



Northern and Yorkshire
Cancer Registry and Information Service

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

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&

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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?

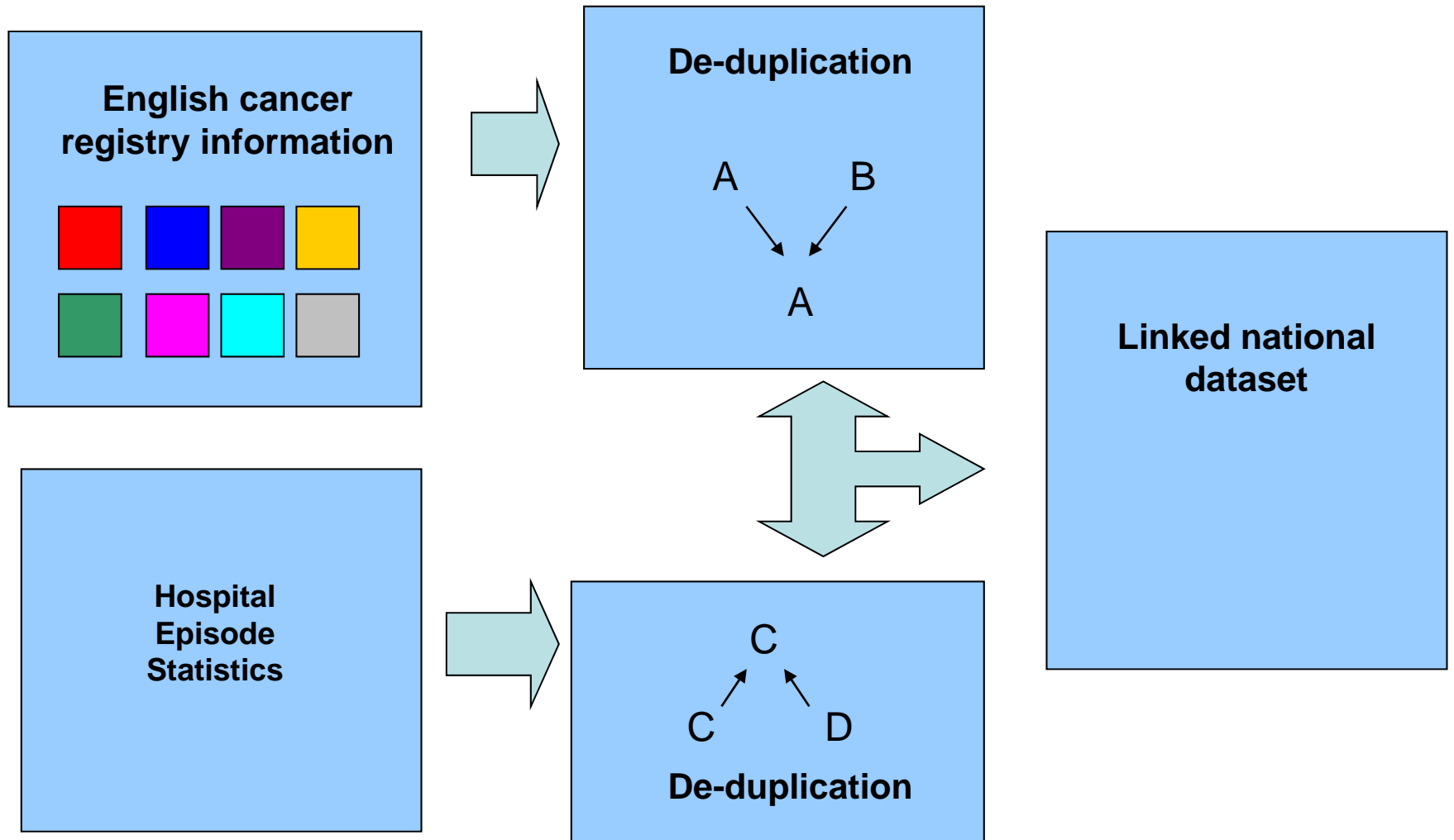


National Cancer Data Repository

- 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



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?



