

# THE LANCET

## Infectious Diseases

### Supplementary appendix

This appendix formed part of the original submission and has been peer reviewed. We post it as supplied by the authors.

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## A clinical case definition of post-COVID-19 condition by a Delphi consensus

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## Appendix 1. Agreement rules and thresholds for consensus and disagreement

**'Consensus'** will be obtained on a question **if 70% or more** of the responses fall within the same response on a 9-point Likert scale.

**'Disagreement'** will occur **if 35% or more of responses fall in both of the two extreme ranges** of possible options on the Likert scale.

All other combinations of panel answers will be considered **'partial agreement'**.

Limited importance			Important but not critical			Critical to include			
(1)	(2)	(3)	(4)	(5)	(6)	(7)	(8)	(9)	Not my expertise
<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

## Appendix 2. Repository of published/available definitions of Post COVID-19 condition

Source	Text
Wellcome	Symptoms persisting beyond four weeks after symptom onset suggestive of COVID-19. <sup>1</sup>
Lancet	Multiorgan symptoms after COVID-19 are being reported by increasing numbers of patients. They range from cough and shortness of breath, to fatigue, headache, palpitations, chest pain, joint pain, physical limitations, depression, and insomnia, and affect people of varying ages. At the Lancet–Chinese Academy of Medical Sciences conference on Nov 23, Bin Cao presented data (in press at <i>The Lancet</i> ) on the longterm consequences of COVID-19 for patients in Wuhan, and warned that dysfunctions and complications could persist in some discharged patients for at least 6 months. So-called long COVID is a burgeoning health concern and action is needed now to address it. <sup>2</sup>
NICE	Signs and symptoms that develop during or after an infection consistent with COVID-19, continue for more than 12 weeks and are not explained by an alternative diagnosis. <sup>3</sup>
Scientific American	Individuals whose symptoms persist or develop outside the initial viral infection, but the duration and pathogenesis are unknown. <sup>4</sup>
Royal Society	The onset of persistent or recurrent episodes of one or more of the following symptoms, within x* weeks of infection with SARS-CoV-2 and continuing for y* weeks or more. <sup>2</sup>
French Auth. de Santé	Three criteria: Having presented with a symptomatic form of Covid-19; presenting with one or more initial symptoms 4 weeks after the start of the disease; and none of these symptoms can be explained by another diagnosis. <sup>5</sup>
CDC	Long COVID: While most persons with COVID-19 recover and return to normal health, some patients can have symptoms that can last for weeks or even months after recovery from acute illness. Even people who are not hospitalized and who have mild illness can experience persistent or late symptoms. <sup>6</sup>
Wikipedia	Condition characterized by long-term sequelae—persisting after the typical convalescence period—of coronavirus disease 2019 (COVID-19). <sup>7</sup>
Nature	post-acute COVID-19 as persistent symptoms and/or delayed or long-term complications of SARS-CoV-2 infection beyond 4 weeks from the onset of symptoms. <sup>8</sup>
	...

### References:

1. Perego E, Callard F, Stras L, Melville-Jóhannesson B, Pope R, Alwan NA. Why the Patient-Made Term 'Long Covid' is needed. Wellcome Open Research. 2020, 5:224.]
2. Editorial. Facing up to long COVID. *Lancet*. 2020 Dec 12;396(10266):1861. doi: 10.1016/S0140-6736(20)32662-3.
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4. Scientific American (By Carolyn Barber on December 29, 2020) <https://www.scientificamerican.com/article/the-problem-of-long-haul-covid/?print=true> [accessed April 22, 2021].
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7. Long COVID From Wikipedia, the free encyclopedia. Available at: [https://en.wikipedia.org/wiki/Long\\_COVID](https://en.wikipedia.org/wiki/Long_COVID) [accessed on April 22, 2021].
8. Nalbandian A, Sehgal K, Gupta A, Madhavan MV, McGroder C, Stevens JS, Cook JR, Nordvig AS, Shalev D, Sehrawat TS, Ahluwalia N, Bikdeli B, Dietz D, Der-Nigoghossian C, Liyanage-Don N, Rosner GF, Bernstein EJ, Mohan S, Beckley AA, Seres DS, Choueiri TK, Uriel N, Ausiello JC, Accili D, Freedberg DE, Baldwin M, Schwartz A, Brodie D, Garcia CK, Elkind MSV, Connors JM, Bilezikian JP, Landry DW, Wan EY. Post-acute COVID-19 syndrome. *Nat Med*. 2021 Mar 22. doi: 10.1038/s41591-021-01283-z. PMID: 33753937



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# Questionnaire for the Post COVID-19 condition clinical case definition WHO Delphi study

Thank you for agreeing to participate in this Delphi study to help develop a clinical case definition of Post COVID-19 condition. Please read through items 1 to 4 before proceeding to the survey page.

## 1. Delphi purpose and description

The purpose of this WHO Delphi study is to obtain opinions, including on which domains, and their eventual values or thresholds, should be applied to the development of a clinical case definition of Post COVID-19 condition.

There are many unknowns and lingering issues on Post COVID-19 condition, including the need for a standard clinical case definition to be used by all parties and in all settings. The list of available, related definitions is growing (see [Appendix 1](#) in the study protocol), but to date none is universal. WHO has engaged in developing a clinical case definition of Post COVID-19 condition based on existing evidence by applying the most objective Delphi methodology.

This Delphi study will consist of two (2) rounds send out for completion in May 2021. You will have five days to complete each round. This is round 1.

## 2. Where did the domains considered for inclusion in the definition come from?

The domains (or variables) were derived from a literature review on current evidence, interviews with patients and consultations with knowledge leaders. COMET DelphiManager software, a web-based system designed to facilitate the building and management of Delphi surveys, will be used to complete this Delphi exercise.

