# Marketing and Customer Discovery Report

# **Key Findings Summary**

Caring for an individual living with dementia can be a complex challenge. Dementia Care Works (DCW) is a platform that is designed to help with this process. Specifically, it aims to help nurses navigate the complexities of dementia care by guiding them through screening, assessments, and care planning. Results of these measures can then inform the primary care provider's (or prescribing clinician) treatment plan. At this time DCW is a user-friendly workable demo version of a larger platform to come. Currently a user can go through the assessment stages of the first two domains, Cognitive Health & Function and Emotional, Behavioral & Spiritual Health. Over time, repeated use can generate a longitudinal report of the person's health, which will help to better assess and address dementia concerns. The current study's aim is to conduct customer discovery interviews and usability sessions with the intent to test if DCW meets dementia care needs and is a usable product in real world healthcare settings.

Research was done via two forms of interview, the customer discovery interview and the usability session. The goal of the customer discovery interviews was to get a better understanding of both the current systems in place to assist in dementia care and the different potential environments that the DCW tool could be used in. The usability sessions served a dual purpose as a proof-of-concept meeting and demonstration to stakeholders as well as to collect feedback on the DCW tool as it exists to inform the next potential round of development. We interviewed a total of nineteen participants in thirteen sessions. Our findings from these interviews are summarized below.

Finding	Summary			
Communication	Providers and Care Partners need a better communication tool and interviewees saw DCW's potential to fill that void.			
Direct Care	PLWD care needs are complex and not met without explicit care plans and adequate staffing.			
Systemic Challenges	Issues include financial and cultural barriers that nurses face in providing care for PLWD.			
Knowledge	Interviewees identified some key knowledge gaps that Care Partners and Providers have in caring for PLWD.			
Assessments	The DCW assessment system was liked by the interviewees, but the consensus was that the order and phrasing of the assessments needed refinement.			
Data Visualizations	Interviewees liked the visualizations in the DCW report and had some minor requests and suggestions to improve interpretation of the data.			
Technology	New technology can be difficult for PLWD to learn how to use and designing for clinicians should prioritize speed and avoid alert fatigue			

The following are the major recommendations based on the findings of our interviews. There are additional details on each of these along with more minor feature recommendations in the Recommendations section of the report.

Recommendations
Bring the Long-Term Care Team into the DCW system
Separate CP and PLWD Assessment Sessions
Further Introduction to System
Fast vs In-Depth Assessment Paths
Simplify Assessments
Scoring Summary Details Post Assessment
Additional Detail in Scoring Summary
Compare PLWD and Care Partner Assessments
Add Color Coding to Graphs

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## Introduction

Currently, there are over 6 million people living with dementia in the U.S. and this number is expected to double by the year 2050. Living with and/or caring for someone with dementia is very challenging but can be managed by a specialist. In the U.S. however there are only 6,000 physicians trained in geriatrics, this equates to roughly one clinician for every 1,000 persons living with dementia. This gap in available care results in significant costs, both financial and personal, as people living with dementia have higher rates of hospitalizations, institutionalization, poorer health outcomes and premature death.

In response to this growing need for accessible and specialized dementia care, the University of Washington School of Nursing launched the Dementia and Palliative Education Network – a hub of programs that will primarily focus on educating professional nurses and nursing students to become dementia care specialists. We believe nurses are perfectly suited for this training as they comprise the largest segment of healthcare providers in the U.S. and possess a holistic skill set that aligns well with dementia care needs, which include: providing education, management of medications, chronic illnesses and behaviors, providing medical treatments or interventions, developing and implementing goals of care, and coordination with families, community providers and interdisciplinary clinicians.

From prior customer discovery research, the importance of, desire for and willingness to pay for this type of specialized training was widely endorsed by practicing clinicians, managers, healthcare administrators and students. However, with additional research and customer interviews, a solution was needed to clearly identify nursing roles in dementia care and help streamline nurses into the workflow. To fill this gap, Dementia Care Works (DCW), a technology-based platform that contains evidence-based assessments, decision support guides and care tools, was developed. The structure of DCW was created based on the usual Electronic Health Record (EHR) functionality, so that it could eventually be integrated into a healthcare system's EHR. Additionally, utilization of the DCW was meant to help capture nursing practices and identify reimbursable care encounters that could help justify the value, utility and return on investment of dementia care nurses.

Since 2021, Dementia and Palliative Education Network (DPEN) team has been collaborating with the Clinical Informatics Research Group (CIRG) to develop DCW. With the goal of this platform aiming to help registered nurses (RN) engage the dementia care process, by leading them through a series of questionnaires and tools that help assess healthcare status and the needs of people living with dementia and their care partners. The platform has maintained its roots of being developed to be compatible with EHR systems and eventually integrated into a nurses' workflow.

Caring for a person living with dementia can be complex and challenging yet rewarding when done well. Utilizing the Dementia Care Works (DCW) platform will help nurses navigate the complexities of dementia care by guiding them through screening, assessments and care planning. Results of these measures can then inform the primary care provider's (or prescribing clinician) treatment plan and additionally will meet core requirements for G0505 Care Planning code. With the current demo version of Dementia Care Works, the user is able to go through the assessment stages of the first two domains, Cognitive Health & Function and Emotional, Behavioral & Spiritual Health, for a potential person living with dementia and their care partner. It then provides a longitudinal report of the person's health over time to better assess and address dementia concerns.

With the current study it is our aim to conduct customer discovery interviews with the intent to test if DCW is a usable product in real world healthcare settings with the goal to improve outcomes for people living with dementia while also providing a mechanism for reimbursement of nursing care. From our current study we will provide a workable list of feature requests and recommendations based on the desires and feedback of our interviewees. It is our overall goal to obtain a better understanding of what's currently available to assist in the care of people living with dementia, and the different settings of which the DCW tool could be used.

# Study Objectives

The following are the three main goals of the interviews conducted:

- Conduct a set of customer discovery interviews and test our unique value proposition that DCW
  is a usable product for nurses within healthcare settings that will both improve outcomes for
  people living with dementia and provide a mechanism for reimbursement of nursing care
- ◆ Conduct proof of concept meetings and provide a demonstration of product to those stakeholders who already expressed interest in our product
- Evaluate results of interviews and develop implementation plan

#### Methods

We interviewed a total of nineteen participants in thirteen sessions. Eight participated in both the customer discovery and the usability sessions, two participated in only the customer discovery interviews and nine of the participants only participated in a usability session.

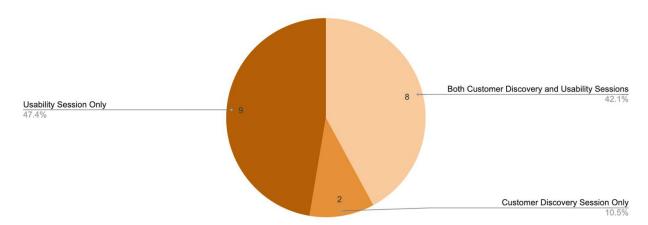


Figure 1. Distribution of Interview Types

# **Customer Discovery Interviews**

The goal of the customer discovery interviews was to get a better understanding of both the current systems in place to assist in dementia care and the different potential environments that the DCW tool could be used in. These were conducted as conversational interviews with an informal script to guide the questions asked by the moderator. Ten of the participants in ten sessions participated in the customer discovery interviews.

