Contents

Proem

When your 10-year-old child plans, purchases ingredients, and prepares dinner for the family every Thursday, that's co-production. When neighborhood residents work closely with police to allocate resources to identify and address local safety risks, that's co-production. When patients and caregivers—people with lived experience—serve as co-Primary Investigators (PIs) in research, that's co-production. Several readers and listeners of last week's episode Walk the Talk. Person-First and Co-Production asked me to say more about co-production. Luckily, I had this episode in the works for a future date. Easy enough to move it up in the queue. Here you go.

Little did I know. Growing into co-production. 02:01

My first experience with co-production occurred in 1997 (although we didn't use the term then). It involved forming member and provider advisory panels as Director of Quality Management at the Troy, NY, office of Value Behavioral Health. Jim Bulger, Executive Director of this managed behavioral health company, wanted the counsel of members and providers about causes of poor satisfaction scores. Both panels came up with common concerns: delays in receiving mental health and substance use treatment for members and frustration with the pre-authorization process for providers. Pre-authorization means that the insurance company requires a call from the clinician to get permission to be paid for treatment. Time consuming. At the time, all visits required pre-authorization. While digesting the feedback with his leadership team, Jim declared that we would be idiots to convene the panels and not listen to them. The outcome: we changed the policy to allot seven visits upon request from any provider in the network. Concerns about abuse? We deal with it when it occurred, and that was more rarely than we'd expected.

Fifteen years later, when I started as Vice President, Quality Management, for Advocates, Inc. in Framingham, MA, which supported 23,000 persons with disabilities, I entered a mature system that

included people we supported at all levels of operations and governance. The organization invested in preparing partners (persons served, family, staff, and leadership) about the issues and reports coming before them. The partnerships resulted in many novel and sustainable changes in clinical practice and family communication. For example, we put more effort into letting residents and family members know in advance when direct care staff moved on to other jobs. Small effort led to significant higher perception scores.

As a patient-caregiver change agent, six years ago I shifted my mission statement from, "*empowering people on their journey toward best health"* to "*learning on the journey toward best health."* My shift from empowering to learning reflects an appreciation of power dynamics in patient-healthcare system relationships. Who was I to empower someone else? Power dynamics are who's up and who's down? I'm talking about people when they wear a patient or family caregiver hat and healthcare professionals and institutions they interact with. I say *when they wear a patient hat*, because when doctors wear the patient hat, they also feel the power dynamic. Learning together is co-production.

Experimenting for change in research 05:17

In co-production we experiment and change. The degree of engagement itself lives on a continuum, as do its participants. It's not all or nothing. Some are in a traditionally power up position – researchers; others in a power down position – patients and caregivers. In this piece, I'll examine those continuums, the benefits of partnerships, and the steps you, we, they, can take to push co-production forward. I won't espouse an ideal state. Rather, I advocate for self-awareness about the continuum of and readiness for power-sharing and advocate for step-by-step forward movement.

> What's a continuum? Swimming is a continuum. From on dry land to fully in the water swimming. In between are putting on bathing suit, toe in water, fully in water, treading water, swimming – a continuum.

Co-production – a power shift 06:15

Co-producing a research project means researchers, clinicians, and the public work together, sharing power and responsibility from the start to the end of the project[i] [ii] Co-production rests on a foundation of trust, humility, respect for varied expertise, mutual coaching and mentorship, self-confidence, and curiosity. It's not about consultation, participation, or engagement – words used to describe situations where those with power let people into their world. It's a power shift to engage in partnering where leadership and decision-making are truly shared. Co-production can occur in all phases of a project: asking questions for research, methods development, governance and budget, recruitment, analysis, dissemination, implementation, and ongoing evaluation.[iii] Co-production is not for the faint of heart, exhausted, insecure, or self-centeredly ambitious. It's work, it's risky—but it is also *so* rewarding. Power shifts usually occur when those with power in the existing system open it up for those with less. We call the exceptions, when people seize that power, revolution. That's not my expertise. I am a lousy revolutionary.

Co-production – from here to where? 08:00

The evolving relationships in co-production begin at zero, where there is no relationship: the researcher knows best and operates in their bubble of expertise with patients as subjects in the study. The next level is a one-way relationship where academic researchers listen to people with lived experience usually through focus groups and one-time forums. The third level involves consultation on specific parts of the study. The highest level is shared leadership and decision-making between researchers and patients across the entirety of the research project.

Researcher's capacity, willingness, and opportunity to participate 08:45

Researchers, often the *up* party in an unequal relationship, are not homogenous, the same. They vary. Perhaps we can group these perceived powerful into those that have already drunk the Kool-Aid of partnering and sharing in decision-making and those who haven't. Some have existing power-equal relationships, know they have a problem to solve that requires expertise they don't yet have access to, and appreciate the expertise of life literacy and lived experience, and some don't. Some have budgeted for engagement and partnership, have self-confidence, aren't threatened by change, are prepared to change. Some aren't. Do you get the idea?

