

Building a National Cancer Data Resource

Chris Carrigan
Head of Coordinating Centre
NCIN

Core Objective #2:
Providing a common national repository for cancer datasets

CRS – Chapter 8 (3/3)

- A new National Cancer Intelligence Network is being established to bring together relevant stakeholders and to act as a repository of cancer data

Data from HES

- 34 million episodes
- 103 fields:
 - Patient identifiers and entities (including GP and ONS date of death)
 - ‘Patient pathway’ entities
 - Diagnosis and surgery
 - Geographies and health organisations of residence and treatment
 - HRGs

Data from Registry (ONS)

- 8.5 million tumours
- 30 fields:
 - Patient identifiers and entities (not names)
 - Tumour registration details including DCO status
 - Treatment type indicators

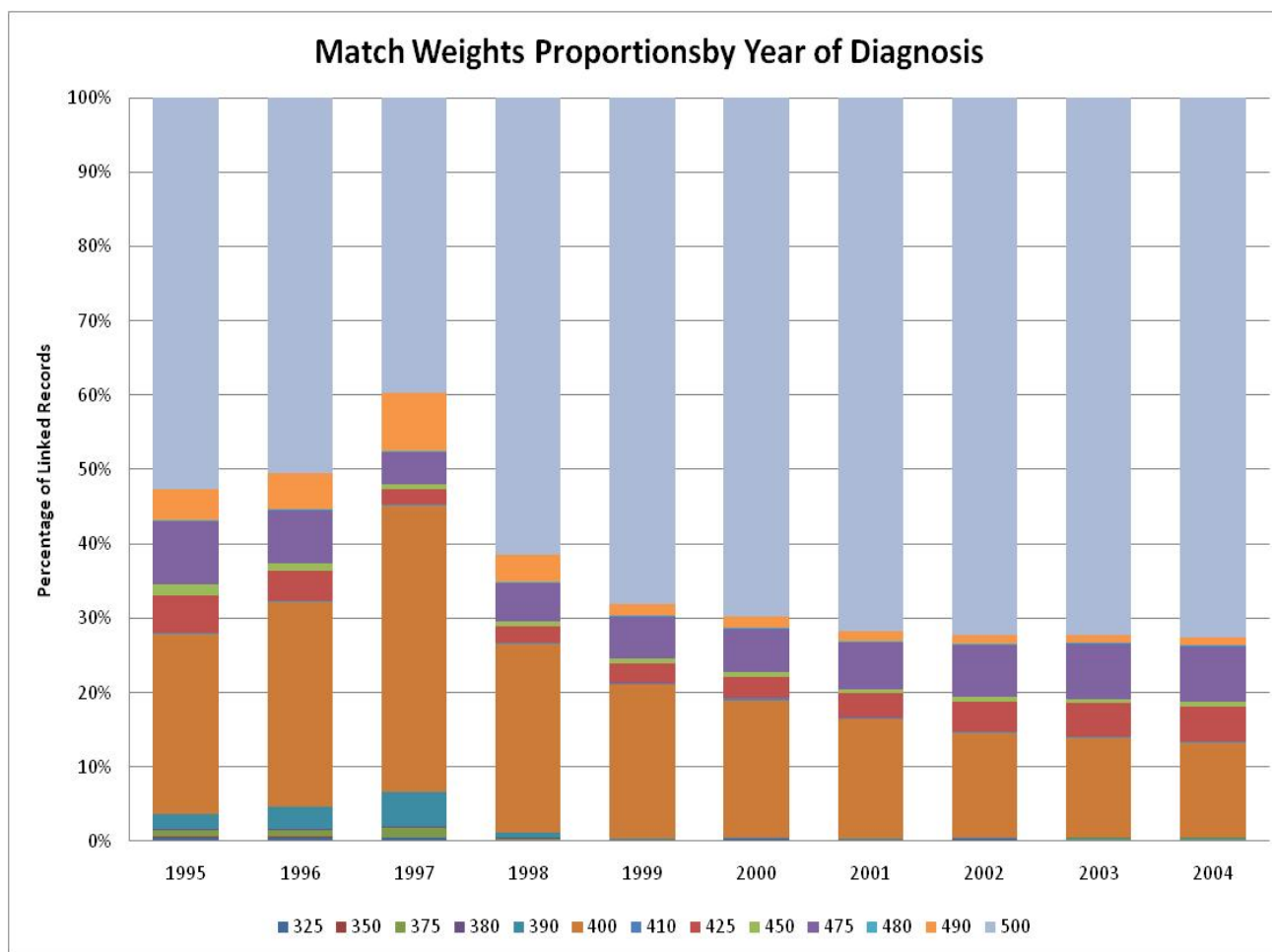
Large Scale Linkage

- Four stages
 - Data Preparation / Data Cleaning
 - Blocking
 - Comparison
 - Link Generation

