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**National Cancer Survivorship Initiative
Active and Advanced Workstream**

LIVING WELL SUBGROUP SCOPING EXERCISE:

“LIVING WELL WITH, AND BEYOND CANCER”

**Macmillan Cancer Support
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Executive Summary

This current scoping report represents a review of the evidence of the benefits of “*living well*” for those with active and advanced disease, along with examining current good practice in this area. This report addresses the NCSI Vision’s five key shifts¹ and feeds into the NCSI commissioning guidance/final Vision document which is to be published in autumn 2010. It is clear that “*Living Well Services*” by their nature met all of the five key shift’s requirements (see pg 6). Results from a non-systematic literature review looking at benefits arising from Living Well Services for people with cancer showed some evidence for these services improving quality of life, however, there is limited evidence about economic cost-savings for the NHS due to lack of research in this area. There is a need for appropriately designed, longitudinal studies to be performed to answer these research questions.

The results section of this report presents supporting evidence that Living Well Services should:

- provide a whole person approach to care,
- allow decisions about care to embrace a person-centred approach, and,
- provide self-management tools.

Living Well Services should also be available via:

- equal access to services (financially and geographically),
- information accessed by a trained key-worker (using the NHS patient information pathways).

Living Well Services should also:

- be financially efficient/ make best use of resources, and,
- allow potential cost savings for NHS.

The whole Living Well approach combines to form a service which aims to help people with active and advanced cancer improve their health, wellbeing and quality of life, whilst also complementing current cancer services offered by the NHS. A model of strategic partnership between health care providers, local authorities/social services, and the voluntary sector can be seen as a strong model of developing Living Well Services which are coherent and sustainable.

It is recommended that the NCSI should concern itself with the delivery of Living Well Services, that is: improved cancer services which enable the whole person to live well (physically, psychologically, socially, financially, spiritually and in terms of lifestyle), as opposed to treating cancers in isolation from the patient. This could be achieved through the “*Cancer Patient-Centred Charter*” (Bray 2010, see appendix II). “*Where all involved in the cancer journey should pay particular attention to work towards the patient’s/carer’s version of living well, and identify and magnify what patients/carers can do, and do for themselves, especially towards living well.*”

Background

The Cancer Reform Strategy (2007)² set out the Department of Health plans for improving National Health Service cancer care by 2012. With the number of cancer survivors ever increasing, a key recommendation of the Cancer Reform Strategy was to create the “*National Cancer Survivorship Initiative*” (NCSI). The aim of the NCSI is, by 2012, to have taken the necessary steps to ensure that survivors get the care and support they need to lead as healthy and active a life as possible, for as long as possible, with the aim of “*improving the services and support available for cancer survivors*” (Cancer Reform Strategy document, pg 4).

The NCSI was created in 2008 and is co-chaired by the Professor Sir Mike Richards Department of Health and the Chief Executive of Macmillan Cancer Support Ciaran Deváne. Together, these partners state they “*are committed to taking steps to ensure that all cancer survivors get the care and support they need to lead as healthy and active a life as possible , for as long as possible*” (NCSI Vision document ¹, pg 2).

Two Million Reasons³ (2008) identified that there are 2 million survivors of cancer in the UK, with 1.6 million people in England living with a diagnosis of cancer¹. With survival rates improving, along with an ageing population presenting more incidence of cancer, it is thought that by 2030 there will be over 3 million people living with cancer¹. There is great need to address the issue of survivorship to allow people to have the best possible experience of living with and beyond cancer.

The NCSI sets out its goals for what cancer care will look like in 2012 in its Vision document¹. It highlights five “*key shifts*” necessary to deliver high quality care and support for people with cancer in England. These shifts are as follows:

Key Shift 1. 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.

Key Shift 2. A shift towards holistic assessment, information provision and personalised care planning. This is a shift from a one-size fits all approach to follow up to personalised care planning based on assessment of individual risks, needs and preferences.

Key Shift 3. A shift towards support for self-management. This is a shift from a clinically led approach to follow up care to supported self-management, based on individual needs and preferences. This approach empowers individuals to take on responsibility for their condition supported by the appropriate clinical assessment, support and treatment.

Key Shift 4. A shift from a single model of clinical follow up to tailored support that enables early recognition of the consequences of treatment and the signs

and symptoms of further disease as well as tailored support for those with advanced disease.

Key Shift 5. A shift from an emphasis on measuring clinical activity to a new emphasis on measuring experience and outcomes for cancer survivors through routine use of Patient Reported Outcome Measures in aftercare services.

The Living Well Subgroup scoping exercise looking at “Living well with, and beyond cancer”

The NSCI consists of seven workstreams to develop the work identified in the Cancer Reform Strategy (2007)². These are: Assessment and Care Planning, Supported Self-Management, Work and Finance, Consequences of Cancer Treatment, Children and Young People, Research, and, Active and Advanced Disease.

This particular scoping report looking at “*Living Well Services*” for people with cancer has been commissioned by the Active and Advanced Disease workstream’s Living Well Subgroup. This subgroup of the workstream focuses on approaches to “*living well*” for survivors of cancer who currently have cancer and are undergoing treatment and/or their cancer is recurring, secondary or metastatic. Many people in the active and advanced disease group will go on to need end of life care (see discussion paper “*Patterns of Active and Advanced Disease*” for details of its natural history⁴).

“*Living Well Services*” in this report refers to any service, programme or activity available to people with active and advanced cancer which may improve wellbeing and quality of life. In a practical sense, this means attending centres offering holistically tailored person-centred services allowing patients to take on board principles of self-management, enabling transformative, sustainable “*living well*” with and beyond cancer.

Living Well Services are relevant to all of the five key shifts in the NCSI vision document:

Key shift 1. Living Well Services provide an opportunity for people to focus on health and well-being after cancer treatment.

Key Shift 2. A holistic needs assessment will identify patient’s “*living well*” needs and enable a tailored approach to this particular aspect of care.

Key shift 3. Patients would ideally move away from follow-up care towards self-management of the health condition, potentially saving money and improving the quality of life of people with cancer. (See Supported Self-Management Workstream review: “*Cancer Follow-up: Towards a personalised approach to aftercare*”, NCSI publication⁵).

Key shift 4. Tailored, person-centred support for active and advanced disease patients allows the right combination of Living Well Services available to support their care.

Key shift 5. Measuring the patient experience of living well programmes will highlight the benefits associated with this approach.

Therefore, this report looks at the potential in commissioning Living Well Services in the context of using the approaches of holistic care, person-centred care and self-management. The report will look at any research evidence to support the effectiveness of such Living Well Services for active and advanced cancer in terms of cost saving/ quality of life improvement. The report will then go on to provide examples of good practice in terms of Living Well Services in the UK and rest of world, and also look towards examples of similar services for other chronic diseases (Heart disease, Arthritis, Diabetes, COPD).

Finally, the findings of this report ultimately feed into the NCSI commissioning guidance/final Vision document which is to be published in autumn 2010.

Definitions of terms used in the report

To aid the reader, specific terms used in the report are defined as follows:

Active and Advanced Disease:

Macmillan's report on cancer survivorship ("*Two million reasons*"³) states that some survivors of cancer may be living with "*active, progressive or recurrent*" disease. From this they mean that cancer may be active and cannot be cured and/or whose cancer has spread to nearby tissues (locally advanced cancer) or other part of the body (metastases). This definition will be used to denote active and advanced disease throughout this report.

Living Well:

Concerns meeting all needs of living well – psychological, spiritual, physical, emotional, social, occupational, intellectual – every aspect of human life.

Compare this to the World Health Authority's definition of Health: "*Health is a state of complete physical, mental and social well-being and not merely the absence of disease or infirmity.*"⁶

Living well can also take a holistic or whole person approach (see below).

Living Well Services encompass the following approaches:

Holistic/Whole person approach/Integrative Healthcare:

Definition of Holistic/Whole Person Approach - from British Holistic Medical Association⁷

"Mind, body and spirit - diagnosis and treatment must take account of the whole person. Open-mindedness to different ways of creating health and managing illness, including complementary medicine. Self-care - the BHMA is committed to promoting the concept of self-care, both for patients and practitioners. The art of medicine - listening and communication, care and compassion are essential for the holistic practitioner. The bigger picture - health has political, economic, environmental, community and family dimensions."

National Wellness Institute USA - Dr. Bill Hettler's six holistic dimensions of wellness: Social, Occupational, Spiritual, Physical Intellectual and Emotional⁸.

Foundation of Integrative Health's definition of Integrative Healthcare: "*an integrated approach means bringing together mainstream medical science with the best of other traditions. Complementary interventions may range from stress reduction techniques to therapies like acupuncture or nutritional therapy.*"⁹

Person-Centred Care:

Carl Rogers (Psychologist) devised Person-Centred Therapy – which is a popular approach in psychotherapy. Person-Centred care is a different concept, but aligned to the therapeutic approach. It is mostly used in the context of dementia care. "*Person-Centred Care (PCC) is ethical and evidence based care that puts the person first regardless their level of mental or physical impairment. Person-Centred Care evaluates the quality of care*

being provided and each person's experience of well being, through the eyes of the person receiving that care.....

Core Beliefs & Principals V + I + P + S = Person Centred Care

V = Value the person regardless of level of dementia

I = Treat people as individuals

P = Look at the world from the person's perspective

S = Provide a positive social environment in which a person can experience well-being to end of life.

Dawn Brooker, Bradford Dementia Group” Person Centred Care Advocate¹⁰.

Patient-Centre Care:

From Kings Fund website definition: ¹¹

“Patient-centred care has many definitions but a well-accepted one is offered by the Institute of Medicine: ‘providing care that is respectful of and responsive to individual patient preferences, needs, and values and ensuring that patient values guide all clinical decisions’. In today’s NHS it has come to mean putting the patient and their experience at the heart of quality improvement. Patient-centred care is one aspect of health care quality, as important as care being safe, clinically effective, timely and equitable. Patient-centred care is multi-dimensional; it encompasses all aspects of how services are delivered to patients. The Institute of Medicine offers this list: compassion, empathy and responsiveness to needs, values and expressed preferences co-ordination and integration information, communication and education physical comfort emotional support, relieving fear and anxiety involvement of family and friends.”

Self-Management Support:

Definition from NCSI Self-Management Support workstream position paper April 2009 ¹²: *“what health services do in order to aid and encourage people living with a long-term condition to make daily decisions that improve health related behaviours and clinical and other outcomes”* (pg 2).

Aims of this report

(Adapted from NCSI Active and Advanced Workstream's Living Well Subgroup meeting minutes, November 2009).

1 – Evidence review (in the context of active and advanced disease) for the effectiveness of Living Well Services around themes of whole person approaches to health, patient-centred approaches to care, and, self-management, with a focus on economic and quality of life benefits.

