Evaluation of Macmillan Cancer Information and Support Service @ Argyll and Bute Libraries

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Introduction

MCISS
The Macmillan Cancer Information and Support Service (MCISS) provides health and practical information, as well as drop-in sessions for a listening ear with volunteers. It has been started in several Scottish locations – including the Beatson West of Scotland Cancer Centre and Glasgow libraries. In 2013 a pilot programme to start MCISS in remote and rural libraries was started in Kintyre and the Isle of Bute.

Evaluation
This report details results from an evaluation of the remote and rural pilot MCISS sites in Campbeltown and Rothesay carried out by the Rural Health and Wellbeing team of the University of the Highlands and Islands between May and September 2014. This was carried out with an awareness that the service has been running for 12 months in Campbeltown (with drop-in operating from October 2013) and 4 months in Rothesay at the time of evaluation.
Executive Summary

Methods
The evaluation was led by Dr. Sarah-Anne Munoz (Senior Research Fellow in Rural Health) with research assistant support from Sarah Bowyer (Doctoral Researcher in Rural Health) between April and September 2014. The objective of the evaluation was to:

Gather evidence to establish whether the service is meeting the needs of the community and operating in a manner that meets the Macmillan Quality Standards for Information and Support Services.

The approach to the evaluation meant that it considered the viewpoint of several key stakeholders: the steering group; service users; volunteers and members of the public. We collected and analysed qualitative data in order to evidence the impacts of the service for these different groups. The data was gathered through a mixture of telephone and face-to-face interviews and focus groups and analysed using thematic analysis underpinned by realist theory.

Data Review
The Argyll and Bute MCISS is reaching fairly similar proportions of the local population to the urban Easterhouse (Glasgow) service. The majority of service users are female and fall into the Level 1 or Level 2 complexity categories (See Appendix 1). In both Kintyre and Bute, it is family members that make up the numerically largest group of service; followed by those living with cancer (with lunch and breast cancer the most common types). Most service users had learnt about the service through the local media or word of mouth. The vast majority of service users contacts occur face-to-face and last
between 6 and 30 minutes. Most people who have accessed the service did so because they “wanted to talk”. The three types of output most common to both Kintyre and Bute are ‘written/audio/visual information’; ‘listening ear’, and ‘verbal info’. The largest number of signposting events in Kintyre (53%) and Bute (86%) are to other Macmillan services.

**MCISS Partnership Working**
The majority of respondents agreed that the aims and objectives of the MCISS in Argyll and Bute are:

- To give access to **information and signpost** to other services.
- To provide **emotional and social support**.

The majority of all participants in the qualitative research, talked about the MCISS in Argyll and Bute as meeting a ‘gap’ in information on cancer and support services locally, where special cancer services are not geographically close. In particular, the service was discussed as filling a gap in emotional and social support. Some stakeholders, especially Council staff, stated the importance of the service providing non clinical information.

There was a good level of awareness of Macmillan’s key role in provision of funding for the service and the “reliable” information on cancer through leaflets and support for the MCISS staff. There was also good awareness of the contribution of Argyll and Bute Council amongst their stakeholders interviewed, in terms of hosting the service and the provision of space within the libraries. The NHS stakeholders felt their role is to signpost to the service in order to meet preventative and health improvement goals; partly through working with GPs. The Macmillan nurses signpost users to the
service. The role of AVA was less well understood – particularly by the volunteers.

Some respondents expressed a feeling that the partnership was not equal, particularly in the early days, but at the same time it was acknowledged that each organisation has knowledge and expertise to contribute. Overall most people felt these challenges were inevitable in partnership approaches and recognised things are now working well.

**Service User Experiences**

In both Bute and Kintyre, three aspects of context were identified that effect why people use the MCISS:

1. **Awareness** of the service.
2. Personal recognition of a need for what the service can offer.
3. Personal feelings of comfort with using the service.

In terms of awareness, we saw evidence of a key role being played by the volunteer coordinator and service manager in terms of making the local community aware that the MCISS is available. All the service users questioned in Campbeltown had found out about the service through contact with management staff or the volunteers themselves.

We had several comments on one particular benefit of the service being in a library resulting in not feeling ‘observed’ by others within the community to be accessing a ‘medical’ service. Users and volunteers talked about the Macmillan corners as creating a particular atmosphere that was “relaxed”. The fact that the drop-in
service is manned by local volunteers was valued by everyone for a number of reasons. Some service users were comfortable to talk to the volunteers because they felt they had a personal understanding of cancer and/or supporting people with cancer. However, some discussions were had with volunteers and service users about concerns of privacy – some felt that their conversations might be heard by other library users.

The main benefits to service users were noted as emotional support and information received – the information being provided in abundance and clearly understood. Providing practical and emotional support was often, therefore, discussed as easing anxiety and, sometimes, feelings of guilt.

Volunteer Experiences
In both Kintyre and Bute, three elements of context were identified that effect why people volunteer:

- The individual is **aware of the service** and the opportunity to volunteer.
- The individual **feels comfortable** that he/she is capable and equipped to fulfil the volunteering role.
- The individual is **motivated** to volunteer.

Most of the volunteers that we spoke to had decided to volunteer for MCISS after becoming aware of the opportunity to do so from a MCISS staff member or someone already involved in the service as a volunteer. When discussing their roles as volunteers, many people raised the issue that they had previous “experience” with cancer –
either as a patient, carer or health professional. They related that this helped give them feelings of confidence that they could empathise with service users and provide appropriate information and support. Coming through a recruitment process also gave several volunteers faith in their ability to fulfil the role. Almost all the volunteers that we spoke to felt the training provided by the volunteer co-ordinator helped them to stay motivated. The main challenge to volunteers’ continued motivation was their frustration with low numbers of service users.

Staff Experiences
MCISS staff highlighted the importance of being associated with Macmillan which provides a supporting network and training for themselves, as well as training materials that they can use with the volunteers. The library staff generally reported positively on the training and support received.

Library Users – Not Current MCISS Users
Overall there was a good awareness in both communities about the existence of the MICSS service but its actual role and what it could provide was not clearly understood by everyone. Once an explanation was given all but one of the participants felt that the library was an appropriate place to hold the service but some improvements regarding access for people with a disability were identified. The majority of people interviewed felt that they were likely to use the service should they feel they needed to in the future.
Consideration of MCISS in Argyll and Bute in the Future

Based on their own experience of using the service, all the service users that we spoke to said that they would be happy to use the service again. Some service users had already recommended the service to others and the remainder said they would be happy to recommend it to friends or family should the need arise.

There was not a consensus across the data of the future path for MCISS Argyll and Bute. Most interviewees were conscious of the need to secure further funding for the service; with some suggestions that it be funded by the public sector. Some felt that if the Macmillan model was followed through or rolled out, this would mean that the service would be delivered by volunteers and supported by library staff. Some stakeholders that we spoke to implied that AVA would support volunteers in the future (through management and training); whilst others were less sure about this. When discussing the future of the MCISS with the volunteers, they stressed the importance of there being well-organised and supportive volunteer coordination. All the library staff that we spoke to were supportive of the service and related instances of directing service users to the MCISS areas within their libraries. However, most were also wary of taking on any greater a role in service delivery or management.

Many people felt that the MCISS is a successful concept that has the potential to deliver benefits more widely within Argyll and Bute if it was to include more library spaces. There was not consensus on how this could best happen. Most volunteers supported the idea of extending drop-in hours into the evening at the Argyll and Bute Libraries. Some suggested that it may be beneficial to service users to extend the scope of the service to include other non-malignant
long-term conditions. It was also suggested that there could be more “social prescribing” to the MCISS.

Discussion
The evaluation shows that the location of the MCISS service within library spaces does encourage people to use the service and may be related to increases in library footfall. The importance of the service being located within the “community” was also validated through the qualitative evidence.

The data review revealed that most signposting from the service is to other Macmillan services. Particularly discussed by volunteers and service users were Macmillan telephone lines. The partnership with Macmillan appears to be working well in terms of encouraging access to these pathways.

The majority of people we spoke to felt the volunteers played an important role in being a “familiar” or “local” face at the drop-in that encouraged people to come along and to talk. However, the evaluation has also shown the role played by the MCISS staff in areas such as awareness-raising and dealing with enquiries, particularly outside drop-in days and times.

95% of the volunteers that we spoke to felt that they received appropriate levels of training and support – which helped them in their role as volunteer to deliver appropriate information and support to service users. Library staff all reported value in attending the training as it helped them understand the service and, therefore, direct library users towards it or even handle queries on the phone.
Through the realist approach we were also able to identify particularly important elements of local and rural context that are related to the MCISS in Argyll and Bute:

- It takes time to embed an initiative in a remote and rural area.
- The role of the MCISS staff within the community.
- Low footfall and volunteer frustration.
- Volunteers as a ‘known face’ – positives and negatives.

- Visibility of using a service.
- Macmillan in Argyll and Bute communities.
- Transport issues.
- Library staff and their relationship with library users.
- The absence of other options (isolation).
- Publicity/awareness and word of mouth.

Macmillan Quality Standards

The Macmillan Quality Standards function as a practical tool for cancer information and support services (CISSs) to assess and develop the quality of their service. This report details the results of an evaluation that demonstrate how the service currently meets these Standards. A summary detailing each Quality Area and how it has been met is provided in the report.

Conclusions

This evaluation highlights the hard work of the MCISS Argyll and Bute Steering Group, staff and volunteers to deliver a service that is meeting Macmillan Quality Standards. With partnership
working reporting as having some teething problems – these were largely considered to have been worked through by the majority of stakeholders.

Service users often access the Argyll and Bute MCISS in order to obtain information or support for themselves, although friends and family members are also accessing it. Particularly appreciated by volunteers and service users was the fact that the service is situated in a non-medical, community-orientated space that is perceived as familiar and friendly.

Several benefits to both service users and volunteers are evidenced in this report – although many related to the acquisition of practical or health-related knowledge, most emphasised the benefits of the reassurance and emotional support provided by the service which resulted in reduced anxiety and stress.

Evidence was seen of a competent and enthusiastic set of volunteers – some suggestions for keeping up volunteer morale were made and have been detailed in this report.

However, the data review has shown that most service user contacts occur outside of drop-in hours and are, therefore, dealt with by MCISS staff rather than the volunteers. It was suggested that it would be beneficial to have more signposting from primary care and hospital staff.

Looking to the future, this evaluation demonstrates that the service is meeting a gap within the remote and rural communities of Kintyre and Bute. Evidence has suggested that the benefits of the service could be enhanced by extended the scope of the MCISS – either geographically or in terms of drop-in times.
Methods
The evaluation was led by Dr. Sarah-Anne Munoz (Senior Research Fellow in Rural Health) with research assistant support from Sarah Bowyer (Doctoral Researcher in Rural Health) between April and September 2014. The objective of the evaluation was to:

*Gather evidence to establish whether the service is meeting the needs of the community and operating in a manner that meets the Macmillan Quality Standards for Information and Support Services.*

Realist Evaluation Approach
The approach to the evaluation meant that it considered the viewpoint of several key stakeholders: the steering group; service users; volunteers and members of the public. We collected and analysed qualitative data in order to evidence the impacts of the service for these different groups. The data was gathered through a mixture of telephone and face-to-face interviews and focus groups and analysed using thematic analysis underpinned by realist theory.

