



IMI2 Project 821522 – PD-MitoQUANT

PD-MitoQUANT – A quantitative approach towards the characterization of mitochondrial dysfunction in Parkinson's disease

WP3 – Project management and communications

D3.5 Update on communication & dissemination activities

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Abstract

The communication and dissemination of project results is central to delivering the impact of PD-MitoQUANT at both scientific and wider societal levels.

Data from this project will be of considerable interest to a broad scientific audience, as PD-MitoQUANT will generate new *in vitro* and *in vivo* models of mitochondrial function/dysfunction and Parkinson's models, in addition to enhancing our basic understanding of the mitochondria in the progression of Parkinson's. To maximise the impact of the project, a Dissemination and Communication Plan (DCP, D3.2) was developed in the early phases of the project involving all consortium members. The plan is regularly reviewed and updated. The plan lays out a roadmap for all key milestones across the duration of the project and utilises a variety of channels to maximise the dissemination of the PD-MitoQUANT data and its impact.

Communication and dissemination has been a continuous process throughout the project, starting with introduction of the project and its aims at the start of the project and with results in the later stages, as they become available. In addition, our communication and dissemination activities create a favourable ground to facilitate exploitation of PD-MitoQUANT data after the end of the project.

Methods

Parkinson's UK led on the development of the DCP, which was further developed by the Communications and Dissemination Committee (CDC). The final version reviewed by the consortium prior to its submission for publication on 29 Apr 2019 (M3). The plan was reviewed in August 2019 and March 2020 by the CDC.

The CDC, which meets ~every 4 months, was established by Parkinson's UK from a broad range of key stakeholders from within the consortium, and includes:

- David Dexter (Chairperson) Associate Research Director at Parkinson's UK
- Beckie Port Research Communications Manager at Parkinson's UK
- Natasha Ratcliff Public Patient Involvement lead at Parkinson's UK
- Amy Dodge Media and Public Relations manager at Parkinson's UK
- Jochen Prehn PD-MitoQUANT Coordinator, RCSI
- Niamh Connolly PD-MitoQUANT Coordinator Representative at RCSI
- Danielle Nicholson Communication and Dissemination expert at PT
- Sara Shnider EFPIA Representative from Teva Pharmaceuticals
- Paula Scurfield Person affected by Parkinson's
- Richard Campbell Person affected by Parkinson's

The purpose of the CDC is to ensure that the objectives of the DCP are on track and, where necessary, update/revise the DCP so as to maximise the communication and dissemination of results from the consortium.

Results

General communication and dissemination

The consortium has actively engaged in communication and dissemination:



Pintail has set up (M2, MS24) and managed a highly effective website for the PD-MitoQUANT project (www.pdmitoquant.eu). Members of the CDC provided feedback on the website design and functionality. Consortium members regularly contribute content for the website, which can be accessed by wider lay and scientific audiences. The website is regularly updated with details of communications made by consortium members to both scientific and academic audiences. Partners also promote the project on social media using the common hashtag #pdmitoquant and as news items on their organisation websites/social media accounts (e.g. PUK blog¹ and LinkedIn/Twitter, etc.). A ResearchGate project has also been created.² Links have also been established with national networks, such as Neuroscience Ireland.³ The project website also features early- and mid-stage researchers from the project (Figure 2).⁴



Figure 1 Early and Mid-Stage Researchers Profile Page (www.pdmitoquant.eu/researchers/)

- Pintail has established an effective **internal e-mail** communication network. UCB also host a **Sharepoint** site for the internal sharing of documents, techniques and data.
- A consortium wide face-to-face (**F-2-F**) **meeting** was held in November in Israel, hosted by Teva. The next F-2-F meeting in July 2020 was impacted by the Covid-19 pandemic and was replaced by a virtual meeting.
- **Teleconferences** have been regularly held at the work package and consortium level to facilitate communication and dissemination.

