What are they?

Macmillan’s Mobile Information and Support Service (MISS) tours the UK throughout the year, offering free, confidential information and support to people in their communities. Anyone is welcome, whether they have a cancer diagnosis, are visiting on behalf of a friend or relative, or are worried about cancer.

Their mobile centres are staffed by Macmillan cancer information and support specialists who can offer a wide range of information and support tailored to a person’s individual needs.

87% of people affected by cancer want to know more about their disease.1

In 2014 the mobile information service helped 78,614 people affected by cancer across England, Wales and Scotland.14

Each mobile centre offers over 400 quality assured cancer information materials, which are updated annually and re-stocked weekly.15

45% of people who accessed the service said they would not have gone elsewhere for help.16

This includes MISS staff also helping over 21,902 people away from the mobile centres in 2014, by giving talks at schools, workplaces and other diverse community settings.16

‘For the last two years I haven’t been able to speak to anyone, but seeing the Macmillan Mobile Information Service here and being able to call in and speak to someone has been wonderful.’

This Impact Brief is part of a suite of Impact Briefs which provide evidence about the impact of Macmillan’s direct and indirect services, available at www.macmillan.org.uk/impactbriefs
INTRODUCTION

Macmillan helps meet the information and support needs of people affected by cancer in a variety of ways including:

- through the support and funding of local and mobile cancer information and support services
- the production and distribution of high quality information and advice materials
- directly through our website
- directly through our telephone helpline (Macmillan Support Line)

Macmillan also provides a national mobile information and support service covering England and Wales. The service offers a flexible, drop-in information and support service and can be positioned anywhere from shopping centres and high streets, to country fairs and corporate events.

We ensure that both our virtual and telephone information services and our Macmillan supported services work to the same high standards and use common resources. We also enable referral to local support services where appropriate across all types of information provision to ensure the client’s needs are met.

SUMMARY OF KEY FINDINGS

- **Gaps in information availability**
  87% of cancer patients want to know more about their disease but many do not receive the right information at the right time in the right way. There are particular gaps in the provision of information addressing emotional, financial and social concern.

- **Personalised mobile service in community settings**
  Macmillan’s mobile information and support services provide personalised, high-quality and accurate information to people affected by cancer, along with appropriate support to understand and act on it. The flexible community setting makes the service easily accessible, anonymous, and confidential; and enables Macmillan to specifically target traditionally harder to reach communities. The staff are skilled to deal with all levels of enquiry including complex cases involving signposting to local health, social and support services.

- **Quality of life**
  The provision of cancer information and support can make a real difference to a patient’s quality of life by helping to improve their physical and mental health, their financial situation and their ability to manage living with cancer.

- **Reduced burden on health care providers**
  There is evidence that effective self-management can reduce burden on emergency services, GP time and hospital beds.
Detailed Findings

1. What is the issue?

Information needs
87% of cancer patients want to know more about their disease.¹ Most people affected by cancer who want information receive it from healthcare professionals at the point of initial diagnosis. Various studies have shown that a significant minority of cancer patients (16%) who would like to receive information about their condition do not receive any at all² and 43% would like more information than they are given.³

Cancer patients’ information needs are complex and vary over time.⁴ People affected by cancer find it harder to get the information, advice and support they want and need during the early stages of the cancer journey.⁵ Many of the financial, emotional and physical problems people with cancer face could be reduced if they are provided with the right information to help them.⁶

Current health information availability and access
In addition cancer patients often feel abandoned by the health system once their treatment is finished due to lack of information and support about next steps in their cancer journey.⁶

Although a GP would seem an obvious source of information almost 40% of British people would put off going to their GP with cancer symptoms because they do not want to bother the doctor. They would also delay making an appointment because they were too embarrassed, scared or worried about what their doctor might find.⁷

Delays in seeking help
In a study looking at the reasons people delay coming forward with cancer symptoms, reasons given included practical barriers such as not having time, being too busy and not having anyone to take them to the doctors, as well as substituting professional support using self-diagnosis e.g. online search engines. These results point to the real need for accessible and reliable cancer information.⁸

There are demographic differences in the reasons given for the delay in seeking help. More affluent people said they were more concerned about the practical barriers, like being too busy and having too many other things to worry about. People from more deprived areas or ethnic minority groups cited different reasons why they would delay, such as being too embarrassed or being worried that they might have cancer.⁷

This could be linked to differences in education or to language barriers, especially since evidence suggests that information recall and recognition of early symptoms is higher in white, older women. Women from other cultures may conceal symptoms of breast, cervical and ovarian cancers because in their communities it is taboo to talk about sexual organs. This means that they may report problems to a doctor only when it is too late for them to be given a potentially life-saving treatment.⁹ This highlights the need for accessible information provision in hard to reach communities such as men and those from ethnic minorities.⁷

