



# Evaluation of Health and Wellbeing Clinics

## Final report

Macmillan Cancer Support

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## Executive summary

OPM, working with specialist health consultancy HPA, was commissioned by Macmillan Cancer Support to evaluate its health and wellbeing clinics, which were piloted in 14 sites across the UK with the aim of improving aftercare for people affected by cancer. This report is the final report of three which have been produced during the one-year evaluation. This report presents the results and findings from the 14 pilot sites.

### Key achievements of the pilot clinics

The evaluation has generated evidence that patients who attend a clinic, where they receive supportive information and have access to networking opportunities, benefit in a number of ways.

They report increased knowledge of symptoms and treatment options, as well as increased confidence to self-manage their health. They report reduced use of health services.

The health and wellbeing clinics have the potential to enhance the quality of care, improve patient reported outcomes and reduce patients' use of health services.

In more detail, some of the key achievements of the pilot appear to be as follows.

#### Quality

- the **informal atmosphere** of the clinics was very popular with patients and appears to have been conducive to the effective delivery of health and wellbeing messages.
- the **combination of volunteers and professionals** was an effective one, with each making a valuable contribution to patients' experience of the clinics. The pilot has demonstrated the potential of volunteers to play a significant role in health and wellbeing.
- there was some degree of improvement to **quality of life** in terms of increased self-reported ability to manage emotional distress and to take part in social activities.

#### Innovation

- while sites took a range of different approaches in terms of the format of clinics, all essentially provided a '**one-stop shop**' for services and support. This enabled patients to **access** a range of services easily, and in many cases led to **unmet needs being identified** and addressed. Patients found out about services they were not previously aware of, and found out how to address unmet need.
- even where patients did not feel the need of information or services currently, the clinics played an important '**reassuring**' role. Patients felt better knowing what services are open to them and how to access these.
- patients valued the **opportunity to meet other patients** and carers and take part in group discussions; this helped to combat a sense of isolation and confirm what is 'normal' to experience and feel for a person affected by cancer. This differentiates the clinics from traditional forms of follow-up such as outpatient appointments.
- **carers and family members** also experienced these benefits from attending clinics with the patient they care for.

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## Prevention and productivity

- clinics **empowered patients** by making them more knowledgeable and confident, which had a knock-on effect on service use. Increased knowledge and confidence may lead to reduced anxiety, more appropriate use of services and earlier intervention, which may be linked to improved outcomes.
- a reduction in patients' **self-reported use of health services** was evident following attendance at a clinic, particularly use of GP and district nursing services. Changes in patient-reported use of other services or support, such as complementary therapies, which tend to be less resource-intensive compared to health and social services, suggest that the clinics may also affect patterns of use of these services.
- where one to one sessions took place at clinics, referrals could be made directly to other services, which increased access to services and impacted on **referral pathways**.
- there was some degree of improvement to patient-reported **physical wellbeing** following a clinic, with fatigue being one of the most frequently mentioned factors that patients felt more able to cope with. Patients benefitted from advice on diet and exercise and referrals to physiotherapy/dietician services, as well as from information about side effects (which led some patients to change medication, with positive effects).
- while the format of clinics and the **numbers of patients** who attended was extremely varied, the pilot suggests that the health and wellbeing clinic has the potential to enable effective delivery of services in terms of productivity.
- clinics successfully **raised awareness of Macmillan** and Macmillan services, which has the potential to reduce demand for mainstream health services.

## Cost case

Some early scoping has been conducted in terms of identifying the range of direct and indirect costs, and the cost of set-up and running, in order to build up intelligence in developing a business case. These findings are available in a separate report.

Economic case studies of three pilot sites demonstrate that it is possible to find monetisable savings, as a result of reduction in service use, for a number of these savings (per unit of service); therefore, the foundations of building up a business case are there. Monetisable savings through reduced service use were found in the three sites, for the types of services affected assuming a reduction per service of one unit per patient. In addition there are a range of currently non-monetised savings such as increases in patient knowledge and confidence, as set out above. In summary:

Case study site	Costs	Benefits to the healthcare system	Benefits to patients
Case study 3: market stall model (8 clinics)	Set-up: £2,499 Running: £7,034	£5,317	Increases in patients' wellbeing and ability to self-manage
Case study 2: traditional model (1 clinic)	Set-up: £5,000 Running: £2,523	£2,418	
Case study 3: volunteer-led model (7 clinics)	Set-up: £4,625 Running: £24,913	£1,678	

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## Department of Health outcomes

The health and wellbeing pilots demonstrate aspects recommended in the Department of Health's Improving Outcomes: A Strategy for Cancer<sup>1</sup>, including:

- promotion of the Big Society agenda, with volunteers and voluntary sector organisations working alongside health and social care professionals to deliver a quality service.
- supporting secondary prevention, through promotion of lifestyle changes, recognition of signs and symptoms of recurrence and quality of life.
- putting the needs of patients and carers first and delivering a service around them.
- addressing health inequalities, by specifically targeting a black and minority ethnic (BME) community (in response to an identified lack of BME patients accessing clinics)
- providing one to one support, which may reduce the need for onward referral to services.

## Macmillan 9 priority outcomes

Macmillan has 9 priority outcomes which its work aims to achieve<sup>2</sup>. They state that, 'In 2030, all 4 million people living with cancer in the UK will say:', followed by a list of statements. The findings of the evaluation suggest that the pilot has made a contribution to some of these priority statements, in particular the following:

- *'I understand, so I make good decisions'*
- *'I get the treatment and care which are best for my cancer, and best for my life'*
- *'I know what I can do to help myself and who else can help me'*
- *'I feel part of a community and I'm inspired to give something back'*
- *'I am treated with dignity and respect'*

## Who are health & wellbeing clinics for?

### Patient throughput

87 clinics were held during the pilot, across 14 sites. In total 764 patients attended.

- There was no evidence of any substantive rejection of the clinics by patients; reasons for non-attendance tended to be practical rather than any 'in principle' objection to this form of service delivery. For example, patients being unwell on the day of the clinic; feeling they did not need extra support; or having too many appointments to attend.

### Identifying patients through risk stratification

It is not yet entirely clear which portion or segment of the patient population is suitable for health and wellbeing clinic attendance as an alternative to outpatient appointments. The portion varies between tumour sites due to different treatment trajectories. For example, it

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<sup>1</sup> Improving Outcomes: A Strategy for Cancer, Department of Health, January 2011

<sup>2</sup> Currently in draft form, to be published July 2011

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may not be appropriate for patients who have complex care needs to attend health and wellbeing clinics as an alternative to regular one-to-one appointments.

Macmillan is currently undertaking work at a number of prototype sites to **pilot a risk-stratified approach to post-treatment care**. This work should generate a clearer understanding of which patients are suitable for health and wellbeing clinic attendance as an alternative to out-patient appointments.

However, the variability and success of clinics within the pilot has demonstrated that the health and wellbeing model potentially has a broad appeal and is suitable for patients who are differentiated by a number of factors:

- **Tumour type and timing** - the clinics were designed and piloted for patients with any tumour type, at or nearing the end of treatment. However, the tumour type may determine to some extent the timing and format of the clinics. For example, for lung cancer patients who are likely to have a poorer prognosis than many other tumour types, clinics were delivered at the point of diagnosis and using a one-to-one format rather than group discussion, to reflect this prognosis. Work carried out by NCSI<sup>3</sup> has identified that patients from differing tumour sites have different needs and clinics can be tailored to meet these.
- **Ethnic group** - one pilot site specifically targeted a BME community in recognition of an identified need to engage BME groups more effectively: for example, the National Cancer Patient Survey found that cancer patients from ethnic minority groups were significantly less likely to be positive about some aspects of communication with them, and the way they were treated by staff, than white patients<sup>4</sup>. By partnering with a local voluntary sector organisation to promote and run clinics, this pilot site achieved an exceptionally high turnout and positive patient feedback.
- **Receptiveness** - some patients may wish to move on from their experience of cancer and not to 'dwell' on it. In this situation, the clinic can demonstrate to patients the benefits of caring for their own health and wellbeing, so that the wish to dissociate themselves from their cancer does not compromise their future health.

## Key differentiators from other forms of service delivery

- **Supports the transition to survivorship**: health and wellbeing clinics support the transition from active treatment to enabling the patient to resume a normal life as possible.
- **A 'one stop shop'**: the concept and format means that the full range of relevant professionals and information can be accessed in one place, at one time (rather than individual appointments to see different clinical and non-clinical staff).
- **Volunteer and peer support**: volunteers help create a welcoming and relaxed atmosphere which patients value; they also value the opportunity to share experiences of living with cancer with volunteers and other patients. For many patients the group setting

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<sup>3</sup> NCSI, Davies et al (2010) Cancer follow-up: towards a personalised approach to aftercare services: a review of current practice and initiatives

<sup>4</sup> National Cancer Patient Programme – Survey Report, Department of Health, 2010

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helped them to access information, by hearing others ask questions that they found relevant to their own experience.

- **Reducing unnecessary follow up:** service use reduced almost uniformly following patients' attendance at a clinic; further to the ongoing work on risk stratification of patients, it appears likely that the clinics can form a key part of the care pathway for those patients suitable for 'supported self management'.
- **Macmillan's involvement:** Macmillan's strong reputation for supporting people affected by cancer encouraged many patients to attend a clinic. Macmillan was seen by patients as a highly professional and expert organisation with an empathetic and personal approach. Patients felt that Macmillan staff and volunteers took the time to listen, explain and empathise with them at the event, as well as informing them about the range of services Macmillan offers and how to access them.

## In practice: making it work

Based on the pilot, it has been possible to identify a number of clear recommendations for future clinics in terms of their core function, staffing, processes and location within the care pathway. These can be found in section 7.2.

## Background to the pilot and clinics

As part of the National Cancer Survivorship Initiative (NCSI) vision and following related work by Macmillan, Macmillan developed the concept of health and wellbeing clinics to help prepare people living with cancer for the transition of moving on to life after treatment by promoting their awareness of cancer survival knowledge, their sense of empowerment and confidence, and their self-management skills.

### What is a health and wellbeing clinic?

This is a new service model and takes the form of a one-off, supportive event for patients, families and carers at the post treatment stage, bringing together a range of service providers from health, social, community and voluntary services. Volunteers work alongside health and social care professionals to:

- provide information relating to health and wellbeing, including on signs and symptoms of recurrence, side effects, physical and emotional wellbeing and healthy lifestyles
- signpost and refer to other resources and services, both clinical and non-clinical (e.g. complementary therapies, counselling and financial advice)
- facilitate interaction with other people affected by cancer.

During the pilot the clinics were not intended to replace other methods of follow-up care, such as one-to-one outpatient support; and were not necessarily integrated into assessment and care planning processes. Going forward, it is recommended that patients attend health and wellbeing clinics as part of a thorough needs assessment and care planning process.

During the pilot, the format of delivery across the pilot sites was flexible, enabling sites to personalise their approach to meet the needs of patients and carers. This resulted in considerable variation in format, size and location of the clinics, and in the professionals involved and the target patient group.

# 1. Background

OPM, working with specialist health consultancy HPA, was commissioned by Macmillan Cancer Support to evaluate its health and wellbeing clinics, which were piloted in 14 sites across the UK with the aim of improving aftercare for people affected by cancer. The 14 sites are listed in table 1, which can be found on page 17 of this report<sup>5</sup>.

This background section includes the following:

- Background and rationale for the pilot
- Commissioning: the context across the UK

## 1.1 Background and rationale for the pilot

### Rationale for the set up of the clinics

There are now about 1.8 million people living in England who have had a cancer diagnosis. By 2030 it is anticipated that there will be 3 million people in England living with and beyond cancer. People living with and beyond cancer often have specific support needs which, if unmet, can damage their long-term prognosis and ability to lead an active and healthy life. These needs can include information about treatment and care options, psychological support, access to financial advice and support in self-managing their condition. Carers also play a vital role in supporting people with cancer and it is important that their needs for information, advice and support are addressed.

In 2010 Macmillan Cancer Support developed the concept of health and wellbeing clinics, a new service model, designed to bring together a range of service providers from health, social, community and voluntary services into a single, universal event or 'fair' to help the transition for people living with cancer of leaving hospital treatment, to recommencing a life after treatment.

Core principles of the health and wellbeing clinics mirror the ethos of the Department of Health's Improving Outcomes: A Strategy for Cancer<sup>6</sup>, such as:

- secondary prevention (encouraging lifestyle changes; enhanced health and wellbeing, and quality of life)
- advice about possible signs of recurrence
- information and signposting to other services
- supporting patients and their carers to regain as normal a life as possible.

The NCSI has developed a transformed care pathway for cancer survivors, which is based on a model of care for people with long term conditions. A risk stratification process, whereby

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<sup>5</sup> The pilot originally comprised 15 sites; North Tyneside withdrew from the pilot in January 2011 and is not included in the evaluation.

<sup>6</sup> Improving Outcomes: A Strategy for Cancer, Department of Health, January 2011. Available online: [http://www.dh.gov.uk/en/Publicationsandstatistics/Publications/PublicationsPolicyAndGuidance/DH\\_123371](http://www.dh.gov.uk/en/Publicationsandstatistics/Publications/PublicationsPolicyAndGuidance/DH_123371) (accessed 25.05.2011)

the clinical team and the person living with cancer make a decision about the best form of aftercare based on their knowledge of the disease, will help to identify which care pathway is most suitable for each patient. The NCSI is currently testing risk-stratified pathways of care, with the aim of demonstrating improvements in patient outcomes and experience alongside reductions in unnecessary outpatient appointments and unplanned hospital admissions.

It is hoped that the Macmillan health and wellbeing clinics will be embedded into the NCSI Transformed Care Pathway, and will become a part of a package of survivorship care for patients living with and beyond cancer.

## Format of the clinics

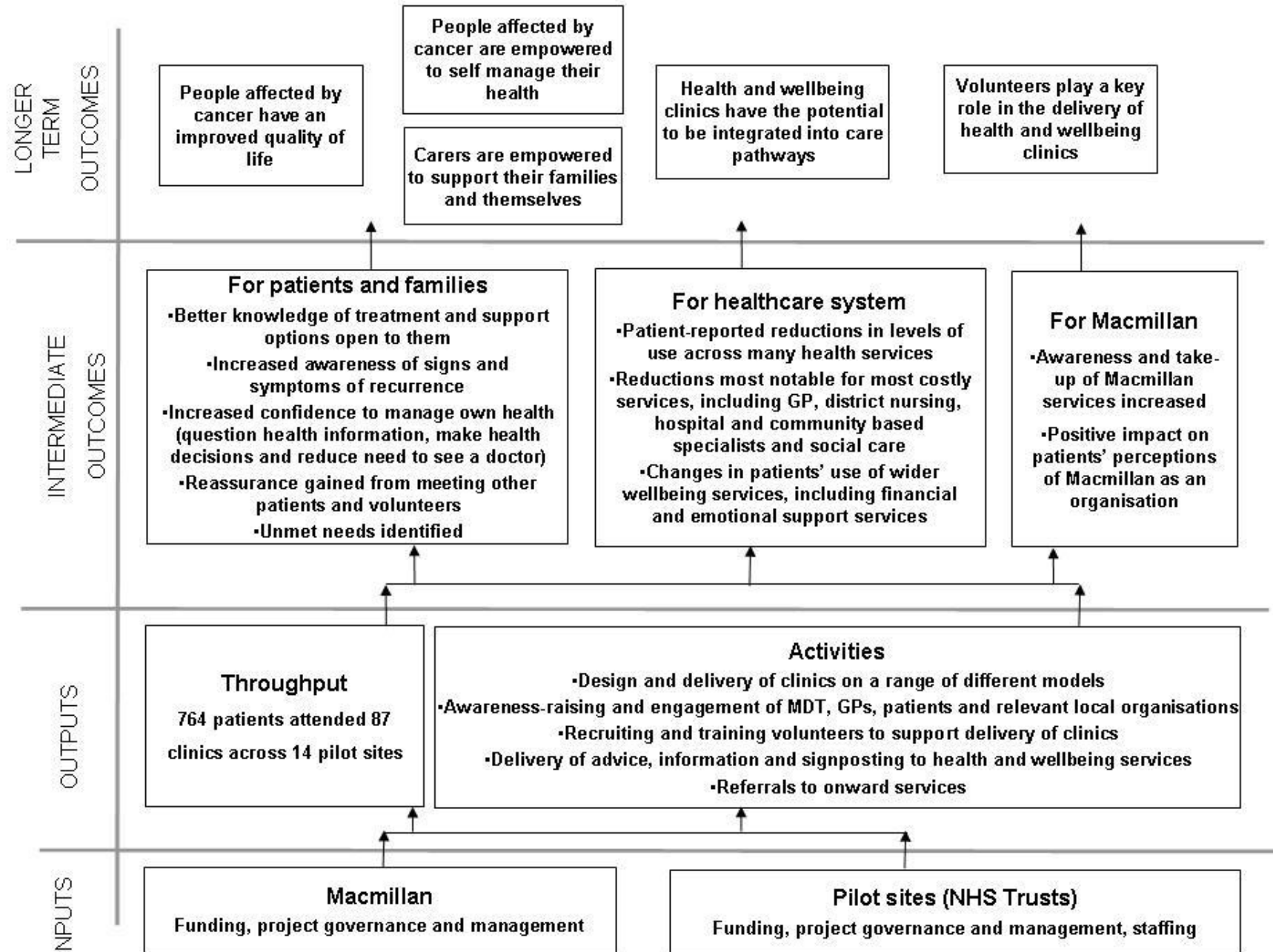
The clinics were designed to provide aftercare once treatment is complete; they were not intended to replace other methods of follow-up care, such as one-to-one outpatients or telephone support. Furthermore, they were not a substitute for a thorough assessment and care planning process. Rather, the clinics were a one-off supportive event to help prepare people living with cancer for the transition of leaving hospital treatment, and recommencing a life after treatment. In addition, the clinics provided signposting to additional resources and contact with other people affected by cancer, carers, volunteers as well as various health professionals, complementary therapists and the voluntary sector. Volunteers played a key role in the clinic model, working alongside health and other professionals to offer support to attendees.

Health and wellbeing clinics were designed to promote people's awareness of cancer survival knowledge, their sense of empowerment and confidence, and their self-management skills. The clinics could be distinguished from other forms of treatment and care in that they provided the opportunity for patients and carers to cover specific issues, for example colostomy care, prosthetic care, lymphoedema, body image and sexuality.

There was a large degree of flexibility and variability in clinics not only in terms of size and location (some were in hospitals while others were in community-based or other non-clinical environments) but also in terms of professional involved, type of cancer, and type of groups served. Clinics occurred at different times and intervals at each test site but the majority of clinics were held between April 2010 and, under the pilot arrangements, April 2011.

## 1.2 Service model

The following page shows the inputs, outputs and intermediate and long term benefits of the health and wellbeing clinic model.



## 1.3 Commissioning: the context across the UK

The pilots have been running across the four nations of the UK, where commissioning processes and commissioning cycles differ. As part of the evaluation, commissioners representing the four nations were interviewed in order to understand the differing approaches to commissioning as well as the outcomes commissioners would wish to see from health and wellbeing clinics.

England and Wales, throughout the project duration, have been in a state of flux with changes taking place either as a result of reorganisation, or as a result of the NHS reforms<sup>7</sup>. Northern Ireland has also gone through a restructuring of commissioning services over the last eighteen months and subsequently looking at their commissioning intentions<sup>8</sup>. Scotland would be keen to commission new services which meet with the NHS Scotland Quality Ambitions (the ambitions are that care is person-centred, safe and effective)<sup>9 10</sup>.

Despite the differing commissioning structures in England and Wales, Scotland and Northern Ireland, there are common outcomes which all commissioners interviewed were keen to see realised by health and wellbeing clinics:

- Added value for patients
  - Patients having an increased knowledge of their condition
  - The patient has greater self management and confidence which then reduces their reliance on health services and other agencies
  - Patients feeling empowered to get back to life
- Additional quality the clinics can bring
  - Changes in pattern of referral to other services
  - Opportunity to get across health promotion and prevention messages
  - Evidence/information to address quality ambitions, such as person centredness elimination of waste and variation, including inequalities and diversity
- Health and wellbeing clinics support appropriate delivery of follow-up care by providing information, and guidance and having an infrastructure in place to do this
- Reduction in demands on primary care from the 'worried well' and reduction in use of other hospital services having attended a health and wellbeing clinic

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<sup>7</sup> In Wales, Designed to Tackle Cancer was published in 2008 and is due to run to 2011. Available online at:

<http://wales.gov.uk/publications/accessinfo/drnewhomepage/healthdrs/Healthdrs2008/desigtackloecancerwales08-11/?lang=en> (accessed 2.06.11)

<sup>8</sup> The Northern Ireland Cancer Control Programme was published in 2007 and is available online at: <http://www.cancerini.net/cancerinni/cancerpolicytargets/cancercontrolprogramme> (accessed 2.06.11)

<sup>9</sup> See <http://www.scotland.gov.uk/Topics/Health/NHS-Scotland/NHSQuality/qualityambitions> (accessed 25.05.11)

<sup>10</sup> The Scottish Government's cancer strategy is Better Cancer Care, An Action Plan, published in October 2008. Available online at: <http://www.scotland.gov.uk/Publications/2008/10/24140351/0> (accessed 2.06.11)

- Health and wellbeing being part of a scheduled care pathway and part of a whole systems approach to managing their needs.

Interviews with the commissioners were conducted at the beginning of the project prior to any reforms taking place within health and social care. Given the timing of the project and the contextual changes taking place, it is suggested that further work takes place to re-engage commissioners around the health and wellbeing initiative.

