



## ACTION ON ACCESS:

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Widening patient participation in clinical trials



**National Institute for  
Health Research**



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The report is published by the NCRI Consumer Liaison Group, whose remit is to bring the patient voice to cancer research, working in partnership with researchers, clinicians and the NHS with the aim of improving patient outcomes through clinical research.

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***The editorial team thanks all the expert patients and trial-friendly clinicians who engaged in this exercise with such generosity and creativity.***

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# FOREWORD

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This report is the outcome of a two-year conversation between cancer patients, carers, clinicians, and researchers. We thank GlaxoSmithKline, who kindly sponsored our meetings by providing venues and paying expenses. The recommendations are those of the participants alone.

As a cancer patient myself, I have spent 12 years volunteering to sit on committees and working groups, helping to produce greater patient benefit from cancer research. I have seen increases both in the number of cancer clinical trials and in the range of cancers included; and reductions in the time it takes to open trials, and in the time it takes for their findings to be translated into improved outcomes for us patients.

I have taken part in clinical trials, and my attitude towards participation has changed. I started out as a very passive recipient of treatment with a vague feeling that taking part in research might help me, and would definitely help fellow patients in the future.

First time around, my access to trials depended on someone else. When I was diagnosed with my second cancer, I had become an information-seeker and asked, 'If there are trials, I want to be on one.'

Why do I still want access to trials? I want to help other people, of course, but there are selfish motives too. I want to have the best possible treatment, and also the best possible monitoring, checking and observation, things that I regard as being integral to best possible care.

I have so far survived two cancers. I have had the best treatments available, based on evidence provided by patients who have participated in trials in the past. I have been both lucky and privileged to add my own evidence for future patient treatment.

But participating in research should not be a question of luck or privilege. Cancer services and outcomes vary across our nation, for a variety of reasons. Access to clinical trials can vary even more widely. This report calls for Action on Access, to redress some of those inequalities; to create an NHS environment where patients are given information; and every eligible patient is given the opportunity to participate in research.

The report suggests actions that commissioners, chief executives and others can take. There is action that we patients and carers can take too. We can continue to ask about research at every step of our cancer journeys. We can help shape research as part of the NIHR's Patient and Public Involvement programme. We can make sure that others heed our call to action.

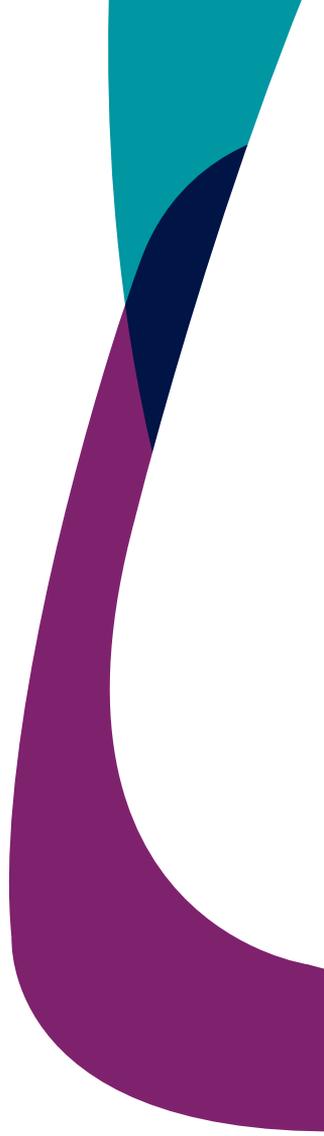
So please read the report – and then let's see some Action on Access!



**Richard Stephens**  
Chair NCRI Consumer Liaison Group



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# EXECUTIVE SUMMARY

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The past decade has seen a fivefold increase in recruitment to clinical studies and UK patient participation in clinical research is the highest in the developed world. In 2011-2012, there were a total 97,089 clinical trial participants. However, there is still much to do, both to increase awareness of and accessibility

to research and for it to become normal practice for people affected by cancer to be told about trials in discussion of their treatment. The National Cancer Patient Experience Survey results show that 95% of people with cancer who were given the opportunity to take part in research said they were glad to have been asked.<sup>1</sup>



## 1. OPENING UP THE HEALTH SERVICE CULTURE SURROUNDING CLINICAL RESEARCH

- The NHS offers a proven, world class, research environment.
- Commissioners are charged with a new commitment to promote research. However, the health service's corporate

and cultural attitudes to clinical research remain overly cautious in practice. NHS providers and commissioners need to take greater responsibility for building a culture of openness and action.

- Every cancer patient should have the right to be informed about relevant clinical research.

- This requires trial-friendly clinicians whose practice includes routinely talking with patients about clinical trials for which they are eligible.

