LRAN

Lupus Research Action Network

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by Lupus Foundation of America

Help Us Solve
The Cruel Mystery
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Lupus Research Action Network Training

May 19, 2024

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WELCOME

Goals and Objectives:

- Increase Understanding and Importance of Lupus Research
- Increase Participation in Lupus Research
- Help Solve the Cruel Mystery!

Meeting Agenda

- Diversity in Clinical Trials
- The Power of Your Voice
- Your Action Plan
- How to Talk about Trials
- Breakout Groups
- Post Training Survey

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Improving Minority Participation and Awareness of Clinical Trials (IMPACT+)

Stephanie Slan, MBA, ACRP-CP
Project Director, IMPACT+
Lupus Foundation of America

IMPACT+ Project

Improving Minority Participation and Awareness of Clinical Trials

- Grant funded by the Office of Minority Health as part of the National Lupus Outreach and Clinical Trials Educations Program
- Program Goal: Demonstrate the effectiveness of interventions for increasing racial and ethnic minority enrollment and retention in lupus-related clinical trials
- Focus on capacity building of LRAN members and improved targeting of marketing materials and enrollment in Research Accelerated by You (RAY), our patient powered database.

IMPACT+ Project Goal One

By September 2026:

Goal 1:

1. Build capacity amongst existing LRAN members and provide enhanced training for 60 highly engaged LRAN members for the expansion of outreach and engagement to increase Black/African American (B/AA) patient enrollment and retention in clinical trials and enrollment in Research Accelerated by You (RAY)
2. Encourage and facilitate LRAN member community outreach and engagement opportunities to increase awareness of the importance of enrollment and participation in the RAY registry and CT amongst B/AA PWL

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IMPACT+ Project Goals

By September 2026

Goal 2:

1. Explore B/AA motivations and preferences for registry and clinical trial participation and translate motivations and preferences into targeted recruitment and communication strategies that are both culturally and linguistically appropriate
2. Pilot test newly developed strategies to examine effectiveness and acceptability within the target population
3. Increase Black/African American enrollment in the RAY patient and caregiver registry by 200 new B/AA participants to ensure inclusive access to the adapted Lupus Conversations Program and clinical trial engagement opportunities sponsored by academic/industry partners using newly developed, multi-level communication strategies

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Lupus Research Action Network

Overview

The Lupus Research Action Network (LRAN) is a group of Individuals living with lupus who are committed and empowered to advance lupus research through advocacy, awareness and education.

Goal: Increase knowledge about and participation in lupus research, including clinical trials, through a trusted peer network, including a focus to increase engagement in lupus research among racial and ethnic minority groups.

Objective: Educate LRAN participants about research, clinical trials and provide best practices and opportunities to speak to others with lupus about participating in lupus research

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Your Role as an LRAN Member

What are we looking for from LRAN Members?

- LRAN Members will be:
  - Knowledgeable about lupus and living with the disease
  - Have an interest in lupus advocacy, research and clinical trials
  - Willing to connect with people living with lupus in their communities and networks
  - Passionate about advancing lupus research and elevating the patient voice in research and clinical trials

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LRAN Member Engagement

How will LRAN members reach others?

- Sharing personal experiences with lupus research at a variety of lupus community events
- Represent the Foundation and lupus community on lupus research focused panel discussions, focus groups, etc.
- Connect one-on-one with people with lupus interested in lupus research
- Share the Foundation's research work among networks on social media
- Report outreach efforts to Regional/Chapter staff upon completion
- Share with other Lupus Warriors how they can learn more about lupus research and take a first step by enrolling in the Research Accelerated by You (RAY) registry

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Diversity in Clinical Trials

Joan T. Merrill, M.D.
Professor, Arthritis & Clinical Immunology Research Program, Oklahoma Medical Research Foundation
OMRF Professor of Medicine, University of Oklahoma

Lupus Clinical Trials: Increasing Diversity

Did you Know?

- There are only **THREE** treatments that have been developed specifically for lupus and approved by the FDA
- Black/African American people make up 43% of SLE cases
  - Black/African Americans make up only 14% of clinical trial participants.
- Racial and ethnic minority women are at greatest risk for lupus
  - As a cause of death in Black and Hispanic women, SLE ranks 5th in people 15–24 years old, 6th for those 25–34 years old and 8th–9th for 35–44 years old.

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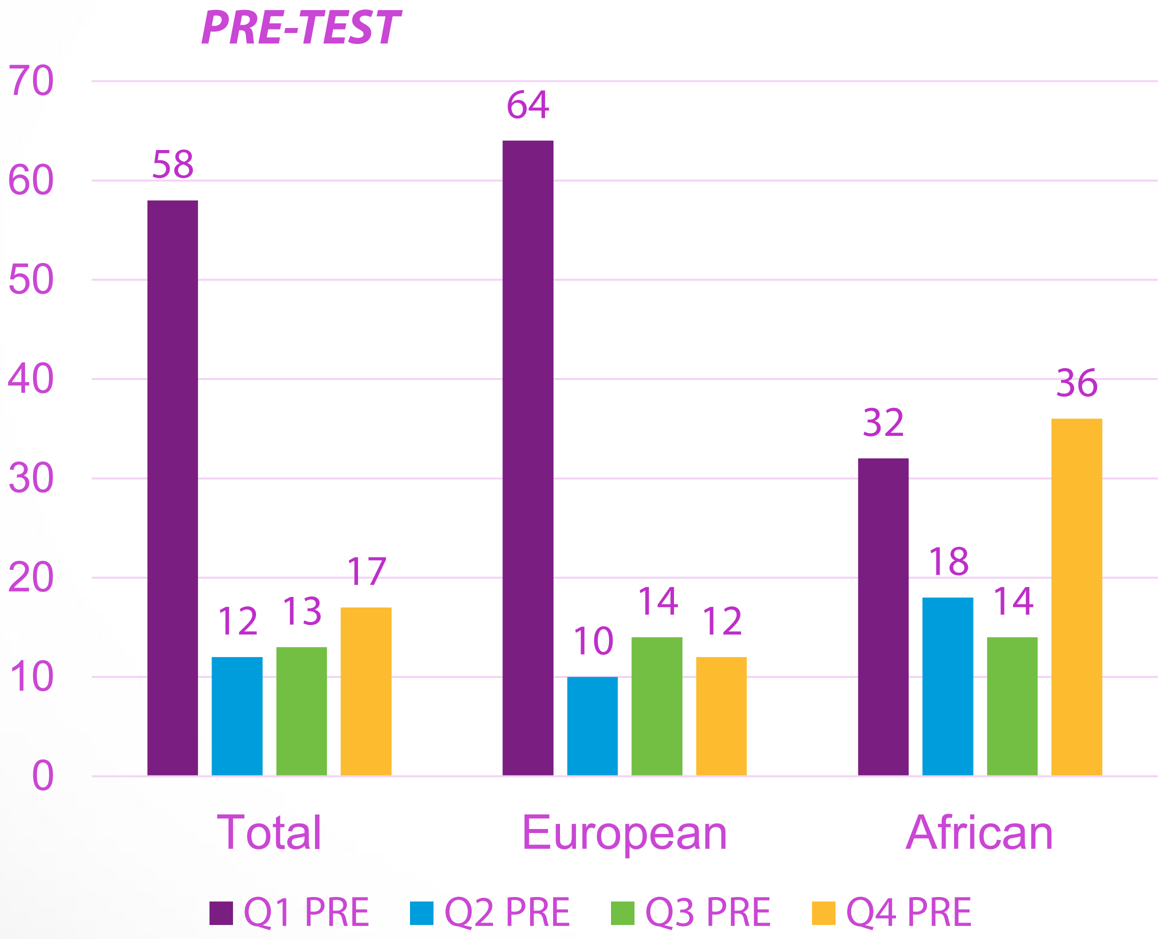
Source: Yen EY, Singh RR. Brief Report: Lupus-An Unrecognized Leading Cause of Death in Young Females: A Population-Based Study Using Nationwide Death Certificates, 2000-2015. Arthritis Rheumatol. 2018 Aug;70(8):1251-1255. doi: 10.1002/art.40512. Epub 2018 Jun 27. PMID: 29671279; PMCID: PMC6105528.

