

# Annual Report 2017



## THE KER UNIT

Knowledge and Evaluation Research Unit  
Mayo Clinic

*Going Global*



# Overview

I don't remember any other time in the history of the Knowledge and Evaluation Research Unit in which more innovation has taken place. I also don't remember feeling so palpably that the innovation is linked to the contributions of individual colleagues leading new thinking with our family of researchers making the innovation bigger, better, tougher, and friendlier.

The generosity of the way we relate to each other, and our commitment to the patient were clear in 2017. It was lovely to hear that much from the distinguished visitors that filled our space and our mind with challenges and inspiration.

It was lovely once again to come together for the community that supports our lives and our work. And yet 2017 was a year of great change in who comprises the Unit and a challenge to define what makes us who we are, how the unit contributes to the work of others.

Important collaborations within and outside Mayo have positioned the KER Unit at the forefront of research for and about careful and kind patient care.

This was also the year of **Why We Revolt**, a book made only possible by the generosity of every one of my colleagues who supported it directly or by picking up what I couldn't.

It is also the year of the Health System and connecting it with the healthcare system, the topic of another unit's participation in TEDX.

It was the year of ICAN and of our work in one of the most underserved areas of the country.

It was the year of AFIB, practice transformation, lung cancer screening, spine, renal failure, end of life, reflection, thyroid cancer, conversational inquiry, choice awareness, and much more.

A successful year in grants, papers and publications. But more importantly a year in which we struggled and came together as a family to build a stronger, friendlier, more scholarly, and more useful unit.

I am grateful to all who make KER their academic home, who contribute through their enthusiasm and brilliance to our quality, and to all who give their love and kindness to grow our 13-year-old family stronger.

— VICTOR

# Milestones

Take a look at some of our group and individual milestones for 2017.

## 33 PUBLICATIONS



## CELEBRATING PROMOTIONS



Kirsten Fleming  
Research Operations Supervisor



Angela Sivly  
Clinical Research Coordinator

## 10,032 DECISION AIDS MAILED



## 122,190 VIEWS OF THE SDM BLOG



# Contents



CHILI CHALLENGE 2017

## SAVE THE DATE

OCTOBER 2-3, 2018

Registration for the 2018 conference on **Minimally Disruptive Medicine** is now open!

Go to:  
<https://ce.mayo.edu/mdm2018>

## FOLLOW US

Twitter: [@KERunit](https://twitter.com/KERunit)

Facebook: [Friends of KER & EPC](https://www.facebook.com/FriendsofKER&EPC)

