Dissemination of a long-term care planning tool, PlanYourLifespan.org, through community-based stakeholder leaders

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Abstract

Background: Geriatrics research generally cumulates in academic journal publications, with variable diffusion to patients and communities. PlanYourLifespan.org is a free, evidence-based tool that assists older adults, and their loved ones, to better understand and plan for their long-term support needs. There is a need to effectively disseminate geriatrics research, such as PlanYourLifespan.org, to communities that may directly benefit from this research.

Objective: To leverage community-based stakeholder leaders, utilizing a train-the-trainer program, to disseminate PlanYourLifespan.org and evaluate the extent of the dissemination.

Methods: Using a train-the-trainer strategy, community stakeholder leaders from the original study paired up with newly recruited community stakeholder leaders. New community stakeholder leaders were trained on dissemination, using a “how-to-disseminate” web-based toolkit—developed as part of this project. Newly trained community stakeholder leaders subsequently trained additional community stakeholder leaders who conducted and tracked dissemination activities in their communities. Google Analytics tracked newly created PlanYourLifespan.org accounts, login sessions, and daily website visitors.

Results: Five newly trained community stakeholder leaders disseminated PlanYourLifespan.org over a three-month period. Cumulatively, on the day of the dissemination activity, there were 11,361 PlanYourLifespan.org log-ins (average: 378.7 log-ins/activity day), 89,068 log-ins (average: 2969 log-ins/activity week) one-week after the activity, and 319,154 log-ins (average: 10,638 log-ins/activity month) one month after the dissemination activity. Approximately 9.4 new PlanYourLifespan.org accounts were created one-week post dissemination activity and over 1100 new accounts in the one-month period thereafter.
Conclusions: Wide dissemination of PlanYourLifespan.org occurred by leveraging a train-the-trainer approach with community stakeholder leaders. Researchers should consider collaborating early on with community stakeholders to meaningfully disseminate results.

KEYWORDS
community-based research, dissemination, long term care planning

INTRODUCTION

Disseminating research results to older adults is crucial for improving patient-centered care and people’s ability to make informed health decisions. However, getting evidence-based research into practice has increasingly been recognized as a challenge. With the amount of misinformation and unsupported science being presented through lay routes (e.g., newsletters, social media, podcasts), researchers need to heavily consider dissemination as part of their geriatrics research. Traditional methods of dissemination such as publications in academic journals are often not accessible or tailored to the audiences that could most benefit from the information (e.g., older adults do not routinely have access to medical journals and may not understand how to interpret statistical results or medical jargon). Prior studies have demonstrated a number of social processes necessary for dissemination, including (1) partnerships between researchers, community members, and practitioners that support dissemination, (2) dissemination agents, and (3) the social context of how people receive the program.

An important research topic for many older adults is the concept of aging-in-place, which is a priority for many older adults and their families. Over time, many older adults experience progressive dependency which impacts their ability to age in place. The Centers for Disease Control and Prevention define aging-in-place as the ability to live in one’s own home and community safely, independently, and comfortably. By 2050, the number of individuals using support services in any setting will be close to 27 million people. Unfortunately, most older adults are unprepared or do not plan for their aging-in-place or long-term care (LTC) needs, which often result in unmet needs, unnecessary caregiver stress, burden, and institutionalization.

We developed and tested PlanYourLifespan.org, an online tool to assist older adults with learning about and planning for their long-term care needs. PlanYourLifespan.org fills a critical gap in that it is important for older adults to understand their future long-term care needs as this knowledge can translate into older adults having a voice in their future needs. PlanYourLifespan.org was tested against an attention control website in a randomized controlled trial among 385 community-based subjects > age 65 years (mean age 71.9 years). Subjects in the PlanYourLifespan.org arm had a one-month planning behavior score that was significantly higher than those in the attention control arm (1.25 points, CI 0.37–2.12, \(p = 0.0054\)) and significantly higher knowledge of LTC services (\(p < 0.05\)). PlanYourLifespan.org was shown to be effective in helping users understand the LTC

Key points

- Dissemination of geriatrics-focused research results to older adult end-users is crucial to making informed decisions.
- Using a train-the-trainer model with community stakeholder leaders, we sought to disseminate PlanYourLifespan.org, which is an NIH and PCORI-funded, evidence-based, proven effective, and aging-in-place/long-term care planning tool.
- Dissemination resources were developed to train and support community stakeholder leaders; community stakeholder leaders recruited and coached additional community stakeholder leaders.
- Tracking dissemination activities (e.g., lectures, meetings) conducted by community stakeholder leaders, PlanYourLifespan.org observed over 89,000 log-ins on the day of activities and over 300,000 visits in the month following the activity.

