Human-centered design in clinical informatics:

Implementing and improving informatics interventions with design thinking

HCSRN – February 11, 2025

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Disclosure

I have nothing to disclose.

Geisinger


Making better
health easier
Geisinger
Geisinger

Geisinger: Integrated health system with $10 billion in combined revenues

We care for patients.

- **10** hospital campuses
- **126** primary and specialty clinics
- **26,000+** employees
- **1,700+** employed physicians

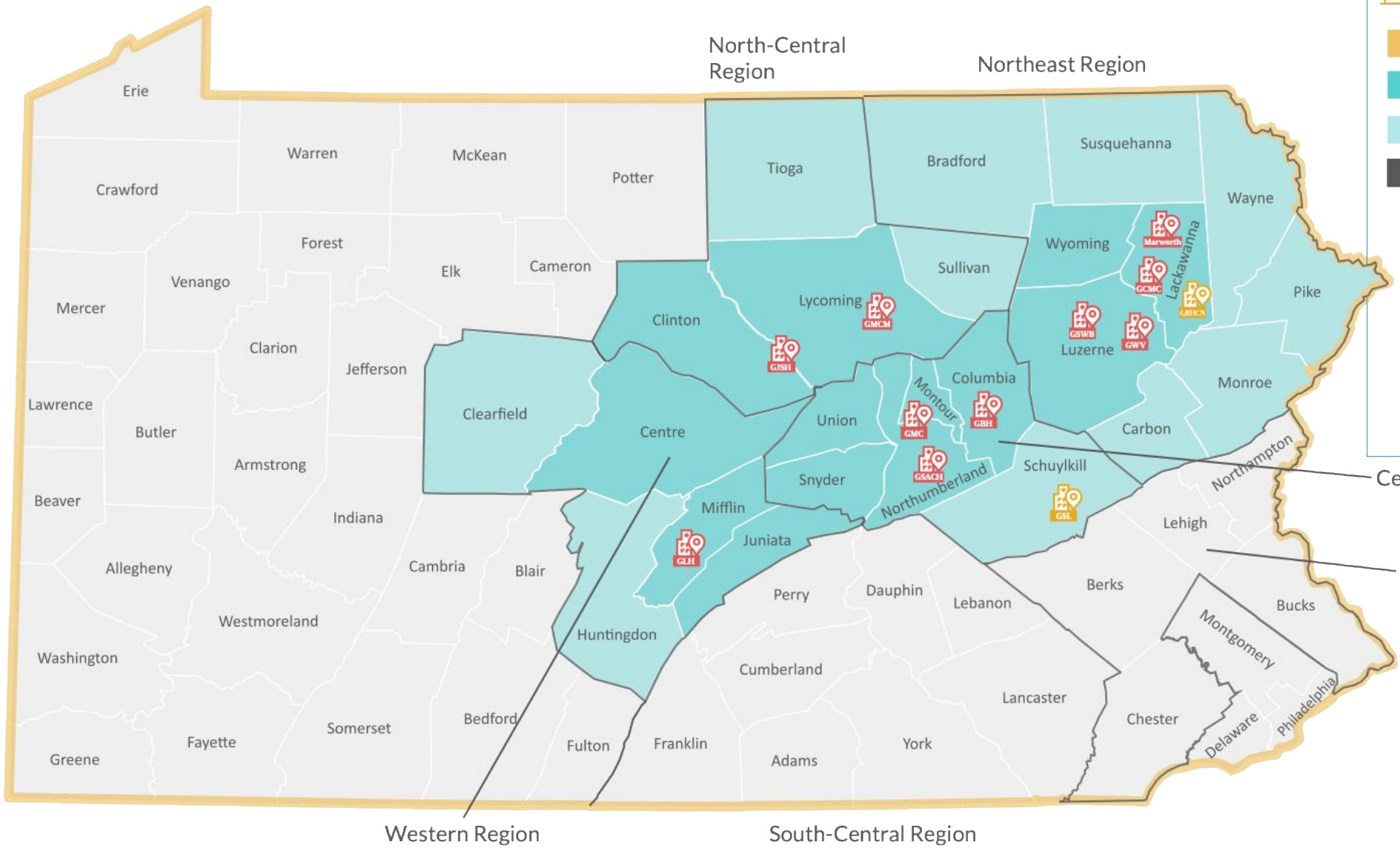
We provide quality, affordable healthcare coverage.

- **More than 550,000** Geisinger Health Plan enrollees
- **More than 65,000 c**ontracted providers in network
- **225+** hospitals in network

We shape the future of medicine.

- **550+** MBS/MD students at Geisinger College of Health Sciences
- **70** students in School of Nursing
- **600+** residents/fellows
- **1,400+** active research projects

Geisinger service area



Region and service area map key

- Geisinger inpatient facility
- Geisinger affiliated hospital
- Geisinger Health Plan service area
- Primary service area
- Secondary service area
- Region outline

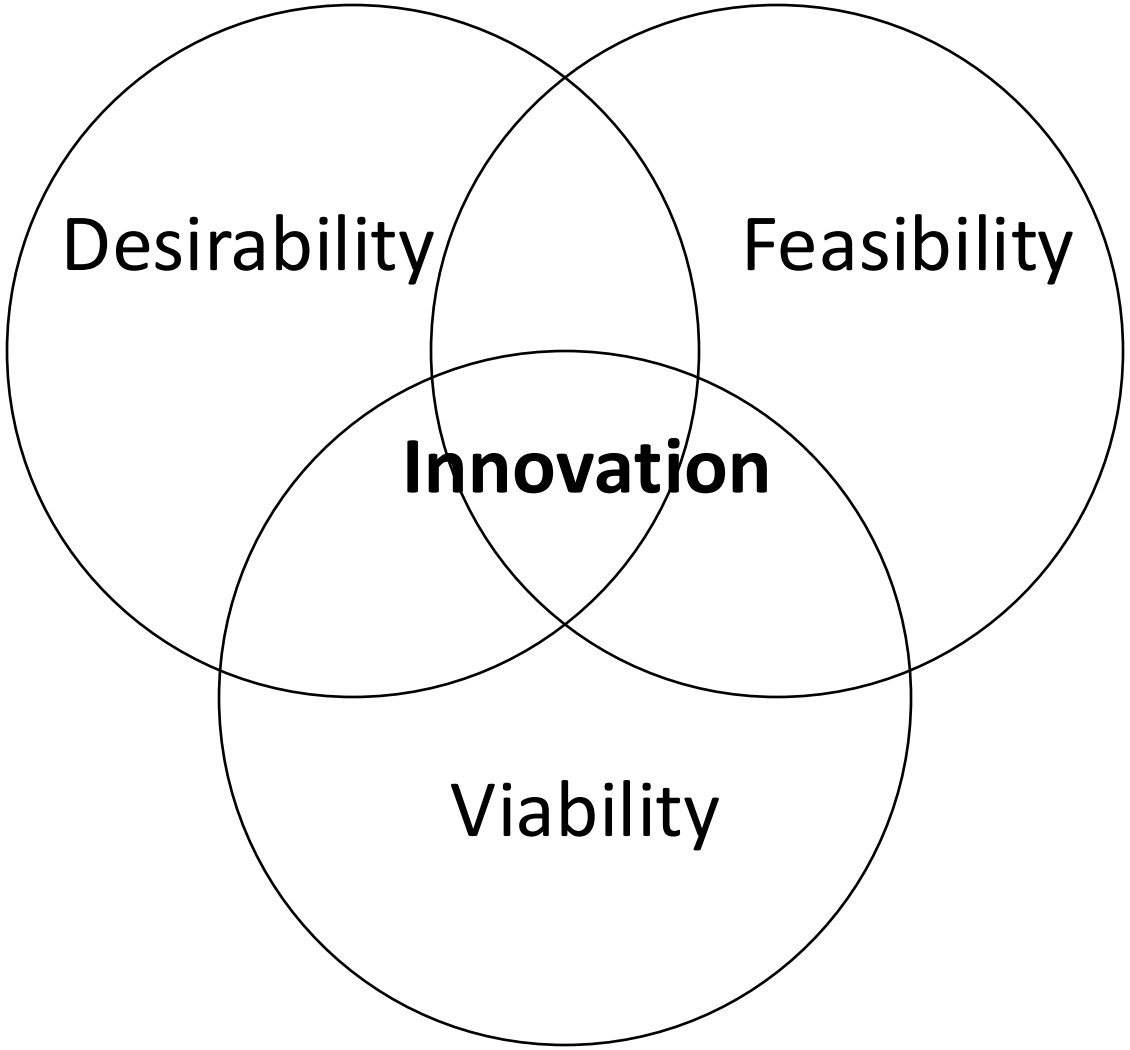
GBH – Geisinger Bloomsburg Hospital
GCMC – Geisinger Community Medical Center
GJSH – Geisinger Jersey Shore Hospital
GLH – Geisinger Lewistown Hospital
GMC – Geisinger Medical Center
GSACH – Geisinger Shamokin Area Community Hospital
GSL – Geisinger St. Luke's
GWV – Geisinger Wyoming Valley Medical Center
GSWB – Geisinger South Wilkes-Barre
Marworth – Geisinger Marworth Treatment Center
GMCM – Geisinger Medical Center Muncy
GBHCN – Geisinger Behavorial Health Center Northeast

Geisinger

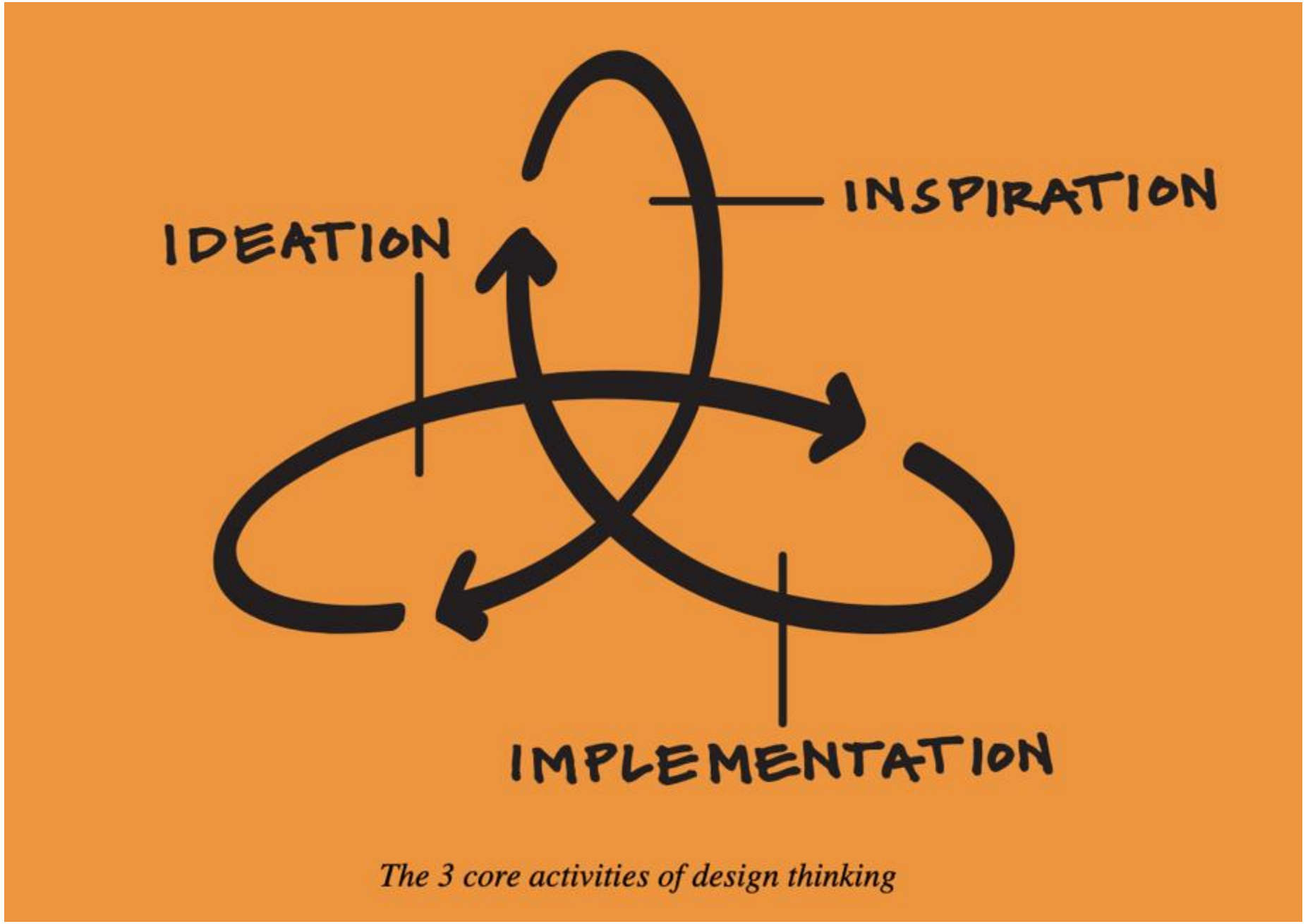
What is human centered design?

*"Design thinking is a **human-centered approach to innovation** that draws from the designer's toolkit to integrate the needs of people, the possibilities of technology, and the requirements for business success."*

—TIM BROWN, EXECUTIVE CHAIR OF IDEO



Credit: IDEO



The 3 core activities of design thinking

Credit: IDEO

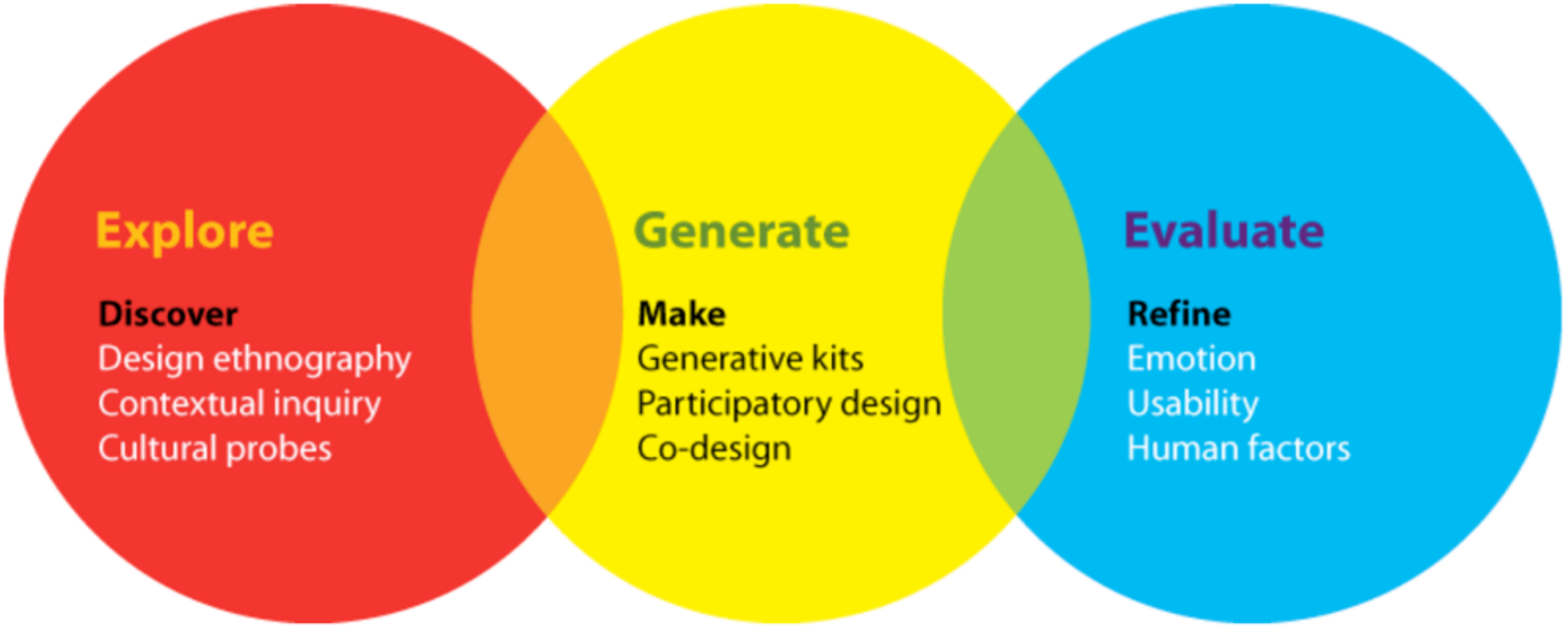
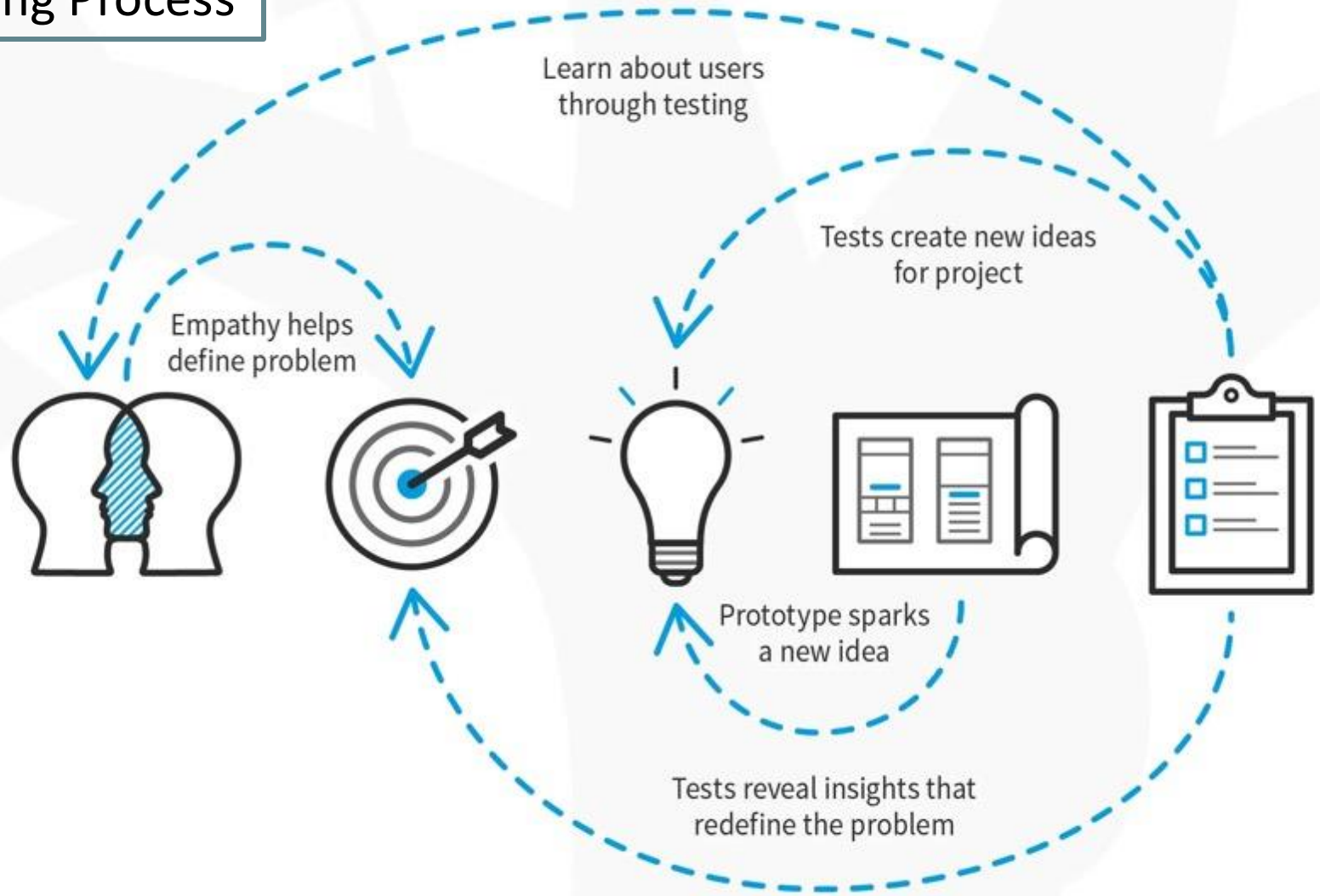


Figure 1: Model of design research

Credit: Hanington, 2007

Design Thinking Process



Source: https://www.interaction-design.org/literature/article/5-stages-in-the-design-thinking-process

What do all these models and processes have in common?

