

<b>Briefing for:</b>	<b>National Assembly for Wales' Communities, Equality and Local Government Committee.</b>
<b>Purpose:</b>	<b>Macmillan Wales response to the Inquiry into Public Libraries in Wales.</b>
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<b>Date:</b>	<b>January 2013</b>

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National Assembly for Wales  
Communities, Equality and Local Government Committee  
Inquiry into: Public Libraries  
Response from: Macmillan Cancer Support

### Introduction

1. Macmillan welcomes this inquiry into public libraries by the National Assembly for Wales' Communities, Equality and Local Government Committee. We are specifically interested in the role that public libraries can play in relation to enhancing information and support around health and wellbeing. We feel this inquiry is timely given the challenging financial climate and the imperative for all organisations and sectors to collaborate to make the best use of all available resources in Wales.
2. For decades Macmillan has been leading the way in cancer care by providing innovative services within health, social care and community settings for people affected by cancer in Wales. Information and support is a key priority area for Macmillan.
3. We believe that every person with cancer in Wales should be enabled to access information and support to meet their individual needs. 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 cancer information and support services, the production and distribution of high quality information and advice materials, many of which are available bilingually, and directly through our website and telephone helpline. Since 2010 we have invested over £2 million in information and support provision in Wales, including £800,000 in information and support services within libraries. We have been developing our services locally and have introduced local cancer information and support centres in five library services across Wales.
4. For many years we have been highlighting the importance for people affected by cancer to have the information and support they need throughout their cancer journey so that they can make the right decisions for them. In June 2012 we were successful in influencing the Welsh Government to include the information and support needs of

people affected by cancer within 'Together For Health – Cancer Delivery Plan for the NHS in Wales', ensuring that information is at the heart of the national strategy. In addition to influencing national policy, we were successful in securing three year funding for the Cancer Strategy Information post, hosted by Public Health Wales, who will be developing a strategy aimed at addressing the need for personalised information and support for people affected by cancer from the point of diagnosis onwards.

5. Our response to this inquiry is based on our learning from our information services and our influencing work in Wales. We have not provided detailed answers to all the questions that you have posed. Our response relates to the specific questions:

- Options for improving the financial sustainability of library services, including alternative models of provision;
- The contemporary and community role of public libraries in Wales.

## **6. Key Points**

- a) In response to people living longer with and beyond cancer, Macmillan has worked in partnership with library services in five local authorities to provide high quality and up to date information to support and empower people to take responsibility for their own health and independence.
- b) We believe that public libraries are well placed to offer supported health and wellbeing information services due to their central location within communities, accessible opening hours and trained staff who are expert in providing information to the public.
- c) A greater role for libraries in relation to health and wellbeing would bring a number of benefits for local authorities, health boards and people affected by cancer. However for this to become a reality the NHS needs to view libraries as a resource for health and wellbeing information and for them to become more integrated into care pathways. In addition, library performance measures may need to be revised to take into account greater responsibility in this area.
- d) With the number of cancer survivors in Wales estimated to double to 217,000<sup>i</sup> by 2030, it is important that everyone has access to the information and support they need to enable them to live well for as long as possible with or after cancer.

## **Macmillan Cancer Support and partnerships with public libraries in Wales**

### **Background**

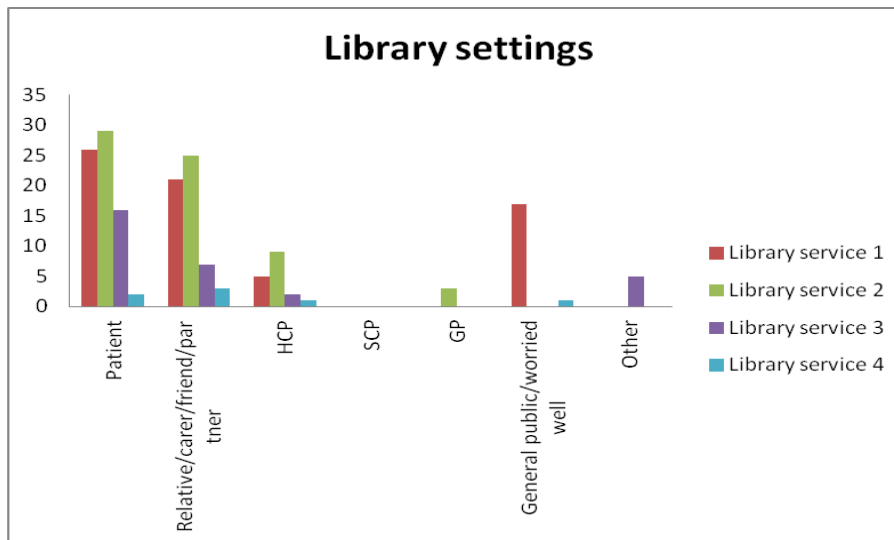
7. As the diagnosis and treatment of cancer is becoming ever more effective, many more people are living longer with and beyond cancer. Whilst sadly for many cancer is still a short-term incurable illness, for thousands of others their experience of cancer is evolving to a long-term condition with many possible outcomes. By 2030, it's estimated that the number of people living with or after cancer in Wales will nearly double to almost a quarter of a million. This growing population will have significant implications for both health and social care and will challenge existing models of cancer care. As more cancer patients experience the disease as a long-term condition, with patterns for many of relapse and remission, cancer survivors will need good quality information and support to self-manage and live as healthy and as good a quality of life for as long as possible.

