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TRANSCRIPT - GR 09 02 22 “Improving Representation in Biomedical Studies”–
Neeta Thakur, MD from the University of California, San Francisco

- So welcome everyone. Hello, Madison! Grand Rounds say we're excited to have Dr. Neeta Thakur from the University of California, San Francisco.

UVA Internal Medicine

00:22:07 Dr. Thakur completed a dual degree program of public health and medicine and University Arizona focused on community health and program development and evaluation. She then went on to Ucsf for a residency in internal medicine and state to complete her pulmonary and critical care.

- 00:22:22 Ah, medicine fellowships If that wasn't enough she then completed a post-doctoral fellowship in clinical pharmacology the nih sponsored research, intensive training program gear towards preparing clinician scientists to become leaders in clinical pharmacology. Research
- 00:22:38 within academia as such she is an expert in Ah, areas of clinical research, social epidemiology, and implementation sciences. She wears many hats in her appointment at Ucsf. Chief among them she serves as the Medical Director of the chess Clinic,
- 00:22:53 medical director and founder of the Critical illness, Recovery, Clinic and Director of Diversity and Social Justice at the Zuckerberg, San Francisco General Hospital,
- 00:23:03 Dr. Cooper's Nih supported research focuses on defining obstructive lung disease phenotypes that exist in racially and ethnically diverse communities
- 00:23:13 identifying individuals at high risk for outcomes and developing targeted interventions aimed at social and environmental factors to improve asthma and gopd and high risk routes. So we're very excited to have her here today, with us, and so, without further ado
- 00:23:31 we'll get things started. I'll bring you up on the screen here, and Dr. Thakur. You can share your screen, and we'll be good to go.

Neeta Thakur (she/her)

00:23:39 Thank you so much for that generous introduction. I really appreciate being here today to share some of the work that I've done in partnership with the American Thoracic Society.

- 00:23:51 Um, I think you should be able to view the right screen, and we've been with the Ats and my own work. We've been really examining the diversity and representation in clinical research studies, understanding that the information we learned here
- 00:24:08 will eventually get translated into our practice and care of patients to start. I have no disclosures today. I hope to be able to cover the current gaps in racial and ethnic representation in biomedical research and potential impact on scientific discovery.
- 00:24:28 Ah! To review the historical contributions and unethical practices that resulted in mistrust in biomedical sciences and research, and then, lastly, to learn strategies and how to implement these strategies across multiple levels, to reduce barriers to research, participation and increase engagement with minoritized population.

- 00:24:49 So I like to start with this slide to reflect on a mandate that the U.S. Congress passed in one thousand nine hundred and ninety three, called the Revitalization Act,
- 00:25:01 and it made law that all NIH funded, biomedical and behavioral research include women and racial and ethnic minorities. And the last point of this quotation from that revitalization act is with no exception for costs.
- 00:25:19 And so
- 00:25:20 I think one important thing is to think about the metrics and see if we've been able to achieve this in our own research in the U.S. And so I like to start with the demographics of the United States in two thousand and nineteen
- 00:25:34 Um. Here we see that in nationally we have about sixty percent of the population that identify. So it's not Hispanic white, and then the rest. And then the next largest group is like Latinx or Hispanic populations, followed by Black Asian, and then other groups in the United States.
- 00:25:52 What I like to do first point out, prior to looking at the racial and ethnic breakdown of clinical research, and in the U.S. Is to say, is to bring this back um forward first.
- 00:26:08 So when approached. And this is key. When approach, acceptance rates do not differ across racial and method groups.
- 00:26:16 And so, when we look at research funded by the NHLBI And look at the amounts of representation and genetic research. First,
- 00:26:27 we see that there is overrepresentation of non-hispanic white populations with seventy percent of that research being conducted in non-hispanic white populations. Um, Then when we look at clinical research, we see it's a little bit better, but not much with sixty seven percent of that research done
- 00:26:46 with non-hispanic white-study populations.
- 00:26:49 Now, when we look at a disease that is known to disproportionately impact the racial minorities in the United States it's specifically African-Americans in the United States and Puerto Rican populations
- 00:27:02 we do a little bit better with fifty-six percent of the research being conducted in non-hispanic white populations, but twenty, one percent being conducted in African-american populations in the United States. However,
- 00:27:16 these these numbers are inflated, and so you can get these from the NIH reporter website,
- 00:27:23 um, and they include studies that are focused on single racial and ethnic groups. And So if you have a study that's only including an African-american population or a Puerto Rican population, you will inflate the numbers here.
- 00:27:39 This is really a really important, because the majority of those single ethnic or racial studies are observational studies. They're epidemiology studies. They're descriptive. They are not focusing on interventions or therapeutics. And the best example of that is when you look at that their biological therapies for asthma.
- 00:27:58 Those are way over represented by non-hispanic white populations. With almost eighty percent of those study populations being not hispanic. White.
- 00:28:08 So this is important that the numbers look better over time, and when you look at disease, but you have to also take the take off the roof and really look at the details to see if there's really been an improvement.
- 00:28:20 I will start with a case study about why this has important implications.
- 00:28:27 So cystic fibrosis, as you guys, as all of you know, is a genetic disorder of the sodium chloride channels located throughout their bodies, as you know, cf predominantly affects the lungs and the pancreas, and leads to impaired lung function and malnourishment.

