

***Healthier Together: Collaborative Networks of
Patients, Clinicians and Researchers Creating
Learning Health Systems***

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PCORI PPRN-1306-01754, ImproveCareNow Network Care Centers, CCHMC Learning
Networks Program



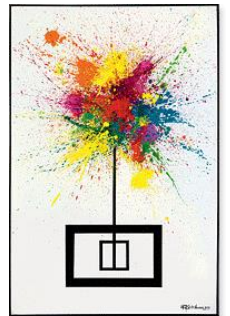






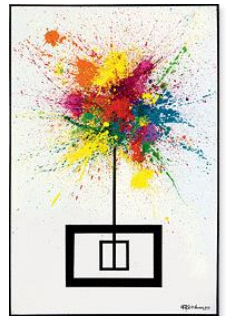
What if....?

...we could create a vastly better chronic care system by harnessing inherent motivation and collective intelligence of patients and clinicians?



What if....?

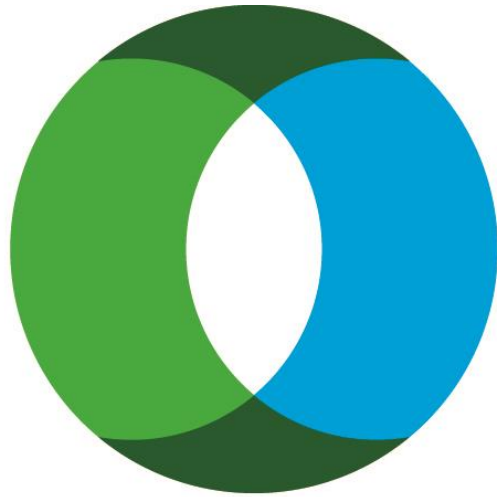
... this system allowed patients and physicians to share information, collaborate to solve problems, use their collective creativity and expertise to act in ways that improve health?



Networks

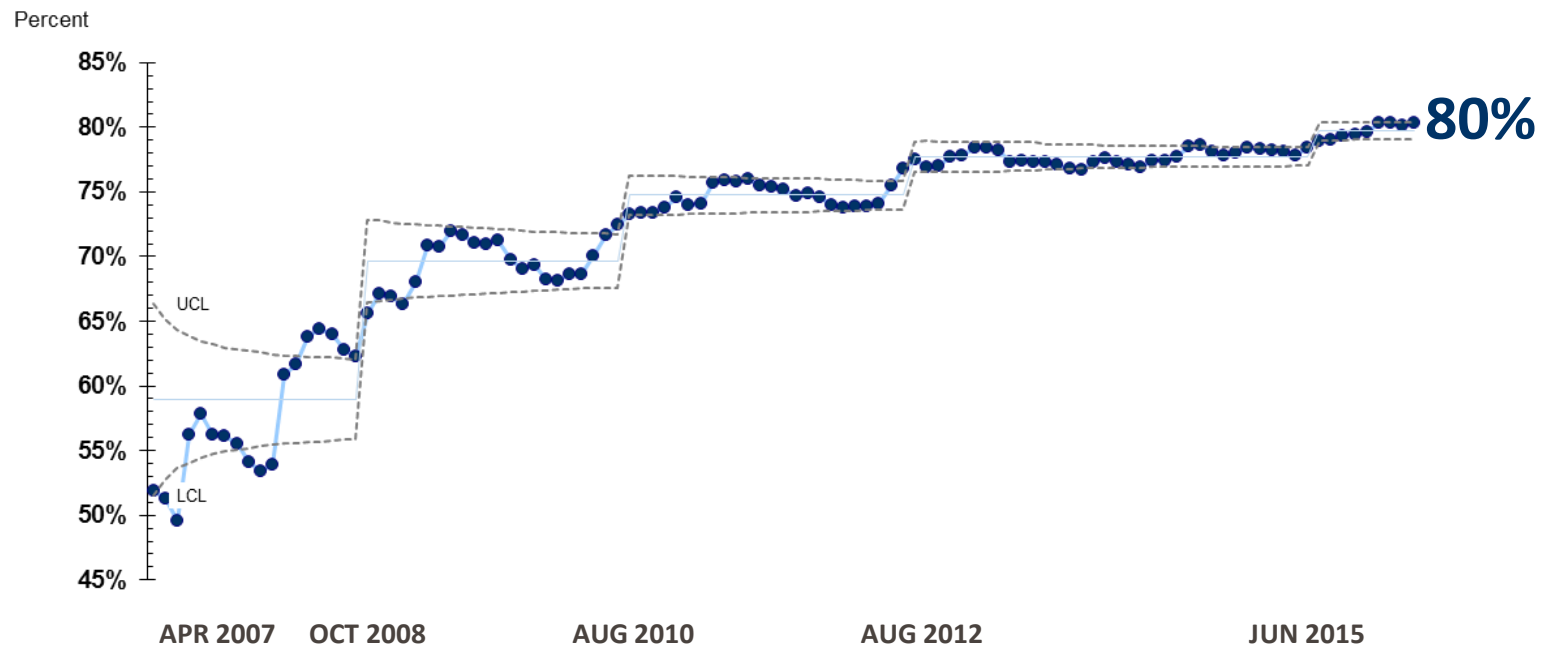


WIKIPEDIA
The Free Encyclopedia



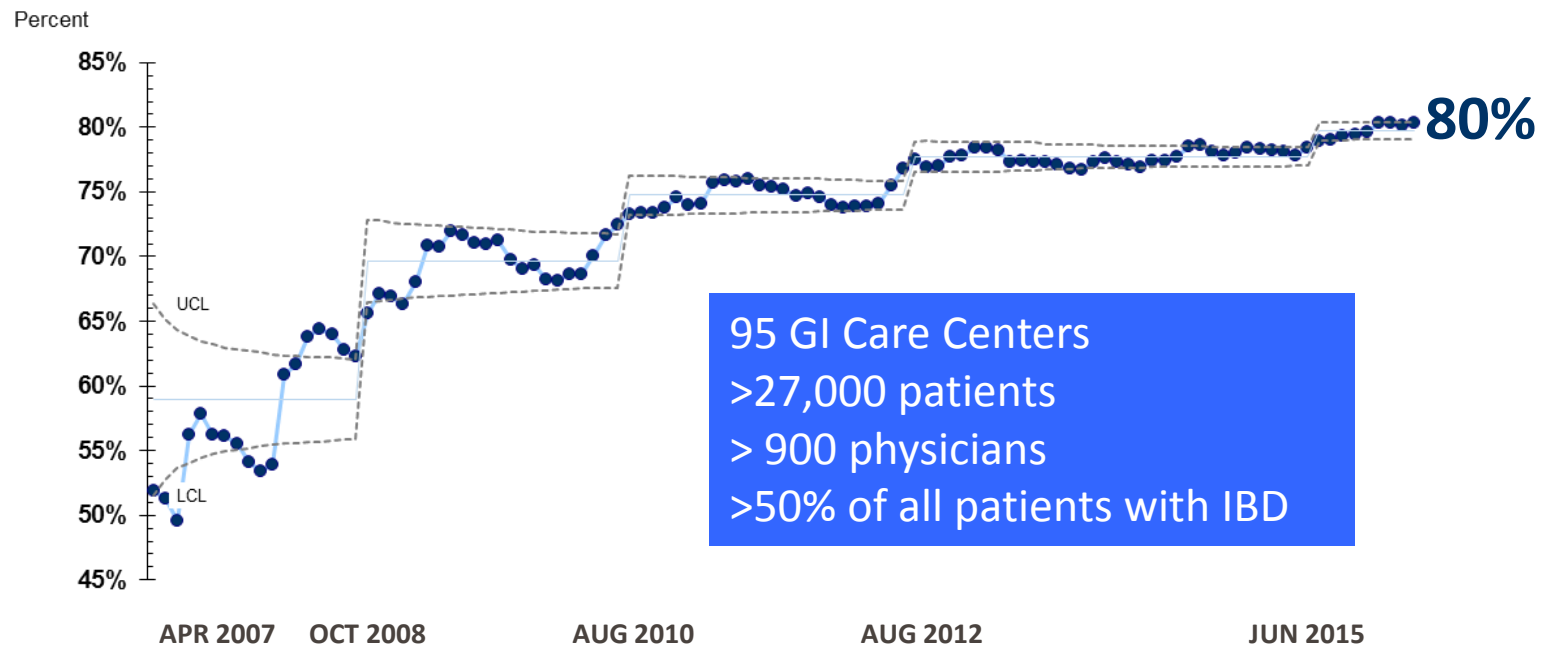
IMPROVE**CARE**NOW

Percent of patients in clinical remission Crohn's Disease and Ulcerative Colitis



Centers >75% registered

Percent of patients in clinical remission Crohn's Disease and Ulcerative Colitis



Centers >75% registered

Design principles

1. Focus on outcome (for full population)
2. Build community
3. Effective use of technology
4. Learning system
 - System science, QI, qualitative research, clinical research



“Data in once” - efficient data capture

“Data in once” - efficient data capture



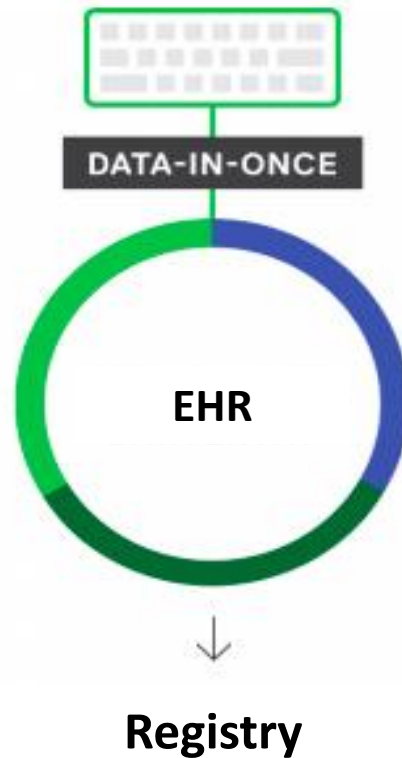
“Data in once” - efficient data capture



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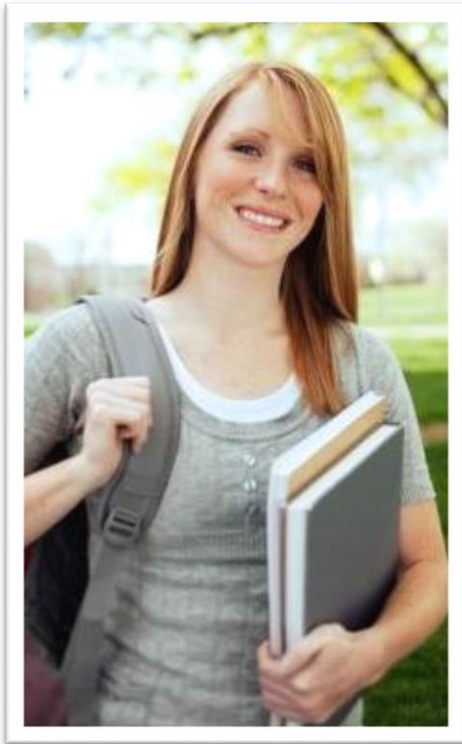
“Data in once” - efficient data capture



“Enhanced” Registry

- Automated chronic care reports
- QI Reports
- Transparent performance data
- Data quality reports
- Data (and technology) for research
 - Comparative effectiveness
 - Clinical trials
 - N of 1

Bianca Simmons, Age 20



“What does not kill you makes you stronger.”