8. People living with cancer tell us that they often feel abandoned once their treatment is over.<sup>ii</sup> Traditional cancer follow-up does not always provide the range of information, or the practical and emotional support that people need and it does not help people prepare for life after cancer. Having the right kind of information, at the right time, helps people make informed choices about their care and it can help take away some of the fear and anxiety associated with a cancer diagnosis and the possibility of recurrence. There is both an economic and social need to address the issues of survivorship and enable people living with and beyond cancer to have the best possible support and information to enable them to lead as active and normal lifestyle as possible.

9. We have developed the Macmillan libraries cancer information and support services in response to the changing nature of cancer and its long term impact and the need to support people affected by cancer to access information and support in their community, after active treatment has finished, promoting self management and wellbeing.
10. Macmillan launched its first Macmillan library service in Rhondda Cynon Taf in autumn 2009, quickly followed by Torfaen in winter 2010, Monmouthshire in summer 2011 and Blaenau Gwent in winter 2011. A new service is currently being developed in North West Wales. In each service there is a Macmillan Cancer Information and support Co-ordinator, whose role is to develop and promote the service, maintain and monitor information points and work with appropriate organisations to provide support opportunities for people affected by cancer and the health care professionals who work with them. As well as the Macmillan Co-ordinator, other library staff have received information and presentations on this service.
11. We believe that public libraries are well-placed to offer health and wellbeing information in the community for a number of reasons:
  - a) **Literacy levels:** 25% of the adult population in Wales is illiterate<sup>iii</sup> and a further 30% have marginal illiteracy. Providing supported information in public libraries could be a valuable resource to help people with low literacy in socially deprived areas in Wales. A high proportion of people affected by cancer are unable to read their prescribed plan and struggle with self-care. Face-to-face support can go a long way towards alleviating this problem.
  - b) **Rurality:** Libraries are located in people's communities and near their home, which is vital given the geography of Wales and the difficulty many people in rural areas face due to the distances they have to travel.
  - c) **Mobility:** High concentrations of social and economic deprivation mean that there are relatively low levels of mobility particularly for the 65+ age group. Through libraries, patients are able to access information and support closer to home and not have to travel for it as they do for treatment.
  - d) **Environment:** Libraries are open to all and provide a community focus point and an informal and welcoming atmosphere. People looking for information or training may find traditional providers, such as schools or colleges, threatening but evidence shows they are more comfortable in visiting their local library. Residents are used to the library service being a multi-faceted resource where a range of community and training opportunities are presented and collaborative services provided.
  - e) **Staff** are already trained and expert in providing information to the public.

### Learning from Macmillan Cancer Information and Support Services in Libraries

12. Locating the Macmillan library cancer information services within communities and outside cancer centres and clinical settings has enabled libraries to reach not only patients, but also relatives, carers and friends, as the table below illustrates.



13. Our research shows that people affected by cancer access the services for a range of enquiries. Common themes include non-clinical issues such as financial worries, emotional support and housing issues, which people feel less able to discuss with clinicians.
14. Evidence shows that the local information and support services can bring significant benefits for people affected by cancer,<sup>iv</sup> including:
- Support with psychological impact:** Evidence from our local information and support services across the UK shows that having access to the right information, along with the support to understand and digest it, enables people affected by cancer to feel more in control, less anxious and less stressed.
  - Increased participation:** Cancer patients who are well informed are better able to understand and participate in their assessment and care plan, experience less anxiety and are more likely to cope better with their illness. With the right information and support patients can look after themselves more efficiently and their quality of life is much improved.<sup>v</sup>
  - Communication:** as a result of receiving information and support cancer patients are able to speak openly about the impact of cancer on themselves and their family, which helps to maintain strong relationships with their families. Many cancer patients find it difficult to talk about their condition, because they don't know how to talk to about it and want to remain strong and positive for their families. Being given information and support has been shown to help ease this pressure.<sup>vi</sup>
  - Holistic support:** Macmillan information and support services also provide a vital signposting facility, referring patients to other support services including appropriate financial advice and assistance services.
  - Impact on health outcomes:** There is evidence that effective information provision can reduce GP appointments as people understand where to go to access support and further information and access healthcare services appropriately.
15. In addition to the development of Macmillan Cancer Information and Support Services within libraries, libraries are also increasingly being utilised as venues for Macmillan's cancer Health and Wellbeing Clinics. Macmillan Health and Wellbeing Clinics are one-stop-shop events that supports people to lead as normal a life as possible with and beyond their cancer. The 'one-stop-shop' enables patients and the carer/ family to receive information from professionals in one place, at one time. The events are tailored to a particular group of people's needs and provide holistic support covering financial, emotional and practical advice, and include information about the signs and symptoms to look out for, and what to do if they have concerns. Macmillan Health and Wellbeing

Clinics are an excellent example of collaboration between Macmillan, Local Health Boards and Local Authorities.