- 00:28:42Um, we know that the management of Cf. Has rapidly improved over the last several decades previously, this disease that caused death in childhood. And now the Median survival is somewhere in the mid forty S. This is really remarkable.
- 00:28:58However, this benefit hasn't been seen across all populations.
- 00:29:03And why is this um Part of this is because of early identification so newborn? Ah! Screening efforts can contain some genetic ah testing. And then also, if you meet the right demographic population, you're more likely to be tested.
- 00:29:19It's also because this Seattle was thought to be a disease of those with European ancestry and genetic studies show the mutations to only show up in high frequency of these groups, however, those genetic studies were only done in European populations. Thus only the mutations of European
- 00:29:39um ancestry are those that have made it to our screening tests. However, while all of the mutations involved in the transport are shown here.
- 00:29:48Um, particularly with the Cf transmembrane conduction Regulator G in the Cftr gene. The exact mutation that causes the problem of this transporter can vary across populations, and
- 00:30:04it's actually estimated that there are about two thousand mutations that have been identified. But we only test for a few.
- 00:30:12So why is this important?
- 00:30:14So we know that the most common mutation is the F five hundred and eight deletion, and so in two thousand and twelve. The first Cftr modulation ivacticator was approved and targeted those with this solution.
- 00:30:29This was revolutionary. The first class of drugs for Cf. To target the mutation as opposed to just managing syntheses. It just changed Cia. It stops it in its tracks, and we can see that patients that are placed on this medication
- 00:30:45no longer have symptoms of Cf. It's. It's amazing,
- 00:30:49however, this class of drugs corrects a mutation that is most commonly present in non-hispanic white populations. But it's only effective for about forty four percent of black and fifty four percent of black. Next individuals, with Cf.
- 00:31:05With the recent discovery of Cftr modulators, there is a greater impetus to include diverse populations in both genetic studies, but also in clinical trials. For these therapies,
- 00:31:17so prior to shifting into the strategies for increasing diversity and biomedical research. I think it's important to reflect on the history of this of research in this country specifically for minoritized populations in the United States,
- 00:31:35and so we go back to the eighteen hundreds um to to start this review, and I will say much of what i'm going to talk about will be, will make many of us in the audience feel unsettled or upset, and some of us not right that,
- 00:31:52and not doing this to make folks feel uncomfortable but to acknowledge the history of our country, and how it has contributed to the ongoing mistrust in the biomedical sciences. So in the one thousand eight hundred. We saw an expansive experimentation that was obtained often by force.
- 00:32:11Much of the work done at this time has influenced modern medicine, such as the field of gynecology, influenced by the work of Sims specifically with gynecological procedures, but need to remember that those procedures were often done by force and without proper and emphasis on,
- 00:32:28and the work at this time has also embedded racial bias in our medical thinking or approach. For example, black patients are less likely to get pain medications in the emergency room.
- 00:32:40This has a direct connection to the experimentation during this time that concluded that black individuals had thicker skin and less pain of receptors, which is not true, but it is a good justification for the ongoing abuse of slaves at the time.
- 00:32:55Another example is for pulmonary function testing.

- 00:32:59 So Cartwright observed that slaves had lower lung function than their white slave owners. He was a slave owner himself, and in his work he did not account for the social environment or the malnourishment that was experienced by the slaves at that time, and when he went on to conclude
- 00:33:18 that race was responsible for this deficiency, and that African, American, or black race was an inferior race, and it was a further justification for slavery.
- 00:33:32 In the early one thousand nine hundreds we saw broad sterilization of marginalized populations, a practice that would continue into the early two thousands for those people that were so that it continued to be incarcerated.
- 00:33:44 I think one notable example of this broad an efforts of sterilization or contraception is the Puerto Rican Birth Control trials of the one thousand nine hundred and fiftys, which targeted four low health literacy women living in public housing.
- 00:34:01 For these studies no consent was obtained. Women were told that the pill was to prevent pregnancy.
- 00:34:08 Yet there was no disclosure that this was an experimental trial; rather that this was just part of routine practice for preventing pregnancy
- 00:34:17 during the trial they had found that the low-dose version of the pill was just effective as the high-dose version of the pill
- 00:34:26 that the high dose Poe was associated with significant side effects,
- 00:34:31 because they really wanted to show that the pill was effective, and the person leading the trial out of the time dismissed the symptoms or side effects reported as being psychosomatic. They decided to
- 00:34:47 continue the trial at the high dose, at the consequences of side effects in the population,
- 00:34:53 just so that they could demonstrate efficacy. So, choosing demonstrating efficacy over the safety of the population.
- 00:35:03 Next, we see two of the most well-known examples of unethical research,
- 00:35:09 so the story of Henrietta Lack were cells from, and was isolated from a biosy for cervical cancer without consent, and the Tuskegee trial, a study led by the Us. Government to understand the natural history of syphilis, and allowed to continue, despite an effect of therapy being discovered in the study.
- 00:35:26 Both are examples of those leading research, those of those leading the research, believing that the work with the benefit of the public health, but are also striking examples of unethical research practices along the ways of each wave of their studies.
- 00:35:41 So we come forward, and we believe that we have learned from this from the unethical practices of past research. But I wanted to share two more examples of unethical research project processes in the modern era,
- 00:35:58 where we still see striking examples of egregious research being ongoing, and I think this is most striking, because this is during a time that we have irb review, and also the bioethical lens coming into research.
- 00:36:14 So The first is a study from one thousand nine hundred and ninety seven um that was focused to understand aggression and boys. Um! In this study all of the boys that were concluded in the study were black or latino. They were separated overnight from their caregivers.
- 00:36:32 They underwent an overnight fast. They weren't given their medications for their chronic medical condition, some of which included asthma, and then where they were also given Fluorine or Fenn Um. The popular appetite suppression known to cause aggressive behaviors.
- 00:36:49 From this study they concluded that a serotonin receptor, present, and Latino, and black boys predispose them to aggressive behaviors. It's important to note that This study included no white children.