In order to meet the evaluation objectives, the research team collected qualitative information from key stakeholder groups in the following broad areas:
<table>
<thead>
<tr>
<th>Stakeholder Group</th>
<th>Areas of Qualitative Investigation</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Steering Group and Project Partners</strong></td>
<td>What works well for them and why?</td>
</tr>
<tr>
<td></td>
<td>• Their role and contributions</td>
</tr>
<tr>
<td></td>
<td>• Meeting their needs</td>
</tr>
<tr>
<td></td>
<td>• Valuing their input</td>
</tr>
<tr>
<td></td>
<td>• Challenges</td>
</tr>
<tr>
<td><strong>Service Users</strong></td>
<td>What works well for them and why?</td>
</tr>
<tr>
<td></td>
<td>• Their perceptions of and experiences of the service (physical space; knowledge gained; usefulness etc.)</td>
</tr>
<tr>
<td></td>
<td>• How they have used it and why; including longer-term impacts</td>
</tr>
<tr>
<td></td>
<td>• Types of support received</td>
</tr>
<tr>
<td></td>
<td>• What did they expected/thought they needed compared to what they got</td>
</tr>
<tr>
<td></td>
<td>• What is missing; barriers to use</td>
</tr>
<tr>
<td><strong>Volunteers</strong></td>
<td>What works well for them and why?</td>
</tr>
<tr>
<td></td>
<td>• Motivations for volunteering (initially and continuing to)</td>
</tr>
<tr>
<td></td>
<td>• Meeting their needs</td>
</tr>
<tr>
<td></td>
<td>• Valuing their input</td>
</tr>
</tbody>
</table>
The evaluation adopted a realist approach in order to establish whether, and if so how, the service is meeting the needs of the community and the Macmillan Quality Standards for Information and Support Services. A realist approach is concerned with the context, mechanism and outcomes associated with an intervention – using, therefore, the guiding question *what works, for whom, under what circumstances?* Thus, the approach explores the relationships between ‘context’ (the intervention’s organisational setting and external constraints); ‘mechanisms’ (the stakeholders’ ideas about how change will be achieved in an intervention) and ‘outcomes’ (the intended and unintended consequences of the intervention).
This allowed the evaluation to consider what works (why and how) for the different stakeholders associated with the cancer information support services:

- The programme partners: NHS Highland; Macmillan Cancer Support; Argyll Voluntary Action and Argyll and Bute Council; other members of the steering group and other key stakeholders.
- Service users.
- Volunteers.
- Members of the public.

For each stakeholder group, we constructed hypotheses of change that were then tested through data collection and analysis. We used ethnographic observation, semi-structured interviews (service users; volunteers; staff; steering group), focus groups (volunteers) and analysis of existing programme documents.

**Stage One: Construction of Hypotheses of change**

The first stage in the evaluation was concerned with formulating hypotheses of change – the potential impacts/experiences/outcomes of being involved in the intervention and why/how these may come about. We identified the ‘basic ideas’ behind the intervention – which were then tested out through the gathering and analysis of qualitative data as the evaluation progresses. The main activities during this stage are outlined below:

- Review of annual report and official documentation in order to identify the objectives of the intervention and potential impacts, experiences and outcomes.
• Design of an interview schedule for use with Steering Group and other project partners, e.g. carers group, to include discussion of local context and wider policy environment).
• Telephone interviews conducted with key contact from each stakeholder organisation on their role, contribution, experiences and challenges (20 interviews were completed).
• Review of data collection on service users from volunteer coordinator in order to identify the characteristics of those using the service, and how it is being used. This included data on all service user interactions, i.e. those with volunteers and staff, both within and outside drop-in times.

**Stage Two: Evidencing Service User’s Experiences**
Building on stage one, the evaluation team collected qualitative data in order to evidence service users experiences. The research team visited the Campbeltown and Rothesay Libraries in order to collect observational data and carry out one-to-one interviews with service users and volunteers (6 service users and 8 volunteers were interviewed). Therefore, this stage involved:

• Preparation of an interview schedule, informed by stage one findings.
• Ethnographic observation – fieldnotes taken on visit to the libraries.
• Interviews with service users.

**Stage Three: Initial Data Analysis**
Thematic analysis was used to identify the common and divergent experiences and outcomes reported by the service users. The PI and
Research Assistant conducted a close reading of each transcript separately and then agreed on a final coding scheme. The coding scheme related to our initial hypotheses of change and allowed us to review how they were confirmed or challenged by the fieldwork findings – the hypotheses were modified as necessary. The analysis produced thematic summaries, drawing on both the ethnographic and interview data, which provided an initial identification of context (organisational setting and external constraints); ‘mechanism’ (the stakeholders’ ideas about how change was achieved) and ‘outcomes (the intended and unintended consequences of the intervention). Each interviewee was given an individual identified relating to their organisation, as follows:

NHS 1, 2, 3 etc. NHS interviewee 1, 2, 3
AVA Argyll Voluntary Action
MM Macmillan
ABC Argyll and Bute Council (including library staff)
CTV Campbeltown Volunteer
CTSU Campbeltown Service User
RV Rothesay Volunteer
RSU Rothesay Service User

Stage Four: Data Validation and Evidencing Experiences
On a second visit to each of the MCISS evaluation sites, we discussed our interpretation of the data (stage three) with service users, staff
and volunteers. This allowed validation of, or challenges to, our initial themes. We spoke with 9 volunteers in Bute and 7 volunteers in Kintyre; as well as 2 library staff in Bute, 4 library staff in Kintyre and 2 MCISS staff.

**Stage Five: Final Data Analysis**

The final stage of the evaluation involved consideration of all the thematic analysis carried out in order to build a ‘story of change’. At this stage we will carried out a cross-case comparison to highlight the ways in which the intervention plays out in both Campbeltown and Rothesay and allowing conclusions to be drawn about generative causality. However, as noted above, this is limited by the shorter time of intervention and smaller number of service users interviewed at the Rothesay site.
Data Review

Overview of Service Users

Kintyre – 4 Quarters until end June 2014

<table>
<thead>
<tr>
<th>Total Number of Service Users</th>
<th>84</th>
</tr>
</thead>
<tbody>
<tr>
<td>Female</td>
<td>69</td>
</tr>
<tr>
<td>Male</td>
<td>15</td>
</tr>
<tr>
<td>Number of returning visits</td>
<td>17</td>
</tr>
<tr>
<td>Level of Complexity 1</td>
<td>45</td>
</tr>
<tr>
<td>Level of Complexity 2</td>
<td>45</td>
</tr>
<tr>
<td>Level of Complexity 3</td>
<td>2</td>
</tr>
<tr>
<td>Level of Complexity 4</td>
<td>2</td>
</tr>
</tbody>
</table>

Bute – 2 Quarters until end June 2014

<table>
<thead>
<tr>
<th>Total Number of Service Users</th>
<th>25</th>
</tr>
</thead>
<tbody>
<tr>
<td>Female</td>
<td>21</td>
</tr>
<tr>
<td>Male</td>
<td>4</td>
</tr>
<tr>
<td>------------</td>
<td>---</td>
</tr>
<tr>
<td>Number of returning visits</td>
<td>1</td>
</tr>
<tr>
<td>Level of Complexity 1</td>
<td>13</td>
</tr>
<tr>
<td>Level of Complexity 2</td>
<td>10</td>
</tr>
<tr>
<td>Level of Complexity 3</td>
<td>1</td>
</tr>
<tr>
<td>Level of Complexity 4</td>
<td>1</td>
</tr>
</tbody>
</table>

Total numbers of service users are lower than seen in other MCISS evaluations such as that of Easterhouse Library (Glasgow) where there were approximately 500 service users, compared to a combined total of 109 in Campbeltown and Rothesay. However, it should be noted that the Easterhouse service has been running for much longer (since 2009) and that when we consider number of service users as a percentage of the local population, we find fairly similar levels of access:

Easterhouse population – 26,495 (1.9% access)

Campbeltown population – 4,852 (1.7% access)

Rothesay – 4,850 (0.5% access); if current level of use is maintained estimated to also be approximately 1-2% of population after 4 quarters.

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The majority of service users are female; despite fairly similar numbers of males and females with cancer diagnosis within the Scottish population (2012, M = 20,838; F=20,484).

20% of contacts in Kintyre are return visits; compared to only 4% in Rothesay, although this is likely due to the shorter duration of the Bute service.

The majority of service users in both locations fall into the Level 1 or Level 2 complexity categories (See Appendix 1). This differs slightly to the patterns seen in Easterhouse and the Beatson² where most interventions are within Levels 2 and Levels 3. Although the lower numbers at Level 4 is a common trend.

**Service User Types**

The two graphs below show the types of service users accessing the service in Kintyre and Bute. It should be noted that both services have received enquiries and usage from people living outside these areas and accessing in Kintyre or Bute does not necessarily indicate that the service user is resident in that local area.

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² Hobbs, N., et. al., (2010) *Evaluation of the Cancer Information Centre in the Beatson West of Scotland Cancer Centre* (University of Stirling)
In both sites, we see the importance of the service to groups including, but beyond those who are currently diagnosed with cancer. In both Kintyre and Bute, it is family members that make up the numerically largest group of service users. There are also several instances of people who have had cancer previously making use of the service.
Cancer Sites
The most common types of cancer that the service came into contact with are outlined below (figures are combined for Kintyre and Bute and exclude those entries that do not name a cancer site, i.e. unknown, not applicable and blank).

**Interactions with MCISS by Cancer Site**

<table>
<thead>
<tr>
<th>Cancer Site</th>
<th>Interactions</th>
</tr>
</thead>
<tbody>
<tr>
<td>NHL</td>
<td>14</td>
</tr>
<tr>
<td>Cervical</td>
<td>6</td>
</tr>
<tr>
<td>Lung</td>
<td>7</td>
</tr>
<tr>
<td>Breast</td>
<td>20</td>
</tr>
<tr>
<td>Bladder</td>
<td>14</td>
</tr>
<tr>
<td>Head and neck</td>
<td>9</td>
</tr>
<tr>
<td>Prostate</td>
<td>2</td>
</tr>
<tr>
<td>Secondary diagnosis</td>
<td>2</td>
</tr>
<tr>
<td>Palliative care</td>
<td>2</td>
</tr>
<tr>
<td>Living with cancer</td>
<td>9</td>
</tr>
</tbody>
</table>

Stage of Pathway of Service Users

**Interactions with MCISS by Stage of Pathway**

- Bereaved: 14
- Undergoing tests: 6
- Recently diagnosed: 7
- Undergoing treatment: 20
- Treatment recently completed: 14
- Secondary diagnosis: 2
- Palliative care: 2
- Living with cancer: 9
The data above are combined for both Kintyre and Bute and excludes entries that do not name a stage of pathway, i.e. not applicable, unknown and blank.

We can see that most of the interactions with the MCISS are with people who are either currently undergoing or recently completed treatment. Family were previously seen to account for a relatively high amount of contacts with the services; here they make up the majority of the bereaved group.

**Types of Interaction with MCISS**

![Percentage of Service Interactions by Method of Hearing about MCISS](image)

The above data excludes interactions with people who have used the service previously (on their second and subsequent visits).
We can see that the local media is very important in terms of awareness raising in both locations; as is word of mouth. A considerable number of interactions with the service stem from people “just passing by”, although this is higher in Kintyre. From the qualitative research, we understand that this category includes service users who heard about the service ‘in passing’ from a volunteer or staff member, i.e. the category does not only include those who became aware of the service by seeing it in the library.

