Macmillan Cancer Support and Glasgow Life

Macmillan @ Glasgow Libraries Cancer Information and Support Service

Interim 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 the Macmillan @ Glasgow Libraries programme. The Macmillan @ Glasgow Libraries service is a tiered model of Macmillan Cancer Information and Support Drop-in Services, which aims to provide cancer-related support and information for people in their local communities through libraries and other community venues.

This interim evaluation has been informed by analysis of project data collected including:

- Referral numbers, data collected by volunteers, and use of library space
- A survey and follow up interviews with library staff and stakeholders
- A survey and follow up focus group with volunteers, a focus group and interviews with project staff and interviews with service users.

Service analysis

- There were 2,446 recorded visits to Macmillan @ Glasgow Libraries in 2016. 59% of these visits were first time visitors. The latest available statistics show that there were 3,440 new cancer registrations in 2014 in Glasgow City. A total of 1,343 referrals were made into the Macmillan @ Glasgow Libraries service between January 2014 and May 2017. Just over 94% of all referrals come from the Improving Cancer Journey (ICJ) programme, a health professional or Macmillan Long Term Conditions.
- Statistics generated by a sample of service users show that the Macmillan
 @ Glasgow Libraries service is supporting people across the entire cancer
 journey. The value of providing emotional support for people affected by
 cancer is reaffirmed by over 1,000 people accessing the service looking for
 'someone to talk to'. The value and the availability of complementary
 therapies and counselling support at local libraries is reflected in the
 proportion of repeat service users.
- The value of the capital investment in five of the libraries hosting the service extends beyond supporting people affected by cancer. The Macmillan branded spaces in Drumchapel, Partick, Dennistoun, Royston and Castlemilk provide facilities for 17 groups for over 65 hours per week in addition to more ad hoc use. There are currently 107 active volunteers for the Macmillan @ Glasgow Libraries.

Stakeholder Views

Most stakeholders were aware of Macmillan @ Glasgow Libraries and understood what the service offered.

Non-clinical professionals/service providers were both more likely to be aware of Macmillan @ Glasgow Libraries and to understand it fully.

Macmillan @ Glasgow Libraries was regarded by stakeholders as a valuable, reliable and high-quality service, which met the needs of those affected by cancer and was well-integrated into the network of cancer support.

Although 61% of stakeholders felt that people affected by cancer were well supported outside tertiary treatment settings, 53% felt that people affected by cancer were largely unaware of where to obtain information and support. This rises to 75% in respect of family and friends of those with a diagnosis.

Macmillan @ Glasgow Libraries Volunteer Views

Volunteers were very proud to be a part of the service, taking pleasure in their role and generally feeling confident in their abilities to support people as a result of training received, day-to-day support and their understanding of their role.

Volunteers reported a range of benefits from volunteering, with the most common being personal satisfaction.

In the volunteers' opinion, emotional support was considered the most important support that the service offered, followed by information and signposting and counselling. It was generally felt by volunteers that the needs of those affected by cancer were met by the service.

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.

Staff believed it to be an important and well-situated service with positive impacts for both service users and the library more widely although the space and resources provided by Macmillan could be used more effectively when volunteers were not present.

Service User Views

The support needs of service users reflect 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 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 advice from volunteers, and access to counselling and complementary therapies, was widely acknowledged, with a quick chat with a volunteer useful in stopping a little niggle 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.

Key Conclusions and Recommendations

- Overall, the service is considered to be of high quality and important, with feedback from service users overwhelmingly positive
- The service has scope to increase service numbers within current resources, although sustained promotion of the service is required
- The lack of coordination of the range of Macmillan services in Glasgow is hindering individual services and there is no coherent offer for those affected by cancer
- Glasgow Life have made a good start at integrating the service, but more is needed to make it part of its core business. The early signs from the sustainability pilots are promising, but there are a still a number of risks.

1 Introduction

Rocket Science, in partnership with Consilium Research and Consultancy, was commissioned in early 2016 to evaluate Phase 2 of the Macmillan @ Glasgow Libraries programme.

The Macmillan @ Glasgow Libraries service is a tiered model of Macmillan Cancer Information and Support Drop-in Services, which aims to provide cancer-related support and information for people in their local communities through libraries and other community venues. It has 35 Cancer Information and Support Service points across the city's libraries. 16 of these are volunteer-led drop in services, with a further 19 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.

Phase 1, launched in June 2012, saw volunteer-led services being delivered through a 'hub and spokes' 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 all operational management and funding.

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
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	B. Library staff and volunteers are considered knowledgeable about cancer support available, supportive, welcoming and respectful
	C. Support is received in a timely and flexible manner that reflects need
	D. Service users report that they are well informed, supported 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	E. Service is sustainably integrated into Glasgow Life core business F. Service is part of an integrated cancer support network in Glasgow
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 profile 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.

To inform this interim 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 a staff focus group with project staff
- Conducted interviews with service users.

Since the interim evaluation it was decided, in discussion with the Macmillan service team, not to conduct observations of the use of library space or analyse the turnover of written material. Both would require 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 this time spent.

We had set up the MoveMore phoneline to collect data on those who did not use the service. Due to staff turnover within the MoveMore team, this only lasted a short period of time and isn't included in this report. We also intended to gather information from Improving the Cancer Journey (ICJ) Glasgow about those who were referred or signposted to Macmillan @ Glasgow Libraries. Due to staff availability, there has been a delay in collecting this information. We expect to have this information available in September 2017 and will provide a short note to the evaluation committee about the key findings from this analysis.

We have started scoping a possible cost-benefit analysis for the evaluation. This is not included in the interim report.

This report is the interim evaluation and is structured as follows:

- Chapter 2 analyses the programme data available
- Chapter 3 outlines the key stakeholder views from our survey and interviews
- Chapter 4 contains the findings from our volunteer survey and focus group
- Chapter 5 presents the views of library staff
- Chapter 6 sets out the messages from our interviews with service users
- Chapter 7 presents our conclusions and recommendations.

The staff focus group was used to work through the key messages of the evaluation and therefore does not have its own chapter.

The final evaluation report is expected in June 2018.

2 Service Analysis

This chapter outlines the key messages arising from the analysis of the service data collected by the Macmillan @ Glasgow Libraries Staff Team. In-depth data analysis can be found in Appendix 1.

Market penetration of the service

"Overall, *3% of men and 4% of women* in Scotland are living with cancer (3,052 and 3,866 per 100,000 population respectively"¹. Applying this to Glasgow City's 2016 population this means that there were *8,970 men and 12,640 women* living with cancer in Glasgow in 2016.² In Glasgow City there were 3,449 new cancer registrations in 2013³ and 3,440 in 2014.⁴

In comparison, there were 2,446 recorded visits to Macmillan @ Glasgow Libraries in 2016. 1,432, or 59% of these visits were first time visitors. 938 of all visitors in 2016 were people affected by cancer, 248 of those were first time visitors.

Over the period October 2015 to May 2017, the Macmillan @ Glasgow Libraries saw 631 new visitors who categorised themselves as a person with cancer.

Assuming that those affected by cancer are the same population living with cancer, this means that in 2016 *Macmillan @ Glasgow Libraries saw the equivalent of 7.2*% of new cancer registrations using the 2014 rate of new cancer registrations. Over the period October 2015 to May 2017, the *Macmillan @ Glasgow Libraries service saw nearly 3% of all people living with cancer.*

Awareness of the service

The value of a community-based service is emphasised by the fact that 15% of all first-time users find out about the service by 'passing by' a library compared to 9% hearing about it from other 'Macmillan services' and 6% from 'libraries' themselves. The large variety of methods of engaging people affected by cancer emphasises both the strength of partnership working to date and the potential for further referrals in the future.

A total of 1,343 referrals were made into the Macmillan @ Glasgow Libraries service between January 2014 and May 2017. Just over 94% of all referrals since January 2014 have come from the Improving Cancer Journey (ICJ) programme, a

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¹ Source: ISD, Cancer in Scotland (April 2017). http://www.isdscotland.org/Health-Topics/Cancer/Publications/2017-04-25/Cancer_in_Scotland_summary_m.pdf

 $^{^2}$ Based on ONS Population estimates - local authority based by single year of age (2016) – downloaded from NOMIS

³ Source: ScotPHO Online Profile Tool, https://scotpho.nhsnss.scot.nhs.uk/scotpho/profileSelectAction.do

 $^{^4}$ Source: ISD. Not published data, sent by Craig from Macmillan. Persons aged over 25.

health professional or Macmillan Long Term Conditions reflecting the development of the ICJ service and the relevance of the service to meeting the holistic needs of people affected by cancer.

The Macmillan @ Glasgow Libraries is currently referring service users to a wider variety of other services than they are receiving referrals from. This is thought to be both in line with the ethos of the service in meeting the personalised needs of people affected by cancer and reflective of the proactive and stable nature of the staff team compared to most other services.

Engagement with the service

A breakdown of the 4,062⁵ service user numbers by location reveals that 18% of engagement with service users is through outreach activities and 10% through the office. This is a reflection of the importance of outreach work or telephone triage to guide enquiries to the best local library or alternative support service. Dennistoun accounted for the highest proportion of visitors overall at 12%.

The value placed on the service, and the availability of complementary therapies and counselling support at local libraries, is reflected in the proportion of repeat service users at each site. For example, 74% of Drumchapel attendances during Phase 2 were repeat visits, whilst more than half of the visitors to Royston, Parkhead, Partick, Dennistoun, the Gorbals and Elder Park library services were also return service users. Consultation also revealed how service users enjoyed accessing the service on a regular basis once they had engaged, making the most of a local site to access either complementary therapies or counselling, or just a chat with a volunteer.

Visitor Profile

Statistics generated by a sample of service users show that the Macmillan @ Glasgow Libraries service is supporting people across the cancer journey including those yet to receive a diagnosis and people having suffered a bereavement. Almost one in three services users (29%) are receiving support during their treatment and just over one quarter (27%) whilst they are living with cancer.

Approximately two thirds of both first time and repeat service users are female which is line with access profiles of Cancer Information and Support Service in general. It is also thought to correlate with a wealth of evidence showing men are more reluctant to ask for support than women, and a greater ease or willingness amongst women to talk about their feelings.

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⁵ There were 4,062 visits between October 2015 (the beginning of Phase 2 of the pilot) and May 2017. See Appendix 1 for more detail.

Whilst just over half of services users were affected by cancer themselves, feedback from service users highlights the relative success of the service in engaging with family members or carers, accounting for 34% of visitors.

This is judged to help meet a common gap in services either commissioned specifically for patients or failing to engage effectively with carers and family members, eg 67% of carers experience anxiety and 42% experience depression with over three quarters not receiving any support⁶.

The value of services which meet the needs of carers is clear given the growing need and impact of carers in the UK. Numbers are projected to rise to approximately 9m by 2037⁷ with the economic value of the contribution made by carers seen to have almost doubled between 2001 and 2015 from £68bn to £132bn⁸. Crucially however, research also highlights the potential negative impact on carers' mental health, quality of life⁹, social isolation¹⁰ and physical health¹¹, reinforcing the value of services which carers are willing and able to access.

Service Provision

The value of the service in providing emotional support for people affected by cancer and their family members or carers is reaffirmed by over 1,000 people accessing the service looking for someone to talk to. This was by far the most popular element of the service offer, gaining over twice as many responses than the next most popular reason for visiting – 'to find out what services are available to them'.

Use of Capital Build Space

The value of the capital investment in five of the libraries hosting the service extends beyond supporting people affected by cancer by providing comfortable and practical environments for use by library visitors and staff, but also community groups and public and third sector organisations requiring a community venue for service delivery. The Macmillan branded spaces in Drumchapel, Partick,

⁶ Cardy P. Worried Sick: The emotional impact of cancer. Macmillan Cancer Support. 2006

⁷ Carers UK. Facts about carers. Policy Briefing, 2014.

⁸ http://www.carersuk.org/for-professionals/policy/policy-library?task=download&file=policy_file&id=5479

⁹ L. Etters, D. Goodall, B.E. HarrisonCaregiver burden among dementia patient caregivers: a review of the literature

J. Am. Acad. Nurse Prac., 20 (8) (2008), pp. 423-428

¹⁰ L. Smith, M. Lawrence, S. Kerr, P. Langhorne, K.LeesInformal carers' experience of caring for stroke survivors

J. Adv. Nurs., 46 (2004), pp. 235-244

¹¹ J. Robinson, R. Fortinsky, A. Kleppinger, N.Shigue, M. PorterA broader view of family caregiving: effects of caregiver conditions on depressive symptoms, health, work, and social isolation

J. Gerontol.: Soc. Sci., 64 (2009), pp. 788-798

Dennistoun, Royston and Castlemilk provide facilities for 17 groups for over 65 hours per week in addition to more ad hoc use by another 10 organisations, groups, MSPs and Councillors.

This multiple-use of the spaces generates value for money and reinforces libraries as hosts for information exchange and support for more groups within society and the local community.

Volunteer Profile

There are currently 107 active volunteers for the Macmillan @ Glasgow Libraries service with the growth in libraries offering the service reflected in the recruitment of 33 volunteers in 2016 – the highest number recruited since the service began.

- 80% of the volunteers are female which compares to 67% of service users overall and 58% of the estimate of those with cancer in Scotland.
- 16% of volunteers have been diagnosed with cancer previously.

3 Stakeholder views

Between January and June 2017, we surveyed and interviewed a range of stakeholders from partner organisations and other service providers. The list of interviewees and the interview and survey questions can be found in Appendix 2.

This chapter outlines the key messages from the survey and interviews including thoughts on the:

- Awareness of Macmillan @ Glasgow Libraries
- Quality and value of Macmillan @ Glasgow Libraries
- Integration and management of Macmillan @ Glasgow Libraries.

68 stakeholders completed at least part of the survey, with 52 completing all questions. Of the 68 that started the survey:

- 33 (49%) were clinical professionals or a clinical service provider
- 20 (29%) were non-clinical professionals or a non-clinical service provider
- 13 (19%) said that their clients could be referred or signposted to Macmillan @ Glasgow Libraries
- 11 (16%) said that Macmillan @ Glasgow Libraries could refer or signpost service users to my service

The graphs in this chapter that break down survey responses include all stakeholders who responded to the question.

Summary

Most stakeholders were aware of Macmillan @ Glasgow Libraries (84% had heard of the service) and understood what the service offered (79% understood at least most of what was offered). Non-clinical professionals/service providers were both more likely to be aware of Macmillan @ Glasgow Libraries and to understand it fully.

Macmillan @ Glasgow Libraries was regarded by stakeholders as a valuable, reliable and high-quality service, which met the needs of those affected by cancer and was well-integrated into the network of cancer support. There was a variety of opinions with regard to how well-managed the service was and whether a volunteer-run service decreased confidence in referring into Macmillan.

Although 61% of stakeholders felt that people affected by cancer were well supported outside tertiary treatment settings, 53% felt that people affected by cancer were largely unaware of where to obtain information and support. 75% of stakeholders felt that the family and friends of those with a diagnosis were largely unaware of where they could obtain information and support. Even when people with a diagnosis (or those affected by their diagnosis) were aware of support and information, there still seemed to be an issue regarding access to this help with 31% of stakeholders feeling that there were barriers to access for people affected by cancer, and 15% of stakeholders feeling there were barriers to access for their friends and family.

Stakeholders were most likely to informally mention Macmillan @ Glasgow Libraries to people, rather than signposting or formally referring into the service. Non-clinical professionals were more likely to have mentioned Macmillan @ Glasgow Libraries frequently, than clinical professionals.

