Nov 5, 2013 MSASS Research Colloquium

Participatory Group Model Building of
The added value of primary care
How to bring patient strengths into health care

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Overview

• 2 works in progress funded by PCORI
  • Methods
  • Early learning
  • Take-home lessons

• Bonus if time allows
  • New Cleveland Foundation planning project:
  • Greater University Circle Community Health Initiative
Patient Centered Outcomes Research Institute

• **Vision:** Patients and the public have the information they need to make decisions that reflect their desired health outcomes

• **5 priority areas**
  - Assessment of Prevention, Diagnosis, & Treatment Options
  - Improving Healthcare Systems
  - Communication and Dissemination
  - Addressing Disparities
  - Accelerating Patient-Centered and Methodological Research

• **Pay attention to**
  - Comparative effectiveness
  - Stakeholder participation
  - Methodology committee
Network on Inequality, Complexity & Health

- Complex systems modeling to improve population health & equity
- Funded by OBSSR
- Feb 24-25, 2014 conference in Bethesda

http://sitemaker.umich.edu/nich/home
Common in the 2 PCORI Projects

• Safety Net Providers’ Strategic Alliance
• Computer simulation modeling
• Group model building
Group Model Building to Engage Patient & Clinician Wisdom to Design Primary Care

Case Western Reserve University
Kurt Stange - Principal Investigator
Johnie Rose - Co-Investigator
Laura Homa - Research Associate
Kelly Burgess - Research Associate
Anindita Biswas - Study Coordinator
Heide Aungst - Medical Writer

Safety Net Providers Strategic Alliance
Ann Reichsman, MD - Director

Washington University at St. Louis
Peter Hovmand – GMB expert
Allison Kraus – GMB expert

University of Michigan
Rick Riolo – computational modeler
Sarah Cherng – computational modeler
Aims

1. Engage the wisdom of diverse patients and primary care clinicians to identify what matters about primary care

2. Adapt a participatory group model building process to agent-based models

3. Develop & evaluate models of primary care mechanisms that affect health & equity
Motivation

- Current efforts to improve quality and reduce inequality focus on the parts (diseases), rather than the whole (people).

- This reductionistic bias may lead to:
  - Ineffective allocation of resources intended to improve health outcomes
  - Actually making health and equity worse by focusing just on disease-specific care quality.


Principles of Primary Care

- **Accessibility** as 1st contact with health care
- **Accountability** for large majority of healthcare needs (comprehensiveness)
- **Coordination & Integration** of care across settings, acute & chronic illnesses, mental health & prevention
- **Sustained partnership** – relationships over time in a family & community context


Methods

- Patient & clinician focus groups/interviews for baseline information & as a tryout for subsequent group model building

- Group model building
  - Patient/clinician stakeholders identify key parameters & relationships
  - Programmers use this to program an agent-based simulation model
  - Participants & programmers refine the model together

- Sources of data
  - Stakeholder experience and evolving insights
  - Stylized facts from relevant literature
Appreciative Method for Framing Focus Groups
Goals

• Ground the initial model in real experiences versus generalizations

• Focus on positive experiences in which solutions are more likely to be found

• Foster energy and motivation for engagement
Appreciative Inquiry

“4D” Cycle

Discovery
“What gives meaning?”
Appreciating Strengths

Dream
“What are the unique opportunities for our Practice?”
Envisioning Results

Destiny
“How to empower, learn, and improvise?”
Doing

Design
“What should be—the ideal?”
Identifying Opportunities

http://ai.cwru.edu
## Adaptation of AI Steps to Focus Groups & Interviews

<table>
<thead>
<tr>
<th>AI</th>
<th>Application</th>
</tr>
</thead>
<tbody>
<tr>
<td>Appreciative Topic</td>
<td>A way of framing the problem that we are studying with the focus group in a way that gets people thinking about when something went really well</td>
</tr>
<tr>
<td>Discover</td>
<td>A specific time things went well around appreciative topic</td>
</tr>
<tr>
<td>Dream</td>
<td>Think in metaphors or pictures of what it would be like if peak experience more common</td>
</tr>
<tr>
<td>Design</td>
<td>Doable steps that might happen to make it a reality</td>
</tr>
<tr>
<td>Destiny</td>
<td>Testing/learning</td>
</tr>
</tbody>
</table>
Sample Characteristics

