**Keywords** Holistic needs assessment/ Electronic form/Cancer recovery

**This article has been double-blind peer reviewed**

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- Development stages of producing an electronic form for use in clinical practice
- Benefits of recording holistic needs assessments electronically

# Designing an electronic holistic needs assessment form

## Key points

**Holistic needs assessments (HNAs) should be offered to all patients with cancer at different points of the pathway**

**HNAs are often done well at diagnosis, but this is not always the case at later points in the disease trajectory**

**Electronic forms are useful to share information between different care settings**

**When creating an electronic document, staff and patients need to be consulted**

**Leeds Cancer Centre has implemented an electronic HNA form with benefits for staff and patients**

ALAMY

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**Abstract** This article looks at the implementation of an electronic holistic needs assessment (HNA) form by the cancer clinical nurse specialist (CNS) workforce at Leeds Cancer Centre. It explains why an electronic HNA form was needed and how it was conceived, designed, tested and implemented. Since its introduction in June 2017, it has been beneficial, particularly in terms of the patient experience.

**Citation** Henry K (2018) Designing an electronic holistic needs assessment form. *Nursing Times* [online]; 114: 11, 57-59.

Holistic needs assessments (HNAs) should be routinely offered to all patients with cancer, but this is not necessarily happening everywhere. In addition, when HNAs are conducted their quality and frequency can vary. In 2017, nurses at Leeds Cancer Centre created and rolled out an electronic HNA form that is already improving the patient experience.

### Holistic needs assessments

There are approximately 2.5 million people living with cancer in the UK and this number is projected to rise to 4 million by 2030 (Bit.ly/CancerStat). As part of the health service's support for people living with and beyond cancer, a cancer recovery package was introduced in 2015, the idea being that all patients would have access to it by 2020 (NHS England, 2015). The cancer recovery package combines different elements:

- HNAs;
- Treatment summaries;
- Cancer care reviews;
- Access to health and wellbeing programmes.

The first element of the recovery package is HNAs, to which all patients are entitled. HNAs are offered to patients at different points of the pathway as a means of identifying what their concerns and needs are, whether physical, social, emotional or other. They are essentially conversations about the person's concerns at any given point in time.

We found in Leeds that HNAs are often done well at diagnosis but this is not necessarily the case at the end of treatment. Armes et al (2009) found that, among 1,425 patients with cancer, 30% reported having more than five unmet needs after treatment, and that effective assessment of people's concerns and needs – and subsequent care planning – can greatly improve care and support for those living beyond cancer.

Leeds Cancer Centre has 27 different cancer multidisciplinary teams, it treats more than 400 new patients every month and is one of the largest cancer centres in the UK. Anecdotal evidence gathered at the centre showed that HNAs were not always carried out for all patients at the end of treatment. When HNAs were done, they were not recorded in a systematic way and were not shared with primary care; this was an area that needed improvement. Table 1 shows HNA practice before the electronic scheme was introduced.

### What is the gold-standard HNA?

To improve our use of HNAs, we decided to create an electronic HNA form. Macmillan Cancer Support provides an electronic template for HNAs, but we could not use it because it was not compatible with our trust's electronic patient record system. As such, we needed to design our own form, which would reflect Macmillan Cancer Support's principles while being compatible with our IT system.

The first step was to consult our clinical nurse specialists (CNSs) on what constitutes a gold-standard HNA. At regular meetings with CNSs, we discussed and agreed the following:

- What should be included in the assessment;
- When it should take place;
- How it should be recorded;
- With whom it should be shared.

The CNSs had an opportunity to contribute and reflect on how the new HNA would work for different patient groups. They thought that, for most patients, having an HNA at diagnosis and another one at the start of treatment was too much, so it was decided that one HNA covering diagnosis and the start of treatment was enough. Getting all CNS teams to deliver all the elements of the gold-standard HNAs (as outlined in Table 1) would take time and be individual to each of the teams, depending on both their resources and their patients' pathways.

