

# **A Collaborative Approach to Creating Knowledge-building Resources for the Early-stage Parkinson's Disease Community**

Soania Mathur<sup>1\*</sup>, Harold de Wit<sup>2\*</sup>, Becky Jones<sup>3</sup>, Evelyn Stevens<sup>4</sup>, Angels Costa<sup>5</sup>, Alexander Klein<sup>6</sup>, Kate Trenam<sup>7</sup>

<sup>1</sup>Patient expert, Toronto, Ontario, Canada; <sup>2</sup>Patient expert, Eindhoven, Netherlands; <sup>3</sup>Parkinson's UK, London, UK; <sup>4</sup>Parkinson's Foundation, New York, NY, USA; <sup>5</sup>Novartis, Barcelona, Spain; <sup>6</sup>UCB, Monheim, Germany; <sup>7</sup>UCB, Slough, UK

\*Joint lead authors

## **Corresponding author:**

Soania Mathur

Patient expert, Toronto, Ontario, Canada

## **ORCID IDs:**

Soania Mathur: 0000-0002-6224-7573

Becky Jones: 0000-0002-3924-0269

Angels Costa: 0009-0007-7926-1543

# Supplementary File 1

## Message testing and narrative creation: Disease modifying narrative in Parkinson's disease (Patients/caregivers) – 20 minutes

25 April 2023

### PROGRAMMING INSTRUCTIONS:

- All programming instructions are in this TEAL colour and do not need to appear in the survey. (Do not need translating)
- No need to show section headers in the survey, they are for identification purposes only
- Please place only one question per screen, except where indicated

### Quotas

|            | US | UK | Germany | Spain |
|------------|----|----|---------|-------|
| Patients   | 40 | 30 | 30      | 30    |
| Caregivers | 40 | 30 | 30      | 30    |

### Incentives

|                     | US     | UK        | Germany   | Spain     |
|---------------------|--------|-----------|-----------|-----------|
| Patients/caregivers | 14 USD | 11.60 GBP | 13.20 EUR | 13.20 EUR |

## Introduction

### C0. HIDDEN – AUTOFILL «Single code»

|   |         |
|---|---------|
| 1 | US      |
| 2 | UK      |
| 3 | Germany |
| 4 | Spain   |

---

---

## QINTRO1. SHOW ALL. TEXT

Thank you for agreeing to take part in this survey. Please use the link below to navigate through this questionnaire. Using the back button on your browser may cause you to exit the survey before the end.

The survey is being conducted by Lumanity, an independent market research agency on behalf of a pharmaceutical company, and we are interested in speaking with other people like yourself, living with Parkinson's or caregiving for someone who has been diagnosed with Parkinson's.

The purpose of this research is to gather feedback on some draft messages in development, relating to the future treatment of Parkinson's.

Please be assured that we act in accordance with **US**: Intellus Worldwide, **UK**: BHBIA (British Healthcare Business Intelligence Association), **ALL**: EphMRA (European Pharmaceutical Market Research Association), ESOMAR (European Society for Opinion and Marketing Research) guidelines. We comply with the **DE/ES**: European Data Protection Law/GDPR / **UK ONLY**: Data Protection Act 2018 / **US**: local privacy laws.

**ALL MARKETS EXCEPT DE**: You may, at any time, ask to know what personal data we hold about you and subsequently request your personal details to be amended or destroyed. Your privacy will be protected at all times unless you give specific permission to be identified. The personal data you provided when signing up to the panel (e.g. name, phone number, address) is stored by the fieldwork agency that invited you to this study. Full details of how they protect your data are available in their privacy policy which you can find in the email invitation you received from them.

**DE ONLY**: You may, at any time, ask what personal data we hold about you and request them to be amended or destroyed. Your privacy will be protected at all times. The personal data you provided when signing up to the panel (e.g. name, phone number, address) is stored by the agency that invited you to this study. Full details of how they protect your data are available in their privacy policy

Lumanity's privacy policy link here: <https://lumanity.com/privacy-policy/>.

---

### S1.1. ASK ALL. SINGLE CODE.

This study is being conducted on behalf of a pharmaceutical company and is strictly non-promotional. The company commissioning this research will not see any information regarding the identity of survey respondents. The survey will take approximately 20 minutes to complete.

Any information you disclose will be treated in the strictest confidence, with the exception noted below regarding the recording and reporting of adverse events, other additional safety information, and/or product quality complaints.

By entering the survey link you understand and agree to the following:

- The information I provide is for market research purposes only. The aggregated results (individual names will not be associated with answers) will be shared with the commissioning pharmaceutical company for analysis and in-house market understanding purposes only.
- By law, we are required to pass on to our client details of adverse events, other additional safety information and/or product quality complaints **[HYPERLINK ATTACHMENT 1 TO THE UNDERLINED TEXT]** that are mentioned during the course of market research. Should you raise an adverse event, other additional safety information and/or product quality complaint in a specific patient or group of patients, we are obliged to promptly report this even if it has already been reported by you directly to the company or to the regulatory authorities.

- **All countries except for DE:** In such a situation you will be asked whether or not you are willing to waive confidentiality in relation to that adverse event, safety information or product quality complaint. You have the right to remain anonymous and, if you choose not to provide your contact details, you will only be identified by role (e.g. nurse, physician, patient, etc.). Everything else you say during the course of the discussion will continue to remain confidential.
- **DE only:** In such a situation you will remain anonymous and will be identified only by role (e.g. nurse, physician, pharmacist, patient, consumer, etc.). If further information is necessary, additional questions will be provided by the company via an agency while retaining your confidentiality.

