

**UKONS Living With and
Beyond Cancer
July 3rd 2009**

Stephen Hindle
Cancer Survivorship Programme Lead

**WE ARE
MACMILLAN.
CANCER SUPPORT**

The number of people living with cancer in the UK on 31 Dec 2008 was. . .

2 MILLION

Who are the 'cancer survivors'?



Who are the two million cancer survivors?

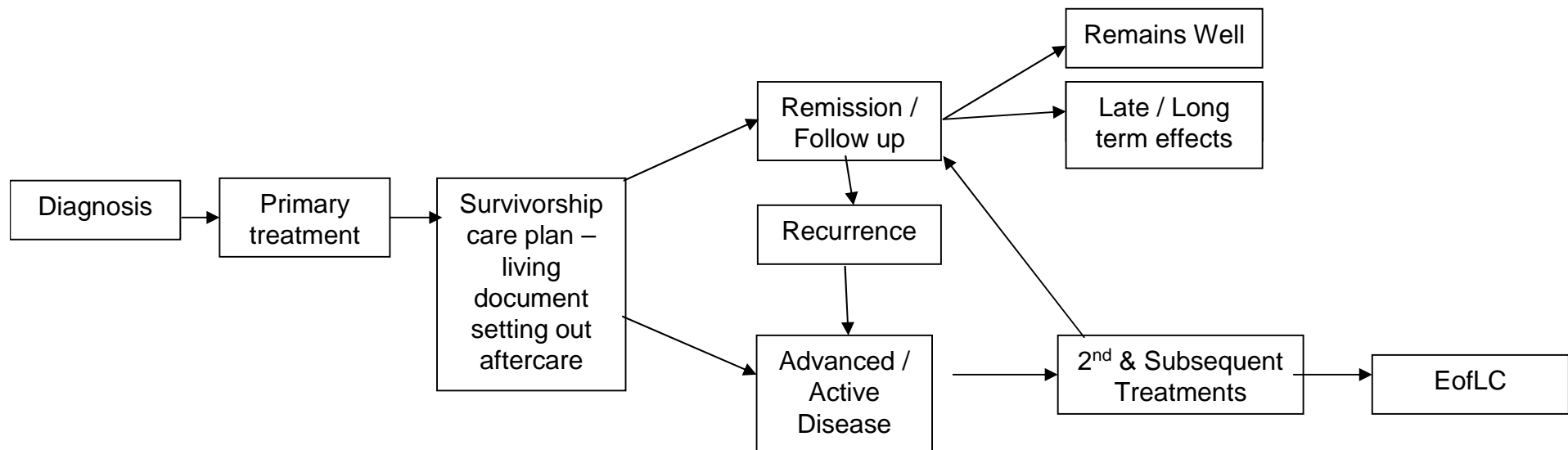
Sex / Age / Site	Cancer survivors	%
Male	800,000	40
Female	1,200,000	60
0-17	16,000	0.8
18-64	774,000	38.7
65+	1,210,000	60.5
Colorectal	250,000	12
Lung	65,000	3
Breast	550,000	28
Prostate	215,000	11
Other	920,000	46

People with cancer have told us what the issues are . . .



In England, a National Cancer Survivorship Initiative has been launched:

Survivorship Care and Support Pathway



Crosscutting themes of work/education, finance, self management, research, information, commissioning

We have six expectations of NCSI

- A document describing our vision of the care of people living with or beyond cancer
- A supporting implementation plan
- A set of models of care which we have piloted and we know work, which will be commissioned by PCTs and practices
- Acceptance of 'survivorship' as a priority for patients
- Translation of the vision into action at a local level, using approaches similar to those tested
- A community of interested people who will continue to lead this agenda

Assessment, Care Planning & Immediate Post Treatment Approaches to Care

Ciaràn Devane

- Development of treatment summary record framework to be completed by acute consultants and sent to GP practice.
- Development of survivorship assessment framework for adults, and links with Common Holistic Assessment Framework and Common Assessment Framework
- Evaluation of GP 6 month review
- Drafts will be reviewed, once draft agreed, will go to test sites for piloting, evaluation planned.
- Will consider existing models and pilot alternative models of Follow Up

Managing active and advanced disease

Roger Wilson

- Roles and responsibilities of MDTs in active and advanced disease;
- Supporting GPs in management of referral for suspected recurrence
- Transitions from active disease to end of life care;
- Testing and evaluating models of care co-ordination
- Patient-centred practice and developing a working definition;
- Improving well-being eg improved access to appropriate exercise;
- Defining different patterns / phases and needs of patients at different phases

Consequences of cancer treatment

Jane Maher

- Mapped natural history of bowel, urinary and sexual problems after pelvic radiotherapy, initial draft recommendations re management of such patients
- Scoping impact of cancer on osteoporosis and heart disease
- Examine issue of lymphoedema
- Manchester project completed baseline mapping beginning testing
- Established framework for managing late effects
- Set up 7 clinics for 30 RAGE members.
- Review of external data sources
- Evaluation of web base information tools

Children & Young People

Carole Easton

Testing models around:

- Development of Survivorship Treatment Plans
- Development of Survivor Pathways with focus on key stages
- Appropriate follow-up models – inc shared care & nurse led FU
- Identifying patients at low, medium and high risk of late effects
- Continuing support of education needs
- Dealing with non-clinical issues to ensure ‘normal’ life following diagnosis and treatment.
- 9 test sites currently mapping baselines.

Self care and self-management

Jessica Corner

Commissioned and completed:

- “Self management support: a review of evidence”
- “Framework for commissioning self management support”, a resource for providers and commissioners
- “Review of H QoL outcomes measures for self management interventions”, to inform evaluation design
- Planning underway to test a ‘whole systems’ approach to implementation of self management.

Work and Finance Barbara Wilson

- Vocational rehabilitation sub group developed draft model of vocational rehabilitation
- Work underway in providing support for employers.
- Identified funding for large scale population study of work and cancer.
- Study being commissioned into patient experience of DWP programmes.
- Developing thinking about carers' issues.

Research John Neate

- Review of evidence (published and non-published) underway
- ‘Survivorship journey’ for common cancers mapped – breast, prostate, lung and colorectal.
- Currently identifying survivorship journey for rarer cancers with Cancer 52.
- Meeting with potential funders identified research interests.

NCSI Test communities:

Gilmour Frew, Adult, NHS Improvement Director

Patricia Morris, C&YP, NHS Improvement Director

- NHS Improvement running adult and children test community sites across England and Wales
- Testing new approaches to integrated health and social care, including assessment and follow up
- Adults – currently seventeen sites running over thirty test communities
- Children and young people – nine test sites
- Will review impact through evaluation and patient experience measures.

Living with and beyond cancer in Wales

- Influenced Welsh Cancer Strategy (2008) – ‘Designed to Tackle Cancer in Wales’ to focus on needs of survivors & carers
- Worked with Welsh Assembly Government to develop Cancer Rehabilitation Standard

Northern Ireland:

- Worked to influence Cancer Service Framework (due Q3 2009) , now includes specific survivorship section
- Recruiting Rehabilitation Lead

Living with and beyond cancer in Scotland

‘Better Cancer Care’ plan :

- joined up provision of services for cancer and other long term conditions
- involving the NHS, local government and the likes of Macmillan
- building on existing (sustainable) services,
 - Specialist benefits advice in every local authority
 - Cancer information through libraries in the Highlands
- making self-management strategy work for cancer patients
- signposting as an integrated part of the patient pathway (information prescriptions)