

Engaging Patients with Aortic Dissections as Partners in Patient  
Centered Outcomes Research

# Research Priorities of the Aortic Dissection Community

## A Report to the Community



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Associate Professor of Surgery

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Division of Vascular Surgery, University of Washington

5/20/2022

# Welcome!

- All lines are muted, due to the large number of participants
- The chat is open for questions or discussion
- This presentation will be made available on our website after today's session ([ADCollaborative.org](http://ADCollaborative.org))

# Disclosures

- Research support from the Patient-Centered Outcomes Research Institute (PCORI)
- Advisory boards for the Ehlers-Danlos Society and Marfan Foundation

A photograph showing a doctor in a light blue shirt using a stethoscope to examine a young child sitting on a table. A woman, presumably the parent, stands behind the child, looking on. The scene is set in a clinical or hospital environment with a white wall and a paper towel dispenser visible in the background.

# Improving Outcomes Important to Patients

PCORI funds studies that can help patients and those who care for them make better-informed healthcare choices.

Established by the 2010 Patient Protection and Affordable Care Act

A government-sponsored 501(c) organization charged with investigating the relative effectiveness of various medical treatments

Funds comparative clinical effectiveness research (CER) that ***engages patients and other stakeholders throughout the research process***

# Bridging the Gap

## Engaging Patients as Research Partners

Patients with aortic dissections face dramatically different options for care without strong evidence for the long-term consequences of those options at an individual level





Engaging Patients with or at risk for Aortic Dissection as Partners in Patient Centered Outcomes Research



**COVID-19-Related Project Enhancement**

By leveraging existing networks to reach the aortic dissection (AD) community through online patient support networks and advocacy and professional

To *create* and sustain a collaborative network of diverse stakeholders, individuals, and organizations

to *understand* patient research needs

and *determine the research methods* best suited to answer the relevant questions



**A**  **ORTIC**  
**DISSECTION**  
**AWARENESS**

 **UK & IRELAND** 

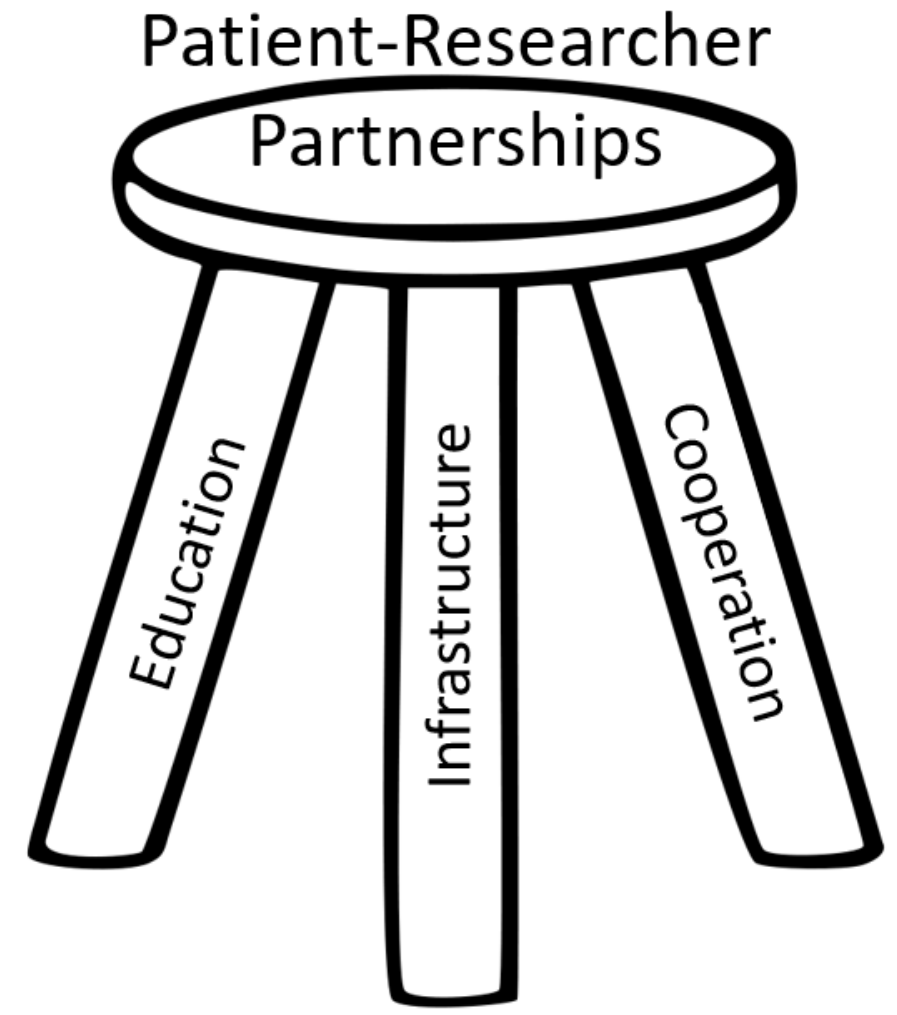
**TODAY IS A GOOD DAY**



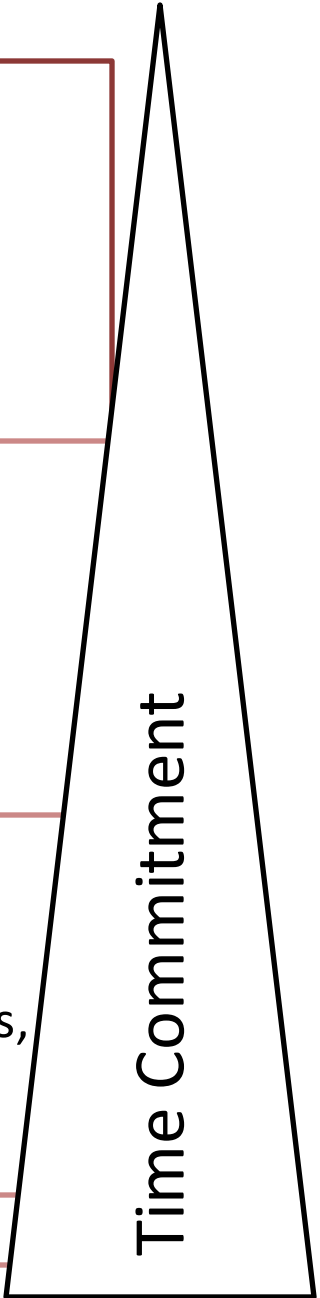
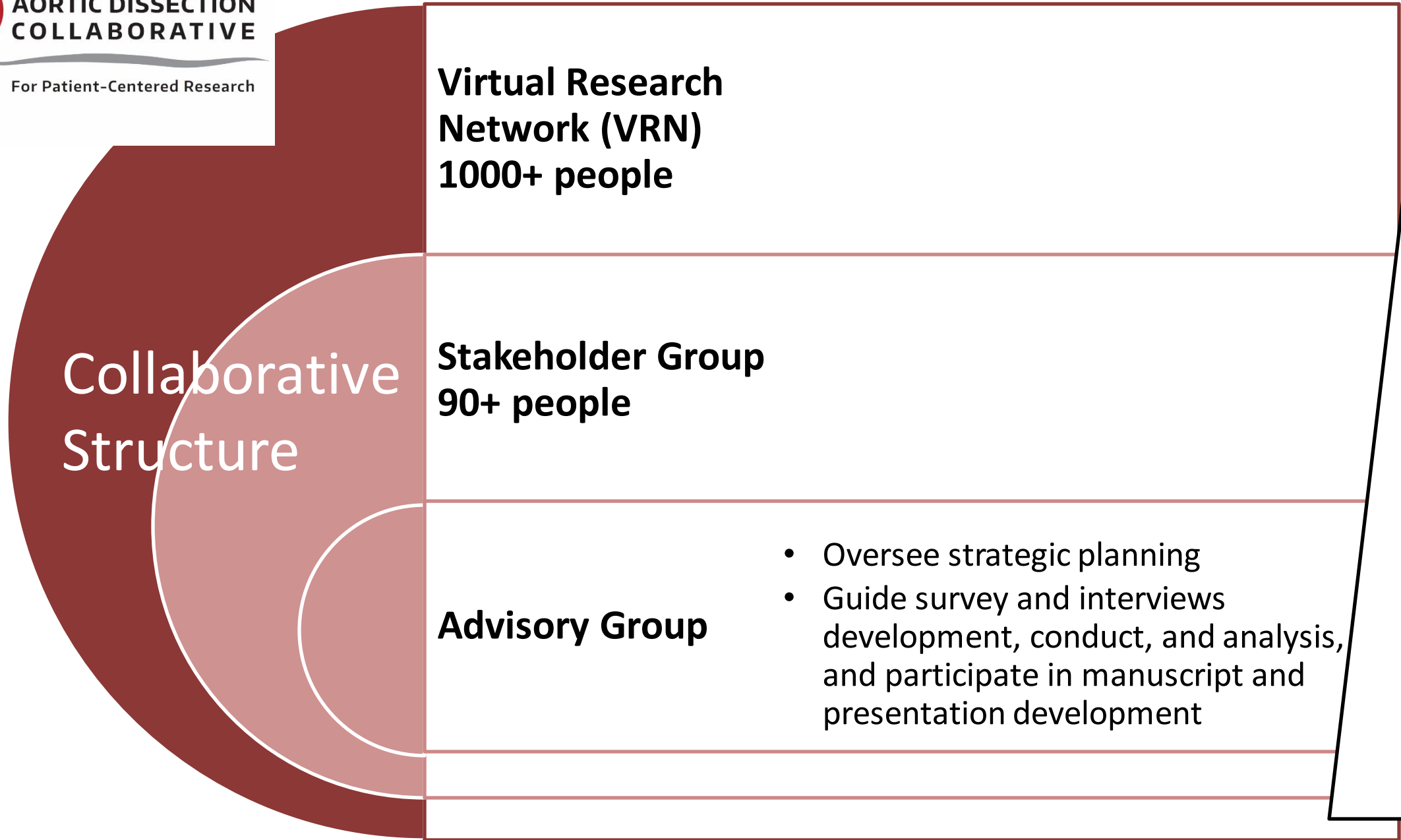
Genetic Aortic Disorders  
 Association **Canada**  
 L'Association **Canadienne**  
 des Maladies Génétiques de l'Aorte