## 2. INCREASING AWARENESS OF CLINICAL RESEARCH

- Many patients do not know that they may be able to enter a clinical trial. Those who do still find it difficult to access detailed up-to-date information.
- Information about clinical trials should be clear and easy to understand and no more than 'one click' away. It should be available in different media and throughout hospitals and in every other healthcare setting including GP clinics and surgeries.
- Innovation is needed to build research awareness across a local health economy as well as continued improvements nationally.

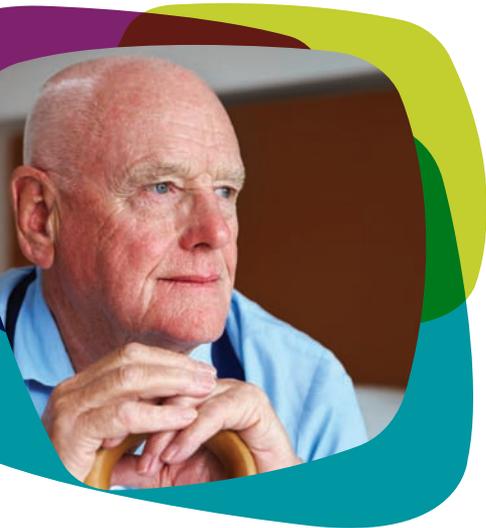
## 3. SUPPORTING CLINICIANS TO BECOME TRIAL-FRIENDLY AND TRIAL-WISE

- All cancer clinicians need to have the same 'trial awareness' as the most trial-active centres.
- Knowledge about clinical trials should be an integral part of health professionals' training and continuing professional education.

- Best practice is to enable patient access to clinical trials as a core multidisciplinary team (MDT) responsibility and consider systematically patients who relapse and/or have metastatic disease.
- Patient data should record patients' potential eligibility for clinical trials and that they have been informed about relevant research.
- NICE quality standards for cancer should include access to suitable clinical trials; peer review measures should include access; and health care providers should publish their research-friendly credentials in their annual Quality Accounts.

## 4. MAKING IT ROUTINE PRACTICE TO DISCUSS TRIAL SUITABILITY

- Best practice needs to spread so that consideration of clinical trial suitability becomes a standard part of all care pathways and is routinely discussed at MDTs. Every MDT should designate a member to act as the 'clinical trials champion'.
- At the point of referral for diagnostic tests, there should be information and a consent form for donation of tissue or other samples to be banked for current and future research.
- Clinicians with patients who may be suitable for a trial at another hospital



should consult, inform and refer patients. This is specifically important for rare cancers.

- Health professionals should have easy access to training and peer support about how to discuss relevant research with patients.

#### 5. IMPROVING EQUITY OF ACCESS TO CLINICAL RESEARCH

- People from some parts of the country as well as older people, people with rarer diseases and people from BME groups tend to be less well represented in clinical trials. An electronic patient tracking tool could be used to audit access to clinical trials.

- Principal investigators and participating centres need to consider how messages are communicated to people whose first language is not English and those with lower levels of literacy.
- Patients should be supported to attend another cancer centre beyond their catchment area, if an appropriate trial is unavailable locally. Groups of providers could work together to deliver access to studies by including smaller centres; underpinned by new technology and innovative ways of working.
- Research funders should work with principal investigators of large scale clinical trials to assess whether or not the demographics of trial participation reflects the wider population of people affected by cancer.

#### 6. CONCLUSIONS: CALL TO ACTION

The report lists on page 28 the top 3 actions for commissioners, chief executives, lead clinicians and research bodies.



# FIVE AREAS FOR ACTION

Government, research bodies, charities and consumer groups have and continue to work together to develop and maintain an effective framework in which research can flourish and patients have ready access to clinical trials. Put simply, strong participation in clinical trials is associated

with a fivefold increase in participation between 2001 and 2012. Prior to the formation of the NCRN, it is estimated that 3.75% of incident cancer cases were recruited to clinical trials; by 2011-2012, that figure had increased to 22.8%.

In 2011 the Government announced in its Plan for Growth<sup>4</sup> how a new health research regulatory agency would streamline regulation and improve the cost effectiveness of clinical trials. Taken together the Life Sciences Strategy,<sup>5</sup> the NHS Innovation Strategy, and the In-novation and Research Strategy<sup>6,7,8</sup> and the Plan for Growth itself signaled a sea-change. The creation of the new Health Research Authority opens up the potential for substantial and fast-paced reform.

