

WE FUND NURSES  
WE CLIMB MOUNTAINS  
WE FIGHT INEQUALITY  
WE GIVE OUR TIME  
WE SUPPORT FAMILIES  
WE PROVIDE GRANTS  
WE MAKE COFFEE  
WE CHANGE LIVES

# The importance of evidence for design and delivery of services and interventions

**Fran Woodard**

Executive Director of Policy and Impact, Macmillan Cancer Support

BPOS and NCRI Psychosocial Oncology and Survivorship CSG Conference

8<sup>th</sup> March 2018

**WE ARE  
MACMILLAN.  
CANCER SUPPORT**

# Outline

1. Evidence drives our work at Macmillan
2. Development, collection and use of evidence is embedded in our ways of working
3. Challenges to building the evidence base
4. Questions and discussion



Evidence validates and guides our direction



# Revealing the scale of the problem.....

British Journal of Cancer (2009) 101, 541–547  
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www.bjcancer.com



## Cancer prevalence in the United Kingdom: estimates for 2008

J Maddams<sup>\*1</sup>, D Brewster<sup>2</sup>, A Gavin<sup>3</sup>, J Steward<sup>4</sup>, J Elliott<sup>5</sup>, M Utley<sup>6</sup> and H Møller<sup>1</sup>

<sup>1</sup>Kings College London, Thames Cancer Registry, 1st Floor Capital House, 42 Weston St, London SE1 3QD, UK; <sup>2</sup>Scottish Cancer Registry, Area 155, Gyle Square, 1 South Gyle Crescent, Edinburgh EH1 2 9EB, UK; <sup>3</sup>Northern Ireland Cancer Registry, Queen's University Belfast, School of Medicine Dentistry and Biomedical Sciences, Mulhouse Building, Grosvenor Road, Belfast BT12 6BJ, UK; <sup>4</sup>Welsh Cancer Intelligence and Surveillance Unit, Floor 13, Brunel House, 2 Fitzalan Road, Cardiff CF24 0HA; <sup>5</sup>Macmillan Cancer Support, 89 Albert Embankment, London SE1 7UQ, UK; <sup>6</sup>University College London, Clinical Operational Research Unit, 4 Taviston Street, London WC1H 0BT, UK

**BACKGROUND:** Identifying and addressing the requirements of cancer survivors is currently a high priority for the NHS, yet little is known about the population of cancer survivors in the United Kingdom.

**METHODS:** Data from cancer registries in England, Northern Ireland, Scotland and Wales were analysed to provide limited-duration prevalence estimates for 2004. Log-linear regression models were used to extend these to complete prevalence estimates. Trends in prevalence from 2000 to 2004 were used to project complete prevalence estimates forward from 2004 to 2008.

**RESULTS:** We estimated that in total, there were 2 million cancer survivors in the United Kingdom at the end of 2008, ~3% of the population overall and 1 in 8 of those aged 65 years and more. Prostate and female breast cancers were the most prevalent. The number of cancer survivors is increasing by ~3% each year. Estimates are also provided by time since diagnosis.

**CONCLUSION:** These estimates are the most up-to-date available, and as such will be useful for statutory and voluntary sector organisations that are responsible for planning and providing treatment and support to cancer survivors in the United Kingdom.

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Published online 30 June 2009

© 2009 Cancer Research UK

**Keywords:** prevalence; survivors; survivorship; UK

British Journal of Cancer (2012) 107, 1195–1202  
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www.bjcancer.com



## Projections of cancer prevalence in the United Kingdom, 2010–2040

J Maddams<sup>\*1</sup>, M Utley<sup>2</sup> and H Møller<sup>1</sup>

<sup>1</sup>Kings College London, Thames Cancer Registry, 1st Floor, Capital House, 42 Weston Street, London SE1 3QD, UK; <sup>2</sup>Clinical Operational Research Unit, University College London, 4 Taviston Street, London WC1H 0BT, UK

**BACKGROUND:** There are currently two million cancer survivors in the United Kingdom, and in recent years this number has grown by 3% per annum. The aim of this paper is to provide long-term projections of cancer prevalence in the United Kingdom.

**METHODS:** National cancer registry data for England were used to estimate cancer prevalence in the United Kingdom in 2009. Using a model of prevalence as a function of incidence, survival and population demographics, projections were made to 2040. Different scenarios of future incidence and survival, and their effects on cancer prevalence, were also considered. Colorectal, lung, prostate, female breast and all cancers combined (excluding non-melanoma skin cancer) were analysed separately.

**RESULTS:** Assuming that existing trends in incidence and survival continue, the number of cancer survivors in the United Kingdom is projected to increase by approximately one million per decade from 2010 to 2040. Particularly large increases are anticipated in the oldest age groups, and in the number of long-term survivors. By 2040, almost a quarter of people aged at least 65 will be cancer survivors.

**CONCLUSION:** Increasing cancer survival and the growing/ageing population of the United Kingdom mean that the population of survivors is likely to grow substantially in the coming decades, as are the related demands upon the health service. Plans must, therefore, be laid out to ensure that the varied needs of cancer survivors can be met in the future.

