

National Cancer Survivorship Initiative

Clinical Outcomes and NCIN/COSD

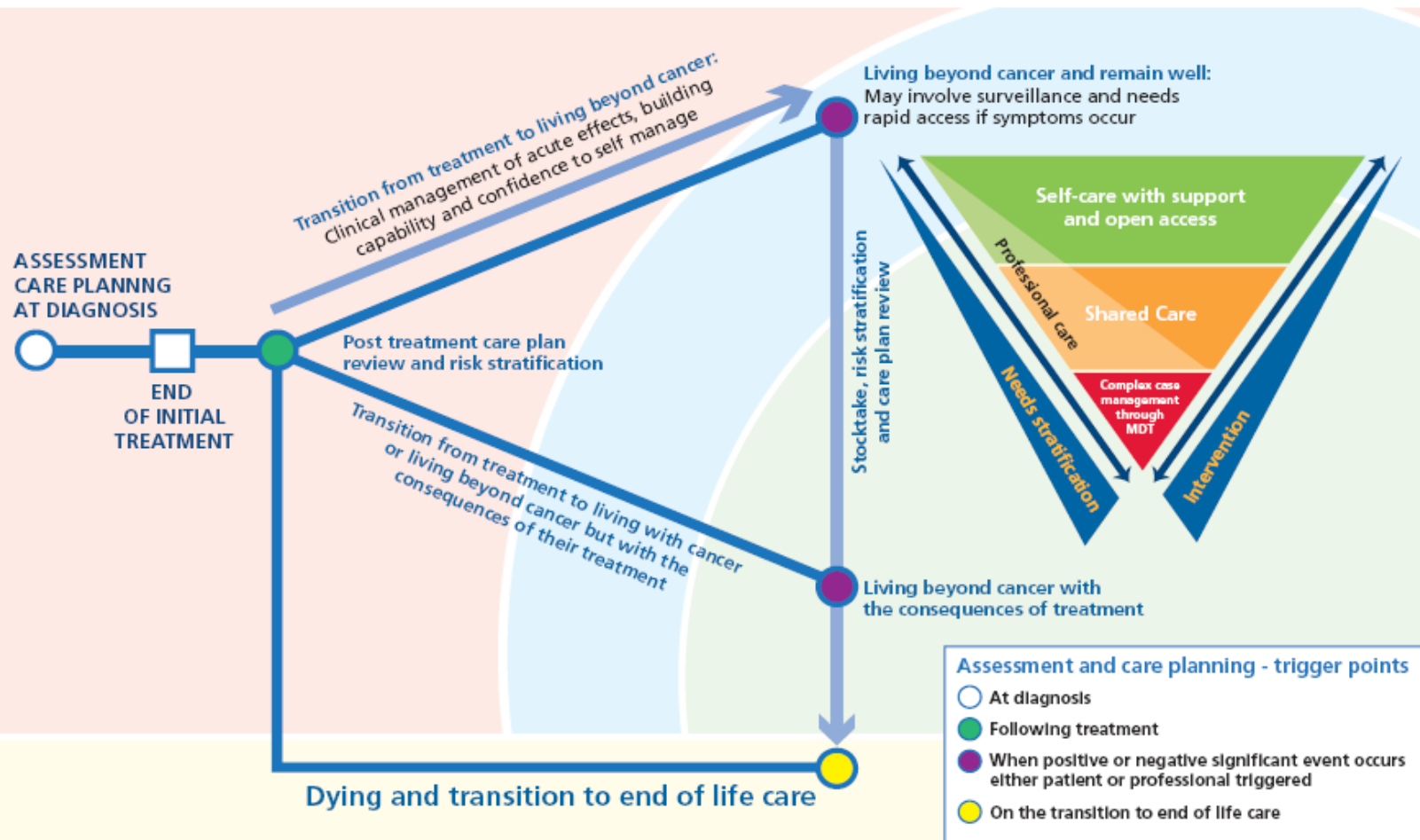
Adam Glaser

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NCSI GOALS by 2015

- Tested survivorship pathways *adult/CYP*
Demonstrated QIPP benefits of new models of care
- National Patient Reported Outcome Survey and wide local routine use of PROMS
- Developed best practice guidelines for late effects of cancer treatment
- Develop best practice guidelines for active and advanced disease
Routine collection of recurrence and metastatic data
- Quality Standards including key indicators of quality survivorship care
Commissioning guidance and payment mechanisms which incentivise high quality personalised care following cancer treatment

