NCDR and clinical trials: experience in colorectal and haematological cancer

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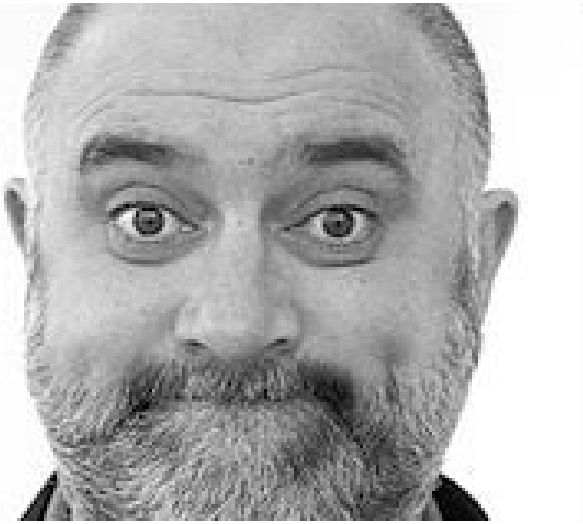
*"Anyone who uses the word workshop outside of light engineering is a ******"*



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- Eva Morris - NYCRIS
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- Jim Allen - Newcastle
- Lisa Lowry - UCL
- Paul Smith -UCL

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

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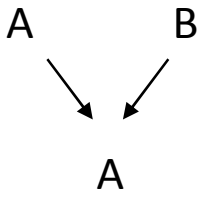
English cancer registry information

King's College London · Oxford Cancer Intelligence Unit · West Midlands Cancer Intelligence Unit · Trent Cancer Registry · ecric · NWCIS North West Cancer Intelligence Service · South West Public Health Observatory · Northern and Yorkshire Cancer Registry and Information Service

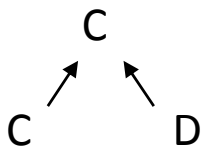
Hospital Episode Statistics

NHS The Information Centre for health and social care

De-duplication



Linked national dataset



De-duplication

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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?

Some examples of completed work and work in progress

- Colorectal
  - CLASICC Trial
- Haematological
  - RCHOP 14 vs. 21
  - ALL trials

Articles

Short-term endpoints of conventional versus laparoscopic-assisted surgery in patients with colorectal cancer (MRC CLASICC trial): multicentre, randomised controlled trial

Lancet 2005; 365: 1718–26
See Comment page 1666

Pierre J Guillou, Philip Quirke, Helen Thorpe, Joanne Walker, David G Jayne, Adrian M H Smith, Richard M Heath, Julia M Brown, for the MRC CLASICC trial group*

Original article

Comparison of treatment and outcome information between a clinical trial and the National Cancer Data Repository

E. J. A. Morris[1], C. Jordan[2], J. D. Thomas[1], M. Cooper[2], J. M. Brown[3], H. Thorpe[3], D. Cameron[2], D. Forman[1], D. Jayne[4] and P. Quirke[5] in collaboration with the CLASICC trialists

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Correspondence to: Dr E. J. A. Morris, Colorectal Cancer Epidemiology Group, Level 6, Bexley Wing, St James's Institute of Oncology, St James's University Hospital, Leeds LS9 7TF, UK (e-mail: eva.morris@nycris.leedsth.nhs.uk)