## 3. What happens after I complete this first Delphi round?

We will inform you when all Round 1 data have been received and analysed. We will then give you access to Round 2, which will include a summary of the responses from Round 1 and empirical evidence for each item derived from further literature review.

You will then re-vote on each item in Round 1 that was scored as "critical" by at least 70% of Delphi respondents and as of "limited importance" by less than 15% of respondents.

## 4. Participation and confidentiality

Participating in this WHO Delphi study is voluntary. Only anonymized and aggregate data will be shared and published. No one other than an authorized member of the research team will be able identify you through your survey responses.

You will be invited to complete all rounds. Note that the results may be compromised if panellists (participants like you) drop out of the study before it is completed. If people drop out because they feel their opinions are in the minority, the final results will overestimate how much participants agreed.

Please complete Round 1 using the set of instructions, next

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## Instructions

All survey questions must be **completed from Tuesday 11 May to Saturday 15 May 2021**. The entire survey should take you **less than 10 minutes to complete**. You may complete the survey in more than one sitting by using the "Save & Return" button at the bottom of the survey page.

Please keep in mind that the purpose of this WHO Delphi study is to help identify the minimum and essential domains to include in a clinical case definition of Post COVID-19 condition.

The candidate reporting domains are organized into 11 categories with several sub-categories for voting purposes.

Please rate the IMPORTANCE of including each of these categories and where necessary, sub-categories.

- A rating of 1 to 3 means that you consider the item to be of limited importance to include in the definition.
- A rating of 4 to 6 means that you consider the item to be important but not critical to include in the definition.
- A rating of 7 to 9 means that you consider the item to be critical to include in the definition.
- You may select "Not my expertise" for items that you feel you do not have the appropriate level of expertise to rate.
- A text box is provided at the bottom of each question for you to provide comments about each candidate domain and/or any explanations you would like to provide for your rating.

Please feel free to contact us directly with any questions. Address your queries to Dr JB Soriano at [sorianoj@who.int](mailto:sorianoj@who.int).

To start this Delphi Round 1 survey with DelphiManager, please click "**Register**" below.

**Domain 1 – History of SARS-CoV-2 infection**

How important is “**having a history of SARS-CoV-2 infection**” to the clinical case definition of Post COVID-19 condition?

- (1) (2) (3) (4) (5) (6) (7) (8) (9) Not my expertise

**Notes:** Suspected/probable/confirmed case of SARS-CoV-2 infection. In the link [https://www.who.int/publications/i/item/WHO-2019-nCoV-Surveillance\\_Case\\_Definition-2020.2](https://www.who.int/publications/i/item/WHO-2019-nCoV-Surveillance_Case_Definition-2020.2) the case definitions for public health surveillance of COVID-19 in humans caused by SARS-COV-2 infection are provided.

Please provide any feedback on the wording of this domain, suggestions for other thresholds or values of this domain and/or an explanation of your rating:

---

**Domain 2 – SARS-CoV-2 laboratory confirmation**

How important is “having a laboratory confirmed previous history of SARS-CoV-2 infection” to the clinical case definition of Post COVID-19 condition?

- |                       |                       |                       |                       |                       |                       |                       |                       |                       |                       |
|-----------------------|-----------------------|-----------------------|-----------------------|-----------------------|-----------------------|-----------------------|-----------------------|-----------------------|-----------------------|
| (1)                   | (2)                   | (3)                   | (4)                   | (5)                   | (6)                   | (7)                   | (8)                   | (9)                   | Not my expertise      |
| <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> |

**Notes:** None

Please provide any feedback on the wording of this domain, suggestions for other thresholds or values of this domain and/or an explanation of your rating:

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**Domain 3 - Onset of Post COVID-19 condition**

How important is **“the inclusion of the following proposed minimum time period (in weeks) between the onset of symptoms of acute COVID-19 (or for asymptomatic cases from date of positive test)”** to the clinical case definition of Post COVID-19 condition?

**4 weeks**

(1) (2) (3) (4) (5) (6) (7) (8) (9) Not my expertise

**8 weeks**

(1) (2) (3) (4) (5) (6) (7) (8) (9) Not my expertise

**12 weeks**

(1) (2) (3) (4) (5) (6) (7) (8) (9) Not my expertise

**16 weeks or more**

(1) (2) (3) (4) (5) (6) (7) (8) (9) Not my expertise

**Notes:** None

Please provide any feedback on the wording of this domain, suggestions for other thresholds or values of this domain and/or an explanation of your rating:

---

**Domain 4 – Minimum duration of symptoms**

How important is “the inclusion of the following minimum duration of the symptoms” to the clinical case definition of Post COVID-19 condition?

**At least 2 weeks**

(1) (2) (3) (4) (5) (6) (7) (8) (9) Not my expertise

**At least 4 weeks**

(1) (2) (3) (4) (5) (6) (7) (8) (9) Not my expertise

**At least 6 weeks**

(1) (2) (3) (4) (5) (6) (7) (8) (9) Not my expertise

**At least 8 weeks**

(1) (2) (3) (4) (5) (6) (7) (8) (9) Not my expertise

**Notes:** None

Please provide any feedback on the wording of this domain, suggestions for other thresholds or values of this domain and/or an explanation of your rating:

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**Domain 5 – Symptoms (and/or impairments)**

How important is “each of the following symptoms” to the clinical case definition of Post COVID-19 condition?

