Mary Jones	654321987	52345678	24/01/1958	10	03/03/2011	12/05/2011 Due date exceeded
Richard Smith	123456789	987654	22/01/1963	8	10/03/2011	23/05/2011 Due date exceeded
Mary Jones	987654321	876543	01/05/1972	8	10/05/2011	23/05/2011 PSA large exceeded

Screenshot 3: The 'Alert' page identifies patients where an action is required either that a test result requires review, a delay has occurred in the test being taken or to indicate that a test tolerance limit has been exceeded.

Breast cancer

Introduction

“Breast cancer services must accommodate an increasing number of cancer survivors, due to the increased incidence related to an ageing population and improved survival due to improved detection and treatment.

The National Cancer Survivorship Initiative seeks to improve patient experience and outcomes and meet the needs of an increasing number of survivors, whilst ensuring services are sustainable and safe.

Models of care are in development which will be risk stratified according to individual patients needs, disease and co-morbidities. This will result in removal of regular planned clinical follow up for most patients (approximately 70%) with information and support for self management.

There are five breast multidisciplinary teams which are testing different aspects of the new models of care including: personalised patient treatment summary and care plan; patient education; mammography surveillance with robust recall systems; assurance of prompt access and intervention when required.

As the newly appointed breast cancer clinical adviser I look forward to working with the clinical teams in Hull, Ipswich, Brighton, Hillingdon and North Bristol as they commence testing the hypothesis based on the risk stratified pathways of care.”

Dorothy Goddard, National Clinical Adviser - Breast Cancer



Dorothy Goddard, National Clinical Adviser - Breast Cancer

Breast cancer overview

Breast cancer is the most common cancer in the UK. Over 50,000 new cases are diagnosed per year, including approximately 300 men with breast cancer. Breast cancer is one of the few cancers where incidence rates are higher for more affluent women and there is a clear trend of decreasing rates from least to most deprived. The incidence is gradually increasing due to the ageing population (81% in women aged over 50 yrs). A report by Cancer Research UK estimates that:

- The lifetime risk of being diagnosed with breast cancer is one in eight for women in the UK
- Female breast cancer incidence rates in Britain are increasing, and have increased by more than 50% over the last 25 years
- In the last decade, female breast cancer incidence rates in the UK have increased by 3.5%.

Survival rates for breast cancer England are over 80% at five years and have been improving for 40 years.

The initial treatment phase can include surgery, chemotherapy, radiotherapy, hormone therapy - sometimes continuing with hormone therapy for several years.

Follow up after treatment for breast cancer is one area where some work has already been done on reducing unnecessary outpatient follow up appointments. This has been achieved by introducing drop in clinics, open access clinics and also empowering patients to self manage from the end of treatment, accessing the CNS by phone and only attending clinics when deemed necessary.

The main reasons cited for traditional regular follow up appointments for breast cancer are:

- Discussing or prompting annual mammography as part of monitoring post treatment
- Monitoring of patients on hormone therapy
- Psychological support and reassurance for the patient
- Facilitation of audit.

Recurrence is estimated to be approximately 10-20% within ten years of diagnosis, although most recurrences occur within five years and the likelihood varies with the type of cancer. Patients should be aware of the symptoms and signs to look out for and when to seek help. Most recurrences are detected by the patients themselves or on mammography surveillance rather than at routine clinical follow up.

There is variation nationally on the frequency and duration of follow up. In the 'Rapid Review of Follow up Practice in England'⁷ the frequency of follow up ranged from one outpatient visit to 12 visits or more over a five year period. Some patients are followed up for life.

NICE guidelines¹⁶ suggest the following surveillance tests:

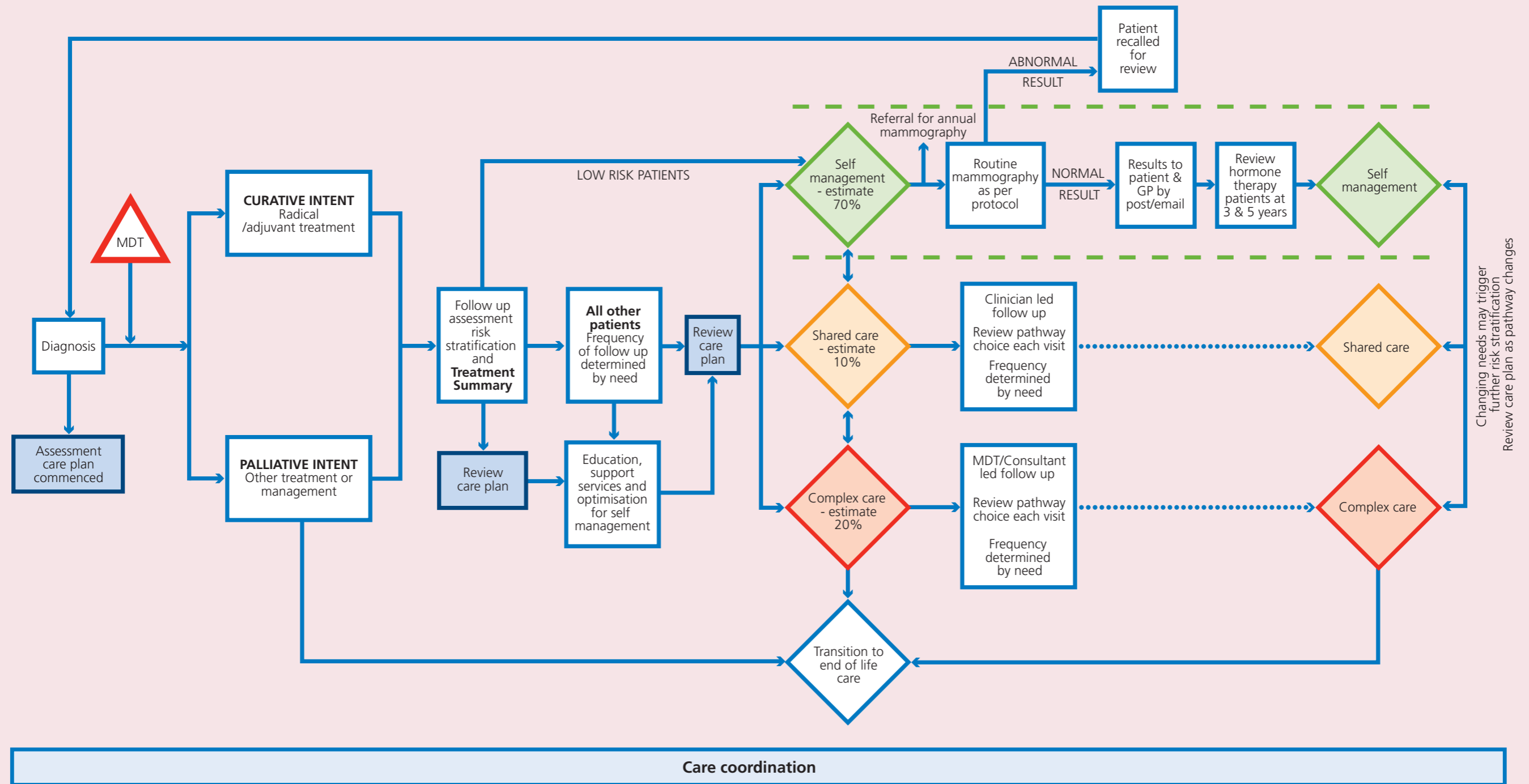
- Offer annual mammography to all patients with early breast cancer, until they enter the Breast Screening Programme or for five years for patients diagnosed with early breast cancer that are already eligible for screening
- Do not offer ultrasound or MRI for routine post-treatment surveillance in patients who have had early invasive breast cancer or ductal carcinoma in situ (DCIS).

Breast cancer treatments can lead to late effects, such as lymphoedema from radiotherapy, infertility and premature menopause from chemotherapy, osteoporosis from hormone therapy, cardiac damage from chemotherapy or radiotherapy and very importantly, breast cancer survivors do have an increased risk of significant depression.

Various charities are supporting the teams in delivering this testing work such as Breast Cancer Care, further information can be found on the resources page.

