

**Richard and the Sacred Bond**  
**A Reflection on Patient-Centred**  
**Nephrology Care**

**Robert Bear**

**Author of *Sorrow's Reward***

**Today's Presentation is about a  
*Health Care Revolution***

**Led by Patients Who Want  
Something Different, Something  
Better from their Care System**

# Learning Objectives

**None!**

# Thought Objective

Just One

# **The Revolution's Rallying Cries**

**From the Heart**

**From the Head**

# From the Heart

**“Nothing About Me Without Me!”**

**“Every Patient is the Only Patient”**

**“Citizen with an Illness”**

# **From the Head**

**Patient-Centred Care**

**Patient Engagement**

**Patient Self-Management**

# Key Elements of PCC

- **Respect**
- **Care co-ordination**
- **Communication & education**

# Key Elements of PCC

- Physical comfort
- Emotional support
- Involvement of family and friends

# PCC

- Explores the patient's *key issues*
- Seeks to understand the *patient's world*
  - Seeks *common ground*

***Is aspirational!***

# Patient Engagement

Individuals taking action to ensure  
that principles of PCC are applied

*Is operational!*

# Patient Engagement is Operational

Engaged patients:

- Express fears and anxieties
- Question
- Explore options
- Ensure focus on quality-of-life and family
- Talk more, listen less
- Are accountable

# Patient Self-Management

One PE Tool

# Support for the Revolution Continues to Grow

- Institute of Medicine
- The Center for Medicare and Medicaid Services
- Obamacare incentives
- Advocacy groups
- The mHealth movement
- 'Inspire'
- 'Patient Translations'
- Leading Canadian hospitals
- Some Canadian Renal Programs

**Yet...How Goes the Battle in  
Renal Care?**

# One View

**“We’re doing OK!”**

**Charlie Chaplin Once Entered a  
Charlie Chaplin Look-Alike Contest.**

**He came in Third!**

Perceptions

# So...In Truth, How Goes the Battle in Renal Care?

**Words are important**

*but*

**Deeds speak**

# **Words are Important**

**Most governments, health systems, hospitals and (renal) programs espouse PCC and, increasingly, patient engagement**

# **But Deeds Speak**

**What Each of Us Knows**

**The Voice of the Patient**

# **What Each of Us Knows**

**Many dialysis care providers say they would choose treatments for themselves that differ from those most commonly provided to patients**



# **Voices of Patients and Loved Ones**

# Fear

*"We sit in the waiting room so afraid of how the needling will go."*

*"I have noticed that patients often go to sleep for 45 minutes or an hour after they have been put on the machine. Just the release from all that stress, I guess."*

# Guilt

*" They are the innocents,  
suffering from my disease.*

*...are the first strands of hate  
covering their hearts?"*

# Anger

*"I had been up all night vomiting. I got there and was immediately chastised for drinking too much fluid."*

*"..air ducts over machines...patients sitting there chilled, wrapped in blankets, shivering... told: 'if you were working here, you'd be hot'."*

# Cultural Distance

*“He will tell me that my blood pressure is high and that I have taken too much fluid and have not followed my diet. He will tell me what will happen to me and try and frighten me. He will tell me this and tell me that, but never talk with me. And I will look into his eyes while he speaks, knowing that he sees only an Indian, and that his concern is false and his spirit weak.”*

# Pain

*"I arrived in the dialysis unit, and a nurse told me I was off the transplant list...forever. Then she just left. There was no-one to talk with. No-one."*

# Annoyance

*“He had to travel from the country into Toronto for 3 separate transplant assessment appointments; it wasn’t necessary; there was the gas, the parking, the time...”*

# Disappointment

*"I put on a brave face, but the truth of it is, I'm afraid of dying. I'm not so afraid of what comes after. It's the actual dying part that scares me."*

# Sadness

*"I found out later I got to change my spot because a patient died. I saw it in the paper."*

*"The one unit I received dialysis at used to place a rose in the WR, first with a name, then without, then nothing."*

# Berwick on PCC

**"A verbal bromide masking real pain."**

**Why is the Battle so Hard?**

# Patient Attitudes?

*"A lot of patients just don't care."*

Is that true? Literacy? Insecurity?

