Journal of Parkinson's Disease 5 (2015) 187–196
DOI 10.3233/JPD-140472
IOS Press

Research Report

Participatory Design in Parkinson's Research with Focus on the Symptomatic Domains to be Measured

J. Artur Serrano[a,b,*], Frank Larsen[a], Tom Isaacs[c], Helen Matthews[c], Joy Duffen[c], Sara Riggare[d], Fulvio Capitanio[e], Joaquim J. Ferreira[f,g], Josefa Domingos[f,g], Walter Maetzler[h,i], Holm Graessner[j] and SENSE-PARK Consortium

[a] *NST-Norwegian Centre for Integrated Care and Telemedicine, University Hospital North Norway, Tromsø, Norway*
[b] *Department of Clinical Medicine, Faculty of Health Sciences, The Arctic University of Norway, Tromsø, Norway*
[c] *The Cure Parkinson's Trust, London, UK*
[d] *Karolinska Institute, Stockholm, Sweden*
[e] *Portal Unidos contra el Parkinson, Spain*
[f] *Laboratory of Clinical Pharmacology and Therapeutics, Faculty of Medicine, University of Lisbon, Portugal*
[g] *CNS - Campus Neurológico Sénior, Torres Vedras, Portugal*
[h] *Department of Neurodegenerative Diseases, Hertie Institute for Clinical Brain Research, University of Tuebingen, Germany*
[i] *German Center for Neurodegenerative Diseases (DZNE), Germany*
[j] *Institute for Medical Genetics and Applied Genomics, University of Tuebingen, Germany*

Abstract.

Background: There is a growing interest in the objective assessment of health related outcomes using technology providing quality measurements to be applied not only in daily clinical practice, but also in scientific research. Differences in the understandings of the condition and the terminology used between people with Parkinson's (PwPs), clinicians and technical developers may influence the progress of a participatory design process.

Objective: This paper reports on a participatory design process to achieve a consensus among PwPs, clinicians and technologists over the selection of a set of symptomatic domains to be continuously assessed, in order to provide results relevant to both PwPs and clinicians.

Methods: The methods used were a Web based user survey, end-user focus groups, ranking by combined methods, a Delphi process performed among clinicians and scientists, and prioritization of the results in a concertation workshop for PwPs, clinicians and technologists.

Results: The following symptomatic domains were commonly agreed by PwPs and clinicians to be of central importance in a system of continuous assessment: hypokinesia/bradykinesia, tremor, sway, gait, sleep and cognition. This list satisfied both the needs of the PwPs and the concerns of the clinicians regarding the means of advancing new strategies in assessment and interventions in PD.

---

[*] Correspondence to: J. Artur Serrano, University Hospital of North Norway, Norwegian Centre for Integrated Care and Telemedicine, P.O. Box 35, N-9038 Tromsø, Norway. Tel.: +47 9668 3435; Fax: +47 77 75 40 99; E-mail: jarturserrano@gmail.com.

ISSN 1877-7171/15/$35.00

Conclusions: A participatory design strategy allowed the definition of a consensual list of symptomatic domains. Both the strategy and the achieved results may be of relevance for similar interdisciplinary approaches in the field of PD using a participatory design involving patients, clinicians and technologists.

Keywords: Parkinson's Disease (PD), People with Parkinson's (PwPs), participatory design, assessment strategies, biomarkers, chronic disease management, combined methods, degenerative disease, diagnostic markers, focus group, symptomatic domain, monitoring

INTRODUCTION

The effective development of future treatments for Parkinson's Disease (PD) relies on the accurate assessment of how it affects people with Parkinson's (PwPs) as individuals [1]. Several studies are already available that report quantitative assessment systems for measuring PD symptoms using wearable technology (reviewed in [2]). The authors conclude that further development is necessary, as "the currently available techniques have not yet found their way into routine clinical assessment". An important reason may be that previous attempts to bring such devices to the market focused on clinicians and scientists, therefore, the data is not directly relevant to patients nor in an understandable format; PwPs thus do not have the opportunity to learn themselves from quantitative data and still are dependent on the judgement of others. In fact, patients suffering from chronic diseases without causal treatment show increasing interest in self-measurement and self-evaluation of potential treatment strategies [3–5]. Patients increasingly interact with their own health data, and share experiences, with the aim of learning from one another for better health outcomes. Therefore, putting the patient with a chronic condition in the "driving seat" of assessment is a promising principle, and was embodied in the European project SENSE-PARK. The project's objective was to develop a technological measurement device that would allow the objective and continuous assessment of specific symptoms of PD, which could be used in the home environment of PwPs. The project combined the expertise from technologists, the experiences of PWPs and the scientific know-how of those who treat them. It focused on one of the most urgent needs in the field of PD, i.e. the development of better methods of unobtrusive, continuous and objective measurement of parameters for the definition of disease state and progression; there is currently no validated system available. Most of the assessments currently used are qualitative, or, at best semi-quantitative, and are not sensitive to change being based in a short period of observation. Moreover, some of the symptoms most relevant to the quality of life of PwPs are often not observed during a clinical visit (such as freezing of gait), or do even not occur by definition (such as sleep problems).

