

Ethical Considerations in the CARESSES experimental protocol – Questionnaire

Please answer the following questionnaire; rely on your own knowledge of the CARESSES study and experimental protocol and take all the time you need.

Once completed please send it back to Linda (linda.battistuzzi@unige.it) or Hiroko (kamide@coi.nagoya-u.ac.jp) if you are in Japan.

Date:

Name:

Affiliation:

1. What kind of attachment reduction procedure will be conducted at the end of the research participants' involvement in the CARESSES study?

- a) The participants' interaction with the robot will be gradually reduced over several days.
- b) The participants will be offered a personalized picture journal chronicling their time and experience with the robot.**
- c) The participants' relatives will be asked to call them more often than usual.

2. Will the research participants be obliged to remain with the robot for the entire duration of the testing procedures?

- a) Yes, the participants will have to remain with the robot the whole time.
- b) No, the participants will be free to leave the robot whenever they like.**

3. How can the robot support and maintain the independence of older adults?

- a) By offering more assistance than is actually needed.
- b) By offering cues and suggestions.**
- c) By reminding older adults that they need help in taking care of themselves.

4. Should care home staff rely on the robot to perform any of their usual caring activities with the research participants?

- a) No, staff should continue providing their care as usual and not rely on the robot.**
- b) Yes, staff may count on the robot for providing some caring activities in their place.
- c) Yes, staff may count on the robot for providing all usual care.

5. Will the research participants be encouraged to set any reminders for medication or treatment?

- a) Yes, medication reminders are extremely useful to older adults.
- b) Yes, but only under the supervision of care home staff.
- c) **No, any system failure could endanger the participants' safety when it comes to health-related reminders.**

6. How can the robot contribute to enhancing the research participants' feelings of dignity and self-worth?

- a) By insisting that the research participants do certain things or talk about certain topics.
- b) By taking care of the research participants' every need.
- c) **By expressing politeness, praise and respect.**

7. Will the privacy of older care home residents' participation within the CARESSES testing procedures from care home staff, residents and visitors be fully ensured?

- a) Yes, the researchers will state in the information forms (and during all recruitment interactions) that the privacy of their participation within the testing procedures from care home staff, residents and visitors will be fully ensured.
- b) No, the researchers will state in the information forms (and during all recruitment interactions) that the privacy of their participation within the testing procedures from care home staff, residents and visitors will not be fully ensured.
- c) **The researchers will state in the information forms (and during all recruitment interactions) that every effort will be made to protect the privacy of their participation within the testing procedures, but that it cannot be fully ensured.**

8. What happens if a prospective research participant refuses to be monitored through the surveillance camera?

- a) **The researchers will explain to her that video surveillance is a safety requirement and cannot be removed; if she refuses to be monitored she will not be able to participate in the study.**
- b) The researchers will say to her that they understand that she prefers not to be monitored by a video camera; they will rely on the microphone for surveillance.
- c) The researchers will say to her that they understand that she prefers not to be monitored by a video camera. Then they will ask her informal caregiver to consent in her place.

9. Will the robot follow the research participants to bathrooms?

- a) **No, never.**
- b) Yes, it's a safety requirement.
- c) Only if the participants ask the robot to do so.

10. How much time will be allocated to the procedure of seeking consent?

- a) At least half an hour; less time would not be enough to explain everything clearly.
- b) As long as is necessary and appropriate.**
- c) An hour at most; more time could tire prospective participants.

11. Will consent be revisited?

- a) Yes, consent will be revisited at least once after it is first obtained to ensure that the research participants have understood everything clearly.
- b) No, once consent is obtained from the research participants there is no need to annoy them by revisiting it.
- c) Yes, the researchers will readdress consent every time they engage with the participants to secure they are happy to participate in the study and data collection.**

12. What kind of an approach will the researchers employ during the observation of a participant's potential manifestation of distress?

- a) They will invite the participant to discuss any issues which concern them or make them feel anxious or vulnerable.**
- b) They will wait and see if the manifestation of distress occurs again.
- c) They will minimize the importance of whatever is causing distress to the participant.

13. In terms of the data collection methods used in the study, which of the following is a measure that will be taken to minimize the likelihood of harm to research participants?

- a) Researchers will employ a conservative and cautious approach during the observation of participants' potential manifestation of distress.
- b) Most of the scales that will be used in the study are validated, reliable, and proven to be acceptable within the older adult population and care home settings.
- c) Researchers will be transparent about their role boundaries.
- d) All of the above.**

14. Which of the following is NOT a measure that will be taken to avoid the stigmatization (including self-stigma) of certain groups (e.g., frail older adults) when undertaking and presenting the research?

- a) Approaching all participants with respect.
- b) Treating participants' experiences and contributions equally.
- c) Acknowledging research participants' individual contribution to the project by recording and storing their full names along with all their data.**

15. What does the principle of data minimization refer to?

- a) It refers to the fact that only few personal data will be collected during the testing procedures.
- b) **It refers to the fact that the collection of personal information from study participants will be limited to what is relevant and necessary to the study.**

16. Where will all the data collected from the research participants be stored?

- a) All the data collected from the research participants will be securely stored locally on a password protected and encrypted drive.
- b) **All the data collected from the research participants will be securely stored online on a password protected and encrypted Google Cloud Drive that will be created for the purposes of this study.**

17. Will the photographs or videos that the research participants may send to friends and relatives using Telegram, Line or other applications be stored locally?

- a) Yes, a copy of the photographs or videos taken during the experimental procedures and sent to friends or relatives using Telegram, Line or other applications will be stored locally on a password protected and encrypted drive.
- b) **No, any photographs or videos taken during the experimental procedures and sent to friends or relatives using Telegram, Line or other applications will be saved on each research participant's personal account and held by each of these applications' servers.**

18. When can the research participants withdraw from the study?

- a) **The participants can withdraw from the study at any point.**
- b) The participants can withdraw from the study once they have completed at least half of the testing procedures.
- c) Once they have consented to join the study, the participants cannot withdraw from it.

19. Which of the following is NOT - in and of itself - a reason why a researcher might decide to withdraw a participant from the study?

- a) The participant has started to express aggression and / or violence towards themselves, the robot and / or the researcher.
- b) The participant no longer has the cognitive or mental ability to participate in the study.
- c) **The participant has displayed some impatience with the robot.**

20. What is an incidental finding?

- a) A result that has to do with an incident that occurred during the testing procedures.
- b) An observation concerning a research participant that has potential health importance and is discovered in the course of conducting research but is beyond or unrelated to the aims of the study.**
- c) An observation concerning a research participant that has potential health importance, is discovered in the course of conducting research and is related to the aims of the study.

21. How will incidental findings be managed in CARESSES?

- a) They will not be taken into consideration.
- b) They will be discussed during the consent process: researchers will ask participants for permission to discuss anything of potential health importance that they should observe during the experiments with the participants' caregivers or other care home staff.**
- c) They will be reported to the participants' caregivers or care home staff, as appropriate, but will not be discussed with research participants during the consent process.

22. Which of the following can be manifestations of psychological distress in research participants?

- a) Behavioral symptoms such as tearfulness or agitation, including pacing, wringing hands, pulling hair or other fidgeting.
- b) Physical symptoms such as sweating and / or excessive trembling, dizziness or feeling lightheaded or faint.
- c) Cognitive symptoms such as repeatedly asking the same questions or not remembering to do routine things.
- d) Emotional symptoms such as irritability or angry outbursts, suspiciousness and/or fearfulness (particularly when facing certain objects or events).
- e) All of the above.**