Bianca’s Goals

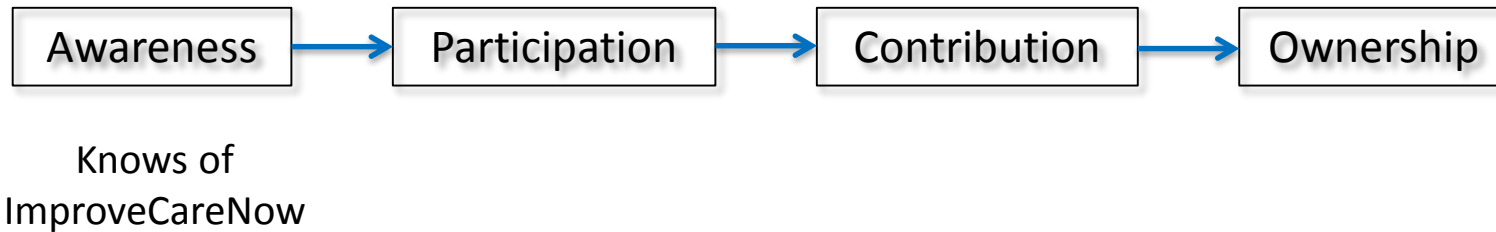
- Keep symptoms at bay
- Be a leader in the IBD community

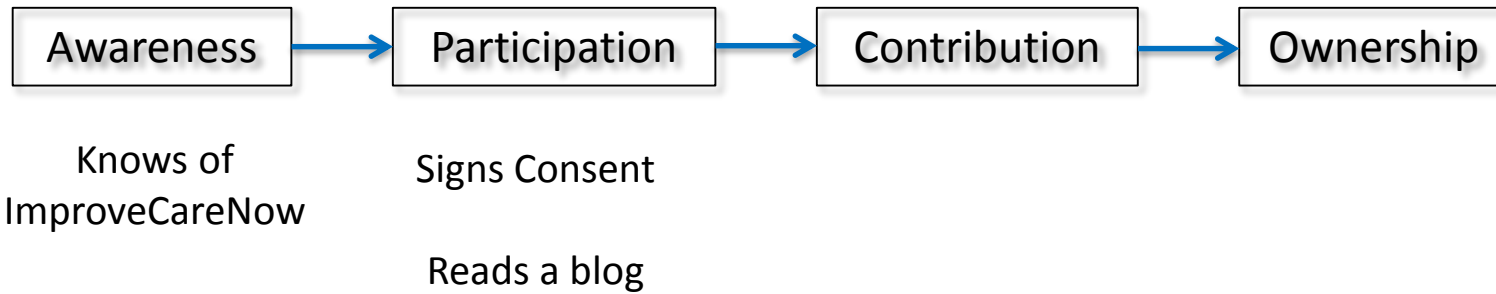


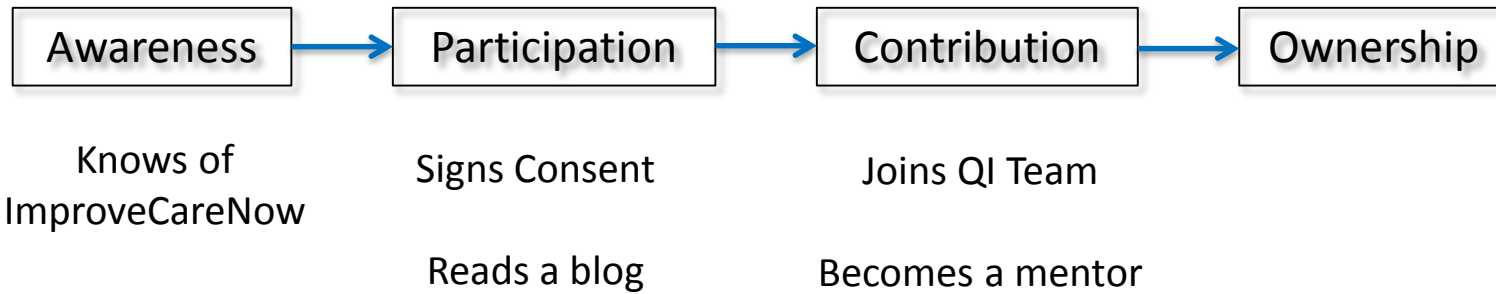
+
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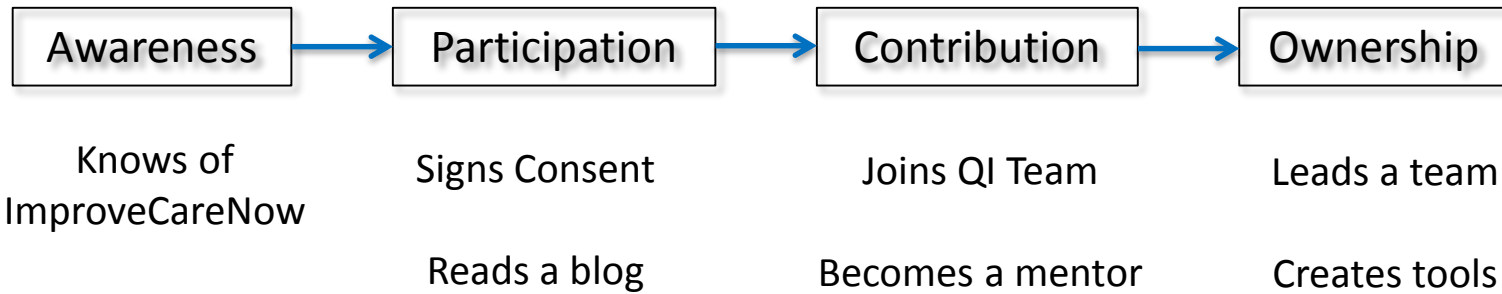










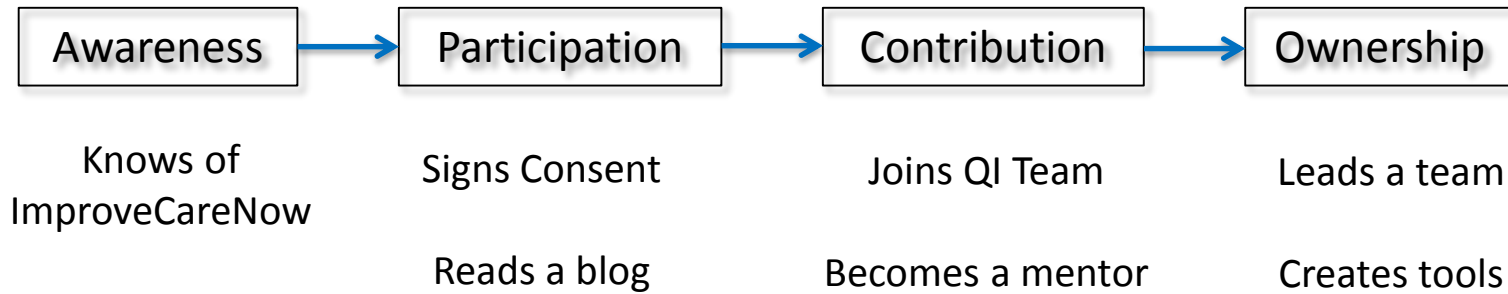


100%

90%

9%

1%



A "Commons" for sharing

ENTERAL THERAPY

Question: Can an established tool for nutritional therapy for induction be implemented across the network?

Enteral Therapy Summary

6 views 0 Likes 0 comments

dcunjon via sarahnocito onto Research

ENTERAL THERAPY

Question: Can an established tool for nutritional therapy for induction be implemented across the network?

Enteral Therapy Summary

34 views 0 Likes 1 repin 1 comment



sarahnocito onto ICN Research Teams

kwegand Improvers are meeting Friday, July 15th at 4:00pm EST to discuss this topic! Call in using the GTM or email me (kendra.wiegand@cchmc.org) to be added to the group email list. GTM:...

Enteral Therapy for Crohn's Disease:

Let them eat...very little

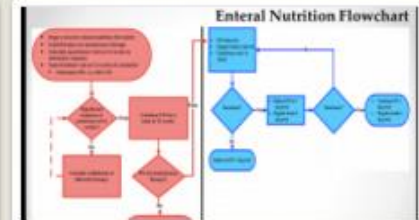


Resources created at NCH for patients on enteral therapy.

44 views 0 Likes 0 comments



jsmith onto Enteral Nutrition



Enteral therapy toolkit includes flowchart, initiation table, and talking points

15 views 1 Likes 0 comments

mollbella via onto Exclusive Enteral Nutrition



Enteral therapy toolkit includes flowchart, initiation table, and talking points

5 views 0 Likes 0 comments

lacyamor via onto Enteral Nutrition



Enteral therapy toolkit includes flowchart, initiation table, and talking points

32 views 0 Likes 0 comments

lacyamor via onto Enteral Nutrition



NCH "NG placing party." In 2013, our team had "Enteral Therapy Thursday." We all did enteral therapy PO for a day.

9 views 0 Likes 0 comments



marci.johnson via jsmith onto Nutrition



NCH "NG placing party." In 2013, our team had "Enteral Therapy Thursday." We all did enteral therapy PO for a day.

