CDRN - PPRN Collaborations
September 29th, 2015

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Outline

• Description of Mid-South CDRN, AR-POWER PPRN, and CCFA PPRN
• Current CDRN-PPRN Collaborations
• Opportunities for collaboration and lessons learned
• Challenges to partnership
• Discussion
**CDRNs and PPRNs**

**Clinical Data Research Networks (CDRNs)** are system-based networks that originate in healthcare systems, such as hospitals, health plans, or practice-based networks, and securely collect health information during the routine course of patient care.

**Patient-Powered Research Networks (PPRNs)** are networks operated and governed by groups of patients and their partners and are focused on a particular condition or population and whose members are interested in sharing health information and participating in research.
Opportunities for Synergy

CDRN
• Detailed clinical data on large numbers of patients across many conditions
• Primary focus is data
• Requires engagement of health systems, clinicians, patients
• Accumulate patients through clinical care

PPRN
• Condition/population-specific patient generated health data (i.e. surveys, mHealth)
• Primary focus on patient engagement
• Accumulate participants through referrals
Opportunities for Synergy

- PPRN
  - Patient-reported
    - Exposures
    - Health behaviors
    - Outcomes

- CDRN
  - Medical Records/Claims
    - Test results
    - Medications
    - Comorbidities
    - Limited Patient reported data

mid-south clinical data research network
Opportunities for Synergy

PPRN
- Patient-reported
  - Exposures
  - Health behaviors
  - Outcomes

CDRN
- Medical Records/Claims
  - Test results
  - Medications
  - Comorbidities
  - Limited Patient reported data
Mid-South CDRN Clinical Reach

Vanderbilt Medical Center: hospitals, >100 clinics engaging 2 million patients

Meharry/Metro General Hospital: 100,000 patients

VHAN: 7 health systems, 34+ hospitals, 350+ clinics engaging >3 million patients

Greenway: 1600 clinics engaging 14 million patients

Phase II will add Carolinas Collaborative
VU Data Aggregation

CLINICAL ENTERPRISE

A. clinic notes/forms
B. identified (RD)
C. de-identified (SD)

INFORMATICS METHODS DEVELOPMENT

Examples: Natural Language Processing, Pattern Recognition, Automated Phenotyping, Automated Study Recruitment Eligibility, End User Research Integration Methods, Anonymization and Reidentifiability

RESEARCH ENTERPRISE

D. BioVU

E. Tool: RECORD COUNTER
F. Tool: SD SYNTHETIC DERIVATIVE
G. Tool: SUBJECT LOCATOR
H. Tool: RD RESEARCH DERIVATIVE

mid-south clinical data research network
PCORI Common Data Model V 3.0

**CONDITION**  v2.0
A condition represents a patient’s diagnosed and self-reported health conditions and diseases. The patient’s medical history and current state may both be represented.

**DEATH**  v3.0
Reported mortality information for patients.

**DEATH_CAUSE**  v3.0
The individual causes associated with a reported death.

**DEMOGRAPHIC**  v1.0
Demographics record the direct attributes of individual patients.

**DIAGNOSIS**  v1.0
Diagnosis codes indicate the results of diagnostic processes and medical coding within healthcare delivery.

**DISPENSING**  v2.0
Outpatient pharmacy dispensing, such as prescriptions filled through a neighborhood pharmacy with a claim paid by an insurer. Outpatient dispensing is not commonly captured within healthcare systems.

**ENROLLMENT**  v1.0
Enrollment is a concept that defines a period of time during which all medically-attended events are expected to be observed. This concept is often insurance-based, but other methods of defining enrollment are possible.

**ENCOUNTER**  v1.0
Encounters are interactions between patients and providers within the context of healthcare delivery.

**HARVEST**  v3.0
Attributes associated with the specific PCORnet datamart implementation.

**LAB_RESULT_CM**  v2.0
Laboratory result Common Measures (CM) use specific types of quantitative and qualitative measurements from blood and other body specimens. These standardized measures are defined in the same way across all PCORnet networks.

