

**Supplementary materials for Psychosocial impact of the COVID-19 pandemic and shielding in adults and children with early-onset neuromuscular and neurological disorders and their families: a mixed-methods study**

**1. Questionnaire**

**2. Final codebook**

**1. Questionnaire**

**Introductory statement**

- Researcher introduces themselves with their name and role
- Statement outlining the purpose of the questionnaire e.g. “the purpose of this questionnaire is to better understand your experiences during the Covid-19 pandemic. The questionnaire should take no longer than 1 hour to complete.”
- Confirm written consent has been provided
- Statement outlining safety aspects e.g. “Your answers will be audio-recorded but all answers are confidential and will be anonymised; you can choose to have a family member/carer with you, and you can stop or pause the questionnaire at any point, and your/your child’s care will not be affected in any way. Information collected up to your withdrawal will still be used.”
- Statement that the researcher is unable to answer questions during the questionnaire e.g. “During the questionnaire I am unable to answer any questions myself but if needed I can advise you on where to get information or support after the questionnaire.”
- Ask if the participant has any questions

**Note to researchers: The questions below are designed to be used where either the patient or a patient’s parent is responding; the pronoun(s) in of each question should be adapted accordingly e.g. “Where were [you/name of patient] living?”**

**Section 1: Prior to the Covid-19 pandemic in the UK (i.e. the beginning of March 2020):**

1. Where was the patient living? e.g. own home, residential care: \_\_\_\_\_
2. Were they able to provide all personal and medical care for themselves?
  - Y
  - N  → a. Did someone assist the patient with some aspects  or all aspects 
    - b. Where care was provided by someone else, was this by (tick all that apply):
      1. Family members? Y  N
      2. Friends? Y  N
      3. Professional carer(s)? Y  N 
        - a. If yes, was this:
          - i. Social care
          - ii. Nursing care
          - iii. 24-hour care
          - iv. Intermittent care
      4. Someone else \_\_\_\_\_ N/A

3. Before the pandemic (i.e. the beginning of March) how frequently did the patient typically leave their residence (for any reason): (tick one)
- a. Every day
  - b. At least four days a week
  - c. At least once a week
  - d. At least twice a month
  - e. At least once a month
  - f. Less frequently than once a month
  - g. Never
  - h. Other \_\_\_\_\_
4. Before the pandemic, did the patient take part in any of the following activities?
- a. Paid work  → Full-time  Part-time  Role
  - b. Volunteering or unpaid work  → Full-time  Part-time  Role
  - c. School or higher education  → Full-time  Part-time
5. Prior to the pandemic, had they planned for any of the following life events to occur between March 2020 and the end of this year (tick all that apply)?
- a. Starting a new job
  - b. Starting a new educational activity
  - c. Going on holiday in the UK
  - d. Going on holiday abroad
  - e. Celebration of significant event(s) e.g. birthday, wedding
  - f. Attendance at a major event e.g. festival, gig, concert, convention
  - g. Other \_\_\_\_\_
6. Have any been cancelled or postponed due to Covid-19? \_\_\_\_\_

## Section 2: Symptoms during the Covid-19 pandemic

1. Since the start of March 2020, has the patient had any of the following symptoms?
- a. New persistent cough
  - b. New shortness of breath
  - c. Fever
  - d. Loss or change to your sense of smell or taste
2. If yes to any of these symptoms, was either of the following contacted?
- a. GP Y  N  → Why not? \_\_\_\_\_
  - b. 111 Y  N  → Why not? \_\_\_\_\_
  - c. Not sure

