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Background

NCPES 2014 includes data on the experiences of 70,141 recently treated patients from the 153 NHS Trusts in England providing acute cancer services, a response rate of 64%.

In 2014 and 2013 questions about the **patient experience of cancer research** included:

"Have you seen information (such as leaflets, posters, information screens etc.) about cancer research in your hospital?"

"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?"

Method

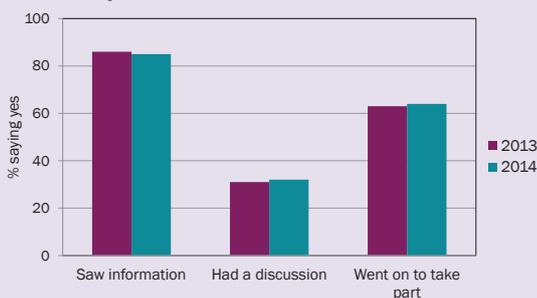
Our analyses look at patients' responses to the research questions. The Pearson's chi squared test was used to test for association between age and having a discussion, and between age and going on to participate in research.

Findings in 2014 show **little change** nationally from 2013 and raise **issues of access of patients to research opportunities:**

| | |
|---------------------------------|------------------|
| Saw information about research: | 86% (2013 - 85%) |
| Had a discussion: | 31% (2013 - 32%) |
| Went on to take part: | 63% (2013 - 64%) |

Results

NCPES research questions and responses

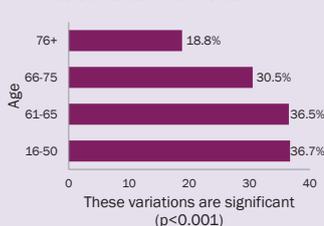


All three questions show statistically significant variations both between Trusts and between tumour types, especially in whether or not patients had a discussion, where Trusts vary from 10% to 61% and tumour types vary from 14% to 37%.

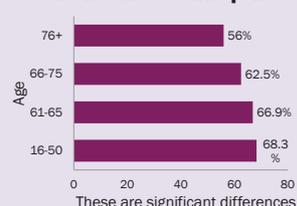
The findings also raise issues about age:

Older patients are asked less often and the difference is significant.

Percentage who had a discussion



Percentage who went on to take part



NCPES responses also show that older patients are more uncertain about whether or not they were asked.

Conclusions

Richard Stephens, Chair of the NCRI Consumer Forum¹ comments:

"Variations between Trusts remain too wide. These findings show inequality of access to research opportunities for cancer patients. And they show that overall things aren't changing.

"There are opportunities for all those working as part of the NIHR Local Clinical Research Networks² to address this swiftly.

"Evidence shows that patients offered research opportunities are more likely to report higher satisfaction with their care, and even more likely to do so if they go on to participate in research.³

"We know too that research-active Trusts are more likely to produce better outcomes for all patients, not just those taking part in research.

"It is in everyone's interest to have more research opportunities in our cancer services, for those opportunities to be offered to cancer patients, and for patients, advocates and charities to ask for them."

Carolyn Morris, NCRI Consumer Forum member, issues a further call to action;

"We need to look at research conversations with older patients. They are missing out. Are we prejudging older patients' readiness or ability to take part? Do we need to reconsider how we introduce the notion of participation and how we communicate the benefits?

"We need to think about study and topic and design too. Older people have greater incidence and we have an ageing population. Issues like co-morbidities need to be seen as challenges and opportunities, not as barriers."

Richard continues:

"The NIHR's annual 'OK to Ask' campaign⁴ offers the NHS opportunities to promote both the availability of and the need for research. I hope that all Trusts will participate next year within their NIHR local networks, especially those Trusts where patients are reporting that they are **not** having discussions with staff about taking part in research.

"Perhaps too the NCRI⁵ and its Partners might instigate a National Cancer Research Week across the UK, linking with "OK To Ask", **to encourage all of us to have the conversations that are not yet taking place."**

Further Information:

The National Report on NCPES 2014 can be viewed or downloaded as a PDF from the Quality Health website: www.quality-health.co.uk where Trusts' reports can also be found. Access is free of charge.

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1. www.ncri.org.uk/about-us/patient-involvement
2. www.crn.nihr.ac.uk/networks
3. Morris C., West R., Stephens R., et. al., "Keeping The Customer Satisfied Is Taking Part In Research Associated With Better Experience of Care?" [Poster]. NCRI Cancer Conference, 2-5 November 2014, Liverpool, UK. Available at www.ncri.org.uk/resources/ncri-consumer-forum
4. www.nihr.ac.uk/get-involved
5. www.ncri.org.uk