There is currently a trend towards a more active role of the patient in the patient–doctor relationship where health care professionals are seen rather as partners of the patients to optimize health ('participatory medicine'). This collaborative and patient-centred model with regard to PD has been discussed in detail in [6]. SENSE-PARK embraced the best of this concept taking patients as team members and involving them in the design of the clinical device from the start. The patient-generated data regarding PD domains generated as a result may add to our understanding of the disease and provide opportunities to directly engage with and support patients.

The project was introduced to over 100 PwPs and their carers or partners in October 2011 at the Royal Society of Medicine, London.

The decision of pursuing a strong collaboration between PwPs and clinicians had already been made. However, this strategy proved to be very challenging due to differences in the understandings of the condition, of the language and terminology used, and also of the expectations relating to the results to be achieved in the project. It was appreciated that, in the initial planning of the approach to be taken to designing a technological measurement device, an understanding and agreement of the set of symptomatic domains (this term includes symptoms and signs [7]) to be monitored was vital.

To the best of our knowledge, there is currently limited information available about which symptomatic domains can serve as useful progression markers and markers sensitive to treatment that are accepted by PwPs and clinicians. PwPs and clinicians differ in their motivation in prioritizing which symptomatic domains should be monitored:

- Which ones lead to a better quality of life for PwPs?
- Which ones lead to a better understanding of what living with PD means?

- Which ones lead to the most scientific relevant research results for clinical treatment?

Important work in this direction has already been performed in the ParkinsonNet [8]. The SENSE-PARK tries to do for PwPs what ParkinsonNet has already done for the healthcare providers. ParkinsonNet has been centred in a professional regional network to improve Parkinson's-specific expertise among health personnel, however no project so far has consequently tried to follow a participatory design approach [9–12], to bring PwPs up to the decision table, where their knowledge can improve the quality and direction of the research being done now and prepare the pavement for the research to be done in the future. Such a process has to tackle the following challenges: on the one hand, the transfer of clinical knowledge from the medical community to the PwPs, and on the other hand, the communication in the opposite direction, of the needs and expectations from PwPs to the medical community. In SENSE-PARK moreover the result had to serve as a starting point for a technological measurement device, therefore, also the technical feasibility had to be considered and thus a third view, the one from the technologists, had to be included.

This paper relates to a story of a journey into Parkinson's where PwPs are the main drivers and where neurologists, sociologists, computer scientists, and other humanitarians are joining. The SENSE-PARK consortium strives to create more knowledge about PD through the search for an objective assessment that will ultimately allow the development of improved therapeutic interventions.

The main objective of this initial work herein presented was the inclusion of PwPs, clinicians and technologists in a participatory design process, to create an understanding and agreement on the set of symptomatic domains to be monitored by the new technological device to be developed in the SENSE-PARK project. However, this strategy came with challenges and barriers due to differences in the understandings of the condition, of the language and terminology used, and also of the expectations relating to the results to be achieved in the project.

METHODS

The following methods were used for the *identification* of the candidate symptomatic domains: (*i*) a *web based user survey*; (*ii*) several *end-user focus groups* performed in the UK, Sweden and Spain; (*iii*) *ranking by combined methods* (obtained from *i* and *ii*); (*iv*) a *Delphi process* performed among clinicians working with PwPs as well as scientists in the field of Parkinson's.

A *concertation workshop* between PwPs and clinicians was finally conducted in order to achieve a final reduced list of symptomatic domains.

Step-by-step description of the used methodology

1. The web-based survey for PwPs

A survey was conducted among PwPs. The survey was distributed via the Web in the autumn of 2011 and included both fixed answer categories and free text boxes for responses. The distribution was made through special interest mailing lists relating to PD.

