Clinical Practice/ Routine Monitoring Version Type 1 Gaucher Disease Patient Reported Outcome Measure (rmGD1-PROM)

PART 1: Please complete each of the questions by putting a checkmark (✓) in the box which matches your best answer

	None of the time	A little of the time	Some of the time	Most of the time	All of the time	Not applicable or prefer not to say
1 Over the past month, my Gaucher disease has restricted my education/job	☐	☐	☐	☐	☐	☐
2 Over the past month, my Gaucher disease has restricted my activities with friends	☐	☐	☐	☐	☐	☐
3 Over the past month, my Gaucher disease has restricted my ability to have intimate relationships with my spouse/partner	☐	☐	☐	☐	☐	☐
4 Over the past month, my Gaucher disease has restricted my ability to take part in hobbies and leisure activities	☐	☐	☐	☐	☐	☐
5 Over the past month, I have been concerned that I am an emotional burden to others because of my Gaucher disease	☐	☐	☐	☐	☐	☐
6 Because of my Gaucher disease, I am concerned I will be at risk of bone disease	☐	☐	☐	☐	☐	☐
7 Because of my Gaucher disease, I am concerned I will be at risk of cancers	☐	☐	☐	☐	☐	☐
8 Because of my Gaucher disease, I am concerned I will be at risk of Parkinson's disease	☐	☐	☐	☐	☐	☐
9 Because of my Gaucher disease, I am concerned I will be a financial burden	☐	☐	☐	☐	☐	☐

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	None of the time	A little of the time	Some of the time	Most of the time	All of the time	Not applicable or prefer not to say
10 I am concerned I will not get the best therapy because of budget issues	☐	☐	☐	☐	☐	☐
11 I am concerned I may not have an expert physician for advice in the future	☐	☐	☐	☐	☐	☐
12 My non-Gaucher problems are more concerning than the Gaucher concerns	☐	☐	☐	☐	☐	☐

	Strongly agree	Agree	Neither agree nor disagree	Most of the time	Disagree	Strongly disagree
13 Over the past month, my health in general has improved because of my Gaucher-specific medication	☐	☐	☐	☐	☐	☐
14 Over the past month, all of my medical concerns have been Gaucher-related	☐	☐	☐	☐	☐	☐
15 Over the past month, my current medication has treated my Gaucher-specific concerns	☐	☐	☐	☐	☐	☐

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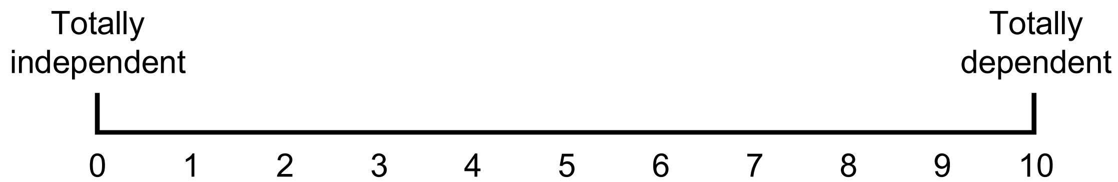
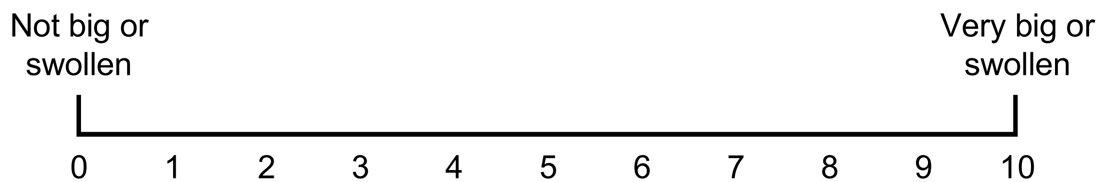
PART 2: Thinking about your Gaucher disease over the past week, please circle the number that is right for you

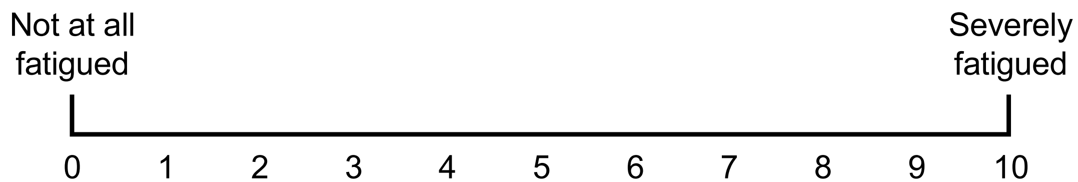
1. Over the past week, how **dependent** on others have you been because of your Gaucher disease?



