

>> GOOD MORNING TO EVERYONE JOINING THE WEBINAR.

WE'RE JUST WAITING FOR PEOPLE TO ENTER THE MEETING ROOM AND WE'LL GET STARTED IN A COUPLE MINUTES.

WHY DON'T WE GET GOING SO WE CAN GET THROUGH THE ENTIRE PANEL, PLANS FOR YOU ALL TODAY. HELLO, GOOD MORNING.

AND WELCOME TO THIS WEBINAR.

I'M SARAH WHITE EXECUTIVE DIRECTOR OF THE MULTI-REGIONAL CLINICAL TRIAL CENTER OF BRINGING AND WOMEN'S HOSPITAL AND IF WE GO TO THE NEXT SLIDE, THIS SESSION ON THE PROMISE OF PLAIN LANGUAGE AND OUR LAUNCH OF A GLOSSARY CREATED TO SUPPORT PARTICIPANT UNDERSTANDING IN CLINICAL RESEARCH.

NEXT SLIDE.

AND WE CAN GO TO ONE MORE SLIDE.

YOU'RE GOING TO GET A CHANCE TO MEET ALL OF THESE PEOPLE IN A VERY SHORT PERIOD OF TIME. SO OUR PLAN OVER THE NEXT HOUR IS TO PROVIDE NOT ONLY AN OVERVIEW OF THE MRCT CENTER'S CLINICAL RESEARCH GLOSSARY PROJECT BUT ALSO A SNEAK PEAK OF THE GLOSSARY WEBSITE ITSELF. AND PERHAPS MOST IMPORTANTLY, WE HAVE A PANEL OF EXPERTS WITH US TODAY TO PROVIDE THEIR THOUGHTS ON THE IMPORTANCE OF USING PLAIN LANGUAGE TERMINOLOGY AND THEY WILL WEIGH BENEFITS AND CHALLENGES OF A COMMON HARMONIZED RESOURCE AND DISCUSS BE OPPORTUNITIES TO INTEGRATE THE GLOSSARY INTO THE ORGANIZATIONAL PROCESS.

NEXT SLIDE, PLEASE.

FOR THOSE WHO AREN'T FAMILIAR WITH THE MRCT CENTER WE'RE A CENTER FOCUSED ON ADDRESSING THE CONDUCT, OVERSIGHT, ETHICS AND REGULATORY ENVIRONMENT OF GLOBAL CLINICAL TRIALS.

NEXT SLIDE.

OUR VISION IN OUR WORK IS TO IMPROVE THE INTEGRITY, SAFETY, AND RIGOR OF GLOBAL CLINICAL TRIALS AND WE DO OUR WORK BY ENGAGING AND CONVENING A MULTI-STAKEHOLDER GROUP OF EXPERTS INCLUDING INDUSTRY, ACADEMIA, GOVERNMENT, NONPROFIT ORGANIZATIONS, AND PATIENT TO PATIENT ADVOCATES TO DEFINE EMERGING ISSUES AND CREATE AND IMPLEMENT ETHICAL ACTIONABLE AND PRACTICAL SOLUTIONS.

AND OVER THE PAST DECADE THE MRCT CENTER'S EFFORTS HAVE RESULTED IN THE IMPLEMENTATION OF BEST PRACTICES, GREATER TRANSPARENCY, AND IMPROVED SAFETY FOR RESEARCH PARTICIPANTS.

NEXT SLIDE.

THE MRCT CENTER HAS BEEN COMMITTED TO HEALTH LITERACY FOR QUITE SOME TIME NOW.

IN 2019 WE COMPLETED A MULTI STAKEHOLDER INITIATIVE FOCUSED ON MAKING IMPACTFUL CHANGE RELATED TO HEALTH LITERACY IN CLINICAL RESEARCH.

AND ONE OF THOSE DELIVERABLES WAS THE HEALTH LITERACY AND CLINICAL RESEARCH WEBSITE.

A SECOND EXAMPLE OF OUR WORK INCLUDES A SET OF PAMPHLETS DEVELOPED IN THE SPRING OF 2020 RELATED TO COVID-19 CLINICAL RESEARCH AND OVER THE LAST YEAR THE MRCT CENTER HAS DESIGNED AND DELIVERED CLINICAL RESEARCH FOCUSED HEALTH LITERACY TRAININGS FOR A NUMBER

OF DIFFERENT ORGANIZATIONS AND GROUPS.

WE REMAIN COMMITTED TO KEEPING THE PATIENT FRONT AND CENTER IN OUR WORK, WE RECOGNIZE THAT PATIENTS AND PARTICIPANTS NEED TO UNDERSTAND WHAT'S BEING SAID TO THEM AND THAT WE ALL NEED TO SPEAK AS CLEARLY AS WE CAN.

WITH THAT INTRODUCTION, I'D LIKE TO PASS IT OVER TO SYLVIA BAEDORF KASSIS WHO'S THE PROGRAM MANAGER LEADING THE HEALTH LITERACY WORK AT THE MRCT CENTER.

OVER TO YOU, SYLVIA

>> THANKS FOR THAT INTRODUCTION AND WE CAN GO TO THE NEXT SLIDE.

I'VE HAD THE PLEASURE ON WORKING ON CLINICAL RESEARCH OVER LAST THREE AND A HALF YEARS AND EVEN BEFORE WE STARTED THIS WORK, RIGHT BEFORE WE LAUNCHED THIS PROJECT ON HEALTH LITERACY AND CLINICAL RESEARCH, WE'VE BEEN WORKING ON RETURN OF RESULTS AND MAKING SURE PLAIN LANGUAGE SUMMARIES OR LAY STUDIES AT THE END OF STUDIES WERE CLEAR AND UNDERSTANDABLE.

THAT'S WHEN HEALTH LITERACY CAME INTO OUR VISION AND OUR THINKING, AND WE IDENTIFIED WITH OUR WORK GROUP OF MEMBERS WHO WERE INVOLVED IN THE HEALTH LITERACY AND CLINICAL RESEARCH PROJECT A NEED FOR A WIDELY ACCESSIBLE PLAIN LANGUAGE PARTICIPANT FRIENDLY RESEARCH GLOSSARY.

WE DID A LANDSCAPE REVIEW AND KNOW THERE ARE MANY DIFFERENT TYPES OF GLOSSARIES OUT THERE ALREADY.

MEDICAL AND HEALTH RELATED GLOSSARIES, DISEASE SPECIFIC GLOSSARIES A VERSIONS OF DIFFERENT TYPES OF INFORMATION OUT THERE.

NONE WERE IN PLAIN LANGUAGE DESIGNED FOR PARTICIPANTS AND PATIENTS IN PARTICULAR AND WERE SORT OF IN THIS NOTION OF PLAIN LANGUAGE AND RESEARCH FOCUSED, CLINICAL RESEARCH FOCUSED.

SO WE REALLY WANTED TO MOVE TOWARDS HARMONIZING DEFINITIONS ACROSS THE INDUSTRY TO BE ABLE TO PROMOTE A UNIFIED APPROACH TO BEST SUPPORT PATIENTS, PARTICIPANTS AND CAREGIVERS BUT ALSO ARGUE THAT HAVING A UNIFIED APPROACH AND COMMON LANGUAGE THAT WE USE HELPS TO BUILD TRUST IN RESEARCH AND BUILDS GREATER TRANSPARENCY IN THE RESEARCH PROCESS.

