

## COVID-19 impact on families taking part in the EPICC-ID study

Thank you for taking the time to take part in our survey. It is really very much appreciated during this very busy period. **The survey is intended to find out how the pandemic has affected you, your family and the health and social care you have been receiving.**

To make our work practically useful, we are especially interested in what is being done to manage these impacts, both in the **NHS** and the **voluntary sector**, and in what is working well and what less well.

We are writing to you because you have taken part in the EPICC-ID study based at University College London. We run the clinical trial of the Stepping Stones Triple P in North and South London and the North East and North West of England.

The survey should take around **15 to 20 minutes** to complete (depending how much you write in the open-ended questions) and the responses you provide are fully confidential. To help us better understand the impact of COVID-19 on health care over time, we ask if you are willing to give your email address, so that we can contact you later for some further data collection. You can complete the survey without leaving your email address if you wish. We ask which region you are based in.

As well as sharing our overall findings with policy makers and study participants, we plan to disseminate it as widely as possible to those likely to be able to make use of the information. We will therefore share our findings on the internet and via social media, as well as publishing in scientific journals. However, the **data will be kept fully confidential**, and no publications will include any information that could allow you to be identified. We are also developing a page of [helpful resources](#), and will add to this as information comes in via this survey and other sources.

The survey has been developed using [UCL Opinio](#) and is hosted on UCL Information Services Division infrastructure. The responses you provide are therefore not processed by any third parties. This study has been approved by [NAME OF REC]. If you have any queries, please contact Prof Angela Hassiotis Chief Investigator of the trial (a.hassiotis@ucl.ac.uk) or Dr Rachel Royston (r.royston@ucl.ac.uk).

Finally, we would like to take this opportunity to thank you for your support of our study especially under these difficult times.

**By clicking on the 'Start' button below, you confirm you have read and understood all of the above text.**

## Demographics

So that we can better understand who has replied to the survey please tell us your:

### **Gender**

- Male
- Female
- Other
- Prefer not to say

### **Age**

- Under 25
- 25 - 34
- 35 - 44
- 45 - 54
- 55 - 64
- 65 or over
- Prefer not to say

### **Ethnic group**

- White – British
- White – Irish
- White – Any other White background
- Mixed – White & Black Caribbean
- Mixed – White & Black African
- Mixed – White & Asian
- Asian or Asian British – Indian
- Asian or Asian British – Pakistani
- Asian or Asian British – Any other Asian background
- Black or Black British – Caribbean
- Black or Black British – African
- Black or Black British – Any other Black background
- Other Ethnic Groups – Chinese
- Prefer not to say
- Other Ethnic Group – Please specify

**Other than your child, are you caring for any elderly or disabled relatives or friends?**

Yes

No

**Which best describes your current situation?**

Sick or self-isolating

Working from home

Mixture of workplace and working from home

Mainly based at workplace

Not at work

**Do you think you have had COVID-19 infection?**

Yes, confirmed

Yes, suspected

No, not suspected

**Do you think anyone in your household has had COVID-19 infection?**

Yes, confirmed

Yes, suspected

No, not suspected

**Work setting and population**

**Which area do you live in?**

North London

South London

North East England

North West England

**Do you work for any of the following:**

- NHS
- Education
- Social care or other local government
- Voluntary sector
- Community or user-led organisations
- Other (please describe)

**Do you use any of the settings below in ordinary circumstances (please select all that apply)**

Services offering one-to-one mental health care in the community, e.g. community mental health teams of all types, out-patient services, psychological treatment services,

Individual Placement and Support services, voluntary services and any other non-crisis services that mainly provide one-to-one contacts

Services providing day or drop in services, parent support services, employment or activity services, other community programmes?

Child minders, nursery, school

Respite services

Other (please describe)

**Which best describes the locality in which you live?**

City or town with a population greater than 100,000

Town with a population less than 100,000

Rural

**Current work and social challenges**

**How relevant has each of the following been to you since mid-March 2020?** Rate from Not very relevant to Extremely relevant. Please try to give a range of scores so that we can see which are the biggest problems

Work:

**Greater workload than usual**

Not relevant   Slightly   Moderately   Very   Extremely relevant

**Working longer hours than usual**

Not relevant   Slightly   Moderately   Very   Extremely relevant

**The risk I or my family could be infected with COVID-19 due to work**

Not relevant   Slightly   Moderately   Very   Extremely relevant

**Having to adapt too quickly to new ways of working**

Not relevant   Slightly   Moderately   Very   Extremely relevant

**Having to learn to use new technologies too quickly and/or without sufficient training and support**

Not relevant   Slightly   Moderately   Very   Extremely relevant

**Being expected to use new technologies without reliable access to necessary tools and equipment**

Not relevant   Slightly   Moderately   Very   Extremely relevant

**Lack of protective clothing (PPE) and equipment needed for infection control**

Not relevant   Slightly   Moderately   Very   Extremely relevant

**Problems commuting safely to work and back**

Not relevant   Slightly   Moderately   Very   Extremely relevant

Health and social-related care:

**Difficulty putting infection control measures into practice in my home**

Not relevant   Slightly   Moderately   Very   Extremely relevant

**Pressures resulting from the need to support my family through the stresses associated with the pandemic**

Not relevant   Slightly   Moderately   Very   Extremely relevant

**Having to manage additional mental health needs for my child relating to COVID-19**

Not relevant   Slightly   Moderately   Very   Extremely relevant

**Feeling less able to support my family because my own well-being has suffered through the stresses of the pandemic**

Not relevant   Slightly   Moderately   Very   Extremely relevant

**Since mid-March 2020, how relevant do you think each of the following problems are for you and your family?**

Rate from Not very relevant to Extremely relevant.

**Loneliness due to or made worse by social distancing, self-isolation and/or**

**shielding**

|              |          |            |      |                    |
|--------------|----------|------------|------|--------------------|
| Not relevant | Slightly | Moderately | Very | Extremely relevant |
|--------------|----------|------------|------|--------------------|

**Lack of access to usual support from NHS health services**

|              |          |            |      |                    |
|--------------|----------|------------|------|--------------------|
| Not relevant | Slightly | Moderately | Very | Extremely relevant |
|--------------|----------|------------|------|--------------------|

**Lack of access to usual support from other services (primary care, social care, voluntary sector)**

|              |          |            |      |                    |
|--------------|----------|------------|------|--------------------|
| Not relevant | Slightly | Moderately | Very | Extremely relevant |
|--------------|----------|------------|------|--------------------|

**Difficulty engaging with remote appointments by phone or via digital platforms**

|              |          |            |      |                    |
|--------------|----------|------------|------|--------------------|
| Not relevant | Slightly | Moderately | Very | Extremely relevant |
|--------------|----------|------------|------|--------------------|

**Lack of access to usual support networks of family and friends**

|              |          |            |      |                    |
|--------------|----------|------------|------|--------------------|
| Not relevant | Slightly | Moderately | Very | Extremely relevant |
|--------------|----------|------------|------|--------------------|

**Worries about me or my family getting COVID-19 infection**

|              |          |            |      |                    |
|--------------|----------|------------|------|--------------------|
| Not relevant | Slightly | Moderately | Very | Extremely relevant |
|--------------|----------|------------|------|--------------------|

**Difficulty understanding current government requirements on social distancing, self-isolation and/or shielding**

|              |          |            |      |                    |
|--------------|----------|------------|------|--------------------|
| Not relevant | Slightly | Moderately | Very | Extremely relevant |
|--------------|----------|------------|------|--------------------|

**Difficulty following current government requirements on social distancing, self-isolation and/or shielding**

|              |          |            |      |                    |
|--------------|----------|------------|------|--------------------|
| Not relevant | Slightly | Moderately | Very | Extremely relevant |
|--------------|----------|------------|------|--------------------|

**Problems with police or other authorities because of lack of understanding of /ability to stick to current government requirements**

|              |          |            |      |                    |
|--------------|----------|------------|------|--------------------|
| Not relevant | Slightly | Moderately | Very | Extremely relevant |
|--------------|----------|------------|------|--------------------|

**Lack of access to or of equitable provision of physical healthcare for COVID-19 for my disabled child**

|              |          |            |      |                    |
|--------------|----------|------------|------|--------------------|
| Not relevant | Slightly | Moderately | Very | Extremely relevant |
|--------------|----------|------------|------|--------------------|

**Diminished access to physical health care for problems other than COVID-19**

|              |          |            |      |                    |
|--------------|----------|------------|------|--------------------|
| Not relevant | Slightly | Moderately | Very | Extremely relevant |
|--------------|----------|------------|------|--------------------|

**Increased drug and alcohol use or gambling**

|              |          |            |      |                    |
|--------------|----------|------------|------|--------------------|
| Not relevant | Slightly | Moderately | Very | Extremely relevant |
|--------------|----------|------------|------|--------------------|

