Special Considerations when Scanning Individuals with ME/CFS

ME/CFS typically involves increased sensitivity to sensory stimuli, and decreased tolerance for sustained attention and cognitive effort. Long or demanding neuroimaging sessions may overwhelm participants with ME/CFS and lead to incomplete sessions or unusable data. There are several considerations to be made when planning scan sessions for ME/CFS participants, which may require modifications to researchers' standard protocols. Many neuroimaging studies have been successfully completed, and researchers with experience conducting those studies have made the following suggestions and notes:

• Optimally, total scanner time per session will be 1 hour or less.

• Protocols lasting 1.5 hours have been used occasionally, though that length may be considered extreme and outside the tolerance of some participants.

• The total scanner time tolerated by participants may be shortened if challenging cognitive tasks or noxious sensory stimuli (i.e., bright visual, loud auditory, or cool temperatures) are administered. Likewise, a participant's tolerance for a series of cognitive tasks may be shortened by the standard scanner environment.

•Movement artifacts detected during MRI scan preprocessing can ruin an otherwise successful run. Participants should be as cushioned and comfortable as possible. Foam support behind the knees should be standard. There should be communication with the operator in case the subject has to move as this will require a new localizer scan.

•For MRI scans, noise and temperature may present a demand on participants. Scanner conditions will likely play a bigger role in task performance and tolerance of ME/CFS participants. Where possible, participants should be given options to change ambient lighting, control body temperature, and reduce perceived scanner noise.

•A mock scanner to practice each task and any button box or other apparatus is helpful to confirm that participants are not likely to have claustrophobia. This however does not preclude participants from having anxiety/claustrophobia which could lead to a panic attack while in the real scanner. Participants should be told that this is possible even if they have not had claustrophobia before, and ask them to be sure and let study/imaging staff know if they started to get anxious. Knowing that participant is beginning to feel anxious may allow study staff to talk the participant through their anxiety and help them feel safe to complete the rest of the scan.

•There is debate about keeping eyes open or eyes closed for scans. It may be preferable to have participants keep their eyes open with the light off because otherwise some may fall asleep during "awake resting scans".

• Cognitive performance may be diminished toward the end of a scanning protocol, even when the total scan time is tolerable. Critical cognitive tasks may be placed at the beginning of the protocol, with scans less susceptible to performance degradation (e.g., structural scans) performed at the end of the session.

• Attention-demanding tasks should be limited in a session, with sustained effort of over 20 minutes likely to be intolerable to participants.

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• Regardless of protocol length, some participants may need breaks out of the scanner. Ask participants to let study/imaging staff know if they need a break to use the bathroom. Some participants may feel embarrassed to bring this up. Protocols would optimally include time for a short break, and methods for resuming scan sessions without harming data quality.

• Participants should be made aware in advance of the total time and effort required to complete the scan session, so that they can adequately plan and pace their activities in preparation, even bring comfortable or warm clothing.

• Even an optimally-designed protocol will have sustained repercussions for many ME/CFS participants. Tasks performed after a scan session may be adversely affected. If possible, the laboratory visit may be limited solely to the scan session, to reduce overall demand.

• Once the entire protocol has been developed, it is suggested that one or two ME/CFS participants complete the protocol and give direct feedback and suggestions. The purpose of these test sessions is to determine if any changes can be made to increase participant comfort and increase session completers.