Awareness of Macmillan @ Glasgow Libraries

Interview findings

The stakeholders we consulted highlighted the scale and quality of the work of the Macmillan @ Glasgow Libraries team, and the Programme Manager in particular, in working to raise awareness of the service. However, the majority of stakeholders also highlighted the scale of the task faced by the service, in not only raising awareness, but crucially also influencing changes in working patterns (eg signposting and referring) among clinical professionals and a range of service providers.

This task is made all the more difficult by the complexity of the cancer network and the 'internal competition' generated by overlapping services seeking to justify their position. Whilst good in terms of providing greater options for accessing support, a number of stakeholders stressed that the cancer support network could often be confusing for people affected by cancer, given the range of referral routes and pathways. Crucially however, it can be equally confusing for clinical staff. This is especially the case given the large numbers of patients coming through large/regional mainstream services and the availability of different service offers with a resulting need to continually reinforce awareness raising.

Stakeholders provided a range of views on the effectiveness of communications and marketing activity to promote and raise awareness of the service (primarily amongst people affected by cancer) with the majority praising the actions of the team. Indeed, both the external and internal marketing of the offer within the libraries service was repeatedly stated to have been much better than other colocated services. In particular, the capital builds are judged to provide a clear visible presence in the libraries, although stakeholders highlighted the benefits of additional permanent external branding outside the venues to help make people aware of the offer inside.

A consistent theme from all stakeholders, particularly given the breadth of services available to both health and social care staff and people affected by cancer, was the need for continual reinforcement of the presence, role and value of the Macmillan @ Glasgow Libraries service. This is typical of community-based services which often represent just one option for the range of practitioners, advisers and service providers making referrals across a range of themes and subject areas including health and social issues. Crucially, there is a need to work at multiple levels to influence buy-in amongst strategic (eg Health Board and Health and Social Care Partnerships), management and delivery staff to highlight the value of community-based care and the role of emotional support and information provision within this. This could include direct links through partnership working in local communities and wider service-specific marketing to reinforce the existence, role and potential impact of the support.

Stakeholders highlighted the role of the Macmillan Programme Manager in attending meetings and presenting at a variety of forums as well as working with a range of partners to reinforce key messages. However, the delivery and updating of messages to frontline staff requires a wider pool of staff to engage regularly with a range of busy professionals who are themselves subject to similar approaches from a host of similar services including both Macmillan and other charities (cancer and other long-term conditions). The staff member responsible for coordinating this activity across the city for all Macmillan services has left and was not replaced. This has not helped the work of the Macmillan @ Glasgow Libraries staff team in its efforts to raise awareness effectively and efficiently.

The service has shown the value of more intensive work and relationship building with partners in small geographic areas (eg the work of the Engagement Coordinator in Easterhouse), but the resources are not available to replicate and repeat this work across the service area. This will reduce the rate at which the service is able to generate higher levels of take-up and inform future plans on expansion or continued investment.

It is this partnership working that the service relies upon to generate demand with activities to stimulate referrals including an e-newsletter sent to 750 partners, presentations to raise awareness, outreach work in health and community venues and close working relationships with key partners including the Citizens Advice Bureau at a local level. This is not matched however by national Macmillan marketing across the city which reinforces the established view of Macmillan amongst many people of end of life care and Macmillan nurses as opposed to the libraries service.

A small number of stakeholders queried the extent to which the service had utilised other partners, particularly the sports and exercise services within Glasgow Life which offer both community venues and access to a larger and broader spectrum of potential service users. Other potential avenues which were queried include the promotion and potential joint offer moving forwards through social housing organisations (e.g. Wheatley Group) and umbrella third sector organisations (e.g. Glasgow Council for the Voluntary Service), emphasising the value of other community venues and organisations that could house or signpost towards drop in services.

Survey findings

Over half of stakeholders that responded to the survey fully understood the Macmillan @ Glasgow Libraries service offer, with the majority understanding at least most of what the service does.

Only 16% of those who responded to this question had not heard of the service. For those who had heard of Macmillan @ Glasgow Libraries, only 5% did not understand what it did, suggesting there was generally good knowledge of the service amongst those aware of it, as outlined in Figure 2 (overleaf).

Overall awareness of Macmillan @ Glasgow Libraries

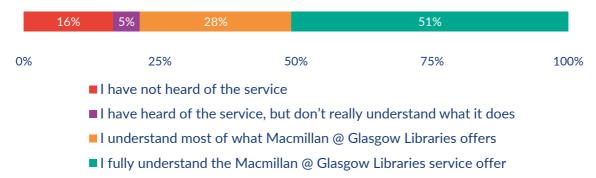


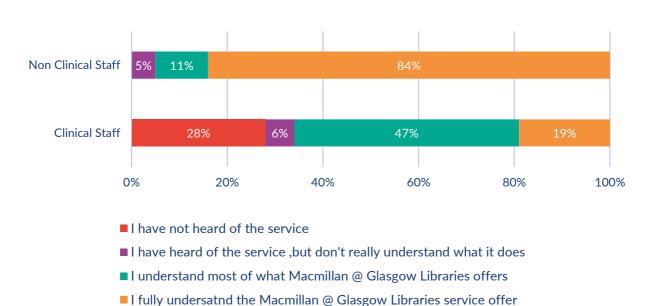
Figure 2 Service awareness by medical staff

However, when comparing clinical and non-clinical professionals, a marked difference appears. Clinicians reported being far less aware of the service, and less likely to fully understand what it offers, than non-clinical professionals. This has clear implications for their propensity to signpost and/or refer people affected by cancer to the libraries service.

Anecdotally, clinicians were felt to often fall back to existing and/or trusted relationships with established partners offering a combination of clinical and non-clinical support rather than explore one of a number of new service offers.

Over a quarter of those who identified themselves as clinical professionals/clinical service providers had not heard of Macmillan @ Glasgow Libraries. Though 66% did understand most of what the service offers, only 19% fully understood it.

Non-clinical professionals/service providers had heard of Macmillan @ Glasgow Libraries and the majority fully understood the Macmillan @ Glasgow Libraries offer.



Awareness of Macmillan @ Glasgow Libraries

Figure 2 Service awareness by clinical/non-clinical

95% of non-clinical professionals/non-clinical service providers understood at least most of what Macmillan @ Glasgow Libraries offers, with 84% fully understanding what the service offered. A small percentage of non-clinical and clinical professionals had heard of the service without understanding most of what it does. No non-clinical professionals stated that they had not heard of Macmillan @ Glasgow Libraries.

Stakeholders felt that large proportions of people with a cancer diagnosis, and those affected by a friend or family's diagnosis, were unaware of where to obtain support and information. However, those with a cancer diagnosis were more likely to be aware of it than their family members and friends given their closeness to sources of advice and guidance during treatment.

Service users also emphasised that an overload of information, especially on or shortly after diagnosis, was often ignored in the first instance until they had come to terms with the news and were in a better place to respond. This reinforces the need for a local source of trusted information, such as a local library, to access information and support either from a leaflet or volunteer when ready to do so.

Three-quarters of stakeholders felt that those who had been affected by a friend or family member's diagnosis were largely unaware aware of information and support. Over half felt that those directly affected were equally unaware of where to go.

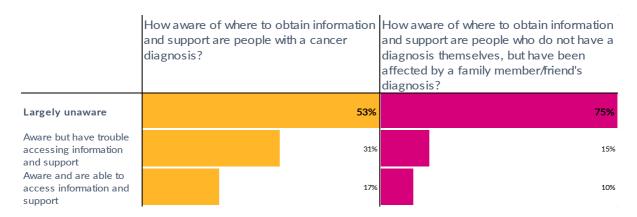


Figure 3 Service awareness by people with cancer and family/friends

In addition, stakeholders felt that there were a reasonable group of those affected by cancer who were aware of where to obtain information and support but would have trouble accessing services – for example due to transport or ill-health.

Though 48% of people with a cancer diagnosis were felt to be aware of services, 31% were felt to have trouble actually accessing this information and support. Only 17% of those diagnosed with cancer, and just 10% of those affected by someone with a diagnosis, were considered to be both aware *and* able to access information and support.

Although only supported by anecdotal evidence linked to the investment in cancer services in Glasgow by a trusted brand such as Macmillan, the most common opinion of stakeholders was that outside tertiary treatment settings, people affected by cancer were well supported by other services, with over 60% believing they were at least adequately supported. However, few thought they were very well supported (Figure 4 overleaf).

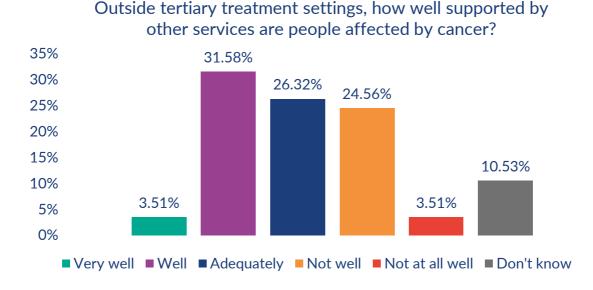


Figure 4 Views on how well supported people affected by cancer are

32% (almost a third) of stakeholders thought individuals affected by cancer were well supported by other services outside tertiary treatment settings. A further 26% felt they were adequately supported.

8% of stakeholders felt very strongly regarding this issue, with 4% stating that people affected by cancer were very well supported, and the same percentage feeling they were not at all well supported.

A quarter of stakeholders thought they were not well supported, and 11% did not know.

Quality and value of Macmillan @ Glasgow Libraries

Interview findings

The majority of stakeholders provided a very positive view on the quality and value of the Macmillan @ Glasgow Libraries service. This emphasises its value in providing an alternative pathway to the range of support for people affected by cancer, accessed either through treatment directly or, for example, the Improving the Cancer Journey programme.

Stakeholders also confirmed the value of the information provided both through drop in services and information points. Crucially, they highlighted the value of an informed chat and emotional support from the volunteers in a local and trusted environment - reinforced by the quality perceptions of the Macmillan branding.

They also stressed the need for culture change amongst health and social care staff (ie around a sense of over-protectiveness towards service users and related reluctance to move from longstanding care pathways) if the value and potential of the service is to be maximised.

The network of support available was praised, from the set up at the Mitchell Library to the offer available through the settings across the city. Stakeholders had particular knowledge of, and trust in/praise for, those libraries benefiting from a capital build. These were seen as crucial in promoting a holistic service; combining the support of volunteers and the counselling and complementary therapies delivered through Cancer Support Scotland in a professional and appropriate environment.

The key aspect of the offer was the potential for the service to provide both reassurance and a trusted brokerage role, either directly through the volunteers or the information points - especially for those not wanting to chat, to a range of other services. Stakeholders also recognised the potential for a host of health and non-health organisations to utilise the spaces with the potential for cross-referrals and information exchange at both at provider and service user level as more people come in contact with the improved libraries offer.

Stakeholders were able to directly attribute only a marginal increase in demand for libraries services to the Macmillan @ Glasgow Libraries service. This is however in line with expectations given the low numbers of people accessing the service at selected times on usually only one day a week.

The majority of any increase in footfall within libraries can be linked indirectly to the service, but will be more directly related to the use of the Macmillan spaces by organisations delivering services in the community throughout the remainder of the week. This will however help to raise the profile of libraries as community hubs for a range of information and services and contributing to a general consensus amongst libraries staff that the service had helped to bring the libraries closer to the community. In particular, it was felt that the public saw and valued the capital investment in the service/building and the positive impression of Macmillan-supported volunteering at a local level.

Survey Findings

Stakeholders felt strongly that Macmillan @ Glasgow Libraries was valuable, both as part of the cancer information and support network in Glasgow, and to those affected by cancer who use it. 82% of stakeholders either agreed or strongly agreed that Macmillan @ Glasgow Libraries was an important and valuable part of the cancer information and support network in Glasgow. Only 7% disagreed, with under 2% strongly disagreeing. 11% were not sure.

Macmillan @ Glasgow Libraries is an important and valuable part of the cancer information and support network in Glasgow

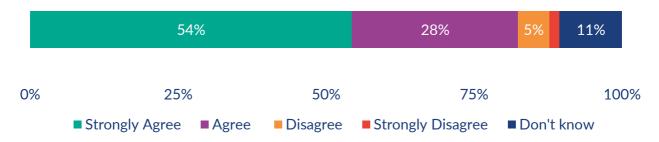


Figure 5 Perceived value of the service

81% of stakeholders either agreed or strongly agreed that Macmillan @ Glasgow Libraries offered valuable support to those affected by cancer. Again, only 7% disagreed with under 2% strongly disagreeing. 12% were unsure.

Macmillan @ Glasgow Libraries offers valuable support to those affected by cancer

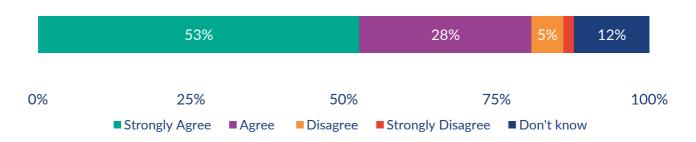


Figure 6 Perception of service as source of valuable support for those affected by cancer

Most stakeholders felt that Macmillan @ Glasgow Libraries met the needs of people diagnosed with cancer and their friends and family.

84% of stakeholders either agreed or strongly agreed that Macmillan @ Glasgow Libraries met the needs of people with a cancer diagnosis. No-one strongly disagreed with this statement, and only 4% disagreed at all. 13% did not know, which could be due to the lack of awareness of the service stated previously by some.

Most stakeholders agreed (53%) or strongly agreed (31%) that Macmillan @ Glasgow Libraries meets the needs of people with a cancer diagnosis. Most stakeholders also agreed (49%) or strongly agreed (25) that Macmillan @ Glasgow Libraries meets the needs of friends and families of those with a cancer diagnosis.

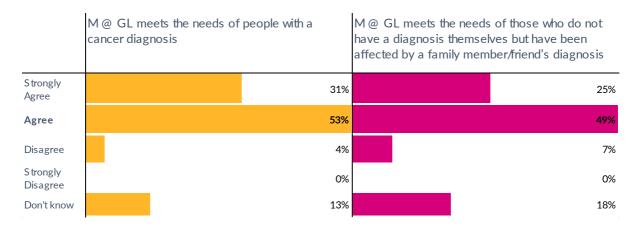


Figure 7 Perceptions of extent to which service meets needs of those with a cancer diagnosis, and friends and family

Almost all stakeholders believed Macmillan @ Glasgow Libraries services to be reliable and of high quality

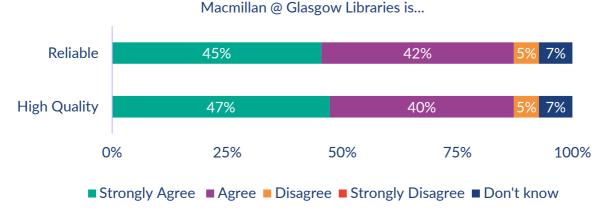


Figure 8 Perceptions of service reliability and quality

87% of stakeholders agreed or strongly agreed that Macmillan @ Glasgow Libraries was reliable. Only 5% disagreed, with no-one strongly disagreeing. 7% did not know. 87% of stakeholders agreed or strongly agreed that Macmillan @ Glasgow Libraries service was of high quality. Again, just 5% disagreed, with no strong disagreement. 7% did not know. These patterns did not vary greatly between clinical and non-clinical responses.

Integration and management of Macmillan @ Glasgow Libraries

Interview Findings

Discussions with stakeholders explored the degree to which the Macmillan @ Glasgow Libraries service is integrated into both the libraries and wider cancer networks in Glasgow.

