



Atrium Health

Developing Health Literacy Skills in Youth: The Health Care System's Approach

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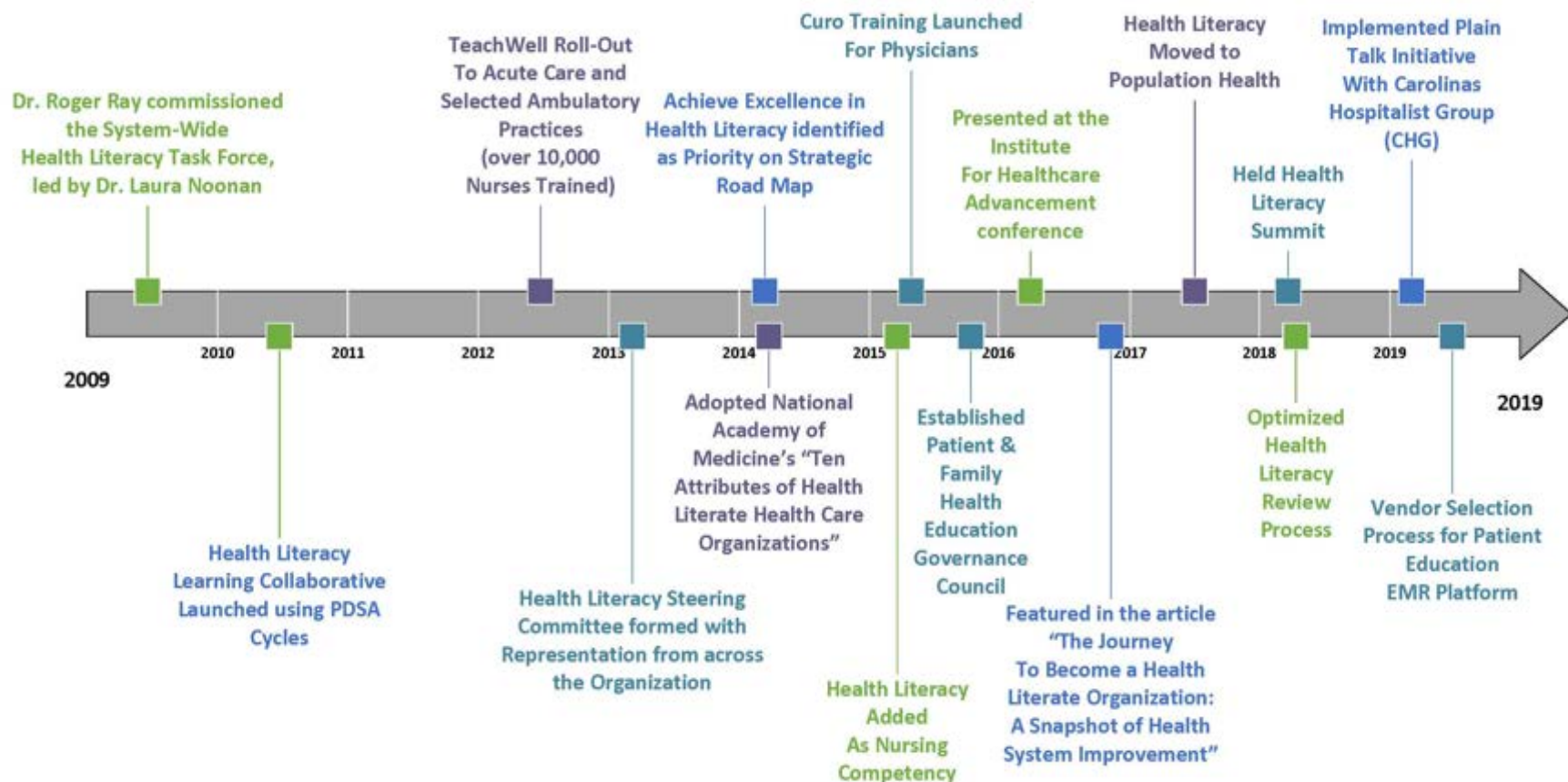
National Academies of Sciences, Engineering, Medicine
Health Literacy Roundtable

Disclosures

I have nothing to disclose.