WE'VE SEEN THAT OVER THE LAUGH YEAR AND A HALF PEOPLE WANT TO UNDERSTAND RESEARCH BETTER AND IF WE ARE ABLE TO START THE GROUND FLOOR WITH MORE UNDERSTANDABLE LANGUAGE BEING USED, MORE COMMONLY ACROSS THE RESEARCH ECOSYSTEM, THAT'S A GREAT PLACE TO START.

ON THE NEXT SLIDE I'LL NOTE A LITTLE BIT ABOUT THE PILOT ITSELF AND BACKGROUND.

WE STARTED LAST SUMMER IN THE SUMMER OF 2020 AND BROUGHT TOGETHER A GROUP OF INDIVIDUALS, ABOUT 27 OF US IN THE END, WHO WERE REPRESENTATIVE OF VARIOUS DIFFERENT STAKEHOLDERS ACROSS THE RESEARCH ECOSYSTEM.

I'LL NOTE THERE THAT THERE'S AT LEAST A THIRD WAS PATIENTS AND PATIENT ADVOCATES AND OTHERS FROM NONPROFITS AND ACADEMIA, MEDICAL WRITING REPRESENTATIVES, LIFE SCIENCE COMPANIES THAT WERE REPRESENTED, AND INDEPENDENT CONSULTANTS AS WELL WHO WORKED THROUGHOUT THE RESEARCH INDUSTRY AND ARE FAMILIAR WITH SOME OF THE CHALLENGES OF THE COMMON VERNACULAR.

WHAT WE DID IN THE PILOT WAS FOCUS ON CO-CREATING DEFINITIONS WITH PATIENTS AND PARTICIPANTS AT THE TABLE FROM THE BEGINNING.

WE FOCUSED ON DESIGNING FOR PUBLIC UNDERSTANDING IN TERMS OF THE SENTENCES, DEFINITIONS THEMSELVES BUT ALSO EVENTUALLY THE INTERFACE THAT WE'RE PUTTING FORTH.

AND ONE OF THE BIGGER POINTS AND CHALLENGES PERHAPS OR OPPORTUNITIES WAS TRYING TO FIND DEFINITIONS THAT WE COULD AGREE UPON THAT WERE ACCEPTABLE TO INDUSTRY AND ACADEMIC STAKEHOLDERS, SORT OF FROM A REGULATORY AND ACCURACY PERSPECTIVE, BUT ALSO COMPLETELY UNDERSTANDABLE OR ACCESSIBLE TO PATIENTS, PARTICIPANTS AND THE PUBLIC.

YOU CAN LEARN MORE ABOUT THE PILOT FOUNDATIONS AT THIS LINK BELOW THERE'S AN ARTICLE THERE IN THE EUROPEAN MEDICAL WRITING ASSOCIATION JOURNAL THAT FOCUSES A LITTLE BIT ABOUT THIS PILOT AND THE BACKGROUND.

ON THE NEXT SLIDE I'LL JUST NOTE AS YOU SAW IN THAT PIE CHART THERE WAS ALL OUR STAKEHOLDER GROUPS, BY GROUP, HERE I JUST CALL OUT THE INDIVIDUAL NUMBERS JUST FOR A MOMENT TO EXTEND A WARM THANKS TO THIS AMAZING, FANTASTIC, WONDERFUL TEAM OF COLLABORATORS WHO SPENT SIX MONTHS WITH ME LAST YEAR DURING A GLOBAL PANDEMIC GETTING TOGETHER REGULARLY TO DEFINE TERMS AND HAVE REALLY INTERESTING AND WARM DISCUSSIONS ABOUT THESE DEFINITIONS AND TERMS AND I CAN SAY PERSONALLY THIS WAS A REALLY BRIGHT SPOT IN MY YEAR LAST YEAR BEING ABLE TO WORK WITH EVERYONE.

SO JUST A BIG SHOUT-OUT TO EVERYONE.

ON THE NEXT SLIDE I'LL SHOW YOU NOW THE BIT OF THE HIGH LEVEL OVERVIEW OF THE APPROACH WE TOOK TO THIS WORK IN THE BEGINNING BEFORE WE CONVENED WE SELECTED WORDS FROM VARIOUS PARTICIPANT-FACING MATERIALS AND EXISTING TECHNICAL GLOSSARY TO FIND SPECIFIC RESEARCH TERMS WE WANTED TO TRY TO FOCUS ON FOR THIS PILOT, RECOGNIZING THAT IT IS A PILOT. WE COULD NOT DEFINE EVERYTHING.

SO WE TRY TO AIM FOR ABOUT 50 AND GOT TO 53 THAT ENDED UP IN THE VERSION.

DURING THIS PROCESS WE USED AGILE METHODOLOGY, TO MOVE THROUGH REVIEWING THE DEFINITIONS AND MOVING THEM TO FINALIZATION SO WE COLLECTED FEEDBACK ON EACH OF THE DEFINITIONS THAT WERE DRAFTED INTERNALLY HERE AT THE MRCT CENTER AND SHARED WITH THE GROUP BY A CLOUD-BASED PROCESS TO COLLECT FEEDBACK FROM EVERYBODY IN THE WORKGROUP. SOME OF THOSE DEFINITIONS WE WERE ABLE TO LAND ON THROUGH THIS CLOUD-BASED PROCESS, BUT MOST I WILL SAY NEEDED TO MOVE TO A DISCUSSION PROCESS.

WE MOVED TO HAVING CONSENSUS CONVERSATION TOSS FINALIZE THE DEFINITIONS IN NOVEMBER AND DECEMBER AND IT WAS RIGHT BEFORE THE HOLIDAYS WE WERE ABLE TO WRAP UP OUR DEFINITIONS TOGETHER AND THAT WAS A REALLY NICE WAY TO END 2020.

AT THE BEGINNING OF 2021 UNTIL NOW WE'VE BEEN CREATING SUPPLEMENTAL INFORMATION AND THE WEB TEMPLATE YOU'LL HAVE TO CHANCE TO SEE AND ALSO FINALIZING THE WEBSITE IN PREPARATION FOR LAUNCH TODAY.

ALL THROUGHOUT THIS PROCESS, WE'VE BEEN ENGAGING PATIENTS AND PATIENT ADVOCATES TO PROVIDE FEEDBACK AND IMPRESSIONS AND CONDUCTING MINI ITERATIVE FEASIBLE TESTING SESSIONS TO BUILD OUT THE WEBSITE, TEST ITS FUNCTIONALITY AND USE AND ALSO RECOGNIZING THIS IS THE BEGINNING AND THIS ITERATIVE PROCESS DOESN'T END.

THERE'S NO ONE SIZE FITS ALL WHEN WE THINK ABOUT HEALTH LITERACY AND MAKING PARTICIPANT

FRIENDLY COMMUNICATIONS.

THERE'S ALWAYS THINGS TO BE LEARNED AND PROGRESS TO BE MADE SO WE WILL CONTINUE TO GROW AND DEVELOP THIS MOVING FORWARD.

SO ON THE NEXT SLIDE I'LL SHARE THAT I THINK THERE SHOULD BE ONE MORE SLIDE, I THINK, BUT MAYBE IT'S NOT HERE ANYMORE.

WHAT I WOULD JUST SAY FOR NEXT STEPS, THEN, I THINK I FORGOT IT WAS THE NEXT SLIDE BUT OUR GLOSSARY -- HERE'S THE URL.

