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# D2.1 / Initial report on user research and co-creation

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## List of abbreviations

AI	Artificial intelligence
Apo	Apomorphine
GP	General practitioner
HCP	Healthcare professional
ICG	Informal caregiver
iRBD	Idiopathic REM sleep behavior disorder
KPI	Key performance indicator
mHealth	Mobile health
MVP	Minimum viable product
PD	Parkinson's disease
PwoP	People without Parkinson's disease, such as ICGs and persons at risk for PD
PwP	Person with Parkinson's disease
R&D	Research and development
UI/UX	User interface/User experience
WP	Work package

## Executive summary

The purpose of deliverable D2.1 “Initial report on user research and co-creation” is to provide an initial documentation on stakeholders and potential user needs and methods employed in research and developing new digital solutions. Different forms of co-creation between developers and users are described, with considerations for co-creation in healthcare application development. As a background, the current status for diagnosis of Parkinson's Disease (PD) and care pathways for people with PD (PwP) is defined through four countries: France, Germany, Spain, and the United Kingdom (UK).

Qualitative methods have been used to gather data to inform the design process and enhance user experiences of the AI-PROGNOSIS ecosystem of digital health tools for advancing PD diagnosis and care. User research is an iterative process that plays a pivotal role in shaping user-centric solutions, ensuring that the end product aligns seamlessly with the expectations and preferences of its intended users. Collected data has provided user needs for the solutions of AI-PROGNOSIS, i.e., the mAI-Health mobile app for persons without PD, the mAI-Care mobile app for PwP, and the mAI-Insights platform and the AI-assisted medication decision support module for healthcare professionals, and are coded, described, and prioritised at the end of the report.

This first deliverable, under T2.2 will be updated by D2.4 “Updated report on user research and co-creation”.

# 1 Introduction

## 1.1 Document scope

D2.1 “Initial report on user research and co-creation” is a key deliverable of WP2. It falls under Task 2.2 “User research and co-creation” which aims to define the needs of relevant stakeholders and effectively engage them in developing tailored AI-driven tools for PD risk assessment and prognosis.

The document defines the user research and co-creation process within the project and presents the findings of the secondary and primary user research, with emphasis on the needs, requirements, and concerns of stakeholders regarding the tools for PD screening and care that AI-PROGNOSIS aims to develop.

## 1.2 Document structure

This report is structured into six additional sections:

- 1) The background (Section 2) is provided for the current status of PD diagnosis and PwP care pathways within selected countries (where AI-PROGNOSIS clinical partners are based), as well as an overview of gender differences within PD and PwP's needs from digital technology.
- 2) Section 3 introduces the common methods of user research and co-creation.
- 3) Section 4 defines user research and co-creation within the project.
- 4) Section 5 provides secondary research findings, as well as initial primary user research findings from focus groups with the AI-PROGNOSIS patient panel and interviews of healthcare professionals (HCPs).
- 5) The identified user needs within the project are described in Section 6.
- 6) Section 7 concludes the report and provides with future work within the project.

At the end of the report, three Appendices are presenting the focus group protocol, as well as the HCPs' interview guide, the checklist for co-creation with focus on patients and informal caregivers (ICGs) as partners, and the personas for HCPs, PwP, and people without PD (PwoP), including ICGs and at-risk individuals.

# 2 Background

## 2.1 Current status for PD diagnosis and care pathways

The current status for PD diagnosis and care is described for the four countries where AI-PROGNOSIS clinical partners are based, i.e., France, Germany, Spain and United Kingdom (UK). There is little evidence about the education level of PwP, as well as their abilities regarding the use of technology, apart from the UK, where patients are described having high abilities of using technology. Levodopa is one of the most common treatments, and the number of visits for clinical assessment differs between the different study sites within the countries from one to four annual visits.

## 2.1.1 France

### 2.1.1.1 Characteristics of patients

#### **Numbers of PwP, distribution Male/Female, age distribution and other demographics**

There are approximately 200.000 PD patients in France, with an average disease onset of 58 years (10% < 40 years old) and a ratio of male to female is 1.5:1. Annually, 25,000 new patients receive the diagnosis (Institute Pasteur, 2020).

#### **Where do they live?**

PD patients are equally distributed in rural areas and cities.

#### **Education level**

There is no specific data on educational level of French PD patients.

#### **Technological abilities**

Similarly for educational level, no data for technological abilities are available for French patients. AI-PROGNOSIS patient panel members (see Section 4) expressed that in their experience, French PD patients may be reluctant for technology use, including applications (apps), tele-visits/telemedicine and wearable sensors. The sole exception is the use of easy-to-use wearable sensors (e.g., the PKG<sup>1</sup> or Sense4Care<sup>2</sup> or FeetMe<sup>3</sup>) for which patients can be helped by healthcare providers with home visits. However, a 2020-2021 web-based survey in France found that the majority (1,239 out of 2,003 respondents, 62%) considered the use of mHealth apps useful but only 27.6% (551 out of 2,003) found video recording/broadcasting useful. Age ( $\leq 55$  years), trust in political representatives, and higher health literacy were factors associated with the perceived usefulness of both technologies (Touzani et al., 2023).

### 2.1.1.2 Characteristics of the healthcare system

#### **How is care for PD delivered?**

PD patients are principally followed by neurologists, both community-based neurologists and hospital-based ones, who frequently collaborate (one visit/year with each one of those physicians). Concomitantly, one epidemiological study in 2017 showed that only 33.5% of PD patients had received a neurology consultation over a one-year study period (Carriere et al., 2017), whereas a neurology consultation every 6 months is the recommended standard of care in the French national protocol for diagnosis and management (PNDS).

#### **How is care for PD funded?**

Care for PD is funded by the National health care system, even if the pharmaceutical industry's contribution to research protocol is allowed and frequently used.

#### **What does the journey to a PD diagnosis look like in France?**

The diagnosis journey depends on whether a patient lives in cities or rural areas. For the latter, access to a specialist for diagnosis may require travel to a city, as the number of specialists may be limited. This can delay diagnosis and treatment. However, in the city this is less of an issue.

#### **What does the standard practice for PD care look like?**

The standard practice of care for PD patients is two visits/year, including one in tertiary hospital. Access to PD nurses and educational therapies programs is possible; however, mainly in university hospitals.

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<sup>1</sup> PKG Health - <https://pkghealth.com/>

<sup>2</sup> Sense4Care - <https://www.sense4care.com/pages/products/>

<sup>3</sup> FeetMe - <https://feetmehealth.com/>

## Available treatments

All oral/transdermal treatments (with the exception of Safinamide, Opicapone, and of Rivastigmine that is available but not reimbursed) and all advanced treatments (Brinker et al., 2023), such as deep brain stimulation (Okun, 2012), Gamma-Knife (Higuchi et al., 2017), apomorphine (apo) pump (Katzenschlager et al., 2018) and Levodopa–carbidopa intestinal gel (LCIG) (Olanow et al., 2014), with the exception of Magnetic resonance (MR)-guided focused ultrasound (MRgFUS) (Martínez-Fernández et al., 2020). Subcutaneous levodopa pumps (Soileau et al., 2022) will be available at the end of 2024.

## Most common treatments

The most common pharmacological treatments are oral dopamine agonists, levodopa, and apomorphine subcutaneous pump. Physiotherapy is also frequently used.

## 2.1.2 Germany

### 2.1.2.1 Characteristics of patients

#### Numbers of PwP, distribution Male/Female, age distribution and other demographics

There are up to 400,000 patients in Germany. PD in Germany is slightly more common in males (50.8%) than in females. As the incidence of PD increases with age, the prevalence of PD is below 1% in those aged 60 or below and over 3% in those aged 75 or above (Heinzel et al., 2018; Timpel et al., 2020).

#### Where do they live?

There is no data regarding whether PD patients are distributed in rural areas or in cities.

#### Education level

No specific data on the educational level of German PD patients exists, and education level is not known as a risk factor for developing PD. However, it could be a risk factor for more rapid cognitive decline (Kierzyńska et al., 2011).

#### Technological abilities

There is little known about PD patients' technological abilities among German patients. One study using the eHealth literacy scale (EHEALS), found an average score of 23 of perceived users' skills (Bendig et al., 2022), however, these patients volunteered to participate in a telemedicine study so they might not constitute a representative sample.

### 2.1.2.2 Characteristics of the healthcare system

#### How is care for PD delivered?

PD patients are principally followed by neurologists (both community-based neurologists and hospital-based ones). In the study by Timpel et al. (2020), mainly elderly and patients with more severe impairment, e.g., in nursing homes, did not see a neurologist for a year.

#### How is care for PD funded?

Healthcare for PD are mostly funded by public insurance companies.

#### What does the journey to a PD diagnosis look like in Germany?

Most frequently, a primary care physician suspects PD and refers the patient to a neurologist. Sometimes, patients suspect the disease and ask their primary care physician to refer them to a neurologist. For public insurances, all referrals to neurologists (private practice and hospital) are from primary care physicians ("Hausarzt").

#### What does the standard practice for PD care look like?

PD patients visit a neurologist every three months. Patients visit specialised a PD centre at least once a year. Most PwP are seen in the outpatient clinics. The most common reasons for

patients to be referred are to receive either a second opinion or an advanced therapy for PD. PD nurses are only available in specialised hospital settings or in care research projects. Care networks ([parkinsonnetze-deutschland.de](http://parkinsonnetze-deutschland.de)) are being built to coordinate interdisciplinary care across disciplines and sectors, however these networks are currently not receiving enough funding.

### **Available treatments**

All oral/transdermal treatments, including Safinamide, Opicapone and Rivastigmine, as well as all advanced treatments (deep brain stimulation, Gamma-Knife, apo pump, LCIG, Levodopa-entacapone-carbidopa intestinal gel (LECIG), subcutaneous levodopa pump (scLEV), and MRgFUS are available.

### **Most common treatments**

The most common pharmacological treatments are oral levodopa, dopamine agonists, COMT inhibitors, safinamide, amantadine, and pumps (all pumps are available). Physiotherapy is often used as well; several PD patients have two physiotherapy sessions per week. Ergotherapy and logotherapy are also used.

## **2.1.3 Spain**

### **2.1.3.1 Characteristics of patients**

#### **Numbers of PwP, distribution Male/Female, age distribution and other demographics**

The incidence rate (per 100,000 person-years) in the population aged 65 to 85 and over years is 186.8 for PD. Incidence rates increased with age in men but decreased beyond the age of 79 in women. Age-adjusted relative risk in men compared with women is 2.55 (95% CI) for PD (Benito-León J et al., 2004). The age and sex distribution are  $62.6 \pm 8.9$  years old and 60.3% males, respectively, based on the COPPADIS study (Santos-García D et al., 2015).

#### **Where do they live?**

No specific data are available regarding whether PD patients live in rural areas or in cities. Most patients seek care in city hospitals, but come from rural and city areas.

#### **Education levels**

There are no specific data regarding the education levels of PD patients in Spain.

#### **Technological abilities**

There are no specific data on the technological abilities of Spanish PD patients; however, based on experience, technology literacy mostly depends on the educational level and age more than the condition.

### **2.1.3.2 Characteristics of the healthcare system**

The Spanish Healthcare system is based on universal public healthcare for all.

#### **How is care for PD delivered?**

Generally, patients with early-stage PD showing good progress and without complications are treated by a general neurologist with visits every six to nine months. In certain provinces in the South of Spain, where the number of neurologists is scarce, some patients are followed by internists before reaching a neurologist in later stages. Geriatricians handle some older patients. Experts in movement disorders typically handle more complex cases in advanced stages, those with a poorer prognosis from the outset, or atypical cases (such as very young patients or genetic cases). The Spanish Neurology Society has 3,500 members. The Movement Disorders Group has 400 members, mostly neurologists and some specialized nurses and physiotherapists.

**How is care for PD funded?**

In general, the public health system covers all necessary resources. Private healthcare is an optional resource.

**What does the journey to a PD diagnosis look like in Spain?**

In general, it is straightforward with accessibility. Patients seek help from the family practitioner, who sends them to the neurologist if they suspect PD. Many times, patients see traumatologists, rheumatologists, and rehabilitation doctors before reaching the neurologist. Waiting lists in the healthcare system for an initial visit to a neurologist are usually around two to three months in the northern half of the country and four to six months in the southern provinces (Andalucia, Extremadura, Murcia). Follow-up appointments typically occur every six to nine months.

**What does the standard practice for PD care look like?**

Care depends on how stable the patient is and the stage of the disease. Generally, if everything is going well, patients usually have two visits per year. If there are many complications, they may have three or four visits yearly. Based on clinical practice and interviews between colleagues, clinicians working in the public sector have time to receive calls and emails from patients regarding changes in health status, although such direct contact is generally not possible within the public sector.

**Which treatments for PD are available?**

All approved treatments for PD are available and covered by the national healthcare system. Oral, transdermal, or inhaled treatments, as well as botox therapy. Advanced therapies such as continuous subcutaneous apomorphine infusions or enteral duodopa and, recently, subcutaneous levodopa are also available. PD surgery with DBS is available in most large reference centers, and high-intensity focused ultrasound (HIFU) is available in three public and three private centers.

**Which treatments for PD are most common?**

In terms of usage, the most common medications include levodopa, rasagiline, dopaminergic agonists, and, in stages with fluctuations, safinamide, opicapone, or the subcutaneous apomorphine pump.

**2.1.4 United Kingdom (UK)****2.1.4.1 Characteristics of patients****Numbers of PwP, distribution Male/Female, age distribution and other demographics**

A Parkinson's UK report of the Clinical Practice Research Datalink (CPRD) using primary care data from 2015 (Parkinson's UK, 2018) found that about 137,000 people were living with PD in the UK. The prevalence rate was 286.5 per 100,000 person-years. The incidence rate was 33.4 per 100,000 person-years, and each year there are about 17,300 new diagnoses of Parkinson's disease in people aged 45 years and above. The prevalence of PD increases with age, i.e., 4-5 per 100,000 people in people aged 30-39 years, compared to 1,696 per 100,000 people aged 80-84 years (equivalent to 1.7% of this age group). Prevalence rates almost double every five-year interval between 50-69 years for both men and women. The prevalence is higher in men than in women; prevalence rates for men aged 50-89 years were more than 1.5 times higher than rates for women in the same age group. This equates to 22 in every 10,000 women and 32 in every 10,000 men diagnosed with Parkinson's disease. By 2025, due to population growth and an increasingly ageing population, the estimated prevalence of Parkinson's disease is expected to increase by 23.2%, and the estimated yearly incidence is expected to increase by 23.9%.



### **Where do they live?**

Urban and non-urban areas.

### **Education levels**

Specific data on educational level of PD patients including immigrants in UK are limited. More than 60% of the population is educated up to university level, 30% to high school and for the 10% of population it is unclear.