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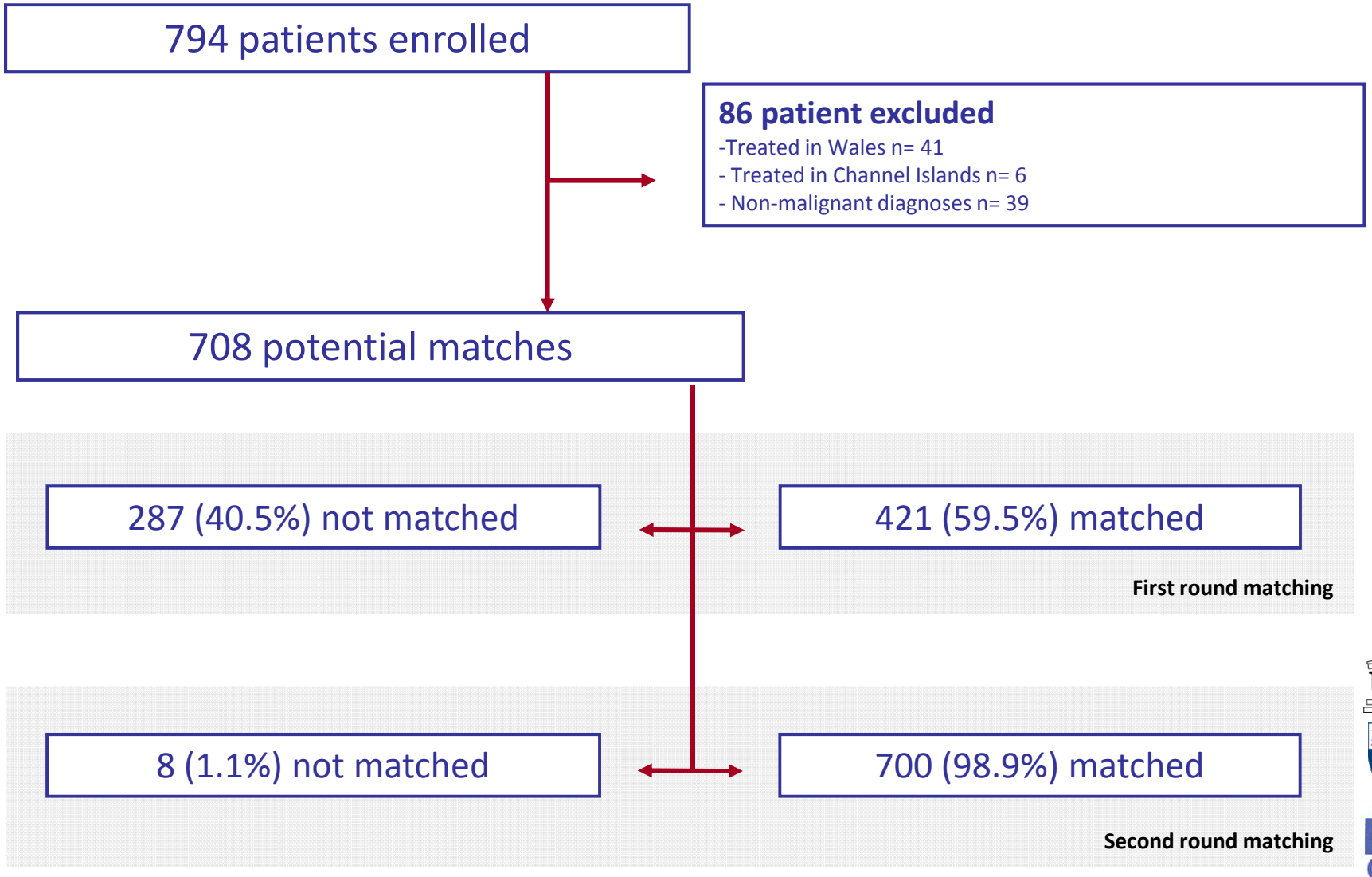
Comparison of Outcome Information



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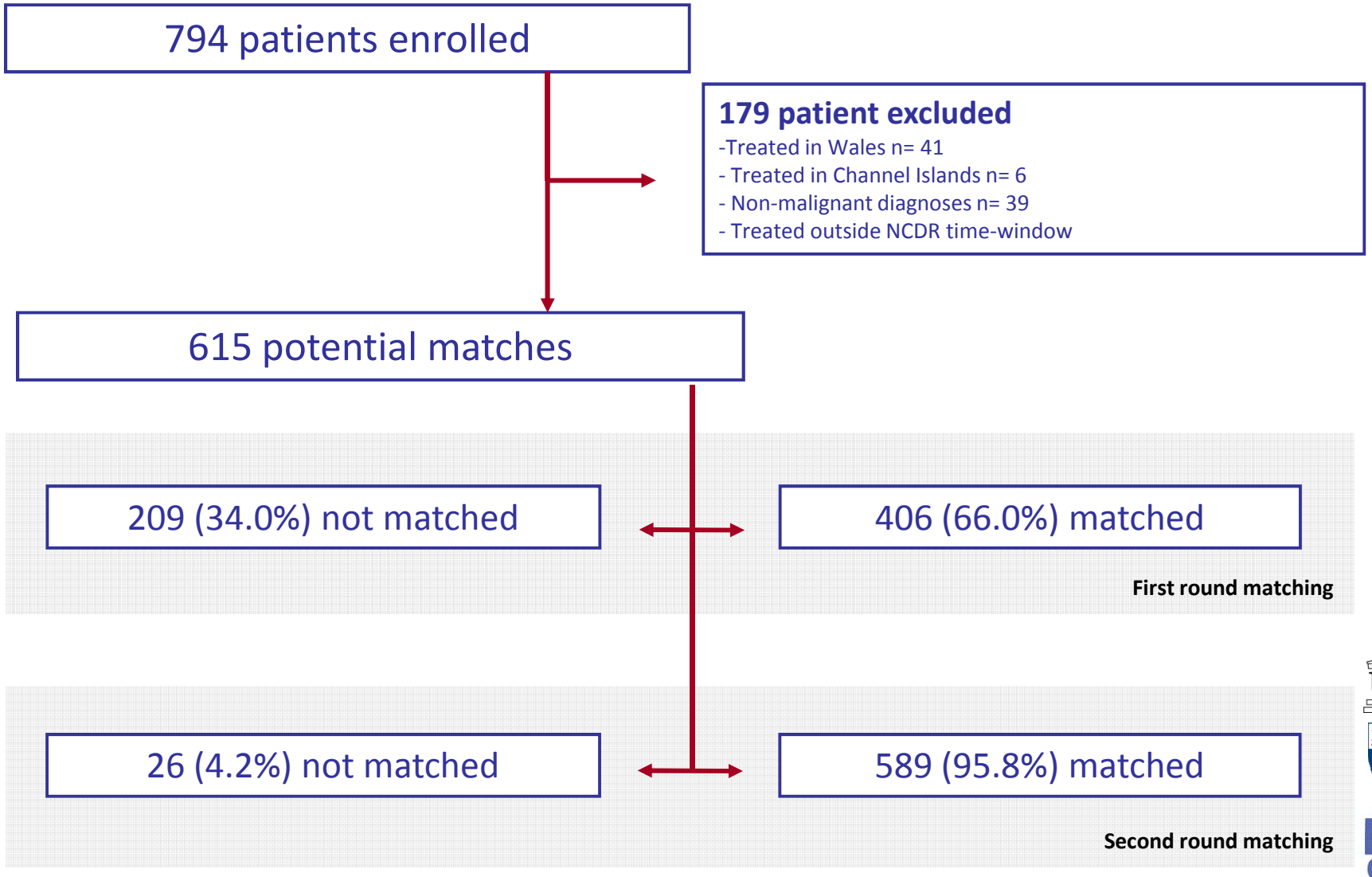
Comparison of Treatment Information



