

PCORnet: Health Plan Research Network Data Linkage and Patient Engagement with Patient- Powered Research Networks

Kevin Haynes, PharmD, MSCE
Principal Scientist
November 15, 2019

Agenda

- Background
- Study Design
- Results
- Patient Stakeholder Structured Interviews

Disclosure: I am an employee of Anthem, Inc.
This work was funded by PCORI
PCORI Award: ME-1503-28785

HealthCore: Abiy Agiro, Xiaoxue Chen, Judith J Stephenson, Biruk Eshete

ABOUT: Rebecca Sutphen, Beth Clark, Cristina Burroughs

ArthritisPower: W. Benjamin Nowell, Jeffrey R. Curtis

Multiple Sclerosis PPRN: Sara Loud, Robert McBurney

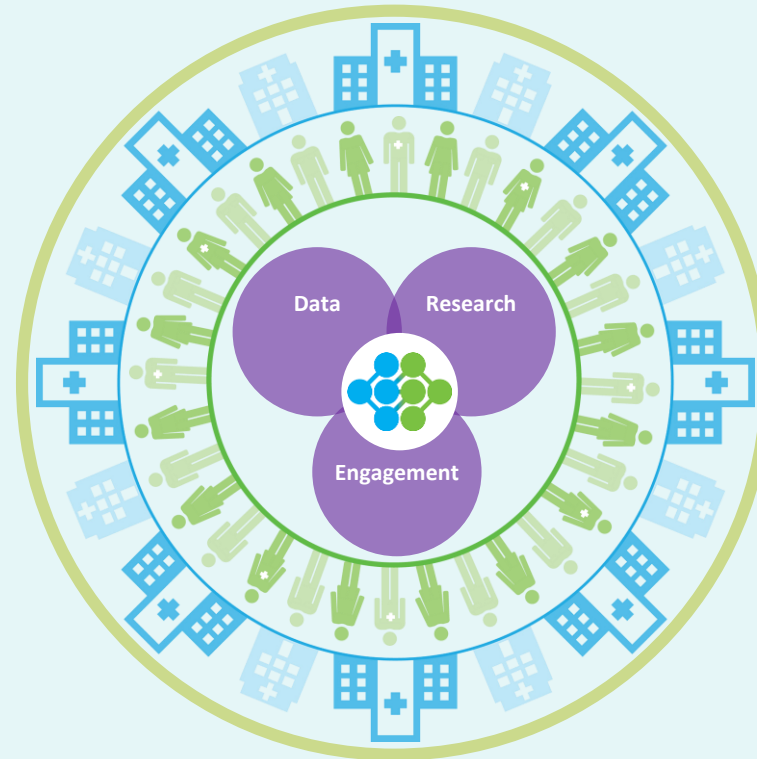
Vasculitis PPRN: Peter A. Merkel, Antoine G. Sreih, Kalen Young

Background

PCORnet: PPRNs, and HPRNs

One of the biggest challenges facing healthcare today is reducing gaps in evidence necessary to improve health outcomes.

PCORnet is a “network of networks” that harnesses the power of partnerships



PCORnet 1.0

Clinical
Research
Networks
(CRNs)

+

Health Plan
Research
Networks
(HPRNs)

+

Patient-
Powered
Research
Networks
(PPRNs)

+

Coordinating
Center

=

A national
infrastructure for
people-centered
clinical research

PPRN Highlights

- Participating organizations and leadership teams include patients, advocacy groups, clinicians, academic centers, practice-based research networks
- Strong understanding of patient engagement
- PPRNs represent different models of partnerships and levels of infrastructure, represent over 100 diseases overall
 - Approximately 50% are focused on rare diseases
 - Phase II brought in two community focused PPRNs
- Variety in populations represented (including children and under-served communities)
- Varying capabilities with respect to developing research data

