

# ASSESSMENT AND CARE PLANNING

## FOR CANCER SURVIVORS

**WE ARE  
MACMILLAN.  
CANCER SUPPORT**

**A concise evidence review**

January 2014

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## **Acknowledgements**

We would like to thank the following people for their assistance with this review:

Glenn Marland; Stuart Milligan; Elaine Stevens; Bill Smith;  
Angela Quigley; Marian Renshaw; AnnMarie Carr;  
Susan Jackson; Paul Canning; Audrey Cund; Douglas Park;  
Noeline Young.

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# Background

The Assessment and care planning (A&CP) working group was set up as part of the National Cancer Survivorship Initiative (NCSI) in 2009 in response to the Cancer Reform Strategy (2007). The aim of the working group was to scope, test and develop services, to improve the identification of unmet needs and the actions needed to support those needs and improve the quality of life in survivorship.

An increasing number of cancer patients are living with the effects of a diagnosis of cancer. There are currently 2 million survivors in the UK and this figure is predicted to rise to 4 million by 2030.

The NCSI report, *Living with and beyond cancer: Taking action to improve outcomes* (2013) identified that 'evidence shows that many of these cancer survivors have unmet needs particularly at the end of treatment, whilst others are struggling with consequences of treatment that could be either avoided or managed'.

The report highlights the importance of changing practice to be able to offer better support and improved outcomes whilst reducing the demand on the health service. Addressing people's needs is identified in this document as a priority to meet the increasing demand on services.

This rapid evidence review was commissioned to review the publications and grey literature and considered six key areas/headings:

1. Currently only around 25% of cancer survivors receive a holistic needs assessment (HNA) and care plan.
2. Lack of Holistic Needs Assessment of people after cancer treatment contributes to poorer outcomes and experience for people living with cancer.
3. There is a lack of specialist skills, knowledge and services within Health and Social Care to adequately assess and plan care for people following cancer treatment.
4. There are a number of short and longer term solutions to the implementation of assessment and care planning for all people affected by cancer.
5. Establishing these changes can lead to significant benefits to patients and cost savings to Health & Social Care.
6. Now that we understand the scale and severity of this problem, there are some clear 'calls to action' for different groups.

These key headings are further subdivided for the purpose of this literature review.

This concise review summarises the literature exploring the impact of HNA in practice. The literature for the evidence review is quoted in the main body of the text and referenced at the end of the document.

The evidence review is intended to inform health care professionals and managers wishing to implement a change in practice to incorporate holistic needs assessment and care planning. Innovation to Implementation A 'how to guide' (2013) is also available which outlines the key principles to changing practice and implementing stratified care pathways.

For the purpose of the evidence review the definitions agreed by the NCSI are available at [ncsi.org.uk](http://ncsi.org.uk) were used and are as follows:

### **Holistic Needs Assessment (HNA):**

Holistic Needs Assessment is a process of gathering and discussing information with the patient in order to develop an understanding of what the person living with and beyond cancer knows, understands and

needs. Holistic Needs Assessment is focused on the whole person. Their entire well-being is discussed – physical, emotional, spiritual, mental, social, and environmental. The process culminates when the assessment results are used to inform a care plan.

The care plan is based on the diagnosis and holistic assessment of the patient. The essential components will include needs and concerns identified by the patient related to the diagnosis. It prioritises the patient's issues and includes a statement on the specific goals, actions and approaches to address them – and recognises issues which may not be readily capable of resolution. The assessment and care plan process should ensure that care is consistent with the patient's needs and progress toward supported self management.

The care plan will be developed in partnership with the patient and become a part of the patient-held record that can be reviewed to ensure that actions have been taken and revisited if health and social needs change.

- Department of Health (2007) Cancer Reform Strategy
- Macmillan Cancer Support (2008) *Two Million Reasons*.
- NCSI (2013). *Living with and beyond cancer: Taking action to improve outcomes*. Department of Health gateway ref. 18455.
- NHS Improvement (2013) *Innovation to Implementation: Stratified pathways of care for people living with or beyond cancer, A 'how to guide*

# Overview

This concise review examines the evidence for Holistic Needs Assessment (HNA) in cancer survivors. It takes a structured approach by categorising levels of evidence pertaining to a series of specific statements.

We therefore begin with summary definitions of terms and a brief description of the evidence categorisation system.

## Definition of Holistic Needs Assessment

Holistic Needs Assessment is a structured method of consultation. It is usually completed by the patient immediately prior to consultation. The clinician then uses this to guide the consultation. The idea is that by using this measure the consultation is thus focused on the most important needs of the patient, as defined by them.

NCSI (2008) define a cancer survivor as someone who:

- has completed initial cancer management and has no apparent evidence of active disease
- is living with progressive disease and may be receiving cancer treatment but is not in the terminal phase of illness (last six months of life)
- has had cancer in the past.

## Definition of Cancer Survivor

Morgan (2009) defines a cancer survivor as: 'an individual who has been diagnosed with cancer, regardless of when that diagnosis was received, who is still living.'

Morgan goes on to outline that there are four essential components of survivorship – prevention, surveillance, intervention and coordination.

