



Public Health  
England

# Delivering on the Review of Informed Choice for Cancer Registration

Progress update  
24 February 2020

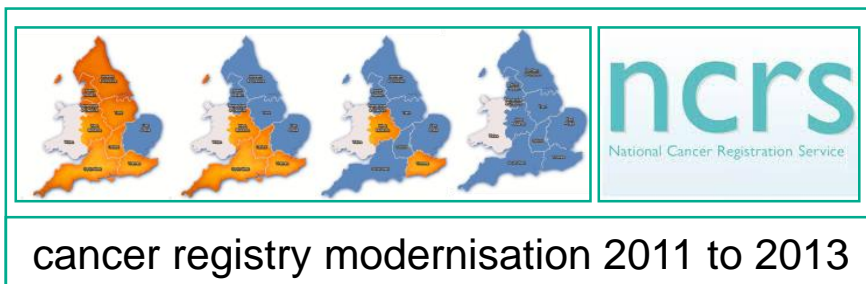
Sophie Newbound, Head of Strategic Engagement  
Megan Inett, Engagement and Awareness Manager  
The National Cancer Registration and Analysis Service  
(NCRAS)

# Overview of presentation

- Background
- The Review of Informed Choice for Cancer Registration
- PHE response plan and priorities
- Areas of progress on the recommendations
- Challenges, alternative approaches and lessons learnt
- Feedback
- Next steps
- Questions and discussion

# National Cancer Registration Timeline

8 regional  
cancer  
registries



Merger of NCIN and  
Cancer Registration to  
create NCRAS



Review of  
Informed Choice  
published

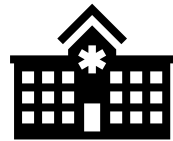
before 2008 2009 2010 2011 2012 2013 2014 2015 2016 2017 2018

# The National Cancer Registration and Analysis Service (NCRAS)

- National dataset with information about every single cancer diagnosis in England
- We collect data on over 300,000 patients diagnosed with cancer each year
- Data collected from:



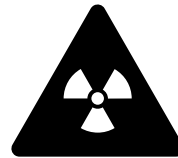
2,000  
Multidisciplinary  
Team Meetings



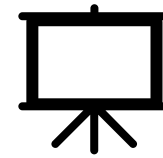
174  
Secondary  
Care trusts



142  
Chemotherapy  
centres



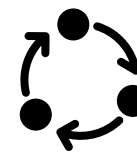
56  
Radiotherapy  
centres



82 Breast  
screening  
centres



22 Molecular  
testing labs



26+ other  
sources

- Produce 10 national data sets
- Supports around 30,000 genetic requests each year
- In 2018/2019, 235 major outputs and publications were released including 6 national statistics and 2 official statistics

# Cancer registration opt-out

- NCRAS operates under Section 251 of the NHS Act 2006
- S251 approval reviewed annually by the Confidentiality Advisory Group
- 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 to verify identity

# Review of Informed Choice for Cancer Registration

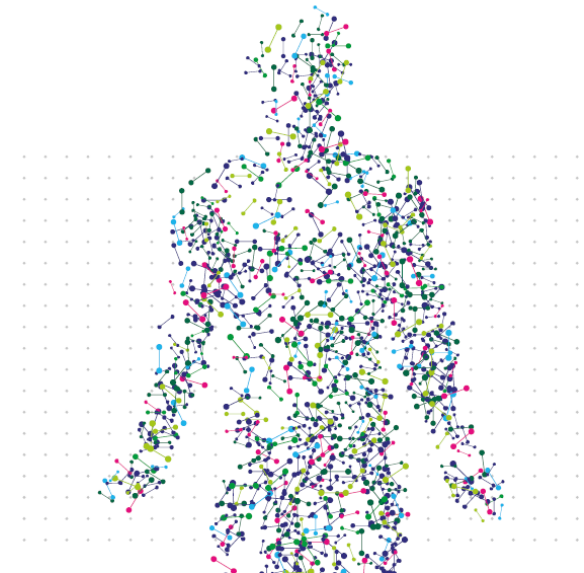
- National Data Guardian review of Health and Social Care Data in 2016 found general awareness of cancer registration to be low
- Review of Informed Choice for Cancer Registration undertaken by Macmillan and CRUK
- Recommendations:
  1. Hospital trusts should be accountable for ensuring patients are made aware of the cancer registry and their ability to opt out
  2. There should be multiple channels through which people can get information about cancer registration
  3. All healthcare staff that directly interact with patients should be able to answer basic questions about cancer registration and signpost to more information
  4. Implementation of awareness-raising strategies should be measurable
  5. General awareness of how the NHS uses healthcare data should be improved

