Information for Patient Benefit

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Chief Executive

Macmillan Cancer Support

Information for patient benefit

**National Cancer Intelligence
Network Launch Event 18 June 2008**

Ciarán Devane - Chief Executive

What I'm going to talk about…

- **What do cancer patients want to know that the NCIN could provide?**

- **What is the scope of the Survivorship Initiative and what are the intelligence needs?**

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What are the cancer intelligence needs of patients and their families?

Information to support decision making

at every stage of the cancer journey

to remove fear/give control

medical and non-medical

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What are the cancer intelligence needs of patients and their families?

- **How should one be treated, where, and by whom?**

- **What is the quantity and quality of my life to be:**
  - **As someone of my age**
  - **At my stage of disease**
  - **Living in my area**
  - **Receiving the same treatment I have had**

- **What are the side effects / late effects of my treatment?**

- **What are the effects of comorbidities?**

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What are the cancer intelligence needs of patients and their families?

- **What can I do to improve my well-being?**

  secondary prevention

  complementary approaches

- **What is the risk for my children?**

  genetic
  lifestyle

- **How do I cope with daily living?**

  provision of services

  effective self-help

- **Am I getting the best treatment at the end of my life?**

What can the NCIN do to help?

- **Provide patients and families with easy to understand answers to their questions about treatment, survival and quality of life**

- **Link data from different sources – patient outcomes and statistics**
  - **To support assessment and care planning**
  - **To predict likelihood of recurrence**
  - **To predict likelihood of late effects**
  - **To design pathways and follow-up**

- **Link social care data and health care data to understand the whole patient/person experience**

The National Cancer Survivorship Initiative will develop medical and non-medical care plans along the whole cancer journey

Making the Cancer Survivorship Agenda a Reality
Think Tank Event
Cumberland Lodge March 10 – 11th March 2008
Report for Think Tank Event Participants

Six streams will develop and test models of care and support

Assessment & care planning

Managing active & progressive disease

Late effects

Children & young people

Work and finance

Self management

Research

Cross-cutting themes
(Information/workforce/ commissioning)

Research required will include prevalence modelling. . .

How many people are living with a cancer diagnosis in the UK ?

Who are they ?

How well are they ?

How many cancer survivors are there?

- **Current estimate is well over 1.2 million in the UK**

- **Prevalence is set to increase in coming years as**
  - **Incidence rises**
  - **Survival rates rise for most cancers**

- **The Thames Cancer Registry and Macmillan currently updating UK prevalence for announcement mid-July**

- **Updated annually**

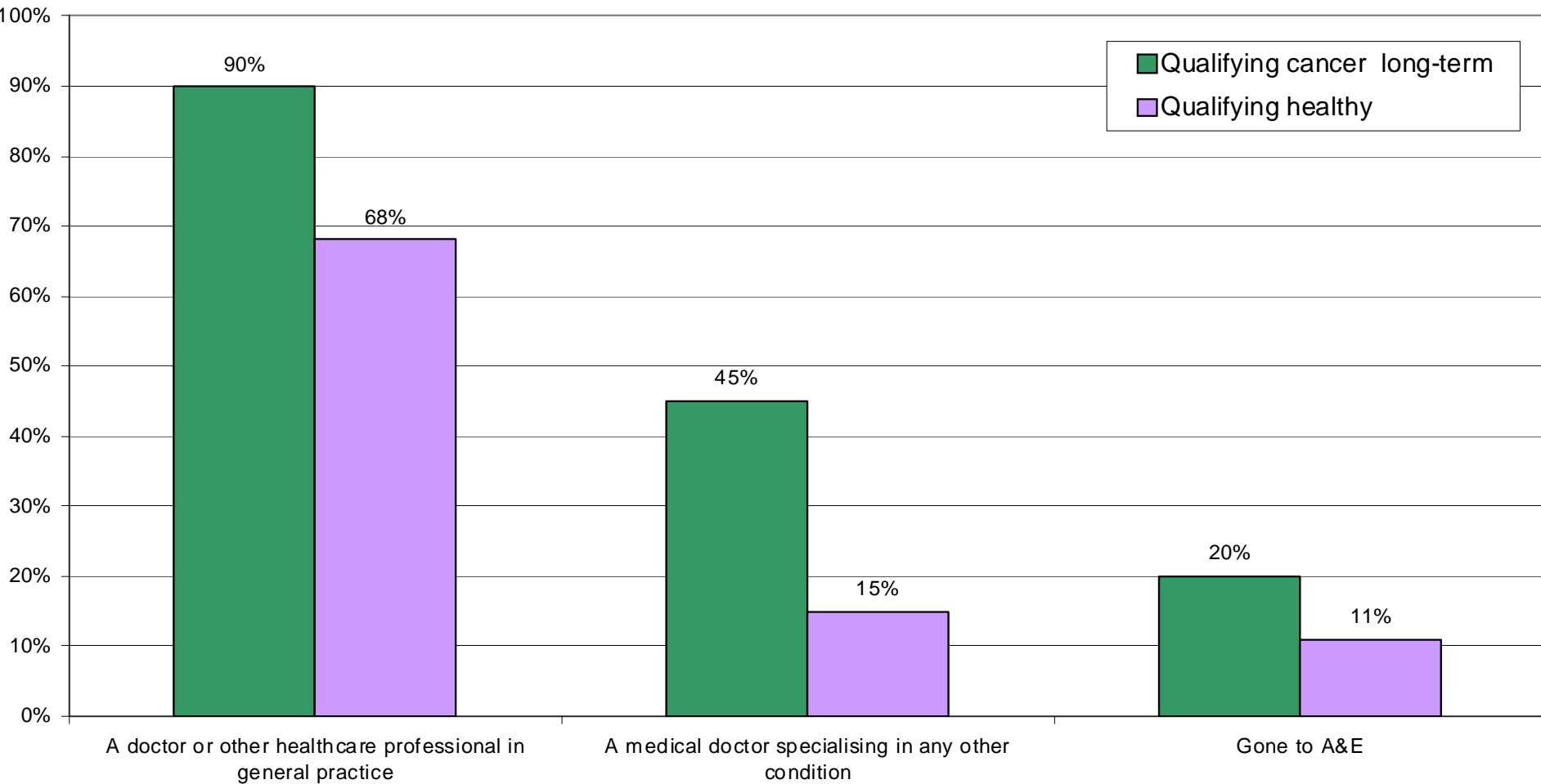# We need patient experience data in health and social care

