## Cancer Patient Experience Survey insights from free-text comments

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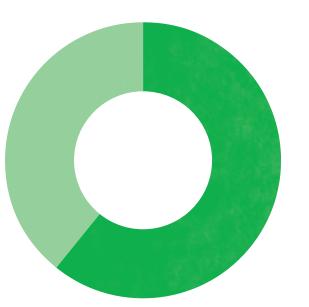
# Background

The first Scottish Cancer Patient Experience Survey (SCPES) was conducted in 2015/16. The survey covered the care that a patient with cancer experiences from the point at which they think that something might be wrong through to the support they receive after their acute-care treatment. Being able to survey a large number and broad range of patients from across Scotland and collect their views and experiences has been invaluable. We thank the patients for their feedback as it will assist in improving services.

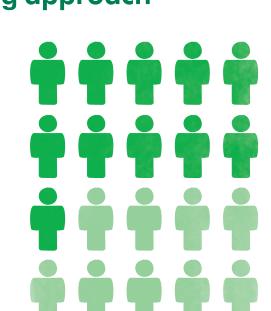
## Methods

The survey included seven free-text comment boxes – one at the end of each section on a different stage of cancer care.

Figure 1: Response rates and coding approach

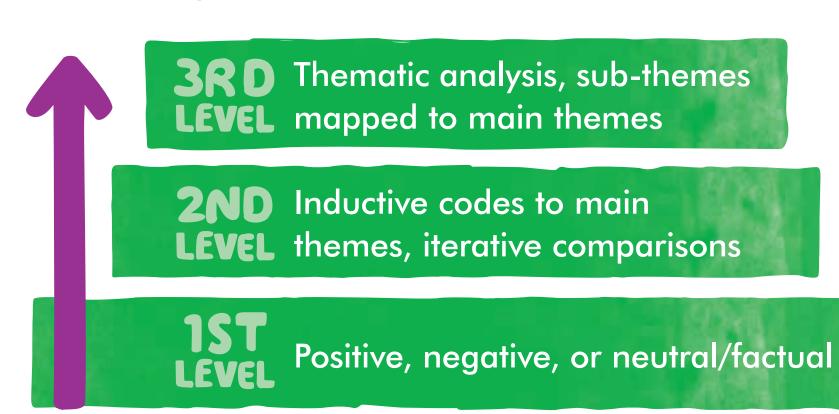


7,949 patients were invited to take part, of which **4,835 (61%)** completed the survey.



6,951 comments were left and **2,663 (55%)** of patients left at least one comment.

## Dataset coding



## What the patients said

'All decisions were fully discussed and explained in a manner which was both sympathetic and sensitive, as well as in terms that I could understand.' Male in the 51-65 age group, upper gastrointestinal cancer

'I was sent home from hospital with no care plan – I live on my own and had a difficult time to do things. The nurse had told me everything was as planned and people would come to my home to help for a few weeks, but no one came. I was left on my own.' Female in the 51-65 age group, lung cancer