# **Usability Sessions**

The usability sessions served a dual purpose. The first was the proof-of-concept meetings and demonstrations to stakeholders laid out in the study objectives. The second was to collect feedback on the DCW tool as it exists to inform the next potential round of development. These sessions were conducted by sending the interviewees the link and login to the demo version of the DCW tool and then asking them to explore the assessment and report and provide us with feedback on the functionality and usefulness of the different elements. The demo version of Dementia Care Works currently allows the user to go through the assessment stages of the first two domains, Cognitive Health & Function and Emotional, Behavioral & Spiritual Health for a potential person living with dementia and their care partner. It then provides a longitudinal report of the person's health over time to help better assess and address dementia concerns. Below Figure 2 pictures one page of the current DCW demo system that the interviewees reviewed. More screenshots of the tool are available in Appendix G.

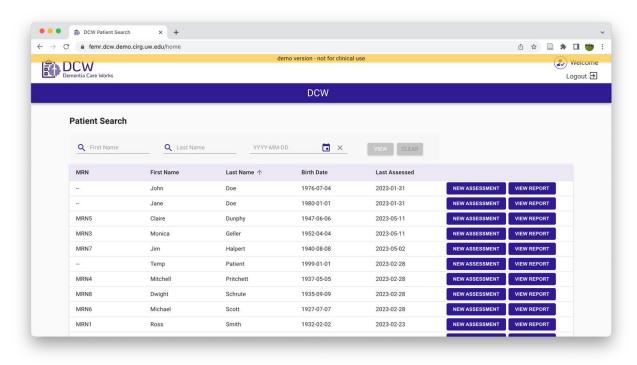


Figure 2. Current DCW System

Seventeen of the interviewees in eleven sessions participated in the usability sessions. Nine of the participants only participated in a usability session, and these sessions were conducted in-person with groups of three participants. These group sessions had the interviewees each taking the role of either the "Nurse", the "Patient" or the "Care Partner" and going through as real as a possible version of the assessment.

#### **Test Environment**

The primary test environment for both the customer discovery interviews and the usability sessions was via a Zoom meeting. Two to three members of the DCW team attended each meeting, with one serving the role of moderator and one to two serving as notetakers. For purposes of additional notetaking, the

sessions were recorded after interviewees provided consent.

The test environment for the three in-person usability sessions was a classroom on the University of Washington campus. The three sessions (each including three students) happened simultaneously with one moderator for one group and another moderator for the other two.

#### **Interviewee Characteristics**

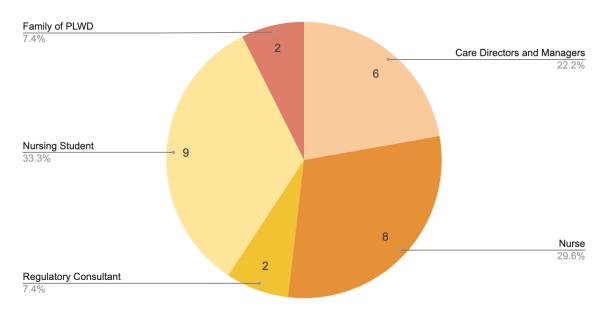


Figure 3. Roles of Interviewees in Dementia Care

The interviewees were a mix of Nurses, Nurse Practitioners, Nursing Students, Health Care Consultants, Family Members of People living with Dementia and Long-Term Care Directors and Managers. Figure 3 shows how many of the people we interviewed were in each role, counting each role a person had individually (for example if someone was both a Nurse and a Family Member of a PLWD they get counted in each category). Below each participant is described in more detail.

#### ALBERT MUNANGA

Albert Munanga, DrBH, MSN, RN, HC has extensive leadership experience in healthcare and senior living settings. He is the current Chief Clinical Officer at Serengeti Home Health care and former clinical instructor of the Long-Term Care Externship for Bachelor of Science in Nursing students at University of Washington. He was interviewed due to his experience in healthcare administration in geriatrics and dementia. He completed both the customer discovery and usability session.

#### AMBER BOYD

Amber Boyd, DNP, MSN is a nurse practitioner in geriatrics and current Vice President of Clinical Practice and Professional Development at Rippl Care — a virtual behavioral healthcare organization that focuses on providing comprehensive care on older adults, which also uses an online platform for collecting data. She was interviewed due to her role in caring for people living with dementia and her leadership position which involves decision making within an organization. She completed both customer discovery and usability session.

#### **CINDY JACOBS**

Cindy Jacobs, RN, JD is a regulatory consultant in healthcare. She was interviewed due to her background as a nurse who was also a care partner of a family member with dementia. She completed both the customer discovery and usability session.

#### DAHLIA MAK

Dahlia Mak is a Managing Director at Moss Adams, a healthcare consulting firm. She is an expert on the lean application process in healthcare systems and focuses on quality and patient safety, process improvement and strategic planning. She was interviewed due to her experience in healthcare protocols, processes, and workflows. She completed both the customer discovery and usability session.

#### HEIDI HAMILTON

Heidi Hamilton is a nurse practitioner and the Division Director of the State of Alaska Pioneer Homes, under the Department of Family and Community Services. There are a total of 6 Alaska Pioneer Homes, which are licensed assisted living homes that are owned and operated by the State of Alaska. Heidi was interviewed due to her background in nursing and geriatrics, and her role as the director of these homes. She completed both the customer discovery and usability session.

#### HILARY STEVENSON

Hilary Stevenson is an ICU nurse in the Oregon Health and Science University (OHSU) hospital. She was interviewed due to her nursing experience in the inpatient setting, which is a potential setting for use of the DCW. She completed both the customer discovery and usability session.

#### JUANA GALLEGOS

Juana Gallegos, MSN, BSN, RN is a nurse who owns an Adult Family Home, that cares for up to 6 older adults with dementia. She is also a clinical instructor for an LPN program. She was interviewed due to her background in nursing and dementia care, as well as owning and managing a care home. She completed both the customer discovery and usability sessions.

#### KATHLEEN HAYDEN

Kathleen Hayden, RN is a nurse in the Harborview Family Medicine Clinic. She was interviewed due to her role as a nurse in an outpatient setting – which is one of the target settings that we hope the DCW will be used. She completed the customer discovery session.

#### Luz Hoff

Luz Hoff, RN, BSN, MHP is a nurse specializing in geriatrics, and owns several Adult Family Homes. She was recommended to us by another interviewee, Cindy Jacobs, due to her excellent knowledge and practice of dementia care. She completed the customer discovery session.

#### ROLAND UPENIEKS

Roland Upenieks, RN is a nurse in the Harborview Family Medicine Clinic. He was interviewed due to his role as a nurse in an outpatient setting – which is one of the target settings that we hope the DCW will be used. He completed both the customer discovery and usability session.

