THE EXPERIENCE OF CARE: PATIENTS AND PROVIDERS AS PARTNERS

Patient & Provider Engagement:

Forging True Partnerships and Changing the Culture

CREATING A CULTURE OF QUALITY
CCQ

Moderator

Jay Ginsberg, MD, MMM

Southeastern Connecticut Nephrology Associates
Co-Chair, Quality Conference Planning Committee
Past-chair, Forum Medical Advisory Council
Past Board Member, Forum Board of Directors

The Experience of Care: Patients and Providers as Partners

A 3-part Webinar Series

Improving Patient Experience of Care:

- How to change the way we look at patient experience of care
- How to use new information to improve the patient experience of care
- Breaking down barriers to communication

ACKNOWLEDGEMENTS

American Association of Kidney Patients for their generous financial donation supporting this webinar series

Northwest Renal Network (#16) for supporting and coordinating the social work and nursing CEs

ACKNOWLEDGEMENTS

Thank you to…

Fresenius Medical Care-NA

DaVita

Dialysis Clinic, Inc.

National Renal Administrator's Association

Renal Physicians Association

The Patient Perspective:

What is the experience of care?
Are we asking the right questions?

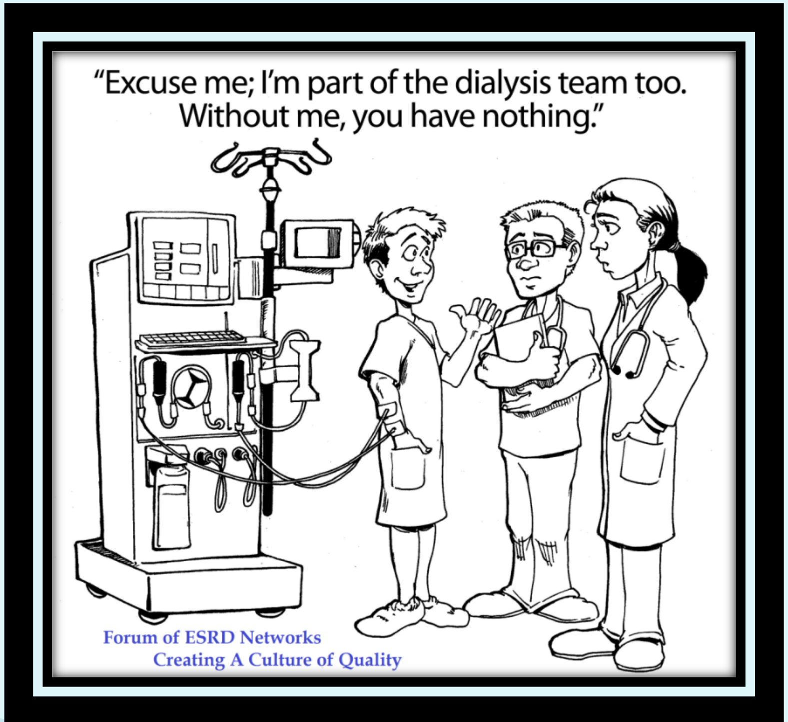
September 14
October 19
November 9

The Provider Perspective:

What do we learn from experience of care surveys?
Can we do better?

Patient and Provider Engagement:

Forging true partnerships and changing the culture


“Excuse me; I’m part of the dialysis team too. Without me, you have nothing.”

Forum of ESRD Networks
Creating A Culture of Quality

WEBINAR #3

Patients & Provider Engagement

Forging True Partnerships & Changing the Culture

- Explain the importance of facility culture, as cultivated by staff and patients, as it relates to ESRD patient engagement
- Describe how peer mentoring supports patient involvement and improves the patient experience of care
- Discuss methods to incorporate life goals and values to improve the experience of care

Patient Provider Collaborations: Findings of the UNC ESRD Patient Engagement Study