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



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

Comparison of Outcome Information

794 patients enrolled

91 patient excluded

- Treated outside England
- Non-malignant diagnoses

703 potential matches

287 (40.8%) not matched

416 (59.2%) matched

First round matching

8 (1.1%) not matched

695 (98.9%) matched

Second round matching

Comparison of Treatment Information

794 patients enrolled

184 patient excluded

- Treated outside England
- Non-malignant diagnoses
- Treated outside time period covered by NCDR data

610 potential matches

209 (34.3%) not matched

401 (65.7%) matched

First round matching

26 (4.3%) not matched

584 (95.7%) matched

Second round matching

Comparison of Surgical Information

579 patients for whom trial had information on surgery performed

498 (86%) had agreement in surgical procedures used

81 (14%) had no agreement in surgical procedures used

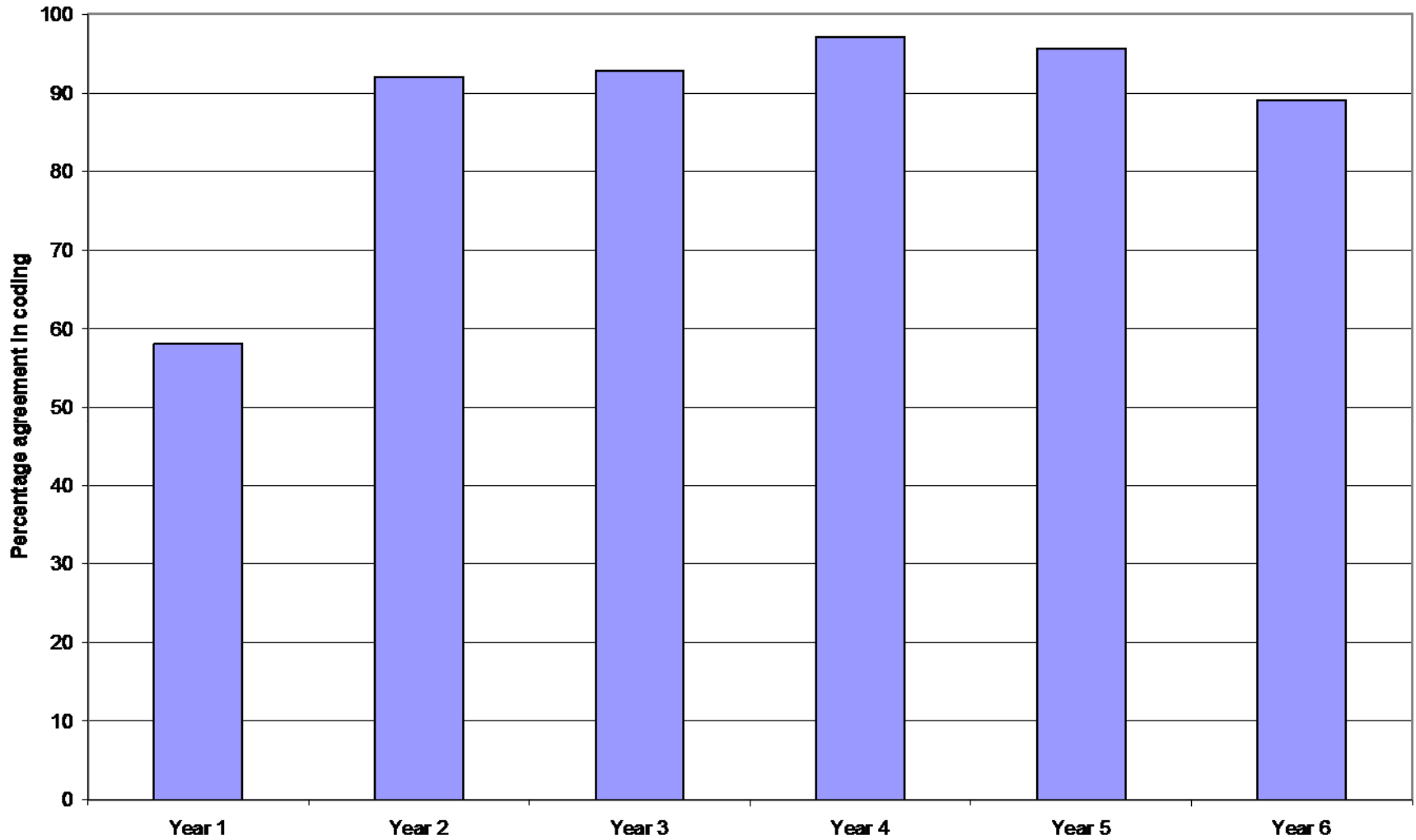
14 (2.4%) incorrect procedure recorded

9 (1.6%) in hospital but not procedure information

33 (5.7%) in NCDR but no episode at time of trial

25 (4.3%) not identified in NCDR

Agreement in treatment coding over time



Approach to surgery

579 patients for whom trial had information on surgery performed

260 underwent a laparoscopic operation

152 (58.5%) listed as laparoscopic in NCDR

111 underwent a laparoscopic operation that was converted to open

22 (19.8%) listed as laparoscopic in NCDR

208 underwent an open resection

207 (99.5%) listed as open in NCDR

Missing surgical information

26 patients for whom no surgery information submitted to the trial

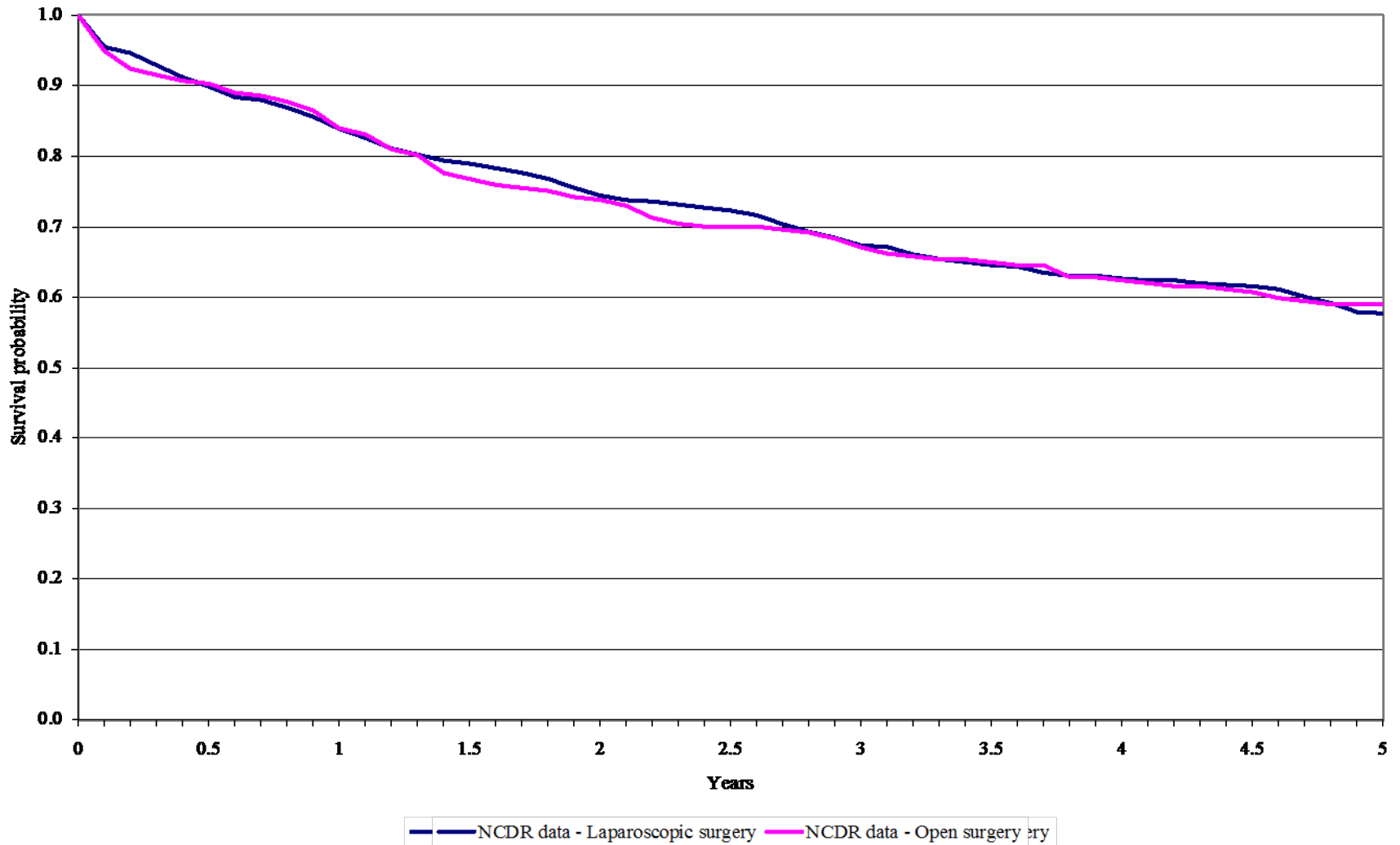
2 (7.6%)
patients
not
identified
in routine
data

