



Public Health
England

ALL in TYA

Linking trial and outcomes data

Tony Moran, Maria Khan, Sabrina Sandhu
North West KIT, PHE

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Public Health
England

ALL

- About 70 patients aged 15-24 years diagnosed each year in England

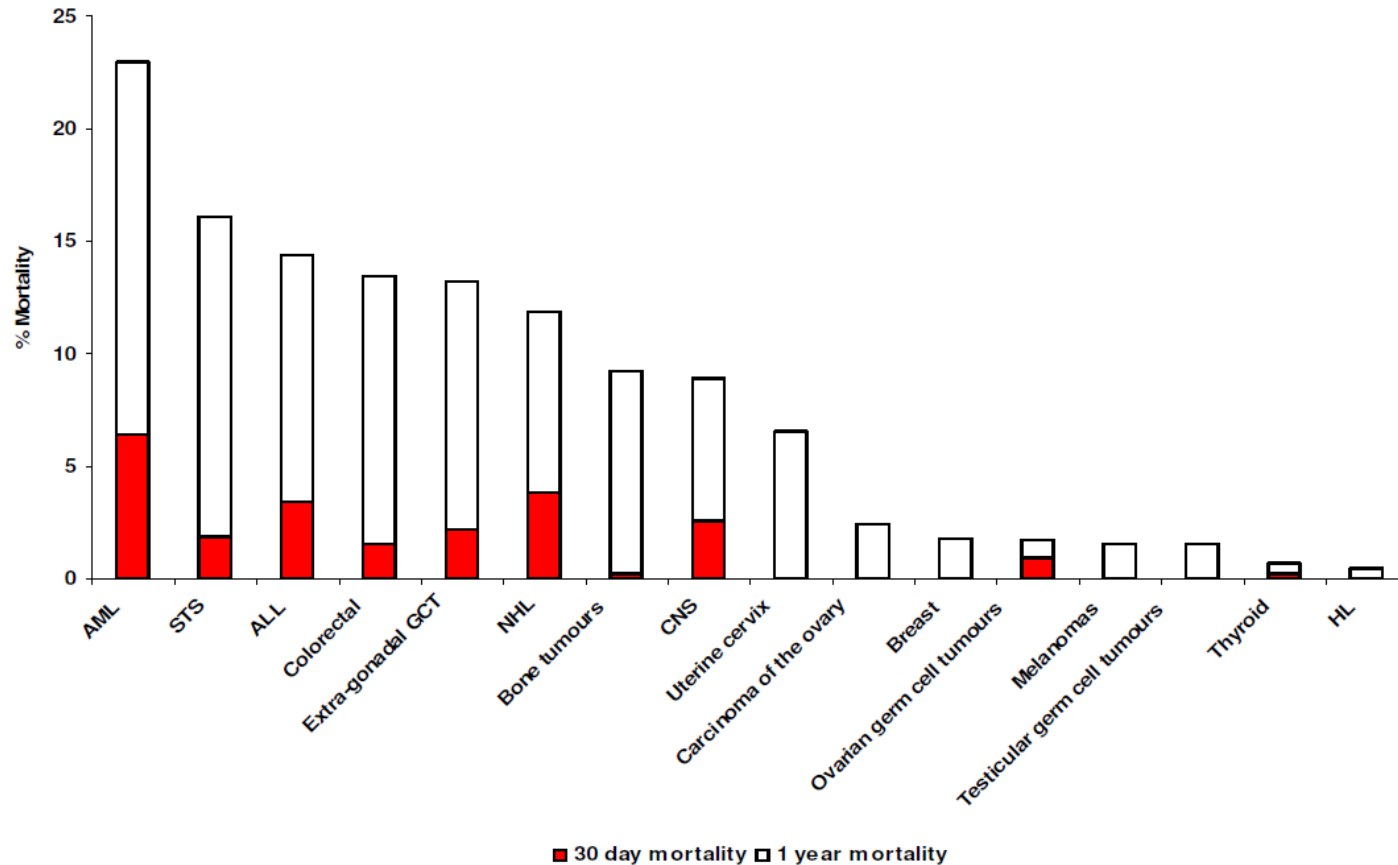


Figure 1 : 30 day and one year percentage mortality for individuals aged 15-24 diagnosed in England, 2005-2009, by diagnostic group

