

## DIPEX.CH – COVID-19 interview guide

### Preamble

In this interview, you are invited to talk about your experiences of COVID-19. You can mention as much as you feel is relevant and important to you.

In the first part of the interview I will ask you to tell me about your experiences. I may also ask you a few follow-up questions to clarify things you have told me or ask for a little more information.

Once you have finished telling me about your experience of COVID-19, I may have a few extra questions about other aspects of your story, such as the ‘medical’, personal or social dimensions of your experience. If at any point you wish to stop, or if there are questions you don’t wish to answer, just let me know.

### Part one. Invitation to tell the story of own experience

Please tell me about your experience of COVID-19, from when you first noticed something was not quite right through to when you felt you were fully recovered, including any experiences you have had with health and medical care and any other supports you received. We are interested to understand not only the physical aspects of being ill with COVID-19 but also the emotional or psychological / mental health impacts, and the impact of having the virus on your personal life, relationships and work or other activities you are involved in.

Please feel free to talk about all that is important for you and which you feel comfortable talking about.

*\* Leave participant to talk as long as she/he/they want or need to.*

Part two: follow-up prompts to cover any topics not covered in interviewee’s narrative (as appropriate to the individual circumstances)

#### 1. Knowledge about COVID-19

- What is your understanding of COVID-19 and what causes it? How do you think you were infected with the virus?
- Can you tell me what you knew about COVID-19 before you realised this was an issue for you?
- What are your main sources of information on COVID-19? (press, websites, tv, ...)

- Throughout your experience of COVID-19, from where did you get information about the virus and what to do if infected? (e.g. health practitioner, clinic, friends / relatives, internet (websites, social media, apps, blogs, online support groups / forums)
- What kind of information were you looking for? (e.g. medical information, people's experiences, information about personal / social aspects of COVID-19, research-based information)
  - Could you find it?
- What kind of stories or rumours have you heard about the origin of COVID-19?
- What kind of information was most / least helpful? Why?
- Do you know someone who had COVID19?

## *2. First signs and symptoms*

- What were the first indications for you that you were unwell?
- Did you think those signs / symptoms may have been due to COVID-19? If not, what did you think they were due to?

## *3. Diagnosis*

- *[If diagnosed]* Could you describe your experience of being diagnosed with COVID-19?
- *[If not diagnosed]* Could you describe your experience of realising that you likely had COVID-19? Did you have contact with (over the phone or in person) a health practitioner about it?
  - *[If no]* Can you tell me a little about why not?
  - *[If yes]* Can you tell me about your experience with the health practitioner and what happened?
- Other topics to ask about re: diagnosis:
  - Any tests / investigations
  - Where the diagnosis occurred (e.g., GP clinic / hospital / specialised COVID-19 assessment clinic ('fever clinic') / other)

- Receiving the diagnosis:
  - Who made the diagnosis?
  - How was your problem named by a health practitioner?
  - How was the diagnosis delivered?
- Other underlying / co-existing health conditions and relationship with COVID-19
- *[If have a partner or family members]* Role / reactions of partner / family members

#### 4. *Physical experience of COVID-19*

- Please describe your experience of what COVID-19 was like for you physically, from when you first noticed symptoms through to when you recovered. (e.g. What symptoms did you experience, did those symptoms change over time and if so how, which symptoms bothered you most / least, how did you manage them, how did your symptoms interact with any pre-existing health conditions?)
- Symptoms to ask about: dry cough, fever, breathing difficulties, fatigue, loss of sense of smell and taste, any other symptoms

#### 5. *Treatment(s) and self-care*

##### Treatment

- Can you tell me about any treatment you had or are currently undertaking for COVID-19.<sup>1</sup> We are interested in both medical treatment (including over-the-counter medicines) and other treatments, e.g. complementary / alternative remedies.
- *[If underwent treatment]:* Decision-making:
  - Can you tell me about how you came to decide to try those treatments?

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<sup>1</sup> There are currently no pharmacotherapies that have been proven to be effective for COVID-19 - we expect that participants' answers will reflect this and likely focus on self-care or respiratory management if they were hospitalized. However, by asking this question in an open-ended way, we may find out if any participants have been offered any kinds of medicines / therapies.