Patient-Powered Research Networks

- **University of South Florida (ABOUT Network)**
- **Global Health Living Foundation (ArthritisPower)**
- *Mayo Clinic (AD PCPRN)*
- *Crohn's and Colitis Foundation of America (CCFA Partners)*
- *University of California Los Angeles (CPPRN)*
- *Genetic Alliance (CENA)*
- *COPD Foundation (COPD PPRN)*
- **Parent Project Muscular Dystrophy (DuchenneConnect)**
- **University of California San Francisco (Health eHeart Alliance)**
- *Cincinnati Children's Hospital Medical Center (ImproveCareNow)*
- *Kennedy Krieger Institute (IAN)*
- *Massachusetts General Hospital (MOOD)*
- **Accelerated Cure Project for Multiple Sclerosis (MS-PPRN)**
- **Arbor Research Collaborative for Health (NephCure)**
- *Duke University (PARTNERS)*
- *Phelan-McDermid Syndrome Foundation (PMS_DN)*
- *Immune Deficiency Foundation (PI-CONNECT)*
- *University of California San Francisco (PRIDENet)*
- *Epilepsy Foundation (REN)*
- **University of Pennsylvania (The Vasculitis PPRN)**

HPRN, Anthem/HealthCore

Our research is fueled by expertise, relationships, and scientific rigor—driven by the industries we serve—always grounded in unparalleled data assets.



