SMART

Social Media & Research Toolkit

This work is supported by a Patient-Centered Outcomes Research Institute (PCORI)
Eugene Washington PCORI Engagement Award (EAIN-3989)

Global Healthy Living Foundation

ABOUT THIS TOOLKIT

This toolkit was developed by the Global Healthy Living Foundation (GHLF). The Global Healthy Living Foundation is the parent organization of CreakyJoints, the go-to source for more than 100,000 arthritis patients and their families world-wide who are seeking education, support, advocacy and patient-centered research and ArthritisPower, the first ever patient-led, patient-centered research registry for joint, bone, and inflammatory skin conditions.

A number of dedicated and hardworking professionals contributed to the creation of this toolkit. For their invaluable input, we would like to thank the our technical consultant team and our patient consultant team: Click here for a detailed bio of each advisory team member.

This toolkit comprises a slide-deck and a user guide and is best used in conjunction with each other.

To download the user guide click here

☒ *THIS IS NOT…*

- A toolkit for using social media **in general**
- Tips for communicating with doctors and other healthcare providers about **clinical care**
- Suggestions for building a **personal following** on social media
- A workshop for how best to **share personal experiences** on social media

☑ *THIS IS…*

- A toolkit for how to use social media across all phases of research

SOCIAL MEDIA AND RESEARCH TOOLKIT (SMART) OBJECTIVES

- To define social media and highlight opportunities and challenges of using social media for research-related roles, activities and engagement
- To present and develop best practices and guidelines for SpA patients and clinicians interested in using online platforms (i.e., Facebook, Twitter, Blogs / patient narratives) for research activities
- To develop a useful toolkit across many conditions and disease communities

SMART: PROJECT PROCESS OVERVIEW

1. We identified spondyloarthritis (SpA) patients and other stakeholders who are active on social media and interested in becoming partners in research to help create a toolkit of best practices for social media engagement in health research.

2. We conducted a three-part research training developed by CreakyJoints to provide an orientation to patients interested in becoming full partners in research.

3. We developed a toolkit with resources for SpA patients and clinicians interested in using social media as a platform for research engagement.

4. We conducted a SMART conference that brought together SpA patient participants, clinicians and researchers to pilot, discuss and refine the SMART toolkit.

INTRODUCTION & GETTING STARTED

DEFINE CORE VALUES: DO’S & DON'TS

DO’S

- Uphold/Adhere to ethical guidelines (to protect human subjects)
- Facilitate research that is patient centered – multi stakeholder, research questions important for healthcare decision making
- Protect privacy/data security of participants
- Get research findings to those who can use it
- Basic/essential info for spa (Dx process) ◎ education, length of time, orient patients to spa diagnostic process
- Develop educational material like glossaries to bridge / get everyone on the same page
- Ensure research done is patient friendly and focused

DON’TS

- DON’T ask for private/personally identifying information
- DON’T use misleading messaging (claims about ‘cure’s’, ‘drug safety’)
- DON’T offer promises that can seem coercive or that can influence individuals to participate
- DON’T exculpatory language
- DON’T ignore how individuals can participate with each other on social media platforms
- DON’T infiltrate a Facebook page or a private forum without permission from the site administrator
- DON’T assume you don’t need IRB permission to ‘spread the word’ about your research study
- DON’T advertise, recruit, contact individuals to participate without protocols such as informed consent

Design Primers: Primers can include tools and materials that can help the research team to understand why they do what they do, and how to do what they do.

STEP 1: CREATE A RESEARCH PRIMER

- **Research 101:** Provide basic training in research methods
- **Research Glossary:** Build a glossary of terms for reference of commonly used terminology in patient-centered outcomes research
- **Ethical guidelines & IRB:** Layout best practices for compliance with IRB principles & ethical conduct of research
- **Research phases:** Provide an introduction to the 3 phases of research

STEP 2: CREATE A SOCIAL MEDIA PRIMER

- What is social media? Start with the basics including types of social media platforms, how they can be used for different audiences
- The 3 phases of Research: Identify opportunities for social media engagement in all 3 phases of research
- Outline the benefits of leveraging social media in research
- Outline the pitfalls of leveraging social medial in research

EXAMPLE OF RESEARCH TRAINING FOR PATIENT PARTNERS IN RESEARCH

Design core sessions for a webinar series on patient-centered research

- **Session 1 –** Introduction and research design
- **Session 2 –** Research instruments and data collection
- **Session 3 –** Data analysis, presentation and interpretation

Training Goals

Outline what the training aims to achieve. Aims can include some of the following:

- Evolving patient role in research: What does patient engagement involve and imply?
- Why researchers do things the way they do
- How to evaluate survey instruments
- How to understand and evaluate research reports and presentations
- How to analyze, interpret, and talk about research results
- What does multistakeholder engagement mean?

START WITH A DEFINITION

WHAT IS (ARE) SOCIAL MEDIA?

- Start by providing basic definitions of what special media platforms your specific research aims to use
- The Oxford Dictionary defines social media as *“websites and applications that enable users to create and share content or to participate in social networking”*
- An article titled *“Can We Use Social Media to Support Content Validity of Patient-Reported Outcome Instruments in Medical Product Development?”* defines social media, as “a group of Internet-based applications (such as Facebook, Twitter, forums, or blogs) that allows the creation and exchange of user-generated content”
- Also referred to as Web 2.0

Outline opportunities and challenges of using social media for research

OPPORTUNITIES

- Facilitates recruitment across geographic areas, not confined to clinical settings
- Permits rapid implementation of surveys
- Allows for easy interaction among different stakeholders
- Lowers cost of research

CHALLENGES

- May bypass provider/clinical validation and oversight
- Privacy and data security risks
- Potentially overwhelming amount of data
- Individuals on social media may not be representative of all patients

SOCIAL MEDIA & THE PHASES OF RESEARCH

SOCIAL MEDIA CAN BE PART OF EVERY PHASE OF RESEARCH

PHASE I: Before

- Building an engaged patient community
- Identifying topics

PHASE II: During

- Creating a survey, measure or other instrument
- Recruiting study participants

PHASE III: After

- Disseminating findings

BEFORE RESEARCH

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BEFORE RESEARCH:
BUILDING COMMUNITY

IDENTIFY

Who is your target population?

