Active and healthy ageing for Parkinson's Disease patients' support: A user's perspective within the i-PROGNOSIS framework

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***Abstract*—In this paper, the user requirements, along with the methodology adopted towards their identification within the i-PROGNOSIS framework (www.i-prognosis.eu), are presented. The latter are placed within the concept of active and healthy ageing (AHA), focusing on the case of Parkinson's Disease (PD) patients' support. The bases for the user requirements identification were face-to-face sessions, focus groups and a large scale Web-survey. Towards the efficient user requirements identification and i-PROGNOSIS components development, exemplified usage scenarios and related business processes the stakeholders of i-PROGNOSIS can perform, are discussed. Overall, 122 functional and non-functional requirements were identified, serving as a basis for the spiral development model of i-PROGNOSIS, revealing the beneficial role of the users in designing solutions within the AHA concept.**

Keywords—Active and healthy ageing; Parkinson's Disease; user requirements; i-PROGNOSIS

I. INTRODUCTION

A. Active and Healthy Ageing (AHA)

Active and healthy ageing (AHA) is the process of optimising opportunities for health, participation and security in order to enhance quality of life as people are getting older. European Innovation Partnership on Active and Healthy Ageing (EIP-AHA) has this concept as part of its strategy, originally derived from a policy framework of the World Health Organisation (WHO) [1] (Fig. 1). 'Health ageing' can incorporate physical, mental, as well as social well-being, whilst 'Active ageing' incorporates a range of aspects, including social, economic, cultural, spiritual and civic affairs, and labour force. EIP considers ageing as an opportunity, whereby older persons are a valued and recognised part of a growing society. It aims to empower these individuals in their communities using innovative service delivery with the user in mind.

Fig. 1. The determinants of active ageing according to the policy framework of the WHO [1].

Innovation in services and products for AHA may require large investments and certainly carries risks. Furthermore, it needs knowledge development and integration of the supply-

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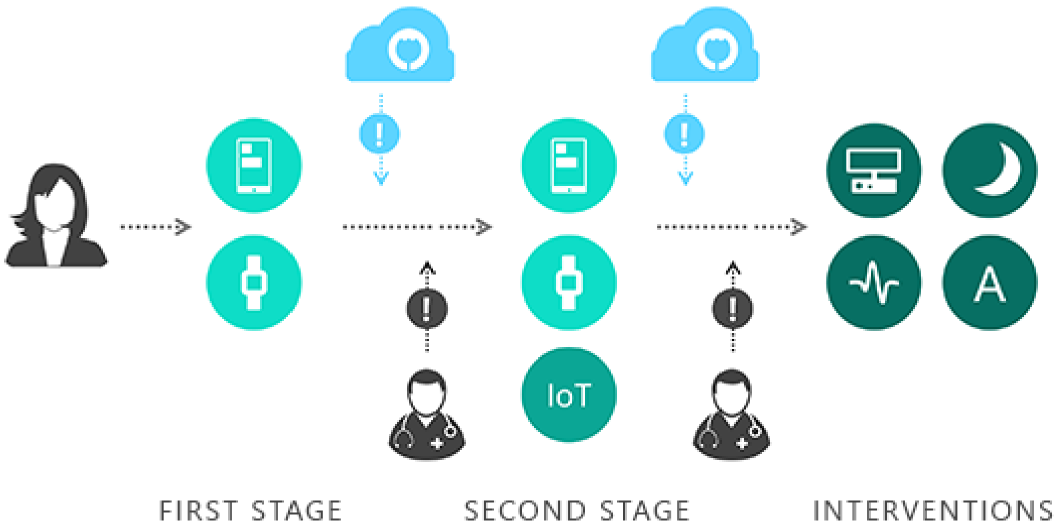


Fig. 2. The i-PROGNOSIS system concept includes two stages for PD detection based on smartphone, smartwatch and internet-of-things (IoT) user interaction and the interventions stage (serious games, nocturnal and assistive interventions, as well as monitoring). Besides, the i-PROGNOSIS automated indication of a user's behavioural change related to PD, the role of the physician is crucial regarding the validation of the indication and the transition from one stage to the next one.

and-demand aspect in line with the whole research and innovation cycle. However, when the solutions are effective, cost-efficient and evidence-based, then the gain is greater and more meaningful. Hence, healthy aging is an economic multiplier, which allows for a better outcome for older adults, healthcare professional satisfaction, quality of life improvements, and financial security for carers, all of which are achieved with improved efficiency and increased productivity of health and social care systems. Innovation is able to bring value to older adults in parallel with delivering long-run budgetary savings as these returns are not mutually exclusive.

