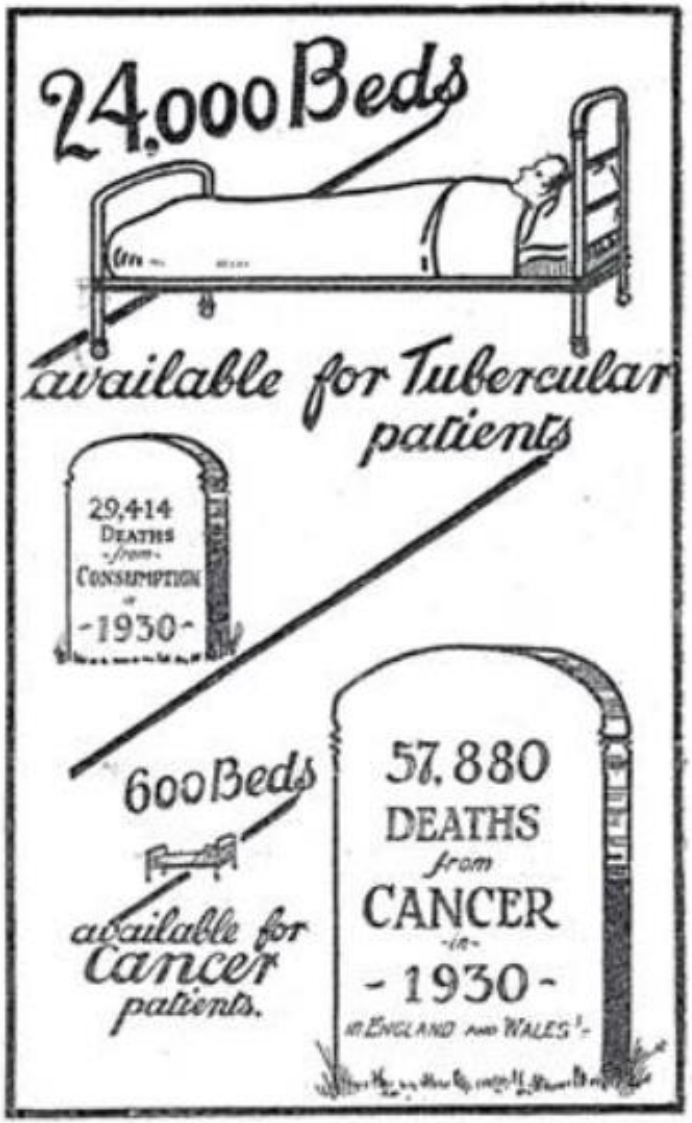
ECPC General Assembly, Brussels
3rd June 2016

Information for patients at its best - beyond leaflets

Jane Maher
Joint Chief Medical Officer
Macmillan Cancer Support, UK

WE ARE MACMILLAN. CANCER SUPPORT


24,000 Beds
available for Tubercular patients
29,414 DEATHS from CONSUMPTION in -1930-
600 Beds
available for Cancer patients.
57,880 DEATHS from CANCER in -1930- in ENGLAND and WALES

