The “P” is for Participation, Partnering and Powerment
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Speaker Introduction

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Conflict of Interest

Jan Oldenburg and Mary Griskewicz

Have no real or apparent conflicts of interest to report.
Agenda

1. Welcome & Introductions
2. The value of this work
3. This is a Journey
4. Digital health capabilities
5. Satisfiers and dis-satisfiers
6. Barriers
7. Strategies
8. Voice of the Patient and Family Caregiver
9. Questions
Learning Objectives

• **Learning Objective 1:** Identify digital health capabilities that will best demonstrate and incorporate participatory health frameworks

• **Learning Objective 2:** Analyze key satisfiers and dis-satisfiers for patients and caregivers in the area of participatory healthcare

• **Learning Objective 3:** Appraise attitudinal and cultural barriers to participatory healthcare in your organization

• **Learning Objective 4:** Differentiate strategies for building participation across process, policy, systems, and attitudes

• **Learning Objective 5:** Identify patient-generated and caregiver-based data to be incorporated when welcoming patient, consumer and caregiver participation in your organization
Focused on Patient Engagement portion of STEPS framework
This is a Journey
Participation

Change Ahead
What is participatory healthcare?

• **Egalitarian:**
  – Patients and caregivers are viewed and included as partners both in their own care and in designing the system
  – Attitudes and behaviors of health system, physicians, employees reflect belief in equality of patients and caregivers

• **Empowering:**
  – The system is designed around patients and caregivers
  – Information and tools are provided to enable patients to understand and participate in shared decision making

• **Easy:**
  – Everything is focused on reducing friction for patients and caregivers
What does “Participatory Health” really mean (part 1)?

- Have a patient council?
- Include patients in design?
- List caregivers in the EHR?
- Train in shared decisions?

What does “Participatory Health” really mean (part 2)?

- Launched a patient portal?
- Is all data downloadable?
- Implemented Open Notes?
- Include PGHD in your EHR?
What does "Participatory Health" really mean (part 1)?

- Have a patient council?
- Include patients in design?
- List caregivers in the EHR?

Start the presentation to activate live content
If you see this message in presentation mode, install the add-in or get help at PollEv.com/app
Include PGHD in Open Notes?

Is all data downloadable?

What does "Participatory Health" really mean (part 2)?

Lunched a patient portal?
Shared Decision Making

9 in 10 U.S. Adults want to share in health decision making, Spring 2014

Source: Altarum Institute Survey of Consumer Health Care Opinions. Spring 2014
Most people want to be more involved in health decisions than they are

Desire vs reality of involvement in medical decisions

- Want to be very involved: 75%
- Felt very involved: 57%

Involvement in major decisions

- Made major health decision myself: 40%
- Made major health decision in partnership with my provider: 40%
- My doctor made the major health decision: 20%

Source: Engaging California patients in major medical decisions
2016 Accenture Study finds Patient access to portal data is rising

2016 Accenture Study finds US Consumers are more aware of available capabilities

- Billing information: 35%
- Personal profile information: 36%
- Immunization status: 37%
- X-rays or nuclear imaging results: 29%
- Lab work and blood test results: 48%
- Physician notes from visits/condition: 33%
- Prescription medication history: 44%

Other consumer trends impact consumer expectations

- Banking
  - Chase
  - Bank of the Pacific

- Smartphones
  - Apple
  - Android
  - Samsung

- Shopping
  - Zappos
  - eBay
  - Amazon

- Exercise
  - Fitness apps

- News
  - The Economist
  - WSJ
  - Star Tribune
  - LA Times
  - USA Today

- Entertainment
  - Netflix
  - HBO Now
  - Hulu
The *Disconnected* Healthcare ecosystem

Healthcare Ecosystem

- Clinic
- Clinic
- Clinic
- Clinic
- Rehab Clinic
- SNF
The Healthcare ecosystem failed them
Partnering
## Continuum of Patient/Family Engagement

<table>
<thead>
<tr>
<th>Levels of engagement</th>
<th>Consultation</th>
<th>Involvement</th>
<th>Partnership and shared leadership</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Direct care</strong></td>
<td>Patients receive information and instructions about a condition or diagnosis</td>
<td>Patients preferences are discussed in treatment planning</td>
<td>Patient makes treatment decisions taking into account personal preferences, medical evidence, clinical advice</td>
</tr>
<tr>
<td><strong>Organizational design</strong></td>
<td>Organization surveys patients about their care experiences and goals</td>
<td>Organization involves patients as advisors or advisory council members</td>
<td>Patients co-lead organizational safety and quality improvement committees</td>
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<tr>
<td>and governance</td>
<td></td>
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<tr>
<td><strong>Policy-making</strong></td>
<td>Organization conducts focus groups with patients to ask opinions about healthcare issues</td>
<td>Patients' recommendations about research priorities are used to make funding decisions</td>
<td>Patients have equal representation on committees that make decisions about resource allocations</td>
</tr>
</tbody>
</table>