Many patients are desensitized  
(NW 14 in Texas)

# **A Continued Focus on the 'Sick' ESRD Patient**

**"Every organization is uniquely  
designed to exactly produce the  
results it achieves" (Senge)**

# **Continued Adherence to an Historic Model-of-Care**

**3x/wk short-run dialysis**

**Traditional staffing**

**A 'production' model**

# **A Focus on Biochemical Outcome Measures**

**Insufficient focus on patient  
outcomes related to life  
satisfaction and quality (more  
difficult to measure)**

# **Lack of Experience/Discomfort with Patient Empowerment**

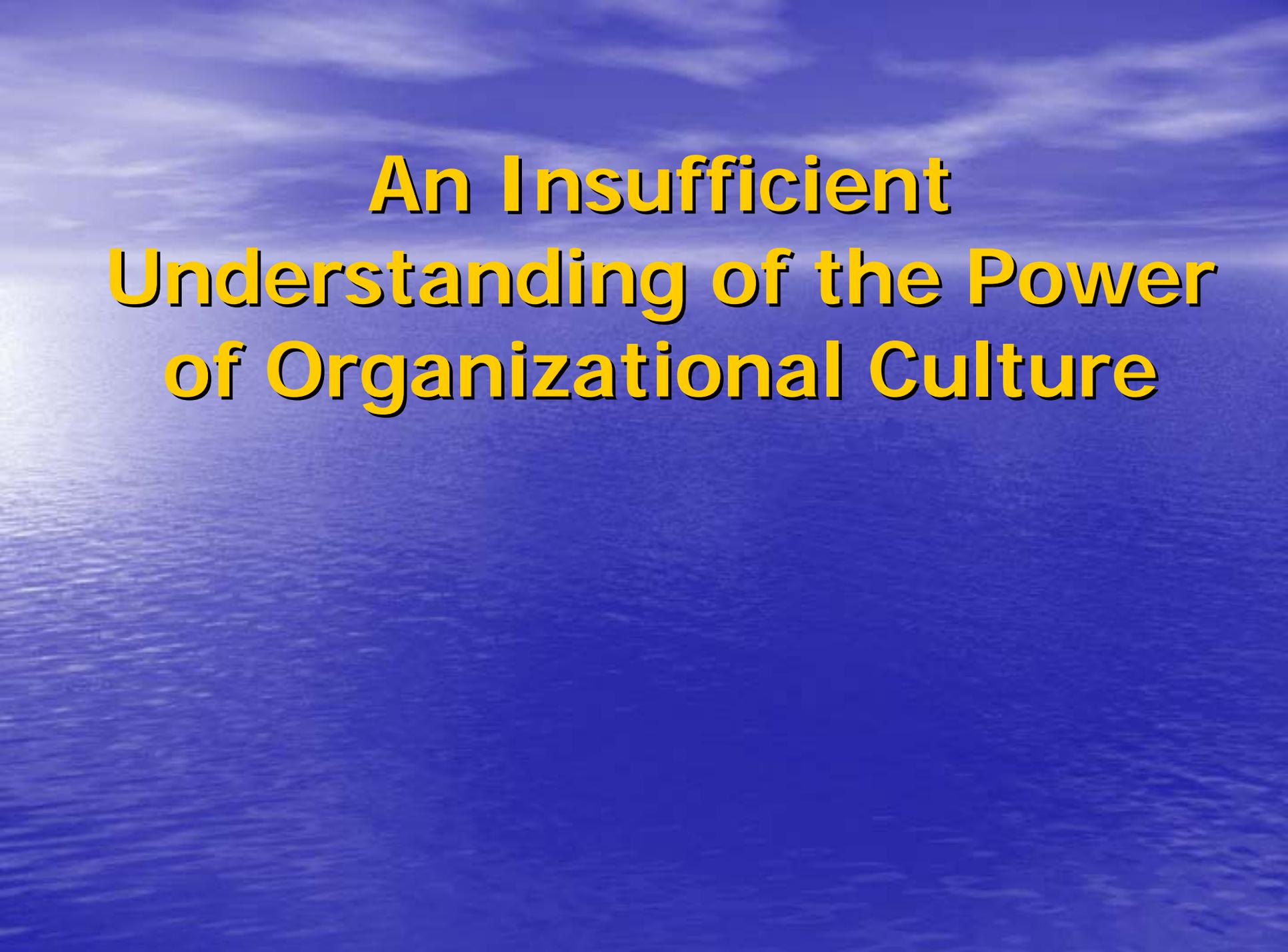
**Not trained for it**

**Threatened by it**

**Inconvenienced**

# Physician Culture & Behaviour

**“What you permit, you promote”  
(Studer Group)**



# **An Insufficient Understanding of the Power of Organizational Culture**

The background of the slide is a photograph of a vast blue ocean under a bright blue sky with wispy white clouds. A bright sun is visible on the left side of the horizon, creating a shimmering reflection on the water's surface.

