

Social Impact Report

Parkinson's Ready Program 2023

World Parkinson Coalition Inc

6th World Parkinson Congress

Barcelona, Spain



February 2024

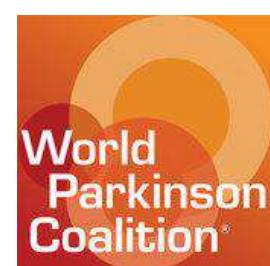


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Introduction

The World Parkinson Coalition, in collaboration with the Associació Catalana per al Parkinson (ACAP) and the Barcelona Convention Bureau (BCB), and sponsored by AbbVie, implemented the "Make the City Parkinson's Ready" (Parkinson's Ready) program alongside the 6th World Parkinson's Congress (WPC 2023) in Barcelona, Spain in July 2023. The purpose of the initiative was to train public facing and customer service groups to improve their understanding of Parkinson's disease and to better support those attending the WPC 2023 in Barcelona.

The World Parkinson Coalition is committed to creating more inclusive cities through this program, which was piloted in 2010. The intention is that after the congress concludes, the knowledge about Parkinson's disease will remain in Barcelona with trainees as part of the World Parkinson Coalition's legacy. This training will empower them to support their communities, including the more than 29,000 people living with Parkinson's disease in Catalonia.

The Barcelona Convention Bureau was particularly interested in measuring the impact generated by this legacy project, aiming to demonstrate its effectiveness and provide a case study that can be effectively communicated.

This report has been created by BCB partner #Meet4Impact, a non-profit organisation registered in Canada with a global scope, specialising in assessing the societal impacts of such initiatives.

"It not only provides education and training to professionals, individuals, family members, and caregivers during the week of the conference, but it also leaves a wellspring of knowledge and awareness within the population and the collective group of individuals who interact with the public.

We like to think of it as the legacy that the (WPC) Coalition leaves behind when we depart a city after the conference. It's not just about the immediate impact; it's about creating a lasting imprint of knowledge and awareness that continues to benefit the community even after the conference has ended." -

- Fulvio Capitano, PR Trainer and PWP



Impact Highlights and Key Statistics

Executive Summary

The Parkinson's Ready program was implemented in Barcelona to help train public facing staff on how to best serve and work with people with Parkinson's Disease. This training was done ahead of the World Parkinson's Congress 2023, where hundreds of people with Parkinson's would be participating as delegates. This report is a retrospective study of the program, demonstrating the short term impact and expected longer term impact of the program on people with Parkinson's, the healthcare and events sectors, and on the city of Barcelona. The research shows that delegates were broadly satisfied with their experience and treatment in Barcelona. Trainees found the bespoke training sessions extremely useful, improving their understanding and helping them be more able to serve people with Parkinson's Disease with understanding and care. Substantial media coverage of the program contributed to heightened public awareness of Parkinson's Disease, and presentations shared with event industry professionals will encourage the implementation of similar projects in other destinations. This has contributed to Barcelona being increasingly perceived as an inclusive and more accessible city.

This report defines a retrospective theory of change for the Parkinson's Ready program, defining outcomes across the short and long term. Data was collected against these outcomes to understand the extent to which each outcome has been achieved. This data has also included several points for reflection and learning, which have been included in the report for consideration for future training programs. Key findings from the research are shown below, aligned with the two overarching program impact goals.



Key Statistics

Impact Goals			
Improve quality of life for people living with Parkinson's disease and their families and caregivers		Transform destinations into a leading region in terms of accessibility and inclusivity for people with diverse mobility needs	
Outcomes			
85% of delegates felt satisfied with their interactions with staff in public facing roles in the city	90% of delegates felt satisfied with their experience travelling to and from Barcelona	Bespoke training sessions for 310 trainees from 16 collectives	100% of trainees had a better understanding of PD after the training, and could accurately list three symptoms of PD when tested
58% of delegates found it was easy to navigate the city for people with Parkinson's	97 Million+ media readership for articles covering the Parkinson's Ready program		Further training requested for 3,000 police officers
41% of delegates believed public taxi services, public transportation, and police in Barcelona became more aware of Parkinson's after the Congress.	94% of trainees agreed their workplace should offer more trainings like this		
31% of trainees reported applying the knowledge in their work	97% of trainees found the knowledge gained useful in their personal life	81% of trainees had discussed the knowledge gained with colleagues	1,000+ event professionals worldwide exposed to the program through 11 global presentations
LIVED EXPERIENCE: The Parkinson's Ready program highlighted the importance of integrating patient perspectives into care and research.		POSITIVE PERCEPTION: Barcelona was seen as more of an inclusive destination, better able to cater to PWP who live in or visit the city	

1. About Parkinson's Disease

Parkinson's Disease presents hidden challenges that are often underestimated and misunderstood by society. The prevalent misconception of Parkinson's hinders awareness of the broader symptomatology and the fact that it can affect people of young ages. Consequently, individuals with Parkinson's face a lack of specialised attention and support, leading to inadequate care and compromised quality of life.

1.1 Shared Purpose of Four Organisations

Four key organisations came together with a shared vision of the impact project they implemented alongside the World Parkinson's Congress 2023. These four organisations are the World Parkinson Coalition, the Catalan Association for Parkinson's, Barcelona Convention Bureau and AbbVie. The Parkinson's Ready program addressed key issues of importance to all four three organisations, and so these organisations collaborated to make the program a success.

The World Parkinson Coalition was established in 2004 with the primary goal of disseminating knowledge, to cross pollinate the community in a meaningful way that will encourage new partnerships and new research to improve the diagnosis and treatment of Parkinson's disease. Alongside the World Parkinson Coalition, the Catalan Association for Parkinson's (ACAP) has been steadfast in its mission since its inception in January 1985, aiming to provide comprehensive care and guidance to individuals affected by Parkinson's and their families. Additionally, AbbVie, a pharmaceutical company, is dedicated to pioneering innovative medicines to address contemporary health challenges and anticipate future medical needs. The vision and objectives of Barcelona Convention Bureau are explored in more detail below.

1.2 Alignment with Barcelona Vision

Barcelona strives to make the city open and accessible to residents and visitors alike, allowing them to enjoy the many attractions that the city has to offer in an environmentally conscious way. The destination is known for its commitment to sustainability and social impact, demonstrated by programs such as the Strategic Tourism Plan and Accessible Barcelona. Barcelona promotes a model of tourism and events based on respect for the city's economic, social, environmental, and cultural resources. The city plans to build on this in the future, further expanding its impact projects and attracting more events that align to the destination's sustainability and legacy goals.

The partnership with the World Parkinson Coalition to host the Parkinson's Ready Program before the 6th World Parkinson Congress was a natural fit for Barcelona, building on the accessibility assessments that have already taken place in venues across the city. The training program supplements some of the infrastructure around accessibility in the city, by training

customer facing staff to recognise symptoms of Parkinson's disease (PD) and to adapt their customer service manner to account for how these symptoms may affect their interactions with people with Parkinson's disease (PWP). Barcelona plans to use the learnings from this project to be able to expand their impact and legacy work, and to apply learnings to other events and congresses in the future.

2. About the World Parkinson Congress

The World Parkinson Congress (WPC) is hosted every three years in a different global city, bringing together scientists, clinical researchers, health care professionals, people with Parkinson's, and care partners, to discuss, learn, and engage in debate around the latest scientific discoveries, medical and comprehensive care practices related to Parkinson's disease.

The 6th World Parkinson Congress was held on 4-7 July in Barcelona, Spain. It brought together a broad range of the Parkinson's community, from researchers to clinicians, patients to caregivers. More than 2,500 delegates from 73 countries attended this year's meeting.



