

REVIEW OF INFORMED CHOICE FOR CANCER REGISTRATION

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Presentation to the useMYdata group

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BACKGROUND: WHY DID WE DO THIS?



National Data
Guardian



Public Health
England

Cancer Registration

– what it is, the
benefits of being
on the register,
and your options



NHS

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WHAT WE DID

8 engagement events

2 online surveys

1 piece of commissioned research

many meetings with senior stakeholders



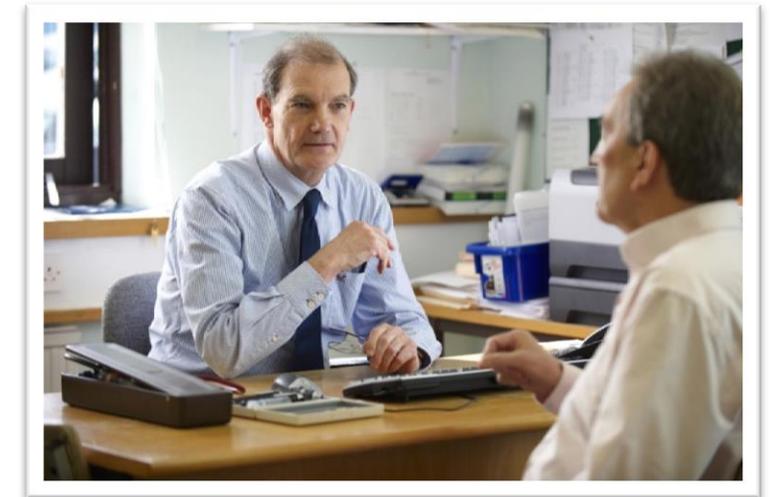
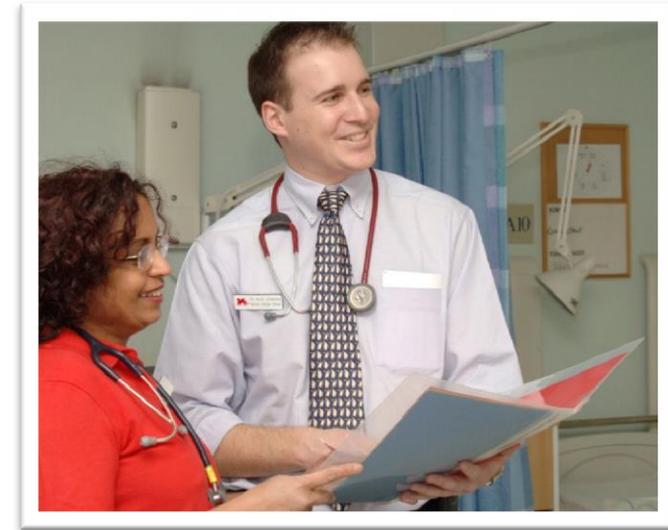
WE ENGAGED WITH...

1400 people affected by cancer

340 health professionals

1000 members of the public

20 cancer charities



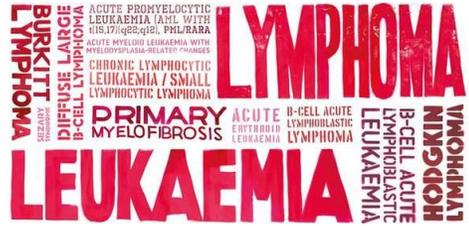
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FURTHER STAKEHOLDER ENGAGEMENT



