Macmillan Cancer Support and Glasgow Life

# Macmillan @ Glasgow Libraries Phase 2 Evaluation Final evaluation







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## **Executive Summary**

#### Introduction and methodology

Rocket Science, in partnership with Consilium Research and Consultancy, was commissioned in early 2016 to evaluate Phase 2 of Macmillan @ Glasgow Libraries. Macmillan @ Glasgow Libraries is a tiered model of Macmillan Cancer Information and Support Services, which aims to provide cancer-related support and information for people in their local communities through libraries and other community venues.

The final evaluation had a specific focus on exploring the barriers and catalysts to organisations and individuals either referring or signposting people affected by cancer to the service. This analysis was informed by telephone and face-to-face interviews with both clinical and non-clinical staff and organisations' representatives and supplemented with discussions with people affected by cancer who, for different reasons, have not accessed the service.

To inform this final evaluation we have:

- Analysed project data collected including referral numbers, data collected by volunteers, and use of library space
- Conducted a survey and follow up interviews with library staff, volunteers and key stakeholders
- Conducted interviews with partners who signpost and refer into the service to varying degrees
- Conducted a staff focus group with project staff
- Conducted interviews with service users and non-service users.

#### Service analysis

There were 7,021 visits recorded between the 1<sup>st</sup> of October 2015 and the 31<sup>st</sup> of May 2018 with an overall upward trend peaking at 342 visits in August 2017. 47% of drop in attendances are first time users. The number of formal referrals made to Macmillan @ Glasgow Libraries has decreased between 2014 and 2018 following the introduction of the Improving the Cancer Journey service which introduced a new service offer, which is universally offered to all new patients at point of diagnosis and in effect acts as a single conduit for referrals.

Most visitors heard about the service by passing by the service (including the outreach services) or while visiting the library. Other common ways that visitors heard about the service was from other Macmillan services or from health professionals or hospitals. The top two reasons why people first attend the service are to talk to someone and to find

out what services are available. However, where people tend to return to the service this is to gain further emotional support through talking with a volunteer.

The number of referrals to other services made by Macmillan @ Glasgow Libraries has increased from 245 in 2014 to 482 in 2018. Since 2015, the proportion of referrals made to Cancer Support Scotland and Improving the Cancer Journey service have increased, while the proportion made to the Macmillan Long Term Conditions service have fallen due to the introduction of Improving the Cancer Journey

#### The view from within

#### Service user views

The support needs of service users reflect the personal nature of each individual's cancer journey and the need for a service to act as a broker to the range of support at a time when they need it most. Some required very specific information whereas others were looking for reassurance or someone to talk to. Around two-thirds had planned their visit with the remainder just approaching the volunteers when in the library for another purpose.

None of the service users had any anxieties or reservations with speaking to a volunteer as opposed to a doctor or other health professional, recognising the boundaries of their role. Specific or more complex issues were delivered through referrals to appropriate specialists.

The value of the emotional support and information from volunteers, and access to counselling and complementary therapies, was widely acknowledged, with a quick chat with a volunteer useful in stopping a small concern turning into a major worry. Knowing that help is available at set times in a trusted, local environment was appreciated with service users highlighting the benefits of the service in improving how they feel about, cope with, and manage their condition.

The majority struggled to see how they would have coped to the same degree without the service, with many outlining its role in increasing their wellbeing, reducing isolation and reducing their worries.

#### Macmillan @ Glasgow Libraries Volunteer Views

Almost all volunteers who responded to the survey reported that they enjoyed their experience and expressed a high level of pride in being part of the service. Almost all intended to continue to volunteer.

Volunteers reported a wide variety of benefits they have gained from their volunteering with the most common being personal satisfaction, making new friends, gaining confidence and skills and having an opportunity to give back to their community - including giving back following their own personal experience with cancer.

Volunteers feel confident in their relationships with Lead Volunteers and the library staff and were very positive about the quality and importance of the service. Almost all respondents felt that the service either met the needs of service users well or very well. Any improvements sought were mainly around further promotion of the service to continue to increase service user numbers.

#### Library staff views

It was common for library staff to have had some involvement with Macmillan @ Glasgow Libraries, with high levels of knowledge of what the service offers. Nearly 90% of respondents fully understood the Macmillan @ Glasgow Libraries offer.

Those staff aware of the service feel that the service is an important part of the libraries offer, fits well within Glasgow Life and has had a positive impact on the libraries with the spaces well used by other library users.

Respondents were however slightly less confident in the more recently introduced Lead Volunteer Role and how best to manage volunteers, despite most feeling well supported during the transfer of responsibility to library staff.

#### From the outside looking in

#### Referrers and non-referrers

Discussions with staff supporting people affected by cancer at the Beatson West of Scotland Cancer Centre revealed little knowledge of the service despite significant efforts by the Macmillan @ Glasgow Libraries team to raise awareness. Staff based at the Beatson tend to signpost people to one or more of the charities based in and around the Beatson with a disconnect apparent between services in acute and community settings.

The libraries service is seen by many staff as a service only for people at the end of their treatment although there is little evidence of signposting from the initial support providers to this (perceived) follow-up provision.

The overriding reason for clinical staff not to signpost or refer people to Macmillan @ Glasgow Libraries was simply a lack of knowledge of, or about, the service. A range of cancer charities revealed tendencies to 'hold on' to clients rather than actively signposting or referring them to wider, more local or different services. This was linked to a perceived specialism and overlap of services amongst charities dealing with specific aspects of site-specific cancers, a belief that the needs of people affected by cancer are already met by their own services, and in one case a distrust of the quality or ability to respond of a volunteer-led service with limited opening hours.

The above issues are exacerbated by the large number of often over-lapping services available to people affected by cancer in Glasgow, which feeds a degree of unease as to whether pilot services are still active, operating in the same place at the same times and of a desired quality to meet specific needs.

Catalysts to greater, and more effective, referring and signposting

Stakeholders consistently stated that there should not be any barriers to signposting to, or indeed from, Macmillan @ Glasgow Libraries, although they reiterated that communication, and signposting activity, needs to be two-way in order to build healthy and collaborative partner relationships.

The introduction of additional volunteering capacity to support the delivery of the Macmillan Information and Support Centre based at the Beatson is expected to increase the capacity of the Centre to meet the needs of more patients and their family members or carers, as well as increase signposting to local services such as the Macmillan @ Glasgow Libraries, and similar services available in other local authorities.

#### Non-users - key themes

Discussions with people affected by cancer (and staff) consulted at the Beatson who have not used Macmillan @ Glasgow Libraries highlighted both the scale of the services offered at the Beatson and the geographical area served by the hospital which includes many people who live outside of Glasgow.

Most people relied on consultants and/or the Clinical Nurse Specialist to provide information and signposting to other services, and most seemed to be happy with that arrangement during treatment.

People affected by cancer who are receiving treatment at the Beatson will almost certainly only be signposted to information and support services based in and around the Beatson. There are no indications of follow-on referrals or signposting to Macmillan @ Glasgow Libraries or other similar services across the local authority areas served by the Beatson despite consultation revealing a demand for the service and few barriers to take-up.

#### Key conclusions and recommendations

- Overall, the service is considered to be important and of high quality and is an important part of provision for services, particularly for friends, families and carers who often don't know how to access support for themselves
- Feedback from service users was overwhelmingly positive
- The sustainability pilot and subsequent integration of the service into library management has been a success
- There is scope and a need to increase service numbers
- There is a risk of reputational damage to the Macmillan branding from a lack of coordination and absence of a coherent and understandable service offer for those affected by cancer
- Greater support from the national Macmillan marketing campaign is still required

- The service's integration into the library has been very positive, but more still needs to be done to ensure that the service is a core part of the wider Glasgow Life picture
- Further referrals from the Macmillan Information and Support Centre based at the Beatson West of Scotland Cancer Centre is key to increasing the number of service users in the library services
- More needs to be done to encourage people to see libraries as hubs for health and wellbeing
- Continual promotional activity is essential
- There is an opportunity to review and potentially reduce the number of drop-in services without compromising the quality of the service

# 1 Introduction and context

Rocket Science, in partnership with Consilium Research and Consultancy, was commissioned in early 2016 to evaluate Phase 2 of Macmillan @ Glasgow Libraries. Macmillan @ Glasgow Libraries is a tiered model of Macmillan Cancer Information and Support Services, which aims to provide cancer-related support and information for people in their local communities through libraries and other community venues. This report is the final evaluation report.

### 1.1 Our methodology

In September 2016, we submitted our baseline report which outlined the focus and framework for the evaluation. Figure 1 below outlines the desired impacts of Phase 2 of Macmillan @ Glasgow Libraries and the corresponding areas for us to evaluate the service against.

Programme Impacts	Evaluation Areas
1. People that are, may be, and work with those, affected by cancer in Glasgow know where to obtain trusted information and support	A. Effective communication and marketing strategy
2. People that accessed the service have improved their quality of life	<ul> <li>B. Library staff and volunteers are considered knowledgeable about cancer support available, supportive, welcoming and respectful</li> <li>C. Support is received in a timely and flexible manner that reflects need</li> <li>D. Service users report that they are well informed, supported</li> </ul>
	and confident about managing their day-to-day lives
3. Glasgow Life and its partner organisations are providing a sustainable, comprehensive, integrated cancer information and support service	<ul><li>E. Service is sustainably integrated into Glasgow Life core business</li><li>F. Service is part of an integrated cancer support network in Glasgow</li></ul>
4. Present and past volunteers report rewarding experience including achieving personal aims	G. Volunteers feel supported and enjoy their experience H. Volunteers have enhanced skills
5. The public perception of libraries includes considering them as reliable sources of health information	I. Libraries have undergone long-term sustainable change in relation to the programme

	J. Increased footfall and service opportunities for libraries
6. Present and past staff report rewarding experience including achieving personal aims	K. Staff have achieved personal and professional development goals
7. Opportunity to improve information and support services on long term conditions across the UK using programme learning	L. Evidence that the service is replicable, including critical enablers and barriers

Figure 1 The Focus for Phase 2 Evaluation of Macmillan @ Glasgow Libraries

To measure this, we set out to:

- Analyse the demographic of volunteers
- Conduct an annual volunteer survey
- Conduct an annual volunteer focus group
- Analyse data collected by volunteers from service users
- Conduct an annual staff survey of library and other Glasgow Life staff
- Conduct an annual staff focus group with project staff
- Conduct interviews with library staff to explore survey findings in more detail
- Analyse referral and service user data collected by the service
- Conduct interviews with service users
- Gather information from other services working with people affected by cancer
- Conduct regular observations of the use of library space using library staff and volunteers to help
- Conduct an annual stakeholder survey
- Conduct interviews with stakeholders and partners to understand survey results in more detail
- Analyse service costs, information on materials turnover, analyse the social media reports and advertising log, library space booking forms and library footfall data.

It was subsequently decided following discussions with the Macmillan service team not to conduct observations of the use of library space or analyse the turnover of written material. Both would have required significant investment of time by either the project or evaluation team. Given both elements were reasonably understood by the programme team, it was decided that the insight it would provide didn't justify the time spent.

We had set up the Move More phoneline to collect data on those who did not use the service. Due to staff turnover within the Move More team, this only lasted a short period of time and isn't included in this report. We also intended to gather outcome information from Improving the Cancer Journey (ICJ) Glasgow about those who were referred or signposted to Macmillan @ Glasgow Libraries. However, while we were able to identify that those who attended the service generally had a positive experience, we were unable to robustly identify the individuals in the data who had been referred to the service but hadn't attended so were unable to draw any meaningful conclusions about why people weren't using the service from this data.

The final evaluation had a specific focus on exploring the barriers and catalysts to organisations and individuals either referring or signposting people affected by cancer to the service. This analysis was informed by telephone and face-to-face interviews with both clinical and non-clinical staff and organisations' representatives and supplemented with discussions with people affected by cancer who, for different reasons, have not accessed the service.

To inform this final evaluation we have:

- Analysed project data collected including referral numbers, data collected by volunteers, and use of library space.
- Conducted a survey and follow up interviews with library staff
- Conducted a survey and follow up focus group with volunteers
- Conducted a survey and follow up interviews with stakeholders
- Conducted interviews with partners who signpost and refer into the service to varying degrees
- Conducted a staff focus group with project staff
- Conducted interviews with service users and non-service users.

## 2 The service

#### 2.1 Service description

Macmillan @ Glasgow Libraries has 33 Cancer Information and Support Service points across the city including 16 volunteer-led drop in services and 17 information points. Over and above this, the service operates a range of outreach sessions. These are pop up services in other community venues, such as hospitals and health centres and community centres. The service has also worked alongside Community Health Centres, sport centres and hospitals to introduce 25 Macmillan Information Displays to enable the public to access information on the Macmillan-funded services across Glasgow.

Phase 1, launched in June 2012, saw volunteer-led services being introduced through a 'hub and spoke' approach, with main 'hubs' delivering a range of services and 'spokes' delivering drop-in services. Phase 2 began in October 2015 and focused on further developing the integrated hub and spoke model to become fully mainstreamed into Glasgow Life structures, including several aspects of the operational management of the service.

#### 2.2 Service numbers

Phase 2 of Macmillan @ Glasgow Libraries delivery started on the 1<sup>st</sup> of October 2015. This section of the report provides a brief breakdown of the service in the 139 weeks between the 1<sup>st</sup> of October 2015 and the 31<sup>st</sup> of May 2018.

There were 7,021 visits recorded between the 1<sup>st</sup> of October 2015 and the 31<sup>st</sup> of May 2018 with an overall upward trend peaking at 342 visits in August 2017.



Figure 2 All visits (October 2015 - May 2018)

The number of referrals made to Macmillan @ Glasgow Libraries has decreased between 2014 and 2018. Since 2015, almost all inbound referrals have been made by Macmillan's Improving the Cancer Journey service. Prior to this, referrals were mostly made by Macmillan Long Term Conditions service. This pattern is as expected given that the Improving the Cancer Journey service now acts as a single conduit for referrals, replacing the Long-Term Conditions service's need to refer directly.



# Number of referrals made to Macmillan @ Glasgow Libraries by other

#### Figure 3 All inbound referrals (January 2014 – May 2018). 2018 data scaled up to a 12-month period

The number of referrals made to other services by Macmillan @ Glasgow Libraries has increased from 245 in 2014 to 482 in 2018. The number of referrals made by the service in any given month is loosely related to the number of visitors in that same month. There is a weak positive correlation between visits and referrals (r=0.38 for all visits and r=0.25 for first visits). This means that while referral numbers do sometimes increase in the months with increased visitor numbers, this relationship isn't strong enough to be a robust conclusion to make. Other contributing factors to the pattern of referrals is likely to include:

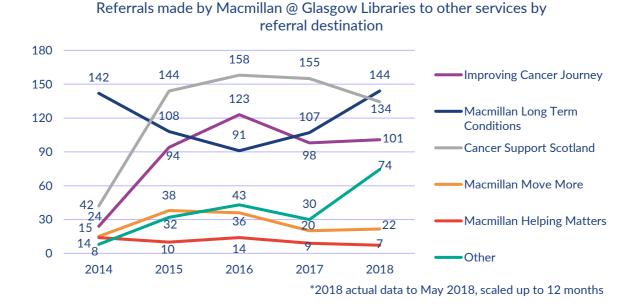
- The experience of volunteers and their confidence in making referrals which varies between volunteers
- The periodic communication between the Macmillan service team with volunteers about referrals which is likely to lead to a subsequent increase in the number of referrals made
- The presence of the Macmillan service team at the library during the drop-in time leading to higher referrals than when the service is staffed by volunteers only
- Variations between service points where some locations, such as the Gallery of Modern Art (GoMA) see more people outside Glasgow so service referrals are less relevant.





