

Sharing good practice

# HOLISTIC NEEDS ASSESSMENT AND CARE PLANNING

WE ARE  
MACMILLAN.  
CANCER SUPPORT

## Noëline Young

Project Manager,  
National Cancer Survivorship Initiative

## Dr Alastair Smith

Honorary Consultant Haematologist and  
Clinical Adviser for Macmillan Cancer Support

## Louise Smith

Cancer Information Specialist and Centre  
Manager and Ipswich Project Lead  
for Survivorship

## Anne Wilkinson

National Improvement Lead,  
NHS Improvement



**Noëline Young**  
Project Manager,  
National Cancer  
Survivorship Initiative  
Macmillan Cancer Support  
nyoung@macmillan.org.uk

# Introduction

## Noëline Young

**Research shows that people living with and beyond cancer often have ongoing needs following active treatment.<sup>1</sup> Studies have also shown that the health and well-being profile of people with cancer is similar to those with other long-term conditions, including diabetes and arthritis.**

Effective assessment and care planning to identify people's concerns and needs can lead to early interventions, diagnosis of consequences of treatment, improved communication and better equity of care. As such, everyone with cancer should be offered a holistic needs assessment (HNA) and a care plan.

The HNA and care plan ensure that people's physical, emotional and social needs are met in a timely and appropriate way, and that resources are targeted to those who need them most. The information gathered from an HNA can also be shared with the multidisciplinary team (MDT) to improve a person's management and care, and the data collected can influence commissioning of future services.

### The HNA and care plan

An HNA should include:

- **Physical concerns**  
Tired/exhausted or fatigued, pain, wound care after surgery, memory or concentration, sexuality.
- **Practical concerns**  
Caring responsibilities, work and education, money or housing, insurance and travel.
- **Family/relationship concerns**  
Partner, children, relatives, friends, other.

- **Emotional concerns**

Loneliness or isolation, sadness or depression, spiritual or religious concerns.

- **Lifestyle or information needs**

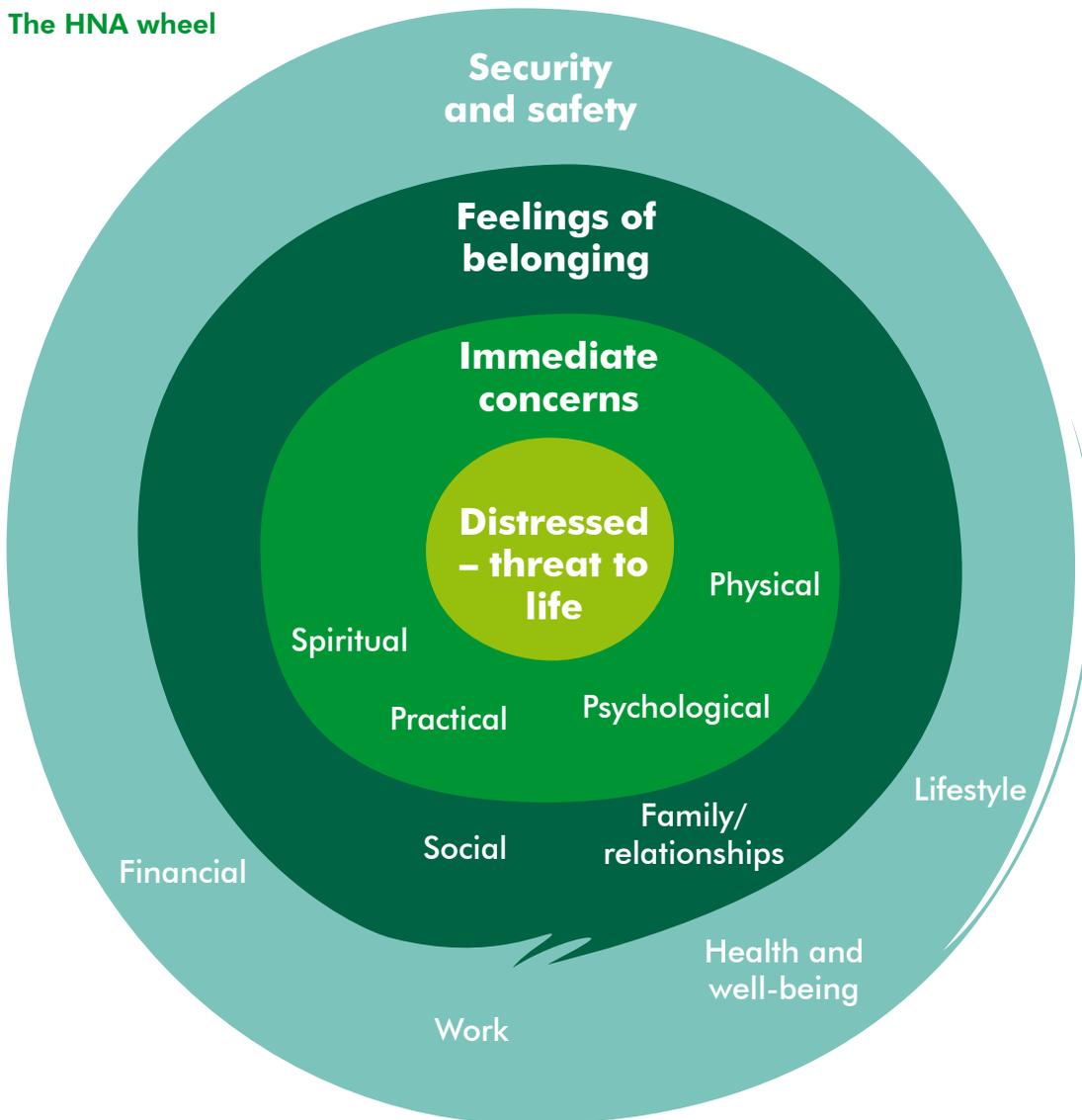
Support groups, exercise and activity, smoking, alcohol or drugs, sun protection, hobbies.