Health Care System Approach

Our Journey 2009-2019



2020: Be a Health Literate Organization



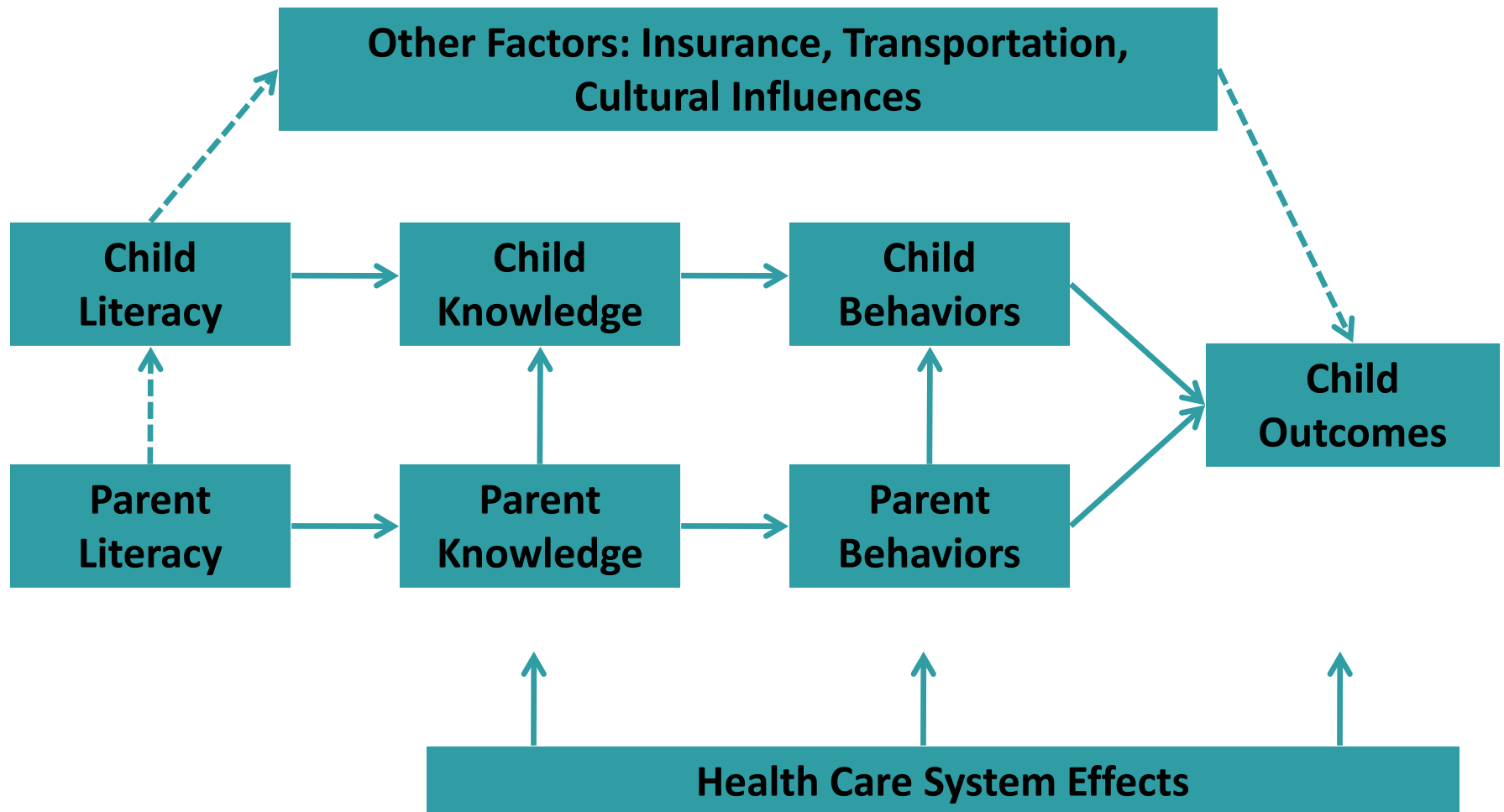
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Mapped Opportunities by Attribute