## SORT criteria

Each of the following statements are supported by evidence that fits into one of the following three categories, with A representing the most robust and C the weakest evidence.\*

\*Please see Ebell MH, Siwek J, Weiss BD, Woolf SH, Susman J, Ewigman B, et al.: 2004. Strength of recommendation taxonomy (SORT): a patient-centered approach to grading evidence in the medical literature. *The Journal of the American Board of Family Practice/American Board of Family Practice* 17:59–67

<b>Code</b>	<b>Definition</b>
<b>A</b>	Consistent, good-quality patient-oriented evidence**
<b>B</b>	Inconsistent or limited-quality patient-oriented evidence**
<b>C</b>	Consensus, disease-oriented evidence**, usual practice, expert opinion, or case series for studies of diagnosis, treatment, prevention, or screening

\*\* Patient-oriented evidence measures outcomes that matter to patients: morbidity, mortality, symptom improvement, cost reduction, and quality of life. Disease-oriented evidence measures immediate, physiologic, or surrogate end points that may or may not reflect improvements in patient outcomes (eg blood pressure, blood chemistry, physiologic function, pathologic findings).

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## **1. Currently only around 25% of cancer survivors receive a Holistic Needs Assessment (HNA) and care plan**

### **1.1 What are the benefits of Holistic Needs Assessment?**

The Holistic Needs Assessment addresses the needs and issues that are important to the patient<sup>1</sup> which are important because these needs are often more pertinent than identifying distress per se<sup>2</sup>. In America the survivorship care plan (SCP) extends from the HNA and is the best strategy to support individual needs by taking account of the individuals day to day challenges of everyday living, eg benefits, work, insurance<sup>3</sup>. An electronic version has been piloted in four sites across England. Early findings suggest there is a rise in the number of HNA completed in comparison to a paper based process. It is faster, saves time, connects professionals and informs better clinical decision making. It was identified that interconnectivity of technology and sharing of data across NHS delayed onset of the projects and limited progress<sup>4</sup>.

**B**

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### **1.2 Does the care plan provide the patient with the details of information and support available to enable self management and the steps needed to achieve their goals?**

The care plan is a communication tool that empowers the user to self manage and improve their quality of life whilst living with cancer<sup>5,6</sup>. The care plan is cited as a strategy to address individual needs,<sup>5</sup> central to which is the identification of the responsibilities key professionals hold to ensure care is coordinated and communicated timely and in a manner that respects the user's needs. It is vital that services are available to meet the needs identified at assessment<sup>7</sup>.

**C**



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### **1.3 Does the HNA process ensure that all patients have the opportunity to discuss their needs, thus offering equity of care and access to services?**

Systematising the process of managing distress appears useful to people in navigating support systems<sup>8</sup>. Language problems may impact on service equity<sup>9</sup> but the opportunity to systematically discuss areas of concern pertinent to the individual is clearly highly valued by patients<sup>1</sup>.

**C**

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### **1.4 Is there data identified to support future service commissioning and development?**

Several NICE guidelines refer to the need for HNA and care plans eg Breast standards. They are also embedded in cancer commissioning toolkit draft specifications eg colorectal item 3.1.21. Cancer is a national priority and key documents across the UK countries set out similar themes in terms of prevention, early diagnosis and treatment of cancers<sup>10-12</sup>. The need to embed the social component of care in commissioning is increasingly recognised<sup>13</sup>.

**B**

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### 1.5 Why do we need to change practice?

We identified that 2 million people are living with and beyond cancer in the UK and this is predicted to increase to 4 million by 2030 as a result of an ageing population, rise in number of long term conditions, lifestyle factors and the rates/incidence of cancer<sup>14</sup>. Combined figures for all cancers (excluding non-melanoma skin cancer) in the UK (2008–2010) show that there is an average 322,923 newly diagnosed cases of cancer each year. There are now 1.24 million cancer survivors who have had their diagnosis for longer than five years. This accounts for a 3.2% growth per year in the number of survivors. The four most common cancers are breast, lung, prostate and colorectal which account for 53% of cases and 47% of deaths. In the UK, men account for 163,100 of cases and 159,823 women<sup>15</sup>. Scotland had the highest cancer mortality rates, around 15 per cent higher than the UK average for both males and females. Almost a third of cancer survivors experienced changes in their work situation after cancer. Problems with obtaining health insurance, life insurance and home loans were also common<sup>16</sup>. Against the backdrop of a growing and aging population, rates/incidence of disease cancer is likely to increase in men and women by 55% and 35 % respectively<sup>17</sup>.

**A**

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### 1.6 With increasing numbers of people diagnosed with cancer do we need to move towards stratified managed care pathways and encourage supported self management?

Recent studies have shown that stratified care pathways complement survivorship care plans by creating and detailing the stages of care (specific to each cancer), the possible outcomes, self management approaches and responsibilities of services and professionals<sup>18</sup>. The benefits of risk stratified care pathways include the potential to reduce duplication and omission of care and connect the interface between acute and primary care<sup>19</sup>.

**B**

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**1.7 Does HNA and care planning identify individual needs, enable those needs to be addressed and promote self management?**

Needs analysis systematically identifies gaps in service provision. Starting at this point led to NHS Improvement designing a model that delivers appropriate evidence based supported self care<sup>20</sup>.

**C**

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**1.8 Is HNA relevant in the wider context of care in relation to other chronic conditions, eg Rheumatoid Arthritis and Diabetes?**

Holistic Needs Assessment is a transferable method of facilitating appropriate person centred care. It is a staple of mental health care<sup>21</sup> and increasingly recognised in chronic disease conditions such as diabetes<sup>22</sup> and rheumatoid arthritis<sup>23</sup>. The need to put the person at the centre of all their care is now embedded in UK health policy<sup>24,25</sup>.

**A**

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## **2. Lack of Holistic Needs Assessment of people after cancer treatment contributes to poorer outcomes and experience for people living with cancer**

### **2.1 Does a lack of assessment and care planning during and following treatment for cancer lead to persistent problems after treatment for people living with cancer?**

Common problems can be identified within the domains of care as physical, social, practical, spiritual and/or psychological.