Create a buzz

Digital ads

Social Media messages on twitter, Facebook, online forums

Use simple language

CONNECT

Reach out to key bloggers/opinion leaders

Partner with patient advocacy organizations

Ask patients to connect you with other patients

Appoint a patient as an ambassador for the project and to help spread the word

SUSTAIN

Encourage interaction

Allow a forum for patients to ask questions

Be clear on what participation entails

Appoint field coordinators

BEFORE RESEARCH:
BUILDING COMMUNITY

Approaches:

- Conduct live engagements with patients (e.g., Twitter chats / Facebook Live)
- Measure and evaluate engagement on Facebook and Twitter

#CREAKYCHATS IS A LIVE ENGAGEMENT

- Monthly patient-centered live Twitter discussion for people with arthritis and related chronic diseases
- Pick consistent date/time and stick with it
- Find partners to collaborate
- Create transcript of chat using Storify.com
- Sample topics:
  - Understanding the Emotional Impact of Chronic Disease
  - Psoriasis Isn’t Contagious: Education Should Be
  - Managing the Stress of the Holidays

Join #CreakyChats

Sleep and Arthritis

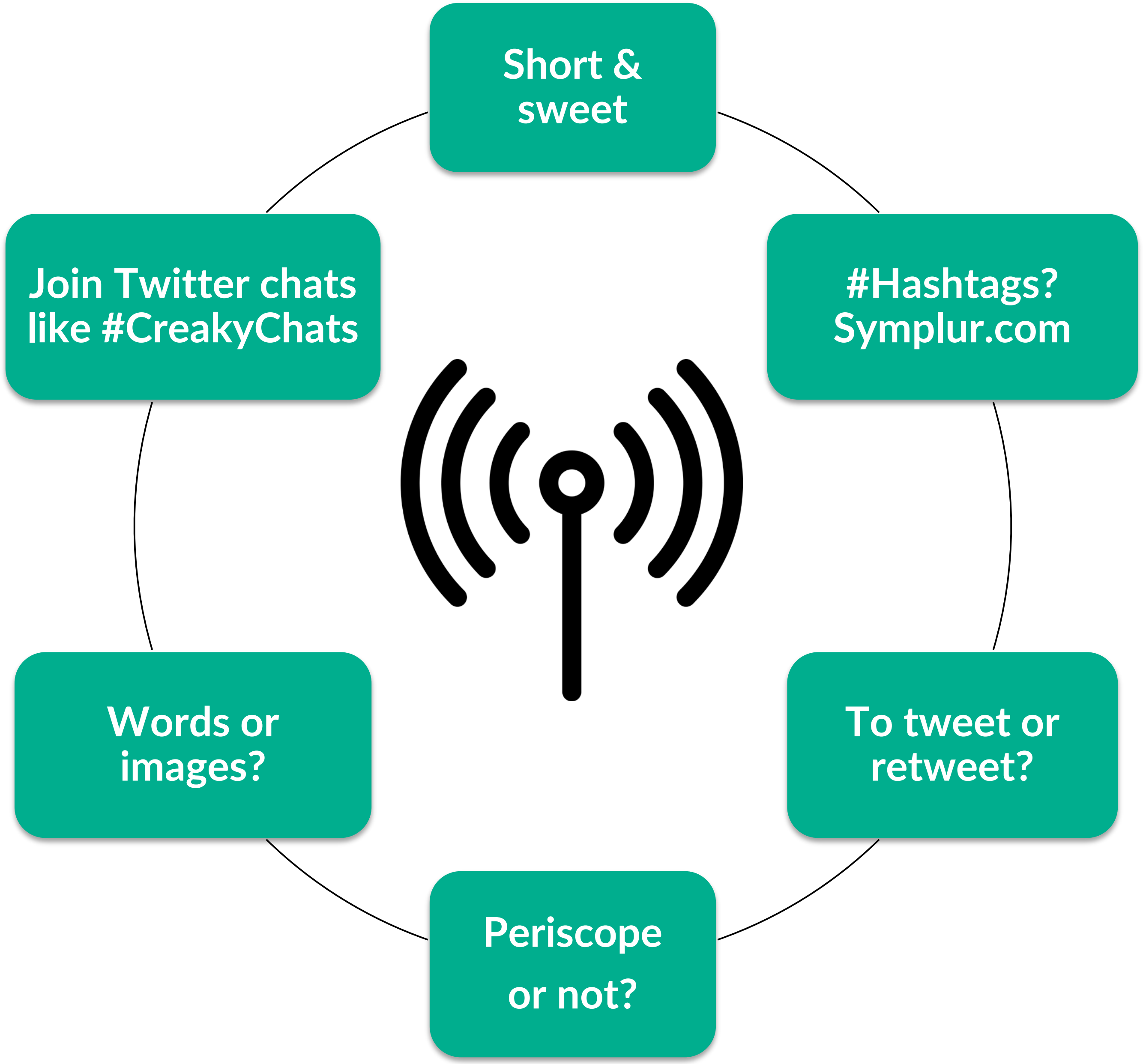
Monday, July 11th at 6:00 PM ET

Hosted by

@CreakyJoints

@sleeptemberorg

TWITTER BEST PRACTICES



Short & sweet

#Hashtags? Symplur.com

To tweet or retweet?