Primary Health Literacy Attribute	Responsible Person(s)	Action Item	Details	Barriers / Challenges	Target Start Date	Target Due Date	Actual Date Complete
1 Leadership Promotes	Hope	Meet with Leadership to Determine Plan	Meet with Leadership Team at Anson to discuss plan to move forward		2/26/16	4/30/16	
3 Prepares Workforce	Hope	TeachWell Train-the-Trainer class	Include therapies, ancillary, Stanly	Schedules of Anson staff - availabiltiy	2/26/16	5/31/16	
	Jan	Health Literacy/Plain Language Workshop	Writing and practice for staff; 2 (4 hour) sessions	Schedules of Anson staff - availabiltiy	2/26/16	5/31/2016	
4 Includes Consumers	Alisha	PFAC Involvement - Invitational Meet & Greet and hold first meeting	PFAC needs something to own - perhaps identify topics for top 10 handouts		2/26/16	12/31/2016	
	Alisha	Diabetes Focus Group - Invitational Meet & Greet	Large poplulation of diabetics in Anson Co. Determine needs of this group		2/26/16	12/31/2016	
	Jan	Representation on Health Ed Committees	Get Anson staff to participate on committees		2/26/16	12/31/16	
5 Meets Needs of All	Alisha	Evaluate diverse populations & determine need for other languages	Create materials and do outreach for this population		2/26/16	12/31/2016	
7 Ensures Easy Access	Rhonda & Alisha	Evaluate Health Literacy of Signage	Make sure signage meets HL standards		2/26/16	12/31/2016	
	Jan & Rhonda	Develop Picture Image Education/Signage	Denise will help find champions to help with development		2/26/16	12/31/2016	
	Hope/Beth	Navigation Card for HealthQuest - determine need and discuss further with Anson staff	Card to provide directions to HealthQuest for those who are eligible and are leaving the ED		2/26/16	12/31/2016	
	Hope	Research adding Carolinas Primary Care to	Add this to both of the big signs outside	See if it complies with			

Child Health Literacy Model

Working Relationship Between Literacy and Child Health Outcomes



Methodological Challenge: Dyadic Roles of Parent and Child

- Which is more influential: child or parental literacy?
- Factors to Consider:
 - Literacy vs. health literacy
 - Child development
 - Intellectual, cognitive, physical
 - The illness or behavior under consideration
 - Transition of self-care activities
 - Often between 11 and 15
 - Complex interaction of factors...

Transition Factors

Family

- Organization and Support
- Maternal Self-Efficacy
- Perception of Child Capacity

Child

- Maturity and Self-Concept
- Initiation of Self-Care
- Academic Achievement
- Involvement in Outside Activities