I confirm that I have been informed of the obligations for the collection and promptly reporting of any adverse events, other additional safety information and/or product quality complaints related to the client's product that are noted by me during the course of this research, and I confirm my agreement to proceed on this basis.

|   |     |                        |
|---|-----|------------------------|
| 1 | Yes | <b>CONTINUE</b>        |
| 2 | No  | <b>THANK AND CLOSE</b> |

---

### S1.2. ASK ALL. SINGLE CODE.

The questions, concepts and any materials shown as part of this market research are strictly confidential, and not to be shared further. Do you agree to keep it confidential?

|   |     |                        |
|---|-----|------------------------|
| 1 | Yes | <b>CONTINUE</b>        |
| 2 | No  | <b>THANK AND CLOSE</b> |

---

### S1.3. ASK ALL. SINGLE CODE.

Do you have any affiliations with any pharmaceutical company (including as a paid consultant), other than for clinical trial purposes?

*Please select one option only.*

|   |     |                        |
|---|-----|------------------------|
| 1 | Yes | <b>THANK AND CLOSE</b> |
| 2 | No  | <b>CONTINUE</b>        |

---

### S1.4. ASK ALL. SINGLE CODE.

Have you participated in any advisory boards to develop messaging on future therapies in the area of Parkinson's in the last 6 months?

*Please select one option only.*

|   |     |                        |
|---|-----|------------------------|
| 1 | Yes | <b>THANK AND CLOSE</b> |
| 2 | No  | <b>CONTINUE</b>        |

---

## Screeners

### S2.1. ASK ALL. SINGLE CODE

Please could you confirm which of the following statements best describes your personal situation?

*Please select one option.*

|   |                                                                         |                 |
|---|-------------------------------------------------------------------------|-----------------|
| 1 | I have been diagnosed with Parkinson's disease by a doctor              | CONTINUE        |
| 2 | I am the main caregiver for a person diagnosed with Parkinson's disease | CONTINUE        |
| 3 | None of these statements describes my situation                         | THANK AND CLOSE |

### S2.2. ASK ALL. NUMERIC. RANGE 0-60

For how many years have you (or the person you care for) been diagnosed with Parkinson's disease?

*Please write the number of years in the box below.*

|                 |                              |
|-----------------|------------------------------|
| [       ] years | THANK AND CLOSE IF > 2 YEARS |
|-----------------|------------------------------|

### S2.3. ASK ALL. MULTICODE

What, if any, treatments do you (or the person you care for) currently take for Parkinson's disease?

*Please select all that apply.*

|    |                                                                           |          |
|----|---------------------------------------------------------------------------|----------|
|    | <b>Oral therapies (tablet, capsule, liquid) or skin patch</b>             |          |
|    | <b>Levodopa</b>                                                           |          |
| 1  | Co-beneldopa (Madopar)                                                    | CONTINUE |
| 2  | Co-careldopa (Apodespan, Caramet, Lecado, Sinemet)                        | CONTINUE |
|    | <b>Dopamine agonists</b>                                                  |          |
| 3  | Pramiprexole (Miraprexin, Pipexus, Glepark, Oprymea, Zentiva)             | CONTINUE |
| 4  | Ropinirole (Adartel, Ralnea, Requip, Spiroco, Ipinnia, Raponer, Ropilynz) | CONTINUE |
| 5  | Rotigotine (Neupro)                                                       | CONTINUE |
|    | <b>Monoamine oxidase-B (MAO-B) inhibitors</b>                             |          |
| 6  | Rasagiline (Azilect)                                                      | CONTINUE |
| 7  | Selegiline (Eldepryl, Zelapar)                                            | CONTINUE |
| 8  | Safinamide (Xadago)                                                       | CONTINUE |
|    | <b>Catechol-O-methyltransferase (COMT) inhibitors</b>                     |          |
| 9  | Entacapone (Comtess)                                                      | CONTINUE |
| 10 | Co-careldopa and entacapone (Stalevo, Sastravi, Stanek)                   | CONTINUE |
| 11 | Tolcapone (Tasmar)                                                        | CONTINUE |
| 12 | Opicapone (Ongentys)                                                      | CONTINUE |
|    | <b>Non-oral therapies</b>                                                 |          |
|    | <b>Apomorphine (dopamine agonist by injection or infusion pump)</b>       |          |

|    |                                                                        |                                            |
|----|------------------------------------------------------------------------|--------------------------------------------|
| 13 | Apo-go                                                                 | THANK AND CLOSE                            |
| 14 | Dacepton                                                               | THANK AND CLOSE                            |
|    | <b>Other</b>                                                           |                                            |
| 15 | Duodopa (via external pump)                                            | THANK AND CLOSE                            |
| 16 | Deep brain stimulation (DBS)                                           | THANK AND CLOSE                            |
| 17 | Other                                                                  | THANK AND CLOSE IF ONLY THIS CODE SELECTED |
| 18 | Currently not taking any treatment for Parkinson's<br><b>EXCLUSIVE</b> | CONTINUE                                   |

#### S2.4. ASK ALL. SINGLE CODE.

Thinking about your Parkinson's disease symptoms (or the symptoms the person you care for experiences), do you (or they) ever experience 'off time'?