Department of Health



PROSTATE
CANCER UK

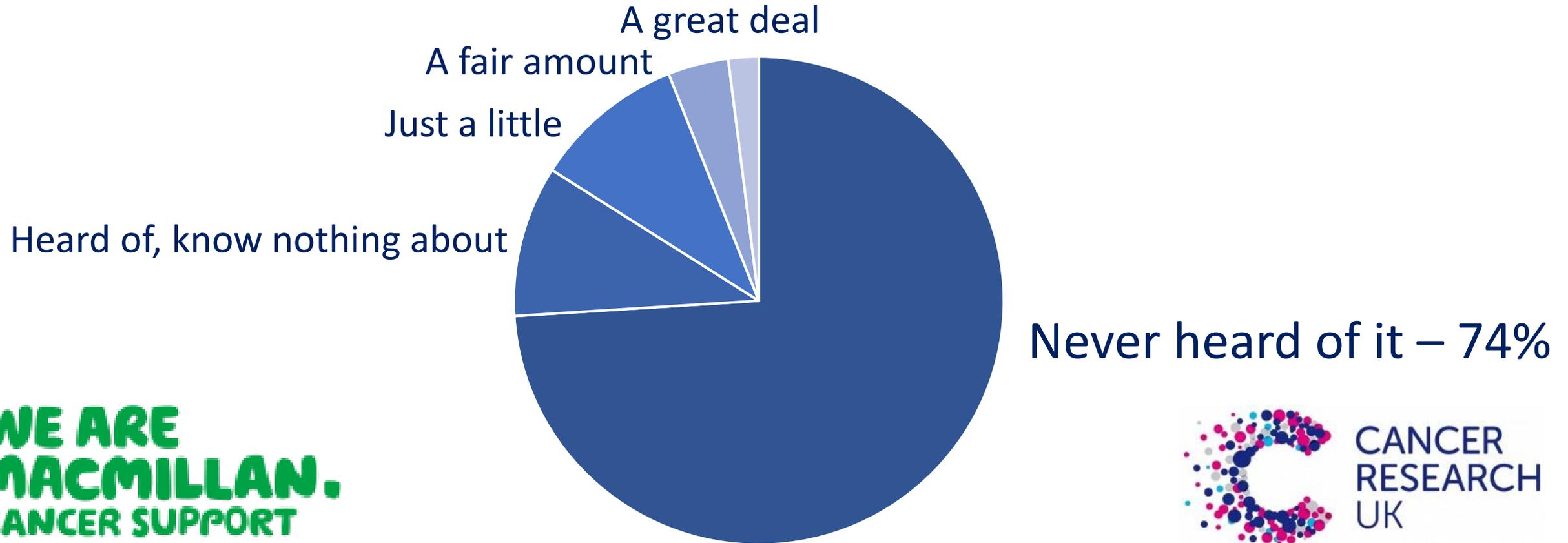


Public Health England



WHAT WE FOUND

before today, how much had you heard about the cancer registry?



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AMBITION: AWARENESS OF THE REGISTRY IS SIGNIFICANTLY IMPROVED AMONG PEOPLE WITH CANCER

83% think it's important that people with cancer are informed about the registry

Most people said they'd prefer to find out about the registry with a health professional caring for them, around the time of diagnosis

Recommendation 1: Hospital trusts should be accountable for ensuring that patients are made aware of the cancer registry and their ability to opt-out at the earliest appropriate time after diagnosis.

"I did not know that I had been on the Cancer Register for 18 years, but I am delighted that such a register exists"

"I feel I guess betrayed that 19 months into my partner's cancer battle we didn't know about this"

"No one ever told me my data was there. Not sure what to think"

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AMBITION: INFORMATION PROVIDED ABOUT THE CANCER REGISTRY IS ACCESSIBLE AND TAILORED TO RELEVANT AUDIENCES

- A conversation near diagnosis should not be the only mechanism by which people should hear about the registry
- Information should be accessible to (for example) children and those who don't speak English

Recommendation 2: there should be multiple channels through which people affected by cancer can find out about the registry and all communication materials need to be tailored to the relevant audiences.

AMBITION: AWARENESS OF THE CANCER REGISTRY IS SIGNIFICANTLY IMPROVED AMONG HEALTH PROFESSIONALS

80% of health professionals surveyed had some awareness of the cancer registry but only 26% knew that patients could opt out of it

83% said they never have conversations about the registry.

Recommendation 3: All healthcare staff that directly interact with people affected by cancer (including support staff and health professionals in primary care and palliative care) should be able to answer basic questions about the registry and signpost to further sources of information.

“I’ve never been told anything about it at any point, even during medical training” – a GP

“It comes up only rarely. When it does, my patients seem very keen that some good should come out of their records” – a palliative care consultant

AMBITION: PROCESSES FOR PROVIDING PEOPLE AFFECTED BY CANCER WITH INFORMATION ABOUT THE CANCER REGISTRY SHOULD BE MEASURABLE

Our proposed system measures at three levels:

- Measuring that Trusts have a policy in place
- Measuring that cancer teams are telling their patients
- Measuring that patient awareness is increasing

Recommendation 4: The implementation of local and national awareness-raising strategies should be measurable.