The majority of stakeholders felt the service added value to both the libraries service and wider cancer network through a friendly and relaxed community-based and 'non-clinical' approach. This was considered to help service users to relax and focus on the advice/support being provided by the volunteers and other partners they currently access or could do after accessing the libraries service.

The Macmillan @ Glasgow Libraries service was seen as integrated into the cancer network by a slight majority of stakeholders. There was an underlying feeling amongst stakeholders that a more fundamental review was required (of all services across the entire cancer referral network) to determine and illustrate the extent and format of the role of services like Macmillan @ Glasgow Libraries within a coordinated package of support. This would provide clarity both on the extent of integration and the scale of success to date relative to the reports and perceptions of relatively low numbers of service users and referrals.

It is also true that a virtuous circle exists, with take up and positive feedback influencing more - and more effective - referrals and signposting activity. It is recognised that forthcoming developments with the NHS Inform service will aid this work both in terms of reducing the confusion amongst staff and people affected by cancer of the support available to them, and strengthening the referral and signposting mechanism between services. Most GPs and primary care staff are felt to be influenced by data on demand, which, when combined with case studies and trust in centralised information services including Aliss, will result in heightened awareness and use of the service in the longer term if effectively integrated in the short to medium term.

Unfortunately, the process of referrals and signposting will not always run smoothly. This may have implications for the efficient movement of people between support services. The service offer may not be convenient in terms of timing or location for example, or carers may not fully appreciate the availability and benefits of the service.

Discussions with both stakeholders and service users also highlighted the relative ineffectiveness of providing too much information about services they could find of benefit at different stages of their cancer journey when they were only just coming to terms with their diagnosis.

Service users also outlined their need, either mentally or physically, to prioritise their uptake of different services (eg Move More, benefits advice etc) according to how they feel and/or the stage of the cancer journey. This has implications for the timing of the promotion of the Macmillan @ Glasgow Libraries service with a need to remind service users of its availability and value.

The Macmillan @ Glasgow Libraries service is seen as almost or fully integrated with the wider libraries service by almost all stakeholders, adding value to and validating the role of libraries in the city. The programme management has been seen to learn from the roll out of the service with the service working from an evolving template tailored to the needs of each library, community and partnership working.

The Macmillan @ Glasgow Libraries service is seen as a core library offer, especially given the evolving role of libraries as information points and a mix of complementary services provided by paid and volunteer staff which the Macmillan service adds to. Indeed, the nature of the drop in facilities adds to the relaxed yet functional (ie a place to meet other people as well as accessing services) nature of the modern library exemplified by the café and Macmillan offer near the entrance to the Mitchell library.

There remain areas however where integration is yet to be fully effective, including the promotion of the service within the wider Glasgow Life offer. This includes the branding of the service offer and its comparative position in marketing campaigns, and the alignment of the online presence with the wider libraries offer. This is concerning as it poses a risk to the service when the Macmillan @ Glasgow Libraries staff team reduces, limiting the amount of promotion they can do. At the moment, it is unlikely that relying solely on Glasgow Life general promotion will allow for sufficient awareness and use of the service. This is addressed in chapter 7.

The service is embedded into Glasgow Life's management and governance processes, driven by the co-location of the Macmillan Programme Manager within the libraries team. However, this raises some concerns in terms of ongoing sustainability and integration as and when direct management capacity is reduced. This is especially the case given the need for continual reinforcement of the service offer with partners, and the public. It is of paramount importance to maintain the Macmillan input in terms of time, if not funding at a strategic level, at least in the short to medium term.

Stakeholders stressed the dangers of reducing the service, particularly given the scale of work that had been undertaken to establish it. They also highlighted the benefits of maximising the use of the new Macmillan spaces by wider partners and the complementarity of the service offer with that required to underpin support for people with other long-term conditions.

Consultation with libraries staff revealed a varied and growing use of the Macmillan spaces outside volunteer time by organisations including CAB, Lifelink, schools, MSPs and councillors, authors giving talks and benefits advisors amongst others.

The introduction of support for a wider range of long term conditions was generally agreed to be a natural next step for the service model. However, it wasn't seen as an immediate priority given the planning required with a need to truly illustrate demand for the Macmillan @ Glasgow Libraries service first.

Survey Findings

Most stakeholders think that Macmillan @ Glasgow Libraries is a well-integrated service within the broader cancer support network.

70% of stakeholders believed that Macmillan @ Glasgow Libraries was well-integrated, with 22% feeling strongly that this was the case. Only 10% disagreed or strongly disagreed, though 20% did not know whether it was well-integrated.

Macmillan @ Glasgow Libraries is a well-integrated service within the broader cancer support network

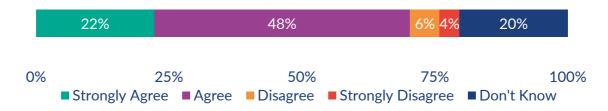


Figure 9 Perception of integration of the service in the wider support network

Management of Macmillan @ Glasgow Libraries was generally felt to be good, although many (20%) did not know enough about the service to answer.

Macmillan @ Glasgow Libraries is a well-managed service

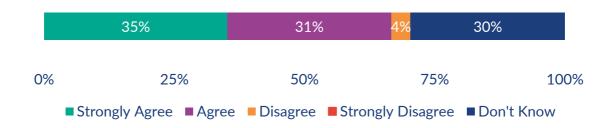


Figure 10 Perception of management of the service

Non-clinical professionals, as a group, felt much more positively about the management of Macmillan @ Glasgow Libraries than clinical professionals. Over half of non-clinical professionals felt strongly that the service was well-managed, compared to 10% of clinical professionals.

It was much more common amongst clinical staff than non-clinical staff not to know whether Macmillan @ Glasgow Libraries was well managed or not.

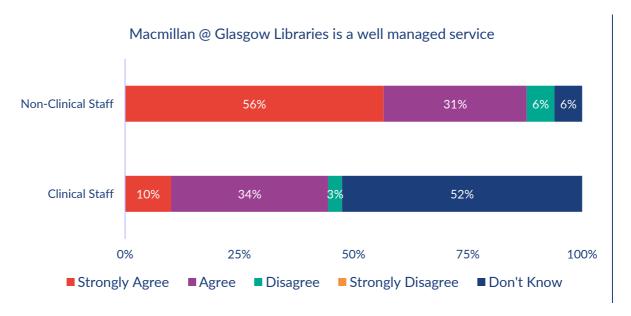


Figure 11 Perception of management of the service by clinical/non-clinical

A volunteer-run service, as opposed to paid staff, did not generally impact on stakeholders' confidence in referring to Macmillan @ Glasgow Libraries. However, non-clinical staff displayed a greater range of opinions than clinical staff, with 22% of non-clinical staff strongly feeling that their confidence was reduced.

Overall, 82% of stakeholders agreed or strongly agreed that their confidence in referring was not decreased by a volunteer-run service. There was greater variation in non-clinical professionals' views. More non-clinical than clinical professionals strongly agreed that a volunteer-led service did not decrease their confidence in referring, but also more strongly disagreed.

Consultation with health practitioners highlighted a lack of full awareness of the scope of the libraries service which could underpin a reluctance to refer or signpost people affected by cancer to the service. In addition, we found mixed evidence regarding whether the non-clinical nature of the libraries service posed an issue for clinical staff referring to the programme. This is an area for further investigation in the lead up to the final evaluation.

A volunteer-run service does not decrease my confidence in referring to the service

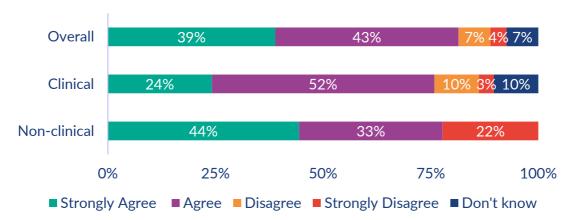


Figure 12 Perceptions of impact of volunteer status staff on referral confidence

Stakeholders are more likely to informally mention Macmillan @ Glasgow Libraries to people than they are to signpost them to the service, and far more likely to signpost than to formally refer them. Signposting seems to be preferred over formally referring.

44% of stakeholders frequently mention or tell people about Macmillan @ Glasgow Libraries, with a further 33% sometimes doing so. Only 10% never mentioned the service to people. 34% of stakeholders frequently signposted people to Macmillan @ Glasgow Libraries but only 15% frequently formally referred them to the service.

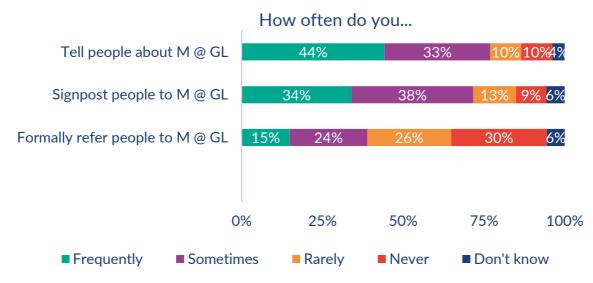


Figure 13 Relative frequency of telling, signposting and formally referring people to the service

When clinical and non-clinical professionals are compared, there is a noticeable difference between them.

Figures 15 and 16 show that non-clinical professionals are more likely to frequently mention, signpost or formally refer someone to Macmillan @ Glasgow Libraries than clinical professionals. This links to non-clinical professionals reporting more awareness of the service than clinical professionals.

Clinical and non-clinical professionals follow the same pattern of being most likely to mention Macmillan @ Glasgow Libraries informally, followed by signposting then formally referring them. However, more non-clinical professionals frequently do all three than clinical professionals, with no non-clinical professionals reporting that they have never signposted people to Macmillan.

Non-clinical staff: How often do you...

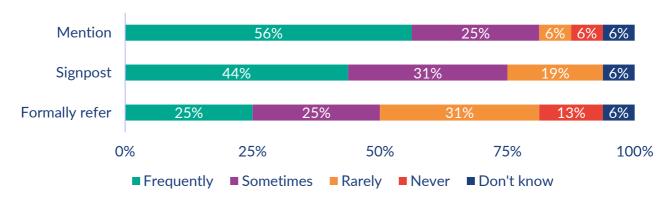


Figure 14



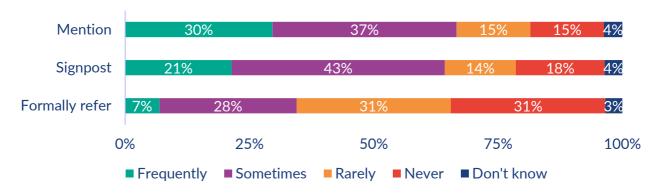


Figure 15

4 Macmillan @ Glasgow Libraries Volunteer Views

During January – June 2017 we surveyed the Macmillan @ Glasgow Libraries Volunteers. 112 volunteers answered at least some of the survey questions¹², 39 answered all the questions. The graphs in this chapter that break down survey responses include all **volunteers** who responded to the question.

On 25 July, we also ran a volunteer focus group to understand their views on the service in more detail. This was attended by 4 volunteers.

This chapter outlines the views captured through the survey and focus group. Appendix 3 outlines the volunteer research materials.

The key messages from volunteers are around the

- Quality of the service
- Accessing the service
- The needs of service users
- The volunteer experiences
- Improvements and suggested changes by volunteers.

¹² We understand that some volunteers lost the original page and so started again. This may explain why there were 112 entries but 107 volunteers. We were unable to control for these repeats.

Summary

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 training, day-to-day support and their understanding of their role, which were all reported as being generally good. Volunteers 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 the Macmillan @ Glasgow Libraries service in a year's time.

Library facilities, written and verbal information given and complementary therapies were all considered 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 the Macmillan @ Glasgow Libraries programme team and the fear of losing these.

Respondents to the survey came from a variety of Libraries and outreach locations. The figure below shows the breakdown of respondent by location. 2 volunteers said they would prefer not to say which library/outreach centre they were from, and the respondent who stated "Other" added that they were from "Helping Matters".

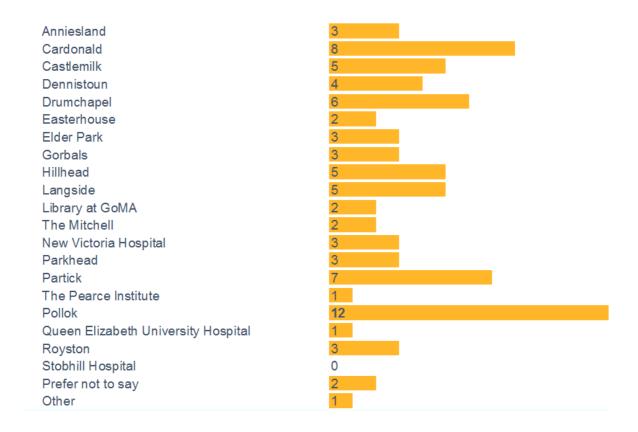


Figure 16

Quality of services

Most volunteers feel promotion of the service is either good or excellent. No volunteers feel it is "very poor". Most volunteers (82%) felt that the promotion of the service is either good (67%) or excellent (15%). 11% of volunteers felt it was adequate and 7% that it was in fact poor. No one said it was very poor.





Figure 17

Figure 19 shows that there was a consensus amongst volunteers that the quality of library facilities was very high. Not one respondent felt facilities supporting the services were poor. 92% of volunteers felt that the quality of library facilities was at least good, with 38% perceiving them as excellent. Just 8% felt they were only adequate and no one felt they were poor or very poor.





Figure 18

The quality of verbal information was considered good or excellent by most volunteers. Every respondent felt that the written information given was at least good, with over half considering it excellent.

53% of volunteers consider the written information provided by Macmillan @ Glasgow Libraries to be excellent. No volunteers rated it as adequate, poor or very poor.

Verbal information was also considered generally good, with 38% considering it excellent. However, 2% felt it was just adequate, with 4% considering the verbal information provided by volunteers was poor. No volunteers felt verbal information provided by volunteers was very poor but 6% did not know the quality of it. This will be explored further in interviews with volunteers to establish what the 4% who rated it poor, and the 6% who doesn't know the quality of the information provided, meant.



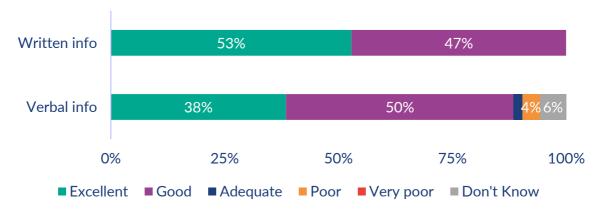


Figure 19

Around three quarters of volunteers believed both the complementary therapies and counselling services, offered in partnership with Cancer Support Scotland at Macmillan @ Glasgow Libraries, to be good or excellent. No-one felt strongly negatively about either, although 6% did consider the complementary therapies poor. We understand that this 6% may be due to issues where services were withdrawn from particular libraries or around double bookings or last minute cancellations which were reported to occur.

Volunteers seemed to feel similarly about the counselling services and the complementary therapies provided. It is interesting to note that 13% of volunteers did not know whether counselling was good and 15% did not know whether the complementary therapies were good.

Quality of complementary therapies and counselling services

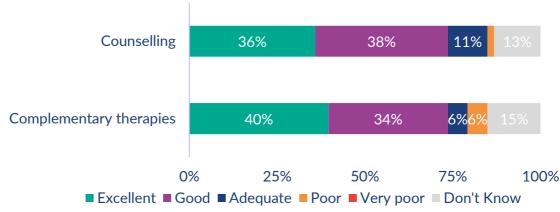


Figure 20

Volunteers were overwhelmingly positive about the service overall. No one felt it was poor or very poor. 94% of volunteers considered the service to be at least good, with 37% believing it to be excellent. Just 6% felt it only to be adequate.