3. If yes to any of the above, did the patient attend A&E due to these symptoms?  
Y  → Admitted to hospital  Treatment in ICU  Intubation   
N  Not sure
4. Has the patient had a Covid-19 test (i.e. swab) in the community or in hospital with symptoms?  
Y  → Positive  Negative  Equivocal  Don't know   
N  Not sure
5. Have they had a Covid-19 test (i.e. swab) in the community or in hospital when they have not had any of the above symptoms e.g. due to a contact being unwell, for research etc?  
Y  → Positive  Negative  Equivocal  Don't know   
N  Not sure
6. Since the start of March 2020, have any of the patient's close contacts (i.e. someone with face to face contact with for more than 15 minutes, or physical contact with) had any of the following symptoms: New persistent cough, breathlessness, fever or loss of smell or taste?  
N  Not sure  Y  → What is their relationship? \_\_\_\_\_  
→ Did the contact have a Covid-19 test (swab)?  
Y  → Positive  Negative  Equivocal  Don't know
7. How worried are you (the participant) about the risk of Covid-19 to the patient's health?  
a. Extremely worried   
b. Very worried   
c. A little worried   
d. Not very worried   
e. Not at all worried   
f. Not sure   
i. Why? \_\_\_\_\_
8. Does the patient have an advanced directive i.e. a decision made to refuse specific treatments at some time in the future e.g. CPR, intubation, antibiotics?  
N  Not sure   
Y  → Do you think this would have been observed if they became unwell due to Covid-19? Y  N   
 Not sure  Why? \_\_\_\_\_
9. If the patient contracted Covid-19 and became very unwell, would you (the participant) want care in ICU to be considered if they were not getting better?  
N  Not sure  Y  → Do you think this would have been respected?  
Y  N  Not sure  Why? \_\_\_\_\_
10. If the patient became unwell due to possible Covid-19, would there be any concerns about seeking medical attention? \_\_\_\_\_
11. Are there any specific concerns about Covid-19 infection in relation to the patient or their family?  
\_\_\_\_\_

12. Have there been any problems with carers being concerned about aspects of care e.g. NIV use and aerosol generation risk, use of PPE etc? \_\_\_\_\_
13. Has advice been sought about the patient's care during the pandemic e.g. how to reduce risk of infection or what to do in an emergency? If so, from where (e.g. online, support groups, hospital teams etc.) \_\_\_\_\_
14. Have there been any difficulties or problems in getting answers or advice about care during the pandemic? \_\_\_\_\_

### Section 3: Changes to non-emergency medical care during pandemic

1. Have any of the patient's hospital appointments or admissions been cancelled/postponed?  
Y  N  Not sure
2. Have any hospital appointments been conducted remotely?  
Y  → what's been your and/or the patient's experience? \_\_\_\_\_  
N  Not sure
3. Have there been any changes in access to advice or prescriptions from the patient's GP? \_\_\_\_\_  
N/A
4. Have there been any changes in care provided by community healthcare professionals e.g. district nurses, dieticians? \_\_\_\_\_ N/A
5. Have there been any problems in accessing medications? \_\_\_\_\_ . N/A
6. Have there been any problems in accessing or repairing medical devices or equipment? \_\_\_\_\_  
N/A

### Section 4: Changes to personal and social circumstances during pandemic

1. "Shielding" encompasses ways to protect people considered to be clinically extremely vulnerable to Covid-19 infection. Those affected were initially advised to stay at home and strictly avoid contact with symptomatic people for an initial period of 12 weeks. Due to the Covid-19 pandemic
  - a. Did the patient get a letter advising them to shield?  
Y  → From which organisation \_\_\_\_\_  
N  Not sure
  - b. Is the patient currently considered to be shielding?  
Y  → When did shielding start? \_\_\_\_\_  
N  Not sure
  - c. If not currently considered to be shielding, have they previously shielded?  
Y  → Between which dates? \_\_\_\_\_  
N  Not sure
  - d. Were the household shielding at the same time?  
Y  For some of the time   
N  Not sure  Not applicable
  - e. When shielding, did the patient go against shielding recommendations e.g. leaving their residence despite advice not to do so?  
Y  → Why? \_\_\_\_\_  
N  Not sure

