Use of the National Cancer Data Repository (NCDR) to Inform Clinical Trials

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Background

- Clinical trials are essential to improving cancer care but many factors may limit their success
  - Costly, especially in relation to long-term follow-up
  - Follow-up often limited to five-years
  - Impossible to identify information on all variables
  - Some patients ‘lost to follow-up’
  - Evidence to suggest some trial populations are not entirely representative of the general population
- Could NCDR overcome some of these problems?

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National Cancer Data Repository

- Numerous routine health data sources available but none contain information about all aspects of patient care
- Cancer registry data contains info about every incident tumour and outcomes
- Hospital Episode Statistics (HES) contains detailed information about treatment
- Link registry-HES data to create a dataset that allows us to track in-patient hospital care of all patients treated within the NHS

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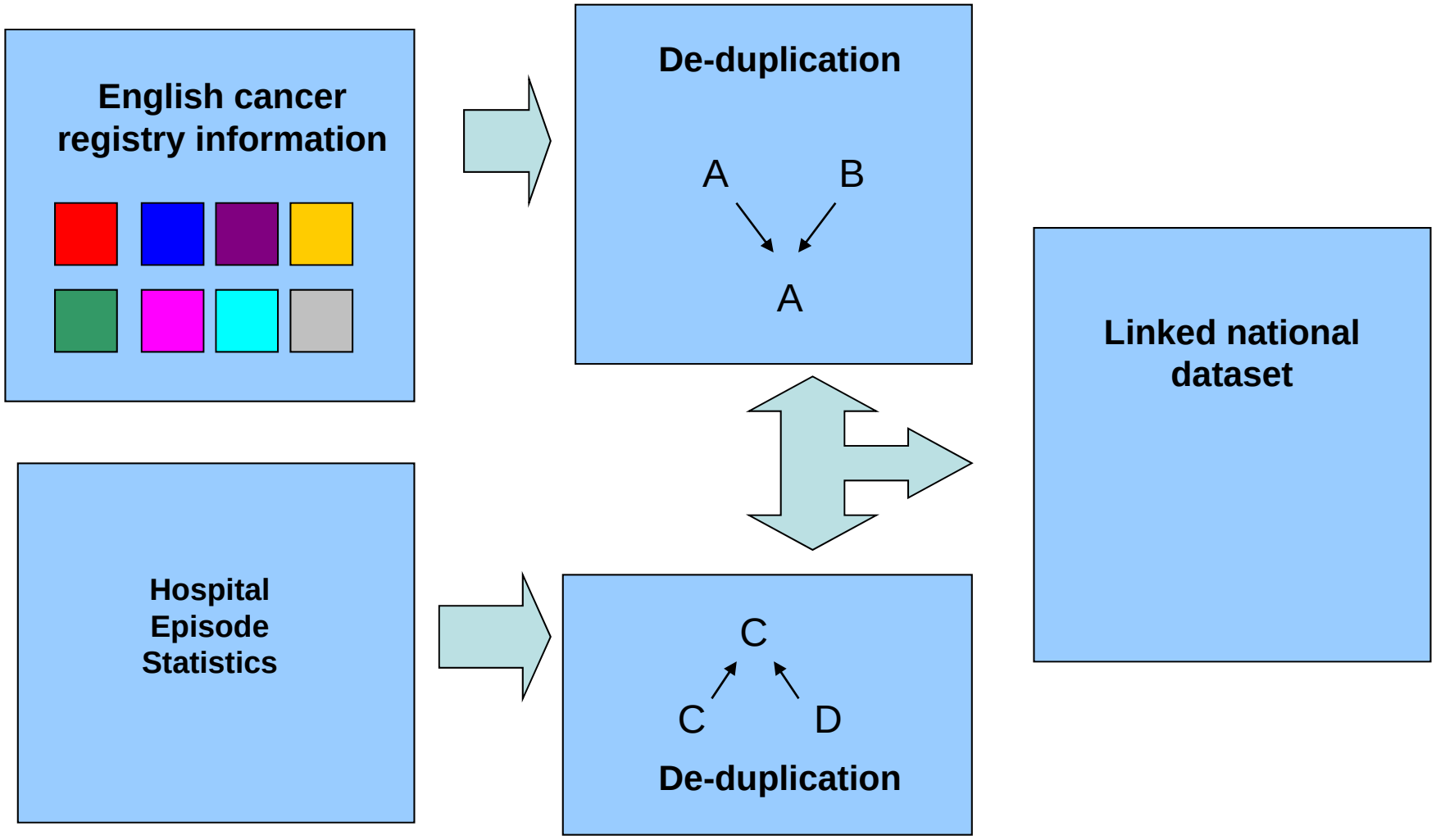
National Cancer Data Repository



Could the NCDR Inform Clinical Trials?

- Enable long-term follow-up by tracking trial participants through the routine data?
- Supplement trial data with missing clinical information?
- Enable comparison of characteristics of trial populations to the general population to determine if truly representative?

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The MRC CLASICC Trial

- Compared outcomes between laparoscopic and conventional open surgery for colorectal cancer
- Recruited 794 patients across the UK between 1996 and 2002
- Reported on short-term end points, three-year survival, costs and, shortly, five-year survival
- Trial demonstrated similar morbidity, mortality and survival to open surgery for colorectal cancer

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Methods

- Confirmed patient identifiers
- Identified individuals recruited into CLASICC in the NCDR
- Converted diagnosis, treatment and organisation coding in CLASICC from trial specific coding systems into standard systems
- Compared for each participant the information collected by the trial to that in the NCDR
- Compared the characteristics of the trial population to the general population