- 00:37:03When this received national attention. After being published in a high impact Psychiatry journal,
- 00:37:11the Irv and the investigators pushed back and stating that the study was ethical. It was only after a external review by their peers and the Us. Government that they eventually agreed that this was an unethical study, for obvious reasons.
- 00:37:29The last study that I wanted to talk about was, they have a supreme genetic study.
- 00:37:35So this study was actually done in partnership with the community. The Havasup High is a native American tribe located in Arizona, and they noticed that obesity of diabetes was running rampant in their community and reached out to researchers at Asc. To better understand this,
- 00:37:55the researchers there formed a community partnership with the habitsup high, and they all agree that a genetic study. To understand if there's predisposed risk would be, would be helpful, so that investigator reached out to a leading and geneticist at Asu to partner on the study.
- 00:38:13This study did go on to show some genetic risk for diabetes in the population. Then the genetic investigator
- 00:38:23also went on without permission of width of the tribes to then go look for genes that may predispose people to alcoholism and mental health disorders.
- 00:38:35This was a misuse of the genetic samples that were provided by the tribe, and also something that was not ever consented to. And so this is another example of how this trust can develop over time when samples are misused or research is misrepresented.
- 00:38:55I think this is something that is come to even more into attention, as we have battled through this pandemic,
- 00:39:04particularly when thinking about a low vaccine uptake among black and brown communities, and one of those sources being linked to mistrust. And I think when we reflect back on this history, we really it really makes a lot more sense about why the vaccine may be mistrusted
- 00:39:23kind of reflecting on the vaccine that came to market on an unprecedented case, and that there were special efforts taken to get this vaccine to black and brown communities who were disproportionately burdened by the pandemic,
- 00:39:37but could be viewed as experimentation to further test out the vaccine prior to it actually being safe for use. With this historic ones this mistrust is much more understandable and justified.
- 00:39:52And so now I wanted to move us forward. Um! In two thousand and twenty one we published a research statement in the Blue Journal of the American Thoracic Society,
- 00:40:04outlining a framework, and also strategies to enhance recruitment and retention of minority populations in clinical research and i'll spend the rest of the time today to take us through that framework.
- 00:40:18And so we proposed a multi-level framework, understanding that there are numerous barriers to participation in research at the both at the individual level, but also extending all the way upwards to the Federal and policy level.
- 00:40:34And we outlined this. We have this framework, including barriers at each one of these levels, but also includes strategies at each of these levels to help
- 00:40:47Ah address these barriers and all of the strategies that we pose in the in the statement are those of a large evidence base um, and that have been demonstrated to increase representation for a research. I want to call attention to the base of the framework.
- 00:41:05Um, which is about thinking about Ah! Working with patient advocacy groups to understand the driving needs, and as a partner, and then also about community engagement. Um, and specifically thinking about community-based participatory research, and how that is foundational to increasing representation and trust and research.