This programme aims to address survivorship needs and will focus on the assessment and care planning especially after end of treatment, information for the patients and the GP and on improving access to support services to enable people to return to as normal a life as possible following their treatment.

Risk Stratified Breast Cancer Pathway - For Testing



KEY FEATURES

Risk stratification decision points

For the majority of patients with low risk factors for disease, treatment effects and individual circumstances it may be feasible to refer to a self managed pathway with annual mammograms immediately after the end of treatment.

Review care plan (following treatment)

The period following end of treatment is key to establishing an appropriate care plan that include supportive care services to enable the patient to self manage.

Support services of particular relevance to breast cancer patients

- **Diet and nutrition** – advice on diet especially where there is concern over weight changes.
- **Exercise** – there is increasing evidence that physical activity helps recovery and reduces risk of recurrence. Behavioural changes require investment of time, expertise, training and encouragement.
- **Peer support** - talking to others about their cancer experiences and meeting others living beyond cancer as positive role models.

Remote monitoring

To incorporate the scheduling and monitoring of annual mammograms for five years with results reviewed by the team and patients recalled to clinic if results are found to be abnormal.

Entry into the National Breast Screening Service Programme if over screening age or auto recall as appropriate until reach the upper screening age range. Open access back into the service is available at all times.

“

The National Cancer Survivorship Initiative seeks to improve patient experience and outcomes and meet the needs of an increasing number of survivors, whilst ensuring services are sustainable and safe. ”

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Current service

The Park Centre for Breast Care opened in Brighton in November 2008 as the first unit of its kind in the country, offering the latest mammography technology and all outpatient services under one roof as part of Brighton and Sussex University Hospitals (BSUH). Our breast screening service is currently rated in the top 10% in the UK by the National Breast Screening Programme.

The unit diagnoses around 575 new breast cancers a year. Most surgery takes place at The Princess Royal Hospital, Haywards Heath with radiotherapy at the main Royal Sussex County Hospital in Brighton. The Trust is planning to be a test site for the 23 hour bed model for breast surgery.

Our current breast cancer follow up protocol includes six consultant led appointments over five years before discharge to the GP.

In 2009, the team trialed an 'information day' for patients and carers that proved very successful and recognised the opportunity that such an event could offer as part of a redesigned pathway of care.

Testing

"Building on our earlier work we are really keen to establish regular information 'events' as part of our mainstream service with a particular focus on weight management, exercise and vocational rehabilitation. Our first event is planned for September" said Venessa Neylen, Clinical Services Manager. "We will hold the first event in the modern post graduate centre which offers good non clinical facilities for such events. We are well on the road to agreeing the agenda and arrangements for the day and hope that many patients will be able to attend."

We are planning to test an end of treatment assessment using the 'Distress Thermometer', the preferred tool across our Trust. We also plan to use the 'Breast Cancer Care' care plan booklet and CD which also allows space for local information and support groups. We are also testing the treatment summary to help improve communication with GPs to assist them with their role in supporting patients in primary care.

Our clinicians are currently working on the revised protocol for risk stratifying patients for follow up that will result in a reduction in unnecessary outpatient visits for many patients.

Finally, one of the key enablers for our new care pathway will be a system for arranging annual mammograms. We are working with NBSS to see if their system for this purpose, which will also help us improve the system for screening high risk familial patients.

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Current service

The breast cancer service for the Trust will be based at Southmead Hospital from June and is where surgery will take place. Chemotherapy and radiotherapy is delivered at University Hospitals Bristol NHS Foundation Trust. We are currently centralising all breast services across the city to Southmead Hospital.

Across the City we see approximately 700-800 new breast cancers a year. We are in the process of implementing the 23 hour ambulatory mastectomy model and have well established nurse led follow up clinics for breast cancer patients.

A member of the team said "We have been running patient 'look after yourself' days for about nine years and as a team have used this project to share and expand this model to develop living well courses with clinical psychology and Penny Brohn Cancer Care. We have previously reduced follow up to one year".

Testing

We have recently expanded our 'look after yourself' programme in partnership with the Penny Brohn Cancer Centre developed 'living well' courses and a 'self management' course with clinical psychology.

We will be testing the new pathway to empower patients to self manage following an initial post treatment with annual mammography and no routine follow up.

We have an automated call and recall system for mammography that is linked with the screening service when patients reach 50.

We will be further developing our local Client Relationship Management System to incorporate the findings from the distress thermometer and an electronic care plan and treatment summary that will be shared with patients and GPs.

We are currently looking at options available for a hand held record for cancer patients.

We will be collecting data on unplanned admissions, prospective follow up slots saved for patients self managing and referrals to support services.

The Hillingdon Hospitals NHS Foundation Trust

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Quotes from members of the team:

“This project gives us the opportunity to formalise the process for risk stratifying patients to a self management pathway and to work on the automation of the call and recall system we have for the annual mammograms that patients require.”

“Whilst we have excellent support services available at the Linda Jackson and Yiewsley Centres we recognise that this is not local to all our patients. We will be working with the NCSI project leads to improve access to exercise, health and wellbeing and vocational rehabilitation to help us to maximise opportunities for our patients in these areas.”

“As professionals we are using this project to streamline all our processes and information so that we are consistent and structured in our approach as a team.”

Testing

We will be using the distress thermometer as both our assessment and stratification tool for patients at the end of their breast cancer treatment. The distress thermometer will be used to address patient's needs and develop an individualised care plan. This work will continue from that developed by our lung cancer team who took part in the assessment and care planning pilot phase.

We will also be testing this pathway in patients diagnosed with advanced disease and developing relevant information packs in conjunction with the Information Prescribing pilot. We will also be working with Breast Cancer Care to evaluate their resources for women with breast cancer.

Current service

The breast service for the Trust is based at Hillingdon Hospital where the majority of surgery takes place. Chemotherapy and radiotherapy are provided at Mount Vernon Cancer Centre. The unit sees approximately 170 new breast cancers per annum.

The self management model of after care has been established over an eight year period with the majority of breast cancer patients being offered a self management pathway post treatment. Patients receive telephone support from their original breast care nurse and direct open access back to either a breast or oncology clinic to a nurse led clinic if required.

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Current service

The breast unit is based at Castle Hill Hospital where all breast surgery, chemotherapy and radiotherapy take place. The unit sees approximately 509 new breast cancers per annum. We are successfully running a nurse led survivorship programme

Quote from member of team:

“Having already recognised the need for support for patients in the survivorship phase of their cancer journey we had already begun looking at assessing patients one year post diagnosis to help provide services to enable them to self manage.

Following an assessment of support services we recognise the need to work with the NCSI project leads to further develop support for health and wellbeing, exercise, self management and vocational rehabilitation in some areas of our patch.

As a team we are using this project to help us to formalise some of the processes we are already working with to empower patients to self manage.”

Testing

We are using an assessment tool based on the Macmillan survivorship assessment and completing a care plan for patients as part of their survivorship pathway.

We are testing the Treatment Summary as we recognise that GPs need more information to help them to play their part and also see this as an excellent summary to have in the patient’s notes at the hospital should they present again, as a summary for the MDT to see at a glance the previous diagnosis, treatment and outcomes.

We will be collecting key measurement data throughout and have implemented a NBSS system to track the call and recall of mammograms required for our patients.

The Ipswich Hospital NHS Trust

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“Having already recognised the need for support for patients in the survivorship phase of their cancer journey we had already begun assessments and education for patients that have completed treatment in all cancers. A four week education programme or twice yearly education days are available to empower patients to self manage to suit individual need. Working with the NCSI project leads, local authorities and PCTs as part of the Fit Villages scheme on exercise and rehabilitation to support self management for cancer patients and we plan to further develop these areas. We have already provided training for local fitness instructors to encompass cancer specific issues to enable our patients to access local leisure facilities.”

Louise Smith, Project Manager.

Testing

We will be using the Anglia Network wide approach to assessment, using an adapted distress thermometer as our assessment tool and completing a combined treatment summary and care plan in one document for patients as part of the hand held record which we are testing.