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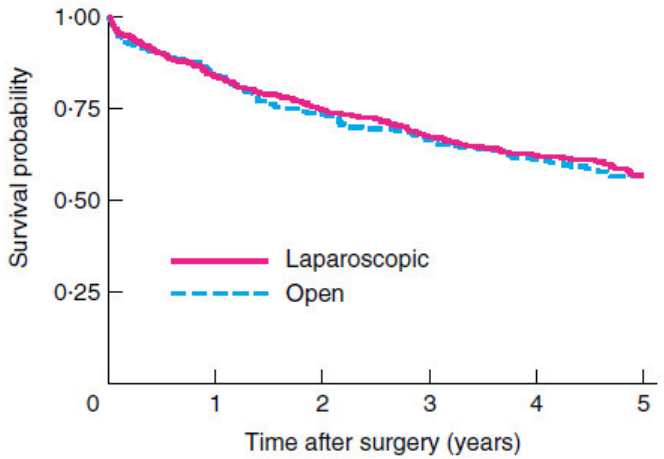
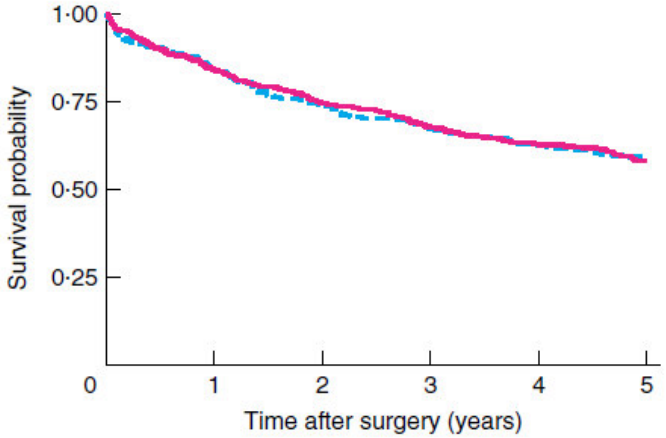
Year	All procedures: *n*	All procedures: Agreement in coding: Type of operation	All procedures: Agreement in coding: Surgeon	Laparoscopic procedures: *n*	Laparoscopic procedures: Agreement in coding
1997–1998	127	75 (59·1)	72 (56·7)	49	26 (53·1)
1998–1999	113	104 (92·0)	101 (89·4)	46	36 (78·3)
1999–2000	111	103 (92·8)	104 (93·7)	47	35 (74·5)
2000–2001	68	66 (97·1)	68 (100)	29	16 (55·2)
2001–2002	118	113 (95·8)	111 (94·1)	64	31 (48·4)
2002–2003	47	42 (89·4)	44 (93·6)	27	9 (33·3)
Total	584	503 (86·1)	500 (85·6)	262	153 (58·4)

	Total bed stay (days)	Total bed stay excluding surgical episode (days)
Laparoscopic	27 (4–196)	15 (1–183)
Open	33 (6–165)	21 (1–150)
Converted	34 (8–614)	20 (1–595)



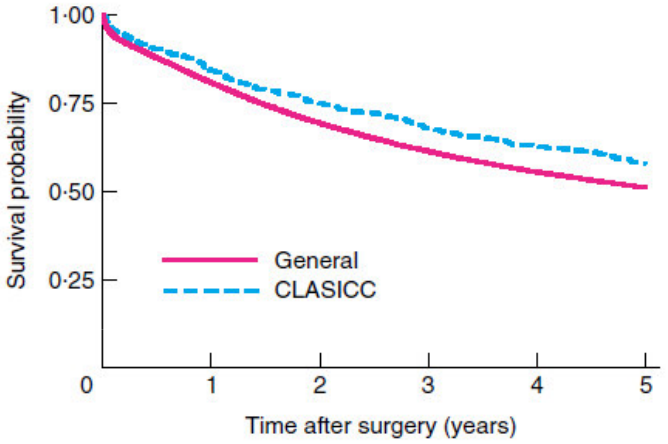
No. at risk						
Laparoscopic	470	392	346	310	261	212
Open	238	199	172	155	133	103

a CLASICC trial data



No. at risk						
Laparoscopic	470	395	351	318	296	273
Open	238	200	176	160	149	140

b NCDR data



No. at risk						
General	77 295	62 337	53 474	47 322	42 789	39 373
CLASICC	610	513	456	413	381	351

