

**PARKINSON'S<sup>UK</sup>** CHANGE ATTITUDES. FIND A CURE. JOIN US.



# PATIENT AND PUBLIC INVOLVEMENT

A resource for researchers



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## What is Patient and Public Involvement?

Patient and Public Involvement (PPI) is when researchers and people affected by health conditions work in partnership to plan, design, implement, manage, evaluate and/or disseminate research.

We believe that involving people affected by Parkinson's at all stages of research produces higher quality, more relevant research and ensures that the benefits are felt by the people who need it most.

At Parkinson's UK, we want the researchers we fund to work in partnership with people affected by Parkinson's as much as possible. We're working on improving how we support the Parkinson's research community to do this.

Researchers frequently tell us that they need more support to:

- a) **understand** what is meant by Patient and Public Involvement (PPI) and where it can be most effective in their work
- b) **bring together** PPI information and resources that are relevant to Parkinson's research in one place
- c) **access** people affected by Parkinson's to be involved in their research

This resource has been created to help all Parkinson's researchers, whatever their area of interest, to effectively and meaningfully involve people affected by Parkinson's in their research.

### Participation, engagement or involvement?

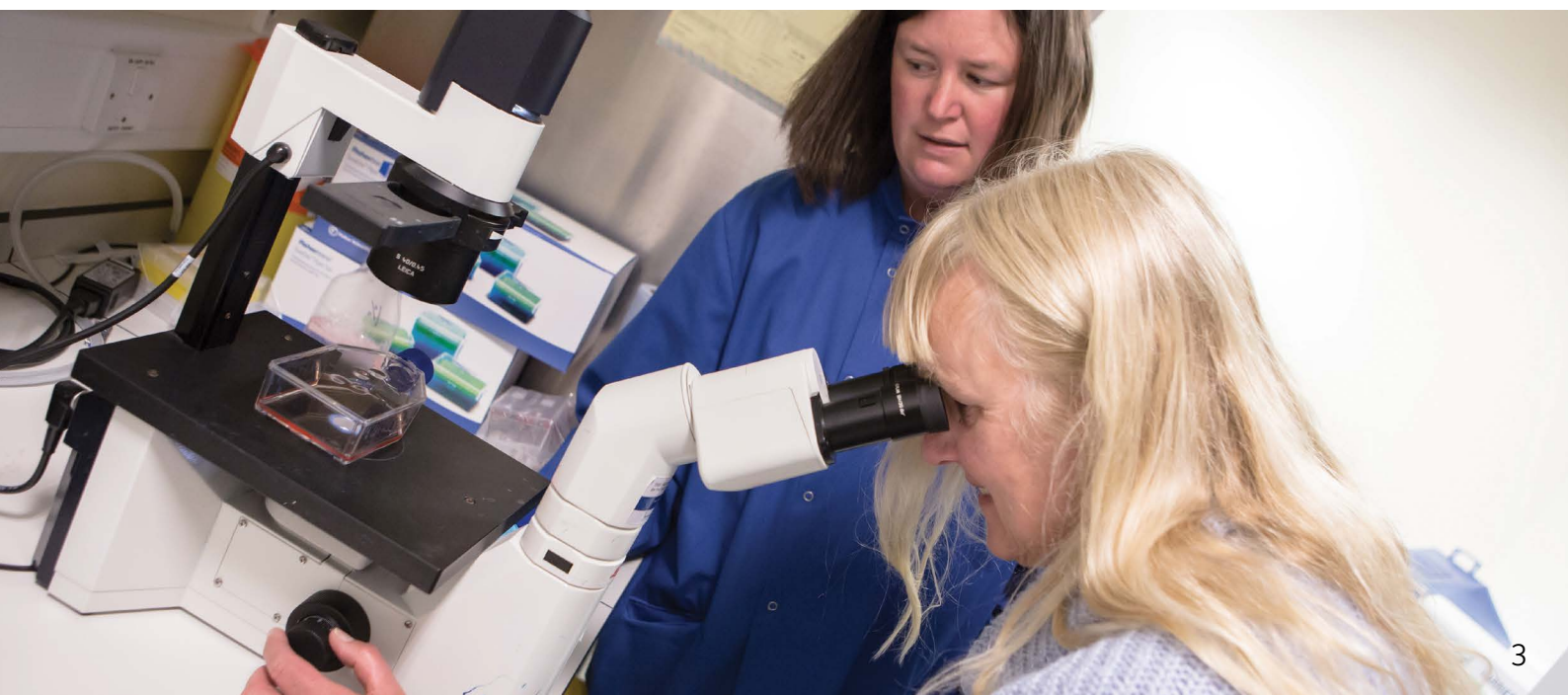
It's important to be clear how patient and public involvement differs from participation and engagement:

#### Participation

Participation refers to the recruitment of people to take part in your study. Whether you are conducting a clinical trial, interventional or observational study, if your aim is to recruit people to take part in your study – this is NOT patient or public involvement.

#### Engagement

Engagement is telling people about your research. Sharing the knowledge you've gained is crucial to ensuring people affected by the condition are engaged with and motivated by research. Engagement can mean holding project visits, attending a local Parkinson's group and/or presenting at a research event. Sharing information about your research to people affected by Parkinson's or the public is NOT patient or public involvement.



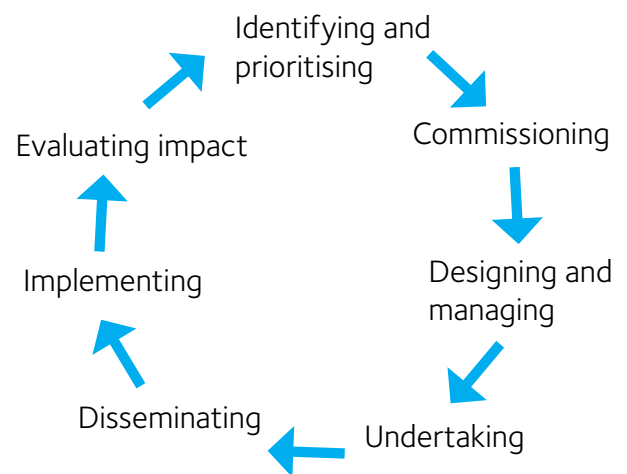
## Methods of involvement

You can involve people affected by Parkinson's at all stages of research to help with:

- **identifying and prioritising** the most relevant research questions for people living with the condition
- approaching funders to **commission** your research. You can develop your funding application by improving the readability of your lay summary and ensuring the research is relevant to people affected by Parkinson's
- **designing** your research protocol to maximise recruitment and creating a retention plan for participants
- **managing** your research as part of a steering group or committee
- **undertaking** your research, such as helping participants to complete questionnaires
- planning how to best **disseminate** your research to lay audiences
- directing how you will **implement** the results of your research, and **evaluate its impact** for people affected by Parkinson's