The survey contained questions about demographics, condition and symptoms (sorted by date of occurrence), external factors influencing symptoms, which kinds of technology they use, both general and disease-related technology.

2. End-user focus groups

Focus groups were set up during the user needs analysis. Six focus group sessions chaired by a PwP and involving more than 15 PwPs as end-users (5 to 8 PwPs in each focus group), were conducted in the following three countries: UK, Sweden and Spain. Three criteria guided the recruitment of participants: both genders should be represented; different age groups should be included; and they should be ICT savvy.

The same protocol was used in the three countries: the sessions followed a semi-structured questionnaire and two persons were present, one person acting as the facilitator and another person taking notes. Prior to the focus group sessions, an expert on qualitative research coached the three focus group facilitators on how to conduct the interviews. Open-ended questions were used for stimulating discussion. The focus group participants were invited to share their views regarding four themes: "what is a good Parkinson's day for you?", "what is a bad Parkinson's day for you?", "is there anything that helps you predict your Parkinson's day?" and "what kind of symptoms do you want to monitor?". The same focus groups were then gathered once more and invited to give a score from a 5 point Likert scale (0 to 4) to each of the symptoms that were mentioned.

3. Ranking of the inputs obtained from the PwPs by combined methods

The two lists, one from the web-based survey and the other from the focus groups, were combined to produce a ranking of symptomatic domains by JAS. The list obtained from the survey is related to the prevalence of symptoms experienced by the PwPs, while the list obtained at the focus groups interviews is an expression of the symptoms they would like to monitor.

The ranked list of symptomatic domains was obtained by multiplying the values of symptoms that are present in both lists, i.e. multiplying a ranking (from the focus groups list) by a proportion (from the survey list). This means to weigh the ranking made by the PwPs at the focus groups sessions with the statistical data obtained from the web-based survey.

4. Delphi process among clinicians and scientists

To obtain a clinical viewpoint, an expert panel of twelve movement disorders specialists and clinicians was set up to propose a list of preferred symptomatic domains which should be assessed.

This list was initially developed by WM and included a selection of symptomatic domains which: (i) are cardinal to Parkinson's, (ii) have been shown to be relevantly associated with quality of life [13]; and (iii) have already been measured with wearable sensors [2]. The list also included relevant parameters associated with the symptomatic domains.

Through a two-round Delphi process adapted from a previous publication [14], the expert panel rated the list related to the impact on progression and sensitivity to treatment.

The results of the Delphi process were condensed in a ranked list of symptomatic domains by WM.

5. Concerted prioritization of all results obtained

A concertation workshop was organized with all PwPs (including "Super-user" PwPs, see acknowledgment section), clinicians and technical developers involved in the process. First, an agreement on terminology of relevant symptomatic domains was developed as this presented a problem for some of the terms used. A single list of symptomatic domains was produced, which matched lay concepts such as stiffness and balance problems, to clinical concepts such as bradykinesia and sway. This process was driven by the PwPs.

This process was followed by a discussion where results of the above-described activities (prioritization of symptomatic domains by PwPs and by clinicians) were merged in a common list that represented the combined opinion of all stakeholders. This list satisfied both the views of PwPs and that of clinicians.

During the discussion, the symptomatic domains were scored according to the following criteria: scientific value, results of survey and focus groups, continuous or snapshot measurement, and specificity.

The task made use of a number of techniques to support the discussion, including cross-tables and mind maps (not shown).

The technical developers were also invited to attend this workshop, and to comment on the results from a feasibility point of view within the project's time frame.

RESULTS

A total number of 198 respondents answered the **web-based survey**. Most of the respondents lived either in the UK or in the USA. As we see in Table 1 there is a good balance between male and female respondents: 103 of respondents are women while 94 are men, and 1 is missing the gender response. The range of the age of the respondents is from 31–84 years, the mean age of is 54 years. Most of the respondents are between 50 and 69 years old. 13% of the respondents are between 31 and 49 years old, and most of them are in their forties. 11% of the respondents are 70 years old or more, but there are only two who are in their eighties.

On the **focus groups sessions**, the last question - "What kind of symptoms do you want to monitor?" - was used to create a list of symptoms for each country. A final list was produced which combined the data obtained in the three countries. The same focus groups were then gathered once more and gave a score from a 5 point Likert scale (0 to 4) to each of the symptoms in this list. The results of this activity are shown in Table 2 on column "Focus Group result".