To shape healthcare innovation, you must understand the current state

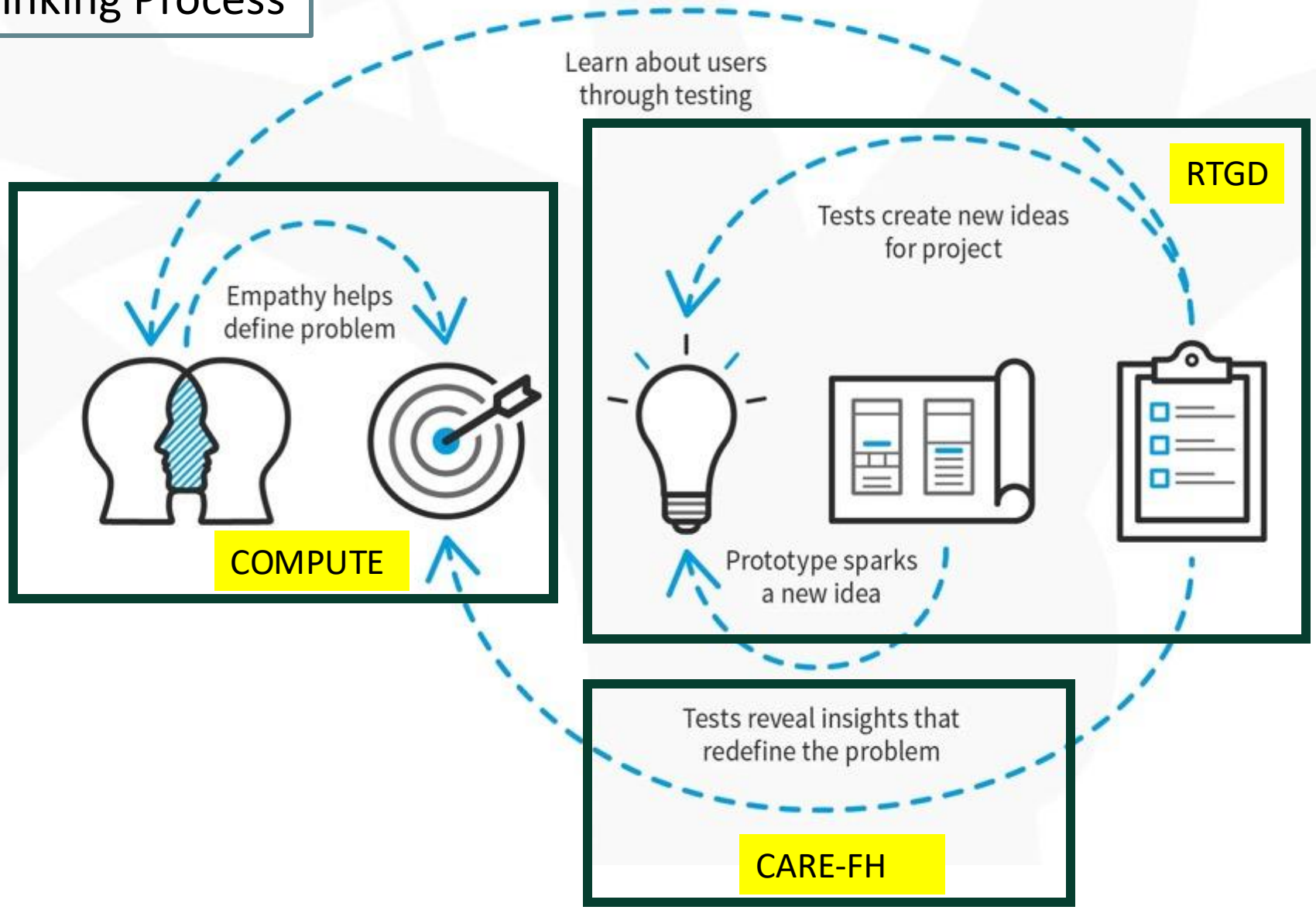
Identify barriers and facilitators to their goals/needs

Identify opportunities for improvement and innovation

Problem identification leads to solutions

Test, learn, test!

Design Thinking Process



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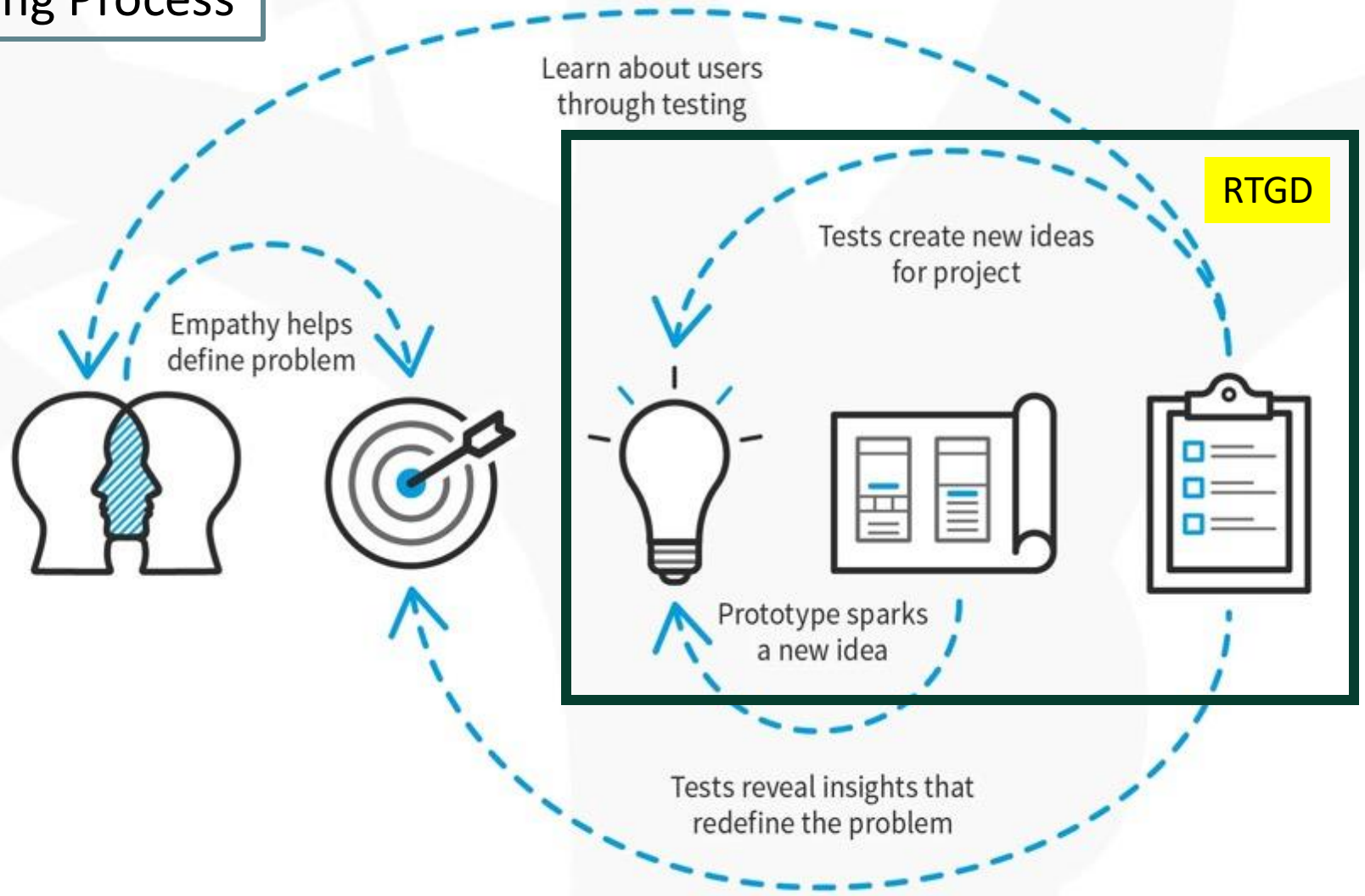

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Supported by the National Human Genome Research Institute of the National Institutes of Health under Award Number R01HG011799.

Real-Time Genetic Diagnosis at the Point of Care (RTGD)

Geisinger PI: Marc Williams

What do we know about *the diagnosis of genetic conditions outside of genetics?*

Research Questions:

- What are the barriers and facilitators of Clinical Decision Support tools with genomic information, according to the literature?
- What is the current experience from a clinician perspective on diagnosing and treating patients with complex disorders that may have an underlying genetic cause? What are the pain points? Where are there areas of opportunity to improve?

Human-centered design and real-time genetic diagnosis

Qualitative research with clinicians

Purpose: Learn how complex genetic conditions are currently diagnosed in nephrology, endocrinology, and cardiology.

Goals:

Understand experience from a clinician perspective on diagnosing and treating patients with complex disorders that may have an underlying genetic cause

Identify pain paints in that experience

Identify areas of opportunity to improve that experience/process with RTGD innovations

Data:

Qualitative interviews

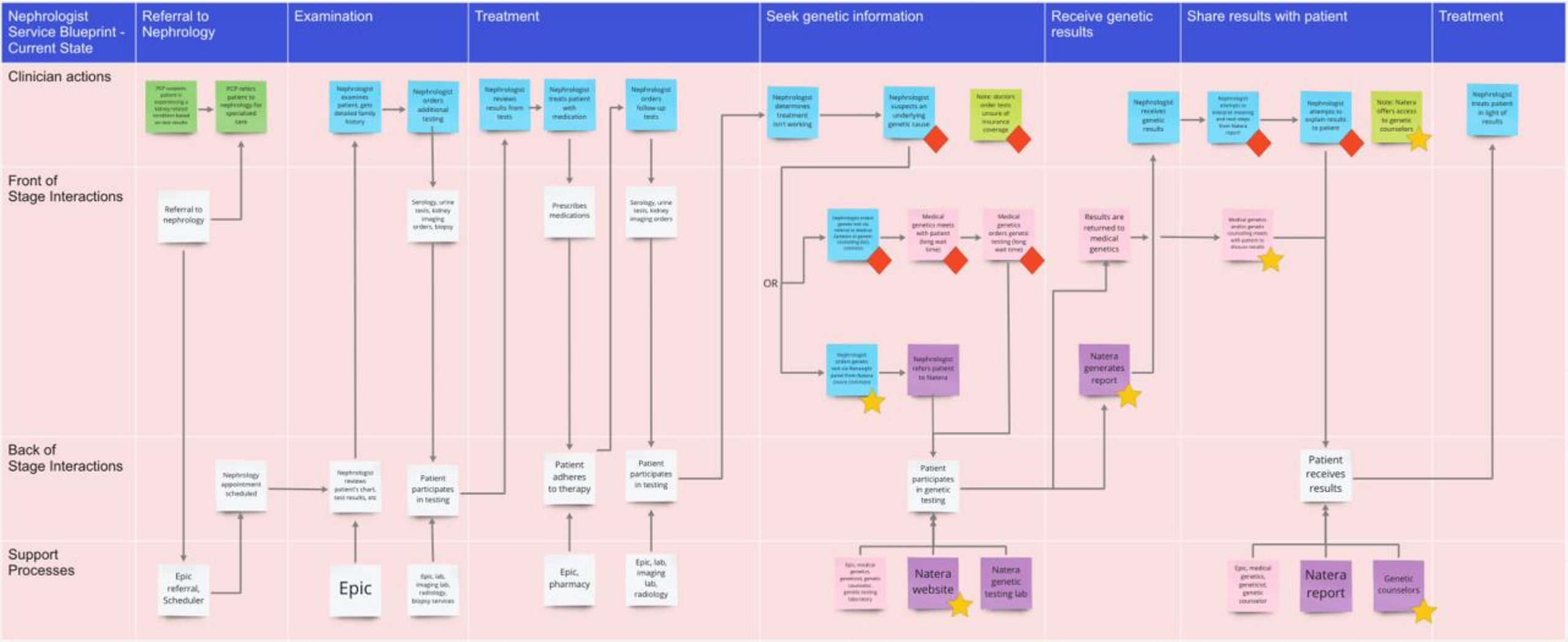
Service Blueprints

Human-centered design methodology for visualizing processes in context

Visual maps that illustrate relationships between different service components tied to user experience of a service

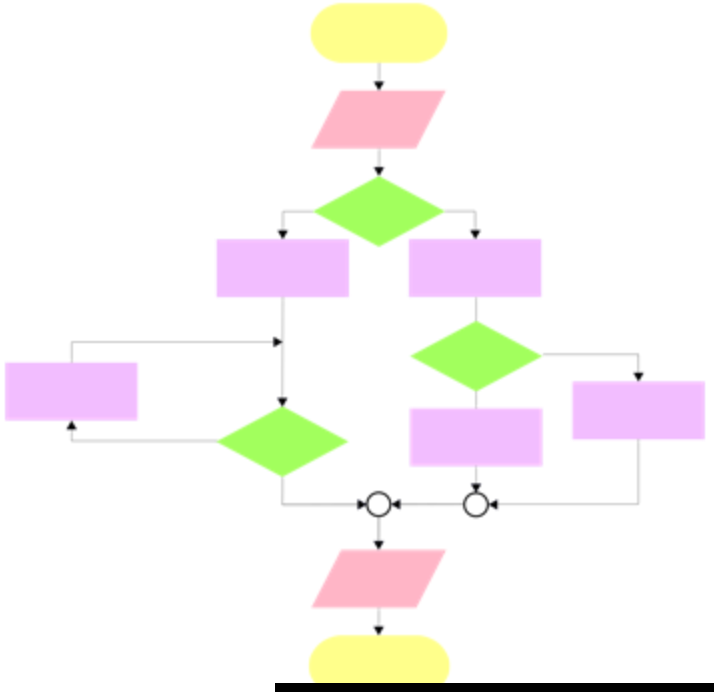
Identify areas of opportunity to innovate and improve service delivery

Service blueprint: Genetic diagnosis in nephrology

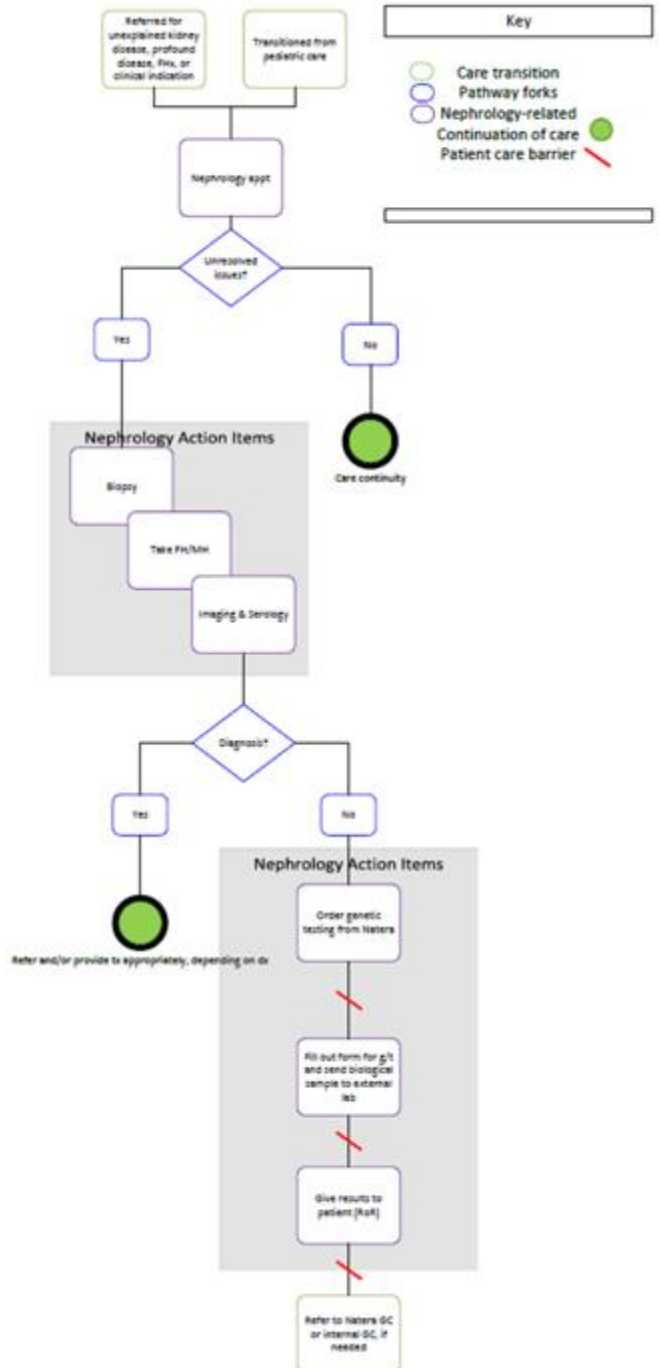


Process mapping

Flowchart that visually represents a sequence of actions for a given activity



Pathway #1: Clinical diagnosis prioritized; If not found through traditional means, genetic testing is considered