The vast majority of contacts with the service in both locations (combined data below) have occurred face-to-face, with a minority of contacts being by telephone or email (this minority has been handled by service staff). The face-to-face contacts are made with staff (approx. 70%) and volunteers (approx. 30%).

![Service Interactions by Method of Contact](image)

The vast majority of interactions with the service occur within the library environment; although some do occur within community locations or outreach events.
The majority of interactions with the service in both locations are either between 6 and 15 minutes or 16 and 30 minutes.

The data collection spreadsheet allows for up to three reasons for visit to be recorded. Many people have one or two reasons and a minority have three. Here we consider the primary reason for accessing the service across the two MCISS Argyll and Bute sites:
The vast majority of service users in both Kintyre and Bute access the service because they want to talk. This is followed by a fairly large number of service users seeking local information and support. Several categories have no response for Bute, this is likely to be related to the shorter time that this service has been up and running. In terms of second and third reasons for accessing the service, some of the more common reasons include travel; carer issues; local information; treatment and side effects; end of life; dietary advice and living with cancer.

**Outputs for Service Users from Accessing MCISS**

Data is routinely collected on the outputs and types of signposting that occur as a result of service users’ interactions with MCISS. The graphs below compare the types of output and signposting that have occurred in both Kintyre and Bute by using the percentages of services users in each case study area. The data presented is only for those interactions recorded as having an output or signposting event, i.e. it does not include services users for which no data is recorded.

![Outputs Graph](image)

<table>
<thead>
<tr>
<th>Outputs</th>
<th>Kintyre</th>
<th>Bute</th>
</tr>
</thead>
<tbody>
<tr>
<td>Written/audio/visual info</td>
<td>25.78</td>
<td>32.43</td>
</tr>
<tr>
<td>Listening Ear</td>
<td>40.63</td>
<td>32.43</td>
</tr>
<tr>
<td>Verbal Info</td>
<td>30.47</td>
<td>35.14</td>
</tr>
<tr>
<td>Help with forms</td>
<td>3.13</td>
<td>0.00</td>
</tr>
</tbody>
</table>
According to the data, the three types of output most common to both Kintyre and Bute are ‘written/audio/visual information’; ‘listening ear’, and ‘verbal info’. In Kintyre some service users had also received help with completing forms.

In terms of signposting the graph below indicates that the largest number of signposting events in Kintyre (53%) and Bute (86%) are to other Macmillan services. Around 10 – 20% of signposting events in both locations are to social care or health professionals.
MCISS Partnership Working

Stakeholder’s Roles and Objectives

The objectives of the MCISS in Argyll and Bute as detailed in the Operational Reports are:

• To develop a successful pilot of cancer information and support in Campbeltown Library and Rothesay Library, that can be used to inform a roll out of the service across Argyll & Bute Libraries for cancer support and other long term conditions.

• To develop the role of libraries as health information centres, by enhancing the range of materials and developing the facilities, and by increasing footfall.

• To enhance the skills of library staff and volunteers.

• To support people living with and beyond cancer who have a range of physical, practical, emotional and financial needs to make informed choices using a community development approach.

• To monitor and evaluate the service.

We set out to consult stakeholders, MCISS and library staff, volunteers and service users about their understandings of the services’ aims and objectives. In addition, we also asked stakeholders whether they felt the service was contributing towards meeting their own organisational expectations and aims. The majority of respondents agreed that the aims and objectives of the MCISS in Argyll and Bute are:
• To give access to **information and signpost** to other services.
• To provide **emotional and social support**.

Most respondents mentioned that the services is for people who are diagnosed, living with cancer or been through treatment [NHS3; CTV2; CTV3; CTSU1; CTSU3; MM1; MM2; MM3; MM4; ABC1; ABC3; ABC5; ABC6; NHS7]; fewer mentioned that the service can also offer support for families [AVA1; CTV2; CTSU1; MM2; MM4; ABC5: NHS7: AVA4] carers and helpers [MM3] or anyone affected by cancer [ABC1; ABC3; NHS7 ABC7; AVA4; MM4] which includes members of the general public that are not necessarily diagnosed with cancer (although as we have seen above, family members do make up one of the largest groups of service users):

“[it’s]... to provide information and support for sufferers and their families – to inform and make it easier for them to get information...” AVA1

“[it’s] to provide a service for people who are diagnosed and living with cancer...” NHS3

“it’s not just for people with a cancer diagnosis it can also be for carers and helpers.” MM3

“A service for people going through cancer or who know someone who is going through cancer.” ABC1

“Family and friends need support as much as the people who have the cancer.’ AVA4
The majority of all participants in the qualitative research, talked about the MCISS in Argyll and Bute as meeting a ‘gap’ in information on cancer and support services locally, where special cancer services are not geographically close [ABC1; ABC3; MM4] – particularly information that is “evidence-based”, “high quality” and “trusted” [NHS 1; NHS2; NHS4; NHS5; NHS6; NHS7; AVA1; AVA3; RV1; CTV2; CTV3; MM1; ABC8]:

“It came locally, here because...there was a gap in information and support for people who had been on a cancer journey... we have limited support networks for people with cancer and this is the only opportunity for face-to-face contact.” NHS2

“[the aim was to] set up services to give reliable and accurate, and authoritative information...” ABC8

In particular, the service was discussed as filling a gap in emotional and social support [NHS2; NHS4; RV1; MM3; MM3; ABC1; ABC4; ABC5; ABC8] that is a face-to-face interaction [NHS2; MM2]; a listening ear [NHS2; NHS5; ABC3; ABC6; MM4]; a chat [AVA2; ABC2; ABC3; ABC5; ABC8; AVA4]; a cathartic or therapeutic conversation [AVA3; MM4] or providing information through picking up a leaflet [ABC2;ABC8]. Some stakeholders, mainly from the NHS, talked about this as also empowering people to look after their own health and wellbeing [NHS3; NHS4; NHS5]. However, in the focus groups with volunteers, in both locations, they felt it was important to note that empowerment does not necessarily occur as a result of an interaction with the service – and whether this results is dependent on a variety of factors including the character of the service user.
Some stakeholders, especially Council staff, stated the importance of the service providing non clinical information [ABC4; ABC6 ;ABC7] with others stating that the service is provided outside a medical area [NHS6; NHS7; ABC7] when it is required or is most appropriately given when people are not in hospital [MM1]. Macmillan staff pointed out that this was an important motivation for setting up the service:

“from our experience people asked for advice on finance, benefits, housing, childcare and work issues because they felt supported by clinical staff- but this information doesn’t necessarily have to be given by clinical staff.’ MM4

Stakeholders mentioned some particular types of information that the service aims to provide relating to benefits [MM2 ;ABC4] or finance [ABC1] on practicalities and travel arrangements to main hospital sites [ABC1; ABC2; ABC3] signposting to local or national activities and services [ABC8; MM3; MM4] and Macmillan services[MM3: NHS5]. One respondent stressed that:

“it’s to provide information – it’s not advice – it’s not counselling...”

ABC5

Others stated an aim is to be freely available [ABC6] to all [AVA4] and to help avoid feelings of isolation [MM3; MM4; AVA4]

“to overcome rural isolation as far as cancer information is concerned unlike a city where numbers will make cancer groups sustainable there are not enough people on the cancer journey
so those directly affected or tenuously affected and those just interested in a friendly welcoming atmosphere.” ABC7

“fair and equal access to information wherever you are.” ABC8

“Macmillan aim to support people living in rural environments to receive the same benefit as those in urban areas.” MM4

Some respondents included certain practical characteristics of the service in their understanding of its aim; such as using a prominent volunteer input [MM2; MM3; MM4; ABC2;] on specific days and times each week [MM2; MM3] for face to face conversation with someone who can signpost them as quickly as possible [MM2].

“Macmillan see the service delivered by volunteers and supported by library staff.” MM4

Whilst other respondents reported the aim to bring more people into the library [ABC2; ABC5]; for Macmillan to reach those who already use the library [ABC2; ABC4] and to enhance the libraries agenda to be more sustainable and varied in service provision [ABC5].

We asked each of the stakeholders, as well as library staff, whether they felt the MCISS contributed to meeting their own organisational goals and what their current role was perceived to be and whether their contributions to the service were valued.

There was a good level of awareness of Macmillan’s key role in provision of funding for the service and the “reliable” information on cancer through leaflets and support for the MCISS staff. Stakeholders
from Macmillan agreed their role included funding and resources to create the space, branding, leaflets [MM1; MM2; MM4]. Macmillan work with partners to market the service e.g. through press releases and launch or celebration events [MM1] bookmarks, information leaflets social media [MM1] and providing signage in libraries [MM3]. They also play a key role with recruitment, training and supporting volunteers [MM1]. Although some identified Macmillan as a fundamental organisation for MCISS, Macmillan’s ability to work collaboratively with other partners was also acknowledged:

“Macmillan identified the case of need then identified the partners to work with, cost it, justify it – it wouldn’t work without Macmillan.” MM3

“ when Macmillan forms new services we are not a bricks and mortar organisation we work in collaboration with multi partners.” MM2

“Macmillan utilises its organisational roles engaging with their environmental team to help with service development team – on the operational level there is the library, the NHS and the A&B voluntary action and patients.” MM3

Macmillan staff felt that the other partners valued the input and experience that Macmillan bring with the MCISS model and had worked together to ‘tweak’ this to localise the service.

“we already worked extremely well with the NHS, Argyll and Bute Council were new partners but Macmillan felt very much part of the programme.” MM4
Macmillan has a guiding mission of 9 outcomes, which are a strategy for meeting people’s needs and helping them to make an informed choice (See Appendix 2). The MCISS helps to fulfil these [MM3; MM4].

There was also good awareness of the contribution of Argyll and Bute Council amongst their stakeholders interviewed, in terms of hosting the service [ABC3; ABC5] the provision of space within the libraries [ABC6; ABC8] and enabling Macmillan to deliver the service more effectively [ABC4]. It was also mentioned that library staff let users know that the MCISS is available [NHS5] and the Council advertised the service through signage and posters [ABC1; ABC2; ABC4] on face book [ABC1; ABC2;] in the local newspaper [ABC2;] on the local radio [ABC2;] and on the council web site [ABC3]. Stakeholders appreciated that the Council support staff at various levels and positions- volunteers, library staff and MCISS operational staff. The library staff have had the Macmillan training and can give information [ABC2; ABC4; ABC6] and direct people to leaflets [ABC4; ABC6] or a volunteer [ABC4; ABC6], they understand they are not there to run the service [ABC3]. The Argyll and Bute Council provides human resources services and line management of MCISS operational staff who deliver [ABC7] and day to day manage the MCISS [ABC8]. Challenges had been worked through in designing and delivering on employment contracts for posts working across collaborative organisations:

“’Working out the logistics of posts funded by Macmillan but line managed by the council was …… but we eventually got over that.’” ABC7
For volunteers Argyll and Bute Council provides the PVG disclosure service [ABC3], training and support [ABC5] and management [ABC8] particularly when facing difficult or emotional situations [ABC5]. The MCISS contributes to meeting the library aim of giving people information [ABC1; ABC4; ABC6] and the library improvement plan, which includes a move into health provision [ABC8].

