Research into less common cancers
An analysis of research spend by Cancer52 members and National Cancer Research Institute (NCRI) Partners in 2012
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**Who are the NCRI?**

The NCRI is a UK-wide partnership between the government, charity and industry which promotes co-operation in cancer research among the 22 member organisations for the benefit of patients, the public and the scientific community.

The NCRI undertakes a number of core activities including organising the annual NCRI Cancer Conference, coordinating and developing clinical research portfolios through the NCRI Clinical Studies Groups and collecting and analysing NCRI Partner cancer research funding data through the NCRI Cancer Research Database.

More information can be found at [http://www.ncri.org.uk/](http://www.ncri.org.uk/)

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**Who are Cancer 52?**

Cancer52 is an alliance of 70 organisations working together to address the inequalities that exist in policy, services and research for the less common cancers, in order to improve the outcomes for patients with these challenging diseases.

Cancer52 members focus on a wide variety of rare and less common cancers with their activities ranging from patient support and advocacy to influencing policy and conducting research.

More information can be found at [http://www.cancer52.org.uk/](http://www.cancer52.org.uk/)
Foreword

We are very pleased to introduce the report ‘Research into less common cancers: An analysis of research spend by Cancer52 members and National Cancer Research Institute (NCRI) Partners in 2012’, the product of a collaboration between Cancer52 and the NCRI.

Less common cancers, defined as cancers which are not breast, colon and rectal, lung or prostate cancer (often referred to as the ‘big four’), represent a significant disease burden with 53% of cancer deaths a result of such cancers. This analysis provides a first look at the research funded by Cancer52 members, the alliance representing organisations focussed on rare and less common cancers, and places this in the wider context of research focussed on these cancers which is funded by NCRI Partners.

The combined spend on less common cancers by NCRI Partners and research-funding members of Cancer52 is over £120m and together with the significant amount of funds directed to research with potential to benefit all cancer patients, a further £287m, there is the opportunity for real progress in understanding the biology of less common cancers and to develop diagnostic tools and effective treatments. Although the total amount of funding for less common cancers is significant, within this the funding for some individual cancers is relatively low. This is not least because there are over 200 different kinds of cancer and highlights the challenge we face. In this regard we hope this report will provide a useful stimulus for dialogue between researchers and research funders to generate and support further high quality research proposals focussed on less common cancers.

Alongside gathering data on research funding levels the analysis identified areas of good practice including use of ‘gold standard’ peer review mechanisms to ensure only high quality research is funded and examples of co-funding of research awards between Cancer52 members and NCRI Partners, meaning that funds of Cancer52 members go further, increasing their potential to make a real difference to patients.

We would like to thank Cancer52 members for submitting data for inclusion in this analysis, and members of the NCRI Secretariat for undertaking the analysis and writing of the report. We hope this report provides a benefit for those with an interest in less common cancer research and encourage readers to contact Cancer52 or NCRI for further information.

Jane Cope
Director
National Cancer Research Institute

Jane Lyons
Chief Executive
Cancer52
1 Introduction

1.1 Background
This analysis arose following discussions between the NCRI and Cancer52 about how the two organisations could work together for the benefit of research on less common cancers in the UK. This led to a survey in 2012 to identify research-active Cancer52 members, followed by this more thorough analysis in 2013. In this analysis we look at Cancer52 members’ research spend and where it is focussed, and place it in the wider context of less common cancer research funded by NCRI Partners.

1.2 Methodology
All Cancer52 members were contacted and those that funded research were invited to submit data to the NCRI for inclusion in the analysis. Research-active Cancer52 members provided data on all awards that were active in 2012 including the name of the principal investigator, location, start and end date, award title and abstract and annualised funding amount.

Each research award was coded using two classification systems – the Common Scientific Outline (CSO) to define the research category and NCRI Cancer Site codes to define the cancer site(s) of focus (see Boxes 1 and 2, respectively, for more information).