2 – Recording examples of good practice in Living Well Services across the UK and internationally in cancer or other long-term chronic conditions.

3 – Look at what could be recommended for future commissioning services.

Methods and search strategy for non-systematic review of Living Well Services for people with active and advanced cancer in the UK

To scope out the relevant research concerning economic and/or quality of life benefit associated with UK *“Living Well Services”*, a pragmatic non-systematic review of the literature was undertaken by an expert Library and Information Specialist based at Macmillan Cancer Support and the author of this report.

The following databases were searched: Medline, CINAHL, BNI and PsychInfo using key words in title and body of the text, restricting to English language only studies and articles published since 2000.

The search terms used were as follows:

(For Living Well Services)

Programme\$ OR programme\$ OR service\$ OR workshop\$ OR initiative\$ OR project\$ group\$ OR approach\$

AND

Well living OR living well OR wellness OR wellbeing OR healthy living OR Holistic OR emotional OR spiritual OR psychosocial OR integrative OR self-management OR education\$ OR whole person OR patient-cent\$ OR patient controlled

AND

Cancer

Articles were sifted for relevance and quality by the expert information specialist and this resulted in only three articles being selected for consideration.

The author of this report then hand searched relevant journals in the Penny Brohn Cancer Care Library (Integrative Cancer Therapies, Cancer Supportive Care and The Journal of Alternative and Complementary Medicine). Reference lists were sought from other academics conducting similar research projects. Online searches using Pubmed starting with the gathered articles and expanding the search to other, related articles was also employed as a strategy for finding other relevant research.

Many documents from their respective organisations (Macmillan, Penny Brohn Cancer Care, NCSI workstreams, NHS Sefton and NHS Medway and Breast Cancer Care) were submitted to the author by members of the Living Well Subgroup. Also, grey literature (eg. audit and internal evaluation documents) was sought from other members of the Living Well Subgroup. Research documents relating to patient-centred care (from Dominic Bray) and self-management (from Lynne Batehup) were sent to the author via the Living Well Subgroup of the Active and Advanced Disease NCSI workstream.

Results of non-systematic literature review of Living Well Services for people with active and advanced cancer in the UK

This results section will be split into three parts:

- Part 1. Evidence for Living Well Services (economic and quality of life benefits);
- Part 2. Evidence for Person-centred care in context of Living Well Services;
- Part 3. Evidence for self-management of health in context of Living Well Services.

Before the research findings are unpacked it is important to elaborate on what the “*living well*” approach encompasses (see definitions above). Living Well approaches are essentially the same concept as the holistic/whole person or Integrative healthcare (see Foundation of Integrated Health for their definition⁹ – the latter is not to be confused with integrative medicine although in the USA integrative medicine is equivocal to the UK’s version of holistic healthcare).

Definition of Living well/Holistic or whole person/Integrated Healthcare approach:

(Derived from the NCSI Active and Advanced Disease workstream’s Living Well Subgroup’s internal meetings.)

“Health and wellbeing are a state, and living well is a process”

The living well sub group identified that people will need different types of ‘living well’ support at different times and look at living well as a constantly evolving process of ‘wellness’:

- *Psychological support (developing coping) is the intervention (where needed) that helps unlock the other aspects of ‘living well’.*
- *Welfare, benefits and other financial support (including assistance with filling in forms)*
- *The patient’s support network – friends, carers etc.*
- *Living well physically through good diet and exercise*
- *Emotional and spiritual wellbeing”*

Results Part 1.

Evidence for Living Well Services (economic and quality of life benefits)

A non-systematic literature review of research evidence was carried out for the effectiveness of Living Well Services for people with active and advanced cancer.

There were two main focuses for this literature review; A) whether Living Well Services had an economic benefit in terms of cost-saving reliance on health care services, and B) whether Living Well Services improved quality of life and/or wellbeing of the people with active and advanced cancer. Findings of his review are detailed below:

A) Economic benefit of providing Living Well Services:

In total it is estimated that cancer cost the UK £18.33 billion in 2009¹³ (in terms of health care costs, costs to patient, family and also losses in productivity from those who could have worked). This cost of cancer is estimated to rise to £24.72 billion by 2020¹³. The 5 key shifts of the NCSI's Vision document¹ highlight the need for the move away from follow-up care to other aftercare approaches (perhaps following the example set by American private healthcare providers Kaiser Permanente¹⁴). In addition, due to the increasing incidence of the disease and improving survival rates, current financial climate, and election promises such as one-to-one cancer care¹⁵, it seems essential that alternative approaches to providing quality cancer care are provided.

A literature search was undertaken for this report to investigate whether any studies had been done looking at whether “*living well*” approaches could offer a cost-effective alternative to current cancer care – perhaps using the QALY (Quality-Adjusted Life-Year) measurement. There was very little research on this topic as a whole, with most evidence from exercise programmes in terms of economic benefit of exercise preventing cancer from occurring¹⁶. With a short-term physical intervention for any health condition costing between £20 and £440 QALY (versus no intervention), a net cost saved per QALY is between £750 and £3,150. There is also extensive research to support the use of exercise programmes for people with cancer; including those with active and advanced disease in terms of cost effectiveness¹⁷. With evidence of prevention against breast and colorectal cancers¹⁸, and improving quality of life (psychological wellbeing in particular)¹⁹.

However, looking at the Living Well Services targeted for investigation by this report (ie. holistically tailored person-centred services allowing patients to take on board principles of self-management) there was no further evidence of financial benefit available at present. Clearly there is a major gap in the evidence base here, and to fill it large scale, longitudinal studies should be performed, comparing current financial costs of cancer using the follow-up service with the alternative use of Living Well Services. To date, this research has been difficult to do due to the current small scale use of Living Well Services, but, as more are commissioned perhaps this will offer an opportunity for this comparative research to be carried out.

B) Is quality of life improved by Living Well Services?

As incidence and length of cancer survivorship increases then it follows that the quality of life (with and beyond cancer) should be as good as possible for every cancer patient. Pinguart and Duberstein's (2010)²⁰ meta-analysis of depression and cancer showed that higher level of depressive symptoms raised cancer mortality. Foley *et al.* (2006)²¹ conducted a qualitative exploration of the experience of cancer 15 years after diagnosis and found that the majority of cancer survivors felt that cancer had either positively influenced their lives (providing and unexpected benefit), or had little long-term impact. However, they also found that those experiencing pain, physical deformities and social isolation had significantly reduced quality of life. In

terms of active and advanced disease, Helgeson and Tomich (2005)²² looked at cancer survivors' physical, emotional, social and spiritual quality of life and found that those who had recurring cancer had reduced quality of life (particularly in terms of physical function eg. fatigue, sleep) compared to those who were disease free 5 years after diagnosis. A central aim of the NCSI's Five Key shifts¹ is to improve the quality of life of people living with or beyond cancer; therefore it is important to assess how Living Well Services may contribute to achieving this aim.

The non-systematic literature review conducted for this report has found a number of research papers investigating the ways that holistic, person-centred (also known as integrative health care) Living Well Services improve quality of life/wellbeing. Evidence was sought from all examples of Living Well Services offering a holistic approach to cancer care for people with active and advanced cancer. The review found that a number of cancer centres offering Living Well Services have conducted their own research to look at the benefits of their approach. However, due to the complex nature of the interventions and outcomes, and use of many different patient outcome measurement tools, it is not possible to compare or collate the evidence as a whole. Instead, much of the evidence is qualitative, or uses different measurement tools to assess outcomes.

The following section provides the general findings from research conducted in Living Well centres in the UK and around the world:

Penny Brohn Cancer Care/Breast Cancer Haven's use of MYCaW:

Polley *et al.* (2007)²³ and Seers *et al.* (2009)²⁴ used the MYCaW (Measure Yourself Concerns and Wellbeing) patient reported outcome measurement tool to investigate the experiences of patients attending two Living Well Service providers: Penny Brohn Cancer Care and Breast Cancer Haven. This research is built upon a number of other studies' use of MYCaW, and its sister MYMOP (Measure Yourself Outcome Medical Profile²⁵).

Penny Brohn Cancer Care (previously known as Bristol Cancer Help Centre) is a holistic cancer charity that provides support to help people live well with and beyond cancer. It has services that use a whole person approach to care and uses a range of self-help techniques complementary therapies, and practical advice on lifestyle including eating well. It offers a residential facility for people with any type of cancer (and their supporters) who wish to find out more about the whole person approach to living well. All services are offered free, and charitable donations asked for.

Breast Cancer Haven is a charity that provides day centres offering support, information and complementary therapies to anyone affected by breast cancer. The Haven Programme is free of charge and has been designed to help patients feel better and develop a healthier lifestyle. The programme is flexible and can be taken before, during or after medical treatment. Breast Cancer Haven works with the NHS and other healthcare professionals to promote and provide responsible and effective integrated breast cancer care.

The MYCaW questionnaire (devised by Dr. Charlotte Paterson²⁶) is a patient reported outcome measure that has been designed to evaluate complementary therapies in cancer support care. MYCaW is currently used in around ten UK cancer support centres and also a few in North America. Paterson *et al.* (2007)²⁷ state that it is popular due to its acceptability, brevity, responsiveness to changing situations. MYCaW produces both qualitative and quantitative data about the concerns and wellbeing of patients. To gather data MYCaW is administered twice: firstly before any therapeutic intervention, when people are asked to state and score their main concerns and overall wellbeing. The MYCaW wellbeing score can be viewed as a measure of quality of life. Then secondly MYCaW is administered after therapies, allowing people to re-score their concerns and wellbeing, and also answer the open-ended questions of “*What else is going on in your life?*” and “*What have been the most important aspects about your visit?*”

Across organisations 782 people took part, 92% were female and the most common cancer reported was breast cancer, 588 were re-assessed at follow-up after their experience of the therapy centres. The concerns reported by patients before the intervention were categorised into four groups: 1) Psychological/emotional; 2) Physical; 3) Medical/hospital associated and 4) Wellbeing – see appendix I for more details of these concerns. Psychological and emotional concerns were the most common, accounting for 42% of all concerns reported and including adapting and coping, body image concerns, confidence issues, depression, emotional problems, family and relationships, fear and anxiety, psychological issues, regaining normality, sleep problems, stress and tension, support and the future.

After the patients had experienced the support of the living well programme offered, a clinically significant improvement in concern score was seen²⁷. A smaller, but still clinically significant improvement in wellbeing score was also reported, indicating that quality of life/wellbeing was improved by attending these centres. However, it is important to stress that this study has an observational design and uses a self-selected sample to report results; therefore it cannot prove cause and effect in a statistical manner.

The study also reported people’s views on the most important aspects of their time at the centres. 508 people responded to this question with the following proportions of responses: therapies (29%); support and understanding (17%); being with other people with cancer (16%); general appreciation of centre and resources (11%); relaxation and time for one’s self (8%); care and kindness (6%); environment and atmosphere of centre (6%); confidence in therapists (3%); negative feedback (2%), other (2%).