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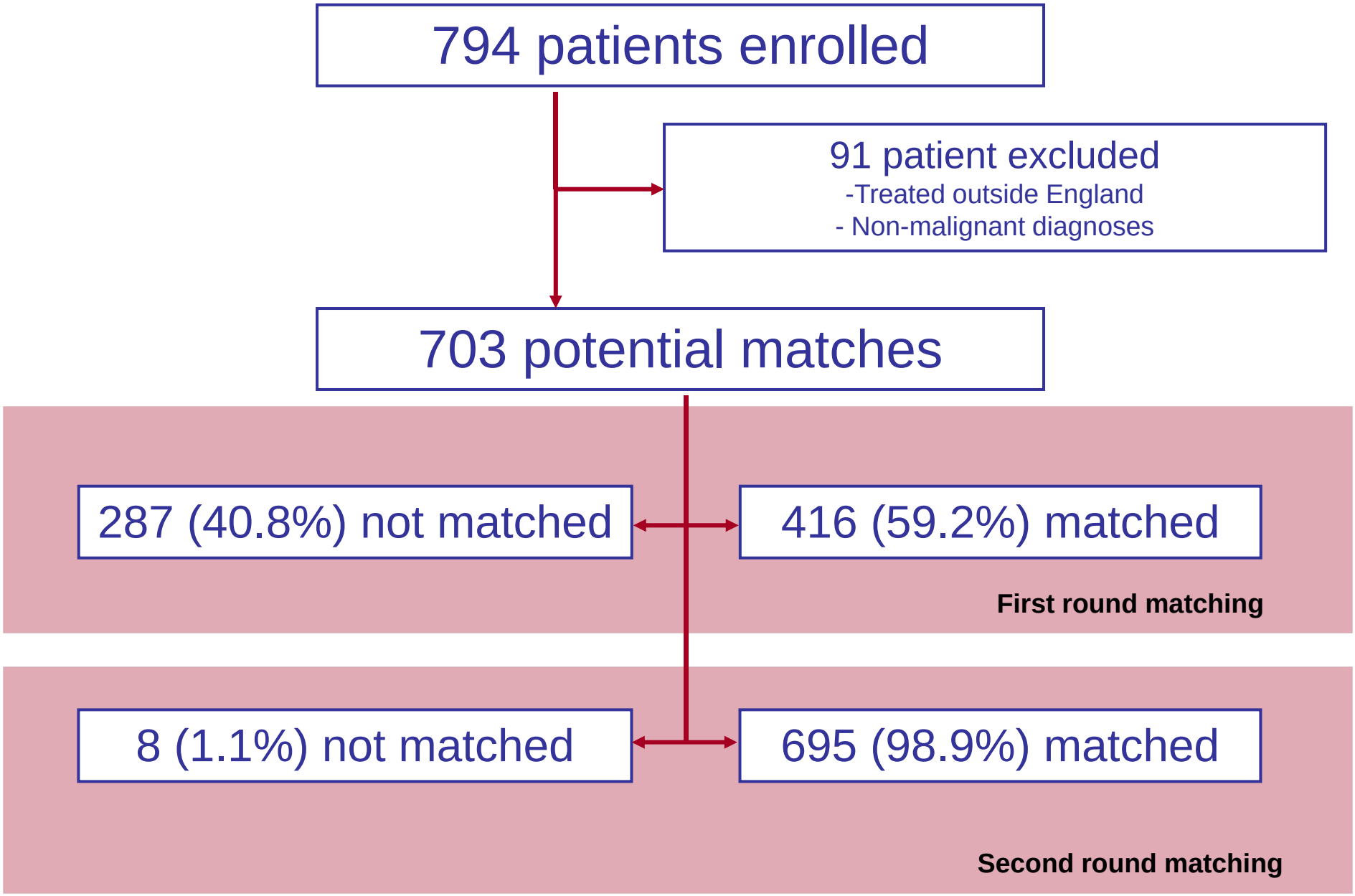