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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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National Institute for Clinical Excellence

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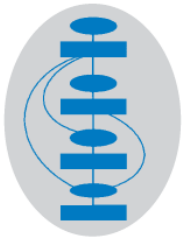
Guidance on Cancer Services

Improving Outcomes in Haematological Cancers

The Manual



Prevalence, incidence and survival rates

There are no precise and reliable figures for incidence and survival rates for the different forms of haematological cancer in England and Wales. Whilst the Office for National Statistics (ONS) and the Wales Cancer Intelligence and Surveillance Unit do publish descriptive statistics (Table 1), there are many problems with these figures. For example, there is evidence that many cases are never reported to cancer registries, so the actual number of patients could be substantially higher than national figures suggest.

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You are here: Home » Trials and research » A trial looking at treatment every 2 weeks or every 3 weeks for non Hodgkin's lymphoma (R-CHOP 14 vs R-CHOP 21)

Trials search
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Types of trials
Planning and organising trials
Finding a trial
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Organisations

A trial looking at treatment every 2 weeks or every 3 weeks for non Hodgkin's lymphoma (R-CHOP 14 vs R-CHOP 21)

This trial was comparing treatment every 2 weeks with every 3 weeks for diffuse large B cell non Hodgkin's lymphoma. But from November 2008, everybody taking part will have R-CHOP every 3 weeks. You may now hear the trial called **R-CHOP 21**.

Diffuse large B cell non Hodgkin's lymphoma is a type of high grade non Hodgkin's lymphoma (NHL). For some time, the standard treatment has been a combination of chemotherapy called CHOP. This is the chemotherapy drugs cyclophosphamide, doxorubicin (Adriamycin) and vincristine, which you have once every 3 weeks. You also take prednisolone steroid tablets once a day for 5 days out of every 3 weeks.

Clinical trials have shown that having a monoclonal antibody called rituximab as well as CHOP is beneficial for some patients. This is called R-CHOP.

Other clinical trials have shown that it may be better to have CHOP every 2 weeks rather than every 3 weeks. But doctors don't know if it is better to have R-CHOP every 2 weeks (R-CHOP 14) or every 3 weeks (R-CHOP 21).

The aim of this trial is to compare R-CHOP 14 and R-CHOP 21 to see which is better for newly diagnosed diffuse large B cell non Hodgkin's lymphoma. Recruitment into the group having treatment with R-CHOP 14 has now closed.

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Degree of matching between RCHOP 14/21 and NCDR (first round)

			Matching with NCDR All cases (% all cases; % with "NHS No.")		
Year of entry	No. cases	"NHS No." (%)	Any	Cancer Registry*	HES+
2005	133				
2006	259				
2007	299				
2008	260				
2009	20				
Total	971				

Data limited to 971 individuals recruited from English Hospitals
*Current linked dataset has cancer registration to 2006
+Current linked dataset has some HES data for 2007

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Degree of matching between RCHOP 14/21 and NCDR (first round)

			Matching with NCDR All cases (% all cases; % with "NHS No.")		
Year of entry	No. cases	"NHS No." (%)	Any	Cancer Registry*	HES+
2005	133	73 (55)			
2006	259	139 (54)			
2007	299	193 (65)			
2008	260	249 (96)			
2009	20	19 (95)			
Total	971	673 (69)			

Data limited to 971 individuals recruited from English Hospitals
*Current linked dataset has cancer registration to 2006
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Degree of matching between RCHOP 14/21 and NCDR (first round)

			Matching with NCDR All cases (% all cases; % with "NHS No.")		
Year of entry	No. cases	"NHS No." (%)	Any	Cancer Registry*	HES+
2005	133	73 (55)	51 (38; 70)	50 (38; 68)	50 (38; 68)
2006	259	139 (54)	77 (30; 55)	68 (26; 49)	75 (29; 54)
2007	299	193 (65)	52 (17; 27)	14 (5; 7)	49 (16; 25)
2008	260	249 (96)	24 (9; 10)	16 (6; 6)	20 (8; 8)
2009	20	19 (95)	1 (5; 5)	1 (5; 5)	0 (-; -)
Total	971	673 (69)	205 (21; 30)	149 (15; 22)	194 (20; 29)

Data limited to 971 individuals recruited from English Hospitals
*Current linked dataset has cancer registration to 2006
+Current linked dataset has some HES data for 2007

Degree of matching between RCHOP 14/21 and NCDR (second round)