Pattern of deaths in the year following diagnosis in cancer patients aged 15-24 years in England. T Moran, C O'Hara, D Purkayastha, available at www.ncin.org.uk/view?rid=2134



Causes of death in the year following diagnosis

- Late stage at diagnosis/delay in diagnosis
- Treatment related



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UKALL2003

- Almost no contraindications to inclusion
- 2004-2011
- Upper age limit raised twice during lifetime of trial



This study

- Participation rates in UKALL2003 in England
- One and two-year survival by trial participation and % deaths
- Trial participation vs TYAC form completed
- Review of death certs of patients who died in first three months

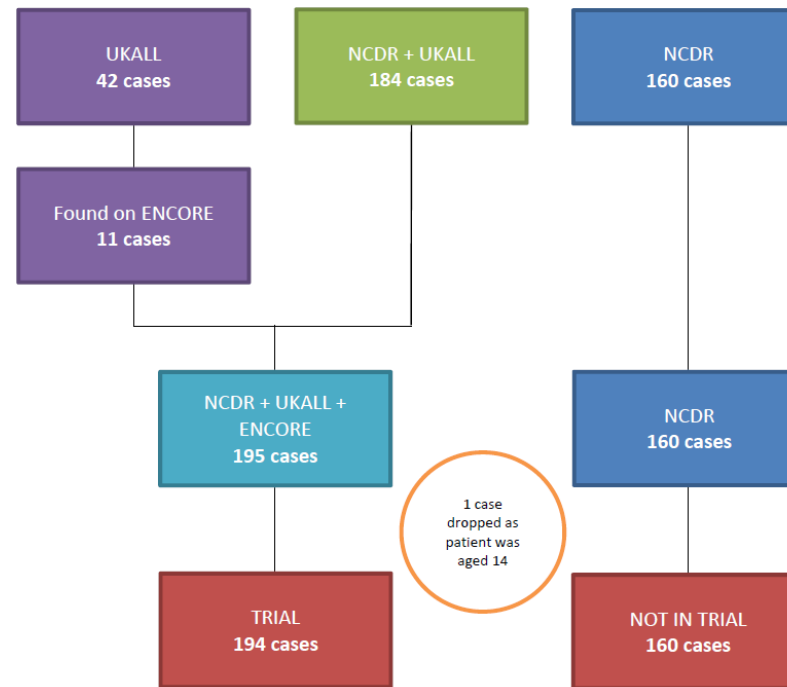


Methods: Participation in Trial

- Matched National Cancer Data Repository against Trial database using NHS number (and other data items)
- Those on Trial not on NCDR matched against ENCORE
- Confined to patients diagnosed in 2006-10



Results of record-matching



Study population: 354
TRIAL = 194 cases
NOT IN TRIAL = 160



Trial Participation by age group for those diagnosed in 2006 - 2010

| | Number in Trial | % in Trial | Number not Trial | % in Trial | Total |
|-------|-----------------|------------|------------------|------------|-------|
| 15-19 | 158 | 66.9% | 78 | 33.1% | 236 |
| 20-24 | 36 | 30.5% | 82 | 69.5% | 118 |
| 15-24 | 194 | 54% | 160 | 45.2% | 354 |



Trial Participation by age group and year of diagnosis

| | 15-19 | | 20-24 | | 15-24 | |
|-----------|-----------------|------------|-----------------|------------|-----------------|------------|
| | Number in Trial | % in Trial | Number in Trial | % in Trial | Number in Trial | % in Trial |
| 2006 | 27 | 48.2% | 0 | 0.0% | 27 | 37.0% |
| 2007 | 28 | 60.9% | 4 | 12.9% | 32 | 41.6% |
| 2008 | 39 | 83.0% | 8 | 34.8% | 47 | 67.1% |
| 2009 | 37 | 72.5% | 10 | 40.0% | 47 | 61.8% |
| 2010 | 27 | 75.0% | 14 | 63.6% | 41 | 70.7% |
| 2006-2010 | 158 | 66.9% | 36 | 30.5% | 194 | 54.8% |