#### STUDENT GROUPS 1-3

These student groups included nine Bachelor of Science in Nursing students (2<sup>nd</sup> year) who were participating in the Long-Term Care Externship course. This course involved working as a nurse technician in skilled nursing facilities and practicing hands-on clinical skills with chronically or acutely

ill adults and people living with dementia. They were interviewed due to their experience in nursing and long-term care. They completed usability sessions only.

# **Customer Discovery Findings**

The following findings are a result of the customer discovery interviews. The term "Provider" refers to the larger category of healthcare and long-term care workers (such as Primary Care Physicians, Nurses and Staff in Assisted Living Facilities or Adult Family Homes or Hospital Staff and Nurses), referred to as more specifically when needed in context. The term "Care Partner" refers to the primary family members or others providing support and care for the PLWD in a non-professional context.

#### Communication

#### Provider-Care Partner Communication

Detailed communication between the family and care partner of a PLWD and the various providers of care (doctors, nurses, care home staff, etc.) is essential to quality care. As one interviewee said, family members are usually the ones to notice and say, "hey mom's not quite acting like herself" or "this is not the way that we're used to these things functioning". That familiarity with the baseline of the PLWD is an important resource to utilize in care. The insight that nurses in care facilities have is also important, they have more continuous contact – family see changes, nurses see the day to day. Nurses are more likely to blame issues on dementia, family members want to see if there is another issue other than dementia that is affecting a change. The journey of dementia is a big one, patients are sometimes aware of their decline and sometimes unaware.

Additionally, dementia care is special in that it is not just about caring for the PLWD, it is also about providing care for the family and care partners as well. Interviewees mentioned a tandem and parallel care model, that would provide support to the care provider, whoever that might be (clinical/family/friend) as well as the PLWD.

The tools our interviewees listed as currently used for communication between providers and care partners include Face Time, Email, Phone, Charting Tools, Group Texting, and Electronic Docu-signing.

#### Provider-Provider Communications

There is no one set way for providers to communicate with each other during patients care transitions, either because of changing care needs (new care home or hospital visit) or during routine checkups. Especially during crisis situations where communication is difficult and can often be skipped, leaving the new provider without details of PLWD's care needs, or even without knowing the patient has dementia. Additionally, nurses from care homes are not able to provide every detail to the primary care provider, and what they choose to present impacts the response and decision from the PCP. The tools our interviewees listed as currently used for communication between providers include; Email, Phone, Charting Tools, Electronic Docu-signing, EMR/MyChart, Notes, Fax, and Paper mailing.

#### DCW as a Communication Tool

Many of our interviewees saw DCW's potential as a communication tool. Our interviewees stated that within dementia care the communication piece is largely missing with Care Partners and family members being left to ferry information between providers, most of the time without being given the context needed to understand the information. It was expressed that there is a need for a tool that allows for easy and simple sharing of information between different health care providers and family

members, that is accessible for patients who must go to the hospital and for clinicians who would be taking over the care of the patient. Our interviewees liked our DCW tool as it reminded them a lot of MyChart, specifically that they liked how it wasn't overly difficult to use but would also like it if there was a patient view and a clinician view. The addition of a patient view, that the Care Partner would also have access to, would help keep the Care Partner informed of the care plan and progress of the PLWD.

It should be noted that while most of our interviewees liked the idea of the DCW tool as a potential communication device we did have a couple of critiques on its potential. One interviewee mentioned that the scales within the tool would not be useful for them as the clientele that they serve is not understanding of what dementia really entails or how extensive the care really is. They were concerned that the DCW tool might cause families to question if the provider is giving adequate care to the patient due to decreasing scores when in reality it just is the progression of the disease. Interviewees in general believed that relying exclusively on the tool to communicate information might not work as the provider might be too busy to go over everything or the PLWD or Care Partner might not be able to process the information on their own. Overall planning for and setting aside time to address key issues collaboratively is important in caring for PLWD.

#### **Direct Care**

#### Staffing

Unfortunately, care facilities, such as Adult Family Homes (AFH) or Assisted Living Facilities (ALF), often face shortages of qualified and adequate staffing, and therefore the care needs of PLWD are not being appropriately met. Providing education and training in dementia to nurses can help mitigate some of these challenges and improve quality of care and life for PLWD. However sometimes the issues are due to the specific staff or caregivers hired being unwilling to do all of the tasks required in AFH. Some examples of positive results of sufficient and well-trained staffing include:

- In Adult Family Homes a nurse is well trained in dementia, and does daily assessments of residents,
- ♦ A hospital having a dedicated person to develop care plan for PLWD,
- Nurses being able to adjust the length of appointment based on needs of the PLWD.

#### Care Plan

Care plans are crucial in identifying needs and related interventions and can guide caregivers or healthcare providers in a protocol for care, that includes appropriate assessment and screening. Care Plans provide instructions to caregivers/healthcare providers, identify the needs/challenges of PLWD, provide protocol and process for assessment or screening, and details on behavioral management including diversion, 1-step directions, family support and ways to give sense of choice and control.

#### Care Needs

Providing care to PLWD is challenging due to their cognitive impairment that affects their ability to communicate, complete forms/assessments, and increases behaviors. PLWD care needs are complex and must be individualized to improve quality of life, yet families and care partners are often left without support and decline in condition is sometimes ignored as it is assumed that changes are due to dementia, instead of a change in comorbid conditions. Families also are unable to manage care needs/behaviors at home and call a home care agency as a last resort.

# Systematic Challenges

#### Financial Barriers

Financially, healthcare settings have inadequate funding to acquire and utilize solutions, due to low reimbursement rates, delayed insurance payments and decreased revenue as a result of the pandemic. Therefore, adequate staff cannot be hired to execute interventions. If adequate funding were available, then addressing workflow barriers can be done by gathering all necessary data from staff at every level of the organization, to identify gaps, staffing roles, and solutions.

#### **Cultural Barriers**

Our interviewees noted a number of cultural barriers to ideal patient care. In the culture of nursing, few want to go into long term/geriatric care, and those who do end up in the field are not respected. This lack of respect is from their peers, but also in the workplace, where nurses sometimes have no authority in their long-term care setting. Additionally, hospitals do not always focus on preventive actions or care and have to respond to frequently changing regulations/requirements for care.

## Knowledge

#### Care Partner Knowledge Gaps

Care Partners are often left out of the loop and left with a lack of understanding how a person used to be isn't how they are now living with dementia. In other words, understanding that the person living with dementia is no longer exactly the same person they used to be mentally or cognitively. It is hard for care givers to understand the choices of a dementia patient, and how they are processing things differently than they did before (family members understand more so than facility care givers, but not limited to). Interviewees also mentioned the benefit of having someone acting as a dementia coordinator who would talk to the family to understand the dementia level being worked with on the patient end and to create a care plan that would take into account the wishes of the PLWD in addition to the family for the hospital (facility) stay and for either long-term or short term stays.