THIS GLOSSARY IS HERE AND AVAILABLE NOW AND ON THE NEXT SLIDE YOU CAN SEE THAT THERE IS OUR HOME PAGE.

WHAT'S WONDERFUL ABOUT IT IS IT'S EASY TO COME IN START VIEWING THE WORDS OR SEARCHING THE MENU TO FIND WORDS.

ALONG THE TOP NAVIGATION BAR THERE'S AN ABOUT TAB WHERE YOU CAN LEARN MORE ABOUT THE BACKGROUND OF THE PROJECT AND WHO WAS INVOLVED AND THERE'S A PART WITH AN EXTERNAL GLOSSARY RESOURCES TAB AND THAT GIVES YOU MORE GLOSSARIES THAT ARE USEFUL AND MORE SPECIFIC, MORE DISEASE SPECIFIC OR CANCER, THERE'S SOME CANCER SPECIFIC GLOSSARIES AND MEDICAL AND HEALTH RELATED GLOSSARIES ALSO POTENTIALLY ABLE TO BE ACCESSED BUT WE WANTED TO MAKE SURE TO HAVE PLACE WHERE PEOPLE TO DIG FOR MORE SPECIFIC DEFINITIONS IF THEY WANTED TO BUT THE FOCUS OF THIS IS OUR GLOSSARY WORDS AND WE HAVE A NUMBER OF THE TERMS ON THE SITE.

WHEN YOU CLICK FORWARD TO THE NEXT SLIDE, IF YOU GO TO THE GLOSSARY WORDS AND SEARCH FOR SOMETHING LIKE INFORMED CONSENT, THIS WILL GIVE YOU THE OVERVIEW OF THE WORD. I'LL SAY, NOT REALLY EXPECTED TO READ ALL THE DETAILS RIGHT NOW.

OF YOU HAVE PLAIN LANGUAGE DEFINITION AND AN IMAGE INCLUDED WITH EACH TERM, A PRONUNCIATION, AUDIBLE OF THE WORD, THERE'S USE IN A SENTENCE.

MORE INFO FOR FOLKS WHO MIGHT WANT TO DIG DEEPER AND WORDS RELATED OR OPPOSITE WORDS WHERE THEY EXIST AND OTHER RESOURCES.

WHERE THERE MIGHT BE OTHER RESOURCES WE COULD POINT TO, FOR EXAMPLE, THE FDA HAS A GUIDE ON INFORMED CONSENT IN CLINICAL TRIALS WE POINT TO HERE.

AND ON THE NEXT ONE YOU CAN SEE WHERE WE DIDN'T INCLUDE IMAGES PER SE, SOMETIMES WE CREATED ACTUAL SCHEMATICS OR GRAPHICS OURSELVES TO TRY TO EXPLAIN THE TERM AND WHAT YOU'LL NOTE WHEN YOU GO ON THE SITE ITSELF, YOU CAN CLICK TO ENLARGE IMAGES AND MAKE THEM MORE VISUAL AND VISIBLE TO YOU.

SO THAT IS SOMETHING THAT YOU CAN USE ALSO FOR YOUR MATERIALS AND FOR UNDERSTANDING THE FUTURE.

SO ON THE NEXT SLIDE THERE'S THE NEXT STEPS THAT AT THIS WANTED TO SHARE WITH YOU EARLIER AND GOT AHEAD OF MYSELF.

WE'RE URGING COMMITMENT TO USING COMMON DEFINITIONS.

NO MEANS SUGGESTING THIS IS MANDATED TO BE USED AND ONLY THIS, THIS IS OF COURSE IS NOTED A PILOT, A SMALL NUMBER OF TERMS TO START BUT WHAT WE REALLY WOULD LOVE IS A CONVERSATION TO CONTINUE WITH HOW WE CAN HARMONIZE AND HAVE A UNIFIED APPROACH, CAN HAVE THIS AS A RESOURCE FOR PATIENTS AND PARTICIPANTS TO USE MOVING FORWARD.

AND WE'RE EXPLORING EXPANSION INTO VERSION 2 OF THIS VIA MULTI STAKEHOLDER CONSORTIUM

OVER THE NEXT FEW WEEKS AND MONTHS SO THERE WILL BE MORE ABOUT THAT IN COMING FUTURE TO BE ABLE TO SEE WHERE THIS CAN GO AND HOW THIS CAN EXPAND AND THAT WILL BE PART OF WHAT WE DISCUSS A BIT WITH OUR PANEL.

ON THE NEXT SLIDE, I'LL JUST QUICKLY GIVE YOU THE NAMES AND POSITIONS OF OUR WONDERFUL ESTEEMED PANELISTS AND THEY WILL HAVE A CHANCE TO SHARE A BIT ABOUT THEIR EXPERTISE AND WHY SOMETHING LIKE A GLOSSARY OF PLAIN LANGUAGE CLINICAL RESEARCH TERMS AND HEALTH LITERACY IS SO IMPORTANT IN THIS TIME IN PARTICULAR.

WE HAVE JULIE HOLTZOPLE WHO'S THE HEAD OF CLINICAL TRANSPARENCY AND DATA SHARING AT ASTRAZENECA.

ALSO JOINED BY IVY TILLMAN, IRB OFFICE DIRECTOR AT AUGUSTA UNIVERSITY AND DESIREE WALKER, PATIENT ADVOCATE AND HEALTH EDUCATOR AND THEY WILL EACH BE ABLE TO SHARE SOME OF THEIR PERSPECTIVES ON THIS RESOURCE.

SO WE CAN GO OFF SCREEN SHARING NOW AND START WITH YOU, JULIE, FOR AN OVERVIEW ON WHO YOU ARE AND WHY YOU'RE HERE TO CELEBRATE THIS LAUNCH TODAY.

>> THANKS, SYLVIA.

SO AS SYLVIA MENTIONED, I'M RESPONSIBLE FOR OUR CLINICAL TRIAL TRANSPARENCY EFFORTS AT ASTRAZENECA.

AND OVER THE PAST SIX YEARS THAT HAS MEANT A HEAVY INVESTMENT IN RETURNING RESULT SUMMARIES, SOME PEOPLE REFER TO THEM AS PLAIN LANGUAGE SUMMARIES OR LAY SUMMARIES FOR ALL OF THE CLINICAL STUDIES, INTERVENTIONAL CLINICAL STUDIES WE'VE DONE FOR THE LAST SIX YEARS.

AND IT'S CRITICAL WHEN YOU ARE FOCUSING SO MUCH ON THESE TYPES OF DOCUMENTS THAT YOU USE EASY TO UNDERSTAND LANGUAGE.

SO THAT'S REALLY BEEN THE BASIS OF MY EXPOSURE TO THIS.

YOU NEED THAT SAME SIMPLE AND EASY TO UNDERSTAND LANGUAGE FOR EVERYTHING THAT YOU'RE WORKING WITH PATIENTS IN DURING THE STUDY, NOT JUST THE SUMMARY THAT YOU CREATE AT THE END OF THE STUDY WHEN THE TECHNICAL RESULTS ARE AVAILABLE.

SO THAT'S REALLY SORT OF MY EXPOSURE AND MY INTEREST AND MY ANGLE INTO THIS WORK.