2015
WE REACHED
5.8 MILLION
PEOPLE

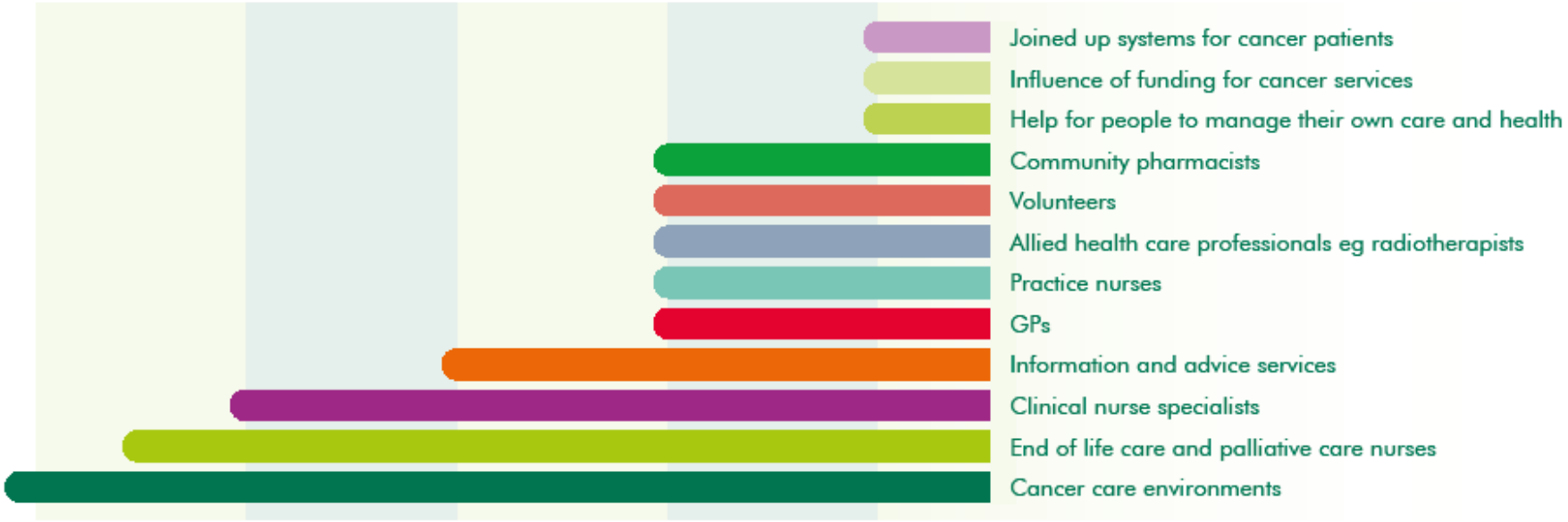
OUR SERVICES ACCESSED 9 MILLION TIMES

WE ARE MACMILLAN. CANCER SUPPORT

OUR SERVICES

Macmillan's journey of cancer support

From the 1970s when cancer wasn't generally survivable, to the present day, when 2.5 million people live with cancer, our services have grown to make sure no one faces cancer alone.



1970s
Cancer wasn't generally survivable, so our services are all about end of life.

1980s
Some cancers are now curable so we make huge investments in hospitals to help people survive.

1990s
Survival rates increase, so we grow our practical advice services.

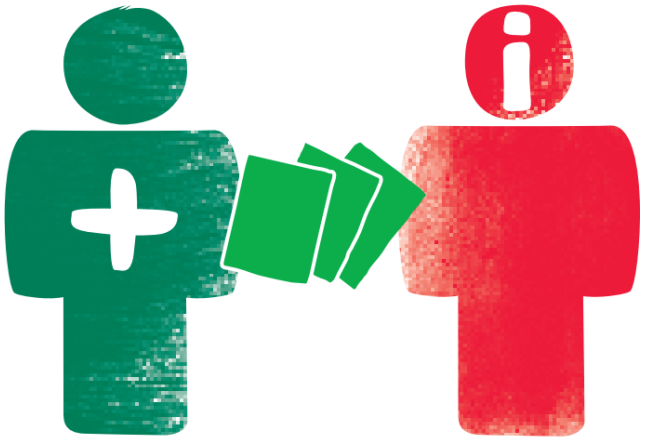
2000s
Survival rates increase significantly, so we focus on training a wider range of health professionals.

2010s
As the 2.5 million people who currently live with cancer rises to 4 million by 2030, we continue to influence and improve the whole system.

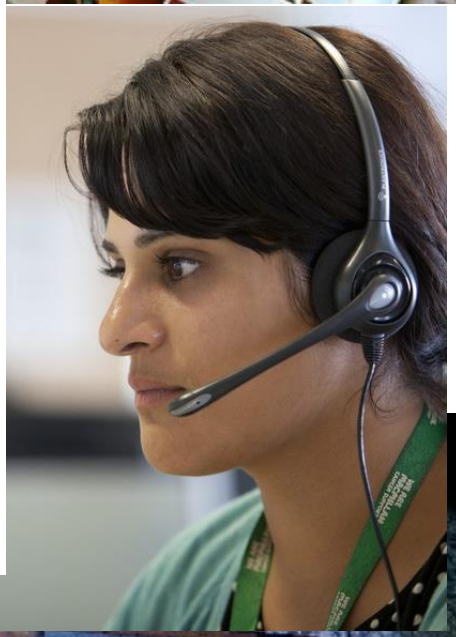
Printed using sustainable material. Please recycle.
Macmillan Cancer Support, registered charity in England and Wales (261017), Scotland (SC039907) and the Isle of Man (604). MAC15518