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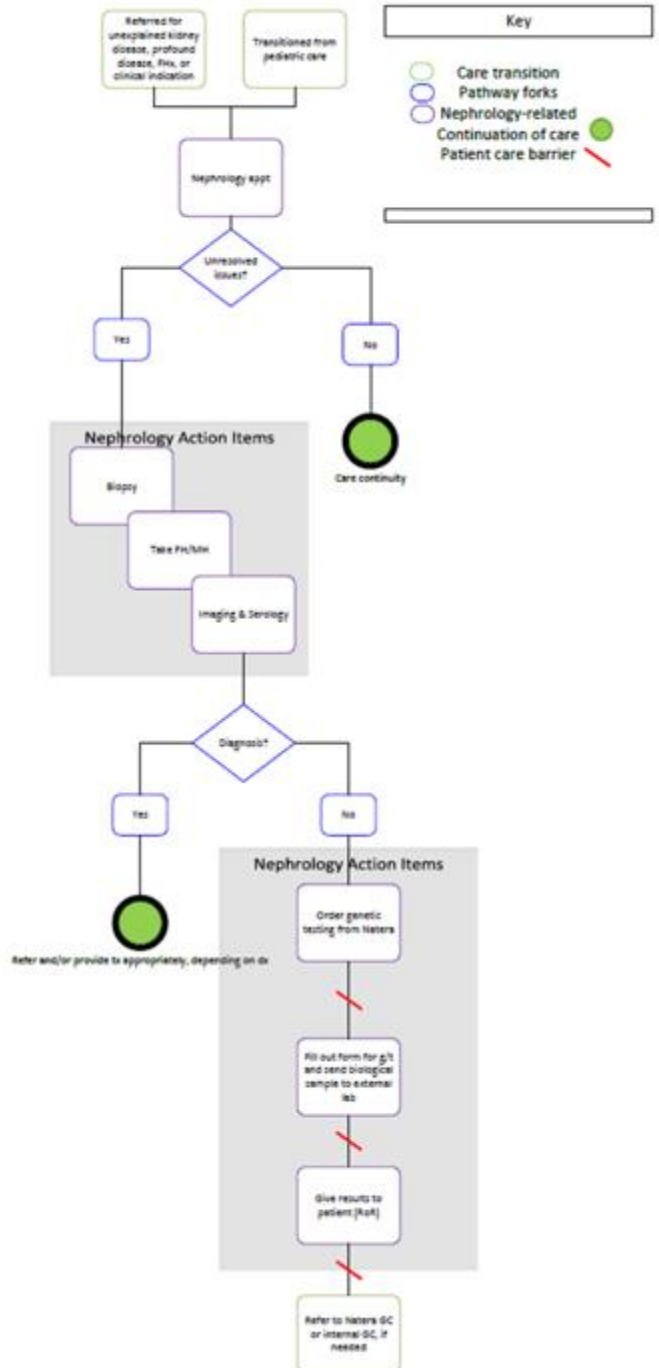
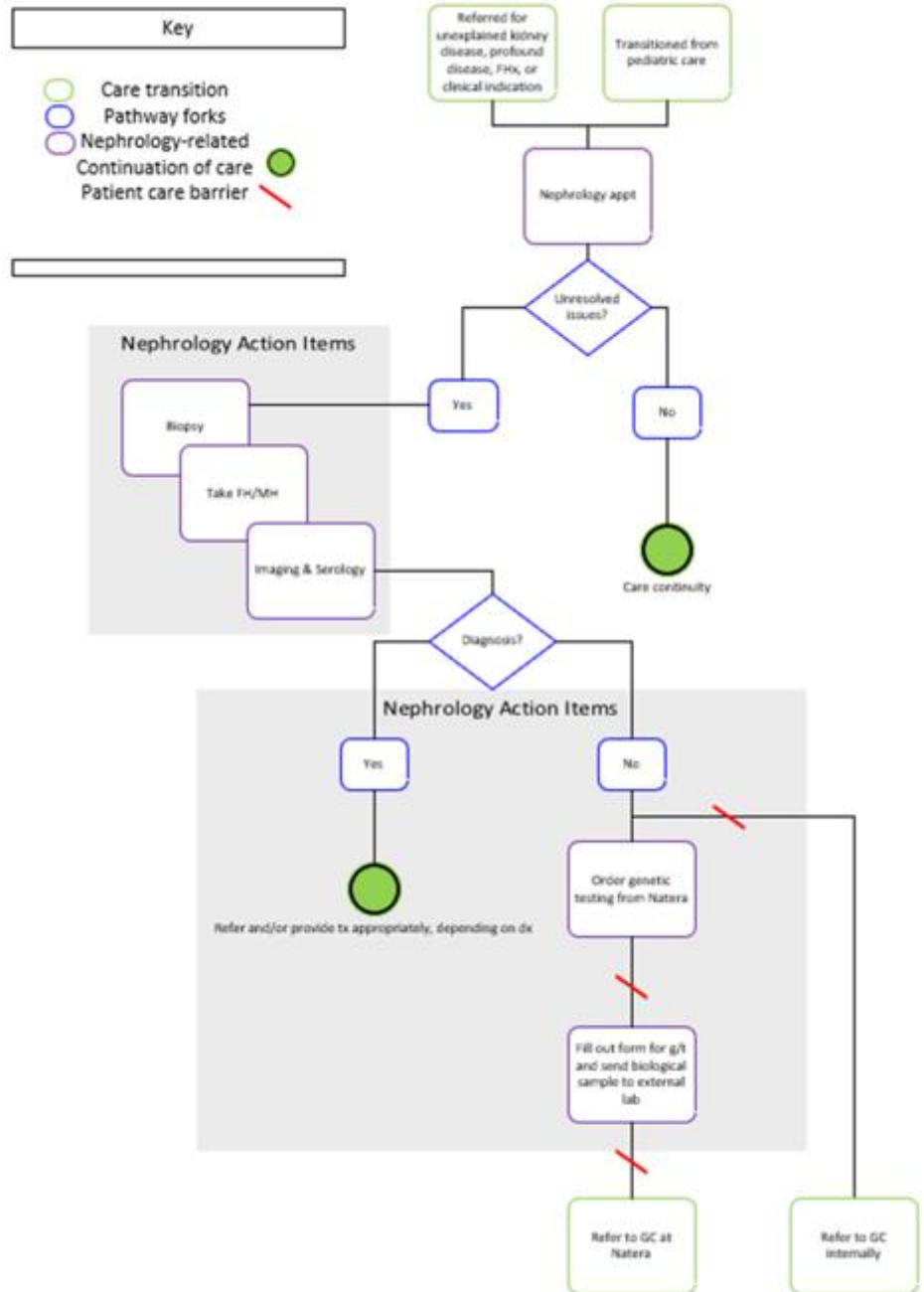


Pathway #3: Clinical diagnosis prioritized; If not found through traditional means, genetic testing is considered but **inconsistent** in GC referral internally **OR** direct to Natera



Summary of Patient Care Barriers Identified

Missing return of results: Participant does not know if all patients are receiving results – Some patients could be falling through the cracks

Insurance criteria: Some insurance companies prioritize clinical symptoms over genetic test results – Unsure what to do with patients with a positive genetic test but without hallmark symptoms (e.g., hemolysis w/ atypical HUS).

Ordering genetic testing: No centralized or standardized process can lead not knowing how to order genetic testing at all --> Could lead to ordering the wrong test and causing patients to pay more.

Test result implications: Not understanding what the results mean or what to do with them.

Complex transition to Genetics: Patients oftentimes do not fill out intake forms. One provider stated 50% of patients do not fill out the intake forms.

Referral inconsistency: Patients may be seen by an internal provider or by a genetic counselor through Natera, but the process is inconsistent.

Question remains:

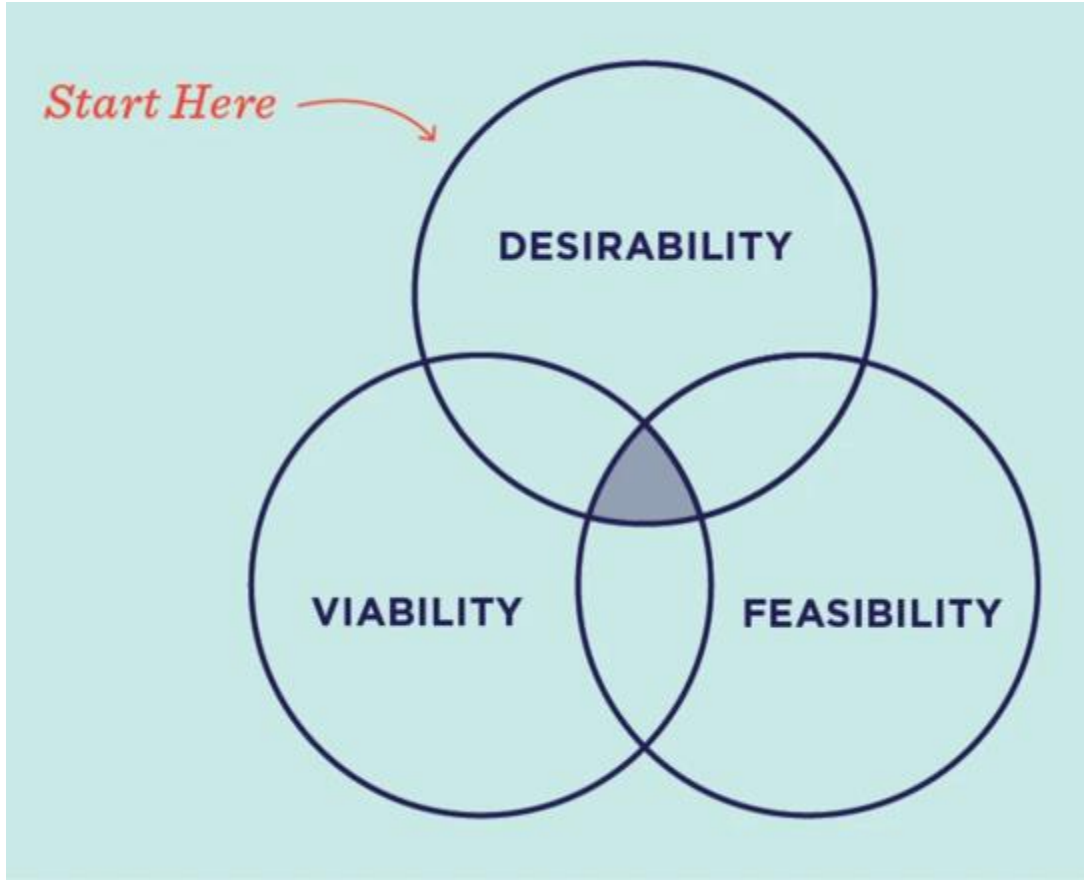
How do we **design** & **implement** real time genetic diagnosis at Geisinger?

What we don't know (yet)

We know current state processes, facilitators, barriers, and what might be ideal for diagnosing patients with a genetic condition

- We don’t know... **what a feasible RTGD intervention looks like**
- We don't know... **how best to implement a RTGD intervention within the current state at Geisinger**

We need your help to design the RTGD prototype process



How might we....?

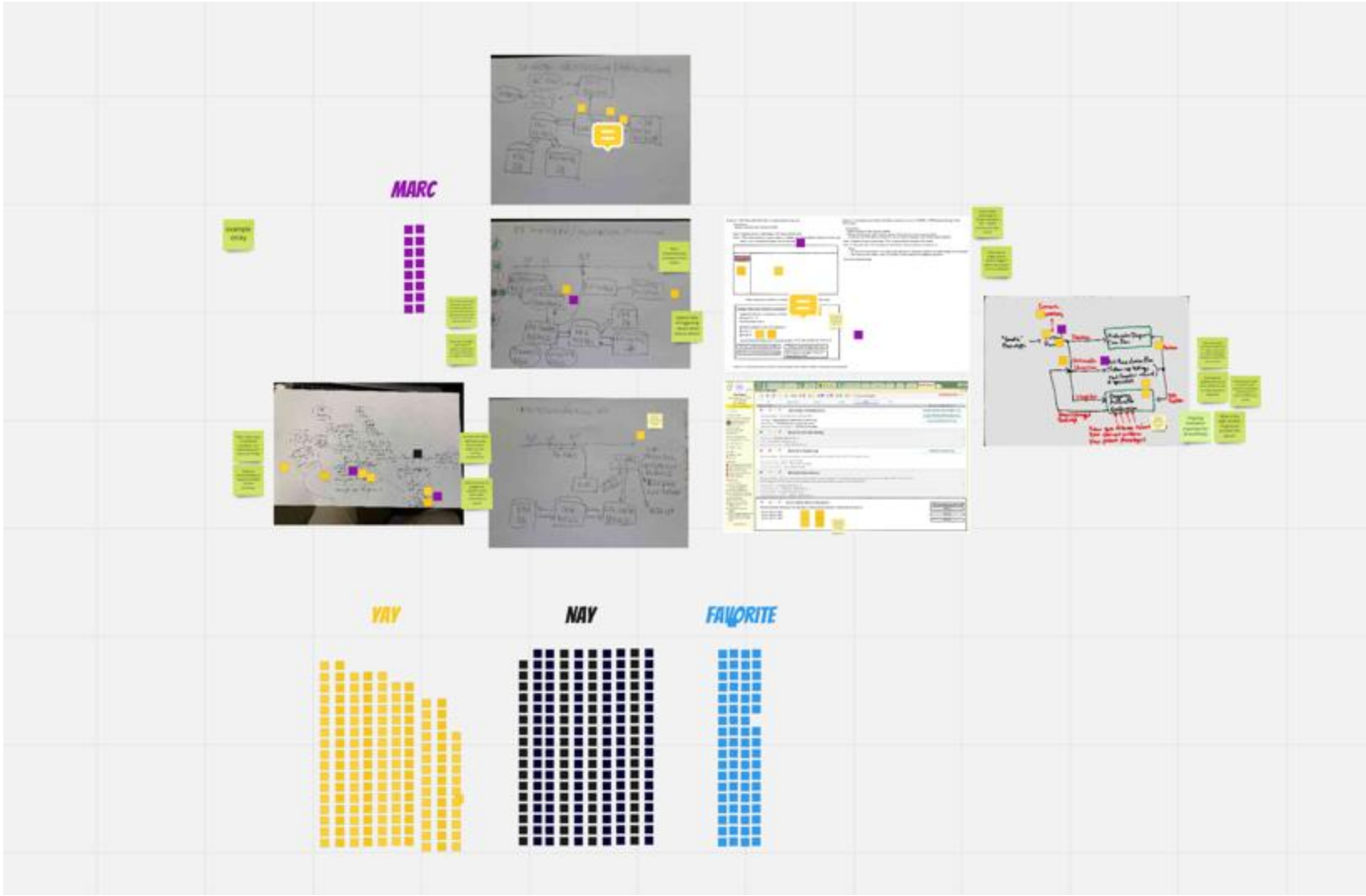
...implement Real Time Genetic Diagnosis in at Geisinger

...with the goal of improving patient care by increasing genetic testing earlier in

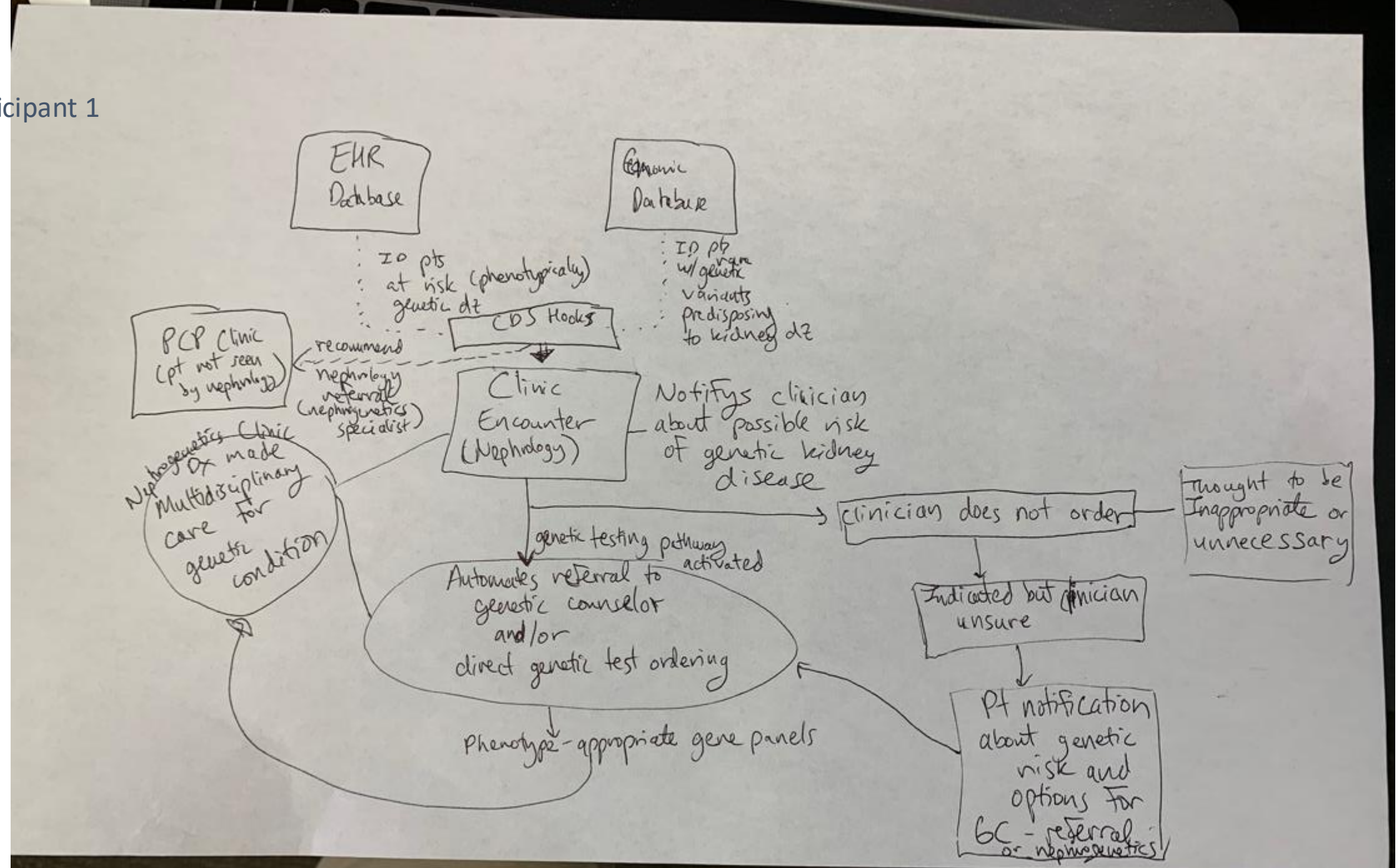
...in a way that is:

- Desirable by clinicians (Acceptability)
- Feasible in the context of Geisinger care and genetic testing (Feasibility)
- Viable economically (Implementable)