Lastly, in response to the question looking at other things affecting your health, responses were scored as either positive (eg. taking exercise, increased social support or improved nutrition) or negative (eg. bereavement, difficulties in maintaining changes to lifestyle). Interestingly, these positive

and negative life events correlated with larger and smaller improvements in the concerns and wellbeing scores, respectively.

Overall, this research is useful as it shows what people with cancer want help with when they come to a holistic support service, and how their experience of the support offered significantly improves their perceptions of their health concerns, thus potentially improving quality of life/wellbeing. It also takes a “*Whole Systems*” approach which allows both qualitative and quantitative research to be combined to present a more coherent view of what is happening in the complex environment of a cancer support centre (see pg 20 for more on the Whole Systems approach).

Evaluation of community group work at Penny Brohn Cancer Care:

This piece of work was conducted at Penny Brohn Cancer Care (PBCC) as part of an internal evaluation of services, and was not published in a peer reviewed journal²⁸. This work looked at the PBCC’s Living Well Services rolled-out to deprived areas of Bristol. It evaluated a 10 week course delivering relaxation/self-help techniques, complementary therapies, group work and health education workshops to 68 people with cancer. The evaluation reported that the majority of the group felt that the course met their expectations, with positive ratings of all of the sessions they experienced. The majority of the group also increased their intake of fruit and vegetable to five or more portions a day and raised their exercise levels after taking part in the group.

Cavendish Cancer Care:

Cavendish Cancer Care is an independent cancer charity that gives free emotional support to people and their families affected by cancer in Yorkshire and Derbyshire. They offer a holistic assessment of needs and tailor care to meet individual needs from a range of services including: emotional support and counselling; relaxation and touch therapies; healing and energy therapies. In 2007 Paterson *et al.*²⁶ reported on the MYCaW results from the Cavendish Cancer Care centre. They reported a significant improvement in concerns and wellbeing scores similar to those reported by Seers *et al.* (2009)²⁴.

Breast Cancer Care:

Breast Cancer Care is a national charity which aims for everyone affected by breast cancer to get the best treatment, information and support. In working with people with breast cancer and medical professionals they aim to “*provide information and offer emotional and practical support; bring people affected by breast cancer together; campaign for improvement in standards of support and care; promote the importance of early detection*”²⁹.

Breast Cancer Care has conducted a number of evaluations of its programmes specifically offered for women with secondary breast cancer. Whilst these publications are only classed as grey literature, their results are useful to this report.

The first piece of grey literature reports on SECA (Support Group for women with secondary cancer)³⁰. SECA is an ongoing group that meets fortnightly at the Trafford Macmillan Centre Manchester, Trafford General Hospital. The support group enables people to talk through any concerns, share experiences and receive the support of other women with secondary breast cancer. Breast Cancer Care interviewed 10 women who regularly attended SECA, and, found that the main benefit from the group was to reduce isolation and anxiety. In addition, they report that the feeling of “owning” their support group had a “positive psychological impact in how the women cope with their illness”³⁰, (page 6 of SECA evaluation report).

The second grey literature evaluation report assessed Breast Cancer Care’s “Living with Secondary Breast Cancer” (LWSBC) pilot programme³¹ which runs in different locations all over the UK. This service allows those with secondary breast cancer to meet face-to-face to gain information relevant to their present and future needs. The service acts as a portal to a whole range of support services, from local organisations, the NHS and Breast Cancer Care. Women were also given the chance to experience relaxation techniques, listen to expert speakers on topics such as exercise, diet or benefits; and also mix with other women with secondary cancer. The main aims of the service it to improve the women’s understanding of their diagnosis and how to manage their condition, promote the benefits of relaxation and massage, and meet other women for peer support. 10 women attended the LWSBC event and filled out pre and post-course questionnaires. All women positively rated their experience of the group and appreciated the information and opportunity for meeting others. The evaluation also showed that the group improved knowledge, understanding and ability to cope with issues arising from secondary breast cancer. Breast Cancer Care are currently working on academic publications to support this work.

Tapestry Retreat programme Alberta, Canada:

Tapestry was established in 1998 and is a retreat programme offered by the Alberta Cancer Board in Canada. It is supported by the Tom Baker Cancer Centre and Cross Cancer Institute, in Canada. The retreat is open to people with cancer all, regardless of financial circumstances, although is not free (around \$500). It offers an ambient environment to provide emotional and social support and promotes reflection and examination of the cancer experience. Therapies offered include counselling, art therapy yoga, meditation and other complementary therapies. Angen *et al.* (2002)³² conducted an assessment of the Tapestry programme and tentatively reported evaluation results. They state that the programme had complex outcomes specific to each individual, therefore making it difficult to assess its impact. However, in terms of quality of life a “City of Hope” tool³³ was used and pre-post course score improvements were seen in terms of improved physical well being, psychological well being, social concerns, and spiritual wellbeing. The authors do note that this work is flawed as it only includes those respondents who were alive at the follow-up period, and does not take into account any other therapies/medical interventions at this time. However,

they do note that the effect size is substantial enough for the improvement in quality of life to be linked to the retreat programme itself.

Inspire Health, Vancouver, Canada:

Inspire Health, previously known as the Centre for Integrated Healing) is a private health care provider that provides integrated care for people with cancer. It offers a number of “*Cancer Care Programmes*” and medical consultations to provide a holistically tailored approach allowing healthy lifestyle changes. Therapies on offer include: nutrition advice, meditation, yoga, support groups, relaxation with music and imagery. (See below examples of good practice section for more information).

In 2008 Brazier *et al.*³⁴ used a mixed methods pre-post test design to investigate the effect of the centre’s cancer programme on patient’s quality of life. 46 patients were measured in terms of quality of life using the FACT-G (Functional Assessment of Cancer Therapy – General³⁵) before taking part in the programme. No changes in FACT-G scores were seen after the programme was experienced; the authors attribute this to the low number of participants taking part in the study. However, qualitative results indicated that patients valued the “*person-oriented*” holistic approach to care. (See below for more on this approach).

Living with Cancer Education Programme, Cancer Council Victoria, Australia:

Derived from the American Cancer Society’s “*I Can Cope*” programme (see examples of good practice section of this report for more details), the Cancer Council of Victoria, Australia provided a “*Living with Cancer Education Programme*” to people with cancer in rural and metropolitan Victoria. The programme consisted of teaching strategies to improve communication with health care professionals and significant others, ways to raise self-esteem, and also diet, exercise and relaxation suggestions. The programme ran weekly for two hours over a course of eight weeks.

Roberts and Black (2002)³⁶ report a study based on this Living with cancer Education programme. Between 1994 and 2000 the programme was provided at many sites across Victoria and 1460 participants took part in pre- and post-evaluations of the programme. Results from these questionnaires showed that there was high satisfaction with the programme offered, significant improvements in communication with health care professionals and significant others, and also, significant improvement in coping skills. (A specific quality of life measurement was not taken).

Stanford Cancer Supportive Care Programme, Centre for Integrative Medicine, Stanford Hospital, California USA:

The Stanford Cancer Supportive Care Programme offers free integrated health care in the form of information and support to cancer patients and their families. A holistic approach is taken to tailoring care to the individual’s needs from some of the following options: support groups/workshops specific to

cancer, exercise and fitness instruction (Pilates, Yoga, Qigong), advice on nutrition, art therapy, creative writing, healing, guided imagery, massage, beauty therapy (Look Good....Feel Better programme), music therapy. The central aim of the centre is to improve physical and emotional well-being and quality of life for people with cancer.

Rosenbaum *et al.* (2004)³⁷ evaluated this supportive care programme attended by 398 patients over a 9 week period in 2002. Over 90% of participants questioned felt that the programme had benefitted them. Massage, yoga and qigong classes were the most popular activity. Initial assessment of quality of life using the centre's own in-house questionnaires showed an improvement in terms of "*medical symptoms, pain reduction, sleep, well-being, energy levels, stress hopefulness and empowerment*" (pg. 294 of report).

Medical Social Services, Mayo Clinic, Rochester, USA:

The Mayo Clinic is an American hospital offering private medical treatment. Miller *et al.* (2007)³⁸ studied the effects of a medical social worker on the quality of life of people with advanced cancer. They found that eight sessions of 90 minute consultations with a multidisciplinary team of a psychologist, nurse, physical therapist, chaplain and/or social worker resulted in improved social quality of life and overall quality of life for people with active or advanced cancer. The authors of this study state that the social worker's support in terms of providing information about financial, social, and legal information had a direct impact on quality of life. Although this study is American, it would be interesting to replicate this investigation in the UK.

Conclusions and future directions for research investigating living well services' impact on quality of life:

As a whole it can be concluded that there is emerging evidence that Living Well Services improve quality of life, however this research is still in its infancy and more can be done to improve the evidence base.

In general, the above research is methodologically flawed as it only uses small, self-selected samples which provide biased results, skewed in favour of the centres conducting the research. Also, many different tools for assessing quality of life after experience of holistic health care³⁹ are used in this research (eg. MYMOP, MYCaW, FACT-G or the City of Hope tool). If one simple, validated tool was used across future studies, perhaps the results could be used as part of a meta-analysis. (Also, see Self-Management workstream document "*Self-Management Programmes for Cancer Survivors: A Structured Review of Outcome Measures*"⁴⁰. This evaluation of other measures recommends the use of the Quality of life in Adult Cancer Survivors (QLACS)⁴¹ measure quality of life for cancer survivors).

In relation to the number of vast number private services that exist offering integrated/ holistic approaches it is apparent that only a few have engaged in a research programme to assess their service's benefits. Verhoef *et al.*

(2010)⁴² looked at the barriers to conducting outcome research in such living well centres and cites organisational cultures negative to research, lack of resources, and inability to conduct research in a sensitive environment.

Unfortunately, the randomised controlled trial paradigm does not easily lend itself to the assessment of quality of life for Living Well Services. This is due to the inability of this study design to reflect the more complex processes occurring in terms of cancer survivorship. Verhoef *et al.* (2010)⁴² instead suggest a “*whole systems research*” approach to overcome the multidimensional and complex nature of these settings, so that research can be meaningful and best reflect what really happens in these centres. A whole systems approach essentially combines qualitative interviews and observations with quantitative patient reported outcome measurements to create a more realistic, fuller understanding of a person’s experience of their health care. Verhoef *et al.* (2007)⁴³ argue that a whole systems approach could be used to evaluate the whole of cancer care as this would allow the holistic, complex nature of the interactions of medical care, psychosocial care, self-management and complementary therapies to be evaluated and understood.

Future work from the NCSI test-community evaluations of pilot living well projects currently taking place will also tell us more about the impact of Living Well Services on wellbeing and quality of life.