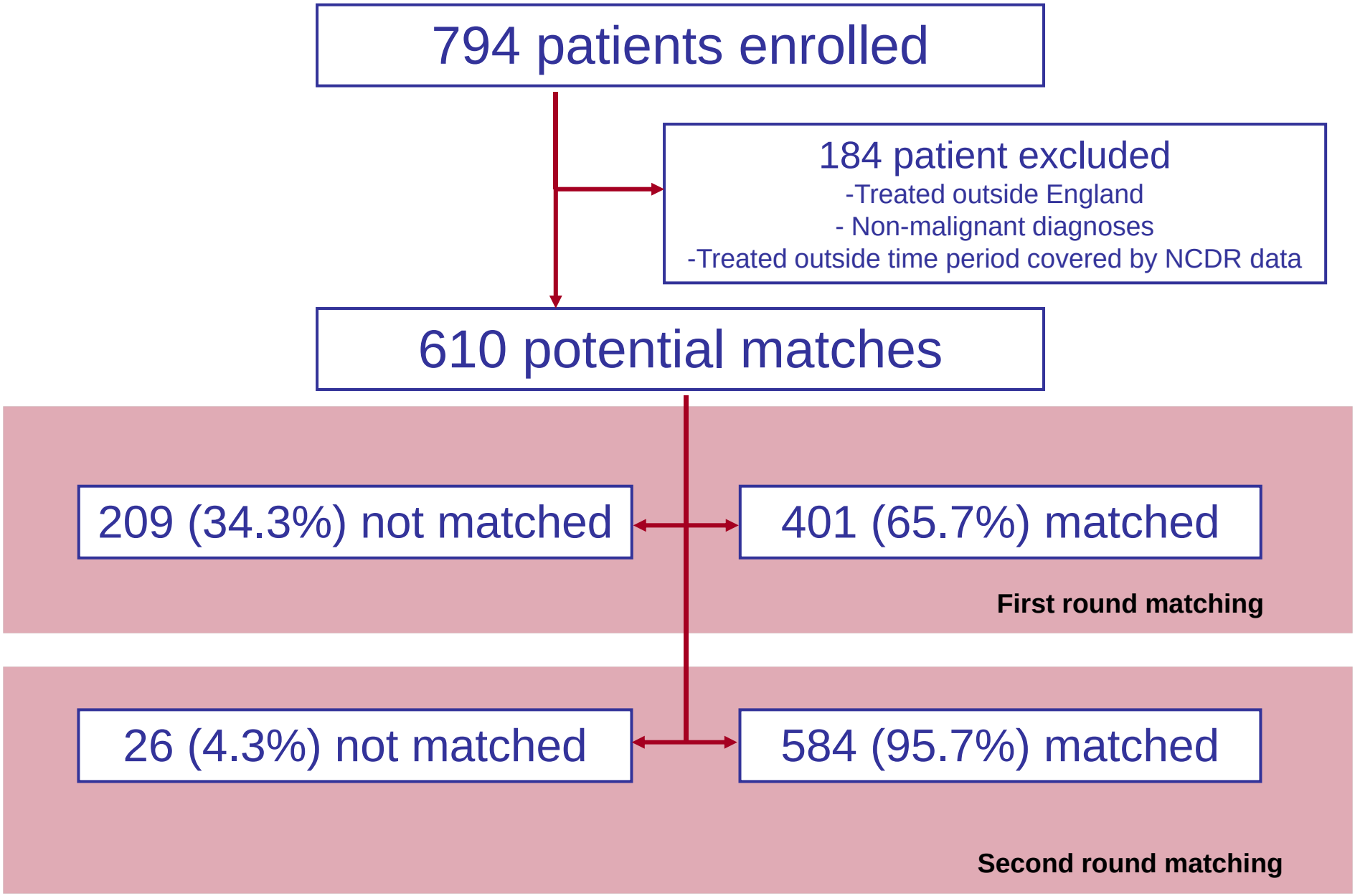
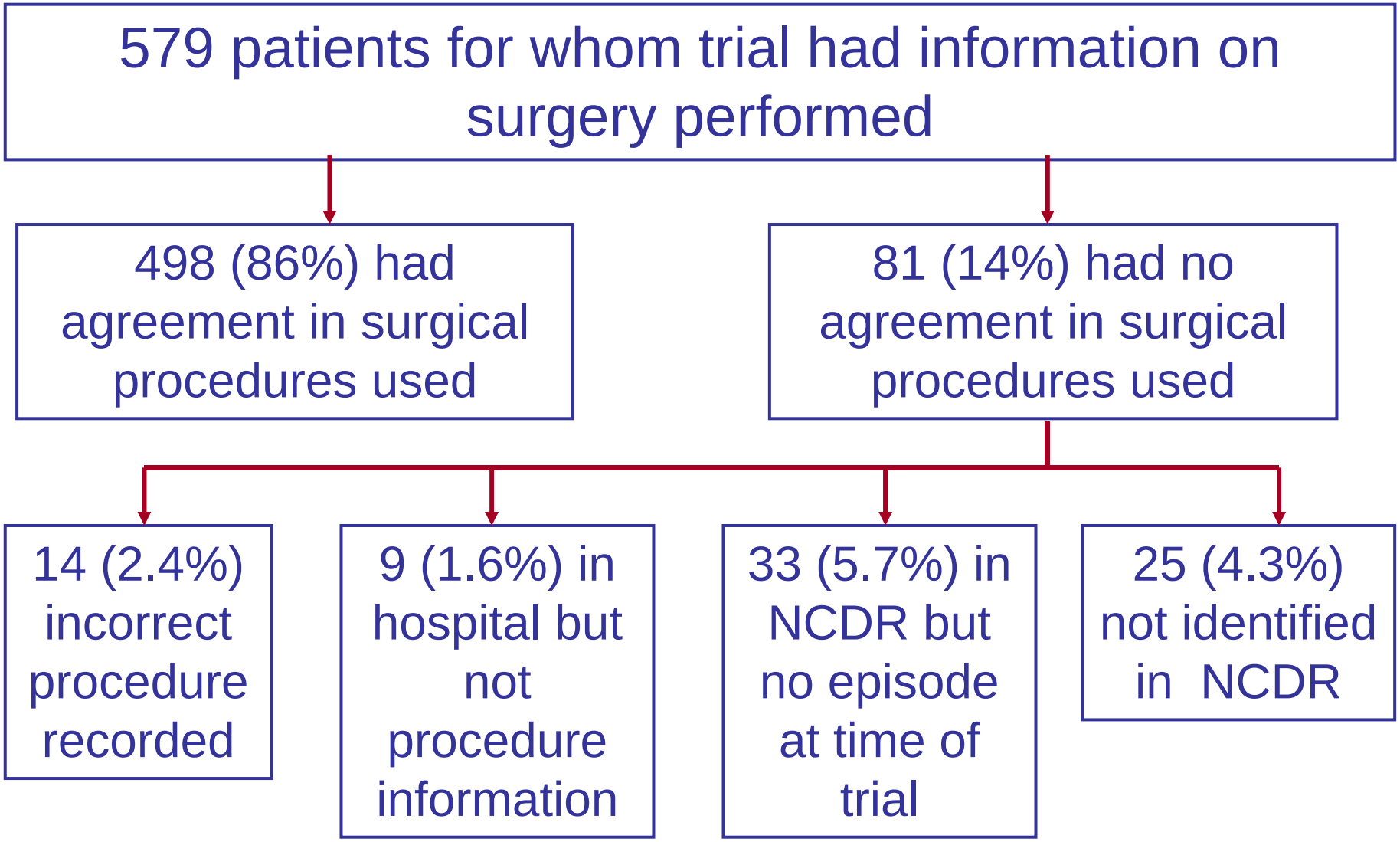
Comparison of Outcome Information