We are planning to test an electronic ‘live’ copy of this document that can be accessed by health care professionals at any time in the pathway. This should greatly improve care coordination. We will be collecting key measurement data on the number of patients self managing, outpatient visits and unplanned admissions.

Current service

Our breast unit is at Ipswich Hospital NHS Trust where the majority of surgery, chemotherapy and radiotherapy takes place. The unit sees approximately 300 new breast cancers per annum and are considering entering the enhanced recovery programme in the near future. We have successfully run nurse led follow up clinics for a number of years, which we are planning to extend as part of the testing. We already have an established remote monitoring system for call and recall for annual mammograms before the transfer to the Breast Screening service.



Colorectal cancer

Introduction

“I think it is important we all support this survivorship programme that turns the spotlight on the care provided for colorectal cancer patients following completion of treatment. With the emerging evidence around diet and exercise in prevention and recovery and changes to secondary treatment options the future holds many opportunities to improve the quality and effectiveness of the care we provide. Furthermore with the introduction of the standards for patient satisfaction this work should give us the tools to deliver the quality of follow up our cancer patients require. I look forward to supporting the clinical teams at Guy’s and St Thomas’ and North Bristol as they develop and test these new risk stratified pathways of care and to support and advise on the development of a computerised remote monitoring system that allows the monitoring of surveillance tests and avoids the need for unnecessary follow up visits.”

John Griffith, National Clinical Adviser - Colorectal Cancer



John Griffith, National Clinical Adviser - Colorectal Cancer

Colorectal cancer overview

Colorectal cancer is common with over 36,000 new cases diagnosed per year. The incidence is gradually increasing due to the ageing population (74% in people over 60 years). Incidence rates vary across the country suggesting that lifestyle and environmental factors may also be contributory factors. Survival rates across England are around 52% at five years and whilst increasing, still lag behind other European countries. These poor results however, relate to the high proportion of patients presenting with advanced disease. Those patients who undergo potentially curative resection have equivalent results to those in Europe.

The majority of patients have surgery, plus or minus chemo radiation therapy during their initial treatment phase. Approximately 20% of these patients have stomas and of these about 80% will have their stoma reversed after about a year.

The management of colorectal cancer follow up after treatment varies although there is general agreement that the reasons for follow up after curative treatment are for:

- Detection of recurrent or metastatic disease at an early or pre symptomatic stage when other curative treatment is feasible
- Provision of psychological support and assurance for the patient
- Facilitation of audit.

The incidence of disease recurrence is estimated to be 9 - 13% and in the vast majority of cases recurrence occurs within two years of completion of multi-modality primary treatment suggesting that more intensive surveillance during this time would be beneficial.

Nurse led follow up is commonplace in many colorectal units however there is variation nationally on the frequency and duration of follow up and the range of surveillance tests offered. In the 'Rapid Review of Follow up practice in England'⁷ follow up visits in this tumour group ranged from 5 -13 visits over five years (average 8.4 visits) across the 21 colorectal units surveyed.

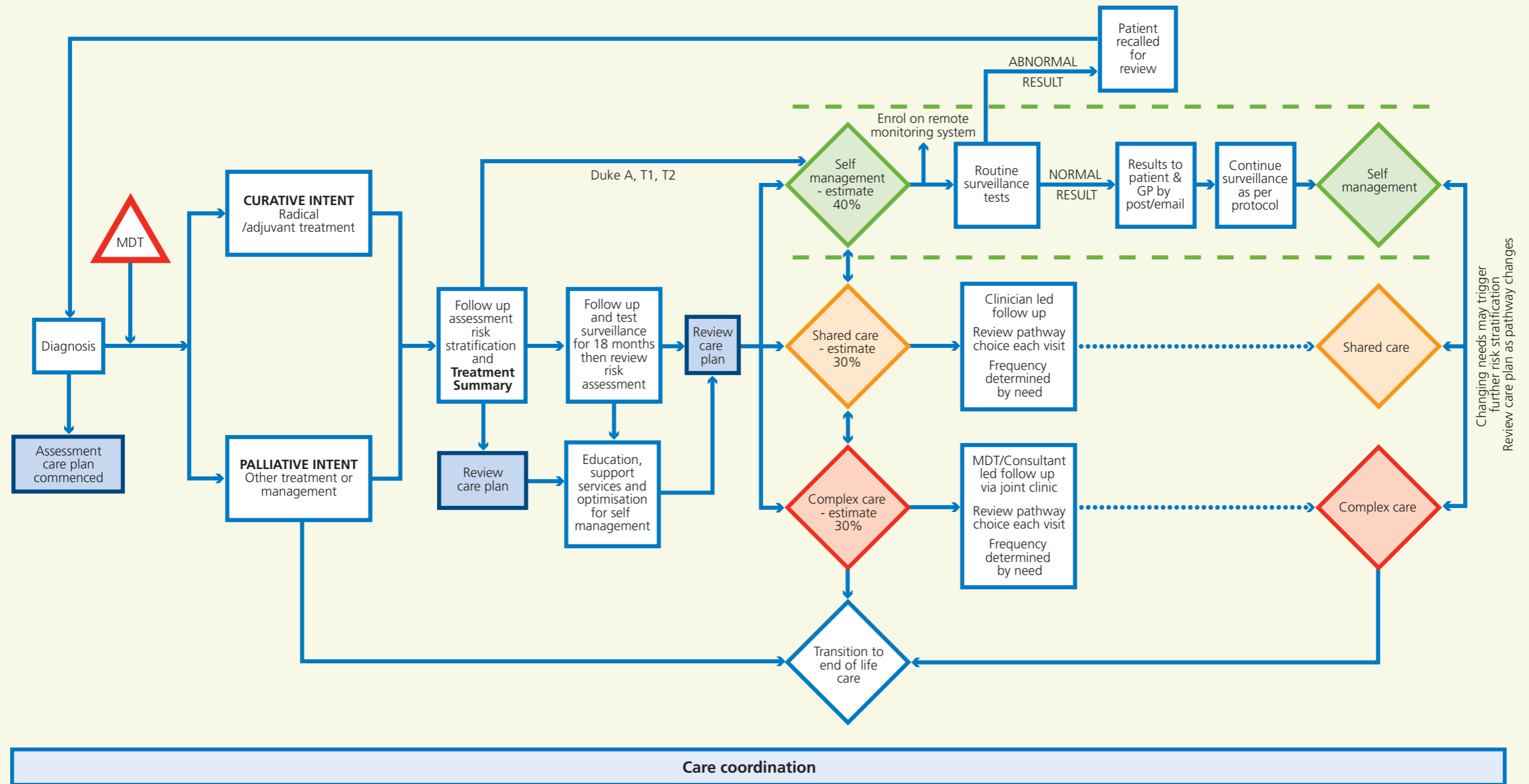
On surveillance tests the recent draft NICE guidelines¹⁷ suggest:

- A minimum of two CTs of the chest, abdomen and pelvis in the first three years
- Regular serum carcinoembryonic antigen (CEA) tests. An elevation in CEA after apparently curable treatment is frequently associated with recurrent disease. The exact frequency of tests should be determined by cancer networks
- Offer a surveillance colonoscopy at one year after initial treatment. If this investigation is normal consider further colonoscopic follow up after five years.

Treatment for colorectal cancer leads to very specific side effects relating to bowel function, sexual function, psychological issues and activities of daily living. Many patients have ongoing needs and often encounter fragmented and poorly coordinated follow up care.

The teams will aim to address these aftercare needs and will focus on the assessment and care planning especially after end of treatment, information for the patients and the GP and on improving access to support services to enable people to return to as normal a life as possible following their treatment.

Risk Stratified Colorectal Cancer Pathway - For Testing



KEY FEATURES

Risk stratification decision points

For patients with low risk disease it may be feasible to refer to a self managed pathway with remote surveillance immediately after the end of treatment. For the remainder this risk assessment will take place at 18 months following end of treatment.

Review care plan (following treatment)

The period following end of treatment especially following pelvic radiotherapy is associated with distressing bowel dysfunction and dietary problems.

Support services of particular relevance to colorectal cancer patients

- **Bowel dysfunction** – advice and exercises to help overcome bowel leakage and incontinence following surgery.
- **Sexual dysfunction** – issues around lack of libido and changes to body image.

