2016 Annual Stakeholder Meeting Summary

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Letter from Principal Investigators

On behalf of the OneFlorida Clinical Research Consortium, thank you for your valuable contributions to our second annual stakeholder meeting. Collaboration is crucial to making the consortium a success, and we are excited by the progress we've made together.

The meeting took place on January 19 and 20, 2016 in Orlando, Florida. Some 53 stakeholders attended the steering committee dinner and networking reception, and 102 stakeholders attended the annual meeting held at the University of Florida Research & Academic Center in Lake Nona.

The first part of this report provides a summary and highlights of the major themes to emerge from the meeting, along with recommendations for next steps. The second part of the report provides notes summarizing the major presentations and work group discussions. And lastly, we include the evaluations from the meeting.

Ultimately, our goal is to work together to improve health, health care and health policy for all Floridians. The annual stakeholder meeting proved to be an important venue for the open exchange of ideas. We appreciate the roles our varied stakeholders have played in making this Consortium possible, and we look forward to our continued collaboration. If you have additional questions regarding the discussions, please contact TaJuana Chisholm, tchishol@ufl.edu.

Thank you,

Betsy Shenkman, PhD
Co PI, OneFlorida Clinical Research Consortium

Bill Hogan, MD
Co PI, OneFlorida Clinical Research Consortium

Section 1. Executive Summary

OneFlorida Clinical Research Consortium is a collaboration among researchers, clinicians and patients that aims to improve health across the state through community-based pragmatic clinical trials and implementation studies in all of Florida's 67 counties. OneFlorida partners include the University of Florida, the University of Miami, Florida State University, Orlando Health, Florida Hospital, Health Choice Network, Bond Community Health Center, Inc., Tallahassee Memorial HealthCare, JaxHERO, Miami Children's Health System and the WellFlorida Council. OneFlorida envisions itself as a learning network, where research is conducted in diverse real-world settings and the lessons learned are systematically captured and translated back into improved health, health care and health policy for Floridians.

Annually, OneFlorida hosts a Stakeholder Meeting to engage its partners across the state in face-to-face presentations and breakout sessions. The 2016 meeting was held with representatives in attendance from every partner as well as community members called Citizen Scientists. The objectives of this meeting were to:

- Report the project milestones and progress to date
- Discuss research priorities and how to move forward related to the PCORnet cross-cutting research groups
- Meet face-to-face with stakeholders on the Programs of the project
- Describe current programmatic accomplishments
- Discuss milestones for the CDRN
- Identify available resources to meet milestones
- Discuss next steps and create an action plan

The dynamic discussions during this meeting touched on a wide range of priorities and recommendations. Two key themes emerged from this collaborative meeting: (1) Establish and maintain ongoing communication within and external to the Consortium specifically related to partner collaboration, external investigator outreach, and community outreach and (2) Develop and enhance preparatory to research tools for the Consortium related to cohort profiles and query development. Recommendations and action items were outlined by the OneFlorida stakeholders and are listed in the main report to follow.

Each of the OneFlorida Programs met to collaborate with the leaders and coordinators to outline the direction of the program going forward. Those Programs include the OneFlorida Data Trust, the Integrated Clinical Research Program, the Patient Population Program (Obesity, DMD, and Hypertension Teams).

Section 2. Report from External Advisory Board

One Florida CDRN
External Advisory Board Report
January 20, 2015

Members

Peter J. Embi, MD, MS, FACP, FACMI (Chair)
Associate Professor of Biomedical Informatics, Internal Medicine, and Public Health
Vice-Chair, Department of Biomedical Informatics
Chief Research Information Officer, Wexner Medical Center
Associate Dean for Research Informatics, College of Medicine
Co-Director, Biomedical Informatics, Center for Clinical & Translational Science
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Ross Brownson, Ph.D.
Professor and Director, Prevention Research Center, Washington University in St. Louis

Electra Paskett, Ph.D.
Professor of Cancer Research
Marion N. Rowley Designated Chair
Division of Cancer Prevention and Control
Department of Internal medicine, College of Medicine
The Ohio State University

Albert W. Wu, MD, MPH, FACP
Professor and Director, Center for Health Services and Outcomes Research
Johns Hopkins Bloomberg School of Public Health

Overview

The OneFlorida Clinical Research Consortium is a collaboration among researchers, clinicians and patients that aims to improve health across the state through community-based pragmatic clinical trials and implementation studies in all of Florida's 67 counties. OneFlorida was recently funded by the **Patient-Centered Outcomes Research Institute** as one of 13 Phase II clinical data research networks (CDRN) in the US. As it was constituted prior to PCORI funding, OneFlorida had already made some progress in establishing the network and hosting multiple funded initiatives at various stages of development. One example is the OneFlorida Cancer Control Alliance, funded by the Florida Department of Health's James and Esther King Biomedical Research Program.

OneFlorida consortium partners include the University of Florida, the University of Miami, Florida State University, Orlando Health, Florida Hospital, Health Choice Network, Bond Community Health Center, Inc., Tallahassee Memorial HealthCare, JaxHERO, Miami Children's Health System and the WellFlorida Council. Together, OneFlorida partners encompass more than 9 million patients or 39 percent of the patient population in the nation's third largest state. OneFlorida envisions itself as a learning network, where research is conducted in diverse real-world settings and the lessons learned are systematically captured and translated back into improved health, health care and health policy for Floridians.

Indeed, some of the milestones that have already been met are laudable, and OneFlorida enjoys many strengths: Funding, particularly by PCORI provides a great boost to expand and mature the consortium; there is a large, diverse network of patients and providers; the opportunity to study team science on a large scale; the size and overall representativeness of the Florida population; strong knowledge and experience with standardizing and harmonizing the data elements needed for the initiative; and a strong network of Universities, hospitals and clinics. The leadership of the consortium is also quite strong and the structure is taking shape. The group has identified near term deliverables, robust business associate and data sharing agreements between consortium partners are nearly complete, and the infrastructure is being put in place that will relatively soon allow testing and utilization of the infrastructure to enable cross-institutional research in a manner not previously possible.

Despite these many strengths and opportunities, there are also some challenges to establishing a fully functional, interconnected data sharing consortium of this type; it is quite a complex undertaking. While the challenges are many and myriad, the most challenging are socio-organizational in nature, rather than technical. What follows are some of the EAB's main observations and suggestions for aspects of the initiative, offered in the spirit of providing guidance and improving the ongoing efforts.

Disease focus areas

Cancer Control Research

The Cancer Control research is focused in 2 areas – tobacco and HPV vaccination. While a good start, the group should seek out more depth and breadth in these areas from all partners across the state. In addition, the scope of research topics can and eventually should be broadened. Moreover, cross-cutting risk factors/diseases beyond traditional cancer-related ones noted above (e.g. obesity) could be a focus for Cancer as much as for other conditions like Diabetes.

Selecting Risk Factors/Disease Focus Areas

The process for picking risk factors/diseases to study is not clear. Certainly some come from the funders, but for other areas, there should be a process. There is a great opportunity to make this data driven, directed at certain populations, and aligned with the interests of the researchers/institutions. Currently the perception is that the latter is the most compelling driver. Data from state sources (e.g. census, cancer registry, vital records, BRFSS, etc.) could be used to identify top disease and risk factors, and pockets of areas that need attention to certain risk factors and diseases. This could result in a very smart, efficient, and innovative way to decide where to focus limited resources for the greatest impact.

OneFlorida Partner engagement

The leadership has done a good job of reaching out to relevant partners, as exemplified by the successful execution of the vast majority of contractual and data sharing agreements and the representation at the meeting. However, to facilitate the buy-in and successfully realize the network's potential, more and deeper engagement may be needed.

However, the current perception is that this is primarily a UF-owned activity. While this may not be true, the perception is what people see and believe, and the persistence of this perception could undermine or at least delay progress. Indeed, this is a theme that arose during several discussions across different aspects of the initiative. To address this, the group may want to include additional committee members representing a broader range of entities. Even just at a practical level, broader engagement, shared leadership and true ownership of key activities by parties beyond UF could help to speed along implementation efforts. In addition, knowledge of this consortium could be better disseminated across partner sites and across the state via newsletters, presentations, meetings at relevant universities/sites and by augmenting groups with additional committee members representing other entities. Anticipating the future potential, the process for using OneFlorida across the state to do research needs to be clearly explained (and documented).

Patient Engagement/Citizen Scientist Program

This is an outstanding and innovative program. There is clear involvement of patient-citizens in OneFlorida, and the model is novel. However, here again, it appears that the citizens may be representative of mainly a group centered in and around UF. Additional Citizen-Scientists should also be added – lay community members – from across the state to better represent key communities. This would greatly strengthen the goal of the program and improve engagement with partners. Beyond inviting the citizen scientists to participate in OneFlorida activities, outreach to the public is key. The public needs to know about the OneFlorida resource. This can be done through town hall meetings, marketing and publicity – using local spokespersons. Some of this appears to be planned, but the EAB wants to emphasize its importance here.

Informatics Infrastructure

The establishment of the Data Trust is well underway, and the team should be justifiably proud of the incredible amount of progress that has been made thus far. This centralized approach to data collection, storage, and standardization across the sites is impressive in its scale. It appears that the majority of partners have already bought into this approach and are more than willing to do the work needed to enable it. The approach of centralizing data for the consortium has the potential to unburden local sites and provide a sustainable model for ensuring quality data availability and access for research. With a consortium as diverse as this one, the approach can make very good sense.

The key to success for any such effort to centralize data from multiple sources is creating a trust fabric, and the group is well on its way to achieving this. However, centralized approaches are often challenged by organizational reticence to "handing over" vast amounts of data to an external party – in this case, the lead partner, UF. Some have taken a federated approach to achieving the goals for this reason. It is also conceivable that a hybrid structure, allowing some partners with less Informatics acumen or resources to deliver data to UF-based Data Trust for management on behalf of OneFlorida CDRN, while some larger and better resourced partners may manage more of the data themselves and serve as additional "nodes" on the network in a federated fashion. If the fully centralized approach to the Data Trust works, then the current approach may be fine, but the group should consider alternative strategies if needed.

Indeed, we say this in part because it appeared during the meeting that some partners may not be as far along as needed nor fully understand what's required to meet timelines. As such, we recommend that the approach to collecting and storing data from partner institutions in the OneFlorida CDNR may need more attention to details if timelines are to be met. Beyond the issue of data centralization, strong consideration should also be given to defining the minimal dataset required for satisfactory implementation in the near term (i.e. what are the minimal variables that are mandated to be in the CDRN). Forward looking for additional data elements is laudable, but too much focus on the future state could hinder near-term efforts. In addition, clear expectations of what is needed to meet ALL deliverables should be clearly communicated to all relevant parties; some appeared confused at the meeting. To facilitate this, there should be regular and more frequent meetings with partner sites and they should be members of relevant committees. Smaller hands-on meetings might help with this also. The new governance structure approved should be widely communicated and should assist in streamlining many approvals of data collection as well as downstream research activities.

Other opportunities and imperatives

Implementation science

The opportunity for innovation, such as in the area of implementation science, is another strength of the program. Possible interventions could be tested in different populations to identify what works best in what population for certain diseases/risk factors. In addition, multi-level interventions can be tested across the consortium. These opportunities should be explored.

Educational, training and mentorship opportunities

A plan for training the next generation should be considered, at multiple levels of education and training. This presents an opportunity for OneFlorida; it sounds like much of this is underway but it could be formalized. In addition a mentoring program should be started. Minority training should be a top priority. Grant writing workshops as well as human subject training and clinical/implementation science research training should be also included. Training for community clinicians should also be a part of this. A Training Committee should be established with dedicated staff to accomplish these goals.

Sustainability, dissemination and implementation issues

A sustainability plan is underway, be sure this is rooted in the dissemination and implementation literature. If this is not started early and paid constant attention, it won't happen. There is a great opportunity with multilevel methods to study not only individual/patient outcomes but also community and organizational effects. More attention could/should be paid to social determinants; some of this can come from archival data (e.g., density of fast food) but some will require new data collection (e.g. patient perception of satisfaction or discrimination in health care). What will it take to scale up what is learned in Florida?

Conclusion

The newly funded OneFlorida CDRN is well underway and its leaders should be justifiably proud of their progress to date. There is a lot of potential in this consortium and we hope that these suggestions will assist in developing the consortium to achieve its full potential to researchers and communities in Florida. The EAB thanks the OneFlorida leadership for the opportunity to contribute in this manner. Please let us know if you have any questions or desire additional information or clarification about points made in this report.

Section 3. Emerging Themes and Recommendations

Theme 1: COMMUNICATION

One of the major themes to emerge during the meeting was the need to establish and maintain ongoing communication within and external to the Consortium. This need arose in three areas; partner collaboration, external investigator outreach, and community outreach.