56 views 0 Likes 1 repin 2 comments

An Owner



An Owner







Replication of the model

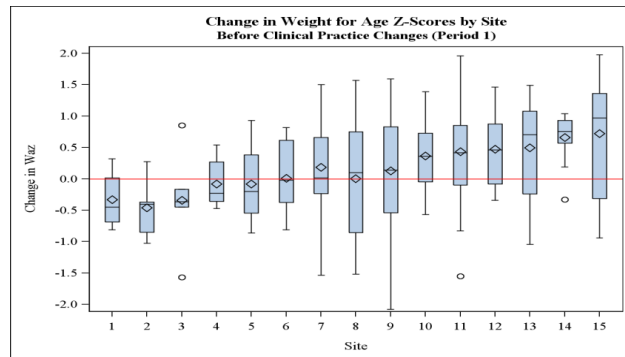


National Pediatric Cardiology Quality Improvement Collaborative

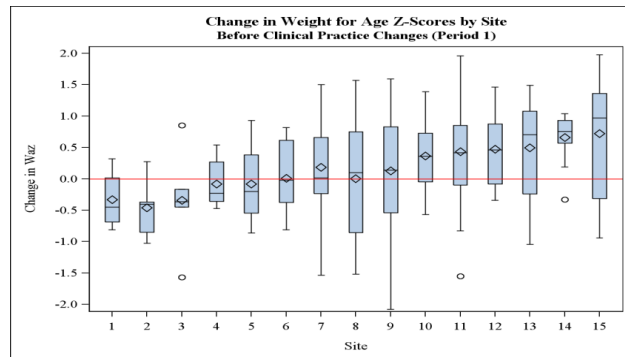
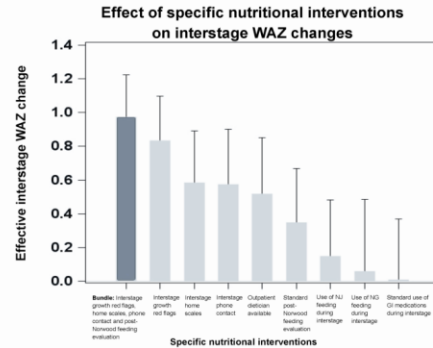


Zoe Madison (Age 6, HLHS)

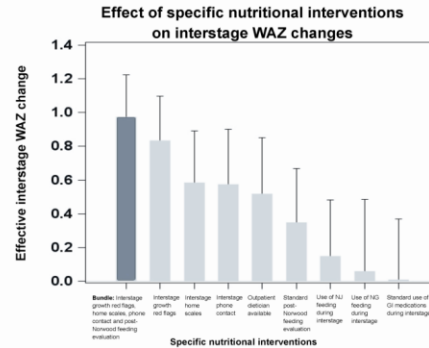
Reducing variation in growth



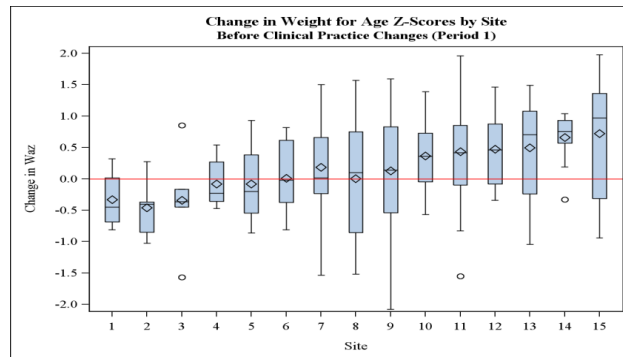
Reducing variation in growth



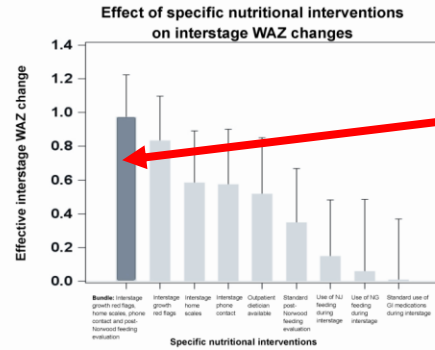
Reducing variation in growth



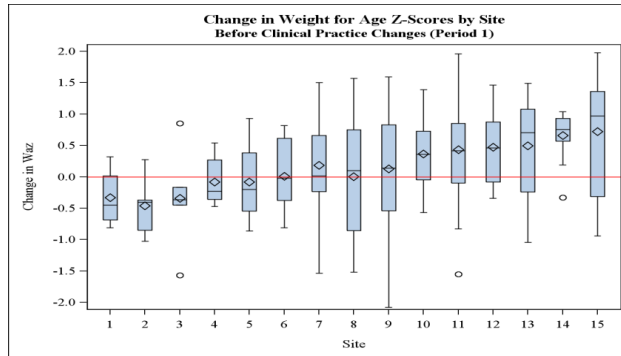
Identified growth bundle 6 months



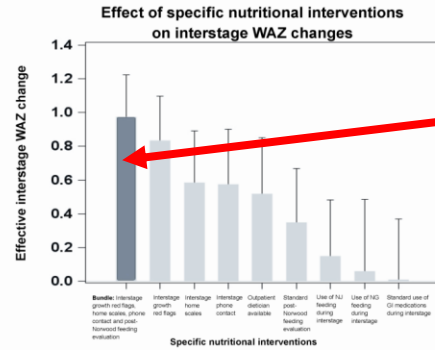
Reducing variation in growth



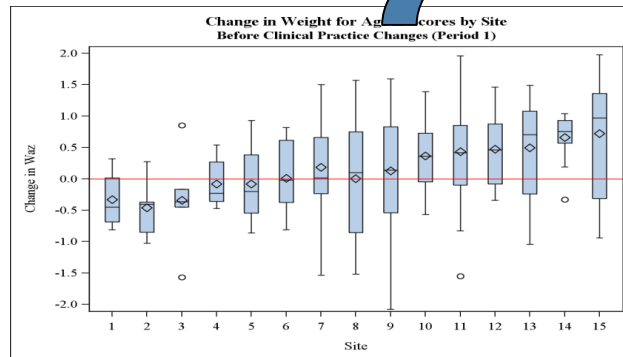
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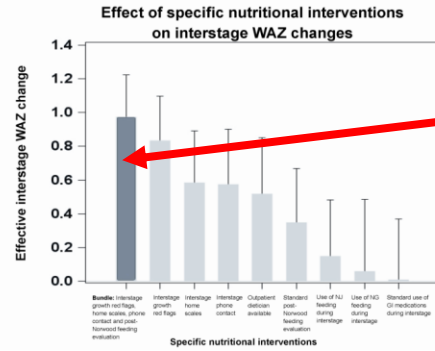
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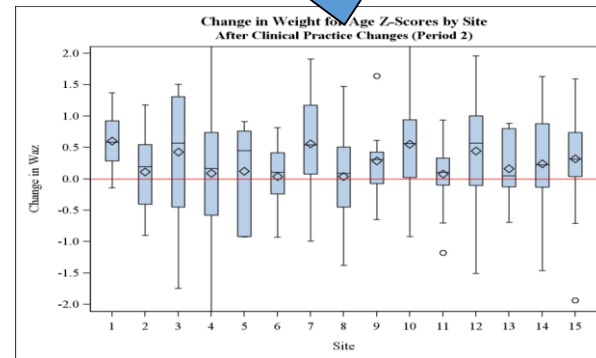
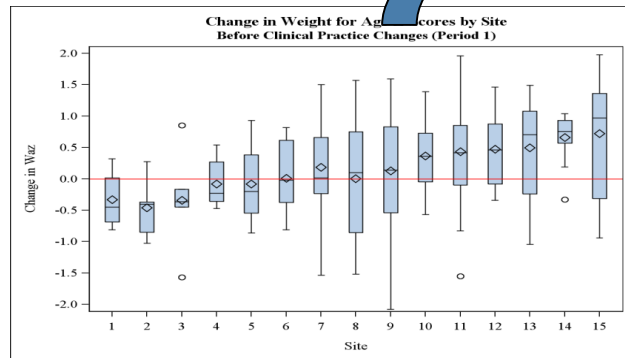
Identified growth bundle 6 months



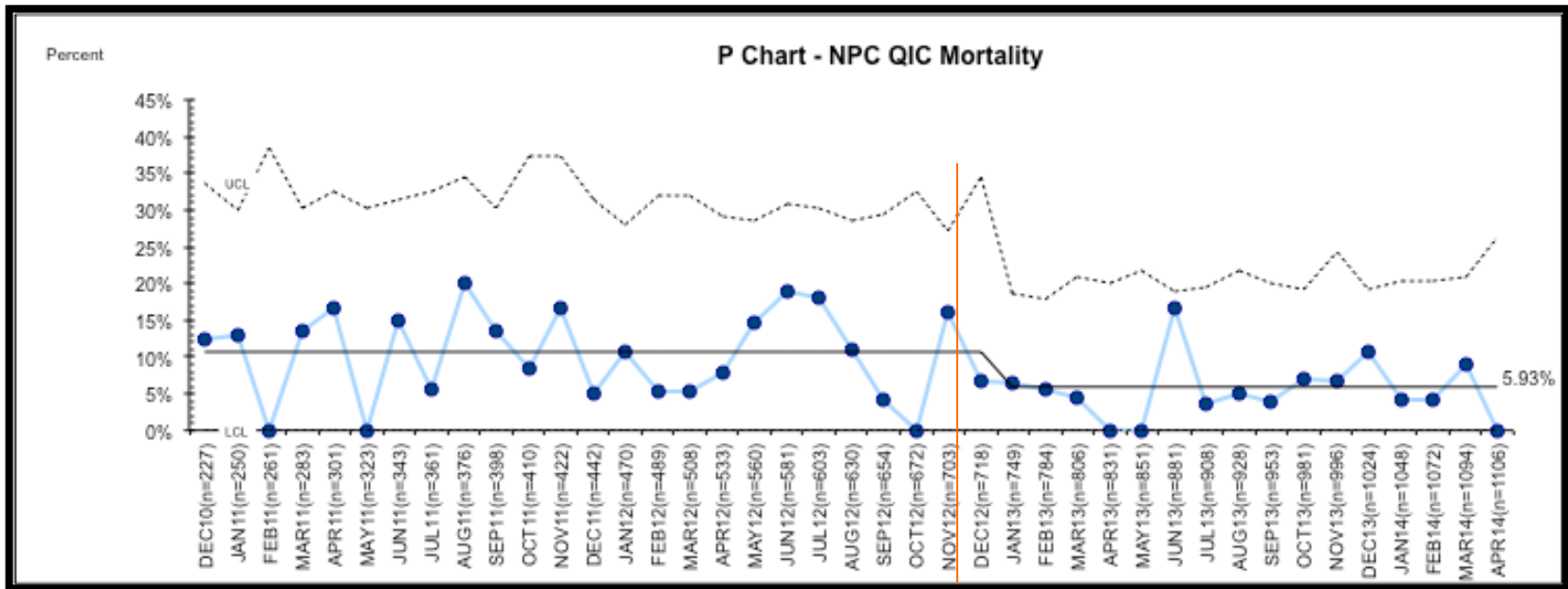
Reducing variation in growth



Identified growth bundle 6 months



Improvement in Mortality



46% reduction in inter-stage mortality

Anderson et al. *Circ Qual and Outcomes*. 2015;8:428-436



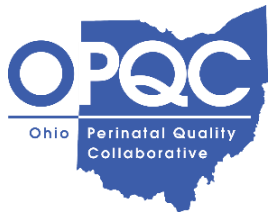
“I’ve learned more about the needs of patients and parents during the few years of the collaborative than in my previous 18 years of clinical practice.”

