

Data to Insight to Change

MDT Conference, March 2010

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Cancer Services at Macmillan
Cancer Support

Data → Insight → Change

- Recent data from NCIN
- Linking prevalence data with other datasets and insights
- The challenge of increasing prevalence
- 5 Key shifts in Survivorship
- Macmillan's Manchester work on health economics
- The Prime Minister's announcement.....

2 MILLION

Who are the two million cancer survivors?

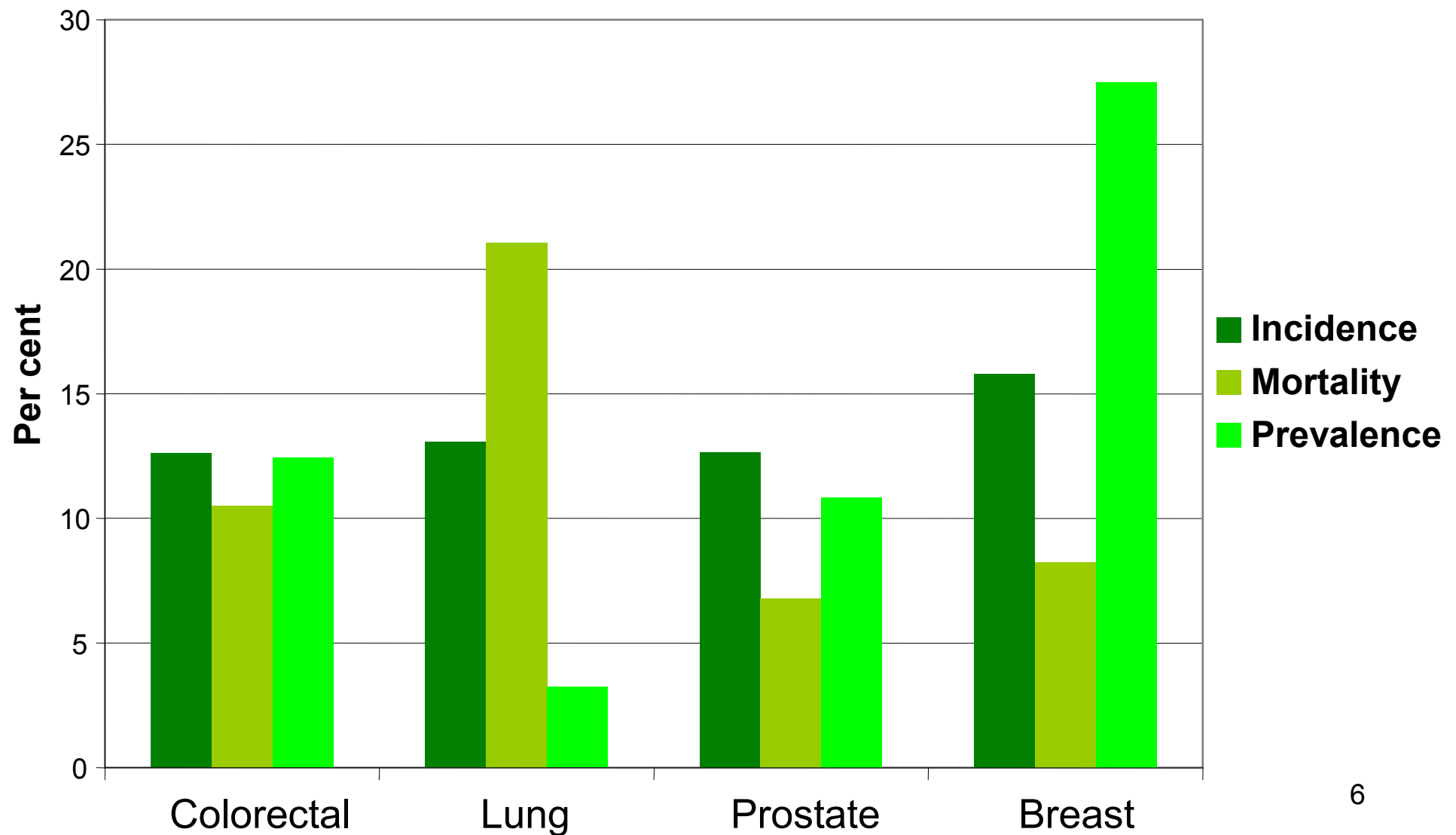
Sex	Cancer survivors	%
Male	800,000	40
Female	1,200,000	60

Age	Cancer survivors	%
0-17	16,000	0.8
18-64	774,000	38.7
65+	1,210,000	60.5

What cancers are they living with?