'Off-time' is when you feel like your current therapy is not controlling your symptoms.

*Please select one option.*

|   |     |                 |
|---|-----|-----------------|
| 1 | Yes | THANK AND CLOSE |
| 2 | No  | CONTINUE        |

#### S2.5. ASK ALL. NUMERICAL. RANGE 0-100

What is your age?

|                 |                                 |
|-----------------|---------------------------------|
| [ _____ ] years | THANK AND CLOSE IF < 18 OR > 80 |
|-----------------|---------------------------------|

#### SCREENOUT1 – TEXT – SHOW ALL WHO SCREENOUT

Thank you for your willingness to participate. Unfortunately, you do not qualify for this particular survey at this time. We hope you will consider us for future surveys.

#### OVERQUOTA – TEXT – SHOW ALL WHO ARE OVERQUOTA

Thank you for your willingness to participate. Unfortunately, the total number of participants for this survey is currently met. We will re-contact you if the survey re-opens.

# Main questionnaire

## 1. CURRENT KNOWLEDGE

**OBJECTIVE:** To assess their level of knowledge and current perceptions around disease-modifying therapies

---

### Q1.1. UK, DE, ES ONLY. SINGLE CODE.

In order to comply with the European Data Protection Regulations (GDPR) we are required to reveal the name of the healthcare/pharmaceutical company sponsoring this market research project. We will only reveal the name of the healthcare/pharmaceutical company at the end of the interview, just in case knowing this biases any responses.

Is this acceptable to you?

|   |     |
|---|-----|
| 1 | Yes |
| 2 | No  |

---

### QINTRO2 / SHOW ALL

Thank you. You are eligible to answer this survey. When you go to the next screen, you will be taken to the remainder of the survey which is about 20 minutes long.

Please answer as completely and as frankly as you can. There are no wrong answers; we are only interested in your thoughts.

The questionnaire is to be completed now, and in one sitting. However, if for any reason you are interrupted (e.g. connection failure), you will be able to restart the questionnaire where you left it by clicking back onto your invitation message link.

**[IF CODE 2 AT Q1.1: The sponsor of this research is UCB.]**

Let's proceed.

---

### QINTRO3 / SHOW ALL

You will be asked to review a set of messages that explain the concept behind a new type of treatment being developed for Parkinson's.

These messages have been developed for people living with Parkinson's and caregivers like yourself.

We are only interested in your opinions, this is **not** meant to be promotional or influence your behavior. The information you see may not be in its final form and will be used for market research purposes only. For the purpose of this market research only, please consider all the information as true and accurate.

Please proceed.

---

### Q1.2 / ASK ALL / 1-7 SLIDER / RANDOMISE ROWS

Before you see the messages, we would like to ask you a few questions to understand your current thoughts and feelings about Parkinson's.

You will now be shown several pairs of opposing statements. Please review them carefully. Then using the sliding scale, position the slider between each of the statements in a given pair which best reflects your opinion.

|   |                                                                            | 1 | 2 | 3 | 4 | 5 | 6 | 7 |                                                                                |
|---|----------------------------------------------------------------------------|---|---|---|---|---|---|---|--------------------------------------------------------------------------------|
| 1 | I have not come to terms with my Parkinson's diagnosis                     |   |   |   |   |   |   |   | I have come to accept my Parkinson's diagnosis                                 |
| 2 | I choose to conceal my Parkinson's diagnosis from others                   |   |   |   |   |   |   |   | I am open about my Parkinson's diagnosis with others                           |
| 3 | My relationships and social interactions have been impacted by Parkinson's |   |   |   |   |   |   |   | My relationships and social interactions have not been impacted by Parkinson's |
| 4 | I am not comfortable engaging with information about future long term care |   |   |   |   |   |   |   | I am comfortable engaging with information about future long term care         |

---

### Q1.3 / ASK ALL / 1-7 SLIDER / SINGLE CHOICE PER STATEMENT

Thank you. We'd now like to ask for your opinion on some statements that relate to the progression of Parkinson's and how it's treated. You are going to be shown 4 statements and we would like to understand your level of agreement with each.

Please indicate the extent to which you agree with the following statements on a scale of 1 to 7, where 1 = "strongly disagree", 4 = "neither agree nor disagree", and 7 = "strongly agree".

|   |                                                                                                                                                     | Strongly disagree |   |   | Neither agree nor disagree |   |   | Strongly agree |
|---|-----------------------------------------------------------------------------------------------------------------------------------------------------|-------------------|---|---|----------------------------|---|---|----------------|
|   |                                                                                                                                                     | 1                 | 2 | 3 | 4                          | 5 | 6 | 7              |
| 1 | I feel well informed about Parkinson's and how symptoms might progress in the future                                                                |                   |   |   |                            |   |   |                |
| 2 | There is a need for treatments that do more than treat the symptoms of Parkinson's                                                                  |                   |   |   |                            |   |   |                |
| 3 | I am motivated by the idea of a treatment that could slow down progression of Parkinson's                                                           |                   |   |   |                            |   |   |                |
| 4 | If there was a safe and effective treatment available that could slow down progression of Parkinson's, I would want to start it as soon as possible |                   |   |   |                            |   |   |                |

---

## 2. OVERALL IMPACT

**OBJECTIVE: Determine which messages or combination of message elements would create the most motivating to use**

---

### **Q2.1 / ASK ALL / RANK / SHOW ALL MESSAGES IN EACH BUCKET / RANDOMIZE ORDER OF MESSAGES WITHIN BUCKET**

You will now be shown a number of messages that are related to a new type of treatment in Parkinson's, called **disease modifying therapy**. The aim of the messages is to explain what disease modifying therapy is to people like yourself, in a way that is clear and motivating.