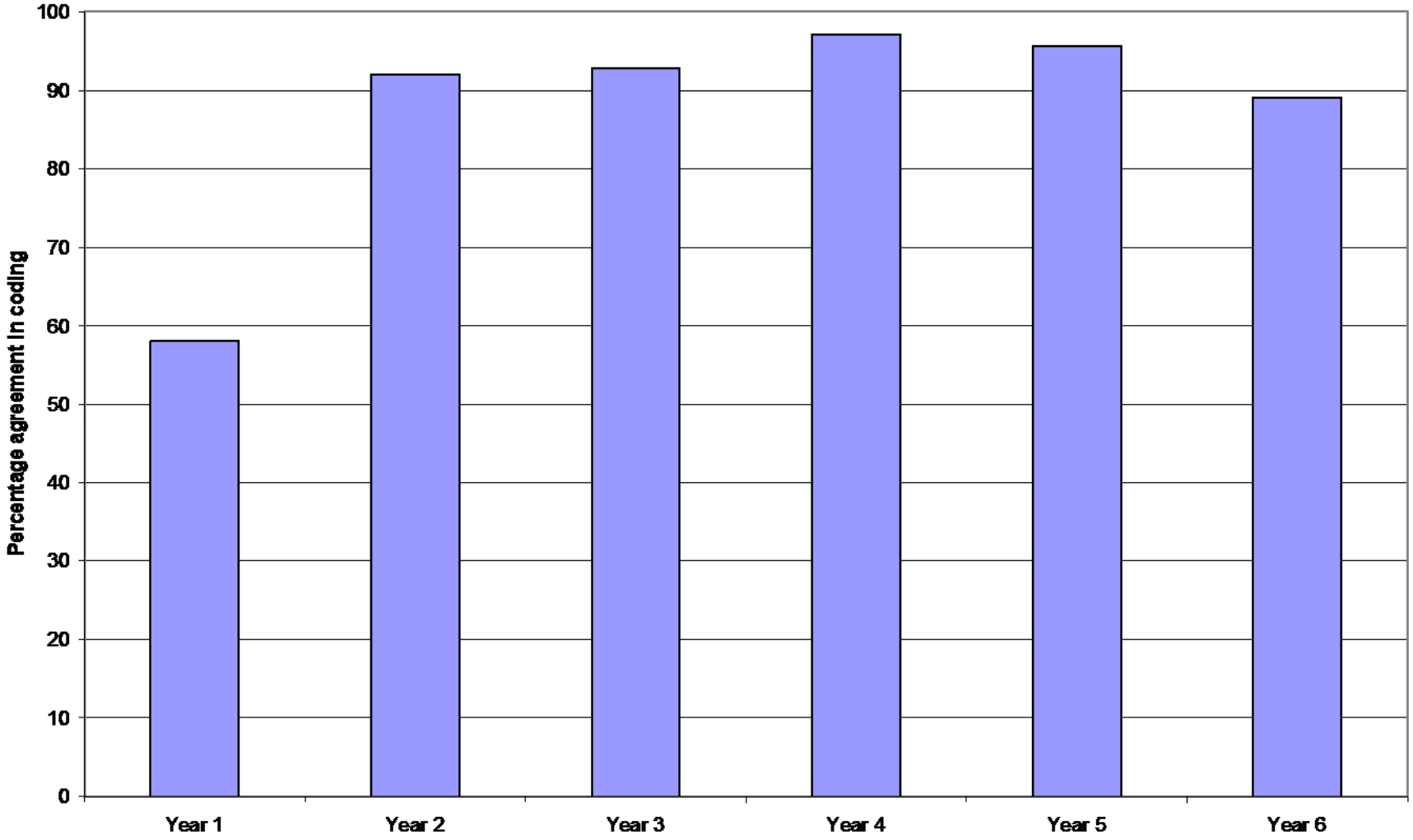
Comparison of Treatment Information



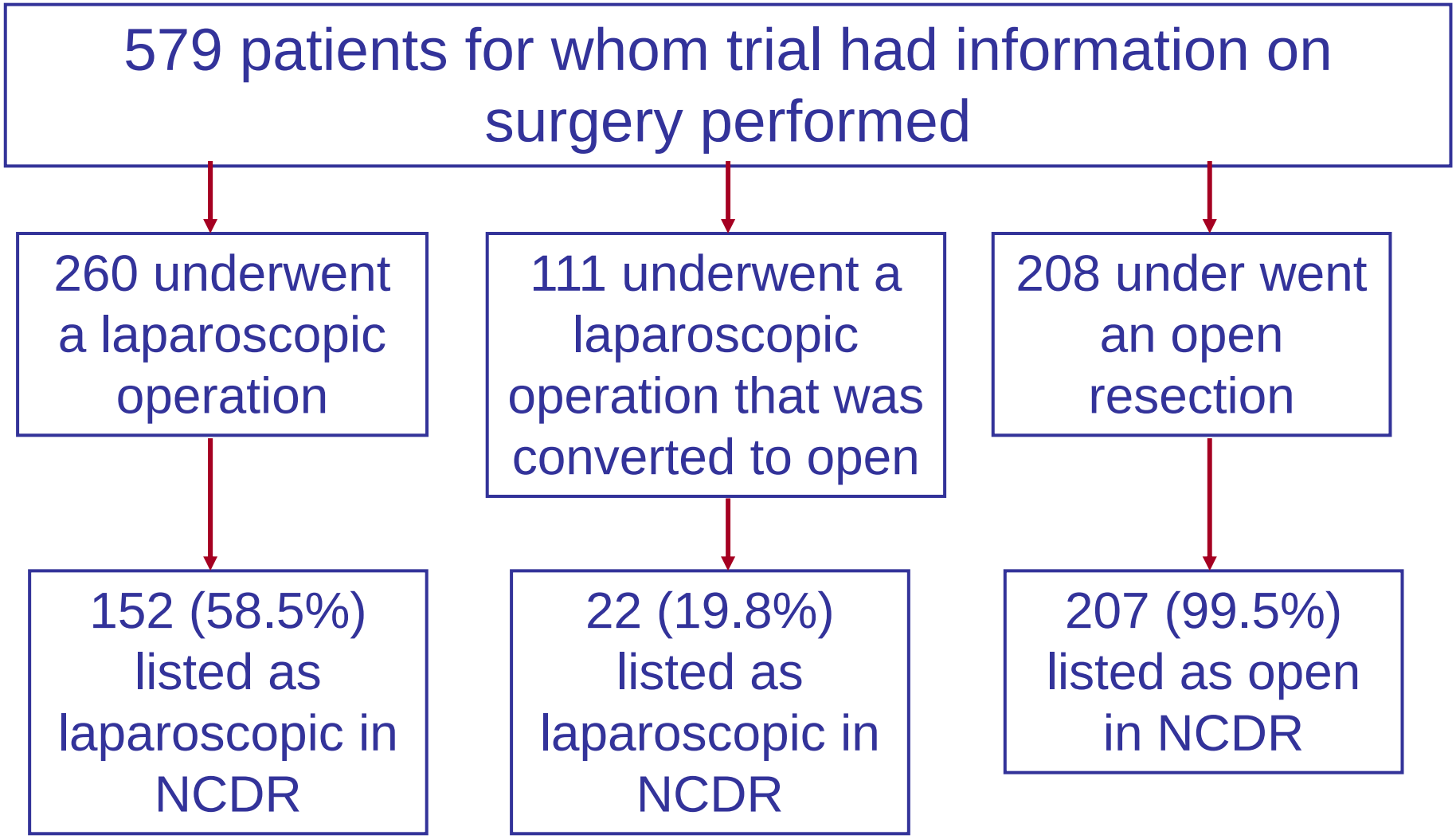
Comparison of Surgical Information