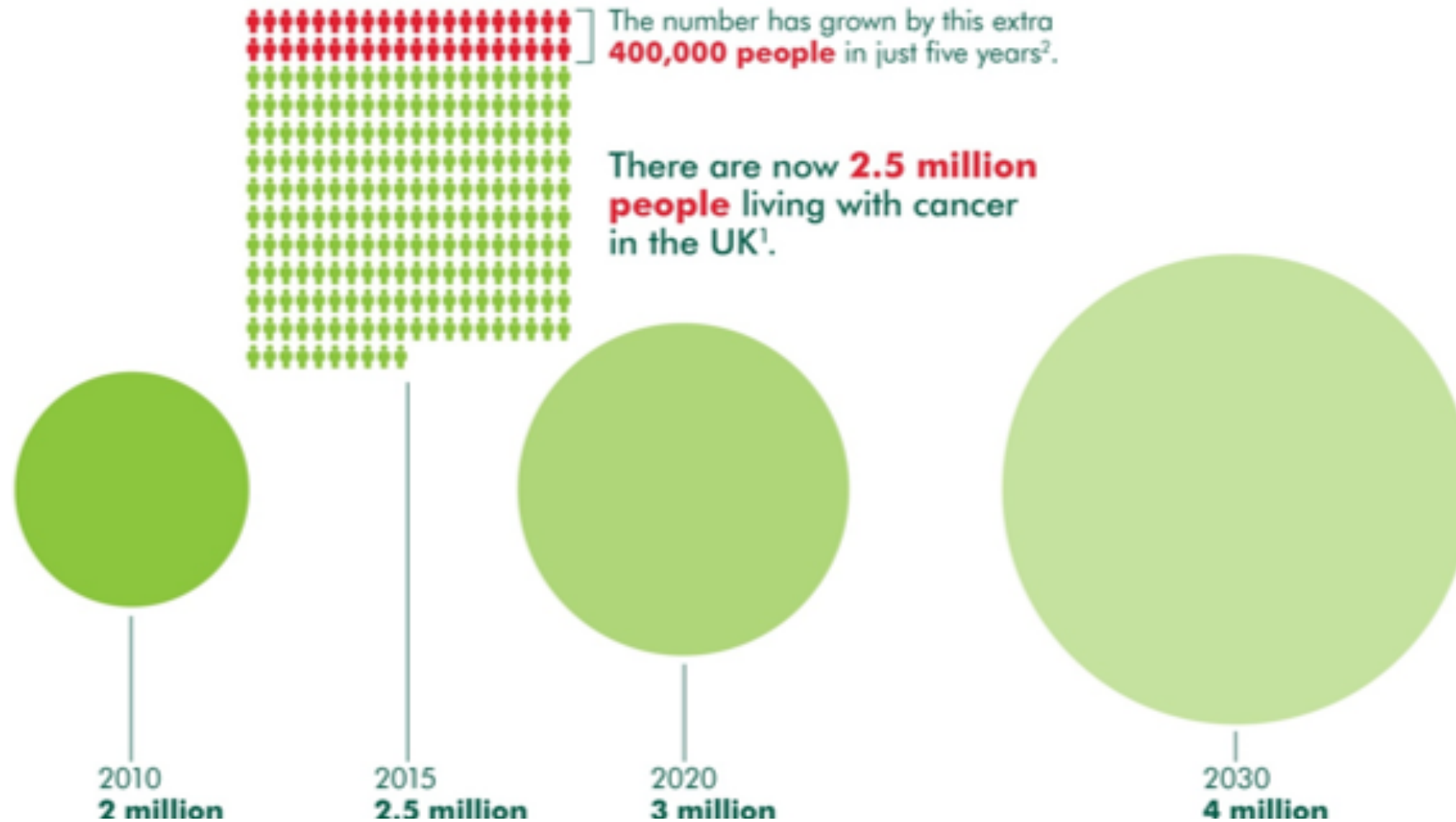
British Journal of Cancer (2012) 107, 1195–1202. doi:10.1038/bjc.2012.366 www.bjcancer.com

Published online 14 August 2012

© 2012 Cancer Research UK

**Keywords:** cancer prevalence; projections; survivors; survivorship; UK

# Rise in cancer cases



1 Macmillan Cancer Support. Estimate for 2015 based on extrapolation of data in: Maddams J et al. Projections of cancer prevalence in the United Kingdom, 2010-2040. Br J Cancer 2012; 107: 1195-1202. (Projections scenario 1)

2 'Five years' refers to 2010-2015

From the Florence Nightingale School of Nursing and Midwifery, King's College London; Cancer Services, Guy's and St Thomas' NHS Foundation Trust; National Cancer Research Institute, Psycho-Social Oncology Clinical Studies Group, London; Cancer Services, Royal United Hospital Bath National Health Service (NHS) Trust, Bath; Oncology Centre, Gloucestershire Hospitals NHS Foundation Trust, Gloucestershire; Division of Specialised Services, University Hospitals Bristol NHS Foundation Trust, Bristol; and the 3 Counties Cancer Network, Chiltonham, United Kingdom. Submitted February 23, 2009; accepted August 11, 2009; published online ahead of print at www.jco.org on November 2, 2009.

Supported by Macmillan Cancer Support and King's College London.

Presented in part at the 2nd COMPASS Annual Scientific Meeting, June 17, 2008, Edinburgh, United Kingdom; United Kingdom Oncology Nursing Society Conference, July 13, 2007, London, United Kingdom; National Cancer Research Institute Conference, September 30-October 3, 2007, Birmingham, United Kingdom; and 14th European Cancer Conference of the European Cancer Organization, September 23-27, 2007, Barcelona, Spain.

The analysis, opinions, and assertions contained herein are those of the authors and are not to be construed as reflecting the views or position of Macmillan Cancer Support or King's College London.

Authors' disclosures of potential conflicts of interest and author contributions are found at the end of this article.

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The Acknowledgment and Appendix are included in the full-text version of this article; they are available online at www.jco.org. They are not included in the PDF version (via Adobe® Reader®).

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

Jo Armes, Maggie Crowe, Lynne Colbourne, Helen Morgan, Trevor Murrells, Catherine Oakley, Nigel Palmer, Emma Ream, 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, 1,425 (79%) returned questionnaires at T0, and 1,152 (62%) returned questionnaires at T1. Mean age was 61 years; and most respondents were female (69%) and had breast cancer (57%). Most patients had no or few moderate or severe unmet supportive care needs. However, 30% 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 unrelated 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 the targeted application of psychosocial resources.

*J Clin Oncol* 27:6172-6179. © 2009 by American Society of Clinical Oncology

### INTRODUCTION

As more people survive cancer, there is growing recognition that they need support during the survival phase of their illness.<sup>1-3</sup> Although completion of treatment is eagerly anticipated,<sup>4,5</sup> few studies focus on the transition period between end of treatment and long-term survivorship (> 5 years).<sup>6</sup> Limited evidence suggests that patients are dissatisfied with care received at this time, as support from oncology professionals tails off with little concomitant increase in alternative support.<sup>7,8</sup>

Estimating quality of life (QoL) is the most common method for ascertaining sequelae in the post-treatment phase, with studies revealing the most frequently reported concerns to be psychological and social.<sup>2,3,9</sup> However, QoL measures were developed to assess patients newly diagnosed and/or

receiving treatment and so may not capture issues pertinent to survivors<sup>3</sup> such as fear of cancer recurrence,<sup>10,11</sup> early menopause,<sup>12</sup> fears about genetic inheritability of cancer,<sup>13</sup> and concerns about sexual function and fertility.<sup>14,15</sup> 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.<sup>16</sup> Several cancer-specific supportive care needs assessment tools have recently been developed for use with survivors.<sup>17-21</sup> Studies using these report that approximately 30% 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

# Revealing unmet needs in this population

From the Florence Nightingale School of Nursing and Midwifery, King's College London; Cancer Services, Guy's and St Thomas' NHS Foundation Trust; National Cancer Research Institute, Psycho-Social Oncology Clinical Studies Group, London; Cancer Services, Royal United Hospital Bath National Health Service (NHS) Trust, Bath; Oncology Centre, Gloucestershire Hospitals NHS Foundation Trust, Gloucestershire; Division of Specialised Services, University Hospitals Bristol NHS Foundation Trust, Bristol; and the 3 Counties Cancer

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Authors' disclosures of potential conflicts of interest and author contributions are found at the end of this article.