WE ARE  
MACMILLAN  
CANCER SUPPORT



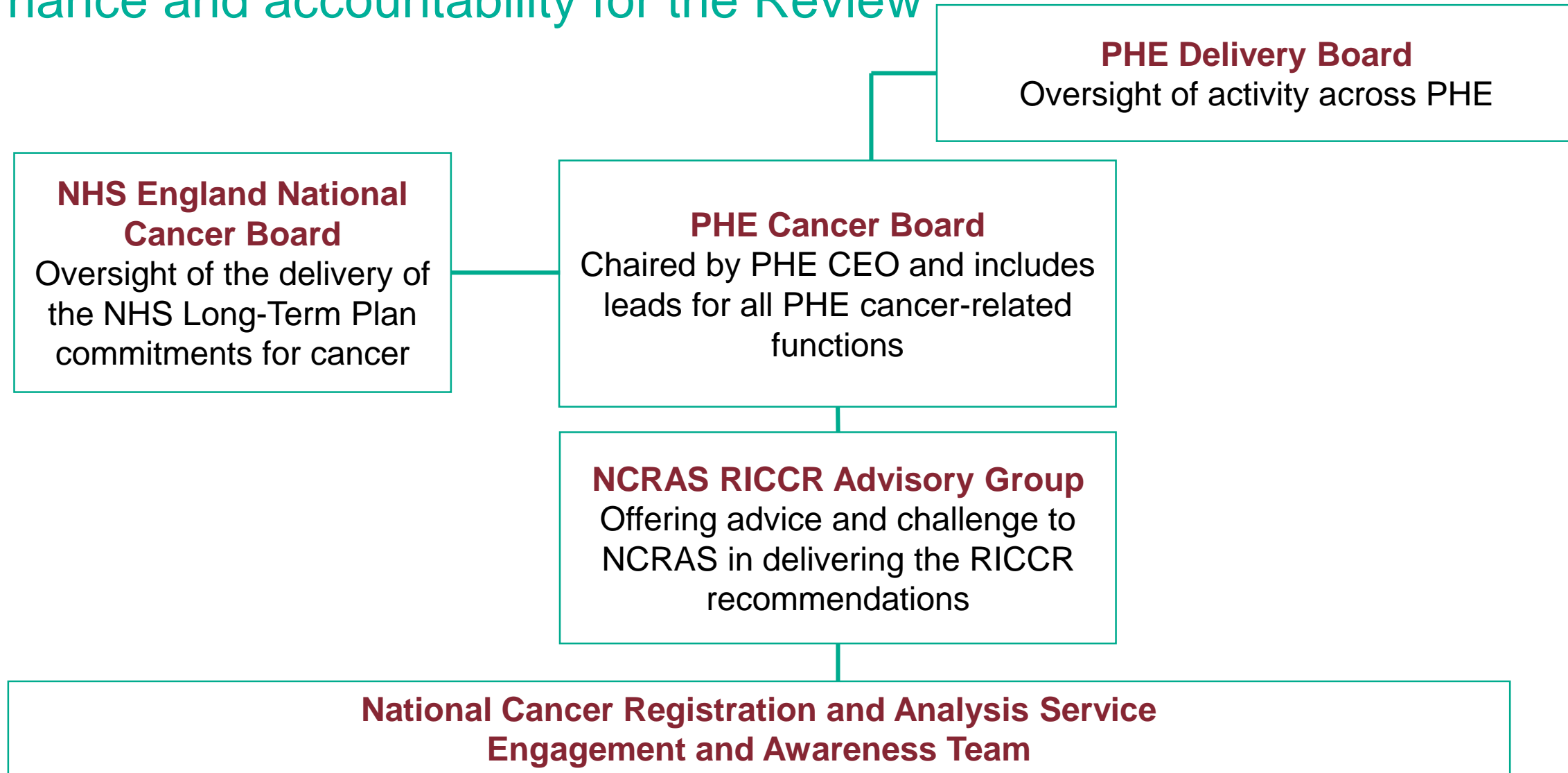
Improving awareness of the English  
cancer registry amongst patients,  
health professionals and the public

Review of Informed Choice for Cancer Registration  
September 2016



View report [here](#)