**PCORNET_TRIAL**  v3.0
Patients who are enrolled in PCORnet clinical trials.

**PRESCRIBING**  v3.0
Provider orders for medication dispensing and/or administration.

**PRO_CM**  v2.0
Patient-Reported Outcome (PRO) Common Measures (CM) are standardized measures that are defined in the same way across all PCORnet networks. Each measure recorded at the individual item level: an individual question/statement, paired with its standardized response options.

**PROCEDURES**  v1.0
Procedure codes indicate the discreet medical interventions and diagnostic testing, such as surgical procedures, administered within healthcare delivery.

**VITAL**  v1.0
Vital signs (such as height, weight, and blood pressure) directly measure an individual’s current state of attributes.
Additional Linkage for “Complete” Data

- Linkage to TN State Health Data (hospitalizations, birth/death data)
- Linkage to TennCare Data
- Linkage to CMS Data (RESDAC, CMMI data)
- Linkage to Vanderbilt Health Plan (Aetna) health data (claims and PBM data)
- Surescripts
- Linkage to Home Health and Nursing Home Data
- Linkage to NC BC/BS Data and NC Medicaid Data
- Linkage to SC Claims data HSSC
Distributed Data Model

1. Queries and Analytic Software Packages from PCORI
2. CDRN returns Counts and Aggregate resulting data

Mid-South CDRN

PCORnet

PopMedNet
Novel Informatics Tools

- Tools for quickly running queries and analyzing electronic health data
- Tools for identifying and contacting patients
  - Email (300,000 at VUMC)
  - My Research at Vanderbilt
  - PeopleLynk (Greenway)
- New electronic consent process
- Expanded survey tools for collection of patient reported outcomes (via web/mobile platforms, automated phone, embedded video/audio, etc.)
- Integration of PROMIS measures into REDCAP
- Electronic payment processes for study participation
- Potential integration of patient survey data into the EHR for clinical use
- Expansion of clinical decision support tools
Patient Facing Tools

PCORI Pre-screening

What is your first name? 

What is your last name? 

What is your date of birth? 

In the past 5 years, have you received treatment at a Vanderbilt health clinic or hospital? 

Screener: Which study are you screening for? 

Determine Eligibility

Email blast to >10,000 Vanderbilt patients!

Mid-South Clinical Data Research Network

Patient Centered Outcomes Research

Vanderbilt University Medical Center is conducting research to help understand what factors influence decisions you make about your health. We invite you to take part in this survey because you have received care at Vanderbilt or other affiliated medical centers.

This survey includes questions about:
- Your background
- Your health habits
- Your willingness to participate in certain types of research studies in the future

Your participation in this survey is totally voluntary. If you choose not to participate, it will not affect your health care or opportunity to participate in future research. Your responses will be kept private. With your permission, we may contact you about future studies you may be interested in. If you participate, we would like to collect some information from your medical chart, such as your height, weight, blood pressure, lab test results, and other health information now and in the future.

There is very little risk involved in this survey. The main risk is that some questions may make you feel uncomfortable. You may choose not to answer any of the questions.

The survey will take about 15-20 minutes and you will receive $10 for your time and participation. If you have any questions or comments regarding the survey, feel free to contact:

David Crenshaw, Study Coordinator
HealthyWeightStudy@Vanderbilt.edu
(615) 343-1765

Thank you!

Date of Birth

By checking this box and entering my birthdate, I agree to participate in this survey and I give permission to have the research team link my answers to my health information that is stored electronically by my doctor.

By checking this box, I am refusing to participate in this survey.

Start Survey
Process for accessing resources

https://midsouthcdrn.mc.vanderbilt.edu/

Welcome to the Mid-South Clinical Data Research Network

The Southern US has the highest rates of obesity, diabetes, cardiovascular disease, and significant rates of health disparities. The Mid-South Clinical Data Research Network (CDRN) centered at Vanderbilt University (VU) focuses on health systems in the Southern United States, but will include the capacity to reach a national population.
Services Provided

- Development and validation of computable phenotypes
- Prep-to-research and simple queries of CDM
- Observational research of de-identified data
- Observational research of identifiable data
- CER and Pragmatic interventions at patient or system (clinic, hospital, etc) level
- Informatics, IRB, Regulatory support
- Access to patients and sites in CDRN
- Stakeholder Engagement
ARTHRITIS POWER
Research by patients, for patients.
A CreakyJoints® initiative.
mid-south clinical data research network