¹ <u>https://medium.com/parkinsons-uk/from-innovation-to-better-treatments-838dd17f78b9</u>

² <u>https://www.researchgate.net/project/PD-MitoQUANT-A-quantitative-approach-towards-the-</u> characterisation-of-mitochondrial-dysfunction-in-Parkinsons-disease

³ <u>https://neuroscienceireland.com/prof-jochen-prehn-coordinates-pd-mitoquant/</u>

⁴ <u>https://www.pdmitoquant.eu/researchers/</u>



- A **joint press release**⁵ for the launch of PD-MitoQUANT was created by Pintail, RCSI and Parkinson's UK. The press release was launched across a variety of media channels and via consortium member institutions/companies.
- Pintail has developed, produced and circulated two **newsletters** (Aug 2019, Jan 2020) for which various consortium members and Parkinson's volunteers have helped generate content.⁶ The third newsletter is being developed for release in Aug 2020.
- A toolkit has been developed for consortium wide use, containing letter templates, project overview slides, templates for reporting and minute taking. Consortium members are being consulted on what other items for the toolkit they would like to see developed. One slide overviews of the project for use in partner presentations at both scientific and general public events were created by the consortium (Figure 2).⁷



Figure 2 General Public' Explainer' Slide

Stakeholder engagement

Parkinson's UK advertised via its Research Support Network (circa 6,000 people affected by Parkinson's) for the recruitment of two volunteers who would serve on the Scientific and Ethics Advisory Board (SEAB) and CDC. Both positions were filled and both volunteers have played an active role in the project, including participation at the face-to-face meeting in M10.

Patient organisation Parkinson's UK is a project partner and has contributed significantly to engagement with patient stakeholders during the reporting period:

• Through Parkinson's UK, two people with Parkinson's (Richard Campbell, Paula Scurfield) have joined the SEAB and participate in the CDC. The patient

⁵ <u>https://www.pdmitoquant.eu/media/</u>

⁶ <u>https://www.pdmitoquant.eu/wp-content/uploads/2019/08/1 PDMQ newsletter Aug2019 approved.pdf;</u>

https://www.pdmitoquant.eu/wp-content/uploads/2020/02/PDMQ-newsletter_2Jan2020_update.pdf

⁷ <u>https://www.pdmitoquant.eu/media/</u>



representatives have contributed their perspectives to the first two project newsletters (Aug 2019, Jan 2020) and attended the face-to-face meeting in M10, presenting their personal perspective about how living with Parkinson's affects them, their views on why PD-MitoQUANT is important and encouraging the consortium to remember the patients that will ultimately benefit from PD-MitoQUANT research. The volunteers also designed questions which formed the basis of interviews of four consortium members at the face-to-face meeting. Richard Campbell also authored a blog post on Medium sharing his perspective on the project following the meeting (Figure 3).⁸



Figure 3 Medium Blog Post from Richard Campbell

- Parkinson's UK holds its own international **conference** every 2 years and for the September 2020 conference, PD-MitoQUANT consortium members have been invited to give platform presentations. Due to Covid-19, this conference is being run in its original format but as a virtual conference.⁹
- A **public event** was planned for World Parkinson's Awareness Month in RCSI on 01 April 2020 but has been cancelled due to covid-19 and will be re-scheduled for a later date. The event will centre on state-of-the-art Parkinson's research in Ireland. Perspectives from research laboratories, the clinic, industry and those with the condition will be shared

⁸ <u>https://medium.com/researchinvolvement/getting-involved-in-an-international-research-project-on-parkinsons-63bb50f30747</u>

⁹ <u>https://www.parkinsons.org.uk/events/online-research-conference-2020</u>



through short talks and a Q&A session. Additional support for the event was received from Parkinson's UK and Young Parkinson's Ireland.

• Parkinson's UK has also approached **other Parkinson's patient organisations** in Europe to see whether they will distribute newsworthy material more widely among the Parkinson's patient community. As news stories develop, this mechanism will be further developed. In addition, a number of consortium partners have fostered engagement with Parkinson's organisations in their own countries. A video from Parkinson's France is featured on the General Public, informational videos page of the PD-MitoQUANT website.

Dissemination

PD-MitoQUANT has also become a member of the **IMI-2 Neuronet project**, which is a crosscutting project spanning several IMI-2 projects with the goal of sharing results, promoting data sharing and sharing of techniques. PD-MitoQUANT signed a Memorandum of Understanding with Neuronet in October 2019. Representatives from PD-MitoQUANT regularly attend Neuronet teleconferences and take part in Neuronet activities. Coordinator Jochen Prehn (RCSI) is PD-MitoQUANT's representative on Neuronet's Scientific Coordination Board.

