Infrastructure and Opportunities Fund Projects

Assessing how children feel and function using objective physical activity data and PROMIS Pediatric measures

Courtney Mann

>> HI. SO, OUR PROJECT, THE PRESENTATION IS ASSESSING HOW CHILDREN FEEL AND FUNCTION USING OBJECTIVE -- SORRY, IS THAT BETTER? I WAS STANDING TOO FAR AWAY. OKAY. SO, MEASURING HOW CHILDREN FEEL AND FUNCTION USING OBJECTIVE PHYSICAL ACTIVITY DATA PROMIS PEDIATRIC MEASURES. SO, THIS PROJECT WAS AWARDED TO EXTEND OUR EXISTING AIM 3 STUDY THAT WAS LOOKING AT PEDOMETRY IN KIDS 13-18, INCLUDING OUR DUKE CENTER THROUGH DUKE AND UNC AND THEN ALSO THE NORTHWESTERN CENTER THROUGH BOSTON CHILDREN'S. TECHNICAL DIFFICULTIES. I THINK SOMETHING HAPPENED. CAN I PRESS THAT? WOULD THAT WORK? OKAY. I CAN DO IT BY HAND. SOUNDS GOOD. THIS IS A LIST OF OUR STUDY TEAM MEMBERS, BECAUSE WE HAVE SO MANY ACCRUING SITES AND STAFF I EVERY INDIVIDUAL ACCRUING SIDE AND STAFF. NEEDLESS TO SAY, IT'S A LOT OF PEOPLE. THANKS TO EVERYONE WHO HAS PARTICIPATED IN THIS STUDY. SO, OUR PRIMARY AIM WAS TO DETERMINE ASSOCIATION BETWEEN ACTIVITY AND PROMIS PEDIATRIC MEASURES, AND WE WERE EXTENDING OUR EXISTING STUDIES IN CANCER AND RHEUMATIC DISEASE TO INCLUDE CHILDREN FROM 8 TO 12 YEARS OLD, AND THEN ALSO ADDING A THIRD CHRONIC CONDITION WHICH WAS ASTHMA. SO, I'M GOING TO START WITH OUR ASTHMA STUDY. THIS IS THE ONE THAT NORTHWESTERN WAS INVOLVED WITH THROUGH WANDA'S GROUP, AS WELL AS A GROUP AT UNC. SO OUR STUDY DESIGN, WE INCLUDED FOR KIDS IN THIS STUDY BECAUSE IT WAS THE NEW DISEASE GROUP, AGE 8 TO LESS THAN 18 YEARS OLD. AND INCLUDED KIDS WHO HAD ASTHMA THAT WAS NOT WELL CONTROLLED. THEY HAD AN INITIAL CLINIC VISIT ON DAY ZERO WHERE THEY COMPLETED A VARIETY OF CLINICAL MEASURES, AND THEY ALSO GOT THEIR PEDOMETER, ON DAYS 7, 14, 21, THEY HAD A SURVEY THEY RECEIVED AN E-MAIL LINK TO AND COMPLETED FROM HOME. THIS HAD A LOT OF SELF-REPORTED SYMPTOMS, SURVEYS, FOR ASTHMA, SEVERITY LEVELS, AND PROMIS SURVEYS, AND THEY ALSO DID AN ECOLOGICAL SURVEY THAT ESSENTIALLY CONTAINED LIKE 8 OR 9 ITEMS THAT ASKED THEM ABOUT PHYSICAL OR OPPORTUNITIES TO PARTICIPATE IN PHYSICAL ACTIVITY, PARENT OR PEER SUPPORT OF THEM PARTICIPATING IN PHYSICAL ACTIVITY, ACCESS TO PLACES OR EQUIPMENT TO DO PHYSICAL ACTIVITY, AND THEN ALSO THEIR PEDOMETER WEAR, HOW MUCH THEY ACTUALLY WORE IT. AND THEN AT THEIR LAST CLINIC VISIT AROUND DAY 28 THEY GOT THEIR CLINICAL MEASURES AGAIN, AND THEN THE FULL SET OF SELF REPORT SURVEYS AS WELL, AND PEDOMETER FOR THE ENTIRE FOUR WEEKS AND RETURNED IT AT THAT LAST VISIT. SO, OUR PARTICIPANT DEMOGRAPHICS FOR THE STUDY, WE ENROLLED 105 PARTICIPANTS. WE ACTUALLY -- OUR MEAN AGE WAS 11.45. WE HAD ABOUT HALF OF OUR SAMPLE WAS FEMALE. AND WE HAD A PRETTY GOOD RACIAL DISTRIBUTION FOR THIS STUDY, RACE AND ETHNICITY, OTHER THAN WE'RE A LITTLE LOW IN OUR REPRESENTATION OF THE ASIAN POPULATION. ALSO WE HAD A PRETTY GOOD DISTRIBUTION OF THE BMI AS WELL. LOOKING AT CORRELATIONS BETWEEN AVERAGE, WEEKLY STEPS PER DAY, SO FOR EACH WEEK THE AVERAGE STEPS PER DAY, AND THE PROMIS MEASURES, WHAT WE FOUND IN WEEK 1 WE HAD SORT OF MODERATECORRELATIONS FOR ASTHMA IMPACT, DEPRESSIVE SYMPTOMS, FATIGUE AND MOBILITY WITH THE STEPS PER DAY. HOWEVER, WHEN WE GOT TO WEEK 2, WE WERE DOWN TO JUST HAVING ASTHMA IMPACT AND MOBILITY HAVE A CORRELATION. AND I DIDN'T LIST WEEK 3 AND WEEK 4 HERE

BECAUSE WE FOUND NO CORRELATION IN WEEK 3 AND WEEK 4 WE'RE REWORKING OUR ANALYSIS BECAUSE WE FOUND A PROBLEM WITH OUR DATA. WE'RE STILL IN OUR SORT OF PRELIMINARY ANALYSIS PHASE RIGHT NOW. SO THESE ARE JUST SCATTER PLOTS. I HAVE A COUPLE. THIS ONE IS FOR THE ASTHMA IMPACT, SO YOU CAN JUST SEE THAT RELATIONSHIP AS IT GOES FROM WEEK 1 TO WEEK 2. AND THEN WE ALSO HAVE ONE FOR THE MOBILITY T-SCORES, OBVIOUSLY IN THE OPPOSITE DIRECTION, SINCE THE INCREASE IN SCORE FOR MOBILITY IS POSITIVE, VERSUS THE ASTHMA IMPACT. SO, I'M GOING TO MOVE ON TO THE PRO-CTCAE STUDY, CANCER STUDY, BEFORE CONCLUSIONS AND NEXT STEPS BECAUSE SOME CONCLUSIONS AN THE NEXT STEPS ARE SIMILAR, I DIDN'T WANT TO TALK ABOUT IT TWICE. WANTED TO BE EFFICIENT. YEAH?

>> [OFF MICROPHONE].