Results Part 2.

Evidence for Person-Centred Care in context of Living Well Services

First, a note on terms used in this section: Person-Centred Care relates to all care (taking a holistic approach) an individual receives and will be the term used in this report. “*Person-Centred Care evaluates the quality of care being provided and each person’s experience of well being, through the eyes of the person receiving that care*”¹⁰. Patient-Centred Care refers to the medical care received. Bauman *et al.* (2003)⁴⁴ state that patient-centred care has three important elements: “*communication with patients; partnerships; and a focus beyond specific conditions, on health promotion and healthy lifestyles*” (Bauman *et al.* (2003), page 253). Both patient-centred and person-centred care relate to the individual being part of shared decision making about their future care, and, for that reason, can be used interchangeably.

This section of the report will focus on how people with active and advanced cancer use Living Well Services. The Living Well Services described throughout this report (detailed later in the section on examples of good practice) are delivered after a holistic assessment of people’s needs and tailored accordingly by the person with cancer making their own “*person-centred*” decisions about their future. In other words the patient is in control of their future care. Person-centred care is a central tenet of the living well approach as it allows empowerment and autonomy for the individual; this is especially important for those with active and advanced cancer.

An internal NCSI document written by Bray and Watts (2009, unpublished ⁴⁵) set out a stance on “*Cancer Patient-Centred Care*” and in it they present a Cancer Patient-Centred Charter (see appendix II also). Here they state that “*all involved in the cancer journey should practice: the identification and magnification of what patients/carers can do, and do for themselves; and the paying of particular attention to what is on the patient’s/carer’s agenda ie. working towards the patient’s/carer’s version of living well*” (pg 3). Here living well is defined by the individual, and is done via making decisions about future care in a patient-centred way. Bray (2010) (personal communication within NCSI Active and Advanced Disease workstream) states that to facilitate the decision making a health care professional may ask the individual to think about the following question “*What is the patient and their carer(s) hoping for in the near and long-term future?*” This then allows the individual to make person/patient-centred health care choices which ensure they access the most appropriate Living Well Services. (Please also see appendix II for Bray’s views on what should be recommended to the NCSI Vision document).

Patient-centred care has been in existence as a concept in healthcare since the 1970s, as a result there is a large amount of research to support and explore the use of this approach. Some of this research has looked at what people want to get out of patient-centred consultations and how these consultation styles affect the future health of the patient.

Dowsett *et al.* (2000) ⁴⁶ found that the patient-centred approach is especially valued by cancer patients when there is a poor prognosis. Bitar *et al.* (2004) ⁴⁷ investigated whether advanced cancer diagnosis effected patient satisfaction with the doctor-patient relationship. They found that those with advanced disease felt less support from doctors than those with less advanced tumours. Gattellari *et al.* (2001) ⁴⁸ investigated shared decision making in cancer care consultations with doctors and patients, and found that the consultations in which the individual or the doctor made the decisions in isolation were the least satisfactory. Mallinger *et al.* (2005) ⁴⁹ looked at the impact of patient-centred care on breast cancer survivors. They found that the women they studied were more satisfied with the information they received on the long-term physical, psychological consequences of the disease when a patient-centred consultation was given. In the context of evaluating patient/person-centred care in a holistic health care setting, Brazier *et al.* (2008) ³⁴ investigated the perceived benefits of attending an integrated health care clinic in Canada (Inspire Health). Their evaluation found that patients found value in the “*person-oriented*” holistic approach allowing active engagement in care, empowered decision making, leading to changes in lifestyle promoting enhanced wellbeing and health. They call for further research to look at the depth to which person-centred care is engaged in and how this affects long-term health outcomes.

Training health professionals to deliver patient/person-centred care:

The role of the key worker (Clinical Nurse Specialist) of holistic needs assessment in providing health care information/support/advice should be

seen as pivotal to facilitating the person-centred approach. It follows that provision for training these health care staff to provide patient-centred/person-centred care should be made. Bray and Groves (2007)⁵⁰ offer the “*Solution Focused*” therapeutic approach as a means for delivering patient-centred care. It allows aims of a “*preferred future*” to be agreed, and identify next steps towards these aims. Bray and Groves’ approach can also be applied to train health care professionals to deliver person-centred care; they provide examples of key consultation questions from linked teaching material:

- What do you do with your life (eg when not in bed)?
- How have you got through things in the past?
- What’s a good day look like in here?
- What would you like of today’s appointment?
- Did you have any things you wanted to bring up/on your agenda?
- What are your hopes for our work together....how will you know it’s been worth your while?
- What are your hopes for a treatment eg. antidepressant?
- How would your best friend describe your qualities?
- What times are thinking about other things than cancer...and what are those things?
- What do you tell yourself that keeps you going?

Results Part 3.

Evidence for Self-Management of health in context of Living Well Services

This section will focus on how to take long-term ownership of health via engagement in Living Well Services which allow self-management. Self-management of health can be defined as “*(the person with the chronic disease) engaging in activities that protect and promote health, monitoring and managing the symptoms and signs of illness, managing the impact of illness on functioning, emotions and interpersonal relationships and adhering to treatment*” (pg 1)⁵¹. This enables the person with the condition: “*to make informed choices, to adapt new perspectives and generic skills that can be applied to new problems as they arise, to practise new health behaviours, and to maintain or regain emotional stability.*” (pg 11)⁵². (Taken from Fenlon and Foster (2009)⁵³ NCSI Self-management support workstream: a review of the evidence, pg 8).

This section of the report is aligned to the Self-Management workstream output which has already published a great deal of work for the NCSI, so will not repeat the extensive work already completed there. Instead it will discuss self-management in the specific context of Living Well Services for people with active and advanced cancer. All Living Well Services by their definition allow people the chance to take person-centred control of their holistically tailored care and support choices. Though these empowered decisions the patient able to learn new skills and techniques taught by the programmes, eg. exercise regimes, diet changes, relaxation techniques,

psychological/emotional coping skill, spiritual support, improved communication in relationships.

Fenlon and Foster (2009)⁵³ reviewed the evidence for self-management for the NCSI. They state that there is increasing evidence to suggest that self-management of long-term health conditions, such as cancer survivorship, allows patients to achieve better health and quality of life than those who do not self-manage. Their review of the literature concludes that targeted self-management programmes achieve more long-term change for patients than generic one-size-fits all programmes. Those programmes which involve healthcare professionals are more successful than those which do not. Self-management programmes may need to add in follow-up sessions after the block of sessions finish. Integrating self-management support with clinical follow-up may be a useful way forward.

Only a minority of people in the UK with long-term health conditions currently engage in self-management⁵⁴, this may be because the approach is still in its infancy, and/or there may be other barriers to people accessing this support. Fenlon and Foster (2009)⁵³ note that not all people with cancer want to take part in self-management programmes which involve groups of survivors meeting. Instead, they suggest that internet based support may offer help to some of these individuals.

The Expert Patient Programme

Currently in England the Expert Patient Programme Community Interest Company (EPP CIC) is the most established self-management programme available (see below section on examples of good practice for more information). However, EPP CIC is not the only self-management programme available, wider initiatives in the NHS include educating health care professionals on how to influence people to self-care⁵⁵. The EPP CIC programme was derived from the Chronic Disease Self-Management Programme (CDSMP) developed by Professor Kate Lorig at Stanford University, California. The EPP CIC programme was piloted by the NHS between 2002 and 2004, and, was then rolled out through primary care trusts across England. In 2007 the EPP became a Community Interest Company, and seeks to substantially expand its uptake of courses from 12,000 in 2006 to 100, 000 people with long-term conditions in 2012. EPP CIC courses are free and provide tools and techniques to help people to self-manage their health conditions. Most of the trained tutors who run the courses have their own experience of living with a long-term health condition.

EPP CIC has conducted research to show the benefits it affords, in terms of how economically beneficial it is for the NHS, as it reduces the use of these services by those with long-term health conditions. The economic saving to the NHS is thought to be around £1, 800 per person per year⁵⁶. They also cite evidence that over a six month period 963 EPP CIC course participants had 7% less GP admissions, 10% less outpatient visits, 16% less A&E attendances and 9% less physiotherapy sessions than they would have done without the self-management support programme's intervention.

The EPP CIC programme does not present research information specific to people with cancer. This would be beneficial future research to conduct as currently people with cancer are attending their courses. Due to the economic savings for the NHS via the EPP CIC, or other self-management programmes (see Macmillan's self-management programmes "*New Perspectives*", "*HOPE*" and "*Cancer: Thriving and Surviving*" in examples of good practice), the development of such similar courses a national level specifically targeted at active and advanced cancer should be recommended. Currently existing Living Well Services for people with cancer in the UK do not have this wider link to the NHS, and perhaps a national self-management programme taking the place of the current follow-up system would be beneficial.

Examples of good practice in living well services

The below lists are only intended as a scoping exercise to illustrate best approaches in this area, highlighting novel and significant organisations which may provide useful partnerships for future services commissioned by the NHS.

Criteria used to determine best practice:

Based on the previous section of the report and the aims of the NCSI Living Well Subgroup, Living Well Services for people with active and advanced cancer should meet the following criteria:

- Take a person-centred approach
- Have a whole person/holistic approach
- Allow self-management
- Be available via equal access to services (financially and geographically)
- Be financially efficient (allowing potential cost savings for NHS)

What follows below is not an exhaustive review of every living well service possible for people with active and advanced cancer, but provides examples to illustrate best practice in this area using the above criteria. This review will cover three main areas:

Part 1. What Living Well Services exist for people living with cancer in the UK?

Part 2. What Living Well Services exist for people living with cancer outside the UK?

Part 3. What Living Well Services exist for other long-term health conditions in the UK?

The following lists of Living Well Cancer Centres in the UK and rest of the world were compiled by three methods. Firstly, members of the Active and Advanced Disease NCSI workstream contacted the author of this report with examples of good practice in Living Well Services that they thought should be in the report. Secondly, the author carried out an internet search for organisations offering best practice in Living Well Services. The criteria used in this internet search were: “*holistic, integrative, living well cancer services*”. Thirdly, the author used the directories of useful organisations for people with cancer listed by the following organisations for examples of recommended centres around the UK and world:

- Cancer Research UK <http://www.cancerhelp.org.uk/about-cancer/treatment/complementary-alternative/complementary-therapy-organisations>
- Leukaemia Care <http://www.leukaemiacare.org.uk/filestore/files/Signpost.pdf>

- Macmillan
(http://www.macmillan.org.uk/HowWeCanHelp/Organisations/Helpful_organisations.aspx)
- and the USA National Cancer Institute resources
https://cissecure.nci.nih.gov/factsheet/FactsheetSearchResult8_1.aspx?~UHViTG5rPTguMSZDYW5jZXJUeXBIPTE%3d-HUxKBQw6%2ffc%3d

Examples of good practice, Part 1.