- **Diet and nutrition** – advice on what to eat and foods to avoid to cope with specific problems after surgery, due to stoma or as result of chemo or radiotherapy treatment.
- **Peer support** - talking to others about their cancer and how to find 'bowel cancer buddies'.
- **Exercise** – there is increasing evidence that physical activity helps recovery and reduces risk of recurrence for patients with bowel cancer. Behavioural changes require investment of time, expertise, training and encouragement.

Remote surveillance

This will incorporate the scheduling and monitoring of surveillance tests for CEA, CT scans and colonoscopy procedures. Test results will be reviewed by the team and patients recalled to clinic if results are found to be abnormal. Open access back into the service is available at all times. Development of a computerised tracking system to facilitate this is underway.

Guy's and St Thomas' NHS Foundation Trust

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We are keen to strengthen our patient care both in terms of how we assess needs and how we respond to these so that patients have a greater understanding of their disease, how to cope with any side effects of treatment and ways to encourage self management. As professionals we are using this project to really explore how we can offer more tailored aftercare based on patients individual needs.

Testing

We started our patient-centred programme by reviewing and understanding our current care pathways and by speaking to our patients groups. Overall the patients were very satisfied with their care but agreed that there could be more initiatives put in place to support patients after treatment has completed.

Underpinning all our work will be assessment and care planning. We already undertake a full assessment of the patient at

diagnosis and this will now be reviewed at end of treatment where patients will be supported and signposted if required to other new support services we will making available such as the exercise programme.

Our first information day for colorectal cancer patients and carers is scheduled for this summer and we have been working with our partner team in N. Bristol, Claire Taylor (Lecturer in Colorectal Nursing at the Burdett Institute) and the Health and Well being pilot sites to develop a suitable agenda for this.

During the summer we plan to introduce the concept of remote monitoring to reduce the need for hospital visits that add no clinical value. We plan to use an IT solution, that will enable remote monitoring, reducing patients' needs to attend clinic, either the one developed in North Bristol or our own that will fully integrate with our existing information systems.

We will be collecting key measurement data throughout, conducting a patient survey and collecting information on patient referrals and prospective outpatient appointments saved.

We believe that this project will lead to further improvements in the quality and effectiveness of our aftercare services.

Current service

The Colorectal Service for the Trust is based at St Thomas' Hospital where the majority of surgery takes place. Chemotherapy is provided on the Guy's site and radiotherapy provided at St Thomas'. The unit sees approximately 140 new colorectal cancers per annum and we are a specialist centre for lower rectal carcinomas and anal cancer. The enhanced recovery programme is well established and we have been successfully provided follow up clinics that are run by nurses for many years. Appointments are aligned to the five year test schedule after which most patients are discharged to their GP.

We have a number of excellent support services available to us such as the Dimpleby Cancer Care Centre for psychological support and access to complementary therapies.

North Bristol NHS Trust

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Current service

Colorectal cancer surgery is undertaken at Frenchay Hospital with chemotherapy and radiotherapy delivered at University Hospitals Bristol NHS Foundation Trust.

The unit sees approximately 370 new colorectal cancers a year. We have a successful enhanced recovery programme that is in its second year and established nurse led follow up clinics.

A team member said:

“As professionals we have used this project to test different models of self management and living well programmes and subsequently to test different models of follow-up management, including telephone follow-up and remote surveillance.”

Testing

We have already developed an in-house self management programme in collaboration with clinical psychology and health and wellbeing courses working in partnership with the Penny Brohn Cancer Centre and will be testing the new pathway to improve support for patients to self manage and give them confidence in the remote monitoring system.

We are leading the work on the national solution for remote monitoring and will be further developing our local Client Relationship Management System to incorporate the findings from the distress thermometer and an electronic care plan and treatment summary that will be shared with patients and GPs.

We are currently looking at options available for a hand held record for cancer patients.

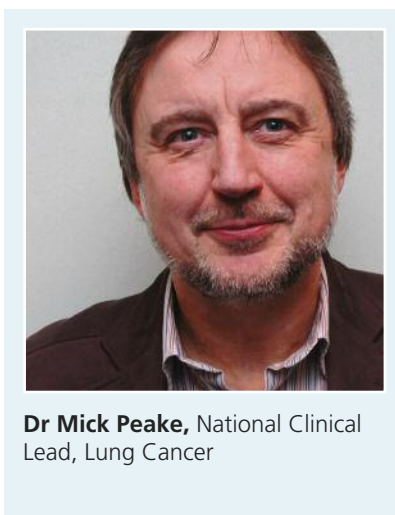
We will be collecting data on unplanned admissions, prospective follow up saved for patients self managing and referrals to support services.

Lung cancer

Introduction

“The issue of how best to follow up lung cancer patients is difficult. This is because it is almost an evidence-free area – as has been recognised in the recently updated NICE Lung cancer guidance¹⁸. These projects, whilst not research, are well positioned to provide an excellent level of practical experience of different ways of following up such patients, both to optimise the experience of care (for them and their families) and to use scarce healthcare resources in the most efficient and cost-effective way. Many patients end up in hospital for problems that could well be prevented or solved in other ways. This work has the potential to greatly improve the quality of care in this difficult disease.”

Dr Mick Peake, National Clinical Lead, Lung Cancer



Dr Mick Peake, National Clinical Lead, Lung Cancer

Lung cancer overview

Lung cancer is the commonest cause of cancer deaths in the UK (22% of all cancer deaths – more than that for colorectal and breast cancer combined). Patients often present late in the course of their disease (>60% have advanced/ incurable disease at presentation). The median survival from time of diagnosis is measurable in months. The average one year survival is around 30% with a five-year survival of 8%. Those diagnosed with early disease are often offered surgery at a specialist centre and these make up the majority of patients who survive beyond five years. Smoking is still the single greatest avoidable risk factor and causes around 90% of lung cancer in men and 85% in women.

The diagnosis and staging process is complex and crucial to making optimal decisions about a wide range of treatment options. Treatment rates are very variable around the UK and the need for highly expert teams to manage these patients is more important than ever. Patients are often highly symptomatic with significant health needs and frequent utilisation of out of hours care. Many patients are newly diagnosed with lung cancer during an emergency admission (38%), some via A&E and present with significant symptoms.

Follow up care tends to be tailored to individual patient needs rather than a prescriptive follow up protocol. This is made more complex because of the fact that, commonly, a number of different specialities are involved in the care of any one patient (sometimes in different hospitals). Increasingly, and where CNS resources exist, nurse led follow up clinics have been established and studies have shown that patients and GPs are highly satisfied with this model of care. Several units have also introduced telephone assessments and an open access service into clinics should the need arise.

The purpose for this project is to test the degree to which risk stratified pathways can be applied to lung cancer patients and work is commencing to undertake a retrospective audit of cancer patients to help determine the criteria that could be used for the future.

