

Improving Patient Engagement

A Strategy for Transformation



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Overview

- What is Patient and Family Engagement?
 - Framework and a continuum of engagement
 - Case Examples
- How this applies to dialysis facilities
 - Latest results from leading edge projects in AV
Fistula
- Bottom lines



Patient- and Family-Engagement

- Patient engagement is increasingly important in ESRD facilities
 - Patient experience measurement and reporting
 - Quality measures influenced by patient actions (AVF rates, etc.)
- But what is it???





Common Misconceptions re: Patient Engagement

- Most people think of patient education, behavior change, getting patients to do what we want them to do.
 - E.g. Get a fistula! Go to Kidney Smart classes!
- Lexicon: Compliance, adherence, “good patients,” “denial,” “taking responsibility”
- Most strategies are ineffective in producing results using this approach.



What's the Problem?

- We focus on education but not **effectively**
- Culture of “compliance” is **disempowering** to people
- Solutions are designed by providers and staff, without patient input.
 - Frequent **misunderstanding** of barriers patients face, their workflow, values, etc.
- Old medical model of doing *for* patients or *to* them, but not with them
- Getting consumers to do what we want them to do
 - “We know best”
 - But often we don't know “most”- what else drives decisions for a particular patient?



What is **effective** Patient- and Family-Engagement?

“Patients, families, their representatives, and health professionals working in **active partnership** at various levels across the health care system – direct care, organizational design and governance, and policy making – to improve health **and** health care.”

- SOURCE: Carman, Kristin; Dardess, Pam; Maurer, Maureen; Sofaer, Shoshanna, Adams Karen; Bechtel, Christine; Sweeney, Jennifer. “Patient and Family Engagement: A Framework for Understanding The Elements And Developing Interventions and Policies.” *Health Affairs* 32 No.2 (2013 223-231).

Engagement

Continuum of Engagement




Level of Engagement

Consultation

Involvement

Partnership & Shared Leadership

Direct Care

Patients receive information about a diagnosis

Patients asked about preferences in treatment plan

Treatment recommendations based on patients' preferences, medical evidence and clinical judgment

Organizational Design & Governance

Organization surveys patients about experience of care

Hospital involves patients as advisors or advisory council members

Patients co-lead hospital safety and quality improvement committees

Policy Making

Public agency conducts focus groups with patients

Patients' recommendations about research priorities used by public agency to shape funding decisions

Patients have equal representation on agency committee that makes decisions about resource allocations



Case Studies

Georgia Health Sciences University:

- Patients serve on every committee in the adult and children's hospital, and all ambulatory clinics.
 - They are full partners with equal voices
- Committees oversee wide range of strategic priorities and QI initiatives, from patient safety to JC accreditation.
- Patients and staff working together resulted in:
 - Improved pt experience scores by 38% in Neuroscience unit
 - Reduced length of stay in Neuroscience unit
 - Decreased staff turnover from 8% to 0% in 3 years
 - Reduced malpractice expenses by 60%
 - Increased profit margin by decreasing costs per admission
 - Improved Joint Commission inspection scores



Case Studies

Dana Farber Cancer Institute:

- More than 400 patients and family members serve on the Board and all committees, including safety and QI teams, facility design, management initiatives.
- Medication examples: Patients and staff working together resulted in:
 - More than a decade of zero fatal medication errors
 - 90% reduction in medication list errors



Improving Quality in ESRD



2 Groups:

- 16 DaVita facilities enrolled in a Special Patient and Family Engagement AV Fistula Collaborative
- 14 independent facilities enrolled in Standard AVF Collaborative
- Facilities located in Virginia, Maryland, and DC:
 - All had AVF rates below the Network average of 59.8 percent in October 2012; and
 - October 2013 patient census of 75 or more.