A care plan should be developed as part of this process. A care plan enables appropriate interventions, including support and information, and signposting or referral to other services if required. The process ensures timely interventions, prevents concerns from escalating and supports self-management.

### NCSI goals and test sites

When the National Cancer Survivorship Initiative (NCSI) set out its goals for cancer care in its 2010 vision document,<sup>2</sup> it highlighted five 'key shifts' necessary to deliver high-quality care and support for people with cancer in England. The second key shift is to develop holistic assessment, information provision and personalised care planning. This is a move away from a 'one-size-fits-all' approach to personalised care planning. *Improving Outcomes: A Strategy for Cancer*<sup>3</sup> also identifies the need for personalised assessment and care planning for people with cancer. This is in line with other similar

The HNA wheel



developments in chronic disease management.

Testing of assessment and care planning was carried out by 11 test communities within the NHS in England from 2010. Testing covered 19 adult tumour groups. Sites also tested the Treatment Summary (see autumn 2011 edition). The test communities mapped their existing services, planned how the assessment and

care planning process would take place, agreed tools for assessment, and how to measure and record baseline and further measurements for evaluation. The changes were evaluated and a final report is available at [ncsi.org.uk](http://ncsi.org.uk)

In 2011, seven more test sites were appointed to transform care and test a risk stratified care pathway. A risk stratification process helps to identify which care

pathway is most suitable for each patient, based on the level of risk associated with the disease, the treatment and the patient's ability to manage, and therefore what level of professional involvement will be required. Included in that work was assessment and care planning for people affected by cancer at two key points in the care pathway: at or near diagnosis and at the end of treatment. Assessment and care planning was not evaluated as a separate process, however some interesting data has emerged and is available and in the document, *Stratified pathways of care...from concept to innovation*.<sup>4</sup>

#### **Outline of test results**

Clinicians said the benefits of undertaking an HNA with patients included: identification of specific problems, greater understanding of the patient, increased competencies and staff satisfaction, and an opportunity to develop a different follow-up process.

Patients had a positive experience of HNA, citing an improvement in their relationship with the clinician and the process being beneficial in eliciting issues, enabling thinking, releasing anxiety and gaining perspective. They said they valued being given contact details and discussing practical issues such as financial benefits.

#### **Assessment tools**

The test sites identified that simple tools were the most effective. The most popular tools were the Distress Thermometer (DT), the Concerns Check List, and the Sheffield Profile for Assessment and Referral to Care (SPARC). These tools were

completed by the patient and then used to facilitate discussion with the healthcare professional. See the NCSI website for more on assessment tools.

The use of an assessment tool is an important part of HNA as it ensures consistency and stimulates the conversation. However the assessment tool should not become a 'tick box' exercise, rather clinicians should focus on exploring and discussing the collected information.

#### **Testing an electronic assessment tool**

The NCSI has also piloted touch screen tablets for self-assessment. Appropriate software can analyse the assessment and the data informs the care plan. Visit the NCSI website for more information.

#### **Peer review measure**

There has been a peer review measure for the implementation of HNA and care planning since April 2011. The measure states that MDTs should have agreed a list of responsibilities with each of the core nurse specialists of the team. These include:

- contributing to the MDT discussion and assessment/care planning decision
- leading on patient and carer communication issues and coordination of the care pathway for patients referred to the team – acting as the key worker or responsible for nominating the key worker for the patient
- ensuring that the results of a patient's HNA are taken into account in the decision making process.

Visit  
**[ncsi.org.uk](http://ncsi.org.uk)**  
for more  
information  
about  
assessment  
tools

# Secondary care perspective

Dr Alastair Smith

**Progress has been made to develop a Treatment Summary that formalises information about treatment and future care for people after cancer treatment. However, until recently, there has been little systematic approach to understanding the care needs and pathways of this group.**

People with cancer undergo follow-up – a medically-driven process aimed at measuring the presence, progress or absence of cancer. As people with cancer live longer, and survival rates increase, this process isn't sustainable and fails to meet the needs of many people living with and beyond cancer.