Physical problems such as bladder and bowel problems<sup>26</sup>, poorer quality of life, psychological distress, sexual problems, problems with social relationships and financial concerns are all common problems<sup>27</sup>. Pain, fatigue, information needs, anxiety, depression and other psychiatric disorders are also frequently discussed<sup>28, 29</sup> with suicidal thinking evident in some adult survivors of childhood cancer<sup>30</sup>.

**A**

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### **2.2 What proportion of people affected in this way?**

Distress is unpredictable<sup>31</sup>. Newly diagnosed people range in their unmet needs from 15–93%<sup>32</sup>. High rates of anxiety, depression and or psychiatric disorders in patients diagnosed with cancer ranged from 16–45%. Prevalence of long term psychological distress in such patients ranges from 20–66%<sup>28</sup>. However, some commonalities exist. Younger people tend to be more distressed<sup>33</sup> and most studies showed that the level of unmet needs was highest after diagnosis and start of treatment and decreased over time. Predictors of unmet needs included: younger age, female gender, depression, physical symptoms, marital status, treatment type, income, and education<sup>32</sup>.

**A**

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### **2.3 What are the negative effects on patient and family experience and outcomes?**

Anxiety and depression were the two predominant problems most often encountered by therapists during therapy (31% and 29%, respectively). Other problems included relationship problems (23%) and saying farewell to life (21%)<sup>34</sup>.

**C**

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### **2.4 What is the cost burden to Health and Social care of this problem?**

Care that has fulfilled all a patient's needs is not more expensive than care that has not fulfilled all perceived needs<sup>35</sup>. The authors therefore recommend care that fulfils patient's self perceived needs. It is known that 10% of people need psychosocial services independent of level of distress<sup>2</sup>.

**B**

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### **2.5 What is the impact on emergency admissions and resource use?**

Emergency admissions of patients with a cancer diagnosis rose by 30% between 1997/98 and 2006/2007 equating to approximately 750 emergency admissions per day across England<sup>36</sup>. There were just over 400,000 emergency bed days in lung cancer in 2008/09 or 5 emergency bed days per patient. The ratio of emergency bed days per patient is significantly lower in other tumour types, averaging around 1 per annum<sup>37</sup>. In lung cancer, a 10% reduction in emergency bed days (ca 40,000 bed days) equates to a saving of £9.3m<sup>37</sup>.

**B**

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## **2.6 What common chronic illnesses could be identified early by holistic assessment eg anxiety and depression?**

Older cancer survivors have higher rates of co-morbid conditions and these conditions can exacerbate the effects of cancer and its treatment on the post-treatment health of older adults<sup>38, 39</sup>. Older adults in particular also worry about a cancer recurrence although physical problems related to cancer and treatment was also a top source of distress in younger patients<sup>40, 41</sup>. After secondary malignancies, cardiovascular disease is the leading cause of late morbidity and death among cancer survivors. The underlying cause is thought to be the late effects of cardio toxic cancer therapy<sup>42</sup>. Peripheral neuropathy is a common side effect of many chemotherapy agents<sup>43</sup>.

**B**

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## **2.7 What proportion of people are affected in this way?**

60% of over 10,000 survivors of child cancers reported at least 1 chronic health condition and almost 30% had a severe condition by a mean age of 26.6 years. The authors state that the curative effect of cancer treatment is profound with damage to surrounding normal tissue and risk of secondary malignancies<sup>44</sup>. Survivorship care plans have clear role in identifying potential and actual comorbid conditions associated directly with cancer and its treatment<sup>45</sup>. In a systematic review of thirty studies examining unmet needs in cancer care the authors<sup>32</sup> found up to 93% people had unmet needs although this level decreased over time.

**A**

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## 2.8 Quantify negative effects on patient and family experience and outcomes

Anxiety scores were higher among women than men and both anxiety and depression scores were highest during years 1–5 compared to the first year and more than five years post diagnosis<sup>46</sup>. Negative effects may also be disease specific. For example couples surviving prostate cancer face long-term challenges in their relationships as they adapt to chronic illness<sup>47</sup>. A robust qualitative appraisal<sup>48</sup> found the following pertinent themes, illustrative of the suspension of normality endured by families and survivors of cancer:

- ‘Life is back to normal and yet not’.
- ‘Life has a shadow death’.
- ‘To share or not to share the illness’.

Kim et al<sup>49</sup> found that some interventions were designed to help caregivers manage their own emotional distress as well as the survivors’ distress, help them to find meaning in the cancer care giving experience and foster supportive familial relationships. This will benefit caregivers by improving their quality of life, not only during the time of diagnosis and treatment but years after.

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## 2.9 What is the cost burden to Health and Social care of this problem?

Annual savings arising from extending one to one support in prostate, lung, head and neck and colorectal Cancer – shown as a reduction in hospital and GP visits is estimated £57 per patient or the equivalent of 1.1 GP appointments<sup>37</sup>. These types of studies are contentious as they have to make assumptions about future care savings; however, they are increasingly being taken seriously as identified in *A Guide to Social Return on Investment*<sup>13</sup>.

**A**

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## 2.10 Can common symptoms (including secondary cancers) be identified by holistic assessment eg lymphoedema?