- *[If partnered / have other family members]* What role did your partner / family members have in the decision to try those treatments?
- What options were presented to you by your health practitioner?
- Did you do your own research? *(Explain that you will ask more about this later.)*
- What kind of support and information did you (and your partner / family member) have in making decisions about treatment? Was it enough / too much?
- Other topics to ask about re: treatment/s:
  - *[If hospitalised]* Experiences of supportive care / respiratory management (e.g. nasal prong, Hudson mask, intubation and mechanical ventilation etc)
  - Effectiveness & side-effects / unwanted effects
  - Emotional / social aspects of treatment (relationships with family, friends etc)
  - Stopping / completing treatment
  - How could information about available treatment/s be improved in your view?
  - have you heard about any complementary or alternative treatments for COVID-19? Did you try any of these?
- *[If did not undergo treatment]* Can you tell me about why you did not have any treatment? What sorts of messages or instructions did you receive from others (e.g. health practitioner / partner / family members) about not having treatment and remaining at home in isolation?

### Self-care

- Please tell me about your experiences of self-care (in home isolation). What advice did you receive about in-home isolation from your health practitioner? Did they monitor you in any way (e.g. telehealth consults)? What were the emotional / social impacts, e.g. how did you feel, did you have anyone to help you, and if so, how was your relationship with those people impacted by your in-home isolation?

### *6. Health care and communication*

- Can you tell me about the health services you had contact with, and what for? (e.g. public or private, hospital or outpatient; for testing / diagnosis / treatment)

- Do you think there are significant differences between private and public care? (if relevant, depending on the context)
- Did you receive any follow-up? (e.g. how often, with whom, what tests, feelings about)
- Encounters with health practitioners? (e.g. what specialties? What was helpful / unhelpful?)

### *7. Emotional / mental health aspects of COVID-19*

- Please tell us a little about how experiencing COVID-19 affected you emotionally / psychologically or impacted on your mental health.
- Other topics to ask about:
  - How did you feel when you were first diagnosed?
  - Were you afraid and why?
  - What was it like being in isolation at home / in hospital while you were ill?
  - Were you fearful of possibly dying from COVID-19? Please tell me a little about that.
  - Did you feel anyone treated you differently because you had COVID-19, whether a health care practitioner or someone you know personally? How did that make you feel?
  - What kind of psychological / mental health support would have been helpful to you while experiencing symptoms of COVID 19?
  - Who do you think should provide this support?

### *8. Impact on personal life and relationships*

- How has experiencing COVID-19 impacted on your sense of self, e.g. your identity / self-esteem / life plans?
- Please tell me a bit about the impact experiencing COVID-19 has had on your everyday life, e.g. work / study / other daily activities.
- Impact on relationships (e.g. partner, children, friends, other relatives) & social life in general
- Other topics to ask about:

- Financial issues (cost of treatment, sick leave, government benefits, health insurance)
- Social support (what kind, from whom)
- Feelings about family members trying to help / understand
- Relationships with others who also experienced COVID-19 *[if any]*
- Did your spirituality/religious views play a role in your experience with COVID-19?

*9. Recovery / advice to others / thoughts about the future:*

- Please tell me a little about your recovery from COVID-19. (alternative in case of long COVID: Please tell me a little about your ongoing recovery from COVID-19 / ongoing experience with COVID-19)
- What advice would you have based on your experience for:
  - others experiencing COVID-19
  - family members and friends of people experiencing COVID-19
  - health practitioners / health services treating people experiencing COVID-19
  - Is there any advice you would like to share with people who are not protecting themselves and the others from COVID-19?
- People who have been through COVID-19 often notice things about testing, diagnosis, treatment or even government policy that don't seem to make sense or seem inefficient, misleading or confusing.
  - Was there anything of this nature that you noticed?
  - If you could change anything about experience (medical and/or social) of other people experiencing COVID-19, what would it be?
- How do you see your future? (e.g. outlook, impact of COVID-19 on your sense of self, long-term health / mental health impacts, work, study, finances, feeling safe)
- When life returns to 'normal', what aspects of your 'old' life do you look forward to having back? What aspects would you not want back?

- What were the best and the worst things in your experience with covid-19? (alternative: what was the most difficult thing? And what did you learn?)
- If there was one thing you wanted people to know about COVID-19, what would that be?
- Accepting to do this interview you accepted to tell and to share your personal experience. what does this mean to you?
- Is there anything else I haven't asked about that you'd like to mention?