Partner Collaboration

Recommendations

- Identify champions within the consortium who can market OneFlorida at each site.
- Collaborate and partner with other Clinical Data Research Networks (CDRNS).
- Create a newsletter about the projects at each site across the state to promote collaboration.
- Communicate CDRN deliverables, roles, deadlines, and responsibilities to partners. Each partner should have a timeline for completing expected deliverables.

Next Steps

- **Data Trust Program:** Develop software that allows partners to link patient data to other data sources such as Medicare claims or Vital Statistics data without sharing identifiable information.
- **Integrated Clinical Research Program (ICRP):** Communicate the priorities and goals of the program to OneFlorida partners.
- **Patient Population Program, Duchenne Muscular Dystrophy (DMD) Team:** Establish computable phenotypes with other partners (PEDSnet, Duchenne Connect). Develop a plan for working together to refine the computable phenotypes.

External Investigator Outreach

Recommendations

- Schedule webinars and town hall meetings around the state to discuss OneFlorida.
- Develop newsletters and other marketing materials to inform investigators about OneFlorida, its resources, and how it can benefit them.
- Develop marketing materials for OneFlorida to reach a wide base of researchers and lay people in Florida.
- Consider creating a members-only OneFlorida website that provides user-friendly resources for the investigators.
- Expand the highly successful On the Road Design Studios to sites beyond the University of Florida (UF) to increase buy-in at partnered sites.
- Market OneFlorida to NIH, AHRQ and National Cancer Institute (NCI) funded researchers.
- Allow ResearchACTS to be open-source so other researchers can use it for their projects.

Next Steps

- **Communications:** Develop a short term and long term OneFlorida communications plan

Community Outreach

Recommendations

- Establish Twitter and Facebook accounts for OneFlorida to reach audiences throughout the state. Consider using a student from the University of Florida's College of Journalism and Communications.
- Develop a communications committee which includes a citizen scientist.
- Increase public awareness of the OneFlorida concept so they can see the efforts being made to encourage patient engagement.
- Advertise OneFlorida to get the community excited about various research opportunities.

Next Steps

- **Citizen Scientist Program:** Citizen Scientists will assist in reviewing abstracts, which helps foster community engagement.

Theme 2: PREPARATORY TO RESEARCH TOOLS

Another theme to emerge during the meeting was the need to develop and enhance preparatory to research tools for the Consortium. This need arose in two areas; cohort profiles, and query development.

Cohort Profiles

Recommendations

- Consider creating community profiles similar to priorities MICA (Missouri Information for Community Assessment), http://health.mo.gov/data/mica/PriorityMICA/

Next Steps

- **Pediatrics Cross-Cutting Research Group:** Adopt the report card concept; consider creating a category for each priority area identified, which can serve as a baseline to guide decisions.
- **Patient Population Program, Obesity Team:** Develop state snapshot/report card to analyze obesity data in a variety of ways (by age groups, population density, geographic areas, etc.). This will be one of the first outcomes of this group. Need to see what data is reported in BRFSS and the Trust for America's Health annual report. This report card can present statistics by county or ZIP code (best we can get). We will use National Institutes of Health (NIH) body mass index (BMI) classes for adults and kids, cut by gender, region, and whatever we can base on the available data. At the very least, county level heat map for kids in different age groups.

Query Development

Recommendations

- Emphasize the need for researchers to use large datasets to investigate issues related to pharmaceuticals that the drug companies do not address (for example, post-marketing studies and issues related to use of multiple drugs).
- Develop strategies to use data queries for continuous quality improvement and to embed using queries into practices. For example, UF Community Health & Family Medicine (CHFM) runs weekly re-admission rates on their patients.
- Run queries to determine issues to expect and provide a starting place for information. For example, quality improvement queries can be used to determine the value of particular interventions for patients.

Section 4. Programmatic Action Items

Data Trust Action Items	Person Responsible	Status	Priority
• Schedule meetings with partners' technical staff to develop the initial data transfer and manage ongoing data transfers.	Bill Hogan	◓	🔴
• Deploy and refine computable phenotypes for hypertension.	Bill Hogan	○	🟢
• Complete PCORnet data characterization	Bill Hogan	◓	🔴
• Develop and maintain a computable phenotype library.	Bill Hogan	○	🔴
• Schedule face-to-face meetings bi-annually for the IT group.	Bill Hogan	○	🟢

ICRP Action Items	Person Responsible	Status	Priority
• Identify and re-engage the clinical champions. Make sure those listed in the CDRN grant are still interested and willing to work for studies at their sites.	Eileen Handberg	○	🔴
• Develop training for clinical champions, including how to conduct research in community settings and how to train others in their clinic. Develop orientation materials for practices in collaboration with the principal investigators (PIs). Clinical champions will need to understand how to develop a study within their respected clinic using the orientation materials provided by OneFlorida.	Eileen Handberg	○	🔴
• Develop a list of training resources for research coordinators and practice facilitators.	Eileen Handberg	◒	🟢
• Using Aspirin Dosing: A Patient-centric Trial Assessing Benefits and Long-Term Effectiveness (ADAPTABLE) as a starting point, develop infrastructure around this study, focusing on practices that can start ADAPTABLE now.	Eileen Handberg	○	🔵
• Develop list of practices that will contribute to the ADAPTABLE Trial.	Eileen Handberg	○	🔵

ICRP Action Items	Person Responsible	Status	Priority
• Create a dissemination plan for the Integrated Clinical Research Program, including a communications plan. Citizen scientists can help develop videos and training for clinics. These trainings should address issues of cultural competency.	Eileen Handberg	○	●
• Develop ICRP infrastructure to support multi-site studies.	Eileen Handberg	◒	●
• Use International Classification of Diseases (ICD) codes to identify patients of interest. Using medical records or electronic health records would allow for the use of ICD 10 to select cohorts of patients.	Eileen Handberg	○	●
• Determine the level of experience needed for a practice facilitator. Many felt that OneFlorida needs to provide an experienced coordinator at study sites and clinics, especially if the PI is new. An experienced coordinator can support a new PI and ensure that a study is successfully conducted.	Eileen Handberg	○	●

Hypertension Cohort Action Items	Person Responsible	Status	Priority
• Create a database of hypertension (HTN) patients	Rhonda Cooper-DeHoff	○	●
• Implement a study focused on equipment, techniques and standardization of blood pressure (BP) measurement.	Rhonda Cooper-DeHoff	◒	●
• Publish academic papers as a team	Rhonda Cooper-DeHoff	○	●
• Understand the landscape of hypertension in Florida. Using data contained in the Data Trust: Stratify hypertension patient aggregate counts by race, ZIP code, family history for high BP or cardiac events. Overlay ZIP code findings with Environmental Protection Agency (EPA) dump sites. Overlay with food deserts by ZIP code	Rhonda Cooper-DeHoff	○	●

Hypertension Cohort Action Items	Person Responsible	Status	Priority
• Disseminate information about study results for educational purposes. We have a great opportunity to work with our stakeholders and citizen scientists to understand how we can share information from OneFlorida studies in a way that's meaningful and accessible	Rhonda Cooper-DeHoff	○	●
• Arrange for Dr. Cooper De-Hoff to speak with Dr. Robinson about the projects she is working on at Bond Community Health Center, Inc.	Rhonda Cooper-DeHoff	○	●
• Explore ways to incorporate social determinants and adherence data to electronic health record (EHR) or data collection	Rhonda Cooper-DeHoff	○	●
• Review Patient Reported Outcomes Measurement Information System (PROMIS) zone data	Rhonda Cooper-DeHoff	○	●
• Schedule a meeting between Dr. Cooper-DeHoff and members of the OneFlorida Data Trust program	Rhonda Cooper-DeHoff	☑	
• Contact Drs. Hogan and Shenkman about possibly sharing the hypertension code and phenotypes with Dr. Pletcher (a partner within the Heart Health Cross-Cutting Research Group).	Rhonda Cooper-DeHoff	☑	
• Deploy and refine computable hypertension phenotypes. Implement a dissemination plan for that phenotype.	Rhonda Cooper-DeHoff	◒	●
• Develop additional data points for Resistant Hypertension not listed in the CDM	Rhonda Cooper-DeHoff	○	●

Obesity Cohort Action Items	Person Responsible	Status	Priority
• Define computable phenotypes related to obesity	Steven Smith Dave Janicke	◒	●
• Complete Patient-Centered Clinical Research Network (PCORnet) progress report	Steven Smith Dave Janicke	☑	
• Work on PCORnet national studies: kickoff meetings coming soon	Steven Smith Dave Janicke	☑	
• Review existing national model data points including Medicaid data	Steven Smith Dave Janicke	○	●

Obesity Cohort Action Items	Person Responsible	Status	Priority
• Develop an obesity report card	Steven Smith Dave Janicke	○	●

DMD Cohort Action Items	Person Responsible	Status	Priority
• Work with PEDSnet to develop an algorithm to identify and flag patients from electronic health records	Barry Byrne Krista Vandenborne	○	●
• Implement a newborn screening for Duchenne Muscular Dystrophy as a pilot project in Florida	Barry Byrne Krista Vandenborne	○	●
• Propose a study around bone health in DMD patients to PCORnet to be developed into a national study conducted within the network	Barry Byrne Krista Vandenborne	☑	
• Develop Computable Phenotype with PEDSnet and DuchenneConnect to address delayed diagnosis of DMD	Barry Byrne Ann Lucas	○	●

Pediatric (Child Health Alliance) Cohort Action Items	Person Responsible	Status	Priority
• Look at available data; identify gaps that need to be filled	Betsy Shenkman	◒	●
• Gather community health assessments from each OneFlorida health system to develop a consortium-wide needs assessment	Betsy Shenkman	○	●
• Create a one-page proposal for developing the child health alliance to submit to the Steering Committee by February 10. Volunteers: Ms. Fesenmaier, Dr. McCafferty and Dr. Janicke	Jennifer McCafferty Dave Janicke	☑	
• Gather preliminary data regarding oral health initiatives. (Ms. Ranka will provide this data.)	Betsy Shenkman	○	●
• Partner with Dental Health Practice-Based Research Network (PBRN), Dental Quality Alliance (DQA) Project at UF.	Betsy Shenkman	☑	
• Use Medicaid data to run cohort discoveries	Betsy Shenkman	○	●

Cancer Cohort Action Items	Person Responsible	Status	Priority
• Engage stakeholders internal and external to OneFlorida in shaping the OneFlorida vision to maximize the value of the Consortium for stakeholder groups (clinicians, citizen scientists, researchers).	Betsy Shenkman	☑	
• Discuss collaborations with other cancer centers in Florida.	Betsy Shenkman	◒	●
• Assign roles and responsibilities to stakeholders who are working with the cancer prevention group	Betsy Shenkman	◒	●
• Make OneFlorida valuable to investigators and craft a communication strategy to market the research infrastructure, emphasizing the "customer experience".	Betsy Shenkman Elizabeth Hillaker Downs	◒	●
• Share statistics for risk behaviors, cancer diagnoses and tobacco use with communities throughout Florida and communicate the importance of cancer prevention activities and research.	Betsy Shenkman	○	●
• Link communities with potential solutions to problems identified. Focus on cancers that are important in Florida and the risk behaviors associated with them, and then look for appropriate funding opportunities.	Betsy Shenkman	○	●
• Work with community organizations and hold events so the community gets to know the researchers, understands the research, and gains trust.	Betsy Shenkman	○	●
• Create a list of research priorities—what cancers and risk behaviors should the cancer prevention group focus on? Obesity may be a good alignment since it is an OneFlorida patient cohort.	Betsy Shenkman	○	●

IRB Action Items	Person Responsible	Status	Priority
• Involve partners in the OneFlorida training for IRB.	Betsy Shenkman	☑	
• Require each institution affiliated with OneFlorida to file its IRB contact with OneFlorida.	Betsy Shenkman	◒	●

Priority	Status
High	Completed
Medium	75% of completion
Low	50% of completion
	25%of completion
	No progress made

Section 5. Meeting Notes

Welcome & Introductions

(Began at 8 a.m.); Discussion led by Dr. Nelson

Dr. Nelson started the meeting by thanking everyone in attendance and introducing all the partners represented:

- University of Florida
- Florida State University (FSU)
- University of Miami (UM)
- Orlando Health
- Florida Hospital
- Tallahassee Memorial Healthcare
- Health Choice Network
- Bond Community Health Center, Inc.
- Miami Children's Health System
- WellFlorida Council
- Florida Agency for Health Care Administration (FL AHCA)

Dr. Nelson acknowledged the presence of the Steering Committee members. He announced that the governance documents have been adopted by the Steering Committee. He also gave an overview of the PCORnet partners and introduced the Scientific Advisory Committee: Drs. Ross Brownson, Peter Embi, Electra Paskett and Albert Wu.

Programs and Workgroups

Dr. Nelson asked for everyone's involvement in the work groups since they are critical for feedback. He provided an outline of the specific work groups:

- Integrated Clinical Research Program
- Data Trust Program
- Patient Population Program – DMD, Obesity, Hypertension
- Patient and Citizen Scientists

Dr. Nelson emphasized the importance of full participation of stakeholders in the work groups and that each group is expected to report back to the larger group.