1 (3.8%)
patient
identified but
no episodes
around
randomisation

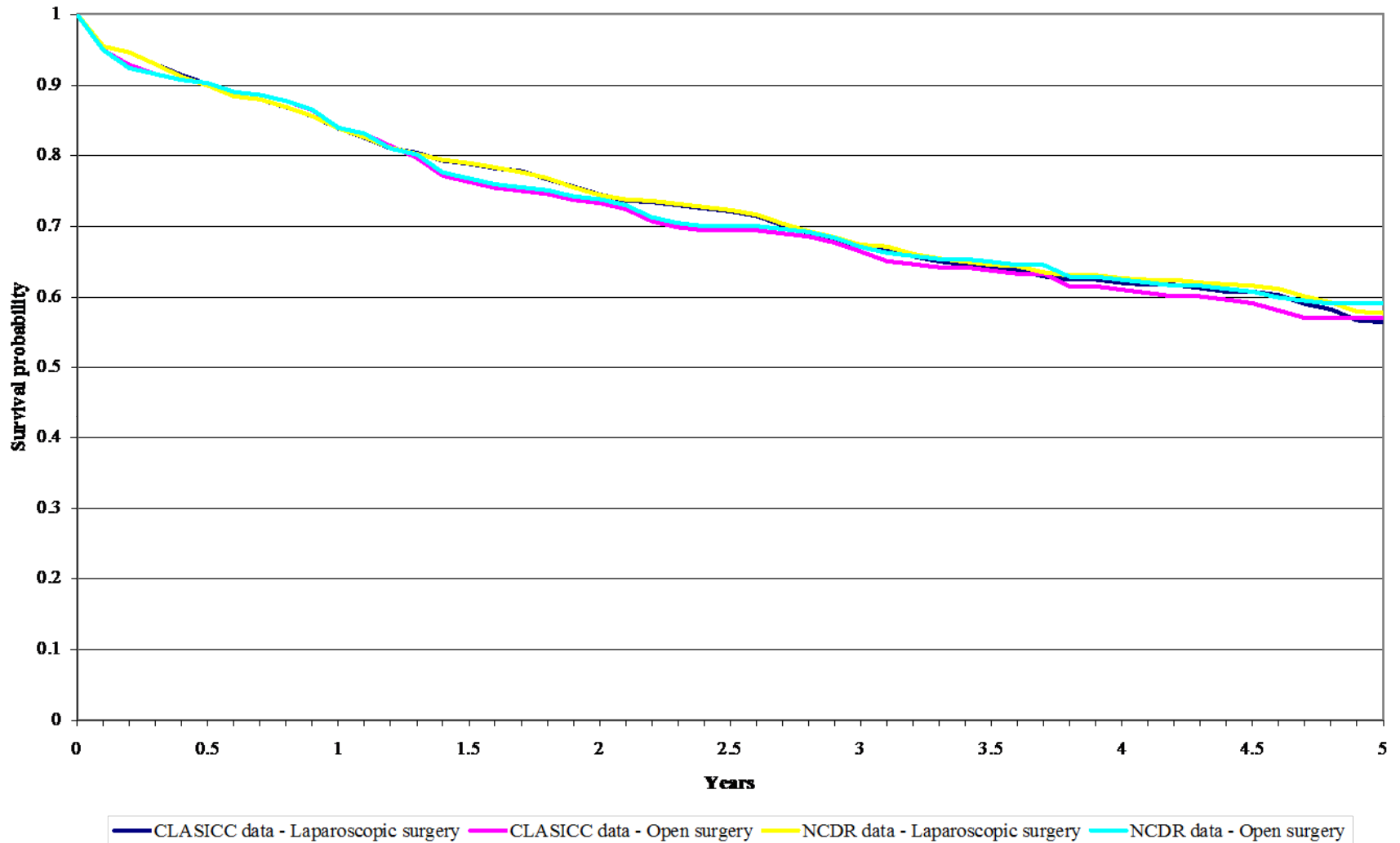
4 (15.4%)
patients in
hospital but
no treatment
information

