

Umbrella Study to Evaluate the Feasibility of Collecting User Interaction Data in Participants Using MapHabit Software

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09 July, 2024 **Summary of Changes from Previous Version:**

| Affected Section(s) | Summary of Revisions Made | Rationale |
|------------------------------|--|---|
| 6.5; additions to section 16 | Additional questionnaires and assessments that may be included in sub-studies of the umbrella protocol | Subsequent sub-studies may include additional questionnaires and assessments that evaluate more specific aspects of outcomes than previous instruments. |
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1. Protocol Summary

1.1. Synopsis

Title

Umbrella Study to Evaluate the Feasibility of Collecting User Interaction Data in Participants Using MapHabit Software

Study Description

This is a multi-center, prospective, observational, sample collection/methods development study, with continuous user interaction data collection.

Objectives

A. Primary Objective:

- Demonstrate the feasibility of collecting user interaction data in participants using MapHabit software

B. Exploratory Objective:

- For AD/RD: Develop measures to qualify and quantify disease progression and severity based on the collected user interaction data. Participants will be expected to utilize the MapHabit application either independently or with the assistance of a caregiver/LAR depending on the capacity of the participant.
- For DS: Develop measures to qualify and quantify independence and improvements in quality of life. Participants will be expected to utilize the MapHabit application under the supervision of the parent or legal guardian.

Endpoints

A. Primary Endpoint:

- Availability of user interaction data
- A set of sub-study specific questionnaires at the start and end of the intervention

B. Exploratory Endpoint:

- Mathematical model to establish a relationship between: behaviors while operating a mobile device as measured by user interaction data collected during this study, and disease severity and progression as measured in subsequent sub-study(ies) conducted by MapHabit Inc.

Inclusion, Exclusion and Withdrawal Criteria:

A. Inclusion Criteria:

- **For Adult population with AD, ADRD, TBI, MCI, or other form of cognitive impairment:** Female or male subjects must be over the age of 18. A legally authorized representative (LAR) must sign on behalf of the subject if the subject does not have the capacity to consent
- **For Down Syndrome Population:** Females and males 5-17 years of age. Parents or Legal guardians must sign for subjects under the age of 18
- A clinical diagnosis of Alzheimer's Disease (AD), Alzheimer's Disease Related Dementia (ADRD), Mild Cognitive Impairment (MCI), Traumatic Brain Injury (TBI), other forms of cognitive impairment OR a diagnosis of Down Syndrome (DS) OR a caregiver of an individual within the two populations above
- Candidate participants over the age of 18 with clinical diagnosis of AD/ADRD, MCI, TBI, or other form of cognitive impairment OR Down Syndrome are screened for capacity to provide Informed Consent (see Section 10)
- Informed Consent obtained from candidate participant or legally authorized representative (LAR), parent, or legal guardian as appropriate

B. Exclusion Criteria:

- Candidate participants with capacity and unwilling to provide Informed Consent for this study, or candidate participants without capacity and unable to provide Informed Consent through surrogacy, are excluded from enrollment

C. Withdrawal Criteria:

- Withdrawal of Informed Consent
- For caregivers of individuals with AD/ADRD, MCI, TBI, or other form of cognitive impairment: dissolution of a suitable patient-caregiver relationship

Study Population:

The maximum number of participants enrolled in the study is 1000. The participants will be using the MapHabit software in scope of MapHabit Inc. sub-studies.

Cohort 1: Must be 18 years of age or older at the time of consent. This study will enroll individuals with cognitive impairments ($n \leq 300$) and the caregivers of individuals with cognitive impairment ($n \sim 250$). Caregivers may be associated with more than one individual. Enrolled individuals with cognitive impairment must have had a previously established clinical diagnosis of Alzheimer's Disease (AD), Alzheimer's Disease Related Dementia (ADRD), Traumatic Brain Injury (TBI), Mild Cognitive Impairment (MCI) or other forms of cognitive impairment.

Cohort 2 (Amended Population): Must be between the ages of 5-17 years old at the time of the study. This study will enroll individuals $n \leq 250$ and the primary caregiver/parent of individuals with Down Syndrome (DS) ($n \sim 250$). Enrolled individuals with DS must have a previously established clinical diagnosis of DS. A parent or legal guardian must consent for subjects under the age of 18 and supervise the child's use of the system.

Recruitment

Study participants will be recruited from the general public and within the MapHabit software. Recruitment material that is provided in-person, digitally, or through the MapHabit software will include:

- Purpose of the study
- Expectation of the participants
- Time commitment for participating
- Location where research is taking place

Compensation is offered for participation, with the monetary amount depending on the sub-study. Monetary amount is based on the duration of the sub-study. Compensation will range from \$50 to \$200. Recruitment material presented within the MapHabit software will have design elements (e.g., font size, color, graphics) consistent with the remainder of the software interface. Reimbursement will be provided for expenses, including transportation to initial or exit interview, which may be incurred related to this study. The MapHabit System will be offered to participants during this study at no cost to the participants or families of the participants during the course of this study.

Description of Study Intervention:

This umbrella study does not introduce any intervention other than the utilization of the MapHabit System during the specified period of the sub-study. Furthermore, subsequent MapHabit Inc. sub-studies may measure or collect cognitive and health outcomes of all study participants. The user interaction data collected in this umbrella study and clinical outcomes data—including protected health information (PHI)—collected in subsequent sub-studies can be analyzed in combination to generate a mathematical model demonstrating the relationship between these two types of measurements. It is hypothesized that such a mathematical model may be used to forecast future changes in cognition and health based on behaviors while operating a mobile device. This forecast may be used by clinicians to guide changes in medical and behavioral therapy, hospital systems and insurers to identify at-risk and high utilization patients, and individuals with cognitive impairment and family members better prepare emotionally and financially for the future. With the recent development of gamification—the application of game playing elements—within the MapHabit system, subsequent sub-studies may measure how user engagement is impacted by the introduction of virtual reality aspects that is associated with the MapHabit system.

Participant Duration:

This umbrella study protocol does not require a minimum or maximum duration of study participation. The duration of participation in a research study will be defined by subsequent MapHabit, Inc. sub-study(ies) in which the subjects or their LAR, parent/legal guardian (where

applicable) will participate in an exit interview at the end of the study. The study will be completed once the maximum number of participants complete the study. Participants in the AD/RD sub-study population will be expected to use the MapHabit System daily for 6 months. Participants in the DS sub-study population will be expected to use the MapHabit System for 3-6 months. Participants may use the MapHabit System for up to 2 years, in which data will be passively collected with no additional expectations of the users.

1.2. Schedule of Activities

| Study Activity | Enrollment (Day 0) | Continuously | End of Participation |
|---|-----------------------|--------------|-------------------------|
| Inclusion/Exclusion screening | X | | |
| Participant completes enrollment to this study within the MapHabit software | X | | |
| Participant is evaluated for ability to provide Informed Consent | X | | |
| Informed Consent is provided by participant or consenting legally authorized representative | X | | |
| Assignment of unique participant number | X | | |
| Initial Baseline Interview with sub-study appropriate questionnaire or survey | X | | |
| Passive data collection | | X | |
| Evaluation of Withdrawal Criteria | | X | |
| Study completion | | | X |
| Exit Interview with sub-study appropriate questionnaire or surveys throughout study | | | X |
| Post intervention survey as appropriate for sub-study | | | X |

2. Introduction

2.1. Study Background and Rationale

As Alzheimer's disease (AD) progresses, an increasing rate of atrophy is seen in the hippocampus [1] while the neostriatum is preserved [2]. The neostriatum is responsible for the development and retention of procedural memory, such as routines and habits.

Down Syndrome (DS) occurs in one in 700 live births. In addition to intellectual disability, people with DS are very likely to eventually develop AD. 70% of people with DS develop the neuro-pathophysiology associated with AD by their 40s, and current research suggests that there could be common pathogenic mechanisms [6]. Importantly, such mechanisms primarily manifest as learning disabilities in children with DS, involving mild to moderate cognitive impairment [7]. Evidence suggests early intervention that address cognitive, language, and social-emotional needs of children with DS can promote child development. Specifically, engagement in strongly responsive interactions with daily routines induce the child's use of various pivotal developmental behaviors, such as attention, initiation, and persistence [8].

The MapHabit software was developed as an assistive technology for individuals living with AD, Alzheimer's disease related dementias (ADRD), and their caregivers. This technology utilizes aspects of visual mapping to enhance the ability of memory impaired individuals to live independently. Visual mapping is a learning technique to diagram relationships between ideas and memories. Despite remarkable success across a wide range of disciplines, there is nothing to deliver the capabilities of visual mapping for individuals living with cognitive impairment. Currently commercial visual mapping software is too complicated for users with memory, cognitive, and physical impairments and are not easily adaptable. The MapHabit software combines features of mind mapping with a dynamically responsive user interface to assist individuals, caretakers, and clinicians.

Here we propose an umbrella trial to evaluate the feasibility of collecting information about user interactivity with the MapHabit software interface. This data has the potential to be used for further development of the MapHabit software and developing measures of disease severity, progression, and independence.

2.2. Description of the MapHabit Software used in Sub-studies

By engaging with the MapHabit software, a user can develop and utilize visual maps to show schedules and activities of daily living (ADL). Visual mapping is a technique to enhance learning and memory that has been studied previously in cognitive intact populations [3][4]. It is hypothesized that the use of the visual maps will enhance the ability of patients with cognitive impairment to improve the quality of their life (QoL). The visual maps are personalized for each individual, created specifically for activities requiring additional assistance, and serve as a constant and available reminder of important information. The gamification of the visual maps mentioned above is a part of the continuing development and improvement of the software, with virtual reality implementation being a part of the gamification initiative. These additions can potentially elevate the experience of the MapHabit software.

After repeated use of the MapHabit software, individuals with impaired memory can develop a habit of routinely using visual maps to independently manage their daily activities. Doing so alleviates dependence of individuals with cognitive impairment from their caregivers. Benefits of the MapHabit software include, but are not limited to, reduced levels of stress, agitation, confusion, frustration, and anger. Individuals become less reliant on caregivers and family members, achieving more autonomy in daily living. Stress and burden experienced by caregivers and family members are significantly reduced, improving QoL for all parties involved.

3. Objectives and Outcomes

| OBJECTIVES | OUTCOMES | JUSTIFICATION FOR OUTCOMES |
|--|--|---|
| Primary Objective | | |
| Demonstrate the feasibility of collecting user interaction data in participants using MapHabit software | Availability of user interaction data | We want to demonstrate that the data collection is technically feasible, and the structure of the collected data is suitable for analysis and measure development |
| Exploratory Objective | | |
| Develop measures of disease severity, progression, independence and quality of life with AD/RD participants based on the collected user interaction data. For DS participants, this study also hopes to develop measures for independence and quality of life based on the collected user interaction data | Mathematical model to establish a relationship between behaviors while operating a mobile device (as measured by user interaction data) and clinical disease severity and progression (as measured by PHI in subsequent sub-studies) | We hypothesize that a subject's behavior within the software is affected by clinical severity and progression of disease and/or may influence the subject's independence, quality of life, or other outcomes as measured by the sub-study specific questionnaires or surveys. |

4. Study Design

Study Design for the ADRD Population:

This is a multi-center, prospective, observational, sample collection/methods development study, with continuous user interaction data collection. This study will enroll two groups of participants:

1. Individuals (n =<300) with a diagnosis of AD, ADRD, TBI, MCI, DS or other form of cognitive impairment. Individuals will participate in sub-study relevant surveys and questionnaires if they have the capacity to do so throughout the study period.
2. Caregivers OR Legally Authorized Representatives (n ~ 250) of enrolled individuals. One caregiver may be assigned to several individuals. Caregivers will participate in sub-study surveys if the individual does not have the capacity to do so.

Study Design for the DS Population:

This is a multi-center, prospective, observational, sample collection/methods development study, with continuous user interaction data collection. This study will enroll two groups of participants:

1. Individuals (n =< 250) between the ages of 5-17 with a diagnosis DS
2. Parents/Legal Guardians (n ~ 250) of the enrolled individuals. Parents must complete surveys and questionnaires on the behalf of the individual throughout the study period.

Study participants will engage with the MapHabit software through a mobile device (e.g., smart phone or tablet) equipped with MapHabit software. This study will collect measures of participant engagement within the MapHabit software via Google Analytics for Firebase platform. The collected data is then transferred to a cloud computing platform for processing and further analysis. Data originating from Google Firebase will be encrypted in transit using TLS/SSL and encrypted at rest using the AES-256 encryption algorithm. The following data types will be collected:

1. Dwell time: the duration of time that an element of the software interface is displayed to the participant without any further interaction. This can be further segmented to:
 - a. Screen dwell time
 - b. Prompt dwell time
2. User input: actions (e.g., tapping, swiping, typing) with all interactive elements (e.g., buttons, dialog box) within the MapHabit software will be recorded with an element identifier and time of interaction
3. Application logs, such as error reports, unexpected shutdowns, etc.

Within sub-studies conducted by MapHabit, inc., clinical outcomes data, including electronic medical records and other PHI of participants, may be transmitted to MapHabit, inc. by partnering sites (i.e., Senior Living facilities) and examined retrospectively to analyze in combination with user interaction data in generating a mathematical model demonstrating their relationship.

Within sub-studies conducted by MapHabit, inc., virtual reality components may be implemented to a small subset of participants to examine how the addition of virtual reality gamification may influence the current user interaction data seen in the MapHabit software. The virtual reality is a supplemental or exploratory condition to examine whether modern game elements can enhance user interaction and engagement with the MapHabit system. Participants are considered enrolled in this study after providing Informed Consent. Informed Consent may be obtained in writing or electronically.

The study will consist of three parts:

1. Enrollment in study (day 0)

2. Continuous data collection
3. End of participation

This umbrella study protocol does not require a minimum or maximum duration of study participation. The duration of participation in a research study will be defined by subsequent MapHabit, Inc. sub-study(ies) for participants with ADRD and separately for children with DS and their parents or legal guardians. The study will be completed once the maximum number of participants complete the study. The MapHabit System is easy to setup upon beginning the study and all participants will undergo an initial onboarding training virtually or in-person.

4.1. Treatment Assignment

Any participant meeting all inclusion criteria is eligible for enrollment in this study. Participants are considered enrolled in this study after providing Informed Consent. Informed Consent may be obtained in writing or electronically.

5. Study Population

The maximum number of participants enrolled in study this 1000. Participants in the first study population cohort are individuals with clinical diagnosis of AD, ADRD, TBI, MCI, or other form of cognitive impairment; and/or their respective caregivers; who are using the MapHabit software in scope of MapHabit sub-studies. All participants are at least 18 years of age on day of consent. No further demographic information regarding sex, gender, race, and location, income, marital status, or living situation is defined at this time. The study will enroll individuals with cognitive impairment ($n = 250$) and caregivers of individuals with cognitive impairment ($n \sim 250$). All individuals with cognitive impairment will have a clinical diagnosis of AD, ADRD, TBI, MCI, or other form of cognitive impairment. We will also be collecting data from caregivers as appropriate for sub-studies.

The second study cohort will feature individuals with a clinical diagnosis of DS; and/or their respective caregivers; who are using the MapHabit software in scope of MapHabit sub-studies. Subjects must be at least 5 years of age on the day of consent. No further demographic information regarding sex, gender, race, location, income, or living situation is defined at this time. This study will enroll individuals with a clinical diagnosis DS ($n \sim 250$) with the supervision of their parents/legal guardians.

5.1. Inclusion Criteria

- **For Adult population with AD, ADRD, TBI, MCI, or other form of cognitive impairment:** Female or male subjects must be over the age of 18. A legally authorized representative (LAR) must sign on behalf of the subject if the subject does not have the capacity to consent

- **For Down Syndrome Population:** Females and males between 5-17 years of age. Parents or Legal guardians must sign for subjects under the age of 18.
- A clinical diagnosis of Alzheimer's Disease (AD), Alzheimer's Disease Related Dementia (ADRD), Mild Cognitive Impairment (MCI), Traumatic Brain Injury (TBI), Down Syndrome (DS) other forms of cognitive impairment, OR a caregiver of an individual with a diagnosis listed above
- Candidate participants with clinical diagnosis of AD/ADRD, MCI, TBI, or other form of cognitive impairment are screened for capacity to provide Informed Consent (see Section 10)
- Informed Consent obtained from candidate participant or legally authorized representative (LAR), parent or legal guardian as appropriate

5.2. Exclusion Criteria

- Candidate participants with capacity and unwilling to provide Informed Consent for this study, or candidate participants without capacity and unable to provide Informed Consent through surrogacy, are excluded from enrollment

5.3. Withdrawal Criteria

- Withdrawal of Informed Consent
- For caregivers of individuals with AD/ADRD, MCI, TBI, or other form of cognitive impairment: dissolution of a suitable patient-caregiver relationship

5.4. Screen Failures

Subjects who are screened that do not meet inclusion criteria will not be enrolled in the trial.

6. Study Methods

6.1. Participants Joining the Umbrella Study from Sub-Study

All participants in any MapHabit, Inc. sub-study engaging with MapHabit software will be offered enrollment in this umbrella study at the time of enrollment to the respective sub-study. User data from participants not enrolled in this study will be handled according to protocols set forth by the MapHabit, Inc. sub-study(ies) the subject may be enrolled in. User data from subjects not enrolled in this umbrella study or subsequent sub-study(ies) will not be collected.

6.2. Pre-recruitment

No pre-recruitment activities.

6.3. Enrollment: Day 0

After creating the account, the subjects proceed to enrollment process, which consists of 2 steps:

1.) Inclusion/Exclusion Criteria Assessment and sub-study relevant pre-assessment questionnaires

a.) Performed by trained and qualified study personnel

2.) Signing of Electronic Informed Consent Form (eICF) and HIPAA Waiver

Please refer to the RESEARCH CONSENT FORM

6.4. Data Collection Period

Participants will not take part in any assessment during the data collection period of the umbrella study. There is no predefined minimum data collection period. User interaction data will be passively collected during the time the participant engages with the software. For sub-studies that involve retrospectively examining clinical outcomes data and PHI of participants, data will be de-identified and collected only during the time the participant engages with the software. For MapHabit sub-studies amongst the AD/RD population, participants and their caregivers will be expected to use the MapHabit System daily for 6 months. For MapHabit sub-studies amongst the DS population, children will need to use the MapHabit system daily for 3-6 months under the supervision of a parent or legal guardian. The maximum duration for passive user interaction data collection is two years. Parent(s) or legal guardians will be administered a periodic assessment on a monthly basis throughout the study in addition to the baseline assessments and the exit interviews for specific sub-studies that will occur at the end of the study period.

6.5. Follow Up Assessments

No follow up assessments are included in this umbrella protocol. Participants of this study may undergo follow up assessments or questionnaires in accordance with subsequent MapHabit, Inc. sub-study(ies) the participant may be enrolled in. Samples of all assessments are included within this document. Baseline, Periodic, and Post Follow-up assessments for a sub-study amongst individuals with AD/RD may include:

- Quality of Life in Alzheimer's Disease
- Zarit Burden Interview
- Pittsburgh Sleep Quality Index (PSQI)
- The Lawton Instrumental Activities of Daily Living Scale
- Neuropsychiatric Inventory (NPI) Questionnaire

- The Montreal Cognitive Assessment (MOCA)
- The Medication Management Instrument for Deficiencies in the Elderly (MedMaIDE)
- Geriatric Depression Scale
- Pain Assessment in Advanced Dementia Scale (PAINAD)
- Caregiver Self-Assessment Questionnaire
- MapHabit, Inc. Final Exit Interview Questionnaire
- Brief Interview for Mental Status – (BIMS) [Sample not included]
- Wisconsin Quality of Life Caregiver Questionnaire
- Pain and Sleep Questionnaire
- Patient Health Questionnaire (PHQ9)
- Generalized Anxiety Disorder Scale (GAD7)
- Anger Management Scale
- Caregiver Self-Assessment Questionnaire
- Bristol Activities of Daily Living Scale (BADLs)

Net Promoter Scale Questionnaire Baseline, Periodic and Post Follow-up assessments for a sub-study amongst individuals with DS may include:

- MapHabit, Inc Final Exit Interview Questionnaire
- LuMind Down Syndrome Caregiver Assessment
- Vineland-3
- Neuropsychiatric Inventory (NPI) Questionnaire
- Adaptive Behavior System Third Edition (ABAS-3) [Sample not included]
- Child Behavior Checklist (CBCL) [Sample not included]
- Behavior Problem Inventory (BPI-01)

7. Statistical Considerations

No inferential statistical evaluation is foreseen in the scope of this study. Data will be listed and summarized by means of descriptive statistics in tabular and graphical formats.