Goals for the Annual Meeting

Dr. Nelson highlighted the goals of the meeting as:

1. Progress - where we have been and where we are now
2. Forum discussions
3. Strategic planning
4. Celebrating partnership

Dr. Nelson reviewed the agenda of the day, providing a highlight of each activity, from 8 a.m. to wrap-up at 4:30 p.m. Dr. Shenkman introduced Dr. Wu, who then led a discussion on patient-centered comparative effectiveness research.

New Year's Resolution: Do More (Patient Centered) Comparative Effectiveness Research

(Began at 8:30 a.m.); Keynote Address by Dr. Wu[1]

Dr. Wu is a Professor at Johns Hopkins University and Director of the Center for Health Services and Outcomes Research. He also directs the Ph.D. Program in Health Services Research & Policy, as well as the Certificate Program in Quality, Patient Safety & Outcomes Research. Dr. Wu was trained in internal medicine and has an MPH from University of California Berkeley. He is a leader in the field of comparative effectiveness and patient-reported outcomes research. Dr. Wu is the PI of the PROMIS initiative, an NIH-funded effort to create high-quality patient-reported outcomes related to physical, mental, and social well-

[1] http://www.jhsph.edu/faculty/directory/profile/1497/albert-wu

being. He is also one of the PIs of the DEcIDE (Developing Evidence to Inform Decisions about Effectiveness) Network, an Agency for Healthcare Research and Quality (AHRQ) effort to gather information about treatment effectiveness.

Dr. Wu's keynote address: The goal of this talk is to convince you to do more comparative effectiveness research (CER) in your network and to make that work patient-centered.

- There is a great need for studies comparing different diagnosis and treatment strategies. OneFlorida could be well positioned to investigate this topic and many others.
- Patient-centered outcomes research (PCOR) can be a tough sell. Medicine is often more doctor-centered than patient-centered. There can be a sense that patients are unreliable narrators and clinicians are not used to interpreting all the information that patients could give us.
- Culture is changing: Dr. Berwick, former administrator of CMS, announced the "triple aim" to improve health care (better health, better health care, and lower cost); a 2015 IOM report, Vital Signs: Core Metrics for Health and Health Care Progress, listed 15 core measures for assessing health and health care, including "well-being" as #2. Accountable care organizations (ACOs) now operate by the charge to be "data rich."
- Patient-Centered Outcomes Research Institute (PCORI) was created in 2010 to help people make better health care decisions and to do research that is guided by patients.
- PCORI aims to study the outcomes that matter most to patients. This research frame is increasingly accepted by the clinical research community.
- PCORnet seeks to improve the nation's capacity to conduct clinical research by creating a large, highly-representative, national patient-centered network that can support more efficient studies. This network will support the widespread capability for the U.S. healthcare system to ask a question and answer it efficiently. Some European countries already have this capability. PCORnet includes 33 CDRNs and patient-powered research networks (PPRNs), including OneFlorida.
- PCOR helps people make informed health decisions by attempting to answer four questions:
    - What should I expect will happen to me?
    - What are my options? What are the potential benefits and harms of each?
    - What can I do to improve my outcomes?
    - How can the health care system improve my chances of achieving those outcomes?
- OneFlorida could answer some big science questions. This consortium is very well suited to answer questions for regular patients across the state, for the largest number of people possible.

Dr. Wu's group is "all in" for PCOR, with several projects underway, some of which are PCORI-funded. One of these projects is developing a methods guide on what PCORI is looking for, which will eventually be available to the OneFlorida group. Dr. Wu's highlighted projects:

- **CDRN:** PaTH, which includes The University of Pittsburgh, Penn State, Temple, and Johns Hopkins. The development of this type of research has been aided by a convergence of patient-reported outcomes (PRO), CER, and EHR. Over the last 20-30 years, there has been an increase in both these domains in health research and in the health care system. Many EHRs now include patient portals that enable the collection of PROs.
  EPIC, the most widely-used EHR, has MyChart, a tethered portal for patients. There are tools already built in that many clinicians are not using. EPIC can collect adult and child measures for generic and specific outcomes. Clinicians can order these measures as they would order lab tests. Using this portal, Dr. Wu set up a series of PROs for their patient cohorts going forward. Data goes right into the electronic chart, where clinicians and researchers can look at the PRO alongside other clinical data. Dr. Wu wrote a white paper on incorporating PROs into electronic health records. PCORnet has been working on this since then. Johns Hopkins has an app to use MyChart to deliver patient questionnaires and is developing a work flow to build in these capacities.
- **CONNECT** is a community-based organization focused on enhancing the neighborhood's network capacity. This is an intervention trial funded by Centers for Medicare & Medicaid Services (CMS), including 20 community-based organizations near Johns Hopkins. Everything we do should be done as a trial. There are many efforts being made that aren't being rigorously evaluated.
- **STRIDE** (Strategies to Reduce Injuries and Develop Confidence in Elders). This is a nationwide cluster randomized parallel group superiority trial. The trial is aimed at helping practices to prevent injurious falls in elders (aged 75+).
- **Stakeholder question: How do these national efforts align with or compete with the precision medicine initiative through NIH?** Dr. Wu believes that in some ways, we are creating new silos, driven by funding programs. At Johns Hopkins, the PI of the PCORnet site is also the associate dean for clinical research. He is sitting in on discussions for both of these efforts, so maybe that helps drive synergy instead of competition. There need to be more national standards, maybe even a national bureau of standards for research.
- **Stakeholder question: Is PCORI working on end-of-life initiatives?** Dr. Wu is unsure if palliative care is being funded. There are people in his research center whose main focus is palliative care and more importantly, a palliative care

approach to care of patients, especially older patients. AHRQ and CMS are very interested in these issues, even if PCORI isn't funding them.

- **Stakeholder question: What are the advantages or disadvantages of OneFlorida being tied to a geopolitical unit (state of Florida)? How can we most capitalize on this, given that only a couple of CDRNs are state-based?** Dr. Wu believes that the advantages and disadvantages are all political. State governments could be very helpful if we are able to convince public health or Medicaid leaders that this is a consortium they can use, that would really help standardize things across the state. Maryland has the advantage of all hospitals being paid the same rate. The state of Maryland is very interested in working with Dr. Wu's team because this work affects state finances.
- **Stakeholder question: What are the costs of improving care?** Dr. Wu and his team are now starting to collect PCOR in clinics routinely through the EHR. Clinicians see those reports and have the opportunity to act on them. For example, the Patient Health Questionnaire (PHQ) 9 can reveal depression, so doctors could help with that. Another thing: by introducing some protocols and standardization, by creating best practices, Dr. Wu believes they are improving practice.
- **Stakeholder question: As a researcher and clinician, how do you reconcile PCOR and CER and clinical practice guidelines?** Dr. Wu does not think there is a real conflict. There are many dimensions to care: what the patient wants and can afford, what the doctor wants, what insurance says the patient can have. Knowing what the patient wants and discussing it in context of those other things doesn't confuse Dr. Wu more, it just gives him a more complete picture.
- **Stakeholder question: Are there opportunities to collaborate with managed care?** Yes, there is a great deal of alignment in trying to keep patients out of hospital and ER.
- **Stakeholder question: Is there anything within PCORI to encourage people to integrate PRO into an existent overall quality dashboard?** Researchers are measuring too many things without knowing how to measure them well. The trick is to set goals. Some things are dictated by CMS, etc., so we can't get out of it. We are trying to establish management structures across hospitals to achieve certain goals, for example to better treat depression. Putting those things on the dashboard and then managing to those goals can benefit patients and make the organization look good to entities that are judging it.

Discussion of Project Milestones and Progress

(Began at 9:15 a.m.); Discussion led by Dr. Hogan

- Dr. Hogan started his presentation with a brief overview of the history of OneFlorida that highlighted achievements based on a timeline. Key points included:
  - In 2013, OneFlorida Clinical Research Consortium consisted of UF, FSU, and UM.
  - In 2014, the consortium received funding from a James and Esther King grant.
  - In 2015, OneFlorida was funded by PCORI and became one of 13 Clinical Data Research Networks (CDRNs) within PCORnet.
- Dr. Hogan pointed out that while patient health and improved health outcomes are of paramount importance, the research OneFlorida conducts must matter to the patients, clinicians and investigators
- A substantial component of OneFlorida is the Data Trust, which will contain EHR of 3 million patients.
- The following details the progress and accomplishments made thus far by OneFlorida:
  - There are currently nine studies in the network, two of which are funded.
  - Memoranda of Understanding (MOUs) and Data Use Agreements (DUAs) have been signed; OneFlorida IRB agreements have been signed; still waiting on one institution. The Data Trust IRB protocol has been approved.
  - Three years of Florida Medicaid records have been transformed to the Common Data Model 3.0 and have been migrated into the Data Trust.
- After discussion of the consortium's progress and accomplishments, Dr. Hogan discussed the CDRN Milestones. The milestones listed below have been completed:
  - Executed collaborations with CDRNS, PPRNs, and Clinical and Translational Science Awards (CTSAs) as described in the PCORI application.
  - Developed the population workgroups (hypertension, obesity, and rare disease – DMD).
  - Completed plans for collaboration with health plans.
- **Stakeholder question: What data elements are available in the Data Trust?** Dr. Hogan stated that encounters, diagnoses, and provider orders for medication dispensing are available in the Data Trust.

Overview of Research Priorities

(Began at 10 a.m.); Discussion led by Dr. Shenkman

- Dr. Shenkman started by pointing out that PCORI provides an opportunity for OneFlorida to collaborate nationally. PCORI sets national research priorities not only as a funder but also through partnerships with other players, such as the National Institutes of Health and industry, among others.
- About 70 million people in the United States are being cared for through health care delivery settings covered by PCORnet
- Dr. Shenkman informed everyone on the upcoming research endeavors: PCORI Health Systems Demonstration Project, Heart Health Cross-Cutting Research Group, Cancer Prevention (together with funding for a tobacco cessation project).
- Members recognized OneFlorida as a fantastic accomplishment, well-funded.
- **Stakeholder question: Does OneFlorida have a responsibility to reach out to the state of Florida (government)?** Dr. Shenkman explained that the state has been involved (since 1993) and some state representatives were in attendance. Ms. Kidder with the FL AHCA said the state has needs and OneFlorida offers exciting opportunities to provide good outcomes. AHCA is committed to continue providing data to the OneFlorida Data Trust.
- Dr. Shenkman added that the Data Trust is OneFlorida's key strength. She commended Ms. Ranka's data team for their effort.
- Health Systems Partnerships:
    - Dr. Shenkman thanked the partners for their support and cited the need to identify key issues that health systems currently face, and how OneFlorida can address the issues.

- Health System Demonstration Projects
    - PCORI will fund up to five one-year research studies on priority topics.
    - Dr. Shenkman asked members to think about how available data can be translated into future studies. She emphasized the need to be responsive and hopes to start as early as July2016.

- Cross-Cutting Research Groups (CCRGs)
    - The purpose of the CCRGs is to have CDRNs work closely together. The idea is to stimulate collaboration, share resources and expertise both in state and nationally. It is important to have a clear entry point in the group.
    - CCRGs include: Heart Health, Women's Cardiovascular Health (hypertension, congestive heart, and heart failure), Diabetes and Pediatrics. Dr. Shenkman will co- chair the Pediatrics group with Chris Forrest from CHOP (PEDSnet).

Small Table Discussion: Health Systems Demonstration

(Began at 10:30 a.m.) Discussion led by Dr. Shenkman (External Advisors: Drs. Wu and Embi)

Participants: Luz Maristany, Nick Tsinoremas, Josh Hanna, William Hogan, Christy Evans, Ravi Bhosale, Richard Bookman, Donna O'Neal, Peter Carek, Lijing Ouyang, Shanique Yee, Garrett Rice, Eric Rosenberg, Myra Hurt, Peter Embi, Greg Riccardi, Lori Bilello, Carlos Maeztu, Betsy Shenkman, Jiang Bian, Beth Kidder, Brittney Roth, Kim Stanfield, Katie Eddleton, Kristi Gafford, Elaine Van der Put

- Dr. Shenkman began the discussion by saying that PCORI wants to leverage the common data model (CDM), so the work group should think about the key questions and topics that would work in favor of the Health Systems Demonstration.
- A highlight of the discussion was that PCORI does not focus on cost-effectiveness but looks at comparative effectiveness, which is the value of health care.
- Managed care was mentioned as a way for OneFlorida to maximize the value of care for health systems.
- The common data model contains de-identified data. This data enables CDRNs to characterize patient-level information and ask interesting questions about their health care utilization patterns and health outcomes. The CDM can be used to identify and manage specific diseases through health care diagnosis. It is also used as an approach to develop alternative models in health care delivery.