Health literacy
In addition to the physical and emotional barriers to information access, 7 million adults in the UK (20% of the adult population) cannot read or understand simple instructions such as those found on medicine labels or locate the expiry date on a driving licence.¹⁰,¹¹ Evidence suggests that over half
the population are unlikely to understand cancer information brochures routinely used in hospital settings.\textsuperscript{10}

There is also evidence which suggests that functionally illiterate adults (as described above) suffer from higher morbidity and mortality than the population as a whole and are less likely to adopt positive cancer avoiding behaviours.\textsuperscript{12} They are less likely to seek medical advice with early symptoms and as such they are therefore more likely to present with cancers at a later pathological stage.\textsuperscript{10}

This means that those most in need of interventions and information are those that are the least likely to be able to find, interpret and absorb such information without support. This therefore suggests that there is a need not only for the provision of information but also a need for information to be explained and delivered in a way that is appropriate to the individual.

**Failings in information provision**

Evidence from two major research studies conducted for the Department of Health also point to significant failings in information provision at all stages of the patient journey, in both hospital and community settings. Failings include inadequate information being provided about treatment options and on the availability of local services and support. The studies highlight that this results in a mismatch between the high levels of trust generally placed in doctors and cultural flaws in the medical profession that result in unmet patient needs for information.\textsuperscript{13}

2. What is Macmillan doing to address the issue?

The Macmillan Mobile Information and Support Service (MISS) consists of a fleet of four customised vehicles and one indoor unit across London and the South East Region (LASER), East Midlands and the North East Region (EMNE) & the Central and South West Region (CSWE). The original UK wide service was launched in 2001. In 2014 the fleet reached over 78,000\textsuperscript{14} people affected by cancer across England, Wales and Scotland. The MISS is staffed by trained specialists and resourced by over 400 quality assured cancer information materials, which are updated annually and re-stocked weekly as needed. Each vehicle contains storage space for printed information and a quiet area for private discussions.\textsuperscript{15}

The MISS and Macmillan Support Line were awarded the Contact Centre Association (CCA) Global Standard Award in December 2013, strongly demonstrating key principles within the industry and commitment to our customers.\textsuperscript{16}

The primary purpose of the MISS is to be a flexible drop-in community service with a particular emphasis on identifying hard to reach communities. The MISS operates for about 10 months a year and typically spends 1-2 days in each location visiting town centres, workplaces, hospitals, county shows, sporting events, educational establishments and faith events. The service has also taken on a proactive outreach role by exhibiting stalls in indoor locations and handing out information packs at large social events such as the Royal Welsh Show, Brighton Pride and the Vitality festival.\textsuperscript{16}

Large events facilitate a great opportunity to address cancer awareness amongst large audiences of the general public. The branding and high profile positioning of the service also acts to raise the profile and awareness of Macmillan.\textsuperscript{17}

The MISS receive queries at all levels of enquiry from the worried well, carers and those living with cancer. Queries range from simple information provision (e.g. a request for a specific piece of information such as a leaflet or contact details) to complex trauma cases requiring sensitive advice and support in combination with information provision and signposting to relevant local clinical, social or supportive services.\textsuperscript{15} In all cases the service complements, and signposts to, additional Macmillan services such as the Macmillan Support Line, local benefits advice centres or the Macmillan website.\textsuperscript{17}
The combination of welcoming environment, quality resources and skilled staff to provide personalised support and advice to understand the information makes MISS unique and valuable services. MISS vehicles are very accessible and can be taken almost anywhere that is required. The service is anonymous and confidential making it particularly appealing to people who are less likely to seek information elsewhere for fear of recognition and stigma.

Visitors to the mobile service commented that they served to clarify the role and remit of Macmillan as previously many had only associated the charity with the provision of specialist nurses.  

The human approach of the staff in the MISS who took the time to not only listen to their problems but also sit down and discuss the literature is highly valued.  

All visitors interviewed in one evaluation recommended the service, highlighting the benefits of the vast amount of information about cancer for patients and carers, information about cancer related financial issues and the ability to be able to talk through experiences with a stranger, especially if afraid to go to the GP.

The presence of the MISS has wider benefits for Macmillan. The overwhelming gratitude felt by people who have benefited from the service inspires them to support us in various ways including through fundraising, donations and campaigning. In 2013 the members of the MISS team gained 116 press articles and took part in part in 18 radio interviews, generating increased awareness of the service and Macmillan’s brand.

