# Patient-participant perspective: Applying a decision aid to future RWE studies

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ArthritisPower

# ArthritisPower

## Patient-Powered Research Network: Research registry of more than 16,000 “activated” patient participants with rheumatic and musculoskeletal disease

- Created in 2015 with support from PCORI, one of 20 PPRNs and 33 networks within PCORnet
- Capacity to designate study cohorts and create customized user flows for each new study
- Novel data collection techniques (passive data)
- Individual health tracking so patients can view symptom data over time and share with their

## Smartphone App for mobile collection of patient data

- Patient-Reported Outcome Measurement Information System (PROMIS®) developed by the NIH
- Other PRO measures in library that can be quickly updated with new instruments as needed
- Custom surveys (via HIPAA-compliant SurveyMonkey API)

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# ArthritisPower Features

- **Tracking -** symptoms; active/past medications; complementary treatments*; add other measures (flares*, depression, disease impact on social satisfaction); personal symptom note entries for context*; import VectraDA® lab results*; future biosensor innovation
- **Analytics -** longitudinal results graphing; overlay medication usage to see how symptoms change with new medications*
- **Share -** electronic reports can be sent to doctors, caregivers and others
- **Research Opportunities -** browse available studies for participation
- **Connect -** invite other patients or caregivers to connect through in-app messaging with option to share notes, analytics*
- **Education -** CreakyJoints social media feed, including patient blogs / Twitter; disease specific content on treatments, coping and support*

*New features developed for v2

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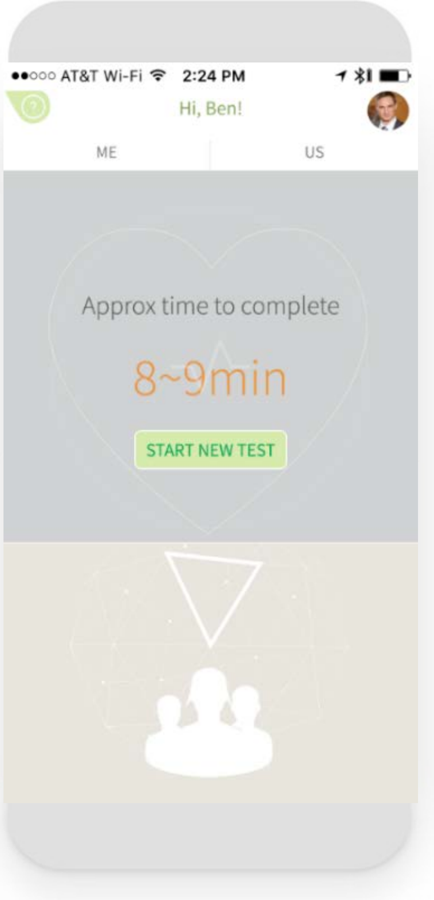
# ArthritisPower Features



●●○○○ AT&T Wi-Fi 2:24 PM

Hi, Ben!

ME US

Approx time to complete

8~9min

START NEW TEST

●●●○○ AT&T Wi-Fi 2:26 PM

Physical Function X

In the past 7 days How tired did you feel on average?