Jennifer E. Flythe, MD, MPH

Assistant Professor of Medicine

University of North Carolina Kidney Center
Chapel Hill, NC

Finding and Harnessing the Patient Voice

Jennifer E. Flythe, MD, MPH

University of North Carolina Kidney Center

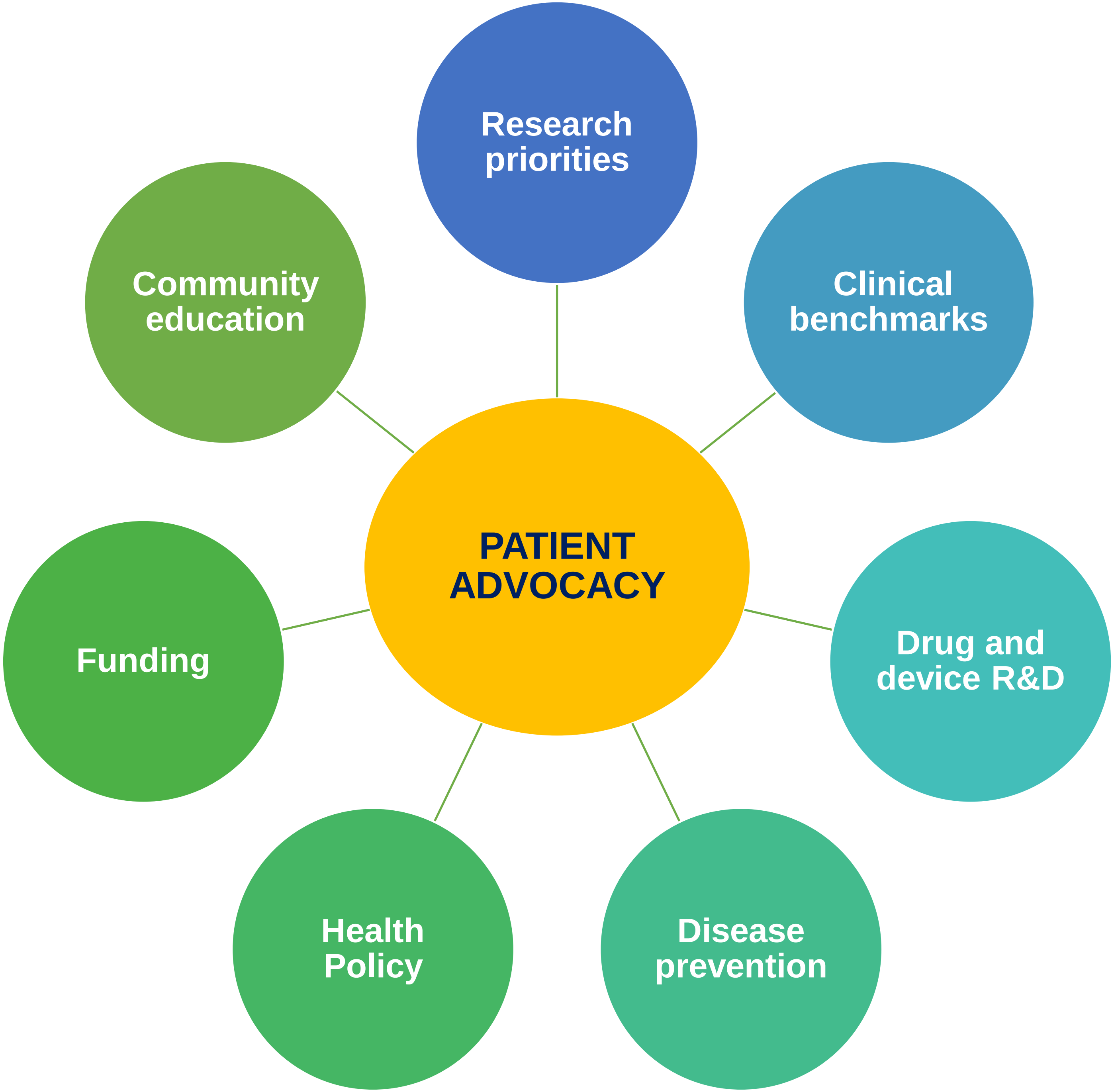
Chapel Hill, NC

UNC HEALTH CARE

KIDNEY CENTER

Frequent congregation
Shared interest

Inertia. Sadly, so many kidney patients just become complacent… the minute they step in-center [for dialysis], they’ve given up.
[63y F]



PATIENT ADVOCACY

Research priorities

Clinical benchmarks

Drug and device R&D

Disease prevention

Health Policy

Funding

Community education

Study Objectives

- To elicit knowledge and perceptions of chronic kidney disease (CKD)-related advocacy among hemodialysis (HD) patients
- To gather ideas for generating advocacy enthusiasm in the dialysis community

CKD advocacy: *the act of speaking out on behalf of persons with CKD or on behalf of a CKD-related cause*