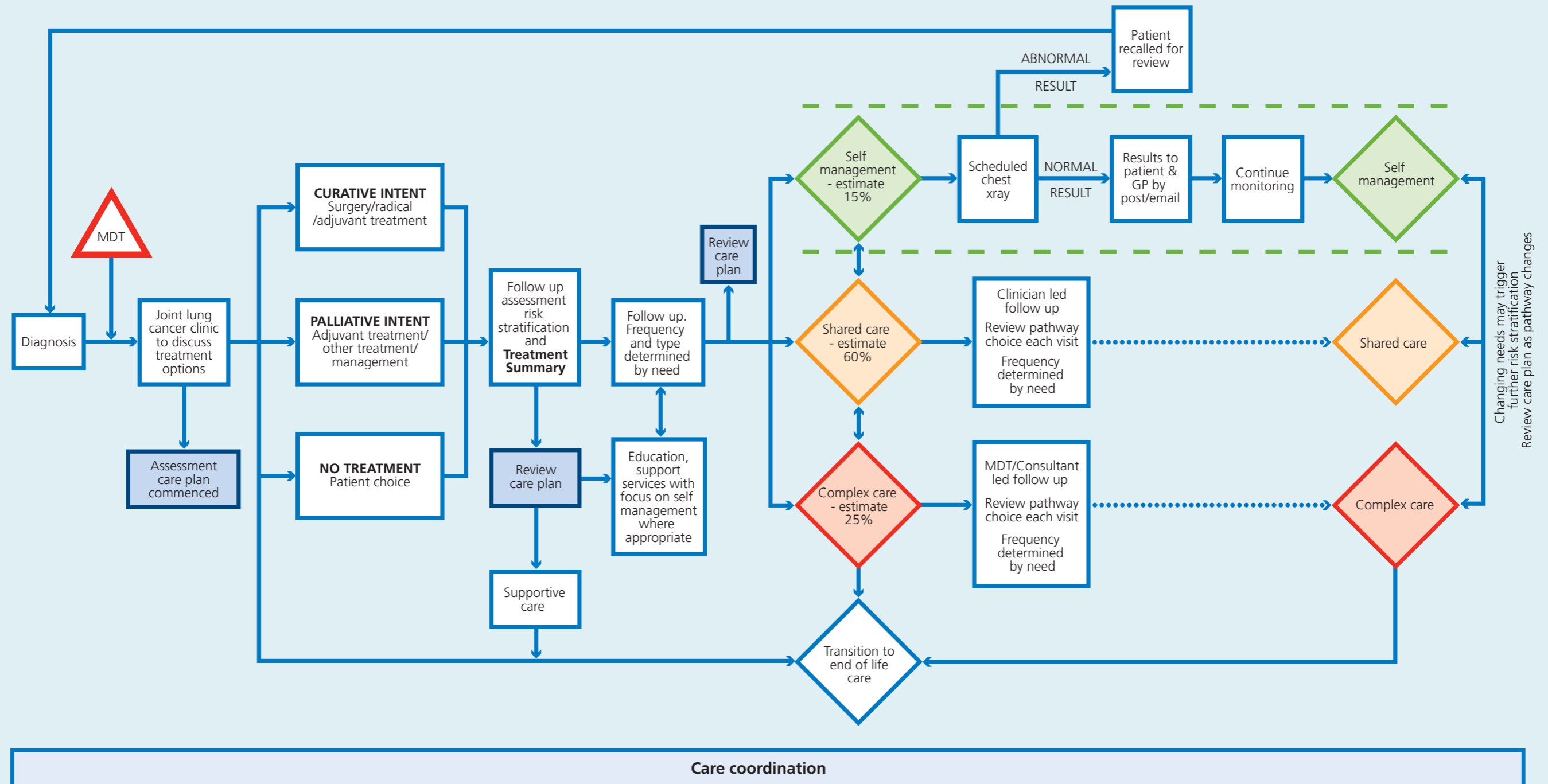
The use and provision of multidisciplinary support (usually involving several different providers across the local health economy) is not well understood and has not previously been described within the UK. Nevertheless, comprehensive seamless care across the local health economy is required as patients transition from active treatment to palliative treatment and end of life care.

The two test sites will also be undertaking a data gathering exercise to look at the type and extent to which lung cancer patients and their carers use health and social care services over the next six month period.

This primary aim of collecting data is to define:

1. The extent of multi-agency support provided to lung cancer patients
2. The quality of survival
3. Key components or patterns of care that enhance quality of care and to provide baseline measurements on which to base future service improvement programmes.

Risk Stratified Lung Cancer Pathway - For Testing



KEY FEATURES

Risk stratification decision points

For patients treated with curative intent it may be feasible to refer to a self managed pathway once surgery is complete and enrol onto a remote surveillance system with surveillance chest X-rays annually for 5 years. For all other patients a self management pathway is unlikely to be an option unless through patient choice.

Care planning

The life expectancy for patients diagnosed with lung cancer is poor and needs will change frequently and sometimes rapidly. Teams need to provide a very flexible approach to care and for some this may need a review of the care plan at each contact with the health care professionals. The care plan review is usually commenced by the lung nurse specialist but can be updated by other professionals involved e.g. community nursing teams. The care plan should be kept in the patient hand held record.

Support services of particular relevance to lung cancer patients

- **Diet and nutrition** – Fatigue and breathlessness can result in poor appetite and nutrition and the advice and input from a dietician can be extremely useful, especially for those who live alone or are isolated.
- **Breathlessness** – the actual experience or fear of breathlessness requires specific advice and support for this group of patients and their carers. Physiotherapy advice via individual referral or breathlessness clinics helps many patients and practical advice on coping mechanisms at home.

- **Anxiety and Depression** – psychosocial issues are extremely common in lung cancer survivors. Uncertainty about disease progression is a common observation and less so in those on a curative pathway where the follow up plan is clearer. Patients often need specific help and advice and often benefit from referral for specialist psychological support.
- **Sleep problems** – common in long term lung cancer survivors. Impacts on quality of life.

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follow up patients are seen. This clinic allows symptomatic patients to self refer or professional-triggered appointments for urgent assessment by either a respiratory or palliative care physician. The capacity for rapid access was increased by minimising unnecessary follow up appointments by contacting patients by telephone a week before their clinic, cancelling and rescheduling appointments if they did not wish to be seen. By avoiding emergency/unscheduled attendances at A&E with the facility to rapidly access lung cancer specialists, there was a reduction in bed days attributable to lung cancer by 329 over six months, a reduction in scheduled routine follow ups by one third and an improvement in patient satisfaction with the service.



Current service

Brighton University Hospital sees approximately 250 newly diagnosed lung cancer patients annually at the cancer centre in Brighton or at the Princess Royal Hospital in Haywards Heath. Patients suitable for lung surgery are referred to Guy's and St Thomas' Hospital.

Work has already been carried out within the lung cancer service at BSUHNT, initiating assessment and care planning and the use of a Treatment Record Summary. This is now fully embedded in current practice.

The service was redesigned and a rapid access cancer clinic (also referred to as the combined cancer clinic) introduced where new and

Testing

We plan to apply a retrospective model for assessing risk to all patients diagnosed over a 12-month period (May 2010 – May 2011). The results of this will be compared with the actual care that patients received to assess the validity of the stratification model before any changes will be made to the way services are currently delivered.

A health and wellbeing clinic will be developed as part of a trial to assess its utility and inform further research into its application in lung (and possibly breast) cancer. The clinic will be staffed by allied specialists in physiotherapy, dietetics/nutrition, Citizen's

Advice Bureau staff (to advise on financial and benefits matters), psychological services and Macmillan Nurse Specialists. Data will be collected on uptake of the service, patients' perception of its effectiveness, unscheduled hospital admissions and cost implications as well as data on patients' understanding of their disease and how to manage symptoms and when/how to access healthcare if needed.

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Current service

The lung cancer unit is based at Castle Hill Hospital where the majority of surgery, chemotherapy and radiotherapy take place. The unit sees approximately 500 new lung cancers per annum.

We have recently introduced EBUS for the trust; this is a valued tool in the diagnosis and staging of lung cancer.

A team member said “We have tested nurse led follow up clinics as part of the pilot phase of the NHS Improvement adult survivorship programme and found this to be extremely beneficial to patients and staff. We hope to build on this testing to refine these processes in this testing.”

Testing

We will continue our nurse led clinics and using the SPARC assessment tool and testing the care plan for our patients.

We will be testing the Treatment Summary process and trying to improve our communication with GPs and primary care colleagues.

Following an assessment of support services we recognise the need to work with the NCSI project leads to further develop support for health and wellbeing, exercise, self management and vocational rehabilitation across our geographical area and also look at the speed and response of referrals for financial support for lung cancer patients where time is of the essence.

We will be collecting data on the unplanned admissions, prospective outpatient slots saved and agencies referred to as part of this project.

Prostate cancer

Introduction

“The rising incidence of prostate cancer and an ageing population have led to a marked increase in demand for urology outpatient appointments. Commissioners faced with the need to pay for the most effective care, closer to home where possible, have wanted to restrict hospital follow up. There has been disagreement among urologists whether prostate cancer patients can be safely followed up in the community. The hypothesis that risk stratified pathways and an IT based remote monitoring system will lead to safe, convenient and cost effective follow up for patients will be tested. I am looking forward to working with the clinical teams in Ipswich, Luton, Hillingdon and North Bristol as they commence testing the hypothesis.”

