

National Cancer Survivorship Initiative

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Cancer Reform Strategy

Dec 2007

“living with and beyond cancer.....” Chapter 5

“In partnership with cancer charities, clinicians and patients will consider a range of approaches to improving the services and support available for cancer survivors”

National Cancer Survivor Initiative Sept 2008

NHS & 3rd sector partnership

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SURVIVOR

Anyone living with or beyond
a diagnosis of cancer

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- Is there a need for change?
- Vision
 - 5 Key shifts

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Does the health economy meet these requirements?

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- The evidence suggests that current **follow up arrangements are not meeting the medical, psychological, social, spiritual, financial and information needs** that cancer survivors may have following their treatment.
- **Routine follow up appointments are not effective in terms of detection of recurrence.** In practice, the large majority of recurrences are detected either by patients themselves or on investigations which can be planned without a patient having to attend a clinic.

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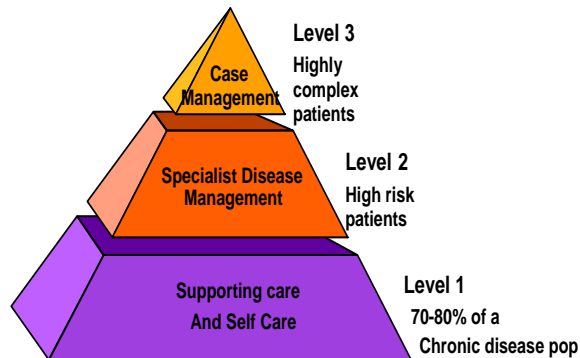
- Follow up strategies vary
 - Nationally, locally & within centres
- Is all follow-up necessary?
- Lack of capacity to continue model **4 million!**
- *Actually*

Not always necessary *empty episodes*
Not always convenient
Not personalised/risk stratified

N.C.S.I.

Risk Stratification

c.j.ham@bham.ac.uk
 Bonn conference



Service Transformation

- Quality
 - Enhanced access to information
 - Diagnosis, treatments, complications, risks, surveillance
 - Survivor & all components of health economy
 - Rapid access to specialist support & advice
- Productivity
 - Reduce unnecessary “empty” episodes
 - Automated surveillance
 - Seamless information exchange
 - 1^o, 2^o, 3^o care and service user
 - Risk stratification

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N.C.S.I and Service Transformation

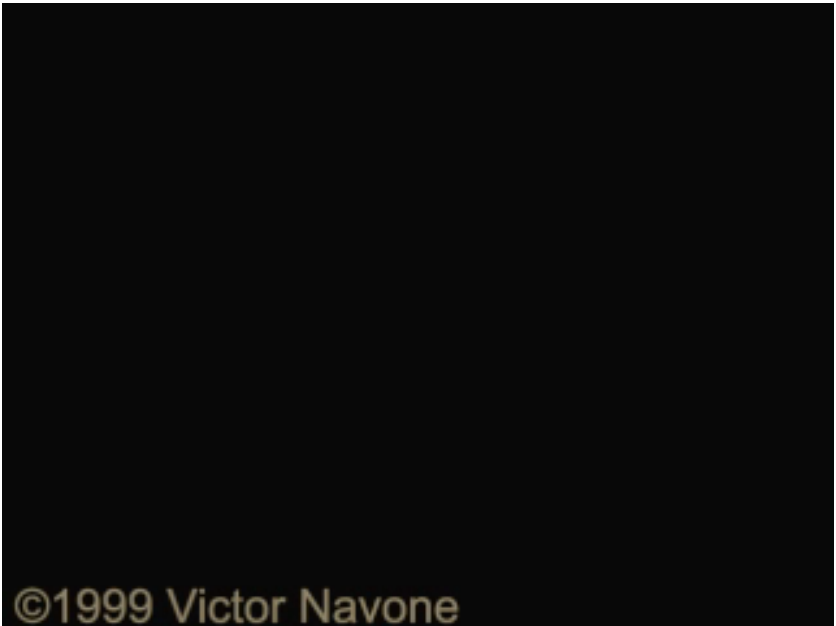
- Compatible with *Quality and Productivity* mantra
- Examine all aspects of follow-up care
 - Utility
 - Setting
 - Risk stratify
- Consider alternative strategies
 - Supported self management
 - Automated surveillance
- Explore alternative strategies & technology

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- Is there a need for change?
- N.C.S.I. Vision

