

SHARING CHOICES

Sharing access to Health records, Agenda-setting, **RespectING CHOICES** to engage families

Multi-Principal Investigators:

Sydney M. Dy, MD

dy1@jhu.edu

Professor, Health Policy & Management
Johns Hopkins Bloomberg School of Public Health

Jennifer L. Wolff, PhD

jwolff2@jhu.edu

Professor, Health Policy & Management
Johns Hopkins Bloomberg School of Public Health

NIA R61AG061882 (R61 PHASE)

09/2018 – 08/2020

Background

Advance care planning (ACP) is a communication process that supports adults at any age or stage of health in understanding and sharing their personal values, life goals, and preferences regarding future medical care.¹

This study will refine and test an ACP intervention for older adults including those with Alzheimer's Disease and Related Dementias through engagement of family in primary care.

1. Sudore RL, Lum HD, You JJ, et al. Defining Advance Care Planning for Adults: A Consensus Definition from a Multidisciplinary Delphi Panel. Journal of pain and symptom management 2017.

Background

- Alzheimer's Disease and Related Dementias (ADRD) are profoundly disabling and costly
- Family is at the forefront of managing ADRD
- Family are not routinely engaged in discussions about surrogate decision-making
- Few interventions target advance care planning in primary care, which is the setting where most persons with ADRD are initially diagnosed and medically managed

SHARING CHOICES Intervention

1. A **letter** from the clinic introducing an initiative to prepare persons and families for Advance Care Planning (ACP);
2. Access to a **facilitator** trained to lead ACP discussions;
3. Patient-family **agenda-setting** to align perspectives about the role of family and stimulate discussion about ACP;
4. Facilitated registration to the **patient portal** (for patient *and* family) as desired;
5. Education & resources about ADRD for clinic staff.

1. Letter from Clinic Introducing ACP

Improving Advance Care Planning
Green Spring Station General Internal Medicine (2015-Present)

Team-based approach:

- Medical office coordinator identifies eligible patients
- Letter 1-2 weeks prior to appointment with an advance directive included
- Reminder to the provider to discuss advance care planning with the patients at visit

Qualitative interviews with patients

- **Normalizing ACP in primary care:** *“It’s important to stress things like advance directives. I know there is a lot of push back ... there are some people saying that’s none of your business. I think it is. I think sometimes people just don’t think about it and I think it’s right for the medical community to ask.”*
- **Early initiation of ACP:** *“I’d rather deal with it now when I have all my faculties than later when I might be in distress and maybe not in a good frame of mind and maybe not pick the right decision.”*
- **Approach to embedding ACP initiative in primary care:** *“The good part about receiving it in a letter, that you have time to, think about it, absorb it because you have to bring it in and then talk with the doctor. I feel it’s also good because then you can engage with it a little bit better than having it roughly thrown at you.”*

2. Respecting Choices

- **Respecting Choices** is an evidence-based communication program for planning for future medical decisions. From the patient perspective, this process includes:
 - **Reflection** of goals, values, and beliefs,
 - **Understanding** of possible future situations and decisions,
 - **Discussing** these reflections with others.
- **ACP Facilitators** integrate ACP as an ongoing component of routine care:
 - Motivate individuals to participate
 - Guide ACP Discussion
 - Identify planning needs
 - Create follow-up plans
 - Document plans and discussions
 - Engage families & decision-makers



3. Agenda-Setting

- Previous proof-of-concept studies ([NCT02986958](#)) establish the feasibility and effectiveness of an agenda-setting checklist to help patients & family prepare for routine primary care visits.
- The **checklist** involves two activities completed while waiting for the visit:
 1. Clarifying the role of the family in the visit;
 2. Identifying issues about the patient's health to discuss with the clinician. The patient and family separately identify their concerns, and then decide together what to discuss.
- We enrolled 93 persons with cognitive impairment (mild to severe) and their family members from 3 primary care clinics in a randomized trial of the agenda-setting checklist and found significant shifts towards patient-centered communication.¹

1. Wolff JL, Roter DL, Boyd CM, Roth DL, Echavarria DM, Aufill J, et al. Patient-Family Agenda Setting for Primary Care Patients with Cognitive Impairment: the SAME Page Trial. J Gen Intern Med. 2018 Jul 18.