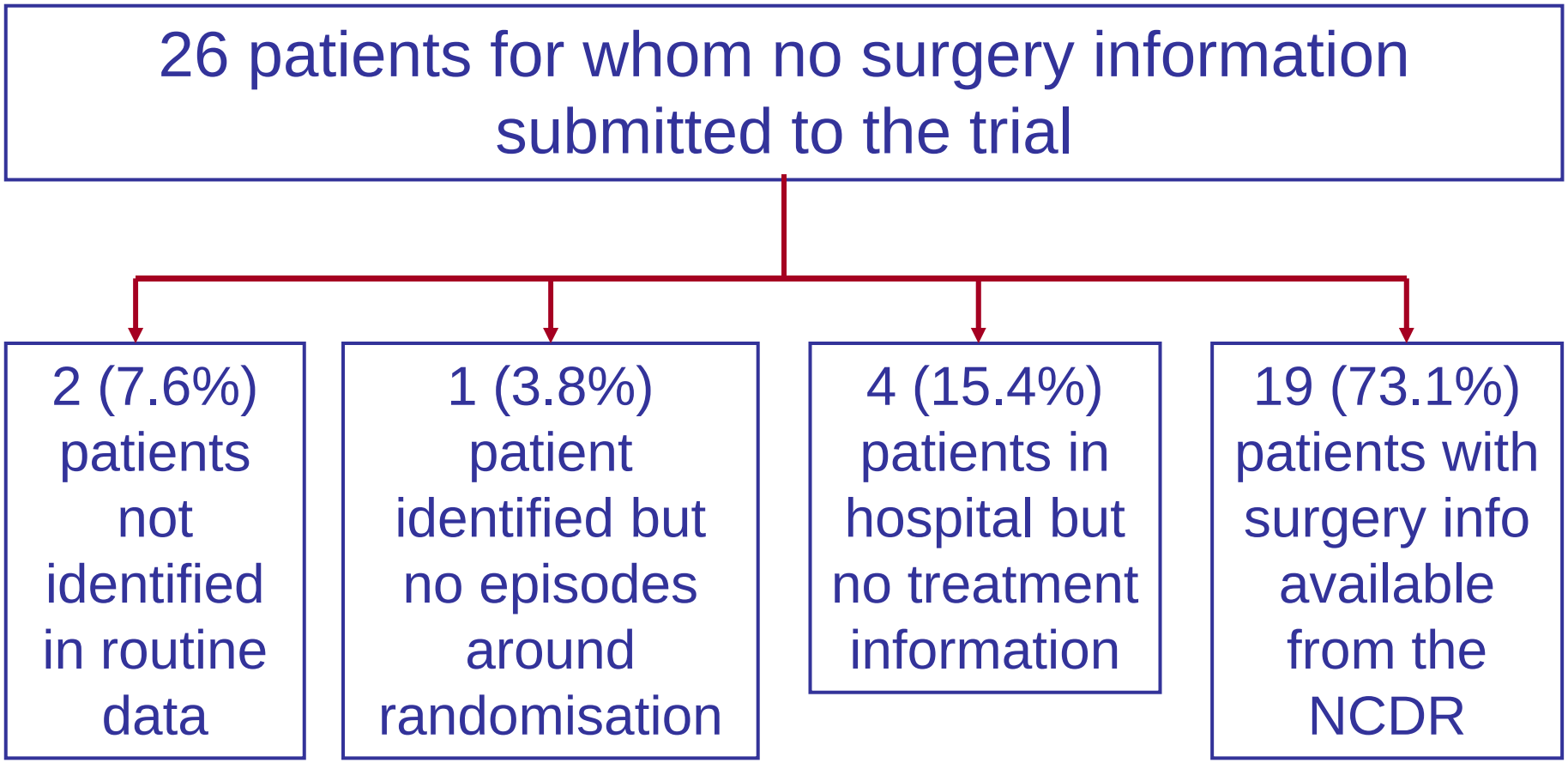
Agreement in treatment coding over time



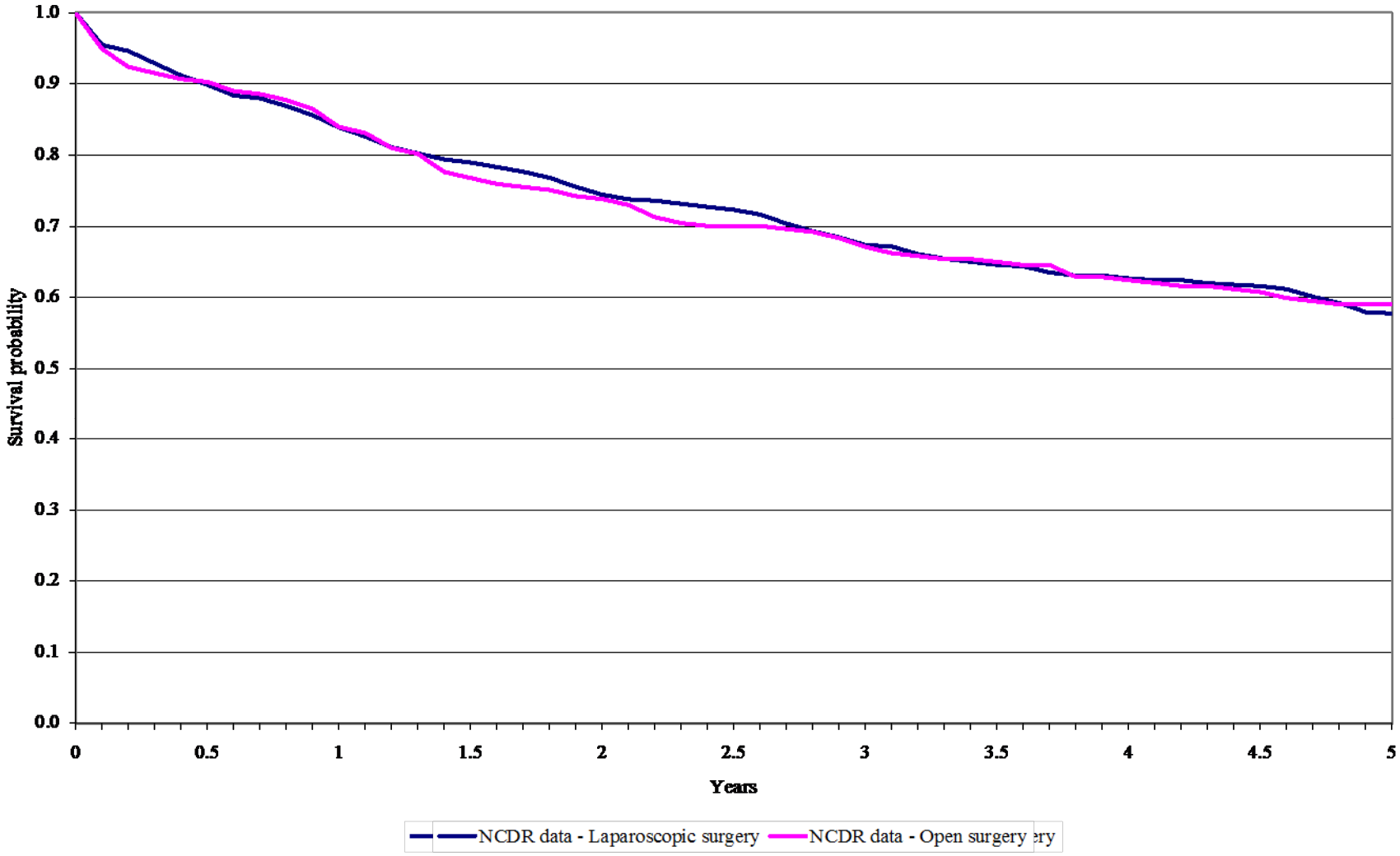
Approach to surgery