7.1. Sample Size Determination

Approximately 250 individuals with cognitive impairment and 250 caregivers of individuals with AD/RD will be enrolled in this umbrella study. Approximately 250 children with DS under the supervision of parents or legal guardians will be enrolled in this umbrella study. No formal sample size calculations were performed, as this is non-interventional, observational research. The number of participants was chosen based on feasibility and is considered sufficient to meet the study objectives and for potential sub-studies.

8. Subject Accountability

Subjects who meet eligibility criteria and agree to participate in this study will be given an Informed Consent form, in writing or electronically, approved by an Institutional Review Board (IRB).

All subjects who meet eligibility criteria and endorse the Informed Consent form are considered enrolled in this study. Subjects enrolled in this study are followed in accordance with this umbrella protocol.

8.1. Withdrawal

If a participant is withdrawn from this study, the reason(s) for withdrawal will be reported to the study data collection system. Data collected up to the point of withdrawal will be used for analysis and retained per protocol. No further user interaction data will be collected from the participant following their withdrawal.

9. Safety

9.1. Risk/Benefit Assessment

9.1.1. Known Potential Risks

There are no known potential risks and/or discomforts associated with the passive collection of user interaction measures through software. For minors involved in the DS population, parental supervision and assent is required. Administrative and technical safeguards in accordance with HIPAA standards are in place to secure the confidentiality of electronic clinical outcomes data and protected health information (PHI), including de-identification, tracking system, recovery plan, and an established security system. For the virtual reality component in some sub-studies, there may be risks of dizziness and disorientation while interacting with the software. Safeguards are in place to ensure that participants have the choice to take a break or fully stop from engaging with virtual reality.

9.1.2. Known Potential Benefits

Potential benefits are currently unknown. Data contributed as part of this study may benefit further development of the MapHabit software and research in cognitive impairment and may lead to development of diagnostic or therapeutic interventions in the future.

9.1.3. Assessment of Potential Risks and Benefits

Overall, the known risks involved in participation are minimal. When desired, study participants may revoke their consent at any time

9.2. Unanticipated Problems

9.2.1. Definition of Unanticipated Problems (UP)

The Office for Human Research Protections (OHRP) considers unanticipated problems involving risks to participants or others to include, in general, any incident, experience, or outcome that meets all of the following criteria:

- Unexpected in terms of nature, severity, or frequency given (a) the research procedures that are described in the protocol-related documents, such as the Institutional Review Board (IRB)-approved research protocol and Informed Consent document; and (b) the characteristics of the participant population being studied.
- Related or possibly related to participation in the research (“possibly related” means there is a reasonable possibility that the incident, experience, or outcome may have been caused by the procedures involved in the research); and
- Suggests that the research places participants or others at a greater risk of harm (including physical, psychological, economic, or social harm) than was previously known or recognized.

This definition could include an unanticipated adverse device effect, any serious adverse effects on health or safety or any life-threatening problem or death caused by, or associated with, a device, if that effect, problem, or death was not previously identified in nature, severity, or degree of incidence in the investigational plan or application (including a supplementary plan or application), or any other unanticipated serious problem associated with a device that relates to the rights, safety, or welfare of subjects (21 CFR 812.3(s)).

9.2.2. Unanticipated Problem Reporting

The principal investigator (PI) will report unanticipated problems (UPs) to the selected commercial Institutional Review Board (IRB) and to the sponsor. The UP report will include the following information:

- Report date, IRB Study number, Study Title, Study Staff Contact Information, Date UP occurred, and date PI was notified about the UP.
- Description of the Unanticipated Problem which occurred during the conduct of the research.
- Provide an explanation for why this Unanticipated Problem occurred.
- Characterize the impact of the Unanticipated Problem on the study.

- Describe the steps which have been taken to resolve the reported occurrence.
- Describe the plan implemented to avoid or prevent future occurrences.
- Inform other study participants as necessary.
- Name all other entities to which this UP has been reported.
- Determine if the UP will require modification of the currently approved study and/or consent form.

Technical issues occurring during the application use can be reported via email support@maphabit.com.

9.2.3. Serious Adverse Event (SAE) Reporting

A Serious Adverse Event (SAE) is an untoward occurrence in human research that results in death, a life-threatening experience, inpatient hospitalization, prolongation of hospitalization, persistent or significant disability or incapacity, congenital anomaly, or birth defect, or that requires medical, surgical, behavioral, social, or other intervention to prevent such an outcome (21 CFR 312.32(a)).

Adverse events and deaths occurring in the course of an approved study that are serious, unanticipated and related or probably related to the research, by the judgment of the investigator, will be reported to the IRB.

If the event satisfies ALL three of these criteria the event must be reported to the IRB within 5 business days of learning of the event. The study sponsor will also be notified within the same timeframe.

9.2.4. Adverse Device Event Reporting

An investigator shall submit to the sponsor and to the reviewing Institutional Review Board (IRB) a report of any unanticipated adverse device effect occurring during an investigation as soon as possible, but in no event later than 10 working days after the investigator first learns of the effect (21 CFR 812.150(a)(1)). A sponsor who conducts an evaluation of an unanticipated adverse device effect under 812.46(b) shall report the results of such evaluation to the Food and Drug Administration (FDA) and to all reviewing IRB's and participating investigators within 10 working days after the sponsor first receives notice of the effect. Thereafter the sponsor shall submit such additional reports concerning the effect as FDA requests (21 CFR 812.150(b)(1)).

9.3. Death Reporting

Death is reported as is stated in section 9.2.3 Serious Adverse Event (SAE) Reporting.

A death that meets all three criteria for an SAE, as above, shall be reported by Study Staff to the IRB within 5 business days of learning of the death. A detailed narrative or death letter may be requested by the sponsor including date of death, place, circumstances, cause of death, and whether the death was witnessed or not.

10. Informed Consent

Subject participation in this clinical study is voluntary. Informed Consent is required from each subject. The Investigator is responsible for ensuring that Informed Consent is obtained prior to the use of any investigational devices, study-required procedures and/or testing, or data collection. Informed Consent in this study will be obtained in writing during a face-to-face encounter with the study investigator or clinical coordinator, or electronically through a website or within the MapHabit software. For participants under the age of 18, a parent or legal guardian must sign on behalf of the participant. An assent form for DS participants will be provided to inform and teach about the significance of the sub-study participants that are minors.

The obtaining and documentation of Informed Consent must be in accordance with the principles of the Declaration of Helsinki, ISO 14155, any applicable national regulations, and local IRB. The ICF must be accepted by the sponsor and approved by the IRB.

The process of obtaining Informed Consent shall at a minimum include the following steps, as well as any other steps required by applicable laws, rules, regulations and guidelines:

- include a description of all aspects of the clinical study that are relevant to the subject's decision to participate throughout the clinical study,
- avoid any coercion or undue influence of subjects to participate,
- not waive or appear to waive subject's legal rights,
- use native language that is non-technical and understandable to the subject or his/her legal representative,
- provide ample time for the subject to consider participation and ask questions, if necessary, ensure important new information is provided to new and existing subjects throughout the clinical study.

Consent forms describing in detail the study intervention, study procedures, and risks are given to the participant and written documentation of Informed Consent is required prior to starting intervention/administering study intervention.

10.1. Assessment of Capacity for Informed Consent

All candidate participants with a clinical diagnosis of AD/ADRD, MCI, TBI, or other form of cognitive impairment are screened using the University of California San Diego Brief Assessment of Capacity to Consent (UBACC) [5]. The UBACC has a 10-item scale, including questions that focus on understanding and appreciation of the disclosed research information. In cases where screening with the UBACC suggests that a candidate participant may lack adequate capacity to consent, Informed Consent may be gathered from a legally authorized representative. All research staff administering the UBACC will undergo training to gain familiarity with the UBACC scoring system prior to administering the screening test.

10.2. Process of Obtaining Informed Consent Through Surrogacy

Informed Consent may be gathered from a legally authorized representative (LAR), parent, or legal guardian in cases where screening suggests that a candidate participant may lack adequate capacity to consent or is under the age of 18. In such cases, the consent interview with the LAR may be conducted in-person or over the phone. In cases where the consent interview is conducted by phone, a copy of the RESEARCH CONSENT FORM is first sent to the LAR, parent, or legal guardian by email or other means for review, prior to the consent interview. Informed Consent is considered obtained after the consent interview has occurred, and a signed and dated copy of the RESEARCH CONSENT FORM is returned from the LAR, parent, or legal guardian to the study coordinator.

11. Protocol Deviations

A protocol deviation is any noncompliance with the umbrella trial protocol. It is the responsibility of the investigator to use continuous vigilance to identify deviations and report them within 3 working days of identification of the protocol deviation, or within 3 working days of the scheduled protocol-required activity. All deviations must be addressed in study source documents. Protocol deviations must be sent to the reviewing Institutional Review Board (IRB) per their policies. The study investigator is responsible for knowing and adhering to the reviewing IRB requirements. Protocol deviations must also be reported in the study data collection system.

12. Study Discontinuation and Closure

This study may be temporarily suspended or prematurely terminated if there is sufficient reasonable cause. Written notification, documenting the reason for study suspension or termination, will be provided by suspending or terminating party to study participants, investigator, sponsor and regulatory authorities. If the study is prematurely terminated or suspended, the Principal Investigator (PI) will promptly inform study participants, the Institutional Review Board

(IRB), and sponsor and will provide the reason(s) for the termination or suspension. Study participants will be contacted via phone or email and be informed of changes to study schedule.

Circumstances that may warrant termination or suspension include, but are not limited to:

- Determination of unexpected, significant, or unacceptable risk to participants
- Demonstration of efficacy that would warrant stopping
- Insufficient compliance to protocol requirements
- Data that are not sufficiently complete and/or evaluable
- Determination that the primary endpoint has been met
- Determination of futility

Study may resume once concerns about safety, protocol compliance, and data quality are addressed, and satisfy the sponsor, IRB and/or Food and Drug Administration (FDA).

13. Data Management

13.1. Data analysis plan

Data will be listed and summarized by means of descriptive statistics in tabular and graphical formats. Map utilization data will be electronically collected by the MHS and consist of cumulating the numbers of maps accessed by each dyad during the six-month course of the study. We still standardize time scales to account for dyads that enrolled and started at different times during the study. Specifically, all dyads' time axes will be rescaled so that Day 1 corresponded to the first use-day of the application, regardless of a dyad's onboarding date. Python Pandas open-source tool will be utilized for data analyses. GraphPad Prism, v10.2.2, will be used to analyze baseline characteristics of care partners and care recipients using descriptive statistics. QOL-18 uses a Likert scale, and a 1-sample t-test will be used to evaluate the difference of the group mean score compared to the null score (3 – no change) of the Likert scale. Analyses of participant satisfaction will use descriptive statistics and comparisons of group means will involve unpaired comparison t-tests.

13.2. Quality control

All research personnel will complete CITI training and be knowledgeable about Good Clinical Practice (GCP), relevant regulations and policies. The Principal Investigator will ensure adherence to the study protocol, regulatory requirements, GCP standards at all times. Additionally, all research personnel will complete HIPAA training and receive certification. Team meeting will be held on a regular basis to review adherence to study protocol, and to discuss any incidents of failures of protocol compliance, keeping adequate and accurate records, and reporting of adverse

events. These outcomes of these meetings will be reported to the sponsor and to applicable regulatory bodies as requested.

13.3. Data handling

The final storage space for the study data will be a cloud database and external file storage system. The database contains a table with the participant codes ("Participant ID", or "userID") assigned to them in the application, and their respective:

- Screen views: for each screen, time during which the screen was displayed to the user
- Interactions with all in-app actionable elements (such as buttons) with the element identifier and the time of such interaction.
- Application logs, such as error reports, unexpected shutdowns, etc.
- Protected health information and clinical outcomes data, if applicable.

Participant ID (or UserID) will not incorporate personally identifiable information.

All electronic files will be password-protected and stored on a commercial secured and encrypted server and will only be accessible to authorized research personnel. All access will be audit logged. As data will exist in de-identified form, the electronic data files may be kept indefinitely, if not stated otherwise in a subsequent MapHabit sub-study. The Principal Investigator will be responsible should receipt and/or transmission of data be required. All data transported/shared will be de-identified.

13.4. Data Collection

User interaction data will be collected passively using the Google Firebase Analytics platform and will be securely transmitted from the application to the sponsor-maintained cloud database. For sub-studies that will be examining clinical outcomes and PHI's relationship with user interaction with the software, data will be transmitted by partnering sites (e.g., Senior Living facilities with separate approval) in a secure manner via a cloud-based healthcare database platform. For sub-studies that will be examining the effect of virtual reality in MapHabit system user engagement, the same standard data collection procedure will take place (i.e., the collection of user interaction data via Google Firebase Analytics platform).

13.5. Study Records Retention

All Protocol Files related to the review and oversight of human subjects' research protocols submitted by the research team to the IRB shall have a cutoff at the end of the fiscal year after the research project has been completed or terminated. Records will be retained for 10 years after the cutoff.

Records include, but are not limited to, the application to the IRB; research protocol and amendments; case reports forms; Informed Consent template and HIPAA Authorization template; reports of adverse events, complaints, and deviations from IRB-approved protocol; data and safety monitoring reports; research findings to date; and all relevant documents and related correspondences between the IRB and the investigators in the review of an associated protocol.

No records will be destroyed without the written consent of the sponsor, if applicable. It is the responsibility of the Study Staff to inform the sponsor when these documents no longer need to be retained.

14. Abbreviations

| Abbreviation | Description |
|---------------------|---|
| AD | Alzheimer's Dementia |
| ADL's | Activities of Daily Living |
| ADRD | Alzheimer's Dementia Related Disease |
| ADE | Adverse Events |
| CITI | Collaborative Institutional Training Initiative |
| eICF | Electronic Informed Consent Form |
| FDA | Food and Drug Administration |
| GCP | Good Clinical Practice |
| HIPAA | Health Insurance Portability and Accountability Act of 1996 |
| ICF | Informed Consent Form |
| IRB | Institutional Review Board |
| MCI | Mild Cognitive Impairment |
| PHI | Protected Health Information |
| PI | Principal Investigator |
| QoL | Quality of Life |
| SAE | Serious Adverse Event |
| TBI | Traumatic Brain Injury |
| UP | Unanticipated Problem |

15. Statement of Compliance

The trial will be conducted in accordance with International Conference on Harmonization Good Clinical Practice (ICH GCP) and applicable United States (US) Code of Federal Regulations (CFR). The Principal Investigator will assure that no deviation from, or changes to the protocol will take place without prior agreement from the sponsor and documented approval from the Institutional Review Board (IRB), except where necessary to eliminate an immediate hazard(s) to the trial participants.

The protocol, Informed Consent form(s), recruitment materials, and all participant materials will be submitted to the IRB for review and approval. Approval of both the protocol and the consent form must be obtained before any participant is enrolled. Any amendment to the protocol will require review and approval by the IRB before the changes are implemented to the study. All changes to the consent form will be IRB approved; a determination will be made regarding whether a new consent needs to be obtained from participants who provided consent, using a previously approved consent form.

16. Potential Sub-Study Surveys & Questionnaires

16.1. Quality of Life in Alzheimer's Disease

Instructions for Interviewers

The QOL-AD is administered in interview format to individuals with dementia, following the instructions below.

The interview is carried out with the subject and/or an informant. The subject should be interviewed alone.

Hand the form to the participant, so that he or she may look at it as you give the following instructions (instructions should closely follow the wording given in bold type):

I want to ask you some questions about your quality of life and have you rate different aspects of your life using one of four words: poor, fair, good, or excellent.

Point to each word (poor, fair, good, and excellent) on the form as you say it.

When you think about your life, there are different aspects, like your physical health, energy, family, money, and others. I'm going to ask you to rate each of these areas. We want to find out how you feel about your current situation in each area.

If you're not sure about what a question means, you can ask me about it. If you have difficulty rating any item, just give it your best guess.

It is usually apparent whether an individual understands the questions, and most individuals who are able to communicate and respond to simple questions can understand the measure. If the participant answers all questions the same, or says something that indicates a lack of understanding, the interviewer is encouraged to clarify the question. However, under no circumstances should the interviewer suggest a specific response. Each of the four possible responses should be presented, and the participant should pick one of the four.

If a participant is unable to choose a response to a particular item or items, this should be noted in the comments. If the participant is unable to comprehend and/or respond to two or more items, the testing may be discontinued, and this should be noted in the comments.

As you read the items listed below, ask the participant to circle her/his response. If the participant has difficulty circling the word, you may ask her/him to point to the word or say the word, and you may circle it for him or her. You should let the participant hold his or her own copy of the measure, and follow along as you read each item.

1. **First of all, how do you feel about your physical health? Would you say it's poor, fair, good, or excellent? Circle whichever word you think best describes your physical health right now.**
2. **How do you feel about your energy level? Do you think it is poor, fair, good, or excellent?** If the participant says that some days are better than others, ask him or her to rate how she/he has been feeling most of the time lately.
3. **How has your mood been lately? Have your spirits been good, or have you been feeling down? Would you rate your mood as poor, fair, good, or excellent?**
4. **How about your living situation? How do you feel about the place you live now? Would you say it's poor, fair, good, or excellent?**
5. **How about your memory? Would you say it is poor, fair, good, or excellent?**
6. **How about your family and your relationship with family members? Would you describe it as poor, fair, good, or excellent?** If the respondent says they have no family, ask about brothers, sisters, children, nieces, nephews.
7. **How do you feel about your marriage? How is your relationship with (spouse's name). Do you feel it's poor, fair, good, or excellent?** Some participants will be single, widowed, or divorced. When this is the case, ask how they feel about the person with whom they have the closest relationship, whether it's a family member or friend. If there is a family caregiver, ask about their relationship with this person. If there is no one appropriate, or the participant is unsure, score the item as missing.

8. **How would you describe your current relationship with your friends? Would you say it's poor, fair, good, or excellent?** If the respondent answers that they have no friends, or all their friends have died, probe further. **Do you have anyone you enjoy being with besides your family? Would you call that person a friend?** If the respondent still says they have no friends, ask **how do you feel about having no friends—poor, fair, good, or excellent?**
9. **How do you feel about yourself—when you think of your whole self, and all the different things about you, would you say it's poor, fair, good, or excellent?**
10. **How do you feel about your ability to do things like chores around the house or other things you need to do? Would you say it's poor, fair, good, or excellent?**
11. **How about your ability to do things for fun, that you enjoy? Would you say it's poor, fair, good, or excellent?**
12. **How do you feel about your current situation with money, your financial situation? Do you feel it's poor, fair, good, or excellent?** If the respondent hesitates, explain that you don't want to know what their situation is (as in amount of money), just how they feel about it.
13. **How would you describe your life as a whole. When you think about your life as a whole, everything together, how do you feel about your life? Would you say it's poor, fair, good, or excellent?**

Scoring instructions for QOL-AD:

Points are assigned to each item as follows: poor = 1, fair = 2, good = 3, excellent = 4.