There is now a general consensus that a structured HNA is essential to planning care after treatment. But there remains vagueness as to how it's done and who is responsible.

Logically, HNA should inform the Treatment Summary. The Treatment Summary provides valuable, practical information that facilitates future healthcare planning and helps identify problems that may need urgent re-referral.

The challenge now is to achieve consistent, secondary care engagement in the process of producing a Treatment Summary and HNA. Introduction of HNA should not represent extra work; rather it needs to be seen as supporting clinical care and potentially reducing the burden on secondary care.

An alternative way of looking at HNA is that it revisits the initial clinical and 'social history', and allows the patient and clinician to identify what may have changed and what can be the same again.

The process is forward-looking – it doesn't require the secondary care team to provide all the answers. It's about recognising issues and how these might be addressed. And not all issues can or should be addressed within NHS provision.

There are simple questionnaires (see previous page) that patients can complete to highlight their issues. These can be filled out prior to the appointment, online or in the waiting room. The information obtained should make the clinic consultation more effective and add value to the Treatment Summary. If done well, the ability to understand and act on the information from the assessment will reduce subsequent health service dependency.

Achieving the necessary process and cultural changes in secondary care to facilitate simple, structured, post-treatment HNA is fundamental to improving cancer survivorship and the sustainability of services. With some simple changes to clinics and the use of HNA tools, secondary care can make a big difference to the quality of people's lives after cancer treatment. Measuring the presence or absence of cancer in an individual after treatment clearly remains important, but the outcome of this must be put in personal and clinical context to support the individual to maximise their quality of life and achieve their goals.



**Dr Alastair Smith**

Honorary Consultant  
Haematologist and  
Clinical Adviser for  
Macmillan Cancer Support  
agsmith@tcp.co.uk

#### About the author

Alastair has over 28 years experience as a consultant haematologist, with an emphasis on management of myeloma, leukaemia, and related haematological cancers.

## Treatment Summary

A Treatment Summary is a document produced by secondary cancer care professionals at the end of a person's treatment. It provides GPs with important information including, possible treatment toxicities, side effects and/or consequences of treatment, signs and symptoms of recurrence and any actions for the GP. Visit [macmillan.org.uk/treatmentsummary](http://macmillan.org.uk/treatmentsummary) for more information.



**Louise Smith**

Cancer Information Specialist and Centre Manager and Ipswich Project Lead for Survivorship  
Louise.M.Smith@ipswichhospital.nhs.uk

**About the author**

Louise is the Cancer Information Specialist and Centre Manager at the John Le Vay Cancer Information Centre at Ipswich Hospital. She is the hospital's project lead for survivorship.

# Test site perspective

## Louise Smith

**The breast and prostate cancer teams at Ipswich Hospital have been testing and implementing new approaches to cancer care for the past two years as part of the NCSI pilot programme.**

At the beginning of the programme, the hospital developed a steering group, led by the head matron and including members of the MDT. The group produced a Trust guideline to advise staff on how and when to complete an HNA.

### Assessment tools

A number of HNA tools are available, but we chose the Distress Thermometer (DT). Our radiotherapy department had previously piloted the tool with 30 patients to help identify their information and support needs. (See *Mac Voice*, summer 2010). People said they liked it and that it was quick and easy to use. It helped patients to focus on their issues and concerns, and it helped healthcare professionals make the interactions more focused and efficient.

In late 2011, we adapted the tool to include two thermometers – one to measure needs and the other levels of distress.

This approach to needs assessment provided timely and appropriate referrals to other support services, such as the benefits advice, counselling and incontinence and psychosexual support. Issues and concerns that may not have been raised as part of the traditional follow-up process, could be acknowledged and explored, with appropriate information, support and advice offered in a timely manner.

### Implementing HNAs

One of the challenges the teams faced was when to offer the assessment. Not all key workers saw their patients face-to-face at every appointment. Time constraints in busy clinics meant they might not have time to sit and go through the assessment with the patient.

Different approaches were tested:

- In the radiotherapy department, patients attend on a daily basis so they could either complete the forms while waiting or bring them back the next day.
- The urology clinical nurse specialist posted her forms to patients following diagnosis with an explanatory letter and self-addressed envelope. Any concerns were followed up over the phone or at the next appointment.
- The breast care nurses gave their forms out at the first appointment following diagnosis and asked patients to return them at their next appointment (around two weeks later) where they would review any issues or concerns with them.

We found patients had more needs and higher distress levels as they moved further along the treatment pathway. The majority of needs were identified at the end of treatment.

### Developing a care plan

With the HNA tool in place, we

created computerised care plan templates, which reflected the individual treatment pathways these patient groups might follow. We decided to combine our care plan with the Treatment Summary documentation. The care plan is commenced following diagnosis and the summary completed once primary treatment is finished.

