

As a contribution to the larger Change AGENTS Initiative, the Dementia Caregiving Network (DCN) considered the emerging topic of family caregiver representation in electronic health records (EHR). Care for a person with Alzheimer’s disease or a related dementia (ADRD) is more than person-centered care: it is family-centered care. Caregivers are essential components of health care provision for any patient who is elderly, but their integral role and significance is magnified and intensified when their loved one has ADRD. When the patient has dementia, it is usually the caregivers—not the patients—who make things happen: they ensure medicine is administered, doctor appointments are scheduled and kept, and care transitions occur as seamlessly as possible. Indeed, care for the patient cannot be separated from the caregiver. Thus, the DCN strongly believed that family caregivers should be authoritatively recognized in all health care encounters and, therefore, set the goal of defining strategies and means of executing the inclusion of caregiver information in EPIC, the leading EHR.

The DCN conducted a survey of patients, caregivers, and professionals working on issues related to aging and dementia. Garnering the most positive response (approximately 95% of the 88 people surveyed) was the notion of having the doctor or medical staff know the name of the caregiver and have his or her contact information. An overwhelming majority reported turning to health care providers for connections to community-based resources that support them in the caregiving role (81.8%) and help with managing health and well-being of the family member with dementia (74.0%). Validation of the DCN’s conclusion regarding caregiver representation in the EHR can be found in the recently released [*Families Caring for an Aging America*](#) (Washington, DC: National Academies Press; 2016), which states that a workable mechanism in the health record for identifying caregivers could optimize the vital role caregivers play in the health care of loved ones.

The DCN achieved its goal of defining strategies and creating corresponding execution plans for caregiver representation in EPIC in partnership with Baylor Scott & White Health (BSWH) in Texas. Through direct engagement of BSWH’s chief medical informatics officer, four approaches were defined. Each was a feasible adaptation of EPIC by the health care organization, supplying family caregiver contact information in a location readily accessible by care providers. One of the four options would result in what the DCN considered to be the most desirable changes in how EHRs captured information from the family caregiver. The four desired characteristics are that (1) family caregiver contact information is clearly visible to clinicians during all health care encounters; (2) information reported by the family caregiver is clearly visible to clinicians during all health care encounters; (3) information is located in a structured field that is reportable; and (4) schedulers and providers are able to enter and edit information about the family caregiver.

Change AGENTS “Go Live” in Texas

Empowered by the findings of the DCN, BSWH is developing a system-wide implementation plan that adapts its use of EPIC to achieve the four desired characteristics delineated above. In addition to the technical modification to EPIC, methods of populating the new fields with information from family caregivers are being defined. Culturally sensitive language is being drafted. Privacy laws are being considered. Before the practice will “go live” (be instituted), staff will be trained by BSWH’s Center for Learning Innovation and Practice.



Leadership and Ongoing Work

BSWH will host a summit to explore further family caregiver representation in EHRs. Planned for January 2017, the summit will bring together invited thought leaders, health care providers, and advocates, including family caregivers, engaged in the topic of family caregiving. The summit will provide an opportunity for shared learning with the goal of engaging additional health care organizations, researchers, and policy makers in efforts that support caregiver representation in EHRs. The summit will also seek to align the work of the DCN with other national initiatives that are engaging and supporting family caregivers in health care delivery, such as Dementia Friendly America and the CARE Act movement.

The project was led by Alan Stevens of Baylor Scott & White, Dallas, TX (alan.stevens@bswhealth.org) with significant contributions from members of the DCN and the BSWH Project Phoenix Team.

The Change AGENTS Initiative was a three-year effort dedicated to improving the health of older Americans, their families, and their communities through practice change. The initiative harnessed the collective strengths, resources, and expertise of the John A. Hartford Foundation's interprofessional community of scholars, clinicians, and health system leaders. The initiative was managed by The Gerontological Society of America with support from the John A. Hartford Foundation.