The NHS stakeholders felt their role is to signpost to the service in order to meet preventative and health improvement goals; partly through working with GPs [NHS4; NHS5; NHS6] and advertising material, word of mouth and through health care professional roles [NHS7]. Although one respondent expressed the opposite:

“*It’s an arm’s length relationship for the NHS who do not necessarily signpost potential service users to the MCISS.*”

*NHS1*

The Macmillan nurses signpost users to the service [NHS2; NHS5; MM2]. For the NHS, the aims and objectives of MCISS fit with their quality strategy and the self-directed care and community empowerment agendas to increase working in partnership at a locality level [NHS6; NHS7].

The role of AVA was less well understood – particularly by the volunteers. From the AVA interviewees’ point of view AVA sit on the steering group to represent the third sector and bring an understanding of local volunteering [AVA2] and to introduce local people and networks (AVA ensure the information is placed on all the networks that they belong to [AVA3, AVA4]. They spread the word locally [AVA4] with posters and leaflets in the office and signposting potential volunteers to the service [AVA1; AVA2; AVA4].
They helped with the initial job descriptions [AVA2] supported recruitment of volunteers [AVA4] and contributed to the design of the physical space within the libraries [AVA4]. Most volunteers that took part in our focus groups and interviews stated that they were not previously aware that AVA is a partner in the MCISS.

AVA operate a time banking scheme so volunteers are able to ‘get something back’ if they wish [AVA4] however the majority of the volunteers were not aware of this – one volunteer who had looked into utilising this remained unclear of how to engage in it. AVA has an organisational aim to increase social resilience so being involved in MCISS meets this aim [AVA1].

The service is delivered in a partnership between the four organisations although this was not always recognised by the volunteers and service users as shown later in this report. One respondent from the stakeholder interviews pointed out that the branding on public material is solely the Macmillan logo – there is no indication of NHS or Argyll and Bute Council or Argyll and Bute Voluntary Action involvement [MM3] but all four logos feature on letterheads for correspondence between the steering group correspondence letters and documents such as minutes etc. [MM3] However, all four logos feature on all branding material for the MCISS except for the signage [NHS5; ABC5]

The stakeholder interviews did include some discussion of challenges of partnership working. Some felt that getting the different partners to work together has been challenging and lengthened the set-up process. Naturally each organisation has its own ways of working:
“the four partners all work to their own guidelines and strategies policies and agenda and this has caused some teething problems and frustration.” NHS5

“The council, Macmillan and the Health Board all wanted their “operatus modi” followed but they all conflict. “ ABC7

But this was acknowledged and it was recognised that this was something that just needed working through:

“frustration by apparent bureaucracy but all (organisations) have governance systems they need to work to.” NHS7

‘Multi partners means different agendas but everyone is willing to listen to other people’s ideas and agenda and people are willing to compromise.” MM2

Some respondents expressed a feeling that the partnership was not equal [NHS4], particularly in the early days, that sometimes there were different agendas [NHS4; ABC6] and it felt like Macmillan were driving decision-making [ABC6; ABC5; NHS4] but at the same time it was acknowledged that each organisation has knowledge and expertise to contribute:

“At first we felt very much the junior partner and were told what to do by Macmillan- it is their money, they do have the experience but they were not..... at recognising local differences.” ABC7
“The other partners have the real local knowledge to create a local Macmillan service.” MM1

“Macmillan are learning from the remote and rural areas and working to address the challenges and helping to resolve these through the partnership” MM4

Other contributory factors for delays in setting up were noted as the size of the organisations [ABC3; ABC6] logistical challenges with regards to availability of staff to attend meetings [ABC3] staff contracted hours to work on the service [NHS7] or bureaucratic processes [ABC 7]. One stakeholder identified a gap in the understanding of or confidence in the approach used:

“Not everyone on the committee understands the benefit of community development and some are nervous of it.” ABC5

Whilst another felt that using standardised frameworks would help efficiency of future work:

“A great network but not sure if all partners appreciate or are using the systems e.g. the Gantt charts.” ABC3

Overall most people felt these challenges were inevitable in partnership approaches and recognised things are now working well:

“I feel it’s a positive partnership – although we are entirely different organisations feel we have done very well to discuss and deal with issues at the steering group and operational group.” ABC8
“Has also been a massive personal commitment by Macmillan and staff have given their own time.” NHS 2

“It’s not necessarily run smoothly but everyone has been very open to listening and it’s a partnership that has now begun to grow.” MM4

However, some felt that efficiency could be further improved:

“It’s easier now than at the beginning but more needs to be done at the operational level – things are discussed at the steering group that could be dealt with at the operational level.” NHS5

Service User Experiences

Why do People Use the MCISS?
In both Bute and Kintyre, three aspects of context were identified that effect why people use the MCISS:

4. Awareness of the service.
5. Personal recognition of a need for what the service can offer.
6. Personal feelings of comfort with using the service.

Awareness of the Service

In terms of awareness, we saw evidence of a key role being played by the volunteer coordinator and service manager in terms of making the local community aware that the MCISS is available. However, the
importance of their role was stronger in Kintyre where both staff members are based:

“\textit{I was going through cancer treatment. I joined the local...group and they [Chris] came to tell us about the service... I didn’t know I could get support... it was then I released that this was open and available, when Chris told us...}” CTSU1

“They [Chris and Deirdre] are a liaison between the volunteers and the public – they can get out there and make our presence felt and, you know, you can’t expect volunteers to do that...” CTV1

All the service users questioned in Campbeltown had found out about the service through contact with management staff or the volunteers themselves. Two knew one of the volunteers; two had come into contact with staff through their own work and one had heard a member of staff give a talk about the service to a support group that they attended.$^3$ We were unable to speak to any service users that had been referred to the service by a healthcare professional – although referral was reported by stakeholders; volunteers were not aware of speaking with anyone who had been referred (they intimated that they might not know why someone had become aware of the service). Several volunteers, and stakeholders, pointed out that if people are diagnosed in Glasgow, they are not necessarily being made aware of the Argyll and Bute services that they can access when they return home. Some felt people should be given information in Glasgow about the Argyll and Bute MCISS.

$^3$ Although the service user reported that this was a Macmillan Cancer Support Group; discussions with MCISS staff indicate that it was a Cancer Support Scotland Support Group or Macmillan fundraising event.
The Macmillan nurses and other NHS staff were reported by stakeholders and volunteers as having been proactive in getting the service set up. The nurses, and others, were reported to have put a massive personal commitment to getting the service up and running; giving their own time. They were also reported as ensuring every new patient knows about the service [NHS1; NHS2; NHS4; NHS7; ABC6; AC7]. In Campbeltown in particular, Macmillan was reported as being a very well-known charity that lots of local people currently fundraise for [NHS2; MM2; ABC5] with the local group helping with the setup of the service:

“In Campbeltown, the Macmillan fundraising group helped with the aesthetics of the library and combatting perceptions about everyone knowing everyone else’s business.” MM2

We have seen in the data review above that the local media are also key in raising awareness – this is in large part due to the work done by MCISS staff in liaising with the media in order to raise awareness of the service [RV1; ABC7; MM2]. The “just passing” category suggests that some service users become aware of MCISS by seeing the Macmillan corner during a visit to the library – although we did not interview any service users who reported finding out about the service in this way. More commonly reported in the qualitative work was hearing about the service “in passing” from a MCISS worker or volunteer:

“I found out about the service through an informal conversation with Deirdre... and I was already aware of Macmillan because I had worked in a charity shop...” CTSU2
The service users that we interviewed were not previously regular visitors to the library and all felt that it wasn’t somewhere they would have previously gone to find health and wellbeing related information; suggesting it may contribute to increasingly library footfall.

Other (non-MCISS users) library users that we spoke to (n=20) were not necessarily aware of the aims and objectives of the service, even though they had seen the Macmillan corner. Some thought it was about fundraising for Macmillan; others did not understand the signage (see section on library users below). Volunteers also mentioned some ideas for increased awareness-raising through making changes to the existing signage – in particular this related to having signage on the outside of the Campbeltown library; having more explanation of the nature of the service on the green Macmillan signage, beyond ‘Macmillan @’ which some volunteers felt did not give a good sense to potential service users of what the service consists of. In both libraries, there is some signage hung from the roof, which volunteers felt was not particularly visible.

**A Need for the Service**

Many of the service users that we spoke to mentioned that they had already identified a need for cancer information or support and when setting out to find it, the MCISS seemed to offer what they were looking for. This validates points from the stakeholders about the service filling a gap locally. Three service users hadn’t necessarily known where to get support, others had asked the Macmillan nurse
previously and were now looking for a different type of post-treatment support:

“Hadn’t thought out where I would get information but had an awareness that I needed some.”

“Hadn’t thought about getting help- when I got my diagnosis I didn’t know where to start”

“Had no idea where to get support – there’s nowhere else in Campbeltown”

“When going through treatment it was MM nurse so now I come here come to drop in in a relaxed atmosphere. “

The fact that it was situated in the library was reported as initially “unexpected” by many of the service users that we spoke to – with one even saying they found it “surprising”. Most indicated that the library was not somewhere they would have previously thought of looking for health information. The majority were seeking information for themselves but one sought information for a family member. Most users could not state where else they would have gone or who else they could talk to, especially in the local area.

**Feeling Comfortable with using the Service.**

It is unlikely that people will use the service unless they feel comfortable in doing so. Our qualitative research highlighted several contextual factors that meant service users were comfortable with the service. The general feedback was that the libraries provided accessible locations, within the ‘main town’ that people visit
regularly for other things such as shopping or meeting friends [NHS1; ABC1; ABC3; CTSU1; MM4]:

“[It’s] easily accessible as I come into Campbeltown most days.”

We had several comments on one particular benefit of the service being in a library resulting in not feeling ‘observed’ by others within the community to be accessing a ‘medical’ service:

“People can come with library book and not be seen to go to doctors.”

With several stakeholders, volunteers and service users stressing the important of the Macmillan corner as being an appealing ‘non-medical’ space. It was reporting as being appealing particularly because it gives people support through the opportunity to chat to someone that is not a health professional [NHS1; NHS5; ABC1] in a place that is not medical [NHS2; NHS5; NHS6; NHS7; AVA1; RV1; AVA2; CTV2; CTV3; CTSU1; CTSU3; MM1; MM3; MM4; ABC1; ABC4; ABC5]

The setup of the Macmillan corner within the library was also highlighted as appealing. Two users particularly commented about it being sited in a secluded corner:

“ I like that it’s in the library. The setup is good.”

“It’s a nice wee corner. It’s good that it’s up here in the corner’ - the fact that its secluded .”

Users and volunteers talked about it creating a particular atmosphere that was “relaxed” – somewhere that “[you]…can have
coffee and be at ease” that is “safe”, “friendly” and “welcoming” [NHS1; NHS5; AVA2; CTSU3; AVA3; MM3; MM4: ABC3; ABC4; ABC2]. Many commented on the appealing and “comfortable” soft furnishings [NHS4; NHS5; AVA1; RSU1; CTV6] and inclusion of a photograph of a local scene [NHS5; RV3; RV4; MM3; ABC4; CTV6].

