

# USING EHNA DATA TO EXPLORE CANCER NEEDS

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## Background

The development of services for people living with cancer should be informed by a clearly articulated understanding of the needs and unmet needs of that group. Macmillan's Electronic Holistic Needs Assessment (eHNA) provides people with cancer an opportunity to record their needs and concerns. This supports a focused discussion with healthcare professionals, to create a tailored care plan. When aggregated, the data can help identify themes of high needs across local cancer populations and how these are addressed by clinicians.

## Methods

We conducted an analysis of data from the eHNA online database, in the 12-month period of 01/09/13–31/08/14. This included data from 5,176 needs assessments carried out in 46 sites participating in the programme, using four comparable questionnaires. As a result 3,855 care plans and 4,788 actions were taken forward by clinicians and patients.

## Results

So far the feedback on the tool has been positive. 54% of people completing an eHNA say it helped them address concerns they would not have thought of otherwise and a further 36% felt more confident to bring up concerns that they would have been embarrassed about.<sup>1</sup>

'I would recommend the questionnaire – out of the whole afternoon at the hospital it was the one meeting that wasn't medical – they weren't talking about treatment – it was actually talking about my circumstances and how I was feeling and how I was going to cope.'

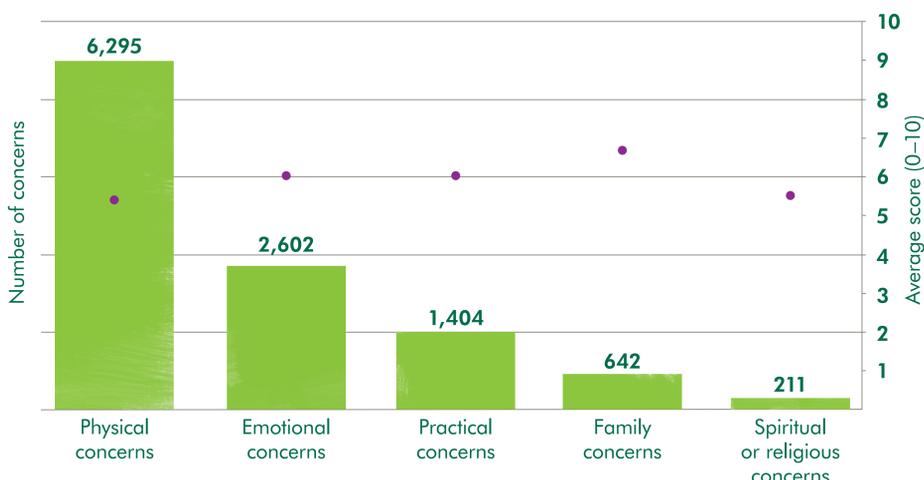
(eHNA user)

## What do people with cancer using eHNA worry about?

People using eHNA express a wide range of concerns. Physical and emotional concerns account for 80% of all worries of people with cancer using eHNA (56% and 25%, respectively) while family concerns are the most highly ranked (average 7 out of 10). These findings align with the wider picture on needs of all people with cancer from other research.<sup>2</sup> 55% of the information needs of people using eHNA\* relate to topics linked to self-management (diet, physical activity and complementary therapies).

Ranking	Top ten concerns*
1	Worry, fear or anxiety
2	Tired/exhausted or fatigued
3	Sleep problems/nightmares
4	Pain
5	Eating or appetite
6	Anger or frustration
7	Getting around (walking)
8	Memory or concentration
9	Hot flushes/sweating
10	Sore or dry mouth

