Macmillan Cancer Information and Support Services (CISS), 2012

01 January – 31 December 2012
## Contents

<table>
<thead>
<tr>
<th>Page</th>
<th>Section</th>
</tr>
</thead>
<tbody>
<tr>
<td>3</td>
<td>2012 Highlights</td>
</tr>
<tr>
<td>4</td>
<td>Headlines</td>
</tr>
<tr>
<td>5</td>
<td>Macmillan impact</td>
</tr>
<tr>
<td>6</td>
<td>2012 analysis</td>
</tr>
<tr>
<td>14</td>
<td>Focus on: Salford Information &amp; Support Service</td>
</tr>
<tr>
<td>22</td>
<td>Looking forward to 2013</td>
</tr>
<tr>
<td>23</td>
<td>Thank you!</td>
</tr>
<tr>
<td>24</td>
<td>Appendix 1: Why do we collect your data?</td>
</tr>
<tr>
<td>25</td>
<td>Appendix 2: What can we do with your data</td>
</tr>
</tbody>
</table>
2012 - highlights

We know that 2012 has brought a lot of change, and some challenges but there has been a lot to celebrate too.

• Based on the analysis of the activity data you have provided you have dealt with over 350,000 enquiries from people affected by cancer in the last year, an increase of over 15% on 2011.

• We launched our very own Macmillan Quality in Information and Support Services (MQuISS) standards to provide a framework to help you to continue to improve and develop your services.

• By the end of 2012 Macmillan Information Prescription Facilitators and Macmillan Network Information Managers had worked with 1500 multi-disciplinary teams across 105 acute trusts in England to help them to provide personalised information for their patients.

• Our new information and support strategy has now been approved, aligning our priorities around integration, improvement, influence and innovation.

• We helped to influence the Department of Health Information strategy to include the importance of support alongside information.
Headlines

This is the full report covering the whole of 2012, and is based on an analysis of all the activity data which has been submitted by Macmillan Cancer Information & Support Services for January to December 2012.

In the final quarter of 2012, 87 services out of a total of 171 open services across the UK (51% of services) submitted data.

- Using the data submitted, and estimated figures to cover services that were not able to submit data in time for analysis we estimate that there were 85,989 enquiries to Macmillan Cancer Information & Support Services in the final quarter of 2012.

- Overall we estimate that there Macmillan Cancer Information & Support Services dealt with 353,831 enquiries between the beginning of January, and the end of December 2012. This represents an increase of more than 15% on the total number of enquiries during 2011.
  - 39% of these were from people living with or beyond cancer
  - 28% were from a carer of people with cancer
  - 66% of enquiries were between levels 2-4 of interaction (see end of report for clarification of definitions of these levels)
Wider work across Macmillan

In 2012, we estimate that we made 9.9 million interactions with 5.7 million people affected by cancer through at least one of our Macmillan services.

The total reach of 5.7 million people breaks down as:

- **1.9 million** people with a cancer diagnosis (compared to 1.7 million in 2011)
- **600,000** carers of people with cancer (compared to 630,000 in 2011)
- **3.2 million** other people affected by cancer including family, friends, colleagues, worried well, etc (compared to 2.6 million in 2011)

The total amount of financial gains (benefit entitlements, grants, payouts, claims, debt write-offs, etc) achieved in 2012 was **£ 245.6 million**

In the same period the Macmillan Support Line (MSL) received a total of **66,023** enquiries (46,807 of these were new callers and 3,918 were made anonymously)

Over the same period the Macmillan mobile units saw **58,620** enquiries to 4 mobile units covering Macmillan regions, CSWE, LASER & EMNE.
Macmillan Cancer Information & Support Services 2012 data analysis
Information centre reach: total & by level of interaction

• The total number of enquiries to Macmillan Information & Support Services was 353,831 in 2012.

• From the data we can see that over 39% were patients and just over 28% were carers.

• Over 66% of enquiries were at level 2-4 interactions.
Analysis by Gender

Year on year data from information services have continued to show us that there are more visits to Macmillan CISS's from women, with only 38% of visits being recorded from men. Although we see a similar trend in the data from the MSL, with 31.1% of enquiries made by men & 68.9% enquiries made by women. We can start to develop conclusions about men’s information seeking behaviour. From our data it appears men prefer face to face interaction rather than picking up the phone and speaking to someone.

Please note that the activity figures throughout this report provide a breakdown of the number of visits to services, some of these visits will be repeat visits so this does not equate to the number of unique visitors.
Who is the enquiry for?

The end of year data reflects the trends we have seen throughout the year with about 39% of enquiries during this period coming from people living with or beyond cancer, just over 28% of enquiries came from carers and about 11% were from health or social care professionals. This information is now being collected more consistently resulting in a smaller number within the ‘other/not recorded’ category.
Are there differences between the people who come into information centre & those who phone Macmillan’s support line?

This analysis breaks down each category of visitors across MSL and information services in 2012. In addition MSL record whether individuals call for themselves or for someone else.

- For MSL 60% callers call for themselves & 40% callers call MSL on behalf of someone else.
- Most patients that call MSL call for themselves.
- CISS see a higher proportion of health or social care professionals than MSL.
- CISS see a higher proportion of carers than MSL.
Gender by subject of enquiry – why do people visit information services?