The fact that the drop-in service is manned by local volunteers was valued by everyone for a number of reasons. Many like the fact that they were non-medical staff because it meant that they did not feel pressured by time-constraints that may apply to conversations with health professional [NHS2; AVA1; RV3; CTV3; CTSU1; CTSU3; RV1; CTV2] or feel the awkwardness when talking to friends or family [RV1; RV2; RV3; CTV2; CTSU1 ;ABC1; ABC6]:

“‘They’re there [the volunteers] because they want to be - not like with some doctors or nurses or paid staff because it’s just their job – so it reassures me that they care and want to listen.”

“Happy that it was Mrs X [that I spoke to] – she’s about giving information, not medical advice or treatment.”

“[it was] not medical speak like a doctor.”

Within a small community, local volunteers may well come into contact with service users that they know as friends, neighbours of acquaintances. We discussed the implications of this with the stakeholders, volunteers and service users. Whilst some stakeholders had reservations about ‘well known’ faces putting people off using the service for reasons of anonymity, most volunteers and service users felt that having local people that were not entire ‘strangers’ was more of a benefit [NHS1; AVA1; RV1; CTV1; CTSU2; RSU1; MM3:
“I like that its local volunteers- people I know- this is a funny wee town and we’ll get each other to talk but if strangers came in they wouldn’t get us to talk.”

Some service users were comfortable to talk to the volunteers because they felt they had a personal understanding of cancer and/or supporting people with cancer [NHS2; AVA1; CTSU1; AVA3; MM3; ABC4; CTV3; CTSU3] :

“ Easy to talk to volunteers, no awkward questions, no pressure. [It’s] nice because people understand what you’ve been through.”

Others commented on the “rapport” that they felt with the volunteers:

“...there’s good banter, a joke... I feel at home.” [CTSU3]

The fact that people can also simply “take leaflets on their own” without speaking to anyone was also noted by one user as being important. Several stakeholders and volunteers also expressed that this was important [NHS4; AVA1; AVA2; CTSU1; RSU1;ABC8; AVA4].

However, some discussions were had with volunteers and service users about concerns of privacy – some felt that their conversations might be heard by other library users. This theme was much more prominent in Rothesay, where the library space is smaller than in Campbeltown. There was an awareness of the availability of a private space in both libraries, should it be needed. The majority of concerns in Campbeltown related to the positioning of a newspaper reading
area adjacent to the Macmillan corner – some volunteers were concerned that this resulted in readers overhearing drop-in time conversations with service users. Most volunteers discussed an awareness of there being no “ideal solution” to the issue of privacy and could see both benefits and drawbacks to the current Macmillan corner layout – with the privacy provided by the corner location, frosted windows and curved screens – but also a welcoming sense of openness by not being a separate room:

“…visibility adds to awareness – we need to have it without a door so people don’t have to open it – they know they can come into the open space…” ABC6

“…they don’t have to knock on a door and ask permission to cross a threshold…” RV1

**What are the Benefits to Service Users?**

If the users had come with expectations of their needs, these had been met in a variety of ways. Volunteers and staff described how they would treat each interaction with a service user as unique and tailor it to the individual. One service user was expecting it to be more health focussed but liked the fact it was directed at their own needs:

“Expected it would be more focussed on health issues – but it’s what you want it to be.”
“A listening ear is a good springboard, like ‘coming out’ to yourself – looking at your cancer and working out what you want to tell someone.. they [service users] can talk about feelings and memories or just about themselves...” RV4

The main benefits were noted as emotional support and information received – the information being provided in abundance and clearly understood. Many of the interviewees felt it was particularly important that the service offered users more than just factual information – through provision of a listening ear and emotional support:

“If I am in, I chat to volunteers about how are you etc. it’s not really about cancer.”

“Talking with people here is great.”

“I like to come in and see someone.”

“Stress made me ill – my stress was helped by talking with someone.”

“Now I feel I’m not alone – I realised other people are going through cancer and we can share experiences.”

It was described how this was particularly important for those in remission who may be feeling particularly isolated – this was echoed by the volunteers during the focus groups who described the completion of treatment as a potentially lonely time when medical attention diminishes and family and friends “step back.”
“[MCISS] met my needs because I’m in remission, so no real issues, because my immediate needs are met. So this was a social support network – not sure what I would have wanted when I was actually going through treatment… but I liked the environment because it wasn’t medical…before anything to do with cancer was in hospital so this was refreshing and relaxed and not clinical.”

“I found it invaluable – knowing it’s here and I can go there – that I don’t necessarily need to go through the medical route– if I just want info or someone to talk to Deirdre and Chris and volunteers nice welcoming, helpful.”

It was also important to service users to know that the service would be there in the future, possibly when they are no longer in remission, providing a feeling of reassurance. They discussed the comfort in knowing they can repeatedly return for on-going social support and not “feel alone”:

“This has been a support network–I haven’t desperately needed as I haven’t been in a desperate place or a bad place but I went to support them too. I want them to be there when my cancer comes back– That’s when I’ll really need them…it reassures me that the service will be there. [My cancer] ...was dealt with before I accessed the service – But I know who to turn to now.”

For those currently going through treatment, or supporting someone who is, accessing the services was also often described as generating feelings of reassurance. With one service user undergoing treatment saying:
“Reassured that I was doing a lot of the right things already and gave me new ideas.”

And another who is currently supporting a family member with cancer saying that the emotional support and being able to find out information about what is available to help their family, resulted in them feeling reassured that:

“‘I’ve done what I can here – now I know it.’”

Others felt more able to support a friend or partner:

“It’s a one stop shop. The first person I asked the question to gave me an answer. Health information on end of life – how to support a friend through that.”

“[a benefit was] finding someone who could help us find somewhere to stay in Glasgow – you’re not in a clear mind to organise yourself if you or your partner has had a diagnosis.”

A feeling of reassurance and comfortableness also came from the non-clinical setting in which the information was received:

“Coming here gives you more info than just getting thrown in the deep end at hospital – you can get info outside clinical appointments (so you’re not time wasting). You can sit and look at leaflets-there are pros and cons to things and here you can sit down when you have time to absorb them…”

Thus, a major benefit of the service is the breadth of people it is able to provide information and support to – not only from cancer
patients to friends and family members – but to people at all stages of their cancer journey. Providing practical and emotional support was often, therefore, discussed as easing anxiety and, sometimes, feelings of guilt. MCISS was seen as a service that ‘wrapped around’ medical treatment and gave support in a different but much needed way. One person noted before treatment:

“\textit{It gave a head start before treatment – MCISS gives you this as time to reflect etc. before treatment.}”

Whilst one said:

“\textit{Cancer is a very personal journey but very profound and when you get to remission you feel dumped; just kind of left; with no medical support and friends and family take a step back as they think that’s it; it’s finished and gone away. But it’s never over for me and that’s where this service comes in someone who understands that – when the other support is gone. Cancer is a continued experience; a psychological and physical threat. It’s [MCISS] there so I can talk to someone- someone who understands that – when the other support is gone.}”

It was noted in the data review that the majority of signposting is to other Macmillan services. Many of the service users that we spoke to confirmed that they had been made aware of helplines available. Others described how it had made them aware of financial benefit entitlements:
“I found out about a number of the different help lines that didn’t know before – I passed this on to my friend - signposted her. “

“Realise now that I should have applied for attendance allowance- but I didn’t know at the time.”

Volunteers and stakeholders also felt a benefit of the MCISS to service users was that it helps to bring the issue of cancer “out into the open”. Several volunteers told us how they had spoke to service users outside of the library, e.g. in the supermarket or the local high street [RV1; RV2; RV3; RV4; CTV2; CTV3]. This was experienced by the volunteers as positive.

What are the Challenges for Service Users?

The vast majority of service users that we spoke to reported that their needs and expectations were met or exceeded by the MCISS. Similarly, volunteers, staff and stakeholders reported a variety of benefits experienced by service users, as described in the proceeding section of this report. Some service users described a feeling of nervousness when accessing the service for the first time:

“First time I came it was nerve racking because not used to talking to people but got a lot out of it- now I go to it for help and information.”
As outlined above, the majority of service users and volunteers reported liking the setting of the service within the library with the only potential negative relating to ensuring privacy:

“I like the service in the library but I would like a bit more privacy – if I was really upset – so I would feel restricted in what I was saying and wouldn’t want people [in the library] seeing me upset. The private room would be better for that but I’d want to get in it before I’m upset... I’m self-conscious if upset.”

“I know it has to be accessible – but could it be a bit more private? I’m not sure how...”

Those service users that we spoke to were happy to access the service within the library and did not feel uncomfortable going into the space. There was an awareness that “passers by” may see service users within the Macmillan area but in general people were more comfortable with this than being seen accessing a medical space such as a health centre and largely reconciled to the idea that maintaining complete anonymity in a small place is difficult:

“Campbeltown is a funny wee place. People might see you and think you have cancer! But rumours start no matter where you locate it [MCISS]”

We spoke to one service user who had accessed the service by email, and was happy doing so, as neither of the libraries in which the MCISS is situated were their local library. Thinking about their local library, this interviewee suggested the provision of information booklets and leaflets but felt the drop-in service would not be appropriate due to the small size of the library and it’s situation
within a primary school – highlighting that privacy concerns would need to be considered in any roll out of the MCISS to other Argyll and Bute libraries. However, putting privacy issues to one side, the majority of service users and volunteers felt the public would benefit from the wider provision of information and support in other Argyll and Bute libraries:

“I think the service should find another source of funding and roll out – this information should be available at every turn....”

When considering potential challenges for service users, interviewees had some suggestions on potential improvements to the service. Some felt that the Macmillan corner could have more “talking points for the shy” such as “...some sort of update, like a poster or day book with the latest news on cancer, like in medical journals, cancer research in the media or feedback on our fundraising...?”. However, most frequently discussed were the opening times of the drop-in service. Although the service users and volunteers that we spoke to were happy with the hours – the vast majority were retired and, therefore, happy to access the service during the day. Some of them felt, however, that evening or weekend drop-in times could be trialled to see if they were needed by working people.

Volunteer Experiences

Why do People Volunteer for MCISS in Argyll and Bute?

We spoke to MCISS volunteers about their reasons for getting involved in the service, how they found out about the volunteering
opportunity and what enabled them to keep motivated and carrying out the voluntary work. In addition, we discussed the benefits of being a volunteer as experienced by the individuals involved. In both Kintyre and Bute, three elements of context were identified that effect why people volunteer:

- The individual is **aware of the service** and the opportunity to volunteer.
- The individual **feels comfortable** that he/she is capable and equipped to fulfil the volunteering role.
- The individual is **motivated** to volunteer.

**Awareness of the MCISS Volunteering Opportunity**

Most of the volunteers that we spoke to had decided to volunteer for MCISS after becoming aware of the opportunity to do so from a MCISS staff member or someone already involved in the service as a volunteer. Others had heard about the opportunity to volunteer at a local community or group meeting where the service was being promoted by the MCISS staff. Fewer had responded to an advertisement for volunteers online or in the local paper. Most of the volunteer were either considering doing, or actively looking for, a voluntary post when they became aware of the MCISS. The majority of volunteers were retired or worked part-time and, therefore, reported “having the time” or “plenty of time” to give to the volunteering role.
When discussing their roles as volunteers, many people raised the issue that they had previous “experience” with cancer – either as a patient, carer or health professional. They related that this helped give them feelings of confidence that they could empathise with service users and provide appropriate information and support:

“I am confident that I have the skills that mean I can do this voluntary job.” RV2

“I used to do listening ear services.” RV3

Other things that contributed to the volunteers’ confidence where knowing that they had come through a recruitment process. This meant they understood and were confident in their role to “welcome, listen and signpost” [RV2; CTV2; CTV3] as they had been selected in a way that matched their skill set with the volunteering position. Although one volunteer felt that the interview was “just an informal chat” and could have been more structured.

