

**National Cancer Survivorship Initiative
Assessment and Care Planning Workstream:
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**Health and Well-Being Clinics: Transition from
Patient to Survivor**

1. Background

The National Cancer Survivorship Initiative (NCSI), borne from the Cancer Reform Strategy (DH, 2007a), has gathered a range of evidence about the current picture of care and support for cancer survivors. The findings suggest that current follow-up arrangements are not all meeting the needs of survivors. This evidence includes the Picker survey of over 2,000 cancer survivors between June and September 2009, which found that 43% of respondents would have liked more information and advice, 75% did not have, or did not know if they had, a care plan and 75% reported not knowing who to contact for advice outside of office hours (Sheldon and Sizmur, 2009).

In an effort to address these weaknesses in the aftercare provided to cancer survivors, the NCSI has been developing and pilot testing alternative models of follow-up that will ensure every cancer survivor is supported to lead as normal a life as possible. One such initiative currently being tested by the Assessment and Care Planning workstream are **Health and Well-Being Clinics**, a one-off event that will enable survivors and their carers to manage the transition between the treatment phase of their care and survivorship. Many cancer patients feel abandoned during this transition (Hewitt, Greenfield, and Stovall, 2005), an experience that is clearly reflected in one comment shared during a supported self-management programme for breast cancer survivors:

“After treatment you feel like there is a black hole – all your support goes. In a way, you feel abandoned.”¹

The Health and Well-Being Clinics are being considered as an adjunct or alternative to current approaches to cancer follow-up, with a strong emphasis on helping to inform and support people after cancer treatment. The clinics comprise a group-delivered programme, delivered in a healthcare or community environment and held at varying times designed to meet the needs of people affected by cancer, which focuses on a broad spectrum of topics found to be relevant to cancer survivorship:

- informing and educating patients about their ongoing management/care requirements
- strategies for managing the early effects of their diagnosis and treatment
- opportunities available for promoting their own health
- lifestyle advice (e.g. exercise, weight maintenance, healthy eating options, etc.)

¹ This comment was made during a focus group conducted to evaluate the Helping Overcome Problems Effectively (HOPE) supported self-management programme for breast cancer survivors at the Birmingham East and North test community.

- agreeing and finalising the survivorship care plan with the individual cancer survivor
- ensuring the end of treatment summary record is initiated and forwarded to the GP
- ensuring that patients have received or are given the relevant forms or instructions relating to their ongoing monitoring/screening requirements and appointments.

The main focus of these clinics is to inform and educate the patient about the clinical and supportive care aspects of their ongoing management. If their needs cannot be addressed at the clinic there is then the ability to signpost them to the relevant supportive care opportunities available to them.

The clinics also provide an opportunity for carers to seek information and support that enables them to support the person affected by cancer to return to “normal” after their cancer treatment.

Key to the success of these clinics is the involvement of regular volunteers, who will have been effected by cancer themselves, who will provide a holistic range of services such as coordination of the clinic, buddying, information and support, and financial advice. The Department of Health (2010a) have highlighted the value of volunteers in efforts to improve health and well-being. In particular, David Cameron’s efforts to ‘rebuild Britain’ comprise the notion of a ‘Big Society’ where services are run by volunteers and work-life balance is restored among busy professionals. Community Service Volunteers (CSV) has demonstrated the feasibility of the ‘Big Society’ in their pioneering project ‘Volunteers in Child Protection.’ Surveys have shown that the public have a desire to volunteer and benefit personally from volunteering (IVR, 2007); the Health and Well-Being Clinics utilise the value of the volunteering culture in the delivery of post-treatment information and support.

In developing and testing Health and Well-Being Clinics, the Assessment, Care Planning workstream of the NCSI are supporting the five key shifts highlighted within the Cancer Vision (Macmillan Cancer Support, and NHS Improvement, 2010). In particular, the clinics support the first shift for **a cultural shift in the approach to care and support for people affected by cancer – to a greater focus on recovery, health and well-being after cancer treatment.** This shift will enable people affected by cancer to be prepared for the long-term – for living with and beyond cancer. Information and support will be supplied in partnership with cancer survivors, including information about sources of support and who to contact with concerns.