Only awards which had passed through a scientific review and were active on 1 April 2012 were included in the analysis. An award was considered ‘active’ either where the award had been made and the grant monies had been distributed or where an award had been made but the grant monies had not yet been distributed. In submitting data, organisations were asked to adhere to one or other definition for their submission to ensure consistency in inclusion of data in the analysis across the alliance.

Twenty-five Cancer52 members indicated they were research-active and submitted data to the analysis. The data from 17 organisations were used in this analysis, with the remaining eight organisations excluded from the analysis as their awards were not active on 1 April 2012.

The data collection and coding processes used for the Cancer52 analysis were identical to those used to populate the NCRI Cancer Research Database, which captures the annual spend on cancer research by NCRI Partners. This common methodology allowed these two datasets to be combined for a more thorough analysis of spend on less common cancer research in 2012.

For the purposes of this analysis less common cancer awards were defined as awards that were focussed at a specific cancer site, which was not breast, colon and rectal, lung or prostate. More common cancer awards were those focussed on either breast, colon and rectal, lung or prostate cancer. Although mainly focussed on less common cancers, some Cancer52 members have a spectrum of interest which does include one or more of the commonest four cancers. Research on the more common cancers, or which is relevant to all cancer sites, is identified separately in the analysis.
Box 1. The Common Scientific Outline (CSO) coding system

The CSO is organised into seven broad research categories within which are a total of 38 sub-codes which are used to classify awards. Awards may be assigned up to seven different CSO sub-codes.

**Biology (CSO 1) – 5 sub-codes**
Research included in this category looks at the biology of how cancer starts and progresses as well as normal biology relevant to these processes.

**Aetiology (CSO 2) – 4 sub-codes**
Research included in this category aims to identify the causes or origins of cancer - genetic, environmental, and lifestyle, and the interactions between these factors.

**Prevention (CSO 3) – 6 sub-codes**
Research included in this category looks at identifying interventions which reduce cancer risk by reducing exposure to cancer risks and increasing protective factors. Interventions may target lifestyle or may involve drugs or vaccines.

**Early Detection, Diagnosis, and Prognosis (CSO 4) – 4 sub-codes**
Research included in this category focuses on identifying and testing cancer markers and imaging methods that are helpful in detecting and/or diagnosing cancer as well as predicting the outcome or chance of recurrence.

**Treatment (CSO 5) – 7 sub-codes**
Research included in this category focuses on identifying and testing treatments administered locally (such as radiotherapy and surgery) and systemically (treatments like chemotherapy which are administered throughout the body) as well as non-traditional (complementary/alternative) treatments (such as supplements, herbs). Research into the prevention of recurrence is also included here.

**Cancer Control, Survivorship, and Outcomes Research (CSO 6) – 9 sub-codes**
Research included in this category includes a broad range of areas: patient care and pain management; tracking cancer cases in the population; beliefs and attitudes that affect behaviour regarding cancer control; ethics, education and communication approaches for patients and health care professionals; supportive and end of life care; and health care delivery in terms of quality and cost effectiveness.

**Scientific Model Systems (CSO 7) – 3 sub-codes**
Research included in this category looks at the development of new animal models, cell cultures and computer simulations and their application to other studies across the spectrum of cancer research.

Each of the seven CSO codes contains a Resources and Infrastructure sub-code. Awards give a Resources and Infrastructure sub-code can include, for example, support for specimen resources, research centre funding, clinical trial infrastructure, biobanks and costs of staff that directly support research.

The full list of CSO codes can be found on the International Cancer Research Partnership (ICRP) website: https://www.icrpartnership.org/CSO.cfm.

Box 2: The NCRI Cancer Site coding system

The NCRI Cancer Site coding system consists of a list of 48 specific cancer sites within the body plus an additional code for Primary of Unknown Origin. Forty-five of these codes are for cancers considered less common. The remaining four codes relate to the common cancers; breast, colon and rectal, lung and prostate cancer. The full list of Cancer Site codes can be found in the NCRI Cancer Research Database data package at: http://www.ncri.org.uk/what-we-do/research-database.

