# CLINICAL NURSE SPECIALISTS IN NORTHERN IRELAND

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## Exploring impact and equality of provision through Cancer Patient Experience Survey data.

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## Objective

Findings from the first Northern Ireland Cancer Patient Experience Survey (NI CPES) were published in October 2015. The survey was jointly funded by the Public Health Agency and Macmillan. It asked patients to provide feedback on the full range of services they received as part of their cancer treatment and care. In February 2015, the survey questionnaire was posted to all patients who had been in active treatment for cancer in Northern Ireland during December 2013 to May 2014. We received 3,217 responses in total, representing a 62% response rate.

NI CPES findings revealed largely positive perceptions of cancer care in Northern Ireland, with 92% of responding patients rating their care as 'excellent' or 'very good'.

Access to a cancer clinical nurse specialist (CNS) emerged as the single most important driver of positive patient experience. Furthermore, a new five-year initiative to fund approximately 60 cancer CNS and support worker posts has recently been agreed in Northern Ireland. Funding comes from the Northern Ireland Health and Social Care Board, Macmillan and Friends of the Cancer Centre. Given this apparent impact and priority, there is a clear rationale for additional analysis of the NI CPES response data. This is to further explore how CNS make a difference to patient experience and which patients are most likely to get the benefits of one.

> Clinical nurse specialists are clinical experts in nursing practice within a specialty area. The specialty may be focused on: a population, such as young people; the type of care, such as palliative care; the type of problem, such as lymphoedema; or a particular type of cancer, such as lung cancer.
>
> Excellence in cancer care: the contribution of the clinical nurse specialist, NCAT, 2010

## Methodology

The analysis carried out in reporting the original NI CPES findings has been revisited and supplemented by:

- highlighting the areas of patient experience which showed the most significant differences between patients with and without a CNS
- testing for significant differences between patients with and without a CNS on a number of questions and variables not covered in the original NI CPES analysis
- segmenting the NI CPES sample by gender, age group, employment status, tumour site, etc and exploring if there are any significant differences in CNS provision for different groups

We used the anonymised NI CPES dataset, which consists of 3,217 adults who responded to the survey.

The additional analyses we carried out were based on Chi square tests for differences between proportions and independent sample T-tests. Differences are reported here as 'significant' based on a 95% confidence interval.

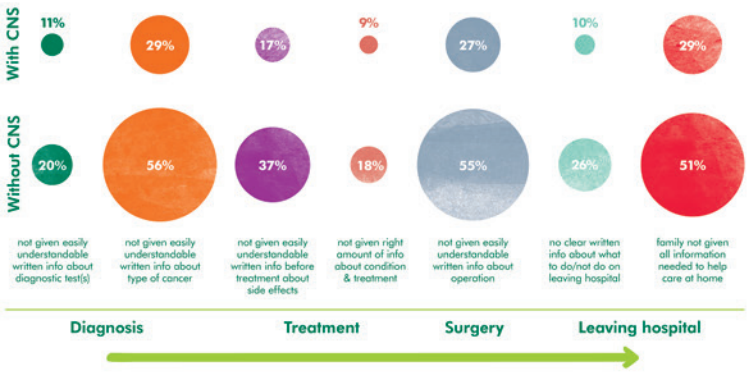
## Results

### How do clinical nurse specialists make a difference to patient experience?

Original NI CPES analysis revealed that CNS provision benefits patients in a number of ways. Responses from those who had been given the name of a CNS were compared with responses from those who hadn't. It was found that on almost all questions (55 of the 62 'scored' questions), those with a CNS gave much more positive views of their experience.[1] This was reflected in findings in England's 2014 CPES results too.[2]

Patients' overall experience of care is better with a CNS.[3] However, the benefits a CNS can provide are also highlighted in the significant variations between patients' experiences across the cancer journey. Many of the biggest differences in positive percentage scores between those with and those without a CNS relate to information provision (Figure 1)[4]:

***Figure 1:*** **Selected information questions across the cancer pathway showing percentage of respondents not given sufficient/easily understandable written information**




However, information provision is only one factor – initial analysis shows that other factors are positively associated with CNS provision, including efficacy of treatment. The analysis looked at patients who had finished treatment. Those who reported having 'no signs or symptoms of cancer' were significantly more likely to have been given the name of a CNS than those whose cancer was still present after treatment (Figure 2)[5].