Abdominal pain

(1) (2) (3) (4) (5) (6) (7) (8) (9) Not my expertise

Altered menstruation

(1) (2) (3) (4) (5) (6) (7) (8) (9) Not my expertise

Altered smell or taste

(1) (2) (3) (4) (5) (6) (7) (8) (9) Not my expertise

Anxiety

(1) (2) (3) (4) (5) (6) (7) (8) (9) Not my expertise

Blurred vision

(1) (2) (3) (4) (5) (6) (7) (8) (9) Not my expertise

Chest pain

(1) (2) (3) (4) (5) (6) (7) (8) (9) Not my expertise

Cognitive dysfunction/brain fog

(1) (2) (3) (4) (5) (6) (7) (8) (9) Not my expertise

Cough

(1) (2) (3) (4) (5) (6) (7) (8) (9) Not my expertise

Depression

(1) (2) (3) (4) (5) (6) (7) (8) (9) Not my expertise

Dizziness

(1) (2) (3) (4) (5) (6) (7) (8) (9) Not my expertise

Fatigue

(1) (2) (3) (4) (5) (6) (7) (8) (9) Not my expertise

Gastrointestinal issues (diarrhoea, constipation, acid reflux)

(1) (2) (3) (4) (5) (6) (7) (8) (9) Not my expertise

Headaches

(1) (2) (3) (4) (5) (6) (7) (8) (9) Not my expertise

Intermittent fever

(1) (2) (3) (4) (5) (6) (7) (8) (9) Not my expertise

Joint pain

(1) (2) (3) (4) (5) (6) (7) (8) (9) Not my expertise

Memory issues

(1) (2) (3) (4) (5) (6) (7) (8) (9) Not my expertise

Muscle pain

(1) (2) (3) (4) (5) (6) (7) (8) (9) Not my expertise

**New allergies**

(1) (2) (3) (4) (5) (6) (7) (8) (9) Not my expertise

**Neuralgias**

(1) (2) (3) (4) (5) (6) (7) (8) (9) Not my expertise

**Pins and needles**

(1) (2) (3) (4) (5) (6) (7) (8) (9) Not my expertise

**Post-exertional malaise**

(1) (2) (3) (4) (5) (6) (7) (8) (9) Not my expertise

**Shortness of breath**

(1) (2) (3) (4) (5) (6) (7) (8) (9) Not my expertise

**Sleep disorders**

(1) (2) (3) (4) (5) (6) (7) (8) (9) Not my expertise

**Tachycardia/palpitations**

(1) (2) (3) (4) (5) (6) (7) (8) (9) Not my expertise

**Tinnitus, and other hearing issues**

(1) (2) (3) (4) (5) (6) (7) (8) (9) Not my expertise

**Notes:** List of symptoms presented in alphabetical order, extracted from:

<https://www.cdc.gov/coronavirus/2019-ncov/long-term-effects.html>

<https://www.acpjournals.org/doi/10.7326/M20-5926>

<https://apps.who.int/iris/bitstream/handle/10665/339629/Policy-brief-39-1997-8073-eng.pdf>

[https://www.who.int/publications/i/item/global-covid-19-clinical-platform-case-report-form-\(crf\)-for-post-covid-conditions-\(post-covid-19-crf-\)](https://www.who.int/publications/i/item/global-covid-19-clinical-platform-case-report-form-(crf)-for-post-covid-conditions-(post-covid-19-crf-))

Please provide any feedback on the wording of this domain, suggestions for other thresholds or values of this domain and/or an explanation of your rating:

---

**Domain 6 – Minimum number of symptoms**

How important is “**having a minimum number of symptoms**” to the clinical case definition of Post COVID-19 condition?

- |                       |                       |                       |                       |                       |                       |                       |                       |                       |                       |
|-----------------------|-----------------------|-----------------------|-----------------------|-----------------------|-----------------------|-----------------------|-----------------------|-----------------------|-----------------------|
| (1)                   | (2)                   | (3)                   | (4)                   | (5)                   | (6)                   | (7)                   | (8)                   | (9)                   | Not my expertise      |
| <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> |

**Notes:** None

Please provide any feedback on the wording of this domain, suggestions for other thresholds or values of this domain and/or an explanation of your rating:

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### Domain 7 – Clusters of symptoms

How important is “**the inclusion of clusters of symptoms**” to the clinical case definition of Post COVID-19 condition?

- (1) (2) (3) (4) (5) (6) (7) (8) (9) Not my expertise

**Notes:** Symptom clusters are defined as consisting of two or more symptoms that are related to each other and that occur together. They are composed of stable groups of symptoms, are relatively independent of other clusters and may reveal specific underlying dimensions of symptoms. [**Reference:** Barsevick A. Defining the Symptom Cluster: How Far Have We Come? Seminars in Oncology Nursing 2016; 32 (4): 334-350.]

Please provide any feedback on the wording of this domain, suggestions for other thresholds or values of this domain and/or an explanation of your rating:

---



**Domain 8 – Nature of symptoms**

How important is **“to include each of the following descriptors on the nature of symptoms”** in the clinical case definition of Post COVID-19 condition?

**Fluctuating**

(1) (2) (3) (4) (5) (6) (7) (8) (9) Not my expertise

**Increasing**

(1) (2) (3) (4) (5) (6) (7) (8) (9) Not my expertise

**New onset**

(1) (2) (3) (4) (5) (6) (7) (8) (9) Not my expertise

**Persistent**

(1) (2) (3) (4) (5) (6) (7) (8) (9) Not my expertise

**Relapsing**

(1) (2) (3) (4) (5) (6) (7) (8) (9) Not my expertise

**Notes:** None

Please provide any feedback on the wording of this domain, suggestions for other thresholds or values of this domain and/or an explanation of your rating:

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**Domain 9 – Sequelae of well-described acute complications of COVID-19**

How important is to **“include only symptoms separate from those that are thought to be a sequela of well-described acute complications of COVID-19 [i.e.,**

**stroke, acute respiratory distress syndrome, acute kidney injury, myocarditis, thrombosis, post intensive care syndrome (PICS)]**” in the clinical case definition of Post COVID-19 condition?