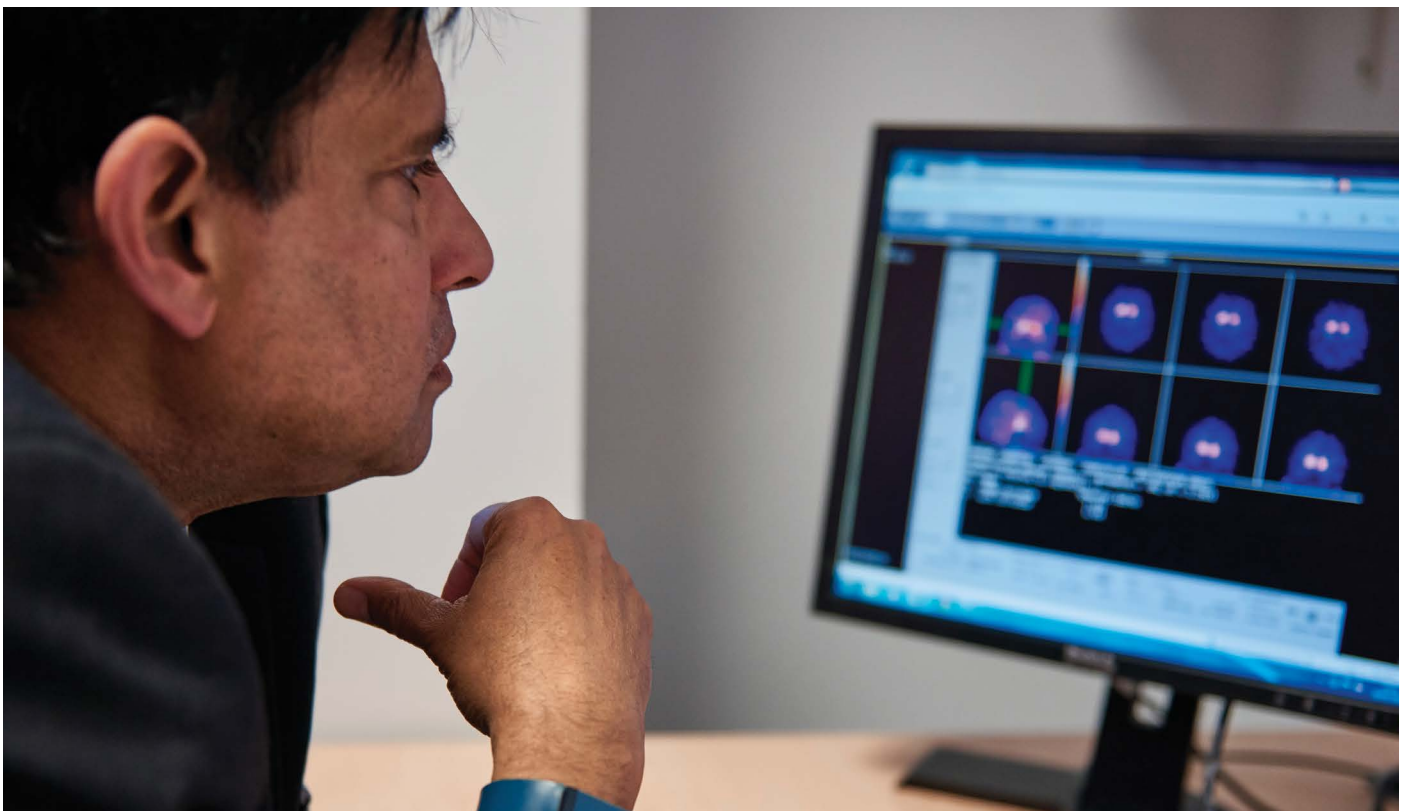
Once you have decided at which stages of your research you want to involve people affected by

### Stages of research



Parkinson's, you need to think about how you are going to do this. Will you consult or collaborate?

There is no 'one size fits all' model for how you should conduct PPI within your research and you don't have to choose one or the other – you could do both at different stages of your research study, and there may often be an overlap of the two.





### Consultation

You can consult people affected by Parkinson's to shape your research. This could be through a survey to shape your research question or by simply holding a single focus group.

#### Advantages:

- Simple and easy to set up.
- Can be carried out at fairly short notice.
- Can deliver the perspectives of a range of people.
- A good opportunity to gather a wide range of opinions from people living with the condition.

#### Disadvantages:

- There may be a number of conflicting perspectives.
- Consultation is usually anonymous, with less opportunity for clarification.
- Consultation can answer certain questions, but it's not ongoing for follow up questions.
- Your group may be less representative of the whole population.

### Collaboration

Collaboration can ensure research is relevant and stays focused on patient needs. It might include working with a small group of people in a patient focus group, or involving at least two people affected by Parkinson's in a study steering group.

#### Advantages:

- Your relationship with this group is ongoing and will support the development of your work through various iterations.
- These relationships may lead to collaboration on further studies and provide co-applicants for your next research project.
- You have a clearer perspective of those you are involving, with lots of opportunity for clarification.
- The patient group may be willing to take on one or multiple roles within your research.

#### Disadvantages:

- This kind of involvement needs to be well planned for it to be effective and meaningful.
- If meetings are face-to-face, you'll need a budget to cover expenses.



## PPI in clinical research

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We know that PPI in clinical research can have a significant impact on the quality and success of a study.

Arguably, any research that has human participants should involve the patient/carer community or members of the public in the planning, design, management and/or dissemination.

