# Measurement to improve well-being of children and families

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> 7 December 2016 Best Start Victoria



#### ANNALS OF MEDICINE

#### THE BELL CURVE

What happens when patients find out how good their doctors really are? by Atul Gawande

DECEMBER 6, 2004

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E very illness is a story, and Annie Page's began with the kinds of small, unexceptional details that mean nothing until seen in hindsight. Like the fact that, when she was a baby, her father sometimes called her Little Potato Chip, because her skin tasted salty when he kissed her. Or that Annie's mother noticed that her breathing was sometimes a little wheezy, though the pediatrician heard nothing through his stethoscope.

The detail that finally mattered was Annie's size. For a while, Annie's fine-boned petiteness seemed to be just a family trait. Her sister, Lauryn, four years older, had always been at the bottom end of the pediatrician's growth chart for girls her age. By the time Annie was three years old, however, she had fallen off the chart. She stood an acceptable thirty-four inches tall but



KEYWORDS Doctors (Physicians); Pediatricians; Cystic Fibrosis (CF); Cystic Fibrosis (CF) Foundation; Page, Annie; Children; Page, Honor and Don Percent of children with cystic fibrosis who are below 5th percentile for weight and are receiving supplemental feedings



Source: Schechter MS & Margolis P. 2005. Improving subspecialty healthcare: Lessons from cystic fibrosis. *Journal of Pediatrics.* 

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Median Predicted Survival Age, 1994-2006



Source: GT O'Connor/Cystic Fibrosis Foundation



Source: Parry, Carson-Stevens, Luff, McPherson, Goldmann. Recommendations for evaluation of health care improvement initiatives. *Academic Pediatrics*. 2013;13:S23-S30.



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## Impact of Improvement



Sources: Billett AL, Colletti RB, Mandel KE, Miller M, Muething SE, Sharek PJ, Lannon CM. Exemplar pediatric collaborative improvement networks: achieving results. *Pediatrics*. 2013 Jun;131 Suppl 4:S196-203. Mandel KE, Kotagal UR. Pay for performance alone cannot drive quality. *Arch Pediatr Adolesc Med*. 2007 Jul;161(7):650-5.

# To achieve an outcome for a population, we are seeking solutions that...

...work at **scale** (do not break down when we try it for everyone)

...will **spread** to others (all organizations implement the change, not just the most "enlightened" organization)

...are **sustained** over time (*do not degrade as attention turns to other topics*)



Every system is perfectly designed to achieve exactly the results it gets.

# "A system is an interdependent group of items, people, or processes working together toward a common purpose."

Associates in Process Improvement, Quality as a Business Strategy, 1987

# How is improving a system different from improving a program?

- Programs can be planned, implemented and evaluated.
- It is not possible to plan and specify each of the detailed actions necessary for a system to produce better results.
- Optimizing one part of a system does not optimize the overall system.
- Meddling with one part of a system often sets off other problems
- Community systems are complex and are never permanently "fixed".

To change outcomes for a population, we need an approach that sets a heading but allows for adaptation and adjustment, using testing to learn its way forward.



# The Model for Improvement



Source: Provost L. Model for improvement: Aims, measures, changes. Associates in Process Improvement.

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"OK people, listen up! The people upstairs have handed us this one, and we've gotta come through. We gotta find a way to make **this** – fit into a hole for **this** – using nothing but **that**."



# Using plan-do-study-act (PDSA) cycles for sequential building of knowledge



Source: Associates in Process Improvement

# Deciding the Scale of Testing

Test small at the outset, when we know less, which make it easier to see cause and effect



Readiness to Make the Change



Source: The Improvement Guide, Langley et al. 2009





#### "I need a flashlight."

"That's not what they have up there. Don't give me anything that they don't have on board."

#### Indicators versus PDSA Data



Example: How much time did it take? Simple tally of "liked" and "didn't like". How many people completed the process?



http://www.youtube.com/watch?feature=player\_embedded&v=jsp-19o\_5vU

# Successful Cycles to Test and Adapt Change Ideas

• Scale down the size of test (# of people who try it, who receive it)

"Cycle of 1" - conduct the test at *one meeting, with one caller, with one potential participant.* 

Think of the smallest possible test that would be useful to you. Then reduce it by half, and by half again!

- Conduct the test over a short time period
- Test with volunteers
- Do not try to get buy-in or consensus for the test
- Collect *useful* data during each test
- Think a couple of cycles ahead
- Plan multiple cycles to test and adapt change
- Share results and discuss with the full team (don't keep results secret)
- Create space for the team to test the idea

#### In later cycles, test over a wide range of conditions

Source: *The Improvement Guide*, Langley et al. 2009



#### How We Collaborate to Innovate

Extraordinary family orientation Put families at the center of care

Clarity of purpose Produce a coherent vision out of many problems

Solutions that scale Create solutions that customize to work for all, spread, and sustain

Bias toward action More "creating and doing", than "meeting and planning"

Embrace experimentation and use of data for learning Build to think and learn

> Embrace ambiguity Expect fog and take small steps to get unstuck

All contribute and take ownership Bring together partners with diverse roles and viewpoints

Sources: StartStrong Co-Creation Session, February 25, 2014 (Business Innovation Factory), and IDEO





"There's 1,000 things that have to happen, in order. We're on number 8. You're talking about number 692."