19 (73.1%)
patients with
surgery info
available
from the
NCDR

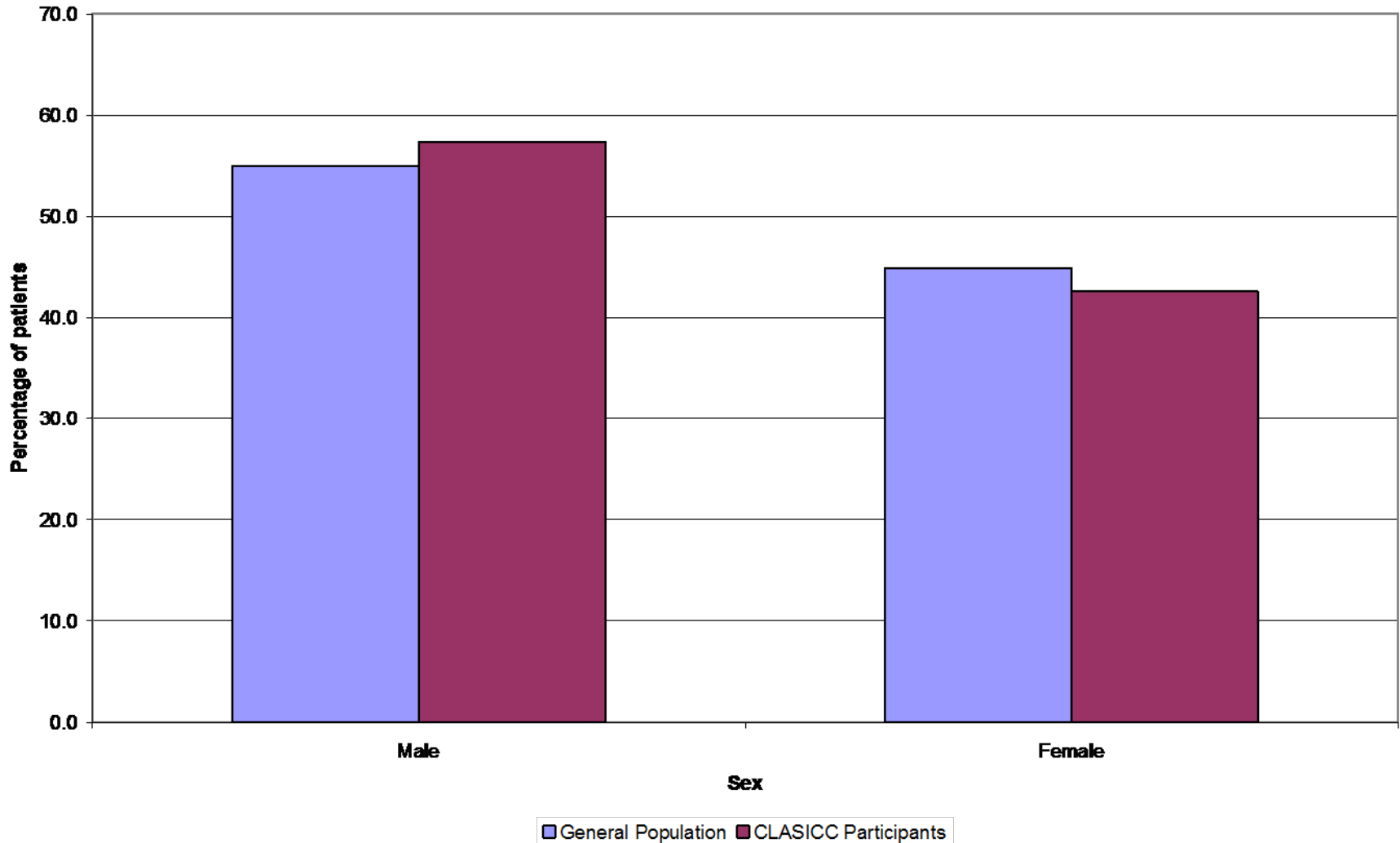
Comparison of Survival



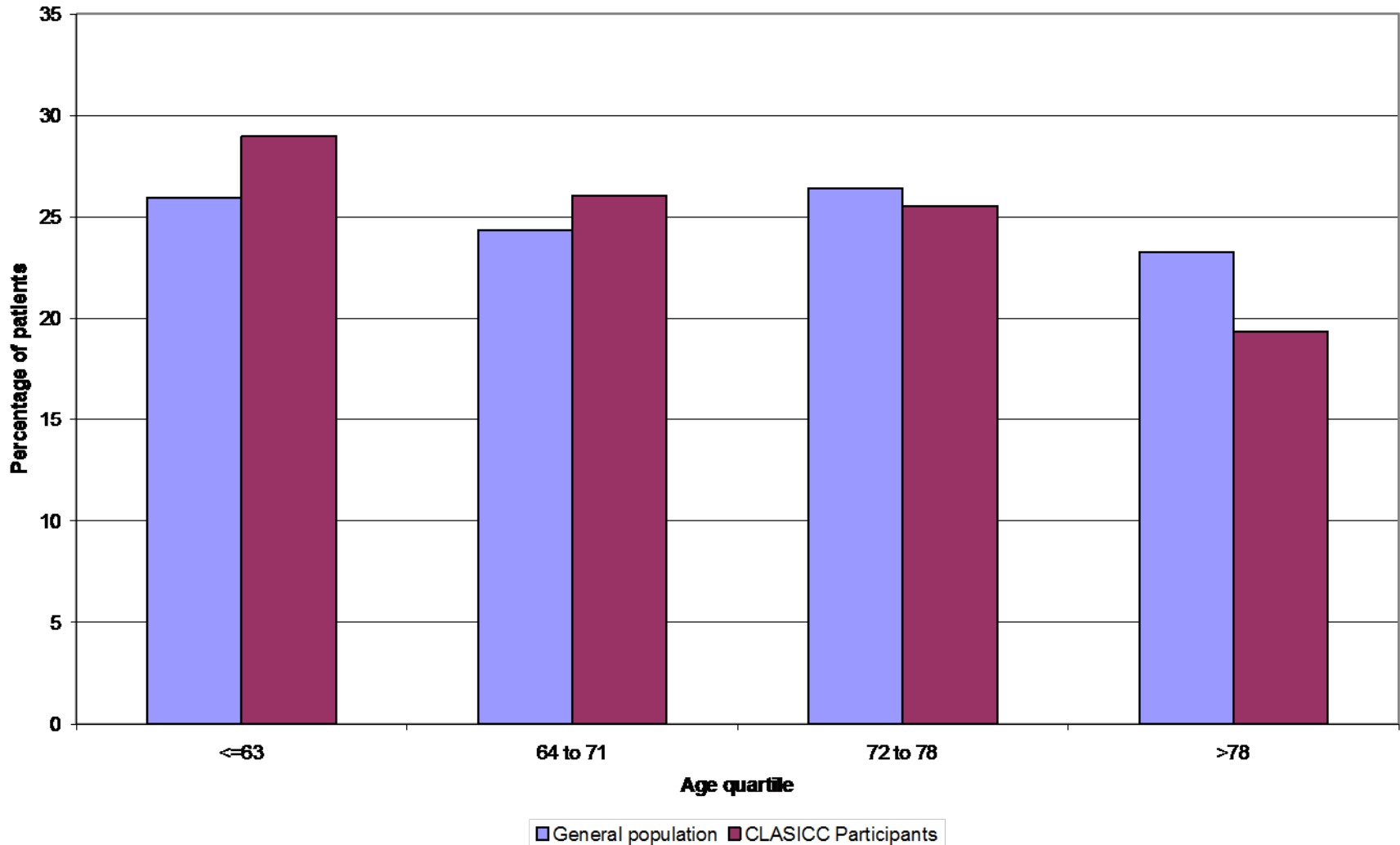
