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Retinoblastoma Registry Project:

Development of an Enhanced Disease Specific Register

19th November 2014

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Project aims

- NCRS in partnership with BCH, RLH and CCLG
- Design bespoke national disease register for the collection, audit and analysis of data on children with retinoblastoma
  - Replace existing in-house registers used in treatment centres
  - direct access to specialist clinicians for audit and analysis
  - Developed and maintained by specialist NCRS registration officers
- Expand and unify current data collection
  - *Family history, genetics, treatment plans, disease progression , second cancers*
- Pilot for other childhood cancer registers and rare adult sites
  - *e.g. Neuroblastoma, Wilms disease etc.*

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Retinoblastoma key facts

- Low incidence (~50 cases pa)
  - 40% bilateral
    - 15% positive family history
    - 85% new germline mutations
  - 60% unilateral
    - 15% genetic

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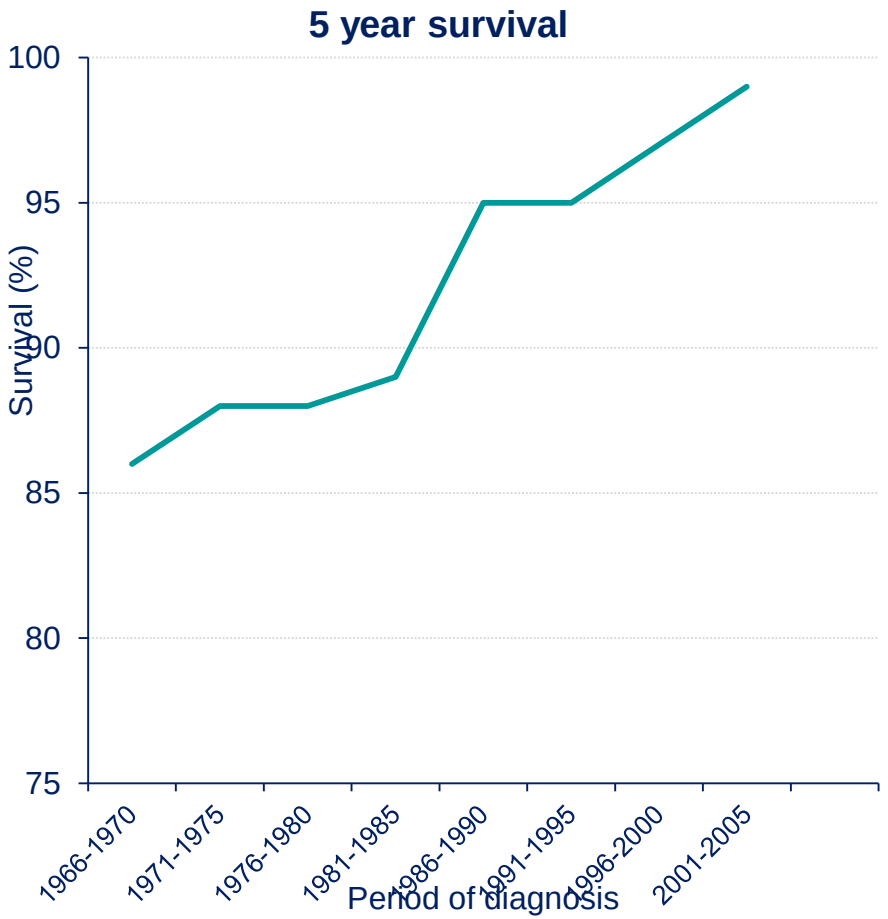
Survival

- 40 - 50 patients per year diagnosed in UK
- < 1 die from disease
- Survival >90% for 2 decades
- Conservative treatments implemented to preserve vision
- Leading cause of death is second cancer
- Newer treatment aimed at limiting radiotherapy
    - Novel chemotherapy delivery
    - Targeted innovative therapies