**What to Do?**

# Strategies & Tactics

- A Plan required, and structures
- Start in CKD clinic (e.g. PSM at HHC)
- In dialysis units, begin simply (e.g. Texas NW14)

# **ESRD Network of Texas (NW14)**

**Patient Engagement Learning  
and Action Network (LAN)**

# Learning and Action Network (LAN)

- Shared learning
- Best practices
- Significant change
- SPREAD

# NW 14 PE LAN

- 1. One Quality Improvement Activity (Staff Education)**
- 2. Two Campaigns (Patient Education)**
- 3. 'Marketing' to 400 facilities (40,000 patients)**
- 4. Report and celebrate (October, 2013)**

# 1. QIA

- 25 'Patient Subject Matter Experts' (SMEs) and 3 family members from 16 facilities
- Education and discussion
- 2 areas of focus selected (patient-provider communication, health literacy)
- 1 intervention identified for each

# **Intervention 1: Teach and Use Communication Essentials for PCC**

- **Heart-head-heart communication**
- **Asking open-ended questions**

# Heart-Head-Heart Communication

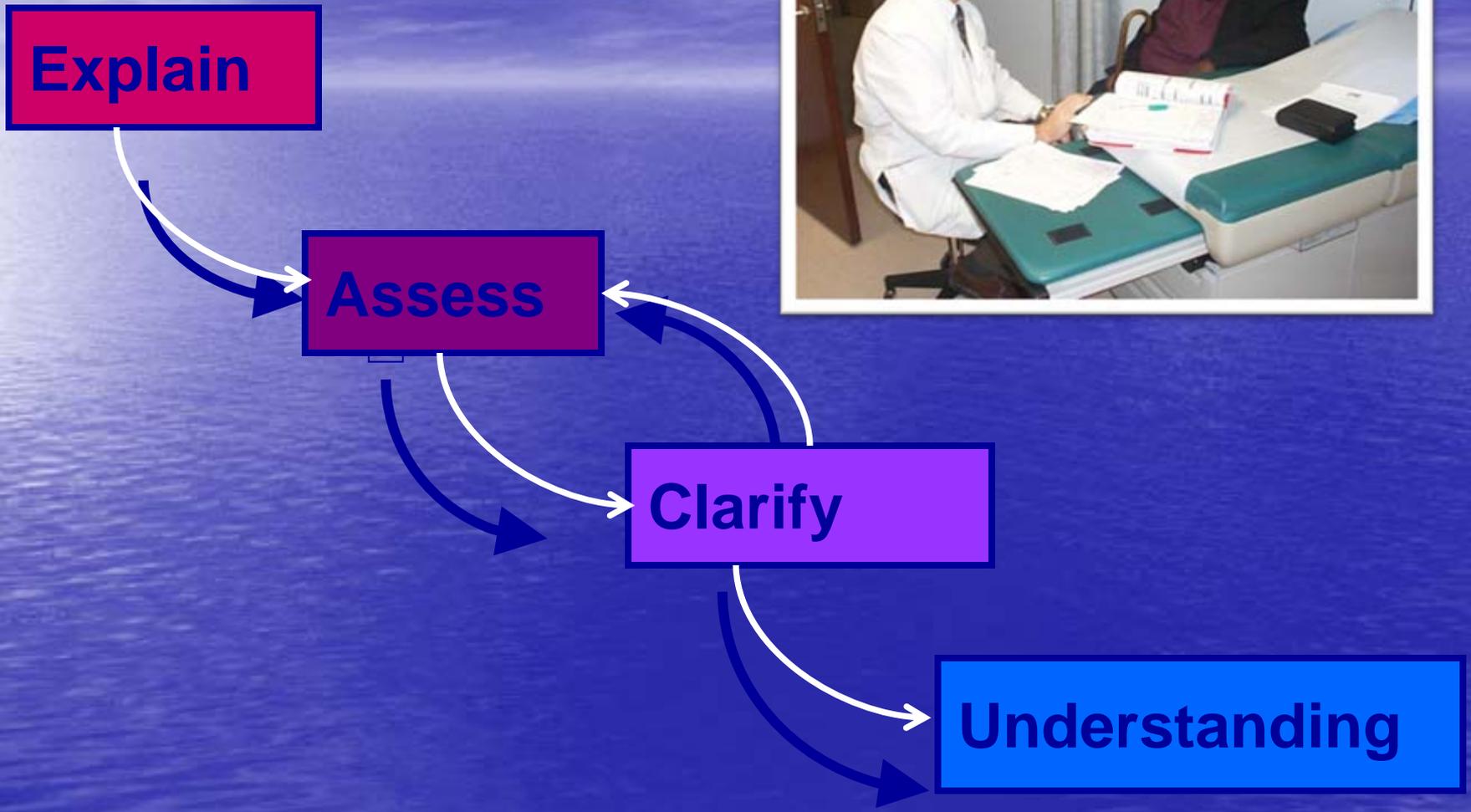
# Asking Open-Ended Questions

# **Intervention 2: Teach Back**

**To improve health literacy**

**(IOM: 90 million American adults have trouble understanding and acting on health information)**

# *Teach-back*



# ICH-CAPS Questions

How often did the dialysis centre staff:

- Listen carefully to you?
- Explain things in a way that was easy to understand?
- Show respect for what you had to say?
- Make you feel comfortable asking whatever you wanted about dialysis care?