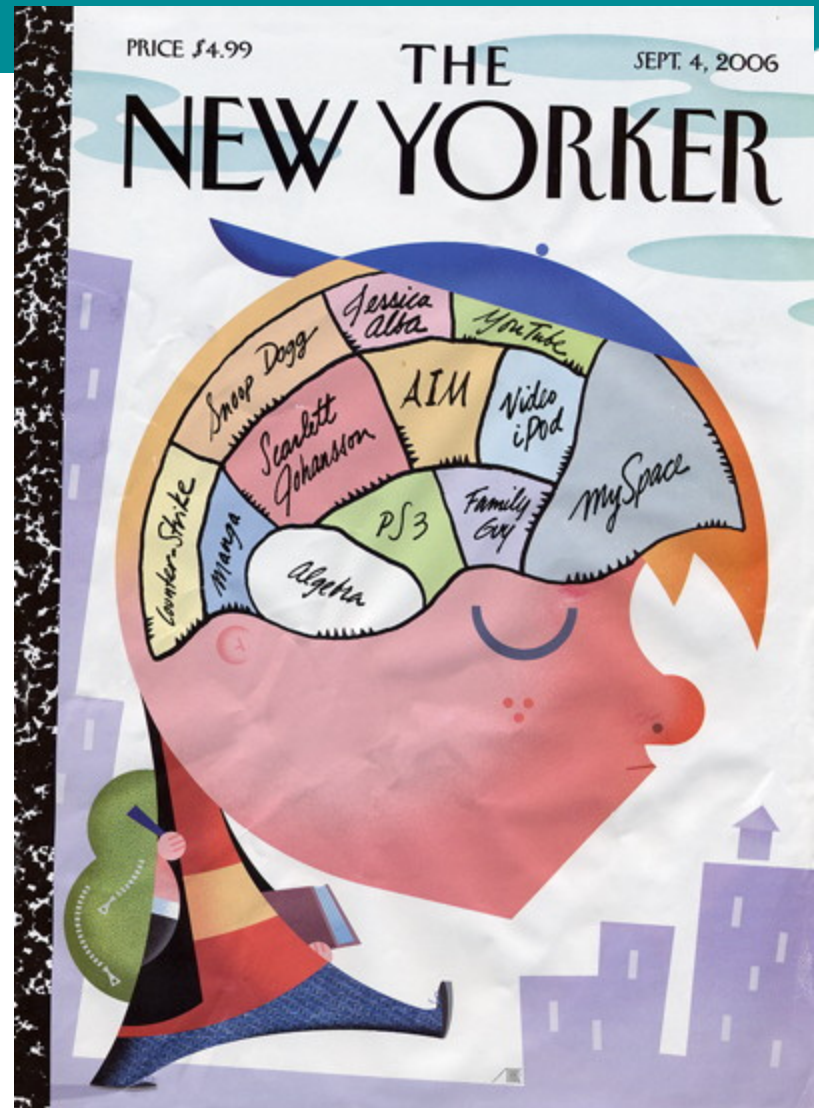
Health and Care

- Duration of Disease
- Shared Decision-making with Medical Provider



Transition: Deception of Age

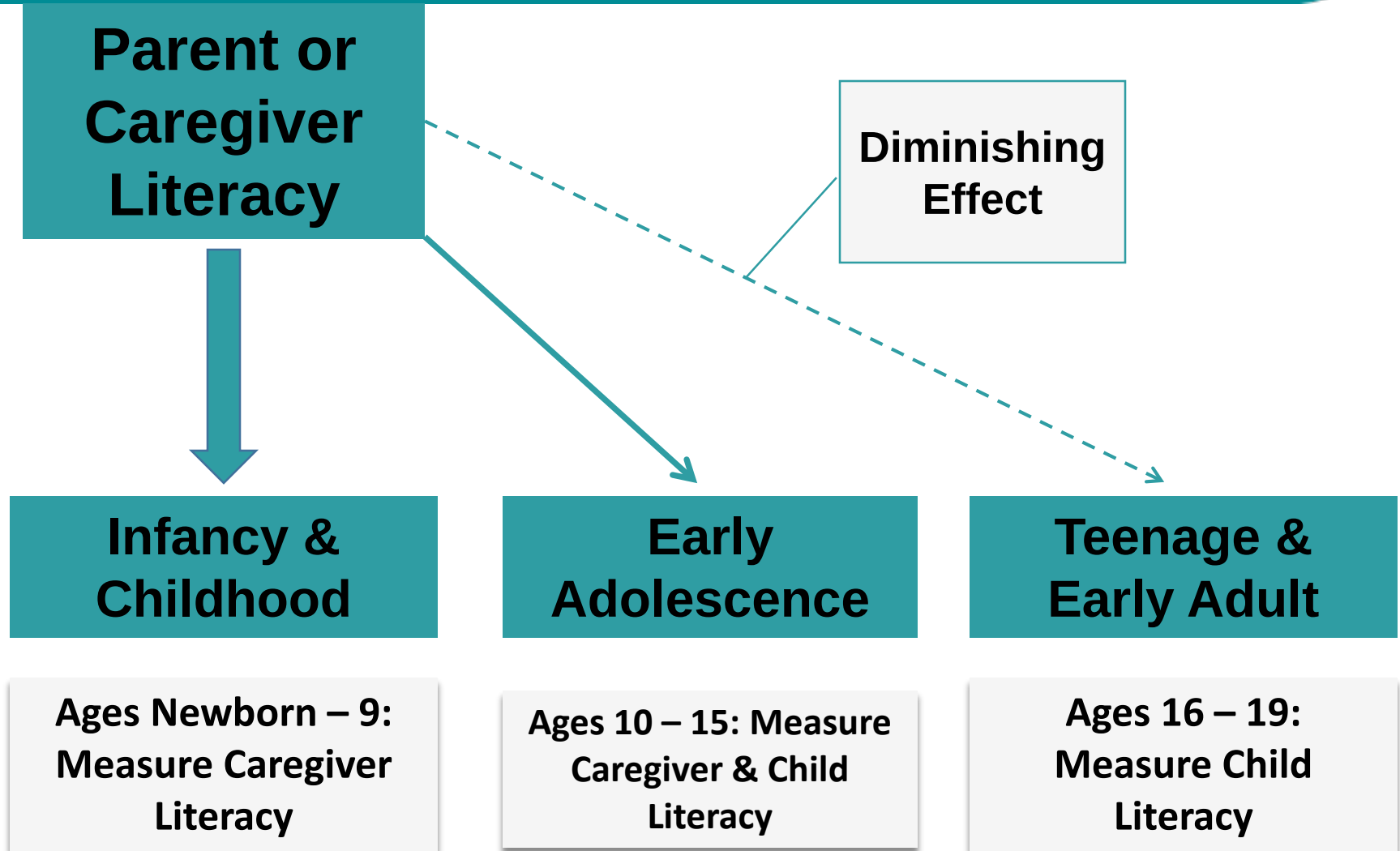
- Age, education level, and possibly literacy can be deceiving...
- Teens sometimes *regress* in their self-care
- Factors other than literacy may be more salient among teens.....



