

**Macmillan Libraries Information and
Support project**

Manchester City Council

Final Programme Evaluation Report

April 2014

Dr Gillian Granville

gilliangranville
associates
www.gilliangranville.com

ACKNOWLEDGEMENTS

I would like to thank all those who contributed to this evaluation. In particular I would like to thank all the people affected by cancer who told me their stories over a period of 18 months. I have tried to ensure that their voices and experiences are heard throughout this report.

I would also like to thank all the many senior stakeholders who took time out of busy schedules to talk about the project and its impact. It was extremely useful to understand the wider picture that the project operates in.

Finally I must thank the Manchester Macmillan Library team. Over a period of two years they have worked alongside the evaluation, collecting large amounts of data and supporting the evaluation fieldwork. It has been a pleasure to work with such a dedicated team who were willing to reflect on their practice and strive for improvement in cancer care.

Contents:

	Pages
Headline achievements	3
1. About this Report	3
2. Setting the scene: national and local context	5
3. The Manchester Project	7
4. The Evaluation Process	9
5. Findings:	10
5.1 One to one support and the service user experience: Outcome 1	10
5.2 Awareness, training and events activity of the project: Outcome 2	17
5.3 Building stronger communities through increased skills, confidence and knowledge of volunteers: Outcome 3	24
6. Discussion: key messages and learning	27
7. Looking ahead: recommendations for moving forward	30
Appendices:	
Appendix 1: Macmillan nine outcomes	32
Appendix 2: Evaluation questions June 2012	33
Appendix 3: Primary data sources	34
Appendix 4: Self-completion questionnaire from awareness events	35
Appendix 5: Team project diaries	36
Appendix 6: Standard Mortality rates for all cancers Manchester wards	37
Appendix 7: Survey data from awareness raising events	38

Manchester City Council Macmillan Libraries Information and Support project

Treatment finished and everything finished, I didn't have the support anymore, I did not have anything. And then I went into the library and saw the Macmillan information stand. I was surprised. I did not expect it in a library (A cancer survivor).

HEADLINE ACHIEVEMENTS

- 3556 contacts in two years (January 2012 – December 2013)
- 180 awareness raising events, workshops and training sessions in two years
- Approximately 72% of events held in wards where the mortality rate for cancer is higher than the English and Manchester average. 25% of these were in wards with the highest mortality
- 740 individual support sessions held in two years
- Groups who traditionally have not engaged with cancer services have been reached
- Men accessing one to one support increased in 2013
- Pakistani people accessing individual support has increased in 2013
- People's confidence to access services and enhance their knowledge about cancer awareness and the importance of early detection has increased
- A contribution to addressing health inequalities that exist across Manchester

1. ABOUT THIS REPORT

This report is the third and final report from the independent programme evaluation of the Manchester City Council (MCC) Macmillan Libraries Information and Support project. It brings together a wide range of primary and secondary data collected between January 2012 and March 2014, and focuses on the outcomes and impact of the three years Big Lottery funding. The report also explores why these changes have occurred and in particular, for whom.

It begins by looking at the national and local context of the project including the partnership with Macmillan Cancer Support, followed by the background to the project developments; section four describes the evaluation process and section five presents the findings against the three outcomes. The report concludes with key messages and learning from the initiative and recommendations for the future.

The audience for this report includes directors and senior managers in Manchester City Council, Public Health Manchester, NHS organisations in Manchester and partners in a range of voluntary and community projects in Manchester. It will be of interest to Macmillan Cancer Support both nationally and regionally and to other individuals and organisations working with people affected by cancer.

2. SETTING THE SCENE: NATIONAL AND LOCAL CONTEXT

2.1 National context

Every year, over 250,000 people in England are diagnosed with cancer, and around 130,000 die as a result of the disease. Annual NHS costs for cancer services are £5 billion, but the cost to society as a whole – including costs for loss of productivity – is £18.3 billion. More people are surviving cancer, although the survival rates in England are still worse than those for other countries that are as wealthy.

Cancer is aligned to Domain 1 of the NHS Outcomes Framework¹ (preventing premature deaths). One of the eight national public health policies² developed by Public Health England is helping more people survive cancer through improving the treatment and diagnosis of cancer and helping survivors to live more comfortably. Public health looks across the whole cancer journey from prevention and early intervention to helping survivors of cancer have improved quality of life.

Survivorship for those living with and beyond cancer has risen up the policy agenda as more people are surviving cancer. Currently 1.8 million people in England live with a diagnosis of cancer and this number is increasing by over 3 per cent a year. It is expected to rise to 3 million by 2030 as more people are diagnosed with cancer, treatment becomes more effective and people live longer after a cancer diagnosis. The recent policy report from the National Cancer Survivorship Initiative (NCSI)³ is a comprehensive document for commissioners and providers, laying out the evidence for improving outcomes in the population and is the Government's central focus for action for the NHS and social care.

In addition, there have been a number of system changes in the context the project is working in, including the Coalition government's reconfiguration of public

¹ <http://www.england.nhs.uk/wp-content/uploads/2012/12/oi-data-table.pdf>

² <https://www.gov.uk/government/topics/public-health>

³ National Cancer Survivorship Initiative (April 2013) Living With and Beyond Cancer: taking action to improve outcomes, London: Department of Health

services in 2012/ 13. This has resulted in reduced budgets to local authorities, a cut in grants to the community and voluntary sector and an increased emphasis on localism and community involvement.

Alongside these changes has been a major reorganisation of the NHS with the abolition of Primary Care Trusts and the emergence of Clinical Commissioning Groups as the commissioners of most services funded by the NHS in England. They now control around two-thirds of the NHS budget. In addition, the public health function moved into the local authority in April 2013, highlighting health as a cross cutting issue for the council, with the intention of keeping the local population healthy and protecting people from threats to their health.

2.2 Manchester context

The latest Joint Strategic Needs Assessment (JSNA) in Manchester⁴ shows that Manchester has the highest rate of premature mortality (people aged under 75) for cancer in England. In 2011-2012 health services in the city spent around £50,000,000 on cancer treatment and ongoing support. This is equivalent to £81 per resident in Manchester. The JSNA recommendations include raising public awareness of the signs and symptoms of cancer and encouraging people to visit their GP earlier.

The Manchester Partnership Health and Wellbeing Board⁵ have eight strategic priorities, and whilst none refer directly to cancer prevention or management, interventions are implicit. For example strategic priority two is: *Education, informing and involving the community in improving their own health and wellbeing*. Responsibility for leading and co-ordinating action on healthy lifestyle outcomes sits with Public Health Manchester, within Manchester City Council.

Cancer prevention and early detection is incorporated into the three Manchester Clinical Commissioning Groups (CCGs) strategic commissioning plans, with each CCG committed to making improvements at a local level.

2.3 Macmillan Cancer Support: context

Macmillan Cancer Support is a national cancer charity that aims to improve the lives of people affected by cancer. It has campaigned for better information and support for people affected by cancer and works closely with government. The brand is familiar and easily recognised by professionals and the public as a gold standard service with the skills and expertise to improve people's lives.

Macmillan works across the whole cancer pathway from early prevention and

⁴ http://www.manchester.gov.uk/info/500230/joint_strategic_needs_assessment/6111/cancer

⁵ http://www.manchesterpartnership.org.uk/info/6/health_and_wellbeing_board

treatment to supporting people living with and beyond cancer and palliative care. It aims to support people with cancer, and their families and carers, to navigate their cancer journey so they become well informed and supported. Its work is framed within nine strategic outcomes (appendix 1).

The Manchester Libraries Macmillan Information and Support team members are Macmillan Professionals, which mean they are supported by Macmillan Cancer Support in a number of ways. These include: membership of the project steering group to support the team with development and opportunities and any challenges (this is attended by the local Macmillan Development Manager); facilitating links to local partners and organisations; offering learning and training opportunities and professional development and resources.

