Coproducing better health outcomes: Mapping the research landscape

Maren Batalden, MD MPH
Cambridge Health Alliance
Harvard Medical School
Jonkoping Microsystem Festival #14
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Learning to see the system
Learning to see coproduction
Patient activation

Patient engagement

- Safety: No needless deaths
- Effectiveness: No needles pain or suffering
- User focus: Care for those served and serve those caring
- Efficiency: No unnecessary waiting
- Equity: No one left out
We can handle everything except naming your baby.
Goods
- cars
- furniture
- books
- clothing
- candy

Services
- teacher
- Doctors/Nurses
- $5 \div 6 + \frac{8}{5} = 13$
- $5 \div 6 + \frac{8}{5} = 11$
Value made by health professionals and given/pushed to patients

Value made by patients with assistance pulled from health professionals

How value is co-created during and healthcare service interaction
<table>
<thead>
<tr>
<th>Coproduction inherent to any service</th>
<th>Individual clinical encounter</th>
<th>System design and performance</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Intentional</strong> efforts to improve the quality of the coproducive partnership</td>
<td></td>
<td></td>
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</table>
Toward a definition of intentional coproduction

Coproduction is about citizens and professionals making better use of each other’s assets, resources, and contributions to achieve better outcomes or improved efficiency. (Governance International)

Passive people with needs
Paternalistic relationships
Focus on services delivered

Active people with assets
Collaborative relationships
Focus on outcomes created

Individual
(Clinical encounter)

OR

Collective
(System-focus)
Co-creation

- Co-commissioning
- Co-design
- Co-planning

- Co-delivery
- Co-management
- Co-evaluation
What forces push us toward greater interest in coproduction?

• Technology
• Values
• Demographics
• Finances
• Commitment to outcomes
Questions:
- what
- who
- which
- where
- when
- why
- how
Community and society

Healthcare system

Patients

Professionals

Shared goals
Shared knowledge
Mutual respect
Effective communication

Healthcare service outcome

Health outcome
Relationships
- Shared goals
- Shared knowledge
- Mutual respect

Communication
- Frequent
- Timely
- Accurate
- Problem-solving

Jody Hoffer Gittell
Heller School for Social Policy and Management
Brandeis University
Patients/ families → Clinicians/Workers → Leaders → Clinicians/Workers

Relational coproduction

Clinicians/Workers → Clients/families

Relational coordination

Clinicians/Workers → Leaders

Relational leadership
A Multidimensional Framework For Patient And Family Engagement In Health And Health Care.

Coproductive partnership continuum

Adapted from Patterson Kirk Wallace
Professionals

Healthcare system

Patients

Shared goals
Shared knowledge
Mutual respect
Effective communication

Healthcare service outcome

Community and society

Health outcome
• What competencies do service users need in order to be able to coproduce effectively at the level of the clinical encounter? At the level of the system?
• How might we best help service users develop those competencies?
• What invitations and incentives are most effective and appropriate at encouraging effective coproductive behaviours?
• How might we understand more clearly the resources that patients and families and communities bring? How might we measure the value of those resources?
• To what extent are we prepared for engaging in true reciprocity in relationships – greater decision-making authority in exchange for shared risk and accountability?
• Recognizing the differential capacity of service users to contribute equally to their health and wellbeing, how do we minimize health disparities?
• How might we facilitate network formation between patients and families?
**Figure 1: 13-Question Patient Activation Measure**

<table>
<thead>
<tr>
<th>Level 1</th>
</tr>
</thead>
<tbody>
<tr>
<td>When all is said and done, I am the person who is responsible for taking care of my health</td>
</tr>
<tr>
<td>Taking an active role in my own health care is the most important thing that affects my health</td>
</tr>
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<table>
<thead>
<tr>
<th>Level 2</th>
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<tbody>
<tr>
<td>I am confident I can help prevent or reduce problems associated with my health</td>
</tr>
<tr>
<td>I know what each of my prescribed medications do</td>
</tr>
<tr>
<td>I am confident that I can tell whether I need to go to the doctor or whether I can take care of a health problem myself.</td>
</tr>
<tr>
<td>I am confident that I can tell a doctor concerns I have even when he or she does not ask.</td>
</tr>
<tr>
<td>I am confident that I can follow through on medical treatments I may need to do at home</td>
</tr>
<tr>
<td>I understand my health problems and what causes them.</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Level 3</th>
</tr>
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<tbody>
<tr>
<td>I know what treatments are available for my health problems</td>
</tr>
<tr>
<td>I have been able to maintain (keep up with) lifestyle changes, like eating right or exercising</td>
</tr>
<tr>
<td>I know how to prevent problems with my health</td>
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</tbody>
</table>

<table>
<thead>
<tr>
<th>Level 4</th>
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</thead>
<tbody>
<tr>
<td>I am confident I can figure out solutions when new problems arise with my health.</td>
</tr>
<tr>
<td>I am confident that I can maintain lifestyle changes, like eating right and exercising, even during times of stress.</td>
</tr>
</tbody>
</table>


Judith Hibbard
Patient Activation Measure

Level 1: Disengaged and overwhelmed

Individuals are passive and lack confidence. Knowledge is low, goal-orientation is weak, and adherence is poor. Their perspective: “My doctor is in charge of my health.”

