Communicating online

How do I communicate with participants online?

Updates can be live or prerecorded depending on your aim for the session and how you'd like your participants to engage with it. They can also be oneway, by sharing information through a presentation or two-way, by creating a discussion. You can email a link to the update, or can you provide them with a link to a website where you'll host your information? From the data we collected, most people are happy to receive information via email.

Platforms that are currently available and have been used for this purpose are:

- Zoom
- Microsoft Teams
- Google Handouts
- Webex
- FaceTime
- Jitsi
- WhatsApp
- <u>LinkedIn</u>
- Facebook live
- Instagram

What are the benefits of creating online updates?

- · Engaging and simple.
- Personal and conversational.
- Keeps participants engaged with the research during and after the study which builds a solid research community.
- Can be used to introduce the team to participants
- Gives participants insight into the intricacies of running the study.
- Learning opportunities for research team members, particularly those who are newer to the research world and have less experience engaging with participants.
- As long as it doesn't include visuals of participants, you can keep the resource for future use. This makes keeping future research participants engaged quick and easy.

Who can create the online update?

Anyone can create an online update. It can be the sponsor or CI, or the research team at a centre. Use PPI and your steering group, to make it powered by people who have a link to the condition you're researching.

What are the benefits of creating online updates?

It's better to think about how you're going to communicate with your participants as early as possible. Not only is it a stipulation within your application but as discovered from our data, people are more likely to take part in research again if they have received effective and meaningful communication from the research team.

Aim to create your online updates when you're building your protocol. Scripting important bits of information that are valuable for you to share with external audiences will help you complete your IRAS form by demonstrating how you'll be feeding back to your participants.

If you're unable to produce your online update until your research is underway, don't worry. Participants will still be interested in hearing everything about the research, from where you have got to with recruitment, to when you think your research is going to be completed. Creating a short session to share this information shouldn't take you long at all.

Who can create the online update?

We recommend you share an update with your participants once every three months. If you're going to host your online update live, make sure you give your participants a couple of weeks notice. Previous examples of successful update sessions have been before data was published.

Who can create the online update?

Step 1: choose a title and a focus

Choosing the title for your update should be the first thing to think about. Similarly to creating a podcast, you need to hook your audience in and make it sound appealing.

When you're choosing the focus of the update, you need to remember your target audience and what they'd like to engage with. Ask some of your participants what they'd like to hear about during the life-span of the research project they're taking part in.

Refer to the results of the Parkinson's UK survey to give you ideas.

Make sure you and your study team, if they're working on the update with you, are comfortable sharing their knowledge about the chosen focus. Your update will come across to the audience in a more meaningful, engaging and natural way.

Step 2: decide the online update format and length

Your online update can be a stand alone session or part of a series. With any session, it's best not to exceed 45 minutes without a break. For a brief update you can have a session as short as three minutes, as long as you make sure it fulfills the purpose of engaging with your participants.

If you're doing your online updates as part of a series, it's best to find a linking theme that joins them together clearly for your audience.

Format your update to be as effective as possible by setting some questions that your participants may want answered in relation to your research.

By focusing your update on what your audience would like to know, you'll instantly make it more relatable. This will also give you the opportunity to identify who in your team may be best to share their knowledge. If you have a couple of people in the session, it's more engaging and helps share the workload.

Step 3: choosing the right platform

There are a whole host of different digital platforms that are now accessible to most people.

Pick the one that you're most comfortable with. And decide whether you'd like your update to be a one-way or two-way engagement.

You can also record updates in advance and host them on YouTube. A link to the recording can be shared with your participants via social media, or hosted as a link to a webpage.