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Participant Information Sheet

PRIME-VR2 at UCL: Accessible Virtual Reality for People with Hyperkinetic Movement Disorders

UCL Research Ethics Committee Approval ID Number: 16685/002

YOU WILL BE GIVEN A COPY OF THIS INFORMATION SHEET

Title of Study:	PRIME-VR2 - Personalised Recovery through a Multi-User Environment: Virtual Reality for Rehabilitation
Department:	Global Disability Innovation Hub, Dept. Computer Science, University College London
Name and Contact Details of the Researcher(s):	Research assistant for the PRIME-VR2 project - Richard Armstrong-Wood Richard.Armstrong-Wood.17@ucl.ac.uk
Name and Contact Details of the Principal Researcher:	Dr Tim Adlam 07547 676 555 t.adlam@ucl.ac.uk

1. Invitation

You are being invited to take part in the PRIME-VR2 research project. We would like to improve the accessibility of virtual reality to people with hyperkinetic movement disorders (HMDs) such as dystonia. To do this we need to understand how people with HMDs move so that we can create a new design of virtual reality controller. To gain the information we need, we will be measuring dimensions, forces, ranges of motion, movement, and the shape of your arms and hands. To help us design interesting and useful virtual reality games, we will interview you about the activities you do, why you do them, and who you do them with.

Before you decide whether to participate, it is important for you to understand why the research is being done and what participation will involve. Please take time to read the following information carefully and discuss it with others if you wish. Ask us if there is anything that is not clear or if you would like more information. Take time to decide whether or not you wish to take part. Thank you for reading this information sheet.

This is a UCL staff research study.

2. What is the project's purpose?

PRIME-VR2 is a project aiming to create accessible virtual reality games and controllers that provide an environment in which people with disabilities can practise moving, with the aim of enabling them to gain useful movements.

This project is funded by the European Commission Horizon 2020 research programme. It has partners across Europe who are working together to create new virtual reality games and controllers. UCL is finding out how a VR controller should be designed to be usable by people with HMDs such as dystonia. Other partners in Cyprus and Malta are working with people with stroke, other forms of cerebral palsy, and sports injuries.

3. Why have I been chosen?

You have been chosen because you have indicated that you have a hyperkinetic movement disorder or you have previously indicated that you would be interested in participating in future work, and have indicated that you are interested in how virtual reality might be used to help people gain useful movement of their arms and hands by responding to our request. We are aiming to recruit 20 people to this project.

To be included in the project, you **should** meet **all** the following **inclusion criteria**:

- a. Be an adult (age 18y or older)
- b. You have indicated that you have a hyperkinetic movement disorder, such as dystonic cerebral palsy, that affects the movement of one or both of your arms or hands;
- c. Be able to communicate your preferences and opinions to an interviewer in English (with communication assistance provided by your personal assistant or communication aid if necessary);
- d. Live within about 1.5 hours travel time of UCL Bloomsbury or UCL Here East;
- e. Be able to understand this information sheet;
- f. Be able to give clear informed consent for your participation in the study by signing the consent form or by an observed verbal or physical indication which will be recorded on the consent form and witnessed by two members of the research team.

You should **not** meet **any** of the following **exclusion criteria**:

- a. Be under age 18y;
- b. Be currently about to receive or have recently received surgery for your arms or hands;

4. Do I have to take part?

It is up to you to decide whether or not to take part. If you do decide to take part you will be given this information sheet to keep (and be asked to sign a consent form). You can withdraw from the project at any time without giving a reason and without it affecting any benefits that you are entitled to. If you decide to withdraw you will be asked what you wish to happen to the data you have provided up that point.

We will collect the following personal data (your name, address, email and phone number) so that we can:

- Contact you to organise your involvement in the project;
- Inform you of further opportunities for working with the project;
- Provide you with updates on progress with the project.

We will also make a brief note of your disability, so that we are able to prioritise whom we contact for involvement in future phases of the project.

This personal data will be stored in a password protected file on secure UCL network storage. Only the UCL project team will have access to the password and the data.

You may ask us to delete your **personal data** (name, contact details, disability note) at any time in the project. If you make this request, we will delete your personal data within two weeks. Once your personal data is deleted, we will not be able to contact you again unless you get in touch with us first.

Your **research data** is the data we collect during the research – during the interview and measurement session. We will fully anonymise your research data up to no less than week and up to two weeks after completion of your data collection.

Anonymisation makes your data ready for sharing with our project partners, and means that we will not be able to tell which data is yours. People who look at your anonymised data will not be able to identify you from it.