Making the most of your visit

This conversation guide is for patients who attend primary care visits with a family member or friend. Together, use this guide to prepare for today's visit.

STEP 1 How can your family member or friend be most helpful today?

Together, decide what types of help you would like. Mark (✓) all that apply:

- Listen and remember what the doctor says or means.
- Prompt you to ask questions or tell the doctor your concerns.
- Ask the doctor questions or give the doctor information directly.
- Allow you time alone with the doctor for some or all of the visit.

STEP 2 What do you want to discuss with your doctor today?

Together, decide which concerns are most important.

Patient Health Issues	Mark (✓) if a concern to:	
	PATIENT	FAMILY
Hearing or vision	<input type="checkbox"/>	<input type="checkbox"/>
Fear of falls, dizziness, or balance	<input type="checkbox"/>	<input type="checkbox"/>
Bladder or bowel problems	<input type="checkbox"/>	<input type="checkbox"/>
Safety at home or when driving	<input type="checkbox"/>	<input type="checkbox"/>
Difficulty bathing, dressing, or walking	<input type="checkbox"/>	<input type="checkbox"/>
Financial matters that affect patient health	<input type="checkbox"/>	<input type="checkbox"/>
Planning for serious illness or progression of current illness	<input type="checkbox"/>	<input type="checkbox"/>
Changes in personality or behavior	<input type="checkbox"/>	<input type="checkbox"/>
Stress, worry, or feeling sad or blue	<input type="checkbox"/>	<input type="checkbox"/>
Trouble concentrating or making decisions	<input type="checkbox"/>	<input type="checkbox"/>
Memory problems	<input type="checkbox"/>	<input type="checkbox"/>
Managing or taking medications	<input type="checkbox"/>	<input type="checkbox"/>
Add other issues: (optional)	<input type="checkbox"/>	<input type="checkbox"/>
	<input type="checkbox"/>	<input type="checkbox"/>

Add other issues: (optional)

STEP 3 How do you want to manage the patient's health information?

If you are interested, the study staff will show you how to use MyChart

Mark (✓) all that apply:

- Set up patient access to MyChart (electronic access to health record).
- Set up family/friend "shared" (proxy) access to patient's MyChart account.

STEP 1: How can your family member or friend be most helpful today?

STEP 2: What do you want to discuss with your provider today?

STEP 3: How do you want to manage the patient's health information after today's visit?

