Existing UK tissue banked from adolescent / young adult cancer patients

Martin McCabe, University of Manchester
on behalf of NCRI Teenage / Young Adult Clinical Studies Group
TYA CSG Biological Studies Group

Cross-cutting biological studies relevant to teenage and young adult cancer

- Personalised medicine
- Age-related pharmacokinetics
- Genetic predisposition
- Disease-specific biology
- Tissue banking
TYA tissue banking

Imperative to ‘sort it out’ from NCRI

TYA tissue bank?

Regional banks?

Disease-specific banks?
Scoping exercise - NCRI Confederation of Cancer Biobanks
The biobank shall have documented access policies and procedures, which are communicated to potential applicants.
'The access policy shall be stated clearly and referenced in all of the biobank's donor-facing and client-facing media. The policy shall ensure that *bona fide* researchers in any sector can be granted access to samples and data.'
Scoping exercise - NCRI Confederation of Cancer Biobanks

Quality standard (v1.0 March 2014)

‘The biobank shall ensure that operational policies do not preclude involvement by any individual or group, or justify clearly why exclusive policies exist.’
Scoping exercise - NCRI Confederation of Cancer Biobanks

Do you have samples on patients aged 13-39 years?

<table>
<thead>
<tr>
<th>Age</th>
<th>Number of donors</th>
<th>Histological breakdown</th>
</tr>
</thead>
<tbody>
<tr>
<td>13-14</td>
<td></td>
<td>Initial diagnosis / relapse</td>
</tr>
<tr>
<td>15-19</td>
<td></td>
<td>Associated metadata:</td>
</tr>
<tr>
<td>20-24</td>
<td></td>
<td>• age</td>
</tr>
<tr>
<td>25-29</td>
<td></td>
<td>• address</td>
</tr>
<tr>
<td>30-34</td>
<td></td>
<td>• gender</td>
</tr>
<tr>
<td>35-39</td>
<td></td>
<td>• staging data</td>
</tr>
<tr>
<td></td>
<td></td>
<td>• clinical symptoms</td>
</tr>
<tr>
<td></td>
<td></td>
<td>• treatment</td>
</tr>
<tr>
<td></td>
<td></td>
<td>• trial recruitment</td>
</tr>
<tr>
<td></td>
<td></td>
<td>• outcomes</td>
</tr>
</tbody>
</table>
Scoping exercise - NCRI Confederation of Cancer Biobanks

Initial contact March 2012 (n=24)

Reminder July 2012

Personal approach to non-responders → replies from 13/24

Exercise repeated March 2014 (n=38)
(updated data for previous responders)
Scoping exercise - NCRI Confederation of Cancer Biobanks

Replies from 15/38 CCB biobanks despite at least 2 attempts for each

Evidence of 3651 ‘malignant’ and 404 benign tumours (cf ~2500 new diagnoses per year in UK)
Scoping exercise - NCRI Confederation of Cancer Biobanks

![Bar chart showing the number of samples by age group.]

- 13-14: 1071
- 15-19: 1124
- 20-24: 269
- 25-29: 315
- 30-34: 554
- 35-39: 925

The University of Manchester
Conclusions

Very few samples banked

Difficult to access information about what is available

Significant proportion of CCB biobanks are not adhering to quality standard regarding data access

Banked samples are not representative of incident cases

Case for a specific TYA tissue banking initiative