

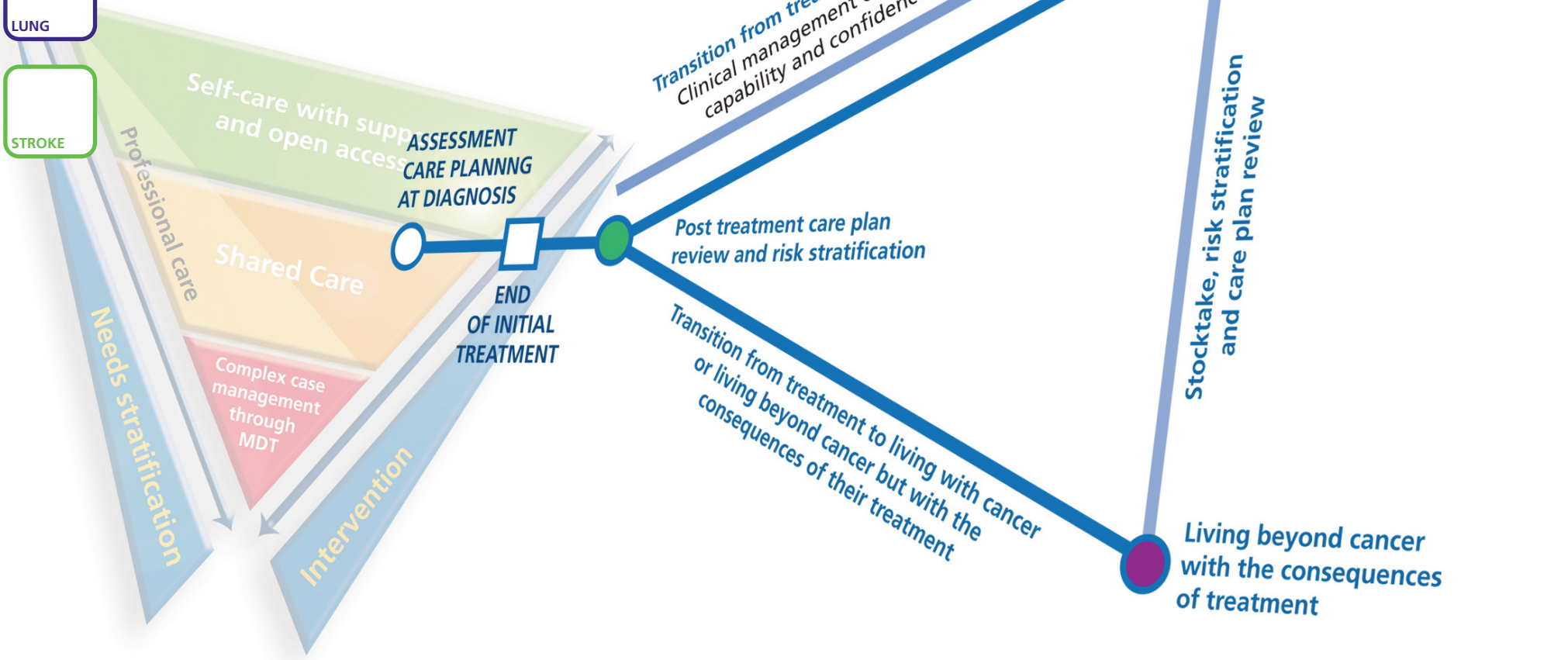


NHS Improvement - Cancer

# Stratified pathways of care... from concept to innovation

## Executive Summary

March 2012





## Stratified pathways of care... from concept to innovation

### Introduction

NHS Improvement is working in partnership with patients, clinical teams, the Department of Health (DH) and voluntary organisations to improve the effectiveness and quality of service delivery for those living with and beyond cancer. The National Cancer Survivorship Initiative (NCSI) was set up as a recommendation in the Cancer Reform Strategy (2007), and the importance of the work reinforced through Improving Outcomes; a Strategy for Cancer (2011).

The current traditional approach to managing patients following initial treatment is based on a medical (illness) model where patients can be in follow-up for two to five years or more following completion of initial treatment. This is unsustainable for two key reasons:

- Incidence and prevalence of cancer continues to increase thereby putting pressure on available resources
- The current arrangements are not meeting all of the needs of those living with and beyond cancer.

The focus for NHS Improvement is to work with clinical teams supporting patients following initial treatment for breast, colorectal, lung or prostate cancer, to redesign the pathway of care and stratify patients into an appropriate level of care.

For breast colorectal and prostate cancers the emphasis has been on supporting patients to get back to living their lives following initial treatment for cancer with remote monitoring replacing routine follow up where appropriate. For lung cancer it was about managing active and advanced disease through proactive rather than reactive management with the focus on improving quality of life.

This work has been supported by the DH cancer team, NCSI project teams, Macmillan Cancer Support, and specialty specific charities such as breast cancer care, beating bowel cancer and the prostate cancer charity.

Evaluation of the testing is on-going and it will be early in 2013 before we see whether the stratified model of care and associated support has improved patient experience and reported outcomes of care. However, the economic benefits of reducing outpatient follow up on both the NHS and individual patients is evidenced through the reduction in the projected outpatient activity compared to the traditional model.