We will delete your research data if you request that we do so within one week of completion of your measurement sessions. After one week, we may have anonymised your data and deletion will not be possible. After your research data has been anonymised, it is not possible to delete it as we cannot tell which data is yours.

We will fully anonymise your research data up to two weeks after completion of your data collection, making it ready for sharing with our project partners. Anonymisation

means that we will not be able to tell which data is yours. People who look at your anonymised data will not be able to identify you from it. Because of this, if you ask us to delete your research data after it has been anonymised, we will not be able to do so because we will not be able to identify your data.

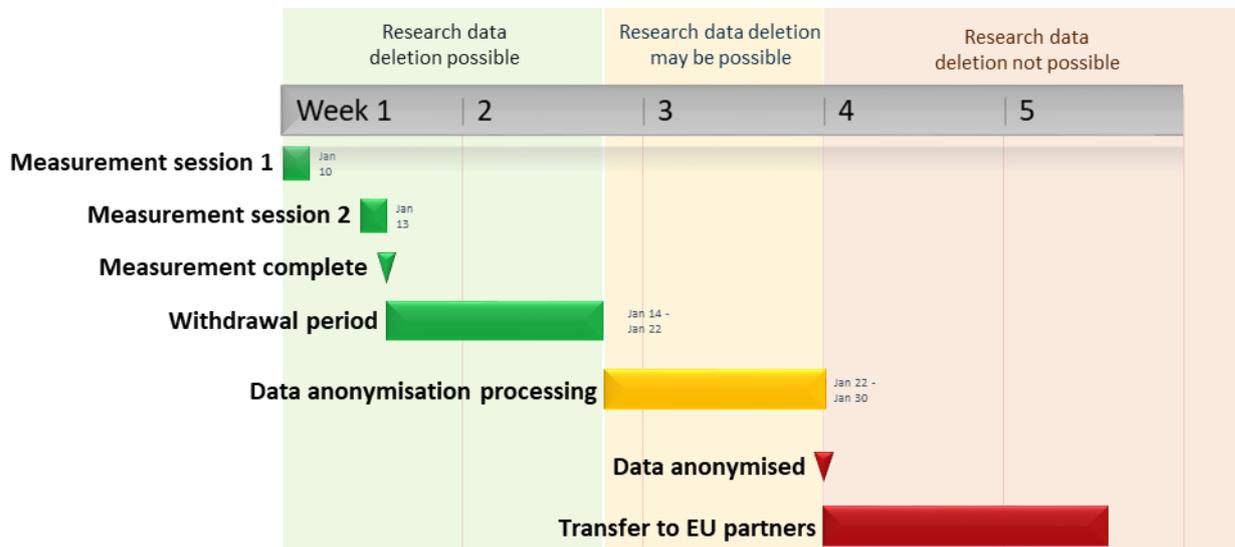


Figure 1: The schedule for data anonymization, showing when it is possible to delete the research data. Personal data will be deleted within 2 weeks of a request being received by the research team.

5. What will happen to me if I take part?

We are aiming to complete this initial phase of the project by June 2020. During this time we will interview and measure 20 people with hyperkinetic movement disorders.

ACTIVITIES

We will interview you to understand your motivation and priorities for using virtual reality technology; measure your arms and hands using photographs, and 3D scan your arm. We expect the duration of these activities to be as below (times are approximate):

Initial remote session:

- (a) An **interview about your disability, activities** and your **objectives for participating** in this project [30 minutes]. The information will help us understand what is important to you and guide the design of the VR games so that they are relevant and interesting to you. We will talk about:
- **What activities are important to** you - this is so that we can choose the right activities for the games we are designing;
 - **What is the purpose of the activities** - so we can set the right objectives for the games we design;

- **Who you do them with, and how you do them together** - this will help us understand how to design our games so that people can play them together.
 - **What movements you use when you engage in these activities**- to help us design the right movements into the games;
- (b) Measurement of the **forces you can apply with your fingers and hands** with simple hand-held force meters (dynamometers) [10 minutes]. We will not ask you to do anything that causes discomfort;
- (c) Measurement of **how you move your arms and hands** when you are doing a simple task, using a **video camera** [10 minutes].
- (d) Observation and video recording of **how you choose to interact** with some sample shapes that might be used for the controller [10 minutes].