Below are the messages regarding **[BUCKET X]**.

Please rank the messages below that you believe explain the concept best and create the most clear and motivating story.

*Please select rank 1 for the most preferred message, rank 2 for the next preferred message, etc.*

**PLEASE REFER TO APPENDIX 2 FOR MESSAGES**

**REPEAT QUESTION Q2.1 PER BUCKET**

**ROTATE ORDER OF BUCKETS BETWEEN RESPONDENTS**

---

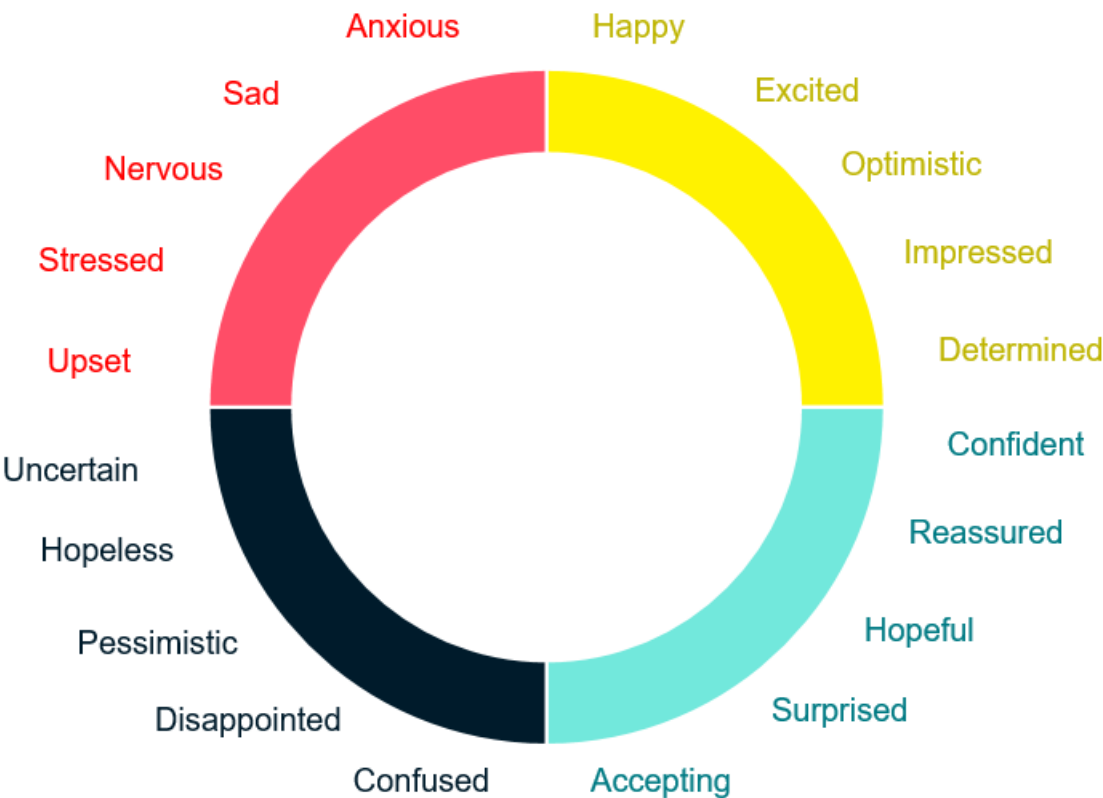
### 3. EMOTIONAL RESONANCE

**OBJECTIVE:** Determine emotional impact of the chosen messages

**Q3.1 / ASK ALL / SHOW TOP 2 MESSAGES FROM Q2.1 / SINGLE CHOICE PER ROW AS A DROPDOWN / RANDOMIZE ORDER OF MESSAGES WITHIN BUCKET**

Below are your top 2 chosen messages regarding [BUCKET X].

Please pick an emotion from the wheel which best describes your **first reaction** when you think about the following messages to explain disease-modifying drugs in Parkinson's.



*Please select one emotion per message.*

|   |           |                             |
|---|-----------|-----------------------------|
| 1 | Message 1 | LIST OF EMOTIONS FROM WHEEL |
| 2 | Message 2 | LIST OF EMOTIONS FROM WHEEL |

**PLEASE REFER TO APPENDIX 2 FOR MESSAGES**

**REPEAT QUESTION Q3.1 PER BUCKET**

**ROTATE ORDER OF BUCKETS BETWEEN RESPONDENTS**

## 4. HIGHLIGHTER TOOL EXERCISE

**OBJECTIVE:** To determine which part(s) / word(s) of each message is considered positive, negative or unclear to ensure an optimal understanding of the messages that will be included in the final communication

---

### Q4.1 / ASK ALL / HIGHLIGHTER TOOL / SHOW ALL MESSAGES IN EACH BUCKET

Now, looking at the messages again, we would like you to think about how they have been written / formulated. Please highlight specific parts which you find positive, negative or unclear / confusing using the 3 different colors:

- **Green for any positive elements**
- **Red for any negative elements**
- **Orange for anything that is unclear or confusing**

Below are the messages regarding **BUCKET X**.