Periscope or not?

Words or images?

Join Twitter chats like #CreakyChats

BEFORE RESEARCH:
BUILDING COMMUNITY

Measure and evaluate

Consider measuring and evaluating social media activities and determine if it meets your goals. For example, you could qualitatively and/or quantitatively measure:

- Comments
- Followers/friends
- Likes
- Participation
- Retweets
- Traffic

Source: http://www.janssen-emea.com/sites/default/files/Social%20Media%20Toolkit%20for%20Patient%20Associations_EMEA.pdf

BEFORE RESEARCH: IDENTIFYING TOPICS

Approaches

- Solicit topics directly from patients and other stakeholders
- Encourage data manipulation among citizen scientists
- Hear what patients care about in online discussions

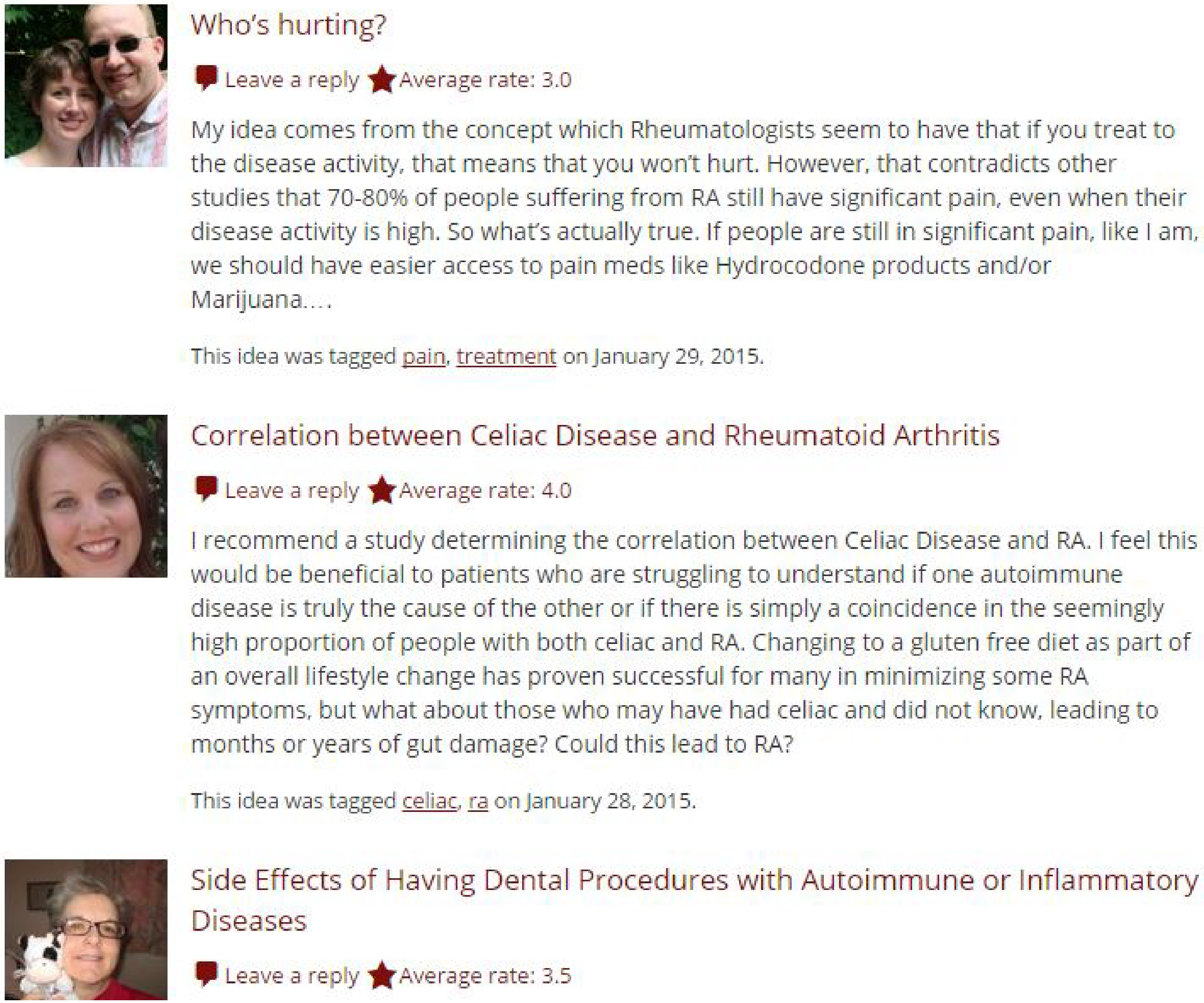
CREAKYJOINTS PATIENTS SUGGESTED DIVERSE TOPICS

- Fatigue
- Pregnancy
- Mental health
- Incontinence
- Endometriosis
- Celiac disease
- Antibiotics
- Access to pain medications
- Medical marijuana

One way to identify broad topics of interest for research may be to ask the patient community what remains important to them. We asked the **CreakyJoints** patient community to suggest what topics mattered to them. Patients suggested diverse topics. As a result, patients partnered with academic rheumatologists at Duke to create a survey examining the family planning and reproductive concerns of patients with inflammatory arthritis.

TELL US WHAT YOU WANT TO KNOW!

Patients proposed and rated research topics using a fillable web form that was promoted on social media



Who's hurting?