# Governance and accountability for the Review

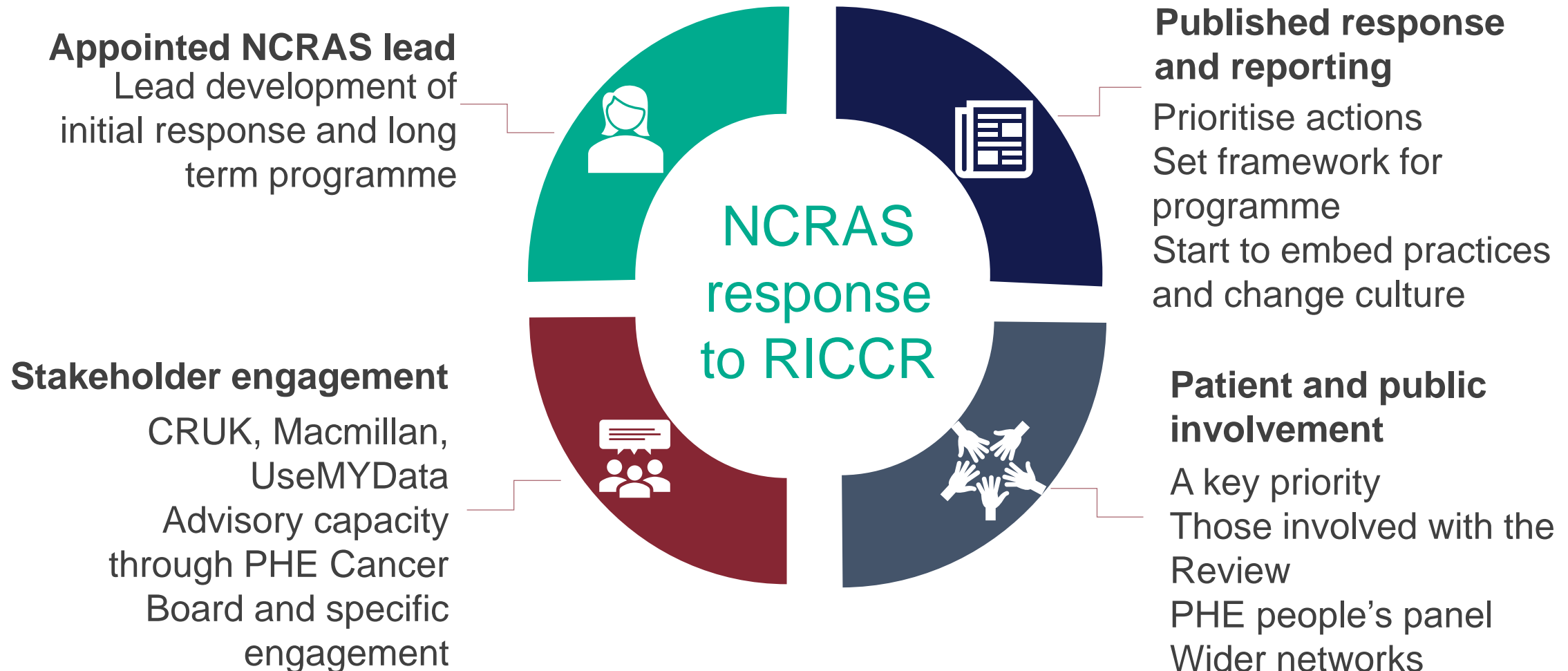


# NCRAS RICCR Advisory Group membership

<b>Name</b>	<b>Affiliation</b>
<b>Alexandra Callaghan</b>	Policy Manager for Health, Macmillan,
<b>Bhavisha Hirani</b>	Engagement and Awareness Project Manager, NCRAS
<b>Bonnie Green</b>	Patient Representative
<b>Janette Rawlinson</b>	Patient Representative
<b>John Marsh</b>	Patient representative
<b>Matt Sample</b>	Policy Advisor, CRUK
<b>Megan Inett</b>	Engagement and Awareness Manager, NCRAS,
<b>Michael Eden</b>	Consultant Pathologist at Cambridge University Hospitals, UK Clinical Lead and Associate Caldicott Guardian for NCRAS
<b>Natalie Doyle</b>	Nurse Director – Patient Experience, Royal Marsden (Chair)
<b>Orfhlaith Kearney</b>	Engagement and Awareness Administrative Officer, NCRAS
<b>Sophie Morris</b>	Public Information Manager, NCRAS
<b>Sophie Newbound</b>	Head of Strategic Engagement and Development, NCRAS



# NCRAS response plan and priorities





Public Health  
England

Protecting and improving the nation's health

## **National Cancer Registration and Analysis Service Response to the Review of Informed Choice**

PHE publications gateway number: 2016701

Published: March 2017

# Priority Actions & Principles

- Our actions and new ways of working will be focused on the following values and principles:
  1. Engagement with people affected by cancer and the wider public will inform the actions that we take, ensuring that the needs of patients and the public are at the heart of what we do
  2. Close working with key partners including health professionals, third sector organisations, academia and other health bodies will enable information about the cancer registry to reach further
  3. Improving our communications and profile to better communicate our work to multiple stakeholders and to see that the work of the cancer registry is acknowledged for its role in healthcare
  4. Developing our capacity and capability to ensure we have the relevant skills and knowledge to deliver on our ambitions

# Addressing 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 possible time after diagnosis”

**Cancer Registration: why it matters and what you need to know**

The National Cancer Registration and Analysis Service (NCRAS), which is part of Public Health England (PHE), collects data on all cancer patients being treated by the NHS in England. Information about their disease and the treatment they are receiving helps to:

- Improve the quality of care
- Plan cancer services
- Track cancer rates and establish survival statistics

It's really important that patients know this is happening and we'd like your help to make sure they do.

**Public Health England**

**Three things PATIENTS with cancer and their carers should know:**

1. Data about them and their cancer diagnosis is automatically collected and passed to PHE.
2. This data helps doctors and researchers understand more about cancer, such as how many people have the disease or who might get it in the future and ensure they get the best care possible.
3. They can opt out if they wish and it won't affect the quality of care they receive.

**Three things STAFF should know about cancer registration:**

1. Every patient diagnosed with cancer should be given our leaflet about cancer registration. Contact [NCRASenquiries@phe.gov.uk](mailto:NCRASenquiries@phe.gov.uk) for more leaflets.
2. Patients prefer to be told about cancer registration by a member of their healthcare team in a face-to-face conversation. As far as is practically possible, patients should be told at the earliest appropriate time after diagnosis\*.
3. Patients should feel able to ask their healthcare team questions about their rights and the way the data about them and their disease is used. They should be helped to get further information if they want it.

**Three things TRUSTS should be doing to make sure they are compliant:**

**Frequently asked questions about cancer registration**

**Public Health England**

**What is cancer registration?**  
The National Cancer Registration and Analysis Service (NCRAS), which is part of Public Health England, collects information from the NHS about the care and treatment of all patients diagnosed with cancer. This information is included in a registry for all cancers in England.

**What information is collected?**  
NCRAS collects information about a patient's diagnosis and treatment as well as their name, date of birth, NHS number and address.