Comparison of Survival



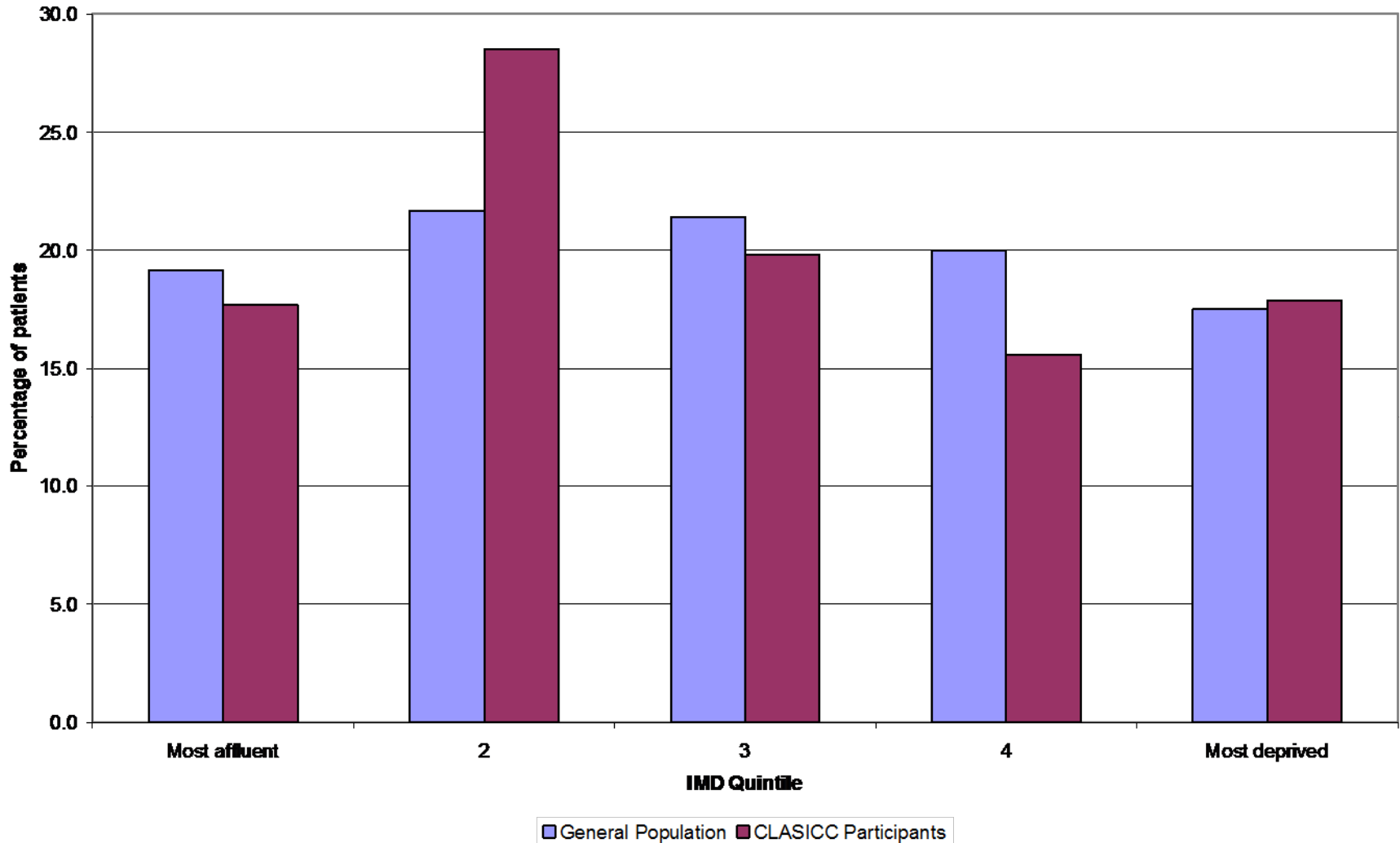
Comparison of the gender of CLASICC participants to the general population