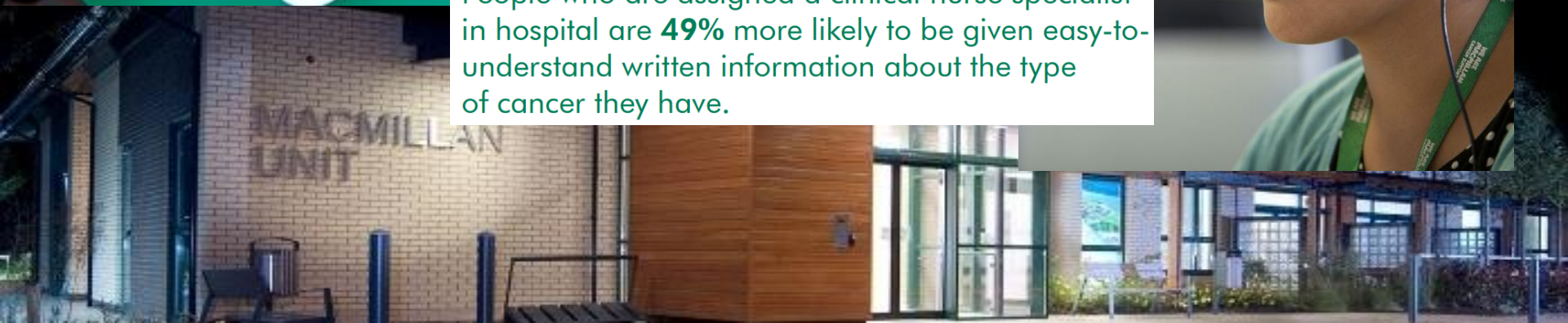
MACMILLAN INFORMATION

500
3000
9

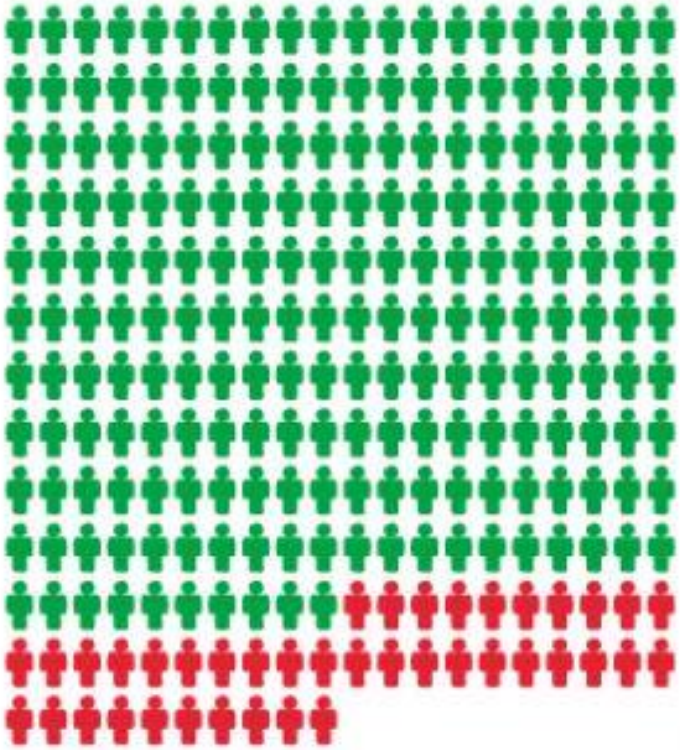


People who are assigned a clinical nurse specialist in hospital are **49%** more likely to be given easy-to-understand written information about the type of cancer they have.





THE CANCER STORY IS CHANGING



There are now **2.5 million** people living with cancer in the UK[1].

The number has grown by this extra **400,000 people** in just five years[2].

Cancers are not the same

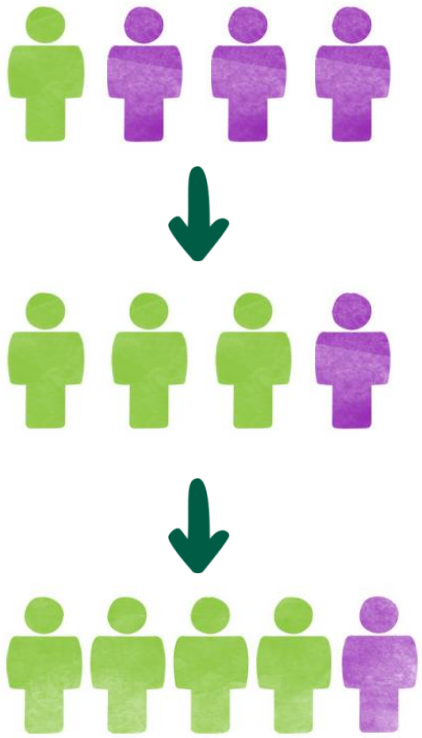
Group 1: many live for more than a decade