Research focussed on a specific cancer site is referred to as ‘site specific’. Research which is not focussed on a specific cancer site is referred to as ‘non-site specific’ and is considered equally applicable to all cancers. Non-site specific research may include, for example, research into basic biology where it is too early to identify which cancers may benefit from the knowledge gained through the research or general palliative care research which is valuable to patients with all types of cancer.
2. Cancer52 member spend

2.1 Overview

Analysis of the data showed that Cancer52 members spent £7,082,333 on all cancer research in 2012. Of this £6,288,071, or 88.8%, was spent on less common cancers. The remaining 11.2% was non-site specific research or research which was focussed on more common cancers.

There were 87 individual awards included in the analysis with 80.7 award equivalents focussed on less common cancers. The average award spend on less common cancers was £77,938 and the median was £52,710 (Table 1).

Table 1. Cancer52 member spend on research in 2012

<table>
<thead>
<tr>
<th>Research on all cancers</th>
<th>Research on less common cancers</th>
</tr>
</thead>
<tbody>
<tr>
<td>Total spend</td>
<td>£7,082,333</td>
</tr>
<tr>
<td>Award equivalents*</td>
<td>87</td>
</tr>
<tr>
<td>Average spend</td>
<td>£81,406</td>
</tr>
<tr>
<td>Median Spend†</td>
<td>£56,013</td>
</tr>
</tbody>
</table>

*Where a grant award related to more than one cancer site, the cost was split between the relevant sites in the analysis. Some awards were not exclusively focused on less common cancers and so leads to some data appearing as fractional ‘award equivalents’.

† Median spend was calculated using all awards which were wholly or partly relevant to less common cancer.

Of the spend on less common cancer research by Cancer52 members 98.0% was undertaken within the UK, equating to over £6.2m of spend. Almost 60% of this research took place within London (defined as within the M25), with lesser amounts of spend in Manchester, Oxford, Leeds and Newcastle upon Tyne (Figure 1).

Figure 1: Cancer52 member spend on less common cancers by city

- London: £1.2m (18.6%)
- Manchester: £0.3m (4.4%)
- Oxford: £0.4m (6.9%)
- Leeds: £0.2m (3.8%)
- Newcastle upon Tyne: £0.5m (7.3%)
- The rest (includes non-UK cities): £3.7m (58.9%)
2.2 Cancer52 member spend by research category

Analysis by research category showed that of the £6,288,071 spent on research on less common cancers, the highest proportion was spent on Treatment with 47.0%. This was followed by Biology at 22.0%, Early Detection, Diagnosis and Prognosis at 12.7% and Aetiology at 10.4%. Cancer Control, Survivorship and Outcomes and Scientific Model Systems accounted for a smaller proportion of the total. Of the seven research categories there was no spend recorded in Prevention (Table 2 and Figure 2).

<table>
<thead>
<tr>
<th>Research category</th>
<th>Spend on less common cancers</th>
<th>Spend as a proportion of less common cancer spend</th>
</tr>
</thead>
<tbody>
<tr>
<td>Biology (CSO 1)</td>
<td>£1,382,553</td>
<td>22.0%</td>
</tr>
<tr>
<td>Aetiology (CSO 2)</td>
<td>£655,183</td>
<td>10.4%</td>
</tr>
<tr>
<td>Prevention (CSO 3)</td>
<td>£0</td>
<td>0.0%</td>
</tr>
<tr>
<td>Early Detection, Diagnosis, and Prognosis (CSO 4)</td>
<td>£799,780</td>
<td>12.7%</td>
</tr>
<tr>
<td>Treatment (CSO 5)</td>
<td>£2,957,729</td>
<td>47.0%</td>
</tr>
<tr>
<td>Cancer Control, Survivorship and Outcomes Research (CSO 6)</td>
<td>£426,253</td>
<td>6.8%</td>
</tr>
<tr>
<td>Scientific Model Systems (CSO 7)</td>
<td>£66,573</td>
<td>1.1%</td>
</tr>
<tr>
<td><strong>Total</strong></td>
<td><strong>£6,288,071</strong></td>
<td><strong>100.0%</strong></td>
</tr>
</tbody>
</table>

