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Keeping the Customer Satisfied #1: 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 2013 includes data on 68 737 patients from English NHS Trusts providing acute cancer services – a response rate of 64%. NCPES 2013 asked about the patient experience of cancer research: “Have you seen information (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?” An overarching question asks patients to rate their care. 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: 30% report having a discussion about taking part in research, with 64% going on to participate. Our analyses show a statistically significant association between research participation and a better patient experience. Among those who are not asked, 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.

Conclusion: There is an association between how people rate their care and how they rate their participation in research. Having a discussion is also associated with better experience, though the association is less strong. The research community has long held that participation in research is linked to better patient experience, but until now it has not been possible to evidence this on such a large scale. These findings support the view that opportunities for research participation should be integral to discussions with patients of their treatment options.