The need for innovative approaches to better foster efficiency of health and social care systems and guarantee their sustainability has been increased due to the growing demand (ageing, chronic disease expansions), the outflow of healthcare professionals, carers, and ongoing budgetary consolidation. Taking also the current economic crisis into account, there is added pressure for citizens' access to affordable health and social care services and products. An urgent action to shift the focus from secondary based care to proactive primary care, which focuses on integration of social and health care is needed. This should be underpinned by promotion of good health, preventative strategies, independent living and integration of health, social, community and self-care. These need to be supported by an environment empowering older adults to remain functional and active. It is also essential that future care systems-while continuing to be based on the common values of universality, access to good quality care, equity and solidarity- must accommodate new realities and acknowledge the need for cost-efficient investments. The work needed is based on three pillars reflecting the 'life stages' of the older individual in relation to care processes, namely:

- Prevention, screening and early diagnosis;
- Care and cure; and
- Active ageing and independent living.

Responding to the complex issue of AHA requires comprehensive work on a broad scale, in order to determine the best way forward and focus on those innovative actions which deliver the highest impact.

B. The i-PROGNOSIS Framework

i-PROGNOSIS is an EU HORIZON 2020 project (www.i-prognosis.eu) that aims to create an intelligent ICT-based approach for early Parkinson's Disease (PD) symptoms detection and early intervention in older adult's everyday life (Fig. 2), promoting AHA, by introducing new ways of health self-managing tools, set within a collaborative care context with health professionals. This would be achieved by creating an ICT-based behavioural analysis approach for capturing, as early as possible, the PD symptoms appearance and applying ICT-based interventions countering identified risks based on early PD detection, relating to progressive frailty, falls and emotional shift towards depression.

i-PROGNOSIS adopts a radically novel approach to capture the risk of transition from healthy status towards PD, by unobtrusive behavioural sensing and large scale collection of users' data, acquired from their natural use of smart devices (mobile smartphone/smartwatch), after their granted permission, via corresponding mobile applications. Based on downloadable applications, the data are collected from a large number (in the range of thousands) of users (40+ years of age), forming the i-PROGNOSIS Community, are anonymised and analysed using big data analytics and machine learning, in order to identify individuals' behavioural feature vectors that could reliably reveal the shift from healthy to PD status; thus, identifying those that are at risk of developing PD and provide to them novel ICT-based interventions. Due to the unobtrusive character of i-PROGNOSIS, the applications are running on the background of the user's mobile phone, and after getting his/her consent, they automatically collect the required information, uploading it to the Microsoft-based data centres (Azure Cloud) for further analysis, complying with all European norms of data security and privacy. The i-PROGNOSIS system concept is depicted in Fig. 2. From the latter it is clear that the i-PROGNOSIS includes two stages for the PD early detection, starting from general population (1st stage) and focussing on specific population (2nd stage), followed by ICT-based early interventions (3rd stage).

Apart from the early PD risk detection, the i-PROGNOSIS project proposes appropriate ICT-based interventions. The designed ICT-based interventions of the i-PROGNOSIS tackle the risks that are related with the effect of PD on the health condition of the older adults that exhibit PD symptoms; that is, frailty (due to reduced physical condition/skills), falls (due to decreased flexibility, balance/gait stability) and depression (due to chemical changes in the brain and frontal lobe under-activation). The proposed interventions are realised via the i-PROGNOSIS Platform, consisting of a game-based suite Personalised Game Suite (PGS), along with nocturnal and assistive interventions, holistically supporting in a personalised way: muscle tension reinforcement, walking pattern/posture reestablishment and gait rhythm guidance, dietary habits adaptation for reduction of constipation/depression, expressive face encouragement, natural blinking reestablishment, depression/ anxiety treatment, handwriting pattern correction/reestablishment, dysathro- and hypo-phonia reduction, improved pattern of relaxation and sleep quality, facilitating communication with others and socialisation. In i-PROGNOSIS intervention Platform, integrated technology modules will be developed to monitor and support older adult's physical (daily/nocturnal) and emotional status enhancement, towards the decrease of the PD-related risks and increase of their quality-adjusted life-years (QALYs). The mutual interaction with the PGS by small groups of remote participants promotes elderlies' social connectivity and fosters health affecting social interaction, peer support and peer mentoring, contributing to the effective lifestyle behaviour changes (physical activity/skills, dietary habits, emotional expression, interaction/socialisation) and adherence to medical plans.