All of the Following Are Important To Understand Before Taking Part in Clinical Research EXCEPT



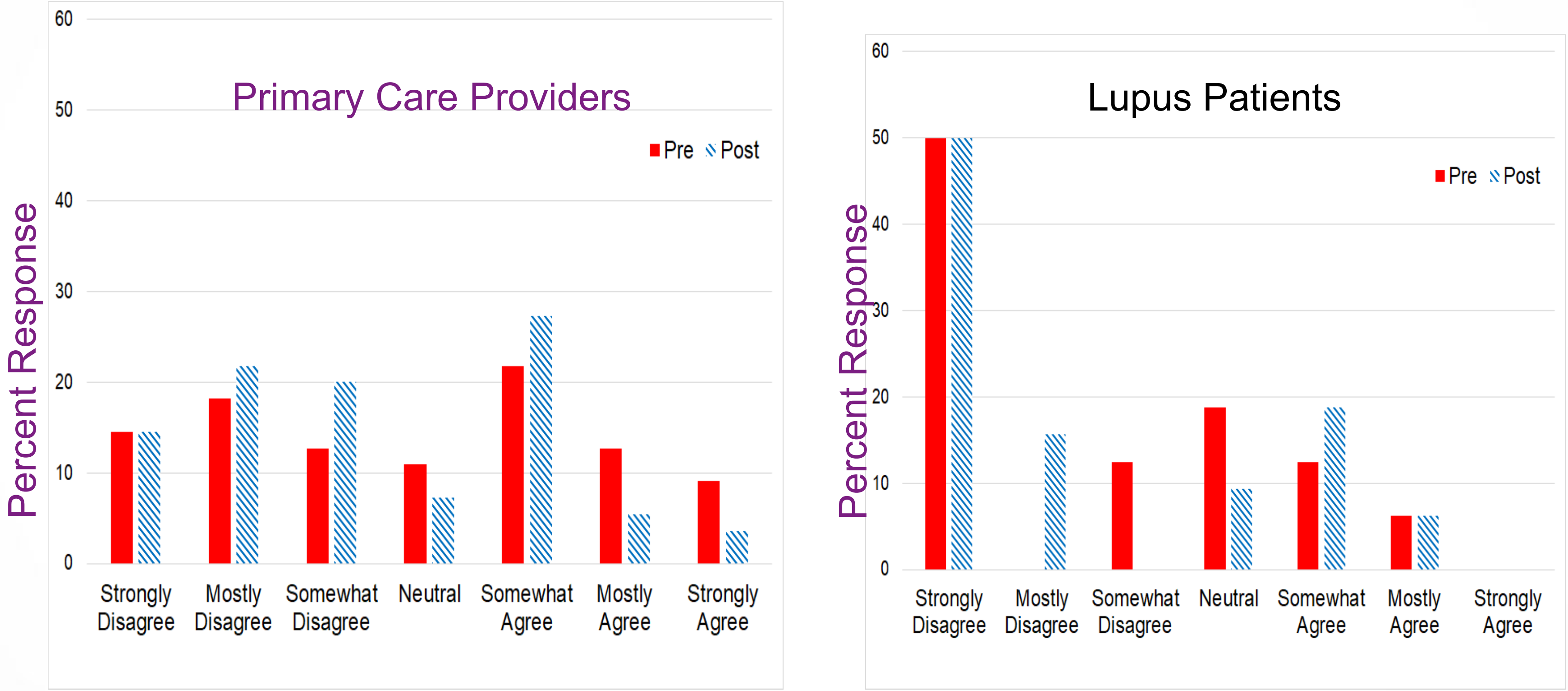
1. Informed consent is a commitment to follow the protocol even when you no longer want to

2. Knowing what side effects or other risks might be

3. Understanding what participation involves

4. Understanding why the study is being done

Perceived Impact of Poverty on Study Protocol Adherence



Patients were less likely to agree that poverty reduced protocol adherence (p=0.0037)
Clinicians did shift towards less strong agreement after taking the program

