Alzheimer's Patient Navigation Model

Prepared by **The Global Council on Alzheimer's Disease (GCAD)**
Authored by **Dr. Harold Freeman, Ruth Gay, Dr. Richard Stefanacci**

Introductory Letter from the Authors

Fifteen years ago, the President's Cancer Panel submitted to President George W. Bush a paper titled, "Voices of a Broken System: Real People, Real Problems."[1] In it, the authors asserted that, despite "profound advances" in cancer research:

"[O]ur health care delivery system is broken. It is the root of vast and unnecessary suffering, personal financial ruin, and loss of dignity for millions of people with cancer, who must fight their way into and through a dysfunctional system even as they struggle to save their very lives."

One core solution to fixing this "dysfunctional system" was Patient Navigation. By creating Patient Navigators to help patients and families, this "patient-centric concept concentrates on the movement of patients along the continuum of medical care… beginning in the community and continuing on through testing, diagnosis, and survivorship to the end of life."[2]

In the years since, Patient Navigation has proven capable of both improving health outcomes and decreasing costs

to the healthcare system. The Harlem Hospital Center, for example, from 1964-1986 saw five-year survival rates among breast cancer victims increase from 39 to 70 percent.[3] One study found that a patient navigation program, "paid for the salaries of two full-time patient navigators in just over three-and-a-half months."[4]

We believe that Patient Navigators can also improve Alzheimer's disease treatment and care. In working with those affected by Alzheimer's disease, a Patient Navigator could help those with Alzheimer's and their families to better manage both medical and social services. Given the unique and devastating nature of Alzheimer's disease, those affected by Alzheimer's are searching for guidance both within the healthcare system and outside it.

In this paper, we—as representatives of Global Council on Alzheimer's Disease (GCAD)—outline a model for Patient Navigation in Alzheimer's disease. Done right, we believe that Patient Navigation can help improve lives for Alzheimer's patients and families.

GCAD was formed to identify and create practical, immediate solutions for those affected by Alzheimer's disease. We are a diverse team of

experts from science, medicine, policy, finance, advocacy, technology, and caregiving who are collaborating to help build an integrated Alzheimer's ecosystem in which the patient and caregiver are at the center of an interconnected web of services and solutions. Patient Navigation, we firmly believe, is a vital step in creating this patient-centered ecosystem.

In the paper that follows, we outline the goals, benefits, and principles of Alzheimer's Patient Navigation, and we suggest how such a concept could be initiated immediately.

Signed,

Dr. Harold Freeman
Ruth Gay
Dr. Richard Stefanacci
Mary Michael

---

[1] National Institute of Health, National Cancer Institute. Voices of a Broken System: Real People, Real Problems. September 2001.

[2] Harold P. Freeman Patient Navigation Institute

[3] Oluwole SF, Ali AO, Adu A et al. "Impact of cancer screening program on breast cancer stage at diagnosis in a medically underserved urban community." J Am Coll Surg. February 2003; 196(2):180-188.

[4] Harvard Business Review: "How Patient Navigation Can Cut Costs and Save Lives."

The Successes of Patient Navigation in Cancer

When Patient Navigation began, it aimed to solve the challenges of navigating a complex medical system, helping those who faced economic, linguistic, and cultural barriers.[1] In the decades since, Patient Navigation has become a "best practice" in oncology—regardless of a patient's race, gender, or socio-economic status.

