



Evaluation of Macmillan health and wellbeing clinics

Executive summary

Macmillan Cancer Support

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Contents

1. Introduction	1
2. Why health and wellbeing clinics?	1
2.1 Key achievements of the pilot clinics.....	1
2.2 Cost case	2
2.3 Service model.....	2
2.4 Who are health & wellbeing clinics for?.....	4
2.5 What's different about health and wellbeing?.....	5
3. In practice: making it work	5
3.1 Function.....	5
3.2 Staffing	6
3.3 Recommended clinic process	7
3.4 Health and wellbeing clinics in the Transformed Model of Care Pathway.....	8
4. Background to the pilot and clinics	9

1. Introduction

This document has been compiled for commissioners and provider organisations interested in the wider implementation of Macmillan Cancer Support's health and wellbeing clinics, piloted in 2010-11. The evaluation of the pilot found that health and wellbeing clinics can enhance the quality of care, improve patient reported outcomes and reduce patients' use of health services¹. This document examines the case for the clinics and provides a guide to implementing the model.

2. Why health and wellbeing clinics?

2.1 Key achievements of the pilot clinics

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.

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

¹ Evaluation of Macmillan Health and Wellbeing Clinics - Final Report, OPM (2011).

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.

2.2 Cost case

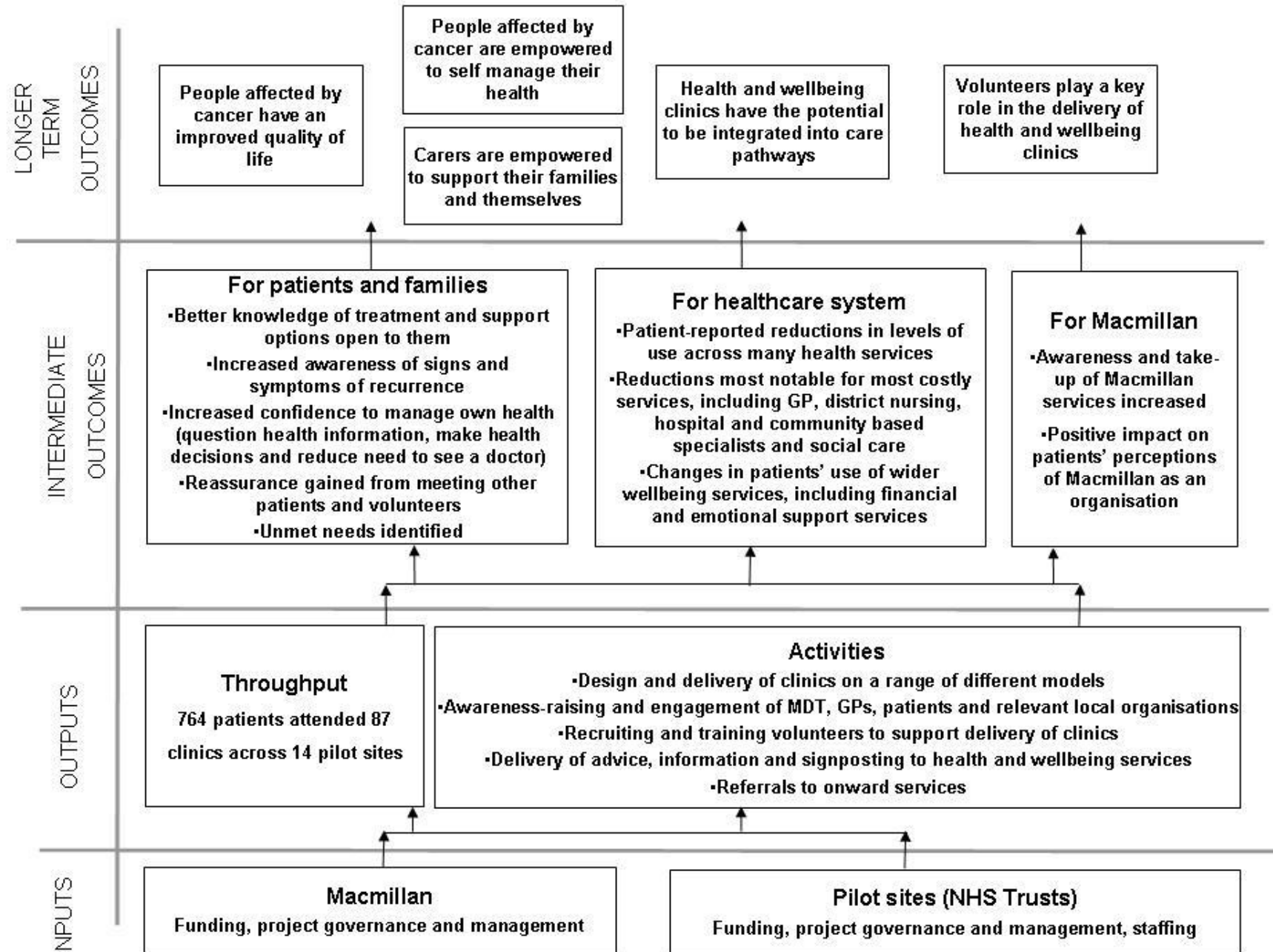
Some early scoping has been conducted in terms of identifying the range of direct and indirect costs, and the cost of set-up and running, in order to build up intelligence in developing a business case. These findings are available in a separate report.

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	

2.3 Service model

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



2.4 Who are health & wellbeing clinics for?

Patient throughput in the pilot phase

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.
- A systematic approach to tracking patients through invitation and attendance should ensure that all patients who can benefit from attending a clinic have opportunity to do so.

Identifying patients for health and wellbeing 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 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 NCSI² 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 patients³. 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.