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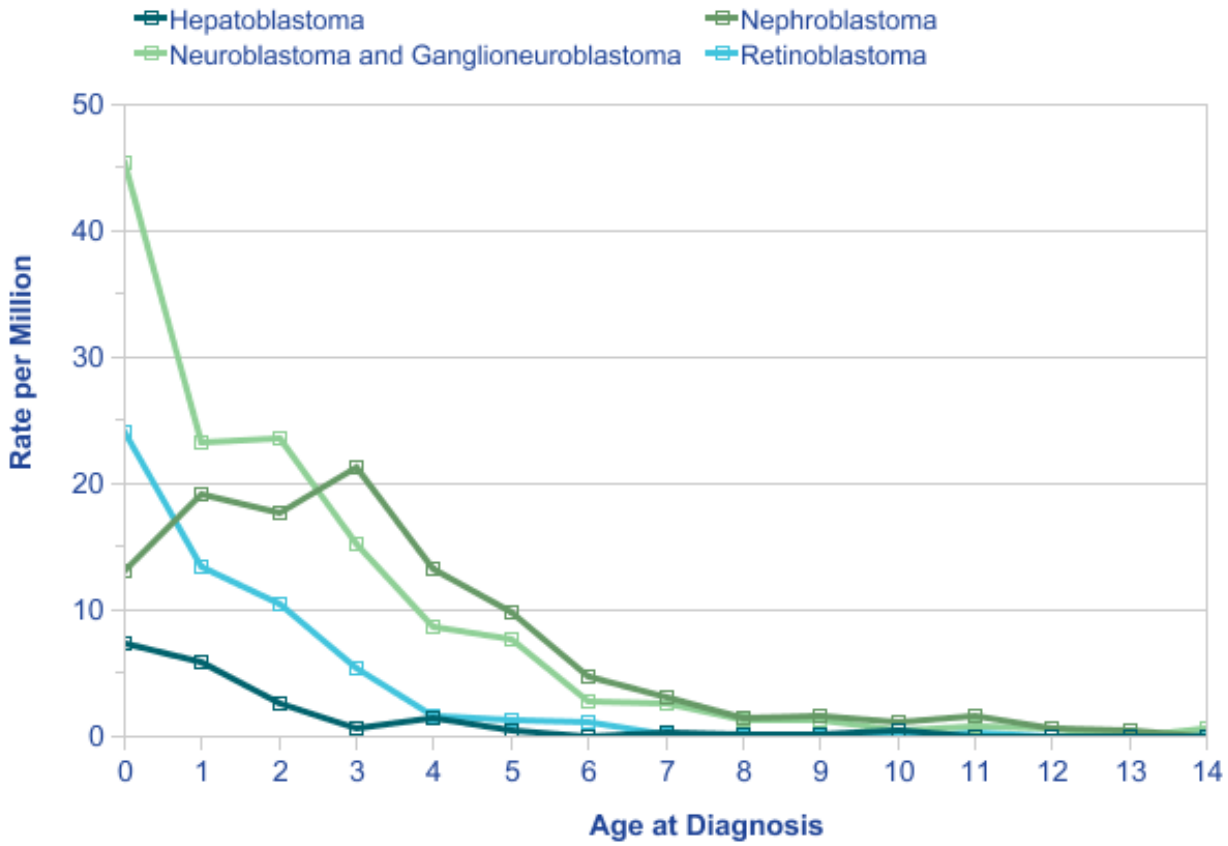
Incidence Rates Great Britain, 1996–2005



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Expanding the data set

COSD and current NHS RB data have little in common

- Key differences
  - site specific stage systems (do not map to TNM)
  - Treatments
  - *cryotherapy*, *enucleation, external beam radiation therapy (EBRT), proton beam therapy*
- **Genetic data**
- follow up information

