

*The following is part of a statement provided by Professor Matt Seymour (Director, NCRN) in June 2013 when requested by Sean Duffy (National Clinical Director for Cancer, NHS England) to provide a response to a parliamentary question concerning the findings of the 2012 National Cancer Patient Experience Survey.*

'The 2012 [National Cancer Patient Experience Survey](#) in England included research questions developed by the NCRN working with our Consumer Liaison Group. It revealed that of the 70,000 patients surveyed in English NHS Trusts, 33% said that taking part in research had been discussed with them. Of these, 95% were glad to have been asked. Of the patients who were not asked about research, 53% said they would have liked to have been asked.

It is true therefore, that two-thirds of patients reported that they had not been offered the chance of participating in a trial, and more than half of those would have liked that chance, and we agree that increasing access to research across the country is an important goal.

To put this in context, participation in clinical cancer research in England has increased more than 5-fold since 2001. Last year, 49,135 cancer patients in England participated in research studies, representing 21.2% of the number of new cancer diagnoses. Over a third of those patients – 17,847 – took part in randomised trials, the most demanding type of research with the best chance of changing clinical practice. In the same year, a further 34,497 people without cancer took part in trials of cancer screening or prevention. For international comparison, no other developed country outside the UK – including the USA, Canada and mainland Europe – is known to include more than 5% of cancer patients in research. The UK achievement is hugely admired and envied around the world, and other countries are now seeking to reproduce the NCRN model.

We know that further improvement is possible. In England, the average rate of patient participation is 21%, but it varies geographically between 10% and 50%. And in the patient survey, the proportion of patients reporting being offered research was 33% overall but in some Trusts reached 60%. So bringing the less active regions up to the performance of the best is an important goal.

However, we must be realistic. Cancer is not a single disease but several hundred, and for research to be worthwhile and ethical it must address well-defined questions within specific populations of cancer patients. It must also gain ethical and regulatory approval at the institution where patients will be approached and treated. Our national portfolio currently has over 750 separate studies open and recruiting patients. This is a huge achievement involving coordination of government, scientists, universities, industry, charities, hospitals and of course patients. It is realistic to aim to increase the average performance to over 50% patients offered a trial and over 30% participating. But 100% is not realistic, since even with unlimited resource we cannot expect there to be a trial open at every point in time for every patient with every type of cancer in every NHS institution.

Patient and public involvement has been a crucial part of the approach of NCRN to achieving its 5-fold increase in research participation. We would highlight the report of our Consumer Liaison Group [Action on Access](#) report. This recommends, as part of the Patient Choice agenda, ensuring that eligible patients are told about trials at the same time as standard treatment options, even when a hospital is not running that particular trial, since many patients are prepared to travel. May we also draw attention to the current NIHR [OK to Ask](#) campaign, which aims to empower both patients and medical staff to raise the subject of research.