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Background

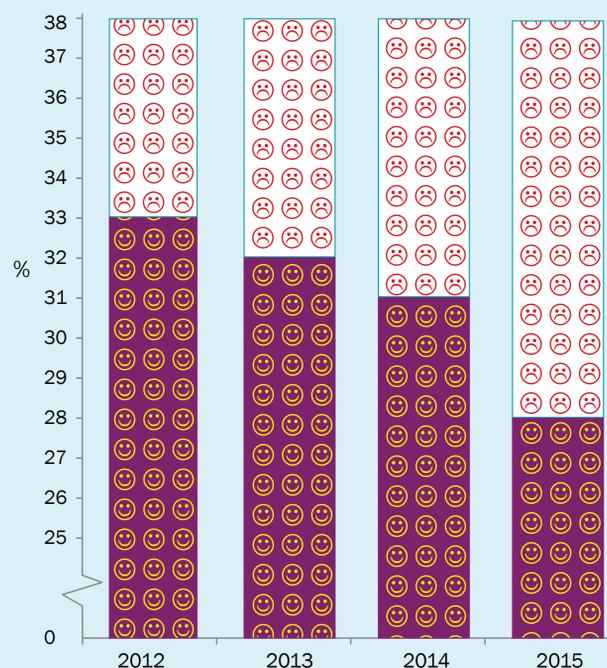
The annual Cancer Patient Experience Survey includes the question, 'Since your diagnosis, has anyone discussed with you whether you would like to take part in cancer research?' The new (2015) national Cancer Strategy, *Achieving World Class Outcomes*, highlighted the importance of patient experience. The Cancer Dashboard (2016) has a key CPES-derived metric for patient experience. Analysis of the 2013 CPES data showed that research participation is associated with higher levels of patient satisfaction with their overall experience¹.

Method

All in-patient and day case cancer patients treated in the 148 acute and specialist Trusts in England between April and June 2015 were offered the opportunity to complete the 2015 NCPES questionnaire. Over 71,000 (66%) responded, with national results published in June 2016, Trust- and CCG-level reports in July 2016².

Results

28% of patients reported having had a discussion about research participation. This compares with 33% (2012), 32% (2013), and 31% (2014). Having a discussion about research participation continues to vary significantly by Trust and cancer type. By Trust the variation extends from 11.7% of patients reporting a discussion to 55.2% of patients. Past years were 14%-56% (2012), 11%-62% (2013), 10%-61% (2014) and 11%-55% (2015)³. By cancer type the variation extends from 13.3% of patients reporting a discussion to 34.8% of patients, consistent with previous years; 15%-39% (2012), 16%-38% (2013), 14%-37% (2014), 13%-35% (2015)⁴.



| Year | Discussion about research (%) |
|------|-------------------------------|
| 2015 | 28 |
| 2014 | 31 |
| 2013 | 32 |
| 2012 | 33 |

Conclusions

Improving the patient experience and encouraging participation in research are both national policy objectives. Thus the continued fall in the proportion of patients reporting a research discussion is doubly disappointing. It may be explained by the changing ecology of cancer research, but the wide variations in performance by Trust suggest otherwise. Significant inequalities still exist for patients in gaining access to opportunities to participate in research and potentially to an improved patient experience.



"The extent of variation between NHS Trusts – with the performance of the top 20% more than double that of the bottom 20% – shows that the responsibility of the NHS to promote research is not being applied uniformly. If we are to achieve our ambition to see three in four patients surviving the disease by 2034, it is vital that every eligible patient is given the opportunity to participate in cancer research."

Professor Peter Johnson, CBE
Chief Clinician, Cancer Research UK

"We know that patients in research-rich hospitals have better outcomes, even if they are not participants themselves. We know that patients who have discussions about research options are more likely to report higher satisfaction with their care. Every hospital and MDT should be talking to their patients about research opportunities. These figures show that we need to talk about why we aren't talking."

Richard Stephens
Chair, NCRI Consumer Forum

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References

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² <http://www.ncpes.co.uk/index.php>
³ http://www.ncri.org.uk/wp-content/uploads/2015/11/Final_NCRI-Consumer-Consumer-Poster-2015A4.pdf
⁴ <http://www.ncri.org.uk/wp-content/uploads/2015/09/Keeping-the-Customer-Satisfied-3.pdf>