**Round 3: Developing digital tools to support young people with a long-term health condition**

**[The following text and questions will be presented as an online questionnaire using Qualtrics. Comments in square brackets will not be visible to the participants. New text for this round is highlighted in blue. Choices removed are in yellow]**

Thank you for your continued participation – we really appreciate your help.

The third round of questions is very similar to the second round but shorter again. We have provided a summary of the results from the second round before each question so you can see what all the participants thought as a group.

We are hoping to reach an agreement among most of the participants as to which emotional themes, technologies and support you think are most important. This is so that we know what to focus on in the future.

Please read the summaries and the questions carefully because they have changed slightly.

If you have any questions or there is anything that you do not understand, please email Jennie: jennie.brown.2@city.ac.uk

**[Demographic questions (Section title for our use)]**

We need to know a little bit about you again because the answers are anonymous. The information you provide will not be shared outside of the project.

**Please select which category best describes you:**

1. I am a young person with a long-term health condition
2. I am the parent/guardian of a young person with a long-term health condition
3. I am a health professional

**[Then only the appropriate question set will show up depending on the answer to the first question…]**

**[If young person**….]

1. Which long-term health condition/s do you have?

Asthma, diabetes, epilepsy, other long-term health condition (please describe) – allow to select multiple

**[If parent…]**

The following questions are about your child/children with a long-term health condition.

1. Which long-term health condition/s does your child have? (Asthma, diabetes, epilepsy, other long-term health condition (please describe) – allow to select multiple)

**[If health professional…]**

1. Please select which role is closest to your profession:

Paediatrician, Paediatric nurse, School nurse, Paediatric psychologist, Paediatric psychiatrist, Teacher, Youth worker, Social worker, Other, please describe…

1. If relevant, which long-term health condition/s do you specialise in? (Asthma, diabetes, epilepsy, other long-term condition or specialisation (please specify), no specialisation or not relevant) – option to pick more than one

**Question 1**

**This question asked about psychological or emotional themes that young people with a long-term health condition may experience.**

**In round two:**

* **48% of participants chose anxiety as their first or second most important theme**
* **39% chose dealing with unsupportive adults as first or second most important**
* **26% chose depression as first or second most important**
* **19% chose wanting to appear ‘normal’ as first or second most important**

**Question 1**

**This time we are asking the same question again, but with less options to rank.**

**Below you will find a list of psychological or emotional themes that young people with a long-term health condition may experience. Please order them according to how important you think they are by clicking and dragging the phrases up and down the list. The most important should be at the top and the least important at the bottom.**

|  |  |
| --- | --- |
|  | **[New presentation order (randomised) and response choice]** |
| 1 | Wanting to appear ‘normal’ and the same as your friends/peers |
| 2 | Anxiety (feeling worried or afraid on most days of the week) |
| 3 | Depression (feeling very sad on most days of the week) |
| 4 | Dealing with unsupportive adults (e.g., teachers who don’t understand or believe my symptoms) |

**[Removed from R2 as <10% chosen as first rank:**

|  |
| --- |
| Worry about the future (e.g., the possibility of future health issues for yourself) |
| Denial of having the condition (believing you do not have the condition when you have been told by health professionals that you have it) |
| Lack of control over symptoms or being unable to predict symptoms |
| Lack of confidence in yourself |
| Issues to do with exercise/sports e.g., worrying about symptoms getting worse with exercise |
| Issues to do with eating e.g., overeating or keeping to a healthy diet |
| Stress |
| Anger |

**Question 3**

**This question asked about technologies we could use for our future study.**

**In round two:**

* **85% of participants chose an app as the first or second most important or useful**
* **52% chose something that measures your body as first or second**
* **28% chose VR as first or second**

**Question 3**

**This time we are asking the same question again, but with less options to rank.**

**Below you will find a list of technologies we could use for our future study. Please order them according to how important or useful you think they are by clicking and dragging the phrases up and down the list. The most important should be at the top and the least important at the bottom.**

|  |  |
| --- | --- |
|  | **[Presentation order (randomised) and response choice]** |
| **1** | An app on your phone |
| **2** | VR (virtual reality) headsets (e.g., used as a distraction to reduce pain) |
| **3** | Something that measures your body (e.g., your heart beat) and can send you a message. For example, a smart watch that sends you a message with some relaxation exercises if your heart is beating fast. |

[Removed from R2 as <10% as first choice: Video games, Emails or websites with links to videos, quizzes, games and other online activities, a website for information]

**Question 4**

**This question asked about emotional wellbeing support we could develop in the future.**

**In round two:**

* **58% of participants thought that education or training for school staff and students would be the first or second most important or useful**
* **48% chose general counselling as first or second**
* **26% chose peer support as first or second**

**Question 4**

**This time we are asking the same question again, but with less options to rank.**

**Below you will find a list of emotional wellbeing support we could develop in the future. Please order them according to how important or useful you think they are by clicking and dragging the phrases up and down the list. The most important should be at the top and the least important at the bottom.**

|  |  |
| --- | --- |
| **#** | **[New presentation order (randomised) and response choice]** |
| 1 | General counselling (talking to a trained counsellor or therapist about issues) |
| 2 | Support from peers or friends |
| 3 | Education or training for school staff and students about long-term conditions |

**[Removed the following as <10% chosen as first or second:**

|  |  |  |
| --- | --- | --- |
| 5 | Changing unhelpful thoughts and behaviours into more helpful ones (Cognitive Behavioural Therapy) | |
| 3 | Supporting all the family (Family therapy) | |
| Focusing on the present moment (Mindfulness) | |
| Relaxation and deep breathing exercises | |
| Working out what is important and how to do more of it (Acceptance and Commitment Therapy) | |
| Things to change behaviours, such as diet or sleep (Behavioural Therapies) | |

**[Voucher question]**

**[Then the following question displays for young people and parents only…]**

**Would you like to receive a £10 voucher for completing the questionnaire?**

**If you tick 'yes' this will take you to another page to enter your email address. Your email address will not be linked to your answers.**

**Please note that:**

* **Vouchers are not sent out automatically (they will be sent via email)**
* **All vouchers will be added together from each round and paid at the end of the study.**
* **You will get £10 for each round of questions you complete.**

Yes [Takes participant to another survey where email address is captured separately]

No [Takes participant to the end or if they do not answer this question then also goes to the end]

**[End of survey message]**

This is the end of the questionnaire. Your responses have been recorded.

Thank you so much for taking part - we appreciate your help.

We may need to do another round of questions - if so, Jennie will contact you again.

If you have any further questions please contact Jennie, email: jennie.brown.2@city.ac.uk

You can now close this window.