The care plan included:

- results of the HNA form
- information prescriptions or other information given
- signposting and any referrals made to other services.
- the treatment plan
- possible side effects
- key contacts.

Completion of the care plan and Treatment Summary at the end of treatment would either be by the patient's key worker or following attendance at our 'Moving on' education programme, which is led by the survivorship project manager. A copy of the care plan and Treatment Summary is given to the patient, and another sent to their GP with a request that they review the care plan in 6–8 weeks time.

### Implementation

Finding time to complete the care plan with patients was an issue for all our key workers. When they first started using the documentation, the care plan took on average 40 minutes to complete. With experience this time was reduced to 30 minutes.

The breast care nurses found they needed a laptop to use in MDT meetings so that they could input key data into the care plan to save time. The other MDTs are

now adopting this approach.

Where the patient case load far exceeded the number of CNSs or key workers able to support them effectively, we have prioritised patients according to the HNA results. For example, the radiotherapy department refers people with higher needs and levels of distress to a specialist radiographer, while less senior staff look after those with fewer needs, such as referral to benefits advice and other services.

### Pilot evaluation

Over the last two years we have piloted the care plan, Treatment Summary and HNA with 220 patients and carers. We sent a feedback questionnaire and self-addressed envelope to all patients and GPs with their copy of the care plan and Treatment Summary. We have received positive feedback from both patients and GPs telling us how useful they have found this approach. Patients say they feel much more confident to manage their symptoms and to think positively about the future following their care planning appointment.

### Integrating the system

We now have a CQUIN (Commissioning for Quality and Innovation) payment framework for HNA, care plans and Treatment Summaries in place; a financial incentive, which if we reach our targets, can be reinvested to further improve our cancer services.

We are in the process of embedding the care plan into our Trust's IT system so that it is available to all members of the MDT. Care plan templates have

been developed for many different tumour groups and we hope that in time, all people with cancer will be offered HNAs and care plans to support their individual needs, issues and concerns.

The pilot has enabled us to raise the profile of these valuable measures and also gain the support of cancer managers and commissioners to support their implementation.



## Top tips

- Create a steering group that includes patient, primary care and commissioner representation.
- Make sure you have operational and lead nursing support so that HNA and care plans are embedded into departmental practice.
- Make sure HNA and care planning is an integral part of CNS or key worker work plans.
- Book patients into CNS/key worker clinic slots to carry out the HNA and care plan. This helps to reduce unplanned readmissions and key worker enquiries.
- HNAs are rarely filled in and returned if left in a box in reception for patients to help themselves to.
- Patients and carers are more likely to complete the forms if they know why you are carrying out the assessment.
- Ensure that there is comparison with the social history taken prior to treatment with where the patient is at the end of treatment.
- Volunteers can be extremely valuable in promoting these services, providing administrative support and data input when resources are stretched.
- Consider support from local/national charities in getting these services embedded.
- Establish two or three simple, rapidly auditable standards for the HNA and make sure these can be easily captured in data collection.
- Visit other units with experience and resources to share.

# Evidence base

## Anne Wilkinson

**The *National cancer patient experience survey 2011/12*<sup>1</sup> found that only 24% of people with cancer said they have been offered an assessment and care plan. Although many organisations are starting to implement a more structured approach to assessment and care planning, we are still a long way from widespread use. This report aims to provide a sample of the evidence on assessment and care planning, and learning gained through testing and implementation in the UK and overseas.**

### Assessing needs

Many studies have assessed patient needs following treatment for cancer. A study by Armes et al<sup>2</sup> of 1,425 patients found that 30% reported more than five unmet needs after treatment. A further UK example<sup>3</sup> of 741 men with prostate cancer, found that patients had significant unmet supportive care needs, especially relating to psychological distress, sexuality and enduring urinary tract symptoms.

While needs generally reduce over time, a study in Australia<sup>4</sup> of people who were 2–10 years post-breast cancer treatment and disease-free, found that irrespective of the years since diagnosis, high rates of anxiety and supportive care needs were reported up to 10 years post treatment. This raises the question of how long-term needs are managed, especially following the end of any formal follow-up.

### Assessment tools

There are several published articles about assessment tools and their validity. A useful study<sup>5</sup> by Richardson et al reviewed over 40 tools, of which 15 were found to help assess needs and inform care planning in people with cancer. The review discusses the importance

of systemic (or holistic) assessment of needs in routine care and the contribution that tools can make to this process. The review concluded that some of the tools had considerable merit, though there was nothing to suggest that one was more fit-for-purpose than another, and that the lack of testing in a practical care setting was a severe limitation of all the tools reviewed.

The Distress Thermometer (DT) and problem checklist have been widely adopted in the UK, but with a variety of adaptations. The DT was originally developed in 1998 by Roth et al, as a quick tool for screening distress in people with cancer. A problem checklist was added to help identify more specific causes of distress. Brennan et al<sup>6</sup> suggests that this combined approach provides healthcare professionals with a structure for an efficient yet collaborative assessment of individual concerns.