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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-eight cancer-treated patients

(62%) returned questionnaires at T1. Mean age was 61 years; and most respondents were female (69%) and had breast cancer (57%). Most patients had no or few moderate or severe unmet supportive care needs. However, 30% 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 unrelated significant event between assessments.

## Conclusion

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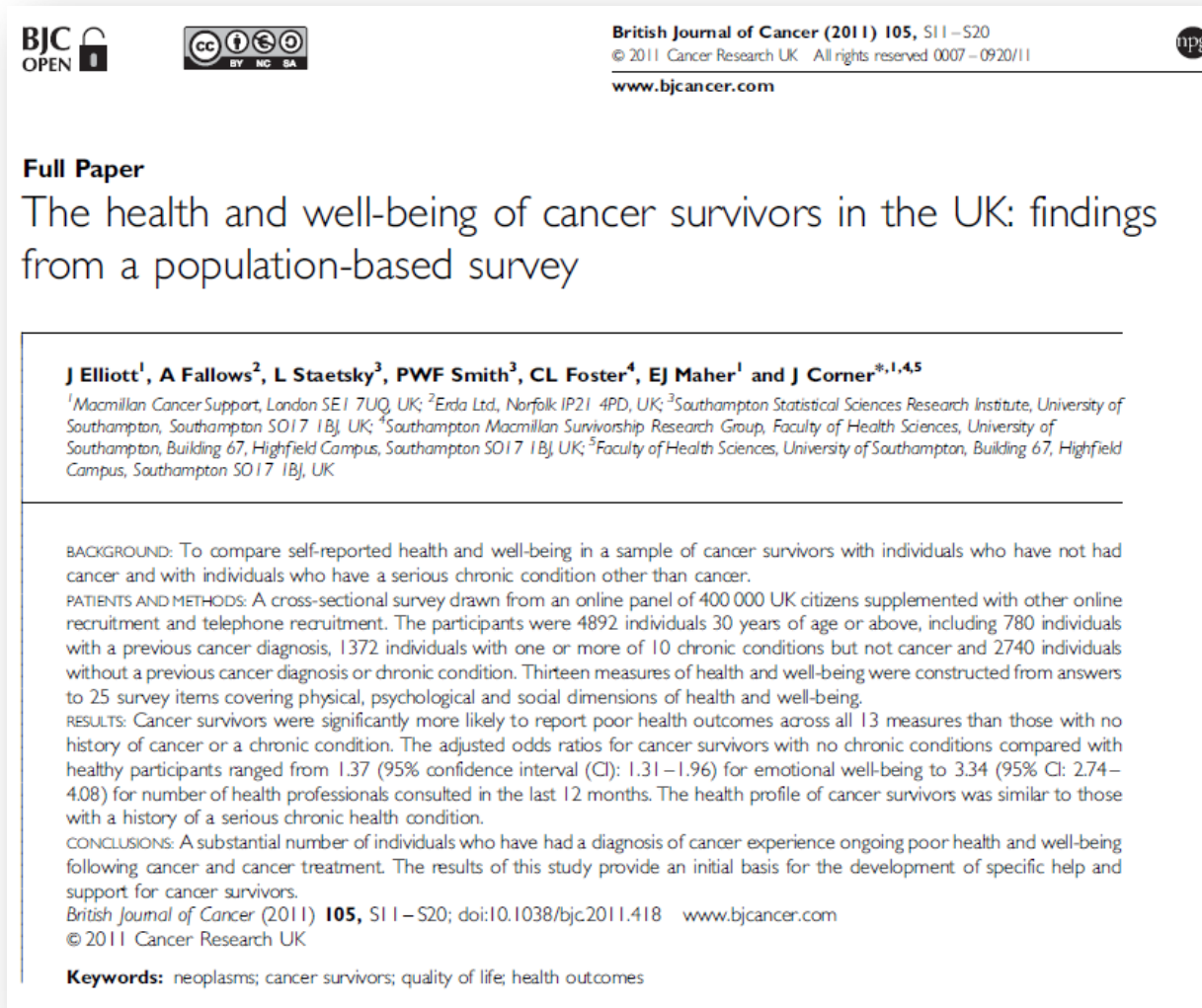
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# Revealing needs that were significant and specific to cancer and its treatment



# ...providing the case for support in the cancer survivorship agenda



British Journal of Cancer (2011) 105, S11–S20  
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www.bjcancer.com



## Full Paper

### The health and well-being of cancer survivors in the UK: findings from a population-based survey

In a previous study, a population-based survey of cancer survivors in the UK. Measures of health and well-being were collected from answers to 25 survey items covering physical, psychological and social dimensions of health and well-being.

**RESULTS:** Cancer survivors were significantly more likely to report poor health outcomes across all 13 measures than those with no history of cancer or a chronic condition. The adjusted odds ratios for cancer survivors with no chronic conditions compared with healthy participants ranged from 1.37 (95% confidence interval (CI): 1.31–1.96) for emotional well-being to 3.34 (95% CI: 2.74–4.08) for number of health professionals consulted in the last 12 months. The health profile of cancer survivors was similar to those with a history of a serious chronic health condition.

**CONCLUSIONS:** A substantial number of individuals who have had a diagnosis of cancer experience ongoing poor health and well-being following cancer and cancer treatment. The results of this study provide an initial basis for the development of specific help and support for cancer survivors.