Cost of running a typical MISS vehicle

Macmillan runs four vehicles as part of the whole MISS services and these vehicles require ongoing funding to keep them on the roads supporting people in local communities. Typical costs for 2014 for one vehicle are shown below.

<table>
<thead>
<tr>
<th>Time period</th>
<th>Cost</th>
</tr>
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<tbody>
<tr>
<td>1 day</td>
<td>£2,398</td>
</tr>
<tr>
<td>1 active month</td>
<td>£35,712</td>
</tr>
<tr>
<td>10 months of the year (average active year)</td>
<td>£357,118</td>
</tr>
</tbody>
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*For more detailed costs of these and other Macmillan services see be.macmillan.org.uk to download The Cost of Macmillan’s Services fact sheet.
3. What is the impact of effective mobile information and support services?

In 2014 the MISS vehicles reached over 78,500 people.\textsuperscript{14} The ease of access and prominent community locations make the MISS a key drop in service for the worried well, carers and family members (making up two thirds of visitors) as well as people affected by cancer.\textsuperscript{21}

Many commented that their visit to the vehicle was the first opportunity they had had to obtain information of any kind.\textsuperscript{27}

Provision of information for family members and carers has historically been poor compared with the provision for people with cancer so the MISS offers a great opportunity to fill the information and support gap for this group. The majority of queries are regarding information about signs and symptoms, specific cancer information, emotional support and financial/benefits advice.\textsuperscript{21}

More importantly the MISS reaches people who typically do not seek information and support. For example they attract more men (43% of total visitors) than conventional methods of delivering this resource.\textsuperscript{16} One review interviewed 21 men about why they found the MISS so appealing. The principle reason given was that it offered an easy access service on their doorstep. Women on the other hand are more likely to seek out information and support for themselves.\textsuperscript{23}

In fact accessibility seemed to be a key factor for all visitors to the service with many visitors happening upon the MISS vehicle by chance and deciding to drop in.\textsuperscript{24}

The majority of visitors are alone when they visit the MISS suggesting that people value the chance to discuss issues or make enquiries without family members or carers around. 45% of people who accessed the service in 2013 said they would not have gone elsewhere for help.\textsuperscript{16}

The MISS has the advantage that it can specifically target harder to reach areas and communities, for example a visit to a mosque in Derby reached over 1,000 members providing them with tailored information and support.\textsuperscript{21}

In addition to its core service the MISS reached over 9,500 people in 2013 via tailored talks or presentations in schools, workplaces or community groups and one to one support when required. These talks help reach the younger and older age groups as well as specific BME communities such as an Albanian women’s group and an African Caribbean men’s health event.\textsuperscript{16}

\textit{‘I just wanted to say thank you. I called into the Macmillan MISS last year with symptoms that I discussed with you, and you encouraged me to visit my GP. Within two weeks I was diagnosed with cancer. I feel I owe my life to the Macmillan MISS.’}\textsuperscript{22}

\textbf{Cancer patient}

\textit{‘As a friend, I don’t really have access to information. If the MISS wasn’t here, then I wouldn’t have got any information at all.’}\textsuperscript{27}

\textbf{Friend of cancer patient}

\textit{‘It was an opportune moment. I saw it advertised and decided to call in, it couldn’t have happened at a better time.’}\textsuperscript{29}

\textbf{Cancer patient}
The majority of interventions are brief interactions; however the development of targeted letters and increased local media coverage has seen a rise in complex cases actively seeking out MISS for advice and support. In 2013 100% of those asked said they were satisfied with their visit to the MISS. 52% of respondents questioned said they visited the MISS vehicle because they wanted to speak to someone face to face and 48% wanted to get practical information. 85% felt more confident following their visit to a MISS.16

Case Study – Person living with cancer, aged 60+18

‘I was walking through town feeling really ill as a result of treatment and the “Macmillan bus” was like a beacon shining in the distance! I found it very helpful; the service for benefit forms has been absolutely brilliant. I would definitely encourage others to use it. They do make a difference and they can help. They talked about benefits and my general condition. The staff put me at ease and sent me a very nice letter back.

When it comes to filling in forms, especially for people in their 60s like me, you can fill in all your personal details but with the rest of the form you think “where the heck do I start?” The staff on the bus were brilliant with this.’

The impact on MISS visitors’ health and wellbeing

i) Relieving anxiety and stress by being able to talk about cancer and creating a more positive outlook on life

Visitors to the MISS commented that the anonymity of their visit and discussion with the staff allowed them the freedom to talk about concerns without anxiety about any repercussions.27

ii) Enabling people affected by cancer to feel more in control and thus improve their ability to self-manage their condition or that of a loved one.