Scientific publications are a key dissemination output. The consortium has agreed a Publication Policy, which includes requirements for funding acknowledgement, open access and Intellectual Property considerations. To date, the consortium has published **seven peer-reviewed papers**, which are featured on the project website¹⁰:

- a-synuclein oligomers and fibrils: a spectrum of species, a spectrum of toxicities, Alam *et al.* **J.** *Neurochem* 2019,
- The PINK1 kinase-driven ubiquitin ligase Parkin promotes mitochondrial protein import through the presequence pathway in living cells, Jacoupy *et al.* **Scientific Reports** 2019,
- a-Synuclein conformational strains spread, seed and target neuronal cells differentially after injection into the olfactory bulb, Rey *et al.* **Biophys J.** 2019,
- Differential Membrane Binding and Seeding of Distinct a-Synuclein Fibrillar Polymorphs, Shrivastava *et al. Biophy J.* 2020,
- The expression level of alpha-synuclein in different neuronal populations is the primary determinant of its prion-like seeding, Courte *et al.* **Scientific Report**s 2020,
- Interaction of the chaperones alpha B-crystallin and CHIP with fibrillar alpha-synuclein: Effects on internalization by cells and identification of interacting interfaces, Bendifallah *et al.* **Biochem Biophys Res Comm** 2020, and
- AMPK preferentially depresses retrograde transport of axonal mitochondria during localised nutrient deprivation, Watters *et al. J. Neurosci* 2020.

Partners have also presented the project at a number of **conferences**:

- R. Melki gave a Plenary Lecture at Frontiers in Neuroscience session of the American Academy of Neurology, May 2019,
- R. Melki gave Scientific Talk and acted as Round Table Moderator at the 5th World Parkinson's Congress, Jun 2019,
- R. Melki gave a Plenary Lecture and acted as Round Table Moderator at the Synuclein Meeting, Sept 2019,

¹⁰ <u>https://www.pdmitoquant.eu/publications/</u>



- O. Corti presented "Mechanisms underlying regulation of mitochondrial quality by the PINK1/Parkin pathway and consequence of their dysfunction" at the 8th Workshop of the European Calcium Society, Sept 2019,
- O. Corti presented "From dysfunction of PINK1/Parkin-mediated mitochondrial quality control to Parkinson's disease" at the 23rd Biennial ESN Meeting, Sept 2019,
- R. Melki presented "Prion-like propagation of alpha-synuclein and Tau assemblies in synucleinopathies and tauopathies" at the International Symposium on Neurodegenerative Diseases, Oct 2019,
- Jochen Prehn gave a talk 'A role for bioenergetics and AMPK in neuronal injury and neurodegeneration?' at Les Conférences de L'ICM. ICM, Sorbonne University, France, March 2019,
- O. Watters presented a poster "The effects of local energetic stress on mitochondrial transport in primary cortical axons" at the Society for Neuroscience Meeting, Oct 2019, and
- S. Chenna presented a poster "Computational Study of mitochondrial Bioenergetic Dysfunction in Parkinson's Disease animal models" at the annual Molecular and Computational Biology Symposium in University College Dublin, Nov 2019.

A detailed list of communication and dissemination activities by the consortium members, including social media posts, press releases, website news, posters presentations, conference presentations, round table discussions, factsheets, tool kit items, blogs, keynote lectures, etc. is given in Appendix 1.

Discussion

All the structural activities around the communication and dissemination activities, such as developing the DCP, website, e-mail and teleconference communication networks, SharePoint, meeting schedules for individual working groups/work packages/consortium wide etc. were all developed as scheduled.

PD-MitoQUANT was launched with a wide variety of press and media activity and then settled down in the set-up phase, establishing shared techniques, etc. in advance of starting the experimental research to address the aims and objectives of the project. During this period, there was an appropriate level of communication and dissemination activity across the whole consortium and using a wide variety of communication platforms.

The Covid-19 pandemic halted the vast majority of research and conferences/public events were cancelled or postponed. This had a knock-on effect on dissemination and communication activities in year 2 of the project, which rely on the supply of data and news stories from research by the consortium. As restrictions from the Covid-19 pandemic are being lifted in the various consortium member countries, research work is starting up again but at reduced capacity initially due to social distancing rules. As the research plans get back on track, the number of communication and dissemination outputs will recover to our previously anticipated levels.