The Manchester Libraries project fits into the Macmillan strategic vision for reaching and improving the lives of people affected by cancer and its nine outcomes (Appendix 1). It has formed partnerships and alliances with local Macmillan professionals and their services and local Macmillan projects including the Macmillan Cancer Improvement Partnership in Manchester; the Macmillan Information and Support Centres within Manchester; Macmillan Clinical Nurse Specialists within Manchester and the Macmillan Cancer Awareness Project within the City of Manchester.

3. THE MANCHESTER PROJECT

The Macmillan Information and Support service was launched at Manchester Libraries in July 2008 with three years funding and support from Macmillan Cancer Support⁶. Traditionally, Macmillan Cancer Support has provided cancer information and support services in clinical settings and the organisation wished to pilot a community initiative to learn lessons before rolling out the model elsewhere.

Learning from these initial three years showed the need for a local information service in a non-clinical setting, tailored to offer information and support to people affected by cancer nearer to where they lived and worked. Some people affected by cancer may be unable, or unwilling, to access hospital services for a variety of reasons, such as distance to travel, reminders of past experiences and treatments and feeling more comfortable in their local community settings.

In 2011, the project was successful in securing a three-year grant from the Big Lottery. This grant saw the service fully funded until the end of 2014 and was recognition of the team's achievements and learning over the previous three years. The project has a unique position across the City in information and support services for people affected by cancer because it is located close to local communities and works with community groups. It is successful in reaching people

⁶ An evaluation was carried out in 2010: Colman Sheila (July 2010) Macmillan Information and Support Services Manchester Libraries: Evaluation Report.

in communities who traditionally do not engage with and access cancer services and raises awareness of the issues of early detection.

The team consists of four part time women staff and a project manager employed by the City Council in the Growth and Neighbourhoods Directorate. The service has two key strands: it offers individual support to people affected by cancer and secondly, awareness-raising sessions, tailored workshops and public events for the public and professionals. It works across the whole cancer journey.

Information is displayed in libraries across the city with facilities at three libraries⁷ for the staff to hold one to one sessions with individuals who request it. Awareness sessions are held in a variety of community settings in partnership with a wide range of statutory and voluntary sector partners and creative ways are used to reach groups such as men and those with learning disabilities. The fourth member of the team who was appointed in October 2012 speaks three community languages, and this has strengthened the existing work being carried out with Black and Minority Ethnic groups, particularly in the North of the City.

A new development in the North and the East of the City, in response to the need to support people who are surviving cancer, are learning and support group activities for people living with and beyond cancer.

3.1 The Big Lottery Project Outcomes

The following three project outcomes were agreed with the Big Lottery:

1. The provision of an accessible, inclusive support service will reach more people affected by cancer, who will benefit by being able to take stronger ownership of their health. Beneficiaries will be able to report that they were able to access emotional support, and tailored information, when and where they needed it, resulting in an improved patient experience.
2. An events, outreach and training programme will engage with over 3600 people by the end of the project. This programme will increase people's confidence to access services and enhance their knowledge about cancer awareness and the importance of early detection
3. Volunteers with the service will increase their skills, confidence and knowledge resulting in improved employability and stronger communities. There will be an on-going programme of engagement and training of beneficiaries, with no fewer than 6 volunteers directly supporting the service at any one time.

The next section outlines the evaluation process and section 5 presents the findings against the three outcomes above.

⁷ Wythenshawe, Gorton and Longsight Libraries

4. EVALUATION PROCESS

The independent evaluation was commissioned in April 2012; it was designed as an integrated service evaluation with the evaluator working alongside the project team, advising on data collection and feeding in emerging findings. These were used to shape the development of the project as it progressed and provided evidence of early outcomes and impact.

The aims of the evaluation were to find out:

1. How effective is the Macmillan Service at Manchester Libraries in providing cancer information and support to the local community?
2. Are there any recommendations on improving impact measures and/or on-going methods of data collection?

The complete set of evaluation questions can be found in appendix 2.

A theory of change (ToC) framework has been used as the approach of choice in the evaluation of a complex social programme. It focuses on impact and outcomes and the factors that have driven those changes. It explains why the changes have occurred and for whom in which particular context, which is of particular importance in this project. It allows the contribution and attribution of the project activities to be measured against the outcomes.

A theory of change workshop was held in May 2012 with 19 stakeholders in attendance. A draft theory of change to guide the development of the project and the evaluation was produced.

A number of qualitative and quantitative methods have been used to collect the data and inform the analysis. There was a particular focus on the views of people using the service, and 9 people affected by cancer were interviewed 2 to 3 times across the two years in order to gather information on the longer-term impact on them over time. A full list of primary data methods can be found in appendix 3.

The Macmillan Libraries team collected significant monitoring data from events and activities. They were also vigilant in evaluating individual awareness sessions, appendix 4, and in evaluating and writing up the learning from individual training and public events, such as the men's comedy night and the learning disability workshops. They also completed regular project reflective diaries, appendix 5.

The evaluation is at programme level, drawing together a number of data sources across the initiative, including primary data gathered by the independent evaluation and secondary data collected by the project team and their partners. The data has been analysed using the three Big Lottery Outcomes as the analytical framework.

5. FINDINGS

Section 5 presents the findings from the evaluation broadly in line with the three Big Lottery outcomes. In the first two years of the project, the Manchester Libraries Information and Support service has achieved the outcomes set by the Big Lottery and in some cases has exceeded them.

Section 5.1 focuses on the evidence from the one-to-one support sessions offered by the service, looking at the scale and reach of the project and in particular the service user experience; section 5.2 focuses on the awareness, training and events activity of the project and section 5.3 explores the volunteers' role and experience in communities. A number of case studies are included⁸.