The natural history of patient experience for each cancer

What is happening to the 'typical' patient/survivor

What is happening to the 'atypical' patient/survivor

We need greater insight into the health of survivors . . .

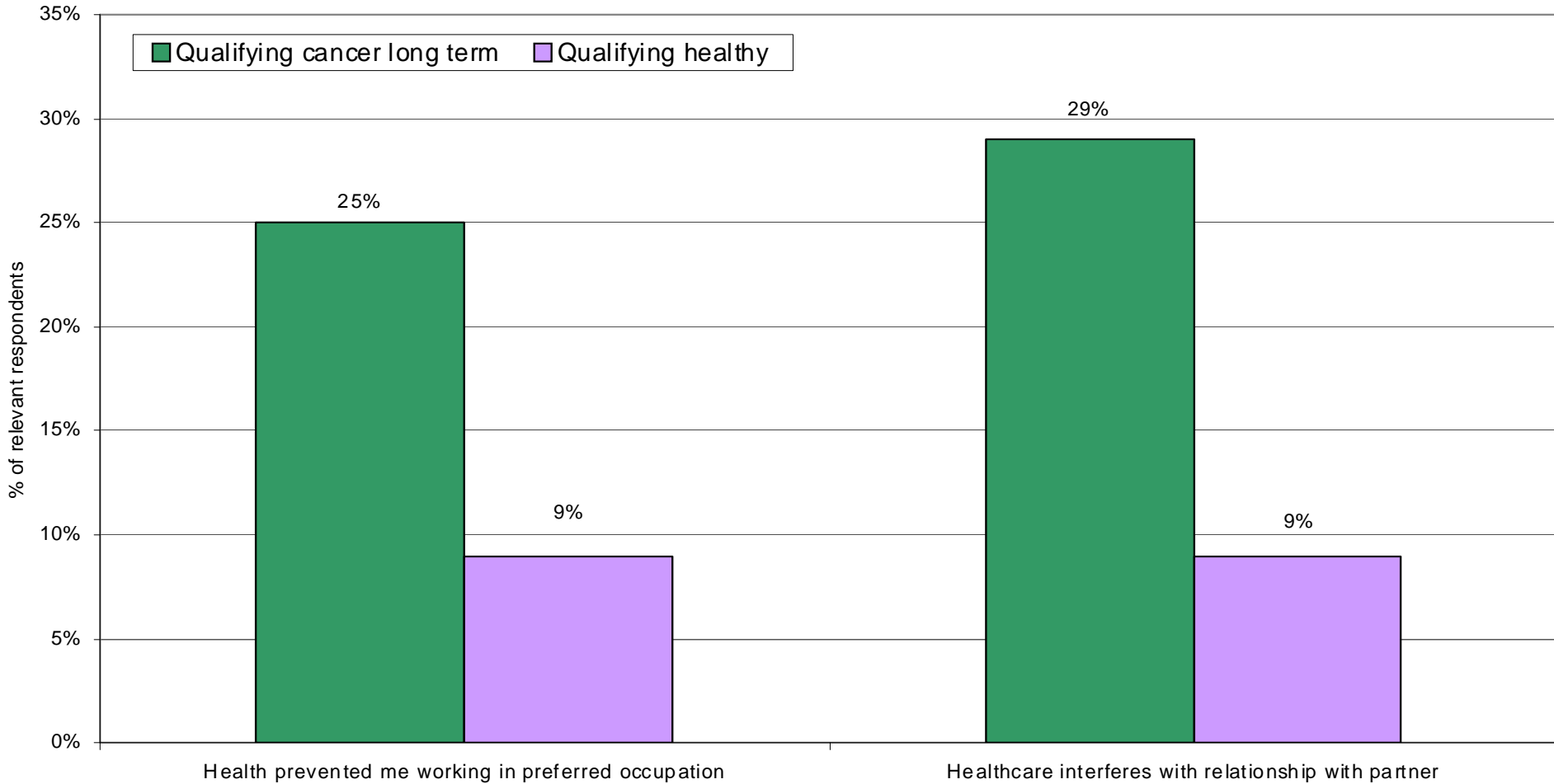**Which of these have you seen/talked to about your health / done in the last 12 months?**