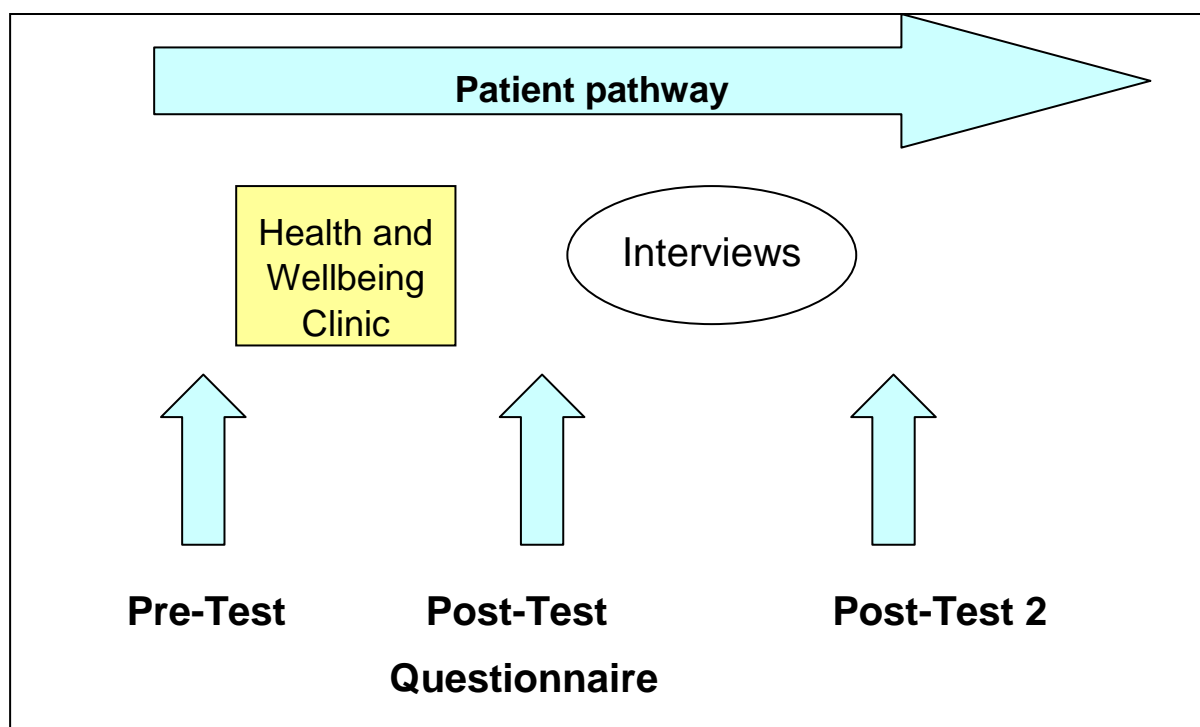
## 2. Evaluation methods

### 2.1 Evaluation design and methodology

The evaluation was designed in three phases: set up, main evaluation and reporting and communication.

**Set up / scoping:** In the set up, or scoping, stage, we gathered relevant background and contextual information to further inform our understanding of the purpose of the clinics and to inform the design of data collection tools. Scoping activities included a review of relevant literature, interviews with key stakeholders and a review of existing data collection instruments.

**Main evaluation:** In the main evaluation stage, we collected data from patients via a paper based, self completion questionnaire at three points in time: baseline (before they attend a clinic), midpoint (shortly after attending a clinic: 2-4 weeks) and follow-on (a longer period after attending a clinic: 3 months). This enabled us to track changes to patients' wellbeing over time. The process is illustrated in the following diagram:



Activities running concurrently to the above during the main evaluation stage were: the collection and analysis of monitoring forms from clinics to provide quantitative data such as levels of attendance; interviews with patients to provide qualitative depth; and clinic visits to observe the running of clinics and gain the views of clinic staff and volunteers through informal interviews at the clinics.

**Reporting and communication** took place via two interim reports (September 2010 and January 2011) and this final report. In the later stages of the evaluation Macmillan asked OPM to undertake two additional pieces of work in relation to the pilot: one to assess patients' perceptions of Macmillan and the value of its involvement in the clinics; and a

second to conduct 'cost consequence' case studies of three sites to give an indication of their costs and monetisable benefits. The findings of the first are incorporated within this report in section 6; the second is summarised in section 5 and the full details are available in a separate report.

Throughout the evaluation we maintained regular contact with clinic leads (three 'Learn and Share' workshops; plus ongoing telephone and email support to clinic staff), the Macmillan Cancer Support Health and Wellbeing steering group (attendance at quarterly meetings) and the project leads at Macmillan (monthly email updates and teleconference calls).

The following section describes in more detail the methods used in the evaluation, including: scoping review and interviews; development of measures; consensus workshop with clinic leads; and the design of questionnaires, interview guides, monitoring forms and clinic visits.

## Scoping stage

### Scoping review

A documentary scoping review was conducted to inform both the design of the evaluation and practice across the clinic pilot sites over the next year. The scoping review aimed to assess the evidence base of similar interventions improving the lived experience of people affected by cancer in the UK; explore best practice, challenges and learning from previous self-management and survivorship interventions; explore patient outcomes associated with well-being and self-management initiatives already carried out and explore learning from similar interventions in non-UK, and non-cancer, contexts. The review identified transferable facilitating factors and opportunities for maximising patient outcomes from similar situations. A summary of the scoping review can be found in Appendix 1.

### Scoping interviews

Scoping interviews were also carried out, in the form of a series of seven semi-structured telephone interviews with key stakeholders who have been involved in the set up of the clinics to varying degrees. The stakeholders were selected to provide a range of perspectives on the vision and implementation of the clinics, and included representatives from Macmillan and the National Cancer Survivorship Initiative (NCSI) and clinical leads and commissioners from across the UK. The purpose of the interviews was to identify key considerations and evidence that shaped the strategy and implementation of clinics; clarify the logic and rationale behind clinics, and their likely and intended impact; and to help ensure that the evaluation was conducted in a meaningful way and designed to support the sustainability of clinics beyond the pilot stage.

### Review of measures

A review of existing measures was conducted to inform the design of the key data collection tool, a patient questionnaire. Measures were mapped against a number of criteria to help us to assess their relevance and validity and a shortlist of potential measures was prepared to be presented to clinic leads at a consensus workshop in May 2010.

## Design and administration of evaluation tools

### Consensus workshop

At a consensus workshop in May 2010, clinic staff gave their feedback on our shortlisted data collection tools, which was used to direct the design of the final questionnaire and follow-up interview guides. A deliberative approach was adopted, which meant ensuring people who took part had the information necessary to engage with the discussion in a focused manner, that they had time to discuss and reflect on their views and that they were assured that their input will have influence on the final outputs.

The purpose of the workshop was to get attendees to articulate why certain measures may be more or less important to them, and to generate consensus about what types of information should be collected across all clinics, and what may be specific to clinics with specific characteristics. The workshop also offered an opportunity to deliver training to the clinic staff on how to administer the questionnaires to patients attending the clinics.

### Patient questionnaire

**Design:** the patient questionnaire was designed based on the review of existing measures and the feedback from the consensus workshop, to ensure that it would elicit information that will effectively demonstrate whether the clinics are meeting their objectives (broadly, to have a positive impact on patients' wellbeing and ability to self-manage). The draft questionnaire was circulated around clinic leads to give them the opportunity to feed into the final design.

**Administration:** The aim was to secure 20 patients to complete questionnaires at each of the 15 test sites. Where 20 patients were not signed up at the first attempt, further patients will be approached at subsequent clinics until the quota is met. Patients were tracked through the evaluation using a unique identifying number assigned to them by OPM. Patients completed a pre-clinic questionnaire (before attending a clinic) and two post clinic questionnaires (at 2-4 weeks after attending the clinic and at 2-3 months after attending), making a total of 60 questionnaires per site and 300 questionnaires at each stage (pre, post 1 and post 2). This totals 900 questionnaires in total across all sites; however as expected there was some attrition over the course of the evaluation and not all patients completed all three questionnaires.

- Questionnaire data were not collected in Leeds because clinics did not begin running until early 2011.

### Patient interviews

**Design:** the patient interviews were designed to elicit further detail from patients around the impact of their attendance at the clinics on their wellbeing and ability to self-manage their condition. Interviewees were also asked for their recommendations for future clinics.

**Administration:** patients were asked on completing the pre-clinic questionnaire whether they would be willing to take part in an interview. The follow-up interviews were conducted by telephone between September 2010 and March 2011. There was a target of 60 interviews with patients (4 interviews for each site, except Leeds where 14 interviews were conducted).

### **Clinic visits and interviews with staff and volunteers**

**Design:** Clinic visits provided an opportunity for the evaluators to observe the running of clinics, and also to carry out informal interviews with clinical and non-clinical staff and volunteers at the clinic, in order to gain their perspectives on the impact of the clinics on patients and recommendations for their future development.

**Administration:** each of the test sites was visited once by OPM/HPA, and the informal interviews with clinic staff and volunteers arranged in advance to ensure they could be undertaken at a time convenient to interviewees during the course of the visit.

- Two sites, Belfast and Milton Keynes, were not visited for logistical reasons. Instead an in-depth telephone interview was conducted with the clinic leads.
- Leeds was visited twice as men's and women's clinics were held separately.

### **Monitoring forms**

Macmillan produced a monitoring form to be completed and returned by clinics on a quarterly basis. The form asked clinics to give details under the following headings: progress review, issues and challenges, proposed solutions, learning points, plan for next clinics and support needed from project lead.

In order to obtain more quantitative data from clinics, OPM made a number of additions to the form. These were:

- attendance - numbers of patients, carers and volunteers attending the clinic
- referral – the different referral routes, including advertising, and numbers of patients referred via each
- clinic services – the types of services (for example presentations or stalls) offered at the clinic and an indication of take-up, to show popular the service was

In addition information about attendees' age, gender, ethnicity and cancer diagnosis was requested (except where the clinic is tumour-specific or gender-specific anyway).

Rather than submitting the returns on a quarterly basis, as was initially intended OPM recommended that test sites were asked to return a separate form after each clinic held, to ensure that each form reflects a single event rather than aggregated numbers across several events. Clinic leads were asked to validate the collated figures for their clinics in February 2011 and again in May 2011, to ensure an accurate picture of overall patient throughput.

Examples of the data collection tools (patient questionnaire, patient interview guide and monitoring form) can be found in Appendices 2-4.

## Data collected

The following table shows the quantities of data from each source collected for each pilot site. It also shows the number of clinics held at each site<sup>11</sup> and the total number of patients attending a clinic at each site.

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<sup>11</sup> The intention of the pilot was for sites to hold 4-6 clinics each. Actual numbers of clinics per site varied widely and 5 sites held fewer than 4 clinics. Reasons for this included clinic cancellations due to poor weather and sickness or turnover amongst lead staff.

**Table 1. Data collected**

Pilot site	Clinics held	Patients attended	Pre clinic questionnaires	Post-1 questionnaires	Post-2 questionnaires	Patient interviews	Clinic visit undertaken
Aintree	9	31	25	18	14	4	Y
Ayrshire & Arran	9	64	16	15	11	4	Y
Barts and the London	22	68	46	33	23	4	Y
Belfast	2	No data received	19	18	14	2	Substitute telephone interviews
Blackpool	3	21	7	5	6	2	Y
Leeds <sup>12</sup>	3	252 <sup>13</sup>	N/A	N/A	N/A	14	Y (two visits)
Lincolnshire	8	53	32	27	23	4	Y
Milton Keynes	3	26	15	10	4	4	Substitute telephone interviews
Portsmouth	5	82	35	24	18	4	Y
Rotherham	5	45	15	12	3	2	Y

<sup>12</sup> Clinics did not begin running until February 2011 and therefore questionnaire data could not be collected within the timescale of the evaluation; additional interviews were undertaken.

<sup>13</sup> In Leeds, one awareness-raising and community engagement event was held, followed by two clinic events targeted at both cancer patients and people who might be at risk of developing cancer; hence the numbers of attendees are higher than at other clinic sites.

<b>Pilot site</b>	<b>Clinics held</b>	<b>Patients attended</b>	<b>Pre clinic questionnaires</b>	<b>Post-1 questionnaires</b>	<b>Post-2 questionnaires</b>	<b>Patient interviews</b>	<b>Clinic visit undertaken</b>
Royal Liverpool	4	46	25	18	14	4	Y
Ulster	3	27	7	4	0	4	Y
Velindre (all)	7	34	31	19	20	4	Y
Velindre (CNS)	4	15	10	6	5	3	Y
<b>Total</b>	<b>87</b>	<b>764<sup>14</sup></b>	<b>283</b>	<b>209</b>	<b>155</b>	<b>59</b>	<b>15</b>

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<sup>14</sup> Please note that this total includes a large number of attendees from the Leeds clinics; see previous footnote.

## 2.2 Purpose and scope of this report

This is the final report of the evaluation and sets out the findings based on all data collected. It follows two interim reports.

- The first (September 2010) set out a full introduction to the health and wellbeing clinic pilot and the evaluation, its methodology and activities, in addition to some early findings which were aggregated across all of the pilot sites. Please refer to the September interim report for the full introduction, methodology and activities, including examples of the data collection tools used in the evaluation (patient survey and interview guide).
- The second (January 2011) reported findings up until December 2010 by pilot site, for pilot sites where sufficient data had been collected.

The interim reports are available on the Macmillan LearnZone website<sup>15</sup>.

### Structure of this report

In the **Mapping the Field** section (3), an overall commentary, based on clinic visits by the evaluation team, draws out the different types of clinic model and the strengths and success factors of each. It includes a 'map of the field' showing the characteristics of pilot sites in table form.

In the **Analysis** section (4), the report presents an overview of the findings across the field, and then compares the suggested key features of a successful clinic with the quantitative and qualitative patient data, to explore what has worked well.

The **Economic case studies** section (5) presents a summary of case studies of three sites, conducted using a cost consequence approach. The full report is available separately.

The **Value of Macmillan's involvement** from the patient perspective is set out in section 6.

In the **Conclusions** (section 7) the key findings of the evaluation are presented, in addition to some practical recommendations for future clinics.

Findings from each of the **pilot sites** can be found in the accompanying report ('Evaluation of Health and Wellbeing Clinics: Findings by Pilot Site'). They include:

- Introduction - a description of the context and activities at the clinic and its key strengths
- Patient throughput – numbers of clinics held and patients attended
- Findings - the impact on patients of attending the clinic.

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<sup>15</sup> <http://learnzone.macmillan.org.uk/>

## 3. Mapping the field

### 3.1 Introduction

This section reports findings from the site visits undertaken by the evaluation team. Following a brief overview of the fieldwork approach it explores what are considered to be potential success factors of the clinics, barriers for success and highlights strategies for overcoming the barriers. The section is summarised in a table that presents the key characteristics of the health and wellbeing clinics at each site.

### 3.2 Approach to clinic visits

The purpose of the visits was to get a real feel for how clinics were set up and run and to capture the views of clinic staff, volunteers and stallholders such as community support groups, financial support and employment advisors. Interviews enabled the evaluation team to find out staff and volunteer experience of the clinics and to what extent they think the clinics make a difference, as well as get a feel for how the clinics are being marketed and branded.

To allow for any initial teething problems pertaining to clinic and systems set up, pilot sites were visited from their second clinic or onwards. All sites received a visit from a member of the evaluation team, except for Belfast and Milton Keynes, where telephone interviews with staff and volunteers were conducted instead. Leeds received two visits, as men's and women's events were held separately.

In advance of visits, project leads were asked to set up interviews with two or three clinical staff and two or three volunteers. These were one to one semi-structured interviews lasting for forty-five minutes each. Due to the duration of the interviews and to avoid disrupting the running of the clinic, they were scheduled before and after clinics. Where this was not possible, in particular for evening visits, a repeat visit was undertaken (Royal Liverpool) or the interview was conducted by telephone (Velindre all). Interviews with stallholders, which took approximately ten minutes each, were carried out during the clinic. In Ulster, volunteers chose not to be interviewed. Project leads in the pilot areas were helpful in both setting up the interviews and welcoming the evaluation team's attendance at the clinic.

### 3.3 Findings from clinic visits

#### Clinic models/types

There are mixed approaches that the sites are taking to piloting the health and wellbeing clinics. On visiting the clinics/events it was evident that they are using different models to interpret the delivery of a health and wellbeing pilot. The pilots can be grouped into five distinct types according to the types of support and provision they offer (see table below).

It should be noted that these 'types' describe only the basic characteristics of each model; they are not necessarily fixed or mutually exclusive. Sites may have aspects of more than one type, and individual clinics within one pilot site may vary as sites experiment with different approaches or adapt to variables such as availability of staff. For example, Rotherham has varied between a 'traditional' model and a market stall. For the purposes of

this report, the categorisation of clinic type has been based on observations at the clinic sessions visited by the evaluation team.

The following table shows the clinic types and which sites have implemented each type:

**Table 2. Clinic type**

Clinic type	Pilot site
'Traditional' (presentation, market stalls, one to one sessions)	Blackpool Liverpool Ulster Leeds (men's and women's events) Belfast
Market stalls	Rotherham Lincolnshire Velindre CNS Milton Keynes
Presentations only	Ayrshire & Arran Portsmouth (plus group exercises)
Volunteer-led self management	Velindre all
Assessment	Barts & the London Aintree

### Further variations in approach

**Clinic title:** all but five of the sites visited are referring to the pilots as health and wellbeing clinics. Rotherham, Velindre all, Milton Keynes, Leeds and Lincoln use the term health and wellbeing 'events', with a view to de-clinicalising the concept (in this report we refer to 'clinics', regardless of the term used in individual pilot sites).

**Setting, timing, frequency:** the clinics/events vary in relation to their setting (clinical/non clinical), timing (day/evening) and frequency.

**Clinical/community base:** Leeds is the only site that focuses specifically on the African Caribbean community; the site was added to the pilot later than the other sites, as it was recognised there may be a need for a targeted approach to recruiting patients of BME background to attend clinics. The Leeds events are supported by a community-based voluntary sector organisation, demonstrating a bottom up, community driven approach to the events, rather than being driven by healthcare professionals in a clinical setting (as is the case in many of the sites). Leadership comes primarily from the third sector (Black Health Initiative, supported by Macmillan Information Unit at Leeds Hospital, and the Macmillan regional development manager). Clinical staff are engaged and invited to attend the events to provide presentations and core clinical messages. The Leeds pilot held a well-attended community engagement event before holding its subsequent events, which were more targeted at patients but included elements of community engagement in terms of raising awareness of signs and symptoms for those who may be at risk of developing cancer.

**Assessment/intervention:** Barts & the London, Aintree, Portsmouth and the two Velindre services deliver interventions at the clinic. The interventions are exercise/relaxation sessions and/or holistic needs assessment. Holistic needs assessments (background information, physical well-being, psychological well-being, spiritual well-being, social and occupational well-being) should be undertaken at key trigger points (point of diagnosis, start of treatment, end of treatment, survivorship, end of life) along the patient pathway. Following the assessment a care plan is drawn up and action planning takes place. Barts & the London and Aintree clinics have been set up to specifically carry out a holistic assessment of the patient's needs at the post treatment phase. Ulster and Belfast carry out a mini assessment of patients' needs (via a pre-clinic questionnaire) to shape the clinic (what stallholders and services to have present) and for booking one to one sessions with a clinician based on need (Ulster only).

**Follow-on from clinic:** Leeds women's event and Milton Keynes have specifically developed additional events/clinics to signpost participants to. Leeds has a Sister to Sister group set up, which provides specific support sessions as a follow on the health and wellbeing event. Milton Keynes run additional psychology, dietetics, welfare and benefits and complementary therapy weekly clinics, to address issues that have been raised at the health and wellbeing clinic. Belfast has negotiated with the local leisure centre and University to provide funded courses for fatigue management, to enable continued support to be provided to participants.

### **Supporting tools and processes**

Some of the clinics have developed or use specific tools and processes to support the running of the clinic. In particular:

#### Barts & the London

- have developed a tracking system to track the number of patients being seen at the clinic and what happens to them after the clinic
- use the distress thermometer to assess patients needs and a care plan
- a follow up card outlining the next stages of the treatment and possible signs and symptoms of recurrence to look for and who to contact.

#### Aintree

- use the distress thermometer for assessing patients' needs and a care plan
- have developed a clinic pro forma for completion and inclusion in the patient case notes.

#### Velindre CNS

- are developing a CD to show at the clinic, presenting information about therapy services and interventions
- have developed a health and wellbeing booklet for giving out to the patients.

#### Velindre all

- have developed a cancer rehabilitation self management folder which is used at the clinic and then for patients to take away afterwards.

#### Lincolnshire

- are developing an action planning self management toolkit based on the Macmillan self management toolkit.

#### Ulster

- have developed a pre clinic questionnaire to ascertain patients' key issues and three priority needs.

#### Belfast

- have developed a pre clinic questionnaire to ascertain patients' key issues, which are used to shape the development and running of the clinic
- developed an evaluation form which is given to patients at the end of a clinic in order to identify the next steps, such as information needs or one to one support.

#### Milton Keynes

- use the Wellbeing Outcomes Star Chart which is used to encourage self-help in patients with long term conditions, through patients identifying what needs to change and what help is needed to support the change. Additionally a Plan for Action is completed
- as the health and wellbeing clinic focuses on signposting, follow-on clinics addressing specific topics are held and patients can choose which of these to attend.

#### Leeds

- for the women's clinic, attendees complete an evaluation form about the next steps in terms of the support needed; the information is taken to a partner organisation (Sister to Sister group) to inform the hosting of further sessions.

### Clinic delivery

On visiting the clinics, the setting (whether it is clinical or a non clinical), appears to be secondary to how messages about health and wellbeing are delivered in terms of what makes an effective clinic. Information about health and wellbeing (and cancer and survivorship), and information about services to support health and wellbeing are integral to this. As outlined above, a range of approaches are being taken by the pilot sites to do this.

Good examples of **information giving** about health and wellbeing and cancer and survivorship are the clinics delivered by Ulster and Liverpool. Both pilot sites in their presentations include core messages about health and wellbeing; prognosis; signs and symptoms of recurrence; management of underpinning symptoms including self management; diet; and exercise. Another good example of promotion of health and wellbeing and awareness of cancer is the men's prostate event at Leeds. Presentations are given about prostate cancer, including symptoms and treatment options, as well as preventative messages about lifestyle choices.

A good example of a market stall **showcasing services** is Rotherham. Market stalls are tailored to the tumour site and are tied in with other local initiatives such as Jamie Oliver Ministry of Food to promote healthy living messages. Practical demonstrations are available, for instance hand massage and Indian head massages. This eclectic mix of services and delivery, along with written information provision, makes the clinic feel enticing and interesting.

The format of clinics in some sites is **sensitive to the prognoses** associated with the tumour type. A good example of this is in Aintree, where one-to-one sessions are offered rather than group sessions, because it was felt that group discussion may be less helpful for patients with lung cancer. This format is likely to be appropriate to complex cancers and palliative care clinics.

Both of the Leeds events, for men (prostate) and women (breast) are exemplars of good practice when **working with BME groups**. Intrinsic to the delivery of the events is the understanding and knowledge of the specific communities involved (for example, the reluctance of men to talk about health), and recognising that an 'entertaining' approach - providing food, music and song/acting - is an important draw to get people to attend but also as a means to get core messages across during the events.