I'VE WORKED CLOSELY WITH PATIENT CENTRICITIES WITHIN AV TO BE INVOLVED IN LOOKING AT THESE DEFINITIONS AND THINKING ABOUT HOW A GLOSSARY LIKE THIS CAN FURTHER SUPPORT EFFORTS ACROSS OUR ECOSYSTEM IN CLINICAL RESEARCH IN ALL THE COMMUNICATIONS WE HAVE WITH PATIENTS.

I'M REALLY EXCITED TO THINK ABOUT HOW THIS CAN BE A BASELINE TO SUPPORT NOT ONLY OUR TRIAL RESULT SUMMARIES AND THANK YOU CARDS AND THOSE OTHER THINGS WE DO FROM A TRANSPARENCY PERSPECTIVE BUT HOW TO MAKE OTHER WAYS WE COMMUNICATE WITH PATIENTS BETTER ON AN EASY TO UNDERSTAND GLOSSARY THAT HAS HAD SUCH A MULTI STAKEHOLDER REVIEW AND INPUT REALLY BECOMES AN AMAZING SOURCE TO HELP WITH THOSE EFFORTS.

>> THANK YOU, JULIE.

IVY, OFF TO YOU.

>> YES, MY NAME IS IVY TILLMAN AND I'M THE IRB OFFICE DIRECTOR AT AUGUSTA UNIVERSITY BUT ALSO OVER HUMAN RESEARCH PROTECTION PROGRAM OR HRPP.

AND OUR INSTITUTION IS QUITE UNIQUE BECAUSE WE ARE HOME TO GEORGIA'S ONLY PUBLIC

MEDICAL COLLEGE AND DENTAL COLLEGE IN ADDITION TO HAVING SOCIAL BEHAVIORAL RESEARCH. SO WE COVER THE GAMUT.

AND I SEE THIS GLOSSARY AS AN OPPORTUNITY FOR IRBS TO DO WHAT BEEN WANTING TO DO AND ADOPT PLAIN LANGUAGE FOR THE PARTICIPANTS AND AN OPPORTUNITY FOR OUR PARTICIPANTS. WITHIN OUR OFFICE WE HAVE LAUNCHED A PRETTY EXTENSIVE COMMUNITY ENGAGEMENT PLAN AND STRATEGY WHERE WE'RE GOING INTO THE SPACES WHERE OUR PARTICIPANTS EXIST AND WE'RE INTERACTING WITH THE COMMUNITY AND THE GATHERING INFORMATION ABOUT THEIR EXPERIENCES. AND ONE OF THE MOST COMMON FEEDBACK IS YOU GUYS MAKE THIS STUFF SO HARD TO UNDERSTAND.

AND SO I SEE THIS GLOSSARY AS BEING A STEP FORWARD AND TO MAKING IT PLAIN.

I THINK HEALTH LITERACY IS SO IMPORTANT AND CLINICAL ASPECTS BUT ALSO IN THE RESEARCH SPACES SO I LOOK FORWARD TO BEING ABLE TO ADOPT THIS GLOSSARY INTO THE WORK WE'RE DOING.

>> THANK YOU, IVY.

DESIREE, OFF TO YOU.

>> GOOD MORNING, THANK YOU SO MUCH.

IT IS A PRIVILEGE TO BE HERE AND TO I APPRECIATE THE OPPORTUNITY TO SHARE THE PATIENT ADVOCATE PERSPECTIVE.

I LIKE TO SAY THAT BECOMING A PATIENT ADVOCATE WAS NOT SOMETHING ON MY TRAJECTORY, BUT I WAS DIAGNOSED TWICE WITH BREAST CANCER AND ALONG THE JOURNEY REALIZED THERE WERE SO MANY GAPS AND NEEDS AND ONCE I WORKED FOR A MAN THAT SAID IF YOU'RE NOT PART OF THE SOLUTION, YOU'RE PART OF THE PROBLEM.

AND AS A RESULT OF THAT I'VE TAKEN IT TO HEART OVER THE YEARS TO SAY IF SOMETHING ISN'T RIGHT I CAN TALK ABOUT IT BUT PERHAPS I NEED TO ACT AS WELL.

I APPRECIATE THE OPPORTUNITY THAT YOU'VE GIVEN ME, SYLVIA, TO HAVE THE OPPORTUNITY TO WORK WITH YOU BOTH REGARDING THE HEALTH LITERACY AND THE GLOSSARY NOW AND SO WE HAVE TWO THINGS UNDER WAY, WHICH IS A HUGE FEAT BUT DEFINITELY A WORTHY ONE.

I WILL SAY THAT FOR ME, HAVING THE PATIENT EXPERIENCE, I OFTEN HAVE TO GET GOOGLE TO REALLY EXPLAIN A LOT TO ME BECAUSE I'M AN INDIVIDUAL THAT WANTS TO UNDERSTAND, I DON'T WANT YOU TO TALK AT ME I WANT YOU TO BE ABLE TO BE IN CONVERSATION WITH ME.

AND BUT NOT EVERYONE MAY HAVE THAT APPROACH.

AND SO I THINK THAT THIS PARTICULAR WORK AND ALSO BECAUSE I'VE ACTUALLY SERVED TO BE A REVIEWER FOR MANY AGENCIES AS WELL, AND I DO A LOT OF WORK WITH INFORMED CONSENT, I REALIZE HOW THINGS ARE NOT CLEAR.

UNFORTUNATELY, WHEN YOU'RE ILL, YOU'RE NOT NECESSARILY AT YOUR BEST.

AND SO THE EASIER THINGS CAN BE IS THE MOST IMPORTANT.

SO I LOOK AT THIS GLOSSARY AS A BEGINNING, BECAUSE I THINK WHAT WE'VE SEEN IN THE PAST 16 MONTHS, ESPECIALLY, PEOPLE KNOW TERMS, BUT UNFORTUNATELY EVERYONE IS NOT DEFINING THINGS THE SAME WAY.

SO THIS TOOL THAT WE'VE WORKED ON AND, YES, IT WAS A LIFT, IT WAS A LIFT, BUT A WORTHY ONE AT THAT, IS REALLY PROVIDING THE OPPORTUNITY FOR EVERYONE TO BE ON THE SAME PAGE AND, AT THE SAME TIME, MAKE SURE THAT THE PATIENT IS AT THE CENTER AND THAT THEY ARE COMFORTABLE, THEY ARE CONFIDENT, AND THEY'RE INFORMED AND THEY CAN ACTUALLY BE AN ACTIVE PARTICIPANT

IN THEIR CARE BECAUSE THEY HAVE KNOWLEDGE

>> THANK YOU SO MUCH FOR THAT INTRO.

AND I THINK I WILL LAUNCH MY FIRST QUESTION, THEN, AT YOU, DESIREE, BECAUSE WE TALK A LOT OVER THE YEARS AROUND EMPOWERMENT AND HOW WE EMPOWER PATIENTS AND PARTICIPANTS TO PARTICIPATE IN RESEARCH.

SO HOW -- WHAT DO THEY NEED TO FEEL EMPOWERED IN RESEARCH AND HOW CAN SOMETHING LIKE AN A LITTLE PLAIN LANGUAGE CLINICAL RESEARCH GLOSSARY HELP ACCOMPLISH THAT?

>> I THINK THEY NEED INFORMATION, THEY NEED THE FACTS, BECAUSE I THINK THAT OFTEN TIMES PEOPLE OPERATE WITHOUT THE FACTS.