You can consult and/or collaborate with people affected by Parkinson's to:

- **plan your research question** – to help you find out what research in your area would have the greatest benefit to the most people
- contribute the **patient perspective in your funding application**. This will identify any pitfalls that may be picked up by a lay reviewer during the funding review process, including the readability of your plain English summary
- design which **study protocols** are most appropriate, and help to highlight any practical issues that you might not have considered that may impact recruitment to your study
- comment on **important study documents**, such as information sheets and consent forms
- help you develop **recruitment and retention plans**, including connecting you to networks of people affected by the condition, and acting as 'buddies' to participants to ensure they feel supported throughout the study
- **collect data** such as PROM questionnaires (participants are likely to be more honest and open with someone who understands and has experience of Parkinson's)
- **analyse or interpret data** from questionnaires from the perspective of someone who understands more about living with the condition
- help you **evaluate what your results mean** and what impact they will have, so you can prioritise your next research question

## PPI in basic research

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While it is thought to be challenging to involve people affected by health conditions in basic or fundamental research, we believe that meaningful involvement is an essential part of the process.

### Sharing your research

It's important that new ideas and knowledge gained from all Parkinson's UK funded research is shared and communicated as widely as possible and that grant holders meet with people affected by Parkinson's. However, we know it can be much harder to communicate the benefits and potential impact of basic research to non-expert audiences. That's why involving people affected by Parkinson's to help you communicate the importance of your research in a funding application or later dissemination plans, can be so beneficial.

You can consult and/or collaborate with people affected by Parkinson's to:

- help **tailor your lay abstract** and plain English summary to make it more readily understandable to non-experts. This is particularly important for more basic research because:
  - the majority of funders, (including Parkinson's UK), place **high importance on the lay perspective** in their funding decision
  - a good lay review can be the difference between getting funded or not, so it's important to think about the **readability of your lay summary** when developing your application
- work in partnership to design ways to communicate your research study to people affected by Parkinson's, for example:
  - helping you **prepare an informative and understandable presentation** when you talk about your research at a local patient meeting, conference, project visit or event
  - advising how best to **report the progress** of your research throughout the lifetime of a grant
  - providing insight into how to talk about the **relevance, impact and future** of your research
- help to identify and prioritise your next research question.

## How Parkinson's UK can help you with PPI

We're fully committed to helping researchers involve people affected by Parkinson's in their work. The Parkinson's UK Research Support Network (RSN) is a resource with an online network of over 1,800 people affected by Parkinson's across the UK with an interest in research.

### Consulting

We're regularly approached by researchers who would like the opinions of people with Parkinson's or to run their research question or study design past those living with the condition.

Through our Research Support Network and other communications channels we can:

- send out online surveys to gather the views of those living with the condition
- arrange for you to consult members of our online forum or social media channels
- invite our research supporters to join a single focus group to discuss plans for your research

### Collaborating

We can help you collaborate or work in partnership with people affected by Parkinson's by:

- highlighting opportunities for a smaller number of RSN members to work with you. This may include
  - commenting on your plain English summary before submission of your proposals
  - attending a focus group to review your study design, patient information sheets or consent form
  - joining the steering group for your project
- providing example role descriptions for PPI representatives or help you to create your own.

### How do I apply for help?

To apply for help with PPI in your study, please see <http://bit.ly/1XuvyhK> to download a 'Patient and Public Involvement request form'.

Once completed, you can return this to the research team at [rsn@parkinsons.org.uk](mailto:rsn@parkinsons.org.uk) along with (if applicable) a copy of your:

- Full protocol, patient information sheet, consent form and ethical approval letter.

We'll be in touch within five working days to discuss how we can support your research.

Alternatively, if you're interested in involving people affected by Parkinson's but are unsure of the best way to do this, email [rsn@parkinsons.org.uk](mailto:rsn@parkinsons.org.uk)

### Our PPI programme

We have recently launched our PPI pilot programme, which means we can support involvement in your research further by:

- providing access to a group of people affected by Parkinson's trained to work in partnership with researchers. These 'PPI volunteers' have an understanding of the research process and where they can contribute, and are keen to work with researchers to improve the quality and relevance of Parkinson's research
- providing some financial support for involving people affected by Parkinson's in your research

For information on how to apply for this support, contact [rsn@parkinsons.org.uk](mailto:rsn@parkinsons.org.uk)



### An interview with...

Mark Mikkelsen, Cardiff University

#### Tell us a little bit about your research

The main objective of our research is to investigate a new potential biomarker for Parkinson's: the neurotransmitter gamma-aminobutyric acid (GABA).