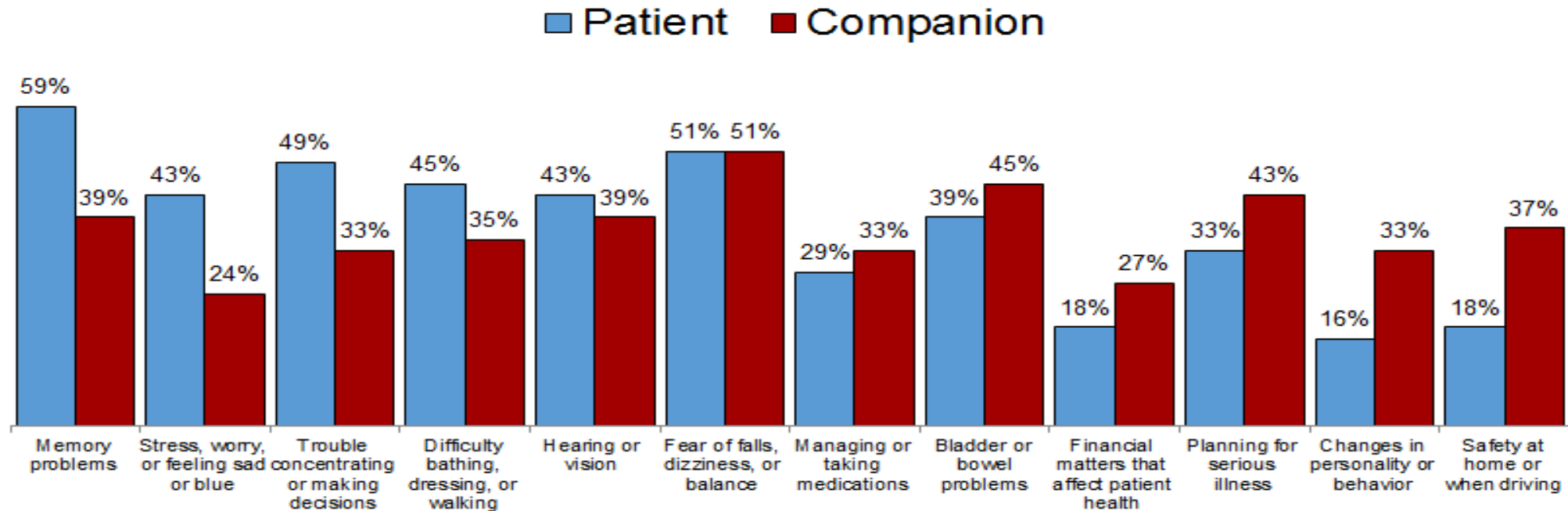
SAME Page Study Participant Comments

- **Patient reliance on caregiver:** “She is my memory” – patient
- **Inherent barriers in communication:** “He doesn’t know that he doesn’t know, so we can’t talk about it.” – companion
- **Under-diagnosis of memory issues:** “She has memory problems, but I don't think she's been diagnosed.” – companion
- **Partnership with caregivers:** “We live together. I'm involved in all her activities. I retired for this purpose [to manage their care]. Every doctor we go to, I'm the backbone. When we go into the doctor's office I wait and see; if she answers incorrectly, I step in. I've grown into where I am with her now.” – companion

STEP 1 How can your family member be most helpful today?

	Checked
1. Help you understand what the provider says or means	91.3%
2. Remind you to ask questions or tell the provider your concerns	84.8%
3. Ask questions or give the provider information	82.6%
4. Listen to what your provider says and take notes	82.6%
5. Allow you time alone with the provider for some or all of the visit	52.2%

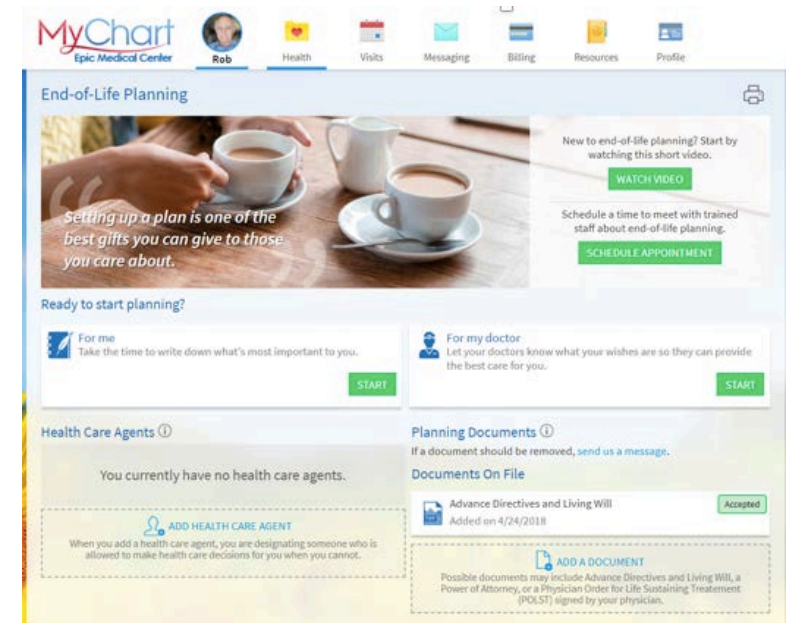
STEP 2 What do you want to discuss with your provider today?



n=49 participants in intervention group of 93 enrolled; 42 of 49 patients responded to checklist.