Source - Macmillan Health and Well-being Survey 2008

and also into the social impact of their health

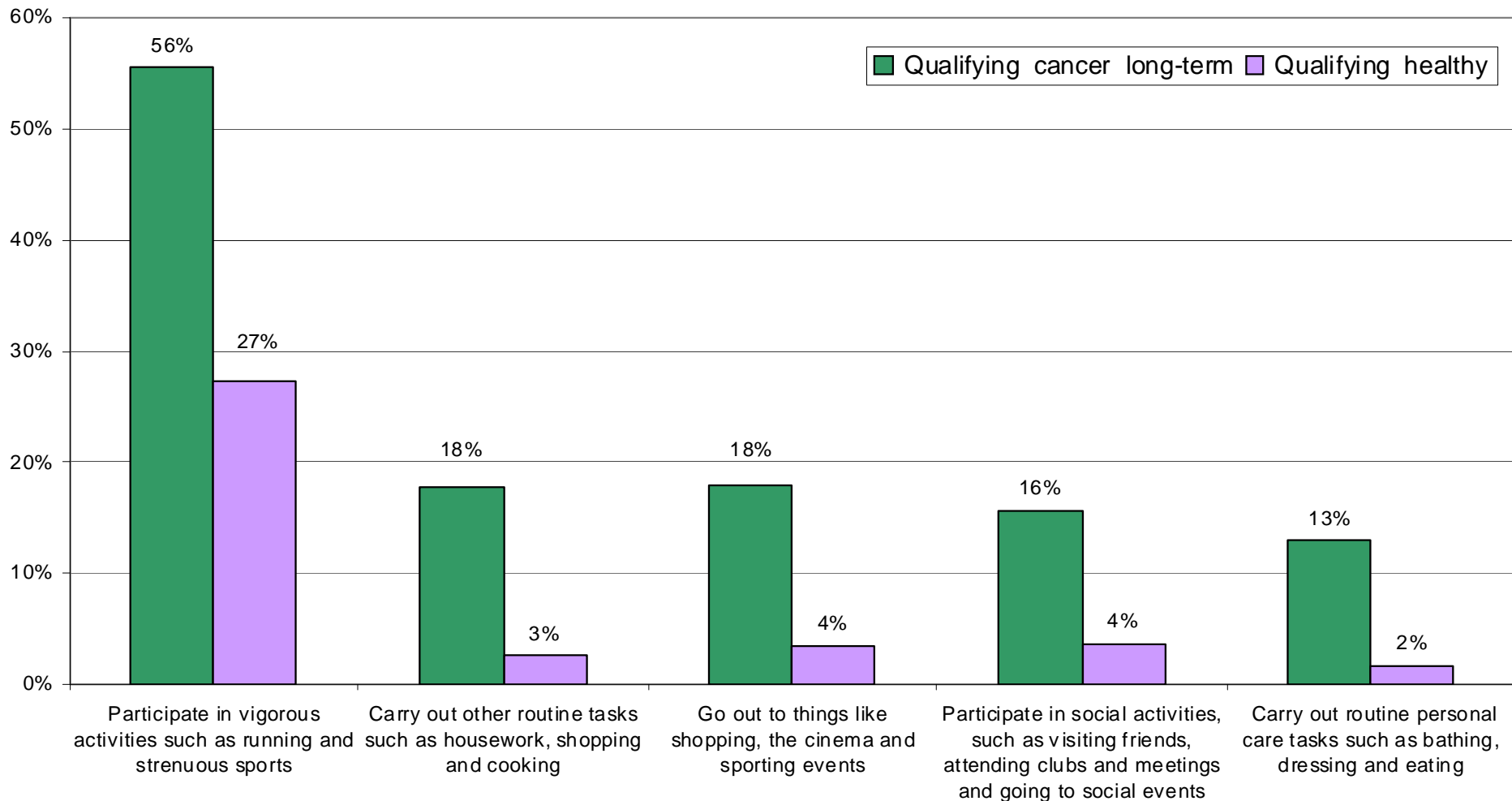**% who agree strongly or slightly with statements**