British Journal of Cancer (2011) 105, S11–S20; doi:10.1038/bjc.2011.418 www.bjcancer.com

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© 2011 Cancer Research UK

**Keywords:** neoplasms; cancer survivors; quality of life; health outcomes

For this broad group of people and needs, we need evidence from diverse sources to guide decisions on:



- Where improvements should be targeted
- Specific patient groups with specific needs
- What new services might be needed



Evidence from patient surveys



# The National Cancer Patient Experience (CPES) Survey

- Developed by Quality Health for the English Department of Health in 2010 and run almost every year since then
- Full census of all cancer patients in treatment during a three-month window (around 120,000 patients every year)
- High response rates: typically 65% to 70%
- All data and documentation is publicly available at [www.ncpes.co.uk](http://www.ncpes.co.uk)

CPES in England is widely acknowledged to have driven significant improvement in cancer care over the last seven years:



# Respondents from London Trusts report a worse experience than non-London respondents:

	2015 Survey	2016 Survey
Number of scored questions	50	52
London scores <b>significantly lower than</b> non-London	<b>39</b>	<b>43</b>

# Further analysis reveals stark inequalities in London

*Felt they got enough care and support from health or social services during treatment:*



*Felt they were given answers they could understand from their Clinical Nurse Specialist:*



*Felt the GPs and nurses did everything they could to support them during treatment:*



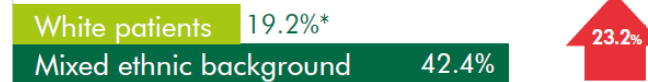
People from the most deprived areas report worse experience on almost **90% of the questions.**

London has a higher proportion of people in poverty (after housing costs) than the rest of England - **27% compared to 21%**

Looking at breakdowns by ethnicity, there are **32 questions** in London that have statistically significant differences.

Minority ethnic groups account for over **40%** of all people living in London.

*Patients felt groups of doctors and nurses talked in front of them as if they weren't there:*



*Patients felt they were seen as soon as necessary by their GP before going to the hospital:*



*Patients felt positive about the length of time they had to wait for their test:*





# Ways we are acting on this evidence:

1. Partnerships in Tower Hamlets
2. Primary and community care projects across London
3. London Cancer Community; Representing London's diversity
4. Holding Trusts accountable



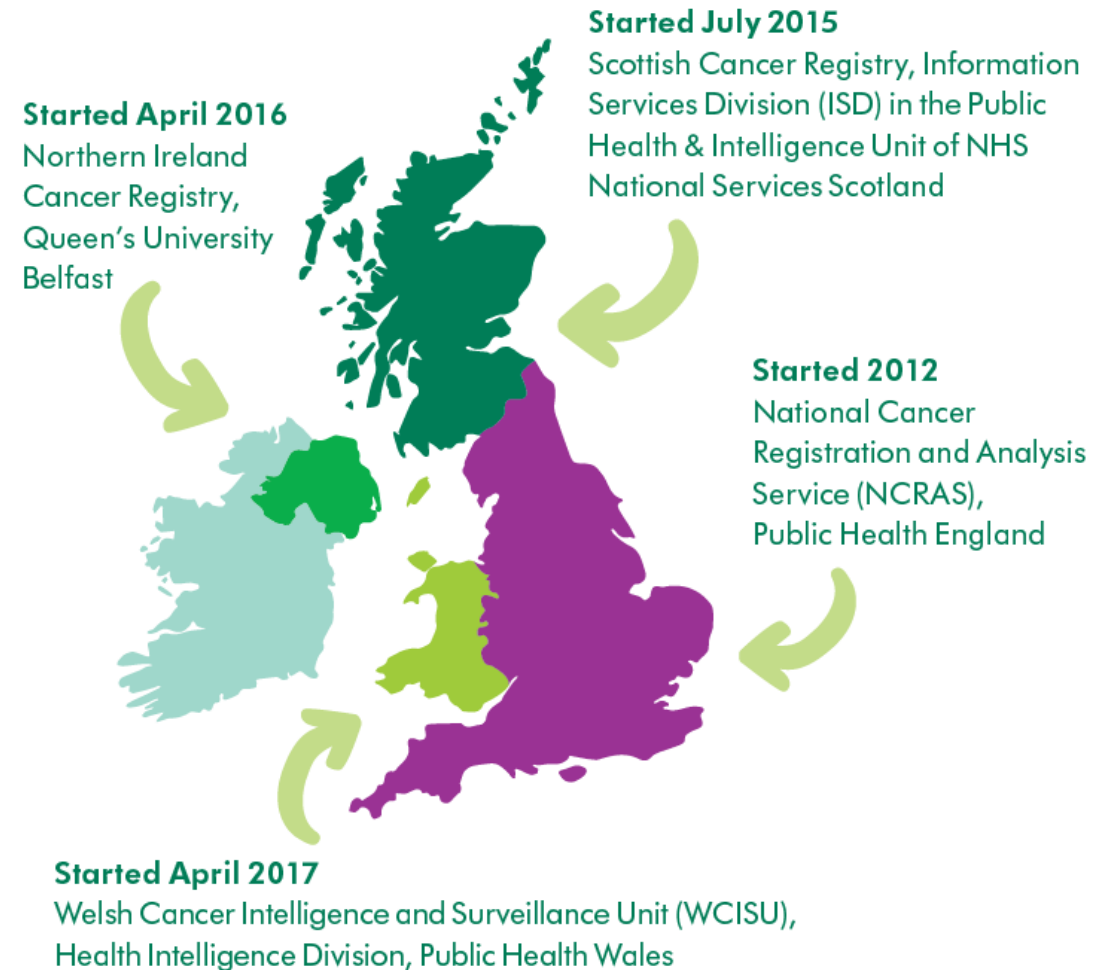
The background is a dark blue and green abstract composition. It features a grid of binary digits (0s and 1s) in a lighter green color. Overlaid on this is a faint, stylized image of a city skyline with various building shapes. The overall effect is a high-tech, digital aesthetic.

Evidence from Cancer Registry data

# Macmillan has an analytical partnership with the cancer registries in each nation.

Incidence and outcome data linked to health, social care, socio-economic and environmental data