In 2018, the Macmillan Long Term Conditions service was the most frequently referred to service, followed closely by Cancer Support Scotland. Referrals to 'other' services (destination not specified in the data) have increased in 2018 indicating that the breadth of services Macmillan @ Glasgow Libraries is referring to is widening.

Most of these 'other' referrals are for Macmillan services in other local authority areas, particularly benefits advice services, carers services, or to other Macmillan services more generally. Across the years of the service there have also been a number of referrals made to various other charities or support groups.

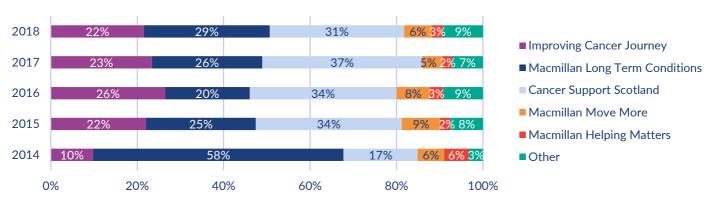


#### Figure 5 All outgoing referrals (January 2014 - May 2018). 2018 data scaled up to a 12-month period

In 2014, almost 60% of referrals were made to Macmillan Long Term Conditions. Since 2015, the proportion of referrals made to Cancer Support Scotland and Improving the

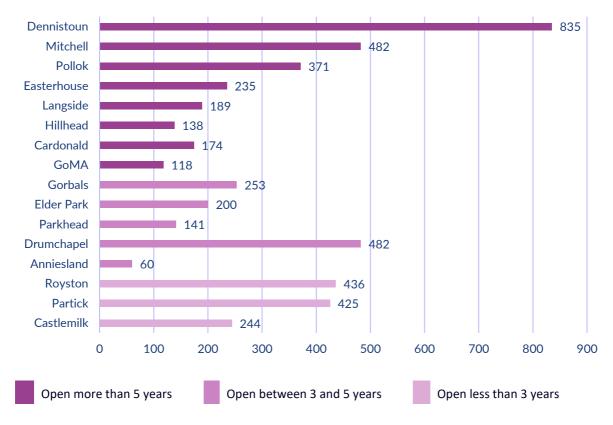
Figure 4 All outgoing referrals (January 2014 - May 2018). 2018 data scaled up to a 12-month period

Cancer Journey service have increased, while the proportion made to the Macmillan Long Term Conditions service have fallen due to the introduction of Improving the Cancer Journey and their <u>Holistic Needs Assessment</u> (HNA), resulting in one singular referral instead of two.



Proportion of referrals made by Macmillan @ Glasgow Libraries to other services by referral destination

*Figure 6 All outgoing referrals (January 2014 - May 2018). 2018 data scaled up to a 12-month period* 

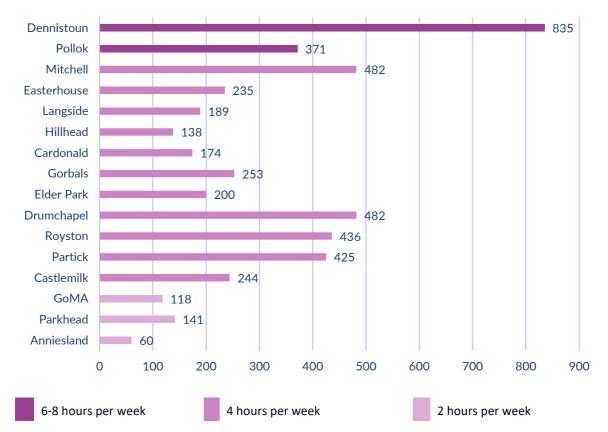


Total Visits by Library - ordered by age of service

Figure 7 Visits to library-based drop in services only (October 2015 - May 2018)

22% of visits were recorded during outreach events, and 12% of visits recorded were contact with the office. The most frequently visited libraries were Dennistoun, the Mitchell, Drumchapel, Royston and Partick. Figure 7 below outlines the number of visits ordered by how long the service has been running.

Despite being newer services, Drumchapel, Royston and Partick experienced some of the highest visitor numbers. As shown in Figure 8 below, these libraries offer 4 hours a week of drop in services but attracts more visitors than Pollok which has longer service hours.



#### Total Visits by Library - ordered by hours of service delivery

#### Figure 8 Visits to library-based drop in services only (October 2015 - May 2018)

The Mitchell, Elder Park and Parkhead libraries host counselling services in partnership with Cancer Support Scotland. Drumchapel, Partick, Castlemilk, Dennistoun and Royston all host counselling and complementary therapies in partnership with Cancer Support Scotland. Generally, libraries that are also hosting one or more services from Cancer Support Scotland have higher visitor numbers, with the obvious exception of Pollok which has high visitor numbers without any hosted services. Castlemilk has relatively lower visitor numbers compared to other libraries despite hosting both complementary therapies and counselling. However, Castlemilk only started hosting complementary therapies and counselling in late 2016 with service numbers doubling in the period between October 2016 and September 2017 compared to the previous year following the introduction of the complementary therapies.

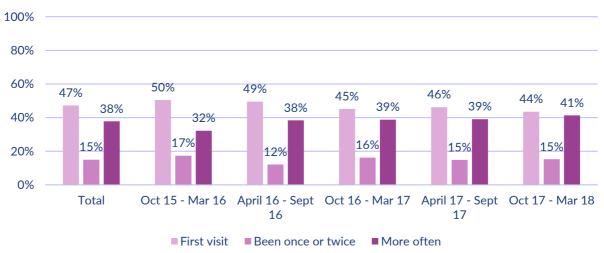


#### Total Visits by Library - ordered by hosted services

#### Figure 9 Visits to library-based drop in services only (October 2015 - May 2018)

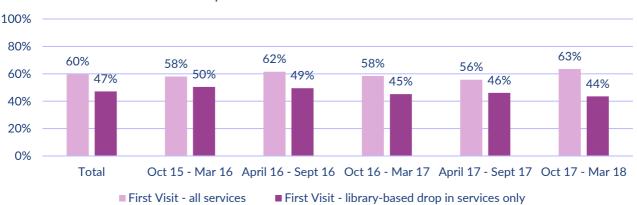
47% of all visits to library-based services were first visits. 15% of visits were the person's second or third time accessing the service, and 38% visits were by service users who had been more often than this.

When looking at all services including office and outreach events, the proportion that are first visits increases to 60%. Most engagements that someone has with an outreach event or who contact the office will be a first visit. It is also likely that when these service users then attend a library that this will also be recorded as a first visit. Another trend to note is that those who visit more than once, tend to return more than twice to the service.



#### Visits by frequency (library-based drop in services only)

Figure 10 Visits to library-based drop in services only (October 2015 - May 2018)



#### Proportion of visits that were first visits

#### Figure 11 Visits to drop in services (October 2015 - May 2018)

65% of visits were by females, this proportion has remained relatively consistent since October 2015. 44% of visits were by people over 65 years old. 2% were by people under 24. This pattern didn't vary across the period but correlates broadly with reported propensity to discuss health issues or seek help when unwell.<sup>1</sup>

<sup>1</sup> https://www.menshealthforum.org.uk/key-data-understanding-health-and-access-services

Of those that answered this question, 52% of visits were by someone with cancer. 33% of visits were by the friends and family of someone with cancer. 5% of visits were by someone who identified as caring for someone with cancer. 3% of visits were people worried by cancer. This pattern was consistent across the period. This demonstrates the demand for information and support services for not only the individual with cancer, but their support network. We also expect that the 5% of carers is an under representation of the number of visitors who have caring responsibilities as many may not identify themselves as carers despite undertaking caring responsibility for their family member or friend.

This is confirmed in figures from the Carers Trust<sup>2</sup> which emphasise the scale of caring responsibilities in the UK reveal that nearly one in eight workers is a carer. Moreover, Scottish Government research<sup>3</sup> estimated there to be 759,000 carers aged 16+ in Scotland - 17% of the adult population.

The research found that often people providing care do not identify themselves as a carer as it is for a family member or because the care related to emotional support or checking on a friend, with women in particular more likely to see their caring as an extension of their role as opposed to something additional.

Most visitors heard about the service by passing by the service (including the outreach services) or while visiting the library. Other common ways that visitors heard about the service was from other Macmillan services or from health professionals or hospitals. Figure 12 below only includes the most common ways people found out about the service - we have excluded sources that less than 1% of first-time visitors reported.

Removing outreach events from the data reduces the proportion of people who find out about the service by passing by. This is to be expected as most people attending an outreach session recorded that they found out by passing.

When analysing how the pattern changed between October-March 2015/16 and 2017/March 2018 the only material changes are:

- The proportion of people finding out about the services from the libraries and by passing by has decreased from 23% to 16% and 24% to 19% respectively as more people are finding out about the service from other means rather than the service seeing a decrease in the absolute numbers passing by
- The proportion of people finding out about the service either online or from word of mouth have both increased by 6 percentage points from 1% to 7% and 12% to 18% respectively.

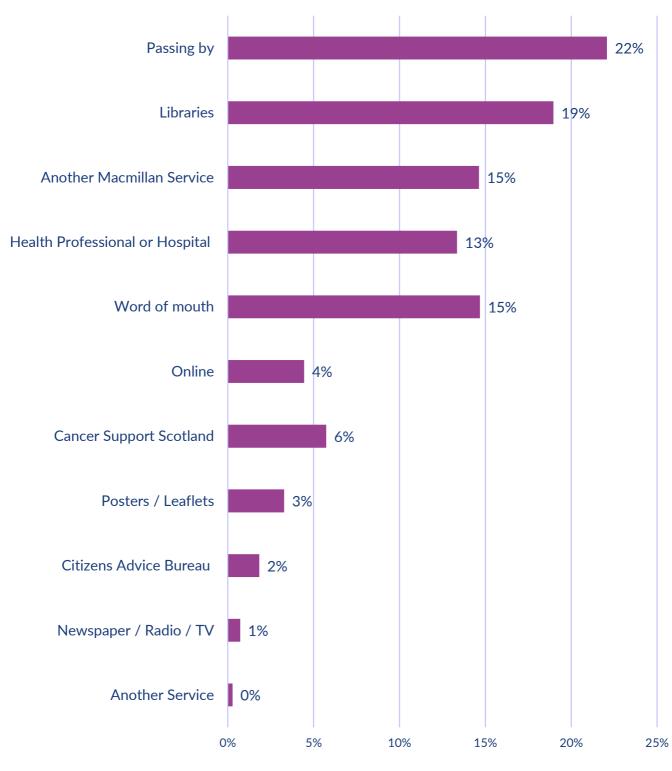
<sup>2</sup> https://carers.org/key-facts-about-carers-and-people-they-care

<sup>3</sup> https://www.gov.scot/Publications/2015/03/1081/2

#### 39% Passing by 19% 22% 10% Libraries 19% 14% Another Macmillan Service 19% 15% 11% Health Professional or Hospital 13% 13% 11% Word of mouth .3% 15% 9% 9% Online 4% 2% 5% **Cancer Support Scotland** 6% 3% Posters / Leaflets 3% 3% **Citizens Advice Bureau** 0% 1% 1% Newspaper / Radio / TV 1% 1% 0% Another Service 10% 30% 40% 0% 20% First visits in all locations First visits all visits excluding outreach First visits all library based visits

#### How did you hear about the service?

Figure 12 First visits only (October 2015 - May 2018)



How did you hear about the service? Library based visits only

#### Figure 13 First visits and Visits to library-based drop in services only (October 2015 - May 2018)

Someone to talk to and finding out what services are available are the top two reasons why people first attend the service. However, people tend to return to the service for

someone to talk to, with most not needing further information on what services are available.

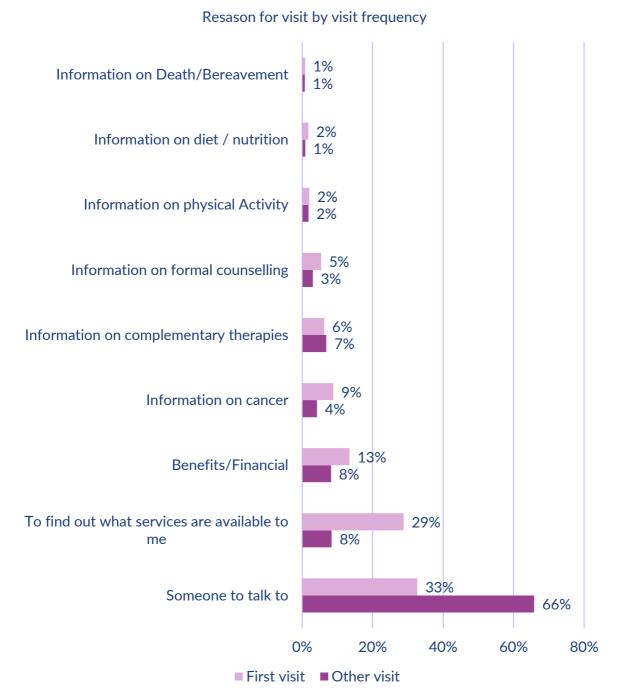
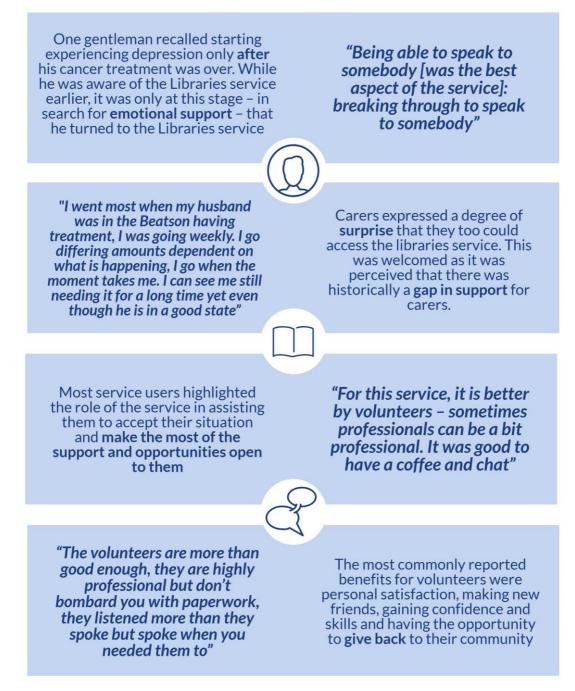


Figure 14 All Visits (October 2015 - May 2018)

# 3 The view from within

The following infographic summarises the impact of Macmillan @ Glasgow Libraries.

# Macmillan @ Glasgow Libraries



Findings from the Rocket Science and Consilium Evaluation

#### 3.1 Service user views

The evaluation team conducted a series of telephone interviews with service users throughout the course of the evaluation. These individuals were recruited by volunteers and Macmillan @ Glasgow Libraries staff to provide a broad range of service users and carers to participate in interviews and provide feedback on each aspect of the service.

This chapter outlines the key messages provided by service users through these interviews to provide feedback on the relative merits and impact of key aspects of the service including:

- Service marketing
- Reason for accessing the service
- Support accessed
- Strengths and weaknesses of the service
- Impact of the service
- Promoting the service service user testimonies

#### 3.1.1 Service marketing

Discussions with service users revealed the breadth of ways through which people are informed about Macmillan @ Glasgow Libraries. There is a broad balance between those signposted or referred to the service by a health and social care practitioner and those finding out through direct contact with their local library venue, (e.g. as a result of seeing the service on previous visits to the library, picking up a leaflet or simply coming across the service by chance).