- **Stakeholder question: How do we tackle the Health Systems Demonstration and complete rapidly?** Collaboration with other CDRNs is important. Also, answer the important questions about the value of care; very important to have Health System Leaders to see the value of OneFlorida. The greatest challenge at the moment is engaging chief executive officers (CEOs) and other C-suites in the health care system.
- OneFlorida should consider having several demonstration projects in various sizes to show outcomes and barriers.
- PCORI is based on value rather than cost; however, CEOs may be more interested in cost-effectiveness. Also, look at health systems from an economic standpoint, supply chain management – helps to figure out the fastest route for quality care.
- **Stakeholder questions**: **How do we look effectively at the type of care received by patients?** This isn't just about EHR but also claims data. The current common data model may not be adequate enough to understand the value of care; have to intervene and use the data to look at outcomes.

- **Data Queries**
    - The systematic review of electronic health record data can help to improve both the efficiency and the quality of care
    - Consultants and providers can work together to make sure data are accurately captured at the point of care .
    - The OneFlorida Data Trust Program could engage physicians and help them understand and interpret their own data OneFlorida can create queries to fully explore a multitude of questions. The OneFlorida Data Trust Program can work with health systems and clinicians to ensure that the query creates appropriate data to answer the question.
    - Because crafting and running queries take time, it is important to discuss the request with someone who is knowledgeable about both the Data Trust and the research/quality question to be explored. This reduces the time spent creating irrelevant datasets.
    - Create a feedback loop that allows the data to be analyzed and to get ideas moving. This will allow everyone to see what the data is doing. As it becomes more valuable to the consortium, the quality will improve Dr. Shenkman asked the group whether clinicians are currently able to access and analyze their own patients' data. Dr. Rosenberg said that at the micro-level, the data is accessible; however, with access to only small numbers of patients at a time, physicians will ask why they're not able to manage their patients more personally. Group member stated there is a cultural shift and queries do take time if done accurately; data is never 100% accurate but can get the process started.
    - Information generated from querying data in the Data Trust needs to be presented in common language that is understandable by the public It is important to devote the time to maintain the database based on queries because this helps with effective follow-up. Better able to follow up with the patient. Also suggested looking through the data early and querying before looking through the data.
    - Dr. Brickman said that for certain types of disciplines, test queries need to run against the data model, and queries will build on the computable phenotypes.
- **Collaborations**
    - Dr. Shenkman raised the question of possible partnership with Drs. Embi, Wu and Brickman. Dr. Embi seemed open to the idea and highlighted that since he is also a part of the newly created CDRN for Ohio State University, it would be a great opportunity to collaborate.
    - It was the consensus that partnership is important for the Health Systems project because this would bring more synergy.
    - Ms. Kidder reported that Medicaid is also interested in partnerships and collaborations, and is constantly striving to improve health outcomes for Medicaid enrollees Ravi Bhosale, a citizen scientist, said that the involvement of the community is needed because the cost of healthcare is high and the community should voice their opinions on how to reduce costs.
    - Dr. Wu mentioned that there is a program similar to a Master's degree for executives to become more engaged and learn about value and effective health care. These Health System Leaders will come on board when they see the competitive advantage.
- **Social determinants of health systems include:**
    - Models of patient outcomes.
    - Program to link outcomes and care.

- Health systems are meant to be competitive and queries allow the systems to make the necessary changes to improve value of care.

- **Patient Care**
  - Ms. Kidder, FL ACHA, suggested that the PORTAL CDRN manages a high health utilizer with using information about a range of patient characteristics.
  - Dr. Tsinoremas said that high utilization patients are not always equipped to deal with the changes.
  - Participant suggested that physicians and clinicians should look beyond the individual patient and more at the patient population.
  - Dr. Embi highlighted a major strength of OneFlorida: it is a multi-institution CDRN with a mix of universities, hospitals, and community perspectives. He also pointed out that what works at a university level may not work at the community level. It is important to capture the patients that move from one hospital to another.
- **Clinicians**
  - Dr. Berg mentioned the importance of finding the right stakeholders (clinicians).
  - Dr. Wu suggested that in order to engage physicians and clinicians, OneFlorida should offer to buy their time.

Small Table Discussion: Heart Health Cross-Cutting Research Group

(Began at 10:30 a.m.) Discussion led by Drs. Cooper-DeHoff and Pearson (External Advisor: Dr. Brownson)

Participants: Steven Smith, Amanda Hicks, Shirley Bloodworth, Renee Reams, Rebecca Essner, Kendra Siler-Marsiglio, Dushyantha Jayaweera, Rhonda Cooper-DeHoff, Larisa Cavallari, Myrtle Graham, LuAnn Duncan, Temple Robinson, Thomas Pearson, Damian Alderman, Joe Nadglowski, Jessica DeLeon, Claire Baralt, Eileen Handberg, Chris Scuderi, Michelle Cardel

- For the CDRN application, OneFlorida was required to select three diseases on which to focus: a common disease (we selected hypertension, or HTN), a rare disease (we selected Duchenne muscular dystrophy, or DMD), and obesity. OneFlorida is the only CDRN to focus on HTN.
- Collaborative health groups also have formed across PCORnet, one of which is the Heart Health Cross-Cutting Research Group, which Dr. Cooper-DeHoff will join as the OneFlorida representative. She represents the area of HTN on the group.
- The group identified hypertension and congestive heart failure as the two groups of focus. Drs. Handberg and Pepine suggested Women's Heart Health as a third group, which has been accepted.
- Participation in this CRG brings collaborative opportunities for us; all of the projects involving the PCORnet CRGs need to involve at least two CDRNs, preferably more. This could allow us to apply and be competitive for additional funding opportunities from PCORI or other outside sources. Attributable risk of HTN to total mortality in the African-American population exceeds 60%. This is a huge diversity disparity issue.
- Focusing on HTN was a major play to say "here is what OneFlorida will contribute". We will have challenges with HTN, but also an incredible number of opportunities. This is one of the major issues facing the nation going forward.
- Since EHRs do not capture the methods used to collect BP readings, we need to ask our partners who are providing the data what type of device is used in their clinics. OneFlorida has an opportunity to educate patients on proper BP methods (quiet room, both feet on the floor, cuff wraps around arm a certain way, etc.) then empower to the patients to say to the nurse that a reading may not be accurate. OneFlorida could give demonstration projects at churches, community events, etc.
- Inaccurate measurements lead to incorrect classification of patients, which could lead to health risks. Some of these health disparities arise from clinics that do not have the supplies needed to classify patients correctly and treat them accordingly. This is a good opportunity to determine whether this is happening in rural vs. urban areas, and could contribute to the disparities in African-American population.
- We should ask ourselves, "In the state of Florida, in the OneFlorida Data Trust, how are we doing?" "Are there pockets, are there regions, and are there demographics of people who need help?" "Where is it that the results are not as good as other places?"

Resistant Hypertension Project

- This project will use well validated resistant hypertension (RHTN) phenotype definitions to identify patients in the Data Trust who have RHTN based on BP level and number of medications prescribed, followed by an evaluation of the characteristics shared by patients who have RHTN compared to those who do not. This project arose after a number of

clinical trials provided information about patients who have RHTN. Then we will determine what the outcomes are. In clinical trials we know that people who have RHTN do worse than people who don't. Is that the same in the real world? Then how can we use what we learned to put programming into EHRs to identify this person in your clinic today as someone who is likely to develop RHTN? As a group, we can develop additional data points not currently included in the CDM that are needed.

Potential areas of focus or additional collaborations

- There are ways to get at some of the data, with ZIP codes and such. But if critical information is not collected as part of routine health care, we need to bring it back to the group and other health systems and say "let's start collecting this". "What are some reasonable ways to collect these?" BP measurement. A patient comes to see me, they are anxious and nervous, their BP is high, and I am not seeing them for HTN so I don't re-measure it. I am curious about how you standardize even the simple things like multiple BP readings in the same day. If you're going to ask physicians to collect additional information, there's got to be the "why". It's got to help them in their practice, so a lot of this has to be meshed into the standard of care delivery.
- Everything that comes out of this group has to be patient-centered outcomes research. We want to put it at the patient level. Given my personal characteristics as a patient, what should I expect will happen to me, what are my options, what are the benefits and harms of those options, what can I do to improve the outcomes most important to me? How can the health care system increase my chances of achieving the outcomes I prefer? We should place emphasis on the patient determining those questions, where I think they should be part of a clinician's standard questions: "What, given my patient's characteristics, will make a difference?" Patient behaviors, such as adhering to recommended treatments and/or being willing to change behavior — can overwhelm any medical recommendation. Currently, there is no way for Epic to capture differences between what providers recommend and how patients choose to behave. This group could create a patient-involvement scenario in which patients input that data on an iPad, which is then given to a provider and implemented in care. OneFlorida has a unique opportunity due to its diversity. These activities could potentially be funded by the legislature.
- In addition, data linkage using census tract data linked to electronic health record data can inform several components of social determinants of health.
- When BP is not under control, two features come into play: 1) If you don't reconcile the patient's medications during every visit, a patient may be prescribed multiple medications from multiple physicians (or the same physician), and the patient will have side effects, so they stop taking everything. One of the things I would like to see is how many times we can capture patient/physician reconciliation of medication at every single visit; 2) is the 30-day supply vs. 90-day supply of medications. If I do 30-day medications, I am going to forget to take them, because we are busy. I imagine people of lower socioeconomic status are going to have a tough time, due to competing priorities (no money to go to pharmacy, co-payments per visit, etc.). I think 90-day supply would make a huge difference in BP reduction. This group will get responses from Dr. Cooper-DeHoff's Health Equity Research Institute (HERI) grant to inform ourselves with information that we should be routinely asking across all clinics that see hypertension patients. One of the challenges is that current EHRs do not collect that information. There is a huge deficiency in tracking data, since this is not something that is recorded. We cannot measure medication adherence and compliance without talking to patients or without some mechanism to track this.
- WellFlorida, our OneFlorida partner, is working with University of South Florida to look at community applications that show asset mapping. So you can know where you can get your medications from, like a church, or transportation to medications, all on a map. There are going to be people trained in this application, and then will be able to educate the clients using this map. The information from these apps can be imported to the health information exchange, and can be put in by the patient themselves. Instead of thinking of ways we can get information from the patient, we may also consider what pre-existing data sets are out there and what information we would need to gather within OneFlorida in order to make that data inter-operable with the pre-existing data sets. Do we need to get patient ZIP codes or county information, so we are not asking the patient how far you are from your nearest grocery store?
- We may want to look at the PROMIS zone data, which is census tract, to really drill down on those health disparities. Also, we are talking about hypertension, but we are in the middle of a study that looks at people who come into the office with repeated elevated BP, but where a diagnosis of HTN has never shown up in the chart. So what is the cause of that? Someone overlooking due to being busy, provider inertia? We have people who we know have HTN, people with RHTN, and people who are walking around who have HTN but it's never been diagnosed or treated. Then we may want to look at the health literacy of the cohort (the patient, the nurse and doctor). Health literacy can be a big factor.
- Per Dr. Smith, in a large health care system, we have moved to using the EHR for everything. If you put too much weight on the EHR, you can't actually manage the populations, clinics, to your rubric here. What we have done is

contract with another company, called Explorys, which builds dashboards and informatics so you can explore the data a lot better than with Epic.

- Per citizen scientist, I think this program needs to look at the accuracy of the BPs. There are outlying clinics that are still doing them manually. I can take my BP, someone else takes it, and we get two different ratings based on how they took them. And the other piece to that is the size of the cuff, which can lead to some ridiculous pressures. And the people taking it have looked at me as if to say, 'You have some nerve to tell me how to do my job, even though I know it's wrong.' Are the automatic cuffs more accurate than the manual? We also need to be consistent about how we take the BPs.
- Something else we may want to look at is ischemic vascular disease (IVD) and its association with long-term amputations, stroke, etc. OneFlorida should continue to focus on high risk populations - rural, low-income, elderly, and minority; Florida offers opportunities to include all of these populations. The OneFlorida Data Trust will include data from Community Health Centers CHCs, Federally Qualified Health Centers (FQHCs), rural clinics, inner-city clinics.
- After the meeting between Dr. Cooper-DeHoff and the Data Trust team, invite Ms. Hillaker -Downs to the hypertension monthly meetings to work on information dissemination.
- Review standardization for coding regarding cardio and peptic ulcer disease (PUD) problems

Small Table Discussion: Pediatrics Cross-Cutting Research Group

(Began at 10:30 am) Discussion led by Dr. Byrne

Participants: Ludmilla Paul, Lee Ann Lawson, Gee Kim, Elena Reyes, Luckey Dunn, Jennifer McCafferty, David Janicke, Julie Fesenmaier, Vernell Clayton, Peter Iafrate, Liz Manini, Deepa Ranka, Michael Muszysnki, Dorothy Mwachiro, Quintina Crawford, Deborah Morrison, Barry Byrne

- The meeting started with brief introductions. Dr. Byrne provided an overview of the ongoing Duchenne project.