		Matching with NCDR All cases (% all cases; % with "NHS No.")			
Year of entry	No. cases	"NHS No." (%)	Any	Cancer Registry*	HES+
2005	133	94 (71)	94 (71; 100)	92 (69; 98)	92 (69; 98)
2006	259	154 (59)	145 (56; 94)	135 (52; 88)	144 (56; 94)
2007	299	205 (69)	92 (31; 45)	18 (6; 9)	90 (30; 44)
2008	260	250 (96)	13 (5; 5)	5 (2; 2)	10 (4; 4)
2009	20	19 (95)	1 (5; 5)	0 (-; -)	1 (5; 5)
Total	971	722 (74)	345 (36; 48)	250 (26; 35)	337 (35; 47)

Data limited to 971 individuals recruited from English Hospitals
*Current linked dataset has cancer registration to 2006
+Current linked dataset has some HES data for 2007

Degree of matching between RCHOP 14/21 and NCDR (third round)

			Matching with NCDR All cases (% all cases; % with "NHS No.")		
Year of entry	No. cases	"NHS No." (%)	Any	Cancer Registry*	HES+
2005	133	130 (98)	129 (97; 99)	125 (94; 96)	127 (95; 98)
2006	259	246 (95)	241 (95; 98)	228 (88; 93)	238 (92; 97)
2007	299	287 (96)	273 (91; 95)	245 (82; 85)	268 (90; 93)
2008	260	260 (100)	79 (30; 30)	21 (30; 30)	75 (29; 29)
2009	20	19 (95)	2 (10; 11)	1 (5; 5)	1 (5; 5)
Total	971	942 (97)	724 (75; 77)	620 (64; 66)	709 (73; 75)

Data limited to 971 individuals recruited from English Hospitals
*Current linked dataset has cancer registration to 2007
+Current linked dataset has some HES data for 2008

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Acute lymphoblastic leukaemia research

This page of the acute lymphoblastic leukaemia (ALL) section is about research into the causes, prevention and treatments of acute lymphoblastic leukaemia.

MRC/NCRI ALL Trials

- UKALLXI
- UKALLXII
- ALL97
- INFANT6
- INTERF 99
- MRD PILOT
- UKALLXIIR
- ALL2003

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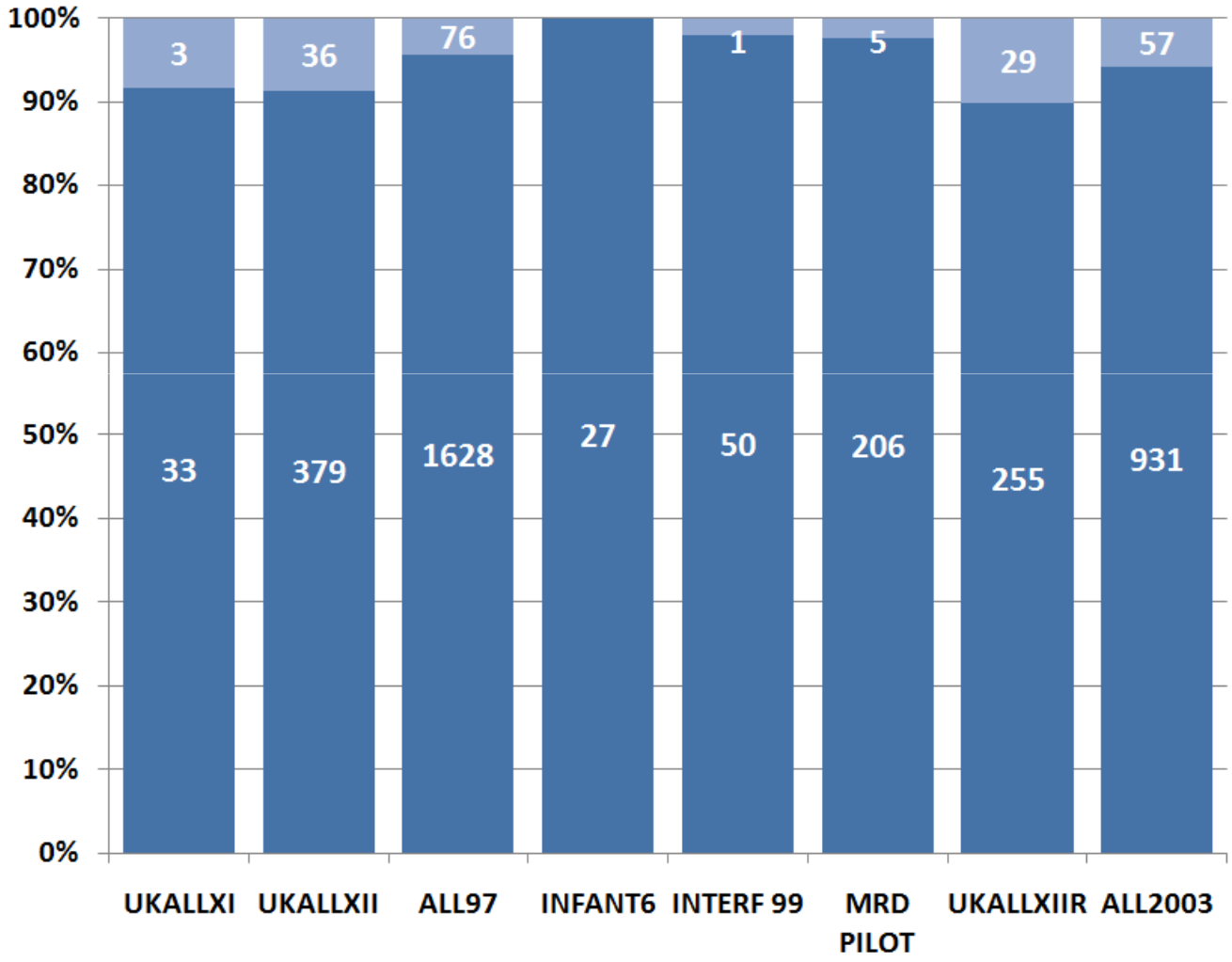
3,716 Trial Participants (1997-2006)
Acute Lymphoblastic Leukaemia
Linkage to NCDR-haem (1st round)