**PLEASE REFER TO APPENDIX 2 FOR MESSAGES**

---

**REPEAT QUESTION Q4.1 PER BUCKET**

**ROTATE ORDER OF BUCKETS BETWEEN RESPONDENTS**

---

## 5. RATIONAL RESPONSE - KEY PERFORMANCE INDICATORS (KPIs)

**OBJECTIVE:** Determine how well the chosen messages perform on the chosen KPIs

---

### QINTRO4 / SHOW ALL

Thank you for your responses so far.

In the next set of questions, we will ask you about your top choices of messages within each category.

The first category is [\[BUCKET X\]](#).

**PLEASE REFER TO APPENDIX 2 FOR MESSAGES**

**ROTATE ORDER OF BUCKETS BETWEEN RESPONDENTS**

---

### Q5.1 / ASK ALL / 1-7 SLIDER / SHOW TOP 2 MESSAGES FROM Q2.1 / SINGLE CHOICE PER ROW / RANDOMIZE ORDER OF MESSAGES WITHIN BUCKET

Rate each message on the extent to which it is clear, i.e. the message is clear and easy to understand for you.

*Please rate this message on a scale of 1-7, where 1 = Not at all, 4 = Somewhat and 7 = Extremely.*

|   |                           | Not at all |   |   | Somewhat |   |   | Extremely |
|---|---------------------------|------------|---|---|----------|---|---|-----------|
|   |                           | 1          | 2 | 3 | 4        | 5 | 6 | 7         |
| 1 | <a href="#">Message 1</a> |            |   |   |          |   |   |           |
| 2 | <a href="#">Message 2</a> |            |   |   |          |   |   |           |

---

### Q5.2 / ASK ALL / 1-7 SLIDER / SHOW TOP 2 MESSAGES FROM Q2.1 / SINGLE CHOICE PER ROW / RANDOMIZE ORDER OF MESSAGES WITHIN BUCKET

Rate each message on the extent to which it is credible, i.e. the language sounds trustworthy and believable to you.

*Please rate this message on a scale of 1-7, where 1 = Not at all, 4 = Somewhat and 7 = Extremely.*

|   |                           | Not at all |   |   | Somewhat |   |   | Extremely |
|---|---------------------------|------------|---|---|----------|---|---|-----------|
|   |                           | 1          | 2 | 3 | 4        | 5 | 6 | 7         |
| 1 | <a href="#">Message 1</a> |            |   |   |          |   |   |           |
| 2 | <a href="#">Message 2</a> |            |   |   |          |   |   |           |

---

### Q5.3 / ASK ALL / 1-7 SLIDER / SHOW TOP 2 MESSAGES FROM Q2.1 / SINGLE CHOICE PER ROW / RANDOMIZE ORDER OF MESSAGES WITHIN BUCKET

Rate each message on the extent to which it is relevant, i.e. the information in the message is appropriate for you as someone living with Parkinson's or for the person you care for.

Please rate this message on a scale of 1-7, where 1 = Not at all, 4 = Somewhat and 7 = Extremely.

|   |           | Not at all |   |   | Somewhat |   |   | Extremely |
|---|-----------|------------|---|---|----------|---|---|-----------|
|   |           | 1          | 2 | 3 | 4        | 5 | 6 | 7         |
| 1 | Message 1 |            |   |   |          |   |   |           |
| 2 | Message 2 |            |   |   |          |   |   |           |

---

**Q5.4 / ASK ALL / 1-7 SLIDER / SHOW TOP 2 MESSAGES FROM Q2.1 / SINGLE CHOICE PER ROW / RANDOMIZE ORDER OF MESSAGES WITHIN BUCKET**

Rate each message on the extent to which it is **motivating**, i.e. the message leaves you feeling motivated to talk to your doctor about this treatment idea.

Please rate this message on a scale of 1-7, where 1 = Not at all, 4 = Somewhat and 7 = Extremely.

|   |           | Not at all |   |   | Somewhat |   |   | Extremely |
|---|-----------|------------|---|---|----------|---|---|-----------|
|   |           | 1          | 2 | 3 | 4        | 5 | 6 | 7         |
| 1 | Message 1 |            |   |   |          |   |   |           |
| 2 | Message 2 |            |   |   |          |   |   |           |

---

**Q5.5 / ASK ALL / 1-7 SLIDER / SHOW TOP 2 MESSAGES FROM Q2.1 / SINGLE CHOICE PER ROW / RANDOMIZE ORDER OF MESSAGES WITHIN BUCKET**

Rate each message on the extent to which it **shifts thinking in a positive way**, i.e. the message has changed your thoughts on disease-modifying therapies and what they could mean for you as someone living with Parkinson's or for the person you care for.

Please rate this message on a scale of 1-7, where 1 = Not at all, 4 = Somewhat and 7 = Extremely.

|   |           | Not at all |   |   | Somewhat |   |   | Extremely |
|---|-----------|------------|---|---|----------|---|---|-----------|
|   |           | 1          | 2 | 3 | 4        | 5 | 6 | 7         |
| 1 | Message 1 |            |   |   |          |   |   |           |
| 2 | Message 2 |            |   |   |          |   |   |           |

---

**QINTRO5 / SHOW ALL**

Thank you.

The next category is **[BUCKET X]**.