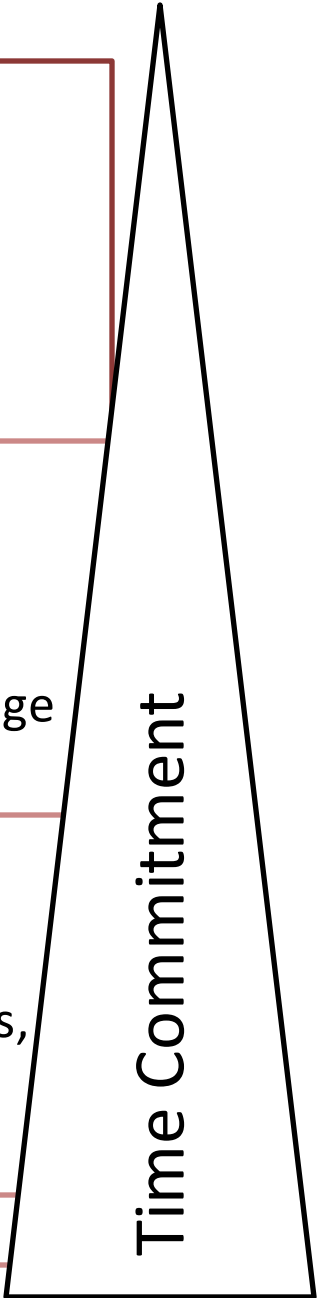
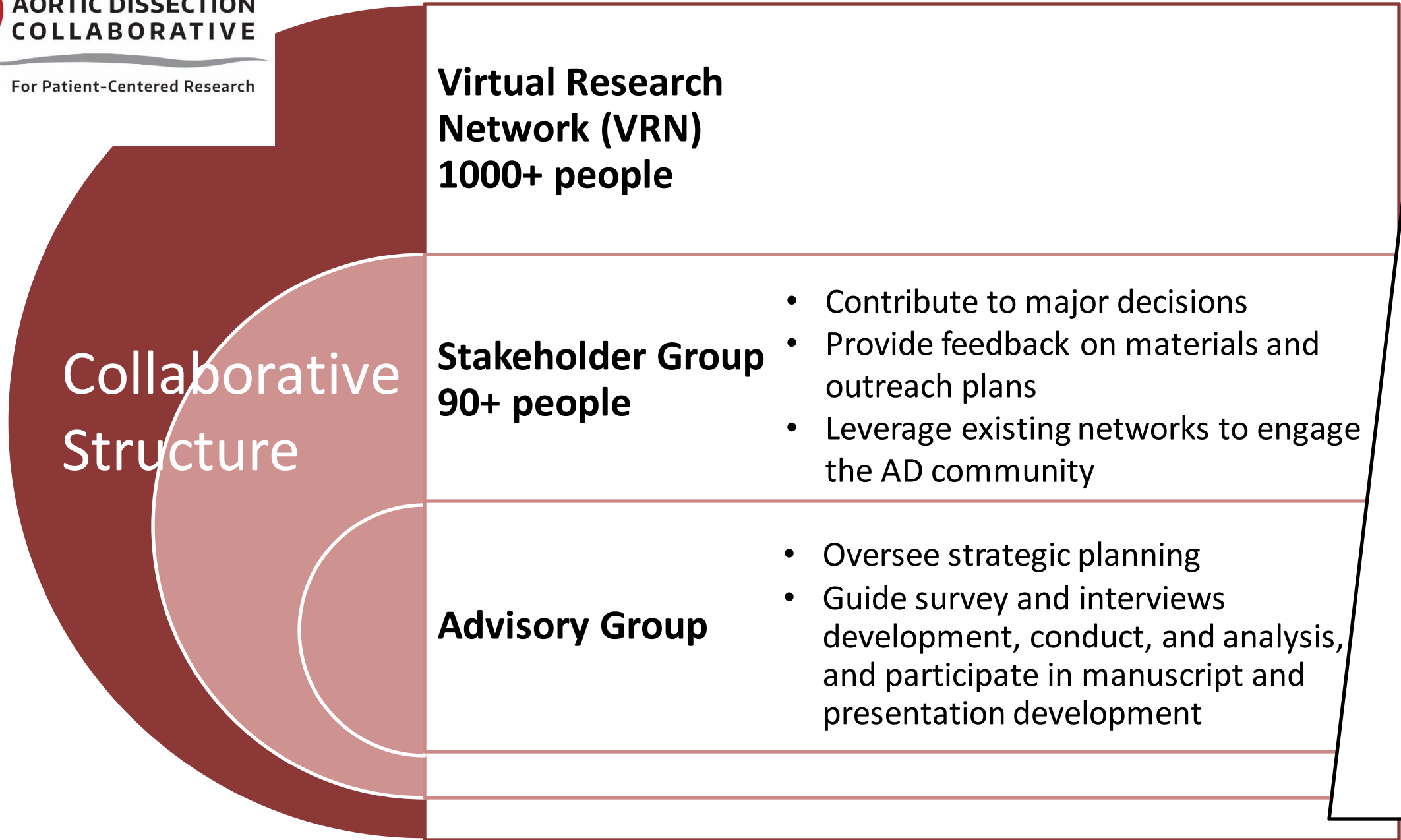