Current overall linkage = 94%

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3,716 Trial Participants (1997-2006)
NCDR Registered Cancer

Registered Cancer	%
Acute Lymphoid Leukaemia (ALL)	95.23%
Diffuse NHL, Lymphoblastic	1.00%
Acute Myeloid Leukaemia (AML)	0.82%
Acute Leukaemia, Unspecified Cell Type	0.74%
Lymphoid Leukaemia, Unspecified	0.44%
Adult T-Cell Leukaemia	0.32%
Leukaemia, Unspecified	0.32%
Chronic Lymphoid Leukaemia (CLL)	*0.27%*
NHL Unspecified Type	*0.24%*
Diffuse NH, Large Cell	*0.09%*
Acute Monocytic Leukaemia	*0.06%*
B-Cell Lymphoma, Unspecified	*0.06%*
Diffuse NHL, Unspecified	*0.06%*
Leukaemia, Other Specified	*0.06%*
Peripheral T-Cell Lymphoma	*0.06%*
Acute Megakaryoblastic Leukaemia	*0.03%*
Burkitts Tumour	*0.03%*
Chronic Leukaemia, Unspecified Cell Type	*0.03%*
Chronic Myeloid Leukaemia (CML)	*0.03%*
Lymphoid Leukaemia, Other	*0.03%*
Myeloid Leukaemia, Unspecified	*0.03%*
T-Cell Lymphoma, Other and Unspecified	*0.03%*
Uncertain Lymphoid, Haematopoetic, Unspecified	*0.03%*

5,968 NCDR registrations
Acute Lymphoblastic Leukaemia (ICD 91.0)

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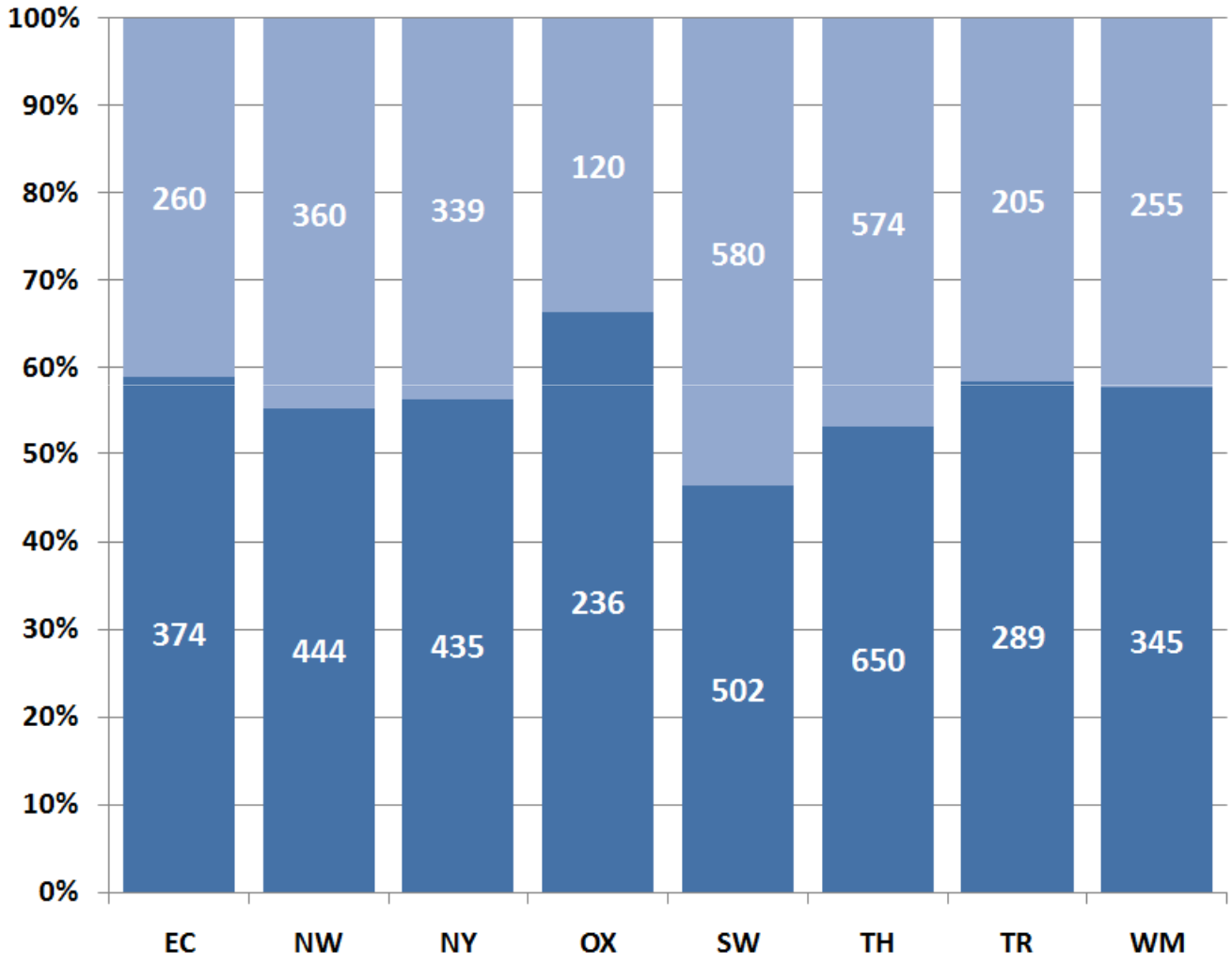
Linkage by Cancer Registry