### Assessing needs – when and where?

The National Cancer Action Team (NCAT) guidance, *Holistic Common Assessment of Supportive and Palliative Care needs for Adults with Cancer*,<sup>7</sup> advises that structured assessments should take place at:



Anne Wilkinson

National Improvement Lead,  
NHS Improvement  
anne.wilkinson@  
improvement.nhs.uk

### About the author

Anne is a National Improvement Lead with NHS Improvement. She has been working with the NCSI for the past three years, supporting clinical teams to test and implement new models of care for those living with and beyond cancer. She is a nurse by background and has over ten years experience working in service improvement. She is committed to improving the quality of services for patients.

- the time of diagnosis
- commencement of treatment
- completion of primary treatment
- each new episode of disease recurrence
- recognition of incurability
- the beginning of end of life
- the point at which dying is diagnosed
- any other time at the patient's request.

Evidence of any structured needs assessment around diagnosis was not found during this literature search. However, we know that the majority of people with cancer are seen by a CNS at diagnosis, where immediate concerns and anxieties are discussed and information relating to the diagnosis, treatment and key contact numbers is provided.

Feedback from some teams suggests that a structured HNA at diagnosis using a self-assessment tool is inappropriate, and that it is better suited for use with people in treatment or at the end of treatment.

A study in the US<sup>8</sup> used the DT and problem checklist with 57 people during their radiology treatment. It found people were receptive to completing the tool and some noted that the experience was the first time they were asked about a number of issues. Staff found the tool easy to use, and reported that it helped identify concerns and opened up a dialogue regarding issues that otherwise may not have been assessed.

A four-month study in the US<sup>9</sup> using the National Comprehensive Cancer Network version<sup>10</sup> of the DT in breast cancer clinics, found that 34% reported high levels of distress

(>5). However, no relationship was seen between high distress and stage of disease, type of current treatment, time since diagnosis, age or other demographic factors. They concluded that the DT was a useful method to screen, triage and prioritise patient interventions, and it promoted communication between the patient and the healthcare team.

A UK study by Gessler et al<sup>11</sup> of 171 outpatients in oncology and palliative care clinics reported that 95% of patients found completing the DT acceptable, and that it is valid and acceptable for use as a rapid screening tool for patients.

Some studies highlighted that a proportion of patients prefer not to participate in any assessment or subsequent care plan discussion. It's interesting to note that in Brennan's<sup>6</sup> study, the response rate to his survey to ascertain concerns was only 53%. Brennan suggests that not all patients may be receptive to reviewing their concerns once treatment is complete. Testing within NHS Improvement test sites during 2011 (see the summary report at [ncsi.org.uk](http://ncsi.org.uk))

also found that even if people indicate issues of concern on a self-assessed checklist, they did not always wish to discuss or be referred as a result.

It's also worth noting that for some people, there is no 'end of treatment', for example people with prostate cancer on hormone treatment, active surveillance or 'watchful waiting'. When is the best time to offer a HNA and care plan review? Perhaps the absence of any obvious review point may explain why so many people in this group suffer long-term, unmet needs.

Some NHS Improvement test

sites offered urology patients an HNA at the point of transfer to a self-management pathway, which was often 1–2 years after treatment ended. This identified patient needs that could have been resolved sooner had the opportunity for a discussion been made available.

A qualitative study<sup>12</sup> in Leeds, which explored the views of staff and patients in assessing needs, found that many patients felt the psychological effects of treatment were not discussed, and oncologists recognised that they do not consistently enquire about it. Patients had differing views about whether to discuss the effects of cancer on their personal/intimate relationships, and both patients and professionals felt this would depend on the age and gender of the clinician and patient. Questions about the roles of different healthcare professionals found that some patients only wanted the oncologist to treat the cancer and preferred to talk about emotional, family and social issues with the nurses.

Testing assessment tools within NHS Improvement test communities in 2010/11 (see summary report)<sup>13</sup> found that some sites sent self-assessment forms to patients to complete prior to the appointment, while others arranged for these to be completed in clinic waiting area prior to the appointment. No preferred method was found, with some preferring to complete it at home with their family, and others with the support of a healthcare professional. Some found the tool raised concerns that made them worry about issues they had not previously thought about. Others commented that the assessment tools focused on past rather than future needs.

The use of touch screen technology or web-based tools to support self-assessment was found to be acceptable in two studies. Velicova et al<sup>14</sup> trialled touch screen assessment tools with 149 people undergoing chemotherapy. Patients found the approach acceptable and easy to use. A study<sup>15</sup> in Sweden tested paper questionnaires versus touch screen questionnaires for a range of quality of life measures. It found both methods yielded almost identical results in quality of care ratings, but the touch-screen method was perceived to be easier to use and to take less time to complete.

