

Getting the Measure of Your Parkinson's

The treatment of Parkinson's has changed very little over the past 50 years. There are many reasons for this, but one of the main ones is that Parkinson's is extremely difficult to measure.

WE can change this. Through better understanding and self-analysis of our Parkinson's, WE can make a valuable contribution to accelerating the most relevant scientific progress in Parkinson's into actual treatments.

This is the goal of SENSE-PARK. Measuring your symptoms can not only help you with your own Parkinson's, but can also help realise better and more targeted therapies which could improve our quality of life in the foreseeable future.



What we all have in common

The one thing that is predictable about our Parkinson's is its unpredictability. We all find it difficult to plan ahead because our symptoms can change from being moderate to horrendous in a matter of hours, sometimes even minutes. Parkinson's is a complex condition involving a myriad of symptoms, in two broad areas:

- Those that affect our movement – Motor symptoms
- Those that affect other aspects of our health and well-being – Non-motor symptoms

What we don't have in common

Although the effects of Parkinson's may be similar in many people, it is very rare to find two people with exactly the same symptoms. We all respond to medication differently and we are all individuals with different priorities in life.



What is missing?

The combination of unpredictability, the fact that we all have different symptoms, and that we respond differently to medication with different priorities contributing to our preferred lifestyle, means that Parkinson's is incredibly difficult to measure. The role of assessing our Parkinson's has traditionally fallen to our doctors, neurologists, specialist nurses etc. but, their methods have been largely constrained by the lack of technology. This restricts them to their subjective and impersonalised snapshots of our condition which can prove to be unrepresentative of the full scope and variability of our lives with Parkinson's.

So why is measurement important?

By collecting information about our day-to-day health, we will be able to establish patterns and trends in our illness so that we can adapt our activities eg. diet, exercise and rest accordingly;

By monitoring and recording our health continuously, we can provide far more accurate and personalised information from which our healthcare advisors will be able to provide the best possible treatment plan to suit our individual circumstances.



SENSE-PARK for clinicians

Current measures and scales used for assessing Parkinson's in clinics only provide a snapshot of a person's Parkinson's. The likelihood of clinical assessment at any one time being fully representative of the scope of a person's Parkinson's symptoms is slim and yet the peaks and troughs of these ever changing symptoms are often the things that have the greatest impact on quality of life for those living with Parkinson's.

By accurately measuring Parkinson's there is a real opportunity to create a more personalised treatment plan which in turn allows the individuals living with Parkinson's to better manage their disease on a day to day basis.

The clinical need for accurate measurement

There are a number of issues around current measurements used in clinic. Current scales are open to interpretation from the clinician, and are subjective. They can be prone to bias and provide only a snapshot of a person's condition taken at a single point in time. It is unusual in normal clinical practice for a clinician to witness the full range of symptoms a patient may experience. Equally patients have different priorities in their lives and have different criteria which contribute to their own individual quality of life.



Through the use of technology, SENSE-PARK allows objectivity in analysing symptoms over time and also enables patients to prioritise the assessment of those Parkinson's symptoms which are the most important to them and within their normal day to day environment.

Visit www.sense-park.eu for a demonstration of how subjective measurement can be in Parkinson's, by rating the videos online.

“Even though people with Parkinson's are evaluated in clinical appointments by both interview and clinical observation, there is significant variation in clinical assessment as the tools used are subjective. The SENSE-PARK project came into being because our clinical practice would benefit from long-term objective measurement. As practitioners, we are very aware of the challenges of measuring a changeable condition such as Parkinson's. By measuring Parkinson's in the home environment, using validated objective measures in conjunction with existing tools, we have an opportunity to gain a real understanding of an individual's condition, and can adapt their treatment plans accordingly. The system being developed by SENSE-PARK also has benefit in clinical trials of potentially disease modifying treatments in detecting the subtle changes in both on and off periods that would not be picked up by current measures.”

Professor Walter Maetzler, scientific coordinator for SENSE-PARK

The Vision: Using continuous objective measurement in disease modifying trials

Disease modification is the holy grail of Parkinson's research. Current measurement that relies on clinical appointments does not provide a continuous objective picture over 24 hours – a picture that becomes essential when considering disease modification. It is possible that new treatments may have benefit in “off” periods, they might have an impact on sleep patterns, or even improve cognition. To map these possible changes, it is essential that continuous objective measurement be implemented.