Research duties were included in the Health and Social Care Act. This is an important first step but one which will not on its own change NHS culture. We need to continue

to press to create the right policy environment. For example, forthcoming consultation on the NHS Constitution will include an amendment so that NHS data can be used for approved research, unless the patient chooses to opt out, and patients can be approached about research studies for which they may be eligible.<sup>9</sup>

with better patient outcomes.<sup>2</sup> The UK's global share of patients in industry clinical trials has been declining,<sup>3</sup> although in cancer the UK-wide National Cancer Research Network (NCRN) has built the infrastructure necessary and achieved a



But we also need to take action in our clinics and our communities, building on the best of current practice, so that the changes heralded by the policy shifts can be introduced and sustained.

The DH report *Innovation Health and Wealth*<sup>10</sup> articulates for the NHS the goal that every willing patient should be able to take part in research. It urges the NHS to explain the benefits of clinical trial participation both to patients and to society at large. Despite weak levels of public understanding of medical research, there is a widespread view that the NHS should be undertaking medical research and offering opportunities for participation in research. Consumers involved in research argue that relevant research should be considered for each patient during discussion about treatment options and that this discussion should not be limited to centres running cancer trials. At the same time, for many cancer patients, care is likely to proceed along well established treatment pathways and trial participation will neither be directly relevant nor possible. For people with cancer who may be eligible to take part in research, discussion about the clinical trial should become the norm.

For the first time, the National Cancer Patient Experience Survey has asked people with cancer about their experience of being asked about participation in research. One third of patients said that taking part in research had been

discussed with them; 67% said it had not and this varied significantly both by cancer type and individual trust. Of those patients who had research discussed with them, 95% said they were glad to have been asked. The proportion of patients saying that taking part in cancer research was discussed with them varies by trust from 14% to 62%.<sup>11</sup>

Although the report focusses mostly on the hospital treatment of patients, there are other cancer trials, notably screening trials, that involve people without any diagnosis and which require better primary care engagement. More broadly, increased primary care engagement in trial-awareness is an important way to improve public understanding of medical research.

The recommendations in this report are a call to 'Action on Access.' We have identified five major areas for action. In each area, we explore what needs to be done and list a number of practical and deliverable ways in which commissioners, health care providers and clinicians can take action to achieve this goal; and suggest 'enabling actions' that could be introduced at national or regional level to facilitate local changes.

### *What needs to be done?*

The health service's corporate and cultural attitudes to clinical research remain cautious and reserved. Some health professionals, especially those working outside active research hospitals, can be overly protective about 'their' patients. Some might feel it 'intrusive' or even 'cruel' to invite a patient with cancer, especially terminal or very advanced cancer, to join a clinical trial.

Yet expert cancer patients say that they would like to see a shift in the culture so that there really is 'no decision about me, without me'. They feel strongly that every potentially eligible patient should have the right to be informed about clinical trials and that ethical practice includes telling patients about trials which they might wish to enter.

This can be achieved only through a new culture of openness and action.

President of the Royal Society Sir Paul Nurse, who won the Nobel Prize for cancer research and who is currently setting up a new collaborative research institute argues that openness and transparency in science challenges the NHS. He says that datasets of information should be shared to make medical research possible and that more of us need to participate in clinical trials to test the effectiveness of new treatments.<sup>12</sup>

Expert services users and trial-friendly clinicians are also calling for a cultural shift. They see patient expectation as one of the most important drivers for change. The National Cancer Patient Experience Survey for England demonstrates patient support for research and will run again in 2012-13 making it possible to track progress.

Public education and changes in professional practice are the keys to embedding research in the culture of the NHS. The core message should be that if you have cancer your health care team is likely to talk to you about trial participation. We need to ensure that all cancer patients receive appropriate information about research and, where appropriate, about clinical trials – with support being offered both to active information-seekers and those who are not internet savvy.

There may also be a case for re-examining the language that is used.

The message from active service users involved in the governance of research is that words such as 'trial' and 'experiment' are less attractive than the term 'study,' although in this report we have continued to use "trial" for ease of reference.

### *How to do it*

- The leaders of cancer services and the wider cancer community including involved patients should work together



to build a more open culture about clinical research, signaling their intention to respond to policies aimed at widening opportunities to participate.

- Commissioners are charged by legislation to promote innovation, research and the use of research.<sup>13</sup> Commissioners should work with individual providers and the wider health economy to ensure research-friendly healthcare using the commissioning levers available to Clinical Commissioning Groups.

- Commissioners, patient groups, site specific cancer groups and multidisciplinary teams in England, should look at their National Cancer Patient Experience Survey results, to see whether there is open discussion with cancer patients about relevant research. Results from individual Trusts show that there are significant variations in the proportion of patients saying taking part in cancer research was discussed with them. Scores in Trusts ranged from 14%, as the lowest score, to 62% as the highest Trust score.<sup>14</sup>

- Commissioners and service providers should encourage positive communication messages about clinical research, focusing on the benefits and potential advantages for healthcare generally. Public and professional education needs to take place within the local health economy - at the pharmacy, practice and clinic – as well as through NHS websites and other media.
- Commissioners, service providers and patient groups should consider running local events to mark International Clinical Trials Day<sup>15</sup> and in this way will also help to raise general community awareness before many people have a diagnosis.
- Commissioners, service providers and research bodies should appoint patient champions for research.