Examples include:

- Walking past the library and seeing the Macmillan branding
- Seeing a poster for the service at Stobhill Hospital
- Seeing information in the library whilst accessing a craft group
- A leaflet found in a GP surgery in Easterhouse
- The national Macmillan helpline
- A Macmillan information stand at a public seminar
- Via 'Care in the Community' after being diagnosed with lung cancer
- The GP providing a phone number to ring.

"The library has been a lifeline - a life saver. I just saw the Macmillan sign, someone must have been on my shoulder."

"Advertisement in a leaflet - I thought, 'Oh I can get to Parkhead'. I had heard about Macmillan nurses before but not this service."

Most service users were more aware of the how the service was promoted in and around the libraries than they were of the marketing and outreach work undertaken by the Macmillan @ Glasgow Libraries team in hospitals etc. Service users were more sceptical of how well the service is known amongst health professionals, with one service user explaining how her GP had not heard about the service but is now very supportive after she told him all about the offer and how it had helped her. Others felt that partners found it easier to signpost to longstanding Macmillan services offering financial support rather than a relatively new service offering support and information through the libraries.

"The GP is only around the corner from the library but there's no leaflet in there."

"Not really seen it advertised anywhere."

"I phoned Macmillan in absolute distress, it even took them quite a while to find it. I have been doing some asking about it and the reason why some people didn't find it easy to access was that they thought libraries must be about books, the sitting with people isn't known till you are part of it, a lot of it is by word of mouth."

Service users confirmed both the benefits of a firm referral from a trusted source (e.g., health practitioner), and the existence of some longstanding and outdated perceptions of Macmillan amongst older generations in particular.

"The first time they told me [about the service] the doctor gave me a Macmillan leaflet, but it would have been better to have told about them directly. When someone gives you five different leaflets you don't pay attention, you just throw them in the house and forget about them."

"I thought they just provided palliative care, that was the impression, only when someone is dying, and experimental work on cancer. I didn't realise they were so much at the front end, that was good to know."

"Don't think there's enough publicity. Macmillan nurses are great, and people know about that, but they don't know about the voluntary side of it, it could be enhanced."

Service users did suggest a range of options to market the service, many of which are already being used (e.g., social media), including outreach work in areas where carers tend to go including shopping centres. Others stressed that it was more difficult to reach an entire community with local newspapers either going online, going out of business or not as popular as was once the case.

"I used to read the local paper cover to cover but not so now."

"Think it best in bus shelters and shop windows. Also, the Metro newspaper on the bus."

Crucially however, consultation with service users did confirm the widely held view that people will not absorb a lot of the marketing activities used to promote the libraries service prior to receiving a cancer diagnosis. It is only when a diagnosis is provided that the value of developing an almost subconscious knowledge of the service's existence comes to the fore, alongside the knowledge of those professionals closest to this moment in order to guide people to the best course of support for them.

#### 3.1.2 Reason for accessing the service

The kind of support service users initially wanted from the service reflects both the personal nature of each person's cancer journey and the need for a service to act as a broker to the range of support available at a time when they need it most.

"I called in and found two lovely people who just put tea in my hand and sat quietly with me."

#### "Wanted to talk to people about the experience. I met people who had been through breast cancer at the service, people from all walks of life."

Whilst some service users required very specific information (e.g. financial assistance for travel for treatment or filling information gaps not provided, or not taken in, at the point of diagnosis), others just needed someone to talk with more specific needs only emerging later.

"To get my questions answered, have my fears either confirmed or not."

"Knowing that help is there is great. The hospital didn't really tell me much – nothing."

# "I went to one of the local libraries and spoke to them: had a chat, a coffee. They were very helpful and nice. After that things started happening: within a week we had arranged for counselling."

For one carer, the service was highlighted as a potential option by his GP to help him cope with the stress of his wife being diagnosed with breast cancer. Whilst more than a little wary to even ask for help, or recognise that counselling or complementary therapies could help, he has since recovered to being something like his old self which he attributes to the service and Cancer Support Scotland services.

"We were looking to get someone to point us in the right direction for help. When you are in this situation you don't know what you are meant to do. Within a few hours we had spoken to the folk and had a wee coffee. We went shopping and came home to a message on the answer service saying someone was contacting us with financial help. There was also a message saying that we could go for a complementary massage the following day for the wife and I to relax."

Around two thirds of service users consulted had planned their visit to Macmillan @ Glasgow Libraries after being informed of its availability. The remainder had just decided

to approach the volunteers with a query when noticing them in the library or from signs or posters advertising the service.

"I'm not in any pain so can often 'forget' about it, I thought I'd just see what they could offer."

"My family were aware I wasn't myself, just not connecting properly."

One service user recalled starting to suffer from depression only after his cancer treatment was over and after having returned to work. While he was aware of the Libraries service earlier, it was only at this stage – in search for emotional support and professional counselling – that he turned to the Libraries service.

Service users also highlighted the value of knowing that help is available at set times in a trusted environment should they need to speak to someone. It was also useful to have someone different to speak to, someone other than family members or a health practitioner.

"It's been valuable on my whole cancer journey, the staff at the hospital were nice but don't always have the time, and the room's jam packed full of people."

#### 3.1.3 Support accessed

Service users consulted provided feedback on their experience of the service from a variety of libraries across Glasgow offering support in both an open plan environment and in bespoke facilities developed with the support of Macmillan funding. Amongst the libraries where service users consulted have used the service are Dennistoun, Partick, Drumchapel, Castlemilk, Pollok, Parkhead, Elder Park and Gorbals.

The frequency of accessing the service was determined by range of factors including the health and treatment plans of either the service user or the friend or family member they were caring for. Several highlighted that they were just too tired to do much when undergoing chemotherapy and radiotherapy, with treatment sessions in the morning in particular restricting their activity in the afternoons.

"I had to go back into hospital and only been 3-4 times since - I feel too nauseous and down now."

"I just nip in every now and again for a chat and to read the leaflets."

#### "I went most when my husband was in the Beatson having treatment, I was going weekly. I go differing amounts dependent on what is happening, I go when the moment takes me. I can see me still needing it for a long time yet even though he is in a good state."

Service users highlighted the value of the local location of the libraries service either to their home or the home of the person they are caring for, especially when compared to the more complicated, tiring and costly trips to hospitals for treatment or check-ups. This relative accessibility also influenced service users' frequency of use with the ability to drop-in a positive feature.

Service users initially accessed the service for reassurance, just someone to talk to or to find out more about the support available to them primarily following a cancer diagnosis. This first interaction tended to guide or inform subsequent visits for a range of support with service users learning of and often using the wider offer including counselling or complementary therapies provided by Cancer Support Scotland, underpinned by further emotional support by Macmillan @ Glasgow Libraries volunteers.

"I've been going every week for six weeks for Reiki and to speak to the volunteers."

"It's a means of reassurance for a friend - she has money issues and can't take time off work."

"Last time I had an Indian Head Massage and aromatherapy after being recommended by counsellor for relaxation therapy – great, brilliant!"

"I had been signed up to the Move More service but was ill and couldn't attend. When they didn't contact me again, I approached the volunteers and asked about exercise."

Several service users highlighted the value of the libraries service in being able to provide reassurance on even the smallest or seemingly trivial issues, especially those that most people affected by cancer would not want to trouble medical staff GP or consultant with. Those consulted stated that a quick chat with a volunteer, often timetabled around their treatment or check-ups, was useful in stopping a small concern turning into a major worry.

"I need reassurance and support in terms of what happens next. What are my options? I live on my own so there is no one else to ask."

"I was overwhelmed by information, I just wanted someone to give me information I could deal with/cope with. Accessing the libraries took me to Macmillan nurses online and therapy nurses. The helpline was really helpful - online and by phone, having a mixture of info is great. The libraries had talked about welfare, and they put me in touch with welfare officers, they told me the benefits I was entitled to."

The majority of service users stated that the emotional support provided by the Macmillan @ Glasgow Libraries volunteers was the best aspect of the service.

"They listen to you ... give out good vibes. They are not patronising and don't look down on you."

"Lots of people don't have family or friends around to talk to, they are on their own. The volunteers were the best element."

"Being able to speak to somebody [was the best aspect of the service]: breaking through to speak to somebody."

"I have two daughters in their 20s, I didn't want to worry them, I needed someone impartial to speak to. I would ask what they thought the best decision would be and I got the chance to weigh things up, I needed that reassurance." The availability of support for carers was highlighted, with those carers consulted expressing a degree of surprise that they too could access the libraries service. This was something that those with a history of caring for family members welcomed given what was perceived as a historical gap in support for people affected by cancer. This was seen as important given the strain of caring responsibilities and a tendency for carers to often neglect their own health whilst caring for others.

"The volunteers are very helpful and have a great understanding of what you are going through. They explained about the different things I could do"

"It's a chance to have a chat, I think I open up more there than at the hospital or GPs. I feel at ease with the counsellor as well."

"Never had anything better than the services in Partick. It takes me to another world."

"When I was diagnosed, I found that with family and friends I had to support them when what I really needed was a hug from them. I really broke down, I needed someone who I didn't need to be brave around. Now it's not going to beat me, that comes from meeting people in the library."

#### 3.1.4 Impact of the service – quality of life

Service users highlighted the benefits of the service in terms of making a difference to their life and/or achieving personal objectives including how they feel about, cope with and manage their condition. The range of outcomes that service users attributed to the libraries service included better management of finances, stress management and controlling pain without the use of medication.

For example, one service user who is both affected by cancer herself and caring for her brother uses the libraries service as a safety valve, dropping in as required for a chat and exploring different routes to coping with pain though Reiki and linked relaxation techniques.

"The Reiki was as good as pain killers. I was also given a relaxation CD to help me sleep – I'd rather use this than the strong painkillers I'd been using to get to sleep."

"The volunteers made it fabulous, they were so helpful. I just thought it was leaflets."

"Most of the time I would be in the house feeling sorry for myself watching TV. Macmillan gets you out."

"Didn't want to cry, when I called Macmillan the first time, but I did. Now I don't cry anymore."

#### 3.1.5 Impact of the service – signposting to further support

Service users offered a number of examples of accessing other kinds of cancer-related support and largely attributed access to the libraries service. Amongst those that had, one service user stressed how Macmillan @ Glasgow Libraries was relatively unique, being like the 'hub in a wheel' and signposting to other offers as appropriate. The strongest trends reported, other than the complementary therapies provided through Cancer Support Scotland, were in terms of being signposted to services that could help with practical support, equipment<sup>4</sup> and financial worries (for example, through the Macmillan benefits service).

"Macmillan gave me a grant which was really helpful, I was having financial issues."

"Macmillan seem to be more helpful than when you go to the doctor!"

The service's role in bringing in other support for service users was also highlighted with many linking the volunteers' support to their obtaining practical support in the home and money for travel to help with their journey.

"Yes, was through the library that I got put on to Improving the Cancer Journey, that's where I got all of the help, e.g. getting in and out of baths, got a handrail, got a stair lift, things like that are really fantastic."

"I felt much more at ease. I took up good advice around exercise, breathing exercises and writing things down. It has really benefited me with my family noticing it mainly. I can see light at the end of the tunnel now. If I hadn't spoken to the volunteers I would have gone back to the doctor by now."

#### 3.1.6 Impact of the service – emotional and practical support

Service users were mostly willing to outline how the service had supported them with their cancer journey from diagnosis. This included how not only having cancer affected them personally but also impacted upon their family and carers. Most highlighted the role of the service in assisting them in accepting their situation and making the most of the support and opportunities open to them.

"I wish I'd known about it earlier, because I took longer than I should have done to get help. I knew Macmillan had an office at the hospital, but I didn't know which services I could do, and which benefits I could get in many ways, particularly for financial problems."

"I went to Pollok every week for 45 minutes, I felt confidence come back - now I'm not scared when I'm alone that I will fall."

"Financially I didn't know which benefits I could get. I went to Castlemilk initially and met many ladies who went through similar problems, for example, one of them has been 8 years with

<sup>4</sup> For example, accessing services that could put in handrails and stairlifts

leukaemia, that showed me that I can live, before I didn't believe I could live longer. Renewed faith made me want to get medication, I started to believe it can help."

Consultation has also reaffirmed the value of the service at various stages of their cancer journey on a personalised basis. They have accessed the service at a wide range of points in their journey from the day of diagnosis to several months later after their initial treatment had ended.

"Was feeling a bit edgy, quite a lot of worries, quite a lot of cancer in my family, most of my sisters have had cancer or have it. I myself had lung cancer, it is in remission now."

"I am the carer, I went because of my husband's cancer, but then I was also diagnosed, and my world crashed around me. My husband was diagnosed as terminal but has survived, there have just been lots of shock moments, it has been so turbulent but at all points I could just go in to Macmillan and say, 'You will never guess what's happened now!'"

"Macmillan are great because they give you a stiff kick and they know what they are talking about, they don't just say, 'Oh poor you'."

#### 3.1.7 Impact of the service – added value of the service

Service users were also willing to discuss the difference the service had made by thinking about what they would have done in its absence. The majority struggled to see how they would have coped to the same degree, with many outlining the role the volunteers and therapies had played in terms of increasing their wellbeing, reducing isolation and reducing their worries next to their relative lack of knowledge of similar services.

"Belief, confidence. I started to think life can carry on, something I had lost for many years."

"I would have been stuck in my house, unable to leave, scared of everything and everyone, couldn't take it. You blame everyone around you, Macmillan change the idea you had when you get the news - you can deal with it, can't blame other people, now it is like weight has been lifted."

"I was in a completely dark place at the time. People were commenting on how my personality had changed. I was really unhappy about that. If not for Macmillan, that could have stayed. Now I feel better."

"If I hadn't got things off my chest it would've affected my recovery otherwise – I would've definitely had struggled more."

One service user was adamant that walking past her local library and finding the Macmillan service had been life changing for her in the immediate aftermath of being diagnosed with cancer.

"I don't think I'd be still be here without the library - I was aiming for the nearest bridge."

However, most service users highlighted the value of the libraries service when compared to the information, advice and guidance provided by health practitioners and particularly on informing them of living and managing with their diagnosis.

"The library feels private, hospital gave me no help or information and the doctor was useless"

"I've not used anything else – I don't know what's out there."

#### 3.1.8 Strengths and weaknesses of the service – a local library venue

Service users stressed the difficulties in travelling to the hospital in particular for treatment and support, with the time taken and the cost of transport the major issues. In contrast, the trusted familiar environment afforded by a local library was much easier to access on foot and lacked the negative associations of a hospital for example.

Most service users also appreciated the quiet nature of most libraries which provided a degree of privacy and discretion even when the Macmillan area is situated in the library itself (e.g., Langside) rather than a distinct room (e.g., Drumchapel). For this reason, whilst community venues with similar characteristics to libraries (e.g., churches or community centres) are seen as offering potential alternatives, suggestions of busier locations including supermarkets or shopping centres were only seen as viable for information points.

"You are not exposed to the whole library - people might not know you are there to see Macmillan"

"A room in a health centre might be ok. Not so happy with a supermarket."

*"Community venues are a better idea - not as off-putting as a hospital which can sometimes be a frightening place."* 

"It's excellent, can just pop in and out. Even if volunteers are not in you can access information."

"A community venue is more personal. Drumchapel has a room the rest of the library do not use."