**High personal risk of severe consequences of COVID-19 infection (e.g. due to physical health comorbidities)**

|              |          |            |      |                    |
|--------------|----------|------------|------|--------------------|
| Not relevant | Slightly | Moderately | Very | Extremely relevant |
|--------------|----------|------------|------|--------------------|

**Difficulty getting food, money or other basic resources**

|              |          |            |      |                    |
|--------------|----------|------------|------|--------------------|
| Not relevant | Slightly | Moderately | Very | Extremely relevant |
|--------------|----------|------------|------|--------------------|

**Having to stay at home in poor circumstances, or not having a home to go to**

|              |          |            |      |                    |
|--------------|----------|------------|------|--------------------|
| Not relevant | Slightly | Moderately | Very | Extremely relevant |
|--------------|----------|------------|------|--------------------|



**Increase in reliance on family/family tensions**

|              |          |            |      |                    |
|--------------|----------|------------|------|--------------------|
| Not relevant | Slightly | Moderately | Very | Extremely relevant |
|--------------|----------|------------|------|--------------------|

**Increased difficulties for my family because of excessive needs**

|              |          |            |      |                    |
|--------------|----------|------------|------|--------------------|
| Not relevant | Slightly | Moderately | Very | Extremely relevant |
|--------------|----------|------------|------|--------------------|

**Lack of usual work and activities**

|              |          |            |      |                    |
|--------------|----------|------------|------|--------------------|
| Not relevant | Slightly | Moderately | Very | Extremely relevant |
|--------------|----------|------------|------|--------------------|

**Relapse and deterioration in mental health triggered by COVID-19 stresses**

|              |          |            |      |                    |
|--------------|----------|------------|------|--------------------|
| Not relevant | Slightly | Moderately | Very | Extremely relevant |
|--------------|----------|------------|------|--------------------|

**Sources of help**

**How important has each of the following been as a source of help and support since mid-March 2020?**

Rate from Not important at all to Extremely important. Please try to give a range of scores so that we can see what is most helpful.

**Guidance disseminated by the NHS , charities or professional bodies**

Not important at all      Slightly      Moderately      Very      Extremely important

**Information from the media or social media**

Not important at all      Slightly      Moderately      Very      Extremely important

**Support and advice from my manager(s)**

Not important at all      Slightly      Moderately      Very      Extremely important

**Support and information from colleagues**

Not important at all      Slightly      Moderately      Very      Extremely important

**The support offered by local volunteers and mutual aid groups**

Not important at all      Slightly      Moderately      Very      Extremely important

**Support and new initiatives from local voluntary sector organisations**

Not important at all      Slightly      Moderately      Very      Extremely important

**National initiatives to support service users and carers, such as helplines and online peer support**

Not important at all      Slightly      Moderately      Very      Extremely important

**Carer well-being initiatives set up during COVID-19 in my workplace**

Not important at all      Slightly      Moderately      Very      Extremely important

**National initiatives to support carer well-being**

Not important at all      Slightly      Moderately      Very      Extremely important

**Adoption of new digital ways of working**

Not important at all      Slightly      Moderately      Very      Extremely important

**Please tell us about guidance or rules that you have received but struggled to put**

into practice, and why this is:

**Are you particularly concerned about any potential long-term consequences from the current pandemic?**

Yes

No

If yes, please tell us about this

### Remote appointment

To what extent do you agree with the following? please rate from Strongly disagree to Strongly agree.

**Telephone calls are often a satisfactory way to have an assessment**

|                   |          |                           |       |                |
|-------------------|----------|---------------------------|-------|----------------|
| Strongly disagree | Disagree | Neither agree or disagree | Agree | Strongly agree |
|-------------------|----------|---------------------------|-------|----------------|

**Video consultations are often a satisfactory way to way to make an assessment**

|                   |          |                           |       |                |
|-------------------|----------|---------------------------|-------|----------------|
| Strongly disagree | Disagree | Neither agree or disagree | Agree | Strongly agree |
|-------------------|----------|---------------------------|-------|----------------|

**Telephone calls are often a satisfactory way to assess the progress of my child as s/he is already known to the team**

|                   |          |                           |       |                |
|-------------------|----------|---------------------------|-------|----------------|
| Strongly disagree | Disagree | Neither agree or disagree | Agree | Strongly agree |
|-------------------|----------|---------------------------|-------|----------------|

**Video consultations are often a satisfactory way to assess the progress of my child as s/he is already known to the team**

|                   |          |                           |       |                |
|-------------------|----------|---------------------------|-------|----------------|
| Strongly disagree | Disagree | Neither agree or disagree | Agree | Strongly agree |
|-------------------|----------|---------------------------|-------|----------------|