One critical milestone came in 2005, when President George W. Bush signed into law the Patient Navigator Outreach and Chronic Disease Prevention Act, which made grants "to provide patient navigator services to improve health outcomes."[2] Another milestone was reached in 2012, when the American College of Surgeons established Patient Navigation as a "standard of care" for all accredited cancer centers.[3] Today, Patient Navigation operates in over 700 sites across the U.S.[4]
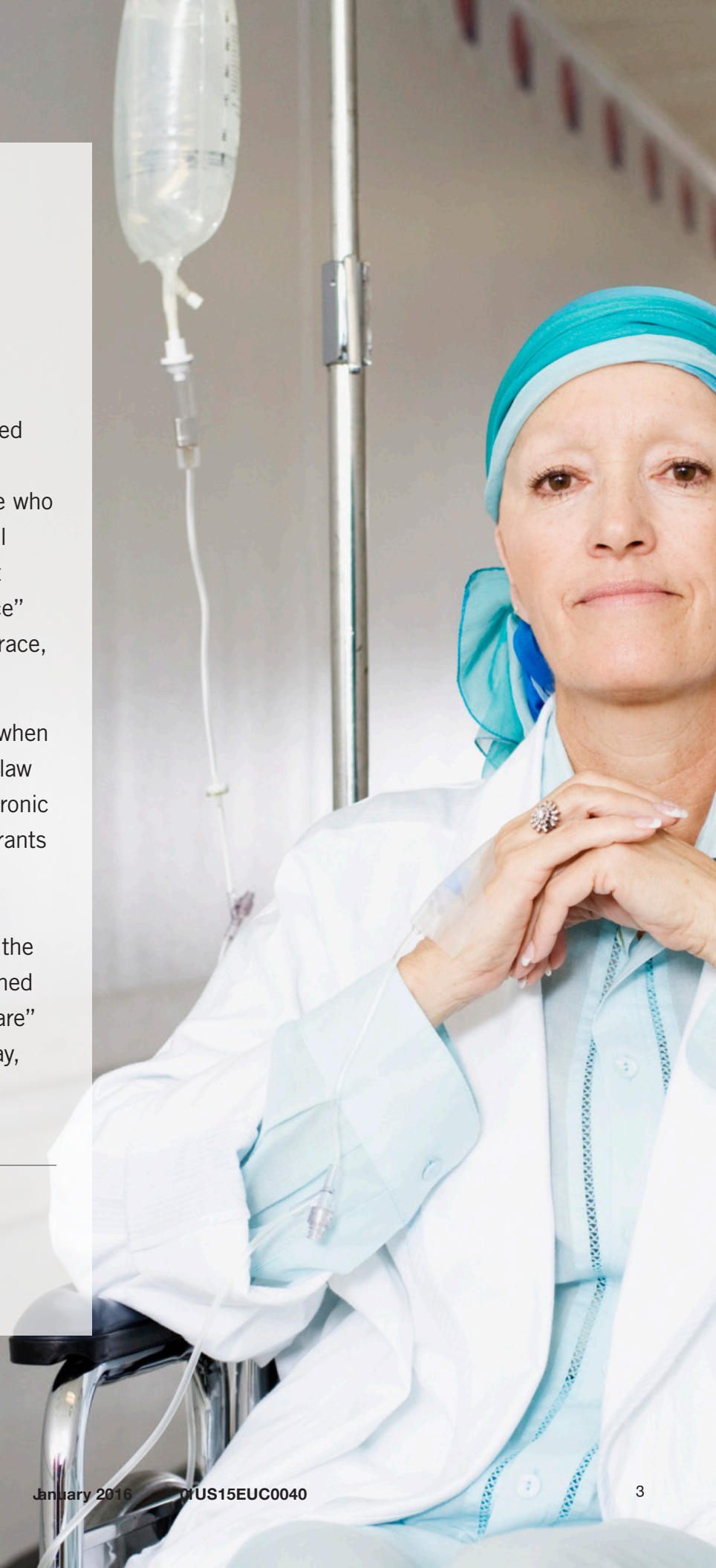
---

[1] Harold P. Freeman Institute for Patient Navigation

[2] Govtrack.us

[3] American College of Surgeons

[4] American Cancer Society

Core Concepts of Patient Navigation

What Cancer and Alzheimer's Have in Common Making Them a Fit for Patient Navigation

CANCER

Stigma

Benefits from early diagnosis

Complex care needs

Disparate impact on low income and minority families

Growing incidence requires efficient and scalable solutions

ALZHEIMER'S

Though cancer and Alzheimer's disease are very different types of diseases—and even though there are vastly different levels of medical solutions to the two diseases—the barriers to treatment and care have much in common. In both, costs and financial implications of care are a major concern; the logistical challenges with appointments, follow-ups, and prescription adherence are many; and learning to manage the caregiving burden is a profound challenge.

Given these shared obstacles, Patient Navigation in oncology holds important lessons Alzheimer's Patient Navigation.

1 **Patient Navigation operates across the continuum of care.** From early prevention to post-diagnosis, Patient Navigation's broader view of care will prove valuable for those with Alzheimer's, where stigma and doubt prevent proactive measures and complex systems slow care.

2 **Patient Navigation works across disease types and patient populations.** Though Patient Navigation began to help reduce the barriers for low-income women in Harlem to receive breast cancer screening and care, it has since grown and proven adaptable to different cancers and patient populations.[1] For Alzheimer's disease—where disease progression substantially impacts care needs—this adaptability will be critical.

