What is risk stratified follow up?

- Refers to redesign of pathway beyond completion of primary treatment (follow ups)

- Replace traditional routine hospital follow up with supported self management
  
  - ‘Stratified’ to appropriate pathway based on their clinical condition and individual needs
  
  - Decision re pathway made by clinical team and the patient
Why?

• To improve aftercare services for those living with and beyond cancer

• To sustain breast (and other cancer) services into the future

What are the proposals for 'self-managed follow up' within the cancer survivorship model?

Incidence rates of common cancers 1975-2011

European Age-Standardised Incidence Rates, Great Britain, 1975-2011

Increasing incidence:
• Lifestyle factors
• Improved detection
• Ageing population
Ten year survival rates trends

Decreasing mortality:
- Earlier detection with greater proportion of earlier stage disease
- Improvements in quality and availability of effective treatments

Beyond primary treatment……..

- Many people will live long and healthy lives following cancer.
- Some may have a range of significant physical, psychological or social needs following cancer.
- People can be left with short or long-term consequences either of the cancer itself or from treatments.
- Others live with chronic or incurable cancer for many years.
- Many older people with cancer have other long term conditions in addition

-what about follow up?
Identifying the cancer care pathway

- **Diagnosis & Treatment**: Newly diagnosed - assumed need of acute sector care
- **Recovery and adjustment**: Surviving the first year - assumed need of rehabilitation
- **Early monitoring**: Up to 5 and 10 years from diagnosis - designated as 'early monitoring'
- **Later monitoring**: Beyond 10 years from diagnosis - designated 'later monitoring'
- **Progressive illness**: Incurable disease but not in last year of life - assumed need more treatment and support
- **End of life care**: In last year - subset of deaths in first year of diagnosis

*The numbers in the progressive illness group will be underestimated and the numbers in the monitoring groups will be overestimated as estimates for significant late effects have not been made.*

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**Total Prevalence - now**
- 2 million

**Total Prevalence - 2030**
- 3.4 million
Conventional medical follow up unsustainable

Total Prevalence - now 2 million

Total Prevalence - 2030 3.4 million

Conventional follow up model

National Cancer Patient Experience Survey 2010

- Conventional face-to-face out patient follow up does not meet patients’ needs.
Cancer Survivors have a range of unmet needs

• The Health and well-being profile of some cancer survivors (without active cancer) comparable to people with a chronic condition such as diabetes or arthritis.

• Some health and wellbeing issues attributed to consequences of cancer treatment – such as:

  **Post breast cancer:**
  - Menopausal symptoms
  - Osteoporosis
  - Pain
  - Lymphoedema – arm and/or breast
  - **Fatigue**
  - Psychological problems

  **Post colon cancer:**
  - 50% patients after pelvic radiotherapy left with bowel problems affecting quality of life

  **Post prostate cancer:**
  - Erectile dysfunction

  **Post childhood cancer:**
  - 60% experience one or more late effects of treatment 10 years following treatment.

Conventional follow up model

• 30% of people after completion of treatment have 5 or more moderate or severe unmet needs – remains constant over 6mths (Armes J Clin Oncology 2009)

• Many survivors have other long term conditions in addition, inappropriate to treat in isolation
Conventional follow up model

- Routine follow up appointments not effective in terms of detection of recurrence.

- Breast cancer follow up:
  - Many studies including Cochrane review 2000 demonstrated conventional clinical follow up ineffective in detection of recurrence or improvement in survival
  - Recurrence or further disease presents outside routine appointment or detected on surveillance mammogram

BUT without routine follow up to prompt Surveillance, need to have reliable ‘remote’ system

- is there a better way?

National Cancer Survivorship Initiative (NCSI)

- Originated from Cancer Reform Strategy (DoH 2007)

- Publication of NCSI Vision (2010) Partnership between Department of Health and Macmillan, supported by NHS Improvement
  - “The aim of the NCSI is to ensure that those living with and beyond cancer get the care and support they need to lead as healthy and active a life as possible, for as long as possible”

- Improving Outcomes for Cancer (DoH 2011) – focus on outcomes and survivorship
National Cancer Survivorship

• Recognition of growing number of cancer survivors and many more people living with and beyond cancer:
  
  Greater focus on recovery, health and well-being after cancer treatment
  
  Replace routine clinical follow up with supportive self-management

  Holistic assessment, care planning and information (includes treatment summary)
  
  Tailored support and surveillance - for early recognition of further disease or post-treatment effects
  
  Greater emphasis on patient experience and outcomes – routine measurement

NCSI : 5 Key elements

• Support through primary treatment from diagnosis
• Promote recovery “recovery package”
• Sustain recovery
• Reduce burden of consequences of treatment
• Support patients with recurrent and active disease
Cancer survivorship - objectives

1. Support through primary treatment from the point of diagnosis
   - All patients are offered/given:
     - Information about cancer and treatment options
     - Support for decision making
     - Optimal treatment to maximise chances of cure and minimise risk of long term consequences
     - Support through treatment itself
     - Advice on work and finances