The aforementioned is supported by i-PROGNOSIS data management system capable of linking large amounts of important and diverse sensed information during the interventions (e.g., response to PGS/nocturnal/assistive interventions, behavioural change data), most of which were not previously available to the healthcare professional, so they can be mined, analysed and modelled to provide the healthcare professional with knowledge and pertinent feedback on demand to make more accurate and informed decisions in relation to older adult's health care. This makes the health professional an informed consultant, who assisted by the ICT-based interventions outcome, supports the older adults, in a personalised way, in achieving his/her optimal health-related quality of life.

C. *The User's Involment*

There is a common belief that user involvement in system development ensures system success [2]–[4], with examples including organizational management research, group problem solving, interpersonal communication and individual motivation [2]. Apparently, satisfaction and acceptance of the system by its ultimately users it is considered as a critical success factor for the project [4]–[7]. Actually, this is due to the users' significant knowledge related to the application domain, the tasks they perform, the context of the system use and their behavior and preferences. Nevertheless, this knowledge is of a tacit nature and, hence, difficult to be expressed with typical elicitation techniques [8]. The focus of this paper is on presenting the way the user requirements were captured and analyzed to inform the development of the i-PROGNOSIS system, as described in the succeeding sections.

II. On Capturing the User's Requirements

The main aim here is the identification of detailed user requirements regarding the i-PROGNOSIS system, including both the detection and the interventions aspects of the system, as well as the detailed definition of usage scenarios. The pool of users includes the main target groups of people aged over 40 years that are at risk of PD and already diagnosed PD patients, as well as health care professionals (e.g., PD expert physicians) and carers of patients. Due to the holistic nature of the proposed system and the diversity of target user groups, the objective was to systematically capture detailed user requirements by employing the following steps:

- Exploiting the expertise of the members of the i-PROGNOSIS consortium to identify the initial set of user requirements, through face-to-face sessions between clinical, user-oriented and technical partners.
- Capturing the opinion of main potential stakeholders of the i-PROGNOSIS system to further shape or enrich the initial set of user requirements, through the organisation of focus groups (small scale survey) and Web questionnaires (large scale survey).
- Elaboration and granularisation of the users-shaped requirements to produce the first detailed version of user requirements based on usage scenarios and respective business processes.

Each agreed requirement (both functional and non-functional) is identified, classified and qualified with respect to its importance ("required", "preferred", "optional"), and its clinical value.

A. *Focus Groups*

As a first step, focus group meetings were initiated to ask potential users, as well as health care professionals, for any subjects to be covered. The process of setting up the focus groups started with identifying who would be:

- Potential users of the application, and

- Healthcare professionals who would be able to judge which features are required to capture clinically relevant details and to protect the required confidentiality of the users.

Once the users were identified, it was then possible to set up focus groups specific to the different groups of people e.g., patients/users/carers and healthcare professionals, such as medical doctors, nurses, allied health specialists, therapists etc. The focus groups were set up to identify useful and informative data collection, user requirements and usability issues. Different types of focus group meetings were organized, i.e.:

- Expert patient group meetings within the Community for Research Involvement and Support for people with PD (CRISP).
- Health care professional (HCP) focus groups (Multi-disciplinary team meetings).
- Evening meetings including patients, carers and HCPs.

Prior to the focus groups discussions, the coordinator of each focus group briefed the participants about the key objectives of the project and the technology that is intended to be used. In the focus groups, general aspects of user requirements for the i-PROGNOSIS application were discussed and a paper questionnaire of user requirements was used for orientation. Furthermore, healthcare professionals of each group, who could not join the discussion round, were provided with a paper questionnaire for completion.

B. *Interviews*

Apart from focus groups, interviews were conducted in a quite flexible way, starting from a general understanding of the i-PROGNOSIS project going through the use of new technologies in general and then in relation to the project. Actually, 35 persons have discussed about healthy ageing, whereas 40 ones about accessibility, new technologies and mobility. While each interviewee was asked to answer from his/her point of view, they were also asked to give a feedback regarding their friends/relatives and on older people in general in their country.

C. *Web-Surveys*

Apart from the focus groups and interviews, a Web survey was conducted in order to identify user requirements, define system specifications and, more generally, evaluate and testify the i-PROGNOSIS concept. The Web survey was performed via a specifically designed Web questionnaire consisting of four parts:

- Part I: Provides an introduction to i-PROGNOSIS project, describes the aim of the questionnaire and identifies if the participant is: i) a Parkinson's disease patient, ii) a healthcare professional or carer, and iii) a healthy person.
- Part II: Includes general demographic questions
- Part III: Includes questions regarding the Parkinson's disease detection functionality of the system. More specifically, there is a brief description along with questions about the smartphone application that is planned to be developed, the smartwatch, the smart belt, the Mandometer plate-scale and the TV smart remote control.
- Part IV: Includes questions regarding the interventions functionality of the system. More specifically, there is a brief description along with questions about the electronic games, night-time intervention, gait intervention and voice enhancement intervention.