5.1 One to one support and the service user experience: Outcome 1⁹

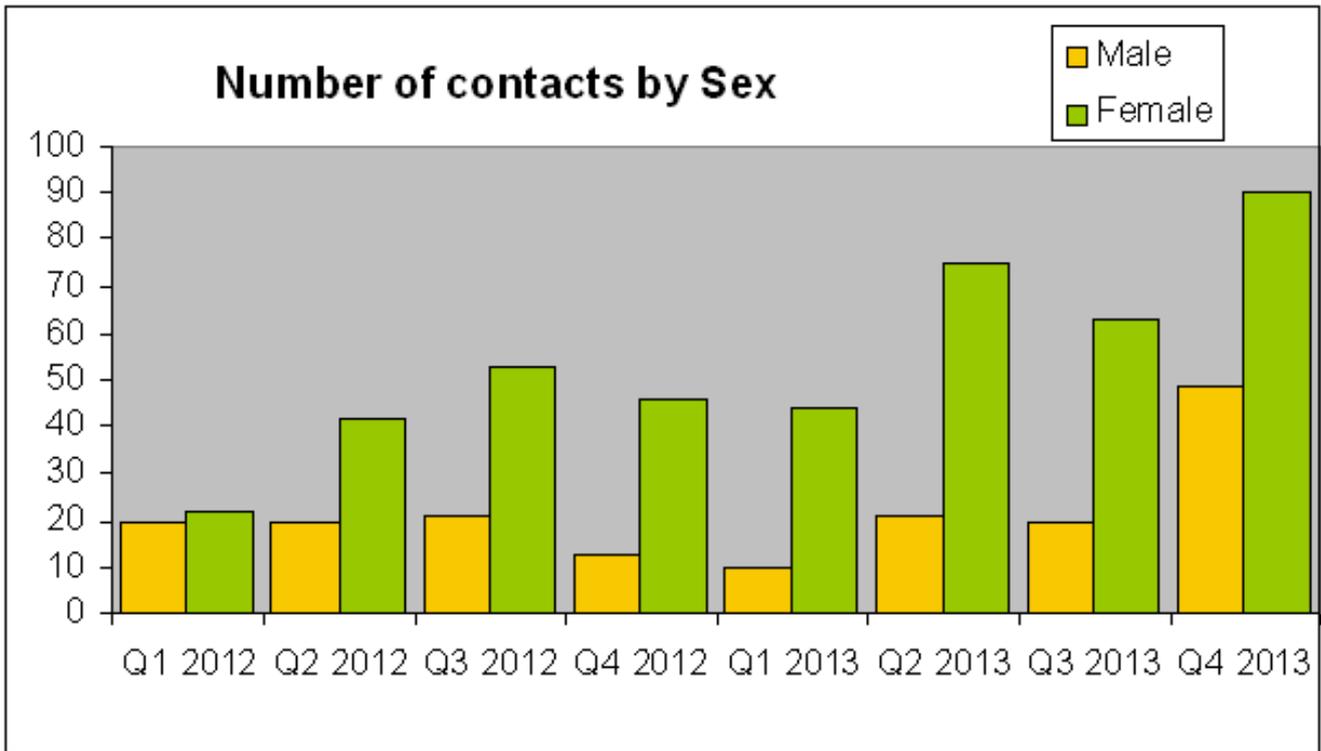
Scale and reach

There have been **740 individual support sessions** held between January 2012 and December 2013 (24 months). The support sessions are either face to face or by telephone, and there are drop in points across the city. In particular, there are contact points at Wythenshawe library, Gorton library and in the North of the City where there are the highest mortality rates for cancers in people aged under 75 years. See Appendix 6 for Manchester wards breakdown for all cancers.

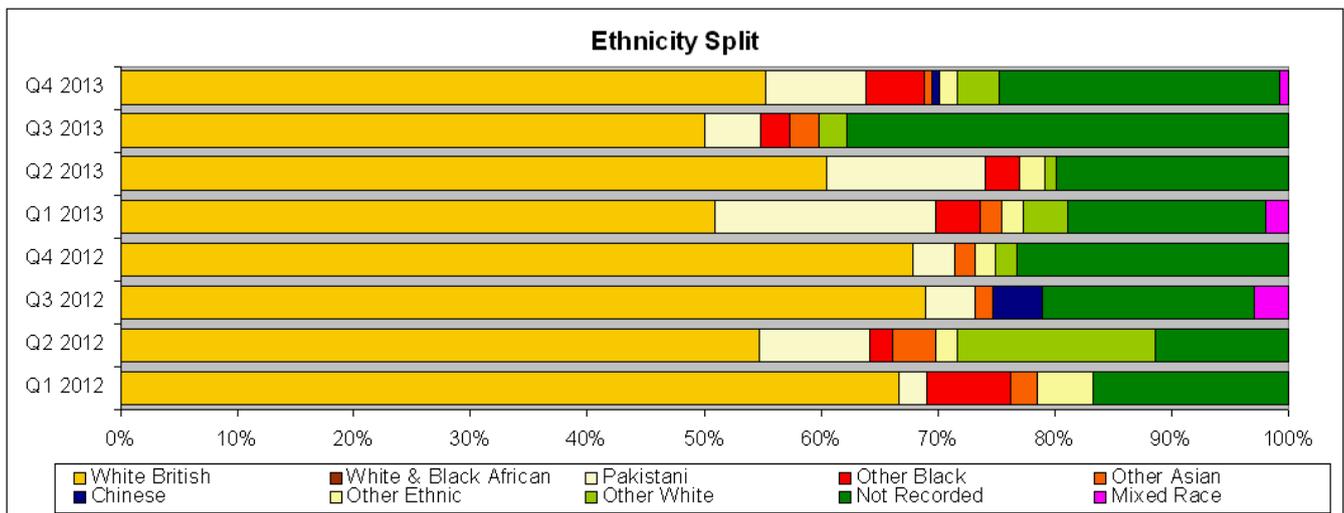
The table below shows that the number of total contacts has increased in the second year of the project. It also shows that in the last 3 quarters of 2013, the numbers of men accessing the one to one support has increased, although the proportion of women is still higher.

⁸ All the names in the case studies have been changed for confidentiality purposes

⁹ BL Outcome 1: The provision of an accessible, inclusive support service will reach more people affected by cancer, who will benefit by being able to take stronger ownership of their health. Beneficiaries will be able to report that they were able to access emotional support, and tailored information, when and where they needed it, resulting in an improved patient experience.



The table below shows the ethnic breakdown of people accessing the one to one sessions. This shows that over 50 per cent are White British, and that the proportion of Pakistani people has significantly increased in year 2.



A new member of staff who speaks three community languages, including Urdu, joined the team in October 2012, and it would be reasonable to suggest that this has contributed to the increase in numbers.

The data shows there are a variety of people affected by cancer that use the service. They include patients, carers, friends, general members of the public, survivors of cancer and health and social care professionals. The contact time varied from less than 5 minutes to 30-60 minutes; for some it is only one contact and for others there are several.

The evaluator carried out 27 individual interviews for this evaluation with a sample of 15 people attending one to one sessions. There were 13 women and 2 men and one woman had a learning disability; 9 people have been followed up 2 and 3 times to measure the changes that occurred for them over time from their first contact with the service. The following themes emerged:

Accessing emotional support and tailored information

The users of the service valued the opportunity to speak face to face with a team member to gain support tailored to their needs and circumstances. One woman explained how she had rung a cancer helpline to get emotional support and had been sent a few booklets to look at. She continued:

I still have them but I don't read. I can read but I can't concentrate, so they were no help to me. I needed to talk to someone (Woman living with cancer).

She subsequently saw the Library service in her local library and has continued to access it when she feels she needs more support.

Many had received cancer information in hospital, through leaflets or speaking to Macmillan nurses over the phone. However, they welcomed the opportunity to talk about their worries in an informal, more familiar setting:

How would I have coped without (the service)? It was the best thing that ever happened (Breast cancer survivor).

One interviewee had a close relative recently diagnosed with cancer. She felt guilty because she herself was upset and did not know how she could support her sister who lived at a distance. She found the service recognised her needs as a relative, stopped her feeling guilty and supported her to find the right information to help her relative and other family members. She recognised that there was a lot of information available on websites and so on about cancer, but the service was tailored to her personal situation and experience.

Six months later she has visited her sister and shared the information with her. They are now able to talk together and gain mutual support. The interviewee explained:

(The service) answered many of the questions we were concerned about in a constructive way and helped us to talk and share together (Relative).

People spoke of feeling vulnerable and fragile from their experiences of cancer and the fact that the staff's approach was non-judgemental, and their issues were listened to, made them feel valued and supported in their distress. The opportunity to have a private space to go to in their local community was also very important to the outcomes.

One woman who was caring for her brother with cancer was desperate and did not know what to do. She went to a carers meeting and met one of the Macmillan Library team, and this was followed up by a one to one session in the library. She explained:

That Monday I was in trouble, no one understood or wanted to know. (Team member) knew how bad I was. It all came out and she is the only one who has sat and listened to me. She did not judge me, professionals do judge you but she didn't, she had a different way (Relative of cancer survivor).

The next day she felt a 'new person':

I felt I could deal with my life; something had happened, my shoulders were not as heavy (Relative of cancer survivor).

Case study 1: Tailored information and support when and where it's needed

Karen's partner died 18 months ago, four weeks after receiving a diagnosis of cancer. She felt that she wasn't coping at all and was struggling to work. She felt very fragile and vulnerable and had very little family support. She had also been told that she would have to wait 6 months to get the benefit of any bereavement counselling and she felt she couldn't wait that long.

A colleague who knew about the Macmillan Library project suggested that she contacted the project and a team member made contact to arrange an appointment. It made a difference that the library was local to where Karen worked because it meant she could go in her lunchtime and did not have to take time away from work.

Karen found the team member a skilled listener, who took her seriously and did not judge her; trust built up very quickly and Karen felt:

It was just what I needed - I could empty my head. I no longer thought 'I am going mad'.

15 months later, she is managing her life better and moving forward:

I have done some really nice things this year and made time for myself to think about Andrew and the good times we had.

She still has some dips of despair but she is confident that if she needs to she can contact the Libraries service. She said about the service:

Macmillan was there when I was the most isolated and had nowhere to go.

