CCFA Partners

Partner with us and make a difference!

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Slides courtesy Michael Kappelman, MD, University of North Carolina
CCFA Partners

IBD patient community

CCFA

IBD Scientific Community
Our vision

• Use Internet-based recruitment and data collection to enroll and follow a large, diverse IBD cohort
  • Efficient and (relatively) inexpensive
• Focus on patient-reported data:
  • Exposures (i.e. diet, medications, smoking)
  • Health behaviors (i.e. adherence, prevention)
  • Outcomes (i.e. fatigue, depression, anxiety, pain)
• Provide a platform for ancillary studies: observational, interventional, translational
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 ancillary studies
- In 2013, received PCORI funding to transform cohort into a patient powered research network
  - $1 million for Phase I
  - $ 2.2 million for Phase II
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
What have we learned so far?

11 manuscripts and >25 abstracts

Cohort development
Dietary patterns
Patient reported outcomes
Depression in elderly

Perceptions of care
Sleep and IBD flares
Vaccine preferences
Beyond Research: patient-inspired functionality

- Data as a two way street
- Moving beyond the conventional research study:
<table>
<thead>
<tr>
<th>Proposed Questions</th>
<th>Votes Cast</th>
<th>Being Researched</th>
</tr>
</thead>
<tbody>
<tr>
<td>61 proposed questions</td>
<td>750 votes</td>
<td>4 questions</td>
</tr>
</tbody>
</table>

### Research Prioritization

#### Popular

- **117 Votes**
  - **Question**: 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.
  - **Vote**: Cast Vote

- **75 Votes**
  - **Question**: Research the validity of VSL#3 probiotic in controlling flare ups or as a factor in remission.
  - **Vote**: Cast Vote

- **72 Votes**
  - **Question**: Compare symptoms of IBD patients who consume dairy and those who avoid dairy.
  - **Vote**: Cast Vote

- **61 Votes**
  - **Question**: I propose a genetics-based investigation that explores why some drugs work for some people but not others.
  - **Vote**: Cast Vote

#### Most Active

- **53 Votes**
  - **Question**: What is the effect of hormones, particularly increased estrogen, on Crohn's disease.
  - **Vote**: Cast Vote

- **53 Votes**
  - **Question**: Are fecal transplants a safe and effective treatment for IBD?
  - **Vote**: Cast Vote

#### Newest

- **45 Votes**
  - **Question**: What is the role of stress and the stress response in autoimmunity?
  - **Vote**: Cast Vote

- **31 Votes**
  - **Question**: 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.
  - **Vote**: Cast Vote

- **30 Votes**
  - **Question**: 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.
  - **Vote**: Cast Vote

- **25 Votes**
  - **Question**: 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?
  - **Vote**: Cast Vote
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.

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 a two groups of patients who have disease objectively “under control.” This could impact every patient with IBD and better guide treatment decisions.

Proposed By...

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
2015-05-17 20:43:07 UTC

csb1975
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
mHealth App and Device
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
Partnering with pSCANNER

• Symptoms (and hence, PROs) do not always correlate with disease activity in patients with IBD
Partnering with pSCANNER

- Combining PROs (CCFA Partners) with objective assessment of disease activity and outcomes (pSCANNER) – comprehensive assessment of IBD
Plans for Studies

• Observational studies on role of
  – Diet
  – Physical activity
  – Stress
    in modifying IBD disease course and outcomes
• Cluster-randomized, interventional trials