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Keeping the Customer Satisfied #3 It's OK to ask – who are we asking? Variations by type of cancer further findings from the National Cancer Patient Experience Survey

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Background: The National Cancer Patient Experience Survey (NCPES) 2013 includes data on 68 737 patients from English NHS Trusts providing acute cancer services – a response rate of 64%. Patient responses are grouped, inter alia, by 14 types of cancer. NCPES 2013 asked about the patient experience of cancer research. We wanted to identify if opportunities to participate in research vary according to their type of cancer.

Method: One of the research questions was "Since your diagnosis has anyone discussed with you whether you would like to take part in cancer research?" The Chi-squared test was used to test for association between cancer site and reporting a discussion about research.

Results: All cancers: Don't know 5.3%, No 64.6%, Yes 30.1%. Results for 14 Tumour sites: YES Urological Cancers 15%, Skin 17%, Gynacological 27%, Head &Neck 27%, Lung 30%, Colorectal & Lower GI 31% Other 31%, Sarcoma 32%, Prostate 33%, Upper GI 33% Haematological 34% Breast 35%, Brain & CNS Cancers 36%, variations significant at the P < 0.001 level.

Conclusion: Patients' opportunities to participate in research vary according to their type of cancer. Skin and urological cancer patients are asked signficantly less often than others. These findings prompt the question: how far do these variations reflect variations in the NIHR CRN Cancer portfolio or other types of research eg tissue banking? We have demonstrated elsewhere (abstract "Keeping the Customer Satisfied"#1) significant association between having a discussion and patients' rating of their care. So a further question arises: what more can be done to widen access to research to those groups with less access? Inequalities between cancer types are likely to attract interest from the new Local Clinical Research Networks, from Clinical Studies Groups, from Patient Groups & Cancer Charities, and from Commissioners and Cancer Peer Reviewers.