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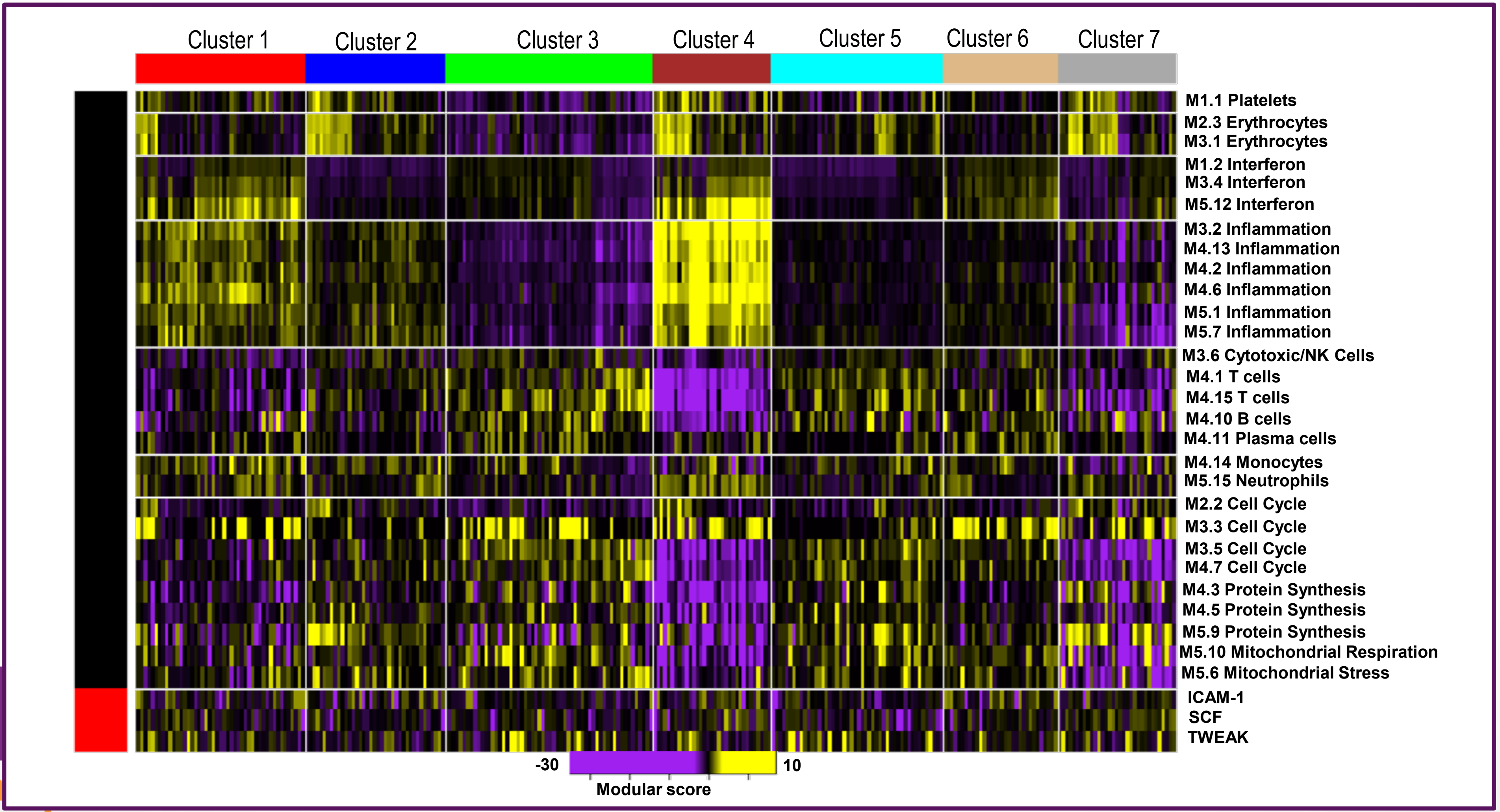
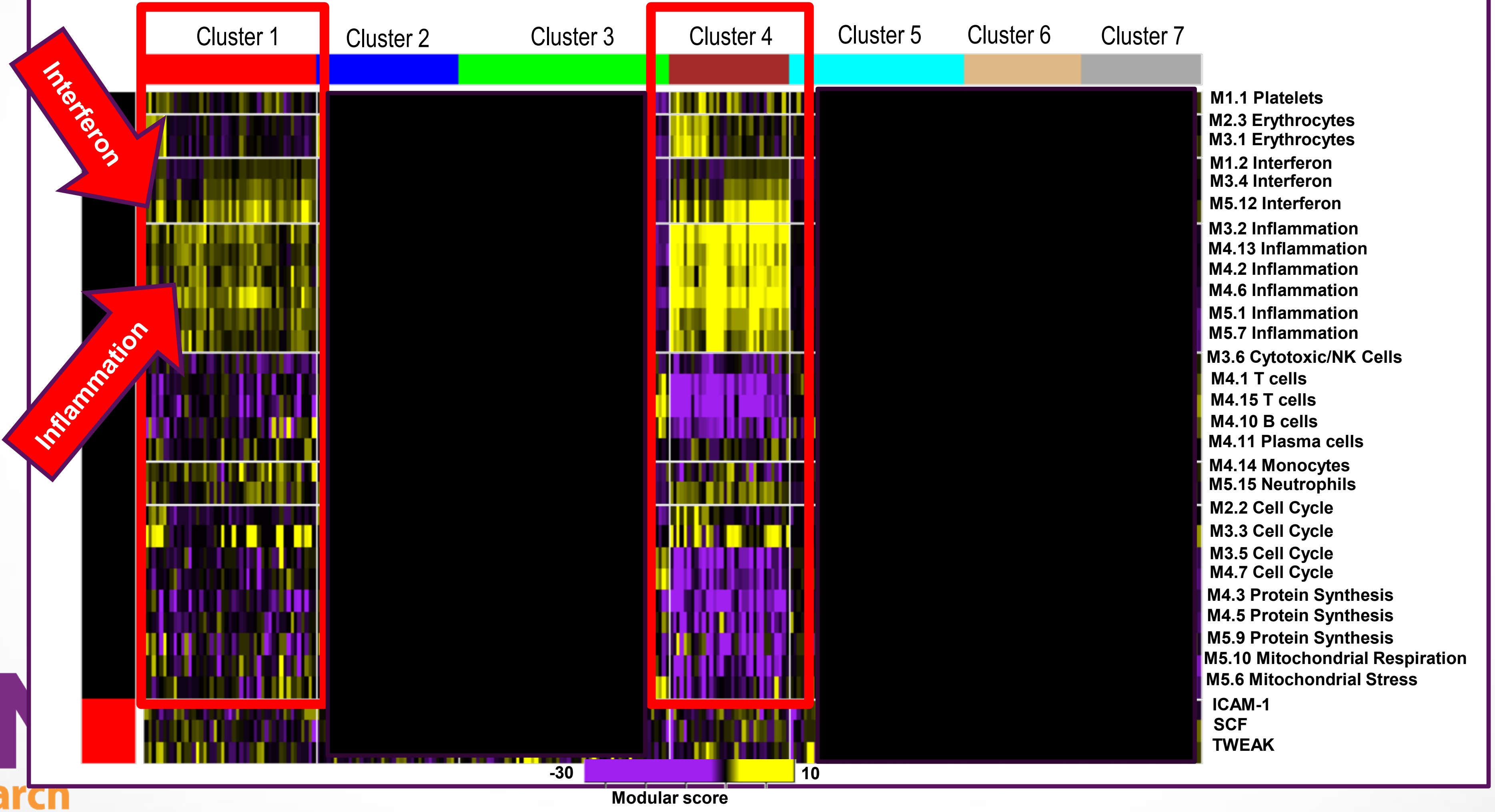
Errr… Could You Go Back and Say That Again in English?