PPMD

- Parent Project Muscular Dystrophy (PPMD) organization started 21 years ago when 2 boys were diagnosed with DMD. Their mother was asked to take the children home since nothing could be done to save them. She started to fundraise and raise awareness about Duchenne.
- There are currently 9 care centers. Aim is to get to 15 centers by end of the year.
- PPMD and Centers for Disease Control and Prevention (CDC) partnered in 2007. They developed DuchenneConnect which is a (national) patient registry. Data points are required for the database, so patients upload their genetic data reports in the registry.
- Cohort identification was highlighted as a major challenge

PPMD, DuchenneConnect and PCORnet

- In phase I for the DuchenneConnect PPRN, the emphasis was on infrastructure development, making the database more user-friendly.
- There is IRB oversight with regard to rare disease. IRB chair Peter Iafrate was asked to comment about protected health information (PHI). In general, data is de-identified. He mentioned that even a ZIP code could be an identifier if there is only a single patient, and that the bigger the number, 'n', the better.
- Dr. Iafrate said OneFlorida Data Trust is unique since the honest brokers are trained. Honest brokers de-identify data before it is entered into the data trust system. The IRB chair summed by saying that PHI is highly guarded and that the data trust cannot have any of the 18 PHI identifiers except for ZIP codes.

Newborn screening

- **Stakeholder question- Is it is possible to do newborn screening in Florida?** Data is available but there are ethical considerations. A pilot study may be conducted but it may not be possible to release results since patient's involvement may be required. If targeting a specific finding, questions may arise such as: how to get information to the patient, who should contact the patient, should the family be involved, what is the implication if initial screening is positive and the re-test is negative? There is also a cost implication for implementing this study. This idea (newborn screening) will be proposed to PCORI.
- **Stakeholder question- Many rare diseases occur in childhood. What data analysis can be done to ensure patients are managed at an early age? Is Duchenne the only focus or can other rare diseases can be focused on?** At this point there were discussions around other child health research priorities.

Child health priority areas identified

- **Mental Health**
  - This topic raised further questions, like the need to be more specific, e.g. focus on services, reimbursements, childhood abuse, etc.
  - Rationale for inclusion is that mental health is co-morbid to many other conditions.
- **Obesity and Physical Health**
  - This could be covered by the existing OneFlorida obesity working group to possibly avoid overlaps.
- **Oral Health**
  - Codes can be misidentified. It is important to prioritize as OneFlorida, as a state, and as a nation.
  - Rationale for inclusion is existing data in Pediatric Dental PBRN.
- **Vaccinations, Asthma management (controlled asthma), Pediatric HIV, Transitions of care**

Developing a Child Health Alliance

- With regard to forming a Child Health alliance, there was a question on how the Cancer Control Alliance was formed. This provided ideas on forming the Child Health Alliance. Ms. Manini, UF, provided an overview of the Cancer Control Alliance.
- To avoid possible overlaps with existing working groups, it was agreed that issues of child health related to cancer and obesity should not be included as priority areas in the Child Health Alliance.
- **Stakeholder question- How do we assure the health systems CEOs that data will not be compared with other health systems and make other health systems feel inferior?** Data contained within the OneFlorida Data Trust will only be released under IRB approval. Health systems may opt out of any study on a case-by-case basis. Publications and presentations based on these data are subject to review by the OneFlorida Steering Committee and PCORnet. All health systems will maintain representation on the OneFlorida Steering Committee. In addition, principles of stakeholder engagement will be employed on an ongoing basis to ensure that the infrastructure, resources, and uses of these resources consider diverse perspectives.
- **Stakeholder question- Is there a need for informational sessions with all health system leaders (not only PI's and scientists)?** Yes, this is already in place and more will be done.

Resources Needed to Operationalize the Creation of OneFlorida Child Health Alliance:

Emphasis Area Identified	Rationale for Inclusion
1)Oral Health	Data available from Dental PBRN as starting point
2)Mental Health	Co-morbid to other conditions
3)Obesity	National Health Priority

<u>Small Table Discussion: Cancer Prevention</u>

(Began at 10:30 am) Discussion led by Drs. Salloum and Staras (External Advisor: Dr. Paskett)

Participants: Nadine Zemon, Michelle Vinson, Francois Modave, Sonya White, Stephanie Staras, Kayla Getz, Mahmoud Enani, Ramzi Salloum, Maribeth Porter, Richard Bookman, Scott Needle, Kristi Gafford, Lori Drum, Katie Blackburn, George Michailidis, Daisy Wang, TaJuana Chisholm, Grant MacDonnell, Mark Roh, Juliette Lomax-Homier, Prabir Mandal, Greg Riccardi, Jenn Nguyen, Karen Russell, Theresa Shannon, Electra Paskett

- Dr. Salloum provided an overview of the **Tobacco Cessation Project**
  - The goal of the project is to use the 5 As and 6 As and provide a referral to patients who are current smokers.
  - OneFlorida's point-of-care tool, ResearchACTS, will screen patients and provide an automatic referral to those identified as current smokers.
  - Three populations will be studied: adults in primary care, children in primary care and childhood cancer survivors.
  - Current smokers will be referred to Area Health Education Council Programs and Florida Quit lines.
  - Community Practice Facilitators will follow up with patients to reduce use of tobacco.
- Dr. Staras provided an overview of the **Human Papillomavirus (HPV) Project,** including her recently awarded NCI-funded R21, Maximizing HPV Vaccination: Real-time Reminders, Guidance, and Recommendations, which will be implemented in the OneFlorida Clinical Research Consortium.

- The goal of the project is to increase community demand for HPV vaccine through postcards and text messages, brochures and link to website (provides information about HPV and vaccination process). Dr. Staras may introduce incentives and motivational interviewing.

Discussion Points

- Physician-patient interaction may be longer than 5 minutes for parents who have many questions and may not know much about HPV and the vaccine.
- The study should be sure they are reaching a wide variety of clinics and diverse population—low socioeconomic status (SES) vs high SES, high-performing clinics vs low-performing clinics.
- There are many strains of HPV so the vaccine may not cover all cases, especially among minority groups who may develop HPV from strains that were not present in the original vaccine.
- The study should provide substantial information to the patient about HPV and the vaccination process before presenting the iPad.
- There was a recommendation made to use TVs in the physician offices to provide information about the research (HPV vaccinations etc.).

Programmatic Meeting: Data Trust Program

(Began at 1 p.m.) Discussion led by Drs. Hogan and Tsinoremas (External Advisor: Drs. Embi and Paskett)

Participants: Luz Maristany, Amanda Hicks, Mahmoud Enani, Sonya White, Lance McCain, Susan Mitchell, Sean Hopkins, Gerrett Rice, Richard Bookman, Kevin Smith, Grant MacDonnell, Greg Riccardi, Donna O'Neal, Elena Reyes, Daisy Wang, George Michailidis, Julie Fesenmaier, Chris Scuderi, Deepa Ranka

- Discussed key milestones that need to be ready for PCORnet trials and others.
  - The Data Trust must house 1 million patients by April 1st.
  - Data characterization must be run on the Data Trust by April 1st.

Next Steps and Recommendations

- A next steps document was distributed to the group for review, which raised the following questions and discussions. **Stakeholder Question: A stakeholder pointed out that tab-delimited text files are mentioned in point 4 but point 7 requests raw files. Do we need to provide raw files?** Point 7 requests raw files if the group decides to do CDM transformation.
- Point 6c states "include a data dictionary for the files including whether your EHR incorporates a major, commercial drug knowledge base for drug codes such as First Databank, Multum, or Medispa". **Stakeholder Question: Who do the partners need to send this information to?** This can be a topic of discussion during the weekly calls. It has not been specified.
- When capturing changes to clinical documentation, it was recommended that a 30-day post would make it easier to ensure that the clinical changes are made. The group agreed that this was reasonable and the best way to proceed.
- OneFlorida has determined that lab results and prescribing information are necessary and, if possible, need to be included even though is the CDM lists this information as optional. It was recommended that weekly calls be scheduled to discuss infrastructure with individual partners.
- The Data Trust is working with the Patient Population Program (Hypertension, Obesity, and DMD Teams) to craft and test computable phenotypes to identify these conditions. Computable phenotypes will be sent as SAS queries from PCORnet and it is recommended that we maintain a library of computable phenotypes.
- The Data Trust is also working on record linkage (entity resolution).
- Enrollment (CDM table) would be from the first visit (January 2012) to the most recent visit. Health Choice Network offered to back-date when available, and it was suggested that the partners do this, but it is not required.
- There are no immediate action items related to natural language processing (NLP) but it should stay on the group's radar. Endeca was given as a recommendation for NLP in the Data Trust.

Comments and Questions

- There is a need to focus on the current infrastructure and milestones before thinking about adding additional data elements.
- When asked about bringing in partners' data stepwise, Dr. Hogan stated that the Data Trust is obligated by the PCORI contract to meet enrollment numbers and must continue to add partners' data.

- Florida Hospital will need until June 1, 2016 to make data available due to the Application Technology Review (ATR) process.
- University of Miami can complete the process of transferring data in a couple of days' time, but the legal agreements are still being processed and finalized.
- A representative asked when additional data elements above the CDM would be requested. Additional data elements will be required on a study-specific basis and during cohort development. Any additional elements will require approval from the Steering Committee. The group would like to know if partners can choose to opt out of the new additional elements.
- In terms of PCORnet expanding its CDM, a request would have to be sent in to the Coordinating Center. As a CDRN, OneFlorida can develop procedures for expanding the CDM. However, the group felt there needs to be a focus on OneFlorida beyond the PCORI grant.
- Temporarily, until all necessary agreements, ATRs, etc. are in place, could data be transformed and queried without being sent to the Data Trust (have data reside on partners' server)? This would not be a suitable solution; because of the data characterization process, partners would need to set up SAS tables and be registered as data marts.
- PCORnet has promised a more reasonable release schedule of new versions of the CDM going forward, possibly once per year. OneFlorida has agreed to update all data within three months of the release of any new versions. When the CDM is updated, all data, previous and new, must be converted.
- Participants from different institutions will be delineated by adding a precursor based on location (ex. FH for Florida Hospital). The OneFlorida software will do this; partners will not be asked to do this on their end.
- Health Choice Network is linking claims data for approximately 150,000 patients, the health plan's representative offered that it may be able to send the data into the Data Trust.
- Florida Hospital also offered to send data from its own employees; hospital administrators have tried working with United but have not had any traction. PCORI wants to engage big national payers.
- **Stakeholder Question:** Could social security number could be used? Yes, but obtaining SSNs would still not resolve all difficulties and would still have to be supplemented since SSN alone would not solve the issue with other information.
- The front end for an investigator will be i2b2 and this would require transforming data into the i2b2 data model. The Steering Committee will have to approve opening this up to investigators on the network. It was suggested that the University of Miami has a tool that may be better suited for this task than i2b2.
- The OneFlorida governance structure currently does not have a group in place to vet query or scientific requests before they are sent to the executive committee for review.

Programmatic Meeting: Integrated Clinical Research Program

(Began at 1 p.m.) Discussion led by Drs. Pepine and Muszynski (External Advisor: Dr. Wu)

Participants: Bruce Berg, Karen Russell, Juliette Lomax-Homier, Ludmilla Paul, Peter Iafrate, D.T Jayaweera, Elaine Van der Put, Mark Roh, Shanique Yee, Scott Needle, Michelle Vinson, Lori Drum, Nadine Zemon, Luckey Dunn

- Implementation of Consent2Share: This has been implemented on UF's side, but each institution will need to develop a Consent2Share plan with its local IRB. In order to complete multi-site trials, Consent2Share will be needed across all partners and institutions. This would allow stakeholders to identify those interested in studies.
- There was increased support among meeting members that a communications committee needs to be created in order to increase awareness for the Integrated Clinical Research Program. The public needs to know that OneFlorida exists. The communications committee could determine the best way to increase community awareness. Create a "call to action" for patients and providers to participate in and become part of OneFlorida. This would also allow for the dissemination of information to the stakeholders and partners, which is important in order to market OneFlorida to the community and clinicians. Focus on the fact that OneFlorida is patient-centered. The UF College of Journalism and Communications could help with the communications plan.
- We need to create a set of expectations: establish guidelines for scheduling studies, and for ensuring that multi-site trials are carried out in a professional manner.
- Focus on the practices that will produce good performance. Start planning small, simple trials that would allow for easy implementation.

- In order to create clinical trials, OneFlorida should look into the budgets of the proposed trials. This would give OneFlorida an idea of what is being asked for and what current resources will be needed. Smaller budgets will make OneFlorida become more innovative about how to create research studies.
- There was consensus that the term "Honest Broker" sends a different message than intended, and could appear negative to patients who are not aware of what the term means.
- Queries will need to be reviewed by the Steering Committee.
- There should be an alternative model for the traditional consent process- Consent2Share allows contact information to become identifiable if a patient is eligible for a study. Identify partners for Consent2Share within each organization.
- The non-UF local IRBs are able to review protocol and submit evaluations but are unable to vote to approve, not approves, or table any individual IRB submission. The University of Florida's IRB will serve as the central IRB. The University of Florida IRB will need to develop electronic training for other sites around the state to learn about the OneFlorida Central IRB.