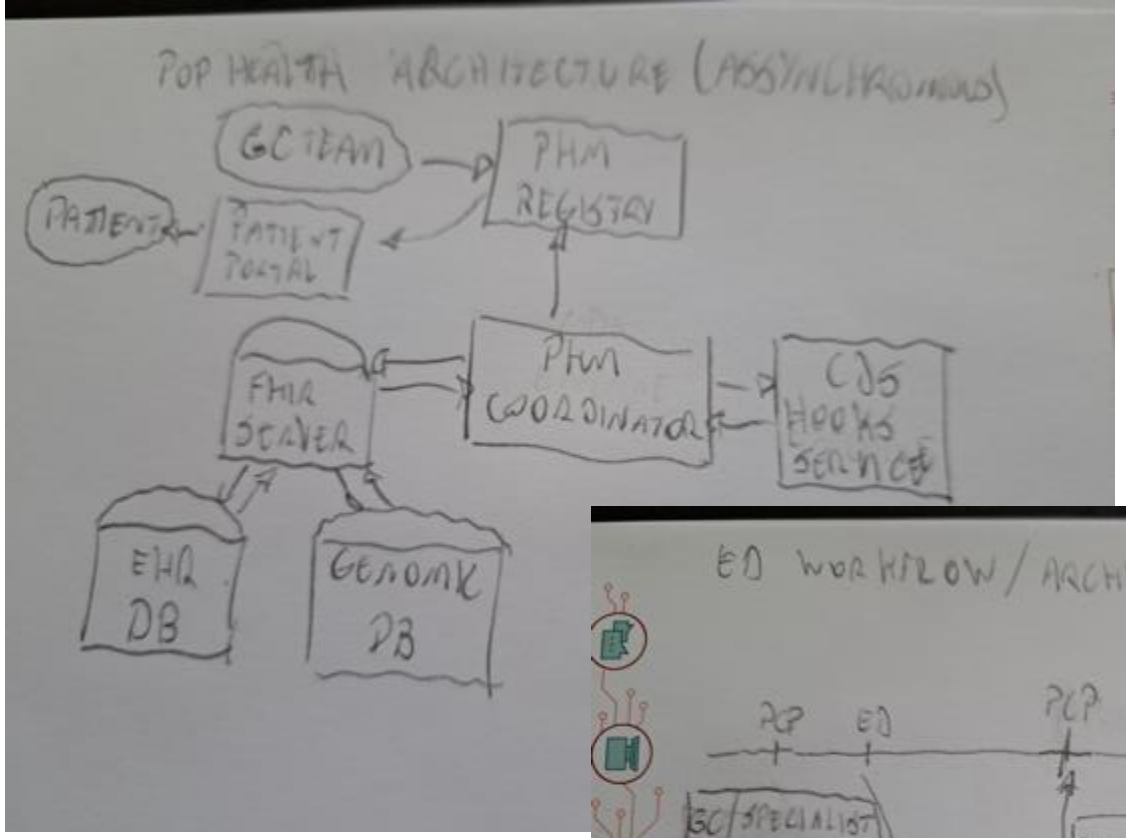
Workshop Results

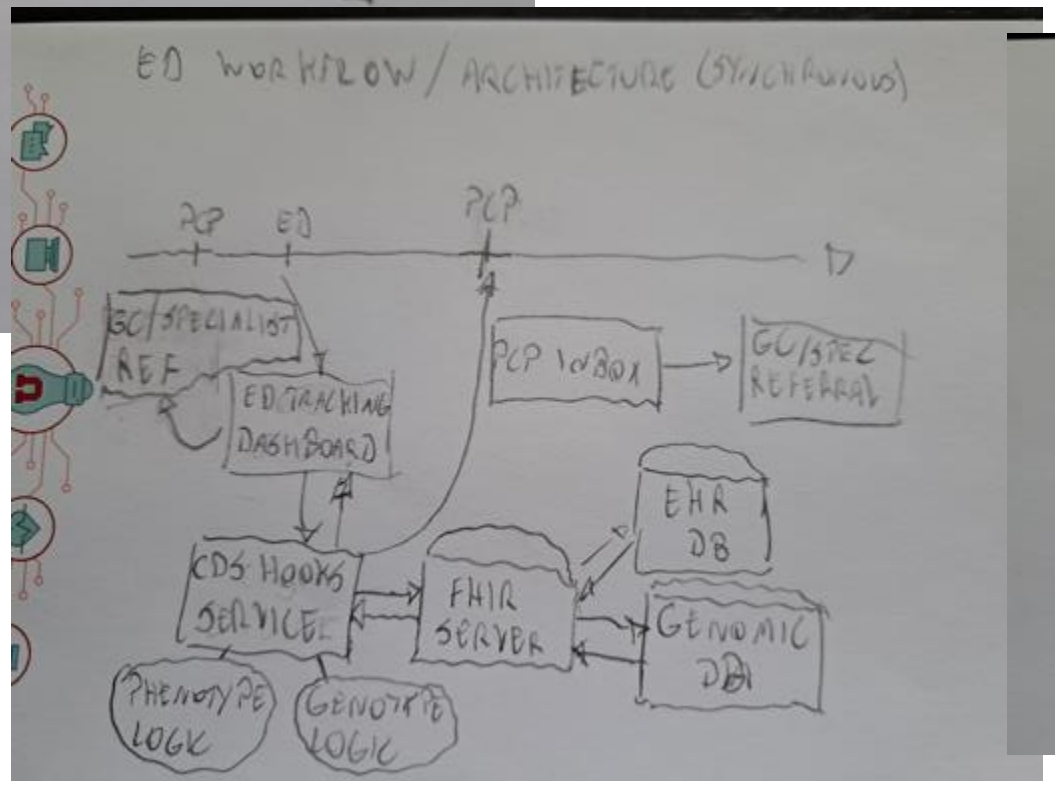


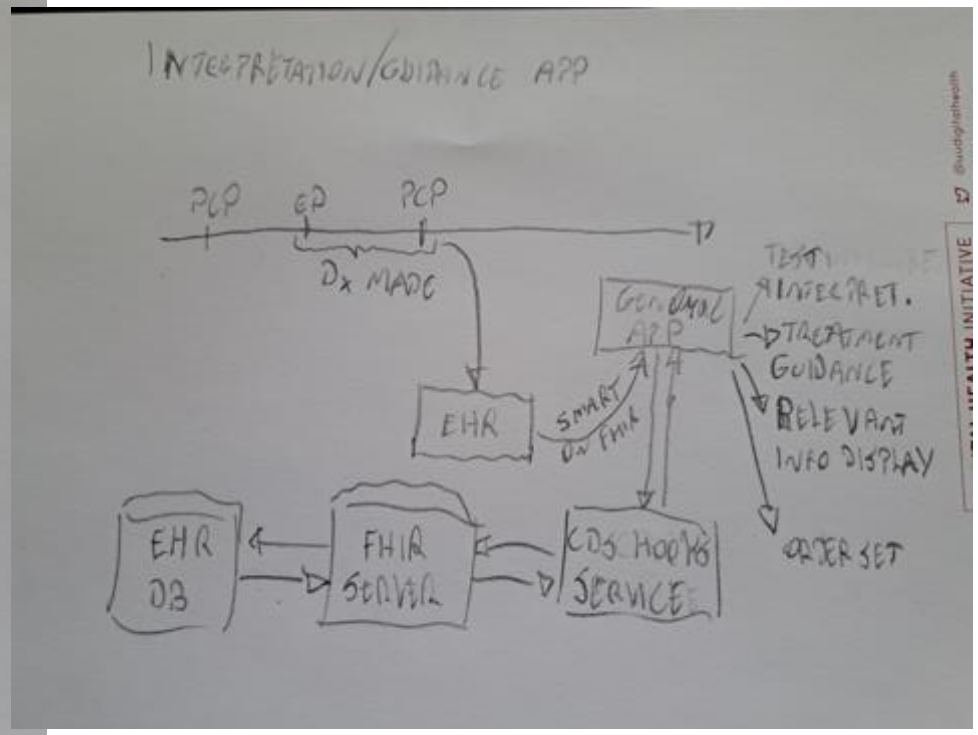
Participant 1



Participant 2







Participant 3

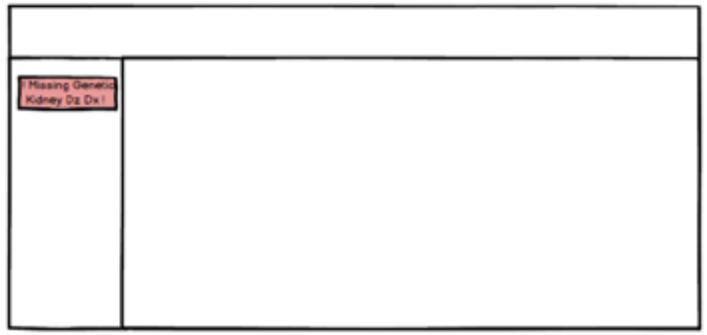
Scenario 1: CDS Hooks Alert/Reminder re: needed genetic diagnosis

Assumptions:
-genetic sequence data already available

Step 1: targeted clinician (nephrologist, PCP) opens patient chart

Step 2: CDS Hooks evaluation to see if there is a needed and missing genetic diagnosis, prompt user

Option 1: put in storyboard (danger: may be ignored)



When hovered over/clicked on, provides additional information and action steps:

MISSING PRESUMED GENETIC DIAGNOSIS FOR KIDNEY DISEASE

Suggested diagnosis: renal genetic condition X

Rationale: X, Y, Z

Recommended actions:

- ☑ Add to problem list and visit diagnosis: X
- ☑ Order A
- ☑ Order B

Launch Disease Manager app to manage condition (If Dz Mgr enabled per Scenario 2)

Turn off - pt does not have condition	Snooze - show me again next visit
Turn off - pt already dx'd and managed	Don't show for me again - I am not responsible provider

Option 2: on-chart-open pop-up version of above (danger: alert fatigue/inability to get governance approval)

Scenario 2 (complementary): Genetic Dx/Mgmt guidance as a part of SMART on FHIR Disease Manager App's CKD module

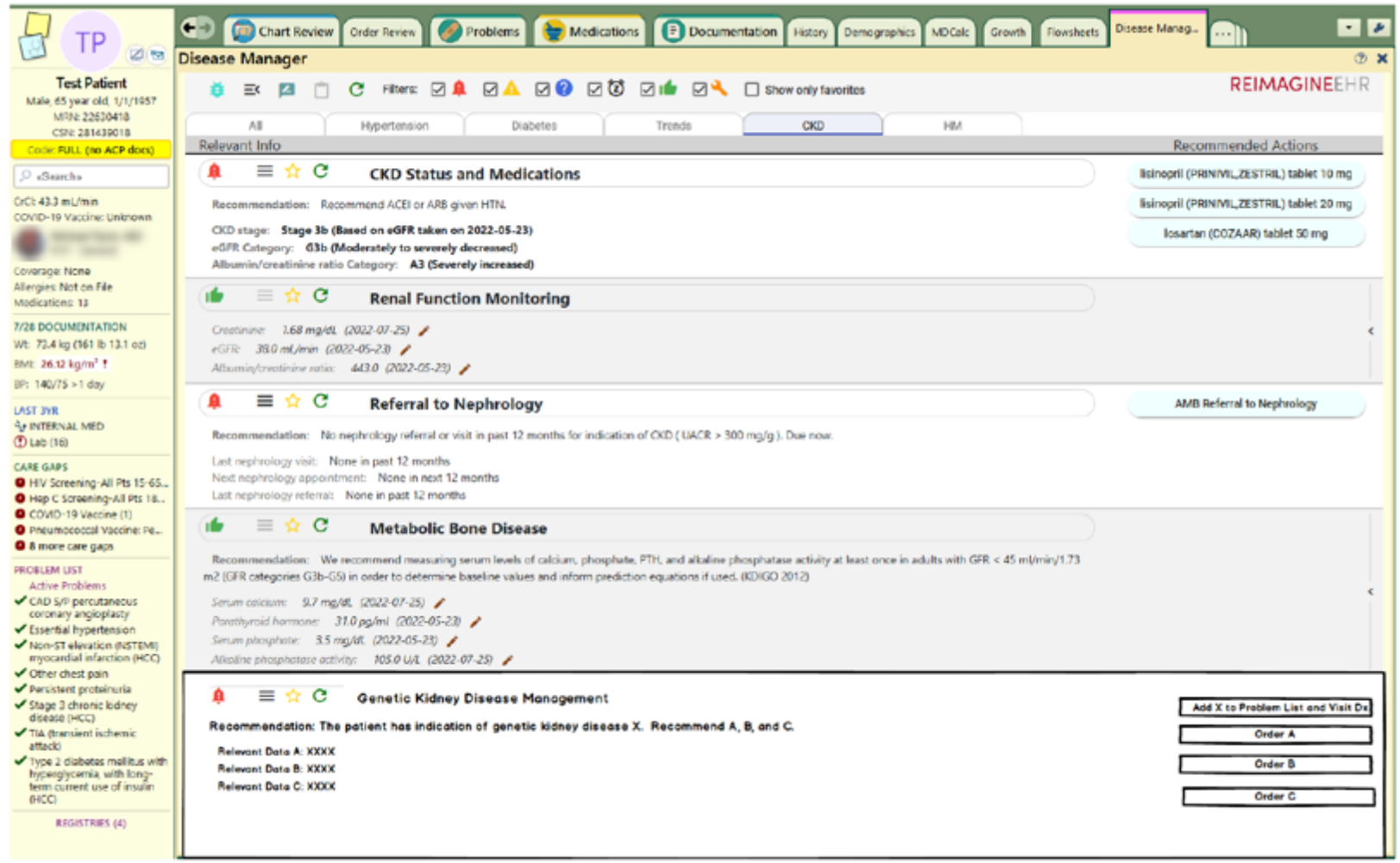
Assumptions:
- genetic sequence data already available
- Disease Manager app being used for general CKD mgmt by at least some providers
  (could also use CDS Hooks to prompt for use of Disease Manager's CKD module where relevant)

Step 1: targeted clinician (nephrologist, PCP) is using Disease Manager CKD module

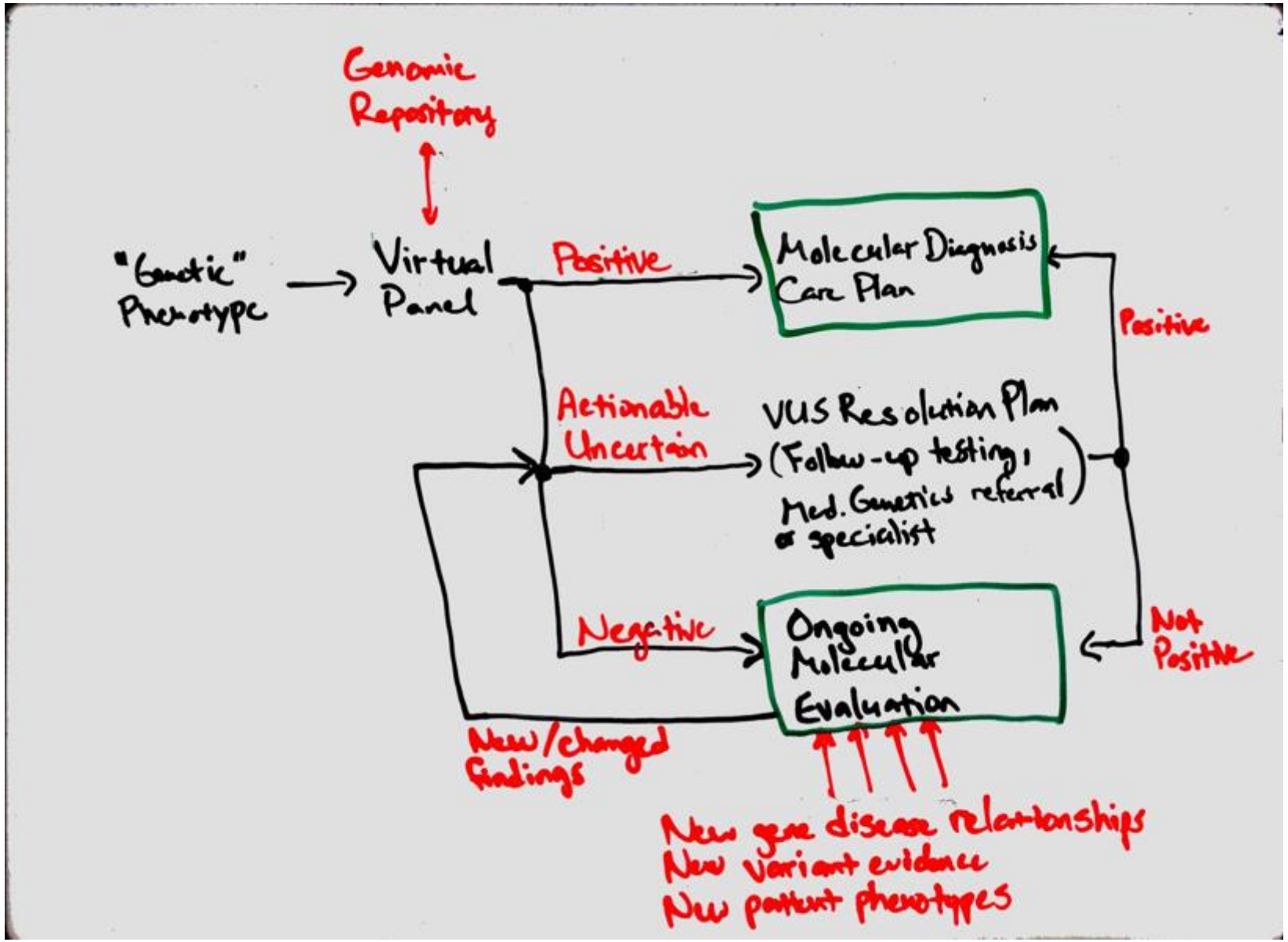
Step 2: along with other CKD management information, provides guidance on genetic dx

Notes:
- for both this and scenario 1, can apply same approach to ordering of genetic test when sequence not available
- This scenario also makes it easy to transition to post-diagnosis management guidance

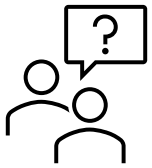
See next screenshot page



Participant 4

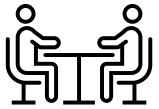


Next steps



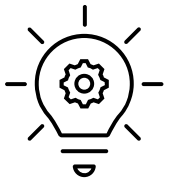
Frame the Question

Identify the driving question that inspires others to search for creative solutions



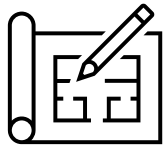
Gather Inspiration

Understand what people really need to solve the problem they are experiencing



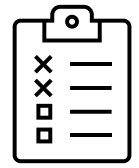
Generate Ideas

Push past obvious solutions to get to breakthrough ideas



Prototype

Build prototypes to learn how to make ideas better.



Test

Understand what people really need to solve the problem they are experiencing

Sharing with nephrologists for feedback

Chart Review | History | Laboratory | Imaging | Genetics | Allergies | Problem List | Medications

Ruth C Black

Gender: female, 74 years old
DOB: Aug 22, 1951

MRN: smart-665677

Risk Adm/ED (%): 0
Isolation: None

Coverage: Medicaid

Allergies: 0

PCP INFORMATION

Joseph P Nichols MD

Ht: 1.778m (5' 10")
Wt: 95.5 kg (210.1 lbs)
BMI: 28.85 kg/m^2
BP: 150/92 > 1 day

Last 10 Visits

Laboratory: Nephrology, Pain Medicine
Radiology, Unknown

GENETIC PROBLEMS (1)
Other Problems (4)

Next Appt: None
Active Rosters: None

Click the 'i' for additional information on ADPKD

Genetic Results should be interpreted by a medical professional trained in genetics

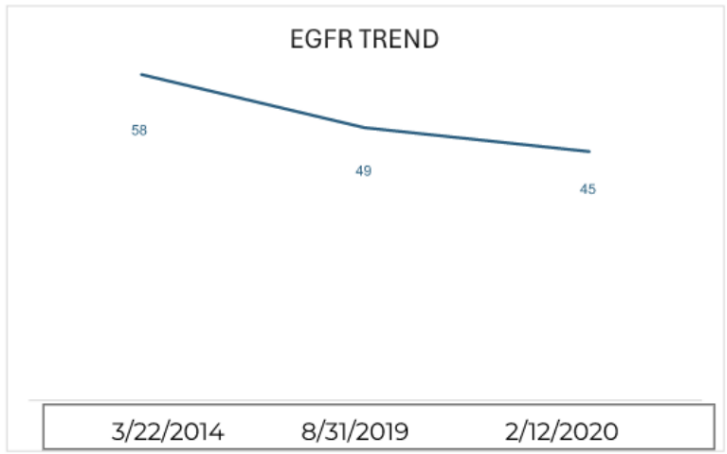
Medical Genetics

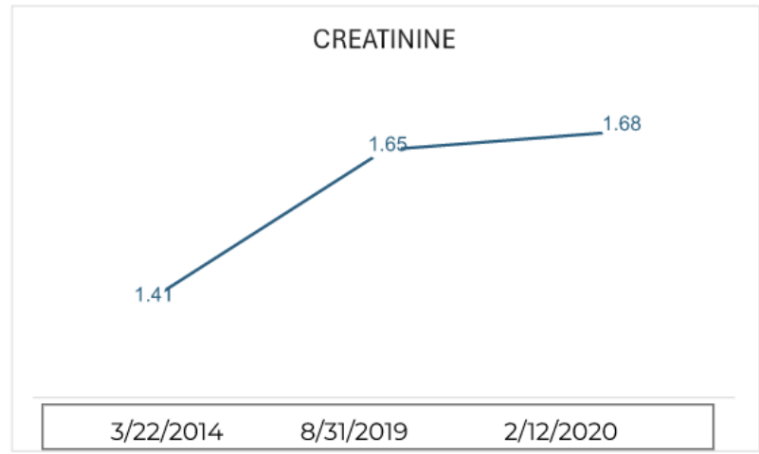
Recommendation: Schedule Genetic Counselor Visit
No genetic counseling referral or visit in past 12 months for indication of ADPKD.