She has increased her understanding of specific cancers through practical information and felt she was given the information when she was ready to receive it; when her partner had just died she wasn't able to take it in.

The library service really helped with the right information at the right time.

One woman living with cancer saw the information in the library and was encouraged by the sign: '*Can we help you?*' She called in and made an appointment to see one of the team. She has used the service several times since and it keeps her feeling positive. At times she wants to talk about any bad news and she has then called the service. Also she has had help with accessing other services such as relaxation classes.

I know (team member) is on the other end of the phone if I need her
(Woman living with cancer).

The people interviewed for the evaluation spoke highly of the service and how they often recommend it to others. One cancer survivor who used the service keeps the telephone number pinned up in her house in case she needs to use it or pass it on to someone else.

I am now more aware about cancer information and would not hesitate to recommend the service to someone else. I had been so desperate I had not known what to do (Relative)

Being part of the local community

Many of the people interviewed stressed the importance of the service being locally available. It was convenient for some because it meant they did not have to have time off work; they could access the service in their lunchtime. For others, they did not have to make long journeys out of the area, particularly in circumstances when they felt vulnerable and insecure.

The library location was significant because it was seen as a local information point and '*someone is always going to the library*'. It provides a community hub for activities and attracts a cross section of the community. One young woman who

lived near the local library was 'curious' about the service and wanted to know more about detecting the early signs of cancer.

But beyond convenience, there was evidence that people valued the service because of its local identity. People felt that the team understood the local circumstances and how that influenced the way they led their lives. Factors such as local employment, cultural activities, transport and housing were all important in understanding the specific needs of the people accessing the service. They were confident that the team members had good local knowledge of the communities as well as information on local community groups and this added to the effectiveness of the service.

This confidence extended to telephone contact. One woman explained:

They know the area and that makes me feel more comfortable (Cancer survivor).

People appreciated the opportunity to find support in their local community rather than in the clinical setting. One woman explained:

It was good to go locally, not the hospital; I have had so much treatment at the hospital (Woman living with cancer).

Taking ownership of personal health

The Macmillan Library Information and Support service offers emotional support and information to individuals affected by cancer. It also offers an important signposting service, referring people to other appropriate services as required and enabling them to begin to take ownership of their own health. A man referred to the health trainer service said:

Thank you for the contact of the 'health trainer service' you found for me, I attended my first meeting on Monday this week and I am sure this is going to be a great help to me (Man living with cancer).

Similarly, one woman reported:

Thank you for the meeting, I really appreciate it. Thank you for sitting with me, and my tears. I have been feeling much better since. I also really appreciate the referral to the Health Trainer. I've had a quick read through the booklet you gave me. It does look very useful and encouraging (Woman living with cancer).

Another man affected by cancer was experiencing financial problems and found the service useful in directing him to new sources of funding. Some felt better able

to cope when they knew about other services; others had help with filling in forms and contacting relevant agencies.

Case study 2: Taking ownership

John, a young man whose partner is in the terminal stages of cancer, sought out the service when he saw a flyer in his local library. He had been struggling to come to terms with what was happening; he felt he needed support himself because he knew he was not dealing well with the situation and worrying his partner. He had had previous drug and alcohol problems and was afraid of '*getting all messed up again*' when his young partner died. He felt that no one asked how he was dealing with it all. He found the emotional support given him by the service had helped him a great deal, and he was able to be honest about how he felt:

It was good to speak to someone with knowledge of cancer – other support services I have used are about 'drugs and alcohol', but this was specific. She (project team member) knows what I am going through (Young man with partner dying of cancer).

The impact for him since using the service is that John has taken some control of his life; he now feels better able to support his partner, and knows that when she dies he will be able to have support with his bereavement by going to bereavement counselling. He believes this will help him from going back to drugs and alcohol.

3 months after using the Libraries service John has learnt to cope with his partner's distress. The community outreach worker keeps in contact with a light touch which John appreciates:

She leaves me to it and I know I can speak to her anytime I need to.

In addition to signposting and facilitating access to other services, the Macmillan Libraries team on occasions acted as an advocate for the person affected by cancer. People affected by cancer have a plethora of information and services available to them, but some found it confusing and not always easy to find the right service for their needs. One woman was very worried because she had not received appointments for her radiotherapy:

I was so anxious, I told (team member) 'I think they have forgotten me' and I have tried ringing (Cancer survivor).

The team member was able, with the woman's permission, to contact the hospital and an appointment followed shortly afterwards.

5.2 Awareness, training and events activity of the project: Outcome 2¹⁰

This section examines the second key work strand of the project which focuses on raising awareness of cancer and the importance of early detection. The awareness events and workshops sessions are a significant part of the Libraries project. This outreach approach brings the project very close to communities that have previously, for a variety of reasons, not accessed traditional services, particularly regarding prevention factors, screening and early presentation of cancer. These groups include adults with learning disabilities, people from Black and Minority Ethnic communities, men and people living in the most deprived areas of Manchester.

The project team works in partnership with a range of local organisations and community groups, tailoring resources and activities to the particular groups needs. Broadly speaking the activities range from information stalls at awareness raising events such as in shopping precincts in disadvantaged areas and Health Fairs, to tailored sessions with specific groups. A range of community venues are used including libraries, shopping centres, children's centres, church halls, a Chinese Centre and an Asian restaurant. For some, the approach has been to join an existing community group and offer cancer awareness sessions as part of the programme of events. Some sessions have been held in the workplace with council employers as well as to groups of professionals in a variety of organisations.

Included in this section is a more recent development in the project. In response to the Living With and Beyond Cancer (LWBC) agenda in Manchester, the team undertook a Conversation exercise with people surviving cancer that took the form of two focus groups in the East and North of the City and 7 telephone interviews. As a result, two groups for learning and support activities are being piloted in the City using themed conversations and peer support. Evidence of outcomes from one of these groups is reported in the section.

Scale and reach

In the first two years of the project it has already achieved it's target for engaging with people, and there is still another 12 months activity in the funded period: **3556 contacts** have been made between January 2012 - December 2013 at **180 events**.

A sample of 328 evaluation surveys (appendix 4) has been completed from the events around awareness and prevention. 296 (90 per cent) of the respondents were female, 26 (8 per cent) were male and 4 did not respond. The majority (50.6

¹⁰ BL Outcome 2: An events, outreach and training programme will engage with over 3600 people by the end of the project. This programme will increase people's confidence to access services and enhance their knowledge about cancer awareness and the importance of early detection.

per cent) were over 50 years of age: 37 per cent were under 50, and 40 people did not record their age.

In terms of ethnicity, those completing the surveys are shown below. There were a significant number of people from Black and Minority Ethnic communities reached: 31.7 per cent (104) were Asian or Pakistani compared with 44.5 (146) per cent White British

Ethnicity	Per cent	No. of people
Asian	24.4	80
Black	5.8	19
Indian	7.6	25
Irish	0.3	1
Mixed Race	1.5	5
Other Ethnic	0.91	3
Pakistani	7.3	24
White British	44.5	146
Not recorded	7.6	25
TOTAL	99.91	328

The greatest majority of people who attended the sessions increased their knowledge of cancer and said they were more likely to notice changes in their body earlier. Similarly, they were more likely to go to their doctor if they noticed changes and more aware of the support that was available to them.

A full list of the responses can be found in Appendix 7.

Accessing groups that traditional services don't reach

There is good evidence that the project has been successful in reaching groups that traditional services have not reached, and where the mortality rate for cancer is high. Approximately 72 per cent of events have been held in wards where the mortality rate from cancer is higher than the English and Manchester average, with 25 per cent held in wards with the highest mortality.

The impact on the groups has been an enhanced knowledge about cancer and the importance of early detection, as well as an increased confidence to access mainstream services, such as speaking to the GP and attending screening opportunities. Some examples are given below.

- **People with a learning disability**

Eight workshops and one event have been designed specifically for people with a range of learning disabilities. The purpose of the sessions is to engage the person

with learning disability directly rather than more traditional methods that are aimed at their carers.