NB: statement about relationship only asked of those in a relationship

We have insufficient insight into social support needs

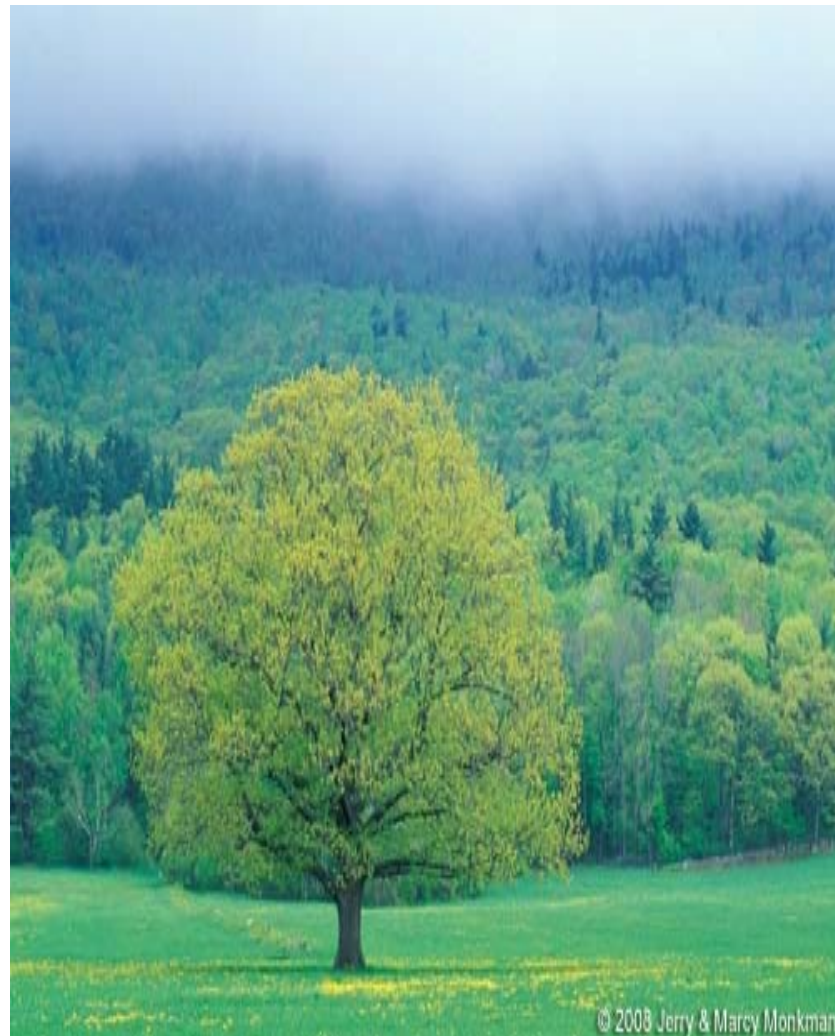## % finding ... somewhat difficult/very difficult/cannot do at all

Legend: ■ Qualifying cancer long-term ■ Qualifying healthy

Activity	Qualifying cancer long-term	Qualifying healthy
Participate in vigorous activities such as running and strenuous sports	56%	27%
Carry out other routine tasks such as housework, shopping and cooking	18%	3%
Go out to things like shopping, the cinema and sporting events	18%	4%
Participate in social activities, such as visiting friends, attending clubs and meetings and going to social events	16%	4%
Carry out routine personal care tasks such as bathing, dressing and eating	13%	2%

We need data to help patients make good decisions . . .

and to help the NCSI develop supportive models of care

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THANK YOU

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