MDM blog

<https://minimallydisruptivemedicine.org/mdm-blog/>

SDM blog

<https://shareddecisions.mayoclinic.org/blog/>

2 | **OVERVIEW | VICTOR MONTORI**

3 | **MILESTONES**

### STAFF INTRODUCTIONS

7 | **NATALY ESPINOZA-SUAREZ** | Research Fellow

8 | **ANGELA SIVLY** | Clinical Research Coordinator

9 | **ANJALI THOTA** | Clinical Research Assistant

10 | **PAIGE ORGANICK** | Clinical Research Assistant

11 | **KEVIN SHAW** | Service Designer

### UNIT EXPERIENCES

13 | **VALENTINA SERRANO**

14 | **NERI ALVAREZ VILLALOBOS**

15 | **THOMAS WIERINGA**

16 | **XIAOJIA DENG**

### THESIS REPORTS

18 | **GABY SPENCER BONILLA**

19 | **MIKE GIONFRIDDO**

### SPECIAL REPORTS

21 | **PETER A. NOSEWORTHY**

22 | **JUAN BRITO CAMPAGNA & MARLEEN KUNNEMAN**

23 | **AARON LEPPIN**

24 | **KASEY BOEHMER**

# Our Community



PATIENT ADVISORY GROUP 2017

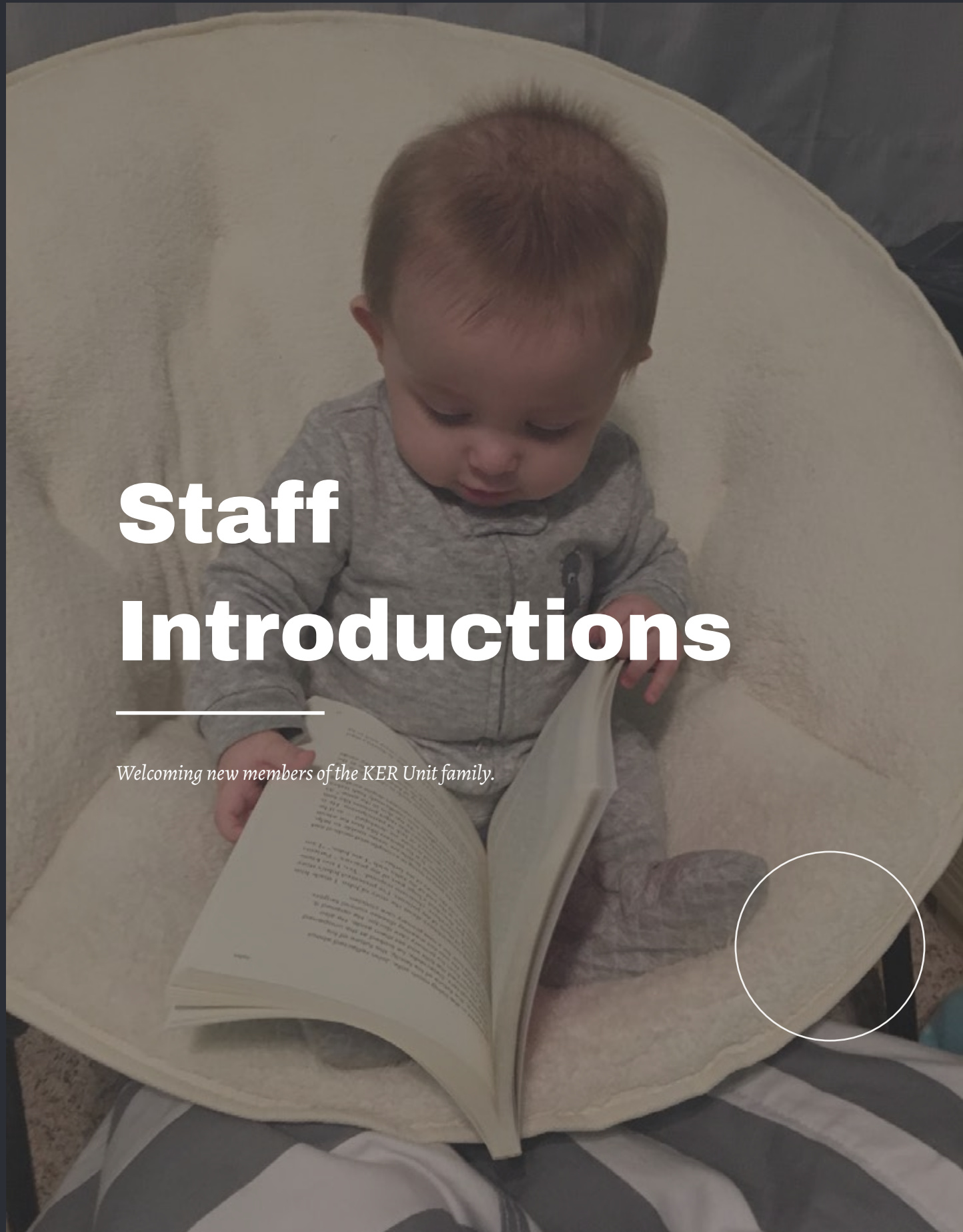


4/23/17  
5:00 AM  
9 lbs, 6 oz  
21 inches

OUR NEWEST MEMBER: **WES BEHNKEN**

*The generosity of the way we relate to each other and our commitment to the patient were clear in 2017.*

— VICTOR



# Staff Introductions

*Welcoming new members of the KER Unit family.*

## Nataly Espinoza-Suarez

*A new research fellow brings her passion for palliative care.*



Being at Mayo Clinic is an incredible experience; I am a Family Physician and love Palliative Care. KER Unit helped me to develop and increase my perception of Palliative Care's importance on daily medical practice, and by using the principals of Minimally Disruptive Medicine and Shared Decision Making allowed me to understand and increase my concern on patients, their health outcomes and quality of life based on their needs and values.

The unit environment is positive; the team is always encouraging people to do their best, to think bigger and not to be afraid of express your ideas. There is always an opportunity to learn new things, to create original ideas and to complete on ideas that are already developing.

If you like sweet things well here is the place to come and enjoy good conversations and amazing desserts, there is no other environment where you would feel welcome and loved.