Face to face session:

- (e) Taking calibrated photographs of your hands and arms to enable us to measure their dimensions [10 minutes];
- (f) Measurement of **how you move your arms and hands** when you are doing a simple task using **lightweight wearable motion sensors** and a **video camera** [10 minutes].
- (g) **3D scanning of your arms with a hand-held 3D scanner**. We will position your hand and arm, and then scan it to inform the designers of the shape of your hands and arms. We will not scan your face or head. You will not be able to be identified from the scan data. We would like you to try to keep still for the scan, but we understand that this may be difficult for you. [up to 30 minutes – this is new work. We do not currently know exactly how long this will take]

Measurements will be carried out at the UCL Virtual Reality Lab on the UCL campus in Bloomsbury, London or at UCL at Here East on the Olympic Park. If it is difficult for you to travel to one of these locations, it may be possible for the research team to travel to you. We will compensate you for your time and travel expenses with £30 on completion of your participation in the session, even if you choose to withdraw early.

We aim to complete the interview and measurements in **one session of under 2 hours**. We will make a break at a convenient point in the middle of the session. *If you wish to take a break at another time, this is fine. Please just let us know.* If you wish to stop the session for any reason before the session is completed, we can arrange other visits to complete the work with you as necessary.

This modest study is a part of the larger PRIME-VR2 project. We aim to complete this study by June 2020. The PRIME-VR2 project is due to be completed in October 2022. The PRIME-VR2 website can be found at <http://prime-vr2.eu>

ETHICAL CONSENT

We will record your ethical consent for participation on a paper consent form. This will cover:

- your consent to collect and store your personal data;

- your consent for your participation in the study activities listed as (a) to (g) under the heading ACTIVITIES above; and ...
- your consent for the collection and storage of your research data.

Personal Data

We will collect the following personal information about you so that we can contact you about organising the research sessions, and with your consent, invite you to participate in future research activities with PRIME-VR2 or other projects the team are running with people with hyperkinetic movement disorders.

- Name
- Address
- Email address
- Mobile phone number
- A brief description of your disability

All or part of your personal data (name, contact information, disability) can be removed from the study at any time.

Activities and Research Data

If you give us **consent**, we will carry out the **research activities** with you, and use them to collect **research data**. Collecting the research data is the main purpose of this project. Your research data (interview data, measurements, scans) can be removed from the project up until it has been anonymised, which we will do no later than two weeks after it is collected. Please see *Figure 1* above for the anonymization schedule. After anonymization, it will not be possible to identify your data and remove it from the project data set.

6. Will I be recorded and how will the recorded media be used?

We would like to video record your movements during the measurement part of the study. We will position the camera so that we do not include your face, and include as little of your body as possible. We will focus on the movements of your arms and hands. This is so that you cannot be recognised from the video. Video data that accidentally includes your face will either be edited so your face cannot be recognised, or deleted.

The video recordings of your activities made during this research will be used only for analysis to inform the design of the controllers and games, and for illustration in conference presentations, lectures and in articles. No other use will be made of them without your written permission, and no one outside the project will be allowed access to the original recordings. You will not be able to be identified from the video. Our European project partners will have access to your anonymised recordings under the same terms that we do.

7. What are the possible disadvantages and risks of taking part?

We do not expect that you will experience any discomfort from participating in this research other than what you might usually experience if participating in a seated table-top activity. **You may ask us to stop an activity at any time without needing to give a reason. If you ask us to stop an activity, we will stop immediately.**

8. What are the possible benefits of taking part?

There is no direct benefit to participation apart from £30 compensation for time and travel. We will pay you £30 at the end of your participation to compensate you for your travel costs and time. It is hoped that this work will lead to the development of enjoyable, accessible and useful virtual reality games that will help people with HMDs to improve their ability to move. This project is the first step towards that aim.

9. What if something goes wrong?

If you feel that there is a problem with your participation in the project and you wish to make a comment or complaint, then please, in the first instance contact either Dr. Tim Adlam (t.adlam@ucl.ac.uk or 07547 676 555) or Prof. Anthony Steed (a.steed@ucl.ac.uk) in the Computer Science Department at UCL. We will also be glad to hear from you if you have suggestions on how we can improve your involvement in the project. We cannot promise to do all you ask, but we will listen to you and give your suggestions serious consideration.

If you feel a complaint has not been handled to your satisfaction, you can contact the Chair of the UCL Research Ethics Committee – ethics@ucl.ac.uk

10. Will my taking part in this project be kept confidential?

Yes.

We won't tell anyone outside the project team that you are participating in the project.

We will collect two types of data from you. These are handled in different ways.