Lu et al ACR 2017

Molecular Phenotypes of Individuals In Clusters:
Random Forest Modeling of Expression in Gene Pathway Modules



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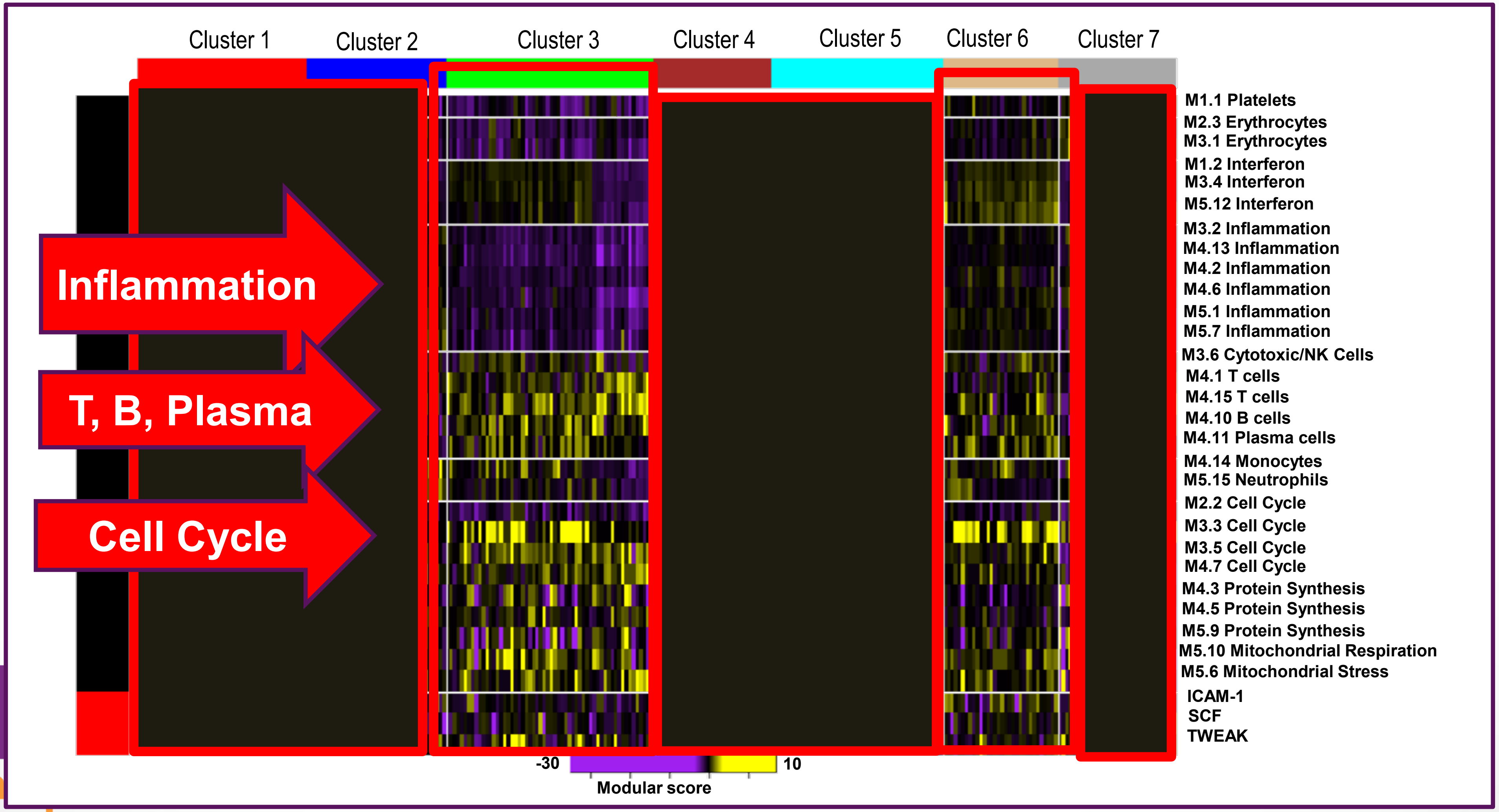
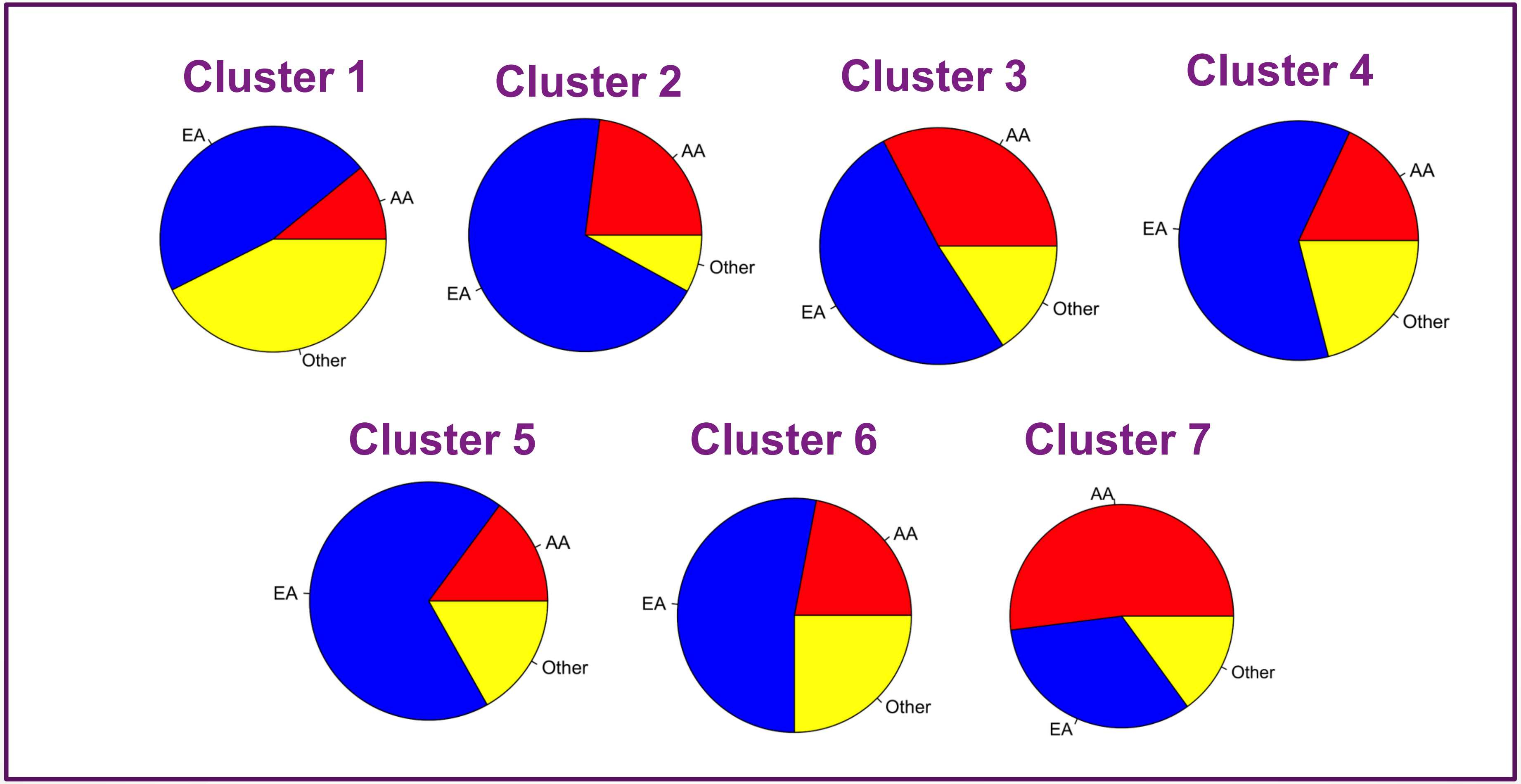
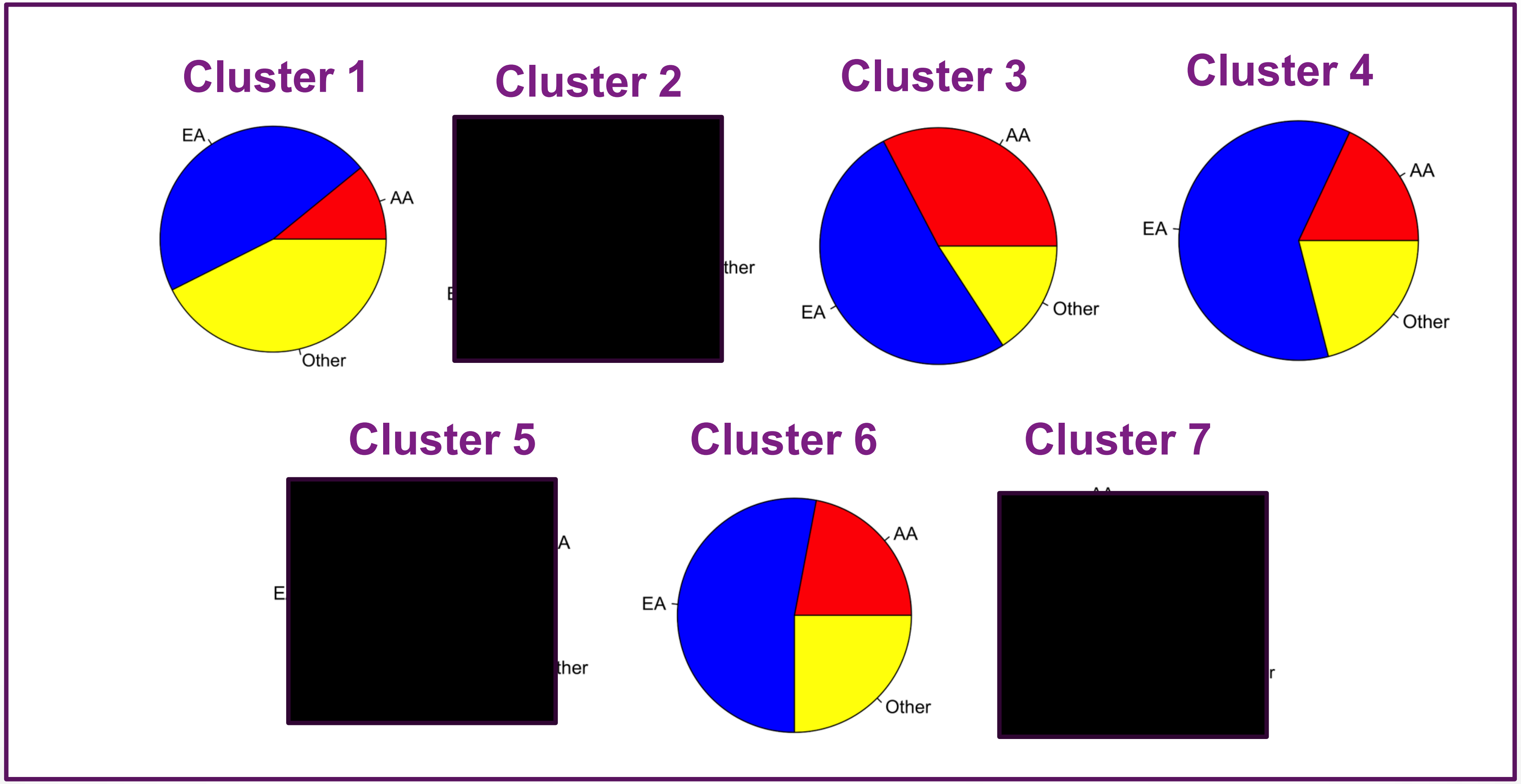