**Telephone calls are a reasonable way to receive psychological treatment**

|                   |          |                           |       |                |     |
|-------------------|----------|---------------------------|-------|----------------|-----|
| Strongly disagree | Disagree | Neither agree or disagree | Agree | Strongly agree | N/A |
|-------------------|----------|---------------------------|-------|----------------|-----|

**Video calls are a reasonable way to receive psychological treatment**

|                   |          |                           |       |                |     |
|-------------------|----------|---------------------------|-------|----------------|-----|
| Strongly disagree | Disagree | Neither agree or disagree | Agree | Strongly agree | N/A |
|-------------------|----------|---------------------------|-------|----------------|-----|

**I am interested in having more video consultations than previously once the COVID-19 pandemic has finished**

|                   |          |                           |       |                |
|-------------------|----------|---------------------------|-------|----------------|
| Strongly disagree | Disagree | Neither agree or disagree | Agree | Strongly agree |
|-------------------|----------|---------------------------|-------|----------------|

**I am interested in making more use of telephone calls than previously once the COVID-19 pandemic is finished**

|                   |          |                           |       |                |
|-------------------|----------|---------------------------|-------|----------------|
| Strongly disagree | Disagree | Neither agree or disagree | Agree | Strongly agree |
|-------------------|----------|---------------------------|-------|----------------|

**Email or text messaging is an acceptable way to keep in touch with my child's health and social care teams**

|                   |          |                           |       |                |
|-------------------|----------|---------------------------|-------|----------------|
| Strongly disagree | Disagree | Neither agree or disagree | Agree | Strongly agree |
|-------------------|----------|---------------------------|-------|----------------|

**I have the necessary equipment and support to be able to take part in video assessments**

|                   |          |                           |       |                |
|-------------------|----------|---------------------------|-------|----------------|
| Strongly disagree | Disagree | Neither agree or disagree | Agree | Strongly agree |
|-------------------|----------|---------------------------|-------|----------------|

**How relevant has each of the following challenges been to you since mid-March 2020?**

Rate from Not very relevant to Extremely relevant.

**Lack of high quality and relevant information for people with intellectual disabilities and/or autism about the COVID-19 pandemics and the requirements that result**

|              |          |            |      |                    |
|--------------|----------|------------|------|--------------------|
| Not relevant | Slightly | Moderately | Very | Extremely relevant |
|--------------|----------|------------|------|--------------------|

**Difficulty for families in explaining the current crisis and the resulting requirements**

|              |          |            |      |                    |
|--------------|----------|------------|------|--------------------|
| Not relevant | Slightly | Moderately | Very | Extremely relevant |
|--------------|----------|------------|------|--------------------|

**Increased need following the withdrawal of educational and support services in the community**

|              |          |            |      |                    |
|--------------|----------|------------|------|--------------------|
| Not relevant | Slightly | Moderately | Very | Extremely relevant |
|--------------|----------|------------|------|--------------------|

**Difficulty engaging families supporting a person with intellectual disabilities and/or autism with remote appointments**

|              |          |            |      |                    |
|--------------|----------|------------|------|--------------------|
| Not relevant | Slightly | Moderately | Very | Extremely relevant |
|--------------|----------|------------|------|--------------------|

**Concerns about discrimination in access to physical health care for COVID-19 for my disabled child**

|              |          |            |      |                    |
|--------------|----------|------------|------|--------------------|
| Not relevant | Slightly | Moderately | Very | Extremely relevant |
|--------------|----------|------------|------|--------------------|

**Difficulty maintaining adequate levels of support for those with significant and complex needs**

|              |          |            |      |                    |
|--------------|----------|------------|------|--------------------|
| Not relevant | Slightly | Moderately | Very | Extremely relevant |
|--------------|----------|------------|------|--------------------|

**Difficulty maintaining adequate support for families looking after a child/young person/adult with intellectual disabilities and/or autism who displays challenging behaviour**

|              |          |            |      |                    |
|--------------|----------|------------|------|--------------------|
| Not relevant | Slightly | Moderately | Very | Extremely relevant |
|--------------|----------|------------|------|--------------------|

**To help us better understand the impact of COVID-19 on health care over time, we ask if you are willing to give your email address, so that we can contact you later for some further data collection.**

Yes, I am willing to give my email address

No, I am not willing to give my email address

If yes, please write your email address:

**Thank you for taking part in our survey.**