#### Provider Knowledge Gaps

In dementia care there is a significant gap in knowledge between the recipients of care and those that support them. This general lack of understanding is seen throughout the different levels of care for dementia patients from a lack of understanding of how the American health care system works from the care providers who work regularly with PLWD to knowing the appropriate standard of care beyond the physical aspects of care, including how to communicate speak with the PLWD. Providers without sufficient training leads to a lack of understanding how dementia disables the care recipient, the different cultural barriers at play and that PLWD can't speak for/defend themselves.

Overall training for working with PLWD is minimal, sometimes as little as an 8-hour course. Additionally, the training tends to focus on the physical aspects of the care rather than how to approach Care Plans, emotional/behavioral aspects of care, and how to properly communicate with PLWD. A lot of time is also dedicated to unteaching people/teaching new ways that are better suited to the care of PLWD. The following are the training types and lengths mentioned by interviewees:

♦ CNAs (who typically act as care givers or home aids), have about 20 hours or less of instructional training on how to work with people living with dementia.

- Washington state also has something similar to CNA training that usually involves weeks
   (MAYBE Month(s)) of training but are not licensed clinicians, that work under the direction of
   Nursing staff, and follow something akin to a minimized care plan.
- ♦ Teepa Snow?
- ♦ Eden Alternative?
- ◆ There is a Grant available for RNs to take a course and be certified as a dementia specialist (apprenticeship program with mentoring, Relias system)

These gaps in knowledge are both impacting and the product of a lack of training and understanding, which is caused by the varying amounts of required training necessary to work with people living with dementia (based on what each education level, certification or employer requires. These challenges are also caused by the fact that training materials don't always have a full enough scope that goes beyond just physical care. It is also important to note that putting the educational trainings into real world practice has been mentioned as a challenge by our interviewees.

# **Usability Findings**

The following findings are a result of the usability sessions. Overall participants in the usability sessions thought that DCW was easy to navigate and simple to understand.

#### Assessments

The following tables are an overview of the feedback we received on the specific assessments within the DCW system.

Current DCW Assessments	Notes from Interviewees			
Everyday Cognition scale (ECog-12)	No relevant comments			
Everyday Cognition scale (ECog-12) Care Partner	One interviewee (Amber Boyd) mentioned that it would be ideal to have the care partner measure before the patient form.			
MINI COGNITIVE ASSESSMENT (Mini-Cog)	No relevant comments			
Saint Louis University Mental Status (SLUMS)	One interviewee (Hillary Stevenson) saw a low functioning score and thought that that meant the patients functioning was low. The Student Groups (The only ones to test administering the SLUMS) had some confusion around the length of the introduction script and the phrasing of the link to print a copy of the SLUMS. They suggested having an option to enter the score for each question as going through the system but didn't want to lose the option to just enter the total score for those that are faster at math.			
Functional Impairments- Activities of Daily Living (ADLs) / Instrumental Activities of Daily Living (IADLs)	One interviewee (Juana Gallegos) stated that the nurse isn't going to want to do ADLs status as they are more likely to ask the patient in the moment individually. She believes that regular ADL charting would be too overwhelming. Another interviewee (Heidi Hamilton) noted that some of their residents have Medicaid waiver with qualification dependent on physical hands-on assistance needs that ADLs do not match what they are assessing for. The student groups			

	(the only ones to administer the ADLs) found reading questions and options aloud to be clunky and thought they would be better asked as open-ended questions. In one group the "Nurse" rephrased questions to be more conversational and open ended and chose the option that best fit the "Care Partner's" response, frequently with follow-up questions. The nuance between the options made it hard to determine which best applied.			
BEHAVE5+	One interviewee (Hilary Stevenson) found these helpful. In the student groups, the "Nurses" and "Care Partners" felt weird about asking questions in front of the patient, especially hallucination. In one group the "Nurse" was unclear if the questions were <b>about</b> the "PLWD" or the "Care Partner", but they did know that they were being asked <b>of</b> the "Care Partner".			
Generalized Anxiety Disorder (GAD-7)	One interviewee (Hilary Stevenson) liked the GAD-7, specifically that it was easy to use and at the end explains the measure. Another interviewee (Juana Gallegos) stated that based on her experience of caring for PLWD, these individuals are not oriented to time/situation and thinks that GAD-7 would be too in-depth, PLWD would not be able to answer. She also stated that the info provided by the GADs-7 wouldn't get used. An additional interviewee (Albert Munanga) said this should be an optional measure.  One interviewee (Hilary Stevenson) found the scores for this measure hard to read, found the yes/no answers harder to follow and that this measure seemed like it jumped around too much. Another interviewee (Albert Munanga) said this should be an optional measure and we should make sure that there are clear suicide concern questions.			
Geriatric Depression Scale (GDS)				
Cornell Scale of Depression (C-SDD)	One interviewee stated (Juana Gallegos) that she wouldn't end up doing anything with the Cornell Scale. Another (Albert Munanga) should be an optional measure. An additional interviewee (Heidi Hamilton) thought the C-SDD needed a lot of clarification:  • That it is for the patient living with dementia • The time frame of which they are asking for the answers over (like a week/month for example). • What is the difference between responses of mild or intermittent vs. Severe. • How to answer if anxiety is "severe" but happens intermittently, so need more explanation of what is being asked.			
	<ul> <li>Lack of reactivity to pleasant events – was a hard to answer question – felt like a double negative for the question.</li> <li>Cornell can be tough for someone who is ESL.</li> <li>Loss of interest questions, confusing to answer.</li> </ul>			

The Student Groups were not sure if the patient could participate
and found the Patient/Resident language to be inconsistent. It was
expressed that this measure was hard, is it asking about frequency or
severity and the answer options were not broad enough. They were
not sure this was the best tool to be used with care partners.

Assessments Recommended by Interviewees	Comparable Assessment (if Applicable)	Notes from Interviewees
PHQ-2 or PHQ-9	GDS	One interviewee (Amber Boyd) stated that in her work using the PHQ has been better, using the GDS can be longer and can be tiring for patients.
A Skin Assessment (looking at the skin of the patient)		One interviewee (Albert Munanga) stated that a Skin assessment is very common and important.

#### Care Partner vs PLWD Assessments

During our usability testing sessions there was a general like for the dual approach of questions asked of the care partner and of person living with dementia. It was noted by interviewees that it was helpful to have both types of measures to get both perspectives on the PLWD's current health. It was also noted that it would be preferable to have the care partner and the PLWD answer the questions in separate sessions from one another, rather than going back and forth between Care Partner assessments and PLWD assessments. Interviewees pointed out that in real situations the patient would probably go do something else during the CP questions and there are sensitive questions asked of the CP about the PLWD that they may not feel comfortable answering in front of them, such as the occurrence of hallucinations. Additionally, some interviewees lost track of who the assessment they were currently in was being administered to, though this was not consistent, and others felt it was very clear. Separately, interviewees pointed out that Care Partners might not know the answers to all these questions, especially if the PLWD is in a Long-Term Care Facility, their nurses might be more equipped to answer these questions.

