**Communication with research participants who stop participating early – example text**

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**Introduction**

This document presents all the example text given in the more extensive guidance document: **Communication with research participants who stop participating early – Guidance for researchers.** It has been produced as a helpful resource, but should not be read in isolation; see the full guidance for more context on how we suggest the example text should be used.

Please note that, although the sections below have been developed in collaboration with patients, they specifically present *examples* rather than suggestions or recommendations, and should certainly be amended to suit the situation. The full guidance also contains additional topics to consider but without example text (either because there is too much variation in practice to present an example, or where writing study-specific text is expected to be straightforward so an example would be of limited value).

The full guidance can be accessed here: <https://ctru.leeds.ac.uk/communication-with-research-participants-who-stop-participating-early/>.

**Message of thanks and appreciation for having taken part**

Thank you again for choosing to take part in this study and for the time and effort you put into the study until now. By deciding to take part you have made an important contribution to improving the healthcare of patients like you in future.

**Losing contact (where applicable)**

Unfortunately, we have not been able to get in touch with you since **[date of last contact]** about your involvement in the **[study name]** study. We therefore assume that you have stopped taking part in the study for now. This means:

* You will no longer receive any study questionnaires
* You will no longer receive any invitations to any hospital visits for the study for now
* See below for what this means for the **[study payments]** you may still be owed

We hope you are doing as well as possible since your last involvement in the study. We would encourage you to contact your study doctor or nurse if you need anything from them, or to let them know how you are doing, if you are happy to do that. You can find their contact details **[below]**.

As you have not specifically said you want to stop all your contributions to this study, we may try again in future to contact you or the doctors looking after you, to see how you are doing. You can ask for us not to do any of these things at any time, if you want to. Please just get in touch with your study doctor or nurse **[add any alternative contact methods]** and we will make sure you and your doctors are not contacted again about your involvement in the study.

You can find out more about the ways we may try to get back in touch in the information sheet you got before you took part in this study. They are:

* If you do get back in touch with your study doctor or nurse and attend any routine hospital appointments, any relevant information from these appointments will still be used for the study.
* We may get in touch with your GP to find out how you are doing.
* We may try to get in touch with you again in future for the same reason.

**Summarising exactly how the participant’s participation has changed: “How has my participation in the [study] study changed?”**

This is our understanding of what is happening with your participation in the **[study name]** study now:

* You have stopped taking the study medication
* You will no longer be asked to complete any study questionnaires
* You won’t attend any more hospital visits specifically for the study
* You are still happy for relevant information about you from future routine healthcare appointments to be used for the study
* You are still happy for the information collected about you so far to be used for further research projects, as long as this is done in a way that means your identity is not shared with anyone outside the research team

If this does not look right, please contact your study doctor or nurse. Otherwise, we will assume that this information is correct.

Remember that there are some limits on completely ending all your involvement in the study. You can find more information about these in **[further information]** and in the information you were given before you agreed to take part in this study**.** The key points are:

* We need to keep the information that we have collected about you until now and use it in the study analysis.
* The **[biological samples]** that you kindly gave as part of this study have now been analysed, so it is no longer possible to destroy them.

We are legally required to collect information about certain side-effects from the study treatment, if you happen to experience these in future

**Further contact about the study: “Will I be contacted again about this study?”**

As you have stopped taking part in the study, we will not need to contact you about the study again unless we learn anything new about the treatment you have received that you might need to know. We will also make sure you find out the results of the study, if you want to know them.

**[Add anything else relevant to the study, for example if participants could still sign up to receive newsletters/updates about the study]**

Please remember to tell your study doctor or nurse (or your GP) if your contact details change or if you move home. If we have your updated contact details, we can still contact you if we need to, and we can share the results of the study with you when they are ready.

**Explaining why participation has stopped: “Why has my participation stopped?” (Where applicable)**

Throughout your time taking part in this study, the doctors looking after your care have been regularly checking that it is still safe for you to continue taking the study treatment. They will continue to make sure all your treatments are safe for you to take after you stop participating in the study, as well.

As you will have been told by your study doctor or nurse, unfortunately it is no longer the best option for you to continue taking the study treatment. This decision was not taken lightly, but was taken in the interests of your health and wellbeing. Do talk to your doctor or nurse about this if you have any questions or concerns.

This does not mean your involvement in the **[study]** study has to end completely, if you don’t want it to. See **[below]** for more about your choices and about what aspects of your participation will continue.

**Clarifying participants’ options in relation to their participation: “What are my choices now about my involvement in the [study] study?”**

You have the right to stop taking part in any aspect of this study at any time, and without giving a reason if you don’t want to give one. Any decision you make about this will not affect your standard of care.

This means you can stop all your involvement in the study if you want to, although remember that there are some limits on ‘undoing’ things that have already been done. We explained these to you before you agreed to take part in the study, and we have reminded you in this message, as well.

This also means that you might be able to make further contributions to the study without giving as much of your time, if you want to.

Specifically, this means:

* **[Add study-specific details about what ‘reduced’ participation might be possible]**

Your study doctor or nurse may have explained your options to you already, but feel free to get in touch with them using the contact details **[below]** if you want to hear more about this.

If you have already said you do not want to make any further contributions to the study, no one will ask you about this again.

Finally, it is up to you whether you want to receive updates about this study in future, including to find out the results of the study when they are available. See **[above section on future contact]** for more on this.

**Signpost to pre-study information sheet**

You may want to look again at the information sheet you were given before you agreed to take part in this study, as it contains some important information about stopping your involvement. If you don’t have a copy of that anymore, speak to your study doctor or nurse to get another one.

They will also be able to help you if you have further questions about any of the points here, or if you would like to discuss what stopping your participation in the **[study name]** study means for you.

**Reminding participants of the option to give a reason for their decisions: “Why might it be helpful to know why I wanted to stop taking part?”**

If you would like to give any general feedback about your experience taking part in the study, we would very much like to hear from you. Please see **[above]**.

You don’t have to give anyone a reason for stopping your involvement in this study. You may already have told your doctor or nurse why you wanted to stop taking part, or you may not want to do this. Either is completely fine.

However, as mentioned in the information you were given before you agreed to take part, it can be helpful for the study if you are happy to give a reason. This is because it can help the people analysing the study to understand the results of the study better. In particular, it is helpful to know if you stopping your involvement has anything to do with changes in your health. We would not need to know any more detail than that. It is completely up to you whether you want to share this information or not.

Feel free to contact your study doctor or nurse if you would like to tell them anything else about why you have decided to stop taking part in the study. Any information you give will be treated sensitively and confidentially.