### **Technological abilities**

A national audit performed by Parkinson's in UK resulted in that 40 national health parkinson's service had suggested that PD patients are user friendly of any technology which helps them to do day to day activities such as applications, tele-visits/telemedicine, including virtual video consultation, and wearable sensors. They are very much compatible and adoptable with technology specifically AI and digital instruments.

## **2.1.4.2 Characteristics of the healthcare system**

### **How is care for PD delivered?**

PwPs receive the best care within specialist clinical settings or movement disorder clinics. In the specialist clinic setting, there is an integrated approach when sharing best practice among different HCPs. A multidisciplinary team (MDT) consisting of different HCPs depending on clinic (neurologist, PD nurse specialist, physiotherapist, occupational therapist, speech and language therapist, dietitian) (Skelly R et al., 2012) are part of the integrated approach.

### **How is care for PD funded?**

Care is funded by the National Health Service (NHS), but contribution of pharma to research protocols is also allowed and frequently used. People living with brain and nerve conditions like Parkinson's could benefit from quicker diagnosis and better coordinated care as part of a new NHS initiative, which is also set to free up millions of pounds to reinvest in patient care (NHS England, 2019).

### **What does the journey to a PD diagnosis look like in the UK?**

PD should only be diagnosed after a consultation with a specialist by referral from a primary care physician. Patients normally are referred to secondary care to see a movement disorder specialist, but this is subject to catchment area and location. A PD specialist will conduct a detailed medical history taking and examination to either rule out or confirm PD.

### **What does the standard practice for PD care look like?**

The standard practice for PD care is three to four visits per year, including one in tertiary hospital. PD patients have access to PD nurses and educational therapies including multidisciplinary teams (mainly in university hospitals).

### **Which treatments for PD are available?**

Available treatments include supportive therapies, such as physiotherapy, occupational therapy, speech and language therapy. Also all oral/transdermal treatments (with the exception of Safinamide, Opicapone and Rivastigmine, that is available but not reimbursed) and all advanced treatments (DBS, Gamma-Knife, apo pump and LCIG), with the exception of MRgFUS are available. Subcutaneous levodopa will be available at the end of 2024.

### **Which treatments for PD are most common?**

The most common pharmacological treatments are oral dopamine agonists, levodopa, and apomorphine subcutaneous pump. Physiotherapist is quite used too.



## 2.2 Digital health technologies in PD

A narrative review of digital health technologies for PD from a patient perspective emphasises the need for such technologies to be more patient-centric (Riggare et al., 2021). The article discusses the current state and potential of digital health technologies in managing PD. Key points include:

- PwPs, as participants in the study, wish to use digital technologies to manage the complexity of their condition, including symptom tracking (motor and non-motor) in relation to various factors like medication, stress, sleep, and exercise. They seek collaboration with their medical teams and access to information, knowledge, and social support.
- Despite significant potential, current digital health initiatives for PD are not fully aligned with patients' expectations. Many technologies are available only to clinicians, and patients often do not have access to their own data. Examples include the Personal Kinetigraph (PKG) and REM-PARK system (Santiago et al., 2019). The mPower smartphone app and Parkinson@Home are notable projects (Michaud M., 2024), but they have yet to provide tangible results for the larger patient community (Riggare et al., 2021).
- The authors propose that future digital health technologies should be directly accessible to PwP, address both motor and non-motor symptoms, support short-term and long-term management, and facilitate collaboration between patients and medical teams. Importantly, these technologies should provide personalised feedback based on collected data.
- For digital health in PD to reach its full potential, the authors recommend recognising patients' right to access their data, providing personalised feedback, and actively involving patients as equal partners in digital health development.
- The article underscores the gap between current digital health offerings and the actual needs and expectations of PwP, advocating for a more inclusive and patient-focused approach in the development of digital health solutions.

For a complete list of available, certified technologies for PD management, the reader is further referred to Section 3 of deliverable D2.3 "Initial report on domain review and datasets".

## 2.3 Sex and gender impact in PD

Sex differences, as biological aspects of a human being, have been found in numerous areas pertaining to disease presentation and provision of care. Research has found sex differences in symptoms and treatment complications. More severe and common symptoms for women are restless legs, pain, loss of taste and smell, fatigue, depression, constipation, weight change, and excessive sweating (Hyperhidrosis) (Martinez-Martin et al., 2012). Even though PD is 1.5 more common for men (Moisan et al., 2015), women have a more benign phenotype, possibly related to female estrogens, menopause and fertile life span, and with increased expectance of tremor (67%). Women have a higher risk of treatment-related complications, lower chances of effective treatment (Picillo et al., 2017), and faster disease progression (Dahodwala et al., 2018). There are known sex-related neurological differences in cortical thickness and connectivity in Parkinson's disease, which may have implications for diagnosis and treatment (Yadav et al., 2016). Further, motor symptoms such as tremor as initial symptom, reduced rigidity, and postural instability emerge later for females (Cerri et al., 2019).

Sex, as well as gender considerations regarding social constructs such as expectations and behaviours stemming from sex differences, also impact the provision of care, when influencing

patient-provider communication and non-pharmacological disease management (Göttgens et al., 2020). There has been minimal sex and gender consideration in mHealth randomized controlled trials for chronic medical conditions like PD (Wang et al., 2020). Hence, such characteristics are important parameters for predictive models within the project, and future sex differences will be identified to ensure inclusivity.

For the ideation and co-creation process for needs mapping, inclusion of sex and gender-balanced groups has so far been considered when recruiting PwPs, HCPs, and PwoPs for the patient panel (see Section 4), as well as for interviews, workshops, and focus groups. Demographics from collected data will also be considered when analysing the data, with focus on sex and/or gender- shaped characteristics such as different needs, adherence, relationships, or other relevant behaviours stemming from gender or sex differences.

## 2.4 AI-PROGNOSIS digital health tools concepts

AI-PROGNOSIS aims to develop an AI-enabled digital health ecosystem to advance PD diagnosis and care. The current concept is that the ecosystem will comprise three tools, the mAI-Health and mAI-Care mobile apps for people without and with PD, respectively, and the mAI-Insights Web app for primary and secondary HCPs. The tools will be powered by the predictive models of PD risk, progression and response to medication that AI-PROGNOSIS aims to develop and allow for collection of the data serving as input to those models. Data may include digital biomarkers (dBM)s (estimated from passively captured smartwatch and smartphone sensor data or through active digital tests), user self-reports on symptoms, and clinical/genetic data entered by HCPs. Users of both mAI-Health and mAI-Care apps will have access to tailored educational content regarding PD, in the form of short articles. Specifically:

### **mAI-Health - Mobile app for persons without PD to track their personalised risk of acquiring the disease**

The app will enable users, with the help of their attending physicians, to track their quantitative PD risk, along with explainable insights, estimated by the AI-PROGNOSIS PD risk assessment model based on a relevant user profile, smartphone/watch-tracked dBM)s data, and occasional self-reports on relevant risk factors/symptoms.

### **mAI-Care - Mobile app for PwP to track disease progression and medication efficacy**

Through the app, PwP and their carers will be able to track symptoms and treatment effects and potentially have access to personalised projections of PD progression, via the AI-PROGNOSIS PD progression predictive model, based on smartphone/watch-tracked dBM)s data, occasional self-reports on their condition, and clinical data shared by their attending physician.

### **mAI-Insights - HCPs' clinical platform (Web app) supporting PD screening, patient follow-up, and medication optimisation**

The platform is intended for both primary and secondary care HCPs. The platform will allow:

- Non-expert (e.g., general practitioners) and expert HCPs (neurologists, movement disorder specialists) to track and identify persons at risk of PD, with explainable estimations of the PD risk assessment model based on clinical data and data shared by users via mAI-Health (dBM)s data and self-reports);
- Expert HCPs to: i) track their patients' status through data shared by patients via mAI-Care (dBM)s data and self-reports), ii) view projections of the AI-PROGNOSIS PD progression prediction model based on patients' clinical profile and mAI-Care data,

and iii) receive individualised predictions of patients' response to PD-specific medication regimens, via the **AI-assisted Medication Decision support (AIMED) module**, powered by the AI-PROGNOSIS medication response predictive model, in order to choose the optimal treatment plan, together with their patients.

Over the course of the project, the AI-PROGNOSIS toolkit (minimum viable products (MVPs)) will be shaped based on the user needs identified (with the initial ones presented in this report) and feedback received by stakeholders during the user research and co-creation activities of the project, as well as the outcomes of the research and development activities of work package WP3 “Predicting PD risk, progression and medication response”, including digital biomarkers and predictive models development, as well as genetic analyses.

## 3 User research and co-creation methods

### 3.1 User research

User research is a multifaceted discipline that centres on gaining a profound understanding of user behaviours, needs, and motivations. Gathering user feedback through various methods provides qualitative and quantitative data, informing design improvements and enhancing user experiences. User research is an iterative process that plays a pivotal role in shaping user-centric solutions, ensuring that the end product aligns seamlessly with the expectations and preferences of its intended users. As such, it can significantly overlap with co-creation, and the two approaches are commonly used in parallel (De Sutter et al., 2022).

#### 3.1.1 User research in healthcare app development

User research in the context of creating medical apps involves systematic gathering and insights analysis from potential end users and stakeholders to inform the design and development process, ensuring the resulting application meets the specific needs, preferences, and usability requirements of HCPs and patients. It begins with identifying potential end users and learning about their specific needs regarding the tool at hand (Schnall et al., 2016). The research includes broader needs, which are then translated into user preferences, such as functional requirements and app aesthetics (Mrklas et al., 2020). User research allows the design team to align the app in development with the needs of its future users.

#### 3.1.2 Special considerations for user research in healthcare app development

Neglecting to conduct user research can lead to suboptimal design and usability, which, in turn, leads to poor adherence and discontinued use. Many healthcare apps go unused because they fail to meet the needs of their end users (Schnall et al., 2016), demonstrated by the number of mHealth apps downloaded, yet rarely used (McCurdie et al., 2012). An additional challenge is that users' expectations and their actual needs are not always aligned (Ahmed et al., 2022).

One study identified personal, social, and health factors for users of a healthcare platform for elderly with PD or dementia and found the user research and involvement of end-users in the design to be crucial steps to the development of the platform (Ahmed et al., 2022). However, the study conducted three methods of user research across five European countries and found that the users' needs were highly diverse and complex, making it challenging for the developers to meet all needs. They highlight the importance of focusing on sub-user groups rather than a one-size-fits-all.

### 3.1.3 Forms of user research

There are many different forms of user research, all targeted at different objectives. This overview of user research methods focuses on forms of user research particularly relevant to the AI-PROGNOSIS context, and what the main benefits of using these methods might be.

#### 3.1.4 Interviews

One-on-one or group interviews are a valuable method in user research thanks to their ability to elicit rich, contextual information directly from participants. Through interviews it is possible to gain a deeper understanding of individuals' experiences, perspectives, and needs. This qualitative approach allows for a nuanced exploration of the complexities inherent in healthcare and medical research, going beyond quantitative data to capture the subjective aspects of individuals' experiences.

Accordingly, interviews serve as a means to place the individual at the centre of the narrative. Patients, for instance, can share their personal journeys, challenges, and aspirations, providing a more complex view of their experiences. This depth of understanding is crucial for developing patient-centred approaches, interventions, or innovations that truly address the real-world needs and concerns of the people involved.

In the context of co-creation, interviews significantly contribute by fostering a collaborative environment. By engaging in interviews, it is possible to establish a direct line of communication with participants, creating a space for open dialogue. This interactive process facilitates the co-creation of knowledge, where all stakeholders actively contribute to the exploration and understanding of healthcare issues. Through dialogue, it is possible to uncover insights that might not be apparent through other research methods, enriching the research process with diverse perspectives. In the co-creation process, interviews enable the identification of unmet needs and gaps. Participants can express their preferences, concerns, and expectations, offering valuable input for improvements.

The dynamic nature of interviews also allows for flexibility in adapting to the unique circumstances and contexts of participants. It is possible to probe deeper into specific issues, explore unexpected themes, and adapt their questioning based on the responses received. This flexibility enhances the co-creation process by making it possible to follow the conversational threads that lead to meaningful insights and solutions.

#### 3.1.5 Focus groups

Focus groups offer a different, yet complementary, approach to understanding diverse perspectives and generating collective insights. Unlike individual or group interviews, focus groups involve a facilitated discussion among a small group of participants. They use set discussion points to guide a discussion. An additional facilitator may be present to help capture the discussion through notetaking and audio recording. Focus groups strive for diverse participants in order to reach consensus through discussion rather than homogeneous perspectives. However, it is still common to separate user groups (such as patients from HCPs). This method fosters group dynamics, interaction, and the exchange of ideas, contributing to a collaborative environment that also supports co-creation.

One of the key strengths of focus groups is the synergy created by group interactions. Participants, represent different backgrounds, experiences, and viewpoints, and can build on each other's ideas and provide a multifaceted understanding of the topic under investigation. This collaborative dynamic facilitates the co-creation of knowledge as participants collectively contribute to the exploration issues, generating a range of perspectives that may not emerge in individual interviews.

Focus groups also serve as a platform for validating and contextualising individual experiences. Participants can relate to and affirm each other's experiences, creating a sense of shared understanding and solidarity. This social validation contributes to the co-creation process by establishing common ground and highlighting shared concerns, needs, or preferences within the group. Furthermore, the group dynamic in focus groups can stimulate idea generation and creativity. Participants can engage in brainstorming and collaborative problem-solving, co-creating innovative solutions or strategies for addressing challenges.

### 3.1.6 Surveys

Surveys are a widely employed user research method, offering a structured and scalable approach to collecting data from a large number of participants. Surveys provide a systematic way to gather quantitative and qualitative information, making it possible to explore a variety of aspects related to experiences and preferences. Surveys also offer a cost-effective and efficient way to collect data from a large number of participants. This scalability is advantageous, as reaching a diverse and geographically dispersed population can be challenging. The ability to gather data from a broad range of individuals enhances the inclusivity of the co-creation process, ensuring that diverse perspectives are considered. Tailoring survey questions to the goals of the co-creation process ensures that the collected data directly informs the development of products or services that align with the needs and expectations of the target population.

Surveys are often designed, disseminated and analysed online. Using Web-surveys, boosts one of the primary advantages of surveys, i.e., their ability to reach a broad and diverse audience. By distributing surveys to a large number of participants, it is possible to gather insights from individuals with varying backgrounds and perspectives. This inclusivity supports the user research process by ensuring a representative sample. This makes Web-surveys an important complement to interviews and focus groups, which will be methods targeted at smaller, select groups.