>> NO, WE HAVEN'T DONE A BY-SITE ANALYSIS YET BUT THAT'S SOMETHING WE'LL END UP LOOKING AT, YEAH. SO FOR THE PRO-CTCAE THIS IS OUR CANCER STUDY, CONDUCTED AT DUKE, UNC-CHAPEL HILL, EMORY, ST. JUDE AND CHILDREN'S HOSPITAL OF PITTSBURGH. STUDY DESIGN FOR CANCER WAS THE PARTICIPANTS GOT THEIR PEDOMETER, SEVEN DAYS BEFORE OR MORE, BEFORE THEIR BASELINE TIME POINT. AND SO THEY WOULD WEAR THE PEDOMETER UP UNTIL THEIR CLINICAL ASSESSMENT FOR THEIR FIRST CLINICAL ASSESSMENT, AND THEN THEY WOULD HAVE ABOUT 7 TO 17 DAYS BETWEEN THEIR BASELINEASSESSMENT AND THEIR FOLLOW-UP ASSESSMENT, FOR MOST OF THE PATIENTS.AND THEN THEY WOULD HAVE A SECOND WEEK OF PEDOMETER WEAR AT THE END, OR RIGHT BEFORE THEIR T2 ASSESSMENT AS WELL, SO MOST OF THE KIDS HAD CHEMO, THOSE WERE THE KIDS 7 TO 17 DAYS BETWEEN ASSESSMENT POINTS, FOR THE KIDS WHO HAD RADIATION IT WAS ACTUALLY 4 WEEKS IN BETWEEN. AND OUR STUDY POPULATION HERE, WE HAVE MEAN AGE OF ABOUT 13.4. AGAIN, WELL, ABOUT 43% FEMALE, AND THEN OUR RACIAL DISTRIBUTION HERE, IT'S NOT QUITE AS DIVERSE AS OUR ASTHMA SAMPLE, BUT THERE'S SOME REPRESENTATION ACROSS GROUPS, AND THEN WE ALSO LOOKED AT CANCER TYPES. SO WE HAVE LEUKEMIA AND LYMPHOMA FOR 58%, BRAIN TUMOR AT 17%, AND SOLID TUMOR. WE LOOKED AT ASSOCIATION BETWEEN PROMIS SCORES AND AVERAGE STEPS PER DAY. IN THIS GROUP WE FOUND PAIN INTERFERENCE AND MOBILITY AND PHYSICAL ACTIVITY WERE SIGNIFICANTLY CORRELATED IN WEEK 1. AND THEN ONCE WE GOT TO WEEK 2, ONLY MOBILITY WAS SIGNIFICANTLY CORRELATED. SO THIS IS A SIMILAR SORT OF PATTERN THAT HAPPENED ACROSS BOTH THE DISEASE GROUPS IN THAT WE HAD MORE SIGNIFICANT RELATIONSHIPS IN THE FIRST WEEK THAN IN THE SECOND WEEK. AND THEN MOVING TO MY NEXT SLIDE, IT'S MORE SCATTER PLOTS, BUT I THINK THE PEDIATRIC MOBILITY IN PARTICULAR MAKES IT REALLY EASY TO SORT OF SEE THAT RELATIONSHIP WHERE WE'RE SORT OF DECLINING AS WE GO FROM WEEK TO WEEK FROM THAT STRENGTH IN THAT RELATIONSHIP. SO, WE ALSO LOOKED FOR CANCER. WE HAVEN'T DONE THIS IN ASTHMA YET BUT FOR CANCER LOOKED AT ASSOCIATION BETWEEN THE CHANGE IN PEDIATRIC PROMIS AND CHANGE IN AVERAGE DAILY STEPS. AND WHEN WE WERE LOOKING AT THIS WE ACTUALLY HAD OUR SIGNIFICANT RELATIONSHIPS WERE WITH MOBILITY AND FATIGUE, WHICH WAS INTERESTING BECAUSE FATIGUE DID NOT SHOW UP IN THE PREVIOUS ASSOCIATIONS. AND THEN IN ADDITION TO THIS, SO THE PRO-CTCAE STUDY IS LOOKING AT SYMPTOM TOXICITIES IN CANCER PATIENTS, SO WE ALSO LOOKED AT THE ASSOCIATION OF THE AVERAGE DAILY STEPS WITH THE PRO-CTCAE ITEMS. IN WEEK 1 THERE WAS A RELATIONSHIP WITH DIARRHEA FREQUENCY, VOMITING FREQUENCY, AND FATIGUE SEVERITY. WHEN WE MOVED TO WEEK 2 WE SAW A REDUCTION IN THOSE RELATIONSHIPS SO DIARRHEA FREQUENCY WAS THE ONLY RELATIONSHIP THAT REMAINED SIGNIFICANT. SO, OUR CARRA STUDY, OUR THIRD DISEASE GROUP, OUR RHEUMATIC DISEASE. THIS IS DUKE, DCRI, DUKE CLINICAL RESEARCH

INSTITUTE,BOSTON CHILDREN, UNIVERSITY OF MINNESOTA, SORRY, MINNESOTA, UCFS, BENOFF CHILDREN'S HOSPITAL AND SEATTLE CHILDREN'S HOSPITAL. THIS STUDY IS MORE SIMILAR TO THE CANCER STUDY, TWO TIME POINTS, THESE ARE SIX MONTHS APART. SO, THEY START WITH THEIR CLINIC VISIT, WITH CARRA AND HAVE THEIR CLINICAL MEASURES TAKEN AND THEY ALSO RECEIVE THEIR PEDOMETER, AND THEN DAYS LATER THEY GOT A FOLLOW-UP SURVEY ONLINE AND COME IN SIX MONTHS LATER FOR CLINICAL VISIT, ANOTHER SURVEY SEVEN DAYS AFTER THAT. AND WE HAVE NOT -- SORRY, GETTING AHEAD OF MYSELF. WE JUST GOT OUR DATA COLLECTION COMPLETED FOR CARRA AND HAVEN'T DONE ANALYSIS YET SO NO RESULTS YET BUT WE SHOULD BE DOING THAT SO, OUR CONCLUSIONS AND NEXT STEPS, PEDOMETER-BASED OBJECTIVE OBSERVATIONAL DATA APPEARS TO CORRESPOND TO HEALTH DATA IN THE FIRST WEEK AND A LITTLE BIT IN THE SECOND WEEK. FOR ASTHMA WE SAW THAT INCREASE IN STEPS CORRELATE WITH INCREASE IN MOBILITY SCORES. AND THE DECREASE IN THE ASTHMA IMPACT SCORES. AND THEN CANCER HAD THOSE CORRELATIONS WITH SELF-REPORTED PHYSICAL ACTIVITY AND MOBILITY, AND THEN DIARRHEA, VOMITING, AND FATIGUE IN THE SYMPTOM TOXICITIES. THERE'S A RELATIONSHIP BUT WE SEE THE RELATIONSHIP DECREASE OVER TIME. AND THAT'S SOMETHING THAT WE WANT TO INVESTIGATE IN THE FUTURE. WE'RE WONDERING IF IT HAS SOMETHING TO DO WITH PEOPLE'S ATTENTION ON THE MONITORS AS THEY WEAR THEM. IT'S SORT OF COMMONLY KNOWN WHEN PEOPLE GET A MONITOR THAT THEIR ACTIVITY WILL INCREASE FOR A WHILE, AND THEN IT WILL DECREASE AS THE NOVELTY WEARS OFF. AND SO IS THERE SOME SORT OF RELATIONSHIP WHERE THE KIDS WHEN THEY GET THE MONITOR FOR THE FIRST WEEK OR TWO ACTIVITY INCREASES WITHIN THE REALM OF WHAT IT CAN INCREASE BASED ON THEIR SPECIFIC CHRONIC CONDITION, AND THEN IT SORT OF DROPS FOR EVERYONE IN LATER WEEKS BUT THAT'S SOMETHING TO EXPLORE LATER. AND THEN USING PEDOMETERS TO MEASURE HEALTH STATUS PRESENTS ITS OWN SET OF CHALLENGES IN RESEARCH. WE DEFINITELY HAD SEVERAL PATIENTS WHO LOST THEIR DEVICES, OR DEVICES THAT CAME BACK AND JUST FOR SOME REASON LIKE WE COULD NOT GET DATA OFF OF THEM. SO THAT IS DEFINITELY AN AREA TO LOOK INTO. AND THEN UPCOMING WORK THAT WE HAVE IS REVISING THE ANALYSES FOR OUR DAY 28 DATA, WITH THE ASTHMA GROUP, WHICH I ALREADY MENTIONED. ALSO OUR CARRA DATA ANALYSIS. WE WOULD LIKE TO EXPLORE OPTIONS FOR HOW TO DEAL WITH THE MISSING DATA IN ALL OF OUR GROUPS, AND ALSO WE'RE GOING TO LOOK AT INTENSITY AND DURATION OF PHYSICAL ACTIVITY IN RELATIONSHIP TO SYMPTOM EXPERIENCE. WE DO HAVE THE GARMIM VIVOFIT MONITORS IN 15-MINUTE INCREMENTS, ACTIVE LEVEL INTENSITY ASSIGNED TO THEM SO WE WANT TO USE THAT IN ANALYSIS AS WELL. AND THEN LASTLY WE WANT TO EXPLORE WAYS TO USE PRO ACTIVITY DATA, PRO AND ACTIVITY DATA IN COMBINATION TO MEASURE HEALTH STATUS, AND THEN ACROSS ALL OF THE GROUPS TO EXPLORE THE METHODOLOGIES THAT WE USE FOR DATA HANDLING SO THAT WE CAN ESTABLISH SOME BEST PRACTICES. THERE'S A LOT OF INFORMATION OUT THERE FOR ACCELEROMETERS, BUT NOT FOR CONSUMER-GRADE PEDOMETERS. OKAY. THE END. SO QUESTIONS, ALSO ACKNOWLEDGMENTS OF ALL OF OUR FUNDING. WE HAVE THE PEPR IOF, THE DUKE PEPR, THE PRO-CTCAE STUDY, AND THEN THE CARRA REGISTRY AND PRO DATA COLLECTED FROM A PRO CORE SYSTEM SUPPORTED BY AN NCI GRANT, SO A LOT OF PEOPLE COME TOGETHER FOR THIS. [APPLAUSE]