---

**REPEAT QUESTIONS Q5.1-5.5 PER BUCKET**

**DO NOT SHOW QINTRO5 IN THE LAST BUCKET**

## 6. STORY CREATION

**OBJECTIVE: To determine a compelling story about disease-modifying drugs in Parkinson's disease**

---

**Q6.1 / ASK ALL / SHOW TOP MESSAGE PER BUCKET / RANGE 0-100 / AT LEAST ONE ANSWER MUST BE 100 / RANDOMIZE ORDER OF MESSAGES WITHIN BUCKET**

Thank you for your responses so far.

Below are the top messages you selected for each category. We would like to understand which of these messages are the most important in explaining the concept of disease-modifying therapies in Parkinson's.

Please give the most important message a score of **100** and rank the other messages relative to that.

*For example, if a message is only half as important, give it a score of 50. If you think that the messages have an equal importance, they can be given the same score. If the message is not important at all, it can be given a score of 0, but the score of 0 does not need to be given if not necessary.*

|   |                                           |           |
|---|-------------------------------------------|-----------|
| 1 | TOP MESSAGES FROM EACH BUCKET, RANDOMIZED | [ _____ ] |
| 2 |                                           | [ _____ ] |
| 3 |                                           | [ _____ ] |
| 4 |                                           | [ _____ ] |
| 5 |                                           | [ _____ ] |

---

**Q6.2 / ASK ALL / SINGLE CHOICE /**

Below is a story from the top messages you selected:

**TOP MESSAGES FROM BUCKETS 1-5 IN ORDER (I.E. SHOW BUCKET 1 FIRST – BUCKET 5 LAST), 1 PARAGRAPH PER MESSAGE**

How well does this story explain the concept of disease-modifying therapies in Parkinson's?

*Please select one option.*

|   |                 |
|---|-----------------|
| 1 | Very well       |
| 2 | Well            |
| 3 | Neutral         |
| 4 | Not that well   |
| 5 | Not well at all |

---

### Q6.3 / ASK ALL / SINGLE CHOICE /

Is there anything you would change in this story, in terms of its order or the length?

*Please select one option.*

|   |     |
|---|-----|
| 1 | Yes |
| 2 | No  |

---

### Q6.4 / IF YES TO Q6.3 / DRAG AND DROP / RANDOMISE ORDER OF MESSAGES

We now would like to focus on how you would organize these messages into a story, to explain disease-modifying therapies in Parkinson's to someone who has never heard of them.

Please drag and drop the statements into the order you believe builds the most clear and motivating story about disease-modifying therapies in Parkinson's.

*Please drag and drop the themes/ categories in the order that you believe builds the most clear and motivating story*

| Story creation                                                                                                                  |                                |                                                                                                                                                    |
|---------------------------------------------------------------------------------------------------------------------------------|--------------------------------|----------------------------------------------------------------------------------------------------------------------------------------------------|
| Messages                                                                                                                        | Order                          |                                                                                                                                                    |
| <b>List of messages selected at Q2.1 as <u>rank 1 &amp; rank 2</u></b><br><br><b>SPLIT EACH MESSAGE TO INDIVIDUAL SENTENCES</b> | <b>First position in story</b> | Allow respondent to drag messages to a box on the right, which has a scale on the side from "First position in story" to "Last position in story". |
|                                                                                                                                 | <b>Box to drop to</b>          |                                                                                                                                                    |
|                                                                                                                                 | <b>Box to drop to</b>          |                                                                                                                                                    |
|                                                                                                                                 | <b>Box to drop to</b>          |                                                                                                                                                    |
|                                                                                                                                 | <b>Box to drop to</b>          |                                                                                                                                                    |
|                                                                                                                                 | <b>Last position in story</b>  | NEED TO DRAG AT LEAST 5 MESSAGES                                                                                                                   |

---

### Q6.5 / ASK ALL / SINGLE CHOICE

Thank you. We would now like to get your feedback on some alternative wording options. You will be shown 5 messages again, which may or may not have been the top messages you selected.

We would like you to review the message below and consider which version of the wording in red you find most clear.

**MESSAGE 1A:** Parkinson's is a condition where cells in certain parts of the brain **die OR deteriorate OR breakdown** over time.

Please indicate which wording is the most clear in this message.

*Please select one option.*

|   |                              |
|---|------------------------------|
| 1 | Die                          |
| 2 | Deteriorate                  |
| 3 | Breakdown                    |
| 4 | Other, please specify (____) |

---

#### Q6.6 / ASK ALL / SINGLE CHOICE

We would like you to review the message below and consider which version of the wording in red you find most clear.

**MESSAGE 3C:** Disease modifying therapies (DMTs) are a new approach to the treatment of Parkinson's that aim to target the underlying **biology OR cause** of the condition

Please indicate which wording is the most clear in this message.

*Please select one option.*

|   |                              |
|---|------------------------------|
| 1 | Biology                      |
| 2 | Cause                        |
| 3 | Other, please specify (____) |

---

#### Q6.7 / ASK ALL / SINGLE CHOICE

We would like you to review the message below and consider which version of the wording in red you find most clear.

**MESSAGE 3C:** Disease modifying therapies (DMTs) slow down the death of **brain cells OR neurons OR brain cells (called neurons)** and delay the worsening of symptoms

Please indicate which wording is the most clear in this message.

*Please select one option.*

|   |                              |
|---|------------------------------|
| 1 | Brain cells                  |
| 2 | Neurons                      |
| 3 | Brain cells (called neurons) |
| 4 | Other, please specify (____) |

---

#### Q6.8 / ASK ALL / SINGLE CHOICE

We would like you to review the message below and consider which version of the wording in red you find most clear.