Linkage Issues

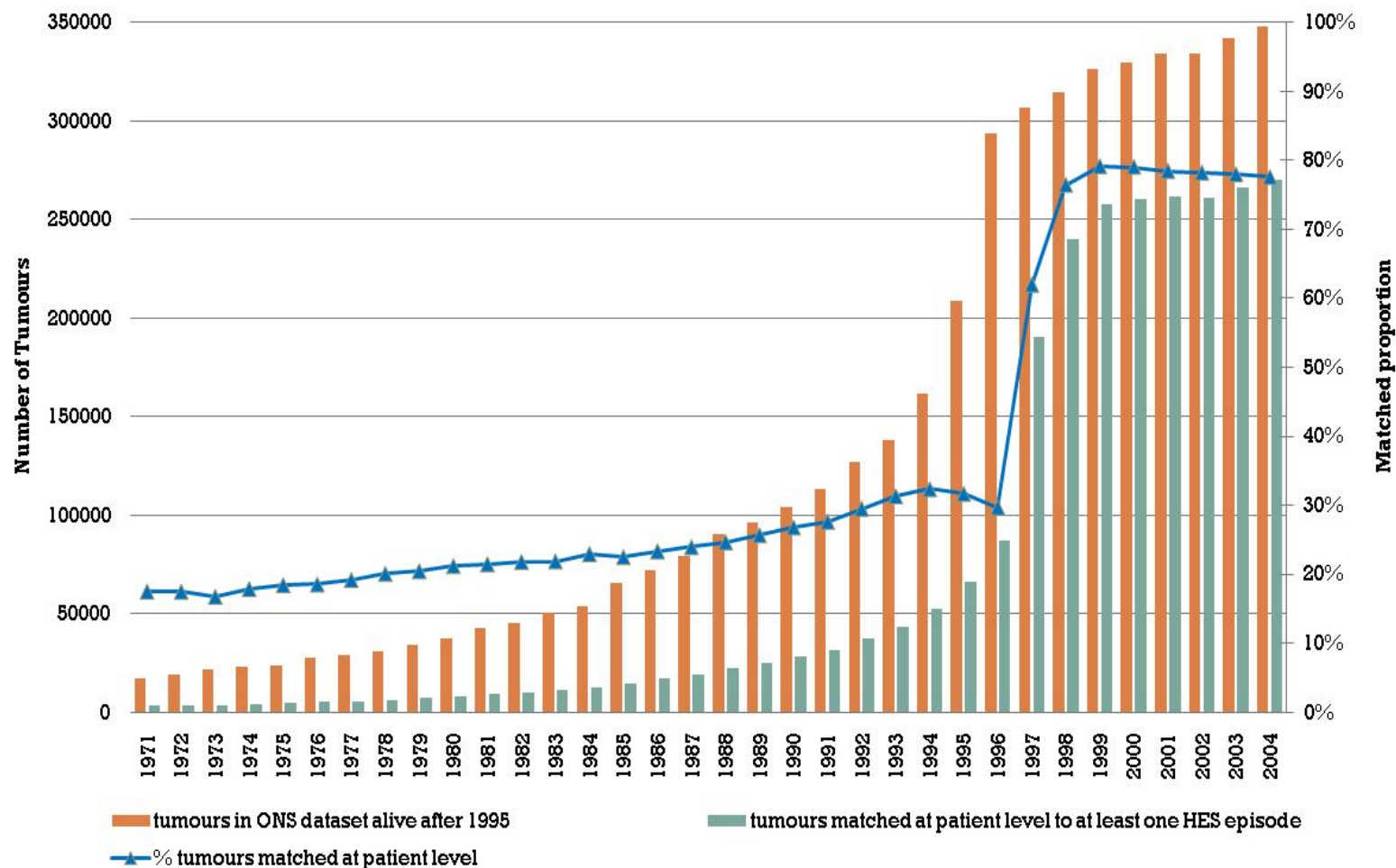
- Not all links generated between ONS and HES patients are one to one:
 - 4% of linked ONS patients linked to >1 HES patient.
 - 5% of linked HES patients linked to >1 ONS patient.
 - 82% of the patient links produced by the match are 1:1