**Why is the information collected?**  
It helps us to measure overall trends in cancer, improve the diagnosis of the disease, develop new treatments and drugs, improve the way cancer services are planned and provided and to inform national policy.

**How is the information used?**  
So that we can identify the causes of the disease and monitor different cancer types. This in turn, helps doctors to improve cancer diagnosis, develop new drugs, improve treatments as well as plan NHS services.

**Is the information shared?**  
Information is sometimes shared with other organisations, like NHS England and Cancer Research UK, which use it to conduct research. Information is only shared under strict conditions and only to improve patient outcomes. Information is never sold.

**Why is it important for patients to know about cancer registration?**  
NCRAS has a legal right to collect this information from the NHS without the patient's permission, but patients need to know this happens and how important the information is for improving cancer care. Patients can choose to opt-out of cancer registration.

**Why is the information collected without consent?**  
NCRAS has special legal permission, as part of section 251 of The NHS Act, 2006. NCRAS can do this because collecting this information to conduct research to improve cancer is so important to public health.

**Who can patients contact if they have any questions or concerns?**  
Patients can talk to their healthcare team, visit the National Disease Registration Service (NDRS) website: [www.ndrs.nhs.uk](http://www.ndrs.nhs.uk) or email [NCRASenquiries@phe.gov.uk](mailto:NCRASenquiries@phe.gov.uk)

**How can a patient opt-out of cancer registration?**  
All patients have the right to opt out of cancer registration. This will not affect the care they receive. To request an opt-out form, email [optout@phe.gov.uk](mailto:optout@phe.gov.uk), or write to: Director, National Cancer Registration and Analysis Service, Public Health England, Wellington House, 133-135 Waterloo Road, London SE1 6UG.

**How does the national opt-out apply to cancer registration?**  
A patient's national data opt-out preferences will not apply to the information we collect. We will apply a patient's preferences on personally identifiable information that is shared with organisations and institutions who want to use it for research and to plan health and care services.

Version 1.0 February 2018

Local contacts

Sent to all hospital trusts

Explored roles and responsibilities, for example Caldicott Guardians

Materials available online

Developed trust guidance

Investigated NHS QST

Ongoing dialogue with trusts

Documenting local practices

# Feedback from trusts about local practices

**Method of distribution: York Teaching Hospitals Foundation Trust** – “Leaflets are placed in oncology outpatient areas, in the Cancer Care Centre Information and Support Services and placed in information packs for newly diagnosed patients with cancer”

**Staff involved in distribution: University Hospitals of North Midlands NHS Trust** – “Cancer Nurse Specialist team member present in clinic will give the new patient information packs and explain the contents”

**Informing staff about their role: Whittington Health Trust** – “The guidance and the distribution of information was discussed at the Cancer Board meeting, disseminated to CNS team during team meeting and shared with staff group”

Public Health England  
England

Cancer registration information: local arrangements  
Version 1.0 February 2019

### Cancer registration information: local arrangements

Please complete this form with the relevant local information for your trust. This document should be shared with all relevant members of staff and updated as and when your arrangements change. When completed please return a copy of this form to [NCRASfeedback@phe.gov.uk](mailto:NCRASfeedback@phe.gov.uk)

TRUST/HOSPITAL:

DATE:

**1. LEAD CONTACT FOR CANCER REGISTRATION INFORMATION**

The person responsible for the completion and implementation of this policy, monitoring compliance and disseminating this information to all relevant staff members involved in care of cancer patients.

Name:

Email:

Role:

**2. CANCER REGISTRATION INFORMATION LEAFLET AND POSTER DELIVERY DETAILS**

The named contact and address for receiving the cancer registration information leaflet and poster. Leaflets are sent on a quarterly basis. The Cancer Registration patient information leaflet is available in accessible formats including large print, audio and Braille and some additional languages. Contact [NCRASenquiries@phe.gov.uk](mailto:NCRASenquiries@phe.gov.uk) if you require more information or additional copies of the leaflet.

Name:

Role:

Delivery Address:

1

# What has changed?

✓ Information on local practices in 103 hospital trusts

✓ Formal guidance available to support practices

✓ SOP for tracking leaflet dissemination

✓ Improved understanding of processes within trusts

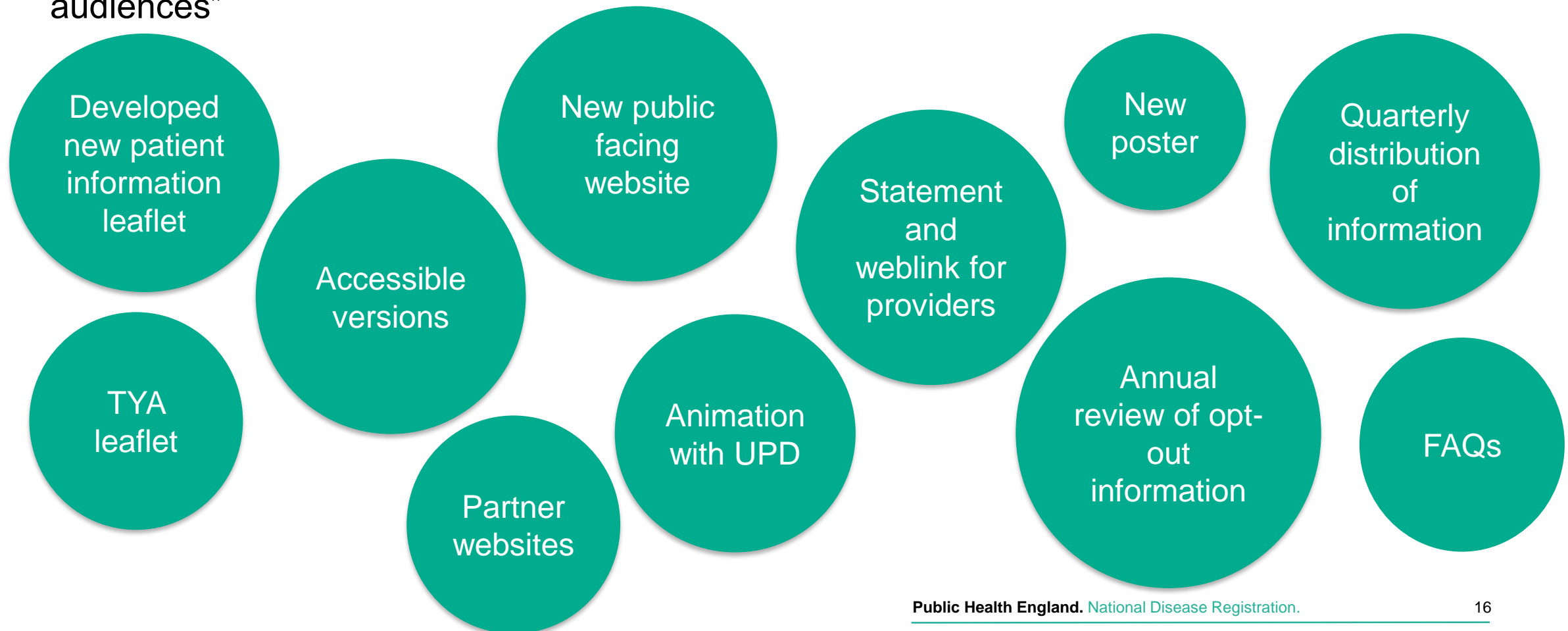
✓ Open dialogue with trust contacts

# Challenges

- No universal approach to accountability across trusts
  - Feasibility of identifying an accountable person in each trust
  - Explored role of Caldicott Guardians as accountable person
  - Changes to NHS Quality Surveillance Team
- 
- ✓ Guidance documents developed to encourage trusts to formalise distribution practices and identify key people involved
  - ✓ Exploring case modelling in specific trusts

# Addressing Recommendation 2

“There should be multiple channels through which people affected by cancer can find out about the registry and all the communication materials need to be tailored to the relevant audiences”





# New patient and public information resources

**Cancer registration**

Why it matters and what you need to know



**Cancer registration**

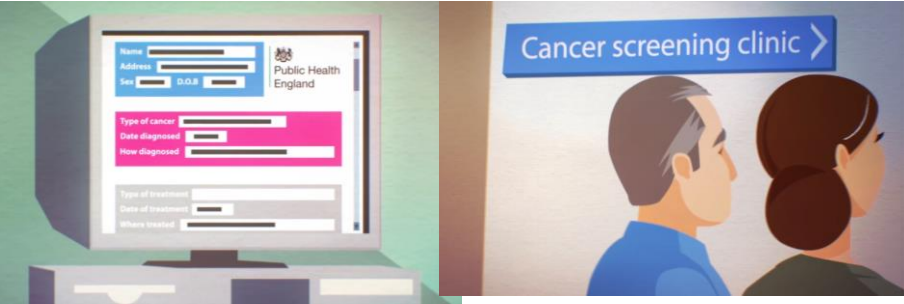
Why it matters and what you need to know

- For more information:**
- pick up a leaflet here;
  - talk to a member of your healthcare team;
  - or go to [www.ndrs.nhs.uk](http://www.ndrs.nhs.uk).



## [www.ndrs.nhs.uk](http://www.ndrs.nhs.uk)

National Disease Registration Service PATIENTS CLINICIANS ABOUT US CANCER DATA STORIES RESOURCES NEWS GET IN TOUCH



Public Health England

### Your guide to your cancer information

Why it's important and what you need to know

#datasaveslives

AN ASSOCIATION WITH TEENAGE CANCER TRUST

# 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

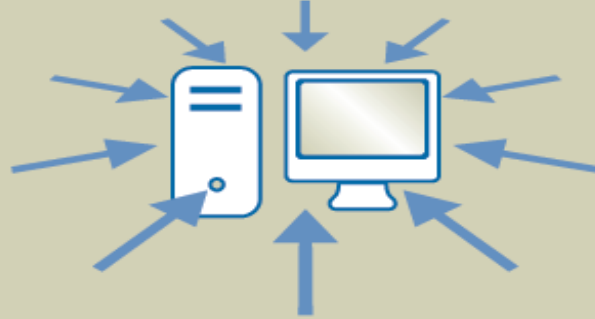


... by their NHS healthcare team. NCRAS\* supports hospitals to code and collate the data