- |                       |                       |                       |                       |                       |                       |                       |                       |                       |                       |
|-----------------------|-----------------------|-----------------------|-----------------------|-----------------------|-----------------------|-----------------------|-----------------------|-----------------------|-----------------------|
| (1)                   | (2)                   | (3)                   | (4)                   | (5)                   | (6)                   | (7)                   | (8)                   | (9)                   | Not my expertise      |
| <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> |

**Notes:** None

Please provide any feedback on the wording of this domain, suggestions for other thresholds or values of this domain and/or an explanation of your rating:

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**Domain 10 - Symptoms cannot be explained by an alternative diagnosis**

How important is **“that Post COVID-19 condition be considered a diagnosis of exclusion determined by a health provider when symptoms cannot be explained by an alternative diagnosis”** to the clinical case definition of Post COVID-19 condition?

- |                       |                       |                       |                       |                       |                       |                       |                       |                       |                       |
|-----------------------|-----------------------|-----------------------|-----------------------|-----------------------|-----------------------|-----------------------|-----------------------|-----------------------|-----------------------|
| (1)                   | (2)                   | (3)                   | (4)                   | (5)                   | (6)                   | (7)                   | (8)                   | (9)                   | Not my expertise      |
| <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> |

**Notes:** None

Please provide any feedback on the wording of this domain, suggestions for other thresholds or values of this domain and/or an explanation of your rating:

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**Domain 11 - Should the definition be applied to all populations?**

How important is “that the Post COVID-19 condition definition can be applied to all populations, including women who are pregnant or post-partum; young children; neonates; people with chronic disease; people living with HIV; older people; or individuals who are immunocompromised because of other conditions” to the clinical case definition of Post COVID-19 condition?

- |                       |                       |                       |                       |                       |                       |                       |                       |                       |                       |
|-----------------------|-----------------------|-----------------------|-----------------------|-----------------------|-----------------------|-----------------------|-----------------------|-----------------------|-----------------------|
| (1)                   | (2)                   | (3)                   | (4)                   | (5)                   | (6)                   | (7)                   | (8)                   | (9)                   | Not my expertise      |
| <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> |

**Notes:** None

Please provide any feedback on the wording of this domain, suggestions for other thresholds or values of this domain, and/or an explanation of your rating:

---

**You have completed this Delphi survey Round 1.**

**We will contact you with Round 2.**

**THANKS!**

## Appendix 4. Questionnaire for Round 2



Delphi questionnaire – v7June2021

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### Questionnaire for a Post COVID-19 condition clinical case definition WHO Delphi study

Thank you again for agreeing to participate in this Delphi study to help develop a clinical case definition of Post COVID-19 condition.

You will see that some questions have been removed or edited from the previous Round 1.

For your information, from the original questionnaire with 11 domains, those outcomes that as per the research protocol achieved 70% or more agreement or 35% or less in either extreme ranges, are excluded. Thus, the domains excluded are:

- Domain 1 – History of SARS-CoV-2 infection (N=253 responses; Mean score:  $7.6 \pm 1.8$ ; 79.4% of responses  $\geq 7$ )
- Domain 5: excluded symptoms

○ Symptom	# of Responses	Mean $\pm$ SD	% $\geq 7$
○ Fatigue	234	$7.6 \pm 1.5$	77.8
○ Shortness of breath	232	$7.5 \pm 1.6$	77.6
○ Cognitive dysfunction	234	$7.2 \pm 1.7$	74.3
- Domain 6 – Minimum number of symptoms (N=239; Mean score:  $5.4 \pm 2.4$ ; 37.7% of responses 7 or greater)
- Domain 10 - Symptoms cannot be explained by an alternative diagnosis (N=231; Mean score  $7.2 \pm 1.8$ ; 71.4% of responses 7 or greater)

In addition, according to feedback and specific comments by respondents, other domains have been rephrased or edited, while one more (Domain 12 - Impact on everyday functioning) has been added to the questionnaire.

You will find tabulated results (Mean score  $\pm$  standard deviation and the % of responses  $\geq 7$ ) for all items again being asked.

Please complete Round 2 using the same set of instructions as per Round 1.

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#### Instructions

All survey questions must be **completed from Monday 7 June to Thursday 10 June 2021**. The entire survey should take you **less than 10 minutes to complete**. You may complete the survey in more than one sitting by using the "Save & Return" button at the bottom of the survey page.

Please keep in mind that the purpose of this WHO Delphi study is to help identify the minimum and essential domains to include in a clinical case definition of Post COVID-19 condition, in keeping with the best current understanding of this condition, acknowledging that the case definition may evolve.

The candidate reporting domains are organized into 8 categories with several subcategories for voting purposes.

Please rate the IMPORTANCE of including each of these categories and, where necessary, subcategories.

- A rating of 1 to 3 means that you consider the item to be of limited importance to include in the definition.
- A rating of 4 to 6 means that you consider the item to be important but not critical to include in the definition.
- A rating of 7 to 9 means that you consider the item to be critical to include in the definition.
- You may select "Not my expertise" for items that you feel you do not have the appropriate level of expertise to rate.
- A text box is provided at the bottom of each question for you to provide comments about each candidate domain and/or any explanations you would like to provide for your rating.

Please feel free to contact us directly with any questions. Address your queries to Dr JB Soriano at [sorianoj@who.int](mailto:sorianoj@who.int)

Finally, should your "Country of Residence" not be listed in DelphiManager, please select "Other" and do write in free text the name. Thanks!

To start this Delphi Round 2 survey with DelphiManager, please click "**Register**" below.

**Domain 1 – History of SARS-CoV-2 infection**

How important is “having a history of SARS-CoV-2 infection” to the clinical case definition of Post COVID-19 condition?