- 00:41:27 I'm. Going to give two examples for my own work about how patient advocacy and community engagement can play out and lead to better science, and also increased trust in the process.
- 00:41:40 The first is a partnership that I formed. Um, maybe now six seven years ago, with the center for youth, Wellness, which was a community organization that started in the Bay View of San Francisco, which is a isolated neighborhood surrounded by freeways,
- 00:42:00 and also is where the majority of the African American population in San Francisco lives, There is a historical reason for that due to gentrification acts, and in the fiftys that pushed people out of a vibrant neighborhood that was located for a big city.
- 00:42:19 The neighborhood also has a concentrated poverty and a higher rate of crime,
- 00:42:26 and Dr. Burke Harris, who was the first and surgeon General of California, started this organization in the mid two thousand,
- 00:42:35 and what she noted in her population that she was seeing as a pediatrician was that many of them presented with high adverse childhood experiences, and she began to screen for aces in her clinic
- 00:42:52 um because she was noticing this pattern of those experiences being associated with poor health and problems in her population, and then she's become a fierce advocate across the country
- 00:43:06 about aces in this work from this early experience, influenced by her patient population, and she also wanted to better understand how early childhood adversity was connected to biological health outcomes,
- 00:43:22 and so, as a patient advocacy group, she reached out to Ucsf and to Ucs at the time Children's Hospital, Oakland now renamed as
- 00:43:32 Benny Off Children's Hospital, like I went through our community engagement core. Um! And so this was a happen chance. Um! Ah, for myself. Um! But a really meaningful relationship that has really grown over the years. And so, while she was connected to many scientists in the Ucsf community, it was with our two groups that she felt the most um alignment in the science. And so we all had a shared idea around the science, and all had an alignment
- 00:44:02 for how that science would be carried out,
- 00:44:07 and together we were able to successfully apply for and obtained a five million dollar grant to do a a study of specifically looking at the effects of early childhood adversity on long term outcomes in pediatric populations, and then also looking at it with a intervention less
- 00:44:28 one of the pieces that has really contributed to the success of that relationship is that we had a very trusted relationship, and also a very broad communication. It was also agreed upon at the very beginning that all three organizations had shared ownership or for the project. I was not the one meeting, the science. It was really Dr. Burke Harris that was setting the priorities in the direction of the science. And I, as a researcher,
- 00:44:58 added the scientific lens and the methodology to ensure that the questions that we were proposing were answerable and done in the correct way. And so this is where one example of shared leadership That, I think is really important when thinking about doing engagement research.
- 00:45:15 The second example, which was a de novo research partnership with Richmond, California. And here we had to start from Scratch. We knew that we wanted to better understand what were the social and environmental
- 00:45:35 um contributors to asthma in the Richmond community, where there we saw the asthma prevalence of children be as high as twenty, five percent compared to eight percent nationally. And we reached out to one of the community health centers that we knew, provided a lot of care for patients in in the area.
- 00:45:54 Um called Lython Medical
- 00:45:56 Um. And below I keep a a picture of what the environment in Richmond California is like with the chevron ref firing into that a high high-front trafficated highway that is specifically for Diesel trucks

um and in addition there's a railroad and a shipyard um, and a this is also a community of predominantly black and Latino individuals who are most like mostly working in

- 00:46:25blue-collar type, work. And so, when we approach them, we asked, first:
- 00:46:32does this resonate with you? What are your concerns around asthma and the number one concern from lifelong, and the community members was around air pollution there. And so we made sure that we
- 00:46:45included that the other concern that was brought forward is that many of the patients that were being seen at lifelong
- 00:46:52were those that had recently immigrated from Central South America, and had experienced recent trauma in their life as a process of their immigration. And so we were also sure to ask about acculturation and history of trauma
- 00:47:07before we even got to the science, though we needed to show that we were a trusted partner in this. And so we also asked about what were the needs of the clinics,
- 00:47:19what the patient population had, and one thing we identified and we
- 00:47:24did together was bring a a veggie giveaway um to the program which we run in partnership. We've also helped lifelong get two grants from the local food banks to continue this, and then, during the start of the pandemic, we ramped up from serving thirty families a week to serving two hundred families a week, and right now serve about one hundred and fifty families a week.
- 00:47:47We also introduced a clothing drive, and that we also have introduced a youth engagement work.
- 00:47:53Um where we hire. Ah, ah! High school research. And so ah High school students from the area to contribute and lead our science, but also as a way to increase exposure to science and medicine.
- 00:48:07Through this we've built a very trusted relationship with lifelong and with life on. They have become our partners
- 00:48:15on research that's related to asthma, and as well as the aces, and we have been successful in being able to recruit and retain our participants from from this trusted partnership. And we actually have retention rates that are as high as ninety five percent
- 00:48:34um With the efforts that we have done.
- 00:48:37And so these are just two examples of like foundational things that can happen to really make research successful going forward. It does require a lot of groundwork and time. But I will say now that the groundwork and the time has been invested, we have been able to really accelerate forward with the actual research projects because they are done in partnership, and there is mutual alignment and goals for that work.
- 00:49:02So when we review the literature, the highest ah number of, or the largest barriers to participating in research at the individual level were time and resource, constraints,
- 00:49:19um language and literacy. Um, Ah! And then transportation. And so I wanted to give a couple of examples from the published literature about how others have addressed these barriers. So the first is the health and aging um in neighborhoods of diversity across the lifespan study.
- 00:49:39Um. What they were attempting to do was to recruit a large representative sample, and what they ended up doing was providing free transportation to the to the research sites.
- 00:49:55They also brought the research to the communities through mobile examination centers. They also allowed for flexible scheduling, so it did not have to be during daytime hours, but evenings and weekends, and then they provided a fair compensation for the time that they were asking of participants,
- 00:50:13and so their results are quite promising. They were able to recruit seven hundred and forty five minority participants, and they experienced a five years, a almost eighty percent retention rate, and really only um of a fraction of those lost to follow up were actually truly lost, follow up. And so this

is an impressive study of showing that when you increase or when you increase accessibility to a research city that can have a large impact.