>> A GREAT WAY TO END, RATHER THAN SAYING THANK YOU, YOU JUST SMILE. QUICK QUESTION. HOW MUCH OF THE -- THIS IS A PRETTY RESOURCE INTENSIVE PROJECT. I'M CURIOUS, BALL PARKING, HOW MUCH OF YOUR COSTS WERE COVERED BY THE IOF VERSUS THESE OTHER SOURCES?

>> SO, MOST OF IT WAS ACTUALLY COVERED BY THE IOF, SO THE WAIT THAT WE WROTE OUR APPLICATION FOR THE PROJECT WE DID SAY IN OUR APPLICATION THAT BECAUSE WE WERE ALREADY DOING THE OLDER AGE GROUPS, IN OUR AIM 3 ANALYSIS, THAT WE WOULD ROLL THE FUNDING FOR THE ANALYSIS INTO OUR PRIMARY GRANT BECAUSE WE'RE ALREADY DOING THE PEDOMETRY ANALYSIS. THAT WAS DEFINITELY COVERED BY US. THE RECRUITMENT AND LIKE SITE STUFF, VALERIE CAME FROM THE PROJECT, FUNDING FOR IOF. FOR PRO-CTCAE OUR AWARD PIGGYBACKS ON THAT STUDY, AND SO THEY ARE COLLECTING PROMIS FOR US AND THEY RECRUITED OUR PATIENTS FOR PEDOMETRY BUT CLINICAL DATA IS PART OF IT, SO OUR STUDY SUPPORTED THE PROMIS AND PEDOMETRY DATA COLLECTION. UH-HUH?

>> CAN YOU REMIND ME HOW EFFECTIVE THE DEVICES ARE? I SHOULD KNOW THIS, TO INFER ANY KIND OF HOURS OF SLEEP OR INACTIVITY THAT MIGHT BE SLEEP OR SLEEP QUALITY, OR IS IT REALLY INSENSITIVE TO THAT?

>> YEAH, I -- THIS IS ONE OF THE THINGS WE'VE TALKED A LOT ABOUT WHEN WE TALKED ABOUT DATA HANDLING. WE DON'T REALLY HAVE A GOOD WAY TO DEAL WITH SLEEP. THE DATA THAT WE GET OUT DOESN'T HAVE THE DATA, LIKE I HAVE A PERSONAL GARMIN MONITOR, AND I CAN LOG INTO MY ACCOUNT ONLINE, IT WILL TELL ME WHEN I SLEPT, HOW MANY TIMES I WOKE UP. BUT THAT INFORMATION DOESN'T COME OUT IN THE DATA THAT WE GET FROM GARMIN. ALL WE HAVE IS A SET OF INFORMATION THAT TELLS US LIKE THE MAX MOTION FOR A GIVEN PERIOD, AND THE MEAN MOTION FOR A GIVEN PERIOD, BUT EVEN WHEN WE LOOK AND SAY MAX MOTION IS ZERO, MEAN MOTION IS ZERO, THEY DIDN'T MOVE AT ALL, SOMETIMES THAT HAPPENS IN THE MIDDLE OF THE DAY IF YOU'RE SITTING ON THE COUCH WATCHING NEXTFLIX, AND YOU'RE A STILL PERSON. SPEAKING PERSONALLY, YES. SO I DON'T THINK THERE'S A REALLY GOOD WAY TO TEASE OUT SLEEP TIME. SO THAT IS SOMETHING THAT WE'RE TALKING A LOT ABOUT DEALING WITH, THAT'S ONE OF THE THINGS WHEN I MENTIONED SORT OF OUR FUTURE WORK, LOOKING AT HOW WE'RE HANDLING THAT DATA AND TRYING TO COME UP WITH BEST PRACTICES BECAUSE THERE'S NOT A REALLY GOOD WAY TO DO IT.

>> (INAUDIBLE).

>> THERE IS TIME STAMPEL. -- STAMPING. WE'RE LOOKING AT PATTERNS OF ZERO-ZERO, AS WE CALL IT. SO IF THERE'S A PERIOD OF LIKE 6 HOURS STRAIGHT, ZERO-ZERO AT NIGHT CAN WE ASSUME THE KID IS SLEEPING, THAT'S WHAT WE'RE LOOKING AT, YEAH.

>> I WAS WONDERING IF YOU COULD COMMENT ON YOUR ASTHMA DATA WHERE YOU HAVE ASSOCIATIONS AT THE BASELINE, BUT NOT AT THE SUBSEQUENT TIME POINTS. I MEAN, ONE QUESTION WOULD BE, IS THERE DIFFERENCE IN THE DEGREE OF DISEASE ACTIVITY AT BASELINE, ARE YOU CAPTURING THEM AT BASELINE BECAUSE THAT'S -- THEY HAPPEN TO BE SICKER AT THAT DISEASE VISIT AND THEREFORE YOU HAVE MORE SIGNAL OR IS IT JUST A FUNCTION, AS YOU SAY, OF HOW MUCH YOU PAY ATTENTION TO YOUR PEDOMETER?

>> SO, I HATE THAT I DON'T HAVE AN ANSWER FOR YOU JUST YET. BUT SINCE WE'RE STILL IN PRELIMINARY ANALYSIS PHASE WE HAVEN'T GOTTEN TO THE ANALYSIS THAT INCLUDES THE DISEASE ACTIVITY. BUT WE DO KNOW THAT A LOT OF THE KIDS IN OUR SAMPLE ALSO WERE IN THE PARTIALLY CONTROLLED AS OPPOSED TO WELL CONTROLLED OR NOT WELL CONTROLLED CATEGORY, AND SO WHEN WE LOOK, WE'RE GOING TO LOOK AT THAT ANALYSIS IN THE FUTURE, BUT WONDERING HOW

MUCH ABILITY WE'RE GOING TO HAVE TO REALLY SEE ANY DIFFERENCES SINCE SUCH A LARGE POPULATION OR PORTION OF OUR POPULATION WAS IN ONE CATEGORY.

>> (OFF MIC.).

>> NO, WE TURN IT OFF ON THE DEVICE BEFORE WE GIVE IT SO IT ONLY SHOWS TIME LIKE A WATCH

WOULD.

>> [OFF MICROPHONE].