Current overall linkage = 55%

Linked to Trial?

- NO
- YES

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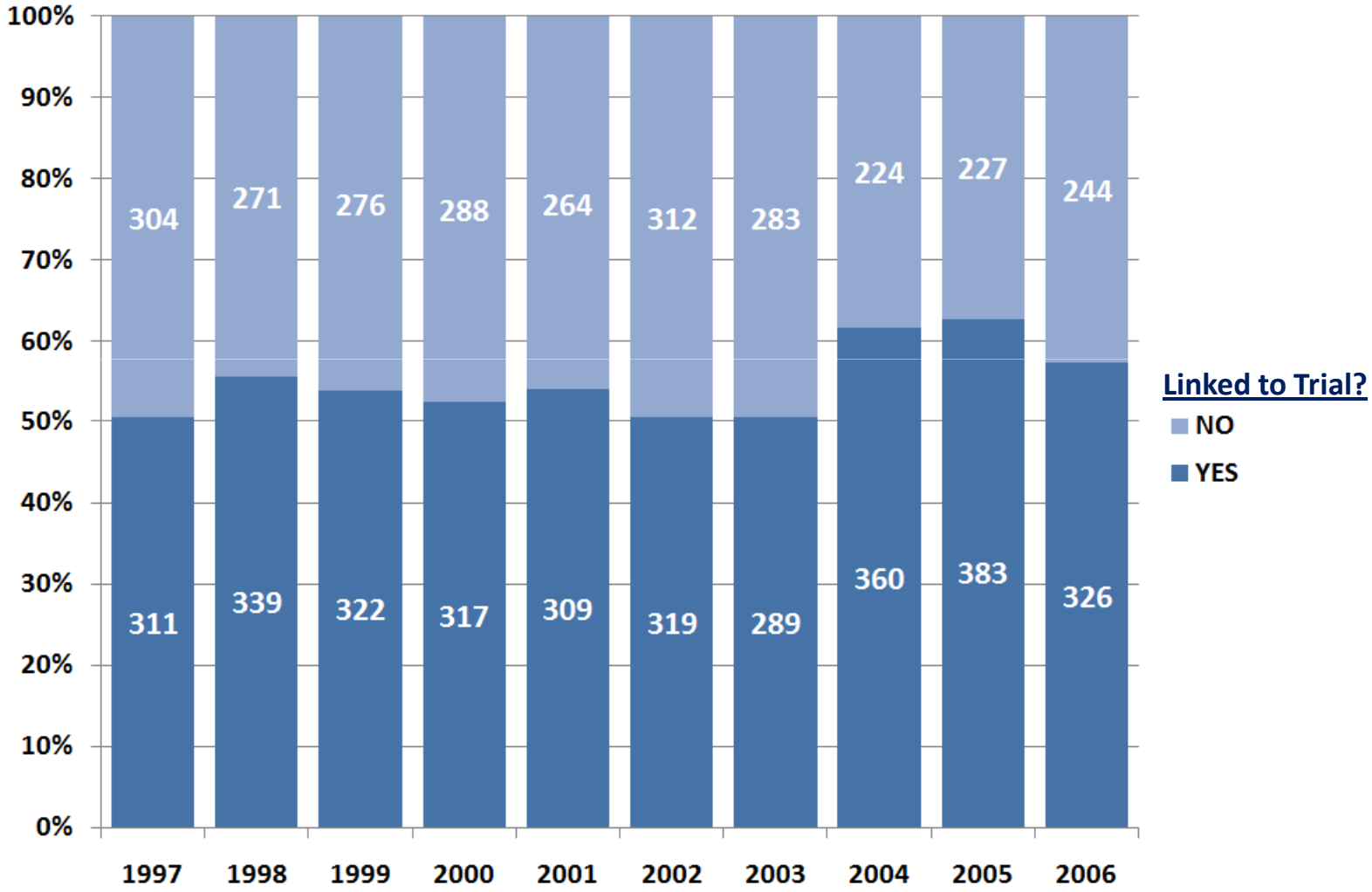
Linkage by Year of Registration