Methods

- Semi-structured interviews

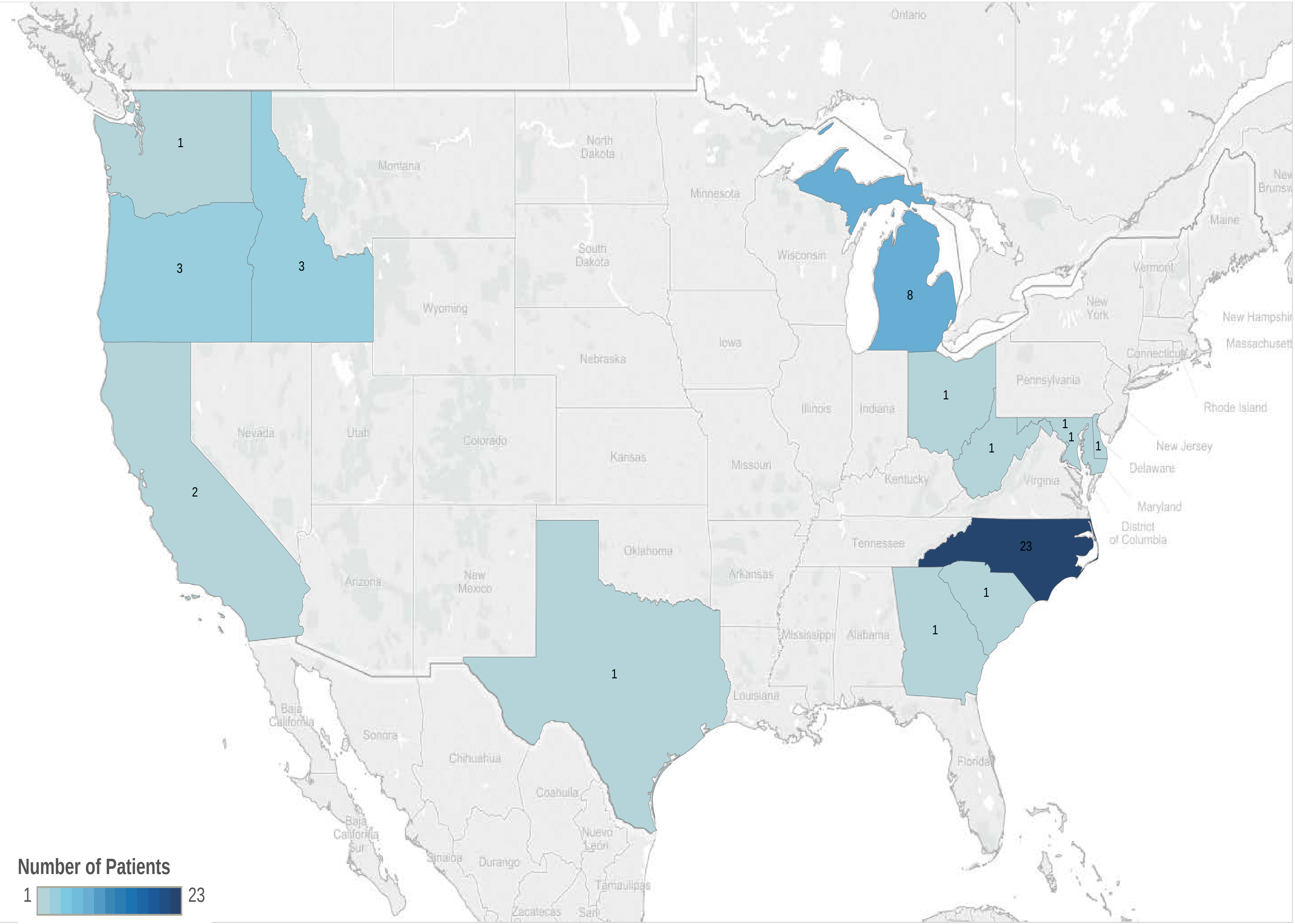
- Thematic analysis

- Selection criteria
    - Age ≥ 18 years
    - On dialysis ≥ 6 months
    - English-speaking

- Local (NC) dialysis facilities and national patient advocacy groups

Interview Topics
Dialysis, health and research experience
Perceptions of ability to influence care/health
Advocacy knowledge and perceptions
Personal advocacy experience
Advocacy motivations

Patient and interview characteristics	Overall (N=48)
Age (y)	54 ± 14
Female	21 (44%)
Black	25 (52%)
Prior kidney transplant	12 (25%)
Dialysis vintage (y)	4 [2, 8]
Dialysis modality	
In-center HD	39 (81%)
PD	5 (10%)
Home HD	4 (8%)
In-person interview	23 (48%)
Interview length (minutes)	78.9 ± 32.9



Ontario
Washington 1
Oregon 3
Idaho 3
Montana
North Dakota
Minnesota
South Dakota
Wisconsin
Wyoming
Michigan 8
Maine
New Brunsw
Vermont
New York
New Hampshir
Massachusett
Iowa
Nebraska
Connecticut
Pennsylvania
Rhode Island
Nevada
Utah
Colorado
Illinois
Indiana
Ohio 1
Kansas
Missouri
West Virginia 1
Maryland 1
District of Columbia 1
Delaware 1
Kentucky
Virginia
New Jersey
Delaware
Maryland
District of Columbia
California 2
Oklahoma
Tennessee
North Carolina 23
Arizona
New Mexico
Arkansas
South Carolina 1
Georgia 1
Mississippi
Alabama
Texas 1
Louisiana
Baja California
Sonora
Chihuahua
Florida
Coahuila
Nuevo León
Baja California Sur
Sinaloa
Durango
Tamaulipas
Zacatecas
San
Number of Patients
1
23

Awareness and interest

- Generally aware that advocacy organizations and patient support groups exist but many unaware of how to connect with such groups

> I think there's a lot of people out there that want to do it, but they don't know how to find each other. [51y M]

> There's none to get involved with. There's many people that I've asked to see if there was something I could start up or something that I could participate in. They had no recollect of anything that would be out there for us. [69y F]

Motivations

- Help others
- Enhance quality of life, purpose
- Educational gains

> I just felt I had to do something… It makes [me] feel better that I'm doing something for a greater good. [50y M]

> Well it gives me a purpose… I mean, I'm not just trying to help myself. I'm trying to help other people because I know this is hard for us to go through. Hemodialysis is just difficult. [67y F]

> I wanted to know more. Because sometimes I feel like patients have been left out of things. [41y F]

Importance of being asked

- Key figure invited participation
- In-person communication

So, I had an annoying, renal social worker who saw that I was depressed or being apathetic about the whole thing and unengaged. She explained to me that I need to be more involved since I'm the one being impacted. So, slowly but surely, she got me interested in various organizations and where there were gaps that I could fill. [51y M]

You have to have someone who motivates them or interests them, puts a little bug in their ear. [69y F]

Advocates vs. non-advocates

- Advocates tended to have greater education and income than non-advocates
  - ➢ **BUT** resource barriers were overcome by many motivated patients who reported sparse personal resources
- Regardless of advocacy classification, almost all participants felt that their personal abilities to participate in advocacy were on-par with the abilities of other patients
  - ➢ **Disconnect** between patient and provider perceptions of ability
- Most non-advocates were never invited to participate
  - ➢ **Selective invitations** may contribute to low participation levels

Patient suggestions for promoting advocacy

- In-person invitations
- Information delivered *by* patients *to* patients
- Incentives and enablers

I think knowing that they could make a difference; that their opinions matter and just having them feel they're somewhat empowered to make a difference. [68y M]

I don't want no Internet. I just want it to be verbal, [so] I can talk to people like you're talking to me. [41y F]

They're in the chair, they don't want other people to get in the chair, so they would speak from their personal point of view what it's been like to them. [64y M]

Patient suggestions for promoting advocacy

Incentives
Education
Food, entertainment, prizes
Enablers
Transportation
Dialysis facility as event location
Patient-led, patient-designed events
Information and education programming
Support groups
Social events