THEY GO BY HEARSAY AND THEIR OWN INTERPRETATION FOR WHATEVER REASON AND WE TALKED ABOUT HEALTH LITERACY BEFORE, THAT ALSO CAN WEIGH INTO SOMEONE NOT TRULY UNDERSTANDING.

AND SO I THINK FOR ME, ONE OF THE THINGS THAT WOULD BE IDEAL AND IF WE CAN EVERY GET TO THIS PLACE I THINK HEALTHCARE WOULD BE SO MUCH BETTER, IS TO ACTUALLY TALK ABOUT THINGS WHEN -- LONG BEFORE SOMEONE NEEDS THAT KNOWLEDGE.

WE TEND TO WAIT UNTIL THE PROBLEM ARISES AND THEN WE ATTEMPT TO ADDRESS IT.

BUT I CAN CLEARLY SAY HAVING BEEN ON THE SIDE OF BEING A PATIENT, OFTENTIMES YOU DON'T HEAR EVERYTHING THAT IS SAID.

AND THEN INDIVIDUALS WILL SAY, WELL, THEY MENTIONED IT AND SO YOU KNOW.

AND SOMETIMES YOU CAN GO INTO A FOG.

AND IF YOU DON'T FULLY UNDERSTAND AND FEEL CONFIDENT TO ASK QUESTIONS YOU'RE OPERATING AT A DEFICIT.

SO I THINK THAT THIS PARTICULAR TOOL PROVIDES, IF IT CAN PROVIDE THE INFORMATION EARLY SO THAT PEOPLE CAN START TO UNDERSTAND THE WHOLE RESEARCH SPACE AND THE TERMS, THAT WHEN THEIR FRIEND, MAYBE THEY MAY HAVE TO OR A LOVED ONE, YOU LAS VEGAS HAVE BEEN INTRODUCED TO IT AND YOU CAN SAY, YEAH, I KIND OF KNOW WHAT THAT IS, LET ME JUST GO GET A REFRESHER, A REFRESHER IS MUCH EASIER THAN A DEEP DIVE.

AND SO I THINK THAT THIS -- BUT ALSO CONVERSELY ON THE RESEARCH SIDE, I DO FEEL THAT RESEARCHERS NEED TO MAKE SURE THAT HOW THEY PHRASE THINGS IS ACTUALLY GOING TO BE CLEAR SO THAT IT'S NOT MISINTERPRETED BECAUSE I CAN TELL YOU I'VE SEEN SO MANY INFORMED CONSENTS WHERE THE WAY IT'S WORDED, YOU KNOW, THEY'RE TELLING YOU THAT THIS IS NOT WHAT THEY WERE SAYING, BUT IT'S THE PERSON WHO'S READING IT.

AT THE END OF THE DAY IF THEY ARE THE PERSON THAT'S GOING TO BE SIGNING ON THE DOTTED LINE TO SAY I'M PARTICIPATING, THEY NEED TO UNDERSTAND WHAT THEY'RE GETTING INTO BECAUSE OFTENTIMES WHEN PEOPLE SIGN AND ARE NOT AWARE, THEY THEN HAVE A MOMENT WHERE THEY CAN'T REALLY FULFILL THIS AND THEY HAVE TO WALK AWAY.

AND THEN EVERYONE IS UPSET.

SO I JUST THINK COMMUNICATION, TRANSPARENCY, MAKING SURE THAT THE LANGUAGE IS CLEAR, BUT ALSO THAT THERE IS UNDERSTANDING AND THERE'S AN OPPORTUNITY TO LEARN MORE IF THAT'S HOW YOU DESIRE, BECAUSE ONE OF THE THINGS I THINK OFTEN DOESN'T HAPPEN IS THE FACT THAT PEOPLE DON'T KNOW HOW TO COMMUNICATE.

SOME HE PEOPLE WANT ALL THE INFORMATION ONE TIME SO THEY CAN PROCESS IT ON THEIR OWN

WAY, AND OTHER PEOPLE JUST WANT SPOONFULS SO YOU ALSO HAVE TO BE ABLE TO PROVIDE THAT SPACE AS WELL.

>> EARLY ON, EARLIER ON THE BETTER.

SO JULIE I KNOW YOU HAVE SOME THOUGHTS ABOUT BEING ABLE TO MAKE THINGS AS EARLY AS POSSIBLE TOO.

>> THANKS.

I WAS LISTENING TO DESIREE TALK ABOUT SOME OF HER EXPERIENCES AND WATCHING OR PARTICIPATING IN SUPPORTING CONSENT FOR VERY ILL INDIVIDUALS.

AND THINKING ABOUT HOW HARD IT IS TO UNDERSTAND A LOT OF INFORMATION ABOUT CLINICAL RESEARCH EVEN WHEN WE DON'T HAVE SORT OF A FOGGY BRAIN, RIGHT?

AND SO WHEN WE THINK ABOUT THE PERSPECTIVE OF MANY SICK INDIVIDUALS THAT ARE COMING INTO CLINICAL RESEARCH IT REALLY JUST DRIVES HOME FOR ME THE IMPORTANCE THAT WE LOOK AT HOW WE CAN TAKE SOMETHING LIKE THIS GLOSSARY AND EMBED IT AS EARLY AS POSSIBLE WITH FIRST INTERACTIONS WITH PEOPLE THAT MAY EVEN BE CONSIDERING CLINICAL RESEARCH OR THEIR LOVED ONES.

WHEN WE THINK ABOUT ALL THE WAYS WE COMMUNICATE THAT CLINICAL RESEARCH, THINK ABOUT THE REGISTRY LISTINGS WHAT CAN WE DO TO MAKE THOSE SITUATIONS BETTER, EASIER TO COMMUNICATE, THE BASIC SUMMARY OF A TRIAL, THE INCLUSION, EXCLUSION CRITERIA, HOW CAN WE USE SOMETHING SUCH AS THIS GLOSSARY TO HELP US WITH THE EARLIEST COMMUNICATIONS IN LOOKING FOR THE RIGHT CLINICAL RESEARCH IN CONSENTING FOR CLINICAL RESEARCH.

SO THAT'S SOME OF THE OPPORTUNITIES I SEE HERE, AND THE VALUE OF GETTING SUCH A GREAT TOOL INVOLVED AS EARLY AS POSSIBLE IN THE WAY WE'RE COMMUNICATING ABOUT CLINICAL RESEARCH.

>> THAT'S RIGHT.

I THINK I'VE TALKED TO IVY AS WELL AND HEARD THE POINT OF ENTRY KIND OF POINT OF VIEW AND I SEE A QUESTION ALSO IN THE CHAT THAT JUST POPPED UP AROUND CONSENTED MAYBE ALREADY TOO LATE TO BE INTEGRATING THIS IN.

SO I KNOW YOU HAVE SOME THOUGHTS ON THAT, IVY.

SO LET'S HEAR IT.

>> YES.

SO REALLY CONSENT IS NOT JUST ABOUT THE DOCUMENT, IT'S ABOUT THE CONVERSATION.

AND THOSE CONVERSATIONS SHOULD BEGIN WELL IN ADVANCE OF ACTUAL PRESENTING THE DOCUMENT AND THE DETAILS.

AND SO WHERE ARE THE POINTS OF ENTRY FOR POTENTIAL PARTICIPANTS, SAY WITHIN YOUR HEALTH SYSTEM OR YOUR RESEARCH CENTER?