Some of the information that is given out at health and wellbeing clinics, either through presentation or market stalls, could and should be **made available earlier** in the patient pathway because it is not necessarily information that is needed post treatment. For instance, Blackpool introduces the Urology CNS team and the service that they provide, when the patient/family would already be familiar with the team having already gone through treatment. On interviewing volunteers during the visits, many of whom have been patients, it was suggested that the information/services promoted at the health and wellbeing clinics would be valuable earlier in the pathway, possibly between diagnosis and first treatment, when it is most needed. Additionally, access to peer support or a volunteer with experience of cancer would be invaluable at that stage as well to support the patient going through the process. This observation and volunteer feedback questions whether health and wellbeing clinics should be offered only post-treatment, or could be made available further upstream.

## Resource implications

The number of clinical staff/non clinical stallholders in attendance at the clinics varies which has resource implications. This, coupled with the frequency of the clinics (weekly, monthly, quarterly), and the timing of the clinic (day or evening) will have a bearing on the likely running costs.

Based on the numbers of staff present, the following pilot sites have potentially high resource implications:

- Blackpool
- \*Royal Liverpool
- \*Ulster
- Velindre CNS
- Ayrshire & Arran
- Lincoln
- Rotherham
- Portsmouth
- Milton Keynes
- \*Belfast

\*have oncologists/surgeons present

The Leeds events have medium resource implications, in terms of costings (mainly for food and music); however there is a high ratio of volunteers to paid staff, who are integral to delivering the events.

Aintree and Barts & the London have potentially lower costs in terms of staff. Aintree is run by one CNS and two AHPs, plus a benefits advisor. Barts & the London has three CNSs running the clinic plus a co-ordinator present.

Velindre all has the lowest resource implications, in that it is volunteer-led and has only one clinician present.

## Role of volunteers

All the pilot sites use volunteers to a greater or lesser degree. For example:

- Velindre all recruited and trained volunteers to **deliver** their health and wellbeing event, which involves running through a rehabilitation self management folder and delivering a relaxation session
- Barts & the London recruited a dedicated volunteer to **support** the clinics
- Portsmouth and Lincolnshire involved volunteers from the start in **planning** the delivery of the clinics, through to post-clinic **review** meetings.
- Ayrshire & Arran and Rotherham run **buddying support** programmes in parallel with their clinics, and draw volunteers for the clinic from these programmes.

Other pilot sites use volunteers to **meet and greet**, talk to patients/families and put them at ease, make refreshments and create a relaxing atmosphere.

The **training** to support volunteers in their roles varies. Where the volunteers have a significant role to play as outlined above, they undergo a rigorous and comprehensive training programme. Velindre all, Rotherham and Ayrshire & Arran all offer robust volunteer training programmes which are valued by the volunteers. The training run by Rotherham and Ayrshire & Arran was specifically designed to support volunteer buddying support programmes.

All volunteers interviewed on the visits reported having **previous experience** of volunteering, prior to the clinics. Most had experience of cancer and of volunteering with cancer patients. They cited 'wanting to help' and to 'give something back' as the motivators for volunteering at the clinics. All valued the experience and plan to continue volunteering at the clinics.

Patients' perceptions of volunteers are described in section 4.3.

## Training for clinic staff

Other than attendance at the Learn & Share events, and training received as part of their profession, clinical staff at thirteen of the pilot sites had not received additional training to support them in their role for health and wellbeing. Lincolnshire and Milton Keynes had training from Macmillan in the use of the self management tool.

When prompted about what training would be beneficial from all the sites, the following suggestions were made by staff:

- advanced communication skills training
- presentation skills
- self management / health education training (to enable staff to empower patients to look after themselves)

- information-giving skills, for example understanding different learning styles and appropriate language to use
- group management for leading open discussions (setting ground rules, dealing with inappropriate questions, managing people who dominate discussions)
- motivational behavioural interviewing techniques e.g. for smoking cessation, fatigue management
- For partner organisations and volunteers, cancer awareness training would be beneficial, to understand more about the condition and gain familiarity with medical terminology
- One site suggested that visiting other sites to see how they are being run would have been helpful.

It may also be helpful for training to include advice to clinic staff on the role and value of volunteers, so that there is a shared understanding of what volunteers can and should contribute to the clinics.

### Impact on referral pathways and access to other services

There were some examples of clinics impacting on referral pathways, as follows:

- Easing up access to psychology services as a result of referral following undertaking the holistic needs assessment (Aintree)
- Patients have been picked up and referred to dieticians, when they may not otherwise have been, so unmet needs have been identified (Ayrshire & Arran)
- The presence of the continence service at the clinic has enabled immediate referrals to be made; whereas usually the patient would need to go via their GP to be referred to the service (Blackpool)
- Uptake of services in other organisations (for instance Breast Haven and Macmillan Support Unit in Leeds).

Where one to one sessions are available (Ulster, Aintree, Barts & the London, Portsmouth, Ayrshire & Arran, Velindre CNS) immediate referrals can be made to other services, which means that patients may be seen and have their needs met sooner.

### Success factors

**Engagement of the MDTs** is crucial to ensuring the success of the clinic, in terms of their understanding of where health and well clinics fit into the pathway as well as their individual roles in referring patients into the clinics. Barts & the London prior to starting the clinics attended the MDT site specific meetings for breast and gynae, and developed a pathway with the health and wellbeing clinic built in, which was taken to the meeting for ratification. This active engagement of the MDT is ensuring promotion of the clinics by the oncologists and surgeons who recommend attendance.

For Royal Liverpool and Ulster, members of the MDT (such as surgeons and oncologist) are actively involved in delivery of the clinic, either through presentations and/or one to one sessions. This ensures that at first hand they can see and get immediate feedback from the patients/family members about the benefits of the clinic. This was particularly the case for Ulster, which at first had little engagement of the MDT. This situation has turned around, and after the championing by one or two clinical stakeholders, now has wide engagement and

plans for rolling out the clinics post pilot phase, with the intention of eliminating follow up clinics.

**Partnership working** with a local community based organisation was integral to effective engagement of BME audiences, as the organisations and their outreach workers understand how to target and get messages across to specific groups within the community. The organisation needs to be visible within the community and integrated within it. For example, Leeds delivers health and wellbeing events through the Black Health Initiative (BHI) which is a community based organisation. BHI leads the development and the running of the events, with input and support from other health partner organisations. The involvement of BHI has enabled a **tailored approach** based on the needs of the target audience, in a number of ways:

- in terms of recruitment to the clinic, the Leeds model uses communication channels likely to reach its target BME group such as notices in church, community radio stations and shops and offers a raffle prize to incentivise people to attend (this helps to attract people who are not current or former patients but whom clinic organisers wish to reach with preventative information).
- in terms of delivery of information, understanding how people respond to health messages influences how the Leeds events are designed. For instance, women tend to be happier talking about health in a group than men, so different formats are appropriate to different events.
- in terms of the clinic environment, the Leeds events are held in the community hall, a comfortable and familiar place, rather than a clinical setting, which can be a barrier to people attending as it may be unfamiliar and intimidating. The Belfast pilot uses the cancer centre at the City Hospital, which is classed as a 'safe place' for people of different religious denominations.

Voluntary Action Rotherham (VAR) is another example of a voluntary sector organisation which has been integral to the running of the pilot.

**Dedicated administrative support time** to facilitate recruitment to the clinics, set up and delivery is core to the success of the clinic. The administration of the clinics reportedly takes between half a day and two days depending on the frequency of the clinic, as well as the pre clinic and post clinic administration required, namely invitation letters, speaking to patients, booking patients into clinics, organising the event and managing post clinic letters to GPs. Rotherham and Velindre CNS clinic have dedicated time from a co-ordinator to support the running of the clinics. Rotherham has a dedicated co-ordinator to support the monthly events, which takes roughly three days a month administrative support. Barts & the London also has a dedicated co-ordinator for their weekly clinics, which accounts for approximately half a day a week to support the pre and post clinic administrative functions. All other clinics are reliant mainly on the lead CNS/AHP to set up the clinic, and often the time for this is additional to their everyday clinical work.

**Underpinning processes** to support recruitment and clinic attendance would appear to be critical to the success of the clinics. There is a range of ways that patients are recruited to the clinics but the most successful methods in terms of uptake seem to be:

- When the clinic is integrated into the pathway and all patients are automatically invited to attend (Barts & the London)
- Consultant referral, which is happening to varying degrees

- Booking systems set up which require patients to book a place at the clinic/event (Rotherham, Portsmouth, Velindre CNS)
- Confirmation letters/phone calls (Velindre CNS, Ulster, Belfast).

**Information provision** is key to the aims of the clinics. Information about the cancer and survivorship phase and health and wellbeing, as well as about what services to access, is core to patients having improved knowledge of their cancer and survivorship and also how they can self manage their condition. Information can be delivered in two main formats:

- **verbal**, either through presentations or one to one. Staff who have a good presentation style and are comfortable with public speaking are able to deliver and communicate information in a way that will be well received by the audience. Presentations were strong at Ulster and Royal Liverpool.
- **written**, i.e. leaflets and other printed material for patients to take away from the clinic with them. Printed information was strong at Rotherham, where attendees were introduced to the stallholders so that they knew what each was offering, and, in a different way, at Aintree, where a volunteer spoke to the CNS about each patient so that the volunteer could give the patient the appropriate information to take away.

Information provision appears to work well where core messages about health and wellbeing and the specific tumour type are delivered via presentations, alongside service providers being present to give out printed information about their service.

**Volunteer support and role** at the clinic is integral to the running of clinics in many of the pilot sites. Velindre all is the only pilot which runs their health and wellbeing event by trained volunteers to promote self management. The role of most of the volunteers from the other sites tends to be 'meet and greet', providing refreshments and signposting to information. The role that they play and how they play it are key to setting the atmosphere of the clinic. For example, the volunteers at Royal Liverpool, Aintree, Lincolnshire, Velindre all, Leeds and Rotherham played a very active role in creating a welcoming and inviting and informal atmosphere at the clinics through their natural openness and chattiness with the patients. Some of the volunteers have taken on board broader roles and seem to communicate more widely with the patients and family members in terms of finding out what their needs are and signposting to staff/services, sharing stories about their own experience. This tends to be the case where the volunteers have a peer support background or are actively part of a peer support programme, and have been trained to do this. Examples where this happened are Rotherham, Ayrshire & Arran and Lincolnshire (some of the volunteers independently provide peer support at the hospital).

## Barriers to success and strategies for overcoming them

**Capacity of numbers** going through the clinic is a potential barrier to the success of the clinic in terms of scalability. Many sites have reported low numbers of attendance at different times of the running of the pilot. The set up of the clinic, as well as the frequency of the running of the clinic will have a bearing on the capacity of numbers of patients attending the clinic. For example, the Aintree clinic has been set up to provide a comprehensive holistic assessment of patient needs through a forty five minute one to one session with their CNS or AHP. With two to three professionals present at the clinic, which runs for two to three hours, the maximum number of patients that can be seen at one clinic is twelve.

*Overcoming barrier*

CNSs know how many patients are approaching the appropriate point in the pathway for health and wellbeing at any one time, and where numbers are low, pilot sites may wish to offer the clinic/event to other tumour sites, or offer a generic clinic (non tumour specific). For example, at Velindre CNS, as it is piloting the clinic to patients with rarer tumour types, the numbers available to attend is limited. There are opportunities therefore for extending the clinic offer to patients with other tumour types, which will provide a broader test bed.

For Barts & the London and Aintree, which have limited capacity due to the length of time required to carry out an assessment, in terms of scalability more staff would be needed to run the clinic or the assessment time would need to be reduced. An alternative, potentially more cost efficient, way of running the clinic may be to have patients self-complete the assessment prior to seeing the clinician. This could be done either at home, or at the clinic in the waiting area.

**Awareness of and 'buy-in' to the clinic.** A lack of patient awareness and staff awareness are potential barriers to the success of the clinic, in relation to referral and uptake. All pilot sites have been active in promoting the clinic and have used a variety of methods to do this such as GP visits, posters, mail drop, radio and newspaper advertising, and promotion in community venues such as churches and shops. However, in addition to these promotional activities the MDTs and clinical staff such as CNSs need to be widely engaged with and understand the purpose of the clinic.

#### *Overcoming barrier*

If MDTs and clinical staff understand the purpose and potential benefits of the clinic/event to patients, they may be more likely to make referrals. Also the identification of clinical champions is important to influence colleagues. At Barts & the London, for example, the clinic was promoted at an MDT meeting before commencing, so that the MDT would be fully aware of it. Patient understanding of the clinic is also key, and the expectation that patients should attend may make a difference to uptake. Also at Barts, at the point of diagnosis the CNSs tell the patient about the health and wellbeing clinic post treatment and this sets the expectation that they need to attend. Furthermore, the clinic has been built into the pathway, which has been signed off by the MDTs. In Leeds, as the events are community based, there needs to be a link/lead within the Trust/network identified to ensure awareness of the events amongst clinicians; integration of health and wellbeing into the clinical pathway.

**Accessibility** of the clinic location/venue can be a barrier. Velindre CNS clinic is run at the hospital in the evening, and some patients have a long trip across the Valleys to get there. This combination of distance plus the evening timing could be a barrier to uptake of the clinic. For those clinics that are held in a clinical environment (Aintree and Velindre CNS), patients having to return to the place where they received treatment may not always be conducive to them wanting to attend the clinic.

#### *Overcoming barrier*

A sensible strategy is in place in some pilot areas, including Lincolnshire, Ayrshire & Arran, Rotherham, Velindre all and Blackpool, where clinics are rotated around different settings, to see if this makes a difference to the uptake of the clinic and to test out what setting works best for their population. Trying out different times of day may also be useful to maximise accessibility by ensuring that patients can get to a clinic at time convenient to them.

**Lack of capacity in onward services** can be a barrier. Needs may be identified at the clinics but the onward services that patients require to meet these needs may not be available, as is the case in Belfast where there is a shortage of sexual functioning and

continence services for prostate cancer patients. This results in unmet needs being identified, but not subsequently addressed.

#### *Overcoming barrier*

Where gaps in services have been identified in this way, sites should continue to collect data on the need for services and develop a costed case for change to influence commissioners.

There may also be opportunities for looking outside traditional healthcare providers, for instance to leisure centres/universities to run funded places for services such as exercise.

## Summary

The table entitled Overview of pilot sites (following page) summarises the key characteristics of the health and wellbeing clinics discussed in this section. It is expected that some of the differences between the clinics may also be reflected in the different experiences of patients as evidenced in their quantitative survey ratings and qualitative comments. Some of these relationships are examined in the next section of this report. Key variables include:

### **Clinic type**

- Traditional, market stall only, presentation only, volunteer led self-management, assessment clinic

### **Effective information giving**

- Through presentations: Ulster, Liverpool, Leeds
- Printed information: Rotherham

### **Resource use**

- High: Blackpool, Liverpool, Ulster, Velindre CNS, Ayrshire and Arran, Lincolnshire, Rotherham, Milton Keynes, Belfast, Portsmouth
- Lower: Aintree, Barts and the London, Leeds
- Least: Velindre all

### **Robust volunteer training**

- Velindre all, Ayrshire and Arran, Rotherham

### **Good engagement with MDT**

- Barts and the London, Liverpool, Ulster

### **Underpinning processes to support engagement**

- Barts and the London, Velindre CNS, Ulster, Portsmouth

### **Dedicated admin support time**

- Rotherham, Velindre CNS, Barts and the London

**Partnership working**

- Leeds, Rotherham

**Table 3. Overview of pilot sites' characteristics**

Type of clinic	Pilot site	Setting	Patient selection	Volunteer presence	Buddying System	HWB as part of pathway?	Assessment/ Care planning	Supporting Tools	Resource Implications	Part of re-design of follow up
Traditional (presentations, market stall)	Blackpool (urology)	Charity building	Invite	Mid	No	No	No	No	High	No
	Royal Liverpool (breast and bladder)	Education centre Hospital	Invite	Strong	No	No	No	No	High	No
	Ulster (plus allocated one to one sessions) (breast)	Breast Clinic	Invite	Mid	No	Yes	No – but written in notes in one to one session and copy to GP	Pre clinic assessment questionnaire	High	Planned
	Belfast (urology)	Cancer Centre	Invite	Strong	No	No	No	Pre clinic assessment questionnaire	High	No
	Leeds (women - breast)	Community centre	Invitation and promotion	Strong	No	No	No	Post event evaluation form for signposting to other services	Medium	No
	Leeds (men - prostate)	Community centre	Invitation and promotion	Strong	No	No	No	No	Medium	No
Market stall only	Rotherham (women's)	Community halls (rotated around a number)	Invitation and promotion	Strong (experience of cancer)	Yes in parallel	No	No	No	High	No
	Lincolnshire (prostate) +	Town & Country Club; football club	Drop in	Strong – all male cancer	No	For prostate	No	Macmillan Self	High	No

Type of clinic	Pilot site	Setting	Patient selection	Volunteer presence	Buddying System	HWB as part of pathway?	Assessment/ Care planning	Supporting Tools	Resource Implications	Part of re-design of follow up
	optional session with clinician			patients/experience of cancer				management to be used		
	Velindre CNS	Velindre hospital	Invite	Strong	No	No	No	Being developed	High	No
	Milton Keynes (haematology)	Macmillan Unit Hospital setting	Invite plus posters	Strong	No	No	No	Star Chart and action plan	Medium	No
Presentations only	Ayrshire & Arran (all)	Health/Community Centre conference room	Invite	Strong non branded – all cancer patients/experience of cancer	Yes in parallel with rehab support programme	No	No	No	High	No
	Portsmouth (breast)	Macmillan Cancer Centre Queen Alexandra Hospital	Invite	Strong	No	No	No	No	High	No
Volunteer led self management	Velindre (all)	Library	Self selecting	Strong – all cancer patients/experience of cancer	No	No	No	Rehab folder with care plan	Low	No
Assessment clinic	Aintree (lung)	Lung clinic	Scheduled appointment time	Mid – all from hospice	No	No	Yes (distress thermometer) in notes, copy to patient and GP	Holistic needs assessment	Medium/Low	No
	Barts (breast & gynae)	Breast clinic	Scheduled appointment time	None at clinic visited; dedicated volunteer since recruited.	No	Yes – systematised approach for booking and selection for all patients	Yes (distress thermometer) in notes, copy to patient and GP	Holistic needs assessment	Medium	No

## 4. Analysis

This section has four parts:

- 4.1 an explanation of the methodology used in the analysis
- 4.2 the quantitative patient findings
- 4.3 an overview of the findings: what impact did the clinics have?
- 4.4 analysis of the findings in relation to clinic characteristics: what worked well?

### 4.1 Analysis methodology

#### Calculating change over time

To measure change over time in the patient questionnaire responses, 'change scores' are calculated. Change scores indicate the change in responses to questions or statements, between three points in time: before attending a clinic ('baseline'), 2-4 weeks after the clinic ('post-1'), and finally 2-3 months after the clinic ('post-2').

At each stage (baseline, post-1 and post-2), for question 1, we calculate the sum of patients who 'strongly agree', 'agree' or 'somewhat agree', and then calculate the difference between the three figures<sup>16</sup>. For question 2, we calculate the difference between numbers of patients who have 'no problems'<sup>17</sup> and the difference between the health thermometer scores<sup>18</sup>. For question 3, we calculate the difference between numbers of patients using services more and less<sup>19</sup>.

The result is the change score, which is expressed as a percentage.

#### Interpreting change scores

Change scores should be interpreted as follows.

##### **Changes in self-care knowledge and confidence (question 1):**

- a positive score indicates a move towards agreement with the statement
- a negative score indicates a move away from agreement with the statement
- a neutral score (0) indicates no change.

##### **EQ-5D measure (question 2):**

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<sup>16</sup> Respondents indicate their level of agreement with statements about self-care knowledge and confidence, on the following scale: strongly agree, agree, somewhat agree, somewhat disagree, disagree, strongly disagree.

<sup>17</sup> Respondents indicate their wellbeing in areas including mobility and anxiety, on the scale: no problems, some problems, severe problems.

<sup>18</sup> Respondents indicate their overall health state, on a scale of 0-100 (0 representing worst imaginable health state and 100 representing best imaginable health state)

<sup>19</sup> Respondents indicate changes in service use, on the scale: use more, use the same, use less.

Wellbeing measures:

- a positive score indicates an increase in patients stating they have no problems
- a negative score indicates a decrease in patients stating they have no problems
- a neutral score (0) indicates no change.

Health thermometer:

- a positive score indicates an improved overall health state
- a negative score indicates a worsened overall health state.

**Changes in service use (question 3):**

- a positive score indicates an increase in service use
- a negative score indicates a decrease in service use
- a neutral score (0) indicates no change.

**Example:**

*Percentage of patients who agree<sup>20</sup> with a statement at baseline (pre-clinic): 30%*

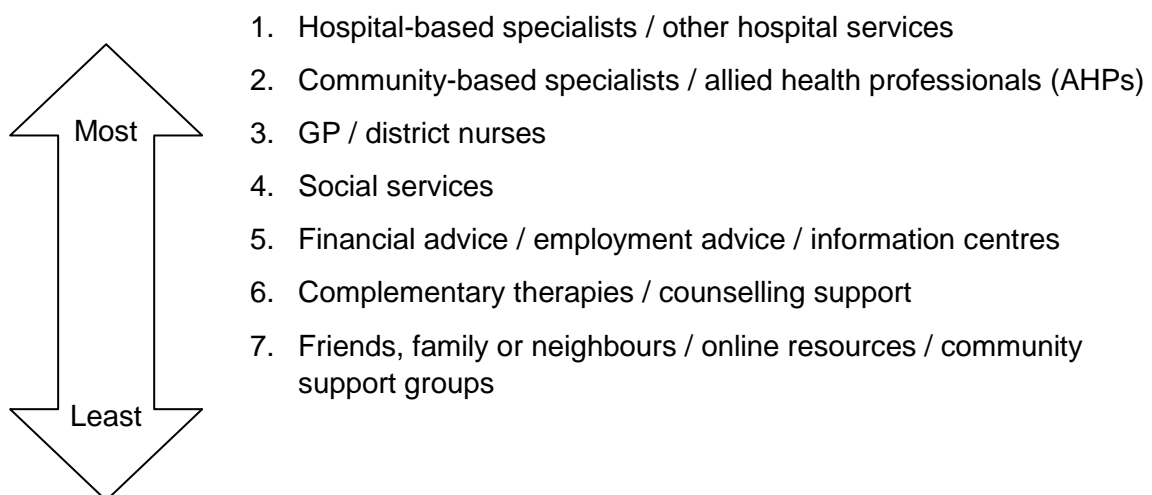
*Percentage of patients who agree with a statement at post-1 (2-4 weeks): 40%*

*Percentage of patients who agree with a statement at post-2 (2-3 months): 55%*

At 2-4 weeks, there was a 10% increase (from baseline) in patients agreeing with the statement. At 2-3 months, this increase was sustained, with a 25% increase in patients agreeing (compared to baseline).

