CANCER RESEARCH UK AND DATA SHARING

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Cancer Research UK

WHAT WE SPEND

– We spent £341m on research in 2014/15
– The money we raise is spent on
  • research
  • information
  • advocacy and public policy

WHERE WE WORK

– Cancer Research UK supports over 500 research groups
– We support research in about 40 towns and cities across the UK
Cancer Research UK’s Ambition

- **10 Year Survival**
  - 1970: 24%
  - 2010: 50%
  - Within 20 years: 75%
What is CRUK’s generic policy on research data sharing?

<table>
<thead>
<tr>
<th>Issue</th>
<th>CRUK’s position</th>
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<tbody>
<tr>
<td>Data outputs</td>
<td>All research data, including unpublished data, -ve results, code…</td>
</tr>
<tr>
<td>Costs</td>
<td>Appropriately justified costs can be included in grant proposals</td>
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<tr>
<td>Metadata</td>
<td>Community standards/minimum information guidelines encouraged</td>
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<tr>
<td>Preservation</td>
<td>Data to be retained for at least 5 years after grant end</td>
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<tr>
<td>Discoverability</td>
<td>Groups should be proactive in communicating the contents of their datasets and showcasing the data available for sharing</td>
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<tr>
<td>Modes of data sharing</td>
<td>Via community or generalist repositories, under the auspices of the PI or a combination of methods</td>
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<tr>
<td>Timeframes</td>
<td>Limited period of exclusive use permitted where justified</td>
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<tr>
<td>Acknowledgement</td>
<td>Secondary users of data should credit original researcher and CRUK</td>
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### Policy to implementation (1): Funding committees

<table>
<thead>
<tr>
<th></th>
<th>Science Committee</th>
<th>Clinical Research Committee (CRC)</th>
<th>Population Research Committee (PRC)</th>
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<tbody>
<tr>
<td><strong>Application stage</strong></td>
<td>Freeform Data Sharing Plan on eGMS</td>
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<td>Detailed template with questions and guidance</td>
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<tr>
<td><strong>After Committee decision</strong></td>
<td>Detailed questions for successful grantees</td>
<td>Detailed questions for successful grantees</td>
<td>Nothing (unless revisions required)</td>
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<tr>
<td><strong>Monitoring</strong></td>
<td>Formal review after 3 years; informal “check-up” at 1 year</td>
<td>Scientific Milestone Report after 1 year</td>
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Responses on data sharing from Oct 2015 Science Committee grantees

*Anticipated restrictions on data sharing?*

- None anticipated
- IPR issues
- Patient confidentiality
Responses on data sharing from Oct 2015 Science Committee grantees

**Grantees’ proposed approaches to enhancing data discoverability**

- Depositing data in a repository
- Publications and conference presenting
- Linking to datasets in publications
- Page on study website illustrating data available
- Data descriptor
Responses on data sharing from Oct 2015 Science Committee grantees

**Grantees’ proposed approaches to governing data access**

- Data shared under the auspices of the PI
- Registered data access via repositories
- Open data access via repositories
- Open access publications
Policy to implementation (2): Costing

Will CRUK provide funds for data sharing?

Cancer Research UK regards the management and sharing of data generated through its funded research as a fundamental component of good scientific practice. Therefore, applicants may include proportionate, relevant data management and sharing activities as a running cost within applications. Funds will need to be fully justified and costed appropriately.
Policy to implementation (3): Strategic activities to accelerate data sharing

NEW APPROACHES TO CAPTURING AND MEASURING DATA SHARING

Work with Yale Open Data Access project to develop metrics to monitor and evaluate data sharing

INCENTIVES

Considering prize mechanisms internally, and watching Open Science Prize...

LEARNING FROM NCI’S TEAM SCIENCE TOOLKIT

Can we develop similar mechanisms to facilitate and reward data sharing?
Policy to implementation (4): Partnerships
THANK YOU!

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