

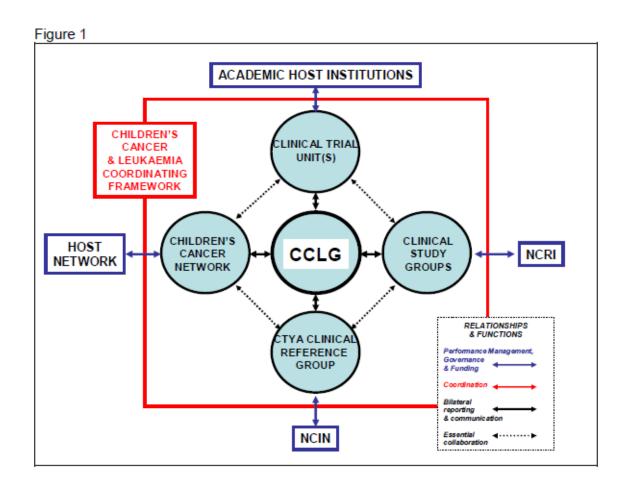
Where now for CTYA?

November 2009



CCLG: Future structure and relationships







SSCRGs - membership



- Colleges and professional groups
- Lead cancer registry
- Relevant national audit team
- NCRI Clinical Study Group
- Patients/consumers
- Voluntary sector groups
- The Cancer Network Director for the tumour site
- Representation from the 'national strategic team' (DH, NCAT, Peer Review Team, NHS Improvement)
- NCIN core management team.



Main issues for SSCRGs



- Identification of current initiatives
- Support for data set development
- Identification of main clinical indicators
- Advising on co-morbidity
- Improving staging (engaging pathologists)
- Promoting clinical (and public) engagement
- Advising on reporting
- Making the most of links with the research community
- Supporting the use of data to change clinical practice



CTYA - priorities for the work programme include:



- Finalising the new proposed National Cancer Dataset, with site / age specific defined data items
- Implementation of the IOG and preparation for Peer Review
- Key clinical outcome analyses
- Augmented data collection to support observational studies





Some key 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?