Ruth C Black has a suggested diagnosis of ADPKD. A genetic counselor can help navigate the disease management in alignment with ACMG recommendations.

- Referral to Genetic Counselor
- Referral to Medical Genetics

Renal Function Monitoring





Albumin/creatinine ratio: 443.0 (02-12-2020)

ADPKD STATUS AND MEDICATIONS

Recommendation: recommend ACEI or ARB given HTN

CKD stage: Stage 3b (Based on eGFR taken on 02-12-2020)
eGFR Category: 03b (Moderately to severely decreased)
Albumin/creatinine ratio category: A3 (Severely reduced)

No medications found.

- Lisinopril Tablet
- Album/Creat Ratio, Urine
- eGFR

Genetic Kidney Disease Management

Recommendation: The patient has indication of Autosomal Dominant Polycystic Kidney Disease.
Recommend confirmatory testing,
regulate blood pressure,
patient instruction packet for CKD, ACE inhibitor, and Tolvaptan

Confirmatory testing: 3-6 weeks
ACE inhibitor: as needed
Patient instruction packet: immediately
Tolvaptan: suggested

- Add ADPKD to problem list
- Confirmatory genetic testing
- Tolvaptan

NATIVE EHR

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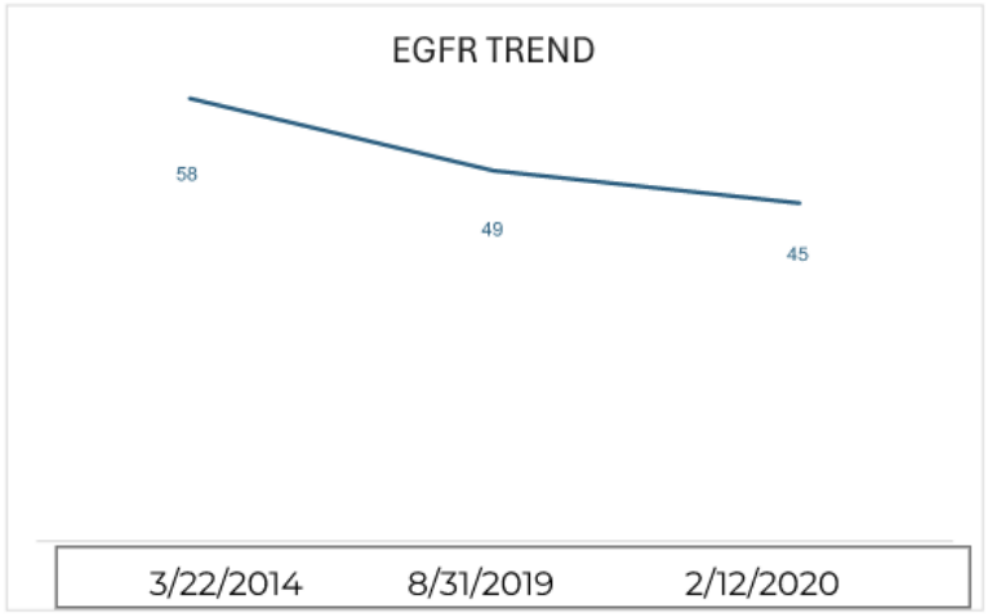

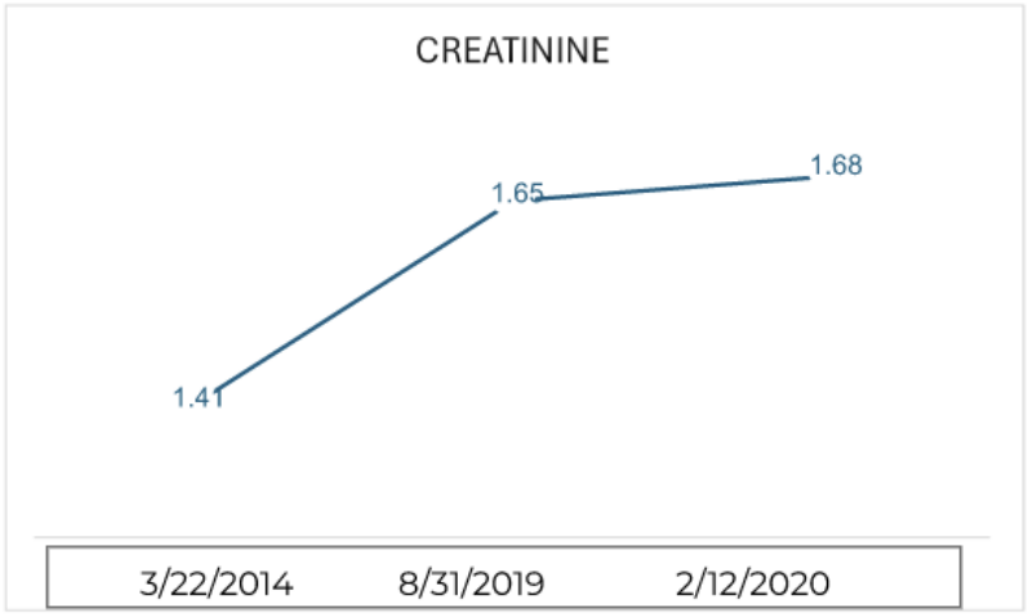

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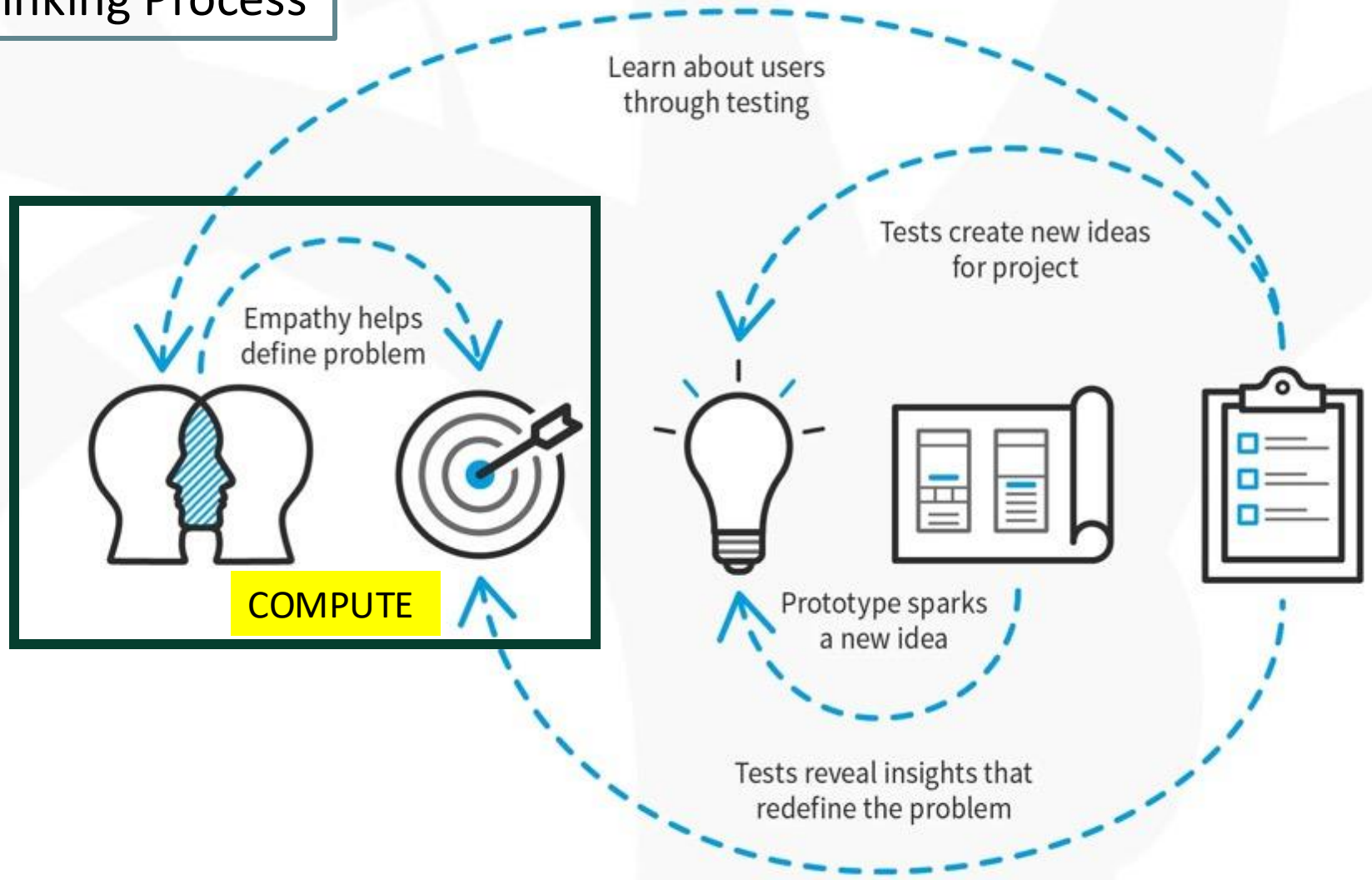
Design Thinking Process



Source: https://www.interaction-design.org/literature/article/5-stages-in-the-design-thinking-process

Trial registration number: NCT04198428.
supported by the National Institutes of Health (NIH) through the NIH Helping to End Addiction Long-term (HEAL) initiative under award number UG1da040316.
Disclaimer The content is solely the responsibility of the authors and does not necessarily represent the official views of NIH or the NIH HEAL initiative.

COMPUTE 2.0

Pragmatic clinical trial of a clinical risk tool for opioid use disorder in primary care (Opioid Wizard)

Geisinger PI: Eric Wright

Investigator Team

HealthPartners Institute

- Rebecca Rossom, MD (Co-Lead)
- Lauren Crain, PhD (Co-I)
- Steve Dehmer, PhD (Co-I)
- Jacob Haapala, MPH (Co-I)
- Stephanie Hooker, PhD (Co-I)
- Kate Miley, PhD (Co-I)
- JoAnn Sperl-Hillen, MD (Co-I; retired)
- Patrick O'Connor, MD (Co-I)
- Leif Solberg, MD (Co-I)

Hennepin Health

- Gavin Bart, MD, PhD (Co-Lead)

Geisinger

- Eric Wright, PharmD, MPH (Site PI)
- Maria Kobylinski, MD (Co-I)
- Katrina Romagnoli, PhD (Co-I)

Essentia Health

- Anthony Olson, PharmD, PhD (Site PI)
- Irina Haller, PhD (Former Site PI)

Emmes

- Jennifer McCormack, MS

NIH/NIDA Scientific Development

- Kristen Huntley, PhD (Science Officer)
- Ron Dobbins, PhD (Program Officer)

COMPUTE 2.0; Opioid Wizard

Design: Cluster-Randomized Clinical Trial within 92 Primary Care clinics across 3 Health Systems (HealthPartners, Geisinger, Essentia)

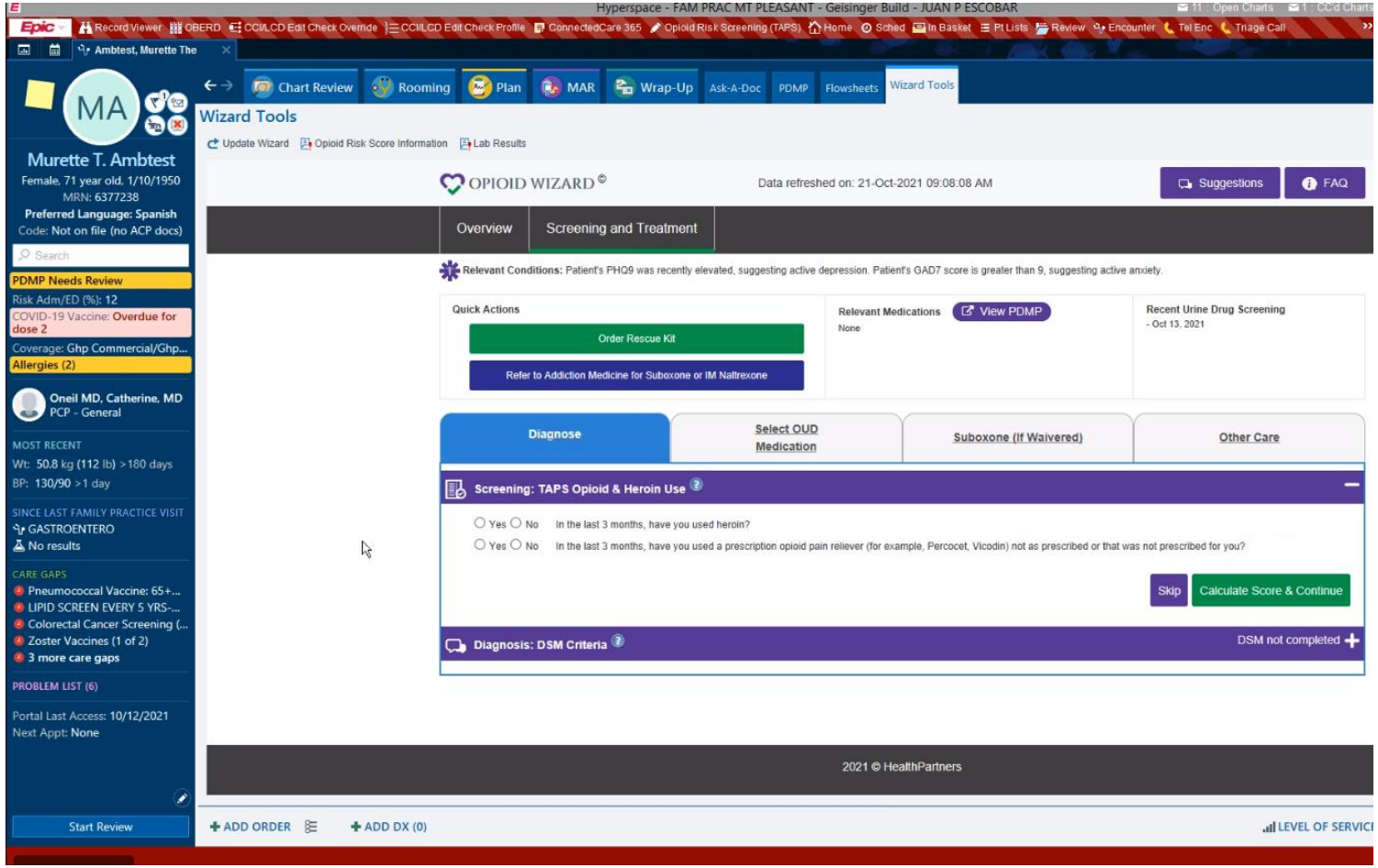
- Go-Live at Geisinger Feb 7, 2022 (still active at 12 interventional sites)

Population: Primary Care patients with an active problem of opioid use disorder or at risk for opioid use disorder by an Epic Risk Score.

Intervention: Clinics with availability of Web-based clinical decision support engine; a.k.a. Opioid Wizard – Identified OUD and at risk for OUD, screened for OUD and provided guidance to clinicians and patients.

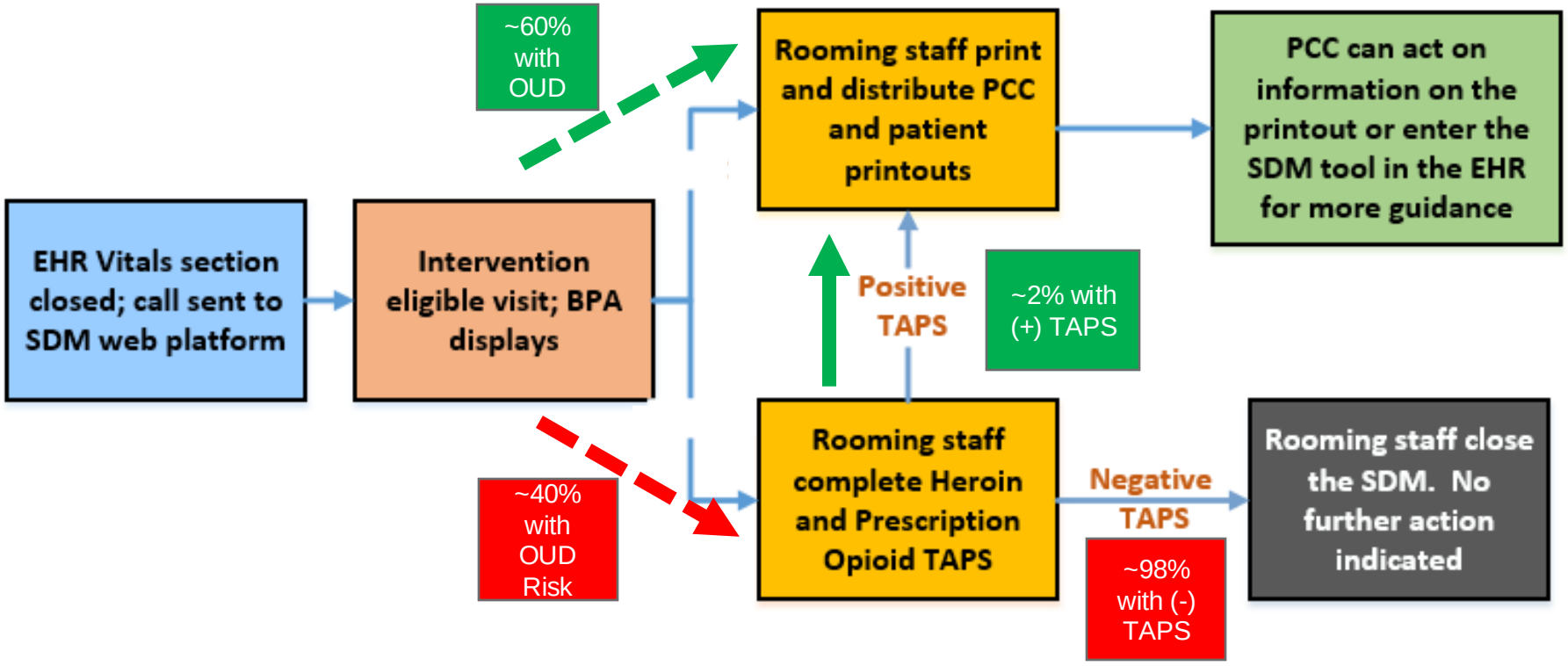
Control: Clinics without Clinical Decision Support

Opioid Wizard: Overview



- Web-based clinical decision support tool integrated with EPIC
- Built on platform (Wizard) that has other capabilities (e.g. cardiovascular)
- Helps PCPs **identify patients** at high risk for OUD or overdose
- One click **populates orders** for labs, medications, and referrals into the EHR to review and sign
- **"Note Builder"** helps document actions taken in the tool

Clinical Workflow



Pre-implementation: Qualitative study

What do patients & clinicians think of opioids in primary care?

