

FFIELD DEPARTMENT OF LINICAL NEUROSCIENCES OXQuip Newsletter Winter 2017



Oxford Study of Quantification in Parkinsonism

Welcome to the first OxQUIP newsletter. The study so far has been a tremendous success and we are so grateful to the over 150 of you who have given your time to participating. We appreciate that coming every 3 months is a lot to ask and are amazed that hardly anyone has dropped out. Particular thanks must go to



several people who are travelling long distances to get to Oxford - and to absolutely everybody for enduring the car parking chaos when you get here!

We plan to keep you posted every few months. In the next newsletter we hope to have some early results to share with you. If you do have any questions or comments please don't hesitate to get in touch.



We send you our best wishes for a happy

Christmas and would like to thank Max Brzezicki, our clinical research fellow, for designing the OxQuip Christmas card. Lastly, very many thanks to UCB for generously providing funding for the study.

Professor Chrystalina Antoniades and Dr James FitzGerald

The OxQuip Study is part of The **NeuroMetrology** research group, led by Prof Antoniades and Dr FitzGerald. The OxQuip Study (Oxford Quantification in Parkinsonism) is designed to develop quick, accurate and objective measurement of Parkinson's Disease. This will enable both the identification of patients suitable to take part in trials and the clinical evaluation of drugs intended to slow or prevent disease progression. The OxQuip Study measures the following:

- Eye movements (measuring oculomotor abnormalities)
- Cognition (using a series of touch-screen tablet tests)
- •Gait (using a set of sensors on arms, legs and torso)
- Finger and toe tapping (using an accelerometer attached to the finger and shoe)

Over 150 patients at various stages of Parkinson's Disease (and the related Progressive Supranuclear Palsy) have been recruited in the last 12 months. All patients recruited for the study come to the clinic to be tested every 3 months. Parkinson's patients who have undergone Deep Brain Simulation (DBS) also constitute part of the study. This treatment has shown to have a very positive effect, but is typically used quite late in the course of the disease when patients have severe symptoms despite trying all available drugs. Better ways of measuring the disease are essential to evaluating the benefits of DBS and judging the optimal time to use it. The data is being collated and analyzed by the team in order to identify a marker that will facilitate the development of new treatments to improve the quality of life for Parkinsonian patients, and even retard the disease.



"Research into measurement is critical to everything else that is going to come." An interview with Dr Jim Sheridan, participant on the OxQuip Study



SW: Why did you decide to take part?

JS: Because I am interested in monitoring Parkinson's. I monitor my own symptoms and medication and I believe a scientific approach is necessary. So when Chrystalina [Antoniades] got in touch with me about the study, I thought it was brilliant and jumped at the chance to participate.

SW: Have you taken part in other research studies?

JS: Yes, I have taken part in the PD Stat trial, Discovery trial, and various research studies in Psychology. Patient participation is vital for research, studies need patients across the spectrum of the condition.

SW: How do you feel the study has evolved since it started one year ago?

JS: The testing is the same, although in some areas it needs to evolve! Particularly in the memory test, as the five words [you have to remember] are always the same. I still dread the letters and keep thinking up new strategies [to recall words beginning with a particular letter]. Those strategies all go out the window, though, when I am put on the spot!

SW: What are the best and the most challenging aspects of the testing?

JS: I like the tablet test. It is probably the most challenging, but also the most fun. The walking is a personal challenge. I know I'm getting worse, but at the end of the test I think "I managed to fake it again". Natural walking deteriorates as muscle memory goes, so I have to think harder to get the same walk.

SW: Now that the study is one year old, what information would you like to know?

JS: What symptomatic measurements are the best indicators of the progression of the condition, and what are the best measurements of 'on' to 'off' states.

SW: What do you hope the study will achieve?

JS: Research into measurement is critical to everything else that is going to come. The first drugs will be very subtle, slowing progression and/or ameliorating symptoms, so precise measurements will be needed to see the effects of these medicines.

I hope that some of these techniques for measurement will also be seen in clinics, as well as used for drug development.

SW: What areas do you think PD research should go in the future?

JS: Working out how to identify, define and understand symptoms better, breaking them down for better assessment. I would also like to see research into measurement being applied to exercise as well as to drugs. SW: What do you feel you have got out of participating?

