**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]**

Living with a long-term physical health condition, like asthma, diabetes, or epilepsy can sometimes be difficult. The purpose of the study is to explore which parts of living with a long-term condition young people (10-18 years old) would most like support with and what types of technology we might use to provide that support.

**Agreeing to take part**

Please tick the buttons below each statement to confirm that you have understood, and you agree to take part. If you no longer want to take part, then simply close this screen.

I have read and understood the participant information sheet about the study that was emailed to me, and if I had questions, the answers given were clear.

* I understand

If I am 10 to 15 years old, I have asked permission from a parent or guardian before taking part. If I am 16 years or older, I do not have to ask anyone for permission. (Please tick, even if you are over 16).

* I understand and have asked permission if needed.

I understand that taking part in the study is voluntary and that I can stop or withdraw from the study at any time and without giving a reason why. If you do withdraw from the study, there will be no disadvantage to you.

* I understand and agree to take part

If you have ticked each of the buttons above, you can now click on the arrow below and go to the survey. At the end of each question there will be arrows at the bottom of the page to go forwards and backwards.

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 would be grateful if you could tell us a little bit about who you are. 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

1. How long have you had this long-term health condition? (Less than 1 year, 1 to 2 years, 3 to 5 years, 6 to 10 years, More than 10 years, My whole life)
2. How old are you? (Select option from 10 – 18 years old)
3. Which of the following best describes your gender identity? (Female, Male, Non-binary, Let me describe…, prefer not to say)

**[If parent…]**

The following questions are about your child with a long-term health condition. If you have more than one child aged 10-18 with a long-term health condition, there is a box at the end to add their details.

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)
2. For how long has your child had this long-term health condition? (Less than 1 year, 1 to 2 years, 3 to 5 years, 6 to 10 years, More than 10 years, For their whole life)
3. How old is your child with a long-term health condition?
4. Which of the following most accurately describes your child’s gender identity? (Female, Male, Non-binary, Let me describe…, prefer not to say)

If you have more than one child aged 10-18 with a long-term health condition, please describe their details in the box below. We would like to know which long-term health condition/s they have and for how long, their age and gender identity. You can leave out any details you do not want to share.

**[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
2. How long have you been working in this role? (Less than 1 year, 1 to 2 years, 2 to 5 years, 5 to 10 years, More than 10 years)

**Question 1**

**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.**

|  |
| --- |
| Anxiety (feeling worried or afraid on most days of the week) |
| Depression (feeling very sad on most days of the week) |
| Denial of having the condition (believing you do not have the condition when you have been told by health professionals that you have it) |
| Fear of possible medication side effects (side effects are consequences of the medication that are not always nice) |
| Dealing with unsupportive adults (grown-ups who don’t understand) |
| Wanting to appear ‘normal’ and the same as your friends/peers |
| Poor sleep |
| A fear of social situations |
| Worry about the future (e.g., the possibility of future health issues for yourself) |
| Lack of confidence in yourself |

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| **Please use the box below to write any comments you have on the list above. For example, why do you think the themes you put at the top of the list are important?**  **If you have no comments, then please leave this blank.** |
|  |
| **Please use the box below to tell us if there are any other psychological or emotional themes (not listed above) that young people with a long-term health condition may experience.**  **If you have no comments, then please leave this blank.** |
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**Question 2**

**Which would be the best way to help young people with long-term health conditions improve their emotional wellbeing? (Please choose one)**

1. Group support with other young people who have a long-term condition
2. One to one support (e.g., with a therapist or other health professional)
3. A mix of one to one and group support

**Question 3**

**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. |

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| **Please use the box below to write any comments you have on the list of technologies above. For example, why do you think the technologies you put at the top of the list are important?**  **If you have no comments, then please leave this blank.** |
|  |
| **Please use the box below to tell us if there are any other technologies (not listed above) that young people with a long-term health condition may experience or want to use.**  **If you have no comments, then please leave this blank.** |
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**Question 4**

**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.**

|  |
| --- |
| Changing unhelpful thoughts and behaviours into more helpful ones (Cognitive Behavioural Therapy) |
| Things to change behaviours, such as diet or sleep (Behavioural Therapies) |
| Relaxation and focusing on the present moment (Mindfulness) |
| Working out what is important and how to do more of it (Acceptance and Commitment Therapy) |
| Supporting all the family (Family therapy) |
| General counselling (talking to a trained counsellor or therapist about issues) |
| Combination of any of these |

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| **Please use the box below to write any comments you have on the list of support above. For example, why do you think the types of support you put at the top of the list are important?**  **If you have no comments, then please leave this blank.** |
|  |
| **Please use the box below to tell us if there are any other types of support (not listed above) that young people with a long-term health condition may experience or want to access.**  **If you have no comments, then please leave this blank.** |
|  |

**[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.**

* 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.

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

You can now close this window.