The problem list of a holistic assessment should help in identifying the common symptoms that people report following treatment for cancer; these include cancer-related fatigue (CSF) that is complex and distressing. It affects 70–100% of patients receiving chemotherapy and a significant number who have completed their treatments<sup>50</sup>. Persistent physical and psychological symptoms such as fatigue, pain, sleep disturbances and fear of recurrence as well as quality-of-life outcomes have been described in women during and after breast cancer<sup>51</sup>. Secondary Lymphoedema may develop after surgery from solid tumours, such as in breast cancer<sup>52</sup>. Long term effects develop during treatment and persist for at least five years, such as neuropathies with related weaknesses, numbness, pain, fatigue, cognitive and sexual difficulties, elevated anxiety and depression<sup>53</sup>. In survivors of childhood cancers approximately two thirds of the survivors experience at least one late effect and about one fourth experience a late effect that is severe or life threatening<sup>54</sup>.

**A**

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## 2.11 What proportion of people are affected in this way?

Up to 2 million cancer survivors cope with Lymphoedema daily, 15–25 % of the breast cancer population alone<sup>55</sup>. Complications for childhood survivors include growth impairment and development, neurocognitive dysfunction, cardiopulmonary compromise, endocrine dysfunction, renal impairment, gastrointestinal dysfunction, musculoskeletal sequelae and subsequent malignancies. It suggests that approximately two thirds of the survivors experience at least one late effect and about one fourth experience a late effect that is severe or life threatening<sup>54</sup>.

**B**



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### **2.12 What are the negative effects on patient and family experience and outcomes?**

Cancer recurrence is described as a distressing experience for survivors and their families<sup>56</sup>. Thoughts and feelings such as 'oh no not again' and shock with the future being perceived as a state of uncertainty. It was suggested that for some families being informed of further cancer diagnosis or return was more devastating to the family than being informed of the first diagnosis<sup>57</sup>.

**B**

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### **2.13 What is the cost burden to Health and Social care of this problem?**

The cost of recurrence to the NHS is high. One study puts the cost at £10,906 per annum per patient<sup>37</sup> in estimating the savings to be made from a one to one system of aftercare support in colorectal cancer. Again it should be stated that these savings are based on assumptions made by these economists. Probably of greater significance is the suggestion that identifying and treating comorbid depression in cancer may not just enhance quality of life but extend the life of depressed cancer patients<sup>58</sup>.

**A**

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### **3. There is a lack of specialist skills, knowledge and services within Health and Social Care to adequately assess and plan care for people following cancer treatment**

Early NCSI work showed that awareness of the benefits of Assessment and care planning amongst health professionals was low and the needs of cancer survivors for information and services are often unmet<sup>59, 60</sup> which may reflect limited Assessment and care planning on the part of health professionals<sup>61</sup>. The need for additional social support has also been identified<sup>62</sup> inferring that professional understanding of the need for systematic holistic assessment may be low. A UK study found that nurses have difficulty identifying distress using their routine clinical judgment and make more false-negative than false-positive errors in the recognition of distress in cancer patients<sup>63</sup>. There is a general lack of understanding as to the benefit of guidelines in improving practice<sup>64</sup>. Assessment and planning are often part of this process and so the issues may be related. Findings from the research literature indicate that medical and nursing staff often lack the skills needed for assessing the holistic needs of patients<sup>65</sup>.

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#### **3.1 Is there evidence of services between clinical teams for patients with multi-morbidities?**

Comparisons regarding the use of health care services by cancer patients with a control group of non-cancer patients in the Netherlands found that cancer patients consulted general practice more frequently and suffered more often from co-morbid chronic conditions. These findings suggest a need for better co-ordination and communication between professionals when multi-morbidities are present<sup>66</sup>. The experience of cancer in those diagnosed with cancer as older adults is often superimposed on existing health conditions, which disproportionately affect the elderly population. Understanding the extent to which having cancer contributes to decrements in physical, mental and social function, above and beyond the influence of other chronic health conditions and normative aging, will be critical to the long-term care of older cancer survivors<sup>39</sup>.

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### **3.2 Are there appropriate assessment tools for a holistic needs assessment to correctly assess the needs of people affected by cancer?**

Distress in cancer has been the subject of significant psychometric study in recent years<sup>67</sup>. However, there is increasing recognition that distress in itself may not be a relevant measure of need, so common methods of needs assessment such as the Distress Thermometer may not be the best tool to identify specific individually pertinent needs<sup>2, 68</sup>. There remains a lack of awareness among health professionals concerning needs of cancer survivors<sup>69</sup>. Future research should therefore test assessment methods designed to identify patients who may benefit from psychosocial interventions<sup>70, 71</sup>.

**A**

The development of a Survivors' Unmet Needs Survey which distinguished between the problems that survivors experience and those they actually want help in managing, reflects how these problems can vary from what health professionals think survivors want<sup>72</sup>. This issue is illustrated further in a qualitative study which described the effects of unresolved post surgical morbidity following prostatectomy and demonstrated the importance of assessment in identifying patients' need for information regarding potential long term problems<sup>73</sup>.

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### **3.3 What if complex issues are raised that are not familiar to the practitioner?**

Health professionals had limited understanding of issues in respect of sexuality and intimacy and the provision of patient centred communication in this respect was linked with staff attitudes and beliefs rather than the evidence<sup>74-76</sup>. This is not made easier by the finding that there are no current assessment tools that account for all aspects of peoples' needs<sup>77</sup> although there is considerable work in this area<sup>78</sup>.

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### 3.4 What about the process of assessment?

Inadequacies in psychometric rigour, problems with scoring methods, use of ineffective interventions and lack of adherence to intervention protocols seem to account for processes to identify unmet care needs being ineffective<sup>79</sup>. A grounded theory study found GPs dissatisfied with level of information they got from hospitals<sup>80</sup>.

