PATIENT INVOLVEMENT AND DISSEMINATION (1 page, Arial 10 pt.)

Lay Summary of potential Clinical or Healthcare benefits

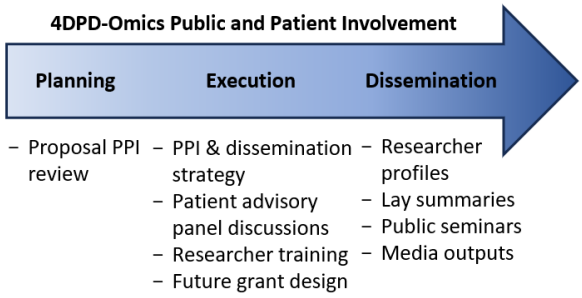
Parkinson's is a growing neurological condition which markedly impacts the quality of life of people it affects, with major societal and economic impact. Current therapies treat clinical symptoms only and have not majorly advanced in the last 50+ years. The development of effective therapies which slow or prevent Parkinson's is therefore an unmet societal need. 4DPD-Omics is a 3-year, lab-based project that aims to address this unmet need by (i) mapping the molecular changes that occur in different cell types in the brain as the disease develops, (ii) unravelling these changes to identify key molecules or cell types that regulate the disease, and (iii) classifying samples according to these observed changes. This will be achieved using brain samples from animals and *post mortem* humans. We envisage that profiling of Parkinson's development over time and identification of key regulators is highly attractive for the future development of targeted treatments/biomarkers and will be of great interest to people affected by Parkinson's. The classification of Parkinson's phenotypes will generate a broader awareness of the spectrum of Parkinson's, increasing societal impact. Creation of 4D representations of diseased cell profiles in the human brain will provide teaching resources for medical doctors and students of basic neuroscience, as well as the interested lay audience.

Specific aims of the patient/public involvement

Experiences and opinions of people affected by Parkinson's are indispensable for the success of the project. The aims of PPI in 4DPD-Omics are: (i) ensure project outputs and dissemination align with the needs of the Parkinson's community, (ii) make the research more accessible to a general audience, (iii) increase awareness of the relevance and importance of basic Parkinson's research and of brain donation, (iv) achieve widespread dissemination of project progress and impact to all relevant stakeholders (scientific community, healthcare workforce, people affected by Parkinson's, the general public), (v) inform patients about Parkinson's types and research to develop therapies for their disease, (vi) train researchers to instigate public engagement and, (vii) design future research emanating from 4DPD-Omics for maximal patient impact.

How will PPI be performed?

4DPD-Omics involves partners in Ireland (RCSI), the Netherlands (AUMC), Germany (DZNE), France (CNRS/CEA) Sweden (ULUND) and Hungary (UD) who already engage with Parkinson's patient groups: Partner AUMC is an executive board member of Parkinsonalliance Netherlands and works with the national Dutch patient organisation,



RCSI coordinates a patient advisory panel, DZNE have close contacts with the DZNE patient advisory board, and CNRS/CEA liaise with France Parkinson. PPI will be led by AUMC in collaboration with the coordinator, and will be incorporated at all partner institutions. We will (1) include a patient representative on the Scientific Advisory Board (SAB) who will advise on the PPI and dissemination strategy (see WP9), be kept informed on project progress, and be invited to attend and present at all consortium meetings; and (2) liaise with patient advisory panels in partner countries. These panels are a diverse network of brain health champions including people affected by Parkinson's. Along with the SAB representative, they will be asked to comment on plain English summaries and press releases/social media posts, and to take part in discussions on how to maximise project impact, optimise dissemination, and design future research emanating from 4DPD-Omics outputs. PPI representatives will be compensated for their time by AUMC and partner patient advisory panels as appropriate. Specific PPI activities include:

- Project website(s), press releases, and social media channels will inform patients and the public about 4DPD-Omics research via project news, progress updates, educational materials, and details of events of interest to the public. Communications will include comments from patient groups where relevant. [all partners]
- PPI researcher training: As part of FutureNeuro and in conjunction with a dedicated Public Engagement Manager, targeted PPI researcher training will equip 4DPD-Omics researchers with the skills to instigate public engagement and embed engaged research throughout the project. [RCSI]
- Public seminars: Dr Connolly [RCSI] will coordinate and host a series of public online seminars featuring presentations from researchers, health professionals and people with Parkinson's. Previous seminars were well attended and promoted engagement from and with the Parkinson's community (https://bit.ly/44fhM71).
- Researcher profiles: We will publish profiles of all our researchers on our website, increasing the accessibility of the research (*e.g.,* https://www.pdmitoquant.eu/team/researchers/). [all partners]
- Plain English summaries, written by researchers in collaboration with patient representatives, will accompany 4DPD-Omics-affiliated publications and will be shared on social media channels and websites. [all partners]
- Project presentations: All team members will give talks to showcase the work and results of 4DPD-Omics, including at meetings that are attended by people affected by Parkinson's. [all partners]
- The 4DPD-Omics team is involved in promoting patient recruitment (multicentre longitudinal cohort 'ProPARK' and other brain donation programs) and will promote awareness of brain donation. [AUMC]

How will PPI be evaluated?

The PPI and dissemination strategy will be reviewed at each consortium meeting and by our affiliate patient advisory panels. It will be updated as required and reported on in annual and final reports. PPI will be evaluated against the above aims, and we will report data on time/budget allocated, audience reach (*e.g.,* website/social media metrics), participant involvement (including demographic details), feedback measures, and PPI-driven implementations, following guidelines from the Public and Community Engagement Knowledge Exchange Framework.