Moreover, Web-surveys can be administered anonymously, encouraging participants to share their opinions and experiences more freely. This anonymity is especially relevant in healthcare contexts where sensitive topics are explored. Participants may feel more comfortable providing honest feedback, leading to more candid and authentic responses that contribute to a more accurate representation of their views. A commonly adopted format is using Likert-items for informants to evaluate. There are some standardised questions that can aid in survey creation for user needs research which are specific to PD and/or mHealth, such as the Parkinson's Disease Questions (PDQ-8) (Jenkinson et al., 1997) and the e-Health Literacy scale (Norman & Skinner, 2006),

## 3.2 Co-creation

Co-creation is a participatory approach that involves collaborative efforts between various stakeholders. Through co-creation, diverse perspectives come together to contribute to ideation, problem-solving, and decision-making. By involving users and other stakeholders in the creative process, co-creation not only ensures that the final output meets their needs and expectations, but also cultivates a sense of empowerment and engagement, leading to innovative and user-centric outcomes.

Several terms have emerged from different fields to convey the concept of including key stakeholders in a development process of some sort though in various context. Namely, co-design, co-production, and co-creation are often confused or used interchangeably, and recent efforts have been made to distinguish between these terms. Co-creation is the most inclusive in terms of being consumer and experience centric whereas co-design is consumer



centric and co-production is company centric (Vargas et al., 2022). Additionally, co-creation is aimed at engaging diverse stakeholder experiences rather than selecting specific stakeholders for a specific purpose, and with the aim of understanding complex problems and designing contextually relevant solutions (Vargas et al., 2022). Therefore, co-creation is considered the overarching approach, or an umbrella term for co-design and co-production. Co-creation entails involving stakeholders at as early a stage as possible, ideally before the problem is even clearly defined, whereas co-production involves stakeholders after there is a clear problem on the table (Vargas et al., 2022).

### **3.2.1 Co-creation in healthcare app development**

Research has demonstrated the benefit of co-creation in the development of medical and health technologies, as it allows end users, such as patients and healthcare providers, to actively participate in the design process. This leads to the development of technologies that better meet their needs and preferences, resulting in improved usability and user satisfaction (Børve et al, 2019). User research is a crucial first step, but co-creation enables constant user feedback iteratively throughout the design and development of the app.

One study which employed a co-design approach to an mHealth app, found key differences in their user research between the patient, physician, and researcher preferences. They conclude that through an iterative process of consulting users and negotiating at every step of development, it was possible to reach a consensus on the core app functional requirements while still preserving the diversity of user perspectives (Mrklas et al., 2020).

### **3.2.2 Special considerations for co-creation in healthcare app development**

As mentioned above, when employing a co-creation approach, including diverse stakeholders and engaging various perspectives is inherent, although this of course creates challenges for tool development. Mrklas et al. (2020) described having to negotiate with all user groups (patients, physicians, and researchers) at every step of the design process, as they showed distinctly differing preferences what app functional requirements were important, desirable, convenient, and actionable. Additionally, it was described that even though there were three distinct thought patterns separating the groups, the patients and physicians were still heterogeneous in their preferences (Mrklas et al., 2020). Research exploring user needs in persons with dementia have found that their needs regarding assistive technologies are diverse and possibly in conflict with the needs of their informal caregivers and HCPs (Ahmed et al., 2022; Meiland et al., 2017).

Another challenge in identifying and negotiating key tool features is that users' expectations do not always meet their actual needs, as found in another study on people with dementia (Guisado-Fernández et al., 2019). This highlights the importance of in-depth exploration of user needs and including multiple stakeholders. In PD, as clinical symptoms fluctuate daily, user needs may also change, requiring again, in-depth exploration of individual needs and the co-creation of a personalized tool (Ahmed et al., 2020).

A technical challenge identified when co-designing with PwP and persons with dementia was the need for educating the users (including HCPs) on the prototype to allow adequate engagement and user feedback (Ahmed et al., 2020).

### **3.2.3 Forms of co-creation**

There are many different forms of co-creation, all targeted at different objectives. This overview of user research methods will focus on forms of co-creation particularly relevant to the AI-PROGNOSIS context, and what the main benefits of using these methods might be.

### 3.2.4 Workshops

Workshops, both digital and in-person, are commonly used to facilitate a hands-on environment for engaging stakeholders. Discussion topics are prepared ahead, and small group discussions and activities are held with a facilitator. There are numerous examples of workshop use in co-creating mHealth tools (Lundell et al., 2022 & Dugstad et al., 2019). One of the primary strengths of workshops in co-creation is their ability to bring together various stakeholders. By assembling a diverse group with different perspectives and expertise, workshops create a space for cross-disciplinary collaboration. This interdisciplinary approach is crucial for co-creating holistic solutions that consider complex dimensions. Workshops also facilitate active participation and engagement among participants. Through structured activities, individuals can contribute their unique insights and experiences. This collaborative energy fosters a sense of ownership and involvement in the co-creation process, empowering participants to play an active role in shaping a project. Furthermore, workshops provide a platform for immediate feedback and iteration. Participants can share their thoughts in real-time, allowing for adjustments and refinements during the co-creation process. This iterative nature ensures that the resulting solutions are responsive to the input and preferences of the participants, contributing to the development of more user-centric and effective interventions.

### 3.2.5 Brainstorming sessions

Brainstorming sessions are creative and focused co-creation activities designed to generate a wide array of ideas and solutions to address specific challenges. These sessions encourage participants to think innovatively, leveraging the collective intelligence of diverse stakeholders to explore new perspectives, interventions, and approaches to various issues. One of the primary advantages of brainstorming sessions in co-creation is their ability to inspire creativity and idea generation. Participants are encouraged to freely express their thoughts, share insights, and propose innovative solutions. Brainstorming sessions are not only about generating ideas but also about prioritising and selecting the most promising concepts. Through facilitated discussions and group evaluations, participants can collectively identify key priorities and focus areas. This collaborative decision-making process ensures that the co-creation effort is guided by the most impactful and feasible ideas.

### 3.2.6 Card sorting

Card sorting provides a structured approach for participants to categorise and organise information or concepts. This method involves the use of physical or digital cards representing different elements, allowing participants to group and prioritise these elements according to their own mental models. Card sorting is particularly useful for information architecture, content organisation, and understanding user preferences. It allows for the identification of common patterns and consensus among participants. The method helps with identifying recurring themes, shared preferences, and areas of agreement. This consensus-building aspect is valuable for making informed decisions in the co-creation process, ensuring that the final product reflects the collective input of the participants.

## 3.3 Use of personas

A user persona, often referred to simply as a persona, is a detailed and fictional representation of a hypothetical user or customer for a product, service, or system. Personas are a fundamental tool in UI/UX design and product development, helping teams better understand the needs and expectations of their target audience – as well as empathise with them. These representations provide a clear and human-centric reference for design and decision-making. By designing for specific personas, teams can create more user-centric solutions that are more likely to meet user requirements and deliver a better user experience. It is essential to create

multiple personas if the intended product or service caters to a diverse user base, as each persona will have different needs and characteristics.

### 3.3.1 Key characteristics of personas

Key aspects of a user persona include, but are not limited to:

- **Name and demographics**  
The persona is given a name and basic demographic information is specified, such as age, gender, location, education, and job title. This helps create a relatable character. It is also helpful to add a photo for stakeholders who are more visually oriented.
- **Background and biography**  
A backstory should be provided for the persona, including their job history, family life, hobbies, and other relevant personal details. This adds depth to the persona, and contextual depth is helpful when deploying persona-based activities.
- **Goals and objectives**  
The persona's primary goals, needs, and objectives should be outlined. What are they trying to accomplish when using the product or service?
- **Challenges and pain points**  
The persona's pain points, obstacles, and challenges that they may face when trying to achieve their goals should be identified. This helps in the creation of complex user scenarios using personas.
- **Motivations and values**  
The persona's motivations, values, and what drives their decision-making should be explored. What are their priorities and preferences? This helps guide behaviour and assist with analyses of use patterns.
- **Behaviour and habits**  
The persona's typical behaviour should be described, including how they might interact with technology, their daily routines, and habits related to the product or service that is being evaluated.
- **Tech savviness**  
The persona's level of familiarity and comfort with technology and the digital world should be outlined, as this significantly impacts their user experience.
- **Communication preferences**  
It can sometimes help to specify how the persona prefers to communicate and what channels they use (e-mail, social media, phone calls).
- **Further customisation**  
It is possible to include quotes, anecdotes, preferences and similar from actual or potential stakeholders to make the persona feel more authentic and relatable.

### 3.3.2 Developing personas further

There are several different methods for further developing personas. Two particularly relevant tools to this context are empathy maps and user journey maps.

#### 3.3.2.1 Empathy maps

An empathy map is a visual tool or framework used in design thinking and UI/UX design to help teams better understand and empathise with their target users or customers. It is a collaborative exercise that allows designers, researchers, and other team members to gain



insights into the thoughts, feelings, needs, and behaviours of the people they are designing for. Empathy maps are particularly useful for building a deeper understanding of user personas and improving the user experience of products, services, or solutions.

An empathy map typically consists of four quadrants, each focused on different aspects of the user's experience, or what they say, think, feel, or do.

- **Saying**

In this quadrant, the explicit statements, phrases, and quotes that represent what the user says are captured, such as their goals, pain points, or specific needs. This information is often gathered from user interviews or surveys.

- **Thinking**

In this quadrant, the user's inner thoughts and considerations are in focus. What might the user be thinking but not explicitly expressing? What are their concerns, hopes, and aspirations?

- **Feeling**

This quadrant is dedicated to the user's emotions and feelings. What are the user's emotional reactions and experiences related to the product or service? How do they feel about specific aspects of their interaction with it?

- **Doing**

Here, the user's actions and behaviours are documented. What actions or behaviours does the user engage in as they interact with the product or service? This can include their physical actions, such as clicking buttons, as well as broader behavioural patterns.

Empathy maps can be generated either through direct input from relevant stakeholders or from information gathered from user research, interviews, observations, or surveys.

### 3.3.2.2 User journey maps

A user journey map is a visualisation or narrative representation of the steps and interactions a user goes through when they engage with a product, service, or system. It is a way to map out the user's various touchpoints and experiences, from their initial contact with the product or service to their eventual goal or outcome.

The goal for user journeys is to serve as a valuable tool for understanding the user's perspective and guide the design to create more user-centric and effective solutions. They are commonly used in UI/UX design to better understand and design for the user's experience.

Using an existing persona, a user journey is undertaken, which can both help strengthen the persona (what information about the persona is missing in order to understand what path they would choose in a specific process) and improve the service or product in question.

- **Touchpoints**

Focuses on identifying the various points of interaction the user has with the product or service.

- **Steps**

Outlines the specific steps or actions the user takes during their journey. This could be a linear progression or a more complex, non-linear path depending on the complexity of the user's interactions.

- **Emotions and motivations**

Documents the user's emotional state and motivations at each step of the journey. This helps in understanding how users feel and what drives their decisions.

- **Barriers and pain points**

Highlights any obstacles, challenges, or pain points the user encounters during their journey. These can be areas for improvement in the user experience.

- **Goals and outcomes**

Specifies the user's goals or desired outcomes. This could be logging an activity, getting information, or achieving some other objective.

- **Channels and devices**

Indicates the devices and channels (e.g., mobile, desktop, in-person, social media) the user may use during their journey.

- **Opportunities for improvement**

The user journey can be used to identify areas where the user experience can be enhanced and where the product or service can better meet the user's needs and expectations.

User journeys can be generated either through direct input from relevant stakeholders or from information gathered from user research, interviews, observations, or surveys.

### 3.4 Stakeholder engagement, follow-up, and adherence (the Samka framework)

The Samka framework is an approach to collaboration in medical research and healthcare that was developed in 2022 (Clareborn et al., 2023). It is based on an extensive review of scientific literature and reports, a series of interviews with patient and next-of-kin representatives, intra-organisational case studies, and several years of dialogue focusing on needs and challenges. A report on this approach was published in 2022 and revised in 2023. The report addresses different approaches to collaboration between different stakeholder groups, such as co-creation. It outlines six main recommendations, or principles, that are vital to successful co-creation. See also below and the checklist in Appendix II.

**Principle 1** Define clear aims, objectives, and evaluation criteria – together

Co-create *with* patients, next of kin, and other end users rather than *for* them. Define common goals early on and establish a process for evaluation and follow-up.

**Principle 2** Confront power imbalances

Good collaboration is based on a balance of competencies that complement each other. Discuss early on which perspectives are valued and how they are valued. Be open to the fact that some or all of the parties involved might have a need for skills development.

**Principle 3** Communicate to build trust and confidence

Clear and transparent communication is an essential component of collaboration. Reflect on the purpose of the communication and how it can be adapted to the wishes and needs of different stakeholders.

**Principle 4** Create conditions for remuneration and representativity

A remuneration model must be in place and agreed upon before any cooperation is initiated. It is also important to create conditions enabling the right level of representativity for the collaborative initiative in question.

**Principle 5** Build a long-term structure for collaboration

Short-termism makes successful collaboration impossible. A long-term and flexible structure for collaboration, for example in the form of processes, IT systems, allocated working time, budget, management systems and adapted leadership, is necessary for sustainable collaborative work.

**Principle 6** Share positive and negative experiences and learn from others

Create conditions for continuous learning and for lessons to be passed on beyond the partners. Avoid reinventing the wheel by learning from the experiences of others and using existing knowledge resources.

A description of the way these principles will be adopted in AI-PROGNOSIS can be found in Section 4.4.

## 4 User research and co-creation in AI-PROGNOSIS

The AI-PROGNOSIS approach regarding user research and co-creation is described in this section. The stakeholders described here are those who will be involved in the user research and co-creation process of AI-PROGNOSIS. To adhere to the co-creation process, a patient panel was involved in the project in order to reach the needs of PwP as stakeholders. Further, a framework was used to ensure that all stakeholders share the same goals and priorities.

### 4.1 Ethical Approval

Ethical approval by the Swedish Ethical Review Authority was needed to allow AI-PROGNOSIS partner UU, leading Task 2.2 on user research and co-creation, to establish the patient panel (see also Section 4.3). The application was submitted in month (M) 3 of the project (September 2023) and approval was given in M6 (December 2023, Dnr 2023-05949-01). This is the reason why user research activities involving the patient panel were initiated at the beginning of 2024 and not in the first semester of the project (July – December 2023) as initially planned.