- f. Has the patient changed their activities or lifestyle due to recent government advice, relaxing limitations on people who are shielding?
- Y  → In what way(s)? \_\_\_\_\_
- N  Not sure
2. During the Covid-19 pandemic:
- a. Is or has the patient been living somewhere different to before the pandemic?
- Y  → Describe: \_\_\_\_\_
- N  Not sure
- b. Is or has the patient lived with different people to before the pandemic?
- Y  → Describe: \_\_\_\_\_
- N  Not sure
- c. Have arrangements for personal care changed? This may include who provides it (e.g. more care provided by family, reducing or stopping external carers, carer shielding with the patient etc.)?
- Y  → Describe: \_\_\_\_\_
- N  Not sure
- d. Have arrangements for medical care at home changed e.g. who provides it, use of PPE?
- Y  → Describe: \_\_\_\_\_
- N  Not sure
- e. If applicable, have the people providing care used PPE?
- Y  → Describe: \_\_\_\_\_
- N  Not sure
- f. Has the type or level of PPE used changed during the pandemic, e.g. in response to advice from PHE for carers, or availability of PPE?
- Y  → Describe: \_\_\_\_\_
- N  Not sure
- g. Have the patient's social activities changed?
- Y  → Describe: \_\_\_\_\_
- N  Not sure
- i. Has the patient had, or expressed any concerns or feelings of isolation or loneliness?
- \_\_\_\_\_
- h. Has the patient's work or educational activities changed?
- Y  → Describe: \_\_\_\_\_
- N  Not sure
3. Has there been any change in the patient's mood or sense of wellbeing during the Covid-19 pandemic?
- \_\_\_\_\_
4. Has there been any change in the patient's sleep during the Covid-19 pandemic e.g. improved or more fragmented or change in bedtime/wake routine? \_\_\_\_\_
5. Can you describe any practical difficulties e.g. getting food or groceries, continuity of care? \_\_\_\_\_
6. Can you describe any financial difficulties related to the Covid-19 pandemic? \_\_\_\_\_
7. Do you think anything positive has come out of the Covid-19 pandemic? \_\_\_\_\_
8. Lastly, how would you describe how you have felt during the Covid-19 pandemic? \_\_\_\_\_

## 2. Final codebook

Category	Code	Description	Sub-code(s)
<b>Access to acute medical care during CV-19 pandemic</b>	<i>Experience and perceptions of acute care in home setting during CV-19 pandemic</i>	Perceptions and experiences of accessing, coordinating and managing medical care for acute illness at home during the CV-19 pandemic, including avoiding or delaying seeking help	<ul style="list-style-type: none"> <li>• Availability of equipment and experienced care providers to manage acute illness at home</li> <li>• Experienced or perceived support or advice from healthcare professionals about acute care at home during pandemic</li> </ul>
	<i>Experience and perceptions of acute care in hospital setting during CV-19 pandemic</i>	Perceptions and experiences of accessing, coordinating and managing medical care for acute illness in hospital during the CV-19 pandemic including concerns about being denied treatment, hospital capacity and avoiding or delaying attending hospital	<ul style="list-style-type: none"> <li>• Advocating for hospital treatment; reasons why they should be given treatment e.g. self-advocacy or by family</li> <li>• Experience and perceptions of required treatment(s) being accessible and available</li> </ul>
	<i>Experience and perceptions of acute care in ICU setting during CV-19 pandemic</i>	Perceptions and experiences of medical care for acute illness in ICU settings during the CV-19 pandemic including concerns about ICU capacity, eligibility and prioritisation for treatment	<ul style="list-style-type: none"> <li>• Experience and perception of prioritisation for ICU level care</li> </ul>
<b>Access to long-term medical care during CV-19 pandemic</b>	<i>Access and adaptations to long-term medical care during CV-19 pandemic</i>	Experiences and perceptions of changes in access and delivery of long-term medical care during the CV-19 pandemic	N/A
	<i>Cancellations, delays and disruption to planned or routine care during the CV-19 pandemic</i>	Experiences of routine or long-term care appointments, investigations and treatments being disrupted, delayed or cancelled due to the CV-19 pandemic	<ul style="list-style-type: none"> <li>• Avoiding or delaying attending GP or hospital for non-acute problems during the pandemic</li> <li>• Disruption to medical equipment e.g. servicing, spares, broken equipment</li> </ul>
	<i>Remote access to long-term medical care during CV-19 pandemic</i>	Perceptions and experiences of remote access to long-term medical care during the CV-19 pandemic	<ul style="list-style-type: none"> <li>• Attitudes to remote access to care – negative</li> <li>• Attitudes to remote access to care – positive</li> </ul>
<b>Clinical implications of CV-19 infection for patient</b>	<i>Clinical features of suspected or confirmed CV-19 infection</i>	Symptoms and outcomes of patients who have had suspected or confirmed CV-19 infection	N/A
	<i>Clinical vulnerability to illness or infection (including CV-19)</i>	Perceptions and thoughts about the patient's vulnerability to illness or infection (i.e. why they might be more likely to become unwell, or to have poor outcomes from illness), and reasons underlying this e.g. disability, respiratory or muscle weakness, impaired immunity	<ul style="list-style-type: none"> <li>• Previous experience of severe illness or prolonged recovery</li> <li>• Risks specifically associated with NMD or treatment e.g. muscle weakness, NIV</li> <li>• Susceptibility to illness or infections</li> </ul>
	<i>Perceived severity and outcomes of CV-19 infection</i>	Perceptions and thoughts about how the patient would be affected clinically if they contracted CV-19 (e.g. symptoms, outcomes incl. death) and reasons underlying this perception e.g. uncertainty, comparison of CV-19 to "normal" infection	<ul style="list-style-type: none"> <li>• Lack of knowledge of CV-19</li> </ul>
	<i>Testing for suspected CV-19</i>	Experience of testing for CV-19 infection when unwell or when asymptomatic e.g. following contact with a suspected or confirmed CV-19, antibody tests	N/A