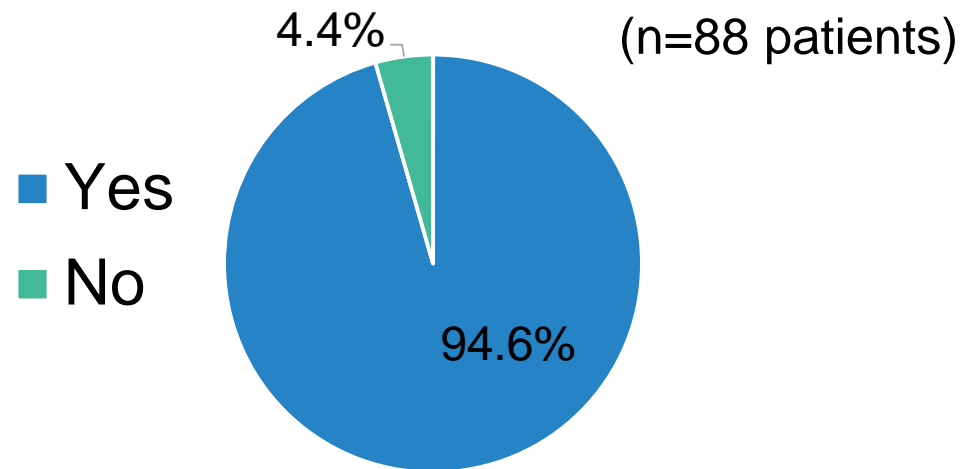
4. Shared Access to Patient Portal

- Registering the family to have access to the patient's electronic health information as desired by the patient.
- Ongoing studies establish the feasibility of facilitating access to the electronic health portal for patients & families. ([NCT03283553](#))
- Our work indicates shared access is a strategy that respects individual preferences for involving family in their care and supports family with comprehensive and timely information about patient health and a mechanism to communicate with clinicians.



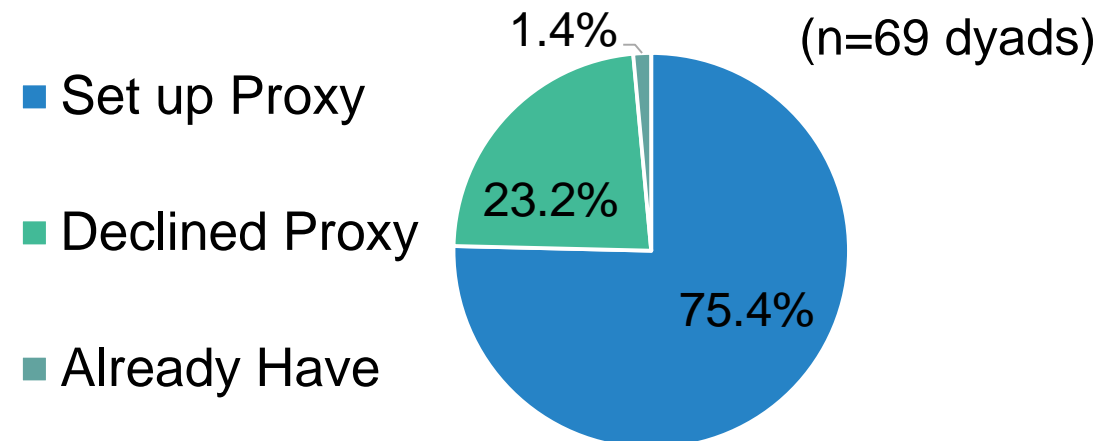
4. Shared Access to Patient Portal

- **94.6%** of patients in the SAME Page study said they would like their companion to have access to their electronic medical information.