The opportunity to discuss the content of the information leaflets is valuable to people in that it enables them to clarify the content and applicability of the information to their personal situation. Visitors to the units commented on how beneficial they had found the experience. They valued both the provision of relevant information and also the informal support

‘I am not unduly anxious about seeing my GP now because I know I have to now I have seen you.’18

Cancer patient

‘It is brilliant, I got some leaflets and the staff answered all the questions. I feel a lot better in my mind, I am glad I came in.’19

Cancer patient

‘For the last two years I haven’t been able to speak to anyone, seeing this here and being able to call in and speak to someone has been wonderful.’23

Cancer patient
they received from staff especially when many felt unable to discuss concerns with a GP. 27

Following a visit to the MISS cancer patients were empowered to take action for themselves, e.g. proactively following up test results and identifying further questions to ask their health care professional. Cancer patients also stated that they felt more knowledgeable about who to turn to for help in the future. 24

Cancer patients who are well informed are better able to understand and participate in their health care plan, experience less anxiety and are more likely to cope with their illness. 10 They are also better equipped and prepared with questions for consultations with health professionals. 25

With the right information and support patients can look after themselves more efficiently and their quality of life is much improved. 26

iii) Promoting a positive change in attitude, leading to a healthier life style

All of the visitors to the MISS in one evaluation appeared more positive and committed to taking further action as a result of their visit to the service. They left with a greater understanding and awareness of where and how to access information and support. They focused on changing their personal lifestyle habits, and also being more directed in seeking and obtaining more information. 27

The financial impact on MISS visitors

Cancer patients are often unaware of the financial benefits that they are entitled to and there is widespread under-claiming of welfare benefits by those eligible for them. 28 There is considerable evidence that cancer patients experience substantial stress around financial issues. 29 Once the financial stress is removed, they are more able to deal with their illness and treatment.

In a US study of 245 cancer patients 42\% percent of participants reported a significant financial burden, 68\% cut back on leisure activities, 46\% reduced spending on food and clothing and 46\% used savings to cover out-of-pocket expenses. 30

Macmillan information and support services including MISS provide a vital signposting facility, referring patients to appropriate financial advice and assistance services. Macmillan-funded research has shown that all patients claimed that benefits received, as a result of welfare advice funded by Macmillan, helped to reduce stress levels, which can in turn aid recovery. 31
The Macmillan MISS (mobile information and support service) is able to offer the specialist cancer knowledge and expertise that is needed to support people affected by cancer in a flexible community setting. The non-clinical environment and the specialist skills of the MISS staff provide people affected by cancer the space and time to express and discuss concerns that reflect the whole life impact of the diagnosis. The service can deal with all levels of enquiry including complex cases that involve signposting to local health, social and support services as well as other charities.

It is this ability to help the client identify and prioritise their concerns, and then to meet this concern with the appropriate information and support, that enables Macmillan to provide a tailored personalised service, successfully meeting the needs of people affected by cancer and helping them to cope with the physical, emotional and social aspects of their diagnosis.

The main advantage of the MISS is that they are an easily accessible community resource, often reaching people who would historically not seek information and support via conventional channels. The anonymous, drop-in style of the service could be a key factor in attracting people who tend not to access traditional sources of information such as men and those from ethnic minorities. They also act as an outreach services exhibiting and presenting talks in schools and businesses as well as raising cancer awareness amongst large audiences. In addition the presence of the MISS vehicles assists Macmillan to raise its profile through greater brand visibility.

Despite the work Macmillan has done over the years there are still many people affected by cancer with unmet information and support needs. With the number of cancer survivors estimated to rise to 4 million by 2030\(^3\) it will become even more important to be able to identify and reach the people who need information and support most through community services like the mobile information centres.

Macmillan continues to fund and provide cancer information and support services and urgently needs more charitable donations to keep these services supporting cancer patients and their families. Go to [www.macmillan.org.uk/donate](http://www.macmillan.org.uk/donate) or call 0300 1000 200 to make a donation.
REFERENCES

10 Manning, D, Dickens C. Health Literacy: more choice, but do cancer patients have the skills to decide. European Journal of Cancer Care. 2006.UK.
14 Macmillan Cancer Support. The Reach of Macmillan’s Services fact sheet. 2015.
16 Macmillan Cancer Support. Mobile information and support services Annual Review 2014. UK.
23 Macmillan Cancer Support. Top five facts about direct services. 2011.UK.
25 Barnard H, Stone V. Review of Macmillan cancer information and support services. BRMB qualitative. 2003.UK