A person with power may have self-confidence, comfort with change, a budget for mentoring and coaching, time and patience, and a well-defined problem that requires expertise their team lacks. In contrast, a person with power may feel threatened by change, have no budget, no time, and yet may want to check a box to demonstrate engagement. The strategy and tactics those two individuals might employ in setting up a research partnership would be radically different, given where they sit on the continuum. Similarly, stakeholders seeking to build partnerships and co-production would approach those individuals differently. And the outcomes of the partnerships they establish are likely to be radically different as well.

Public's capacity, willingness, and opportunity to participate. 10:31

To be sure, the members of the public exist on a continuum as well. Researchers may benefit from understanding the variation among us, the public. We are not homogenous, the same. We have varied comfort and understanding of our lived experience, varied communication skills, varied knowledge of medical terms and systems. Some of us are more networked than others, have more time to devote to advocacy, more desire. Some have transportation to events or high-speed internet access. Some have dependent care responsibilities, and some don't. Some have hutzpah, self-confidence, curiosity, and some have less.

Co-production, self-awareness, and change management depend on meeting people where they are. This is also known as person-first interactions.

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Why bother? It's hard. 12:26

Why co-produce? What's in it for any of us? I've worked with PCORI (the Patient-Centered Outcomes Research Institute) since 2013 in several capacities: patient-caregiver Merit Reviewer (scoring funding applications with scientists and other stakeholders), member and co-chair of several Advisory Panels and now as a member of the Board of Governors. During this service, I've seen multiple challenges in research. Some examples include:

- a gap between the questions people ask about attaining best health and the evidence-informed guidance available to them, when they need it, in a manner they can use.
- the glacial pace at which research findings make it into clinical practice and life habits.
- the exclusion of groups of people in research studies.
- the outsized emphasis on the institutional medical care of individuals rather than the health of communities.
- the inability to respond rapidly to the uncertainty of public health emergencies.

Co-production could help address these challenges. A few opportunities resulting from our current experience managing COVID-19 come to mind. Co-production could:

1. bridge the gap between the questions regular people ask and the evidence-informed guidance available to them. Few people managing COVID in their lives seek guidance in journals and conferences. Co-produced research could listen for questions where people ask them (popular and social media, zoom calls, grocery store), and disseminate in those locations and channels that regular people access and trust.
2. inform and serve the diversity of patient/caregiver communities. Few of us know what we don't know. For example, as the previous episode described, partnering with undergraduate college students expanded my old person perspective on the need for evidence about COVID and food insecurity.
3. build capacity among stakeholders in established, trusting relationships that could be tapped quickly when urgent public health concerns threaten to overwhelm communities. When everyone is flying by the seat of their pants, existing relationships and channels can help prioritize research needed, enroll participants, and disseminate findings.
4. put research findings into clinical practice and life habits faster. Implementation is a concoction of science, workflow, life flow, and trust. Co-production supports people who influence.

Now what? 15:46

Appreciating the diversity, the continuum, meeting people where they are, can overwhelm us. One size does not fit all. Assuming curiosity, discomfort with the current state, the time, some funding, and existing trustful relationships, we can take many steps. By *we,* I mean any of us, researchers, clinicians, the public, funders. We could:

- Spend 15 minutes each week journaling what works and what doesn't for any partnerships with other stakeholders in your research universe. Self-assess where you and yours live on the continuums of co-production. Self-examine satisfactions, or not, with the implementation of your current findings. Share widely wherever you meet peers.
- Budget for engagement and co-production early. If not dollars, pro-bono time. Time is not free for anyone.
- Build on current trusting relationships with peers and stakeholders who have drunk a bit more Kool-Aid than you. Find inspiration there. Experiment with them.
- Embrace failure. Co-production is messy and fraught. I've learned more from what didn't work than did. Adjust, try something else.
- Spend at least 50% of your time with partners with mouth closed, ears open. They know stuff you don't.
- Hone your ability to identify questions and issues that your current team hasn't yet solved. Could people with different abilities, circumstances, conditions, expertise offer a door-opening perspective? Formulate questions they could answer. Have courage.
- No matter how good you are in your bubble of expertise, professional or lived experience, seek and accept coaching about co-production. If you've had some success with co-production budget time for mentorship, paid or pro bono.

Reflection 18:13

Thank you, followers, for asking for more about co-production. Realistically, partnerships, co-production is work and rare, anywhere. The bottom line for me is self-awareness, courage, small step progress, and variable solutions. Today, as I finish this script, this article, I'm thinking about how we might measure progress we take in co-production - dollars spent, decisions made, people involved? I don't know. Have any ideas? Let me know. Onward. See you around the block.

[i] https://www.invo.org.uk/wp-content/uploads/2019/04/Copro_Guidance_Feb19.pdf
[ii] *BMJ 2021; 372 doi: https://doi.org/10.1136/bmj.n434 (Published 16 February 2021)*

[iii] Patient Engagement In Research: Early Findings From The Patient-Centered Outcomes Research Institute
Laura P. Forsythe, Kristin L. Carman, Victoria Szydlowski, Lauren Fayish, Laurie Davidson, David H. Hickam, Courtney Hall, Geeta Bhat, Denese Neu, Lisa Stewart, Maggie Jalowsky, Naomi Aronson, and Chinenye Ursla Anyanwu Health Affairs 2019 38:3, 359-367

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