16. We understand that libraries have also been involved in many other varied activities in relation to health and wellbeing. However, as the recent publication by the Society of Chief Librarians in Wales 'Public Libraries in Wales Health, Wellbeing and Social Benefits' (2012) has shown, libraries' contribution to this area is often overlooked. Our experience from our services shows this in that it can be difficult to foster partnerships between library services and healthcare and integrate services within care pathways.
17. We believe that enhancing public library services to include further supported health and wellbeing information would have a number of benefits for patients, local authorities and health boards. For example, for local authorities it will fit with the Health and Wellbeing element of 'Vision for Libraries in Wales – Libraries Inspire', and support local authorities to deliver on the information elements of a number of strategies, including the 'Carers Strategies (Wales) Measure', 'The Strategy for Older People in Wales' and the future 'Social Services and Well-being (Wales) Bill'. For Health it will support Health Boards to deliver the information element of delivery plans relating to long term conditions, including the 'Together for Health - Cancer Delivery Plan' and 'Together for Health – a Diabetes Delivery Plan', and support them to deliver on the 'Carers Strategies (Wales) Measure' and on 'Cancer Rehabilitation Standards' and NICE guidance. Furthermore it will also support self-management agenda as outlined in Together for Health and support delivery on addressing health inequalities, particularly health literacy e.g. 'Fairer Health Outcomes for All'. However for this to become a reality, partnerships will need to be developed across health and public libraries to ensure referral pathways. In addition performance indicators may need to be re-considered to recognise libraries' contribution to this area. Macmillan would be interested in working with public libraries on this agenda.

### Macmillan Professionals

18. Public libraries have a key role to play within the health and wellbeing sector and Macmillan has a role to play to support the link between health care and library services through our 250 professionals across Wales. Macmillan can support the development of links with primary and community care through combining our networks to work strategically across primary care and library services.

### Conclusion

19. Despite the work Macmillan and others have done over the years, there are still many people affected by cancer with unmet information and support needs. In England the 2012/13 cancer patient experience survey highlighted that only 71% of patients reported that they were given easy to understand written information about their cancer and only 61% said that their family, or someone close to them, were given the information needed to help care for them at home. The first all Wales Cancer Patient Experience survey results are due to be published in late January 2014 and will provide us with evidence of the progress made in meeting the information and support needs of people affected by cancer in Wales.
20. With the number of people living with cancer in Wales estimated to rise from 120,000 to 217,000 by 2030<sup>vii</sup>, it is important that action is taken to ensure everyone has access to the information and support they need to enable them to live with or after cancer.

### Appendix

#### About Macmillan Wales

21. Macmillan Wales improves the lives of people affected by cancer, which includes carers, relatives and patients. We provide practical, medical, emotional and financial help to people affected by cancer and push for better cancer care across Wales.

22. Macmillan Wales is also a force for change; listening to people affected by cancer and working together to improve cancer care. People who live with cancer are experts by experience. They are a powerful resource, telling us what is needed and what must change. Together we can use this knowledge to make a positive difference to the lives of people affected by cancer. We believe that the voice of people living with cancer needs to be heard at all stages of health and social care services, from the design and implementation to the evaluation of cancer services.

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<sup>i</sup> Source: Internal analysis by Intelligence & Research, Corporate Development Directorate, based on figures from: Maddams J et al. (2008) Cancer prevalence in the United Kingdom: Estimates for 2008. British Journal of Cancer.

<sup>ii</sup> Macmillan Health and Wellbeing Survey (2008) and Patient Reported Outcomes Measure survey (2011)

<sup>iii</sup> NIACEDC <http://www.niacedc.org.uk/facts>

<sup>iv</sup> Macmillan Cancer Support 'Local Information and support services: An evidence review'

<sup>v</sup> Coulter, A. (2002) The Autonomous Patient: Ending paternalism in medical care. The Nuffield Trust.

<sup>vi</sup> Cardy P, Jackson N, Shearn K, Sparham L, Corner J, Evans J: Worried Sick: (2006)The Emotional Impact of Cancer : Opinion Leader Research

<sup>vii</sup> Source: Internal analysis by Intelligence & Research, Corporate Development Directorate, based on figures from: Maddams J et al. (2008) Cancer prevalence in the United Kingdom: Estimates for 2008. British Journal of Cancer.