- 00:50:41 Um. The second is the health is wealth study, which was a Filipino study to understand breast cancer and the Filipino population. Um. They partnered with their community members and community health workers to understand the best ways to get high participation in this study.
- 00:51:01 And so what they came out with from that is to do a word of mouth campaign. So, having key leaders in the community talk about the study with the community,
- 00:51:14 they also had presentations by the Filipino director in the community doing church announcements. And then they had female project liaisons that went out and did outreach,
- 00:51:24 and they also ensured that there was an appropriate compensation or incentive of being in this study.
- 00:51:30 So in this study they were able to recruit five hundred and thirty for liquidia women, and they experienced a seventy, six percent retention at two years. So this talks about the outreach part and trusted voices in the community going out and bringing people in, and by
- 00:51:49 increasing awareness of the study you're also able to increase the ability to recruit and retain participants.
- 00:51:57 The next level um I wanted to talk about was those that are at the interpersonal or relational level. Um, And so these are capturing um issues around trust um bias and discrimination, and then also around engagement.
- 00:52:13 Um, So we wanted. I wanted to focus on two parts of this. Um. So thinking about how do you build trust? So one way is to add community members to the team, and then also forming trusted relationships with key leaders. So I'm going to give two examples of these. The first is with adding community members to the team.
- 00:52:33 So this is the Uh. C study, which was a smoking cessation study, and I include the flyer from their study here on the on the left side of the screen. This went out into three phases, and the first phase
- 00:52:49 the investigator team was only of those in academia. The intervention also only took place at the academic center.
- 00:52:59 Um! They noted not a lot of recruitment or retention in the study, and in that first phase only thirteen point. Eight percent of those recruited were retained in the study.
- 00:53:11 Then they went to the community and asked how to improve upon this, and so
- 00:53:17 what the community members sought is that if they moved the study to a community venues, and then also employed people from the community to be the interventionist over healthcare providers, they would have more engagement with the study and higher retention, and what they saw that was in fact, true so by phase three they had sixty-seven point nine percent retention, and they also saw that the retention of African American participants in
- 00:53:45 also increased over the phases. So by phase three they had a retention in this group of eighty, four point six. So this is one example of incorporating community members, but also moving to a community venue where you can improve retention in the study.
- 00:54:03 The second is with this: Ah, the recruit maneuver! Ah! Which is a trust that forms the trust triangle. So i'm going to take a step back and kind of describe it like from my own perspective. What I think about it as being a physician in my and my clinic at the county hospital.
- 00:54:23 So if I was asked to recruit for a study, and it was just given a fire or a brief email that was study. The likelihood of me presenting the research to my patients is pretty low, because one I don't have a relationship with the study investigator,
- 00:54:41 and I also don't know the ins and outs, or the understandings of the study to really understand if my patient would be put at risk, or if it's something that would be a benefit for them to participate in
- 00:54:52 um. However, if the investigator came to our clinic

- 00:54:59and specifically asked to meet with me to talk to me about the study, and then also Um presented it to my colleagues. I would be much more invested, and be more likely to present the study to my Asian population, mostly because I could better describe what the study involved to them. But then I also felt like I knew the person that leading the study, and I trusted that person, and so, therefore vicariously, I send that trust to the patient. And so that's this idea of the trust triangle,
- 00:55:28and they found in a cancer study for prostate cancer that this methodology of recruitment increased growth, recruitment, and retention. In this study
- 00:55:40the next level is thinking about system and institutional barriers for recruitment.
- 00:55:47And so there is definitely mistrust in academic centers in general. There's also within the academic enterprise or health system enterprise. There's also competing goals where clinical and research priorities are often at ends at each other or at odd ends at each other. And then, lastly, the availability of trials for patient populations may only be available through academic centers,
- 00:56:15and not be reaching out to the clinics that are more likely to serve low, socioeconomic and diverse populations.
- 00:56:26Study um! And I realized ah, one of them I forgot to ah hide. So apologize for the embedded ehr around here. Um: So the all of us research program is a national study which is supposed to be the largest cohort study to understand health, and in the population
- 00:56:45and the Banner health system with the University of Arizona was tapped to a diverse population, with more than fifty percent, being from traditionally from groups, traditionally under representative science.
- 00:56:58They are assault also tasks to accrue a large number of patients quickly. So um fourteen thousand in one year.
- 00:57:07And so they wanted to approach this through a multi-pronged effort that meant that they had to align their their clinical enterprise with their research enterprise quickly.
- 00:57:19So what they did was partnered with academic centers that had served the desire-patient population. So this means that they partnered with four hospitals in Southern Arizona in the Tucson Pema county area that predominantly served a Latino population. Um to help them be able to access the patient population that they were wishing to target. They also a partnered with federally qualified health centers that were there.
- 00:57:49Knowing that they had a more trusted relationship with the population.
- 00:57:52They also ensured that their staff was multilingual, so that they would be able to have a native Spanish speakers on site, so that they did more facilitate enrollment into the study,
- 00:58:06and they also focus on stakeholder engagement and asking partners like, What would it take to um be able to be successful in this study and incorporate those ideas into the study?
- 00:58:18He also allowed for multiple points of that entry, so that he means having stations in the community for enrollment in the hospital, and then also through the patient portals in the electronic health record. I think the smartest thing they did in this study was also ensure that they were health system leader champions. So the person at the top.
- 00:58:40It was engaged with this study and made it a priority, and by having that top engagement and prioritization it made it a lot easier and faster to be able to be successful.
- 00:58:51And
- 00:58:53here's all they did. So This is the number of um patients enrolled per quarter. Here is their goal. Um, and you can see that they completely surpass their goal by almost one and a half times. And we're actually able to recruit thirty thousand people in that first year, and the breakdown of the study population is located on the left.
- 00:59:14The last strategy that I wanted to talk about was addressing those at the Federal and policy level. So thinking about the funding mechanisms for research, accountability and supports for five pop investigators. And so I wanted to focus on this last point first,

