



Public Health
England

Improving awareness of cancer registration

Engagement and Awareness Team
National Disease Registration Service
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Here to tell you about...

- Implementing the Review of Informed Choice for Cancer Registration
- The Cancer Data Conference 2020

What the Review of Informed Choice said

- NDG review of Health and Social Care Data in 2016 found general awareness of cancer registration to be low
- The NDG initiated the **Review of Informed Choice for Cancer Registration**

Five RICCR recommendations:

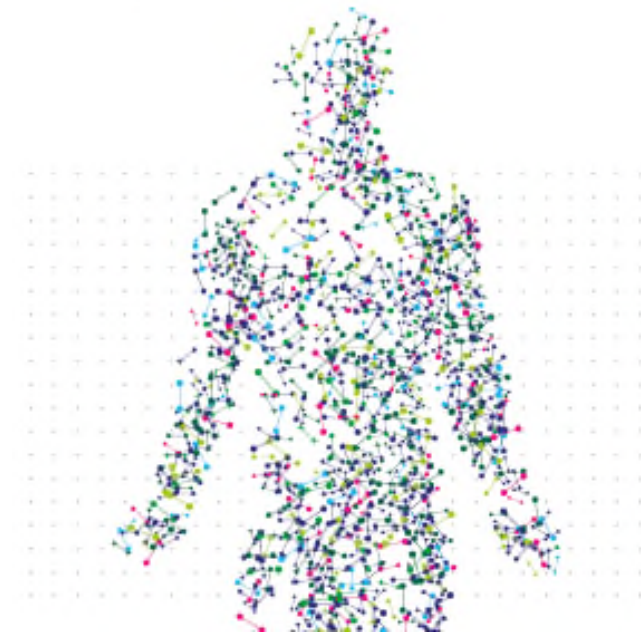
1. Trust accountability
2. Appropriate information through multiple channels
3. Role of healthcare staff
4. Measurable actions
5. Wider awareness of how the NHS uses healthcare data

WE ARE
MACMILLAN
CANCER SUPPORT



Improving awareness of the English
cancer registry amongst patients,
health professionals and the public

Review of Informed Choice for Cancer Registration
September 2018



Ultimately what this means is...

Every person who receives a cancer diagnosis should be informed about cancer registration and how their data is used and that they have a right to opt out if they wish

Opting out of cancer registration

- Everyone has the right to opt-out
- Separate to national data opt-out programme
- Does not affect the care a person is receiving
- Must be done in writing
- More information including FAQs on www.ndrs.nhs.uk

What have we been doing?

- Redeveloped patient information materials with involvement of patients and healthcare professionals
- General leaflet and specifically for teenagers
- Guidance for Trusts about their role and how they can support getting information to patients
- Created a number of public information resources
- Working closely with a number of trusts to model best practice which we can then share

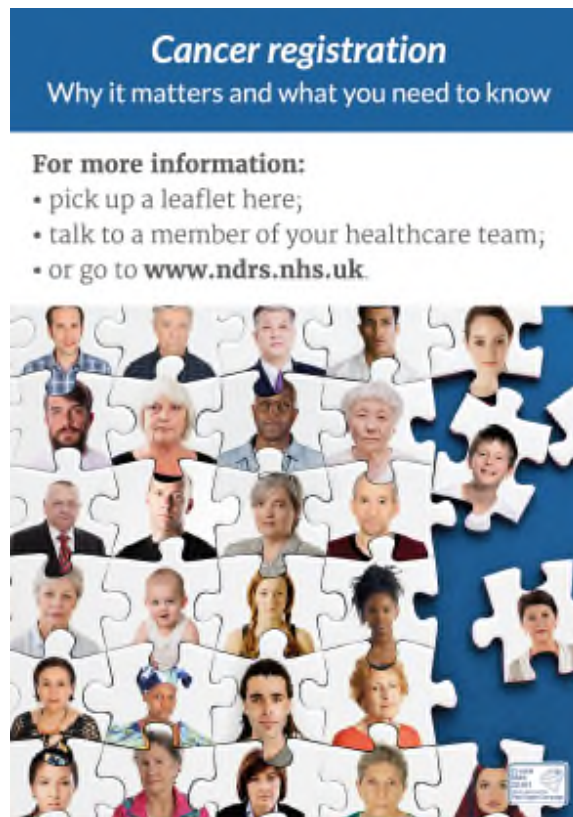
Resources



Cancer registration

Why it matters and what you need to know

A vertical leaflet cover with a blue header and a grid of diverse people's faces on a white puzzle background.



Cancer registration

Why it matters and what you need to know

For more information:

- pick up a leaflet here;
- talk to a member of your healthcare team;
- or go to www.ndrs.nhs.uk.

A horizontal leaflet content area with a blue header, text, a list of bullet points, and a grid of diverse people's faces on a white puzzle background.

www.ndrs.nhs.uk



National Disease Registration Service

PATIENTS CLINICIANS ABOUT US CANCER DATA STORIES RESOURCES NEWS GET IN TOUCH

For the big picture on cancer and rare diseases

A website header featuring a navigation menu, a central image of a puzzle with people's faces, and a tagline.



Public Health England

Your guide to your cancer information

Why it's important and what you need to know

#datatosaveslives

THERAPY RESEARCH FINANCED TOGETHER

A vertical leaflet cover with a teal background, white text, and the Cancer Research UK logo.

Cancer registration - the data journey



1

The patient

The patient's cancer journey is the source of the data

2

Patient's data is created and collected



... by their NHS healthcare team. NCRAS* supports hospitals to code and collate the data

4

Data is put in to a secure central system

... where it can be linked with data sources from other organisations



3

Data sent to NCRAS Cancer Registration Teams



... who securely collate and quality assure the data



5



The data is then used by†:

NCRAS analysts, academic researchers, charity organisations, NHS, policy makers and commissioners

To inform and improve a range of functions, including:

Future NHS services for cancer, NHS workforce for cancer, understand and address inequalities, environmental causes, better outcomes for patients



*National Cancer Registration and Analysis Service, run by PHE

†Patient data is only released under strict regulations and for medical purposes

How can you support?

- Check that leaflets are available to patients
- Contact us if you need more!
- Ask colleagues if they know about the need to ensure patients are informed, particularly healthcare staff
- Share any examples of practice with us
- Let us know if you need any more support

NDREngagement@phe.gov.uk

Cancer Data Conference 2020

Addressing variation and inequalities



Public Health
England



Save the Date
1st-2nd July 2020

Nottingham Trent University

Cancer Data Conference 2020



Public Health
England

- 1st -2nd July 2020, Nottingham Trent University City Centre Campus
- Conference theme: **Using data to understand variation and address inequalities in cancer**
- Registration now open
- Abstract submission open until 16th February 2020
- Exhibition and sponsorship opportunities
- Go to conference website to find out more: www.phe-events.org.uk/cdc20
- For more information contact the team: NDRengagement@phe.gov.uk