AND REALLY EXAMINING THOSE AND BEGIN HAVING THOSE TERMS FROM THE GLOSSARY USED AT THOSE POINTS OF ENTRY.

FOR EXAMPLE, SAY YOU HAVE A CANCER CENTER, AND PATIENTS ARE REGISTERING AND SITTING IN WAITING ROOM AND SO FORTH.

BEGIN HAVING SOME OF THIS TERMINOLOGY, A SHORT VIDEO OR JUST CLIPS ON KIOSKS OR EVEN IN THE WAITING ROOMS.

SO FOR INSTANCE, WE ARE A RESEARCH UNIVERSITY.

SO INDIVIDUALS WHO COME TO OUR HEALTH SYSTEM KNOW THEY MAY BE APPROACHED FOR



RESEARCH.

SO WE CAN HAVE MORE INFORMATION JUST ABOUT WHAT RESEARCH IS.

OFTENTIMES PEOPLE CONFUSE A STUDY WITH A CLINICAL TRIAL.

IS THAT THE SAME THING?

STARTING THERE.

WE OFFER CLINICAL TRIALS, WHAT ARE CLINICAL TRIALS?

HOW DOES IT HELP THE COMMUNITY?

HOW DOES IT HELP YOU?

WHAT DO YOU NEED TO KNOW?

AND I THINK GOING BACK TO WHAT DESIREE SAID, TRULY EMPOWERING INDIVIDUALS IS PROVIDING THEM THE INFORMATION UP FRONT EARLY ON AND THEN ALLOWING THEM TO FIGURE OUT HOW THEY WISH TO NAVIGATE AND LEARN MORE.

>> AWESOME.

JUST AWESOME.

WE NEED TO REALLY HAVE THIS EARLIER ON AND I LOVE THIS IDEA OF NORMALIZING IT IN THE SPACES THAT PEOPLE ALREADY MOVE THROUGH.

WHEN WE'VE MADE OUR CLINICAL TRIAL LIFECYCLE, WE HAVE RECRUITMENT AND INFORMED CONSENTS ON STUDY AND END OF STUDY BUT BEFORE ALL THAT WE HAVE A LITTLE ICON FOR DISCOVERY AND THAT'S REALLY THE PLACE WHERE PEOPLE ARE JUST LEARNING ABOUT RESEARCH OR ENCOUNTERING RESEARCH AS A CONCEPT FOR THE FIRST TIME MAYBE COMING TO YOUR HEALTH CENTER OR IN THEIR COMMUNITY HEALTH CENTER, WHEREVER IT MIGHT BE.

THE MORE WE CAN HAVE RESEARCH FEEL LIKE A NORMAL PART OF EVERYDAY HEALTHCARE THE REASON WE HAVE SOME OF THE MEDICINES AND TREATMENTS WE HAVE IS BECAUSE RESEARCH HAS BEEN DONE AND SO THE MORE PEOPLE CAN SEE THAT AS A NORMAL PART, THE BETTER I THINK IT CAN BE FOR THE OVERALL JUST MISSION OF RESEARCH TO INCLUDE AS MANY PEOPLE AS POSSIBLE AND HAVE REPRESENTATION OF DIVERSE POPULATIONS IN RESEARCH.

SO THANK YOU FOR THAT, THE FIRST SET OF RESPONSES.

WHEN I THINK ABOUT BUILDING ON THIS IDEA OF USING THE GLOSSARY AS EARLY AS POSSIBLE OR USING PLAIN LANGUAGE TERMS AND INTRODUCING RESEARCH AS EARLY AS POSSIBLE I THINK A LITTLE BIT ABOUT ORGANIZATIONS SPECIFICALLY AND HOW CAN ORGANIZATIONS START TO INTEGRATE A RESOURCE LIKE THIS, LIKE INTO THEIR PROCESSES AND STANDARD OPERATING PROCEDURES FROM TODAY ON.

HOW CAN PEOPLE START TO MOVE THIS INTO THEIR WORK FLOWS?

AND, DESIREE, I THINK YOU MIGHT HAVE SOME THOUGHTS ON THIS ALREADY.

>> YEAH.

I THINK ONE OF THE GROUPS THAT I THINK WOULD BE IMPORTANT FOR THEM TO EMBRACE THIS ARE THE FUNDERS.

I DO BELIEVE THAT MANY HAVE TEMPLATES.

THEY OFFER RESOURCES.

BUT I THINK THAT IF THEY MAKE THE PUSH SO THAT ARE THE STUDY TEAMS KNOW THAT THIS IS WHAT WE EMBRACE.

AND SO YOU NEED TO UTILIZE PLAIN LANGUAGE AND HERE ARE TERMS SO THAT YOU CAN MAKE SURE

THAT THE TERMS YOU'RE USING ARE THE ACCURATE ONES, I FEEL THAT THAT WILL GO A LONG WAY BECAUSE I ALWAYS SAY WHO PAYS YOU IS WHO YOU PAY ATTENTION TO.

AND SO I PUT MY CORPORATE HAT OR FORMER CORPORATE HAT ON TO SAY IT HAS TO COME FROM THE TOP DOWN IN CERTAIN INSTANCES.

I WOULD ALSO SAY THAT I FEEL THAT WE SHOULD ALSO THINK ABOUT POTENTIALLY GETTING THIS INFORMATION OUT TO THE PATIENT ADVOCACY ORGANIZATIONS AS WELL, BECAUSE THEY'RE OFTEN TRYING TO SUPPORT INDIVIDUALS, FRIENDS AND LOVED ONES, TO BE ABLE TO ALSO SUPPORT. SO I THINK PROVIDING THEM WITH THIS ACCESS TO THIS INFORMATION WOULD BE IMPORTANT AS WELL.

BUT I ALSO THINK FROM THE CANCER CENTER PERSPECTIVE, IT WOULD BE IMPORTANT PERHAPS FOR AACI TO SAY THAT WE'VE HEARD THAT THIS IS AVAILABLE, WE WANT TO MAKE SURE IT'S ON THE RADARS OF ALL OF THE CANCER CENTER DIRECTORS, AND THEN THEY CAN THEN FILTER IT DOWN TO THE DEPARTMENTS THAT ARE DEALING WITH CLINICAL RESEARCH AND SAY, AGAIN, WE APPROVE THAT THIS IS THE WAY THAT YOU CAN START TO UTILIZE IT.

SO I THINK THOSE ARE SOME ASPECTS THAT WE CAN APPROACH TO SEE HOW FAR WE CAN GO, BECAUSE IT'S GOING TO BE IMPORTANT THAT THE WORD GETS OUT AT THE END OF THE DAY.

I ALWAYS SAY IT'S GREAT TO HAVE LOVELY TOOLS, BUT IF NO ONE KNOWS ABOUT IT AND DON'T HAVE ACCESS TO IT, THEN THE WORK IS REALLY NOT AS --

>> THANK YOU, DESIREE.

I THINK -- WE'RE GOING FROM A BROAD SENSE OF FUNDERS, LEADING ORGANIZATIONS AND THEN IVY YOU MIGHT HAVE A MORE NARROW THINKING OF IRBS AND THAT PERSPECTIVE.

>> YES.

SO WE'RE EXCITED.

I'M EXCITED TO USE THIS TOOL WITHIN OUR ORGANIZATION.

AND FROM THE IRB PERSPECTIVE, REALLY HAVING LANGUAGE WE CAN ADOPT.