Patient-led, patient-designed events

- Capitalize on shared experiences
- Provide education
- Provide opportunity for patients to be heard
- Empower patients
- Demonstrate potential impact with past examples

Importance of dialysis facility culture

I think clinics that have mentors and involve patients in how the clinic runs get more patients engaged and involved. It’s hard, if you’re at a clinic and you’re not engaged, to all of a sudden jump on board with some organization -- I think that’s a difficult leap. The dialysis experience itself needs to be somewhat positive, as much as it possibly can be at least. So I think it all starts at the clinic level. [49y M]

I think I would let the patients help design it… I think it might be a different answer for every center. [60y M]

Summary

- Untapped potential patient advocacy in dialysis community
- Need for education and outreach
- Avoid selective invitations (be inclusive)
- Importance of local, in-person, patient-led initiatives

> Sometimes, you just have to talk to them.
> [69y F]

Patient Provider Collaborations: Practical Applications Using Peer to Peer Mentoring

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Jennifer St. Clair Russell, PhD, MCHES

Duke University

Peer Up!

TOGETHER MAKES US BETTER

A Peer-to-Peer Program for Dialysis Patients

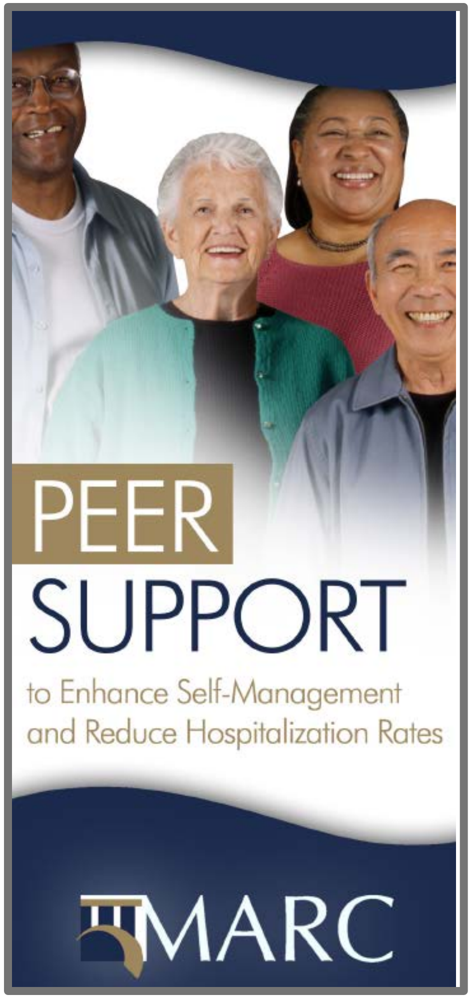
Jennifer St. Clair Russell, PhD, MCHES

MARC

Mid-Atlantic Renal Coalition ◆ A Quality Insights Company

How did this begin?

- Funded by Medicare
- May 2014 – December 2015
- Governmental Task Leader Shiree Southerland, PhD, RN, BSN
- Contracting Officer’s Representative
  Edwin Huff, PhD, MA


PEER SUPPORT
to Enhance Self-Management and Reduce Hospitalization Rates
MARC

Where was the program?

- University of Virginia
  Lynchburg Dialysis

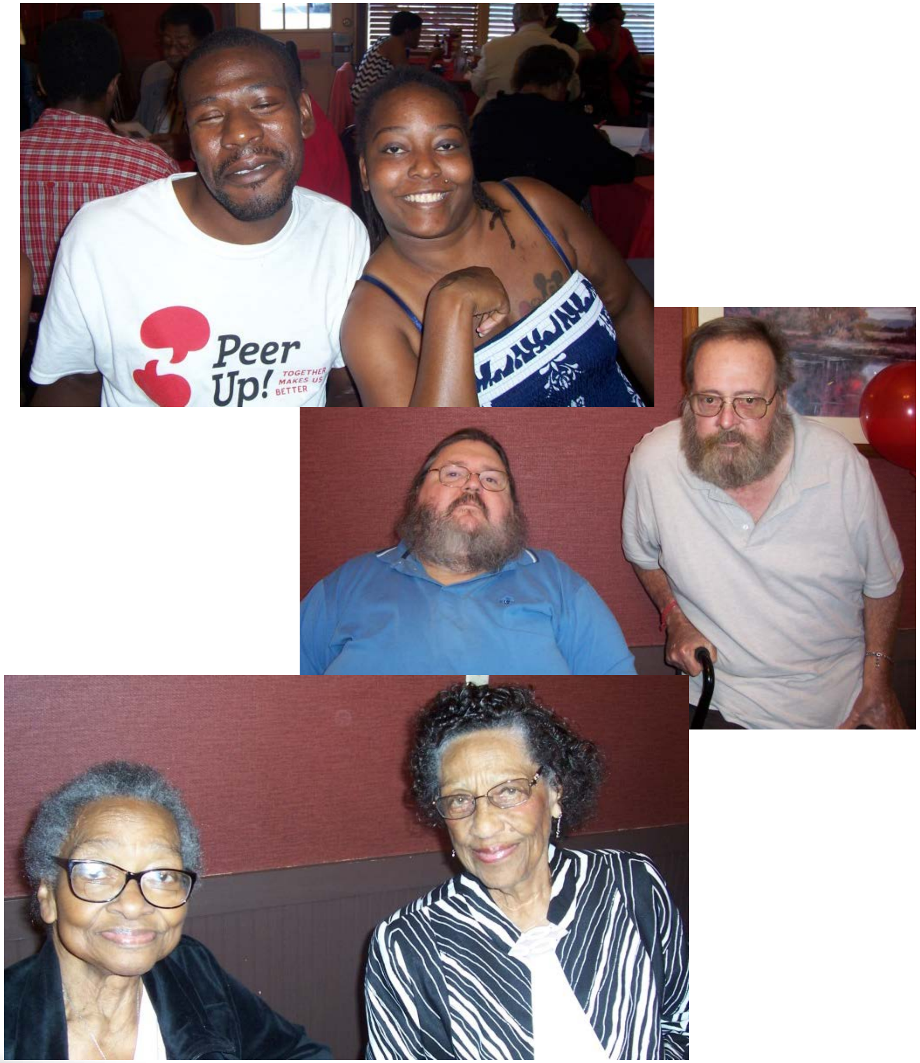
- 249 in-center patients
  - 43 chairs
    (includes 1 isolation chair)
  - 6 shifts