3 **Patient Navigation is efficient and scalable.** Patient Navigators can be placed into the field quickly, requiring neither substantial changes to the medical system, nor years of training for the Navigators. The training programs for Navigators can be expedient, cost-effective, and results-oriented.[2]

---

[1] The National Patient Navigation Leadership Summit

[2] See, for example, the Harold P. Freeman Institute for Patient Navigation.

While we recognize that the lessons from oncology may have some limits for Alzheimer's disease, we do suggest that years of growth and success with Patient Navigation in oncology holds lessons for building a Patient Navigation Model for Alzheimer's.

We believe that the benefit of Patient Navigation in Alzheimer's disease is escalating. Today, it is becoming more common for people to begin their Alzheimer's journey without a family member or capable caregiver. Multiple factors have led to this situation: higher divorce rates, lower marriage rates, increasingly mobile adult children who have relocated to different states and regions, and also increased longevity, in which an adult outlives his or her spouse and siblings by years and even decades. As more adults without family caregiver support get Alzheimer's disease, the need for Patient Navigation skyrockets.

In the next section, we detail the specific needs of Alzheimer's disease patients and families, and we identify exactly the problems that Patient Navigation can overcome.

The Goals of Patient Navigation in Alzheimer's Disease

Ensure the initial conversations are successful

Assuring a timely diagnosis

Coming to terms with a diagnosis

Starting the Alzheimer's conversation

Patient navigation overcomes the obstacles to drive toward each goal

Curating information and resources

Caring for the caregiver

Identifying the right option for care

Setting and managing expectations and treatment

The goal of Patient Navigation in Alzheimer's disease is to provide essential, needed assistance to those affected by Alzheimer's. From both research and professional insights, Patient Navigation could best accomplish the following goals. Below, we outline the obstacles families currently face, the ways that Patient Navigation can assist them, as well as the metrics for measuring success.

STARTING THE ALZHEIMER'S CONVERSATION

Obstacle: When someone first develops symptoms of Alzheimer's disease, it can be hard to determine if anything is "wrong." For both the person affected by Alzheimer's and the family, there is reluctance to begin conversations especially with their healthcare providers (HCPs), because they fear where these discussions might lead.

How Patient Navigation Can Help: Patient Navigators can help make the initial Alzheimer's conversations feel easier and more comfortable by providing support, education, and they can outline how to best take advantage of the resources that the healthcare provider has to offer.

Results: Patients and caregivers feel empowered and HCPs are engaged at the earliest stages of the disease.

ENSURING THE INITIAL ALZHEIMER'S CONVERSATIONS ARE SUCCESSFUL

Obstacle: Anecdotally, it has been reported that it can be difficult for AD patients and their families to communicate effectively with HCPs.

How Patient Navigation Can Help: Patient Navigators can speak with the person with Alzheimer's and the family before the consultation with the HCP. These preliminary coaching sessions can set the foundation for candid, useful conversations, and they can also set expectations for the visit with the HCP.

Results: People living with the disease and families feel more confident following the first conversation with HCPs. They also might feel more comfortable that they can work with HCPs and team over the entire course of the disease.

ASSURING A TIMELY DIAGNOSIS

Obstacle: Often, the primary care HCP will give a referral to a specialist or for additional testing after the initial consultation. Referrals can be a source not only of great anxiety, but also a logistical hardship, given the potential difficulties in scheduling, insurance coverage, and the "unknowns" that exist.

How Patient Navigation Can Help: Patient Navigators can help with scheduling and insurance. They can find the right site of care to meet the particular needs of the person with Alzheimer's. Patient Navigators can also provide resources to help allay the anxiety during the interim period.

Results: The person with Alzheimer's would follow through with a referral or a specialty consultation in a timely manner.

COMING TO TERMS WITH A DIAGNOSIS

Obstacle: After an Alzheimer's diagnosis, the person with the disease and the family has numerous questions. Their questions increase in the period after the diagnosis, as they research online and talk to others in their community.

How Patient Navigation Can Help: Patient Navigators can be available to help answer questions right after the diagnosis and in the following weeks and months. The Patient Navigator can have these conversations in support of the directions of the HCP and team.