Level 2: Becoming aware, but still struggling

Individuals have some knowledge, but large gaps remain. They believe health is largely out of their control, but can set simple goals. Their perspective: “I could be doing more.”

Level 3: Taking action

Individuals have the key facts and are building self-management skills. They strive for best practice behaviors, and are goal-oriented. Their perspective: “I’m part of my health care team.”

Level 4: Maintaining behaviors and pushing further

Individuals have adopted new behaviors, but may struggle in times of stress or change. Maintaining a healthy lifestyle is a key focus. Their perspective: “I’m my own advocate.”

Increasing Level of Activation

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Minimally Disruptive Medicine

ICAN tool to facilitate conversation

Self management

Self-management education programmes by lay leaders for people with chronic conditions.
Foster G¹, Taylor SJ, Eldridge SE, Ramsay J, Griffiths CJ.
Cochrane Database Systematic Review 2007
17 trials involving 7442 participants

Lay-led self-management education programmes may lead to small, short-term improvements in participants' self-efficacy, self-rated health, cognitive symptom management, and frequency of aerobic exercise. There is currently no evidence to suggest that such programmes improve psychological health, symptoms or health-related quality of life, or that they significantly alter healthcare use.

Personalised care planning for adults with chronic or long-term health conditions.
Coulter A¹, Entwistle VA, Eccles A, Ryan S, Shepperd S, Perera R.
Cochrane Database Systematic Review 2015
19 studies involving a total of 10,856 participants

Personalised care planning leads to improvements in certain indicators of physical and psychological health status, and people's capability to self-manage their condition when compared to usual care. The effects are not large, but they appear greater when the intervention is more comprehensive, more intensive, and better integrated into routine care.
Our Success

- 93% have satisfactory growth
- 78% are in remission
- 95% are not taking steroids
- 49% have sustained remission for at least 1 year
- 90% show satisfactory nutrition

- 610 pediatric gastroenterologists caring for 20,600 children with IBD
- 74 care centers in 34 states + England
- 35 of the top 50 children's gastroenterology centers including
- 7 of the top 10 honor roll children’s hospitals

Data from ImproveCareNow centers with greater than 75% registration of eligible IBD patients

April 2015
EQUALITY  EQUITY  REALITY
• What competencies are necessary for health professionals to be effective coproductive partners?
• How might we help health professionals develop those competencies – both those currently in practice and those preparing to practice in the future?
• How do we most effectively invite (and incentivize?) health professionals to be good coproductive partners?
• How can traditional asymmetries of information between professionals and service users be overcome so as to draw in user expertise most effectively?
• How should health professionals appropriately use the power of standardizing and customizing care?
Figure 1: Co-production of health in consultations for people with long-term health conditions

Kalamazoo consensus (Bayer Institute, 2001)

Build the doctor-patient relationship

Open the discussion

Gather information

Understand the patient’s perspective

Share information

Reach agreement on problems and plans

Provide closure

Clinician’s skills
(Pawlakowska, Leach et al. 2007)
- Establishing rapport
- Questioning style
- Active listening
- Empathy
- Summarising
- Reflection
- Appropriate language
- Silence
- Responding to cues, patient’s ideas, concerns and expectations
- Sharing information
- Social and psychological context (Hall and Roter, 2007)
- Clinical examination
- Explore beliefs about self-management support (Shawler, Miller et al. 2009; Coleman, Austin et al. 2009)
- Partnership
- Honesty
- Safety netting/follow up/housekeeping

Patient’s skills
(Department of Health, 2001) based on Kate Lorig’s model
- Problem solving
- Decision making
- Resource utilisation
- Developing effective partnerships with healthcare providers
- Taking action in behavioural changes
- Health literacy

Purposes of the relationship
(Hall and Roter, 2007)
- Informative
- Receptive
- Facilitative
- Medically functional
- Participatory

Outcome of a co-productive relationship
- Highly individualised care (Bellencourt, Ostrom et al. 2002)
- Within a long-term relationship (Bovaird, 2007)
- Shared Information (Bellencourt, Ostrom et al. 2002)
- Shared decision making (Needham and Carr, 2009)
- Acknowledgement of client’s resources and expertise (Cohn, 2000)
- Empowerment of front-line staff (Needham and Carr, 2009)