The total score is the sum of all 13 items.

| UWMC/ADPR/QOL Aging and Dementia: Quality of Life in AD Quality of Life:AD (Family Version) | | | | | Score (for clinician's use only) |
|---|-------------------------|--|------|-----------|---|
| ID Number □□□□□□ | Assessment Number □□ | Interview Date □□ □□ □□ Month Day Year | | | |
| Instructions: Please rate your relative's current situation, as you see it. Circle your responses. | | | | | |
| 1. Physical health | Poor | Fair | Good | Excellent | |
| 2. Energy | Poor | Fair | Good | Excellent | |
| 3. Mood | Poor | Fair | Good | Excellent | |
| 4. Living situation | Poor | Fair | Good | Excellent | |
| 5. Memory | Poor | Fair | Good | Excellent | |
| 6. Family | Poor | Fair | Good | Excellent | |
| 7. Marriage | Poor | Fair | Good | Excellent | |
| 8. Friends | Poor | Fair | Good | Excellent | |
| 9. Self as a whole | Poor | Fair | Good | Excellent | |
| 10. Ability to do chores around the house | Poor | Fair | Good | Excellent | |
| 11. Ability to do things for fun | Poor | Fair | Good | Excellent | |
| 12. Money | Poor | Fair | Good | Excellent | |
| 13. Life as a whole | Poor | Fair | Good | Excellent | |
| Comments: _____ _____ | | | | | Total |

16.2. The Zarit Burden Interview

The Zarit Burden Interview

Circle the response that best describes how you feel.

| | Never | Rarely | Sometimes | Quite frequently | Nearly always |
|--|-------|--------|-----------|------------------|---------------|
| 1. Do you feel that your relative asks for more help than he/she needs? | 0 | 1 | 2 | 3 | 4 |
| 2. Do you feel that because of the time you spend with your relative that you don't have enough time for yourself? | 0 | 1 | 2 | 3 | 4 |
| 3. Do you feel stressed between caring for your relative and trying to meet other responsibilities for your family or work? | 0 | 1 | 2 | 3 | 4 |
| 4. Do you feel embarrassed over your relative's behavior? | 0 | 1 | 2 | 3 | 4 |
| 5. Do you feel angry when you are around your relative? | 0 | 1 | 2 | 3 | 4 |
| 6. Do you feel that your relative currently affects your relationships with other family members or friends in a negative way? | 0 | 1 | 2 | 3 | 4 |
| 7. Are you afraid what the future holds for your relative? | 0 | 1 | 2 | 3 | 4 |
| 8. Do you feel your relative is dependent on you? | 0 | 1 | 2 | 3 | 4 |
| 9. Do you feel strained when you are around your relative? | 0 | 1 | 2 | 3 | 4 |
| 10. Do you feel your health has suffered because of your involvement with your relative? | 0 | 1 | 2 | 3 | 4 |
| 11. Do you feel that you don't have as much privacy as you would like because of your relative? | 0 | 1 | 2 | 3 | 4 |
| 12. Do you feel that your social life has suffered because you are caring for your relative? | 0 | 1 | 2 | 3 | 4 |
| 13. Do you feel uncomfortable about having friends over because of your relative? | 0 | 1 | 2 | 3 | 4 |
| 14. Do you feel that your relative seems to expect you to take care of him/her as if you were the only one he/she could depend on? | 0 | 1 | 2 | 3 | 4 |
| 15. Do you feel that you don't have enough money to take care of your relative in addition to the rest of your expenses? | 0 | 1 | 2 | 3 | 4 |
| 16. Do you feel that you will be unable to take care of your relative much longer? | 0 | 1 | 2 | 3 | 4 |
| 17. Do you feel you have lost control of your life since your relative's illness? | 0 | 1 | 2 | 3 | 4 |
| 18. Do you wish you could leave the care of your relative to someone else? | 0 | 1 | 2 | 3 | 4 |
| 19. Do you feel uncertain about what to do about your relative? | 0 | 1 | 2 | 3 | 4 |
| 20. Do you feel you should be doing more for your relative? | 0 | 1 | 2 | 3 | 4 |
| 21. Do you feel you could do a better job in caring for your relative? | 0 | 1 | 2 | 3 | 4 |
| 22. Overall, how burdened do you feel in caring for your relative? | 0 | 1 | 2 | 3 | 4 |

Instructions for caregiver: The questions above reflect how persons sometimes feel when they are taking care of another person. After each statement, circle the word that best describes how often you feel that way. There are no right or wrong answers.

Scoring instructions: Add the scores for the 22 questions. The total score ranges from 0 to 88. A high score correlates with higher level of burden.

16.3. The Pittsburgh Sleep Quality Index (PSQI)

Instructions: The following questions relate to your usual sleep habits during the past month only. Your answers should indicate the most accurate reply for the majority of days and nights in the past month. Please answer all questions. During the past month,

1. When have you usually gone to bed? _____
2. How long (in minutes) has it taken you to fall asleep each night? _____
3. When have you usually gotten up in the morning? _____
4. How many hours of actual sleep do you get at night? (This may be different than the number of hours you spend in bed) _____

| 5. During the past month, how often have you had trouble sleeping because you... | Not during the past month (0) | Less than once a week (1) | Once or twice a week (2) | Three or more times a week (3) |
|---|-------------------------------|---------------------------|--------------------------|--------------------------------|
| a. Cannot get to sleep within 30 minutes | | | | |
| b. Wake up in the middle of the night or early morning | | | | |
| c. Have to get up to use the bathroom | | | | |
| d. Cannot breathe comfortably | | | | |
| e. Cough or snore loudly | | | | |
| f. Feel too cold | | | | |
| g. Feel too hot | | | | |
| h. Have bad dreams | | | | |
| i. Have pain | | | | |
| j. Other reason(s), please describe, including how often you have had trouble sleeping because of this reason(s): | | | | |
| 6. During the past month, how often have you taken medicine (prescribed or "over the counter") to help you sleep? | | | | |
| 7. During the past month, how often have you had trouble staying awake while driving, eating meals, or engaging in social activity? | | | | |
| 8. During the past month, how much of a problem has it been for you to keep up enthusiasm to get things done? | | | | |
| | Very good (0) | Fairly good (1) | Fairly bad (2) | Very bad (3) |
| 9. During the past month, how would you rate your sleep quality overall? | | | | |

16.4. The Lawton Instrumental Activities of Daily Living Scale

A. Ability to Use Telephone

1. Operates telephone on own initiative; looks up and dials numbers1
2. Dials a few well-known numbers.....1
3. Answers telephone, but does not dial.....1
4. Does not use telephone at all.....0

B. Shopping

1. Takes care of all shopping needs independently.....1
2. Shops independently for small purchases0
3. Needs to be accompanied on any shopping trip.....0
4. Completely unable to shop.....0

C. Food Preparation

1. Plans, prepares, and serves adequate meals independently1
2. Prepares adequate meals if supplied with ingredients0
3. Heats and serves prepared meals or prepares meals but does not maintain adequate diet0
4. Needs to have meals prepared and served.....0

D. Housekeeping

1. Maintains house alone with occasion assistance (heavy work).....1
2. Performs light daily tasks such as dishwashing, bed making.....1
3. Performs light daily tasks, but cannot maintain acceptable level of cleanliness.....1
4. Needs help with all home maintenance tasks1
5. Does not participate in any housekeeping tasks0

E. Laundry

1. Does personal laundry completely1
2. Launders small items, rinses socks, stockings, etc1
3. All laundry must be done by others0

F. Mode of Transportation

1. Travels independently on public transportation or drives own car1
2. Arranges own travel via taxi, but does not otherwise use public transportation1
3. Travels on public transportation when assisted or accompanied by another1
4. Travel limited to taxi or automobile with assistance of another0
5. Does not travel at all0

G. Responsibility for Own Medications

1. Is responsible for taking medication in correct dosages at correct time.....1
2. Takes responsibility if medication is prepared in advance in separate dosages.....0
3. Is not capable of dispensing own medication.....0

H. Ability to Handle Finances

1. Manages financial matters independently (budgets, writes checks, pays rent and bills, goes to bank); collects and keeps track of income1
2. Manages day-to-day purchases, but needs help with banking, major purchases, etc1
3. Incapable of handling money0

Scoring: For each category, circle the item description that most closely resembles the client's highest functional level (either 0 or 1).

16.5. The Neuropsychiatric Inventory Questionnaire

The Neuropsychiatric Inventory–Questionnaire: Background and Administration

The Neuropsychiatric Inventory–Questionnaire (NPI-Q) was developed and cross-validated with the standard NPI to provide a brief assessment of neuropsychiatric symptomatology in routine clinical practice settings (Kaufer et al, J Neuropsychiatry Clin Neurosci 2000, 12:233-239). The NPI-Q is adapted from the NPI (Cummings et al, Neurology 1994; 44:2308-2314), a validated informant-based interview that assesses neuropsychiatric symptoms over the previous month. The original NPI included 10 neuropsychiatric domains; two others, Nighttime Behavioral Disturbances and Appetite/Eating Changes, have subsequently been added. Another recent modification of the original NPI is the addition of a Caregiver Distress Scale for evaluating the psychological impact of neuropsychiatric symptoms reported to be present (Kaufer et al, JAGS, 1998;46:210-215). The NPI-Q includes both of these additions.

The NPI-Q is designed to be a self-administered questionnaire completed by informants about patients for whom they care. Each of the 12 NPI-Q domains contains a survey question that reflects cardinal symptoms of that domain. Initial responses to each domain question are "Yes" (present) or "No" (absent). If the response to the domain question is "No", the informant goes to the next question. If "Yes", the informant then rates both the Severity of the symptoms present within the last month on a 3-point scale and the associated impact of the symptom manifestations on them (i.e. Caregiver Distress) using a 5-point scale. The NPI-Q provides symptom Severity and Distress ratings for each symptom reported, and total Severity and Distress scores reflecting the sum of individual domain scores.

Most informants will be able to complete the NPI-Q in 5 minutes or less. It is recommended that responses to the NPI-Q be reviewed for completeness by a clinician and for clarifying uncertainties after each administration. The first time an informant completes the NPI-Q, it may be useful to verbally review the instructions. In some instances, it may be necessary to conduct the NPI-Q in part or entirely as an interview.

The NPI and NPI-Q are both copyright-protected by Jeffrey L. Cummings, MD. The NPI-Q was developed by Daniel Kaufer, MD with permission. **Use of the NPI or NPI-Q in investigational studies sponsored in whole or part by for-profit entities is prohibited without express written consent.**

For inquiries regarding the NPI-Q, contact:

Jeffrey L. Cummings, MD
Mary S. Easton Center for Alzheimer's Disease Research
10911 Weyburn Ave; #200
Los Angeles, CA 90095
jcummings@mednet.ucla.edu

The NPI-Q can be found at:
www.NPItest.net

Circle "Yes" only if the symptom(s) has been present in the last month. Otherwise, circle "No". For each item marked "Yes":

a) Rate the SEVERITY of the symptom (how it affects the patient):

- 1 = Mild** (noticeable, but not a significant change)
- 2 = Moderate** (significant, but not a dramatic change)
- 3 = Severe** (very marked or prominent, a dramatic change)

b) Rate the DISTRESS you experience due to that symptom (how it affects you):

- 0 = Not distressing at all**
- 1 = Minimal** (slightly distressing, not a problem to cope with)
- 2 = Mild** (not very distressing, generally easy to cope with)
- 3 = Moderate** (fairly distressing, not always easy to cope with)
- 4 = Severe** (very distressing, difficult to cope with)
- 5 = Extreme or Very Severe** (extremely distressing, unable to cope with)

Please answer each question carefully. Ask for assistance if you have any questions.

Delusions Does the patient have false beliefs, such as thinking that others are stealing from him/her or planning to harm him/her in some way?

Yes No SEVERITY: 1 2 3 DISTRESS: 0 1 2 3 4 5

Hallucinations Does the patient have hallucinations such as false visions or voices? Does he or she seem to hear or see things that are not present?

Yes No SEVERITY: 1 2 3 DISTRESS: 0 1 2 3 4 5

Agitation/Aggression Is the patient resistive to help from others at times, or hard to handle?

Yes No SEVERITY: 1 2 3 DISTRESS: 0 1 2 3 4 5

Depression/Dysphoria Does the patient seem sad or say that he /she is depressed?

Yes No SEVERITY: 1 2 3 DISTRESS: 0 1 2 3 4 5

Anxiety Does the patient become upset when separated from you?
Doeshe/she have any other signs of nervousness such as shortness of breath, sighing, being unable to relax, or feeling excessively tense?

Yes No SEVERITY: 1 2 3 DISTRESS: 0 1 2 3 4 5

Elation/Euphoria Does the patient appear to feel too good or act excessively happy?

Yes No SEVERITY: 1 2 3 DISTRESS: 0 1 2 3 4 5

Apathy/Indifference Does the patient seem less interested in his/her usual activities or in the activities and plans of others?

Yes No SEVERITY: 1 2 3 DISTRESS: 0 1 2 3 4 5

Disinhibition Does the patient seem to act impulsively, for example, talking to strangers as if he/she knows them, or saying things that may hurt people's feelings?

Yes No SEVERITY: 1 2 3 DISTRESS: 0 1 2 3 4 5

Irritability/Lability Is the patient impatient and cranky? Does he/she have difficulty coping with delays or waiting for planned activities?

Yes No SEVERITY: 1 2 3 DISTRESS: 0 1 2 3 4 5

Motor Disturbance Does the patient engage in repetitive activities such as pacing around the house, handling buttons, wrapping string, or doing other things repeatedly?

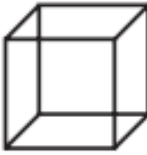
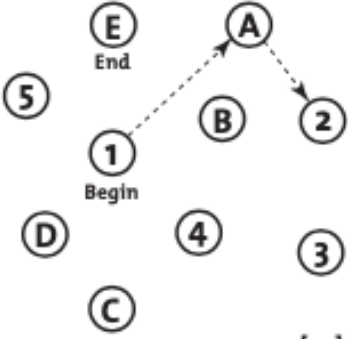



Yes No SEVERITY: 1 2 3 DISTRESS: 0 1 2 3 4 5

NPI-Q SUMMARY

| | No | Severity | | | Caregiver Distress | | | | | |
|------------------------------|-----------|-----------------|---|---|---------------------------|---|---|---|---|---|
| Delusions | 0 | 1 | 2 | 3 | 0 | 1 | 2 | 3 | 4 | 5 |
| Hallucinations | 0 | 1 | 2 | 3 | 0 | 1 | 2 | 3 | 4 | 5 |
| Agitation/Aggression | 0 | 1 | 2 | 3 | 0 | 1 | 2 | 3 | 4 | 5 |
| Dysphoria/Depression | 0 | 1 | 2 | 3 | 0 | 1 | 2 | 3 | 4 | 5 |
| Anxiety | 0 | 1 | 2 | 3 | 0 | 1 | 2 | 3 | 4 | 5 |
| Euphoria/Elation | 0 | 1 | 2 | 3 | 0 | 1 | 2 | 3 | 4 | 5 |
| Apathy/Indifference | 0 | 1 | 2 | 3 | 0 | 1 | 2 | 3 | 4 | 5 |
| Disinhibition | 0 | 1 | 2 | 3 | 0 | 1 | 2 | 3 | 4 | 5 |
| Irritability/Lability | 0 | 1 | 2 | 3 | 0 | 1 | 2 | 3 | 4 | 5 |
| Aberrant Motor | 0 | 1 | 2 | 3 | 0 | 1 | 2 | 3 | 4 | 5 |
| Nighttime Behavior | 0 | 1 | 2 | 3 | 0 | 1 | 2 | 3 | 4 | 5 |
| Appetite/Eating | 0 | 1 | 2 | 3 | 0 | 1 | 2 | 3 | 4 | 5 |
| TOTAL | | | | | | | | | | |

16.6. The Montreal Cognitive Assessment (MOCA)

Sample, can be administered and scored virtually:

| MONTREAL COGNITIVE ASSESSMENT (MOCA) | | | | | | NAME : _____ | Education : _____ | Date of birth : _____ | | | | | | | | | | | | | | | | | | | | |
|--|----------|------------|------------|-----------|---------|---|--------------------------|--|--|------------|------------|-----------|---------|-------------------------------|--------------|-----------|--|--|--|--|---------------------|-----------|--|--|--|--|-------|-----------|
| Sex : _____ | | | | | | DATE : _____ | | | | | | | | | | | | | | | | | | | | | | |
| VISUOSPATIAL / EXECUTIVE | | | | | | Copy cube  | | Draw CLOCK (Ten past eleven) (3 points) | POINTS | | | | | | | | | | | | | | | | | | | |
|  | | | | | | <div style="display: flex; justify-content: space-around;"> [] [] </div> | | <div style="display: flex; justify-content: space-around;"> [] [] [] </div> <div style="display: flex; justify-content: space-around; font-size: small;"> Contour Numbers Hands </div> | ___/5 | | | | | | | | | | | | | | | | | | | |
| NAMING | | | | | |  | |  |  | ___/3 | | | | | | | | | | | | | | | | | | |
| <div style="display: flex; justify-content: space-around;"> [] [] [] </div> | | | | | | | | | | | | | | | | | | | | | | | | | | | | |
| MEMORY | | | | | | Read list of words, subject must repeat them. Do 2 trials. Do a recall after 5 minutes. | | <table border="1" style="width: 100%; border-collapse: collapse; text-align: center;"> <tr> <td></td> <td>FACE</td> <td>VELVET</td> <td>CHURCH</td> <td>DAISY</td> <td>RED</td> </tr> <tr> <td>1st trial</td> <td></td> <td></td> <td></td> <td></td> <td></td> </tr> <tr> <td>2nd trial</td> <td></td> <td></td> <td></td> <td></td> <td></td> </tr> </table> | | | FACE | VELVET | CHURCH | DAISY | RED | 1st trial | | | | | | 2nd trial | | | | | | No points |
| | FACE | VELVET | CHURCH | DAISY | RED | | | | | | | | | | | | | | | | | | | | | | | |
| 1st trial | | | | | | | | | | | | | | | | | | | | | | | | | | | | |
| 2nd trial | | | | | | | | | | | | | | | | | | | | | | | | | | | | |
| ATTENTION | | | | | | Read list of digits (1 digit/ sec.). Subject has to repeat them in the forward order [] 2 1 8 5 4 Subject has to repeat them in the backward order [] 7 4 2 | | ___/2 | | | | | | | | | | | | | | | | | | | | |
| Read list of letters. The subject must tap with his hand at each letter A. No points if ≥ 2 errors [] FBACMNAAJKLBAFAKDEAAAJAMOFAB | | | | | | | | ___/1 | | | | | | | | | | | | | | | | | | | | |
| Serial 7 subtraction starting at 100 [] 93 [] 86 [] 79 [] 72 [] 65 4 or 5 correct subtractions: 3 pts, 2 or 3 correct: 2 pts, 1 correct: 1 pt, 0 correct: 0 pt | | | | | | | | ___/3 | | | | | | | | | | | | | | | | | | | | |
| LANGUAGE | | | | | | Repeat : I only know that John is the one to help today. [] The cat always hid under the couch when dogs were in the room. [] | | ___/2 | | | | | | | | | | | | | | | | | | | | |
| Fluency / Name maximum number of words in one minute that begin with the letter F [] _____ (N ≥ 11 words) | | | | | | | | ___/1 | | | | | | | | | | | | | | | | | | | | |
| ABSTRACTION | | | | | | Similarity between e.g. banana - orange = fruit [] train - bicycle [] watch - ruler | | ___/2 | | | | | | | | | | | | | | | | | | | | |
| DELAYED RECALL | | | | | | <table border="1" style="width: 100%; border-collapse: collapse; text-align: center;"> <tr> <td>Has to recall words WITH NO CUE</td> <td>FACE []</td> <td>VELVET []</td> <td>CHURCH []</td> <td>DAISY []</td> <td>RED []</td> <td rowspan="3" style="font-size: small;">Points for UNCUED recall only</td> </tr> <tr> <td>Category cue</td> <td></td> <td></td> <td></td> <td></td> <td></td> </tr> <tr> <td>Multiple choice cue</td> <td></td> <td></td> <td></td> <td></td> <td></td> </tr> </table> | | Has to recall words WITH NO CUE | FACE [] | VELVET [] | CHURCH [] | DAISY [] | RED [] | Points for UNCUED recall only | Category cue | | | | | | Multiple choice cue | | | | | | ___/5 | |
| Has to recall words WITH NO CUE | FACE [] | VELVET [] | CHURCH [] | DAISY [] | RED [] | Points for UNCUED recall only | | | | | | | | | | | | | | | | | | | | | | |
| Category cue | | | | | | | | | | | | | | | | | | | | | | | | | | | | |
| Multiple choice cue | | | | | | | | | | | | | | | | | | | | | | | | | | | | |
| Optional | | | | | | | | | | | | | | | | | | | | | | | | | | | | |
| ORIENTATION | | | | | | [] Date [] Month [] Year [] Day [] Place [] City | | ___/6 | | | | | | | | | | | | | | | | | | | | |
| © Z.Nasreddine MD Version November 7, 2004 | | | | | | Normal ≥ 26 / 30 | | TOTAL ___/30 Add 1 point if ≤ 12 yr edu | | | | | | | | | | | | | | | | | | | | |
| www.mocatest.org | | | | | | | | | | | | | | | | | | | | | | | | | | | | |