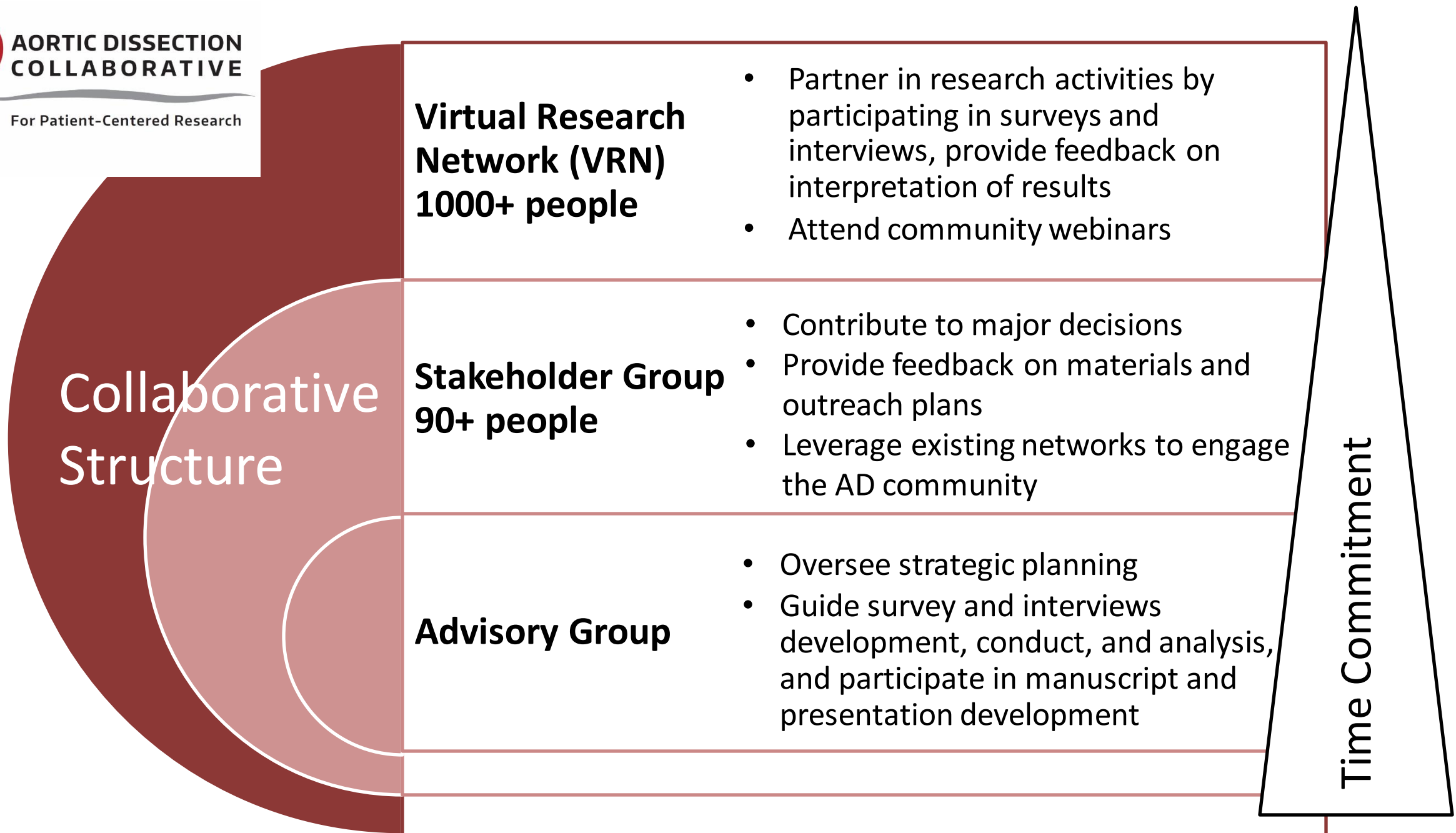
# Engagement Strategy



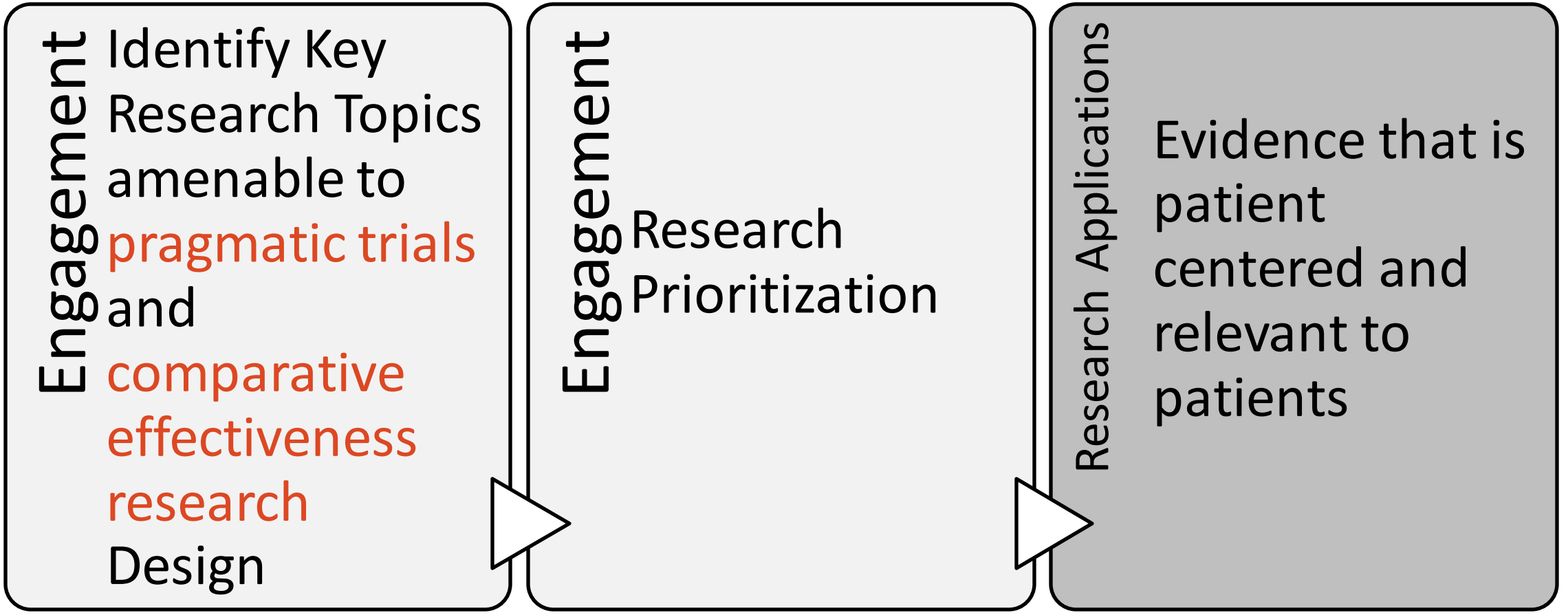








# The goals of engagement work





# Aortic Dissection Collaborative for Patient-Centered Research

**Take our  
Community Survey**

Patients with aortic dissection face dramatically different options for care without strong evidence for the long-term consequences of those options at an individual level. What is absent in the decision-making process in this complex landscape is the patient's voice.

Providing opportunities for patient involvement will help ensure the patient voice is well represented in research related to aortic dissection.



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**The Aortic Dissection Collaborative is currently gathering perspectives of those affected by aortic dissection, and we need your help!**

The Aortic Dissection Collaborative currently has two opportunities for you to provide input on your experiences with aortic dissection:

- **The COVID-19 Survey explores healthcare for aortic dissection during the COVID-19 pandemic.**

Who is eligible to take this survey? People with or at risk for aortic dissection; family members/care partners of those with or at risk for aortic dissection; and care providers for those with or at risk for aortic dissection. All participants must be over the age of 18.

**Take our  
COVID-19 Survey**

**Surveys  
closed on  
9/30/2020**



## Aortic Dissection Collaborative Reports to the Community

**May 15, 2021**

### **Final survey results from the aortic dissection community about healthcare experiences, challenges, and information sources**

[View the presentation - closed captioning available](#)

[Read the presentation transcript](#)

[Read the summary of the Q&A/discussion session following the presentation](#)

Engaging Patients with Aortic Dissections as Partners in  
Patient Centered Outcomes Research

Experiences of the Aortic Dissection Community  
A Report to the Community



**April 7, 2021**

### **Results of interviews with the aortic dissection community about the effects of the COVID-19 pandemic on their healthcare**

(click the image below to view)

Engaging Patients with Aortic Dissections as Partners in  
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the COVID-19 Pandemic  
A Report to the Community

# Community-Identified Research Priorities

STEP 1: First  
community  
survey

People living  
with Aortic  
Dissection

STEP 2: Second  
community survey  
& interviews

People living w/ or  
at risk for Aortic  
Dissection &  
caregivers

STEP 3: Topic  
working groups

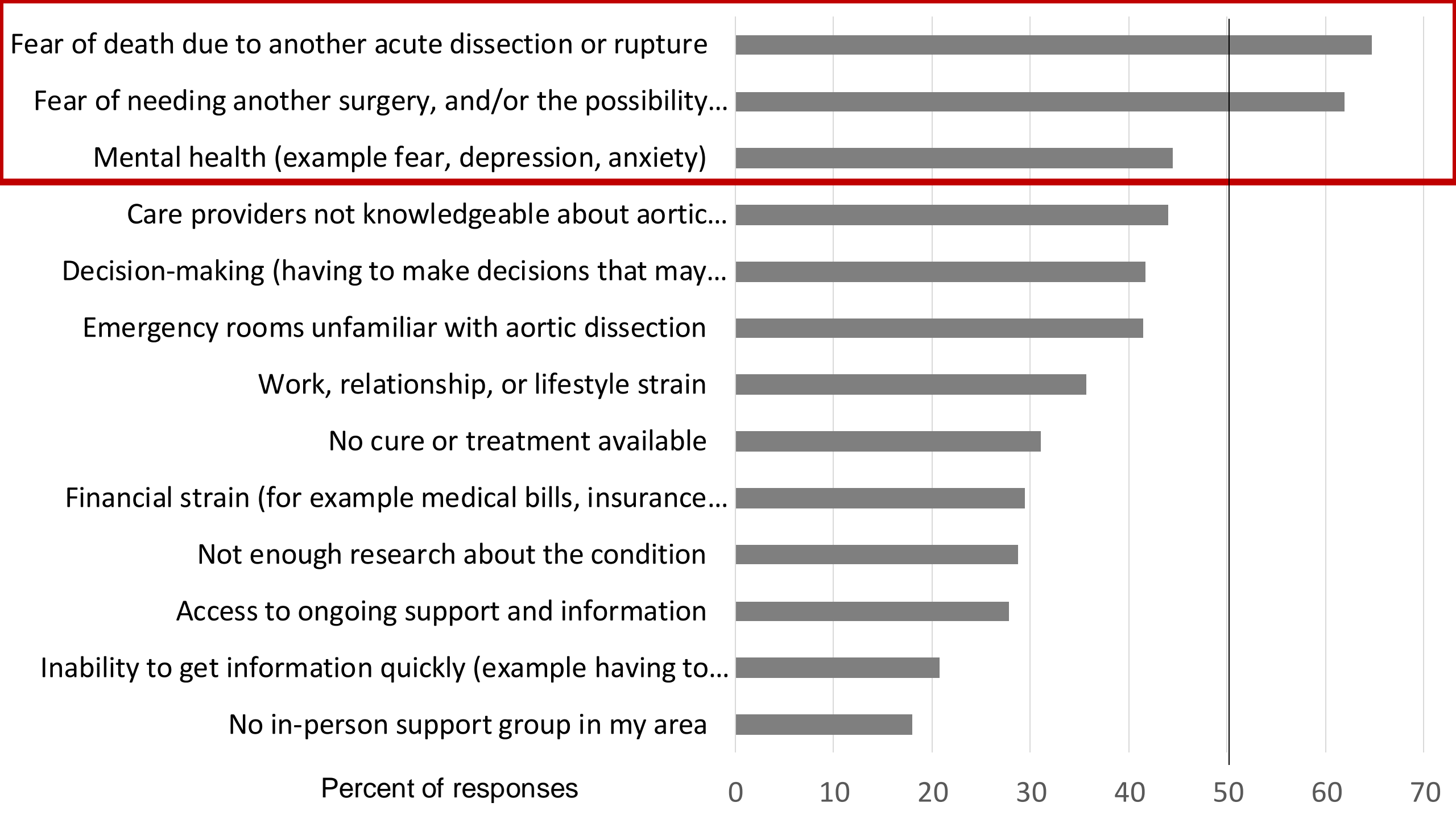
Patients, advocates,  
clinicians, researchers  
identify evidence gaps  
and recommend  
research questions for  
Comparative  
Effectiveness Research

STEP 4: Research  
Prioritization Survey

Sharing results  
today!

What is the most frustrating aspect of the aortic  
dissection diagnosis?  
Please check all that apply





Fear of death due to another acute dissection or rupture

Fear of needing another surgery, and/or the possibility...

Mental health (example fear, depression, anxiety)

Care providers not knowledgeable about aortic...

Decision-making (having to make decisions that may...

Emergency rooms unfamiliar with aortic dissection

Work, relationship, or lifestyle strain

No cure or treatment available

Financial strain (for example medical bills, insurance...

Not enough research about the condition

Access to ongoing support and information

Inability to get information quickly (example having to...