# Initial Results

**Significant increases in  
positive responses to  
questions in 15 of 16 facilities**

# QIA 'Spread'

- 49 additional facilities (8,000 patients)
- Staff trained in interventions
- ICH-CAPS questionnaire to be re-administered in October

## **2. NW 14 PE LAN Campaigns**

**105 Facilities, 8000 Patients, 20% of  
NW 14 Patient Population**

**Campaign 1: "Ways you can get  
involved in your care" and "How  
active am I in my care?"**

**Campaign 2: "SPEAK UP"**

## Ways You Can Get Involved in YOUR Care!

### Share your concerns with your care team

- **Keep a list of questions for your doctor.** Bring it to your clinic visits.
- **Ask for a private meeting with your doctor if you need to.** You may not want to talk about some private health concerns at the clinic.
- **Keep a list of ALL of your medicines.** Include over the counter ones, too.
- **Tell your doctor if you have medicine side effects.** Some may go away in time. Others may mean that you need a change in medicine or dose.
- **Tell your care team if you feel bad or ill during or between treatments.**
- **Ask questions! You will feel more in control.** Keep asking until you get answers. Good times to ask are:
  - ✓ When your care team asks you if you have questions.
  - ✓ When the charge nurse makes rounds.
  - ✓ During plan of care meetings.

### Take part in your care. *It's your life!*

- **Know your medicines:**
  - ✓ Ask what new medicines are for and what side effects to watch for.
  - ✓ Fill or refill your prescriptions on time.
  - ✓ Know what each of your medicines does for you.
  - ✓ Talk to your doctor *before* you stop taking a medicine!
- **Know your access and care for it.** Clean your fistula or graft before treatment.
- **Go to access surgeon and transplant appointments if you have them.**
- **Go to your plan of care meetings.** Ask for one if your care team does not offer, or if you want to talk to them between meetings.
- **Go to support groups if you can find them.**
- **Exercise.** You'll have more energy! Talk with your doctor before you start.
- **Know your dialysis treatments.**
  - ✓ What days and times do you need to be at the clinic?
  - ✓ How long do you run, and what is your goal weight?
  - ✓ How should you feel during and after a treatment?
  - ✓ What is your fluid limit? Measure your fluid intake. You'll feel better!
- **Know your options.** Which type of dialysis would fit YOUR life best? Can you get a kidney transplant? Are you on the list?
- **Talk with the social worker if you want to work, go to school, or volunteer.**



## How Active Am I in My Care?

A group of patients made this list to help you.

<b>How I share my concerns with my care team:</b>		<b>Always</b>	<b>Often</b>	<b>At times</b>	<b>Never</b>	<b>N/A</b>
1	I keep a list of questions for my doctor and bring it to clinic visits.					
2	I ask for a private meeting with my doctor if I need one.					
3	I keep a list of ALL of my medicines.					
4	I tell my doctor if I have medicine side effects.					
5	I tell my care team if I feel bad or ill during or between treatments.					
6	I ask questions (and choose good times to ask).					
7	I keep asking until I get answers.					

<b>How I take part in my care:</b>		<b>Always</b>	<b>Often</b>	<b>At times</b>	<b>Never</b>	<b>N/A</b>
8	I ask what new medicines are for and what side effects I may have.					
9	I know what each of my medicines does for me.					
10	I fill or refill my prescriptions on time.					
11	I talk to my doctor before I stop taking a medicine.					
12	I clean my fistula or graft before each treatment.					
13	I go to vascular surgeon or transplant appointments (if I have them).					
14	I go to my plan of care meetings.					
15	I go to support group meetings (if I can find them).					
16	I exercise so I can have more energy.					
17	I talk with the social worker about work, school, or volunteering.					
		<b>Yes</b>		<b>No</b>		
18	I know what days and times to be at the dialysis clinic.					
19	I know how long I run and my goal weight.					
20	I know how I should feel during and after a treatment.					
21	I know my fluid limit.					
22	I know my options for dialysis and kidney transplant.					