### *Enabling action*

- Scotland's Get Randomised media campaign helped increase awareness and receptiveness to clinical trials. The 'halo' effect was still evident six months after the campaign and it also helped change the attitudes of health professionals. For more information: <http://getrandomised.org/home.htm>
- The new Health Research Authority will signal the culture change necessary in hospital trust R&D departments.
- The NHS Constitution should champion the value of patient access to research and specifically should include an amendment so that NHS data can be used for approved research, unless the patient chooses to opt out.



*What needs to be done?*

We need to raise patient awareness about clinical research so that this then starts to drive change. Many patients and their families do not know about eligibility for clinical trials and those who do still find it difficult to access sufficiently detailed up-to-date information about clinical research. Participation in clinical trials should be seen as a normal part of healthcare. This requires easier access to relevant information and direct communication between clinicians and patients.

*How to do it*

- Information about clinical trials should be clear and easy to understand. Information, including posters, and newer media, for example, DVDs and interactive kiosks. Information should be available throughout hospitals and in every department, including radiology, for example.
- Information about clinical trials should be available in every healthcare setting, so that the topic becomes a normal and expected part of health care. For example, is information about research being embedded in ‘information prescriptions?’
- Advertising for trial recruitment should be displayed in every healthcare setting and on intranet sites. Short video clips could be made available through online sites such as YouTube.
- Signpost to regularly updated databases to make people more aware of what trials are available.
- Information about clinical studies should be in Plain English and patients should be involved in writing and reviewing relevant information.
- Clinicians should raise the topic of relevant research at the initial consultation, so that the patient and family are prepared when the topic comes up later.
- All direct written communication to the patient should include relevant information about participation in clinical trials.
- Think innovatively. GP practices might wish to consider the possibility of linking up with clinical trial centres to advertise trials being performed by the partnering organisation. Trial recruitment could be publicised through patient groups, charities and patient support group websites.

*Enabling action*

- Research funders should ask how people will be made aware of and be able to gain access to the trial, as part of the funding application process.

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- The UK Clinical Trials Gateway now provides a ‘one-stop shop’ for information about trials at <http://www.ukctg.nihr.ac.uk/default.aspx>. The National Research Ethics Service (NRES) publishes lay summaries of approved studies at <http://www.nres.nhs.uk/researchsummaries/>. CR-UK’s CancerHelp UK clinical trials database offers user-friendly lay summaries of UK cancer trials at <http://cancerhelp.cancerresearchuk.org/trials/>.
  - Expert service users and trial-friendly clinicians are calling for ‘one click’<sup>16</sup> access and user-tested lay summaries which are done once and shared. To be effective, databases need to start from the patient’s perspective and indicate studies for which they might be eligible. They should avoid acronyms and medical jargon and present information in a simple format, with studies having a single identifying

name rather than being referenced as a name in one format and a number in others. (Although until that time, both the name and number should always be indicated, so that searchers can find what they are looking for.)

- Because of the difficulties associated with one comprehensive database, some expert service users and trial-friendly clinicians suggest a ‘bottom-up’ approach, with trial updates being directly uploaded by Clinical Trials Units that have the information to hand – along the lines of a Wikipedia site for clinical trials.
- Cancer charities are grappling with these issues and new partnerships are emerging with the potential to link individual patient data with clinical trials - for example, collaboration between the charity Brainstrust and the National Brain Tumour Registry.<sup>17</sup>



*What needs to be done?*

The National Cancer Research Network has provided UK wide leadership and built the infrastructure necessary to demonstrate that the UK is a world class trials centre. This has resulted in a five-fold increase in access to clinical trials and studies over the 12 years that NCRN has operated. The core principle is of embedding research in the cancer care environment, by providing dedicated research staff.

The challenge now is to spread trial-friendly and trial-wise practice further. All cancer clinicians, particularly cancer nurse specialists, need to have 'trial awareness' regardless of whether or not they are participating directly in research. Clinicians who are trial active are very aware of the trials they lead but are not always fully aware of the national breadth of trial availability.

Research should not be seen as an 'add-on' activity or as something that adds to administrative burdens. There needs to be a competitive advantage for hospitals that create research-friendly environments, so that this becomes part of what excellence in healthcare is about. The number of cancer centres offering access to clinical trials needs to be widened. Through its annual review of each of the 32 Local Cancer Research Networks, NCRN is able to map which hospitals are active in research and,

working locally, to encourage expansion. For industry-sponsored clinical trials, through its 'green shoots initiative',<sup>18</sup> the NCRN has already shown that greater involvement can be achieved. This needs to be built upon, paying particular attention to supporting patients who wish to participate in clinical trials that are not being offered by the centre that they have been attending.