Provides a comprehensive picture of the cancer pathway





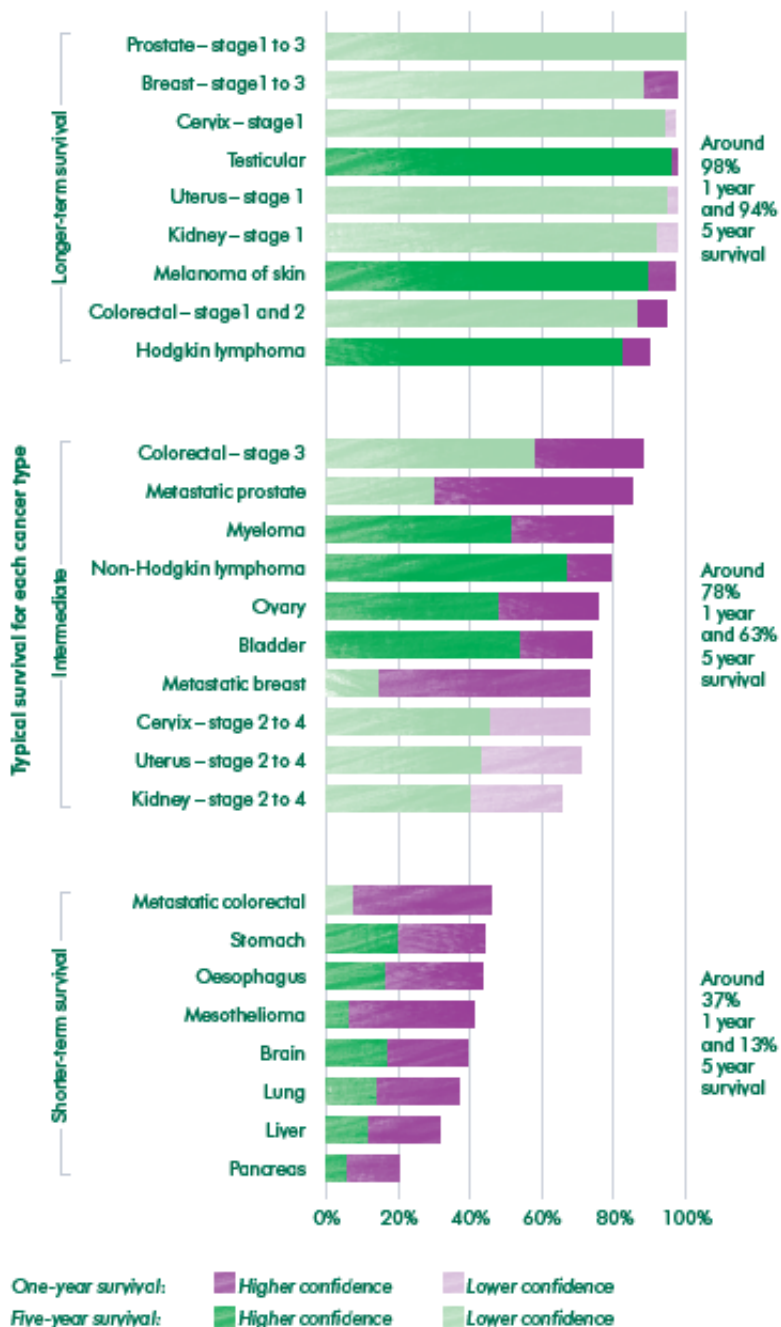
# Different cancers have different 'shapes'



K. Yip, H. McConnell, R. Alonzi, J. Maher. Using routinely collected data to stratify prostate cancer patients into phases of care in the UK: implications for resource allocation and cancer survivorship. Br J Cancer 2015.



