

Grant 13 HDANI Oculus Trial – February 2021

ADDOR is pleased to announce a grant in the continued fight against Huntington's disease (HD), by providing financial assistance to support a trial project of the virtual reality (VR) system, Oculus Quest 2, to assess the benefits of the system for HD sufferers. This trial will be conducted by the Huntington's disease Association Northern Ireland (HDANI), if successful the aim will be to extend the use of Oculus devices to other HD sufferers.

Oculus Quest 2



Oculus Quest 2 is a big name in the current wave of VR and a standalone device, however this doesn't mean you can't enjoy PC VR on the company's new headset; you'll just need to get an accessory cable for it.

The Oculus 2 is powered by a Qualcomm Snapdragon 865, a considerable upgrade in power over the original Quest. It offers a comprehensive VR experience in a single package with no wires needed (except to charge the headset), and currently provides the highest resolution of any consumer VR headset at 1,920 by 1,832 per eye. It has two motion controls for full head and hand motion tracking, and offers a surprisingly robust library of VR software in its on board store.

Oculus Trial

The trial undertaken by HDANI, will involve ten HD users and be conducted over a one year period.

The aim will be to test the benefit to HD sufferers, which is expected to show in the mental stimulation for the users, a very important factor in the latter stages of HD.

A report of the effectiveness of the trial and its applications will be prepared and details of the findings will be published on the ADDOR website in the future.

Current Oculus Usage Information

ADDOR has been in contact with Natalie Marnica, whose mother Joann is an HD sufferer and is currently using the Oculus device. Natalie writes:

“Thank you for contacting me. I've been using the Oculus 2 with my mom who is in the late stages of Huntington's disease. We have been watching YouTube VR travel and adventure videos since Nov 2020. She really enjoys being in there and I've noticed she expresses herself more vocally when she is using it.

Here are a few examples of what it looks like, I post weekly on my Instagram page to show people.

[IG with Mom 1](#) [IG with Mom 2](#)

The tech is pretty simple to use, I set it up and then put the device on her. “

Natalie also wrote in her Instagram blogs:

“Found some cirque du soleil 180 videos on YouTube for mom to watch. She loved it! And I love watching her explore stuff.

We also found some awesome videos that were taken by astronauts overlooking earth, and went on a quick trip to Stonehenge, not bad for a Friday evening.

I can't recommend this [Oculus Quest 2](#) enough to all my friends who have sick and/or disabled family members. It's the best therapy my mom has access to, in the last stages of Huntington's disease. It's my hope more people will use this for therapeutic applications.”

And

“It's been more than one month since our oculus VR set arrived and my mom has just been so happy being able to see things and experience things that she wouldn't be able to anymore. Yesterday she watched videos for almost an hour, that's the longest she's used the machine so far.

Each time I put on new travel videos for her to places she has always wanted to go but never did. In this video I took her to Sydney, Australia and her face just lit up, she hasn't smiled or talked or been this expressive in almost 2 years.

I can't express how grateful I am to everyone that contributed to this and to whoever made this technology, because it's been a blessing to us. I'm praying that these Co-vid restrictions will ease up a bit, so that I can visit my mom more often and let her explore the different realities than the one she's in.”

ADDOR is very pleased to provide £560 to HDANI to purchase an Oculus Quest 2 256GB All-In-One VR

Headset, a USB-C Link cable and a breakdown service plan for the trial purposes and for future use.

Natalie Marnica on learning of our project wrote “That's amazing to hear! I really hope it helps more people suffering with HD. Feel free to use whatever you need on your site. If there's anything else you need feel free to reach out.”

If you would like to help in the fight to defeat HD, fund research and help other HD sufferers

Please donate at addor.co.uk



HDANI Information on Oculus Virtual Reality

HDANI was provided a grant by the ADDOR Foundation to run a trial on the potential benefits of virtual reality to people with Huntington's disease. We will be loaning the device out for 21 days at a time in the hope of providing 10 households with a trial over the course of a year. We would appreciate your feedback to see if you found the device of any benefit to you or a loved one so that the information might be used to help other people with Huntington's Disease.