# Angela Sivly

*An experienced research coordinator "boomerangs" back.*



Angela Sivly has happily returned to the KER Unit as a Clinical Research Coordinator. She has been at Mayo Clinic for 5 years as a coordinator, with most of her time spent at KER. She is a recent graduate of Winona State University, receiving a Bachelor's Degree in Applied Science. She lives in Rochester with her husband (Shad) and two beautiful daughters that bring joy to her life each day. Her girls are Mercy (4) and Luna (1). Angela really enjoys her time with her family and listening to Dave Mathews Band with them.

# Anjali Thota

*A communication major joins the family trade... Medicine!*



Anjali is originally from San Diego and moved to freezing cold Rochester, MN for the Mayo Clinic. After having completed a 6-week summer internship with the KER Unit, she couldn't stay away and decided to come back as a Clinical Research Assistant in October. Anjali earned her Bachelor's degree in Communications at Chapman University in 2013. After graduating she realized she didn't want to do anything in that field and instead decided to pursue a career in medicine (much to the horror and incredible support of her parents). She is currently on the track to become a physician and is grateful to learn about SDM and MDM at this point in her career. Anjali loves to host dinner parties at her apartment, bake chocolate chip banana bread, and eat pasta.

# Paige Organick

*A young sociologist explores healthcare.... organickally.*



Paige recently moved to Rochester from Walla Walla, Washington, the town so nice it was named twice! Holding a BA in Sociology from Whitman College, Paige enjoys working with individual patients and with a larger, macroscopic lens in public health or health policy. Paige brings experience from the Assisted Living home to the KER unit, hoping to apply MDM and SDM to the geriatric community. As mayo is her favorite condiment, Paige has dreamed of working here for years, and is so thankful to the KER unit for providing her with this opportunity. When not frantically figuring out her life path, Paige enjoys attempting to make Great British Baking Show-worthy breads, playing with her cat Ollivander, hiking, and swimming.

# Kevin Shaw

*An anthropological doodler finds his roost.*



Kevin is a perennial transplant who has lived in Washington State, Taiwan, China, and now Minnesota. Prior to joining the KER Unit, Kevin worked and studied abroad as a Fulbright Fellow and Blakemore Freeman Fellow.

As a service designer, Kevin draws on his diverse experiences in medical anthropology, design, and art. He is excited to be the newest addition to KER's design team. He feels at home in KER's unique approach to humanistic design and research, which balances academic rigor with pragmatism and empathy.

Kevin appreciates the opportunity to work alongside patients and clinicians to inject kindness, humanity, and rigor into healthcare conversations. In his free time, Kevin likes to climb rocks and make rock (music).



# Unit Experiences

*Celebrating visitors, guests, and friends passing through.*

## Valentina Serrano

I had the pleasure of doing a postdoctoral research fellowship at KER unit from July 2015 to July 2017.

My purpose was to learn about evidence-based medicine (EBM) and ways to apply this evidence to patients. To my surprise, at KER unit I met a great working group that not only worked in EBM but, above all, in different ways to take care of patients living with chronic diseases and offer them the best therapeutic options according to their values, preferences and context.

**THIS PERSON HAS  
VALUES, PREFERENCES,  
AND A LIFE OF THEIR  
OWN, BEYOND THEIR  
DISEASE.**

I learned a way to practice medicine different from the traditional paternalistic way, where the patient-centered care, shared decision-making (SDM) and minimal disruptive medicine (MDM) were the cornerstone of health care and research. I learned not to treat diseases, but people who live with diseases and

not to do research for reducing “numbers” but to do research looking for improving patient-important outcomes. A patient is a person living with a disease but who is not defined just by that single disease. This person has values, preferences, context and a life of his/her own, beyond his/her disease.

I did not just have an academic growth, I also met a wonderful group of people, a family, that do not only work together, but also love and care for each other and I am happy to realize that in this team, the co-workers show concern for each other, are generous among themselves and are friends and family both at work and out of their workplace.

Finally, back in my country -Chile- with my heart full of love and unforgettable memories of everything I learned, both in the academic aspect as well as a person, I am working in transmitting this kind of practicing medicine to my colleagues here in Chile.

Thank you everyone who shared and walked with me along this experience.

A big hug to all the people in KER unit, and I hope I will return to visit you in a near future.

Valentina.

# Neri Alvarez Villalobos

I started my trip to Mayo Clinic on September 2016. As a visiting research fellow at KER Unit I had the opportunity to know people from different cultures, nationalities, ages, and lifestyles. They were the most diverse team to the naked eye but all of them following the same goal; produce knowledge to improve patient's lives.

From the beginning with great generosity each one of the members of this team showed me their projects and invited me to participate. Increasing me exponentially the opportunity to learn.