Leave a reply Average rate: 3.0

My idea comes from the concept which Rheumatologists seem to have that if you treat to the disease activity, that means that you won't hurt. However, that contradicts other studies that 70-80% of people suffering from RA still have significant pain, even when their disease activity is high. So what's actually true. If people are still in significant pain, like I am, we should have easier access to pain meds like Hydrocodone products and/or Marijuana....

This idea was tagged pain, treatment on January 29, 2015.

Correlation between Celiac Disease and Rheumatoid Arthritis

Leave a reply Average rate: 4.0

I recommend a study determining the correlation between Celiac Disease and RA. I feel this would be beneficial to patients who are struggling to understand if one autoimmune disease is truly the cause of the other or if there is simply a coincidence in the seemingly high proportion of people with both celiac and RA. Changing to a gluten free diet as part of an overall lifestyle change has proven successful for many in minimizing some RA symptoms, but what about those who may have had celiac and did not know, leading to months or years of gut damage? Could this lead to RA?

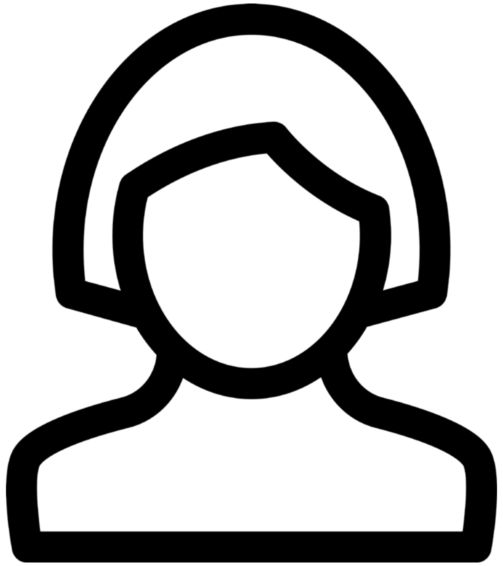
This idea was tagged celiac, ra on January 28, 2015.

Side Effects of Having Dental Procedures with Autoimmune or Inflammatory Diseases

Leave a reply Average rate: 3.5

WE CAN HEAR WHAT PATIENTS CARE ABOUT

Patient narratives can be treated as qualitative data from which researchers may extract recurrent and major themes that can be used in the development of surveys or research questions



This is really annoying: when I wake every morning, I take at least 30 minutes to 1 hour to get out of bed and then I put my foot down and it feels like there is a rock under my toes. Arrgh!!! But you know, I gotta do, what I gotta do - my family needs me, my kids and I have a dog, by the way - my kids and my dog are saviors - like literally. So whatever - I just keep moving ahead - stay strong huh - what else can you do? And my meds - yeah, they first made me really sick - like nauseous but now, I guess, I'm kind of used to it. Besides they help me with the pain - so it's worth it. Yeah, it really is worth it.

WE CAN HEAR WHAT PATIENTS CARE ABOUT

Where to listen:

- Patient blogs / forums
- Facebook pages
- Twitter

What to listen for:

- Patient discussions of diagnosis and disease management
- Experiences with therapies and side effects
- Social/emotional coping

How to transform what patients care about into research questions:

- Gather qualitative data → Code data → Find themes → Test out assumptions

DURING RESEARCH

PHASE I: Before

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AN EXAMPLE:

Patient narratives can be studied to better understand disease burden. Search for published literature on previous studies on patient experiences reported online to understand how online narratives that can inform already established and existing measures to study disease burden.

Using self-reported patient experiences to understand patient burden:

Learnings from digital patient communities in ankylosing spondylitis

Prashanth Sunkureddi1, Dawn Gibson2, Stephen Doogan3, John Heid4, Samir Benosman5 and Yujin Park6, 1Rheumatology, Clear Lake Rheumatology Center, Nassau Bay, TX, 2The Global Healthy Living Foundation, Upper Nyack, NY, 3Real Life Sciences, New York, NY, 4Kinapse, Inc, London, United Kingdom, 5Advisory Services, Kinapse, Inc, London, United Kingdom, 6Novartis Pharmaceuticals Corporation, East Hanover, NJ

Meeting: 2016 ACR/ARHP Annual Meeting

Date of first publication: September 28, 2016

Using self-reported patient experiences to understand patient burden:
Learnings from digital patient communities in ankylosing spondylitis

METHOD

- **46.6%** were patient health networking sites
- **24.9%** disease-specific patient forums
- **13.5%** general health forums
- **8.3%** treatment reviews
- **6.0%** doctor Q&A
- **0.6%** mainstream social media