However, to realise the full potential of this redesigned model of care, commissioners need to focus not on activity but on providing the resources through a bundle of care to support

patients to self-manage. This will include support to enable patients to return to living their lives and a robust monitoring solution to detect relapse or recurrence over time. Service providers need to ensure that they have systems in place for timely access should patients experience difficulty and work with commissioners to ensure they have the right people with the right skills in the right place to support patients to self-manage.

Commissioners and providers should embrace this work and proactively support the shift from the traditional activity based medical model to a safe and effective stratified model that meets patients' needs whether they are being professionally managed or are being supported to self-manage.

This is a summary report of this year's work and a more comprehensive report can be found on our website at:

[www.improvement.nhs.uk/cancer](http://www.improvement.nhs.uk/cancer)

#### **Gilmour Frew**

Director - NHS Improvement

## STRATIFIED PATHWAY OF CARE: **BREAST**

“ I thought I was the only one who felt like me. This group (*Moving On*) has increased my confidence and given me a positive direction. ”

Patient

### Background and context

The traditional model of follow up has been to offer annual mammography and outpatient reviews over a period of three to five years.

Data has shown that recurrences are more commonly picked up by the patient between appointments or following mammogram scans rather than an outpatient consultation.

Increased demand has led to overbooked clinics with insufficient discussion time for those who still have complex emotional and psychosocial needs after their treatment has ended.

Five teams have tested stratified pathways of follow up care. An expected 70% of breast patients were predicted to be suitable for a supported self management pathway.

The duration of follow up had already started to reduce in some Trusts. All were keen improve information, education and support services for patients.

### What we did?

Baseline data was gathered and the current pathways were mapped.

The baseline patient experience survey found the main issues for breast cancer patients were:

- Fatigue
- Fear of recurrence
- Signs and symptoms of recurrence.

Breast specific or generic cancer education events were held in most organisations with the focus on information, overcoming the above issues and rebuilding lives.

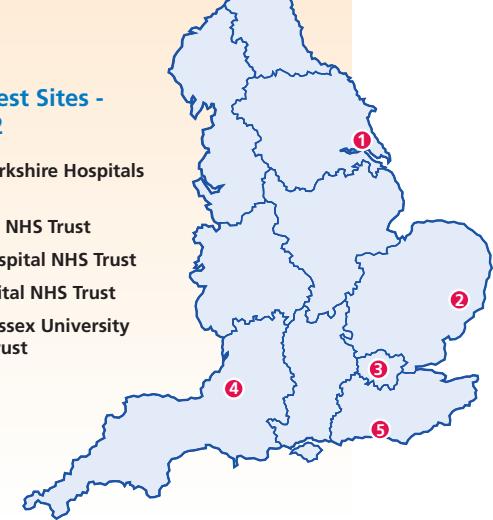
All teams established links with community schemes with particular focus on physical activity. Several teams have provided oncology awareness training for leisure centre staff.

All teams have introduced holistic needs assessment at the end of treatment where a future care plan is agreed.

All sites have separated the annual mammography test from the outpatient visit with results sent by post.

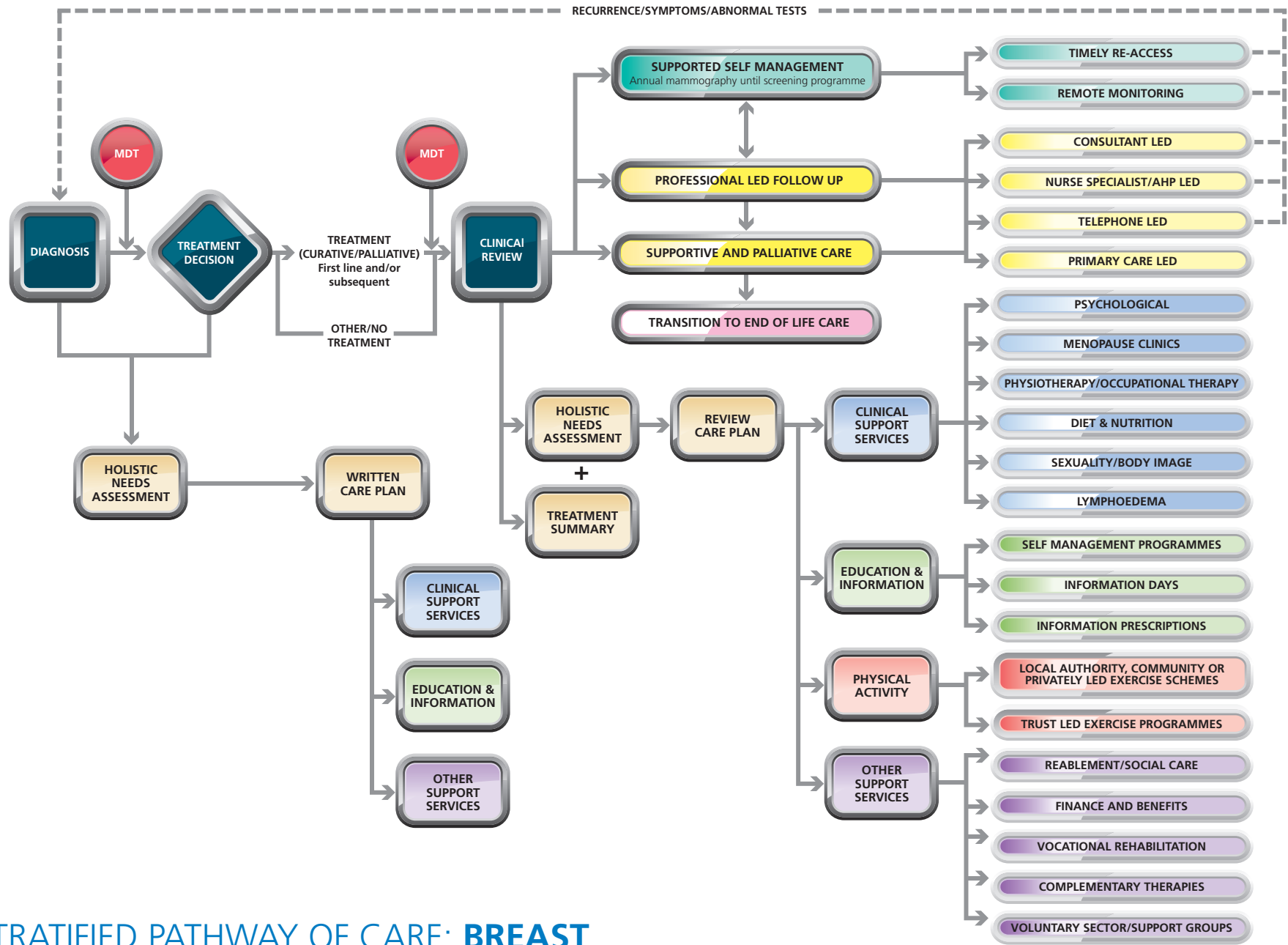
### Survivorship Test Sites - Breast 2011/12