### 4.2 Stakeholders for user research and co-creation

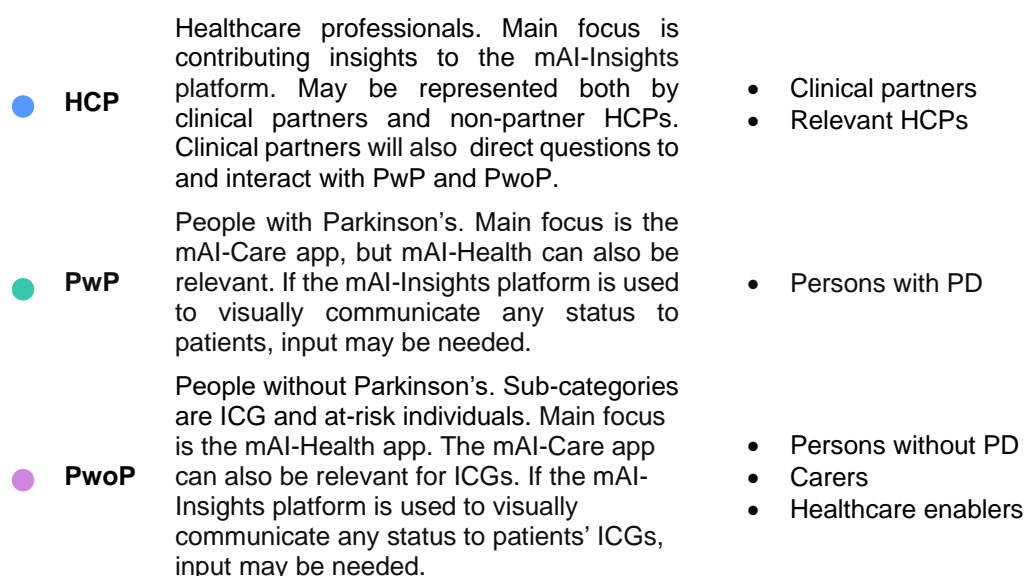
Partner stakeholders for user research and co-creation are defined as:

- Clinical partners
- User-oriented partners
- Technical partners

Non-partner stakeholders for user research and co-creation are defined as:

- Persons with PD
- Persons without PD
- Carers
- Relevant HCPs

Two of these groups are only involved in user research and co-creation as enablers or facilitators. These groups are user-oriented partners and technical partners. The other stakeholders are listed in **Figure 1**. The context where the various stakeholder groups are most likely to contribute is also included, as well as a mapping of the stakeholder groups to project activities.



**Figure 1** Overview of AI-PROGNOSIS user characteristics.

### 4.3 Patient panel

To fulfil the AI-PROGNOSIS objective for co-creation and effectively engaging key stakeholders in the design and development of the AI-PROGNOSIS tools, a patient panel was established under the initiative of partner UU. To establish the panel, an ethics approval application was submitted to the Swedish Ethical Review Authority in month 3 (M3), and approval was granted in M6 when the recruitment of members started. Panel members were recruited using purposive and snowball sampling with an email from a project member who has contact with many patient organisations as a PwP herself. The criteria were that panel members have a PD diagnosis, live in one of the six countries of interest (France, Germany, Portugal, Spain, Sweden, the UK), know sufficient English to participate, and have a base understanding of AI/eHealth to follow the discussions. The sampling aimed at recruiting an equal spread across the six participating countries while achieving diversity in other areas, including employment status, level of knowledge of AI and PD, diagnosis and treatment experiences, causes of PD (e.g., genetic), previous research participation, age, and sex.

Those who responded to the email with interest were sent textual information and either invited to an information session or provided the recording of an information session, with the opportunity to ask questions and think about it. Once a participant agreed to participate, informed consent was obtained and recorded verbally, and an onboarding interview was conducted on the Zoom platform (zoom.us). The interviews included background on each member's diagnosis journey, opinions on AI in health care generally, and expectations, hopes, and concerns for the project. There are 13 active members of the patient panel at the moment, with an average age of 52 years and a standard deviation (SD) of 10.12 years, 38% females, 62% men, and an average of 9 years since diagnosis with an SD of 4.57 years.

**Table 1** tabulates an overview of the planned patient panel composition and outlines the maximum capacity (measured in patient panel units) of patient panel members for this project. However, fewer participants have actually been recruited to allow a buffer for future recruitment of additional perspectives, such as informal caregivers or (genetically) at-risk individuals.

**Table 1** AI-PROGNOSIS patient panel overview.

Country	No. of participants	No. of meetings/person	Patient panel units*
Sweden	4	5	20
UK	4	5	20
Spain	4	5	20
France	4	5	20
Germany	4	5	20
Portugal	4	5	20
<b>Total</b>			<b>120</b>

\* Patient panel units = no. of patient panel participants x no. of meetings per person

## 4.4 Stakeholder engagement in AI-PROGNOSIS

The Samka framework (see Section 3.4), and its principles are integrated into AI-PROGNOSIS to ensure that representativity and democratic principles guide the user research and co-creation processes. As well as that all stakeholders share the same outlook on goals and priorities. Each of the six principles (see **Table 2**) are given specific attention. Using the principles as a common point of departure is helpful in guiding shared decision-making and co-creation activities in a way that ensures that all stakeholders are involved at the earliest possible stage. Special attention will be given on clarifying beforehand the impact of patient's input regarding decision-making.

**Table 2** The Samka principles and how they are integrated in AI-PROGNOSIS.

<b>Principle 1 - Define clear aims, objectives and evaluation criteria</b>
To ensure adherence to this objective, the aim is to clarify this ahead of planned co-activities. For instance, this is done by informing the participants by clearly stating the purpose of the co-activity, and what the next steps will be, how they as participants will get feedback on their input, and with a main focus on how the input will be used. This is done in writing, e.g., in a participation information letter.
<b>Principle 2 - Confront power imbalances</b>
Using the principles as a common point of departure will be helpful, as all stakeholders will be aware of the issue of power imbalances throughout. Special care will be given to addressing power imbalances in mixed co-creation sessions, such as workshops with many different stakeholders. One important aspect is clearly stating everyone's role and expertise and understanding their expectations of the project. For instance, this can be done by informing all participants ahead of the co-activity regarding which stakeholder groups will be represented and what their roles will be. As well as collecting their expectations by asking them orally or in writing and trying to meet them throughout the whole project.
<b>Principle 3 - Communicate to build trust and confidence</b>
Within a project's integrated communication strategy, focus should be on stakeholder inclusivity and openness, which will help ensure adherence to build trust and confidence. For instance, the actions taken in support of principles 1 and 2 above will be relevant here, in addition to keeping stakeholders in the loop regarding new developments in the project as an iterative process of the users' needs.
<b>Principle 4 - Create conditions for remuneration and representativity</b>
Within a project, funds for remuneration of participation need to be secured. Representativity, such as professional backgrounds, different knowledge of the intended development/intervention, diversity

of symptoms and treatments as patients, country, age, sex and gender, will be an important focus in the consolidation of participation and will also be reviewed throughout the project.

#### **Principle 5 - Build a long-term structure for collaboration**

It will be important to address the future of the ecosystem and to what extent stakeholder input will be made feasible in the long term. This is an iterative process throughout the whole project to ensure and build trust and lay a foundation for further collaboration. In this process, it is important to meet the needs and expectations of the participants, as well as show how their input affects the progression of the project. This is done through a good communication strategy (see principle 3) and recurring meetings with participants to ensure that the projects and development meet their needs. This will often lead to further collaboration since the participants realize that their input is relevant to the project and to other contexts in which it functions.

#### **Principle 6 - Share positive and negative experiences and learn from others**

This principle ensures openness, visibility, and reuse of project approaches and outcomes through open science, effective dissemination/communication, and strategic networking/joint activities. Positive and negative experiences in user research and co-creation activities will be shared and discussed in various contexts per the project's dissemination strategy.

In terms of networking and joint initiatives, as described in Principle 6, UU collaborates with the European Patient Involvement organization (EUPATI) and several other PwP stakeholder initiatives and regularly contributes to related networking activities. Other networking initiatives have also started within the project and will be reported in deliverable D6.3 “First report on project visibility and educational material”.

## **4.5 User research**

User research is a central part of AI-PROGNOSIS and will lay the foundation for an agile process that will involve PwP, PwoP, HCPs, and other relevant stakeholders in the design, development, and testing of the AI-PROGNOSIS tools. An overview of the user research flow is depicted in **Figure 2**. Secondary research of existing evidence (see Section 5.1) that is relevant to the tools the project aims to develop will create the primary hypotheses and assumptions around the behaviour and needs of key stakeholders, as well as current solutions utilised and the standard clinical practice. Primary user research will follow. Generative semi-structured interviews with clinicians and need-identification focus groups with PwP, PwoP, carers, HCPs, and healthcare enablers, together with clinical and technical AI-PROGNOSIS teams, will give more detailed insights on the current clinical standard on PD screening, prognosis, and care, and enable the discovery of users' motivations and needs. Interviews and focus groups have already been organised by patient-research partner UU, with the help of clinical partners (CHUT, KCL, TUD, FIN), and they have been facilitated by UU and technical partner AUTH (see Sections 5.2 and 5.3). Feedback from interviews and focus groups will be analysed and interpreted to inform the final round of hypotheses and assumptions that will be validated against a greater population with web surveys for general value assessment and prioritisation.

Outputs of this foundational user research process will yield the core set of user needs and, eventually, user stories that will shape the product backlog, guide research and development (R&D), and assess sex/gender impact across all project processes and products. User research will be performed iteratively during the whole development process, beyond initial needs identification, as prototypes are being tested for usability, effectiveness, and user satisfaction, but will be then encompassed in the co-creation process (see next section).

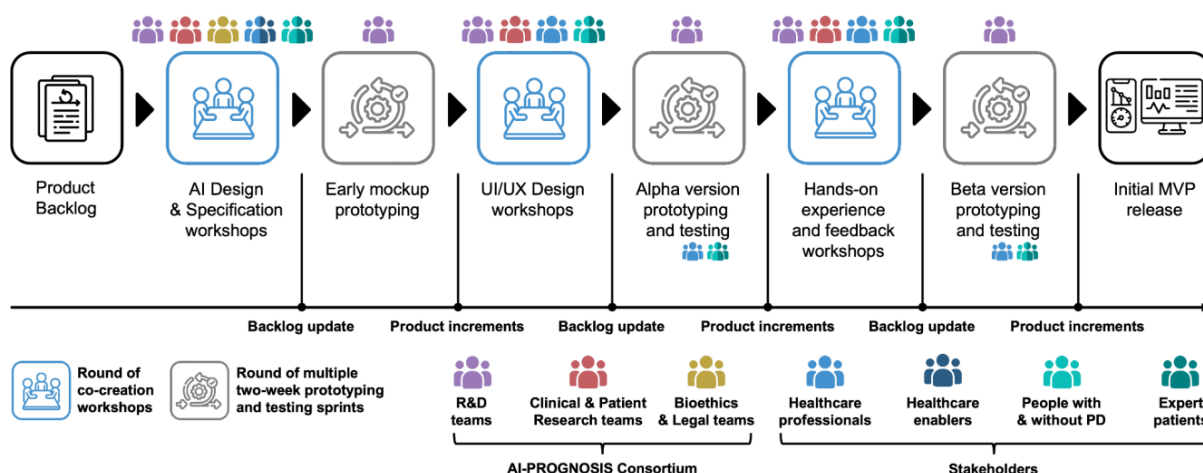




Figure 2 User research in AI-PROGNOSIS

## 4.6 Co-creation

In AI-PROGNOSIS, stakeholders, as defined in Section 4.2, will iteratively collaborate in order to design AI-PROGNOSIS tools in a way that is meaningful, relevant, and satisfies user, industry, and societal needs. An agile methodology will be followed with three rounds of strategic co-creation workshops (Figure 3). The procedure of co-creation workshops is based on four distinguished phases of design thinking: exploration, ideation, prototyping, and reflection. During the exploration phase, participants introduce themselves and present the main scope of the workshops, setting the objectives for the next phase. The ideation phase includes moderated discussions and activities where participants respond to the issues presented, share personal insights, and brainstorm together and in subgroups. During prototyping, storyboards of the selected ideas are created, focusing on user journeys and value propositions of the proposed features for each AI-PROGNOSIS tool. The co-creation workshops end with a reflection from all participants, a decision on the next steps, and a collection of all observations and materials to be later analysed by the technical partners during prototyping sprints and create the basis of the MVPs.



**Figure 3** Co-creation of MVPs in AI-PROGNOSIS; people with PD and expert patients are now part of the patient panel.

The first round of co-creation workshops focuses on Trustworthy AI design and specifications (see also D2.2 “Trustworthy AI development and evaluation framework (fundamental version)”), with an emphasis on human autonomy, fairness and equality, explainability and transparency, and the ethical and user-driven concerns around the use of AI in healthcare and self-care. The first co-creation workshops on AI with the participation of the patient panel have already been organised and facilitated by UU, technical partners AUTH and AING, and bioethics partner UOXF (see Section 5.5).

Following the first round of co-creation workshops, a series of prototyping development sprints (organised by partner SQD leading software development) will update the initial product backlog focusing on each one of the tools, based on the feedback collected during user

research and the insights of the first co-creation workshops lead to the first product increment with early mock-up prototyping and internal testing. The second round of co-creation workshops will focus on each tool's UI/UX design to explore the importance and granularity of the insights, metrics, and symptom-tracking features, engaging the various target audiences. Another round of prototyping sprints, moderated and unmoderated usability testing with a small pool of participants, will have as an outcome the alpha version of the tools. The final round of co-creation workshops focuses on hands-on experience and feedback with the tools from all target audiences to identify and refine the features with the highest value and impact potential and set the final technical and product requirements and fixes. The final round of prototyping and testing sprints of the beta versions of the AI-PROGNOSIS tools will produce the initial MVPs. Therefore, the pool of recruited participants is expanding as we move towards more extensive alpha and beta testing of the prototypes. Co-creation workshops will be performed in-person and remotely to further increase accessibility, utilising suitable collaborative tools for brainstorming (Miro, [miro.com](https://miro.com)), interactive mock-ups (Figma, [figma.com](https://figma.com)) and usability testing (UsabilityHub, [usabilityhub.com](https://usabilityhub.com)).

## 4.7 Timeline and distribution of stakeholder input over time

**Table 3** includes a tentative timeline of user research and co-creation activities described in Sections 4.5 and 4.6, along with the concurrent activities of stakeholders involved and the distribution of patient panel units. The different activities are explained below:

- **Panel consolidation and introduction:** Representatives from the patient panel participated in the introductory activities described in Section 4.3.
- **Focus group participation:** Representatives from the patient panel participated in the focus groups described in section 5.2.
- **AI workshop preparation (prep) and participation:** Representatives from the patient panel and HCPs contributed to the preparations for and participated in the AI workshops described in Section 5.4.
- **Survey prep:** Representatives from the patient panel and partner HCPs will contribute to the preparations for the validation web surveys.
- **Survey participation:** HCPs will participate as survey respondents.
- **Persona review:** Representatives from the patient panel and HCPs will participate in continuously reviewing, improving, and adding to the personas used in co-activities.
- **UI/UX workshop prep:** Representatives from the patient panel and HCPs will contribute to the preparations for the UI/UX workshop.
- **UI/UX workshop participation:** Representatives from the patient panel and HCPs will participate in the UI/UX workshop.
- **Survey feedback:** Representatives from the patient panel and HCPs will be invited to give feedback on the survey results.
- **Plenary meeting participation:** Representatives from the patient panel will be invited to participate in plenary meetings if there is a need for stakeholder input in workshops or similar activities that will take place during these meetings. Alternatively, co-production activities can be scheduled in conjunction with plenary meetings, if practical.
- **Hands-on experience and feedback workshop prep:** Representatives from the patient panel and HCPs will contribute to the preparations for the hands-on experience and feedback workshop.
- **Hands-on experience and feedback workshop participation:** Representatives from the patient panel and HCPs will participate in the hands-on experience and feedback workshop.