2.1 Past WPC Event Legacy

Although WPC 2023 was the biggest and most formalised version of the Parkinson's Ready program in the event's history, there have been initiatives at past conferences that have contributed to the scale of impact we can see today. The first Parkinson's Ready training program took place in Glasgow in 2010, at the second ever WPC conference. This program consisted of just a few training sessions with groups central to the organisation of the conference.

In Montreal at the WPC 2013, the program was a small project with modest resources and time dedicated to its success, but there was tangible interest and engagement from the World Parkinson Coalition community. The convention centre and front of house hotel workers were the primary focus of the training program. While the project itself was limited, it generated multiple learnings which could then be applied to future training programs.

Subsequent training sessions also took place in Portland in 2016, and in Kyoto in 2019. In 2016 the program trained hotels, police, and firefighters as well as the convention centre staff. They also worked with the hotels in Portland to create door signage to indicate that the resident had Parkinson's, so that hotel staff could be cognisant of that when dealing with visitors.

Kyoto 2019 had different challenges due to cultural perceptions around illness, so more focus was put on public information campaigns, and fewer resources were invested in training on the ground. However, there were a few collaborations that formed resulting from the conference, which helped to amplify impact globally. Such initiatives include the launching of Parkinson's Africa by a woman with young onset PD, the creation of the global advocacy group called the 'PD Avengers', which empowers young onset Parkinson's disease (YOPD) community members and focuses on advocacy, and a project called "My Moves Matter" which focuses on women and Parkinson's to see how symptoms can present differently in women and how the disease and medication are impacted by issues such as menopause or pregnancy.

3. WPC 2023 - Impact and Legacy

3.1 Context

The mobility limitations caused by Parkinson's Disease not only restrict their ability to travel independently and enjoy a fulfilling lifestyle, but also result in heightened stress, anxiety, and increased reliance on caregivers during travel. These challenges necessitate a greater understanding and tailored accommodations from the hospitality industry, destinations and society at large to improve the travel experiences and well-being of individuals with Parkinson's.

Public administrations and relevant stakeholders have yet to fully address the unique needs of this population, including support and allocation of resources to address their specific requirements.



When PWP feel anxious or nervous, e.g. about travelling to a new city and not knowing how to navigate it, it can cause their symptoms to worsen - it can be a vicious cycle. Also, because PWP are travelling to new destinations, they often will want to eliminate as many unknown variables as possible, so they will do their utmost to find out the information required ahead of time. This means that communications lines such as phone lines and emails are often heavily used to accommodate for the need for additional information. Organisations in the destination should be made aware of this.

The Barcelona Context

When asked about the needs in the local ecosystem in Barcelona, interviewees mentioned several key issues. The biggest was the lack of awareness and understanding of what Parkinson's disease is, and how symptoms can present in PWP. In particular, this can be an issue in contexts such as public transportation or in airports. Operators should be aware of people with limited mobility issues, or hyperactive movement (dyskinesia) resulting from too much medication. At airports for example, PWP could show signs of shaking or losing speech - this should not be mistaken for nerves, being uncooperative or being perceived as being inebriated. There is a risk of customs officials misunderstanding these symptoms and refusing people entry or sending them back to their home country. As well as these common concerns, there are some issues that may be more culturally relevant to Spain. One example of this is that people in Spain tend to be quite facially expressive in how they communicate. Some PWP may lose the ability to be facially expressive; this is called, "masked face". When this happens it can be difficult to know how they feel due to their lack of expression. Knowing this would help people to know that this is not intentional and may help them feel more at ease when communicating with PWP, making the experience better for everyone.



3.2 Impact Intentions

The Parkinson's Ready project was designed with multiple key objectives in mind. The main objectives can be categorised into the following four groups:

- Improving the experience of PWP visiting the World Parkinson Congress.
- Increased public knowledge and awareness of Parkinson's disease.
- Leaving a lasting legacy on the city of Barcelona by improving the capacity of local workers to understand and accommodate the needs of PWP.
- Fostering collaboration and partnership to improve the lived experience and treatment of PWP in Catalonia.

The project has multiple purposes and intentions, aimed at both supporting PWP and improving the local ecosystem to provide adequate service and care for PWP. Meet4Impact interviewed several key stakeholders including BCB, ACAP, WPC and people with lived experience of PD to understand their impact priorities and craft a Theory of Change (see below).



Key Impact Objectives

One primary goal of the project was for people with Parkinson's to feel reassured that people will understand them and their illness and that they can get support and feel welcomed in Barcelona. The intention was to improve the conference experience for delegates with PD. Both training service industry workers and promoting public awareness could help improve the general reception of PWP. Additionally, the knowledge that this work had been done ahead of the conference could be hugely beneficial for PWP, since it could potentially reduce the burden of worry about how they would manage travelling to a new destination and therefore could reduce the visibility of some stress-related symptoms.

For this it was also important to engage the general public in discourse to debunk common misconceptions about Parkinson's and reduce stigma. This included raising awareness about different symptoms of Parkinson's, and improving the understanding of how to respond to people with Parkinson's with some of these symptoms. As well as improving the general perception of and treatment of PWP, awareness raising could also have the long-term effect of encouraging early diagnosis, if more people know to be aware of certain signs and symptoms. Another key purpose of the project was to improve the capacity of organisations in Barcelona to accommodate for PWP. To this end, one goal was to ensure that the front of house and emergency staff were aware of Parkinson's disease, how to recognise signs in patients, and potential issues. Knowing that the WPC was coming to Barcelona made the issue more urgent and valuable for public service staff members, and so this was a great opportunity to share knowledge and increase capacity at a time when more PWP would be present in the city and could benefit from such measures. The intention was to create a simple understanding of the symptoms and challenges and how to interact with PWP in a way that does not invalidate them or their experiences. Part of this was for workers in people facing roles to feel comfortable around and able to support PWP. The assumption here is that knowing how to respond in certain common situations can limit confusion, reduce friction and improve the treatment of PWP in public places. This includes educating front line emergency response professionals, including the fire and police departments, about Parkinson's disease.

One key project intention was to build new alliances between the local Parkinson's community and the service industry so they could continue the relationship well beyond the week of the World Parkinson Congress. Collaborations between different organisations could help to improve the day-to-day lives of PWP and their families. This was the longer-term vision from the goals listed above, so that PWP in general living in and visiting Catalonia can feel comfortable and confident in and around the region.

From the perspective of the Barcelona Convention Bureau (BCB), the Parkinson's Ready program was a great way to prepare Barcelona to welcome delegates to the 6th World Parkinson Congress. The training helped to educate public services and hospitality industry leaders about PD, ensuring a welcoming and safe experience for congress delegates. The longer-term intention is for the program to leave a lasting impact on the city's awareness and understanding of PD. Ideally, the program would leave the city better off than when the congress arrived, meaning the local PD community would subsequently be surrounded by city and hospitality workers who have a better understanding about PD.

Theory of Change

These various and interconnected impact goals and intentions have been summarised in the below Theory of Change. Meet4Impact created this Theory of Change for the purpose of evaluating the Parkinson's Ready project. The outcomes and impact goals were based on the information we were able to access, with the final Theory of Change being validated with the client. It was important for us to generate a thorough understanding of the different impact pathways of the project, so that we could evaluate whether the project had indeed contributed to the intended outcomes, and to what extent. The Theory of Change was developed as an evaluation tool for this reason.

