Digitally Facilitating Reminders and Alerting for Individuals Struggling with Young-Onset Alzheimer's Disease

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Abstract

Approximately 658,000 struggle with Young-Onset Dementia (YOD) in the United States alone. While on a percentage basis, these individuals represent a small subsection of the Alzheimer's community overall, the needs associated with these individuals are highly unique and tremendously underrepresented both in academic research as well as in available age-specific Alzheimer's services. Individuals with YOD experience a unique blend of biological, diagnostic, financial, and emotional challenges, many of which differentiate YOD individuals from their late-onset AD counterparts. This project utilizes investigation into these unique challenges to provide a foundational basis for the design and testing of the smartphone tool, *Noted!*, which aims to service the daily-life task-management needs of young-onset individuals struggling with stages one through four of AD. Utilizing a two-phased iterative testing approach with non-demented participants of similar demographic standing to the target user base, the final finessed prototype included necessary revisions prior to future testing of the fully developed application with members of the YOD community.

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Chapter 1: Introduction

The human body is a uniquely outstanding yet fragile ecosystem. The human brain alone stands far apart from its mammalian counterparts, with remarkable intellectual distinction facilitated in part by a notably large cerebral cortex as well as the approximate 100 billion neurons and 1 trillion non-neural glial cells that it contains (Herculano-Houzel, 2009). However, with such complexity there comes potential for unexpected deficiencies in a once perfectly operating cognitive system. One such disorder is Alzheimer's Disease.

Globally, approximately 47 million people are unfortunate enough to develop dementia ("Dementia," 2017; Prince et al., 2015). In 2015, the World Alzheimer Report claimed that the world will likely see this number rise to 131.5 million by the year 2050, a steady increase of approximately 9.9 million new cases of dementia each year (Prince et al., 2015). Dementia, a syndrome caused by a host of neurodegenerative disorders, progressively interferes with an individual's memory and behavior, causing a slow degradation in an individual's memory and behavior (Millenaar et al., 2017; "Dementia," 2017; Alzheimer's Association, 2006). While dementia can be caused by a variety of diseases and/or conditions including, but not limited to, Parkinson's, Lewy Body, and Huntington's diseases, the most prevalent form of dementia in European and North American populations is Alzheimer's disease (AD) (Page & Keady, 2010; "Dementia Gateway: Young Onset Dementia," 2013; Beattie, Daker-White, Gilliard, & Means, 2004).

Alzheimer's disease is associated with the detrimental accumulation of Tau proteins inside brain cells and decomposed amyloid protein plaques outside brain cells that progressively disrupt electrochemical signals (Alzheimer's Australia, 2013; Kapsambelis, 2017), eventually leading to brain atrophy (Crandell, Crandell, & Zanden, 2012, p. 564). The median life expectancy for individuals with the disease is about three to eight years after diagnosis, with no known cure (Alzheimer's Australia, 2013, p. 5). Applied medication regimens initiated post-diagnosis act as a means of slowing the

disease's progression and/or alleviating cognitive and/or behavioral symptoms, but do not cure the disease (Alzheimer's Association, 2017a). Approximately 9.4 million Americans currently live with Alzheimer's disease (Prince et al., 2015).

While this disease is most prevalent with the 65 and older population, there is a community of younger individuals struggling with the same diagnosis. Multiple labels have been used to describe the medical condition of these 65 and younger individuals with Alzheimer's throughout literature, including terms such as 'early-onset dementia' (Vieira et al., 2013; Vliet et al., 2013; Harris, 2004), 'presenile dementia' (Ron, Toone, Garralda, & Lishman, 1979), and 'working-age dementia' (Alzheimer's Society, 2015b). However, many researchers have adapted the label of 'Young-Onset Dementia' (YOD) in an effort to more clearly indicate the age of the individuals affected as opposed to the earlier stages of the typical dementing process (Hodges, McKinnon, Kelso, Mioshi, & Piguet, 2015).

Some estimate that approximately 67 to 81 in every 100,000 individuals struggling with Alzheimer's disease is between the ages of 45 to 65 years old (Rossor, Fox, Mummery, Schott, & Warren, 2010; Millenaar et al., 2017). However, individuals as young as 31 years old have also been diagnosed with this syndrome (Alzheimer's Australia, 2013). Given a combination of issues such as insufficient research and general difficulties in a proper medical diagnosis, it is likely that the number of individuals struggling with young-onset Alzheimer's Disease is greatly underestimated (Rossor et al., 2010). This is especially true given only one in four people are diagnosed properly with young-onset Alzheimer's Disease (Kapsambelis, 2017). Some research has noted the number of individuals struggling with young-onset Alzheimer's Disease to be as high as five to ten percent of all Alzheimer's patients (Bryan, 2005). These higher percentages fall more in line with other research across the globe such as Australia's 2015 approximation that seven percent of their country's AD patients are under the age of 65 years old. This equates to approximately 25,100 individuals with YOD in Australia alone (Hodges et al., 2015). Following this seven percent paradigm, it could be assumed that there are approximately 658,000 Americans struggling with YOD in the United States.

While on a percentage basis, these young-onset individuals represent a small subsection of the Alzheimer's community overall, the needs associated with these individuals are highly unique and tremendously underrepresented both in academic research as well as in available age-specific Alzheimer's services.

This project utilizes investigation into the unique challenges that plague the young-onset Alzheimer's community to provide a foundational basis for the design and iterative testing of the smartphone tool, *Noted!*, which aims to service the daily-life task-management needs of young-onset individuals struggling with stages one through four of AD. The research aims to provide successful groundwork for future alpha-testing with members of the YOD community.

Chapter 2: Challenges of Young-Onset Alzheimer's Disease

A unique blend of biological, diagnostic, financial, and emotional challenges afflict individuals diagnosed with young-onset Alzheimer's. Many of these challenges differentiate YOD individuals from their late-onset AD counterparts. The subsequent section will discuss the various trials that young-onset AD patients face as members of the AD community, as well as the additional tribulations faced by also being middle-aged members of society. These obstacles will provide foundational knowledge regarding the proposed application's user base and will help determine the heuristics needed to properly service this unique and underrepresented community of young to middle aged adults.

Biological Challenges

The impaired ability to recall recent events while effectively retaining long-term memories is the most prevalent symptomatic presentation of AD, with disease progression eventually leading to degradation of other cognitive domains such as attention, higher order functioning, visuospatial skills, and language and/or speech (Koedam et al., 2010). While memory deficit is commonly associated with AD, there is far less societal awareness of the varying symptomatic experiences of AD patients (Koedam et al., 2010; Pendleton & Schultz-Krohn, 2013, p. 925). The presentation of these more atypical indicators are especially apparent in the young-onset population, one-third of whom experience disproportionate impairment in a domain other than memory (Roach, 2017). This level of prominence differs greatly from the late-onset population of whom only five percent experience these less characteristic symptoms (Roach, 2017).

In 1988, Dr. Barry Reisberg sought to better document and categorize the various symptomatic presentations of primary degenerative dementias such as AD (Bonder & Bello-Haas, 2009; "Seven Stages of Dementia," 2016) in the Global Deterioration Scale/Functional Assessment Staging (GDS/FAST) system. This seven-stage categorization scheme was quickly adopted by healthcare professionals as it markedly improved in tracking the common patterns of AD decline (Auer & Reisberg, 1997). To

this day, the GDS/FAST continues to serve as the most widely used staging methodology for quick assessments, especially in a non-specialized setting (Borson & Chodosh, 2014).

In the GDS/FAST system, fully functioning individuals devoid of cognitive impairment are designated as 'stage one' (B. Reisberg, Ferris, de Leon, & Crook, 1982). The second stage reveals subjective complaints of mild cognitive strain. Periodic difficulties in recalling items held in working (aka short-term) memory, such as object placement and name recall, become intermittently jeopardized though this may not yet be realized by close loved ones or coworkers (Bonder & Bello-Haas, 2009; J. D. Huntley & Howard, 2010; B. Reisberg et al., 1982). In the non-demented human brain, working memory is already known to have a limited capacity (Kohl, 2015a; Weinschenk, 2011, p. 46) with short-term retention heavily relying on an individual's ability to focus on salient stimuli (Weinschenk, 2011, p. 47). This natural limitation on working memory is compounded in stage two, as an individual's ability to maintain focus weakens. For older generations, these symptoms are typically attributed to normal age-related forgetfulness. For working-aged adults these symptoms are frequently misattributed to stress and/or depression (Johannessen & Moller, 2011).

During stage three of the GDS/FAST system, an individual's capacity for sustained concentration over a prolonged period of time becomes more significantly impaired, further damaging his/her ability to retain and transfer short-term information—i.e. details in recently read material, the names of recently introduced people, and tasks, goals, and/or appointments—to longer-term storage mechanisms (Bonder & Bello-Haas, 2009, pp. 224–225). Common executive strategies such as chunking large sets of information into smaller, more consumable parts remain an effective technique for adults in this stage, provided he/she exhibits focused attention (J. Huntley, Bor, Hampshire, Owen, & Howard, 2011). Splitting tasks and/or goals into separate components not only to provide ample time for individuals to successfully process the information, but also to facilitates focus on a single small task at a time (Hodges et al., 2015, p. 10; Kohl, 2015a). At stage three, these techniques can begin to lose value for spatial working memory (J. D. Huntley, Hampshire, Bor, Owen, & Howard, 2017; G. A. Miller, 1956; Weinschenk,

2011, pp. 46–50). Spatial challenges such as these are particularly unusual for the average adult, as human beings are characteristically much more adept at remembering visual experiences over words (Weinschenk, 2011, p. 54).

Approximately thirty-three percent of the young-onset AD population, experience symptoms apart from the common early-stage working memory challenges (Koedam et al., 2010). The most common atypical AD phenotype is Posterior Cortical Atrophy (PCA), which has significant effects on the patient's symptomatic experiences, most commonly visuospatial dysfunction (Koedam et al., 2010). These persons may begin to experience mild difficulties in one or more of the following areas: 1) recognizing objects in photographs (especially if the pictures were taken from an obscure angle or if the captured objects are in some way incomplete), 2) recognizing faces, 3) understanding spatial relationships and/or distances between himself/herself and surrounding objects, and 4) perceiving objects speeds (including seeing stationery items as sometimes moving) (Crutch et al., 2012; dementiaresearch, 2010). This dysfunction of spatial localization and perception often leads to confusion, disorientation, and reduced detail when describing recently experienced events (Bonder & Bello-Haas, 2009). Similar to typical memory related manifestations of AD, the severity of these symptoms progresses throughout the stages of the disease.

As a result of these more noticeable cognitive/behavioral changes in stage three, loved ones and co-workers begin to gain awareness of these individuals' changing levels of performance at work and at home (Barry Reisberg, 1988). As symptoms begin to disrupt the lives of these adults, mild to moderate anxiety grips the patient as denial of symptoms begins to slowly enter into the patient's mind (Glogoski, 2013, p. 926). However, even despite these pervasive symptoms that degrade his/her developmental age from an adult level to that of someone just over the age of twelve years old (B. Reisberg et al., 1982), individuals in this third stage retain the ability to participate in everyday routines independently, continuing to carry out work related tasks despite increased difficulty in doing so (Bonder & Bello-Haas, 2009, pp. 224–225). For the typical individual with AD, the third stage can be fairly long-lasting, averaging seven years

("Seven Stages of Dementia," 2016). However, symptoms are known to progress more rapidly in the young-onset populations as compared to the late-onset groups (Shinagawa et al., 2007, p. 45), suggesting that young-onset AD patients may progress through this stage more rapidly.

Alterations in an individual's executive functions—i.e. the ability to direct thought and action towards independently overcoming challenges, carrying out complex tasks, and prioritizing goals (E. K. Miller & Wallis, 2009)— become more noticeable with the transition into the fourth stage of disease progression. As an individual's cognitive state moderately declines into the developmental equivalent of an eight to twelve-year-old, difficulties in handling finances, planning travel, and shopping become more apparent (Barry Reisberg, 1988). The ability to effectively carry out these more cognitively-taxing tasks is highly dependent on the individual's ability to draw from working memory, to selectively attend to salient information, and to maintain efficient and effective interchange between multiple tasks (Bunge & Souza, 2010; Diamond, 2013). Conversations and tasks begin to become more labored, as individuals have difficulties staying on topic (Bonder & Bello-Haas, 2009, p. 225). In clinical interviews, practitioners often test these individuals' capacity to selectively attend while performing a cognitively-taxing task using a system known as serial subtractions (Sandberg, 2011). During this test, patients are asked to count backwards from one-hundred by increments of seven. By stage four, this task is close to impossible.

For those individuals experiencing a less common symptom progression, minor presentations of stage three symptoms vastly worsen in stage four. For those experiencing more visuospatial concerns, a degraded ability to understand spatial relationships and distances, coupled with difficulty judging the speed of moving objects impairs the ability to drive safely (Crutch et al., 2012; dementiaresearch, 2010). Non-realistic or abstracted images are increasingly challenging to recognize. Additionally, the ability to recognize familiar faces or travel to a familiar location independently becomes compromised (Barry Reisberg, 1988). An individual's capacity to understand and retain information from long

textual passages becomes heavily impaired as lines are accidentally skipped over or sections are mistakenly re-read (Crutch et al., 2012; dementiaresearch, 2010).

Often it is around this time that denial becomes a dominant defense mechanism for these AD-sufferers, leading patients to blame those around them for misunderstandings and dismiss forgotten items as unimportant in an effort to lighten the emotional burden (Bonder & Bello-Haas, 2009, p. 225; B. Reisberg et al., 1982). Disease progression begins to warrant minor outside assistance. This fourth stage lasts approximately two years on average ("Seven Stages of Dementia," 2016).

Given the fact that motor skills require far fewer mental resources than cognitive and visual processing (Weinschenk, 2011, p. 65), it is not unsurprising that motor difficulties frequently occur much later in the disease progression. While it is not extremely uncommon for mild instances of impairment, such as changes in tone, reaction speed, movement time, and standard gait, to surface around stage five, more severe motor deficits are seen in stages six and seven. It is during stage six that difficulties in dressing, eating, and the mechanics of toileting are experienced (Bonder & Bello-Haas, 2009; Barry Reisberg, 1988; "Seven Stages of Dementia," 2016). Changes also include severely compromised reaction time, changes in movement, and degraded speech (Bonder & Bello-Haas, 2009, p. 225). These symptoms worsen to also include incoherent speech, incontinence, and loss of basic psychomotor skills such as the ability to walk. It is at this seventh, and final, stage that the mind and the body outwardly appear to be separate entities, unable to communicate with one another, as an individual loses the ability to walk and cannot eat or go to the bathroom without assistance.

In stages one through four, the level of maintained independence and working knowledge of habitual technologies provides the ideal canvas for utilizing the familiarity of a YOD individual's smartphone as a means of personalized support. However, beyond stage five, due to cognitive and motor deficits, an assistive tool that depends on an individual's ability to successfully interact with a mobile device becomes untenable. The mobile application's function of establishing a sense of self-reliance and autonomy is undermined by the level of dependency in later stages of the disease. It is for this reason

that mobile aid designed for patient use best serves individuals who have not yet progressed to stage five. As such, primary emphasis is placed on stages one through four of the disease progression throughout the preliminary research process and within the designed application itself.

Diagnostic Challenges

The process of diagnosing Alzheimer's disease has long proved to be a time-consuming challenge for the medical community (Mendez & Cummings, 2003, p. 6; Rockwood & MacKnight, 2001, p. 9). There is immense value in diagnosing AD early, including facilitating a greater understanding of the disease progression, utilizing medications such as Tacrine to slow the disease progression (Crandell et al., 2012, p. 566), and helping prepare for the future, all of which assist in improving the patient's quality of life (Pendleton & Schultz-Krohn, 2013, pp. 923–4). However, regardless of age, there is currently no definitive way to diagnose an individual with Alzheimer's disease antemortem (Alzheimer's Australia, 2013). Multiple studies have validated that the most conclusive diagnosis can be made only through analysis of AD-related biomarkers (i.e. enlarged brain cavities known as ventricles) in brain neuroimaging techniques (Pendleton & Schultz-Krohn, 2013, p. 924) or, most clearly, through analysis of amyloid plaques, neurofibrillary tangles, and death or harm to brain cells (Kapsambelis, 2017; Bonder & Bello-Haas, 2009) during an autopsy ("Alzheimer's Disease Facts and Figures," 2017, p. 64; Medicine, 2015).

In an attempt to better facilitate an accurate Alzheimer's diagnosis prior to death, several diagnostic benchmarks were established by the medical community. The Diagnostic and Statistical Manual of Mental Disorders (DSM-IV-TR) criteria (APA, 2000), for example, relied on the patient exhibiting signs of impaired recent and episodic memory as well as issues in at least one other cognitive area to receive an AD diagnosis (Bonder & Bello-Haas, 2009, p. 219). However, the National Institutes of Neurologic and Communicative Disorders and Stroke and the Alzheimer's Disease and Related Disorders Associated Work Group (NINCDS-ADRDA) (McKhann et al., 1984), removed the memory impairment requirement and instead stipulated that as long as impairment was

seen in two or more spheres of cognition (i.e. deficits in memory, language, visuospatial perception, motor functions, executive functions, personality, and/or emotional awareness), a "clinically probable AD" diagnosis was warranted. An individual that demonstrates deterioration in three or more areas, on the other hand, is more conclusively characterized as harboring AD (Bonder & Bello-Haas, 2009, p. 220).

Unfortunately, even with the presence of this diagnostic system, the ability to definitively diagnose AD is far from perfect. Approximately one-third of individuals with AD do not receive a diagnosis for over a year after he/she first seeks medical help for noticeable symptoms (Wilkinson, Stave, Keohane, & Vincenzio, 2004). This is in large part due to a difficulty in accurately recognizing and categorizing early symptoms (many of which can be attributed to other medical conditions) as well as the general risk in prematurely presenting an inaccurate medical diagnosis (Iliffe, Wilcock, & Haworth, 2006). Additionally, research has found that there remains a certain level of ambiguity in modern antemortem diagnostic criteria themselves. Autopsies revealed that approximately one-third of individuals previously diagnosed with AD via the NINCDS-ADRDA guidelines were subsequently found to not exhibit the brain changes characteristic of AD ("Alzheimer's Disease Facts and Figures," 2017; Chouraki & Seshadri, 2014; Medicine, 2015; Spinney, 2014). Until additional aspects of this disease are understood, the frequent discrepancy between pre and post-mortem diagnoses remains a challenging feat to completely overcome.

Unfortunately, this systemic challenge is only further complicated for individuals under the age of sixty-five years old. The largest contributing factor to a delayed diagnosis is that the medical community is less inclined to consider Alzheimer's Disease to be a diagnosis within this younger population (Werner, Stein-Shavachman, & Korczyn, 2009; Williams, Cameron, & Deardon, 2011). Due to this fact, it is common for individuals with YOD to be more cognitively impaired than LOD counterparts at the time of diagnosis (Picard, Pasquier, Martinaud, & Godefroy, 2010). Moreover, the atypical early stage symptoms frequently witnessed in the younger AD population makes diagnosis even more challenging. Behavioral and personality changes that are commonly

categorized in more psychosocial terms lead to frequent misdiagnoses of stress or depression (Johannessen & Moller, 2011). Additionally, minimal memory loss in menopausal-aged women can be attributed solely to hormonal changes (Crandell et al., 2012, p. 494). Misdiagnoses such as these largely contribute to the fact that an accurate diagnosis can take four to six years for individuals under the age of sixty-five (65) (Alzheimer's Association, 2006; Claire Bamford, Eccles, Steen, & Robinson, 2007; Holzer & Warshaw, 2000; Vliet et al., 2013) and leave patients in a much more progressed stage of the disease by the time appropriate assistance is received.

Financial Challenges

These diagnostic difficulties have a profound impact on the financial position of the young-to-middle aged adults during the time of symptom emergence. YOD individuals often still have financial obligations to dependent children and the care of elderly parents. There is a tremendous amount to lose as progressive symptoms slowly steal the capacity to effectively carry out responsibilities in the workplace.

All too frequently, the inability to receive a diagnosis prior to a loss of job prohibits YOD individuals from receiving compensation through work-provided disability insurance or other government programs aimed at assisting those unable to receive Social Security due to age such as Social Security Disability Insurance (SSDI) and Supplemental Security Income (SSI). As the care partner of a young-onset Alzheimer's patient stated in an interview with the Alzheimer's Association in 2006, "we were not aware that the problem was Alzheimer's disease when the person had to quit work two years before diagnosis. Therefore, we didn't apply for disability insurance" (Alzheimer's Association, 2006). Approximately 29% of YOD individuals ages fifty-five (55) through sixty-four (64) live without any form of health insurance. Many were turned away from private medical insurance after receiving a diagnosis due to their pre-existing condition (Alzheimer's Association, 2006). While some people are successful in purchasing insurance, these individuals are frequently met with high out-of-pocket expenditures for uncovered care as well as high premiums, deductibles, and copayments (Alzheimer's Association, 2006).

The YOD individuals who are able to obtain a diagnosis while in the work force are faced with yet another challenge; the possibility of receiving a denial from the Social Security Administration on the grounds that he/she is still deemed to be able to "work and learn new skills in spite of diagnosis" (Alzheimer's Association, 2006). Health and Retirements Study (HRS) data (2000) indicates that only 29% of individuals aged fifty-five (55) through sixty-four (64) with a cognitive impairment receive SSDI and only eighteen-percent (18%) get SSI disability payments. The loss of salary and lack of financial assistance for a large majority of YOD patients leaves an increased financial burden during an unexpected time in these individuals lives.

Transitions into the fourth stage results in increasing financial crisis as medical care and at-home assistance is needed. While planning for this future of decreased autonomy and increased long-term care expenditures, many patients and loved one's are greeted with the reality that under the age of sixty (60), adults are denied eligibility to many long-established AD care programs which are all geared towards the late-onset majority. YOD individuals are deprived of inexpensive long-term Administration on Aging (AoA) services such as family caregiver support services, adult day care, transportation, and meals-on-wheels (Alzheimer's Association, 2006). Instead, funds for these types of assistance often come out of the family's pockets, leaving some families deciding between basic living expenses and needed medical care. Depending on the individual's desired level of care after surpassing level 4 of AD, annual care costs can typically range from $43,539 to $92,378 for live-in facilities, $68 per day for adult day care, and $20 per hour for a home health aide (Alzheimer's Association, 2017b), costs which quickly accumulate. As a result, these individuals and their loved ones tend to be extremely money conscious as they move into the stages of needing long-term care. The minimal one-time cost of the proposed smartphone application would instill initial positive associations with the assistive technology given its lack of contribution to any pre-existing financial burden.

Emotional Challenges

By the time a diagnosis, is received, most patients are overwhelmed by the impending tidal wave of costs and emotional burdens quickly descending on their loved ones, without means of personally providing the assistance he/she was recently able to give. Overpowering feelings of loss, fear, and isolation significantly impede an individual's intrinsic feelings about quality of life and often lead those with YOD to experience low self esteem and depression (Millenaar et al., 2017; Harris & Keady, 2009). Fortunately for those seeking to better understand the disease, YOD individuals retain the ability to clearly understand needs and relay personal experiences more effectively than those with late-onset versions of the disease (Beattie et al., 2004; "Dementia Gateway: Young Onset Dementia," 2013). As a result, a large percentage of the medical community's venture into the study of YOD has focused on gathering the stories of these middle-aged adults to provide a more complete picture of the disease from inside the minds of those who are struggling with it.

In an effort to better understand the emotions that user's will bring with them while using the proposed assistive application, the following section will discuss the three most common contributing factors mentioned by individuals suffering from the disease—loss of autonomy (Millenaar et al., 2017), strain on interpersonal relationships (Harris, 2004; "Dementia Gateway: Young Onset Dementia," 2013), and lack of age-appropriate resources (Alzheimer's Society, 2015b; Beattie et al., 2004, p. 360). Since an individual's emotional state holds immense power over his/her perceived experiences (Kohl, 2015b), proper understanding of these commonly-held feelings can greatly inform and positively affect the application design process, assisting in avoiding attributes that would compound these negative emotions and taint the user's perception of the application as a whole, while simultaneously instilling attributes that would best support a positive user experience.

