

The AQUA-Trial

Diagnosing children who are showing some of the signs and symptoms associated with attention deficit/hyperactivity disorder (ADHD) can be a difficult task.

The AQUA-Trial

A new computerised assessment, called the QbTest, has been designed to try and improve the measurement of ADHD symptoms. This test objectively measures the core signs of ADHD (attention, impulsivity, activity) and produces a report graphing the child's performance. The aim of the AQUA-Trial by the Collaboration for Leadership in Applied Health Research and Care (CLAHRC) East Midlands was to see whether the QbTest can help clinicians assess whether a child has ADHD. The AQUA-Trial specifically wanted to see if the QbTest can reduce the time needed to confirm or exclude ADHD. The trial took place in child and adolescent mental health services and community paediatric settings across 10 sites in England.

Our Public Involvement Journeys

Charlotte Hall (Researcher) and Nikki Brown (Public Contributor)

Were you confident about including the public voice in your study and how did you feel it would help?

Charlotte: I had a negative view of public involvement and was not confident. My previous experience was not good, it was more a tick box exercise which I never felt benefited the study. 'Oh no, not public involvement!' was the general feeling at the start.

At the very start I wasn't convinced it would be helpful. As researchers we are generally driven to recruit into trials and get results for publication within a short time frame. Patient and public involvement takes time.

How did Nikki become involved?

Charlotte: I met Nikki, a parent of a young person with ADHD, through a research nurse helping with the study. I talked with her and realised how helpful she would be. She was great at getting her opinion and experience across and I could see she could help with recruitment. Often team meetings can be intimidating but she was confident enough to speak.

Nikki: I found out about the trial from the ADHD Nurse Practitioner who saw my daughter. She was working on the trial with Charlotte. I had also set up and was running a support group at my daughter's school for parents of special needs children.

When you were first introduced to the team – what did you feel you could bring?

Nikki: At the first meeting I sat and listened for the first hour – they probably thought 'she is not going to contribute anything' – but I used this time to gather information. Then I found my voice and questioned everything.

Charlotte: Nikki was confident in team meetings and passionate. The study was personal to her as she felt there was a lack of support for parents who had to do their own research to get and share reliable information.

What did you learn?

Nikki: I learnt about the trial and how it could help with diagnosis. Through the research and information from the team I gained confidence about the subject which I could share with others.

Charlotte: A lot, especially the importance of public involvement. It is worth the investment to listen and be prepared to act upon what they say, and it is not actually a large investment of time.

What difference did the involvement make to the research? How do you know?

Nikki: The timescale of diagnosis was added as an additional output measure and the protocol was rewritten on the basis and strength of what I said.

Charlotte: We got great data from interviews and there was an impact from having appropriate questions. Protocols changed and the forum meetings with all stakeholders were brought to life with Nikki's personal accounts. Clinicians and researchers often are immersed with the data rather than the experience and you can only hear part of the story not the whole journey.

What difference has this experience made to you?

Nikki: It is nice to be involved in something where you feel you are important and your voice counts. I am proud that my name is on a paper as an author and proud that I can help other parents in the same situation.

Charlotte: As a result, I believe we had a more successful trial with recruitment above target and fantastic retention. I am now a strong believer in public involvement. I am more confident going forward and more able to use it, I have built a great relationship with Nikki and am now able to help support others to do involvement. Nikki has also played a pivotal role in our new NIHR RfPB grant, taking a key role in informing the protocol - she is now an invaluable member of our team.

“I strongly believe that the relationship we had with Nikki, our clinicians and our industry partners (Qbtech) was a key factor in the success of the trial, we all worked together.” Charlotte

“Knowledge is power and if I can help my own daughter or other parents and children then it's worth being involved.” Nikki

About INVOLVE

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As a national advisory group our role is to bring together expertise, insight and experience in the field of public involvement in research, with the aim of advancing it as an essential part of the process by which research is identified, prioritised, designed, conducted and disseminated.

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