*How to do it*

- Knowledge about clinical trials and how to access in-depth information about research should be an integral part of health professionals' training and continuing professional education.
- All multidisciplinary team (MDT) lead clinicians should have 'trial awareness.' Clinical nurse specialists should be aware of what is available for which group of patients - for example, what is available for women with stage 4 ovarian cancer of certain pathology.
- The National Cancer Research Institute Clinical Studies Groups have led an initiative to produce trial portfolio maps,<sup>19</sup> which are flow-charts of clinical studies currently available. These are available to all on the NCRI website [www.ncri.org](http://www.ncri.org) and NCRN <http://www.ncrn.org>. They can be made locally relevant and are continuously updated.
- Considering patient access to clinical

trials should be one of the MDT's core responsibilities and participation should be discussed at the multidisciplinary team meeting (MDM). There should be systematic consideration of trial eligibility of patients with relapsing/metastatic disease. Although these patients may not be routinely discussed at MDM, at the very least the team should discuss trial possibilities for first-time relapsing patients.

- MDTs should record patients' eligibility for clinical trials and whether or not the patient chose to take part in the research. In time this could become part of the national cancer data set.
- Hospitals should include information about access to relevant research in their annual Quality Accounts so patients can see at a glance whether their provider is research-friendly.

### *Enabling action*

- The National Institute for Health Research is best placed to lead work on trial awareness and of their importance in enabling best future care. NCRN already regularly updates information on open studies, linked to the portfolio maps and such information could be made easier to access.
- To make it possible for patients to participate actively in their own care and for clinicians to advise and support

them, a smart-phone 'App' should be developed so that patients and clinicians alike can be automatically advised of new studies in their specialist treatment area.



- Research bodies could consider how best to involve more centres and smaller centres in clinical trials; and ensure the recognition of everyone who takes part in the group responsible for a clinical trial - for example, by listing all names at the end of the study report.
- NICE quality standards for cancer should include access to relevant clinical studies.

### *What needs to be done?*

The expert service users and trial-friendly clinicians whose views fed into 'Action on Access' articulated a straightforward aim: that everyone affected by cancer should hear about relevant research from a healthcare professional. This requires a shift in culture and MDT action and requires that research considerations should be an integral part of the care pathway. Patients should be made aware of relevant research – and not just about clinical studies - from the first point of presentation, whatever their route to diagnosis, and throughout their care.

Both the treating clinician and the wider MDT have real potential to offer greater participation in clinical studies. It should be seen as standard practice that MDT members are involved in recruiting people to clinical trials. Clinicians should always be thinking: which trial might this patient be suitable for?

### *How to do it*

- Every MDT should know of all current studies in its specialist treatment area and where they are available – not just the studies they are running themselves. This is especially important in rarer cancers but as a minimum standard every clinician should understand the range of clinical trials applicable to the patients they care for and treat.
- Opportunities for patient-to-patient information-sharing about relevant research should be included in all stages of the care pathway. This should include not only information on clinical studies but relevant research on quality of life, patient-related outcomes, diet and long-term effects of treatment. The information provided will need to change and adapt over the course of time to reflect the patient's individual situation.
- A member of the MDT – for instance, the research nurse or clinical nurse specialist - should be designated to act as the 'clinical trials champion', responsible for providing patients with information about appropriate trials, being their point of contact and representing the patient at meetings.
- At the point of referral to diagnostic tests, there should be information and a consent form for donation of tissue or other samples to be banked for current and future research, if that is the patient's wish. It is important that this tissue is linked to outcomes data. It would also make a big difference if it were possible to give generic consent rather than consent only for a specific use of the tissue, which is mostly the situation at present, although some centres are beginning to introduce generic consent. Consent should be enduring for NRES-approved studies,