The service overall is:

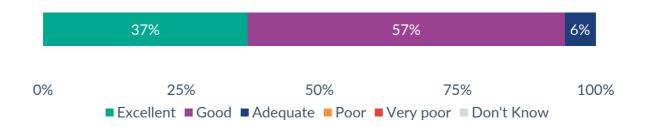


Figure 21

Access to services

Volunteers were asked to rate the ease of access to library services both in terms of the timing (opening hours) of the service and location. Nearly all volunteers (98%) either agreed or strongly agreed that access in terms of timing is good and all of them agreed that the location was good.

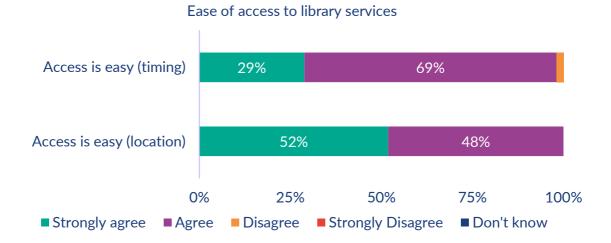
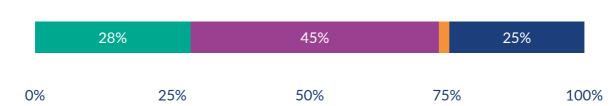


Figure 22

72% either agreed or strongly agreed that the impact of "pop up" events was positive, although a quarter of volunteers stated they did not know the impact of outreach events. 28% of volunteers strongly agreed that the impact of "pop up" events was positive, 45% agreed, 2% disagreed and no volunteers strongly disagreed. 25% were unsure of the impact.



■ Strongly agree ■ Agree ■ Disagree ■ Strongly Disagree ■ Don't know

The impact of outreach "pop up" events is positive

Figure 23

Needs of service users

Volunteers were asked to rank support types in order of how frequently they were sought by people affected by cancer. There were 5 types of support, and the scale was from 1-5 where 1 was most important and 5 was least important. Emotional support had a mean score of 1.81 meaning it was felt most important to people affected by cancer. Information and signposting was next most important, then counselling then benefits information and guidance. Complementary therapies were considered least important and sought after of the five.

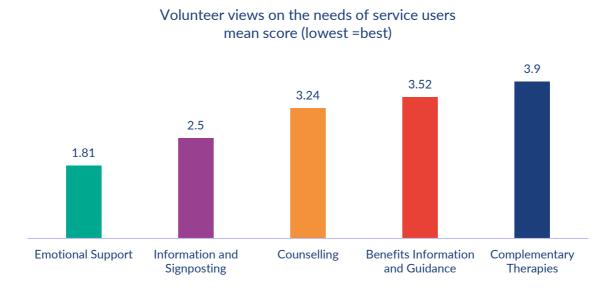


Figure 24

26 volunteers, over 60% of those who answered, thought emotional support was the most sought after form of support. It was considered far more important than all other categories of support put together. This complements the views of stakeholders in the value of a local service offering people affected by cancer the opportunity to find reassurance or comfort in a chat with trusted Macmillan @ Glasgow Libraries volunteer in a friendly environment. Other services, (eg counselling or complementary therapies) are a positive by-product of this initial interaction.

Are there any other forms of support people affected by cancer seek?

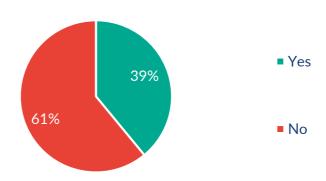


Figure 25

A considerable number of volunteers felt that other forms of support were also sought. Most commonly, volunteers stated that people just wanted "a listening ear" and someone to have "a cuppa" with, "just someone to talk to, not necessarily to do with cancer". Family and sibling support was mentioned as important, as were other activities like gardening.

Nine volunteers independently mentioned people affected by cancer just wanting someone to talk to at Macmillan @ Glasgow Libraries, particularly someone who understood "what they are going through". Several people mentioned that information about support outwith Macmillan or Glasgow had been asked for, and "practical information" reflecting the personalised nature of the support required such as where to access "bras, liners for bras, shampoo for encouraging hair growth/make hair look thicker" or activities to "pass the time". Others mentioned "non-CSS counselling", "travelling expenses to appointments", "support groups" and "physical support".

When asked how often these forms of support were sought, Figure 27 shows that almost half answered "sometimes", with a third reporting that these were sought frequently. This suggests a strong desire for these other forms of support.



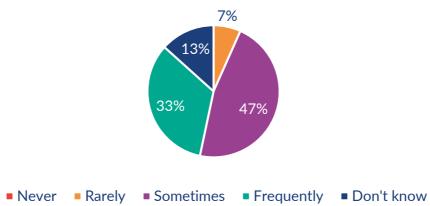


Figure 26

Figure 28 shows that there is a general consensus that people's needs are well met by Macmillan @ Glasgow Libraries, with over half of volunteers considering them very well met. No volunteers felt they were not well met.

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

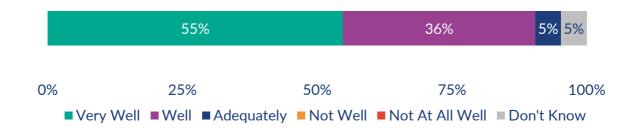


Figure 27

The volunteer experience

Volunteers were asked to rate various aspects of the volunteering experience and the results are shown in Figure 29. Training was most commonly rated as excellent, with 68% rating their training as excellent. 100% of volunteers rated their understanding of their role as at least good. 93% rated the day to day support they received from the project team was good or excellent.

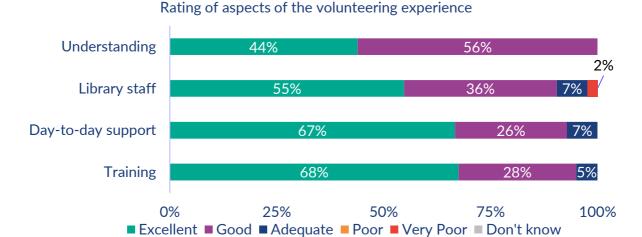
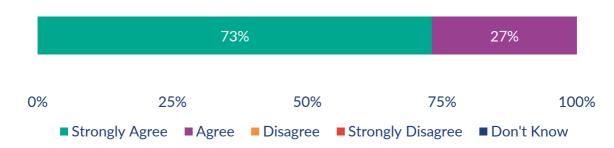


Figure 28

Volunteers had a lot of pride in being part of Macmillan @ Glasgow Libraries. Figure 29 shows that all the volunteers were proud to be part of the service with 73% saying the strongly agreed that they were proud to be part of the service.



I am proud to be a part of the service:

Figure 29

All volunteers felt a degree of confidence in supporting people with cancer, with over half feeling strongly about this. 51% of volunteers strongly agreed that they felt confident supporting people with cancer, with the other 49% agreeing. No volunteers felt unconfident.

I feel confident in supporting people with cancer:

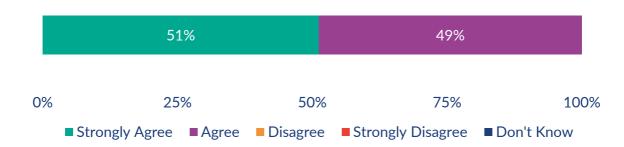


Figure 30

80% of volunteers found the experience very enjoyable. No volunteers reported finding it unenjoyable.

How do you find the volunteering experience?



Figure 31

Potential improvements and expansions of the volunteering role

Volunteers were asked about potential changes and improvements that could be made to volunteering role.

The majority of volunteers wanted more specialised training and more effective relationships with library staff. There was however, less consensus the questions of more volunteering hours and greater responsibility.

55% of volunteers didn't want more volunteer hours. 31% wanted more hours. Opinion about the scale of responsibility wanted as volunteers was divided. 40% did not want to have greater responsibility, however, 38% did.

Around a quarter of volunteers were not sure if the programme needed more volunteers. 63% agreed or strongly agreed that there should be more specialised training, and 66% that there should be more effective relationships with library staff. This mix of responses is expected and has minimal impact for the way the current service is structured which offers volunteers options around hours, training and levels of responsibility.

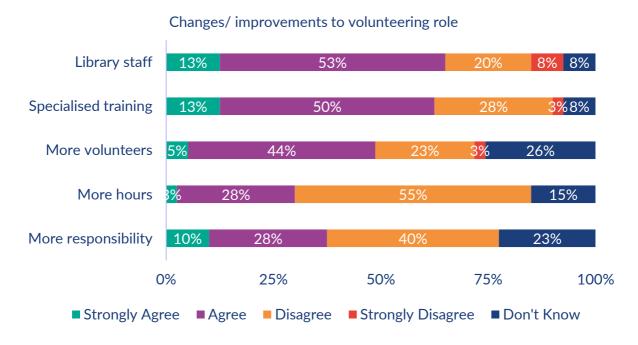


Figure 32

Some volunteers commented on other improvements they would like to see. One of the most popular comments was the need for a "private area" for users who were "not comfortable discussing their problems" or for "sensitive issues". Promotion and advertising were mentioned as in need of improvement. In particular, "more explicit promotion", eg on days when the service was running, was wanted. One volunteer expressed frustration that poor awareness of library services was a problem that recurred "again and again". Some volunteers had practical suggestions such as "weatherproof banners inviting passers-by to use the service on the railings outside the library". The stand-up sign outside was felt to be ineffective. Another suggested that some libraries could open only in the mornings rather than all day, as mornings were busier, with footfall dropping in the afternoon. Similarly, a couple of evening sessions were suggested as was opening at weekends.

Volunteers were asked about what they gained from volunteering and the results are in Figure 34. Volunteers were able to choose all that they felt applied to them, rather than being asked to rank the options or select only one.

Personal satisfaction was the benefit most commonly gained from volunteering for the service (17%). New friends, an opportunity to give something back having been affected by cancer, an opportunity to support the local community, more confidence, transferable or specialised skills, as well as greater connection to others and to the community, were all things gained by lots of volunteers. Fewer felt volunteering improved job prospects and other skills which is unsurprising given most volunteers are retired.

What do you get from volunteering?

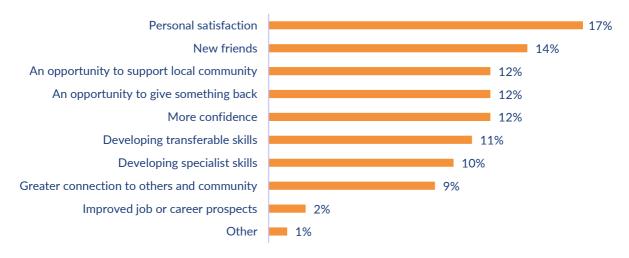


Figure 33

Volunteers are offered accredited training as part of their induction to the service. Volunteers felt overwhelmingly positive towards this training. 78% felt the initial accredited volunteer core training was excellent, and 100% that it was at least adequate.



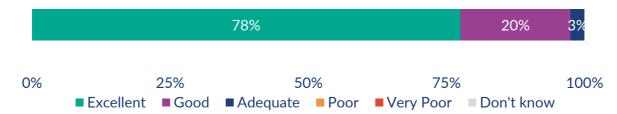


Figure 34

Volunteers are also offered additional learning opportunities. These opportunities were considered excellent by 53% of volunteers and good by a further 43% of volunteers (see Figure 35). No volunteers felt that this programme of training was poor or very poor.



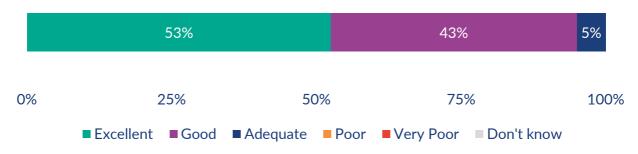


Figure 35

Other informal training and support provided was also rated well by volunteers. 44% rated the information training and support they received as excellent, with a further 46% rating this support and training as good (see Figure 36).

How would you rate the informal training and support you recieved within the services



Figure 36

Figure 37 shows that communication from the Macmillan @ Glasgow Libraries team was considered by the majority of volunteers to be excellent (68%), with a further 25% rating this as good. 5% felt that it was adequate and 3% that it was poor. No-one felt that it was very poor.



Figure 37

When asked if they would still be volunteering with the service in 12 months' time, the vast majority (76%) of volunteers indicated that they would be. Around two in ten (21%) were not sure and a small number (2%) indicated that they would not be.



Figure 38

Volunteers provided some reasons for why they may/may not be volunteering in a year's time and these are shown overleaf.

Yes "Because I get a great deal of satisfaction for doing it"

"It means so much to me to be able to be there for anyone with cancer issues"

"I really enjoy my volunteering with the Glasgow Libraries"

"personal satisfaction, giving back, engagement with community, support from Macmillan team..."

"it's a great feeling when you see the difference in someone from when they first come into the library & they keep coming back & you see the big changes in them"

"Why not? It doesn't take a huge amount of my time, and we really are helping people"

"Team I work with are all really friendly and work well together"

"I enjoy it and do not want to stop"

"I think there is a very strong need for the service we provide and I am proud to be part of it"

"I have found myself more confident talking about my own journey through cancer treatment and have on occasion explained eg radiotherapy treatment"

"I really like meeting new people. It must be really hard for someone to ask a stranger for help and if in a small way I have been helpful I hope to continue to contribute to this excellent service"

"because of the ongoing support/interaction from the Macmillan team and opportunity to support people in the community and be of use to them"

"It has become part of my monthly planning"

Unsure

"If Macmillan want their volunteers to be capable of covering more areas within the service then ongoing core training is required"

"Will have to see more service users to make a difference to my role satisfaction level"

"I need new challenges"

"I volunteer a lot in the afternoons and am not seeing many service users at all"

"Other commitments and work"

56% of volunteers that responded felt happy with being managed by library staff in the future. 20% felt happy provided there were some changes/clarifications. Only 7% were unhappy, with no-one very unhappy. 17% volunteers were unsure how they felt about this move.

How do you feel about being managed by library staff in the future?

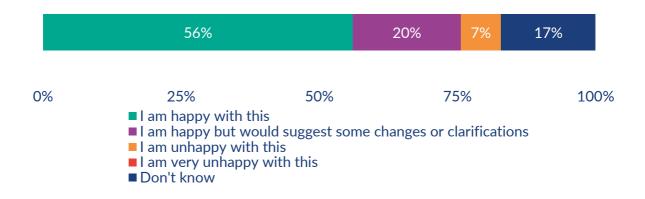
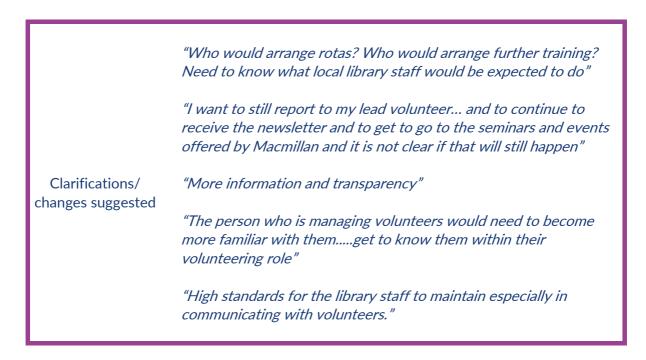


Figure 39

Some further comments on this were provided and these are shown in the box over the page.



