

Keeping The Customer Satisfied - It's OK to Ask - Is Taking Part In Research Associated With Better Experience of Care?

Findings from the 2013 National Cancer Patient Experience Survey

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BACKGROUND

The National Cancer Patient Experience Survey (NCPES) 2013 (ref 1) includes data on 68,737 recently treated patients from NHS Trusts in England providing acute cancer services. This represents a response rate of 64%. The sample includes patients seen in outpatients and those treated as inpatients, patients being treated for cancer for the first time and those returning, over the 3-month period September – November 2012.

Two new questions about the patient experience of cancer research were introduced this year, either side of a tracker question about being asked about research:
"Have you seen information (such as leaflets, posters, information screens etc) about cancer research in your hospital?"
"Since your diagnosis has anyone discussed with you whether you would like to take part in cancer research?"

"If so did you then go on to take part in research?"

Finally, an overarching question at the end of the NCPES asks patients to rate their experience of care:
"Overall, how would you rate your care: Excellent, Very Good, Good, Fair, Poor"

We wanted to test if taking part in research is associated with better experience of care.

METHOD

Our analyses look at patients' overall rating of their care and participation in research, tested with Pearson's chi-squared test for association.

RESULTS

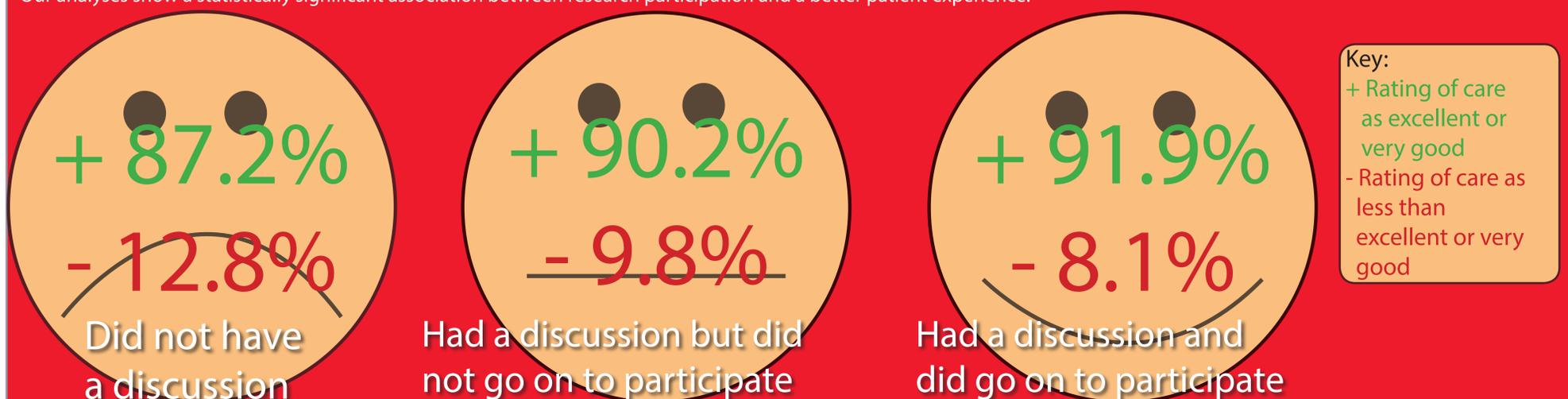
The 2013 NCPES data show that:

85% of respondents report seeing information about cancer research in their cancer care setting
30% report having a discussion about taking part in research, of whom 64% go on to participate.

Access to research is unequal:

Both the Trust where patients were treated and the type of cancer they have show significant variation in all 3 questions. Our earlier work (ref 2, 3 & 4) identified age and deprivation as other major factors significantly affecting patient chances of discussing research.

Our analyses show a statistically significant association between research participation and a better patient experience:



Key:
+ Rating of care as excellent or very good
- Rating of care as less than excellent or very good

This association between research involvement and satisfaction has been tested and seen to be highly statistically significant. There is less than 1 in 1000 probability that the result we see is through chance.

CONCLUSION

There is an association between how people rate their care and how they rate their participation in research. Among those who are not asked, and so never have the opportunity to participate, 87.2% rate their care as excellent or very good. This percentage increases to 90.2% when patients are asked about research but do not go on to participate, and to 91.9% if they are asked and do participate.

The research community has long held that participation in research is linked to better patient experience, and this survey provides the first evidence on a large scale to support that view. These analyses indicate that having a discussion is also associated with better experience, though the association is less strong. Further analyses are needed to provide new insights for the theory and practice of recruiting patients to studies, and for tackling inequalities in access.

- For patients, for clinicians and for commissioners, our findings support the view that opportunities for research participation should be integral to treatment options.
- The association between taking part and quality of experience for patients makes it all the more important to intensify efforts to reduce inequalities of patient access to research.
- "The NHS introduced Patient Choice to create more satisfied customers. This survey shows that cancer patients are more satisfied if that choice extends to research participation too. We may not take part in the research, but we do regard the offer as being part of the best care." Richard Stephens, Chair, NCRI Consumer Liaison Group (CLG).