- (1) (2) (3) (4) (5) (6) (7) (8) (9) Not my expertise

**Notes:** Suspected/probable/confirmed case of SARS-CoV-2 infection. In the link [https://www.who.int/publications/i/item/WHO-2019-nCoV-Surveillance\\_Case\\_Definition-2020.2](https://www.who.int/publications/i/item/WHO-2019-nCoV-Surveillance_Case_Definition-2020.2) the case definitions for public health surveillance of COVID-19 in humans caused by SARS-COV-2 infection are provided.

Please provide any feedback on the wording of this domain, suggestions for other thresholds or values of this domain and/or an explanation of your rating:

---

**Domain 2: SARS-CoV-2 laboratory confirmation**

How important is **“having a laboratory-confirmed history of SARS-CoV-2 infection, when there is access to laboratory testing”** to the clinical case definition of Post COVID-19 condition?

- |                       |                       |                       |                       |                       |                       |                       |                       |                       |                       |
|-----------------------|-----------------------|-----------------------|-----------------------|-----------------------|-----------------------|-----------------------|-----------------------|-----------------------|-----------------------|
| (1)                   | (2)                   | (3)                   | (4)                   | (5)                   | (6)                   | (7)                   | (8)                   | (9)                   | Not my expertise      |
| <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> |

**Notes:** None

Please provide any feedback on the wording of this domain, suggestions for other thresholds or values of this domain and/or an explanation of your rating:

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**Domain 3: Onset of Post COVID-19 condition**

How important is “the inclusion of a minimum time period (in months) from the onset of COVID-19 to the presence of symptoms” to the clinical case definition of Post COVID-19 condition?

**1 month**

(1) (2) (3) (4) (5) (6) (7) (8) (9) Not my expertise

**2 months**

(1) (2) (3) (4) (5) (6) (7) (8) (9) Not my expertise

**3 months**

(1) (2) (3) (4) (5) (6) (7) (8) (9) Not my expertise

**4 months**

(1) (2) (3) (4) (5) (6) (7) (8) (9) Not my expertise

**6 months or more**

(1) (2) (3) (4) (5) (6) (7) (8) (9) Not my expertise

**No minimum time period**

(1) (2) (3) (4) (5) (6) (7) (8) (9) Not my expertise

**Notes:** The proposed time periods are from the onset of symptoms of acute COVID-19 (or for asymptomatic cases from date of positive test) to the diagnosis of Post COVID-19 condition.

Please provide any feedback on the wording of this domain, suggestions for other thresholds or values of this domain and/or an explanation of your rating:

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**Domain 4: Minimum duration of symptoms**

How important is **“the inclusion of any of the following minimum duration of symptoms”** to the clinical case definition of Post COVID-19 condition?

**At least 0.5 months (2 weeks)**

(1) (2) (3) (4) (5) (6) (7) (8) (9) Not my expertise

**At least 1 month (4 weeks)**

(1) (2) (3) (4) (5) (6) (7) (8) (9) Not my expertise

**At least 1.5 months (6 weeks)**

(1) (2) (3) (4) (5) (6) (7) (8) (9) Not my expertise

**At least 2 months (8 weeks)**

(1) (2) (3) (4) (5) (6) (7) (8) (9) Not my expertise

**At least 3 months**

(1) (2) (3) (4) (5) (6) (7) (8) (9) Not my expertise

**At least 6 months**

(1) (2) (3) (4) (5) (6) (7) (8) (9) Not my expertise

**No minimum duration**

(1) (2) (3) (4) (5) (6) (7) (8) (9) Not my expertise

**Notes:** None

Please provide any feedback on the wording of this domain, suggestions for other thresholds or values of this domain and/or an explanation of your rating:

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**Domain 5: Symptoms (and/or impairments)**

How important is **“to include, in addition to FATIGUE, SHORTNESS OF BREATH AND COGNITIVE DYSFUNCTION, any of the following symptoms”** to the clinical case definition of Post COVID-19 condition?

Altered smell or taste

(1)	(2)	(3)	(4)	(5)	(6)	(7)	(8)	(9)	Not my expertise
<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

Anxiety

(1)	(2)	(3)	(4)	(5)	(6)	(7)	(8)	(9)	Not my expertise
<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

Chest pain

(1)	(2)	(3)	(4)	(5)	(6)	(7)	(8)	(9)	Not my expertise
<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

Cognitive dysfunction/brain fog

(1)	(2)	(3)	(4)	(5)	(6)	(7)	(8)	(9)	Not my expertise
<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

Cough

(1)	(2)	(3)	(4)	(5)	(6)	(7)	(8)	(9)	Not my expertise
<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

Depression

(1)	(2)	(3)	(4)	(5)	(6)	(7)	(8)	(9)	Not my expertise
<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

Dizziness

(1)	(2)	(3)	(4)	(5)	(6)	(7)	(8)	(9)	Not my expertise
<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

Fatigue

(1)	(2)	(3)	(4)	(5)	(6)	(7)	(8)	(9)	Not my expertise
-----	-----	-----	-----	-----	-----	-----	-----	-----	------------------

Headaches

(1) (2) (3) (4) (5) (6) (7) (8) (9) Not my expertise

Intermittent fever

(1) (2) (3) (4) (5) (6) (7) (8) (9) Not my expertise

Joint pain

(1) (2) (3) (4) (5) (6) (7) (8) (9) Not my expertise

Memory issues

(1) (2) (3) (4) (5) (6) (7) (8) (9) Not my expertise

Menstrual and period problems

(1) (2) (3) (4) (5) (6) (7) (8) (9) Not my expertise

Muscle pain/spasms

(1) (2) (3) (4) (5) (6) (7) (8) (9) Not my expertise

Neuralgias

(1) (2) (3) (4) (5) (6) (7) (8) (9) Not my expertise

Post-exertional malaise

(1) (2) (3) (4) (5) (6) (7) (8) (9) Not my expertise

Shortness of breath

(1) (2) (3) (4) (5) (6) (7) (8) (9) Not my expertise

Sleep disorders

(1) (2) (3) (4) (5) (6) (7) (8) (9) Not my expertise

Tachycardia/palpitations

(1) (2) (3) (4) (5) (6) (7) (8) (9) Not my expertise

Tinnitus, and other hearing issues

(1) (2) (3) (4) (5) (6) (7) (8) (9) Not my expertise

Please list up to two other symptoms that you consider very important to include in the definition:

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**Notes:** List of symptoms presented in alphabetical order, extracted from:

<https://www.cdc.gov/coronavirus/2019-ncov/long-term-effects.html>

<https://www.acpjournals.org/doi/10.7326/M20-5926>

<https://apps.who.int/iris/bitstream/handle/10665/339629/Policy-brief-39-1997-8073-eng.pdf>

[https://www.who.int/publications/i/item/global-covid-19-clinical-platform-case-report-form-\(crf\)-for-post-covid-conditions-\(post-covid-19-crf-\)](https://www.who.int/publications/i/item/global-covid-19-clinical-platform-case-report-form-(crf)-for-post-covid-conditions-(post-covid-19-crf-))

Please provide any feedback on the wording of this domain, suggestions for other thresholds or values of this domain and/or an explanation of your rating:

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**Domain 6 – Minimum number of symptoms**

How important is “having a minimum number of symptoms” to the clinical case definition of Post COVID-19 condition?

- |                       |                       |                       |                       |                       |                       |                       |                       |                       |                       |
|-----------------------|-----------------------|-----------------------|-----------------------|-----------------------|-----------------------|-----------------------|-----------------------|-----------------------|-----------------------|
| (1)                   | (2)                   | (3)                   | (4)                   | (5)                   | (6)                   | (7)                   | (8)                   | (9)                   | Not my expertise      |
| <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> |

**Notes:** None

Please provide any feedback on the wording of this domain, suggestions for other thresholds or values of this domain and/or an explanation of your rating:

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### Domain 7 – Clusters of symptoms

How important is “**the inclusion of clusters of symptoms**” to the clinical case definition of Post COVID-19 condition?

- (1) (2) (3) (4) (5) (6) (7) (8) (9) Not my expertise

**Notes:** Symptom clusters are defined as consisting of two or more symptoms that are related to each other and that occur together. They are composed of stable groups of symptoms, are relatively independent of other clusters and may reveal specific underlying dimensions of symptoms. [**Reference:** Barsevick A. Defining the Symptom Cluster: How Far Have We Come? Seminars in Oncology Nursing 2016; 32 (4): 334-350.]

Please provide any feedback on the wording of this domain, suggestions for other thresholds or values of this domain and/or an explanation of your rating:

---

**Domain 8: Nature of symptoms**

How important is **“to include, in addition to PERSISTENT, other descriptors of the nature of symptoms”** to the clinical case definition of Post COVID-19 condition?

**Fluctuating**

(1) (2) (3) (4) (5) (6) (7) (8) (9) Not my expertise

**Increasing**

(1) (2) (3) (4) (5) (6) (7) (8) (9) Not my expertise

**New onset**

(1) (2) (3) (4) (5) (6) (7) (8) (9) Not my expertise

**Persistent**

(1) (2) (3) (4) (5) (6) (7) (8) (9) Not my expertise

**Relapsing**

(1) (2) (3) (4) (5) (6) (7) (8) (9) Not my expertise

**Notes:** None

Please provide any feedback on the wording of this domain, suggestions for other thresholds or values of this domain and/or an explanation of your rating:

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**Domain 9: Sequelae of well-described acute complications of COVID-19**

How important is **“to exclude symptoms which are directly related to acute complications of COVID-19 (such as stroke, acute respiratory distress syndrome, acute kidney injury, myocarditis, thrombosis, post-intensive care syndrome)”** in the clinical case definition of Post COVID-19 condition?

- |                       |                       |                       |                       |                       |                       |                       |                       |                       |                       |
|-----------------------|-----------------------|-----------------------|-----------------------|-----------------------|-----------------------|-----------------------|-----------------------|-----------------------|-----------------------|
| (1)                   | (2)                   | (3)                   | (4)                   | (5)                   | (6)                   | (7)                   | (8)                   | (9)                   | Not my expertise      |
| <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> |

**Notes:** None

Please provide any feedback on the wording of this domain, suggestions for other thresholds or values of this domain and/or an explanation of your rating:

---

**Domain 10 - Symptoms cannot be explained by an alternative diagnosis**

How important is “that Post COVID-19 condition be considered a diagnosis of exclusion determined by a health provider when symptoms cannot be explained by an alternative diagnosis” to the clinical case definition of Post COVID-19 condition?

- |                       |                       |                       |                       |                       |                       |                       |                       |                       |                       |
|-----------------------|-----------------------|-----------------------|-----------------------|-----------------------|-----------------------|-----------------------|-----------------------|-----------------------|-----------------------|
| (1)                   | (2)                   | (3)                   | (4)                   | (5)                   | (6)                   | (7)                   | (8)                   | (9)                   | Not my expertise      |
| <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> |

**Notes:** None

Please provide any feedback on the wording of this domain, suggestions for other thresholds or values of this domain and/or an explanation of your rating:

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**Domain 11: Should the definition be applied to all populations?**

How important is **“to include a separate clinical case definition for Post COVID-19 condition to apply for children”**?

- |                       |                       |                       |                       |                       |                       |                       |                       |                       |                       |
|-----------------------|-----------------------|-----------------------|-----------------------|-----------------------|-----------------------|-----------------------|-----------------------|-----------------------|-----------------------|
| (1)                   | (2)                   | (3)                   | (4)                   | (5)                   | (6)                   | (7)                   | (8)                   | (9)                   | Not my expertise      |
| <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> |

**Notes:** None

Please provide any feedback on the wording of this domain, suggestions for other thresholds or values of this domain, and/or an explanation of your rating:

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**Domain 12: Impact on everyday functioning**

How important is “that the symptoms experienced have an impact on everyday functioning” in the clinical case definition of Post COVID-19 condition?