- We spoke to:
  - 26 Geisinger patients who are currently or previously opioid users; and/or have a diagnosis of OUD; or are at increased risk of developing OUD
  - 13 clinicians who treat patients who meet the same criteria
- Our goal was to understand their perspective about communication about the risks of opioids and OUD, to inform how we implement Opioid Wizard at Geisinger.
- Identify barriers & facilitators to implementation

How we implemented our findings: Trainings

Clinicians may hesitate to use OW because:

- Concern about how patient will react
- Lack of time and resources

We structured clinician and rooming staff trainings to address these concerns directly and support the therapeutic alliance between doctor and patient

Clinician Feedback: Common Themes

- Clinicians vary in their comfort and experience with discussing opioids with patients.
- Clinicians may feel hesitant to bring up opioid use, out of fear of a negative reaction or lack of time.
- Most clinicians refer patients to receive MAT from a specialty provider.
- **Clinicians are looking for guidance on how to approach opioid discussions effectively.**
- **Clinicians are concerned about the amount of time using Opioid Wizard will require.**

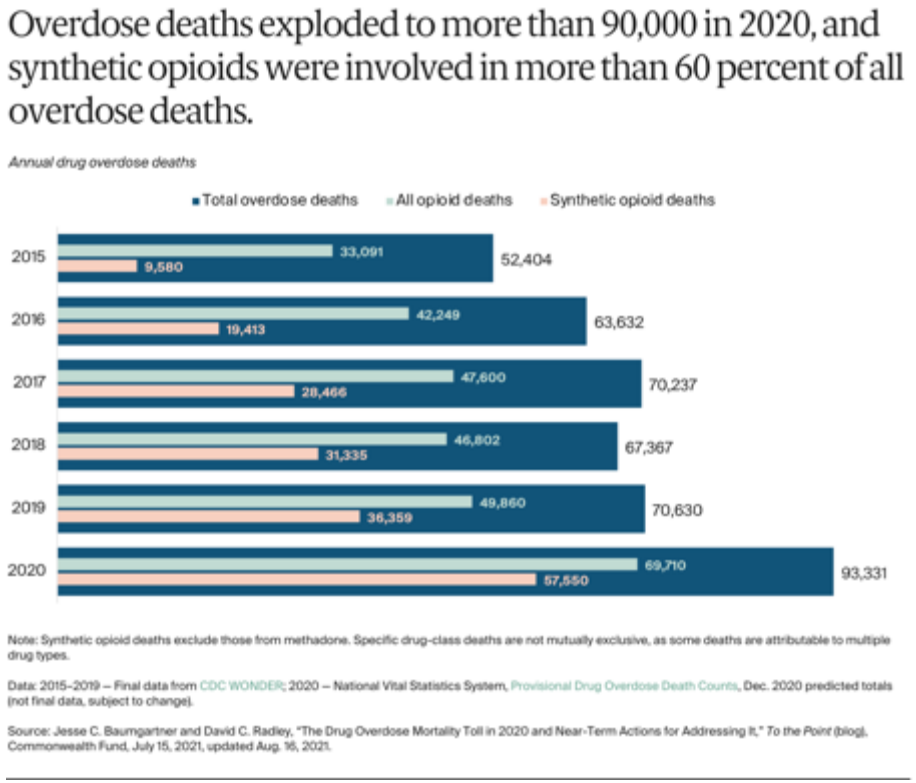
How do you use qualitative research to inform the implementation of an external tool? **Influence the training**

Structure	Emphasis	Provide
Structure training on why Opioid Wizard will be helpful	Emphasize how Opioid Wizard will reduce time needed to diagnose someone with OUD if appropriate – check engine light	Provide tools to help hesitant clinicians feel more comfortable

Why will Opioid Wizard be useful?

Opioid Epidemic

More than 90,000 overdose deaths in 2020



All-time high of opioid deaths in 2020: 93,331deaths nationwide[1]

Low screening rates: US does not screen for or diagnosis OUD enough

Low MOUD prescribing rates: Only 25% of those with OUD diagnosis receive a medication for opioid use disorder (MOUD) like suboxone[2]

Few clinicians are able to prescribe MOUD: <5% of PA doctors have waiver to prescribe, and only 28% of those waivered actually prescribe[3]. 60% of rural counties don't have a single waivered clinician[4]

Federal government waived the training requirements to for physicians prescribe buprenorphine (April 2021)

https://www.samhsa.gov/medication-assisted-treatment/become-buprenorphine-waivered-practitioner

1 Baumgartner and Radley, 2021. 2. SAMHSA 2014; 3 Hutchinson AnnFM 2014; 4 Andrilla AnnFM 2017

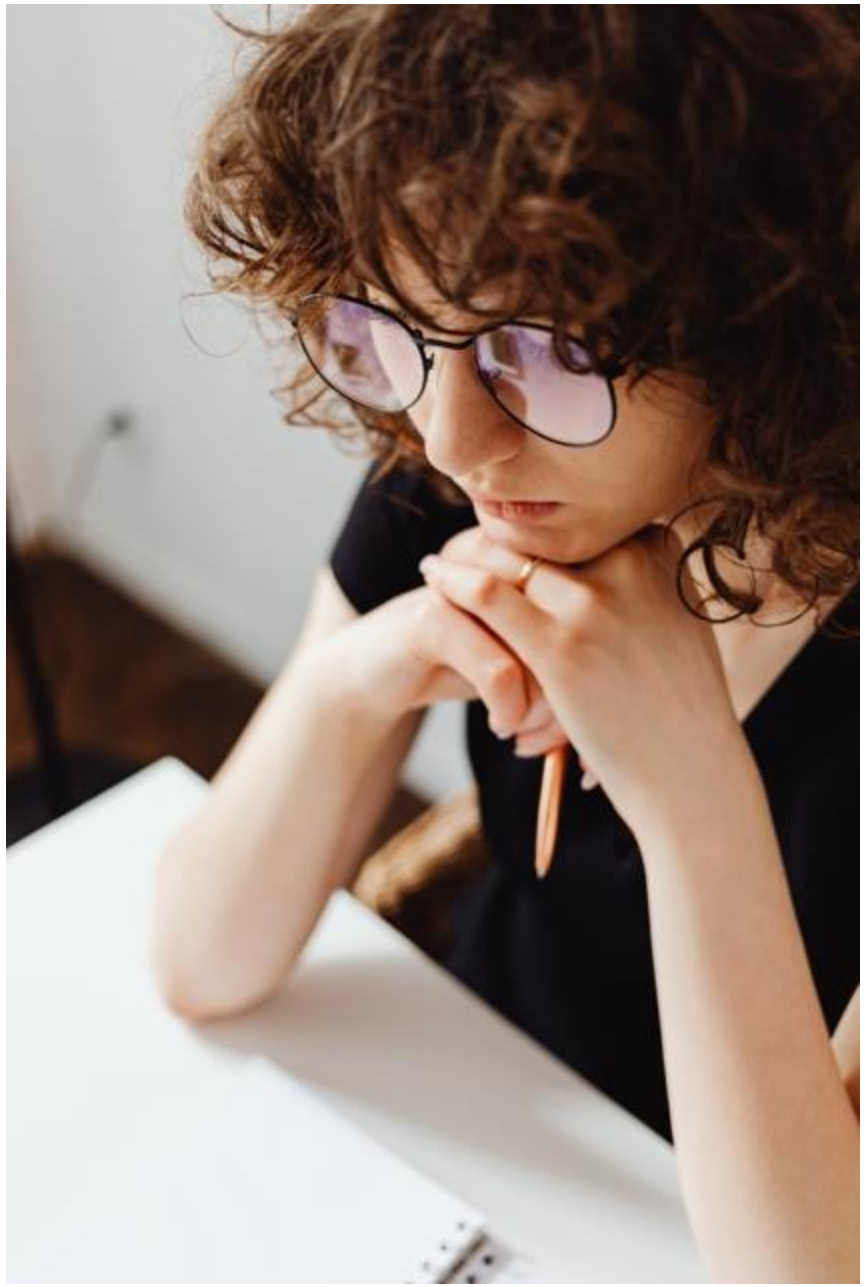
Why will Opioid Wizard be useful?

Example patient: Erin

- Erin [not her real name] is a middle-aged woman from a small town.
- She has chronic pain and mental health problems. She lost her parent to an opioid overdose.
- Erin was prescribed opioids for pain as a teenager, and became addicted. Another provider cut her off cold turkey – but did not help her find help. She began buying opioids from her parent.

"I was afraid of going cold turkey."

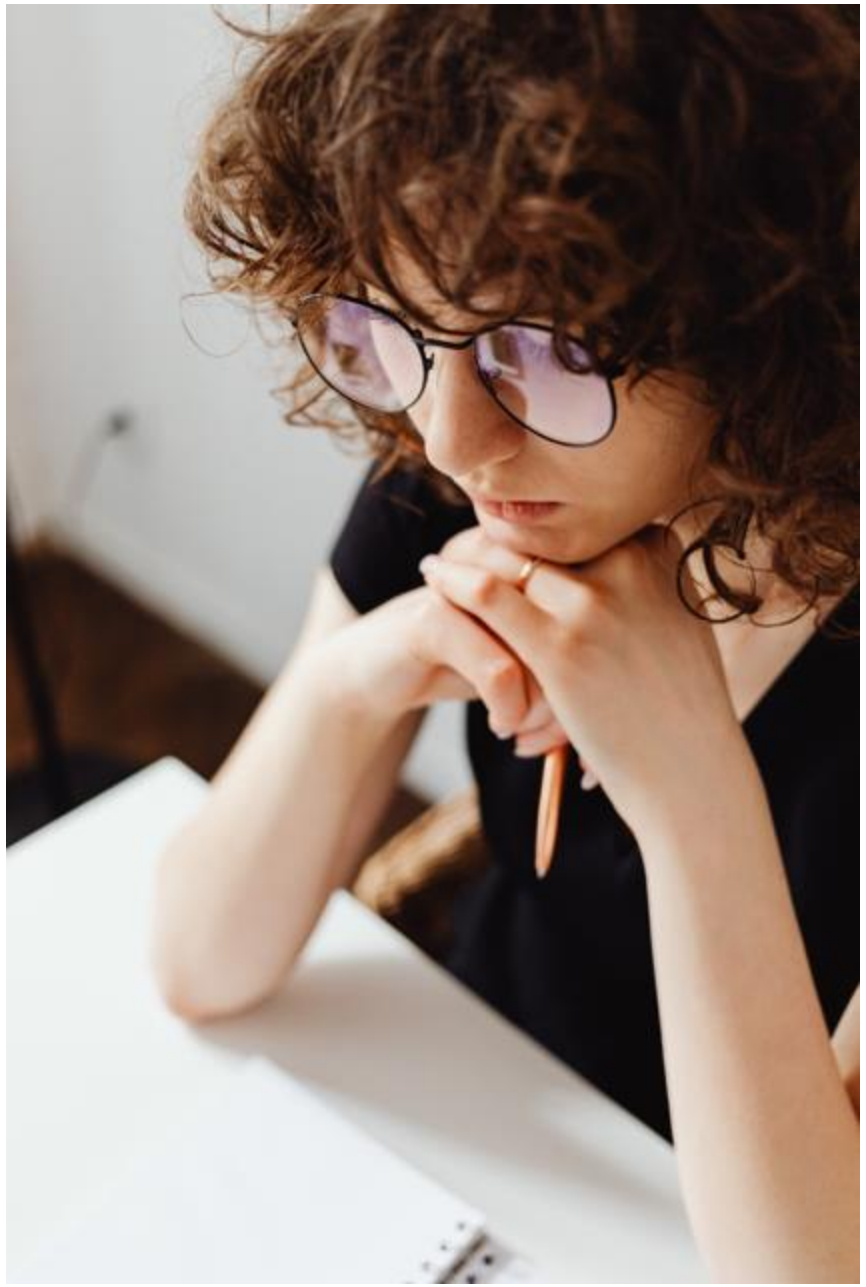
"I feel so gross that [buying pills from parent] even happened."



Why will Opioid Wizard be useful?

Example patient: Erin

- Erin realized she had a problem but was afraid to talk to her doctor about it.
- She found a suboxone clinic on her own and has been on suboxone for 5 years.
- She wishes she had known her PCP was a safe person who could have helped her, instead of doing it on her own.

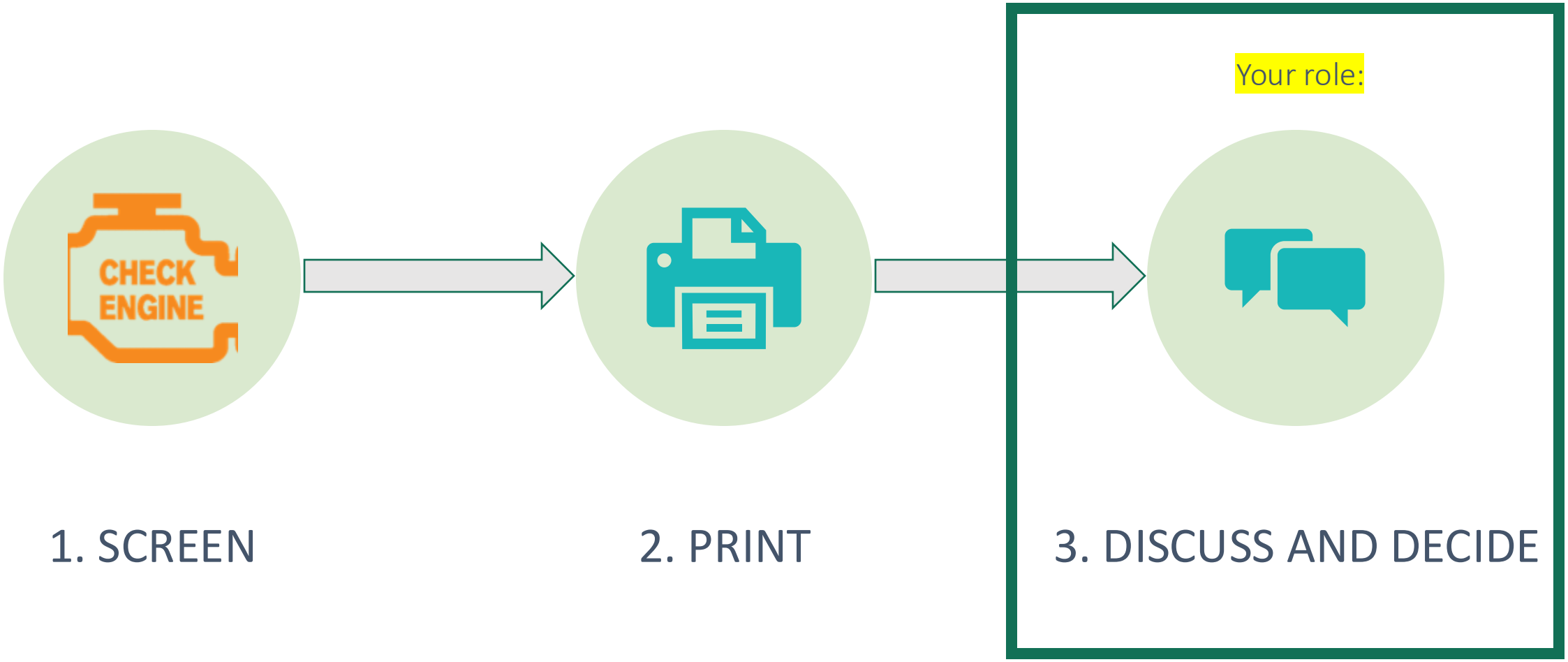


"I was beyond embarrassed to tell [PCP] because of what happened previously…I told him after I started on suboxone…I guess he could have helped me find a suboxone doctor."

"It's really been a blessing for me that [suboxone] helps so much, and I didn't become any more destructive than I was."

Opioid Wizard won't be time consuming

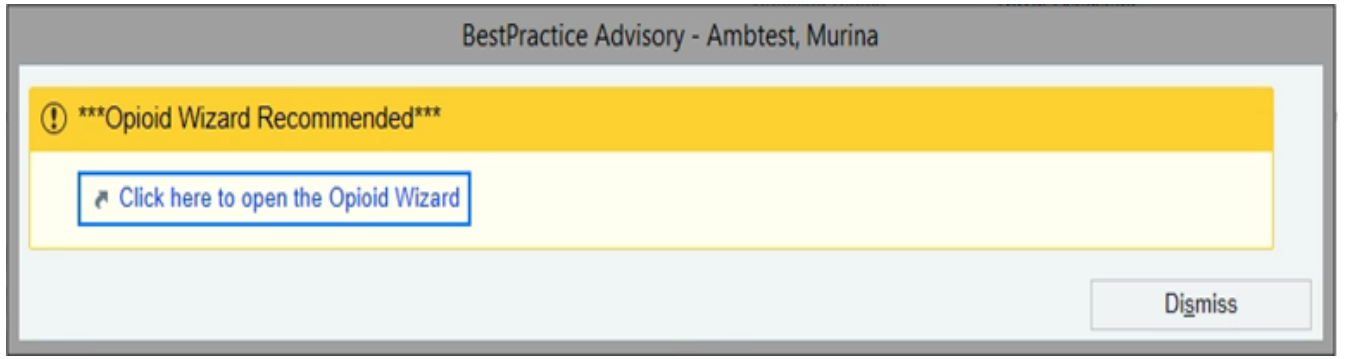
Opioid Wizard: Process



Opioid Wizard won't be time consuming

Step 1: Screen

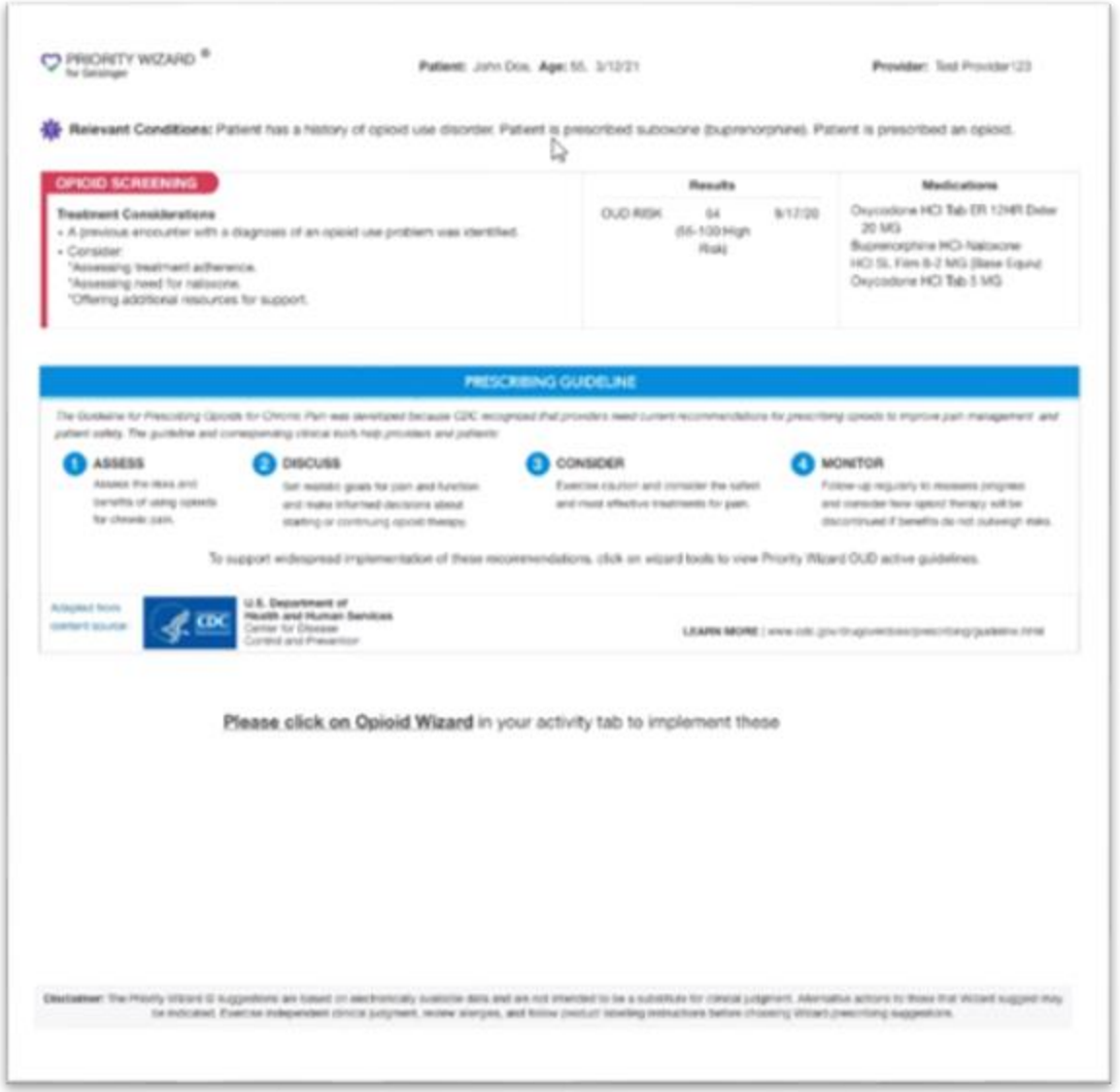
- **Rooming visit:**
  - Opioid Wizard runs on patient. IF patient score >55, flag appears.
  - For patients 18-75 AND either:
    - OUD diagnosis or opioid overdose
    - OR
    - OUD risk (Epic Risk Score)
    - Then -
    - BPA for rooming staff:
    - **Approximately 2% of all visits**



