**Distress Guide**

**Level 1 Mild Distress:**

*Respondent actions:*

* Change in voice tone or volume
* Change in focus
* Hesitancy to answer questions or probes
* Fidgeting
* Use of inappropriate language
* Non-relevant answers

*Interviewer actions:*

* Pause give respondent time to recover/compose themselves
* Check if respondent wants to continue if they have not already indicated that they would like to stop – terminate interview if necessary
* Change topic/move to next question/topic
* Inform PI
* Offer appropriate helpline numbers at the end of the interview

**Level 2: Moderate distress**

*Respondent actions:*

Level one signs plus…

* Long pauses and sighing
* Tearful / crying
* Extreme forms of agitation
* Non-responsiveness
* Nonsensical responses to questions or probes
* Asks for your advice/help
* Says, does not want to continue with interview

*Interviewer actions:*

* Stop interview and offer helpline numbers
* Inform PI and Operations team lead
* Complete respondent distress report form
* Operations team lead to submit incident report to ERB

**Level 3: Severe distress**

*Respondent actions:*

* Mentions suicidal thoughts
* Talks about wishing another person was dead or talks about committing harm to another person
* Respondent asks for immediate help from a health care professional

*Interviewer actions:*

* Stop interview and offer helpline numbers
* Inform PI and Operations team lead
* Complete respondent distress report form
* Operations team lead to submit incident report to ERB

**Helpline telephone numbers and web resources**

***For help with emotional distress[[1]](#footnote-2):***

National Suicide Prevention lifeline #**988**

Additional resources can be found on the CDC Website: <https://www.cdc.gov/violenceprevention/>

Resources for Cognitive Health and Older Adults

[Cognitive Health and Older Adults | National Institute on Aging (nih.gov)](https://www.nia.nih.gov/health/brain-health/cognitive-health-and-older-adults)

More Information about Cognitive Health, Dementia and Alzheimer’s:

NIA Alzheimer’s and related Dementias Education and Referral (ADEAR) Center ([www.nia.nih.gov/alzheimers](https://www.nia.nih.gov/alzheimers)) Phone Number: 800-438-4380

Email: [Adear@nia.nih.gov](mailto:Adear@nia.nih.gov)

**Alzheimer's Association**  
800-272-3900   
866-403-3073 (TTY)  
[info@alz.org](mailto:info@alz.org)  
[www.alz.org](http://www.alz.org/)

**Alzheimer’s Foundation of America**  
866-232-8484  
[info@alzfdn.org](mailto:info@alzfdn.org)  
[www.alzfdn.org](http://www.alzfdn.org/)

The CCQDER operations study team lead **Kristen Gregory-Lee/Amanda Titus** and the study PI will be informed of distress displayed during the interview.

The operations team lead will be responsible for reporting any signs of **moderate or severe** distress to the ERB.

**Respondent Distress Report form**

CASE ID number\_\_\_\_\_\_\_\_\_\_\_

Interviewer name\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_

Name of PI\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_

Level of distress (moderate/severe)\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_

Distress Description

\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_

Interviewer Actions

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Date reported to PI and Operations team lead\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_

Severe distress

Date reported to ERB\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_

Name of operations team lead making report\_\_\_\_

1. Links and phone numbers updated on: 06/24/2024 [↑](#footnote-ref-2)