Ranked list of symptomatic domains obtained from combined methods (PwPs)

Table 2 gives the ranked list of symptomatic domains obtained from the combination of methods performed together with the PwPs (in the table were only included the symptomatic domains that obtained a value for the combined methods that is greater than zero). The column "Survey result" is related to the question "Which symptoms do you experience at this time?". This

Table 1
Respondents of web-based survey (% in brackets)

Gender	Number (%)
Female	103 (52)
Male	94 (48)
Not answered	1 (-)
Age	Number (%)
31–49	25 (13)
50–59	64 (33)
60–69	86 (45)
70–84	22 (11)
Total	198

Table 2

Ranked list of symptomatic domains obtained from combined methods

Symptomatic domain of Parkinson's disease	Survey result	Focus group result	Comb Methods= Survey * Foc. Group	Rank by survey	Rank by focus group	Rank by combined methods
Slowness of movement	0,794	2,8	2,223	1	3	1
Constipation and other gut related problems	0,472	4	1,889	11	1	2
Difficulty with fine motor movement	0,573	3	1,719	4	2	3
Stiffness	0,759	2,2	1,669	2	5	4
Lack of energy	0,553	2,8	1,548	5	3	5[1]
Tiredness/exhaustion	0,553	2,8	1,548	5	3	5
Tremor	0,663	2,2	1,459	3	5	7
Loss of sense of smell	0,523	2,2	1,150	7	5	8
Daytime sleepiness	0,472	2,4	1,134	11	4	9
Pain	0,477	2,2	1,050	10	5	10
Balance problems	0,508	2	1,015	8	6	11
Memory problems	0,322	2	0,643	14	6	12
Weight loss or weight gain	0,342	1,8	0,615	13	7	13
Inability to organise	0,251	2,4	0,603	18	4	14
Excessive sweating	0,296	2	0,593	16	6	15
Difficulties with speech	0,382	1,2	0,458	12	10	16
Depression	0,266	1,6	0,426	17	8	17
Anxiety	0,296	1,4	0,415	16	9	18
Difficulties with eyesight	0,231	1,4	0,324	21	9	19
Freezing	0,226	1,4	0,317	22	9	20
Falling	0,186	1,6	0,297	24	8	21
Dystonia	0,241	1	0,241	20	11	22
Dribbling	0,251	0,8	0,201	18	12	23
Difficulty instigating movement	0,246	0,8	0,197	19	12	24
Changes in behaviour	0,121	1,6	0,193	25	8	25
Obsessive compulsive behaviour	0,090	1,4	0,127	27	9	26
Dyskinesia	0,312	0,4	0,125	15	13	27
Hypersexuality	0,060	1,2	0,072	28	10	29
Hallucinations	0,060	1	0,060	28	11	30
Festination	0,040	1	0,040	29	11	31
Difficulty swallowing	0,186	0,2	0,037	24	14	32

[1] Note that both Lack of energy and Tiredness/exhaustion have the same score, therefore the same ranking by the combined methods.

was a multiple-choice question where a number of symptomatic domains could be chosen from a predefined list. The number represents the fraction of answers mentioning that symptomatic domain. Then a score was obtained for each symptomatic domain present in both lists by combining the scores given both by the respondents in the survey and in the focus group. The resulting score was then used to produce a prioritized list which has been ordered by the column "Rank by combined methods".

In the score of symptomatic domains by combined methods, three large decays are observed: between the first and the second (slowness of movement - constipation and other gut related problems); between the 7th and the 8th (tremor - loss of sense of smell); and finally between the 11th and the 12th (balance problems - memory problems). The highest ranked symptomatic domain in the focus group, constipation, comes only in 11th place in the survey. A similar situation can be observed for the symptomatic domain "daytime sleepiness".

List of symptomatic domains obtained from the two-round delphi process (clinicians and scientists)

To guarantee the applicability of the results achieved with the PwPs, as presented above, in a way that the patient data captured by the device could eventually be used in the development of new therapies, and consequently obtain the agreement from the medical community, an expert panel of twelve clinicians and movement disorders specialists was set up.

The panel was asked to classify the importance of assessing a given number of symptomatic domains, and specifically how important their assessment in a home environment would be.