#### DCW Assessment Introductions

During the assessment introductions our interviewees noted that there needed to be more information provided at the beginning about the different measures that were about to be given. Interviewees also noted that there needed to be more of an explanation around how the branching logic works. Our interviewees also expressed that it would be helpful to have more information at the beginning of each individual assessment to present more of a "why" behind each set of questions so that the person giving the assessment had a better understanding of the measures they were administering. Additionally, the interviewees expressed a desire for there to be information regarding the expected length of the full assessment to be better able to plan for scheduling. Our interviewees also noted that having the assessments be adaptable would be helpful, for example having the mental health assessments be optional so as to help streamline the process when needed. Another example being measure

preferences by the Nurse or facility, such as using the PHQ instead of the GDS, or even using the PHQ-2 and having the ability to pivot mid-screener to a shorter screener if possible.

#### **Question Phrasing**

While going through the DCW assessments interviewees noted a few ways that the questions and answers need refinement. First was that depending on the day or time of day, the functioning of PLWD can vary, so they are wanting the questions to be answered about the PLWD at their best, worst or average ability. Second, the measures have different levels of difficulty. For example, it was mentioned that the Cornell scale was hard, with questions not being broad enough. With the ADL measure, question #1 was noted as needing more details in the response options as the interviewee wasn't sure how to answer for "verbal cuing". Interviewees also mentioned that with there being very small nuances between different answers to questions in the ADLs it made it hard to determine how to answer. Third, interviewees expressed a desire for there to be open-ended questions as well as having the questions be formatted in a more conversational and open-ended way. This being so that CP can choose the options that best fit and can allow for follow-up questions.

#### Screener Completion

In general screeners are difficult for PLWD to complete without a facilitator. According to interviewees, general screeners and tools are completed about 50% of the time, going down to 15% completion with severe dementia. They expressed frustration with other screening tools that only worked when fully completed. PLWD need multiple approaches for forms to get done, such as verbal assessment, reminders, and 3<sup>rd</sup> party assistance. Most assessments are created to be done in person or proctored but are not easily adaptable to be done remotely, especially if there is no family member or care partner available to facilitate. Assessments do sometimes need to be done virtually as doctor's visits are a limited period of time, though sometimes there is flexibility in order to address a specific problem. Additionally, these assessments and screeners are sometimes only given annually leaving little information to work with. PLWD are unable to complete forms independently.

When interviewees reviewed the DCW assessments one noted that the assessments were too in-depth for later stage dementia patients. One interviewee stated that "I don't think this is realistic. Thinking of my patients, they wouldn't be able to answer the questions presented here. When ask them, they have a hard time saying their name, and where there are, let alone if they were worried five mins ago or how often they were worried." (Juana Gallegos). Another said that the DCW tool would be less useful the worse the dementia got, and wondered if there would be cut offs for assessments being shown as the scores got worse.

The setting in which the assessment will be administered also will impact the completion of assessments. Interviewees said that nursing homes or long-term care facilities, may be more open to implementing the DCW assessments and they may be more valuable to them, since it is long term care and solutions. In doctor's visits they spend less amount of time per patient, so it would be difficult to implement. Other settings may also be conducive to these assessments such as when administered by floor nurses or social workers where the staff see the patients over a longer period.

#### **Data Visualizations**

#### **Scoring Summary**

Our interviewees overwhelmingly liked the scoring summary. They saw it as clean, user friendly and closely aligned to what is taught to care teams. They thought it would be a useful summary for busy nurses to review all the results in a single location as well as being good for quick communication between providers. Most interviewees particularly liked the compared to last arrows to quickly see how the PLWD has been doing over time, one noting that they wished existing tools they were using had this feature. There were some minor suggestions from the interviewees including adding the prior score to the compared to last column, adding more degrees of "good" and "bad" to the arrow indications and adding an ability to share a simplified version of the summary with patients or care partners via email as there isn't always time in appointments to review.

#### Assessment Graphs

Interviewees appreciated the tiered approach to data in the assessments' graphs. They found the link between the scoring summary and the graph that had the ability to view the specific data points to be easy to navigate. One interviewee in particular really liked the focus on visual representation of data and felt that the report did not require excessive clicking to navigate and they did not feel like there was a lot of extraneous data to look past, helping to avoid alert fatigue. Another interviewee saw the graphs as a tool to see how interventions are impacting the patient's health over time. Two critiques from the interviewees were that they would like a little more clarity on the graphs themselves and that this level of information would be overwhelming for home care aid trained staff

# **Technology**

#### Dementia and Technology

While technology can make things easier for providers, it can cause problems for people living with dementia. One of the problems our interviewees brought up was that PLWD completing remote surveys can be an issue and a challenge as much as a solution. This is because the patient may not have known how to use the tools or technology they are being asked to use now before their dementia, so now it is even harder for them to use. Without assistance from a care partner the PLWD can easily become confused and forget the task they were completing. Additionally, as dementia progresses it can be very difficult for PLWD to complete surveys even with assistance and guidance. During the interviews one of the questions we asked was "Where in the range of dementia severity do you think DCW would be useful?". Our interviewees responded that it would be most useful in the pre-diagnosis through the early to moderate stages of dementia. They thought that the DCW tool would be useful to track the patient's journey through that progression but that once they reach the moderate to severe stage it "is a lot more intensive as patients can't fill things out all the way which results in only 15% completion of screeners" (Amber Boyd).

#### Alert Fatigue

Another problem that was brought up was alert fatigue on the clinicians' part, this meaning that the clinician is less attuned to realizing there is an action to be taken. This is a widespread issue that arises from excessive datafication of everything in clinical practice. This also means that there is a tendency for care teams to copy and paste info and not look holistically at patient care which leads to the possibility

of missing important information. Our interviewees emphasized that the DCW tool should prioritize
speed of use and low training threshold to get providers started.

#### Recommendations

These recommendations are based on both the customer discovery interviews and the usability sessions. They are divided into Major Recommendations, Feature Requests and Clinic/Care Home Recommendations. Most of these recommendations can stand on their own when it comes to implementation, they do not require the implementation of the other recommendations to function.