2. The Rationale for Health and Well-Being Clinics

The concept of Health and Well-Being Clinics emerged from a scoping exercise designed to assess the evidence base of similar interventions, as well as to explore best practice and patient outcomes. The rationale for these clinics is thus multifaceted and based on evidence within the literature, examination of current practice in cancer aftercare, and consideration of the current economic climate, all of which are outlined below.

2.1. The Benefits of Group-Delivered Aftercare

Much learning has come from work in long-term chronic conditions (Vieira et al., 2007; Escobar, 2001), with reported benefits of group-delivered interventions including improved

self-efficacy and symptom control (Sadur et al., 1999). **One of the key contributors to these benefits is reported to be that the content of group-delivered programmes is, in the main, patient-led and dependent on patient questions and concerns** (Shahady 2006). Researchers have concluded it to be a promising approach to chronic care management for motivated patients (Jaber, Braksmajer, and Trilling, 2006; Trento et al., 2004).

Fletcher et al. (2006) examined the acceptability of group visits in comparison to individual follow-up, in a heterogeneous sample of urological patients. Patients (n = 287) were invited to participate in a 'drop-in group medical appointment,' where appointments were made based on gender rather than diagnosis. Most diagnoses were prostate cancer, erectile dysfunction, benign prostatic hyperplasia, incontinence, neurogenic bladder and chronic discomfort syndromes. Patient satisfaction with the drop-in group medical appointment model was as high as that of individual follow-up, with 87% of group patients rating their experience as excellent or very good vs. 88% by individualised follow-up patients. **Not only does this study indicate that group-delivered aftercare can, at the very least, offer equivalent patient satisfaction at a reduced cost, but it also demonstrates the efficacy of group-delivered programmes for people dealing with sensitive issues, which is often the case for cancer survivors.**

More specific to cancer survivors is the recent pilot testing of a breast cancer survivors 'support conference' at Brighton and Sussex University Hospital NHS Trust (Chatfield and Simcock, 2008). Feedback from attendees was positive, with over 50% reporting the conference to be 'very helpful' or 'helpful' and endorsing the benefit of providing holistic information, reassurance and the opportunity for discussion with peers. **The initiative reduced pressure on clinic time; 30 patients were removed from routine clinical follow-up, equating to 30 scheduled appointments and up to a further 240 appointments collectively.**

More recently, Bingen and Kupst (2010) have demonstrated an educational programme to be effective in increasing self-reported survivorship education for adolescent and young survivors of childhood cancer, families, and health care providers (Bingen and Kupst, 2010). The programme also increased resource awareness, ultimately enhancing the support available to survivors.

The literature suggests that group sessions are favourable among cancer survivors. For example, in one study that included four sessions at two-week intervals (two face-to-face group sessions and two one-to-one telephone sessions), 55% thought that an additional group session should be added due to the "*real value in that kind of exchange*" (Cimprich et al., 2005). Indeed, peer modelling has been found to assist in the transition from patient to survivor in breast cancer (Stanton et al., 2004). Peer discussion has been found to improve psychological well-being in prostate cancer survivors (Lepore et al., 1999). **Group settings generally provide an opportunity for social comparison and learning through vicarious experience, which can enhance self-efficacy in ability to cope with and manage personal health and well-being.**

Comparisons with survivors who are further along the disease trajectory can be reassuring and enhance levels of hope, as demonstrated in the recent pilot testing of a supported self-management programme for breast cancer survivors (Macmillan Cancer Support, NCSI, 2010). Focus group data highlighted particular reassurance from peer tutors who had experience with cancer. One participant commented on how the facilitator had *“been through this time that we’d been through but had come out the other end,”* whilst another shared how a personal conversation with the tutor helped her cope with treatment-related decisions:

“I had, well I haven’t had it but talking about reconstruction with [name removed] as well. And that was wonderful. I was talking to her and she helped.”

Another example, at a prostate H& WB clinic an attendee, reluctant to speak to a professional, brought up an issue of incontinence with a volunteer, who was able to share his experiences and facilitate the individual seeking professional support.

