**Round 2: 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 second round of questions is very similar to the first round but even shorter. We have provided a summary of the results from the first 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.

Please read the summaries and the questions carefully because there are new options to rank in each list of choices. We have added new options based on the additional suggestions you had in the first round.

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**

**Summary of results for question 1 in the first round:**

**This question asked about psychological or emotional themes that young people with a long-term health condition may experience. In round one, 26% of participants ranked anxiety as their first choice for being most important, followed by depression (16% chose this first) and wanting to appear ‘normal’ and the same as your friends/peers (16% chose this first).**

**Question 1**

**This is the same question for round 2, but the choices of themes have changed slightly based on your feedback.**

**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.**

|  |  |
| --- | --- |
|  | **[Presentation order (randomised) and response choice]** |
| 1 | Dealing with unsupportive adults (e.g., teachers who don’t understand or believe my symptoms) |
| 2 | Anxiety (feeling worried or afraid on most days of the week) |
| 3 | Depression (feeling very sad on most days of the week) |
| 4 | Worry about the future (e.g., the possibility of future health issues for yourself) |
| 5 | Denial of having the condition (believing you do not have the condition when you have been told  by health professionals that you have it) |
| 6 | Lack of control over symptoms or being unable to predict symptoms |
| 7 | Lack of confidence in yourself |
| 8 | Issues to do with exercise/sports e.g., worrying about symptoms getting worse with exercise |
| 9 | Issues to do with eating e.g., overeating or keeping to a healthy diet |
| 10 | Stress |
| 11 | Wanting to appear ‘normal’ and the same as your friends/peers |
| 12 | Anger |

**[Removed: Fear of side effects, poor sleep and fear of social situations because they had <10% chosen as first, second or third]**

**Question 2**

**Summary from the first round:**

**Most participants (75%) suggested that a mix of one to one and group support would be the best way to help young people with long-term health conditions improve their emotional wellbeing. We reached agreement so do not need to ask the question again for round 2.**

**Question 3**

**Summary of results for question 3 in the first round:**

**This question asked about technologies we could use for our future study. 61% of participants thought that an app would be the most important or useful, followed by something that measures your body (14% chose this first) and a website for information (9% chose this first).**

**Question 3**

**In this round, we are asking the same question again.**

**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.**

|  |
| --- |
| A website for information |
| An app on your phone |
| Emails or websites with links to videos, quizzes, games and other online activities |
| VR (virtual reality) headsets (e.g., used as a distraction to reduce pain) |
| Video games |
| 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. |

**Question 4**

**Summary of results for question 4 in the first round:**

**This question asked about emotional wellbeing support we could develop in the future. 50% of participants thought that a combination of any of the support types would be the most important or useful, followed by changing unhelpful thoughts and behaviours into more helpful ones (18% chose this first) and then things to change behaviours, such as diet or sleep (13% chose this first).**

**Question 4**

**This is the same question for round 2, but the choices of support types have changed slightly based on your feedback. We have removed the option for a combination of support types because we now want to find out which specific types of support you think would be helpful.**

**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.**

|  |  |
| --- | --- |
| **#** | **[Presentation order (randomised) and response choice]** |
| 1 | Education or training for school staff and students about long-term conditions |
| 2 | General counselling (talking to a trained counsellor or therapist about issues) |
| 3 | Focusing on the present moment (Mindfulness) |
| 4 | Supporting all the family (Family therapy) |
| 5 | Support from peers or friends |
| 6 | Relaxation and deep breathing exercises |
| 7 | Working out what is important and how to do more of it (Acceptance and Commitment Therapy) |
| 8 | Things to change behaviours, such as diet or sleep (Behavioural Therapies) |
| 9 | Changing unhelpful thoughts and behaviours into more helpful ones (Cognitive Behavioural Therapy) |

**[Removed ‘combination of any of these’]**

**[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 in June.**
* **If you complete one round you will get £10, if you complete two rounds you will get £20 and if you complete all three rounds you will get £30.**

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.

Jennie will be in contact about the final (third) round of questions – this will be even shorter.

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

You can now close this window.