Creaky Joints

GLOBAL HEALTHY LIVING FOUNDATION
Patient Governor Group

Kelly C. Rockton, IL

Shantana H. Bridgeport, CT

Marta G. Trujillo Alto, Puerto Rico

Britt J. Burbank, CA

Rachelle C.-H. Chesterfield, MI

Bryan L. Scottsdale, AZ

Jon A. Olathe, KS

Whitney W. Birmingham, AL

Leslie R. New York, NY

Elizabeth F. New York, NY

Carole W. Kona, HI
JOIN ARTHRITIS POWER

CreakyJoints has teamed up with rheumatology researchers at the University of Alabama at Birmingham to launch Arthritis Power, a non-profit, patient-inspired and patient-managed research initiative.
Recruitment Efforts

THE POWER IS YOURS!
Join the First Ever Patient-Led, Patient-Centered Research Database for Arthritis Patients

What is Arthritis Power? Arthritis Power is the first ever patient-led, patient generated, patient centered research registry for arthritis. Using the web-based and mobile application (“app”), patients from around the world are tracking symptoms to support future research to compare treatments, identify new treatments and, perhaps, find elusive cures.

Who’s in for? Arthritis Power is open to patients living with arthritis and other related conditions of the joints, bones or skin, such as:
- Ankylosing Spondylitis
- Fibromyalgia
- Gout
- Crohn’s related (Enteropathic) Arthritis
- Juvenile Idiopathic Arthritis
- Lupus
- Myositis (Inflammation of the Muscles)

How Do I Get Started? 1. Visit the ArthritisPower.org website or download the mobile app. 2. Read and sign the consent. 3. Fill out the registration questionnaire. 4. Start tracking!

What does patient-centered mean? Patient centered research means investigating topics that are important to patients and helping them make informed health care decisions. Arthritis Power is led by a committee of Patient Governors who help identify research needs for study development and prioritize research requests from the CreakyJoints patient community around the world. Different studies will be listed in the Arthritis Power app and each patient can decide when and how to participate.

How will collected data be used? Registered patients will enter their personal data into the Arthritis Power mobile application or web-based equivalent. The information you share will be securely stored and used by university-based researchers and the Arthritis Power patient community. Research results will be shared on the Arthritis Power app.

Who created Arthritis Power? CreakyJoints, the online, non-profit, patient support community for arthritis patients with over 80,000 members created Arthritis Power. Technical support and human subjects protection oversight are provided by the University of Alabama at Birmingham.

TRACK, SHARE, SEND & DISCUSS: Arthritis Power participants can easily share and send their personal health information to their doctors via the “My Reports” function in the app. An emailed report lists current medications and selected symptoms data. Empower yourself to lead conversations with your healthcare team!

JOIN ARTHRITIS POWER TODAY: www.ArthritisPower.org

Dear Friend,

Living with arthritis (or other conditions of the bones, joints or skin) can sometimes be difficult. We understand and we’re passionate about helping.

We are excited to tell you about Arthritis Power, the first ever patient-led, patient-centered research registry for arthritis and other conditions of the bones, joints or skin. Created by CreakyJoints, the trusted online resource for patients, Arthritis Power was designed for you as an app on your smartphone or on the web at www.ArthritisPower.org. It can help you keep track of your symptoms and take control of your condition. You can even choose to participate in other research projects through Arthritis Power. By using Arthritis Power, you are joining thousands of others already donating their information to support future research to compare treatments, identify new treatments and, perhaps, find elusive cures.

Your participation in Arthritis Power is voluntary and there is no cost to you for participating. If you decide to join Arthritis Power, you will be asked if you want to share your Vanderbilt electronic health records with the registry for scientific studies and to make these records available for your easy viewing. Your electronic health information will remain secure and confidential.

We hope you’ll consider downloading this app or using it online. Visit www.ArthritisPower.org or see the attached flyer to learn more.

Please let your provider know if you have any questions.