Table 3
The table for the agreed symptomatic domains to constitute the pool of measurements obtained during the observational study

Clinical terminology	PwP terminology	Motor (m) or non-motor (nm)	Rationale for inclusion
Hypokinesia/ bradykinesia	Slowness of movement	m	Ranked in the combined methods list as #1.
Tremor		m	Rank in the combined methods #7.
Sway	Balance problems	m	Rank in the combined methods #11. It will be assessed in combination with falls, ranked #21.
Gait	Difficulty instigating movement	m	Ranked #24 in the combined methods but the higher prioritization resulted from the Delphi process with clinicians and scientists.
Sleep		nm	Resulting from the Delphi process with clinicians and scientists.
Cognition		nm	This is not expressed as such in the combined methods list but includes, amongst other symptomatic domains, "Memory problems" ranked #12 and "Inability to organize" ranked #14.

The most relevant symptomatic domains for the home environment, the main target of the project, were: physical activity, gait, balance (together with falls), cognitive deficits, autonomic dysfunction, sleep, speech, rigidity and bradykinesia, and dyskinesia.

This list was obtained in a separate process from the one in which PwPs had participated. That is, no PwPs were involved and the list purely reflects a clinicians' view.

Concerted prioritization of all results

The concertation workshop resulted in a matching of terminology and in the final agreed list of symptomatic domains.

The terminology matching achieved after the agreement process is given in Table 4 (Appendix).

The final result of the concerted prioritization is an *agreed list of symptomatic domains derived from the input of PwPs and clinicians and was incorporated in the subsequent observational study*. This is presented in Table 3. The list satisfied both the needs of the PwPs as well as the concerns of the medical staff regarding their relevance to use in the possible advance of new therapies.

DISCUSSION, CONCLUSIONS AND FURTHER WORK

The two most important findings were: 1) a ranked list of symptomatic domains (Table 2) obtained from combined methods after inputs received by PwPs, both from a web-based survey and several focus groups sessions; and 2) a final agreed list of symptomatic domains (Table 3). Moreover, the whole process of interaction between patients and clinicians generated additional important findings. The first relates to what is presented below as the interaction dynamics between PwPs and clinicians. The second refers to the different expectations that PwPs and clinicians have about the system. As the SENSE-PARK project is developing a technological measurement device, the technical feasibility of the measurements is also a central issue. The implications of having technologists involved in the process also resulted in interesting findings relating to the impact their opinions have in the direction of the work, as described below.

The obtained lists of symptomatic domains

A weakness of the used method is that the patients' group may not be representative for all PwPs. This may be true for the survey, as the distribution was made through existing interest groups and then it followed a process of self-recruitment; and also for the focus groups, as the participants were included by direct invitation.

This is also a possible strength as, from the start of the process, the users were involved in the process of prioritizing the symptoms to be measured. Also, only users that were technology savvy and experts in living with the condition (as they are patients themselves), were invited to participate in the focus groups. Largely, this is also true for the web-based survey, as the interest groups to which it was distributed had members that are PwPs and also more knowledgeable and interested in advances on technologies and therapies to deal with the condition than the usual patient.

Another possible weakness is that the respondents of the web-based survey got a previously elaborated list. This selection was made by experts on the disease (work coordinated by The Cure Parkinson's Trust, London, UK). The correspondent strength is that this avoided the ambiguity and spreading of terminology usually associated with free text answers. In the focus groups, open-ended questions were used because in this method the problem of ambiguity and spreading is minimized; in this case there is a coached discussion which promotes dialogue and agreements between participants.

Considerations on the six selected symptomatic domains

A limited number of symptomatic domains had to be chosen. The specific number took into consideration the timeframe and the budget of the project, but also it had to cover other necessary aspects. Although from a data collection perspective, the more data the better, there was a limit of how many measurement devices a PwP would be willing to carry and how many tests he or she would be willing to do. It seemed that six symptomatic domains was an appropriate number, letting us obtain enough data, with a system that the users considered within acceptable levels of obtrusiveness, and feasible for the project's time and budget frame. The rationale for inclusion of the domains is given in Table 3.

As seen in the results section, the highest ranked symptomatic domain in the focus group, constipation, comes only in 11th place in the survey. This means that although less than half the respondents of the survey experienced this symptom (0,472), the participants in the focus groups felt this was a symptom they would want to monitor. A possibility is that PwPs perceive current care as not providing enough answers to constipation. Constipation is not part of the list in Table 3 as the way to measure it would be by self-reporting and not automatically by the technological device.