Lu et al ACR 2017

Racial Distribution in Each Molecular Phenotype Cluster



Racial Distribution in Each Molecular Phenotype Cluster



[redacted]

[redacted]

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How Can We Interpret This?

- Race Does Not Dictate What Drug is Best For You
- More people of a given race may have a given immune imbalance
  - Although people of other races will be sharing it, there will not be as great a percent of them
  - Therefore, imbalance in representation of any race may mean treatments are not being optimally tested for them

People are not identical, but they overlap

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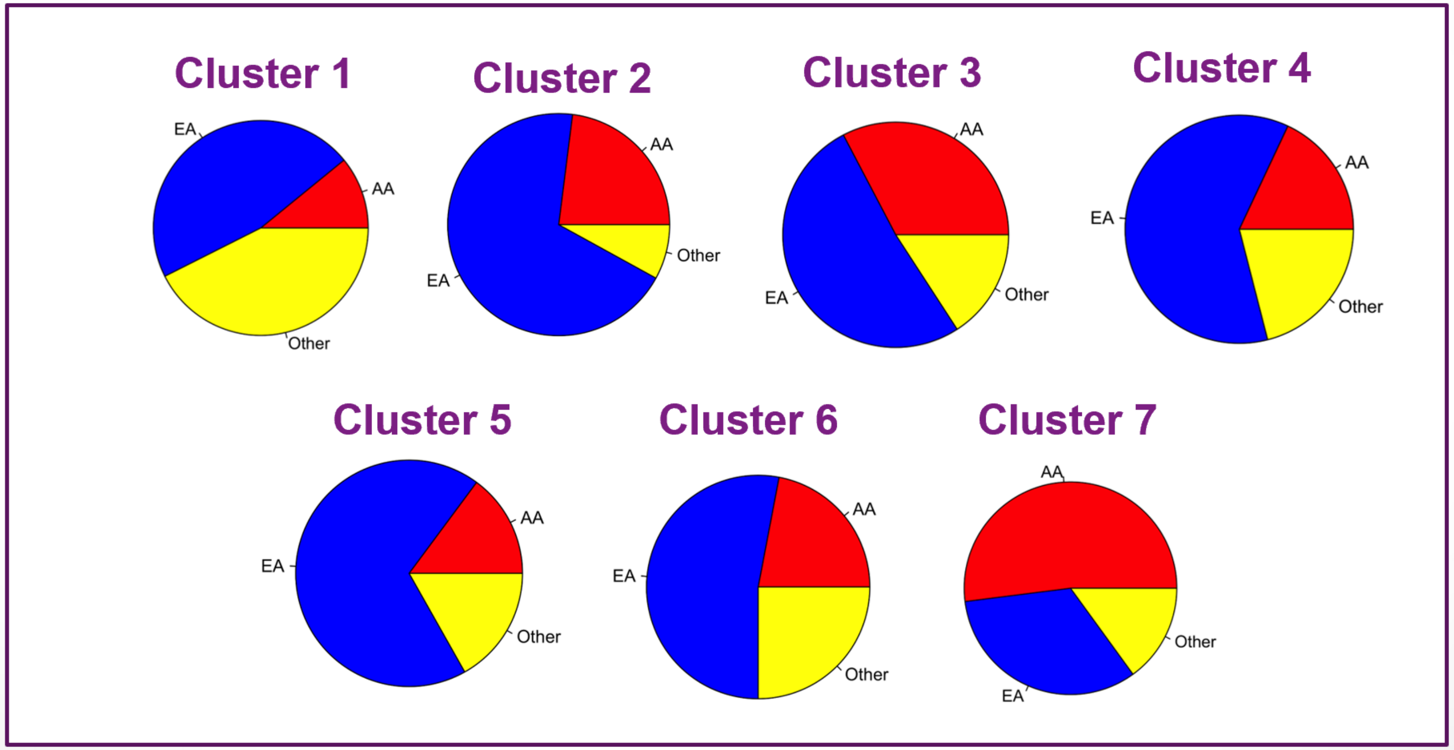
Belimumab