FINDINGS

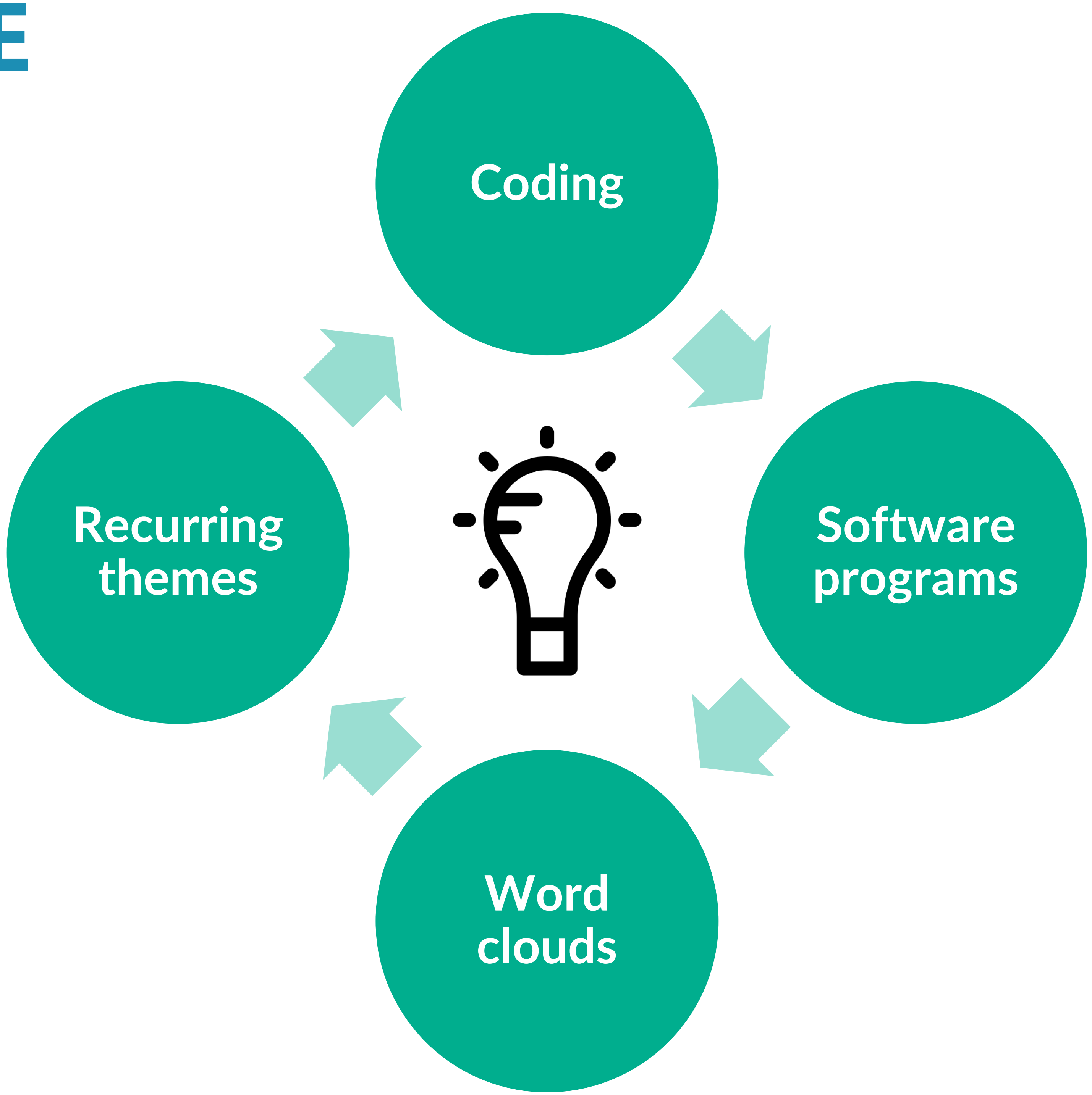
- Concepts like depression & pain effectively addressed by existing PRO instruments
- Other concepts are not
- This study helps identify opportunities to refine existing PRO instruments

DURING RESEARCH:
CREATING AN INSTRUMENT

Methods

1. Seek direction from patient nodes
2. Engage patient expert consultants to assist coders to capture patient in-group terminology alongside mainstream medical slang
3. Code for patient slang & technical jargon (i.e., insomnia, painsomnia, & sleep issues are all used interchangeably)
4. Ask patients to “reality check” raw data for authenticity