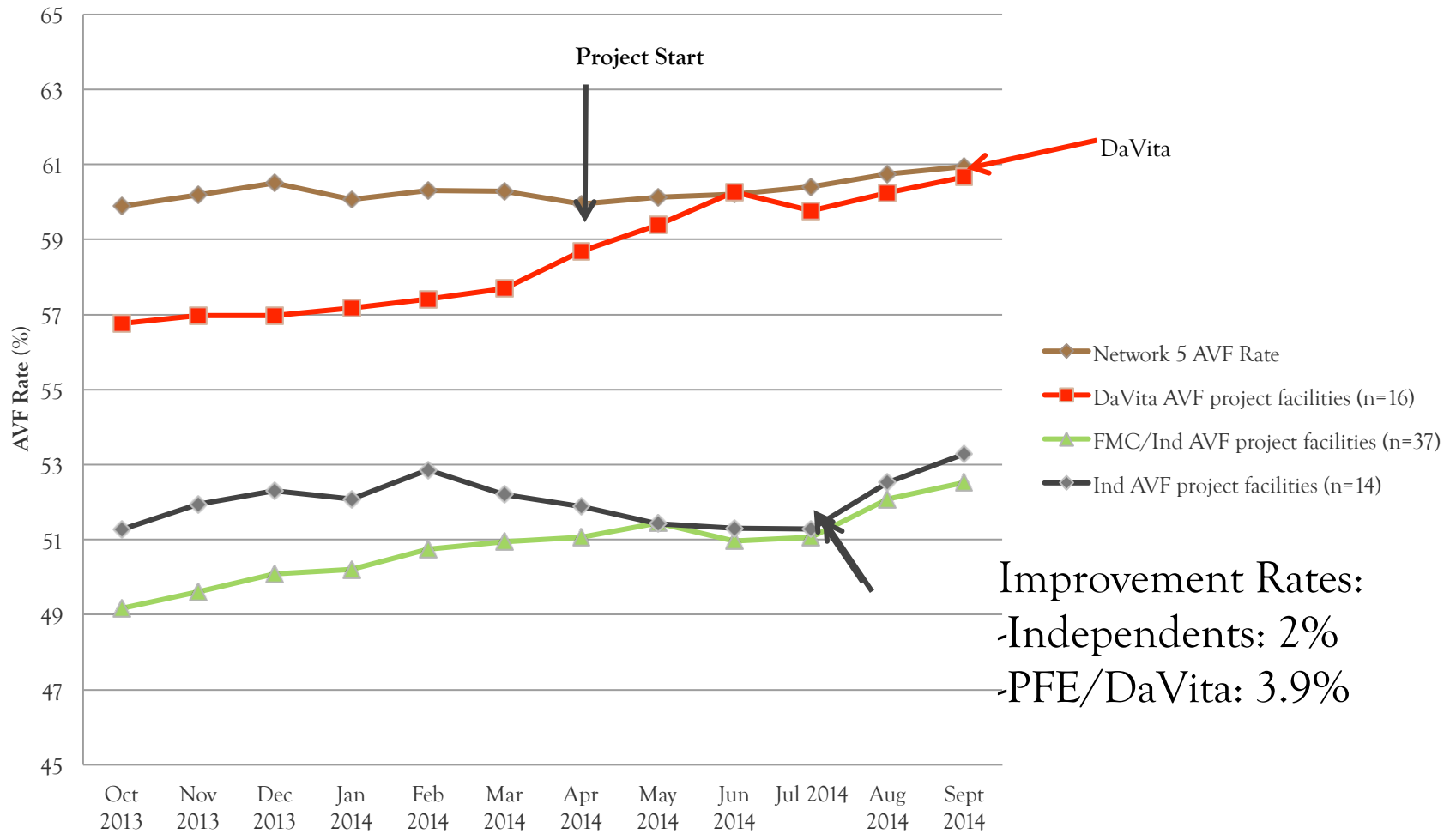
MARC Patient & Family Engagement Collaborative

- Facilities selected their own focus areas, based on data and the 13 Fistula First Change Concepts
- MARC and Bechtel Health provided education and technical support re: engagement concepts and strategies
- DaVita corporate “blessed” the project
 - Regular participation from Group Outcomes Mgr
- Small group support via monthly con. calls
 - April-October



