Project Description

Reorganisation and improvements within the National Health Service are encouraging a much clearer focus on research and on the involvement of patients in research studies and clinical trials. The NIHR Clinical Research Networks have been working hand in glove with these changes to promote patient access to research across the length and breadth of England. While this awareness raising has been encouraging, the changes in the commissioning structure of service provision present particular opportunities to work closely with the organisations responsible for commissioning health services.

The Dementias and Neurodegenerative Diseases Research Network (DeNDRoN) piloted work in the south west of England to collaborate with the Clinical Commissioning Groups to ensure that appropriate wording was added to their invitations to tender and contracts documentation. This wording was designed to ensure that giving patients access to research is considered equally with other aspects of patient care. There was also an emphasis on ensuring that it was prominently mentioned to ensure that the requirements as set out in the NHS Mandate to ensure the new commissioning system promotes and supporting participation by NHS organisations and NHS patients in research is fulfilled.

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The National Health Service (NHS) is undergoing a period of enormous change as a wholesale restructure is implemented and sweeping reforms are adopted. Part of this brave new world, captured in the Health and Social Care Act published in 2012, is to place an increased emphasis on research and the use of research-based evidence in treatment choices. In fact, the Act places a statutory duty on the NHS Commissioning Board (NHSCB) and Clinical Commissioning Groups (CCGs) to promote research, in the exercise of their functions, on matters relevant to the health service and to ensure that the evidence obtained from this research is used across the health service. This research keystone has been re-iterated in the Government’s mandate to the NHSCB, the NHS Operating Framework and the NHS Outcomes Framework.

Such diktats are immensely important as the NIHR Clinical Research Networks strive to embed a culture of research and to ensure that everyone in England has knowledge of and access to leading edge research studies and clinical trials. However, whilst such high level decrees are essential in encouraging new ways of thinking at a national level, it is often the change that is implemented at a local level that has the biggest impact on people on a day-to-day basis.

The challenge is supporting the new commissioners to use invitations to tender (ITTs) and contracts appropriately to increase the opportunity for patients to participate in research particularly when the NHS is in a time of transition. Putting the requirements into contracts, and supporting organisations to deliver with the NHCR CRN is essential for all research. However, the Dementia and Neurodegenerative Diseases Research Network (DeNDRoN) decided to look at this as it relates to dementia on a regional level, focusing on the south west of England and using the high-profile of dementia to create a starting point.

While the ultimate aim is to foster a standard contract across all NHS funded services so that no clinical service could be commissioned without optimising patient participation in research, the DeNDRoN initiative spearheaded a project to encourage the addition of appropriate and standardised wording into ITTs and contracts relating to dementia services. The project was an ambitious one that, by starting locally, was directed at catalysing a sea change in dementia services healthcare commissioning nationally which could then be adapted to all clinical areas.

**Project Design and Implementation**

In order to ‘think global, act local’, the team responsible for delivering this project set some impressive a priori aims. This spectrum ranged from fashioning and promoting specific wording that could be used as boilerplate text in standard service specifications to gaining endorsement from senior NHS or Department of Health personnel with a view to widespread adoption.

Working across a diverse number of stakeholders, the team successfully managed to create wording that was largely accepted. CCGs will wish to consider the need, when procuring services, and monitoring and renewing contracts, to ensure that their providers have processes in place to facilitate recruitment of patients into research studies.

This wording was included in the ‘Information to support applicant CCGs in making declarations of compliance’ and was also posted on the NHSCB website.

Dr Peter Brindle, the project lead in the south west, explains that the wording needed to capture the essence of research in its broadest sense. ‘It is vital that it is understood that research covers a very broad gamut of possibilities. Everything from questionnaires investigating the components of care for people with dementia to possible new curative molecules for treating dementia is covered by the term research. When it comes to raising awareness, having this phrase incorporated in CCG authorisation documentation and on the NHSCB website is an important move in the right direction.

“The move towards any qualified providers adds urgency to the project. Most new providers will not have a history of research and will not think to make their service research-friendly unless requested to do so by the commissioners. If we are not careful, we could be faced with large sections of the population being denied the chance to take part in research.”

**Challenges and Learning Points**

Implementation of the Health and Social Care Act is a huge task and elements of such a huge reform need to be prioritised. One of the biggest challenges to the project team was the recognition that the research angle was not given the urgency that other vital issues like CCG authorisation and recruitment into new posts were.

Adam Smith, programme manager with DeNDRoN, recognises that this project is still in its infancy. Progress has not been linear due to the changing policy context. So the benefits have not yet filtered down to increasing the numbers of patients into studies. But it is important to remember that this project was set up with the historical backdrop of absolutely no engagement with commissioners regarding research.

Going forward, it is recognised that this small step in the right direction could have profound, long-lasting effects in the future. Discussions are on-going with senior members of the NHSCB regarding wider and stronger avenues of endorsement and practical change within the NHS.

Producing a service specification, which can be adopted by other CCGs creates a firm foundation for the next commissioning year, and DeNDRoN can now focus on further engagement with commissioners, to help promote delivery. Adam Smith, programme manager for DeNDRoN concludes “The NIHR Clinical Research Network’s work can also be really helpful in driving this agenda, publishing data on how Trusts have performed on research has really driven some organisations to looking at how they work with the research community, and using all the tools in our box will help from commissioning through to one-to-one engagement.”

**Impact of the Project**

Whilst there remains some disappointment at not being able to gain a firmer foothold within the NHS Standard Contract, the team has benefitted from garnering endorsements at both local and national levels.

Emma Moody, Bristol CCG Programme Manager for Older People, recognises the impact that the project has had. “While redesigning our dementia services and drafting our service specification, Bristol CCG were very keen to address the Prime Minister’s challenge to leading edge research studies and clinical trials. However, whilst such high level decrees are essential in encouraging new ways of thinking at a national level, it is often the change that is implemented at a local level that has the biggest impact on people on a day-to-day basis.

The team has benefitted from garnering endorsements at both local and national levels. Emma Moody, Bristol CCG Programme Manager for Older People, recognises the impact that the project has had. “While redesigning our dementia services and drafting our service specification, Bristol CCG were very keen to address the Prime Minister’s challenge to improving the opportunities for patients to take part in research studies. This south west DeNDRoN project gave us the practical tools to include in our service specification without which we would have to have started from scratch, on the background of limited expertise around research issues.”

She also recognises that the initial feedback that the project has received could have very substantial long-term repercussions in creating a culture in which giving patients access to research is a routine part of a service.

This is echoed by Adam Smith, DeNDRoN Programme Manager. He says “Working with CCGs and the NHSCB to help them deliver on their duty in the Health and Social Care Act to promote research, especially around the appropriate use of contracts, is absolutely crucial. In this respect, this project makes a very important contribution to turning the Act into action.”

In addition, research now features on the agenda of the south west Strategic Clinical Network for dementia with resulting actions to integrate research opportunities for patients with service redesign.
Tips

• Perseverance is essential. Recognise that, within the evolving nature of the NHS, project slippage can occur and that it is difficult to gauge realistic timelines for implementing change at the level of the CCGs.

• Appreciate the time involved in building a network of the individuals and groups around a single idea, and how these individuals have many other priorities and may have constantly changing roles.

• Work effectively with these networks on an ongoing basis to ensure that research remains on the agenda.

• Discuss documents and websites where research could be incorporated with these networks ensuring that the text is appropriate, succinct and informative.

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