Levels of volunteer motivation, similarly to levels of confidence, were often linked to personal context. Many volunteers were motivated due to their personal connections with cancer and a desire to:

“help a service that will relieve burden on health service and staff such as the Macmillan nurses.” CTV2
Some related that their previous experience of receiving help, or knowing of someone who had, from the Macmillan nurse motivated them to “give something back”. Several had also previously fundraised for Macmillan.

However, we also discussed with volunteers what helps or hinders them to stay motivated. Almost all the volunteers that we spoke to felt the training provided by the volunteer co-ordinator helped them to stay motivated as it “provided the training we needed”. Only one suggestion for improvement to training was given, stating that “it wasn’t holistic enough and focused too much on welfare issues.”

The main challenge to volunteers’ continued motivation was their frustration with low numbers of service users. The volunteers clearly want to help others and this need was not met when they experienced drop-in sessions in which no service users came along. Some volunteers suggested more advertising in order to get the MCISS more widely known – however, the data review in this evaluation report has shown that although overall numbers of service users are lower in Argyll and Bute compared to Glasgow, the proportions of population being reached are fairly similar. Each volunteer in a remote and rural MCISS is, therefore, more likely to encounter fewer service users. Considering whether there are other activities that the volunteers could do in “quiet drop-in times” could, therefore, be a way to ease frustration. Many volunteers indicated that they would be willing to take on some other tasks during “downtime” and/or act as “local champions” for the MCISS and support the staff in publicity activities.

Some volunteers’ motivations were also challenged by a lack of understanding of how the MCISS in Argyll and Bute as a whole is functioning. They felt that motivation could be raised by facilitating
opportunities for the volunteers to get together and speak to each other, as well as to receive feedback, such as overall service user numbers on a regular basis from MCISS staff, e.g. in a short service update flyer. In general, it was felt that greater opportunities for the volunteers to support, and learn from, each other would be beneficial in maintaining motivation:

“The getting round the table and the banter between the volunteers was an important part... it’s important to get together and swap stories and talk about our experiences.” [CTV1]

“I’d like to hear the stories from other volunteers and the actions that people took/ advice given.” [CTV4]

On-going motivation was also seen to be connected to the understanding that the volunteers would receive training in the future on a regular basis. Many felt having the “security” and assistance of the MCISS staff helped them to keep going. Although they were keen to help as much as they could, in ways that they considered to be productive, few felt they would continue to be motivated if the MCISS became an entirely volunteer-led service:

“there’s support for the volunteers – you think you can keep giving but you need to be able to debrief.”

“If Chris wasn’t here, nothing would get done. No volunteer would take that on or do it as effectively.” CTV1
Benefits to Volunteers

As motivated individuals, keen to help people affected by cancer, the majority of volunteers said they felt a sense of “satisfaction” and “fulfilment” in their role. Many talked about “giving something back”, doing something “productive” and “worthwhile” to help others. One volunteer explained how volunteering for MCISS provided him with a role and “identity” beyond that of “carer”. Many related how the volunteering role also gave them an opportunity to share their own experiences of cancer or caring with each other, as well as service users. AVA highlighted the ‘time bank’ service that is available to volunteers however as previously mentioned in this report, most volunteers were unaware of this.

Staff Experiences

Staff Roles and Support

MCISS staff highlighted the importance of being associated with Macmillan which provides a supporting network and training for themselves, as well as training materials that they can use with the volunteers. The library staff generally reported positively on the training and support received. The library staff reported being enthusiastic about the service – and their enthusiasm was also reported by several of the volunteers. Some library staff were unsure about the future direction of the service – as discussed elsewhere in this report.
Library Users

Are non-service users aware of the MCISS?
Library users who were local residents were invited to complete an anonymous structured interview as they left the library during the second week of the evaluation fieldwork, on the ‘drop in day’ of the local MICSS service. The interview was carried out by the research assistant and taken by 20 library users who are not MCISS users – 10 in each area. In both areas the sample represented a mix of age groups and genders. The aim was to investigate the awareness of the existence of the service, the understanding of the aims of the service and the perceived appropriateness of the service setting.

Rothesay
More people than not were aware of the MCISS in their local library (6 out of 10). Some (4) were aware of this through noticing it whilst visiting the library, others (2) had been involved in the service planning through a consultation in the library by Argyll and Bute Council and 1 had been made aware of it by library staff. Just 1 person mentioned seeing an article in the newspaper.

Although more people than not were aware of the service, its purpose was not entirely clear to everyone. It was clear that it was to provide support for individuals themselves, or their families and friends affected by cancer but no one accurately described what the support consisted of. 2 people thought its purpose was to raise awareness and access Macmillan services such as Macmillan Nurses. 3 people said they didn’t know what it was for but a verbal explanation of the service provision was given by the interviewer
before the remainder of the interview and one such respondent was reminded by this, that they had read about it in the newspaper:

“'Oh I saw that in the local paper if people wanted to speak to someone about problems with cancer.’”

Once they understood the purpose and service offered the majority of respondents felt that it was appropriate that it was situated in the library:

“I felt it was an encroachment into the library and what the library is about but at the same time we use the library now for computers and as a writing place so I’m quite happy it’s there.”

Just one person felt that it wasn’t appropriate to stage such a service in the library rather than a health centre:

“It’s quite odd because you go to the library to go to a different world to cut yourself off- it would be better in a medical centre or where there’s medical people.”

It was felt to be accessible due to the library being a place open to everyone but one able bodied person felt that people with a disability may not find it so easy. It was felt it could raise people’s attention to cancer:

“People may not pay much attention (to cancer) outside but they would if browsing in the library and they see the corner – but it’s more high profile (cancer) these days.”
The atmosphere was described as quiet, comfortable (new high quality furniture noted) and relaxing therefore inductive to having ‘a chat’. It was felt that there was space in the library and that people could walk into the building and inconspicuously access the corner. It was pointed out though that for disabled people it was not easy to access the corner via a short, direct route which meant it would be difficult to go unnoticed.

“’It’s not accessible for disabled users as they have to negotiate the back door and the double doors and then get along through the shelves to reach it.’ (Perception of an able bodied person)

On the other hand people felt that if it was more visible more people might go in and use it more. Suggestions echoed those given by volunteers to improve signage above.

“’Yes it is accessible- it could be more noticeable with signage.’

Interviewees were asked if they felt others were aware of the service – most answered no or not sure (6). One felt that people would be through involvement in the Macmillan charity.

As far as anyone can say, the majority felt that they would, or were likely to, access the service should they feel the need in the future-only one respondent felt not and would prefer to attend in a medical premises:

“’I wouldn’t use it in the library – I would prefer to use that sort of service in a health centre.’”
Two people remarked on their potential use because of the apparent friendliness:

“*Yes everyone seems very friendly in there.*”

“*Yes- in a small community here, people are friendly and will help you.*”

One person remarked to have accessed the area on a non ‘drop in day’,

“*I have used the area to sit in and whilst there I picked up and read a few leaflets- Yes I would be happy to use the service in the future.*”

**Campbeltown**
The majority of people had seen the Macmillan corner (8). Awareness was stated to have been through seeing it in the library (4), posters (2) newspapers (2) TV adverts (1) and word of mouth from service staff (2) (library and volunteer coordinator):

“*Chris came to talk to us at the U3A.*”

One resident new to Campbeltown remarked:

“I have used the library but I didn’t know it was there – I know it’s in Glasgow in Motherwell. This big poster (pull up) is better than the wee signs- they should put it on these screens.’

Two could accurately state what the purpose of the service is:
“It’s not a medical thing – its people pointing victims of cancer or relatives or carers in the way of support - an ear- to know about support available locally.’’

“An opportunity for people who are suffering or know someone who is suffering with cancer. To get support through talking – whether it extends to medical support I am not sure.”

Three were aware of the service aim of being a listening ear or help in supporting people or their families affected by cancer with one of these respondents believing a ‘home visit ‘ service to be offered:

“IT’S about support- a one to one talk or someone to visit you if necessary at home.”

Three had a confused understanding and thought that it was specifically about Macmillan nursing services or fundraising:

“If you need care and if you need the help of Macmillan nurses or if you need to talk to somebody.”

“Awareness of the services that Macmillan offer.”

“It’s about cancer – they want money to fight it and awareness for people to fight it.”

Just two respondents could not describe the service at all. A verbal explanation of the service provision was given by the interviewer before the remainder of the interview to ensure the respondents were clearly aware of the aims and objectives of the service.
As far as positioning the service in the library every respondent felt it was appropriate and a number of reasons were given including the fact that the library was used by a lot of people from all age groups, it provides free access to information, it provides a comfortable relaxed environment:

“I think it might be better in here because when you have cancer you have had enough of hospitals.”

The informality of the setting was also noted. There was some concern that the conversations could be overheard by other library users, although one respondent was aware of the private room being available (see comment below in last section).

One comment related to the perception of a close knit community where it is difficult to keep personal facts private:

“It’s a good idea not being in the health centre – if you are seen at the health centre people presume ‘other things.”

Another highlighted the mutual benefits to the library service and the Macmillan service of the positioning of the MCISS

“Oh yes it’s a two way thing – a library is a place where people drop in or come regularly and see the Macmillan is here and people who know that the Macmillan is here might then come in and use the library.”

Other comments related to development of the library service and its role in a community:
“It’s a gathering centre, a local hub- it’s not just about books anymore.”

“I think the library should be the hub of a place.”

However, two comments suggested the service is limited:

“It’s a start to get the message around.”

“People will ask ‘what’s that all about?’”

Most respondents felt that it was accessible:

“Pretty accessible – people without making a big issue about it can just stroll over no need to knock on a door or make an appointment.”

On being asked if others were aware of the service two respondents responded positively that other people knew about it but the majority felt that it wasn’t well known. One person commented about communicating awareness by using the newspaper:

“Yes I think so- it’s been in the paper and most people in Campbeltown buy the paper.”

But even so it had been missed by at least one respondent who said:

“Unless you come to the library you wouldn’t know it was here –it would be a good idea to have a piece in the local paper.”
It was generally stated that you had more chance of awareness if you used the library or if you, or someone you knew had /was affected by cancer.

As far as anyone can say the majority felt that they would (2), or were likely to (7) access the service should they feel the need in the future- only one respondent felt not but this was not due to any aspect of the service but a personal preference:

“’No I wouldn’t – because of my personality I would deal with it in different ways.’”

And another comment hailing the service emphasised that not everyone will want or need to use certain aspects of it:

“’Some people don’t want to talk about things-others do and so for them it’s good that it’s there.’”

One respondent supporting the idea of the service also identified a need for such a service to help with other long term conditions:

“’I don’t need it at the moment but I might use it in the future- I think that another thing that should be thought about is Alzheimer’s as there’s an awful lot of people affected by that.’”

Two comments favoured the fact that the volunteer staff would know them:

“’Aye definitely as in a local community I know the people that are in there.’”
“I think so- I used to think if I had a problem to just keep it to myself but now I think a problem shared is best – if I knew the people in there it wouldn’t put me off because to me community is important.”