Opioid Wizard won't be time consuming

Rooming staff: Step 2: Print Provider Sheet

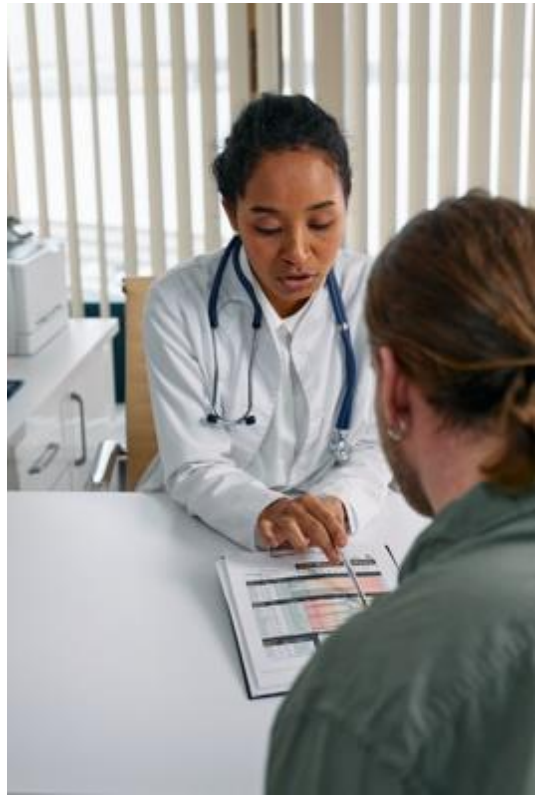
Printed and attached to exam room door for Provider by Rooming Staff



Opioid Wizard won't be time consuming

Provider: Step 3: Discuss and decide

Talk to patient about concerns



Use Opioid Wizard as guide

Tool to help clinicians feel comfortable

This is where you matter the most

How to frame uncomfortable conversations with empathy and non-judgment:

1. **NORMALIZE: Normalize the problem by using universality statements:**
   - "Many people find it difficult to talk about opioid use. I know it's uncomfortable. I'm not here to judge."

2. **TRANSPARENCY: Explain why you are asking:**
   - "I need to ask you some questions about opioid use. This will help me provide you with the best care."

3. **PERMISSION: Ask permission to ask:**
   - "Is it okay if I ask you these questions?"

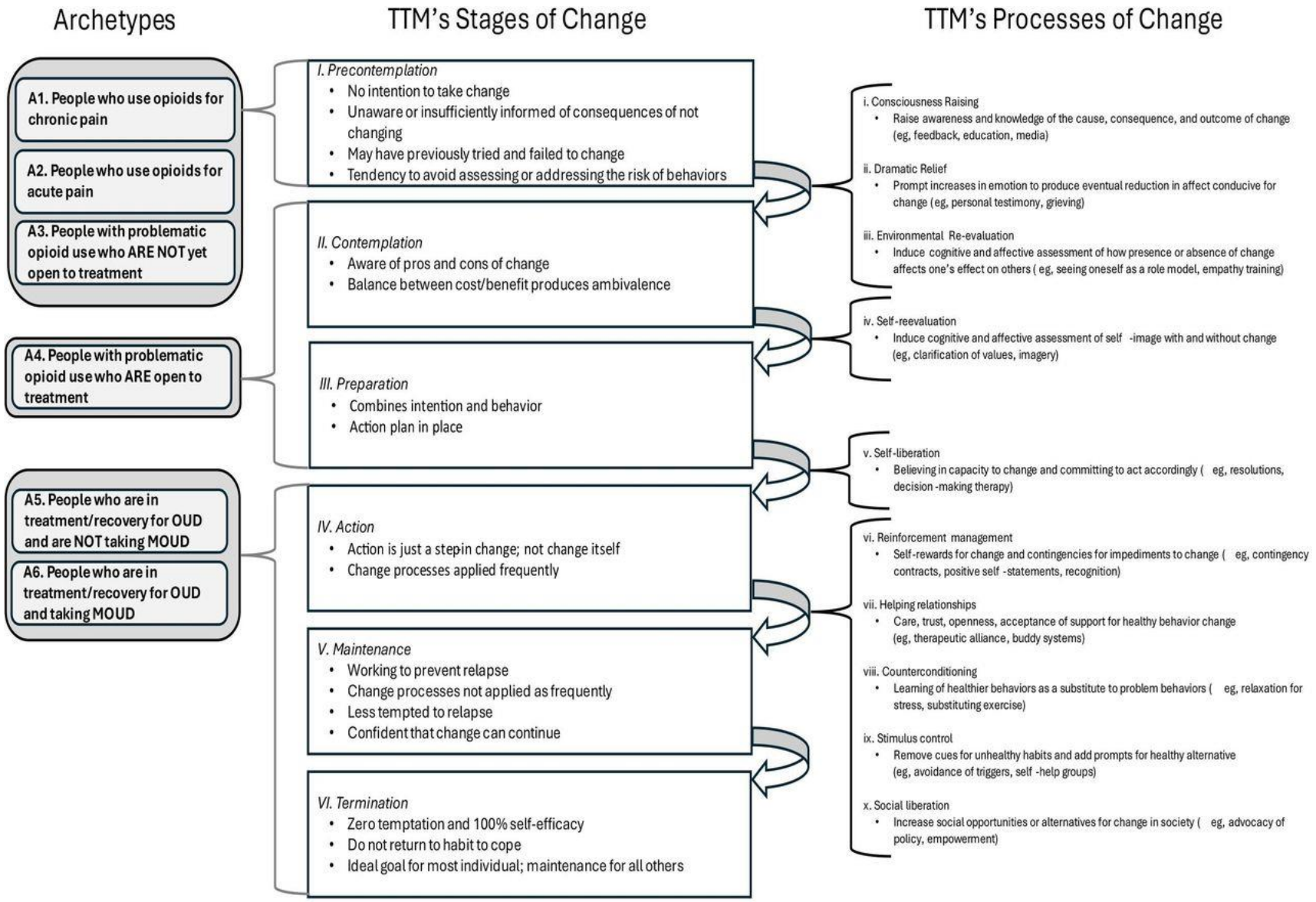
Source: McBride, R. (2010) "Talking to Patients About Sensitive Topics: Techniques for Increasing the Reliability of Patient Self-report." NIDA Centers of Excellence for Physician Information. https://www.drugabuse.gov/sites/default/files/sensitive-topics-handout_0.pdf

….and beyond to inform patient - clinician interactions about opioids!

Olson AW, Bucaloiu A, Allen CI, Tusing LD, Henzler-Buckingham HA, Gregor CM, Freitag LA, Hooker SA, Rossom RC, Solberg LI, Wright EA, Haller IV, Romagnoli KM. 'Do they care?': a qualitative examination of patient perspectives on primary care clinician communication related to opioids in the USA. BMJ Open. 2025 Jan 7;15(1):e090462. doi: 10.1136/bmjopen-2024-090462. PMID: 39773800; PMCID: PMC11749487.

Sub study:
Archetypes to transtheoretical model of health behavior change

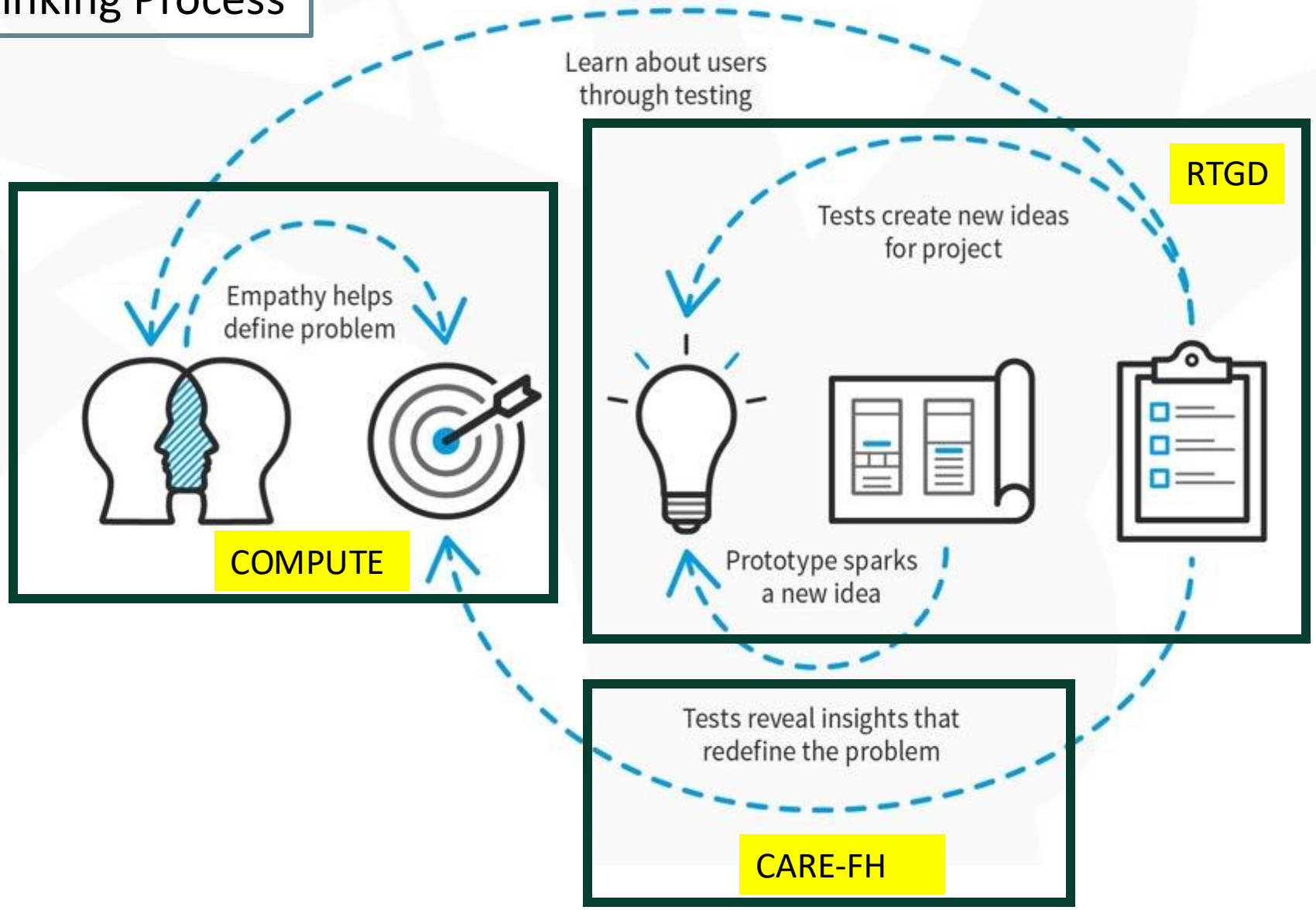
"The updated six-archetype framework may help clinicians and practice staff more effectively navigate conversations with patients diagnosed with or at high risk for OUD by considering how to discuss opioid risks and use opioid-related terminology preferred by the patient."



Anthony W Olson et al. BMJ Open 2025;15:e090462

BMJ Open

Design Thinking Process



Source: https://www.interaction-design.org/literature/article/5-stages-in-the-design-thinking-process

CARE-FH

Collaborative Approach to Reach Everyone with Familial Hypercholesterolemia

PI: Samuel Gidding

Supported by the National Heart, Lung, And Blood Institute of the National Institutes of Health under Award Number R61HL161775 and R33HL161775.

Photo by Karolina Grabowska: https://www.pexels.com/photo/set-of-medical-products-for-taking-and-checking-blood-from-vein-4226922/

Collaborative Approach to Reach Everyone with Familial Hypercholesterolemia: CARE-FH

NHLBI R33 HL161775

1-year prep: $422,934

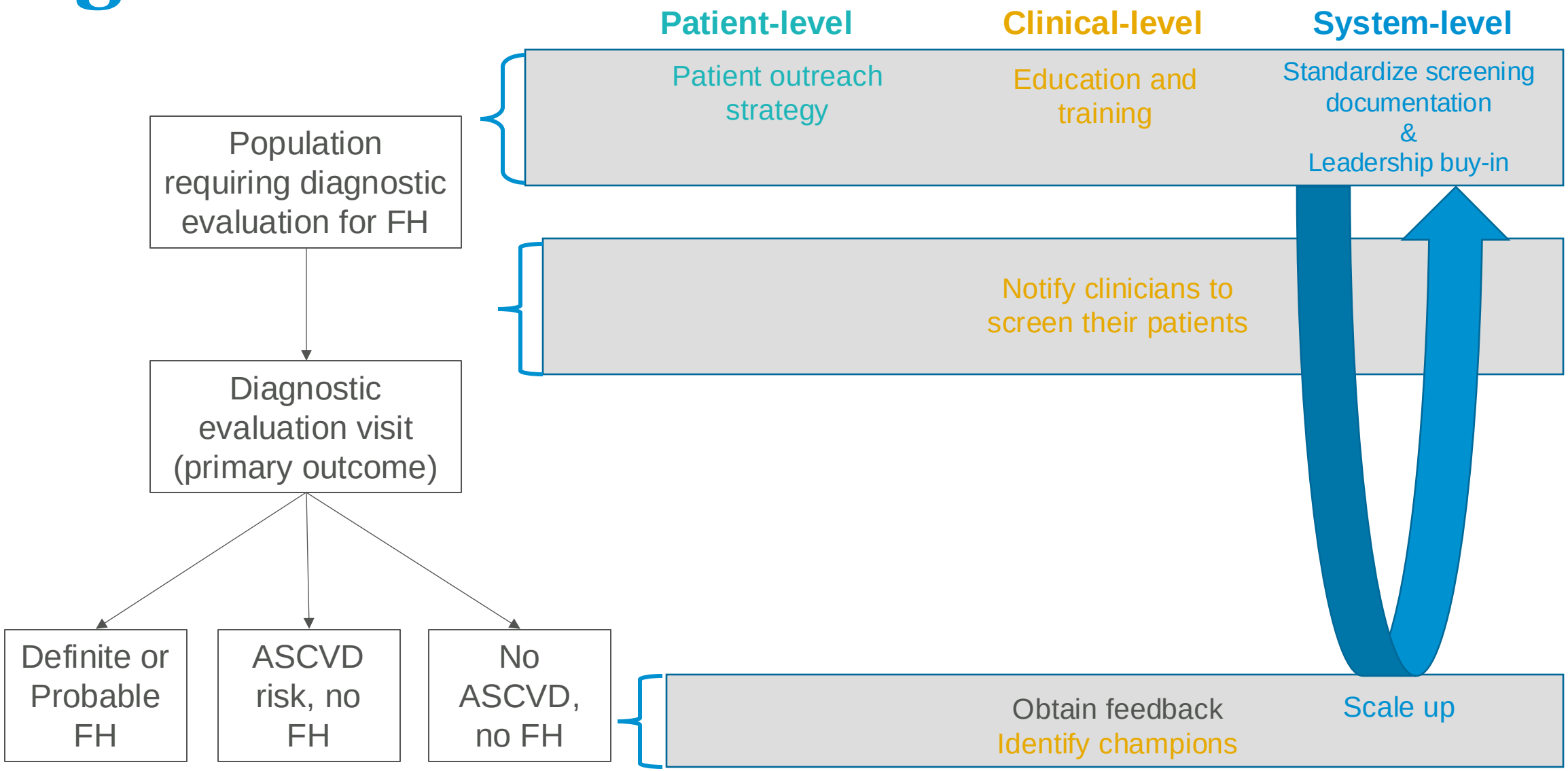
4-year clinical trial:$2,916,836

- Design and implement a clinical trial to screen for FH in primary care using implementation science methodologies
- Improve identification of adults and children with FH

Mission

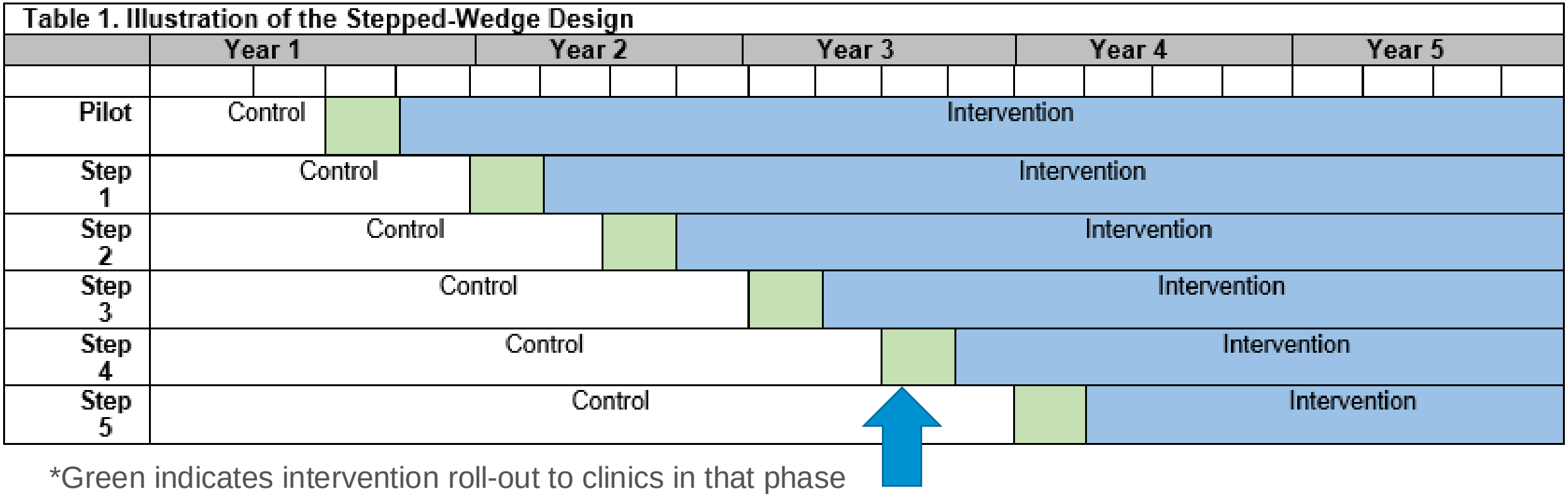
Improve diagnosis	Identify 30-50% with genetic FH in the Geisinger population
Demonstrate Value	Demonstrate the high value of engaging primary care clinicians in the diagnostic evaluation process for FH
Utilize new methods	Use implementation science and human centered design to create novel strategies

Diagnostic Evaluation



Clinical trial design

Table 1. Illustration of the Stepped-Wedge Design



*Green indicates intervention roll-out to clinics in that phase

Implementation Science Learnings

- Developed electronic health record tools
- Simplified genetic test ordering
- Cholesterol screening identified as a Quality Metric for pediatrics
- Unable to do point of care cholesterol testing
- Pilot site roll out during trial development phase and presentation of results has provided valuable feedback
- Conducted lipid learning sessions
- Managing IT resources has led to many delays

Methods

Research Question: What is the **current state** of screening, diagnosis, and treatment of FH at Geisinger?