# **Summary of Major Recommendations**

Recommendation	Associated Finding
Bring the Long-Term Care Team into the DCW	Communication (Provider-Provider),
system	Communication (DCW as a Communication Tool),
	Assessments (Screener Completion)
Separate CP and PLWD Assessment Sessions	Assessments (Care Partner vs PLWD
	Assessments), Communication (DCW as a
	Communication Tool)
Further Introduction to System	Assessments (DCW Assessment Introductions)
Fast vs In-Depth Assessments	Assessments (Screener Completion)
Simplify Assessments	Assessments (Screener Completion), Technology
Scoring Summary Details Post Assessment	Data Visualizations (Scoring Summary)
Additional Detail in Scoring Summary	Data Visualizations (Scoring Summary)
Compare PLWD and Care Partner Assessments	Data Visualizations (Assessment Graphs)
Add Color Coding to Graphs	Data Visualizations (Assessment Graphs)

#### Bring the Long-Term Care Team into the DCW System

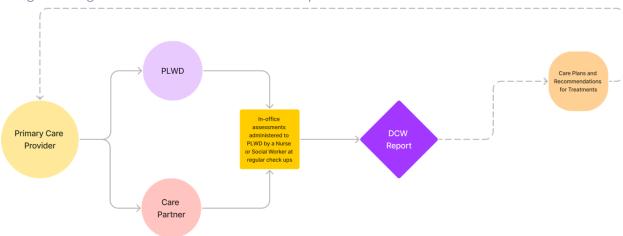


Figure 4. Current DCW Flow (dotted lines represent planned elements of the system)

Currently the DCW assessment system puts too large of a time strain on the primary care provider. Some of the recommendations below cover smaller scale solutions for this issue that could be implemented concurrently or separately to this suggestion. We recommend bringing, when applicable, the Long-Term Care team of a PLWD into the DCW system. This would address a variety of the issues discussed in the findings section above, including communication difficulties between types of providers, families/Care Partners not always knowing the details of the PLWD's day to day care and

health because they no longer live together and difficulties with screener completion rates in primary care settings. Adding assessments to the system directed to the LTC team interacting with a PLWD on a regular basis would allow the report to have more nuanced data. These reports could be emailed to a care team to quickly fill out on a regular basis. The PCP would then be able to dedicate their limited appointment time to more in-depth assessments and discussions of care plans for the PLWD. The LTC team would then also get the benefit of the data trends and care plans from the DCW system.

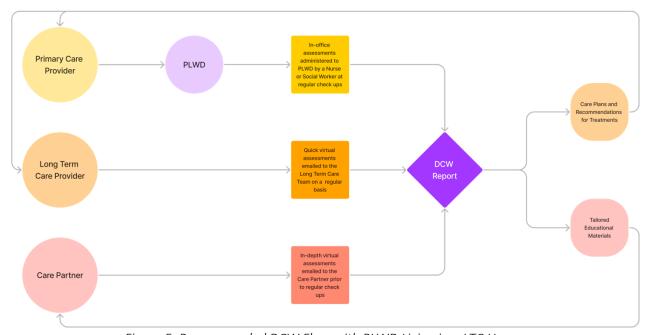


Figure 5. Recommended DCW Flow with PLWD Living in a LTC Home

#### Provide Individualized Educational Resources for the CP of a PLWD

Multiple interviewees have expressed interest in seeing a platform that could provide the educational information that is needed for Care Partners to fully understand what their PLWD is going through and that could be easily accessible for people at all educational levels. If these education materials were individually tailored to the specific situation of the PLWD and provided to their Care Partner in a format that would be quick and easily accessible it would make a significant difference in the care of the PLWD.

#### Separate CP and PLWD Assessment Sessions

As pointed out above in the Assessment Section, in the real world it would be better to have the CP and PLWD assessments be administered in their own bundles rather than going back and forth between the two. This would allow for more flexibility when it comes to scheduling the assessments, as the CP could potentially do their assessments prior to appointments via email.

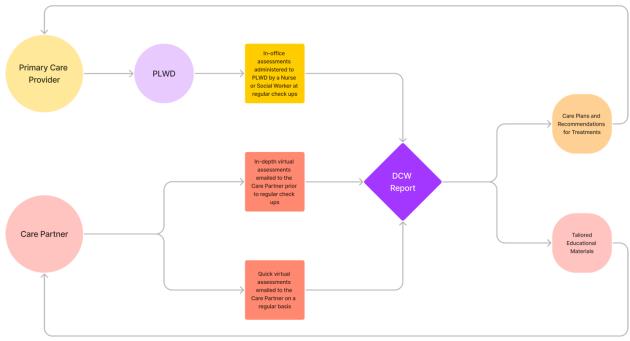


Figure 6. Recommended DCW Flow with PLWD Living with a Care Partner

#### Further Introduction to System

There are two ways we recommend adding more introduction to the DCW system. The first is within the assessment itself, interviewees noted that the unique branching logic that the system uses should be properly introduced so that providers, patients and care partners all know what to expect. Outside the assessments interviewees noted the need for training tools to educate staff on the resources and tools in the DCW system, to handle if a RN is not familiar with ADL, GDS or Cornell).

#### Fast vs In-Depth Assessments

We recommend adding an option, similar to the "Is the Care Partner present today?" question, that asks how long there is available for administering assessments this day. This would allow the provider to quickly and easily decide to do a quick version of that shows only the most prioritized assessments (and potentially shorter versions of assessments as well) if the patient is having a bad day or if the provider is running behind schedule.

#### Simplify Assessments

The current assessments within the DCW system are too long to be regularly administered in a doctor's appointment setting, especially considering that there are only two of the six planned modules in the system currently. We recommend either reducing the total number of assessments and the length of each assessment by reviewing the questionnaires in the system and removing some completely and replacing others with shorter equivalents or adding the ability to break the assessments into shorter sequential visits. Some of the assessments that interviewees reported needing more attention include the ADLs and Cornell.

#### Scoring Summary Details Post Assessment

There was interest expressed by interviewees to be able to immediately review the score of an assessment themselves before moving on to the next assessment. We recommend that the individual relevant line of the scoring summary be displayed on the final page of that assessment. This would allow a provider to go over the scores with the patient as they go through the assessments if there is time for that in the appointment that day, if not it is not a major difficulty to skip past.

#### **Scoring Summary**

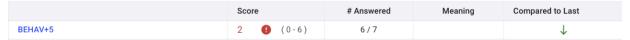


Figure 7. Individual Scoring Summary

#### Additional Detail in Scoring Summary

Some interviewees wanted more nuance in the trend indicator in the scoring summary to differentiate between big and small changes in score. Some requested to add more colors to the red and green arrows to create more of a stoplight indication to differentiate between small and big changes. Others requested to add the previous score to the "Compared to Last" column to do the same differing small and big changes. Both options are mocked up below.