- **Process evaluation:** All patient panel representatives will be invited to discuss their experiences with and give feedback on the co-activities over the course of the project.

The 120 units of patient panel time (see Section 4.3) should be distributed in proportion to project needs. This distribution will necessarily be subject to adjustments over time, depending on, for instance, the composition of the panel in terms of stakeholder perspectives and representativity. An example of this would be if a current PwP also has experience as an informal caregiver to a PwP and as an at-risk individual, which is a feasible scenario.

**Table 3** Timeline of user research and co-creation activities, along with stakeholders' activities and the allotted patient panel units. ● PwP ● PwoP

Project month	Activity	Panel activity	Panel units	Partner HCP activity	Non-partner HCP activity
<b>M7</b> (Jan 2024)		Panel consolidation and introduction.	N/A		
<b>M8</b> (Feb 2024)		Focus group participation	●●●●● ●●●●●	Interview participation	Interview participation
<b>M9</b> (Mar 2024)	AI design and specification workshop(s)	AI workshop prep and participation.	●●●●● ●●●●● ●●	Interview participation	Interview participation
<b>M10</b> (Apr 2024)	Early mock-up prototyping sprints				
<b>M11</b> (May 2024)	Early mock-up prototyping sprints	Survey prep.	●	Survey prep.	
<b>M12</b> (Jun 2024)	Early mock-up prototyping sprints	Persona review Survey prep.	●●● ●●●		Survey participation
<b>M13</b> (Jul 2024)	Early mock-up prototyping sprints	Persona review. UI/UX workshop prep.	●●●●● ●●●	Persona review UI/UX workshop prep.	Survey participation
<b>M14</b> (Aug 2024)	UI/UX design workshops	UI/UX workshop prep.	●●●●● ●●●	UI/UX workshop prep.	Survey participation
<b>M15</b> (Sep 2024)	UI/UX design workshops	UI/UX workshop participation.	●●●●● ●●●	AI workshop participation	Survey participation

Project month	Activity	Panel activity	Panel units	Partner HCP activity	Non-partner HCP activity
		Feedback on survey result		UI/UX workshop participation	
				Feedback on survey result	
<b>M16 (Oct 2024)</b>	Alpha version prototyping sprints	Persona review	● ● ●	Persona review	
		Feedback on survey result	● ●	Feedback on survey result	
<b>M17 (Nov 2024)</b>	Alpha version prototyping sprints	Persona review	● ● ●	Persona review	
<b>M18 (Dec 2024)</b>	Alpha version prototyping sprints	Persona review	● ● ● ●	Persona review	
<b>M19 (Jan 2025)</b>	Alpha version testing sprints	Persona review. Plenary meeting 4 participation	● ● ● ●	Persona review	
<b>M20 (Feb 2025)</b>	Alpha version testing sprints	Persona review	● ● ● ●	Persona review	
<b>M21 (Mar 2025)</b>	Alpha version testing sprints	Persona review Hands-on experience and feedback workshop prep.	● ● ● ● ● ● ● ●	Persona review Hands-on experience and feedback workshop prep.	Hands-on experience and feedback workshop prep.
<b>M22 (Apr 2025)</b>	Hands-on experience and feedback workshop(s)	Hands-on experience and feedback workshop participation	● ● ● ● ● ● ● ●	Hands-on experience and feedback workshop participation	Hands-on experience and feedback workshop participation
<b>M23 (May 2025)</b>	Hands-on experience and feedback workshop(s)	Hands-on experience and feedback workshop participation	● ● ● ● ● ● ● ●	Hands-on experience and feedback workshop participation	Hands-on experience and feedback workshop participation
<b>M24 (Jun 2025)</b>	Beta version prototyping and testing	Persona review	● ● ● ●	Persona review	

Project month	Activity	Panel activity	Panel units	Partner HCP activity	Non-partner HCP activity
<b>M25</b> (Jul 2025)	Beta version prototyping and testing	Persona review  Plenary meeting 5 participation	 	Persona review	
<b>M26</b> (Aug 2025)	Beta version prototyping and testing	Persona review	 	Persona review	
<b>M27</b> (Sep 2025)	Beta version prototyping and testing	Persona review	 	Persona review	
<b>M28</b> (Oct 2025)	Initial MVP release	Project process evaluation	 		

## 4.8 Key performance indicators of user research and co-creation

The key performance indicators of the AI-PROGNOSIS user research and co-creation activities are listed below.

- 1 round of focus groups/surveys
- 3 rounds of co-creation workshops
- $\geq 3$  prototyping sprints
- $\geq 500$  persons with/without PD from  $\geq 4$  countries involved across all activities
- $\geq 50$  HCPs from  $\geq 4$  countries involved across all activities

Prototyping sprints refer to software development sprints, at the end of which, testing of product increments with a small number of stakeholders will take place.

## 5 User research and co-creation findings

In this chapter, secondary research findings from the literature and initial primary research findings from interviews with HCPs and focus groups with the patient panel are presented. Initial findings for co-creation are also presented. Research findings within the project identified HCPs views for enhance compliance with PwP and PwoP as users of different applications (mAI-Health and mAI-Care mobile applications). It was preferable with “fun” features, e.g., gamification for expressing mood, both by HCPs and PwPs. It was noted that those at risk may need more motivation than those already diagnosed. Focus from secondary research findings are more of ethical considerations and privacy concerns for AI monitoring. This goes in line with the initial findings from PwP, where concerns were also expressed regarding the communication of the risk of acquiring PD through an app, rather in person from an HCP.

## 5.1 Secondary research findings

Most research on AI for early diagnosis and monitoring is focusing on AI-based wearables (Radu Ilesan et al., 2022). However, here we focus on secondary research findings providing for a background on the view of AI as an application (and additionally watch-tracked dBMs data) for tracking persons at risk of acquiring PD, to track disease progression, and as a support for follow-up and medication efficacy.

Plouvier et al (2015) found that PwP divide the diagnostic pathway into three time “intervals”: recognition of the symptoms; the decision to seek help; and the process of diagnosing PD. Research has identified both potential benefits and ethical challenges for each time interval. It is also described that just over half of the PwP believed that their diagnosis was delayed, although in some cases, due to their own delayed healthcare-seeking choices (Plouvier et al., 2015). Additionally, the majority reported that their GP did not recognise the symptoms, even when the patient suggested PD. However, the majority of participants reported being satisfied with their diagnosis trajectory (Plouvier et al., 2015).

Schaeffer et al (2020) surveyed PwP in which they were asked (retrospectively) if they wished they had been notified of their PD risk prior to diagnosis. They found that PwP saw a benefit to disease detection, as long as the news was delivered appropriately, highlighting the importance of follow-up and agency when giving an early diagnosis of (prodromal) PD. Most of the PwP were sceptical regarding early risk disclosure, especially with regard to the lack of pharmacologic options. However, once reminded of the potential ability to mitigate with exercise and diet changes, the percentage who supported early risk disclosure nearly doubled (85%). The informants also expressed the importance of freedom of choice. Schaeffer et al (2020) stressed the need to establish an early diagnosis “culture” within healthcare, including early clarification of the patient’s desire to know as well as implementing regular support and follow-up after risk disclosure.

Kayis et al (2023) investigated the attitudes of neurologists toward risk disclosure in prodromal PD. They found that the majority (77.9%) of the 222 neurologists questioned favoured disclosing the risk of PD among idiopathic REM sleep behavior disorder (iRBD) (polysomnography-confirmed) patients depending on the circumstances - mainly given that the patient provided consent. A small majority reported always or never disclosing PD risk, although the number who initially reported never disclosing risk was reduced by half once they were informed/reminded of the potential protective factor of lifestyle changes in the prodromal stage. These findings along with Schaeffer et al (2020), demonstrate the importance of lifestyle interventions and education. No significant differences were found based on age, sex, gender, academic title, or field of interest.

Ho et al. (2023) explored ethical consideration of AI monitoring among PwP. The participants expressed ethical concerns as well as potential benefits on individual, interpersonal, professional, and societal levels. Overall, participants expressed potential for more effective and personalised care (both clinical and self-care), as longitudinal monitoring could capture more nuances than a physician does in short and infrequent visits, which is important in a fluctuating disease like PD. Additionally, those who live alone might get a more accurate picture of their condition with the help of AI, as there is no one else to provide such insights (Ho et al., 2023). In another study, PwP recalled that recognizing symptoms (pre-diagnosis) took a while from when they first noticed something was abnormal and that it was friends and family who often first noticed, which led to the decision to seek help. (Plouvier et al, 2015).

Privacy was a top concern for PwP regarding AI monitoring (Ho et al., 2023). For many, it is crucial that nothing more than is needed is monitored. For example, to monitor facial

expressions, regular face-to-face camera check-ins suffice, as exemplified by one participant, and having cameras around the home would be too much. All informants stressed the importance of consent when using AI monitoring and predictive analytics, although many questioned how to ensure informed and voluntary consent, especially with disease progression, which can often cause cognitive decline. Another concern was illness identity, as constant monitoring and use of technology for their disease could serve as a constant reminder that they are “ill.”

## 5.2 Initial primary research findings - Patient panel focus groups

As of M8 (February 2024), two focus groups have been carried out with the patient panel (February 15-16, 2024). The aim was to identify and prioritise patient-faced user-needs regarding mAI-Health (where the members of the patient panel acted as proxies of PwOP) and mAI-Care tools, which were then reported to the development team (partner SQD).

There were two groups in order to allow more members to participate while keeping the size small enough for productive conversation and deeper data collection. The content was similar between the two focus groups, though the facilitators gave the second more time on questions that were not answered thoroughly or at all by the first group to ensure data on all topics of interest. The panel members were divided by which day suited the members better as well as to increase diversity (e.g., a male from France on each day rather than together).

Each focus group consisted of a primary and secondary facilitator as well as one additional project member, who facilitated note-taking. Focus group 1 (1 hour 48 min) consisted of four patient panel members (two female and two male, with an average of 9.5 years since diagnosis, and an average age of 49 years) from three different countries, and focus group 2 (1 hour 43 min) consisted of five patient panel members (three female and two male, with an average of 7.4 years since diagnosis, and an average age of 55 years) from four countries. Overall, one or more PwP participated from England, Germany, Portugal, Sweden with various professional backgrounds, knowledge of AI, and diversity of PD symptoms and treatments. The focus group guide is presented in Appendix I.

The focus groups will be further analysed using thematic analysis; however, thus far, initial findings have been extracted from the two facilitators and a third project member and listed as user-needs (see Section 6). One of these findings is that the patient panel unanimously felt that risk should not be conveyed by an app but rather by a person. Another finding was the desire for an element of gamification, where the streak count and streak freeze features of the Duolingo language app were referenced. Confirmation of successfully sent tests/data was also emphasized across the board.

## 5.3 Initial primary research findings – Interviews with HCPs

HCPs, both internal project members and external, recruited with help from clinical partners, were interviewed via Zoom (February-March 2024). The 11 HCPs spanned from five countries and various professions (neurologist, sleep specialist, research coordinator, nurse, specialist nurse), and 64% female and 36% male representation. The aim of the interviews was to identify and prioritise HCP identified user-needs. The interview guide began by asking about the HCPs background (diagnosis, treatment, late-stage PD, etc.) and focused on two parts: providing feedback and a rating of patient-identified user-needs for the mAI-Health and mAI-care, and self-identifying user-needs for the mAI-Insights platform (see Appendix I).

An initial combing through the data to identify user-needs from an HCP perspective was done and reported to developers. The initial finding included feedback on elements of data

collection, notifications, and reporting of data. Regarding data collection, gamification and “fun” features, e.g., counting streaks and using cartoon characters for expressing mood, were viewed positively to enhance compliance. It was noted that those at risk may need more motivation than those already diagnosed. It was also deemed of high importance that confirmation is given once data is submitted.

There was an agreement that clinicians – a general practitioner (GP) for those undiagnosed and a neurologist for those diagnosed – should be automatically notified of deviations in condition or when the model predicts something above a certain clinical threshold. The majority of clinicians felt an email would be the most appropriate medium for being notified of such deviations. Integrating mAI-Insights into the already existing EHR was mentioned as a way to integrate into clinical routine, although another HCP mentioned that in order for this to internationally be implemented, since EHR systems differ between countries and even within countries, a common portal applicable in all countries might be best, even if it means logging into a separate portal. Logging into mAI-Insights prior to a scheduled visit is not seen as a problem for neurologists; however, for GPs, it would be. GPs should instead receive emails of abnormalities and/or the app can suggest and guide the patient to contact their GP in the event of deviations.

There was consensus that the data should be presented in a pre-visit report summary of maximum one page and contain mostly graphs (quick and easy to visualize) of changes since the last visit. The possibility to extract the report as a PDF or Excel, as well as to click which data to visualize is desired.

## 5.5 Initial co-creation findings - Patient panel workshops on AI

As part of the projects’ co-creation initiative, two workshops were held between technical partners (AUTH, AING), ethical partners (UOXF), and UU and the patient panel on the topic of trustworthy AI. The workshops were held on two separate occasions in M9 (March 2024) with a different diverse sub-group of patient panel members (6 PwP in workshop one, 5 PwP in workshop two) in each workshop. The first focused on the mAI-Health tools and the second on mAI-Care.

The structure of the workshop began with a round of introductions from everyone and then an introduction from AUTH into the meaning of trustworthy AI. An overview of the tools of focus (mAI-Health or -Care) was given and an introduction to personas (see Appendix III) that could be referenced when answering the questions. The workshop was then split into two smaller groups using Zoom “break out rooms” in which there was a moderator from UU, 1-2 developers from AUTH, 2-3 PwP (mixed gender and nationalities), and in some groups, an ethicist from UOXF. The smaller groups allowed both technical partners and PwP to discuss issues of trustworthiness in AI and co-create solutions for the project. The discussion was organized around five topic areas: trustworthy AI design, human autonomy in healthcare and self-care, fairness and equality, explainability & transparency, and other considerations.

The data will be analysed in-depth for a research focus at a later time. The initial findings from combing through the transcripts and reviewing the workshop notes include skepticism from PwP that a tool will be able to account for the complexities of the disease and suit the diverse patient group. The patient panel expressed, however, that they would trust a doctor’s treatment and diagnosis decisions which were informed by AI, but only if the reasoning were explained – something they expect regardless of whether AI is used or not. PwP believed that additional educational content would increase trust and use of AI tools. Additionally, it was mentioned that the AI predictions should not be presented as certain, but rather as a low/medium/high (%) chance of a health outcome occurring, and with consideration of the



individual's ability to process the information without negative mental health consequences. Overall, the PwP were welcoming AI into clinical practice, but only as an aid and not a replacement for human interaction and decision-making.