Government



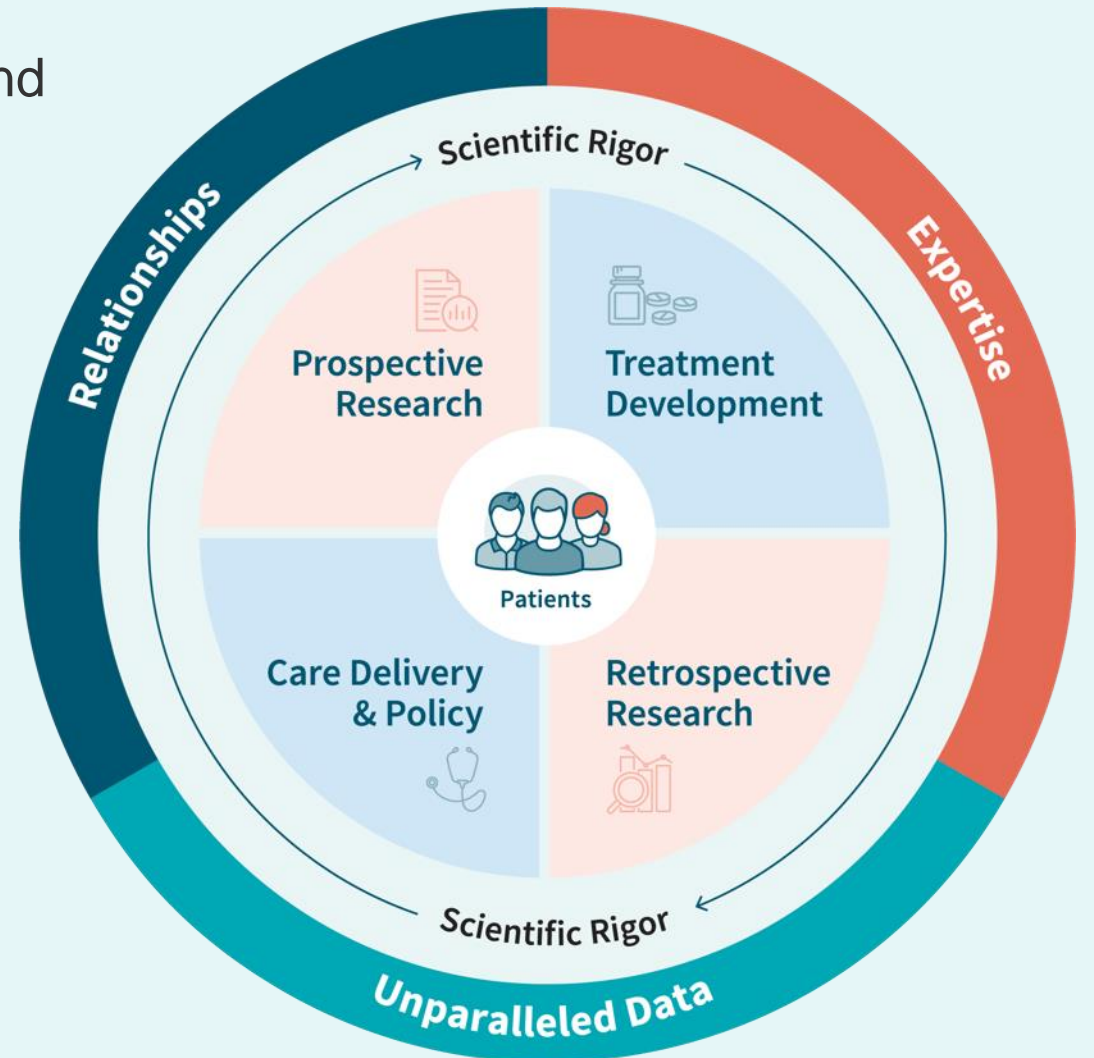
Life Sciences



Collaborations



Payors



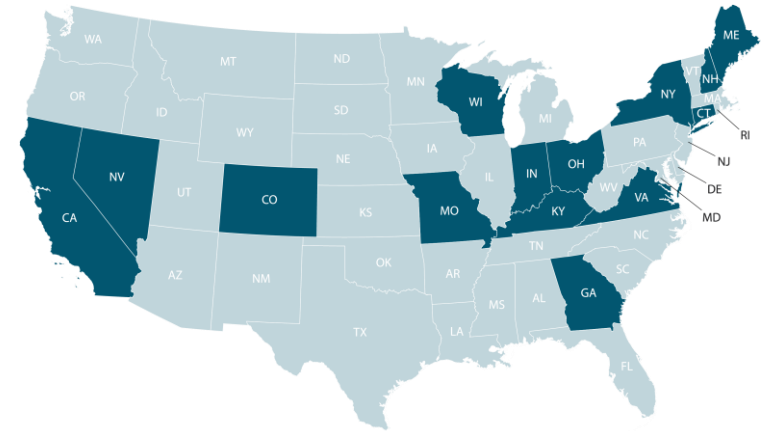
Anthem: A Health Benefits Leader

Membership



1 in 8 Americans
are medical members in
affiliated health plans

**Anthem
states**



Subsidiaries



HealthCore: By the Numbers

Data Assets



40+M total medical members
in affiliated health plans



73M total lives served

Medical
& Pharmacy
Claims



+

Lab
Results



+

Clinical
Data



+

Patient-
Reported
Outcomes



+

Healthcare
Utilization



+

Social
Determinants
of Health



+

Costs
Data



multiple integrated data assets
providing a more complete picture of patient care