Model of Care: Living With and Beyond Cancer



PATHWAY WORK

Establish proof of principle that risk-stratified pathways:

1. Enhance quality of care delivered
2. Enhance support for those with currently unmet needs
3. Remove empty episodes from the care pathway
Free up time and resources for service users and providers
4. Reduce routine OP and unplanned hospital activities

Enablers

- Automated remote surveillance
- Care co-ordination

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Quality Standards & Clinical Outcome Data

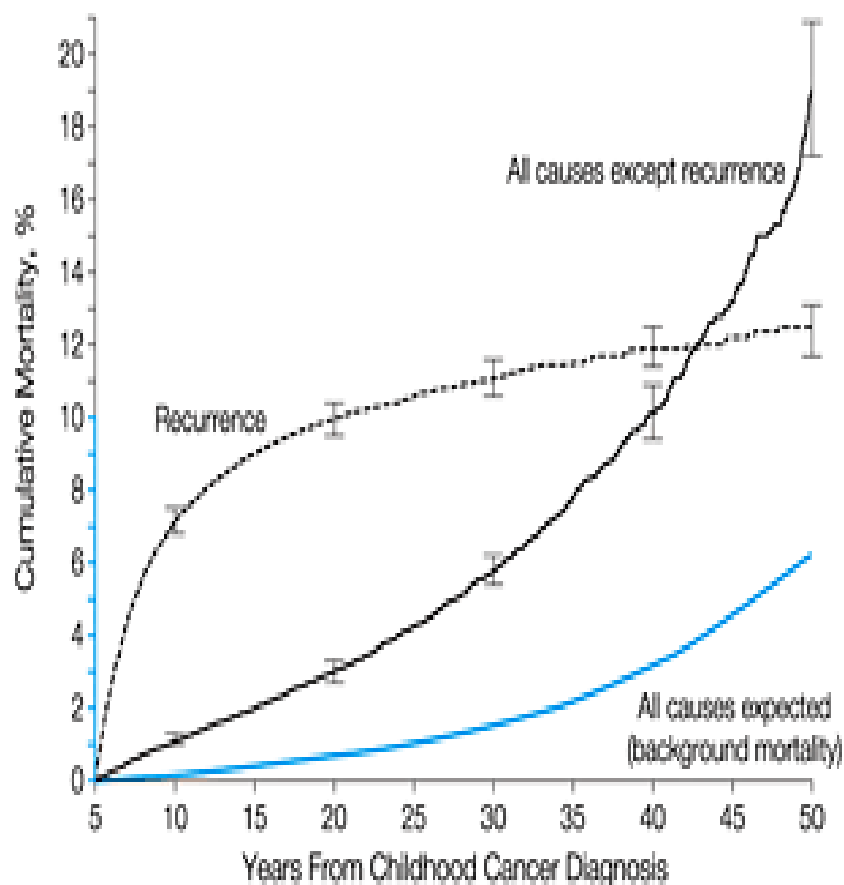
Systematic evaluation of outcomes

- Recording of chemotherapy, radiotherapy, surgery data
- Recording of key clinical outcomes
 - recurrence and metastatic data
 - routine collection of SMN data
 - long term toxicities
 - social function