Loss of Autonomy

The value that young-to-middle age adults place in their work is immense, often with sense of identity, worth, and social status heavily reliant on measures of

occupational success. It is this profoundly influential identity that is often fractured first, as early-stage symptoms are often first noticed at the workplace (Harris & Keady, 2009). As an individual transitions into early stage symptoms, so too does he/she slip into a decreased capacity for self-reliance (Glogoski, 2013, p. 925). The necessity for increased assistance in simple tasks slowly creeps into the work day. The speed with which tasks are accomplished wanes (Bonder & Bello-Haas, 2009, p. 225). Frequent reminders are needed to recall certain tasks (Glogoski, 2013, p. 926). Conference room locations are sometimes forgotten, leaving individuals to search through the office themselves or embarrassingly ask those around them to recount this piece of information that was once so easy to recall (Alzheimer's Society, 2015a, p. 7). Slowly, the loss of the ability to complete even these simple tasks progressively hinders the ability for these individuals to contribute to the workplace (Alzheimer's Association, 2006; Johannessen & Moller, 2011). Once invigorating careers that supplied a sense of accomplishment and purpose quickly disintegrate as YOD patients are forced off the career ladder altogether due to symptoms which will eventually render these individuals career-less homebodies struggling to find a sense of meaning and purpose (Harris & Keady, 2009). As one individual explained in a 2009 interview with Phyllis Harris and John Keady:

> I lost everything that defined me as a productive and meaningful man when I had to stop working because of my symptoms. Eight months prior I had to quit driving because of running red lights and beginning to be in fender benders because of the cognitive problems and lack of visio-spacial coordination. This took the one 'thing' that gave me the most freedom. The [sic] whole role in life shifted from being the main breadwinner to now being Mr.Mom. (Harris & Keady, 2009)

Once symptom progression renders a person incapable of continuing his/her career, independence is often further tested at home. A loss of agency in decision making processes compounds these individuals' profoundly negative feelings of being forced into a state of perpetual dependency. Left career-less, simple goals such as meeting a friend for lunch or learning a new skill become the new valued exertions of autonomy.

However, once these somewhat menial actions are perceived by loved ones as risky, removal of these opportunities is often the response (Millenaar et al., 2017). Given the intact cognitive capacities of these young AD victims, research suggests that invitation into conversations regarding associated risks as well as jointly developing an associated strategy for treatment is more beneficial for the YOD patients. This in turn allows families to mediate flawed perceptions of risk and danger and accommodate autonomy for as long as possible (Beattie et al., 2004, p. 366). In a journal article, YOD sufferer Ann Johnson (2010) emphasizes the importance of tailoring these conversations to the level of ability and understanding of the person. Through her personal experience with the disease, she cherishes the ability to actively participate in these discussions in a manner that does not push her past her limits (Ann Johnson, 2010, p. 9).

Medical professionals and loved ones alike struggle to find the proper balance of respecting the individual's self-sufficiency while concurrently providing needed support (Millenaar et al., 2017, p. 29). Frequently upon diagnosis, members of the medical community turn to the patient's loved ones when discussing AD care, leaving the patient feeling like a second-class citizen regarding his/her own medical care (Millenaar et al., 2017, p. 28; Beattie et al., 2004, p. 365). To many YOD patients, doctor and caregiver confidentiality seems to reign supreme. As a part of this process, there are also moments where many family members withhold information about impending changes from their struggling loved ones in an effort to alleviate further emotional burden (Beattie et al., 2004). This reality further degrades trust between the patient and his/her family members, a schism that the disease will only further divide (Beattie et al., 2004).

Research challenges the medical community to consult with the diagnosed individual directly (C. Bamford & Bruce, 2000; Beattie et al., 2004), especially since these individuals are capable of expressing his/her opinions throughout most stages of disease progression if properly engaged with appropriate consultation methods (Allan, 2001). Regardless of whether the patient is in an individual or group setting, numerous studies have demonstrated that it is possible for YOD individuals to express experiences, needs, and present and future desires (Beattie et al., 2004, p. 361). Involvement in daily

decision-making including care planning, needs assessments, and evaluation of necessary services, has been shown to positively affect the reported quality of life of individuals struggling with YOD (Millenaar et al., 2017). Additionally, concrete knowledge of the stages of the disease allow its victims to effectively accept and determine coping mechanisms moving into the future (Clare, 2004).

Strain on Interpersonal Relationships

As diagnosed adults struggle to balance their deteriorating cognitive abilities with their current responsibilities at home and in the community, strain can be placed on friends and family. AD's strong association with the elderly populations often impedes the broader community's ability to accept or understand this diagnosis in individuals under the age of 65 years old. In a 2009 interview, one YOD individual explained the social isolation experienced after receiving a diagnosis, stating that "I no longer have friends; they found it too depressing in someone so young. They were unable to watch the changes" (Harris & Keady, 2009, p. 5). Even those with more understanding friendships were often left for a majority of the day without their typical social outlets, as their working-aged friends attended to his/her full-time jobs. Still able to function independently at home with minor assistance at stage four, these individuals find themselves with few social and intellectual outlets. As one individual put it "now my friend is my TV" (Harris & Keady, 2009, p. 5). At home, these individuals are often left to struggle with self-awareness of his/her active cognitive deterioration and its effects. This common experience leads to an overwhelming desire to be seen as "normal" and not be cast aside as an "other" (Beattie et al., 2004, p. 363).

Lack of Age-Appropriate Support

Unfortunately, feelings of otherness are compounded by the lack of age-appropriate support provided by the community. Placed in a senior individual's framework of care, these young-to-middle-aged adults are often lost to gaps in the disability and elderly care systems (Hodges et al., 2015, p. 4). In 2004 interviews, a majority of YOD patients indicated age related concerns as being most emotionally debilitating, expressing extreme discomfort with the large majority of support groups,

resources, and adult daycare programs that are geared towards the elderly (Alzheimer's Association, 2006, p. 9; Beattie et al., 2004, p. 364). While interacting with younger individuals with AD was associated with improved morale, placement in a senior care program degraded these individuals' perceived quality of life significantly (Alzheimer's Association, 2006, p. 9) frequently resulting in refusal to partake of these programs all together.

This divide is especially evident in assistive technology designed for those experiencing the effects of AD. Given seniors' compounding age-related physical struggles and lesser familiarity with computing devices (Smith, 2014), the AD community has spent little time developing a broad repertoire of AD-related services designed specifically for patient use. This is especially true in the realm of mobile-based tools. With only 18% of seniors incorporating smartphone usage into his/her everyday lives (Smith, 2014), the opportunity for assistive mobile applications to positively affect the elderly AD majority is quite small.

As such, many mobile applications instead focus their efforts on supporting the millions of caretakers and loved ones of individuals with AD. A large majority of these working-aged custodians are steeped in years of familiarity and overarching positivity regarding technological devices, with approximately 88% of individuals 30 to 49 years old and 74% of adults aged 50 to 64 relying on a smartphone (Pew Research Center, 2017). Approximately 11-13% of these individuals rely on a cellphone as the sole means of digital connection to the outside world (Pew Research Center, 2017).

Devoid of old age-related physical difficulties with smartphone usage and steeped with years of familiarity and concurrent confidence related to a mobile device, the younger-onset population is a member of the same smartphone culture as these digitally supported caretakers. Yet even so, approximately 658,000 Americans are set apart by the complications of young-onset AD. Trapped between two worlds, these individuals are fated to scour the app store for applications geared towards individuals without cognitive distress or select a more AD specific tool that is geared towards the elderly.

Chapter 3: Evaluation of Existing Technical Services

Analysis of the early stages of YOD suggests that inexpensive personalized assistance at the user's fingertips may alleviate the effects of AD's symptoms while concurrently improving the emotional well-being associated with the ability to maintain some level of independence. In an effort to improve the lives of individuals struggling with symptoms of AD, several mobile phone applications have been developed with this purpose in mind. Three of these applications seem particularly effective for the YOD population, providing support for the potential value of my proposed automated reminder and alerting system.

It's Done!

AJ Lester & Associates, Inc. (2017) developed the mobile application, *It's Done!*, to provide "a checklist for life's everyday critical tasks such as locking doors, feeding pets, taking medication, and turning off the stove", specifically geared towards individuals who "suffer short-term memory loss due to brain injury, dementia, or other related medical conditions" (AJ Lester & Associates, Inc., 2017). This application is the Alzheimer Association's recommended task application (Alzheimer's Association, 2013). *It's Done!* aims to alleviate the problem of forgetfulness by allowing its users to manually create defined tasks, view self-assigned tasks by day, and mark/unmark tasks that have been completed or are needed to be completed again (AJ Lester & Associates, Inc., 2017).

Many features of this application do not properly support the needs of the YOD community. As a non-impaired avid technological user, I was a bit surprised by my own level of confusion when using the application. Upon entering the application for the first time, users are introduced to the home screen with three automatically added tasks – "Lock Car," "Lock Door," and "Take daily Vitamins" – garnering initial focal attention in the center of the screen (see Figure 1). There are neither provided instructions introducing the user to the application and its provided features, nor any indication on where to go and what to do upon first entry. This is especially detrimental for early-stage

AD individuals struggling with remembering spatial relationships and sequences as lack of clarity on how to proceed through the application's intended functionality could serve as a frustrating deterrent (Barry Reisberg, 1988). For some users, there may even be confusion as to why these three particular tasks were already added without having taken any action to create them.

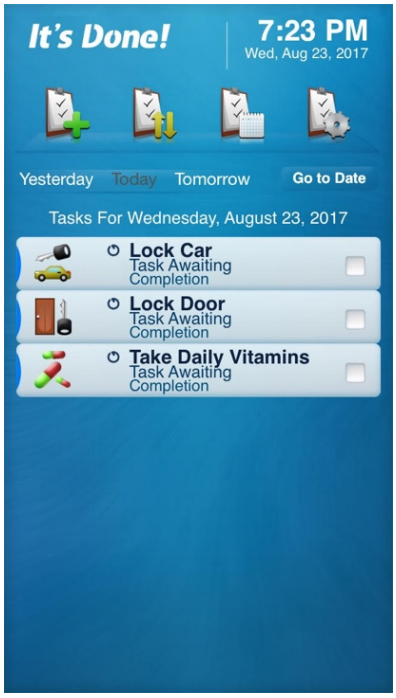

Figure 1. Automatically added tasks within the *It's Done!* homepage (Its Done!, 2017).

On the top of the screen, four unlabeled images of similar appearance are displayed beneath the branding with the current date and time (see Figure 2). Each icon exemplifies a piece of paper clipped to a clipboard with a unique symbol on the bottom-right corner. Given the lack of visual-indicators that typically indicate a digital item's click-ability, there is a possibility that some users would mistake these images as purely decorative and miss a large portion of the tool's functionality (Weinschenk, 2011, p. 17).

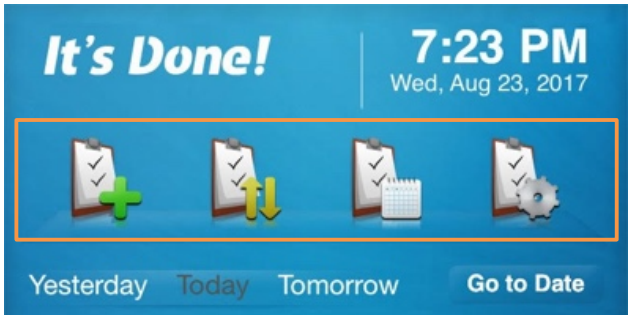

Figure 2. Unlabeled primary buttons within the *It's Done!* homepage (AJ Lester & Associates, Inc., 2017). Orange highlighting overlaid for demonstrative purpose.

Moreover, according to WSAG 2.0 guidelines, the lack of textual labels prohibits users from clearly understanding the purpose of each of the four pictures (W3C, 2012). Without the provision of in-app guidance for basic functionality, the user's only option is to explore the functionality of these various components via trial-and-error. Through persistent investigation, a user confident in his/her ability to experiment within the application would ideally be able to uncover the tool's functionality. However, relying on users to intuit the behavior through trial and error is an unreasonable expectation for a fully adept user, much less a clientele struggling with the cognitive deficiencies of Alzheimer's Disease. Members of the YOD community are looking to identify avenues of combating symptoms, rather than compounding cognitive difficulties in an ever-expanding world of puzzles.

Adding a New Reminder

To create a new task entry within the *It's Done!* application, the user must complete an eight-field form shown in Figure 3 below. This new task input form is accessed by clicking the clipboard icon with a green plus in the lower left corner. From this form, the user can begin by picking from forty pre-defined task options with associated icons, or define his/her own unlisted task.

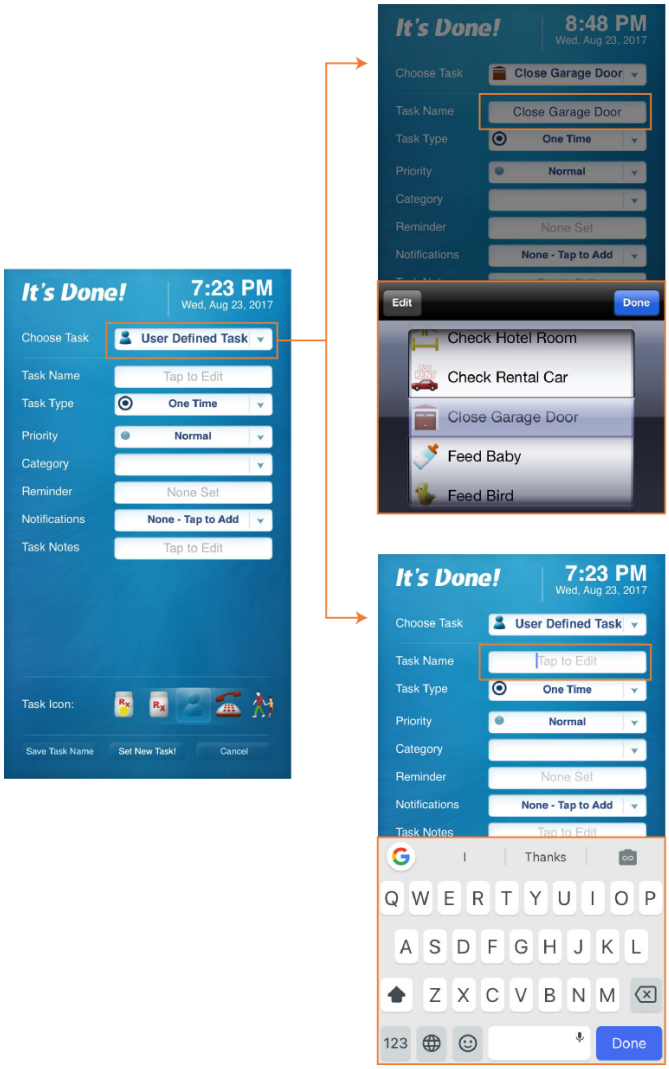

Figure 3. Task input methods within *It's Done!* (AJ Lester & Associates, Inc., 2017). New tasks can be input using manual keypad entry or by choosing a preset task option. Orange highlighting overlaid for demonstrative purpose.

While the provided list of task options could be extremely beneficial in reducing the cognitive load on the user (Weinschenk, 2011, p. 53), the provided manual entry system could stand to be improved. The input mechanism provided by the application relies on the phone's keyboard to input characters and formulate the desired task. Research has found that not only does phone based typing increase physical and cognitive effort, mobile typing has also been found to decrease entry speed by two-and-a-

half to three times when compared to a standard computer keyboard (Bao, Pierce, Whittaker, & Zhai, 2011). These statistics indicate that the current manual keypad-based entry system provides a non-optimal experience for a forgetful user base. For these users, the ability to quickly input content prior to short term loss is key, something which phone-based typing does not easily facilitate. Adaption of a faster content input system could be beneficial in assisting the user in quickly inputting his/her tasking information with as little manual typing as possible.

Vast improvements to this entry system could be made by simply decreasing the number of form fields visible at a single moment in time and, instead, progressively disclosing information as the user completes the form (Jarrett & Gaffney, 2008; Zmily & Abu-Saymeh, 2013). A progress bar indicator could directly relay the user's degree of completion, remaining on the screen as a visual reminder whenever needed. Given humanity's instinctive drive towards mastering new achievements, small signs of progress has been found to have a large motivating effect (Weinschenk, 2011, p. 127). In this way, information overload, a factor which is likely to be more dramatically felt by the YOD population (Bonder & Bello-Haas, 2009), could be more effectively avoided by establishing a clear relationship between the drop-down form fields and the associated options. By avoiding the associated heightened arousal state, application performance would improve and error counts would diminish significantly (Yerkes & Dodson, 1908).

Also, within an individual task's creation or edit screen, the *It's Done!* application provides two fields for facilitating task-based alerts — "reminder" and "notifications." The similarity between these chosen terms and the application's lack of clear differentiation between them may cause user confusion. Probing leads to the discovery that "reminder" is internally defined as the time that an in-app reminder should be received by the user, whereas "notifications" is a request to receive an external alert via text, email, or both. As is shown in Figure 4, the inputs for these two fields differ greatly, causing an increased difficulty in understanding these two conventions. The reminder field utilizes a scrollable time input overlaid on the lower half of the screen. Clicking on the notifications form field initiates an overlaid modal window with an un-labeled four-

way toggle and three additional type-base entry form fields. The lack of a clear label, as well as the proximity of the toggle to the form fields could reasonably indicate to some users that switching the toggle would affect the form fields below (Weinschenk, 2011, p. 21), which is not the case. To properly adhere to users' expectations, intuitive labels with standardized terminology and consistent functionality should be more effectively utilized.

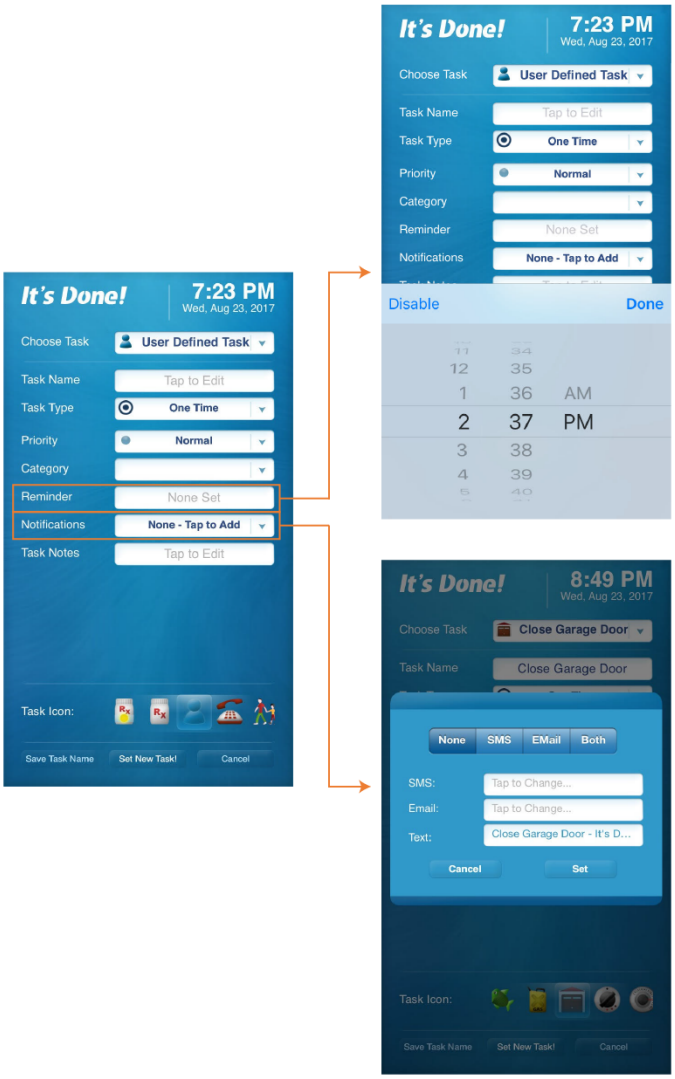

Figure 4: 'Reminders' versus 'Notifications' form field entry within *It's Done!* (AJ Lester & Associates, Inc., 2017). Orange highlighting overlaid for demonstrative purpose.

Receiving Reminders

While the established alerting system successfully informs the user of the need to perform a previously delegated task at the specified time and location when the application is open, the in-app messages are not delivered if the application is closed during the time of intended notice. A more useful application for AD patients would enable a constant stream of reminders, regardless of the applications open/close state. The likelihood of a YOD user accidently closing a mobile application and forgetting to re-open it is exponentially higher than with a non-impaired user, and as such fail-safes should be incorporated. Mistakenly closing an application is extremely easy to do, and remembering the necessity of keeping a particular application open should in no way be obligatory.

A soft, single "ping" and a short mobile notification indicate the successful receipt of an in-app notice. However, upon receiving this initial reminder, the application lacks alerting persistence. This repetition of instruction is extremely valuable for the YOD population (Zmily & Abu-Saymeh, 2013). If the preliminary alert is missed or ignored, the user has effectively lost his/her only chance of being reminded of the task. There is no opportunity to snooze the reminder. If the task remains incomplete, no additional notices will be automatically sent after a set period of time. It is only through actively choosing to re-enter the application that a user notices a flag with accompanying red text indicating that task remains incomplete. The only available workaround in the application is to duplicate the task and add a different reminder time, necessitating additional steps and extra effort. Ideally, this functionality would be included within the task reminder form, so all functionality can be conveniently located in one place. By including an efficient means of customizing the desired frequency of reminders up front, the user is granted comfort in knowing that their smartphone will properly facilitate his/her needs even if those desired needs are later personally forgotten.

Marking Task Completion

Upon successful receipt of an alert, a simple click of the notification takes the user to the application's homepage containing all relevant tasks for the day. Focused effort is required to recall and associate the previously clicked alert with the correct item on the screen, as all tasks are visible. As seen in Figure 5, clicking on a checkbox next to a task indicates that the task had been completed, marking it with a checkmark and a completion timestamp.

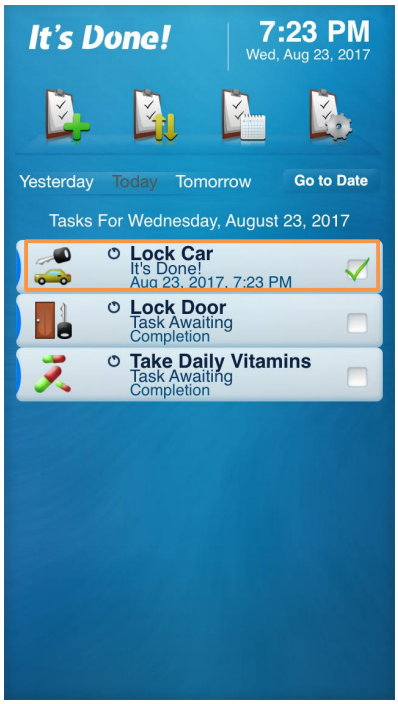

Figure 5. An item flagged as completed within *It's Done!* (AJ Lester & Associates, Inc., 2017). Orange highlighting overlaid for demonstrative purpose.

However, a misguided click on the task container as opposed to the small checkbox itself present the user with an overlaid modal containing additional task information, as well as four additional unlabeled icons that are similar in appearance to those presented on the top of the applications main page (see Figure 6). Similar to the four homepage icons, mental effort is needed to effectively decipher the implications of clicking on these images. The associated cognitive strain of determining the intended functionality is emotionally burdensome to YOD individuals already struggling with

aspects cognitive deterioration. Consequential stress lead struggling users to be more likely to make errors (Weinschenk, 2011, p. 190) or give up on the task entirely. Additionally, if a user mistakes these visualizations as non-interactive elements, much of the value is lost, as only the "Back" button visibly appears to be interactive. This misunderstanding would leave users unable to perform key functionality such as the ability to edit a reminder.

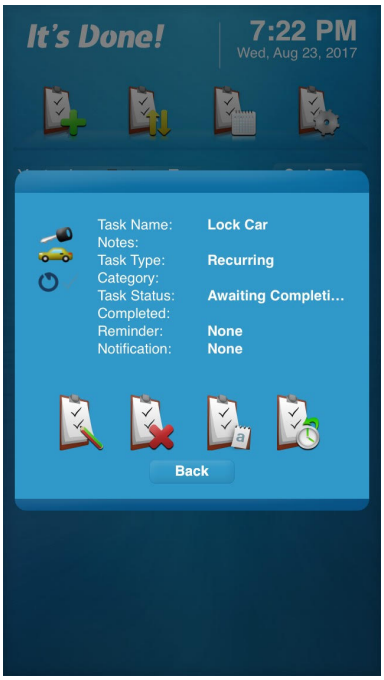

Figure 6. Task summary modal with unlabeled icons within *It's Done!* (AJ Lester & Associates, Inc., 2017).

If it was necessary to complete a task multiple times throughout the day, a user would need to uncheck the check box prior to rechecking it to capture the most recent time stamp of effective completion. While this system would likely be successful for once-a-day tasks, this specific workflow could be detrimental for users needing to remember to perform the same task throughout the day. It is mentally taxing to remember to go to the application not only to check an item off of a list, but also to remember to return to uncheck a task prior to fulfilling it again. Given that the utility of the *It's Done!* is highly dependent on user recall, this functionality is unreasonable for those YOD users

who are already struggling with cognitive deficiencies in this area. Through utilization of a system that more heavily relies on recognition, the user's needs could better be met.