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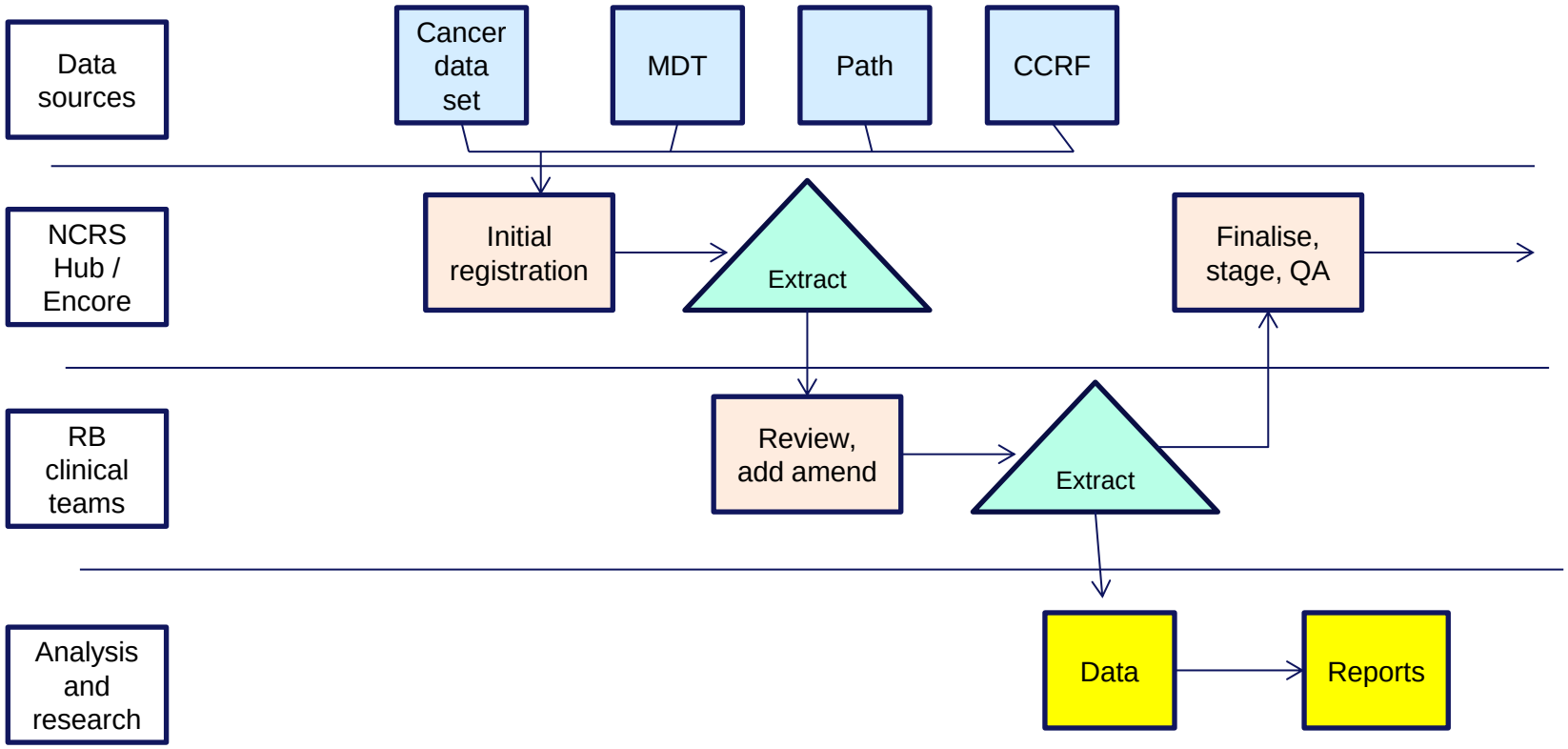
Data flow



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Next Steps

- Analysis of legacy data collected in treatment centres
- Request SSCRG to include site specific staging in COSD
- Using BCCOM on ENCORE as development model
- Contact with Childhood Eye Cancer Trust (CHECT)
- **Develop IG consent model – *how to link familial genetic info to cancer patient data within section 251 framework***
  - ***Seek parental consent***
  - ***Link to tissue bank consent form***

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Why do it?

Improving Outcomes

- making cancer registration more responsive to clinicians' needs
- encouraging greater clinical ownership of data
- Create consistency in recording, coding, QA and audit of data
- Single platform to inform treatment planning
- more effective commissioning
- Provide access for research teams to link clinical data with tissue samples
- pilot for bespoke registration of other rare cancers

- PHE business plan