5 Key shifts

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5 Key Shifts

- Cultural shift to focus on recovery, health and well-being after treatment
 - Shift towards assessment and personalised care planning based on individual risks, needs and preferences
 - Shift towards support for self-management
 - Supported self management
 - Shift from "one model fits all" clinical follow-up to a personalised information prescription and specialist support allowing early recognition of signs/symptoms secondary, recurrent or advanced disease
 - Shift from emphasis on measuring clinical practice to measuring experience and outcomes for cancer survivors through PROMS in aftercare services

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Focus on recovery, health & well-being after treatment

- Life following primary cancer treatment
- Can survive cancer
 - 5 year survival 78% children
 >60% adults
- May not be cured but can live for long periods
 - metastatic prostate cancer
- Need to help ensure we maximise the quality of survival

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Assessment, information provision and care planning

>25% cancer patients have
unmet needs a year after
treatment

Armes et al, JCO, 2009.



Every patient will have an assessment, information,
and a personalised care plan, so that their unique
needs can be met

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Current situation

2009 Picker survey of over 2,000 survivors:

- 43% wanted more information and advice
- 75% did not have, or did not know if they had, a care plan
- 75% did not know who to contact for advice outside of office hours.

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Testing impact of:

- consistent approach to assessment & care planning
- MDT communication to primary care (treatment summary record) at end of treatment
- templates for improving quality of GP Cancer Care review
- Health and Well Being reviews



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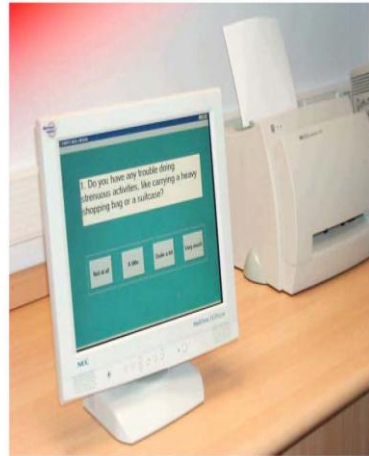
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Using self assessment tools to stimulate better conversations

Significantly better discussions between patients and both doctors and nurses when person affected by cancer has completed an electronic self assessment form

Velikova et al,2005



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Who are the two million cancer survivors?

Sex / Age / Site	Cancer survivors	%
Male	800,000	40
Female	1,200,000	60
0-17	16,000	0.8
18-64	774,000	38.7
Colorectal	250,000	12
Lung	65,000	3
Breast	550,000	28
Prostate	215,000	11
Other	920,000	46

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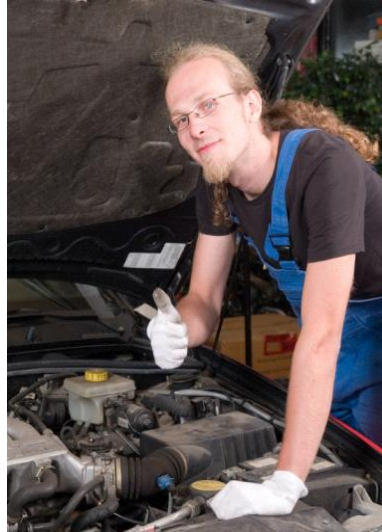
23

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Supporting patients return to work

- Testing model of vocational rehabilitation through pilots.
- Work underway in providing support for employers.
- Study into patient experience of DWP programmes.
- Developing thinking about carers' issues.



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5 Key Shifts

- Cultural shift to focus on recovery, health and well-being after treatment
- Shift towards assessment and personalised care planning based on individual risks, needs and preferences
- **Shift towards support for self-management**
 - **Supported self management based on individual needs and preference with appropriate clinical assessment and support**
- Shift from "one model fits all" clinical follow-up to a personalised information prescription and specialist support allowing early recognition of signs/symptoms secondary, recurrent or advanced disease
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Lifestyle change more important for cancer survivors than others



Obesity

Dietary fat intake



Exercise

Smoking



Health and well being clinics offer opportunities to learn more than how to manage their disease

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Shift from "Follow-up" to "Aftercare"

Level of need	Estimated % of patients (vary according to cancer, individual & treatment)	Currently
Level 1 – <i>supported self-care</i> with quick access back into the system if and when needed to improve early detection	c75%	(<10%)
Level 2 – level of requirement requiring <i>regular</i> primary or secondary care input	c 20%	(90%)
Level 3 – <i>highly complex patients requiring case management by an assigned key worker</i> (often a CNS) actively managing and "joining up" care for the patient	c 5%	(<1%)