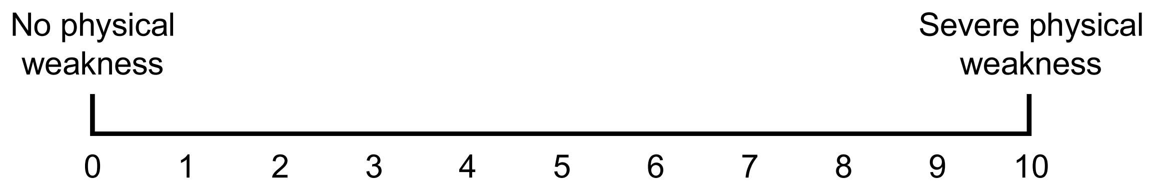
2. Over the past week, how **visibly big or swollen has your abdomen** looked because of your Gaucher disease?



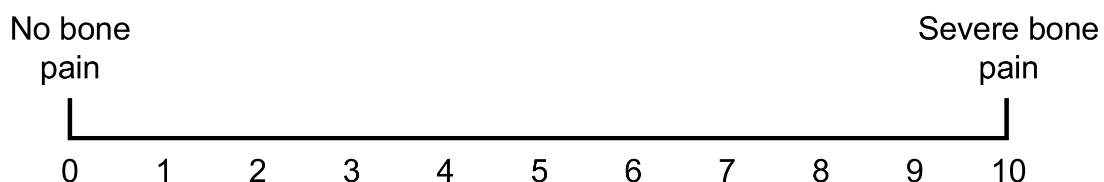
3. Over the past week, how **fatigued** have you been because of your Gaucher disease?



4. Over the past week, how **physically weak** have you been feeling because of your Gaucher disease?



5. Over the past week, how severe has your **bone pain** been because of your Gaucher disease?



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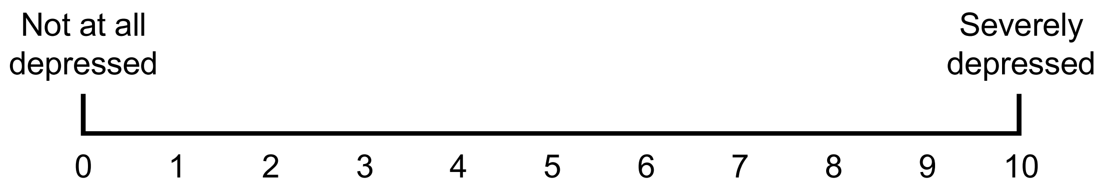
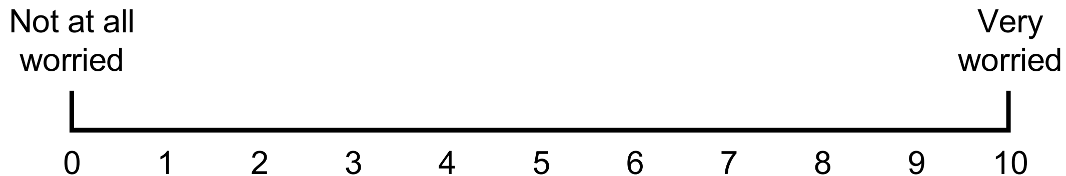
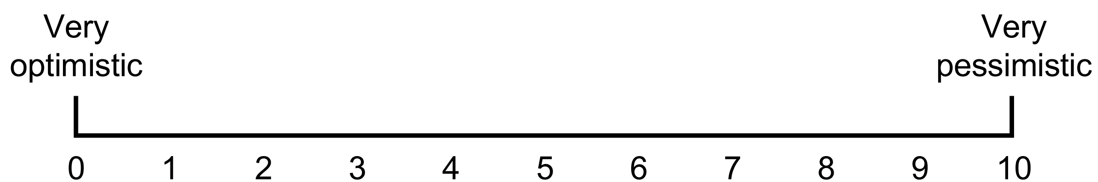
6. Over the past week, how **depressed** have you been because of your Gaucher disease?



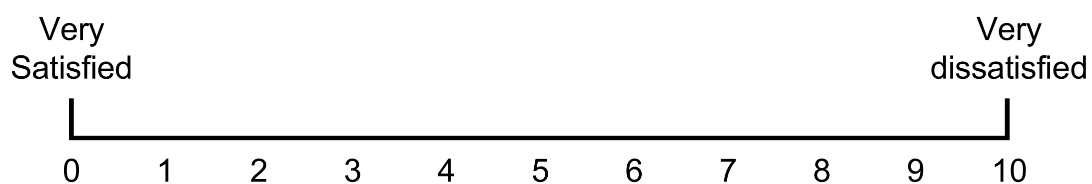
7. Over the past week, how **worried** have you been because of your Gaucher disease?



8. Over the past week, how have you felt about your **future** with Gaucher disease?



9. Over the past month, how **satisfied** have you been with your Gaucher medical treatment?



Thank you for completing this form

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