Nudgu Reminders

Similar to the aforementioned mobile aide, the *Nudgu Reminders* (2016) application is a tool aimed to assist the memory of independently living individuals with memory problems. Specifically geared towards assisting older adults unfamiliar with smartphones, this mobile application is dedicated to helping young-to-middle-aged adult phone-savvy caregivers remind his/her loved ones of important items remotely via the landline phone. Entering the *Nudgu* application for the first time, busy caretakers are greeted with a clean and simple home screen. A mid-tone grey message reading "No reminders created" resides in the center of the screen, indicating the landing page's intended purpose and the fact that no user action has yet been taken.

From here, the user's attention is quickly shifted to the only instances of color on the screen, dark purple instructional text with a downward arrow pointing to the primary action button. As shown in Figure 7 below, upon clicking on this purple 'Add' icon, a dark overlay obscures the information on the entry screen, focusing the user's attention instead on the presentation of two options in pictorial and written form. Each option is defined in simple and concise language, ensuring that the user is properly informed of the available actions and clearly understands the consequences of said actions prior to selection.

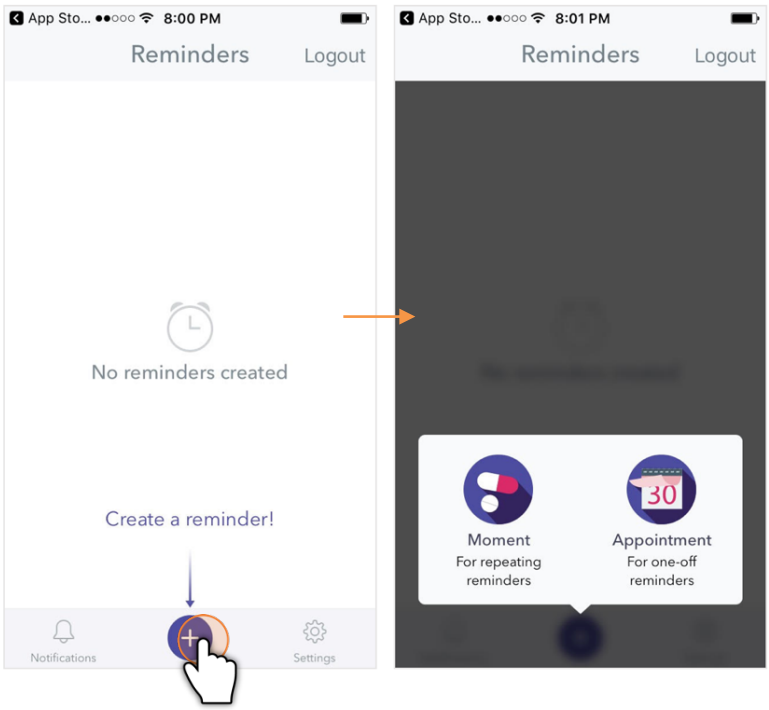

Figure 7: Transition into *Nudgu Reminders'* "Create a reminder" pop-up modal (*Nudgu Reminders*, 2016). Hand and orange markings are overlaid for demonstrative purpose.

The user has the ability to create a "moment: for repeating reminders" or an "appointment: for one-off reminders." While this verbiage provides immense clarity, the pictorial representations above the text lack a level of specificity necessary for a YOD user base, particularly for the repeating reminder category. Rather than unmistakably evoking the pictorial equivalent of the presented word-based descriptors, the "repeating reminder" icon of two medicinal pills provides merely a representations of a single possibility of that path. Given that many YOD individuals struggle with recognizing abstracted images and/or concepts that require higher order reasoning (Koedam et al., 2010; Barry Reisberg, 1988), the abstract nature of the icon-to-text pairing could lead to possible confusion. Deciphering the somewhat obscured intention of the icon would likely prove to be difficult. Without reading the accompanying text, many individuals would likely take the icon at face value, perceiving the path to be solely for medications, thereby reducing the applications facility to assist in other non-medicinal repetitive tasks. Moreover, the flat, no-border design of the two buttons could impede the clear visual

indicator that these are clickable buttons (Weinschenk, 2011, p. 17), presenting the opportunity for users to become stranded at the application's home screen, unsure of what action to perform next.

Whether recording a "moment" or an "appointment," successful selection of either pathway forward lays out the reminder-entry form in the same manner (see figure 8), establishing a sense of familiarity for users navigating between the two form periodically for task input needs. The screen is uncluttered, facilitating focused on-screen attention to each element. The removal of extraneous elements is especially beneficial for the YOD population whose ability to selectively attend to salient environmental stimuli degrades over time (Koedam et al., 2010). Only four form fields present: the title, reminder time, recipient, and record audio reminder button. The entry mechanisms are identical between the "moment" and "appointment" forms, aside from the time-entry field that differs slightly to accommodate for a single or repeated reminder.

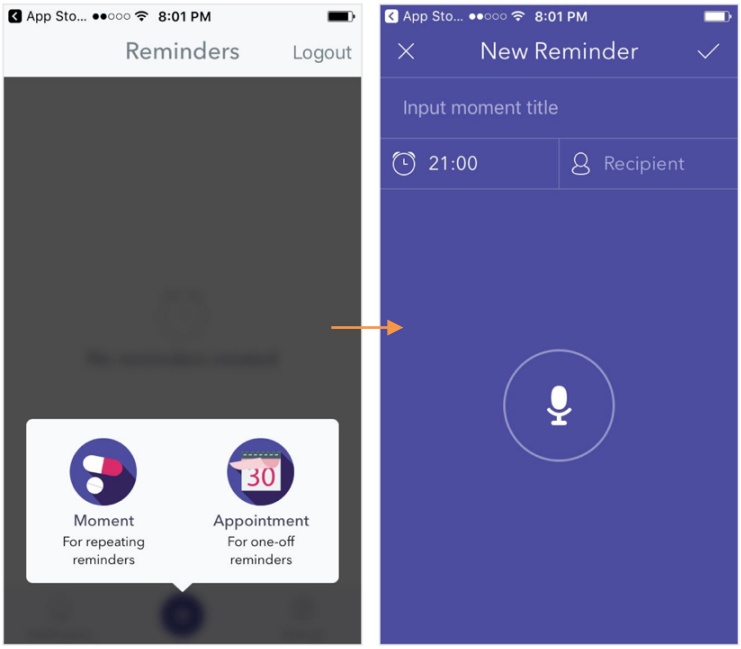

Figure 8: Transition into *Nudgu Reminders'* "New reminder" entry screen (*Nudgu Reminders*, 2016). Orange arrow is overlaid for a demonstrative purpose.

Adding a New Reminder

Taking up three quarters of the screen's real estate, *Nudgu* places its primary emphasis on the tool's main attraction, the audio record feature. Indicated solely by a microphone icon surrounded by a thin-outlined circle, the record button's functionality relies strongly on user understanding of the image as well as general comfort with technological experimentation to uncover the functionality of this unique audio-recorder presentation. While reasonable for the application's intended user base of young-to-middle aged caregivers, these characteristics would prove to be challenging to those early-onset AD patients experiencing pronounced struggles with deciphering the intention behind symbolic representations (Koedam et al., 2010; Barry Reisberg, 1988). With the understanding of clicking the microphone symbol to begin recording lost, YOD users would be left without a means of utilizing the application's primary data entry mechanism. Unable to progress beyond the first data entry screen, the entire tool would provide no further use to a struggling user base.

Upon clicking on the microphone, the icon transforms into a square 'stop' icon (see Figure 9). Concurrently, a bright white stroke snakes its way clockwise around the thin surrounding circle, indicating the passage of time throughout the ongoing recording process. Clicking on the stop button halts the recording. Similarly, to the initiation of the recording session, the inability for YOD patients to discern functionality upon first use could serve as an impediment to a positive user experience. By utilizing a more familiar, industry-standard audio recording convention, users with YOD would be better able to rely on his/her well-practiced skills garnered through years of smartphone usage (Weinschenk, 2011, p. 99). With reduced need to consciously attend to the discernment of intended audio recording functionality, more mental capacity can be instead devoted to more imperative tasks, such as successfully recalling the intended message to record.

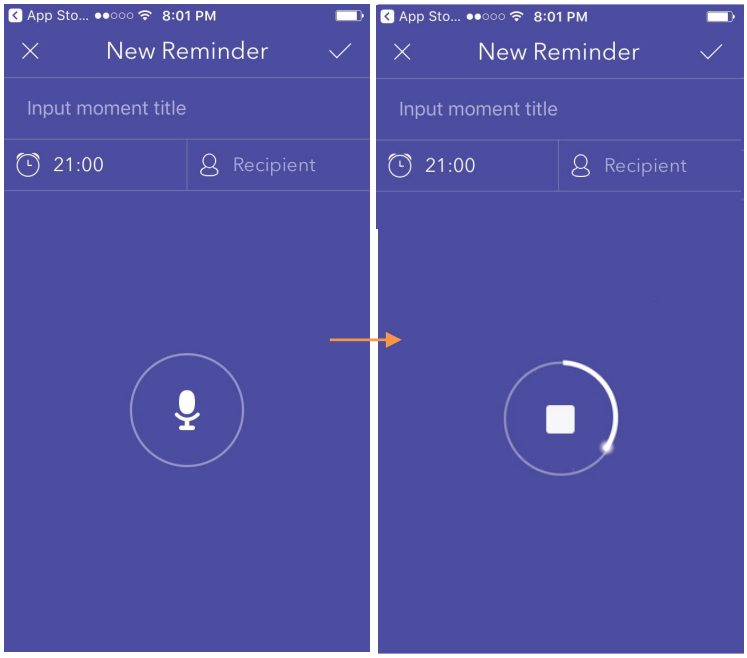

Figure 9. Nudgu Reminder's transition between starting and stopping audio input (*Nudgu Reminders*, 2016). Clicking on record button begins audio intake and transforms the microphone 'record' icon into the square 'stop' icon. Orange arrow overlaid for demonstrative purpose.

Three additional fields are present in the upper quarter of the screen throughout the audio recording process: the title, reminder time, and intended recipient. Each respective input area is designed to be as consistent as possible, utilizing familiar industry-standard input methods that align with smartphone-savvy user's expectations. This set-up would benefit working-aged adults with AD, as familiarity and consistency acts as a strong comforting force that consequentially assist memory (Hodges et al., 2015) especially necessary during the initial reminder creation process. *Nudgu* further utilizes familiarity by utilizing user-entered information stored in the user's phone contacts (see Figure 10). The ability to easily rely on previously stored information within the application provides users with familiar names, often accompanied by photographic representations. This would prove to be extremely assistive to the unique complexities of the YOD population who, at times, struggles to put names to faces (Barry Reisberg, 1988). Providing a means for users to utilize this previously stored data expands the utility of already established

friend/family profiles that can be in turn utilized within the application for memory aide purposes.

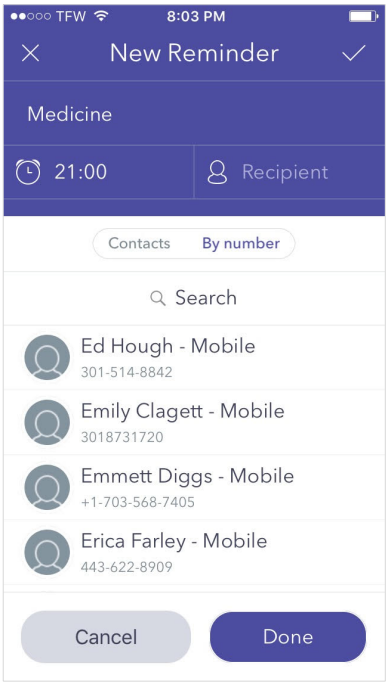

Figure 10. Nudgu Reminders use of phones stored contact list when attempting to add recipients to the reminder (*Nudgu Reminders*, 2016).

Throughout the input process, however, the lack of visual ties between the field in the upper portion of the screen and the input component in the lower portion of the screen could prove to be disorienting for members of the YOD community. The executive functioning necessary to accurately connect the intertwined relationship between these two visually dissociated sections is increasingly impaired during the disease progression (Bonder & Bello-Haas, 2009; Crutch et al., 2012). Additionally, YOD individuals are prone to mistakenly skip over information or revisit it multiple times (Crutch et al., 2012; dementiaresearch, 2010). A stronger tie between the input field and entry component could benefit forgetful users by providing a visual reminder of the field the user is actively operating upon, thereby increasing progress clarity and reducing accidental errors.

Receiving Reminders and Marking Task Completion

Upon completing the four fields and clicking 'Done', the recorded audio will automatically be sent to the landline home phone of the specified loved one at the designated time or time interval. Given the application's reliance on the landline phone for message delivery, there is no established mechanism for the message recipient to relay that the message was received and understood, or that the requested task was completed. As such, the recipient must receive and respond to the audio message without the need for persistent reminders.

Application to the Proposed Tool

While this entire system is geared towards forgetful independent older adults solely relying on landline phones, the previously mentioned features of this application that could be effectively tailored towards younger generations of AD individuals in a mobile setting. A similar streamlined interface with voice-based entry could provide middle-aged adults familiar with mobile phone usage with the ability to utilize voice-based reminders as a means of quickly inputting reminders into the phone. By running the recordings through a speech-to-text parser, these audio messages could then be repeated back at a specific time or time interval in an audible and/or written format. This would in turn provide the capability for YOD individuals to utilize multiple modalities to ingest the reminder information. In addition, consolidating forms to their most basic elements would provide users with an un-cluttered layout that reduces stress, increases focus, and enhances productivity. By applying these key features within the proposed *Noted!* application, those with YOD could maintain a sense of much valued autonomy and self-reliance by having a dependable, non-obtrusive means of self-reminding.

Round Health

Deviating slightly from the trend of producing a generalized reminder application, several development firms have dedicated their efforts towards the production of mobile applications specified towards a specific genre of reminders—medication regiments. Circadian Design, Inc. (2017) is one such firm to specifically design and develop a free mobile application, Round Health, to allow its users to view his/her medications, set

schedules with customizable persistent reminders, define dosage amounts, and request refill notices when he/she is running low. Given the application's sole focus on medication reminders, users are immediately ushered into making a medication related-entry upon first entering the application.

Adding a New Reminder

The process of adding scheduled medicines and/or vitamins in *Round Health*'s set-up includes two steps, each of which has three components. Step one consists of naming the medicine, defining the dose strength, and stating whether the medication will be taken as needed or on scheduled intervals. In this first step, two of the three components allow the users to safely stay within the confines of the screen real estate. Predictive type-ahead allows users to quickly find the intended medication with as few characters as possible typed in the phone's keyboard entry system (see *Figure 11*) and the 'how many doses taken' toggle quickly flips at a single touch.

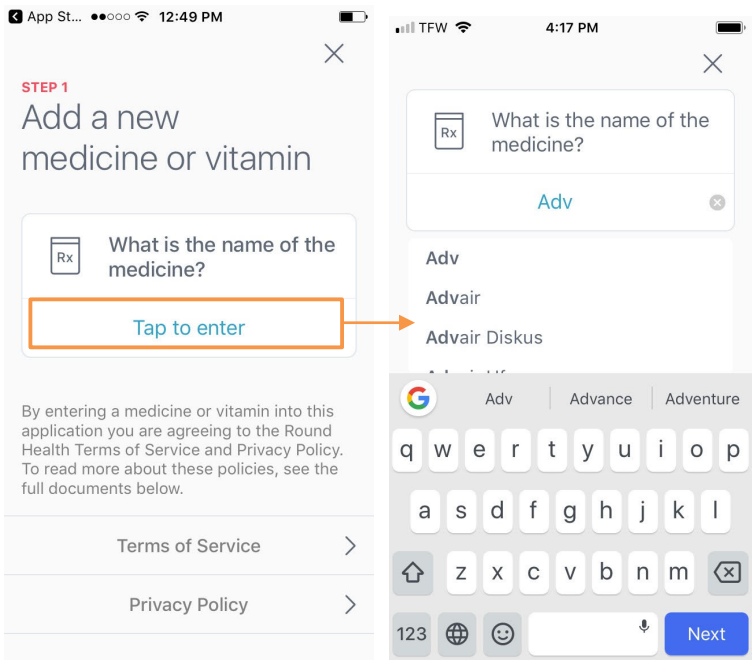

Figure 11. Round Health's medication name form field entry (Circadian Design, Inc., 2017). Predictive type ahead limits typing and allows quick recognition. Orange markings are overlaid for demonstrative purpose.

The process of defining dosage strength is unique in that it transitions users to a separate accompanying screen to input this additional information (see *Figure 12*). This divergence from the clearly labeled 'step one' screen exposes opportunity for possible confusion. Presented with only a sampling of dosage amounts, a young person struggling with AD would likely struggle to efficiently recall the associated medication found on the previous screen. Given the lacking provision of context, the effectiveness of accurate dosage strength selection is likely to be greatly reduced, causing users to submit incorrect information or forgo entering this information entirely. This is extremely detrimental as reduced accuracy in the reminder creation stages has the possibly of causing a life threatening mistake. By simply repeating the medication chosen in the previous step, a great amount of confusion could be avoided.

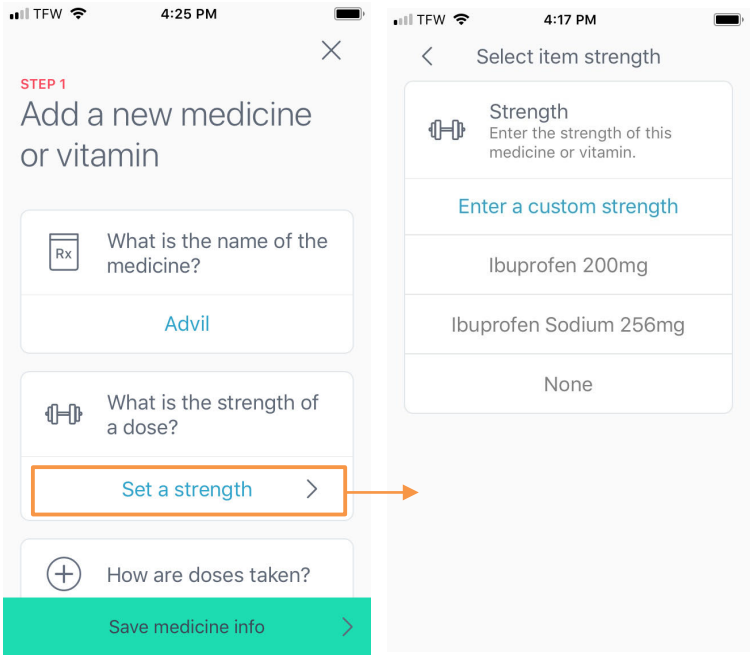

Figure 12. Round Health's dosage strength form field entry (Circadian Design, Inc., 2017). Orange arrow and rectangular outline is overlaid for demonstrative purpose.

In step two, all three form fields temporarily redirect the users to a stand-alone entry screen. A bright sea-foam green color is strategically placed in an otherwise monotone setting as a means of grabbing and/or transitioning the user's attention

(Weinschenk, 2011). While overlaid pop-up modals are used for defining frequency and dosage amount, upon clicking into the 'dosage timing' field, a separate screen with two-step functionality slides in from the right (see *Image 13*). Users are presented with a hollow circle with a thick multi-colored outer stroke representing a single day.

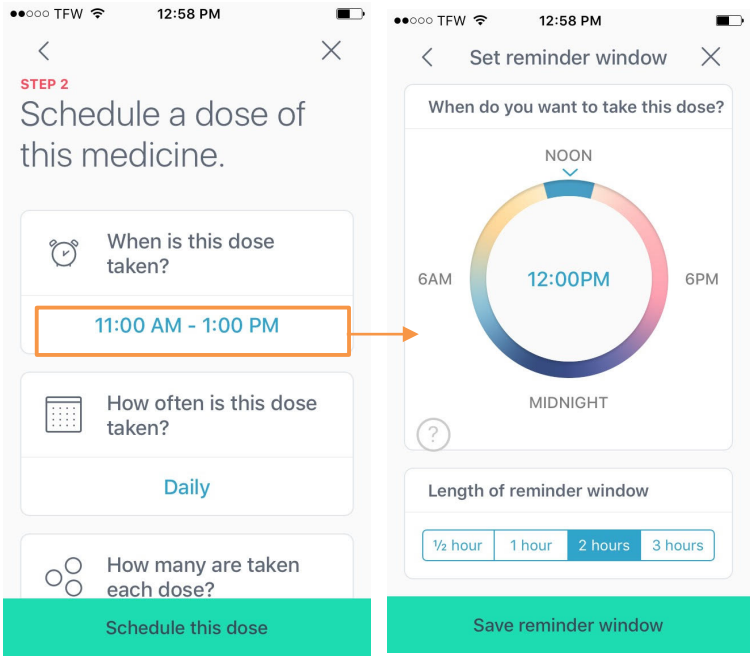

Figure 13. Round Health's transition into dosage scheduler time-picker component (Circadian Design, Inc., 2017). Orange arrow and rectangular outline is overlaid for demonstrative purpose.

While exquisite in appearance, the distinctive functionality of this time-picker component is not intuitive. Diverging from patterns seen in other commonly used applications' time-based selection methods, this system instead opts to move a blue wedge around the wheel to delineate the intended dosage window. The size of this blue facet is based on the user's requested reminder window indicated via a toggle-button selection below. While beautifully presented, this feature would most likely be cumbersome for a YOD patient to clearly understand as it differs greatly from typical input methods. Largely unable to effectively build off of long-term pre-established mental models garnered from industry standards, young dementia patients would likely experience an almost insurmountable learning curve that far exceeds that of the average

adult given deficiencies in working memory (B. Reisberg et al., 1982). Upon successful completion of the step two form fields, the user clicks the bright sea-foam green ‘schedule this dose' button to officially add the medication to application.

Receiving Reminders

After properly establishing the desired medical routines and returning to daily activities outside of the smartphone, users are eventually reacquainted with the application’s home screen. Similar to the *It’s Done* application, phone banner-based notifications for Round Health do not automatically persist when the application is closed. This is an unfortunate feature. The application places a small red circle with a notification count in the upper right-hand corner of the application icon, indicating that the closed application has notifications awaiting review. This feature could be easily overlooked by YOD individuals who readily struggle to decipher abstract concepts such as a red dot indicating an imperative reminder. While a less conceptual pictographic indicator could greatly improve comprehension, the implementation of persistent text-based reminders devoid of abstraction would likely serve as the best means of improvement for YOD users.

If the application remains open in the background, a series of evenly spaced reminders persist within the established ‘reminder window,’ urging the user to take action. The first reminder occurs at the first minute of the established time window, sending two strong consecutive ‘ting’s’ and a notice– “time to take your medicine”—to the user’s phone. If ignored, a second message with the same accompanying sound effect will appear within the next five minutes. If ignored, this second message will persist throughout the reminder window to ensure proper action is taken. The persistence of these reminders is instrumental in facilitating a level of trust between the user and the mobile application. Confidence in the application’s successful provision of medicine reminders is imperative for the application’s continued usage.

Marking Task Completion

After clicking on a received reminder, users are transported to the application’s ‘today’ page. The central button acts as the application’s homepage, presenting a view of

the current day with small blue callouts within the circular “clock” to indicate the medication windows (see Figure 14). While consistent in appearance to the time-picker feature found in the form-based medicine entry screens, this feature presents the same learning curve difficulties, making the page aesthetically pleasing but much more cognitively-taxing to decipher. If the user was able to successfully uncover the designers’ intention in the prior use-case, he/she would be remiss to discover that the intention and functionality of this version differ. Rather than using touch-and-drag to set wedges in their proper placements inside the colored wheel, the user has to click the hollow center of the circle to mark the task as done. Faint text reading ‘tap to take’ resides in the center of the circle in an attempt to inform the user’s actions.

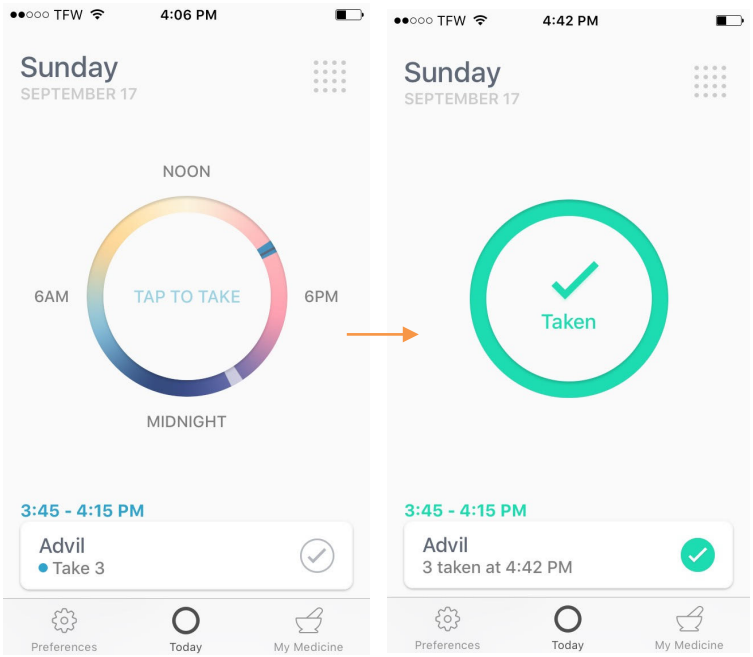

Figure 14. Steps for task completion on *Round Health*’s homepage (Circadian Design, Inc., 2017). Orange arrow and rectangular outline is overlaid for demonstrative purpose.

