

- Locally and nationally
- And across types of cancer and groups of patients.

NCPES Research Questions & Findings:

- 2012 asked if patients had had a discussion about research, if those asked were glad, and whether those not asked would like to have been.
- 2013 built on these questions, retaining, as a tracker, the question about having a discussion, and asking also if patients had seen any information in their hospital about research – and whether, if asked, they had then gone on to take part in research.
- 2012 findings were included in *Action on Access** and supported *It's OK to Ask!*, campaigns CLG members played large parts in. Briefly, 2012 data showed 33% of patients had a discussion and that 95% of those asked were glad.
* <http://www.ncri.org.uk/wp-content/uploads/2013/07/2012-NCRI-Action-on-access-report.pdf>
- Posters we've presented analysing data from 2012, 2013 and 2014 are available for you to download from the consumer liaison group resource library:
<http://www.crn.nihr.ac.uk/cancer/pcpie/the-consumer-liason-group>
- One important finding: research *is* associated with better experience of care.
- We have highlighted some questions raised by the findings. You – and your group – may well come up with further questions. We'd really like you to capture them and feed them back to us. While remembering WE don't have the capacity to undertake further analyses.
- What we may be able to do – as might you – is spur interest in collaborative approaches to seeking funding for further work.

ACTING ON THE FINDINGS

In Practice, In the Clinic and In the Waiting Room...

Making Access for All a Reality:

- NCPES clearly shows that information about research is not equally accessible. We hope that with your help these findings will prompt action to make information about research more widely – and equally – available.
- Information is only part of the issue. How can we ensure more focus is given to helping health professionals have conversations with patients and their carers?
- Are some teams more effective than others in converting discussions into participation? What can we learn from them?
- Now we understand better which patient groups are less aware of research – how can we better meet their information and access needs?
- Something you may like to take to your CSG or sub-group: 2012 data showed enthusiasm for taking part amongst many who had not had a conversation. What more can be done to facilitate high quality studies in those tumour groups where opportunities to take part in trials are more limited?
- You'll see too that variations in having a conversation are statistically significant – variations by Trust, by cancer type, and by patient demographics such as age and deprivation status. Access is, not yet, for all.
- Please do use the data here to support conversations about how research is communicated and to challenge inequalities of access.

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