A UK study identified five key times in the cancer journey as being especially significant to survivors and suggested that the lacking component is a constant, known clinician who offers a holistic approach<sup>81</sup>. A recent Cochrane Review found no standard instruments that measured continuity of care in cancer patients and no evidence that current models of management made a difference to the health-related outcomes of cancer patients<sup>82</sup>.

**A**

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### 3.5 Is there a need for cultural change and team working?

Cancer survivors often report that their medical needs are met, but psychosocial needs may remain unaddressed<sup>83</sup>. Psychosocial issues were rarely reported as triggering referral to specialised palliative care services among medical staff surveyed. Referrals were mainly for physical symptoms related reasons<sup>84</sup>. This aligns with the impression gained from a Lancet article that non physical issues do not appear to be a priority to physicians<sup>85</sup>. Professionals lack the necessary skills for assessing and detecting patient distress, but medical staff often feel this is the responsibility of nurses<sup>86</sup>.

There are no standardised measures that allow for the empirical investigation of continuity of care between teams<sup>82</sup>. There is a clear need for more service-user involvement in planning and implementation of cancer care and in developing services at an operational level<sup>87</sup>. New models of survivorship care include the engagement of cancer survivors and advocacy groups who strongly support the fostering of collaboration and partnership between clinicians and cancer survivors<sup>69</sup>. Sharing care through the development of survivorship care plans and electronic records have been shown to be of value to primary care providers, increasing their knowledge about survivors' cancer history and influencing the care they provide<sup>88</sup>.

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### 3.6 Is there enough time and facilities to adequately implement this change in practice?

The increasing cost of cancer treatments and prolonged survival of cancer patients is placing a strain on care services and will require innovative strategies to ensure there is adequate provision to meet the future needs of people affected by cancer<sup>89, 90</sup>.

Nurses identified that the greatest barriers to providing 'survivorship care' were time and funding<sup>91, 92</sup>. Lack of time is a common perception<sup>93</sup>. For primary care physicians volume of correspondence is also given as a factor<sup>92</sup>. A US study to evaluate agreement of treatment summaries and survivorship care plans showed gaps in agreement and noted a substantial time burden in preparing and delivering survivorship care plans<sup>94</sup>. However, there is also evidence that systematic management of unmet needs within consultation takes no more time than treatment as usual<sup>95</sup> and care that meets people's expressed needs is no more expensive than care that does not<sup>35</sup>. An evaluation by NCSI in the UK into the use of electronic Holistic Needs Assessment also identified time burden as one of the principal reasons for low and varied completion of paper based HNAs but suggested that time savings could be achieved in moving to an electronic system<sup>96</sup>.

There are conflicting incentives and rewards from care providers<sup>97</sup>. In the US, increasing costs of cancer management and perverse incentives for reimbursement of care providers can act as a barrier to patients accessing care<sup>98</sup>. US online survey of 399 nurses found that 46% thought that lack of time and funding was one of the greatest barriers to providing survivorship care<sup>91</sup>. Data from the US National Health Interview Survey (NHIS) from 2003 to 2006 indicated that more than 2 million US cancer survivors did not get one or more needed medical services because of financial concerns during this period<sup>99</sup>.

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### 3.7 What processes hamper effective assessment of people living with cancer?

There is no process in place to identify where and when in the care pathway is appropriate to assess people's needs.

Socio-demographic and disease-specific variables affect the level of perceived unmet needs<sup>100</sup>. There is a lack of coordinated patient treatment across multiple healthcare providers, with a tendency of medical professionals to refer patients back to specialists<sup>101</sup>. Some cancer patients receive a lot of information about their disease and medical tests but are dissatisfied about the information provided regarding side effects, rehabilitation, psychological support and effects on their social and sex lives<sup>102</sup>. Because oncology practice tends to focus on treatment, management and detecting recurrence of disease, this leads to inadequate assessment and management of problems resulting from the initial treatment they received<sup>103</sup>.

One of the barriers identified in the NCSI testing was the lack of a process/key marker to identify the end of initial treatment.

Patients often lack the necessary information and support to help them effectively manage the transition from being a patient on treatment to becoming a survivor<sup>104, 105</sup>. Discharge from hospital follow-up is a key point in the cancer journey but in a study that explored survivors' experiences of discharge from hospital follow-up, approximately one-third of respondents were not discharged 5–16 years post diagnosis<sup>61</sup>.

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### **3.8 Is there a mismatch of health care professional's perception of patient needs and the reported needs of patients?**

In contrast to widespread assumptions about patients' need for counselling, many patients use friends and families for support. A study set up to identify and provide for the needs of patients with a diagnosis of non-curative cancer found that services focussed on professional agendas, rather than those of patients<sup>106</sup>. Even in advance care planning patients choices are not always adhered to<sup>107</sup>. A survey of 1,130 oncologists and 1,021 primary care physicians regarding follow-up care of breast and colon cancer survivors showed they differ in their beliefs regarding who provides specific aspects of care and highlighted a need for better care coordination<sup>108</sup>. There is evidence of confusion regarding treatment plans, staff roles, vocabulary used, unmet emotional needs<sup>109</sup>.

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#### **4. There are a number of short and longer term solutions to the implementation of Assessment and care planning for all people affected by cancer**

More training relating to communication and shared decision making skills for health care professionals may improve patient centered care planning<sup>110</sup>. Communication between the health care provider and the patient can play an important role in determining who will engage with health improving lifestyle behaviours and how effectively patients recognise and report on symptoms<sup>111</sup>.