<b>Experience and perceptions of getting guidance and information about CV-19</b>	<i>Access, provision and availability of guidance, support and information on CV-19 (excl. PPE)</i>	Descriptions of how and where information and guidance has been obtained e.g. healthcare professionals, support groups, government, online, shielding letters (excluding PPE which is coded separately)	N/A
	<i>Determining risk of CV-19 transmission and protecting patients</i>	Approaches, thoughts and experiences about how patients and or their family try to determine the risk of CV-19 transmission to them	<ul style="list-style-type: none"> <li>Family - Perception of responsibility to protect and support patient</li> <li>Patients - responsibility to protect and support themselves</li> </ul>
	<i>Interpretation and application of guidance in context of personal situation (excl. PPE)</i>	Experience and perceptions on how and when information and guidance has been interpreted to influence the patient or family's behaviour or actions during the CV-19 pandemic (excluding PPE which is coded separately)	<ul style="list-style-type: none"> <li>Conflict between national guidance and healthcare professionals</li> </ul>
	<i>Perceived gaps, problems and unmet needs of support and guidance during CV-19 pandemic (incl. PPE)</i>	Experience and perceptions of where there are gaps or problems in access or provision of guidance, support and information on CV-19 including that relating to PPE	N/A
<b>Other</b>	Other	Information not covered by existing codes or sub-codes	N/A
<b>Perceived attitudes towards clinically vulnerable and disabled people</b>	<i>Patients, families and carers as experts in their condition and management</i>	Perceptions and experiences of patients, their families and carers being or considered experts in their condition and its management	N/A
	<i>Perception of attitudes towards vulnerable and disabled people in clinical settings</i>	Perceptions and experiences of attitudes towards clinically vulnerable and disabled people in clinical settings	N/A
	<i>Perception of general attitudes towards vulnerable and disabled people</i>	Perceptions and experiences of attitudes towards clinically vulnerable and disabled people outside clinical settings	N/A
<b>Perceived positive aspects and outcomes of CV-19 pandemic</b>	<i>Perceived benefits as a result of the CV-19 pandemic for person or family</i>	Perception and experience of positive aspects and outcomes of the CV-19 pandemic for patients with NMD and their families	N/A
	<i>Perceived benefits as a result of the CV-19 pandemic for population or society</i>	Perception and experience of positive aspects and outcomes of the CV-19 pandemic for the population and society in general	N/A
<b>Perceptions and experiences of shielding</b>	<i>Experiences and perceptions of contact with people outside household</i>	How patients and their families have minimised contact with people outside their household during the CV-19 pandemic, and their thoughts and feelings about doing so	<ul style="list-style-type: none"> <li>Considering or examples of maintaining social and physical distancing</li> <li>Feelings about contact with people outside household e.g. worry, excitement</li> <li>Permissible or acceptable reasons to meet people outside household e.g. meeting outside, school or work</li> </ul>
	<i>Experiences and perceptions of leaving home environment during CV-19 pandemic</i>	How patients and their families have minimised going out of their home during the CV-19 pandemic, and their thoughts and feelings about doing so	<ul style="list-style-type: none"> <li>Feelings about going out e.g. worry, excitement</li> <li>Permissible or acceptable reasons to go out</li> </ul>

