



## **What the Beyond the Form team did:**

Workshop participants were asked about seven commonly used communication strategies. We explored what their experiences had been, and what they would recommend to those developing study protocols and budgets.

## **What we want YOU to do:**

Review the findings on the next few pages and think about how you have seen these strategies used, or what guidance you would need to use them in your work.

Every strategy won't be right for every study, but there are concrete ways we can make communication during clinical research easier.

At the end there is a link to a discussion board to share your thoughts with us and others in the sector.



## **Strategy 1: Having a dedicated contact person or phone number**

It's important that the person is professional and able to get answers to my questions

### **Participant experience:**

Participants wanted consistency in who they spoke to, and for that point of contact to be able find answers to any questions.

### **Suggestions for executing this strategy well:**

- Provide clear channels for participants to contact the research team, including a dedicated phone number for calls or texts.
- Ask participants about preferred means of contact and train staff to communicate with humanity and compassion.
- Provide guidance to staff about what can and can't be discussed with participants, so that they are empowered to discuss as much as possible.



Updates about how the study is going contribute to a sense of meaning and the importance of my contribution

## **Strategy 2: Sending updates about progress of the study**

### Participant experience:

These are particularly important for lengthy studies, or when it will be a long time between when the participant finishes and study results are released.

### Suggestions for executing this strategy well:

- Milestones for sending updates should be pre-set in discussion with consumers and site staff to develop a schedule that is feasible to implement and not overwhelming for participants.
- Updates could be about progress with recruitment or changes in staffing or sites if updates about interim results are not available.
- Updates should be formatted like a press release, with the key points in simple language up front.
- Possible formats include phone calls, texts/emails, newsletters, podcasts, presentations or workshops in the community



## Strategy 3: Sharing information about individual results

Participant experience:  
Should be an option where possible, but needs to include a clear summary and explanations of the information.

### Suggestions for executing this strategy well:

- Share clear expectations on what can or can't be shared with participants.
- Any graphics and wording of results should be co-designed with consumers. and discussion points shared with site staff.
- Format should be sharable with their health team

My way of conquering my fear is  
to seek knowledge

I really wanted something I  
could share with my family and  
my doctor



Information given needs to match people's ability to understand the science

## **Strategy 4: Share overall study results or outcomes**

Participant experience:  
Most workshop participants reported that they had never received these. They were consistently seen as a way of demonstrating respect.

### Suggestions for executing this strategy well:

- Set expectations on what will be shared, and when
- Having layered information will increase accessibility. This could be by having a plain language dot point summary followed by more detail, or sharing publications on request
- Negative results or future research on the topic are also useful for participants to know.
- Having the information in a format they can share with their care team is a way of increasing the translational impact of the study.



## **Strategy 5: Create opportunities for participants to improve their understanding of their health condition.**

Participant experience:  
Can be a powerful way to improve the overall research experience and  
improve recruitment to future studies.

### Suggestions for executing this strategy well:

- Ask consumer group about most relevant materials or experiences.
- Options include linking with existing materials or services, workshops for research participants, or presentations to related community groups (such as disability choirs)
- Connecting to these should be opt-in.

I was asked if I wanted to be connected to different resources relevant to my condition, which was really useful for me.



## **Strategy 6: Thank you cards and completion certificates**

Participant experience:  
Impactful if personalised, but need to consider carefully if they are right for the type of trial. Can be a retention activity

Suggestions for executing this strategy well:

- Discuss best timing and content for these with reference group, as they can come across as insensitive if poorly done
- Consider current participant circumstances before sending
- Could also be a thank you call or video recording, or include artwork from participants in the research

It's nice when they put the effort in to send something personally



## **Strategy 7: Including a support person in communications**

### Participant experience:

Support people may provide invaluable assistance with translating or simplifying language, health literacy, logistical or emotional support.

### Suggestions for executing this strategy well:

- Participant needs and preferences for support may change over the study, so this should be checked and contact list kept up to date.
- Consider the information needs of the support person as well.
- Should be opt-in

Anything that can provide carers with information, support and where to go to find help, is good to keep them in the loop about their loved ones, including their treatment or therapy teams.





## **What we want YOU to do:**

To share how you have seen these strategies used, or what guidance you would need to use them in your work, visit our feedback board:

[click here.](#)

## **What the Beyond the Form team will do:**

We will use all the feedback collected to create a toolkit tailored to the Australian clinical research sector. If you want to discuss this with us directly, please email [beyondtheform@ctiq.com.au](mailto:beyondtheform@ctiq.com.au)