Whilst another hesitated due to the privacy aspects of the service:

“’I’m not sure – It depends on how vulnerable you felt to being exposed- But if there is anything to be discussed in private I believe there is a room you can go to.’”

A further comment referred to the local rural environment:

“’Yes because everyone has to look after your family – there aren’t the opportunities here in Campbeltown that there are outside.’”

Overall
The staging of the evaluation provided an opportunity for the service to be advertised to more library users in two ways:

1. The library staff informed users that they might be asked by the research assistant if they were happy to be asked a few questions about MICSS and

2. The research assistant explained to everyone – even the ones declining to take part, exactly what the MICSS is and could offer.

Two people (one resident one visiting relatives) who spoke to the research assistant had very recently been affected by cancer.
Following the conversation with the research assistant they stated that they could see the value of the service and were very likely to use it.

Overall there was a good awareness in both communities about the existence of the MICSS service but its actual role and what it could provide was not clearly understood by everyone. Once an explanation was given all but one of the participants felt that the library was an appropriate place to hold the service but some improvements regarding access for people with a disability were identified. The majority of people interviewed felt that they were likely to use the service should they feel they needed to in the future.

**Consideration of MCISS in Argyll and Bute in the Future**

Based on their own experience of using the service, all the service users that we spoke too said they would be happy to use the service again:

“*Quite happy to do this as Deirdre was lovely and gave all information needed. No question could go back to her. Like the email option as no travel involved, but know you’re getting good information.”*

“*Would feel happy to use again if I needed to- and I would suggest to someone to use it- psychologically worried so information from Macmillan is a big help.”*
“Yes I will continue to come because I need support to continue while my family are going through this. I’m not wanting to speak to a stranger though...”

Several volunteers also told us about service users that had visited the drop-in times on more than one occasion. Some service users had already recommended the service to others and the remainder said they would be happy to recommend it to friends or family should the need arise.

“I have recommended to those I know but people can be funny in Campbeltown because they think it [news of their using the service] might be all round the town – it always take time for something to take hold in Campbeltown- people watch it and wait and see .....‘if it’s still there in six months and such and such is still going then maybe I’ll go...”

Organisational Set-up

We discussed the future of the Argyll and Bute MCISS with all our interviewees and within the focus groups. There was not a consensus across the data of the future path for MCISS Argyll and Bute. Most interviewees were conscious of the need to secure further funding for the service; with some suggestions that it be funded by the public sector:

“I’d like to see it [MCISS funding] being integrated into the core funding of the libraries...” [ABC3]
Some felt that if the Macmillan model was followed through or rolled out, this would mean that the service would be delivered by volunteers and supported by library staff. If Macmillan is to fund the service, the service will need to be delivered in line with their national governance:

“Macmillan provide information governance around what the service delivery model actually is – it can’t be all things to everyone.” MM4

However, there was acknowledgement that Macmillan would need to do this in a way that included listening to the other partners and working with them.

All interviewees and focus group participants were conscious of the potential for volunteer, MCISS staff and library staff’s roles to change in the future provision of MCISS. Some stakeholders that we spoke to implied that AVA would support volunteers in the future (through management and training); whilst others were less sure about this.

When discussing the future of the MCISS with the volunteers, they stressed the importance of there being well-organised and supportive volunteer coordination. Some went so far as to say that they would cease to volunteer if they felt things became disorganised in the future. They felt that the coordination role needed appropriate management skills and time to devote to management. They could see how this was currently fulfilled by the MCISS staff, but had reservations about this being entirely placed in the hands of one volunteer; AVA or the library staff. More positive discussions were around the potential for several volunteers to take
on some level of coordination, whilst still supported by a paid staff member. In both Kintyre and Bute, this was suggested:

“There could be some combination of AVA, the volunteers and the library staff to manage the service; alongside a combined managerial and volunteer coordination role.”

“we could take on more of this but it doesn’t mean that every one [of the volunteers] want to take this on.” CTV2

All the library staff that we spoke to were supportive of the service and related instances of directing service users to the MCISS areas within their libraries. However, most were also wary of taking on any greater a role in service delivery or management – in particular capacity was mentioned with current reliance on relief staff that would be stretched further if additional duties were added:

“Staff would need to buy into this... and be protected and may not want to do this for personal reasons.” ABC4

Information and Locational Scope

Many people felt that the MCISS is a successful concept that has the potential to deliver benefits more widely within Argyll and Bute if it was to include more library spaces. There was not consensus on how this could best happen – with issues around funding, as well as volunteer capacity and privacy issues in smaller libraries raised most frequently. As noted above, most volunteers supported the idea of
extending drop-in hours into the evening at the Argyll and Bute Libraries – at least on a trial basis.

Some interviewees and discussions with volunteers concerned the focus of the service in the future. Some suggested that it may be beneficial to service users to extend the scope of the service to include other non-malignant long-term conditions. Both positive and negative aspects to this idea were discussed. Some volunteers felt it may increase the number of service users but were wary of potentially having a lack of knowledge to support people with other long-term conditions. Volunteers and staff felt another organisation(s) like Macmillan may need to come on board to provide appropriate training and information in the way that Macmillan provide currently.

Some volunteers felt there was a need to extend the service to reach people in their own homes who are not able or willing to come into the library. It was suggested that this could function like a specialist befriending service, although issues of confidentiality and health and safety were acknowledged.

**Raising Publicity**

Although in interviews and focus groups, volunteers expressed a desire to get the service more widely known in the area in order to increase usage [CTV1]:
“Should we have a small advert in the paper? I don’t know how to get the message across but people out there don’t understand what we are doing.”

The most popular way was seen to do this by forging better links with primary care and more social prescribing[^4] to MCISS [NHS4]; continued work to promote service to GPs [NHS6; RV2]. It was suggested that GPs could come and visit the MCISS service to see what it’s like. Some volunteers felt there was a gap for children and young people.

The need for hospital staff to raise awareness with patients of the MCISS being available in their local area was also raised:

“wherever people receive their treatment we need to make sure that staff are mindful to support by advising what is available to patients in their local area.” MM4

Discussion

Hypotheses of Change – Validating and Conflicting Evidence

As we took a realist approach to this evaluation, our initial data collection, analysis, participant verification and further rounds of analysis were guided by hypotheses of change devised before the

[^4]: An approach that seeks to improve health by tackling patients’ social and physical wellbeing through GP’s providing prescriptions for activities which typically include things from exercise and dance classes to knitting groups and cookery clubs. The suggestion here being that local GPs could offer a prescription to the MCISS.
start of the fieldwork and data collection. This section of the report gives an overview of how the findings presented have both validated some hypotheses but raised conflicting evidence in relation to others.

Because the service is in a library, this attracts service users and increases library footfall.
Most users that we spoke to were not already regular library users before accessing the MCISS service, suggesting that it may increase the numbers of Argyll and Bute library users.

Because the service is in the local community, this attracts service users and leads to improvements in quality of life because they have accessed the service.
The importance of the service being located within the “community” was validated through the qualitative evidence. Not only did volunteers and service users report that the service filled a gap in locally available information and social support but that the location in the “main town” was convenient for people and therefore encouraged use. The vast majority of non-MCISS users that we spoke to would be happy to use the service within the library if they saw the need. Most people valued the fact that the MCISS was in a non-clinical space. For those service users that were inclined to access MCISS because it was in a convenient and community-orientated space, benefits were experienced in relation to improved quality of life – particularly highlighted were reduced feelings of anxiety, reduced feelings of isolation and increased feelings of capability.
Because the service is an integrated partnership, this makes referral pathways available and quality of life improvements for service users because they can access these pathways.

The data review revealed that most signposting from the service is to other Macmillan services. Particularly discussed by volunteers and service users were Macmillan telephone lines. The partnership with Macmillan appears to be working well in terms of encouraging access to these pathways. Less evidence of referral from hospital or primary care staff to the MCISS was seen – interviewees expressed the feeling that more ‘social prescribing’ could happen.

Because the underlying design and rationale of the services is that it is volunteer led and individually focused, it offers appropriate and useful information and support and quality of life improvements for service users.

There are positive and negatives to the volunteer element of the service. The evaluation has also seen the role played by the MCISS staff in areas such as awareness-raising and dealing with enquiries, particularly outside drop-in days and times. However, the majority of people we spoke to felt the volunteers played an important role in being a “familiar” or “local” face at the drop-in that encouraged people to come along and to talk.

Because volunteers and library staff are trained and supported this increases their skills and allows them to deliver a service that impacts positively on users’ quality of life

95% of the volunteers that we spoke to felt that they received appropriate levels of training and support – which helped them in
their role as volunteer to deliver appropriate information and support to service users. We had much collaborating evidence for the importance of MCISS staff in supporting the volunteers but also some suggestions for potential improvements specifically relating to a greater level of feedback to volunteers on the overall performance of the service. Conflicting opinions within the volunteer body appeared to be related to the differing backgrounds and existing levels of skills that they brought to the voluntary post. Library staff all reported value in attending the training as it helped them understand the service and, therefore, direct library users towards it or even handle queries on the phone.

**Important Elements of Local and Rural Context**

Through the realist approach we were also able to identify particularly important elements of local and rural context that are related to the MCISS in Argyll and Bute:

- **It takes time to embed an initiative in a remote and rural area.** Both the Kintyre and Bute services have been running for relatively short periods of time. Many interviewees and focus group participants felt, from personal experience, that it takes a bit longer to embed a new service in a rural area than it would in a more urban location.

- **The role of the MCISS staff within the community.** Both the data review and the qualitative work illustrated that the MCISS staff have been important in raising awareness of the service in Kintyre and Bute. Many of those we spoke to felt it was
particularly important to have such advocates in rural areas where people may be less likely to happen across the service “by chance”.

- **Low footfall and volunteer frustration.** This report has illustrated that a remote and rural MCISS service may reach similar percentages of a local population when compared to an urban MCISS. However, with overall numbers of service users being smaller in a remote and rural area, this can lead to individual volunteers feeling frustrated at a lack of service users contacts at the drop-in times.

- **Volunteers as a ‘known face’ – positives and negatives.** Most people that we spoke to were in favour of having local people volunteering at the drop-in times. Some stakeholders expressed concern that residents may not wish to speak to someone that they “recognised” or “knew from the local area”. However, we did not speak to any service users that raised this as an issue. Non-MCISS users also seemed to view this as more positive than negative – with the feeling being that those in a rural community would rather speak to someone they know as opposed to a stranger.

- **Visibility of using a service.** It was pointed out that in a smaller community, service users may feel particularly “visible” using a community-based service. However, most felt the benefits of the community setting, i.e. being non-clinical outweighed this.
There were some suggestions that a greater degree of privacy may be beneficial – particularly in Rothesay.

- **Macmillan in Argyll and Bute communities.** Many interviewees, service users and volunteers, reported that the involvement of Macmillan in the service was positive and encouraged people to use it. Often, people associated this to the “good name” of Macmillan that is a particularly well-supported charity in Kintyre and Bute. In addition, many spoke of the valuable role played by the Macmillan nurses in both of these rural communities – as one of the only other sources of support. The respect held locally for the nurses encouraged people to volunteer and use the service as something “trusted”.