- 1 Hull and East Yorkshire Hospitals NHS Trust
- 2 Ipswich Hospital NHS Trust
- 3 North Bristol Hospital NHS Trust
- 4 Hillingdon Hospital NHS Trust
- 5 Brighton and Sussex University Hospitals NHS Trust



### What we found

- Self managed follow up is safe, acceptable and often welcomed by patients
- Self management was suitable for around 77% patients treated with curative intent within one year of diagnosis as long as patient has a review of needs at end of treatment and continued open access to the specialist team
- Only two pathway options were required; supported self management and professionally led follow up
- Mammography screening can be separated from the outpatient visit. Some reporting processes offer scope for further development
- Information events are cost effective and offer value to patients. Take up rates were dependant upon how and who invited them and perceived importance
- Access to physical activity and other support services have been welcomed
- Resources may need to shift from medical to nursing budgets to support additional holistic needs assessments and educational initiatives
- The stratified pathway model needs to be reinforced at new staff induction.



STRATIFIED PATHWAY OF CARE: **BREAST**

## STRATIFIED PATHWAY OF CARE: COLORECTAL

“It’s great to see so many of us with the same cancer.. it lets you know that you are not alone. Thank you.”

Patient feedback from the information day

### Background and context

Colorectal cancer affects about 36,000 new cases annually. Five year survival is around 52% and whilst increasing, still lags behind other European countries.

The majority of patients have surgery plus or minus chemo radiation therapy during their initial treatment phase. Treatment often leads to side effects relating to bowel function, sexual function, psychosocial issues that often remain unresolved at end of treatment.

CT scans, endoscopy and carcinoembryonic antigen (CEA) tests detect the majority of recurrences and often in advance of symptomatic changes identified by the patient.

A stratified pathway of care was developed that suggested 40% of colorectal cancer patients may be suitable for a self management pathway as long as they were well informed and tests continued to be scheduled and reported as normal.

### What we did?

Current pathways were mapped. Follow up was mainly nurse led with 9 to 12 outpatient visits over a five year period. One site has offered nurse led telephone follow up since December 2010. Test regimes varied slightly between sites.

The baseline patient experience survey found the main issues for colorectal patients were:

- Bowel and urinary problems
- Erectile dysfunction and sexual issues
- Signs and symptoms of recurrence.

Education events were tested in all sites with focus on information, education and ways to overcome the above.

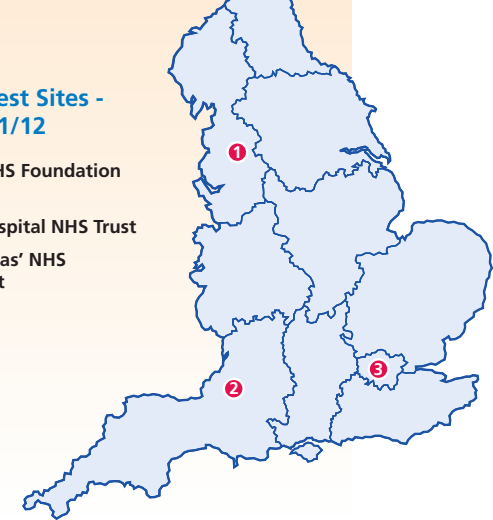
All teams worked with ‘Beating Bowel Cancer’ charity to develop a range of video clips on FAQs.

All teams have or plan to introduce holistic needs assessment and care planning discussion six weeks after the end of treatment.

Remote monitoring solutions are being introduced in each Trust to enable the specialist to schedule and monitor surveillance tests without the need for face to face follow up.