>> WE COULDN'T. SO WE CONNECT THE DEVICE TO LIKE A GARMIN ACCOUNT THAT DOESN'T -- IT HAS LIKE A PATIENT ID ASSOCIATED WITH IT, LIKE A STUDY E-MAIL ADDRESS ASSOCIATED WITH IT. WE GIVE THEM THE MONITOR WITH EVERYTHING SHUT OFF EXCEPT FOR THE TIME AND THEY WOULD WEAR IT FOR FOUR WEEKS FOR ASTHMA. OR TWO TO THREE WEEKS FOR CANCER. AND THEN A WEEK AT A TIME FOR CARRA AND BRING IT BACK AND WE WOULD UPLOAD THE DATA. AT THE END OF THE STUDY PERIOD WE WOULD TURN EVERYTHING BACK ON AND GIVE IT TO THEM AND DISASSOCIATE WITH OUR GARMIN ACCOUNT SO THEY CAN SET UP THEIR OWN ACCOUNT BUT THEY CAN'T SEE IT AND WE DON'T HAVE IT TILL THEY BRING THE MONITOR BACK TO US.

>> [OFF MICROPHONE].

>> YES. I DO THINK THAT.

>> [OFF MICROPHONE].

>> IT'S POSSIBLE, YEAH. I THINK THEIR ABILITY TO ACTUALLY MEASURE CHANGE IN THEIR ACTIVITY WOULD DEFINITELY INFLUENCE THEIR ACTIVITY LEVEL.

>> THANK YOU SO MUCH, COURTNEY. THAT WAS TERRIFIC. MARISA, YOU'RE UP NEXT. SO WHEN PEPR WAS AWARDED, PART OF THE RFP POINTED TOWARDS THE NEED FOR RELATING ENVIRONMENTAL VARIABLES TO PATIENT-REPORTED OUTCOMES. AND WE'VE DONE THAT IN DIFFERENT WAYS IN OUR INDIVIDUAL PROJECTS, BUT WE'RE REALLY EXCITED TO HAVE MARISA LEADING A PROJECT THAT IS ACTUALLY GEO CODING SEVERAL OF THE PARTICIPANTS IN OUR COHORTS, AND SO SHE WILL GIVE AN UPDATE, WHERE SHE STANDS, AND THEN HARALD WILL YOU BE PRESENTING ON BEHALF OF ELIZABETH NEXT? OKAY, GREAT.

Geomarkers and chronic disease: Mapping the PROMIS measures

Marissa Hauptman

>> I LIKED WHAT CHRIS AND JIM SAID LOOKING BACK AND FORWARD. THIS PROJECT SOON AFTER I RETURNED FROM MATERNITY LEAVE.MY DAUGHTER IS CLOSE TO 2, IT STILL HAS A LOT OF LEARNING AND WORK TO BE DONE TO RAISE THE LITTLE WONDERFUL THING BUT HOPEFULLY WE'RE FAR FROM WHERE WE WERE LAST YEAR. SO, I'VE SPOKEN ABOUT THIS BEFORE. JUST TO SORT OF MAKE SURE WE'RE ALL ON THE SAME PAGE, BIOMARKER IS ANY SUBSTANCE, STRUCTURE, PROCESS THAT CAN BE MEASURED IN THE BODY, OR ITS PRODUCTS AND INFLUENCE AND PREDICT INCIDENCE OF OUTCOME OR DISEASE. THIS PROJECT IS FOCUSING ON GEOMARKERS, ANY OBJECTIVE CONTEXTUAL OR GEOGRAPHIC MEASURE THAT INFLUENCES OR PREDICTS OUTCOME OF DISEASE, YOU COULD ADD

PROMIS MEASURES OR THE LIVED EXPERIENCE, THAT'S WHAT WE'RE SET OUT TO LEARN. COMING INTO THIS PROJECT, I'VE BEEN DOING GIS FOR A DECADE OR MORE AT THIS POINT IN TIME. I WANT TO THANK WANDA WHO BELIEVED IN ME AND THE ABILITY TO SORT OF RUN THIS IOF STUDY, AND THE INTEREST CAME OUT OF THE MAJORITY OF GIS RESEARCH, ONE DISEASE PROCESS, ONE GEOGRAPHIC AREA, FEW STUDIES FOCUS ON JOINT AND INTERACTIVE EFFECTS OF ENVIRONMENTAL AND SOCIAL STRESSORS, WHAT I DEDICATE MY CAREER TO INTERVENE ON. AS EVERYONE KNOWS, PEDIATRIC PATIENTS WITH CHRONIC DISEASE REPRESENT A MIX OF RISK FACTORS, I'M A GENERALIST, SO THIS INCLUDES MANY DISEASES IN MY STUDY LIKE I DO IN MY PRACTICE AT BOSTON CHILDREN'S IS VERY APPEALING TO ME. SO THE AIM OF OUR STUDY WAS TO LEVERAGE THIS WONDERFUL CONSORTIUM INFRASTRUCTURE BY COLLECTING GIS DATA FROM PARTICIPANT ADDRESSES AND I SET TO DO THAT WITHOUT BREACHING PROTECTED HEALTH INFORMATION, AND THEN HOPEFULLY TO UNDERSTAND THE RELATIONSHIP BETWEEN THESE GEOMARKETERS, PROMIS MEASURES AND HEALTH CARE UTILIZATION IN CHRONIC DISEASES. I'LL GO THROUGH THIS QUICKLY. WHEN I SUBMITTED THE PROPOSAL I DIDN'T KNOW ABOUT CINCINNATI CHILDREN'S, A WONDERFUL PARTNER, DEVELOPED THE TECHNOLOGY INNOVATIONS TO ALLOW THIS IOF STUDY TO CONTINUE WITHOUT HAVING TO TRANSMIT PROTECTED HEALTH INFORMATION IF IT HAD NOT ALREADY BEEN INCLUDED IN CONSENT FORMS AND IRBs. SO THIS TECHNOLOGY CALLED DEGAUSS, STUDIES SEND DE-IDENTIFIED DATA TO THE COORDINATING CENTER, ANALYSIS DONE ESSENTIALLY. WE THROUGHOUT THE LAST YEAR DEVELOPED GEOMARKERS WHICH I'LL GO INTO IN FURTHER DETAIL, SHIPPED THEM OUT TO THE COHORTS THAT WERE PARTICIPATING, ALLOWING THOSE THAT NEVER TOUCHED A MAP OR GIS OR ANYTHING OF THE LIKE TO SYSTEMATICALLY ASSIGN PARTICIPANTS'' ADDRESSE TO LATITUDE, LONGITUDE AND GIS MARKERS AND STRIP PROTECTED HEALTH INFORMATION AND SEND US BACK SOLELY THE VALUES OF THE GEOMARKERS. SO, I'LL GO THROUGH THESE IN FURTHER DETAIL. THESE ARE FOUR OF THE DOMAINS THAT I WANT TO FOCUS ON BASED ON PRIOR LITERATURE OF GEOMARKERS AND DIFFERENT CHRONIC DISEASES, AND LIKELY THERE WILL BE TWO OR THREE PAPERS THAT COME OUT OF THIS THAT LOOK AT SORT OF THE INDEPENDENT AS WELL AS EFFECTS OF THESE DOMAINS AS WELL AS JOINT AND SYNERGISTIC EFFECTS. FIRST IS DEPRIVATION INDEX, DIFFERENT THAN YOU'VE HEARD DISCUSSED PREVIOUSLY. THIS IS SIX COMPONENT VARIABLES, YOU KNOW, THAT WHICH IS ALSO INCLUDED IN THE ADI THAT'S BEEN DISCUSSED, BUT THIS IS DEVELOPED IN CINCINNATI, AND, YOU KNOW, MANY OF THE DEPRIVATION INDEXES MEASURE THE SAME THING, POVERTY, NO HEALTH INSURANCE, MEDIAN INCOME, IT'S INTERPRETED THE SAME WAY AS ADI, THE HIGHER THE INDEX, THE MORE DEPRIVED THE NEIGHBORHOOD AND YOU CAN ALSO CREATE PERCENTILES AS WELL. THIS IS ONE AREA I REALLY WANTED TO INCORPORATE BECAUSE I THINK IT'S BEEN MISSING FROM MANY ADIs, AN AREA WORKING IN INNER CITY BOSTON I SEE A LOT OF AND DON'T REALLY TOTALLY UNDERSTAND THE IMPACT ON OUR PATIENTS, AND THEIR LIVED EXPERIENCE. BUT THIS IS A DATASET WE PURCHASED FOR THE PURPOSE OF THIS PROJECT THAT ALLOWS US TO ON A VERY SMALL POPULATION LEVEL IDENTIFY THE ROLLING 7-YEAR AVERAGE OF CRIME AS A RATE, AS WELL AS ABLE TO CALCULATE BOTH NATIONAL TOTAL CRIME INDEX PERCENTILE FOR A GIVEN GROUP AS WELL AS VIOLENT CRIMES AND PROPERTY CRIMES. THIS IS AN AREA I'VE HAD EXPERIENCE WITH IN THE PAST, TRAFFIC PROXIMITY, AS PROXY FOR AIR POLLUTION. WE WERE ABLE TO DEVELOP INDEX TO LOOK AT BOTH THESE PRIMARY ROADS WHICH ARE DISPLAYED HERE AS WELL AS MORE SECONDARY ROADS WHICH SORT OF ARE NOT THE INTERSTATE HIGHWAYS BUT MAJOR ROADS IN COMMUNITIES. PARALLEL TO THAT WE HAVE THE GREEN STATES INDEX WHICH WE DEVELOPED TAKEN SORT OF IN 2018 AT THE PEAK OF VEGETATION ACROSS THE UNITED STATES, IN JUNE, AND WERE ABLE TO DEVELOP BUFFERS AROUND EACH OF THE PARTICIPANTS' RESIDENCES, 500,