- 00:59:30our last point at the last piece of this, because I think this is an important underused mechanism of in that we use, and to recruit and retain individuals that are from traditionally under representative groups in medicine and stem, and those are the Nih diversity supplements.
- 00:59:51You can extend these all the way to the high school level through those that are coming onto faculty. And it's actually a mechanism that you can use to facilitate transition to faculty.
- 01:00:03So it's a supplement that is, to an existing research grant with the and Nih, and it's an administrative supplement. So the review process is slower, and they are generally funded, and for those at the early career getting into a mentor position, it provides almost one hundred thousand dollars. Support to that person's salary.
- 01:00:25What they found is that those that were that were brought into science are retained in science through diversity. Supplements were more likely to stay in science and achieve research careers. So this is definitely a proven underused mechanism for recruitment.
- 01:00:44So many of the things I talked about require a lot of ah efforts, and so we also um created a low-hanging group table. Um in the publication to talk about ways that you might be able to adapt your research. Now to how increase representation.
- 01:01:04And this includes everything from thinking about culturally sensitive visuals on patient-facing material So, making sure that the depictions or graphics you use include diverse populations
- 01:01:17and also written at a level that is understandable for the patient population that you're trying to reach, and including in the language of the population that you're trying to read
- 01:01:27um. We get active feedback from our past participants and our advisory boards on our materials to make sure that they are being interpreted and received in a positive manner,
- 01:01:40and have been able to be successful in changing our materials rapidly to respond to that, and it's a very low
- 01:01:48thinking fruit way of doing that for a retention collecting multiple methods of contact. Um to facilitate being able to contact people in the future. That is something that I think is probably the hardest thing is like maintaining contact. And so we always get, like three numbers, an email, even a social media contact from our participants, knowing that that is the the largest reason for being lost To follow up is not having a good working context
- 01:02:17for the future.
- 01:02:19Um! And then the last piece I would say that we've had a lot of success in is having flexible scheduling and also having your studies available in a modular format. So that means having maybe your survey is being able to be self-completed or done over the phone as opposed to having to come in for an in-person visit. And then, if you have something that requires an In-person visit
- 01:02:42scheduling that for a much shorter time period for them to have to actually physically
- 01:02:48come in and do so we actually deliver all of our surveys, either self-completion or by phone, based on the preferences of the of the person, and then we will have them come in for a twenty, thirty minute. Blood draw, and quick clinical exam to complete the study. And so there are different ways of being able to meet and increase accessibility to to the research study,
- 01:03:11and i'll real reiterate
- 01:03:14that um. It requires time and investment and a need to really address, not just those barriers at the individual level, but thinking about the upstream factors to really try to increase retention and recruitment and research. And so
- 01:03:33thinking about concerted efforts and resources for multiple stakeholders, including, but not limited to educational and healthcare institutions and organizations. Um and the Nih are really needed to buy these strategies and increase to embrace representation. I just like to thank the full workshop committee. Um! This is

- 01:03:51a forty percent effort to get this document together, and it's a publication form and really appreciate the knowledge and learnings that I had on from that experience. And I think we have some time for questions.

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01:04:07Yeah, that was great. Thank you so much for that. Um, I one thing that kind of kept popping up in my mind, I think. Um, I just wanted maybe a word of advice for our medical students and residents was, it often seems to me, maybe, like a zero sum game between being involved in a community and helping underserved populations, and then being academically rigorous and pursuing like a research career,

- 01:04:32it appears that you've kind of done both in that aspect, and it certainly provided a framework for others to do something similar. So any advice you would give to residents or medical students who are trying to
- 01:04:45choose. They're trying to figure out that balance between being engaged in their community, but also wanting to do research.

Neeta Thakur (she/her)

01:04:54Yeah, it's, It's that I think a really important point is that I think I've said maybe five or six times through that presentation. This work requires time and investment, and when you're early in your career,

- 01:05:10time and investment is not the thing that you have to be viewed as being successful in academia. So my advice to my mentees is to select
- 01:05:23early on a low hanging fruit project. So something that is clear that there is a timeline and product for publication, because that is going to be the thing that retains some in science to be able to form those engagements. At the same time.
- 01:05:40I also ask them to think thoughtfully about the research problem that they're going to eventually want to address and then start forming those relationships because
- 01:05:52you want to be able to do two things at once. You want to be able to get your science and get your publications done quickly, because that's the thing that you're going to be. Um Ah! Viewed and critically evaluated on. But you also want to start thinking about what is the impact that you want to make? Who are the communities that you want to work with in your research and start making those engagements at that time,
- 01:06:15even though you may not have the exact research problem that you want to work with.
- 01:06:21Talk about. Ah, one of my colleagues Um, who recently came on faculty, and she knows that she wants to work with adolescents and addressing batting image, particularly in the African-american security. And so, while she does not have an exact research project
- 01:06:40for working with a community group, she has already proactively started talking with one of the community groups that she knows would be a valuable partner in the future.
- 01:06:53When co-developing a research priority or a list and what she has done is she has reached out and said, Hey, this is an area I'm interested in. What is your experience? What you have learned, and what do you view as the biggest issues in this area.
- 01:07:12Then she followed that up with, I think, a really important piece, which is the
- 01:07:18that. And after learning about the organization offering her skills. So as clinicians as researchers, we have skills that are useful to community members and community groups. And so, as

someone that has data and analysis skills. She offered just a look at some of their metrics that they were trying to do for their own practice and for their own outreach efforts to see if there's any like just doing simple descriptive to statistics