In our research group we measure GABA using magnetic resonance spectroscopy (MRS), which is an MRI technique that can quantify chemicals in the brain non-invasively. Our project involves investigating GABA's potential as a molecular biomarker for Parkinson's. After some methodological development, we aim to use our MRS techniques to measure GABA in the brains of those with Parkinson's and compare this to levels of GABA in those who do not have the condition.

#### At what stage/s have you involved people affected by Parkinson's in your work?

During the drafting stage of a grant application we met with a group of six people affected by Parkinson's to discuss our project. Specifically, we distributed draft copies of our application to the group who then gave us their feedback. We followed up with everyone after the event and continued a dialogue via email about how our application could be further improved. We foresee continuing our collaboration even after the submission of this particular grant application (eg, in other research that we are or will be conducting in the future).

#### How did you get access to people affected by Parkinson's?

We worked with the Parkinson's UK Research Support Network as part of their PPI pilot programme (see page 7).

#### What were your goals for involving people affected by Parkinson's and what impact did you feel it had on your research?

We primarily wanted to make sure that our proposed project was as relevant as possible for those affected by Parkinson's and that the scan session was appropriate.

The volunteers' feedback was immensely beneficial for drafting our application. Their involvement made our research aims more relevant for those affected by Parkinson's, both in the proposed outcomes of the study and in the methodological design.

Our experience of working with the volunteers was very positive. It gave us a whole new perspective of what clinical research is and what it should be about. The ability to involve members of the public who would benefit from the research in question has a number of advantages. It would be wonderful to see more researchers make use of this invaluable resource.

#### What advice would you give to other Parkinson's researchers thinking about PPI?

Firstly, it will without question benefit your research, at whatever stage you involve the lay perspective. We suggest you make the most of their involvement as, in our experience, PPI volunteers have a unique insight that researchers would hugely benefit from. Related to this, it would be better to start a longer term collaboration rather than a one-off bout of involvement. For example, if you're designing a study, it will likely take a few revisions before the proposal meets both your and your volunteers' standards.





## PPI case studies

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### An interview with...

Lorna Rixon, City University, London

#### Tell us a little bit about your research

The Parkinson's help project, which aims to encourage and empower people to seek help for non-motor symptoms, is an applied clinical research study with four phases.

Phase 1: People were screened for undeclared, burdensome non-motor symptoms and interviewed about the reasons why they had not sought help.

Phase 2: A large survey was disseminated to more than 300 people to test whether these reasons were significantly associated with not seeking help, and whether this reluctance to seek help was associated with the individual or with particular symptoms.

Phase 3: The results from phases 1 and 2 were used to develop a supportive intervention to encourage and empower help seeking.

Phase 4: A feasibility study will be conducted to examine the efficacy of the intervention.

#### At what stage/s have you involved people affected by Parkinson's in your work?

We adopted a person-centered approach and involved people affected by Parkinson's at every stage of the research process. Our project had an advisory group from the start. Through discussion and collaboration of the qualitative and quantitative findings from phases 1 and 2, a number of volunteers have been involved with developing and designing the structure, format and content of the intervention in phase 3.

#### What were your goals for involving people affected by Parkinson's and what impact did you feel it had on your research?

Our goal was to improve the acceptability and feasibility of the research design and methodological procedures used. However, during this process we formed a team and a number of working relationships that allowed us to surpass this goal.



The input of the people we involved has been invaluable in the developmental work. They brought their own ideas, had a clear understanding of the intervention techniques and provided feedback on the acceptability and feasibility of techniques that we have proposed.

#### How did you get access to people affected by Parkinson's?

We have had involvement from members of the Parkinson's UK Research Support Network and from the local hospital.

#### What advice would you give to other Parkinson's researchers thinking about PPI?

We would recommend involving a variety of volunteers with different experiences and access to a range of services and versatility in both the type (eg advisor and collaborator) and mode (eg. face-to-face, telephone or email) of involvement to gather perspectives from a range of people with different health and life circumstances.

