

Accessing Data

An introduction to the Cancer Analysis System

Sally Vernon

National Cancer Registration Service

sally.vernon@ecric.nhs.uk

Cancer Outcomes Conference 2013

The National Cancer Intelligence Network is now operated by Public Health England



Overview

- Why do we need to improve access to data?
- What is the Cancer Analysis System?
- Why a centralised system?
- What are the key challenges?
- How can I get involved in shaping the CAS?

Acronym Alert!

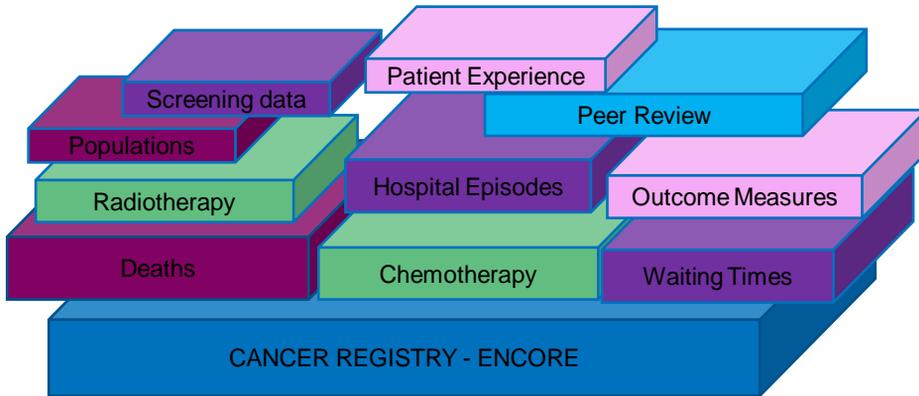
CAS

Cancer Analysis System

**Why do we need to improve
access to data?**

Growing range of data

There is an ever growing and improving range of data sets relating to cancer:



Wide range of analysts

And a huge variety of organisations wanting to research on cancer data



Public Health
England

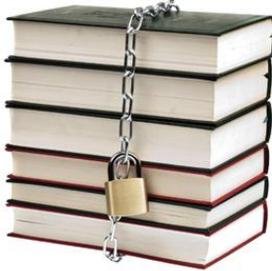


**WE ARE
MACMILLAN.**
CANCER SUPPORT



Data is worthless if not used

Health data is sensitive and confidentiality and information governance are key



However, if no-one ever does anything with the data, collecting it is pointless!

Improving access to data

If done carefully

- Respect confidentiality
- Access for approved users only

**Improved access to data will help in
the fight against cancer**

- Better information and intelligence
- Improved cancer care and cancer outcomes

What is the Cancer Analysis System?

What is the CAS?



A big computer!

16 core 2.4GHz server

128 GB RAM, 20 x 0.9TB hard drives

Secure and encrypted

What is the CAS?



- Cancer data in a database on the server
- All National Cancer Registration Service data
- Also linked data sets
- Updated and refreshed regularly

What is the CAS?



- Server can be accessed from 'safe havens' around the country
- Users can run queries on linked datasets
- Data items and cases visible depends on user permissions.

Why a centralised system?

Reduce duplication



- Data loading and management
- Share standard queries
- Arranging permissions and data sharing agreements



Reduce divergence of datasets

- Different datasets extracted on different dates
- Linked using different methodologies
- Cleaned and Quality Assured by different teams



Huge confusion!

Calculated fields standardised

- Researchers calculate fields
- Calculated fields can be hosted in the CAS
- Available for all other users
- Standardises methodologies



Improves audit

- If datasets are handed out to researchers, cannot monitor usage
- Central system allows us to check who has logged in and what queries they have run
- Safer for patients and for researchers!



What are the key challenges?

Joined up vision

Work with other organisations to share solutions,
not duplicate



Wider Public Health England, Information Centre, etc

Increase data available

- Arrange access to further datasets
 - Radiotherapy/ Chemotherapy
 - Hospital Episode Statistics
 - Cancer Waiting Times etc
- Host more calculated fields
 - Co morbidity
 - Routes to diagnosis etc



Widen the userbase

Currently, access to the CAS is for Public Health England employees only



But need to do this with appropriate safeguards – anonymised data, review of planned research etc as appropriate

How can I get involved in shaping the CAS?

CAS Stakeholder Group

- Functioning CAS important for many organisations
- Need a group that can influence and shape the CAS and keep it looking forwards and outwards
- Establishing a CAS Stakeholder group

Get involved!

Conclusions

- Improved access to data leads to an improved understanding of cancer care
- The Cancer Analysis System allows us to
 - Standardise
 - Reduce duplication

giving access to timely, high quality, national data to be used for analysis.