Best wishes,

Leslie J. Crofford, MD
Professor of Medicine
Director, Division of Rheumatology & Immunology

Seth D. Ginsberg
Arthritis Patient
Co-Founder, CreakyJoints

For any questions or comments about this letter please contact
Dr. Bebo Tanner or
Shari Barto
shari.barto@Vanderbilt.edu
615-936-2474
Recruitment Efforts with Mid-South

• Unique phenotype – ICD-9 codes used to identify possible participants (requiring at least 2 or more dx)

• Site champion - Ideally, letter should come from someone patients know or, at a minimum, the institution they know
  • Site letterhead
  • Dx should not be directly implied to the patient in the event the dx is incorrect
  • Suggestion: “You or someone you know may have been affected by condition X”

• Unique URL – Using a unique link for each recruitment site enables tracking the relative success of efforts at each site
IRB and ArthritisPower Consent

• Vanderbilt ceded IRB responsibility to UAB, making UAB the IRB of record

• By signing the AR-PoWER “Arthritis Power” consent form participants consent to:
  • Joining the registry to capture data of various types (e.g. surveys, passive data)
  • Bring in external data (e.g. EHR data from CDRN, biomarkers from commercial lab)
  • Share data with external data partners (e.g. CDRNs, other research groups)
  • Provides a frame for additional ‘add on’ studies (e.g. interventional studies, biospecimen collection)
4 Key Pillars

1. Patient engagement, community integration and education via bloggers, arthritis news, social media, support

2. Personal longitudinal health & medication tracking by providing participants’ access to PRO and other health-related data

3. Health care decision making by allowing participants to share health tracking reports

4. Research opportunities by providing a platform where new research opportunities can be browsed by participants
Welcome!
Welcome to the AR-POWER Registry. We are glad that you are part of our patient community. Over the next 9 months, we will be rolling out a number of exciting new features. Click on Track at the bottom left to get started.

Early Access Site
Thanks for taking the time to check out our Early Access instance of the RheumPRO Framework. The server hosting this instance is a development server, which means it will be updated regularly and may occasionally have some bugs. Please let us know if you experience any difficulties.
Research Platform

• Cohort Subtypes
  • All inclusive
  • Opt-in
  • à la carte

• Study enrollment
  • Driven by perception of value to community
Data Types Able to be Captured

• Patient Demographics, Employment, Name of Insurance Carrier, Disease, Rheumatologist Name, E-mail

• Treatment History: Current & Past Medications, Preventive Tests (bone density, cancer screening), Vaccine History

• Patient-Reported Outcome (PRO)
  • All PROMIS-CAT Instruments (Pain, Fatigue, Sleep)
  • Fixed short forms (RAPID3, MDHAQ, Patient Global)

• Additional Features
EHR = Electronic Health Record; PPRN = Patient Powered Research Network
PRO = Patient Reported Outcomes; API = Application Programming Interface
Motion Device Sensors (e.g. Fitbit)

External data (e.g. Corrona)

PROs:
- NIH PROMIS
- Traditional PROs

Connector API

Web API

Other PPRNs
- EHR in CDRNs
- CDRN

EHR = Electronic Health Record; PPRN = Patient Powered Research Network
PRO = Patient Reported Outcomes; API = Application Programming Interface
CCFA Partners

Partner with us and make a difference!
CCFA Partners

- IBD patient community
- CCFA
- IBD Scientific Community
Our vision

Use Internet-based recruitment and data collection to create a cohort of IBD patients

- Follow natural history of disease
  - Large, diverse population

- Patient generated data
  - Exposures, health behaviors, outcomes

- Include diverse data sources
  - Surveys, health apps/devices, personal health records

- Create widely-used resource
  - Support a diverse array of studies

- Increase patient partners/citizen scientists
  - Goal of improving outcomes
Overview

• Enrolled >14,000 adult IBD patients from CCFA email rosters, CCFA web-page, social media, walks, etc.
• Use 6-month surveys to evaluate treatments and health status
• Use 3-month contacts to deliver educational messages and update participants about new research findings
• Open and transparent process to support research studies
IBD Patients and Researchers: A Revolutionary Partnership

Welcome to CCFA Partners - a patient powered research network brought to you by the Crohn’s & Colitis Foundation of America (CCFA) and the University of North Carolina School of Medicine. CCFA Partners is an internet-based study of patients with Crohn’s disease or ulcerative colitis. By filling out a short survey twice a year, patients can have an active role in the research process. But CCFA Partners is more than a survey - you will also have access to tracking tools and a community of thousands to help you manage your own health! You can:

- Participate in groundbreaking research
- Propose, discuss, and vote on research questions and topics
- Connect your mobile health apps to better manage your disease

Join
Already a Member? Sign In.
Are you a researcher? Click Here.
Under age 18? Join CCFA Partners Kids & Teens.