Some service users were less happy about those community venues, including libraries, where the Macmillan drop in facility would be located in an open, public location, (e.g., in the middle of an open plan library).

"If it is out in the open then it's far too public, if it was a pharmacy where you could have a little space tucked away then that would be fine. Really important to get the right information at the right time, especially written info, books are like my bibles now, have had them at the right stages, showed me it wasn't fault."

"My only criticism I ever had was when trying to discuss a delicate subject, it was in a public place, there was somebody very close by." "The only problem was confidentiality, members of the public were using computers nearby that are in earshot, I am quite a private person."

#### 3.1.9 Strengths and weaknesses of the service – a volunteer-led service

No service users had any reservations with speaking to a volunteer as opposed to a doctor or other health professional. Volunteers are perceived by service users to provide a warm welcome. Service users develop a relationship with the volunteers based on the volunteer's experience, knowledge and professionalism backed up by the trust in the Macmillan brand.

"For this service, it is better by volunteers – sometimes professionals can be a bit professional. It was good to have a coffee and chat."

Service users are aware that the volunteers are there primarily to offer information and emotional support with specific or more complex issues (i.e. health and non-health) delivered through referrals to appropriate specialists.

"You wouldn't know they were volunteers."

"The first approach is crucial. They were very welcoming and set the right tone. They acknowledge people when they come in. They know them."

"A lot of problems can be solved by talking about them with a cup of tea."

"Initially I was a little unsure but that's me! Even the GP doesn't know exactly how you feel or what to expect as they haven't been through it – they are the one asking you how you feel!"

"I don't know why people may be reluctant to engage with the service."

"People know and trust Macmillan."

"I'm very comfortable with the volunteers, they put you at ease knowing its confidential" "I'm more at ease than at the doctors - Macmillan breeds trust."

"The volunteers are more than good enough, they are highly professional but don't bombard you with paperwork, they listened more than they spoke but spoke when you needed them to."

# 3.1.10 Strengths and weaknesses of the service – meeting service user needs

Most service users were happy with the service and stated that it had met all their needs either directly in terms of emotional support and use of therapies or by providing links to wider support including benefits advice. One service user did highlight the value of having more male volunteers, but the overwhelming message was for more people in similar situations to them to be aware of the service and be able to benefit from it through improved marketing and extended opening hours.

"People should know where to go. They need to speak to someone."

"[Partick is] manned by volunteers just once a week on Saturdays – more would be good."

"They need a spread of volunteers and it would be good if there were more men. Men like to pretend that they are very macho, and cancer is not a macho disease."

The one main area of criticism relates to the availability and access to complementary therapies with reports of cancelled or double-booked sessions which, while outside of the control of the Macmillan @ Glasgow Libraries' service as it is delivered by a partner organisation, can undermine the trust gained through the volunteers.

"I had two sessions with alternative therapies and both were cancelled at the last moment, that was sad. I mean good reasons were given but it was a shame. Once it was actually double booked. I just wanted head and shoulder massage, something to de-stress me, I wanted something just for me and unfortunately that was the part that didn't work. Through talking to people, I found that it hadn't worked for a lot of people either, cancellations seemed common".

"Getting reiki and reflexology has been great but I have used up all the amount I can get. Even if I could have it once a month that would really help me, seems to be a shame to let it go, would be back to zero if I didn't get them. I am with her for an hour and all the stress has been taken away, great for a good few days after but then can feel myself going back to zero."

#### 3.1.11 Promoting the service – service user testimonies

Service users were asked to describe Macmillan @ Glasgow Libraries to someone else. A selection of the verbatim quotations provided is found below:

"Amazing"

"Very relaxing, very informed – wisdom with the right amount of empathy"

"Very helpful people and a nice atmosphere"

"It keeps your head clear and lets you keep on top of things."

"Excellent service and people should make full use of it either for gaining information or just talking."

"As a point of first contact – it's an excellent, friendly, easily accessible and in my case very reactive service."

"People make you feel very relaxed, so you can open up. You can tell them anything – what's said in the library stays in the library. It was beneficial for me, I would recommend it. They are really, really, nice people. They are so experienced – they know their jobs. They have been through it as well."

"Good port of call for starting out on your cancer journey, getting info about the range of services."

"It is lonely when you have cancer and you have no one to talk to, going there stopped me feeling that. It has increased my confidence, Macmillan is absolutely amazing. It was only when I went, I found I wasn't on my own."

#### "Invaluable"

"Would just like to say my thanks, has been very positive. It sounds silly, but when you're in situations like this you become very insular, it's nice to talk to other folks. I met a lady in her 40s and she told me she had cancer at 4, that doctors told her that odds were she was not going to make it. But there she was. She had worse prognosis than me, and that takes away the edge, you can put things in perspective."

#### 3.2 Macmillan @ Glasgow Libraries volunteers

The views of the Macmillan @ Glasgow Libraries Volunteers were gathered through a mixed method approach. During the interim evaluation, we conducted an online survey completed by 39 of the 112 volunteers. We followed this up with a volunteer focus group attended by four volunteers. In the lead up to this final evaluation, we conducted another online survey to assess changes in perceptions and views.

#### Key messages from the interim evaluation

Volunteers were very proud to be a part of the service, taking great pleasure in their role and generally feeling confident in their abilities to support people. This is likely to be due to the training and day-to-day support received and their understanding of their role, which were all reported as being generally good. Volunteers also reported a range of benefits from volunteering, with the most common being personal satisfaction. Three quarters of volunteers said they would still be volunteering with Macmillan @ Glasgow Libraries in a year's time.

Other aspects of the service including library facilities, written and verbal information given, and complementary therapies were all considered to be good. Ease of access and promotion of Macmillan @ Glasgow Libraries Service were also highly rated.

In the volunteers' opinion, emotional support was considered the most important support that the service offered. Information and signposting and counselling were also considered important. More often than not, service users were just looking for a chat, practical advice and a "*cuppa*". It was generally felt by volunteers that the needs of those affected by cancer were met by Macmillan @ Glasgow Libraries Service.

Over half of volunteers felt happy with being managed by library staff in the future. However, some wanted clarifications/changes, and others were unhappy with the idea. This was attributed by several respondents to the good relationships' volunteers had with Macmillan @ Glasgow Libraries team and the fear of losing these.

#### Key messages from the final evaluation

Almost all volunteers who responded to the service enjoyed their experience and expressed a high level of pride in being part of the service. Almost all intended to continue to volunteer. The few that were uncertain about their future with the service cited largely personal circumstances rather than unhappiness with being part of the service.

Volunteers reported a wide variety of benefits they have gained from their volunteering. The most commonly reported were personal satisfaction, making new friends, gaining confidence and skills and having the opportunity to give back to their community including giving back following their own personal experience with cancer.

Generally, volunteers felt that they understood their role and were confident in their ability to support people affected by cancer, including knowing where to refer participants to.

Volunteers also felt confident in their relationships with Lead Volunteers and the library staff. As one volunteer said, "it now feels as though Macmillan volunteers and library staff are part of a team". Volunteers were also largely happy with the support and training they receive.

Overall, volunteers were very positive about the quality and importance of the service. Almost all respondents felt that the service either met the needs of service users well or very well. Improvements sought were mainly around further promotion of the service to continue to increase service user numbers. The top barriers to people affected by cancer accessing the service identified by volunteers was lack of knowledge of the service, not being referred or signposted to the service, and not understanding what the service was.

Most volunteers were happy with the number of hours they were volunteering, as well as the management of the volunteers. Many volunteers were keen to:

- Work more effectively with library staff
- Receive more specialised training
- See an increase in the number of volunteers.

About half of the respondents were keen to take on more responsibility and/or take on a wider and more varied role as a volunteer.

With the transfer of the service management now largely sitting with the libraries and library staff, we asked volunteers how happy they were with the way the service is currently managed. Almost all rated the service as 7 out of 10 or higher.

Volunteers were generally happy with the transition of some volunteer and operational management from the Macmillan @ Glasgow Libraries team to Library Staff. However, results were more mixed around the extent to which volunteers understood these changes - specifically in how it relates to their support and management. Many respondents commented that they felt up to date on, and understood, the changes to the service. They found library staff helpful, friendly and seemed to enjoy having the service in their libraries. However, a some of volunteers were less clear about the different roles and responsibilities following the changes, and a few noted that in some libraries the library supervisor's shifts don't match the volunteer hours of the service, so they don't get to see them very often which can limit the support they receive.

A detailed analysis of the volunteer survey from May 2018 is included in Appendix 1.

#### 3.3 Staff views

We sought views from two groups of staff:

- The Glasgow Life library staff including staff with direct, indirect or no interaction with Macmillan @ Glasgow Libraries
- The Macmillan @ Glasgow Libraries staff team who are employed by Glasgow Life but funded by Macmillan.

This section summarises the views of the Glasgow Life library staff. The Macmillan @ Glasgow Libraries staff team's views were sought through an online survey and discussed at several focus groups. This research focused on understanding the early findings of the evaluation and exploring opportunities and challenges to address our conclusions and recommendations. The views of Macmillan @ Glasgow Libraries staff are therefore woven throughout this evaluation and not summarised in this section of the report.

#### 3.3.1 Library staff

During the evaluation we engaged with library staff in advance of the interim evaluation through an online survey and follow up telephone interviews, and for the final evaluation through an online survey.

#### Key messages from the interim evaluation

Arising from our survey and interviews at the time of the interim evaluation, we found that it was common for library staff to have had some involvement with Macmillan @ Glasgow Libraries. Even when they hadn't, all library staff seemed to be aware of the service and what it did.

Staff felt it to be an important and well-situated service. Staff feel that Macmillan @ Glasgow Libraries has a positive impact on service users. The effect generally on the library was positive too, and that its benefits extended to other library-users.

#### Key messages from the final evaluation

78 library and other Glasgow Life staff completed an online survey in May 2018. 62 were library staff, and 13 identified themselves as other Glasgow Life staff. 72% of Library Staff who responded had experience of a Macmillan @ Glasgow Libraries volunteers drop in service in their library, and 53% had experience of a Macmillan @ Glasgow Libraries information point in their library. Of the respondents who identified as another Glasgow Life staff member, 46% had experience of a volunteer drop in service, and 69% had experience of a Macmillan information point.

12% of all respondents to this survey stated that they had 'lots' of involvement in Macmillan @ Glasgow Libraries, 52% had 'some' involvement, and the rest had no involvement.

The nearly 90% of respondents fully understood the Macmillan @ Glasgow Libraries offer despite 35% of respondents having no involvement in the service, and a further 52% only having some involvement with the service.

Respondents were asked a range of questions about the service. The choice 'not aware' was used a number of times across the questions, particularly in relation to the more detailed questions about the operation of the service.

Of those that did express a view other than 'not aware', most respondents felt that:

- The service was an important part of the libraries offer,
- The service fit well within Glasgow Life
- The service made sense to be in the libraries
- The service has had a positive impact on the libraries.
- The spaces were well used by other library users.

Respondents were slightly less confident in the lead volunteer role and how best to manage volunteers. In relation to the transfer of responsibility to library staff, around 60% felt that they had been well supported by the Macmillan @ Glasgow Libraries team, and around 55% felt they had been well supported by their line manager.

A detailed analysis of the library staff survey from May 2018 is included in appendix 2.

### 3.4 Summary of the view from within

### 3.4.1 Service user views

The support needs of service users reflect the personal nature of each person's cancer experience and the need for a service to act as a broker to the range of support at a time when they need it most. Some required very specific advice whereas others just needed reassurance or someone to talk to. Around two-thirds had planned their visit with the remainder just approaching the volunteers when in the library for another purpose.

None of the service users had any issues with speaking to a volunteer as opposed to a doctor or other health professional, recognising the boundaries of their role, with specific or more complex issues delivered through referrals to appropriate specialists.

The value of the emotional support and information from volunteers, and access to counselling and complementary therapies, was widely acknowledged, with a quick chat with a volunteer useful in stopping a small concern turning into a major worry. Knowing that help is available at set times in a trusted, local environment was appreciated with service users highlighting the benefits of the service in improving how they feel about, cope with and manage their condition.

The majority struggled to see how they would have coped to the same degree without the service, with many outlining its role in increasing their wellbeing, reducing isolation and reducing their worries.

### 3.4.2 Macmillan @ Glasgow Libraries volunteer views

Around 90% of volunteers who responded to the survey enjoyed their experience and expressed a high level of pride in being part of the service. Almost all intended to continue to volunteer.

Volunteers reported a wide variety of benefits they have gained from their volunteering with the most common being personal satisfaction, making new friends, gaining confidence and skills and having an opportunity to give back to their community - including giving back following their own personal journey with cancer.

Volunteers feel confident in their relationships with Lead Volunteers and the library staff and were very positive about the quality and importance of the service. Almost all respondents felt that the service either met the needs of service users well or very well.

Any improvements sought were mainly around further promotion of the service to continue to increase service user numbers.

### 3.4.3 Library Staff Views

It was common for library staff to have had some involvement with Macmillan @ Glasgow Libraries, with high levels of knowledge of what the service offers. Nearly 90% of respondents fully understood the Macmillan @ Glasgow Libraries offer.

Those staff aware of the service feel that the service is an important part of the libraries offer, fits well within Glasgow Life and has had a positive impact on the libraries with the spaces well used by other library users.

Respondents were however slightly less confident in the lead volunteer role and how best to manage volunteers despite most feeling well supported during the transfer of responsibility to library staff.

### 4 From the outside looking in

The evaluation team conducted a series of telephone and face-to-face interviews with both clinical and non-clinical staff and organisations' representatives who, to varying degrees, refer and signpost people affected by cancer into Macmillan @ Glasgow Libraries. These consultations have been supplemented with discussions with people affected by cancer, their carers and families who do not use the service.

This chapter outlines the key messages provided by both current and potential referral organisations and non-users of Macmillan @ Glasgow Libraries users through these interviews and linked data analysis.

### 4.1 Interviews with referrers and non-referrers

To understand why organisations and practitioners are or aren't referring or signposting to the service, we undertook a range of interviews with organisations and practitioners who:

- Currently referred or signposted to the service to understand why they make referrals and signposted their clients
- Didn't refer or signpost to the service but worked with clients for whom the service would be relevant to understand why they don't make referrals and signposted their clients

Interviews were undertaken with a variety of staff at different levels and varieties of role (i.e. management and patient-facing) to explore the degree to which referrals are made to (and from) Macmillan @ Glasgow Libraries, including a review of barriers and catalysts to increasing signposting and referrals between the service and a range of clinical and non-clinical organisations.

The consultations were tailored to three groups of actual or potential referrers to the service as follows:

- Stakeholders that refer people to Macmillan @ Glasgow Libraries
- Stakeholders that are likely to signpost people to Macmillan @ Glasgow Libraries but are not referring
- Stakeholders that are likely to know about Macmillan @ Glasgow Libraries but neither refer nor signpost people.

For a list of the organisations that were consulted regarding this, see Appendix 3.

### 4.1.1 Propensity to refer or signpost to Macmillan @ Glasgow Libraries

Consultations confirmed low levels of referrals to Macmillan @ Glasgow Libraries with most of those consulted not having a formal process in place. Across the 25 organisations consulted, less than one third (28%) had made referrals into the Macmillan@ Glasgow Libraries service.

Despite this, it is important to point out that those that do refer found the referral process itself efficient and easy to navigate.

Referrers said they would like to receive more information as to whether the person they had referred to the Libraries Service ended up engaging with the Service. While referrers recognised that there may be data protection issues that may restrict this information, it was felt that knowledge of the impact of accessing the Service amongst people they had referred would make them more likely to refer in the future.