"We get so much support from existing [Macmillan] staff who are informed and motivated I can think the Library staff would be as willing or able to provide such a service"

Reasons for unhappiness

"In a couple of the libraries I have volunteered in the Library Supervisor is at another library during the Macmillan service day. The rest of the library staff are nice enough and some are helpful but others don't engage or really understand what we are doing there and we certainly don't feel included in anything. I feel this would have to change quite substantially for the volunteers to feel properly supported in their role"

"Being managed by a dedicated team with core responsibilities is always better than one that has many other responsibilities especially when the support provided is so personal to the individual affected by cancer"

5 Library staff views

Between January and July 2017, we interviewed and surveyed a number of library staff. 53 staff answered at least some of the survey questions, with 41 fully completing the survey. 100% of respondents were library staff members.

This chapter outlines the key messages arising from these engagements including views on:

- Their involvement, awareness and experience of Macmillan @ Glasgow Libraries
- The importance of the Macmillan @ Glasgow Libraries service in the libraries
- The impact of the Macmillan @ Glasgow Libraries service
- The use of Macmillan @ Glasgow Libraries
- The communication and management of Macmillan @ Glasgow Libraries.

Appendix 4 contains the research materials to engagements with Library Staff.

Summary

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 believed it to be an important and well-situated service. Staff feel that Macmillan @ Glasgow Libraries has the greatest positive impact on service users. The effect generally on the library was positive too, and that its benefits extended to other library-users. The space and resources provided by Macmillan were not used effectively when volunteers were not present.

Involvement, awareness and experience

Awareness, experience and involvement with Macmillan @ Glasgow Libraries is common amongst library staff.

Over 79% of library staff who responded to the survey had at least some involvement with Macmillan @ Glasgow Libraries, though the majority had some (60%), rather than a lot of involvement. Only 21% had no involvement whatsoever with the service.

This corresponds with the nature of the Macmillan @ Glasgow Libraries offer, including a combination of information points and drop in services. The scale and scope of interaction with the service amongst libraries staff is naturally greater in those libraries providing drop in services given the presence and input of the volunteers.





Figure 40

All library staff sampled had heard of Macmillan @ Glasgow Libraries, with 98% understanding what the service did. This suggests that in general library staff, including those with no involvement in the programme, tend to be aware of it and how it works.

The Macmillan @ Glasgow Libraries team has taken a range of steps to raise awareness of and buy-in to the service, with core messages and updates disseminated through library supervisors (e.g. on the role out of and learning from the Sustainability Pilot) and newsletters. Awareness raising of the service is also provided as part of staff inductions reflecting its role in libraries core business whilst an e-learning course undertaken by libraries staff also explained the offer, the volunteer role and emphasised the fact that Macmillan team are employed by Glasgow Life.

As a result, libraries staff should be increasingly aware of the service, its benefit to customers and their role in supporting the servicing the offer (e.g. signposting customers to the information points, a drop in service or central helpline) or supporting volunteers practically (eg by facilitating access to a telephone, private space or photocopying facilities).





Figure 41

Experience of a Macmillan drop-in service was most common, with 27 library staff reporting this. Only slightly fewer--21 staff--had experience of an info point at their library. This sums to a total of 48 with experience, and since there were only 43 individual respondents, this indicates that some library staff had experience of both drop-in services and information points at their library.

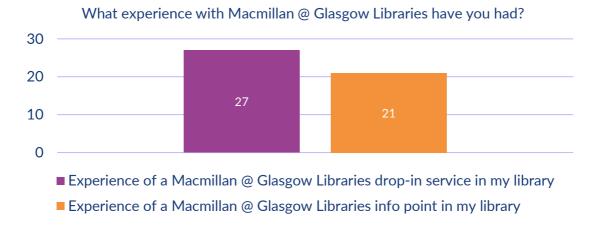


Figure 42

Importance and fit as part of the libraries offer

Staff felt Macmillan @ Glasgow Libraries was an important and well-situated service.

The majority of library staff felt that cancer information fitted both into libraries and into the work of Glasgow Life. 88% agreed or strongly agreed that it was an important part of the libraries offer, with relatively few staff across the board disagreeing with these three statements. No staff felt strongly that Macmillan services were unimportant or ill-fitted to libraries/Glasgow Life.

	Libraries is an important part	Macmillan @ Glasgow Libraries fits well into the work of Glasgow Life	It makes sense to place cancer information and support within libraries
Strongly Agree	67%	57%	59%
Agree	21%	299	32%
Disagree	7%	10	5%
Strongly Disagree	0%	O	6 0%
Don't know	5%	51	5%

Figure 43

Library supervisors reported that recognition and appreciation amongst staff of the value of the service and their role of staff as part of the service has increased markedly overtime. This in part reflects the work of the Macmillan team in emphasising the role of the service and the consistency of this message. It also reflects the value of time and experience as libraries staff realise that their fears of the service's impact on their role (e.g. volunteers taking on libraries roles and vice versa) were unfounded.

Many staff felt that Macmillan @ Glasgow Libraries has had a positive impact on the libraries.

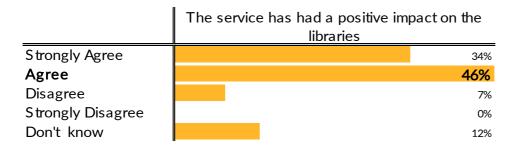


Figure 44

80% of staff either agreed or strongly agreed that Macmillan @ Glasgow Libraries has had a positive impact on libraries. 7% disagreed and 12% of respondents were unsure. More could be done to raise awareness of the benefits of the service.

Consultation with staff revealed anecdotal evidence that library footfall may have increased slightly as a result of the service, and that it reinforced the library's role in providing trusted information to the public at the heart of the local community.

The ownership of, and buy-in to, the service amongst libraries staff is seen as a further movement towards more libraries staff recognising and/or accepting the evolving nature of the libraries service towards a wider offer. Macmillan is seen as a trailblazer in many ways, breaking down barriers whilst establishing a new service across Glasgow libraries supported through a combination of paid staff and volunteers.

There is a growing recognition that, whilst the subject area can be sensitive or difficult, especially for staff members with personal experience of cancer, the service fundamentally represents a continuation of the libraries role in information exchange to support the local community.

There is a consensus that the Macmillan @ Glasgow Libraries service has also helped to strengthen the bond between the libraries and their local communities. There was a concern around the extent of the impact of the service given the short time per week volunteers are present in most libraries and the perceived low numbers of people accessing the service despite the work to promote the service.

Libraries staff stated that the service was very well marketed within Glasgow Life, although they were less able to comment on promotional work in the community where they didn't live locally. There were also anecdotal examples of health practitioners not raising awareness of the service when supporting family or friends affected by cancer, with benefits advice appearing to take priority over the emotional support and information available through the libraries service in the community.

Impact of Macmillan @ Glasgow Libraries

More than half of library staff strongly agree that users of the service appreciate the service.

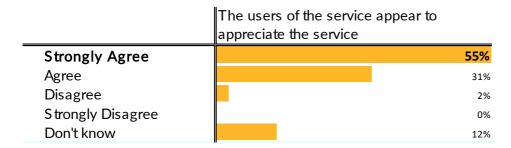


Figure 45

Consultation with libraries staff illustrated a widespread belief that the service has a positive impact on service users with the volunteers' skills and experience, and even a friendly face - replicating the relationships built up between libraries staff and regular customers, providing reassurance whilst delivering informed information either directly or through signposting people to other resources.

Staff also stressed the value of the coverage of the service and their ability to highlight the availability of a drop-in service in a library only one bus ride away in most cases should a service user present outside of volunteer hours or at library with just an information point. The complementarity of the information on cancer with the library staff's knowledge of other support services was also acknowledged with staff able to signpost to other organisations as part of holistic approach to meeting customers' needs.

Use of Macmillan @ Glasgow Libraries

Figures 46 and 47 show Library staff views on how well the Macmillan @ Glasgow Libraries provided resources and space were used outside of drop-in service hours, and by other library users.

The space and resources provided by Macmillan @ Glasgow Libraries are well-used by other library users

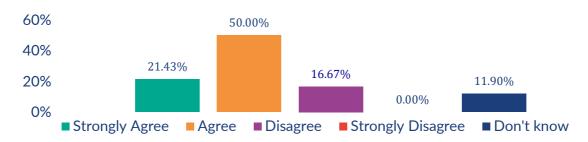


Figure 46

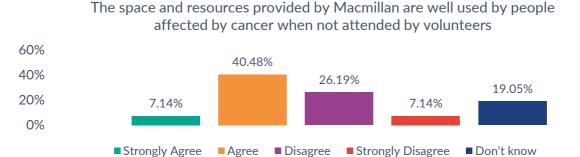


Figure 47

Over 70% of library staff believed the space and resources provided by Macmillan were well-used by other library users, suggesting benefits extend beyond those affected by cancer.

Opinion was divided as to whether the Macmillan spaces and resources were well used by people affected by cancer when not attended by volunteers. Whilst almost half of library staff thought they were well used, a third disagreed.

Consultation with library supervisors highlighted the use of the Macmillan spaces developed through the capital build programme by a range of agencies and organisations. The spaces are thought to generally be of a higher quality than most other community facilities and therefore provide a comfortable environment for MSPs or Councillors' surgeries, employability support, skills training, English for Speakers of Other Languages (ESOL) courses and benefits advice amongst other activities. Indeed, it is these services that are thought to generate almost all of any

linked use of libraries services as a result of the Macmillan @ Glasgow Libraries service. The spaces are also used by libraries staff for meetings and reviews, author talks, schools activities as well as by regular customers looking for somewhere comfortable to read.

Communication and management

At the time of our interviews and survey, the management transfer to Glasgow Life was being piloted in several libraries. How this transfer would occur and what it would mean for library staff was well understood by staff in pilot libraries, and few issues were raised by library supervisors about the changes to roles and responsibilities following the transfer of service management.

Our interviews with library staff revealed that where a message had been delivered consistently on the implications of the pilot in terms of job roles and responsibilities staff, little or no negative feelings were found.

Consultation with library supervisors revealed few issues with changes to roles and responsibilities linked to the evolving volunteering roles as long as they were in receipt of the appropriate training and knowledge to adequately fulfil the tasks involved to the required standard. Indeed, the main issues were small and often procedural in nature (eg managing expenses, reporting non-attendance etc.) or related to the amount of time spent in one library (eg if performing supervisor roles in multiple venues) which may impede their ability to perform reviews in an informed manner.

Since our interviews and survey, this transfer has been communicated more widely to all library supervisors and staff. We will explore how staff and supervisors feel about the transfer in the lead up to the final evaluation.

6 Service user views

The evaluation team conducted a series of telephone interviews with service users. Volunteers and Macmillan @ Glasgow Libraries staff identified and recruited service users willing to participate in interviews. This chapter outlines the key messages provided by service users through these interviews.

The service

Discussions with service users revealed the breadth of ways through which people are informed about the Macmillan @ Glasgow Libraries service. 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 almost by accident).

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
- 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."

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. Whilst some service users required very specific advice (eg 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.

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

"My friend refuses to claim anything even though her husband is also ill and cannot really function despite being mobile. She is missing out on things."

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

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 affected by breast cancer. Whilst more than a little weary 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."

"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."

Around two thirds of service users consulted had planned their visit to the Macmillan @ Glasgow Libraries service 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."

Service users consulted offer experience of the service from across Glasgow and from a variety of libraries 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.

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.

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

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

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."

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 their 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 little niggle 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."

"Last time I had an Indian Head Massage and aromatherapy after being recommended by councillor 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."

"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."

"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."

"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."

"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."

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 the same family members or a health practitioner.

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 - something which those with a history of caring for family members welcomed given what was seen 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 of GPs. I feel at ease with the councillor 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."

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."

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

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."

The service's role in bringing in other support for service users was also highlighted with many linking the volunteers' advice 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."

"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."

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

"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."

"It was so nice to have somewhere with professionalism, but that was voluntary. There was no judgement, I could say whatever I wanted, I could say I hate my husband and no one would say, 'Oh it's the cancer you hate not him', they would just listen. And there was reassurance. I have only been up here a year so I had no friends to just chat openly and honestly with."

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."

Impact on the service user

Service users were mostly willing to outline how the service had supported them with their cancer journey from diagnosis including how having cancer affected them personally but also 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 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'."

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 the Macmillan @ Glasgow Libraries service 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 accessing practical support and equipment and assistance with financial worries 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!"

Whilst most service users stressed the differences between the services they offered, (i.e. the Macmillan @ Glasgow Libraries linked people with complementary as opposed to similar services), the one element raising a negative comparison (in one instance) was in terms of availability of complementary therapies.

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 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."

"I received a grant from Macmillan initially for new bedding as I was suffering from night sweats. They also organised my PIP payment and helped with transport costs."

"I got support from Cancer Care in the Community, including help with white goods like a washer and kettle, full length curtains, draught proofing. They provide the practical support whilst Macmillan offer the emotional support."

"I used Improving the Cancer journey for financial help and that was fine. It was them that recommended Drumchapel. The massage was quite de-stressing, the first thing when you have cancer is that you get stressed, so that was helpful and the financial help was great. Some of them in the library had cancer too and it was quite good hearing their stories."

Improvements, strengths and weaknesses

Whilst the sample is skewed slightly (given all those consulted had accessed the Macmillan @ Glasgow Local authority service), all were very positive about accessing support in a community venue like a library. Service users stressed the difficulties in travelling to the hospital in particular, 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.

The majority of service users also appreciated the quiet nature of most libraries which maintained a degree of privacy and discretion even when the Macmillan area is situated in the library itself (eg, Langside) rather than a distinct room (eg, Drumchapel). For this reason, whilst community venues with similar characteristics to libraries (eg, 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 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, (eg, 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."

There was also a thought from one service user that some community venues, including libraries, are better suited to older people with some benefits to be gained from identifying relevant locations which younger people relate to more.

"A library is good, especially for over 40s but I think a shopping centre could be good because everyone shops - under 40s don't tend to come to the library."

All service users had no issues at all with speaking to a volunteer as opposed to a doctor or other health professional. Volunteers are judged by service users to provide warm welcome. Service users develop a relationship a volunteer based on the volunteer's experience, knowledge and professionalism backed up by the trust in the Macmillan brand.

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."

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 advice and guidance 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 (eg, health practitioner), and the existence of some longstanding and outdated perceptions of the Macmillan brand 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 (eg, 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.

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."

"It's 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 could 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."

"I feel as if most of the volunteers are ladies, I would like more male volunteers and counsellors, ladies don't get prostate cancer."

Service users were asked to describe the Macmillan @ Glasgow Libraries service 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."

"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."

7 Conclusions and Recommendations

This chapter outlines the conclusions of our research and analysis and the resulting recommendations.

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

Overall the programme is seen as a high quality and important service by stakeholders, volunteers, library staff and service users alike. Both the internal and external marketing of the offer within the libraries were repeatedly stated to have been much better than other co-located services, providing a benchmark from which future initiatives can be judged. 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

Given the service numbers recorded for Macmillan @ Glasgow Libraries, it would be hard to determine the effect of the service by analysing library footfall numbers. However, what 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 information points and a mix of complementary services provided by paid and volunteers staff.

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 thing 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 that were there to support carers and family members, with the perception of most services is that they 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 with an outsider's perspective.
- Many service users attributed their use of other services to Macmillan @ Glasgow Libraries
- There were several concerns regarding the reliability of Cancer Support Scotland complementary therapies which seemed to come and go or double book and cancel appointments
- 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.

2 The service has scope to further increase service numbers within current resources

While it is difficult to calculate the exact unmet demand for cancer information and support in Glasgow, we consider that there is scope for the service to continue to increase its service numbers. In addition, we expect that the service will be able to cater for higher service numbers within the current resources (volunteers, library spaces and drop-in times). We recommend the following to increase service numbers.