Analysis of the total Resource and Infrastructure sub-code spend across the seven research categories showed that this accounted for 41.5% of the less common cancer spend by Cancer52 members. This included support for research centres, enrolling patients onto clinical trials and individual research posts and Professorial positions. The remaining 58.5% of spend is on distinct research projects including laboratory-based studies, interventional and observational research and epidemiological studies.
Box 3: Interpreting kite diagrams

The kite diagram is a method of presenting data which helps illustrate the ‘centre of gravity’ of research and is useful when comparing the relative level of spend across multiple research categories. The total percentage figure for each data point is the sum of the percentages above and below the line of origin. The categories are discrete, not continuous: joining the points and presenting a mirror image below the x-axis are simply intended to provide a memorable visual display.

Figure 2: Kite diagram (see Box 3 for explanation) showing Cancer52 member spend on less common cancers by research category

2.3 Cancer52 member spend by cancer group

Cancer52 members fund research across 27 less common cancer sites of the 45 less common cancer sites defined in the NCRI Cancer Site coding system. The figures for each are too small for comparison to be statistically valid and it is more helpful to aggregate data relating to groups of cancers as shown in Table 3.

Blood cancers received the largest proportion of Cancer52 member spend, accounting for 41.8% of the less common cancer research spend. This was followed by cancer of the Brain and Nervous System which represented 25.0% and Gynaecological cancer which corresponded to 14.8%. Gastrointestinal and Urological accounted for 6.8% and 1.7%, respectively, while there was no recorded spend on Head and Neck cancer research (Table 3 and Figure 3).
Table 3: Cancer52 spend on less common cancers by cancer group

<table>
<thead>
<tr>
<th>Cancer group</th>
<th>Spend by cancer group</th>
<th>Spend by cancer group as a proportion of less common cancer spend</th>
<th>Cancer sites included</th>
</tr>
</thead>
<tbody>
<tr>
<td>Blood</td>
<td>£2,629,837</td>
<td>41.8%</td>
<td>Leukaemia, Myeloma, Hodgkin's Disease, Non-Hodgkin's Lymphoma</td>
</tr>
<tr>
<td>Brain and Nervous System</td>
<td>£1,569,645</td>
<td>25.0%</td>
<td>Brain, Eye, Neuroblastoma, Pituitary, Primary CNS Lymphoma, Retinoblastoma, Nervous System</td>
</tr>
<tr>
<td>Gynaecological</td>
<td>£927,594</td>
<td>14.8%</td>
<td>Cervical, Endometrial, Ovarian, Vaginal, Vulva</td>
</tr>
<tr>
<td>Gastrointestinal</td>
<td>£428,790</td>
<td>6.8%</td>
<td>Oesophageal, Gallbladder, Liver, Pancreatic, Small Intestine, Stomach</td>
</tr>
<tr>
<td>Urological</td>
<td>£108,280</td>
<td>1.7%</td>
<td>Bladder, Kidney, Wilms' Tumour</td>
</tr>
<tr>
<td>Head and Neck</td>
<td>£0</td>
<td>0.0%</td>
<td>Laryngeal, Nasal Cavity and Paranasus, Oral Cavity and Lip, Parathyroid, Pharyngeal, Salivary Gland, Thyroid</td>
</tr>
<tr>
<td>Other</td>
<td>£623,924</td>
<td>9.9%</td>
<td></td>
</tr>
<tr>
<td><strong>Total</strong></td>
<td><strong>£6,288,071</strong></td>
<td><strong>100.0%</strong></td>
<td></td>
</tr>
</tbody>
</table>

Figure 3: Cancer52 spend on less common cancers by cancer group

- **Blood**: £0.6m (9.9%)
- **Brain and Nervous System**: £2.6m (41.8%)
- **Gynaecological**: £0.9m (14.8%)
- **Gastrointestinal**: £0.4m (6.8%)
- **Urological**: £0.1m (1.7%)
- **Other**: £1.6m (25.0%)
3. Combined spend on less common cancers