"I found it difficult to find out whether the people actually connected to the service."

### "It would be good for our benefit - if we are a funded project - to find out if a tenant has actually engaged with the service without chasing the tenant up."

More generally, the majority of organisations and staff in both clinical and non-clinical roles acknowledged an awareness of Macmillan @ Glasgow Libraries and an ability and willingness to signpost into Macmillan @ Glasgow Libraries. Signposting, in this case, could involve handing out a flyer on the Service or simply telling a service user about the Service. However, most were unable to confirm the effectiveness of the process given both a lack of knowledge of the outcome (e.g. did the person actually attend the library for support) and the often, small scale of signposting. We identified that there is likely to be inconsistency in the way that referrals occur, with some professionals only referring or sign posting some patients and others not referring or signposting at all.

For example, discussions with 20 staff across a variety of roles (e.g. radiographers, GPs, radiotherapy assistants, day care staff, NHS staff nurse, volunteers for the Beatson Cancer Charity, welcome desk advisors, pharmacy staff) as part of a site visit to the Beatson West of Scotland Cancer Centre found that just 2 (10%) had heard of Macmillan @ Glasgow Libraries. Moreover, of the two staff members with knowledge of the service, one didn't think they knew enough about it to refer or signpost people towards it. The other regularly handed out flyers but did not formally refer people into the service.

Crucially in terms of work to improve the propensity to signpost through to Macmillan @ Glasgow Libraries, consultation with staff in the same or similar roles within the same department (e.g. radiography) had very different levels of knowledge and understanding of the service. As a result, the potential to signpost patients to the service differed considerably.

This reaffirms the need for continual and different forms of awareness raising and information dissemination (e.g. presentations, items in newsletters, one-to-one

discussions etc.) to effectively reach and gain buy-in from as many staff members as possible.

Consultation with staff based at the Beatson West of Scotland Cancer Centre emphasised the distinction made by many stakeholders (including clinicians) between information, advice and support services within an acute setting and those based in the community. This is reflected in the propensity of staff based in the hospital to refer or signpost people affected by cancer to other services based at the setting due to their proximity to their place of treatment rather than, or in addition to, their home address. In fact, the low level of awareness of the Libraries Service may be specific to the Beatson West of Scotland Cancer Centre due to the wide range of other cancer information, advice and support services present on the site.

This is reflected in the tendency of staff (40%) to typically signpost people to the <u>Maggie's Centre</u> or <u>Calman Cancer Support Centre</u> at Gartnavel General Hospital close to the Beatson West of Scotland Cancer Centre due to the perceived ease of access whilst undertaking treatment.

*"It can be easier to signpost people to Maggie's as opposed to the library as it is so close by."* 

In addition, numerous staff members confused the Libraries services with the Macmillan Information and Support Centre based in the same building. The latter is a common signposting route from members of the clinical team at the Beatson West of Scotland Cancer Centre and there is the expectation, at least for those that had knowledge of the community-based service, that ongoing referrals and signposting to the communitybased support offer would be made as appropriate to Glasgow-based patients and their carers/families.

For those that do refer or signpost to the Libraries service, the community-based nature of the service, (i.e. the possibility for service users to access a service in close proximity to their home), was highlighted as the most beneficial aspect of the Libraries service.

This community-based nature of the service was seen as particularly beneficial for those that have accessibility issues and for whom travelling to a specialist service would pose a problem:

"It often works best for older people as they may not have their own transport - so accessibility is important."

### 4.1.2 Barriers to referring and signposting

The overriding reason for organisations or staff supporting people affected by cancer not to signpost or refer people through to Macmillan @ Glasgow Libraries is still a lack of knowledge of, or about, the service. The sheer size of Glasgow and the number and breadth of services available makes it challenging for Macmillan @ Glasgow Libraries to reach all those that could be referrers and makes it challenging for referrers to keep up with the wide variety of services on offer for their patients and service users.

However, there are several other barriers to increasing referrals and signposting. These are described below.

### Lack of time to make an informed referral

Clinical staff, and particularly those whose role does not directly link to provision of information and support needs of people affected by cancer, highlighted the lack of time within their own role to meet these wider support needs. The scale of the cancer treatment and support provided at the Beatson<sup>5</sup> (e.g. between 500-550 people visit radiology each day) adds a further complication to the ability of staff to signpost to services. The lack of time to make a referral was also brought up by a staff member who said that, during a time when their organisation was facing capacity issues (an issue that is presently resolved), they simply did not have the time to refer people to the Libraries service and were only able to signpost them at this stage.

"When we were understaffed, we simply did not have the time to refer, then the signposting was much quicker."

### The stage in the cancer journey

A range of stakeholders, including staff consulted at the Beatson within radiology, highlighted that people will often compartmentalise their treatment and linked support needs. As a result, many people affected by cancer will only begin to think about their non-clinical support needs at the end of their treatment. Work-related advice and/or benefits take-up were highlighted as the notable exceptions for which a direct referral to the Long-Term Conditions and Macmillan Service can be quickly arranged.

There was a feeling amongst the radiography staff consulted that their service was often best placed to introduce the idea of wider, holistic support post treatment. This was also seen as a way to avoid overloading people with too much information earlier in their cancer journey which could be forgotten about or left unused.

The importance of the stage in the cancer journey is also reflected in the scale of referrals to other services. For example, the Macmillan Move More Service will tend to receive referrals post treatment. However, it is important to point out that other third sector organisations emphasised that they would signpost people at any point of their cancer journey to the Libraries service.

"We refer people at any stage of their journey."

<sup>5</sup> The Beatson provides all the radiotherapy, and much of the chemotherapy, for patients with cancer in the west of Scotland - 2.8m people or 60% of Scotland's population.

## Perception that Macmillan @ Glasgow Libraries does not provide the kind of service their clients (and their carers) need

Several providers highlighted that their own services were able to meet the needs of people affected by cancer independent of Macmillan @ Glasgow Libraries. For example, some staff members of charities offering a range of services for site-specific cancers (e.g. lung, prostate) were reluctant to signpost to what they see as generic services which offer little or no added value to their client who often have particular access issues or reluctance to 'mix' with other people affected by cancer. However, in the case of those charities providing information and support services similar to those offered through Macmillan @ Glasgow Libraries from a limited number or just one location, this view highlights a lack of recognition of the value offered by a local service or simply the opportunity to talk to someone new at an alternative service.

Bowel Cancer UK also highlighted a difference in objectives between the respective services, stating that its service had more of a focus on health and cancer information to support early diagnosis rather than the perceived emphasis of Macmillan @ Glasgow Libraries on support post diagnosis and treatment. This however highlights a need to emphasise the full scope of the Macmillan @ Glasgow Libraries offer both in terms of adding to and complementing that promoted by other cancer-specific services through from health awareness and/or health promotion to emotional support for those with a diagnosis.

### Lack of knowledge of the specific services Macmillan @ Glasgow Libraries provides

As noted above, there is a general lack of awareness of the service amongst both clinical and non-clinical staff and organisations. However, a lack of knowledge of the precise scale and scope of the Macmillan service was raised by a number of stakeholders. For example, there is an understanding that GPs struggle to identify those services which they can be sure are best (and still available at the times and costs advertised) for each patient's needs from the range of services available.

This is still the case despite the work of the Macmillan @ Glasgow Libraries team and that of Primary Care Facilitators to distribute information and speak to staff in GP practices.

### "If somebody just want to have a quick chat but don't come under criteria of benefit referral, then we signpost them to Macmillan @ Glasgow Libraries"

"Mostly refer to Macmillan long terms conditions and ICJ. I only refer to Macmillan @ Glasgow Libraries in cases where what the people were looking for didn't fit into the other two. If it is more general information that people are looking for, I refer to the service." Some stakeholders were aware of the Libraries service but did not know how to refer into the service, or that there was a possibility to refer into the service.

"I think I got the contact for the other two services [Macmillan benefits and Maggie's] easier – this has always been my referral route. We don't have that much information about the Libraries service."

"I have not heard that there is a formal referral process."

"I have referred them to ICJ, but I wouldn't know how to refer to Macmillan @ Glasgow Libraries."

Along this line, one stakeholder perceived the Libraries service as primarily a drop-in service, and, as such, felt that referrals are not necessary.

"I think signposting may be better and drop-in may be better. If you are referring people, it does a bit defeat the point of having a drop-service."

This highlights the importance of continuously advertising and making partner organisations aware of the process through which they can refer service users to the Libraries service.

Specifically, there is a feeling that the varied days and timings of the service between different libraries adds to the potential doubt in some practitioners' minds that the service is available, their information is up to date, that the service has capacity to meet people's needs. In addition, it was at times felt that the varied nature of Libraries service offer in terms of locations and open hours is simply harder to describe, compared to a comparator service (e.g. Maggie's) which is open 9am-5pm Monday to Friday a short walk away from the hospital.

"Cancer doesn't just occur for two hours a week."

"People would rather signpost to something they know exists."

"The time-window is a barrier for people accessing it. It should be clearer when the opening times are."

### Perceived quality of the Service

There is very little evidence of a lack of trust in a volunteer service, especially amongst those consulted with a working knowledge of the service. Where any doubts over quality did arise, these were linked to a lack of knowledge of the service and were answered on learning about the parameters of the service and degree of training provided to volunteers.

"Their volunteers are very knowledgeable and well-trained in the field."

"Volunteers are good, some have lived experience. That can be beneficial."

### "I couldn't believe how much training the volunteers receive"

Indeed, just one provider of support services for people affected by cancer with a degree of overlap with Macmillan @ Glasgow Libraries highlighted concerns around the quality of the service. These concerns are founded in a context of similar provision provided by paid staff on a full-time, 'professional' basis and a fear that volunteers may stray beyond the agreed parameters of the service and their training. Doubts on the quality of the Libraries service concerns are, according to this provider, reinforced by the large number of Macmillan services across Glasgow which were stated to be of varying quality, forming a 'green fog' of confusion of what is on offer, whether the service is a pilot of a longerterm service, where it is available and at what times.

"I need more information - Macmillan services seem to be fragmented - I am not sure who and where to phone. You just don't know what person is representing each different service. My suggestion would be for Macmillan to have a central triage system that direct you to the relevant person after hearing your query. "

Moreover, any perceived or actual reports of poor quality within one service will also influence the propensity to signpost to other Macmillan services. This is exacerbated by a range of competitive providers that also provide cancer information, advice and support services. One provider described the third sector market as "saturated", emphasising the increasing difficulty for service user-facing staff to keep up to date with the range of services being offered.

Whilst influenced by a degree of competition for footfall and outputs to highlight impact of their own service, the comments highlight the need to identify and rigorously promote the specific role of Macmillan @ Glasgow Libraries alongside its availability to stress the added value to the person affected by cancer.

## Lack of a Macmillan @ Glasgow Libraries Service in close proximity to the person's home

One of the potential barriers to referring raised by staff at the Beatson West of Scotland Cancer Centre was the fact that many of the Centre's patients and their carers live outside of Glasgow. Staff are very much aware of the sensitivities involved in offering a service to someone affected by cancer but living outside of the catchment area of one (or part of one) of the five Health Boards served. This was thought to contribute to either a lack of signposting activity or a move to a 'fallback position' of only signposting to the services available at the hospital for people undergoing treatment. This is supported by greater knowledge of the multiple charities based in a small footprint in and around the Beatson.

#### Service user choice

Consultations with numerous stakeholders revealed that, generally, they do not refer but only signpost service users to advice and information services. They perceive their role as being a provider of information, (i.e. informing clients about the services on offer) and, as such, giving them the choice of which service, they would like to take up.

"We would just respond to the needs of the patient. If they wanted to be referred, then we refer. If they want only to be signposted, we signpost. We respond to the wishes of the patient - this is patient-centred and about how they would like to approach it."

"We'll signpost, and it is up to them whether they want to go."

"Our job is about empowering and supporting carers, so we want them to make that decision of where and whether they go. We don't need to make referrals for any organisations. Carers should make that choice. "

This highlights the importance of making partner organisation aware of the advantages of making a referral rather than signposting in terms of likelihood of accessing a service.

### 4.1.3 Catalysts to greater, and more effective, referring and signposting

Consultations revealed a limited amount of signposting of people to other information, advice and support services across Glasgow and the wider West of Scotland region. Since the scale of signposting was stated to not be too significant, it suggests that the relative or perceived lack of referrals and/or signposting into Macmillan @ Glasgow Libraries may be part of wider trend rather than an outlying anomaly.

Several stakeholders reinforced the point that there should not be any barriers to signposting to, or indeed from, Macmillan @ Glasgow Libraries with a spirit of transparent two-way referrals/signposting required to boost knowledge, engagement and support levels for people across Glasgow. More regular contact and coordination of support between different services will build momentum in cross-referrals and more regular signposting activity.

It was acknowledged however that there are capacity issues for some providers which could limit the scale and/or frequency of referrals and signposting. The impact of volunteers in supporting many of these services was acknowledged by most stakeholders consulted. Indeed, the Macmillan Information and Support Centre based at the Beatson is set to benefit from increased volunteering capacity - rising to nine initially and potentially up to 20, to not only boost its ability to meet the support needs of multiple people at one time but also widen the scope to signpost people to other locally based services such as Macmillan @ Glasgow Libraries to meet their needs outside of the hospital settings. This builds on the successful instances of Glasgow Life staff supporting the Macmillan Information and Support Centre to cover staff absence/holidays and in showcasing the libraries service as part of Christmas and summer fairs.

Some of cancer site-specific charities (e.g. Prostate Cancer UK) recognised the value of Macmillan @ Glasgow Libraries in complementing the groups established and support on offer in different parts of the city. One charity highlighted the different scale of use of the service by its own support workers to meet the additional needs (e.g. literacy/numeracy or emotional/practical 'handholding' support) in the east end of Glasgow in order to access benefits and wider support.

Some of stakeholders also highlighted the importance of partnership working, (i.e. a clear commitment to cross-refer between the different services). Numerous stakeholders suggested that the lack of a referral agreement between their services and Macmillan @ Glasgow Libraries is their reason for not referring.

"With the other two services [Macmillan Long Term Conditions and ICJ] we have welldefined pathways. We regularly host sessions with the other two services. "

As a result of this, this stakeholder only refers to the Libraries Service "in cases where what the people were looking for didn't fit into the other two services [Macmillan Long Term Conditions and ICJ]. If it is more general information that people are looking for, I refer to the service [Libraries service]".

Hence, further increasing knowledge of the service and better partnership working with relevant stakeholders are likely to also increase referrals:

*"If I knew more about the service, I would potentially refer. We don't have a referral pathway set up. We ourselves as workers we don't have a direct contact."* 

"In order to refer someone down to that, I would first get someone from Macmillan to speak to the person. I don't have enough information about what they offer."

"More information would it make it easier for us to refer: if we had direct access to a referral route - and know the exact person and number, what areas they cover and what exactly they offer."

Discussions with stakeholders in a variety of roles highlighted the value of light-touch training (i.e. enabling people to provide a short synopsis of the service offer and guidance on how to access information on service opening times) for all clinical and nonclinical staff. This could, and should, be provided in as many formats as possible in order to meet and reinforce messages to as many organisations and members of hospital staff as possible. Potential approaches could include utilising existing CPD and teaching sessions for clinical staff, messages for all staff in emails, intranet services and relevant newsletters as well as word of mouth. Another opportunity could be to have volunteers in the Beatson service raise awareness of its service and let healthcare staff know that there are appropriate services that the Beatson service would refer onto including the library-based services.

