

# New report reveals Scottish patients' experience of cancer care

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Credit: University of Stirling

A new report by the University of Stirling has been published on patients' experience of cancer care in Scotland.

Over 2600 patients provided almost 7000 "free text" comments in response to the first ever national cancer experience survey, funded by Macmillan Cancer Support and the Scottish Government.

An independent analysis by cancer care experts from the Nursing, Midwifery and Allied Health Professions (NMAHP) Research Unit,

found over 2500 positive comments and almost 2000 negative comments, with the rest classed as neutral or factual.

The positive comments praised the good clinical care, good support overall and clear and relevant information.

One man said: "All decisions were fully discussed and explained in a manner which was both sympathetic and sensitive." Another said: "I had very good pre-op and post-op care".

The research team, led by Professor Mary Wells, found the main themes among the negative comments suggested that patients' experiences of care were affected when they did not feel confident in the system or when their needs as an individual were not met.

Poor communication, poor care and lack of emotional support all emerged as issues, and many patients noticed differences in the quality of care they received on cancer wards or high dependency units compared to general wards.

One woman said: "I was sent home from hospital with no care plan. I live on my own and had a difficult time."

This is the second report based on almost 5000 responses to the first ever Scottish Cancer Patient Experience Survey.

The first report, launched by First Minister Nicola Sturgeon and Health Minister Shona Robison in June, found 94% of cancer patients in Scotland were positive about their care.

However among those who needed it, 46% didn't get the care and support they needed from health and social care professionals during treatment, rising to 55% after. Only 22% had a care plan, despite those

who had a care plan having a markedly better experience than those who did not.

Professor Mary Wells of the Faculty of Health Sciences and Sport, said: "Getting an account of positive and negative experiences in patients' own words is invaluable to further improving cancer care in Scotland. We now have a unique insight into what matters most prior to diagnosis, during treatment and after people leave hospital.

"It's clear that one bad experience can knock a patient's confidence in the system and badly affect their entire journey. We need to ensure that every contact a patient has, from talking to their GP to travelling to the hospital and getting important letters on time, is joined up.

"We now know that having an established care plan is a major contributor to a patient's overall experience. The differences in care provided between specialist and general wards was also a factor for many people, who felt more isolated on general wards. Given that patients spend a relatively short time in these specialist units, it's important we ensure staff in all settings are knowledgeable, well trained and confident in caring for people with cancer.

"This is a huge challenge in the context of ever more complex treatments and a growing number of people living with and beyond cancer, but it is vital that we equip our staff to recognise and respond to patients' needs, wherever they present within the healthcare system.

"While the majority of cancer patients have a positive experience overall, implementing changes like these will help ensure the thousands of people who are affected by cancer have a more positive experience at what is an incredibly difficult and upsetting time."

Macmillan's head of cancer services in Scotland, Janice Preston, said:

"For the first time we have comments from thousands of people with cancer about what they thought was good about their care, as well as where it should have been better. While it is good news the positive comments outweigh the negative, these [negative comments](#) represent people with cancer, already going through one of the worst times of their life, whose experience was poorer than it should have been.

"Too many patients don't feel listened to or respected. They don't feel treated as individuals and helped to find the support they need to cope with the wider emotional, practical and financial problems cancer causes. The lack of care after treatment is also a real cause for concern. There is an urgent need to ensure everyone has a good experience of care, moving from our current one-size-fits all approach that sees patients as a set of symptoms to treat rather than as a person who must be asked what they want and need.

"The Cancer Patient Experience Survey means there is now an unprecedented level of insight available to health boards on where their cancer care is working well and where it needs improvement. Every one of them must urgently put an improvement plan in place."

**More information:** The report is available online:  
[www.gov.scot/Publications/2016/10/1882](http://www.gov.scot/Publications/2016/10/1882)

Provided by University of Stirling

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