Parts II and III apply to all participants, while Part IV applies only to healthcare professionals/carers and PD patients. The Web questionnaire was based on the focus group questionnaire and the number of questions was kept as small as possible in order to facilitate participation. The Web questionnaire was realised in Google Forms that is a free, convenient and fully customisable tool to create and analyse surveys.

III. Analysis Axes

For the efficient analysis of the Web survey results, the responses to questionnaires were accumulated and processed collectively. A simple, yet adept, statistical analysis took place in order to extract the frequencies of each available response for the majority of questions. Only the responses of participants that were aged over 40 were considered in the above procedure, because younger participants do not constitute the target group of the project and are not the prospective users of the system. The statistical analysis of the responses was conducted separately for the three participant categories, i.e., healthy, patients and healthcare professionals/carers, in order to identify potential diverse opinions and needs. The analysis results are presented in the following section in the form of stacked bar plots for a more conclusive interpretation.

IV. Resulst and Discussion

A. *Focus Groups/Interviews Outcomes*

This section presents qualitatively the key outcomes derived from the focus groups and interviews and relate to user requirements and concerns, in the form of discrete focus group observations (FGO#), as tabulated in Table I.

TABLE I. User Requirements and Concerns as Identified from Focus Groups and Interviews

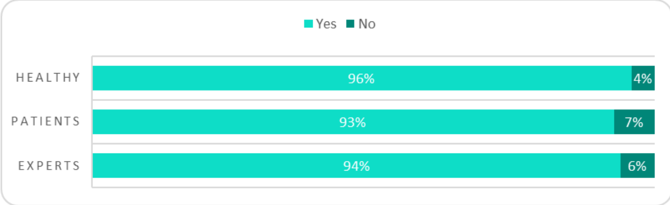
FGO#	User Requirements
FGO1	Privacy, anonymization and data protection is very important for the i-PROGNOSIS project
FGO2	There must be versions of the i-PROGNOSIS application in different languages.
FGO3	The consent form must be carefully structured and clearly state what data will be captured, the reason why and how will be processed and exploited.
FGO4	The consent form must be readable with ease on the display of a mobile device.
FGO5	There must be an option for the users to withdraw their consent.
FGO6	Photos of users processed must be anonymized also.
FGO7	Brief instructions when installing the i-PROGNOSIS application are preferred instead of extensive instructions

FGO#	User Requirements
FGO8	Notifications and feedback via the i-PROGNOSIS detection application should not be included as this may affect the users' natural use of their smartphones and, in turn, this could skew the collected data.
FGO9	The system must include technical support.
FGO10	The smartwatch/fitness tracker must support regular watch functionalities, i.e., display the time and provide alarms.
FGO11	The smart belt must be thin, light and comfortable, with a clear indication of which way the belt should be worn. Its materials must be soft and hypoallergenic in order to be worn directly on the skin.
FGO12	The i-PROGNOSIS detection application must not provide feedback regarding the ECG captured by the smart TV remote, as this may distress users.
FGO13	Feedback regarding captured data provided by the i-PROGNOSIS applications must be provided as a summary on a weekly/fortnightly basis.
FGO14	Headphones involved in the targeted nocturnal intervention must be comfortable and soft.
FGO15	The gait rhythmic guidance intervention must be capable of intervening automatically.
FGO16	The voice enhancement intervention is considered useful.
FGO17	Accessibility must be seriously taken into consideration in designing the i-PROGNOSIS applications.
FGO18	Services and processes of the i-PROGNOSIS applications must not have significant impact on the battery life of mobile devices.
(FGO#)	**Concerns**
FGO19	There were concerns about the smartphone and new technology in general penetration in the elderly population.
FGO20	There were concerns about the availability of internet connection at homes of the elderly population.
FGO21	There were concerns about the usefulness of capturing eating mechanics using the Mandometer and the user friendliness of capturing constipation data using the smart belt during the i-PROGNOSIS detection phase.
FGO22	There were concerns about the user acceptance of the targeted nocturnal intervention.
FGO23	The role of the physician must remain central in the process of PD diagnosis.
FGO24	Reliability of the i-PROGNOSIS applications must be reassured before making them available to the public as the first experience must be positive in order not to discourage users.