Health Outcomes

- Knowledge and behavior most frequently measured outcomes
- Parental low literacy often associated with poor health knowledge and behaviors
- Adolescent low literacy associated with adverse “risk taking” behaviors
- Fewer studies between LL and health-related services and health status, mixed results
 - *Still difficult to draw conclusions about the cause and effect relationship between literacy and child health outcomes*

Thinking About Who to Measure



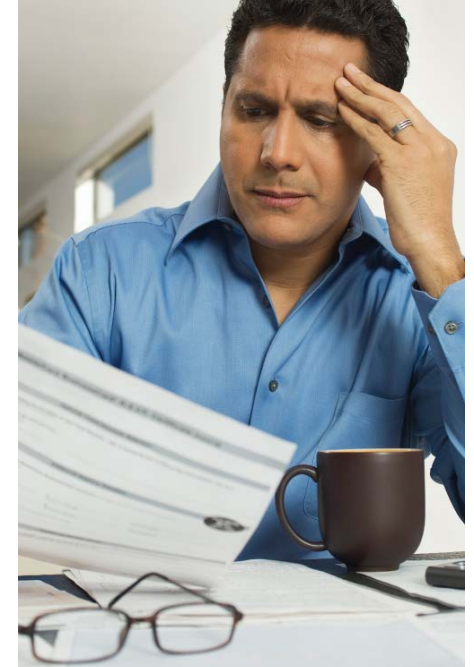
Health Literacy Equation



x



=



Skills / Abilities x Difficulty / Complexity = Health Literacy

Burden and Capacity

- **Burden** of informational complexity placed on patients by health care providers and systems
- **Capacity** of patients to understand providers and navigate systems

Burden and Capacity

- Reducing burden
 - Non-interactive
 - Interactive
- Increasing capacity
 - Directly
 - Indirectly
- **Changing systems of care**

Changing Systems of Care: Organizational Approaches

3 Key Strategies

Improve youth health literacy through use of:

- Co-Production
- Quality Improvement
- Patient Portals

Using Co-Production

It's producing things—in this case improvements in care and outcomes—together.

Co-production is patients, families, clinicians, and researchers collaborating as equal and reciprocal contributors to produce **information** (e.g., clinical data, patient reported outcomes), **knowledge** (informal insights and formal research), and **know-how** (expertise) to improve healthcare and health outcomes.

In plain language please . . .

In “co-production,” patients, parents, and providers work with each other to create the best system of care.

Key items:

- work as equals
- every person adds value
- as a team, we will “produce” (make)
 - o data
 - o insight
 - o skill
- results improve care and health for all

Burden vs. Capacity

Co-production requires equality and reciprocity, however we start from an unequal position:

Health care providers do this work as their work

≠

Parents must do this in addition to caring for an ill child, managing the family, working outside the home, etc.

To adjust for this, we need to think about new ways to work.

Using Co-Production

Co-Production helps to balance the scale by approaching health literacy from both directions:

- increase skills and capacity
- decrease burden and complexity

Co-Production in Action



Co-Production in Action



Pediatric Nephrology
CENTER OF EXCELLENCE

MISSION STATEMENT

Promote patient and family-centered care for children impacted with kidney disease by leveraging patient & clinician engagement, clinical research, improvement science and best practices to transform the overall patient experience and quality of life.

