Ymchwil Iechyd a Gofal Cymru
Health and Care Research Wales

BRAIN
Repair & Intracranial Neurotherapeutics

sewtu
South East Wales Trials Unit
Uned Ymchwil De-ddwyrain Cymru

Ariennir gan Lywodraeth Cymru
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Getting ENGAGEd with research

Keeping active - we all know how important it is to our everyday health.

But it also has the potential to make a real difference to those living with Huntington's disease.

Huntington's disease is an inherited neurological disease, which over time results in progressive problems with movement, thinking and behaviour, and ultimately, difficulties in undertaking usual activities of daily living.

Although we know that keeping active can have real benefits, it has been difficult to develop an exercise programme which can be easily maintained, as the day-to-day realities of people living with Huntington's disease can make it challenging to complete.

Researchers at Cardiff University's Huntington's Disease Research and Management clinic, in collaboration with the South East Wales Trials Unit (Centre for Trials Research, Cardiff University), are trying to find a solution to this problem by working with people who have Huntington's disease, their family members, carers and professionals.

The ENGAGE-HD study, funded by Health and Care Research Wales, has evaluated a home-based activity programme delivered by a trained physical activity coach, which included a purpose developed exercise DVD and a Physical Activity Workbook.

Astrid Burrell, Involving People Network Member, and Professor Monica Busse, Researcher, talked to us about the public involvement at the heart of this study.

Professor Monica Busse, Researcher

How did you find members of the public to become involved in the research study?

We wanted to capture varied perspectives from people with Huntington's disease, their family members, carers and professionals.

People with Huntington's disease and their caregivers (both formal carers and informal carers, i.e. family members) were invited to participate in a series of focus groups, contacted through regional care advisors of the Huntington's disease Association of England and Wales (HDA).

The HDA maintain a confidential mailing list of members who have agreed to be contacted in this way.

All correspondence was initiated by the HDA and no personal details were provided to the research team without the consent of the involved individuals.

Additional members of the public were identified via the Wales Huntington's Disease Involving People Group.

What role have members of the public had?

Eight focus groups were conducted with a total of 56 people.

At the outset, the members of the public shared

> **“ Involving people in this research has been crucial to the success of the subsequent research study. ”**

their experiences of physical activity and discussed aspects of their condition that created barriers for them to exercise.

They also helped us to identify an approach that they considered to meet their needs in terms of supporting them to exercise.

Following this, two members of the Group were closely involved in reviewing and commenting on the ENGAGE-HD physical activity workbook.

We posted hard copies of all the materials to their homes and arranged to phone them to discuss at their convenience. We also provided postal paid return envelopes so that they could send us written copies of their comments.

How did members of the pubic make a difference to the research study?

Through the focus groups and in depth discussions, the study team were confident that the intervention that was developed would meet the needs of people with Huntington’s disease, and was truly a shared intervention.

Involving people in this research has been crucial to the success of the subsequent research study. The ethics committee commented on the quality of the study documentation and did not require any amendments, as it was evident that it was truly a shared process.

I also learnt how much it meant to the public to be involved in the project and that they considered it to be a rewarding process.

Why do you think public involvement is important?

It is very clear to me that without this consultation process we would not have developed an intervention that was suitable for a follow up research study.

The intervention that the study team had initially planned to develop was very different from what we ended up developing and this was as a result of the open discussions and valuable feedback from the public over a six month period.

What advice would you give to researchers who are looking to involve the public in their research?

It is very important to give very clear aims of your work and to develop a shared process for discussing the research.

It is important that the patient and public reviewers feel that you listen to them and are willing to act on their advice or input. We often don’t give enough time to public involvement activities.

We should be doing this right from the outset rather than as an after sight or a requirement of a funder or ethics body.

Astrid Burrell, Involving People Network Member

How did you get involved with the research study?

I was already a member of the Wales Huntington’s Disease Involving People Group. [A group of members of the public involved in the work of the Cardiff Huntington’s Disease Research and Management clinic.]

Monica Busse was pleased with my work on other studies, and we had developed a very good working relationship. She e-mailed me to ask if I would be willing to review the ENGAGE-HD workbook.

What interested you about getting involved?

I was particularly interested in this study regarding physical fitness, as my own husband with Huntington's disease had managed to stay fit longer than we dared hope, because of his physical fitness, walking and somehow playing golf almost right up to the time he went into care.

I knew I could bring a lot of experience to this study.

I wanted to put my past experiences to some use and to play my small part in helping to improve the lives of people with Huntington's disease.

What activities have you been involved in as part of your role?

I was involved in the focus groups that were conducted to inform the production of the ENGAGE-HD Workbook.

I then reviewed the actual ENGAGE-HD Workbook to ensure that everything could be fully understood and easily read by Huntington's disease participants.

In addition, I always proof-read any work with which I am involved, and I now have a reputation for being very thorough! This was of course particularly important when the Workbook was to be printed and published, and proof-reading is something which I love doing, as well as my role as a reviewer.

After reviewing and sending my comments in, Monica and I had telephone communication to clarify various things and we have developed a friendship and a lot of respect for each other.

What have you learned from being in the research study?

Above all, I think I have learned of the dedication and enthusiasm of the team in Cardiff. They are a wonderfully inspiring group of people who go over and above the call of duty to try to improve the lives of Huntington's disease families. I had never been aware of how much research was going on before I joined the group and I have learned to have great hope for the future.

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Why do you think public involvement in research is important?

It is vital that members of the public fully understand any research studies that they are asked to participate in, and that they also fully understand the implications.

Sometimes researchers may use language that we lay people do not understand and it is important that that is clarified.

Despite maybe not having scientific or medical knowledge, sometimes we family members know more about actually living with an illness than a researcher could possibly know, and this information can be useful to researchers planning and evaluating their research.

All the researchers I have met have welcomed and respected this input.

The Wales Huntington's Disease Involving People Group is now part of the Brain Repair and Intracranial Neurotherapeutics (BRAIN) Unit INVOLVE Group: www.brain.wales

If you're interested in getting involved in their work contact: brainunit@cardiff.ac.uk

For information on joining the Involving People Network visit: www.healthandcareresearch.gov.uk/involving-people-network