Cancer Site	Cancer survivors	%
Colorectal	250,000	12
Lung	65,000	3
Breast	550,000	28
Prostate	215,000	11
Other	920,000	46

Prevalence by site differs from incidence and mortality by site



What are the NCIN priorities ?



**Variability/ postcode
lotteries**

**The whole pathway;
use of resources
(HES)**

Then we need to link prevalence data with other data sets and insights . . .

- 90% survive early stage bowel cancer
- 1.25 million people have made it past 5 years
- 150 000 people die of cancer each year
- GP education doubles urgent referral for bowel cancer
- 71% of people those in the 10+ years cohort report physical and emotional problems
- Good Community palliative care allows 80% to die where they choose

And we need to link the prevalence data with what we know about health and wellbeing and health economics (count the cost)

- Use of Primary Care in the last 12 months by cancer survivors was 90% (wider population 68%)**
- Use of specialist doctor 45% (wider pop 15%)**
- A&E 20% (wider pop 11%)**
- Prevented from working in preferred occupation 25% (9%)**



Patients' Supportive Care Needs Beyond the End of Cancer Treatment: A Prospective, Longitudinal Survey

Ju Anna, Maggie Crowe, Lynne Callaway, Helen Morgan, Trevor Murray, Catherine Oakley, Nigel Palmer, Brian Rouse, Annie Young, and Alison Richardson

ABSTRACT

Purpose To estimate prevalence and severity of patients' self-perceived supportive care needs in the immediate post-treatment phase and identify predictors of unmet need.

Patients and Methods A multicenter, prospective, longitudinal survey was conducted. Sixty-six centers recruited patients for 12 weeks. Patients receiving treatment for the following cancers were recruited: breast, prostate, colorectal, and gynecologic cancer and non-Hodgkin's lymphoma. Measures of supportive care needs, anxiety and depression, fear of recurrence, and positive and negative affect were completed at the end of treatment (T0) and 6 months later (T1).

Results Of 1,850 patients given questionnaire packs, 1,435 (78%) returned questionnaires at T0, and 1,152 (62%) returned questionnaires at T1. Mean age was 61 years, and most respondents were female (85%) and had breast cancer (57%). Most patients had no or few moderate or severe unmet supportive care needs. However, 50% reported more than five unmet needs at baseline, and for 60% of these patients, the situation did not improve. At both assessments, the most frequently endorsed unmet needs were psychological needs and fear of recurrence. Logistic regression revealed several statistically significant predictors of unmet need, including receipt of hormone treatment, negative affect, and experiencing an unwanted significant event between assessments.

Conclusion Most patients do not express unmet needs for supportive care after treatment. Thirty percent reported more than five moderate or severe unmet needs at both assessments. Unmet needs were predicted by hormone treatment, negative mood, and experiencing a significant event. Our results suggest that there is a proportion of survivors with unmet needs who might benefit from targeted application of psychosocial resources.

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INTRODUCTION

For many cancer survivors, there is growing recognition that they need support during the immediate post-treatment phase of their illness.¹⁻³ Although completion of treatment is eagerly anticipated,^{4,5} it is also a time of transition, a period between end of treatment and long-term survivorship (> 5 years).⁶ Limited evidence suggests that patients are dissatisfied with care received at this time, as support from oncology professionals falls off with little concomitant increase in alternative support.^{7,8}

Estimating quality of life (QoL) is the most common method for ascertaining unmet needs in the post-treatment phase, with studies revealing the most frequently reported concerns to be psychological and social.⁹⁻¹² However, QoL measures were developed to assess patients newly diagnosed and/or

receiving treatment and so they not capture issues pertinent to survivors¹³ such as fear of cancer recurrence,^{14,15} early menopause,¹⁶ fears about genetic inheritability of cancer,¹⁷ and concerns about sexual function and fertility.¹⁸⁻²⁰ QoL measures can also be criticized because participants rate presence and/or severity of an item, rather than whether it is a problem for which they need help.

Needs assessment tools explicitly assess the gap between patients' experiences of services they receive and those they perceive they need.²¹ Several cancer-specific supportive care needs assessment tools have recently been developed for use with survivors.²²⁻²⁴ Studies using these report that approximately 50% to 50% of survivors have unmet needs, mainly for psychological support and coping with fear of recurrence. Predictors of unmet supportive care needs include younger age, advanced

stage, and negative affect. A high positive affect score indicates someone who is alert and optimistic, whereas a high negative score reflects high levels of distress. Items provided information on personal, clinical, and treatment factors.

