

HOBIT GOSE Guide

General

It is crucial that both the participant and caretaker are interviewed to obtain as much information as possible.

The single most important question is “why”. It’s critical to understand WHY someone cannot do something. Is the reason related to the TBI or something else (e.g., physical injury, weather, finances, pandemic rules)? Often you have to ask multiple, detailed questions to fully understand what someone cannot do and why not.

Ask what the participant CAN do, not what s/he HAS done. Examples of what the participant has done are very helpful and lend confidence to the scoring, however, it is not necessary that the participant has actually done something to be considered as able.

Participants and caretakers will sometimes contradict each other. Whenever possible, interview them separately. It is up to you to determine what answer is most credible. Oftentimes when a person with a TBI is severely disabled, s/he lacks insight so the caretaker may be more reliable. When this happens, it may be helpful to go back to the first person interviewed, (carefully) point out discrepancies and ask additional questions.

Except in cases where the participant is vegetative, all questions on the interview form must be asked.

The GOSE is meant to be a largely hierarchical interview. It is unusual (but not impossible) for the participant to be able to do something (e.g., shopping, work) further down the list of questions if unable to do something earlier in the list (e.g., be left alone for 8/24 hours). When this happens, return to earlier questions and ask for more information to determine whether one of the scores is incorrect.

Question #1. Vegetative State.

If the participant is talking to you, you do not need to ask this question.

If the participant cannot talk or obey any commands, the GOSE assessment stops at this point.

Question #2. Independence at Home.

It is important to explicitly ask about being able to be left alone for 8 hours and (if applicable) 24 hours.

Being left alone means that the participant would be safe (i.e., not wander from home, could handle an emergency by calling for help) and can meet his/her most basic needs. It does not mean that s/he must be able to do things like cook an elaborate meal, clean the entire house or even shower.

Be aware that caregivers and family members can sometimes be overly cautious. They may not WANT to leave the participant alone. Probe to determine whether it would be possible if absolutely necessary.

Medication management is sometimes given as a reason that someone could not be left alone. When this comes up, consider if not taking the medications would be life threatening in 24 hours (or 8 hours).

Question #3. Shopping

Be clear when interviewing that this question does not include transportation to the store. Ask "if driven to the store by someone..."

This question is also not about any kind of elaborate shopping trip. Simply ask about going into a store, shopping for a single item (such as a loaf of bread), paying for it and leaving.

If the participant is in a wheelchair (even if due to TBI related reasons), it is ok if someone has to push him/her in the store. Ask if the participant could navigate to, choose and pay for an item.

Question #4. Local Travel

If the participant is driving, there is no need to ask questions about taking public transportation.

If the participant is thought to be able to drive safely, but is waiting for medical clearance, use your best judgement regarding the reason clearance has not yet been given when determining if the person could drive. (Or just ask questions about public transportation.)

Most participants will not be back to driving yet, so ask whether the participant can take public transportation such as a bus, taxi or Uber.

To be considered “able” the participant must be able to make travel arrangements, direct the driver/know what stops to use and pay the fare.

Rides with friends or family do not count. If this is all the participant has done thus far, ask what s/he COULD do.

In places where no forms of public transportation are available, ask what the participant could do if they were available.

Question #5. Work

This question can be difficult because there are many factors to consider.

Begin this question by asking what the participant was doing for work before.

Next, find out if the participant is working his/her previous job in the previous capacity. If not, find out exactly why. Is the reason TBI related or due to some other cause (e.g., physical injury, seasonal job, layoffs)?

If the participant is working a different job, ask questions to determine if the new position is of a similar nature/requires similar abilities. If it does not, determine whether the participant changed to this new position because of TBI related reasons or any other cause.

Ask whether the participant is working to the same level of capacity (e.g., as many hours and as efficiently and effectively). If not - determine whether the reasons are TBI related.

If there are any other (non-TBI) reasons for reduced work, determine what the participant could do if these other factors were no longer an issue.

Any level of reduction in job status or performance is considered “reduced” work (if any of the reduction is determined to be TBI related). Any paid, competitive work that is not at least equal to (in terms of type, amount or efficiency) the participant’s previous work status, is considered to be “reduced”. For instance, if a participant is currently unable to work in her former position as a nurse, but could work in a simpler, paid job (e.g., store greeter), this would be considered reduced work.

The category of “sheltered” or “unable” is reserved for when a participant is completely unable to work or could only hold a noncompetitive position (e.g., a special program created for individuals with brain injuries).

If someone was unemployed, but seeking work prior to the injury, ask questions about whether the TBI related issues would likely impact his/her ability to find employment and work to previous capacity. (Given the complexity of this situation, it is suggested that you contact the central outcome monitors to help tease out the correct answer.)

School is considered work. Ask students about the type and number of courses taken as well as their performance in these courses as compared to pre-TBI. If they have accommodations in place, this is considered reduced capacity.

If someone was retired prior to the TBI, ask questions about what type and amount of work the participant could have done immediately before the injury and whether this has been negatively impacted by the TBI.

If the participant was not working and unable to do any kind of work pre-TBI (and remains unable) mark this question as able to work in previous capacity.

Question #6. Social and Leisure Activities

This question can also be difficult for many of the same reasons as the WORK question.

Begin this question by asking what the participant did for fun before the TBI in an open-ended way. Do not list out or ask about specific activities.

Next, find out if the participant is (or could be) participating in the same types of activities and the frequency of this participation in comparison to baseline. If there has been any change in the type or frequency of the activities, find out exactly why this is. Is the reason TBI related or due to some other cause (e.g., physical injury, seasonal activity, financial issues, pandemic)?

If there are any other (non-TBI) reasons for changed/reduced activities, determine whether, in the absence of these other reasons, the participant would be able to engage in previous activities at the previous frequency. If not, what would be the reduction in frequency if only the TBI related issues remained?

Lack of interest in participating in activities CAN be a TBI related reason. Ask lots of questions about this and, ultimately, use your clinical judgment to determine whether this is the case for this participant.

Question #7. Psychological Disruption Affecting Relationships

There are two main components of this question that must BOTH be present to answer this question affirmatively. Psychological problems and disruption of relationships.

Don't confuse the psychological problems (e.g., irritability, anxiety, depression, childish behavior) of the participant with cognitive impairment. Also, when speaking to caregiver, don't confuse their feeling of relationship strain or burnout with caring for the participant as a whole or the participant's cognitive difficulty/agitation. Again must ask why.

Sometimes it's helpful to talk in terms of "strain" on relationships rather than disruption. The word "disruption" can sometimes confuse people.

When determining the extent of the disruption, tolerability trumps frequency. For example, if the disruption is daily, but tolerable, mark "frequent" not "constant" on the GOSE form.

The final step in this question is to determine whether the current disruptions were present prior to the TBI. If they were present and at the same severity and frequency, mark "yes". If either the severity or frequency have increased, mark "no".

Question #8. Other Problems Affecting Daily Life

If there are any problems present, but not already asked about, mark "yes". It is not necessary to ask about an exhaustive list of problems. One issue is sufficient.