“This new research model really is a game-changer. For the first time, patients are involved at every step of the way – from overseeing the research process to being participants in studies. By being involved, I am empowered, and I really believe I am helping to shape the future of IBD.”
- Nick, patient

“By tracking my health with CCFA Partners, I have better control over my Crohn’s Disease than ever before. Plus, I feel great about supporting innovative research that really listens to patients and looks for new ways to find a cure for IBD.”
- Jessica, patient

“I am excited to be involved with CCFA Partners because it is completely focused on patient-reported outcomes. For the first time, we have a study that is asking the questions that patients care about: diet, sleep, fatigue, quality of life. The answers to these questions will allow us to provide better care.”
- Dr. Robert Sandler, researcher

www.ccfapartners.org
Partnering with Researchers across the U.S.

- Secondary analyses of existing data
- Supplemental focused surveys
- Additional data types (biopspecimens, chart extraction)
- Interventional studies
- Screening and recruitment for outside studies

To date:
- 34 applications submitted
- 20 approved
- 7 completed
What have we learned so far?

12 manuscripts and >25 abstracts

<table>
<thead>
<tr>
<th>Cohort development</th>
<th>Perceptions of care</th>
</tr>
</thead>
<tbody>
<tr>
<td>Dietary patterns</td>
<td>Sleep and IBD flares</td>
</tr>
<tr>
<td>Patient reported outcomes</td>
<td>Vaccine preferences</td>
</tr>
<tr>
<td>Depression in elderly</td>
<td></td>
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</tbody>
</table>
Beyond Research: patient-inspired functionality

- Data as a two way street
- Moving beyond the conventional research study:
# Research Democracy

## Community Contributions

<table>
<thead>
<tr>
<th>Proposed Questions</th>
<th>Votes Cast</th>
<th>Being Researched</th>
</tr>
</thead>
<tbody>
<tr>
<td>61</td>
<td>750</td>
<td>4</td>
</tr>
</tbody>
</table>

## Research Prioritization

<table>
<thead>
<tr>
<th>Votes</th>
<th>Question</th>
<th>Vote</th>
</tr>
</thead>
<tbody>
<tr>
<td>117</td>
<td>We should compare individuals who manage their disease with medication and those who manage their disease with popular diets in the IBD community, such as SCD, FODMAPs, paleo, etc.</td>
<td>Cast Vote</td>
</tr>
<tr>
<td>75</td>
<td>Research the validity of VSL#3 probiotic in controlling flare ups or as a factor in remission.</td>
<td>Cast Vote</td>
</tr>
<tr>
<td>72</td>
<td>Compare symptoms of IBD patients who consume dairy and those who avoid dairy.</td>
<td>Cast Vote</td>
</tr>
<tr>
<td>61</td>
<td>I propose a genetics-based investigation that explores why some drugs work for some people but not others.</td>
<td>Cast Vote</td>
</tr>
<tr>
<td>53</td>
<td>What is the effect of hormones, particularly increased estrogen, on Crohn's disease.</td>
<td>Cast Vote</td>
</tr>
<tr>
<td>53</td>
<td>Are fecal transplants a safe and effective treatment for IBD?</td>
<td>Cast Vote</td>
</tr>
<tr>
<td>45</td>
<td>What is the role of stress and the stress response in autoimmunity?</td>
<td>Cast Vote</td>
</tr>
<tr>
<td>31</td>
<td>We should determine why the prevalence of IBD in developing countries is so low, yet immigrants from those countries and their children are at increased risk of IBD.</td>
<td>Cast Vote</td>
</tr>
<tr>
<td>30</td>
<td>We need to develop a better understanding of how nutrition as a whole affects IBD and put together a more comprehensive diet plan that includes the definite triggers.</td>
<td>Cast Vote</td>
</tr>
<tr>
<td>25</td>
<td>Nicotine has shown to be effective for UC in some individuals, both prior- and non-smokers. What is the mechanism? Does nicotine affect the microbiome, the immune system or both?</td>
<td>Cast Vote</td>
</tr>
</tbody>
</table>
Research Democracy

We should compare individuals who manage their disease with medication and those who manage their disease with popular diets in the IBD community, such as SCD, FODMAPS, paleo, etc.