- 01:07:47that they didn't have bandwidth or knowledge on how to do, but by offering that service. Um! She's now being able to build a relationship that this this relationship is reciprocal, and then it's not one where I'm continually going to ask for things. So that's one example,
- 01:08:05and which I think is really useful for those that are earlier in their career and trying to build those relationships over time as a strategy to start doing that early, but being able to focus the majority of your time on doing the low hanging for a research project

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01:08:23that was great. Thank you.

- 01:08:25There we got a question here from Colin in the audience.
- 01:08:29Thank you so much for that stimuli. And Todd. My question has to do with the interaction between race and racial groups versus population groups.
- 01:08:41Um and uh, you know, genetic uh different genetic groups. So. Um I noticed kind of in the how it's you fit on your work. You did a lot on um under representative minorities in terms of racial groups.
- 01:08:57I've always struggled with the tension between those designations as really coming from running edge of um European racism. Um, And it seems in biomedical research, it's um in many cases more useful, as you point out, for example, when Cf. To to look at um potentially um genetic groups or population groups,
- 01:09:18I wonder if you could just comment on that interaction and kind of paradox there.

Neeta Thakur (she/her)

01:09:24Yeah, I think that's a really important question that the biomedical research community is having a large reckoning with right now is thinking about the constructs of race and ancestry, and how we consider those.

- 01:09:39So I will start off with two pieces of information before we're addressing your question.
- 01:09:47So the first is um the Omb. So the office of management budget for the United States has designated certain racial and ethnic categories. So that's the two part census question that we get asked, which is, What is your race followed by What is your ethnicity?
- 01:10:05Um. Unfortunately, the way we distribute resources across this country is based off of those designations. It's also how we, as researchers, are required to report our study populations to the to the Us. Government.
- 01:10:23And so in some ways we're struck, stuck in this dynamic of having to use those designations in our in our work and our study, even though they may fail to recognize the vast diversity of the Us. And how
- 01:10:42One individual, the you know, the Latinx population is a great example, and is where it's an aggregate of many different, You know subgroups that are quite heterogeneous, but are designated as one group under that definition. And so but on this list.
- 01:11:00If we know that resources are distributed by those designations, then it is important to show where there is health inequities incurring by those aggregation to help increase resources towards those communities. So it's one piece. The second is about race.
- 01:11:18So race is a social construct. It's.

- 01:11:21It is a grouping that that as you, as you brought up, that came from really trying the dominant community trying to place their social hierarchy on the
- 01:11:37population at large to demonstrate superiority by the white race in allowing for racial discrimination to be embedded into our policies and our laws over time, and that have contributed the injustices that we still see today.
- 01:11:56And
- 01:11:57and while the racial groups, groupings may share some phenotypic Ah! Similarities, the biology and genetics across racial groups is ah quite heterogeneous. And actually we see more heterogeneity within one racial group designation than we do across
- 01:12:17um. And so I think that's important. And we. We talk about ancestry as being our answer, and I would also say that we should be careful with doing that, because we know, and I'll give one example. So, for example, your skin color for
- 01:12:36ah, for black populations. Your skin color is seventy percent determined by your genetic African ancestry. So the more African ancestor you have, the darker your skin is going to be.
- 01:12:49We know that in our society, not just us, but across the world, that the darker that your skin is the more racial discrimination that you are going to experience. So we, while some will want to separate out African ancestry as a biological determinant. I caution against that, because we know that that's going to be completed with the social experiences that individual has going through life, and therefore also the environment that they
- 01:13:18are in, and the thing and the things that they're exposed to. So we um are trying to understand what is the best path forward The importance of diversity in clinical research or biomedical research when thinking about genetics
- 01:13:36studies is that we do know that certain mutations concentrate in different ancestral populations. And so, without having diversity in your research study, you're not going to be able to recognize that rare variant
- 01:13:55that may be in higher prevalence in one population. But actually it could be present to require an entire population. And a great example of that is.
- 01:14:05And so that's a metabolism for this to three enzyme, and so in a South Asian and East Asian population, a mutation exists
- 01:14:19where that eclipse is metabolized very differently than it is in populations of European ancestry, but that mutation exists across the entire population.
- 01:14:32And so I know for myself from doing twenty, three of me. I actually have the variant that doesn't allow it, if that, and metabolizes it too fast. So criterion is not effective in me or my family, who has a high prevalence of heart disease.
- 01:14:45But I do know, because since we lived in the United States, which is predominantly white, that is not routine to test for that mutation which I think is actually an unfortunate incident, because I think we should be widely testing for that. Um, because we know It's a rare variant that exists across all population is just concentrated in one population. So that's the reason for the call for diversity and genetic studies and clinical and therapeutic trials. But it also cause for us to
- 01:15:12look at disparities or equities by racial and ethnic groups, so we can better allocate resources. So there is this tension. But that's how I kind of approached it and thinking about ways of trying to address it in.