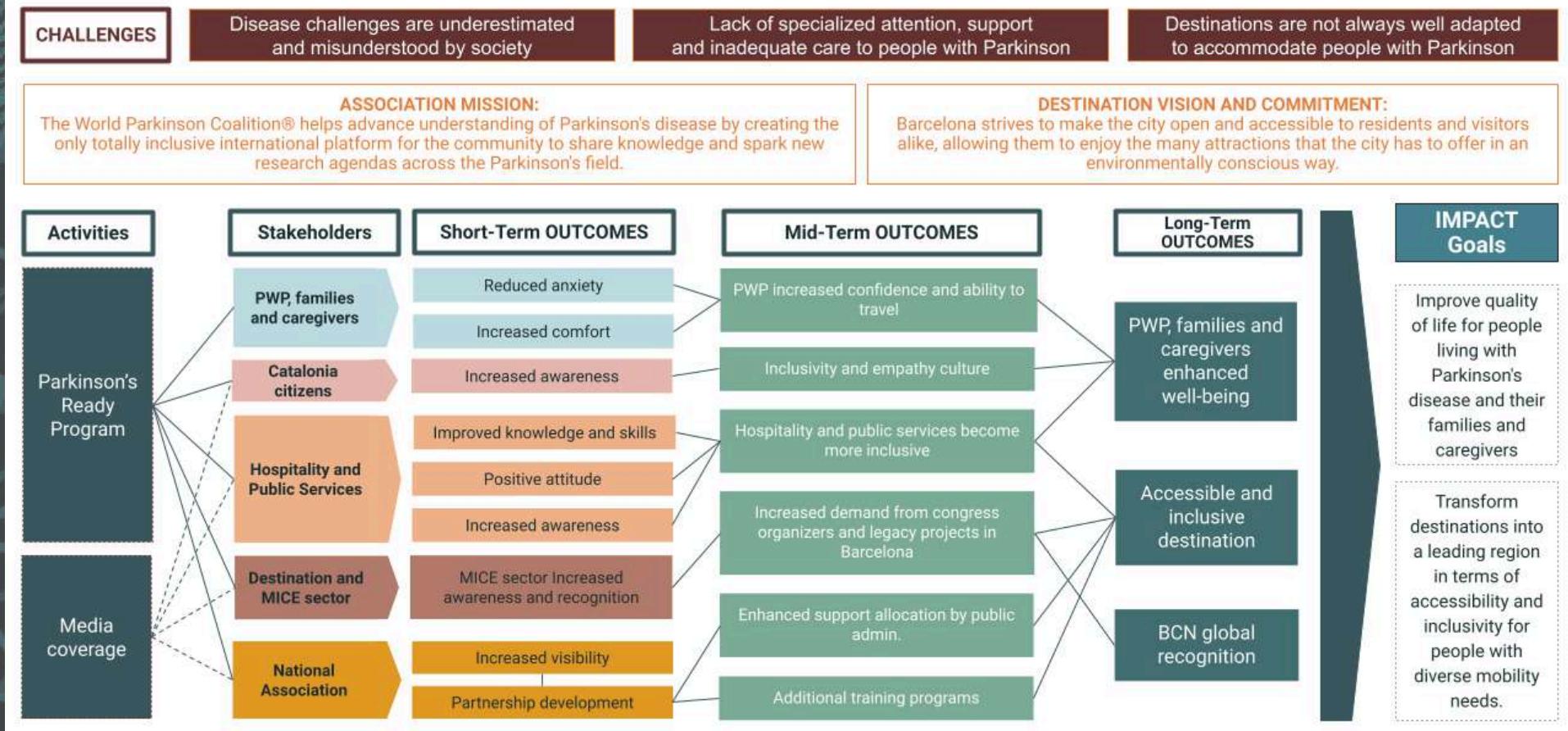
From the Theory of Change, we can see that there are two long term impact goals that the Parkinson's Ready program was trying to contribute towards: Improving the quality of life for PWP and their families and caregivers, and Transforming destinations to become more accessible and inclusive for people with diverse mobility needs. These impact goals are very broad and long term, and the scope of this report is too limited to truly showcase the extent to which the lives of PWP have improved, or how much Barcelona as a destination has transformed. Therefore, this report will focus on demonstrating the impact generated against the six key mid-term outcomes listed in the Theory of Change:

1. People with Parkinson's increase in confidence, improving their ability to travel
2. Inclusivity and understanding from the general population
3. Hospitality and public services become more inclusive
4. Increased demand from congress organisers for legacy projects in Barcelona
5. Enhanced support and funding allocation from public administration
6. Amplification of learnings

This report explores each intended outcome in turn, analysing data to prove the extent to which each intended outcome was realised. As well as this, we have included an additional section that explores the impact on the destination in more detail.



Parkinson's Ready 2023 – Theory of Change



3.3 Impact Projects

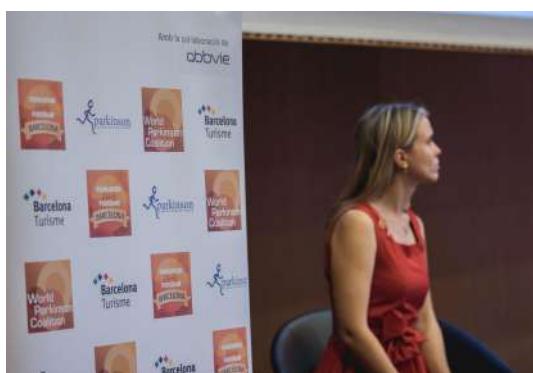
Parkinson's disease affects more than 10 million people across the world, and this number is expected to grow rapidly. There are around 150,000 PWP in Spain, of which 29,000 live in Catalonia. The World Parkinson Congress is the first global scientific event dedicated to PD that also invited people with lived experience of the disease, as well as their families or carers, to attend, collaborate and further research to help PWP. After the first conference, the World Parkinson Coalition saw the need for the host city to be prepared to receive hundreds or even thousands of PWP, and so the Parkinson's Ready program was born. The first iteration of the program consisted of a Parkinson's Nurse Specialist delivering a small number of trainings to frontline workers who then shared the learnings with their colleagues. This program has grown over the years, with 2023 being the biggest year yet for Parkinson's Ready in terms of scale, reach and impact. This was due to the close interaction and collaboration between the Catalan Parkinson's Association (CPA), Barcelona Convention Bureau (BCB) and the World Parkinson Coalition. The Barcelona Convention Bureau was instrumental in making the project a success.

Parkinson's Ready is a collaborative training program designed with the aim of educating and preparing Barcelona's front-line staff to interact with delegates with Parkinson's during the World Parkinson's Congress 2023. The program was launched on World Parkinson's Day on the 11th April 2023 and ran until the end of June, just two weeks before the conference began.

The Parkinson's Ready program aimed to train several groups of public-facing workers about PD, including common symptoms and how to best respond to PWP in public places. The program trained groups including hotels, the convention centre staff, taxi drivers, police and firefighters. There was even an online training for the Spanish, and global staff, of AbbVie Pharmaceuticals, the main supporter of the program.

The list of organisations trained in Barcelona is as follows:

- Local security forces;
- Airport and customs personnel;
- Convention Center Staff;
- Staff of the hotels involved;
- Staff of the Professional Congress;
- Operator (BCO Congresos);
- Public transport professionals from Barcelona (metro and buses);
- Cab drivers;
- Tourist office staff;
- Members of the BCB (restaurants, stores, mu-and attractions);
- Cruilla festival staff members (a festival that coincided with the congress)





The innovation for 2023 was that the training was adapted to the different groups who received the training. Each training session was delivered in two parts - the first part included information about Parkinson's, common symptoms and how they present. The second part was specifically designed for each group, exploring scenarios that could happen in the workplace with PWP. Based on past trainings, ACAP took the lead in designing a culturally appropriate training curriculum. They took insights from patients and carers about their access needs for travel to a new destination and used this to inform the training. This was particularly useful because the insights were taken from real life experiences of PWP. Trainees learnt to approach situations with a different mindset, giving themselves time to think and reflect before acting e.g. instead of assuming someone could be violent, they can consider alternatives and tailor their approach accordingly. There was also a Q&A part of the training, allowing participants to ask questions specific to their context.