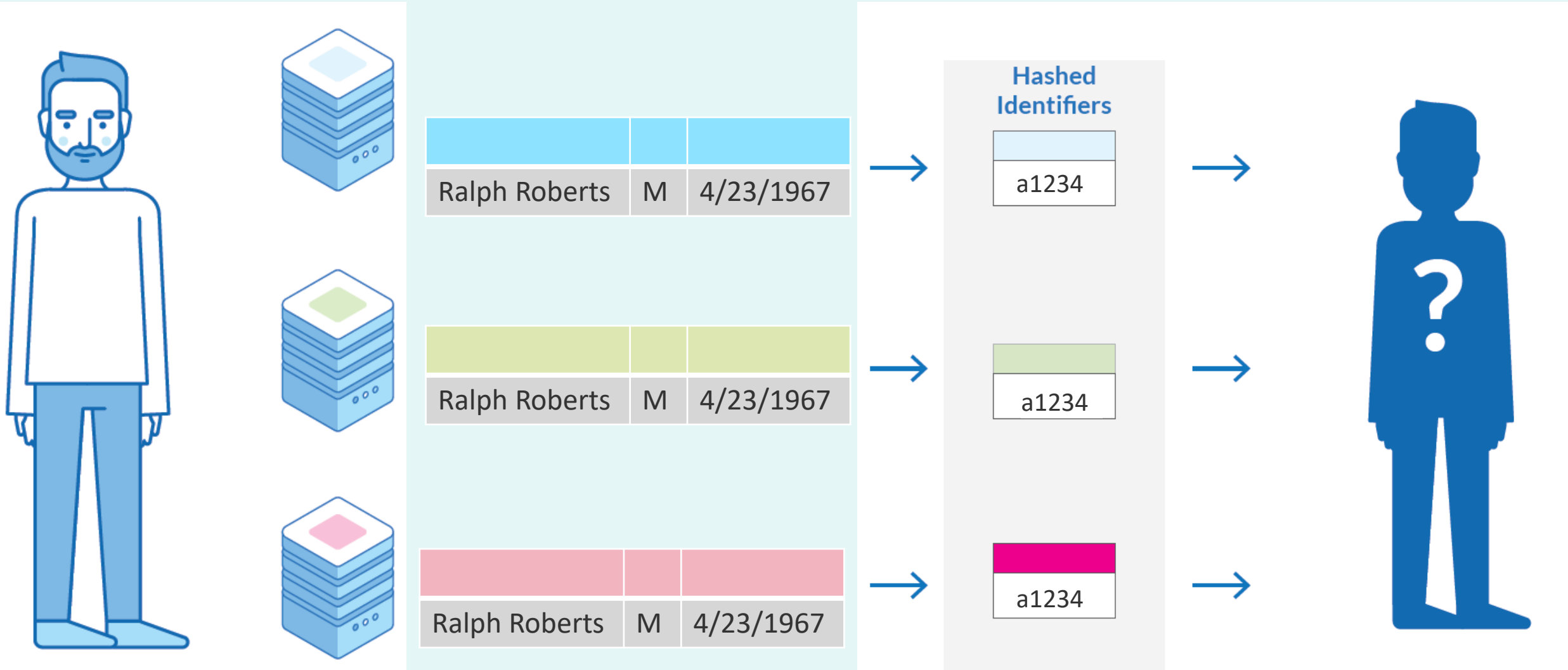
Study Design

Concept, Data Linkage, Computable Phenotype,
Recruitment

Study Concept



Privacy Preserving Record Linkage



Aim 1: Computable Phenotype Validation

- To assess the confirmation rate and validate PPRN computable phenotypes using members already engaged in PPRN research utilizing administrative claims data.
 - Anonymous linkage
 - Computable phenotype algorithm refinement
 - Confirmation rate $A/(A+C)$

	PPRN Member	Not PPRN Member
Anthem member identified with computable phenotype of interest	A	B
Anthem member not identified with computable phenotype of interest	C	D

Aim 2: Pragmatic Engagement Research Trial

- to quantify health plan members' registration rates in any of four disease-specific PPRNs following the deployment of two common payer-initiated outreach methods for inviting member participation: mail and email
- Health Plan data were queried to identify members who met strict definition computable phenotypes between December 1, 2017 and February 28, 2018
- The primary outcome of interest was registration in a disease-specific PPRN, defined through privacy-preserving record linkage

	Participate	Did not Participate
Randomized to US mail	A	B
Randomized to email	C	D

Results

Computable Phenotype and Recruitment

Journal of the American Medical Informatics Association, 26(7), 2019, 594–602

doi: 10.1093/jamia/ocz012

Advance Access Publication Date: 2 April 2019

Research and Applications



Research and Applications

Data linkages between patient-powered research networks and health plans: a foundation for collaborative research