B. *Web Survey Results*

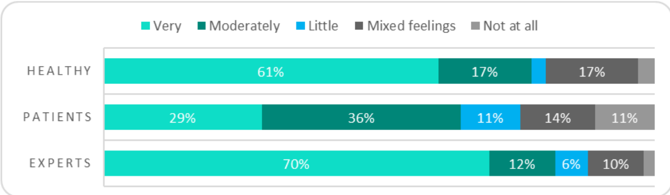
This section provides the quantitative results of the Web surveys. For the sake of space, indicative questions of the survey are presented (the full list of questions can be found at www.i-prognosis.eu), accompanied with a percentage histogram based on the answers of three groups of users, i.e., healthy adults over 40 years of age (Healthy), PD patients (Patients) and experts (physicians or caregivers) with experience in PD (Experts). Results presented in this section are based on answers from 877 Web survey participants, 648 belonging to the Healthy group (> 40 years old), 114 belonging to the Patients group and 115 belonging to the Experts group, received by the beginning of June, 2016. Each question (Q#) is accompanied by a brief working observation (WO#) deduced from the results:

Q1: Could you imagine participating in such a project which implies the installation of a specific application (the i-PROGNOSIS application), sharing of health data, etc.?



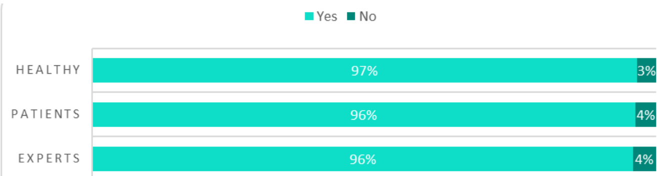
WO1: The vast majority of the target group is willing to participate in a project like i-PROGNOSIS. So, the i-PROGNOSIS application is expected to exhibit increased popularity, leading to the collection of sufficient amount of data.

Q2: How important is it to you to have the option to select which data are collected by the application?



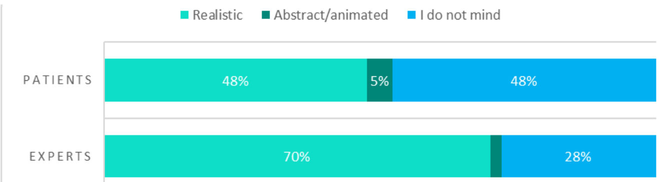
WO2: The i-PROGNOSIS application should offer the option to the user to select which data are collected by the application.

Q3: Would you consent to share your health status data and daily routines for research purposes in an anonymous and secure manner?



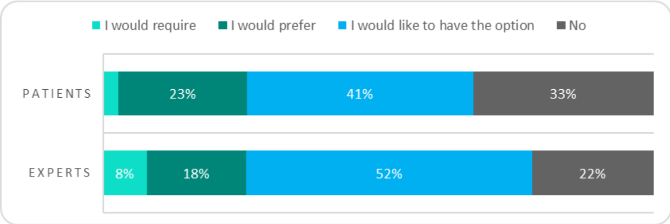
WO3: The i-PROGNOSIS concept has a huge potential to be realised since the vast majority of the target group is willing to share, in a secure and anonymous manner, health status data and daily routines for research purposes.

Q4: Would you prefer the graphics of the games to be realistic or abstract/animated?



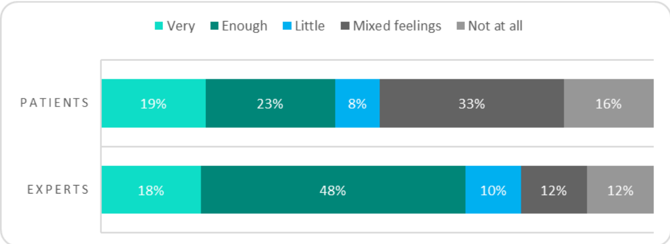
WO4: Based on the experts, mainly, the graphics of the games should be realistic.

Q5: Is it important to you to have a social dimension in the game suite (e.g., collaboration, competition)?



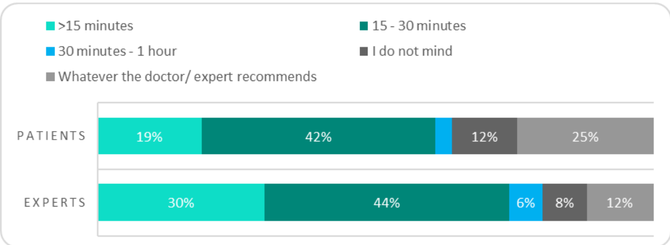
WO5: The game suite should include optional social-based features.