- (1) (2) (3) (4) (5) (6) (7) (8) (9) Not my expertise

**Notes:** Impact on everyday functioning is better understood by the WHO ICF framework which classifies functioning, health and disability. The ICF shifts focus to "life", i.e. how people live with their health conditions, and takes into account the social aspects of disability. In ICF, the term “functioning” refers to all body functioning, activities (such as activities of daily living) and participation society. ICF also lists environmental factors and personal factors that interact with these components: <https://www.who.int/standards/classifications/international-classification-of-functioning-disability-and-health>

Please provide any feedback on the wording of this domain, suggestions for other thresholds or values of this domain and/or an explanation of your rating:

---

**You have completed this Delphi survey Round 2.**

**THANKS!**

## Appendix 5: Score for every domain/value in Delphi Rounds 1 and 2

Domain	Round	Text	n	Sum 1 to 3 (%)	Sum 7 to 9 (%)
1	1	How important is “ <b><u>having a history of SARS-CoV-2 infection</u></b> ” to the clinical case definition of Post COVID-19 condition?	252	4	79
	2	<i>Not asked in Round 2</i>		-	-
2	1	How important is “ <b><u>having a laboratory confirmed previous history of SARS-CoV-2 infection</u></b> ” to the clinical case definition of Post COVID-19 condition?	253	14	51
	2	How important is “ <b><u>having a laboratory confirmed previous history of SARS-CoV-2 infection</u></b> ” when there is access to laboratory testing, to the clinical case definition of Post COVID-19 condition?	194	10	52
3	1	How important is “ <b><u>the inclusion of the following proposed minimum time period (in weeks) between the onset of symptoms of acute COVID-19 (or for asymptomatic cases from date of positive test)</u></b> ” to the clinical case definition of Post COVID-19 condition?			
		• 4 weeks	253	29	44
		• 8 weeks	233	18	46
		• 12 weeks	230	16	60
		• 16 weeks or more	228	29	47
3	2	How important is “ <b><u>the inclusion of a minimum time period (in months) from the onset of COVID-19 to the presence of symptoms</u></b> ” to the clinical case definition of Post COVID-19 condition?			
		• 1 month	194	13	46
		• 2 months	192	14	43
		• 3 months	189	14	59
		• 4 months	187	27	40
		• 6 months or more	184	34	37
		• No time period	178	29	38
4	1	How important is “ <b><u>the inclusion of the following minimum duration of the symptoms</u></b> ” to the clinical case definition of Post COVID-19 condition?			

		<ul style="list-style-type: none"> <li>• At least 2 weeks</li> <li>• At least 4 weeks</li> <li>• At least 6 weeks</li> <li>• At least 8 weeks</li> </ul>	243 239 235 235	44 21 23 23	31 41 47 52
	2	How important is “ <b><u>the inclusion of any of the following minimum duration of symptoms</u></b> ” to the clinical case definition of Post COVID-19 condition? <ul style="list-style-type: none"> <li>• At least 0.5 months (2 weeks)</li> <li>• At least 1 months (4 weeks)</li> <li>• At least 1,5 months (6 weeks)</li> <li>• At least 2 months (8 weeks)</li> <li>• At least 3 months</li> <li>• At least 6 months</li> <li>• No minimum time duration</li> </ul>	184 184 183 183 178 177 171	38 17 20 17 23 37 47	28 42 42 47 40 32 27
5	1	How important is it “each of <b><u>the following symptoms</u></b> ” to the clinical case definition of Post COVID-19 condition?			
		<b>Abdominal pain</b>	221	27	27
		<b>Altered menstruation</b>	210	32	24
		<b>Altered smell/taste</b>	232	9	57
		<b>Anxiety</b>	230	16	49
		<b>Blurred vision</b>	225	17	38
		<b>Chest pain</b>	230	7	55
		<b>Cognitive dysfunction</b>	234	3	74
		<b>Cough</b>	232	8	63
		<b>Depression</b>	232	13	50
		<b>Dizziness</b>	230	8	47
		<b>Fatigue</b>	234	2	78
		<b>Fever</b>	229	14	46
		<b>Headache</b>	226	8	56
		<b>Impaired memory</b>	230	6	65
		<b>Joint pain</b>	231	8	52
		<b>Muscle spasms</b>	231	5	64
		<b>Neuralgia</b>	225	9	49
		<b>New onset allergies</b>	222	32	27
		<b>Pins and needle sensations</b>	227	15	39
		<b>Post-exertional malaise</b>	231	2	67
		<b>Shortness of breath</b>	232	3	78
		<b>Sleep disorders</b>	231	6	62
		<b>Tachycardia</b>	230	8	60
		<b>Tinnitus</b>	226	13	45
	2	How important is “ <b><u>to include, in addition to FATIGUE, SHORTNESS OF BREATH AND COGNITIVE DYSFUNCTION, any of the following symptoms</u></b> ” to the clinical case definition of Post COVID-19 condition?			
		<b>Abdominal pain</b>	178	29	24