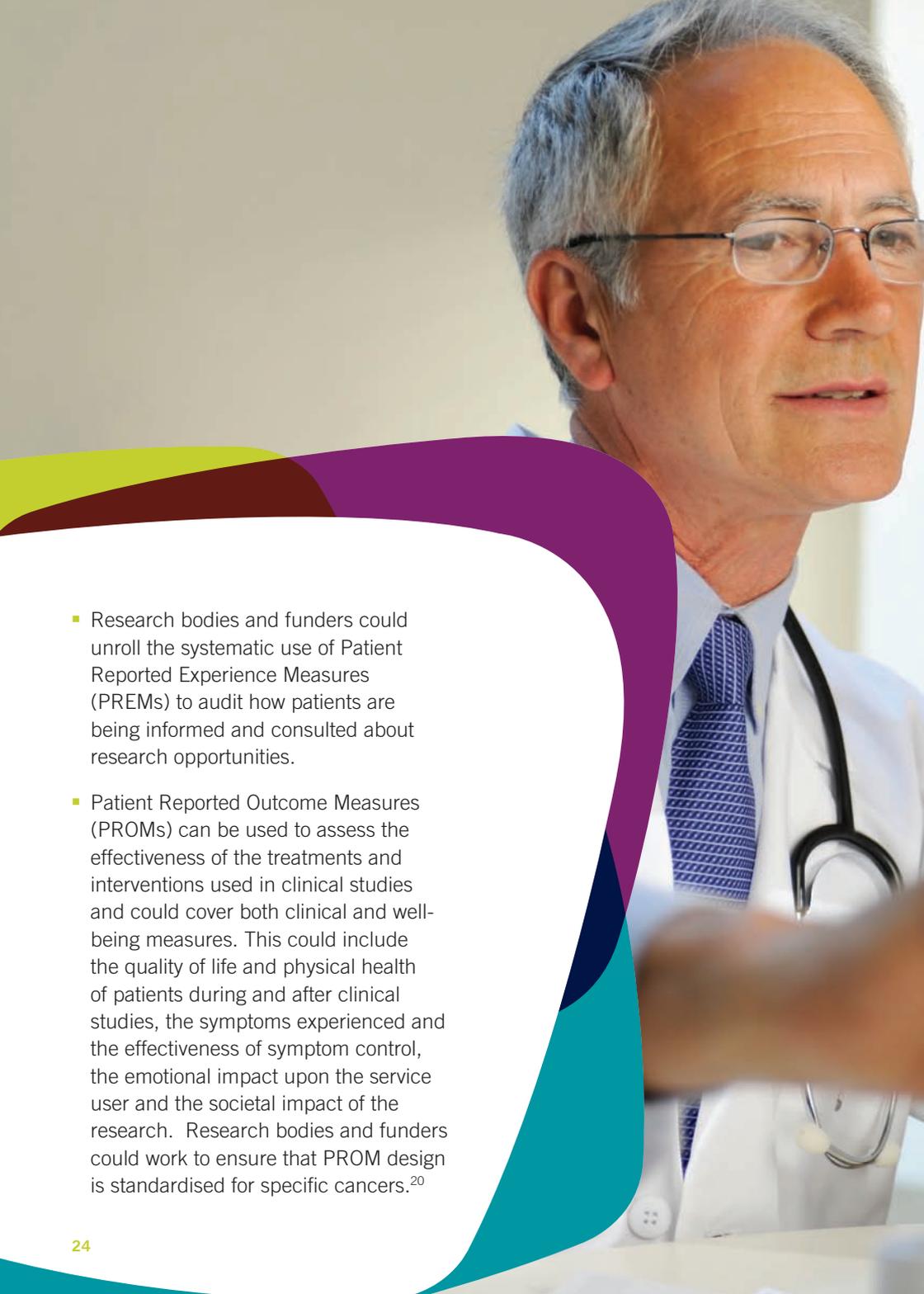
with tissue and data considered as a 'gift' to research, avoiding the need to return to donors for new consent.

