Involving people affected by Parkinson’s in service redesign and development

This short guide highlights key issues to consider when involving people with Parkinson’s, their carers and families in shaping services.

People living with Parkinson's, their carers and families need to be at the heart of Parkinson's service development and redesign. Involving people affected by the condition will enable you to design more efficient person-centred services that meet the needs of your users.

User involvement can provide you with a different perspective and give better understanding of whether any changes are effective.

Key issues to consider when involving people with Parkinson’s, carers and families in shaping services:

• Who do you need to involve?
• What is the best method to engage people?
• What are you expecting from people?
• Do you have support in place to enable people to take part?
• How will you ensure people are not out of pocket as a result of being involved?
• How will you let people know the impact or outcome of their involvement?

Who do you need to involve?
People with Parkinson's and their carers represent a diverse population. People will be in different stages of the condition and have experience of a range of care settings. They will vary in age and be from different ethnic backgrounds.

Generally, you should aim to involve representatives from across the whole of the Parkinson’s community in service development and redesign. But it’s important to consider what you are trying to achieve – if you are looking to improve support at diagnosis for example, it may sensible to restrict involvement to people who have been diagnosed in the last year.
What is the best method to engage people?
There are lots of ways to engage people in the process and you can combine different methods. A summary of different approaches and their strengths and weaknesses is in Appendix 1 on page 4.

You should adapt your approach depending on the specific population you want to participate in service development and redesign. For example, people with advanced Parkinson’s may benefit from a one-to-one interview. Younger people are more likely to be working during the day or have other responsibilities such as looking after children. They might not be able to attend a meeting during the day, but may be comfortable sharing their views using social media.

What are you expecting from people?
You should consider:

• Will a person’s involvement be a one-off occasion or ongoing?
• Do people need training and support to participate and if so, who will provide this?
• Will the person with Parkinson’s be expected to give comments as an individual or will they act as a representative for a wider group? How will they be supported in this role?
• Do people need to be introduced to other people involved in the process? Who will do this?

Once you have determined what you expect from someone, be explicit about this and consider putting it in writing.

Do you have support in place to enable people to take part?
Depending on the level of involvement, people may need training before they participate in the user involvement process. Appropriate support may also be needed before, during and after meetings. People should understand what support is available and how to access it.

It is good practice to have more than one person affected by Parkinson’s as a representative. Sharing responsibility can help reduce the pressure on someone with a fluctuating condition who may feel obliged to attend a meeting they have committed to, even if they are unwell. It provides a support network for the individuals involved. It can also help people with Parkinson’s and their carers to feel less outnumbered by professionals at an event and may mean they are more willing to speak out.

Involving everyone in the Parkinson’s community is possible with the right support in place. For example:

• People with dementia may find it difficult to process information quickly or communicate. Allowing extra time or using communication aids can offer people an opportunity to contribute. Some people with dementia will find it easier to participate in a familiar environment, so consider which methods may be more appropriate.

• People with Parkinson’s who have learning difficulties will have varying needs. Allowing additional time, using easy-read publications, and seeking specific advice from a speech and language therapist can help. Some people may feel more able to offer their views through other
forms of communication, such as music, art or drama so it is important to bear this in mind when choosing a method of engagement.

- People with Parkinson’s who have mental health needs will vary in the support they will require. Check with each individual what their support needs are and try to accommodate these as far as possible.

- People from black and ethnic minority groups and lesbian, gay, bisexual and transgender people can sometimes feel excluded from patient participation initiatives. Their views may not always be specifically sought or they may feel that their needs do not match the majority views and are therefore reluctant to participate. Depending on the needs of the population you want to speak to, you may need to arrange meetings or focus groups for one particular group only. Identify if language is a barrier and when appropriate, arrange for an interpreter to attend.

**How will you ensure people are not out of pocket as a result of being involved?**

Expenses should cover all costs, not just travel. If someone is required to attend a meeting, expense forms should be sent out beforehand. At the meeting, people should be reminded to complete the forms and told where they should return them to.

People living in a care home may need a carer with them if they attend a meeting. The care home will have to pay to back fill cover for that member of staff. This cost should be covered by the meeting organisers and budgeted for at the beginning of the process.

If someone cares for their partner, spouse or family member with Parkinson’s, they may need to arrange respite care to enable them to attend a meeting or event. The cost of this respite care should be covered. Similarly, a person with Parkinson’s or a carer who has childcare responsibilities should also be able to claim expenses for childcare costs.

**How will you let people know the impact and outcome of their involvement?**

Analyse the results you have gathered and share them with the people who have been involved in the process. Let participants know how their contribution has made a difference.