Embrace ambiguity Expect fog and take small steps to get unstuck

Purpose of Indicators	Accountability	Improvement	Research		
Key question	"Are we better or worse than?"	"Are we getting better?"	"What is the truth?"		
Penalty for being wrong	Misdirected reward, penalty, resources	Misdirection for an initiative	Misdirection for the profession		
Requirements and characteristics	Risk adjusted, with denominators, validity	Real time, raw counts, consistent definitions, utility	Complete, accurate, controlled, glacial pace, expensive		
Typical displays	Performance relative to benchmarks and standards	Run charts, control charts, time between events	Comparison of control and experimental populations		
Social conditions for use of indicato	Neutrality; leaders are the primary users	Data shared in low- stakes, safe environment that is conducive to change	Meets scientific standards of discipline; utility to participants is usually secondary		
Adapted from Solberg, Mosser, McDonald Jt Comm J Qual Improv. 1997 Mar;23(3):135-47.					

# Don Berwick – The "Moral Era"



Era 1 – The authority of the profession

- The profession judges the quality of its own work
- This was shaken by unexplained variation in practice, errors in care, injustice by race and social group

Era 2 – The present

Accountability, scrutiny, use of rewards and punishment and pay for performance

Era 3 – The "moral era"

- Do less of: excessive measurement, complex incentives
- Do more of: use improvement science; measure only what matters, and mainly for learning; listen to people/families



# A "Perfect Family Outcome at 1 Month of Life"

KEY INDICATOR	Y or N		
Basic needs stably met (housing, safety, food, transportation, income)			
Parents have hope and aspiration for baby and themselves			
Mom attending to own well-being, sees herself as important, in addition to baby			
Fathers feel important, valued and contributing effectively			
Parent trusts us ALL as a functioning 'team'			
Baby sleeping only on his/her back, has crib/bassinet			
If a smoker, mom quit smoking and no relapse after delivery, partner counseled			
Parents have plan for next pregnancy, postpartum visit, reproductive health			
Parents identify 1-2+ trusted people to turn to for help for stress, hardship			
Services are centered around what the family needs			
Mother and father know where to turn to for help and for what issues			
Excellent, structured, efficient ways to communicate across all elements of team			
Breastfeeding successfully			

### **Measuring Experiences in a Process**



Source: Future State Mapping. Veterans Engineering Resource Center (VERC)

Identify reliability problems, and co-design how processes are going to work

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# Measuring progress for a population



# **Understanding Family and Community Conditions**



#### Measurement for Learning

"The provider/staff shared with me local resources for social support"





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Apr May Jun Jul

date Jan Feb Mar

Source: The Improvement Guide, Langley et al. 2009

# **Displaying Data for Learning**

- Summary statistics hide information
- In improvement efforts, changes are not fixed, but are adapted over time
- Run charts annotated with changes and other events provide evidence of sustained improvement and help generate support for change efforts

# Run charts help us to....

- Understand what "better" means.
- Distinguish between special cause (events outside a system that influence a result) and common cause (problems built into the system, such as mistakes, waste, and rework).
- Learn what to do to improve processes.
- Track the new process to make it reliable.
- Make sure we don't lose our gains as soon as we turn our back for a minute.

# **Example of Learning Cycles**

# What are parents experiencing now?



(Source of information: Community survey)

Change Idea: Ask our clients if they need support for depression

Are we ready to implement?

- How do we raise the topic?
- How do we fit this question into our workflow?
- How can we reliably respond (have something to offer) if the parent wants support?

## Planning for Multiple PDSA Cycles



the question ask the respond questions question (linkage)

Source: The Improvement Guide, Langley et al. 2009, p 10

Question: Will clients react well to being asked about depression?

**Prediction**: Clients will not mind being asked.

**Plan**: One staff member from each of two departments will ask clients one of the two items from the PHQ-2 depression screener.

**Do:** Each staff member will ask one client, next Tuesday.

**Study:** Both clients answered the question readily. One client shared that it showed we care about how she's doing. The wording of the item seemed formal instead of conversational so it didn't really fit into the nature of the discussions we were having.

**Act**: We will create a 2 sentence script to explain why we are asking about depression. Instead of reading the item, we will put the question into our own words. Also, we will ask the question at the end of the encounter, not at the beginning or middle, as more of a "wrap up" question. We predict that this way, the question will seem more empathic. On Thursday, two staff members will each test with 2 clients.





# **Effective Use of Data for Learning**

- A "family" of indicators that represent the key influences on the outcome
- Indicators that help partners <u>examine</u> their contributions and actions
- Indicators that are <u>feasible</u> to collect considering what can be scaled and spread
- Providing information about the system in "real time"
- Include <u>expectations</u> for change (numeric goal targets)
- Include feedback <u>reported by people</u> who use the service, who are the "voice of the system"
- <u>Embedded</u> in a learning system

### Summary

- Feedback supports learning by:
  - offering a visual display of what matters;
  - seeing the system we are trying to put in place;
  - showing expectations for change;
  - inspiring and tracking progress overall, and for each sector and partner.
- Indicators need to be embedded in improvement, to help move from planning to action