### **Do patients find care plans valuable?**

Although there are some excellent guidance documents available in the UK<sup>16</sup> and elsewhere,<sup>17,18</sup> there is little evidence available that explores the value of a care plan to the patient once completed. However, a survey\* of 1,200 patients conducted by Ipsos MORI in 2011, found that of the 21% patients who reported having a care plan, the vast majority (84%) said that it was useful.

Irrespective of what assessment tool is used, the most important aspect is that the assessment leads to a discussion with the patient and that, where possible, needs and concerns are addressed. The offer of a written care plan should always be made.

The NCAT practical guide for healthcare professionals<sup>19</sup> provides no specific structure for a care plan but it does suggest core, minimum content.

A study in the US<sup>20</sup> to test the implementation of 'survivorship care plans' in four organisations found

\* National Cancer Survivorship Initiative. *Evaluation of Adult Cancer Aftercare Services – Wave 1 Report*. 28 October 2011. (Available at [improvement.nhs.uk](http://improvement.nhs.uk))

them to be flexible documents that can be successfully adapted for use in a variety of settings, from primary to secondary care. Assessments were led by either the doctor or nurse; some were conducted by phone and some supported by education programmes covering a variety of survivorship topics. All plans contained a Treatment Summary, assessment of needs, follow-up plans and any further interventions.

### **So why has uptake been slow?**

We know that the formal introduction of assessment and care planning presents challenges for teams, especially in the current climate. CNS shortages, time, space and skills are all factors, and some adjustments to the working week are usually required to ensure 'protected session time' to complete assessments.

Other barriers identified at a workshop<sup>22</sup> led by NCAT for cancer network leads in 2009 included: a lack of confidence to undertake assessments, a culture that still focuses on the disease rather than the person, unclear ownership of assessment information and practical issues relating to CNS time and space.

A study by Macguire and Pitceathly<sup>23</sup> on the reasons why professionals distance themselves from discussing patients' distress included: lack of communication training, fear of difficult questions and causing distress, and a lack of practical and emotional support.

A recent study in Southampton<sup>24</sup> looked at the role of the CNS and the perceived lack of time to undertake an HNA due to

competing demands. It found that there was duplication of tasks between the CNS and MDT coordinators, and that each CNS spent 1.5 hrs a day on administrative duties. The study also recorded some of the barriers to implementation, such as concerns about the lack of available support services or worries about uncovering problems that can't be solved.

Lack of training is an important factor and feedback suggests that staff don't always feel confident undertaking assessments. A training programme available to NHS organisations found<sup>25</sup> that training helped improve self-confidence to recognise different levels of distress and manage issues as they arose.

Professionals also have a role in supporting patients return to active and fulfilling lives. Rollnick et al<sup>26</sup> describes motivational interviewing as a guiding style to engage with patients, clarify their strengths, aspirations and motivations, and promote autonomy of decision making. It has particular relevance at the end of treatment when people may wish to set new goals.

### **Conclusion**

There is a wealth of evidence on the needs of people with cancer and the use and validity of assessment tools. However, there is very little evidence to support the value of the HNA process and care plan to the patient. More widespread adoption of HNA and care planning will provide opportunities for further research and evidence gathering, and ensure that it really does improve the experience and coordination of care for people with cancer.

# Policy

## England

### NHS Outcomes Framework (NHSOF)

The NHSOF is used to monitor the progress of the NHS Commissioning Board and to measure quality of cancer services at a national level. HNA will be essential for achieving the outcomes under Domain 2 (Enhancing quality of life for people with long-term conditions) and Domain 4 (Ensuring that people have a positive experience of care). Visit [tinyurl.com/7ftfgdd](http://tinyurl.com/7ftfgdd)

### Commissioning Outcomes Framework (COF)

The COF measures the health outcomes and quality of care achieved by Clinical Commissioning Groups. Indicators 2.1 (proportion of people feeling supported to manage their condition) and 2.2 (employment of people with long-term conditions) should incentivise professionals to implement HNA as part of their day-to-day practice. Visit [nice.org.uk/aboutnice/cof/cof.jsp](http://nice.org.uk/aboutnice/cof/cof.jsp)

### Improving Outcomes: A Strategy for Cancer, 2011

This strategy puts patients at the heart of cancer services, notably by aiming to reduce the proportion of people who report unmet physical or psychological support needs following cancer treatment. Chapter 5 (Improving outcomes for cancer patients: quality of life and patient experience) acknowledges that patients' needs include:

psychological support, financial advice, support to self-manage, and information about treatment and care options. Visit [tinyurl.com/improvoutcomes](http://tinyurl.com/improvoutcomes)

### NICE quality standards

These standards are a set of statements designed to measure quality improvements within a particular area of care. HNA is included in some quality standards (end-of-life care for adults and lung cancer), but is absent in others (breast, ovarian and colorectal cancer), showing that HNA is not yet considered throughout the whole care pathway and for all conditions. Visit [nice.org.uk/aboutnice/qualitystandards/qualitystandards.jsp](http://nice.org.uk/aboutnice/qualitystandards/qualitystandards.jsp)