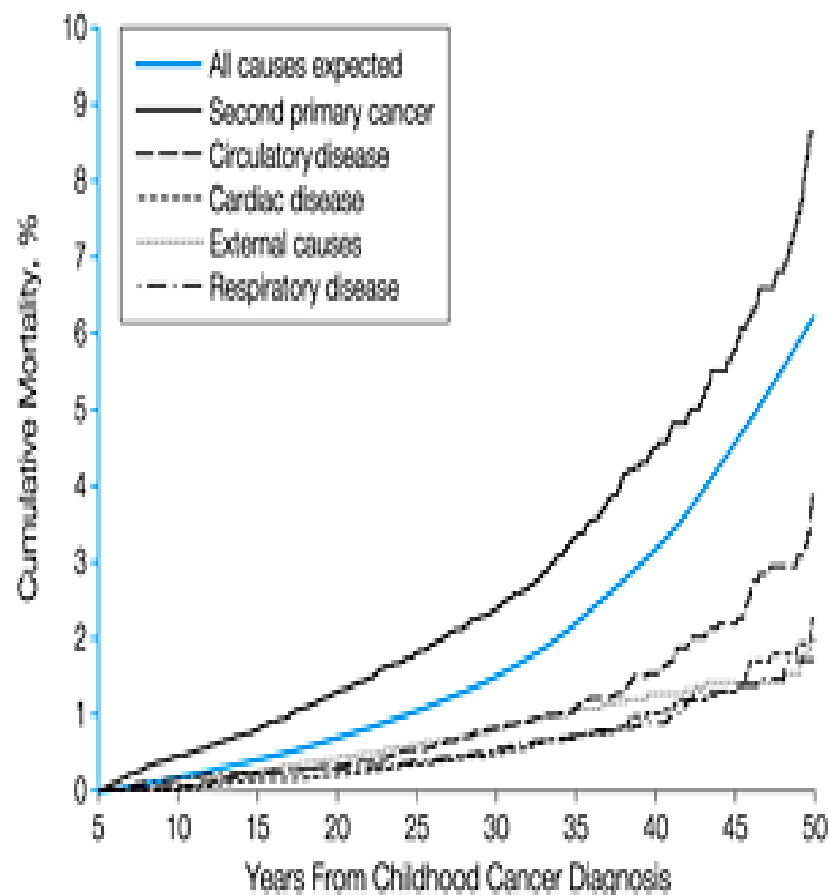
Clinical Outcome Data & long term toxicities

- What to record?
- Need for realism/pragmatism

BCCSS entire cohort causes of death Reulen et al 2011 JAMA



No. at risk 17981 16631 16012 12673 9176 6264 3807 2304 1034



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Clinical Outcome Data & long term toxicities

- What to record?
 - Need for realism/pragmatism
 - Proposal: Record morbidity burden linked to excess mortality
 - Second primary malignant neoplasm 50% excess mortality
 - Circulation/cardiac 25% excess mortality
 - Pulmonary 15% excess mortality
- Reulen R, 2011 JAMA*
- Proposal: Record non-fatal morbidity burden
 - Endocrine

Quality Standards & Clinical Outcome Data

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Clinical Outcome Data & Social Function

Chapter 5 Improving Outcomes: A Strategy for Cancer

- Reducing % survivors with unmet physical, psychological, social support needs
- % cancer survivors able to live independently
- % survivors able to work
- % survivors CYP cancer in education/employment

Clinical Outcome Data & Social Function

- Domains
 - Live independently
 - Able to work
 - Education/employment
- What to record?
 - Same questions as General Household Survey
 - Normative data available
- Mechanism for data collection?

National Cancer Morbidity Surveillance Programme

- Robust infrastructure for the early detection of, and consequent reduction in late mortality from, known secondary health events arising as a consequence of survival from malignancies
- COSD
 - identify individuals at risk
 - Store population based late-effects data within COSD
- NHS Cancer Screening Programme
 - Provision of logic, expertise and framework for systematic surveillance
- Cancer Treatment Centres, Primary Care Providers
 - Co-ordinate local care pathways for surveillance /management of identified events

COSD and Clinical Outcomes

- Opportunity but need to be pragmatic
- Possible Levers:
 - Quality Standards/Improving Outcomes: A strategy for Cancer
- Potential Fields
 - Easy
 - Treatment data
 - Recurrence, second primary malignant neoplasms
 - Harder
 - Cardiac/pulmonary/endocrine data
 - Much Harder
 - Social function: education/employment/independent living
- Unresolved: Mechanism of data capture