Programmatic Meeting: Hypertension Team

(Began at 1 p.m.) Discussion led by Dr. Cooper-DeHoff (External Advisor: Dr. Brownson)

Participants: Shirley Bloodworth, Vernell Clayton, Jessica DeLeon, Elizabeth Hillaker Downs

- Some believe that there are certain blood pressure and blood sugar levels for patients with diabetes and obesity that could be good predictors of health outcomes. Looking at patients in OneFlorida, do the target levels make sense in the real world? There is definitely a patient care education component to this. A lot of patients have this mentality, "I am not going to check my BP at night, because if it is too high then I will not know what to do". It is apparent that there is an educational piece that is missing for the patient. If there was someone they could call or talk to for reassurance in the above situation that would go a long way.
- Once the Data Trust is set up, the hypertension team will need a few questions answered:
  - Can phenotypes be validated immediately?
  - Who actually runs the queries?
  - How long will it take between submitting a phenotype and getting the query back?
  - What is the limit of projects that can be worked on at one time?
- OneFlorida currently needs some victories and "wins". This will generate more funding and recognition.
- We could link the hypertension and women's heart disease groups together by looking at the relationship between BP and pregnancy. What is the proper BP target during each stage of pregnancy? Does the mother's BP during pregnancy affect health outcomes for the child and the child?
- Once data gets put into the data trust, we can move forward with some studies. What is the percentage of the patient population in OneFlorida with multiple BP readings greater than 140/90 and undiagnosed hypertension? This would take us about three months to write and run.
- First communication goal is to get the partners organized and our faces out there. Use the audiences that we already have before we launch our social media presence. Social media, at the moment, with the information that we are currently putting out is not really going to elicit much diversity in online traffic.
- Choose one or two strategies for information dissemination; craft the information and messaging to the specific target audience.
- When it comes to prioritizing areas of study and ideas to focus on, have an idea board where you can throw out ideas and focus on certain things.
- We learned earlier in the day that the OneFlorida Data Trust team is looking to test the Data Trust. Hypertension team can run their phenotypes through the system in order to test queries. This will benefit both the Hypertension Team and the Data Trust Program.
- For the American Heart Association (AHA) meeting on March 1st, we need to show some data. We will need a real code that we can share.
- One way to disseminate the information is through public forums. Get the community involved and then get live feedback as you present your results.
- If we want to get statewide feedback, we need to consider a road show.
- Also, to diversify our responses, we do not want to limit ourselves to just college campuses. We could work with IFAS to reach out to the community, maybe distribute information in barbershops and churches. Possibly working with Health Street as well.
- Review heart failure guidelines that focus on the inpatient side of care, which examines how well patients with heart failure are treated with guideline-directed therapies.

Programmatic Meeting: DMD Team

(Began at 1:00 pm) Discussion led by Dr. Byrne (External Advisor: Dr. Brownson)

Participants: Ann Lucas, Betsy Shenkman, Barry Byrne, Lori Cavallari, Beth Kidder, Lijing Ouyang, Gee Kim, Dorothy Mwachiro

Overview

- One of the focus areas in the initial application was partnership with DuchenneConnect; with special interest in patient-centered group called Parent Project Muscular Dystrophy (PPMD) and their initiatives at patient-reported outcomes in a program called DuchenneConnect. DuchenneConnect is a PCORI-funded PPRN which runs a patient registry with has about 3,500 registrants.
- Currently, there is a big push to diversify and provide increased awareness to that program for both control populations and education to the patient community so that the data set can be used by other research scientists through a data-sharing agreement.
- Specific efforts within OneFlorida as relates to DuchenneConnect and other rare diseases in general is to establish a computable phenotype based on work originally done with that group in the CDC, MD STARnet (a CDC-funded Muscular Dystrophy Surveillance tracking and Research Network) in collaboration with health centers caring for Duchenne patients.
- Identifying DMD patients from electronic medical records is very challenging because based on ICD9 codes, there is not enough specificity to do proper cohort identification. This provides an opportunity for research to look at other specific identifiers such as gender, age, and potentially laboratory data that will aid in cohort identification.
- Patient identification has been stagnant for the past 20 years and now there is an opportunity for treatment that will depend on early detection and other subsequent testing.
- Other programs that have been initiated include bone health in patients that may be at risk for fractures, and new bone screening for early detection.

The potential to begin universal early detection and newborn screening for DMD appears to be unique to Florida. Widespread screening has been attempted in California and Ohio has screened a subset of patients (20,000). We could have a big impact and we could be leaders in this effort. In Florida, we have many screening opportunities per month and this is a unique opportunity.

PPMD overview by Ms. Lucas

- PPMD has had electronic health records for over 20 years, which is why PPMD chose to partner with PCORnet during Phase I. The ultimate goal was not only to invite people to join the Duchenne project but also to access electronic health records. Initially 11 people were identified in the electronic health records using ICD9 code. The clinician who attended to them confirmed the number to be 25; about 5 people were in both systems. Unfortunately, no updates were received from that project.
- In UCLA system, 120 letters were sent out to invite people to join the registry. So far, only 4 people have joined the registry using the code provided to them.
- PPMD has now partnered with PEDSnet, pSCANNER (Patient-Centered Scalable National Network for Effectiveness Research) and the Greater Plains Collaborative.
- PPMD is also involved in newborn screening and there is a potential for OneFlorida to join.

Programmatic Meeting: Obesity Team

(Began at 1p.m.) Discussion led by Drs. Smith and Janicke (External Advisor: Dr. Brownson)

Participants: Dave Janicke, Carlos Maetzu, LuAnn Duncan, Myrtle Graham, Steven Smith, Joe Nadglowski, Dominick Lemas, Lori Bilello, Myra Hurt, Michelle Cardel

- The obesity workgroup met on January 6th in Gainesville, FL, and had a very productive meeting. The overarching theme of this group will be to look at diversity in lots of ways (age groups, rural vs. urban, social determinants of health). The group conceptualizes its work as falling into one of several topics 1) early childhood 2) healthy obesity (haven't decided how to identify these folks) and 3) severe obesity. We will also be able to look at weight trajectories.
    - This group will participate in two national PCORnet studies on bariatric surgery outcomes and early use of antibiotics.
    - We hope to integrate Patient Reported Outcomes more and we will need to obtain these from patients themselves.

  - Many of the topics we look at will cut across age groups.
- This group has a natural opportunity to look at differences between geographic populations, rural, suburban, and urban. We could partner with some other CDRNs, too, to investigate rates of obesity, comorbidities, patient-reported outcome measures (such as desire for treatment), and differences in referral patterns. As OneFlorida develops a child health alliance there may be opportunities to work on other hot topics. Is there overlap in terms of major areas of need (oral and mental health?); for example, is a child at risk for other poor health outcomes?
- We discussed potential for community needs assessments, which started from the idea of report card. We are thinking of long-term goal, ultimately, something that would help give us better guidance on how to better serve kids in underserved rural areas. We have a lot of data that would help us develop initiatives.
- The group discussed a project Ms. Drum is evaluating, implementing the "Go, Slow, Whoa" system in Broward County, and whether our data could evaluate pre- and post- obesity rates there.
- Group discussed the Trust for America's Health report, which uses behavioral risk factor surveillance system (BRFSS) data. In comparison, our data will be at the system and provider level. Could we spin it around obesity and health care instead of just obesity in FL? We aren't a random sample or necessarily representative of Florida. We will do a report card of people within the health care system.
- The group discussed the topics of immigration and whether we track that in our data. Florida is well positioned to talk about migration status. Should we break it down by legal status of immigrants? No good empirical data on this. If we can cross-walk to census data, they might have some of that data available. Or we could ask patients in PRO. We can also look at this topic by focusing on the clinics that specifically serve the undocumented population (Health Choice Network?). We can ask questions like how long the immigrant has been in this country or whether or not their parents were born in this country.
- The group discussed reviewing alternative sources of data, such as Head Start or voluntary prekindergarten (VPK). Our report card might serve as a bridge to these groups, give them useful information and demonstrate gaps.

External Scientific Advisory Committee Meeting

(Began at 2 p.m.) Discussion led by Drs. Tom Pearson, Electra Paskett, Peter Embi, Ross Brownson, Albert Wu

Participants: Peter Carek, TaJuana Chisholm, Christy Evans, Kristi Gafford, Thom George, Francois Modave, Dave Janicke, Liz Manini, Peter Iafrate, D.T. Jayaweera, Michael Muszynski, Joe Nadglowski, David Nelson, Thomas Pearson, Temple Robinson, Mark Roh, Eric Rosenberg, Karen Russell, Chris Scuderi, Theresa Shannon, Betsy Shenkman, Steven Smith, Elaine Van der Put, Heather Williams

Prioritization of OneFlorida Research Topics

- The external advisors suggested that OneFlorida should prioritize what stakeholders want, not just Florida and not just patients. Some stakeholders are providers and managed care, it is important to do something that providers are interested in, too.
- Goals need to be set by what Florida needs and then a plan needs to be created on how to reach these goals.
- Per Dr. Wu, PCORI wants products immediately. OneFlorida should show items that have improved care for patients and addressed gaps in knowledge.
- It was also suggested that the focus be shifted away from specific cities and onto the state as a whole.

OneFlorida Outreach

- The group agreed that more people – both researchers and lay people – need to know about OneFlorida and the resources that are offered.
- It is important to foster team science among the academic institutions.

OneFlorida Programs

- The group agreed that the specifics about program deliverables was not understood by everyone in the breakout groups. There is a need to specify what each partner is supposed to do and by when.
- There needs to be a more hands-on approach in the smaller meetings. Smaller meetings should focus on developing goals and discussing steps for reaching each goal.

- **Next steps**
  - Dr. Embi will provide a report summarizing the overall thoughts of each Scientific Advisor.

Section 6. Evaluation Results

53	Steering Committee and Reception attendees
102	Meeting attendees
112	RSVP's received
8	Community members
8	Clinicians
4	External Scientific Advisors
2	Joined via conference call
29	Evaluation sheets returned

1. **What was most valuable to you today?**
   - ✓ Dialogue, meeting other OneFlorida members, learning about OneFlorida and projects.
   - ✓ Learning what OneFlorida is doing and meeting other partners in the Consortium.
   - ✓ Great overview of OneFlorida systems.
   - ✓ Dr. Wu's presentation.
   - ✓ Networking and introduction to OneFlorida.
   - ✓ Opportunity to get to know the stakeholders better and to start to understand how OneFlorida really works.
   - ✓ Albert Wu's talk.
   - ✓ Bill Hogan's update, Dr. Wu.
   - ✓ The morning overview and data trust working sessions.
   - ✓ Outcomes/Everything.
   - ✓ The opportunity to interact with others.
   - ✓ Moring session which describes the overall view of the organization.
   - ✓ Cancer prevention breakout session.
   - ✓ Meeting colleagues and discussing problems of how to move forward.
   - ✓ Networking.
   - ✓ The information that was shared by the speakers, and I really enjoyed the breakout sessions. The entire stakeholder meeting was extremely informative.
   - ✓ Networking with other Consortium members.
   - ✓ The most valuable thing from the Stakeholder Meeting was the networking and putting faces to the voices that are heard on the conference calls.
   - ✓ Morning overview sessions.
   - ✓ Networking with all statewide partners.
   - ✓ Meeting people face to face.
   - ✓ Feedback from the external advisory group members.
   - ✓ Being able to be face-to-face with collaborators in the consortium; meeting people from other working groups.
   - ✓ The opportunity to network with people from other sites
   - ✓ Hearing about the milestones, and the plans moving forward Meeting others involved
   - ✓ Sharing information at breakout meetings

2. **What was least valuable to you today?**
   - ✓ Too many acronyms.
   - ✓ Breakout groups.
   - ✓ Better explanation of some acronyms.
   - ✓ Programmatic meetings--I am not on this committee regularly so could not contribute at a meaningful level.
   - ✓ Programmatic meetings—ICRP—felt like most people had no idea what was being discussed (including me).
   - ✓ Workgroup reports, while useful, were time-consuming, perhaps short summaries disseminated later could be a substitute.
   - ✓ Afternoon group meeting.
   - ✓ Report back—presentations not well organized.
   - ✓ Not applicable.
   - ✓ Nothing.
   - ✓ The second half of my afternoon session.
   - ✓ Nothing.