No in-person support group in my area

Percent of responses

0

10

20

30

40

50

60

70



Which of these questions about aortic dissection are important to you?  
Please check all that apply

Management

- Knowing what my blood pressure goal should be
- Knowing how often I need screening
- Knowing the most effective medicines to take
- Understanding the best way to manage my condition

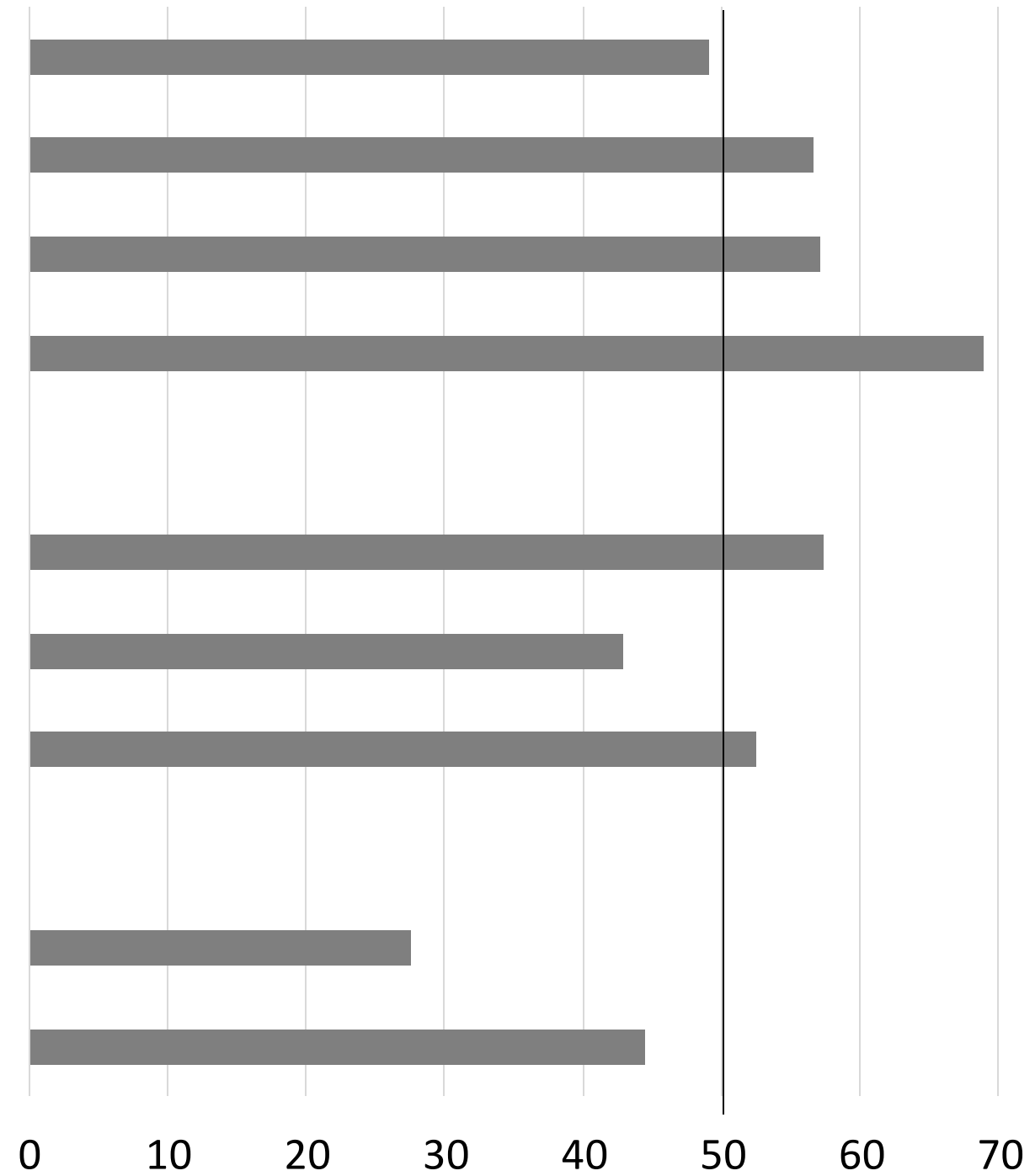
Surgery

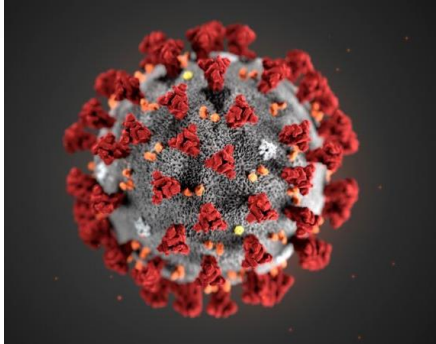
- Effectiveness of new surgical techniques (e.g. stent procedures)
- What is the best type of surgery for my aorta
- Knowing when I need surgery for my aorta

Genetics

- Knowing if genetic testing would help me manage my health
- Follow-up and screening for family members

Percent of responses





# COVID-19 Enhancement Award:

**The Aortic Dissection Collaborative is currently gathering perspectives of those affected by aortic dissection, and we need your help!**

The Aortic Dissection Collaborative currently has two opportunities for you to provide input on your experiences with aortic dissection:

- **The COVID-19 Survey explores healthcare for aortic dissection during the COVID-19 pandemic.**  
Who is eligible to take this survey? People with or at risk for aortic dissection; family members/care partners of those with or at risk for aortic dissection; and care providers for those with or at risk for aortic dissection. All participants must be over the age of 18.

- Lack of clear guidance about how aortic health status contributes to COVID-19 risk; adopting protective behaviors is both a risk- and anxiety-reduction strategy in this context.
- The pandemic increased the complexity/burden of navigating an already complex healthcare environment for people with/at risk for Aortic Dissection
- **Telehealth** is a critical component of how the AD community is navigating access to care during the COVID-19 pandemic, but not all telehealth is effective care



# Key Research Topics

Education

Genetics

Medication

Mental  
Health

Pregnancy

Surgery

Telehealth

# Executive Summary of the Aortic Dissection (AD) Collaborative<sup>☆</sup>

Sherene Shalhub<sup>\*</sup>, for the Aortic Dissection Collaborative<sup>#</sup>

Division of Vascular Surgery, Department of Surgery, University of Washington School of Medicine; 1959 N.E. Pacific Street, Box 356410, Seattle, WA 98195, United States

## The Aortic Dissection Collaborative: Methods for building capacity for patient-centered outcomes research in the aortic dissection community

Jenney R. Lee<sup>a</sup>, Sarah O. Lawrence<sup>b</sup>, Michael Soto<sup>b</sup>, Melanie Case<sup>c</sup>, Novelett Cotter<sup>c</sup>, Jake Howitt<sup>c</sup>, Timo Soderlund<sup>c</sup>, Debra Trotter<sup>c</sup>, Peter H. Byers<sup>d</sup>, Sherene Shalhub<sup>e,\*</sup>, on behalf of the Aortic Dissection Collaborative<sup>#</sup>

<sup>a</sup> Department of Urology, University of Washington School of Medicine, 1959 NE Pacific Street, Box 356510, Seattle WA, 98195

<sup>b</sup> Surgical Outcomes Research Center, Department of Surgery, University of Washington, Seattle, WA

<sup>c</sup> Aortic Dissection Collaborative Advisory Group, Seattle, WA

<sup>d</sup> Division of Medical Genetics, Department of Medicine, University of Washington, Seattle, WA

<sup>e</sup> Division of Vascular Surgery, Department of Surgery, University of Washington, Seattle, WA

## Lived experiences of people with or at risk for aortic dissection: A qualitative assessment

Jenney R. Lee<sup>a,\*</sup>, Courtney Segal<sup>b</sup>, Jake Howitt<sup>c</sup>, Melanie Case<sup>c</sup>, Novelett Cotter<sup>c</sup>, Timo Soderlund<sup>c</sup>, Debra Trotter<sup>c</sup>, Sarah O. Lawrence<sup>d</sup>, Sherene Shalhub<sup>e</sup>, on behalf of the Aortic Dissection Collaborative<sup>#</sup>



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# Seminars in VASCULAR SURGERY

Caitlin W. Hicks MD, MS  
Editor

## Experiences Engaging Stakeholders in Setting Research Priorities for Aortic Dissection

Sherene Shalhub, MD, MPH  
Guest Editor

<https://www.sciencedirect.com/journal/seminars-in-vascular-surgery/vol/35/issue/1>

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**Surgery****Firas Mussa**

Akiko Tanaka

Tabea Hoffstaetter

Avery Trudell

Akili Smith-Washington

Richard Goldenberg

Takeyoshi Ota

George Arnaoutakis

Sherene

Sreek Vemulapalli

Lurdes del Río Solá

**Education**

Rebecca Gluck

**Karen Woo**

Gareth Owens

Deb Trotter

Jacob Watson

Timo Söderlund

Eileen Masciale

Sarah Lawrence

Lindsey Rusche

Meredith O'Neal

Mark Ajalat

Earl Goldsbrough

Dejah Judelson

Marvin Chau

**Medication**

Melanie Case

Eva Kline-Rogers

Jenney Lee

**Kim Eagle**

Myra Ahmad

Julie Pham

Rob Pena

Siddarth Prakash

Marion Hofmann Bowman (pending)