2.2. The Benefits of taking an Educational approach to Information Provision and Aftercare

Group sessions in the form of group delivered programmes aimed at informing and educating the patient about the clinical aspects of their ongoing management and care offer innovative quality improvement. Not only do they support other aftercare services, but they go further in their potential to increase health literacy. Health literacy is the capacity to seek, understand and utilise health information to participate in decisions about one’s own health. It is central to a person’s participation in their healthcare – knowing when to seek medical advice; communicating effectively with healthcare professionals; and adhering to treatment (Jordan et al. 2008). Many cancer survivors desire greater control over their own health and well-being, they can only do so effectively with access to the appropriate information and educational support. This has been recognised in *‘Better information, better choices, better health’* (DH, 2007b), which highlights information as being fundamental in providing people with personal control and enabling them to stay healthier for longer. Lack of information can reduce patient autonomy to fully engage in their care, and can also have a number of adverse health consequences. For example, observational studies have found inverse relationships between information satisfaction and post-treatment anxiety and depression (Fallowfield et al. 1994).

Educational initiatives combined with peer group support have been found to be more effective than education alone (Lepore et al., 2003). This is because information provision is an active and ongoing process requiring more than merely distribution of written material. Once information has been provided, further discussion is often required as patients make sense of the information and interpret its personal relevance. Health and Well-Being Clinics provide a setting for not only receiving information but also understanding and exploring it so that it becomes useable.

- Overall, group-oriented models of aftercare are educationally focused precursors to patient-initiated follow-up, which requires the skills and confidence to self-manage as well as to navigate the healthcare system (Davies and Batehup, 2009). Patient-initiated follow-up is becoming increasingly popular and Health and Well-Being Clinics could play a fundamental role in preparing survivors for this.
- The new health White Paper places considerable emphasis on Shared Decision Making: *'The White Paper details how the government plans to put patients at the heart of the NHS and make shared decision making the norm'*. The educational component of the H&WB clinic facilitates shared decision making between clinicians and patients which reflects a more egalitarian relationship, in which the patient can make a more personal contribution to decisions about their recovery care and support.

2.3. User Satisfaction

The rationale for Health and Well-Being clinics is further supported by comments from attendees:

"Please convey our sincere thanks to all Macmillan Cancer Support Staff and Volunteers who were involved in the organisation of the Prostate Cancer Health & Wellbeing Event on Wed 30th June at Lincoln City Football Club. Pat and I were so pleased we decided to attend, because the information, support and advice obtained, has removed a great burden from our minds. It's bad enough living with this disease without having to worry about the future. Again sincere thanks to you!"

Letter sent to co-ordinator of H&W clinic

"On listening to the talk from the clinical psychologist at the Belfast Breast Clinic, I realised that it wasn't just me who felt like this. My husband was amazed that we were not alone in what we were going through and having the chance to talk to other husbands, for him, was fantastic. I came away thinking that I was relieved that what I was going through was normal."

Comment made by attendee at Belfast H&W clinic

The clinic, for these people, normalised their experiences, provided support, and enabled a focus on the future. It could also be hypothesised that by addressing these issues during the Health and Well-Being Clinics, this may have prevented these patients contacting a range of health professionals because of unmet needs for information, signposting and reassurance.

3. Challenges to Address

In highlighting the strengths and rationale for Health and Well-Being clinics, a number of challenges have been identified and addressed, as described below.

3.1. Should all cancer survivors be offered the opportunity to attend Health and Well-Being Clinics on completion of primary treatment?

The Cancer Reform Strategy information vision highlights that improved information can empower patients to be more involved in decision-making about their healthcare (DH, 2007a). The vision also outlines plans for 'National Information Pathways' and tailored information prescriptions to ensure that patients receive high-quality information at each stage of the care pathway. The emphasis is on information delivery being fully integrated into cancer care and support, reinforcing face-to-face communication with healthcare professionals and being available in primary and secondary care as well as from dedicated information and support centres.