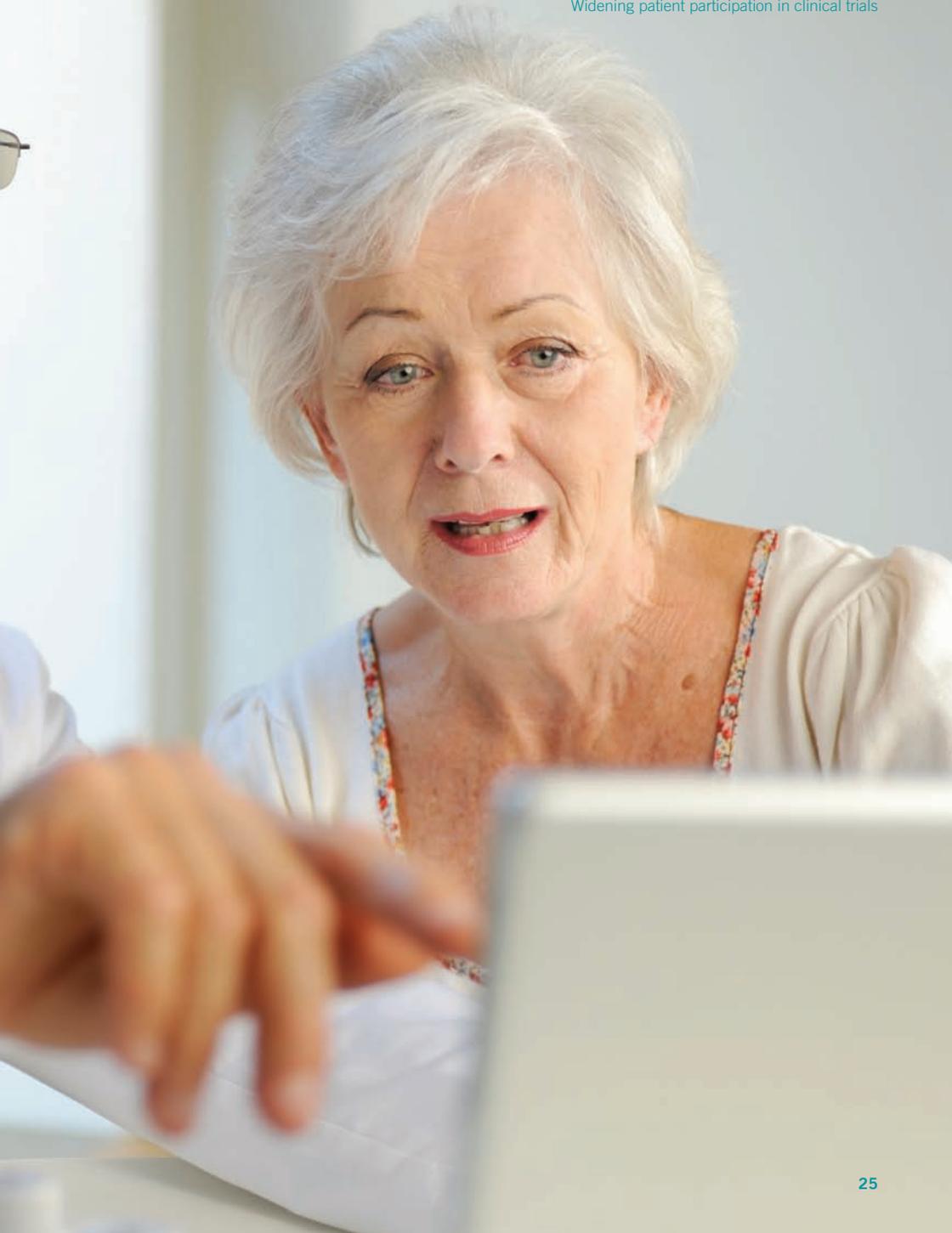
- Everyone involved with a cancer clinic should know about the trials being offered and inform patients that at some stage of the pathway someone will discuss this with them. It might also be possible to provide generic information about clinical studies when giving people their scan, biopsy or other test results – although it is important not to raise false hopes.
- Consideration of patient eligibility for clinical studies should be routinely discussed at MDMs, whether or not the hospital is conducting those studies.
- Patients could be allowed to have copies of MDT recommendations or be involved in the discussions so they know whether their suitability for a study is being considered. They should also have easy access to proposed clinical trial protocols. When signing consent forms for treatment, the patient could also acknowledge that research has been discussed.
- Every patient taking part in a clinical trial should have a named contact to support them through their time on the trial and to advise them on any future research that could be relevant to them.
- Every patient should receive a simple

information sheet – that patients have been involved in producing – which explains what a clinical trial is, before they join a condition-specific trial. This should include a web address to enable patients to access an up-to-date source of information about relevant studies. The ground rules for stopping any trial should be clear from the outset. If, for example, not enough patients have been recruited this must be communicated to other trial participants.

#### *Enabling action*

- Research and professional bodies should offer easy access to training about how to discuss medical research with patients. This would enable clinicians to deliver information in the context of the patient's needs and wishes, allowing them to make an informed choice when they feel ready to do so. At Tees, Esk and Wear Valley NHS Foundation Trust any clinician, however senior, who is likely to come into contact with trial participants must undertake a good clinical practice course.
- To spread best practice and reduce unnecessary barriers, there should be standardisation and cross recognition of good clinical practice courses. The Medicines and Healthcare Regulatory Agency could take the lead in introducing this improvement.