	<i>Shielding - perceptions, experiences and attitudes</i>	Perceptions and experiences about the activities and behaviours involved in shielding, attitudes towards it and deciding when to shield	e.g. walks, park, hospital or GP, work <ul style="list-style-type: none"> <li>Activities and support making staying at home easier e.g. online deliveries, family going to the shops, going out in the garden, support bubbles</li> <li>Deciding when and how to shield</li> <li>Hope for relaxing restrictions or shielding e.g. vaccines</li> </ul>
<b>Practical issues experienced by patients and their families during CV-19 pandemic</b>	<i>Practical difficulties e.g. shopping, finances during the CV-19 pandemic, recruiting carers</i>	Practical issues experienced by patients and families as a result of the CV-19 pandemic e.g. related to finances, shopping	N/A
<b>Preventing transmission of CV-19 in the home environment by adapting care arrangements, cleaning, and using personal and protective equipment (PPE)</b>	<i>Perceptions, use and guidance on practical approaches to reducing CV-19 transmission incl. PPE</i>	Perceptions, use and guidance on practical approaches to minimising the risk of CV-19 transmission e.g. personal and protective equipment (PPE), enhanced cleaning	<ul style="list-style-type: none"> <li>Attitudes and perceptions of PPE including effectiveness</li> <li>Guidance and safety aspects of PPE including mask fitting, AGPs</li> <li>Sourcing PPE and how and when to use it</li> </ul>
	<i>Risk of CV-19 transmission from or to carers, and care adaptations to minimise risk</i>	Adaptations to care arrangements in the home setting as a result of the pandemic and possible transmission of CV-19 between patient and carer(s)	<ul style="list-style-type: none"> <li>Actual or potential impact of carer (including family) getting CV-19</li> <li>Describing adaptations to care arrangements due to the CV-19 pandemic e.g. stopping all care; restarting care after first lockdown</li> <li>Responsibility of patient or family in employing and coordinating carer(s)</li> </ul>
<b>The biological, psychological and social impact of the CV-19 pandemic on people with NMDs</b>	<i>Impact on patient's activities, personal goals and social interactions during CV-19 pandemic</i>	The impact of the CV-19 pandemic on patient's social and leisure activities, including personal goals and major events	<ul style="list-style-type: none"> <li>Maintaining social contact remotely</li> </ul>
	<i>Impact on patient's physical health during CV-19 pandemic e.g. sleep, activity, diet</i>	The perceived impact of the CV-19 pandemic on patient's biological factors e.g. sleep, diet, general health	N/A
	<i>Impact on patient's professional and educational activities during CV-19 pandemic</i>	The impact of the CV-19 pandemic on patient's professional and educational activities	N/A
	<i>Psychological impact of CV-19 pandemic on patients</i>	The psychological and emotional impact of the CV-19 pandemic on patient including mental health concerns	<ul style="list-style-type: none"> <li>Patients - Negative emotional impact</li> <li>Patients - Neutral emotional impact</li> <li>Patients - Positive emotional impact</li> </ul>
<b>The impact of the CV-19 pandemic on the families of people with NMDs</b>	<i>Impact on family as a result of managing patient care</i>	The impact of shielding during the CV-19 pandemic of the immediate and extended family of patients with NMDs due to managing patient care	N/A
	<i>Impact on family as a result of supporting work or education</i>	The impact of shielding during the CV-19 pandemic of the immediate and extended family of patients with NMDs due to supporting patient's work or education	N/A

	<i>Impact on family due to shielding</i>	The impact of shielding during the CV-19 pandemic on the immediate and extended family of patients with NMDs including on their work and education	<ul style="list-style-type: none"><li>• Impact of shielding on family members' work and education</li></ul>
	<i>Psychological and emotional impact on family</i>	Positive and negative psychological and emotional impact of the CV-19 pandemic of the immediate and extended family of patients with NMDs	N/A