Why does this paper matter?

In order to disseminate research to people in the community, researchers should partner with community stakeholder leaders for widespread national and international dissemination of their geriatric-focused results.
services available to them, plan for their future needs, and communicate their plans with others. In having an effective tool that helped older adults plan for their LTC needs, we felt that it was imperative to disseminate PlanYourLifespan.org, and these results direct to the older adults and their families.

In developing and testing PlanYourLifespan.org, a panel of community stakeholder leaders provided input on its creation and assisted with recruitment for the earlier trial. Building on the successes of these partnerships, we sought to leverage their neighborhood connections to disseminate PlanYourLifespan.org directly to people in the community. With community stakeholder leaders, there is a knowledge gap on how to facilitate and leverage their social networks and processes to disseminate geriatrics research.

For this dissemination research, we developed a train-the-trainer PlanYourLifespan.org resource toolkit and tasked the original community stakeholder leaders with partnering with new community stakeholder leaders for dissemination training. The new community stakeholder leaders then trained additional community stakeholder leaders. The train-the-trainer concept has been proven effective with students, clinicians, peer-to-peer in similar diseases, and palliative care. To our knowledge, the train-the-trainer method has not been evaluated with community stakeholder leaders in patient-centered geriatrics research. Subsequently, the aim of this research was to evaluate the extent of the dissemination of PlanYourLifespan.org, directly to older adults and their supporters, using a train-the-trainer model with community stakeholder leaders.

METHODS

Organizing conceptual model of dissemination

As a framework, we leveraged the Model of Diffusion of Innovations in Service Organizations, which identifies the main domains in which factors influence the implementation of interventions in organizations. While the full model is expansive, the most relevant features for this research focus on the characteristics of the 1. Innovation in itself (e.g., the relative benefit of use for members, low complexity, compatibility with an organization), 2. Communication and Influence of Champions (e.g., social networks, peer opinion, change agents), and 3. Linkages (e.g., shared meaning, effective knowledge transfer, user orientation). From this model, innovations are more easily adopted if they have (a) Clear unambiguous advantage in effectiveness (relative advantage/benefit of use to members) (b) Compatibility with the intended adopters’ values, norms, and perceived needs, and (c) Perceived as simple to use.

Building off this theory and conceptual model, as an intervention, PlanYourLifespan.org has a high degree of relative advantages and compatibility (supporting seniors aging-in-place which is a goal of most seniors and our partnering senior-support organizations), and low complexity which makes it ripe for dissemination/implementation. Interpersonal influence through social networks (defined as patterns of friendship, advice, communication, and support that exist among members of a social system) has been shown to be critical to the dissemination/implementation of innovations.

With our strong patient partner/stakeholder engagement, an obvious next step is linking original community stakeholder leaders with new trainees/future trainers to create exponential active community-based PlanYourLifespan.org dissemination. A train-the-trainer program has never been tried with patient partners/stakeholders in disseminating patient-centered outcome research. This linkage between trainers and trainees is a key part of the conceptual model and provides effective knowledge transfers and support. The train-the-trainer model leveraged the social networks of patient partners/stakeholders to actively expand PlanYourLifespan.org dissemination to multiple diverse communities and end-user seniors.

Development of a PlanYourLifespan.org dissemination toolkit

The research team partnered with the original community stakeholder leaders on developing the content on how to encourage the use of PlanYourLifespan.org in their communities. We initially conducted semi-structured interviews with 10 stakeholders to examine their experiences in disseminating patient-centered outcomes research results and characterize lessons learned that may facilitate future researcher-stakeholder dissemination partnerships. Questions included describing what was most important, concerns, key behaviors, trouble-shooting, and advice when disseminating PlanYourLifespan.org. Coders then utilized constant comparative and thematic analysis to analyze the responses and this data-informed content of the toolkit for dissemination training. The community stakeholder leaders and research team then drafted and finalized content for the online toolkit through an iterative process. The final PlanYourLifespan.org Dissemination resource toolkit, available both online and in print, included lay language PowerPoint presentations, handouts, suggestions for audiences, and dissemination of troubleshooting questions.
Using the PlanYourLifespan.org dissemination toolkit to train-the-trainer of additional community stakeholder leaders

