How to optimise patient outcomes and system improvements by redesign of cancer follow up pathways

Lesley Smith, NHS England
Hazel Brodie, Prostate Cancer UK
Emma Hallam, Nottingham University Hospitals NHS Trust
| Lesley Smith | • Why redesign follow up for people living with and beyond cancer?  
• What are the key features of the new pathways?  
• Highlights from breast cancer follow up redesign |
| Hazel Brodie | • Project to test self-managed follow up for men living with and beyond prostate cancer |
| Emma Hallam  | • Service that addresses late effects and poor quality of life after radiotherapy |
| Lesley Smith | • Success factors for redesign  
• Where to from here? |
@Lesleylesleys @NHSEngland @ProstateUK @EmmaHallam6 @TeamNUH

#LivingWithAndBeyondCancer
Five year programme

• Based on Cancer taskforce ambitions:
  • Fewer people getting avoidable cancers
  • More people surviving cancer for longer after a diagnosis
  • More people having a positive experience of care and support
  • More people having a better long-term quality of life
• We are making radical changes, as part of a five-year plan to improve NHS cancer services

• We’re already making rapid progress – but know there is more to do

• We’re on track to make long term changes that will put NHS cancer services up with the best in the world.
Achievements so far

• Ten multi-disciplinary diagnostic ‘one stop shops’ for rapid assessment and diagnosis
• Faster diagnosis pathways published for prostate, colorectal and lung cancers – early implementers show promising signs – more people getting treated faster
• £130 million radiotherapy upgrade programme
• Establishing pilots of lung cancer case finding to diagnose patients more quickly
• World leading quality of life metric
• Fast track funding for the most promising new cancer drugs
• £600 million programme to transform care by 2020/21
More people are now surviving cancer. World-class cancer care is not just about ensuring people live longer, it’s also about ensuring they live as well as possible.
Yesterday’s women
The story of R.A.G.E.

Pelvic Radiation Disease Association

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Traditional Follow Up Model
‘One size fits all’

Diagnosis Of Cancer → Treatment → Regular scans/tests for recurrence + Professional-led clinic follow-up → Discharge from follow-up
# Cancer Prevalence

<table>
<thead>
<tr>
<th></th>
<th>1990</th>
<th>2015</th>
<th>2030</th>
</tr>
</thead>
<tbody>
<tr>
<td>Number of people living with cancer (UK)</td>
<td>1.2 m</td>
<td>2.5 m</td>
<td>4.0 m</td>
</tr>
<tr>
<td>Of whom the number getting cancer for the first time each year</td>
<td>240,000</td>
<td>340,000</td>
<td>430,000</td>
</tr>
<tr>
<td>How long people live on average after diagnosis</td>
<td>~ 2 years</td>
<td>~ 10 years</td>
<td>?</td>
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Ref: macmillan.org.uk/research
## Costs

<table>
<thead>
<tr>
<th></th>
<th>2015</th>
<th>2020</th>
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<tbody>
<tr>
<td>Monitoring and follow up</td>
<td>£0.3 bn</td>
<td>£0.4 bn</td>
</tr>
<tr>
<td>Managing consequences of treatment</td>
<td>£0.9 bn</td>
<td>£1.0 bn</td>
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There is no proof it is the best way
Demand for follow up care will continue to increase
Waiting lists are under pressure
Not cost effective
Poorer patient experience and unnecessary personal expenditure
Does not support self-management

Keeping the traditional model is not an option
Background

2008 – 2013
National Cancer Survivorship Initiative

2015-2020 NHS England
Living With & Beyond Cancer
National strategy recommendations

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Living With and Beyond Cancer Transformation Programme

- Personalised (stratified) Follow Up

- Prevention → Diagnosis → Treatment → Recovery → Follow-Up → End of Life

- Personalised Care & Support Planning based on Holistic Needs Assessments

- Health and Wellbeing Support

- Treatment Summaries

- Cancer Care Reviews

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Personalised (Stratified) follow-up model

Personalised Care and Support Planning based on Holistic Needs Assessments
Ongoing support for Health and Wellbeing

- Diagnosis
- Prehabilitation
- Treatment
- Needs Assessment
- Shared decision about follow-up
- Stratification criteria
- Professional-led follow-up
- Patient-triggered follow-up INCLUDING REMOTE MONITORING
- Treatment Summary
- Regular scans/tests
- Monitoring for side effects
- Rapid re-access to clinic
- Telephone Support
- Support for self-management
- Signposting or referral to support / advice / services
- Cancer Care Review

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What it means for people

- Access to the cancer team at any time
- Support and information for self-management
- Referral for support services such as psychology, return to work, financial advice, managing long-term side effects
- Information shared with you & your GP
- ‘Remote’ monitoring
Benefits of patient triggered follow up

MORE
• Personalisation of care and support
• Physical and emotional needs met

BETTER
• Patient experience
• Confidence and skills to self-manage
• Scheduling of routine tests/scans