Case study 3: Impact of tailored workshop

Sharon attended a session on breast awareness, which was held for women at her place of work. Sharon is a woman in her forties with a learning disability and the workshop was designed to meet the specific needs of the group. There was clear information in mini guides, practical interaction such as making reminder cards and using the breast-training model, and feedback forms with smiley faces.

Sharon learnt lots of new things at the session, which she found very useful and she checks her breasts more often:

It was really good; it made me think about things a lot more

Four months later, Sharon remembered the session and she still uses the leaflet and her own experience to talk to women she supports at the Centre. She tells them what to look out for and also:

If you are worried about anything, go to the Macmillan service

14 months after the workshop, Sharon was still able to recall the information; in particular she knew that she should go to the doctor if she found a lump in her breast. She was also due to attend her first cancer-screening test, and although she was worried she still said she was going to attend.

Sharon was aware that she had forgotten some of the information and that a refresher course would be useful. She said that it was also important because there were new people at the Centre who had not attended a workshop.

Observations by the evaluator at a session organised for people with a profound learning disability who live with their carers in small group homes showed the ability of the team to adapt information to the needs of the group. Different methods of communication were used including a role-play between a 'doctor' and the 'patient' and simple diagrams to explain symptoms. The session illustrated the value of working in community venues, which were near people's homes as it was accessible and familiar. It also enabled carers to come along and learn about cancer in order to support the people they care for. In addition, the carers had their own awareness raised about the signs and symptoms of cancer in themselves.

- **Men**

It is well documented that men visit their GP 20 per cent less often than women, are 60 per cent more likely to develop cancer and 70 per cent more likely to die

from the disease¹¹. It was for this reason that the Library project wanted to reach men, particularly in the most deprived areas where health outcomes were worse.

One example of the way the team sort to achieve this was to work in partnership with local organisations¹² and in January 2014 a Comedy Night was held in a local club. The area chosen for a pilot was Wythenshawe because of the older population and the residents report poorer health than the Manchester population¹³.

The event attracted approximately 80 people and there were slightly more men than women. 18 men aged between 28 and 69 years took part in a snapshot survey during the interval; they had heard about the event through a variety of sources including poster and leaflets at the local library. They had come along for a range of reasons including supporting a cancer charity, knowing people who have had cancer, having a good laugh and to find out more. One man had come along: '*Because a lot of family have died of cancer*'. 49 people took part in the exit poll, with 48 saying they had '*had a cracking time*'.

The results of a follow up survey undertaken 1-3 weeks after the event with 13 men are still being collated, although already one man has changed his mind as a result of the event and will now take part in the bowel cancer screening. Learning from the Comedy Night will be used to plan other events targeted at men.

- **Black and Minority Ethnic Communities**

The team members have been working with local community organisations to reach people in Black and Minority Ethnic groups and from the numbers reached, this has been successful. The team's approach has been to work with existing groups, such as ESOL classes and a Black women's group to introduce information on cancer awareness and early detection. Two other examples are presented here from the evaluation data.

Asian Women's group in North Manchester: A team member who speaks Urdu has been visiting an Asian Women's Group over a period of time and has developed a relationship with the members. She has used dialogue and humour to get the messages across rather than written information.

Evidence collected for this evaluation shows that changes have occurred through the team member gaining the confidence and trust of the group. The women said:

¹¹ Men's Health Forum <http://www.menshealthforum.org.uk/>

¹² This was a good example of how the team works in partnership. The other organisations were: Bowel Cancer Screening Programme Health Improvement Team, Macmillan Information and Support team University Hospital South Manchester, Wythenshaw FM, Wythemshaw Community Housing Group, Health Living Network and Manchester United Foundation.

¹³ Evaluation report produced by the BCSP and Macmillan Cancer Support

(Team member) explains in our language, she knows our culture, background and religion, knows our needs and our problems. This gives the ladies confidence (Asian Woman).

Women in the group don't read letters sent to them from the NHS because they are either written in English or they don't understand the content. There was also a view that, because the women don't understand the signs and symptoms of cancer, they sometimes worry unnecessarily and put off going to their doctor. However, after the sessions with the Library team worker, one woman said:

Women here are housewives and they never go to their GP, but after the session, she explained it very nicely and I went to the GP with pain (Asian woman)

Some of the women said they now do the bowel-screening test, and others said they had attended or would attend the breast screening service in the future.

The women who went to the group also spread the messages in their own community and through this 'word of mouth' other women in the community found reassurance and understanding of the issues.

Women who attended other awareness sessions with the team member gave this feedback through the survey:

Felt able to ask questions in (my) own language (Pakistani women under 50 years).

Now I understand better in Urdu (Pakistani woman over 50 years).

One participant of a session felt she had learnt a lot about cancer; in particular she found the discussion on de-stigmatising cancer very helpful and would no longer see a cancer diagnosis as the end of her life. She now checks her breasts regularly which she didn't do before.

The Chinese community: Several awareness sessions have been held with the Chinese community, for example working through translators with groups at the Wai Yin Centre. The team worked with a woman's group that translated information on breast awareness so it was more accessible in terms of language and cultural norms. Multiple information methods were used including DVDs in Cantonese, practical demonstration and participation, and one to one sessions.

At the Manchester Chinese Centre one of the project team ran a workshop around cancer awareness, signs and symptoms, for 25 people who attend the Centre. The event was supported by 7 of their young volunteers. The Centre itself has over 40 young volunteers who go into their communities and talk to older members and pass on information to help and support them to open up and talk about cancer.

For example, over 5000 leaflets were given out at events during the Chinese New Year. One of the participants of the workshop explained why the information was necessary:

Chinese people are very secretive about cancer; they try not to talk about it. The volunteers learn what is important to know about cancer and give out the information. The volunteers get the information right into the community (Chinese participant at the Chinese Centre).

This was a good example of how working with a cultural organisation that knows its own community can provide the right approach to reach the people.

Public events

Another approach used by the project in order to reach into communities and increase people's confidence to access services and enhance their knowledge about cancer awareness is through a comprehensive programme of public events, often working in partnership with other organisations and taking opportunities to 'piggy back' on other events. The team has an information stand of leaflets and other information, which they combine with a proactive engagement approach to reach local people.

Observations at two events confirmed the importance of using a proactive approach. The high level of engagement skills displayed by the team enabled them to draw people to the information and tailor it to their needs. In some cases they used a survey form to start the engagement of people using a busy shopping centre.

An evaluation¹⁴ carried out by the team at Wythenshawe Forum in 2013 suggested that few people using the Forum knew about the Macmillan service. It proved more effective to speak to people face to face than rely on the Macmillan signage and leaflets. Once engaged, some people were filtered through to the one to one service in a private room in the library.

Pop-up shop: Another example of a public event was the Pop-up shop held in a busy high street shopping area in North Manchester. The project worked in partnership with the North Manchester Hospital Macmillan Information service over four days, making use of a vacant shop to raise awareness of cancer and the services available. Other partners included a Jewish Voluntary group, the NHS Bowel Cancer screening programme, Macmillan Solutions and the local college.

The Macmillan Libraries team stood out for their engaging skills, proactively bringing people into the service and explaining about cancer in a person-centred way. It was estimated on the first day that the team engaged with 70-80 people

¹⁴ Macmillan Information and Support Service: Wythenshawe Forum Spring 2013

and carried out 11 sessions with the breast demonstration model¹⁵. Another finding was that on the day of the evaluation observation the Macmillan Libraries team had a team member who spoke three community languages. She was able to greet people who were hesitating near the door in their own language and explain the purpose of the event. This encouraged several members of the Black and Minority Ethnic Communities to visit the stalls.

Living With and Beyond Cancer Activity

Following an exploratory study, a third strand to the awareness, training and events activity of the project has recently been included. The project team had been looking at a range of options to give on-going support to people affected by cancer through courses or group activities. Following the study, it was decided to pilot two learning and support group activities for three months – one in the North and the other in Central/ East Manchester - that combined an educational element through themed conversations with a self-support approach for people living with and beyond cancer.