- (a) We will collect your **name and contact details** (email and phone number). We will also collect a brief **description of your disability**. If you choose to participate in the project, we will retain this information until the end of the project (October 2022). This is so that we can contact you about your possible involvement in other parts of the project and provide you with updates on project progress. If you choose to withdraw from the project we will destroy your contact and disability information and will not be able to contact you again. We will not share your contact and disability data with anyone outside of our project team. If you decline to participate in or withdraw from the project, your contact and disability data will be destroyed.

Your contact and disability data will be stored in secure password protected UCL network storage space to which only the project team has access.

- (b) Your participation in the **research activities** will generate **research data** as described in paragraphs **Error! Reference source not found.**. This data will be collected, processed by our research team, and then anonymised. We will not share your data with anyone outside of the project team before it is anonymised.

Anonymisation means that we will delete any information included in your research data that could enable you to be identified from the data. After anonymization it will not be possible to identify which data is yours in the project data store.

We will use your anonymised data to:

- Inform the design of the virtual reality games and controllers that form the main part of this project.
- Present our work at conferences, seminars, in articles, on our website, blogs and on social media.

We will store your research data initially on the project laptop in encrypted files, and then transfer it to secure UCL network storage space to which only the project team has access.

After we have anonymised your research data, we will also transfer your anonymised data to our European project partners for them to use in their design work using a secure file sharing space at Strathclyde University. This space is password protected and access is only available to the project partners.

Your anonymised data will be retained by UCL for 10 years after the end of the project.

11. Limits to confidentiality

Please note that confidentiality will be maintained as far as it is possible, unless during our conversation or research we hear anything which makes us worried that someone might be in danger of harm. We might have to inform relevant agencies of this.

If we have concerns about your health, we will give you a letter in a sealed envelope about our concerns that you can give to your GP. It will be your choice as to whether you pass on the letter.

12. What will happen to the results of the research project?

The results of this research will be useful to UK and international researchers in virtual reality and rehabilitation. It will feed into the PRIME-VR2 design team's work on the

design of new accessible controllers and virtual reality games for people with hyperkinetic movement disorders, for example, Dystonic Cerebral Palsy.

The results of the research will be anonymised, compiled into a Persona Report, and shared with our PRIME-VR2 European project partners to assist with their design work.

We will write articles about the project for publication, present our project at conferences and meetings, and publish data on our website. These articles and presentations may include your anonymised data. We will protect your identity - you will not be able to be recognised from what we publish or show. Published outputs will be available on or linked to from the project website.

We will also inform people about the project using social media that link to the project website.

13. Local Data Protection Privacy Notice

NOTICE

The controller for this project will be University College London (UCL). The UCL Data Protection Officer provides oversight of UCL activities involving the processing of personal data, and can be contacted at data-protection@ucl.ac.uk

This 'local' privacy notice sets out the information that applies to this particular study. Further information on how UCL uses participant information can be found in our 'general' privacy notice:

For participants in health and care research studies, click [here](#)

The information that is required to be provided to participants under data protection legislation (GDPR and DPA 2018) is provided across both the 'local' and 'general' privacy notices.

The categories of personal data used will be as follows:

- Personal data
 - Name
 - Address
 - Email address
 - Phone number

- Special category personal data
 - A brief description of your disability to enable us to appropriately select people to invite to participate in future related work on this project.

The lawful basis that would be used to process your *personal data* will be the performance of a task in the public interest.

The lawful basis used to process your *special category personal data* will be for the purposes of research.

Your personal data will be processed until the end of the project in October 2022. We will anonymise your research data, and securely store your personal contact data and disability note. You will not be able to be identified from the disability note. Your personal data will not be able to be linked with your anonymised research data.

If you are concerned about how your personal data is being processed, or if you would like to contact us about your rights, please contact UCL in the first instance at data-protection@ucl.ac.uk.

Your personal data will not be transferred outside of the UCL project team, and will be stored securely on UCL network storage using password protection and encryption.

Who is organising and funding the research?

This research is funded by the European Union Horizon 2020 research programme

14. Contact for further information

For further information, please contact Dr Tim Adlam who is leading this part of the PRIME-VR2 project or Richard Armstrong-Wood the Research Assistant:

Richard Armstrong-Wood – Research Assistant
Email: Richard.Armstrong-Wood.17@ucl.ac.uk

Dr Tim Adlam
Email: t.adlam@ucl.ac.uk
Telephone: 07547 676 555

Global Disability Innovation Hub,
UCL at Here East,
8-9 East Bay Lane,
Queen Elizabeth Olympic Park,
London, E15 2GW.

You will be given a copy of this information sheet and a signed consent form to keep.

Thank you for reading this information sheet and considering taking part in this research study