Appreciative Focus Groups
- N = 45 (9 groups)
- Sex
  - 73% Female
  - 27% Male
- Race/Ethnicity
  - 67% White/Caucasian
  - 22% Black/African American
  - 18% Hispanic
- Age
  - 24% Ages 18-25
  - 62% Ages 26-64
  - 13% Ages 65+
- Chronic Disease Conditions
  - 47% no chronic diseases
  - 54% one or more chronic diseases

Comparison Groups
- N = 25 (4 groups)
- Sex
  - 64% Female
  - 36% Male
- Race/Ethnicity
  - 4% White/Caucasian
  - 96% Black/African American
- Age
  - 48% Ages 60-64
  - 52% Ages 65+
Types of Experiences Discussed

**Appreciative Focus Groups**
- Rich details about positive personal experiences
- Exploration of mechanisms of action
- Importance of relationship as a facilitator

**Comparison Groups**
- “The biggest problem is…”
- Negative experiences more detailed in description
- Relationship/rapport as barrier
Motivation & Engagement

Appreciative Focus Groups
• 44/45 (98%) participants interested in continuing with GMB sessions
• “I would have done this without the money”
• Relationship with research staff developed

Comparison Groups
• 8/25 (32%) participants agreed to follow up interview
• “How much will you pay me?”
Conclusions

• Similar questions, similar discussion topics, very different results
• Framing the question in a way that appreciates positive experiences leads to rich details and a better balance between positive and negative discussion
• Appreciative method energized participants and engaged them to continue with the project
Group Model Building Sessions

1. Problem set up & learning about models by example
2. Developing a simple model
3. Experiment with, and blow up the initial model
4. Add complexity to the base case
5. Add more primary care factors
6. (TBD) Test hypotheses, consider model uses/audiences
7. (TBD) Refine the model and test more hypotheses
8. ?

• Issues/challenges encountered
  – Discovering an appropriate boundary object for agent-based models
  – Keeping the model simple amidst many good ideas
Different types of agents

Individuals

Organizations

represented in our example by stick figures for individuals and boxes for organizations
Agent states and traits

fill color of stick figures or boxes
An environment

easel paper or a square dry-erase board
Agent decision rules

written in caption bubbles above agents. If ___, then ___
System facts

written on rays coming from a sun figure
Agent actions and interactions

solid arrows between figure elements
<table>
<thead>
<tr>
<th>Primary Health Care</th>
<th>Relationship-Based:</th>
<th>Episodic:</th>
</tr>
</thead>
<tbody>
<tr>
<td>Patients</td>
<td>• Treat all diseases • Option to visit regularly for well care • Prevention focus improves patient health behaviors</td>
<td>• Treat all diseases • Only treat diseases</td>
</tr>
</tbody>
</table>

- **High Accessibility:**
  - Seek care when health declines below threshold
  - Visit relationship-based care every six months for prevention visit (and get any illnesses cared for then too)

- **Low Accessibility:**
  - Visit either type of care only when health declines below threshold

Patients
Care seeking determined by:
Base model

• Patients
  – Health (0 ↔ 1)
  – Have behaviors that affect disease probability
  – At risk for 4 kinds of diseases
    • Acute
    • Acute life-changing
    • Chronic
    • Mental illness
  – [Health loss threshold for seeking care related to accessibility]
  – 1 kind of agent seeks care only when ill
  – Another kind also comes in for well-care

• Clinicians (relationship or episodic)
  – Both treat all diseases
  – Different focus & effectiveness
  – Primary care also does well-care visits
4 Disease Trajectories

- Chronic
- Acute Life-Changing
- Acute
- Mental Illness

Graphs showing the trajectory of individual health over time (weeks).
Test Hypotheses About

• Factors affecting care seeking
• Comprehensive vs. narrow focus of care
• Relationship
• Trade-offs
What are we learning?

