

# \* Using patient data - where are we now?

use MY data is a movement for cancer patients; it aims to build confidence in the use of patient data for analysis and research.

use MY data will increase the involvement of patients in decisions about how *their* data is used and in communicating the importance of this work.

use MY data was established by the National Cancer Intelligence Network, with the support of Cancer Research UK. To become involved or to obtain more information, please email

[usemydata@ncin.org.uk](mailto:usemydata@ncin.org.uk)

# \* Updates: Using patient data...

## Cancer registration

- Staging
- Chemotherapy data
- Radiotherapy data
- Prescriptions (sample)
- Imaging (sample)

# \* Updates: Using patient data...

## Cancer intelligence

- “Routes” site-specific briefings and comms
- Chemotherapy mortality
- Routes by Stage

## Toolkits

- Cancer Commissioning Toolkit migration
- GP Profiles on Fingertips
- CancerData portal
- Taskforce CCG Dashboard (initial)

# \* Updates: Using patient data...

## Data Release

- Office for data Release (ODR) running
- Clear and transparent processes
- Release register on web
- Additional resource approved with partners

# \* Updates: Using patient data...

## Serious risk to cancer data and intelligence.....

- The Health & Social Care Information Centre (HSCIC) has been instructed by the Department of Health to act on the Type 2 objections received following the care.data public information campaign.
- The National Data Guardian (NDG) for Health and Care, Dame Fiona Caldicott, has been asked by Secretary of State to advise on a new national consent and objection model covering the whole of the health and care system.

# \* Updates: Using patient data...

## Serious risk to cancer data and intelligence.....

- Both Type 2 objections and the new consent model mean that patients will be able opt out of their confidential information being shared
  - (except to support direct care and for notifiable infectious diseases.
- Cancer registration is **not** expected to be one of the exempt purposes.



# \* ACHIEVING WORLD-CLASS CANCER OUTCOMES: A STRATEGY FOR ENGLAND 2015-2020 - July 2015

“An inability to link data sets and make these available to providers, commissioners and researchers sustains the provision of sub-standard care. There is extensive evidence that cancer patients want their data to be used for research and to improve care. **We must harness their support, ensuring cancer patients are placed at the heart of strengthening our cancer data intelligence.**”