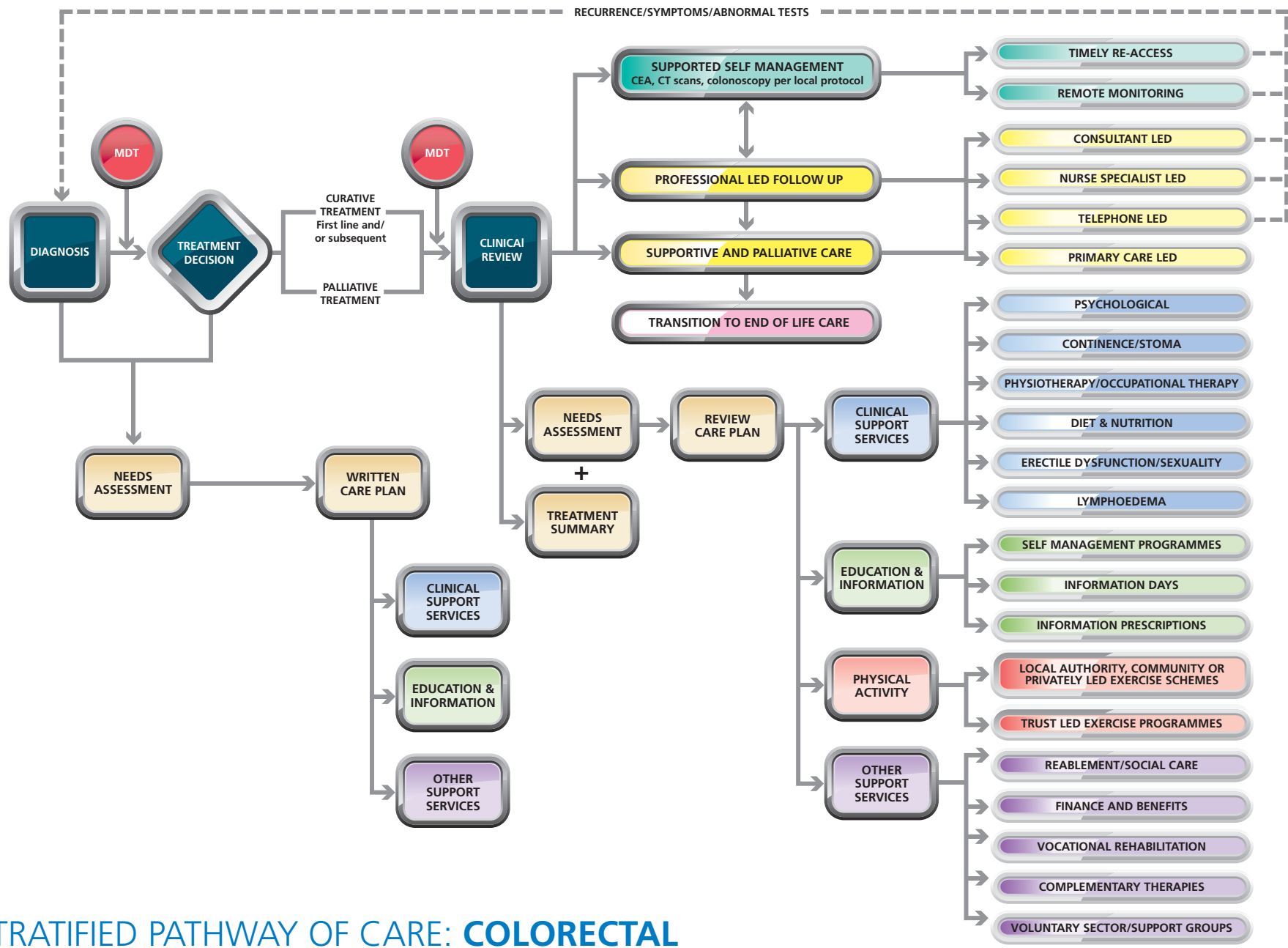
### Survivorship Test Sites - Colorectal 2011/12

- 1 Salford Royal NHS Foundation Trust
- 2 North Bristol Hospital NHS Trust
- 3 Guy’s & St Thomas’ NHS Foundation Trust



### What we found

- Clinicians are supportive of the supported self management approach as long as remote monitoring systems are robust and safe
- Around 45% (230) patients were assessed as suitable for a supported self management pathway
- Supported self management options can be considered at any point in the patient journey
- Holistic needs assessments were best timed six weeks after end of treatment. Self assessment tools helped identify issues not normally raised
- Holistic needs assessment clinics have proved challenging to implement though expected to ease as follow up attendances reduce
- 45% of male patients experience erectile dysfunction problems however direct referral to erectile dysfunction clinics without recourse to the GP is not available in all Trusts
- Information events were well received and suggested be scheduled four to six months post treatment. Take up rates were dependant upon how and who invited them
- A proportion of patients with recurrent disease receive treatment at other centres and their follow up pathway is often unclear.



STRATIFIED PATHWAY OF CARE: **COLORECTAL**

## STRATIFIED PATHWAY OF CARE: LUNG

“ I was very impressed with the kindness and consideration given to me by all members of the team from the doctors and nurses down to the tea man. ”

Patient

### Background and context

Lung cancer is the commonest cause of cancer deaths in the UK (22% of all cancer deaths). Patients often present late in the course of their disease with around 70% having advanced or incurable disease at presentation. About 38% of patients are first diagnosed following an emergency admission.

Lung cancer patients are highly symptomatic often with significant health needs. Many experience difficulties with breathing, fatigue, anxiety and depression along with poor appetite and nutritional needs.

Two teams in Hull and Brighton were invited to test the degree to which risk stratified pathways could be applied in lung cancer with focus on providing a more proactive rather than reactive management approach and on improving quality of life. It had been suggested that 15% of patients may be suitable for a self managed pathway.