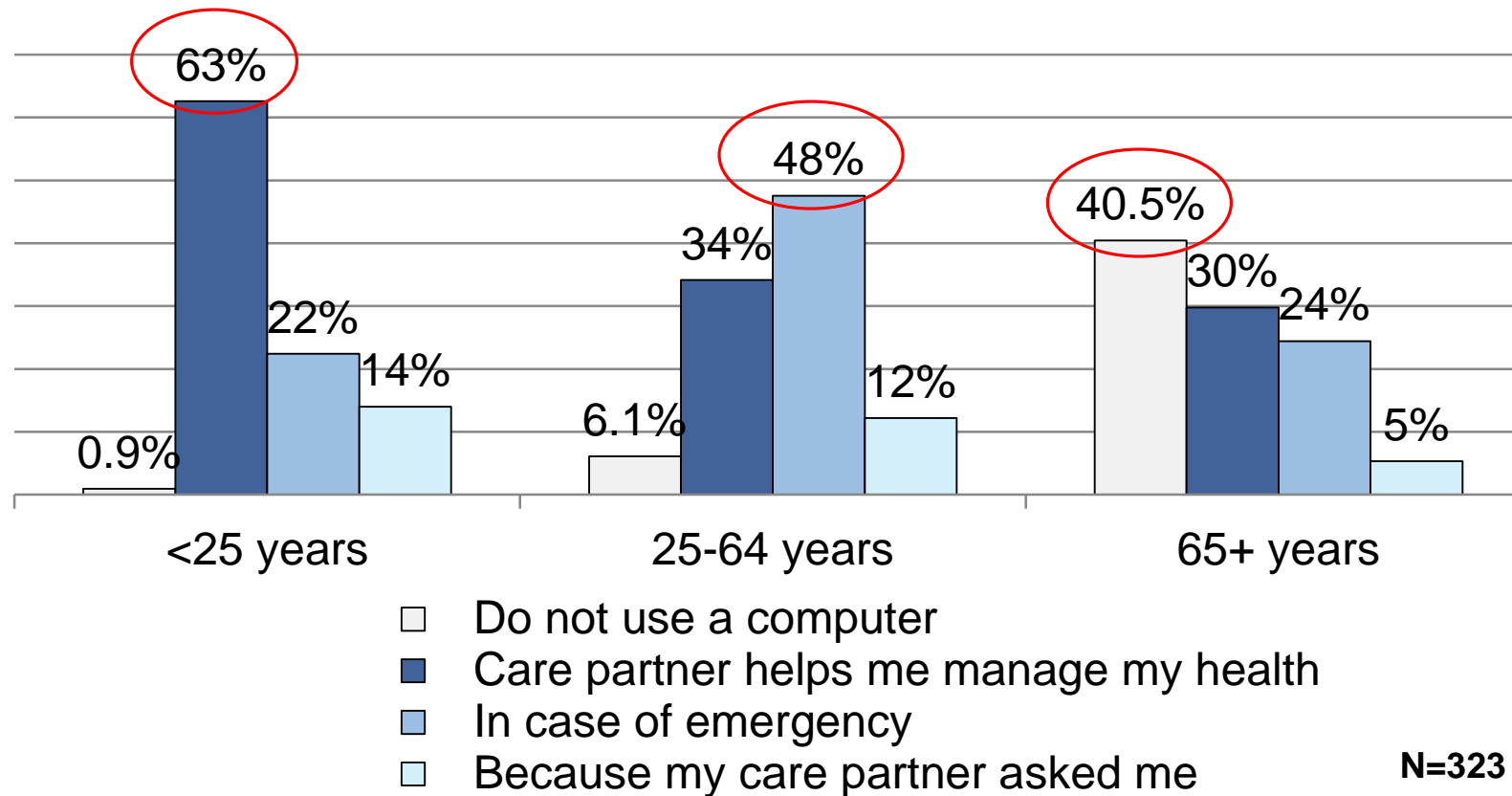
Source: *"Involving Family to Improve Communication in Primary Care"* (NCT02986958)

- **75.4%** of intervention patients in the Sharing in Care study opted for proxy access when offered.



Source: *"Involving Family to Improve Communication in Breast Cancer"* (NCT03283553)

Shared Access at an Integrated Health System: What Are Patients' Motivations for Sharing Access?



Source: Wolff JL, Berger A, Clarke D, Green JA, Stametz RA, Darer J., JAMIA 2017.