Evidence for the evaluation confirmed the value of the group for those who participated and the impact on their lives. The group appeared to help them in two main ways: it was a source of information and problem solving and it was a peer support group.

The group session began with a discussion on fatigue (chosen from the exploratory study) and there was the opportunity to take Macmillan information leaflets on the topic. The group contributed their own experiences and ways of coping. The group was facilitated by a team member from the Macmillan Libraries and supported by a member of the North Manchester Hospital's Macmillan Information and Support service. Skilful group facilitation created a safe and comfortable environment, enabling all members of the group to contribute; there was a great deal of information exchange.

The opportunity to share experiences with other cancer sufferers was highly valued. One participant described it as:

A 'levelling' environment where we may not be 'all in it together', but nevertheless we are certainly 'all in it' and for a couple of hours 'we are all together' (group member)

Another member described it as:

You can talk about it without upsetting people – there is an acceptance (in the group) that you can cope (group member)

¹⁵ A full write up of the 4 day event is being produced up by the North Manchester Hospital Macmillan Information and Support team

The impact of the support was on improving mental health, lifting low mood and reducing isolation. Some felt it improved their relationships with family and friends.

I feel much better when I am driving home than when I arrived (group member).

It takes away the isolation, being with people in the same position as you – although different (group member).

For some of the group members, the opportunity to support other people was a morale boost. One woman described what it felt like to share solutions with other people affected by cancer:

It's a morale boost, you recognise that you have moved forward from what it had been like when you tell people what helped you (group member).

The group also found the group uplifting, 'not all doom and gloom'. Some members had attended other cancer support groups but had found that a lot of the time was spent complaining about care and treatment. They found the Libraries approach more supportive and the atmosphere created was described as therapeutic.

The project team will be looking at rolling out a similar series of events in other parts of the city. The current groups in North Manchester and Gorton will be encouraged to develop into a support group format with input from, but not led by, the team.

5.3 Building stronger communities through increased skills, confidence and knowledge of volunteers: Outcome 3¹⁶

A key strand of the Libraries Information and Support project is the involvement of volunteers to increase their skills, confidence and knowledge resulting in improving their employability. It also is a mechanism to strengthen communities.

The first wave of volunteers in 2012 was recruited from the City Council workforce in order to raise cancer awareness with the large number of people employed by the council. Initially there was a lot of enthusiasm and 9 volunteers were recruited to the project but as many of the activities of the project took place in working

¹⁶ Outcome 3: Volunteers with the service will increase their skills, confidence and knowledge resulting in improved employability and stronger communities. There will be an on-going programme of engagement and training of beneficiaries, with no fewer than 6 volunteers directly supporting the service at any one time.

hours, it proved difficult for the council employers to have time off to support events. This led to alternative recruitment methods being explored.

In 2013, the Manchester Macmillan Library project decided on a new approach and four women from the community were recruited; three of the volunteers were cancer survivors, although this was not part of the criteria for recruitment. The volunteers' role was to support the team at public events and awareness sessions; those with experience of living with cancer also talked about their experiences at tailored workshops set up by the team. The volunteers never worked alone and the individual team member who was carrying out the activity supported them. Three volunteers who were cancer survivors had one to one interviews for this evaluation and some interesting themes emerged.

They were all motivated to volunteer because, after their own experiences of cancer, they wanted to give something back to the community and in some cases to Macmillan Cancer Care. Some of them during their illness had sought out for themselves friends or colleagues who had been through a cancer experience and found it extremely supportive. One volunteer explained:

I wanted to do something, help someone going through it - get more involved. A friend who had cancer got in touch with me recently because I had been through it. She said I made her feel better, in the same way I did from (my colleague) (Volunteer cancer survivor).

It's a lovely feeling doing something for Macmillan; they did so much for me, (Volunteer cancer survivor)

They all felt that their experience of cancer brought an additional dimension to the project and, with the support of the team in appropriate settings they could share with people how it feels to have cancer. They thought this was valuable information to share with people affected by cancer. One woman said:

I have been through the experience myself, a bit of an expert really because of the 'lived experience'. I can give valuable experience from a patient's perspective (Volunteer cancer survivor).

I don't mind sharing my experiences; I 'get' some of the things they say (Volunteer cancer survivor).

The impact on volunteering on one volunteer was very positive; her own confidence and self-esteem has improved and she feels able to consider finding work. She feels less afraid of cancer and has been able to get things more into perspective and move her life forward.

However, for another volunteer there were challenges: as a cancer survivor she found it hard to move on after sharing her experiences and she felt she needed a more emotional distance from the experience whilst still retaining a connection.

In addition, the team have also been supporting volunteering in the City by taking part in joint training with other cancer partners^{17 18}. They work together to share resources, ideas and training sessions amongst their volunteers. For example, one team member devised and developed training for volunteers from a range of cancer services for the 'Talking about the C word' project. Participant feedback was positive; participants found it valuable to meet other volunteers and the training improved their communication and confidence to talk about cancer:

(I have) increased confidence on how to deal with difficult situations and how to approach the subject of talking about cancer (Volunteer on joint training programme).

Training like this is so useful for me. As volunteer I have found myself at times at a loss, not knowing what to say to the people affected by cancer (Volunteer on joint training programme)

The final sections of this evaluation report include a discussion of key lessons and learning that have emerged, and recommendations for moving forward.

¹⁷ Macmillan cancer information and support at University Hospital of South Manchester, Volunteer Support Worker, Macmillan Solutions, Macmillan Community Outreach Officer, MCC Library Service, Manchester City Council and Macmillan Community Project Officer, The Christie NHS Foundation Trust

¹⁸ Mac Voice, Winter Edition 2013

6. DISCUSSION: KEY MESSAGES AND LEARNING

The Manchester Macmillan Libraries Information and Support service has already achieved its first two outcomes in two years of a three-year project; the third outcome on volunteering is on track. The team should be congratulated on the scale and reach of the project through its awareness and activity events and the one-to-one support sessions. The team is small and they have achieved and maintained a high level of operational delivery.

The Libraries service has filled an important gap in cancer information and support, spanning the whole cancer journey from early intervention and prevention to bereavement and survivorship. It has engaged a wide range of people affected by cancer including cancer survivors, carers, relatives and professionals and has offered information and support to people when and where they need it. The information and support is also offered in a way that people can receive it. Evidence in this report demonstrates the value the users of the service have put on the emotional support, advocacy and signposting to other services.

The unique role of the Libraries service is its positioning in the local community, rather than, as traditionally with cancer information services, being in a clinical setting. The libraries and drop-in points have provided a central focus to extend the information and support into local communities and it has engaged people who would not have found information and support elsewhere. It is offering an alternative to clinical based information and support services.

Contributing to reducing inequalities in health in Manchester

The project has been particularly successful in engaging groups who traditionally have not engaged with prevention and early intervention cancer services and mainstream services. They have shown positive changes for people with learning disabilities and Black and Minority Ethnic communities in Manchester, and it is reaching out to men in deprived areas who have high cancer mortality rates. Over time, this will contribute to addressing health inequalities that exist across Manchester; Public Health Manchester and the three Manchester Clinical Commissioning Groups will be interested in this finding for informing future commissioning decisions.

Partnership with Macmillan Cancer Support

The partnership of the City Council with Macmillan Cancer Support has contributed to the Macmillan nine outcomes for people affected by cancer (Appendix 1). In particular, through its volunteer programme it is supporting people in communities to feel inspired to give something back. There is also evidence in this report that people feel treated with dignity and respect, and they know how they can help themselves.

The project has also contributed to the strategic vision of Macmillan Cancer Improvement Partnership in Manchester, in particular by responding to supporting people living with and beyond cancer.

What is driving the change?