TOOLS TO CREATE AN INSTRUMENT FROM SOCIAL MEDIA CONTENT


Coding

Software programs

Word clouds

Recurring themes

DURING RESEARCH:
RECRUITING PARTICIPANTS

Multiple Platforms

Facebook, Twitter, YouTube, Emails, Blogs, Instagram

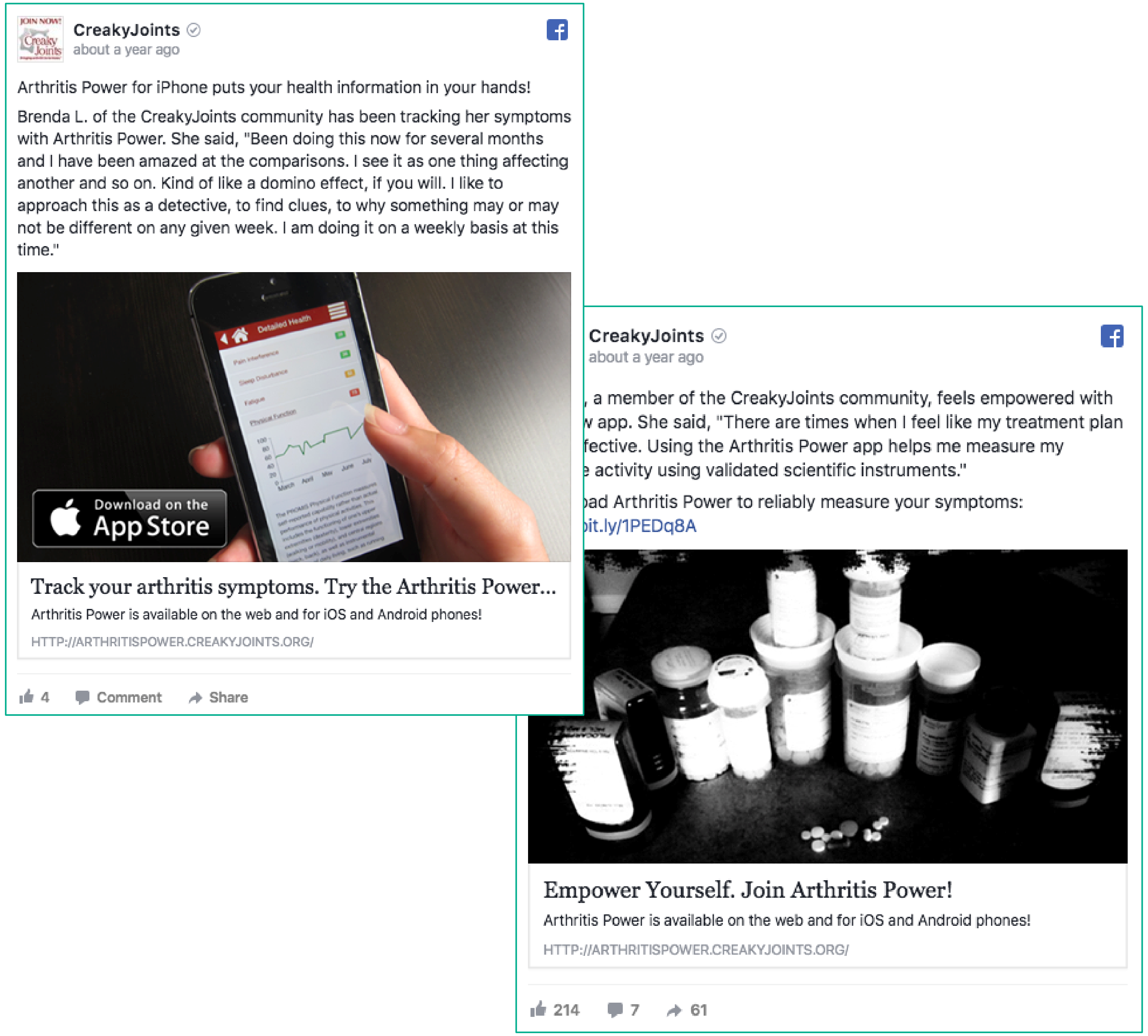
Multiple Objectives

- Recruit participants to participate
- Deploy messages to target populations
- Use metrics to assess effectiveness of posts/messages

FACEBOOK ADS AID RECRUITMENT

Ads with testimonies drive most clicks and lowest cost per conversion

- Use an image
- Create short call-to-action
- Consider boosting posts
- Use Facebook Live to stream interesting moments



CreakyJoints
about a year ago

Arthritis Power for iPhone puts your health information in your hands!

Brenda L. of the CreakyJoints community has been tracking her symptoms with Arthritis Power. She said, "Been doing this now for several months and I have been amazed at the comparisons. I see it as one thing affecting another and so on. Kind of like a domino effect, if you will. I like to approach this as a detective, to find clues, to why something may or may not be different on any given week. I am doing it on a weekly basis at this time."

Track your arthritis symptoms. Try the Arthritis Power...

Arthritis Power is available on the web and for iOS and Android phones!

HTTP://ARTHRITISPOWER.CREAKYJOINTS.ORG/

CreakyJoints
about a year ago

, a member of the CreakyJoints community, feels empowered with
v app. She said, "There are times when I feel like my treatment plan
fective. Using the Arthritis Power app helps me measure my
e activity using validated scientific instruments."

oad Arthritis Power to reliably measure your symptoms:
bit.ly/1PEDq8A

Empower Yourself. Join Arthritis Power!

Arthritis Power is available on the web and for iOS and Android phones!

HTTP://ARTHRITISPOWER.CREAKYJOINTS.ORG/

FACEBOOK ADS AID RECRUITMENT

- Try different messages for different audiences
- Identify messages that are driving enrollment
- Optimize by metrics like cost per conversions, clicks, and click-through-rate
- Shift budget to best performing ads, create more like them
- Use Facebook re-targeting ads
- Always ask for an email address on the sign-up form so you can email those who did not enroll

USE LIBERATED ORBITAL CONTENT

Traditional Model

- Sites have content
- We (users) orbit around them
- We reach out to site whenever we want content/connection
- These demands change sites (e.g., responsive design)

New Model

- Distillation
  - Content stripped to “bare bones” message
  - Remains HIGHLY attributed (clear where it came from)
- Association
  - Content is associated with a user (e.g., Facebook account)

PROVIDE A SOCIAL MEDIA RECRUITMENT KIT FOR YOUR RESEARCH TEAM

- Information on who should use the recruitment kit and how
- Templates for Tweets, Facebook posts and/or blog posts
- Hashtags and handles, if applicable
- Videos
- GIFs
- Shareable images
- Physical materials

AFTER RESEARCH

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AFTER RESEARCH:
DISSEMINATING FINDINGS