Upon properly indicating task completion, the colorful wheel transitions to a solid mint-green color and a similarly colored check mark with ‘taken’ written below appears in the center. Additionally, a solid mint-green circle with an included white checkmark graces the right-hand side of the medication reminder details below, effectively tying the

action above to the named event below. Aside from this, no clear prior indication is given on what medication the user is attesting to have successfully taken. More successful association between these two visualizations could properly support understanding of the provided graphical representations. Given that the human brain tends to associate items positioned closer together as coupled (Weinschenk, 2011, p. 21), accommodation could be made by placing the elements in closer proximity to one another.

With the entire task completion marking system revolving around this non-standard system, it is likely that few successful and/or accurate markings will be made, resulting in perpetual reminders that, in the user's mind, have no way of being turned off. The resulting frustration would likely lead to insurmountable negativity that would lead the user away from further application usage. As such, the usage of the circle visualization as a means of marking task completion should likely also be avoided. Similar to its form-based counterpart, substitution of this non-traditional task completion system with a more familiar standard would greatly aide YOD individuals in effective utilization of more automated processes achieved through long-term practice in other mobile applications.

Syncing Capabilities

One of the most unique features that this product offers is its ability to sync with other assistive technologies as a means of automating the experience of receiving dosage reminders. The *Round Bottle* is a technologically equipped medicine bottle designed to wirelessly log medicine consumption (see *Figure 15*) (Circadian Design, Inc., 2017).

Figure 15. Round Health's medicine bottle (Circadian Design, Inc., 2017).

The bottle's child-resistant cap houses Bluetooth capabilities for wirelessly linking to the *Round Health* smartphone application and an accelerometer to track when the cap is being removed from the pill bottle's base, assuming that in doing so the patient has successfully taken the required medicine. Users equipped with *Round Bottle* can forgo the manual 'tap to take' feature on the phone. Receiving the application's smartphone reminder and opening up the associated pill bottle is the only action needed to mark effective task completion. This functionality provides immeasurable benefit for YOD individuals, providing a persistent and automated means of tracking pill consumption while allowing the user to expend minimal mental effort.

In addition to receiving phone-based notices via *Round Health*, the outer edge of the pillbox cap begins to glow when it is time to take the medication, serving as another visual reminder if the application-based reminders fall short. Refill capabilities are also facilitated through this device, allowing a quick press and hold of the button on the cap to order another smart bottle with pills in the mail. Additional application features include facilitating caretaker alerts and notices if the bottle is not opened for an extended period of time, a feature that would be extremely beneficial for the YOD community. This inclusion ensures that imperative medical needs are met in the event that a YOD user accidently ignores a reminder notification.

Application to the Proposed Tool

The *Round Health* pill-bottle syncing suggests that there is a breadth of opportunity for assistive devices that can automatically pair with an application to provide forgetful individuals with a more automated experience that requires less cognitive strain. In turn, this frees up mental resources to attend to other important matters, providing YOD users with positive feelings of self-reliance and normalcy. Even so, this suite of technologies still has room for improvement. For those suffering from early-onset AD, the reality of having to keep track of multiple pill bottles may be distressing. Many individuals with this disease take multiple medications aimed to combat the varying symptoms, and as a result are more likely to rely on a week-based pill box to keep everything in a single place. This is something that the *Round* technology

does not currently support. Additionally, no global positioning system is incorporated into the smart pill-box to facilitate ease of finding a misplaced bottle upon receiving the reminder via *Round Health.* With frequent visuospatial deficiencies in the YOD population, geolocation would prove highly beneficial.

While remembering to take prescribed medications is an area of tremendous concern for YOD patients and his/her caretakers given its ability to reduce the severity of symptoms and slow overall disease progression, extending these more automated features beyond medication-only solutions could better support multiple aspects of AD patient's lives. For example, allowing an assistive application to automatically sync to an individual's stove by accommodating inputs from accelerometers placed in stove knobs could permit automatically sent reminders to an associated application, warning the user that the burner has been left on for over a half hour and confirming that this was intentional. Features such as these could properly support early onset AD patients, making them feel as though they are independent but also having nonjudgmental outside support. These outcomes are imperative for facilitating a positive user experience and a valued sense of independence.

Chapter 4: Proposed Application Heuristics

Using the knowledge gained through in-depth research and analysis of current technological solutions, the following heuristics were compiled be utilized throughout the development of the proposed assistive YOD application, hereby referred to as *Noted!*:

- **Engage multiple modalities to ease cognitive burden and keep users engaged |** By utilizing speech-to-text within the mobile application, an individual's auditory task input can be efficiently captured and automatically transformed into a written record. This provides the user with the opportunity to engage tasks in two different ways, either audibly via listening to his/her replayed audio message or visually via the text-based format (Hodges, McKinnon, Kelso, Mioshi, & Piguet, 2015, p. 10). In this way, comprehension can be reinforced and auditory time-based comprehension stressors eased. Additionally, the usage of multiple modalities would greatly enhance the transfer of information into cognitive storage mechanisms by utilizing complementing processes to focus the user's attention on the primary goal of completing the task input process (Kohl, 2015).
- **Break content into small chunks to increase information retention and reduce information overload |** By effectively utilizing a combination of chunking and progressive disclosure, the mobile application can help compensate for the user's attentional deficits that negatively impair the ability to successfully process new information. Facilitating shifts in attention via a provision of small, incremental steps, screen-based distraction can be reduced and periodic breaks to rejuvenate can be instilled into the workflow.
- **Keep written language clear and simple** | Consistent with WCAG 2.0's accessibility guidelines (W3C, 2012), all included text should be kept at a reading level consistent with a secondary education level. With a section of the user base experiencing a developmental age of twelve years old, this is especially important. Unfamiliar terminology relies on cognitively taxing cognitive decoding methods that deplete already scare short-term memory resources and greatly

hinder the user's capacity to comprehend the presented material (Johnson, 2014, p. 330). As such, textual items should be written in a concrete and tangible manner, devoid of metaphors, acronyms, or slang (Hodges et al., 2015, p. 12; W3C, 2012) that can confuse the user.

- **Place application features in accustomed and logical places to support user's expectations** | By strategically placing text and form-based elements in familiar locations experienced within commonly used mobile applications, automatic scanning tendencies based developed expectations will facilitate a more positive user experience (Weinschenk, 2011, p. 13). Human being's natural inclination is to reserve energy, attention and short-term memory for only the most important of tasks (Johnson, 2014, p. 243). Faced with disease related impairments to once-menial, individuals with YOD are likely less amenable than their non-impaired counterparts to explore less familiar paths that threaten to strain their ever-shrinking capacity for energy-saving automatic processing. By remaining consistent with user mental models, a sense of familiarity and routine can be properly incorporated and maintained, conserving effortful working memory and energy for successful task completion (Kohl, 2015).
- **Ensure actionable items clearly indicate their intended functionality** | Items such as buttons should have clear affordances that cue the user into correctly interpreting what the object is as well as its intended interaction (Weinschenk, 2011, p. 15). Similar to buttons in the physical world, a digital button with a defined container and an outer-edge shadow properly hints at its ability to be activated by pressing the object inward. Given the inability of a smartphone to relay affordance cues via hover, extra attention should be given to ensuring that items look clickable at all times. In doing so, users' perception of the available application features and functionality is properly facilitated.
- **Make actionable items large to reduce motor load** | The natural tendency for human beings be fairly imprecise at making accurate clicks should be mitigated. When a user perceives an intended click location, his/her hand naturally

accelerates with increasing speed towards the target without much control prior to the individual's hand-eye feedback loop initiating (Fitts, 1992). This process often leads to inaccurate clicks of varying severity, the gravity of which increases tremendously when items are small or closely placed to other actionable objects (Weinschenk, 2011, p. 66). For YOD patient's struggling with diminished hand-eye coordination, the degree of click inaccuracy would likely exceed that of similarly-aged peers. As such, the importance of ensuring that targets are accommodate a larger click radius is even more imperative for ensuring that YOD users are able to complete his/her intended actions.

- **Enable error correction |** Accommodating revisions to all initial verbal task inputs ensures the user correctly demarcates true intentions if words initially fail. Amidst stressful life circumstances and likely surrounded by a host of environmental distractions during smartphone usage, the likelihood of user error is naturally high (Weinschenk, 2011, p. 190). Provision of user error correction post initial data entry establishes a positive repertoire with the user base, relaying that initial stress associated with completing a reminder entry mistake-free is unnecessary. This positive association will only further enhance user's perceptions of the application. Additionally, accommodation of modification of system-provided speech-to-text translation upon completion of spoken task entry, ensures that machine learning systems are properly informed of user intention to better facilitate the proper response in the future.
- **Persist reminders to accommodate forgetfulness** | By relaying periodic audible and visible push notifications, a user has multiple opportunities to forget about a task but also be subsequently reminded. Ideally notifications should be interactive to accommodate a quick click to 'mark as complete' or 'snooze' for a set period of time, without the need to return to the application itself to mark completion. This accommodates expedient entry directly into the system with a single click.
- **Support entity extraction on task input to reduce typing** | By automatically extracting properties from verbal task entry such as due date and time, an

individual will have less to manually enter in form fields. This in turn speeds up the input process, relieving individuals of memory stressors more efficiently (Johnson, 2014). Utilizing perceptual support garnered through the previously entered tasking alleviates cognitively taxing recall methods otherwise necessary to complete a series of form elements.

- **Enrich names to phone contact information** | When possible, spoken or manually input names should be enriched with the information stored in the phone's contacts. The timing and coordination necessary to reactivate the neural pathways necessary to recall items stored in long-term memory without perceptual support is naturally more challenging (Johnson, 2014, p. 260). Given the disease related cognitive deterioration of YOD patients, this naturally occurring challenge for the human brain is degraded even further. As such, providing quick access to associated phone numbers and profile pictures would better stimulate recognition of the intended reference in a less cognitively taxing manner. Human beings, including YOD individuals in the early stages of the disease, are particularly adept at recognizing human faces (Johnson, 2014, p. 256; Reisberg, Ferris, de Leon, & Crook, 1982; Weinschenk, 2011, p. 9). During the initial reminder creation process, the enrichment of mentioned names would ensure that users would have access to supplemental information that is likely key to effective task completion.
- **Ensure relatability and usability for the average adult** | Similar to the current mainstream infatuation with fidget spinners initially intended to assist the needs of the ADHD community, the needs of the YOD community can be best served by having specific needs met in a manner that others around them can also contribute to and participate in (Johannessen & Moller, 2011). This reduces the feeling of otherness and greatly contributes to increased quality of life (Beattie et al., 2004, p. 363).
- **Inform loved ones in the event of prolonged absence in response** | In the event that a reminder is not responded to for an extended period of time, an alert should

be automatically sent to a specified loved-one to provide final confirmation. This failsafe is particularly important for tasks such as remembering to turn off the burners or to take necessary medications. This feature would alleviate some of the emotional strain placed on caregivers struggling to properly balance the YOD individual's autonomy and safety. As such, the likelihood of increased accommodations of YOD patient independence during the early stages of AD is likely to increase. This in turn could lead to intrinsic feelings of a higher quality of life for those suffering with the disease.

Chapter 5: Methodology

The subsequent study investigated the best methods for designing the smartphone application *Noted!*, a smartphone tool aimed to service the daily-life task-management needs of young-onset individuals struggling with stages one through four of AD. Specific emphasis was placed on the means of facilitating undemanding task entry that alleviates time-based entry stressors as well as an assistive reminder/alerting output system. In an effort to meet this overarching goal, a two-part qualitative study was conducted to inform and validate the *Noted!* application prototype. Iterative modifications were made to the *Noted!* application following feedback garnered from phase one's low-fidelity paper-based prototype and phase two's high-fidelity digital prototype. These iterative adjustments were meant to properly position *Noted!* for future in-field live alpha testing with individuals struggling with YOD. The specifics of the two phases of testing will now be presented in further detail.

Phase 1: Low Fidelity Paper Prototype User Testing

Materials

Utilized materials included a moderator script (see Appendix A), user consent form (see Appendix B), user task sheet outlining the five representative user tasks (see Appendix C), and a series of deconstructed paper prototype components established based on the heuristics garnered through previous background research. The initial paper prototype prior to post-testing modification is available in Appendix D.

Procedure

Given the resource constraints of a single investigator, qualitative testing employed the predictive testing model inspired by usability scholars Jakob Nielsen and Thomas K. Landauer (1993). Their research states that approximately 31% of usability problems are discovered by a single user test, and consequently, only 15 participants are needed to effectively discover all usability concerns within a given design (Figure 1) (Nielsen & Landauer, 1993; Nielson, 2000). In accordance with this research, phase one utilized a sample size of 15.

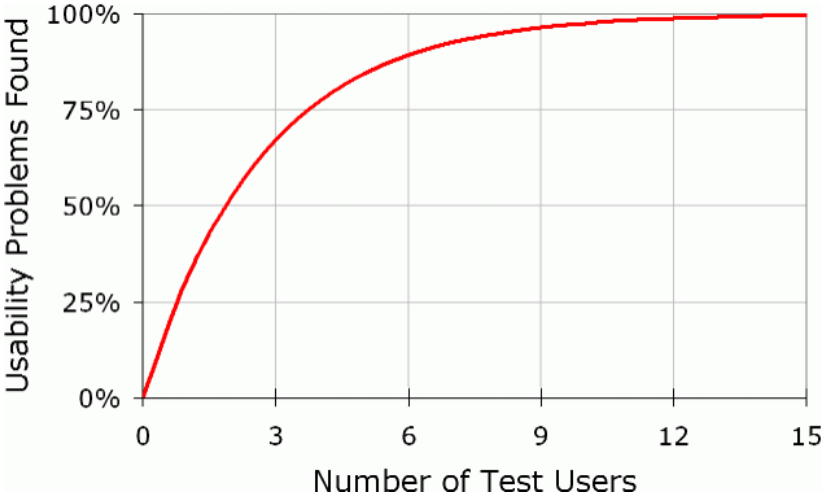

Figure 16. Percentage of usability problems found by number of test users. Plotting the 31% curve reveals that approximately 15 users need to be tested to discover all of the usability problems within a design (Nielsen & Landauer, 1993; Nielson, 2000).

According to Nielsen (2000), approximately 85% of the usability problems are discovered within the first five test sessions, 15% are discovered in a second round of five user tests, and the final 2% of remaining issues is realized while testing the third round of five users (Nielson, 2000). In an effort to iteratively design and evaluate design improvements upon receiving a breadth of representative feedback, phase one was split into three small studies of five participants each. After every five sessions, feedback garnered from written notes and audio/video recordings was used to quickly iterate on the low-fidelity prototype prior to beginning the next five testing sessions. In this way the design could be repeatedly improved and evaluated in multiple stages of phase one testing.

The 15 one-on-one user test sessions took place in a home setting in the presence of standard home-based distractions likely to be present in the application's typical usage (ex. other people moving about, television quietly playing, etc). Upon arriving at the testing location, participants were briefly informed about the study and asked to complete a consent form. This signature indicated his/her permission to 1) participate while wearing a small ear-mounted video camera that visually and audibly record his/her interactions with the paper prototype and 2) have the anonymized collected data

published. Session times varied based on the participant's level of ease performing the indicated tasks but averaged a half hour in length. Participation in the research study was completely voluntary, with participants maintaining the right to withdraw from the testing at any time.

Using a predefined script to ensure consistency across the various sessions, the moderator relayed a series of five tasks one at a time in verbal and written formats. Each task represented a key workflow that users would engage in while using the *Noted!* application: adding a reminder, editing a reminder, adding an emergency contact, responding to a reminder alert, and viewing historic data. The complete list of user tasks can be viewed in Appendix C.

While each task was only presented verbally once, the participant could reference the written task at leisure. Upon hearing each task, the participants were encouraged to interact with the presented paper components as if it was the live application, tapping the prototype with his/her finger to complete each presented task (Figure 2). As the participant interacted with the wireframes, the investigator fulfilled the role of the 'computer,' moving and layering the paper components to properly convey the application's intended behavior based on the participant's interactions.

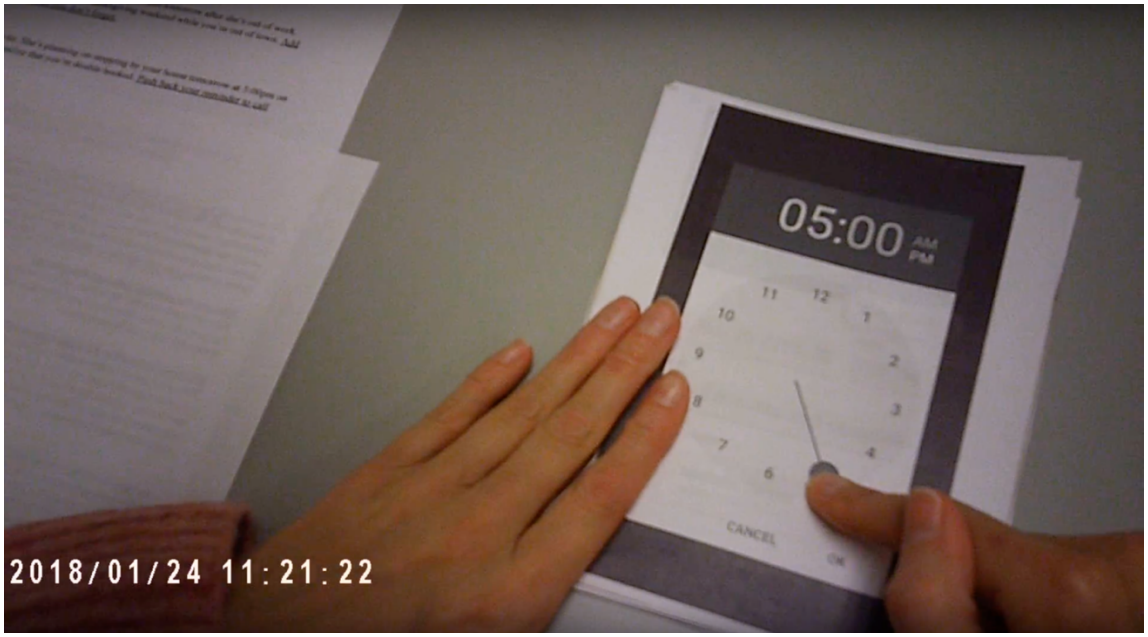

Figure 17. Participant taps the paper prototype to complete given task.

Participants were asked to indicate task completion by vocalizing the word "done" or "finished." If a user was unable to effectively execute a task without moderator assistance, the task was denoted as a failure. In these instances, the investigator walked the participant through the intended interactions in an effort to comprehensively understand the points of confusion and gather user feedback. Each round of testing concluded with a debriefing session in which each user was asked to provide his/her overarching likes, dislikes, points of confusion, etc. of the *Noted!* application. At the conclusion of the debrief, each participant was additionally asked to provide his/her age and to rate his/her level of confidence using smartphones (one being the lowest level of confidence and five being the highest) to contribute to demographic metrics.

Participants

Given the incomplete design implementation and somewhat abstracted nature of early-stage prototype interactions (factors that would impede effective participation of an individual with young-onset Alzheimer's Disease), the participants were selected based on demographic similarities to the young-onset dementia (YOD) population.

Synonymous with the age demographics associated with YOD, participant ages ranged from thirty-five (35) to sixty-five (65) years old, with the mean age of the participants leaning towards fifty (50) years old. Ten (10) women and five (5) men were asked to participate in each session, aligning to the statistic that approximately two-thirds of Americans with Alzheimer's Disease are women (Alzheimer's Association, 2016). All participants self-reported no cognitive deficiencies, placing them at a stage one equivalent level of cognitive dexterity. Additionally, all participants reported owning a smartphone and using it on a daily basis.

Phase 2: High Fidelity Digital Prototype User Testing

Materials

Utilized materials will include a moderator script (see Appendix E), user consent form (see Appendix F), user worksheet outlining the same representative tasks as phase one (see Appendix C), and a high-fidelity digital InVision prototype with click through

functionality incorporating all phase one revisions. The initial digital prototype prior to post-testing modification is available in Appendix G.

Procedure

Consistent with phase one, a total of 15 participants engaged in one-on-one test sessions in a home setting. However, unlike phase one, all participants tested the same digital prototype as opposed to being split into three smaller studies of five participants each in order to more effectively document the remaining points of weakness across the testers. After receiving the signed consent form indicating the individual's permission to participate wearing an ear-mounted video camera and have their anonymized data published, participants were encouraged to interact with a high-fidelity InVision digital prototype presented on a provided 2nd Generation Android Moto G smartphone. Participation in the research study was completely voluntary, with participants maintaining the right to withdraw from the testing at any time. The prototype, refined throughout phase one testing, allowed click-through functionality on a smartphone device to more authentically relay the application experience. Session times varied based on the participant's level of ease performing the indicated tasks but averaged fifteen minutes in length.

Using a predefined script to ensure consistency across the various sessions, the moderator relayed the series of five representative tasks consistent with phase one testing, one at a time in verbal and written formats. While each task was only presented verbally once, the participant could reference the written task at leisure. Upon hearing each task, the participants were encouraged to interact with the digital prototype as if it was the live application, tapping the phone with his/her finger to complete each presented task (Figure 3).

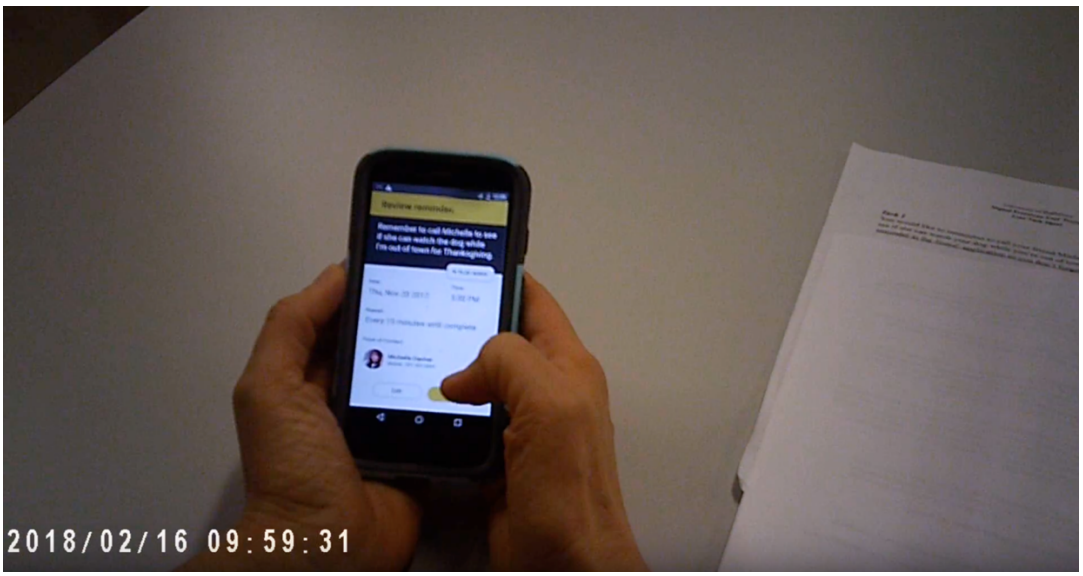

Figure 18. Participant clicks through the digital prototype to complete given task.

Participants were asked to vocalize the word "done" or "finished" upon completing a task. If a user was unable to effectively execute a task without moderator assistance, the task was denoted as a failure. In these instances, the investigator walked the participant through the intended interactions in an effort to comprehensively understand the points of confusion and gather user feedback. Consistent with phase one testing, each user test concluded with a debriefing session in which each user was asked to provide his/her overarching likes, dislikes, points of confusion, etc. of the *Noted!* application. At the conclusion of the debrief, each participant was additionally asked to provide his/her age and to rate his/her level of confidence using smartphones (one being the lowest level of confidence and five being the highest) to contribute to demographic metrics

Participants

Participant selection was consistent with phase one's approach. Ten women and five men all ranging in ages from thirty-five (35) to sixty-five (65) years old, were asked to participate in phase two of the study. All participants reported owning a smartphone and using it on a daily basis. Additionally, all participants self-reported no cognitive deficiencies, placing them at a stage one equivalent level of cognitive dexterity.

