**Communication with research participants who stop participating early – process summary and checklist**

**Version 1.0**

**22 April 2022**

**This project was funded by the National Institute for Health and Care Research (NIHR) CTU Support Funding scheme. The views expressed are those of the author(s) and not necessarily those of the NIHR or the Department of Health and Social Care.**

Contents

[**Introduction** 2](#_Toc101791233)

[**Process flow diagram** 3](#_Toc101791234)

[**Checklist: information to provide to research participants who stop taking part early** 5](#_Toc101791235)

**Introduction**

This short document summarises the practical guidance contained in the more extensive guidance: **Communication with research participants who stop participating early – guidance for researchers.** It has been produced as a simpler way to engage with that longer resource. The more detailed guidance should be consulted wherever needed to explain any of the brief points made here.

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

# **Process flow diagram**

# **Checklist: information to provide to research participants who stop taking part early**

|  |  |
| --- | --- |
| **Important new information about changing involvement in the study** | **Included in planned communication?** |
| Message of thanks and appreciation for having taken part |  |
| Losing contact (where applicable) |  |
| Summarising exactly how the participant’s participation has changed  *Example heading: “How has my participation in the [study] study changed?”* |  |
| Further contact about the study  *Example heading: “Will I be contacted again about this study?”* |  |
| Explaining why participation has stopped (Where applicable)  *Example heading: “Why has my participation stopped?”* |  |
| Information about study payments/incentives/vouchers  (May fit best with the information in this section, or in ‘other’ information, depending on the study) |  |
| Clarifying participants’ options in relation to their participation  *Example heading: “What are my choices now about my involvement in the [study] study?”* |  |
| **Important new information about post-study arrangements and the transition to these** | **Included in planned communication?** |
| Immediate arrangements after the study  *Example heading: “What needs to happen now that I have stopped taking part?”* |  |
| Arrangements for post-study care  *Example headings: “What will happen to my care now? Can I still access the study treatment? Might there be more side-effects in future?”* |  |
| Available support  *Example heading: “What support is available while I end my participation in the study?”* |  |
| **Important reminders and signposting** | **Included in planned communication?** |
| Signpost to pre-study information sheet |  |
| Reminder about what will happen to data already collected  *Example heading: “What will happen to the information you have collected about me?”* |  |
| Reminder about what will happen to biological samples already collected  *Example heading: “What will happen to the biological samples you have collected from me?”* |  |
| Possibility of finding out what treatment was received  (For ‘blinded’ studies where the participant and/or doctor do not know what treatment the participant is getting)  *Example heading: “Can I find out what treatment I have been receiving?”* |  |
| Availability of the overall study results  *Example heading: “When can I find out the results of the study? How can I find them out?”* |  |
| Availability of individual test results  *Example heading: “Can I find out my own test results from the study?”* |  |
| Complaints  *Example heading: “What if I have a complaint?”* |  |
| **Other information** | **Included in planned communication?** |
| Giving feedback on the study experience  *Example heading: “Can I give any feedback about my experience taking part in this study?”* |  |
| Reminding participants of the option to give a reason for their decisions  *Example heading: “Why might it be helpful to know why I wanted to stop taking part?”* |  |
| Possibility of research involvement  *Example heading: “Can I get involved in any other research, or help improve how research is done in future?”* |  |
| Current update on study status or other news about the study |  |
| Frequently asked questions |  |