- ✓ Some of the operational updates were very routine.
- ✓ Worksheets for every individual in a group did not work. It did not seem like people were clear what they should write. Also, this is not necessary in a group discussion. One person (volunteer) could note down main points to report back instead of everyone having to write.
- ✓ It was all valuable.
- ✓ Workgroup reporting to larger Consortium.
- ✓ The Wednesday morning presentations did not seem to be very productive.
- ✓ Later afternoon sessions; lost momentum.
- ✓ Being unclear of the goal of the session.
- ✓ The working lunch.
- ✓ The breakout sessions. Were very unclear and disorganized.
- ✓ Some of working groups overlapped so wasn't possible to attend.
- ✓ No real down side - thought the most was made of the time available. Good organization
- ✓ Plastic tumbler promotional handout

3. <u>What would you suggest we do differently for the next annual meeting? (Try to be as specific as possible.)</u>

- ✓ Dialogue on specific studies, successes in some studies.
- ✓ What is each partner's role, how can we get more involved, etc.
- ✓ Shorter, more intense sessions (my brain started to swell on the long sessions).
- ✓ More logic on who is assigned to which group; provide information up front on what committees have been doing (research, themes, accomplishments).
- ✓ More explanation, more specific goals for each group, sent with an agenda.
- ✓ Get input from larger group for agenda and groups' leaders.
- ✓ Train facilitators to be facilitators, better allocate participants to groups-several were not engaged.
- ✓ Would like to have some reprints, or tangible info about the milestones, and perhaps some of the outstanding posters
- ✓ Optional travel accommodations/hotel arrangement information even if not reimbursable.
- ✓ No change.
- ✓ Provide an organization chart of OneFlorida, who is in which committees.
- ✓ Perhaps teach how to write for grants, this was a group heavily weighted towards career researchers merged with "others who may not have as much knowledge".
- ✓ Prevention is better than cure; focus more on minority education in cancer prevention.
- ✓ More focused workgroups.
- ✓ Let people select own workgroups/topics. - Make it as participatory as possible; e.g. brainstorm in the larger meeting what key issues need to be reported back from workgroups. If keys areas have already been identified, discuss each item in plenary to ensure everyone is clear what needs to be done.
- ✓ This was my first meeting and I felt it was well organized.
- ✓ More networking time during the day of the event.
- ✓ I would suggest that the presentations are done in a way that is a little more productive and fosters more conversation. Also, I think it would have largely increased productivity if we received information about the goals of the small group meetings prior to attending the Stakeholder Meeting.
- ✓ Find ways to keep momentum up throughout the afternoon. The scientific advisors' meeting took away from the afternoon meetings.
- ✓ It would be better if we would attend these knowing what was intended for us to accomplish. Even the breakout groups seemed a little disorganized, just no clear goal.
- ✓ Different meeting space.
- ✓ The groups were not evenly distributed; possibly having a poll during an online registration method would help with people choosing the meetings to attend. It would be nice to limit the poll to certain spaces (so for Patient Population, x number would be the limit and then it would be marked off as filled, so even distribution could occur). If someone really wanted to be in a group, they could email and try to get a spot; of course the experts in the group should automatically be placed.
- ✓ Would have a section detailing upcoming studies in OneFlorida, Also would have time devoted to a discussion on barriers -- this is a great time for everyone to discuss issues they are having at the site level and share what they are doing to address these challenges. Everyone can learn from sessions like that and take it back to their entity.
- ✓ More coffee.
- ✓ More time for afternoon sessions - morning sessions didn't seem as pertinent.

- ✓ The method of notetaking during the breakout sessions distracted me. The expectations were not clarified at the beginning of the breakout sessions, and the discussions did not always follow or address what we were asked to record. These factors combined made it difficult to record something that the research coordinators would be able to make sense of. It also took my attention away from my own notes. I would suggest either doing away with this altogether and letting the research coordinators take notes without aggregating our notes, or creating a system where (a) expectations are clarified, (b) the discussion explicitly addresses those expectations, and (c) attendees can keep a copy of what they produce.
- ✓ In advance of conference send bios of presenters as well as a brief description of topics to be presented& expectation of goals for breakout sessions

4. In what ways could we best engage and keep you informed over the coming year?

Newsletter (email)	Newsletter (print)	Monthly webinar	Monthly conference call
24	**7**	**10**	**5**

Anything else?

a. Minutes from committees/workgroups.
b. Updates on goals/potential trials.
c. Can we have a more "open forum" to allow input from members?
d. Newsletter for everyone, conference calls for specific workgroups.
e. More information and connection with Health Street

5. In what ways would you like to interact with OneFlorida over the coming year?

Conduct a research study	Participate in a workgroup	Contribute to a grant application	Contribute to publications/presentations
9	**17**	**6**	**7**

Anything else?

a. As a citizen scientist, it's fantastic to just be informed and updated on accomplishments.
b. Staff.
c. Participate in data discussions-CDM.
d. Continue to grow and improve the role of "Citizen Scientist"
e. Learn more about it

Project Milestones/Updates (Dr. Hogan)				
Excellent	Very Good	Fair	Poor	No response
11	**12**	**5**		**1**
Keynote address (Dr. Wu)				
Excellent	Very Good	Fair	Poor	No response
21	**4**	**3**		**1**
Overview of Research Priorities (Dr. Shenkman)				
Excellent	Very Good	Fair	Poor	No response
16	**10**	**2**		**1**
Small Table Discussion (Cancer Prevention, Health Systems Demonstration, Heart Heath, Pediatrics)				
Excellent	Very Good	Fair	Poor	No response
11	**11**	**7**		
Working Lunch				
Excellent	Very Good	Fair	Poor	No response
5	**10**	**13**	**1**	
Programmatic Meeting (Data Trust, Integrated Clinical Research Program, Patient Population Programs, External Scientific Advisors meeting)				
Excellent	Very Good	Fair	Poor	No response
6	**11**	**9**	**3**	
Opportunity to interact with participants				
Excellent	Very Good	Fair	Poor	No response
17	**8**	**4**		

Engagement of different stakeholders (clinicians, patients, researchers) throughout the day				
Excellent	Very Good	Fair	Poor	No response
15	**10**	**4**		
Registration process				
Excellent	Very Good	Fair	Poor	No response
22	**7**			
Helpfulness of event staff on site				
Excellent	Very Good	Fair	Poor	No response
22	**7**			
Meals and refreshments				
Excellent	Very Good	Fair	Poor	No response
12	**12**	**5**		
Overall event experience				
Excellent	Very Good	Fair	Poor	No response
15	**13**	**1**		

6. **Other comments**
   - ✓ Well done!
   - ✓ Rotate cities.
   - ✓ Need water/drinks throughout the day.
   - ✓ To extent possible let people choose which groups to be in (by their expertise, interests, etc.). To not overburden the group, have participants give several choices and priorities
   - ✓ Especially grateful for non-meat options.
   - ✓ Food and drink disappeared after lunch.
   - ✓ Map to building and directions as to where to park was missing.
   - ✓ Difficult to hear the commentary from the facilitators during the second session. The conversation became somewhat one-sided between those who were active participants already in the research. The remainder of the group sat mute.
   - ✓ Meals heavily weighted towards shrimp—tough for those with a seafood allergy.
   - ✓ Lunch was one of the few times to network with other consortium members so it was too bad that this was also a time where we needed to be listening to presentations.
   - ✓ It would be nice to have meal options for those with diet restrictions.
   - ✓ The lunch food was not enough food to make it through an entire afternoon. And there were no drinks available in the afternoon. At the least there should be coffee and water. Also, need to have signs in front of the food so that people with allergies know what is in the food. The sandwiches were not identified by type of meat, and that is important. May not be necessary to have the meeting be a full day until there are more agenda items to discuss.
   - ✓ Appreciate the opportunity to participate, these are exciting times in the medical, and patient experiences. Thanks

7. **Changes for next year**
   - ✓ Poster session during lunch.
   - ✓ Send out the steering committee agenda prior to the meeting.
   - ✓ Give meeting attendees a shuttle schedule.
   - ✓ Attendees choose appropriate breakouts or let them vote.
   - ✓ Coffee and bottled water all day.
   - ✓ Arrange roundtables so attendees can see each other, panels with all program leaders to report on updates.
   - ✓ Inform leaders on responsibilities prior to the meeting.
   - ✓ Have quarterly in-person meetings at each of the OneFlorida partner sites.
   - ✓ Provide a cell phone number on the invitation for a direct contact person.
   - ✓ Provide information about parking in advance and other logistical information.
   - ✓ Provide information in advance on what programs have been doing.
   - ✓ Have partners involved in the agenda development; have steering committee set goals for the annual stakeholder meeting and then develop a task force to organize the meeting.
   - ✓ Scientific advisors and faculty leads leaving at 2 p.m. made it awkward.
   - ✓ Structure the meeting as a conference so people can register.

- ✓ Link to hotels in the area.
- ✓ Send out a briefing book 2 weeks prior to the meeting.

Section 7. Glossary

5As: Agency for Healthcare Research and Quality's (AHRQ) five major steps to intervention: Ask, Advise, Assess, Assist, and Arrange.
6As: Agency for Healthcare Research and Quality's (AHRQ) six major steps to intervention: Anticipate Ask, Advise, Assess, Assist, and Arrange.
Agency for Healthcare Research and Quality (AHRQ): AHRQ is part of the US Department of Health and Human Services, which supports research and is designed to improve the outcomes and quality of healthcare. Additionally, the organization seeks to reduce costs, address patient safety and medical errors and broaden access to effective services. More information.
Area Health Education Centers (AHEC): A US Program established to improve the supply, distribution, retention and quality of primary care and other health practitioners in medically underserved areas.
Aspirin Dosing: A Patient-centric Trial Assessing Benefits and Long-term Effectiveness (ADAPTABLE): The main objective of this pragmatic randomized clinical trial is to identify the optimal dose of aspirin for secondary prevention in atherosclerotic cardiovascular disease. This trial will constitute the initial randomized comparative-effectiveness trial conducted by PCORnet: The National Patient-Centered Clinical Research Network. More information.
Clinical and Translational Science Award (CTSA): Under NCATS' leadership, the Clinical and Translational Science Awards (CTSA) Program supports a national network of medical research institutions — called hubs — that work together to improve the efficiency and effectiveness of translational science. CTSA Program support enables research teams including scientists, patient advocacy organizations and community members to collaborate to tackle common system-wide and operational problems in clinical and translational research that no one team can overcome. Both the University of Florida and the University of Miami have a Clinical and Translational Science Institute (CTSI).
Clinical Data Research Network (CDRN): The Patient-Centered Outcomes Research Institute (PCORI) has awarded $141.3 million to support 33 health data networks that together comprise PCORnet, the National Patient-Centered Clinical Research Network, in its second phase. PCORnet is a large, highly representative, national network for conducting clinical outcomes research. In its second phase, PCORnet will integrate data from 13 Clinical Data Research Networks (CDRNs) -- networks that originate in healthcare systems such as hospitals, health plans, or practice-based networks and securely collect health information during the routine course of patient care – and 20 Patient-Powered Research Networks (PPRNs) -- networks operated and governed by groups of patients and their partners who are focused on a particular condition or population and whose members are interested in sharing health information and participating in research. Funding support for the phase II networks was approved by PCORI's Board subject to a business and program review and issuance of final research contracts. OneFlorida Clinical Research Consortium is a new CDRN in Phase II.
Cohort: In research, a group of individuals who share a characteristic at some specific time and who are then followed forward in time, with data being collected at one or more suitable intervals.
Common Data Model (CDM): A way of organizing data into a standard structure. The approach PCORnet is using to do this mirrors the approaches used by other large national research consortia. Each PCORnet partner network will map data to the same consistent format. The PCORnet CDM is based on the Mini-Sentinel Common Data Model (MSCDM) and has been informed by other distributed initiatives. The PCORnet CDM leverages standard terminologies and coding systems for healthcare (including ICD, SNOMED, CPT, HCPSC, and LOINC) to enable interoperability with and responsiveness to evolving data standards.
Comparative Effectiveness Research (CER): The direct comparison of existing healthcare interventions to determine which interventions work best for which patients and which interventions pose the greatest benefits and harms. The core question of CER is which treatment works best, for whom, and under what circumstances.
Computable Phenotypes: An electronic algorithm used to identify certain conditions or characteristics. This process can be used to identify cohorts of individuals for studies.
Consent2Share: The UF Consent2Share initiative was launched to develop, pilot and expand a consent process by which patients under UF Health care can consent to be contacted about opportunities to participate in research at UF Health.
Data Linkage: The task of finding records in a data set that refers to the same entity across different data source.
Data Query: A request for information from a database
Data Use Agreement (DUA): Contractual documents used for the transfer of non-public data that is subject to some restriction on its use. DUAs serve to outline the terms and conditions of the transfer. Specifically, DUAs address important issues such as limitations on use of the data, obligations to safeguard the data, liability for harm arising from the use of the data, publication, and privacy rights that are associated with transfers of confidential or protected data.
Dataset: A collection of data. Most commonly a data set corresponds to the contents of a single database table, or a single statistical data matrix, where every column of the table represents a particular variable, and each row corresponds to a given member of the data set in question.

