



Cancer Research and Cancer Patients: It feels better and it does you good

RICHARD STEPHENS¹ MATTHEW BAKER¹ CAROLYN MORRIS¹
¹NCRI CONSUMER FORUM

BACKGROUND

The National Cancer Patient Experience Survey (NCPES) annually captures data provided by patients recently treated by NHS Trusts in England providing cancer care services. Response rates hover around 65%, an annual population of approximately 70,000 patient respondents.

The 2015 *National Cancer Strategy, Achieving World Class Outcomes*, highlights the importance of patient experience and the Cancer Dashboard (2016) has a key NCPES derived metric for patient experience.

FINDINGS

Patients report higher levels of satisfaction with their care when they have participated in research.

Downing A, Morris EJA, Corrigan N, et al (2016)² found that patients treated in hospitals with high rates of research activity benefitted from lower levels of post-operative mortality and higher levels of five year survival.

Our analysis of the 2012, 2013, 2014, and 2015 NCPES data³ however shows that the percentage of patients that report having had a discussion about participating in research has fallen progressively over this period from 33% of respondents in 2012 to 28% of respondents in 2015. Having a discussion about research participation also varies significantly by Trust and by cancer type, and occurs less frequently when the patient is older or from a socially deprived background.

METHOD

The NCPES questionnaires elicit information on a range of topics, including patient participation in cancer research, and also ask respondents to rate the quality of cancer care they experience. Our analysis of the 2013 survey¹ shows an association between how people rate their care and how they report their participation in research.

Downing A, Morris EJA, Corrigan N, et al (2016)² analysed the survival of over 200,000 colorectal cancer patients diagnosed in England between 2001-2008, and set the data in the context of treatment in trusts with high or low rates of running clinical trials.

CONCLUSIONS

The analysis of the 2013 NCPES provides the first evidence on a large scale to support the long-held view of the research community that research participation is linked to better patient experience. Downing A, Morris EJA, Corrigan N, et al (2016)² provide evidence that patient outcomes are better in a research-active cancer care environment.

As part of the Patient Choice agenda, informed patients may wish to consider participating in research and/or being treated in a research-active trust, to improve their own experiences and outcomes. Charities and support groups may wish to consider signposting the evidence to support that consideration and to promote access to better experiences and outcomes for those who by virtue of geography, age, or deprivation may be currently excluded from these.

NHS England and the NIHR must ensure that all patients have equality of opportunity to benefit from the improved care and outcomes that research offers, as patients and carers themselves called for in their 2012 report, *Action on Access*.⁴

THE EVIDENCE
INDICATES THAT
PARTICIPATION IN
RESEARCH IS ASSOCIATED
WITH BOTH BETTER
OUTCOMES AND WITH
HIGHER LEVELS
OF PATIENT
SATISFACTION



IN 2015 FEWER THAN
3 CANCER PATIENTS
IN 10 REPORTED HAVING
HAD A DISCUSSION
ABOUT PARTICIPATING
IN RESEARCH



¹AUTHORS

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

REFERENCES

- <http://www.ncri.org.uk/wp-content/uploads/2015/09/Keeping-the-Customer-Satisfied-1.pdf>
- <http://gut.bmj.com/content/early/2016/10/14/gutjnl-2015-311308>
- <http://www.ncri.org.uk/wp-content/uploads/2015/07/2016-NCRI-Consumer-Consumer-Poster-NCPES.pdf>
- <https://www.ncri.org.uk/wp-content/uploads/2013/07/2012-NCRI-Action-on-access-report.pdf>