Results: Mid-Atlantic Renal Coalition

Network 5 ESRD Collaborative





Important Lessons

- Patient partners made projects better and **more impactful**
 - Ex: survey results were better because they avoided “lingo” patients/families didn’t understand.
- Patients generated **new ideas** for ways to improve AVF rates that facilities wouldn’t have considered or were **unaware of**
 - Move timing of access education, create roadmap for access, spur better education from nephrologists, etc.
- Patients added **new momentum** to important strategies:
 - Patient voices became strategic point of leverage, enabling new relationships and discussions with essential partners (hospitals, nephrologists, etc.)
- Clinicians and staff found **joy** in the work
- Patients were **eager to help**



Partnering **with** Patients for Results

- **Testing Innovation and Support: 3 Projects:**
 - MARC 2014 (DaVita only)
 - MARC 2015 (Mix of independent facilities and DaVita, rates below national benchmarks)
 - Heartland Kidney Network 2015 (mix of DaVita and FMC, below and above national benchmark)
- **Promising results in 2015**
 - MARC: More standardized approach: 3 subgroups
 - HKN: Many approaches, some commonality



Basic Roadmap for Partnership

- Identify a Vascular Access area that is **important** to your facility
 - Use the 13 Change Concepts to ID opportunities
- Have clear problem statement and draft goals
- Gather data from patients to inform strategy and plan, revise as necessary.
 - E.g. interviews, surveys, focus groups, etc.
- Identify patients who can help as advisors/partners (relevant experience)
- Co-design intervention in collaboration with patients
- Implement and measure intervention impact



The **Leading Edge** in Dialysis

Example Strategies:

- Interviewing/surveying patients to ID barriers and motivators for converting from graft or CVC to fistula, creating action plans (with patients) based on findings.
- Measuring experience with in-hospital education and access placement, engaging hospital leaders
- Revamping education processes, modalities, etc.
- Assess multiple aspects of facility and access placement process (cannulators, education, surgeons, etc.)



Sample: Understanding why patients do/don't switch from CVC to AVF

- A group of facilities needed to understand more about effective ways to help patients to convert from CVC to AVF.
 - Dialysis facilities in Maryland, Virginia and DC collected data from patients with a CVC (n=86) and have an AVF but used to have CVC (n=147).
- Convenience samples
- Data not currently publicly available; will be released in the future.