DataMart: Within PCORnet, a DataMart refers to a specific data resource that can be uniquely defined and queried using the PCORnet distributed research network (DRN) Query Tool. Networks will create their DataMart(s) through an (Extract, Transform, and Load) ETL of source data. PCORnet DataMarts are DataMarts that adhere to the PCORnet CDM.
De-Identified Data: The following identifiers of the individual or of relatives, employers or household members of the individual must be removed for health information to be considered de-identified: names; all geographic subdivisions smaller than a State; all elements of dates (except year) for dates directly related to an individual; telephone numbers; fax numbers; email addresses; social security numbers; medical record numbers; health plan beneficiary numbers; account numbers; certificate/license numbers; vehicle identifiers and serial numbers; device identifiers and serial numbers; web URLs; IP addresses; biometric identifiers; full face photographic images and any comparable images; and any other unique identifying number, characteristic, or code.
Design Studio: Held in Gainesville, Florida with in-person and webinar participation options, the Design Studios provide an opportunity to: 1) discuss clinical concerns, 2) link clinicians, patients and researchers together, and 3) provide technical assistance and research coordinator support to further develop innovative ideas into protocols.
Dissemination: The process of spreading knowledge and information to practice settings.
Duchenne Muscular Dystrophy (DMD): A genetic disorder characterized by progressive muscle degeneration and weakness. It is one of nine types of muscular dystrophy. DMD is caused by an absence of dystrophin, a protein that helps keep muscle cells intact. Symptom onset is in early childhood, usually between ages 3 and 5. The disease primarily affects boys, but in rare cases it can affect girls.
DuchenneConnect: A robust and cutting-edge website and registry of patients with Duchenne and Becker muscular dystrophy developed with the review, direction and advice from a group of experts. Advisors contribute to DuchenneConnect in many areas including reviewing educational materials, providing programmatic direction, advising on processes and procedures, and facilitating opportunities for outreach and collaboration. More information.
Electronic Health Record (EHR): A digital version of a patient's paper chart. EHRs are real-time, patient-centered records that make information available instantly and
EpicCare: Patient-centered electronic health record software. Epic encompasses the complete patient registration, scheduling, clinical and billing information for mid-size and large medical groups, hospitals and integrated healthcare organizations.
Florida Agency for Health Care Administration (AHCA): An Agency statutorily created by Chapter 20, Florida Statutes as the chief health policy and planning entity for the state. Primarily responsible for the state's estimated $22.9 billion Medicaid program that will serve a projected 3.48 million Floridians in SFY 2013-14, the licensure of the state's 45,000 health care facilities and the sharing of health care data through the Florida Center for Health Information and Policy Analysis. More information.
Florida Cancer Data System (FCDS): A Florida Statewide Cancer Registry that has been collecting incidence data since 1981. In October 1994, the Florida Cancer Data System became part of the National Program of Cancer Registries administered by the Centers for Disease Control. Through this program the CDC provides funding for states to enhance their existing registry to meet national standards for completeness, timeliness and data quality set forth by the North American Association of Central Registries, the American College of Surgeons, Commission on Cancer and the Surveillance, Epidemiology and End Results reporting program of the National Cancer Institute (NCI). More information.
Honest Broker: An appointed entity that keeps private information, but distributes parts of those sets of data to other entities (researchers) who do not need all of the information. The purpose of this is to protect identity, and this person (or persons) is also a decision maker in whether to allow use of the existing data or materials.
Human Papillomavirus (HPV): The most common sexually transmitted infection in the US. There are many different types of HPV; some types can cause health problems including cancers.
Hypertension: Also known as high blood pressure is a common condition in which the long-term force of the blood against your artery walls is high enough that it may eventually cause health problems, such as heart disease.
Implementation Science: Implementation science is the study of methods to promote the integration of research findings and evidence into healthcare policy and practice. It seeks to understand the behavior of healthcare professionals and other stakeholders as a key variable in the sustainable uptake, adoption, and implementation of evidence-based interventions.
Informatics for Integrating Biology and the Bedside (i2b2): The UF Health IDR Team has deployed i2b2, an NIH sponsored Query and Analysis tool. This tool and its data were approved by the UF IRB and can be used to access the UF Health IDR, which contains clinical data from a variety of clinical and administrative information systems within the institution. Currently, i2b2 can be used by faculty researchers to query clinical data across Gainesville-area health system locations.
Integrated Data Repository (IDR): Supported by the UF CTSI and Shands HealthCare, the UF Health Integrated Data Repository (IDR) is a large-scale database that collects and organizes information from across UF Health's clinical and research enterprises. The UF Health IDR enables new research discoveries as well as improvements in the quality and safety of patient care. The IDR consists of a secure, clinical data warehouse that aggregates data from the university's various clinical and administrative information systems, including the EpicCare electronic health record system.

International Classification of Diseases (ICD): The standard diagnostic tool for epidemiology, health management and clinical purposes. This includes the analysis of the general health situation of population groups. It is used to monitor the incidence and prevalence of diseases and other health problems, proving a picture of the general health situation of countries and populations.
IRB-01: This IRB accepts and reviews all protocols submitted including the broad category of 'Medical' research, regardless of funding.
James and Esther King (JEK) Biomedical Research Foundation Grant: The James and Esther King Biomedical Research Foundation Grant was used to develop the OneFlorida Clinical Research Consortium - an infrastructure to support pragmatic clinical trials and implementation science studies focused on cancer prevention and control.
Limited Data Set (LDS): A limited set of identifiable patient information as defined in the Privacy Regulations issued under the Health Insurance Portability and Accountability Act (HIPAA). A "limited data set" of information may be disclosed to an outside party without a patient's authorization if certain conditions are met.
Medicaid: A social health care program in the United States for families and individuals with low income and limited resources. The Health Insurance Association of America describes Medicaid as a "government insurance program for persons of all ages whose income and resources are insufficient to pay for health care."
Medicare: A national social insurance program, administered by the U.S. federal government since 1966, currently using about 30 private insurance companies across the United States. Medicare provides health insurance for Americans aged 65 and older who have worked and paid into the system. It also provides health insurance to younger people with disabilities, end stage renal disease and amyotrophic lateral sclerosis.
Memorandum of Understanding (MOU): A legal document outlining the terms and details of an agreement between parties, including each parties requirements and responsibilities.
Milestone: A task of zero duration that shows an important achievement in a project. Milestones are a way of knowing how the project is advancing if you are not familiar with the tasks being executed. They have zero duration because they symbolize an achievement, a point of time in a project.
National Cancer Institute (NCI): Part of the National Institutes of Health (NIH), which is one of eleven agencies that are part of the US Department of Health and Human Services. The NCI coordinates the U.S. National Cancer Program and conducts and supports research, training, health information dissemination, and other activities related to the causes, prevention, diagnosis, and treatment of cancer; the supportive care of cancer patients and their families; and cancer survivorship. More information.
National Institutes of Health (NIH): An agency of the US Department of Health and Human Services, it is the primary agency of the US government responsible for biomedical and health-related research. The NIH both conducts its own scientific research through its Intramural Research Program and provides major biomedical research funding to non-NIH research facilities through its Extramural Research Program. More information.
Natural Language Processing (NLP): A field of computer science, artificial intelligence, and computational linguistics concerned with the interactions between computers and human (natural) languages.
Obesity: As defined by the Centers for Disease Control and Prevention, weight that is higher than what is considered as a healthy weight for a given height is described as overweight or obese.
On-the-Road Studios: Studios that rotate among the five districts of the state every other month. Clinical Champions and Community Practice Facilitators (CPFs) residing within each of the districts co-lead the On-the-Road-Studios. The Clinical Champion works with local physicians to identify a practice or health system site for the meeting and invites local patients, health system administrators, and researchers to attend. Research topics, including those focused on health system improvement research, are selected for further development based on the ability to form robust teams that include the necessary patient, clinician, and researcher expertise and the potential to meaningfully address critical clinical issues and outcomes for patients and clinicians
Our Community, Our Health (OCOH): A platform for open dialogue to help patients and consumers understand health research findings, and to identify community-driven research priorities using community-based participatory research principles. The forum is conducted in community settings using a two-hour, town hall format that begins with a discussion about the community's health needs and concerns, includes two presentations on related research topics, and concludes with a discussion about ways to talk with health professionals about health concerns.
Parent Project Muscular Dystrophy (PPMD): The largest most comprehensive nonprofit organization in the United States focused on finding a cure for Duchenne muscular dystrophy. More information.
Patient- Centered Outcomes Research (PCOR): Research that addresses the questions and concerns most relevant to patients, and we involve patients, caregivers, clinicians, and other healthcare stakeholders, along with researchers, throughout the process.
Patient Engagement: As defined by PCORI, the meaningful involvement of patients and caregivers throughout the research process – from topic selection through design and conduct of research to dissemination of results. Such engagement can influence research to be more patient centered, useful, and trustworthy and ultimately lead to greater use and uptake of research results by the patient and broader healthcare community.

Patient Reported Outcome (PRO): Any report of the status of a patient's health condition that comes directly from the patient, without interpretation of the patient's response by a clinician or anyone else.
Patient Reported Outcomes and Measurement Information System (PROMIS): Funded by the National Institutes of Health (NIH), is a system of highly reliable, valid, flexible, precise, and responsive assessment tools that measure patient–reported health status.
Patient-Centered Outcomes Clinical Research Network (PCORnet): An innovative initiative of the Patient-Centered Outcomes Research Institute (PCORI), PCORnet integrates health data for studies and catalyzes research partnerships among two types of networks: Clinical Data Research Networks (CDRNs), which are based in healthcare systems such as hospitals and health centers, and Patient-Powered Research Networks (PPRNs), which are run by groups of patients and their partners who are focused on one or more specific conditions or communities, and who are interested in sharing health information and participating in research. Their efforts are supported by a Coordinating Center. More information.
Patient-Centered Outcomes Research Institute (PCORI): The Patient-Centered Outcomes Research Institute (PCORI), an independent nonprofit, nongovernmental organization located in Washington, DC, was authorized by Congress in 2010. Their mandate is to improve the quality and relevance of evidence available to help patients, caregivers, clinicians, employers, insurers, and policy makers make informed health decisions. Specifically, they fund comparative clinical effectiveness research (CER), as well as support work that will improve the methods used to conduct such studies. More information.
Patient-Powered Research Network (PPRN): Patient-powered research networks (PPRNs) were funded by PCORI with the intent of supporting communities or networks of patients motivated to participate in clinical research through the National Patient-Centered Clinical Research Network (PCORnet) and to develop their capacity to govern the research activities of their networks. PCORI will fund up to eight individual research projects under this limited PCORI Funding Announcement.
Personal Health Information (PHI): Any information about health status, provision of health care, or payment for health care that can be linked to a specific individual.
Phenotype: The composite of an organism's observable characteristics or traits, such as its morphology, development, biochemical or physiological properties, phenology, behavior, and products of behavior.
Policies and Procedures (P&P): Policies are a set of principles, rules, and guidelines formulated or adopted by an organization to reach its long-term goals and typically published in a booklet or other form that is widely accessible. Procedures are the specific methods employed to express policies in action in day-to-day operations of the organization. Policies and procedures are designed to influence and determine all major decisions and actions, and all activities take place within the boundaries set by them.
Practice-Based Research Network (PBRN): PBRNs are groups of primary care clinicians and practices working together to answer community-based health care questions and translate research findings into practice. PBRNs engage clinicians in quality improvement activities and an evidence-based culture in primary care practice to improve the health of all Americans. As of September 2015, there are 176 PBRNs registered with the Agency for Healthcare Research and Quality (AHRQ) PBRN Resource Center.
Principal Investigator (PI): The lead researcher for a particular well-defined project, usually in the sciences, such as a laboratory study or a clinical trial.
Protocol: A document that describes the background, rationale, objectives, design, methodology, statistical evaluation of the data, and organization of a clinical research project.
ResearchACTS: A web-based application that can be accessed by any device connected to the internet. ResearchActs allows users to see only the information needed based on their relationship to the data and was reviewed and approved by the UF Privacy Office and Health Science Center Information Technology Group. The database is located on secure servers at the UF Health Science Center (HSC).
Statistical Analysis System (SAS): A software suite for advanced analytics, multivariate analyses, business intelligence, data management, and predictive analytics.
Socioeconomic status (SES) is an economic and sociological combined total measure of a person's work experience and of an individual's or family's economic and social position in relation to others, based on income, education, and occupation.
Strategic Planning: An organization's process of defining its strategy, or direction, and making decisions on allocating its resources to pursue this strategy. It may also extend to control mechanisms for guiding the implementation of the strategy.
Tobacco Cessation: Also known as smoking cessation, the process of discontinuing tobacco smoking.
Translational Science: A multidisciplinary form of science that bridges the recalcitrant gaps that sometimes exist between fundamental science and applied science, necessitating something in between to translate knowledge into applications.