5. Education & Resources about ADRD

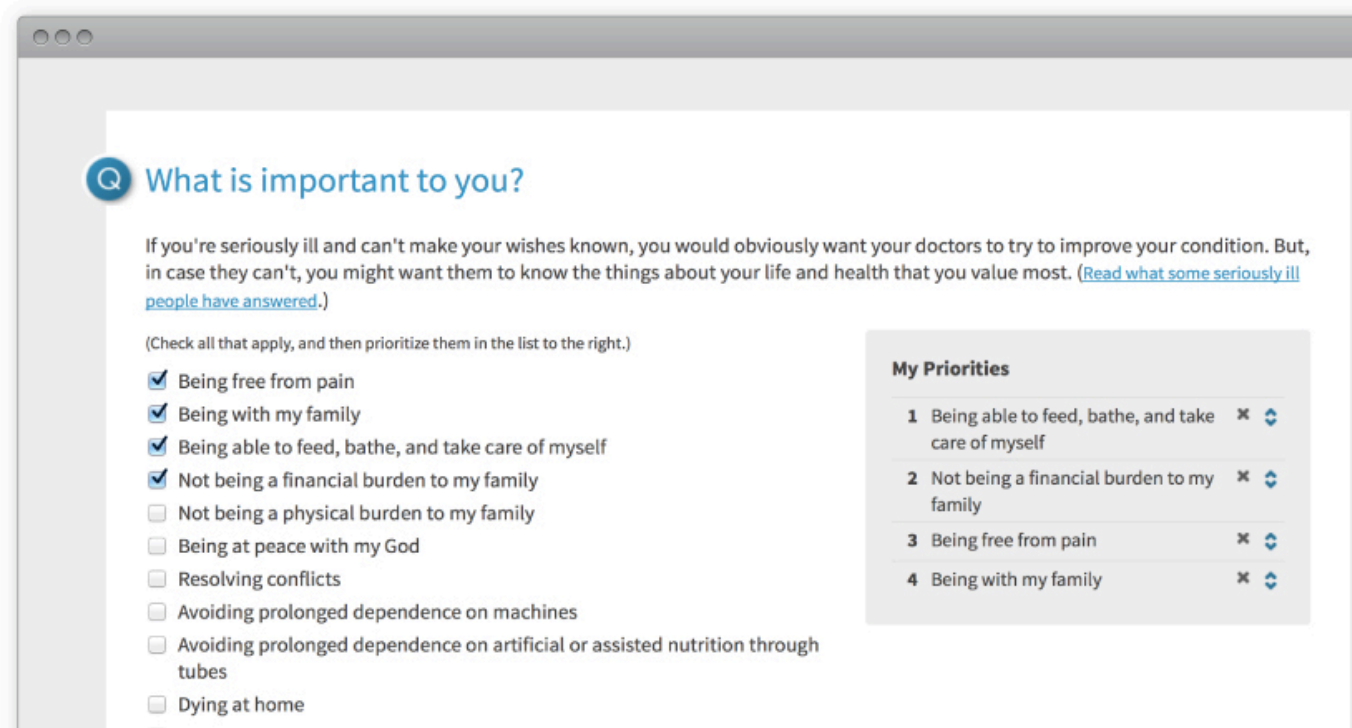
- Patients and family expect primary care practices to provide reliable information about dementia.
- The study will provide education and resources about ADRD at participating intervention clinics to support dementia-friendly care delivery which may include:
 - Tool kits,
 - Training curriculum,
 - Billing codes,
 - Referral resources.



Easy to Create

MyDirectives makes it easy to create a state-of-the-art emergency, critical and advance care plan.

You can answer questions in your own words or pick from a selection of the most common answers. Add your thoughts with as much detail as you wish. You can even add your own video responses.



Easy to Share

You can share your emergency care plan with anyone at any time. Hospitals that link to MyDirectives can access your care plan when you are admitted.

Capture the power of your voice.

Download the MyDirectives MOBILE™ app to add your own video statement to your profile.