## Northern Ireland

### Service Framework for Cancer Prevention, Treatment and Care

The framework sets standards that span the whole patient pathway from prevention through to survivorship. Several standards include performance indicators on HNA and care planning to be achieved over three years to 2014. It was developed by the Northern Ireland Cancer Network on behalf of the Department for Health, Social Services and Public Safety. Visit [dhsspsni.gov.uk/sqsd\\_service\\_frameworks\\_cancer](http://dhsspsni.gov.uk/sqsd_service_frameworks_cancer)

### Transforming Your Care – A Review of Health and Social Care in Northern Ireland

This 2011 review sets out plans for the transformation of health and social care in Northern Ireland over the next five years. It promotes

joined-up assessment and care planning. Visit [tinyurl.com/transformyourcare](http://tinyurl.com/transformyourcare)

### Scotland

#### NHS Scotland Quality Strategy

This strategy underpins the development of the NHS in Scotland. It has three ambitions related to quality (person-centred, safe, effective), all of which support assessment and care planning through a focus on self-management and continuity of care. Quality outcomes two (People are able to live well at home or in the community) and four (Everyone has a positive experience of healthcare) are particularly relevant to HNA and care planning. Visit [scotland.gov.uk/publications/2010/05/10102307/0](http://scotland.gov.uk/publications/2010/05/10102307/0)

#### Transforming Care After Treatment

This programme is being delivered by the Scottish Government in

partnership with Macmillan. It's a new work stream of the Scottish Cancer Taskforce and assessment and care planning will be a major part of the programme. Visit [www.qihub.scot.nhs.uk/programmes/cancer.aspx](http://www.qihub.scot.nhs.uk/programmes/cancer.aspx)

### Wales

#### Together For Health – Cancer Delivery Plan

This plan sets out the Government expectations of NHS Wales in tackling cancer up to 2016. Local health boards are expected to assign a named key worker to assess and record the clinical and non-clinical needs of everyone diagnosed with cancer in a care plan. This includes regular assessment of the consequences of treatment, and other needs, such as access to financial, emotional and spiritual advice and support, to ensure a holistic, person-centred approach. Visit [tinyurl.com/togetherforhealth](http://tinyurl.com/togetherforhealth)



## Resources

### **A Practical Guide to Holistic Needs Assessment, 2011, National Cancer Action Team**

This guide provides practical advice for health professionals, including examples of assessment tools and case studies. It's downloadable from [tinyurl.com/9qjodbj](http://tinyurl.com/9qjodbj)

### **Holistic common assessment of supportive and palliative care needs for adults requiring end-of-life care, 2010, NHS National End of Life Care Programme**

This document highlights five core areas or domains for HNA, and sets out the content within each of these so that teams can benchmark their local processes and tools. It also highlights a range of existing assessment and planning tools, guidance and relevant policy, and signposts to other resources where appropriate. Visit [tinyurl.com/95vzbql](http://tinyurl.com/95vzbql)

### **Holistic Common Assessment of Supportive and Palliative Care Needs for Adults with Cancer: Assessment Guidance, 2007, King's College London and NCAT**

This guidance is for practitioners and managers providing or coordinating the care of adults with cancer. It's intended to enable them to adopt a unified approach to the assessment and recording of patients' needs. Visit [tinyurl.com/93haefl](http://tinyurl.com/93haefl)

### **Patients' Needs Assessment Tools in Cancer Care: Principles and Practice, 2005, Richardson A, Sitzia J, Brown V, Medina J, King's College London**

This report is based on three strands of research: a rapid appraisal of the relevant literature; a scoping exercise on the actual use of assessment tools among networks; and discussions with those involved in the Single Assessment Process for older people. It's based on research commissioned by the Department of Health and NCAT. Visit [tinyurl.com/9fxvqv9](http://tinyurl.com/9fxvqv9)

## Macmillan resources

### For professionals

#### **Assessment and care planning folder MAC13689**

This folder helps health professionals to conduct a self-assessment and care plan with their patient.

### For patients

#### **Macmillan Organiser MAC13281\_0112**

This folder is designed to help patients keep track of their treatment, make notes and find information and support.

#### **Assessment and care planning for people with cancer MAC12957**

This leaflet explains HNAs and how care is planned for people affected by cancer.

Order these free at [be.macmillan.org.uk](http://be.macmillan.org.uk) or call 0800 500 800.

**References pages i–iii**

<sup>1</sup> Armes J et al. Patients' Supportive Care Needs Beyond the End of Cancer Treatment: A Prospective, Longitudinal Survey. *Journal of Clinical Oncology*. 2009. Vol 27; No 36.

<sup>2</sup> *Vision*. 2010. National Cancer Survivorship Initiative.

<sup>3</sup> *Improving Outcomes: A Strategy for Cancer*. 2011. Department of Health.

<sup>4</sup> *Stratified pathways of care...from concept to innovation*. 2012. NHS Improvement.

