



## Informed Consent Form

### Study Title:

**Quantifying patient preferences in neuromuscular disorders.**

### Head of study:

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Principal Investigator  
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*Please read each of the following bullet points and if you agree with them all, please tick the box of consent.*

- ☐ I have read the information sheet version 2.0 (18/02/2020) regarding this study and I have had an opportunity to ask questions or discuss any concerns about it;
- ☐ I was given sufficient time to decide whether I am willing to participate in this study;
- ☐ I am aware that participating in this study is completely voluntary and deciding not taking part will not affect my current or future health care;
- ☐ I am aware that although I may be answering questions about medical products these responses will not lead to any change on my current health care nor to a drug prescription;
- ☐ I am aware that I can stop participating in this study at any time without affecting my current or future health care;
- ☐ I give permission for the researchers in the team to collect information about me as described in the information sheet version 2.0 (18/02/2020) and remove the types of identifiable data that will not be used for this study like my email account before analysing the data;
- ☐ I give permission for my personal information (i.e. Identifiable data) to be stored for maximum 15 years, and I am aware that I can request this to be deleted within 30 days after confirmation of receipt of my request; I'm aware that such a request may

not be fulfilled in case that deletion renders or seriously impairs the study objectives, or that regulations and laws that apply to this research require my personal data to be retained;

- ☐ I give permission for the information gathered for this study to be entered as coded (pseudonymized) data into a secure electronic database for analysis and give permission to share this coded data among the PREFER partners (EU and non-EU countries) following the standards established by the European General Data Protection Regulation (GDPR), national and local laws;
- ☐ I give permission that my coded data will be used to address future research questions by the PREFER partners following the standards established by the European General Data Protection Regulation (GDPR), national and local laws;
- ☐ I give permission that the study results can later be used for publications as well as educational purposes;
- ☐ I hereby confirm my consent with the points mentioned before and my voluntary participation in this project.

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Click here if you do

☐

Click here if you  
prefer not to participate and  
exit this survey now.

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