For further information please email
helen@cureparkinsons.org.uk or call +44 (0)20 7929 7656

What is SENSE-PARK?

SENSE-PARK is a European funded initiative which aims to address the critical issue of accurate measurement of Parkinson's through a series of technical devices designed to allow objective and precise analysis of the most important aspects of Parkinson's as verified by those living with the condition themselves.

SENSE-PARK features the following important attributes which set it apart from other initiatives involved in this area:

- 1. SENSE-PARK is a project which has been overseen by people with Parkinson's every step of the way ensuring it is relevant, focused and practical*
- 2. SENSE-PARK also draws on the technical expertise of renowned Parkinson's centres around Europe which should ensure that the devices used and the measurement criteria will continue to be scientifically validated safeguarding their wide scale use and application*
- 3. SENSE-PARK aims to evolve with advances in technology ensuring its longevity as the most up to date resource in accurate symptom assessment in Parkinson's*

Listening to the priorities of people with Parkinson's

People living with Parkinson's have shaped SENSE-PARK. Initial surveys, verified by focus groups created a priority target symptom list, which in turn has focused the project on the relevant needs. The project has researched the technology uses with people with Parkinson's to assess which platforms to use, and how to shape apps linked to the project. This has subsequently been verified by Delphi Studies carried out by the University of Lisbon, and the technological needs of people with Parkinson's have been investigated by AbilityNet.



Current project status

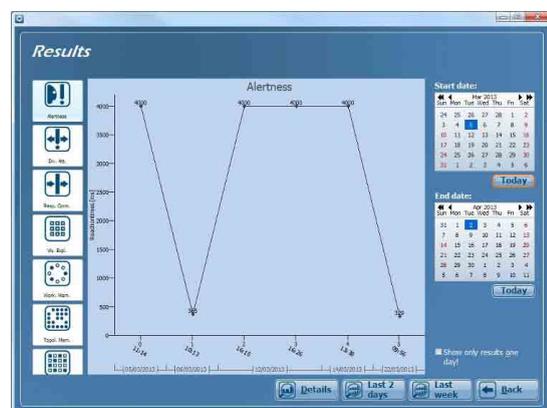
The SENSE-PARK team has designed a prototype sensor and device system, linked to an interface, that generates reports which are relevant for people with Parkinson's and clinicians. The prototypes are currently being tested by users to validate the symptom domains prioritised by people with Parkinson's before the whole system enters a clinical trial in Spring 2014.

How can SENSE-PARK help?

The devices developed by the SENSE-PARK team will allow continuous assessment of motor symptoms within the context of an everyday living environment. Information is captured by wearable devices which have the ability to 'sense' fluctuations in motor symptoms. The SENSE-PARK system also incorporates a series of tests which focus attention on non-motor aspects of Parkinson's such as mental agility, mood and sleeping patterns.

N.B. Using SENSE-PARK devices

The measuring devices used in SENSE-PARK have been designed to be as easy to use as possible so that they do not impinge on daily life. The non-motor tests have also been designed to be minimally intrusive so that repeated use does not become laborious or boring. There are, however, some important points to note about the use of SENSE-PARK devices:



1. While measuring your own Parkinson's might put you in a better position to understand aspects of your own illness, any change to medication regimes should be first discussed and agreed with your healthcare professional.
2. Parkinson's is a degenerative neurological condition and while it is hoped that SENSE-PARK will improve quality of life for its users and contribute to the earlier development and availability of new treatments, people with Parkinson's are advised not to expect the use of the devices to have a direct effect on the progressive nature of the illness and to be aware that over time this is likely to be reflected in the measurement feedback.
3. Users of the SENSE-PARK devices should be conscious of their own prioritisation of symptoms so that they can adopt the use of devices which assess those issues which are most important in the enjoyment of their own lives. By doing this SENSE-PARK becomes a more personalised and individual approach to symptom measurement and the management of one's Parkinson's by healthcare professionals can be optimised.