## Presentation of service use data

At post-1 and post-2, respondents to the questionnaire indicated changes in how much they were using a range of different services and sources of support, compared to before attending a clinic. For the purposes of analysis, some of these services and sources of support have been aggregated into categories according to their approximate cost. In order of costliness, with the most costly being first, the categories are as follows:



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<sup>20</sup> 'Agree' refers to the sum of patients selecting 'agree', 'strongly agree' or 'somewhat agree', to reflect overall level of agreement.

## 4.2 Quantitative findings

The tables below present the change scores for the pilot sites. The second column of the tables shows the actual numbers of patients completing questionnaires at each of the three points in time. It is important to note that:

- across all sites, numbers are different at each of the three points in time, with the general trend being that most questionnaires were completed at baseline stage (total 283), fewer at post-1 (total 209), and fewer again at post-2 (total 155)
- different numbers of questionnaires were returned from different pilot sites

Where numbers are lower, findings should be interpreted with more caution.

Colour coding is used in the tables to highlight the direction of change, as follows:

- green = move towards agreement (question 1); fewer health and wellbeing concerns (question 2); or decrease in service use (question 3)
- amber = no change
- red = move away from agreement (question 1); more health and wellbeing concerns (question 2); or increase in service use (question 3)

Table 3.1 Knowledge, confidence and wellbeing (1)

Pilot site	Number of patients pre / post-1 / post-2	I know how to cope with further problems concerning my health condition (q1a)			I am aware of the different treatment and support options open to me (q1b)			I am confident that managing my own health will reduce the need to see a doctor (q1c)		
		% change			% change			% change		
		Baseline-post 1	Baseline - post 2	Post 1 - post 2	Baseline-post 1	Baseline - post 2	Post 1 - post 2	Baseline-post 1	Baseline - post 2	Post 1 - post 2
Aintree	25 / 18 / 14	3	22	19	19	16	-3	8	15	7
Ayrshire and Arran	16 / 15 / 11	12	1	-11	12	10	-2	-7	-13	-6
Barts and the London	46 / 33 / 23	8	20	12	9	24	15	6	21	15
Belfast	19 / 18 / 14	4	14	10	-6	9	15	4	1	-3
Blackpool	7 / 5 / 6	29	30	1	28	28	0	28	28	0
Lincolnshire	32 / 27 / 23	20	19	-1	11	16	5	3	3	0
Milton Keynes	15 / 10 / 4	7	-43	-50	6	-44	-50	7	-43	-50
Portsmouth	35 / 24 / 18	15	3	-12	26	19	-7	0	-9	-9
Rotherham	15 / 12 / 3	0	0	0	6	6	0	-3	13	16
Royal Liverpool	25 / 18 / 14	25	15	-10	18	11	-7	1	5	4
Ulster	7 / 4 / 0	28	N/A	N/A	15	N/A	N/A	15	N/A	N/A
Velindre (all)	31 / 19 / 20	11	21	10	12	18	6	0	15	15
Velindre (CNS)	10 / 6 / 5	3	20	17	3	20	17	4	20	16

Table 3.2 Knowledge, confidence and wellbeing (2)

Pilot site	Number of patients pre / post-1 / post-2	I know what to look for in terms of new symptoms or changes to my body (q1d)			I feel confident that I can keep the fatigue caused by my health condition from interfering with the things I want to do (q1e)			I feel able to question or challenge information about my condition if necessary (q1f)		
		% change			% change			% change		
		Baseline-post 1	Baseline - post 2	Post 1 - post 2	Baseline-post 1	Baseline - post 2	Post 1 - post 2	Baseline-post 1	Baseline - post 2	Post 1 - post 2
Aintree	25 / 18 / 14	20	20	0	6	1	-5	-3	10	13
Ayrshire and Arran	16 / 15 / 11	12	8	-4	6	1	-5	-3	9	12
Barts and the London	46 / 33 / 23	4	26	22	14	25	11	-3	2	5
Belfast	19 / 18 / 14	-6	7	13	-7	2	9	-11	-9	2
Blackpool	7 / 5 / 6	57	23	-34	57	41	-16	1	1	0
Lincolnshire	32 / 27 / 23	8	14	6	14	18	4	-3	5	8
Milton Keynes	15 / 10 / 4	3	-37	-40	20	-5	-25	7	-18	-25
Portsmouth	35 / 24 / 18	32	20	-12	21	12	-9	1	4	3
Rotherham	15 / 12 / 3	0	0	0	17	-7	-24	-8	0	8
Royal Liverpool	25 / 18 / 14	-11	-1	10	4	-16	-20	-8	-10	-2
Ulster	7 / 4 / 0	3	N/A	N/A	29	N/A	N/A	14	N/A	N/A
Velindre (all)	31 / 19 / 20	15	20	5	14	20	6	12	12	0
Velindre (CNS)	10 / 6 / 5	-14	20	34	3	20	17	9	10	1

Table 3.3 Knowledge, confidence and wellbeing (3)

Pilot site	Number of patients pre / post-1 / post-2	I feel confident making my own health related decisions (q1g)			I feel able to take part in social activities (q1h)			I feel confident that I can keep the physical discomfort or pain of my health condition from interfering with the things I want to do (q1i)		
		% change			% change			% change		
		Baseline-post 1	Baseline - post 2	Post 1 - post 2	Baseline-post 1	Baseline - post 2	Post 1 - post 2	Baseline-post 1	Baseline - post 2	Post 1 - post 2
Aintree	25 / 18 / 14	-13	14	27	13	19	6	17	2	-15
Ayrshire and Arran	16 / 15 / 11	-2	13	15	0	-3	-3	12	-3	-15
Barts and the London	46 / 33 / 23	-4	11	15	-5	-3	2	4	17	13
Belfast	19 / 18 / 14	-6	8	14	1	0	-1	3	-16	-19
Blackpool	7 / 5 / 6	43	43	0	0	0	0	-20	-16	4
Lincolnshire	32 / 27 / 23	0	-1	-1	-4	-8	-4	4	16	12
Milton Keynes	15 / 10 / 4	6	6	0	33	33	0	20	-5	-25
Portsmouth	35 / 24 / 18	15	6	-9	3	-16	-19	18	-5	-23
Rotherham	15 / 12 / 3	5	12	7	6	6	0	6	5	-1
Royal Liverpool	25 / 18 / 14	1	16	15	-9	1	10	-12	-16	-4
Ulster	7 / 4 / 0	-25	N/A	N/A	15	N/A	N/A	-11	N/A	N/A
Velindre (all)	31 / 19 / 20	14	20	6	-5	11	16	4	-1	-5
Velindre (CNS)	10 / 6 / 5	14	30	16	9	10	1	13	30	17

Table 3.4 Knowledge, confidence and wellbeing (4)

Pilot site	Number of patients pre / post-1 / post-2	I feel confident that I can keep the emotional distress caused by my health condition from interfering with the things I want to do (q1j)		
		% change		
		Baseline-post 1	Baseline - post 2	Post 1 - post 2
Aintree	25 / 18 / 14	-13	-21	-8
Ayrshire and Arran	16 / 15 / 11	12	-8	-20
Barts and the London	46 / 33 / 23	-3	13	16
Belfast	19 / 18 / 14	-1	-3	-2
Blackpool	7 / 5 / 6	-5	15	20
Lincolnshire	32 / 27 / 23	8	8	0
Milton Keynes	15 / 10 / 4	34	9	-25
Portsmouth	35 / 24 / 18	17	-3	-20
Rotherham	15 / 12 / 3	-3	14	17
Royal Liverpool	25 / 18 / 14	4	3	-1
Ulster	7 / 4 / 0	-11	N/A	N/A
Velindre (all)	31 / 19 / 20	7	13	6
Velindre (CNS)	10 / 6 / 5	3	20	17

Table 4.1 EQ-5D (1)

Pilot site	Number of patients pre / post-1 / post-2	Mobility (q2a)			Self care (q2b)			Usual activities (e.g. work, study, housework, family or leisure activities) (q2c)		
		% change			% change			% change		
		Baseline-post 1	Baseline - post 2	Post 1 - post 2	Baseline-post 1	Baseline - post 2	Post 1 - post 2	Baseline-post 1	Baseline - post 2	Post 1 - post 2
Aintree	25 / 18 / 14	7	-3	-10	0	-1	-1	-1	9	10
Ayrshire and Arran	16 / 15 / 11	-3	8	11	6	-3	-9	9	7	-2
Barts and the London	46 / 33 / 23	1	2	1	-4	7	11	-7	0	7
Belfast	19 / 18 / 14	-1	9	10	5	11	6	-7	1	8
Blackpool	7 / 5 / 6	-11	-4	7	0	0	0	3	10	7
Lincolnshire	32 / 27 / 23	-4	-4	0	5	-6	-11	-6	-12	-6
Milton Keynes	15 / 10 / 4	17	2	-15	-3	7	10	10	15	5
Portsmouth	35 / 24 / 18	-8	-16	-8	-5	-14	-9	10	4	-6
Rotherham	15 / 12 / 3	-4	13	17	0	0	0	-2	7	9
Royal Liverpool	25 / 18 / 14	-3	0	3	3	13	10	-4	-19	-15
Ulster	7 / 4 / 0	-7	N/A	N/A	-11	N/A	N/A	21	N/A	N/A
Velindre (all)	31 / 19 / 20	-13	-15	-2	-2	-6	-4	-19	-15	4
Velindre (CNS)	10 / 6 / 5	33	30	-3	40	0	-40	20	10	-10

Table 4.2 EQ-5D (2)

Pilot site	Number of patients pre / post-1 / post-2	Pain/discomfort (q2d)			Anxiety/depression (q2e)			Health thermometer (q2f)		
		% change			% change			% change		
		Baseline-post 1	Baseline - post 2	Post 1 - post 2	Baseline-post 1	Baseline - post 2	Post 1 - post 2	Baseline-post 1	Baseline - post 2	Post 1 - post 2
Aintree	25 / 18 / 14	8	9	1	-1	-4	-3	-3	-2	1
Ayrshire and Arran	16 / 15 / 11	-5	7	12	23	29	6	0	10	10
Barts and the London	46 / 33 / 23	7	6	-1	-4	13	17	-3	3	6
Belfast	19 / 18 / 14	4	23	19	-8	-15	-7	2	5	3
Blackpool	7 / 5 / 6	23	-7	-30	30	17	-13	-3	-3	0
Lincolnshire	32 / 27 / 23	10	4	-6	8	4	-4	0	5	5
Milton Keynes	15 / 10 / 4	-13	2	15	-10	-10	0	12	19	7
Portsmouth	35 / 24 / 18	5	13	8	1	-4	-5	0	-3	-3
Rotherham	15 / 12 / 3	-34	0	34	0	0	0	-1	16	17
Royal Liverpool	25 / 18 / 14	-16	-3	13	-10	-10	0	-3	3	6
Ulster	7 / 4 / 0	0	N/A	N/A	-18	N/A	N/A	18	N/A	N/A
Velindre (all)	31 / 19 / 20	5	-1	-6	-20	-17	3	9	2	-7
Velindre (CNS)	10 / 6 / 5	7	0	-7	30	10	-20	7	2	-5

Table 5.1 Service use (1)

Pilot site	Number of patients pre / post-1 / post-2	Hospital-based specialist or other hospital			Community based specialists/Allied health			GP / district nurse		
		% change			% change			% change		
		Baseline-post 1	Baseline - post 2	Post 1 - post 2	Baseline-post 1	Baseline - post 2	Post 1 - post 2	Baseline-post 1	Baseline - post 2	Post 1 - post 2
Aintree	25 / 18 / 14	4	11	6	-10	-15	-5	0	-50	-50
Ayrshire and Arran	16 / 15 / 11	-24	-43	-19	-21	-38	-17	-23	-63	-40
Barts and the London	46 / 33 / 23	-23	-33	-11	3	-47	-50	-2	-17	-15
Belfast	19 / 18 / 14	-15	-40	-25	-35	-50	-15	-18	-47	-28
Blackpool	7 / 5 / 6	-20	-25	-5	0	-75	-75	0	-71	-71
Lincolnshire	32 / 27 / 23	15	3	-12	0	5	5	13	-62	-75
Milton Keynes	15 / 10 / 4	-17	-80	-63	13	-50	-63	-10	-80	-70
Portsmouth	35 / 24 / 18	-7	-21	-15	-6	-20	-14	-13	-33	-21
Rotherham	15 / 12 / 3	-12	50	62	-13	50	63	-24	-100	-76
Royal Liverpool	25 / 18 / 14	-30	-7	23	-38	-38	1	-13	-53	-40
Ulster	7 / 4 / 0	-33	N/A	N/A	-33	N/A	N/A	-43	N/A	N/A
Velindre (all)	31 / 19 / 20	-16	-8	8	7	-14	-21	-17	-88	-71
Velindre (CNS)	10 / 6 / 5	17	-14	-31	33	0	-33	25	-100	-125

Table 5.2 Service use (2)

Pilot site	Number of patients pre / post-1 / post-2	Social services			Financial / employment advice / Information centres			Complementary therapies / counselling		
		% change			% change			% change		
		Baseline-post 1	Baseline - post 2	Post 1 - post 2	Baseline-post 1	Baseline - post 2	Post 1 - post 2	Baseline-post 1	Baseline - post 2	Post 1 - post 2
Aintree	25 / 18 / 14	-38	-17	21	-20	-40	-20	-8	17	25
Ayrshire and Arran	16 / 15 / 11	-83	-67	17	-26	-36	-10	-7	-33	-27
Barts and the London	46 / 33 / 23	-44	-57	-13	-19	-63	-44	-3	-27	-24
Belfast	19 / 18 / 14	-29	-25	4	-38	-25	13	-40	-63	-23
Blackpool	7 / 5 / 6	0	-100	-100	-25	-100	-75	0	-100	-100
Lincolnshire	32 / 27 / 23	0	-43	-43	17	-4	-21	6	-38	-45
Milton Keynes	15 / 10 / 4	-33	-400	-367	-11	0	11	30	50	20
Portsmouth	35 / 24 / 18	-40	-80	-40	-22	-40	-18	-13	-20	-8
Rotherham	15 / 12 / 3	-75	0	75	-43	0	43	0	100	100
Royal Liverpool	25 / 18 / 14	-33	-67	-33	-11	-36	-25	11	-33	-44
Ulster	7 / 4 / 0	-33	N/A	N/A	-14	N/A	N/A	0	N/A	N/A
Velindre (all)	31 / 19 / 20	-60	-14	46	-25	-13	13	-8	5	13
Velindre (CNS)	10 / 6 / 5	0	0	0	0	0	0	33	50	17

Table 5.3 Service use (3)

Pilot site	Number of patients pre / post-1 / post-2	Family, friends / online resources / community support groups		
		% change		
		Baseline-post 1	Baseline - post 2	Post 1 - post 2
Aintree	25 / 18 / 14	6	-20	-26
Ayrshire and Arran	16 / 15 / 11	10	0	-10
Barts and the London	46 / 33 / 23	0	-24	-24
Belfast	19 / 18 / 14	-13	-6	8
Blackpool	7 / 5 / 6	-17	-50	-33
Lincolnshire	32 / 27 / 23	24	-3	-27
Milton Keynes	15 / 10 / 4	6	-25	-31
Portsmouth	35 / 24 / 18	6	-25	-31
Rotherham	15 / 12 / 3	0	0	0
Royal Liverpool	25 / 18 / 14	13	-11	-24
Ulster	7 / 4 / 0	-18	N/A	N/A
Velindre (all)	31 / 19 / 20	22	3	-19
Velindre (CNS)	10 / 6 / 5	25	10	-15

## 4.3 Overview of findings

This section presents an overview of the findings across the pilot sites, drawing out the impact of the clinics in relation to their quality, productivity and preventative aspects (which form part of the QIPP agenda<sup>21</sup>; the innovation aspect of the clinics in relation to the QIPP agenda is discussed in the concluding section, 7).

### Key messages

- **Prevention:** increases in patient knowledge, confidence and wellbeing reflect a strong preventative function of the clinics, indicating that patients are better able to self-manage, to identify symptoms for concern and to address these by seeking appropriate services in a timely manner.
- **Productivity:** reductions in the use of resource-intensive health services, and changes in the use of wider wellbeing-related services (such as financial advice and counselling), reflect a strong performance in terms of productivity.
- **Quality:** positive feedback from patients about the clinics, including positive interactions with volunteers, reflects a good quality of patient experience.

The principle source of data is the quantitative data (patient questionnaires)<sup>22</sup>; this is supplemented by qualitative interview data where relevant. Key trends in terms of changes in patients' knowledge and confidence to self-manage, and changes in service use are discussed, based on the numbers of positive and negative scores for each of the patient variables.

- Please note that one of the 13 sites did not return post-2 data, therefore the maximum possible number of positive or negative scores for any variable at post-1 is 13, while the maximum possible number of positive or negative scores at post-2 is 12.

### Prevention: impact of clinics on patients' knowledge, confidence and wellbeing

#### Prevention: summary

- Knowledge (of symptoms and treatment) and confidence (to manage health concerns) are thought to be key components of patients' ability to self-manage, which is likely to reduce their reliance on services. Positive changes in patients' knowledge and confidence were evident in the majority of sites.
- Average increase in levels of agreement with all of the statements in question 1 (regarding knowledge, confidence and wellbeing) from baseline to post 1 and post 2 (that is, a greater number of sites showed a move towards agreement than showed a move towards disagreement, for every statement).

<sup>21</sup> The QIPP Programme, see Department of Health website at <http://www.dh.gov.uk/en/Healthcare/Qualityandproductivity/QIPP/index.htm>

<sup>22</sup> except for Leeds where quantitative data were not collected

- Overall ability to cope with health problems increased across the sample as a whole, as evidenced through the strong movement towards agreement with the statement, *I know how to cope with further problems concerning my health condition* (1a). At post-1, 12 out of 13 sites showed a positive score (the remaining site showed no change); at post-2, 10 sites continued to show a positive score, with over half (7) of these having maintained or increased the level of agreement since post-1.
- There was also some change in the confidence of patients to manage physical pain and discomfort, including fatigue.

## Knowledge

Across the field, clinics performed strongly in relation to the two variables indicating changes in patients' knowledge: awareness of treatment and support options, and knowledge of symptoms.

Knowledge was increased particularly in the shorter term (between baseline and post-1), when it may be assumed that information received at a clinic is still fresh in the minds of patients. Increases in knowledge were generally maintained in about half of sites between post-1 and post-2.

- *I am aware of the different treatment and support options open to me* (1b)
  - All but one of the sites (12 out of 13) show a move towards agreement between baseline and post-1
  - All but one of the sites (11 of 12) continue to show positive scores at post-2, in relation to baseline, with over half (7) having maintained or increased their level of agreement since post-1.
  - The one site which showed a negative score at post-1 reversed the direction of change at post-2, when a positive score compared to baseline was shown.
- *I know what to look for in terms of new symptoms or changes to my body* (1d)
  - A move towards agreement was observed for two thirds of sites (9 of 13) between baseline and post-1; and about the same (9 of 12 sites) at post-2.
  - Eight sites maintained or increased their level of agreement at post-2, compared to post-1.

## Confidence

In terms of patients' confidence to address their health concerns, change scores for three variables (reduction in the need to see a doctor; confidence to make health decisions; ability to question health information) suggest an overall increase in confidence across the sample.

For the second two variables, the increase from baseline was more marked at post-2 than at post-1, suggesting that confidence may grow over time, with patients' experience of managing their own health.

- *I am confident that managing my own health will reduce the need to see a doctor* (1c)
  - Levels of agreement increased (in 9 of 13 sites) or stayed the same (in 2 of 13 sites) for the majority of sites between baseline and post-1.

- At post-2, this positive picture was broadly maintained, with three quarters of sites (9 of 12) continuing to show an increase in levels of agreement since baseline; 8 of these maintained or increased the level between post-1 and post-2.
- *I feel confident making my own health-related decisions (1g)*
  - Just over half of sites (7 of 13) showed an overall increase in patients' agreement at post-1 as compared to at baseline.
  - At post-2, a further increase since baseline was visible, with patients at 11 out of 12 sites agreeing with the statement.
  - Ten sites maintained or increased their agreement between post-1 and post-2.
- *I feel able to question or challenge information about my health if necessary (1f)*
  - Less increase overall than the previous statement discussed, but a similar pattern in that patients at around half of the sites (6 of 13) increased their levels of agreement between baseline and post-1, but more sites – 8 of 12 – had increased their levels of agreement by post-2.
  - Ten sites showed an increase from post-1 to post-2.

Qualitative findings on the themes of knowledge and confidence reinforce the quantitative data, with the majority of patients agreeing that their knowledge of symptoms and of the available support options was increased by a clinic, and for many this led to them feeling more confident about managing their own recovery.

### Physical wellbeing

As well as confidence to manage health concerns in terms of seeking support, using information and making decisions, as discussed above, patients also benefited, although to a lesser extent, from increased confidence to manage their physical health.

Patients showed the most positive initial results in terms of managing fatigue.

#### *Physical discomfort and fatigue*

Confidence to manage fatigue and physical discomfort or pain is a key factor in patients' wellbeing, and a mixed picture was presented in terms of change. Initial improvements in confidence seemed to rise at post-1 and subsequently fall slightly by the post-2 stage, for both fatigue and physical discomfort.

- *I feel confident that I can keep the fatigue caused by my health condition from interfering with the things I want to do (1e)*
  - Patients in the majority of sites showed an increase in agreement between baseline and post-1 (12 out of 13 sites) and between baseline and post-2 (9 out of 12 sites).
  - While this is broadly positive, there was a decrease in levels of agreement between post-1 and post-2 for over half of sites (7 out of 12), suggesting that the initial spike in confidence to manage fatigue was not sustained for all patients.
- *I feel confident that I can keep the physical discomfort or pain caused by my health condition from interfering with the things I want to do (1i)*
  - Agreement was slightly lower than for the statement on fatigue.
  - An initial increase in agreement at post-1 (in 10 sites of 13) dropped off by post-2 (when 5 sites of 12 showed positive scores).