"Raising awareness in different healthcare settings would be really helpful - being there regularly with a stall." "Not everyone in the staff team may have the same level of understanding. Services also may change over time. There may be more things that I could refer people for to Macmillan @ Glasgow Libraries, so a staff meeting would be very informative"

It was also suggested that clinicians in particular may need to be convinced of the merit of non-clinical support that Macmillan provides. Regarding this, one interviewee suggested that the clinical benefits of non-clinical support (e.g. for example clinical benefits gained through exercise classes) are key to promoting the Libraries service amongst clinical staff:

"Educate the clinicians what benefits they would get from a clinical perspective - make it real for them. Don't only think about the patient, but actually what the benefits is for them [clinicians]."

## Suggestions of ways to improve the propensity of organisations to refer people to Macmillan @ Glasgow Libraries revolved around the following issues

- Developing trust from long term and two-way referral relationships;
- Incorporating more examples of impacts and outcomes in the monitoring and evaluation of the Libraries service to emphasise quality and suitability for a range of people supported by potential referrers;
- Celebrating the role of volunteers, emphasising both the impact of their role via case studies and the scale of training and support they benefit from;
- Maximising the improved partnership working amongst the services involved in the Hub Group at the Beatson to co-design approaches to meeting all partners' need for cross-referrals in the best interest of those affected by cancer visiting the Beatson;
- Revisiting the delivery of Holistic Needs Assessments (HNAs) in libraries with private rooms;
- Continue to establish and reaffirm the scale and scope of the service including inclusion in any service mapping or referral mechanism being developed for cancer-related services<sup>6</sup>;
- Information raising activities in CPD or teaching sessions for clinical staff.

<sup>6</sup> The West of Scotland Cancer Network (WoSCAN) Psychological Therapies and Support Framework was published in November 2015 and refined in August 2017 to provide a structure to define the service which should be available to all those affected by cancer and those identified to have specific psychological support needs. The overall aim is to bring existing services together in a collaborative manner and illustrate a good practice model thereby providing equitable and efficient access to the appropriate services for people affected by cancer. Macmillan @ Glasgow Libraries is not currently included due to issues around short-term funding and geographic ringfencing.

### 4.2 Interviews with non-users

Face-to-face interviews were undertaken with a range of patients, carers and family members attending the Beatson West of Scotland Cancer Centre to assess the knowledge of people attending the hospital of Macmillan @ Glasgow Libraries. Discussions were held in waiting rooms, cafes and the hospital foyer in order to engage with as wide a variety of people as possible.

Of the 19 people consulted approximately half were patients with the remainder carers and/or family members. The majority (approximately 15 out of 19) of those consulted lived outside of Glasgow which reflects the Beatson patient catchment area and links directly to just two people having heard of Macmillan @ Glasgow Libraries.

Of the two people with knowledge of the service, one had heard about it from Clydeside on Asbestos<sup>7</sup> whilst the other had come across it by chance when visiting Govanhill Library where he took away some leaflets from the Macmillan information stands. The other people consulted living in Glasgow stated that after hearing about the service, it sounds like something they would be interested in using.

Those consulted highlighted the reliance on clinical staff, typically a Clinical Nurse Specialist, for either direct support for information, with most being satisfied that their needs had been met.

### "The CNS answered everything"

Of the 19 people consulted, 16 stated that they had not accessed any other sources of information and support beyond those provided to them by clinical staff with just one person acknowledging needing further support. Three people stated that they had been signposted to either the Maggie's Centre or the Macmillan Information Service in the Beatson although just one had actually engaged with either service - taking home some leaflets.

Although limited in terms of sample size, the trends complement the findings of discussions with staff supporting people affected by cancer at the Beatson with a tendency to signpost people to one of the charities (e.g. Macmillan, Maggie's or Cancer Support Scotland) based in or around the Beatson for further information but with little immediate or following links to the community-based libraries service.

Discussions raised few barriers to people accessing Macmillan @ Glasgow Libraries for information and support needs - it was simply that they had not heard of it or hadn't remembered receiving information on it.

The only reluctance to accessing the support of the service was found with two men who either didn't like to ask questions, relying on the medical staff to directly provide them with information or relying upon their wives to enquire further as required.

<sup>7</sup> http://www.clydesideactiononasbestos.org.uk

"Asking questions is not my thing, I'm happy to just take things one step at a time and let the doctor tell me what I need to know"

None of the people consulted has any problems with accessing the service in a library setting and were happy to adapt their plans in most cases to meet the opening hours subject to knowing when and where they could access support in their local area.

The Macmillan brand was found to bring reassurance about the quality of the support on offer with people just pleased to access support from a trained volunteer, especially those that had survived cancer given that they would be more likely to know what they were going through.

### 4.3 Summary of the view from the outside looking in

Overall, consultations confirmed the low level of formal referrals to Macmillan @ Glasgow Libraries, inconsistent levels and propensities amongst potential referral agencies/services to signpost people affected by cancer into the service and an underlying lack of knowledge of the specific service offer.

### 4.3.1 Referrers and non-referrers

- The majority of organisations operating within or linking into the Glasgow 'cancer network' acknowledged an awareness of Macmillan @ Glasgow Libraries although few were able to evidence the extent to which they refer or signpost clients towards the service. Where they do, numbers were generally low.
- Discussions with staff supporting people affected by cancer at the Beatson West
  of Scotland Cancer Centre revealed little knowledge of the service despite
  significant efforts by the Macmillan team to raise awareness. Staff based at the
  Beatson will signpost people to one or more of the charities based in and around
  the Beatson (i.e. Macmillan Information and Support Centre, Maggie's or Cancer
  Support Scotland) with a disconnect apparent between services in acute and
  community settings.
- The libraries service is seen by many staff as a service only for people at the end of their treatment although there is little evidence of signposting from the initial support providers to this (perceived) follow-up provision.
- The overriding reason for clinical staff supporting people affected by cancer not to signpost or refer people through to Macmillan @ Glasgow Libraries was simply a lack of knowledge of, or about, the service. This is complicated by the geographically-specific offer of the service to Glasgow within an extensive acute setting aiming to meet the needs of hundreds of people per day from across five Health Boards across the entire west of Scotland.
- A range of cancer charities revealed tendencies to 'hold on' to clients rather than actively signpost or refer them to wider, more local or different services. This was linked to a perceived specialism and overlap of services amongst charities dealing with specific aspects of site-specific cancers, a belief that the needs of

people affected by cancer are already met by their own services, and in <u>one</u> case a distrust of the quality or ability to respond of a volunteer-led service with limited opening hours.

 The above issues are exacerbated by the large number of often over-lapping services available to people affected by cancer in Glasgow, which feeds a degree of unease as to whether pilot services are still active, operating in the same place at the same times and of a desired quality to meet specific needs.

### 4.3.2 Catalysts to greater, and more effective, referring and signposting

- Consultations revealed a limited amount of signposting overall between services and agencies supporting people with cancer and other information, advice and support services across Glasgow and the wider West of Scotland region.
- Stakeholders consistently stated that there should not be any barriers to signposting to, or indeed from, Macmillan @ Glasgow Libraries, although reiterated that communication, and signposting activity, needs to be two-way in order to build healthy and collaborative partner relationships.
- The introduction of additional volunteering capacity to support the delivery of the Macmillan Information and Support Centre based at the Beatson is expected to boost both the service's ability to meet more patient needs at the Beatson and increase signposting to local community-based services across the West of Scotland including Macmillan @ Glasgow Libraries.
- Additional information and awareness raising activity to support both clinical and non-clinical staff based at the Beatson to signpost people towards the Libraries services at all stages of the cancer journey is seen as both realistic and a positive step towards boosting signposting activity.

### 4.3.3 Non-users - key themes

The following themes and conclusions emerged from the discussions with people affected by cancer (and staff) consulted at the Beatson:

- The scale of the services offered at the Beatson coupled with the geographical area served represents a barrier to staff signposting people to services ringfenced to Glasgow. In effect, Macmillan @ Glasgow Libraries represents a small cog in a large information and support machine across the West of Scotland.
- Some people affected by cancer are generally reliant upon, and satisfied with, the information and support provided by, or signposted to, from consultants and/or Clinical Nurse Specialists. This tends to meet their immediate needs with several people stating that they 'compartmentalise' their needs along their cancer journey as part of a 'one step at a time' approach.

 People affected by cancer receiving treatment at the Beatson will almost definitely only be signposted to information and support services based in and around the Beatson. There are no indications of follow-on referrals or signposting to Macmillan @ Glasgow Libraries despite consultation revealing a demand for the service and few barriers to take-up.

### 5 Findings and recommendations

# 5.1 Overall, the service is considered to be important and of high quality

Macmillan @ Glasgow Libraries is recognised as a high quality and important service by stakeholders, volunteers, library staff and service users alike. The service was also considered to be an important advocate of how to implement truly holistic support. Our research has identified tangible and important benefits for both:

- People affected by cancer
  - While the service does not expect to be the right fit for all those affected by cancer, the service is recognised as providing an important pathway option for those seeking support in their community.
- Libraries
  - We can say is that the service is seen by library staff as a core library offer, especially given the evolving role of libraries as a source of health and wellbeing information and a venue to access support in the community.

### 5.1.1 Feedback from service users was overwhelmingly positive

Feedback from service users of the drop-in sessions was overwhelmingly positive, with the emotional support provided by volunteers identified as the most important element of the service. Overall, service users felt that:

- The proximity of the services was important as many service users can be too tired or unwell to travel too far, or have caring responsibilities that mean that leaving the house for too long can be difficult
- Reassurance was a major benefit that service users reported getting and seeking from the service
- Knowing help is available was considered important even if they aren't accessing the service frequently
- Many were surprised that there were services to support carers and family members, with the perception that most services were there for those with a cancer diagnosis
- Impacts of the service on users included: helping them to accept their situation, receiving reassurance, taking advantage of opportunities in life, coping with stress, being able to talk through options and weigh them up with an outsider's perspective

- Many service users attributed their use of other services to Macmillan @ Glasgow Libraries
- The one main area of criticism relates to the availability and access to complementary therapies with reports of cancelled or double-booked sessions which, while outside of the control of the Macmillan @ Glasgow Libraries' service as it is delivered by a partner organisation, can undermine the trust gained through the volunteers
- Some indicated that they were comfortable speaking in public spaces, others were not. This indicates that having an optional private room is useful to widen the suitability of the service.

# 5.1.2 The support provided to family, friends and carers of those with cancer is vital

- 33% of recorded visits to the service were by the friends and family of someone with cancer, and 5% were by someone who identified as caring for someone with cancer. We also expect that the 5% of carers is an under representation of the number of visitors who have caring responsibilities as many may not identify themselves as carers despite undertaking caring responsibility for their family member or friend.
- One in five people aged 50 to 64 have caring responsibilities in the UK. 65% of carers over 60 have a long-term health problem or disability themselves, nearly 70% of older carers report that being a carer has an adverse effect on their mental health and more than 30% say they have cancelled their own treatment, appointments or operations due to their caring responsibilities.<sup>8</sup>
- Our research identified that carers can often struggle to know where to access support and information for themselves with most services geared up for the person affected by cancer rather than those around them.
- The high proportion of people accessing the service who are friends, family and carers is encouraging.

# 5.2 The sustainability pilot and subsequent integration of the service into library management has been a success

There has been a wealth of positive feedback about how well the libraries and Macmillan @ Glasgow Libraries have worked together with consultation revealing a growing shared understanding of mutual roles and objectives. This is reflected in the minimal time demands placed upon Library supervisors to manage volunteers and growing relationships between library staff and volunteers which has, amongst other things, seen

<sup>8</sup> https://carers.org/key-facts-about-carers-and-people-they-care

venue inductions being undertaken by library staff to the benefit of wider resourcing for the Macmillan team.

The study team notes that work is still ongoing to ensuring there is wide spread and consistent understanding of respective roles and responsibilities across lead volunteers, library staff and the Macmillan team. However, understanding is generally thought to be good, if not yet consistent, with further understanding across all roles and service points acknowledged to need time before becoming fully engrained.

This process is being supported by bi-annual group workshops with supervisors from all drop-in venues to aid in consistency and understanding of individual roles and responsibilities. An internal Macmillan Service Review, completed towards the end of Summer 2018, should see further progress being made on standardising processes across the Macmillan @ Glasgow Libraries services.

# 5.3 We still consider there to be scope and a need to increase service numbers

In the interim report, we identified that it was important to continue to increase service user numbers and that there was still capacity in the service to increase service numbers. There are a number of elements to doing this.

5.3.1 We still think there is more to be done on overcoming the lack of coordination of the range of Macmillan services in Glasgow - there is no coherent offer for those affected by cancer - even within Macmillan branded and Macmillan funded services

There are a large number of cancer related services in Glasgow. This is a landscape that Macmillan @ Glasgow Libraries will need to navigate and fit in with and, in a number of ways, is beyond Macmillan @ Glasgow Libraries' control. However, there are also a number of Macmillan-branded and Macmillan-funded services in Glasgow. All provide services that a single person affected by cancer may want to use at different points in their cancer journey, (e.g. Move More, Improving the Cancer Journey, Long Term Conditions and Macmillan Service, and the Support and Information Centre at the Beatson).

Consultation with a variety of Macmillan and partner stakeholders to inform both the interim and final reports raised concerns around the degree to which cancer services in Glasgow operate largely in isolation from each other. They are marketed independently, their inbound and outbound referrals operate independently, and their cross referrals are surprisingly low. Each service is approaching health care professionals and other services independently. This risks the services being ignored by frustrated service providers, as well as creating greater confusion about where to send their patients. There also appears to be limited cross referrals occurring between services.

During our research we heard frequent stories of Macmillan branded or funded services lining up behind other Macmillan branded or funded services to get space on the agenda of groups or to get through the door of providers to promote their service.

A vital group to have referring to the service are clinical staff. This is also the group with the least time to keep informed of all the various services their patients might find useful.

Arguably, Macmillan branded or funded services themselves, particularly the helpline, are better placed to match people with appropriate services than relying on other service providers - particularly clinical service staff - to understand the breadth of Macmillan branded or funded services and send their patients to the right one.

Greater coordination of effort between Macmillan branded or funded services, vitally cross-promotion, is a key method to ensuring that promotion efforts are efficient, affordable and sustainable. Identifying other service providers with similar aims and objectives willing to share capacity and costs in undertaking intensive local partnership building activities could help to achieve shared targets and inform future relationships.

Targeted work in specific communities, as is done through current outreach, should be continued with a focus on addressing accessibility issues and barriers to service take-up within specific 'hard to reach' cohorts including the BME community. For example, looking at whether there are cultural or language barriers to engaging and whether the targeted recruitment of BME volunteers enables the service to engage more effectively with specific cultures.

Addressing this should be a priority for Macmillan Cancer Support, without greater coordination (e.g. exploring the viability of joined up outreach provision based in libraries offering emotional support alongside practical support and therefore closing the circle of missed opportunities for more efficient service provision) Macmillan Cancer Support is undermining the independent effort of their own services.