What living well services exist for people living with cancer UK?

The following list of services illustrates what is available to people with active and advanced cancer in the UK. A number of services are free, whilst others are private, with costs ranging from a minimal contribution (eg. £5), ranging to hundreds of pounds. Services are located throughout the UK, and are accessible to many people; however, those in rural areas with long-term health conditions may not be able to easily access those services which are located in metropolitan areas. There is increasing availability of services online; however, not all people with cancer will be able to access them due to financial and educational levels or preference. Please note that the below list represents an illustration of services provided, it is not a definitive list of all services that exist at the time of writing this report.

Name of organisation:	BACSUP (Bournemouth After Cancer Survivorship Project) Active Wellness Programme
Type of organisation:	BACSUP Active Wellness is a public sector (Bournemouth Borough Council) initiative based at the Littledown Centre and provided in partnership with Royal Bournemouth Hospital, NHS Bournemouth and Poole, Bournemouth University and Macmillan Cancer Support. Working with a range of associates from public, private, voluntary and community sectors to provide participants more opportunity and potential to live well with, and, beyond cancer.
Relevance to living well with and beyond Active and Advanced Cancer:	BACSUP provides support... <i>"to enable people treated for breast, colo-rectal or melanoma cancer, currently in active follow up with the hospital, to take part and enjoy the wide reaching benefits of leading a more active life in a safe, structured, supportive and encouraging environment. The programme is supplemented with a wide range of life enrichment activities provided in increase the participants opportunities and potential to live well with and beyond cancer. The programme also serves family members and carers."</i> www.activehealthlink.com/net

	<p>Clients are referred from NHS/Clinical Nurse Specialist. Each patient has a holistic, person-centred assessment of health needs to determine which options from the BACSUP programme are most beneficial/appropriate. Given a fitness and quality of life assessment at the start and end of the 12 week programme. Also assess nutrition/weight management and shoulder function (latter for breast cancer patients only). Given opportunities to access health education events – BACSUP acting as a portal to all other relevant health and social care wellbeing activities available to the patients locally.</p> <p>Benefits from the programme are stated as:</p> <p><i>“Improved physical, psychological, social and emotional fitness and wellbeing. Participants gaining an understanding of how to create and maintain a health benefiting way of life. Collaborative working relationships between local authority, secondary and primary care organisations, voluntary and community service providers. Opportunities for cancer survivors and carers to engage in self-care practices. Management of shoulder function. Nutritional status.”⁵⁷</i></p> <p>Examples of services offered include:</p> <p>Dietician, Nutritionist, Chiropractor, Exercise Scientist, Life Coach, Physiotherapist, Hairdresser/Beauty therapist, Lingerie service for women after breast cancer, Tai Chi or Qui Gong or Nordic Walking Instructor, Support with returning to work from Job Centre, All of Littledown Leisure Centre’s exercise facilities, links to Pink Champagne Dragon Boat Racing and Swimming group.</p>
Target clients:	Those breast, colorectal and melanoma cancers who are at the end of their treatment, who are in “active follow-up” with the hospital.
Location:	Bournemouth area
Cost:	Core programme is free to patient (funded) life enrichment activities can be free/subsidised/funded/discounted (eg. Life coach for £5).
Contact details:	<p>Layne Hamerston Active HealthLink Partnerships and Development Littledown Leisure Centre Chaseside, Bournemouth Dorset BH7 7DX www.activehealthlink.com/net layne.hamerston@bournemouth.gov.uk</p>

Name of organisation:	Breast Cancer Care
Type of organisation:	Charity
Relevance to living well with and beyond Active and Advanced Cancer:	<p>Breast Cancer Care offers support to all people affected by breast cancer. They also provide tailored support to people with secondary breast cancer. The following services are offered specific to active and advanced disease:</p> <ul style="list-style-type: none"> • Living with secondary breast cancer course. This course aims to bring people with secondary breast cancer together to gain information and peer-support. Courses run at various locations in the UK and run for one day, with a follow-up day taking place one month later. Course covers the latest information on health, lifestyle and wellbeing. Topics covered include fatigue, stress and relaxation, and treatments. • Telephone support groups for people with secondary breast cancer • Seca – a support group for people with secondary breast cancer, meeting weekly for around two hours each time. It is run by Breast Cancer Care at various locations in the UK • Online support and Information for people with secondary breast cancer
Target clients:	All people affected by breast cancer
Location:	Various locations across the UK, offices based in London, Sheffield, Glasgow and Cardiff
Cost:	All services free of charge
Contact details:	<p>Breast Cancer Care Central office in London: 5-13 Great Suffolk Street London SE1 0NS Tel 0808 8006000 www.breastcancercare.org</p>

Name of organisation:	Breast Cancer Haven
Type of organisation:	Charity
Relevance to living well with and beyond Active and Advanced Cancer:	<p>Holistic, person-centred programme offered providing support, information on self-management and complementary therapies for people affected by breast cancer. Specialising for advanced breast cancer by offering support groups for secondary breast cancer.</p> <p>Therapies include: Acupuncture, Alexander Technique, Aromatherapy, Art</p>

	Therapy, Bach Flower Remedies, Counselling, Creative Writing, Craniosacral Therapy, Creative Visualisation for Health and Healing, Ear Acupuncture, Emotional Freedom Technique (EFT), Hands on Healing, Haven Introduction Day, Herbal Medicine, Homeopathy, Hypnotherapy, Indian Head Massage, Kinesiology, The Lebed Method, Life-Work Coaching, Looking Good, Lymphoedema Awareness, Massage Therapy, Mind Body Therapy, Mindfulness Meditation, Neuro- Linguistic Programming (NLP), Nutri-Energetic Systems(NES), Nutrition, Qi Gong and Tai Chi, Reiki, Reflexology, Shiatsu, Sound Therapy, Yoga
Target clients:	All women with breast cancer
Location:	London, Hereford and Leeds, also online resource available to anyone from home
Cost:	Free access to services – access by NHS health care professional referral.
Contact details:	Breast Cancer Haven, Effie Road, London SW6 1TB 020 7384 0099 www.breastcancerhaven.org.uk

Name of organisation:	Cavendish Cancer Care
Type of organisation:	Charity
Relevance to Active and Advanced Cancer:	<p>Aim is: <i>"To help local people in Yorkshire and Derbyshire adjust to, cope with and ease the impact of living with cancer. We aim to improve the quality of local people's lives and enrich the emotional wellbeing of people touched by cancer in our region."</i> www.cavcare.org.uk</p> <p>Service offered:</p> <ul style="list-style-type: none"> • Emotional Support and Counselling (counselling, hypnotherapy, relaxation classes, art therapy) • Relaxation and Touch Therapies (aromatherapy, reflexology, shiatsu, massage therapy) • Healing and Energy Therapies (healing, acupuncture, herbal medicine, homeopathy) <p>Holistic care programme tailored in a person-centred way, promoting self-management of the condition.</p> <p>Also outreach services in several regional hospitals: Weston Park Hospital, Sheffield (services provided here: Massage, Reflexology, Hypnotherapy and Visualisation and Shiatsu). Macmillan Palliative Care Unit at Northern General Hospital, Sheffield (services provided here: Reiki, Massage,</p>

	Aromatherapy and Healing). Ashgate Hospice, Chesterfield (Services provided here: Massage, Aromatherapy, Reiki and Reflexology). Also, services linked to Rotherham Cancer Care Centre, Rotherham.
Target clients:	Anyone with a diagnosis of cancer, primary carer or children of people affected by cancer
Location:	Yorkshire and Derbyshire
Cost:	Free
Contact details:	The Cavendish Centre, 27 Wilkinson Street, Sheffield S10 2GB 0114 278 4600 www.cavcare.org.uk

Name of organisation:	Expert Patients Programme Community Interest Company (EPP CIC)
Type of organisation:	Not-for-profit community interest company, delivered by many primary care trusts throughout the UK
Relevance to living well with and beyond Active and Advanced Cancer:	<p>EPP CIC does not provide holistic assessment access to therapies. Instead, it provides tools to develop self-management skills.</p> <p>EPP CIC provides and delivers courses aimed at helping people who are living with a long-term health condition self-manage their condition. Typical courses run for 6 weeks with meetings lasting 2 ½ hours. Courses run by two trained tutors (who also are living with long-term health conditions themselves). Topics covered by the courses include:</p> <ul style="list-style-type: none"> • <i>“Dealing with pain and extreme tiredness</i> • <i>Coping with feelings of depression</i> • <i>Relaxation techniques and exercise</i> • <i>Healthy eating</i> • <i>Communicating with family, friends and professionals</i> • <i>Planning for the future”</i> <p>http://www.expertpatients.co.uk/about-us/what-we-do</p> <p>The Generic Chronic Disease Self-management Course (CDSMC) – originally developed by Stanford University, California is the most popular course provided. Other self-management courses are available for specific problems (eg. substance abuse, recovery from mental health condition, support for people with learning difficulties, returning to work). Currently there is no specifically tailored programme available for people with cancer.</p> <p>EPP CIC also offers support online for those with health</p>

	conditions who may not be able to attend meetings and programmes specifically for health and social care practitioners who want to increase their awareness of self-management. EPP CIC also provides support to other organisations who seek to develop their capacity to deliver self-management programmes.
Target clients:	All people with long-term health conditions
Location:	<p>EPP CIC offices at various regional locations throughout the UK:</p> <ul style="list-style-type: none"> • Northern region (Cheshire, County Durham, Cumbria, Greater Manchester, Lancashire, Merseyside, Northumberland, Tyne & Wear, Tee Valley & Yorkshire) • London region (Greater London) • Central region (Birmingham, The Black Country, Nottinghamshire, Derbyshire, Lincolnshire, Leicestershire, Warwickshire, Worcestershire, Herefordshire, Shropshire & Staffordshire) • Eastern region (Bedfordshire, Cambridgeshire, Essex, Great Yarmouth & Waveney, Hertfordshire, Luton, Norfolk, Northamptonshire & Suffolk) • Southern region (Avon, Buckinghamshire, Dorset, Gloucestershire, Kent, Hampshire & Isle of Wight, Oxfordshire, Somerset, South West Peninsula, Surrey & Sussex, Thames Valley & Wiltshire) <p>Also, many EPP CIC courses delivered through primary care trusts throughout UK, eg. NHS Suffolk</p>
Cost:	Free
Contact details:	<p>EPP CIC 32-36 Loman Street Southwark London SE1 0EH Tel: 0800 954 0650 http://www.expertpatients.co.uk</p>

Name of organisation:	Hamar Help and Support Centre
Type of organisation:	Public sector, located in Royal Shrewsbury Hospital, NHS
Relevance to living well with and beyond Active and Advanced Cancer:	A wide range of supportive services are offered by this hospital run cancer support centre. Suggested options are holistically tailored in a person-centred way by a counsellor and/or specialist nurse. Information given builds upon that already provided by the multi-disciplinary team of health care professionals in the hospital. Lifestyle advice given on exercise, healthy diet, sleep, relaxation, hobbies, spiritual