- Two thirds of sites (8 out of 12) showed decreases in their scores between post-1 and post-2, suggesting that confidence to manage physical discomfort was not sustained for all patients.

In interviews, about a third of patients reported improved physical wellbeing after a clinic. Fatigue management was one of the most frequently mentioned factors. For some patients, simply understanding that it is usual to experience fatigue led them to feel more able to cope with it; for others, advice received at the clinic on techniques for coping with fatigue was useful. The other frequently mentioned factor for those reporting improved physical health was advice on diet and exercise received at the clinic or referrals received to physiotherapy/dietician services. Information about side effects also played a part, with some patients having changed their medication as a result.

## Productivity: impact of clinics on service use

### Productivity: summary

- Across the sample as a whole, overall reductions in service use were reported by patients across the majority of services.
- Reductions are particularly notable for health and social care services, which are the more resource-intensive ones.
- Results suggest that the clinics may be having a positive impact in terms of reducing patients' need to access costly health and social services.
- Changes in patient-reported use of other services or support, such as complementary therapies, which tend to be less resource-intensive compared to health and social services, suggest that the clinics may also be affecting patterns of use of these services.

### Use of health and social services

Across all three health service categories (hospital; community/AHP; GP/district nursing):

- at least two thirds of pilot sites showed no change or reductions in patient-reported usage between baseline and post-1 (the vast majority of these showed reductions).
- this trend was sustained or increased at post-2 in relation to baseline, i.e. service use generally continued to reduce, for all three categories of service.

There were no increases in the use of social services reported by patients at any site between baseline and post-2.

- **GP or district nursing** services showed the most notable and sustained change in the health category.
  - Patient-reported use of these services in 11 of 13 sites either decreased (9 sites), or showed no change in (2 sites), between baseline and post-1. At post-2, however, all 12 sites showed decreased patient-reported usage, representing decrease from post-1 to post-2 across all sites.
- **Community-based specialists or AHPs** followed a similar pattern to that of GP/district nurse use, although there was slightly less overall reduction than in that category.
  - Patients at about half of sites (7 of 13) decreased their use of community-based specialists or AHPs at post-1, and slightly more by post-2 (9 of 12).

- **Hospital-based** service use was reported to have decreased by patients in about three quarters of sites at post-1 (10 out of 13) and at post-2 (9 out of 12 sites) compared to baseline.
  - About the same number showed a decrease between post-1 and post-2 (8 of 12).
- **Social services** were not being used more at any site between baseline and post-1 (patients at 10 sites reported decreased use and the remaining 3 stayed the same).
  - At post-2, there were still no sites at which patients reported using social services more than they were before the clinic (at baseline).
  - However there were 5 sites at which patient-reported use of this service increased since post-1, i.e. there was a reversal of the direction of change in just under half of sites at post-2.

Very few patients interviewed were using or planning to use health services more than before a clinic; however for those who were, reasons for this were:

- to seek further advice regarding side effects of medication, having been alerted to the need to do so at a clinic
- to seek medical help more often, having realised that it is essential to do so rather than ignore symptoms
- to address concerns in between oncologist appointments, by telephoning the CNS.

These increases in services use may all be seen as positive in that they address previously unmet need. They are also balanced by opposite shifts in use of health services reported by interviewees: a number of patients interviewed said that they were more likely to call the Macmillan telephone support line instead of their nurse specialist, which represents a cost-saving in terms of health services.

### Use of other services

The general trends observed in the 'other' categories were:

- a notable decrease in use of financial/employment advice and information centres, suggesting that information provided at the clinic on these topics may have reduced the need for patients to seek it elsewhere
- a more mixed picture in terms of complementary therapies and counselling support, with about half of sites showing decreased use
- an initial increase in the use of family/online resources/community support groups, followed by a subsequent decrease.

#### *Financial and employment advice and information centres*

There was a decrease in patient-reported use of services providing financial/employment advice or information centres.

- At post-1, 11 of 13 sites showed this decrease, and a further 1 sites showed no change (i.e. there was an increase in usage at only one site).
- At post-2, there continued to be less usage overall than at baseline (9 sites using less and 3 sites using the same as baseline).
- Between post-1 and post-2, however, 4 sites increased their use of these services.

These changes in use seem to suggest that the clinics performed well in terms of providing financial and employment information to patients, and that the need for patients to seek this type of information elsewhere was reduced, particularly in the shorter-term (post-1). The slight increase at some sites between post-1 and post-2 may indicate that some patients did not seek financial or employment support services immediately after the clinic, but having gained the knowledge of how to access these services, may have done so at a later point.

#### *Complementary therapies and counselling support*

There was a mixed picture in terms of changes to complementary therapies and counselling support being used.

- At post 1, about two thirds of sites maintained (3 sites) or reduced (6 sites) their use of complementary therapies or counselling at post-1.
- By post-2, 7 sites had reduced and one increased use since baseline.

As discussed above in relation to financial/employment advice and information centres, the change may reflect a reduced need for services following the clinic for some patients, while others may have taken up services having been referred or found out about them at the clinic. In patient interviews, this category of services was the most frequently mentioned by those patients who were using a new service having found out about it at a clinic.

#### *Family and friends, online resources and community support groups*

This category contains the least resource-intensive sources of support.

- In contrast to other service use categories, patients reported an increase in uptake at post-1 for two thirds of sites (8 out of 13). Patients at two sites reported the same use, while only three sites reported increased use of these sources of support.
  - In interviews, a number of patients indicated that they had accessed Macmillan's online resources since attending a clinic, which may account for some of the increase in uptake in this category.
- By post-2, the picture is reversed: patients at two thirds of sites (8 of 12) reported using support in this category less than at baseline. Even those who continued to use this support more than at baseline generally reported a decrease between post-1 and post-2 (10 of 12 sites showed a decrease between these two stages; one was unchanged).

### **Impact on Macmillan profile**

Patients' awareness of Macmillan and its support and services was generally increased by attending a clinic, according to patients interviewed. Most were aware of the clinics being a Macmillan initiative at the invitation stage, and the rest became aware of this at the clinic itself through the Macmillan branding and staff presence.

Many patients already knew about the kind of support and services that Macmillan provides before the clinic, but even these patients tended to agree that they gained more knowledge of the Macmillan offer through the clinic.

- For example, some patients had known about specific services, such as Macmillan nurses, but were not previously aware of the breadth of support available, such as financial advice and the telephone helpline.

- Other patients had not realised that they could continue to use Macmillan services post-treatment, or beyond a certain period of time after treatment.

Having met Macmillan staff at the clinic, a number of patients said they were more likely to make contact with Macmillan in the future.

## Quality

### Quality: summary

- The vast majority of patients interviewed were extremely positive about their experience of attending a clinic.
- Patients like the atmosphere of the clinics, the opportunity to talk to staff and interact with other patients in a group setting.
- Volunteers contributed to the quality of patient experience.
- Carers, partners and family members benefitted from attending clinics.
- Increases in patients' confidence to manage emotional distress and take part in social activities suggest improved quality of life.

### Quality of the clinic experience

The clinics were a distinct and different way of accessing information and services for patients. They liked the informal, friendly and relaxed atmosphere, and the opportunity to meet and talk to other patients, share experiences and feel that they are not unique or alone in what they are going through. This aspect of the clinics stands out as a key differentiator to traditional forms of follow-up such as outpatient appointments. The clinic as a forum for peer support adds value, offering patients something that they would not otherwise be able to access.

They also appreciated having the opportunity to ask questions and the time to talk to staff, compared to traditional appointments in which patients can feel that there isn't time to ask everything they might wish to.

### Quality of volunteer interaction

Patients' experiences of **volunteers** at the clinics contributed to the overall quality of experience, at sites where volunteers were present and patients interviewed were aware of them (which was the case in most sites). Volunteers helped to make the clinics accessible and beneficial to patients, in a number of ways:

- they were friendly and welcoming, helping to create the relaxed atmosphere and put patients and family members at ease
- they provided information and signposted to relevant professionals at the clinic
- they explained in simple terms complex medical advice
- they brought empathy and understanding to their interactions with patients.

Many, if not most, of the volunteers had personal experience of cancer, and it was this which added unique value to their role, from the patients' perspective. Having been through cancer, volunteers were also able to offer hope and encouragement to patients, to feel positive about their own futures. At some clinics, volunteers who were formerly patients gave testimonials

describing their own experiences, and interviewees generally found this very valuable. The role of volunteers, and how patients experienced it, varied considerably between sites, but it is clear that volunteers have the potential to contribute significantly to the impact of the clinic on patients and in some sites they did so.

### **Improvements to patient quality of life**

The emotional and social aspects of wellbeing are key to patients' quality of life. Patients at about half of sites reported improvements in these areas.

#### *Emotional distress*

- *I feel confident that I can keep the emotional distress caused by my health condition from interfering with the things I want to do (1j)*
  - About half of sites (7 of 13) showed an increase in agreement from baseline to post-1, and this increased slightly in terms of numbers of sites (to 8 of 12) at post-2 in comparison to baseline.
  - Comparing the levels of agreement at post-1 and post-2, however, shows an even split between those sites where patients maintained or increased their agreement from post-1 to post-2, and those where agreement decreased.

Reasons for improvements in emotional wellbeing were identified through the interviews. The theme of reassurance came across strongly. Patients felt reassured that they are not alone, that others share their experiences and that recovery is achievable. They also felt reassured that they have the information they need to identify symptoms; and that services and support were available to be accessed. In some cases emotional wellbeing was linked to specific support or services accessed at or as a result of the clinic, most frequently complementary therapies and counselling/psychology services. Emotional wellbeing was often closely linked with knowledge and confidence, with interviewees connecting their improved knowledge and confidence to their improved emotional health.

#### *Social functioning*

- *I feel able to take part in social activities (1h)*
  - About half of sites (7 of 13) showed an increase in agreement from baseline to post-1 and this remained about the same by post 2 (6 of 12).
  - Eight sites maintained or increased agreement from post-1 to post-2, so overall the clinics appear to have performed reasonably well in terms of impact on social functioning.

### **Benefits to carers**

Several clinics invited patients to bring their carers/family members to clinics (Aintree; Milton Keynes and Ulster) and/or provided support for carers at the clinics (Blackpool - Carers' Association was present - and Lincolnshire - Carers' Partnership was present).

Ten sites reported figures on the number of carers attending a clinic, via the monitoring forms. Across the ten sites a total of 175 carers attended the clinics, which varied between a total of 7 and 30 carers at each pilot site (across all clinic sessions). The following table shows the numbers of carers attending at each of the ten sites.

Site	Number of carers	Number of patients	% of patients accompanied by a carer
Aintree	24	31	77%
Ayrshire and Arran	8	67	12%
Barts & the London	10	68	15%
Blackpool	7	21	33%
Lincolnshire	30	51	59%
Milton Keynes	13	26	50%
Rotherham	13	45	29%
Royal Liverpool	26	46	57%
Ulster	28	27	100%
Velindre CNS	16	15	100%

The variations in levels of carer attendance could be related to several factors, including whether or not carers were explicitly invited to attend, and patients' wellbeing at the time of the clinics and whether they felt they needed the support of a carer (physically or emotionally) on the day.

#### *Rationale for inviting carers to clinics*

The scoping document review and scoping interviews identified the rationale behind inviting carers to health and wellbeing clinics. It is expected that carers may obtain many of the same benefits as patients do, including:

- Peer support benefits carers, who are comforted by knowing that there are others in the same situation. Meeting other carers who are further down the line in the patients' treatment trajectory offers an opportunity to learn from their experience. Carers can make connections with others.
- Carers can be signposted to services that they can access to support their own wellbeing (i.e. support available in the community).
- The information, knowledge and awareness that carers can gain from the clinic is empowering and promotes an increased sense of control over their and the patients' health and wellbeing.
- Volunteers at clinics provide a source of support by helping to give carers peace of mind, letting them know what the future holds and putting them at ease about worries they may have about treatment, outcomes and future life with someone who is living with cancer/side effects.

#### *Benefits reported by carers*

The evaluation itself did not formally assess carers' experiences (carers were not interviewed, nor patients asked specifically about whether their carer had attended). However, an interview was conducted with a carer on her husband's behalf, as they had attended a clinic together, and approximately ten other patient interviewees mentioned that their partners, carers or family members attended clinics with them and talked about the

value of this. Other interviewees suggested that partners/carers should be formally invited to attend, as they would have benefitted too. The feedback received identified a number of benefits of carers attending clinics.

- **Peer support:** for the carer who was interviewed, the opportunity to speak to other people going through the same experience was her initial motivation for attending the clinic. Several patients interviewed reported that their partners had benefitted from this too: one mentioned that her partner was happy that he could talk to other carers at the clinic; another that his partner was put at ease by the emotional support and advice on offer; one thought her partner got a better understanding of what she was going through as a cancer patient by attending the clinic.
- **Empowerment:** having the opportunity to ask questions was an important aspect of the clinic for carers. The carer interviewed made the most of being able to talk to professionals separately from the patient, as it is rare to have this opportunity at routine hospital appointments and she felt it was uncomfortable for her to ask certain questions in front of the patient.

One of the patient interviewees mentioned that her partner had questions that she had not even thought of, but which were useful. She felt that made sense for her husband to be there with her, as they had gone through the experience of cancer together.

In two cases, carers had encouraged patients to attend the health and wellbeing clinic, playing an important role in supporting patients to obtain the knowledge and confidence that they need to self-manage.

- **Integration of services in a relaxed environment:** the interviews demonstrated that carers were receptive to the range of health and wellbeing services available at the events and the non time-pressured environment within which to receive information and support from staff. The carer interviewed found the health and wellbeing clinics and events informative and relaxed, and appreciated that they could see who they wanted to without the pressure of feeling rushed. In addition, the presence of different services and professionals in the same place was seen as a key benefit by the carer interviewed. One of the patients interviewed highlighted the fact that he and his partner were very impressed with the low-key and laid-back nature of the event they attended.

## 4.4 Analysis of findings in relation to clinic characteristics

The previous section looks at data across all pilot sites in order to assess the impact of the clinics on the patient sample as a whole.

This section looks at the factors that appear to have increased or inhibited positive impact in relation to prevention and productivity. Taking the service characteristics thought to be associated with effective clinic delivery, we examined the patient findings to see whether there appears to be a corresponding impact on patients.

The **service characteristics** identified in the earlier section as being key to the effectiveness of a clinic are:

- clinic type
- effective information giving
- resource use
- robust volunteer training
- good engagement with the MDT
- underpinning processes to support engagement
- dedicated admin support time
- partnership working

Some of these characteristics appeared to show a relationship with patient impact (as in the previous section, impact is indicated by change scores: a positive score suggests a positive impact); these relationships are discussed below.

As the attendance of patients at clinics is a pre-requisite to both clinics' effectiveness in terms of prevention and to the productivity of this model, the issue of non-attendance (where patients are invited but do not attend a clinic) is also discussed in this section.

### Clinic type

As explained earlier the pilot sites have been grouped into a number of types, according to their format (see Table 2). Some clinics include aspects of more than one type, but for the purposes of evaluation, they have been assigned to one type. This section looks at how clinic type may relate to changes to patients' knowledge, confidence, wellbeing and service use.

#### Clinic type: summary

- In relation to knowledge, all clinic types showed positive changes
- In relation to confidence, all clinic types showed positive changes in terms of reducing patients' need to see a doctor, except for the presentation clinic type
- In relation to wellbeing, all clinic types did well in relation to increasing ability to manage fatigue; and across all of the wellbeing variables, market stall clinics stand out in terms of improvements
- In relation to service use, traditional and presentation clinic types were associated with the greatest reduction in patients' use of health, social and other services. Market stall

types showed the most increase in use of other services (other services include financial/ employment/ counselling/ complementary therapies etc).

### **Patient knowledge, confidence and wellbeing in relation to clinic type**

As discussed in the overview of findings earlier, the findings suggest that all of the clinic types have been effective in terms of prevention (educating patients and increasing their confidence to self-manage and their wellbeing). There were very few substantive differences between the clinic types; however, it is worth highlighting the following findings:

- The volunteer-led self-management clinics at Velindre (all) showed consistently positive results: change scores for knowledge and confidence increased between post-1 and post-2, as well as from baseline, suggesting that impact was sustained effectively over time<sup>23</sup>. The findings appear to confirm that the two key characteristics of this clinic type - led by volunteers; with an emphasis on self-management – may be effective in terms of building patient knowledge and confidence. The clinic provides a comprehensive 'handbook' for patients to take away, which may help to sustain knowledge and awareness. There was also positive change seen for 3 of the 4 wellbeing variables.
- Presentation clinic sites showed a small decrease in knowledge between post-1 and post-2, suggesting that the positive change was not sustained at the same level across time. This may highlight the need to supplement presentations with printed information for patients to take away with them. In relation to wellbeing, results also suggested that improvements in wellbeing were not sustained over time. In relation to reducing the need to see a doctor, presentation sites showed a move towards disagreement, which contrasts with the majority of other sites (9 out of 12 at post-2), in which patients felt more confident that managing their own health would reduce the need to see a doctor.
- Market stall clinics showed improvements on baseline across all 4 wellbeing variables, with only a few exceptions (which may be due to small sample sizes at post-2). As the market stall format allows a wide range of services to be present at the clinic, it is unsurprising that they are able to produce changes to the range of aspects of wellbeing.
- Assessment clinics both show improvements on baseline in relation to two wellbeing variables (those relating to fatigue and physical discomfort); the two sites diverge in relation to the other variables. Across all wellbeing variables except socialising, Aintree tended to decrease agreement between post-1 and post-2, which may be attributable to the prognosis of its patients (lung cancer).

### **Service use**

Again it is very difficult to identify substantive differences between clinic types in relation to productivity (service use). However:

- Traditional and presentation clinic types showed decreased use of all four categories of health and social services. Both clinic types also showed less use of all 'other' services at post-2 compared to baseline. Traditional clinics were the only group to decrease use of

<sup>23</sup> As Velindre (all) was the only site to use a volunteer-led self-management model, there are no comparator sites in terms of model and therefore attribution of change to the model can only be tentative.

friends & family/ online resources/ community support groups at post-1 (3 out of 4 sites did so).

- Market stalls were the only clinic type which did not indicate a decrease in patients' use of financial/employment advice (at 3 out of 4 market stall sites, use stayed the same at post-2). Market stall clinics also showed the most increase in use of counselling/ complementary therapies. The provision of information on a wide range of services, which characterises market stall clinics, does appear to have led to an impact on patients' take up of such services.
- Volunteer-led self management clinics also showed decreasing usage of all 4 health services, although use of social services was reduced considerably less at post-2 than it was at post-1. There was decreased use of financial/employment services but increased use of complementary therapies/counselling.
- Within the assessment group, Aintree showed reduced service use for all variables except for hospital-based, which may be expected given the nature of the tumour type catered for (lung).

## Other service characteristics

### Other service characteristics: summary

- In relation to resource use and productivity, clinics using more resources in terms of clinician's time did not necessarily demonstrate better outcomes than those using less
- In relation to volunteer role, the most impact was made on quality of patient experience where volunteers were able to share their own personal experiences of cancer with attendees
- In relation to partnership working, this approach enabled access to experienced volunteers and a network of relevant community/voluntary support organisations; and increased opportunities for promotion of clinics
- In relation to engagement of the MDT, effective engagement appeared to support referral and good levels of attendance at clinics, which is crucial to the productivity of the clinics
- In relation to underpinning processes and administrative support, these may support attendance and may be important in tracking patients through the pathway to ensure that health and wellbeing needs are addressed at the correct stage(s)
- In relation to information giving, all sites were effective. Leeds men's event represented an innovative example, by incorporating preventative messages aimed at men who had not experienced cancer, as well as at patients.

### Resource use

As resources have been invested into the clinics in terms of health professionals' time, it is desirable that this should have the effect of reducing patients' use of health services after attending a clinic. In this way cost-savings in service use post-clinic might equal or exceed the investment in the clinics.

Looking across the sample of pilot sites:

- It can be noted that there do not appear to be any major differences in terms of changes in service use according to whether a clinic requires high, lower or least investment of resources
- Similarly with regards to impacts on knowledge, confidence and wellbeing, the lower/least resource-intensive clinics do not appear to have less impact on patients than the more resource-intensive clinics.

Therefore it would seem that other factors are likely to be more important than resource use in determining the effectiveness of clinics. A detailed breakdown of costs and monetisable savings associated with a sample of three pilot sites can be found in a separate report<sup>24</sup>.

### **Volunteer role**

In some sites volunteers went beyond the 'meet and greet' role, sharing their own experiences as people who had lived with cancer and giving out/signposting to information.

#### *Information-giving*

At three sites patients interviewed mentioned the role of volunteers in providing information through pointing them to the relevant leaflets and/or stalls (Belfast, Leeds men's clinic, Aintree). At Aintree in particular, this was a part of volunteers' role and all of the 4 patients interviewed mentioned it, suggesting that making it a specific task for volunteers does have an impact on them. At Velindre all, being a volunteer-led model, volunteers provided all of the information: their skill at facilitating discussion in the group was complimented. As these sites represent a minority of clinics, however (4 out of 13 sites), it may be that the volunteer role in relation to giving could have been expanded at more sites within the pilot.

#### *Sharing personal experience*

By far the more frequently-mentioned aspect of volunteers' roles by patients was their sharing of their own experiences of cancer, either in conversation or through a presentation/testimony. Patients interviewed from nearly all sites (10 out of 13) thought that hearing volunteers' own experiences was helpful. It may be that a testimonial presented to the group of patients has particular value in that it reaches all attendees, including those who might not feel comfortable in approaching a volunteer and asking what may be quite personal questions. Ideally volunteers might give a testimonial as a way of breaking the ice and then make it known that they are happy to also talk more informally with attendees. This combined approach maximises the opportunity for patients to benefit from the volunteer presence. Quantitative feedback also indicated volunteers' impact on patients:

- Confidence to self-manage: two of the three sites associated with robust volunteer training, Velindre all and Rotherham, showed positive change on the statement *I am confident that managing my own health will reduce the need to see a doctor* (1c), where scores improved between post-1 and post-2. This may suggest that volunteers can have a positive impact on patients' confidence. Generally volunteers tend to be people who have themselves lived with cancer or have cared for family members who have lived with

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<sup>24</sup> Evaluation of Macmillan health and wellbeing clinics: economic case studies, OPM (2011)

cancer; seeing someone survive cancer and continue to live a 'normal' life can be reassuring and motivating for others who are going through the same process.