**References pages viii–xi**

<sup>1</sup> Department of Health. *National Cancer Experience Survey 2011/12 National Report*. August 2012.

<sup>2</sup> Armes J et al. Patients' Supportive Care Needs Beyond the End of Cancer Treatment: A Prospective, Longitudinal Survey. *Journal of Clinical Oncology*. 2009. Vol 27; No 36.

<sup>3</sup> Ream E et al. Supportive care needs of men living with prostate cancer in England. *British Journal of Cancer*. 2008. 98; 1903–1909.

<sup>4</sup> Hodkinson K et al. Breast cancer survivors supportive care needs 2–10 years after diagnosis. *Supportive Care Cancer*. 2007. 15: 515–523.

<sup>5</sup> Richardson A, Medina J, Brown V, Sitzia J. Patients' needs assessment in cancer; a review of assessment tools. *Supportive Care Cancer*. 2007.

<sup>6</sup> Brennan J et al. Refinement of the Distress Management Problem list as the basis for a holistic therapeutic conversation among UK patients with cancer. *Psycho-oncology*. 2011. Online 10:1002/pon.2045.

<sup>7</sup> National Patient Access Team. *Holistic Common Assessment of Supportive and Palliative Care Needs for Adults with Cancer – Assessment Guidance*. 2007.

<sup>8</sup> Caryl D Fulcher et al. Distress Assessment: Practice change through guideline implementation. *Clinical Journal of Oncology Nursing*. 2007. 11:817–821.

<sup>9</sup> Dabrowski M et al. Clinical experience with the NCCN distress thermometer in breast cancer patients. *Journal of the National Comprehensive Cancer Network*. 2007. 5(1): 104–111 33.

<sup>10</sup> National Comprehensive Cancer Network is based in the US and represents 21 of the world's leading cancer centres working together to improve the quality, effectiveness and efficiency of cancer care.

<sup>11</sup> Gessler S et al. Screening for distress in cancer patients: is the distress thermometer a valid measure in the UK and does it measure change over time? A prospective validation study. *Psycho-Oncology*. 2008. 17: 538–547.

<sup>12</sup> Velicova G et al. The clinical value of quality of life assessment in oncology practice – a qualitative study of patient and physician views. *Psycho-Oncology*. 2008. 17: 690–698.

<sup>13</sup> National Cancer Survivorship Initiative. *Assessment and Care Planning – Lessons Learned*. November 2010. (Available at [www.ncsi.org.uk](http://www.ncsi.org.uk)).

<sup>14</sup> G. Velikova et al. Automated Collection of Quality-of-Life Data: A Comparison of Paper and Computer Touch-Screen Questionnaires. *Journal of Clinical Oncology*. March 1999. Vol. 17 no. 3 998.

<sup>15</sup> Bodil Wilde Larsson. *Touch-screen versus paper-and-pen questionnaires. Effects on patients' evaluations of quality of care*. Division for Health and Caring Sciences, Karlstad University, Karlstad, Sweden. (Available at [www.emeraldinsight.com/0952-6862.htm](http://www.emeraldinsight.com/0952-6862.htm)).

<sup>16</sup> National Patient Access Team. *Holistic Common Assessment of Supportive and Palliative Care: Needs for Adults with*

*Cancer – Assessment Guidance*. January 2007.

<sup>17</sup> Canadian Partnership Against Cancer. *Guide to Implementing Screening for Distress, the 6th vital sign*. 2009.

<sup>18</sup> Ganz P et al. Implementing a Survivorship Care Plan for Patients with Breast Cancer. *American Society of Clinical Oncology*. 2008.

<sup>19</sup> National Patient Access Team. *Holistic Needs Assessment for People with Cancer: A Practical Guide for Healthcare Professionals*. 2011.

<sup>20</sup> Hahn E & Ganz M. Survivorship Programs and Care Plans in Practice: Variations on a theme. *Journal of Oncology Practice*. 2011. Vol 7, Issue 2: 70–74.

<sup>22</sup> Claire Morris. *Report from 1st HNA workshop*. November 2009. National Patient Access Team.

<sup>23</sup> Maguire P & Pitceathly C. Improving the psychological care of cancer patients and their relatives: The role of specialist nurses. *Journal of Psychosomatic Research*. 2003. 55; 469–474.

<sup>24</sup> Richardson A. *Finding the time for teams to undertake holistic needs assessment*. Poster presentation from Southampton University Hospitals NHS Trust. (Available at <http://ncat.nhs.uk/sites/default/files/NCAT%20Poster%20-%20HNA%20and%20lean.pdf>).

<sup>25</sup> Jenkins K et al. Beyond communication: The development of a training program for hospital and hospice staff in detection and management of psychological distress – Preliminary results. *Palliative and Supportive Care*. 2010. 8, 27–33.

<sup>26</sup> Rollnick S, Butler C, Kinnersley P, Gregory J, Mash B. Motivational Interviewing. *BMJ*. 2010; 340 doi: 10.1136/bmj.c1900.