		<b>Altered menstruation</b>	172	34	22
		<b>Altered smell/taste</b>	180	6	61
		<b>Anxiety</b>	183	15	49
		<b>Blurred vision</b>	177	20	30
		<b>Chest pain</b>	182	7	56
		<b>Cough</b>	181	8	58
		<b>Depression</b>	180	18	46
		<b>Dizziness</b>	181	10	39
		<b>Fever</b>	178	17	40
		<b>Headache</b>	181	8	54
		<b>Impaired memory</b>	180	4	69
		<b>Joint pain</b>	181	7	53
		<b>Muscle spasms</b>	180	4	63
		<b>Neuralgia</b>	177	11	45
		<b>New onset allergies</b>	172	36	20
		<b>Pins and needle sensations</b>	177	14	29
		<b>Post-exertional malaise</b>	180	2	67
		<b>Sleep disorders</b>	179	6	65
		<b>Tachycardia</b>	180	6	59
		<b>Tinnitus</b>	177	12	38
<b>6</b>	1	How important is “ <b><u>having a minimum number of symptoms</u></b> ” to the clinical case definition of Post COVID-19 condition?	239	25	38
	2	<i>Not asked in Round 2</i>		-	-
<b>7</b>	1	How important is “ <b><u>the inclusion of clusters of symptoms</u></b> ” to the clinical case definition of Post COVID-19 condition?	237	8	55
	2	How important is “ <b><u>the inclusion of clusters of symptoms</u></b> ” to the clinical case definition of Post COVID-19 condition?	179	4	68
<b>8</b>	1	How important is “ <b><u>to include each of the following descriptors on the nature of symptoms</u></b> ” in the clinical case definition of Post COVID-19 condition?			
		• <b>Fluctuating</b>	231	17	52
		• <b>Increasing</b>	231	17	49
		• <b>New onset</b>	233	7	69
		• <b>Persistent</b>	237	5	78
		• <b>Relapsing</b>	230	9	62
	2	How important is “ <b><u>to include, in addition to PERSISTENT, other descriptors of the nature of symptoms</u></b> ”			

		to the clinical case definition of Post COVID-19 condition?	184	10	55
		<ul style="list-style-type: none"> <li>• <b>Fluctuating</b></li> <li>• <b>Increasing</b></li> <li>• <b>New onset</b></li> <li>• <b>Relapsing</b></li> </ul>	182	22	36
		<ul style="list-style-type: none"> <li>• <b>Increasing</b></li> <li>• <b>New onset</b></li> <li>• <b>Relapsing</b></li> </ul>	183	5	69
		<ul style="list-style-type: none"> <li>• <b>New onset</b></li> <li>• <b>Relapsing</b></li> </ul>	183	6	65
9	1	How important is to “ <b><u>include only symptoms separate from those that are thought to be a sequela of well-described acute complications of COVID-19 [i.e., stroke, acute respiratory distress syndrome, acute kidney injury, myocarditis, thrombosis, post intensive care syndrome (PICS)]</u></b> ” in the clinical case definition of Post COVID-19 condition?	230	18	60
	2	How important is “ <b><u>to exclude symptoms which are directly related to acute complications of COVID-19 (such as stroke, acute respiratory distress syndrome, acute kidney injury, myocarditis, thrombosis, post-intensive care syndrome)</u></b> ” in the clinical case definition of Post COVID-19 condition?	180	14	63
10	1	How important is “ <b><u>that Post COVID-19 condition be considered a diagnosis of exclusion determined by a health provider when symptoms cannot be explained by an alternative diagnosis</u></b> ” to the clinical case definition of Post COVID-19 condition?	231	5	71
	2	<i>Not asked in Round 2</i>		-	-
11	1	How important is “ <b><u>that the Post COVID-19 condition definition can be applied to all populations, including women who are pregnant or post-partum; young children; neonates; people with chronic disease; people living with HIV; older people; or individuals who are immunocompromised because of other conditions</u></b> ” to the clinical case definition of Post COVID-19 condition?	230	7	69
	2	How important is “ <b><u>to include a separate clinical case definition for Post COVID-19 condition to apply for children</u></b> ”?	173	2	79
12	1	<i>Not asked in Round 1</i>			

	2	How important is “ <b>that the symptoms experienced have an impact on everyday functioning</b> ” in the clinical case definition of Post COVID-19 condition?	178	2	77
--	---	--	-----	---	----

## Appendix 6: Recommendation for the Conducting and Reporting of Delphi Studies (CREDES) checklist

Section/Topic	#	Checklist Item Description	Where reported
<b>Rationale for the choice of the Delphi technique</b>			
Justification	1	The choice of the Delphi technique as a method of systematically collating expert consultation and building consensus needs to be well justified. When selecting the	<b><i>“Added value of this study” Lines 101 to 108</i></b>
<b>Planning and design</b>			
Planning and process	2	The Delphi technique is a flexible method and can be adjusted to the respective research aims and purposes. Any modifications should be justified by a rationale and be	<b><i>“Methods” Lines 163 to 166</i></b>
Definition of consensus	3	Unless not reasonable due to the explorative nature of the study, an a priori criterion for consensus should be defined. This includes a clear and transparent guide for action on (a) how to proceed with	<b><i>“Methods” Lines 227 to 229, and Figure 1</i></b>
<b>Study conduct</b>			
Informational input	4	All material provided to the expert panel at the outset of the project and throughout the Delphi process should be carefully reviewed and piloted in advance in order to	<b><i>“Methods” Line 161, and reference 6 (pre-print of protocol)</i></b>
Prevention of bias	5	Researchers need to take measures to avoid directly or indirectly influencing the experts’ judgements. If one or more members of the research team have a conflict of interest,	<b><i>“Methods” Lines 208 to 215</i></b>
Interpretation and processing of	6	Consensus does not necessarily imply the ‘correct’ answer or judgement; (non)consensus and stable disagreement provide informative insights and highlight differences in	<b><i>“Methods” Lines 208 to 215</i></b>
External validation	7	It is recommended to have the final draft of the resulting guidance on best practice in palliative care reviewed and approved by an external board or authority before	<b><i>Not applicable</i></b>
<b>Reporting</b>			
Purpose and rationale	8	The purpose of the study should be clearly defined and demonstrate the appropriateness of the use of the Delphi technique as a method to achieve the research aim. A	<b><i>“Added value of this study” Lines 101 to 108</i></b>