² NCSI, Davies et al (2010) Cancer follow-up: towards a personalised approach to aftercare services: a review of current practice and initiatives

³ National Cancer Patient Programme – Survey Report, Department of Health, 2010

- **Receptiveness** - some patients may wish to move on from their experience of cancer and not to 'dwell' on it. In this situation, the clinic should be presented in such a way as to reassure patients of the value of health and wellbeing, so that the wish to dissociate themselves from their cancer does not compromise their future health.

2.5 What's different about health and wellbeing?

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 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'.

The value of Macmillan's brand and 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, and as an organisation in which they can have confidence.

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 (including hospital-based Macmillan information centres, financial advice and a buddy support network).

3. In practice: making it work

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.

3.1 Function

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

3.2 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.

Type of staffing	Clinical/non-clinical staff	Volunteers	Administrative support
Who	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
Function	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.

Training	Details
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.

3.3 Recommended clinic process

The following table shows recommended components of planning, delivery and follow-up. Examples of pilot sites where these were demonstrated effectively are shown in italics.

Stage	Components
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<p>Pre-clinic design and inputs</p>	<ul style="list-style-type: none"> • Awareness and engagement of patients, MDT, primary care, voluntary sector, commissioners <i>eg Barts & the London</i>. • Pathway integration (of clinics into cancer and survivorship pathways) <i>eg Barts & the London</i> • Tailor design and branding of the clinic to the target patient group (e.g. consider partnership with a community organisation to target BME groups; one-to-one sessions are more appropriate to complex and palliative needs) • Agree appropriate model (ideally, including ‘market stalls’ to promote a wide range of health and wellbeing services) • Agree role of volunteers (ideally, ensuring opportunity for volunteers to share their personal experiences with patients) • Training of staff and volunteers <i>eg Rotherham, Velindre All</i> • Pre clinic needs assessment, based on assessment and care plan / holistic needs assessment • Referral mechanisms • Administrative support (paid/voluntary) <i>eg Rotherham, Velindre CNS</i> • Agree data collection and patient tracking processes
<p>Processes at the clinic</p>	<ul style="list-style-type: none"> • Processes (tracker system) <i>eg Barts & the London</i> • Interventions (for example, care action planning, exercise or relaxation techniques) <i>eg Milton Keynes, Velindre All</i> • Communication models (for example, presentations, market stalls, one to one support) • Information giving including key health and wellbeing messages (verbal; written; signposting); tailored to audience • Data collection for tracking and evaluation
<p>Outputs and actions following the clinic</p>	<ul style="list-style-type: none"> • Documentation (e.g. letter to GP) <i>eg Aintree</i> • Referral to buddy support programme <i>eg Ayrshire & Arran</i> • Timely referral and access to other services and support networks to ensure sustained benefit <i>eg Milton Keynes, Aintree, Ulster and Belfast</i> • Information for patient to take away <i>eg Velindre CNS</i> • Tracking and evaluation data processed

3.4 Health and wellbeing clinics in the Transformed Model of Care Pathway

Clinics were originally conceived to address needs of patients at the post-treatment stage⁴, but the pilot has demonstrated that clinics may work well earlier in the pathway, depending on patients’ needs and tumour site (for example, lung cancer patients benefitted more from clinics when they attended closer to the point of diagnosis). Pilot sites catered for patients at various points, including:

- Lung – at the point of diagnosis for those not receiving treatment with curative intent
- Breast - at the point of diagnosis and 4-6 weeks post active treatment

⁴ Post treatment is defined as being after the active treatment phase of surgery, chemotherapy and radiotherapy

- Gynaecology – 4-6 weeks post active treatment
- Haematology – within 6 months of treatment
- Prostate – within 6 months-1 year of treatment.

Following commencement of the health and wellbeing clinic pilot, work on a Transformed Model of Care has been developed by the NCSI. Currently they are testing a risk-stratified pathway to determine various approaches for managing aftercare. Health and wellbeing clinics can fit into this model. Integrating health and wellbeing as part of the pathway means that care is scheduled and anticipated, and becomes part of a whole-systems approach to managing patient needs. There are key factors underpinning high quality patient care throughout the pathway, including clinics as a successful element of it, which include: a) comprehensive needs assessment and care planning and b) care co-ordination (case management/key worker) to support communication and the interface between different sectors.

4. 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.

Evaluation of the pilot

OPM, working with specialist health consultancy HPA, was commissioned to evaluate the pilot across the 14 UK sites between January 2010 and April 2011, with the following aims:

- To assess whether the clinics meet the needs of cancer patients and their carers/families
- To identify areas of unmet need for patients and carers/families
- To assess the clinics' effectiveness as a forum for signposting to other services
- To generate recommendations for further refinement of the clinics and further roll-out.

Please note that 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.

Commissioning of clinics – the view so far

As part of the evaluation, we interviewed commissioners from the four nations of the UK, where commissioning processes and cycles differ. Interviews took place in 2010 (prior to planned reforms within health and social care) and identified the following outcomes which all commissioners were keen to see realised by the clinics:

- Added value for patients
 - Patients having an increased knowledge of their condition and confidence to self-manage, which reduces their reliance on health and other services
 - Patients feeling empowered to move on to life after cancer
- Added value for services
 - Opportunity to get across health promotion and prevention messages
 - Support for appropriate delivery of follow-up care and changes in patterns of referral
 - Part of a scheduled care pathway and whole systems approach to patient needs.

The health and wellbeing pilots demonstrate aspects recommended in the Department of Health's Improving Outcomes: A Strategy for Cancer⁵, 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.

⁵ Improving Outcomes: A Strategy for Cancer, Department of Health, January 2011