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Acute Lymphoblastic Leukaemia (ICD 91.0)

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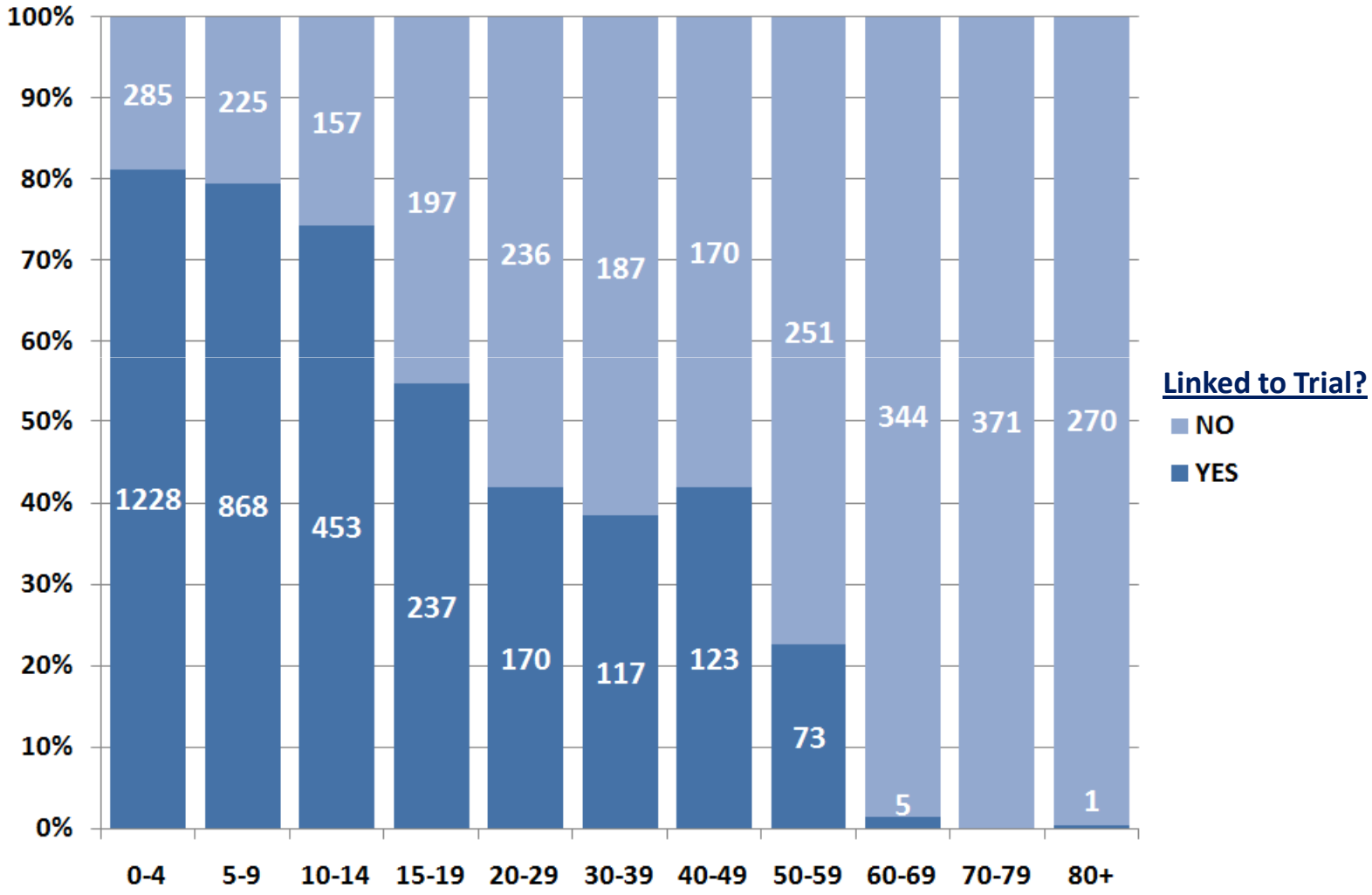
Linkage by Age Group



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Conclusions

- The NCDR can complement existing trial data
- Constraints
  - Underlying quality of NCDR
  - Time window
  - “National”
  - “Refresh rate”
  - Information Governance and ethics
  - Linking variables
  - Staff capacity and resources
- Industrialising a cottage industry