## 6 Identified user needs

From the collected data, described above (Section 5), user needs for each AI-PROGNOSIS tool (Section 2.4) are defined.

### 6.1 mAI-Health mobile app

For mAI-Health Mobile App, user needs were collected and are described in **Table 4**.

**Table 4** User needs for PwP and HCPs – mAI-Health mobile app.

User needs mAI-Health app (UR.mH)		
Need ID	Need description	Priority
<b>UR.mH.01 - User interaction</b>		
UR.mH.01.01	For authentication, a no-type solution based on facial or fingerprint recognition should be used, such as Passkey.	High
UR.mH.01.02	The iOS and Android apps should not have differences in functionality.	High
<b>UR.mH.02 – Data collection</b>		
UR.mH.02.01	As much data as possible should be collected automatically, reducing the input need for users.	High
UR.mH.02.02	Data that has every-day relevance should be shown to users in-app.	High
UR.mH.02.03	Data shown in-app should be presented in an accessible and visually appealing manner.	High
UR.mH.02.04	There should be an option to choose when during the day data is collected.	High
UR.mH.02.05	Elements of gamification should be added to the app.	Medium/High
UR.mH.02.06	Elements of gamification should be customizable to correspond with users' preferences.	High
UR.mH.02.07	With gamification, a 'streak freeze' option should be available, allowing users to skip a day without losing their streak.	High
UR.mH.02.08	Input options should be offered for other relevant data, such as menstrual cycle, psychological measures, and individually relevant task data, such as 'eating soup with a spoon'.	Low
UR.mH.02.09	Clear motivations should be provided regarding why a specific type of data entry is relevant.	High
UR.mH.02.10	Notifications/reminders should be given by the app for data entry.	High
UR.mH.02.11	Confirmation should be given by the app that data has been successfully uploaded.	High
<b>UR.mH.03 – PD risk assessment model</b>		

UR.mH.03.01	Risk scores should be presented and explained by a human being who has been trained for that situation.	High
<b>UR.mH.04 – Explainable insights</b>		
UR.mH.04.01	The app should also take atypical PD into consideration.	Low/Medium
<b>UR.mH.05 – User interface</b>		
UR.mH.05.01	The user interface should be very basic and easy to navigate and understand.	High
UR.mH.05.02	Users' data entry should be as simplified as possible.	High
UR.mH.05.03	Safeguards should be implemented, making it impossible for users to enter data in the wrong way.	High
UR.mH.05.04	Special care should be given to ensuring accessibility in the user interface.	High
<b>UR.mH.06 – Data Visualization</b>		
UR.mH.06.01	Patient can choose in settings/app setup to see summary of their tracked data in graph or text/bullet point summary format.	High
UR.mH.06.02	Patient data should not be presented to patients as plain numbers but rather visual and/or descriptive (text).	High
UR.mH.06.03	Patient data should be presented as big picture trend i.e. symptoms over past month, not over 1 day, definitely not hour by hour.	High
<b>UR.mH.07 – Symptom and Treatment Tracking</b>		
UR.mH.07.01	Confirm detected concerning symptoms e.g. your watch detected that you have fallen recently, is this correct? Y/N	Medium/High
UR.mH.07.02	Prompt with action to take e.g. to schedule visit e.g. "your watch reminds you to schedule a visit if you are falling more often".	Medium/High
UR.mH.07.03	When deviation detected, ask about common symptoms for infection etc. which are common non-PD culprits for worsening PD symptoms e.g. contact primary care if experiencing any of following: fever, pain upon urination (UTI), etc.	Medium/High
<b>UR.mH.08 - Education</b>		
UR.mH.08.01	Education module for common symptoms e.g. constipation, poor sleep, etc. Add note that if not better seek HCP.	Medium

## 6.2 mAI-Care mobile app

For mAI-Care Mobile Application, user needs from PwP and HCPs were collected and are described in **Table 5**. Several user needs are the same as for mAI-Health Mobile Application.

**Table 5** User needs for PwP and HCPs – mAI-care mobile app.

User needs mAI-Care app (UR.mC)		
Need ID	Need description	Priority
<b>UR.mC.01 – User interaction</b>		



UR.mC.01.01	For authentication, a no-type solution based on facial or fingerprint recognition should be used, such as Passkey.	High
UR.mC.01.02	The iOS and Android apps should not have differences in functionality.	High
UR.mC.01.03	To combat isolation and loneliness, the app should offer interactions with other PwPs in a similar situation.	High
<b>UR.mC.02 – Data collection</b>		
UR.mC.02.01	As much data as possible should be collected automatically, reducing the input need for users.	High
UR.mC.02.02	There should be an option to choose when during the day data is collected.	High
UR.mC.02.03	Elements of gamification should be added to the app.	Medium/High
UR.mC.02.04	Elements of gamification should be customizable to correspond with users' preferences.	High
UR.mC.02.05	With gamification, a 'streak freeze' option should be available, allowing users to skip a day without losing their streak.	High
UR.mC.02.06	Clear motivations should be provided regarding why a specific type of data entry is relevant.	High
UR.mC.02.07	Notifications/reminders should be given by the app for data entry.	Medium/High
UR.mC.02.08	Confirmation should be given by the app that data has been successfully uploaded.	High
UR.mC.02.09	The app should collect data and give positive reinforcement for actions targeted at slowing down symptom progression.	High
UR.mC.02.10	Allow PwP to log sleep problem (if they develop) vivid dreams, nightmares, hallucinations, etc. (can occur and PwP do not disclose because they do not know they are related to PD).	High
<b>UR.mC.03 – PD progression predictive model</b>		
UR.mC.03.01	PwP should be able to review the input data themselves.	High
UR.mC.03.02	There should be as much detailed information as possible about the model and how accurate it is.	Medium
<b>UR.mC.04 – Symptom and treatment tracking</b>		
UR.mC.04.01	Data that has every-day relevance should be shown to users in-app.	High
UR.mC.04.02	Data shown in-app should be presented in an accessible and visually appealing manner.	High
UR.mC.04.03	Input options should be offered for other relevant data, such as menstrual cycle, psychological measures, and individually relevant task data, such as 'eating soup with a spoon'.	Medium/High
<b>UR.mC.05 – User interface</b>		
UR.mC.05.01	Data visualization should take into consideration that users can interpret visual elements like graphs very differently.	High
UR.mC.05.02	Special care should be given to ensuring accessibility in data visualizations.	High

UR.mC.05.03	Visualization of data needs to be relevant, understandable, and contextualized.	High
<b>UR.mC.06 – Clinical data integration</b>		
UR.mC.06.01	There should be as much information as possible about the clinical data used, what it contributes, and so forth.	High
<b>UR.mC.07 – User and caregiver access</b>		
UR.mC.07.01	PwP users should be able to choose what (if any) information to share with informal caregivers.	High
UR.mC.07.02	Clear information should be offered regarding how data security and privacy are safeguarded.	High

### 6.3 mAI-Insights HCP clinical platform

For mAI-Insights HCP clinical platform, user needs from HCPs were collected and are described in **Table 6**.

**Table 6** User needs for HCPs – mAI-Insights HCP clinical platform.

<b>User needs mAI-Insights platform (UR.ml)</b>		
<b>Need ID</b>	<b>Need description</b>	<b>Priority</b>
<b>UR.ml.01 - Reporting</b>		
UR.ml.01.01	Report summary should be sent 2-3 days or 1 week prior to scheduled visits.	Medium
UR.ml.01.02	To generate a report should be fast, preferably in the encounter.	High
UR.ml.01.03	The format of the report should be in PDF or Excel.	Medium/High
UR.ml.01.04	The report should be visualized in a pre-existing portal or otherwise by email.	High
UR.ml.01.05	Graphs/trends should be used as visualization.	High
UR.ml.01.06	The visualization of the report should follow the structure of a traffic light, i.e., 'red' denotes concerning, 'yellow' denotes monitor, 'green' denotes good.	High
UR.ml.01.07	There should be comparisons e.g., now vs last visit, or now vs 6 months ago (e.g., value x is -20% compared to the previous check).	High
UR.ml.01.08	The brevity should be month-to-month or week-to-week option (not day to day trend).	High
UR.ml.01.09	It should be easily to filter out information to include in the report.	High
UR.ml.01.10	It should be possible to see how often the patient is logging data (how much data the model and report is based on and address why the patient is not tracking).	High
<b>UR.ml.02 – Data collection</b>		
UR.ml.02.01	A graph showing the relationship between medication and when symptoms/side effects occurred, should be included.	High

UR.ml.02.02	Include a bar graph, or something similar, to show what time there are most fluctuations-dyskinesias, meaning most fluctuations between tremor and dyskinesias.	High
UR.ml.02.03	Include data to show the bradykinesia score.	High
UR.ml.02.04	Include data to show the dyskinesia score.	High
UR.ml.02.05	Include sleep data for PwP, to find out vivid dreams, nightmares, hallucinations, and/or sleep problems that develop.	Medium
<b>UR.ml.03 – Daily life overview</b>		
UR.ml.03.01	Include lifestyle score as an option to receive averaged or separate 3-4 lifestyle factors (some wanted composite score and some wanted individual, but maximum 3-4).	Medium/High
UR.ml.03.02	To present insights from the "most difficult daily task" as proportion and graph, e.g., 3 of 30 days patient had (most) difficulty with x in the morning and a graph of most difficult tasks over months.	High
UR.ml.03.03	To include a daily living score, e.g., dressing, eating, personal hygiene (+1/-1) improved/worsened.	High
<b>UR.ml.04 – Alerts/Functions</b>		
UR.ml.04.01	To alert clinician upon "red flags" and certain deviations, e.g., increase in falls, new symptoms, hallucinations, apathy by email/other.	High
UR.ml.04.02	To alert of abnormalities concerning data via email	High

## 6.4 AI-assisted Medication Decision support (AIMED) Module

For the AIMED module, user needs from HCPs were collected and are described in **Table 7**.

**Table 7** User needs for HCPs – AIMED module for medication decision support

<b>User needs AI-assisted medication decision support module (UR.mM)</b>		
<b>Need ID</b>	<b>Need description</b>	<b>Priority</b>
<b>UR.mM.01 - Data collection</b>		
UR.mM.01.01	PwP self-input medication info (what they are prescribed, when take it, etc.) vs. having HCP input via their portal (PwP)	High
UR.mM.01.02	PwP can self-report common/key lifestyle factors (e.g., stress, diet, constipation) which can impact medication response	High
<b>UR.mM.02 – User interface</b>		
UR.mM.02.01	Allow medication regimen (type/dose/timing) to be compared to observed signs/symptoms	High
UR.mM.02.02	Track when symptoms occur (AM/PM) in order to adjust medication	High
UR.mM.02.03	Identify onset of non-motor symptoms in relation (hours apart) to medication	High
<b>UR.mM.03 – Notification system</b>		

UR.mM.03.01	Mobile pop-up/alert of medication due which is easy to tap when PwP as taken medication.	High
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## 7 Conclusions

The D2.1 report focused on user experiences and co-creation to address the needs of relevant stakeholders for the AI-PROGNOSIS ecosystem of digital health tools for advancing PD screening and care. The user research and co-creation processes were presented and exemplified through validated methods and a framework to ensure that all stakeholders share the same goals and priorities. To adhere to the co-creation process, a patient panel was recruited and was involved in the research and design processes.

Secondary research and initial primary research findings are described, focusing on needs and concerns for PD screening and care that AI-PROGNOSIS aims to address. The secondary research emphasises that technologies for PD could be more patient-centric, as well as PwP wishes to use technologies to manage the complexity of their condition and, for this, seek collaboration with their medical team. Ethical considerations and privacy concerns for AI monitoring are also expressed. It is reported in the literature to be minimal sex and gender considerations in mHealth randomized controlled trials for chronic medical conditions like PD. Hence, for the ideation and co-creation process for needs mapping, the inclusion of sex and gender-balanced groups has been considered in the project. Also presented in this deliverable are the initial primary research findings from focus groups with the patient panel (PwP), interviews with HCPs, and workshops with technical partners (AUTH, AING), ethical partners (UOXF), UU, and the patient panel, on the topics of user needs and trustworthy AI. One of the findings is that the patient panel unanimously felt that risk should not be conveyed directly by an app, but rather by a person. Still, the PwP would trust a doctor's treatment and diagnosis decisions which were informed by AI, but only if the reasoning is explained. PwP believed that additional educational content would increase trust and use of AI tools. Overall, the PwP were welcoming AI into clinical practice, but only as an aid and not a replacement for human interaction and decision-making. Another finding was the desire for an element of gamification, which was acknowledged by HCPs as well, to enhance compliance. It was noted that those at risk may need more motivation than those already diagnosed. It was also deemed highly important that confirmation is given once data are submitted. There was an agreement that clinicians should be automatically notified of deviations in condition or when the model predicts something above a certain clinical threshold.

As co-creation and user research are iterative concepts, this document will be enriched with more updated content (D2.4) alongside the development of the AI system within AI-PROGNOSIS.

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## Appendix I Discussion Guides

The interview guide for onboarding interviews with the patient panel is provided below.

### Interview guide: Participation in PD Patient Panel – AI PROGNOSIS

(Brief explanation about the purpose of the focus group, that it will be recorded, etc.)

#### **1. Personal background**

1.1 Tell us about your background. E.g. age, occupation.

#### **2. PD Background**

2.1 Diagnosis timing

- When were you diagnosed with Parkinson's disease?

2.2. Diagnosis process

- Could you briefly describe the diagnosis process?

- What steps were involved, and how did you experience it?

#### **3. Experiences with Participation in Research and/or Patient Panels**

3.1 Previous participation

- Do you have any prior experience participating in research projects or patient panels?

3.2 Experiences

- If so, could you share your experiences and what you found most meaningful or challenging?

#### **4. Expectations and/or concerns with Participation in this Project**

4.1 Expectations

- What expectations, if any, do you have about participating in this specific research project?

4.2 Concerns

- What concerns about participating in this specific research project, if any, do you have?

4.3 Hopes/Goals

- What do you hope to achieve by participating in this project?

#### **5. View on Prediction Models Generally**

(Brief introduction of the work to be done in AI-PROGNOSIS incl. the 3 planned prediction models (PD diagnosis, disease progression, and prediction of medication effect.)

5.1 General interest

- How do you view prediction models in general within healthcare and research?

5.2 Advantages and challenges

- What do you see as the specific advantages and challenges of using prediction models?

#### **6. View on Prediction Models planned in AI-PROGNOSIS**

6.1 General perspective

- What is your perspective on the use of prediction models to predict Parkinson's disease diagnosis, disease progression, and medication effects?

6.2 Specific advantages and challenges

- Are there specific advantages or challenges you see when it comes to using prediction models for PD diagnosis, disease progression, and medication effect?

#### **7. Closing Questions**

7.1 Participation and significance

- How do you perceive your own involvement in the research process, and how important do you think patients' perspectives are in such projects?