**4**

## Data is put in to a secure central system

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



**3**

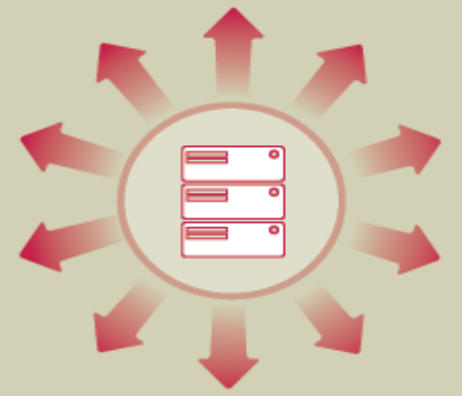
## Data sent to NCRAS Cancer Registration Teams



... who securely collate and quality assure the data



**5**



## The data is then used by†:

NCRAS analysts, 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

# What has changed?

✓ Process for oversight of distribution of leaflets

✓ 2016 – 41,620 leaflets to 162 hospital trusts

✓ 2019 – 326,355 leaflets to 174 hospital trusts and 118 additional specific locations

✓ 2020 – Dissemination of TYA leaflet to CTYA clinics

✓ Public facing website

✓ 9 organisations with website information

✓ Increase in number of places contacting us for more resources

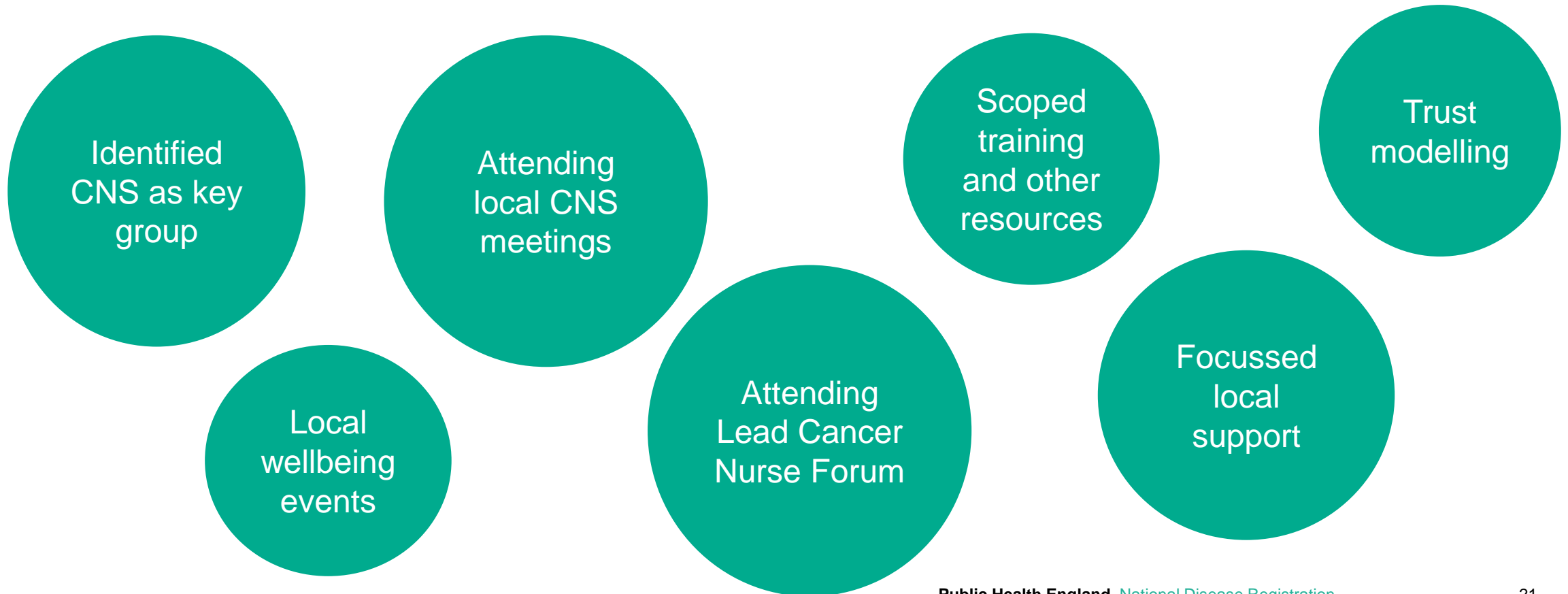
✓ Increase in number of enquiries from patients

# Challenges

- Multiple channels for information is important as no right time in a patients' journey to receive this information
- Other organisations do not prioritise the information – contacted 50 charities, 9 added information on their website
- No incentive to prioritise this information over other patient information
- ✓ Trusts provided with statement and website address to add to own leaflets, letters and information sources as part of trust guidance documents
- ✓ Actively seeking additional locations and alternative means to get information to patients and their families

# Addressing Recommendation 3

“All healthcare staff that directly interact with people affected by cancer should be able to answer basic questions about the registry and signpost to further sources of information”