- Clinicians who play a role in screening, diagnosing, and/or treating FH at Geisinger
  - Primary care and family medicine doctors
  - Pediatricians
  - Adult cardiologists
  - Pediatric cardiologists
  - Lipid specialists
- Contextual inquiries: observations of clinician in clinic paired with indepth qualitative interviews.
- Participants **designed their ideal experience** of receiving communication about genetic testing.
- Thematic and content data analysis using rapid framework analysis and affinity diagramming
- Output: journey maps

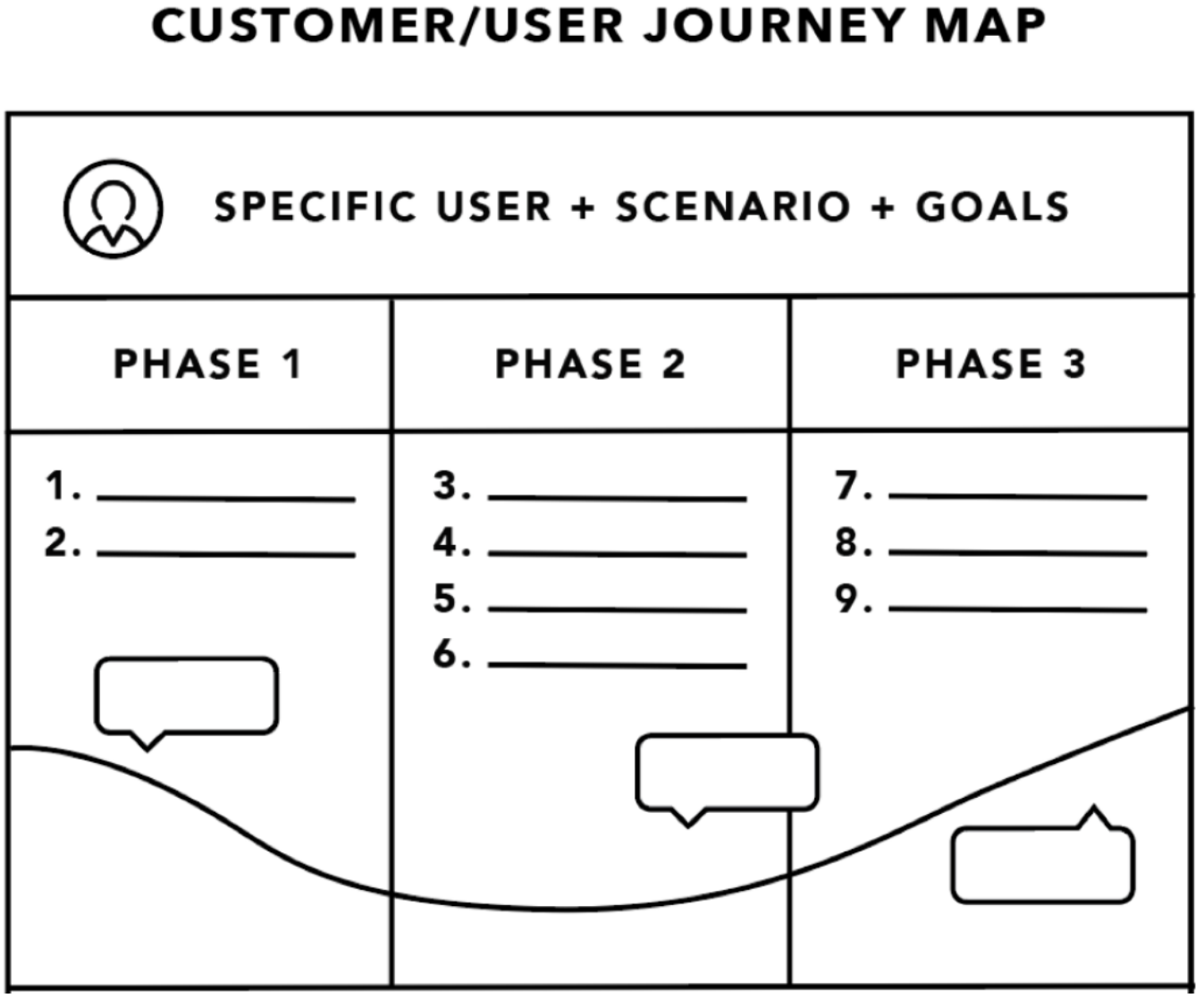
Photo by Karolina Grabowska: https://www.pexels.com/photo/medical-stethoscope-with-red-paper-heart-on-white-surface-4386467/

Journey maps

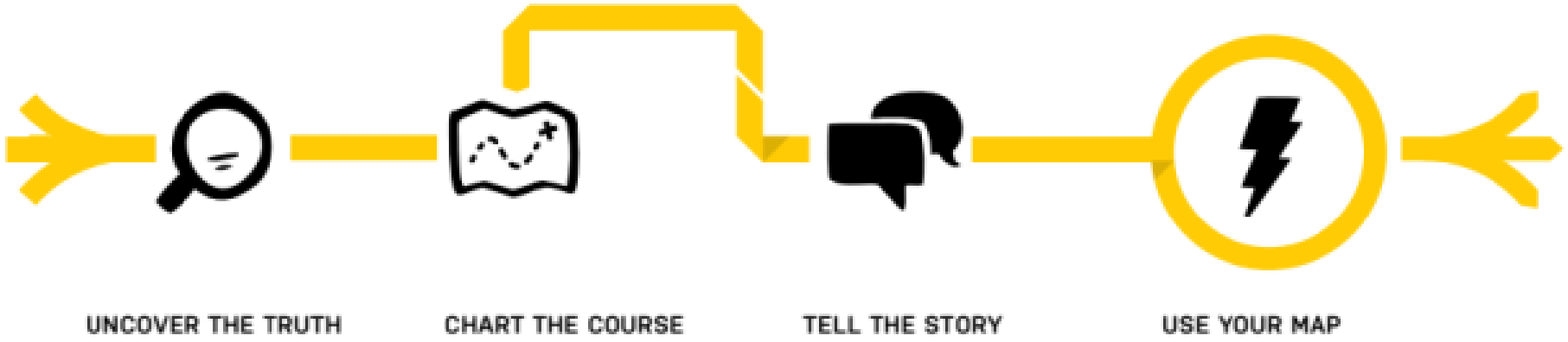
Definition: A journey map is a visualization of the process that a person goes through in order to accomplish a goal.

– Nielsen/Norman

Value: Identify **opportunities** for improvement and innovation of the current state



Journey mapping of FH screening and diagnosis process



- Contextual Inquiries with clinicians – observations paired with interviews
  - Lipid Clinic
  - Primary Care
  - Cardiology
- Analyze and synthesize findings
- Journey map of clinicians diagnosing patients with FH
- Identify areas of opportunity to innovate and improve the experience of diagnosing and caring for patients with FH
- Use map to communicate with stakeholders during the design and implementation of a clinical trial

Primary care journey map

	Identification	Diagnosis	Treatment
Feeling	Positive: I'm busy in primary care, but this is the job! I wish I had more time to cover everything they need today. Negative	I think this person might have FH – let's do some tests.	What should I do to treat someone who has FH? Is it different from regular high cholesterol?

Activities	• Wellness visit
	• Follow-up appointment
	• Received positive result via MyCode
	• Experienced cardiac event
		• Takes family history
		  • Looks for early MIs, deaths, heart disease
		• Orders lipid panel
		  • Looking for elevated lipids (most did not specify levels)
		• Refers to cardiology
		  • In some cases
			• Medications
			  • PCSK9 inhibitors
			  • Atorvastatin (homozygous patients)
			  • Ezetimibe (Zetia)
			  • High intensity statins
			  • Rosuvastatin highest dose
			  • Highest dose statin and Zetia
			  • Immediate statins >190 LDL
			• Lifestyle modifications
			• Regular lab testing (lipids)
			• Follow-up appointments
			• Family lab and genetic testing

Resources Used	• Exam room
	• EHR
		• Exam room
		• EHR
		• Phlebotomy
		• Lab
		• Cardiology
		• Information resources
		  • UpToDate
		  • AHA guidelines
		  • NLA educational resources
		  • Scientific literature
		  • Blogs
		  • Colleagues
			• EHR
			• Colleagues
			  • Cardiologists
			  • Nutritionists/dieticians
			  • Pharmacists
			  • Nurse practitioners
			  • Geneticists
			  • Genetic counselors
			• Guidelines
			  • AHA guidelines
			  • Gidding criteria
			• Patient materials
			  • Lifestyle modifications
			• Genetic testing

Thinking	• How do I prioritize in 20 minutes? • I didn't know the lipid screening was recommended for every 9–11-year-old, regardless of weight • I wonder if they might have high cholesterol • It's hard to get parents to agree to a blood draw.	• What is the right lipid panel to order? • Will they get the screening done? • This person has a strong family history of early heart disease • Is there a workup for this? • Should I send them to genetics or to cardiology? • What will the genetic test cost? • Who else needs to know about this diagnosis?	• How do I order a genetic test? • What is the right medication to put them on? At what dose? • How do I convince them to take this seriously? • Should I refer them to cardiology? • What is the LDL level I should be aiming for? • How do I convince the family to do lipid screening and genetic testing? • How do I ensure they come to follow-up appointments?

Who:
-Primary care
-Internal medicine
-Family medicine
-Pediatrics

Barriers:
-Lack of time
-Low FH screening rates
-Resistance to blood tests
-Not recognizing importance
-Not knowing correct work up for FH
-Not knowing treatment guidelines for FH
-Emphasizing lifestyle modifications

Facilitators:
-MyCode
-Colleagues
-Multi-disciplinary care

Cardiology Journey Map

	Identification	Diagnosis	Treatment
Feeling	Positive I love being a cardiologist, but I want to prevent future heart disease so I'm not needed! I wish this person was screened earlier. Negative	I think this person might have FH – let's do some tests.	I'm so glad we can treat FH and prevent future illness. I need to treat FH aggressively and get LDL levels as low as possible to prevent early heart disease and death.

Activities	• Referred by PCP or pediatrician
	  • High cholesterol from lipid panel
	  • Treatment resistant
	  • Positive genetic test for FH
		• Takes family history
		  • Looks for early Mis, deaths, heart disease
		• Orders lipid panel
		  • Looking for elevated lipids, LDL >190
			• Medications
			  • Immediate statins >190 LDL
			  • PCSK9 inhibitors
			• Regular lab testing (lipids)
			• Follow-up appointments
			• Family lab and genetic testing
			• Goal: LDL as low as possible. <90 or <79

Resources used	• Exam room
	• EHR
	• Lipid panel results
	  • Would like advanced lipid panels
	• Genetic test results
	• Prior medications
	• Cardiac event at a young age
		• Exam room
		• EHR
		• Phlebotomy
		• Lab
		• Cardiology
		• Information resources
		  • AHA guidelines
		  • NLA educational resources
		  • Scientific literature
		  • Colleagues
			• EHR
			• Colleagues
			  • Nutritionists/dieticians
			  • Pharmacists
			  • Nurse practitioners
			  • Geneticists
			  • Genetic counselors
			• Guidelines
			  • AHA guidelines
			  • NLA guidelines
			  • Gidding criteria
			• Patient materials
			  • Lifestyle modifications
			• Genetic testing
			  • Invitae

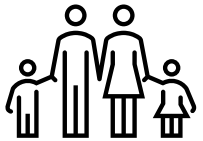
Thinking	• I wish this person had been identified earlier • This cardiac event could have been prevented	• I wish I could order an advanced lipid panel for more detail • This person has a strong family history of early heart disease • What will the genetic test cost? • I hope this person talks to their family about being tested, too	• Let's get this patient's LDL as low as possible. Below 90 or even 70. • How do I convince them to take this seriously? • How do I ensure they come to follow-up appointments? • How do I treat the whole family? • FH isn't a free pass to eat anything you want, but lifestyle modifications can only do so much in FH

Who:
-Adult cardiology
-Pediatric cardiology

Barriers:
-Low FH screening rates
-Low FH knowledge in primary care

Facilitators:
-MyCode
-PSCK9 inhibitors
-Guidelines
-Multi-disciplinary care

Problems identified -> implementation strategies



Patient level strategies

Problem: Patients aren't aware of FH

Solution: Patient outreach strategy

Reach out directly patient populations, through a targeted mass media campaign to recommend screening for high cholesterol FH and to discuss with their PCP

Clinician level strategies

Problem: Clinicians are unfamiliar with FH

Solution: Education and training

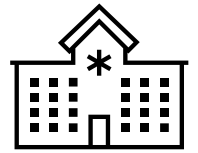
Study staff will provide CME accredited training to clinicians and distribute helpful educational materials

Clinician level strategies

Problem: Clinicians are not notified about FH

Solution: Clinician notification

Notify clinicians that their patients need to be screened for FH



Healthcare system strategies

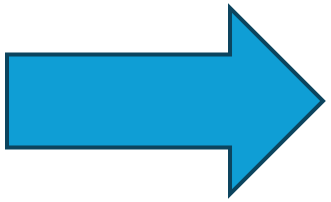
Problem: Limited time during appointments for FH

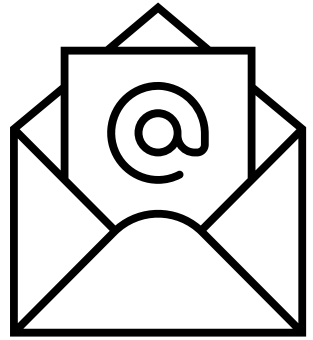
Solution: Incentivize FH screening

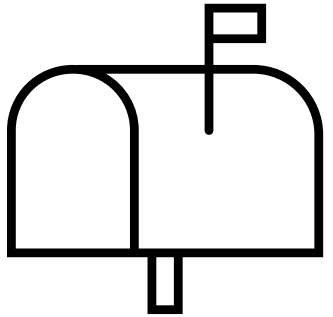
Offer incentives to clinicians to screen for FH or obtain lipid panel

Patient-level: Patient outreach strategy

- Post-MI
- FH genetic variant
- High recorded LDL-C values
- No recorded LDL-C value in past 5 years







Data prepped 2 weeks; Sent out 1 week prior to next month

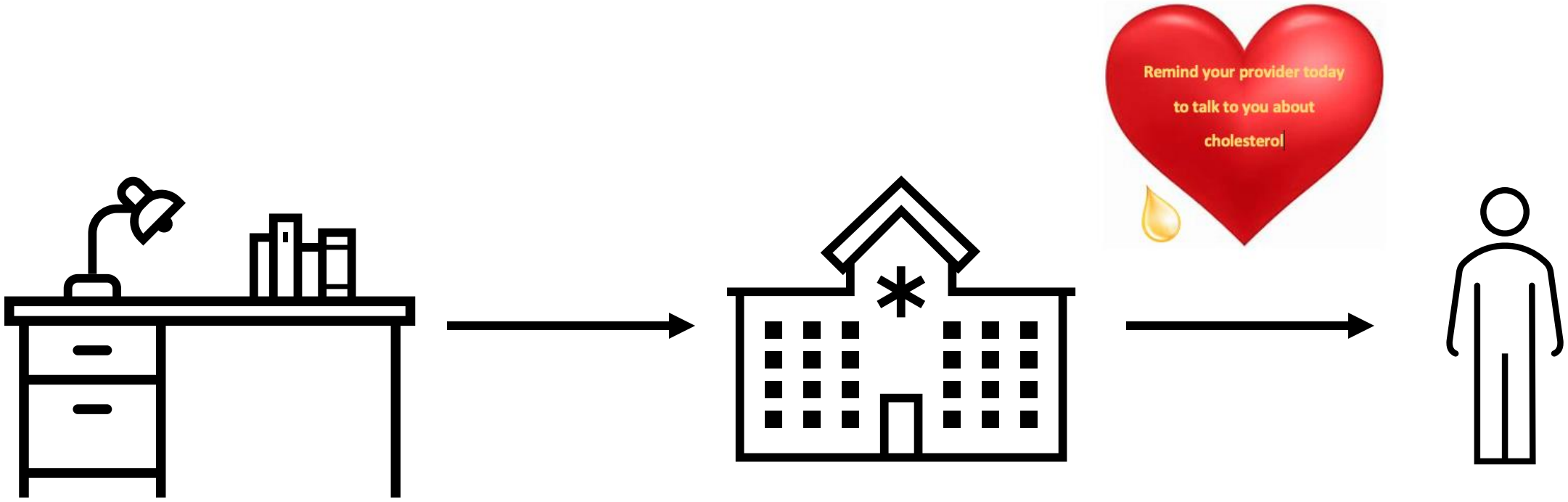
Clinical-level: FH Education and Training

Scientific and medical information

Screening, diagnosis, and management in primary care

System-level electronic health record tools to improve documentation

Clinical-level: Clinician notification



What about when the grant ends?

Clinical Sustainability Action Tool: measures organizational factors contributing to long-term sustainability in clinical settings to inform opportunities to increase intervention sustainability

CSAT Subdomain	Intervention opportunity	Intervention adjustments
Engaged Staff and Leadership	System leadership has increased awareness of importance of FH screening and diagnosis.	**System change**: FH screening is being added as an internal clinical quality metric in primary care.
Engaged Partners	Same as above.	Same as above.
Organizational Readiness	Same as above.	Same as above.
Workflow Integration	Clinicians indicate workflow process for ordering genetic testing in pediatrics is suboptimal. Clinicians suggested improvements to informatics tools to improve workflow integration and clinician use of tools.	**Workflow change**: Pediatrics patients will be referred directly to medical genetics, instead of pediatricians ordering the tests themselves. **Informatics tools changes**: Changes in progress with informatics team to the FH Best Practice Alert (BPA), FH Smart Set, Smart Phrases, and Dutch Lipid Clinical Network (DLCN) criteria calculator.
Implementation and Training	Persistent clinician knowledge gaps exist after training.	**Clinician training change**: Educational materials for clinicians have been made more specific, with additional information added about the genetic testing process, lipoprotein A, and differences between FH and hypertriglyceridemia.
Monitoring and Evaluation	Not yet assessed.	N/a.
Outcomes and Effectiveness	Care gap letters sent to patients did not demonstrate effectiveness in rate of FH screening and diagnosis.	**Patient communication change**: Care gap letters are no longer being mailed to patients.

Thank you!
Questions?

Contact me:
kmromagnoli@geisinger.edu

Geisinger College of Health Sciences

Google Scholar:
https://scholar.google.com/citations?user=_KBrxXsAAAAJ&hl=en&inst=2438481962696796233

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