Results: The Navigator helps as part of the care team (HCP, Nurse, caregiver, etc.) to support a patient with their treatment and change in care. Over the course of the disease, the person with Alzheimer's will have regular appointments with their HCP to work with their symptoms or address changes in mood or function. The Navigator can help ensure that the patient and family understand options and have access to the appropriate medications or support recommended.

ACCESSING INFORMATION AND RESOURCES

Obstacle: There is no shortage of educational materials about the science, care, and treatment of Alzheimer's. These materials, however, can be overwhelming, contradictory, and unhelpful, even false and inaccurate. Additionally, persons faced with the disease face many hurdles accessing care and services.

How Patient Navigation Can Help: Patient Navigators can "curate" the materials. They can act as manager of the materials, providing accurate and appropriate information that lays out best practices. Patient Navigators can also address financial barriers, such as understanding insurance requirements, addressing lack or insufficient insurance and lack of access to care services, and facilitate more timely care across the care continuum.

Results: Existing materials are utilized.

SETTING AND MANAGING TREATMENT AND EXPECTATIONS

Obstacle: People with Alzheimer's and their families may feel that the medication is not working, or that the side effects of treatment outweigh the benefits. The patient may be declining in their cognitive ability and the family may be discouraged or at a loss of what to do.

How Patient Navigation Can Help: Patient Navigators can keep an ongoing dialogue throughout treatment in order to set and manage expectations. Patient Navigators can also provide guidance, informed by, aligned with and supportive of the directions of the patient's treating HCP, on non-pharmacological management techniques, like diet, exercise, social engagement, education for families, etc.

Results: The person with the disease and the family explore options and make informed decisions about treatments. The patient adheres to the course of treatment recommended by the HCP.

IDENTIFYING THE RIGHT OPTION FOR CARE

Obstacle: It can be hard for AD patients and their families to understand what options are out there and how to secure support and care is needed along the journey.

How Patient Navigation Can Help: Patient Navigators counsel AD patients and families through the options for care and also connect them with representatives from different organizations that provide care and support. In addition, the Patient Navigator can help the family make the right financial decisions with in-home care, assisted living care, etc. In some cases, the Patient Navigator can help AD patients and their families understand the dynamics involved in each, including independence, socialization, medical attention, etc. Also, Patient Navigators can connect AD patients and their families to support groups and advocacy organizations that specialize in the use of to professional care.

Results: AD patients and their families understand their options and connect to third parties, whether support groups, caregiving organizations or providers.

CARING FOR THE CAREGIVER

Obstacle: It is common for caregivers to experience their own health issues, given the stress and demand of their new role. They often have neither the time nor the energy to proactively seek professional medical help for themselves. Additionally, non-clinical affairs can become overwhelming and go unresolved.

How Patient Navigation Can Help: Patient Navigators can guide caregivers to make the right decisions about both their own health needs and their non-health demands, like work, financial planning, and legal issues. The Patient Navigator can connect families to the resources they need to manage this complex set of affairs.

Results: Increased services for the caregiver means that the caregiver can enjoy good health through not bearing a care burden alone.

Benefits of Patient Navigation for the Healthcare System

When people who suffer from Alzheimer's disease are better managed both medically and non-medically, their overall consumption of healthcare resources should decline. For example, research has shown that those with Alzheimer's disease have high rates of hospitalization and emergency department visits, which lead to increased costs for healthcare systems. One study by the U.S. Department of Health and Human Services (HHS), for example, found that 34% of those with cognitive impairment had emergency department visits, compared to just 24% of non-cognitively impaired peers.[1] In addition, research has also found that the burden of medical comorbidity in those with Alzheimer's is greater than those without dementia.[2] The mean excess cost attributed to Alzheimer's is estimated to be $2,300.[3]

It is our hypothesis that Patient Navigation for Alzheimer's disease can become a tool for delivering accountable care. The hypothesized "results" above have obvious benefit to many patients, caregivers, HCPs, as well as the health system. Widespread adoption of the Patient Navigator model will likely be driven by how it can reduce costs to the system. To this end, Patient Navigation can be measured by the "hard costs and returns", or outcomes, it provides to the healthcare system. Initially, we propose that the "outcome measures" are focused on the points of care that have the greatest costs. Success within these areas of focus will likely trigger quick uptake within a healthcare system. We propose the following "outcome measures":

		Average with Patient Navigation	Average without Patient Navigation
Does the cost of care decrease?	Cost of care in mild stage of AD		
	Cost of care in moderate stage of AD		
	Cost of care in severe stage of AD		
Do hospitalizations and skilled nursing facility placements decrease?	Number of hospitalizations and skilled nursing facility placements in mild stage of AD		
	Number of hospitalizations and skilled nursing facility placements in moderate stage of AD		
	Number of hospitalizations and skilled nursing facility placements in severe stage of AD		

[1] Feng, Coots, Kaganova et al. "Hospital and Emergency Department Use by People with Alzheimer's Disease and Related Disorders: Final Report." The U.S. Department of Health and Human Services. August 2013.

