

NCIN

national cancer
intelligence network



Using information to improve quality & choice

www.ncin.org.uk

Welcome.... & the purpose of the day



1. Background to NCIN
2. Reviewing, understanding and utilising what is available:

National data collection – how it is changing; how it feeds commissioning; the implementation of COSD

Using and publishing analyses of data that are available – updates on the Children's & TYA work streams & other work

3. Co creation – new work

Quality metrics to supplement peer review

Using information to improve quality & choice

1. Background to NCIN (CTYA perspective)



- Objectives
- Structure
- Challenges
- Themes

Principal Objective

To promote the use of data to:

change clinical practice &

improve outcomes for patients

Structure

Lead registries with designated responsibility for specific cancer 'sites'

NWCIS – TYA cancer

CCRG (NRCT) – Children

(Site Specific) **Clinical Reference Groups**

CTYA SSCRG

Challenges for (SS)CRGs

- Identification of / response to current policy initiatives
 - “Improving Outcomes: a strategy for cancer” Jan 2011
 - Early diagnosis / Patterns of care / Outcomes
- Support for data set development
 - NCDS, now COSD, mandated from January 2013
- Identification of important clinical indicators
 - IOG implementation & other quality measures
- Promoting clinical (and public) engagement
 - What matters to patients / families?
- Links with the research community
 - Patients outside clinical trials

Some general issues....

- Where is data currently recorded and how will it be captured?
- Will we really use the data we think we need to collect?
- How different are the needs of CTYA from those of other patients with cancer?
- The changing landscape of cancer registration

CTYA Work Programme Themes

Registration: data completeness & data quality

Diagnosis: the value of the 2 week wait and time to diagnosis; the impact of emergency admission at diagnosis

Place of treatment: referral to PTC; impact of shared care; place of death; referral for supra regional care

Patterns of treatment: patterns of delivery of RT; entry to trials

Equality: age; socio economic; ethnicity; geographical location; - influence on access and outcomes

Outcomes: relapse; survival (early & late); second cancer; life years gained; survivorship metrics; monitoring rare diagnoses treated against guidelines; centre to centre variations; co-morbidity

2. Using Data for CTYA with Cancer



- National data collection – how it is changing; how it feeds commissioning; the implementation of COSD
- Updates on the Children's & TYA work streams
- Early diagnosis
- NCIN publications & key messages on CTYA cancer
- Other work in progress