

Supplementary Table 1. Results of the questionnaire to evaluate patient engagement

Question	Completely disagree	Disagree	Neutral	Agree	Completely agree
I feel part of the GCT research	2*	0	2	8	4
I would like to be more involved in the GCT research	0	1	1	7	7
The interaction with the research team helps me to better understand my disease	0	0	2	7	7
When I have a specific question about the research or GCT in general, I feel I can always approach the research team	0	1	4	9	1
The current GCT research encompasses the most relevant research questions	0	0	4	9	1
	Preparation	Execution	Implementa- tion	None/not applicable	
In which phase of research would you like to be involved (more answers may apply)	4	4	9	5	
	Auditor	Think along	Advisor	Partner	Initiator
Which role** would you like to fulfill in the GCT research (select one answer)	7	5	1	2	1

* The two respondents that do not feel part of the research, commented that their material is not (yet) used for study purposes.

** Auditor: someone is being informed, e.g. reading the research proposal.
 Think along: a patient is asked for her opinion, e.g. on study procedures and/or the patient information letter.
 Advisor: Advisory role, e.g. to give feedback on study questionnaires.
 Partner: the patient works together with the researchers, e.g. as co-writer of a research proposal.
 Initiator: the patient takes the initiative and is the driving force, e.g. when creating a website to share information on the research projects.