Don’t forget to thank people for their efforts – people appreciate this recognition and it may encourage them to get involved again in the future.

If you produce a final report, make sure it is available in a range of formats, such as a hardcopy and online and let people know how and where they can access a copy.

**How can Parkinson’s UK help you?**

Parkinson’s UK can provide support for User Involvement. We can also provide up-to-date information about the experiences of local services from people with Parkinson’s and their carers.

For more information, please contact our User Involvement team on **020 7963 3901**. In Northern Ireland, please contact **0344 225 3680**.
## Appendix 1 - Direct and indirect methods of engagement

### Direct methods

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<th>Method</th>
<th>Advantages</th>
<th>Disadvantages</th>
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| Focus groups, workshops, consultation events | • An efficient way of gathering a large amount of information at one time.  
• Participants can explore ideas and views in depth.  
• Groups whose views are not normally heard can be invited to attend sessions.  
• Some people may feel more able to speak in a focus group than in a more formal situation. | • Participants may feel that they need to conform to the views of the wider group or give positive feedback in front of healthcare professionals, if they are present.  
• It may be difficult for people with communication issues to share their opinions.  
• It may be difficult for people with Parkinson’s to travel to attend a group or event, or for carers to find someone to do their role while they attend. They may be particularly inaccessible for people living in rural areas. |
| One-to-one interviews (Face-to-face or over the phone) | • Allows you to speak to people with Parkinson’s from under-served groups, such as people with communication difficulties, people with dementia, or people who live in care homes. | • Interviews can be time consuming.  
• They may only involve a small sample of the total population of people affected by Parkinson’s. |
| Representatives on project or strategic groups | • Allows the views of people with Parkinson’s and their carers to be heard at a high level.  
• The group can have real influence. | • The group’s overall aims may not be Parkinson’s-specific.  
• The view of a few may not represent the whole Parkinson’s population. |
| Questionnaires or surveys                   | • Allows you to gather a lot of information in a short amount of time.  
• Allows people to answer in their own time.  
• Reduces bias – everyone is answering the same questions.  
• Can be economical if done by email or hand delivered. | • It can be difficult to get in-depth information if people are asked closed questions.  
• People may misinterpret questions, especially if they are worded poorly. This can lead to poor information being gathered.  
• The response rate may be low.  
• The results can be time consuming to analyse.  
• Some people may find writing difficult. |
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| Analysis of complaints       | • Provides comments from people with Parkinson’s and their carers who have first-hand experience of using a service.  
                               | • Offers the opportunity to gather very detailed information on specific matters.                      | • Can be biased towards negative experiences.                                                             |
|                              |                                                                            | • May be difficult to gather a general opinion of the service because of the nature of individual complaints. |
|                              |                                                                            | • May not be able to share some of the information due to the confidential or sensitive nature of the complaint. |
| Social media                 | • Potential large audience.                                                | • Can be very time consuming – someone often needs to monitor feedback constantly.                     |
|                              | • Can target specific groups of people with Parkinson’s.                   | • It is difficult to control what people post or comment on.                                             |
|                              | • The Parkinson’s UK forum may be a useful place to engage people          | • Responses may not represent the whole Parkinson’s population.                                          |
|                              |    (Visit parkinsons.org.uk/forum to find out more).                      |                                                                                                         |
| Public meetings or open days | • Can be an opportunity to raise an issue which would otherwise remain hidden. | • A meeting may be taken over by someone with a different agenda.                                        |
|                              | • Can be a good platform to publicise less common issues to a large audience. | • People may not speak up if their opinion differs from the majority.                                   |
|                              |                                                                            | • There is a risk meetings become a one-sided conversation.                                             |
| Suggestion boxes             | • Can highlight issues that were not obvious.                              | • May receive lots of negative feedback.                                                                  |
|                              | • Allows people to provide lots of information on a particular issue      | • Does not always reflect the view of the whole Parkinson’s population.                                    |
|                              |    that affects them.                                                     |                                                                                                         |
| Attending local support      | • People are usually already engaged in what you are talking to them about. | • Groups may not have a representative mix of people with Parkinson’s.                                    |
| group meetings               | • People will have a direct experience of using services.                 | • A meeting may be taken over by someone with a different agenda.                                        |
|                              | • Can ask very focused questions and receive immediate answers.           |                                                                                                         |
The UK Parkinson’s Excellence Network is the driving force for improving Parkinson’s care, connecting and equipping professionals to provide the services people affected by the condition want to see.

The tools, education and data it provides are crucial for better services and professional development.

The network links key professionals and people affected by Parkinson’s, bringing new opportunities to learn from each other and work together for change.

Visit parkinsons.org.uk/excellencenetwork