Variation in survival rates between the three cancer groups



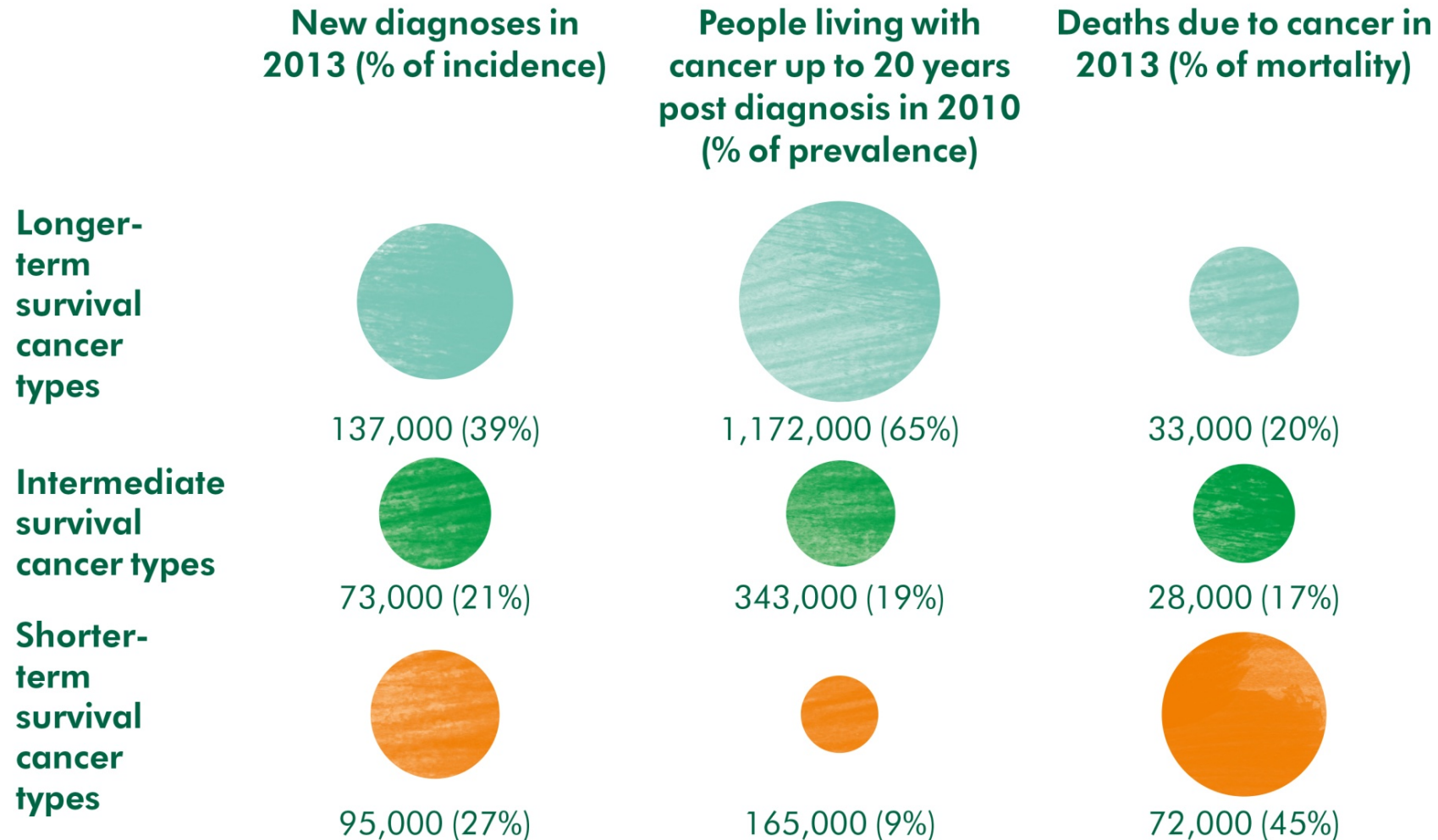
# THREE CANCER GROUPS

❖ Longer term survival

❖ Intermediate

❖ Shorter term survival

# Three cancer groups in numbers



# Pathways are different

Group 1:  
Many live for more than a decade

Group 2:  
Most similar to a long term condition

Group 3:  
Survival for the majority is short term

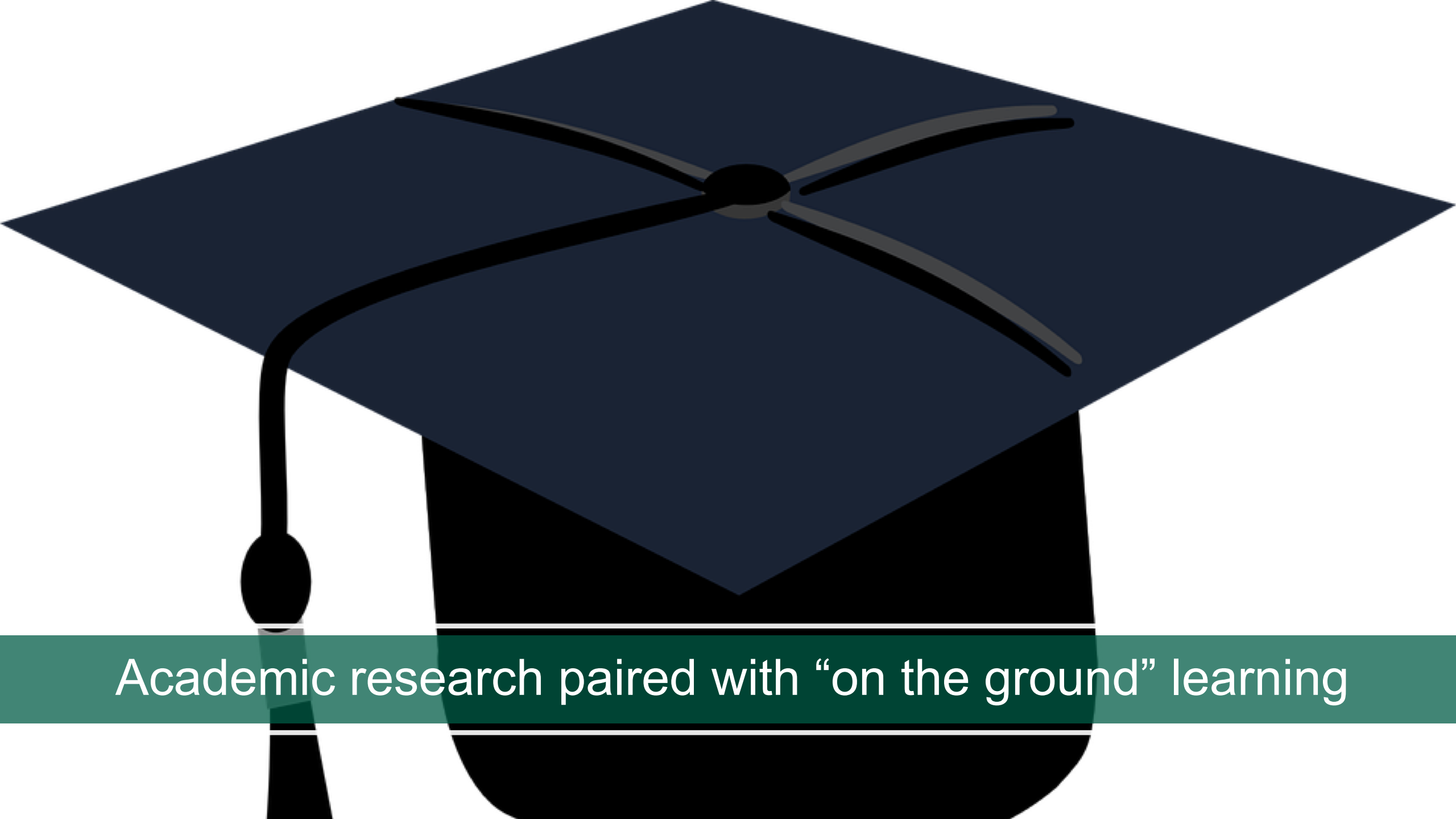
# Focus for intervention will differ for people in each group

Group 1: Reduce overtreatment, focus on recovery

Group 2: Balance acute intervention and chronic illness management

Group 3: Diagnose earlier; manage comorbidity early; palliative care for most





Academic research paired with “on the ground” learning

# “Real-world” pilot studies based on academic findings provide more actionable findings

- The real world setting is different to a study.
- We combine academic learnings with what people on the ground tell us.
- Develop pilots that learn and improve as they go.
- Some things don't work but eventually, some things will.



[https://commons.wikimedia.org/wiki/File:Florida\\_State\\_College\\_for\\_Women\\_students\\_experimenting\\_in\\_the\\_chemical\\_lab-\\_Tallahassee,\\_Florida\\_\(6859458328\).jpg](https://commons.wikimedia.org/wiki/File:Florida_State_College_for_Women_students_experimenting_in_the_chemical_lab-_Tallahassee,_Florida_(6859458328).jpg)

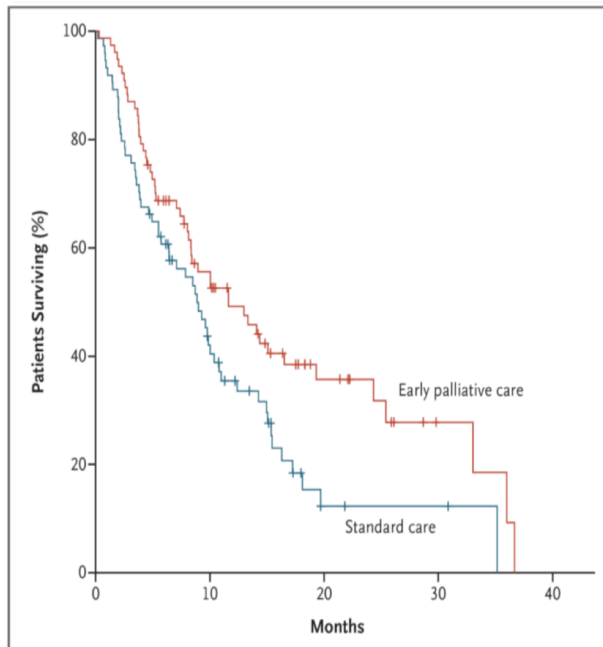
# The case for early introduction of palliative care services