Continual promotion of the service is required

There are a number of factors that mean that this service will always need continual promotion:

- The Glasgow service landscape is confusing and busy. Services in Glasgow are not well organised. This is not unique to Cancer or even health services in Glasgow. Moreover, service providers are busy and overstretched.
 Smaller and non-clinical services will 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 highlighted that they
 both feel bombarded with information on multiple layers of interconnected
 services. This is particularly true for people coming to terms with a new
 cancer diagnosis. Service users in particular outlined that they prioritise
 their support uptake, starting with the most urgent, with emotional support

often coming much later in the list of priorities to get sorted. 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 timing

- People only tend to notice the service when they are looking for it, for
 example after a diagnosis of themselves or a family/friend or a patient with
 a particular need. Becoming visible as a service has additional complexities
 when it is only relevant for a particular group.
- The stakeholder survey indicated that people are more likely to signpost than formally refer. 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 signposts to service attendance. For example, business card sized information on the service to see if they are more likely to be kept by potential service users than larger pamphlets.

Therefore, we recommend that continued effort is put into service promotion ensuring that this works at multiple levels:

- Influencing buy-in amongst strategy partners such as the Health and Social Care Partnership
- Ensuring buy in for the service at service management levels
- Helping delivery to be informed on the service, its offer, and how to refer
 in with joint professional development or case reviews one way for
 partners to see the full experience of clients navigating through the
 different pathways emphasising the libraries service's role.

Crucially the benefits of the emotional support, information and links to a range of wider support for people affected by cancer as part of a more holistic package of support throughout their cancer journey needs to be articulated at all levels.

We also recommend that other potential avenues are explored including social housing organisations and umbrella third sector organisations such as Glasgow Council for the Voluntary Service. We understand that the Macmillan @ Glasgow Libraries staff team have already undertaken work along these lines.

The lack of coordination of the range of Macmillan services in Glasgow is hindering individual services, as there is no coherent offer for those affected by cancer – even within Macmillan 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's control. However, there is 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. For example: MoveMore, Improving Cancer Journey, Macmillan Benefits Team, and the Support and Information Service at the Beatson.

Currently these services 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. However, the most concerning element is that 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.

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.

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

Arguably, Macmillan 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 services and send their patients to the right one.

Greater coordination of effort between Macmillan services, vitally crosspromotion, 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 community, 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, exploring whether improved responses to cultural or language issues or the recruitment of volunteers able to engage more effectively with specific cultures.

Addressing this should be a priority for Macmillan, without greater coordination (eg 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 is undermining the independent effort of their own services.

Greater support from the national Macmillan campaign is required

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 the Macmillan @ Glasgow Libraries service. We consider this an opportunity for Macmillan to back up their investment – without it we consider that Macmillan is undermining its own investment by limiting the reach the service can have.

In addition, it seems that further reinforcement 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 should look to do this as part of the greater coordination of their local Macmillan services. For example, posters that say – find your local Macmillan support services and include reference to Macmillan @ Glasgow Libraries, MoveMore, Improving Cancer Journey, etc.

Glasgow Life has made a good start at integrating the service, but more is needed to make it part of its 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 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 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 will have a significant impact on the service's ongoing ability to attract new service users.

Early signs from the sustainability pilots are promising, but there are a still a number of risks

Early signs of the transfer of the service from a central team to each library are positive. Library staff appear informed and keen, and most volunteers are comfortable being managed by library staff. There are some situation specific concerns and issues to work through, but generally speaking the transition appears to be going well.

However, there are a still a number of risks to the ongoing sustainability of the service when the direct management capacity is reduced. These are discussed below.

Who will carry out the continual promotion required?

As identified, this service is likely to need continual promotion. Presently the service is largely doing their own promotion rather than benefiting from belonging to Glasgow Life and Macmillan networks. We have recommended that this is addressed earlier in this chapter.

However, we consider there to be a residual risk if there is no person responsible for the ongoing promotion of the service. We consider that there is a case for ongoing staff resource to have this responsibility, particularly if efforts to better coordinate Macmillan services and further integrate the service into Glasgow Life strategy and promotion fail.

To supplement this effort, we also suggest that a new volunteer position be created targeting specifically the ongoing promotion of the service and networking with required partners and services. This role would require a different skill set from the current drop-in service volunteers.

There is a risk that services will become siloed by library

With the management of the service largely moving from management by a central team to management by individual libraries, there is a risk that the service begins to change library by library. To ensure that there is consistency in the service and shared learning between drop in services we recommend that the following is investigated during the rest of Phase 2:

- Ensuring that there is a key contact across the libraries that coordinates the various library managers in terms of service maintenance and decisions about service delivery
- Creating a Volunteer Board where volunteers are able to share what is going on in their libraries and lessons learned. This helps to provide ongoing ownership of the service by volunteers, and ensure that volunteers are informed to ask their library managers for what they need.

8 Next steps

Our final evaluation report is due end of June 2018. Between now and June 2018 we intend to:

- Continue to interview service users as their details come through
- Continue to try to interview health professionals.

Between January and June 2018, we intend to:

- Conduct another volunteer survey and follow up with more detailed conversations with volunteers
- Conduct another library staff survey and follow up with staff interviews
- Conduct another stakeholder scorecard and follow up with interviews.

In addition, we will work with the project team to gather the following information:

- Data from ICJ about referrals made to Macmillan @ Glasgow Libraries and ICJ service user feedback on the library service
- Service user profile data
- Volunteer profile data
- Library space usage by other organisations and groups
- The turnover of leaflets.

Based on what we have learned from the interim evaluation we propose to make the following changes to our methodology for the final evaluation period:

- Greater engagement with Volunteers. With low turn out to the Volunteer Focus Group, we recommend replacing this focus group with interviews with volunteers to ensure that we get a larger cross section of volunteers
- Engagement with health professionals. We sought to interview a range of health professionals but for various reasons this did not pan out during the interim evaluation. We plan to start our engagement with them in September 2017 and carry on throughout the first half of 2018 in the lead up to the final evaluation as a way to ensure that we have sufficient opportunities to engage with health professionals when best suits them.

In addition, the final evaluation period will be when we conduct a cost-benefit analysis on the service. During the next year we will need to agree what other modelling would be useful so that this can be incorporated into our field research. We do not envisage that we will need to change the methodology to gather the required information.

We also recommend that the findings of this interim report are disseminated including:

- The evaluation team working with the programme team to design a 1 pager of key messages for distribution to volunteers, service users, library staff, and other service providers
- Presentation of key findings Library Staff for challenge, Partners clinical and non-clinical.

Appendix 1: Service Data

This appendix analyses the management data available for Macmillan @ Glasgow Libraries. This service data is largely collected by volunteers during the drop-in service. Volunteers work through a service data form with service users that asks a range of questions. In addition to this data, the Macmillan @ Glasgow Libraries team keep records of:

- All inbound and outward referrals for the service
- The use of capital build spaces outside of the drop-in times
- Volunteer numbers and profile.

This appendix also contains data collected by the Improving the Cancer Journey (ICJ) Glasgow service.

Visitor Numbers

Phase 2 began in October 2015. Between the beginning of Phase 2 and the end of May 2017 there were 4,062 recorded attendances at the Macmillan @ Glasgow Libraries drop-in services. Of these 4,062, 2,174 identified themselves as first time visitors. Removing the 378 that did not specify, 59% of all reported attendances were from first time visitors.

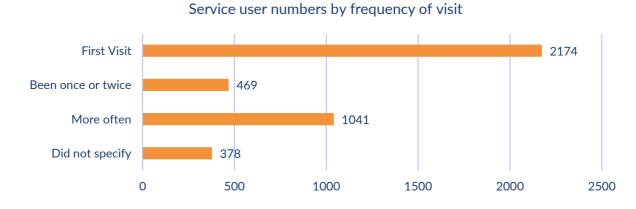


Figure 48

Phase 2 has seen a slight upward trend in service attendances. Numbers dropped temporarily in December each year, which is likely due to the holiday season.



Figure 50 shows the service user trends for all visits (in orange) and just the first-time service user visits recorded (purple). The trend is broadly similar.



Figure 50

Figure 51 overleaf shows how service users found out about the service. Passing by is the dominant way that service users found out about the service, followed by other Macmillan services and through the libraries. We expect that there is a reasonable amount of cross over between Passing by and Libraries.

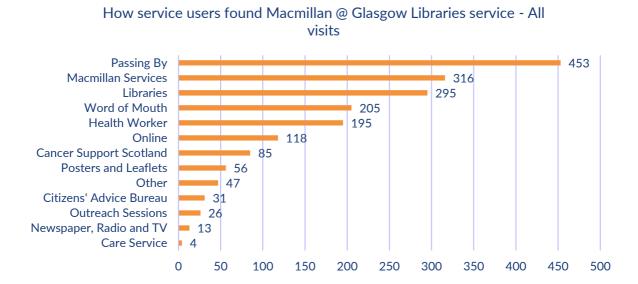


Figure 52 looks only at the 2,174 first-time service users in an attempt to isolate repeated answers by the same service user. Broadly the same pattern emerges with Passing by, other Macmillan Services and Libraries being the top three ways that service users find the service.

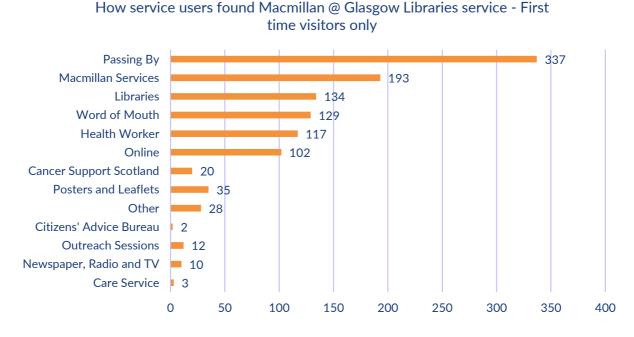


Figure 52

Figure 51

We received data from Improving the Cancer Journey programme that outlined when they referred their clients to the service, whether that client attended, and qualitative comments

on how they found the service, or why they chose not to attend. This covers the period from March 2014 to September 2016. In total, 166 referrals were made to Macmillan @ Glasgow Libraries from ICJ. Outcome data was collected for 43 of those referrals. 53% of those 43 referrals attended the service.

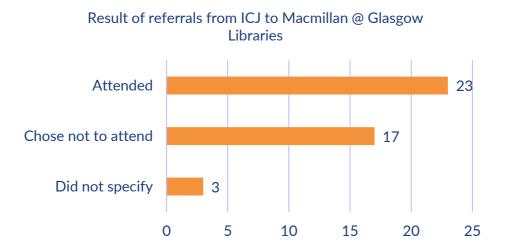


Figure 53

Of those that didn't attend, eight did not specify why. Four felt already well supported. Two had trouble physically accessing the service due to their situation. One called the service and received support that way. The final two didn't want to go to the library, or didn't want to discuss any issues.

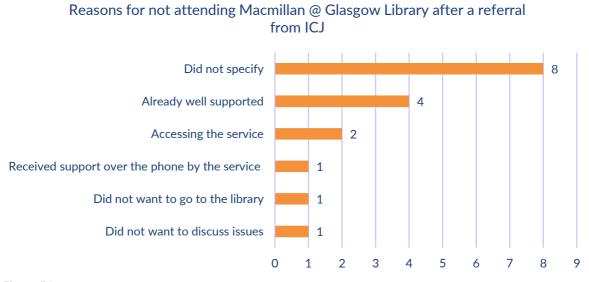


Figure 54

Based on the qualitative comments provided by the Improving the Cancer Journey programme, most of those attending provided positive feedback. The few exceptions to this largely revolved around situations where their complementary therapy arranged through the service was cancelled or double booked.

A total of 1,343 referrals were made into the Macmillan @ Glasgow Libraries service between January 2014 and May 2017. Just over 94% of all referrals since January 2014 have come from Improving Cancer Journey, a health professional or Macmillan Long Term Conditions. Less than 6% have come from Cancer Support Scotland, Move More, Helping Matters, Citizens' Advice Bureau or other sources. Figures 55 and 56 look at the pattern of incoming referrals for that 94%.

The overall trend for referral numbers has been relatively flat since January 2014, although referral numbers are very volatile from month to month.

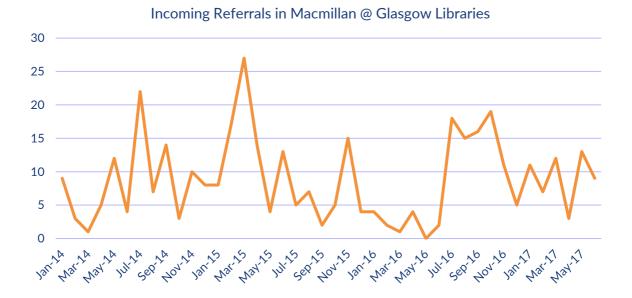


Figure 55

The mix of incoming referral sources (pictured overleaf) has changed since 2014 also. Macmillan Long Term Conditions was once the largest source of referrals, with a sharp decrease in 2015 and further decreases in 2016 and 2017. Improving the Cancer Journey on the other hand has seen the opposite trend. This is to be expected given the Improving the Cancer Journey programme developed from the Macmillan Long Term Conditions service so many service users began to come through ICJ rather than Macmillan LTCs. Health professionals were providing a reasonable proportion of service referrals in 2014, but this has also decreased since 2015.

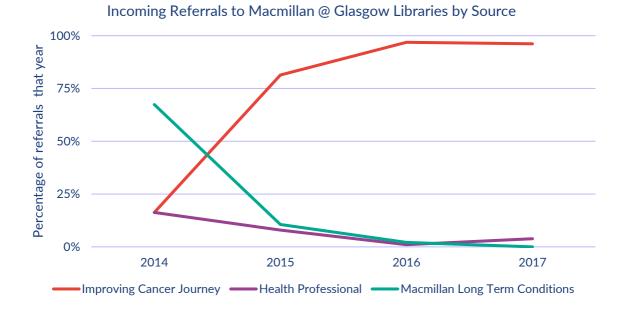


Figure 56

Outgoing referral numbers have on the other hand increased since January 2014, although face a similar volatile profile as inbound referral.

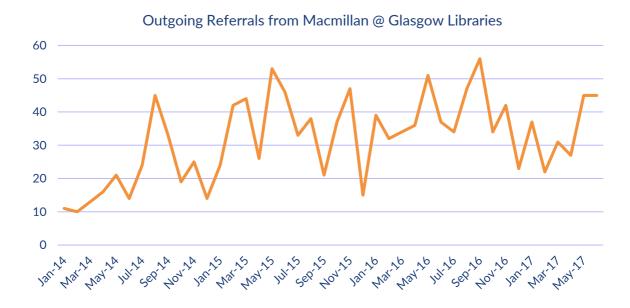


Figure 57

Figure 58, overleaf, compares outward referral numbers with the total service visits. We would expect to see these follow similar patterns. There are a number of occasions where the patterns differ from each other.

 Between December 2015 and January 2016, service numbers increased by 76% (77) but referral numbers increased by 160% (23)

- In October 2016 visitor numbers had increased 9% (20) from September 2016, however referral numbers were 39% (22) lower than September
- Between January and February 2017 attendance numbers dropped by 9% (19) yet referral numbers dropped by 41% (15). This pattern, which reflects the high level of repeat visitors to those libraries offering complementary therapies and counselling in particular, was similar in January and February 2016 where visitor numbers were similar but referral numbers dropped 18% (7) between the two months.