Conclusion

The communication and dissemination activities of PD-MitoQUANT were excellent and according to plan in the opening and set-up phase of the projects. The onset of the Covid-19 pandemic and shutting down of research facilities across had an impact in year 2 of the project due to reduced



experimental, communication and dissemination activities. However, as research re-starts, the activities will resume and a vast amount of new data will be generated. We anticipate that there will be a growth in communication and dissemination output as a result, in line with our original plans for the project.





Appendix 1

#	Type of activity	Lead partner	Title/Description of activity	Date	Place
1	Social media	PT, all	Twitter Hashtag		#PDMitoQUANT
2	Website	РТ	Project website		www.pdmitoquant.eu
3	Factsheet	N/A	PD-MitoQUANT – A quantitative approach towards the characterisation of mitochondrial dysfunction in Parkinson's disease.		імі
4	Factsheet	N/A	PD-MitoQUANT – A quantitative approach towards the characterisation of mitochondrial dysfunction in Parkinson's disease		CORDIS
5	Press release	RCSI	Parkinson's disease research project secures EU funding.	9/03/2019	Pharma Technology Focus; pharmaceuticaltechnology.com:
6	Press release	RCSI	Briefly Bio.	9/03/2019	Site Selection Online Magazine:
7	Press release	RCSI	Ireland to lead on €7 million Parkinson's research project.	9/03/2019	Hospital Healthcare Europe
8	Press release	РТ	EU funding to support Parkinson's research in the RCSI.	9/03/2019	European Commission in Ireland News You Can Use
9	Press release	RCSI	FUTURENEURO PRINCIPAL INVESTIGATOR TO LEAD €7 MILLION PARKINSON'S RESEARCH PROJECT.	9/03/2019	FutureNeuro (RCSI)
10	Press release	RCSI	RCSI to lead €7m Parkinson's research project.	9/03/2019	IDA
11	Press release	DZNE	DZNE scientists funded for Parkinson's research through EU Innovative Medicines Initiative.	9/03/2019	IDW Informationsdienst Wissenschaft
12	Press release	ICM	[Actualité scientifique] 7 millions d'euros alloués à la recherche sur le Parkinson.	9/03/2019	Délégation Île-de-France Gif-sur- Yvette
13	Press release	CNR	Malattia di Parkinson: mitocondri sotto la lente del Cnr.	9/03/2019	Corriere Nazionale





#	Type of activity	Lead partner	Title/Description of activity	Date	Place
14	Press release	RUMC	Grant to study mitochondrial morphofunction in Parkinson's disease.	12/03/2019	Web
15	Press release	Parkinson's UK	£6 Million Grant to Address "Key Knowledge Gap" in Parkinson's Research.	12/03/2019	Web
16	Press release	GeneXplain	A software from Wolfenbüttel helps in the fight against Parkinson's.	12/03/2019	Web
17	Press release	MIMETAS	MIMETAS joins European consortium to help bridging 'key knowledge gap' in Parkinson's research.	12/03/2019	Web
18	Press release	РТ	PD-MitoQUANT, 7 million euro awarded for Parkinson's research through Innovative Medicines Initiative.	12/03/2019	Web
19	Press release	ICM	7 MILLION EURO AWARDED FOR PARKINSON'S RESEARCH THROUGH EU INNOVATIVE MEDICINES INITIATIVE	12/03/2019	Web
20	Press release	DZNE	Parkinson's research: EU Innovative Medicines Initiative promotes DZNE scientists.	12/03/2019	Web
21	Press release	CNR	Cnr-In: finanziamenti Imi per studi sulla malattia di Parkinson.	12/03/2019	Web
22	Press release	Lundbeck	Lundbeck Enters New Research Collaboration to Investigate the Role of Dysfunctional Mitochondrial in Parkinson's Disease.	12/03/2019	Web
23	Press release	RCSI	Ireland to lead €7 million Parkinson's research project.	12/03/2019	Bioengineer.org
24	Press release	RCSI	Ireland to lead €7 million Parkinson's research project.	12/03/2019	SCIENMAG
25	Press release	RCSI	Ireland to lead on €7 million Parkinson's research project.	12/03/2019	Hospital Pharmacy Europe
26	Press release	RCSI	Ireland to lead €7 M Parkinson's research project.	12/03/2019	Bio Spectrum Asia:
27	Press release	RCSI	Ireland's RCSI to lead €7m Parkinson's research project.	12/03/2019	SiliconRepublic.com
28	Press release	RCSI	€7m boost for research into Parkinson's	12/03/2019	Irish Mirror
29	Press release	RCSI	Ireland to lead €7 million Parkinson's research project.	12/03/2019	Noticias de Salud
30	Press release	RCSI	Ireland to lead €7 million Parkinson's research project.	12/03/2019	ManufacturingChemist.com