#### **Scoring Summary** Score # Answered Meaning Compared to Last MINI COGNITIVE ASSESSMENT (0-5)2/2 (0-48) 13 / 13 16 ECOG-12 (for Care Partner) 24 (0-48) 13 / 13 Functional Impairments (ADL/IADLs) 18 11 / 11 (0-45)Anxiety (GAD-7) (0-21) 7/7 Mild Anxiety **Geriatric Depression Scale** (0-15) 13 / 15 Depression Cornell Scale of Depression 18 / 18 1 (0-36)BEHAV+5 (0-6) 6/7 $\downarrow$

Figure 8. Stoplight Compared to Last Scoring Summary

1/1

(0-30)

# **Scoring Summary**

SLUMS

	Score	Score		Meaning	Compared to Last
MINI COGNITIVE ASSESSMENT	4	(0-5)	2/2		_
ECOG-12	16	(0-48)	13 / 13		**
ECOG-12 (for Care Partner)	24	(0-48)	13 / 13		18 🕇 +6
Functional Impairments (ADL/IADLs)	18	(0-45)	11 / 11		
Anxiety (GAD-7)	8	(0-21)	7/7	Mild Anxiety	
Geriatric Depression Scale	6 1	(0-15)	13 / 15	Depression	
Cornell Scale of Depression	3	(0-36)	18 / 18		19 ↓ -16
BEHAV+5	2 •	(0-6)	6/7		3 ↓ -1
SLUMS	6 1	(0-30)	1/1		

Figure 9. Numeric Compared to Last Scoring Summary

#### Compare PLWD and Care Partner Assessments

In some instances, the same assessment is administered to both the care partner and the PLWD. When working with PLWD they can have trouble accurately answering questions about their health and wellbeing over time. It would be useful for interpreting scores to be able to see both assessment scores on the same graph to see how the PLWD interpretation of their own health differs from an outside perspective. Below the mock-up shows how layering the two assessment graphs makes it easier to interpret the difference in scores.

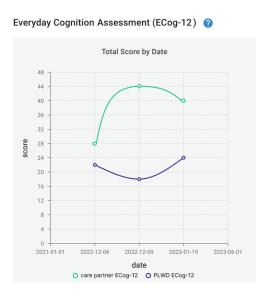


Figure 10. Dual Graphing

#### Add Color Coding to Graphs

Many of the interviewees liked the indications on if a score change was "good" or "bad" in the scoring summary but expressed that it would be more difficult to quickly determine the trend in the graphs of the scores over time. We recommend adding shading to the trend graphs to indicate the ranges of concerning scores. Below are two examples that illustrate how adding shading would make the trend of the assessment graphs easier to interpret.

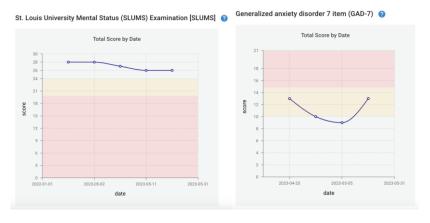


Figure 11. Shaded Trend Graphs

# **Feature Requests**

The following were items that interviewees specifically requested or showed interest in being added to the system that we felt did not need the deeper explanations of the above section.

Request	Details
Non-Medical	While this request might be addressed with the addition of the planned module
Tracking	additions, an interviewee requested tracking and planning for non-medical
	things such as the PLWD's interests or hobbies. This also would include the
	PLWD's psychosocial needs and preferences.
Bulk Data Export	Add the ability to export raw data for clinic wide analysis purposes.
Individual Data	Add the ability for exporting all an individual's data as well as their report to
Export	show to a new provider who does not have access to the DCW system
Retain Paper	One of the interviewees expressed interest in being able to upload scanned
Assessments	versions of the paper assessments being administered. They want the ability to
	review other's interpretations of the PLWD's drawings in assessments like the
	Mini-Cog or SLUMs.
Mobile First	The interviewees were interested in viewing and administering assessments and
	reports on tablets and mobile devices. While the DCW site is currently mobile
	friendly, there are more adjustments that could be made if users are more likely
	to be using a mobile device over a computer.
Navigation	Interviewees wanted to be directed to a patient's report after finishing their
	assessment rather than the patient list.
Patient ID	Add a Patient ID for better patient identification
Increase Size of	Interviewees requested that the font size of the patient's identifying information
Patient Info	(Name and Birthday) be increased for quicker recognition.
Birth Date Format	Change birth date format to M/D/Y rather than Y/M/D, multiple interviewees
	noted this out as a point of confusion.
Meaning in	Change the "Meaning" column in the scoring summary to be titled
Scoring Summary	"Interpretation" or "Indication" instead as we want to have clinician make a
	determination on a diagnosis.
Provide Care Plans	Include recommendations in the Care Plan for the care of the PLWD as well as
for both the PLWD	self-care recommendations for the Care Partner to help them avoid burn out.
and the CP	
Provide Care Plans	Interviewees were interested in and supported the existing plan to develop care
to Providers as a	plans based on PLWD's individual care needs. This is less a recommendation and
Protocol for Care	more a confirmation of the intentions of the DCW team.

#### Clinic/Care Home Recommendations

The following are recommendations based on our customer discovery and usability interviews that we felt were not able to be addressed by the DCW system.

Recommendation	Associated Finding
Programs/certifications that prepare professionals for understanding the behavioral aspect of the job.	Provider Knowledge Gaps
Changing regulations/requirements for care: having regulations that make sense or are approved by the right people before they go into effect therefore people don't have to undo things later.	System challenges
Hospitals do not focus on preventive actions or care	System challenges

#### Conclusion

The aim of this study was to assess clinical care challenges in dementia, evaluate usability and utility of DCW in real world healthcare settings and determine how it might impact care for people living with dementia, while also providing a mechanism for reimbursement of nursing care. Customer discovery interviews revealed primary themes of Communication, Direct Care, Systemic Challenges, and Knowledge. Results of usability interviews generated themes around Assessments, Data Visualizations, and Technology. What emerged from these common themes was a list of major recommendations for moving forward in developing Dementia Care Works. Our list of recommendations includes bringing the long-term care team into the DCW system, separating CP and PLWD assessment sessions, further introduction into the system, fast versus in-depth assessments, simplifying assessments, scoring summary details post assessments, additional explanatory content in the scoring summary, comparing PLWD and care partner assessments, and adding color coding to graphs.

In addition to this list of recommendations, we developed a feature requests list, that is compiled of items that the interviewees specifically showed interest in or requested but didn't need deeper explanations. While we were able to describe and outline the above-mentioned themes, recommendations and listed feature requests, we also generated three recommendations from both the discovery and usability interviews that we felt could not be addressed by the DCW system but needed to be noted. These recommendations included: programs/certifications that prepare professionals for understanding the behavioral aspect of the job, changing regulations/requirements for care (i.e., developing reasonable regulations that make sense or are approved by the right stakeholders before they go into effect) and restructuring hospital care to focus on preventive measures.

In conclusion, our study was successful in helping to find the areas in which DCW could be improved and helping to inform whether or not DCW could be used in a real-world setting. Based on the results from our analysis of the interviewees responses, we are of the opinion that there is a need for a platform such as DCW, mainly as a communication tool that would help in the development of care plans and addressing the care needs of PLWDs. Almost all of our interviewees responded positively and expressed that DCW has the potential to be a valuable tool in aiding those who participate in dementia care. Below we have included a check list of recommendations for DPEN content and CIRG Development to aid in the future development process of the Dementia Care Works platform based on our overall findings.