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Tailored aftercare - consequences of treatment

- New illnesses may emerge months, years, decades after treatment.
 - >25 % adult survivors live with significant consequences of treatment
 - 60% childhood ca survivors experience 1 or more late effects 10y after Tx
- Reduce unnecessary follow-up
Increase support where needed
- Aim for
 - avoidable consequences to be avoided
 - unavoidable consequences to be recognised & managed to minimise their impact

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Personalised support for those with advanced disease

Requires

- Pathways for rapid re-entry into the system
 - self-referral
 - from primary care
- Planning by MDT
 - therapeutic options
 - transition to End of Life Care
 - timely involvement of palliative care
- Specialist services

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Patient Reported Outcome Measures (PROMS)

- Promote more effective interactions with professionals
- Trigger “information prescriptions”
- Monitor change
- Measure outcomes
- Identify & target populations with needs

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Next Steps

- Many of the changes required to improve care and support are already in use, others are being piloted.
- 38 pilot sites around the country, testing approaches to care and support
- Almost 80 centres involved

NCSI Test Communities

- Models of Care
- Children and Young People
- Assessment and Care Planning

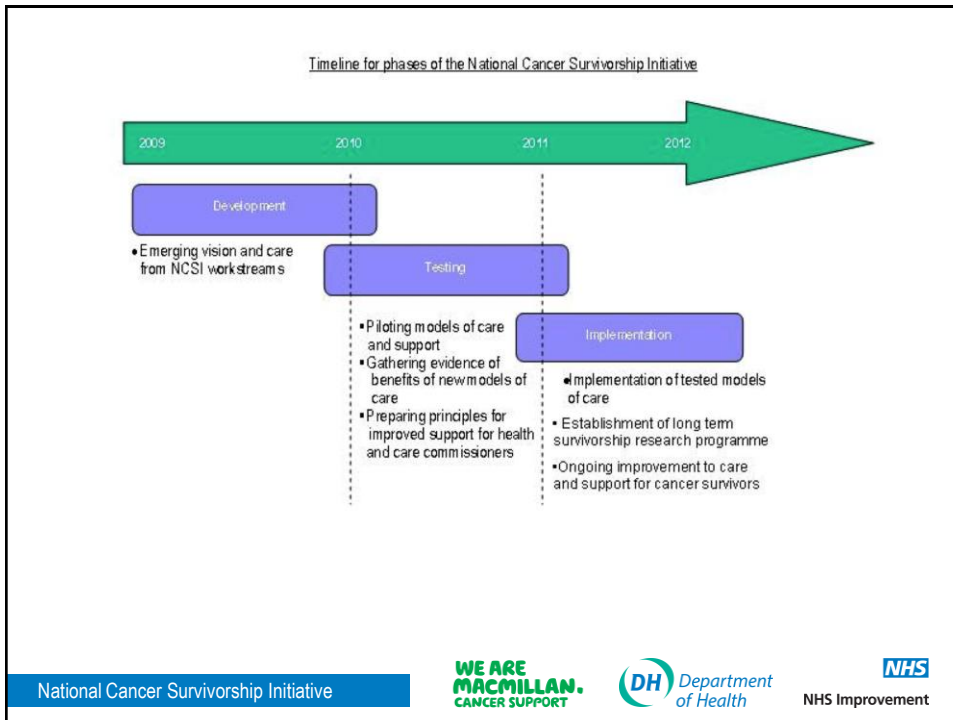


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5 Key shifts needed

Alien

- a greater focus on recovery, health and well-being
 - a shift towards *holistic assessment, information provision and personalised care planning*
 - a shift towards *support for self-management*
 - a shift to *tailored support for consequences of treatment, signs and symptoms of further disease*
 - a shift to a new emphasis on *measuring experience and outcomes*
- Help to look beyond the dance-floor
 - Support to think about itself
 - Engage to enable it to look after itself
 - Inform of risks of falling disco-balls
 - What did it all feel like for you?
 - Crushing?

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N.C.S.I.

- Clear vision and direction
 - 5 Key shifts
- 38 commissioned projects
 - extending to approximately 80 sites
- National support
 - Macmillan and other 3rd sector partners
 - NHS Improvement
- Significant investment (for at least 1 year more)
- *Exciting opportunity to transform the care and support delivered to the increasing numbers living with & beyond cancer*

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