Health Foundation, 2011
The SHARE Approach
Essential Steps of Shared Decision Making

STEP 1: Seek your patient's participation
STEP 2: Help your patient explore and compare treatment options
STEP 3: Assess your patient's values and preferences
STEP 4: Reach a decision with your patient
STEP 5: Evaluate your patient's decision

Five steps for you and your patients to work together to make the best possible health care decisions
Community and society

Healthcare system

Patients

Professionals

- Shared goals
- Shared knowledge
- Mutual respect
- Effective communication

Healthcare service outcome

Health outcome
• How might we collect and analyze measures of performance relative to unique patient-determined goals and preferences?
• How do we balance priorities among stakeholders for outcome data – metrics that matter to patients and families, clinicians, administrators, payers?
• How can we use qualitative methods to measure coproduced outcomes over time?
• In measuring outcomes to understand and improve effective coproduction, how can we limit the potentially negative consequences of using this data for judgement inappropriately?
Patient-related outcome measures

- Clinical measure: Spirometry
- Symptom report: Dyspnea score
- Condition-related function: Respiratory-related quality of life and function
- General well-being: General quality of life and function
Content of Widely-Used Patient-Reported Outcome Measures

<table>
<thead>
<tr>
<th>CONCEPTS</th>
<th>Psychometric</th>
<th>Utility Related</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>SIP</td>
<td>HIE</td>
</tr>
<tr>
<td>Physical functioning</td>
<td>●</td>
<td>●</td>
</tr>
<tr>
<td>Social functioning</td>
<td>●</td>
<td>●</td>
</tr>
<tr>
<td>Role functioning</td>
<td>●</td>
<td>●</td>
</tr>
<tr>
<td>Psychological distress</td>
<td>●</td>
<td>●</td>
</tr>
<tr>
<td>Health perceptions (general)</td>
<td>●</td>
<td>●</td>
</tr>
<tr>
<td>Pain (bodily)</td>
<td>●</td>
<td>●</td>
</tr>
<tr>
<td>Energy/fatigue</td>
<td>●</td>
<td>●</td>
</tr>
<tr>
<td>Psychological well-being</td>
<td>●</td>
<td>●</td>
</tr>
<tr>
<td>Sleep</td>
<td>●</td>
<td>●</td>
</tr>
<tr>
<td>Cognitive functioning</td>
<td>●</td>
<td>●</td>
</tr>
<tr>
<td>Quality of life</td>
<td>●</td>
<td>●</td>
</tr>
<tr>
<td>Reported health transition</td>
<td>●</td>
<td>●</td>
</tr>
</tbody>
</table>

SIP = Sickness Impact Profile (1976)
HIE = Health Insurance Experiment surveys (1979)
NHP = Nottingham Health Profile (1980)
QLI = Quality of Life Index (1981)
COOP = Dartmouth Function Charts (1987)
DUKE = Duke Health Profile (1990)
MOS FWBP = MOS Functioning and Well-Being Profile (1992)
MOS SF-36 = MOS 36-Item Short-Form Health Survey (1992) = Quality of Well-Being Scale (1973)
PROMIS = Patient Reported Outcomes Measurement Information System
QWB = Quality of Well-Being Scale (1973)
EUROQOL = European Quality of Life Index (1990)
HUI = Health Utility Index (1996)
SF-6D = SF-36 Utility Index (Brazier, 2002)

Source: Adapted from Ware, 1995
## Sources of Suffering

<table>
<thead>
<tr>
<th>Unavoidable</th>
<th>Avoidable</th>
</tr>
</thead>
<tbody>
<tr>
<td>(Providers' goal: mitigate)</td>
<td>(Providers' goal: eliminate)</td>
</tr>
<tr>
<td>Associated with diagnosis</td>
<td>Associated with treatment</td>
</tr>
<tr>
<td></td>
<td>Associated with health care delivery system dysfunction</td>
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</tbody>
</table>

### Examples

<table>
<thead>
<tr>
<th>Unavoidable</th>
<th>Avoidable</th>
</tr>
</thead>
<tbody>
<tr>
<td>Symptoms of disease including pain</td>
<td>Unnecessary pain resulting from failure to identify and treat the source.</td>
</tr>
<tr>
<td>Loss of functioning (temporary or permanent)</td>
<td>Hospital acquired conditions</td>
</tr>
<tr>
<td>Fear or anxiety arising from the implications of the diagnosis for health and functioning</td>
<td>Fear or anxiety resulting from lack of coordination and teamwork, lack of respect shown to patient, and loss of trust in providers.</td>
</tr>
<tr>
<td>Fear or anxiety due to unfamiliar processes, disruption in daily life, and loss of control.</td>
<td>Misdiagnosis</td>
</tr>
</tbody>
</table>

