Parkinson's UK
For every Parkinson's journey

A researcher's toolkit

Staying connected with your participants

What’s the toolkit and why have we made it?

This toolkit is a basic framework, designed through extensive work and user testing, to help you keep your research participants updated.

Communicating with your participants is a requirement of the UK Policy Framework for Health and Social Care Research. We know this can be time consuming. That’s why we’ve developed this toolkit to make it easy for the research community to keep people who’ve taken part in research updated and engaged.

We’ve developed this toolkit as part of our Continuous Engagement project, which aims to improve communication with people after they’ve taken part in research. As part of the project we conducted a survey that found 80% of respondents would be more likely to take part in future research if they were kept up to date with the study progress.

Find the full results of the survey on the RSN Continuous Engagement poster.

We know that people would like to receive some form of communication from you or the research team every three months. The things people told us they would like to hear about are:

- more about the research study itself
- the time point the research has currently reached
- future plans for the research
- links to information about symptoms and useful support relevant to the research.

The participants would prefer to be kept up to date via email or on a website.

You’ve already created most of this information in your research application, so it should be easily available to you.

By preparing these documents and your communication plan prior to the start of your research, you’ll have everything ready to go to complete your ethics application.

> “
>
> **I do realise it is time consuming for the researchers to update the research participants, but if I do not get any feedback it makes me less likely to volunteer.**
>
> Continuous Engagement survey response
>
> ”

Who is this toolkit for?

This toolkit is for you; people who are designing, developing and undertaking research. It's been put together by a steering group of members of the Parkinson's community, healthcare professionals and research professionals.

The resources you create with these tools can also be used to inform your peers and other healthcare professionals on the progress of your research.

The toolkit will help you construct information that can be incorporated into your lay summary when your data has been collected and analysed. By creating short updates, you'll be completing your work as you go.

For guidance on writing in plain English, see the 'Plain English Campaign'. For examples of plain English summaries of research, see NIHR Evidence. We can also help you to improve the readability of your research summary, by involving people with Parkinson's. Find out more about our patient and public involvement support on our website.

The toolkit has been developed with the HRA (Health Research Authority) and RECs (Research Ethics Committees) and reflects accepted good practice for communicating with participants.

What's in the toolkit?

The toolkit consists of this guide as well as all the different templates and resources that you can use to communicate effectively with your participants. These are as follows:

1. Notecard template

The purpose of this notecard is to provide your participants with a simple explanation about your research, who to contact and where to look for more information. The template we have designed for you can be completed and provided to the participant either electronically or printed on durable card. We'd suggest printing it so your participants have something physical they can refer back to.

2. Last active visit template

This template should be given to your participant at their last active research visit, be it online or in person. You simply replace the red text on the template with information relevant to your study and either hand it to, email or post to your participant.

3. End of recruitment template

When you have recruited your last participant into your study, fill in this template and share it with all your research participants. The purpose of this template is to let your participants know what to expect from you next.

4. Newsletter template

This two-side A4 template should help you pull together an annual newsletter to keep your participants engaged. This asset can be emailed, shared on a website or posted.

We've suggested a layout, but we encourage you to include the following fields:

- Timelines of the study
- Recruitment numbers
- A photo of the research team
- Where the study is happening
- More about the research trial, such as a recap on its purpose, how the research fits into the bigger picture, what came before
- Future plans for the research
- Next communication steps.

5. Short updates template

These short updates are designed to help keep your participants engaged and feeling valued throughout their research experience. They can be created ahead of starting recruitment, be used as part of your lay summary and be relevant to other research projects. We've produced a simple template for you to use and examples of other short updates on topics that participants have said they would like to hear about. You can take inspiration from these for lay language and ideas in particular (rather than content). Once you've shared an update with your participants it can be used again at a later date. For more information about topics of interest for your participants, review our RSN Continuous Engagement poster.

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6. Communicating with participants via podcasts

We’ve put together this handy guide to help you create a podcast, or a series of podcasts, to communicate with your participants. A podcast is an audio file which is uploaded to the internet and can be downloaded to a variety of devices. Podcasts can be delivered as part of a series, based around a particular theme or as a stand alone session.

7. Communicating with participants online

This guidance is about how to use visual digital platforms such as Zoom and Microsoft Teams to engage with your participants. The aim is to give you more confidence to use these systems to share your research and make your participants feel valued.

> “People usually come up with excuses for not updating their participants but now they can’t. This is something to get people started.
>
> Chrystalina Antoniades”

When should the toolkit be used?

We've put together this communication plan, to help you to schedule when to send out your updates. The blue crosses represent time-specific assets and shouldn't be shared at any other time. All other assets can be shared when you feel appropriate, and we advise engaging with your participant at least every 3 months.

Key

X Time-specific, can't be shared at any other time than shown here.

X Flexible, share when you feel best.

	Time point								
	First study activity	Last individual study activity	Last participant recruited into study	3 months post last active study visit for 1st participant	6 months	9 months	1 year	Ongoing 3 month intervals until publication	Publication
Notecard	X								
Last active visit template		X							
End of recruitment template			X						
Short updates template				X	X	X		X	
Newsletter							X		X
Podcast/ online updates				X	X	X		X	
Lay summary									X

How should I use this kit?

We've outlined guidance for your updates, but feel free to use them in a way to best suit your participants. If you've done effective PPI (Patient and Public Involvement) and have a steering group, ask them to help you use the templates. These tools are designed to keep your recruited participants informed and engaged with your research in line with ethical requirements. They are not for participant recruitment.

All of the communications that you produce need to be written in lay language. Depending on the type of study you're conducting, this toolkit can be used in different ways:

Online questionnaires

- Share all tools digitally.
- If your research only requires a one-off participation activity, share the note card and last active visit template at the same time.
- If your research is anonymous and doesn't collect contact details of participants, at the end of their participation, provide the end of recruitment template in a downloadable format and state clearly where your final written report will be available on it.
- To give your participants the best research experience, provide a website link to further updates and information about your planned publication.

Online longitudinal or observational studies

- Collect email addresses from participants at the beginning of the study to make it easy to send updates.
- If there are large gaps in time between interactions with your participants in the active part of your research, use the short updates to keep your participants engaged.
- If possible, direct your participants to a website for updates.

Clinical trials or in person studies

- Sponsors should provide and support the content for ongoing updates with participants.
- Complete templates before the beginning of the study so you have a personalised information resource collection ready to be shared.
- Make the updates you share relevant to your participant in relation to your research aims, especially if you are introducing them to a new device or drug.
- Share information about the assessments that may have been experienced by the participants during the study and their relevance to your research.

Contact us

We always appreciate feedback about our products, so feel free to get in contact with us about your thoughts.

If you need extra help, we're here to support you with accessing the toolkit and linking with our Patient and Public Involvement (PPI) volunteers to produce communications that will make your participants feel appreciated and valued.

Get in touch with us via email at
participation@parkinsons.org.uk