People of African Descent underrepresented in Original Trials
So, the FDA said You must do a Trial Just for one Race
Was that a good idea?



We Need Representation of Diverse People to Help Each Person Know what Drugs are more likely to work for them-as an Individual

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The Power of Your Voice

Dr. Rosalind Ramsey-Goldman
Professor of Medicine, Feinberg School of Medicine
Northwestern University

Popular Opinion Leader Model

Background and Introduction:

- This model is being adapted for use in the IMPACT+ program
- The Popular Opinion Leader (POL) Model will be used to lead community education strategies
- Educating people living with lupus about clinical trials
  - In-person, one-on-one interactions
  - Events
  - Social Networks

Popular Opinion Leader (POL) Model

- What is a Popular Opinion Leader?
  - These are individuals who are typically respected, well-informed, and trusted members of a social group
- Popular Opinion Leader Model
  - Multi-level intervention model, developed by the CDC, and successfully employed in a variety of public health contexts
  - Intervention designed to influence norms, behaviors, intentions and prompt actions at the community level

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How will the POL Model work?

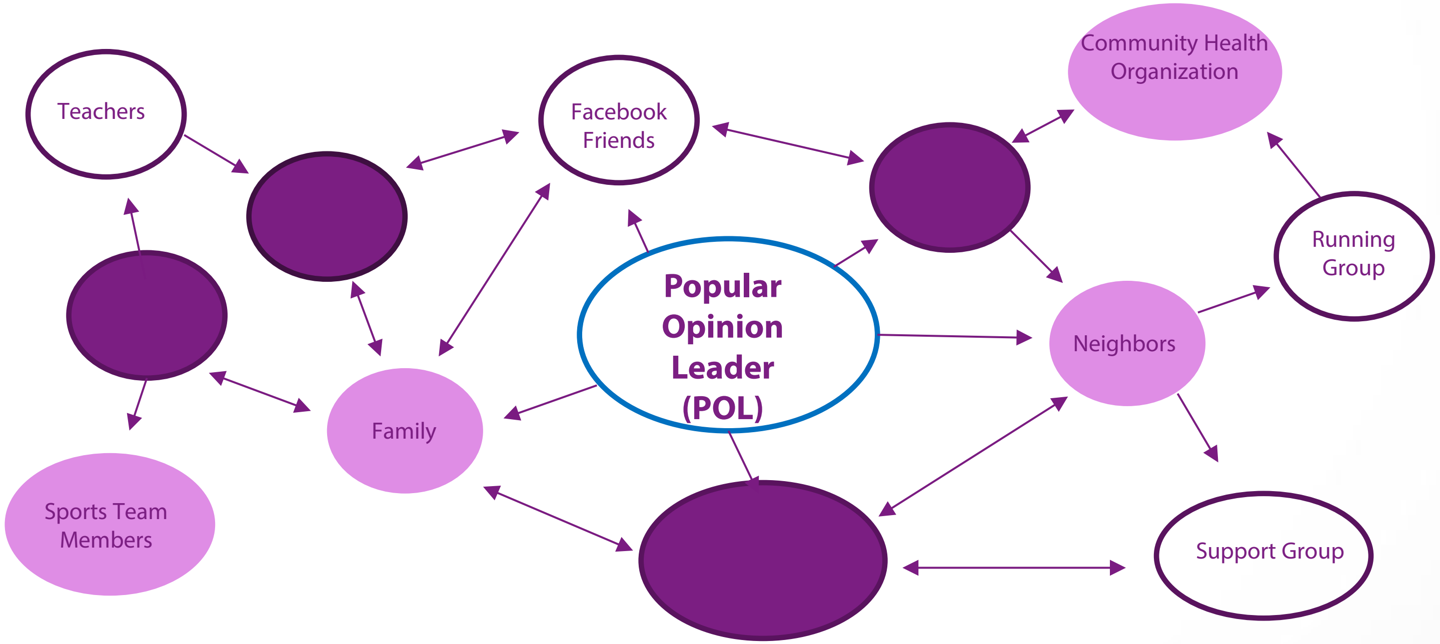
- As a Popular Opinion Leader, you will be sharing information on clinical trials throughout your community:
  - Communicate trust
  - Increase knowledge and awareness of clinical trials
  - Change perceptions of clinical trials
  - Increase participation in lupus clinical trials
- POL model is based on the social diffusion theory; behaviors change in a population can be initiated and will then diffuse to others if enough opinion leaders within the populations are known to adopt, endorse, and support the behavior

LRAN Participants are Popular Opinion Leaders!

How Does a POL Influence Their Community?

- Social Network: a set of individuals or organizations who share common interests
- POLs can share information about health and scientific research through their social networks
  - Friends and Family
  - Fraternity/Sorority
  - Faith-based organizations
  - Social Media
  - Civic Group (Kiwanis club, Elks, Knights of Columbus)
  - Lupus support groups and other lupus events

Popular Opinion Leader (POL) Social Network



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How POLs Help Their Community?

- By spreading information, POLs help to…
  - Increase awareness and understanding of lupus in a community
  - Help lupus patients reach specialists to help care for their lupus
  - Spread positive messages about science-based research and clinical trials
  - Build partnerships between researchers and the surrounding community

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How do POLs Spread Information?