**Table 1. Holistic needs assessments at Leeds Cancer Centre: old practice and gold standards**

| Aspect of HNA | Practice pre-implementation of electronic HNA form | Gold-standard HNA |
|---|---|---|
| **Time offered** | At:<br>● Diagnosis – offered by all teams<br>● Diagnosis of recurrence – offered by most teams<br>● End of treatment – very variable | At four key points:<br>● Diagnosis<br>● End of treatment<br>● Diagnosis of incurable disease/recurrence<br>● End of life<br>Plus at any other point as requested by the patient |
| **Recording of information** | Not always recorded electronically | Recorded electronically |
| **Information sharing** | Not consistently shared with primary care | Shared with primary care |
| **Content** | Inconsistencies between teams regarding what is discussed and recorded (this meant the recommendations of the National Cancer Survivorship Initiative were not being met) | Includes:<br>● Physical concerns<br>● Practical concerns<br>● Psychological concerns<br>● Relationship issues<br>● Lifestyle concerns |
| **Care planning** | Production of care plan variable; patient copy offered by small number of teams only | Care plan always produced; all patients offered a copy |
| **'Concerns checklist'** | Offered to patients by one or two teams only before completing HNA | Patients can complete before HNA is done |

HNA = holistic needs assessment

**QUICK FACT**
**1,970**
Number of electronic HNA forms completed since December 2017

### Linking with primary care

One of the drivers behind the project was a redesign of the trust's electronic patient record (EPR) system, with the new version linking to community EPRs. This meant that, if we could manage to include an electronic HNA form in the new system, we would be able to share information with GPs and other community care providers.

Discussion with the CNS teams had highlighted that very few teams were sharing their assessments with primary care colleagues and that, even for colleagues in secondary care, HNAs were not easy to find in the system – they were conducted as part of normal consultations and not labelled as HNAs.

As more patients are successfully treated and/or live longer with the side-effects of cancer or cancer therapy, there is a push for people to be cared for closer to home and for primary care to be more involved. The 'cancer care review' element of the recovery package is intended to take place in primary care, as it is an opportunity to discuss with patients how they will learn to live with cancer treatment, or after it. Without the necessary information from HNAs and treatment summaries, primary care colleagues will find it difficult to become more involved – and it cannot be expected that patients keep explaining the same things over and over again to different health professionals.

Treatment summaries form a separate work stream at our trust; they are led by medical and surgical clinicians and are seen as an extension to the letters they already send to GPs around the end of treatment.

### Getting it right for all

Once it had been agreed what the HNA should be and that we needed to be able to share it with primary care, the next step was to work with the IT department to develop a proforma that would suit everyone. CNSs were involved in designing the form; CNS representatives attended every IT session to ensure the form would be user friendly.

As many different cancers are diagnosed and treated at Leeds Cancer Centre, each with its own complexities and pathways, designing a form that would suit everyone was never going to be easy. We wanted to make sure people would feel as though they owned the form and would want to use it. We also wanted to get it right for patients. The working group included a patient member: her comments on the importance of HNAs being done at regular intervals and patients being able to take away a care plan were key.

### Testing and evaluation

Three CNS teams agreed to test the new electronic HNA form: those in gynae-oncology, head and neck cancers, and upper gastrointestinal/hepatobiliary cancers. An informal pilot phase took place from 1 April to 30 June

*"CNS representatives attended every IT session to ensure the form would be user friendly"*

2017, after which the teams were asked to give their feedback at a CNS meeting.

The outcomes of the testing were mixed, with the pilot teams reporting that parts of the form did not flow well and some of the questions felt unnatural – which meant CNSs left some fields blank. Some of the sections felt too 'busy'; it was felt that the various options could be streamlined to become more user friendly.

Among the positive comments, staff who were new to their post welcomed a more structured format. They also found that the different sections were useful as prompts in the conversation with patients and encouraged them to discuss all the patients' concerns, not just those related to their physical health. Further positive feedback included being able to print the care plan as a standalone document so patients could receive a copy and have a note of the actions, such as signposting and referral to other services, that the CNS intended to carry out.

A more formal evaluation was then conducted in August and September 2017, with each of the three teams producing detailed information that would be useful for the IT department. Other CNS teams were also consulted to ensure no essential points were missed.