Hoffman scheduler

**Telemedicine**

Katie Wright

**Laura Drudi**

Sarah Lawrence

Novelett Cotter

Thamanna Nishath

Xiaoyi Teng

Chris Burke

Jeniann Yi

**Genetics**

Peter Byers

**Dianna Milewicz**

Jesse Teindl

Jake Howitt

Sarah Lawrence

Madeline Drake

Chrisanne Campos

Milewicz scheduler

Alana Cecchi

Scott Damrauer

Jonny Medina

**Pregnancy****Rana Afifi**

Carmen David

Jenney Lee

Melissa Russo

L'Oreal Kennedy

Catherine Albright

Christeen Samuel

Mattie Boehler-Tatman

Aaron Roberts

**Mental Health**

Harleen Sandhu

Gretchen McCarrick

Mario D'Oria

Jake Howitt

Jenney Lee

Max Wohler

Ella Taubenfeld

Maisoon Yousif

Asaf Rabin

Nicole Ilonzo

Jacob Budtz-Lilly

Claudine Henoud

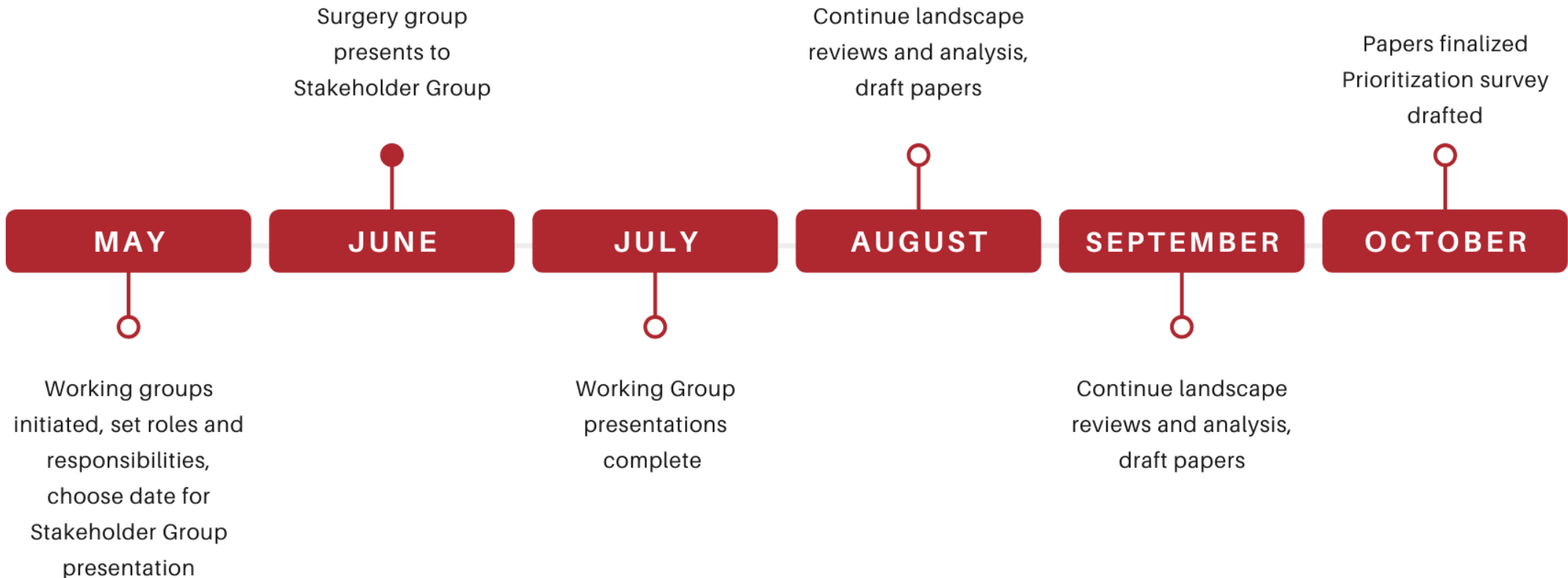
# Working Groups Charge

1. Conduct landscape review in topic area
  - a) What research or initiatives have been conducted in this area?
2. Identify gaps and opportunities
  - a) What questions still haven't been answered?
  - b) What could be completed in the more immediate term, with fewer resources?
  - c) What lends itself to a comparative effectiveness research trial and/or will require more resources to complete?



# AORTIC DISSECTION COLLABORATIVE

Research topic prioritization working group timeline



## **An assessment of the current medical management of thoracic aortic disease: A patient-centered scoping literature review**

Robert C.F. Pena<sup>a,\*</sup>, Marion A. Hofmann Bowman<sup>b</sup>, Myra Ahmad<sup>c</sup>, Julie Pham<sup>c</sup>, Eva Kline-Rogers<sup>d</sup>, Melanie J. Case<sup>e</sup>, Jenney Lee<sup>c</sup>, Kim Eagle<sup>c</sup>, on behalf of the Aortic Dissection Collaborative<sup>#</sup>

## **Knowledge gaps in surgical management for aortic dissection**

Akiko Tanaka<sup>a,\*</sup>, Avery M. Hebert<sup>b</sup>, Akili Smith-Washington<sup>b</sup>, Tabea Hoffstaetter<sup>c</sup>, Richard Goldenberg<sup>d</sup>, Sreekanth Vemulapalli<sup>e</sup>, Lourdes del Río-Solá<sup>f</sup>, George J. Arnaoutakis<sup>g</sup>, Firas Mussa<sup>h</sup>, Takeyoshi Ota<sup>i</sup>, on behalf of the Aortic Dissection Collaborative<sup>#</sup>

## **Implementation of telemedicine in the care of patients with aortic dissection**

Thamanna Nishath<sup>a</sup>, Katie Wright<sup>b,c</sup>, Christopher R. Burke<sup>d</sup>, Xiaoyi Teng Novelett Cotter<sup>c</sup>, Jeniann A. Yi<sup>f</sup>, Laura M. Drudi<sup>g,h,\*</sup>, on behalf of the Aortic Dissection Collaborative<sup>#</sup>



## **The mental health impact of aortic dissection**

Nicole Ilonzo<sup>a,b</sup>, Ella Taubenfeld<sup>b,c</sup>, Maisoon D. Yousif<sup>b,d</sup>, Claudine Henoud<sup>b,e</sup>, Jake Howitt<sup>b</sup>, Max Wohlaer<sup>b,f</sup>, Mario D'Oria<sup>b,g</sup>, Gretchen MacCarrick<sup>b,h,\*</sup>, for the Aortic Dissection Collaborative<sup>#</sup>

## **Current state and future directions of genomic medicine in aortic dissection: A path to prevention and personalized care**

Alana C. Cecchi<sup>a,\*</sup>, Madeline Drake<sup>b</sup>, Chrisanne Campos<sup>c</sup>, Jake Howitt<sup>d</sup>, Jonathan Medina<sup>e</sup>, Scott M. Damrauer<sup>f,g</sup>, Sherene Shalhub<sup>h</sup>, Dianna M. Milewicz<sup>a</sup>, on behalf of the Aortic Dissection Collaborative<sup>#</sup>

## **Aortic dissection in pregnancy and the postpartum period**

Melissa Russo<sup>a</sup>, Mattie Boehler-Tatman<sup>b</sup>, Catherine Albright<sup>c</sup>, Carmen David<sup>d</sup>, L'Oreal Kennedy<sup>e</sup>, Aaron W. Roberts<sup>f</sup>, Sherene Shalhub<sup>g</sup>, Rana Afifi<sup>h,\*</sup>, on behalf of the Aortic Dissection Collaborative<sup>#</sup>

## **Stakeholder perspectives on education in aortic dissection**

Stephanie D. Talutis<sup>a</sup>, Jacob Watson<sup>b</sup>, Earl Goldsborough III<sup>c</sup>, Eileen Masciale<sup>d</sup>, Karen Woo<sup>a,\*</sup>, on behalf of the Aortic Dissection Collaborative<sup>#</sup>

**Seminars in  
VASCULAR  
SURGERY**

# Research Priorities Survey



# Research Priorities Survey

From your perspective, which of the following research topics matter most? Please rank each of these topics in order of their importance to you. **Drag and drop each item to list them in order of importance, with the most important at the top and least important at the bottom.**

Does having genetic testing improve the health or healthcare of people with/at risk for aortic dissection?

Would having the right educational resources about aortic dissection for patients and family members improve the health or healthcare of people with/at risk for aortic dissection?

Would having the right educational resources about aortic dissection for doctors (e.g., primary care or emergency doctors) improve the health or healthcare of people with/at risk for aortic dissection?

What kind/how much exercise is safe and beneficial for people with/at risk for aortic dissection?

For someone with an aortic dissection, when is the right time to have surgery and when is it okay to wait?

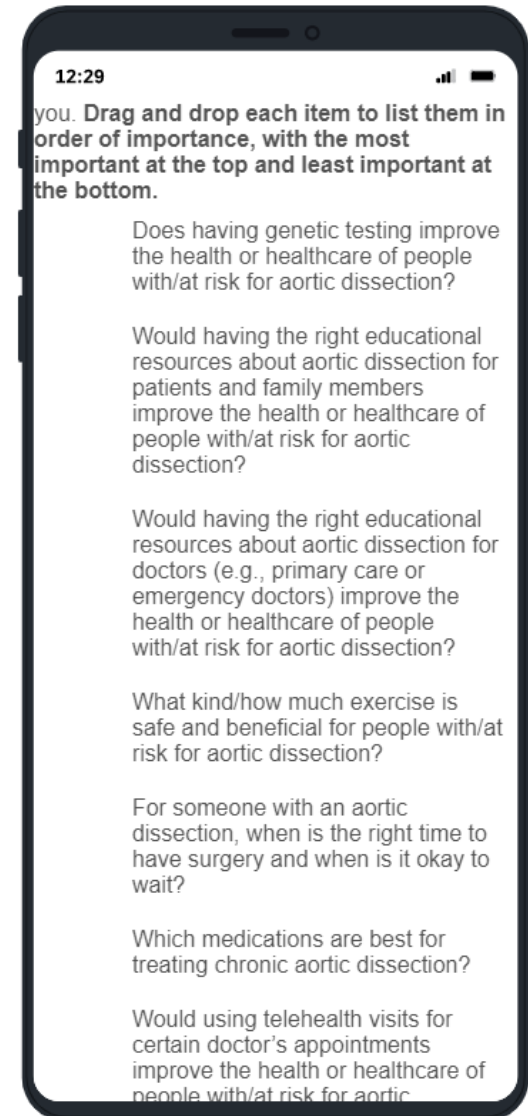
Which medications are best for treating chronic aortic dissection?

Would using telehealth visits for certain doctor's appointments improve the health or healthcare of people with/at risk for aortic dissection?

What kind of mental health supports (e.g., peer support group, therapy) are most useful for people with/at risk for aortic dissection?

Is there another research topic that is most important to you?