- Managing emotional distress: interaction between patients and volunteers may give the former some insights into managing emotional distress. Velindre all and Rotherham showed positive change scores at post-2 compared to baseline for the statement regarding managing emotional distress (1j).

### **Partnership working**

Clinics in the Leeds and Rotherham pilots demonstrated a partnership approach between community/voluntary and healthcare partners (Voluntary Action Rotherham – VAR - and Black Health Initiative – BHI - in Leeds).

- Advantages of this from the perspective of those running the clinics include: access to a wider range of resources, knowledge and experience; access to experienced volunteers; access to a network of relevant community/voluntary support organisations; opportunities for promotion of clinics.
- From a patient perspective, qualitative interviews with patients who attended Leeds and Rotherham clinics would seem to suggest that they experienced benefits from this approach too. Patients from both clinics were enthusiastic about the lively atmosphere created by the involvement of local voluntary organisations, and several patients became involved with parallel community services through attending a clinic (in Leeds, the women's Sister to Sister group, in Rotherham, the buddying support programme).
- In Leeds the role of BHI was crucial in promoting the event to ensure good attendance.

### **Good engagement with the MDT**

Strong engagement of the MDT in the clinics can be useful in two ways: firstly, engaged MDT members are more likely to refer patients to the clinic, thereby boosting attendance; secondly, their presence at the clinic can contribute to the patient experience.

- Barts & the London and Ulster offer good examples of increased attendance and MDT engagement. This is reflected in the comparison of numbers of invitations sent and numbers of patients attending the clinics.
  - At Barts, a proportion of 93% of patients invited to a clinic attended 18 clinic sessions held over 5 months (68 patients attended out of 73 invited).
  - At Ulster, a proportion of 71% of patients invited to a clinic attended 3 clinic sessions (27 patients attended out of 38 invited).
- Changes to service use may be linked to MDT presence at the clinics: where patients meet MDT members they may subsequently use services less, having had their questions answered at the clinic; or they may use particular services more, having found out about their availability at the clinic.
  - At Royal Liverpool, as with the majority of other sites, there was an overall decrease in service use from baseline to post-1 and post-2. However, there was a small increase in scores between post-1 and post-2 demonstrating higher usage of some health services (hospital-based, community-based/allied health services). Only 3 other sites showed a similar increase (4 out of 12 in total).

- This might suggest that meeting MDT professionals led to some patients seeking out these services having attended a clinic. It may be seen as positive that patients are seeking services to address previously unmet needs; it may also be worth exploring whether the MDT presence at the clinic can pre-empt this by identifying and meeting some of these needs at the clinic itself, for example through better information provision or more opportunity for one-to-one time.

### **Underpinning processes and administrative support time**

Underpinning processes to support recruitment of patients to the clinic may have an impact on levels of attendance. Barts and the London and Ulster clinics have such processes in place and both demonstrate high attendance figures, as indicated above. The figure for Barts may also reflect the dedicated administrative support time which the site has in place for the set-up and general running of the clinics.

If health and wellbeing is to be integrated into the patient pathway, both processes and dedicated time within a job role to implement them are likely to be essential.

### **Effective information giving**

In relation to sites identified as examples of effective information-giving, the quantitative findings do not seem to indicate that these examples are any more effective in this respect than other sites. The picture in relation to information-giving is positive across all sites.

- At the Leeds clinic for men, information-giving was identified as being especially comprehensive. It covered not only symptoms and treatment but also included preventative messages and addressed specific barriers to health in relation to men and to men of African Caribbean communities in particular. Interviewees reported that the information received at the clinic had a very positive impact on their knowledge of prostate cancer symptoms and treatment, and that they would be more likely to seek medical advice if concerned about their health, as compared to before the clinic.

### **Non attendance**

Levels of attendance at clinics are an important factor in their productivity and their effectiveness as a part of the treatment pathway as a whole: clinics with low numbers may impact extremely positively on patients who attend, but they are unlikely to represent an efficient use of resources if few patients are involved. For this reason the evaluation sought to identify some of the factors impacting on levels of attendance from the patient perspective.

Data on non-attendees was sought from four sites, in order to examine reasons as to why patients invited to clinics did not attend on the day. Aintree shared this data with the evaluation team as it had already been collated by the clinic lead. Three other sites (Blackpool, Velindre all and Rotherham) sent out flyers to non-attendees who they could contact, inviting them to get in touch with the evaluation team, or in Rotherham's case with the clinic organisers, to give their feedback on why they had not attended. Unfortunately the response rate was low, with only three people responding to explain their reasons for not attending a clinic. Interviews were to be conducted with those that got in touch, to find out more about why they may not have attended, what they thought a clinic might be like, how they heard about the clinic, and any support needs that were not being met. However, respondents either declined to be interviewed or were contacted unsuccessfully.

Aintree provided data on 16 patients who were invited but who either declined to attend a session or for whom attendance was not required. The majority of non-attendees were either unwell on the day of the clinic (4) or felt they didn't need extra support/they receive sufficient support from family and friends (4). Some non-attendees were already known to the hospice where the clinic took place (2) or were referred on to this hospice as they were unwell on the day of the clinic (2). Other reasons were: they had too many appointments to attend (1) or passed away unexpectedly after the invitation was sent and before the day of the clinic (1). There was no information available on the reason for non-attendance for two people.

Out of the other three people who contacted the evaluation team directly, one person was away at the time of the clinic and therefore could not attend; another person felt he had enough support from the radiotherapy team and cancer nurse. The last person had a hospital appointment at the same time as the clinic, and therefore could not attend.

In summary, from the limited data available there was **no evidence of a substantive rejection of the clinics by patients.**

### **Implications**

The limited data available suggests that a systematic approach to tracking patients invited to a clinic may be useful (as was done by Aintree), in order to identify reasons for non-attendance and where appropriate, to ensure patients' needs are met through alternative means. For example, if a patient was not able to attend due to a clash of appointments, they should be invited to the next available clinic session; and/or a system devised to ensure that appointments and clinics do not coincide. If a patient chose not to attend because they didn't feel the need of support, clinic organisers should assure themselves that this is genuinely the case and that patients do not have unmet support needs.

## 5. Economic case studies

Case studies of three pilot sites were conducted in order to contribute to an early assessment of the economic case for the clinics, alongside the evidence of wider impacts presented in this report.

The case studies were conducted using a cost consequence approach (CCA). A CCA does not require all costs and benefits to be measured in the same units (e.g. monetary units). The approach sets out the costs, both direct and indirect, involved in setting up and running the clinics, and reports the types of benefits accrued as consequences of the costs incurred.

A full report showing a breakdown of costs and benefits in the three pilot sites is presented in a separate report. In summary:

Case study site	Costs	Benefits to the healthcare system (monetisable savings through reduced service use)	Benefits to patients (quality benefits)
Case study 3: market stall model	Set-up: £2499 Running: £7034 (8 clinics)	£5317	Increased: awareness of treatment and support options and of symptoms or changes to look for. confidence to question health information, and that managing own health will reduce the need to see a doctor. confidence to manage physical discomfort and manage fatigue. confidence to manage emotional distress.
Case study 2: traditional model	Set-up: £5000 Running: £2523 (1 clinic) <sup>25</sup>	£2418	Increased: confidence to make health-related decisions. confidence to manage emotional distress.
Case study 3: volunteer-led model	Set-up: £4625 Running: £24,913 (7 clinics)	£1678	Increased: awareness of treatment and support options and of symptoms or changes to look for. confidence to question health information, to make health-related decisions, and that managing own health will reduce the need to see a doctor. confidence to manage fatigue and emotional distress and ability to take part in social activities.

<sup>25</sup> Three clinics were held in this site but the case study covered only one; therefore the set up costs are spread over three clinics rather than one.

## 6. Value of Macmillan's involvement

In order to assess the impact and value of the Macmillan brand to the clinics, as perceived by patients who attended clinics, a selection of patients who had already been interviewed as part of the evaluation were re-contacted and asked if they would be willing to participate in a second follow-on telephone interview. Fifteen interviews were conducted with patients from nine of the clinic sites in June 2011. The interviews were designed to elicit further detail from patients around their awareness and perception of Macmillan's role and contribution to the clinics/events. A copy of the interview guide is in Appendix 5.

### 6.1 Awareness of Macmillan before and at a clinic

All interviewees were aware of Macmillan as an organisation and service provider before being invited to/attending a health and wellbeing event. Their awareness has been gained primarily through radio, television or other advertising, or through family or friends.

While they were aware that Macmillan provided services, there were varying levels of knowledge amongst patients as to what services Macmillan offers. Most interviewees knew of Macmillan nurses. Many thought that Macmillan only supported those who were terminally ill with cancer. A small number of interviewees had greater knowledge of the range of support Macmillan offers to those living with cancer, including advice on financial support, benefits advice, support networks and referrals onto other services. This knowledge was gained through a range of channels including

- Previous use of Macmillan services by patients' family and friends
- Patients' previous attendance at Macmillan hospital-based clinics and sessions
- Patients' volunteering experiences with Macmillan.

#### Decision to attend

Most of the interviewees (12 out of 15) knew Macmillan was involved in setting up the health and wellbeing events before attending the clinic, in the following ways (in order of how frequently they were mentioned):

- from letters of invitation to a clinic, which included the Macmillan logos
- from consultants or nurses, either in person at the hospital or by telephone, when the member of staff explained that the clinics were run or funded by Macmillan
- through 'word of mouth' (for example, from a friend)
- through local radio adverts for the clinics.

Those patients who did not know of Macmillan's involvement before attending the clinics assumed that these were hospital-organised events. One patient felt that the difference between NHS and Macmillan nurses during her hospital treatment was not clear and this affected her understanding of the role of Macmillan and the NHS in the health and wellbeing clinics.

Six interviewees said that the fact that Macmillan was involved in the clinics influenced their decision to attend.

- For some patients this was due to Macmillan's positive reputation for supporting people living with cancer:

*'Because of the dedication and general [positive] perception that I have of Macmillan.'*

- For others, the experiences that family members and friends had of Macmillan enhanced their perception of what the organisation could offer them:

*'Macmillan clarifies the processes, options and choices that you have.'*

### **Macmillan branding at event**

Most patients felt that at the clinics themselves, Macmillan's involvement was evident in a range of ways, including:

- Macmillan logos on banners, literature (books, leaflets, brochures), adverts, posters
- Staff and volunteers with name tags and Macmillan t-shirts
- Introductions and presentations explaining Macmillan's involvement in the events.

Two interviewees reported that there was a lack of Macmillan branding (such as name badges and logos to identify Macmillan members of staff), at the clinic they attended, which meant that Macmillan's involvement was less obvious to them.

## **6.2 Appeal of Macmillan as an organisation**

All of the interviewees who knew that Macmillan was involved in the clinics expressed, without being prompted by the interviewer, a positive overall image of Macmillan as an organisation. They felt that this perception was enhanced by their attendance at the health and wellbeing clinic. No interviewees expressed a negative perception of Macmillan as an organisation.

The appeal and awareness of Macmillan, and the services it offers, were broadly due to two main factors: the professionalism of Macmillan staff and volunteers, and the reputation of Macmillan as an organisation.

### **Professionalism**

Patients highlighted several aspects of Macmillan's approach to supporting those living with cancer and their families which contribute to a professional attitude, upheld by both Macmillan staff and volunteers, that was very appealing to attendees of the health and wellbeing events.

- Macmillan breaks down negative stereotypes of cancer and gives a more optimistic outlook to patients and families. It does this by promoting the positive benefits of the support that individuals and carers can access with Macmillan's help
- Macmillan uses a patient-centred approach, which is enhanced by knowledgeable volunteers who have more time than health professionals in hospitals to dedicate to patients and carers:

*'Information that Macmillan can give is wider than in an outpatient clinic.'*

*'[Healthcare staff are] very busy and don't have as much time as Macmillan staff [...] who have the patience and time to help you – I didn't feel guilty about approaching them [Macmillan staff].'*

- Macmillan volunteers and nurses use their personal experiences to explain treatment and support options in an easy-to-understand and empathetic way, as the following quotes demonstrate:

*'Macmillan combines professional expertise and a great deal of knowledge.'*

*'Macmillan provides a human and compassionate approach [to people living with cancer].'*

*'Macmillan tend to speak more in layman's terms and when they speak to you, you feel they do understand rather than you just being a name or number and they break it down for you.'*

## Reputation

Macmillan was seen by interviewees as a well-known, trusted organisation that people living with cancer can approach for a range of support they might need. Some of the opinions that patients have of Macmillan are highlighted by the following quotes:

*'Macmillan is a caring name'*

*'I have a high opinion of Macmillan'*

*'Macmillan is an absolutely wonderful organisation'*

*'Macmillan is under-rated.'*

This strong reputation was further enhanced by Macmillan's presence at, and involvement in, health and wellbeing clinics, as illustrated below:

*'I have trust in Macmillan – I thought if Macmillan is involved then it must be good for the patients.'*

*'Macmillan is well-established, so you know it's going to be well-founded advice that they give you.'*

*'Macmillan have been very much like a safety net for me, I've great confidence in them, it's the reassurance you get from them.'*

## 6.3 Impact of Macmillan's involvement at clinics

Patients commented on the impact that Macmillan's presence at the events had on their experience of the clinic and on their health and wellbeing. Ten interviewees felt that Macmillan had helped them in some way at the events. The majority of patients became more aware of and developed a greater understanding of the range of services Macmillan offers or can refer people living with cancer to, such as financial advice, alternative therapies, wig-fittings and social work advice.

*'I feel more informed about services Macmillan offers.'*

*'I didn't realise how vast Macmillan's activities were.'*

*'I knew there were Macmillan nurses, but at the event I found out how big the organisation is and there are a lot of people you could go to about everything from benefits to wigs! I didn't know anything about that before.'*

*'I didn't know they could help with financial aspects, I thought it was just home help.'*

Other patients were very appreciative of the direct support they received from Macmillan, whether a Macmillan service or a referral to another service.

*'I didn't know about help with hair and make-up – I found that very helpful.'*

*'I learnt about the buddy system and was put in touch with a buddy and they [Macmillan] referred me for extra counselling.'*

### **Support network**

Some interviewees reported that Macmillan acts as a support network to those living with cancer and their families. This support network can be experienced in different ways by patients depending on their needs, for instance use of Macmillan hospital-based centres, the Macmillan telephone helpline and referral to financial and benefits advisers.

*'I am more aware of [Macmillan and cancer-related] services outside of the hospital environment. I didn't want to annoy my breast nurse or consultant – I can now go to the Macmillan centre at the city hospital.'*

*'I've phoned the Macmillan helpline, which was a tremendous help to me. I wasn't aware of the helpline until the clinic.'*

*'Macmillan staff [...] were very open. When I went to the stalls and asked for information they directed me to other individuals who could offer extra support [...] in finance and benefits.'*

Through Macmillan's links with other relevant services and professionals, patients, carers and families are able to access emotional and wellbeing services that they would otherwise not have known about, or might not have been referred to by medical staff. This linking role was valued by interviewees:

*'[Macmillan is a] positive organisation who I have found to be very helpful. They try to be there as a go-between families and health professionals. I feel they do a good job.'*

The buddying system allows patients to call a Macmillan volunteer whenever they feel they need to talk. This gives patients an extra form of support in-between hospital appointments if they have concerns they want to discuss away from a medical setting or before their next appointment.

In summary, our sample of patients was extremely positive about Macmillan as an organisation. The key value of Macmillan's involvement in the health and wellbeing clinics can be summarised as follows.

- Macmillan's strong reputation for supporting people affected by cancer encouraged patients to attend a clinic
- Key perceptions about Macmillan were:
  - it is a highly professional and expert organisation
  - it has a highly valued empathetic and personal approach
  - it is a trusted organisation in which patients can have confidence, and from which they gain reassurance
- Key impacts of Macmillan's involvement on patients were:
  - they felt that Macmillan staff and volunteers took the time to listen, explain and empathise with them at the event

- they were better informed about the range of services Macmillan offers
- they were better informed in relation to how to access these services, who they are open to and at what point in treatment
  - for example, some misconceptions were corrected, such as that Macmillan only helps terminally ill cancer patients, or patients undergoing active treatment
- they accessed services that they otherwise would not have done, including hospital-based Macmillan information centres, financial advice and a buddy support network.

A small number of interviewees were less aware of Macmillan's involvement and role in the clinics; this highlights the importance of a clear brand and message at the invitation/advertising stage (to encourage attendance) as well as at the clinics themselves (to ensure patients and families go away from the clinic with a good knowledge of the services they can access through Macmillan and how to do so).

## 7. Conclusions

The 14 health and wellbeing pilot sites represent an extremely varied field for evaluation, both in terms of the wide range of approaches they have taken to design and implementation (e.g. clinic model, role of volunteers, resource use, MDT engagement), and in terms of the patient groups they have engaged (e.g. tumour type, timing in relation to treatment, age). Clearly, there are many factors and variables that may have impacted on the effectiveness of clinics in terms of their impact on patients' health, wellbeing and service use.

Bearing this in mind, there are a number of key conclusions that emerge from the findings. In this concluding section, we draw out these key conclusions, and then propose a model for the integration of health and wellbeing clinics into the patient pathway, based on what appear to have been the most successful aspects of the clinics.

### 7.1 Key findings of the evaluation

#### Key achievements of the pilot clinics

Across the field there is evidence to suggest that the clinics have had a positive impact in terms of prevention, through increased patient knowledge and confidence, and (to a lesser degree) improved wellbeing. This has beneficial implications for patients and for health and other services in terms of productivity: patients overwhelmingly felt more able to cope with their health condition after attending a clinic, while use of the more resource-intensive services in particular was reduced.

Some of the key achievements of the pilot appear to be as follows.

#### Quality

- the **informal atmosphere** of the clinics was very popular with patients and appears to have been conducive to the effective delivery of health and wellbeing messages.
- the **combination of volunteers and professionals** was an effective one, with each making a valuable contribution to patients' experience of the clinics. The pilot has demonstrated the potential of volunteers to play a significant role in health and wellbeing.
- there was some degree of improvement to **quality of life** in terms of increased self-reported ability to manage emotional distress and to take part in social activities.

#### Innovation

- while sites took a range of different approaches in terms of the format of clinics, all essentially provided a **'one-stop shop'** for services and support. This enabled patients to **access** a range of services easily, and in many cases led to **unmet needs being identified** and addressed. Patients found out about services they were not previously aware of.
- the clinics offer a unique opportunity for patients **to meet and talk to other patients**, share experiences and feel that they are not alone in what they are going through. This aspect of the clinics adds value and stands out as a key differentiator to traditional forms of follow-up such as outpatient appointments.

- even where patients did not feel the need of information or services currently, the clinics played an important **'reassuring' role**. Patients felt better knowing what services are open to them and how to access these.

### Prevention and productivity

- clinics **empowered patients** by making them more knowledgeable and confident, which had a knock-on effect on service use. Increased knowledge and confidence may lead to reduced anxiety, more appropriate use of services and earlier intervention, which may be linked to improved outcomes.
- while the format of clinics and the **numbers of patients** who attended was extremely varied, the pilot suggests that the health and wellbeing clinic has the potential to enable effective delivery of services in terms of productivity.
- there was some degree of improvement to patient-reported **physical wellbeing** following a clinic, with fatigue being one of the most frequently mentioned factors that patients felt more able to cope with. Patients benefitted from advice on diet and exercise and referrals to physiotherapy/dietician services, as well as from information about side effects (which led some patients to change medication, with positive effects).
- a reduction in patients' self-reported **use of health services** was evident following attendance at a clinic, particularly use of GP and district nursing services.
- clinics successfully **raised awareness of Macmillan** and Macmillan services, which has the potential to reduce demand for mainstream health services.

### Macmillan's priority outcomes

Macmillan has 9 priority outcomes which its work aims to achieve. They state that, 'In 2030, all 4 million people living with cancer in the UK will say:<sup>26</sup>, followed by a list of statements. The findings of the evaluation suggest that the pilot has made a contribution to some of these priority statements, in particular the following:

- *'I understand, so I make good decisions'*
  - Patients showed increases in their knowledge and their confidence to make health-related decisions
- *'I get the treatment and care which are best for my cancer, and best for my life'*
  - The range of services and support showcased at clinics enabled patients to select those which best meet their needs
- *'I know what I can do to help myself and who else can help me'*
  - The information that patients received at clinics increased their own capacity to help themselves (for example by identifying symptoms) and their knowledge of the services and support open to them.
- *'I feel part of a community and I'm inspired to give something back'*

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<sup>26</sup> Currently in draft form, to be published July 2011

- Many volunteers had a strong sense of ‘giving something back’ through their role at the clinics. Several patients interviewed also expressed an interest in potentially volunteering in this capacity in the future.
- *‘I am treated with dignity and respect’*
  - Interactions with staff and volunteers at clinics were reported by patients to be overwhelmingly positive: they were friendly, informative and had time to listen and talk with patients.

## What worked well

Comparison of data between pilots revealed few substantive differences, with all sites performing well. Neither the format of clinics, nor their resource use, appeared to make a substantive difference to their impact on patients (bearing in mind that the evaluation has not formally evaluated cost-effectiveness). This is testament to the benefits of allowing sites to innovate and adapt the model of delivery to their specific needs and circumstances.

However, the analyses did reveal a number of components that appear to be associated with more effective provision. These include:

- supporting referral and attendance through engagement of the MDT, systematic referral processes and dedicated administrative time
- the use of market stalls to promote a wide range of services related to wellbeing, not just the more traditional health services
- the full use of volunteers, particularly by creating opportunities for volunteers to share their personal experiences of cancer with attendees
- tailoring the design and branding of the clinic to the patient group
- partnership working with a community organisation to target BME groups, creating benefits in terms of recruitment and attendance, and in terms of designing the clinic to maximise the reach of health and wellbeing messages
- ensuring continued support for patients following the clinic, so that positive impacts on patients are sustained: this may entail building on links and networks of volunteer-led or community-based support services; and/or offering the option for patients to attend subsequent clinics.

## The future

While it may be expected that service use reduces post-treatment, and it is not possible to determine the precise extent of the clinics’ influence in this regard, the evidence does suggest that the clinics have the potential to form a useful component of the patient pathway.

- On this basis the clinics have real potential to be embedded in **patient pathways**.
- Macmillan and the pilot sites should consider sustaining and further integrating the clinics into **routine local provision** based on the findings from this work.