WE CURRENTLY HAVE WHAT'S CALLED AN OPTIONAL LANGUAGE GLOSSARY AVAILABLE FOR OUR RESEARCHERS FOR CERTAIN TERMS.

OUR LANGUAGE GLOSSARY IS PRETTY LARGE, AND LOOKING AT YOUR GLOSSARY COMPARED TO OURS I SEE THAT THERE'S AN OPPORTUNITY FOR US TO REALLY MAKE THE LANGUAGE PLAIN.

AND SO HAVING OUR IRBS ADOPT IT BUT ALSO ENCOURAGE OUR RESEARCHERS TO USE IT, I CAN SEE US DOING A WEBINAR WITHIN OR INSTITUTION JUST HOW CAN WE USE THIS TOOL WITHIN YOUR RESEARCH SPACES.

ADDITIONALLY, I THINK ABOUT EDUCATING THE PUBLIC.

ANOTHER PIECE OF FEEDBACK WE RECEIVED IN THESE COMMUNITY SPACE IS ABOUT TRUST, AND WE WERE -- THEY WERE VERY CLEAR.

WE DON'T TRUST YOU WHEN YOU'RE USING THOSE BIG COMPLICATED WORDS WE THINK YOU'RE TRYING TO DO SOMETHING.

SO TO HAVE THIS GLOSSARY AVAILABLE AND SAY LOOK WE'RE USING THIS TOOL AS A WAY TO EMPOWER THE COMMUNITY REGARDING UNDERSTANDING RESEARCH I THINK IS NEEDED.

AND THEN, ALSO, AT OUR INSTITUTION, WE TRAIN THE FUTURE SCIENTISTS AND PHYSICIANS AND DENTISTS AND CLINICIANS.

AND IF WE CAN BEGIN USING THIS LANGUAGE NOW WITH THE INDIVIDUALS WHO WILL BE OUR

FUTURE RESEARCH INVESTIGATORS, I THINK IT WILL BE WONDERFUL.

I THINK OF COURSE THEY HAVE HEALTH LITERACY COURSES AND SO FORTH, BUT INFUSING RESEARCH TERMS INTO THAT HEALTH LITERACY SO THAT OUR FUTURE INVESTIGATORS DON'T HAVE TO START USING THIS LANGUAGE WHEN THEY BECOME AN INVESTIGATOR IS PART OF THEIR EVERY DAY VERNACULAR.

I SEE A LOT OF OPPORTUNITIES TO ADOPT THIS FROM AN ACADEMIC MEDICAL CENTER PERSPECTIVE. I LOOK FORWARD TO LEARNING HOW OTHERS WILL BE ADOPTING IT.

>> THANK YOU.

JULIE?

INDUSTRY.

>> SO I MENTIONED THE OPPORTUNITIES WITH INFORMED CONSENTS, WITH PLAIN LANGUAGE SUMMARIES, WITH JUST INTERACTIVE COMMUNICATIONS THAT OCCUR WITH PATIENTS.

WHAT'S INTERESTING TO ME IS WHEN YOU THINK ABOUT THIS ACROSS ALL THE OTHER ACTIVITIES THAT ARE TAKING PLACE, THE FOCUS ON BETTER COMMUNICATING WITH THE PUSH PUBLIC AND PATIENTS IS A SIGNIFICANT AREA OF EFFORT ACROSS INDUSTRY AND HAS BEEN FOR SEVERAL YEARS.

SO I THINK ONE OF THE THINGS THAT WE HAVE TO FIGURE OUT IS HOW WE USE TOOLS LIKE THIS AND OTHER TOOLS THAT ARE COMING INTO PLAY SUCCESSFULLY AND WHAT IS THE OPPORTUNITY WHEN WE THINK ABOUT THE TERMS WITHIN THIS GLOSSARY, THE 52 TERMS I THINK YOU MENTIONED, SYLVIA, HOW IT COULD POTENTIALLY GROW, HOW IT CAN BE REFERENCED WHEN THERE'S ALSO OTHER GLOSSARIES AND IVY YOU REFERENCED THIS ABOUT HAVING TO MANAGE THAT FROM AN IRB PERSPECTIVE.

WHEN IT COMES TO EASY TO UNDERSTAND LANGUAGE, I ALWAYS USE THE EXAMPLE THAT IF TWO OF US WERE SITTING IN THE SAME PLACE HAVING A COFFEE IN THE SAME CITY LOOKING AT THE WEATHER WE WOULD DESCRIBE IT DIFFERENTLY EVEN IF WE WERE BOTH NATIVE ENGLISH SPEAKERS, HAD LIVED IN THE SAME CITY, THERE'S JUST A TENDENCY IN HUMAN NATURE TO DESCRIBE THINGS DIFFERENTLY. PART OF WHAT IS REQUIRED OF US TO OVERCOME AS WE THINK ABOUT THE ADOPTION OF SOMETHING LIKE THIS IS WE HAVE TO BE WILLING TO SAY, OKAY, MY PARTICULAR DESIRE TO CHANGE THIS WORD ISN'T NECESSARY.

AND I SEE THAT OFTEN WHEN WE'RE REVIEWING OUR RESULT SUMMARIES, FOR EXAMPLE, THAT SOMEBODY HAS A PREFERENCE ON THE WAY TO SAY SOMETHING.

I ALSO KNOW IT EXISTS WHEN IT COMES TO ICF'S AND WE HAVE TEMPLATES WHERE WE THINK WE'VE PUT THE BEST WE CAN INTO IT.

THERE'S ALWAYS OPPORTUNITY TO IMPROVE.

BUT THEN FOR EVERY STUDY IT GETS EDITED OR ADOPTED OR AN ICF HAS THEIR VERSION OF THE RIGHT -- IRB HAS THEIR VERSION OF THE RIGHT ICF.

AS WE WORK TOGETHER ACROSS THE ECOSYSTEM, WE HAVE TO AT SOME POINT CHOOSE COMMON TERMINOLOGY OVER PREFERENCES.

THAT'S NOT AN EASY THING TO GET HUMANS TO ACCEPT.

AND I THINK THAT'S WHY THIS IS SO IMPORTANT, THIS MULTI STAKEHOLDER VIEW OF HOW CAN WE SAY YOU KNOW WHAT, IT'S NOT THAT INDUSTRY KNOWS BEST OR PATIENTS KNOW BEST OR THE IRB KNOWS BEST, IT'S THAT SIMPLICITY OR BEYOND SIMPLICITY, IT'S THE COMMON LANGUAGE

OUTWEIGHS THE BENEFIT ME PUTTING MY SPIN TON, IVY PUTTING HER SPIN AND DESIREE PUTTING HER SPIN ON IT.

HAVING THIS COMMON LANGUAGE HAS MORE BENEFIT BECAUSE IF WE HAVE A COMMON LANGUAGE WE CAN START TO BUILD AN UNDERSTANDING AROUND THAT COMMON LANGUAGE.

AND SO IT'S ABOUT AWARENESS, PEOPLE CAN'T USE THIS TOOL IF THEY'RE NOT AWARE, BUT IT'S ALSO ABOUT WILLINGNESS TO ADOPT AND HOW DO WE SHIFT THE MENTALITY TO SAY NOT ONE STAKEHOLDER IS THE EXPERT BUT IN FACT EFFORTS LIKE THIS WHERE WE COME TOGETHER ARE THE RIGHT PLACE TO START FOR THIS COMMON LANGUAGE.