HPRN-PPRN Record Linkage

Journal of the American Medical Informatics Association, 2019, Vol. 26, No. 7

597

Table 1. Patient counts for PPRN-HIRE matching

Steps	Description	All PPRNs	ABOUT Network	ArthritisPower	iConquerMS	VPPRN
1	PPRN memberships	24 131	6513	11 343	4176	2099
2	PPRN memberships obtained and hashed	21 616 (90%)	5665 (87%)	11 343 (100%)	2509 (60%)	2099 (100%)
3	PPRN memberships linked with 14 health plans (ie, final linkage result)	4 487 (21%)	1435 (25%)	2166 (19%)	543 (22%)	343 (16%)
4	Linked PPRN members who were commercially insured including Medicare Advantage (ie, final study sample)	3546 (16%)	1228 (22%)	1600 (14%)	444 (18%)	276 (13%)
5	Linked PPRN members with at least 5 years of uninterrupted insurance coverage (ie, sample size for sensitivity analysis on members)	684 (3%)	187 (3%)	314 (3%)	116 (5%)	67 (3%)

Values are n (%) using step 2 as denominator. HIRE data contained claims from 14 health plans.

ABOUT: American BRCA Outcomes and Utilization of Testing Network; HIRE: HealthCore Integrated Research Environment; PPRN = patient-powered research network; VPPRN = vasculitis patient-powered research network.

Aim 1: Computable Phenotype Confirmation Rates

Journal of the American Medical Informatics Association, 2019, Vol. 26, No. 7

599

Table 3. Confirmation rates of claims-based diagnosis as percentage of self-reported diagnosis from PPRN members regardless of duration of insurance coverage

PPRN	Diagnosis from PPRN Member Self-Report	Denominator	Broad definition confirmation in claims		Strict definition confirmation in claims	
			n	% (95% CI)	n	% (95% CI)
ABOUT Network	PPRN memberships overlapping with health plans	1228				
	Breast or Ovarian Cancer	519	373	72 (68-76)	309	60 (55-64)
	Breast Cancer	474	311	66 (61-70)	275	58 (53-63)
	Ovarian Cancer	62	42	68 (55-79)	39	63 (50-75)
ArthritisPower	PPRN memberships overlapping with health plans	1600				
	Arthritis or Psoriasis	935	467	50 (49-53)	323	35 (32-38)
	Rheumatoid arthritis	699	357	52 (48-56)	257	37 (33-41)
	Psoriatic arthritis	147	76	52 (43-60)	46	31 (24-40)
	Psoriasis	139	64	47 (38-55)	22	16 (10-23)
	PPRN memberships overlapping with health plans	444				
iConquerMS	Multiple sclerosis	444	335	75 (71-79)	323	73 (68-77)
VPPRN	Number of PPRN membership overlapping with health plans	276				
	Vasculitis	177	118	67 (59-74)	74	42 (35-49)

Confirmation rate for claims-based computable phenotype using patient self-reported diagnosis as the reference standard. No minimum duration of health plan enrollment required.

ABOUT : American BRCA Outcomes and Utilization of Testing; CI: confidence interval; PPRN: patient powered research network; VPPRN = vasculitis patient-powered research network.

Aim 1: Computable Phenotype Confirmation Rates ≥ 5 yr

Table 4. Confirmation rates of claims-based diagnosis as percentage of self-reported diagnosis for PPRN members with 5 or more years of uninterrupted insurance coverage

PPRNs	Diagnosis From PPRN Member Self-Report	Denominator N	Broad Definition Confirmation in Claims		Strict Definition Confirmation in Claims	
			n	% (95% CI)	n	% (95% CI)
ABOUT Network	PPRN memberships overlapping with health plans	187				
	Breast or ovarian cancer	78	71	91 (82-96)	70	90 (80-96)
	Breast cancer	72	65	90 (81-96)	64	89 (79-95)
	Ovarian cancer	11	11	100 (72-100)	10	91 (59-100)
ArthritisPower	PPRN memberships overlapping with health plans	314				
	Arthritis or psoriasis	199	133	67 (60-73)	115	58 (51-65)
	Rheumatoid arthritis	160	107	67 (59-74)	94	59 (51-67)
	Psoriatic arthritis	30	20	67 (47-83)	14	47 (28-66)
	Psoriasis	19	15	79 (54-94)	9	47 (25-71)
iConquerMS	PPRN memberships overlapping with health plans	116				
	Multiple sclerosis	116	108	93 (87-97)	107	92 (86-96)
VPPRN	PPRN memberships overlapping with health plans	67				
	Vasculitis	51	41	80 (67-90)	26	51 (37-65)

Confirmation rate for claims-based computable phenotype using patient self-reported diagnosis as the reference standard. Five or more years of health plan enrollment was required.