The study team recognises the work of the Macmillan @ Glasgow Libraries team in encouraging partners to buy in to attempts to improve this situation through the creation of a single, city-wide engagement group through the amalgamation of multiple steering groups. With this group meeting twice to date, plans approved for a complementary city-wide Macmillan Volunteering Hub and a positively received Macmillan Services Day held to share information on respective services, we acknowledge the steps being taken to improve the coordination of services for people affected by cancer in Glasgow. 5.3.2 We also consider that greater support from the national Macmillan Cancer Support campaign is still required with the newly formed city-wide engagement group having the potential to exert greater influence with the national Macmillan communications team

Stakeholders and volunteers have pointed out the large number of generic national Macmillan campaign posters around Glasgow. They saw this as a missed opportunity to advertise the local Macmillan footprint - including Macmillan @ Glasgow Libraries. We consider this an opportunity for Macmillan Cancer Support to back up its investment - without it we consider that Macmillan Cancer Support is undermining its own investment by limiting the reach the service can have.

In addition, it seems that further effort is required to change the perception that Macmillan is only there to provide nurses and end of life care which undermines the value of community-based emotional support and information services.

To make this more practical, Macmillan Cancer Support should look to do this as part of the greater coordination of their local Macmillan branded or funded services. For example, posters that say - find your local Macmillan support services and include reference to Macmillan @ Glasgow Libraries, MoveMore, Improving Cancer Journey, etc.

# 5.3.3 The service's integration into the library has been very positive, but more still needs to be done to ensure that the service is a core part of the wider Glasgow Life picture

Note that there is still confusion with Glasgow Life staff outside the libraries teams as to whether this is a Glasgow Life or a Macmillan service. Library staff have made massive efforts and were successful at integrating it into library service. Glasgow Life has made a good start at integrating the service, but more is required to make it part of core business.

Interest and positive adoption of the service by the library staff has been high. Library staff recognise the importance of the service and where the sustainability pilots have been rolled out, staff appear well informed and keen to participate in the service and its management. Library staff and Glasgow Life as an organisation should be proud of this.

Glasgow Life now needs to further integrate the service at a management and strategic level. Primarily when it comes to supporting the ongoing promotion and advocacy for the service. Just like the other Macmillan services, there is scope for greater promotion of the service by Glasgow Life, both internally and externally.

 Internally - more work could be done to ensure that Glasgow Life staff are aware of the service and what it offers. This is particularly important for any Glasgow Life staff member with a role that involves promotion of Glasgow Life's services and offer. • Externally - equally more work could be done to ensure that the service is part of the core Glasgow Life external engagement. Where Glasgow Life staff are engaging with relevant stakeholders, Macmillan @ Glasgow Libraries should be part of the offer they discuss.

Presently the Macmillan @ Glasgow Libraries staff team are independently doing this internal and external marketing. Given the limited resources available this limits the promotional reach. When Phase 2 funding comes to an end, active promotion of the service will too, as Macmillan and Glasgow Life are both providing limited promotion outside what the Macmillan @ Glasgow Libraries staff team do. We think that this could have a significant impact on the service's ongoing ability to attract new service users.

5.3.4 Further referrals from the Macmillan Information Service based at the Beatson West of Scotland Cancer Centre is key to increasing the awareness of, and attendance at, Macmillan Information and Support Services in local communities across Scotland

There is no structural reason why there aren't more referrals coming from the Macmillan Information Service based at the Beatson West of Scotland Cancer Centre. There is a great opportunity to utilise the forthcoming expansion of volunteering capacity at the Beatson to build knowledge of Macmillan @ Glasgow Libraries (and the other community-based services in other local authority areas) amongst both people affected by cancer and staff based at the Beatson. With the benefit of targeted objectives and the value of increased capacity we would expect to see both knowledge of, and referrals to, the Libraries service increase as more volunteers are active at the Beatson.

Volunteers can be key to this influence by:

- Fostering closer operational working between the Macmillan Information Service at the Beatson and community-based services – including services across other local authority areas
- Highlighting the availability and value of the community-based service to people affected by cancer to complement the services available in around the Beatson
- Communicating the role and objectives of the Libraries, and other communitybased services in other local authority areas, to identified staff across the Beatson (e.g. reception staff in each department) and information on how to signpost people to their nearest available service via the relevant Glasgow Life webpage.

# 5.3.5 More needs to be done to encourage people to see libraries as hubs for health and wellbeing

The Macmillan service is limited by the fact that it is largely the only externally marketed health and wellbeing service in libraries. While there are other examples for example dementia awareness activities, hearing loss groups, post-natal depression services and healthy reading offers, libraries are largely not seen as health and wellbeing hubs. Now is time to further encourage libraries to be seen as health and wellbeing hubs and places to go. They now have a proven example in Macmillan @ Glasgow Libraries. The service is also highly valued by library staff. Until libraries are seen as places to go for health and wellbeing, the Macmillan service will be battling to get its message out there in an environment where people don't think about libraries as a place to go for help.

This should be done in a number of ways:

- It is time to start thinking about services and information for other long-term conditions other areas have done well by being part of social prescribing and holistic health needs groups and pathways.
- Encouraging greater use of the Macmillan spaces for small group and one-to-one sessions outside of volunteer service hours by other community groups (for health and non-health activities) and health and social care services. This is already occurring within Glasgow libraries, but there is scope to build this further. This not only improves the use of the spaces but also further emphasises the role of libraries in health and wellbeing to the public and health and social care services.
- Examples of additional uses could include ICJ staff using the spaces to undertake Holistic Needs Assessments (HNAs) for people affected by cancer and their carers, especially where there is value in discussing care needs outside of the home. The spaces could also be used for small group or one-to-one sessions (subject to space constraints) by both cancer-specific groups and groups supporting people with long-term conditions. This not only provides greater use from the spaces, but also provides a wider group of people including those with comorbidities, with knowledge of the service and ready-access to the information available in each library.

### 5.3.6 Continual promotion activity needs to occur

While it is not possible to calculate the exact unmet demand for cancer information and support in Glasgow, given the size of Glasgow and health and demographic factors meaning that more people will be living with and beyond cancer, it is reasonable to assume that there is potential for the service to continue to increase its service numbers within the current resources (volunteers, library spaces and drop-in times).

We recognise the work of the Macmillan staff team in continuing to test and evolve promotional activities and partnership working to raise awareness of the service amongst both potential referrers and the general public. This includes strategic work with Health and Social Care Boards and core partners such as ICJ in addition to targeted work with Housing Associations and Jobcentre Plus offices which have started to generate positive responses. Awareness raising activities targeting both the public and health practitioners include a major postal door drop and the roll out of information displays in clinical areas complemented by a guidance pack for support staff. Plans are also at an advanced stage for a small-scale social media campaign to be implemented later in 2018.

However, despite the efforts of the Macmillan team, many of the factors that necessitate continual promotion of the service will continue to hold true for the foreseeable future:

- Although work is underway to map and clarify the support available to people affected by cancer across Glasgow and wider area, the Glasgow service landscape remains confusing and busy for partners and the public. Although not unique to cancer or wider health services in Glasgow, services could be both coordinated better and remain very busy. Smaller and non-clinical services will therefore need to continuously and proactively engage with a range of services and stakeholders to keep their service on their radar.
- Discussions with both stakeholders and service users consistently highlight that people affected by cancer often feel bombarded with information from multiple layers of interconnected services. This is particularly the case for people coming to terms with a new cancer diagnosis who are not in the 'right place' to absorb the full implications and related options for support.
- Service users and stakeholders highlighted a tendency for people to therefore compartmentalise their cancer journey which tends to see them prioritising their support uptake to treatment and immediate financial support. Emotional support often comes much later in the list of priorities to be addressed and often only once initial treatment has been completed. People therefore only tend to notice the service when they realise, they need it. Becoming visible as a service has additional complexities when it is only relevant for a particular group. This means that repeated promotion to the same stakeholders and people affected by cancer has value, as well as ongoing discussions regarding other onward referrals that might be appropriate at the right time.
- Consultation with both clinical and non-clinical partners reaffirmed previous
  messages that people are more likely to signpost than formally refer into the
  service. Formal referrals are powerful in that they provide the service with
  something tangible to follow up and the service should continue to encourage
  referrals wherever possible. However, the service should think further about
  how it could improve the conversion of sign-posts to service attendance, for
  example building on the increasing number of people learning about the service
  online.

Therefore, we recommend that continued effort is put into service promotion on a number of levels including work to influence strategic partners, encouraging buy-in at service management level and raising awareness of the service and how to refer into it amongst delivery staff. In particular:

- Anything that can be done to bring together the variety of service offers into a single 'way in' for referrers will help to simplify the information required for referrers. This includes working together with other charities in the Beatson to identify a way to encourage cross referrals and work together on messaging for health professionals
- Promoting service user case studies to provide feedback to referrers on the types of impacts that service users see
- Promoting volunteer case studies to demonstrate the level of skill, training and experience held by volunteers and to provide a clear understanding of what volunteers do and don't do within the service.

Recommendations to increase service numbers include:

- Utilise the improvements in partnership working with other Macmillan services, other cancer charities and wider health partners to produce a simple (as possible) information resource on all services available in Glasgow for people affected by cancer. Such a document providing comprehensive coverage of all services would be more influential than an individual service adding to the already confused picture of support across the city and highlight the value of Macmillan @ Glasgow libraries service as a means of linking people affected by cancer to relevant services whilst offering emotional support from a local base.
- Continuing and where possible increasing efforts to promote both the service and the benefits of emotional support and information as part of a holistic package of support for people affected by cancer in recognition of the slow and incremental nature of learning and culture change amongst partners linked, amongst other things, to over-stretched services and staff turnover.
- There is also a challenge to change a culture of habitual referrals (i.e. those opting for their usual or favourite option rather than the best option, or combination of options in and out of acute settings for people affected by cancer). Working with other charities in particular those at the Beatson will be important to manage these and generate more cross referrals for any inappropriate referrals made due to the habits of referrers
- Opportunities to promote the service to clinical staff in hospital settings, for example as part of ongoing CPD sessions, should continue to be requested and utilised alongside opportunities to disseminate information to larger numbers of clinical staff by email, intranet services and relevant newsletters.

- Targeting those geographic areas and population cohorts highlighted by partners and service statistics as likely to either need or take-up the service offer, for example, people living in the east end of Glasgow or those requiring additional support to 'regain control' of their working and social lives following treatment.
- Promoting both the importance/impact and ability of partners to refer into the service by reiterating agreed or introducing new processes for those unaware of the option or how to action it.
- Maintaining and enhancing current online promotion in response to the emerging impact of this communications channel highlighted in service user feedback.
- Supporting the availability of online service information and specifically details of how to access the service in each library through the dissemination of small cards which can be easily placed in a purse or wallet with details of the website and phone number to access service availability.
- It is envisaged that these simple cards can facilitate light-touch promotion of the availability of the service by a range of health and non-health partners. They can also support more in-depth or targeted work with specific organisations, professionals or hospital departments (e.g. radiography or phlebotomy given the high number of patients supported each day).
- Keep clarifying the benefits of the availability of the library service at multiple service points in local communities across Glasgow complementing and adding value to services offered by other charities and services at only one or limited locations and charities rather than competing for 'exclusive service users.
- Consultation with referrers highlighted the value of case studies in reinforcing not only the parameters and quality of the service but also the impact of the support available on people affected by cancer. The development and dissemination of case studies in a range of formats (e.g. hard copy, audio and video clip) and using a range of communication channels (e.g. web-based, mainstream advertising, e-shots) would be particularly useful in engaging clinical stakeholders including GPs with limited time to absorb large amounts of text. Crucially, these case studies should also focus on the role and quality of support provided by Macmillan volunteers and emphasise the amount of training, knowledge and experience they add to the service.

# 5.3.7 Feeding back to referrers and organisations about what happened to their referral - data protection can be overcome

Consultation with partners who currently refer or signpost into the service, but significantly also those who do not, confirmed the need for a two-way relationship characterised by reciprocal activity and sufficient feedback on the outcome of that referral or signposting activity – largely around the extent to which people benefit from the service.

 The development of a simple feedback mechanism on the outcome of particularly referrals to and from the service between partners which satisfies data protection regulations can help to strengthen relationships and therefore between partners and therefore the scale and quality of support for people affected by cancer. This doesn't need to be specific to the individual that they referred – but could be a greater use of case studies on service users and volunteers.

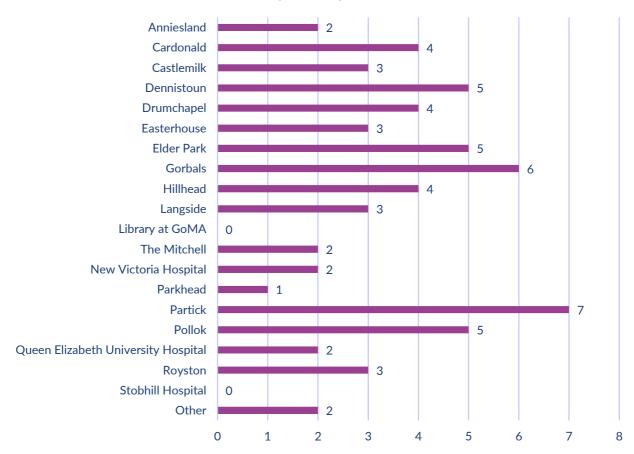
# 5.4 Ensuring the efficient distribution of resources whilst maintaining quality

It is important that Macmillan @ Glasgow Libraries continually appraises the allocation of resources across the service points in response to service user data and the challenges of maximising quality and coverage relative to changes in funding.

- Whilst the current service review being undertaken by the Macmillan team will
  provide more detailed insight, a review of service data coupled with the number
  and distribution of service points to the potential to rationalise the service
  without unduly affecting the service available to service users. Indeed, by
  identifying those service points with least demand for volunteer time there is
  scope to convert services to information points and/or redivert resource into
  outreach. This decision should factor in the location and opening times of other
  service points as well as accessibility factors such as public transport between
  neighbouring libraries.
- There is an opportunity to offset any concerns about the closure of a volunteer service in one library by emphasising the availability of the nearest other services and telephone helpline through a targeted marketing campaign which could lead to greater take-up overall.

### Appendix 1 Volunteer survey analysis

49 Macmillan @ Glasgow Libraries volunteers answered an online survey in May 2018. Figure 15 below outlines the libraries the respondents volunteer in.

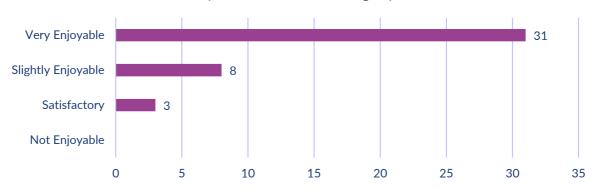


### Library of respondents

### Figure 15 Library of volunteer survey respondents

### Volunteer views on their volunteering role

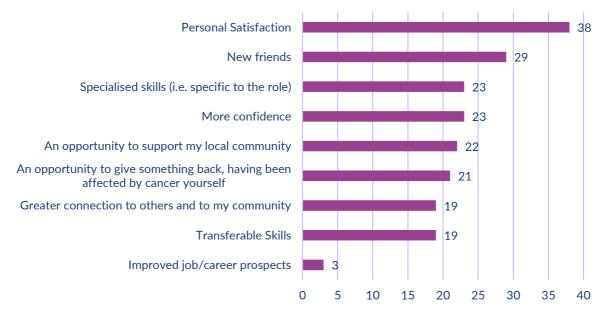
As can be seen in Figure 16 overleaf, almost all volunteers who responded to the service enjoyed their experience and expressed a high level of pride in being part of the service. Almost all intended to continue to volunteer. The few that were uncertain about their future with the service cited largely personal circumstances rather than unhappiness with the service.