[2] Duthie A., Chew D. and Soiza R.L. "Non-psychiatric comorbidity associated with Alzheimer's disease." QJM. July 2011. 104(11).

[3] Zhao, Kuo, Weir et al. "Healthcare costs and utilization for Medicare beneficiaries with Alzheimer's." BMC Health Services Research. May 2008.

Next Steps

We have outlined the Patient Navigation Model for Alzheimer's disease with the goal of creating a practical, implementable solution that can be launched expediently. While we recognize larger changes within the healthcare system could be made to better meet the needs of those touched by Alzheimer's disease, we must value solutions that can work in the near term.

To that end, we believe the following strategies can help launch the Patient Navigation Model for Alzheimer's disease:

- **Identify and Train the Navigators:** In Patient Navigation in oncology, it is imperative for the Navigator to understand fluently the inner workings of the healthcare system, given the complex set of medical procedures that occur after diagnosis. The situation in Alzheimer's is different, of course, due to a paucity of medical treatment options. Therefore, the ideal Patient Navigator must be one who both understands how to manage the healthcare system, but also has the capacity and skillset to work with people and connect them to the resources they need "outside the clinic." Training materials must be developed to this end.

- **Secure Funding:** Patient Navigation in cancer has received a wide range of funding, from both public and private donors. We anticipate that these organizations, who already understand and believe in the Patient Navigation concept, could prove fruitful in securing initial funds for Patient Navigation in Alzheimer's disease. Options include: Health Resources and Services Administration (HRSA), Center for Medicare and Medicaid Services (CMS), National Institute on Aging (NIA), and the Centers for Disease Control (CDC).

- **Learn Best Practices:** Patient Navigation centers in oncology can become partners to teach methods, training curricula, best practices, etc. The Harold P. Freeman Patient Navigation Institute stands as an example.

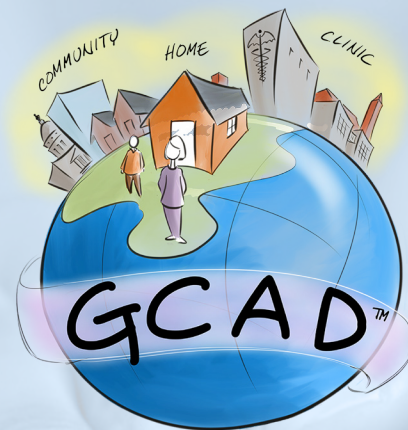- **Pilot Programs:** Pilot Programs can test the Patient Navigation Model that this paper has outlined and provide lessons to shape future launches. We believe the Center for Medicare and Medicaid Innovation could be a strategic pilot partner, as well as their ACOs.

- **Embed Patient Navigation Within Quality Measures Work:** CMS defines quality measures as "tools that help us measure or quantify healthcare processes, outcomes, patient perceptions, and organizational structure… includ[ing] effective, safe, efficient, patient-centered, equitable, and timely care." As the entire healthcare system migrates to a more outcomes-based system, Patient Navigation can integrate into the migration within Alzheimer's treatment and care.

- **Link to Other Innovative Programs:** Medicare's PACE initiative–Program of All-Inclusive Care for the Elderly–would be, for example, an ideal partner program, given its focus on "helping people meet their health care needs in the community avoiding the burden of nursing homes or other care facilities." PACE, along with other programs like Medicaid's Cash for Caregiving Program, shares overlapping end-goals with Patient Navigation, could operate cooperatively to create synergies. Another example includes Medicaid's Cash and Counseling Program.

The Patient Navigator's Check List

- ☐ Identify and train the navigators
- ☐ Secure funding
- ☐ Learn best practices
- ☐ Pilot programs
- ☐ Embed patient navigation within quality measures work
- ☐ Link to other innovative programs

GCAD™

Global Council on Alzheimer's Disease™