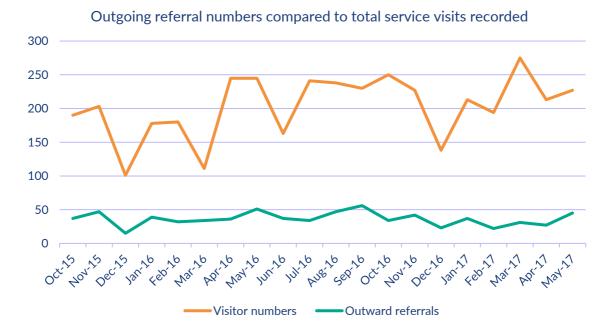


Figure 58

Macmillan @ Glasgow Libraries is referring service users to a wider variety of other services than they are receiving referrals from. This is thought to be a strength of the programme, reflecting both the proactive and stable nature of the staff team compared to most other services. Figure 59 overleaf shows that the largest referral sources are ICJ, Cancer Support Scotland and Macmillan Long Term Conditions. The proportion of outward referrals that were to Macmillan Long Term Conditions dropped markedly between 2014 and 2017.

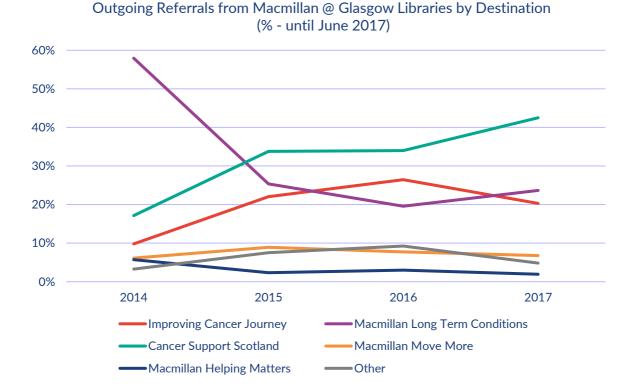
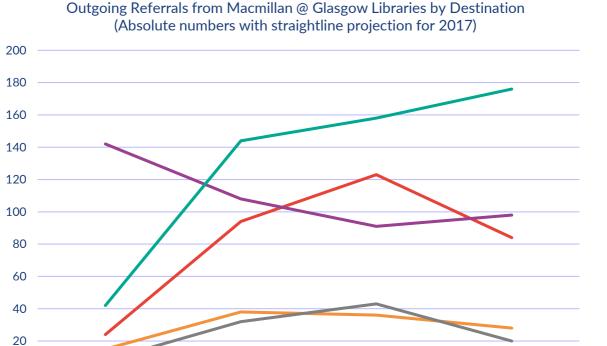


Figure 59

Figure 59 only shows the proportions of referral destinations rather than absolute numbers. Figure 60 shows absolute referral numbers for 2014 – 2017. As the data is only available until June 2017, we have assumed that the same rate of referrals occurs for the second half of 2017 as does the first half, i.e. we have doubled the number of referrals to come up with a full year estimate.

Cancer Support Scotland referrals have increased consistently across the years, with Macmillan Move More and Helping Matters services remaining relatively stable at a low level. Referrals to Macmillan Long Term Conditions decreased in the across each year between 2014 and 2016, with slightly higher numbers expected for 2017 than 2016. Improving the Cancer Journey numbers peaked in 2016 with much lower figures expected for 2017. We understand that this represents a change in the way that clients are referred. Prior to the Improving the Cancer Journey programme, Macmillan Long Term Conditions provided referrals directly into Macmillan @ Glasgow Libraries. As Improving the Cancer Journey grew, they began to act as the single point of referral for service users. This means that Long Term Conditions service users were already likely to have had a referral to the Macmillan @ Glasgow Libraries service from Improving the Cancer Journey.



2016

Other

Macmillan Move More

Macmillan Long Term Conditions

2017

Figure 60

0

2014

Figure 61 breaks down the 4,062 service user numbers by location. 18% of engagement with service users is through Outreach and 10% through the office, reflecting the importance of contacts generated through the office and outreach work in particular. Dennistoun is the most popular library with 12% of all visitors attending the service at Dennistoun. It is worth noting that Springburn is no longer a drop-in location

2015

Improving Cancer Journey

Cancer Support Scotland

Macmillan Helping Matters

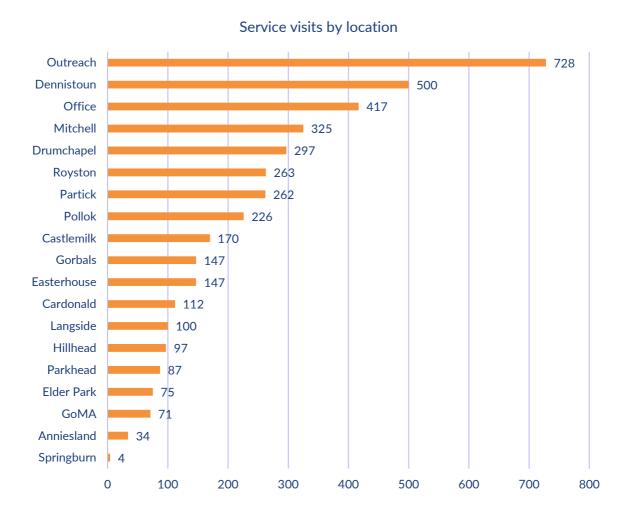


Figure 61

In terms of repeated service use by location, 74% of Drumchapel attendances during Phase 2 were repeat visits. More than 50% of the visitors for Royston, Parkhead, Partick, Dennistoun, the Gorbals and Elder Park were return service users. The presence of Cancer Support Scotland Complementary Therapies in Dennistoun, Drumchapel, Castlemilk, Royston and Partick libraries, with counselling also delivered (in addition to the aforementioned venues) in Parkhead, Elderpark and the Mitchell libraries may lead to higher service user returns, both for appointments and because it can become part of their weekly schedule.

The office and outreach visits had low ratios of return visitors. Return service users are not expected as part of outreach given the one-off nature of the service. Equally, service users are not expected as part of the office based service as service users would be signposted to the library based drop-ins as part of their engagement with the office. Given the high numbers of total service users coming through the office or outreach this indicates that while it is a good entry point to the service, it isn't proving to be the way that people are engaging with the service long term.

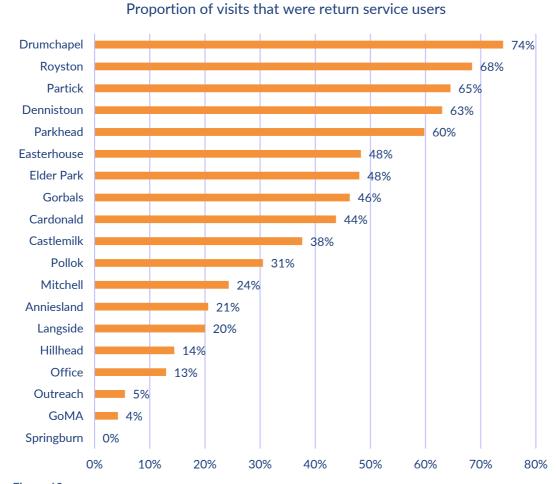


Figure 62

Visitor Profile

About two thirds of service users are female. This percentage holds when looking at first time versus multiple visits, indicating there probably isn't a noticeable difference between the frequency with which the service is used depending on gender. This trend is in line with Cancer Information and Support Services generally as well as many other emotional support services with wider research13 highlighting differences in how comfortable men and women feel when accessing such services to talk about feelings etc.

UK men's attitudes towards seeking professional psychological help. British Journal of Health Psychology [Advance online publication]. doi:10.1111/bjhp.12089

¹³ See: Developing male-friendly interventions and services, Roger Kingerlee, Luke Woodley & John King, Clinical Psychology Forum 285 – September 2016, https://www.bps.org.uk/system/files/user-files/Division%20of%20Clinical%20Psychology/public/CAT-1861.pdf or Sullivan, L., Camic, P. & Brown, J. (2014). Masculinity, alexithymia and fear of intimacy as predictors of UK men's attitudes towards seeking professional psychological help. British Journal of Health



Figure 63

64% of service users indicated whether they were diagnosed with cancer themselves, a family member/carer, etc. Just over half of all reported visits were by people with cancer. A further 34% were a family member or carer of someone with cancer.

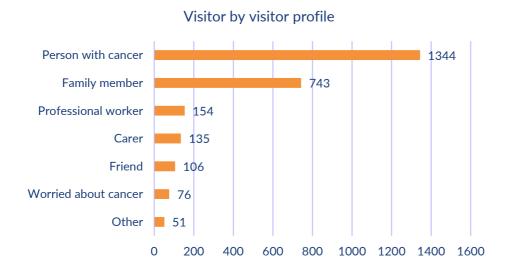


Figure 64

The point in the cancer journey was recorded for 47% of service visits. The service is supporting people at all points in the cancer journey. Nearly a third are receiving support during their treatment. This is closely followed by 27% of service users receiving support while they are living with cancer. Figure 71 breaks this down

further by service visitor numbers. and Figure 72 shows this breakdown by percentages.

Receiving palliative care

None of these apply

Bereaved

0

50

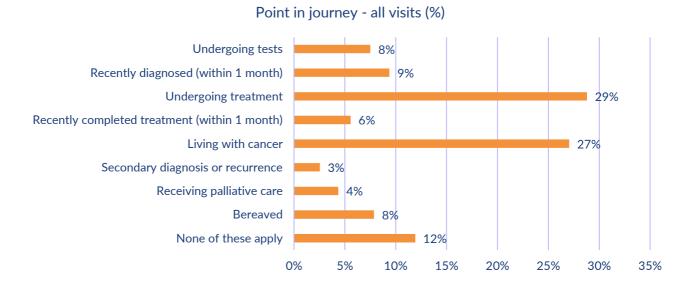


197

100 150 200 250 300 350 400

450 500

Figure 65



72

130

Figure 66

Service provision

1,005 service users came to the service looking for someone to talk you. The next common reason was the 478 who wanted to find out what services were available to them. Figure 67 breaks down all 2,660 answers by reason. Note, a number of people answered more than one. Therefore, the 2,660 answers represent less than 2,660 individual service attendances.



Figure 67

Use of capital build space

The Macmillan spaces in each library are available for use outside of volunteer hours. These are used by library visitors, staff, community groups as well as other public and third sector organisations for service delivery. The use of the space in the five capital build libraries is recorded. The Macmillan branded spaces in Drumchapel, Partick, Dennistoun, Royston and Castlemilk provide a regular home for 17 groups who use these spaces for more than 65 hours each week as shown in Figure 68. These spaces are also used occasionally by another 10 organisations, groups and Local Councillors.

Use of the capital build spaces by others

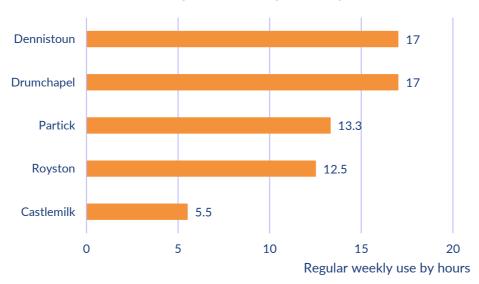


Figure 68

Figure 69 overleaf outlines who uses the spaces.

Who uses the Macmillan spaces in libraries?				
Community Groups	Public Sector Services	Third Sector Organisations	Other	
Writers Group	ESOL class	Citizens' Advice Bureau	Cordia	
Crochet & chat	Jobs and Business Glasgow	Improving Cancer Journey	Local Councillor surgeries	
Sewing Group	NHS	TCAT		
Book Group	Adult literacy and numeracy classes	Autism Resource Centre		
Knitting Group		Lifelink		
		Glasgow Association for Mental Health		
Photography Class	Clyde Gateway	South Carers Group		
Homework classes		Action on Hearing Loss		
Coderdojo				

Figure 69

The use of these spaces in increasing with new groups using the space each month. Wellbeing Scotland and Aspire have indicated that they are interested in using the space, as well as Autism Resource Centre and Lifelink increasing their use, and returning after a period of non-use respectively.

The tables overleaf outline the current schedule for the capital build spaces outside of dropin service hours.

	Monday	12:30 - 3pm	South Carers Group
Castlemilk	Tuesday	1pm - 3pm	Community adult craft group
		Monthly	Action on Hearing Loss drop in session
	Friday	2:30pm - 3:30pm	SAMH
	Prior uses		Local Councillor surgeries
	Tuesday	10am - 3:30pm	Citizens Advice Bureau
	Wednesday	1pm - 8pm	Lifelink counselling
Royston	Other occasional uses		Local Councillor surgeries
	occasional uses		Coderdojo classes
			Homework classes
	Monday	11am - 12pm	NHS breastfeeding class
	Tuesday	10am - 1pm	Citizens Advice Bureau
		1pm - 2pm	Baby Massage with Clyde Gateway
		2:30pm - 4pm	Community sewing group
		5:30pm - 7:30pm	ESOL class
	Wednesday	10am - 12pm	Cordia
Dennistoun		1pm - 3pm	GAMH
Demistour	Thursday	Last Thursday evening of every month	Community book group
	Friday	10am - 12pm	ESOL class
		2pm - 4:30pm	Community knitting group
	Other occasional uses		Jobs and Business Glasgow on Fridays as needed
	Prior uses		Photography class
			Local Councillor

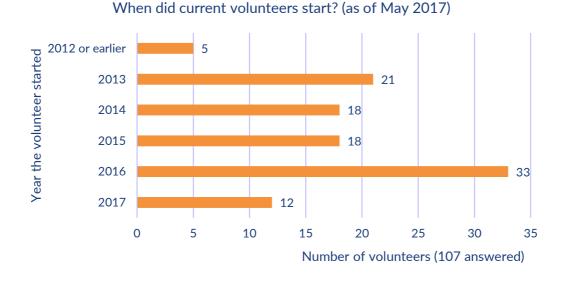
	Monday	Every second Monday	Writers Group
	Tuesday	1pm - 4:30pm	CAMH
	Wednesday	10am - 5pm	Jobs and Business Glasgow
	Fridays	10am - 12:30pm	Citizens' Advice Bureau
Partick	Other occasional uses		Improving Cancer Journey for Health Needs Assessments
			Women's Aid for appointments
			TCAT assessments
	Prior uses		Autism Resource Centre
	Monday	Afternoon	ESOL course
	Tuesday	10am - 5pm	Jobs and Business Glasgow
	Wednesday	1pm - 4pm	Citizens' Advice Bureau
	Wednesday	Evening	Adult literacy and numeracy classes
Drumchapel	Friday	10am - 5pm	Jobs and Business Glasgow
	Other occasional uses		Councillor's surgery
	occasional uses		Crochet & chat
			Library admin team meetings
			West Dunbartonshire's Volunteer Development sessions
			GAMH

Figure 70

Volunteer profile

There are currently 107 active volunteers for the Macmillan @ Glasgow Libraries service. The Macmillan @ Glasgow Libraries staff team collect and store data on their volunteers. This was provided to the evaluation team in May 2017.

Figure 71 breaks the volunteer numbers down by start date.



80% of the volunteers are female. This compares to 67% of service users are female, and 58% of the estimate of those with cancer in Scotland.

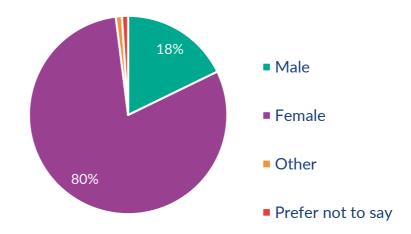


Figure 72

22% of volunteers are older than 65, with 49% above the age of 55 and 69% over the age of 45.