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- Research bodies and funders could unroll the systematic use of Patient Reported Experience Measures (PREMs) to audit how patients are being informed and consulted about research opportunities.
  - Patient Reported Outcome Measures (PROMs) can be used to assess the effectiveness of the treatments and interventions used in clinical studies and could cover both clinical and well-being measures. This could include the quality of life and physical health of patients during and after clinical studies, the symptoms experienced and the effectiveness of symptom control, the emotional impact upon the service user and the societal impact of the research. Research bodies and funders could work to ensure that PROM design is standardised for specific cancers.<sup>20</sup>



## 5.

### *What needs to be done?*

Cancer patients' access to clinical trials varies and is dependent on a number of extraneous factors. The main obstacle is geographical location, meaning those who live some distance from study centres are less likely to participate. Older people, people with rarer diseases and people from BME groups also tend to be less well represented.<sup>21</sup> In addition people tend not to be referred to hospitals outside their own catchment area, which may lead to low participation in some areas. In a recent study, respondents cited lack of clinical trial data supporting treatment choices as the second highest-ranking challenge of treating older people.<sup>22</sup>

The needs of people with less common cancers can be overlooked in clinical trials. Patient groups say that people with less common cancers find themselves being shoehorned into a one-size-fits-all system.

Every eligible and willing cancer patient should be given the chance to participate in a clinical trial.

### *How to do it*

- Principal investigators and participating centres need to consider how messages are communicated to people whose first language is not English and those with lower levels of literacy.

- Make local arrangements so that patients are given the opportunity to attend another cancer centre beyond their catchment area if an appropriate local trial is not available; and for travel



expenses to be paid. This would need the active support of commissioners and excellent communication between the principal investigator and the referring hospital. It would also require

special protocols to cover eventualities such as toxicities: would the patient be looked after in their own geographical area or admitted into the hospital hosting the trial, for example?

- Cancer patients should be given the chance to participate in clinical research wherever they are being treated. Groups of providers could work together by including small centres in order to deliver wider access to studies. Collaborations can be underpinned by new technology and innovative ways of working including mobile study units.

- Electronic patient tracking tools could audit which cancer patients are getting access to trials. Some clinicians are already using this in the form of electronic patient pathway management.

Increasingly the software supporting cancer dataset collection will make it possible to record all trial-relevant data.

### *Enabling action*

- Research funders could work with patient groups to review investment,

infrastructure and regulation in order to ensure small patient populations receive appropriate treatment. Expert patients and trial-friendly clinicians argue for dedicated centres of excellence for rarer cancers research and, in particular, for international rarer cancer research collaboratives. See, for example, what is being achieved through the International Rarer Cancers Initiative at <http://science.cancerresearchuk.org/research/how-we-deliver-our-research/others/by-programme/international-rare-cancers-initiative/>

- The Department of Health's National Cancer Equality Initiative has recommended that the National Institute of Health Research Cancer Research Network considers working with the principal investigators of large scale clinical trials to assess whether or not the demographics of trial participation reflects the wider population of people affected by cancer.<sup>23</sup>
- Commissioners and providers should use patient experience measures to track progress in including patients in discussion about research and in England can use current National Cancer Patient Experience Survey data as the baseline.<sup>24</sup>

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# CONCLUSION: CALL TO ACTION

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The aim of this report is to build on success to date by further stimulating action on the ground. It contains detailed suggestions for action. To get started, there are three steps which commissioners, chief executives, lead clinicians and researchers could each take:

## *Commissioners*

- 1 Encourage work across the local health economy, to build a more open research culture where information about clinical studies is visible and widespread.
- 2 Commission research friendly healthcare, by making it explicit in

contracts that providers are expected to offer patients participation in research; and follow up by including reporting on access to research in your monitoring and review.

- 3 Make local arrangements for patients to attend another cancer centre, if an appropriate local trial is unavailable. This will require special protocols.

## *Chief executives*

- 1 Walk your environment: are posters and other media making it immediately clear that yours is a research-friendly environment?

- 2 Include patient access to participation in clinical research in your annual Quality Account.

- 3 Appoint a research champion to the board with responsibility for patient access as well as quality.

## *Lead clinicians*

- 1 Make sure each MDT knows of relevant clinical studies for which patients may be eligible, not just the studies available onsite, so that every patient can be informed about research relevant to them.



- 2 Discuss every patient's potential suitability for participation in research at the multidisciplinary team meeting (MDM).
- 3 Record patient eligibility for clinical trials and whether or not the patient chose to take part in the research.

### *Research bodies*

- 1 Consider how best to spread trial awareness to all lead clinicians and not just those already undertaking research, so that every cancer patient can expect to be told about studies for which they may be eligible.
- 2 Champion the standardisation and cross recognition of good clinical practice courses, so that it becomes easier for every trust to insist that all clinical staff, however senior, attend one.
- 3 Prioritise the systematic use of Patient Reported Experience Measures to audit how patients are being informed of and consulted about research opportunities.

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*The actions set out in this report were generated by expert patients, Commissioners, providers and research bodies who embed an active patient voice within their strategic and decision-making functions are best placed to widen patient participation in clinical trials. Working together, we can embed research in clinical services, ensuring that we have - and act upon - evidence to improve outcomes and the quality of care.*

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ACTION ON ACCESS:  
Widening patient participation in clinical trials