Martha Clabby, Pediatric cardiologist, CHOA



**“Learn from one another
and get better faster...”**

Sarah Vinje, Mom to Cecilia

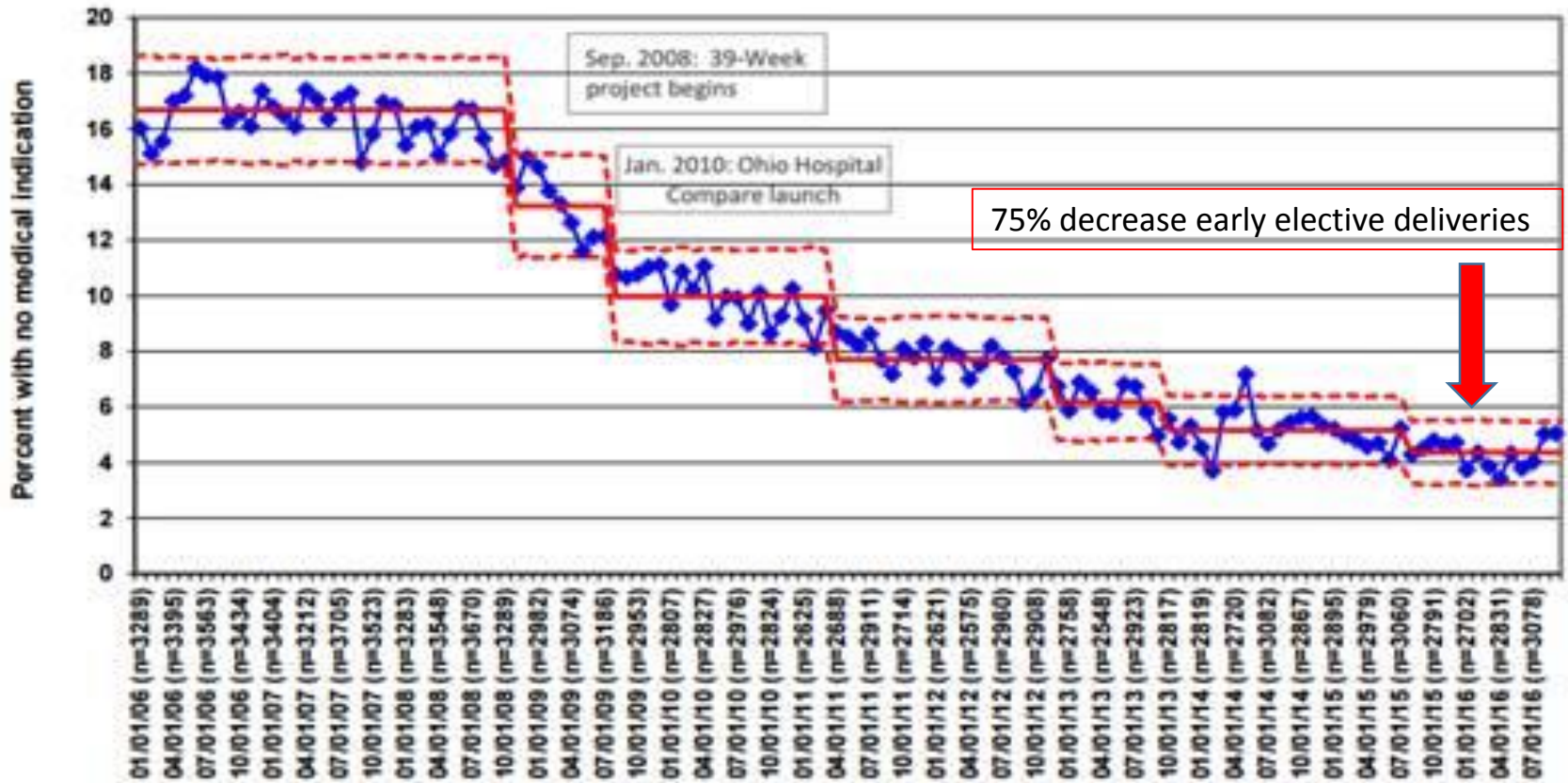


Ohio Perinatal Quality Collaborative



OPQC = 108 maternity hospitals

Births induced at 37-38 weeks with no apparent medical indication for early delivery,
by month, 2006-2016
Aggregate of Ohio maternity hospitals



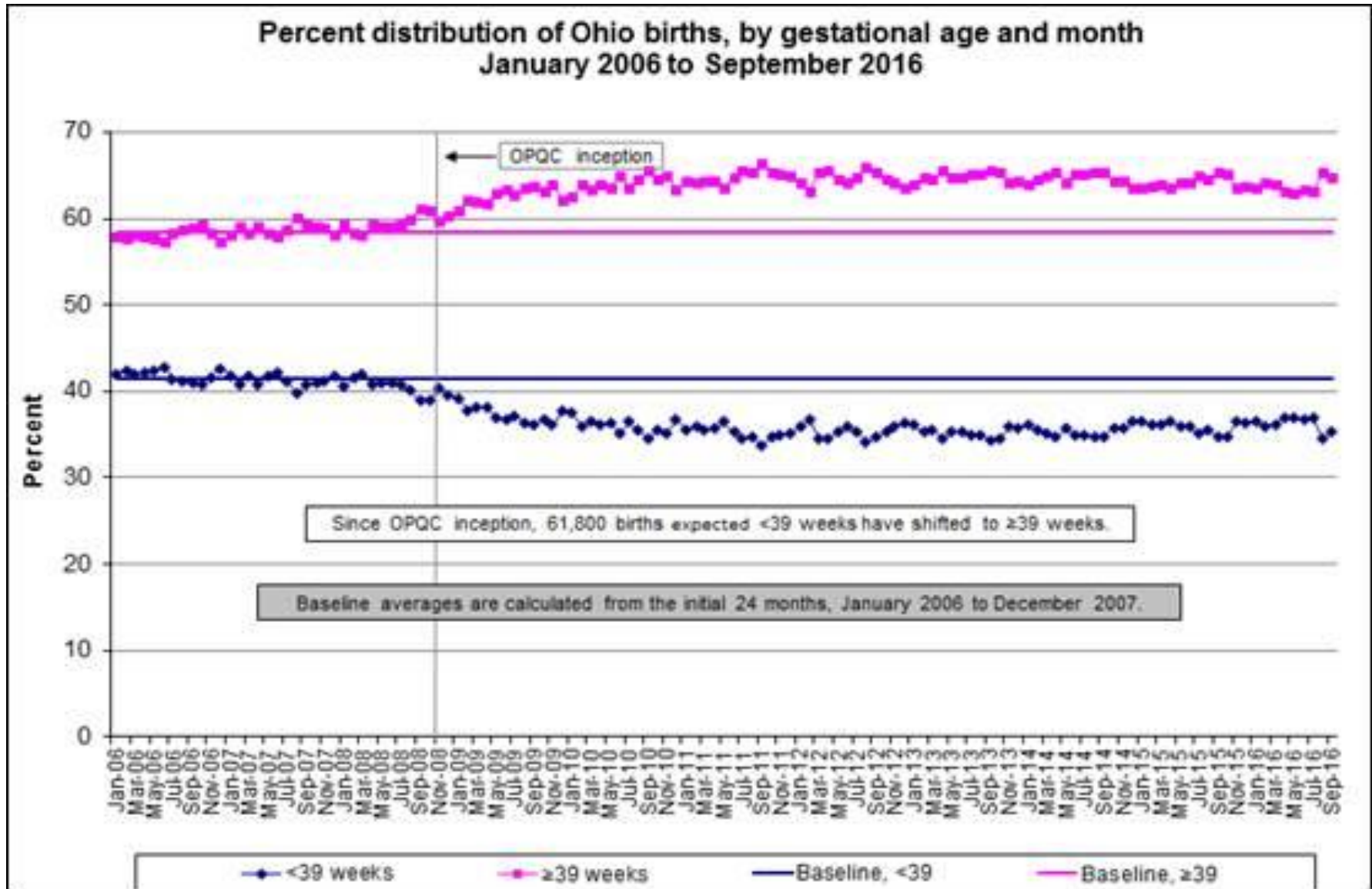
Source: Ohio Department of Health, Vital Statistics

—◆— Monthly Percent

— Baseline Average Percent

- - - Control Limits

Since 2008, > 61,000 births shifted to term



Clinical Practice and Quality

A Statewide Progestogen Promotion Program in Ohio

Jay D. Iams, MD, Mary S. Applegate, MD, Michael P. Marcotte, MD, Martha Rome, RN, MPH, Michael A. Krew, MD, MS, Jennifer L. Bailit, MD, MPH, Heather C. Kaplan, MD, MSCE, Jessi Poteet, BS, Melissa Nance, MPH, David S. McKenna, MD, RDMS, Hetty C. Walker, RNC-OB, Jennifer Nobbe, BS, Lakshmi Prasad, MPH, Maurizio Macaluso, MD, DrPH, and Carole Lannon, MD, MPH

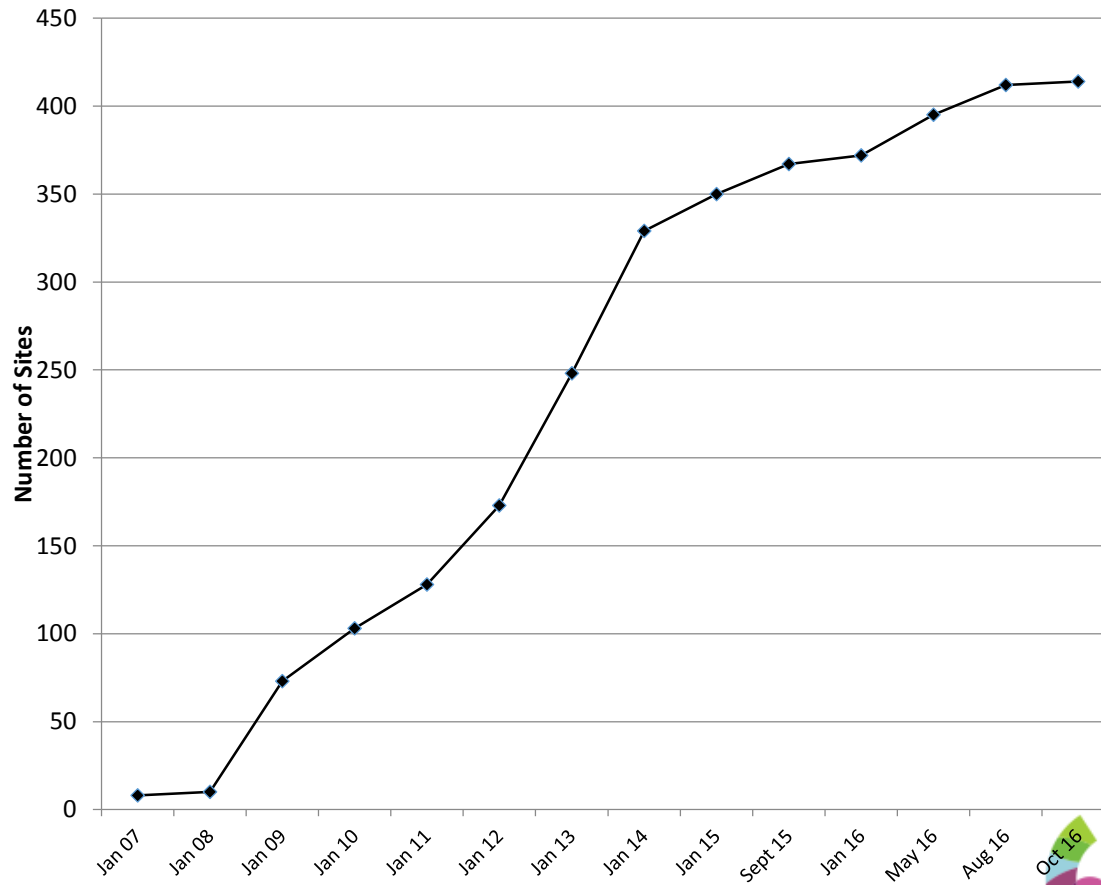
Births before 32 weeks of gestation to women with prior preterm birth decreased by 20.5% in all hospitals, by 20.3% in African American women, and by 17.1% in women on Medicaid.