3.1 Overview

Combining the Cancer52 member data with that of NCRI Partners, as captured in the NCRI Cancer Research Database, provides a more complete picture of the less common cancer research being undertaken by UK organisations. The combined total spend on all types of cancer research by Cancer52 members and NCRI Partners in 2012 was £512,438,177. Approximately 44%, or £225,394,257, of this demonstrated a clear cancer site of focus with the remaining 56%, or £287,043,920, being non-site specific research. Of the site specific spend, 54.9% was focussed on less common cancers equating to £123,776,277, with Cancer52 members accounting for 5.1% of this spend (Table 4).

In the combined dataset 97.5% of less common cancer research was within the UK. The largest proportion of spend was in London which represented 35.1%, followed by Cambridge, Oxford, Birmingham and Leeds (Figure 4).

3.2 Combined spend by research category

Analysis of spend by research category highlighted the largest proportion of spend on less common cancers was in Treatment at 36.5%, followed by Biology at 24.6%. Early Detection, Diagnosis and Prognosis accounted for 15.9% and Aetiology for 12.3%. There was less spend recorded in Cancer Control, Survivorship and Outcomes Research, Scientific Model Systems and Prevention (Table 5 and Figure 5).

The combined dataset makes it possible to compare the spend on less common cancers with that on the four most common cancers, by research category. Research spend in Treatment for less common cancers was significantly higher in percentage and cash terms when compared with more common cancers. By contrast research into Prevention, Early Detection, Diagnosis and Prognosis and Cancer Control, Survivorship and Outcomes Research was higher, in percentage and cash terms, for the more common cancers. There were similar amounts of relative spend on Biology, Aetiology and Scientific Model Systems (Table 5 and Figure 5).

Table 4: Combined spend on research in 2012

<table>
<thead>
<tr>
<th></th>
<th>Research on all cancers</th>
<th>Research on site specific cancer</th>
<th>Research on less common cancer</th>
</tr>
</thead>
<tbody>
<tr>
<td>Spend</td>
<td>£512,438,177</td>
<td>£225,394,257</td>
<td>£123,776,277</td>
</tr>
<tr>
<td>Award equivalents*</td>
<td>2815</td>
<td>1501.7</td>
<td>908.3</td>
</tr>
<tr>
<td>Average award spend</td>
<td>£183,538</td>
<td>£150,093</td>
<td>£136,275</td>
</tr>
<tr>
<td>Median award spend†</td>
<td>£71,111</td>
<td>£73,102</td>
<td>£73,060</td>
</tr>
</tbody>
</table>

*Where an award related to more than one cancer site, the cost was split between the relevant sites in the analysis. Some awards were not exclusively focused on less common/site specific cancers and so leads to some data appearing as fractional award equivalents.

†Median spend was calculated using all awards which were wholly or partly relevant to less common/site specific cancer research.

Table 5 and Figure 5.

1 Children with Cancer UK is both a Cancer52 member and a NCRI Partner. Their research spend is included within the Cancer52 dataset to generate this figure.
### Figure 4: Combined spend on less common cancers by city

<table>
<thead>
<tr>
<th></th>
<th></th>
<th></th>
<th></th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td>London</td>
<td>£40.5m</td>
<td>32.7%</td>
<td>£43.5m</td>
<td>35.1%</td>
</tr>
<tr>
<td>Cambridge</td>
<td>£6.8m</td>
<td>5.5%</td>
<td>£7.6m</td>
<td>6.2%</td>
</tr>
<tr>
<td>Oxford</td>
<td>£10.5m</td>
<td>8.5%</td>
<td>£14.9m</td>
<td>12.0%</td>
</tr>
<tr>
<td>Birmingham</td>
<td>£14.9m</td>
<td>12.0%</td>
<td>£10.5m</td>
<td>8.5%</td>
</tr>
<tr>
<td>Leeds</td>
<td>£7.6m</td>
<td>6.2%</td>
<td>£10.5m</td>
<td>8.5%</td>
</tr>
<tr>
<td>The rest (includes non-UK cities)</td>
<td>£14.9m</td>
<td>12.0%</td>
<td>£10.5m</td>
<td>8.5%</td>
</tr>
</tbody>
</table>