Source: Press Ganey

Original Investigation

Effect of Financial Incentives to Physicians, Patients, or Both on Lipid Levels
A Randomized Clinical Trial

David A. Asch, MD; Andrea B. Troxel, ScD; Walter F. Stewart, PhD, MPH; Thomas D. Sequist, MD, MPH; James B. Jones, PhD; AnneMarie G. Hirsch, PhD, MPH; Karen Hoffer, BS; Jingsan Zhu, MBA; Wenli Wang, MS; Amanda Hodlofski, MPH; Antonette B. Frasch, MD; Mark G. Welner, MD; Darra D. Flinnerty, BS; Meredith B. Rosenthal, PhD; Kelsey Gangemi, MPH; Kevin G. Volpp, MD, PhD

RESULTS  Only patients in the shared physician-patient incentives group achieved reductions in LDL-C levels statistically different from those in the control group (8.5 mg/dL; 95% CI, 3.8-13.3; P = .002). For comparison of all 4 groups, P < .001.

<table>
<thead>
<tr>
<th>Low-Density Lipoprotein Cholesterol Level</th>
<th>Incentives Group</th>
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<tbody>
<tr>
<td></td>
<td>Shared</td>
</tr>
<tr>
<td>Mean reduction (95% CI), mg/dL</td>
<td>33.6 (30.1-37.1)</td>
</tr>
<tr>
<td>Baseline, mg/dL</td>
<td>160.1</td>
</tr>
<tr>
<td>12 Months, mg/dL</td>
<td>126.4</td>
</tr>
</tbody>
</table>
• To what extent can collective approaches to co-production escape the equity challenges of individualistic approaches, where more assertive users tend to benefit most from their active participation?
• How might we think about budgeting across social sectors to ensure effective partnership in meeting the needs of service users?
• How might healthcare service innovations effectively strengthen the core economy and its capacity for enhancing community health and well-being?
DETERMINANTS OF HEALTH

- Social & Economic Factors: 40%
- Health Behaviors: 30%
- Clinical Care: 10%
- Physical Environment: 10%
- Genes & Biology: 10%
CULTURE OF HEALTH ACTION FRAMEWORK

ACTION AREA 1
MAKING HEALTH A SHARED VALUE

ACTION AREA 2
FOSTERING CROSS-SECTOR COLLABORATION TO IMPROVE WELL-BEING

ACTION AREA 3
CREATING HEALTHIER, MORE EQUITABLE COMMUNITIES

ACTION AREA 4
STRENGTHENING INTEGRATION OF HEALTH SERVICES AND SYSTEMS

OUTCOME
IMPROVED POPULATION HEALTH, WELL-BEING, AND EQUITY

Robert Wood Johnson Foundation
Professionals

Healthcare system

Patients

Shared goals
Shared knowledge
Mutual respect
Effective communication

Community and society

Healthcare service outcome

Health outcome
• What design features of a healthcare delivery system facilitate and inhibit effective partnership between patients and families and health professionals?
• What strategies work for partnering with patients and families in the work of designing and improving healthcare service systems?
• What are the costs of coproduction to all stakeholders involved and how these costs might be measured?
• What sorts of technologies (both assistive health technologies and interactive web platforms) are required to support coproductive approaches?
• What are the institutional barriers to rolling out more radical forms of collective co-production? How can resistance be overcome?
• How can the balance between short-term costs and longer-term benefits of ‘preventative coproduction’ be illustrated more clearly to stakeholders?
Coproducing improvement?

Vanuit het hart of vanuit het systeem? Uit: Verdraaide Organisaties
Donabedian’s Quality Framework

Structure
Characteristics of institutions & providers

Process
What is done to the patient

Outcomes
What happens to the patient

Relationships?
The Dartmouth Microsystem Improvement Ramp

- Value compass
  Measures that matter

- Coproduction change concepts

- Interviews
  Observation
  Patient journey mapping

- Specific aim
  Change ideas

- Global aim
  Flowchart

- Assessment
  * 5P Assessment/Effective Meeting Skills

- Shared goals
  Patient and family aim

- Patients and families on teams
Design Thinking

**Empathy**
- Learning about the audience for whom you are designing

**Define**
- Redefining and focusing your question based on your insights from the empathy stage.

**Ideate**
- Brainstorming and coming up with creative solutions.

**Prototype**
- Building a representation of one or more of your ideas to show to others

**Test**
- Returning to your original user group and testing your ideas for feedback.
old power  new power

Currency
Held by a few
Pushed down
Commanded
Closed
Transaction

Current
Made by many
Pulled in
Shared
Open
Relationship

Jeremy Heimans  TED talk “What new power looks like”
https://www.youtube.com/watch?v=j-S03JfgHEA

@HelenBevan  @JodiOlden  #EdgeTalks