- 53 home patients

- Only facility in Lynchburg

How did *Peer Up!* work?

- 4 month Program
  (March – June 2015)
- Mentor/Mentee pairs
- "Bookend" program with social mixers
- Training required for Mentors



What did the participants do?

- Peer pairs asked to talk at least once per week during intervention (total of 16 interactions for program period)
  - At least 2 meetings per month in-person (total of 8 in-person meetings for program period)
  - Remaining meetings can be by phone or email

- Peer meetings were held at the facility (in the treatment bays or lobby) or offsite, if mutually agreeable

- Mentors completed a meeting log after each interaction capturing information such as length of visit, location, topics discussed, use of any informational materials, and any referrals to staff

What were the results?

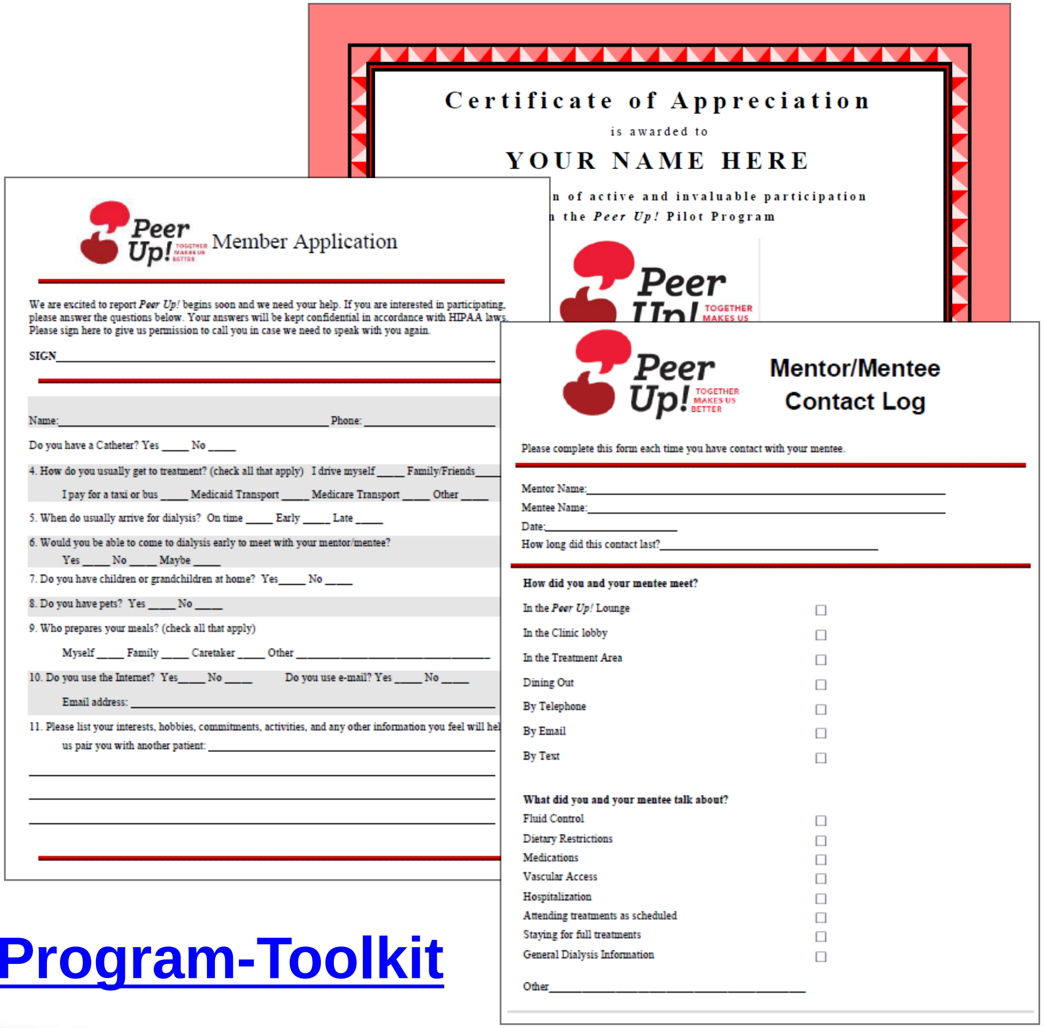
- Mentees
  - Increases in…
    - Knowledge
    - Self-Efficacy
    - Social Support
    - Dialysis Support
    - Quality of Life
  - Decrease in…
    - Missed Appointments

- Mentors
  - Increases in…
    - Knowledge
    - Dialysis Support
    - Dialysis Self-Management

How can I implement *Peer Up!*?