- Seven sites have plans to sustain the health and wellbeing initiative post-pilot<sup>27</sup>
  - several of these involve further assessment and engagement of other existing services with which health and wellbeing clinics may dovetail
  - one site plans to raise awareness of clinics within GP practices, encouraging GPs to refer patients to a clinic with the aim of reducing GP visits
  - one site plans to hold a focus group with patients to inform the design of future clinics
  - the volunteer-led pilot site plans to continue clinics in this format and incorporate ‘refresher’ training for volunteers.

Where and how the health and wellbeing clinics might be integrated into the pathway, building on learning from the pilot, is explored in the following section.

## 7.2 Integrating health and wellbeing clinics into the patient pathway

The **core elements** of the health and wellbeing model are function (what the clinic does) and staffing (who delivers it). Guidance on these, and a recommended process for planning, delivering and following up a clinic, are set out below, along with an illustration of health and wellbeing clinics in the context of the care pathway.

### Recommended functions and staffing

#### Functions

The core functions are information-giving and signposting to other services. Information should be provided on the following:

Cancer type and symptoms	Health and wellbeing messages (diet, exercise)
Treatment	Benefits advice
Prognosis	Return to work
Management of symptoms e.g. fatigue	Access back into the system post-treatment
Signs and symptoms of recurrence	(optional) Complementary therapies, counselling

#### Staffing

**Type of staff and their roles:** an effective clinic has a mix of professional and non professional staff and volunteers, including an administrative co-ordinator role.

The following table shows possible functions for each of these; however, in practice there should be flexibility around who performs what function. For example, administrative support may be undertaken by a paid member of staff *or* a volunteer; presentations on some topics may be performed by a clinical member of staff *or* a suitably trained volunteer.

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<sup>27</sup> The evaluation did not formally gather information on sites’ plans for the future; however representatives from sites shared some of these ideas and intentions at the Learn & Share event in May 2011.

<b>Type of staffing</b>	<b>Clinical/non-clinical staff</b>	<b>Volunteers</b>	<b>Administrative support</b>
<b>Who</b>	Clinical: members of MDT e.g. surgeon/oncologist; CNS; AHP; psychologist. Non-clinical: benefits/return to work advisors (complementary therapists; counsellors)	Should be experienced or trained so they understand the needs of cancer patients and their families. May be recruited from existing volunteer pools, e.g. those already volunteering in hospitals; or via volunteer organisations	The administrator or co-ordinator role may be part of an existing role, or a function of key worker roles. May be an unpaid role to be undertaken by a volunteer
<b>Function</b>	Provide information and signposting, on the topics set out above	'Meet and greet'; provide refreshments Signpost to relevant professionals and information, at the clinic and outside it Give 'testimonials' of own survivorship experiences Input into planning of the clinics and participate in post-clinic review meetings Buddying support programme Admin support pre and during clinics (e.g. register patients on arrival)	Set up the clinics (arrange dates, venues and staffing) Administer invitations and track referrals Liaise with patients/carers

**Required skills and competencies:** a training package for all staff involved in health and wellbeing clinics might cover the following.

<b>Training</b>	<b>Details</b>
Communication, presentation and information-giving skills	For example, understanding different learning styles and appropriate language
Self management / health education training	To enable staff to empower patients to look after themselves
Group management / facilitation skills	For leading open discussions (setting ground rules, dealing with inappropriate questions, managing people who dominate discussions)
Motivational behavioural interviewing techniques	For example, in relation to smoking cessation, fatigue management
Cancer awareness training (for partner organisations and volunteers)	To ensure non-clinical staff understand have good understanding and familiarity with medical terminology.

**Staffing levels:** staffing of clinics may be based on the following options; as stated above, these should be interpreted flexibly and to suit the circumstances of particular trusts and patient groups.

Administrative support and a volunteer presence are recommended for every option.

Option 1: 'traditional'	Option 2: 'market stall'	Option 3: 'volunteer-led'
A clinic with presentations and market stalls	Range of manned stalls	Delivered by trained volunteers and supported by a clinical staff member
4 MDT members	3 MDT members	1 MDT member plus volunteers
CNS AHP Consultant Psychologist <i>+ administrative support</i> <i>+ volunteers</i>	CNS AHP Psychologist <i>+ administrative support</i> <i>+ volunteers</i>	CNS/AHP Volunteers <i>+ administrative support</i>

**Preferred clinic model:** while those implementing clinics should be free to innovate and tailor the clinics to the intended patient group or groups, it is suggested that the 'traditional' option (1 in the table above) may offer the most potential as an effective model and a platform for support. Underpinned by robust referral and patient tracking processes, it allows patients access to multi-professional staff and volunteers, as well as local services such as benefits advice; provides a mix of ways in which key health and wellbeing messages can be delivered; ensures printed information is available to take away, and should allow sufficient time for patients to seek out information that will better equip them to manage their health and wellbeing.

### Recommended components and processes

Because of the variation in health and wellbeing models that have been piloted, it has been possible to draw out what appear to be the effective aspects or 'components' of a health and wellbeing clinic, at the pre-clinic stage, at the clinic itself, and as follow-up.

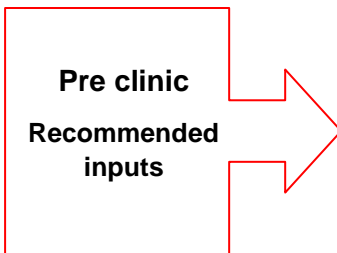
Using these core components, it is possible to build a range of health and wellbeing models depending on the style and delivery methods that have evolved in the pilots. It allows for community- and health-based models. The components have been split into inputs; process (what takes place at the health and wellbeing clinic) and outputs.

Drafts of the components diagram were shown to clinic leads at Learn and Share events in January and May 2011, where it was very positively received. Feedback from event attendees was taken into account in developing the final version. It is intended for sites implementing clinics in the future to select the inputs, processes and outputs that will best meet the needs of their patient groups.

Supporting materials for the set up and running of clinics, including templates for presentations and volunteer training packages, are available on the Macmillan LearnZone website<sup>28</sup>.

The component options are illustrated on the following pages. Examples of sites where these were implemented effectively are shown in italics.

<sup>28</sup> <http://learnzone.macmillan.org.uk/>



### **Awareness & Engagement**

- Community & patient engagement and awareness raising through promotional activities *e.g. Leeds*
- MDT engagement via attendance at NSSGs *e.g. Barts & the London*
- Primary care and DN awareness and engagement
- Patient informed at appropriately agreed points in the pathway (tumour dependent) *e.g. when HNA undertaken (for Velindre All this needs to be at the point of diagnosis)*
- Voluntary sector organisations' awareness and engagement *e.g. Leeds, Rotherham*
- HWB included in all new patient letters
- Integration of model with Macmillan Information & Support Managers *e.g. Ulster*

### **Agree appropriate clinic model**

- Including the role that volunteers will play

### **Pathway Integration**

- HWB into cancer and survivorship pathways
- HWB information integrated into patient information pathways

### **Training**

- Staff training package in place
- Volunteer training package in place *e.g. Velindre All, Rotherham, Ayrshire & Arran*

### **Pre HWB Assessment**

- Comprehensive HNA undertaken prior to HWB
- Pre HWB questionnaire and returned from patients/carers to shape event and respond to individual needs *e.g. Belfast, Ulster*

### **Referral, tracking and monitoring mechanisms**

- Establish referral mechanisms (including self referral), booking systems and confirmation *e.g. Velindre CNS, Ulster, Belfast*
- Establish patient tracking and monitoring systems *e.g. Barts & the London*

**At the clinic:  
Recommended  
processes**

**Processes**

- Tracker system and data collected for evaluative purposes

**Intervention**

- HNA and care plan (supported by volunteer) *e.g. Aintree, Barts & the London*
- Outcomes Wellbeing Star Chart & Action Plan *e.g. Milton Keynes*
- Self management tool and techniques *e.g. Lincolnshire*
  - Folder and action plan
- Exercises / relaxation techniques *e.g. Velindre All, Velindre CNS*

**Communication models**

- Consider tumour-specific vs generic
- Presentations by MDT, primary care, patients, volunteers, social care/voluntary sector *e.g. Liverpool, Ulster, Belfast, Portsmouth*
- Market stalls *e.g. Rotherham, Lincoln, Milton Keynes, Velindre CNS*
  - Consider permanent market stalls within hospitals
- Music/song/dance/drama *e.g. Leeds*
- One to one support with health and social care professionals *e.g. Lincolnshire, Milton Keynes, Ulster*
- Group work/open discussions *e.g. Leeds*
- CDs/video/photo loops *e.g. Velindre CNS*

**Information giving (verbal and written)**

- Health and wellbeing messages (cancer and survivorship) and services to access
- Information leaflets

**Post clinic:  
Recommended  
outputs**

**Documentation**

- Letter to the GP *e.g. Aintree*, copy to the patient and action in notes
- Follow up card with contact points and signs and symptoms of recurrence *e.g. Barts & the London*
- Action plan revisited at an agreed point in time *e.g. Milton Keynes*
- Post clinic/event evaluation and targeted support *e.g. Belfast, Leeds*

**Buddy Support Programme (not part of the external evaluation)**

- Patient referred into peer support programme where they exist *e.g. Rotherham, Ayrshire & Arran*

**Timely referral & access to other services/clinics**

- Other third sector organisations **e.g. Sista2Sista group Leeds**
- Dedicated programmes *e.g. fatigue management (Belfast model of referral to Ulster University); cancer rehab programmes*
- Supportive care clinics *e.g. Milton Keynes*

**Information**

- Information pack/health and wellbeing booklets/rehab folder

**Tracking and monitoring**

- Evaluative data collected and stored

## Health and wellbeing in the Transformed Care Pathway

The NCSI has developed a Transformed Care Pathway for survivorship. The transformed care pathway uses a risk-stratified approach to deliver a new model of aftercare which is currently being tested. Based on the learning from the evaluation of the health and wellbeing pilots, a health and wellbeing pathway has been developed, which can be integrated into the transformed care pathway.

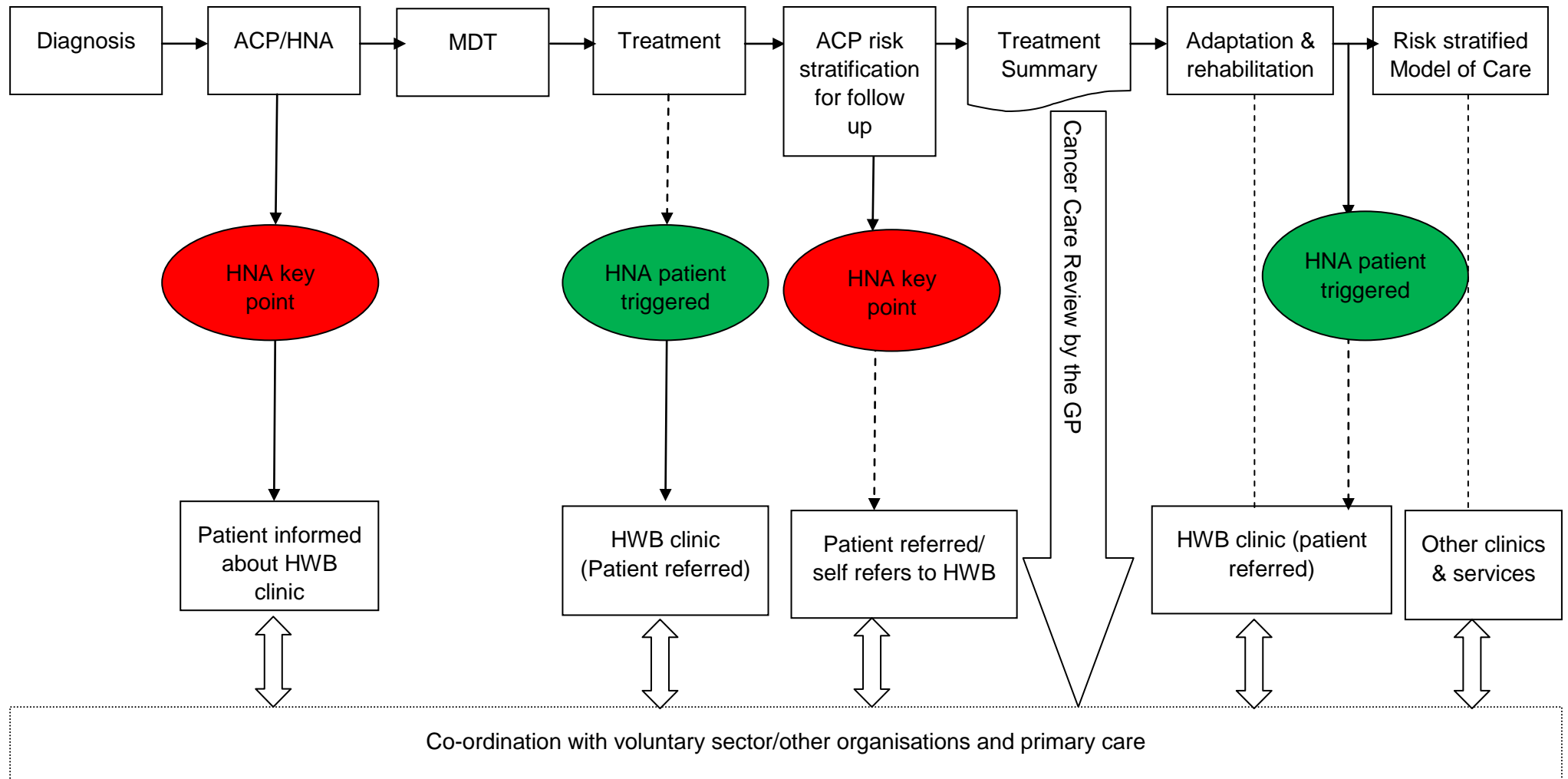
There are several key factors to delivering high quality care throughout the transformed care pathway. One is holistic needs assessment: it is clear from the evaluation that holistic needs assessments are not always undertaken, but that they could and should be integrated into the pathway. Holistic needs assessments may be patient-triggered (outside of key point for assessment), and should lead to referral to a health and wellbeing clinics earlier in the pathway if appropriate. It has emerged from the pilot that health and wellbeing clinics do not have to be offered always or only at the post treatment stage. Timing should be determined by patients' needs and tumour site, for example, lung cancer patients benefitted more from attending the clinic closer to the point of diagnosis.

Another key factor is the need for care co-ordination, to support communication and the interface between different sectors, organisations and individuals involved in providing high quality care to a patient. This role might be played by a key worker or a care co-ordinator, on a paid or unpaid basis.

The integration of health and wellbeing clinics into the transformed care pathway is illustrated on the following page.

**Health and wellbeing in the Transformed Care Pathway**

The following diagram shows the NCSI's Transformed Care Pathway, and how a Health and Wellbeing Pathway, including holistic needs assessment (HNA), fits into it as an integral component.



## 7.3 Recommendations for further evaluation activity

The health and wellbeing pilot evaluation has answered a number of questions and raised many more. Some further possible lines of enquiry are listed below, which Macmillan may wish to consider as part of its ongoing health and wellbeing clinic programme:

- It is advisable to follow-up the patient sample at 12 months to assess whether any changes reported as a result of the clinics have been sustained.
- There is potential to embed health and wellbeing clinics in patient pathways and replace established systems such as hospital out-patient appointments. A further phase of the programme should exploit this potential given pilot results.
- It is not entirely clear which portion or segment of the patient population is suitable for health and wellbeing clinic attendance as an alternative to out-patient appointments. The portion varies between tumour sites due to different treatment trajectories. These matters should be the focus of a further phase of practice development and evaluation.
- The value of the clinics to carers is insufficiently understood particularly in respect of patients' reported increase in a reliance on families and friends. This theme needs more dedicated exploration.

## 8. Appendices

### Appendix 1. Scoping review summary

This appendix is a **summary** of the scoping review, which is available in full on the Macmillan Learnzone website. The review covers the following areas:

- Similar interventions for people affected by cancer in the UK
- Facilitators and barriers to wellbeing and self-management
- Patient outcomes associated with wellbeing and self-management interventions
- Learning from non-cancer and non-UK contexts
- Learning from guidance or toolkits
- Volunteer impact
- Unmet needs of cancer patients

#### **Similar interventions for people affected by cancer in the UK**

The scoping review found that service provision at the post treatment stage is mixed and lacking in evidence to support particular pathways or approaches. Interventions tend to be medically led and lack focus on wellbeing or self management. That said, where primary care follow-up existed, some **wellbeing** interventions were available mainly through Cancer Nurse Specialists (CNS) and other medical staff and third sector organisations such as Macmillan and Maggie's Centres. These interventions included benefits and back-to-work advice, emotional support and healthier lifestyles advice, and were delivered through a variable assortment of verbal advice, printed information and access to groups.

In terms of **self-management**, the Department of Health has a number of initiatives, outlined in the NCSI self-management support workstream position paper<sup>29</sup>. They include an Expert Patient's programme and patient accessible records. Macmillan also runs programmes on self management including New Perspectives<sup>30</sup> and is piloting a self-management toolkit<sup>31</sup>.

The lack of evidence on wellbeing and self-management interventions found by the scoping review demonstrates the need for other aftercare services – such as the clinics - to be tried and tested, to see if they can provide an alternative and innovative method of support for people living with cancer.

The scoping review identified a range of **learning** relevant to the delivery of the clinics, covering guidance for service providers about what types of advice and formats for delivering

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<sup>29</sup> NCSI (2009) Self management support workstream position paper

<sup>30</sup> <http://www.macmillan.org.uk/HowWeCanHelp/Courses/NewPerspectivesCourse.aspx>

<sup>31</sup>

<http://www.macmillan.org.uk/Documents/GetInvolved/CancerVoices/Conferences/2009Documents/SelfManagement.pdf>

it are most valued by patients differentiated by age, gender and tumour type<sup>32</sup>; advice to patients about how to get the most out of interactions with health staff<sup>33</sup>; benefits advice, which is found to be useful but hard to access<sup>34</sup>; and vocational rehabilitation: it has been shown that maintaining a regular working life can be a key element in recovery<sup>35</sup>.

### **Facilitators and barriers to wellbeing and self-management**

The key factors for enhancing self-management and wellbeing of people affected by cancer identified in the literature tended to be focussed around education, information provision, emotional support, and more targeted care plans and programmes. In addition, the literature identifies the pivotal role of certain groups of people, namely staff and volunteers, in the facilitation of the aforementioned activities.

In terms of barriers, a key challenge concerns how best to tailor aftercare to the needs of different people living with cancer. Other challenges relate to barriers presented to the uptake of interventions, which can be categorised as patient factors (e.g. work or domestic commitments, reluctance to change lifestyle, dislike of groups), service factors (e.g. accessibility, parking), and professional factors (e.g. professional belief in effectiveness, referral processes)<sup>36</sup>. Perhaps the most pertinent challenge for the clinics is around the need to change attitudes so the role of the patient as an *active* partner in their healthcare is recognised and supported.

### **Patient outcomes associated with well-being and self-management initiatives**

*'A healthy way of life may not always stop cancer from coming back or spreading. But healthy choices make you feel at your best every day.'*<sup>37</sup> This statement from the MD Anderson Cancer Centre supports the underlying concept of the clinics, which is about empowering people affected by cancer and encouraging healthy choices. The scoping review considered some of the symptoms experienced by people affected by cancer and evidence around the efficacy of certain interventions that address them. There was (limited) evidence identified for the efficacy of exercise in addressing fatigue, for CBT in addressing emotional distress and depression, and for support groups in relation to social and relationship needs. However the evidence was sparse on the whole and challenges remain around the delivery of interventions that are thought to be effective.

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<sup>32</sup> NCSI, Davies et al (2010) Self management support for cancer survivors: Guidance for developing interventions

<sup>33</sup> Patient Education Office, MD Anderson Cancer Center, University of Texas (2008) Survivorship: living with, through and beyond cancer

<sup>34</sup> <http://www.macmillan.org.uk/HowWeCanHelp/FinancialSupport/BenefitsMadeClear.aspx>

<sup>35</sup> Scottish Government (2007) Coordinated, integrated and fit for purpose: a delivery framework for adult rehabilitation in Scotland. Available at <http://www.scotland.gov.uk/Publications/2007/02/20154247/6>

<sup>36</sup> Singh (Presentation) Cardiac rehab: where we are now and the future.

<sup>37</sup> Patient Education Office, MD Anderson Cancer Center, University of Texas (2008) Survivorship: living with, through and beyond cancer, p 11

## Learning from non-UK and non-cancer contexts

Health and wellbeing interventions from other contexts and places were also considered in the document review, to look for learning that could be adapted to the cancer population and reflected in the clinics. In terms of learning from other conditions (including pulmonary, cardiac, brain injury, stroke, MS and diabetes), the review suggested that clinics should try to **prevent health inequalities** by promoting access to all, and especially to those who are susceptible to exclusion and disadvantage<sup>38</sup>. Other outcomes-focused goals identified in the literature as increasing health and wellbeing, and that the health and wellbeing clinics are largely already intending to meet, are: increasing **health literacy**; setting good examples around **healthy behaviours**; and **co-creating** health through information provision, self-management support, and the presence of multi-disciplinary professionals.

The review highlights a lack of evidence on **one-off supportive events** similar to the health and wellbeing clinics; therefore it is difficult to compare the provision of a universal event for other long-term conditions with that of the clinics. However, where one-off events have been held at regular intervals, such as workshops for people living with MS and care events for those living with diabetes, support has also been provided for their **families**. The clinics might therefore wish to consider providing one-off events specifically for families, so that carers, parents and children and other family members can receive support at the same time (carers and family members are normally welcome at clinics anyway).

In terms of learning from countries outside the UK, the most useful evidence came from Canada and the USA. In Canada, a survivorship programme for people affected by breast cancer develops a **personalised self-management care plan** and focuses on patient **empowerment**. The elements of the programme valued most by participants were: learning coping skills, time spent with a medical oncologist and information sharing between patients<sup>39</sup>. In the USA, a programme offering skill-building activities to breast cancer patients around behaviour management demonstrated that again, the participants valued peer support and guidance from professionals<sup>40</sup>. The findings from both of these examples about what patients value correspond in particular with the focus of the Macmillan breast cancer health and wellbeing clinics.

Also in the USA, using a similar model / approach to that of the Macmillan clinics, the MD Anderson Cancer Clinic takes an interdisciplinary approach to planning patients' treatment. Teams include doctors, nurses, case managers, pharmacists, therapists, dieticians, and social workers, and patients can meet their team on a one-to-one basis or in a group<sup>41</sup>. This demonstrates the importance of enabling participants to consult **multidisciplinary professionals** at clinics.

