
Survivorship and End of Life Care Research: How should we move forward?

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Context

- Where have we come from?
- What progress have we made?
- Current drivers for change
- Thoughts on the future

Where have we come from? (1)

Psychosocial Research



Supportive and Palliative Care



Survivorship and End of Life Care

Where have we come from? (2)

NCRI Strategic Planning Group report (2004)

- Research outputs second to USA, but behind some other European countries when adjusted for population size (i.e. quite good, but could do better)
- Dispersed academic workforce (over 40 locations)
- Most academic units lacked critical mass and interdisciplinary working (e.g. psychology, social sciences, nursing, palliative medicine, oncology)

What progress have we made?

- Establishment of 2 research collaboratives
- Some dedicated funding (e.g. for lung cancer research)

Current drivers for change

- Policy developments
 - Cancer Reform Strategy
 - End of Life Care Strategy
- Interests of potential major funders
 - Cancer Research UK
 - Macmillan Cancer Support
 - Marie Curie Cancer Care
 - NIHR
 - ESRC and MRC
- The financial downturn

Policy developments: Cancer

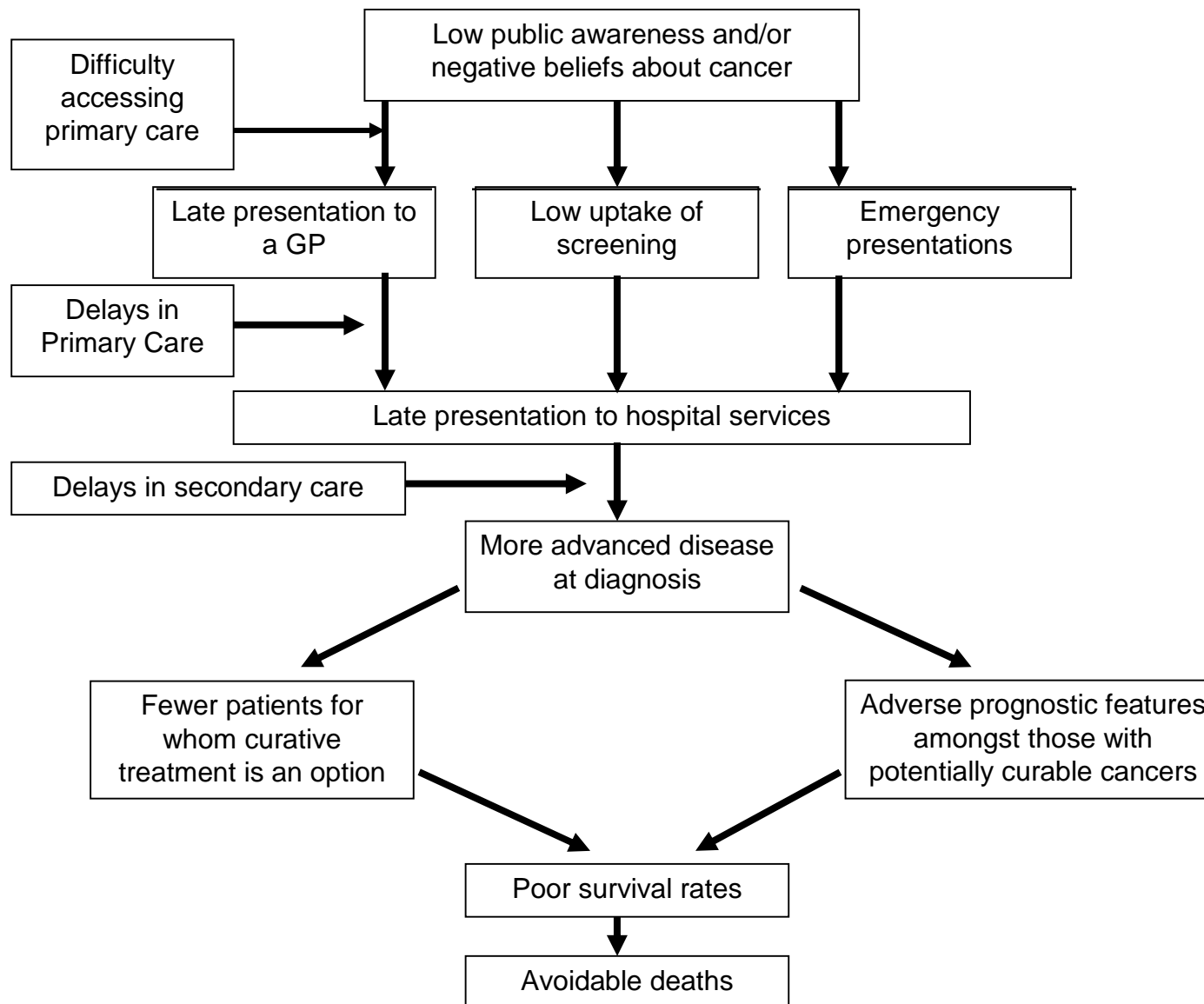
- The main focus of the NHS Cancer Plan (2000) was on:
 - Building capacity (workforce, equipment, funding etc.)
 - Establishing MDT working
 - Reconfiguring services where necessary to give critical mass
 - Tackling long waits
 - Expanding screening (breast and bowel)
 - Increasing investment in specialist palliative care
- The Cancer Reform Strategy puts a new emphasis on what happens before referral (NAEDI) and what happens after primary treatment (survivorship)