Contents include…

- Program Background & Overview
- Program Management
- Recruitment & Retention
- Mentor Training
- Patient Support Resources
- Assessments/Evaluation



Certificate of Appreciation

is awarded to

YOUR NAME HERE

n of active and invaluable participation

n the *Peer Up!* Pilot Program

Peer Up! TOGETHER MAKES US

Peer Up! TOGETHER MAKES US BETTER Member Application

We are excited to report *Peer Up!* begins soon and we need your help. If you are interested in participating, please answer the questions below. Your answers will be kept confidential in accordance with HIPAA laws. Please sign here to give us permission to call you in case we need to speak with you again.

SIGN____

Name:____________________________ Phone: ________________

Do you have a Catheter? Yes _____ No _____

4. How do you usually get to treatment? (check all that apply) I drive myself _____ Family/Friends_____
I pay for a taxi or bus _____ Medicaid Transport _____ Medicare Transport _____ Other _____

5. When do usually arrive for dialysis? On time _____ Early _____ Late _____

6. Would you be able to come to dialysis early to meet with your mentor/mentee?
Yes _____ No _____ Maybe _____

7. Do you have children or grandchildren at home? Yes_____ No _____

8. Do you have pets? Yes _____ No _____

9. Who prepares your meals? (check all that apply)
Myself _____ Family _____ Caretaker _____ Other ____________________

10. Do you use the Internet? Yes_____ No _____ Do you use e-mail? Yes _____ No _____
Email address: ____________________________________

11. Please list your interests, hobbies, commitments, activities, and any other information you feel will hel
us pair you with another patient: ____________________________

____

____

____

Peer Up! TOGETHER MAKES US BETTER

Mentor/Mentee Contact Log

Please complete this form each time you have contact with your mentee.

Mentor Name:____________________________________
Mentee Name:____________________________________
Date:_______________
How long did this contact last?________________________

How did you and your mentee meet?

In the *Peer Up!* Lounge ☐
In the Clinic lobby ☐
In the Treatment Area ☐
Dining Out ☐
By Telephone ☐
By Email ☐
By Text ☐

What did you and your mentee talk about?

Fluid Control ☐
Dietary Restrictions ☐
Medications ☐
Vascular Access ☐
Hospitalization ☐
Attending treatments as scheduled ☐
Staying for full treatments ☐
General Dialysis Information ☐

Other__________________________________

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www.esrdnet5.org/Peer-Up!-Program-Toolkit

Questions???

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Phone: 919-668-2362

Mid-Atlantic Renal Coalition

Nancy Armistead, Executive Director
narmistead@nw5.esrd.net
Website: **www.esrdnet5.org**
Phone: 804-320-0004

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Practical Approaches to Identifying Patient Goals & Values

Dori Schatell, MS

Executive Director

Medical Education Institute

MEDICAL EDUCATION INSTITUTE

Goal-Setting:

How to Motivate Your Patients to Move Forward

Dori Schatell, MS
Executive Director
Medical Education Institute

MEI Mission: *Help people with chronic disease learn to manage and improve their health.*

FIFTH EDITION

Core Curriculum for the Dialysis Technician

A Comprehensive Review of Hemodialysis

My life, My Dialysis Choice

If your kidneys fail, dialysis can save your life.

But, dialysis is not just a medical treatment.

It can also affect every aspect of your lifestyle.

This tool will help you choose the right treatment for *you*, so you can feel your best *and* live the way you want to.

Help, I Need Dialysis!

How to have a good future with kidney disease

Dori Schatell, MS & Dr. John Agar

The fast, easy way to **use, score,** and **manage** the **KDQOL-36!**

Save hours of staff time on KDQOL-36 paperwork with KDQOL-COMPLETE

- Enter patient answers quickly & easily on one simple screen, **let patients take the survey online,** or let us enter them for you!
- Keep all KDQOL-36 data safe & secure in one place, and export data for CMS reporting when needed
- Print KDQOLs & patient reports – in English, Spanish, & other languages (as offered)
- Evaluate clinic-wide results for CQI & compare clinics with one easy tool

Life Options is a program of research, research-based education, and outreach founded in 1993 to help people live long and live well with kidney disease. A national panel of doctors, researchers, patients, nurses, social workers, dietitians, and ESRD Network directors reviews all Life Options materials and helps guide research.

Kidney School™ is an interactive, web-based kidney learning center with 30 minute modules.

www.kidneyschool.org

Free Life Options Materials

Download our free print materials, research-based fact sheets, posters, and booklets. Fact sheets are also available in Spanish!

Feeling Better with Exercise: A Video Guide for People on Dialysis (DVD)

Teach your patients about all modalities at Home Dialysis Central

Vaccination Education Materials

For patients: Dialysis and your (health-related) quality of life

THERE'S NO PLACE LIKE HOME DIALYSIS CENTRAL

Choosing home dialysis can put you in control of your health and your life.

www.HomeDialysis.org

Kidney School™

Fresenius Medical Care

Kidney School is supported by an exclusive, unrestricted educational grant from Fresenius Medical Care North America.

Attend a Fresenius Medical Care Treatment Options education session.

What We’ll Cover

- Challenges to working with ESRD patients
- The importance of MOTIVATION & HOPE
- How to help patients move toward their goals

Challenges to Working with ESRD Patients

DIALYSIS IS A TSUNAMI IN PATIENTS’ LIVES

STRONG EMOTIONS ARE NORMAL

TERROR, ANGER, DEPRESSION...