Descriptive measures were used to examine the point prevalence of supportive care needs at both time points for individual items and by mean difference in score was assessed using *t* tests. A Multivariate Chain Monte Carlo method was used to replace missing data imputed values using SAS V9 procedures MI and MANOVA. In SAS/STAT[®] all 1,435 patients at T0 contributed to the imputation. Subscale means were calculated for each data set. The analysis data set included those patients who responded at T0. Selection of unmet need for each NCSS domain were identified using a stepwise logistic regression. For each analysis, the dependent variable dichotomized into no needs (score = 1 to 3) and those reporting at least moderate/severe need (score = 4 to 5). All independent variables (in Table A1, online only) were included in the initial model. A model fit to each imputed data set, and results were combined. The least significant variable was removed until only those statistically significant at the nominal level. Sensitivity of some models was low. Examination of residualized other factors that might better explain the variance in scores. Finally, we included a new variable that represented participants who did not respond to the question that they had experienced a significant event between assessments. This was categorized as post-treatment complication/relapse of a pre-existing condition/new diagnosis, or non-reported negative life event. We assessed for possible clustering effects at treatment center by fitting a random intercept and, separately, a random slope for center to the model. The effect was negligible; therefore, we excluded from all subsequent models.

RESULTS

Figure 1 outlines flow of participants through the study. Of 1,850 patients given a questionnaire pack, 78% returned the baseline questionnaires. Eighty-two percent of those completing T0 questionnaire followed up questionnaires. The number that completed

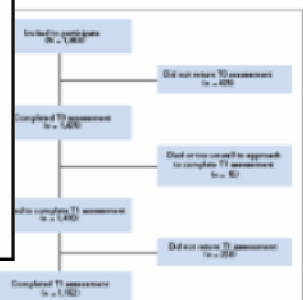
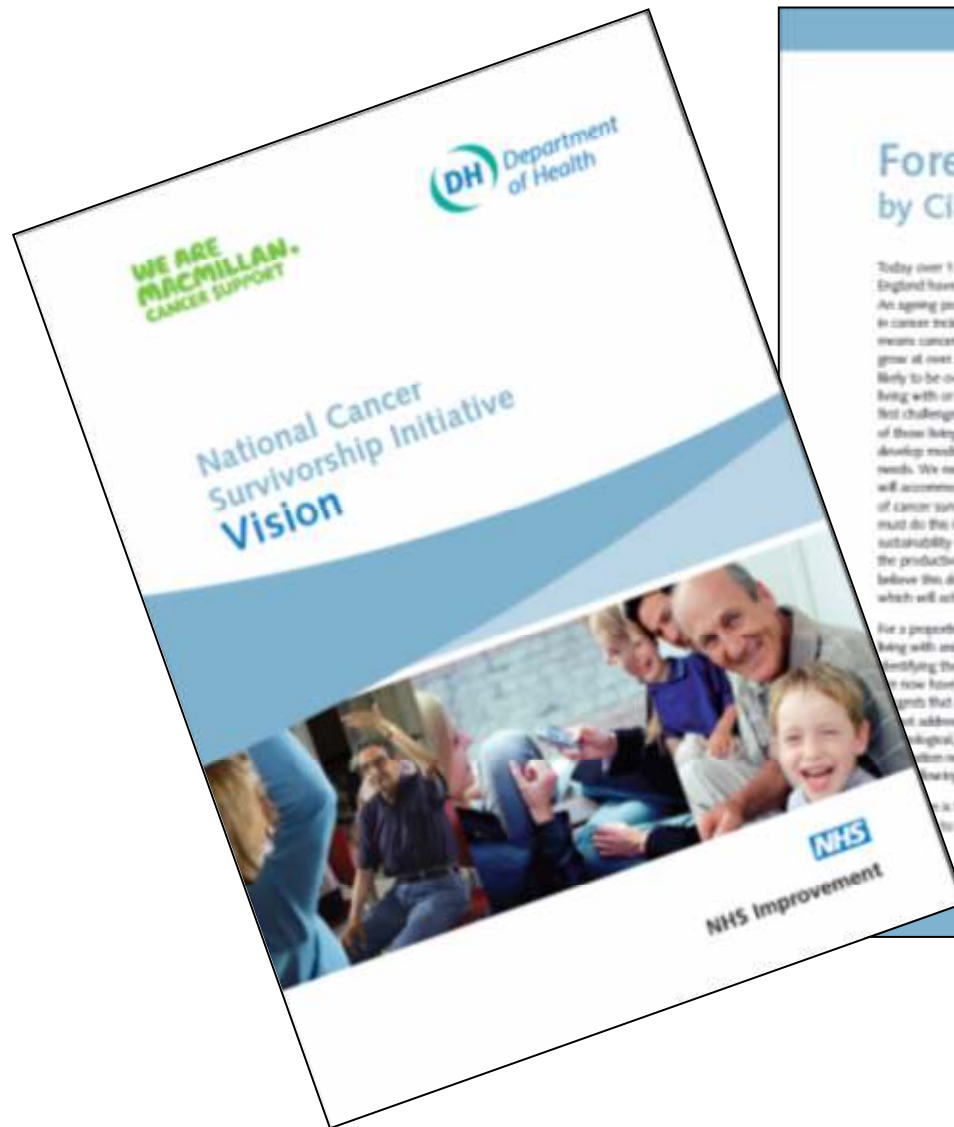


