Parkinson's Europe

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Guidelines for successfully working with Parkinson's patient organisations

November 2023

Summary

This document aims to outline some essential practical considerations for treatment industry companies to consider when looking to collaborate with Parkinson's Europe (and/or our member organisations) on joint projects.

It is split into five sections – please be sure to **check each section** before approaching Parkinson's Europe with regards to working on a collaborative project/activity:

1. **Introduction** – and examples of partnered activities
2. **Key principles** that our partners need to consider when working with patient organisations such as Parkinson's Europe and our members
3. **Checklist** for your company to review before discussing a potential project/activity with Parkinson's Europe
4. **DOs and DON'Ts** – what works well, what does not work, and the importance of communication
5. **Involvement of 'patient experts'** in industry-related panels, workshops or focus groups
6. **Timelines** for specific deliverables, key dates and milestones to take into account when working with small-sized Parkinson's patient organisations.

Introduction

Parkinson’s Europe benefits from the generous support of a number of treatment industry partners. Our collaboration with our funding partners includes the possibility to develop bespoke partnered projects that benefit the European Parkinson’s community.

Common examples of these include:

- the development of a **content campaign** on an agreed topic – shared via our Parkinson’s Life online magazine
- the development of targeted online **surveys** directed at the Parkinson’s community
- the organisation of **workshops** and/or **roundtable discussions** that aim to gather valuable insights from the Parkinson’s community.

According to our partnership model, these possibilities are available for our **Gold and Diamond** partners.

Key principles for a positive partnership

According to our own code of practice – as well as the codes of practice developed by the European Medicines Agency (EMA) and the European Federation of Pharmaceutical Industries and Associations (EFPIA), which we also adhere to – any Parkinson’s Europe collaboration with treatment industry partners will be informed by the following **principles**:

- equal partnership in the interests of the European Parkinson’s community
- mutual understanding
- complete independence for Parkinson’s Europe
- complete transparency on both sides
- no endorsement of a specific product, therapy, or technology by Parkinson’s Europe.

In addition, any collaborative project should – as with any other activity developed by Parkinson’s Europe – be consistent with Parkinson’s Europe’s vision and mission, and contribute to at least one of the four **Parkinson’s Europe strategic goals**:

1. To provide people with Parkinson’s, their families and caregivers the right information at the right time to help manage their treatment, care and wellbeing.
2. To help advance good practices in treatment, care and wellbeing by acting as a hub for the exchange of information between local, national, European and global organisations operating in the field of Parkinson's.
3. To facilitate better understanding of Parkinson’s among healthcare professionals and political decision makers – and to highlight gaps/discrepancies that exist in treatment and care.
4. To support and facilitate collaboration between people with Parkinson’s and those stakeholders involved in clinical research.

Checklist

Whenever Parkinson’s Europe is invited to take part in any kind of project, activity or initiative developed together with an external stakeholder, we always consider the following questions as a preliminary checklist. A **positive response to all these questions** is necessary in order for us to agree to start a new project or activity.

- Is there **clear value** for Parkinson's Europe and the Parkinson's community from the proposed project/activity?
- Does the activity/project clearly fit into Parkinson's Europe **strategic goals**?
- Is the request clear enough? And has Parkinson's Europe been **clear and transparent** with the stakeholder in return with what we have agreed to and can deliver?
- Is the activity/project **ethical and above board**? Does it fit within Parkinson's Europe's code of practice?

Provided the above criteria are met, the Parkinson's Europe Board and Team will assess if the proposed initiative is feasible according to Parkinson's Europe's own **workload and priorities**, and make a decision on this basis.

DOs and DON'Ts

It is important for our company partners to **always remember that Parkinson's Europe is an umbrella patient organisation**. It must be remembered that our structure, governance, priorities and ways of working are different from those of a business (corporate) company.

Parkinson's Europe members – which are national Parkinson's organisations from more than 20 European countries – are fully **independent organisations** that vary a lot in size and resources (ranging from large organisations such as Parkinson's UK to very small associations managed uniquely by volunteers). All our members therefore have different priorities, governance structures and ways of operating.

What works well?