START ALMOST DONE DONE

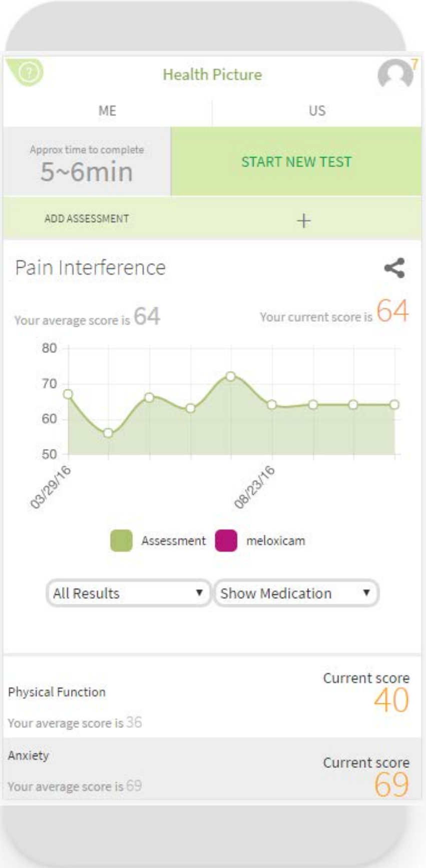
Not at all

A little bit

Somewhat

Quite a bit

Very much



Health Picture

ME US

Approx time to complete 5~6min

START NEW TEST

ADD ASSESSMENT +

Pain Interference

Your average score is 64

Your current score is 64

🟩 Assessment 🟪 meloxicam

All Results ▾ Show Medication ▾

Physical Function

Current score 40

Your average score is 36

Anxiety

Current score 69

Your average score is 69

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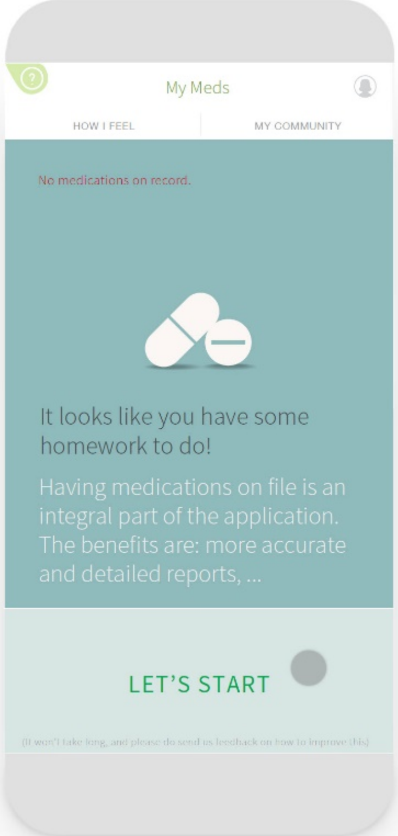
# ArthritisPower Features

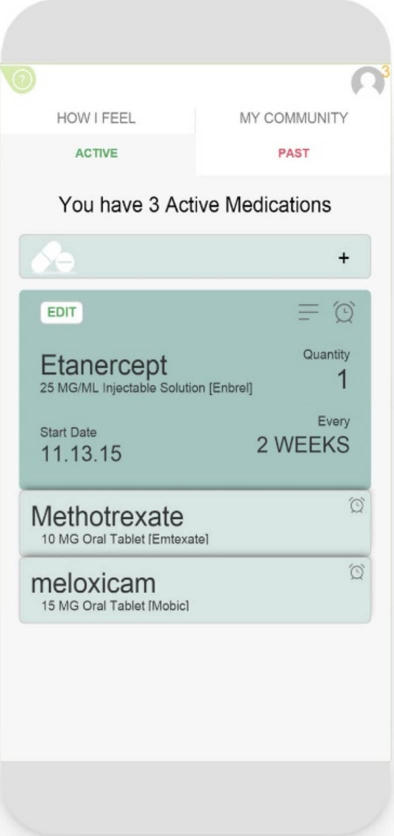


No medications on record.

It looks like you have some homework to do!

Having medications on file is an integral part of the application. The benefits are: more accurate and detailed reports, ...

(It won't take long, and please do send us feedback on how to improve this)

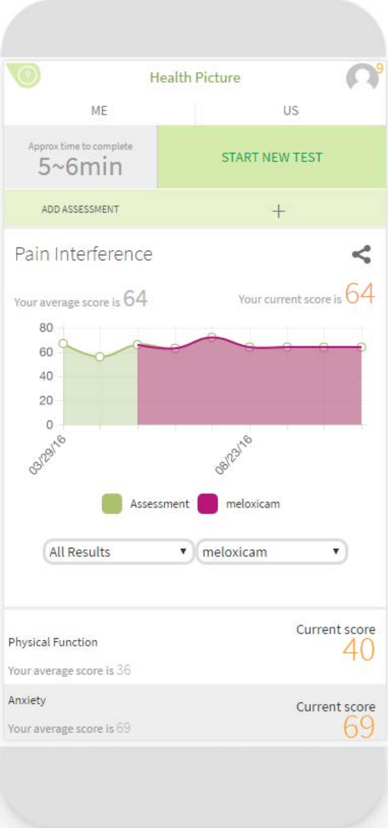


You have 3 Active Medications

Etanercept
25 MG/ML Injectable Solution [Enbrel]
Quantity 1
Start Date 11.13.15
Every 2 WEEKS

Methotrexate
10 MG Oral Tablet [Emtexate]

meloxicam
15 MG Oral Tablet [Mobic]



Approx time to complete
5~6min

Pain Interference

Your average score is 64

Your current score is 64

Physical Function
Your average score is 36
Current score 40

Anxiety
Your average score is 69
Current score 69

# Engagement

- What information do patients **need** to make a decision?

  Research → Information → Health care decision

- Which **data** and **study design** will permit us to answer the research question?
- Which **partners** are appropriate?

  Shared values, Access to data

- Which **data** and **study design** will permit us to answer the research question AND engage our partners?

  Participant experience (UI/UX), Consent, Incentive

# The Comparative Health Outcomes in Immune-mediated diseases CollaborativE (CHOICE) Study

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# Aims of CHOICE Study

1. **Evaluate the comparative risks for infection, heart attack and stroke**
2. **Evaluate the comparative clinical effectiveness of various medications using Patient Reported Outcomes (PROs)**

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# What is the need?

**Patients and doctors want to know which treatment works best, for whom, and under what circumstances**

# What is the need?

**What we know:**

Physicians and patients need to make challenging decisions among a variety of treatment options. This can be difficult given widely variable safety profiles and limited data on medication effectiveness from a patient's perspective. Most of our approved medications work reasonably well, for most patients, most of the time.