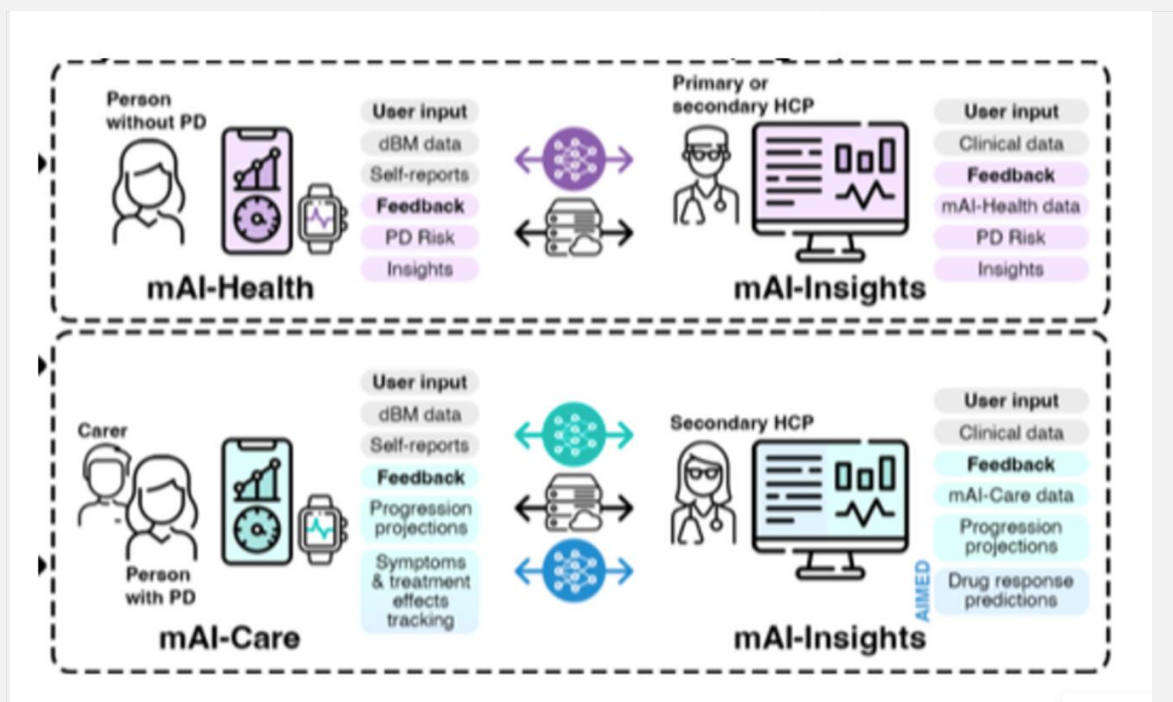
7.2 Any additional wishes

- Do you have any additional wishes or things you would like to highlight in connection with your participation in this research project?

The interview guide from data collection of HCPs is here provided:

### Introduction + Consent to record

- Welcome and thanks for participating.
- Who am I & what is the purpose of the interview? (To gather insights on the prioritization of features for the tools mAI-Health, mAI-Care, and mAI-Insights. Show image below.)
- Assure confidentiality and explain how the information will be used.
- Ask consent for recording.



### Background

- Please briefly tell me a bit about yourself (professional role, length of time working there, etc.)
- What stage of PD are you involved in? (Prodromal/diagnosis/medication/other?)

Information about mAI-Insights HCP platform, as a platform that has three distinct modules:

- 1) PD risk monitoring module (for HCPs involved in PD screening/diagnosis)
- 2) PD progression module including condition tracking based on mAI-Care data, and progression projections (for HCPs involved in PD care)
- 3) The AIMED module, focusing on medication response prediction (for HCPs adjusting medication regimens)

1. From your perspective, what features do you envision for mAI-Insight? Please prioritize them as high/medium/low in terms of importance.

- If resources and technology limitations were not a concern, what would be your dream feature for mAI-Insight?

2. How do you envision these features impacting your work as HCP or addressing existing challenges?

- What about improving/impacting the patient experience?

### **Prioritization of User-Identified Features**

From the two focus groups with the patient panel (9 PwP from 4 countries and various experiences related to PD diagnosis, symptoms, treatment, etc.), identified features for mAI-Health and mAI-Care were provided.

3. Please give your perspectives on these desired features by prioritizing them as high/medium/low in terms of importance and motivate why.

### **HCP-identified mAI-Health features**

4. For mAI-Health, are there any additional functionalities you would like to see, and how would you prioritize them?

5. What criteria do you use to determine the priority of features? (e.g., impact on daily tasks, efficiency, user satisfaction)

6. Are there any specific user needs or pain points that influence your prioritization of features?

7. How would you, as a primary care HCP, like to be notified about and, if necessary, monitor the risk of a mAI-Health user?

8. How would you decide which patients should use this app?

### **HCP-identified mAI-Care features**

9. For mAI-Care, are there any additional functionalities you would like to see, and how would you prioritize them?

10. What criteria do you use to determine the priority of features? (e.g., impact on daily tasks, efficiency, user satisfaction)

11. Are there any specific user needs or pain points that influence your prioritization of features?

### **Closing**

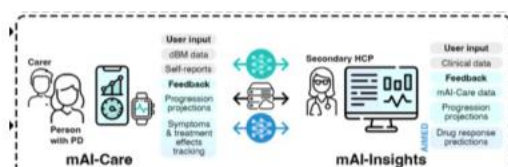
- Any additional thoughts or questions?

Thank you for your time!

The introduction and instructions for the workshops with PwP (patient panel) and technical partners are provided here:

## Introduction to workshop 1(3)

### mAI- Care



- 1. User Interaction:**
  - Persons with Parkinson's (PwP) and their caregivers interact with the mAI-Care mobile app on smartphones.
- 2. Data Collection:**
  - The app collects data from multiple sources:
    - SmartWatch-Tracked Data
    - Occasional Self-Reports on Symptoms and Condition
    - Clinical Data Shared by Attending Physician
- 3. PD Progression Predictive Model:**
  - The collected data feeds into the PD Progression Predictive Model.
  - The model generates personalized projections of PD progression for the individual.
- 4. Symptom and Treatment Tracking:**
  - Users can input and track their symptoms in the app.
  - Users can log information about their treatment, medication efficacy, and any side effects experienced.
- 5. User Interface:**
  - The app displays personalized projections of PD progression in an easy-to-understand format.
  - Graphical representation of symptom trends and treatment effects for better visualization.
- 6. Clinical Data Integration:**
  - Integration with clinical data shared by the attending physician for a comprehensive overview of the individual's health.
- 7. Notification System:**
  - Implement a notification system to remind users to input self-reports and take medications.
  - Caregivers may receive notifications or updates about the PwP's condition.
- 8. Data Security and Privacy:**
  - Ensure robust security measures to protect sensitive health data.



## Introduction to workshop 2(3)

- Patient panel members and technical partners discuss together. **All contribute!**
- Mixed groups with one moderator each
- Both groups will discuss the same questions
- The breakout rooms will also be recorded

## Introduction to workshop 3(3)

- Personas
  - Enable more objective way to discuss user needs
  - Complement existing patient panel perspectives
  - Feel free to refer to personas during discussions
  - Provide extra insights into extreme complexity of PD

<p><b>Mattias Ericsson</b></p>  <p>Mattias is a 55-year-old Swedish man working as a chief accountant in a large company. He is married and he has three children: Max (13 years old), Sara (11 years old), and Eli (6 years old). The family lives in a suburb of Stockholm. Mattias and his wife Maria both have very demanding jobs and their children also have busy schedules. As a</p>	<p><b>Marie Pinardo</b></p>  <p>Diagnosed in her early 40s, Marie is now 56 and well versed in her routine. She is a nurse and knows a lot about PD already. She always lived a healthy lifestyle, as she knows how important it is, but now that she has PD, she makes sure to exercise daily, no exceptions. She also monitors her protein intake in relation to her medication. Marie hopes her healthy lifestyle will help keep her from progressing. She has children and is passionate about her job.</p>	<p><b>Jean Tremblay</b></p>  <p>Jean is 87 and was diagnosed at 79. His mobility is limited, and he uses a walker to get around even in his home.</p> <p>One of his friends who has now passed away had PD, so he knows</p>
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Further instructions for the workshops were five themes with specific questions and assignments:

T1 – Trustworthy AI design

- What makes an AI system relating to health data?

T2 – Human Autonomy in healthcare and self-care

- Would you like to be informed about the involvement of AI in decision-making in your/a persona's healthcare? If so, how?
- Would knowing that a human healthcare professional is overseeing the AI's decisions affect your level of comfort? How?
- In which situations would it be important for a human to have the final say, even if AI is used in the process?

T3 – Fairness and Equality

- How would you define fairness in AI?
- How can potential biases in healthcare delivery be addressed?

T4 – Explainability & Transparency

- Is it important to know how the AI makes predictions?
- Would understanding how the AI works make you trust its predictions more?
- What would transparency regarding how the AI makes decisions mean to you?

Q5 – Other Considerations

Are there any other considerations you believe should be prioritized when AI is used in healthcare?

The introduction and instructions for the focus groups with PwP (patient panel) are here provided:



The slide features a dark blue background with white text. In the top left corner, there is a logo for 'ai-prognosis' consisting of three overlapping circles in blue, green, and orange, followed by the text 'ai-prognosis'. In the bottom left corner, there is the European Union flag logo, followed by the text 'Funded by the European Union'. The main title 'Focus group on user needs' is centered in a large, bold, white font. At the bottom right, the text 'PwP focus group 2' and '22 February 2024' is displayed in a smaller white font.

ai-prognosis

# Focus group on user needs

Funded by the European Union

PwP focus group 2  
22 February 2024



## First things first

- Research participant information was sent out ahead of the meeting
- Questions?
- Record consent

2 

## Workshop agenda

1. Introductions
2. Workshop targets
3. Definitions & assumptions
4. The AI-PROGNOSIS tools
5. Discuss high-level product features and user needs (in Miro)
6. Next steps

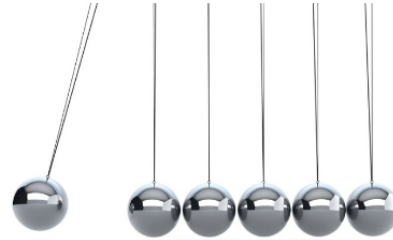
*Break when needed*



3 

## Workshop targets

- Get an overview of app features
- Identify and prioritise user needs
- If there is time...
  - Identify and discuss potential user challenges



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## Definitions 1(2)

### High-level features

- will deliver value to the end users of the AI-PROGNOSIS apps.
- Examples:
  - mAI-Health - users (persons without PD) will be able to track their risk of Parkinson's disease
  - mAI-Care - users (PwP) will be able to track disease progression
  - mAI-Insights - users (secondary care professionals) will be able to see projections of their attending patients' progression.

### User needs or user requirements

- functions that the users expect/want the application to support.
- Examples:
  - The mAI-Health app users should be able to see metrics about their risk of getting PD. (Priority: Low)
  - The mAI-Care app users should be able to view when the next tasks/tests must be performed. (Priority: High).

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## Definitions 2(2)

### Functional requirements

- product features or functions that developers must implement to enable users to accomplish their tasks.
- Examples:
  - The mAI-Health app must allow the user to perform a memory test (Priority: High).
  - The mAI-Care app should allow the user to choose what time of the day they receive their unperformed task reminders (Priority: Medium).

### Non-functional requirements

- system qualities and constraints. They will be more or less common across the three products.
- Examples
  - UI accessibility, e.g. color contrast, text size
  - system security, e.g., encrypted databases, data transmission over HTTPS.

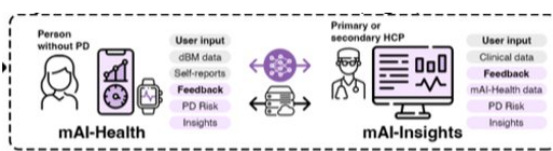
7 

## Assumptions

- Process
  - Your input will have an impact
  - Focus will be on user needs
- Products
  - The AI-PROGNOSIS tools will be based on the "study app"
  - The apps will be in both iOS & Android
  - The AI models will work perfectly

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## mAI- Health



### High level feature

### User need

#### 1. User Interaction:

- Users interact with the mAI-Health mobile app on their smartphones.

#### 2. Data Collection:

- The app collects data from two primary sources:
  - SmartWatch- Tracked Data
  - Self-reports on Relevant Risk Factors/Symptoms

#### 3. PD Risk Assessment Model:

- The collected data feeds into the PD Risk Assessment Model.
- The model calculates a quantitative PD risk score based on the input data.

#### 4. Explainable Insights:

- The app provides explainable insights derived from the PD risk assessment.
- Users receive understandable information about their personalized risk of acquiring Parkinson's Disease.

#### 5. User Interface:

- The app displays the results and insights in a user-friendly interface.

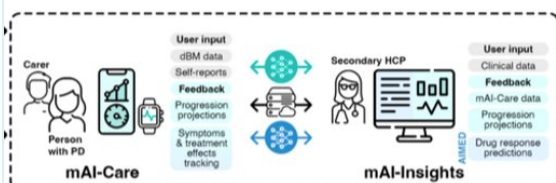
#### 6. Data Visualization:

- Visual representation of data (charts, graphs)
- Clear presentation of the quantitative PD risk score and associated insights.

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## mAI- Care



#### 1. User Interaction:

- Persons with Parkinson's (PwP) and their caregivers interact with the mAI-Care mobile app on smartphones.

#### 2. Data Collection:

- The app collects data from multiple sources:
  - SmartWatch- Tracked Data
  - Occasional Self-Reports on Symptoms and Condition
  - Clinical Data Shared by Attending Physician

#### 3. PD Progression Predictive Model:

- The collected data feeds into the PD Progression Predictive Model.
- The model generates personalized projections of PD progression for the individual.

#### 4. Symptom and Treatment Tracking:

- Users can input and track their symptoms in the app.
- Users can log information about their treatment, medication efficacy, and any side effects experienced.

#### 5. User Interface:

- The app displays personalized projections of PD progression in an easy-to-understand format.
- Graphical representation of symptom trends and treatment effects for better visualization.

#### 6. Clinical Data Integration:

- Integration with clinical data shared by the attending physician for a comprehensive overview of the individual's health.

#### 7. Notification System:

- Implement a notification system to remind users to input self-reports and take medications.
- Caregivers may receive notifications or updates about the PwP's condition.

#### 8. Data Security and Privacy:

- Ensure robust security measures to protect sensitive health data.