New community stakeholder leaders were identified through multiple means, including word-of-mouth, in-person contact at presentations, and outreach through personal social network connections. Each original community stakeholder leader paired up and trained an additional community stakeholder leader using the PlanYourLifespan.org Dissemination Toolkit. The pairs completed an initial half-day training session in person. The original community stakeholder leaders had intimate knowledge of the toolkit as they helped develop it and utilized the toolkit to use as part of the training. The community stakeholder leader pairs also completed two additional virtual one-on-one follow-up sessions (30–60 min) to reinforce training. The training was flexible and the timing of the training was tailored to the schedules of pairs. Original community stakeholder leaders were available as needed to troubleshoot and support the new community stakeholder leaders throughout the project. After the training sessions were completed, the newly trained community stakeholder leaders had access to the PlanYourLifespan.org Dissemination Resource Toolkit and focused on disseminating PlanYourLifespan.org by recruiting and training additional 1–5 trainee community stakeholder leaders to further disseminate. Trainee community stakeholder leaders were eligible for participation if they were: (1) age >18 years; (2) able to understand spoken English; and (3) Score ≥4 questions correctly on the Brief Cognitive Screen. For participating in training (3–4 h) and pre/post surveys (2 h), each trainee community stakeholder leader was compensated with $150 (via the Patient-Centered Outcomes Research Institute funding). (Figure 1).

Measuring dissemination of PlanYourLifespan.org through community stakeholder leaders

Community stakeholder trainees tracked their dissemination activities within their communities for a three-month period. Specific outcomes tracked included the number of presentations or events given related to PlanYourLifespan.org, participant attendance, quantities of printed and distributed copies of PlanYourLifespan.org resources, media placements (e.g., newspapers, radio, etc.), newsletter recipients, and e-mail inquiries about PlanYourLifespan.org. Research staff collected these logs after the three-month dissemination period. To quantify the impact of the dissemination trainees’ activities and to measure PlanYourLifespan.org usage, Google Analytics tracked the number of unique accounts created and visits to PlanYourLifespan.org, geocoding of unique accounts, and timing of those metrics in relation to the dissemination activities.

RESULTS

Two original project community stakeholder leaders located in Illinois and Indiana partnered and trained two new dissemination trainees in Indiana and Hawaii. The two newly trained community stakeholder leaders each recruited and trained three additional community stakeholder leader trainees during the study period, for a total of six, although one of the trainees withdrew from the study. Five community stakeholder leaders disseminated PlanYourLifespan.org during the three-month period. Community stakeholder leaders were diverse in terms of their occupational background as well as their geographical area of dissemination. Examples of community stakeholder leaders included a nurse leader of an Area Agency
on Aging serving rural Indiana, a social work leader of a case management and physician extender company serving the Hawaiian islands, an Agency on Elderly Affairs, and older adult patients who had experience caregiving in urban communities in Chicago, Illinois, and Indianapolis, Indiana. Community stakeholder leaders worked closely with older adults in the community and had a passion for helping older adults age in place with adequate support services.

Trainee community stakeholder leaders reported using the PlanYourLifespan.org dissemination toolkit as part of their dissemination activities, most notably during the dissemination training, to help prepare for their activities, and during the dissemination activities period. They found the resources pages, which included the printable information cards, handouts, and frequently asked questions sections as the most helpful.

Community stakeholder leaders conducted 31 in-person dissemination activities over the course of the three-month activity period and directly reached 1080 individuals during these dissemination activities. The dissemination modalities targeted three specific groups: (1) caregivers and older adults, (2) clinical/healthcare professionals, and (3) other patient partners/community stakeholders. Examples of dissemination activities included: church group presentations, community health fairs, presentations to local community college students, and presentations to local legislative forums. The dissemination activities occurred either (1) specifically to promote the use of PlanYourLifespan.org (e.g., community group lectures) or (2) in conjunction with other events (e.g., book clubs, coffee socialization hours). The reach and impact beyond the in-person attendance of these activities were measured by new PlanYourLifespan.org accounts created as well as where in the country those accounts were created, registered log-ins to PlanYourLifespan.org and overall web traffic to the website.

In the study period, there were 281 newly created PlanYourLifespan.org user accounts in the 1-week post-dissemination activities (9.4 accounts/activity) and 1101 new accounts in the 1-month period post dissemination activities (36.7 new accounts/activity). Of the newly created accounts 1-week post-activity, 73/281 (26%) occurred in the same state as the dissemination activity and in 1-month post activity, 252/1101 (22.9%). We believe the relatively low percentage of accounts created in the same state as the dissemination activity may point to people sharing the website with people in other states (Table 1). On the day of the dissemination activity, there were 11,361 log-in sessions (average: 379 log-ins/activity day) where users logged in using their unique accounts. One-week after the dissemination activity, 89,068 log-ins were registered (average: 2969 log-ins/activity week), and 319,154 log-ins (average: 10,638 log-ins/activity month) 1-month post dissemination activity. Cumulatively, on the day-of dissemination activities, 89,562 website visitors (average: 2985 visitors/activity day) were registered (Table 1).