- POLs spread the information they know by speaking with communities, congregations, and their own social networks
- Participate in round-table discussions or community forums
- Conduct surveys or ask others about their knowledge of lupus, clinical trials, and healthcare, and spread the information they know
- Give out fact sheets, info-cards, or other tools as "conversation starters" and to remind people of the information they discussed

How is a POL's Success Measured?

- The POL model is often used in partnership with academic centers
- POL participation in studies is just as valued as professional input
- POLs record who they've spoken with and observations about meetings
- POL success if measured by the number of people they are able to engage and persuade with the intended message
- POLs demonstrate their influence by changing health seeking norms, in this case increasing the understanding of lupus clinical trials in their communities.

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Prepping for Impact:

Becoming a Trusted Opinion Leader in the Community

Edith Williams, M.S., Ph.D.

Director, Center for Community Health and Prevention, University of Rochester

Hetlena Williams, Ed.S.

Lupus Awareness Advocate

Time for Lunch

Please be ready to reconvene at 2pm

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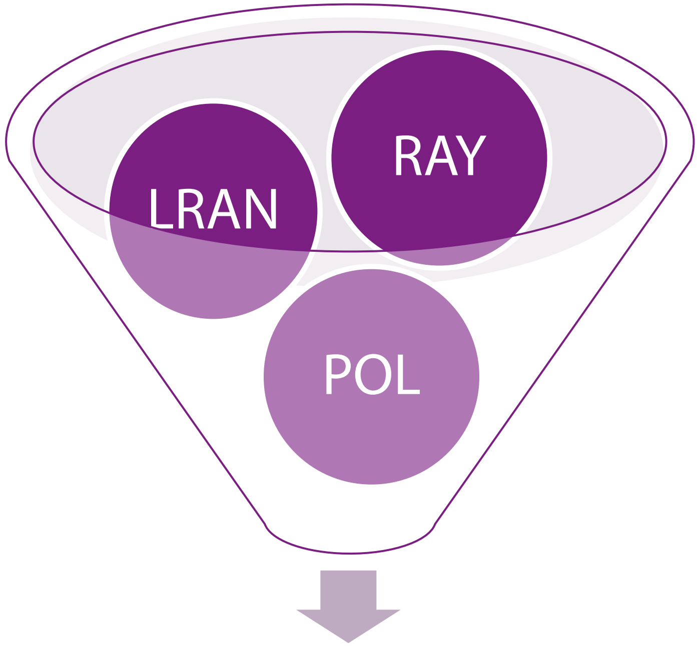
How to Talk About Trials: What, Where, When, and Who

Edith Williams, M.S., Ph.D.
Director, Center for Community Health and Prevention
University of Rochester
Hetlena Williams, Ed.S.
Lupus Awareness Advocate



IMPACT+

Improving **M**inority **P**articipation and **A**wareness of **C**linical **T**rials

+Patients with Lupus
+ Medical Community

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You ARE the Popular Opinion Leader!

- What you do can make a difference:
  - Trusted source, community leaders
  - Raise awareness and understanding within your community and networks
  - Share resources and information
  - Connect to opportunities
  - Expand reach
  - Elevate the patient voice in lupus research

How to Talk about Trials

Elements of the Conversation

- Introduction/Start the conversation (note the context):
  - Ask questions to engage the audience and introduce the topic:
    - Have you heard about RAY?
    - Are you looking for new treatment options?
    - Did you know that you can help researchers find new treatments for lupus?
    - Are you interested in learning more about what you can do to advance lupus research?
- Share your story
  - Share your experience…with lupus, quality of life, with treatments, with clinical trials.
    - Identify with the audience and communicate trust.

How to Talk about Trials

Elements of the Conversation

- Why it's important…to you…to all people with lupus:
  - Why are you participating in LRAN, why is lupus research important to you, share your experience, if applicable
  - Share key points – clinical trials are the only way to develop new treatments, participations of PWL is essential, ethnic and racial minority groups are underrepresented in clinical trials
- How to learn more… the "Ask":
  - Share opportunities (don't tell them what to do):
    - LFA website/Antidote
    - RAY
    - Ask your doctor

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Tips and Suggestions

- Keep conversation focused:
  - Interactions with you and the person living with lupus or your audience, if in a group setting, are about them, not you
- Keep your own story brief:
  - Stories should be short and have a purpose (you want them to learn more about opportunities to participate in RAY and lupus research and clinical trials)
  - Use your story to relate to your audience or the person you are speaking with, relate why research and trials are important to you, your experiences and how/why you decided to get more involved. Communicate trust. You are a Lupus Warrior too.
  - Your story should only be 3-4 bullets/key points

The Why: Key Points

- Clinical trials offer high quality care
  - Lupus specialists, expert medical care
  - Access to new treatments before they are widely available
  - Potential for compensation for participating
- Lupus trials need more participation and diversity
  - Black/African Americans make up 43% of lupus cases nationally, yet only 14% of participants in lupus clinical trials
  - Hundreds of research studies and trials are available and need patients to participate

The Why: Key Points

- Clinical trials are the only way to get new treatments
  - There are seven FDA approved treatments (three developed specifically for lupus)
  - Lupus affects each person differently, a diverse group of people living with lupus participating in research helps to ensure treatments have the greatest effect on the largest number of patients
- Participation is always voluntary, and safety is a priority
  - Your decision to participate is not permanent, you may choose to leave the study at any time
  - Researchers follow detailed protocols and safety requirements to make each trials as safe as possible

How to Learn More: The Asks

- Research Accelerated by You (RAY)
  - Enrollment allows access to information on clinical trial opportunities. Share what is most important to PWL and what it is like to live with lupus.
- Ask you Doctor for more information
  - Your doctor may be able to tell you about trials available for which you may qualify. They can help explain the benefits and risks and whether a trial may be right for you.
- LFA Resources
  - National Resource Center on Lupus

    https://www.lupus.org/resources (search clinical trials)
  - Antidote: clinical trial search tool

    https://www.antidote.me/conditions/lupus

Where to Talk about Trials

We will share opportunities with you!