Consistency over time



Linkages made

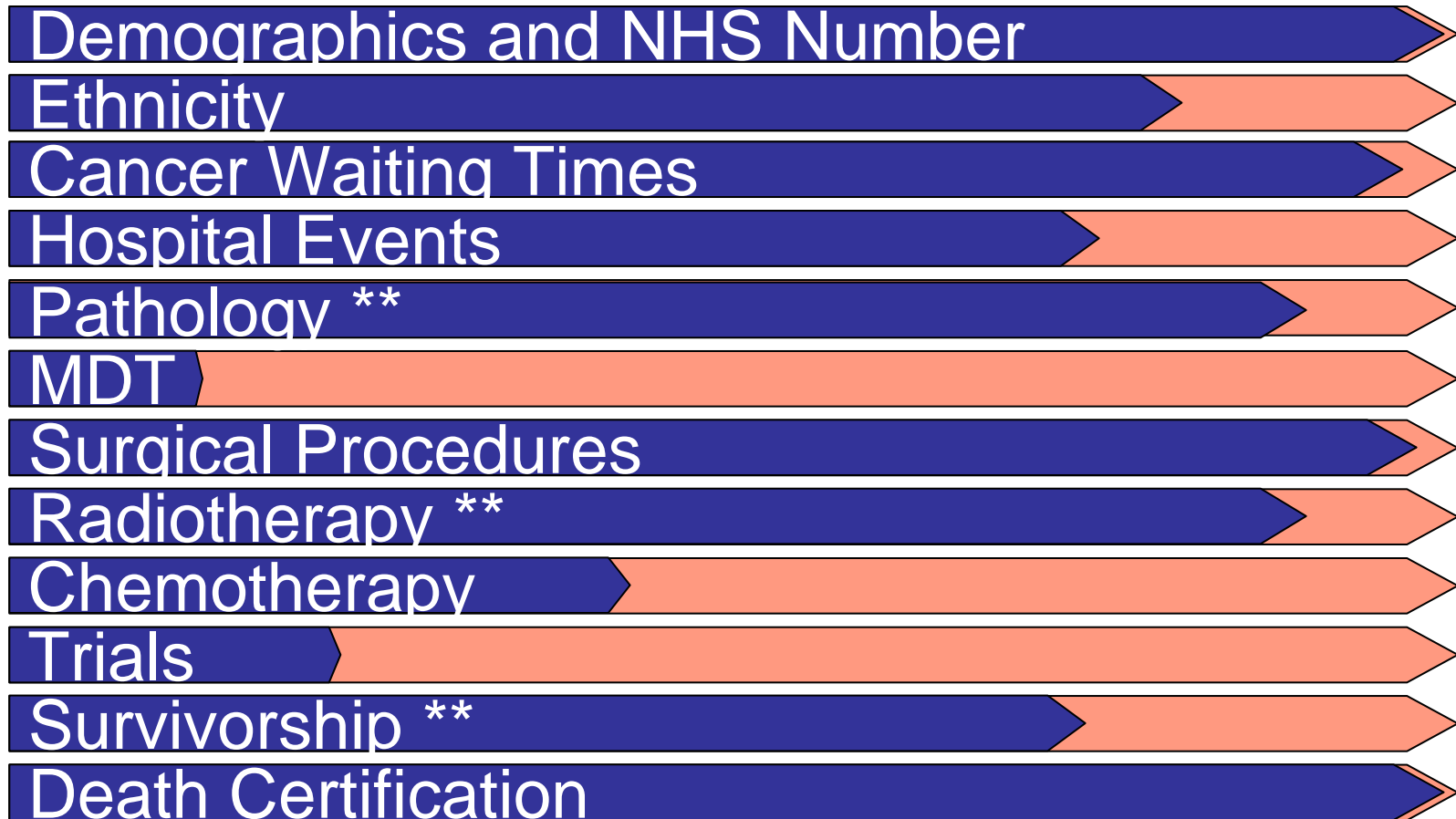
Number and proportion of tumours matched



> Sum of the Parts

- CR+HES = (CR+HES) + Ethnicity + Comorbidity + Activity + Length of Stay + Measures of Deprivation + Cost + Impact + Outcomes + statistical significance +++

Further Data Sources....



Future Linkage Steps

- Use patient linkage experiences to determine appropriate methodology for efficient tumour linkage and treatment linkages
- Incorporate experiences of other HES users to improve linkage effectiveness / performance

“The best cancer information system in the world”



- Extended linkage:
 - Genetic data
 - Primary care data
 - Outpatient, Radiotherapy, Chemotherapy
- Population-based QoL and Survivorship
- Research data repositories (through the NCRI Informatics Initiative)

New opportunities...

- For example:
- Does place of death from cancer vary for different ethnic groups?
- Variation in incidence, stage, treatment and survival with ethnicity by cancer site

which leads nicely to....