	<p>and philosophical concerns, emotional effects of cancer. Services offered: counselling, group therapy (either relaxation and self-care/life skills or art and creativity), and individual supportive therapies: aromatherapy, touch therapy, reiki, Bowen, reflexology). Also have peer support groups one a month. Garden and summerhouse for a tranquil space.</p> <p>“Cancer Zone” http://www.sath.nhs.uk/cancer/default.asp provides access online information and resources for people with cancer for every aspect of living with the disease (information on cancer types and treatments, lifestyle advice, palliative care information, wider cancer services in the local area available).</p>
Target clients:	<p>People with cancer and other long-terms and serious illnesses, also support for relatives and carers. Access services by telephoning or dropping in to service to then make arrangements for further support. Services available for inpatients at Royal Shrewsbury Hospital.</p>
Location:	<p>Shropshire, Telford and Wrekin and Mid-Wales</p>
Cost:	<p>Free</p>
Contact details:	<p>Hamar Help and Support Centre Royal Shrewsbury Hospital Mytton Oak Road Shrewsbury SY3 8XQ Tel: 01743 261035 http://www.sath.nhs.uk/patient_information/advice_and_support/hamar_support_centre.asp</p>

Name of organisation:	<p>The healthpod</p>
Type of organisation:	<p>Private health care, but based at the Hospital of St. John and St. Elizabeth, London</p>
Relevance to living well with and beyond Active and Advanced Cancer:	<p>The healthpod is a health and lifestyle assessment service, based at the Hospital of St. John and St. Elizabeth in London, which aims to optimise “<i>health, wellbeing and activity</i>” http://www.thehealthpod.org.uk</p> <p>The healthpod offers the expertise of professionals specializing in sports science, exercise science, nutrition, sports medicine, therapeutic massage and stress management. After a person-centred holistic assessment, tailored feedback is given to then establish a 12 week individualised action plan, giving access to professional advice on training, recovery, nutrition, performance and health and lifestyle. During the 12 week programme motivation and support is offered, at the end of the programme assessments and further action plans are</p>

	<p>offered. Other programmes are offered to supplement the support given (“<i>Stepping Stones</i>” programme). These courses focus on stress, weight, fitness and general health, offering access to exercise, pilates, walking groups, relaxation and mindfulness sessions, sleep hygiene, nutrition advice and vocational rehabilitation.</p> <p>The healthpod programme has been successfully piloted for cancer patients and their carers at the Hospital of St. John and St. Elizabeth and St. John’s Hospice. Lifestyle and wellness were assessed over a period of time, allowing feedback to be given to both healthcare professionals and the clients. Results mapped psychological behaviour against physiological reactions, allowing a connection to be seen between the two. Clients were then offered the Stepping Stones programme to support their lifestyle changes. Measurements taken showed improvement in fatigue, BMI, waist measurements, and increase in exercise. The programme <i>“aims to be a dynamic, innovative solution that will assist the growing number of cancer survivors achieve the highest quality of life possible”</i>⁶⁸. The programme also aims to reduce co-morbidities such as diabetes, heart disease and Alzheimer’s and also reduce economic burdens associated with cancer patients’ use of respite care, health care professionals, medication and carers.</p>
Target clients:	Anyone with long-term health condition, and/or interested in improving health and wellbeing. Access of services via self-referral or referral from a medical practitioner.
Location:	North West and Central London
Cost:	Approximately £375 per patient cycle
Contact details:	<p>The healthpod Hospital of St. John and St. Elizabeth 60 Grove End Road, St. John's Wood, London NW8 9NH Tel: 020 74328256 http://www.thehealthpod.org.uk</p>

Name of organisation:	Look Good...Feel Better
Type of organisation:	Charity
Relevance to living well with and beyond Active and Advanced	Look Good...Feel Better is a charity set up by the Cosmetic Toiletry and Perfumery Association (CTPA). It is supported by 40 companies selling beauty products. This charity offers free make-up and skincare workshops to improve self-esteem, feelings of control, regaining normality,

Cancer:	<p>confidence and wellbeing after cancer treatment.</p> <p>Look Good...Feel Better workshops are run weekly, fortnightly or monthly for up to 12 people at a time. The sessions are offered in over 50 hospitals and specialist cancer support centres across the UK. The Look Good...Feel Better Programme available internationally in 20 countries worldwide.</p> <p>Useful as part of a holistic programme in a cancer care centre. Service offered by volunteer beauticians providing service tailored to needs of the individual.</p>
Target clients:	Women with cancer, although there is information for men too.
Location:	Across the UK
Cost:	Free
Contact details:	<p>Look Good...Feel Better West Hill House 32 West Hill Epsom Surrey KT19 8JD Tel: 01372 747 500 http://www.lookgoodfeelbetter.co.uk</p>

Name of organisation:	Macmillan Cancer Support
Type of organisation:	Charity
Relevance to living well with and beyond Active and Advanced Cancer:	<p>Macmillan Cancer Support provides information, specialist health care, medical and financial support to people affected by cancer. Macmillan also looks at the emotional, practical and social impact that cancer can have and campaigns for improvements in cancer care.</p> <p>Information provided by website and help lines and in person at many Macmillan cancer information support centres around the country. Macmillan offers access to health and social care professionals (including nurse counsellors) with expertise in different areas of cancer care. Macmillan also offers an online community blogging service for people to share their thoughts and get peer support online: http://community.macmillan.org.uk/blogs. They also have a Macmillan Quality Environment Mark – assessing the suitability of environments built for cancer care.</p> <p>Macmillan offers an extensive range of information which can be ordered online. They also offer access to (and</p>

	<p>support for) the hundreds of independent cancer self-help support groups across the UK.</p> <p>As an alternative to the EPP CIC programmes, Macmillan also offers an extensive range of courses for people affected by cancer to promote self-management. Current courses are: “<i>New Perspectives</i>”, and “<i>HOPE</i>” meeting at various times and locations across the UK. Also piloting an online self-management course in partnership with Stanford University School of Medicine in the United States called “<i>Cancer: Thriving and Surviving</i>”.</p>
Target clients:	Anyone affected by cancer
Location:	Throughout the UK
Cost:	Free
Contact details:	<p>Macmillan Cancer Support 89 Albert Embankment London SE1 7UQ 0808 808 00 00 http://www.macmillan.org.uk</p>

Name of organisation:	Maggie’s Centres
Type of organisation:	Charity
Relevance to living well with and beyond Active and Advanced Cancer:	<p>Maggie’s Centres offer individual or group support, information, benefits advice and courses and stress reducing strategies for people with cancer and their supporters. Support is holistically tailored to the individual allowing person-centred decisions about support and care. Particular care is taken with the architectural design of the buildings, to provide a tranquil and uplifting space.</p> <p>The programme offered by all the centres has five core elements A six week course called “<i>Living with Cancer</i>” is offered, which presents all of the components of the programme:</p> <ul style="list-style-type: none"> • Emotional and Psychological Support (group support, individual support or psycho-educational courses) • Relaxation and Stress Management techniques taught • Information to support the individual’s understanding of their diagnosis – tailored to the needs of the individual (person-centred care) • Benefits Advice • Other Support for Living with Cancer include: Tai Chi, Look Good...Feel Better sessions and nutrition workshops

	In addition to its physical centres Maggie's also hosts an Online Centre for anyone affected by cancer. It offers peer support, emotional support and information and hosts live chat sessions led by a clinical psychologist.
Target clients:	Anyone affected by cancer
Location:	Centres open throughout the UK: Edinburgh, Glasgow, Dundee, Highlands, Fife, London, Oxford, South West Wales, Lanarkshire, also planned in Nottingham, North East, Cotswolds, Hong Kong, Barcelona
Cost:	Free
Contact details:	Maggie's Centres 8 Newton Place Glasgow G3 7PR Tel: 0131 537 2456 http://www.maggiescentres.org

Name of organisation:	Penny Brohn Cancer Care
Type of organisation:	Charity
Relevance to living well with and beyond Active and Advanced Cancer:	<p>Penny Brohn Cancer Care (PBCC, formally Bristol Cancer Help Centre) has at its core the principle of helping people to live well with and beyond cancer. It runs a variety of residential and non-residential courses, as well as a day clinic called "<i>Cancerpoint</i>". Using a whole person, person-centred living well approach Penny Brohn Cancer Care aims to provide physical, emotional, psychological, welfare and spiritual support, by helping people to integrate useful lifestyle self-help techniques and other complementary therapies and support into their journey with cancer.</p> <p>Penny Brohn Cancer Care's services all follow the "<i>Bristol Approach</i>". This is a unique combination of complementary therapies and self-help techniques designed to work alongside medical treatment. The courses content includes:</p> <ul style="list-style-type: none"> • Lifestyle advice, information, complementary therapies and self-help techniques • Support through treatment and recovery • Support for positive health, physical and psychological wellbeing <p>Services offered include:</p> <ul style="list-style-type: none"> • "<i>Living well with, and beyond cancer course</i>" (see below for more information) • Specialist support (psychotherapy/counselling, doctor

	<p>sessions, nutritional advice, group work)</p> <ul style="list-style-type: none"> • Self-help techniques (relaxation, meditation, imagery, breathwork, natural pain management, gentle exercise) • Complementary therapies (massage, shiatsu, healing, music therapy, art therapy) • Helpline for support and an evidence-based information service about complementary therapies • Support groups are also run by psychotherapists for anyone diagnosed with cancer. Groups typically run for 10 weeks, meeting once a week. <p>The new <i>“Living well with, and beyond cancer course”</i> course is currently being piloted within the NCSI test communities. This course explored the way that people with cancer can live well and provides training and expert advice on managing the impact of cancer emotionally, psychologically and physically in terms of eating well, stress reduction, exercise and how complementary therapies can support. The course can be delivered in a number of ways, over two days or over 7-8 weeks of weekly attendance. Evaluation and audit is ongoing.</p>
Target clients:	All people with cancer and their supporters
Location:	Bristol
Cost:	All services are offered free, and charitable donations asked for.
Contact details:	Penny Brohn Cancer Care, Chapel Pill Lane, Pill, Bristol BS20 0HH Tel: 0845 123 23 10 www.pennybrohncancercare.org

Examples of good practice, Part 2.

What living well services exist for people living with cancer outside UK?

The USA and Canada offer a number of private health care organisations which offer *“integrated medicine”*, equivalent to holistic care in the UK. The following list scopes out a few examples of what is offered by charities providing supportive informational and private health care providers.