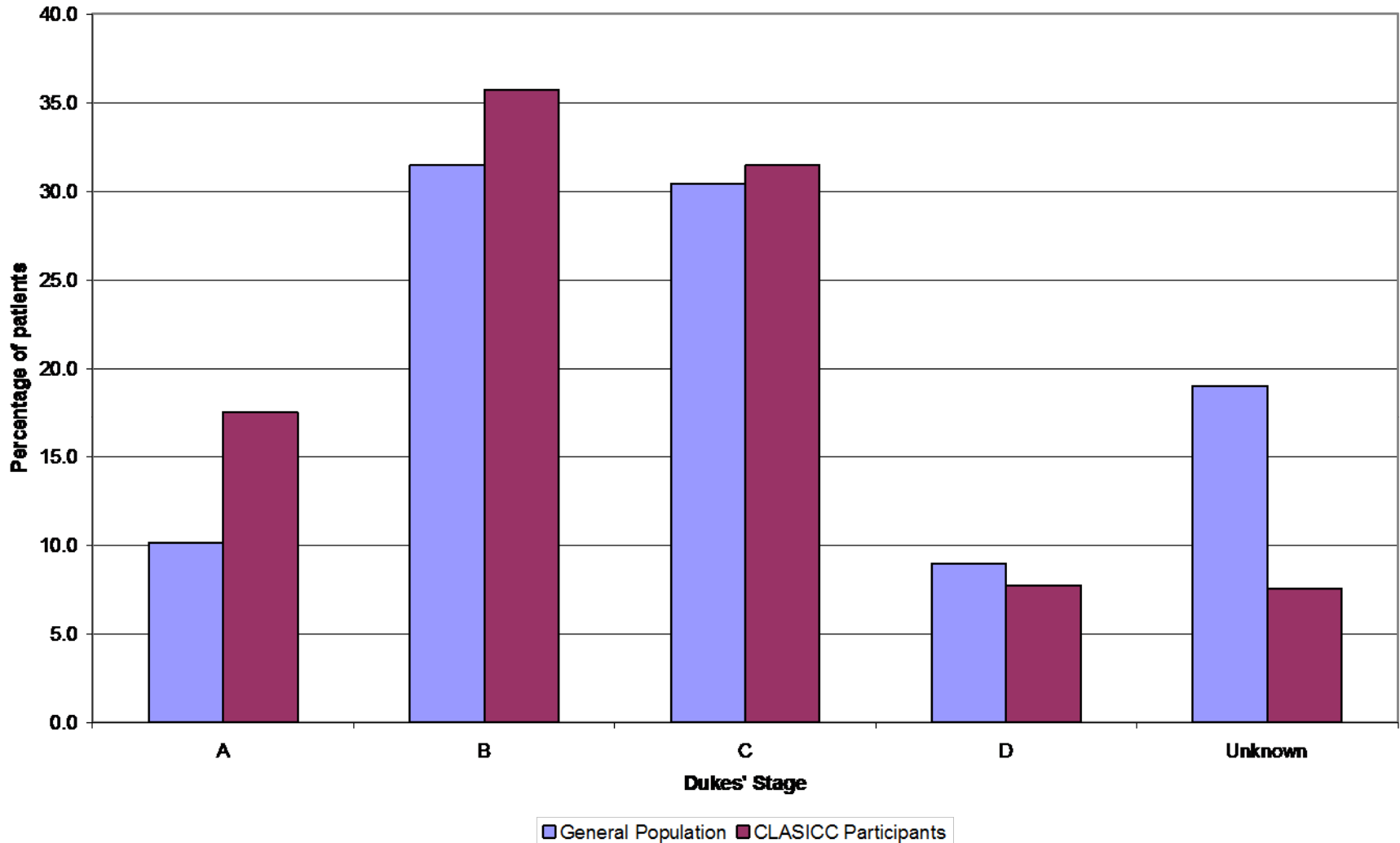
Comparison of age profile of CLASICC participants to the general population