16.7. Live Alone Assessment Adapted from the University of Iowa

Live Alone Assessment

| | | | |
|---|---|---|--|
| <p>The following conditions may indicate when a person with dementia is no longer safe to live alone or will require more services, assistance or placement. Place a check by each statement that is known or observed. Calculate scores in each section and utilize recommendations from Boxes A – C.</p> | | | |
| GRADE | | | |
| <p>A = Emergent</p> <p>Only <u>one condition</u> needs to be present. Immediate help or placement is required.</p> | <p>A / B Emergent/ Semi-Emergent</p> <p>Can be either A or B depending on the cause, severity, and the person's response to the situation.</p> | <p>B = Semi-Emergent</p> <p>> <u>2 conditions</u> indicate that there are safety concerns that must be addressed and remediated.</p> | <p>C = Non-Emergent</p> <p>> <u>3 conditions</u> are present. Additional help will be beneficial. Re-evaluate monthly.</p> |
| OBSERVED OR REPORTED CONDITIONS | | | |
| <p>___ Weight loss of > 6 pounds or 10% body weight in 6 months, evidence of protruding bones</p> <p>___ Presence of paranoia, hallucinations, delusions, aggression or thoughts of suicide</p> <p>___ Threatens violence with/without weapons</p> <p>___ Evidence of caregiver injury/domestic violence</p> <p>___ Repeated ER visits, hospitalizations</p> <p>___ Evidence of substance abuse</p> <p>___ Frequent calls to police or emergency services</p> <p>___ Wandering outside the home</p> <p>___ No food/rancid food in the home</p> <p>___ Lack of safety with stove, power tools, yard</p> <p>___ Unable to take medications correctly</p> <p>___ Live stock/other animals receive inadequate care</p> <p>___ Eviction notice served</p> | <p>___ Malfunctioning plumbing</p> <p>___ Thermostats not set appropriately for weather conditions</p> <p>___ Chronic anxiety, panic attacks, worry or depression is present</p> <p>___ Unsafe driving or refuses to stop driving</p> <p>___ Neighbors calling police</p> | <p>___ Not able to manage bowel/bladder care</p> <p>___ Repeated calls to family/others asking what to do next</p> <p>___ Dirty/infested household</p> <p>___ Garbage accumulation</p> <p>___ Food stored inappropriately</p> <p>___ Taken advantage of by family, friends, neighbors</p> <p>___ Refuses personal care for prolonged period of time</p> | <p>___ Phone calls from community members advising help is needed</p> <p>___ Vegetative or socially isolated behavior (sitting all day with TV on or off)</p> <p>___ Missing belongings, hiding things</p> <p>___ Poor grooming, wearing the same clothing all the time, soiled appearance</p> |
| Total A: | Total A/B's: | Total B: | Total C: |

Adapted from the University of Iowa, 2004

16.8. Medication Management Instrument for Deficiencies in the Elderly (MedMaIDE™)

MEDICATION MANAGEMENT INSTRUMENT FOR DEFICIENCIES IN THE ELDERLY (MedMaIDE™)

| <i>What a Person <u>Knows</u> About Their Medications</i> | YES | NO |
|--|------------|-----------|
| **1. Name all the medications taken each day including prescription and over-the-counter medications (including milk of magnesia, nutritional supplements, herbs, vitamins, Tylenol, etc.) | | |
| **2. State the time of day for each prescription medication to be taken | | |
| **3. Can you tell me how the medications should be taken (by mouth, with water, on skin, etc.) | | |
| **4. State why he/she is taking each medication | | |
| **5. Tell me the amount of each medication to be taken at each time during the day | | |
| 6. Identify if there are problems after taking the medication (i.e., like dizziness, upset stomach, constipation, loose stool, frequent urination, etc.) | | |
| 7. Does the resident get medication help from anyone? If YES, by whom? Type of help? | | |
| 8. What other medications do you have on hand or available? (i.e., eye drops, creams, lotions, or nasal sprays that are outdated, unused or discontinued) | | |
| <i>If a Person Knows <u>How To Take</u> Their Medications</i> | YES | NO |
| **1. Can fill a glass with water | | |
| **2. Can remove top from medication container (vial, bubble pack, pill box, etc.) | | |
| **3. Can count out required number of pills into hand or cup | | |
| **4. Can put hand with medication in it to open mouth; put hand to eye for eye drops; hand to mouth for inhaler; draw up insulin, or place a topical patch. | | |
| **5. Sip enough water to swallow medication | | |
| Record how the medications are currently being stored. | | |
| <i>If a Person Knows <u>How to Get</u> Their Medications</i> | YES | NO |
| **1. Identify if a refill exists on a prescription | | |
| **2. Identify who to contact to get a prescription refilled | | |
| **3. Do you have resources to obtain the medication? (Can arrange transportation to pharmacy, pharmacy delivers, daughter picks it up, etc.) | | |

Reference: Orwig D. Brandt N. Gruber-Baldini AL. (2006) Medication Management Assessment for Older Adults in the Community. Gerontologist. 2006;46:661-668. Please contact author(s) prior to using this form at respective numbers (410) 706-8951 or (410) 706-1491 or via email dorwig@epi.umaryland.edu or nbrandt@rx.umayland.edu. Copyright 2002, University of Maryland, Baltimore

06/23/11

| | | |
|--|-------------------|----------------|
| 4. After getting a new refill, do you look at the medication before you take it to make sure it is the same as the one you finished? | | |
| 5. Do you have a prescription card? Do you use your prescription card? If YES : specify type:_____ | YES YES YES | NO NO NO |
| 6. Are there medications that you need that you cannot obtain? If YES, ask resident to explain. | YES | NO |

** If **NO**, it is counted as a 1 in the Deficiency Score

TOTAL DEFICIENCY SCORE: _____

(sum of three deficiency scores: maximum total score=13)

[illegible]

Reference: Orwig D. Brandt N. Gruber-Baldini AL. (2006) Medication Management Assessment for Older Adults in the Community. Gerontologist. 2006;46:661-668. Please contact author(s) prior to using this form at respective numbers (410) 706-8951 or (410) 706-1491 or via email dorwig@epi.umaryland.edu or nbrandt@rx.umayland.edu. Copyright 2002, University of Maryland, Baltimore

06/23/11

16.9. Geriatric Depression Scale

Choose the best answer for how you have felt over the past week:

1. Are you basically satisfied with your life? YES / **NO**
2. Have you dropped many of your activities and interests? **YES** / NO
3. Do you feel that your life is empty? **YES** / NO
4. Do you often get bored? **YES** / NO
5. Are you in good spirits most of the time? YES / **NO**
6. Are you afraid that something bad is going to happen to you? **YES** / NO
7. Do you feel happy most of the time? YES / **NO**
8. Do you often feel helpless? **YES** / NO
9. Do you prefer to stay at home, rather than going out and doing new things? **YES** / NO
10. Do you feel you have more problems with memory than most? **YES** / NO
11. Do you think it is wonderful to be alive now? YES / **NO**
12. Do you feel pretty worthless the way you are now? **YES** / NO
13. Do you feel full of energy? YES / **NO**
14. Do you feel that your situation is hopeless? **YES** / NO
15. Do you think that most people are better off than you are? **YES** / NO

Answers in **bold** indicate depression. Score 1 point for each bolded answer.

A score > 5 points is suggestive of depression.

A score ≥ 10 points is almost always indicative of depression.

A score > 5 points should warrant a follow-up comprehensive assessment.

16.10. Pain Assessment in Advanced Dementia Scale (PAINAD)

Pain Assessment in Advanced Dementia Scale (PAINAD)

Instructions: Observe the patient for five minutes before scoring his or her behaviors. Score the behaviors according to the following chart. Definitions of each item are provided on the following page. The patient can be observed under different conditions (e.g., at rest, during a pleasant activity, during caregiving, after the administration of pain medication).

| Behavior | 0 | 1 | 2 | Score |
|--|---|--|---|-------|
| Breathing Independent of vocalization | <ul style="list-style-type: none"> Normal | <ul style="list-style-type: none"> Occasional labored breathing Short period of hyperventilation | <ul style="list-style-type: none"> Noisy labored breathing Long period of hyperventilation Cheyne-Stokes respirations | |
| Negative vocalization | <ul style="list-style-type: none"> None | <ul style="list-style-type: none"> Occasional moan or groan Low-level speech with a negative or disapproving quality | <ul style="list-style-type: none"> Repeated troubled calling out Loud moaning or groaning Crying | |
| Facial expression | <ul style="list-style-type: none"> Smiling or inexpressive | <ul style="list-style-type: none"> Sad Frightened Frown | <ul style="list-style-type: none"> Facial grimacing | |
| Body language | <ul style="list-style-type: none"> Relaxed | <ul style="list-style-type: none"> Tense Distressed pacing Fidgeting | <ul style="list-style-type: none"> Rigid Fists clenched Knees pulled up Pulling or pushing away Striking out | |
| Consolability | <ul style="list-style-type: none"> No need to console | <ul style="list-style-type: none"> Distracted or reassured by voice or touch | <ul style="list-style-type: none"> Unable to console, distract, or reassure | |
| TOTAL SCORE | | | | |

(Warden et al., 2003)

Scoring:

The total score ranges from 0-10 points. A possible interpretation of the scores is: 1-3=mild pain; 4-6=moderate pain; 7-10=severe pain. These ranges are based on a standard 0-10 scale of pain, but have not been substantiated in the literature for this tool.

Source:

Warden V, Hurley AC, Volicer L. Development and psychometric evaluation of the Pain Assessment in Advanced Dementia (PAINAD) scale. *J Am Med Dir Assoc.* 2003;4(1):9-15.

PAINAD Item Definitions

(Warden et al., 2003)

Breathing

1. *Normal breathing* is characterized by effortless, quiet, rhythmic (smooth) respirations.
2. *Occasional labored breathing* is characterized by episodic bursts of harsh, difficult, or wearing respirations.
3. *Short period of hyperventilation* is characterized by intervals of rapid, deep breaths lasting a short period of time.
4. *Noisy labored breathing* is characterized by negative-sounding respirations on inspiration or expiration. They may be loud, gurgling, wheezing. They appear strenuous or wearing.
5. *Long period of hyperventilation* is characterized by an excessive rate and depth of respirations lasting a considerable time.
6. *Cheyne-Stokes respirations* are characterized by rhythmic waxing and waning of breathing from very deep to shallow respirations with periods of apnea (cessation of breathing).

Negative Vocalization

1. *None* is characterized by speech or vocalization that has a neutral or pleasant quality.
2. *Occasional moan or groan* is characterized by mournful or murmuring sounds, wails, or laments. Groaning is characterized by louder than usual inarticulate involuntary sounds, often abruptly beginning and ending.
3. *Low level speech with a negative or disapproving quality* is characterized by muttering, mumbling, whining, grumbling, or swearing in a low volume with a complaining, sarcastic, or caustic tone.
4. *Repeated troubled calling out* is characterized by phrases or words being used over and over in a tone that suggests anxiety, uneasiness, or distress.
5. *Loud moaning or groaning* is characterized by mournful or murmuring sounds, wails, or laments in much louder than usual volume. Loud groaning is characterized by louder than usual inarticulate involuntary sounds, often abruptly beginning and ending.
6. *Crying* is characterized by an utterance of emotion accompanied by tears. There may be sobbing or quiet weeping.

Facial Expression

1. *Smiling or inexpressive*. Smiling is characterized by upturned corners of the mouth, brightening of the eyes, and a look of pleasure or contentment. Inexpressive refers to a neutral, at ease, relaxed, or blank look.
2. *Sad* is characterized by an unhappy, lonesome, sorrowful, or dejected look. There may be tears in the eyes.
3. *Frightened* is characterized by a look of fear, alarm, or heightened anxiety. Eyes appear wide open.
4. *Frown* is characterized by a downward turn of the corners of the mouth. Increased facial wrinkling in the forehead and around the mouth may appear.
5. *Facial grimacing* is characterized by a distorted, distressed look. The brow is more wrinkled, as is the area around the mouth. Eyes may be squeezed shut.

Body Language

1. *Relaxed* is characterized by a calm, restful, mellow appearance. The person seems to be taking it easy.
2. *Tense* is characterized by a strained, apprehensive, or worried appearance. The jaw may be clenched. (Exclude any contractures.)
3. *Distressed pacing* is characterized by activity that seems unsettled. There may be a fearful, worried, or disturbed element present. The rate may be faster or slower.
4. *Fidgeting* is characterized by restless movement. Squirming about or wiggling in the chair may occur. The person might be hitching a chair across the room. Repetitive touching, tugging, or rubbing body parts can also be observed.
5. *Rigid* is characterized by stiffening of the body. The arms and/or legs are tight and inflexible. The trunk may appear straight and unyielding. (Exclude any contractures.)
6. *Fists clenched* is characterized by tightly closed hands. They may be opened and closed repeatedly or held tightly shut.
7. *Knees pulled up* is characterized by flexing the legs and drawing the knees up toward the chest. An overall troubled appearance. (Exclude any contractures.)
8. *Pulling or pushing away* is characterized by resistiveness upon approach or to care. The person is trying to escape by yanking or wrenching him- or herself free or shoving you away.
9. *Striking out* is characterized by hitting, kicking, grabbing, punching, biting, or other form of personal assault.

Consolability

1. *No need to console* is characterized by a sense of well-being. The person appears content.
2. *Distraught or reassured by voice or touch* is characterized by a disruption in the behavior when the person is spoken to or touched. The behavior stops during the period of interaction, with no indication that the person is at all distressed.
3. *Unable to console, distract, or reassure* is characterized by the inability to soothe the person or stop a behavior with words or actions. No amount of comforting, verbal or physical, will alleviate the behavior.

16.11. Caregiver Self-Assessment Questionnaire

Caregivers are often so concerned with caring for their relative's needs that they lose sight of their own wellbeing. Please take just a moment to answer the following questions. Once you have answered the questions, turn the page to do a self-evaluation.

During the past week or so, I have...

- | | |
|---|---|
| 1. Had trouble keeping my mind on what I was doing <input type="checkbox"/> Yes <input type="checkbox"/> No | 15. Been satisfied with the support my family has given me <input type="checkbox"/> Yes <input type="checkbox"/> No |
| 2. Felt that I couldn't leave my relative alone..... <input type="checkbox"/> Yes <input type="checkbox"/> No | 16. Found my relative's living situation to be inconvenient or a barrier to care <input type="checkbox"/> Yes <input type="checkbox"/> No |
| 3. Had difficulty making decisions <input type="checkbox"/> Yes <input type="checkbox"/> No | 17. On a scale of 1 to 10, with 1 being "not stressful" to 10 being "extremely stressful," please rate your current level of stress. _____ |
| 4. Felt completely overwhelmed..... <input type="checkbox"/> Yes <input type="checkbox"/> No | 18. On a scale of 1 to 10, with 1 being "very healthy" to 10 being "very ill," please rate your current health compared to what it was this time last year. _____ |
| 5. Felt useful and needed <input type="checkbox"/> Yes <input type="checkbox"/> No | |
| 6. Felt lonely <input type="checkbox"/> Yes <input type="checkbox"/> No | |
| 7. Been upset that my relative has changed so much from his/her former self..... <input type="checkbox"/> Yes <input type="checkbox"/> No | |
| 8. Felt a loss of privacy and/or personal time <input type="checkbox"/> Yes <input type="checkbox"/> No | Comments: (Please feel free to comment or provide feedback) |
| 9. Been edgy or irritable <input type="checkbox"/> Yes <input type="checkbox"/> No | _____ |
| 10. Had sleep disturbed because of caring for my relative <input type="checkbox"/> Yes <input type="checkbox"/> No | _____ |
| 11. Had a crying spell(s) <input type="checkbox"/> Yes <input type="checkbox"/> No | _____ |
| 12. Felt strained between work and family responsibilities..... <input type="checkbox"/> Yes <input type="checkbox"/> No | _____ |
| 13. Had back pain <input type="checkbox"/> Yes <input type="checkbox"/> No | _____ |
| 14. Felt ill (<i>headaches, stomach problems or common cold</i>) <input type="checkbox"/> Yes <input type="checkbox"/> No | _____ |

For additional tools for caregiving or aging, visit www.CaregiversLibrary.org

16.12. LuMind Down Syndrome Caregiver Assessment

Caregiver Survey on Independence in Down Syndrome

1. Contact Information

- a. Name: _____
- b. Company: _____
- c. Address: _____
- d. Address 2: _____
- e. City/Town: _____
- f. State Province (If in the United States): _____
- g. ZIP/Postal Code: _____
- h. Country: _____
- i. Email Address: _____
- j. Phone Number: _____

2. Who is completing this survey? Please select all options below that best describes your relationship to the loved on with Down Syndrome

- a. Parent
- b. Sibling
- c. Other Caregiver
- d. Other (Please specify)

3. Your age?

- a. Under 18
- b. 18-24
- c. 25-34
- d. 35-44
- e. 45-54

- f. 55-64
 - g. 65+
- 4. Highest Education Level
 - a. Elementary School
 - b. Middle School
 - c. High School Graduate
 - d. College Graduate
 - e. Post-Graduate Degree
- 5. What country do you live in?
 - a. _____
- 6. In which town or city do you live in?
 - a. _____
- 7. If in the U.S., which U.S. state do you live in?
 - a. _____
- 8. What is your zip code (if you live in the U.S.) or postal code (if you live outside the U.S.)?
 - a. _____
- 9. What is your approximate average household income?
 - a. Under \$49,999 (Under R44,730)
 - b. Between \$50,000 and \$99,999 (Between €44,731 - 89,463)
 - c. Between \$100,000 and \$149,999 (Between €89,464 - 134,195)
 - d. Between \$150,000 and \$199,999 (Between €134,196 - 178,927)
 - e. Over \$200,000 (Over 178,928)
 - f. Prefer not to answer.
- 10. What was the date of birth of the loved one with Down Syndrome?
 - a. _____
- 11. Does the loved one with Down syndrome live in the location listed previously?