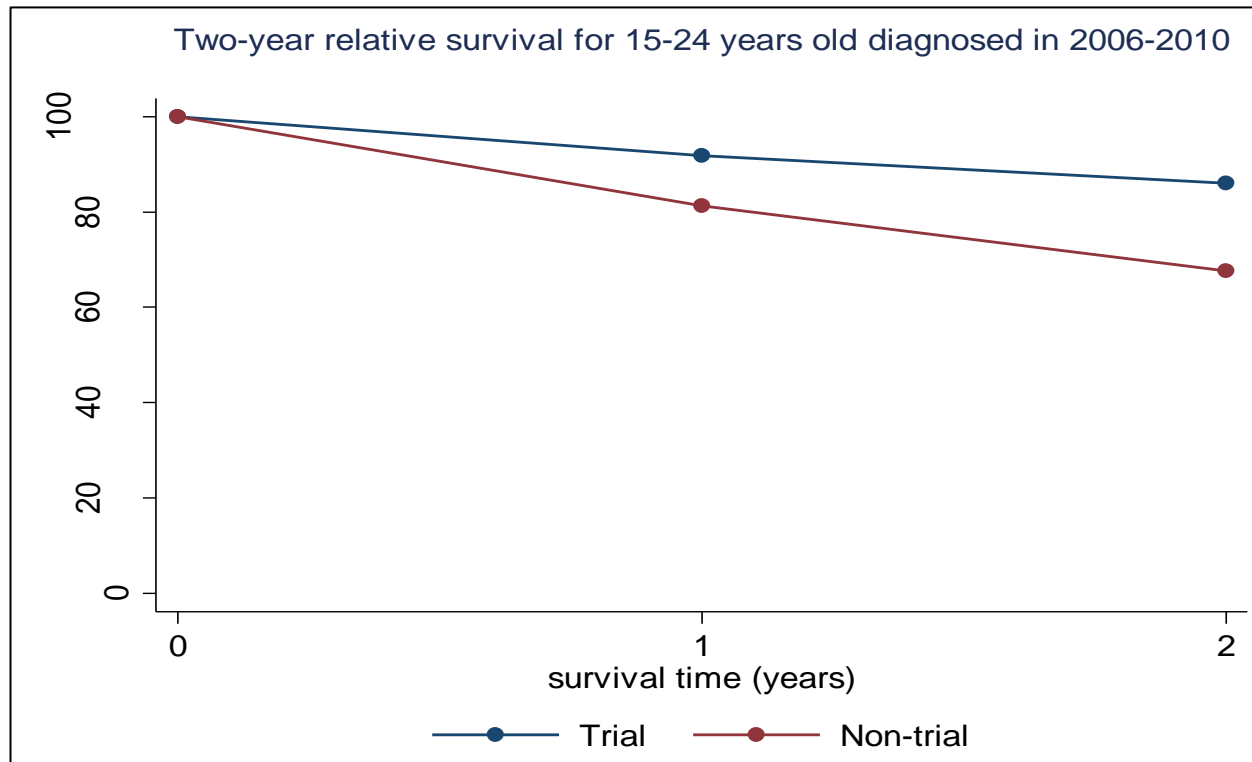


Methods: survival and deaths

- One and two year-relative survival
- Number and proportion of deaths by month, quarter and year