Gait is one of the chosen symptomatic domains although not highly ranked by the PwPs as "difficulty instigating movement" is placed #24 in Table 2. Reasons for this may be connected to the lack of a term in both the survey and the focus groups that is explicitly related to gait. Another possibility is that current care is seen by PwPs as already offering possible answers to gait problems.

All selected domains have been regarded as very important for assessment in a home environment as a result of the Delphi process with clinicians and scientists. They also had the agreement of PwPs. However, the achieved list of symptomatic domains is a consensus out of the PwPs ranking, which shows the needs they feel (in Table 2, resulting from the combined methods); the clinicians ranking, which mainly focus on how to best understand the disease so better treatments can emerge and improve patients' lives (resulting from the Delphi process); as well as the technical feasibility.

The choice of having a consensus, rather than, for example, selecting the six highest ranked symptoms, was preferred because of diverse constraints and strengths within the project. For example, the measurements should cover both motor and non-motor domains; they also should be continuous in time, rather than snapshots; and non-obtrusive. Technological constraints were also present: what is currently feasible? What is the extra effort the measurements are imposing on patients? All these issues had to be balanced and agreed upon by all stakeholders. Therefore, it seemed that a consensus process had to be carried out.

Considerations regarding other symptomatic domains

Some symptomatic domains are closely related and their assessment may be performed together. Examples of these are stiffness and freezing as well as dyskinesia that will be assessed in the frame of hypokinesia/bradykinesia. So, although dyskinesia was highly ranked both among clinicians and scientists (Delphi process), it was not included in the final list because its assessment could most probably be performed in the frame of hypokinesia / bradykinesia assessment [16].

Some other symptomatic domains are extremely difficult to measure in a continuous home assessment both for logistic reasons and for technological impossibilities, for example domains related to the autonomic function (hypersexuality, or constipation and other gut related problems).

Automated speech analysis is currently under much research but there is clearly a pressing need for further high-quality research to produce sufficient evidence on which to recommend a comprehensive set of methods for a standard clinical voice evaluation [17]. Eye motility and vision were considered but current technology is still not advanced enough to propose a feasible continuous monitoring solution comfortable and inconspicuous enough for home use. Maybe such technologies will emerge (such as more advanced eye tracking systems) and these and other domains could be included in future studies.

In Table 4 some concepts could not be matched in a one-to-one relationship. One such situation was that PwPs used several concepts to describe different mental states, depression and anxiety, which were clustered under the general term "behaviour". Another example was seen regarding "physical activity and fitness", which is used by the medical community. However, the PwPs mentioned not only "physical activity", which can be directly related to the clinical terminology, but they also mentioned "tiredness and exhaustion" which did not have a direct match to a clinical concept. Therefore "tiredness and exhaustion" was also associated with the term "physical activity and fitness".

Interaction dynamics between PwPs and clinicians

During the whole process, it was clearly observed that there was a different type of interaction in the relationship between PwPs and clinicians from that usually observed in a doctor appointment's setting. In the meetings, the patients felt that they were heard not only regarding their symptoms but also on their expert views of living with the disease. The interaction between patients and clinicians was meant to achieve a common goal. Whereas in a usual appointment the goal is the improvement of the patient's health, the target here was to achieve a better understanding of the disease, that would both improve the health and quality of life of the PwP, and promote the advance of therapies and the understanding of how patients react to them. The ultimate aspiration for both PwPs and clinicians is to contribute to finding a cure for Parkinson's.

What PwPs wanted from the system was slightly different from what clinicians wanted: improving quality of life vs. knowing more about the disease and improving treatment. So, PwPs were more interested in a system that would help them better understand how their daily life is affected by differences in the intake of medication (time and dosage), exercise, sleep, diet, etc. Clinicians preferred a monitoring system that would produce clinical data to give evidence of how PwPs react to different therapies. At the end, these two needs are well matched, for example, by adapting individual therapies based on the measured clinical data. This would both improve daily life and help the understanding of patient reactions to the therapy.

The impact of technologists

Once all the views had been gathered, the ultimate question for the project was how could these findings be turned into useful input to help the technologists design the technological measurement device. How could the results obtained from the PwPs and those from the clinicians be combined to produce a working system? The technological challenge is described in [18]. Although both views of clinicians and PwPs were considered, a final hurdle was assessing the technical possibility of measuring the identified symptomatic domains. If it were not possible to devise a technological solution to monitor a certain symptomatic domain within the available timeframe (about 2 years), the symptomatic domain was not included in the final list.