**FOR THE STAFF  
OF THE KER UNIT,  
NOTHING IS CRAZY AND  
EVERYTHING CAN BE A  
REALITY.**

During 9 months I managed to participate in more than 15 projects in my rotation. In this moment I am still working remotely with KER Unit and KS unit. Among all the projects, there is a distance course where I was able to contribute since the beginning to the end. This project was recently carried out on

October 2017 at Mayo Clinic. The main objective of the distance course was to support in a basic introduction to the SDM-MDM work shop face-to-face as well as to encourage interaction and communication between the participants and the course instructors. This project (distance course) was started as a crazy idea but I realized that for the staff of KER unit mainly their leader Dr. Victor Montori nothing is crazy and everything can be a reality.

In Mexico life goes on, in the month of February 2018 I will defend my doctoral thesis, nowadays I am participating in the national network of Family Medicine researchers, I am a mentor of an elite group of young researchers at the UANL and I am still working as a family doctor.

Currently, the main project in which I participate in Monterrey, Mexico is in the collaboration of the creation of an evidence-based center that we hope to inaugurate in March 2018.

I want to end by thanking for so many teachings and for allowing me to continue participating, mainly for teaching me how to create and execute ideas.

Kind regards  
Neri

# Thomas Wieringa

When I arrived in Rochester, I did not know what to expect of my stay at the KER Unit.

At the first day, some things were really remarkable: a couch in the office, a standing table, and even a basket and a ball?

The idea behind this all became clear pretty soon: the space should invite to collaborate and to initiate ideas together.

The first week I missed my family, but the second week I realized I had a second family at the KER Unit.

Everyone is willing to support each other (whether it is work-related or not) and is open for criticism and other ideas.

The word "together" and "inspiration" are central in my first weeks here at the KER Unit.

Patient-centeredness, integrity and generosity are central in the KER Unit and every sense of these words are carried out in practice.

I am really happy and thankful to have the chance to be part of the KER Unit for six weeks.

In my opinion, we should incorporate the KER Unit's way of working and view on patient care into the work of medical research everywhere around the world.

Namely, in collaboration and as a generous team a lot is achievable, which applies to both individual patient care and medical research.

This makes the KER Unit a place where ideas start, and patient-care improves."

**I REALIZED I HAD A  
SECOND FAMILY AT THE  
KER UNIT.**



# Xiaojia Deng

I had a fruitful year at the KER unit in 2017. I enjoy working in the KER unit since I not only gained more professional experience and participated the patient's better outcome, but also made more good friends and built the family relationship with my coworkers. Their thoughtfulness and encouragement help me to grow and build my confidence to work as a new role.

From a phlebotomist's point of view, clinical decision-making is quite a new field for me to get involved in. I am delighted to participate in such clinical activities to benefit patient care as recruiting and consenting patients, data collection and compilation, and so on. I appreciate in a better way how clinical knowledge is gained and translated into good patient care through team work. I gained administrative experience and hosted a group presentation during the workshop. I also had chance to attend the clinical coordinator orientation training in December, which expanded my knowledge and skills in related areas. It has been a great pleasure and experience for me to contribute to patient care in a different role other than a phlebotomist.

**THEIR  
THOUGHTFULNESS  
AND ENCOURAGEMENT  
HELPED ME TO GROW**



# Thesis Reports

*Learning with our expert scholars.*

# Gaby Spencer Bonilla

*The work of being a patient with type-2 diabetes.*

After 2 years at the KER unit, Gaby Spencer successfully defended her thesis on “the work of being a patient with type 2 diabetes” in July of 2017. The thesis was composed of 3 sections produced through collaboration with members of the KER and KS units as well as other local, national and international collaborators.

The first section of the thesis was a methodological evaluation of measures that have been created to date to assess the burden of treatment. While burden of treatment has not historically been formally evaluated, this section and the resulting manuscript “Assessing the Burden of Treatment” published in the Journal of General Internal Medicine (<http://bit.ly/2EWm5sR>) proposes ways in which regularly assessing the burden patients are assigned to care for their health can help create healthcare that is kind and careful to patients.

The second section examined the effect of including social networks in interventions to manage diabetes. In this systematic review and meta-analysis, published in BMJ Open, (<http://bit.ly/2qo3naF>) we found that interventions that include social networks offer a modest benefit in terms of

social support and short term glycemic control but that these interventions focused largely on diabetes education rather than on relationships.