Growth of Learning Networks

414 teams, 272 sites, 43 states + DC, 3 countries

Teams in CCHMC Supported Learning Networks



Where do research and innovation ideas come from?

- Top Down - Formal priority setting based on gaps and needs of patients, families, clinicians, researchers, and health system leaders
- Bottom Up - Innovators and researchers inside and outside ICN monitor performance, see problems, understand gaps and work to fix them.

In March 2016, a total of 164 healthcare professionals, parents, and patients ranked these 22 research topics, based on what they believed would result in the greatest improvement in health and well-being for pediatric IBD patients.

1

Do the effects of dual therapy differ for patients who start both treatments at the same time versus those who start biologics then step-up to dual therapy?

2

What are the characteristics (i.e. IBD phenotype and patient demographics, treatment course) of children who are unable to achieve remission within the first two years of being diagnosed?

3

What are the IBD and patient characteristics that should influence decision-making on the most effective treatments?

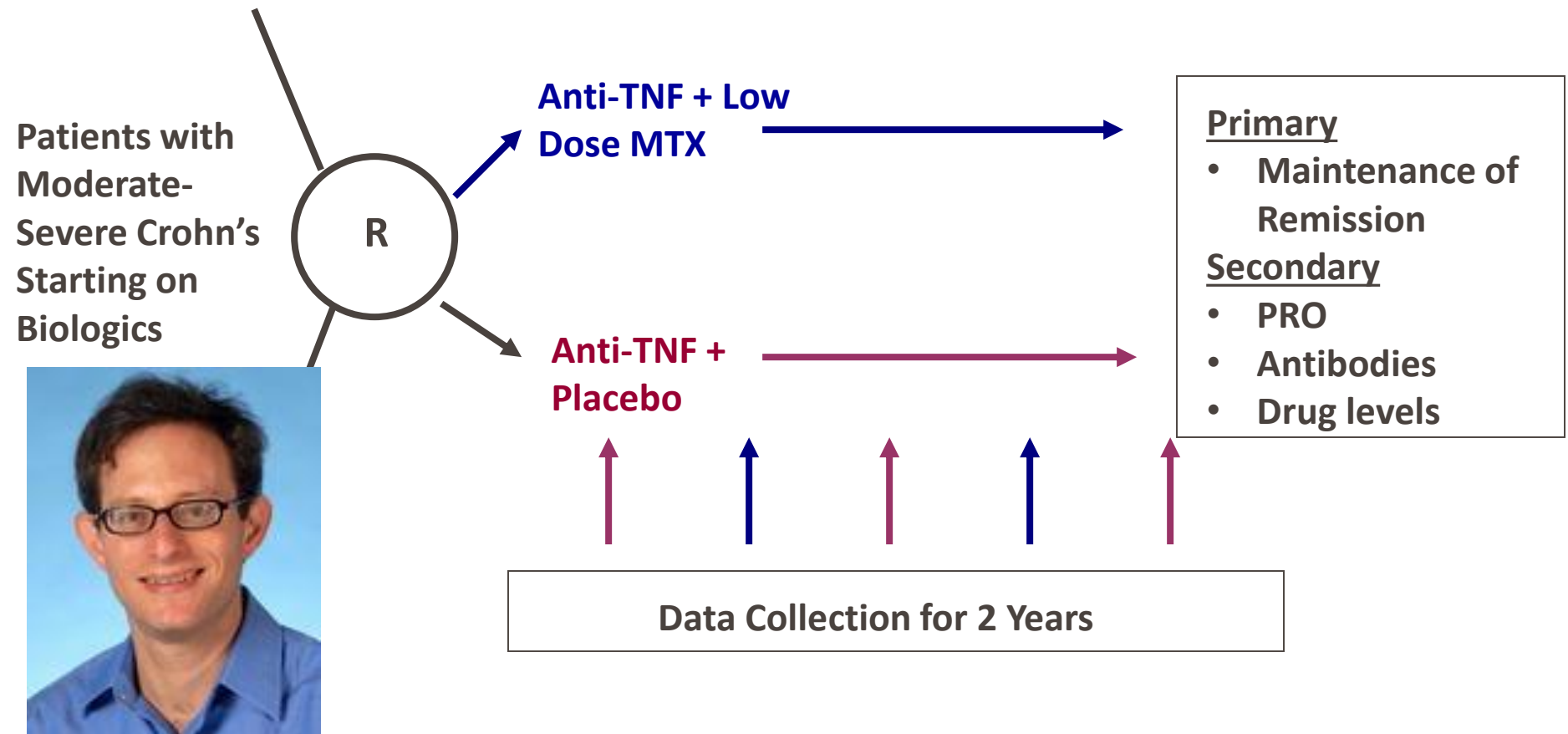
4

Compare the effectiveness of biologic agents (e.g., Infliximab, adalimumab) vs. enteral feeds to decrease inflammation

5

What is the comparative effectiveness of enteral therapy versus medications for treatment of IBD?

Anti-TNF Monotherapy vs. Combination Therapy with Low Dose Methotrexate in Pediatric Crohn's disease



#14: How effective is a low sugar and/or carbohydrate diet (i.e. SCD) in reducing the symptoms and disease markers of IBD in outcomes?

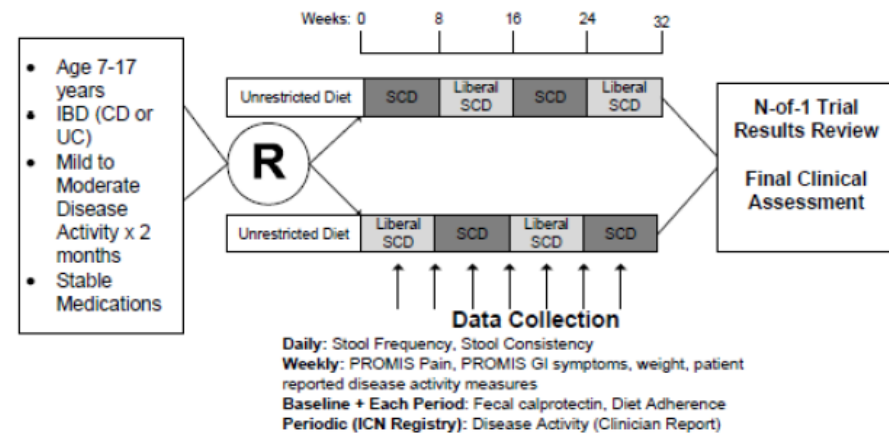
“One of the most difficult things for me about my child getting a Crohn’s diagnosis was that there seems to be so little attention given in the MD community to how dietary changes might help. I’m not advocating managing Crohn’s with food alone; but I can’t help feel that it is crazy to focus only on giving medication and not worry about what she eats other than ‘no popcorn or seeds.’” Mom on Smart Patients



- THE TRIAL WAS SO EXCLUSIVE THAT
NO ONE WAS EVER RANDOMIZED.

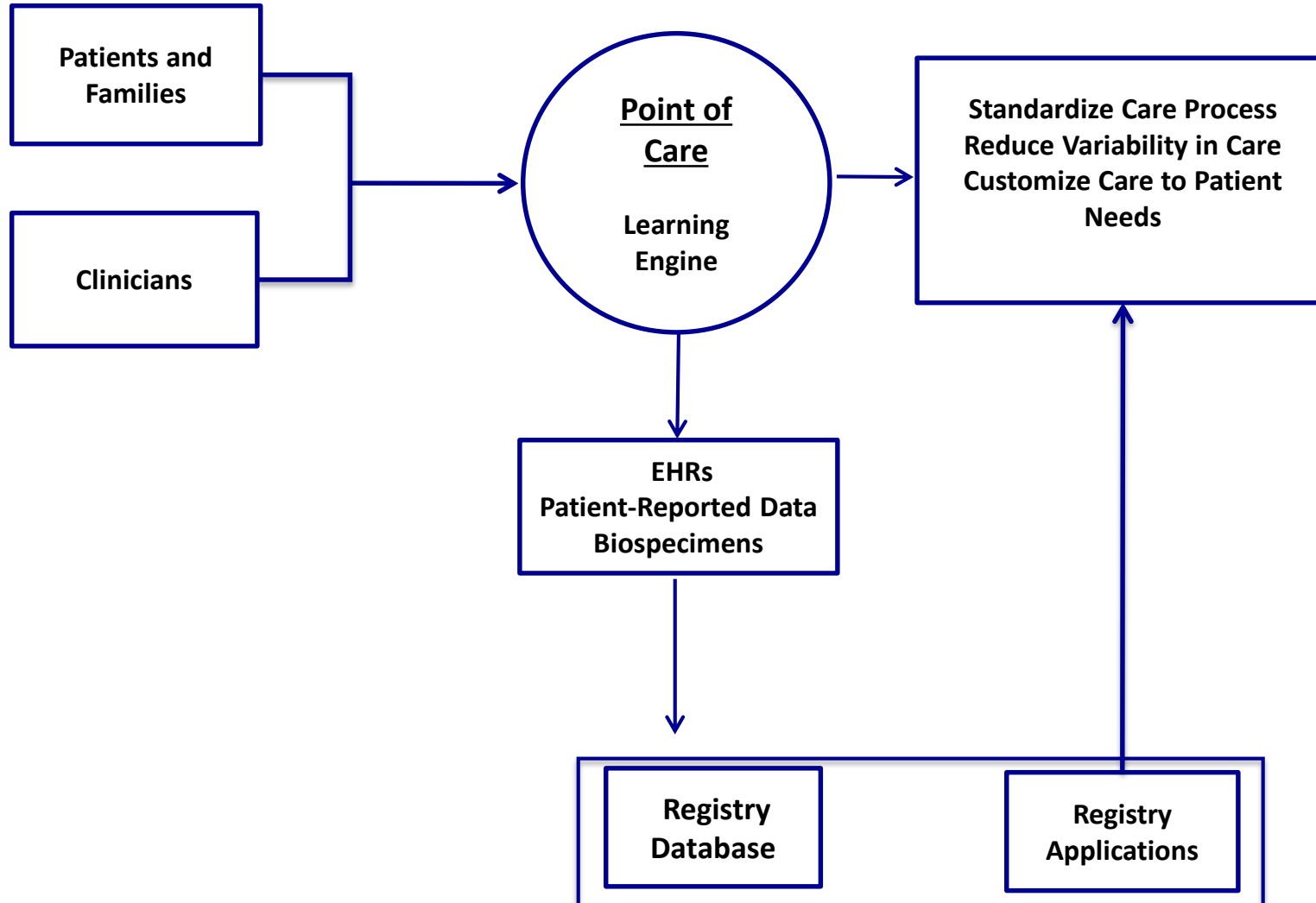
The ICN SCD N-of-1 Study

- ▶ Series of individual N-of-1 trials comparing SCD to a liberalized SCD
- ▶ Randomized to SCD or liberalized SCD and alternate between these two conditions for four 8-week treatment periods
- ▶ Patients and clinical team will use an app and web portal to facilitate data collection, tracking intervention status, and reviewing individual trial results
- ▶ Each individual will have personalized answer about effectiveness of SCD vs. more liberalized SCD in managing their symptoms
- ▶ Results of the individual N-of-1 trials aggregated to estimate population level effectiveness