What is an Oculus Quest 2?

It is a virtual reality headset which allows people to play games, travel the world, attend live music gig, workout, or simply relax from the comfort of their home. It is owned and operated by Facebook.

What is the science involved?

A virtual reality headset is a head-mounted device that provides [virtual reality](#) for the wearer. Virtual reality (VR) headsets are widely used with [video games](#) but they are also used in other applications, including simulators and trainers. They comprise a [stereoscopic head-mounted display](#) (providing separate images for each eye), stereo sound, and head motion tracking sensors. Some VR headsets also have [eye tracking](#) sensors and [gaming controllers](#). There is **some** evidence to show that virtual reality can have various therapeutic benefits to people living with disability, mental health issues and dementia by improving wellbeing.

Who should use the Oculus?

We specifically want people with Huntington's to use the device as we believe it might be helpful to them but other people in your house are welcome to try it out too. We are especially interested to see if it has any affect on a person's mood or level of engagement/communication.

When should it be used?

As virtual reality changes a persons' perception of the world around them we strongly advise that the oculus is used from the safety of a comfortable chair/sofa or bed to minimise risk of falls. Ideally a person with HD who has any mobility or communication issues should not be left unattended wearing the Oculus.

How long should it be used?

We suggest you start for a very short period of time for example 5 or 10 minutes to see how you or the person using the device finds it. Once you /they are more comfortable with the sensations it can be enjoyed for longer periods of time but do keep an eye for any signs of a person being uncomfortable or overwhelmed.

Immersive technology like VR headsets can cause some people to feel temporarily nauseous have irritated or strained eyes or headaches. So be aware of any indications of side effects.

What should it not be used for?

It shouldn't be left on a wearer for long periods of time unsupervised.

It shouldn't be used in a standing position by anyone with mobility or balance issues, particularly if they are unaided.

It shouldn't be used if the wearer experiences side effects.

How should I care for the device?

The device and accessories are expensive and our trial depends on the equipment being kept safe and clean. Please use the device in accordance with the instructions and store it safely in its case between uses.

What if we don't like the Oculus?

If you have difficulty using the device, then please get in touch as soon as possible for help but if it's a case that for some reason the person with HD doesn't like the device and you wish to end your trial then let us know and we will arrange collection.

Terms of Use

By signing below, I am accepting receipt of the device and accessories from HDANI, on loan for 21 days, as part of a trial, and am responsible for its appropriate use and safekeeping.

User Name: _____ Date: _____

Delivered by: _____ Date: _____

Due for return: _____

HDANI Oculus Feedback

HDANI was provided a grant by the ADDOR Foundation to run a trial on the potential benefits of virtual reality to people with Huntington's disease. We will be loaning the device out for 21 days at a time in the hope of providing 10 people with a trial over the course of a year. We would appreciate your feedback to see if you found the device of any benefit to you or a loved one so that the information might be used to help other people with Huntington's Disease.

Your name: _____

If you used the device yourself, please answer the questions below:

How often did you use it? Every day, some days, once a week, now & again

Did you like using it?

Please use any words you would associate with using the device e.g. relaxing, annoying, exciting, enjoyable, calming, overwhelming, fun, sickening

What kind of things did you use the device for? E.g. Travel, games, movies, music

How long did you use the device for at any one time e.g. 5 minutes, an hour...

Would you recommend virtual reality devices to other people?

Any other comments?

If someone else used the device, please answer the questions below:

How often did they use it? -

How much time did they generally spend on it? _____

What did they watch or play? _____

Did they like using it? E.g did they communicate or express themselves in any way while using the device _____

Did their reactions/responses differ over time? _____

Please circle any words you would associate with the person using the device

Relaxing calming uncomfortable warm restrictive annoying
engaging less fidgety deep breathing better sleep agitated
more communicative better mood anxious comfortable
aggressive

frustrated content expressive nauseous increased movements

How did you know when it was time to end a session?

Any other comments?

If possible, would you be interesting in loaning the device again? _____