AMBITION: THE GENERAL PUBLIC ARE MORE AWARE OF HOW HEALTHCARE DATA, INCLUDING CANCER DATA, IS USED AND SHARED BY THE NHS AND OTHERS

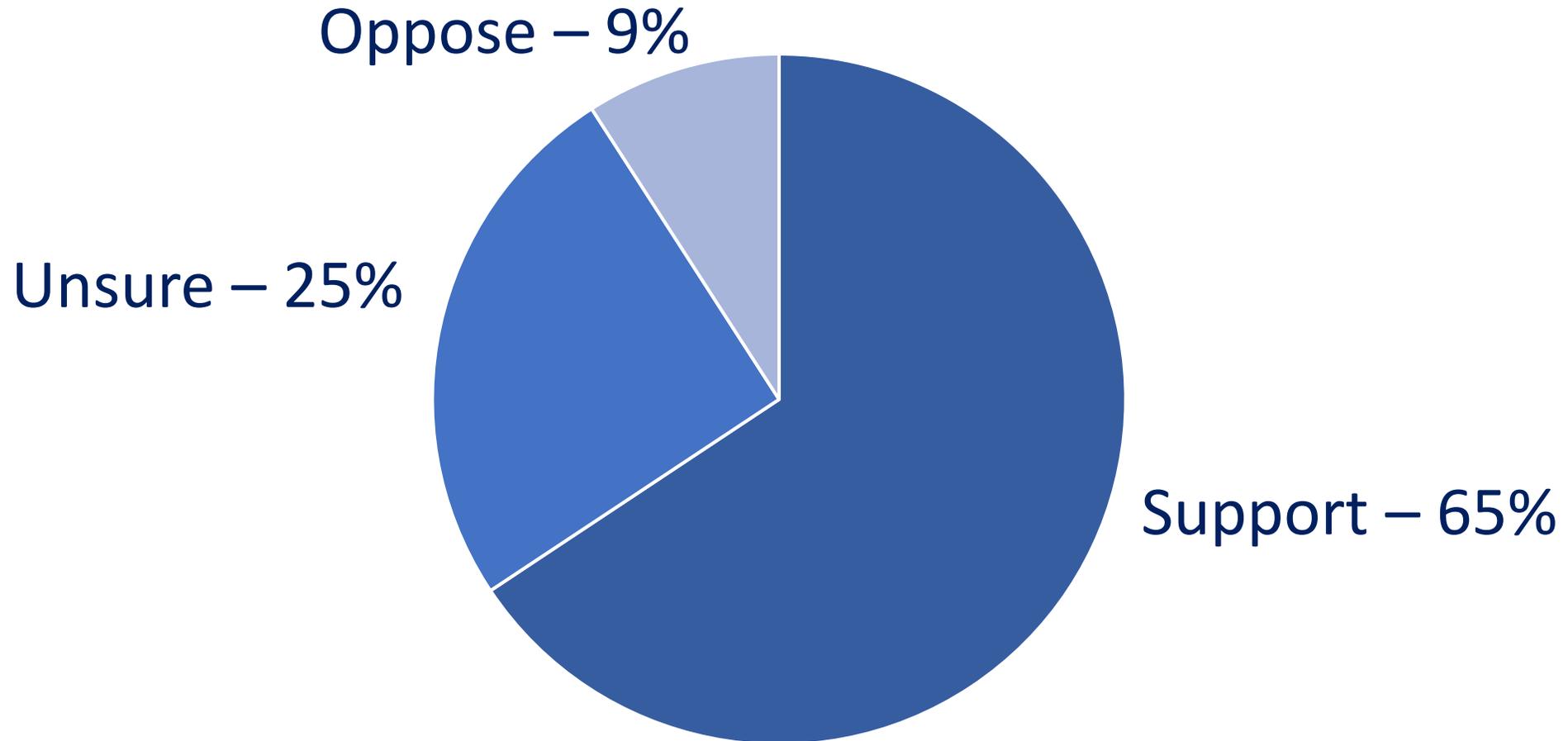
80% of the general public have never heard of the cancer registry

73% of people with cancer and 74% of the public think it's important that people know about the cancer registry regardless of whether they themselves have a cancer diagnosis

Recommendation 5: General awareness of how the NHS uses healthcare data, including cancer data, should be improved.

THE CONSENT MODEL

Do you support or oppose the current way of collecting data for the cancer registry?



“If the person involved doesn't know about the registry, how can they opt to have the information removed. So an opt in option is preferable”

“I would go further and include it by law, like contagious diseases. EVERYBODY knows someone who has had cancer; 1 in 2 of us will get it. We are all in it together; cancer registration should be a legal requirement”

NEXT STEPS

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