**MESSAGE 4B:** Scientific research is important to grow understanding in Parkinson's and to develop new treatments. Clinical trials are important to test how well these new treatments work, and so taking part in clinical trials **could help people with Parkinson's in the future OR could help you contribute to the wider Parkinson's community.**

Please indicate which wording is the most clear in this message.

*Please select one option.*

|   |                                                              |
|---|--------------------------------------------------------------|
| 1 | Could help people with Parkinson's in the future             |
| 2 | Could help you contribute to the wider Parkinson's community |
| 3 | Other, please specify (____)                                 |

---

#### Q6.9 / ASK ALL / SINGLE CHOICE

We would like you to review the message below and consider which version of the wording in red you find most clear.

**MESSAGE 5C:** Disease modifying therapies could help people living with Parkinson's enjoy **time OR quality time** with their loved ones for longer.

Please indicate which wording is the most clear in this message.

*Please select one option.*

|   |                              |
|---|------------------------------|
| 1 | Time                         |
| 2 | Quality time                 |
| 3 | Other, please specify (____) |

---

## 7. CLOSING QUESTIONS

### Q7.1/ ASK ALL / 1-7 SLIDER / SINGLE CHOICE PER STATEMENT

Thank you. We would like to now revisit the statements that you reacted to at the beginning of the survey. Having now reviewed the messages on disease-modifying therapies, we would like to understand whether your level of agreement with each statement has changed.

Please indicate the extent to which you agree with the following statements on a scale of 1 to 7, where 1 = “strongly disagree”, 4 = “neither agree nor disagree”, and 7 = “strongly agree”.

Your previous answers were: [SHOW ANSWERS](#)

|   |                                                                                                                                                     | Strongly disagree |   |   | Neither agree nor disagree |   |   | Strongly agree |
|---|-----------------------------------------------------------------------------------------------------------------------------------------------------|-------------------|---|---|----------------------------|---|---|----------------|
|   |                                                                                                                                                     | 1                 | 2 | 3 | 4                          | 5 | 6 | 7              |
| 1 | I feel well informed about Parkinson's and how symptoms might progress in the future                                                                |                   |   |   |                            |   |   |                |
| 2 | There is a need for treatments that do more than treat the symptoms of Parkinson's                                                                  |                   |   |   |                            |   |   |                |
| 3 | I am motivated by the idea of a treatment that could slow down progression of Parkinson's                                                           |                   |   |   |                            |   |   |                |
| 4 | If there was a safe and effective treatment available that could slow down progression of Parkinson's, I would want to start it as soon as possible |                   |   |   |                            |   |   |                |

---

### Q7.2 / ASK ALL / SINGLE CHOICE

Would you be willing to be re-contacted in the future, if we have any clarifications or further questions?

*Please select one option only.*

|   |     |
|---|-----|
| 1 | Yes |
| 2 | No  |

---

### QCLOSE1 / SHOW ALL

Thank you for participating in this study. Your contribution is greatly appreciated.

**[IF CODE 1 AT Q1.1: The sponsor of this research was UCB.]**

## APPENDIX

### ATTACHMENT 1

| Term                                | Definitions                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                         |
|-------------------------------------|---------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------|
| <b>Adverse Event</b>                | Any untoward medical occurrence in a patient or clinical-trial subject administered a medicinal product and which does not necessarily have to have a causal relationship with this treatment. An adverse event can therefore be any unfavorable and unintended sign (e.g. an abnormal laboratory finding), symptom, or disease temporally associated with the use of a medicinal product, whether or not considered related to the medicinal product.                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                              |
| <b>Adverse Reaction</b>             | A response to a medicinal product which is noxious and unintended. Response in this context means that a causal relationship between a medicinal product and an adverse event is at least a reasonable possibility.                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                 |
| <b>Product Complaint</b>            | <p>A Product Complaint is any verbal, written or electronic expression of dissatisfaction with the product's identity, quality, stability, reliability, safety, effectiveness, performance or usage. More specifically, a Product Complaint can either be a:</p> <ul style="list-style-type: none"><li>• Product Quality Complaint (PQC): A Product Complaint regarding suspected defective products or suspicion of counterfeiting.</li><li>• Medical Complaint (MC): A Product Complaint linked to the efficacy and/or safety of the product (e.g. efficacy: lack/loss of effect; safety: adverse event).</li></ul>                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                               |
| <b>Special Reporting Situations</b> | Those situations in which information must be collected, whether or not there is an associated adverse event/adverse reaction. These include 1) use during pregnancy (i.e. drug exposure to a fetus in utero, whether the fetus is exposed via the mother taking the product or transmission via semen following paternal exposure), 2) exposure to a drug during breast-feeding/lactation, 3) overdose (whether intentional, accidental or prescribed), 4) drug abuse or misuse, 5) medication errors (including dispensing errors, accidental exposure, maladministration, etc.), 6) unapproved or off-label use (i.e. intentional medical use of a product not in accordance with the authorized product information), 7) lack of therapeutic effect/lack of efficacy, 8) withdrawal reactions / rebound effects, 9) exacerbation of existing disease, 10) suspected use of counterfeit/ falsified medicines/tampering, 11) drug-drug / drug-food interactions, 12) suspected transmission of an infectious agent via a medicinal product, 13) occupational exposure (as a result of one's professional or non-professional occupation), 14) unexpected benefit. |