As part of the program, each participating organisation was sent recorded videos and learning materials so that they could pass the learnings on to additional members of staff who were not present in the training. WPC recorded all the activities and made the trainings replicable so that other cities could repurpose the same materials and modify them as needed for cultural appropriateness.

Parkinson's Ready was designed to be "a gift" to the city of Barcelona after the conference, leaving behind a legacy of knowledge and awareness that can help PWP and those with other diseases and disabilities visiting or living in Barcelona in the future.

The program was communicated to participants of the WPC before the event, as well as during the event when a poster was presented and displayed of the program training outputs. The poster for the program was presented at the congress and was well received.

Other Initiatives

Alongside the Parkinson's Ready Program, there was also the Bike to Barcelona initiative, where PWP cycled from cities across Europe to Barcelona for the start of the conference. More than 50 cyclists, many of whom are living with Parkinson's disease or caring for someone with PD, travelled by bike from all over Europe to Barcelona to attend the WPC. Cyclists came from the US and Australia as well as across Europe to participate in the 'Tour de Parkinson'. Three teams of cyclists travelled almost 3,000km to reach Barcelona, with international groups starting from Brighton in the UK, Ventimiglia in Italy, and a local group from Valencia in Spain participating. The completion of the cycle was marked by a seven-hour welcome festival, where others were waiting for the cyclists to arrive. This included a partnership with the council to set up a stall promoting tourism by Bike in Barcelona. Both Bike to Barcelona and the welcome party were covered by the media both before and after the event, increasing public awareness and understanding of the issue.

There were also other activities at the conference itself which would have contributed to longer term impact, such as the Parkinson's 101 sessions (where delegates learned how to make the most of the conference) and the leadership forum (knowledge sharing and best practices for PD leaders of different kinds). The conference itself also made efforts to make the event as inclusive as possible, for example with the CCIB catering leadership being educated carefully about food for people with Parkinson's, including by taking care to provide appropriate plates, straws and cutlery to maximise accessibility. A pre-event toolkit was sent

to all participants to help them navigate the city and access the conference with confidence. There were training sessions at the conference for families and caregivers, for those with Young PD, and about advocacy. There was a renewal room for rejuvenation, and a ping-pong pilot to test how playing the game can have a positive impact on PWP.



4. Parkinson's Ready, WPC 2023 - Generated Impacts

There were multiple expected positive outcomes that organisers were hoping to achieve as a result of the PR program, and of the WPC 2023 conference itself.

The conference itself benefits patients by giving them a network of shared experience, enabling them to meet with people at different stages of the illness and see how they live and manage their symptoms. The conference is also a great way to bridge the gap between patient and practitioner knowledge, allowing doctors to learn more from lived experience and helping them to be more supportive and encouraging of PWP. The conference also aimed to be inclusive, having a gender balanced speaker program and including a lot of content in Spanish and Catalan. 60-70% of the content has simultaneous translation in Spanish.

These benefits are useful and necessary for the objectives of the World Parkinson Coalition and their network of patients, practitioners and other stakeholders. However, the scope of this study just considers the outcomes generated by the Parkinson's Ready program. The six outcomes identified in the Theory of Change above are explored here in more detail.

1. People with Parkinson's Increase in Confidence, Improving their Ability to Travel

The first mid-term outcome focuses on how PWP can benefit from having a good experience at and around WPC 2023. The assumption here is that PWP will feel less anxious and more comfortable in Barcelona, and this will help them to feel more empowered to be able to access support when needed and therefore feel more confident in their ability to travel.



There are several indicators that can demonstrate the positive impact of this training. One outcome that has been mentioned by several officials is the feedback from participants on site - in 2023 there were noticeably fewer complaints on site than there have been in previous conferences. One interviewee said that they "don't get as much negative feedback" as they had in the past. The interviewee said that even though they have not seen much positive feedback during or immediately after the conference, this is typical of their past events. The biggest difference was in the amount of negative feedback received. This decrease in negative feedback may result from the fact that workers at and around the conference venue were better equipped to work with PWP as a result of the PR program.

Experience in the City of PWP

We asked attendees of the WPC about their experience at the conference and in the city of Barcelona. There were generally positive perceptions around the ease of navigation around the city. When asked whether they felt satisfied with their experience travelling to and from Barcelona, 90% of delegates agreed or strongly agreed. 90% of delegates also agreed that they felt comfortable navigating around and staying in Barcelona. 85% of delegates reported feeling satisfied with their interactions with staff in the city (including hotels, airport, taxis, public transport networks, and the convention centre).

Multiple delegates also noted the availability of support and willingness to accommodate from the general public, as well as transport professionals.

"Several times I was offered seats on the subway; taxi drivers were very accommodating. I felt that people were looking for others who might need assistance."

- Delegate

"The experience with the people around was very good and to see that there was designed a program for the people, professionals, around to know more about Parkinson's and how to manage with PD people... is amazing, great congratulations"

- Delegate

Some delegates did note that the effects of the Parkinson's Ready program were more keenly felt at and around the convention centre, including the nearby restaurants and hotels. These delegates did not feel any noticeable accommodation or support in other parts of the city.

"The staff at the convention centre was excellent. Otherwise I did not notice it throughout the city."

- Delegate



"I just felt the people were aware of who we were and open to accommodating at restaurants and especially around the conference centre"

- Delegate

The longer term intended impact for this outcome was that PWP would be more confident and independent. The logic behind this is that if PWP have a good experience in a new destination, they will feel comfortable, confident and supported, and this will encourage them to continue being independent, perhaps by visiting new destinations. By showing that Barcelona can be an accessible destination, PWP may feel more confident navigating the city and may be more likely to return in the future. The data we have collected does demonstrate that the short- and mid-term outcomes related to this longer-term outcome have been partially realised. Further data will be required to fully understand the extent to which this longer-term outcome will have been achieved in the future.

Awareness of the PR Program

One of the benefits of the Parkinson Ready program is that it can provide some peace of mind and reassurance for PWP. The knowledge that if symptoms arise during the day people in public services are better able to communicate effectively and assist them can be extremely helpful in terms of preparation and the sense of comfort felt in the city.

"I felt totally at ease in Barcelona knowing people would be willing to help "

- Delegate

"As a person with PD I experience misunderstandings and suspicion of my motor symptoms in public AND my thoughts and worries about how my symptoms are seen by others. Just the fact of me knowing that staff and public servants have been informed makes this easier and my stay less stressful, hence less symptoms."

- Delegate

There was a multi-pronged comms approach to help delegates to know about the existence of the program before and during the conference. The World Parkinson Coalition sends out newsletters by email, as well as promoting the project using social media and press releases. Before the conference the World Parkinson Coalition also sends out a physical letter including a conference pack to delegates that includes details about the conference and navigation. The Parkinson's Ready program was mentioned in this pack. This pack also includes a wallet insert that includes details about PD in Spanish so that if a PWP delegate had an issue that impeded their ability to communicate when outside of the conference, then first responders would know how to react. This card insert could also be used at the airport or with police, if necessary.

