Data for and from clinical trials

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NCIN CTYA SSCRG Workshop
11 December 2013

NCRN CCL

"A leading network internationally for the conduct of clinical trials in children's cancer and leukaemia delivering world leading survival and outcomes"

"Supporting research to make patients and the NHS better"

Background

- Clinical Trials are core part of management of children with cancer
- National portfolio of 40 recruiting studies
- More than 50% of these studies are international
- More than 60% of children with cancer are treated within a clinical trial on the national portfolio
- In 2012 – 2013, 1365 children were recruited to a CCL portfolio study ~ 85% of incidence

Opportunities

Improved data linkage between service and research:

- Better feasibility assessment for new studies
- Monitor and increase equity of access to research studies for children and young people
- Enable PTCs to benchmark their activity in portfolio studies
- Optimise collection of follow-up information for research studies

What we would like to see

- **Data items collected once**, and shared between NHS service and research needs
- **Improved timeliness** for availability of data from service and research datasets
- Data collected on **100%** of patients
- All patients offered the opportunity to participate in research studies
- Robust feasibility assessments so studies completed on time and to target

COSD

Current data fields relating to clinical trials:

- CR1290 (Mandatory)
  - EE: Patient eligible, consented and entered into clinical trial
  - ED: Patient eligible, declined trial

- CR1260 (Required)
  - Type of treatment covered by cancer clinical trial
  - Surgery, chemotherapy, hormone therapy, immunotherapy, radiotherapy, combination

Limitations

- Can only be collected **once** per patient, **at diagnosis**
- Just **clinical trials**, not other forms of research
- What about patients who were not considered for clinical trial, or who were ineligible?
- Timeliness and completeness of reporting

National research activity databases

- National database of recruitment to portfolio studies – uploaded by Clinical Trials Units
- All new NIHR Clinical Research Networks required to have Local Portfolio Management System
- Many centres already collect data on patients screened for research studies
- Ability to link with other data systems is a requirement

National research activity databases - limitations

Recruitment database

- Timeliness of uploads
- Patient age at recruitment is not mandatory field

Local Portfolio Management Systems

- Patient screening information fields not mandatory
- Data collection limited to patients recruited to or considered for research study

Use of NHS number

- NHS number to be collected with consent for increasing number of trials at request of CTAAC (e.g. Inter-B NHL-ritux 2010).
- Ability to link to this data to be explored in the future.

Summary

- Recruitment to high quality clinical research studies are core part of managing children with cancer
- More than 60% of children treated within clinical trials
- Data needs for research can be integrated better leading to improvements in:
  - Equity of access to research studies
  - Recruitment activity at sites
  - Study feasibility, delivery and follow-up
  - Clinical outcomes

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