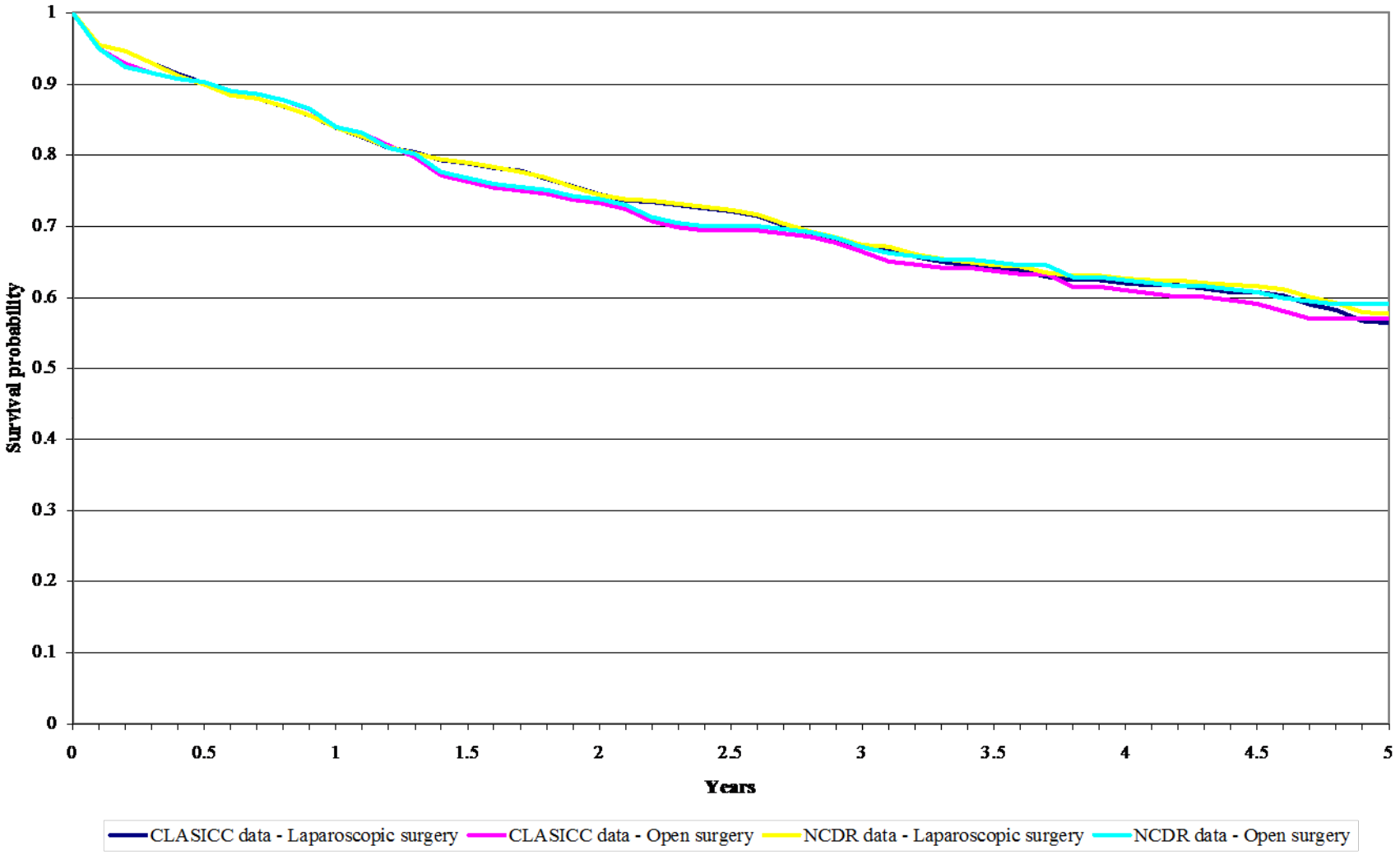
Missing surgical information



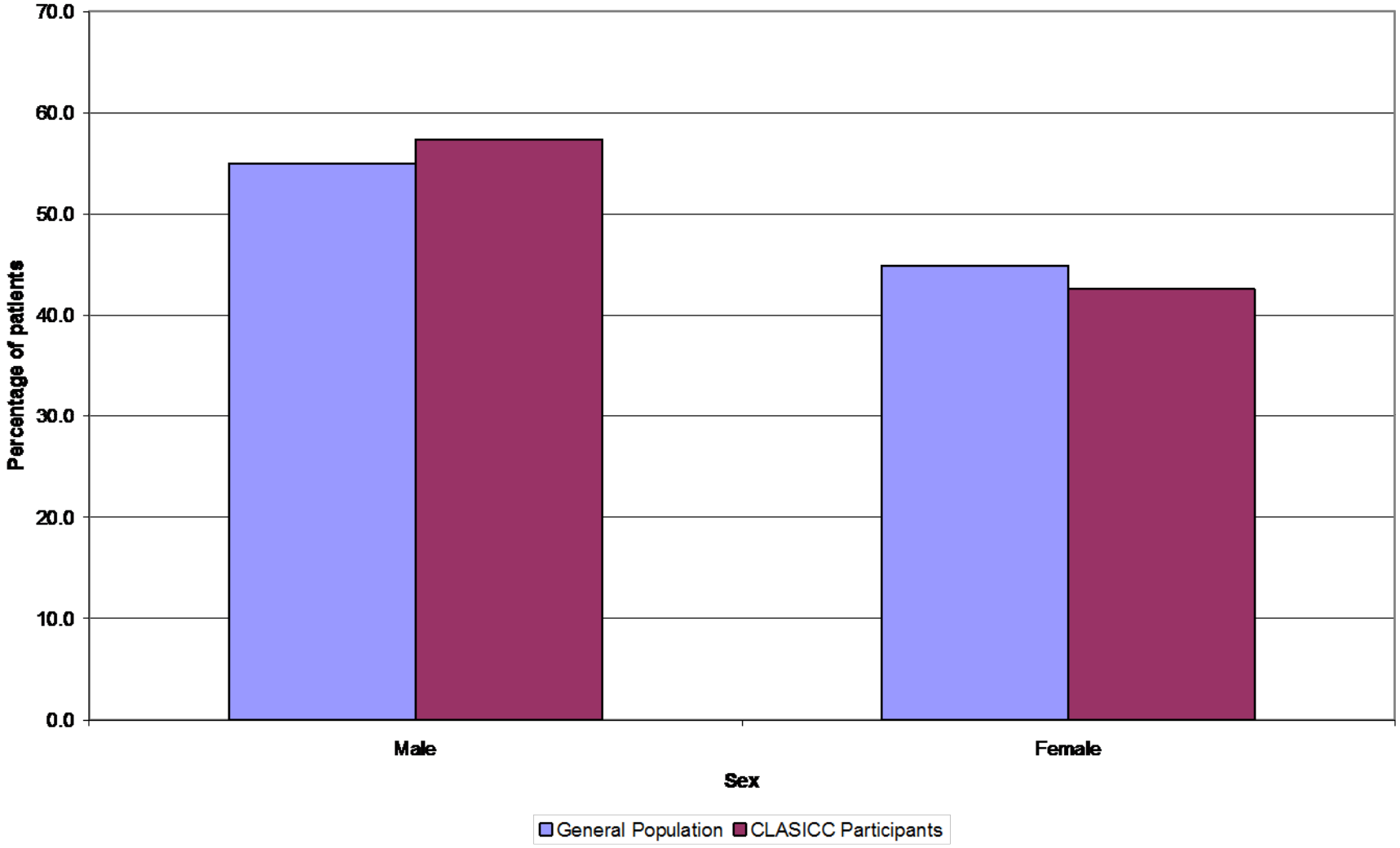
Comparison of Survival



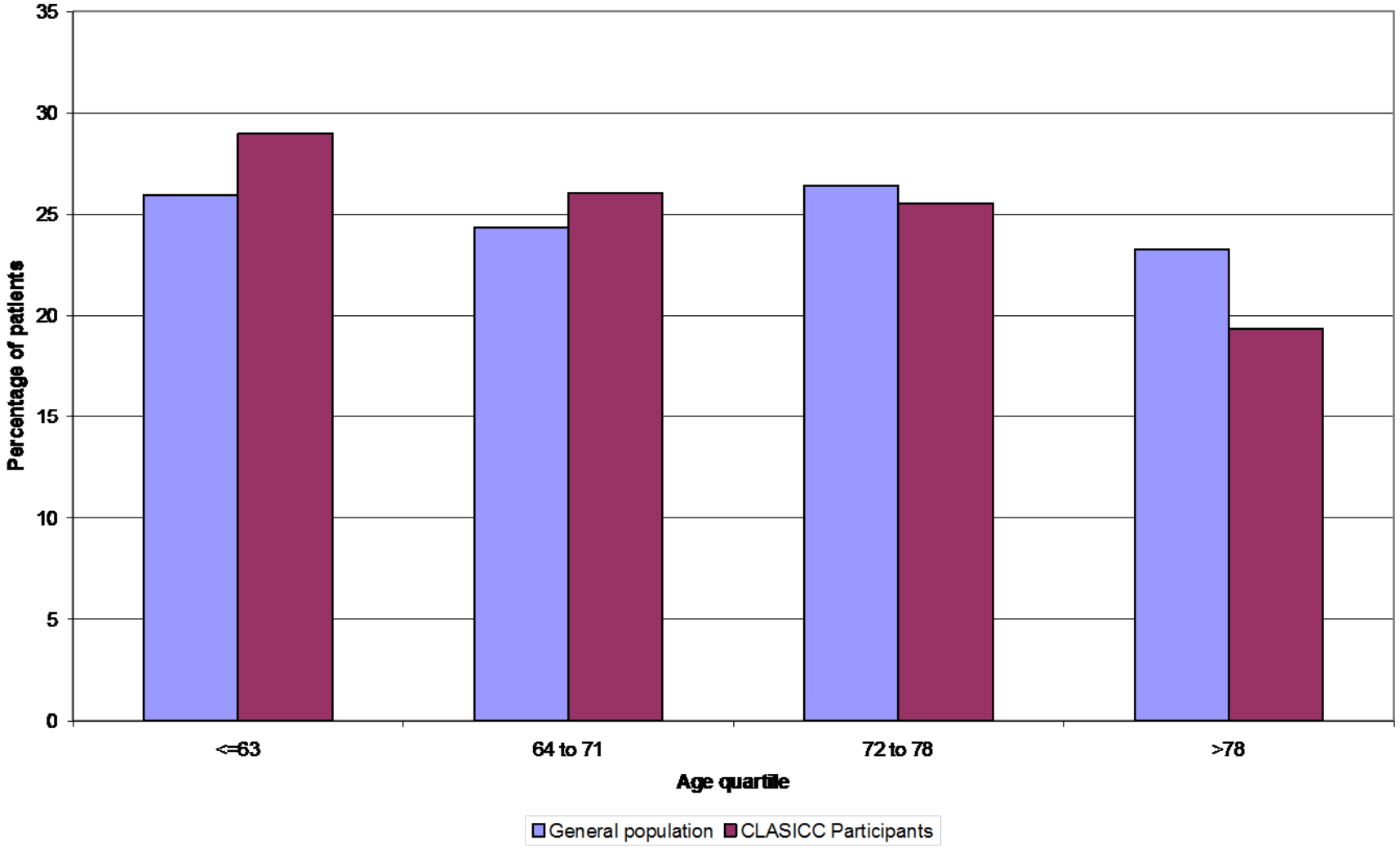