National Awareness and Early Diagnosis Initiative (NAEDI)

Rationale

- Late diagnosis is likely to account for a large part of the gap in survival between the UK and other developed countries – and for much of the gap in survival between rich and poor (and probably for the gap between ethnic groups)
- Reasons for late diagnosis in the UK are less clearcut (e.g. patients delays, doctor delays, system delays or combinations)
- Very little is know about how best to promote earlier diagnosis
- but ... over 90% of cancer patients presents symptomatically – so it matters

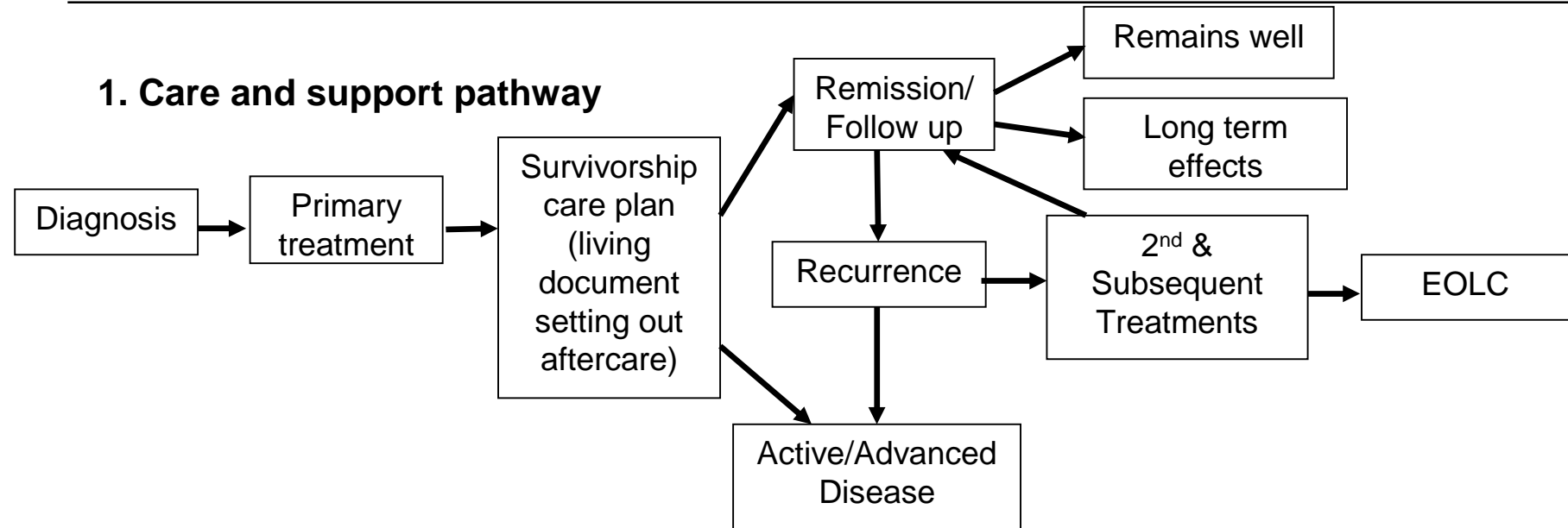
NAEDI Pathway



National Cancer Survivorship Initiative (NCSI)

- ‘Survivorship’ terminology is now well established in the USA – and becoming so in the UK (though with mixed views)
- Patients are ‘survivors’ from diagnosis to death, but NCSI will largely focus on interval between end of primary treatment and start of ‘end of life’ care
- NCSI is still in its infancy