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<sup>38</sup> Bernstein et al (2010) Enabling effective delivery of Health & Wellbeing: an independent report

<sup>39</sup> NCSI, Davies et al (2010) Self management support for cancer survivors: guidance for developing interventions

<sup>40</sup> Davies, Macmillan Cancer Support (2009) Self management programmes for cancer survivors: a structured review of outcomes

<sup>41</sup> Patient Education Office, MD Anderson Cancer Center, University of Texas (2008) Survivorship: living with, through and beyond cancer

The scoping review found a lack of evidence of cancer aftercare and survivorship interventions in other European countries, suggesting the Macmillan clinics potentially represent a pioneering pilot programme in Europe.

### Learning from guidance or toolkits

There are limited guidance documents, good practice examples or toolkits available regarding survivorship strategies. **NCSI** suggests a process for setting up self-management interventions<sup>42</sup> which encompasses the following steps: needs assessment; decide intervention type, delivery method and techniques; implementation plan; evaluation. At the moment, some of these elements are in place in some of the clinics, such as aspects of needs assessment, methods of intervention delivery, intervention techniques and evaluation. However, more attention should perhaps be paid to **needs assessment** to ensure high risk groups are identified and in turn the correct methods of intervention and techniques are used.

The **MD Anderson Cancer Centre** details the various **internal survivorship resources** available for patients, specifying whether referral is needed for a service. Resources span a wide range of clinics specialised in different sectors of health and social care. This is a useful large-scale model, although we recognise that such a model might not be needed for each individual health and wellbeing clinic, as they are offering services on a much smaller scale. The Centre also lists some **external resources** (books and websites) for people living with cancer (please see Appendix 1 for a list). These types of resources might be useful for signposting people attending the clinics to external resources that they can use as and when they please.

### Volunteer impact

The Department of Health (DoH) and NHS Improvement reference the **benefits** of volunteering in health and wellbeing interventions to individual volunteers, organisations and service users. The evidence shows that volunteers can share their expertise, experience and understanding in support roles such as information provision, peer support, mentoring and befriending. The clinics should act as a setting for volunteers to provide emotional and informal support by connecting with patients and carers in a meaningful way. Volunteering can add value, therefore, and also save money<sup>43</sup>, as identified in the NHS Improvement rapid review of current service provision which highlights the need for more volunteering to help clinical teams improve their local service provision<sup>44</sup>.

The scoping review also considered an **impact** report on the WRVS (formerly the Women's Royal Voluntary Service) volunteering services<sup>45</sup>. It identifies emotional benefits to service

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<sup>42</sup> NCSI, Davies et al (2010) Self management support for cancer survivors: guidance for developing interventions, p 9

<sup>43</sup> Department of Health (2010) Volunteering: Involving people and communities in delivering and developing health and social care services, Executive summary; Department of Health (2010) Impact assessment of "Volunteering - involving people and communities in delivering H&SC"

<sup>44</sup> NHS Improvement (2009) Rapid review of current service provision following cancer treatment

<sup>45</sup> Sudbury et al, Public Aspect (2009) WRVS Impact Report

users (feeling less isolated, more confident and more independent); tangible benefits such as being more able to attend medical appointments, go shopping, meet new people; and also reports that service users felt that services were delivered by volunteers in a way that provided dignity and respect, value for money, flexibility and choice, and the ability to make suggestions for change and improvement. The impact report also indicates that volunteer support gave carers more freedom, respite and peace of mind.

WVRS volunteers outlined their **motivations for volunteering**, which include wanting to 'give something back', to keep busy and active and to have the opportunity to meet new people. They appreciated the flexibility they are given about the amount of time they work and felt that they were valued by WVRS, service users and carers. These motivations provide valuable insight for Macmillan and the clinics about how to maximise the engagement of their volunteers.

### **Unmet needs of cancer patients**

Various NCSI documents identify unmet needs, such as improving engagement of '**hard-to-reach**' groups (i.e. BME, older, single, and unemployed). We recommend that clinics aim to target vulnerable groups using specific techniques to engage them. For example, telephone support for BME males, older individuals, and perhaps the unemployed who may prefer one-to-one support from the comfort of their own homes, for various reasons: mobility issues, lack of means to access the clinic, or to avoid feeling awkward as a member of a minority group amongst a majority one.

Unmet **tumour specific needs** are outlined in a follow-up NCSI review document of current practice and initiatives<sup>46</sup> for cancers of the breast, lung, prostate and colorectal cancer. Different unmet needs are identified and therefore different emphases are found to aid the effectiveness of interventions for different tumour types. We recommend that those clinics focusing on the abovementioned tumour types take into account such specific unmet needs when developing interventions, for example ensuring availability of sustained self-management support, knowledge of consequences of treatments and accessible follow-up care.

An evaluation of **NCSI test community projects** focussing on different types of cancer, which were set up in September 2008 to test new models/approaches of care, highlights the following unmet needs<sup>47</sup>: additional help required with **social and emotional aspects** of living after cancer; additional help required with **physical needs** such as feeling tired, weak or frail; concerns about **economic aspects** of living with cancer and concerns about **returning to work**. Hence the literature confirms the need for clinics to have a broad focus in terms of wellbeing, and indeed the vision for many of the clinics is to provide multi-professional assessment, information and support on emotional, social, physical and economic aspects of living with cancer.

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<sup>46</sup> NCSI, Davies et al (2010) Cancer follow-up: towards a personalised approach to aftercare services: a review of current practice and initiatives

<sup>47</sup> Sheldon et al, Picker Institute (2009) An evaluation of the NCSI test community projects: report of the baseline patient experience survey

Overall, this review of published literature supports the shape and direction of the health and wellbeing clinics but there is potential for realising and enhancing the benefits even further.

## Appendix 2. Patient questionnaire

### Baseline (pre clinic) questionnaire



Centre ID:	Subject ID:
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### Macmillan Cancer Support Health and Well Being Clinics: Example Questionnaire

**NB If you have already attended a clinic, please do not complete this questionnaire.**

The XXXXX Health and Wellbeing Clinic is taking part in an evaluation which seeks to understand what differences the clinic can make to the lives of people who use it. Feedback of this type helps us to know what we are getting right and to identify how we can improve. It also provides information which enables our funders to understand the experiences of people who use our services.

This questionnaire takes between 5 and 10 minutes to complete and asks about your health state and the actions you may plan to take in the future to support your health. The information you provide will be treated confidentially and if your responses are used in any report it will not be possible to trace answers back to particular individuals.

Please take a few minutes to complete this questionnaire. You can hand in your completed questionnaire to a member of clinic staff.

**THANK YOU FOR YOUR TIME AND ATTENTION**

## SECTION ONE

**For each statement, please tick one box to rate the degree to which you agree with the following:**

	Strongly agree	Agree	Somewhat agree	Somewhat disagree	Disagree	Strongly disagree	N/A
a. I know how to cope with further problems concerning my health condition	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
b. I am aware of the different treatment and support options available to me	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

	Strongly agree	Agree	Somewhat agree	Somewhat disagree	Disagree	Strongly disagree	N/A
c. I am confident that managing my own health will reduce the need to see a doctor	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
d. I know what to look for in terms of new symptoms or changes to my body	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
e. I feel confident that I can keep the fatigue caused by my health condition from interfering with the things I want to do	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

	Strongly agree	Agree	Somewhat agree	Somewhat disagree	Disagree	Strongly disagree	N/A
f. I feel able to question or challenge information about my condition if necessary	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
g. I feel confident making my own health related decisions	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

	Strongly agree	Agree	Somewhat agree	Somewhat disagree	Disagree	Strongly disagree	N/A
h. I feel able to take part in social activities	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
i. I feel confident that I can keep the physical discomfort or pain of my health condition from interfering with the things I want to do	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
j. I feel confident that I can keep the emotional distress caused by my health condition from interfering with the things I want to do	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

## SECTION TWO

By placing a tick in one box in each group below, please indicate which statements best describe your own health state today.

### Mobility

- I have no problems in walking about
- I have some problems in walking about
- I am confined to bed

**Self-Care**

- I have no problems with self-care
- I have some problems washing or dressing myself
- I am unable to wash or dress myself

**Usual Activities** (*e.g. work, study, housework, family or leisure activities*)

- I have no problems with performing my usual activities
- I have some problems with performing my usual activities
- I am unable to perform my usual activities

**Pain/Discomfort**

- I have no pain or discomfort
- I have moderate pain or discomfort
- I have extreme pain or discomfort

**Anxiety/Depression**

- I am not anxious or depressed
- I am moderately anxious or depressed
- I am extremely anxious or depressed

To help people say how good or bad a health state is, we have drawn a scale (rather like a thermometer) on which the best state you can imagine is marked 100 and the worst state you can imagine is marked 0.

We would like you to indicate on this scale how good or bad your own health has been on average over the last two weeks, in your opinion. Please do this by drawing a line from the box below to whichever point on the scale indicates how good or bad your health state is today.

**Your own  
health state  
over the last 2  
weeks**

Best  
imaginable

100

90

80

70

60

50

40

30

20

10

0

Worst

imaginable

## SECTION THREE

### About You

a. What is your age?

- 16 – 20     21 – 30     31 – 40     41 – 50  
 51 – 60     61 – 70     71 – 80     81 +

b. What is your gender?

- Female                       Male

c. If a patient/service user, what is your cancer diagnosis?

- Head or neck     Breast             Prostate             Oesophageal      
 Gynaecological     Haematology     Lung                       Urological     Other  
 (please specify)

d. When did your treatment end?

- 1-2 weeks ago                       2-4 weeks ago     1-2 months ago     2-3 months ago  
 3 months or more ago     ongoing                       N/A

e. What is your ethnic origin?

#### White

- British  
 Irish  
 Any other

#### Black or Black British

- |  |           |  |
|--|-----------|--|
|  | Caribbean |  |
|  | African   |  |
|  | Any other |  |

#### Mixed

- White and Black Caribbean  
 White and Black African  
 White and Asian  
 Any other  
 Other ethnic origin

#### Asian or Asian British

- |  |                      |  |
|--|----------------------|--|
|  | Indian               |  |
|  | Pakistani            |  |
|  | Chinese              |  |
|  | Do not wish to state |  |

**THANK YOU FOR YOUR TIME AND PARTICIPATION**

**Post 1 and 2 questionnaires – sections one and two as for baseline, plus additional section:**

**SECTION THREE – Support and service use**

**Since attending the clinic, do you use the services listed below more, less or about the same? Please tick the option that most applies to you and briefly explain your reason. Please leave blank those services you have not used.**

<b>Service</b>	<b>Use More</b>	<b>Use the same</b>	<b>Use less of</b>	<b>If using more or less please briefly explain why</b>
Hospital based cancer specialists e.g. oncologists, cancer nurse specialists, Macmillan nurses				
Other hospital services e.g. A&E				
Community based cancer specialists e.g. palliative care teams, Macmillan nurses, community matrons				
Allied health professionals e.g. physios, OTs, dieticians, speech and language therapists, lymphoedema specialist				
Your GP				
District nurses				
Social services				
Complementary therapies				
Family, friends and/or neighbours				
Financial support services				
Employment advice				
Online information and resources				

Information centres				
Community support groups, voluntary services				
Counselling support				
Any other services or support (please specify)				

## Appendix 3. Patient interview guide

### Introduction

Thank you for agreeing to take part in this interview/our project.

Background to the clinics:

In 2008 the National Cancer Survivorship Initiative (NCSI) was formed to improve the experiences of patients living with and beyond cancer. NCSI is a partnership between the Department of Health and Macmillan Cancer Support. As part of their role, Macmillan has developed Health and Wellbeing clinics in NHS Trusts across the UK to support people with a cancer diagnosis and their carers during and at the end of cancer treatment.

Macmillan has commissioned the Office for Public Management (OPM) and Hopwood Palin Associates (HPA) to conduct an evaluation of the Health and Wellbeing Clinics. The key aim of this evaluation is to demonstrate the difference these clinics can make to the lives of people affected by cancer. It also aims to identify any improvements that can be made so they better meet the needs of people living with cancer and their carers/family members.

We are carrying out a series of informal telephone interviews to ask people who attend the clinics to tell us about their experiences of the clinics and what difference the clinic has had on their life. The findings from these interviews will help us to develop a clear picture of the health and wellbeing clinics and inform our approach to evaluating them.

### Explain interview procedure

This telephone interview will last about 45 minutes. There are no right or wrong answers; we are interested in your views and experience. Is this still a convenient time for you to talk to us?

### Stress confidentiality

Anything you say will remain confidential within the evaluation team and, although we may use direct quotes, you will not be identified by name in any report that we produce.

Your participation in this interview will not affect any form of treatment you receive.

Do you have any questions before we begin?

### Questions

#### 1. Appeal and motivations

- a. How did you hear about the clinic?
- b. Why did you decide to attend the clinic?
- c. What appealed to you about attending the clinic?
- d. What were your motivations before attending the clinic?

Probe: Was it for financial or emotional reasons, to receive medical support; to meet new people etc.

#### 2. Expectations

- a. What expectations did you have? What were you hoping to gain by attending the clinic?

- b. How well did the clinic meet your expectations?
- c. In what ways did the clinic not meet your expectations?

**3. Experience of the clinic**

- a. Before attending the clinic did you have a needs assessment and care plan carried out?
- b. What did you do at the clinic?

Probe: Did you receive any care planning advice or an assessment of needs?

- c. How did you receive information and advice at the clinic?

Probe: 1:1, group, presentation, written, oral etc

Probe: what did you prefer? Why?

- d. Who provided you with information/advice at the clinic?
- e. What information/advice did you receive at the clinic?

Probe: Of this, which information/advice did you receive that you weren't previously aware of?

- f. If you were concerned about your health, would you know where to go to seek help or advice?

- g. What did you most like about the clinics?

Probe: concept, set-up, staff, volunteers, information/advice provision, services provided, location, length

- h. What did you most dislike about the clinics?
- i. What was the most helpful aspect of the clinic?
- j. What was the least helpful aspect of the clinic?

- k. What was missing?

**NB: Note for interviewer – do not ask lung cancer patients question 3l**

- l. What do you think about the timing of the clinic in relation to your treatment?

Probe: too soon after treatment, just right, not soon enough. Why?

- m. Are you aware that the health and wellbeing clinics have been set-up by Macmillan?
- n. Has your attendance at the clinic increased your awareness of the kind of support Macmillan offer?

**4. Impact of the clinic**

- a. Has your attendance at the clinic made a difference to your life? In what ways?

Probe: specifically what has changed? Exactly what differences have been made?

Symptoms / Self-management techniques	Positive / improved	Negative / decreased	No change / stayed the same	What about the clinic enabled change?
Physical health,				

e.g. diet, weight gain, breathlessness, exercise				
Emotional health and wellbeing, e.g. feelings of stress, anxiety, depression				
Sleep pattern				
Side effects				
Appetite				
Independent living				
Socialising				
Confidence to manage own recovery				

**b.** In addition to what you have said, do you anticipate anything else that you might do differently in the future?

### 5. Follow-on from clinic

**a.** Since attending the clinic, which follow-on support are you using or planning to use?

Probe:

- friends, family, neighbours
- medical/health services (GP, specialist services e.g. oncology etc, A+E etc, any other)  
**NB: note for interviewer** - probe on exactly which medical services used or planning to use
- financial support
- employment advice
- online information/resources
- community support groups, voluntary services
- counselling support
- any others

**b.** Of those, which would you not have used or planned to use if you hadn't attended the clinic?

**c.** Have you been offered/have you booked any follow-on appointments of any kind, for any type of support?

**d.** If you need advice about cancer-related health conditions/symptoms, would you know where to go/who to go to?

Probe: Do you know how to recognise signs and symptoms to look for? Would you know who to go to/where to go about specific/certain symptoms?

e. Thinking about the services you were using before attending the clinic, are you using any of them less?

Probe: Which? Why?

f. Are there any other changes to service use that you plan to make in the future?

## 6. Impact of volunteers

a. Did you talk to any volunteers at the clinic?

b. Did the volunteers provide you with any useful information/advice?

Probe: what information/advice?

c. What did you think about the way they communicated with you/treated you?

Probe: examples of both good and bad experiences of interacting with volunteers

d. Did you gain any particular insights from the volunteers' experiences themselves?

Probe: advice from professional volunteers (able to share expertise) or volunteers sharing life experiences (of living or caring for people with cancer)

e. Did the volunteers offer you things that professionals might not have been able to provide you with?

## 7. Recommendations

a. Do you have any recommendations to make about future clinics?

b. How could the clinic be improved?

## 8. About you

a. What is your age?

16 – 20     21 – 30     31 – 40     41 – 50

51 – 60     61 – 70     71 – 80     81 +

b. What is your gender?

Female             male

c. If a patient/service user, what is your cancer diagnosis?

Head or neck     Breast     Prostate     Oesophageal     Gynaecological  
 Haematology     Lung     Urological     Other (please specify)

d. When did your treatment end?

1-2 weeks ago             2-4 weeks ago     1-2 months ago     2-3 months ago  
 3 months or more ago     ongoing             N/A

## Thanks and close.

Interviewer to provide information about how the findings will be used and next steps in the evaluation.

## Appendix 4. Monitoring returns form

***Survivorship Programme  
Health and Wellbeing Clinic Test Communities  
Progress Report***

<b>Test Community</b>	
<b>Project Lead</b>	
<b>Date</b>	

Please use one form for each clinic. If you would like to add new information about a previous clinic, use a separate form, indicating the date of that clinic.

<b>Progress Review</b> <i>Use this section to summarise the work undertaken by providing details of any specific details that could be beneficial to other test communities e.g. volunteer resources, patient experience stories, useful information regarding venues, joint working initiatives, etc.</i>
<b>Issues &amp; Challenges</b>
<b>Proposed solutions</b> <i>(Including what other resources may be needed)</i>

<b>Key Learning Points</b> <i>(What worked well, what didn't work well, what would you do next time)</i>
<b>Plan for next clinics</b> <i>(Include any changes needed to make the clinic work well/better)</i>
<b>Support needed from Project Lead</b>

Attendance	
Number of patients attending clinic	
Number of carers/family members/partners attending clinic	
Number of volunteers attending clinic	
List of people contributing to the clinic	

Referral		
<i>How did you advertise or invite attendees to the clinic?</i>	<i>Please tick</i>	<i>Of those who attended, can you estimate the proportion who were referred through each route (e.g. Letter of invitation, 25%)</i>

<b>Letter of invitation</b>		
<b>Through clinician discussion</b>		
<b>Through GP discussion</b>		
<b>Poster/leaflet at hospital</b>		
<b>Poster/leaflet at GP surgery</b>		
<b>Radio/newspaper advert</b>		
<b>Other (please specify)</b>		
<b>Other (please specify)</b>		

<b>Clinic services</b>	
<i>Service (eg presentation, information stand, advice)</i>	<i>Take up (this doesn't have to be an exact number, just an indication of how popular the service was)</i>

If you have collected this data, please indicate the number of patients in each of the following categories

<b>Age</b>			
<b>16-20</b>		<b>51-60</b>	
<b>21-30</b>		<b>61-70</b>	
<b>31-40</b>		<b>71-80</b>	
<b>41-50</b>		<b>81+</b>	

<b>Ethnicity</b>			
<b>White</b>		<b>Black or Black British</b>	
British		Caribbean	
Irish		African	
Any other		Any other	
<b>Mixed</b>		<b>Asian or Asian British</b>	
White and Black Caribbean		Indian	
White and Black African		Pakistani	
White and Asian		Chinese	
Any other		Any other	
<b>Other ethnic origin</b>		<b>Do not wish to state</b>	

<b>Gender</b> (only complete if tumour type is not gender-specific)			
<b>Female</b>		<b>Male</b>	

<b>Cancer diagnosis</b> (only complete if clinic covers more than one tumour type)			
<b>Head or neck</b>		<b>Haematology</b>	
<b>Breast</b>		<b>Lung</b>	
<b>Prostate</b>		<b>Urological</b>	
<b>Oesophageal</b>		<b>Other</b>	
<b>Gynaecological</b>			



## Appendix 5. Patient interview guide – perceptions of Macmillan’s involvement

### Before attending the clinic

1. Did you know that Macmillan was involved in the clinic/event you attended before attending it?

a. If so:

i. how did you know this?

ii. *did you think Macmillan was the lead (or only) organisation for the clinic/event? Why do you say that?*

*Probe: told by the person who invited you (and who was this?), branding on the invitation letter*

b. If no:

*i. who (which organisation) did you think was responsible for the clinic/event? Why do you say that? (Probe)*

2. Had you heard of Macmillan before attending the clinic/event?

a. If so:

i. what was your understanding of what Macmillan as an organisation does, before you attended the clinic / event?

ii. What were your perceptions of Macmillan before attending the event?

3. Did the fact that Macmillan was involved in the clinic / event influence your decision to attend? Why do you say that?

*Probe: What was it about the name ‘Macmillan’ made you want to attend the clinic / event? What does the organisation project in terms of image?*

### When attending the clinic

4. Was it clear to you at the clinic/event you attended, that Macmillan was involved?

a. If yes:

i. why do you say that? (e.g. aware that Macmillan staff were there, visibility of Macmillan material, etc)

1. *if they mentioned Macmillan staff/volunteers, ask what they thought of the role they played and how they interacted with patients*

2. *if they didn’t mention Macmillan staff/volunteers, probe whether they were aware of Macmillan staff or volunteers, and then ask for their perception of role and interaction*

- ii. what was good about Macmillan being involved in the event/clinic?  
*(probe: would it have been a different experience if Macmillan had not been involved?)*
  - iii. Did it make a difference that Macmillan was involved in the event/clinic?
  - iv. Would you be able to compare, in some way, what Macmillan offered to what outpatient hospital services offer? Can you explain?
- b. If no, why do you say that? *(e.g. not visible enough? Not aware Macmillan staff were there, etc?)*

#### **Awareness / knowledge of Macmillan**

5. Having attended the clinic / event, do you think you now have a better understanding of the type of organisation Macmillan is and the work they do? If yes, what led to this?  
*Probe: did you find out more about what support / activities the organisation offers? What specifically were you not aware of before attending the clinic / event?*
6. Having attended the clinic/event, what is your current opinion of Macmillan?
7. Is this different from before you attended the clinic/event? If yes, what led to the change?

#### **Future**

8. Would you be interested in attending Macmillan events in the future?

For you, is Macmillan a trusted organisation?