Comparison of Survival



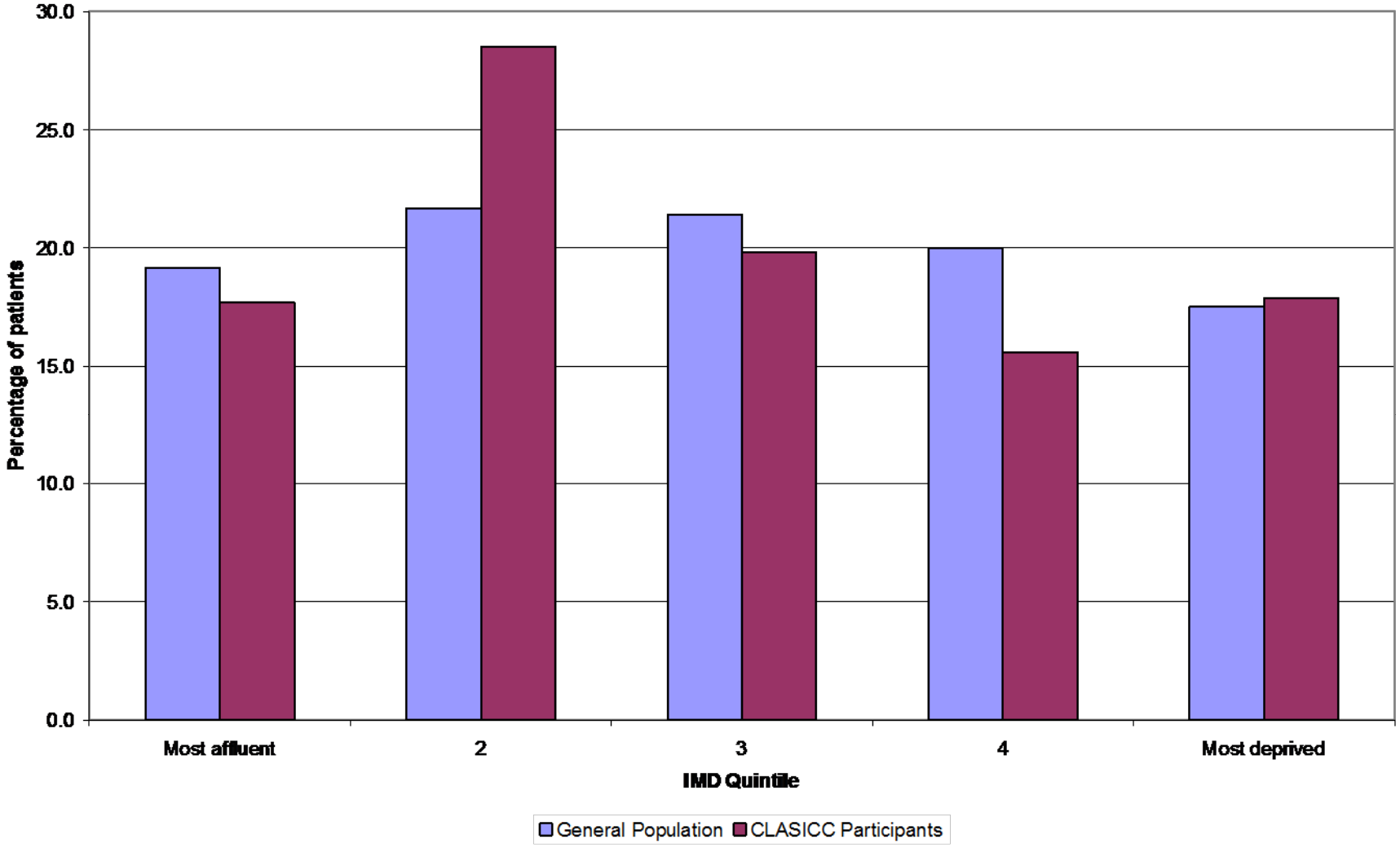
Comparison of the gender of CLASICC participants to the general population