This experience has been so positive that I would not only like to consult, but also collaborate with people affected by Parkinson's in all of my future research because of the different perspectives, skills and experience they contributed to the team.

## Ensuring your PPI is meaningful

We appreciate that scientific proposals are being modified right up until submission deadlines, and sometimes it can be difficult to see how and when you can involve people affected by Parkinson's in your research.

We know this is often why researchers approach PPI in a haphazard, rushed and last-minute way, making it less meaningful and valuable to the research.

Therefore, sometimes patients and carers who have become involved in research have described the experience as tokenistic, and that they do not feel they have had an impact.

To ensure the PPI in your research is both meaningful and valuable, while fitting in with the deadlines of your research, there are a number of key elements you can consider:

### Planning involvement

As early as possible when planning your research, think about the following questions.

- What, exactly, do you want from those getting involved – are you clear how this will influence your research?
- How many people affected by Parkinson's do you need?
- How are you going to budget for your PPI?
- What method of involvement would be most suitable for gathering this input – consultation and/or collaboration?
- Does it involve a focus group or event or will your interaction be over the phone or via email?

### Preparing for involvement

Once you know who you are going to involve and what you are going to do it's important to:

- communicate well which questions you would like them to answer and what you would like them to contribute
- be clear on the deadlines you'll need them to work to
- consider some of the practical issues associated with living with the condition and be sensitive to the needs of the people you are working with
- keep the communication channels open, and be consistent and reliable if those involved have questions
- be prepared to be flexible on the method of involvement if a difficult situation arises
- transcribe and record the outcomes of involvement carefully, and follow-up where necessary
- think about some of the challenges you might face in a meeting, such as keeping the discussion focused and ensuring everyone is heard
- feedback as much as possible to those who have been involved about the impact they have had
- always thank those who have been involved formally, such as with a letter, reinforcing the impact they have had

You can contact us directly for advice on planning involvement in your research, we're very happy to help wherever we can (see page 7).







## Further PPI resources

Read some examples of involving patients and carers in other health conditions which could be used in Parkinson's-related research.

- Providing the perspective of someone affected by Parkinson's in writing your grant application. <http://bit.ly/1JVf6yo>
- Advising you on study design and outcome measures from the perspective of someone living with a health condition. An example of a breast cancer study. <http://1.usa.gov/1JVf7IM>
- Helping you produce a robust plan for recruiting and retaining participants or joining your study steering group to ensure that you have the voice of people affected by Parkinson's in the management of the research. <http://bit.ly/1cZ3Ofz>

### How PPI can make an impact

Measuring the impact of PPI on research is complex. However, there are some great examples of the difference PPI can make to the quality of research studies.

- Exploring the impact of public involvement on the quality of research: examples. <http://bit.ly/1FkfLmk>

- Literature review – Exploring Impact: Public involvement in NHS, public health and social care research. <http://bit.ly/1JRCMoq>
- Find out how PPI is key to Sheffield University's work. <http://bit.ly/1FXFA2g>
- Read how Senior NIHR Researchers involved patients in their work. <http://bit.ly/1BoHwK5>

### INVOLVE

Funded by the NIHR, INVOLVE aims to support active public involvement in the NHS, public health and social care research. It is one of the few government funded programmes of its kind in the world.

We have highlighted several key INVOLVE resources below:

- Consultation and collaboration in the INVOLVE guidelines <http://bit.ly/1VILAE>
- Writing a lay summary <http://www.invo.org.uk/makeitclear>
- Budgeting for involvement <http://bit.ly/1elO8TK>



Every hour, someone in the UK is told they have Parkinson's – a brain condition that turns lives upside down, leaving a future full of uncertainty.

Parkinson's UK is here to make sure people have whatever they need to take back control – from information to inspiration.

We want everyone to get the best health and social care. So we bring professionals together to drive improvements that enable people to live life to the full.

Ultimately, we want to end Parkinson's. That's why we inspire and support the international research community to develop life-changing treatments, faster. And we won't stop until we find a cure.

**Together we can bring forward the day  
when no one fears Parkinson's.**

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Free confidential helpline **0808 800 0303**  
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