JS: A sense of hope and recognition that the right things are being done so when a cure comes along they'll be able to accurately measure it. You can't underestimate the psychological benefits of taking part. Feeling involved gives you a lot of hope.

By Sarah Washbrook Research Administrator I love coming to participate as it "grounds" me, and makes me think about my own health and what I can achieve. (LL-M)

"I congratulate you all on the atmosphere you create and the relaxed way in which all the tests are conducted. Test conditions can feel daunting sometimes but you manage to make the experience enjoyable, interesting and unthreatening." (SG) "It's a real pleasure to participate in this PD study. The tests are fun to do - except when we have to predict where a red blob would appear next on a screen. Still don't "get" that one! The researchers are friendly and seem genuinely interested in us - unusually! And we get a morning out in Oxford. What's not to like?" (DM)

Preliminary Data Samples from the Study

Since the OxQuip study began in October 2016, we have recruited over 150 participants who have made 435 visits to the clinic. Most participants have been tested at least twice and a number of participants are now on their fifth visit of nine. As we collect repeat data from each participant, we will be able to build a picture of how better to measure and track the symptoms and progression of Parkinson's. We hope to publish the first results in the next 12 months.



The study is divided into groups of PD (Parkinson's), PSP (Progressive Supranuclear Palsy), DBS (Deep brain Simulation) and HC (Healthy Controls).

Thanks to the dedication of those recruited to the study, and the efforts of our research team, we have retained nearly 95% of participants. Therefore, we are only now looking to recruit newly diagnosed PD patients that have not yet started taking any PD medication and people diagnosed with PSP.



The sway test is an example of one of the measurements in the study.



This is a simple way to measure postural sway in all our participants. Subjects are instructed to stand with hands at their side. A spacer blocker is placed between the feet to ensure that all participants have the same distance between their feet. The sensors then measure objectively the sway in each participant while they keep their eyes shut. Some graph examples can be seen below, showing how different each participant is.



Measuring objectively postural sway in Parkinson's is important for the accurate diagnosis and staging of PD, but also for monitoring the rate of progression.

Parkinson's 200th Anniversary Events

This year marks the 200th anniversary of the publication of the first codified description of the condition that we now know as Parkinson's disease. Its author, James Parkinson, called it the Shaking Palsy. Associate Professor Chrystalina Antoniades from the Nuffield Department of Clinical Neurosicences, and Dr Patrick Lewis from the University of Reading co-organised a number of events to mark the anniversary, along with the Oxford branch of Parkinson's UK.

James Parkinson: the Shaking Palsy and beyond 11 September 2017 – 19 September 2017, Blackwell Hall, Weston Library



Parkinson's 200 Plus Conference 18 September 2017, Wesleyan Memorial Church, Oxford

The flagship event put on by the Oxford branch of Parkinson's UK to mark this historical year was the Parkinson's 200 Plus conference. A packed venue saw Prof Chrystalina Antoniades give a scene-setting presentation on the



clinical research undertaken currently in Oxford. OxQUIP featured strongly in this, showing the great need to move from subjective observation to objective measurement. The programme then moved to an expert panel discussing the prospects for new therapies, and answering some challenging questions from the audience.

Dealing with Parkinson's isn't all about medicines. There were talks on the value and importance of exercise, then a series of presentations and a panel discussion on how to retain and even improve your quality of life while living with Parkinson's. The perfect end to the conference saw the comedy writer Paul Mayhew-Archer talk about the funny

side of Parkinson's.

We can speculate what James Parkinson would have thought of the conference. Even 200 years on, there is a lot he would recognize and, we hope, would have appreciated, especially the determination, character and positivity on show.

For more information visit www.parkinsons200plus.org

Kevin McFarthing, 17 October 2017

For more information on the Neurometrology Research group and the OxQuip Study visit: https://www.ndcn.ox.ac.uk/research/neurometrology-lab https://www.ndcn.ox.ac.uk/research/neurometrology-lab/research-studies/the-oxquip-study Or contact Dr Sarah Washbrook at sarah.washbrook@tss.ox.ac.uk or 01865 226905