Several factors are driving the changes that are occurring in Manchester. These factors include:

- **Part of the local community:** The library and drop-ins centres have brought cancer information and support closer to where people live and given people the opportunity to use it in a non threatening, familiar environment. The extensive outreach programme, working in partnership with local community groups, services and community leaders has enabled meaningful engagement with local communities.
- **The team** brings together four people and a manager with a range of skills and attributes, allowing the service to be flexible and responsive to varying needs. For example, the appointment of a team member who speaks 3 community languages has gained the trust of BME communities and enabled them to engage meaningfully in awareness sessions. The individuals work well as a team and their commitment and enthusiasm for the issues to be addressed has made a difference.
- **Tailored provision:** a key driver for change has been the skills and abilities of the team to design and develop tailored packages that have reached out, engaged and informed a range of different groups in the community. This tailored approach, that meets the information and support needs of individuals and groups, such as people with learning disabilities, men and those from different ethnic communities across the whole cancer journey has been significant in enabling people to take stronger ownership of their health.
- **Flexibility of the service:** The availability of staff with a range of different skills, attributes and personalities, providing one to one information and emotional support, is essential to giving individual support every step of the way on the cancer journey
- **The Macmillan Manchester Partnership:** The partnership with Macmillan has been a key factor in the success of the project. This has occurred through developing local alliances and partnerships with other Macmillan projects and working with Regional Managers. It has also been important in engaging members of the community because the brand is universally known and trusted by the public.
- **Alliances and Partnerships:** As illustrated in this report, the team have been particularly successful in forging a number of partnerships and alliances

across Manchester, which has extended the reach and accessibility of the service. The majority of delivery is through partnerships.

- **Learning, evaluation and reflection:** the team have paid attention to capturing and recording data from their activities. In addition, they have made intelligent use of the data to develop and adapt the programme in line with its intended outcomes. They have regularly evaluated their activities, produced evaluation reports and used that learning in adapting their existing programme and planning new developments. A good example here is the support to people living with and beyond cancer, and the evaluation of the men's comedy night.

The final section in this report looks ahead and makes **five recommendations** for the future.

7. LOOKING AHEAD: RECOMMENDATIONS MOVING FORWARD

7.1 Continue to strengthen and develop the **strategic links and networks** with other cancer services in the City, particularly in the NHS, the Clinical Commissioning Groups, Public Health Manchester and the Macmillan Partnership, making it explicit how the Library service meets their strategic priorities for improving the health and well being of the people in Manchester and reducing inequalities. Raise the profile of the service with strategic leaders across the council and demonstrate the links with the cancer survivorship agenda.

7.2 Continue to build on and refine the success of the **tailored provision** for raising awareness and support, targeting and reaching into communities that have the highest inequalities and mortality for cancer. This requires the team to retain and expand its mix of skills so that different communities are accessed and engaged. For example, the data is showing that men are not accessing the service as much as women. The team may wish to discuss using the evidence to find different ways of engaging men in the service, either through specific activities or in volunteering.

7.3 Continue to develop and expand the work with **people living with and beyond cancer** as part of the City's response to the growing numbers of people surviving cancer. Continue to work in partnership with statutory and voluntary organisations to uncover the gaps in provision and discover how the library service is best placed, with its reach into communities and tailored response, to meet this important agenda.

7.4 Continue the good work on **collecting and using demographic and evaluation data** to learn from and improve the service. Explore using simple data analysis tools so that the results of surveys and so on can be more easily inputted and analysed for use by the service. Work closely with public health colleagues and commissioners in a two way exchange to ensure the service's requirements for data intelligence are met and that the data collected by the service is both relevant and appropriate for targeting geographical areas and communities of interest most in need. It would be useful to look at some simple economic cost benefit comparisons, using evidence from two recent reports^{19 20}.

7.5 Continue to **expand the work with volunteers**, clarifying where volunteer skills and attributes will have the greatest impact and how the team will manage this part of the service. The role of service champions should be developed, recruiting people from communities that can reach and engage their peers to use and develop the service. In addition a small group of volunteers who have a lived experience of cancer should be recruited and supervised to share their experiences

¹⁹ National Cancer Survivorship Initiative (April 2013) *Living with and beyond cancer: taking action to improve outcomes*, London: Department of Health

²⁰ Patient Information Forum (2013) *Making the Case for information*, www.pifonline.org.uk

of cancer at awareness raising events and tailored workshops. Consider appointing a volunteer co-ordinator to the team to expand and support the role of volunteers in the project.

Appendix 1: Macmillan nine outcomes

By 2030, the four million people living with cancer in the UK will be able to say:

'I was diagnosed early'

'I understand so I make good decisions'

'I get the treatment and care which are best for my cancer and my life'

'Those around me are well supported'

'I am treated with dignity and respect'

'I know what I can do to help myself and who else can help me'

'I can enjoy life'

'I feel part of a community and I am inspired to give something back'

'I want to die well'

Appendix 2: Evaluation questions June 2012

1. Is the service reaching a diverse group of people affected by cancer? What features of the service are effective in reaching groups of people living in less advantaged communities?
2. Are the libraries the right mechanism for engaging people? Do different people use the library than access the outreach service? Why? What is the difference between large and small Macmillan Information Points in terms of service users experience?
3. Where are the outreach services being delivered? Do they reach a different client group to libraries? If so, how?
4. What is people's experience of using the service? Does it meet their individual needs? Is the service timely and easily accessible in terms of location and format?
5. What impact does offering more appointment-based support have on people's experience of the service as against 'drop in'? Is it reaching a diverse group of service users?
6. Did the service increase people's confidence to access other support services? If so, how and which services?
7. In what ways are people taking ownership of their own health? Can they use the information and support to change their response to their diagnosis and treatment? Do they feel emotionally stronger? How?
8. Did the events, outreach and training programmes reach 3600 people by the end of the project? Who were they? Which part of the service did they use? Did they become more aware of the importance of early detection?
9. What impact does having volunteers working with the service have on service users experiences and the changes they make? Do the volunteers increase their own skills, confidence and knowledge and what are the implications of this for the volunteers and their families?
10. What impact does using local volunteers have on the local community and the participation in the project? Are the volunteers themselves affected by cancer and if so how does this help or hinder delivery?
11. What are the advantages and disadvantages of the service shifting from library management to Manchester Public Health? Is the service meeting local public health outcomes identified in the Joint Strategic Needs Assessment and in reducing inequalities in health?

Appendix 3: Primary data sources

The main data collection methods are shown below, and there were in addition numerous structured conversations with professionals and service users at events

1. Service user telephone interviews and cohort follow through

Total interviews: **27**

- 3 were followed up over 18 months and 6 were followed up over 6-9 months
- There were 13 women and 2 men. One woman had a learning disability

Case studies:

1. Tailored Information and Support when and where it's
2. Taking Ownership
3. Impact of tailored workshop

2. 'Observations and conversations' visits to awareness raising and training events

- 'Pop up' shop in Cheatham Hill
- Asian Women's Group
- Manchester Chinese Centre
- Learning disability awareness-raising workshop
- Survivorship 1st group meeting – fatigue
- Gorton library and coffee morning
- Longsight Library
- Wythenshaw Foyer public event
- Boots Pharmacy Manchester: outreach in store

3. Two focus group

- 6 participants in Living With and Beyond Cancer group,
- 3 women from the Asian women's group in North Manchester

4. Volunteers

- Interviews with **3** volunteers – who were all cancer survivors

5. Stakeholder telephone interviews

- **12** from a range of local and regional stakeholders

6. Project diaries

- **31** produced throughout the project by the project team

Appendix 4: Self-completion questionnaire from awareness events



Please circle one for each question:

Are you: Male Female

Are you: Over 50 Under 50

Are you: White Mixed

Asian or Asian British Black or Black British

Other Ethnic Group

What is your postcode:

1. Do you understand the benefits of taking early action if you're worried about a sign or symptom of cancer?

Strongly agree Agree Don't know Disagree Strongly disagree

2. Do you understand more about the symptoms of cancer now?

Strongly agree Agree Don't know Disagree Strongly disagree

3. After today, are you less afraid about cancer?

Strongly agree Agree Don't know Disagree Strongly disagree

4. After today, are you more likely to go to your doctor if you notice any changes in your body?

Strongly agree Agree Don't know Disagree Strongly disagree

5. Are you likely to share what you learned today with your family and friends?

Strongly agree Agree Don't know Disagree Strongly disagree

6. Do you think you would use the Macmillan Library Service if you were affected by cancer?

Strongly agree Agree Don't know Disagree Strongly disagree

7. Please tell us what has changed for you as a result of taking part in the session today?

Your comments are very important to us and help us to continue to support people affected by cancer. Please leave your name and phone number(s) if we can call you at a later date.