2. Promoting recovery – ‘the recovery package’
   - All patients offered a tailored package of care including:
     - An end of treatment summary - diagnosis, treatment, follow up management plan, information re side effects and what to look out for, key contact details
     - A care plan based on holistic needs assessment (HNA) at diagnosis and on completion of acute treatment
     - ‘Needs’ include: physical and lifestyle, social, financial, occupational, psychological and spiritual
Cancer survivorship - objectives

2. Promoting recovery
   • Exercise programmes – tailored to the individual
   
   • All patients offered attendance at a health and well-being event/programme
     • Multi-professional advice on recovery (e.g. ‘Moving On’ days)
   
   • Primary Care – Cancer Care Review (GP or practice nurse)

Moving On Day

Opportunity for survivors to meet with professionals, ask questions, meet allied organisations
Cancer survivorship - objectives

3. Sustaining recovery
   - Routine clinical follow up replaced by: Supported self-management for all suitable patients with discharge from clinical follow up on completion of primary treatment.

Risk stratified model of care

Breast cancer 80%
Colorectal 50%
Prostate 40%
Cancer survivorship - objectives

3. Sustaining recovery
   - Remote monitoring for mammography (blood markers, PSA monitoring, CT scans, colonoscopies,)
     • Requires effective IT systems to ensure surveillance tests are done, results checked, patient/GP informed
     • Nurse/Allied health professional follow up/often by telephone or at routine surveillance points - such as mammography (or PSA, CEA, CT scans)
       » include routine Patient Reported Outcome Measures (PROM’s – provide evidence of unmet needs or consequences of treatment)

   - Recommended levels of physical activity
   - Information re healthy lifestyle and warning symptoms/signs of further problems
     • How to re-access specialist services
Cancer survivorship - objectives

4. Reducing the burden of long term consequences of treatment
   - All patients informed of possible consequences of treatment at start and end of primary treatment and what to look out for eg lymphoedema, osteoporosis, sexual/menopausal, cardiotoxicity, post radiation problems
   - Aiming for prevention or early detection of treatment consequences
   - Access to specialist services for complex complications.

5. Supporting patients with active and advanced (recurrent/metastatic) disease
   - Identifying all patients with active/advanced or recurrent disease and for discussion by multidisciplinary team (MDT)
   - Rapid access back into the system
   - Multi-professional assessment of needs and care planning
   - Access to cancer nurse specialist/key worker and the multidisciplinary team
   - Effective interface with end of life care services
Risk stratified follow up

Evidence?

Is it safe?

Bath Breast Service: since 2003
  • No routine clinical follow up post completion of treatment for most patients
  • Open access with return to clinic as appropriate – either via cancer nurse specialist or Family Doctor
  • Regular questionnaires conducted with radiographers at annual visit for mammographic surveillance (PROM’s)
  • Annual mammograms prompted by breast imaging (IT database)
  • Quarterly ‘Moving on’ programme

  – Rates of recurrence not increased compared with rest of England
  – Survival rates (at 1 year, 5 years and 10 years) at least England average with 10 year survival 88% (>90% 2012)
Results of 2 months audit (327 patients)

- NFA 286
- BCN Advice 12
- BCN refer GP 15
- Clinic appt 14

- 8 reassured
- 6 further investigation
- 1 new cancer - lung

Is it effective?

- National Institute for Health and Clinical Excellence (NICE) guidance:
  - NICE Quality Standards for Breast Cancer 2011

NICE Quality Standards describe markers of high quality cost-effective care; to guide commissioning
Is it effective?

• National Institute for Health and Clinical Excellence (NICE) guidance:
  • Increased quality and improved productivity published Sept 2013

  Redesigning services for those living with or beyond cancer had proven improvements in quality and productivity
  http://www.evidence.nhs.uk/qipp

What is the Patient’s Experience?

• Bath Breast Unit since 2003.
  – Regular patient experience surveys with 75% rating service as excellent or very good

• Survivorship at 9 (+6) pilot sites across England in 2010 (2011)
  Ipsos MORI service evaluation study 2011, 2013
  – 71% rated quality of after-care excellent or very good
  – 83% confident about self managing own health
  – 74% considered had sufficient information to manage own health
  – 61% considered had sufficient information to detect return of cancer
Helping people help themselves – Evidence

• 2011 Health Foundation Review of the literature based on the results of almost 600 studies published in the UK and internationally: there is evidence that supporting self-management can improve people’s quality of life, clinical outcomes and health service use.

• By learning to self manage, people with chronic diseases - including some people with cancer - are more likely to achieve better health outcomes, make best use of health systems and remain integrated into society and the workforce.

Is it Sustainable?

• Fewer patients requiring routine follow up
• Assessment and care planning
• Remote monitoring/surveillance
• Better ambulatory care assessment/management of patients when they develop problems

• Fewer emergency admissions
• New services for patients with consequences of treatment
• New models of care to support patients with relapsing and active disease – Metastatic CNS’s
Improving aftercare services for those living with and beyond cancer

Thank you
– any questions?

“The cancer’s always there in the background. Not that I’ve had it in my mind all the time, but you can’t completely forget it. It’s always there in your life”.

We are Macmillan. Cancer Support

National Cancer Survivorship Initiative

Department of Health

NHS

NHS Improvement