The use of needs assessments, care plans and treatment summaries were already embedded in practice on both sites.

### What we did?

In Brighton, a pilot health and wellbeing clinic was established to address the most frequent needs of patients: anorexia and weight loss, breathlessness and fatigue and financial and benefits issues.

Also in Brighton, for patients not on active treatment yet remaining under specialist care, a pre clinic telephone assessment was implemented one week prior to the outpatient appointment. A similar flexible approach to appointments exists in Hull, with patients added to or removed as needs change.

Criteria have been defined that may predict the need for complex, supported or self managed care – analysis is ongoing. In Hull, a set of pragmatic criteria were developed to support the transfer of immediate care responsibility to the community teams

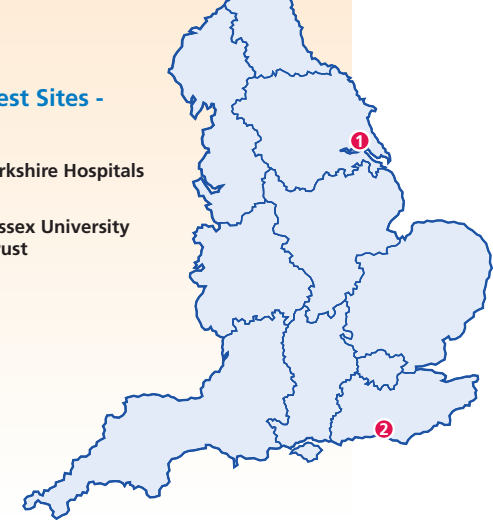
In Hull, nurse led end of treatment review clinics were established building on the needs assessment carried out at diagnosis.

### What we found

All patients require some form of professional led care but several can self manage for periods of the pathway and can be supported by telephone assessment during this period.

### Survivorship Test Sites - Lung 2011/12

- 1 Hull and East Yorkshire Hospitals NHS Trust
- 2 Brighton and Sussex University Hospitals NHS Trust



In Hull, 33% of patients seen in the nurse led post treatment clinic, met the criteria for discharge under the care of the community team. This clinic was best timed four to six weeks after end of treatment.

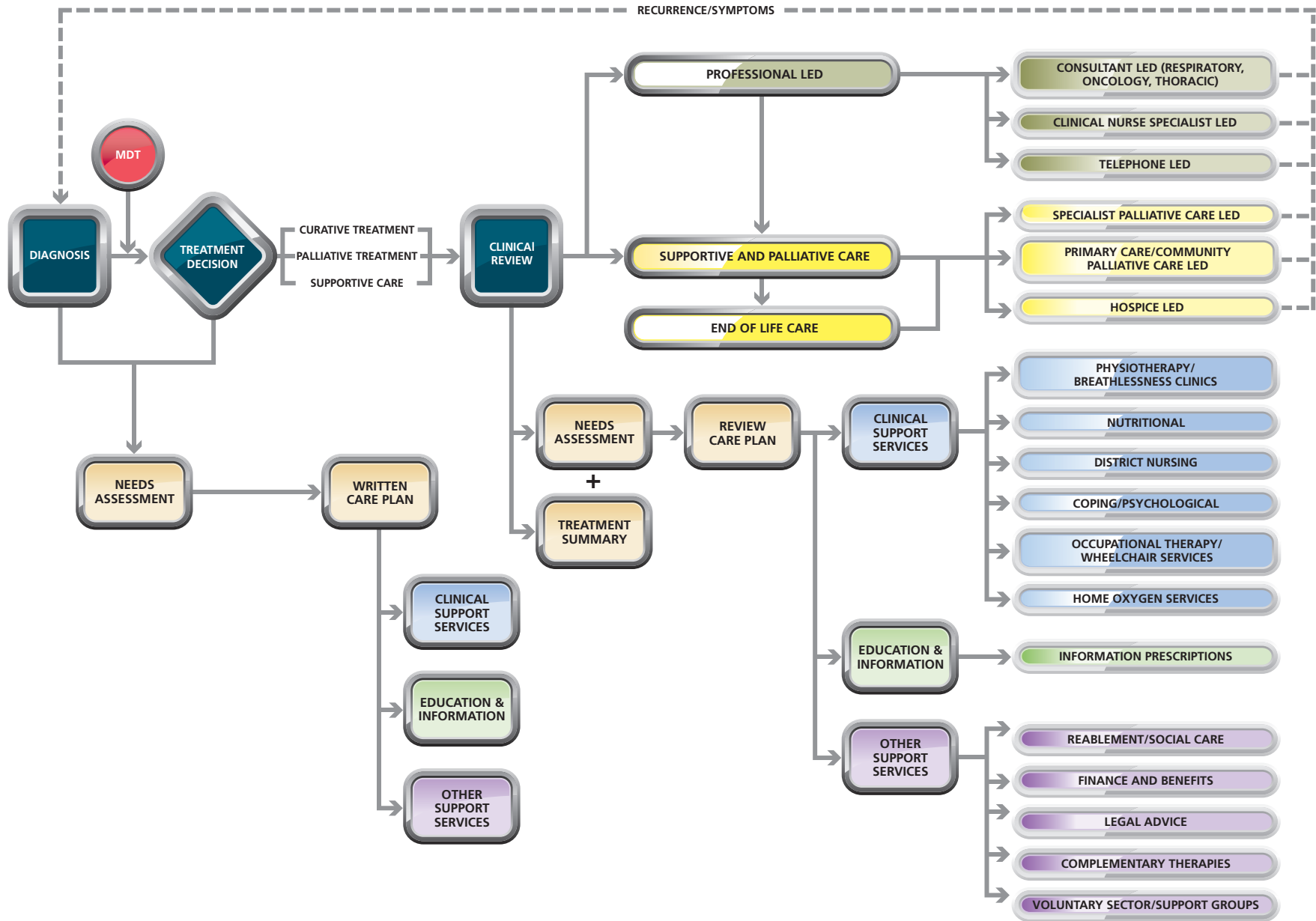
Offering tailored care packages can impact on emergency admission rates and unnecessary attendances at hospital clinics without causing harm:

- Both sites recorded 6% to 8% reductions in unplanned admissions. In Hull, there were 34 fewer admissions over eight months in 2011 compared to 2010
- Brighton recorded a 25% reduction in bed days
- In Brighton, around 20% to 25% of clinic appointments were cancelled and rescheduled as a result of the pre clinic telephone calls. 18% of appointments were arranged at patient or professional request avoiding and emergency admission.

Holistic care plans, educational resources and well-being clinics allow patients to have a greater understanding of their condition, provide a greater sense of control and merit future investment.

Implementing tailored packages of care requires considerable administrative support which should be accounted of in the commissioning of services.





STRATIFIED PATHWAY OF CARE: **LUNG**

## STRATIFIED PATHWAY OF CARE: PROSTATE

“It’s much better on both sides as it saves time for everyone and we don’t have to keep coming up to the hospital.”

Patient

### Background and context

The incidence and prevalence of prostate cancer is increasing and the service is struggling to cope with the demand. The traditional model is to outpatient follow up, or when the condition is deemed stable and two years out of initial treatment to discharge the patient to primary care. There are a few urology clinical teams who manage their patients remotely through PSA testing with the database being clinically managed by a CNS supported by a urology consultant.

A consensus meeting and further discussions were held to identify potential levels of care, key pathway components and the potential split of patients into the different levels of care. Within the test sites the current follow up attendances ranged from 8 to 10 over a five year period though we know that PSA monitoring for many patients continues for life.

The emphasis was on recovery following initial treatment, preparing patients to self-manage with support, which includes on-going monitoring of PSA and timely access should problems occur.

### What we did?

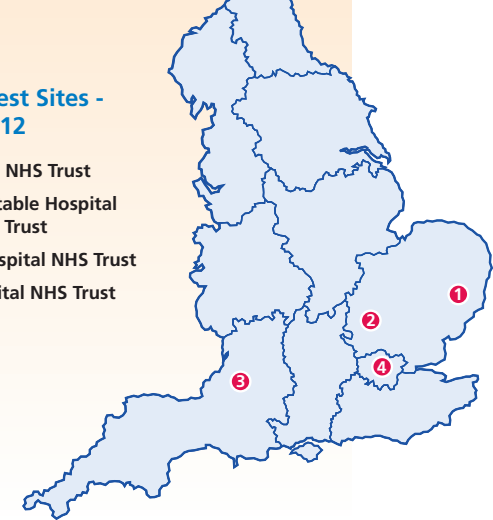
Four urology clinical teams participated in the testing of the risk stratified model of care. Baseline information was obtained from the test sites such as current pathway and patient flows. A baseline Ipsos MORI patient survey showed that the key areas for improvement were:

- Better information on signs and symptoms to look out for; 40% did not have all the information they needed)
- Better management of erectile dysfunction; 44% of those with a problem continue to have problems
- Better continence management; of the 55% who had continence problems following initial treatment, in 20% they continued to have a problem.

It was interesting that 80% of patients felt fairly or very confident in managing their own health. Risk stratification into three levels of care were tested and test sites were asked to include an individual assessment, including a self-assessment triage tool for patients post treatment, a summary treatment record for the patient and GP/primary care team, and a hand held record where key contacts, outcomes of interactions and tests could be recorded.