Although no two survivors of cancer will have the same care needs and priorities, nor the same issues surrounding transition from patient to survivor, most will desire information that will assist them to make informed decisions (Coulter, 2003). Lack of information can reduce patient autonomy to fully engage in their care, and can also have a number of adverse health consequences. Observational studies have found inverse relationships between information satisfaction and post-treatment anxiety and depression (Fallowfield et al. 1994). Users of healthcare services vary enormously in the amount of information they wish to receive about their health and healthcare (Detmer et al. 2003); it is argued that resources such as the Health and Well-Being Clinics allows freedom of choice in what and how much information to access.

By contributing to improvements in health literacy, the clinics will be helping to close the gap in health inequalities. The accessibility of the clinics to all cancer patients, regardless of type of cancer, personal needs, socioeconomic status, ethnicity, etc., is also anticipated to improve aftercare for 'hard to reach groups,' including ethnic minorities and those from socially deprived areas.

There are examples of clinics being moved around areas to ensure there is equity of provision. For example in Rotherham, clinics for women's health, have been moved around the city including a clinic being held in a BME community. In Wales where there are many rural communities clinics are taking place in out reach venues to meet the needs of the patient population

In a recent study by Walsh et al. (2010), almost 96% of patients with varying types of cancer (n=1,841) reported obtaining information from at least one source, and 69% reported obtaining information from a source other than treatment staff. Information is clearly of huge priority to patients in that the majority do appear to seek further information outside the clinical environment. Health and Well-Being Clinics ensure the information being accessed is accurate, relevant, and from a reliable source.

3.2. What is the relationship between Health and Well-Being Clinics and individualised assessment and care planning?

Whilst individualised assessment and care planning for all post-treatment cancer survivors is the key aim and the 'gold standard' in aftercare (DH, 2010b), the feasibility of this remains a challenge within practice. Not all patients will, at present, receive individualised assessment and care planning. This is highlighted in the Picker survey, where as many as 75% of respondents did not have, or did not know if they had, a care plan. These survivors are thus missing out on vital information that could facilitate their social reintegration and ability to manage their condition and treatment side-effects. Health and Well-Being Clinics could, at least in part, help address the disparities in aftercare available to cancer survivors by making vital information available within a supportive and educational environment.

Not all patients feel able to disclose all of their care needs when in a face-to-face or one-to-one situation. However, information perceived as embarrassing could be collected at the Health and Well-Being clinics, ensuring that all patients regardless of ability to disclose personally-relevant details will be able to have their holistic needs addressed.

Health and Well-Being clinics might even complement and facilitate individualised assessment and care planning by providing an opportunity to consider one's needs and explore one's options prior to individual consultations. In turn, this can help them prepare questions in advance and thus gain the most from their individualised assessment.

Health and Well-Being Clinics are not a replacement for individualised assessment and care planning, but an adjunct that could be highly valuable both pre- and post- consultations aimed at developing a care plan in partnership with survivors. Similarly, the presence of high quality assessment and care planning in any given health setting does not preclude the additional benefit of a group delivered programme.

3.3. Are Health and Well-Being Clinics feasible in terms of current post-treatment care pathways?

A number of organisations currently offer post-treatment groups to cancer survivors, such as the Good Hope Hospital, Birmingham East and North PCT. Clinics can be undertaken with limited resources if they are supported by existing staff and volunteers. Clinics can be co-ordinated by a CNS and/or Information and Support Manager and additional professional time can be on a sessional basis if required. Further examples can be seen in Portsmouth, Lincoln, North Tyneside and Liverpool where the clinics are co-ordinated by the professional who is also in attendance to answer any clinical questions that may arise. Where the clinics work particularly well, the lead professional organises their work schedule to accommodate the clinic as part of the working week, rather than it being seen as an extra activity. This actually saves time and money as they are seeing a cohort of patients in a group rather than individual appointments.

Another way in which Health and Well-Being Clinics have been made feasible is via risk assessment. For example, at the Belfast Breast Health and Well-Being Clinic, attendees have been risk stratified by the consultant so that low risk patients are being offered attendance at the clinic.

