

Parkinson's Europe Research Strategy - Executive summary

Parkinson's Europe's overarching vision is that people with Parkinson's and their families have access to the highest standards of treatment, support and care they need to live a full and comfortable life. A key part of our mission is to work with other global Parkinson's organisations to provide current information, share good practices, and highlight research that will benefit the whole Parkinson's community.

The purpose of this strategy is to direct and focus the research ambitions of Parkinson's Europe. Work packages and activities will be driven by the themes and needs outlined in this document.

Ambitions:

Parkinson's Europe's ambitions in the research space are:

- To **unite** the Parkinson's community in Europe to want to be part of research and know it is their right to do so
- To **build** communication systems to help people find out more about what research is available and how they can connect with it
- To **connect** industry and academics with the Parkinson's community in Europe to ensure better-quality future research, and to make sure that the voices of the community are represented in all research work
- To **facilitate** the research conversation, breaking down the barriers associated with understanding research

Audiences:

Parkinson's Europe has two key audiences that are at the heart of these collaborations. The first is our [Member Organisations](#) and the wider Parkinson's community. The second is our treatment industry partners and the business field linked with Parkinson's. Each of these audiences have specific needs and interests.

Audience 1: Our Member Organisations and the wider Parkinson's community

Strategic themes

The following themes were identified from data and discussions between our Member Organisations and Parkinson's Europe staff.

Communication:

Create a clear and streamlined system for how we share research news and opportunities. Most of this activity will be working from other people's information and making sure it is shared in an accessible way with the most appropriate audience. Developing a clear 'language' for how we talk about research will also support our Member Organisations.

Starting the conversation through learning materials and information-sharing:

We need to help 'start the research conversation' by getting everyone on the same page through the creation of consistent and accessible language and knowledge about research. We need to:

- Support our Member Organisations with materials and signposting that they can share with their members to build confidence with their research conversations.
- Start building local expertise and facilitate/encourage the development of local research interest groups or networks.
- Create guidance materials for how to support the conversation about research between healthcare professionals and people living with Parkinson's.

- Provide a central resource that our Member Organisations can utilise if they have questions about research they are funding or supporting.

Involvement and engagement:

For those Member Organisations that are already actively working with research, some have research involvement deliverables; however, the majority of them have no structure or understanding of what research involvement is or how it can be developed. To enable consistency and more active involvement, Parkinson's Europe's focus needs to be on creating a clear picture of research involvement, what it is and how our Member Organisations can support it.

From an engagement angle, more support is needed to publicise future research activities/interests and help people in the Parkinson's community overcome the barriers around becoming engaged with research. Overall, a greater understanding about research outreach and activities in Europe is needed.

Audience 2: Treatment industry partners and the business field linked with Parkinson's

Strategic themes

The key strategic needs of the industry contacts we spoke to were identified as follows:

Outreach to the Parkinson's community

Many of the professionals we spoke to expressed a need to reach the wider community but they have no consistent or systematic way to do this. The governance required for each approach is complicated and means companies cannot independently effectively reach out to the Parkinson's community.

Consultation about and support with research engagement and involvement

From the data we collected, most organisations do seem to want to do engagement and involvement but don't have the inhouse expertise to do so in a meaningful way. We can help provide this skill and knowledge to help companies to develop and grow their understanding about the difference between engagement and involvement activities, and how this can greatly benefit the Parkinson's community.

Linking learning opportunities with relevant Parkinson's community members (individuals and organisations)

From knowing what activities are going on for both our Member Organisations and our industry partners, we can more effectively bring those with common goals and interests together, benefitting both communities at the same time.

Supporting collaborations with the wider research community

As part of our wider ambitions, we are looking to increase our outreach and engagement. Part of this is linking with new audiences that we don't currently have access to such as academic researchers and research centres. As we grow our stakeholder networks and relationships, it will also be beneficial to link them with our industry contacts and partners to potentially accelerate Parkinson's research delivery in Europe.

Help support the use of accessible language to bridge the communication gap between research professionals and the extended Parkinson's audience

As noted in the communication element within the Member Organisation strategic themes, one of the biggest issues is making sure everyone can understand each other. By working with industry partners we can align the terminology they use with what is being shared by us with our Member Organisations, therefore helping to bridge the gap between the two audiences.