Co-Production in Action

- Education
- Quality Improvement
- Innovation
- Research



Co-Production: Education

- Focus Groups: help with decision support materials
- Individual Groups: examine old materials to create new and understandable content
- Round Robin Table Time: discuss ideas and implement
- Organize materials into “must know” vs. “want to know more”



Co-Production: Education



What Are Kidneys?

Kidneys normally come in pairs and look like a kidney bean. Each kidney is about 5 inches long and about 3 inches wide — about the size of a computer mouse.

To find your kidneys, put your hands on your hips, then slide your hands up until you feel your ribs. If you put your thumbs on your back, you will know where your kidneys are.



Co-Production: Education

What Do Kidneys Do?

The kidneys clean your blood and make pee

What else works with the kidney to produce pee?

Ureters: tubes that carry pee from each kidney to the bladder

Bladder: a sac that collects the pee

Urethra: a tube that carries the pee from the bladder out of the body



Using Quality Improvement

Key QI tools also benefit health literacy approaches, e.g.

- finding root cause
- looking through the eyes of the end user
- testing changes with small, rapid cycles
- using data to drive the work

Using Quality Improvement

Youth involved in:

- Improve Care Now (ICN)
- Pediatric Rheumatology Care & Outcomes Improvement Network (PR-COIN)
- Improving Renal Outcomes Collaborative (IROC)
- Epilepsy Learning Health System
- ST3P-UP Transition Program: Sickle Cell Quality Improvement Collaborative

Using Quality Improvement

For example, the **ST3P-UP Transition Program: Sickle Cell Quality Improvement Collaborative** is using QI to structure the work of teams:

- Pediatric provider
- Youth partner
- Adult provider
- Local sickle cell organization

Quality Improvement in Action

Learning sessions and action periods include youth members who:

- Sit on teams
- Speak on panels
- Share their experience with disease
- Work on processes to make it easier for patients
- Use data to understand process

Results in increased skills in participating youth, and decreased complexity of health care processes

Quality Improvement in Action

Developing a health literate communications policy, e.g. PARTNERS:

PURPOSE & SCOPE OF POLICY

All written communications from PARTNERS will include key elements of health literacy, as defined by guidelines from the AHRQ and other experts. As a patient-powered research network, PARTNERS places the highest value on patient engagement. Families must understand what the organization or individual providers are telling them in order to participate to their fullest capacity. PARTNERS' work must include the voice of the patient to achieve our full potential.

PARTNERS is committed to ensuring an opportunity for all patients and their families to help drive the future of their treatment. This means all information must be shared in a way that families can understand, and communication must be structured in a way that encourages patients and families to share their ideas openly.

This document has been created to guide all PARTNERS subcommittees as they develop information for public dissemination, for collaborative projects that involve lay people, and for dialogue between the medical community and families. The procedures below will apply to any form of communication, including but not limited to education pamphlets, research results, consent forms, recruiting material, announcements, etc.

Using Patient Portals

Patient portals can be very powerful tools for adolescents:

- increase capacity by making records, videos, education materials accessible in one location
- youth typically more digitally savvy than other age groups; internet extensive part of normal life

Using Patient Portals

But patient portals also present special challenges in this age group, e.g.

- parent and physician written permission required for use between ages 14 – 17
- limited internet access / WiFi
- ease of navigation around portal site
- intermittent cell phone minutes

Why Health Literacy Universal Precautions?

- You can't tell by looking
- Improve Spoken Communication
- Improve Written Communication
- Improve Self-Management and Empowerment
- Improve Supportive Systems

Each of these areas are critical to youth health literacy

Areas for Future Research

- Does being involved in opportunities like co-production increase health literacy? Can that be measured?
- Is there anything available through transition readiness assessment measurements that could be used as a proxy measure for health literacy skills?
- We need more exploration of the risks, benefits, and ramifications of privacy and policies regarding portal use by 14 – 17 year olds.

These materials are from the works of the following groups and individuals:

- Darren DeWalt, MD, MPH
- Ashley Hink
- H. Shonna Yin, MD, MS
- Cindy Brach and the AHRQ
- Somnath Saha, MD, MPH
- ST3P-UP Transition Program: Sickle Cell Quality Improvement Collaborative
- PARTNERS: Patients, Advocates, and Rheumatology Teams Network for Research and Service
- Atrium Health's Pediatric Nephrology Center of Excellence