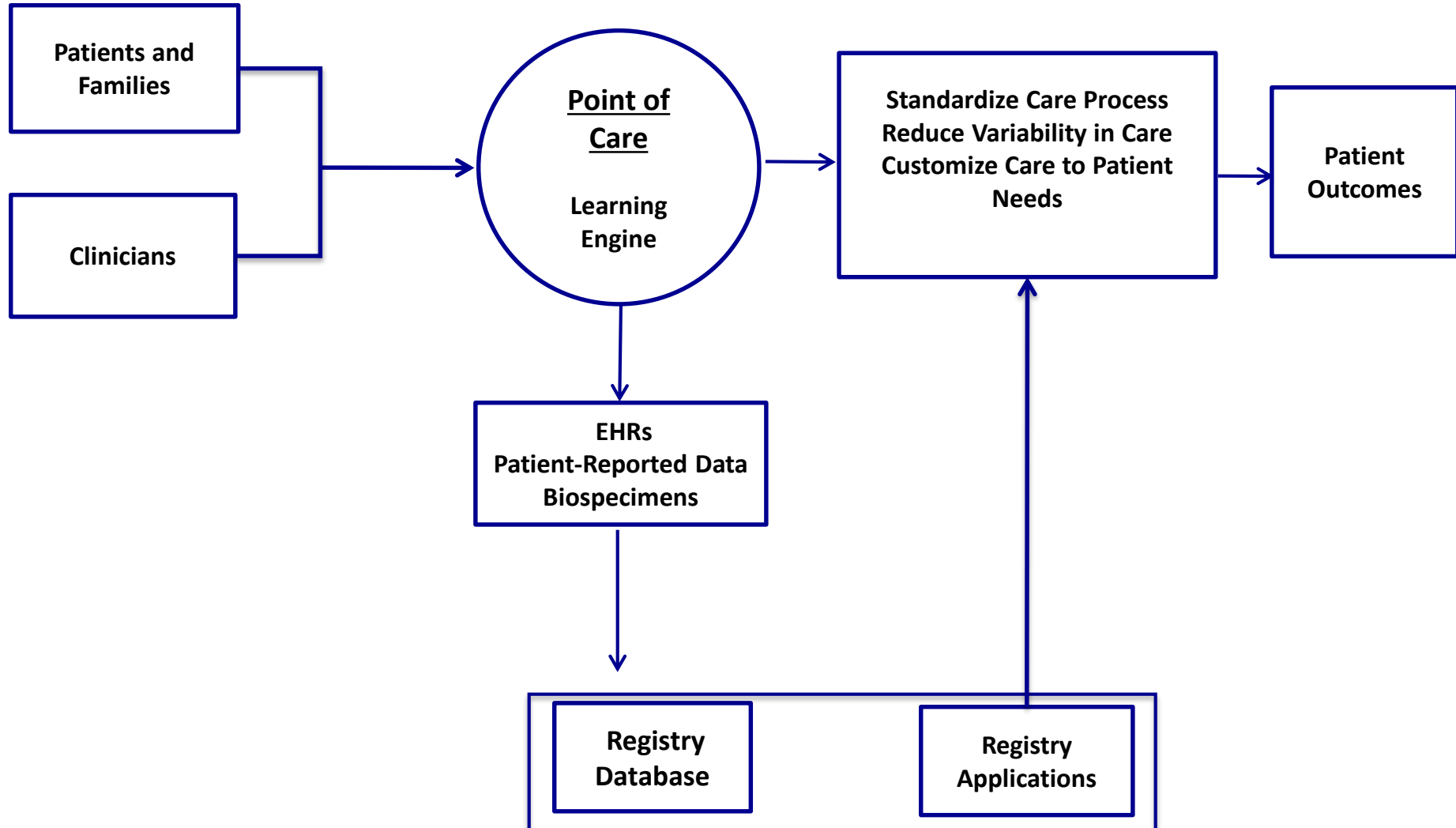


Improving Outcomes with a Learning Health System - Health care delivery, improvement and research *together as part of the same system*