Q6: Is it important that you receive motivational messages (e.g. "you are doing very well – please keep up")?



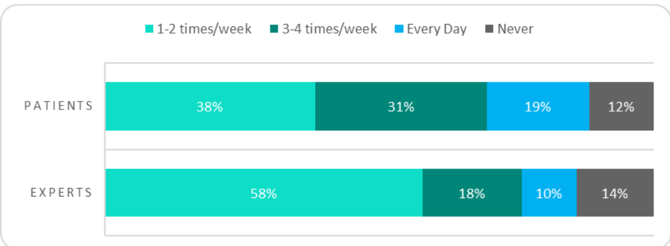
WO6: Motivational messages should be provided to the user, based, mainly, on the experts' opinion.

Q7: What would be a convenient duration of a game session for you?



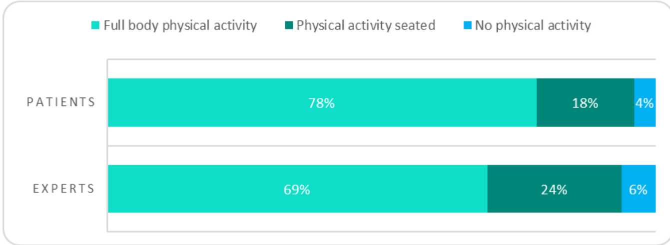
WO7: A game session should not last longer than 30 minutes, unless the doctor/expert recommends.

Q8: How often do you imagine yourself playing the games?



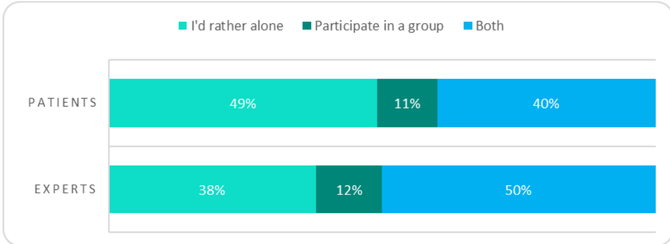
WO8: The majority of the target groups would engage at least once a week with the intervention games.

Q9: What type of Exergames would you be interested in?



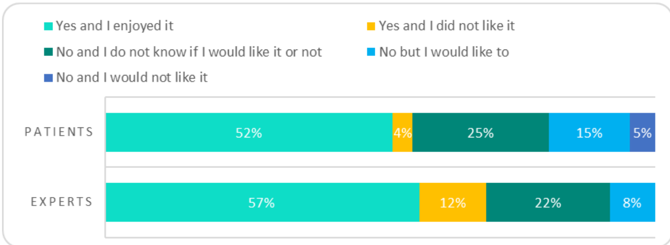
WO9: The Exergames should engage full body physical activity.

Q10: Would you like to play the games alone or with other people in the same room?



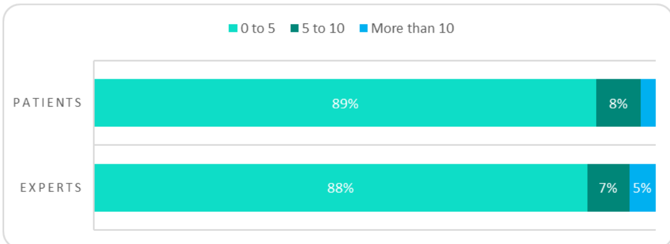
WO10: The games may include a local multiplayer option.

Q11: Have you ever played games with other family members (grandchildren, nephews, etc.) and how did you like it?



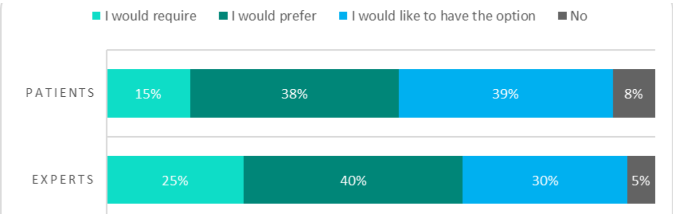
WO11: About half of the target group has positive previous experience with playing games with other family members while the rest do not have such kind of experience.

Q12: How many gait freezing episodes do you experience in a week?



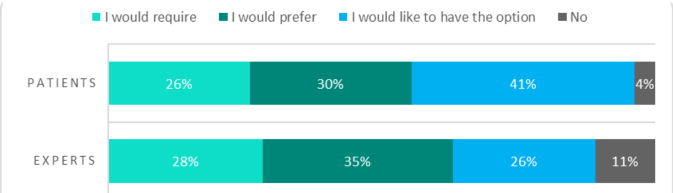
WO12: Only, a few freezing episodes are experienced every week. However, the gait intervention, when it will be enabled, could improve the everyday life of PD patients, so it should be taken as a development priority.