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## Appendix II Checklist for Collaboration 2.0


Recommendations	Already doing	Will review
<p><b>1</b> Define clear aims, objectives and evaluation criteria – together</p> <p><b>Can help ensure that:</b></p> <ul style="list-style-type: none"> <li>• Collaboration is evaluated and monitored in terms of its aims, objectives and effects</li> <li>• The problem of symbolic collaboration is reduced thanks to a clear collaborative framework</li> <li>• Partners with the right competencies for the task are included in relevant parts of the process</li> <li>• Negative effects of perspective drift are reduced through clear roles</li> </ul>	<input type="checkbox"/>	<input type="checkbox"/>
<p><b>2</b> Confront power imbalances</p> <p><b>Can help ensure that:</b></p> <ul style="list-style-type: none"> <li>• An equal and inclusive environment is created, where there is a balance of power rather than an imbalance of power</li> <li>• Trust in the expertise of the other collaborative partners is enhanced</li> <li>• All parties are actively involved and it is clear who is expected to contribute what</li> <li>• Knowledge exchanges take place between all parties and everyone is given the opportunity to develop their skills</li> </ul>	<input type="checkbox"/>	<input type="checkbox"/>
<p><b>3</b> Communicate to build trust and confidence</p> <p><b>Can help ensure that:</b></p> <ul style="list-style-type: none"> <li>• Long-term relationships within the collaborative initiative are built and maintained thanks to trust-building communication</li> <li>• All perspectives and views are gathered through an open flow of information in all directions</li> <li>• A culture change takes place, thanks to the building of trust and confidence</li> <li>• Challenging problems get new potential solutions through open dialogue</li> </ul>	<input type="checkbox"/>	<input type="checkbox"/>

Recommendations	Already doing	Will review
<p><b>4</b> Create conditions for remuneration and representativity</p> <p><b>Can help ensure that:</b></p> <ul style="list-style-type: none"> <li>• Power imbalances are reduced or eliminated</li> <li>• More perspectives can be included through the introduction of flexible remuneration models</li> <li>• Key stakeholders who would otherwise be missed can be included through adaptation to individual needs of participation</li> <li>• Trust and belonging are promoted through the introduction of an inclusive way of working</li> </ul>	<input type="checkbox"/>	<input type="checkbox"/>
<p><b>5</b> Build a long-term structure for collaboration</p> <p><b>Can help ensure that:</b></p> <ul style="list-style-type: none"> <li>• Costs and time are reduced by not having to reinvent the wheel every time you need to collaborate</li> <li>• The problem of purely symbolic collaboration is eliminated when collaboration is a permanent feature in the organization or system</li> <li>• Recruiting representatives for different collaborative initiatives is easier because a structure is already in place</li> <li>• Trust and confidence in an organization grow if the organization signals that collaboration is such a priority that a solid structure is in place</li> <li>• Loss of knowledge and skills is reduced because there is a structure to manage them over time</li> </ul>	<input type="checkbox"/>	<input type="checkbox"/>
<p><b>6</b> Share positive and negative experiences and learn from others</p> <p><b>Can help ensure that:</b></p> <ul style="list-style-type: none"> <li>• Others are helped to collaborate better, leading to an improved culture of collaboration throughout society</li> <li>• New cross-organizational and cross-system collaborations are made possible thanks to the wide dissemination of results and experiences</li> <li>• A collaborative approach is normalized through open dialogue</li> <li>• Public understanding and interest in collaboration increase</li> </ul>	<input type="checkbox"/>	<input type="checkbox"/>

## Appendix III Personas


This Appendix contains the most basic iteration of the personas that will be used as a basis for the user research and co-creation activities in AI-PROGNOSIS. They are divided into three separate groups, HCP, PwP and PwoP. The latter can also be divided into two sub-categories, informal care givers (ICGs) and at-risk individuals. While HCP can have a more complex representativity, as simultaneously HCP, PwP, and PwoP, they are treated as a separate group only representing the HCP perspective here. The pictures of the personas were generated by artificial intelligence using the online tool Canva (canva.com).


### III.1 Personas for people with Parkinson's

PwP persona 1	
Persona name	Mattias Ericsson
Picture	
Backstory	<p>Mattias is a 55-year-old Swedish man working as a chief accountant in a large company. He is married and he has three children: Max (13 years old), Sara (11 years old), and Elli (6 years old). The family lives in a suburb of Stockholm. Mattias and his wife Maria both have very demanding jobs and their children also have busy schedules. As a hobby, Matthias has been playing tennis with the same group of friends twice a week for the last five years.</p> <p>Six months ago Mattias started experiencing muscle stiffness, slow movement, and sleep problems. The symptoms affected his work productivity and made it hard to play tennis and be active with his children. He got tired quickly. After a period of misdiagnosis, Mattias recently got diagnosed with Parkinson's. At first, Mattias was shocked by his Parkinson's diagnosis, and he did not know what this disease included.</p> <p>He wants to live his life in the same way for as long as possible and is interested in what he can do to reduce symptom severity, and maybe even slow disease progression.</p>
Resources	<p>Mattias is familiar with and competent in using digital tools. He uses a smartwatch and applications on his mobile to monitor his health (e.g. HR and step count). Mattias's meeting-filled schedule is hectic, making it difficult to control his medication and diet routine. His doctor emphasised exercise. However, he only has time twice a week - when he plays tennis with his friends whom he wants to keep seeing. He is unsure of what other forms of exercise he could do anyway.</p>




<b>Emotions</b>	<p>Mattias feels overwhelmed since his diagnosis and is uncertain about the future. He worries about not being able to work or play tennis or play with his kids anymore. He feels like a changed man and is afraid to tell his tennis buddies and colleagues about the diagnosis because he does not want people to see him differently.</p> <p>He feels like he's lost control over his life and he wants to take back control. He has read that other PwP benefitted from optimising their medication regimen, diet, and exercise. He wants to change his lifestyle so that he can feel optimal.</p>
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PwP persona 2	
<b>Persona name</b>	<b>Marie Pinardo</b>
<b>Picture</b>	
<b>Backstory</b>	<p>Diagnosed in her early 40s, Marie is now 56 and well versed in her routine. She is a nurse and knows a lot about PD already. She always lived a healthy lifestyle, as she knows how important it is, but now that she has PD, she makes sure to exercise daily, no exceptions. She also monitors her protein intake in relation to her medication. Marie hopes her healthy lifestyle will help keep her from progressing. She has children and is passionate about her job.</p> <p>From the outside, no one hardly notices that Marie has PD. She, however, notices that she is slower and has GI and sleep issues.</p>
<b>Resources</b>	<p>As an RN, Marie has pre-existing medical/health knowledge as well as access to other HCPs for questions/advice. She has access and the ability to understand scientific publications, even those with a paywall.</p> <p>Time, however, is something limited. She has a strict routine in order to manage her stressful career, healthy lifestyle, and family time.</p>
<b>Emotions</b>	<p>Marie can feel frustrated sometimes that she appears "normal" on the outside but feels and notices changes in her mind and body. She is however motivated to keep this healthy lifestyle and fight the progression of this disease. Her family are most important to her, and she doesn't want PD to take away her time playing with the grandchild which is on its way.</p>


PwP persona 3	
Persona name	Jean Trembley
Picture	
Backstory	Jean is 87 and was diagnosed at 79. His mobility is limited, and he uses a walker to get around even in his home.
Resources	One of his friends who has now passed away had PD, so he knows it can affect people differently. His grandson always tells him about research he has read, but Jean does not always agree or understand. Jean attends weekly online PD exercise classes with help from his grandson, who turns on the computer for him to follow along. Jean lacks technical abilities.
Emotions	He feels rather confined to the home due to mobility challenges such as freezing of gait and imbalance. He feels that he can be a burden to his family, as they often check in on him.

## III.2 Personas for people without Parkinson's


PwoP persona 1	
Persona name	David Wolf
Picture	

<b>Backstory</b>	David has been to his family practitioner a few times over some symptoms he has been having that he read online could be PD. His MD referred him to a neurologist, but it is a long wait to get an appointment. Among the symptoms he's been having are fatigue, mood and cognitive changes, bradykinesia and constipation.
<b>Resources</b>	His wife is supportive and has been up late googling with him and observing his health. It is a long drive to the neurologist and a long wait, but they have a car. They are not very tech-savvy.
<b>Emotions</b>	David and his wife are worried, but having a diagnosis would be a sense of relief because they would know what is causing these new symptoms. They have not told the family about his worsened health nor about the doctor's visits, they want to first figure out what the culprit is.


<b>PwoP persona 2 (PwoP/ICG)</b>	
<b>Persona name</b>	<b>Emma (and Erik) Thomsen</b>
<b>Picture</b>	
<b>Backstory</b>	Emma's husband Erik has had PD for 5 years now. She helps him remember his appointments, monitor his symptoms and overall wellbeing between visits, and always attends his doctor's visits. She is recently retired.
<b>Resources</b>	She is very organised and good at tracking Erik's signs and symptoms. She writes down questions for the doctor, but sometimes has trouble deciphering what information is correct on the internet. She is a bit mentally drained from trying to wear multiple hats.
<b>Emotions</b>	Sometimes Emma finds it hard to balance being a wife with being a caretaker. Her relationship with her husband changed a lot when he got his diagnosis. Emma also has had trouble finding time for her own hobbies lately, since Erik has been having more "off" periods and so she avoids leaving him alone. She recently retired and is hoping that will create more balance.

PwoP persona 3 (PwoP/ICG/At risk)	
Persona name	Paul (and Robert) Aaldenberg
Picture	 A photograph of two men, Paul and Robert Aaldenberg, standing outdoors. Paul is on the left, wearing a blue button-down shirt, and Robert is on the right, wearing a dark blue polo shirt and glasses. They are both smiling and looking towards the camera.
Backstory	His father Robert was diagnosed with PD a few years back and was told that he also carries the <i>GBA</i> gene. This makes Paul very worried about his dad and his own future. He visits his dad weekly, as he lives in a nearby town. He tries to get his father to use more digital solutions for communication and monitoring of his symptoms.
Resources	He is young and adept at searching for information about his father's PD. He drives and can quickly and easily get to his father. He does not have time to join his father for medical appointments but is involved as much as possible. He finds it confusing, however, that there is so much conflicting information regarding his likelihood of getting PD passed down.
Emotions	Paul is worried he will get PD just like his father. He is also sad to see his father's mobility gradually deteriorate, as they used to hike together.


## II.3 Personas for healthcare professionals

HCP persona 1	
Persona name	Susanna Lind
Picture	 A portrait of a woman, Susanna Lind, with blonde hair and glasses, wearing a white lab coat over a grey top. She is holding a white folder or clipboard in front of her.


<b>Backstory</b>	Susanna is a 44-year-old Swedish medical doctor working as a neurologist at a major university hospital in a large city in southern Sweden. She spends about 60% on clinical work and 40% on research-related tasks. She also manages the four research nurses at the neurology unit. Her workload is significant. Typically, the time devoted to patients coming in for return visits and patients participating in research amounts to 15-20 minutes of face-to-face time and 40-45 minutes administrative work (preparing for a visit, documenting a visit, and communicating with/distributing tasks to support staff).
<b>Resources</b>	Susanna is familiar with and competent in using digital tools. She uses numerous applications and systems in her daily routine. The hospital's computers and other digital tools are not always up to date, and it can take long until the newest software release is rolled out hospital wide. There is availability to technical support at the neurology unit, but waiting times are sometimes long. Susanna's English skills are excellent, and she switches between English and her native Swedish seamlessly. IT support is only available for Swedish-language software.
<b>Emotions</b>	Susanna is frustrated by the number of applications and programs she needs to get (and stay) familiar with just to perform her daily tasks. She delegates what she can to the unit's research nurses in order to secure more face time with patients. She is resistant to having to integrate additional digital tools into her routine.

HCP persona 2	
<b>Persona name</b>	Ingrid Sjöström
<b>Picture</b>	
<b>Backstory</b>	Ingrid is a 40-year-old <b>specialised RN</b> who has been working in neurology for 8 years. She has seen PD patients progress at all different rates and with various signs and symptoms, and wishes she could do more for her patients. She knows her staff feel the same, but they all are pressed for time and are not able to be as patient-centered as they would like.
<b>Resources</b>	Ingrid and her coworkers are short on time. She has familiarity with a wearable from when the department implemented a research project on home-monitoring. However, she finds it difficult to balance being a care provider with conducting research.

<b>Emotions</b>	The department has participated in research before, using wearables to track tremor and patient-reported variables. She likes the idea in theory but found that the tech wasted a lot of her time explaining how to use it and troubleshooting with patients when that is not their job. She sometimes feels like a “ <b>car salesman</b> ” pushing a device her patients are uninterested in. Therefore, she is worried and skeptical about participating in research or implement new technologies again.
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HCP persona 3	
<b>Persona name</b>	<b>Alexandria Haglund</b>
<b>Picture</b>	
<b>Backstory</b>	Alexandria is a 50-year-old RN and PhD who has been working as the department's <b>coordinating research nurse</b> for the past 6 years. She has seen PD patients progress at all different rates and with various signs and symptoms, and wishes she could do more for her patients. She got involved research because she is hoping that research will bring new solutions for her patients' wellbeing.
<b>Resources</b>	As a manager, she spends a lot of time on paperwork, mostly electronically as the Swedish healthcare system is fairly digitalised. She is comfortable using those systems as well as home-monitoring and tele-health tools which they have used in research projects previously.
<b>Emotions</b>	Alexandria believes in research and digital solutions, that is why she got involved in research. She really enjoys it, however, it takes a lot of energy. She has to put a lot of time and effort into explaining the technology to her patients, playing tech-support, and many other tasks which she does not get credit nor any reward for. She knows it is important to ensure she does not lose any study participants. She is stressed out from the high workload. She is optimistic that the research they conduct will lead to a better future.



HCP persona 4	
Persona name	Ayesha Abdeel
Picture	
Backstory	Ayesha is a 25-year-old <b>newly hired nurse</b> . She worked in another department for 2 years previously and is new to the neurology department. She is originally from Syria and has been living in Sweden since she was a child.
Resources	Ayesha is tech-savvy and a quick learner. She wears a smartwatch and tracks her own health metrics that way and is planning to encourage the same of her patients. She does not, however, have experience working with people with Parkinson's nor other neurodegenerative disease.
Emotions	She is excited to work in neurology now. She has a strong <b>interest in mHealth</b> and is looking forward to knowing more about how her new team works and what sort of research projects they are participating in.

HCP persona 5	
Persona name	Lars Limberg
Picture	
Backstory	Lars is a 30-year-old <b>nurses aid</b> . He has been working for about a decade and been forced into several research projects that the department decided to join.



<b>Resources</b>	With extensive experience in the department, Lars knows a lot about PD patients as well as technology. He is pressed for time, however, and does not earn enough to feel motivated to do any additional tasks.
<b>Emotions</b>	Lars has experienced the added stress of yet another task when the department conducted research. He had to explain to elderly and confused patients with severe tremor how to use an app they could not navigate. He feels that he does not get any benefit from carrying out the research tasks and has begun to just ignore them because he is fed up. He has enough on his plate and a bad enough salary as it is.