#	Type of activity	Lead partner	Title/Description of activity	Date	Place
31	Press release	RCSI	Irish team lead major Parkinson's project.	12/03/2019	Irishhealth.com
32	Press release	RCSI	Ireland to lead €7 million Parkinson's research project.	12/03/2019	BioSpectrum
33	Press release	RCSI	Irish Unit lead preeminent Parkinson's task.	12/03/2019	TheInnersane.com
34	Press release	RCSI	New research study exploring better Parkinson's treatments.	12/03/2019	Pharma Business International
35	Press release	RCSI	€7m project aims to deepen understanding of Parkinson's.	12/03/2019	BioPortfolio
36	Press release	RCSI	€7m project aims to deepen understanding of Parkinson's.	12/03/2019	European Pharmaceutical Manufacturer
37	Press release	RCSI	Irish scientists secure EU funding for Parkinson's research project.	12/03/2019	CPhI.cn
38	Social media post	GeneXplain	"GeneXplain is honored to participate in the PD-MitoQUANT project devoted to investigation of Parkinson's disease molecular mechanisms. The recent kick- off meeting which took place in Dublin on March 6-8 has given the start to this no doubtfully great initiative of IMI (Innovative Medicines Initiative)"	03/2019	LinkedIn
39	Social media post	MIMETAS	MIMETAS joins European consortium to help bridging 'key knowledge gap' in Parkinson's research: <u>https://lnkd.in/gZifmCD</u>	03/2019	LinkedIn
40	Press release	РТ	"The Innovative Medicines Initiative, Mitochondrial dysfunction and Parkinson's"	8/04/2019	Health Europa
41	Conference presentation	CNRS	Plenary lecture Scientific Community (Higher Education, Research) [No: 3,000]	8/05/2019	Frontiers in Neuroscience session of the American Academy of Neurology (AAN), Philadelphia
42	Blog	PUK	From innovation to better treatments (<u>https://medium.com/parkinsons-uk/from-innovation-to-better-treatments-838dd17f78b9)</u>	27/05/2019	PUK website
43	Scientific talk, round table moderator	CNRS	5th World Parkinson Congress (WPC) 2,500 participants	4-7/06/2019	Kyoto, Japan



#	Type of activity	Lead partner	Title/Description of activity	Date	Place
44	Web news	РТ	https://www.imi-neuronet.org/scientific-coordination-board-meeting- gathers-project-leaders/	07/07/2019	online
45	Social media post	PUK	We have announced partnerships with two European-wide research projects <u>#PDmitoQUANT</u> . We discover how these collaborative projects aim to accelerate research and deliver new treatments for Parkinson's: <u>https://prksn.uk/2QzMUt2</u> .	07/2019	LinkedIn
46	Newsletter	PT, all	https://www.pdmitoquant.eu/2019/08/check-out-our-first-newsletter/	8/08/2019	Web
47	Social media post	GeneXplain	"We are delighted to share the first newsletter of the <u>#PDMitoQUANT</u> project geneXplain is extremely proud to be a part of!"	13/08/2019	LinkedIn, <u>https://lnkd.in/dbVtvBf</u>
48	Social media post	PUK	We're collaborating with pharmaceutical companies and researchers across Europe on the <u>Innovative Medicines Initiative (IMI)</u> <u>#PDMitoQUANT</u> research project to better understand the role of mitochondria in the causes of <u>#Parkinsons</u> . This important research will get us one step closer to much needed treatments and a cure. Read the first newsletter: <u>https://prksn.uk/2OVghJi</u>	16/08/2019	Twitter, LinkedIn
49	Web news	РТ	https://www.imi-neuronet.org/join-the-pd-mitoquant-team/	02/09/2019	online
50	Conference presentation, conference organization	ICM	23rd Biennial ESN meeting, "From dysfunction of PINK1/Parkin-mediated mitochondrial quality control to Parkinson's disease" <u>https://drive.google.com/file/d/1wP_4kh00gxAgsphmYU7PeGyMBCI gXXzd/view</u>	3/09/2019	Milan, IT Scientific conference
51	Keynote lecture, round table moderator, Conference	CNRS	Ronald Melki, CNRS delivers plenary and moderates roundtable at Synuclein meeting in Porto, <u>https://www.pdmitoquant.eu/2019/09/cnrs-ronald-melki-delivers-plenary-and-moderates-roundtable-at-synuclein-meeting-in-porto/</u>	3/09/2019	Synuclein meeting Porto, PT Scientific community, 150
52	Conference present ation	ICM	8th Workshop of the European Calcium Society, "Mechanisms underlying regulation of mitochondrial quality by the PINK1/Parkin pathway and consequence of their dysfunction", <u>http://8thworkshopecs.com/page1.html</u>	19/09/2019	Coimbra, PT