- Prioritising the needs of people with Parkinson's and their families
- Aligning agendas to reach a win-win situation
- Understanding each other's culture and ways of working
- Setting mutual expectations at the start of the project
- Establishing realistic timelines – for all parties, including the wider Parkinson's community
- Allowing necessary flexibility when required
- Trust and transparency on both sides

What does not work?

- Not considering the needs and priorities of people with Parkinson's and their families
- Bringing a corporate approach to a patient organisation
- Setting unrealistic expectations
- Establishing unrealistic timelines that do not work for all parties – and trying to rush through projects at short notice
- Changing timelines at short notice without understanding the impact this will bring to the patient organisations involved and/or the project/activity
- Lack of flexibility
- Lack of transparency

Communication is key!

Continuous, timely and transparent communication is fundamental for Parkinson's Europe to develop successful projects together with our partners. It is important to:

- agree on clear aims and objectives from the start

- have regular updates between partners
- periodically review the progress of the project
- review and evaluate the success of the project at the end.

Therefore, remember that most, if not all, partnered projects require Parkinson's Europe to communicate with our own external stakeholders and audiences – such as Parkinson's Europe member organisations and other Parkinson's organisations, people with Parkinson's, healthcare professionals, etc.

Please be aware that it is important for Parkinson's Europe to communicate all relevant details of the project clearly and transparently with external stakeholders – if their active involvement is to be assured. This includes clearly explaining the project's aims and objectives, in addition to the collaboration between Parkinson's Europe and the treatment industry partner, as well as the calls to action we are requesting. All communications from Parkinson's Europe must be in patient-friendly language, and the project's outcomes, results and any follow-ups must be clearly and timely communicated.

In summary, any project that aims to leverage Parkinson's Europe's networks for communication, dissemination, participation and/or feedback needs to consider this diversity. Remember that the ultimate success of Parkinson's Europe-partnered projects will depend on the ability and willingness of individuals and Parkinson's organisations to be involved. Ultimately, their participation is beyond Parkinson's Europe's control; however, putting in place a clear and transparent communication plan with reasonable timescales with our members (and other external stakeholders) is fundamental to ensuring their involvement.

Industry wanting insights from 'patient experts'

It is common for treatment industry companies to ask Parkinson's Europe if they can include people with Parkinson's and/or their family members or carers into 'listening initiatives' such as **discussion panels, workshop meetings, focus groups, surveys** or **interviews** in order to obtain a better understanding of the needs and priorities of people living with the condition – especially, for example, for what concerns the design and implementation of clinical trials. These people with Parkinson's/carers are often referred to as **'patient experts'**.

As a patient organisation, Parkinson's Europe fully supports including the 'patient voice' in the industry's decision-making processes, with the goal to build more patient-friendly clinical trials and ultimately develop more effective treatments for people with Parkinson's.

When looking to include 'patient experts' in any industry-led activity, the following principles should be followed:

- The activity should be structured so that **participants' input and points of view are effectively and meaningfully included** and taken into account. This means:
    - using a clear and patient-friendly language in all communications
    - allowing all participants to express their views within workshop meetings and focus groups – ideally with the help of a facilitator who will ensure all participants are given the same time to speak
    - family members/caregivers being included in the workshop/focus group discussions
    - providing adequate pre-meeting information materials, and following up with all participants after the event to highlight meeting results and next steps.

- Logistical organisation of the activity should **take into account the needs of people living with Parkinson's**. In particular:
    - travel and accommodation arrangements (when possible) should take into account any Parkinson's-related difficulties people may have. Ensuring the safety and comfort of participants must always be an absolute priority
    - for in-person meetings, the location, timings, breaks and food catering provision should take into account possible motor and other Parkinson's-related difficulties participants may have
    - virtual meetings should be timed taking into account the need for frequent breaks and other possible Parkinson's-related issues, such as difficulties in talking and using virtual video-call platforms.
- An **adequate honorarium** should always be provided to compensate for participants' time – in addition, any travel, accommodation and subsistence costs should always be covered. Travel and accommodation should ideally be organised directly by the treatment industry company, and adequate agreements should be signed between the company and participants.

We require our partners to **provide sufficient information** when requesting Parkinson's Europe to involve 'patient experts' in their projects/activities. The kind of information we need to receive is detailed in our stakeholder request form.