Roger Kocklebergh, National Clinical Adviser - Prostate Cancer



Roger Kocklebergh, National Clinical Adviser - Prostate Cancer

Prostate cancer overview

Prostate cancer is the most common cancer in men in the UK with around 38,000 new cases diagnosed per year. The incidence is rapidly increasing, at least partly due to the ageing population and the use of PSA testing.

Prostate cancer is very common in asymptomatic elderly men, who will often have an excellent prognosis. Hence survival rates are partly dependent on the proportion of these men who are diagnosed with prostate cancer. National and regional differences in the investigation of men, usually with PSA, and late presentation in some UK regions are likely to account for many of the reported differences in survival.

There are uncertainties about treatment selection; hormone therapy is established in the treatment of metastases while radiotherapy and surgery have been shown to be superior to no treatment in localised disease. These carry significant side effects, hence many men with a good prognosis will choose active monitoring, using the PSA test to trigger a change to a more active treatment. For elderly or unfit men who are unlikely to benefit from active treatment watchful waiting is commonly used, this describes a plan to delay hormone therapy until progression occurs.

Most of the patients described above will have a prolonged survival, their follow up will be based on PSA testing in most cases and remote monitoring will hopefully save the patients time and inconvenience and release clinical time for patients who cannot be monitored remotely.

Follow up after treatment for prostate cancer varies greatly according to the disease, treatment and individual. The main reasons for traditional follow up appointments are:

- PSA testing or giving of results
- Post surgery checks
- Monitoring of patients on hormone therapy
- Careful monitoring of 'watchful wait' patients
- Metastatic patients and those with castrate resistant prostate cancer that need complex care and careful monitoring.

There is variation nationally on the frequency and duration of follow up. In the 'Rapid Review of Follow up practice in England'⁷ follow up is generally for life with regular annual PSA testing for most patients. Unstable patients are generally managed by the consultant and stable patients by the CNS or the GP under shared care or as a Locally Enhanced Service (LES).

NICE guidelines¹⁹ give the following recommendations:

- Healthcare professionals should discuss the purpose, duration, frequency and location of follow-up with each man with localised prostate cancer, and if he wishes, his partner or carers.
- Men with prostate cancer should be clearly advised about potential longer term adverse effects and when and how to report them.
- Men with prostate cancer who have chosen a watchful waiting regimen with no curative intent should normally be followed up in primary care in accordance with protocols agreed by the local urological cancer MDT and the relevant primary care organisation(s). Their PSA should be measured at least once a year.
- PSA levels for all men with prostate cancer who are having radical treatment should be checked at the earliest six weeks following treatment, at least every six months for the first two years and then at least once a year thereafter.
- Routine digital rectal examination (DRE) is not recommended in men with prostate cancer while the PSA remains at baseline levels.

- After at least two years, men with a stable PSA and who have had no significant treatment complications, should be offered follow-up outside hospital (for example, in primary care) by telephone or secure electronic communications, unless they are taking part in a clinical trial that requires more formal clinic-based follow-up.
- Direct access to the urological cancer MDT should be offered and explained.

There are various late effects that tend to be associated with prostate cancer. Following radical treatment these may include:

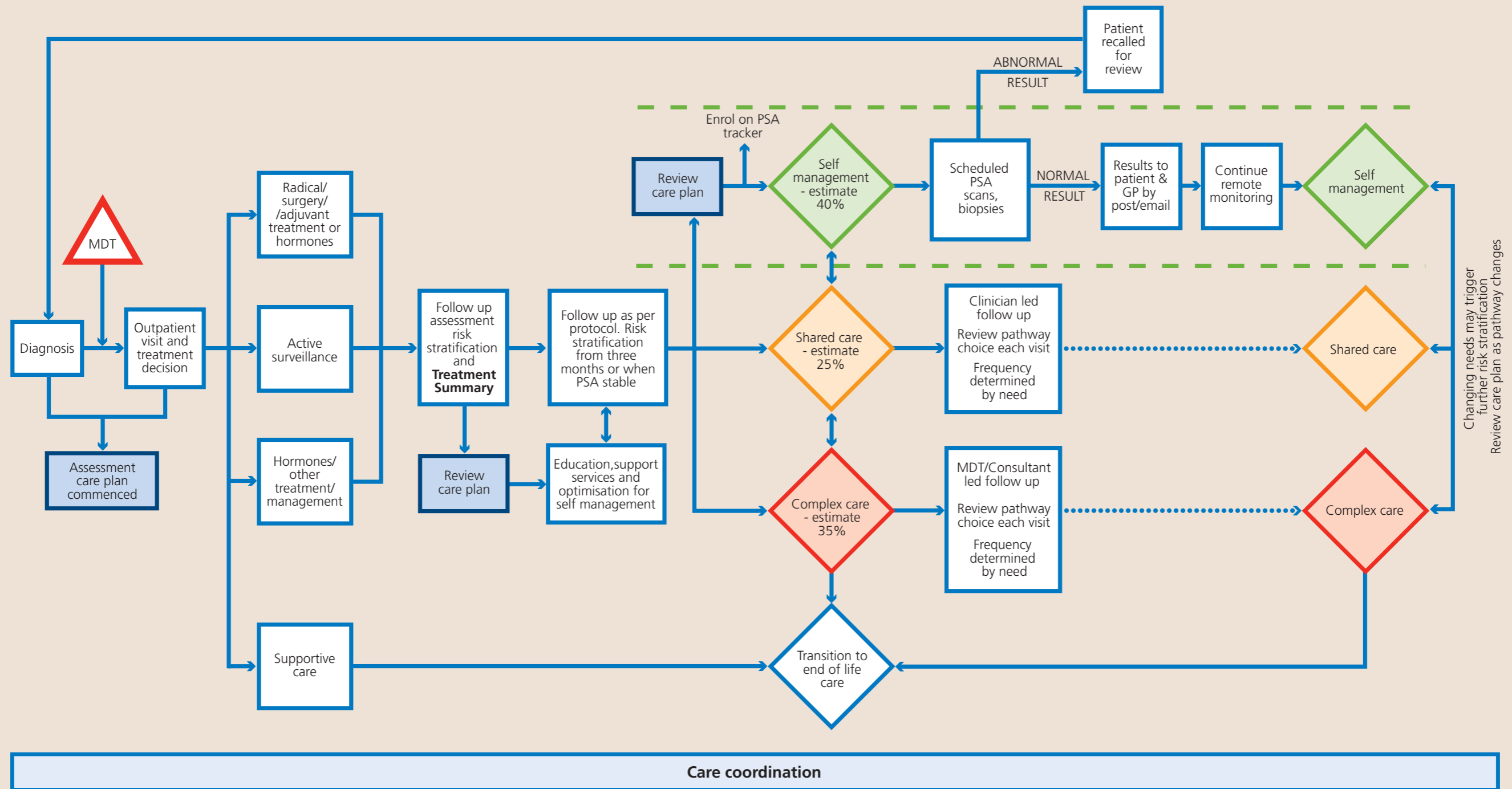
- Rectal symptoms including bleeding and urgency
- Urinary symptoms including incontinence and obstruction
- Erectile dysfunction
- Increased risk of other pelvic cancer.

Following hormone therapy these may include:

- Osteoporosis leading to a raised fracture risk
- Elevated cardiovascular risk.

This programme aims to address survivorship needs and will focus on the assessment and care planning especially at end of treatment, information for the patients and the GP and on improving access to support services enabling people to return to as normal a life as possible following their treatment.

Risk Stratified Prostate Cancer Pathway - For Testing



KEY FEATURES

Risk stratification decision points

For the many patients with low risk factors for disease, treatment effects and individual circumstances it may be feasible to refer to a self managed pathway with remote monitoring as appropriate. A draft criteria for risk stratification table is on page 44. This has been discussed by the prostate tumour group and is being tested by some of the sites.

Review care plan (following treatment)

The care plan should be reviewed at the end of treatment/decision not to treat to establish an appropriate care plan that includes supportive care services to enable the patient to self manage.