ABOUT: American BRCA Outcomes and Utilization of Testing; PPRN: patient powered research network; VPPRN = vasculitis patient-powered research network.

Aim 2: Health Plan Outreach

- Currently enrolled eligible health Plan members
- Strict computable phenotype definition of one of four PPRNs,
- Both email and mail contact information

N=29,145	Mail group		Email group	
	N	%	N	%
Total sample for outreach after randomization	14,571	100%	14,574	100%
Undeliverable addresses	9	0.1%	3,546	24.3%
Do not contact (DNC)	728	5.0%	823	5.7%
Deliverable address	13,834	94.9%	10,205	70.0%

Aim 2: Health Plan Outreach

As randomized analysis	Mail group (N=14,571)			Email group (N=14,574)			P value
	N	%	95% CI	N	%	95% CI	
Member engaged by the intervention	78	0.54%	0.42% - 0.67%	24	0.16%	0.11% - 0.25%	<.001
As treated analysis	13,834			10,205			
Member engaged by the intervention	78	0.56%	0.45% - 0.70%	23	0.23%	0.14% - 0.34%	<.001

	Mail group			Email group			
	n	N	%	n	N	%	P values
ABOUT	29	6,777	0.43%	4	6,778	0.06%	<0.0001
ArthritisPower	39	6,489	0.60%	15	6,490	0.23%	0.0001
MS-PPRN	7	1,180	0.59%	4	1,180	0.34%	0.548
VPPRN	3	125	2.40%	1	126	0.79%	0.37

Conclusions

- **Linkage between PPRNs and HPRN, worked, TWICE**
- **Moderate concordance between patient self-report disease status in a PPRN matching to clinical claims diagnoses**
- **Health plan engagement was modest. US Postal Service mail worked better than email**

Patient Structured Interviews

Semi-Structured Interviews with 9 PPRN Patient Leaders

- 60-minute telephone interview open-ended questions following a discussion guide
- A descriptive thematic content analysis using standard qualitative methods
- **Objective:** to better understand how patients from PPRNs value HPRN research, outreach from HPRNs, data privacy and linkage needs, and how health plans can better serve patients through patient-oriented research
 - Patient representatives' understanding and perceptions of the value of HPRNs
 - Patient representatives' points of view about HPRN outreach regarding the involvement of PPRNs in research opportunities
 - Patient representatives' feelings about data linkage opportunities and methods to preserve patient privacy
 - Opportunities for HPRNs to better serve patients through patient-oriented research

Theme 1: Value of HPRNs and Collaboration

“The health plan has access to the data, as opposed to relying on patients’ memory or recollections. It brings higher quality data for study.”

“You really can get a 360 view of what’s happening to the patient that is so much richer than what you can get if you only get one of the three types of data.”

“There is this huge concern and ongoing distrust of health plans in general, a dislike of the process that’s put in place by health plans with regards to clinical care and coverage of services that then makes people less likely to trust them when their name is on research.”

Theme 1: Value of HPRNs and Collaboration

Access data not otherwise available

- Help with the recruitment of patients
- Identify hard to reach population (rare disease)

Broader view of the patient

- Cross health system data
- Resource for clinical trial

Trust

- Concern that research data could be used to limit access
- uncertain political climate, participants were concerned with the future of protections for pre-existing conditions

Theme 2: HPRN Outreach

"I am more informed than many, many families or many individuals that are dealing with this type of a condition, and not to be arrogant about it, I guess I would look at it quite different than an individual who may be less informed."

"I am self-employed, so I change health plans every year, so I have no emotional relationship to my insurance company."