1500, 2500 MEETERS TO GIVE A SENSE HOW GREEN THEIR AREAS ARE BUT ALSO TO COUNTERACT POLLUTION AS OFTEN THEY CAN BE ANTAGONISTIC TO EACH OTHER. LASTLY LOOKING AT HEALTH CARE ACCESSIBILITY, WE DEVELOPED THESE -- THIS GEOMARKERS LOOKING AT DRIVE TIME AND DISTANCE TO CARE SITES WHERE THE PATIENTS OR PARTICIPANTS ARE RECRUITED FROM. IT HAS LIMITAIONS, NOT ALL PATIENTS SAY FOR ST. JUDE'S ARE GETTING THEIR DAY-TO-DAY MEDICAL CARE AT ST. JUDE'S BUT WE THOUGHT THIS WAS A FEASIBLE WAY TO DEVELOP AN ACCESSIBILITY INDEX IN TERMS OF HOW FAR THESE CHILDREN WITH CHRONIC DISEASE HAD TO TRAVEL TO SOME CARE SITES. THIS IS SORT OF DURING AVERAGE TRAFFIC TIMES, AS WELL AS THE DISTANCE IN METERS. FROM OTHER STUDIES HERE WE LOOKED AT PRIMARY OUTCOME BEING PROMIS MEASURES, BOTH IN PARENT AND CHILD AS WE PRIORITIZE THOSE PROMIS MEASURES IN FOUR DISEASE COHORTS AND ALSO ABLE TO – I SPENT THE LAST MONTH DOING HARMONIZATION OF STUDY SITES AND CREATING MEASURES OF HEALTH CAREUTILIZATION, SO HOSPITALIZATION, E.D. VISITS, OVERALL FOR EACH PARTICIPANT AND SPECIFIC DISEASE PROCESSES. DATA THAT'S INCLUDED IN THIS STUDY IS BASELINE DATA, SO AT LEAST FOR NOW LOOKING AT THE CROSS-SECTIONAL DATA, AND WE'LL BE ABLE TO LOOK AT THE INDEPENDENT JOINT AND INTERACTIVE EFFECTS, USING FULL INFORMATION MAXIMUM LIKELIHOOD MODELING DATA AND INCLUDE MULTI-VARIATE REGRESSION MODELS HARMONIZED BETWEEN COHORTS, AGE, SEX, RACE/ETHNICITY AND SITES. WE HAD 1400 AND CHANGE PARTICIPANTS THE COHORTS AGREED TO PARTICIPATE IN THE GIS PART OF THE PEPR CONSORTIUM. WE HAVE TWO SITES THAT HAVE ASTHMA. BOTH RECRUITED FROM BOSTON CHILDREN'S HOSPITAL AS WELL AS MEDICAL COLLEGE OF WISCONSIN, AS WELL AS SICKLE CELL DISEASE, TYPE 1 BY DIABETES FROM UNIVERSITY OF WISCONSIN, DERMATITIS, CANCER SURVIVORS IN GREEN, BLUE DOTS MULTI-DISEASE COHORT. AND THE REST OF THE DATA DOESN'T HAVE THE NORTHWESTERN GROUP INCLUDED, THE NUMBERS AND ANALYSES WILL CHANGE IN JANUARY WHEN WE INCORPORATE THE DATA FROM THERE. BUT IN TOTAL WE'LL HAVE 1453 PARTICIPANTS, THIS DATA FOR THESE MEASURES INCLUDES 1200 PARTICIPANTS, SO AS YOU'VE SEEN LOTS OF DIVERSITY IN TERMS OF AGE, A LITTLE BIT MORE MALE PREDOMINANT AT 54%, 34% AFRICAN-AMERICAN, 35% HISPANIC, AND THEN PRETTY NICE DIVERSE RANGE OF DISEASE PROCESSES. SO THE REST OF THE PRESENTATION I'LL FOCUS MOSTLY ON THE DEPRIVATION IN CRIME. PEOPLE'S HEADS SPIN IF I USE TOO MANY GEOMARKERS. THIS IS COMMUNITY DEPRIVATION INDEX ON THE LEFT BY DISEASE PROCESS. CAN YOU SEE THERE'S A STATISTICALLY SIGNIFICANT DIFFERENCE IN TERMS OF MEDIAN DEPRIVATION DISEASE, CERTAINLY DEPRIVATION AND CRIME ARE CORRELATED BUT IT'S NOT 1:1 SO THERE'S LOTS OF THINGS WE CAN LEARN BY LOOKING AT THEM, BOTH INDEPENDENTLY AS WELL AS THE INTERACTIVE EFFECT. THIS IS A CORRELATION COEFFICIENT FOR THE PROMIS CHILD T-SCORES BY GEOMARKERS, SO THE COLORS, DARKER COLOR RECOMMENDS A LITTLE BIT MORE STRONGLY CORRELATED, BOTH IN THE NEGATIVE IN BLUE AND POSITIVE IN RED, AND THE DOTTED LINES ARE SORT OF HYPOTHESIZED RELATIONSHIPS, SO PEER RELATIONSHIP, MOBILITY, YOU WOULD SEE INVERSE FROM THE OTHER PROMIS MEASURES. SO DEPRIVATION INDEX WE FOUND NEGATIVE .2, MORE DEPRIVED, LESS MOBILE, OPPOSITE FOR PAIN INTERFERENCE. AND THEN SORT OF WEAKER CORRELATIONS FOR TOTAL CRIME, GREEN SPACE, AND THEN DISTANCE TO CARE, THE RELATIONSHIP SURPRISED ME THAT IT SEEMS AT LEAST PRELIMINARILY THOSE THAT ARE FURTHER FROM THE CARE SITE MAY HAVE MORE POSITIVE PROMIS MEASURES, IF YOU WILL. THIS IS SHOWING MULTIVARIATE REGRESSION, ADJUSTED FOR THE RACE, EFFECT SIZE IS IN THE HYPOTHESIZED DIRECTION, THE TWO THAT CAME OUT IN TERMS OF BEING STATISTICALLY SIGNIFICANT WERE MOBILITY AND PAIN. I'VE LEARNED A LOT TODAY IN TERMS OF POTENTIALLY FUTURE DIRECTIONS FOR THE T-SCORES AND NATIONAL -- SORRY, PERCENTILE RANK. SO FAR THIS IS REPRESENTING T-SCORES. SO FOR EACH DECREMENT IN AREA DEPRIVATION INDEX