THE NEW ENGLAND JOURNAL of MEDICINE

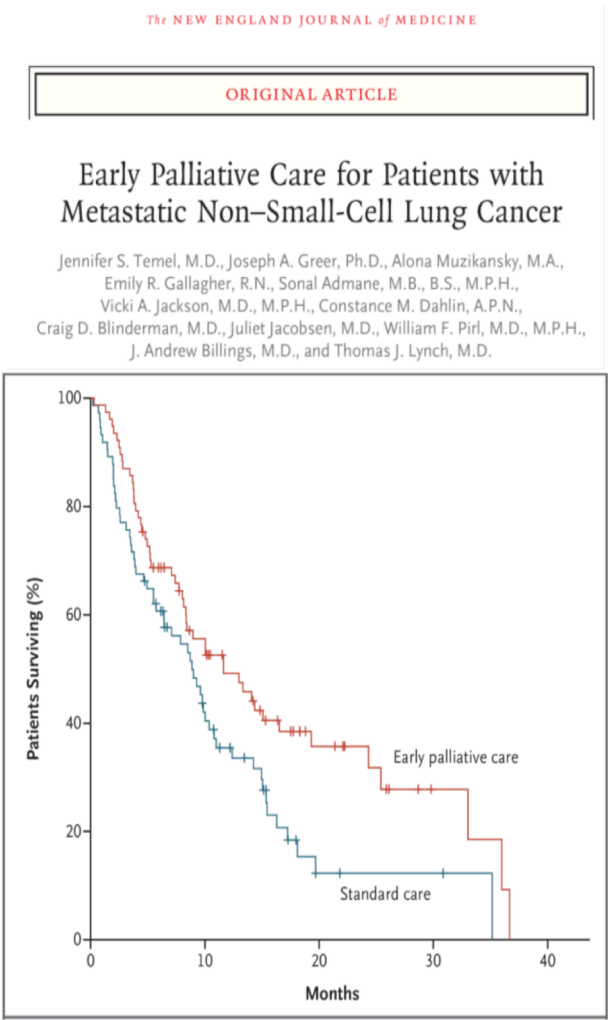
ORIGINAL ARTICLE

## Early Palliative Care for Patients with Metastatic Non–Small-Cell Lung Cancer

Jennifer S. Temel, M.D., Joseph A. Greer, Ph.D., Alona Muzikansky, M.A., Emily R. Gallagher, R.N., Sonal Admane, M.B., B.S., M.P.H., Vicki A. Jackson, M.D., M.P.H., Constance M. Dahlin, A.P.N., Craig D. Blinderman, M.D., Juliet Jacobsen, M.D., William F. Pirl, M.D., M.P.H., J. Andrew Billings, M.D., and Thomas J. Lynch, M.D.



# The case for early introduction of palliative care services



Early palliative care

2.7 months (Temel NEJ 2010)

\$6,000

Bevacizumab

2 months (ECOG 4599)

\$115,000

Nivolumab

3.3 months (J. Brahmer, NEJM 2015)

\$140,000



# Early introduction of palliative care

## OUR RESULTS AND FINDINGS IN MIDHURST



84% of people died in their preferred place of care in 2012/13, which is significantly up on the national average.



By using their different specialisms, team members ensure **a person-centred approach and optimum use of time**



If the service was replicated elsewhere, the total **cost of care could be reduced by 20%**



**Volunteers fulfil many important roles** and are a key part of the service.



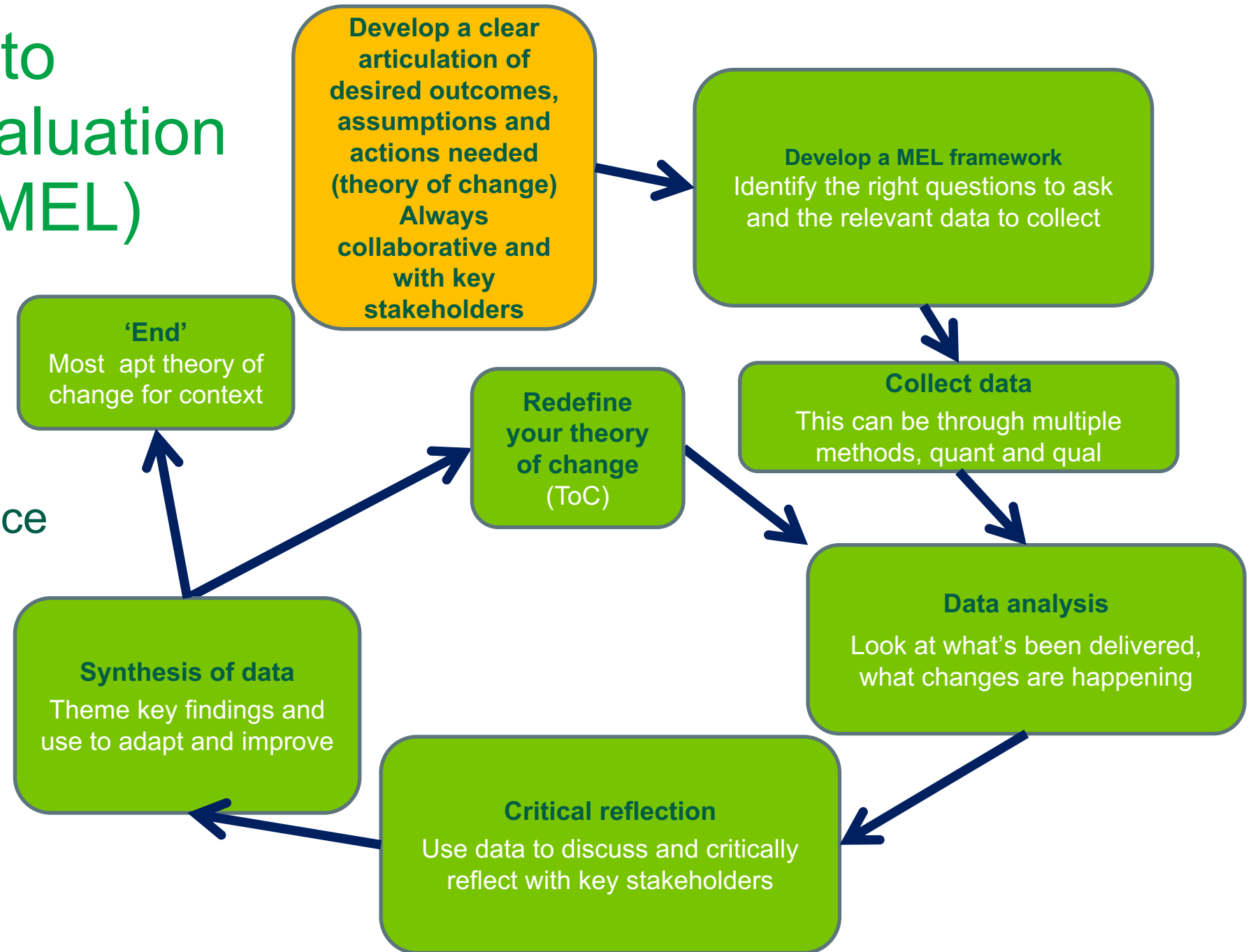
The service has resulted in **fewer A&E visits and nights in hospital** from the people who use it.