### Table 5: Combined spend on less common, and more common, cancers by research category

<table>
<thead>
<tr>
<th></th>
<th></th>
<th></th>
<th></th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td>Biology (CSO 1)</td>
<td>£30,404,773</td>
<td>24.6%</td>
<td>£21,446,541</td>
<td>21.1%</td>
</tr>
<tr>
<td>Aetiology (CSO 2)</td>
<td>£15,272,929</td>
<td>12.3%</td>
<td>£12,988,848</td>
<td>12.8%</td>
</tr>
<tr>
<td>Prevention (CSO 3)</td>
<td>£2,853,425</td>
<td>2.3%</td>
<td>£6,433,788</td>
<td>6.3%</td>
</tr>
<tr>
<td>Early Detection, Diagnosis, and Prognosis (CSO 4)</td>
<td>£19,707,295</td>
<td>15.9%</td>
<td>£20,179,686</td>
<td>19.9%</td>
</tr>
<tr>
<td>Treatment (CSO 5)</td>
<td>£45,135,350</td>
<td>36.5%</td>
<td>£28,768,473</td>
<td>28.3%</td>
</tr>
<tr>
<td>Cancer Control, Survivorship and Outcomes Research (CSO 6)</td>
<td>£7,076,897</td>
<td>5.7%</td>
<td>£10,609,631</td>
<td>10.4%</td>
</tr>
<tr>
<td>Scientific Model Systems (CSO 7)</td>
<td>£3,325,609</td>
<td>2.7%</td>
<td>£1,191,014</td>
<td>1.2%</td>
</tr>
<tr>
<td><strong>Total</strong></td>
<td><strong>£123,776,277</strong></td>
<td><strong>100.0%</strong></td>
<td><strong>£101,617,980</strong></td>
<td><strong>100.0%</strong></td>
</tr>
</tbody>
</table>
Figure 5: Kite diagram (see Box 3 for explanation) showing combined spend in less common cancers, and more common cancers, by research category.

The combined data showed spend on Resources and Infrastructure related to less common cancers was 27.0%. This spend included funding for National Institute for Health Research Biomedical Research Centres and Experimental Cancer Research Centres as well as core funding for other centres, clinical trial hubs and biobanks. Resource and Infrastructure spend for the more common cancers represented 24.8% of total spend.

3.3 Combined spend by cancer group

NCRI Partners and Cancer52 member together fund research on 43 of the 45 less common cancer sites defined in the NCRI Cancer Site coding system. Blood cancer research represented 39.2% of the combined less common cancer spend, followed by Gynaecological cancer which accounted for 17.0%. Over 12% of the combined less common cancer spend was focussed on Gastrointestinal cancers and a further 7.3% was on cancers of the Brain and Nervous System. Urological and Head and Neck Cancers accounted for 6.2% and 5.1%, respectively (Table 6 and Figure 6).
### Table 6: Combined spend on less common cancers by cancer group