Chapter 6: Results

A total of thirty (30) individuals participated in one-on-one user test sessions either in paper format (Phase 1) or digital format (Phase 2). While the median age (53 years old) and the eldest participant age (63 years old) remained consistent between the two phases of testing, the distribution of ages notably differed (see Figure 19 below). In Phase 1, 50% of participants fell between 41 and 56.5 years old (a variance of 15.5 years) whereas in Phase 2, 50% of participants were between the ages of 44.5 and 57 years old (a variance of 12.5). Additionally, there was a five-year difference in youngest participant between the two phases. Phase 2's youngest participant was 40 years old as opposed to Phase 1's 35-year-old. Generally, a larger age variance was witnessed in the lower quartile as compared to the upper quartile within both phases, indicating a wider spread of younger participant ages.

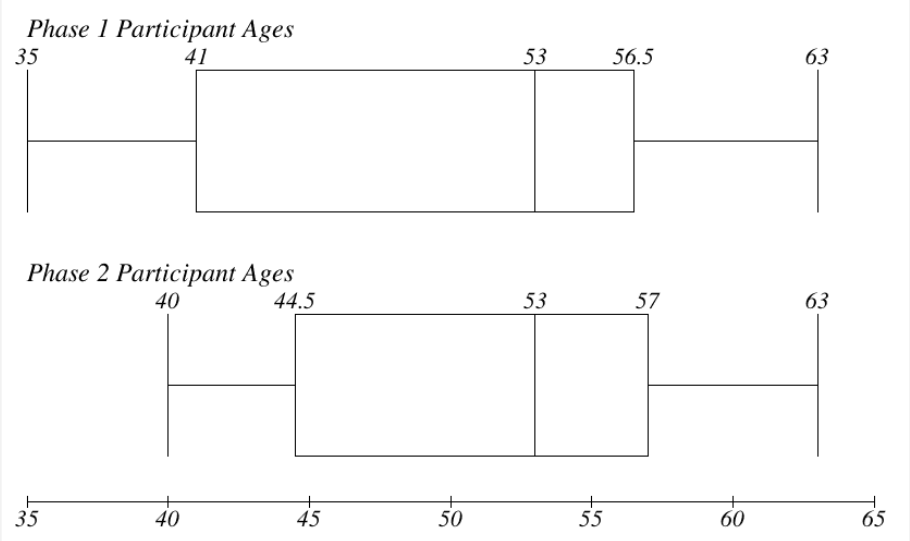

Figure 19. Comparative summary of participant ages across phased testing.

Similarly, participants' self-prescribed confidence level of smartphone usage varied between the two sets of fifteen (15) participants. As is indicated in the box-and-whisker plot below, there was a consistent range of user confidence levels between the two phases of testing. The lowest indicated confidence level was 2 and the most confident users professed a score of 5. However, the dramatic size difference between

Phase 1 and Phase 2's boxes indicate a profound difference in the middle 50% of scores. The variance of scores within Phase 1 participants differed more greatly than within Phase 2; a difference of 2 as opposed to 0.5. This indicates that on average, Phase 2 participants felt more confident using a smartphone device than Phase 1 participants.

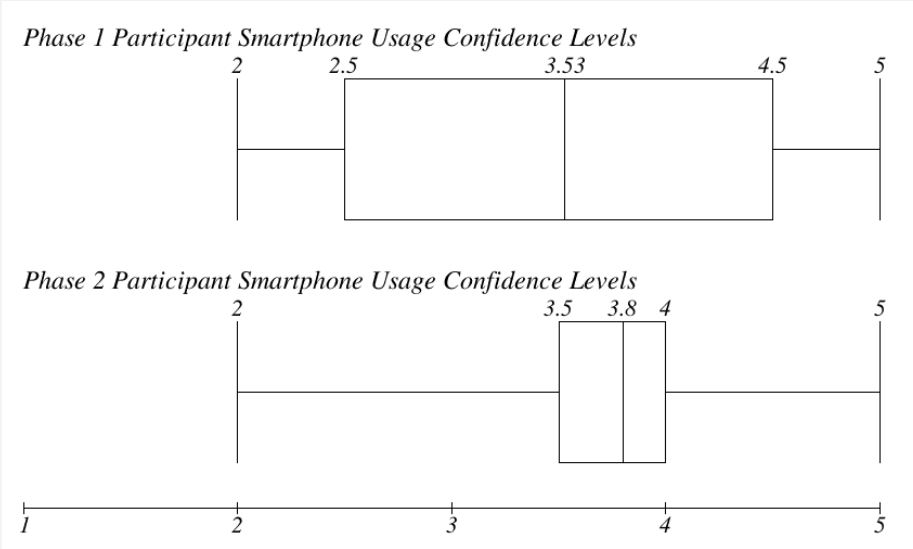

Figure 20. Comparative summary of participant smartphone usage confidence levels across phased testing.

This age and smartphone usage confidence level data was used throughout the testing to inform witnessed trends. Throughout the two phases of user testing, gathered feedback was compiled, analyzed, and utilized to iteratively improve upon the *Noted!* application.

Phase 1: Low Fidelity Paper Prototype User Testing

The various challenges and user recommendations witnessed within the three five-user sets during Phase 1 testing are discussed in detail below.

Set 1

Within the first set of five users, there was a total of 12 task successes, 11 task successes with noticeable challenges, and two task failures. Refer to Table 1 below for a complete outline of the successes and failures witnessed while testing the second set of five users.

Table 1

User 01-05 Task Success Rates

	Task 1: Add a reminder	Task 2: Edit a reminder	Task 3: Add emergency contact	Task 4: Respond to reminder	Task 5: View historic event
User 01	☐	☒	☑	☒	☑
User 02	☐	☐	☑	☑	☑
User 03	☐	☐	☑	☑	☐
User 04	☑	☐	☐	☑	☐
User 05	☑	☐	☐	☑	☑

Note. A checkmark delineates a task that was completed successfully without error. An empty square indicates a task that was completed successfully but with some degree of error. An 'x' indicates a failed task that required investigator intervention.

Task 1. While 40% of participants completed the task of adding a new reminder successfully without error, 60% of participants experienced a slight degree of difficulty, specifically on the initial audio input screen. Below are the specific challenges witnessed during phase one, set one of user testing:

- ■ ***Challenge #1: Assuming Audio Recording Doesn't Start Automatically.*** Upon being transitioned to the audio recording page, one user (U01) immediately clicked the pause button. After doing so and witnessing the "pause" button transition to "play," she quickly recognized her misinterpretation and self-corrected. She later described that she was unaware that the recording had begun automatically and was simply trying to begin her audio recording manually. Given the singleton nature of this point of confusion, this interaction was flagged as being a feature to watch in proceeding sets of testing to see if any trends developed prior to making any wireframe modifications. The initial assumption was that the use of a

functioning time ticker and sound input intensity indicator (the circle that expands and collapses around the pause button in conjunction with the user's vocal patterns), would easily alleviate this misunderstanding. As such no changes were made to the wireframes.

- ***Challenge #2: Pressing Pause to Stop.*** Two users (U02/U03) clicked the centrally located "pause" button upon completing their audio reminders, rather than clicking the smaller "done" button in the lower right. In both cases this interaction was extremely quick, almost acting as a muscle memory response to where they perceived the stop button to be. When asked about this response in the session debrief, one user mentioned that her assumption was that the done button would be in the center of the screen because that is how photos and video recording on smartphones tend to work. In order to alleviate this issue in future testing, the location of stop and pause were switched to more prominently emphasize the stop recording feature (see Figure 21). Additionally, the text "click to stop recording" was added above the stop button with an arrow pointing down to the stop button. This provided an extra means of reinforcement, especially during first time use.

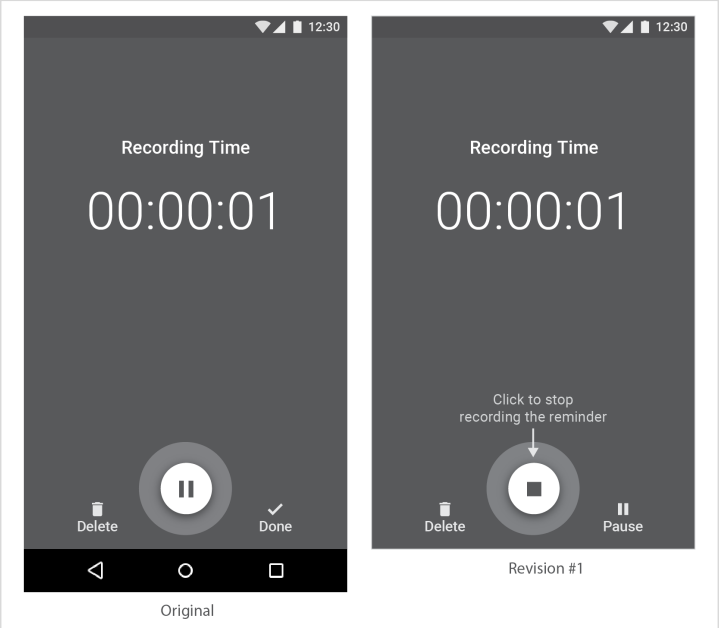

Figure 21. Phase 1 revisions to audio input screen.

Task 2. Various points of difficulty were witnessed with all five participants when attempting to edit the reminder:

- ■ ***Challenge #1: Inability to Open Individual Task Page.*** One participant (U01) struggled to effectively open their previously created task from the home screen without moderator assistance, resulting in a denoted task failure. The user did not understand the clickable nature of the homepage line items, instead clicking all items on the page that appeared to be clickable buttons (play, settings, history, and the page title) prior to laughing slightly and saying: "I don't know what else is a button to try." In an effort to correct for this issue prior to the next set of five testers, the styling of each individual task was treated as a "card" with a visible container to better imply that it was a clickable unit (see Figure 22). This revision was also incorporated into the homepage screen given its similar layout.

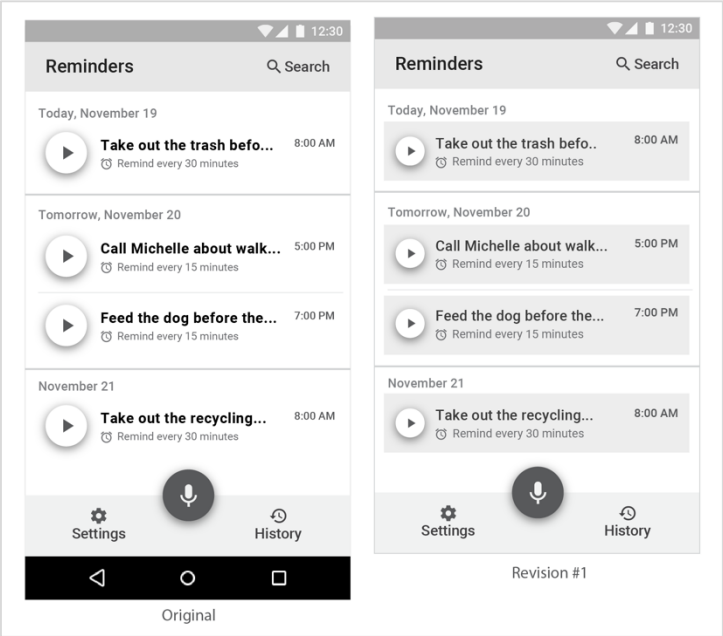

Figure 22. Phase 1 revisions to upcoming reminder homepage.

- ■ ***Challenge #2: Difficulty Locating Edit Button.*** While the remaining four out of five participants were able to effectively open the individual task page, they experienced difficulty entering into edit mode. One confused user (U02)

attempted to click the speech-to-text area on the top third of the screen, vocalizing that she assumed that it would open her phone's keyboard and allow her to edit the type. It was only after recognizing that her assumptions were disparate from the current application functionality, that she was able to locate the "edit" button located at the bottom of the task page. Three users (U03/U04/U05) clicked on the time element they intended to change, assuming that this action would allow editability. When that action did not result in the desired machine response, all three individuals located the "Edit" button at the bottom of the screen to officially enter edit mode. Aligning with one of these participant's suggestions during debrief, future functionality was revised to allow the user to enter into edit mode in either way: by tapping the form element itself or by clicking the edit button. The pink boxes overlaid on the wireframes below in Figure 23 showcase various edit mode entry points before and after phase 1 revisions were implemented.

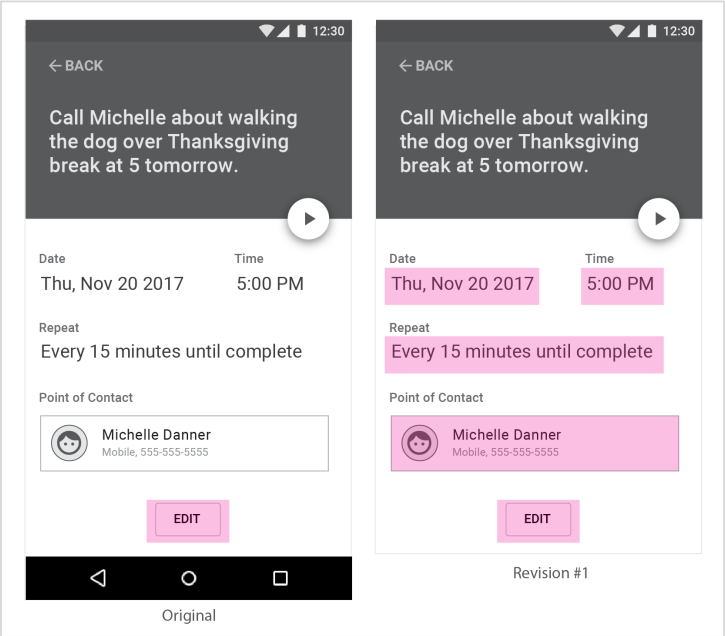

Figure 23. Phase 1 revisions to task details page. Overlaid pink markup is for demonstrative purpose only and was not present during testing.

- ***Challenge #3: Lacking Awareness of Being Within Edit Mode.*** Upon successfully entering edit mode, 60% of participants relayed confusion as to whether or not they had indeed arrived in edit mode despite the addition of a title bar. In order to facilitate an immediate recognition of the task transitioning from standard viewing to an edit mode, form field underlines were supplemented with a grey form field background (see Figure 24). In this way, users could have multiple reference points to delineate the transition into form field elements. Additionally, the done button itself was darkened to enhance its visual presence.

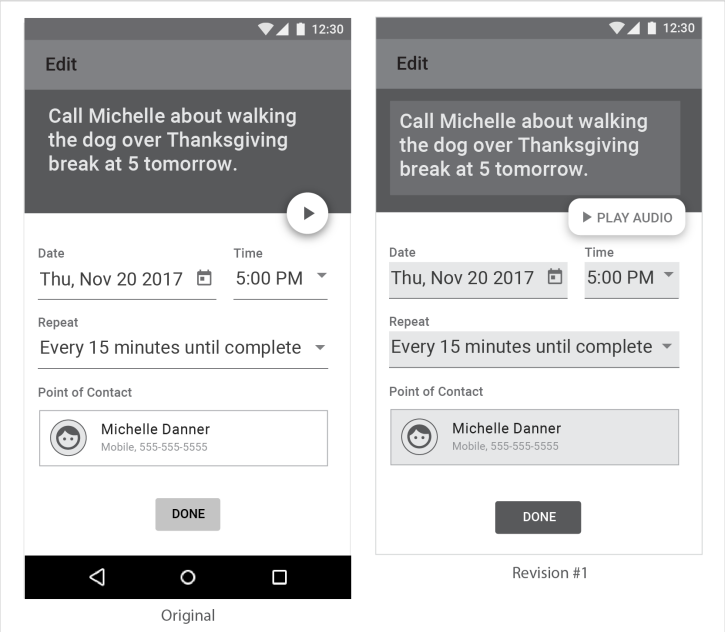

Figure 24. Phase 1 revisions to reminder in edit mode.

- ***Challenge #4: Edited Data Versus Speech-to-Text Confusion.*** Three out of five participants expressed some degree of confusion regarding the difference in information between the recently edited time form element and the speech-to-text verbiage on the upper third of the screen. These users wanted the information to change in both locations upon being edited via the form field. In response, revisions to form field elements were then represented as tied to the speech-to-text verbiage. In essence, this means that

if a time is changed in the form-field, that change is also reflected in the speech-to-text area.

- ***Challenge #5: Struggle to Return to Homepage.*** Two of the five participants had difficulty returning to the application's homepage from within the individual task page. After taking 13 seconds to evaluate the correct location to tap to return to the homepage, the final set one participant (U05) pointed to the bottom phone specific navigation bar saying: "I don't know what these are doing down here. Is this part of the phone or the app?". In fact, both users were initially drawn to the phone specific bottom navigation as a means of returning to the requested page. This visual focus on the lower section of the screen, in turn distracted focus away from the "← Back" button on the top left. In both instances, confusion regarding the functionality of the three phone navigation buttons (an unlabeled circle, square, and triangle) prevented a mis-click and prompted further exploration for the in-app back button. However, given the lower phone navigation bar was the only phone specific feature within the mockups, this bar was removed for future testing (refer to Figure 25). Instead all elements of the wireframes focused on the application itself, assuring that all functionality could be performed within the application itself. Additionally, a semi-transparent background was added to the Back button to reinforce its clickable nature.

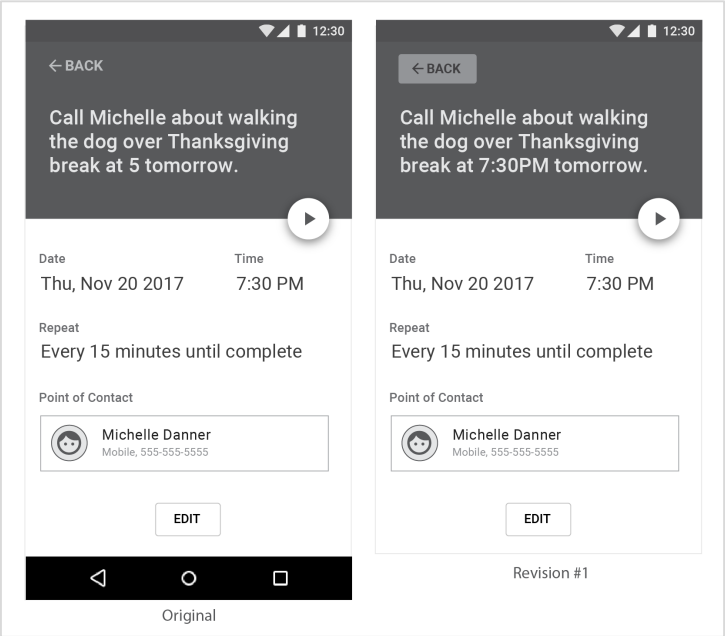

Figure 25. Phase 1 revisions to aide users' return to homepage from task page.

Task 3. While three of the first five participants completed the task without any notable challenges, two individuals experienced their own individual challenges with adding an emergency contact:

- ***Challenge #1: Lacking Intuition on Feature Placement.*** When attempting to begin task three, one user (U03) stated that, though it was not "the most intuitive place to look" she clicked the Settings button "by process of elimination." With only a single user expressing this point of confusion and without this difficulty causing an irreparable mistake, this interaction was flagged as a feature to watch closely during the next set of participant changes prior to initiating mockup revisions. No revisions were made.
- ***Challenge #2: Struggle to Return to Homepage.*** Similar to Task #2, two out of five participants struggled to return to the application's homepage from within the Settings page. One user (U04) noted that she still wanted to use the bottom phone-specific navigation to go back but had learned from the previous task that it wasn't the desired action. The other user stated that his assumption was that the left-facing arrow next to the Settings title indicated

returning to a Settings home screen. Even with this preconception he continued to click the back arrow assuming it was the only appropriate action to complete the moderator request. Similar to Task 2, the removal of the phone-specific navigation bar was done in an effort to mediate a portion of this confusion. Additionally, the placement and styling of the button was revised. The upper-left-positioned arrow next to the title was removed and a large "Done" button was added to the bottom portion of the application screen (see Figure 26). Given the layout similarities between the 'Settings' page and the 'History' page, these revisions were also incorporated within 'Settings'.

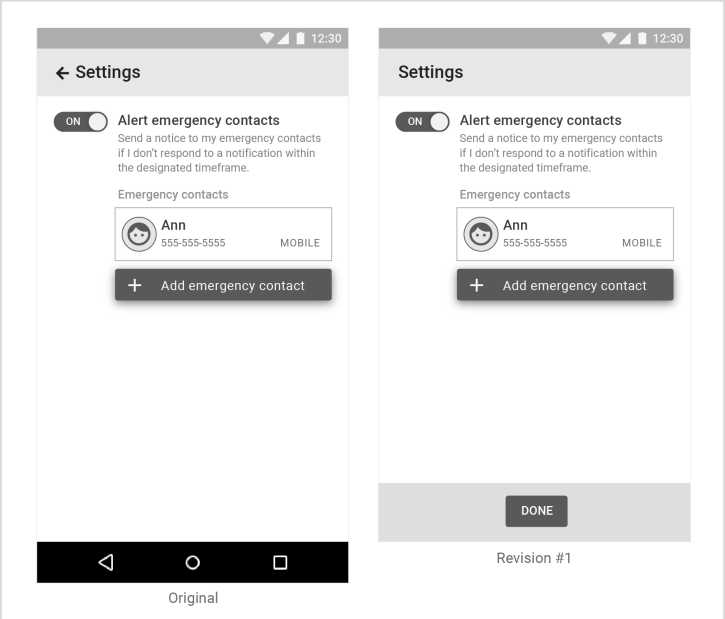

Figure 26. Phase 1 revisions to aide users' return to homepage from settings.

Task 4. Four of the five participants completed the task of successfully responding to a reminder. However, one individual experienced some difficulty when attempting to complete this task:

- ■ ***Challenge #1: Marking Completion Without Performing Task.*** One of the five participants (U01) immediately marked the task as being complete without performing the requested action. This was denoted as a task failure. Additional guidance from the investigator was necessary to remind the user that the indicated action hadn't been completed yet. This misunderstanding is likely due to a misunderstanding of the presented task. This error was flagged as an item to re-approach if additional participants encountered the same issue.

Task 5. Only one area of difficulty was witnessed during the fifth, and final task within the first set of five participants:

- ■ ***Challenge #1: Inefficient Content Scanning.*** Two users (U03/U04) appeared to have difficulty scanning the content quickly. Momentary confusion appeared to be focused on determining the sorted date order as well as differentiating between the two different times provided for each completed task (the reminder time versus the task completion time). Even despite these slight scanning difficulties, both users were able to complete the task without error. Data was insufficient in identifying the source of the momentary struggle and as such, this challenge was flagged as an item to re-approach if additional participants encountered the same issue in subsequent testing.

Debrief. In addition to noticeable difficulties witnessed during the test sessions, multiple points of kudos were extoled during the debriefing sessions, including:

- *U04:* "I'd definitely use this myself."
- *U05:* "I really like the division of upcoming tasks and completed tasks in history. A lot of applications remove the tasks completely after they're done which isn't super helpful."
- *U05:* "This [application] would be good for regular people too…I'd use it!"

Set 2

Task success rates dramatically improved during the second set of users, with a total of 19 task successes, 5 task successes with noticeable challenges, and only 1 task

failure. Refer to Table 2 below for a complete outline of the successes and failures witnessed while testing the second set of five users.

Table 2

Participant 06-10 Task Success Rates

	Task 1: Add a reminder	Task 2: Edit a reminder	Task 3: Add emergency contact	Task 4: Respond to reminder	Task 5: View historic event
User 06	☐	☐	☑	☑	☐
User 07	☑	☑	☑	☑	☑
User 08	☑	☒	☑	☑	☑
User 09	☑	☑	☑	☑	☐
User 10	☑	☑	☑	☑	☐

Note. A checkmark delineates a task that was completed successfully without error. An empty square indicates a task that was completed successfully but with some degree of error. An 'x' indicates a failed task that required investigator intervention.

Task 1. While four out of five participants successfully navigated the add a reminder task, one individual had a singular point of confusion:

- ■ ***Challenge #1: Assumption of Siri-like Audio Controls***. In the midst of vocalizing her audio task in an unstructured format, one user (U06) re-evaluated input methodology questioning out loud: "Is this like Siri?" Immediately upon reflecting on this rhetorical question, she began to rephrase her statement in a structured format similar to Siri input mechanisms, providing both her input as well as her assumptions as to the system's output. While this point of confusion still allowed her to successfully add the task by the tool's standards, her long recorded response would likely not meet her assumptions of the tool's Siri-like functionality. Instead of merely recording the responses to her self-posed questions, the full

extent of her vocalizations would be recorded from start to the click of the stop button. In an effort to avoid similar confusion, a "helpful hint" was added to the recording screen to cue the user into the applications desired input method (see Figure 27).