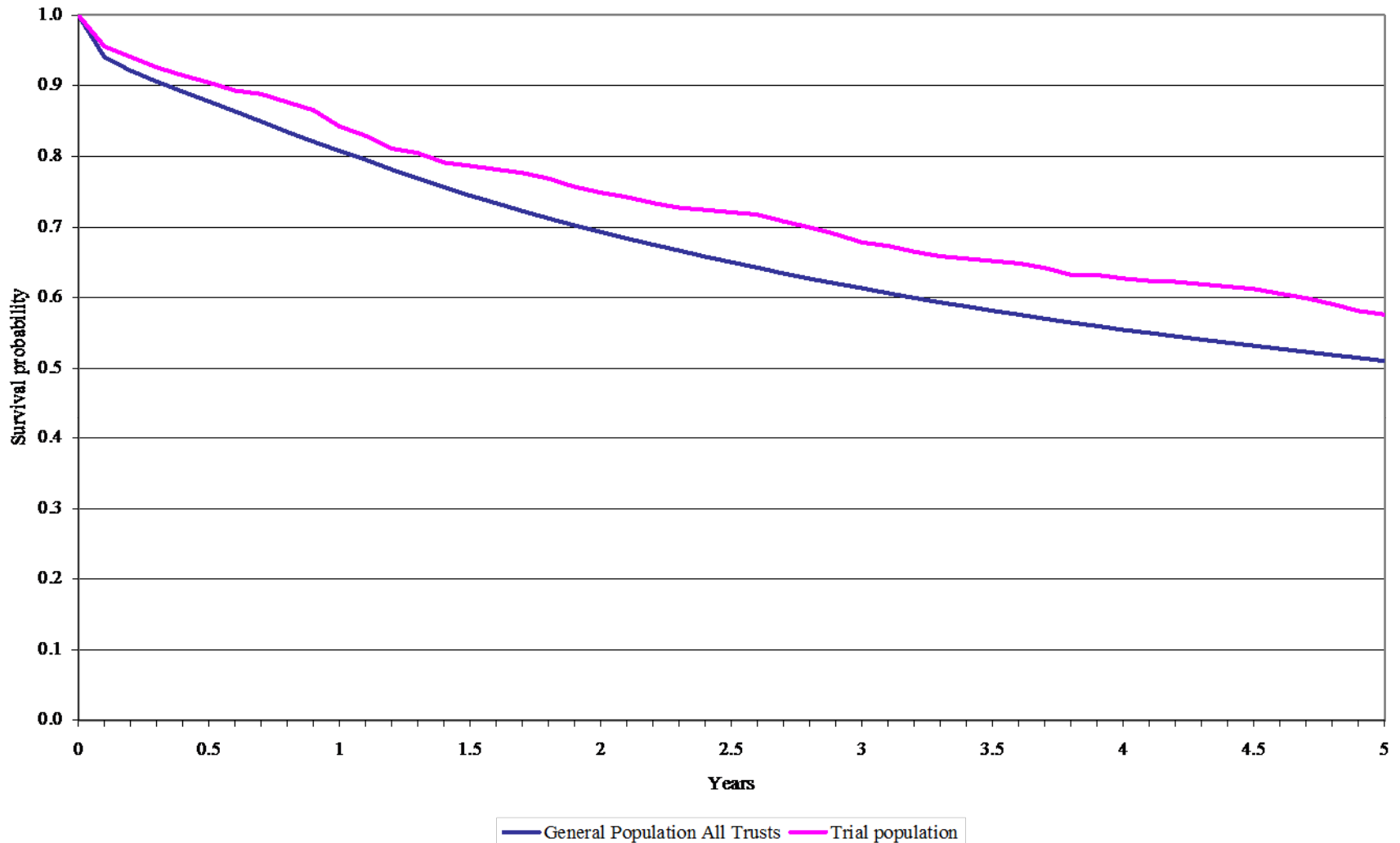
Comparison of IMD profile of CLASICC participants to the general population



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



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