## Number of concerns of PLWC using eHNA and their average score by category\*

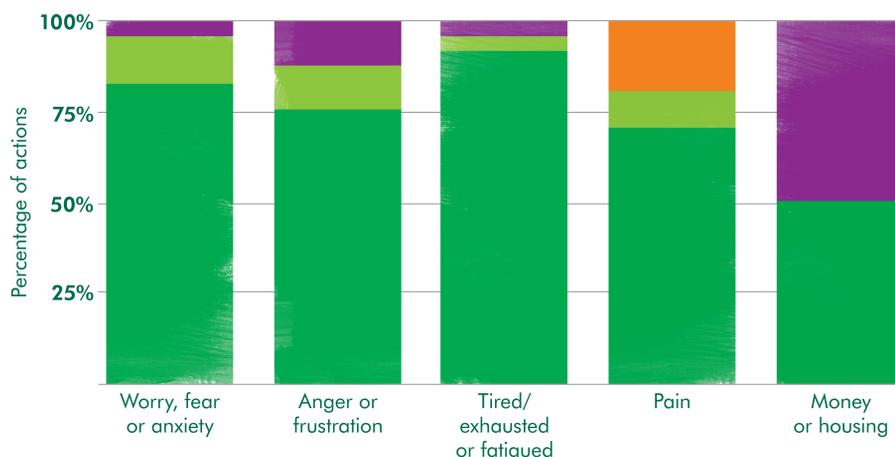


## How are the worries of people with cancer using eHNA addressed?

'Worry, fear or anxiety' is the single most frequently reported concern among eHNA users. Interestingly for 59% of those using eHNA the conversation during assessment and care planning itself helps to ease worries.<sup>1</sup>

Overall, the majority of patients feel they received support at the right time (85%) and in the right setting (82%).<sup>1</sup> The ratio of clinician to patient actions is 5:1. 68% of clinicians' actions are information and advice giving during the assessment and care planning session. Meanwhile for patients 79% of actions are carried out after the session. Information giving is the predominant action for all types of concerns.

## Top emotional, physical and financial concerns and actions taken as a result



- Information/advice
- Signposting/referral to specialist services
- Signposting/referral to generalist services
- Medication review/change

## An interesting case study

Only 3% of the clinicians' follow-up actions and 10% of the patients' follow-up actions relate to increasing their physical activity level, even though a fifth of information needs relate to that topic and the same proportion of concerns could be alleviated by physical activity.

Concerns and needs	Actions
20% report tiredness and fatigue	3% referred to physical activity assessment
22% of information needs are physical activity related	11% advised to increase physical activity levels

\*Concerns Checklist only

## Conclusions

The evidence base on the needs of people with cancer is currently patchy. Little evidence is available on the needs of people with cancer in small geographies. As presented above, the routinely collected data, such as those from the eHNA, can provide insights into the needs of its users and how these are addressed. Used on a local level, the data can help fill in gaps in the knowledge about the needs of populations reached by different health trusts. Macmillan is currently facilitating the use of aggregated eHNA data amongst its partner sites to help tailor their local plans, influence the development of existing and new services and add evidence to conversations with key decision makers and partners.

## Caveats

There is an underrepresentation of men and older people (aged 65+) in the cohort of people with cancer using eHNA (9% and 20% fewer when compared to cancer incidence, respectively). The former is due to the current predominance of breast cancer patients amongst initial pilot users. The latter could be related to concerns amongst staff that older patients or those less technology literate would struggle with the electronic assessment.<sup>1</sup> Meanwhile, the research has shown that a high degree of user satisfaction has been found in using touch screens across all genders and age groups.<sup>3</sup>

It is also worth bearing in mind that eHNA is used mostly during diagnosis and treatment (65%), as these stages offer the most convenient moments for a needs assessment, given the number and length of clinician/ patient interactions at these stages.

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## References

- 1 Ipsos Mori for Macmillan Cancer Support. 2014. Evaluation of the electronic Holistic Needs Assessment (eHNA).
- 2 'Worried Sick' – The emotional impact of cancer' (2006) showed that 41% of people with cancer report physical needs. 25% of people surveyed for the 'Not alone' - Facing the Fight Alone: Isolation among Cancer Patients' (2013) reported emotional needs.
- 3 Bischoff-Ferrari and Vodechens. 2005. Validation and patient acceptance of computer touch screen versions of the WOMAC 3.1 osteoarthritis index.