## APPENDIX 2 – MESSAGES TESTED

| <b>Pillar 1: DISEASE &amp; UNMET NEED</b> |                                                                                                                                                                                                                                                                                                                                                                                                                                                             |
|-------------------------------------------|-------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------|
| <b>1A</b>                                 | Parkinson's is a condition where cells in certain parts of the brain die over time. Living with Parkinson's brings challenges and affects everyone differently. The uncertainty of the condition can mean that people with Parkinson's often avoid thinking about the future.                                                                                                                                                                               |
| <b>1B</b>                                 | Parkinson's is a condition where neurons, which are cells in your brain, die over time. Current treatments can help manage the symptoms of Parkinson's, but they don't stop Parkinson's from getting worse. Living with Parkinson's brings challenges and affects everyone differently. People with Parkinson's may find that they take each day as it comes and focus on maintaining their current quality of life, rather than thinking about the future. |
| <b>1C</b>                                 | Parkinson's is a condition where brain cells in certain parts of the brain die, and it gets worse over time. Treatments for Parkinson's have not changed much in                                                                                                                                                                                                                                                                                            |

|                                           |                                                                                                                                                                                                                                                                                                                                                                       |
|-------------------------------------------|-----------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------|
|                                           | <p>decades, but research is ongoing. Living with Parkinson's brings challenges and affects everyone differently.</p> <p>People with Parkinson's often want to find ways to feel more in control of their future.</p>                                                                                                                                                  |
| <b>1D</b>                                 | <p>Parkinson's disease is a disorder that primarily affects the brain's ability to control movement. While current treatments offer symptomatic relief, there remains an unmet need for therapies that can slow the progression of disease and improve the quality of life of people affected by Parkinson's.</p>                                                     |
| <b>Pillar 2: CURRENT TREATMENT</b>        |                                                                                                                                                                                                                                                                                                                                                                       |
| <b>2A</b>                                 | <p>Current Parkinson's treatments work by helping to control the signs of Parkinson's. They do not rescue or slow brain cell death, and as this continues over time, Parkinson's gradually gets worse.</p>                                                                                                                                                            |
| <b>2B</b>                                 | <p>In Parkinson's, brain cells that make dopamine are affected. Current Parkinson's treatments work by increasing the amount of dopamine in the brain. This helps to control symptoms in the short term. As brain cells continue to die, increasing the amount of dopamine becomes less effective at controlling symptoms, and over time, Parkinson's gets worse.</p> |
| <b>2C</b>                                 | <p>Current treatments help to control the motor symptoms, such as tremors and stiffness, but not the underlying cause of Parkinson's. As the disease further progresses and the brain cells, called neurons, continue to die, symptoms become less responsive to treatments which then become more severe over time.</p>                                              |
| <b>Pillar 3: DISEASE MODIFICATION</b>     |                                                                                                                                                                                                                                                                                                                                                                       |
| <b>3A</b>                                 | <p>Disease modifying therapies (DMTs) are potential treatments that aim to tackle the causes of brain cell death and slow the progression of Parkinson's.</p>                                                                                                                                                                                                         |
| <b>3B</b>                                 | <p>Disease modifying therapies (DMTs) are a new approach to the treatment of Parkinson's. DMTs slow down the death of brain cells, while your other treatments work on managing symptoms.</p>                                                                                                                                                                         |
| <b>3C</b>                                 | <p>Disease modifying therapies (DMTs) are a new approach to the treatment of Parkinson's that aim to target the underlying biology of the condition. DMTs slow down the death of brain cells and delay the worsening of symptoms.</p>                                                                                                                                 |
| <b>3D</b>                                 | <p>Disease modifying therapies (DMTs) are potential treatments that aim to maintain your quality of life for longer, by protecting the brain cells that Parkinson's affects.</p>                                                                                                                                                                                      |
| <b>Pillar 4: THE FUTURE OF PD THERAPY</b> |                                                                                                                                                                                                                                                                                                                                                                       |
| <b>4A</b>                                 | <p>Before new treatments can be given to people with Parkinson's, scientists spend years researching and developing them. Once new treatments are developed, clinical trials are important to confirm that they work and won't be unsafe for</p>                                                                                                                      |

|                        |                                                                                                                                                                                                                                                                        |
|------------------------|------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------|
|                        | people to take. Taking part in clinical trials could help propel research towards a potential new treatment for Parkinson's in the future.                                                                                                                             |
| <b>4B</b>              | Scientific research is important to grow understanding in Parkinson's and to develop new treatments. Clinical trials are important to test how well these new treatments work, and so taking part in clinical trials could help people with Parkinson's in the future. |
| <b>Pillar 5: VALUE</b> |                                                                                                                                                                                                                                                                        |
| <b>5A</b>              | Disease modifying therapies bring hope to the Parkinson's community.                                                                                                                                                                                                   |
| <b>5B</b>              | Disease modifying therapies could help people living with Parkinson's think about the future with more certainty.                                                                                                                                                      |
| <b>5C</b>              | Disease modifying therapies could help people living with Parkinson's enjoy time with their loved ones for longer.                                                                                                                                                     |
| <b>5D</b>              | Disease modifying therapies could provide people living with Parkinson's a way to feel more in control of their future.                                                                                                                                                |
| <b>5E</b>              | Disease modifying therapies could help people living with Parkinson's stay independent for longer, providing more freedom to live as they choose.                                                                                                                      |