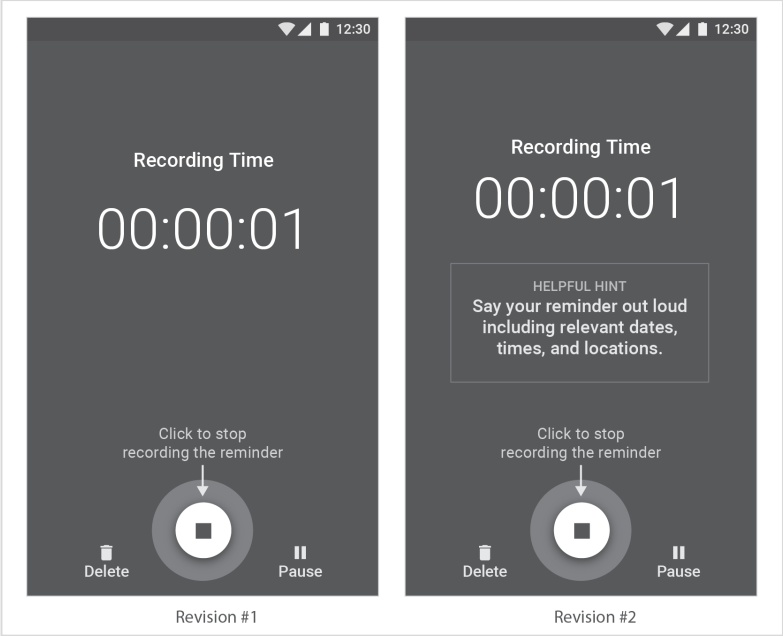

Figure 27. Phase 2 revisions to audio input screen.

One successful user recommended a way of improving the input system in the future:

- ***Recommendation #1: Provide Ability to Error Correct Speech-to-Text Early.*** Especially with the technological capabilities today, the means of providing flawless speech-to-text is not available. As such, it becomes imperative to be able to see and correct the machine's interpretation of human voice as early as possible. If Noted! is heavily relying on speech-to-text to extract information used within the multiple choice selection portion of the task entry, it is vitally important that the initial text is correct. The ability to error correct via keypad or re-record the reminder audio is key. Upon completion of the second set of testing, the mockups were revised to include a single speech-to-text translation error as well as an immediate text correction capability prior to moving into the multiple choice question task

set-up process. The new wireframe created in support of this recommendation can be seen in Figure 28 below.

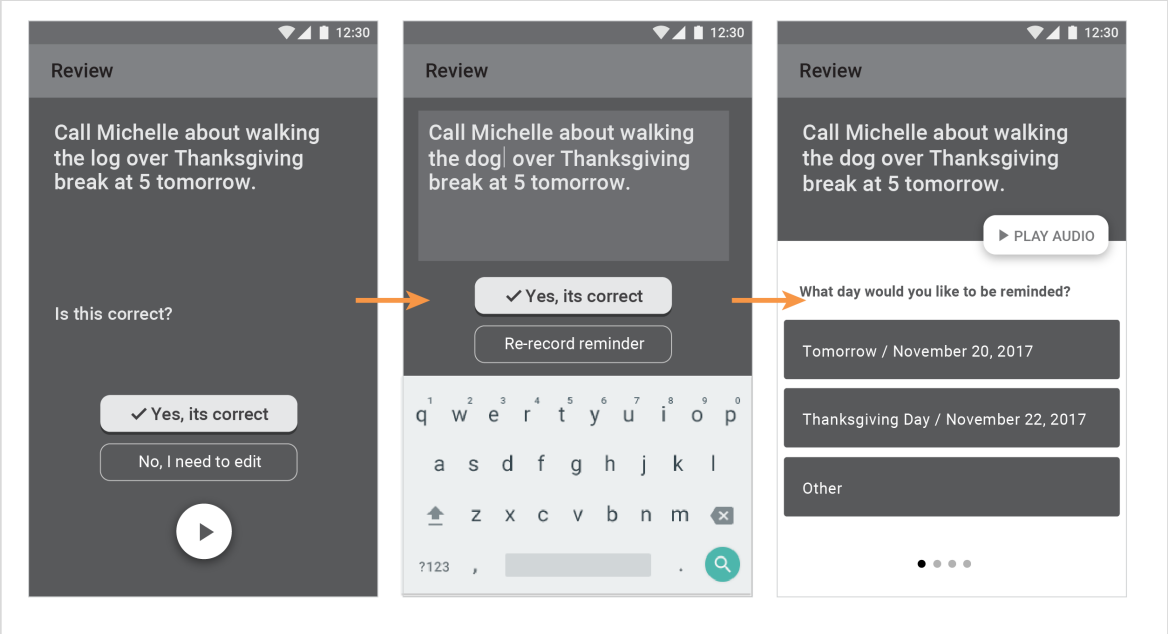

Figure 28. Phase 2 addition of immediate speech-to-text editing.

Task 2. Two points of difficulty were witnessed with two participants when attempting to edit the reminder:

- ■ ***Challenge #1: Assumption of Audio Based Editing.*** After entering into the individual task page, one user (U08) immediately began to vocalize her desired task revisions, assuming that the application would function based on verbal commands. After the system failed to function in a manner consistent with her expectations, the moderator eventually had to intervene to walk her through the intended functionality. As such this was denoted as a task failure. During her debrief session the user stated: "My instinct since you're doing it by voice is that I can do [editing] by voice too." With only a single user expressing this point of confusion, this interaction was flagged as a feature to watch closely during the next set of participant changes prior to initiating mockup revisions.

- ***Challenge #2**: **Misunderstanding of Two Step Time Set-up.*** While this point of confusion did not cause a costly mistake, the user (U06) indicated during her debriefing session that the clock time entry did not align to her initial assumption. When dragging the clock hand, she assumed that stopping between the 7 and 8 on the clock would define the time as 7:30 (reference Figure 29). Instead, dragging the hand between 7 and 8 set the hour to the 7 given it was the number closest to her finger at the time. At this point the clock reset to define the minutes. As soon as the change of the clock took place, she explained that she almost immediately understood that the time was broken into two parts, later stating that she "thought the clock thing that you did was neat. Super easy! Although at first I will admit that I didn't know…I had to think about it for a second because I hadn't seen this paradigm before." Given that this misunderstanding was limited to a single individual and did not result in any entry errors, no associated changes were made to the wireframes. The area was flagged however as a point to pay close attention to during the third set of testing.

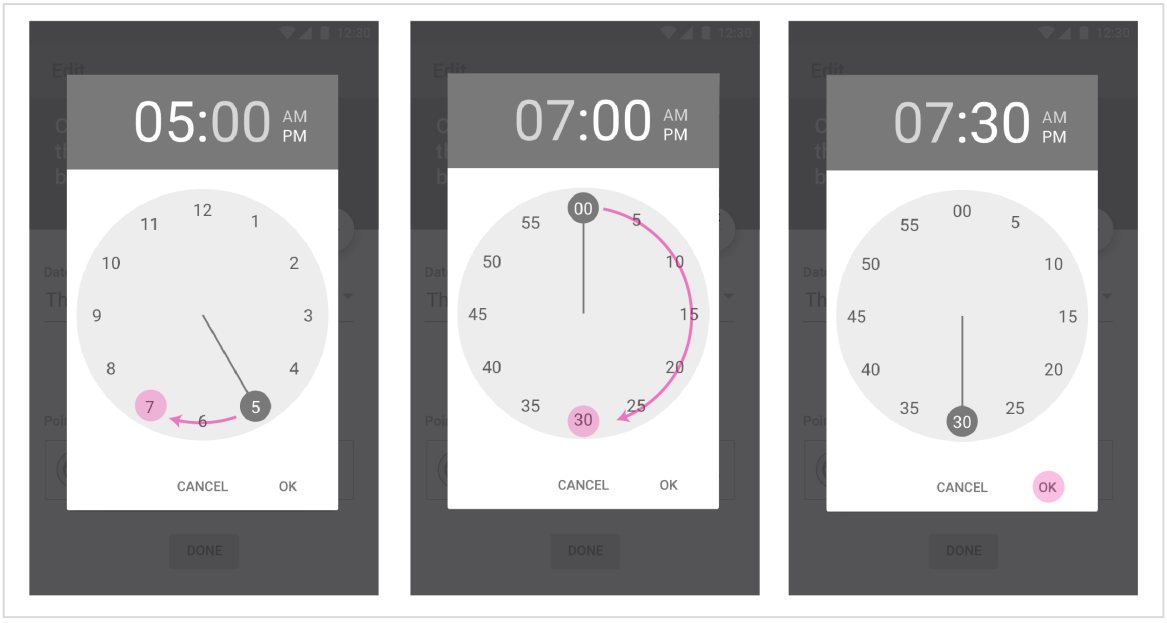

Figure 29. Phase 2 edit time screen progression. Magenta overlays are to demonstrate functionality and were not present during user testing.

- ***Challenge #3: Delayed Visibility of Back Button.*** One participant (U02) took 10 seconds to effectively locate the back button to return to the homepage. She later indicated that the term back indicated she was going back into edit mode and not home. In order to improve the button's intention, the button's terminology was changed from "Back" to "Home" (see Figure 30).

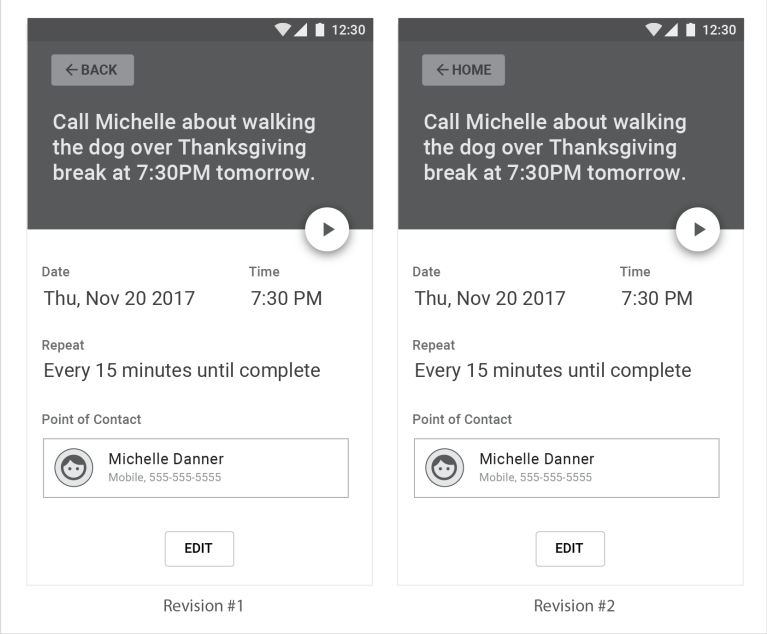

Figure 30. Phase 2 revision to task details page.

Task 3. While all five participants were able to complete the task of adding an emergency contact without difficulty, one participant had a suggestion for further improvement:

- ***Recommendation #1: Introduce Emergency Contact Concept Early.*** There is no way for a user to know that the emergency contact feature is available other than stumbling upon it in the Settings area. It would be helpful for the concept of emergency contacts to be introduced early, possibly as a part of the application on-boarding process. This could also include the ability for first time users to add an emergency contact during the application's initial set-up. If desired, this first time set up can be skipped but it would also provide a

means of informing users where to find the information in the future if they so desire. Upon completion of the second set of five users, a screen was added to the application's intro pages to accommodate this request (see Figure 31).

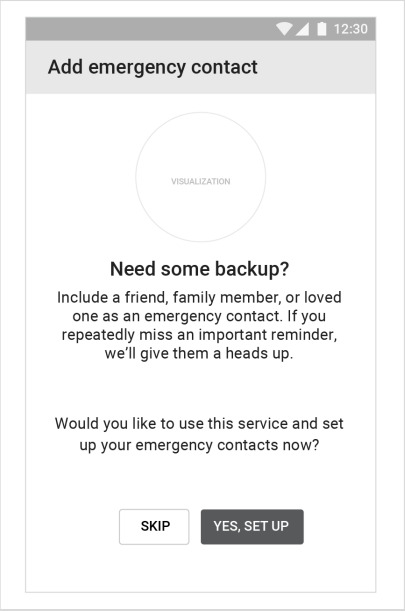

Figure 31. Phase 2 addition of early emergency contact feature awareness.

Task 4. All five participants completed the task of adding an emergency contact without visible difficulty. One participant even showcased the ease of self correction after she called her "friend" and hung up before saying anything. Recognizing her mistake, she was able to effectively use the application to re-attempt the call before claiming that task was completed.

Task 5. Three out of five participants exhibited signs of struggle with three primary aspects of the task:

- ***Challenge #1: Expectation of Viewing Historic Items on Homepage.*** When attempting to complete the task, one user (U10) vocalized: "My first instinct is that I wanted to drag down the screen for the historical data but I do see the history button so that would be my next best bet." Given that the user was able to overcome her preconceived notions quickly and was the only participant to note this possible struggle thus far, no changes were made to the

wireframe. However, this challenge was flagged for further investigation during later test sessions.

- ***Challenge #2: Misunderstanding Historic Date Sorting.*** Two users (U06/U09) did not immediately grasp that previously dismissed tasks were organized from most recently dismissed to least recently dismissed. As a result, the layout was modified to better emphasize the date as a parent to the tasks below. A container was added to encapsulate each of the children completed task elements (see figure 32). This revision gave increased emphasis to the dates. Given the similar layout on the homepage, these revisions were also made on the *Noted!* homepage in an effort to match the layout and enhance familiarity.

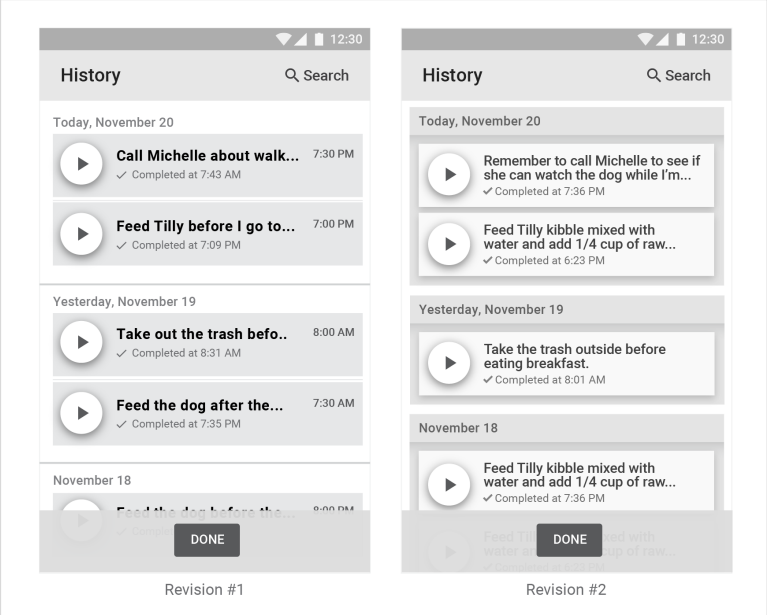

Figure 32. Phase 2 revision to the history page.

Debrief. In addition to noticeable difficulties witnessed during the test sessions, multiple points of high-level kudos were extoled during the debriefing sessions, including:

- *U06:* "Everything felt really easy, really really normal."

- *U10:* "It was straightforward. Even in the cases where I made a mis-click, I was able to recover. I knew how to recover immediately. And there are few enough things on the screen that even if I did mis-click, I'm not going to get lost."
- *U10:* "The sizing felt good. I could see everything and I could touch the things I was expecting to touch."

Set 3

Task success rates dramatically improved during the second set of users, with a total of 18 task successes, 7 task successes with noticeable challenges, and 0 task failures. Refer to Table 3 below for a complete outline of the successes and failures witnessed while testing the second set of five users.

Table 3

Participant 11-15 Task Success Rates

	Task 1: Add a reminder	Task 2: Edit a reminder	Task 3: Add emergency contact	Task 4: Respond to reminder	Task 5: View historic event
User 11	☑	☑	☑	☑	☑
User 12	☑	☐	☐	☑	☐
User 13	☑	☑	☑	☑	☑
User 14	☑	☑	☐	☑	☑
User 15	☑	☐	☐	☑	☐

Note. A checkmark delineates a task that was completed successfully without error. An empty square indicates a task that was completed successfully but with some degree of error.

Task 1. All five participants were able to complete all steps necessary to complete the add a reminder task without difficulty.

Task 2. Throughout the reminder editing task, only two participants showed evidence of slight confusion. The witnessed challenges are described below:

- ***Challenge #1: Mistakenly Clicking Play to Open a Reminder.*** Two of the five participants (U12/15) clicked on the play button next to the reminder of interest in an effort to open task details. One user (U12) verbally expressed her confusion as her action initiated an audio version of the reminder to play aloud, stating: "I know on my phone for alarms I just click on the alarm and it brings it up." She then hesitantly clicked on the reminder once again, this time clicking outside of the click radius of the play button. When the screen transitioned to the task details page she exclaimed, "Yeah, I thought that's what I clicked in the first place." In response to this misunderstanding, the play button was decidedly removed from the homepage (see Figure 33). This change simplified functionality, removing the duality in clicking and instead allowed the entire task card to be one clickable area with a single end point. The user could still access the playback of his/her recording from the individual task pages. With the extra available space, the time size was also increased to enhance visibility.

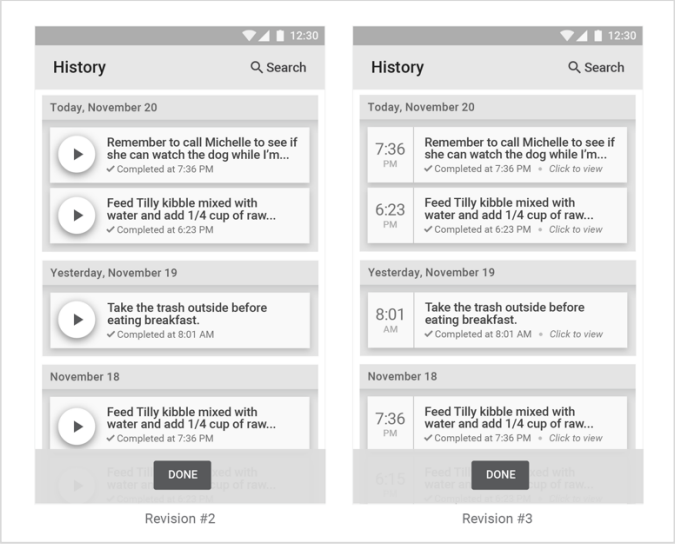

Figure 33. Phase 3 revision to upcoming reminder homepage.

- ***Challenge #2: Difficulty Opening a Reminder.*** When first attempting to complete the task, one user (U15) clicked on the settings button, the history

button, and the play button prior to clicking the reminder text as intended. In order to facilitate increased clarity on the available actions, the phrase "click to view text" was added to each task card on the homepage as a helpful reminder of its clickable nature. This revision is captured in Figure 33 shown above.

Task 3. A singular usability challenge was noted by three out of the five participants for the task of adding an emergency contact.

- ***Challenge #1: Clicking "Add Emergency Contact" Button as Means of Final Task Completion.*** After effectively and efficiently adding an emergency contact, three participants (U12/U14/U15) clicked on the "Add Emergency Contact" button a second time. Each participants' intention was to finalize their emergency contact selection. Contrary to their expectations, clicking this button would allow the addition of a second emergency contact. Since this was not the task's intention, each struggling participant was able to exit out of the "Select a Contact" page. After returning to the Settings page each participant was then able to find the Back button upon rescanning the page. In response, the "Add emergency contact" button was de-emphasized and more strongly differentiated from the "Done" button (see Figure 34).

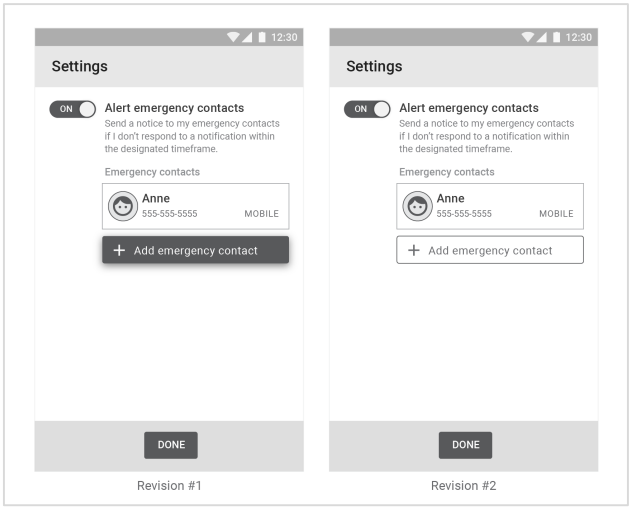

Figure 34. Phase 3 revision to Settings page.

Task 4. None of the five participants struggled to complete the task of responding to a reminder.

Task 5. Two out of the five participants experienced the same misunderstanding when attempting to view and gather information from a historic event:

- ***Challenge #1: Searching Homepage for Historic Information.*** In an effort to locate information regarding an already completed task, two users (U12/U15) immediately attempted to search the *Noted!* homepage for relevant terminology. This indicates either 1) a lack of clarity regarding division of upcoming tasks and historic tasks into two separate pages or 2) an assumption that the homepage search allows the user to search within the entire application and not just the present page. In an effort to correct for both of these possibilities, helpful hints were added to the returned search results that returned zero matches. A user who mistakenly searches for historic information within the upcoming reminder section would be presented with a pointer to the history page. Refer to Figure 35 below.

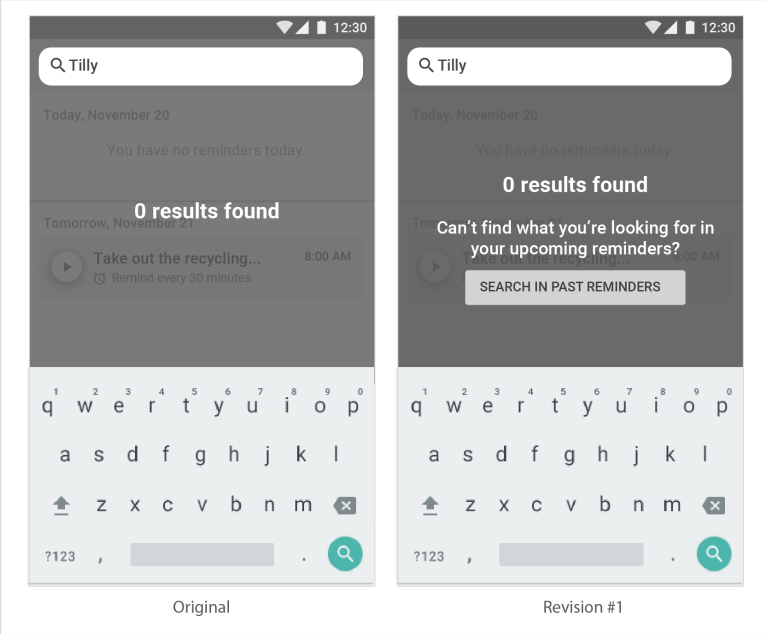

Figure 35. Phase 3 revision to search.

Debrief. In addition to the challenges witnessed during the test sessions, several positive application features were highlighted during the debriefing sessions, including:

- *U13:* "Everything felt really easy, really really normal."

Phase 2: High Fidelity Digital Prototype User Testing

Upon completion of Phase 1 of testing, the modified greyscale paper wireframes were translated into a full-color digital prototype. The complete set of Phase 2 prototype screens are available in Appendix G. As is shown in Figure 36 below, a soft, inviting sea-foam green was paired with mustard yellow highlights to evoke a relaxing, yet exuberant work space for young-to-middle-aged adults. Color was used throughout deliberately as a means of focusing the user on key components and transferring focus methodically around the tool. The yellow was used sparingly, primarily for primary action buttons.

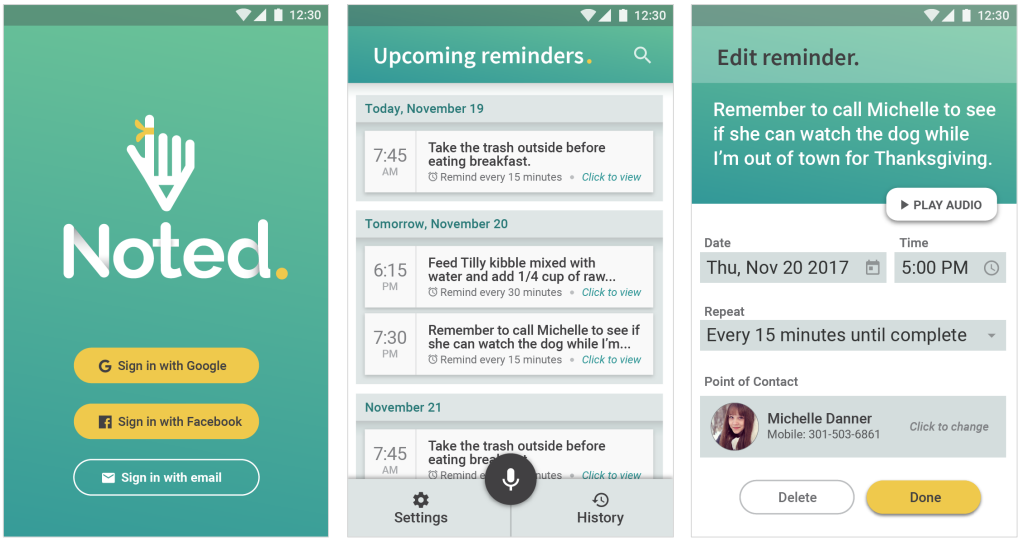

Figure 36. Samples of the *Noted!* color palette and branding.