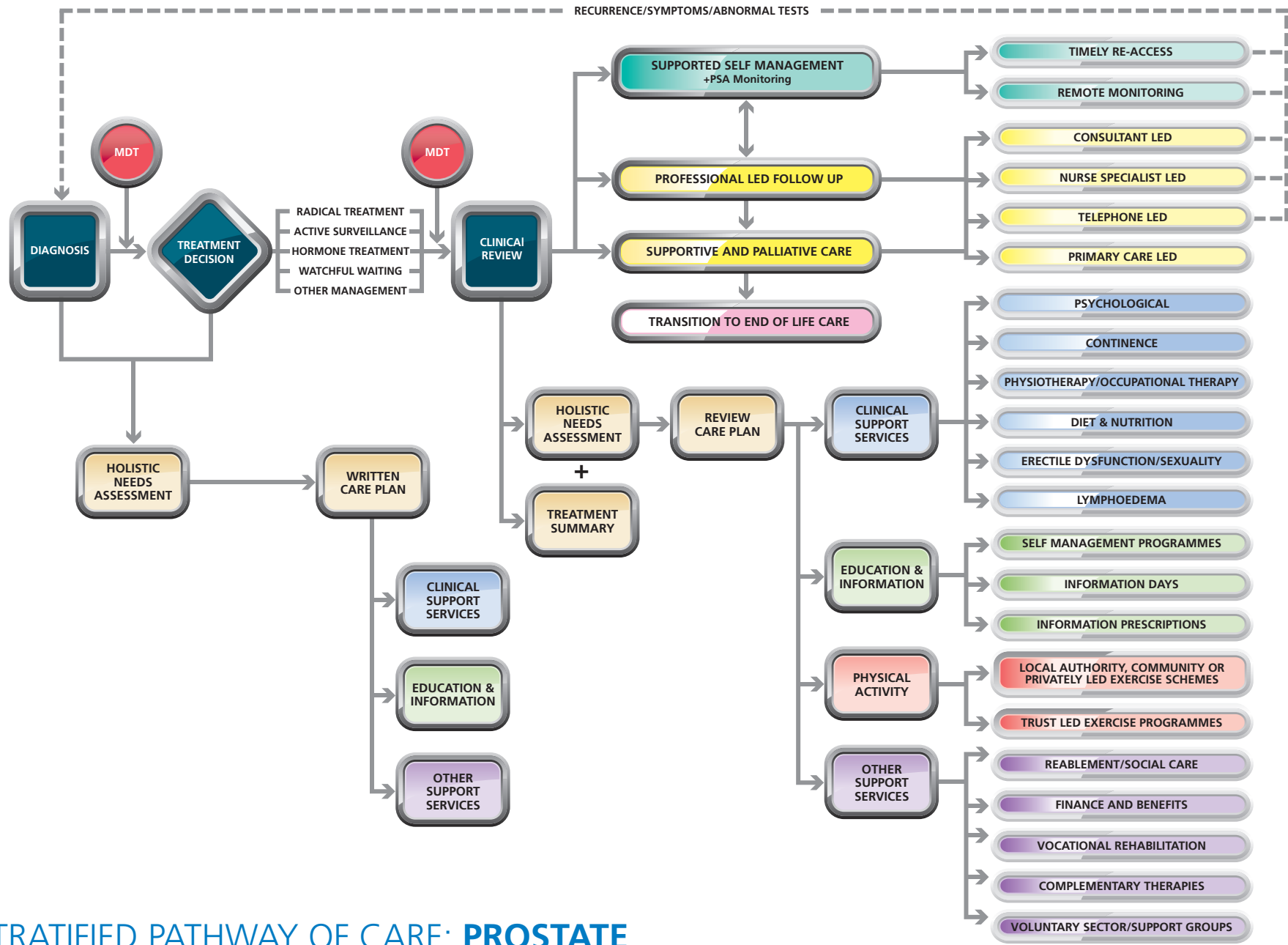
### Survivorship Test Sites - Prostate 2011/12

- 1 Ipswich Hospital NHS Trust
- 2 Luton and Dunstable Hospital NHS Foundation Trust
- 3 North Bristol Hospital NHS Trust
- 4 Hillingdon Hospital NHS Trust



### What we found

- During the testing it became apparent that for prostate cancer there were a number of management pathways which through the leadership of the National Clinical Advisor were distilled down into two levels of care following stratification; supported self-managed or professionally managed
- Supported self-management is a safe and accepted alternative to outpatient follow up where a robust remote management solution is in place
- From the testing, between 28% and 44% were stratified to self-management but it was felt as confidence in remote monitoring became established the number stratified to this level of care would increase
- Needs assessment informs the conversation about what matters to the individual patient
- Specific needs around erectile function and continence continue to be an area of concern which can have physical, social and psychological consequences for patients and their families if unresolved
- Information and education help inform patients and the conversation can be supplemented through Macmillan and the Prostate Cancer Charity publications
- On-going evaluation is required to collect the evidence that the interventions and support provided is making a real difference to patient experience and outcomes of care.



STRATIFIED PATHWAY OF CARE: **PROSTATE**

## STRATIFIED PATHWAY OF CARE: REMOTE MONITORING

“There was scepticism that patients would accept ‘self care’, imagining that these patients would value regular surveillance. When the rationale was properly explained it becomes obvious that the opposite was the case and most patients were delighted to accept the logic of the scheme.”

### Consultant Oncologist

#### Background and context

Remote monitoring in this context describes the way specialist cancer teams can monitor large numbers of patients in the community without the need for face-to-face follow up. Remote monitoring is a key enabler for patients stratified to a self management pathway.

All patients enrolled for remote monitoring will have been assessed for suitability, have the information and support they need with open access back into the service if required.

Good examples of remote monitoring exist in England, however, adoption and spread has been hampered by lack of IT development resources, constrained IT architecture, lack of full MDT support or concerns around financial instability from reduced outpatient activity.

All participating teams were asked to test a remote monitoring solution/s for patients stratified to a self management pathway. These could be in house systems or the NHS Improvement sponsored solution.

Several breast teams had established systems in place for ongoing mammogram monitoring using either local radiology or parallel national breast screening systems.

#### What we did?

NHS Improvement sponsored the development of a remote monitoring solution capable of interfacing with local IT systems to support prostate cancer (PSA monitoring) and colorectal cancer (CEA, CT scans and endoscopy procedures). System requirements included the ability to schedule and monitor tests, issue standard result letters, trigger defaults and record all outcomes.

The modules became available in summer 2011, however, few organisations were able to progress implementation at that time due to existing workload commitments.