C

Survivorship Care Plans can help to achieve structured support for patients and also contribute to communication between patient and healthcare team. There is also widespread recognition that nurses have a poor awareness of the concept of survivorship care planning<sup>6, 112</sup>.

Cancer survivorship is not established as a core topic within education programmes<sup>113</sup>. However, it is beginning to become more common. Survivorship is now being seen as a specific phase of the cancer journey with nurses being pivotal in the Assessment and care-planning process; however, barriers, including attitudes to implementing services remain apparent<sup>6, 114</sup>.

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##### **4.1 How can Holistic Needs Assessment improve the care pathway?**

Focussing on the local and national services available to people living with cancer eg support groups, physical activity, and social groups can help to improve the care pathway. These may not be cancer specific and could be used across a range of conditions.

C

All national policy advocates the use of self-management strategies and encourages joint working with health and social services and independent organisations such as Macmillan Cancer Support and Maggie's Centres<sup>10-12</sup>. For example, the 'Chronic Care Model' discusses how oncology professionals can use it to empower and enable patients and their families to engage in self-management activities<sup>115</sup>.

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#### **4.2 Is there a need to integrate Holistic Needs Assessment into the care pathway and ‘give permission’ to the patient to reassess should health and social needs change?**

There is evidence of evolution here with the Institute of Medicine (IOM) recommending the implementation of survivorship care plans and the development of an electronic patient self-assessment and management tool<sup>116</sup>. For example, the online tool discussed in this article was developed originally for use by cancer survivors themselves; however, health care professionals have utilised it to help them provide survivorship care plans within practice and have reported a high level of satisfaction with the tool<sup>113</sup>.

C

The electronic self-assessment tool could potentially increase GPs and other primary care team members’ awareness of survivors and caregivers needs<sup>116</sup>. From a contractual point of view there is a need to embed the principles of Holistic Needs Assessment within service commissioning<sup>13</sup>.

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#### **4.3 Can innovations like nurse led assessment clinics, use of electronic solutions such as touch screens, which draws together common tools and resources, help?**

Nurse-led services are considered to deliver evidence based, patient-centred care<sup>117, 118</sup>. However, there is limited robust evidence currently available to support the potential of nurse-led, cancer survivorship clinics to enhance long-term survivor outcomes<sup>119</sup>. Likewise touch screen initiatives are promising<sup>4</sup> but need further evidence of their impact given their associated resource issues<sup>120</sup>.

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#### 4.4 Are there commonly identified issues and barriers to change?

Lack of time, resources and facilities are often cited as barriers to change although there are other issues as identified here.

Remote monitoring has been constrained by lack of resources (especially IT resources)<sup>120</sup>. Few cancer survivors report receiving lifestyle counselling from their oncology professionals, although the reasons for these omissions are not known<sup>121</sup>.

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#### 4.5 Is there a need for further training?

Additional skills may be required by professionals helping patients make the transition from traditional care to a self care model<sup>120</sup>. Better training of health care providers (and patients) in communication and shared decision making skills might improve patient-centred treatment planning<sup>110</sup>. A separate skills set is required by clinicians supporting patients to develop self care behaviours<sup>122</sup>. Few health care providers have received training in how to monitor the physical health of cancer survivors<sup>123</sup>. Few health or social care professionals in oncology or primary care have received formal education in cancer survivorship<sup>124</sup>.

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#### 4.6 Is there a need for commissioning of services?

A briefing paper on cancer survivorship recommended that the provision of ongoing support following primary cancer treatment should be included in commissioning guidance for all local health authorities<sup>125</sup>. Calls have been made for services for cancer patients to be more joined up, to reduce the gaps in provision which currently exist<sup>126</sup>. The need to focus on wider social impact of commissioning has already been mentioned<sup>13</sup>. It should also be remembered that value for money is defined as the optimum combination of whole-of-life costs and quality (or fitness for purpose) of the goods or services to meet the user's requirement. Value for money is not the choice of goods and services based on the lowest cost bid<sup>127</sup>.

C

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#### 4.7 Is there a lack of leadership or a cohesive approach?

In the United States, all patients approaching the end of oncology care should have a Survivorship Care Plan written by the oncology team<sup>124</sup>. However, implementation of this recommendation has proved extremely problematic<sup>108</sup>. One study found the use of a Survivorship Care Plan to support the transition from hospital care to primary care did not affect short or longer term patient satisfaction or other patient outcomes compared to normal primary care follow up<sup>128</sup>. There is a lack of guidance on who should plan and co-ordinate post-cancer patient care. Nurses may have a role to play<sup>5</sup>.

C

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#### 4.8 Does Holistic Needs Assessment and care planning help patients to better understand their needs and improve their ability to self manage?

Information events for people living with breast cancer were found to be cost effective and to offer value for patients, but uptake was variable<sup>120</sup>. The benefits of a four-week information and support programme for breast cancer survivors in Malaysia were still apparent after two years<sup>129</sup>. Cognitive Behavioural Therapy administered as an interactive, individually tailored Internet intervention led to improved outcomes for a group of cancer survivors experiencing insomnia<sup>130</sup>. The 'Taking CHARGE' programme successfully facilitated the transition to survivorship for women treated for breast cancer<sup>131</sup>.

B

Women undergoing the transition from breast cancer treatment to survivorship have specific information needs which are inconsistently addressed<sup>132</sup>. A systematic psycho-educational intervention was associated with improved quality of life in women receiving breast cancer treatment. The beneficial effect was still apparent six months after the intervention<sup>133</sup>. A review of evidence from the UK suggests that individual and group education are increasingly being used to achieve successful survivorship<sup>134</sup>.