It is important to note that the whole process of selection of the symptomatic domains described in this paper was impacted by the presence of technologists. They were involved in the selection process because it was necessary to guarantee the technical feasibility of the proposed solution. This was a strength because it prevented the discussions from moving into scenarios that would be impossible to implement.

We conclude that the three views from the PwPs, from the clinicians and from the technologists were imperative and necessary. This is true in relation to the focus of SENSE-PARK to produce a technological measurement device for the assessment of the Parkinson's condition in a time horizon of two years.

CONCLUSIONS

This paper presents a concerted approach to combine the views of PwPs, with clinicians and technical developers, and align their understanding over a set of symptomatic domains that are relevant for the detection of progression of the condition of PD and responses to treatment. The achieved list of symptomatic domains (Table 3) is the best possible compromise out of the ranking of the needs of PwPs and those of clinicians, tempered by technical feasibility so that a measurement system could be developed to promote the understanding of the disease and the likelihood of identifying better treatments, for the overarching goal of improving patients' lives. Some symptomatic domains (e.g. autonomic function, including constipation and other gut related problems, voice [17], vision and eye motility) that are obviously important but are extremely difficult to measure in a continuous home assessment both for logistic reasons and for technological impossibilities, are not included in the final list. These may however be included as soon as the technical development has reached a level which allows for valid continuous measurement. This process therefore included decisions that were to a certain extent subjective, and we would like to emphasize that we opted for one strategy to tackle the problem of "speaking the same language" among the stakeholders which led to the results presented here; of course a different strategy could have the potential to generate different results.

This report may be of relevance for similar interdisciplinary approaches in the field of PD using a participatory design, and in general for any projects that need concerted inputs from PwPs, clinicians and technologists.

FURTHER WORK

At the time of writing, the development of the technological measurement device has reached the state of a fully functional prototype. This device comprises: a) a set of sensors based in accelerometers to be placed on one or both wrists, the same on the feet and one on the waist; b) a mobile App to be installed in the user smart phone which has both a functionality for the registration of user reported time-stamped events and is able to store the sensor collected data; c) PC software to upload the data from the App and display it in a graphical user interface. The PC software also incorporates a series of tests to be performed by the PwPs which focus attention on non-motor aspects of Parkinson's such as mental agility, mood and sleeping patterns. The device, its design, prototyping and functionalities, is presented in [18]. The measurement device has been tested in a multi-site observational case-control study including 11 PwPs who wore the sensor system for a period of 12 weeks. The study aimed at testing if the device is able to capture in a meaningful way for both PwPs and clinicians the relevant parameters related to the agreed symptomatic domains and evaluate the usability and user acceptance of the device, therefore providing relevant feedback about the usefulness of the process reported here. The study was concluded in October 2014. Several publications will report on the obtained results.

ACKNOWLEDGEMENTS

We express our grateful thanks to all the study participants for their enthusiastic support and input, and we thank in particular the following "super-users" Tom Isaacs, Fulvio Capitanio, Sara Riggare, Alan Lewin, Eros Bresolin and Dr. Jon Stamford for their invaluable contributions to this work. They contributed to the success of SENSE-PARK from the very beginning of the project. The term "super-users" includes the following capabilities: he/she is himself/herself a PwP, adopts an intrigued and active attitude towards new technologies/devices regarding the self-management of the chronic characteristics of their condition, and is willing to try out and give feedback on the devices produced in the project.

The present research is part of the EU project SENSE-PARK, funded under the Seventh Framework Programme, Cooperation – ICT, Grant Agreement no. 288557.

CONFLICT OF INTEREST

The authors have no conflict of interest to report.

REFERENCES

[1] Maetzler W, Nieuwhof F, Hasmann SE, & Bloem BR (2013) Emerging therapies for gait disability and balance impairment: Promises and pitfalls. *Mov Disord*, **28**, 1576-1586.

[2] Maetzler W, Domingos J, Srulijes K, Ferreira JJ, & Bloem BR (2013) Quantitative wearable sensors for objective assessment of Parkinson's disease. *Mov Disord*, **28**, 1628-1637.

[3] Paul Wicks P, Timothy E, Vaughan TE, Michael P, Massagli MP, & James Heywood J (2011) Accelerated clinical discovery using self-reported patient data collected online and a patient-matching algorithm. *Nat Biotechnol*, **29**, 411-414.