**November 2021 - February 2022**

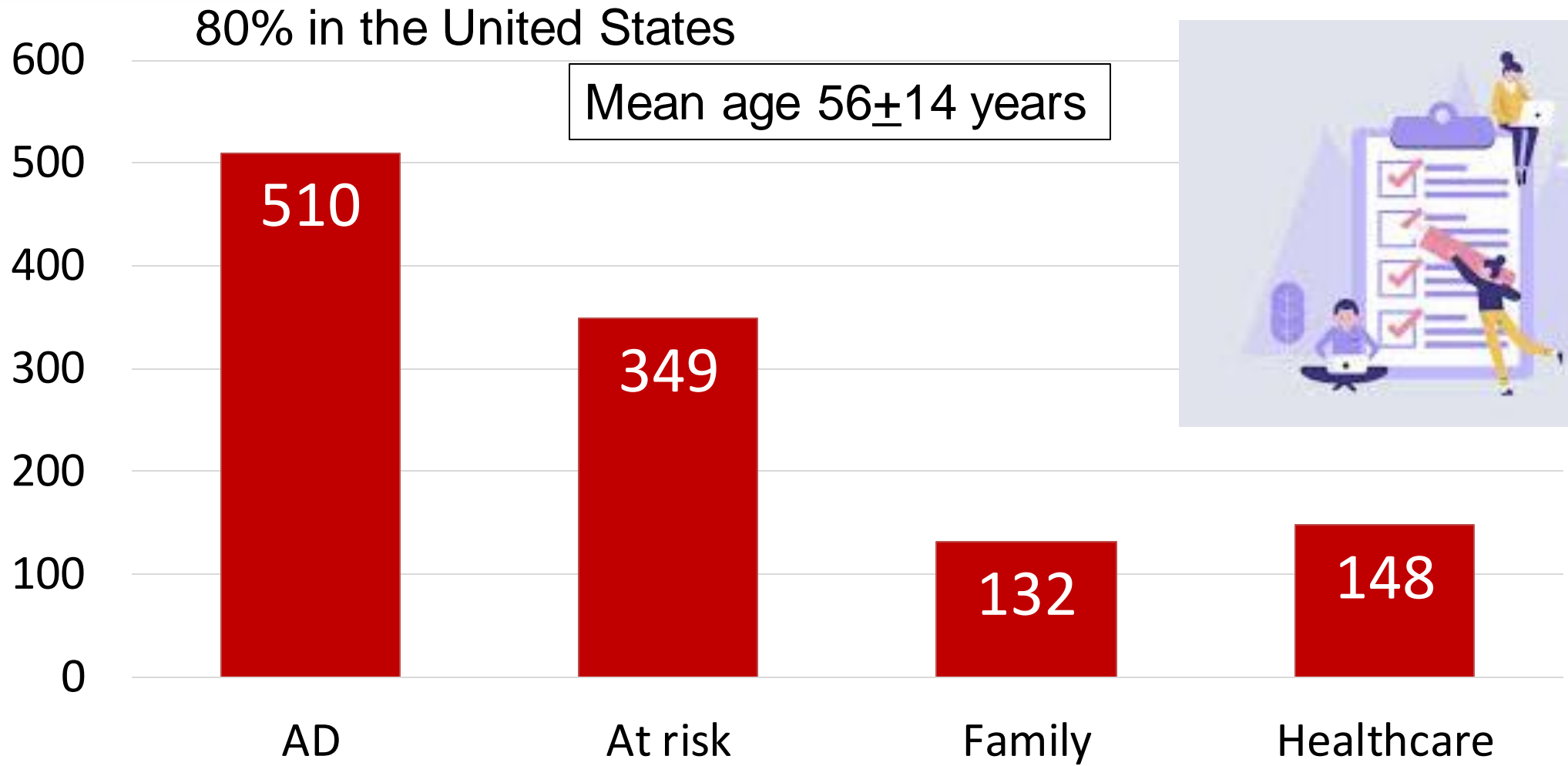


<b>States</b>	<b>N=910</b>	<b>%</b>
MI	356	39.1
CA	56	6.2
TX	51	5.6
FL	32	3.5
NY	32	3.5
OH	29	3.2
NC	26	2.9
WA	26	2.9

<b>Countries</b>	<b>N=200</b>	<b>%</b>
Canada	78	39.0
United Kingdom	36	18.0
Australia	12	6.0
Germany	10	5.0
New Zealand	7	3.5
France	6	3.0
Ireland	6	3.0
Sweden	6	3.0
Italy	5	2.5
Spain	5	2.5

