Living With and Beyond Cancer – where next?

Lesley Smith, Senior Programme Manager, LWBC, NHS England National Network of Colorectal Cancer Nurses, Sept 2018
Disclosure

Trustee (unpaid) of the Pelvic Radiation Disease Association
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@NHSEngland
#LivingWithAndBeyondCancer

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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
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

www.england.nhs.uk
National Cancer Programme

Living With and Beyond Cancer workstream

Workstreams on
- Early Diagnosis
- Cancer Alliance Support
- Data & Evaluation
- Strategy and Policy

19 Cancer Alliances

Cally Palmer
National Cancer Director

David Fitzgerald
NHS England Cancer Programme Director

National Clinical Director for Cancer

Other Arms Length Bodies (PHE, HEE, CQC, NHSI etc)
Cancer Alliances

North
1. Northern Cancer Alliance
2. Lancashire and South Cumbria
3. West Yorkshire and Harrogate
4. Humber Coast and Vale
5. Greater Manchester
6. Cheshire and Merseyside
7. South Yorkshire, Bassetlaw, North Derbyshire and Hardwick

Midlands and East
8. West Midlands
9. East Midlands
10. East of England
12. Thames Valley

London
13. North West and South West London
15. South East London

South
11. Somerset, Wiltshire, Avon and Gloucestershire
16. Peninsula
17. Wessex
18. Surrey and Sussex
19. Kent and Medway

http://bit.ly/Cancer_Alliance_Map
www.england.nhs.uk
How confident are you in your knowledge of LWBC?
# Cancer prevalence

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

Ref: macmillan.org.uk/research

www.england.nhs.uk
## Costs

<table>
<thead>
<tr>
<th></th>
<th>2015</th>
<th>2020</th>
</tr>
</thead>
<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>
</tr>
</tbody>
</table>


www.england.nhs.uk
People affected by cancer

“I did suffer from depression and anxiety during my treatment and I tried counselling. It was very hard to readjust to life after cancer and I couldn’t find a local support group at the time here in North Wales. I just didn’t know anyone who had ever had this disease.” Jackie Hill (Bowel Cancer UK website)

“I was told damage caused by radiotherapy was irreversible. No one was aware of a specific problem. I was given the feeling that I was lucky to have got over cancer. I felt very isolated, vulnerable.” Anonymous (PRDA website)
Yesterday’s women
The story of R.A.G.E.
Background to national work

2008 – 2013
National Cancer Survivorship Initiative

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

www.england.nhs.uk
NHS England commitments

Acceleration of the commissioning and provision of services to support people affected by cancer to live as healthy and as happy lives as possible.

- Personalised (‘Stratified’) Follow Up
- Recovery Package interventions
- Quality of Life Metric
Living With and Beyond Cancer Transformation Programme

Prevention Diagnosis Treatment

Personalised Care & Support Planning based on HNA

Health and Wellbeing Support

Treatment Summaries

Cancer Care Reviews

Personalised (stratified) Follow Up

Recovery Follow-Up End of Life
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
Keeping the traditional model is not an option

- 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
Personalised (Stratified) follow-up

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

Diagnosis

Prehabilitation

Treatment

Holistic Needs Assessment

Stratification criteria

Shared decision making

Professional-led follow-up

Self-managed follow-up

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

www.england.nhs.uk
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 self-managed 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
Criteria for Supported Self-management (example)

- All colorectal cancer patients will be considered for entry onto the colorectal supported self-management pathway unless:
  - Unable to self-manage due to physical, cognitive or emotional reasons
  - The individual chooses not to.

- For individuals in clinical trials, follow-up will be determined by the clinical trial protocols.

- The final decision regarding entry onto the supported self-management pathway is conducted in collaboration with the patient.

Based on London Cancer Colorectal Cancer Stratified Follow-up Pathway Guidelines
https://www.uclh.nhs.uk/OurServices/ServiceA-Z/Cancer/NCV/LC/Pages/Colorectalpathwayboard.aspx
33% of trusts who responded to the survey had criteria/protocols for colorectal cancer stratified follow up.

Where stratified pathways were in use, 49% of colorectal patients were assigned to self-managed follow up.

**Indicative targets for the proportion of patients suitable for self-managed follow up:**

<table>
<thead>
<tr>
<th>Proportion of Patients</th>
<th>Colorectal</th>
</tr>
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<tbody>
<tr>
<td>40 – 49%</td>
<td>7</td>
</tr>
<tr>
<td>50 – 59%</td>
<td>2</td>
</tr>
<tr>
<td>60 – 69%</td>
<td>1</td>
</tr>
<tr>
<td>90 – 100%</td>
<td>1</td>
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## Baseline Survey Jan-Mar 2017

<table>
<thead>
<tr>
<th>% of patients</th>
<th>Colorectal</th>
<th>All cancers</th>
</tr>
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<tbody>
<tr>
<td>Having an HNA</td>
<td>30%</td>
<td>31%</td>
</tr>
<tr>
<td>Having a care plan</td>
<td>15%</td>
<td>15%</td>
</tr>
<tr>
<td>Having a treatment summary</td>
<td>9%</td>
<td>8%</td>
</tr>
<tr>
<td>Attending a health and wellbeing event</td>
<td>9%</td>
<td>8%</td>
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Personalised Care and Support Planning based on Holistic Needs Assessment

A practical guide to living with and after cancer

WE ARE MACMILLAN.
PLANNING YOUR CARE AND SUPPORT
Having a holistic needs assessment

www.england.nhs.uk
Personalised Care and Support Planning based on Holistic Needs Assessment

A way of capturing and recording conversations, decisions and agreed outcomes in a way that makes sense to the person.