- Lupus Walk
- Lupus and You Meetings
- Support Group Meetings
- Advocacy Summit
- Doctor's Office
- Social and community gatherings, such as church or other community organizations you are involved with
- Engaging with other Lupus Warriors
- Social Media

Make M.O.R.E. of an IMPACT with RAY

- **MAKE** the person aware of opportunity,
- **OWN** what you do and don’t know,
- **REFER** to how they can get involved and resources,
- **EMPOWER** and encourage them now that they are informed with reasons to make a decision

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BREAKOUT GROUPS

How to Talk About Trials

- Making an IMPACT by Doing MORE! As a group, brainstorm about the four key elements:
  - Start the conversation/Introduction
  - About you
  - Why? Why important to you… and all people living with lupus
  - How to learn more… the Ask - what they can do
- Facilitated discussion
- Breakout Rooms (4 Groups)
- Each group will share their ideas following the breakout

How to Talk About Trials:

Example Conversation

- This approach aims to engage the audience, share personal experiences, and acknowledge the specific concerns of the community, ultimately fostering a more open and trusting dialogue about clinical trials.
- Key Elements:
  - Start the Conversation
  - Share Your Story
  - Engage the Audience
  - Identify with the Audience and Communicate Trust

Breakout Groups:

- Group 1
  - Scenario: You are at a Lupus Walk at the Lupus resources table
- Group 2
  - Scenario: You are at a support group meeting
- Group 3
  - Scenario: You have been asked to present at a Lupus & You (L&Y) education event.
- Group 4
  - Scenario: You are at the National Lupus Advocacy Summit

Breakout Group Reports

Let's Share

- Each group shares key takeaways and strategies for talking to their communities about clinical trials.
- By encouraging open dialogue and building trust, we can empower communities to make informed decisions about clinical trials and pave the way for a brighter future for everyone living with lupus.

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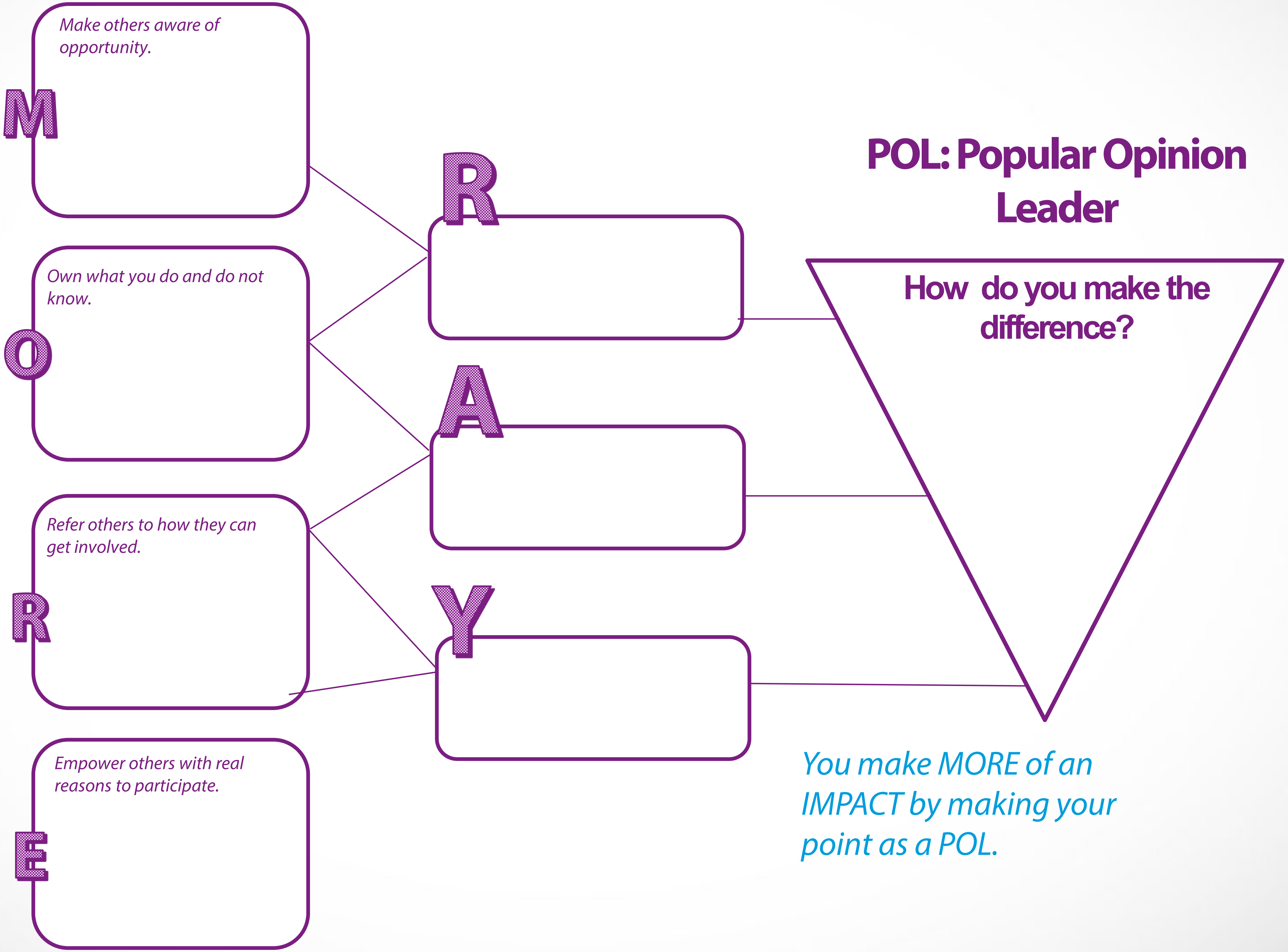
Your Action Plan:

Next Steps and Resources

POL: Popular Opinion Leader



M

Make others aware of opportunity.

O

Own what you do and do not know.

R

Refer others to how they can get involved.

E

Empower others with real reasons to participate.

R

A

Y

How do you make the difference?

You make MORE of an IMPACT by making your point as a POL.

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Now What?

Next Steps and Resources

- Its time to use the information you have learned today
- We have created some tools to help you as you share your knowledge with other people living with lupus
- We will be here to support you as you speak in your communities.

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BEHIND EVERY NEW

TREATMENT

ARE **VOLUNTEERS** WHO PARTICIPATE IN

CLINICAL RESEARCH STUDIES

Lupus Clinical Trial Resources

- Variety of resources about clinical trials and value of volunteer participants
  - Specific resources available tied to minority participation in research
- Learn about clinical trials
  - What is a clinical trial?
  - Why should I volunteer?
  - What lupus trials are enrolling?
- How do I find a trial near me?
- Find lupus clinical trials
- Explore ways to get involved in research
  - lupus.org/advancing-research/get-involved-in-research

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Lupus Clinical Trial Resources

- Online HUB available exclusively for LRAN members
  - Information about RAY and links to enroll
  - Fact sheets and links to information about clinical trials
  - Antidote search tool to identify trials near you and for which you may be eligible to participate
  - Talking points, handouts, sample presentations to guide you in speaking at events
  - Information and public links you can share to learn more about clinical trials
  - LRAN training presentations
  - Continuously updated with additional content, including based on your feedback

LRAN Engagement

- Forum for LRAN participants to share experiences and engage with each other
- Sharing your activities
  - Regional Directors, Chapter Leaders, LFA national staff
  - Details: date, locations, audience
  - Best Practices: what works, what can be improved
  - Your ideas and needs: how can we help you?

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Program Evaluation

Melicent R. Miller, DrPH, MSPH

Director, Federal Grants and Public Health Programs
Lupus Foundation of America

THANK YOU!