PEOPLE CAN’T LEARN WHEN THEY ARE SCARED

EMOTIONAL INFORMATION IMPAIRS MEMORY FORMATION – Lindström BR, Bohlin G. Emotion. 2012 Apr;12(2):384-93

Importance of Motivation & Hope

HOPE & DIALYSIS ADJUSTMENT

N=103 UK adults on dialysis[1]

Higher levels of hope predicted:

- Less anxiety
- Less depression
- Reduced burden of kidney disease
- Better mental functioning

"Hopefulness could serve to lessen the emotional impact of ESRD and treatment by empowering the individual to reframe threats as challenges"

[1] Billington E et al. 2008 ***Br J Health Psychol.*** 13:683-99

HOW Do We Offer Hope?

- **Help patients reach THEIR life goals**
- Teach ALL of the treatment options
- MATCH treatment to preferred lifestyle
- Share stories of successful patients
- Foster peer support

CMS Requires Dialysis to be Patient-centered

- **494.70(a) (Vtag 456): The patient has the right to be informed about and participate, if desired, in all aspects of his or her care**

- **4949.80(a) (Vtag 512): The patient's comprehensive assessment must include, but is not limited to, evaluation of the patient's abilities, interests, preferences, and goals, including the desired level of participation in the dialysis care process, the preferred modality and setting, and the patient's expectation for care outcomes**

Make Your Clinic More Patient-Centered

- Care for *yourself* so you can give the most to your job
- Introduce yourself
- Explain what you are doing
- Give choices
- Get an interpreter when needed

Patient-Centered Care Improvement Guide – Picker Institute
http://www.planetree.org/Patient-Centered%20Care%20Improvement%20Guide%2010.10.08.pdf

Not so good	Much better
No, or I can’t	What I can do is…
I don’t know	I’ll find out for you
That’s not my job	I’ll get someone to help
You’re right, this stinks	I understand your concern
That’s not my fault	Let’s see what we can do about this
We’re short-staffed	Tell me how I can help
I’m busy right now	I’ll be with you in just a moment

Patient-Centered Care Improvement Guide – Picker Institute
http://www.planetree.org/Patient-Centered%20Care%20Improvement%20Guide%2010.10.08.pdf

Foster a Collaborative Atmosphere in Your Clinic

WE Are All Patients, Too!

Do unto others as you would have them do to you

How to help patients move toward their goals

What is a Goal?

- VISION for how things should be
- Important TO THE GOAL SETTER
- Can be SHORT, MEDIUM, or LONG-TERM

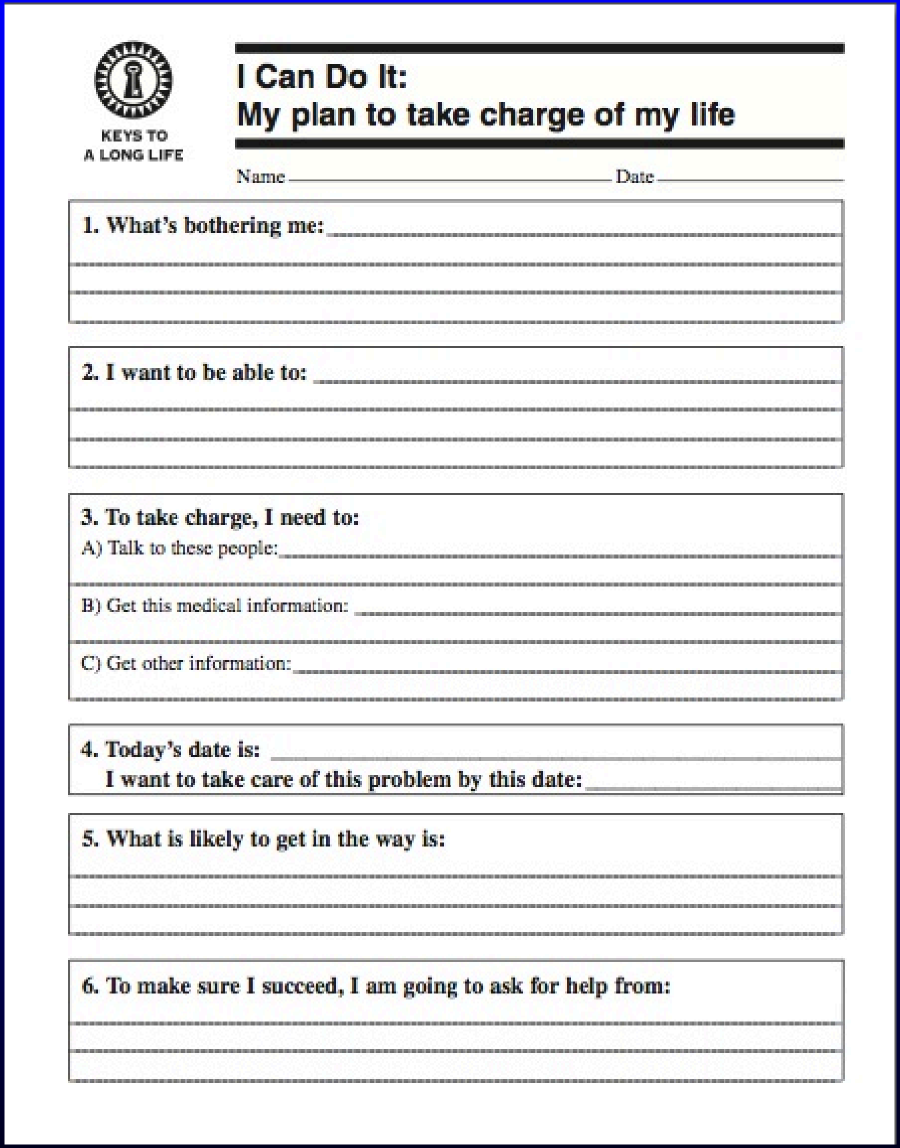
How Do You Learn Patients' Goals?