# What's changed?

✓ Dialogue with key staff groups to inform resources and approaches

✓ Site visits and provided guidance

✓ NDRS website is providing key information for healthcare professionals

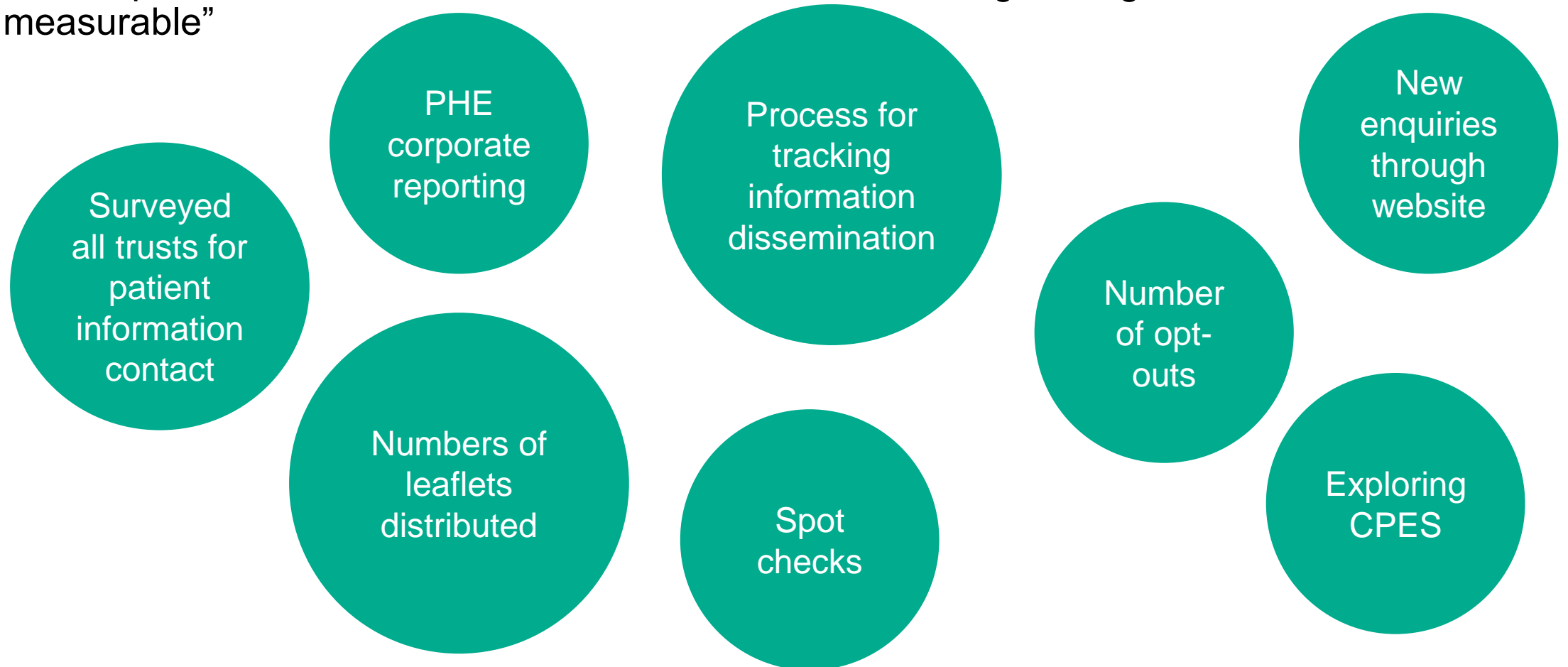
✓ Understand challenges in delivering in practice

# Challenges

- Reaching all staff members within each trust and primary care
  - Healthcare professionals struggle to deliver all that is required
  - Cancer registration information not considered a top priority
  - Lack of awareness with consultants in particular
- 
- ✓ Case modelling with specific trusts
  - ✓ Explore possibilities through Royal Colleges

# Addressing Recommendation 4

“The implementation of local and national awareness-raising strategies should be measurable”





# What's changed?

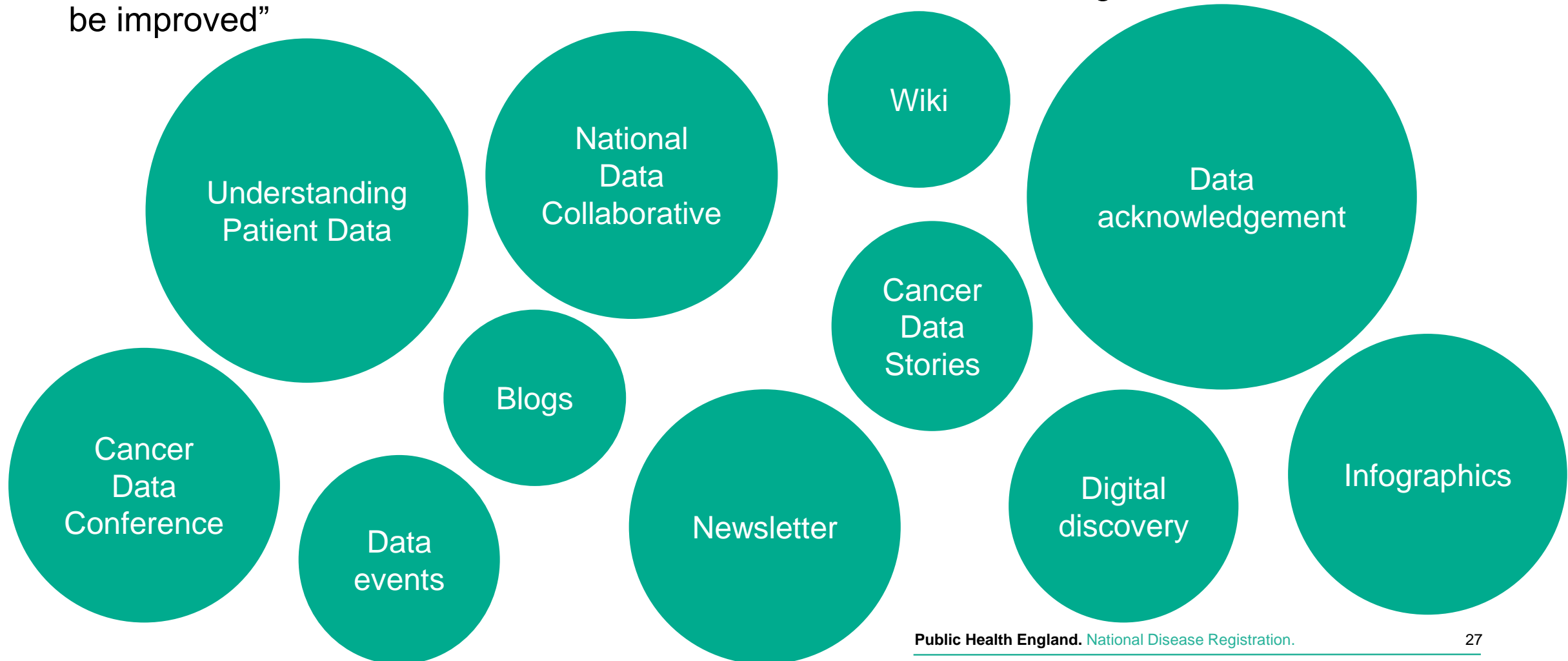
- ✓ Leaflet dissemination monitoring documents 2016 to present
- ✓ Improved relationship with patient information contacts
- ✓ SOP for tracking leaflet dissemination
- ✓ All formal and anecdotal feedback recorded, including spot checks 2017 to present
- ✓ Reporting to PHE Cancer Board/ PHE Business Plan
- ✓ RICCR Advisory Group
- ✓ SOP for information material development and review