Fig 1. Flow of participants through the study, baseline for the end of treatment (T0), 6 months after baseline.

4 MILLION



Foreword

by Ciarán Devane and Mike Richards

Today over 1.6 million people live in England with a diagnosis of cancer. An ageing population, the resulting increase in cancer incidence and improved treatments mean cancer prevalence will continue to grow at over 5% a year. By 2030 it is likely to be over 2 million people living with or beyond their cancer. Our first challenge is to understand the needs of those living with cancer today and develop models of care which meet these needs. We need to design services which will accommodate the increasing numbers of cancer survivors in the future and must do this in a way which ensures the sustainability of NHS services and the productivity of NHS resources. This document identifies a vision which will achieve these aims.

For a proportion of the 1.6 million people living with and beyond cancer, we are identifying their needs, our meeting them. We now have a range of evidence and reports that current follow-up care does not address the full range of physical, psychological, social, spiritual, financial and other needs that cancer survivors have following their treatment.

It is a vision that cancer survivors should be able to live as healthy and as

The National Cancer Survivorship Initiative Vision

Preface

by Professor Ann Keen, Parliamentary Under Secretary of State for Health

As a nurse, I am very aware that the significant investment and improvements the Government has made to the NHS over the past 10 years mean that cancer services are improving and cancer mortality is falling.

The dramatic improvements in survival rates mean that we need to challenge widespread beliefs about cancer. Cancer is increasingly an illness which might be cured or which might have the characteristics of a long term or chronic condition that people can live with for many years.

It is therefore very important that the increasing numbers of people living with and beyond cancer, their carers and their families have the support and services they need to resume as normal a life as they can following cancer treatment.

Through the National Cancer Survivorship Initiative we are committed to taking steps to ensure that all cancer survivors get the care and support they need to lead as healthy and active a life as possible, for as long as possible.

Our vision is that people living with and beyond cancer have a personalised

assessment, information and care plan and are empowered to manage their condition, based on their needs and preferences. Our vision is for people to be informed and prepared for the long-term effects of living with and beyond cancer, and that health and care services are responsive to individual needs and ensure access to specialist care when needed.

Following cancer treatment some people will be left with physical or psychological problems which affect their health and well-being. There are some very practical actions we can take to make a difference to people following cancer treatment. Hair loss following cancer treatment can cause huge distress and anxiety – just at a time when people are recovering from their treatment and wanting to get back to as normal a life as possible. That is why the Department of Health is working with Trevor Sorbie's charity My New Hair to support cancer patients dealing with hair loss following cancer treatment. This is just one of the many things we can do to make a huge difference to individual patients.

I am delighted that there are now 38 test communities around the country piloting improvements for cancer survivors. We

The Survivorship Vision has 5 key Shifts

1. A greater focus on recovery, health and wellbeing after treatment.
2. Holistic assessment, information and personalised care planning
3. Support for self management
4. Tailored support instead of a single model of follow up
5. Measuring experience and outcomes (PROMS)



67

30

16

6

1

650,000

61

48

Ian's story – a success?

- Aged 57, married with a son and lives in Surrey
- Headteacher
- Diagnosed in 5 years ago with colorectal cancer + liver secondaries
- Chemotherapy, radiotherapy and surgery
- Is alive



Success is using that insight to get better care for 2 million people like Ian

- Diagnosed in 2 weeks not several months
- Treatment does not require colostomy
- No consequent hernia
- Still at work
- Confident
- A real success





THANK YOU