USA

Name of organisation:	American Cancer Society
Type of organisation:	Charity
Relevance to	The American Cancer Society (ACS) is one of the largest

living well with and beyond Active and Advanced Cancer:	<p>voluntary health agencies in the USA. Its aim is to eliminate <i>“cancer as a major health problem by preventing cancer, saving lives, and diminishing suffering from cancer through research, education, advocacy, and service.”</i></p> <p>www.cancer.org</p> <p>Amongst its many services, the ACS offers various support projects for people with Active and Advanced Cancer. These include:</p> <p><i>“I can Cope”</i> – an educational program delivered in group setting or online, for people affected by cancer, covering topics such as diagnosis and treatment, side effects of treatment, self-esteem and intimacy, communicating concerns and feelings, community resources, financial concerns, pain management, nutrition and physical activity, cancer-related fatigue, keeping well in mind, body, and spirit</p> <p>The ACS also offers access to the <i>“Cancer Survivors Network”</i>. This is an online network created for cancer survivors and their supporters, promoting and facilitating peers support.</p>
Target clients:	All people affected by cancer
Location:	USA
Cost:	Free
Contact details:	American Cancer Society www.cancer.org

Name of organisation:	Stanford Cancer Supportive Care Programme, Centre for Integrative Medicine
Type of organisation:	Private health care
Relevance to living well with and beyond Active and Advanced Cancer:	The Stanford Cancer Supportive Care Programme offers free integrated health care in the form of information and support to cancer patients and their families. A holistic, person-centred approach is taken to tailoring care to the individual’s needs from some of the following options: support groups/workshops specific to cancer, exercise and fitness instruction (Pilates, Yoga, Qigong), advice on nutrition, art therapy, creative writing, healing, guided imagery, massage, beauty therapy (Look Good....Feel Better programme), music therapy. The central aim of the centre is to improve physical and emotional well-being and quality of life for people with cancer.
Target clients:	Anyone affected by cancer
Location:	Stanford, California, USA
Cost:	Free
Contact details:	Stanford Cancer Centre 875 Blake Wilbur Drive

	Stanford, CA 94305 http://cancer.stanford.edu/patient_care/amenities/cancerPatientServices/supportiveCareServices/
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Name of organisation:	Preventative Medicine Research Institute
Type of organisation:	None Profit, private organisation,
Relevance to living well with and beyond Active and Advanced Cancer:	The Preventative Medicine Research Institute (PMRI) is headed by Dr. Dean Ornish. The institute aims to investigate the diet and lifestyle choices on health and disease. Ornish has developed " <i>The Spectrum Programme</i> " which provides information and support regarding the benefits of good nutrition, exercise, stress management and social/emotional support and relationships. Ornish's original work centred on heart disease, however, it is now being widened by many private health care providers in America to be relevant to people with cancer. Research ⁵⁹ conducted by the PMRI has recently shown that " <i>intensive lifestyle changes may effect the progression of early low grade prostate cancer</i> " http://www.pmri.org .
Target clients:	People with heart disease, but some programmes widening remit to those with cancer and other long-term health conditions.
Location:	Several hospital sites in USA – Pennsylvania, Connecticut, Oregon, West Virginia
Cost:	Private health care providers in USA
Contact details:	Preventative Medicine Research Institute http://www.pmri.org

Name of organisation:	The Lance Armstrong Foundation or Live Strong
Type of organisation:	Charity
Relevance to living well with and beyond Active and Advanced Cancer:	The Lance Armstrong Foundation provides " <i>the practical information and tools people with cancer need to live life on their own terms</i> " (http://www.livestrong.org). They campaign to improve the quality of life for cancer survivors. The Livestrong Survivorship Centre of Excellence Network represents the Lance Armstrong Foundation and is represented at cancer centres throughout the USA, it provides access to the Livestrong Survivor Care program, which covers: <ul style="list-style-type: none"> • Counselling and support • Financial or employment support • Information on new clinical trials

	<ul style="list-style-type: none"> • Fertility support and options • Help with medical and psychosocial challenges that may arise <p>They also offer specific support advice concerning survivorship in the booklet <i>“The Road to Survivorship, Living after Cancer treatment”</i>. This covers physical, emotional, and practical effects of cancer survivorship.</p> <p>Livestrong also has affiliated links with The Cancer Support Community and its Wellness Community which provides online support, providing holistic, person-centred action planning and information about survivorship. http://www.thewellnesscommunity.org</p>
Target clients:	Anyone affected by cancer
Location:	USA
Cost:	Free
Contact details:	Lance Armstrong Foundation 2201 E. Sixth St, Austin, Texas USA http://www.livestrong.org

Canada

Name of organisation:	Inspire Health
Type of organisation:	Private not-for-profit health care provider receives government funding.
Relevance to living well with and beyond Active and Advanced Cancer:	<p>Inspire Health, (previously known as the Centre for Integrated Healing) is a private health care provider that offers integrated care for people with cancer. It runs a number of <i>“Cancer Care Programmes”</i> and medical consultations to provide a holistically tailored approach allowing healthy lifestyle changes. Therapies on offer include: nutrition advice, meditation, yoga, support groups, relaxation with music and imagery.</p> <p>The <i>“LIFE”</i> programme runs over two-days and is run by medical doctors and Inspire Health staff. The programme presents information on fitness, rest, relaxation, healthy nutrition and stress reduction for people with cancer. <i>“Patients and their families engage in an integrated whole person approach to cancer care empowering them to make choices that inspire new levels of self-care and greatly improve quality of life.”</i> http://www.inspirehealth.ca/programs</p>
Target clients:	Anyone affected by cancer

Location:	Vancouver, BC, Canada
Cost:	Courses cost a range of prices, for example \$375 those attending the LIFE programme
Contact details:	InspireHealth 200—1330 West 8th Avenue Vancouver, BC V6H 4A6 Canada http://www.inspirehealth.ca/programs

Examples of good practice, Part 3.

What living well services exist for other long-term health conditions in the UK?

Other long-term health conditions (eg. heart disease, arthritis, diabetes, COPD) may highlight new approaches for the current service provision of Living Well Services in the UK. Overall, it can be noted that the services offered for the below long-term conditions centre on self-management of the condition, rather than holistic, patient-centred care which may be more relevant to cancer.

This section will provide a brief overview of what type of services currently exist in the UK (please note, this is not a complete guide, instead it is several examples of good practice).

Heart Disease

It is widely accepted that lifestyle plays a major role in heart disease prevention and treatment⁶⁰. The British Heart Foundation (www.bhf.org.uk) promotes their Heart Matters campaign, offering advice on lifestyle, exercise, weight, alcohol, and provides ongoing support for people with this long-term health condition. Several research studies have found benefits in people with heart disease undertaking self-management programmes in terms of improving care received⁶¹ and decreasing hospital readmissions⁶². In America the Preventative Medicine Research Institute, headed by Dean Ornish has rolled out programmes of lifestyle change for people with heart disease which are supported by positive health outcomes⁶³. Lastly, recent research shows that happiness wards off heart disease⁶⁴.

Arthritis

Arthritis is a long-term condition which also is seen to benefit from self-management skills being taught to the patient, resulting in better disease management, pain reduction and improvement in psychological wellbeing⁶⁵. In addition, there is growing support for a patient-centred approach for this condition⁶⁶. At present, the leading charity offering support to people with Arthritis is Arthritis Care (www.arthritis.org.uk). This organisation offers advice on living with arthritis looking at issues of working, parenting, eating, exercise, house adaptations and benefits.

Diabetes

Diabetes UK (www.diabetes.org.uk) offers advice on coping with Diabetes and provides support. The EPP CIC currently runs self-management courses tailored to diabetes known as the “X-PERT Diabetes Course”. This course covers topics such as diet, exercise, lifestyle, and how to work with healthcare professionals to achieve optimal self-management of the condition. The course also provides an opportunity for peer support to be gained. EPP CIC state that the course feedback shows that the participants improved their body weight status, reduced use of diabetes tablets/insulin, improved lifestyle and quality of life, and reduced blood pressure and cholesterol levels⁶⁷. The EPP CIC also states that their programme would save the NHS £1,664 per person per year⁵⁶. Chodosh *et al.* (2005)⁶⁸ conducted a meta-analysis of the efficacy of chronic disease management programmes and found clinically important benefits including reduction in pain and increase in function for elderly people with diabetes. Steed *et al.* (2003)⁶⁹ conducted a systematic review of psychosocial outcomes following self-management and psychological interventions for people with diabetes and found that depression was improved after psychological intervention and quality of life improved after self-management techniques were taught.

COPD (Chronic Obstructive Pulmonary Disease)

The British Lung Foundation (www.lunguk.org) provides lifestyle tips and support for people with this long-term health condition. Co-creating Health (linked to EPP CIC) runs a joint initiative between NHS Cambridgeshire and Addenbrooke’s Hospital run self-management courses for COPD which aim to improve quality of life and being more active in self-care⁷⁰. This course allows people the chance to reduce the severity of their symptoms, know how to engage effectively with health care services, make positive changes to lifestyle(eg. relaxation, exercise, diet and use problem-solving, goal-setting and follow-up and agenda setting) to self manage their condition effectively. EPP CIC also offers self-management programmes for people with COPD, and state that their approach would save the NHS £1, 848 a year per patient⁵⁶. Bourbeau (2003)⁷¹ conducted a review of the benefits of disease-specific self-management programmes on patient with COPD and found benefits in the form of improvements in health and reduction in visits to the GP or hospital.

Conclusions and Recommendations

Recommendations for future commissioning of Living Well Services:

During the course of meetings within the NCSI Active and Advanced Disease Workstream's Living Well Subgroup (internal conference calls), it was decided that any recommendations about future commissioning of Living Well Services should consider:

1. What do patients want from Living Well Services when they have cancer?
2. What are the main concerns for patients and how can services be established to meet these needs?
3. Recommendations need to be approaches which are cost effective and/or improve quality of life.

The above results section of this report provides answers to the second two questions, with the first question currently being addressed by the test community work being carried out in many Living Well centres across the UK for the NCSI (<http://www.ncsi.org.uk/test-communities>).

The main concerns of people with cancer accessing Living Well Services have been outlined in a number of pieces of research, most notably Seers *et al.* (2009)²⁴. This observational study found that concerns could be grouped into: 1) Psychological/emotional; 2) Physical; 3) Medical/hospital associated and 4) Wellbeing. (See appendix I for more details of these concerns). These areas can therefore serve as a guide for the development of Living Well Services for people with cancer.

At present evidence to show the cost-effectiveness of Living Well Services is not available due to methodological constraints of needing longitudinal research studies. However, there is evidence from the EPP CIC self-management programme in terms of cost savings for the NHS (well within the QALY of £30,000 per person per year from NICE's guidelines for commissioning⁷²). There is an emerging evidence base to show that Living Well Services improve the quality of life of people with cancer, therefore a person-centred, holistic approach to care should be recommended for these benefits. More research still needs to be conducted into the benefits derived from Living Well Services; studies using appropriate methodology (eg. whole systems research) should be funded to investigate the complex results from attending these programmes and centres.