This topic has received 117 Votes

One of the great questions in the IBD community is, understandably, about food. Some people are able to manage their disease with diet alone, but many take medication. So, what’s the difference? Why do particular meds work for some, and particular diets work for others? I propose comparing individuals who manage their condition with diet vs. those who manage their condition with medication, with the goal of figuring out whether it’s genetics, the microbiome, or some other factor that makes a particular strategy effective for an individual. Ideally the “diet” and “med” groups would be as similar as possible (same disease in same location, similar initial clinical courses, same objective markers of inflammation, etc), and we’d want two groups of patients who have disease objectively “under control.” This could impact every patient with IBD and better guide treatment decisions.

Proposed By: Jessica J
Nashville

Comments

Anonymous User
Scott I still have crohns iam going for my colonoscopy next Tuesday at hurley hospital I must be there at hurley hospital at 11:30 am to sign in for colonoscopy my colonoscopy exam is at 12:00 pm the exam is being done by new gastroenterologist he will talk to me before the after the exam
2013-03-17 20:48:07 UTC

csb1978
Hi Jessica, I'm glad you wrote a research question about diets, and that it is receiving many votes. A large proportion of people with IBD think that the food they eat matters. They want to know more about how to eat to help them control their bowels. In my mid-20s, I had severe crohn's flares while I experimented with my
Sharing Results with Patients

Lay Summaries

Infographics

Disease Activity Based on Diet

- Improve Symptoms
  - Non-leafy vegetables, spicy foods, nuts, seeds, coffee, and beans were more frequently reported to improve symptoms.
- Worsen Symptoms
  - Yogurt, rice, and beans were more frequently reported to worsen symptoms.

Scientific Abstract:

Results: Disease activity based on diet with emphasis on leafy vegetables, spicy foods, nuts, seeds, coffee, and beans. Improved symptoms associated with non-leafy vegetables, spicy foods, nuts, seeds, coffee, and beans. Worsened symptoms associated with yogurt, rice, and beans.

Infographic:

- Disease Activity Based on Diet
  - Improve Symptoms: Non-leafy vegetables, spicy foods, nuts, seeds, coffee, and beans.
  - Worsen Symptoms: Yogurt, rice, and beans.
3 Month Messages

Important Results from CCFA Partners

Thank you for joining the CCFA Partners community! Your continued participation is very important -- you are helping researchers understand and ultimately improve the lives of people with IBD. Our goal is to understand changes in lifestyle over time—that’s why it is so important for our Partners to complete an updated survey ever six months.

Please click here to complete your [baseline / follow-up] survey today [only seen by those who have not].

Below are new findings about sleep and IBD flares from the Partners study. These findings would not have been possible without the help of Partners like you. With your continued participation we will be able to answer other questions that impact people with IBD.

- We studied 3,173 IBD patients in Partners, among whom 1,798 were in clinical remission.
- Disease activity, depression, female gender, smoking, and use of corticosteroids or narcotics were associated with sleep disturbance at enrollment.
- Among 1,291 Crohn’s disease patients in remission at baseline, those with impaired sleep were twice as likely to relapse at 6 months.

You can read more about these results, as well as other publications from CCFA Partners under the Results tab at www.ccfapartners.org

CCFA Partners cares about your health!

Tips for improving sleep hygiene:

- Try to go to bed at the same time each day.
- Avoid using your bedroom to work, study or eat.
- Avoid watching TV before bedtime.
- Avoid coffee, tea and chocolate after 5 p.m.
- Avoid alcohol close to bedtime.
- Keep your room’s temperature comfortable.
- Noise and light can lead to poor sleep. Thus, try to sleep in a silent dark room.
- Regular physical activity can improve the quality of your sleep.
- Establish a bedtime routine.
- A warm bath close to bedtime is recommended to fight insomnia.
- Sleep only the time sufficient for you to feel refreshed. Do not stay in bed longer than necessary.
- When you can’t sleep, get up and do something boring or repetitive, such as reading an uninteresting book.