- **ALLIGN** – Show that you care. Build a relationship.
- **ASK** "What Matters to You?" - They may tell you
- **LISTEN** – "I wish I could…" "I used to love..."
- **COACH** – "It seems like you might want to…"

Break Goals into Steps

Good Goals Are:

- Concrete
- Measurable
- Realistic
- Time-limited
- Accountable



KEYS TO
A LONG LIFE

I Can Do It:
My plan to take charge of my life

Name ______ Date ______

1. What's bothering me: ______

2. I want to be able to: ______

3. To take charge, I need to:
A) Talk to these people: ______
B) Get this medical information: ______
C) Get other information: ______

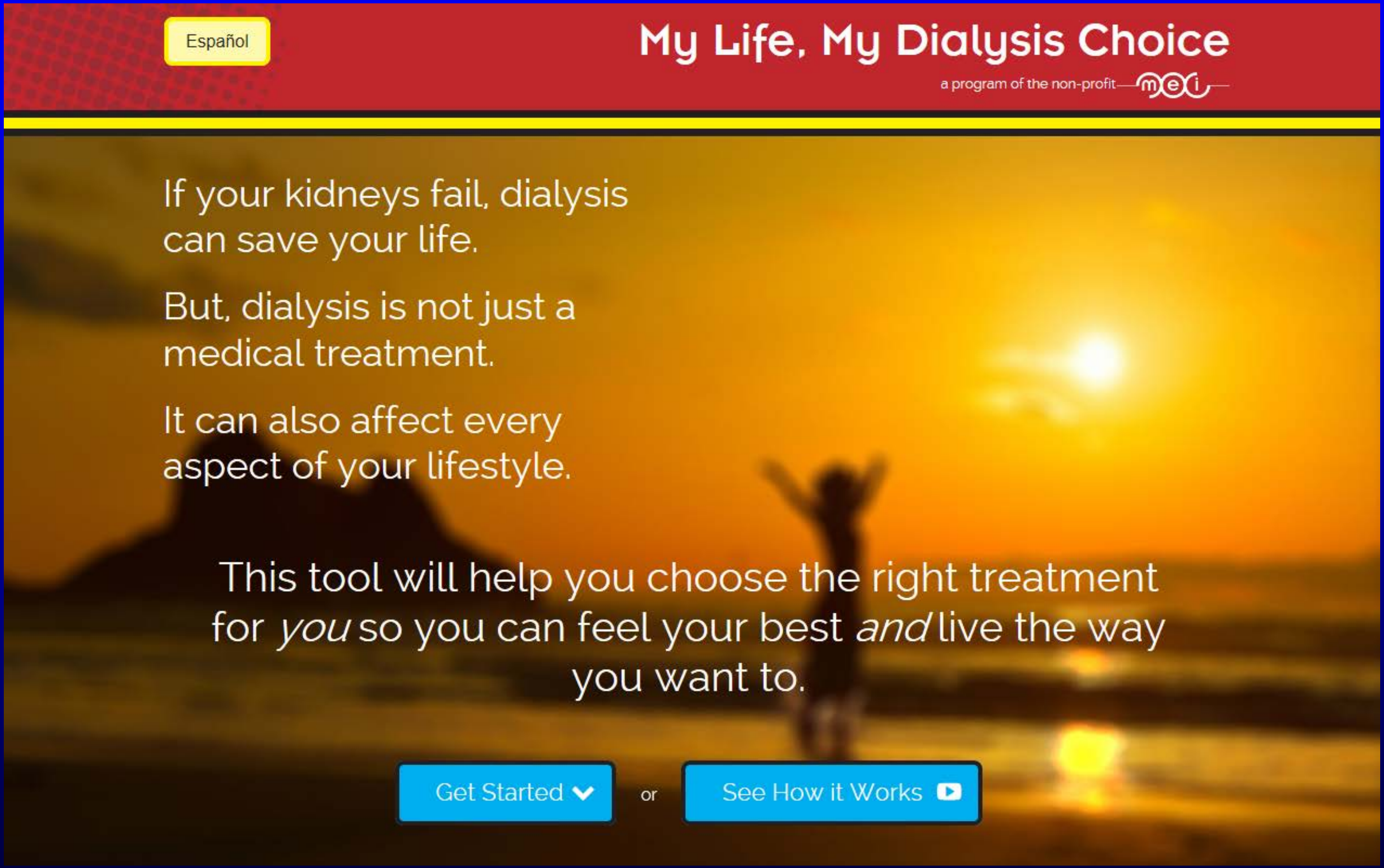
4. Today's date is: ______
I want to take care of this problem by this date: ______

5. What is likely to get in the way is:

6. To make sure I succeed, I am going to ask for help from:

http://www.lifeoptions.org/catalog/pdfs/worksheets/Goalsheet.pdf

Help Patients Match Treatment Options to Their Life Goals



If your kidneys fail, dialysis can save your life.

But, dialysis is not just a medical treatment.

It can also affect every aspect of your lifestyle.

This tool will help you choose the right treatment for *you* so you can feel your best *and* live the way you want to.

www.mydialysischoice.org

CONCLUSIONS:

- ESRD causes chaos and a storm of emotions
- Hope—and motivation—help people cope & move forward
- We can help patients by helping them set and reach goals

AUDIENCE POLLING QUESTION

QUESTIONS & ANSWERS

Use the "Question" box on your GoToWebinar panel to submit your questions

All unanswered questions will be reviewed by our co-chairs and speakers; they will be summarized in a Q & A document which will be posted to the Forum website after the webinar.

THANK YOU FOR JOINING US

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