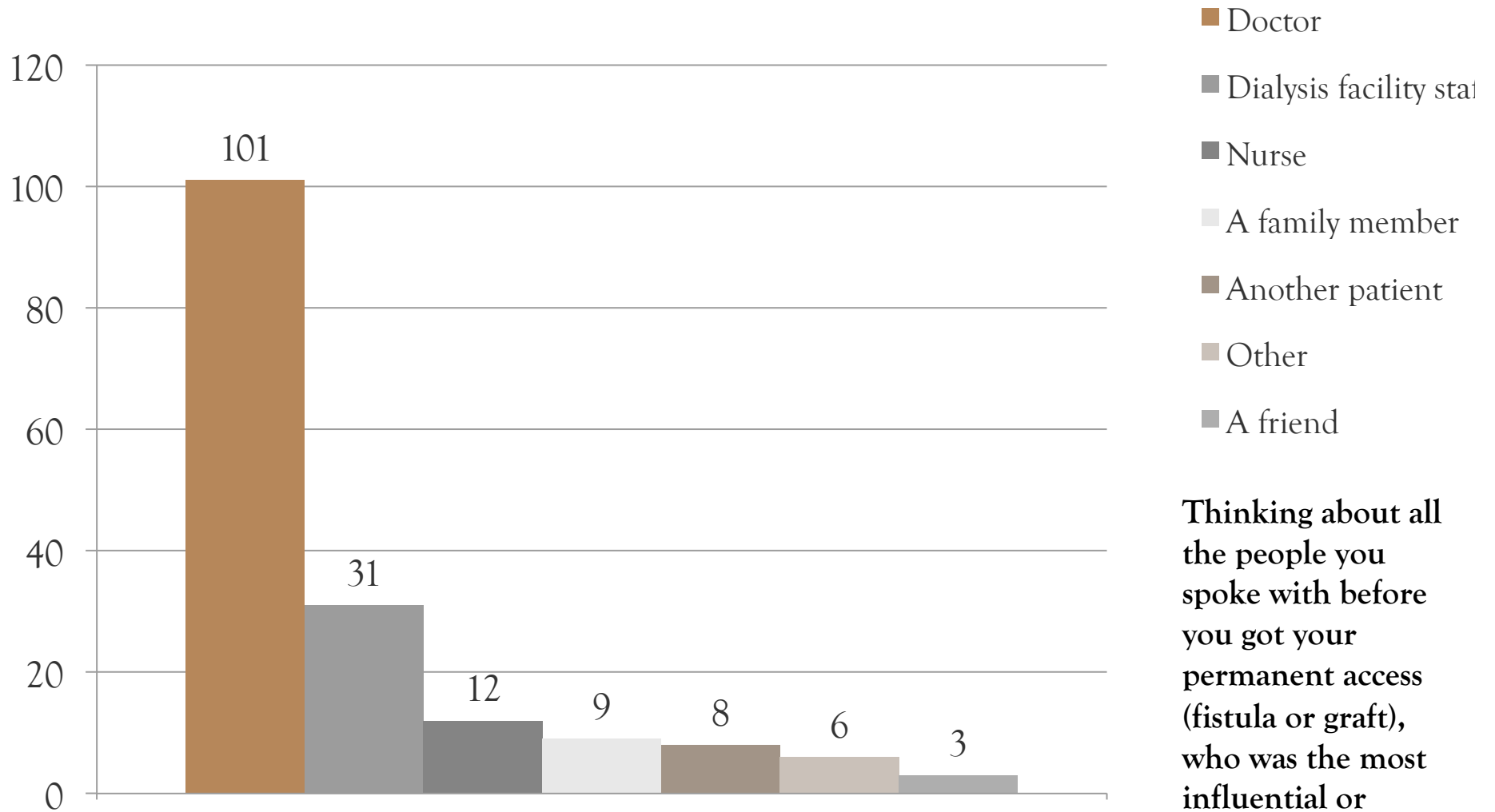


Sample of Interesting Findings

- **Most trusted educators:** Doctors, nurses, dialysis facility staff
 - Not other patients. Only 10 of 86 said they trusted other patients “a lot” re: permanent access.
- **Top concerns among CVC vs. AVF patients:**
 - Needles (63%), body image (42%), surgery (40%)
 - Bleeding after Tx (79%), Skilled cannulators (74%)
Needles (66%)
- **Top reasons to switch:**
 - CVC: Avoid infection, doc or staff recommendation, longer life span
 - AVF: Doc recommendation, AVFs last longer, Shorter and better dialysis



Most Influential in Decision to Get AVF



Thinking about all the people you spoke with before you got your permanent access (fistula or graft), who was the most influential or helpful?




Impact

- Understanding the views and experiences of patients informs our work in new ways:
 1. Assess effectiveness of the education they receive
 - Dialysis staff, nephrologists, etc.
 2. Helps focus efforts on where they will pay off
 3. Powerful strategy for creating/strengthening relationships, or getting others to act



Bottom Lines

- Working with patients leads to **better interventions**.
 - Patient and family engagement is a **strategy for improvement**, not a “behavior control” method
- As a strategy for improvement, you can deploy it at many levels (care, QI, governance, etc.)
 - More likely to get it right, and **faster**
- Done well, it’s a highly **satisfying process for staff** with potential to improve retention rates
- Patients and families can help!
 - They are unique resources, untapped innovators
 - Subject matter experts with experiences we don’t have
- This strategy can work for a wide range of improvement initiatives



Q: If you build it, will they come?

A: If you build it with them... they will already be there.

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