Survivorship care plans should contain explicit details of the services responsible for the different aspects of ongoing care<sup>135</sup>. Clinical nurse specialists were found to be important sources of ongoing psychosocial support among British cancer survivors<sup>134</sup>.

C

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#### 4.9 What about open access patient triggered follow up?

A robust monitoring system is required to detect relapse or recurrence among patients stratified to self management<sup>120</sup>. A proposed electronic patient self-assessment and management system covering quality of life and symptom measures would 'flag up' any issues of concern to the patient's primary care team<sup>116</sup>. Increasingly, telephone and web-based systems are being used to facilitate access to individually-appropriate after care<sup>134</sup>. An internet-based resource has been developed to meet the ongoing psycho-educational and support needs of survivors of stem cell transplantation<sup>136</sup>.

Patients can be safely stratified to professional management or self management. Up to 70% of breast cancer patients could be safely helped to self manage<sup>120</sup>. It is possible to achieve successful self-care even in people experiencing the advanced stages of cancer<sup>137</sup>. A review of self care programmes has highlighted how these programmes enable and empower patients, particularly through information, support and the provision of new skills<sup>115</sup>. A Grounded Theory study of survivors of breast cancer found that women experienced empowerment out of adversity through a process involving self healing, adjustment and growth<sup>138</sup>. Empowerment was one of the outcomes recognised in a review of studies of British cancer survivors, achieved through the encouragement of self-care and self-management<sup>134</sup>.

C

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#### **4.10 Does increasing our understanding of the need for a Holistic Needs Assessment and individualised care planning improve the experience of those living with cancer and their ability to self manage?**

Publishing evidence in peer reviewed journals enhances the credibility and leverage to encourage this approach.

Publishing creates consensus<sup>112</sup> and provides an evidence base for clinical decisions<sup>113</sup>. It stimulates debate and publicises innovative practice.

Using aggregated data from assessments can be used to inform future service needs.

Bilotti et al developed a care plan aggregating different information together to ensure best practice for people with myeloma<sup>45</sup>. Survivorship care plans need to be personalised and combine information to assess needs of minority groups and to inform their care<sup>139</sup>. Use of combined patient information to plan care is a more efficient use of resources and may reduce needless use of other services<sup>140</sup>. It allows for a more responsive service that meets needs<sup>18</sup>. This aspiration has a long history in the NHS<sup>141</sup>.

C

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#### **4.11 Does improving the identification and ongoing measurement of assessment inform the care planning process?**

There are number of factors impacting on this question, all supporting the need for ongoing assessment and the likely impact of that assessment. If these unmet needs were identified then there could be more targeted use of psychosocial resources<sup>105, 142</sup>. Traditional hospital follow up does not meet psycho-social or information needs. Nurse led services more responsive and favourable. Services led by colorectal CNS may be a more effective model of follow up care<sup>143</sup>. Length of survivorship does not predict the long term effects of cancer, and this supports the need for ongoing individualised holistic needs assessment<sup>144</sup>.

B

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#### 4.12 What is the impact and quality of effective holistic needs assessment and care planning?

Research on the introduction of holistic needs assessment found no increase in follow up referrals but better targeted to meet needs. Use of combined patient information to plan care. More efficient use of resources may reduce needless use of other services<sup>140</sup>. Patients were satisfied with using online self-care plans (LIVESTRONG care plan). Improved amount of information given on survivorship which combined with clinical discussions to improve care<sup>113</sup>.

C

Understanding the impact of this approach and the patterns of resource use will be beneficial to commissioning.

Understanding survivors' needs can identify how to improve care<sup>91</sup> in a responsive manner<sup>18</sup>. Systematic tools support this process<sup>145</sup>. Cultural issues such as language need to be factored in. For example, in English services lower English proficiency survivors had more symptoms<sup>9</sup>. Resource use data always needs to be factored into any aspect of commissioning<sup>37</sup>.

B

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## 5. Establishing these changes can lead to significant benefits to patients and cost savings to Health & Social Care

There is systematic understanding at the policy and strategic level that operationalising person centred care in health is both moral and more efficient<sup>10-12, 14, 15, 19, 20</sup>. The impact at personal level is evidenced across multiple case studies. People who are listened to and have their needs met feel more empowered<sup>146, 147</sup>. There is evidence that behavioural techniques have a positive effect on fatigue and stress, and the physical exercise interventions are beneficial in fatigue, depression, body-image and health related quality of life<sup>148</sup>. It is recognised that holistic care is needed to address the detrimental consequences of treatment in head and neck cancer survivors<sup>149</sup>.

**B**

Routine use of HNA improves efficiency by directing and apportioning appropriate referrals<sup>140</sup>. For example, in this small study about access to welfare rights it enabled patients to obtain benefits (acknowledged area of unmet psycho-social need) which helped with necessities such as heating etc, offset associated costs of cancer travel, clothes, food, lessened impact of loss of wages, provision of safety net resulting in lessened worry<sup>150</sup>. Patients were more satisfied with clinic visits when greater attention was paid towards psychosocial aspects<sup>151</sup>.