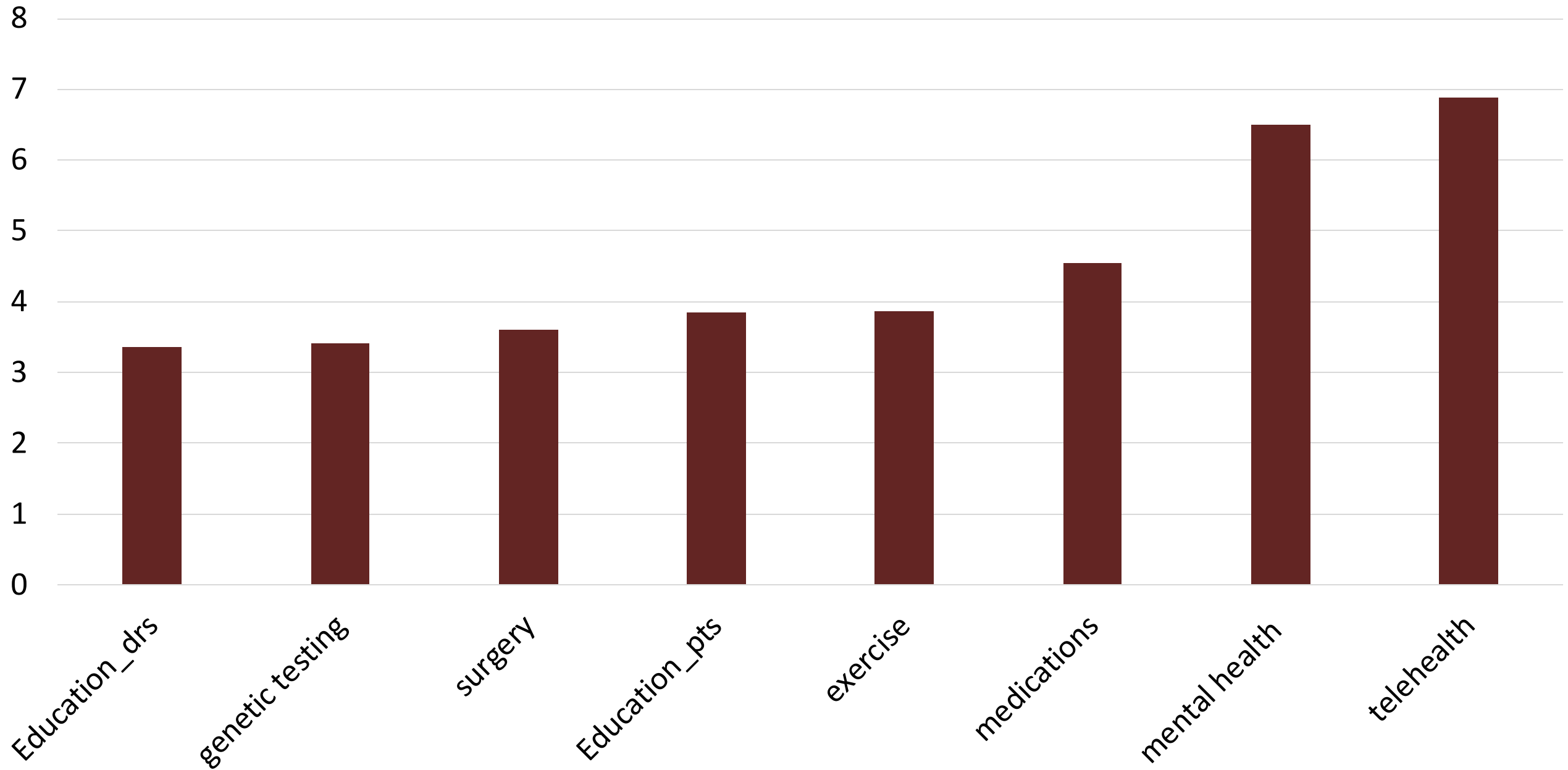
# Research Prioritization Survey

## November 2021 - February 2022

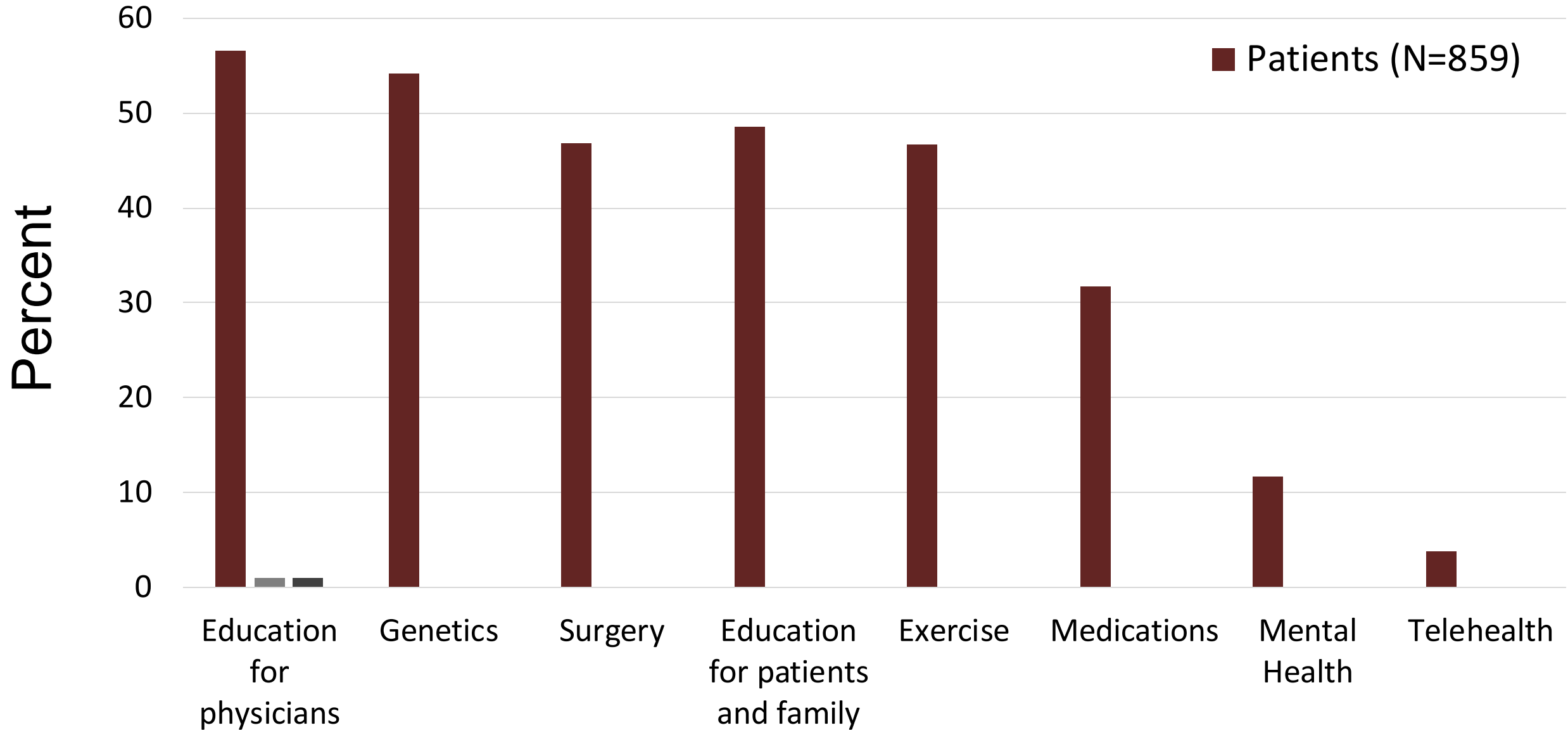




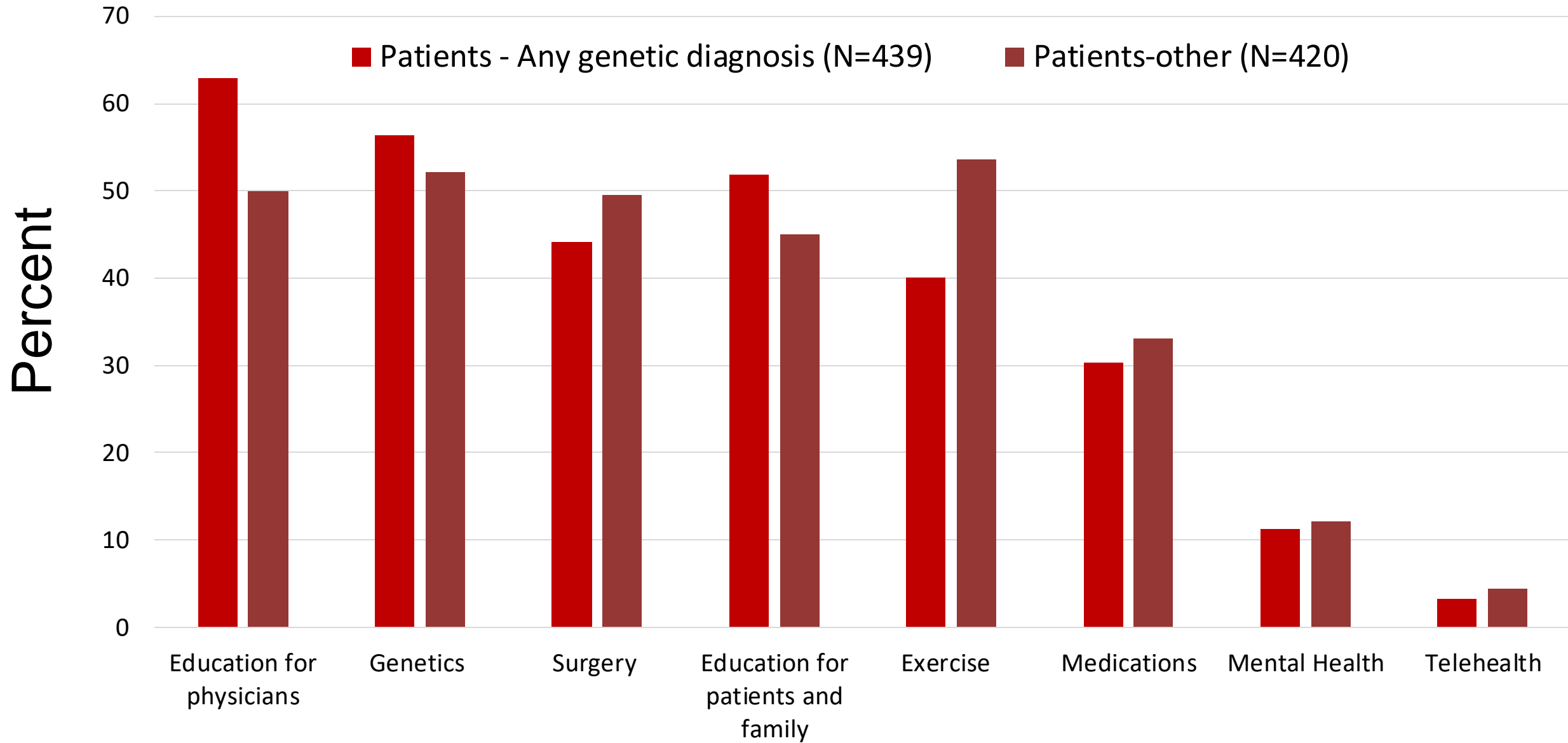
# Research priorities by mean score



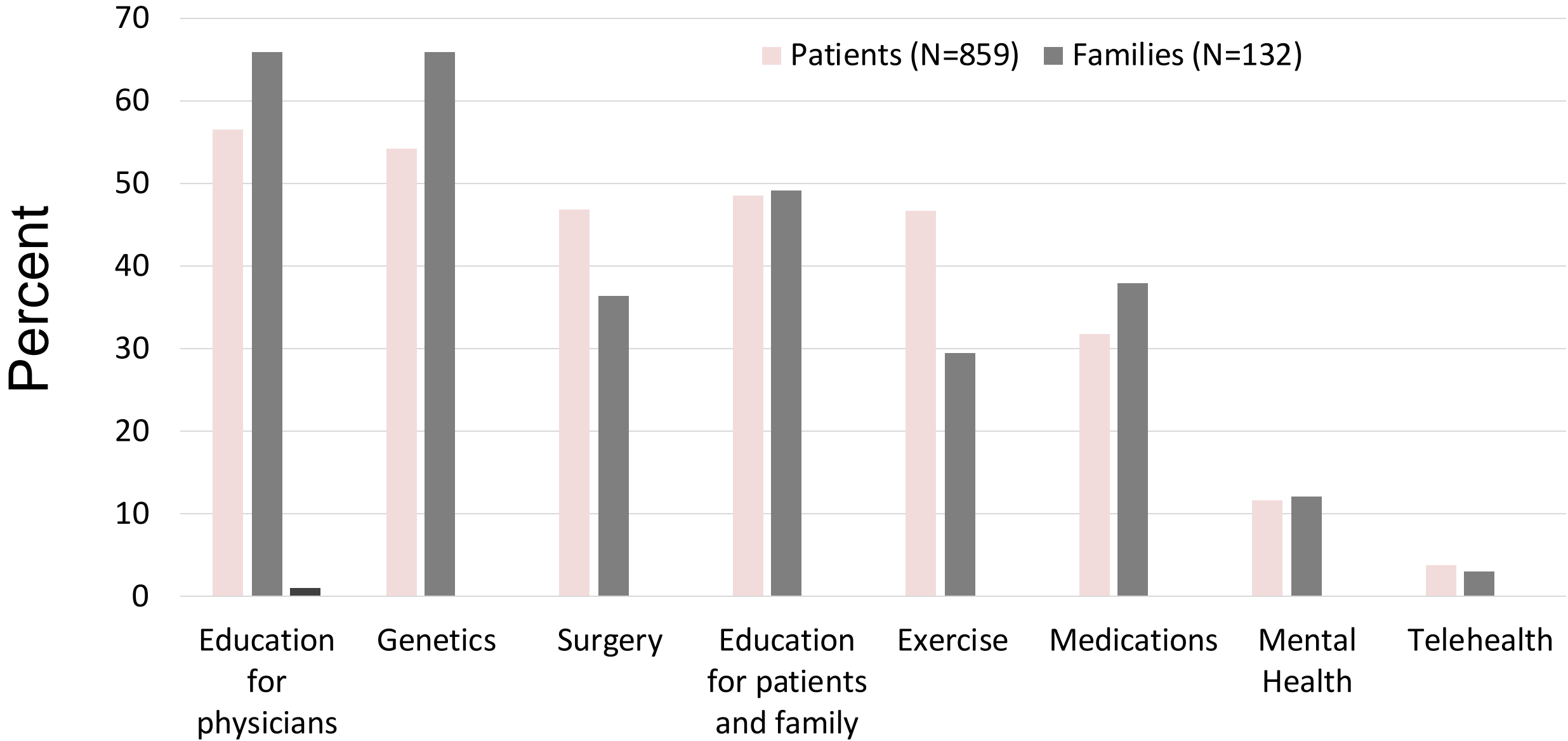
# Research Priorities by top 3



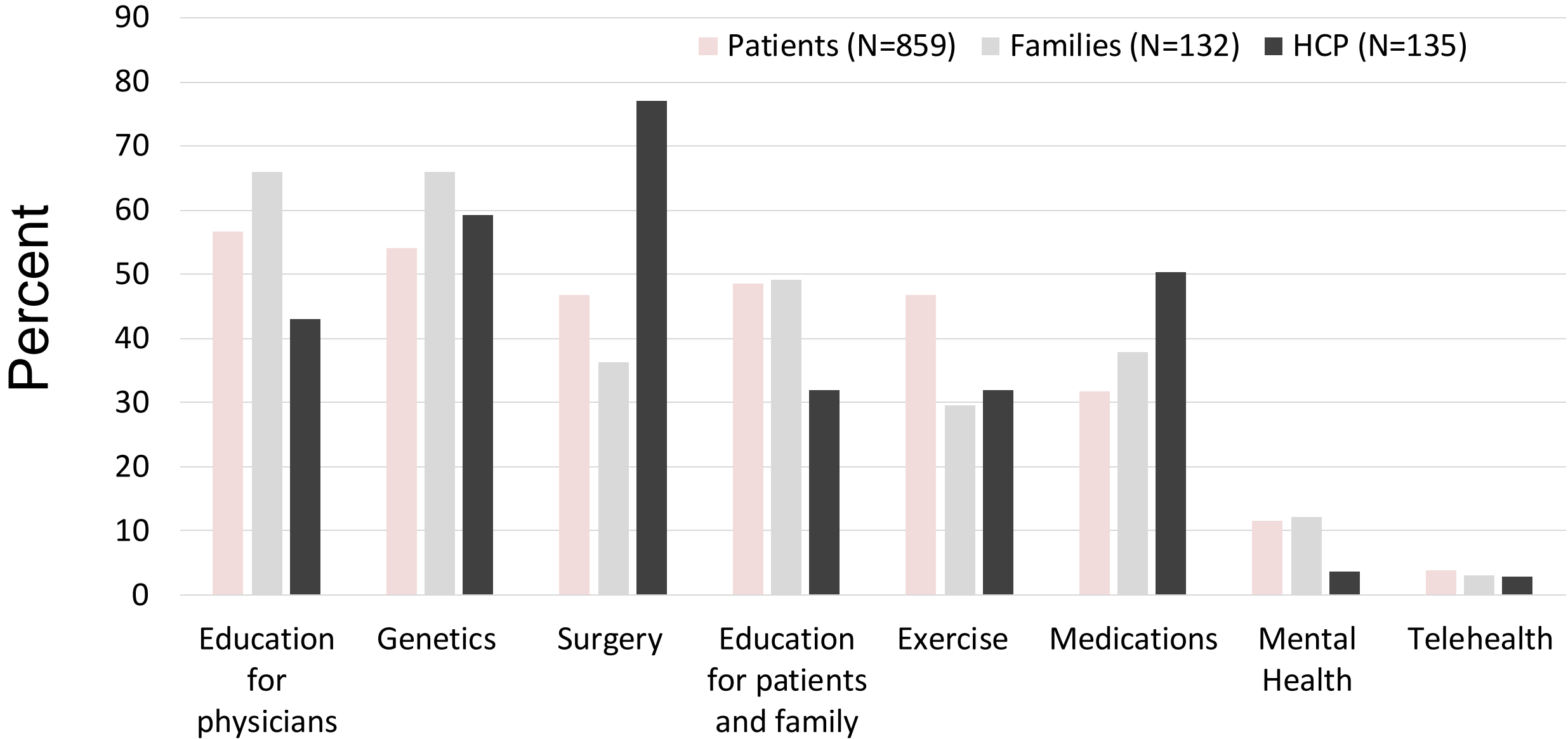
# Research Priorities by top 3



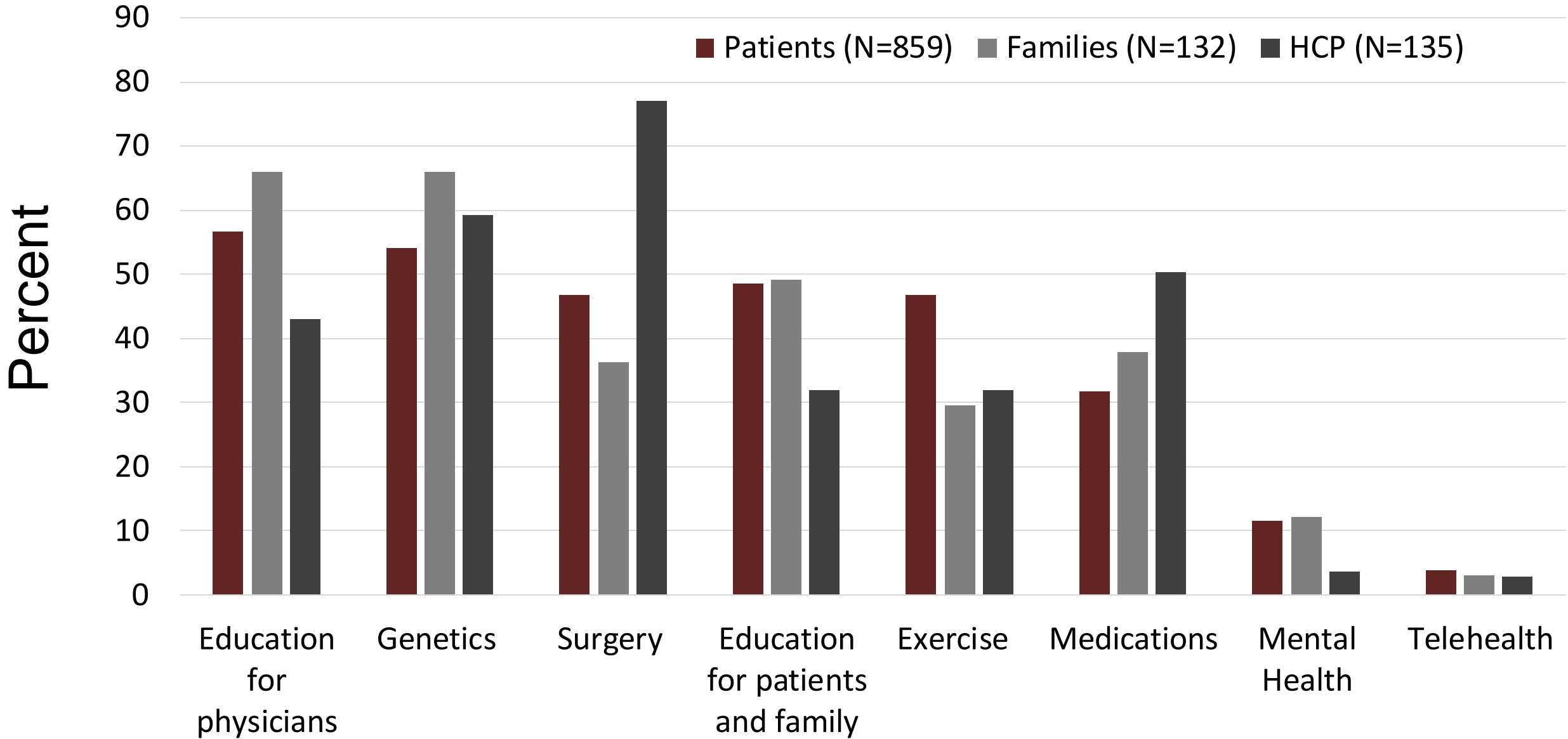
# Research Priorities by top 3



# Research Priorities by top 3



# Research Priorities by top 3







# Next Steps



- Patient-centered research proposals & projects



# Next Steps: Sustainability

Patient-centered  
research proposals &  
projects



**PURPOSE**

**Preventing unnecessary suffering because of the unknown**

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**VISION**

**To make TAD a routine part of the doctor and patient conversation**

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**MISSION**

**To raise awareness of TAD through research, education and advocacy**



<https://www.sciencedirect.com/journal/seminars-in-vascular-surgery/vol/35/issue/1>



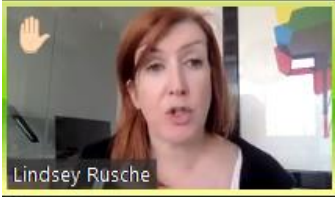
@ADCollab

adcollaborative.org