DPE	N	Content Recommendations		
		Bring the Long-Term Care Team into the DCW system		
Į		Separate CP and PLWD Assessment Sessions		
Į		Further Introduction to System		
Ţ		Simplify Assessments		
Ţ		Non-Medical Tracking		
	<b>1</b>	Provide Care Plans for both the PLWD and the CP		
Ţ		Provide Care Plans to Providers as a Protocol for Care		
Ţ		Identify the "fast track" assessments		
CIPC Davidonment Recommendations				
_	_	Development Recommendations		
Ļ		Bring the Long-Term Care Team into the DCW system		
		Separate CP and PLWD Assessment Sessions		
		Scoring Summary Details Post Assessment		
Ţ		Additional Detail in Scoring Summary		
		Compare PLWD and Care Partner Assessments		
Ţ		Add Color Coding to Graphs Bulk Data Export		
	<b>_</b>	Individual Data Export		
	<b>_</b>	Retain Paper Assessments		
Ţ		Mobile First		
		Navigation		
	<b>_</b>	Patient ID		
Ţ		Increase Size of Patient Info		
Ţ		Birth Date Format		
Ţ		Meaning in Scoring Summary		
Г	٦.	Fact vs In-Denth Accessments Paths		

# **Appendix**

# Appendix A: Customer Discovery Script

Hello, thank you for your participation! We are from the University of Washington School of Nursing and are doing research on a product for nurses within healthcare settings that will simplify a nurse's delivery of care for people living with dementia.

Do you consent for the research session to be recorded and for your anonymous data to be used in research reports, articles, or training content?

- 1. What is your role in patient care?
- 2. What big picture pain points and challenges do you have? What holds you up in your daily workflow?
- 3. What is your current role in and relationship with caring for people living with dementia?
  - 3.1. How often/ what %?
- 4. What is your approach with PLWD?
  - 4.1. What tools do you currently use to support this care?
  - 4.2. How much time do you have to dedicate to them per appointment?
- 5. What are your pain points and challenges in providing care to people living with dementia?
- 6. What solutions have you tried in addressing these challenges?
  - 6.1. Why are you using that solution?
  - 6.2. How hard was it to implement this solution?
  - 6.3. What would be your ideal solution?
  - 6.4. What solutions have you considered but decided against?
- 7. Is anything preventing you from implementing your ideal solution?
  - 7.1. What would motivate you?
- 8. How do you acquire solutions?
  - 8.1. What is the review process?
- 9. Any other questions or comments?
- 10. Any referrals to others to interview that are involved in the decision-making process?

Thank you again for your participation! Would you be interested in us following up in a few weeks with findings or follow-up questions?

Appendix B: Customer Discovery Notes

**Customer Discovery Notes** 

# Appendix C: Customer Discovery Analysis

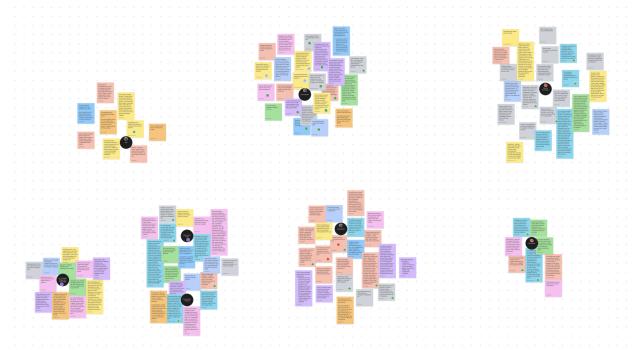


Figure 12. Customer Discovery Sticky Note Analysis

# Appendix D: Usability Session Script

Hello! I am/we are from the University of Washington School of Nursing and are doing research on a product for nurses within healthcare settings that will improve outcomes for people living with dementia.

Thank you for your participation! I want to emphasize that we are testing the application, and not you. We want your honest feedback to improve it. As you go through each task, I will ask you to think out loud, to help me better understand your thoughts. Please describe your actions, emotions, and thoughts as they happen.

Do you consent for the research session to be recorded and for your anonymous data to be used in research reports, articles, or training content?

#### Pre-Task Questions:

- 1. What is your current experience with caring for people living with dementia?
- 2. What is your current experience with using digital tools in a healthcare setting? Have you done an assessment via digital tool?

Task 1: Start a new assessment for Claire

Task 2: View Claire's report

Post-Task Questions:

- 1. What was working, what can be improved, and what was missing? Do you have any suggestions for the product?
  - 1.1. How would you prioritize those suggestions?
  - 1.2. What do you think about the addition of Guided Care Plans?
    - 1.2.1. Do you feel that this gives you actionable next steps?
- 2. (If relevant) Based on your experience working with people living with dementia, would this product be useful?
- 3. Where in the range of dementia severity do you think this will be most useful?
- 4. Do you think this would be as effective in a real-world situation?
  - 4.1. How immersed were you in the scenario?
- 5. Any other questions or comments?

Appendix E: Usability Session Notes

**Usability Session Notes** 

Appendix F: Usability Session Analysis

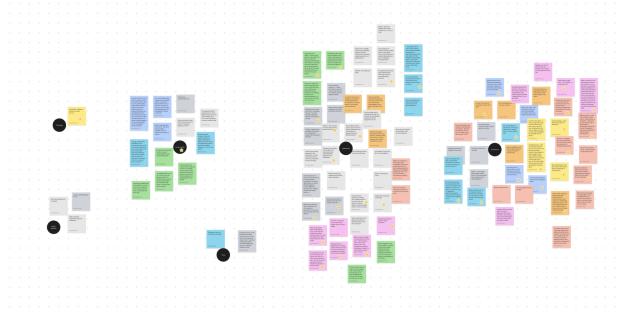


Figure 13. <u>Usability Sticky Notes Analysis</u>

# Appendix G: DCW System Screenshots

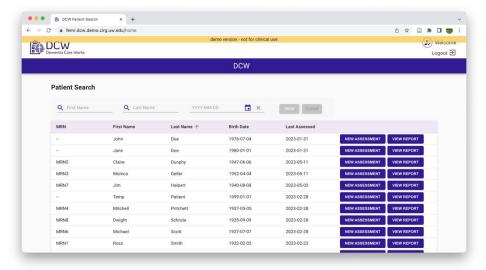


Figure 14. Patient Search Page

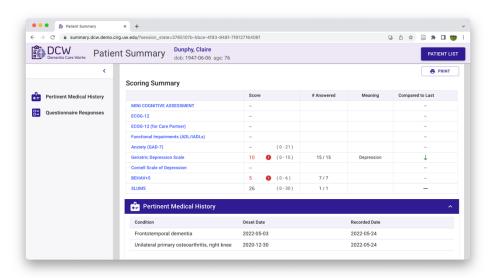


Figure 15. Patient Summary/Report (Scoring Summary)



Figure 16. Patient Summary/Report (Assessment Graph)

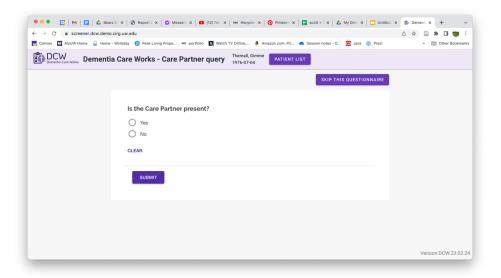


Figure 17. Questionnaire in the Assessment System