Geocoding of log-in addresses showed extensive mapping to the same and neighboring states of the community stakeholder leaders as well as further national and international outreach (Figure 2).

### DISCUSSION

Disseminating a geriatrics-focused long-term care planning tool, PlanYourLifespan.org, through a train-the-trainer approach with community-based stakeholder leaders...
leaders was effective in reaching large geographic audiences. The impact of this stakeholder-based dissemination was strongly felt in terms of the number of systems and community groups adopting PlanYourLifespan.org as a result of dissemination efforts. Even though small in number at first look, community stakeholder leaders were central to the dissemination success of this project. Community stakeholder leaders assisted in the development of the dissemination toolkit, were involved in the training and mentoring of the dissemination trainees, and used their networks to help disseminate PlanYourLifespan.org. In addition, they developed ways to integrate PlanYourLifespan.org into their existing services, which enabled greater sharing of the website and also helps to strengthen future sustainability efforts.

As an example, the community stakeholder leader at FirstVitals Health & Wellness embedded PlanYourLifespan.org into their Welcome to Medicare and Annual Medicare Visit intakes. The community stakeholder leader with the Agency on Elderly Affairs in the County of Kauai shared PlanYourLifespan.org during their intake visits, sharing the website as a resource for older adults, their caregivers, and families who visit their office and request services. Aging and In-Home Services of NE Indiana continues to share PlanYourLifespan.org with their clients at several of their programs including Wellness Café meal programs for older adults and as a resource at their Aging and Disability Resource Center. Their case managers are familiar with PlanYourLifespan.org and offer this regularly as a resource to their clients. Individual community stakeholder leaders continue to disseminate to peers in small group settings, especially caregiver support groups and in faith-based settings. These examples demonstrate future researchers how specifically community stakeholder leaders can be a critical partner in disseminating study findings.

The findings of this study are somewhat limited by potential contamination. Because the goal of this study was to disseminate PlanYourLifespan.org, we did not restrict access to it. Website users who were not community stakeholder leader dissemination trainees were able to access PlanYourLifespan.org during the same study period. Results from prior research had been presented at national conferences and non-study-related individuals were free to share PlanYourLifespan.org during the study time, which may have led to an overestimate of the dissemination impact of the community stakeholder leader train-the-trainer strategy. Another limitation to the study was that at the time, PlanYourLifespan.org had to be accessed on a tablet or desktop computer and it is not mobile-friendly. While disseminating, some community stakeholder leaders found that having a computer present that people could use to access the website made for easier instruction. Subsequently, PlanYourLifespan.org has been modified to make it viewable on a smartphone. We anticipate that PlanYourLifespan.org will be even easier to disseminate with smartphone accessibility, but further research is needed to test this hypothesis.

Well beyond this project, PlanYourLifespan.org continues to be accessed and is nationally disseminated, largely due to our expanding community stakeholder leader efforts. After the project ended, Epic Systems Corporation (Verona, WI, USA) learned of PlanYourLifespan.org through our dissemination efforts and reached out to include PlanYourLifespan.org as part of their MyChart/Patient resources page. This partnership allows patients to access the website through their patient portal, and it also enables physicians to share PlanYourLifespan.org as a resource in the patient printout after their medical visit.

This study provides evidence that community stakeholder leaders can be leveraged to disseminate geriatrics research. Researchers should consider dissemination early on in their projects and establish relationships with community partners. By continuing to form connections with more community partners, we have built an ever-expanding network of people who are spreading our results and intervention. With these results, we have shown that community members can continue to pave the way for future, meaningful research implementation.

**AUTHOR CONTRIBUTIONS**

All authors met the criteria for authorship by providing a substantial intellectual contribution to the study's conception and design (Lee A. Lindquist, Chris Forcucci, Norine Wong, Beverly Rogers, and Vanessa Ramirez-Zohfeld), data acquisition (Chris Forcucci, Norine Wong, Ana Ramirez, and Vanessa Ramirez-Zohfeld), data analysis (Lee A. Lindquist, Ana Ramirez, and Vanessa Ramirez-Zohfeld) and interpretation (Lee A. Lindquist, Chris Forcucci, Norine Wong, Beverly Rogers, Ana Ramirez, and Vanessa Ramirez-Zohfeld); drafting the article or revising it critically for important intellectual content (Lee A. Lindquist, Ana Ramirez, and Vanessa Ramirez-Zohfeld); and approving the final version to be published (Lee A. Lindquist, Chris Forcucci, Norine Wong, Beverly Rogers, Ana Ramirez, and Vanessa Ramirez-Zohfeld).

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CONFLICT OF INTEREST
All authors declare no conflict of interest.

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The sponsor was not involved in the design, methods, analysis, interpretation of the data, and preparation of the manuscript.

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