**What we don't know:**

- How ***well*** do these medications work?
- How ***quickly*** do they work?

# Which data?

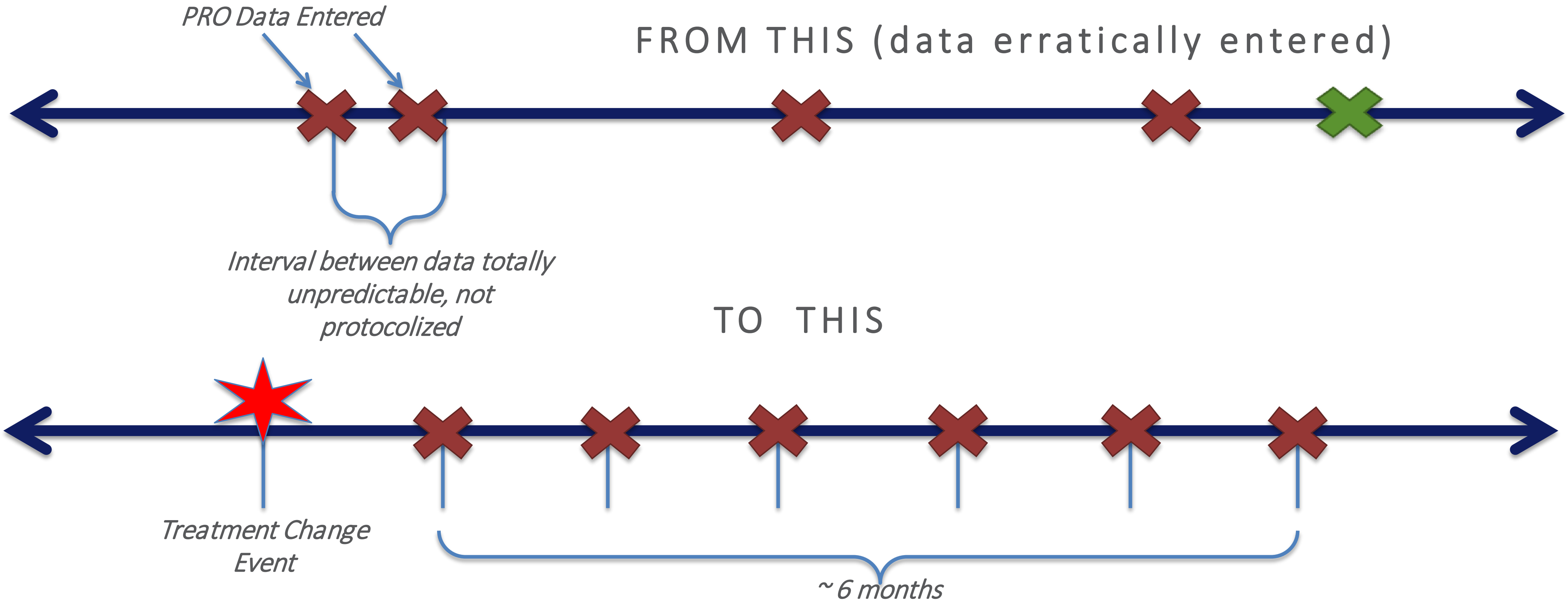
**Diagnosis & Treatment:**

- Self-reported data (condition, physician name, treatment
- Additional screening questions
- Linked EMR or claims data

**Patient experience:**

- Symptoms, patient-reported outcomes (PRO)
- Reasons for changing or stopping treatment

# Effectiveness: Important to have PRO data contributed regularly



*PRO Data Entered*

FROM THIS (data erratically entered)

*Interval between data totally unpredictable, not protocolized*

TO THIS

*Treatment Change Event*

*~ 6 months*

# Which partner?

## What does this have to do with me as a patient?

You are the **only one** who can tell us how well or not well a treatment works for you.

*When you tell us how well a medication is working (or not working) for you, your* ***Patient Reported Outcome*** *(PRO) describes your experience with this medication. Your voice is heard and this benefits other people like you.*

Data like this from you and thousands of other patients is turned into information that physicians and other patients can use to make decisions about treatments.

# Which partner?

## How can I help?

As a member of ArthritisPower, ***when you contribute regular data***, you are helping to make comparative effectiveness information available.

There are three easy steps:

1. **Fill out your medication data and keep it current**
2. **Complete your ArthritisPower PROs regularly**
3. **Be sure to include WHY changes were made**

# Considerations…

- Harmonizing data collection with other partners
  - What are others' collecting, how and with what frequency?
- Additional data required for validation
- Adjustments to informed consent
- Incentive
- Patients' visualization of their own data, comparisons with others
- Participant experience on digital platform, UX
- Dissemination of findings to patient participants
- Integration with clinical care

# Thank you