### How do you find the volunteering experience?

### Figure 16 Volunteer enjoyment of their role

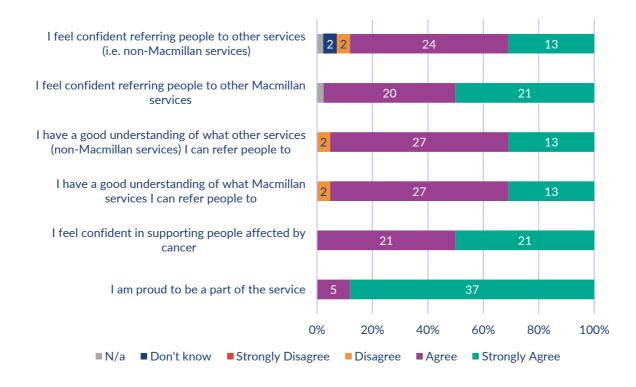
Volunteers reported a wide variety of benefits they have gained from their volunteering. the most commonly reported was personal satisfaction, making new friends, gaining confidence and skills and having an opportunity to give back to their community – including giving back following their own personal journey with cancer. This can be seen in figure 17 below.



### What have you gained personally from your volunteering role?

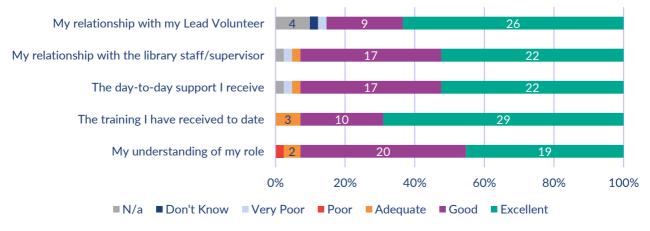
Figure 17 Volunteer views on what volunteering has given them as individuals

Figure 18 below shows that generally, volunteers felt that they understood their role and were confident in their ability to support people affected by cancer, including knowing where to refer participants to



### Figure 18 Volunteer views on their ability to deliver the service

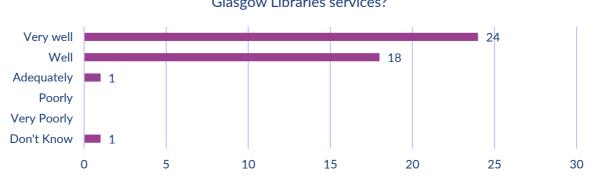
As per Figure 19 below, volunteers also felt confident in their relationships with Lead Volunteers and the library staff. As one volunteer said, "[i]t now feels as though Macmillan volunteers and library staff are part of a team". Volunteers were also largely happy with the support and training they receive.



### Figure 19 Volunteer views on their role and support

### Volunteer views on the service

Figures 20-22 below and overleaf show the volunteers views on various elements of the service. Overall, volunteers were very positive about the quality and importance of the service. Almost all respondents felt that the service met the needs of service users well or very well. Improvements sought were mainly around further promotion of the service to continue to increase service user numbers.



How well do you think people's needs are met by attending Macmillan @ Glasgow Libraries services?

Figure 20 Volunteer views on how well the service meets the needs of its visitors

The top barriers to people affected by cancer in accessing the service identified by volunteers was lack of knowledge of the service, not being referred or signposted to the service, and not understanding what the service was.

## What barriers do people affected by cancer face to learning about and accessing Macmillan @ Glasgow Libraries?

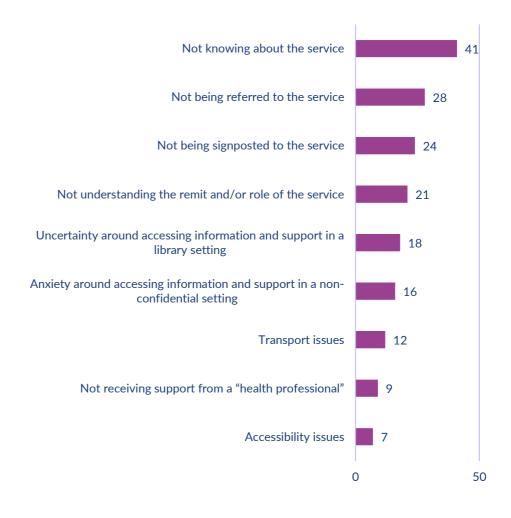


Figure 21 Volunteer views on the main barriers facing service users and potential service users

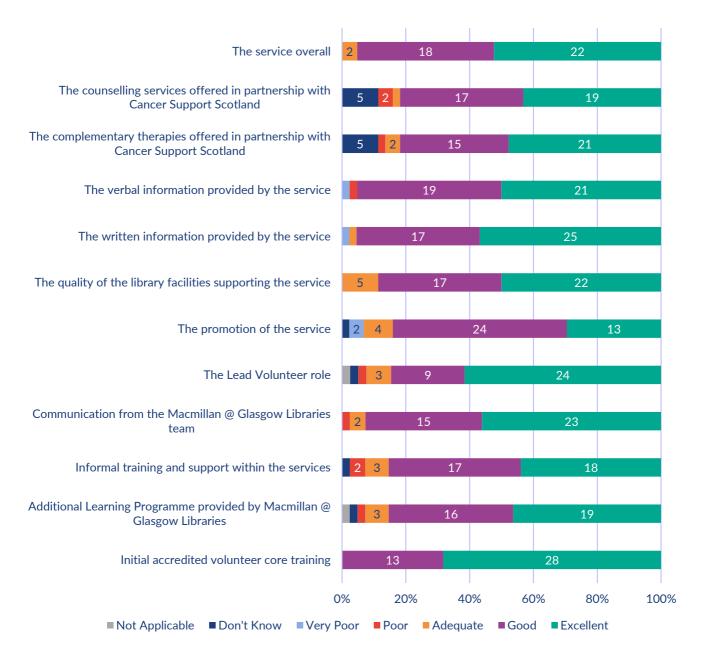


Figure 2216 Volunteer views on the quality of various elements of the service

### Changes to the volunteer role

As shown in Figure 23, most volunteers were happy with the number of hours they were volunteering, as well as the management of the volunteers. Many volunteers were keen to:

- Work more effectively with library staff
- Receive more specialised training
- See an increase in the number of volunteers.

About half of the respondents were keen to take on more responsibility and taken on a wider and more varied role as a volunteer.

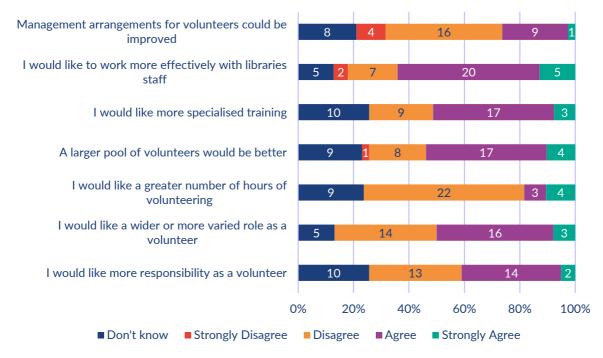
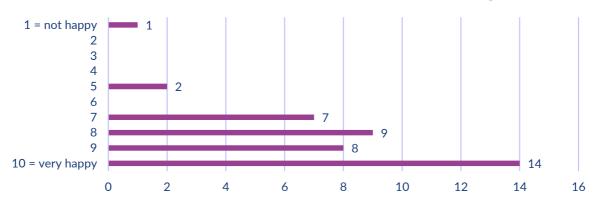


Figure 23 Volunteer views on changes to their role

### Volunteer views on the sustainability management changes.

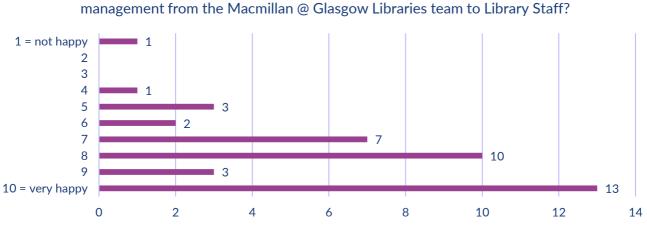
With the transfer of the service management now largely sitting with the libraries and library staff, we asked volunteers how happy they were with the way the service is currently managed. Almost all rated the service 7 out of 10 or higher in terms of how happy they were with the way the service is managed. This is outlined in Figure 24 below.



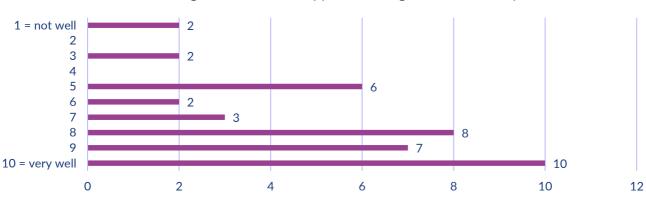
How happy are you with the way the service is currently managed?

#### Figure 24 How happy volunteers are with the service's management

As is shown in Figure 25 overleaf, volunteers were generally happy with the transition of some volunteer and operational management from the Macmillan @ Glasgow Libraries team to Library Staff. However, as shown in Figure 26 overleaf, results were more mixed around the extent to which volunteers understood these changes – specifically in how it relates to their support and management. Many respondents commented that they felt up to date on, and understood, the changes to the service. They found library staff helpful, friendly and seemed to enjoy having the service in their libraries. However, a number of volunteers were less clear about the different roles and responsibilities following the changes, and a few noted that in some libraries the library supervisor's shifts don't match the volunteer hours of the service, so they get very little face time.



How happy are you with the transition of some of the volunteer and operational management from the Macmillan @ Glasgow Libraries team to Library Staff?



How well do you understand the changes in regards to your support and volunteer management that has happened during the sustainability work?

Figure 26 Volunteer views on the changes to the service's management

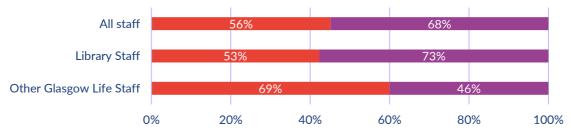
Figure 25 Volunteer views on the change to the service's management

### Appendix 2 Library staff survey analysis

78 library and other Glasgow Life staff completed an online survey in May 2018. 62 were library staff, and 13 identified themselves as other Glasgow Life staff.

### **Respondent profile**

72% of Library Staff who responded had experience of a Macmillan @ Glasgow Libraries volunteers drop in service in their library, and 53% had experience of a Macmillan @ Glasgow Libraries information point in their library. Of the respondents who identified as another Glasgow Life staff member, 46% had experience of a volunteer drop in service, and 69% had experience of a Macmillan information point.

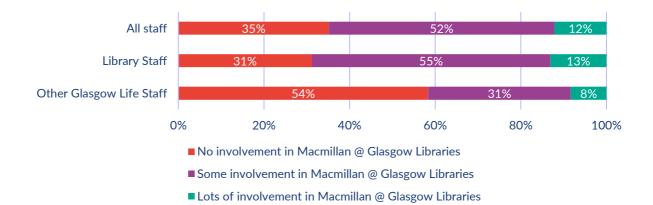


Experience of a Macmillan @ Glasgow Libraries information point in my library

Experience of a Macmillan @ Glasgow Libraries volunteers drop in service in my library

### Figure 27 Respondent profile

12% of all respondents to this survey stated that they had 'lots' of involvement in Macmillan @ Glasgow Libraries, 52% had 'some' involvement, and the rest had no involvement.



### Figure 28 Respondent profile

The vast majority of respondents fully understood the Macmillan @ Glasgow Libraries offer.



I have not heard of the service

I have heard of the service but don't really understand what it does

I understand what Macmillan @ Glasgow Libraries does

### Figure 29 Level of understanding of the service amongst respondents

### Respondent views of the service

Respondents were asked a range of questions about the service. The choice 'not aware' was used a number of times across the questions, particularly in relation to the more detailed questions about the operation of the service. Figure 30 shows respondents' views with the 'not aware' answer, while figure 31 removes these and shows the views of respondents who did express them.

Most respondents felt that the service was an important part of the libraries offer, fit well within Glasgow Life, made sense to be in the libraries and has had a positive impact on the libraries. Most respondents also felt that the spaces were well used by other library users.

Respondents were slightly less confident in the lead volunteer role and how best to manage volunteers. In relation to the transfer of responsibility to library staff, just over half felt that they had been well supported by the Macmillan @ Glasgow Libraries team, and just under half felt they had been well supported by their line manager.

Macmillan @ Glasgow Libraries is an important part of the libraries offer	4 3 5	22		42	
Macmillan @ Glasgow Libraries fits well into the work of Glasgow Life	338	26		36	
It makes sense to place cancer information and support within libraries	2 3	30		40	
The service has had a positive impact on the libraries	16	3 6	22	29	
The space and resources provided by Macmillan are well used by people affected by cancer when not attended by volunteers	23	7	18	19	9
The space and resources provided by Macmillan are well used by other library users	13 3	3 10	33		17
The users of the service appear to appreciate the service	19	2	24	31	
The transition to library staff supporting the Macmillan @ Glasgow Libraries volunteers has been successful		42	<mark>2</mark> 3	3 23	5
I feel confident that library staff are able to take on this responsibility		32	7 8	21	7
I am comfortable with the lead volunteer role		37	13	7 8	3 9
I understand the issues that I may need to deal with when managing volunteers		36	11	7 12	9
I feel I have been well supported by the Macmillan team in this process		41	8	3 5 12	2 8
I feel I have been well supported by my line manager in this process		38	9	10	14 4
(	0% 20	0% 40	0% 60	% 80%	6 100%
Not Aware Strongly Disagree	Disagree	Agree	Strongly A	Agree	

Figure 30 Views of the service including 'not aware' answers

Macmillan @ Glasgow Libraries is an important part of the libraries offer	35	22		42	
Macmillan @ Glasgow Libraries fits well into the work of Glasgow Life	38	26		36	
It makes sense to place cancer information and support within libraries	3	30		40	
The service has had a positive impact on the libraries	36	22		29	
The space and resources provided by Macmillan are well used by people affected by cancer	7	18		19	9
The space and resources provided by Macmillan are well used by other library users	3 10		33		17
The users of the service appear to appreciate the service	2	24		31	
The transition to library staff supporting the Macmillan @ Glasgow Libraries volunteers has	2 3		23		5
I feel confident that library staff are able to take on this responsibility	7	8	2	1	7
I am comfortable with the lead volunteer role	13		7	8	9
I understand the issues that I may need to deal with when managing volunteers	11	7		12	9
I feel I have been well supported by the Macmillan team in this process	8	5	12		8
I feel I have been well supported by my line manager in this process	9	10		14	4
0 Strongly Disagree Disa	% 20 gree A		0% 60 trongly Ag	)% 80 gree	% 100%



### Appendix 3 Organisations interviewed

Stakeholders from the following organisations were interviewed regarding whether they know of, signpost or refer into Macmillan @ Glasgow Libraries.

- Alliance Scotland, Link Officer (2 interviews)
- Bowel Cancer UK
- Breast Cancer Care
- Cancer Support Scotland
- CLIC Sargent
- Glasgow South East Carers Centre
- Glasgow South West Carers Centre
- GlenOaks Housing Association
- Health and Social Care Alliance Scotland
- Improving the Cancer Journey (3 interviews)
- Macmillan Move More Glasgow
- Long Term Conditions and Macmillan service
- Maggie's
- NHS Greater Glasgow and Clyde
  - Charge Nurse
  - Primary Care Facilitator
  - Smokefree Services (2 interviews)
  - Support and Information Officer (2 interviews)
- Prostate Cancer UK
- St. Margaret of Scotland Hospice
- Roy Castle Lung Cancer Foundation
- Sanctuary Scotland Housing Association