Q13: When a freezing episode is detected, should the gait intervention start automatically?



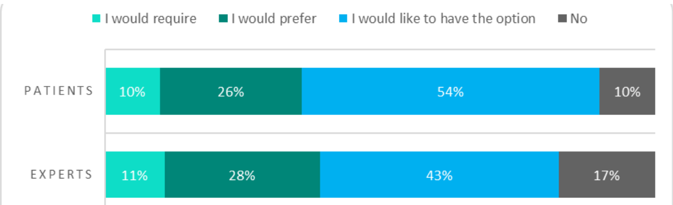
WO13: It would be useful if the gait intervention could be started automatically.

Q14: Should this application have an option to give you a discreet signal when it detects your voice is not loud or clear enough, so that you can try to balance your voice before activating the intervention?



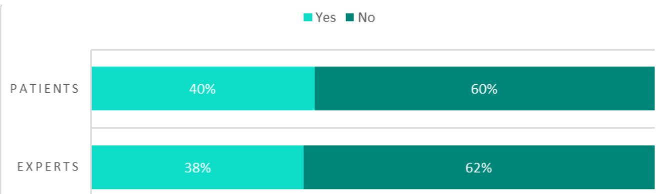
WO14: The voice enhancement intervention should notify the user when his/her voice is not loud/clear and allow for self-management, prior to the activation of the intervention.

Q15: Would you like to use this intervention when you are in a face-to-face conversation?



WO15: The voice enhancement intervention should have the option to be used in face-to-face conversations.

Q16: Would you mind if this intervention changed the tone and pitch of your voice during a phone call to achieve better understanding?



WO16: Distortion of voice features would not disturb the users.

C. Usage Scenarios and Business Processes

Taking into account the identified user requirements, the i-PROGNOSIS usage scenarios (US) and business processes could be derived. In particular, the US refers to a description of how the system will be used from the perspective of the user, and the actors (Table II) and the components of the system are defined. To facilitate this, a unified modelling language (UML) case diagram is included [9], illustrating the relationships between the actors and the interactions with the system components. Finally, via the business processes, a granular break-down of the USs into a detailed description of the tasks included in it is developed. An example of the latter is US-1, which unfolds when an adult chooses to download and install the i-PROGNOSIS detection application on her/his smartphone for the first time from the application store. Fig. 3 illustrates cumulatively the use cases and the actors in US-1 as a UML use case diagram.

TABLE II. LIST OF ACTORS PARTICIPATING IN THE I-PROGNOSIS USAGE SCENARIOS AND BUSINESS PROCESSES

Actor	Definition
Adult	An adult that is interested in participating in the i-PROGNOSIS first or second stage of detection.
Caregiver	A person (professional or not) close to the interventions user that helps her/him with her/his activities of daily living.
Diagnosed PD patient	An adult that has been medically diagnosed with PD, without being a participant in the i-PROGNOSIS detection stages.
Expert physician	A physician with expertise in PD diagnosis and treatment and with knowledge of the i-PROGNOSIS solutions.
First stage user	An adult that participates in the i-PROGNOSIS first stage of Parkinson's detection and uses the respective system components.
Game friend	A separate interventions user that has been linked to the interventions user of interest (through their expert physician) and, together, they participate in a healthy competition regarding their gamified interventions performance.
Interventions user	An adult that follows the i-PROGNOSIS interventions and uses the respective components.
Second stage user	An adult that participates in the i-PROGNOSIS second stage of PD detection and uses the respective system components.

V. CONCLUDING REMARKS

From an overall perspective, it is clear that a systematic approach towards the identification of user requirements of the i-PROGNOSIS project was adopted. As the user is the central pillar of the project, the approach involved a series of actions-certain of them involving the major stakeholders directly-in order to capture detailed requirements and resolve ambiguous issues relating the development of the i-PROGNOSIS components under a holistic approach in tackling PD detection and intervention. The basis for the identification of user requirements was set and built upon by the i-PROGNOSIS consortium experts through face-to-face sessions. Requirements derived from this procedure were further refined by the focus groups'/interviews' observations and the results of the i-PROGNOSIS Web survey. The latter had a triple role:

- to source user requirements directly from a large population belonging to the target groups (healthy, PD patients and PD experts),