THERE'S 7.1 -- FOR EACH INCREASE IN AREA DEPRIVATION INCREEKS, 7.1 DECREMENT IN MOBILITY. AND 11-POINT INCREASE IN PAIN. TOTAL CRIME WAS SMALLER EFFECT SIZE, MOBILITY AND FATIGUE SORT OF SEEMED TO RISE TO THE TOP IN TERMS OF THIS STATISTICAL SIGNIFICANCE. AND I SHOULD SAY THERE'S A LOT MORE ANALYSIS IN EVALUATION OF THE DATA BECAUSE WHEN WE LOOKED BEFORE WE WERE ABLE TO MERGE THE COHORTS, CRIME FOR OUR INNER CITY ASTHMA COHORT ACTUALLY WAS SORT OF MUCH MORE SIGNIFICANT IN MANY OF THESE DOMAINS SO I THINK THERE'S A LOT OF INTERESTING RELATIONSHIPS THAT WE CAN GLEAN FROM LOOKING SORT OF BY DISEASE AS WELL. BUT THIS IS POOLED. THIS IS AGAIN HOSPITALIZATIONS OVER TIME, BY QUARTILES OF CRIME. SO THOSE THAT WERE IN THE HIGHEST QUARTILE BY CRIME HAD 3.0 TIMES HIGHER ODDS THAN THOSE THAT WERE IN THE LOWEST QUARTILE FOR CRIME PERCENTILES NATIONALLY. AND IT SURPRISED ME THIS WAS MORE PROFOUND THAN AREA DEPRIVATION, I WANTED TO HIGHLIGHT WHAT WE HAVE SO FAR. AND SO A LITTLE BIT, I THOUGHT I WOULD -- I'M SHORT ON TIME BUT I TALK FAST. WE DID -- ACCOMPLISHED FOUR DATA USER AGREEMENTS OVER THE LAST 12 MONTHS, INCLUDING SEVEN COHORTS, SIX DISEASES, FOR THE STUDY, AND I THINK THERE'S A LOT MORE THAT WE CAN LEARN AND I HAVEN'T SHOWN THE GREEN SPACE AND TRAFFIC PROXIMITY BUT SIMILAR FINDINGS WERE SEEN IN THOSE GROUPS. THIS IS CROSS-SECTIONAL WITH SOME LIMITATIONS ESPECIALLY AROUND HOSPITALIZATION AND DIFFERENT PROMIS MEASURES THAT WERE INCLUDED, SOME COHORTS, NOT THE OTHERS, AND I THINK THERE'S A LOT MORE DATA TO DO, DATA ANALYSIS TO ACCOMPLISH. SO, IN THE IMMEDIATE SHORT-TERM FUTURE I'M GOING TO SUBMIT THIS HOPEFULLY, DUE IN EARLY JANUARY, AND THEN FOCUSING REALLY ON THE INDEPENDENT AND JOINT EFFECTS OF THESE GEOMARKERS AND POSSIBLY CREATING AGGREGATE SCORE, FOR THE SHORT-TERM GOALS. AND I APPLIED FOR K23 AWARD IN JUNE OF LAST YEAR TO THE NIEHS AND WAS COMPETITIVELY SCORED, SO MORE TO COME. [APPLAUSE]

>> ONE LAST THING, THANK YOU TO EVERYONE IN THE ROOM. I MAY HAVE OMITTED SOMEONE THAT I DIDN'T MEAN TO, BUT FROM WANDA BEING MY PRIMARY MENTOR TO CHRIS FROM THE BEGINNING AND JULIE BEING A WONDERFUL PARTNER IN WISCONSIN, AND EVERYONE ELSE, THANK YOU.

>> TERRIFIC, MARISSA. A COUPLE QUESTIONS, COMMENTS? WE'RE STARTING TO LOSE PEOPLE HERE. YES.

>> [OFF MICROPHONE].

>> THE QUESTION IS I DIDN'T SEE DATA ELEMENT GEOMARKER FOR ACCESS TO PUBLIC TRANSPORTATION OR BARRIERS. SO EACH OF THESE, I MAKE IT SEEM EASY THAT, YOU KNOW, THAT WITH THE PARTNERSHIP WE WERE ABLE TO DEVELOP GEOMARKERS.EACH ARE TIME INTENSIVE, SO WE HAD TO PRIORITIZE, WE HAD TO START SOMEWHERE IN TERMS OF DEVELOPING ON THE BACK END GEOMARKERSES THAT COULD BE DEPLOYED EASILY. I THINK I REMEMBER THAT QUESTION FROM BEFORE, AND I THINK JUST FEASIBILITY IN TERMS OF ACCESS WE WEREN'T AT THIS POINT ABLE TO ACCOMPLISH THAT BUT I THINK --

>> [OFF MICROPHONE].

>> YES, IN MY K, I'LL GET THERE.

>> ARE YOU THINKING ABOUT WRITING AN ARTICLE THAT TALKS ABOUT THE INTEGRATION OF ENVIRONMENTAL DATA WITH PATIENT-REPORTED OUTCOMES?

>> YES. SO I WOULD LOVE FOLKS' FEEDBACK. THE FOLKS ON THE SLIDE, MANY OF THEM HAVE BEEN WONDERFUL, SORT OF SOUNDING BOARDS OVER THE LAST YEAR IN TERMS OF MONTHLY MEETINGS, AND REALLY UNDERSTAND THE DATA. I THINK MY FIRST PATH IS PROBABLY GOING TO BE LIKE A PAPER ON CRIME AND DEPRIVATION, A SECOND PAPER ON GREENSPACE AND TRAFFIC, AND THEN ACCESSIBILITY. AND THEN SORT OF SYNTHESIS PAPER POSSIBLY, BECAUSE I THINK, YOU KNOW, REALLY DIVING INTO THE LITERATURE OF THE BACKGROUND I THINK THERE'S MUCH WE LEARNED ON EACH OF THESE IN INDEPENDENT RELATIONSHIP AS WELL AS AGGREGATE. THAT'S HOW I'VE SORT OF OPERATIONALIZED THE WORK.

>> THANKS. OKAY. THE LAST PRESENTATION NOW, AND COULD YOU PRONOUNCE YOUR NAME. I DON'T WANT TO GET IT WRONG. THUY DAN TRAN. THANK YOU, THUY DAN TRAN, PRESENTING ON BEHALF OF ELIZABETH COX, AND HARALD KLIEMS. I THINK THIS IS RIGHT, HARALD, YOU WERE PRESIDENT OR PAST PRESIDENT OF THE MADISON BIKE CLUB?

>> I AM.

>> HARALD IS MY HERO. HE DON'T STOP BIKING EVEN IN POLAR VORTICES. HE'S BIKED IN MINUS 25-DEGREE WEATHER. FOR ALL OF YOUR WINTER BIKING NEEDS, SEE HARALD. AND YOU DON'T OWN A CAR, RIGHT? IT CAN BE DONE IN THE UNITED STATES. THIS IS THE MAN TO TALK TO. YEAH, EVEN IN MADISON, WHERE I UNDERSTAND THEY PLOW THE BIKE TRAILS BEFORE THE ROADS. SOMETIMES, OKAY.