a. Yes

b. No

12. What country does the loved one with Down syndrome live in?

a. _____

13. In which town or city does the loved one with Down syndrome live in?

a. _____

14. If in the US, which state does the person with Down syndrome live in?

a. _____

15. What is the loved one with Down syndrome zip code (if they live in the United States) or postal code (if they live outside the US?)

a. _____

16. Does the loved one with Down syndrome live:

a. Independently

b. In a group home

c. With family

d. Other (please specify) _____

17. Which race/ethnicity best describes the loved one with Down Syndrome? (Please choose)

a. White or Caucasian

b. Black or African American

c. Hispanic or Latinx

d. Asian or Asian American

e. Native American or Alaska Native

f. Native Hawaiian or other Pacific Islander

g. Another race

18. What is the loved one with Down syndrome's gender?

- a. Female
- b. Male
- c. Non-Binary
- d. Other

19. My loved one with Down syndrome has an additional diagnosis, which has been confirmed by a medical professional, (choose all that apply) of:

- a. Attention Deficit Hyperactivity Disorder (ADHD)
- b. Autism or autism spectrum disorder (ASD)
- c. Regression
- d. Sleep Apnea
- e. Celiac Disease
- f. Obsessive Compulsive Disorder (OCD)
- g. Mental Health diagnosis
- h. Dementia or Alzheimer's Disease
- i. Crohn's Disease
- j. Moya Moya
- k. Obesity
- l. Medically Complex
- m. Mobility (Please describe below)
 - i. _____
- n. None of the above
- o. Other diagnosis that you think affects the loved one with Down syndrome's
(Please specify)
 - i. _____

20. I feel the following **SAFETY** topics are important for my loved one with Down syndrome
(Check all that apply):

- a. Social media safety
 - i. Achieved already
 - ii. Not achieved but not important
 - iii. No achieved but important to me now
 - iv. Not achieved but may be important to me in the future
 - v. Don't know
- b. Internet safety
 - i. Achieved already
 - ii. Not achieved but not important
 - iii. No achieved but important to me now
 - iv. Not achieved but may be important to me in the future
 - v. Don't know
- c. Bullying
 - i. Achieved already
 - ii. Not achieved but not important
 - iii. No achieved but important to me now
 - iv. Not achieved but may be important to me in the future
 - v. Don't know
- d. Sexual Abuse
 - i. Achieved already
 - ii. Not achieved but not important
 - iii. No achieved but important to me now
 - iv. Not achieved but may be important to me in the future
 - v. Don't know
- e. Verbal Abuse
 - i. Achieved already

- ii. Not achieved but not important
 - iii. No achieved but important to me now
 - iv. Not achieved but may be important to me in the future
 - v. Don't know
- f. Stranger Danger
 - i. Achieved already
 - ii. Not achieved but not important
 - iii. No achieved but important to me now
 - iv. Not achieved but may be important to me in the future
 - v. Don't know
- g. Safely crossing a street/parking lot
 - i. Achieved already
 - ii. Not achieved but not important
 - iii. No achieved but important to me now
 - iv. Not achieved but may be important to me in the future
 - v. Don't know
- h. Bolting/Elopement (running away from caregiver)
 - i. Achieved already
 - ii. Not achieved but not important
 - iii. No achieved but important to me now
 - iv. Not achieved but may be important to me in the future
 - v. Don't know
- i. Kitchen/cooking safety
 - i. Achieved already
 - ii. Not achieved but not important
 - iii. No achieved but important to me now

- iv. Not achieved but may be important to me in the future
- v. Don't know

j. Water safety

- i. Achieved already
- ii. Not achieved but not important
- iii. No achieved but important to me now
- iv. Not achieved but may be important to me in the future
- v. Don't know

k. Staying with a babysitter or other caregiver

- i. Achieved already
- ii. Not achieved but not important
- iii. No achieved but important to me now
- iv. Not achieved but may be important to me in the future
- v. Don't know

l. Left home alone for greater than 2 hours

- i. Achieved already
- ii. Not achieved but not important
- iii. No achieved but important to me now
- iv. Not achieved but may be important to me in the future
- v. Don't know

m. Go out alone

- i. Achieved already
- ii. Not achieved but not important
- iii. No achieved but important to me now
- iv. Not achieved but may be important to me in the future
- v. Don't know

n. Other (please explain): _____

- i. Achieved already
- ii. Not achieved but not important
- iii. No achieved but important to me now
- iv. Not achieved but may be important to me in the future
- v. Don't know

21. Top 3 choices for **SAFETY** from question 20

- a. 1st Choice: _____
- b. 2nd Choice: _____
- c. 3rd Choice: _____

22. I feel the following SELF-CARE topics are important for my loved one with Down syndrome:

- a. Dress and undress self
 - i. Achieved already
 - ii. Not achieved but not important
 - iii. No achieved but important to me now
 - iv. Not achieved but may be important to me in the future
 - v. Don't know
- b. Putting on/tying shoes
 - i. Achieved already
 - ii. Not achieved but not important
 - iii. No achieved but important to me now
 - iv. Not achieved but may be important to me in the future
 - v. Don't know
- c. Use toilet independently
 - i. Achieved already

- ii. Not achieved but not important
 - iii. No achieved but important to me now
 - iv. Not achieved but may be important to me in the future
 - v. Don't know
- d. Grooming, brushing teeth, combing and/or brushing hair
 - i. Achieved already
 - ii. Not achieved but not important
 - iii. No achieved but important to me now
 - iv. Not achieved but may be important to me in the future
 - v. Don't know
- e. Wash himself/herself (shower or bath)
 - i. Achieved already
 - ii. Not achieved but not important
 - iii. No achieved but important to me now
 - iv. Not achieved but may be important to me in the future
 - v. Don't know
- f. Shaving
 - i. Achieved already
 - ii. Not achieved but not important
 - iii. No achieved but important to me now
 - iv. Not achieved but may be important to me in the future
 - v. Don't know
- g. Cutting fingernails and toenails
 - i. Achieved already
 - ii. Not achieved but not important
 - iii. No achieved but important to me now

- iv. Not achieved but may be important to me in the future
 - v. Don't know
- h. Female hygiene needs
 - i. Achieved already
 - ii. Not achieved but not important
 - iii. No achieved but important to me now
 - iv. Not achieved but may be important to me in the future
 - v. Don't know
- i. Healthy eating/portion control
 - i. Achieved already
 - ii. Not achieved but not important
 - iii. No achieved but important to me now
 - iv. Not achieved but may be important to me in the future
 - v. Don't know
- j. Take own medications
 - i. Achieved already
 - ii. Not achieved but not important
 - iii. No achieved but important to me now
 - iv. Not achieved but may be important to me in the future
 - v. Don't know
- k. Self-reporting feelings and health
 - i. Achieved already
 - ii. Not achieved but not important
 - iii. No achieved but important to me now
 - iv. Not achieved but may be important to me in the future
 - v. Don't know

I. Understanding of puberty

- i. Achieved already
- ii. Not achieved but not important
- iii. No achieved but important to me now
- iv. Not achieved but may be important to me in the future
- v. Don't know

m. Healthy understanding of sexuality

- i. Achieved already
- ii. Not achieved but not important
- iii. No achieved but important to me now
- iv. Not achieved but may be important to me in the future
- v. Don't know

n. Someone "safe" to talk to about thoughts and feelings

- i. Achieved already
- ii. Not achieved but not important
- iii. No achieved but important to me now
- iv. Not achieved but may be important to me in the future
- v. Don't know

o. Other (please explain)

- i. Achieved already
- ii. Not achieved but not important
- iii. No achieved but important to me now
- iv. Not achieved but may be important to me in the future
- v. Don't know

23. Top 3 choices for **SELF-CARE** from question 22:

- a. 1st Choice: _____

b. 2nd Choice: _____

c. 3rd Choice: _____

24. I feel the following **DAILY LIVING** topics are important for my loved one with Down syndrome:

- a. Drink independently from a cup
 - i. Achieved already
 - ii. Not achieved but not important
 - iii. No achieved but important to me now
 - iv. Not achieved but may be important to me in the future
 - v. Don't know
- b. Eat meals independently
 - i. Achieved already
 - ii. Not achieved but not important
 - iii. No achieved but important to me now
 - iv. Not achieved but may be important to me in the future
 - v. Don't know
- c. Move around in or out of the house
 - i. Achieved already
 - ii. Not achieved but not important
 - iii. No achieved but important to me now
 - iv. Not achieved but may be important to me in the future
 - v. Don't know
- d. Navigating public transportation alone
 - i. Achieved already
 - ii. Not achieved but not important
 - iii. No achieved but important to me now

- iv. Not achieved but may be important to me in the future
 - v. Don't know
- e. Traveling alone (on planes, trains, etc.)
 - i. Achieved already
 - ii. Not achieved but not important
 - iii. No achieved but important to me now
 - iv. Not achieved but may be important to me in the future
 - v. Don't know
- f. Living independently/semi-independently
 - i. Achieved already
 - ii. Not achieved but not important
 - iii. No achieved but important to me now
 - iv. Not achieved but may be important to me in the future
 - v. Don't know
- g. Driving
 - i. Achieved already
 - ii. Not achieved but not important
 - iii. No achieved but important to me now
 - iv. Not achieved but may be important to me in the future
 - v. Don't know
- h. Doing errands, including shopping in stores
 - i. Achieved already
 - ii. Not achieved but not important
 - iii. No achieved but important to me now
 - iv. Not achieved but may be important to me in the future
 - v. Don't know

- i. Use money
 - i. Achieved already
 - ii. Not achieved but not important
 - iii. No achieved but important to me now
 - iv. Not achieved but may be important to me in the future
 - v. Don't know
- j. Manage daily finances (keep track of cash, checking account, pay bills, etc.)
 - i. Achieved already
 - ii. Not achieved but not important
 - iii. No achieved but important to me now
 - iv. Not achieved but may be important to me in the future
 - v. Don't know
- k. Carry out domestic activities (make bed, pick up around the house, light housecleaning, etc.)
 - i. Achieved already
 - ii. Not achieved but not important
 - iii. No achieved but important to me now
 - iv. Not achieved but may be important to me in the future
 - v. Don't know
- l. Doing laundry, washing and drying
 - i. Achieved already
 - ii. Not achieved but not important
 - iii. No achieved but important to me now
 - iv. Not achieved but may be important to me in the future
 - v. Don't know
- m. Use a watch

- i. Achieved already
 - ii. Not achieved but not important
 - iii. No achieved but important to me now
 - iv. Not achieved but may be important to me in the future
 - v. Don't know
- n. Follow a schedule
 - i. Achieved already
 - ii. Not achieved but not important
 - iii. No achieved but important to me now
 - iv. Not achieved but may be important to me in the future
 - v. Don't know
- o. Time Management
 - i. Achieved already
 - ii. Not achieved but not important
 - iii. No achieved but important to me now
 - iv. Not achieved but may be important to me in the future
 - v. Don't know
- p. Prepare simple meals (requiring no mixing or cooking, including sandwiches, cold cereal, etc.)
 - i. Achieved already
 - ii. Not achieved but not important
 - iii. No achieved but important to me now
 - iv. Not achieved but may be important to me in the future
 - v. Don't know
- q. Cook meals (fry eggs, make pancakes, etc.)
 - i. Achieved already

- ii. Not achieved but not important
 - iii. No achieved but important to me now
 - iv. Not achieved but may be important to me in the future
 - v. Don't know
- r. Weight Management
 - i. Achieved already
 - ii. Not achieved but not important
 - iii. No achieved but important to me now
 - iv. Not achieved but may be important to me in the future
 - v. Don't know
- s. Other (please explain)
 - i. Achieved already
 - ii. Not achieved but not important
 - iii. No achieved but important to me now
 - iv. Not achieved but may be important to me in the future
 - v. Don't know

25. Top 3 choices for **DAILY LIVING** from question 24:

- a. 1st Choice: _____
- b. 2nd Choice: _____
- c. 3rd Choice: _____

26. I feel the following **SOCIAL/LEISURE TIME** topics are important for my loved one with

Down syndrome:

- a. Engages in leisure time appropriately
 - i. Achieved already
 - ii. Not achieved but not important
 - iii. No achieved but important to me now

- iv. Not achieved but may be important to me in the future
 - v. Don't know
- b. Able to manage disruptions to routines or schedules
 - i. Achieved already
 - ii. Not achieved but not important
 - iii. No achieved but important to me now
 - iv. Not achieved but may be important to me in the future
 - v. Don't know
- c. Watching TV
 - i. Achieved already
 - ii. Not achieved but not important
 - iii. No achieved but important to me now
 - iv. Not achieved but may be important to me in the future
 - v. Don't know
- d. Listening to music
 - i. Achieved already
 - ii. Not achieved but not important
 - iii. No achieved but important to me now
 - iv. Not achieved but may be important to me in the future
 - v. Don't know
- e. Volunteering
 - i. Achieved already
 - ii. Not achieved but not important
 - iii. No achieved but important to me now
 - iv. Not achieved but may be important to me in the future
 - v. Don't know

- f. Playing games (card games)
 - i. Achieved already
 - ii. Not achieved but not important
 - iii. No achieved but important to me now
 - iv. Not achieved but may be important to me in the future
 - v. Don't know
- g. Participate in hobbies (painting, gardening, writing, dancing, etc.)
 - i. Achieved already
 - ii. Not achieved but not important
 - iii. No achieved but important to me now
 - iv. Not achieved but may be important to me in the future
 - v. Don't know
- h. Sports activities
 - i. Achieved already
 - ii. Not achieved but not important
 - iii. No achieved but important to me now
 - iv. Not achieved but may be important to me in the future
 - v. Don't know
- i. Walking
 - i. Achieved already
 - ii. Not achieved but not important
 - iii. No achieved but important to me now
 - iv. Not achieved but may be important to me in the future
 - v. Don't know
- j. Hanging out with friends
 - i. Achieved already

- ii. Not achieved but not important
 - iii. No achieved but important to me now
 - iv. Not achieved but may be important to me in the future
 - v. Don't know
- k. Going out to eat
 - i. Achieved already
 - ii. Not achieved but not important
 - iii. No achieved but important to me now
 - iv. Not achieved but may be important to me in the future
 - v. Don't know
- l. Religious activities (church, etc.)
 - i. Achieved already
 - ii. Not achieved but not important
 - iii. No achieved but important to me now
 - iv. Not achieved but may be important to me in the future
 - v. Don't know
- m. Going to the movies
 - i. Achieved already
 - ii. Not achieved but not important
 - iii. No achieved but important to me now
 - iv. Not achieved but may be important to me in the future
 - v. Don't know
- n. Other (please explain)
 - i. Achieved already
 - ii. Not achieved but not important
 - iii. No achieved but important to me now

- iv. Not achieved but may be important to me in the future
- v. Don't know

27. Top 3 choices for **SOCIAL/LEISURE TIME** from question 26:

- a. 1st Choice: _____
- b. 2nd Choice: _____
- c. 3rd Choice: _____

28. I feel the following **VOCATIONAL/EMPLOYMENT** topics are important for my loved one with Down syndrome:

- a. Reading and writing
 - i. Achieved already
 - ii. Not achieved but not important
 - iii. No achieved but important to me now
 - iv. Not achieved but may be important to me in the future
 - v. Don't know
- b. Driving
 - i. Achieved already
 - ii. Not achieved but not important
 - iii. No achieved but important to me now
 - iv. Not achieved but may be important to me in the future
 - v. Don't know
- c. Navigating public transportation alone
 - i. Achieved already
 - ii. Not achieved but not important
 - iii. No achieved but important to me now
 - iv. Not achieved but may be important to me in the future
 - v. Don't know

- d. Traveling alone (on planes, trains, etc.)
 - i. Achieved already
 - ii. Not achieved but not important
 - iii. No achieved but important to me now
 - iv. Not achieved but may be important to me in the future
 - v. Don't know
- e. Time management
 - i. Achieved already
 - ii. Not achieved but not important
 - iii. No achieved but important to me now
 - iv. Not achieved but may be important to me in the future
 - v. Don't know
- f. Interpersonal skills
 - i. Achieved already
 - ii. Not achieved but not important
 - iii. No achieved but important to me now
 - iv. Not achieved but may be important to me in the future
 - v. Don't know
- g. Money management
 - i. Achieved already
 - ii. Not achieved but not important
 - iii. No achieved but important to me now
 - iv. Not achieved but may be important to me in the future
 - v. Don't know
- h. Ability to ask for help when needed
 - i. Achieved already

- ii. Not achieved but not important
 - iii. No achieved but important to me now
 - iv. Not achieved but may be important to me in the future
 - v. Don't know
- i. Respecting personal boundaries
 - i. Achieved already
 - ii. Not achieved but not important
 - iii. No achieved but important to me now
 - iv. Not achieved but may be important to me in the future
 - v. Don't know
- j. Appropriate behavior
 - i. Achieved already
 - ii. Not achieved but not important
 - iii. No achieved but important to me now
 - iv. Not achieved but may be important to me in the future
 - v. Don't know
- k. Ability to focus on task at hand
 - i. Achieved already
 - ii. Not achieved but not important
 - iii. No achieved but important to me now
 - iv. Not achieved but may be important to me in the future
 - v. Don't know
- l. Organization skills
 - i. Achieved already
 - ii. Not achieved but not important
 - iii. No achieved but important to me now

- iv. Not achieved but may be important to me in the future
 - v. Don't know
- m. Understand what he/she reads
 - i. Achieved already
 - ii. Not achieved but not important
 - iii. No achieved but important to me now
 - iv. Not achieved but may be important to me in the future
 - v. Don't know
- n. Use verbal communication
 - i. Achieved already
 - ii. Not achieved but not important
 - iii. No achieved but important to me now
 - iv. Not achieved but may be important to me in the future
 - v. Don't know
- o. Be understood by others, even with limited language
 - i. Achieved already
 - ii. Not achieved but not important
 - iii. No achieved but important to me now
 - iv. Not achieved but may be important to me in the future
 - v. Don't know
- p. Use telephone
 - i. Achieved already
 - ii. Not achieved but not important
 - iii. No achieved but important to me now
 - iv. Not achieved but may be important to me in the future
 - v. Don't know

- q. Use a computer for internet and e-mail
 - i. Achieved already
 - ii. Not achieved but not important
 - iii. No achieved but important to me now
 - iv. Not achieved but may be important to me in the future
 - v. Don't know
- r. Other (please explain)
 - i. Achieved already
 - ii. Not achieved but not important
 - iii. No achieved but important to me now
 - iv. Not achieved but may be important to me in the future
 - v. Don't know

29. Top 3 choices for **VOCATIONAL/EMPLOYMENT** from question 28:

- a. 1st Choice: _____
- b. 2nd Choice: _____
- c. 3rd Choice: _____

30. I feel the following **COMMUNICATION TOPICS** are important for my loved one with

Down syndrome:

- a. Communicating wants and needs
 - i. Achieved already
 - ii. Not achieved but not important
 - iii. No achieved but important to me now
 - iv. Not achieved but may be important to me in the future
 - v. Don't know
- b. Browse picture books without reading
 - i. Achieved already

- ii. Not achieved but not important
 - iii. No achieved but important to me now
 - iv. Not achieved but may be important to me in the future
 - v. Don't know
- c. Write his/her own name
 - i. Achieved already
 - ii. Not achieved but not important
 - iii. No achieved but important to me now
 - iv. Not achieved but may be important to me in the future
 - v. Don't know
- d. Understand what he/she writes
 - i. Achieved already
 - ii. Not achieved but not important
 - iii. No achieved but important to me now
 - iv. Not achieved but may be important to me in the future
 - v. Don't know
- e. Comprehend reading aloud
 - i. Achieved already
 - ii. Not achieved but not important
 - iii. No achieved but important to me now
 - iv. Not achieved but may be important to me in the future
 - v. Don't know
- f. Write to communicate
 - i. Achieved already
 - ii. Not achieved but not important
 - iii. No achieved but important to me now

