ALL in TYA
Linking trial and outcomes data

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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
Causes of death in the year following diagnosis

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

UKALL
42 cases

NCDR + UKALL
184 cases

NCDR
160 cases

Found on ENCORE
11 cases

NCDR + UKALL + ENCORE
195 cases

1 case dropped as patient was aged 24

TRIAL
194 cases

NOT IN TRIAL
160 cases

Study population: 354
TRIAL = 194 cases
NOT IN TRIAL = 160
## Trial Participation by age group for those diagnosed in 2006 - 2010

<table>
<thead>
<tr>
<th>Age Group</th>
<th>Number in Trial</th>
<th>% in Trial</th>
<th>Number not Trial</th>
<th>% in Trial</th>
<th>Total</th>
</tr>
</thead>
<tbody>
<tr>
<td>15-19</td>
<td>158</td>
<td>66.9%</td>
<td>78</td>
<td>33.1%</td>
<td>236</td>
</tr>
<tr>
<td>20-24</td>
<td>36</td>
<td>30.5%</td>
<td>82</td>
<td>69.5%</td>
<td>118</td>
</tr>
<tr>
<td>15-24</td>
<td>194</td>
<td>54%</td>
<td>160</td>
<td>45.2%</td>
<td>354</td>
</tr>
</tbody>
</table>
**Trial Participation by age group and year of diagnosis**

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

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

<table>
<thead>
<tr>
<th>Year</th>
<th>In trial</th>
<th>Not in trial</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Number of patients at start of Year</td>
<td>Number of deaths</td>
</tr>
<tr>
<td>1</td>
<td>158</td>
<td>11</td>
</tr>
<tr>
<td>2</td>
<td>147</td>
<td>7</td>
</tr>
<tr>
<td>1&amp;2</td>
<td>158</td>
<td>18</td>
</tr>
</tbody>
</table>

### 20 to 24 year olds

<table>
<thead>
<tr>
<th>Year</th>
<th>In trial</th>
<th>Not In trial</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Number of patients at start of Year</td>
<td>Number of deaths</td>
</tr>
<tr>
<td>1</td>
<td>36</td>
<td>5</td>
</tr>
<tr>
<td>2</td>
<td>31</td>
<td>3</td>
</tr>
<tr>
<td>1&amp;2</td>
<td>36</td>
<td>8</td>
</tr>
</tbody>
</table>
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

<table>
<thead>
<tr>
<th>Age group</th>
<th>% of patience with a TYAC Form who were in Trial</th>
<th>% of Patients without a TYAC Form who were in Trial</th>
</tr>
</thead>
<tbody>
<tr>
<td>15-19</td>
<td>78.9%</td>
<td>63.3%</td>
</tr>
<tr>
<td>20-24</td>
<td>61.5%</td>
<td>38.1%</td>
</tr>
<tr>
<td>15-24</td>
<td>73.5%</td>
<td>52.9%</td>
</tr>
</tbody>
</table>
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?