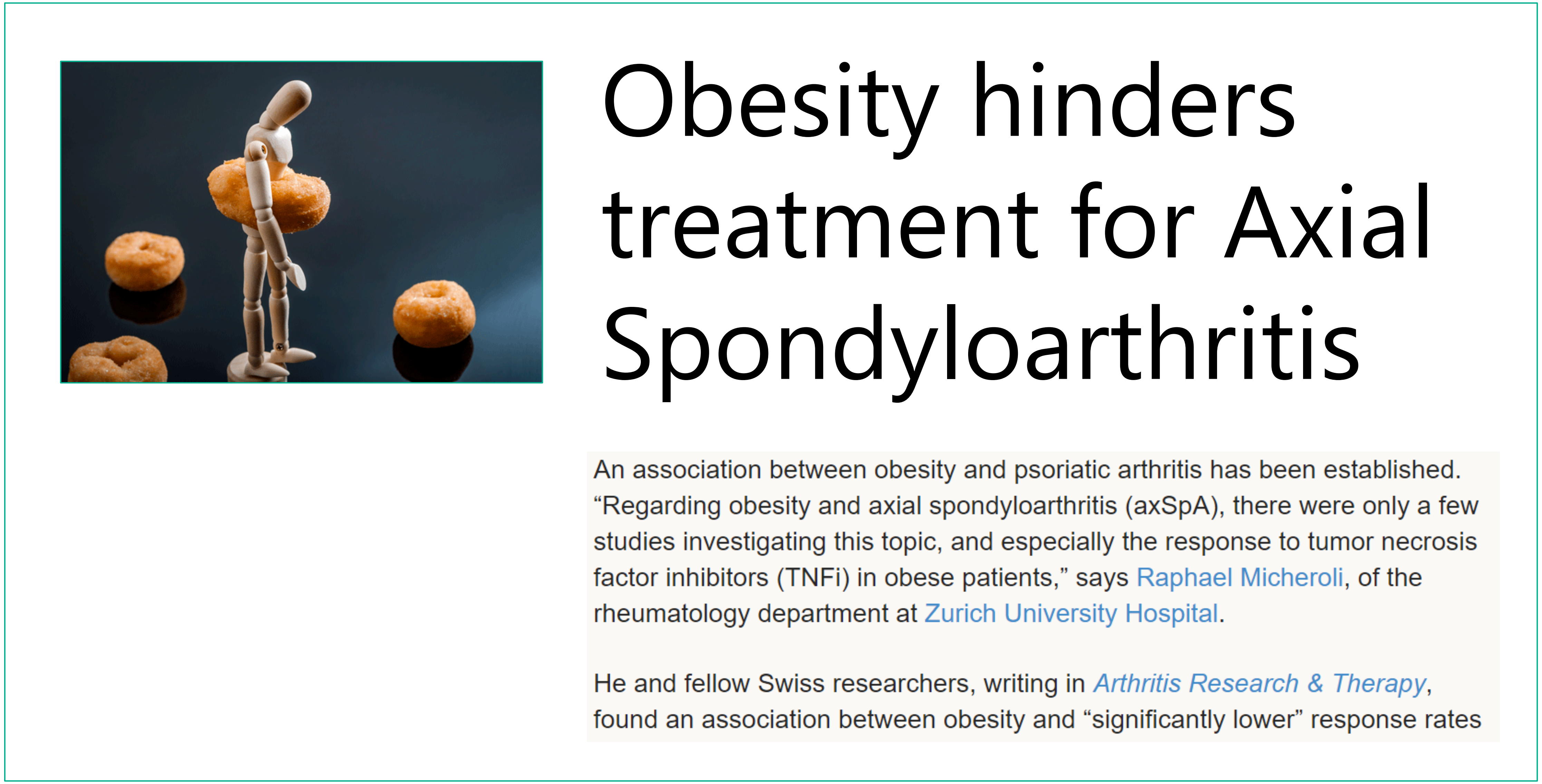
- **WHAT** information are you sharing?
- **WHY** is it important to share this information?
- **WHO** are your partners to help share this information?
- **HOW** are you going to disseminate this information?
- **WHEN** are you able to share it?

AFTER RESEARCH:
DISSEMINATING FINDINGS

Approaches

- Post concise news headline (with image) that links to full news article, research publication or abstract
- Create stand alone infographics for quick consumption
- Conduct Facebook Live or Twitter chats to discuss findings
- Direct patients to blogs summarizing research findings in accessible language
- Use a combination of social media and print media to share information with providers