References:

1. Ananthakrishnan AN, Long MD, Martin CF, Sandler RS, Kappelman MD. Sleep Disturbance and Risk of Active Disease in Patients with Crohn’s Disease and Ulcerative Colitis. Clin Gastroenterol...
mHealth App and Device
myHealthMeasures

Quality of life: Crohn's Disease

SIBDQ (short inflammatory bowel disease questionnaire) is an instrument that measures health related quality of life. This score ranges from 10-70.

SIBDQ scores for CCFA Partners Participants range from 10-70

Low Quality of Life
10

Median=48

High Quality of Life
70

Your SIBDQ is 37
myDashboard
Summary

- Harness the power of the Internet to efficiently enroll and follow unprecedented numbers of IBD patients
- Largest US study of the impact of IBD.
- Help to advance methods in patient reported outcomes for clinical research and epidemiology
- Platform to recruit for other studies
- Potential to impact patient lives through improved disease insight and management
Mid-South-AR-PoWER Collaboration

• Identify local PI as partner (Dr. Bobo Tanner)

• Identify patients:
  • Use basic query to identify patients with condition of interest (for counts: ) (IRB exemption)
  • More rigorous de-identified query to identify patients based on multiple criteria (ex. condition, medications, labs, visits) (IRB exemption)
  • Use of identifiable data for specific clinics, physicians, email contact (requires IRB approval)
## Mid-South AR-PoWER Collaboration

### Vanderbilt Arthritis Counts for AR-Power project

<table>
<thead>
<tr>
<th>Criteria</th>
<th>Patient Count</th>
</tr>
</thead>
<tbody>
<tr>
<td>2 or more mentions of ICD 9 Arthritis <strong>AND</strong> Subjects in MRAV cohort list</td>
<td><strong>3,337</strong></td>
</tr>
<tr>
<td>2 or more mentions of ICD 9 <strong>AND</strong> Patients with one or more encounters at the Vanderbilt rheumatology clinic in the past 2 calendar years <strong>AND</strong> Subjects in MHAV cohort list</td>
<td><strong>6,070</strong></td>
</tr>
<tr>
<td>2 or more mentions of ICD 9 <strong>AND</strong> Patients with one or more encounters at the Vanderbilt rheumatology clinic in the past 2 calendar years <strong>AND</strong> Subjects in EPIC cohort list</td>
<td><strong>2,152</strong></td>
</tr>
</tbody>
</table>
Collaboration Letter

Dear Patient,

As the Director of the Rheumatology & Immunology Division at Vanderbilt, I am writing to tell you about Arthritis Power, the first ever patient-led, patient-centered research registry for arthritis and other conditions of the bones, joints or skin. A patient research registry is a place to store detailed information about patients with a specific disease or condition. In focusing on arthritis as well as other bone, joint or skin conditions, the goal of Arthritis Power is to collect health data from tens of thousands of patients to support future research to compare treatments, identify new treatments and, perhaps, find elusive cures.

If you decide to join the registry on the Arthritis Power site, you will be asked if you want to share your Vanderbilt electronic health records with the registry. For more information about this opportunity please click on the “Arthritis Power” link. Your participation in Arthritis Power is voluntary and there is no cost to you for participating.

We hope you will consider this opportunity. Please visit www.ArthritisPower.org or see the attached flyer to learn more.

Please let your provider know if you have any questions.