Group 2: most similar to a long term condition

Group 3: survival for the majority is short term

McConnell H, White R, Maher J. *Understanding variations: Outcomes for people diagnosed with cancer and implications for service provision*. 2014. European Network of Cancer Registries Scientific Meeting and General Assembly

Surviving cancer does not mean living well



3 in 4 people living with cancer are in the survivorship stage[1]

1 in 4 of them deal with consequences of their treatment[2]

1 in 5 of cancer survivors may have unmet needs[3]

1. Maher J and McConnell H. New pathways of care for cancer survivors: adding the numbers. Br J Cancer. 2011. 105: S5-S10
2. Macmillan Cancer Support. *Throwing light on the consequences of cancer and its treatment.* 2013. London
3. Armes J et al. Patients' supportive care needs beyond the end of treatment: A prospective, longitudinal survey. Journal of Clinical Oncology.2009. 27:36 6172-6179

Cancer affects all areas of people's lives

Loneliness[1] **23%**

Financial needs[2] **83%**

People with cancer are **37% more likely to be unemployed** than the general population

1.Macmillan Cancer Support. Facing the fight alone. Isolation among cancer patients. 2013. London
2.Macmillan Cancer Support. Hidden at home. 2015. London
3.De Boer et al. Cancer survivors and unemployment: a meta-analysis and meta-regression. JAMA. 2009. 301: 753-762

MACMILLAN AT WORK
Training. Support. Knowledge.

MACMILLAN AT WORK
Training. Support. Knowledge.
UPDATE
WE ARE MACMILLAN. CANCER SUPPORT

Helping you train others
If you're part of a large organisation our new programme can help support your workforce.

We will train up groups of staff to upskill line managers to better support staff affected by cancer.

What you will gain
Attendees of our train the trainer programme will learn about:
- the impact of cancer on a person at work
- how to support staff to manage and talk about cancer
- where to signpost for support.

We can adapt the programme to suit your needs. And we'll provide you with the materials and skills to establish a sustainable training model across your organisation.

Interested? Get in touch
Contact the team on **020 7840 4725** or email **workandcancer@macmillan.org.uk** for more information.

Our **downloadable PDF** gives information about all of our training offers.

MORE ON TRAINING >

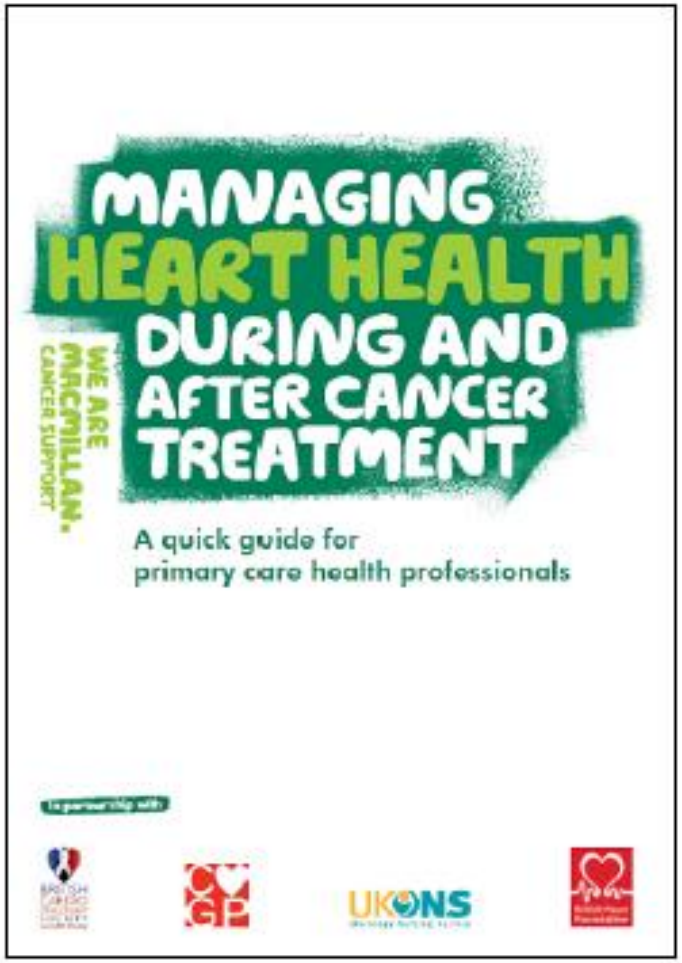
Walk to Work Week
11-15 May

Healthy competition
Why not challenge colleagues to feel the benefits of walking more for one whole week? It might be that they get off their train a stop early or go the whole distance.