Should be proportionate, flexible and coordinated and adaptable to a person’s health condition, situation and care and support needs.

Should include a description of the person, what matters to them and all the necessary elements that would make the plan achievable and effective.

Treatment Summary

Dear Dr X,

Date: Add patient's name, address, date of birth and record number.

Your patient has now completed their initial treatment for cancer and a summary of their diagnosis, treatment and ongoing management plan is outlined below. The patient has copy of this summary.

<table>
<thead>
<tr>
<th>Diagnosis</th>
<th>Date of diagnosis</th>
<th>Organ/Stage</th>
<th>Local/Stage</th>
</tr>
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<tbody>
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Summary of treatment and relevant dates:

- Treatment start date:
- Treatment end date:

Possible treatment side effects and/or adverse effects:

- Advice given to patient and/or supportive care register:
- 30/30 application completed:
- Prescription Change exemption arranged:

Alert symptoms that require referral back to specialist team:

- Contacts for referrals or queries:
- In House:
- Out of hours:

Secondary Care Contacting Management Plan (tests, appointments etc): Other service referrals made:

- Dietitian
- Social Worker
- District Nurse
- Clinical Nurse Specialist
- Paediatrician
- Rehabilitation Service
- Other:

Required GP Authorisation in addition to GP Cancer Care Review (e.g. ongoing medication, second opinions and second screening):

Summary of information given to the patient about their cancer and future plans:

Additional information including issues relating to lifestyle and support needs:

Completing Doctor: Signature: Date:
Colorectal Health and Wellbeing Event
August 22, 2018 Latest

The Northern Trust is hosting a Health & Wellbeing event entitled “Living with and Beyond Colorectal Cancer” on Monday 24th September 2018, 1.30pm – 4.45pm, in the Rosspark Hotel, 20 Doagh Road, Kells, Ballymena BT42 3LZ. This event is designed for patients who have completed or are still receiving treatment for colorectal cancer, and who would like more information on how to move on after a diagnosis. The event provides a range of health and wellbeing advice for patients in

Wellbeing programme for people affected by cancer
April – June 2018
Macmillan Support and Information Service
Support when you need it

www.england.nhs.uk
Health and Wellbeing Support

Other sources of support:
- Online Forums
- Support groups
- Cancer Information Centres
Health and Wellbeing Support

Examples of other sources of support:

• Community based physical activity schemes
• Advice centres for finance, housing, disability support etc

www.england.nhs.uk
Cancer Care Review

Transforming Cancer Services Team

4 Point model for holistic cancer care reviews: cancer as a Long Term Condition

November 2017
Whole system pathway redesign
Consequences of Treatment

Managing the long-term consequences of colorectal and anal cancer

Guidance for healthcare professionals

macmillan.org.uk/colorectal

Consequences of Cancer and Treatment
rcgp.org.uk/coc

The psychological impact of cancer: commissioning recommendations, pathway and service specifications on psychosocial support for adults affected by cancer

Commissioning Guidance for Lymphoedema Services for Adults Living with and Beyond Cancer

healthy london.org.uk

Transforming Cancer Services Team for London
Quality of life metric Pilot project

Testing QoL questionnaires in 5 Cancer Alliances

Breast, colorectal, prostate

Provide evidence on where and how services should improve

Using the questionnaires will empower individuals

Roll out from 2019

www.england.nhs.uk
Where Next?

• Maximise the roll out of stratified follow up and recovery package interventions
• Continue to evaluate, refine and evolve these
• Management of Consequences of Treatment (especially for GI and psychological problems)
• Ways to predict and/or prevent CoTs
• Prehabilitation
• Quality of Life metric
Where Next?

Use research and data to inform service improvement

• NCRI Priorities for research in LWBC

• CREW study [https://www.southampton.ac.uk/msrg/ourresearch/macmillan-crew-cohort/macmillan-crew-cohort.page](https://www.southampton.ac.uk/msrg/ourresearch/macmillan-crew-cohort/macmillan-crew-cohort.page)

• Colorectal PROMs studies

• Cancer Patient Experience Survey [www.ncpes.co.uk](http://www.ncpes.co.uk)

• eHNA data

• Local surveys – patient feedback; staff feedback

www.england.nhs.uk
Where Next?

Culture shifts

• Person-centred care
• Quality of life and experience matter as much as survival
• Shared decision making
• Supporting patient empowerment and self-management
Action

- Personalised (Stratified) Follow Up
- Recovery Package interventions
  - Trusts: HNA, Care Planning, Treatment Summaries
  - Community providers: HNA, Care Planning
  - GP practices/CCGs: Cancer Care Reviews
  - CCGs/STPs/Alliances: Health and Wellbeing Support
- Consequences of treatment
- Quality of Life metric from 2019
- Collect and use data
- Culture shift on quality of life and experience
Thank you

Questions?

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#LivingWithAndBeyondCancer