Support services of particular relevance to prostate cancer patients

- **Diet and exercise** - healthy eating and physical activity can help recovery and reduces risk of recurrence. Behavioural changes require investment of time, expertise, training and encouragement.
- **Peer support/community support** - talking to others about their cancer experiences and meeting others living beyond cancer as positive role models but also non cancer groups within the community.

Remote monitoring

To incorporate the scheduling and monitoring of PSA tests and biopsies where required, with results reviewed by the team and patients recalled to clinic if necessary. Open access back into the service and contact numbers for cancer related issues in and out of hours will be provided for patients.

Draft Criteria for Risk Stratification (to be tested)

Pathway	Complex	Shared care	Supported self management	Trigger for re-referral
Curative	All patients for first two years Patients with symptoms (unstable or awaiting treatment).	Those unable to comply with self management.	Potentially all patients once symptoms stable. Follow up with 6 monthly PSA.	Any rise in PSA after surgery Rise above 2 + nadir after RT.
Active monitoring	PSA alone is not an adequate tool. Repeat biopsy schedules are not yet fully defined.			
Watchful waiting		Those unable to comply with self management.	All patients.	Symptoms or PSA rise. Trigger points poorly defined but 2 or 3 consecutive rises is predominant trigger.
High risk (T3/4, or PSA >20 or Gleason >7) no metastases	Increasingly treated with radiotherapy and hormones.	Long term hormones hence cardiovascular risk and bone health monitored in primary care.	Patients with stable symptoms and PSA after 2 years.	Symptoms or 2 or 3 PSA rises if on hormones. Rise above 2 + nadir after RT.
Metastases and hormone therapy	Symptomatic and those with < 90% fall in PSA.	Cardiovascular risk and bone health monitored in primary care.	Patients with 90% fall in PSA who are asymptomatic.	Symptoms or 2 or 3 PSA rises.
Metastases and no immediate treatment	Need careful monitoring. Triggers based on symptoms, marker levels and rate of change.			
Castrate resistant prostate cancer	Managed by MDT but mostly managed by oncologists once 2nd or 3rd line therapy failed.			

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Quote from member of team:

“As professionals we have used this project to test different models of self management and living well programmes and subsequently to test different models of follow-up management, including telephone follow-up and remote surveillance.”

We are leading the work on the national electronic solution for remote monitoring and will be further developing our local Client Relationship Management System to incorporate the findings from the distress thermometer and an electronic care plan and treatment summary that will be shared with patients and GPs.

We are currently looking at options available for a hand held record for cancer patients.

We will be collecting data on unplanned admissions, prospective follow up saved for patients self managing and referrals to support services.

Current service

The prostate cancer service for the Trust is based at the Southmead Hospital site where surgery takes place. Chemotherapy and radiotherapy is predominantly delivered at University Hospitals Bristol Foundation Trust. We are currently reconfiguring urology inpatient and emergency services across both Bristol Trusts so they will all be delivered at Southmead Hospital.

Testing

We have already developed health and wellbeing courses working in partnership with the Penny Brohn Cancer Centre and an in house self management programme in collaboration with clinical psychology and will be testing the new pathway to improve support for patients to self manage and give them confidence with the remote monitoring system.

North Bristol NHS Trust sees approximately 550 new prostate cancers per annum with approximately 800 new prostate cancers per annum across the city. We are the supra-regional specialist centre for penile cancer and network centre for complex prostate and bladder cancer. We have an established enhanced recovery programme and successful nurse led follow up clinics for prostate cancer.



The Hillingdon Hospitals NHS Foundation Trust

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Current service

The prostate cancer service for the Trust is based at Hillingdon Hospital where the majority of surgery takes place. Chemotherapy and radiotherapy take place at neighbouring Mount Vernon Cancer Centre. The unit sees approximately 285 new prostate cancers per annum.

Quotes from the team:

“This project gives us the opportunity to formalise the criteria for risk stratification and reduce the number of patients attending clinic for PSA test results.”

“A gap analysis of our supportive services showed that we have some great services locally but we need to improve access to exercise and vocational rehabilitation for our prostate cancer patients and we will be in touch with the NCSI project leads for these areas.”

“We are using this project to review how we communicate with other key professionals involved in the patient journey and to give us the opportunity to truly engage with teams outside the hospital to ensure a timely, consistent and structured team approach.”

Testing

We will be using the distress thermometer, care plan and treatment summary tested by our colleagues in the lung cancer team last year in the assessment and care planning pilot phase. This will be used throughout the pathway through to end of life care.

We will also be testing the national solution being developed to track PSA test as part of the remote monitoring for prostate cancer patients.



The Ipswich Hospital NHS Trust

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Current service

Our prostate service is based at Ipswich Hospital NHS Trust, surgery is done at Cambridge or Norfolk and Norwich Hospitals with chemotherapy, radiotherapy, other treatments and follow ups here at Ipswich. The unit sees approximately 250 new prostate cancers per annum. We hope to extend our established nurse led follow up clinics as part of the testing.

Quote from a member of the team:

“Having already recognised the need for support for patients in the survivorship phase of their cancer journey in all cancers, as with our other tumour groups, a four week education programme or twice yearly education days are available to empower patients to self manage, as appropriate.”

“Working with the NCSI project leads, local authorities and PCTs as part of the ‘Fit Villages’ scheme on exercise and rehabilitation to support self management for cancer patients and we plan to further develop these areas.”

Testing

We will be using a locally adapted Distress Thermometer assessment tool and combined treatment summary and care plan in one document for patients as part of their hand held record.

We are planning to test an electronic ‘live’ copy of this document that can be accessed by health care professional at any time in the pathway.

We will be collecting data on the number of patients risk stratified to self management, outpatient slots saved and unplanned admissions.

We are hoping to test a PSA tracker IT system locally to build on existing arrangements with our GPs.

“

We believe a large proportion of patients will be suitable for self management and it will be interesting to see whether this turns out to be the 40% envisaged within the NCSI draft pathways for testing.”

Team Member - Luton and Dunstable Hospital NHS Foundation Trust

Luton and Dunstable Hospital NHS Foundation Trust

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Current service

The prostate cancer service is based at Luton and Dunstable Hospital (L&D). Chemotherapy services are delivered locally, however, patients requiring surgery are referred to the Lister Hospital in Stevenage and those requiring radiotherapy referred to Mount Vernon Hospital. All are referred back to L&D once their treatment is complete.

The unit sees approximately 180 new prostate cancer patients per annum. The current follow up pathway includes eight follow up appointments over five years with many patients having their PSA results monitored by the hospital for life. Until a year ago a large number of follow up patients were managed via a nurse led clinic however this ended when the CNS left and patients reverted to consultant led appointments.

A team member said "This project has come at a perfect time for our urology team. "We believe a large proportion of patients will be suitable for self management and

it will be interesting to see whether this turns out to be the 40% envisaged within the NCSI draft pathways for testing."

Testing

Over recent weeks the team have been working hard to put in place all elements of the new pathway. The clinicians have agreed draft criteria for risk stratifying patients and since April patients with stable disease are being transferred to a self managed pathway of care. We are continuing to refine the referral process and data collection systems.

Remote monitoring is critical to the new pathway for managing PSA follow up tests. The Trust plans to use the national solution until the same functionality can move to 'Infoflex', the local Cancer Information System. Patients that have completed treatment will have a phone call from the CNS to enrol them on the remote monitoring system.

The CNS team commenced end of treatment assessments and care planning using the Pepsi Cola assessment tool to guide the discussions. Motivational interviewing skills training for staff is planned. We are working with prostate cancer charities to improve patient information.

"We are particularly keen to raise the importance of activity and exercise for this group of patients" said Jan, "not only to benefit their recovery from treatment for their prostate cancer but also to benefit their general health and wellbeing". The team have met with 'Luton Active' to develop exercise referral pathways and a training session on cancer awareness has been delivered to the Luton Active Group. A local service directory to aid staff in referring and signposting patients is expected to be available shortly.