Two-year relative survival for 15-24 year olds diagnosed in 2006-2010



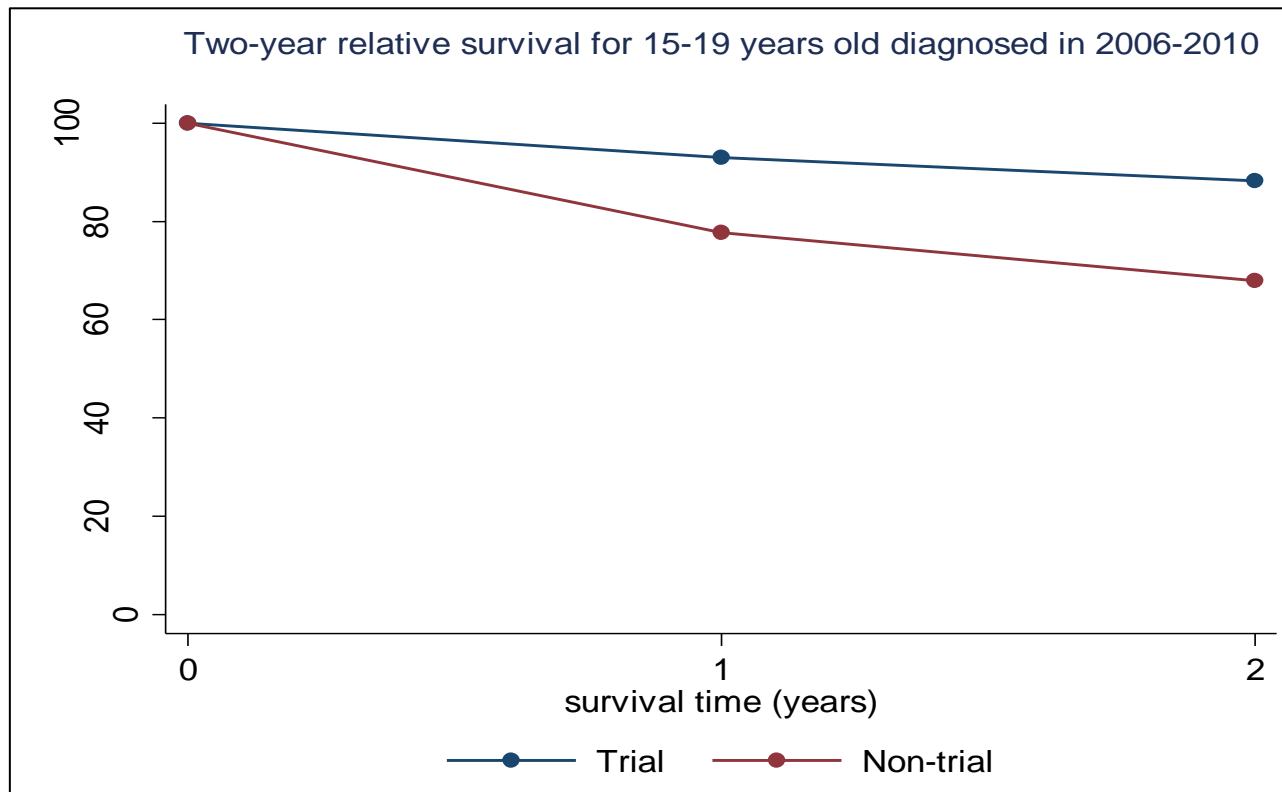


Two-year relative survival for 15-24 year olds diagnosed in 2006-2010

| Year | | N | D | R Sur (%) | 95% CI |
|------|--------------|-----|----|-----------|-------------|
| 0-1 | Trial | 194 | 16 | 91.8% | 86.9 – 94.9 |
| | Not in trial | 155 | 29 | 81.3% | 74.2 – 86.6 |
| 1-2 | Trial | 178 | 10 | 93.8% | 88.8 – 96.7 |
| | Not in trial | 126 | 20 | 83.3% | 75.2 – 88.9 |
| 0-2 | Trial | 194 | 26 | 86.1 | 80.2 – 90.4 |
| | Not in trial | 155 | 49 | 67.7 | 59.6 – 74.5 |