Annual leave: should it be used for medical appointments?
Getting time off work for medical appointments is a pressing need for employees with cancer. To help

Barbara's blog
Our resident blogger and HR expert, Barbara Wilson, considers this month's topic: What should employers consider when

HEART HEALTH



“It’s the little things put together that get us down …..”

Gastrointestinal problems

ERECTILE DYSFUNCTION

CONSENSUS

CLINICAL PRACTICE

Development of UK recommendations on treatment for post-surgical erectile dysfunction

M. G. Kirby,[1] I. D. White,[2] J. Butcher,[2] B. Challacombe,[4] J. Coe,[5] L. Grover,[1] P. Hegarty,[6] G. Jackson,[6] A. Lowndes,[7] H. Payne,[5] J. Rees,[8] V. Sangar,[9] A. Thompson[2]

SYSTEMATIC REVIEW

CLINICAL PRACTICE

Development of UK guidance on the management of erectile dysfunction resulting from radical radiotherapy and androgen deprivation therapy for prostate cancer

I. D. White,[1] J. Wilson,[2] P. Aslet,[3] A. B. Baxter,[1] A. Birtle,[4] B. Challacombe,[5] J. Coe,[6] L. Grover,[7] H. Payne,[8] S. Russell,[9] V. Sangar,[10] N. Van As,[11] M. Kirby[12,13]

Treating erectile dysfunction after surgery for pelvic cancers

A quick guide for health professionals: supporting men with erectile dysfunction

WE ARE MACMILLAN. CANCER SUPPORT

Treating erectile dysfunction after radical radiotherapy and androgen deprivation therapy (ADT) for prostate cancer

A quick guide for health professionals: supporting men with erectile dysfunction

WE ARE MACMILLAN. CANCER SUPPORT

PROSTATE CANCER UK

BRITISH SOCIETY FOR SEXUAL MEDICINE BSSM

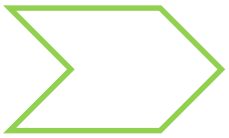
SexualAdvice Association

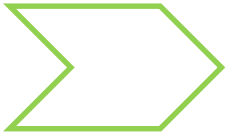
How important is information ?

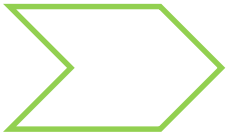
- **Outcomes measured**
  - knowing what to do next
  - anxiety
  - ability to make decisions
  - feeling of control

Findings and implications

- complex relationship between support and action
- people use multiple formats
- supported information sometimes used to challenge professionals