In terms of equity and choice, not all Living Well Services were free to access (therefore excluding some who have financial limitations). Also, access for some services to people in rural areas was limited, online access to services are available to those who may not be physically able to attend a centre, however, this alternative may not be suitable for all people.

With the current financial climate demanding reduction in public spending, but more people requiring increased levels of quality care, the QIPP⁷³ tool has

developed to help deliver services in this challenging time. QIPP stands for: “Quality, Innovation, Productivity, and Prevention”. In the context of QIPP, Living Well Services which deliver useful, high quality interventions which also allow improvement in health and quality of life, leading to less reliance on the NHS in terms of follow-up support would be very relevant and recommended for commissioning. Commissioners should also consider the benefits of the holistic approach of Living Well Services, with examples such as the BACSUP project of Hamar Help and Support Centre (see above examples of good practice) providing a central hub from which all relevant local services for people with cancer can be accessed. Such partnerships between the public, private and voluntary sector would facilitate the uptake of services, and allowing relevant person-centred and self-management decisions by people about their future health care and support.

Based on the results section of this report, Living Well Services commissioned for people with active and advanced cancer should meet the following criteria:

- Take a person-centred approach
- Have a whole person/holistic approach
- Allow self-management
- Be available via equal access to services (financially and geographically)
- Be financially efficient (allowing potential cost savings for NHS)

The means by which Living Well Services are accessed in terms of information provision and sign-posting should also be considered. At the moment, information prescriptions are provided by the NHS for people with long-term health conditions, allowing access to relevant and reliable information, engendering independent, control and self-management of their condition. Care should be taken to ensure that information regarding Living Well Services is easily accessible on these pathways. An informal audit (Peter Kent, UK Information Projects Manager, Macmillan Cancer Support, in personal communication with author), of the information on these pathways has shown that future work needs to be done to fill in gaps in these pathways relating to self-management, assessment care planning and Living Well Services.

Furthermore, if Living Well Services are to be commissioned, then it is important to consider the role of a key worker signposting people to services. To ensure a person-centred, holistic approach is provided in the way people access Living Well Services, key workers should be appropriately trained. Bray and Groves (2007)⁵⁰ “*solution focused*” training programme is a useful example of how health care professionals may be trained to help people access services appropriately.

Conclusions

Holistic, person-centred care leading to self-management of the long-term condition of cancer should be recommended as a useful way of meeting the demands of the NCSI's five key shifts which aim to improve cancer care. In this context, Living Well Services provide an opportunity for people to focus on health and well-being after cancer treatment. A holistic needs assessment identifies patients' *"living well"* needs, and, enables a tailored approach to this particular aspect of care. Moving away from follow-up care towards self-management of the health condition could potentially save money and improve the quality of life of people with cancer. Tailored, person-centred support for active and advanced disease patients allows a sense of empowerment and the right combination of Living Well Services to be accessed to support care and improve quality of life. Future research work should measure the patient experience of living well programmes and will build upon the emerging evidence that exists that currently describes the benefits associated with this approach.

Bray and Watts (2010)⁴⁵, set out the Cancer Patient-Centred Charter below. This emphasises the drive behind the development of Living Well Services, (see appendix II for full statement). Here Bray states that all involved in the cancer journey should:

- *"pay particular attention to work towards the patient's/carer's version of living well.*
- *identify and magnify what patients/carers can do, and do for themselves, especially towards living well."*

In sum, the Living Well approach potentially allows more people with cancer to live healthier, better quality lives with less reliance on medical support and less strain on carers, and wider society. Moving towards such an approach is a cultural shift in future cancer care, but a shift which reflects the human side of cancer care – patient-centred, holistic and self-managed.

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Appendix I

From; Polley MJ, Seers HE, Cooke HJ, Hoffman C, Paterson C. How to summarise and report written qualitative data from patients: a method for use in cancer support care. *Support Care Cancer*. 2007 Aug;15(8):963-71

Penny Brohn Cancer Care and Breast Cancer Haven's breakdown of categories of 'concerns and problems' reported by people with cancer, using MYCaW (Measure Yourself Concerns and Wellbeing):

Super Category 1. Psychological and Emotional Concerns

- a. Adapting and coping
- b. Body image concerns
- c. Confidence issues
- d. Depression
- e. Emotional problems
- f. Family and relationships
- g. Fear and anxiety
- h. Psychological issues
- i. Regaining balance and normality
- j. Sleep problems
- k. Stress and tension
- l. Support
- m. The future

Super Category 2. Physical Concerns

- a. Arm problems
- b. Hot flushes and night sweats
- c. Fertility
- d. Pains/Aches
- e. Physical problems
- f. Poor energy levels
- g. Recurrence and spread

Super Category 3. Hospital Cancer (Medical)

Treatment Concerns

- a. Cancer treatment in general
- b. Lymphoedema
- c. Side effects of chemotherapy
- d. Side effects of hormonal treatment

Super Category 4. Concerns about Well-being

- a. Exercise
- b. General well-being and mind/body connection
- c. Healing
- d. Information and guidance on complementary therapies
- e. Nutrition
- f. Relaxation

Appendix II

Dominic Bray – Patient-Centred Charter:

1.1 Fundamentally, the NCSI should concern itself the delivery of improved cancer services which enable the whole person to live well (physically, psychologically, socially, financially, spiritually and in terms of lifestyle), as opposed to treating cancers in isolation from the patient. The following statement should be prominent in the final NCSI Vision document:

The Cancer Patient-Centred Charter

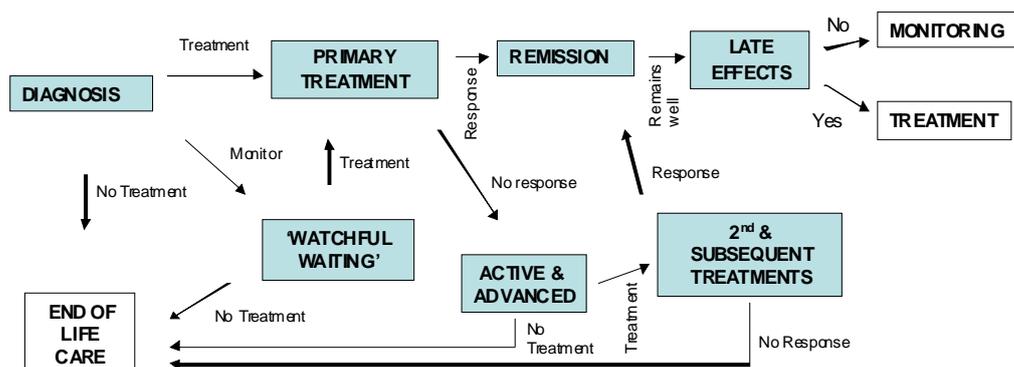
All involved in the cancer journey should:

- pay particular attention to work towards the patient's/carer's version of *living well*.
- identify and magnify what patients/carers can do, and do for themselves, especially towards *living well*.

1.2 An integration of the Cancer Patient-Centred Charter with the 'Care and Support Pathway' would look like this:

MODIFIED CARE AND SUPPORT PATHWAY

(Integrates medical events and patient-centred practice)



KEY POINTS WHERE CANCER PATIENT-CENTRED CHARTER APPLIES

- What is the patient/carer's version of *living well*? (this includes not only their hopes for life as a 'survivor', but also their preference for their degree of sharing in the decision-making process)
- What can the patient/carer **do for themselves**? (they may also report benefits from their experiences but this does not imply that all patients should be required to be 'positive')

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1.3 This implies the need for a **cultural shift** in many professionals' practice, away from exclusively expert-driven diagnosis-treatment models towards a more inquisitive, patient-centred approach, focusing on what the patient/carer wants, not only in their general life (physically, psychologically, socially, financially, spiritually and in terms of lifestyle), but also during the consultation. For example, some patients/carers may prefer a more directive style, with suggestions, signposting etc.; others may wish to be a key decision-maker. Good 'diversity' practice should also be observed, with sensitivity to cultural, generational and other group-based differences in preferred appointment style. Just as the patient/carer's preferred style of consultation is likely to change during their cancer journey, their version of 'living well', and the support needed to do this, will also change.

1.4 The 'cultural shift' will also need to encompass and embrace cancer patient/carers' *own competences* over and above those which simply pertain to 'coping' with cancer symptoms and in addition to taught strategies eg relaxation. For example, professionals should build on patient/ carers' ability to achieve a quality of life during previous significantly adverse life events, where present.

1.5 The 'Living Well' subgroup would potentially envisage these principles as applying at every stage of the cancer journey, although it is mindful of its 'Advanced and Active' disease remit. They also apply beyond consultations to whole services and community-based support, whether in primary care, secondary care, local authority and third-sector providers.

1.6 These principles are not new.

- They are a restatement, and incorporation into the NCSI structure, of the **Macmillan People-Centred Care Statement** (Macmillan Statement V5 161203):

"People with cancer and their carers want to form an effective working relationship with their healthcare professionals. Two-way communication is vital for people with cancer to be able to give relevant information about themselves. Most of all, people with cancer want doctors to be approachable and they want to be treated like a human being and as an individual, with dignity and respect for culture, lifestyle and beliefs. People with cancer want to be treated with respect, "like a human being", and not "as a tumour to be processed". They want to be empowered to have their voices heard and to be valued for their knowledge and skills."

- They closely correspond with the **Self-Management's Workstream's Position Paper (April 2009)**:

"The important aspect of this [overarching, single care plan] is that the care planning discussion has taken place with an emphasis on goal setting, equal partnership, negotiation, and shared decision making. (note that the self-management workstream would want these features to be strongly evident in the assessment framework being developed by the assessment and care planning workstream)"

..... “Health professional training: In order for cancer survivors to become effective self managers, there is a need for professionals to be able to support and encourage self-management, arguably a quite different skill set from the current cancer professional skill set.”

- They are also fully consistent with the letter and the spirit of the Darzi (2008) **Next Stage Review: High Quality Care for All** and with the **NHS Constitution for England (2009)**, for example :

“NHS services must reflect the needs and preferences of patients, their families and their carers. Patients, with their families and carers, where appropriate, will be involved in and consulted on all decisions about their care and treatment”.

1.7 By means of the NCSI ‘Assessment and Care Planning’ mechanism, thence the cancer peer-review structure, all professionals should be able to **provide evidence** that they are adhering to the principles of the Cancer Patient-Centred Charter. A cultural shift in many professionals’ practice is unlikely to happen without this key ‘driver’.

1.8 To support this, all professionals should receive **training** in consultation skills, as appropriate to their role, in some cases to compliment the national communication skills programme for cancer professionals. This would also form the basis of an excellent **test community**.