Please note that, in case your company would like to involve 'patient experts' with a **specific scientific and/or research expertise**, it may take more time, effort and difficulty from Parkinson's Europe's perspective to involve them – as the number of people with this kind of background is relatively limited across Europe.

Timelines

Parkinson's Europe is a small organisation, with **limited resources** and a **small team**. Despite these limitations, we manage a high number of projects – often under tight timelines and involving multiple stakeholders. For this reason, our team members often find themselves **working on multiple activities at the same time**, balancing the needs and requests of several external stakeholders – including our funding partners. In addition, we typically have a **very dense communications calendar**, as one of our main goals is to disseminate relevant information to the Parkinson's community.

All the above needs to be considered by our funding partners when proposing a new joint project with Parkinson's Europe. We must be **informed well in advance** about any plans our industry partners may have about developing a joint project. We set out our ideal timeline scenarios in the section below.

Timelines for specific deliverables

Our most common projects developed together with our industry partners include **online surveys, media articles and patient workshops**. The preparation, production and fulfilment of these deliverables normally involve several internal and/or external parties (such as Parkinson's Europe Board members, external stakeholders, our communication agency and/or other external consultants) as well as a substantial amount of strategic and planning work from multiple Parkinson's Europe Team members. It is important for our industry partners to understand that these processes **require time** in order to achieve meaningful results.

The list below outlines the normal **minimum timelines** for each of the most common projects we deliver in collaboration with our funding partners.

- **Consultancy** by the Parkinson's Europe team on topics chosen by the company: at least 2-4 weeks, depending on the complexity of the matter and on the possible need to involve other experts.
- **Involvement of 'patient experts' in 'listening initiatives':** at least 1 month, depending on the number of participants needed and what countries they would ideally come from.
- **Review of communication materials produced by a company partner:** ideally 1-2 months, depending on length/complexity.
- **Social media support of communication/awareness initiatives:** ideally 1-2 months, depending on the content and supporting materials provided.
- **Parkinson's Life sponsored article(s):** ideally 1-2 months from first contact with the editorial team to the publication, although timelines can sometimes be shorter.
- **Parkinson's Life sponsored podcast episode:** ideally 2-3 months from first contact with the editorial team to the launch of the episode.
- **Patient workshop:** at least 3-4 months from the first discussion of the workshop idea to the actual meeting. *Please note: this time can vary according to the number or participants.*
- **Patient survey:** at least 3-4 months from the first discussion of the survey idea to the launch of the agreed survey. *Please note: this time can increase if translation of the survey in several languages is required*.
- **Communication campaign (a mix of sponsored articles, podcasts and social media): ideally** 4-6 months from the first discussion of the campaign idea to the launch of the campaign itself.

Please note that all the timelines above need to consider:

- internal review/approval by the Parkinson's Europe Board
- when necessary, review/approval by Parkinson's Europe external scientific experts
- internal review/approval by the company partner's own legal/compliance departments.

Key dates and milestones

There are a number of **important dates in the year for the Parkinson's community** when communication activities tend to intensify, and Parkinson's organisations and stakeholders – including Parkinson's Europe and our member organisations – tend to be particularly busy.

The following need to be considered in any project timeline, especially with regards to online communication:

- **April** is the busiest month in the Parkinson's calendar – not only is there World Parkinson's Disease Day (11 April each year) but also Parkinson's Awareness Week (especially in the UK) around 11 April each year, and Parkinson's Awareness Month (especially in North America) in April each year
- International Congress of Parkinson's Disease and Movement Disorders (MDS): normally in September of each year
- World Parkinson Congress (WPC): normally in June/July every three years.

In addition, it is important to remember that most European Parkinson's organisations (including Parkinson's Europe member organisations) are **small, with limited resources/teams** and are in some cases managed mostly by volunteers. For this reason, most of them tend to reduce or **close their activities in the summer holiday period** (between late June and late August of each year) and during the **Christmas break**.

At Parkinson's Europe, we close our activities in August and during the Christmas break each year.

Any plan for projects that involve/impact stakeholders from the Parkinson's community needs to consider – and plan around – the dates above.

Thank you for supporting Parkinson's Europe and for taking these guidelines into consideration.
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