Source: Adapted from Sample Consumer Engagement Framework American Institutes for Research [http://forces4quality.org/print-preview/6771.html](http://forces4quality.org/print-preview/6771.html)
Barriers to enterprise engagement

• Existing attitudes and beliefs:
  – Patients
  – Physicians and staff

• Insufficient or weak leadership

• Belief that consumers don’t really want things to be different

• This seems like a lower priority than other required changes

• No perceived ROI
Implications for enterprise engagement

• Listening is not enough
• Patients and caregivers expect more than lip service:
  – A seat at the table
  – The opportunity to impact budgets, strategy, policy, process
  – Real change, indicated by changes to their experience
• Partnership requires leadership:
  – Attitude and culture change (perhaps even more than systems change)
  – Training and continuing education; peer mentorship
  – Follow-through at all levels
Where to start with enterprise engagement?

1. Establish a patient and caregiver advisory board
2. Train physicians and staff on shared decision-making principles
3. Bring patients and caregivers into process or technology/selection design—even at the departmental level
4. Celebrate successes with patient involvement
5. Tell patient and caregiver stories—and not just the good ones
   - Use them to explore how things could be improved
   - Follow up on negative evaluations
6. Above all: lead from where you stand; lead by example
Empowerment

Patients need personalized engagement strategies

<table>
<thead>
<tr>
<th>Attitude toward clinicians</th>
<th>Resistant</th>
<th>Passive</th>
<th>Informed</th>
<th>Empowered</th>
<th>Self-Actualized</th>
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</thead>
<tbody>
<tr>
<td>Partners</td>
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<td>Advisors</td>
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<td>Authorities</td>
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**Vector of empowerment**

Extrinsic  | Motivation  | Intrinsic
Framework for individual engagement

Axis of motivation

Extrinsic
- Participation motivated by team rewards
- Participation motivated by social good

Intrinsic
- Participation motivated by rewards for individual accomplishments
- Participation motivated by self improvement

Axis of involvement

Community

Individual
Where to start with patient-focused technology

1. Make sure your portal is more than a “check the box” offering:
   – Ensure everyone has a role
   – Reinforce how the portal can help at every interaction

2. Keep improving your capabilities:
   – Survey patients about what they want to see next (minimal)
   – Include them in the actual prioritization sessions

3. Consider apps, text messaging, as well as web solutions to reach all audiences:
   – Text messaging can be very effective for reminders
   – Different solutions fit different situations, needs
   – Try apps for doctors to "prescribe" for behavior change

4. Build process, workflow, and policies around technology to ensure you don’t undermine it
Directions for technology choices

• Offer information, engagement at different levels
• One solution does not meet all
• Invest in analytics to personalize engagement offerings:
  – Not all diabetics are motivated by the same things
  – Health and demographic information is not enough to determine engagement patterns
• Provide options:
  – Range of technology
  – Options for mix of interpersonal/technology approaches
  – Sophisticated choices for sophisticated consumers
• Partner with consumers throughout development/selection process
Directions for technology choices

• Use technologies that are already working, perhaps in other business verticals
• Benchmark others
• Patient financial health technologies should also be considered
• Partner with your technology companies
• Education is required for clinicians, ancillary providers, patients and family members
• Usability is key—if it isn’t easy, it won’t get used
Industry Examples

Improved Symptom Awareness at Tucson Medical Center | 05/01/2015

- Tucson Medical Center has equipped each patient room with a computer allowing providers to easily share information with their patients
- Images from scans help transform medical terminology into understandable language for patients and help improve patient knowledge about conditions and symptoms
- Educating patients is important if health outcomes are truly to be achieved outside of medical facilities


Consumer Engagement at Yale New Haven Health System, | 10/4/16

- The Humm app is a product that originated in the restaurant industry. Leveraging the technology to get real-time feedback from our patients and families so that they could intervene in real time, rather than trying to respond to month-old data
- Analytics have been key, along with the ability to present that visibly on the patient care units as our nurses and executives are doing rounds
- The tool and the technology were important, but the culture around seeing and responding to the data was key

Be Effective

“Effective patient engagement technology is not about what people should do, but how to make it easier to do the right thing”

Source: HIMSS, The State of Patient Engagement in Health IT, 2014
The “P” is for Participation, Partnering and emPowerment

- **Participation**: bring patients and caregivers into your design process; give them a seat at the table where critical decisions are made

- **Partnering**: train both clinicians and patients on what it means to be a partner in healthcare decisions, with a focus on shared decision-making and access to clinical data

- **emPowerment**: focus on shifting attitudes and culture toward empowering consumers and patients in decisions, information to make decisions, overall approach and culture
HIMSS Patient Engagement STEPS framework
Your Journey Continues

“A Journey Of A Thousand Miles Begins With A Single Step.”

Lao-Tzu
Questions

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• http://www.tinyurl.com/ParticipatoryHealthcare

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