**C**



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### **5.1 What are the costs to the Health and Social Care system?**

There is robust evidence from an economic evaluation running alongside a randomised controlled trial of the cost effectiveness of nurse led telephone follow-up as compared to hospital visits and a short educational group programme in the first year after breast cancer treatment<sup>117</sup>. Patients appeared to be satisfied with nurse led follow up which was a practical alternative to conventional hospital follow up. Patients with breast cancer found patient initiated follow up convenient but conventional hospital follow up more reassuring. Patients with lung cancer expressed more satisfaction with nurse led telephone follow up and more were enabled to die at home<sup>118</sup>. A literature review of 37 papers led to the conclusion that nurse led follow up was acceptable appropriate and effective<sup>152</sup>. It is difficult to know if this is directly related to the type of assessment undertaken, but communication is often problematic in follow up care<sup>80</sup> so it is intuitively plausible that personalised care is cost effective care.

**A**

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### **5.2 Are there potential savings associated with appropriate assessment, screening and follow up care?**

There is consistent and good quality evidence that in lung cancer the improvements in quality of life and symptom control associated with the involvement of palliative care teams results in a reduction in hospital re-admission rates and in-patient hospital days therefore reducing overall costs<sup>153</sup>. The reviewers of a one to one programme of aftercare in all cancers across the UK claimed provision of this level of care would actually save money, despite its initial cost of £60m per annum<sup>37</sup>.

**A**

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### **5.3 Are there potential savings associated with identifying early the common symptoms of associated chronic illnesses?**

This is a function of the age of the person affected, their probability of survival and quality of life and the type of chronic illness, thereby precluding straightforward summary. In general, early detection is better than late detection<sup>154</sup>. For example, treatment of depression secondary to pain in cancer should be identified and treated early as part of routine cancer care<sup>155</sup>.

**B**

Discharge from hospital follow-up is a key time point in the cancer journey. With recommendations for earlier discharge of cancer survivors, attention to the discharge process is likely to become increasingly important<sup>61</sup>. Cancer services understand this. For example, patients with pre-existing cardiopulmonary conditions prior to cancer reported that their needs were better met while they were undergoing cancer treatment<sup>156</sup>.

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### **5.4 Are there potential savings in relation to emergency admissions?**

Emergency admissions can be reduced with proactive organisation of services in general<sup>157</sup>. Deprivation, ethnicity and gender are significant predictors of emergency admission<sup>158</sup> whereas being able to consult a particular GP, an aspect of care continuity was not. This strongly suggests that proactive care grounded in a solid therapeutic relationship such as engendered by holistic needs assessment and the survivorship care plan can mitigate emergency hospital use<sup>159</sup>.

**B**

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### 5.5 Are there benefits to families, carers and society more widely?

Carer/family benefits may be in the form of case studies of individuals or evaluations of specific interventions.

80-90% of all care of people with long term conditions is performed by the person themselves or their family and recent studies are starting to acknowledge and support the significant role of the family here<sup>160, 161</sup>. Holistic Needs Assessment could highlight issues that are relatively straightforward to support but often difficult for families to navigate such as welfare benefit access<sup>150</sup> although there is evidence that this service could be improved<sup>79</sup>. Sensitive and person centred care also extends to the family beyond death of the person with cancer<sup>162</sup>.

**B**

Benefits to society could include enabling patients to return to work.

The Health Foundation found that 'proactive, behaviourally focused self-management support designed to increase self-efficacy can have a positive impact on people's clinical symptoms, attitudes and behaviours, quality of life and patterns of healthcare resource use'<sup>150 piv</sup>.

## 6. Now that we understand the scale and severity of this problem, there are some clear 'calls to action' for different groups

Actions required from:

- Research community to build on/ratify evidence base

There is an evidence base developing. The research community has a lot of information to assimilate. It must be stressed that assigning a value to this research as we have done here does not tell the full story or expose the most important gaps in this evidence base. For example, often research that we have categorised as B or C is also the best and most appropriate research to be done on that particular issue. We only make this point because building on this research base is not necessarily a matter of aiming for level A evidence but aiming for the best evidence to address the research question in hand.

The major research questions emerging from a review such as this pertain to the impact of Holistic Needs Assessment (HNA). As we have seen there is growing recognition of the importance of HNA combined with elements of inconsistency as to how it is applied, who should be applying it and what should

happen as a consequence. These assumptions all need to be tested in a systematic manner so the evidence can develop in the most useful way for survivors of cancer. For example, how does listening to someone with cancer in a structured manner make a difference to that person? University of the West of Scotland in partnership with Macmillan Cancer Support UK are currently studying this. There are many more similar research projects underway and many more are needed. While the principles of person centred care embedded in HNA are moral and politically popular the evidence for their articulation requires innovative and rigorous evaluation.

- Clear leadership in championing HNA

Associated with a clear research agenda is clear leadership. Macmillan Cancer Support has invested considerable resources in championing HNA and continues to lead the way in focusing attention on survivorship as well as other important aspects of cancer care.

- Selected Peer-credible Health and Social Care professionals – ('Clinical Champions') to raise profile of the need to implement HNA.

The best way of operationalising this agenda is to have dedicated people in post to support projects designed to raise the profile of structured needs assessments. Ideally these clinical champions would partner a research organisation in embedding evaluation at the heart of any new venture.

- Voluntary sector to raise awareness and profile of the process

There is not enough evidence of systematic assessment of holistic needs in the voluntary sector to identify specific recommendations. However, it would seem intuitive to suggest that any method of systematically identifying and addressing needs that are important to the individual would be a transferable positive way of working in any sector.

- UK Governments and commissioners to incorporate policy/financial levers

Whilst clearly part of current policy<sup>10-12</sup> and aspiration, further incentives are likely to be needed to embed HNA and care planning in routine clinical practice.

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