When directly asked about the Parkinson's Ready program, there was some mixed feedback from delegates. Around half the respondents were not aware of the PR program at all. This



shows that perhaps communications could be better utilised to help PWP know that measures are being taken to improve their experience at and around the conference, helping them to feel more confident and at ease. Other delegates spoke about how reassured and comforted they felt by the fact that the PR program existed, since they could feel less anxious about their outings and be more confident in requesting additional support where appropriate.

Delegate Stories and Attribution

Some PWP delegates shared stories, both positive and negative, about their experiences at and around the conference and how it pertained to the PR program.

"I had an experience at Olympic Park that was special. My husband Jeff and I had walked up the long steps to get to the tram/gondola. I was freezing (my gait) and standing in line I was getting a bit worried (which exacerbated my freezing) about how I was going to do at entering the gondola cars that were moving. One of the staff must have seen my struggle and discussed this with their coworkers and when I was about to get on, they paused the moving of the gondola so I could step on. They did this without any fanfare or acknowledgement, but I knew they had noticed and was very appreciative too. No one said anything to me which was a nice surprise. Coming down, I was not noticed as I was then "on". I felt so special and not being acknowledged or noticed or discussed was awesome!"

- Delegate

One interviewee did recall a negative complaint about one of the tour operators that the conference organisers had listed as a partner organisation, where delegates could book on to tours of the city in their own time. One couple attended a tour but their needs were not catered to. They were asked to walk for long distances and their concerns were not listened to by the tour leader at the time. They did return and raise a complaint with WPC, which the interviewee noted to be a good thing. This is because it meant that the couple were both empowered enough to ask for better treatment in the moment. The couple knew about the existence of the PR program and so they knew they should have been provided with tailored support, so they raised the issue to the WPC as they knew it would be of interest to them. The PR program did in fact train the company management of that particular tour company, but this feedback illustrates that perhaps those trainings were not shared with the wider staff team as the PR trainers had hoped. This helps us to keep this in mind the efficacy of 'train the trainer' models and how they can perhaps be better executed in the future. One interviewee said that they had now decided that all tour partners must commit to all of their staff being trained through the PR program, otherwise they will not be listed as a partner provider by WPC. In the future the WPC organisers will be more forthright about expectations and conditions.

As well as this, some delegates shared additional stories about some negative experiences when navigating the city.



"I think public transport like bus services and airport staff need some more training to know about Parkinson's. With me they just left me and my daughter at the airport without providing any solution. That was the worst part of my journey."

- Delegate

There are also some issues of attribution, as illustrated in the delegate quote below. Since we asked questions about the general experience of navigating Barcelona, as well as about the Parkinson Ready program itself, it could be difficult to know whether particular instances can be attributed to the program or not.

"I'm not sure if what I experienced was an active attempt at accommodation, or if the people were just a bit more slower-paced and chill than I am used to."

- Delegate

Since much of the work of Parkinson's Ready is about removing obstacles, increasing public awareness and reducing stigma for PWP, it can be difficult to find data to show exactly how much of a positive impact this training program may have had. This is because we cannot truly know what the experience of delegates attending the conference would have been like had the Parkinson's Ready not taken place. However, the data collected does give us some indication of the realised benefits and potential gaps resulting from the PR program.

2. Inclusivity and Understanding from the General Population

The program aimed to increase general awareness and understanding of PD amongst the general public, reducing stigma and improving perceptions of the disease. The idea was that an improvement in understanding would eventually culminate in a more understanding society and encourage some people to take personal actions to help PWP, such as donating or volunteering.

Media Coverage

The Parkinson's Ready program was featured or mentioned in over 30 media outlets, including newspapers, radio and TV. Several pieces referred to the importance of recognising symptoms of Parkinson's to help protect and support PWP. A few of the articles went into some detail about the lesser-known symptoms of Parkinson's, serving as public awareness support alongside the conference. A few articles also highlighted that a study was currently being conducted in Catalonia to collect data from individuals in order to promote early diagnosis and preventative treatment. One article also mentioned the participation criteria, serving as a recruitment support as well as a public awareness piece.

Multiple press pieces were published about the Parkinson's Ready program, across a range of platforms. We were able to get viewership estimates for some of the media, totalling to over 97 million views. However, we were only able to get viewer numbers from around 60% of the



press pieces published before the start of the conference, not including the media pieces published during or after the conference. Therefore, we can reasonably estimate that the total number of media views reached the hundreds of millions.

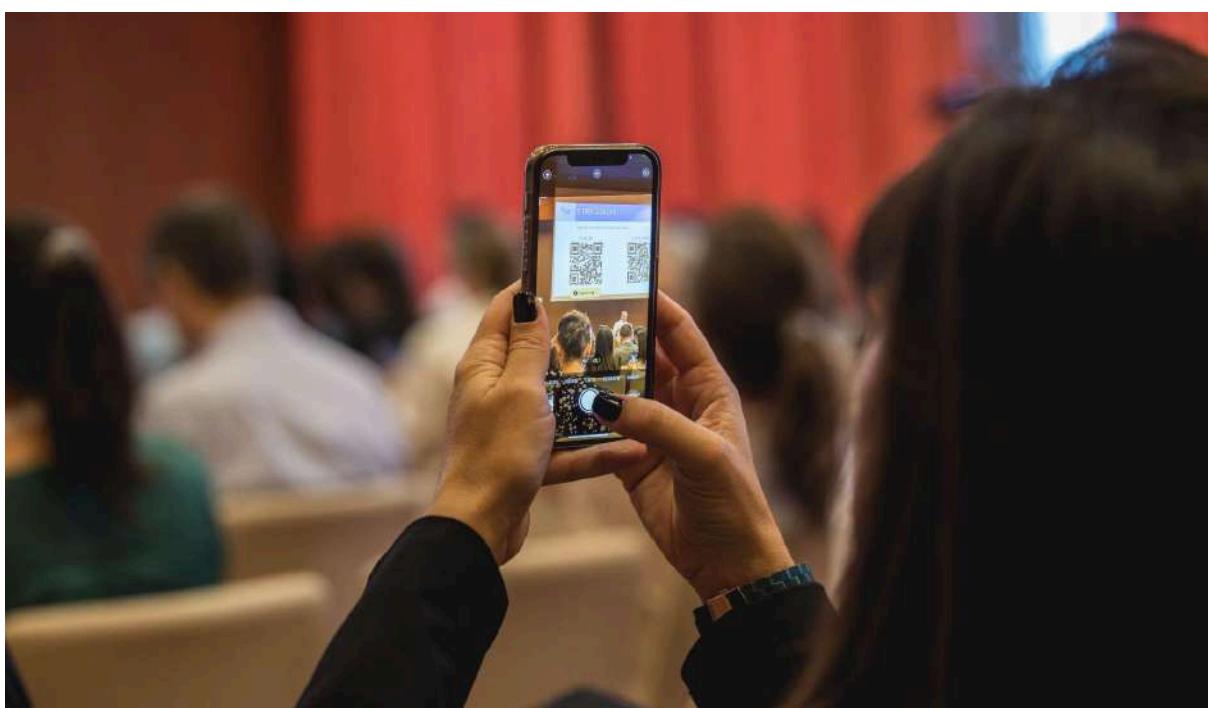
Awareness of Further Resources and Institutions to Learn About PD and Support PWP

Another function of this general awareness was to improve the understanding of where to ask for help. This was the goal for ACAP, so that they can be a better source of information and support for the community. The intention was that if more individuals and organisations know about PD, and they are aware of support institutions like ACAP, they will be more aware of both the need to accommodate for PWP and where to source further information to do so.