@ShereneShalhub





Lindsey Rusche



Sherene Shalhub



Katelyn Wright



Jen McNamara (she/her/hers)



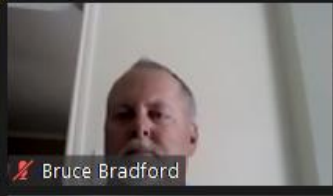
Heidi Manning



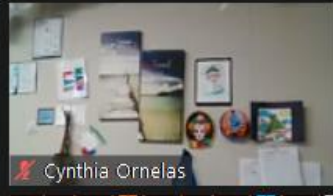
Richard Goldenberg



DAVID GOODMAN



Bruce Bradford



Cynthia Ornelas



Evelyne Asselin



Dorothea Cernera



Jake Howitt



Carmen David



Sarah O. Lawrence (she/her)



Keith



Gaye Varnay



Emile Shahadi



Heather McLaughlin



Pieter de Haan



Mark Martucci



Jenney Lee



Charlotte Grass



Ellen Hostetler (she/her)



Mark Fasano

David Huntley



David Huntley

Irman Forghani



Irman Forghani

Vickie Dalton



Vickie Dalton

Susan Grossi



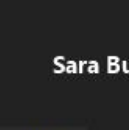
Susan Grossi

Novelett Cotter



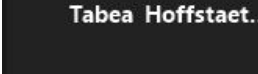
Novelett Cotter

Sara Burns



Sara Burns

Tabea Hoffstaetter



Tabea Hoffstaetter

Karen Heikel



Karen Heikel

Keith Fowler



Keith Fowler

Jida El Hajjar



Jida El Hajjar

Chris Faulkner




Chris Faulkner

Dianne Adams



Dianne Adams

Melissa Yee



Melissa Yee

JEANMARIE REGINATO




JEANMARIE REGINATO

Julie Vogelsang




Julie Vogelsang

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