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Keeping the customer satisfied #2 It Is OK To Ask –who are we asking, and who participates? Further findings from the National Cancer Patient Experience Survey 2013

Richard Stephens¹, Carolyn Morris¹, Robert West², Matthew Baker¹, Ekaterini Blaveri³, Rachel Brannen³, Sheila Fisher⁵, Jane Hanson⁴, Sue Pavitt², Reg Race⁶

¹NCRI Consumer Liaison Group

²Leeds Institute of Health Sciences, University of Leeds

³National Cancer Intelligence Network

⁴NIHR Local Clinical Research Network: Kent Surrey Sussex

⁵NIHR Clinical Research Network Cancer

⁶Quality Health

Background: NCPES 2013 includes data on 68 737 recently treated patients from the 162 NHS Trusts in England providing acute cancer services. This represents a response rate of 64%. Questions about the patient experience of cancer research include “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?” Patient’s responses can be analysed by gender and age, with patients’ ages grouped 16–50; 51–65; 66–75; 76+.

Method: Chi – squared test was used to test for association between gender and having a discussion & going on to participate; and similarly for association with age.

Results: Who has a discussion? Our findings show no significant difference by gender: Female 30.7% Male 29.5%. Age shows significant variation ($P < 0.001$): 36.7% 16–50 year olds report a discussion; 36.5% of 51–65 year olds; 30.5% of 66–75 year olds & 18.8% of those aged 76+. Who then goes on to take part? Gender again shows little difference: of Females who had a discussion, 62.4% participated in research; Males 65.5%. Age differences are significant, with 68.3% of 16–50 year olds going on to participate, 66.9% of 51–65 year olds; 62.2% of 66–75 year olds & 56% of those 76+. We are now examining “conversion rates” for each age group.

Conclusion: There is little variation by gender in whether patients report a conversation about taking part in research. There is a clear decline in being asked with age: over the age of 75 there are both fewer discussions and less participation. However over half the patients approached do participate. The influences of tumour type, co-morbidities, socio-economic status, ethnic/cultural background, location within the UK, all need further analysis.