All the feedback from the two evaluations was gathered and shared with the IT team so they could modify the form as necessary. As more changes were needed than anticipated and completing them took longer than expected, roll-out of the new form was postponed while the changes were being made.

The overall process, from starting the discussion regarding what HNAs should look like to having a fully functional electronic form, has taken about a year – this is longer than we had anticipated. However, all the changes to the electronic HNA form have been made and the form began to be rolled out across all CNS teams at the centre in December 2017.

## Outcomes so far

Since the initiative was rolled out in December 2017, 1,970 HNA forms have been completed. The IT team are now able to report:

- At what stages in the pathway HNAs are taking place;
- What concerns patients report at HNAs;
- What interventions CNSs are planning as a result.

On the whole, CNS teams are positive about the new form and can see the benefits, particularly relating to the ability to give patients a copy of their care plan and share information with primary care. There is also less variation in the standard of HNAs, meaning that all patients have access to the same level of care.

Our primary care colleagues have reported being able to see the HNAs online. A community CNS carrying out cancer care reviews in GP practices has explained that being able to view the latest HNA conducted at the acute trust makes a huge difference to the conversation she has with patients, as she can see what concerns have been discussed and what actions have been taken.

Being able to share HNAs with primary care is one of the main benefits of this project in terms of improved patient experience, as patients no longer need to repeat their story to different professionals in different settings. As well as knowing who is taking over responsibility for their care and who they should contact if they have concerns, patients also want a clear, seamless journey between care settings.

## Lessons learned

It was always going to be challenging to move from a system in which individual nurses were documenting information in a way that best suited them and their personal style to a system requiring information to be entered consistently and in a structured manner. For anyone thinking of embarking on a similar project, the following points may be useful:

- Involve patient representatives to ensure proposed changes truly meet patients' needs;
- Involve future users from the start to gain a clinical perspective and encourage ownership of the end product;
- Keep people up to date and involved with developments as they happen to ensure engagement is continuous;
- Be prepared for negative feedback and look at how it can be used constructively to improve the end product;
- Set realistic timescales – things may well take a lot longer than originally anticipated.

*"Being able to share holistic needs assessment forms with primary care is one of the main benefits of this project"*

## What next?

Further work is required to fully embed the electronic HNA form into practice and ensure it is consistently used. This involves meeting with all the teams on a regular basis and encouraging ongoing feedback about the form and its functionality. The following additional actions will help make the process smoother and more efficient:

- As well as clinical information and the number of care plans completed, also collect data on the number of HNAs completed and at which points in the pathway they are undertaken;
- Identify a formal way of alerting clinicians in primary care that an HNA has been completed for their patient;
- Explore a way for patients to access the HNA form from an app so they can self-complete some of the information before the consultation;
- Develop a tailored 'end-of-treatment' version of the HNA form, as the information required at this point is different to the information needed at diagnosis.

The electronic HNA form works well at Leeds Cancer Centre, but the option for sharing the form electronically only works for patients living in Leeds. As such, we need to address how to make the assessments accessible to primary care teams outside of the Leeds postcode area. **NT**

### Further resources

- *Carrying Out an Effective Cancer Care Review*
  **Bit.ly/MacmillanCareReview**
- *Holistic Needs Assessment: Care and Support Planning*
  **Bit.ly/MacmillanHolisticNA**
- *Improving Cancer Care and Support for People Living with and Beyond Cancer*
  **Bit.ly/MacmillanImprove**
- *Living With and Beyond Cancer: Taking Action to Improve Outcomes*
  **Bit.ly/WithAndBeyond**

**References**

**Armes J et al** (2009) Patients' supportive care needs beyond the end of cancer treatment: a prospective, longitudinal survey. *Journal of Clinical Oncology;* 27: 36, 6172-6179.

**NHS England** (2015) *Achieving World-Class Cancer Outcomes: A Strategy for England 2015–2020 – One Year On 2015–16.* Bit.ly/NHSECancer16

**For more on this topic online**

- Living with and beyond cancer 1: how well are we helping patients?
  **Bit.ly/NTBeyondCancer1**