"I know we were very happy with the mailing that went out for the PPRN. We did see some increase in numbers. We saw some people that actually picked out that box, 'How did you hear about us' and they put in that they'd gotten a mailing from their insurer."

Theme 2: HPRN Outreach

Patients may be skeptical about outreach

- Average patient would have concerns and questions if approached by their health plan to participate in research
- Questions around health plan motivations

Lack of a meaningful relationship with health plans

- Health plans are also known to put their own interests first by restricting access, increasing premiums and denying coverage.
- Relationships with health plans are short term

Multiple forms of communication

- Mail was mostly junk and it would most likely end up in the trash
- Follow-up must convey credibility and importance and may even need to be an in-person meeting or phone call

Theme 3: Data Linkage and Patient Privacy

“There’s a lot of concerns that the laws are going to change and they’re going to deny me coverage or they’re going to put me in a high-risk pool. Until we can stabilize health insurance coverage and guarantee that people will have coverage regardless, affordable coverage, I think we’re still going to run up against some of these issues.”

“I need to know for sure it’s anonymous. I need to know about unprotected data breaches and that if the data is subpoenaed, it would not be shared.”

“Getting different systems to talk to each other is trying to get Apple and Windows and Linux to all talk to each other. It’s worse than a family reunion. Good luck. They were all built independently, they’re all built with different protections, and you’ve got to break that protection to share the data, which makes you vulnerable to attack.”

Theme 3: Data Linkage and Patient Privacy

Level of concern varies depending on the information

- Patients want to be able to control what is shared and understand how it is shared, how is it used, and how it is being protected
- Specific treatment information, prescribing information, diagnosis, test results are considered to be the most useful but also the most concerning from a privacy standpoint

Consents need to be specific

- Inform patients know exactly what and how information will be shared
- Assure patient privacy and protection through de-identifiers that are clearly explained
- Shorter, easier to read format

Logistics of different platforms communicating

- Unsure where data would be linked and stored
- Fears about the potential consequences of identification ranged from discrimination to being denied life insurance to being classified as high risk and being denied coverage

Theme 4: Opportunities for HPRNs

“We have questions that aren’t being answered and that can probably be more easily answered if you involved us. We have questions you haven’t thought of.”

“We’re really in this era where patient-focused or patient-centered research is sort of the catch phrase right now. That’s why we have PPRNs. One of the big demands from that is that patients want to know what were the results, what happened, whether it be good or bad. ...Depending on what type of research it was, if you can align with a PPRN or a patient advocacy group that represents that community, you’ve got to build an audience there to disseminate the results from that research. Ultimately, it could make a difference in health care decisions or outcomes.”

Theme 4: Opportunities for HPRNs

Bi-directional engagement

- Help PPRNs identify important research issues
- Listen to PPRN patients on what research topics are of interest to them

Sharing knowledge

- Sharing their knowledge and awareness of programs, trials, and other resources that are available
- Data and knowledge sharing will build trust between organizations

Ongoing Work

IBD Partners PCORI PaCR: Health Plan Recruitment

- Aim 1: adults with CD who are starting ustekinumab or vedolizumab after no response to an anti-TNF medicine
- Aim 2: adults with UC who are starting tofacitinib or vedolizumab after no response to an anti-TNF medicine

Comparing Treatments for Patients with Inflammatory Bowel Disease Who Don't Respond to Anti-TNF Therapy

✉ Sign Up for Updates to This Study



Project Summary

PCORI supports Patient-Powered Research Networks (PPRNs), communities of patients participating in clinical research, as part of the National Patient-Centered Clinical Research Network (PCORnet). In 2017, PCORI launched an initiative on [Partnerships to Conduct Research within PCORnet](#) to support the PPRNs in conducting comparative clinical effectiveness research on questions that are important to patients and other stakeholders. The initiative funded this project and others.



How can we help you?



Work with PCORnet. Visit us at www.pcornet.org to get the relationship started.

Discussion

Kevin Haynes, PharmD, MSCE
khaynes@healthcore.com

**Finding evidence and truth
at the core of healthcare.**

HealthC^öre