- iv. Not achieved but may be important to me in the future
 - v. Don't know
- g. Read for pleasure
 - i. Achieved already
 - ii. Not achieved but not important
 - iii. No achieved but important to me now
 - iv. Not achieved but may be important to me in the future
 - v. Don't know
- h. Understand what he/she reads
 - i. Achieved already
 - ii. Not achieved but not important
 - iii. No achieved but important to me now
 - iv. Not achieved but may be important to me in the future
 - v. Don't know
- i. Use verbal communication
 - i. Achieved already
 - ii. Not achieved but not important
 - iii. No achieved but important to me now
 - iv. Not achieved but may be important to me in the future
 - v. Don't know
- j. Be understood by others, even with limited language
 - i. Achieved already
 - ii. Not achieved but not important
 - iii. No achieved but important to me now
 - iv. Not achieved but may be important to me in the future
 - v. Don't know

- k. Use telephone
 - i. Achieved already
 - ii. Not achieved but not important
 - iii. No achieved but important to me now
 - iv. Not achieved but may be important to me in the future
 - v. Don't know
- l. Use computer to play
 - i. Achieved already
 - ii. Not achieved but not important
 - iii. No achieved but important to me now
 - iv. Not achieved but may be important to me in the future
 - v. Don't know
- m. Use a computer for internet and e-mail
 - i. Achieved already
 - ii. Not achieved but not important
 - iii. No achieved but important to me now
 - iv. Not achieved but may be important to me in the future
 - v. Don't know
- n. Sharing personal information appropriately
 - i. Achieved already
 - ii. Not achieved but not important
 - iii. No achieved but important to me now
 - iv. Not achieved but may be important to me in the future
 - v. Don't know
- o. Getting to/Making/Asking questions at doctor appointments
 - i. Achieved already

- ii. Not achieved but not important
 - iii. No achieved but important to me now
 - iv. Not achieved but may be important to me in the future
 - v. Don't know
- p. Ability to consent to medical treatment
 - i. Achieved already
 - ii. Not achieved but not important
 - iii. No achieved but important to me now
 - iv. Not achieved but may be important to me in the future
 - v. Don't know
- q. Able to verbalize, sign or use assistive communication device to express wants and needs
 - i. Achieved already
 - ii. Not achieved but not important
 - iii. No achieved but important to me now
 - iv. Not achieved but may be important to me in the future
 - v. Don't know
- r. Expresses emotions appropriately
 - i. Achieved already
 - ii. Not achieved but not important
 - iii. No achieved but important to me now
 - iv. Not achieved but may be important to me in the future
 - v. Don't know
- s. Ability to participate in a conversation (verbal, sign language or via a communication devise)
 - i. Achieved already

- ii. Not achieved but not important
 - iii. No achieved but important to me now
 - iv. Not achieved but may be important to me in the future
 - v. Don't know
- t. Other (please explain): _____
- i. Achieved already
 - ii. Not achieved but not important
 - iii. No achieved but important to me now
 - iv. Not achieved but may be important to me in the future
 - v. Don't know

31. Top 3 choices for **VOCATIONAL/EMPLOYMENT** from question 30:

- a. 1st Choice: _____
- b. 2nd Choice: _____
- c. 3rd Choice: _____

32. Which statement below best describes your wishes as a **CAREGIVER** for your loved one with Down syndrome?

- a. Be as independent as possible
- b. Achieve some independence
- c. Independence is not a priority

33. The following **CAREGIVER** self-care topics are important to me as the caregiver of a loved one with Down syndrome in terms of MY independence. This question is about YOUR ability as a caregiver to be independent of your loved one with Down syndrome.

- a. Run errands with loved one safely at home
 - i. Achieved already
 - ii. Not achieved but not important
 - iii. No achieved but important to me now

- iv. Not achieved but may be important to me in the future
 - v. Don't know
- b. Run errands with loved one safely at my side
 - i. Achieved already
 - ii. Not achieved but not important
 - iii. No achieved but important to me now
 - iv. Not achieved but may be important to me in the future
 - v. Don't know
- c. Vacations
 - i. Achieved already
 - ii. Not achieved but not important
 - iii. No achieved but important to me now
 - iv. Not achieved but may be important to me in the future
 - v. Don't know
- d. Respite care
 - i. Achieved already
 - ii. Not achieved but not important
 - iii. No achieved but important to me now
 - iv. Not achieved but may be important to me in the future
 - v. Don't know
- e. Financial planning
 - i. Achieved already
 - ii. Not achieved but not important
 - iii. No achieved but important to me now
 - iv. Not achieved but may be important to me in the future
 - v. Don't know

- f. Ability to care for self
 - i. Achieved already
 - ii. Not achieved but not important
 - iii. No achieved but important to me now
 - iv. Not achieved but may be important to me in the future
 - v. Don't know
- g. Ability to call for emergency at appropriate times
 - i. Achieved already
 - ii. Not achieved but not important
 - iii. No achieved but important to me now
 - iv. Not achieved but may be important to me in the future
 - v. Don't know
- h. Ability to know how to get help
 - i. Achieved already
 - ii. Not achieved but not important
 - iii. No achieved but important to me now
 - iv. Not achieved but may be important to me in the future
 - v. Don't know
- i. Understanding entitlement programs such as Medicaid and Social Security
 - i. Achieved already
 - ii. Not achieved but not important
 - iii. No achieved but important to me now
 - iv. Not achieved but may be important to me in the future
 - v. Don't know
- j. What will happen after I am gone
 - i. Achieved already

- ii. Not achieved but not important
 - iii. No achieved but important to me now
 - iv. Not achieved but may be important to me in the future
 - v. Don't know
- k. Burden of multiple medical appointments
 - i. Achieved already
 - ii. Not achieved but not important
 - iii. No achieved but important to me now
 - iv. Not achieved but may be important to me in the future
 - v. Don't know
- l. Reduce stress of the planning for my loved one with DS's options after age 22
 - i. Achieved already
 - ii. Not achieved but not important
 - iii. No achieved but important to me now
 - iv. Not achieved but may be important to me in the future
 - v. Don't know
- m. Other (please explain)
 - i. Achieved already
 - ii. Not achieved but not important
 - iii. No achieved but important to me now
 - iv. Not achieved but may be important to me in the future
 - v. Don't know

34. Top 3 choices for **CAREGIVER** self-care from question 33:

- a. 1st Choice: _____
- b. 2nd Choice: _____
- c. 3rd Choice: _____

35. Do you have ideas on further research into practical solutions for supporting greater independence?

a. No

b. Yes (please explain) _____

16.13. Vineland-3 Adaptive Behavior Scales



Vineland Adaptive Behavior Scales, Third Edition (Vineland™-3)
Domain-Level Teacher Form Report
Sara S. Sparrow, Domenic V. Cicchetti, and Celine A. Saulnier

Examinee Information

ID:
Name: Jordan Sample
Gender: Male
Birth Date: 01/23/2008
Age: 8:4
Overall IQ Score: 73

Test Information

Test Date: 06/08/2016
Respondent Name: Katherine C. Smith
Type of Teacher: Special Education Teacher
Examiner Name:

OVERALL SUMMARY

The Vineland-3 is a standardized measure of adaptive behavior--the things that people do to function in their everyday lives. Whereas ability measures focus on what the examinee can do in a testing situation, the Vineland-3 focuses on what he or she actually does in daily life. Because it is a norm-based instrument, the examinee's adaptive functioning is compared to that of others his or her age.

Jordan Sample was evaluated using the Vineland-3 Domain-Level Teacher Form on 06/08/2016. Katherine C. Smith, Jordan's Special Education Teacher, completed the form.

Jordan's overall level of adaptive functioning is described by his score on the Adaptive Behavior Composite (ABC). His ABC score is 66, which is well below the normative mean of 100 (the normative standard deviation is 15). The percentile rank for this overall score is 1.

The ABC score is based on scores for three specific adaptive behavior domains: Communication, Daily Living Skills, and Socialization. The domain scores are also expressed as standard scores with a mean of 100 and standard deviation of 15.

The Communication domain measures how well Jordan listens and understands, expresses himself through speech, and reads and writes. His Communication standard score is 65. This corresponds to a percentile rank of 1. This domain is a relative weakness for Jordan.

The Daily Living Skills domain assesses Jordan's performance of the practical, everyday tasks of living that are appropriate in the school setting. His standard score for Daily Living Skills is 79, which corresponds to a percentile rank of 8. This domain is a relative strength for Jordan.

Jordan's score for the Socialization domain reflects his functioning in social situations. His Socialization standard score is 57. The percentile rank is <1. This domain is a relative weakness for Jordan.

16.14. Behavior Problems Inventory

THE BEHAVIOR PROBLEMS INVENTORY - 01 [BPI-01]

| The Client | | |
|--|-------------------------------|---|
| ID: _____ | Age: _____ years _____ months | Gender: <input type="checkbox"/> male <input type="checkbox"/> female |
| Ethnicity/Race: <input type="checkbox"/> Caucasian <input type="checkbox"/> African-American | | |
| <input type="checkbox"/> Asian/Pacific Islanders <input type="checkbox"/> American Indian/Eskimo/Aleutian <input type="checkbox"/> Hispanic-American White | | |
| <input type="checkbox"/> Hispanic-American Black <input type="checkbox"/> Mixed ethnic background <input type="checkbox"/> other/do not want to answer | | |
| Intellectual Disability: <input type="checkbox"/> mild ID (IQ 56-70) <input type="checkbox"/> moderate ID (IQ 41-55) | | |
| <input type="checkbox"/> severe ID (IQ 26-40) <input type="checkbox"/> profound ID (IQ < 26) <input type="checkbox"/> unknown | | |

| The Respondent | | |
|---|--|--|
| Relationship to the client: <input type="checkbox"/> biological parent <input type="checkbox"/> guardian or foster parent | | |
| <input type="checkbox"/> non-parental relative <input type="checkbox"/> teacher/day program staff <input type="checkbox"/> psychologist | | |
| <input type="checkbox"/> case manager <input type="checkbox"/> behavior specialist <input type="checkbox"/> other | | |
| Time you typically spent with the client per day: _____ | | |
| How long have you known the client: _____ | | |

| BPI-01 Results Summary | | |
|---------------------------------|-------------------------|------------------------|
| Subscales | Sum of frequency scores | Sum of severity scores |
| SIB | | |
| Stereotyped Behavior | | |
| Aggressive/Destructive Behavior | | |

Instructions

On the following pages you will find generic definitions followed by specific descriptions of three types of behavior problems: self-injurious behaviors (items 1-15), stereotyped behaviors (items 16-40), and aggressive/destructive behaviors (items 41-52).

Please indicate which behaviors you have observed in this individual **during the past two months** by circling the number in the appropriate boxes to indicate (a) how often the described behavior typically occurs (frequency) and (b) how much of a problem the behavior represents (severity).

If the behavior has never been observed during the last two months, check "never" (i.e., number "0").

Scoring

Below are examples of three items scored for the behavior of a person named Jane:

1. Jane has never been seen biting herself (check "never" or "0" for item 1).
2. However, Jane slaps and punches her face. When unobserved, she does it almost constantly (check "hourly" or "4" for the frequency scale of item 2). This behavior potentially causes serious harm and Jane has thick calluses on her forehead (check "severe" or "3" on the severity scale).
3. Jane is also known to slap her thighs; this happens less frequently, every five to ten days or so (check "weekly" or "2" on the frequency scale of item 3). Nevertheless this behavior has been a big concern because it has caused serious bruises (check "severe" or "3" on the severity scale of item 3).
4. To obtain the subscale scores for these three items, sum up the numerical values of the checked boxes, separately for the frequency and the severity scales.

| | | Frequency | | | | | Severity | | |
|---|--|-----------------|---------|--------|-------|--------|----------------|----------|--------|
| | | Never | Monthly | Weekly | Daily | Hourly | Mild | Moderate | Severe |
| 1 | Self-biting (so hard that a tooth print can be seen for some time; bloodshot or breaking of skin may occur) | X | 1 | 2 | 3 | 4 | 1 | 2 | 3 |
| 2 | Hitting head with hand or other body part (e.g., face slapping, knee against forehead) or with/against objects (e.g., slamming against a wall, knocking head with a toy) | 0 | 1 | 2 | 3 | X | 1 | 2 | X |
| 3 | Hitting body (except for the head) with own hand or with any other body part (e.g., kicking self, slapping arms or thighs), or with/against objects (e.g., hitting legs with a stick, boxing the wall) | 0 | 1 | X | 3 | 4 | 1 | 2 | X |
| | | Frequency Total | | | | 6 | Severity Total | | 6 |

| SELF-INJURIOUS BEHAVIOR | | | | | | | | | |
|--|--|-----------|---------|--------|-----------------|--------|----------------|----------|--------|
| Generic definition: Self-injurious behavior (SIB) causes damage to the person's own body; i.e., damage has either already occurred, or it must be expected if the behavior remained untreated. SIBs occur repeatedly in the same way over and over again, and they are characteristic for that person. | | | | | | | | | |
| | | Frequency | | | | | Severity | | |
| | | Never | Monthly | Weekly | Daily | Hourly | Mild | Moderate | Severe |
| 1 | Self-biting (so hard that a tooth print can be seen for some time; bloodshot or breaking of skin may occur) | 0 | 1 | 2 | 3 | 4 | 1 | 2 | 3 |
| 2 | Hitting head with hand or other body part (e.g., face slapping, knee against forehead) or with/against objects (e.g., slamming against a wall, knocking head with a toy) | 0 | 1 | 2 | 3 | 4 | 1 | 2 | 3 |
| 3 | Hitting body (except for the head) with own hand or with any other body part (e.g., kicking self, slapping arms or thighs), or with/against objects (e.g., hitting legs with a stick, boxing the wall) | 0 | 1 | 2 | 3 | 4 | 1 | 2 | 3 |
| 4 | Self-scratching (so hard that reddening of the skin becomes visible; breaking of the skin may also occur) | 0 | 1 | 2 | 3 | 4 | 1 | 2 | 3 |
| 5 | Vomiting and rumination (deliberate regurgitation of swallowed food with rumination) | 0 | 1 | 2 | 3 | 4 | 1 | 2 | 3 |
| 6 | Self-pinching (so hard that reddening of the skin becomes visible; breaking of the skin may occur) | 0 | 1 | 2 | 3 | 4 | 1 | 2 | 3 |
| 7 | Pica: Mouthing or swallowing of objects which should not be mouthed or swallowed for health or hygiene reasons (non-food items such as feces, grass, paper, garbage, hair) | 0 | 1 | 2 | 3 | 4 | 1 | 2 | 3 |
| 8 | Inserting objects in body openings (in nose, ears, or anus, etc.) | 0 | 1 | 2 | 3 | 4 | 1 | 2 | 3 |
| 9 | Pulling finger or toe nails | 0 | 1 | 2 | 3 | 4 | 1 | 2 | 3 |
| 10 | Inserting fingers in body openings (e.g., eye poking, finger in anus) | 0 | 1 | 2 | 3 | 4 | 1 | 2 | 3 |
| 11 | Air swallowing resulting in extended abdomen | 0 | 1 | 2 | 3 | 4 | 1 | 2 | 3 |
| 12 | Hair pulling (tearing out patches of hair) | 0 | 1 | 2 | 3 | 4 | 1 | 2 | 3 |
| 13 | Extreme drinking (e.g., more than 3 liters per day) | 0 | 1 | 2 | 3 | 4 | 1 | 2 | 3 |
| 14 | Teeth grinding (evidence of ground teeth) | 0 | 1 | 2 | 3 | 4 | 1 | 2 | 3 |
| 15 | Other: | 0 | 1 | 2 | 3 | 4 | 1 | 2 | 3 |
| | | | | | Frequency Total | | Severity Total | | |

| STEREOTYPED BEHAVIOR | | | | | | | | | |
|--|---------------------------------------|-------|---------|--------|-------|--------|------|----------|--------|
| Generic definition: Stereotyped behaviors look unusual, strange, or inappropriate to the average person. They are voluntary acts that occur repeatedly in the same way over and over again, and they are characteristic for that person. However, they do NOT cause physical damage. | | | | | | | | | |
| | | Never | Monthly | Weekly | Daily | Hourly | Mild | Moderate | Severe |
| 16 | Rocking back and forth | 0 | 1 | 2 | 3 | 4 | 1 | 2 | 3 |
| 17 | Sniffing objects | 0 | 1 | 2 | 3 | 4 | 1 | 2 | 3 |
| 18 | Spinning own body | 0 | 1 | 2 | 3 | 4 | 1 | 2 | 3 |
| 19 | Waving or shaking arms | 0 | 1 | 2 | 3 | 4 | 1 | 2 | 3 |
| 20 | Rolling head | 0 | 1 | 2 | 3 | 4 | 1 | 2 | 3 |
| 21 | Whirling, turning around on spot | 0 | 1 | 2 | 3 | 4 | 1 | 2 | 3 |
| 22 | Engaging in repetitive body movements | 0 | 1 | 2 | 3 | 4 | 1 | 2 | 3 |
| 23 | Pacing | 0 | 1 | 2 | 3 | 4 | 1 | 2 | 3 |

| | | Never | Monthly | Weekly | Daily | Hourly | Mild | Moderate | Severe |
|-----------------|---|-------|---------|--------|-------|--------|----------------|----------|--------|
| 24 | Twirling things | 0 | 1 | 2 | 3 | 4 | 1 | 2 | 3 |
| 25 | Having repetitive hand movements | 0 | 1 | 2 | 3 | 4 | 1 | 2 | 3 |
| 26 | Yelling and screaming | 0 | 1 | 2 | 3 | 4 | 1 | 2 | 3 |
| 27 | Sniffing own body | 0 | 1 | 2 | 3 | 4 | 1 | 2 | 3 |
| 28 | Bouncing around | 0 | 1 | 2 | 3 | 4 | 1 | 2 | 3 |
| 29 | Spinning objects | 0 | 1 | 2 | 3 | 4 | 1 | 2 | 3 |
| 30 | Having bursts of running around | 0 | 1 | 2 | 3 | 4 | 1 | 2 | 3 |
| 31 | Engaging in complex hand and finger movements | 0 | 1 | 2 | 3 | 4 | 1 | 2 | 3 |
| 32 | Manipulating objects repeatedly | 0 | 1 | 2 | 3 | 4 | 1 | 2 | 3 |
| 33 | Exhibiting sustained finger movements | 0 | 1 | 2 | 3 | 4 | 1 | 2 | 3 |
| 34 | Rubbing self | 0 | 1 | 2 | 3 | 4 | 1 | 2 | 3 |
| 35 | Gazing at hands or objects | 0 | 1 | 2 | 3 | 4 | 1 | 2 | 3 |
| 36 | Maintaining bizarre body postures | 0 | 1 | 2 | 3 | 4 | 1 | 2 | 3 |
| 37 | Clapping hands | 0 | 1 | 2 | 3 | 4 | 1 | 2 | 3 |
| 38 | Grimacing | 0 | 1 | 2 | 3 | 4 | 1 | 2 | 3 |
| 39 | Waving hands | 0 | 1 | 2 | 3 | 4 | 1 | 2 | 3 |
| 40 | Other | 0 | 1 | 2 | 3 | 4 | 1 | 2 | 3 |
| Frequency Total | | | | | | | Severity Total | | |

| AGGRESSIVE/DESTRUCTIVE BEHAVIOR | | | | | | | | | |
|---|--|-------|---------|--------|-------|--------|----------------|----------|--------|
| <i>Generic definition: Aggressive or destructive behaviors are offensive actions or deliberate overt attacks directed towards other individuals or objects. They occur repeatedly in the same way over and over again, and they are characteristic for that person.</i> | | | | | | | | | |
| | | Never | Monthly | Weekly | Daily | Hourly | Slight | Moderate | Severe |
| 41 | Hitting others | 0 | 1 | 2 | 3 | 4 | 1 | 2 | 3 |
| 42 | Kicking others | 0 | 1 | 2 | 3 | 4 | 1 | 2 | 3 |
| 43 | Pushing others | 0 | 1 | 2 | 3 | 4 | 1 | 2 | 3 |
| 44 | Biting others | 0 | 1 | 2 | 3 | 4 | 1 | 2 | 3 |
| 45 | Grabbing and pulling others | 0 | 1 | 2 | 3 | 4 | 1 | 2 | 3 |
| 46 | Scratching others | 0 | 1 | 2 | 3 | 4 | 1 | 2 | 3 |
| 47 | Pinching others | 0 | 1 | 2 | 3 | 4 | 1 | 2 | 3 |
| 48 | Spitting on others | 0 | 1 | 2 | 3 | 4 | 1 | 2 | 3 |
| 49 | Being verbally abusive with others | 0 | 1 | 2 | 3 | 4 | 1 | 2 | 3 |
| 50 | Destroying things (e.g., rips clothes, throws chairs, smashes tables) | 0 | 1 | 2 | 3 | 4 | 1 | 2 | 3 |
| 51 | Being mean or cruel (e.g., grabbing toys or food from others, bullying others) | 0 | 1 | 2 | 3 | 4 | 1 | 2 | 3 |
| 52 | Other: | 0 | 1 | 2 | 3 | 4 | 1 | 2 | 3 |
| Frequency Total | | | | | | | Severity Total | | |