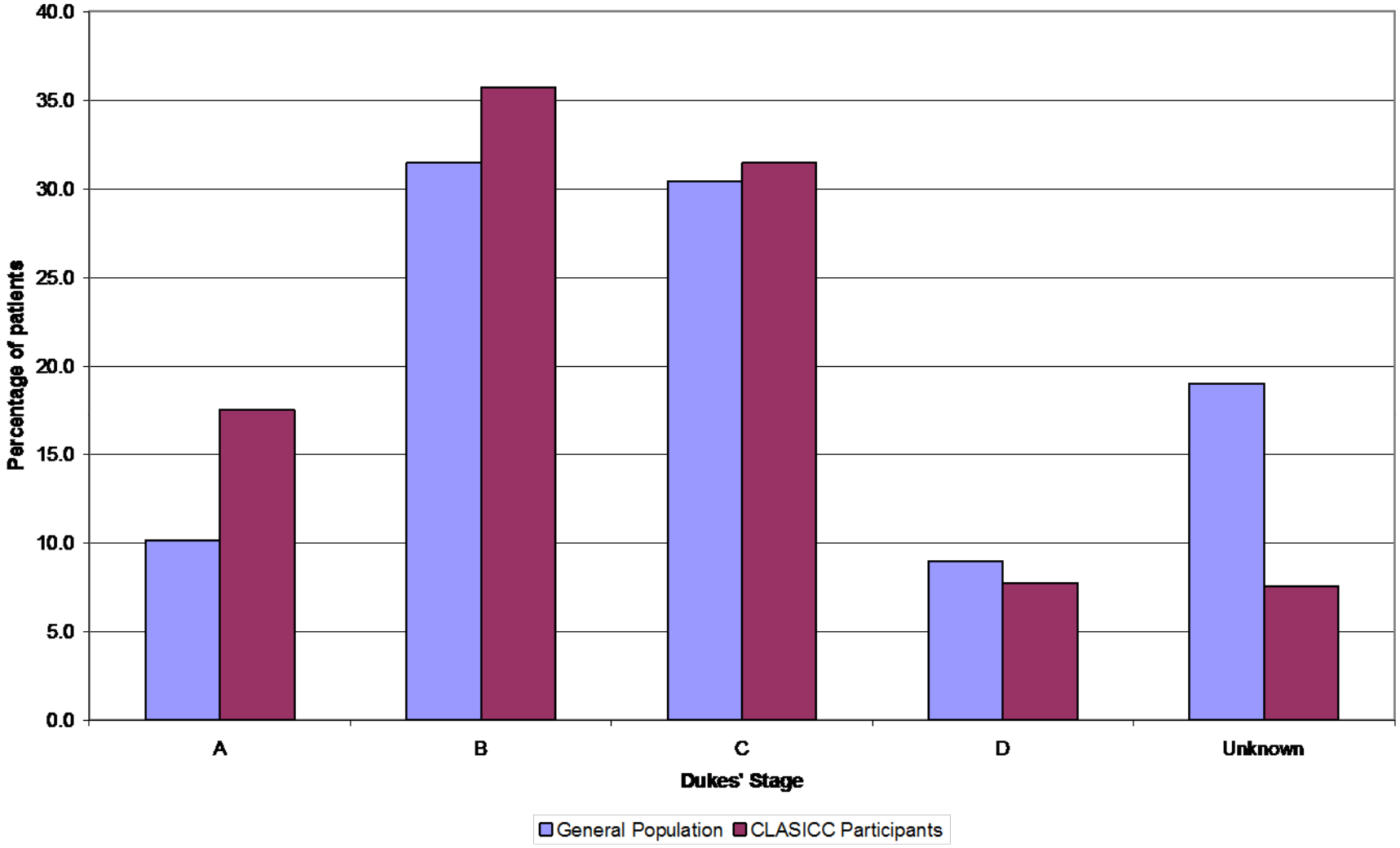
Comparison of age profile of CLASICC participants to the general population



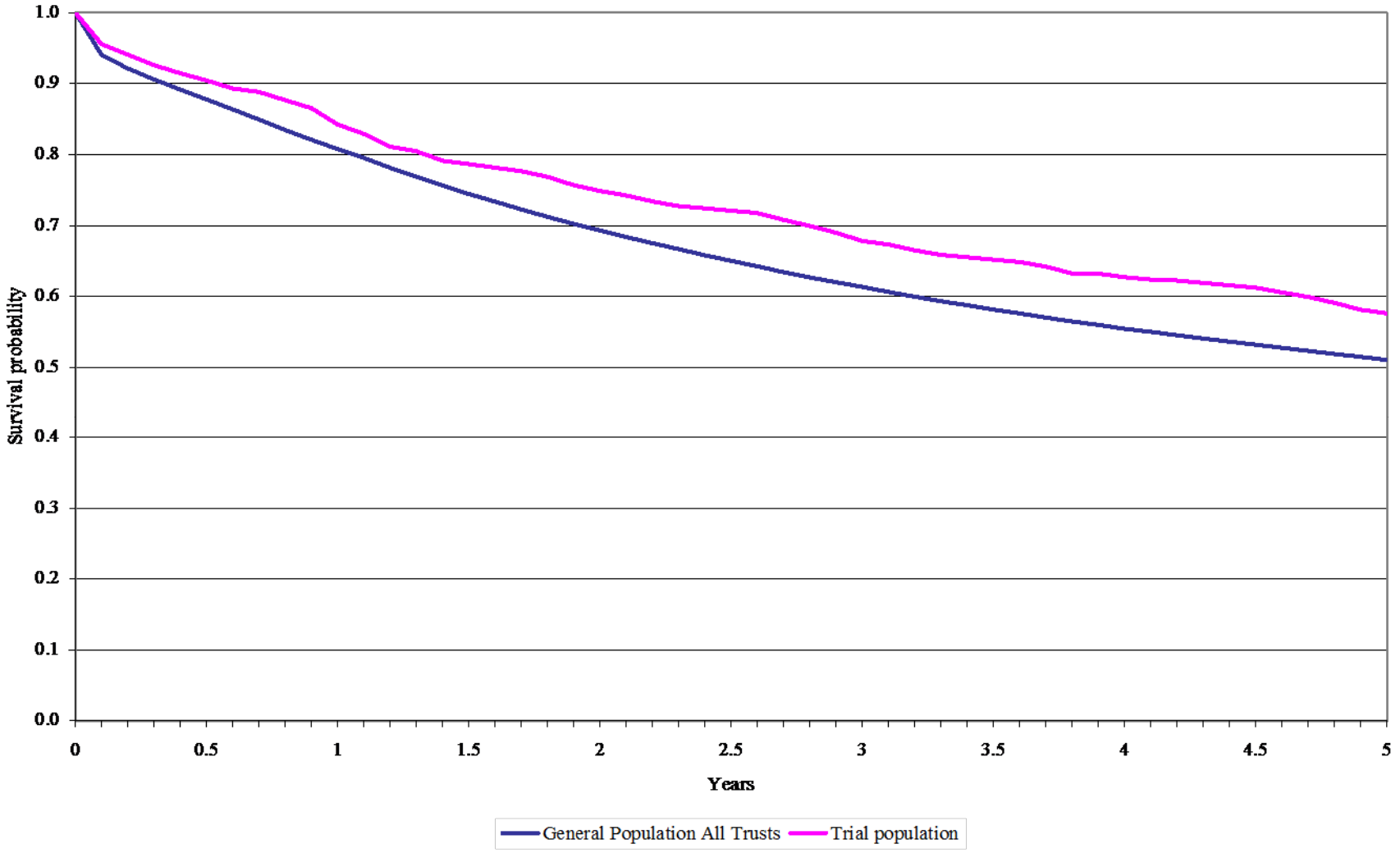
Comparison of IMD profile of CLASICC participants to the general population



Comparison of Dukes' stage profile of CLASICC participants to the general population



Comparison of the overall survival of CLASICC participants to the general population



Conclusions

- Possible to identify around 99% of trial patients in NCDR
- Good agreement in the clinical information between the trial and NCDR
- NCDR provided identical outcome data to the trial
- NCDR allowed comparison of trial population to general population
- The NCDR has enormous potential to inform clinical trials

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Further development of NCDR

- Expand resource to cover the whole of the UK
- Expand resource to incorporate other data sources
  - Outpatient data
  - Primary care data
  - Screening data
  - Chemotherapy data
  - Radiotherapy data
  - Genetic data
- Repeat this work using other clinical trials
- Determine if the NCDR can be used for Phase IV surveillance studies

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