3. Hospitality and Public Services Become More Inclusive

The PR trainings were designed to help improve the knowledge and understanding of PD by public facing staff, to improve the experience of WPC delegates and to make Barcelona a more accessible place.

One survey was conducted with the trainees before and after the training sessions, to understand their general level of understanding of PD and what they had gained from the training session. A different group of trainees was surveyed a few months after the conference to understand their level of understanding of PD after time, and how the training has helped them in their jobs. Both surveys were taken by a range of trainees including transport professionals, hotel staff, convention centre staff and police officers.



Understanding and Awareness of PD

In each training session, trainees were equipped with three to four fundamental tips that could positively impact their interactions and help them to better assist PWP. This helped them to improve their approach, communication and support for PWP. By implementing training insights, trainees can make a positive difference. This is especially true since the training had been tailored for each group, to explore the most likely situations to arise within that particular context.

One trainee survey was conducted immediately after the training sessions. 74.4% of trainees found the training very useful and informative, with a further 23.7% finding it somewhat useful and informative. When surveyed again three months later, 100% of trainees agreed or strongly agreed that they had a better understanding of PD after the training, with 97% saying that they now have a good understanding of how to respond to the symptoms of PD.

100% of trainees surveys could accurately list three different symptoms of PD when asked. All trainees were also able to list appropriate supportive behaviours when interacting with someone currently experiencing PD symptoms. Behaviours listed included speaking slowly and clearly, allowing for reaction time, accompanying the person and offering physical support, and reassuring them that you are aware and able to provide support.

We also surveyed delegates to understand their experience of how the training has been implemented. 41% of delegates agreed that they believed that public taxi services, public transportation, and the police in Barcelona had become more aware of Parkinson's disease after the World Parkinson Congress, with 51% remaining neutral and 8% in disagreement.

Perceived Value of the Training and Practical Application of Learnings

After the training, facilitators noted that trainees were interested and enthusiastic, asking unexpected questions. Some participants requested that more sessions be scheduled so that colleagues could also benefit from the insights learned. There was a good level of attention in the sessions, showing that participants could see the value of participation. The feedback received afterwards was positive and encouraging. Every group was welcoming, and a few requested multiple training sessions. 97% of trainees said that they found the knowledge gained in this training useful in their personal life. Some participants shared that after their training, they had a better understanding of friends or acquaintances who may have PD or similar conditions.

100% of trainees agreed that it is important that people working in public facing roles have a better understanding of PD, showing that they believed in the importance and value of the training. 94% of trainees agreed or strongly agreed that their workplace should offer more trainings like this.



88% of trainees said that the training was useful in their work. Despite this, only 31% of trainees reported applying the knowledge gained in this training in their work, with many saying that they had not been in a situation where it was needed. However, several trainees did note that they are now more alert and will be more able to spot situations in the future.

Broader Impact of the Training

81% of trainees said that they had spoken to colleagues about the knowledge they had gained from the training, showing that the positive effects of the training may extend beyond the training rooms themselves. This contributes to the increase in public awareness of PD, and to the spread of knowledge within Barcelona.

90.4% of trainees said it would be helpful to do a follow up training with the Catalan Parkinson Association in 2024. When asked about the possible benefits of the training over time, trainees listed several impacts, including many that have been echoed by other key stakeholders. Benefits included improved awareness and understanding of PD, ability to support PWP and others with mobility needs, and making Barcelona more inclusive.



Benefits of the Training - Quotes from Trainees

“That people with Parkinson's can have a better quality of life and that we can help them together.”

“Increased knowledge of the disease and improved performance of public-facing staff.”

“In my field of work they are very useful in promoting tourism for all.”

“A more inclusive city.”

“Being acutely aware of the barriers and obstacles that many patients and attendees experience when arriving at our convention centre.”

Several trainees asked for supplementary trainings to further the impact of this work. Some requested regular refresher trainings, and others suggested hosting more training sessions to reach more public facing staff members. This is great because it shows that the trainees see the value of the learnings and they think they should be bolstered to increase the impact. It also shows that trainees are keen to learn more to supplement their knowledge and understanding of PD. One additional benefit of the training is that people who were trained will now know to go to ACAP if they need further support.

Training Feedback - Quotes from Trainees

“This is a very good initiative to give visibility to this type of diseases and to bring them closer to the population.”

“It was a very positive experience, and it should be extended in some way to the rest of society, for diseases of this type.”

“The training generated a flow of empathy towards the assistant and an awareness of the obstacles they faced. The result was to provide physical and human resources to make the patient's experience at the centre comfortable and positive at all times.”

The trainers worked with several different groups to implement the training. One of these groups was the police, at both the local and the national level. After the training, the police asked for a purpose-built hotline for officers to call if they encounter a PWP and need advice or support. This was a fantastic outcome since it showed that there was a genuine concern from the police about managing their interactions with PWP responsibly. The police also requested additional training for their entire staff, totalling around 3,000 people, after the conference. ACAP have now finalised a partnership with the police to host annual training sessions for the benefit of their staff. This is a tangible example of lasting impact for Barcelona and Catalonia, long after the WPC 2023.

In the future we hope that more trainings like this can be offered to further increase the impact, and that additional partner organisations can also support to improve collaboration.

4. Increased Demand from Congress Organisers for Legacy Projects in Barcelona

The PR program has been a source of inspiration and a great case study for many to follow. Because of this, the program summary has been presented at 11 conferences and events all over the world, including Türkiye, Panama, USA and of course Spain. Over 1,000 event industry professionals have been able to learn about and gain insight from the PR program through these presentations. This shared learning can potentially bring about similar copycat programs in other destinations, and possibly addressing other diseases, bringing further benefit to the scientific community and the general population at large.

Showcasing this positive impact project will be a great way to show other event organisers how they can leverage their expertise to provide benefit for both their delegates and the local community. Event organisers will also be aware that they can tap into the existing stakeholder network developed by Barcelona, and so impact oriented events will be more attracted to come to Barcelona in the future. Currently we have not been able to collect data against this since this outcome is longer term. In the coming months and years we will be able to understand the extent to which this outcome has been achieved.

5. Enhanced Support and Funding Allocation from Public Administration

The PR program intended to draw in additional support from local and national government to help further support for PWP across the country and worldwide. By demonstrating a practical program that highlighted the needs of PWP and the existing gaps in society, the PR program could show to government and business officials that these adjustments are feasible and important, and to highlight the importance of managing PD in a timely and comprehensive manner.

Collaboration and Engagement

Collaboration was a key expected outcome of the PR program, since the planning, execution and communication of the project required contributions from a wide range of stakeholders. This collaboration also helped to draw in different parties including state representatives, businesses, research institutions and interest groups.

AbbVie, a large multinational pharmaceutical company, agreed to sponsor the PR program since they had a good relationship with the World Parkinson Coalition. This was the first time that the PR program had been sponsored. AbbVie in particular was keen to see the impact data and understand how the program generated positive change around and beyond WPC 2023. They hope to replicate in other parts of Spain and other countries

ACAP also benefited by building relationships with local stakeholders. Increased awareness of ACAP as the first Parkinson's patient association in Spain is a key benefit for ACAP in the



region. The program was also able to improve the general perception of the World Parkinson Coalition, according to several interviewees.

The Parkinson's Ready program opened doors for the local association to talk to the government and speak with them about Parkinson's like they do with other diseases.

The Mayor of Barcelona was invited to attend the Bike to Barcelona welcome party. The organisers did attempt to collaborate with the Mayor's office, but this was tricky due to the elections falling just before the conference.