<table>
<thead>
<tr>
<th>Cancer group</th>
<th>Combined spend by cancer group</th>
<th>Combined spend by cancer group as a proportion of less common cancer spend</th>
<th>Cancer sites included</th>
</tr>
</thead>
<tbody>
<tr>
<td>Blood</td>
<td>£48,526,304</td>
<td>39.2%</td>
<td>Leukaemia, Myeloma, Hodgkin’s Disease, Non-Hodgkin’s Lymphoma</td>
</tr>
<tr>
<td>Gynaecological</td>
<td>£21,038,084</td>
<td>17.0%</td>
<td>Cervical, Endometrial, Ovarian, Vaginal, Vulva</td>
</tr>
<tr>
<td>Gastrointestinal</td>
<td>£15,656,224</td>
<td>12.6%</td>
<td>Oesophageal, Gallbladder, Liver, Pancreatic, Small Intestine, Stomach</td>
</tr>
<tr>
<td>Brain and Nervous System</td>
<td>£8,995,993</td>
<td>7.3%</td>
<td>Brain, Eye, Neuroblastoma, Pituitary, Primary CNS Lymphoma, Retinoblastoma, Nervous System</td>
</tr>
<tr>
<td>Urological</td>
<td>£7,655,911</td>
<td>6.2%</td>
<td>Bladder, Kidney, Wilms’ Tumour</td>
</tr>
<tr>
<td>Head and Neck</td>
<td>£6,309,335</td>
<td>5.1%</td>
<td>Laryngeal, Nasal Cavity and Parasinus, Oral Cavity and Lip, Parathyroid, Pharyngeal, Salivary Gland, Thyroid</td>
</tr>
<tr>
<td>Other</td>
<td>£15,594,424</td>
<td>12.6%</td>
<td></td>
</tr>
<tr>
<td><strong>Total</strong></td>
<td><strong>£123,776,277</strong></td>
<td><strong>100.0%</strong></td>
<td></td>
</tr>
</tbody>
</table>

### Figure 6: Combined spend on less common cancers by cancer group

[Pie chart showing the distribution of spend by cancer group.]

- Blood: £48.5m (39.2%)
- Gynaecological: £15.6m (12.6%)
- Gastrointestinal: £15.7m (12.6%)
- Head and Neck: £21.0m (17.0%)
- Urological: £9.0m (7.3%)
- Brain and Nervous System: £7.7m (6.2%)
- Other: £6.3m (5.1%)
4. Reflections on the data

This Cancer52 and NCRI joint project has for the first time given a figure to the level of research funded by Cancer52 members and the amount of funding targeted to less common cancers by NCRI Partners and Cancer52 members combined. Although we were unable to analyse the data at individual cancer site level, strengths and relative weaknesses in the Cancer52 portfolio and the combined Cancer52 and NCRI portfolio can be seen, as can similarities and differences between the two datasets. Key findings include:

- In 2012, Cancer52 members spent £6,288,071 on research into less common cancers which represented 88.8% of their total research spend. The combined research spend on less common cancers by NCRI and Cancer52 organisations was £123,776,277 in 2012, with Cancer52 members accounting for 5.1% of this total.

- The average size of awards funded by Cancer52 members compared to the average in the combined less common cancer dataset is considerably smaller. This is as a result of the significant number of large infrastructural awards supported by NCRI Partners. The median spend per Cancer52 award on less common cancers was £52,710, with the median from the combined less common dataset being £73,060.

- Less common cancer research spend in both the Cancer52 and combined datasets is heavily weighted to London and the South-East. This focus towards the South-East is seen across all health research.

- Treatment was the strongest research category for the less common cancers especially among Cancer52 members where it formed 47.0% of the total. In the combined dataset Treatment accounted for 36.5% of less common cancer spend.

- Biology research represented the next largest proportion of spend in less common cancer cancers by Cancer52 members, accounting for 22.0%. The combined spend on the less, and the more, common cancers represented a similar percentage of the respective total spend.

- There was no Prevention research in the Cancer52 dataset and only 2.3% recorded in the combined less common cancer dataset. This is low compared to the 3.6% spent on Prevention by NCRI Partners overall, which includes spend on both site specific and non-site specific cancer research.

- Over 41% of the Cancer52 spend was coded to a Resources and Infrastructure sub-code compared with under 30% within the combined dataset for both the less common, and more common, cancers. Within the Cancer52 data this includes awards to enrol patients on clinical trials and funding of individual research posts and Professorial positions.

- The analysis showed that 41.8% of Cancer52 member spend on less common cancers was focussed on Blood cancers. This represented a similar percentage of funding to that seen in the combined less common cancer dataset where 39.2% was focussed on Blood cancers. This was in part due to dedicated Blood cancer focussed members of Cancer52 and the high level of leukaemia research recorded within the NCRI Cancer Research Database.