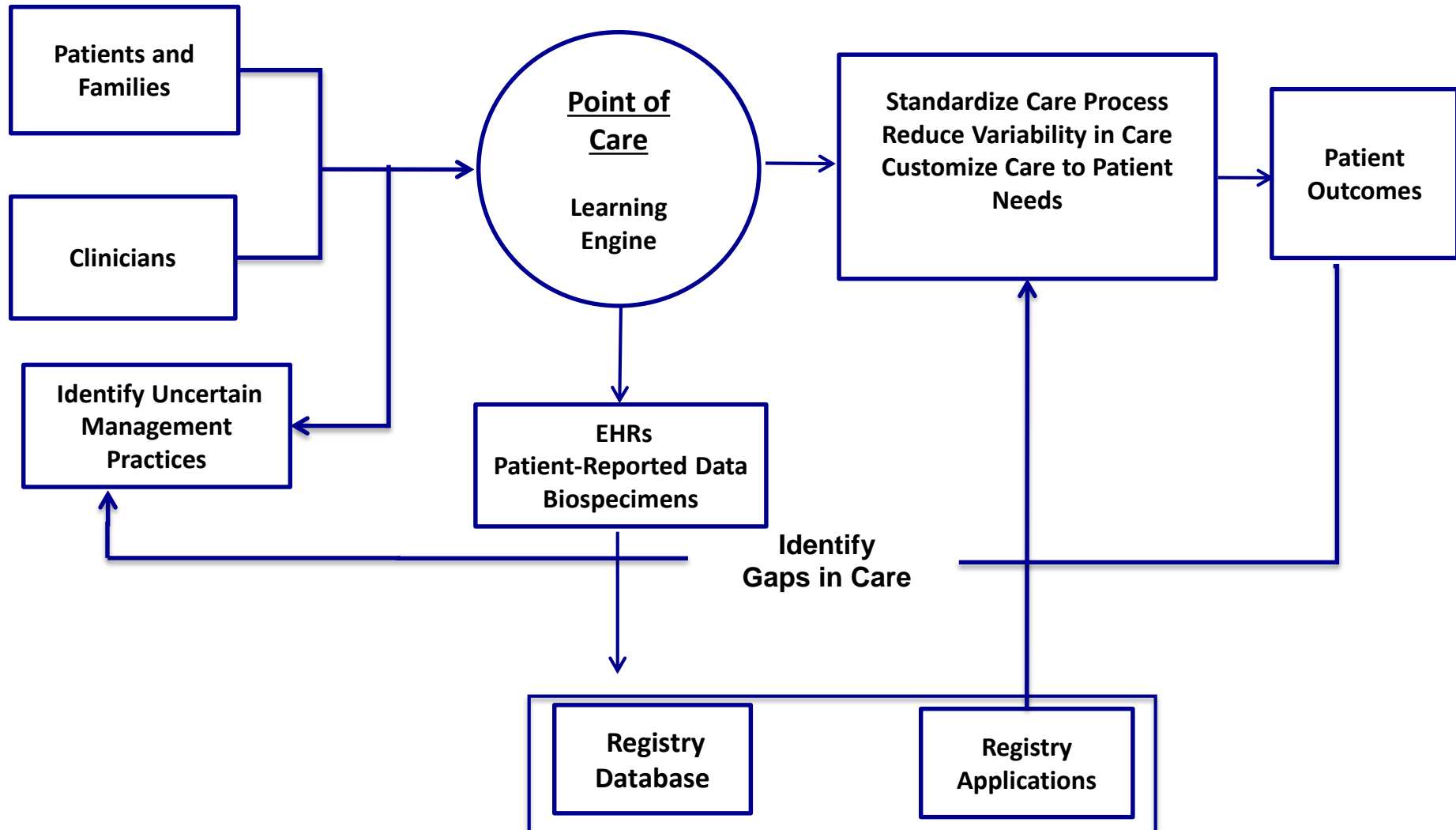
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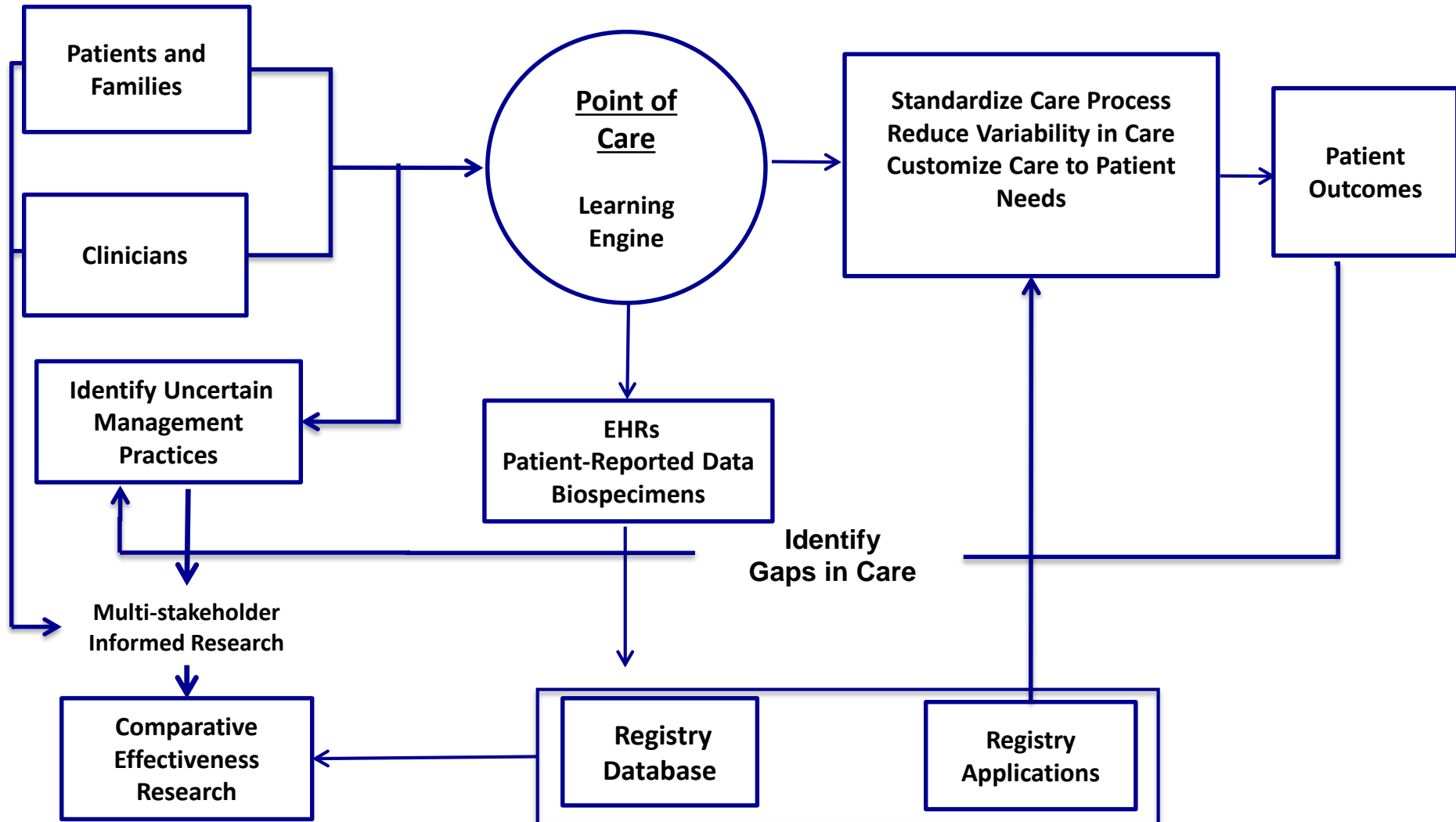
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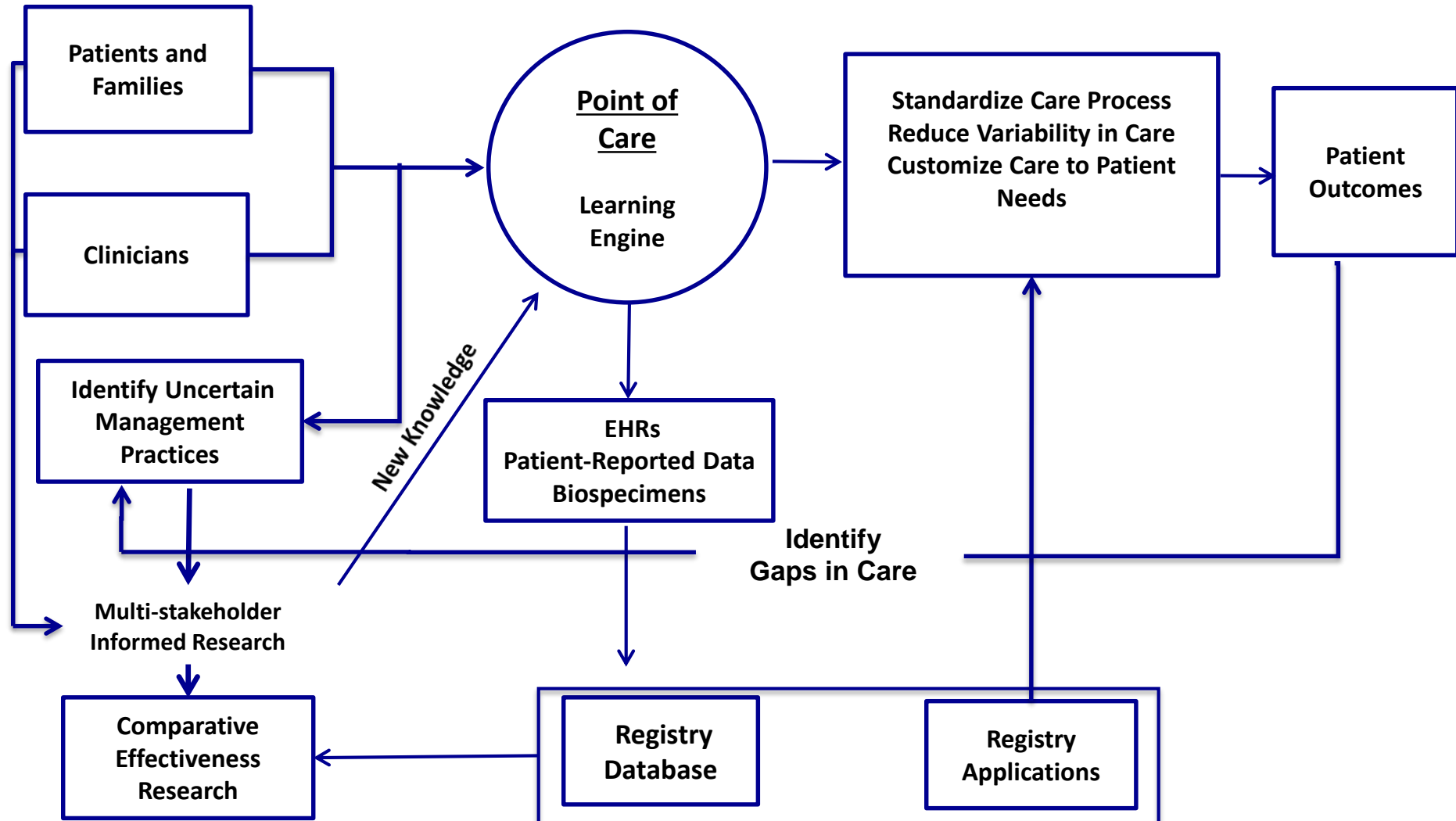
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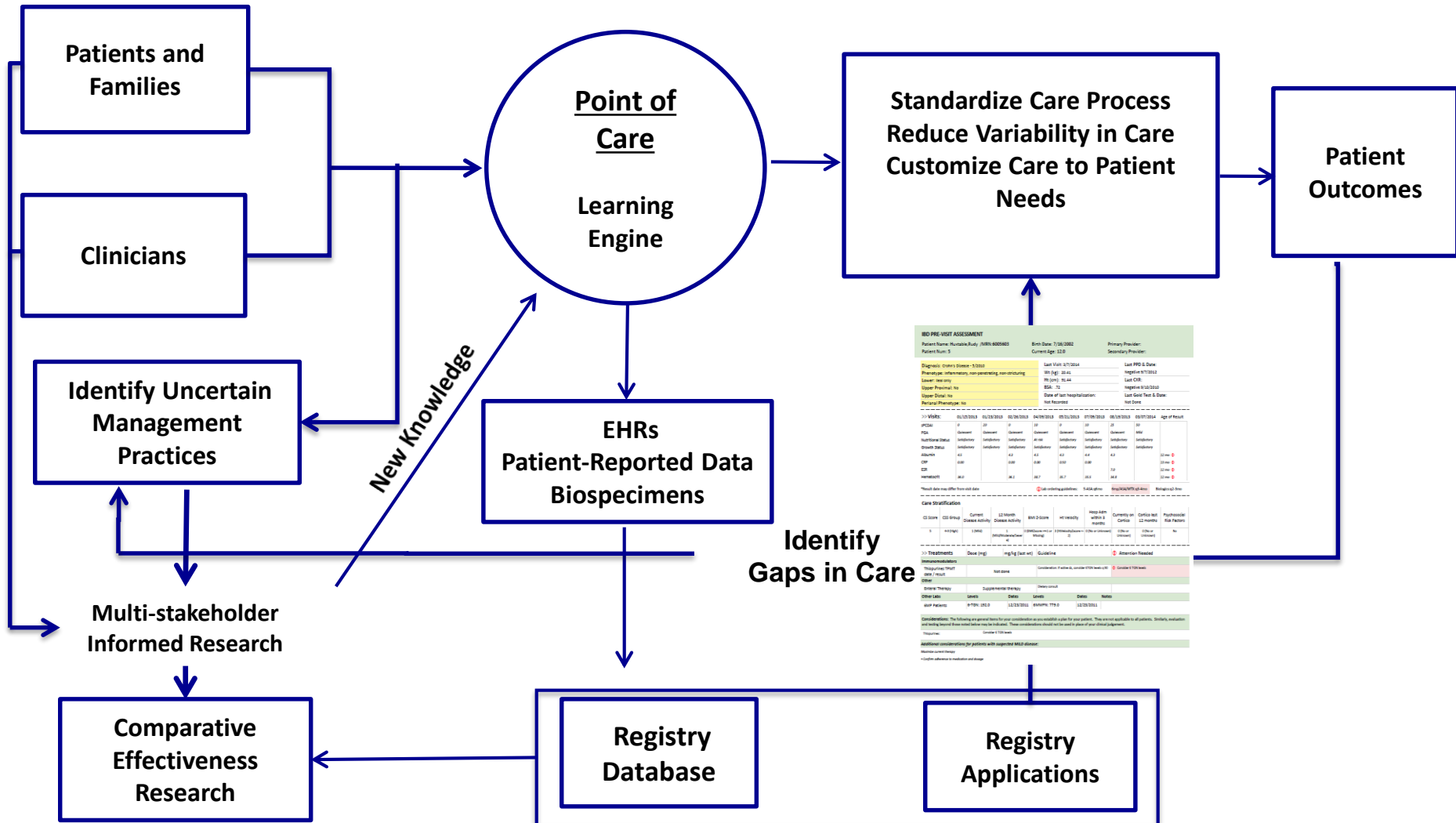
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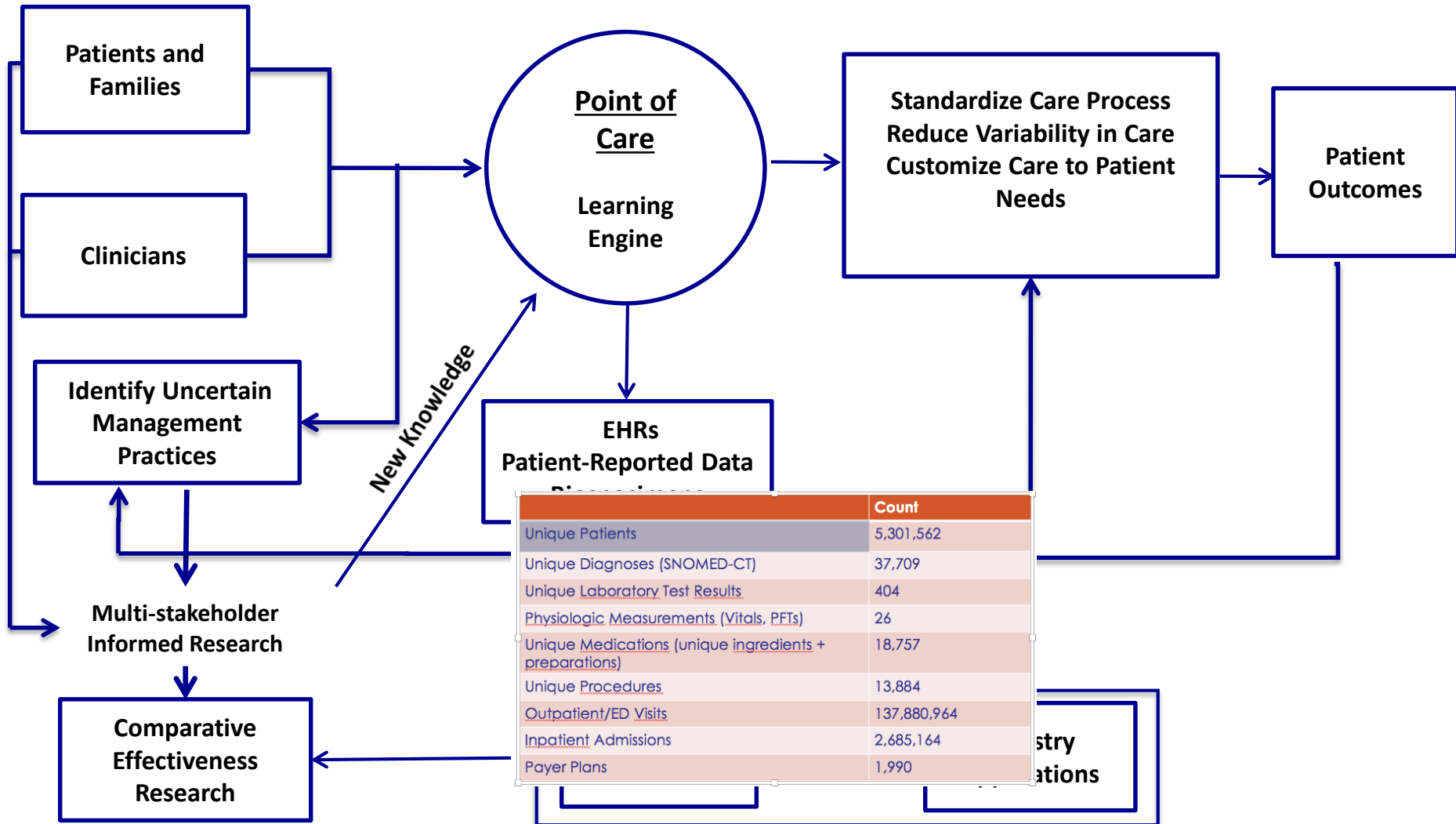