Make a statement.
Make it yours.
Make it available.

MyChart
Epic Medical Center

Rob | Health | Visits | Messaging | Billing | Resources | Profile

English | Rob Theodore Kraft | Log Out

End-of-Life Planning

Setting up a plan is one of the best gifts you can give to those you care about.

New to end-of-life planning? Start by watching this short video.

[WATCH VIDEO](#)

Schedule a time to meet with trained staff about end-of-life planning.

[SCHEDULE APPOINTMENT](#)

Ready to start planning?

For me
Take the time to write down what's most important to you.

[START](#)

For my doctor
Let your doctors know what your wishes are so they can provide the best care for you.

[START](#)

Planning Documents

If a document should be removed, [send us a message](#).

Documents On File

Advance Directives and Living Will [Accepted](#)
Added on 4/24/2018

[ADD A DOCUMENT](#)

Possible documents may include Advance Directives and Living Will, a Power of Attorney, or a Physician Order for Life Sustaining Treatment (POLST) signed by your physician.

[BACK TO THE HOME PAGE](#)

Related Links

- [Ask a question](#)
- [Speak with someone now](#)

Planning Questionnaires

Filling out the End-of-Life Planning questionnaires helps your care team understand your wishes, but it does not replace up-to-date legal documentation of your end-of-life plans.

Helpful Resources

These resources will help you make care decisions and prepare for conversations with your family, friends, and doctors.

- [Five Wishes](#)
Help others understand what matters most to you.
- [Helping With Comfort and Care](#)
Advice to cultivate comfort and happiness towards the end of life.
- [Plan Your Lifespan](#)
Help you plan for health events that may happen as you get older.

Feb 2018

Site Map | Terms & Conditions | Contact Us | High Contrast Theme | MyChart® licensed from Epic Systems Corporation © 1999 - 2018

Patients may upload any end-of-life planning documentation without needing to remember their paper forms!

MyChart
Epic Medical Center

English -
Rob Theodore Kraft
Log Out

Health Care Agents ⓘ
You currently have no health care agents.

New Health Care Agent

Health Care Agent: Susan Kraft (Spouse)

Relationship: Spouse Agent Relationship: Health Care Agent

Legal document for this relationship: Power of Attorney.pdf (Just uploaded)

Street Address: 5604 Lacy Rd.

City: Fitchburg State: Wisconsin ZIP: 53711

County: DANE Country: United States of America

Home Phone: Mobile Phone: 608-878-1548

Work Phone: Email:

Your changes to the Agent Relationship and/or attached Legal Document will be accepted pending our review.

SAVE CHANGES CANCEL

[BACK TO THE HOME PAGE](#)

Planning Documents ⓘ
If a document should be removed, send us a message.

Documents On File

Advance Directives and Living Will
Added on 4/24/2018 Accepted

Documents In Review

Power of Attorney.pdf
Uploaded on 4/24/2018 In review

ADD A DOCUMENT
Possible documents may include Advance Directives and Living Will, a Power of Attorney, or a Physician Order for Life Sustaining Treatment (POLST) signed by your physician.

And fill out the necessary information to designate a health care agent.

Aug 2018

Intervention Components

Component	Rationale	Evidence of Effectiveness
1. Primary care initiated advance care planning (ACP)	Most patients expect primary care practices to initiate advance care planning. Proactively introducing advance care planning normalizes these discussions.	Primary care initiatives to increase advance directive completion are effective and well-received.
2. Education and availability of non-clinician led advance care planning	Advance care planning videos increase patient & family awareness, knowledge and skill. Respecting Choices is a structured advance care planning curriculum.	Advance care planning is associated with delivery of goal concordant care, greater confidence among surrogate decision-makers & reduced costs.
3. Person-Family Agenda Setting	Individuals & families often have different concerns. Agenda-setting stimulates discussions about advance care planning & the role of family.	Agenda-setting helps clarify concerns, goals, and expectations, and increase engagement in care.
4. Access to Electronic Health Record Via Patient Portal	The patient portal facilitates timely and accurate information about patient health, diagnoses, test results, & prescribed treatments. Families are provided their own identity credentials to access information and communicate with clinicians.	The patient portal operates through mechanisms of convenience, continuity, activation, and understanding. Prior studies find clinical benefit of supporting family through technology.
5. Dementia Resources & Training in Clinic	Patients and family expect primary care practices to provide reliable information about dementia but clinics are often ill prepared.	Tool kits, training curriculum, billing codes, & referral resources support dementia-friendly care delivery.