<b>S</b>	<p><b>Speak up</b> when you have questions or concerns. You have the right to protect your body and your health:</p> <ul style="list-style-type: none"> <li>• All of your questions are good questions.</li> <li>• If you don't know what your care team is telling you, ask until you do.</li> </ul>
<b>P</b>	<p><b>Pay attention</b> – and <i>speak up</i> if you see a mistake made in your care:</p> <ul style="list-style-type: none"> <li>• Be sure you get the care meant for YOU—not someone else.</li> <li>• Watch for gloves—ask staff to put on clean ones before they touch you.</li> <li>• Don't worry about hurting someone's feelings. Your life is at stake!</li> </ul>
<b>E</b>	<p><b>Educate yourself!</b></p> <ul style="list-style-type: none"> <li>• Learn about your dialysis so you know when it is done right.</li> <li>• Learn about your diet, fluid limits, and medicines.</li> <li>• Ask questions, go to the library, or look online to learn.</li> </ul>
<b>A</b>	<p><b>Ask the right person on your Care Team:</b></p> <ul style="list-style-type: none"> <li>• <b>Doctor/Nurse:</b> ask about your health, treatment options, and medicines.</li> <li>• <b>Dietitian:</b> ask about what you can eat and drink (and what to avoid).</li> <li>• <b>Social worker:</b> ask about how to cope with kidney disease and pay for it.</li> <li>• <b>Tech:</b> ask how the machine works and what the alarms mean.</li> </ul>
<b>K</b>	<p><b>Keep a list of questions:</b></p> <ul style="list-style-type: none"> <li>• It's easy to forget what you meant to ask your Care Team.</li> <li>• Write down your questions and bring your list to dialysis.</li> <li>• Keep questions for your doctor visits, too.</li> </ul>
<b>U</b>	<p><b>Understand the best times to ask your Care Team questions:</b></p> <ul style="list-style-type: none"> <li>• The staff is the most busy when treatments are starting or ending.</li> <li>• Wait to ask until they have a bit of time to spend with you.</li> <li>• In most cases, this will be after all of the treatments have started.</li> </ul>
<b>P</b>	<p><b>Plan to take part in your Care Team meetings:</b></p> <ul style="list-style-type: none"> <li>• You are a key member of your Care Team and you need to be there.</li> <li>• Your Care Team should meet at least monthly, but ask if you need one.</li> <li>• You can ask for a meeting to be done while you are NOT getting dialysis.</li> </ul>



Created for you by the ESRD Network of Texas, Inc.  
*Patient Engagement Learning and Action Network.*  
 To file a grievance or for questions contact Network 14 at Phone: 1-877-886-4435\*  
 Fax: 972-503-3219 \* Email: [info@nwa14.esrd.net](mailto:info@nwa14.esrd.net) \* Address: 4040 McEwen Rd, Suite 350,  
 Dallas, TX 75244 \* Website: [www.esrdnetwork.org](http://www.esrdnetwork.org).



# NW 14 PE Campaign Outcome Measure

Question: "Based on the materials provided, do you plan to take a more active role in your care and talk more with your health care team?"

- Baseline (April 2013): 73.4%
- Outcome Measure Target (October 2013): 10% improvement

# **3. Marketing to 400 Texas Dialysis Facilities**

# 4. Annual Meeting: “Nephrology Today and Tomorrow” October 25

- Reporting and celebration
- Next step: **EOL Care?**

# **How to Ensure the Revolution Succeeds**

**Employ strategies and tactics**

**Use these to change  
Organizational Culture**

# Organizational Culture

## Question

What is the Organizational Culture in your program/unit?

*"Culture eats strategy for lunch."*  
(Schein)

# Culture and Leadership

*" An organization's culture is its lifeblood. It is squeezed from the deeds of its leaders, drop by precious drop. It trickles down, infusing all other attitudes and actions."*

- Carole D'Amico, in *Sorrow's Reward*

# Culture and Leadership Actions

- **Explicit communication**
- **Culture of PCC and PE the preferred culture**
  - **A Plan, and supporting structures**
  - **The 'voice of the patient' to guide**

# Culture and Each of Us

- Each of us must understand our power to influence, to make a difference
- Often, our smallest & most quiet deeds will be the most important ones

# Thought Objective

# *Is Right on the Side of this Revolution?*

'Patient Activation' improves patient satisfaction, improves outcomes, lowers costs

## *Does it Matter?*

In an increasingly technical health care world, it anchors us in caring, compassion, empathy, and humanism

**“It is not more light that is needed in this world, it is more warmth. We will not die of darkness, but of cold.”**

Jenny Read 1947-1976

# Questions and Discussion