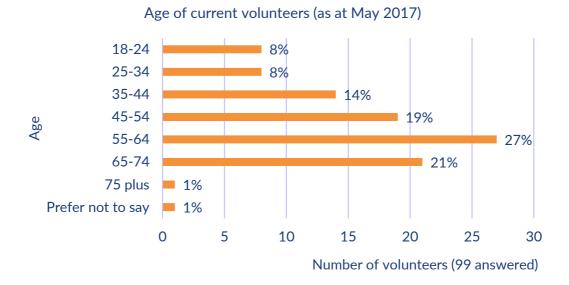


Figure 73

9% of volunteers identified as having a disability. In comparison to 22% of the service user population and an estimated 25% of the Scottish population in 2014.¹⁴

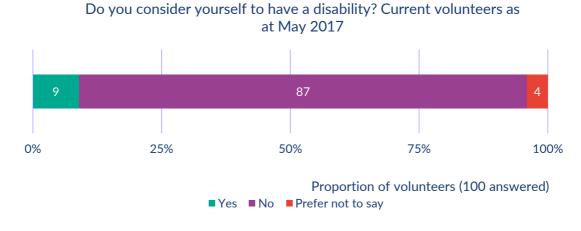


Figure 74

¹⁴ http://www.gov.scot/Topics/People/Equality/Equalities/DataGrid/Disability

16% of volunteers have been diagnosed with cancer previously.

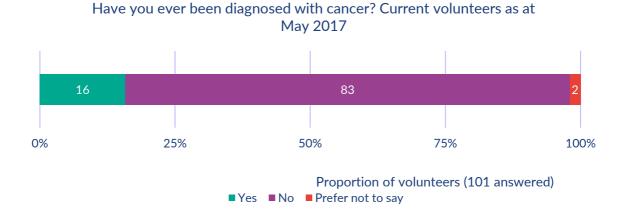


Figure 75

The majority of volunteers are Scottish and from a white background.

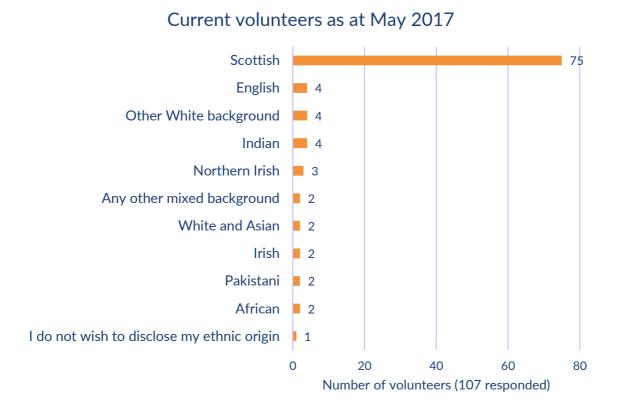


Figure 76

Appendix 2: Research Materials

Stakeholder and staff engagement

Name	Organisation
Gerry Mitchell	Alliance
Madaline Alexander	Cancer Support Scotland
Christine Campbell	CRUK
Sandra McDermott	Glasgow City Council
Andrew Olney	Glasgow Libraries
Alex Byers	Glasgow Libraries
Gordon Anderson	Glasgow Libraries
Karen Donnelly	Glasgow Libraries
Dawn Vallance	Glasgow Libraries
Neil Paterson	Glasgow Libraries
Jacquelyn Stoner	Glasgow Libraries
Mhari Mackintosh	Glasgow Libraries
Effie Flood, Library Supervisor	Glasgow Libraries
Karyl Seguin, Library Supervisor	Glasgow Libraries
Elaine Thomson, Library Supervisor	Glasgow Libraries
Fiona Porter, Library Supervisor	Glasgow Libraries
Allison Reid, Library Supervisor	Glasgow Libraries
Craig Menzies	Glasgow Libraries
Annemarie Galbraith	Glasgow Libraries
Steph	Glasgow Libraries

Pip Lawrenson	Glasgow Libraries
Diane Cunningham	Glasgow Life
Alison Murphy	Improving Cancer Journey
Michelle Gallagher	Macmillan Cancer Support
Margaret Greer	Macmillan Cancer Support
Fred Beckett	NE Carers Cancer
Kevin Hutchison	NHS 24
Susan Middleton	NHS GG&C
Dr Francesca Gray	NHS GG&C
Carol MacDougall	NHS Inform, NHS 24

Staff Interview Guide

Introduction:

Thank you for agreeing to provide feedback on the Macmillan @ Glasgow Libraries service.

Your views are important in assessing the impact and effectiveness of the service, what works and whether there are areas that could be improved.

All responses will be treated in the strictest confidence.

About You

- 1. Can you summarise your role in the programme?
- 2. How well is the service marketed?
- 3. What works in terms of promoting the service?
- 4. What could be improved?
- 5. How are library staff involved in outreach community engagement activities (e.g. promotion, involvement)?
- 6. What are the strengths and weaknesses in the relationship between libraries staff and volunteers?
- 7. What makes these relationships work? What are the challenges?

- 8. What kinds of support do people affected by cancer seek most? Please rank the following:
 - a. Emotional support
 - b. Information on aspects of living with and beyond cancer
 - c. To access benefits information and guidance
 - d. To identify links to other sources of information
 - e. Counselling and complementary therapies
 - f. To access other local service
 - g. Other (please state)
- 9. How well do you think people's needs are met? Why do you say that?
- 10. To what degree do you feel that the service is integrated into the Glasgow Libraries? Why do you say that?
- 11. To what degree do you feel that the service is integrated into the wider cancer network in Glasgow? Why do you say that?
- 12. How has the service changed the way that libraries work?
- 13. Are these changes for the better? Are they sustainable?
- 14. Have the new spaces provided additional benefits to library users? If so, in what way?
- 15. How are the Macmillan spaces used by staff outside of the times when manned by volunteers?
- 16. What differences in use (i.e. footfall and type of use) by the public have you noticed in the following aspects of the library use when volunteers are not present?
 - a. Taking cancer leaflets away
 - b. Reading cancer leaflets
 - c. Reading healthy lifestyle books
 - d. Reading other books
 - e. Enjoying the Macmillan space in the library
 - f. Library footfall overall
 - g. Take up of other services (which?)
 - h. Other (please state)
- 17. What are the key skills sets required to support the programme in the longer term?
- 18. What support (e.g. formal and informal training) have you received to support the delivery of the service?
- 19. How effective was this support?

- 20. What additional support would you want to improve your performance and effectiveness?
- 21. Do you think that the transformation of the library spaces has contributed to the community at all?
- 22. What factors make for a successful Macmillan branded space in a library?
- 23. Do you have any other comments about the service and/or your role?

Client Interview Guide

Introduction

Hello, my name is X, calling from Rocket Science as arranged about your experience of Macmillan @ Glasgow libraries - thank you for agreeing to provide feedback on the support you've received.

We are working with Macmillan @ Glasgow Libraries to evaluate the service they provide to people affected by cancer. We would like to understand things from your perspective in terms of how helpful the service has been and whether there is anything more they could do to support you.

All responses will be treated in the strictest confidence and we will not use your name when we write up the interviews. Anything you tell us will not affect your use of the library service.

The chat will take approximately 25 minutes. We would like for this experience to be as convenient and easy as possible for you, so it's possible either to complete this interview in one go, or alternatively in 2 or 3 parts. If, when we are going through the questions, you would like to have a break, please let me know and we will be more than happy to arrange this. If there are any questions you don't want to answer that's fine.

I will take notes but the interviews won't be recorded. Are you happy to take part?

The service

- 1. How did you first hear about the service?
- 2. What kind of support did you want from the service initially and what were your initial thoughts of it?
- 3. Was it a spur of the moment decision or carefully thought about?

- 4. In which library(s) or other places have you used the service and how often have you accessed the service since?¹⁵
- 5. (If accessing more than once) What kinds of support did you return to the service for?
- 6. What, for you, was the best aspect of the service?
- 7. Have there been benefits in terms of differences to your life/achieving personal objectives as a result of the service?
- 8. Has the service changed the way that you feel about, cope with and manage your condition? (Explore and attribute any changes to the service)
- 9. If you hadn't used the service, or it hadn't existed, would things have been very different for you? How do you think things might be now if you hadn't used the service?16

About you

Would you mind telling me a bit more please about your cancer, for example when was it diagnosed and how having cancer has affected you and your family?17 How does the service fit into this? In terms of:

- Just once
 - Weekly
- Fortnightly
- Monthly
- Other

- a. Increased/reduced/same ability to make informed decisions
- b. Increased/reduced/same anxiety, depression or other emotional conditions
- c. Increased/reduced/same reassurance
- d. Accessing wider local support networks
- e. Accessing national support networks
- f. Work affected
- g. Social life affected
- h. Wouldn't have accessed any support
- i. No change in any area

 Experiences up to and after diagnosis including initial treatment, follow up care, what was most helpful, the most positive experience and why

¹⁵ Choose from:

¹⁶ (Where data is available refer to answer provided previously and explore whether they feel they could they have achieved the same outcomes (to date)) – areas to explore could include:

¹⁷ Discussion could cover:

- 10. How long ago did you first use the service?
- 11. What stage were you at in your cancer journey or treatment?
- 12. Have you used any other kinds of cancer-related support? (Explore whether access can be attributed to the service)¹⁸ How do they compare to Macmillan?
 - a. Better
 - b. Worse
 - c. Same
 - d. Different (does it occupy/fill a unique space/provide a unique type of support not offered elsewhere)
 - e. Complementary to other services

Improvements, strengths and weaknesses

- 13. What are your thoughts on the service being provided in a community venue like a library rather than a health centre or hospital for example?
- 14. How do you feel about the possibility of it being somewhere like a shopping centre or supermarket?¹⁹
- Role of/as a carer (if relevant)
- Discussion of issues they have faced e.g. financial, emotional, practical, have they been offered any/adequate support for these
- Current position
- Point in the cancer pathway when accessing the service (i.e. pre-diagnosis, post-diagnosis, treatment, later

- a. National helplines Macmillan
- b. National helplines non-Macmillan
- c. Online support Macmillan
- d. Online support non-Macmillan
- e. GP
- f. Social care
- g. Hospital based service
- h. Other service (e.g. Maggies centre)
- i. Employer
- j. CAB or similar
- k. Other

¹⁸ Could include:

¹⁹ Explore thoughts on pros and cons of, and interested in, different venues. Be aware that the client may have engaged through an outreach service in a health centre or hospital.

- 15. How comfortable did you feel speaking to a volunteer as opposed to a doctor or other health professional? (for example, quality/them not being a health professional)
- 16. What are the strengths and weaknesses of a service delivered by volunteers?
- 17. Can you think of any reasons why people affected by cancer might be reluctant to use the service?²⁰ (privacy, quality)
- 18. How well do you think the service is publicised?²¹ (awareness of service + how they think it could be better marketed)
- 19. Is there any other kind of support or improvements you would have liked the service to have provided or enabled you to receive? (Has the service met all of your needs?²²)
- 20. Finally, could I also ask how you would the describe Macmillan @ Glasgow Libraries service to someone else?

Stakeholder Interview Guide

Introduction:

Thank you for agreeing to provide feedback on the Macmillan @ Glasgow Libraries service.

Your views are important in assessing the impact and effectiveness of the service, what works and whether there are areas that could be improved.

All responses will be treated in the strictest confidence.

- Accessing services in a library
- Fear of a lack of privacy/seeing others from the local community
- Not wanting to ask for help
- Not knowing about the service
- Concern about the quality of the service
- Not receiving support from a health and/or advice 'professional'
- Other (e.g. location (outreach vs libraries), literacy levels, language issues, link to trust if not from a medical or Macmillan background?) Judgement from other library users?

²⁰ (Where data is available refer to answer provided previously and explore further)

²¹ Give explanation of what precisely this means if they seem unclear including where they have seen the service advertised, the quality of the promotional activities and any alternative ways the service could be promoted.

²² (Explore whether personal objectives changed as a result of accessing the service)

Not all questions will be applicable to all stakeholders.

- 1. Can you summarise your role in the programme?
- 2. How well is the service marketed?
- 3. What works in terms of promoting the service?
- 4. What could be improved?
- 5. What is the status of referrals and signposting to the service? How could this be improved?
- 6. Can you outline the importance and effectiveness of the role of library staff in outreach community engagement activities (e.g. promotion, involvement)?
- 7. How would you rate the standard of service provided by staff and volunteers?
- 8. Did library staff develop ownership of the programme?
- 9. What factors were critical to the level of buy-in?
- 10. Do you feel that the service has been successful in providing additional and/or higher quality benefits to service users?
- 11. Is the service responsive to the needs of PABC and the input of partners?
- 12. Do you feel that the service is meeting the needs and expectations of PABC?
- 13. Is the programme seen as a success and integrated?
- 14. What impact has the transition to Glasgow Life had? Has it been successful?
- 15. How has the service impacted on the libraries and library staff (e.g. roles, working styles and workload)?
- 16. Can the service be linked to any of Glasgow Life's strategic outcomes?23
- 17. What was the nature and effectiveness of any support provided to library staff to manage operational transition including volunteer needs

²³ Glasgow citizens will flourish in their personal, family and community life (through regular participation in learning, sport, cultural and creative opportunities); Enhanced skills and learning among (and contribute to the employability of) our citizens; Glasgow's local, national and international image, identity and infrastructure are enhanced; (Contribute to) Glasgow is a safer, greener and more sustainable city; Glasgow Life is a continuously improving, effective and efficient organisation providing high quality services; Glasgow's cultural heritage is protected and shared with its citizens and visitors; Reduced inequalities in Glasgow (relative to Scotland and between Glasgow Citizens); Enhanced health and wellbeing for all those who live and work in Glasgow.

- 18. What has been the strength of partnership working across the cancer network in Glasgow?
- 19. Has this changed over time?
- 20. Are there further aspirations for partnership working (e.g. outcomes, fewer/more partners)?
- 21. Have the level and direction of referrals from partners including health professionals met expectations?
- 22. What are the barriers to encouraging referrals? What has worked?
- 23. How does the service complement other Macmillan services in Glasgow including Improving the Cancer Journey24 and Move More25? Is there any duplication?
- 24. How valuable is partnership working to creating engagement and referrals in and out of the service?
- 25. Have partners and stakeholders been able to shape the service to achieve mutual objectives, supporting mainstreaming etc.?
- 26. How has the relationship between Glasgow Life and Macmillan worked in practice?
- 27. Have you noticed changes in the library offer and/or management that can be linked to the service?
- 28. Has the service added value to the physical and/or spiritual space in libraries?
- 29. Have there been changes in the way that libraries and library staff work?
- 30. What is the viability of the library's role in being a source of health information for people with a range of long-term conditions?
- 31. Has there been an impact on the take up of other services offered by libraries? (Increase / decrease use/impact of Macmillan branded spaces in and out of volunteer-manned times?)
- 32. What opportunities have there been for personal and professional development for libraries staff linked to the service?

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 $^{^{24}}$ A service helping people with cancer access whatever types of support they need based on a Holistic Needs Assessment

^{(&}lt;a href="http://www.macmillan.org.uk/aboutus/healthandsocialcareprofessionals/newsandupdates/macvoice/">http://www.macmillan.org.uk/aboutus/healthandsocialcareprofessionals/newsandupdates/macvoice/ /winter2014/improvingthecancerjourney.aspx)

²⁵ http://www.glasgowlife.org.uk/communities/goodmove/movemore/Pages/default.aspx

- 33. How would you assess the availability, quality and effectiveness of any training and support provided to libraries staff?
- 34. What are the critical success factors behind any successes of the service?
- 35. Do you have any other comments about the service and/or your role?