Two colorectal teams opted to develop in house solutions and these are expected to go live April 2012. The IT functionality developed at Guys and St Thomas' enables use across several tumour groups.

Two organisations required formal business case approval to proceed. Two additional associate sites at St Georges, London and the Royal United Hospital Bath were also recruited to test the prostate cancer module.

Systems for mammography surveillance proved straightforward. Most patients are referred at the post surgery MDT meeting for ongoing mammograms (as per NICE guidelines) with results sent by post.

#### What we found

- IT resources need to be identified at the start of the project and time scheduled into IT work plans for implementation and testing before go live.
- Stratified pathways of care can be introduced in advance of the remote monitoring solution being made available
- Clinical leads and their teams need to ensure that governance arrangements, such as standard operation procedures, are in place to support the system
- Resources required to support implementation should include general project management time, plus approximately 20 days IT resource over a minimum period of three months
- Teams should meet with commissioners early in project to allay concerns about shifting activity to primary care. Any impact on phlebotomy services is expected to be minimal
- Savings associated with reduced outpatient activity need to be off set against the cost (people and kit) to support remote monitoring. In Bath, the prostate service requires one CNS session per week to support about 700 patients
- Remote monitoring solutions for prostate and colorectal cancers have taken longer than expected to implement.

## STRATIFIED PATHWAY OF CARE: CARE COORDINATION

“The most surprising and pleasing thing about this project was discovering what facilities already existed in the community and that by exploring these and networking with providers we could greatly enhance our service simply by being aware of existing services and using them properly.”

Healthcare Professional

### Background and context

Care coordination is the seamless experience of care which encompasses information and communication between patients, their carers and providers, and between those providing services across the individual patient pathway. It is therefore a function to ensure that as far as possible those who will be working in partnership with patients have access to appropriate information (with the patients consent) to provide an effective service.

The key areas of care coordination addressed during this phase have been:

- Assessment and care planning including treatment summaries
- Information, education and advice
- Self-management and timely re-access
- Working across care sectors and organisations.

### What we did?

Our aim was to create a cultural shift from the patient being clinically managed to being supported through a recovery phase to increase their confidence to be able to self-manage their own health with support through monitoring and timely access should problems occur.

To facilitate this cultural shift clinical teams were offered:

- Assessment tool training
- Motivational interview training.

The sites tested different methods of information delivery to meet the learning needs of the individual patients. This included information days, health and wellbeing clinics, survivorship courses, one to one sessions, and information prescriptions.

The care plan resulted from a needs assessment and sites tested various assessment tools including self-assessment to focus the conversation on the needs of the individual. As an outcome from the assessment patients would be referred or signposted to support services that could support meeting their needs.

The treatment summary provided a useful tool for patients and GP's to understand the disease stage, what treatment the patient received, a management plan and what to look out for in the future. This was either part of the care plan or a separate document.

Hand held records were developed or modified in several of the sites to include the treatment summary, key information and contacts should the individual need advice or support.

### What we found

- Clinicians may need additional skills to manage the transition in moving patients from a medical to a self-management model of care
- Assessment and care planning is time consuming and needs to be focussed on the conversation and what makes a real difference to the individual patient
- Information is power, and the confidence this gives the individual in knowing about their disease and what to look out for and take control of their own health is critical to enable self-management
- Care coordination requires professionals across all sectors to communicate effectively to provide a consistent service and to respond to needs proactively where appropriately thereby averting crisis intervention.

## ACKNOWLEDGEMENTS

We are grateful for the enthusiasm and commitment of all the test site teams to this work over the past year. You have all embraced the changes with determination and resolve and the scale of what has been achieved in such a short timescale has been commendable. We will continue to develop and learn from your experience and trust you will be the ambassadors for change in your organisation and beyond in the future.

Our thanks go to Adam Glaser our National Clinical Lead and the four National Clinical Advisors; Mick Peake, John Griffith, Dorothy Goddard and Roger Kocklebergh for their clinical leadership during this phase of testing.

Our special appreciation to Noeline Young, NCSI Project Manager, and to colleagues from Macmillan Cancer Support, Breast Cancer Care, Beating Bowel Cancer and the Prostate Cancer Charity for their advice and support over the past year.

Finally, our thanks to the IT development team at North Bristol NHS Trust and John McFarlane at Royal United Hospital Bath for their support in the development of a remote monitoring solution.

Through your work we now have a wealth of experience knowledge and skills to take this agenda forward and continue to improve the quality and effectiveness of services for those living with and beyond their diagnosis of cancer.

Thank you all again for your contribution.

**NHS Improvement -  
Adult Survivorship Team**

“

I hold a firm belief that both medical and psychological care go hand in hand in supporting patients through their personal journey of cancer. The project has allowed the focus to shift away from the medical model to a more holistic approach for all patients. It has helped me to think outside the box in helping patients feel more empowered both physically and emotionally.”

**Cancer Nurse Specialist**



### NHS Improvement

NHS Improvement's strength and expertise lies in practical service improvement. It has over a decade of experience in clinical patient pathway redesign in cancer, diagnostics, heart, lung and stroke and demonstrates some of the most leading edge improvement work in England which supports improved patient experience and outcomes.

Working closely with the Department of Health, trusts, clinical networks, other health sector partners, professional bodies and charities, over the past year it has tested, implemented, sustained and spread quantifiable improvements with over 250 sites across the country as well as providing an improvement tool to over 1,500 GP practices.

### NHS Improvement

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