Further analysis of data enables us to identify the most popular subjects of enquiry:

• Benefits and financial issues are very clearly the most popular area of enquiry, particularly for men visiting the CISS.

• Enquiries about diagnosis/tests, and about treatment/treatment side effects are also identified with higher numbers.

These numbers suggest that slightly more women than men visit CISS seeking information about:

• End of life issues
• Talking to loved ones & children
• Return to work issues
Macmillan services: an analysis

Macmillan has a vast range of service offerings for people affected by cancer. Many information services work with Macmillan mobile units who are able to take face to face services to people who may not know about the whereabouts of their local Macmillan information centre. The following is a breakdown of the analysis of the number of enquiries to Macmillan mobile units against Macmillan cancer information & support services in 2012.

The graph to the left here illustrates the total number of enquiries to the different mobile units. There are two units within EMNE. The mobile units cover different geographical regions and therefore the demographics of reach differ.

The graph to the right illustrates the level of interaction and reach over the mobile units and Macmillan CISS. As the mobile units visit locations for defined periods of time they record level 0 visits in addition to level 1-4 i.e. they are able to record the fact that some people choose to browse information, but do not have any interaction with the information team. There were 69% of level 0 enquiries to Mobile units. If we exclude these from our analysis we can see that the mobile teams see a slightly higher proportion of level 1 enquiries, around the same proportion of level 2 enquiries, and a much smaller number of level 3-4 enquiries.
Macmillan services: an analysis of visitors to mobile units & CISS

- CISS and the EMNE North of England unit recorded a slightly higher percentage of visitors with a cancer diagnosis.

- Mobile units record a higher proportion of enquiries from ‘other’ groups e.g. general public, employers, health and social care professionals.

- CISS record a higher proportion of visits from carers.
Focus on: Macmillan Information & Support Service in Salford

Detailed analysis using data submitted in ‘raw’ format.
Services analysis

The following slides focus on the Macmillan cancer information & support centre in Salford. Using raw data we are able to give a detailed picture of the enquiries/enquirers to the information service. We can analyse gender data by age group, which shows that Salford saw a higher proportion of women in the 45 - 54 age group (29.3% vs 17.1% of male visitors), whereas they saw a higher proportion of men from the 55-64 age group (31.7% vs 24.8% of female visitors).

The graph to the left shows that over half the number of male visitors to the information service were aged between 55 - 74 years old (56.3%). What does this tell us about men visiting Salford? In order to draw further conclusions we need to use the data to analyze this further.

We can break down the data about the 55 -74 age group further to show who these visitors were. The pi chart to the right shows that 74% of enquiries from this group were from patients, 11% a family or friend and 6% are carers. This type of information can be extremely useful for planning purposes e.g. identifying the most appropriate resources to stock in the service.
Services analysis

Further analysis of these male visitors that identified themselves as patients can be completed to show further detail. A large number of this group are men who have locally advanced cancer, followed by male patients who present themselves as advanced/metastatic/secondaries.

<table>
<thead>
<tr>
<th>First subject of enquiry</th>
<th>No.</th>
</tr>
</thead>
<tbody>
<tr>
<td>Benefits/Financial</td>
<td>121</td>
</tr>
<tr>
<td>Complementary Therapies</td>
<td>4</td>
</tr>
<tr>
<td>Counselling/Psychological Support</td>
<td>4</td>
</tr>
<tr>
<td>Diagnosis/Tests</td>
<td>31</td>
</tr>
<tr>
<td>Diet/Nutrition</td>
<td>17</td>
</tr>
<tr>
<td>Emotional or psychological support</td>
<td>13</td>
</tr>
<tr>
<td>Fundraising/Donations</td>
<td>5</td>
</tr>
<tr>
<td>Genetics</td>
<td>1</td>
</tr>
<tr>
<td>Health Care Services</td>
<td>3</td>
</tr>
<tr>
<td>Living with consequences of cancer</td>
<td>3</td>
</tr>
<tr>
<td>National Organisations/Local services</td>
<td>1</td>
</tr>
<tr>
<td>Other specify</td>
<td>10</td>
</tr>
<tr>
<td>Practical help</td>
<td>12</td>
</tr>
<tr>
<td>Sexuality</td>
<td>2</td>
</tr>
<tr>
<td>Site specific Info</td>
<td>11</td>
</tr>
<tr>
<td>Support/Self Help groups</td>
<td>15</td>
</tr>
<tr>
<td>Suspected Symptoms</td>
<td>3</td>
</tr>
<tr>
<td>Symptom Control</td>
<td>8</td>
</tr>
<tr>
<td>Travel Insurance/Holidays</td>
<td>10</td>
</tr>
<tr>
<td>Treatment/Treatment side effects</td>
<td>13</td>
</tr>
<tr>
<td>End of Life Issues</td>
<td>3</td>
</tr>
<tr>
<td>Prevention/Awareness</td>
<td>1</td>
</tr>
</tbody>
</table>

The table to the left shows the first subject of enquiry that was recorded for each of the men in this group. This shows that 121 enquiries were made about benefits & financial advice. Followed by 31 enquiries about ‘diagnosis/tests’ and 17 enquiries about ‘diet & nutrition’. Again this information is extremely helpful and can inform the way that resources are identified, or outreach opportunities are approached.