Additionally, color was paired with animation to emphasize the transition away from the application's homepage. For example, when the user clicked the "create new reminder" button on the homepage, the homepage design and the record new reminder design flipped like a playing card. This concurrently transitions the user from bright whites and soft blue-greens into a darker palette, complete with a dark grey backdrop (see Figure 37). Yellow was maintained for accents and to bridge the two color schemes together. After the user completed the necessary steps to add the new reminder, the palette was once again shifted back to the lighter version.

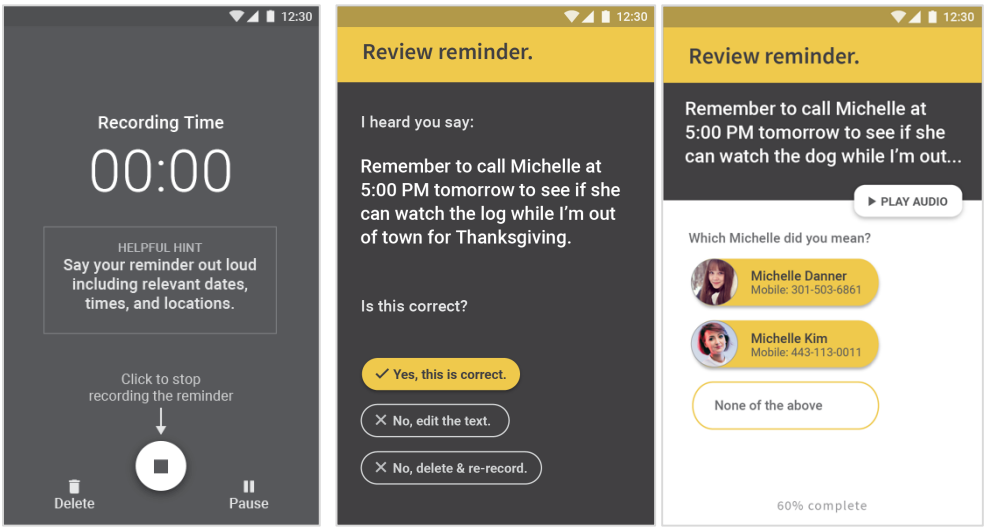

Figure 37. Samples of the *Noted! "Add new reminder"* dark color palette.

Similarly, color and movement was used to indicate transition from the *Noted!* homepage to the secondary 'Settings' and 'History' screens. As is shown in Figure 38 below, once a bottom menu item was clicked, the secondary screen design pushed the homepage design off screen. Parallel to this brief animated sequence, the blue-green top bar of the home screen became a mid-tone grey to further emphasize deviance from the primary page.

Figure 38. Slider animation between homepage and secondary pages.

Ultimately, the Phase 2 fifteen participants experienced a much greater level of success than participants within Phase 1. A total of 66 task successes, 7 task successes with noticeable challenges, and 2 task failures were revealed throughout this second phase of testing. Refer to Table 4 for a complete outline of the successes and failures witnessed while testing the fifteen participants. The various challenges are discussed in detail below.

Table 4

Participant 16-30 Task Success Rates

	Task 1: Add a reminder	Task 2: Edit a reminder	Task 3: Add emergency contact	Task 4: Respond to reminder	Task 5: View historic event
User 16	☑	☑	☑	☑	☐
User 17	☑	☐	☑	☑	☐
User 18	☑	☑	☑	☑	☒
User 19	☐	☑	☑	☑	☑
User 20	☑	☑	☑	☑	☑
User 21	☑	☑	☑	☑	☑
User 22	☑	☑	☑	☑	☑
User 23	☑	☑	☑	☑	☑
User 24	☑	☑	☐	☑	☒
User 25	☑	☑	☐	☑	☑
User 26	☑	☑	☐	☑	☑
User 27	☑	☑	☑	☑	☑
User 28	☑	☑	☑	☑	☑

User 29	☑	☑	☑	☑	☑
User 30	☑	☑	☑	☑	☑

Note. A checkmark delineates a task that was completed successfully without error. An empty square indicates a task that was completed successfully but with some degree of error. An 'x' indicates a failed task that required investigator intervention.

Task 1. Approximately 93.3% of participants did not visibly experience discomfort when adding a new task to the *Noted!* tool. Only one user appeared to struggle during the reminder recording portion of the task.

- ■ ***Challenge #1: Assuming Audio Recording Doesn't Start Automatically***. Consistent with the challenge witnessed during Phase 1-Set 1, a single participant (U19) appeared to not understand that the audio recording began automatically upon entering the record task page. Unlike Phase 1, however, this participant was presented with a working time ticker and audio recording indicator that simulated matching participant vocal patterns. The participant watched these indicators and read the associated help text for a few seconds without saying anything. He then clicked the stop button and immediately began to say the reminder out loud. Given the lack of vocalization during the task record segment itself, he was transitioned into a blank speech-to-text page with the option to re-record. In spite of his initial error, he was able to self-correct and return to the screen to re-record successfully. This indicates that while the means to self-correct is effective, additional clarity should be added to the initial reminder screen. In an effort to improve clarity, the "helpful hint" text should be revised to indicate that the recording is in progress (refer to Figure 39 below).

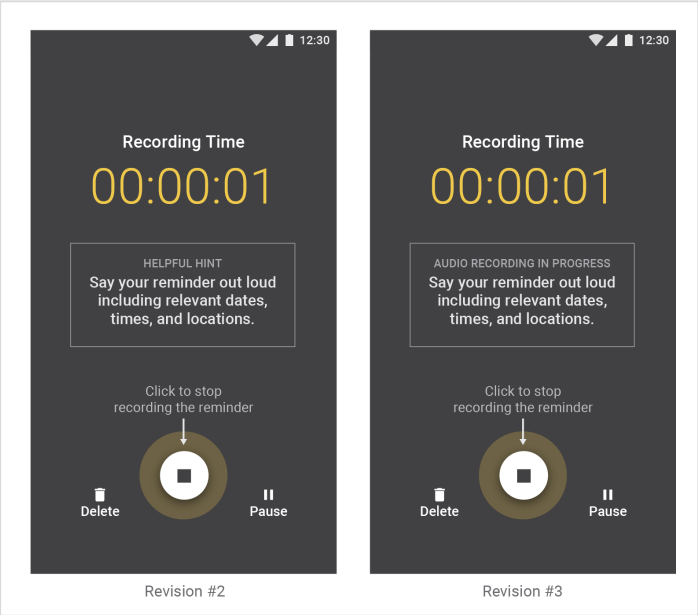

Figure 39. Phase 3 revision to reminder record screen.

Task 2. Approximately 93.3% of Phase 2 participants edited an existing task without difficulty. However, one participant was challenged by the task.

- ***Challenge #1: Difficulty Understanding Task Intention***. One user (U17) hesitated 24 seconds after the task was read, looking at the screen but not clicking anything. He then clicked on settings, the record button, and the settings button again, then the record button two more times before clicking on the intended reminder block. Throughout this process, he continually re-read task two on the provided task sheet. This indicated possible confusion with understanding the provided task itself. However, once he opened the previous task he was able to independently complete all steps without error. Given that future testing will be on a fully-functional whitelisted alpha version of the application that allows users to input his/her own data, confusion such as this will likely be avoided. However, this possible point of confusion should be flagged as a possible area to revisit if the same problem is encountered in future studies.

Task 3. While 73.3% of users were able to add an emergency contact without difficulty or error, 26.7% of participants experienced the same singular challenge.

- ***Challenge #1: Assuming Emergency Contact Hasn't Been Officially Added***. Upon effectively selecting the emergency contact name from the contact list, four participants (U21, 24, 25, 26) clicked on the add emergency contact button a second time. During session debrief, several of these individuals indicated that he/she had assumed that the addition of the contact hadn't been officially made. As such it was assumed that the "Add emergency contact" button effectively added the chosen emergency contact. The application intention, however, was to use that button to add additional emergency contacts to the list. In an effort to navigate this misunderstanding, the button's phrasing was revised to indicate that its intention is for adding additional contacts.

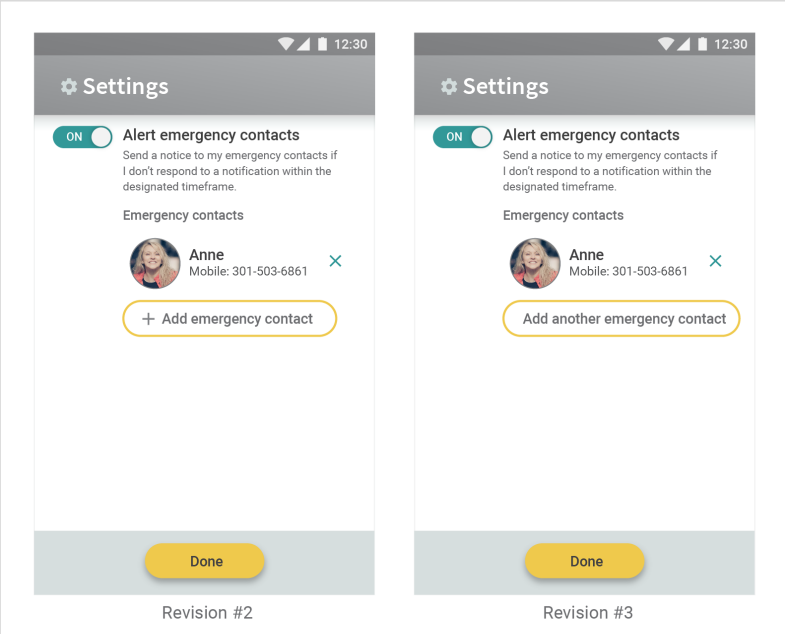

Figure 40. Phase 3 revision to Settings page.

Task 4. No visible user errors were witnessed during the task of responding to a reminder. All participants were able to complete the task effectively and efficiently.

Task 5. While a majority of users completed the task of utilizing information from a previously dismissed reminder, 2 participants experienced some level of difficulty and another 2 users could not complete the task without moderator assistance.

- ■ ***Challenge #1: Searching Homepage for Historic Information.*** Similar to the two Phase 1 - Set 3 users, a single individual (U16) attempted to search the homepage for historic information. While this user's assumption that the information would be found in this location was false, the user successfully used the "Search in Past Reminders" button to transfer her to the history page to find the information. Therefore, while this user's methodology was not extremely efficient, it allowed the information to be successfully located. As such, no design features were changed. However, it is recommended that this area be further analyzed with members of the YOD population in the future.
- ■ ***Challenge #2: Task Confusion.*** Two participants (U18, U24) were unable to complete the task without moderator assistance. Both users scanned the homepage for keywords and not finding the information, jumped to their own conclusions. The first individual was quickly distracted by her concern that there was not a reminder to feed the dog for tomorrow within the application's mock-data, stating in her debriefing session that she "figured that [she] had fed her today since it wasn't on that [homepage] list". The second participant thought aloud, "there are no more reminders for today so I'm thinking I would have already fed her at 7:45 today since animals have to be fed every day and I have a reminder for tomorrow to feed the dog at 7:45." While explanation of the application's intended functionality seemed to assuage and make sense to the first struggling participant (U18), the second individual (U24) remained confused even after receiving moderator direction. Through extensive discussion during debrief, it was determined that the fake data included within the prototype was the source of the confusion. Since the next phase of testing will be on a fully-functional whitelisted alpha version of the application that allows users to input his/her own data, confusion surrounding dummy data will likely be avoided in the future. As such, no changes to the application are recommended at this time.

Chapter 7: Conclusion

The feedback garnered through user testing provided invaluable assistance in the identification and correction of common errors made by non-demented individuals prior to future testing with members of the YOD community. It was encouraging to see that iterative modifications to early design-work resulted in an increasingly successful user experience for the everyday, non-impaired user. While participants were not members of the primary user base for the *Noted!* application, this study established an improved baseline for future testing with the intended user base. Improved implementation of utilized heuristics instilled clearer language, enhanced error correction capabilities, improved visual chunking of information, and adhered more pronouncedly to users' usability expectations from the initial paper prototype. User testing also confirmed the validity of application usage outside of the primary user base, thereby establishing a likelihood of a broader user base beyond the YOD community for which it was intended. This feature is likely to engender a positive sense of inclusion amongst YOD individuals and their non-impaired peers.

While participants adhered to similar age demographics, one should acknowledge that the gathered insights may not encapsulate all possible points of difficulty experienced by the YOD community. Further challenges may present themselves in new and unexpected ways for these symptomatic individuals. As such, it is imperative that future testing of the *Noted!* application focus on participants with stages one to four of the disease to ensure utmost product quality.

Additionally, it is noted that the inability to test live data within a fully functional application served as a research limitation. While the study's digital prototype was able to simulate the necessary interactions on a real Android device, this method created an increased dependence on remembering and responding to fictional moderator-provided scenarios. Throughout the reminder creation task, for example, a majority of participants referred to the task sheet numerous times prior to completion in an effort to ensure adherence to the provided task. This does not mimic real-world usage. Moreover, testing

of speech-to-text and entity extraction capabilities were not able to be effectively tested in the simulated testing environment. The ability for participants to interact with a fully-functional, live application in an unscripted manner could provide additional insights into ease of use and necessary functionality that a script could not effectively provide. This unscripted, in-field testing approach would likely prove especially beneficial when exploring the user experience competency of the *Noted!* application on early-stage individuals with YOD in future testing.

All in all, the foundational principles researched, tested, and finessed throughout this study serve as an important contribution to the needs of the underserved community of young-to-middle-aged adults struggling with AD. With approximately 88% of individuals 30 to 49 years old and 74% of adults aged 50 to 64 relying heavily on smartphones (Pew Research Center, 2017), there is great opportunity to harness this popular technology to serve the needs of various communities. It is time that this technological endeavor be extended to the phone-savvy members of the largely-forgotten YOD community. With increased dialog surrounding the needs of individuals with YOD, there remains great hope that smartphone devices can provide these individuals with some of the necessary support needed and not yet effectively provided.

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Appendix A: Phase 1−Paper Prototype Moderator Script

Introductions

Thank you for agreeing to meet with me. I'm Kate Coates and I'm a current graduate student in Interaction Design & Information Architecture at the University of Baltimore. As a part of my graduate thesis, I'm working to design a smartphone application that will service the daily-life task-management needs of young-onset individuals struggling with the early stages of Alzheimer's Disease. The purpose of today's session is to work together to figure out how to make this interface as user-friendly as it can be.

The prototype still has some rough edges. I'm still thinking through how it should work and some parts of it are incomplete. My goal is to get some feedback. When we're finished, I'll review today's feedback to help determine what revisions or additions should be made.

Do you have any initial questions before we continue? *[Pause for questions.]*

To begin, I'm going to walk you through a form verifying your consent to participate in the test session. Afterwards, we'll be ready to begin.

[Read through consent form together and receive signature.]

Paper Prototype Orientation

[Lay out first screen of paper prototype on the table.]

This is the paper prototype of the mobile application you'll be working with. Let's assume that you have already downloaded the application and opened it. This screen is your starting point.

Interactions with the Prototype

As mentioned in the consent form, during the session I'll relay a series of five tasks one at a time in verbal and written formats. While the task will only be read-aloud once, you'll be able to reference the written copy of the task anytime throughout the process. Upon hearing each task, you'll need to interact with the paper model as if it were the live application, tapping on paper components to complete the task. As you interact with the prototype, I'll move the paper pieces around to convey the applications intended behavior based on your interactions.

Throughout this process please say your thoughts and feelings out-loud to help me understand what you're thinking. While vocalizing your questions is really important, I'll not answer them right away. It's important to fully understand the application gaps without outside intervention. In the real world, I won't be there to help people figure it out. After completing each task, say "done" or "finished" to move on.

Remember that we're testing the interface, we're not testing you. We'll end in approximately a half hour, but if you need to stop or take a break before then, just let me know. Are you ready to start?

Tasks

This sheet has five tasks written on them. *[Hand the user the "User Task Sheet" document and only reveal the first task on the sheet.]* We'll walk through each of these tasks one by one. I'll read it out loud to you the first time but feel free to reference the paper at any point. Let me know if a task does not make sense to you. Whenever you're ready feel free to begin. [Reveal tasks one by one as the user completes them].

Debrief

Thank you for taking the time to review the *Noted!* application. After going through this exercise is there anything that you especially liked? Disliked? Didn't work the way that you expected? Missing that you would add?

Appendix B: Phase 1−Consent for Participation in Research Activities

Whom to Contact about this study:
Principal Investigator: Katherine Coates
Organization: University of Baltimore
Department: Interaction Design and Information Architecture
Telephone Number: 301-503-6861

Consent for Participation in Research Activities
Project Title: "*Noted!* Application Paper Prototype User Testing"

1. Purpose of this research

The goal of this study is to investigate the best methods for designing a smartphone application designed to aid an individual struggling with the early stages of Alzheimer's Disease with common tasks. The application testing will result in an application prototype ready for development and deployment to members of the young-onset Alzheimer's community.

2. Procedures

As a part of this study, you will participate in a half-hour session with a moderator in a home setting. You will be asked to wear a small ear-mounted video camera that will visually and audibly record your interactions with the prototype. Only what you look at and what you say will be recorded. You will then be asked to complete a series of five (5) tasks on a paper version of the application prototype. Instructions will be provided to you orally as well as in a hard copy format. As you interact with the prototype, the moderator will move the paper pieces around to properly convey the application's intended behavior based on your interactions. You are encouraged to vocalize your thoughts out-loud. You should notify the moderator when you feel the task has been completed. No personally identifying information will be collected regarding your responses.

After completing the five tasks, the moderator will ask for your feedback of the experience "using" the application.

3. Voluntary Participation

Your participation in this study is voluntary. You have the right to withdraw from the study at any time without penalty.

4. Privacy & Confidentiality

All personally identifiable information learned and collected in this study will be strictly confidential. All data collected in this study will be securely stored on the University of Baltimore's network protected Google Drive storage system. Only the investigator and members of the research team will have access to these records. Your responses will be identified by a study code number only. Your name will NOT be used for any portion of this study. If any information is published, there will be no information that would identify you as a participant.

By signing this form, you agree to allow the research study investigator to make the records, which shall remain anonymous, available to the University of Baltimore Institutional Review Board (IRB) and regulatory agencies as required by law. Consenting to participate in this research

indicates your agreement that collected information may be used by current and future researchers in such a fashion that your personal identity will remain protected. Such use will include sharing anonymous information with other researchers for checking the accuracy of study findings and for future approved research that has the potential for improving human knowledge.

5. Potential Risks and Benefits

Your participation in this study does not involve any personal risks. All information obtained from the session notes and the audio/video recordings will remain strictly confidential and are used solely to evaluate the application itself, not the participant.

Your participation in this research will help provide invaluable feedback on how to facilitate the best user experience possible. This research will provide valuable data on how a mobile application that provides an automated reminder and alerting system can provide a significant value to the unique needs of this underrepresented community of young to middle aged adults with Alzheimer's Disease.

By signing below, you are agreeing to participate in a research study. Be sure that any of your questions about the study have been answered to your satisfaction, and that you have a thorough understanding of the research. If you have other questions or concerns about the research project, you may contact the Principal Investigator, Katherine E. Coates at (p) 301-503-6861 or (e) kate.coates@ubalt.edu, or the Faculty Sponsor, Dr. Deborah Kohl at (p) 410-837-4698 or (e) dkohl@ubalt.edu. For questions about your rights as a participant in this research study, contact the UB IRB Coordinator: 410-837-6199, irb@ubalt.edu.

6. Permission to Record

☐ **Yes, I give permission for my voice and hand gestures to be recorded during the session.** I agree to wear a small ear-mounted video camera to record my interactions with the prototype. I understand that only what I look at and what I say will be recorded. My face will not be visible.

☐ **No, I do not give permission for my voice and hand gestures to be recorded during the session.**

Permission for Anonymized Publication

☐ **Yes, I give permission for the anonymized recorded data to be used in scientific publications.**

☐ **No, I do not give permission for the anonymized recorded data to be used in scientific publications.**

Participant's Signature: _____ Date: _____

Printed Name: _____ Date: _____

Investigator's Signature: _____ Date: _____

Appendix C: Phase 1-3−User Task Sheet

Task 1

You would like to remember to call your friend Michelle at 5:00pm tomorrow to see if she can watch your dog while you're out of town for Thanksgiving. Add this reminder to the Noted! application so you don't forget.

Task 2

Your sister, Anne, is planning on stopping by your house tomorrow at 5:00pm on her way home from work. You now realize that you're double booked. Push back your reminder to call Michelle until 7:30pm.

Task 3

You want your sister, Anne, to receive notifications when you accidentally miss an important reminder repeatedly. Add Anne as an emergency contact.