"The collaboration from the involved groups and the support we have received from the public administration (city council, regional government) and security forces such as the National Police, Mossos d'Esquadra, and the Municipal Police has been outstanding. They haven't raised any objections and, on the contrary, have provided us with all the necessary support and facilities."

- Fulvio Capitano, PR Trainer and PWP

Science & Industry

There were also several benefits for the scientific community. The PR program, alongside the conference in general, highlighted the importance of including the patient perspective in care and research. One positive outcome of this event is that it has inspired healthcare providers and researchers to value the perspectives of different stakeholders.

The way that the program was managed and executed also challenged the idea that only doctors can lead programs of this nature. The healthcare industry is diverse, and there are a huge number of professionals specialised in particular diseases that have more than enough expertise and experience to lead trainings of this nature. This program can serve as evidence of the efficacy of using a variety of specialists and not just relying on doctors. This could contribute to addressing potential prejudices that some people may have about the importance of hierarchy in the medical field. This highlights that specialists in different professional roles can have deep and valuable knowledge about their areas of expertise, which they can share with broader audiences in a way that benefits patients.

This program could also serve as an inspiration for associations that specialise in other diseases and illnesses that also represent patient interests and that invite patients to their events. programs like PR that prepare the city for the arrival of a large group of people with distinct needs could be incredibly helpful for the city to prepare to become welcoming and accessible, and for the delegates themselves to feel supported and comfortable in a new destination.

6. Amplification of Learnings

The amplification and fortification of the impact generated by the PR program was essential to the success of the program. This has already been touched on in the outcomes mentioned previously. Key examples of amplification include:

- Additional trainings requested by the Police
- Trainees sharing learnings with colleagues
- Trainings planned to continue after WPC 2023 in response to demand, both in cities that will host the Congress in the future and cities that do not have plans to host it
- Presentations made to industry
- Collaboration with partners and government

5. Impact on the Destination

Collaboration

For Barcelona, the priority was to build alliances with key groups, raise awareness, raise the importance of the issue with the public administration, and support patients and carers in the destination. Catalonia is home to many world-renowned neurologists. The Catalan association of patients and relatives inspired the establishment of the Valencia and Madrid delegations, and the Spanish Parkinson's Federation. So Catalonia has expertise in social and familial care as well as research and medical expertise.

ACAP was keen for WPC 2023 to come to Barcelona so that PD could be placed higher on the political agenda. They also wanted to help patients and families to better understand and manage the disease, and reduce reliance on medical services. Through the conference, ACAP also wanted PWP living in Barcelona to meet people with similar experiences and more expertise, so that they could be better equipped to manage their own health in the future. Another intended goal was to support young patients and caregivers from the region.

Through the project, stakeholder relationships have been developed and strengthened. This includes between key local and community actors such as the police, public transit and venues. These relationships will hopefully lead to more collaboration in the future, creating more innovative projects to generate social impact. One intention is that the success of the PR program can inspire other similar training programs for other diseases and illnesses, to help improve the experience of delegations visiting Barcelona for other conferences. Continued communication will be key to maintaining and expanding these benefits in the future.

The local relationships are the most impactful, to keep local community actors engaged and involved. The police were very positive - both Barcelona and regional Catalonia police. The chief of the Catalan police said he wanted to train all of his 3,000 staff, and so WPC put them



in touch with the Catalan Association to continue the work after the conference. They also asked for a hotline to be put in place to ask questions. They were sincere in their desire to help and support.

Supporting the Local Community

The event fits the destination brand because it has been organised in line with the needs and requirements of the city and because it will bring more people in to visit Barcelona. There was support from the city in the form of buy-in from leadership of different Barcelona organisations including ACAP, and the Barcelona Convention Bureau.

"Airport bus service was very good, taxi driver friendly, most places walkable."

- Delegate

There were several intended outcomes for the conference in general, and the PR program in particular, to take place in Barcelona. There are 160,000 PWP in Spain, with 29,000 of them in Catalonia alone, demonstrating the importance of this to the destination.

Reputation of Barcelona as an Inclusive City

Most importantly, the intention was to improve the perception of Barcelona as an inclusive city. When surveyed after the event, 58% of delegates agreed that Barcelona is easy to navigate for people with Parkinson's disease, with 36% remaining neutral, and 7% disagreeing with the statement. Just 32% of delegates agreed that Barcelona as a city was more accessible than most other destinations they had visited, which shows that the city still has some room for improvement in terms of accessibility. However, 68% of delegates intend to return to Barcelona in the future. This is a good sign for future growth and general perceptions of Barcelona as a welcoming city.

The project also aimed to significantly increase awareness and understanding of Parkinson's disease in Barcelona amongst the general public. The PR program has helped to transmit some knowledge from the scientific community to the general population in a practical way. Interviewees agreed that the conference has enhanced the reputation or visibility of Barcelona as an accessible and inclusive destination for WPC delegates with Parkinson's. Overall, the intention is for Barcelona to be seen as a Parkinson's friendly city.

"I think that the PD sensitivity program made all the tourist and transit sector people I interacted with more open and aware to every visitor to Barcelona, not just people with PD."

- Delegate

The PR project aimed to empower public facing workers to better assist people with Parkinson's. The training initiative highlighted the responsibility of and provided recognition to service providers for their role in caring for PWP. 56% of trainees agreed or strongly agreed



that the training has helped them to make better decisions at work. 97% of the trainees agreed or strongly agreed that the training was beneficial of PWP living in and visiting Barcelona.

One hotel manager was interviewed who participated in the training, even though their hotel did not host any WPC 2023 delegates. They said that they had found the training extremely useful. The manager had passed this information on to additional departments of the hotel, and they are implementing the suggested actions and recommendations across the hotel so that guests in the future can benefit. This particular hotel is located close to one of the largest hospitals in Barcelona, and so the hotel staff really saw the value in the training outcomes and how they can apply to various conditions, as well as PD.

The front-line staff at a nearby music festival were also trained. The WPC conference coincided with the Cruïlla Festival, which was held at the Forum and joined the PR program to train the 500 workers who were on the front line of the music event. The collaboration was welcomed by Cruïlla Festival organisers, who had taken significant measures to make the music festival more accessible in other ways, including improving venue accessibility and providing sign language interpreters.

One interviewee said that the biggest future potential impact would be to continue training locally in Catalonia, before expanding throughout Spain. In the future this will be a much bigger public health issue for all host cities, since PD is on the rise with the global ageing population, so this could be really impactful.

Platforming Local Professionals

One major benefit of the PR program and the conference in general is the opportunity to platform local professionals who specialise in PD treatment. It was great to use local expertise to plan and deliver the PR program, with some external support.

The PR program has been a great test case to show Barcelona's commitment to generating positive social change. This initiative has provided prestige and credibility to Barcelona as a destination that cares about social impact and legacy in a tangible way.

6. Key Learnings and Recommendations

2023 was the first time that before and after surveys were conducted of the Parkinson's Ready program. The data was broadly positive and was shown at the WPC itself, helping with communications of both the fact that the program existed and its level of success in the short term.

Barriers to Success

Limited barriers were noted by interviewees. The Catalan association ACAP was very involved in the project. ACAP was established as one of the first Parkinson's associations in Spain, and so for a long time had historically served as Spain's leading organisation representing the interests of PWP. There was a general sense that different organisations were collaborating well and working together to alleviate barriers to the success of the program. Additional organisational support could have potentially helped the program to gain further reach beyond Catalonia, and support the spread of learnings throughout Spain for the benefit of PWP across Spain.