Developing, collecting and using evidence is embedded in our work



# Our approach to monitoring, evaluation and learning (MEL)

Understanding and evaluating the difference our services and interventions make



# Funding new evidence



WE ARE  
MACMILLAN.  
CANCER SUPPORT

# MACMILLAN RESEARCH GRANTS SCHEME



# Funding new evidence



THE UNIVERSITY  
of EDINBURGH



UNIVERSITY OF LEEDS



The ROYAL MARSDEN  
NHS Foundation Trust



University of  
Chester

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Read more about the new projects on the Research Funding pages of the Macmillan website.

Go to [www.macmillan.org.uk](http://www.macmillan.org.uk) and search 'research funding'

UNIVERSITY OF  
Southampton



LEEDS  
BECKETT  
UNIVERSITY

Funding new evidence

WE ARE  
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CANCER SUPPORT

# MACMILLAN RESEARCH GRANTS SCHEME



2018 Call for Research

Launching April 2018

[researchgrants@macmillan.org.uk](mailto:researchgrants@macmillan.org.uk)

# Working together to drive research impact

## MACMILLAN RESEARCH IMPACT FRAMEWORK

Maximise the impact of  
research Macmillan funds

Co-produced with people  
affected by cancer

Support researchers to plan,  
deliver and monitor impact

Launching alongside the 2018 call





Challenges in building the evidence base



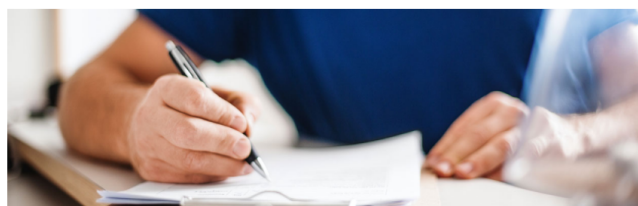
We need more than data; we need the right data



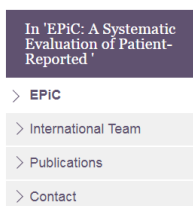
"So things are good, stuff is OK, and I reiterate my request for more specific data."

# Improving PROs data collection in clinical trials

EPiC: A Systematic Evaluation of Patient-Reported Outcome (PRO) Protocol Content and Reporting in UK Cancer Clinical Trials



A mixed-methods study investigating PRO protocol content and reporting in UK cancer clinical trials.



Centre for Patient Reported Outcomes Research



UNIVERSITY OF BIRMINGHAM

Clinical Review & Education

JAMA | Special Communication

## Guidelines for Inclusion of Patient-Reported Outcomes in Clinical Trial Protocols The SPIRIT-PRO Extension

Melanie Calvert, PhD; Derek Kyte, PhD; Rebecca Mercieca-Bebber, PhD; Anita Slade, PhD; An-Wen Chan, MD, DPhil; Madeleine T. King, PhD; and the SPIRIT-PRO Group

# The Quality of Life Metric for cancer survivors

- Macmillan working with NHS England on a pilot
- Results will form part of a National Cancer Dashboard
- Results of pilot to be reported in March 2019



# We need to support research that matters to patients

A strong patient voice in research funding decision-making...



...and in setting research priorities



James  
Lind  
Alliance

Priority Setting Partnerships

**Living With and Beyond Cancer James Lind Alliance Priority Setting Partnership**

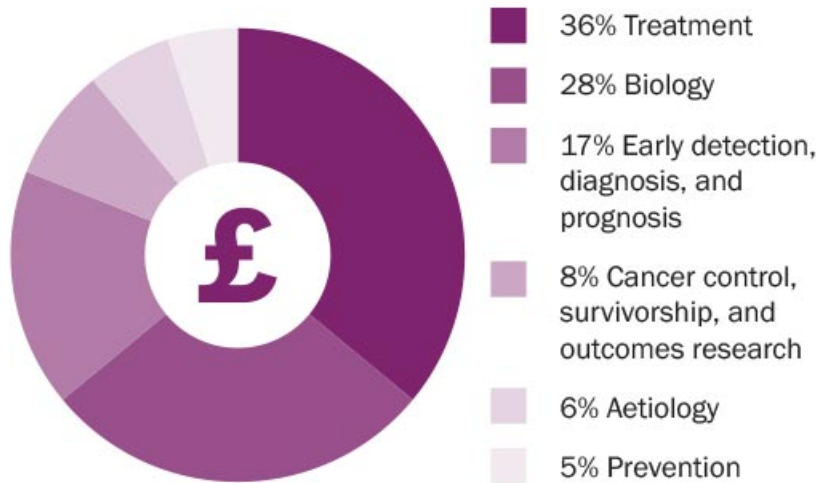
As part of the NCRI Living With and Beyond Cancer initiative, the Priority Setting Partnership aims to identify research priorities that matter most to people affected by cancer and relevant health care professionals.



# We need sustained investment to build research capacity

## Spend by research type

As in previous years, research into **cancer treatment** and **biology** make up around **two thirds** of the value reported. **Treatment** research now accounts for **36%** of research spend recorded.\*




Granstmanship – to upskill the research community



Securing large scale research infrastructure investments



# Challenges in building the evidence base



What are the other challenges we face?

What else could we try to address these challenges?

How can we best work together to make a difference?

**ANY  
QUESTIONS?**