900 PRE-VISIT ASSESSMENT									
Patient Name: Murtha, Rudy / MRN: 000060		Birth Date: 7/28/2002		Primary Provider:					
Patient Num: 5		Current Age: 12.0		Secondary Provider:					
Diagnosis: Other's Disease: 13.000	Last Visit: 07/20/2014	Last PFD & Date:							
Diagnosis: other's disease, non-pregnancy, non-structuring	08/18/2014	Register: 07/20/2014							
Lower: none any	08/18/2014	Last CR:							
Upper: Pediatric: no	08/18/2014	Register: 07/20/2014							
Upper: Dental: no	Date of last Hospitalization:	Last Visit Test & Date:							
Pharmac: Phenothiazine: no	Not Reported	Not Done							

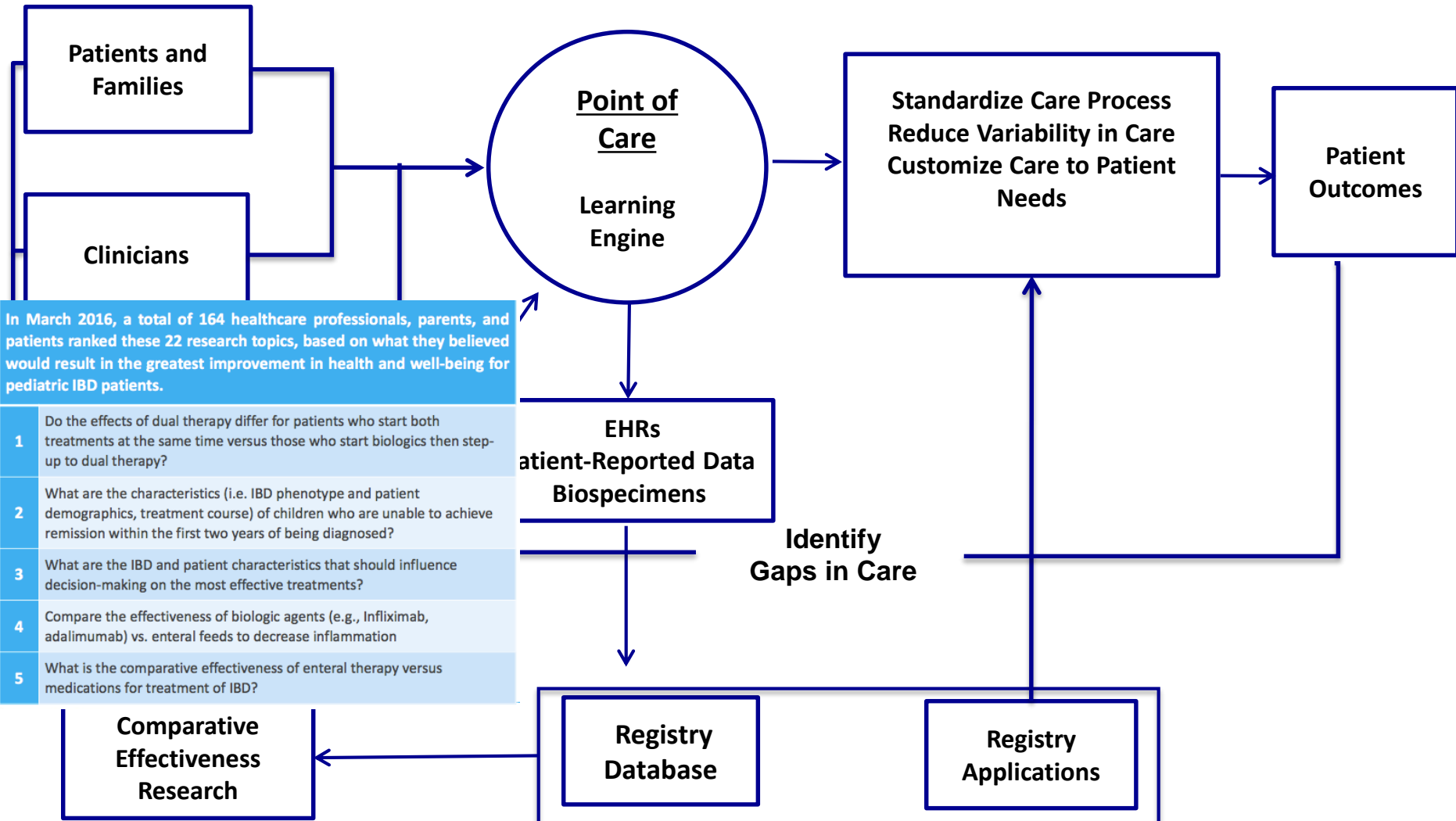
Vitals									
	01/13/2013	02/13/2013	02/26/2013	04/16/2013	05/13/2013	07/09/2013	08/19/2013	09/07/2013	Age of Patient
APACHE	0	0	0	0	0	0	0	0	12.0
PCA	0	0	0	0	0	0	0	0	0
Nutrition Status	ambulatory	ambulatory	ambulatory	at risk	ambulatory	ambulatory	ambulatory	ambulatory	ambulatory
Weight Status	ambulatory	ambulatory	ambulatory	ambulatory	ambulatory	ambulatory	ambulatory	ambulatory	ambulatory
Albumin	4.1	4.1	4.1	4.1	4.1	4.1	4.1	4.1	3.9 mg/dL
CRP	0.00	0.00	0.00	0.00	0.00	0.00	0.00	0.00	0.00 mg/L
ESR	0.0	0.0	0.0	0.0	0.0	0.0	0.0	0.0	0.0 mm/hr
hemoglobin	16.1	16.1	16.1	16.1	16.1	16.1	16.1	16.1	16.1 g/dL

Care Stratification									
CD Score	CD Group	Current	12 Month	24 Month	36 Month	48 Month	60 Month	72 Month	84 Month
0	447891	13860	1	13860	1	13860	1	13860	1

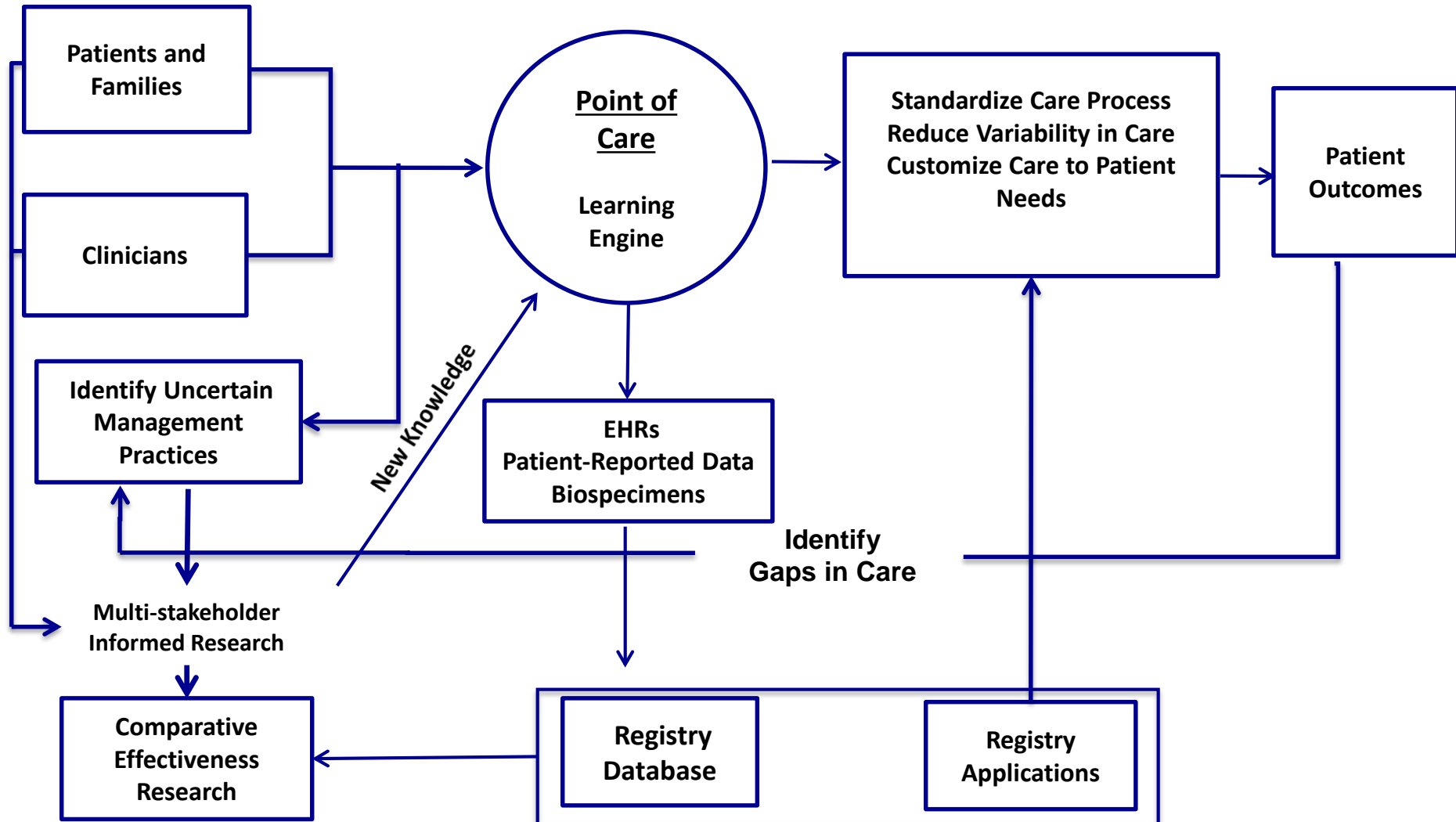
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What we've learned

- Relentless focus on outcomes and transparency
- Increase number of participants
- Variety of ways to accumulate and share resources (a 'commons')
- Structures and processes make it easier to collaborate
- Cooperative behaviors emerge
- Design one system - meet needs and goals of all stakeholder simultaneously

What we have to learn

- Shifting power dynamics
- Education for co-production
- Managing capacity
- How to lead and foster cooperation