The final section reported on a mixed methods study where patients with type 2 diabetes were surveyed about treatment burden and the work they did to take care of their health using a smartphone application to collect real-time data which included photographs and reflection. Patients most often reported treatment burden in the areas of finances, health services delivery and exhaustion with self-care despite being a largely insured and employed patient population. The different aspects of treatment burden had largely inter-related consequences. For example, a patient who described financial challenges due to self-care could also describe the financial strain created tension within her family.

Gaby is endlessly grateful for the generosity of the KER unit and for having found a family away from home during her 2 years in Rochester. She is currently in her last year of medical school and applying for internal medicine residency.

# Michael Gionfriddo

*Understanding 'step-down' in adolescents with asthma*

Asthma is a common chronic condition with significant impacts on life and health. This impact varies over time. This can create a situation where individuals with asthma are on more medication than they need to treat their symptoms. In this situation, there are two reasonable courses of action: maintaining the current level of medication or reducing the amount of medication, a process known as ‘step-down’. To better understand the process of step-down in adolescents with asthma my thesis explored: (1) the evidence behind the efficacy and safety of stepping down medication in asthma, (2) the experience of asthma, medication taking, and step-down in adolescents with asthma, and (3) how evidence and experience can be brought together through a process of inquiry (shared decision making) to help the adolescent and their clinician think and talk through how to manage asthma. To accomplish this, systematic reviews of the literature, both quantitative and qualitative, were conducted as well as semi-structured interviews with adolescents with mild asthma. Findings from these investigations

indicated that (1) there is uncertainty in the evidence around step-down, but it is likely safe for certain individuals. (2) the experience of asthma and adolescents perspectives on medication-taking vary, but adolescents often engage in a process of trial and error as they work to understand the benefit of the medications and how it affects their asthma and activities. (3) there are many tools to support shared decision making, but limitations in the body of evidence result in uncertainty about their effectiveness in supporting conversations and improving outcomes. Recommendations for a novel approach to shared decision making and to the design, testing, and implementation of tools to support shared decision making are presented. By engaging clinicians and individuals with asthma in conversation, healthcare can be made more careful and kind through the creation of a plan of care that fits with each individual’s unique circumstances and values.

# Special Reports

*Dispatches from the field.*

## Peter A. Noseworthy

*Update on anticoagulation choice trial*

I am pleased to report continued progress on the anticoagulation choice shared decision making randomized controlled trial. This project was funded through the National Institutes of Health (RO1 HL131535) which began funding in April of 2016. We enrolled our first patient in the study, at Mayo Clinic, in February of 2017 and made good progress over the year surpassing our enrollment goals at Mayo and meeting our targets for the study overall. Across three sites, we have a monthly enrollment target of 42 patients; since May of 2017, we have been enrolling 38-55 patients per month. By March 2019, we intend to enroll 999 patients, and currently we have enrolled 395.

We have made considerable effort to improve the enrollment of minority subjects which has been a challenge at the Mayo Clinic site. Park Nicollet has enrolled 14 non-white patients (approximately 9%) and Hennepin County Medical Center has enrolled 15 non-white patients, accounting for approximately 35% of their enrollment. Overall, only 11% of the subjects enrolled in the study at all three sites are of a non-white race. We have set a goal of 20% and hoping for continued enrollment at Hennepin County

and Park Nicollet to reach these targets. We are in the process of developing infrastructure enrollment within the Somali community of Minneapolis and continue to make efforts not to miss opportunities to enroll elsewhere.

While the project is ongoing, we have written several papers and have others in preparation on reporting on the tool, our research methodology, and reviewing the importance of shared decision making in the context of atrial fibrillation. Using the Optum Labs data warehouse, we conducted a study examining long-term risks of stroke and bleeding which informed our 5-year risk prediction for the tool. We felt that many patients required a longer risk horizon in order to make nuance decisions about balancing the risks and benefits of therapy in the context of their everyday lives. This data has been useful in communicating these risks with patients. Dr. Marleen Kunneman published our study protocol in the journal *Trials*. This outlined the approach to our study and will increase awareness of our study and ongoing work at Mayo Clinic. In collaboration with other authors, Drs. Brito and

# Juan P. Brito Campana & Marleen Kunneman

*2017: the year of Shared Decision Making*

Noseworthy published a review article discussing the role for shared decision making in Cardiology care in the Emergency Department. This paper discussed our tool in broad strokes and discussed the implementation of shared decision making within a busy emergency department context. Other manuscripts are in various stages of development of submission and revision.