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01:15:35Thank you for that.

- 01:15:38I did. If people in the audience on zoom have a question. You are welcome to unmute yourself as well, and then, if you have any questions you want would feel more comfortable just writing down. You can put them in the chat.
- 01:15:58Give people a little bit of time.
- 01:16:01Um!
- 01:16:03Well, I have. I guess I'll have one more question for you here, too. I I, you know I get the pleasure of reading People's Cvs when they when they're presenting, and you've also had a pretty good like um career trajectory.
- 01:16:18Uh, and I think that people for the residents here most of my questions kind of focus on like advice giving to residents um for someone going into um academia early on in their career. Um, And they're interested in these sort of disparities. Would you have any advice on their kind of um how to get involved in this research, or what they would. I think you may have answered this somewhat in your first and my first question. Um, But just people who are interested in uh on this top.
- 01:16:48How, maybe how you approach this in your life, and how maybe others could emulate what you've done.

Neeta Thakur (she/her)

01:16:56I think that's a that's a great important question. Um, you know. I I will say I've been called stubborn in my convictions of, of always taking a public health funds to the work that I do. So I guess one thing is, uh figure out what motivates you and be uh,

- 01:17:16you know, um
- 01:17:17be stubborn in some ways is helpful as a guiding light, because I tell my mentees that if you can't find something that excites you, or you feel like It's worth working hard for. You're going to burn out really quickly. And this this won't be a career for you. Um! But if you can find meaning in your work, whatever that may be. Um, it doesn't have to necessarily be with addressing health and equity.
- 01:17:42But if you can find meaning in the work that you're doing, and that motivation it's the thing that will carry you through hard times.
- 01:17:51Number one, number two is finding good mentorship. So finding people that do work that is similar to you, or at least ancularly related. I in my division when I was starting there, wasn't actually anyone doing health disparities research in the way that I was thinking about it.
- 01:18:11And so I had to find mentors outside of my division to help provide. Not just Ah, the scientific expertise or the lens on how to approach my work, but also the moral support that the work that I was doing was important, and providing that guiding light.
- 01:18:28And then the third piece of advice that I received at a particularly low point from Dr. Dean Shepher, the former division chief for pulmonary here.
- 01:18:40Um! It is right. After one of my training grants was not reviewed by study. Section my mentorship team was falling apart, and I was a second-year pulmonary fellow at Ecsf, and I met with
- 01:18:55met with him to talk about what I should do? And he gave me some important advice, and it's like Sometimes the opportunity that's in front of you may not be the exact opportunity that you would have selected for yourself, and sometimes it's just it's worth
- 01:19:15leaning into it for a little bit while a little while and trying it out, because you just don't know where it may lead you Um! And that actually, uh led for me to be me in the midst of a genetic lab.
- 01:19:28Um, that you know that I actually was looking at genetics across diverse populations. And so it also led to my chance meeting with the center for new wellness, which has been a lot of that work, has been the basis of my my research, and it also extended the work that I was doing to take on um, trying

to look at the biological embedding of environment of social, social, social, and social environment that can contribute to.

- 01:19:57 And so I think that would be one piece of advice to say, like. Sometimes there are opportunities that may not feel like the right fit, but it can be worth feeling it out for a little while before dismissing it entirely, because you don't know what you don't know.

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01:20:15 Great.

- 01:20:16 Yeah. And then we have. We do have more of a clinically directive question here, this room, Dr. John Kim. Great talk can you comment on the Spirits Blue Journal paper? You are a part of examining social determinants and race ethnicity on co-related outcomes? We are aware of any ongoing efforts to improve. How we capture these other structural factors that contribute to these.

Neeta Thakur (she/her)

01:20:40 That is a great question. So just to quickly summarize for those that Haven't reviewed that paper by Dr. Bao and the spyronic investigators. We found that a more universally applied. Ah, pulmonary function, prediction equation correlated better with symptoms of clp or black participants than using the re-specific

- 01:21:05 um prediction equations which are the currently recommended guidelines suggesting our current methods as to underestimate true morbidity and populations of color. We are actively preparing an Ats research statement on this topic
- 01:21:25 that should be coming out in the next six months to go delineate these research priorities, and also talk about what we need to do in order to change the current guidelines.
- 01:21:40 There's also a paper by Dr. Baka in chest from two thousand and twenty one, that a few of us that were
- 01:21:49 leading this other effort and kind of um coming from a pulmonologist's point of view that has also given some intermediary and recommendations for consideration for thinking about this problem.
- 01:22:02 Thank you. That

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01:22:04 right,

- 01:22:07 And I think that pretty much wraps it up for today. Thank you so much for coming and speaking with us. I We all thought it was a great talk, and I hope you enjoy the rest of your day.

Neeta Thakur (she/her)

01:22:18 Thank you.