Guidance for use of pediatric PROMIS in ambulatory clinics

Harald Kliems

Thuy Dan Tran

>> ALL RIGHT. THANKS, EVERYONE, FOR COMING TODAY AND SHARING YOUR PRESENTATIONS. I'LL BE BRIEF BECAUSE SOME OF YOU HAVE TO CATCH SOME FLIGHTS. AGAIN WE'RE FROM THE UNIVERSITY OF WISCONSIN, MADISON, HERE TO PRESENT ON THE IOF PROJECT LED BY DR. ELIZABETH COX, GUIDANCE FOR USE OF PEDIATRIC PROMIS MEASURES AND AMBULATORY CLINICS. SO AS WE KNOW PROMIS PRESENTS AN OPPORTUNITY TO MEASURE PATIENT-REPORTED OUTCOMES IN A CONSISTENT VALIDATED MANNER. HOWEVER UPTAKE AND PEDIATRIC AMBULATORY SETTINGS HAS BEEN LIMITED. SO THERE'S GUIDANCE THAT EXISTS ON THE CLINICAL USE OF PRO SUCH AS ISOQOL AND PCORI, NOT SPECIFIC TO PEDIATRICS OR PROMIS. IDENTIFYING GAPS SUCH AS CONCERNS ABOUT INTERPRETING SCORES OR TALKING ABOUT SCORES WITH FAMILIES COULD FOSTER USE INTO CLINICAL PRACTICE. FURTHER, USE ACROSS TO ADULT CARE. GOAL TO REDUCE GUIDANCE. I'LL FOCUS ON PROVIDING HEALTHCARE SYSTEM NEEDS FOR SUCCESSFULLY IMPLEMENTING PROMIS IN PEDIATRIC AMBULATORY SETTINGS. SO FOR THIS PROJECT WE HAD THREE MAIN OBJECTIVES OF WHICH THE FIRST TWO HAVE BEEN COMPLETED, THE FIRST WE SUMMARIZE EXISTING GUIDANCE AND LITERATURE ABOUT THE CLINICAL USE OF PROMIS. ITS LIMITATIONS WITH REGARD TO PEDIATRIC POPULATIONS AND ANY POTENTIAL GAPS THAT NEED TO BE ADDRESSED. AND THE SECOND OBJECTIVE WE CONDUCT QUALITATIVE INTERVIEWS TO UNDERSTAND WHAT KEY TOPICS SHOULD BE INCLUDED. LASTLY CREATE GUIDANCE RESPONSIVE TO IDENTIFIED KEY TOPICS WITH -- IN COLLABORATION WITH PEPR MEMBERS AND EXPERTS, TO BE PUBLISHED AS PEER-REVIEWED ARTICLE IN A PEDIATRIC JOURNAL, THAT'S WHAT

WE'RE WORKING TOWARDS. THE GUIDANCE IS INTENDED FOR HEALTHCARE SYSTEM LEADERS, THOSE WHO OPERATIONALIZE PROMIS, CHAMPIONS. WE HAVE SEVEN EXPERTS IN PEDIATRIC HEALTHCARE QUALITY MEASUREMENT. STEERING COMMITTEE PROVIDED FEEDBACK THROUGHOUT THE PROJECT FROM SUGGESTING POTENTIAL INTERVIEWEES AND GUIDANCE, VETTING FINAL TOPICS AND REVIEW THE GUIDANCE BEFORE FINAL SUBMISSION. THESE ARE THE MEMBERS. TWO ARE IN THE ROOM, THANK YOU VERY MUCH. WE WILL MEET THREE TIMES DURING THIS PROJECT SO WE HAVE ONE MORE MEETING COMING UP. AND THEN MOVING ON TO THE OBJECTSIVE ONE, THE REVIEW OF AVAILABLE GUIDANCE, SO THE PROJECT TEAM REVIEWED EXISTING LITERATURE AND RELEVANT WEBSITES SUCH AS HEALTH MEASURES TO SYNTHESIZE INFORMATION OUT THERE AND IDENTIFY GAPS. WHAT WE FOUND IS THAT ALTHOUGH THERE'S LITERATURE OUT THERE ON THE CHALLENGES TO THE USE OF PROs AND PROMIS IN CLINICAL PRACTICE WE'VE NOT IDENTIFIED GUIDANCE FOR USE OF PROMIS SPECIFICALLY IN AMBULATORY PEDIATRICS. THERE'S GUIDANCE FOR THE USE SUCH AS ISOQOL BUT GEARED TO THE GENERAL PUBLICATION AND OTHERS LIKE GERHARDT'S IS GOING USED BUT NOT PROMIS SPECIFIC. THERE'S SOME ARTICLES THAT DISCUSS USE OF PROMIS IN PEDIATRIC POPULATIONS, THOSE ARE IN FORMS OF CASE STUDIES OR FEASIBILITY STUDIES, AND OTHER RESEARCH FOCUSED IMPLEMENTATIONS, THESE MATERIALS CONTAIN LIMITED INFORMATION TO UNDERSTAND THE CONTEXT OF THE PROMIS IMPLEMENTATION, OR TO SUPPORT HEALTH SYSTEMS IN OVERCOMING CHALLENGES TO PROMIS USE, IN PEDIATRIC AMBULATORY CLINICAL SETTING. SO THIS MOVES US TO OBJECTIVE 2, CONDUCTING THE QUALITATIVE INTERVIEWS, INTERVIEWS GUIDE AND SOLICITING INTERVIEWEES WAS INFORMED BY LITERATURE REVIEW AND STEERING COMMITTEE INPUT, WE INTERVIEWED 18 HEALTH SYSTEM LEADERS, PRO IMPLEMENTERS AND AMBULATORY PEDIATRIC PROVIDERS. IF YOU INCLUDED END USERS OF THOSE USING PROMIS AND IMPLEMENTING OR WISH TO IMPLEMENT IT. SO FROM HERE INTERVIEWS WERE TRANSCRIBED, CODED NVIVO, USING 21 CODES FROM INITIAL CODING OFFIVE INTERVIEWS. FROM HERE WE FOUND THERE ARE MANY FACTORS THAT INFLUENCE CLINICAL USE GUIDANCE CAN ADDRESS THESE SUCH AS STAFF NEEDED, IMPLEMENTATION, INTEGRATING INTO ELECTRONIC HEALTH RECORD, OR DOING A FEASIBILITY ASSESSMENT. SO WE TRIED TO NARROW THIS DOWN, 21 CODES TO SIX SPECIFIC TO PEDIATRIC AND PROMIS. SO THESE WERE THE SIX THAT WE HAVE WHICH INCLUDE MODE OF PROMIS ADMINISTRATION, OPTIMIZING RESPONSE RATES FOR CHILDREN AND PARENTS, USING CAT TO REDUCE SURVEY BURDEN AND INCREASE RELEVANCY OF MEASURE. NEXT IS CONFIDENTIALITY OF RESPONSES WITH CONTEXT ABOUT HOW A CHILD AND ADOLESCENT DATA IS KEPT PRIVATE, IN STORAGE AND FOR CLINICAL USE. THIRD IS SELECTION OF MEASURES OF ADMINISTRATION, WHICH OUTLINES APPROACHES TO CHOOSING MEASURES THAT WORK ACROSS THE AGE SPECTRUM AND FOR SPECIAL POPULATION SUCH AS CHILDREN WITH DIFFERING ABILITIES. USE OF PROMIS PROXY MEASURES, WHAT STRATEGIES THERE ARE TO ENSURE THE DATA IS FROM THE DESIRED RESPONDENT, PUTTING INTO CONSIDERATION SPECIAL POPULATIONS AGAIN THAT WOULD PERSUADE USE OF PROXY MEASURES. SCORING AND INTERPRETATION OF PROMIS, A VARIETY OF PEDIATRIC POPULATIONS, INCLUDING INTERPRETATION OF DATE OVR TIME. IT WILL POINT OUT HOW PROVIDERS CAN INTERPRET DIFFERENCES BETWEEN PROXY AND SELF REPORT. AND THE LAST TOPIC IS USING PROMIS SCORES CLINICALLY, ASKING THE QUESTIONS HOW CAN PROVIDERS USE PROMIS SCORES TO INFORM CLINICAL PRACTICE AND DECISION MAKING, WHAT KIND OF TRAINING AND TOOLS ARE AVAILABLE TO PREPARE PROVIDERS AND CLINIC STAFF TO USE PROMIS IN CLINICAL PRACTICE, WHAT MECHANISMS CAN PROMOTE OR PROVIDE FEEDBACK ABOUT USE OF PROMIS SCORES BY PROVIDERS. AND THEN AS WE'VE MENTIONED THROUGHOUT TODAY AND EARLIER IN THESE TOPICS, WE RECOGNIZE THERE'S SPECIAL POPULATIONS THAT HAVE