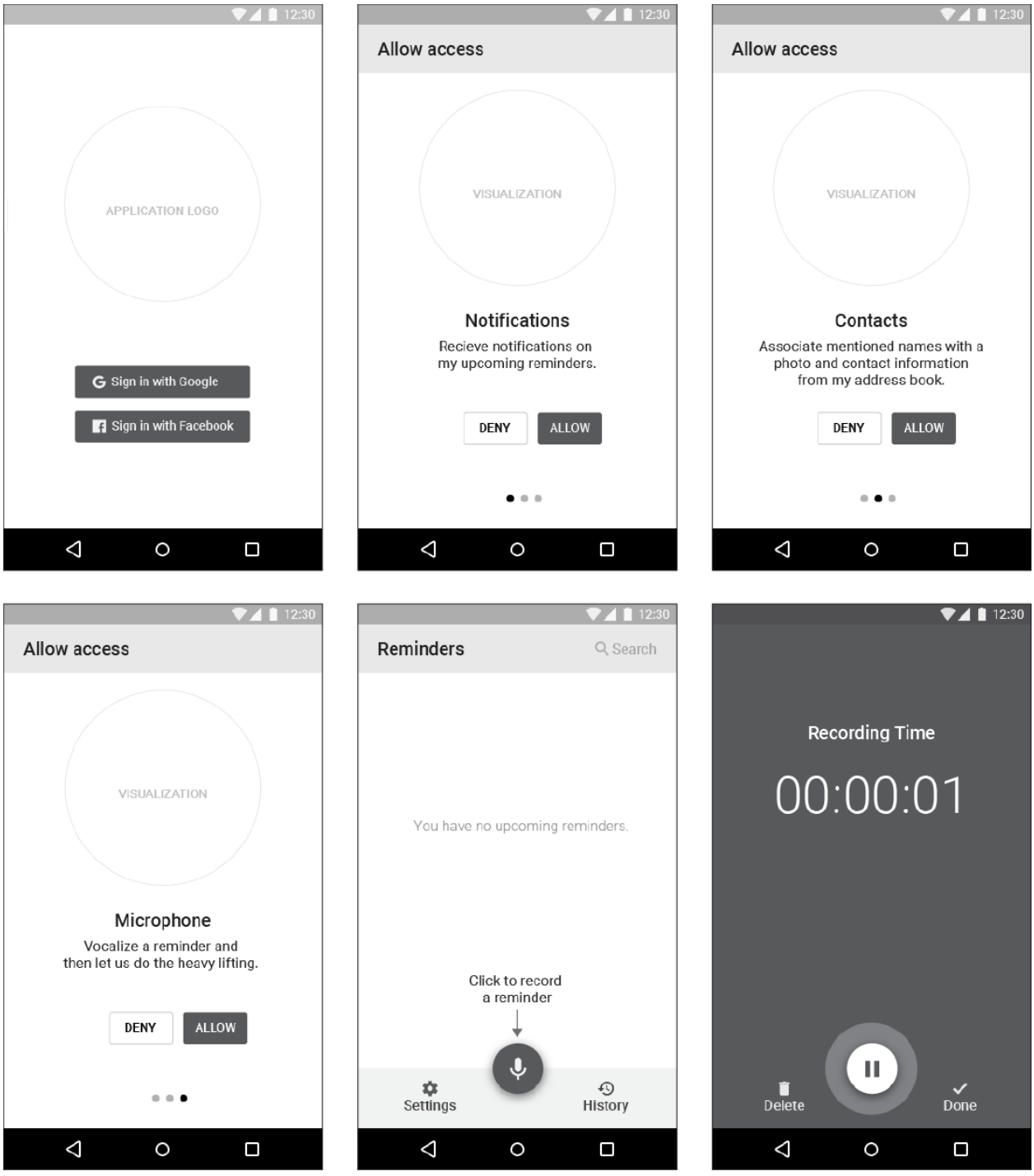
Task 4

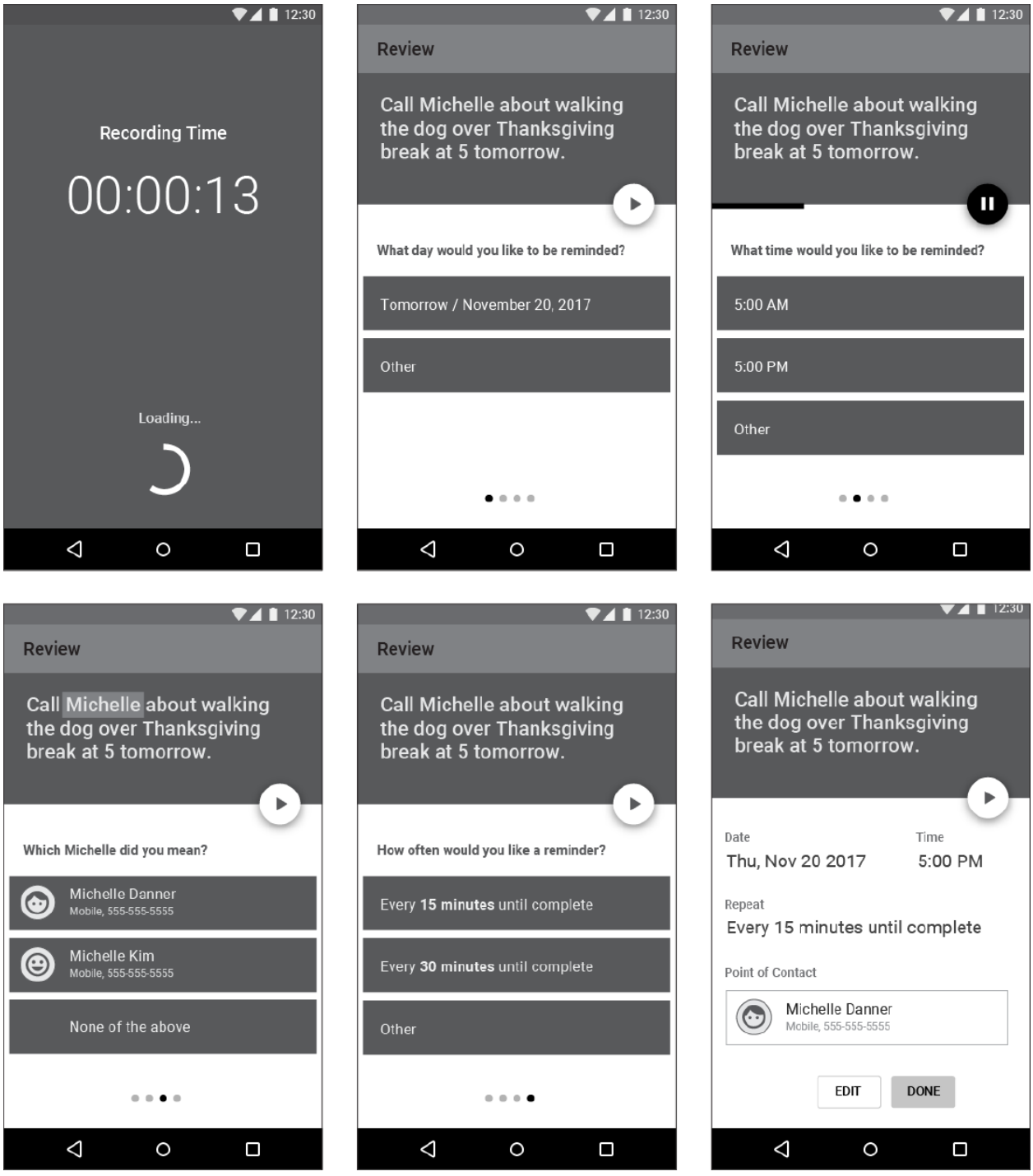
It's 7:30pm and you hear an alarm sound from your phone. View the notification and take the appropriate actions to respond to and dismiss the alert.

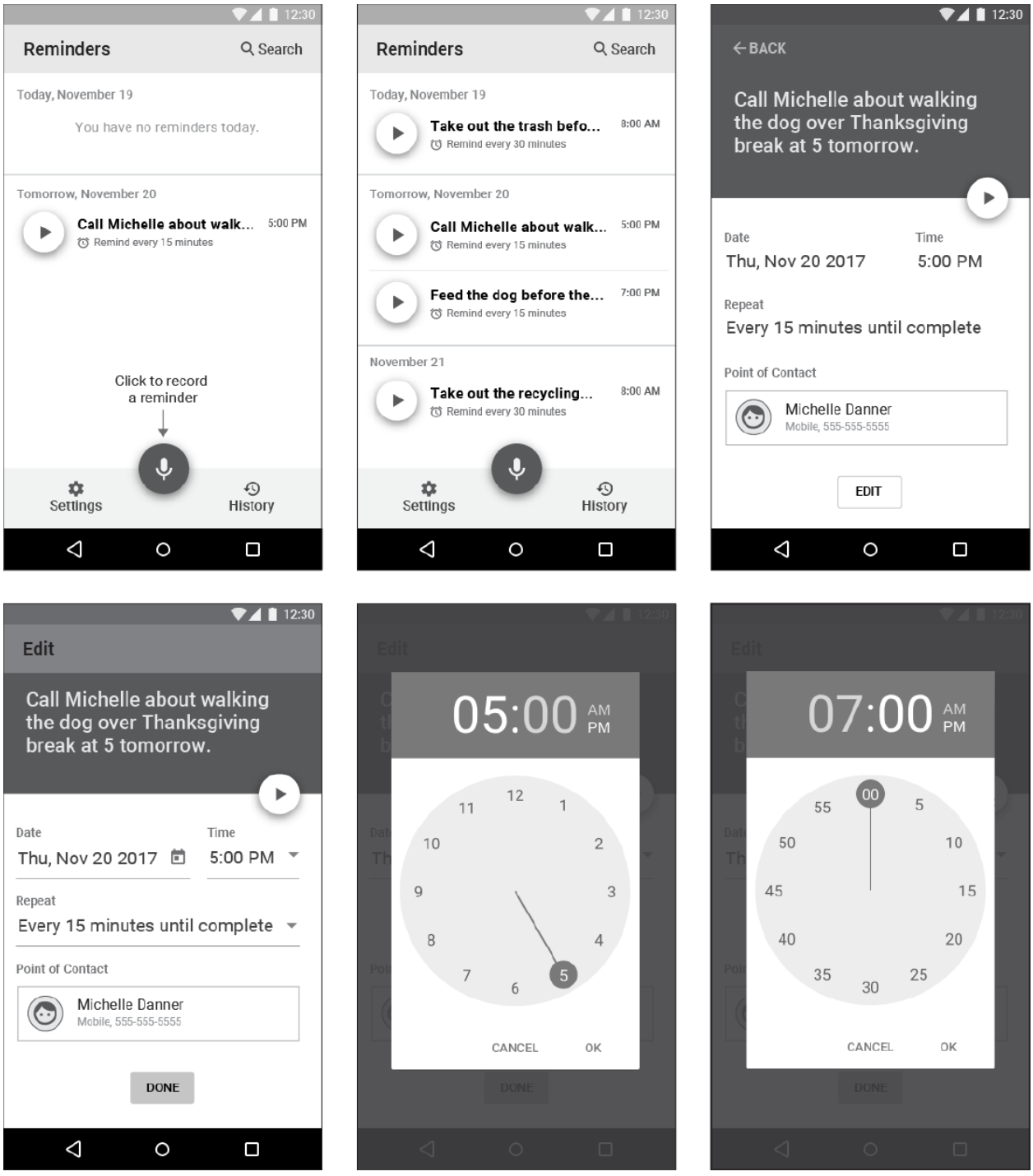
Task 5

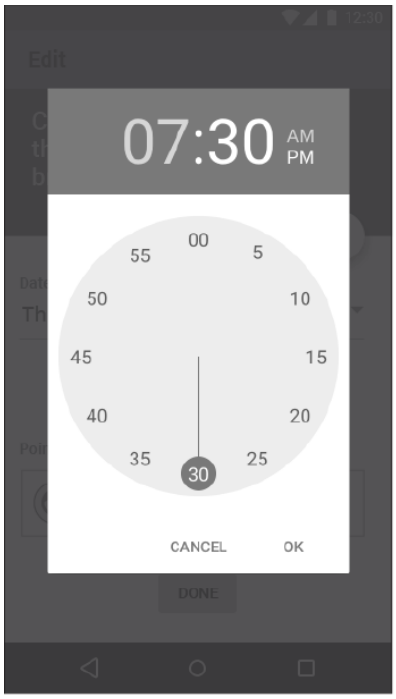
You've used the application for several weeks. You forgot when you last fed your dog, Tilly. Figure out when you last fed Tilly.

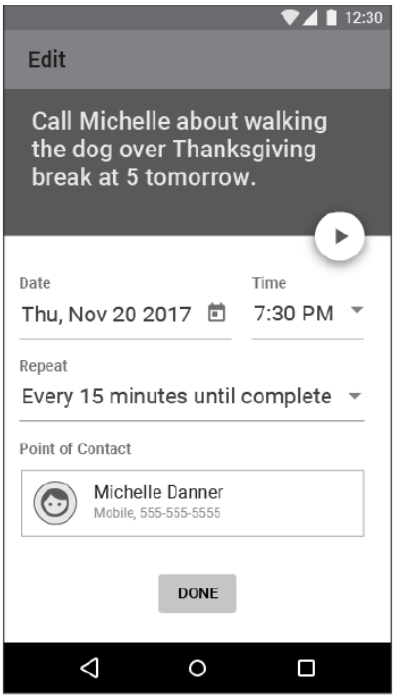
Appendix D: Phase 1−Paper Prototype

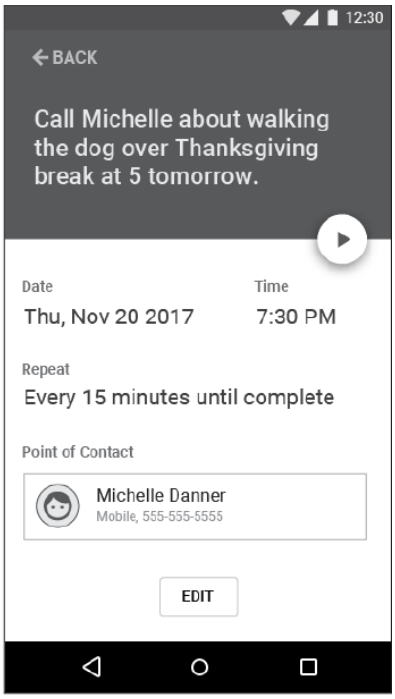


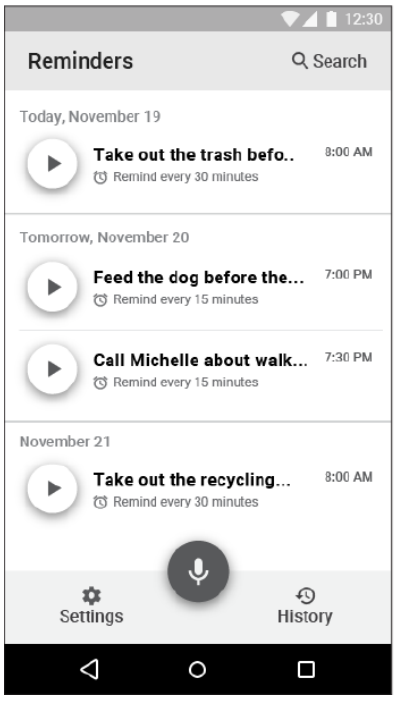


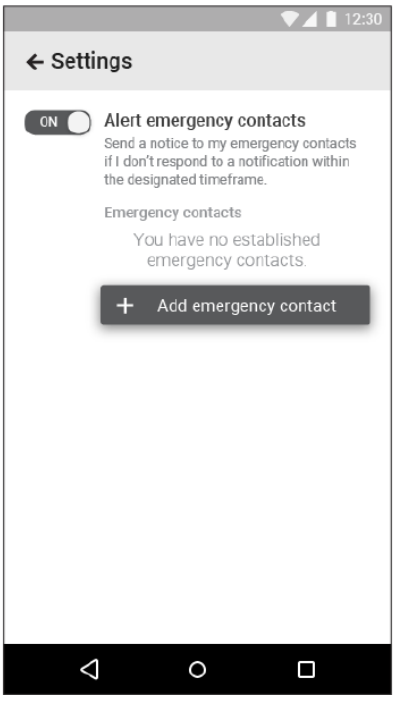


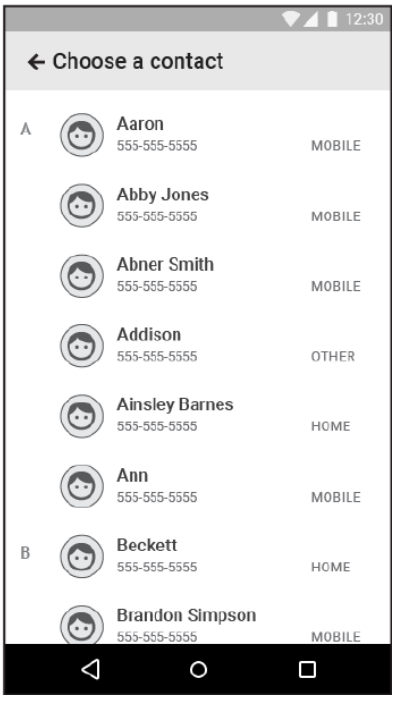


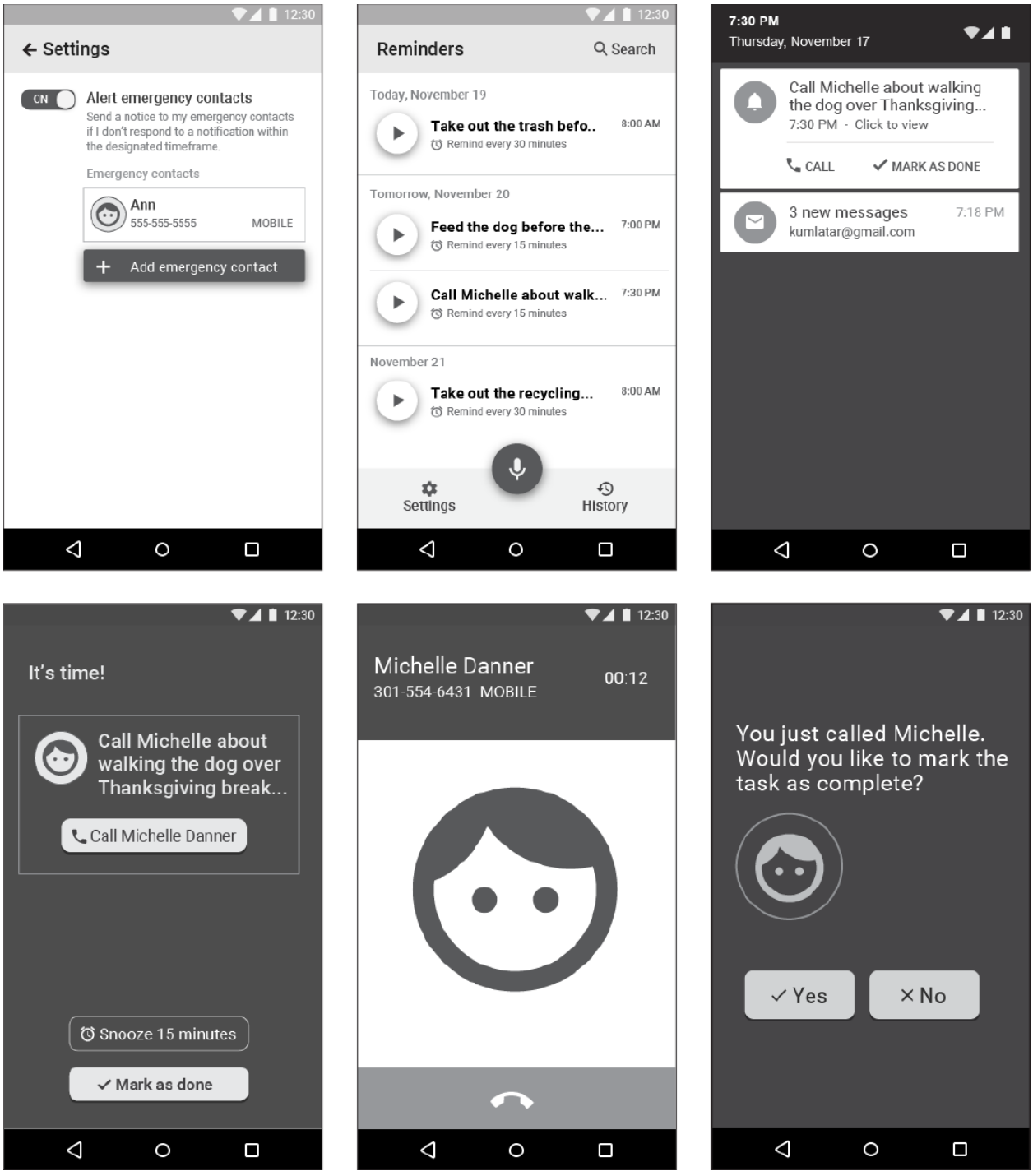


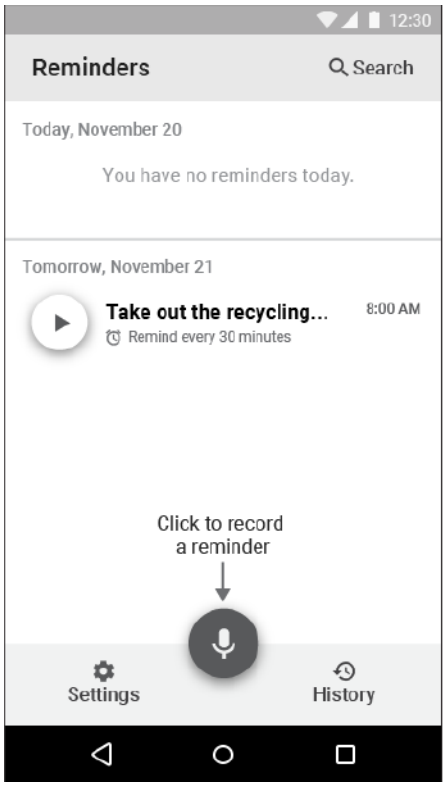


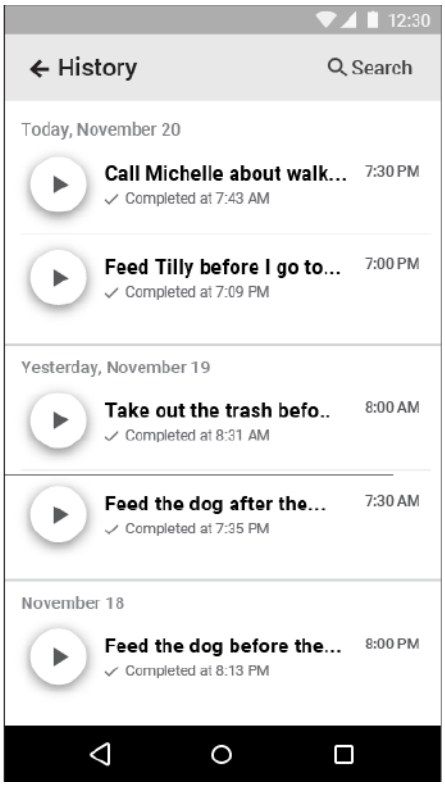












Appendix E: Phase 2−Paper Prototype Moderator Script

Introductions

Thank you for agreeing to meet with me. I'm Kate Coates and I'm a current graduate student in Interaction Design & Information Architecture at the University of Baltimore. As a part of my graduate thesis, I'm working to design a smartphone application that will service the daily-life task-management needs of young-onset individuals struggling with the early stages of Alzheimer's Disease. The purpose of today's session is to work together to figure out how to make this interface as user-friendly as it can be.

The prototype still has some rough edges. I'm still thinking through how it should work and some parts of it are incomplete. My goal is to get some feedback on how well this design works. When we're finished, I'll review today's feedback to help determine what revisions or additions should be made.

Do you have any initial questions before we continue? *[Pause for questions.]* I'm going to walk you through a form verifying you and your loved one's consent to participate in the session, then we'll be ready to continue. *[Read through consent form together and receive signature.]*

Digital Prototype Orientation

This is the digital prototype of the mobile application you'll be working with. Let's assume that you have already downloaded the application and opened it. This screen is your starting point.

Interactions with the Prototype

As mentioned in the consent form, during the session I'll relay a series of five tasks one at a time in verbal and written formats. While the task will only be read-aloud once, you'll be able to reference the written copy of the task anytime throughout the process. Upon hearing each task, you'll need to interact with the digital prototype as if it were the live application, tapping on the screen to complete the task.

Throughout this process please say your thoughts and feelings out-loud to help me understand what you're thinking. While vocalizing your questions is really important, I'll not answer them right away. It's really important to fully understand the application gaps without outside intervention. In the real world, I won't be there to help you figure it out. After completing each task, say "done" or "finished" to move on. Remember that I'm testing the interface, I'm not testing you. We'll end in approximately a half hour, but if you need to stop or take a break before then, just let me know. Are you ready to start?

Tasks

This sheet has five tasks written on them. *[Hand the user the "User Task Sheet" document and only reveal the first task on the sheet].* We'll walk through each of these tasks one by one. I'll read it aloud to you the first time but feel free to reference the paper at any point. Let me know if a task does not make sense to you. Whenever you're ready feel free to begin. [Reveal tasks one by one as the user completes them].

Debrief

Thank you for taking the time to review the *Noted!* application. After going through this exercise is there anything that you especially liked? Disliked? Didn't work the way that you expected? Missing that you would add?

Appendix F: Phase 2−Consent for Participation in Research Activities

Whom to Contact about this study:
Principal Investigator: Katherine Coates
Organization: University of Baltimore
Department: Interaction Design and Information Architecture
Telephone Number: 301-503-6861

Consent for Participation in Research Activities
Project Title: "*Noted!* Application Paper Prototype User Testing"

You are being asked to participate in a testing session for a research project at the University of Baltimore. Please make sure you understand the information below before you sign this document.

1. Purpose of this research

The goal of this study is to investigate the best methods for designing a smartphone application designed to aid an individual struggling with the early stages of Alzheimer's Disease with common tasks. The application testing will result in an application prototype ready for development and deployment to members of the young-onset Alzheimer's community.

2. Procedures

As a part of this study, you will participate in a half-hour session with a moderator in a home setting. You will be asked to wear a small ear-mounted video camera that will visually and audibly record your interactions with the prototype. Only what you look at and what you say will be recorded. You will then be asked to complete a series of five (5) tasks on a digital prototype presented on a provided smartphone. Instructions will be provided to you orally as well as in a hard copy format. Upon hearing each task, you will be encouraged to interact with the digital model as if it were the completed application, tapping on the screen to effectively complete the task. You should notify the moderator when you feel the task has been completed. No personally identifying information will be collected regarding your responses.

After completing the five tasks, the moderator will ask for your feedback of the experience "using" the application.

3. Voluntary Participation

Your participation in this study is voluntary. You have the right to withdraw from the study at any time without penalty.

4. Privacy & Confidentiality

All personally identifiable information learned and collected in this study will be strictly confidential. All data collected in this study will be securely stored on the University of Baltimore's network protected Google Drive storage system. Only the investigator and members of the research team will have access to these records. Your responses will be identified by a study code number only. Your name will NOT be used for any portion of this study. If any information is published, there will be no information that would identify you as a participant.

By signing this form, you agree to allow the research study investigator to make the records, which shall remain anonymous, available to the University of Baltimore Institutional Review Board (IRB) and regulatory agencies as required by law. Consenting to participate in this research indicates your agreement that collected information may be used by current and future researchers in such a fashion that your personal identity will remain protected. Such use will include sharing anonymous information with other researchers for checking the accuracy of study findings and for future approved research that has the potential for improving human knowledge.

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Your participation in this study does not involve any personal risks. All information obtained from the session notes and the audio/video recordings will remain strictly confidential and are used solely to evaluate the application itself, not the participant.

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6. Permission to Record

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☐ **No, I do not give permission for my voice and hand gestures to be recorded during the session.**

Permission for Anonymized Publication

☐ **Yes, I give permission for the anonymized recorded data to be used in scientific publications.**

☐ **No, I do not give permission for the anonymized recorded data to be used in scientific publications.**

Participant's Signature: _____ Date: _____

Printed Name: _____ Date: _____

Investigator's Signature: _____ Date: _____

Appendix G: Phase 2−Digital Prototype