- keep support offer open
- maintain multi-format
- expect challenge

WE ARE MACMILLAN. CANCER SUPPORT

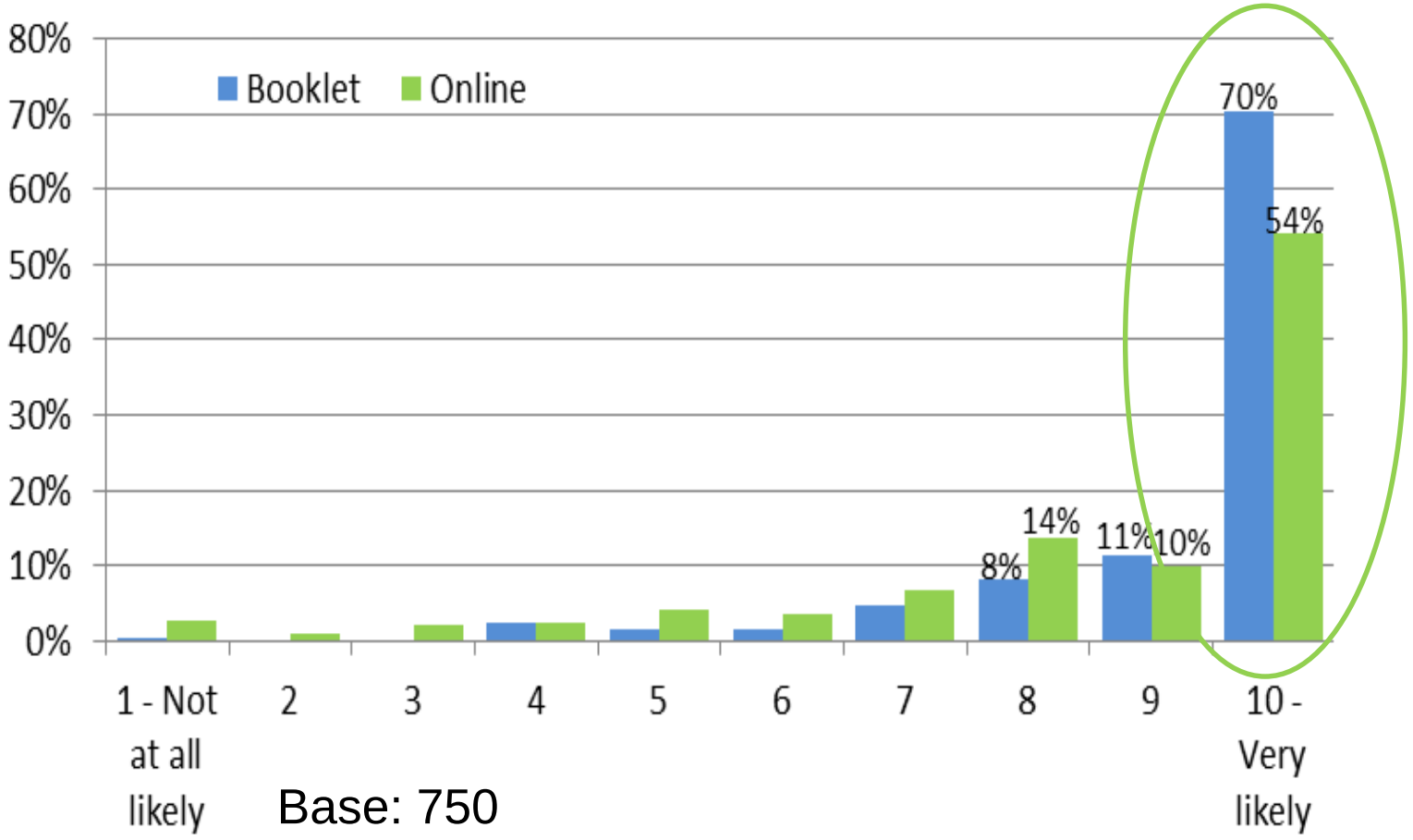
Key findings

- Most **took further action and 1 in 4 would not have done so** without the information

- 4/ 5 **would not have been aware of financial issues without the information**

WE ARE MACMILLAN. CANCER SUPPORT

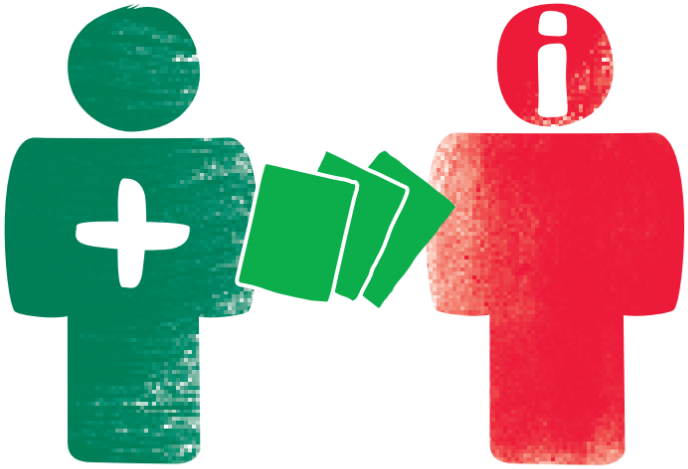
booklet versus online



NOT YET BEYOND LEAFLETS

“Introducing” information?

MORE SUPPORT, BETTER INFORMED



People who are assigned a clinical nurse specialist in hospital are **49%** more likely to be given easy-to-understand written information about the type of cancer they have.

Department of Health. Cancer Patient Experience Survey. National Report. 2013. (England and Wales)

Macmillan Information Team

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

WE ARE MACMILLAN.
CANCER SUPPORT