DIFFERENT CHALLENGES AND SOLUTIONS IN EACH TOPIC SUCH AS MINORITY LANGUAGE, SOCIOECONOMIC STATUS, DIFFERING ABILITIES, WE'VE ENCOURAGED WRITERS TO PUT THIS INTO THEIR TOPICS AND MAKE THIS INTO A CONSIDERATION. THIS MOVES US TO OUR CURRENT STATE, THE NEXT STEPS, WHICH IS OBJECTIVE THREE, WRITING AND DISSEMINATING GUIDANCE. CURRENTLY WE HAVE CONTENT EXPERTS FOR EACH OF THE SIX TOPIC FROM REACHING OUT TO STEERING COMMITTEE MEMBERS AND PEPR BROADLY AS WELL AS OUR OWN RESEARCH AND FROM INTERVIEWS. CURRENT TIMELINE TO WRAPPING UP, WE'RE IN A CYCLE OF DRAFT AND REVISION WITH THE AUTHORS, COMPILING ALL TOPICS BETWEEN NOW AND FEBRUARY, WE RECEIVED ALMOST ALL OF THE FIRST DRAFTS FROM OUR AUTHORS WHICH IS EXCITING, AND THEN WE'LL PROVIDE THE AUTHORS AND STEERING COMMITTEE COMPILED DRAFTS FOR APPROVAL IN MARCH, ANTICIPATION OF SUBMITTING BY APRIL OF 2020. THANK YOU. DOES ANYBODY HAVE ANY QUESTIONS? [APPLAUSE]

>> YOU HEAR A LOT ABOUT INTEREST IN DISSEMINATING AND IMPLEMENTING PROMIS MEASURES IN CLINICAL PRACTICE AND CLINICAL TRIALS. GIVEN WHAT YOU WILL PRODUCE WITH THIS PROJECT, WHAT DO YOU THINK THE GAPS ARE GOING TO BE THAT WE SHOULD FILL IN GOING FORWARD?

>> HARALD?

>> SURE, I CAN SPEAK TO THAT. YEAH, THIS GUIDANCE IS REALLY GOING TO BE FOCUSED ON CLINICAL USE IN THE AMBULATORY SETTING, GOING TO BE PEER-REVIEWED ARTICLE WHICH POSES LIMITATIONS, WE TALKED ABOUT WHITE PAPERS AND EXAMPLES THAT THUY DAN MENTIONED, PATIENT-REPORTED OUTCOMES, 50-PAGE DOCUMENT WHICH GOES INTO DETAIL, THAT IS I THINK NEEDED IF YOU REALLY WANT PEOPLE TO ADOPT THESE MEASURES IN CLINICAL USE. I I THINK THERE'S A LONG WAY TO GO BASED ON WHAT WE HEARD IN INTERVIEWS WITH TECHNICAL CONCEPTUAL PROBLEMS HOW DOES IT FIT INTO THE WORKFLOW, WHAT DO WE KNOW ABOUT HOW TO INTERPRET THESE MEASURES, HOW DO WE MAKE SURE THAT WHEN TRANSITIONS HAPPEN FROM PROXY REPORT, SELF REPORT, WHEN TRANSITIONS HAPPEN FROM PEDIATRIC MEASURES TO ADULT MEASURES, HOW DO I AS A PROVIDER INTERPRET THAT. SO I THINK THERE'S STILL A LOT TO BE DONE. SO I WAS VERY HAPPY TO HEAR THAT I THINK THAT IS SOMETHING THAT NEEDS LIKE SOME PROJECT TO MOVE THAT FORWARD.

>> THIS WOULD BE -- THIS WOULD BE TERRIFIC PRELIMINARY DATA FOR THE DNI GRANT I THINK WE'RE GOING TO HAVE TO WRITE. YEAH, ELLEN?

>> I DON'T KNOW HOW COMMON DAY HOSPITALS ARE ACROSS PEDIATRICS. I KNOW IN SICKLE CELL THEY ARE PRETTY POPULAR FOR KIDS WHO ARE TOO SICK TO GO TO SCHOOL BUT CAN, YOU KNOW, BE IN A DAY HOSPITAL. WOULD YOU CONSIDER AFTER THIS IS DONE TO ADDRESS DAY HOSPITALS AND SEE IF YOU CAN DEVELOP THESE MEASURES IN THAT SETTING?

>> I MEAN, MAYBE MORE GENERALLY SPEAKING. I MEAN, THERE ARE DIFFERENT SETTINGS WHERE PEOPLE RECEIVE CARE. THIS BEING ONE OF THEM. PRIMARY CARE, COMMUNITY-BASED CARE. AND I MEAN I'M NOT SURE IF I CAN ANSWER THE QUESTION, HOW DIFFERENT THEY ARE, AND HOW DIFFERENT CONSIDERATIONS ARE FOR IMPLEMENTING THOSE MEASURES. PROBABLY THEY ARE DIFFERENT. THEY SERVE DIFFERENT POPULATIONS. AND SO, YEAH, THERE'S STILL LOTS OF GROUND TO BE COVERED.

>> SO, DO YOU CONSIDER TO PUT GUIDELINES, OR HEALTH MEASURE NETWORK WEBSITE, BECAUSE WE IN HEALTH MEASURE, WE HAVE THE PEDIATRIC, THE RECOMMENDED MEASURES FOR SPECIFIC

PEDIATRIC DISEASE. SO NOW WE HAVE (INDISCERNIBLE). GREAT TO HAVE ALL THESE RESOURCES CONNECTED TO EACH OTHER.

>> YEAH, I THINK THE PEER-REVIEWED PUBLICATION IS LIKE THE FIRST STEP, TAKING THAT TO CONFERENCES, WE HAVE TALKED, THEY ARE INTERESTED IN DISSEMINATING, GETTING THE WORD OUT. LET'S GET THE PAPER TOGETHER AND THEN WE'LL SPREAD THE WORD AROUND IT.

>> ANY OTHER QUESTIONS? THUY DAN, THANK YOU VERY MUCH.

>> THANK YOU. [APPLAUSE]

>> AND THAT APPLAUSE IS NOT ONLY FOR THE PRESENTATION BUT FOR EVERYBODY WHO STUCK IT OUT TO THE BITTER END. JIM AND I HAD TO BE HERE.

>> I JUST HAVE A QUICK QUESTION BEFORE NIH LEAVES. SO, THIS IS AN AMAZING AMALGAMATION OF DATA AND LIKE OPPORTUNITY. IS THERE ANY PLAN IN THE FUTURE FOR SOME TYPE OF RFA OR SUPPORT TO CONTINUE SUPPORT SOME OF THE DATA CLEANING AND ANALYSIS? I MEAN LIKE IF MARISA GETS THE K, SHE HAS A LIFETIME OF WORK AHEAD OF HER WITH THE GIS. I'M LISTENING TO THIS.

>> WE HOPE SO.

>> OKAY. ALL RIGHT. RIGHT? DON'T YOU THINK, CHRIS?

>> PART OF THE REASON FOR THE FUTURE DIRECTIONS IS JIM'S DIABOLICAL PLAN TO PUT TOGETHER SOMETHING THAT HE CAN THEN SHARE, AND YOU JUST NEVER KNOW WHAT COMES UP. END OF THE YEAR FUNDS, THAT SORT OF THING.

>> YEAH.

>> IT'S GOING TO BE OPPORTUNISTIC.

>> I THINK THERE'S AMAZING OPPORTUNITY.

>> WE'VE GOT TO TALK ABOUT THE WEBSITE IN THE LAST FEW MEETINGS, WE'VE ACTUALLY UPGRADED IT, SO IT WOULD BE NICE TO EMPOWER EACH OF THE CENTERS TO BE ABLE TO UPDATE IT FOR THAT'S WHAT WE WANT TO TALK ABOUT IN JANUARY. ALL RIGHT. THANK YOU, EVERYBODY. IT WAS A PLEASURE HAVING THIS MEETING. THANK YOU, JIM, JULIA, AND JANA IN PARTICULAR, AND COURTNEY FOR YOUR GREAT ORGANIZING. JULIA, I NOTICE THE BOXES HAVE YOUR NAME ON THEM IN CASE YOU WANT TO TAKE THEM HOME. THANKS VERY MUCH. SAFE TRAVELS, EVERYBODY.