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53	Website	РТ	PD-MitoQUANT on Neuronet website, Related Projects <u>https://www.imi-neuronet.org/ongoing-projects/</u>	9/10/2019	online
54	Poster	RCSI	SfN 2019 meeting: The effects of local energetic stress on mitochondrial transport in primary cortical axons	19/10/2019	Chicago, IL, USA 27562, scientific, clinical
55	Web news	РТ	https://www.imi-neuronet.org/neuronet-scientific/	23/10/2019	online
56	Conference presentation	CNRS	International Symposium on Neurodegenerative Diseases, "Prion-like propagation of alpha-synuclein and Tau assemblies in synucleinopathies and tauopathies"	25/10/2019	Dallas, Texas, US 150 scientific
57	Slide	РТ	PD-MitoQUANT- in-one –slide for lay audience	19/11/2019	online
58	Slide	РТ	PD-MitoQUANT- in-one –slide for scientific audience	19/11/2019	online
59	Poster	RCSI	"Computational Study of mitochondrial Bioenergetic Dysfunction in Parkinson's Disease animal models"	21/11/2019	University College Dublin
60	Web news	РТ	https://www.imi-neuronet.org/highlights-of-pd-mitoquant/	28/11/2019	online
61	Web news	РТ	https://www.imi-neuronet.org/pd-mitoquant-pis-organise/	12/12/2019	online
62	Website	РТ	IMI Project Factsheet <u>https://www.imi.europa.eu/projects-results/project-</u> factsheets/pd-mitoquant	01/02/2020	online
63	Newsletter	PT, all	January 2020 PD-MitoQUANT Newsletter 2, <u>https://www.pdmitoquant.eu/2020/02/pd-mitoquant-publishes-its-</u> second-newsletter/	03/02/2020	online
64	Popular press	РТ	Neuroscience Ireland newsletter <u>https://neuroscienceireland.com/nsi-newsletter-march-2020/</u>	04/03/2020	online
65	Blog	РИК	https://medium.com/researchinvolvement/getting-involved-in-an- international-research-project-on-parkinsons-63bb50f30747	25/03/2020	online
66	Social media	РТ	https://www.linkedin.com/feed/update/urn:li:activity:665176358827493376	03/04/2020	LinkedIn



#	Type of activity	Lead partner	Title/Description of activity	Date	Place
67	Social media	РТ	https://www.linkedin.com/feed/update/urn:li:activity:665402749579017830 5	06/04/2020	LinkedIn
68	Social media	РТ	https://www.linkedin.com/posts/pintail-ltd_interview-with-pi-dr-olga-corti- icm-activity-6658311454913024001-Xuc6	21/04/2020	LinkedIn
69	Web news	ICM, CNRS	https://scanr.enseignementsup-recherche.gouv.fr/project/821522	19/042020	online
70	Social media	PT, all	Research Gate profile established; <u>https://www.researchgate.net/project/PD-MitoQUANT-A-quantitative-approach-towards-the-characterisation-of-mitochondrial-dysfunction-in-Parkinsons-disease</u>	16/04/2020	Online