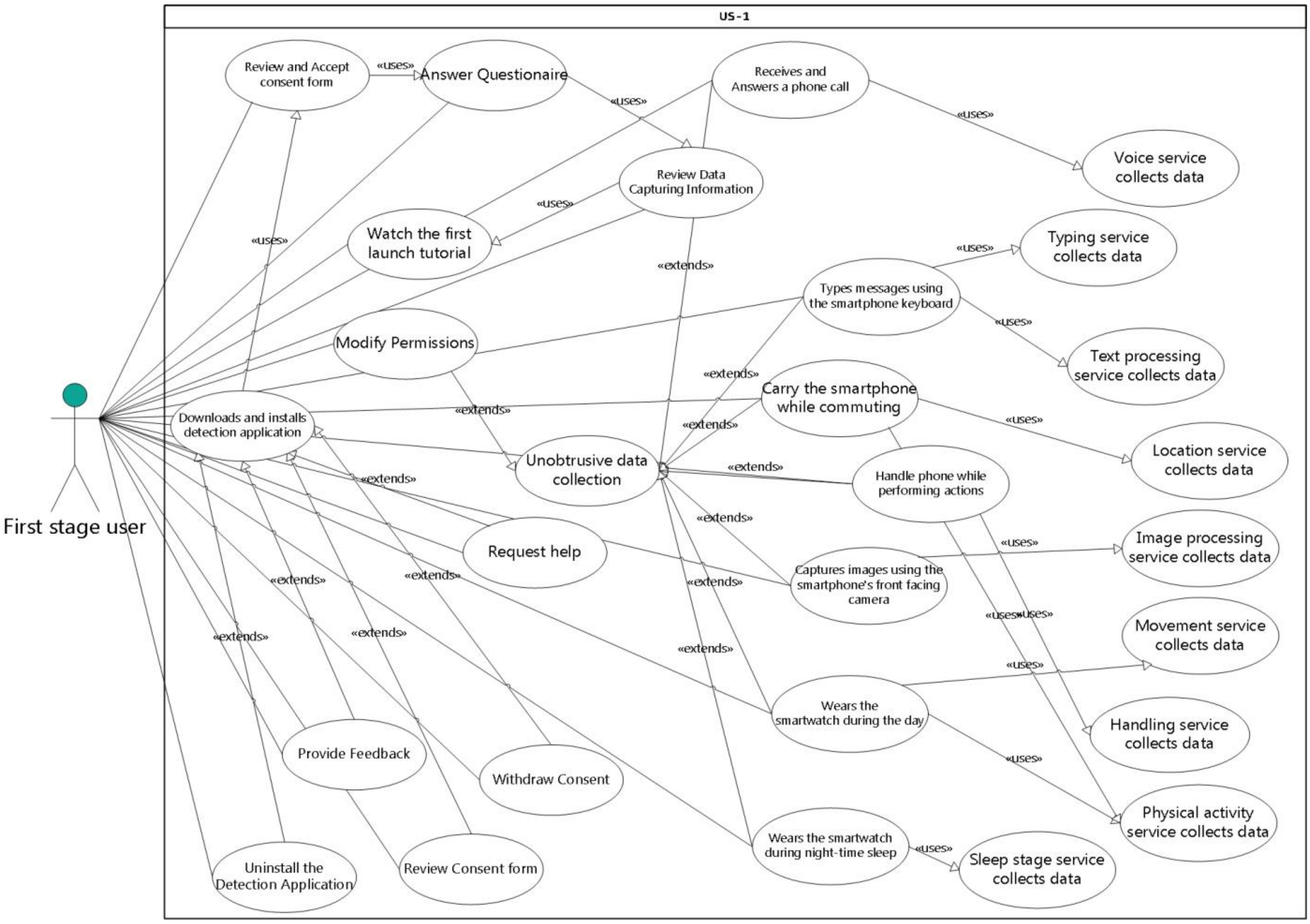


Fig. 3. The use cases and the actors in US-1 as a UML use case diagram.

- to validate or shape certain technical specifications of the i-PROGNOSIS components, and
- to collaterally and early disseminate the project to the target population.

Results of the Web survey were consistent in terms of the answers the different groups of participants gave and no controversies were observed. Overall, 102 functional and 20 non-functional user requirements were identified in this first version of the analysis. As i-PROGNOSIS has adopted a spiral development approach, the first set of user requirements is expected to be updated mainly after the first pilots and the first user acceptance evaluation, as well as by the continuous stream of data from the Web surveys. Finally, a granular approach from usage scenarios to business processes was adopted, helping to identify user requirements in a more efficient way, further facilitating the development of the i-PROGNOSIS components.

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