Organisers noted that limited resources were available to implement the project. The BCB was able to negotiate with key contacts to secure some venues to host the training sessions for free. Some additional venues were paid for by the sponsor AbbVie. Three trainers, a photographer and two videographers were used. Abbvie organised the photographer and the videographer for the interviews. BCB recorded and edited the last training session into a summary training video. This video was then shared with all the trained groups, so that they could further share the learnings and best practices with their colleagues.

Since 2023 was the first year that the PR program was being thoroughly analysed, one barrier identified was that people with Parkinson's had not previously participated in interviews or provided feedback. This made it a little difficult to fully understand the impact of the program this year compared to previous years.

One notable barrier to success was the minimal involvement of city political officials. Political figures attended the Bike to Barcelona Welcome Party, but there was little involvement beforehand due to an election in May, before the conference, which prohibited their participation in the event and impact projects.

Another barrier is that since the conference only takes place once every three years, this may be too long for the program to have compounding effects. There may be a need to replicate the training sooner than the 3-year program cycle, but careful considerations need to be made of how to implement this beyond the conference cycle. However, it can be possible with ownership from the city, since WPC will not need to lead on the trainings in the destination city.

The research also showed that there was limited take up in the 'train the trainer' model that had been used to work with both hotels and taxi companies. While some representatives were trained and given training materials, it does not appear likely that these trainees then followed through and provided the same training to their colleagues. This is something that should be further investigated and monitored more closely in the future.

Learnings



The PR program generated multiple learnings and best practices for consideration in the future. This includes considerations about stakeholder management, sharing best practices, collaboration and securing external support.

Several hotels were invited to participate in the PR training. Invitations were sent to 400 hotels across Barcelona. Many members of hotel staff were trained, and some shared these learnings further with their colleagues. In the future, it may be beneficial to establish a working group of hotel managers to support and discuss the training program. This could help to increase buy-in, and enable collective learning and peer-learning. It would also be helpful to track how many hotels shared the learning materials with their members of staff, and to know how many members of staff have been exposed to the materials. Further collaboration would be a great way to secure additional support from local organisations and businesses in the future.

One interviewee noted that while training materials were shared, after the training, they were not provided with prior knowledge or information ahead of the training. In the future, program trainers could consider sending materials out ahead of time so that participants could familiarise themselves with the contents to help improve their learning.

There have been calls to continue trainings between conferences, to compound learnings and to respond to interest from both trainee organisations and sponsors to provide more training sessions to increase impact. It could also be beneficial to hold more training sessions for additional groups such as pharmacies and shops, to further compound the learnings and expand the reach of the program.

Buy-in from the convention bureau was key to ensuring the success of the project, and in future this should be a key foundation of the program.

One major learning outcome by the program organisers was that impactful projects can be done with few resources by collaborating. It is not necessary to dedicate a huge amount of funds to a project in order for it to be a success. However, there is a significant need for collaboration between organisers and stakeholders to achieve genuine impact.

This project has also contributed to a shift in perspective for some key stakeholders. Destinations that benefit from social impact projects can recognise the value that events can bring to their cities, beyond the economic impact. Barcelona can leverage events to help understand and improve their local social and health needs. Implementing this project has also contributed to the skillset of BCB and key partners, in better understanding how to design, plan and execute social impact projects.

Recommendations



Several suggestions were made regarding how to improve the PR program in the future. This includes suggestions on session structure, the provision of materials, vehicles of collaboration and how to further improve the training program.

In the future the program can take many directions. One approach could be research and government support to find a cure. Another could be to increase public awareness to support the perception of and interactions with people with PD.

It would be helpful for the World Parkinson Coalition to create a best practices manual for trainees of the PR program, so that future iterations of the program would be able to build on the successes and learnings from past versions in an intentional and strategic way. Trainees would be able to use these best practice examples as tangible case studies for them to refer back to and use as a reference point to further improve their service delivery and refresh their learnings after the training has ended. This additional resource will help host destinations in the future to implement and support the project in a way that is most effective and impactful.

One learning from this initiative was the importance of communication to explain the benefits to the public. This is particularly important for a project like the PR program, since understanding that the program existed actually helped PWP to alleviate some of the challenges they faced. It is also important for the general public to be aware of the program so that they can appreciate the importance of the issue at hand and help to spread knowledge and awareness about the issue.

AbbVie is keen to replicate the project in the future. The PR program doesn't always have to be alongside the WPC. AbbVie has 77 offices worldwide so this could become a much wider program. Currently they are exploring 'train the trainer' models to be able to further spread the impact.

The regional government in Catalonia was very interested in the PR program and showed a willingness to engage with ACAP to provide additional support at the political level for PWP. This is an excellent outcome that should be leveraged to its full potential to expand support and services for PWP living in Catalonia.

In the future, further efforts should also be made to better engage with the national association and other local organisations with an interest in PWP. Collaboration is crucial for stakeholder engagement and the success of impact projects, so including more organisations with aligned priorities will strengthen the project and the local investment in the project in the future.

Conclusion

The Parkinson's Ready program was intended to improve the experience of People with Parkinson's visiting the WPC conference, and to improve the perception of Barcelona as an inclusive destination. The data demonstrates that PWP generally had a great experience around the conference and in Barcelona city, although some PWP did also have negative experiences. Trainees benefited greatly from the training, and requested additional training to supplement and expand their learnings. Overall, the Parkinson's Ready program did successfully contribute to some intended short term outcomes. Further study is required to understand the impact of the program on secondary stakeholders, and outcomes generated in the medium and longer term.



7. Annex

A. Impact Measurement Approach

#Meet4Impact was responsible for collecting the data to analyse the effectiveness and impact of the Parkinson's Ready program.

We used a wide variety of primary data sources for this including:

- Pre-conference interviews
- Post-conference interviews
- Surveys to delegate attendees (in English and Spanish)
- Surveys to trainees (in Spanish)

We conducted several interviews and received over 200 survey responses, resulting in a wealth of data for us to analyse and interrogate to understand the impact of the program.

We also analysed several secondary sources of data including:

- Media articles - local to Catalonia/Spain, and some event industry publications
- Pre and post training survey findings collected by ACAP, WPC and BCB
- Interviews recorded by AbbVie

We analysed this data using a standardised coding technique based on the outcomes identified in the Theory of Change.

B. Limitations of the Study

There are also some learnings to keep in mind regarding measurement and data collection. The measurement project was confirmed at a late stage, and so we had limited opportunity to engage with data collection before and during the PR program. The option to gather additional insights before the program would have been really helpful in fully understanding the change created by the program. Additionally, the surveys we had sent out were received by the target groups later than intended. Limited time meant that the time frames for data collection were not optimal. In the future, surveys should be sent out to trainees sooner after the training has concluded, and to delegates within a month of the conference.

The scope of the study was to collect and analyse first level data from those directly involved. This study did not include those indirectly affected by the program, such as members of the general public to understand public awareness. Collecting additional data from second level stakeholders and outcomes would help to give a fuller picture of the impact created by the project on a wider scale.

For the next WPC conference, we should keep a record of the number of complaints made during and after the conference so that we can use this as a data point and potentially ascertain long term effects over future conference iterations. In the future we would also benefit from doing more interviews with PWP and trainee organisations to gain a bigger sample size of data.



In the future, we should consider establishing a standardised monitoring and evaluation framework that collects data that is comparable year on year and aligns with standardised impact metrics. This should include collecting both primary and secondary data sources from first level and second level stakeholders. This should also include a study across a longer time frame, to gain a fuller understanding of the medium and long term outcomes resulting from the program.

Acknowledgements

This report was written and designed by the following members of the #Meet4Impact team:

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