QUICKER
• Access to team when cancer recurrence suspected
• Access to results of tests/scans

LESS
• Travel costs / time off work
• Out-patient clinic resource use
• People lost to follow up
Progress in Transforming Breast Cancer Follow Up

2018/19 NHS Planning target for breast cancer stratified follow up

Survey of trusts (60% response rate) Jan-March 2017

- 49% of trusts reported having criteria and protocols for breast cancer stratified follow up
- 67% of patients on patient-triggered follow up (indicative target 70%)

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Aintree:

Patients are told at diagnosis about patient triggered follow up

All patients are eligible except certain groups e.g. : metastatic disease / nursing home residents

4 months after treatment - key worker introduces self-management
Liverpool

Patients making more healthy lifestyle choices as a result of support for self-management.

Royal Marsden

61% of people in open access follow up had at least one unmet need and 18% had $\geq 5$ needs. Consistently higher levels of unmet needs were identified using Holistic Needs Assessment checklist (v. from EPR)
Calderdale and Huddersfield:
Follow-up education programme for patients at low to moderate risk

Audit showed
• Reduced overall patient anxiety
• Reduced routine hospital appointments
• Standards of care maintained
• Patients provided with an effective support network


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Macmillan Northern Ireland:

- Saving of nearly 2 appts per year per new breast cancer diagnosis
- 39% reduction in duplication of review appointments
- High levels of patient satisfaction

Without the project, the system could not have sustained the demand being placed upon it and waiting lists would have become much worse.

TrueNTH UK
Supported Self-Management and Follow Up Care Programme

Hazel Brodie, Project Consultant, H.Brodie@soton.ac.uk
TrueNTH Objective:

To significantly improve the lives and experiences of men with prostate cancer, their partners, carers and family members
Care Pathway:

• A man who enters the care programme is offered:
  • Knowledge and skills to co-manage his health and well being
  • A needs assessment
  • Remote monitoring of his health and well being by the urology team
  • Rapid access to his clinical team if concerned

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Care Pathway:

- This is achieved by:
  - A transition workshop to introduce men to care programme and give them new knowledge and skills
  - A support worker who acts as the co-ordinator and first point of call for the men
  - An IT platform with patient and clinician facing elements
  - A simple needs assessment tool: the Health MOT
The nurse will run a virtual clinic, and see list of patients who can be ranked by a number of fields:
Overview of progress:

• Over 3500 men across 5 sites now on the pathway
• Subset or men participated in mixed method, non-concurrent controlled cohort study.
• Four publications pending
• Toolkit developed
• Now working with health care providers across UK
Evaluation findings:

• Outcomes for men in the programme group were for the most part equivalent to men in the comparator group, with very modest improvements in the programme group in relation to unmet existential need, bowel symptoms, and psychological wellbeing.

• The direct per patient cost over the 8 month follow up period was higher in the programme group compared with the comparator group (£101 vs £59). However, the overall per patient cost was lower (£277 vs £326). This is because wider health service utilisation was lower in the programme group.
• Successful implementation of the programme required behavioural and cultural changes on behalf of the clinical team. These included adopting new processes, and developing trust in self-management, and the role of the support worker.

• The programme was perceived, by staff at the sites, to improve the quality of care provision.

• The introduction of the support worker role was seen as overwhelmingly positive, providing significant support for nurse specialists.
• The workshop is considered a fundamental part of the programme. Training was needed in facilitation skills, and the less directive delivery style was initially counter-intuitive for some nursing staff.

• The workshops are appropriate for men with a variety of treatment experiences.
• The better the PSA Tracker was integrated into the incumbent IT systems, the more useful it was. There were workload implications when the integration was not completed, with clinical teams having to spend additional time manually inputting data into the system.

• Six out of every ten men signed up to use the IT system, although not all of them used the service regularly. The remaining 4 out of ten chose not to sign up, and their follow up was managed by telephone and letter.
Participant interview:

“I hate this issue of being in the dark all the time, as I said, **we live from result to result, and that period in between, we are left in the dark. I’m not any longer, I’m there, I’m with them, I’m up there with them. Any query, any issue, it’s like going to the board meeting isn’t it where decisions are being made and I can be part of those decisions being made. I really feel I am now part of the team, if you like, and not waiting for the answers, I’m up there with them now, and that’s what team work is all about, isn’t it”
Contact details:

Hazel Brodie (Project Consultant)

H.Brodie@soton.ac.uk

www.southampton.ac.uk/TrueNTH-SSM
Nottingham Late Effects Service
Emma Hallam
Macmillan Radiotherapy Information & Support Radiographer

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Rationale

• Living life with a history of cancer is unique for each person however a common thread is true for most that life is different after cancer
• The effects of radiotherapy treatment can last a lifetime and often have a devastating consequence on a patient’s quality of life
• Patients are often living with such consequences which are often ignored or not recognised by other health professionals
Macmillan Facts & Figures