• Appreciative inquiry can liberate a sense of possibility
• The importance of the boundary object
• Creating space for spontaneity requires a lot of planning
• Sharing control means sharing vulnerability
Patient-Identified Personal Strengths (PIPS) vs. Deficit-Focused Models of Care

Case Western Reserve University
Kurt Stange - Principal Investigator
Johnie Rose - Co-Investigator
Shirely Moore, Co-Investigator
Laura Homa - Research Associate
Kelly Burgess - Research Associate
Anindita Biswas - Study Coordinator
Heide Aungst - Medical Writer

Safety Net Providers Strategic Alliance
Ann Reichsman – Director, Co-investigator

University of Oslo
Cornelia Ruland – Co-investigator

University of North Carolina
Kristen Hassmiller – Co-investigator
Aims

1. Identify patient-identified personal strengths (PIPS) relevant to illness management.

2. Develop a strength-focused computer-supported Interactive Tailored Patient Assessment Tool.

3. Engage diverse patients, caregivers and primary care clinicians in identifying mechanisms by which leveraging PIPS might affect the processes and patient-centered outcomes of health care.

4. Quantitatively simulate the effect of alternate approaches to leveraging PIPS on patient-oriented outcomes and provider resources compared to usual deficit/symptom-focused care.
Methods

• Appreciative focus groups to identify patient strengths
• Iteratively refine a computer-supported Interactive Tailored Patient Assessment Tool (ITPAT)
• Group model building of the mechanisms by which the Patient Strengths ITPAT can affect the processes and outcomes of care.
• Model deficit/symptom-focused care vs. care informed by patient-identified personal strengths.
Patient Strengths Initial Categories

- Personal strengths
- Supportive Relationships
- Neighborhood, community, health care resources
Concluding Remarks

• PCOR can benefit from methods that are
  – Participatory
  – Combine quantitative & qualitative data

• An appreciative approach appears helpful

• Agent-based models let you
  – think at the level of the individual
  – AND at the level of the system
  – understand how individual choices affect macro-level system dynamics
  – begin to understand mechanisms of the complex system of health care
Greater University Circle Community Health Initiative

• 1 year planning project
  – University Circle Anchor Institutions
  – 7 surrounding neighborhoods

• Develop an inventory of ongoing projects, interested people, and untapped potential for collaboratively promoting health

• Cultivate shared understanding & relationships

• Develop two social network analyses

• Plan next steps
Extra Slides
US Healthcare System

• “Fundamentally flawed” (IOM)

• #37 in the health or our people (WHO)
  – Between Costa Rica & Slovenia

• Most expensive in the world
  – 17% of GDP
  – Medicare bankrupt by 2019


Problem

• We treat the complex system of health care with a reductionist approach that assumes that health is the sum of the parts

• This leads to fragmented, inefficient, inequitable, often ineffective care
Paradox of Primary Care

• Poor quality of care by evidence-based disease-specific process of care measures in clinical studies
• Better quality at population level
• Better population health
• Lower resource use, cost & inequality

Participants

- Diverse patients – including those with multiple health conditions, low SES, and racial and ethnic minorities
- Primary care clinicians from a safety net practice-based research network
- Monthly group model building sessions
Hypotheses

• An appreciative inquiry approach to focus groups and interviews will elicit positive energy, grounded ideas, and possibilities for superb patient-centered care and outcomes;

• It is possible to engage diverse patients and primary care clinicians in a participatory process to elucidate patient-centered primary care processes and outcomes;

• An iterative, participatory group model building process can be adapted from its prior use in system dynamics models, to develop agent-based computer simulation models;

• These models can be used to answer PCOR questions comparing mechanisms by which primary care can be organized to maximize
The Paradox & the Principles
(Hypotheses about how primary care affects health & equity)

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Paradox of Primary Care

- Poor quality of care by disease-specific process of care measures
- Better population health
- Lower cost
- Less inequality
- Better health care quality