It was clear from the recent review of self-management interventions (Davies and Batehup, 2010) and from piloting work in NHS settings that not all patients require the same intensity of preparation for self-managing recovery and rehabilitation. Indeed, many patients are well able to risk stratify themselves as they are aware of their own needs and capabilities. It could be predicted that a proportion of patients will not desire or take up an invitation to attend a post-treatment event. This leads further to the potential feasibility of this initiative.

Some of the examples of successful group-delivered interventions highlighted within this document are much more resource-intensive than the Health and Well-Being Clinics (i.e. they are longer in duration and medically-led). The success of such programmes supports the feasibility of Health and Well-Being Clinics, which are one-off, volunteer-led events.

3.4. Are Health and Well-Being Clinics cost-effective?

The cost-effectiveness of Health and Well-Being Clinics requires further evaluation. However, the core components of the clinics, and some of the evidence-base presented within this document, support that they would be cost-effective in a number of ways:

- 1) The clinics will be reliant on peer input and volunteer involvement, and thus costs should be saved in terms of health professional's time. This supports the 'Big Society' vision.
- 2) It is highly likely that the educational aspect of the clinics will assist survivors with self-management and subsequently reduce unplanned telephone contact with clinical nurse specialists and other health professionals. It might also assist in reducing other unscheduled contact with primary and secondary health services.
- 3) Through signposting, survivors will have greater knowledge of how to navigate the healthcare system.
- 4) Group-delivery is fundamentally more cost-effective than other modes of aftercare, reaching a large group of people within a condensed period of time. This is one reason for its frequent application within long-term chronic conditions. This makes the assumption that attendance at such a group is by invitation and that alternatives are available for those who may feel this would not suit them.
- 5) Failures in the provision of information are among the most common reasons for official complaints by patients and relatives, which can involve hours of medical, managerial, and legal time and expense (Ombudsman 1995).

4. The Future of Health and Well-Being Clinics

The benefit of group-delivered educational clinics is that they can be designed, in the future, to address different stages of survivorship. For example, another period of transition or adjustment can be the 5-year milestone, which is widely acknowledged as a time when risk

of recurrence is reduced. Whilst this can be a time of relief, it can also be a time when family and friends are eager to move on from the disruptions of the cancer experience, leaving some survivors to work through unresolved questions and feelings alone (Lewis and Field, 1995). Re-establishing contact with health services and peers might be beneficial during this period.

They can also be modified according to different delivery modalities. The internet is increasingly being utilised in the delivery of aftercare for cancer survivors, including workshops that are available to 25-30 participants at a time (Lorig et al., ongoing). It is possible that, in the future, Web-Based Health and Well-Being Clinics could be used to reach cancer survivors who have restricted mobility or who avoid group-based activities.

They are also an opportunity for carers to hear the health promotion/prevention messages that can be shared across families, and which could potentially decrease the health burden.

5. Investing in Health and Well-Being Clinics

In conclusion, the following is a summary of the key strengths inherent within the Health and Well-Being Clinics for cancer survivors:

- They support **a cultural shift in the approach to care and support for people affected by cancer – to a greater focus on recovery, health and well-being after cancer treatment.**
- Cancer survivors desire more information than they are currently receiving.
- Cancer survivors will seek information beyond the hospital; Health and Well-Being Clinics can provide accurate, relevant, and trust-worthy information in a context where they can get support to use it effectively.

- They are designed to educate as well as inform, thus tackling health literacy and resultant health inequalities.
- The group environment is conducive of factors found to help survivors with self-management skills, such as the opportunity for vicarious experience and peer support from people further into the survivorship trajectory.
- They enable survivors to access the type and amount of information they desire, in partnership with those supporting them.
- They provide signposting and are thus likely to improve service navigation and healthcare utilisation.
- Information is provided on self-management skills as well as signs and symptoms of recurrence, which is likely to reduce unplanned medical appointments.
- They are highly supported by volunteers, saving clinician time and facilitating the success of the 'Big Society.'
- Group-delivered interventions are more cost-effective than one-to-one consultations.
- They offer a feasible adjunct to assessment and care planning.
- There is the potential to develop the clinics further in terms of audience and delivery method.

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