- 2 million people are living with consequences from their cancer treatment
- Problems are both physical and emotional
- Cancer survivors are estimated to rise to 4 million over the next 20 years

Of those 2 million people......
- 40% say they were unaware of long term side effects
- 78% have experienced physical health problems in the last 12 months
- 40% are living with emotional problems and have not sought any help
- 71% of those who finished treatment 10 years ago have experienced physical health problems in the last 12 months

Identifying Radiotherapy Late Effects

- It is well-known that treatment side effects especially radiotherapy can be difficult to diagnose and management can be complex.
- More damage can be done to the irradiated tissues by inappropriate investigations and treatment.
- Can develop from 6 months to many decades later.
- Often progressive and multi-factorial.
- Multi-modality treatments increase the risk - for example chemo-radiotherapy.
- Evidence suggests that such patients can have a reduced quality of life if their complex needs aren't appropriately addressed.
Three year Macmillan funded project, trust funded since Sept 2017

Aim to provide highly specialist care for cancer patients throughout Nottinghamshire who have been cured of cancer but who are suffering from the disabling consequences of their cancer and treatment

Our LE service is one of a few such services nationally and it aims to provide a cost-efficient, highly effective and innovative model of care to be used by other leading Cancer Centres

The LE service has been developed in line with the NHS cancer plan and the National Cancer Survivorship Initiative and we sit as part of the recovery package
Nottingham Late Effects Service

- Patients can self-refer, be referred by GPs or by clinical teams
- Referral criteria: any patient regardless of tumour site who has to have completed treatment more than 6 months prior to referral
- Prior to the clinic visit the full clinical history is reviewed. Holistic needs assessments and specialised screening tools are used to target needs
- Welcoming, friendly, individualised, holistic approach with no time constraints
- Constantly researching late effects globally for information on late effects
- Specific information sheets provided
- Referral onto one of the clinical pathways if appropriate
- Follow up appointment either in clinic or by phone
Health and Care
Innovation Expo

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Can be like opening a Pandora's box........
What can the late effects service offer?

- Lymphoedema management
- Peripheral neuropathy management
- Skin changes care & advice
- HOPE course
- Bowel & Bladder Advice
- Pelvic radiation disease management
- Psychological therapies
- Pain management & acceptance
- Referral onto other services
- Sexual dysfunction
- Exercise prescription
- Tinnitus & hearing loss advice
- Fatigue management
- Mindfulness & motivational interviewing

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What are we achieving?

398 patients seen since Sept 2014

<table>
<thead>
<tr>
<th>Outcome of attending LE clinic</th>
<th>% of patients</th>
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<tbody>
<tr>
<td>Advice only</td>
<td>40%</td>
</tr>
<tr>
<td>Referral to other AHP services</td>
<td>44%</td>
</tr>
<tr>
<td>Referral to Consultant/other medical teams</td>
<td>17%</td>
</tr>
</tbody>
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‘Distress Thermometer’ score (0 = low, 10 = high distress)

- Before LE clinic attendance majority of people score very highly on distress thermometer (9 or 10)
- 3 months after LE clinic assessment
  - Average reduction in **3.45 points** (n=157)
  - Clinically significant
Benefits and Achievements

• Massive improvement in quality of life.
• High quality patient experience.
• Effectively meeting holistic needs in a complex and often disregarded patient group.
• Greatly improved communication, networking and clear pathways between services that support this patient group.
• Award-winning: Winner of 2016 UK Quality in Care award for Long-term conditions. Winner of 2016 Macmillan Excellence Award.

Our biggest achievement is the difference we are making to these patients and their testimonials.

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Patient feedback

This service is really needed.”

“Very helpful and informative.”

“She really gets it, I can see it in her eyes that she understands. Giving me a sense of relief.”

“Amazing – light at the end of the tunnel.”

“Gave me hope that the ever current problem may be able to be controlled.”

“I felt relaxed and comfortable as we both explored the symptoms associated with my conditions. Everything was explained in easily understood language and it was so good having someone listen, understand and explain without being dismissive. She was so kind.”

“Provided me with the motivation to carry on.”
Conclusion

Lesley Smith
Personalised (stratified) follow up – success factors for implementation

- Clinical leadership and Commissioning Support
- Project management
- Flexibility of pathway - co-design with people affected by cancer
- HNA/Care planning; Treatment Summary; Health & Wellbeing Support
- Workforce e.g. support workers/navigators
- IT
- Monitoring and evaluation

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Personalised (stratified) follow up – where to now?

- Roll out in Breast Cancer March 2019
- Roll out in Colorectal and Prostate Cancer 2020
- Other cancers?
- Evaluation
- Evolution – greater personalisation, wider partnerships, better integration of recovery package interventions, NICE guidance

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Thank You

Questions?

@Lesleylesleys @NHSEngland @ProstateUK @EmmaHallam6 @TeamNUH #LivingWithAndBeyondCancer