



Is This As Good As It Gets?

The English Cancer Patient Experience Survey 2016 – Research Discussions Reported by Patients Since 2012

RICHARD STEPHENS¹ CAROLYN MORRIS¹ MATTHEW BAKER¹ **NCRI CONSUMER FORUM**

BACKGROUND

England's Cancer Strategy¹ highlighted the importance of patient experience. The Cancer Dashboard has a key metric to capture it, derived from the annual Cancer Patient Experience Survey (CPES). CPES includes the question, 'Since your diagnosis, has anyone discussed with you whether you would like to take part in cancer research?' Research participation is associated with significantly higher levels of satisfaction in patients' overall experience.²

METHOD

All cancer patients treated in the 148 acute and specialist Trusts in England between April-June 2016 were sent the 2016 CPES questionnaire. Over 72,000 (64%) responded, with national, Trust- and CCG level reports published in summer 2017.³

RESULTS

29% of patients nationally reported having had a discussion about research participation. This is broadly consistent with CPES results 2012-2015, which ranged from 33% (2012) to 28% (2015).⁴

By Trust the responses extend from 11% to 59%. Previously ranges were 10%-14% to 55%-61%.

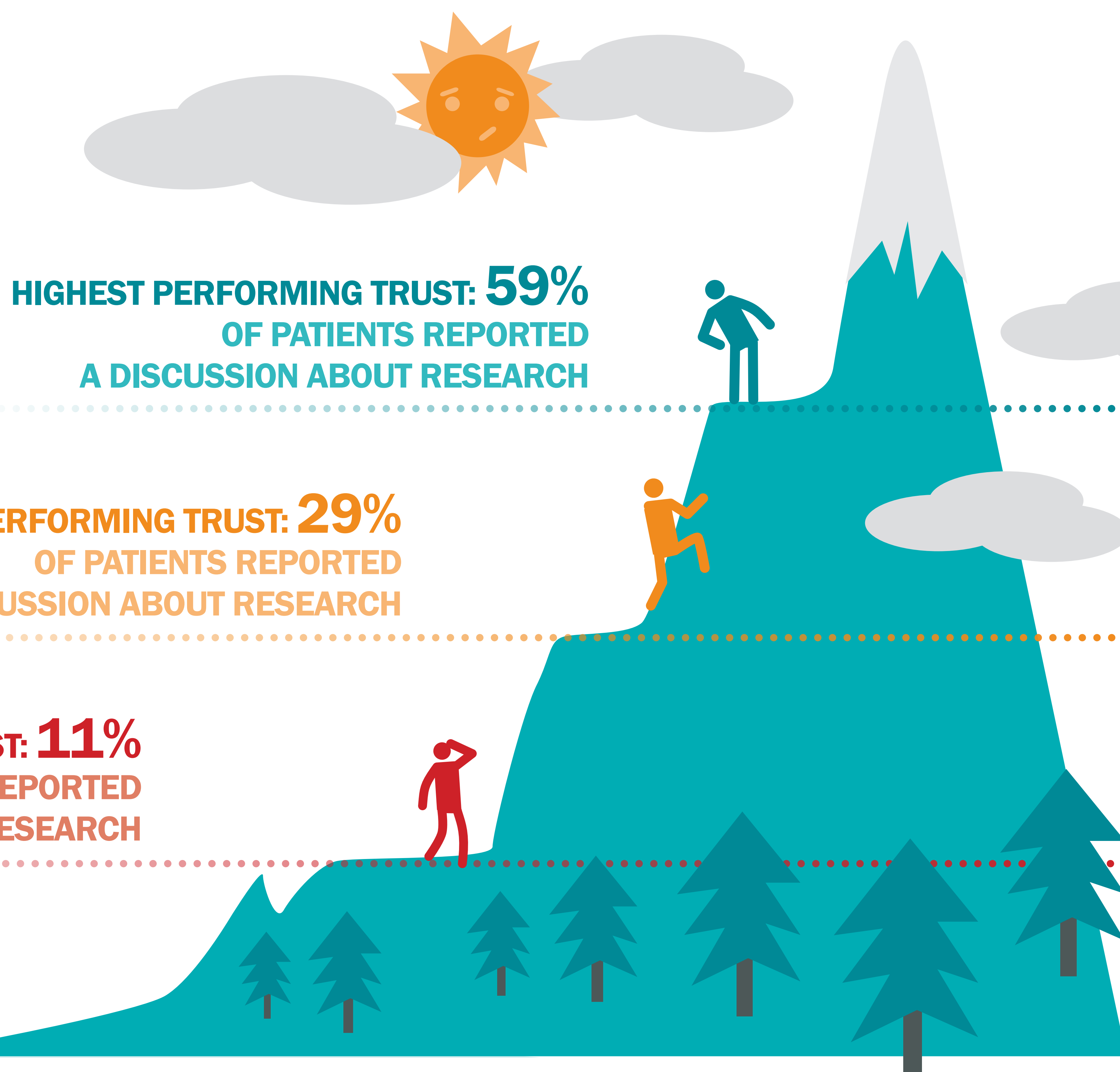
CONCLUSIONS

We seem to have reached a plateau nationally for patients having discussions about research during their treatment pathways, but local variations remain wide. The difference between the worst- and best-performing Trusts has fluctuated between 34 and 51 percentage points during 2012-2016, but the lower range has been consistently below 15% annually.

The group recording the highest level of research conversations are teenagers and young adults (41%), and older patients (65+) are also significantly more likely to have research discussions, including 14% of patients aged 85+.

Findings from CPES 2016 suggest that age inequalities reported in previous years⁴ are being addressed. Nevertheless geographical variation remains as the widest and most persistent inequality. Moreover the differences are not necessarily between large or small hospitals nor between specialist or generalist centres.

The local CPES data continue to offer rich opportunities for evidence-based and focussed conversations among patients, NIHR Patient Research Ambassadors, representatives from Trusts and the NIHR Local Clinical Research Networks. Half a decade of CPES results have shown that cancer patients are happy to be approached about research participation, but the majority of them are still not being asked.



¹AUTHORS

Richard Stephens NCRI Consumer Lead, Chair of NCRI Consumer Forum
Carolyn Morris NCRI Consumer Forum
Mat Baker NCRI Consumer Forum Steering Group
Please contact the authors via natalie.salhov@ncri.org.uk

REFERENCES

- <https://www.england.nhs.uk/wp-content/uploads/2016/05/cancer-strategy.pdf>
- <http://www.ncri.org.uk/wp-content/uploads/2015/09/Keeping-the-Customer-Satisfied-1.pdf>
- <http://www.ncpes.co.uk/index.php>
- <http://www.ncri.org.uk/patient-and-public-involvement/ncri-consumer-forum-resources/>