***Figure 2:*** **Respondents who have had effective treatment compared to those who still have signs of cancer, by clinical nurse specialist provision**

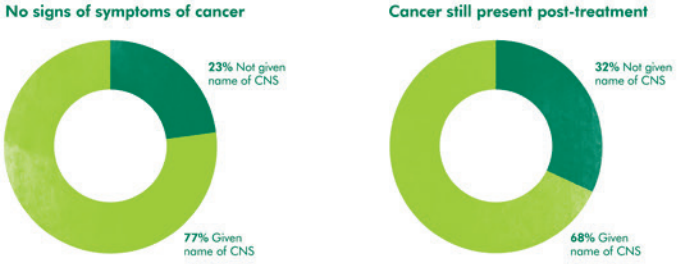
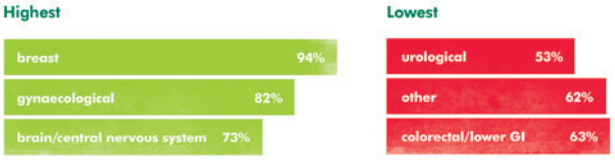



***Figure 3:*** **Tumour sites with the highest and lowest proportions of cancer nurse specialist provision[7]**

### Which patients are least likely to get the benefits of a CNS?

Despite these demonstrable benefits, there are still inequalities in access to CNS, with provision not yet uniform across different cohorts. Published results revealed unequal CNS provision across different tumour sites (Figure 3).




Inequalities are also seen across a number of other variables[6]:

***Figure 4:*** **Men were significantly less likely than women to have been given the name of a CNS[8]**

**35% of men v 21% of women were not given the name of a CNS**

***Figure 5:*** **Retired people were significantly less likely than employed people to have been given the name of a CNS[9]**

**About 1 in 3 (31%) retired people were not given the name of a CNS**

**About 1 in 4 (23%) employed people were not given the name of a CNS**

This finding is supported when exploring the provision of CNS by age category. Those in the highest age category (over 75 years old) were significantly less likely to be given the name of a CNS compared to those 75 and under[10]

***Figure 6:*** **Those who were treated for a recurring cancer or second cancer were statistically less likely to have been given the name of a CNS compared to those who were being treated for the first time.[11]**

**About 1 in 3 (34%) respondents with recurring cancer or being treated for a different (second) cancer did not have a named CNS**

**About 1 in 4 (26%) respondents being treated for cancer for the first time did not have a named CNS**

## Conclusion

From the results, we can see that the impact of having a clinical nurse specialist is felt across the cancer pathway in terms of information provision. Proportionally twice as many patients without a CNS did not receive understandable written information about their diagnostic test compared to those who had one. As many as 1 in 4 patients without a CNS did not receive clear written information about what to do when leaving hospital. This compares with just 1 in 10 among those who had a CNS.

This analysis has allowed us to explore and evidence the value of CNS by identifying some of the specific areas where they provide the most significant benefits to patients. We made an initial exploration of cohorts which are more or less likely to have access to a CNS. This demonstrated that there are still areas which require further improvement to allow all patients equitable access to these benefits. The new CNS workforce plan in Northern Ireland should go a long way to addressing these inequalities, particularly across different tumour sites.

**References**

1. Quality Health. Northern Ireland Cancer Patient Experience Survey 2015 All Trusts Report. October 2015. Scored questions are those where respondents give views about their care (as opposed to routing or information only questions).
2. Quality Health. Methodology and Data Tables Supplement Report for England. 2014. p 74. On 59 out of 63 scored questions, those with a clinical nurse specialist reported more positive experiences.
3. Quality Health. Northern Ireland Cancer Patient Experience Survey 2015 All Trusts Report. October 2015. As many as 94.8% of those with a CNS rated their care as 'excellent' or 'very good' overall compared to 86.0% of those without one. And 27.3% of those with a CNS were offered a written assessment and care plan compared to just 7.4% of those without one. Both show statistically significant differences between CNS/no CNS scores.
4. We explored the differences between positive scores of those with and those without a CNS across all the questions where there is statistically significant difference. We ranked them from the largest to the smallest difference to understand the areas in which having a CNS made the biggest difference to scores. Questions relating to information appeared in 8 of the top 13.
5. Macmillan analysis of NI CPES data.
6. Inequalities are not seen across all factors and not all factors can be tested, therefore the list is not exhaustive. No significant differences in CNS provision are found according to deprivation index for example.
7. Excluding skin and sarcoma owing to small base sizes.
8. Quality Health. Northern Ireland Cancer Patient Experience Survey 2015 All Trusts Report. October 2015.
9. Macmillan analysis of NI CPES data. This showed there was a statistically significant difference between the 69% of retired respondents and 77% of full/part-time employed people who'd been given the name of a CNS. This was based on respondents' self-classification of working status in the CPES survey.
10. Macmillan analysis of NI CPES data. This showed there was statistically significant difference between the 27% of over 75-year-old respondents and 34% of those 75 and under who hadn't been given the name of a CNS. This was based on respondents' self-reported ages at the time of filling in the survey.
11. Quality Health. Northern Ireland Cancer Patient Experience Survey 2015 All Trusts Report. October 2015.

**Acknowledgements**

Quality Health, who administered and reported the results of the survey.

Full research reports are available at quality-health.co.uk/resources/surveys/northern-ireland-cancer-patient-experience-survey/2015-northern-ireland-cancer-patient-experience-survey/northern-ireland-cancer-patient-experience-survey-reports

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We would also like to thank the 3,217 people with cancer who filled in and returned the 2015 survey to give us this data and valuable insight into their experiences.

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**Digital version of this poster available from macmilllan.org.uk/cns**