- **Transport issues.** Although information on transport issues does not appear as a particular high category in the data analysis, the qualitative work revealed that volunteers are providing practical information on travel to Glasgow. Several service users, volunteers and stakeholders mentioned that having transport information as part of the service is particularly important due to the complexities of travelling to Glasgow for treatment.

- **Library staff and their relationship with library users.** Several library staff commented that they know many people within the community, including regular users of the library – some who they have seen grow up. They felt the relationship between library staff and users is closer in smaller places –
which makes it easier for them to appropriately signpost library users to the Macmillan corner.

- **The absence of other options (isolation).** The qualitative research revealed a prominent theme within stakeholder, service user and volunteer discussions related to the potential for feeling isolated, with a lack of options for accessing support or information, in the rural areas. Most felt the MCISS was the only service of its kind in the area and that without it people would not receive emotional or practical support.

- **Publicity/awareness and word of mouth.** Both the Argyll and Bute MCISS sites have shown the importance of publicity awareness raising through the local media but also more “informal” personal contacts. Many of our participants felt that the local knowledge of the MCISS staff and volunteers was particularly necessary in a rural area, where residents may be more reluctant to use such a service.
Macmillan Quality Standards

The Macmillan Quality Standards function as a practical tool for cancer information and support services (CISSs) to assess and develop the quality of their service. This report has detailed the results of the evaluation that demonstrate how the service currently meets these Standards. A summary detailing each Quality Area and how it has been met is provided in this section.

Quality Area One: Planning
The service has a clear overall purpose (with the primary goal of providing both information and social support to anyone affected by cancer largely understood by all stakeholder, volunteers and service users). Both staff and volunteers are clear on what the service will achieve – this is grounded in their understanding of the needs and expectations of users. Progress is monitored regularly through the data collected by volunteers and staff, and the reporting to the Steering Group. Feedback from service users is collected through “post boxes” at each site that service users can post suggestion cards into. There is clear evidence that there was community engagement in the design and set-up of the Macmillan spaces in each library.

Quality Area Two: Governance
The roles and responsibilities of the service, Macmillan and the partner organisation are agreed, understood and documented. The service works effectively with Macmillan and the partner organisation and meets their requirements.
Roles are agreed by the partners within the MCISS Argyll and Bute – although there is a lack of consensus about how these roles will play out in the future. AVA’s role is less well understood, particularly by the volunteers and service users. The Stakeholders, library staff, MCISS staff and volunteers agree and are aware of their roles in the day-to-day running of the service. The partner organisations all felt that the service is meeting their requirements in terms of helping them reach organisational goals. An annual report is produced and agreed by the Steering Group.

**Quality Area Three: Leadership and Management**

*The service has leadership which develops staff motivation and initiative. Good internal communication increases commitment to the service’s plans. The service manager oversees the service’s development, the quality of its activities, and it progress against agreed outcomes.*

There is evidence that both the service manager and volunteer coordinator exhibit leadership which develops staff (and volunteer) motivation and initiative. The volunteers talked of the support offered by both members of staff. The library staff also felt currently supported. Progress is regularly monitored through data collection and preparation of reports to the Steering Group. Volunteers would like more opportunities for formal internal communication with each other – and feedback on overall performance of the service.

**Quality Area Four: User-Centred Service**

*The service identifies its users, and places them at the centre of its design, delivery and review of services and activities. The service*
avoids unfair discrimination, and makes its services accessible. The service is focused on achieving better outcomes for users and represents their interests.

We collected evidence that demonstrated that the MCISS staff and volunteers are motivated by providing as good a service as possible to those affected by cancer. Initial design of the service was informed by community feedback. There were no major negative points about service accessibility – there were some suggestions that the drop-in hours could be extended and varying views on signage. The drop-in times were purposefully selected as the libraries’ busiest times. MCISS staff are engaged in outreach to inform different sections of the population about the service. Volunteers demonstrated that they understand how to deliver a person-centred service and signpost users to other information and services.

Quality Area Five: Managing People

Staff and volunteers have the appropriate skills, knowledge and experience to provide a safe and reliable service, and information is shared in the team. They know who they are accountable to, understand their role and area supported to carry it out in order to achieve the aims of the service.

We found the staff and vast majority of volunteers agree with this criterion (in Rothesay we saw this for an original and a second cohort of volunteers). Appropriate procedures for volunteer recruitment had been followed and documented. Volunteer training had been carried out, with associated evaluation. Plans for regular volunteer ‘meet up’s were underway. Recruitment and management procedures have followed Argyll and Bute Council procedures.
Volunteers largely felt supported by the volunteer coordinator and service manager.

**Quality Area Six: Learning and Development**

*Training and other opportunities for learning are seen as an essential part of individual and service development. The service learns from its own and others’ knowledge, expertise and experience, and uses this learning to achieve continuous improvement. Learning and development are resourced, encouraged and monitored.*

Evidence was collected that demonstrated volunteer training, informed by Macmillan guidance, had been carried out and evaluated by the volunteer coordinator. The staff also record their personal development and report to the Steering Group.

**Quality Area Seven: Managing Money**

*The service meets all legal requirements in relation to money and spends its money on agreed purposes. There are basic financial procedures in place.*

Outside the scope of this evaluation.

**Quality Area Eight: Managing Resources and Information**

*There are enough resources to manage and deliver planned information services and other activities safely, efficiently and effectively. The services uses a variety of methods to provide accessible, high quality information, including generating and dispensing Information Prescriptions The service manages resources in a way which helps protect the environment.*
We found no evidence to contradict this criterion. There is evidence of the service providing information through leaflets, face-to-face at the drop in, face-to-face with service staff and by telephone and email. Resourcing issues discussed all related to the potential roll out of the service to other areas in the future.

**Quality Area Nine: Communications and Promotion**

*The service is clear about what it wants to communicate and to whom, and communicates effectively in accessible formats with users and stakeholders. It takes steps to promote its work to users, professionals and related organisations, and represents the needs of its users.*

We collected evidence that demonstrates the MCISS staff are proactive in promoting the service to users, professionals and related organisations. Informally, the volunteers are often local ‘ambassadors’ for the service. There were some suggestions for further promotional ideas. The service is clearly identified as a Macmillan service – although some non-users associated this with fundraising, rather than information-giving.

**Quality Area 10: Working with Others**

*The service builds relations and networks with other relevant organisations, working with them effectively to support its specific aims and to benefit users. It creates opportunities to work with others to improve efficiency and effectiveness, influence change and achieve better outcomes for users.*
Although stakeholders talked about having to learn to work together – most felt teething problems had now been worked through. Opportunities and relationships had been forged for the benefit of service users, e.g. with complementary therapists and local support groups. Volunteers and staff are clear on how to signpost service users – and this is recorded in the regular data collection templates. There were some suggestions for more social prescribing. The majority of signposting is to Macmillan services.

**Quality Area 11: Monitoring and Evaluation**

*The service routinely tracks its activities and outcomes. It assesses how well it is doing and uses this information for decision making and planning and to report to Macmillan and the partner organisation.*

There are clear procedures in place for collecting routine information on service use. This is fed back to the Steering Group. The volunteers requested to also be able to see this data.

**Quality Area 12: Results**

*Users are satisfied with the services and receive identifiable benefits. The service has competent staff and volunteers, and the working environment is good. Planned services are carried out and quality improvements made. There is evidence of contributions to the wider community.*

As has been detailed in this report, many benefits to service users have been realised and observed. The staff and volunteers understand the purpose of the service and feel competent in delivering it.
Conclusions

This evaluation has highlighted the hard work of the MCISS Argyll and Bute Steering Group, staff and volunteers to deliver a service that is meeting Macmillan Quality Standards. Many of the successes of the pilot service are outlined in this report. We have seen, for example, that the service is reaching similar proportions of the population as a more urban MCISS. With partnership working reporting as having some teething problems – these were largely considered to have been worked through by the majority of stakeholders.

Service users often access the Argyll and Bute MCISS in order to obtain information or support for themselves, although friends and family members are also accessing it. This evaluation report has demonstrated the ways in which the MCISS can function within remote and rural communities as one of the only forms of practical and social support for those affected by cancer. Particularly appreciated by volunteers and service users was the fact that the service is situated in a non-medical, community-orientated space that is perceived as familiar and friendly.

Several benefits to both service users and volunteers have been evidenced in this report – although many related to the acquisition of practical or health-related knowledge, most emphasised the benefits of the reassurance and emotional support provided by the service which resulted in reduced anxiety and stress.
Evidence was seen of a competent and enthusiastic set of volunteers – some suggestions for keeping up volunteer morale were made and have been detailed in this report.

However, the data review has shown that most service user contacts occur outside of drop-in hours and are, therefore, dealt with by my MCISS staff rather than the volunteers. This demonstrates a key role played by the staff in providing support outside the drop-in sessions. We have also seen their key role in publicising the service locally. Although stakeholders provided evidence that the Macmillan nurses will signpost to the service, we did not speak to any service users that had been signposted to MCISS from other parts of the healthcare sector. It was suggested that it would be beneficial to have more referral from primary care and hospital staff.

Looking to the future, this evaluation has demonstrated that the service is meeting a gap within the remote and rural communities of Kintyre and Bute. Evidence has suggested that the benefits of the service could be enhanced by extended the scope of the MCISS – either geographically or in terms of drop-in times. Consensus between the stakeholders will need to be achieved in terms of how to take this forward. In thinking about alternative service management models, it will be important to ensure that the volunteer body continue to feel supported. If taking the service to other library spaces within Argyll and Bute, it will be important to consider issues of funding and privacy.
Appendix 1: Macmillan Levels of Intervention Criteria

LEVEL 1

- Interaction of five minutes or less (face-to-face, telephone or email)
- Specific enquiry (likely to be single topic)
- Outcome will be answering enquiry verbally, provision of one or two items of information, or signposting
- Worker/volunteer takes no further action
- Further contact unlikely

LEVEL 2

- One to one interaction that involves discussion (face-to-face or telephone) to assess person’s information needs
- Worker/volunteer provides verbal support as part of interaction to enable user to understand the information in order to be reassured, make a decision, or take action
- User requires information involving more than one topic
- Outcome will be formal referral or some other further action by the worker/volunteer following the visit
- 50% possibility of further support required at follow up stage

LEVEL 3

- One to one interaction that involves discussion (face-to-face, telephone) to assess person’s information needs
- Worker/volunteer provides verbal support as part of interaction to enable user to understand the information in order to be reassured, make a decision, or take action
- User has complex or multiple issues that cross at least two information areas (e.g. cancer information and finance)
• Outcome will involve at least one further action by the worker/volunteer other than or as well as referral
• More than 50% chance of further support required at follow up

LEVEL 4
• One to one interaction that involves discussion (face-to-face, telephone) to assess person’s information needs
• Worker/volunteer provides verbal support as part of interaction to enable user to understand the information in order to be reassured, make a decision, or take action
• User has complex or multiple issues that cross at least two information areas including therapeutic or treatment decisions/actions
• Follow-up action by worker/volunteer is essential within one week
• At least one further action at follow up expected

Appendix 2: Macmillan 9 outcomes
1) I was diagnosed early

2) I understand, so I make good decisions

3) I get the treatment and care which are best for my cancer, and my life

4) I am treated with dignity and respect

5) I know what I can do to help myself, and who else can help me

6) Those around me are well supported

7) I can enjoy life

8) I feel part of a community and I’m inspired to give something back

9) I want to die well
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