[4] Wicks P, Vaughan T, & Heywood J (2014) Subjects no more: What happens when trial participants realize they hold the power? *BMJ* **348**, g368. Erratum in: *BMJ* **348**, g3383, 2014.

[5] Vayena E, & Tasioulas J (2013) Adapting standards: Ethical oversight of participant-led health research. *PLoS Med*, **10**, e1001402.

[6] Eijk M, Frouke, Nijhuis FAP, Marjan MJ, & Bloem BR (2013) Moving from physician-centered care towards patient-centered care for Parkinson's disease patients. *Parkinsonism Relat Disord*, **19**, 923-927.

[7] Merriam-Webster Inc. (2006) *Merriam-Webster's Medical Dictionary*. ISBN-13:9780877798538

[8] Nijkrake MJ, Keus SH, Overeem S, Oostendorp RA, Vlieland TP, Mulleners W, Hoogerwaard EM, Bloem BR, & Munneke M (2010) The ParkinsonNet concept: Development, implementation and initial experience. *Mov Disord*, **25**, 823-829.

[9] Dix A, Finlay JE, Abowd GD, Beale R. (2003) *Human-Computer Interaction*. Prentice Hall, 3 edition, ISBN-10:0130461091

[10] Schuler D, & Namioka A. (1993) *Participatory Design: Principles and Practices*. CRC Lawrence Erlbaum Associates, ISBN-10:0805809511

[11] Muller MJ, & Sarah KS (1993) Participatory design. *Commun AC*, **36**, 6.

[12] Sutcliffe A, Thew S, De Bruijn O, Buchan I, Jarvis P, McNaught J, & Procter R (2010) User engagement by user-centred design in e-Health. *Philos Trans A Math Phys Eng Sci*, **368**, 4209-4224.

[13] Soh SE, McGinley JL, Watts JJ, Iansek R, Murphy AT, Menz HB, Huxham F, & Morris ME (2013) Determinants of health-related quality of life in people with Parkinson's disease: A path analysis. *Qual Life Res*, **22**, 1543-1553.

[14] Cheng EM, Siderowf A, Swarztrauber K, Eisa M, Lee M, & Vickrey BG (2004) Development of quality of care indicators for Parkinson's disease. *Mov Disord*, **19**, 136-150.

[15] Ling H, Massey LA, Lees AJ, Brown P, & Day BL (2012) Hypokinesia without decrement distinguishes progressive supranuclear palsy from Parkinson's disease. *Brain 135(Pt 4)* 1141-1153.

[16] Griffiths RI, Kotschet K, Arfon S, Xu ZM, Johnson W, Drago J, Evans A, Kempster P, Raghav S, & Horne MK (2012) Automated assessment of bradykinesia and dyskinesia in Parkinson's disease. *J Parkinsons Dis*, **2**, 47-55.

[17] Roy N, Barkmeier, Kraemer J, Eadie T, Sivasankar MP, Mehta D, Paul D, & Hillman R (2013) Evidence based clinical voice assessment: A systematic review. *Am J Speech-Lang Pathol*, **22**, 212-226.

[18] Serrano JA, Thoms A, Weber P, & Consortium SENSE-PARK (2014) Patients initiated timeline marking of events in Parkinson's Disease: Visualization of time correlation between patients marked events and acquired data from sensors. *In Foundations of Augmented Cognition. Advancing Human Performance and Decision-Making through Adaptive Systems, Lecture Notes in Computer Science*, Volume 8534, pp. 325-334. http://link.springer.com/chapter/10.1007/978-3-319-07527-3_31, Last updated June, 2014, Accessed on Septembe, **23**, 2014.

APPENDIX – MATCHING TERMINOLOGY TABLE

Table 4
The "terminology table" with the matching between PwPs' normally used terms and clinical terminology

PwP terminology	Clinical terminology	Motor (m) or non-motor (nm)
Slowness of movement	Hypokinesia and bradykinesia [15][1]	m
Balance problems	Sway	m
Difficulty with fine motor movement	Distal motor movements	m
Physical activity	Physical activity and fitness	m
Constipation and other gut related problems	Autonomic function	m
Tiredness/exhaustion	Physical activity and fitness	nm
Inability to organise	Cognitive function	nm
Depression	Behaviour	nm
Anxiety	Behaviour	nm
Difficulties with eyesight	Eye motility and vision	m
Difficulty instigating movement	Gait / gait initiation	m

[1] Slowness of initiation with progressive reduction in speed and amplitude of repetitive action.