Best wishes,

Leslie J. Crofford, MD
Professor of Medicine
Director, Division of Rheumatology & Immunology
Mid-South AR-PoWER

- **Consent Patients**
  - via Mid-South CDRN or AR-PoWER PPRN (IRB applications at UAB and VU)

- **Survey Patients**
  - Via AR-PoWER Registry

- **Share Data**
  - Send specific data from Mid-South CDRN to PPRN via one-time data-share, or API
  - Link to TDOH, TnCare and CMS data for hospitalizations and other claims data
Mid-South-CCFA Collaboration

• Identify local PI as partner (Dr. Sara Horst)

• Identify patients:
  • Use basic query to identify patients with condition of interest (for counts: ) (IRB exemption)
  • More rigorous de-identified query to identify patients based on multiple criteria (ex. condition, medications, labs, visits) (IRB exemption)
  • Use of identifiable data for specific clinics, physicians, email contact (requires IRB approval)

• Validation of computable phenotype (via chart reviews)
Mid-South CCFA Collaboration

- Contact Patients at VU and UNC

<table>
<thead>
<tr>
<th>Vanderbilt IBD Counts for CCFA project</th>
<th>Patient Count</th>
</tr>
</thead>
<tbody>
<tr>
<td>Criteria: 3 (or more) ICD-9 diagnosis codes of 555.<strong>XX</strong> (Crohn’s) OR 556.<strong>XX</strong> (UC)</td>
<td>6,400</td>
</tr>
<tr>
<td>Criteria: 1 (or more) ICD-9 diagnosis codes AND any IBD medication</td>
<td>7545</td>
</tr>
</tbody>
</table>
Mid-South CCFA Collaboration

• Consent Patients
  • via Mid-South CDRN or CCFA PPRN (IRBshare with UNC and VUMC)

• Survey Patients
  • Via CCFA Registry

• Share Data
  • Send specific data from Mid-South CDRN to PPRN via one-time data-share, or API
Vasculitis PPRN

• PPRN Phase I
  • Identify patients with rare vasculitides
  • Perform validation of computable phenotypes
  • Identify, contact and refer patients to Vasculitis PPRN

• TAPIR Study (RCT of weaning steroids in GPA)
  • Identify patients at VU, VHAN, and Greenway with GPA on steroids
  • Confirm eligibility with MD and refer to study site for consent/enrollment into RCT
PPRN-CDRN Demonstration Project

- AR-PoWER, CCFA, Vasculitis, ICN, and PARTNERS PPRNs
- Mid-South (VU, VHAN, Greenway, UNC, MUSC) and PedsNet CDRNs

**Aim 1**
- Identify patients with conditions of interest on biologics at Mid-South and PedsNet sites
- Examine adverse events

**Aim 2**
- Contact patients with conditions of interest and refer to registries for collection of PROs and longitudinal assessment of biologics over time
Value Proposition for CDRNs

• Engage local PIs/Clinicians with interest in the condition(s) of interest
• Benefit local patients/stakeholders within the CDRN
• Introduce new study opportunities to the CDRN
• Provides access to additional patient/family stakeholders from the PPRNs for current and future projects
• Financial compensation for work provided
Value Proposition for PPRNS

- Opportunity to create, compare/validate, and refine computed phenotypes
- Identify potential PPRN participants within CDRNs and send PPRN recruitment materials
- Compare demographic and clinical characteristics of those who do and don’t join PPRN, to assess, generalizability of PPRN membership
- Linkage can enhance PPRN data with rich clinical data
- Dissemination potential
CDRN Challenges

• CDRN’s typically need a CDRN level PI to oversee local project needs (IRB, clinician engagement, data validity/acquisition issues)

• CDRN’s may also need a site PI for each participating site to deal with similar issues

• CDRN PIs/site-PIs need opportunities for scholarship and/or financial compensation

• CDRN’s need financial compensation

• Different approaches for patients engagement at different sites (Ex. direct engagement vs via physician, mail vs phone vs email vs portal)

• Different sites have different levels of “complete data”

• IRB and contracting issues require significant work

• CDRN’s need a “Value Proposition”. Needs to be for research – not just referral to registries.
PPRN Challenges

• Bandwidth and competing priorities
• Tension between maintaining tone/personality of PPRN patient community vs. parameters of what CDRN and IRB allow in patient messages
• Funding
• Low perceived return on investment may discourage similar collaborations in future
Conclusions

• Significant opportunities for CDRN-PPRN collaborations
• Still a “work in progress” to define and operationalize these opportunities
• Requires value proposition for both sides (ex. Give/Get Model)
• Exciting and innovative area for future research
Discussion