# Challenges

- Measuring changes in awareness is difficult, therefore using measurements of outputs and activity
- Explored inclusion in CPES
- Physical checks done when possible
- ✓ Expanded tracking to include regular email contact, recording all feedback about how information is being used and displayed and tracking completed local practice forms we are sent
- ✓ Qualitative and anecdotal feedback helping to shape next steps

# Addressing Recommendation 5

“General awareness of how the NHS uses healthcare data, including cancer data, should be improved”



# What's changed?

✓ Increased engagement and collaboration with whole system

✓ Suite of new resources

✓ SOP for standard acknowledgment use

✓ Active in sharing information and messages

# Challenges

- Identity
  - Volume of information
  - Requires involvement of whole system to achieve overall improvements
- 
- ✓ Continue to work closely with patients and members of the public to inform our practices
  - ✓ Exploring engagement through new channels
  - ✓ Increase collaborations with others in healthcare data field

# Key Achievements

- ✓ Dedicated team to support goals of RICCR
- ✓ Cancer Registration leaflet distribution January 2019 to January 2020
  - **326,355 leaflets sent out to:**
  - 174 hospitals
  - 24 additional Macmillan Information Centres
  - 17 radiotherapy centres
  - 7 private care providers
  - 1 charity
  - 5 support centres
  - 27 disease specific clinics
  - 4 research studies
  - TYA leaflets being sent to 33 TYA units
- ✓ Established the NCRAS Review of Informed Choice for Cancer Registration Advisory Group
- ✓ Increased collaborative working and transparency
- ✓ Cancer Data Stories and Blogs
  - Breast cancer – Predict tool & BARD project
  - Lung cancer
  - Brain Tumour
  - Ovarian cancer
  - Risk of suicide after cancer diagnosis
  - Pancreatic cancer
  - Chemotherapy consent form
- ✓ New Resources
  - TYA information leaflet
  - Cancer data stories and blogs
  - Publication library
  - Redeveloped FAQs
  - Data journey infographics
  - Monthly NDR newsletter to 2,024 recipients
- ✓ One day events
  - Developments in Data for Rare and Less Common Cancers
  - Developments in genomic and molecular cancer data
- ✓ Formalising and embedding practices, SOPs, regular reviews, culture of ‘so what’



“It’s important that everyone has access to a range of information about cancer registration, what it is and how the data is used. Having been involved with NCRAS as a member of the Advisory Group for the Review of Informed Choice on Cancer Registration as a cancer patient partner from its beginning, from my perspective great strides have been made in providing, through a range of communication channels that is cancer data stories and infographics, evidence of how cancer registration data is used to improve cancer care and thus improve public and professional awareness.”

**Bonnie Green, Cancer patient partner and member of NCRAS RICCR Advisory Group**

# Challenges

- Accountability and responsibility
  - Reaching the right people
  - Prioritisation of other information
    - Pressures of service delivery
- Practical implementation
  - Roles of others in healthcare data system
  - Organisations priorities



# Current priorities

- Case modelling with Royal Marsden and Kingston in first instance
- Expanding reach of our information materials
- Refining resources based on feedback
- Update of NDRS to reflect people's main queries and information needs
- Work with Royal Colleges to identify possible training opportunities
- Using lessons learnt to identify alternative approaches

# Discussion points and questions

1. To gain the steering group members feedback
2. Any specific comments regarding the challenges
3. To review the reporting procedures to the NDG to take account of the development in programme objectives and ongoing work

# Thank you

Sophie Newbound, Head of Strategic Engagement

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