Useful resources

NHS Improvement Adult Survivorship website
www.improvement.nhs.uk/cancer/adultsurvivorship

NCSI website
www.ncsi.org.uk

Macmillan website
www.macmillan.org.uk

NCAT website
www.ncat.nhs.uk

NCAT Holistic assessment page
www.ncat.nhs.uk/our-work/living-with-beyond-cancer/holistic-needs-assessment

National Cancer Intelligence Network (NCIN)
 The NCIN is a UK-wide initiative, working to drive improvements in standards of cancer care and clinical outcomes by improving and using the information collected about cancer patients for analysis, publication and research. The E-Atlas provides data on survival and prevalence.
www.ncin.org.uk/cancer_information_tools/eatlas.aspx

The National Lung Cancer Audit
 This is now a well-established national programme and annual reports are produced, showing a wide range of measures by trust and network across the UK. The reports are available via the NHS Information website (www.ic.nhs.uk) and the report for patients first seen in 2009 is due for publication on 23 May 2011.

National Institute for Health and Clinical Excellence (NICE)
www.nice.org.uk

CHARITIES AND VOLUNTARY ORGANISATIONS SUPPORTING THE TESTING WORK

Breast Cancer Care
 This charity covers the UK and their vision is for every person affected by breast cancer to get the best treatment, information and support. They produce a range of information in many formats and have a "Moving Forward" resource pack specifically for patients living with and beyond cancer.
www.breastcancercare.org.uk

Beating Bowel Cancer
 A leading UK charity for bowel cancer patients, working to raise awareness of symptoms, promote early diagnosis and encourage open access to treatment choice for those affected by bowel cancer. They provide a wide range of services including buddy and peer support for patients and deliver numerous awareness and education programmes aimed at the public as well as professionals.
www.beatingbowelcancer.org

Bowel Cancer UK
 This UK charity aims to save lives by raising awareness of bowel cancer, campaigning for best treatment and care and providing practical support and advice. They produce a large range of patient leaflets and run the Bowel Cancer Advisory Service - a full time national freephone advice and information service for all those affected or concerned about the disease.
www.bowelcanceruk.org.uk

Cancer Research UK
 This charity, dedicated to beating cancer by research, has a wide range of information on their website including links to all the latest incidence, mortality and survival rates. There are resources available for patients and professionals.
<http://info.cancerresearchuk.org/cancerstats/types/prostate>

The Prostate Cancer Charity

Provides support and information for patients, families, carers and health professionals on living with prostate cancer.

www.prostate-cancer.org.uk

Roy Castle Lung Cancer Foundation

Provide practical and emotional support for those affected by lung cancer including support for smokers who want to quit and guidance for children and young people to make informed decisions about smoking and the tobacco industry. They campaign vigorously to increase research funding and awareness about how to detect the early signs of lung cancer and produce a range of information leaflets and resources for patients and their carers.

www.roycastle.org

British Lung Foundation

The British Lung Foundation (BLF) is the only UK charity working for everyone affected by lung disease. They focus on providing support for people affected by lung disease and through patient information leaflets and campaign to bring about positive change in lung health and improving treatment, care and support for people affected by lung disease. They run a patient support group Breath Easy, provide a helpline and arrange meetings around the UK for patients to meet.

www.lunguk.org

Breakthrough Breast Cancer

This UK charity aims to save lives and change futures through research, campaigning and education to remove the fear of breast cancer for good. They have information and resources at:

www.breakthrough.org.uk

Marie Curie Cancer Care

Marie Curie aim to support everyone with cancer and other illnesses will have the high quality care and support they need at the end of their life in the place of their choice. Their website has a wide range of information and resources at:

www.mariecurie.org.uk

NHS choices

NHS choices provides information and useful links on many health concerns including cancer.

www.nhs.uk/conditions/cancer

PROFESSIONAL ORGANISATIONS**Association of Coloproctology of Great Britain and Ireland**

The objectives of the Association are to advance the science and practice of Coloproctology, promote best practice through advancement of education and training; promote the most efficient and effective use of healthcare resources; to provide and disseminate information and to promote study and research into coloproctology and facilitate the publication of the useful results.

www.acpgbi.org.uk

Association of Breast Surgery

This is a new association representing healthcare professionals treating malignant and benign breast disease in the UK, Ireland and Worldwide. It focuses on education, audit and guidelines.

www.associationofbreastsurgery.org.uk

BASO - The Association for Cancer Surgery

This association represents surgeons from the UK and Ireland and aim to promote the science and art of cancer surgery, for the benefit of the patient, and to encourage and showcase cancer research for public good.

www.baso.org.uk

British Associate of Urological Surgeons (BAUS)

This association aims are to promote the highest standard in the practice of Urology for the benefit of patients. They have links to education and information on prostate cancer. www.baus.org.uk

British Associate of Urological Nurses (BAUN)

This association aims to promote and maintain the highest standards in the practice and development of urological nursing and urological patient care.

www.baun.co.uk

National Lung Cancer Forum for Nurses

Provide information to patients, carers and for health professionals whose work involves those with lung cancer.

www.nlcfn.org.uk

British Thoracic Oncology Group

A multi-professional organisation dedicated to lung cancer and mesothelioma. It has an annual conference (January) which attracts speakers and delegates from around the world, not just the UK. It designs and develops clinical trials and runs a number of national educational events.

www.BTOG.org

British Thoracic Society

A registered charity whose objective is to improve the standards of care of people who have respiratory diseases. The British Thoracic Society Lung Cancer and Mesothelioma Specialist Advisory Group have produced a guidance document, Giving Information to Lung Cancer Patients, to assist healthcare professionals in discussion of options for patients on the lung cancer pathway.

www.brit-thoracic.org.uk

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Acknowledgements

Throughout the testing work and into this next phase, we continue to be grateful to all of our test sites for their tremendous commitment and hard work during the course of testing as part of the National Cancer Survivorship Initiative. Our thanks go to Professor Jane Maher and Dr Alastair Smith for their clinical leadership during the pilot phase over the last couple of years.

The sites expertise and enthusiasm combined with excellent clinical leadership, service improvement leadership from the National Improvement Leads, support from the cancer networks, patient representatives and our NCSI partners have brought us to this exciting phase of testing with a wealth of experience, knowledge and skills to take this agenda forward in these challenging times - together.

Thank you all again for your contribution.

**NHS Improvement -
Adult Survivorship Team**



the 1990s, the number of people in the UK who are employed in the public sector has increased from 10.5 million to 13.5 million, and the number of people in the public sector who are employed in health care has increased from 2.5 million to 3.5 million (Department of Health 2000).

There are a number of reasons for this increase in the number of people employed in the public sector. One of the main reasons is the increasing demand for health care services. The population of the UK is ageing, and there is a growing number of people with chronic conditions who require long-term care. This has led to an increase in the number of people employed in health care, particularly in the public sector.

Another reason for the increase in the number of people employed in the public sector is the increasing demand for social care services. The population of the UK is ageing, and there is a growing number of people who are unable to care for themselves. This has led to an increase in the number of people employed in social care, particularly in the public sector.

A third reason for the increase in the number of people employed in the public sector is the increasing demand for education services. The population of the UK is growing, and there is a growing number of people who are entering the workforce. This has led to an increase in the number of people employed in education, particularly in the public sector.

There are a number of challenges facing the public sector in the UK. One of the main challenges is the increasing demand for services. The population of the UK is ageing, and there is a growing number of people who require long-term care. This has led to an increase in the number of people employed in health care, particularly in the public sector.

Another challenge facing the public sector is the increasing demand for social care services. The population of the UK is ageing, and there is a growing number of people who are unable to care for themselves. This has led to an increase in the number of people employed in social care, particularly in the public sector.

A third challenge facing the public sector is the increasing demand for education services. The population of the UK is growing, and there is a growing number of people who are entering the workforce. This has led to an increase in the number of people employed in education, particularly in the public sector.

There are a number of ways in which the public sector can meet these challenges. One way is to increase the number of people employed in the public sector. This can be done by recruiting more people to the public sector and by providing training and development opportunities for existing staff. Another way is to improve the efficiency of the public sector. This can be done by reducing waste and by improving the quality of services.



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