16.15. MapHabit, Inc. Final Exit Interview Questionnaire

Date: _____

Name or ID: _____

Compared to three months ago, before you and ____ (name) ____ started using the MapHabit System:

- Are you now experiencing:
- Is ____ (name) ____ now experiencing:

Please use the scale indicated

1 = Much negative change 2 = Some negative change 3 = No change 4 = Some positive change 5 = Much positive change

1. Improved mood
2. Improved independence
3. Improved ability to carry out some ADL
4. Completes ADLs more quickly
5. Needs less reminding during an ADL
6. Improved social interaction
7. Less depression
8. Less anxiety
9. Less frustration
10. Less anger
11. Better coping ability
12. Improved memory for some things
13. More social engagement
14. An overall better quality of life
15. More enjoyment of life
16. More better moments
17. Expresses appreciation more
18. More cooperative

19. How satisfied are you with your progress in this program?

3 = Completely. 2 = Somewhat. 1 = Not at all

20. Overall, do you feel you are:

5 = Much better. 4 = Better. 3 = About the same. 2 = Worse. 1 = Much worse

21. Would you recommend the MHS to your colleagues? 2 = Yes. 1 = No

16.16 Wisconsin Quality of Life Index (W-QLI)

| BACKGROUND INFORMATION | |
|---|--|
| What is your date of birth? _____ | |
| You are? <input type="checkbox"/> Male <input type="checkbox"/> Female | |
| What is your highest school grade completed: _____ | |
| What is your current relationship/marital status? | |
| <input type="checkbox"/> Single/Never Married | <input type="checkbox"/> Committed relationship |
| <input type="checkbox"/> Married | <input type="checkbox"/> Separated |
| <input type="checkbox"/> Divorced | <input type="checkbox"/> Spouse deceased |
| How many times have you been married?_ _____ | |
| What is the source of your income? (Check all that apply) | |
| <input type="checkbox"/> Paid employment | <input type="checkbox"/> Unemployment compensation |
| <input type="checkbox"/> Social Security Disability Income (SSDI) or Supplemental Security Income (SSI) | <input type="checkbox"/> Retirement, investment or savings |
| <input type="checkbox"/> Veterans disability or pension benefits | <input type="checkbox"/> Alimony or child support |
| <input type="checkbox"/> General assistance | <input type="checkbox"/> Money shared by your spouse/partner |
| <input type="checkbox"/> AFDC | <input type="checkbox"/> Money from your family |
| | <input type="checkbox"/> Other source: _____ |
| What is your racial/ethnic background? (Check all that apply) | |
| <input type="checkbox"/> American Indian/Native American | <input type="checkbox"/> Hispanic/Latino |
| <input type="checkbox"/> Asian | <input type="checkbox"/> White |
| <input type="checkbox"/> African American | <input type="checkbox"/> Other, specify: _____ |
| During the past four weeks, you lived: (Check all that apply) | |
| <input type="checkbox"/> alone | <input type="checkbox"/> with parents |
| <input type="checkbox"/> with roommate/friend | <input type="checkbox"/> with significant other/spouse |
| <input type="checkbox"/> with children | <input type="checkbox"/> with other, please specify: _____ |
| Who would you like to live with? (Check all that apply) | |
| <input type="checkbox"/> alone | <input type="checkbox"/> with parents |
| <input type="checkbox"/> friend/roommate | <input type="checkbox"/> with significant other/spouse |
| <input type="checkbox"/> with children | <input type="checkbox"/> with other, please specify: _____ |
| During the past four weeks, you lived primarily: (Check one) | |
| <input type="checkbox"/> in an apartment/home | <input type="checkbox"/> at school/college |
| <input type="checkbox"/> in a boarding home | <input type="checkbox"/> in an institution (i.e. hospital or nursing home) |
| <input type="checkbox"/> in an group home or halfway house | <input type="checkbox"/> in jail/prison |
| <input type="checkbox"/> homeless | <input type="checkbox"/> other, please specify: _____ |
| Where would you like to live? (Choose one) | |
| <input type="checkbox"/> in an apartment/home | <input type="checkbox"/> at school/college |
| <input type="checkbox"/> in a boarding home | <input type="checkbox"/> in an institution (i.e. hospital or nursing home) |
| <input type="checkbox"/> in an group home or halfway house | <input type="checkbox"/> in jail/prison |

☐ homeless☐ other, please specify: _____

| SATISFACTION LEVEL | | | | | | | |
|---|--------------------------|--------------------------|--------------------------|-----------------------------------|--------------------------|--------------------------|--------------------------|
| | Very dissatisfied | Moderately dissatisfied | A little dissatisfied | Neither satisfied or dissatisfied | A little satisfied | Moderately satisfied | Very satisfied |
| How satisfied or dissatisfied are you with the way you spend your time? | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| How satisfied or dissatisfied are you when you are alone? | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| How satisfied or dissatisfied are you with your housing? | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| How satisfied or dissatisfied are you with your neighborhood as a place to live in? | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| How satisfied or dissatisfied are you with the food you eat? | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| How satisfied or dissatisfied are you with the clothing you wear? | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| How satisfied or dissatisfied are you with the mental health services you use? | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| How satisfied or dissatisfied are you with your access to transportation? | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| How satisfied or dissatisfied are you with your sex life? | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| How satisfied or dissatisfied are you with your personal safety? | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |

We have asked how satisfied you are with different parts of your life. Now we would like to know how important each of these aspects of your life are.

| | Not at all important | Slightly important | Moderately important | Very important | Extremely important |
|--|--------------------------|--------------------------|--------------------------|--------------------------|--------------------------|
| How important to you is the way you spend your time? | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| How important is it to feel comfortable when alone? | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |

| | | | | | |
|--|--------------------------|--------------------------|--------------------------|--------------------------|--------------------------|
| | | | | | |
| How important is your housing? | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| How important is your neighborhood as a place to live in? | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| How important to you is the food you eat? | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| How important to you is the clothing you wear? | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| How important to you are the mental health services you use? | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| How important to you is your access to transportation? | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| How important to you is your sex life? | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| How important to you is your personal safety? | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| ACTIVITIES AND OCCUPATIONS | | | | | |

During the **past four weeks**, you have: (Check one)

- ☐ been working/studying or doing housework in your usual manner
☐ been working/studying or doing housework but less often
☐ stopped working/studying or doing housework

About how many hours a week do you work or go to school? Hours per week = _____

What is your main activity? (Check one).

- ☐ Paid employment ☐ Treatment/rehabilitation program ☐ Other, Please Specify
☐ Volunteer or unpaid work ☐ Craft/leisure time/hobbies
☐ School ☐ No structured activity

How satisfied or dissatisfied are you with the main activity that you do? (Check one)

| | | | | | | |
|--|--|--|--|---|---|---|
| <input type="checkbox"/> Very dissatisfied | <input type="checkbox"/> Moderately dissatisfied | <input type="checkbox"/> A little dissatisfied | <input type="checkbox"/> Neither satisfied or dissatisfied | <input type="checkbox"/> A little satisfied | <input type="checkbox"/> Moderately satisfied | <input type="checkbox"/> Very satisfied |
|--|--|--|--|---|---|---|

Do you feel that you are engaged in activities: (Choose one)

- ☐ Less than you would like ☐ More than you would like ☐ As much as you want

What would you like to have as your main activity?

- ☐ Paid employment ☐ Treatment/rehabilitation program ☐ Other, Please Specify
☐ Volunteer or unpaid work ☐ Craft/leisure time/hobbies
☐ School ☐ No structured activity

PSYCHOLOGICAL WELL-BEING

Now we would like to know how you feel about things in your life. For each of the following questions, check the boxes that best describe how you have felt in the **past four weeks**.

| | | |
|-----|----|--|
| YES | NO | |
|-----|----|--|

| | | |
|--------------------------|--------------------------|---|
| <input type="checkbox"/> | <input type="checkbox"/> | Pleased about having accomplished something? |
| <input type="checkbox"/> | <input type="checkbox"/> | Very lonely or remote from other people? |
| <input type="checkbox"/> | <input type="checkbox"/> | Bored? |
| <input type="checkbox"/> | <input type="checkbox"/> | That things went your way? |
| <input type="checkbox"/> | <input type="checkbox"/> | So restless that you couldn't sit long in a chair? |
| <input type="checkbox"/> | <input type="checkbox"/> | Proud because someone complimented you on something you had done? |
| <input type="checkbox"/> | <input type="checkbox"/> | Upset because someone criticized you? |
| <input type="checkbox"/> | <input type="checkbox"/> | Particularly excited or interested in something? |
| <input type="checkbox"/> | <input type="checkbox"/> | Depressed or very unhappy? |
| <input type="checkbox"/> | <input type="checkbox"/> | On top of the world? |

In the **past four weeks**, would you say that your mental health has been:

☐ Poor ☐ Fair ☐ Good ☐ Very Good ☐ Excellent

SYMPTOMS/OUTLOOK

During the **past four weeks**, you have: (Check one)

- ☐ generally felt calm and positive in outlook
☐ been having some periods of anxiety or depression
☐ generally been confused, frightened, anxious or depressed

There are many aspects of emotional distress including feelings of depression, anxiety, hearing voices, etc. In the **past four weeks**, how much distress have these symptoms caused you?: (Check one)

☐ Not at all ☐ A little ☐ Some ☐ A moderate amount ☐ A lot

| In the past four weeks : | Never | Occa- sionally | Frequen- tly | Most of the time | Constan- tly |
|---|--------------------------|--------------------------|--------------------------|--------------------------|--------------------------|
| How much has feelings of depression, anxiety, etc. interfered with your daily life? | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| Have you felt like killing yourself? | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| Have you felt like harming others? | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |

PHYSICAL HEALTH

In the **past four weeks**, you would best describe your physical health as:

☐ Poor ☐ Fair ☐ Good ☐ Very Good ☐ Excellent

How do you feel about your physical health? (Check one)

| | | | | | | |
|--|---|--|--|--|---|--|
| <input type="checkbox"/> Very dissatisf- ied | <input type="checkbox"/> Moderat- ely dissatisf- ied | <input type="checkbox"/> A little dissatisf- ied | <input type="checkbox"/> Neither satisfied or dissatisf- ied | <input type="checkbox"/> A little satisfied | <input type="checkbox"/> Moderat- ely satisfied | <input type="checkbox"/> Very satisfied |
|--|---|--|--|--|---|--|

| | | | | |
|---|---|---|---|--|
| <input type="checkbox"/> Not at all important | <input type="checkbox"/> Slightly important | <input type="checkbox"/> Moderately important | <input type="checkbox"/> Very important | <input type="checkbox"/> Extremely important |
|---|---|---|---|--|

Are you currently taking psychiatric medications? ☐ Yes ☐ No (If no, go to next page)

If you are currently taking psychiatric medications, do you take them as prescribed? (Check one)

- ☐ Never ☐ Sometimes ☐ Always
☐ Very infrequently ☐ Quite often

If you are currently taking psychiatric medications, do you have side effects from them?

- ☐ None ☐ Slight ☐ Mild ☐ Moderate ☐ Severe

If you take medications for mental health problems, do you feel the medication helps control your symptoms?

- ☐ Not at all ☐ Some ☐ A fair amount ☐ Quite a bit ☐ Eliminates all symptoms

How do you feel about taking your psychiatric medications?

| | | | | | | |
|--|--|--|--|---|---|---|
| <input type="checkbox"/> Very dissatisfied | <input type="checkbox"/> Moderately dissatisfied | <input type="checkbox"/> A little dissatisfied | <input type="checkbox"/> Neither satisfied or dissatisfied | <input type="checkbox"/> A little satisfied | <input type="checkbox"/> Moderately satisfied | <input type="checkbox"/> Very satisfied |
|--|--|--|--|---|---|---|

ALCOHOL & OTHER DRUGS

Over the **past four weeks**, have you drank any alcohol?

- ☐ Yes ☐ No

If yes, on how many days have you had any alcohol to drink? _____
(number of days)

What do you think about your alcohol use? (Check one)

- ☐ It is a big problem ☐ Not a problem ☐ It helps a lot
☐ It is a minor problem ☐ It helps a little

Over the **past four weeks**, have you used any street drugs (cocaine, marijuana, heroin, speed, LSD, etc.)?

- ☐ Yes ☐ No

If yes, on how many days have you used any street drugs? _____
(number of days)

What do you think about your drug use? (Check one)

- ☐ It is a big problem ☐ Not a problem ☐ It helps a lot
☐ It is a minor problem ☐ It helps a little

SOCIAL RELATIONS / SUPPORT

| | | | | | | | |
|--|-------------------|-------------------------|-----------------------|-----------------------------------|--------------------|----------------------|----------------|
| | Very dissatisfied | Moderately dissatisfied | A little dissatisfied | Neither satisfied or dissatisfied | A little satisfied | Moderately satisfied | Very satisfied |
|--|-------------------|-------------------------|-----------------------|-----------------------------------|--------------------|----------------------|----------------|

| | | | | | | | |
|--|-------------------------------|------------------------------|------------------------------|---------------------------------|--------------------------|--------------------------|--------------------------|
| | | ied | | ied | | | |
| How satisfied or dissatisfied are you with the number of friends you have? <input type="checkbox"/> No friends | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| How satisfied or dissatisfied are you with how you get along with your friends? | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| How satisfied or dissatisfied are you with your relationship with your family? <input type="checkbox"/> No family | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| If you live with others, how satisfied or dissatisfied are you with the people you live? <input type="checkbox"/> Live alone | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| How satisfied or dissatisfied are you with how you get along with other people? | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| How many people do you count as your friends? | <input type="checkbox"/> none | <input type="checkbox"/> 1-2 | <input type="checkbox"/> 3-5 | <input type="checkbox"/> over 5 | | | |

| IMPORTANCE LEVEL | | | | | |
|---|--------------------------|--------------------------|--------------------------|--------------------------|--------------------------|
| | Not at all important | Slightly important | Moderately important | Very important | Extremely important |
| How important is it to have an adequate number of friends? | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| How important is it to get along with your friends? | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| How important are family relationships? | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| If you live with others, how important are the people with whom you live? | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| How important is it to get along with others? | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |

During the **past four weeks**, you have (check one):

- ☐ been having good relationships with others and receiving support from family and friends
- ☐ been receiving only moderate support from family and friends
- ☐ had infrequent support from family and friends or only when absolutely necessary

MONEY

Are you paid for working or attending school? ☐ Yes ☐ No

| | Very dissatisfied | Moderately dissatisfied | A little dissatisfied | Neither satisfied or dissatisfied | A little satisfied | Moderately satisfied | Very satisfied |
|---|--------------------------|--------------------------|--------------------------|-----------------------------------|--------------------------|--------------------------|--------------------------|
| How do you feel about the amount of money you have? | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| How satisfied are you about the amount of control you have over your money? | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| | | | Not at all important | Slightly important | Moderately important | Very important | Extremely important |
| How important to you is money? | | | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| How important is it to you to have control over your money? | | | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |

How often does lack of money keep you from doing what you want to do?

☐ Never ☐ Sometimes ☐ Frequently ☐ Almost always

ACTIVITIES OF DAILY LIVING

Below are activities that you may have participated in recently. Please check YES or NO to indicate whether you have done the activity in the **past four weeks**.

| | YES | NO | | YES | NO |
|-------------------------------------|--------------------------|--------------------------|------------------|--------------------------|--------------------------|
| Gone to a restaurant or coffee shop | <input type="checkbox"/> | <input type="checkbox"/> | Gone shopping | <input type="checkbox"/> | <input type="checkbox"/> |
| Gone for a ride in a bus or car | <input type="checkbox"/> | <input type="checkbox"/> | Prepared a meal | <input type="checkbox"/> | <input type="checkbox"/> |
| Cleaned the room/apartment/home | <input type="checkbox"/> | <input type="checkbox"/> | Done the laundry | <input type="checkbox"/> | <input type="checkbox"/> |

During the **past four weeks** you:

- ☐ have been able to do most things on your own (such as shopping, getting around town, etc.)
- ☐ have needed some help in getting things done
- ☐ have had trouble getting tasks done, even with help

In the **past four weeks**, how often have you had any problems with personal grooming (e.g. taking showers, brushing your teeth)? ☐ Never ☐ Sometimes ☐ Frequently ☐ Almost always

GOAL ATTAINMENT

What did you hope to accomplish as a result of your mental health treatment? Please write below up to 3 goals:

Goal 1: _____

How important is this goal to you? Please check the box below to indicate how important this goal is to you. (NR = No Response)

Not at all ☐ 1 ☐ 2 ☐ 3 ☐ 4 ☐ 5 ☐ 6 ☐ 7 ☐ 8 ☐ 9 ☐ 10 **Extremely Important** ☐ NR

To what extent have you achieved this goal? Please check the box below to indicate the extent to which you have achieved this goal.

Not at all ☐ 1 ☐ 2 ☐ 3 ☐ 4 ☐ 5 ☐ 6 ☐ 7 ☐ 8 ☐ 9 ☐ 10 **Completely achieved** ☐ NR

Goal 2: _____

How important is this goal to you?

Not at all ☐ 1 ☐ 2 ☐ 3 ☐ 4 ☐ 5 ☐ 6 ☐ 7 ☐ 8 ☐ 9 ☐ 10 **Extremely Important** ☐ NR

To what extent have you achieved this goal?

Not at all ☐ 1 ☐ 2 ☐ 3 ☐ 4 ☐ 5 ☐ 6 ☐ 7 ☐ 8 ☐ 9 ☐ 10 **Completely achieved** ☐ NR

Goal 3: _____

How important is this goal to you?

Not at all ☐ 1 ☐ 2 ☐ 3 ☐ 4 ☐ 5 ☐ 6 ☐ 7 ☐ 8 ☐ 9 ☐ 10 **Extremely Important** ☐ NR

To what extent have you achieved this goal?