Thank you.

Name _____ Tel. _____

Appendix 5: Team Project Diary

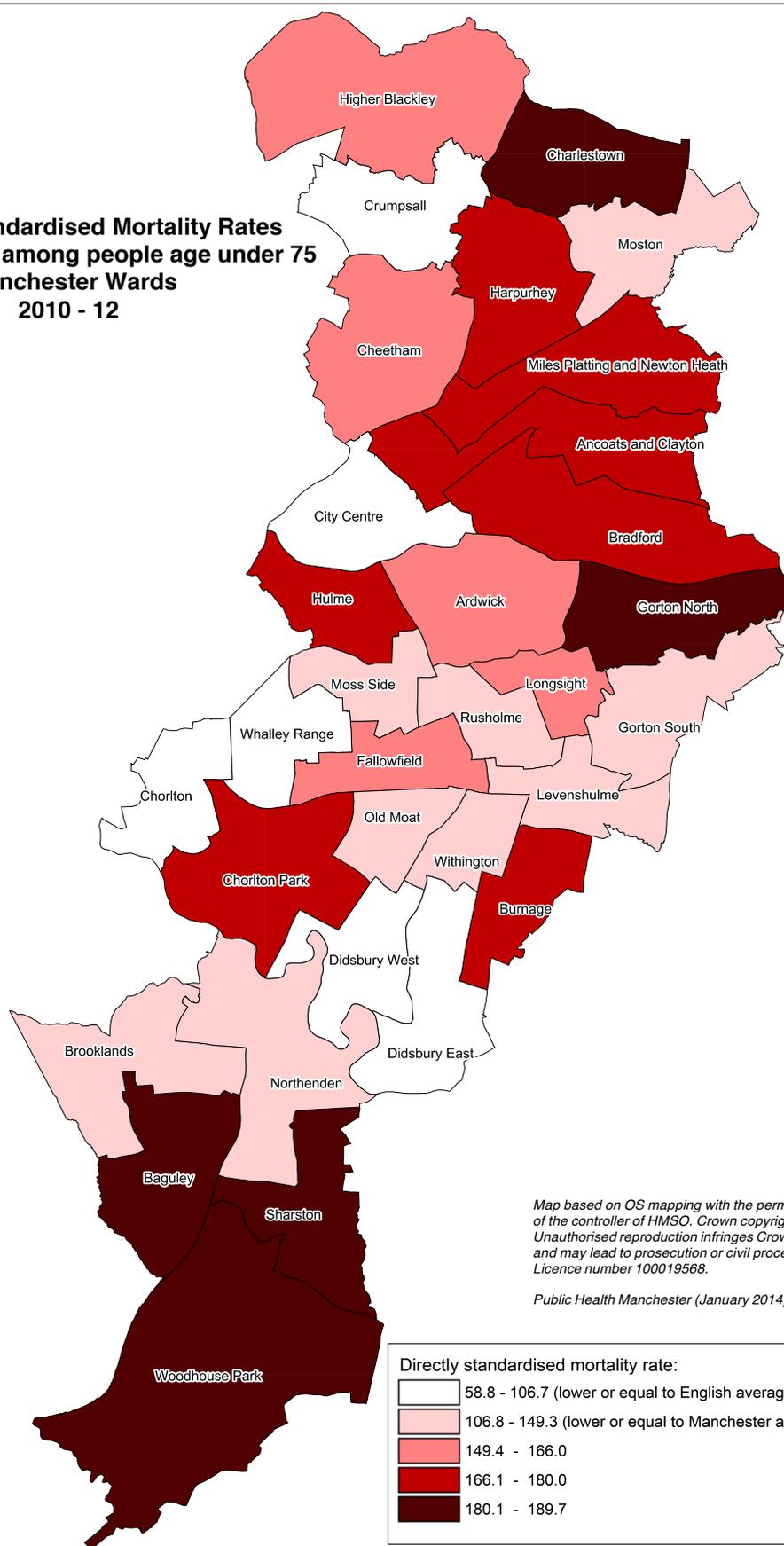
Suggestions for use:

- It is subjective so it is your experiences – there are no right or wrong answers
- Complete quickly, don't dwell for too long – about 5 minutes maximum
- Complete electronically on a (monthly or sessional) basis

Name:.....**Date:**.....

What 3 things did I expect to happen this (month or session)?	
What 3 things did happen?	
What has been the most significant thing that happened?	
What have I learnt?	
How do I feel now?	

**Directly Standardised Mortality Rates
for All Cancers among people age under 75
Manchester Wards
2010 - 12**



Map based on OS mapping with the permission of the controller of HMSO. Crown copyright. Unauthorised reproduction infringes Crown Copyright and may lead to prosecution or civil proceedings. Licence number 100019568.

Public Health Manchester (January 2014)

Appendix 7: Survey data from awareness raising events

Q1 - Do you understand the benefits of taking early action if you're worried about a sign or symptom of cancer?

79% - Strongly Agreed, 19.8% Agreed

Q2 - Do you understand more about the symptoms of cancer now?

218 people (66.5%) Strongly Agreed; 102 people (31.1%) Agreed

Q3 After today, are you less worried about cancer?

104 people (31.7%) Strongly Agreed; 127 (38.7%) Agreed

Q4 After today, are you more likely to go to your doctor if you notice any changes in your body?

217 people (66.2%) Strongly Agreed; 98 (29.9%) Agreed

Q5 Are you likely to share what you have learned today with your family and friends

241 people (73.5%) Strongly Agreed; 79 (24.1%) Agreed

Q6 Do you think you would use the Macmillan Library service if you were affected by cancer?

204 (62.2%) Strongly Agreed; 106 (32.3) Agreed

Below are some of the comments taken from the forms

- *Would go for a smear after today's session.*
- *Know how to check for breast cancer and I will make my family more aware.*
- *I find the visuals really helpful and feel more confident about checking now.*
- *The importance of spotting symptoms early.*
- *Feel much better informed about signs and symptoms and more hopeful about survival rate.*
- *Being more aware and look out for any changes in the body. Not to be afraid to ask questions or go to the GP.*
- *I would feel less embarrassed going to my GP. I also gained a lot of important information and facts today.*

- *I will go to the doctor as soon as I see any signs without hesitation. Really interesting, useful and informative session.*
- *That I need to go to other services apart from my GP - as he does not listen to me. I feel that I have a lump on my left breast but GP won't take any notice.*
- *Am more aware of the symptoms of cancer. More information on how I need to look after myself, ie. Checking my body on a regular basis.*
- *It has made me more aware of the different kinds of cancer and not to be afraid of going to doctors for myself or with someone who wants to go.*
- *More aware of the importance of regularly checking myself and what to look for not just the pea size lump*
- *I will be revisiting my GP re some concerns that I have*
- *Knowing that the area for the breast is larger than I thought (i.e. under the arm and your upper chest)*
- *Understand more easily in Urdu*
- *Feel able to ask questions in own language*
- *Understanding that prompt action is necessary if you feel things are not just right, in any part of your body.*
- *Have learnt more than I thought I knew and would not hesitate about going for a check if I was worried.*
- *It will make me get the things that have been on my mind checked.*
- *I understand how better to support our service users in understanding cancer and undertaking screening. I also know where to get further advice and info.*
- *Being more aware of changes to clients' bodies as well as my own. Very good session. (She) put it across in layman terms and no jargon!*
- *Less afraid of talking about cancer now and going to GP.*