- Cancer of the Brain and Nervous System accounted for 25.0% of the Cancer52 less common dataset, but only 7.3% of the combined less common cancer spend. This difference reflects a strong representation by brain cancer focussed charities within the Cancer52 alliance.
• Gynaecological cancer accounted for 14.8% of Cancer52 spend on less common cancers and 17.0% of combined less common cancer spend, with ovarian cancer making up the greatest proportion of spend in both datasets.

• There are few organisations within Cancer52 which focus specifically on cancer sites included within the Urological, Head and Neck or Gastrointestinal cancer groups hence research spend was relatively low in these areas. In the combined less common dataset these cancer groups accounted for a larger proportion of spend reflecting the support of several large NCRI Partners, who fund across the cancer spectrum, for these cancer types.

In gathering the data, the NCRI identified a number of areas of good practice including projects in which Cancer52 members and NCRI Partners jointly fund awards. Such co-funding provides an effective route through which to boost research into specific less common cancers ensuring the funds go further. Members of Cancer52 are also funding strategically to get the most out of their available funds, focussing their research on the needs of patients and on ensuring the most is made of available clinical trial opportunities through the support of specific posts, or groups, for the development of, and recruitment to, trials.

All Cancer52 members contacted for the analysis had some method of review in place to allocate research funding based on scientific merit. The review methods ranged from the ‘gold standard’ of external peer review in open competition to less formal processes such as consulting with individual experts in the field before allocating funding. There are difficulties for smaller charities and those funding less common cancers to conduct a thorough peer review for all awards. These can include both the time and the expense of administering peer review as well as identifying relevant experts for each less common cancer site. It may be possible in the future for Cancer52 members to share their peer review experiences and processes in order to raise the standard across the alliance.

The NCRI and Cancer52 will continue to engage regularly to build on this project. Organisations with an interest in less common cancers are also encouraged to join Cancer52 to further strengthen the joint voice for less common cancers and benefit from shared learning between members. It is hoped that a similar analysis may be performed in the future to assess the direction and progress of cancer research into less common cancers.
Contributions and thanks

We would like to thank Cancer52 for their participation in this report; in particular those members who submitted data for this analysis. These were AMMF – The Cholangiocarcinoma Charity, Bone Cancer Research Trust (BCRT), Brainstrust, British Thyroid Foundation, Cancer of Unknown Primary (CUP) Foundation – Jo’s friends, Childhood Eye Cancer Trust, The Children’s Cancer and Leukaemia Group (CCLG), Children with Cancer UK\(^2\), Chris Lucas Trust, CORE, Debbie Fund, Guy Francis Bone Cancer Research Fund, Myeloma UK, Myrolytis Trust, NET Patient Foundation, Neuroblastoma Society, Orchid Cancer Appeal, Ovarian Cancer Action, Pancreatic Cancer UK, Sarcoma UK, Target Ovarian Cancer, Teenage Cancer Trust, The Brain Tumour Charity, The Eve Appeal, Wellbeing of Women.

We also appreciate the continued commitment of the NCRI Partners who annually provide data to populate the NCRI Cancer Research Database. These Partners are the Association for International Cancer Research, Biotechnology and Biological Sciences Research Council, Breakthrough Breast Cancer, Breast Cancer Campaign, Cancer Research UK, Children with Cancer UK\(^2\), Department of Health, England, Economic and Social Research Council, Leukaemia & Lymphoma Research, Ludwig Institute for Cancer Research (Oxford), Macmillan Cancer Support, Marie Curie Cancer Care, Medical Research Council, The National Institute for Social Care and Health Research, Northern Ireland Health and Social Care Research and Development, Prostate Cancer UK, Roy Castle Lung Cancer Foundation, Scottish Chief Scientist Office, Tenovus, The Wellcome Trust.

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\(^2\)Children with Cancer UK is both a Cancer52 member and a NCRI Partner.