R61 Phase: Interview, Refine, Pilot

Aim 1A. To iteratively refine the SHARING CHOICES protocol through in-depth interviews with:

- 10-20 Primary Care Clinicians
- 5-10 Administrators
- 5-10 Staff Members (office coordinators, medical assistants, front desk)
- 5-10 Case Managers

Aim 1B. To iteratively refine the SHARING CHOICES protocol through in-depth interviews with persons with ADRD (mild to severe) and family (n=18-24 dyads).

Aim 2. To pilot the resultant protocol with 20 person-family dyads at 2 clinics (40 dyads total) to establish feasibility and acceptability of all processes and infrastructure for the R33 trial.



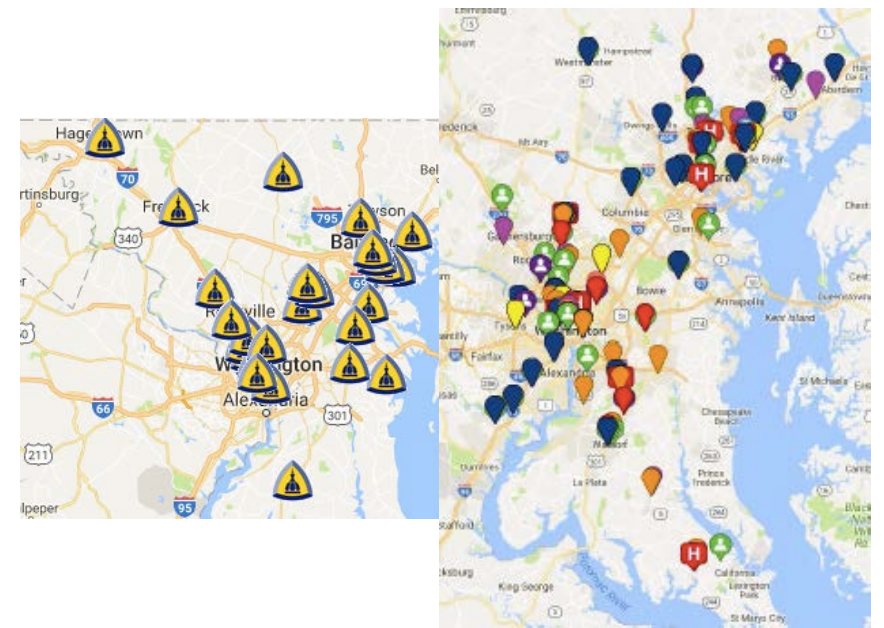
R33 Phase: Multisite Pragmatic Trial

Aim 3. Multisite pragmatic trial at up to 100 primary care clinics in 2 health systems with 67 clinics assigned to control protocol & 33 clinics assigned to SHARING CHOICES.

Aim 4. Test the effects of SHARING CHOICES in those ages 65+ and those with a diagnosis of ADRD. The study will assess whether patients at intervention clinics will be:

1. More likely to have a documented advance directive in their electronic health record at 12 months;
2. Less likely to experience burdensome end-of-life care;
3. Have higher quality of end-of-life care & quality of end-of-life decision-making.

Aim 5. Evaluate implementation and contextual factors that may facilitate or impede dissemination and sustainability in primary care.



Questions?



@LipitzCenter @jwolff_sph



<https://www.jhsph.edu/research/centers-and-institutes/roger-c-lipitz-center-for-integrated-health-care/index.html>



Subscribe to our Lipitz Center Quarterly Newsletter!

<https://app.e2ma.net/app2/audience/signup/1876970/1888797.53847581/>