Enquirers to the information service can come with multiple enquiries and this is reflected in data.
Analysis of Postcode

This map details the postcode locations of the people that visited the Salford service to attend specialist sessions (e.g. Look Good, Feel Better) during the final quarter of 2012 using the first 3 digits of the postcode in order to maintain the anonymity of the individuals concerned.
Analysis of Postcode - deprivation

This map adds in additional information about the level of deprivation recorded for the area. This provides information that can be used by the service during planning processes, and can help them to identify areas for further investigation.

IMD ranks: Indices of deprivation 2010 by lower super output area. Areas are ranked depending on their levels of deprivation with rank 1 being the most deprived. The higher the rank the less deprived the area. Hence darker green areas represent more deprived areas.

Analysis of Postcode – Information & support services users

This map shows the locations of all the enquiries to the information and support centre at Salford for whom a location was recorded.

For this analysis a mixture of postcodes, towns and place names were recorded. This does make data analysis more time consuming as data needs to be cleansed in order to get the overall picture.

With partial postcode data (first half of the postcode) it is possible to complete analysis at this level. The full postcode offers the opportunity to use ‘augmented’ data to look at other social factors e.g. social groups, wealth etc) to provide more detailed profiles.
This map adds in information about cancer prevalence levels across the area.

The red areas are postcode areas with a high cancer prevalence, yellow for medium cancer prevalence, and green relatively low.

This map identifies some areas of high cancer prevalence which could be further investigated (e.g., population level, treatment pathway, specific population demographics) to see if additional services could be beneficial.
Analysis of Postcode

The ellipse in this picture is a 20 mile journey from the information & support centre by postcode. The black dots represent callers to MSL (xx callers per dot), with the lighter dots representing visitors to the Salford service. The cancer prevalence data forms the background. This enables us to highlight areas from which we are not seeing calls to MSL or visitors to the information & support service, and again can help to inform planning. This type of information is also used more widely by Macmillan to help with planning e.g. information campaigns.
Looking forward to 2013

We hope you are all looking forward to our information and support professionals’ event which will be taking place on 3rd-4th June 2013 at Selsdon Park, South Croydon. We will be sending out invitations nearer the time with details of how to register, and look forward to seeing you all there and introducing our new Improvement Team.

Many of you have already attended training sessions to help you to implement Macmillan Quality in Information and Support Services (MQuIß) quality standards, and will now be using them to support local service development and improvement activities. Please do get in touch if you would like to share your experiences (positive or negative) with other teams, or if you need additional support in any areas.

Join our LinkedIn Group at: http://www.linkedin.com/groups/Macmillan-Cancer-Information-Support-Services-4495318/about
Contact us at cissinfo@macmillan.org.uk
Call us on: 0207 840 7829
Use the resources on our Learnzone page: http://learnzone.macmillan.org.uk/course/view.php?id=348
Thank you

As we approach the end of the year, on behalf of the Information & Support Team – Thank you to everyone who has submitted data during 2012.

Thank you to Ian Ainscough – Macmillan Information manager at the information & support service in Salford for letting us use his data as an example of what can be done with good activity data.

A big thank you to Marina Garcia Pinella from Macmillan’s Data Insight team and Tanvi Barretto from Intelligence & Research for their work on creating the maps & their support for the overall analysis.

If you have any questions about any of the report please do not hesitate to contact the team on the cissinfo email address below.

- If you aren’t sure how to submit your data, are having problems with it, or simply have questions about what we will do with it, please do not hesitate to get in touch. We can also explain how to submit data from other collation systems as long as you collect the Macmillan dataset.

For more information, or if you have any questions please contact: cissinfo@macmillan.org.uk
Appendix 1: Why do we collect your data?

To support your service!

• Activity data shows who is being reached by your service

• Activity data can be analysed to provide detailed information about the types of enquiries being supported through your service, which helps to ensure that your team have access to the rights information and support so that they can provide an excellent service to people affected by cancer

• Activity data provides key evidence to help identify gaps, and therefore opportunities to develop and improve your service

• We are starting to receive requests from our fundraising team for data in relation to individual services. They have used the data to support local fundraising, e.g. In the past few months we have provided reports for two services in London which have received funds from trusts. Their data helped to demonstrate the impact of their services, and therefore supported the fundraising activity.
Appendix 2: What else can Macmillan do with your data?

• We are continually looking at what else we can do to ensure that the hugely valuable services that you offer are recognised, funded and importantly sustained.

• If we can collate robust evidence across the UK, we can use this to continue to campaign for better access to Cancer Information and Support for people affected by cancer.

• Evidence helps us to explain to partner organisations why they should be supporting your services, and helping you to develop and improve them.

• We can develop targeted information resources if your data demonstrates that there is a gap in the information that is available.

• We can work to identify learning and development opportunities, both for your own personal development and to help you with providing the best service possible in your local area.