POST HEADLINE AND IMAGE TO RAISE INTEREST

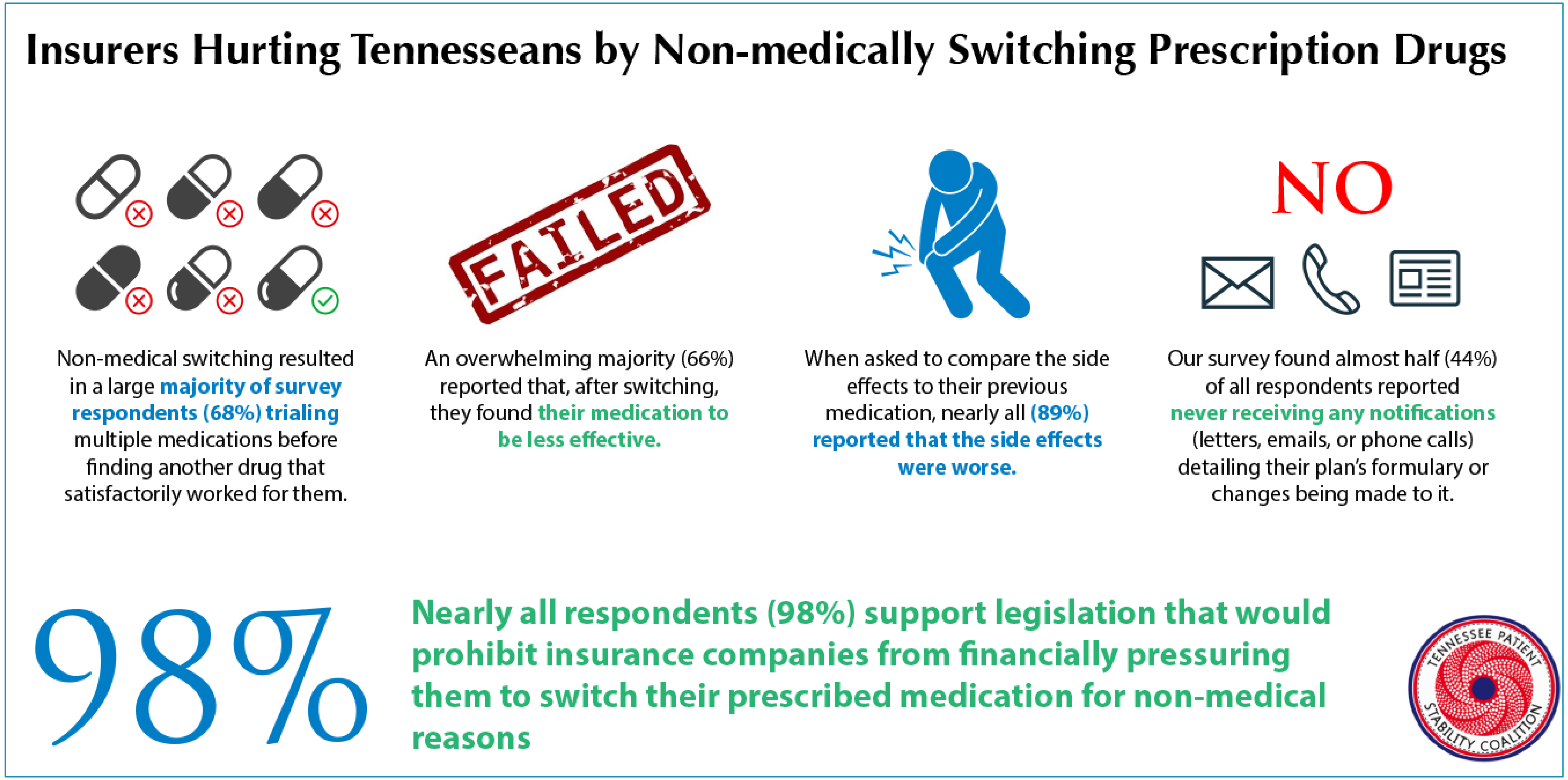


Obesity hinders treatment for Axial Spondyloarthritis

An association between obesity and psoriatic arthritis has been established. “Regarding obesity and axial spondyloarthritis (axSpA), there were only a few studies investigating this topic, and especially the response to tumor necrosis factor inhibitors (TNFi) in obese patients,” says Raphael Micheroli, of the rheumatology department at Zurich University Hospital.

He and fellow Swiss researchers, writing in *Arthritis Research & Therapy*, found an association between obesity and “significantly lower” response rates

INFOGRAPHICS ARE A CONCISE WAY TO SHARE INFO



Insurers Hurting Tennesseans by Non-medically Switching Prescription Drugs

Non-medical switching resulted in a large **majority of survey respondents (68%) trialing** multiple medications before finding another drug that satisfactorily worked for them.

An overwhelming majority (66%) reported that, after switching, they found **their medication to be less effective.**

When asked to compare the side effects to their previous medication, nearly all **(89%) reported that the side effects were worse.**

Our survey found almost half (44%) of all respondents reported **never receiving any notifications** (letters, emails, or phone calls) detailing their plan's formulary or changes being made to it.

98%

Nearly all respondents (98%) support legislation that would prohibit insurance companies from financially pressuring them to switch their prescribed medication for non-medical reasons

KEYS TO DISSEMINATING RESEARCH FINDINGS

- Develop short, visibly engaging posts to get the most ‘views’
- Translate findings into language that a general audience can understand
- Highlight why the research findings matter and to whom they matter
- Use graphics or images

SOCIAL MEDIA CAN BE PART OF EVERY PHASE OF RESEARCH

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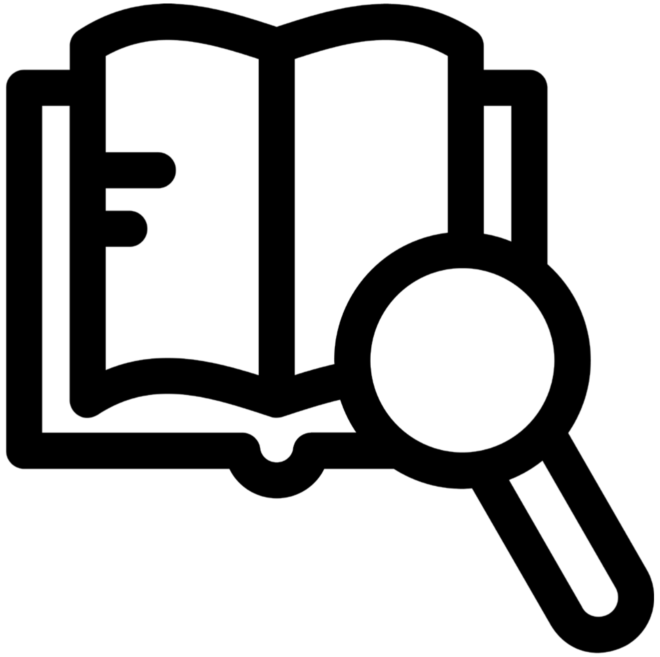
IRB: RECRUITING VIA SOCIAL MEDIA

- Ensure text follows IRB guidance for recruitment materials
- Describe target population and rationale for targeting
- Provide plan for frequency of messages, communication method (i.e. private Facebook messages) and process for responding to incoming messages
- Specify which study staff will be communicating out and monitoring a recruitment account & procedures to monitor the activity of those staff
- Specify if you will collect data via social media as part of recruitment process
- Describe how you will communicate to potential subjects that information shared via social media is not secure
- Include ALL images/text that may be used for recruitment

PROVIDE A GLOSSARY OF TERMS



- Glossaries can contain disease specific terminology, patient centered research terminology and social media terminology
- Never assume that everyone has the same level of familiarity with social media
- Providing a glossary of terms with links and resources
- It may also be useful to ask patient partners and researchers to review your glossary of terms and provide input on whether additional terms need to be added
- When providing definitions, always provide appropriate citation for definitions