Survivorship Care Pathway



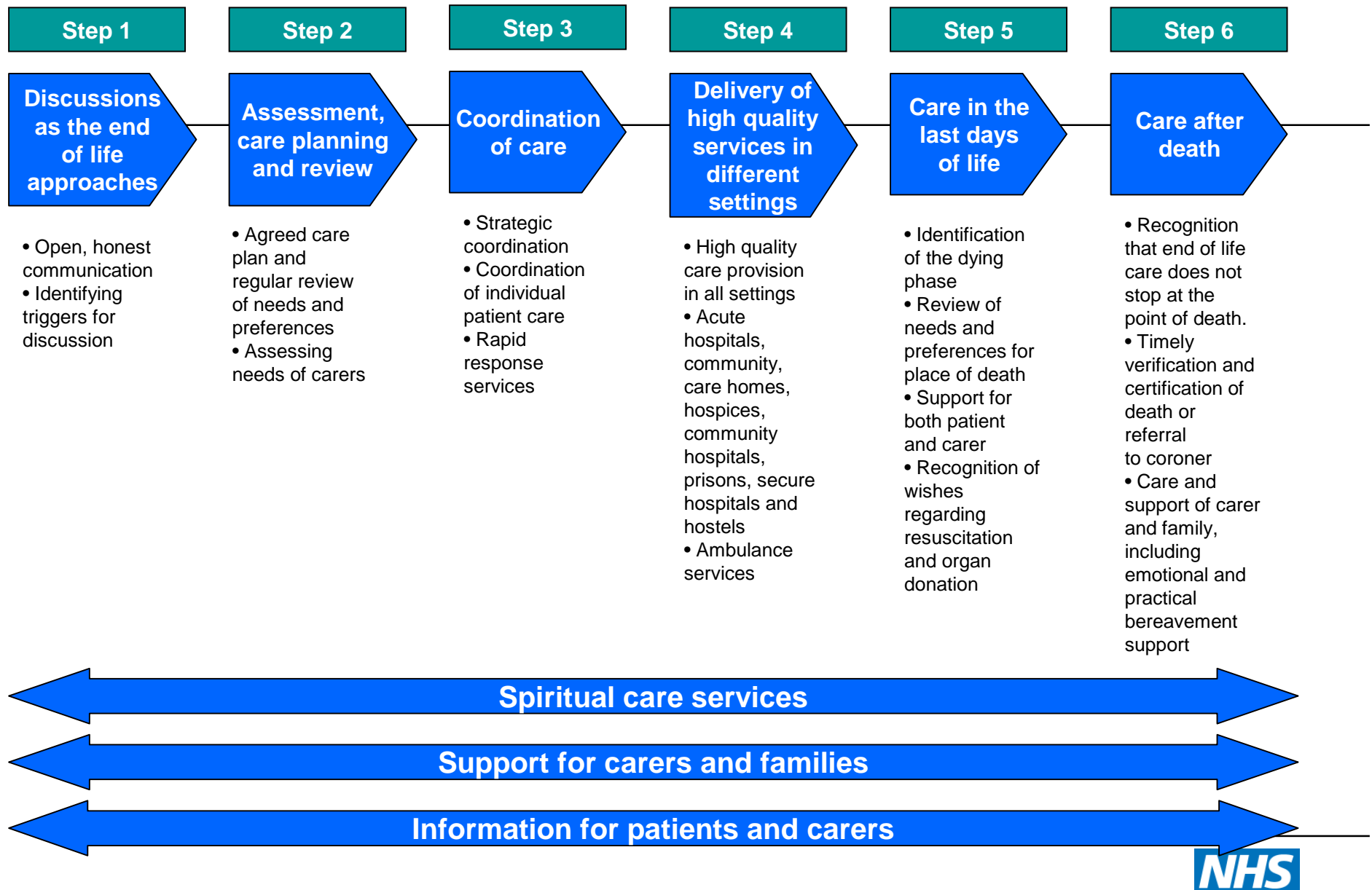
Cross cutting themes:

Work, education, finance, self management, information, commissioning, research

End of Life Care Strategy (2008)

- Builds on 2005 government manifesto commitment (to improve choice at the end of life and double investment in palliative care)
- Covers all conditions and all settings
- Emphasises importance of societal attitudes to death and dying
- Presents an end of life care pathway to focus thinking about what needs to be done

The End of Life Care Pathway



Future research: Some early thoughts

- Align with the policy agendas (e.g. NAEDI, Survivorship, End of Life Care)
- Many service developments will be implemented by PCTs, cancer networks and others 0 these developments will need to be evaluated. How can we best bring ‘developers’ and ‘evaluators’ together?
- Major research efforts should focus on areas where:
 - The absence of knowledge is hampering improvements in care delivery
 - Interventions are likely to be costly (e.g. to the NHS) or could potentially do harm to patients

Potential research themes: NAEDI

- Patient delays
 - What is the frequency/extent of patient delay?
 - How are public awareness and beliefs about cancer related to early/late presentation?
 - What interventions will lead to earlier presentation (without flooding GPs surgeries)?
- Primary care delays
 - What is the frequency/extent of primary care delay?
 - What are the barriers to earlier diagnosis?
 - How can we best help GPs to investigate/refer appropriately?
- International comparisons
 - Why are survival rates in the UK poorer than those in other countries?

Potential research themes: Survivorship

- Prevalence and well being of survivors
 - How many of the 2 million cancer survivors in the UK are in different states (remission; active/advanced disease; end of life) and what is their QOL?
 - Late effects
 - Incidence, prevention, early identification, management
 - Active/advanced disease
 - What models of care work? How should MDTs function for patients with advanced disease?
 - Supported self management: What works?

Potential research themes: End of Life Care

- Societal attitudes towards death and dying
 - What are they now?
 - Can they be modified?
- Managing transitions
 - Long term conditions → end of life care
 - End of life care → dying
 - Childhood → adult
(prognostication; communication)
 - Support for carers (including bereavement)
 - Spirituality
 - Evaluating new services (e.g. coordination centres; EOLC registers; discharge nurses etc.)