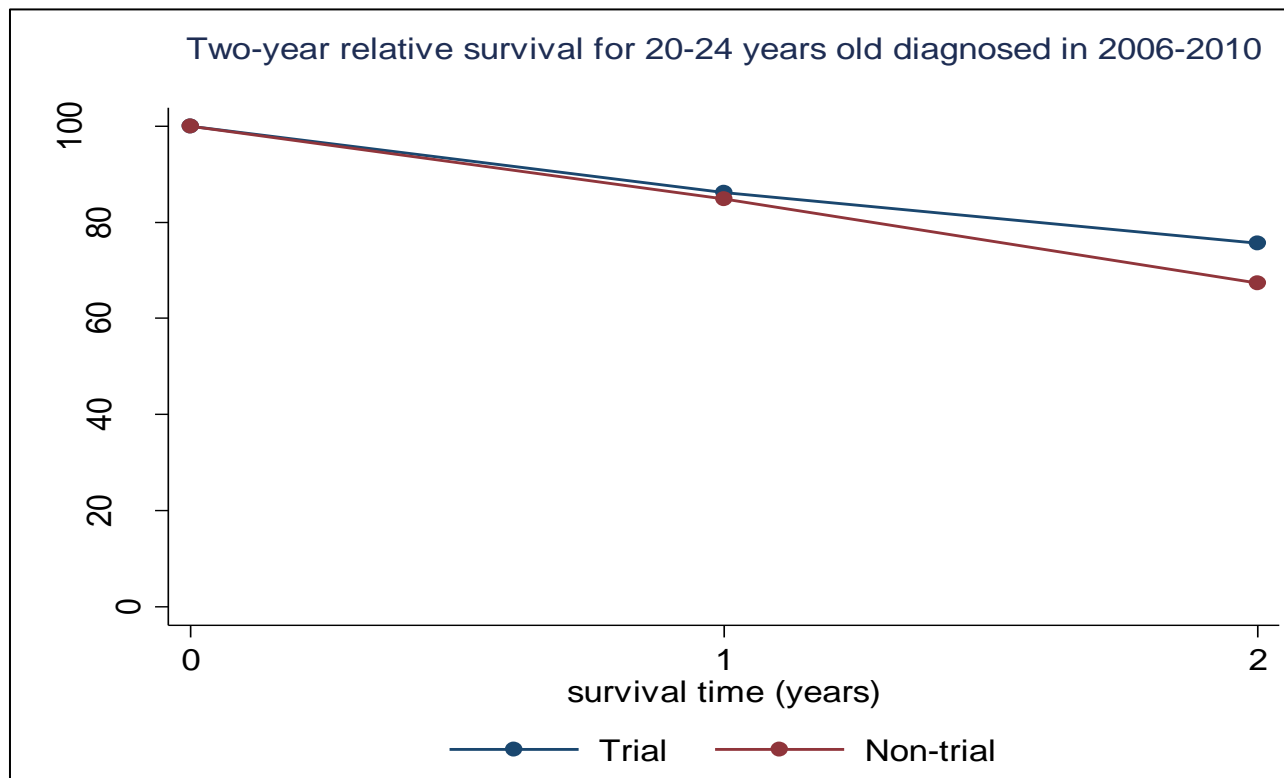


Two-year relative survival for 15-19 year olds diagnosed in 2006-2010





Two-year relative survival for 20-24 year olds diagnosed in 2006-2010





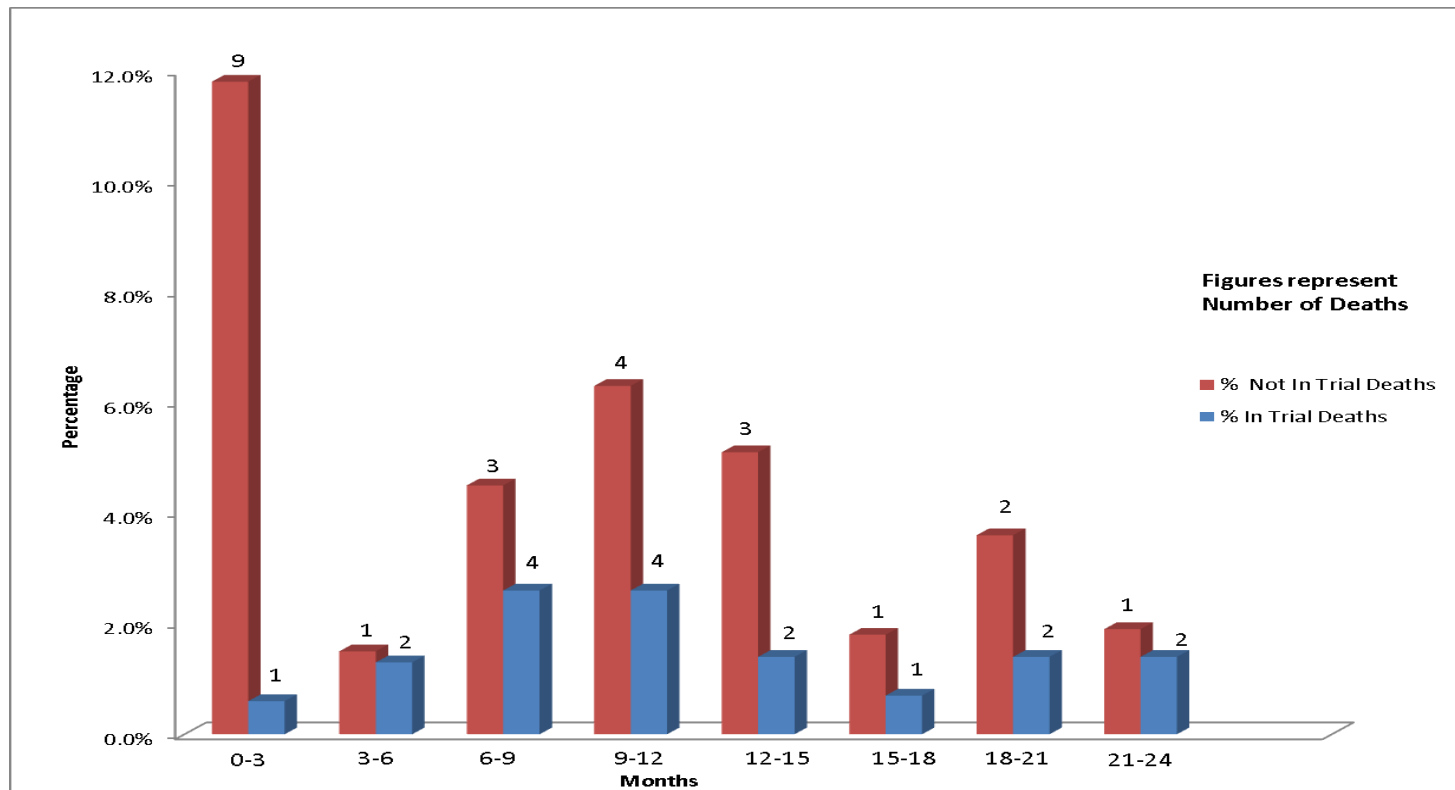
Number and % deaths per year

| 15 to 19 year olds | | | | | | |
|--------------------|-------------------------------------|------------------|-------------|-------------------------------------|------------------|-------------|
| Year | In trial | | | Not in trial | | |
| | Number of patients at start of Year | Number of deaths | % of deaths | Number of patients at start of Year | Number of deaths | % of deaths |
| 1 | 158 | 11 | 7.0% | 76 | 17 | 22.4% |
| 2 | 147 | 7 | 4.8% | 59 | 7 | 11.9% |
| 1&2 | 158 | 18 | 11.4% | 76 | 24 | 31.6% |

| 20 to 24 year olds | | | | | | |
|--------------------|-------------------------------------|------------------|-------------|-------------------------------------|------------------|-------------|
| Year | In trial | | | Not In trial | | |
| | Number of patients at start of Year | Number of deaths | % of deaths | Number of patients at start of Year | Number of deaths | % of deaths |
| 1 | 36 | 5 | 13.9% | 79 | 12 | 15.2% |
| 2 | 31 | 3 | 9.7% | 67 | 13 | 19.4% |
| 1&2 | 36 | 8 | 22.2% | 79 | 25 | 31.6% |