We plan to continue our work in shared decision making in atrial fibrillation care, and in collaboration with University of Utah, we are seeking funding from the American Heart Association DECIDE program which will plan to evaluate implantation of these shared decision making tools and determine the relative effectiveness of various approaches.

In 2018, we look ahead to continued robust enrollment in the anticoagulation choice trial. We will continue to strive to maximize minority enrollment in the trial and will continue to disseminate our knowledge through presentations at the national/international meetings and scholarly publications.

2017 really was a shared decision making (SDM) year! We started the year by enrolling the first participants into our SDM4Afib study, a large NIH funded, multicenter trial in which we test a conversation aid to support patients and clinicians in making decisions about blood thinners. Recruitment is also ongoing in other SDM projects in the care of patients with advanced kidney disease, thyroid cancer, and back pain, for patients considering lung cancer screening, the Watchman device for cardiovascular problems, code status, and help for their alcohol use, and for conversations about (over-) use of diagnostic tests.

We received a grant from the Arnold Gold Foundation to explore the role of reflection in evaluating SDM (following up on our ongoing Gold-funded systematic review on mechanical versus humanistic SDM), a three-year award from the Moore Foundation to assess the role of SDM tools in

supporting cost conversations, and a PCORI grant to implement and disseminate the Chest Pain Choice conversation aid. Also, JP won the Shark Tank award to create an online resource for thyroid cancer SDM.

2017 was also the year of sharing our SDM experiences across the world. We represented KER at the Pope's children's hospital in Rome (Italy), the Mapping the Landscape symposium for humanistic healthcare in Chicago, the ISDM conference in Lyon (France), and at ICCH in Baltimore. In Washington, DC, Victor and JP each had a plenary presentation at the PCORI annual meeting. We ended the year with a think-tank type retreat and presentation to the staff at the Agency for Healthcare Research and Quality (AHRQ). This retreat focused on moving beyond the current state of the SDM field and brainstormed about possible and necessary next steps to innovate SDM in patient care.

# Aaron Leppin

## *Adventures in the public sector: health & aging*

Aaron was accepted for appointment as a 2017-2018 Health and Aging Policy Fellow (healthandagingpolicy.org). The Health and Aging Policy Fellows Program brings a diverse group of researchers and practitioners to Washington DC to give them mentored training in health policy. All Fellows complete a month-long orientation on key issues in aging and health policy and an introduction to how the government operates (with somewhat behind the scenes access!). Fellows then interview for and obtain placements in personal or committee congressional offices, federal agencies, or other relevant entities. Aaron completed his DC-based orientation and is now working to advance state-wide plans for healthy aging in Minnesota with the MN Board on Aging and Department of Health. He will make several trips to DC over the year to participate in fellowship-related activities and for networking.

Aaron gave a TEDx talk about his research at TEDx ZumbroRiver in May of 2017. It can be viewed here: <https://www.youtube.com/watch?v=vuEjYBXp4tA>. This marks the 2nd straight year that the KER Unit was represented at this event. The talk was well received and has been picked up by key stakeholders. This has resulted in Aaron being invited to give keynote and plenary addresses at two conferences in 2018. It also spurred discussions with partners in the Mayo Clinic Care Network eager to collaborate.

# Kasey Boehmer

## *Update on Minimally Disruptive Medicine*

The Minimally Disruptive Medicine program has been incredibly active this year! This year, we have put out six papers in the MDM space including a piece on measuring the Burden of Treatment, and a systematic review on health coaching for cancer survivors and its effect on patient capacity. We are currently executing a multi-site randomized trial to test the ICAN Discussion Aid, a tool to support MDM, across four health systems in Minnesota, Wisconsin, Kentucky, and North Carolina. This trial was funded late last year by the Gordon and Betty Moore Foundation. We received three new grants to support MDM research this year. These include: an AHRQ-funded R03 grant to develop and ICAN Implementation toolkit, a collaborative grant with Arizona State University to explore the work of and treatment burden associated with being a patient with end-stage kidney disease, and the

Presidential Award from Mayo's Center for Clinical and Translational Sciences to begin a qualitative program of research exploring the patient experience. Finally, we hosted our second-annual MDM Workshop in Rochester on October 23rd and 24th. We had approximately 15 faculty members and 19 participants who joined us from around the world for a meaningful, rich learning experience. We look forward to seeing the many partnerships, papers, and blogs flourish in the future as a result of the two days together. Those interested in this experience next year should mark their calendars for October 2nd and 3rd, 2018!