Not at all ☐ 1 ☐ 2 ☐ 3 ☐ 4 ☐ 5 ☐ 6 ☐ 7 ☐ 8 ☐ 9 ☐ 10 **Completely achieved** ☐ NR

Below are activities that you may have participated in recently. Please check Yes or No to indicate whether you have done the activity in the **past four weeks**.

| | YES | NO | | YES | NO |
|-------------------------|--------------------------|--------------------------|-----------------------------------|--------------------------|--------------------------|
| Gone for a walk | <input type="checkbox"/> | <input type="checkbox"/> | Gone to a social group | <input type="checkbox"/> | <input type="checkbox"/> |
| Gone to a movie or play | <input type="checkbox"/> | <input type="checkbox"/> | Read a magazine or newspaper | <input type="checkbox"/> | <input type="checkbox"/> |
| Watched TV | <input type="checkbox"/> | <input type="checkbox"/> | Gone to church, synagogue, mosque | <input type="checkbox"/> | <input type="checkbox"/> |
| Played cards | <input type="checkbox"/> | <input type="checkbox"/> | Listened to a radio | <input type="checkbox"/> | <input type="checkbox"/> |
| Played a sport | <input type="checkbox"/> | <input type="checkbox"/> | Gone to a library | <input type="checkbox"/> | <input type="checkbox"/> |

Please check the box below to indicate how you feel about your quality of life during the **past four weeks**.

Lowest quality means things are as bad as they could be. Highest quality means things are the best they could be.

LOWEST QUALITY ☐ 1 ☐ 2 ☐ 3 ☐ 4 ☐ 5 ☐ 6 ☐ 7 ☐ 8 ☐ 9 ☐ 10 **HIGHEST QUALITY**

If your quality of life is less than you hope for, how hopeful are you that you will eventually achieve your desired quality of life? (Check one)

☐ Not at all ☐ Somewhat ☐ Moderately ☐ Very

How much control do you feel you have over the important areas of your life? (Check one)

☐ None

☐ Some

☐ A moderate amount

☐ A great amount

| How important are each of the following factors in determining your quality of life? | Not at all important | Slightly important | Moderately important | Very important | Extremely important |
|--|--------------------------|--------------------------|--------------------------|--------------------------|--------------------------|
| Work, school or other occupational activities | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| Your feelings about yourself | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| Your physical health | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| Friends, family, people you spend time with | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| Having enough money | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| Ability to take care of yourself | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| Your mental health | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| Other, please specify: | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |

Is there anything else you would like us to know?

16.17 Pain and Sleep Questionnaire (PSQ-3)

PAIN AND SLEEP QUESTIONNAIRE 3 QUESTION

Thinking back over the last week, how has pain affected your sleep? For each of the following questions, place a slash (/) through the line at the point your feel applies to you.

1. How often have you had trouble falling asleep because of pain?
NEVER _____ ALWAYS
2. How often have you been awakened by pain during the night?
NEVER _____ ALWAYS
3. How often have you been awakened by pain in the morning?
NEVER _____ ALWAYS

16.18 Patient Health Questionnaire (PHQ9)

PATIENT HEALTH QUESTIONNAIRE (PHQ-9)

16.19

ID #: _____ DATE: _____

Over the last 2 weeks, how often have you been
bothered by any of the following problems?
(use "✓" to indicate your answer)

| | Not at all | Several days | More than half the days | Nearly every day |
|---|------------|-----------------|-------------------------------|---------------------|
| 1. Little interest or pleasure in doing things | 0 | 1 | 2 | 3 |
| 2. Feeling down, depressed, or hopeless | 0 | 1 | 2 | 3 |
| 3. Trouble falling or staying asleep, or sleeping too much | 0 | 1 | 2 | 3 |
| 4. Feeling tired or having little energy | 0 | 1 | 2 | 3 |
| 5. Poor appetite or overeating | 0 | 1 | 2 | 3 |
| 6. Feeling bad about yourself—or that you are a failure or have let yourself or your family down | 0 | 1 | 2 | 3 |
| 7. Trouble concentrating on things, such as reading the newspaper or watching television | 0 | 1 | 2 | 3 |
| 8. Moving or speaking so slowly that other people could have noticed. Or the opposite —being so fidgety or restless that you have been moving around a lot more than usual | 0 | 1 | 2 | 3 |
| 9. Thoughts that you would be better off dead, or of hurting yourself | 0 | 1 | 2 | 3 |

add columns + +

(Healthcare professional: For interpretation of TOTAL,
please refer to accompanying scoring card).

TOTAL:

| | | |
|--|----------------------|-------|
| 10. If you checked off <i>any</i> problems, how difficult have these problems made it for you to do your work, take care of things at home, or get along with other people? | Not difficult at all | _____ |
| | Somewhat difficult | _____ |
| | Very difficult | _____ |
| | Extremely difficult | _____ |

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Generalized Anxiety Disorder Scale (GAD7)

Generalized Anxiety Disorder Screener (GAD-7)

| Over the <i>last 2 weeks</i> , how often have you been bothered by the following problems? | Not at all | Several Days | More than half the days | Nearly every day |
|---|----------------------|--------------------|-------------------------|---------------------|
| 1. Feeling nervous, anxious or on edge | 0 | 1 | 2 | 3 |
| 2. Not being able to stop or control worrying | 0 | 1 | 2 | 3 |
| 3. Worrying too much about different things | 0 | 1 | 2 | 3 |
| 4. Trouble relaxing | 0 | 1 | 2 | 3 |
| 5. Being so restless that it is hard to sit still | 0 | 1 | 2 | 3 |
| 6. Becoming easily annoyed or irritated | 0 | 1 | 2 | 3 |
| 7. Feeling afraid as if something awful might happen | 0 | 1 | 2 | 3 |
| | Add columns | | | |
| | Total Score | | | |
| 8. If you checked off any problems, how difficult have these problems made it for you to do your work, take care of things at home, or get along with other people? | Not difficult at all | Somewhat difficult | Very difficult | Extremely difficult |

When did the symptoms begin? _____

16.20 Anger Management Scale

APPENDIX A**Full (36-item) Anger Management Scale**

The following statements are about you or the relationship between you and your partner. Please read each statement and decide how much you *agree* with it.

| | Strongly Disagree | | Strongly Agree | |
|--|----------------------|---|-------------------|---|
| 1. When my partner picks a fight with me, I fight back. | 1 | 2 | 3 | 4 |
| 2. When my partner won't give in, I get furious. | 1 | 2 | 3 | 4 |
| 3. I often take what my partner says personally. | 1 | 2 | 3 | 4 |
| 4. My partner believes I have a short fuse. | 1 | 2 | 3 | 4 |
| 5. I can feel my blood rising when I start to get mad at my partner. | 1 | 2 | 3 | 4 |
| 6. Taking a break from my partner is a good way for me to calm down. | 1 | 2 | 3 | 4 |
| 7. When my partner is around, I feel like a bomb waiting to explode. | 1 | 2 | 3 | 4 |
| 8. I prefer to get out of the way when my partner hassles me. | 1 | 2 | 3 | 4 |
| 9. It is my partner's fault when I get mad. | 1 | 2 | 3 | 4 |
| 10. When my partner is nice to me I wonder what my partner wants. | 1 | 2 | 3 | 4 |
| 11. No matter how angry I am, I am responsible for my behavior toward my partner. | 1 | 2 | 3 | 4 |
| 12. When my partner provokes me, I have a right to fight back. | 1 | 2 | 3 | 4 |
| 13. I can feel it in my body when I'm starting to get mad at my partner. | 1 | 2 | 3 | 4 |
| 14. My partner does things just to annoy me. | 1 | 2 | 3 | 4 |
| 15. There is nothing I can do to control my feelings when my partner hassles me. | 1 | 2 | 3 | 4 |
| 16. My partner is rude to me unless I insist on respect. | 1 | 2 | 3 | 4 |
| 17. My partner likes to make me mad. | 1 | 2 | 3 | 4 |
| 18. When my partner annoys me, I blow up before I even know that I am getting angry. | 1 | 2 | 3 | 4 |
| 19. I recognize when I am beginning to get angry at my partner. | 1 | 2 | 3 | 4 |
| 20. I am able to remain calm and not get angry at my partner. | 1 | 2 | 3 | 4 |
| 21. I can usually tell when I am about to lose my temper at my partner. | 1 | 2 | 3 | 4 |
| 22. I take time out as a way to control my anger at my partner. | 1 | 2 | 3 | 4 |
| 23. I take a deep breath and try to relax when I'm angry at my partner. | 1 | 2 | 3 | 4 |
| 24. I can set up a time-out period during an argument with my partner. | 1 | 2 | 3 | 4 |
| 25. When I feel myself getting angry at my partner, I try to tell myself to calm down. | 1 | 2 | 3 | 4 |

Anger Management Scale

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| | | | | |
|--|---|---|---|---|
| 26. I often think of something pleasant to keep from thinking about my anger at my partner. | 1 | 2 | 3 | 4 |
| 27. When I'm angry at my partner, I try to handle my feelings so no one gets hurt. | 1 | 2 | 3 | 4 |
| 28. If I keep thinking about what made me mad, I get angrier. | 1 | 2 | 3 | 4 |
| 29. When arguing with my partner, I often raise my voice. | 1 | 2 | 3 | 4 |
| 30. I do something to take my mind off my partner when I'm angry. | 1 | 2 | 3 | 4 |
| 31. When I'm mad at my partner, I say what I think without thinking of the consequences. | 1 | 2 | 3 | 4 |
| 32. When my partner's voice is raised, I don't raise mine. | 1 | 2 | 3 | 4 |
| 33. My partner thinks I am very patient. | 1 | 2 | 3 | 4 |
| 34. I can calm myself down when I am upset with my partner. | 1 | 2 | 3 | 4 |
| 35. When I feel myself starting to get angry at my partner, I try to stick to talking about the problem. | 1 | 2 | 3 | 4 |
| 36. I am even-tempered with my partner. | 1 | 2 | 3 | 4 |

16.21 Caregiver Self-Assessment Questionnaire



The header of the questionnaire features a light blue background with a faint, abstract pattern. On the left, the title "Caregiver Self-Assessment Questionnaire" is written in a large, teal, cursive font, followed by the subtitle "How are you?" in a smaller, black, sans-serif font. On the right, the American Medical Association logo is displayed, including the text "American Medical Association" and "Physicians dedicated to the health of America". Below this, it says "Distributed by:" followed by the "National Caregivers Library" logo, which is a yellow oval with the text "National Caregivers Library" in black and red. To the right of the logo is a circular seal of the American Medical Association.

Caregivers are often so concerned with caring for their relative's needs that they lose sight of their own wellbeing. Please take just a moment to answer the following questions. Once you have answered the questions, turn the page to do a self-evaluation.

During the past week or so, I have...

- | | |
|---|---|
| 1. Had trouble keeping my mind on what I was doing <input type="checkbox"/> Yes <input type="checkbox"/> No | 15. Been satisfied with the support my family has given me <input type="checkbox"/> Yes <input type="checkbox"/> No |
| 2. Felt that I couldn't leave my relative alone..... <input type="checkbox"/> Yes <input type="checkbox"/> No | 16. Found my relative's living situation to be inconvenient or a barrier to care <input type="checkbox"/> Yes <input type="checkbox"/> No |
| 3. Had difficulty making decisions <input type="checkbox"/> Yes <input type="checkbox"/> No | 17. On a scale of 1 to 10, with 1 being "not stressful" to 10 being "extremely stressful," please rate your current level of stress. _____ |
| 4. Felt completely overwhelmed..... <input type="checkbox"/> Yes <input type="checkbox"/> No | 18. On a scale of 1 to 10, with 1 being "very healthy" to 10 being "very ill," please rate your current health compared to what it was this time last year. _____ |
| 5. Felt useful and needed <input type="checkbox"/> Yes <input type="checkbox"/> No | Comments: |
| 6. Felt lonely <input type="checkbox"/> Yes <input type="checkbox"/> No | (Please feel free to comment or provide feedback) |
| 7. Been upset that my relative has changed so much from his/her former self..... <input type="checkbox"/> Yes <input type="checkbox"/> No | _____ |
| 8. Felt a loss of privacy and/or personal time <input type="checkbox"/> Yes <input type="checkbox"/> No | _____ |
| 9. Been edgy or irritable <input type="checkbox"/> Yes <input type="checkbox"/> No | _____ |
| 10. Had sleep disturbed because of caring for my relative <input type="checkbox"/> Yes <input type="checkbox"/> No | _____ |
| 11. Had a crying spell(s) <input type="checkbox"/> Yes <input type="checkbox"/> No | _____ |
| 12. Felt strained between work and family responsibilities..... <input type="checkbox"/> Yes <input type="checkbox"/> No | _____ |
| 13. Had back pain <input type="checkbox"/> Yes <input type="checkbox"/> No | _____ |
| 14. Felt ill (<i>headaches, stomach problems or common cold</i>) <input type="checkbox"/> Yes <input type="checkbox"/> No | _____ |

16.22 Bristol Activities of Daily Living Scale (BADLs)

Bristol Activities of Daily Living Scale

Name of patient:.....

Patient number:

Carer's Name:.....

Assessment date:/...../.....

Relationship:.....

This questionnaire is designed to reveal the everyday ability of people who have memory difficulties of one form or another.

For each activity (No. 1 - 20), statements a - e refer to a different level of ability.

Thinking of the last 2 weeks, tick the box that represents your relative's/friend's AVERAGE ability. (If in doubt about which box to tick, choose the level of ability which represents their *average* performance over the last 2 Weeks. Tick 'Not applicable' if your relative never did that activity when they were well).

| | | |
|--------------------------|--------------------------|--|
| 1. PREPARING FOOD | <input type="checkbox"/> | a) Selects and prepares food as required |
| | <input type="checkbox"/> | b) Able to prepare food if ingredients set out |
| | <input type="checkbox"/> | c) Can prepare food if prompted step by step |
| | <input type="checkbox"/> | d) Unable to prepare food even with prompting and supervision |
| | <input type="checkbox"/> | e) Not applicable |
| 2. EATING | <input type="checkbox"/> | a) Eats appropriately using correct cutlery |
| | <input type="checkbox"/> | b) Eats appropriately if food made manageable and /or uses spoon |
| | <input type="checkbox"/> | c) Uses fingers to eat food |
| | <input type="checkbox"/> | d) Needs to be fed |
| | <input type="checkbox"/> | e) Not applicable |
| 3. PREPARING DRINK | <input type="checkbox"/> | a) Selects and prepares drinks as required |
| | <input type="checkbox"/> | b) Can prepare drinks if ingredients left available |
| | <input type="checkbox"/> | c) Can prepare drinks if prompted step by step |
| | <input type="checkbox"/> | d) Unable to make a drink even with prompting and supervision |
| | <input type="checkbox"/> | e) Not applicable |

| | | |
|-------------------------------|--|--|
| 4. DRINKING | | a) Drinks appropriately |
| | | b) Drinks appropriately with aids, beaker/straw etc. |
| | | c) Does not drink appropriately even with aids but attempts to |
| | | d) Has to have drinks administered (fed) |
| | | e) Not applicable |
| 5. DRESSING | | a) Selects appropriate clothing and dresses self |
| | | b) Puts clothes on in wrong order and /or back to front and /or dirty clothing |
| | | c) Unable to dress self but moves limbs to assist |
| | | d) Unable to assist and requires total dressing |
| | | e) Not applicable |
| 6. HYGIENE | | a) Washes regularly and independently |
| | | b) Can wash self if given soap, flannel, towel, etc. |
| | | c) Can wash self if prompted and supervised |
| | | d) Unable to wash self and needs full assistance |
| | | e) Not applicable |
| 7. TEETH | | a) Cleans own teeth/dentures regularly and independently |
| | | b) Cleans teeth/dentures if given appropriate items |
| | | c) Requires some assistance, toothpaste on brush, brush to mouth etc |
| | | d) Full assistance given |
| | | e) Not applicable |
| 8. BATH/ SHOWER | | a) Bathes regularly and independently |
| | | b) Needs bath to be drawn/shower turned on but washes independently |
| | | c) Needs supervision and prompting to wash |
| | | d) Totally dependent, needs full assistance |
| | | e) Not applicable |
| 9. TOILET/ COMMODE | | a) Uses toilet appropriately when required |
| | | b) Needs to be taken to the toilet and given assistance |
| | | c) Incontinent of urine or faeces |
| | | d) Incontinent of urine and faeces |
| | | e) Not applicable |
| 10. TRANSFERS | | a) Can get in/out of chair unaided |
| | | b) Can get into a chair but needs help to get out |
| | | c) Needs help getting in and out of a chair |
| | | d) Totally dependent on being put into and lifted from chair |
| | | e) Not applicable |
| | | |

16.23 Net Promoter Scale Questionnaire

| Please rate how satisfied you are with your and your elder's progress in the MapHabit program | | | | | |
|---|-----------------------|-----------------------|-----------------------|-----------------------|-----------------------|
| | Very satisfied | Satisfied | Neutral | Dissatisfied | Very Dissatisfied |
| How satisfied are you with your and your elder's progress in this program? | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> |
| reset | | | | | |
| Please rate how you, as a care partner, feel since starting the MapHabit program | | | | | |
| | Much better | Better | About the same | Worse | Much worse |
| Overall, do you feel you and your elder are ____ since starting the MapHabit program | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> |
| reset | | | | | |
| Please rate how likely you are to recommend the DailyStim program to colleagues and friends | | | | | |
| | Very likely | Likely | Neutral | Unlikely | Very unlikely |
| How likely are you to recommend the MapHabit system? | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> |
| reset | | | | | |
| Please rate how satisfied you were with the DailyStim program | | | | | |
| | Very satisfied | Satisfied | Neutral | Dissatisfied | Very dissatisfied |
| How satisfied are you with the DailyStim program in engaging with your elder? | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> |
| reset | | | | | |
| please rate how beneficial the DailyStim program was for you and your elder | | | | | |
| | Very beneficial | Beneficial | Neutral | Not beneficial | Very not beneficial |
| How beneficial was the DailyStim program to you and your elder? | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> |
| reset | | | | | |
| Please rate how likely you are to recommend the DailyStim program to colleagues and friends | | | | | |
| | Very likely | Likely | Neutral | Unlikely | Very unlikely |
| How likely are you to recommend the DailyStim program? | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> |
| reset | | | | | |

17. Assent Form

17.1. Assent Form for Minors with Down Syndrome

This handout is about the MapHabit Down Syndrome Study. The MapHabit System features an app for your smart phone device or tablet that seeks to help you learn and gain independence.



We are asking that you join our study because we want to learn more about the health of children with Down Syndrome



You will be a part of a study that includes other children with Down Syndrome at different locations across the United States!



A group of professionals called an IRB reviewed this study for us. Their job is to assure that this study is safe and that participants like you are protected.



You will be using the MapHabit System and application for 6 months. You may have a few visits to a study site OR a virtual study meeting during the time you are in the study. You will come with your study partner. Your study partner will be a parent, other family member, or caregiver!



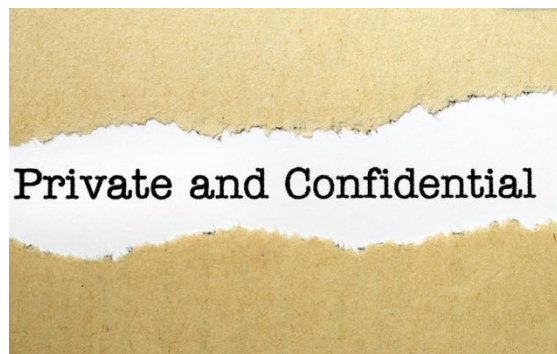
Your study partner will complete a set of questionnaires on your behalf at the start and at the end of the study. You are only expected to use the MapHabit System daily with the supervision of your study partner.



If you have any questions, you and your study partner may ask a member of the study team!



This study is private. Only your study partner and the study team will know that you are participating in this study. Your personal information (name, address, pictures, audio, or video) will not be shared beyond your designated study partner and the study team.



We anticipate that using the MapHabit System will be a positive and fun learning opportunity however—you do not have to be in this study if you do not want to and there are no consequences if you choose not to participate. You will always have the right to stop at any time.



Thank you for learning about the study and we hope that you join us! If you have any questions, you and your study partner may ask the study coordinator or a member of the study team!



18. References

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