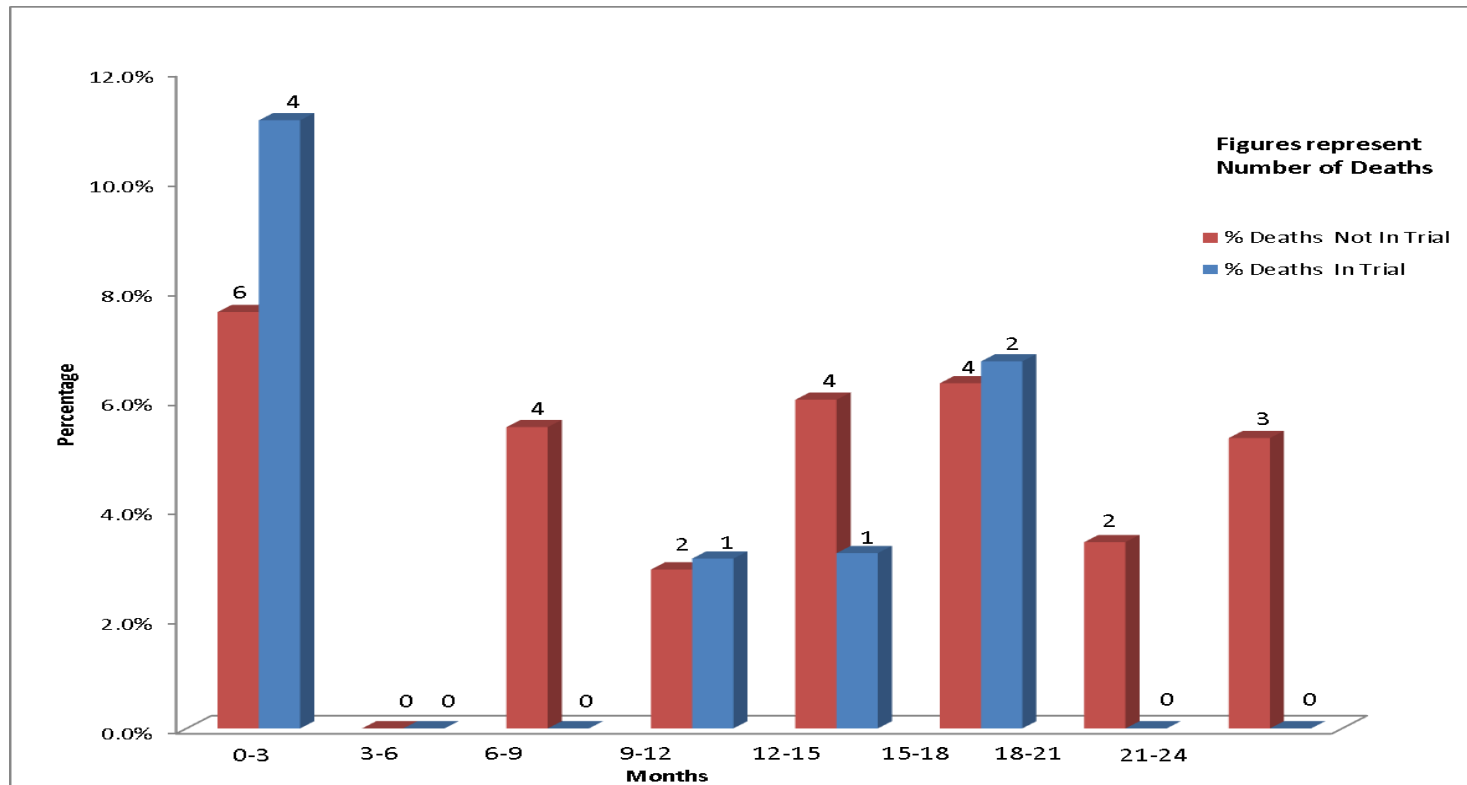


Number and percentage of deaths by quarter in those aged 15-19 years





Number and percentage of deaths by quarter in those aged 20-24 years





Methods: Matching TYAC and Trial

- 2009-2010 study population (134)
- Matched against TYAC database using NHS number
- 83 matched; 51 not matched



Percentage of patients in trial by whether TYAC form received by age group in 2009-2010

| Age group | % of patients with a TYAC Form who were in Trial | % of Patients without a TYAC Form who were in Trial |
|-----------|--|---|
| 15-19 | 78.9% | 63.3% |
| 20-24 | 61.5% | 38.1% |
| 15-24 | 73.5% | 52.9% |



Conclusions 1: Participation in Trial

- Considerable % not in trial
- Higher % of 15-19 in trial even for most recent years
- Many patients on trial not found on registry



Conclusions 2: Survival and Deaths

15-19 year olds

- Two year survival better for those in trial
- Biggest difference in first three months

20-24 year olds

- Moderate difference in second year



Conclusions 3: TYAC form and Trial

- Those with a form about 20% more likely to be in trial



Way forward

Complete work

- Review of death certs
- Explore why patients not on registry
- Add 2004 and 2005?
- Publish

Further actions

- Increase participation in trials?
- Outcomes by where and how managed?