# Findings

Figure 2: What patients said worked well and what needs to improve

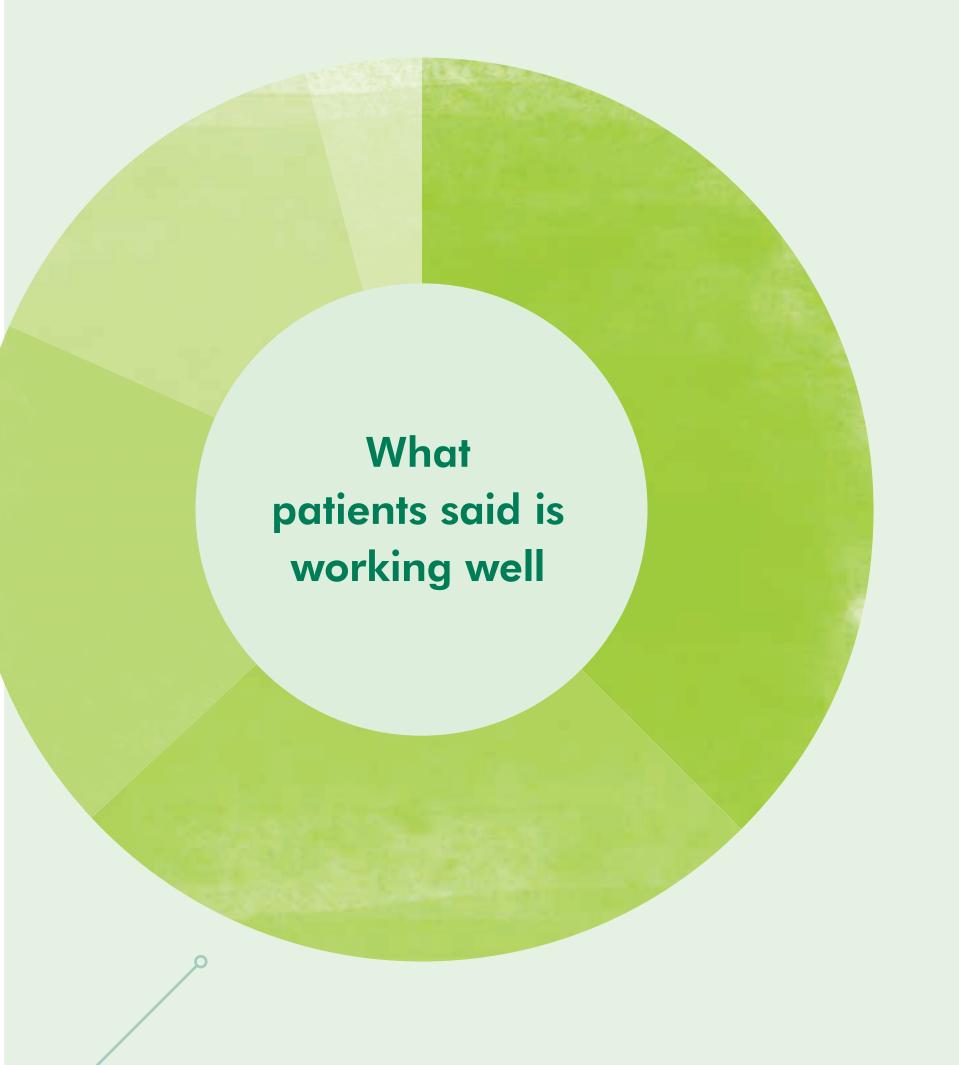


There were more positive (2,528) than **negative** (1,961) comments. There were 1,208 factual or neutral comments and 585 miscellaneous.

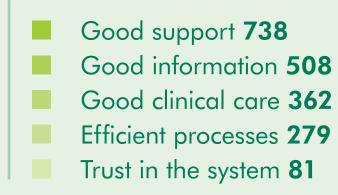


**59%** of those who commented were female and 41% were male.

79% of those who commented were over 55-years-old.







Not feeling confident within the system Poor care **375** Inadequate aftercare **262** Difficulty getting into the system 200 Inconsistent or inappropriate information 158 Lack of faith in the system 158 Inadequate contact 50

## Not feeling that individual needs were met Information 407 Poor communication 345

Emotional support and responsiveness 270 Involvement and choice 97 Specific and unusual circumstances 34

#### **Unsatisfactory structures** Unsuitable or uncomfortable environment 145 Staffing levels 143

Privacy **67** Transport 49 **Unsatisfactory processes** 

Waits and delays **454** Ineffective and unreliable processes (organisational systems) 289 Fragmented care **276** 

# Conclusion

Previous analysis of the closed-ended questions in the survey found that 94% of respondents rated their overall experience of care as good or very good. Analysis of the free-text comments provided more detail on particular issues respondents encountered during their cancer care, allowing the patient perspective to directly influence cancer service improvements.<sup>2</sup> It was found that:

- confidence in the system can be shaken or eroded at any time on the care continuum every encounter with the health care system matters,
- experiences both in the lead up to diagnosis and after treatment finishes need special attention,
- services and processes are not always sufficiently patient-centred,

Family 21

- good relationships and tailored information are central to people feeling recognised as individuals, and
- needs and experiences must be assessed and evaluated throughout the trajectory of care.

## Working together







A digital version of this poster is available from macmillan.org.uk/research-posters

For more information please contact evidence@macmillan.org.uk

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