HARMONY OVER OUR OWN PERSPECTIVE IS GOING TO BE KEY IN ADOPTION.

WE DON'T KNOW HOW WE ACHIEVE THAT BUT I THINK IT'S CONVERSATIONS LIKE THIS AND EFFORTS SYLVIA LIKE THE ONE YOU CREATED TO GET TO THESE 52 TERMS AND IT'S GONNA TAKE MORE AND MORE COLLABORATION AMONGST DIFFERENT STAKEHOLDERS TO DRIVE FOR THE VALUE OF HARMONY OVER MY PERSPECTIVE ALONE BEING MOST IMPORTANT.

SO THAT'S -- WHEN I THINK ABOUT THE TACTICS OF ADOPTION, IT'S A LOT OF NOT ONLY AVAILABILITY BUT CHANGING MENTALITY WE HAVE TO THINK ABOUT AS WELL.

BUT IT SURE WOULD BE NICE THAT PATIENTS ACROSS STUDIES IN A COMMON THERAPEUTIC AREA PATIENTS IN MULTIPLE CLINICAL RESEARCH STUDIES THAT WHEN SOMEBODY DESCRIBES ANONYMIZED DATA IT'S IS ALWAYS DESCRIBED THE SAME WAY OR DESCRIBES A BLOOD DRAW IT'S DESCRIBED IN THE SAME WAY.

HAVING THIS IDEA THAT YOU LEARN WHAT THAT WORD MEANS BECAUSE IT'S ALWAYS DESCRIBED THE SAME WAY WOULD BE SO GREAT FOR THE PUBLIC AND THE PATIENTS.

SO THAT'S WHY THIS HARMONY HAS SUCH VALUE AND IT'S WORTH PUSHING THROUGH THE ADOPTION CHALLENGES THAT WE KNOW WE NEED TO OVERCOME.

>> THANK YOU, JULIE.

AND I SEE SOME QUESTIONS COMING UP ALSO AROUND THIS BEING SORT OF U.S. CENTRIC OR NORTH AMERICA CENTRIC.

HOW CAN WE MAKE COMMON LANGUAGE THAT'S GLOBAL AND SO WHAT I'LL NOTE IS THIS IS A GLOSSARY THAT'S IN ENGLISH RIGHT NOW.

AND THE WORK GROUP DID INCLUDE REPRESENTATION FROM INDIVIDUALS IN THE UK AND PARTS OF EUROPE, ENGLISH WAS THEIR FIRST LANGUAGE OR SECOND LANGUAGE BUT SO WE HAVE A LENS TOWARDS THINKING ABOUT GLOBAL REGULATORY APPLICABILITY.

I KNOW THAT WHEN WE'VE DISCUSSED THE DEFINITION OF ADVERSE REACTION, FOR EXAMPLE, WE TOOK INTO ACCOUNT SOME EU REGULATORY DOCUMENTS AS WELL TO REALLY MAKE SURE THAT THOSE WERE ALIGNED.

SO WE'RE DOING OUR BEST TO TAKE THAT INTO ACCOUNT AND WILL THINK ABOUT THAT MOVING FORWARD AS WE CONSIDER EXPANSION EFFORTS.

AND SO WHEN WE DO THINK ABOUT THE IDEA OF CULTURAL, LINGUISTIC FACTORS THAT CAN BE BUILT INTO AN ONLINE RESOURCE, HOW CAN WE DO THAT FOR SOMETHING LIKE A CLINICAL RESEARCH GLOSSARY THAT'S ONLINE AND BUILD CULTURE AND LANGUAGE MORE MEANINGFULLY INTO THE -- AN ONLINE RESOURCE LIKE A CLINICAL RESEARCH GLOSSARY?

IVY, I THINK YOU HAVE SOME THOUGHTS ABOUT THIS.

I MIGHT HAVE BEEN ON MUTE.

I CUT MYSELF ON OFF TOO FAST

>> YES, I DO.

I THINK THAT HAVING INFORMATION PRESENTED IN A CULTURALLY RELEVANT MANNER IS REALLY IMPORTANT.

HOW WE DO THAT, WE'D HAVE TO REALLY DISCUSS IT WITH INDIVIDUALS FOR WHOM IT WOULD BENEFIT THE MOST, RIGHT?

BUT IT COULD BE AS SIMPLE OR THE BEGINNING AS JUST WITH THE GLOSSARY, WHICH I THINK IS WONDERFUL, WHERE YOU HAVE THE WORDS THAT ARE SIMILAR TO OR RELATED TO THE WORD, INCLUDING CULTURALLY RELEVANT LANGUAGE THERE.

SO THAT IF I'M LOOKING AT THE DEFINITION OF ADVERSE REACTION AND I'M STILL KIND OF, WHAT'S THAT MEAN FOR ME, HAVING SOMETHING THAT I CAN RELATE TO IN A LANGUAGE THAT FITS HOW I TALK WILL DEFINITELY HELP AND SUPPORT PARTICIPANTS AND ALSO REALLY HELPS WITH TRUST AGAIN. I THINK TRUST IS KEY.

AND AS WE BREAK DOWN BARRIERS AND CHALLENGES FOR INDIVIDUALS PARTICIPATING AND CONTINUING PARTICIPATION, I THINK THAT THAT'S DEFINITELY NEEDED.

>> IVY, A FOLLOW-UP QUESTION ON WHAT THAT COULD LOOK LIKE IN THE CURRENT GLOSSARY AS SYLVIA DEMONSTRATED IT TODAY.

CAN YOU GIVE AN EXAMPLE HOW WE MIGHT EXPAND THE GLOSSARY TO ADD THESE CULTURALLY RELEVANT TERMS WHILE ACHIEVING THE HARMONIZATION IN THE DEFINITIONS?

>> YES.

SO WE WERE TALKING ABOUT IT EARLIER, FOR INSTANCE, I THINK SOMEONE THERE WAS AN EXAMPLE OF A DEFINITION OF DATA AND THE WAY THAT WE USE DATA.

SO IN ACADEMIA WE USE IT IN THE PLURAL, DATA ARE.

IN MOST SPACES DATA IS.

WHILE WE WISH TO REMAIN GRAMMATICALLY CORRECT, ARE WE RELATING TO THE INDIVIDUALS FROM WHOM WE ARE OBTAINING THE DATA?

JUST THAT'S AN EXAMPLE THAT I'M SOMEONE MRCT SHARED THIS MORNING AND I'M SURE THERE ARE OTHERS, JUST BREAKING THEM DOWN AND REALLY ASKING THOSE INDIVIDUALS WHO ARE PARTICIPATING OF, INDIVIDUALS LIKE DESIREE WHO CAN TELL US IN THOSE SPACES WHEN SHE'S CONSENTED OR WITNESSES CONSENT, HOW ARE INDIVIDUALS PROCESSING AND UNDERSTANDING AND RELATING TO WHAT THEY ARE BEING TOLD.

>> AND I KNOW WHEN WE WERE WORKING ON THE GLOSSARY AS WELL, SORT OF SOCIAL CONSIDERATIONS THAT WE BROUGHT INTO CREATING THE DEFINITIONS AS WELL.

SO ONE, FOR EXAMPLE, WAS AROUND THEY AS A SINGULAR PRONOUN AND THERE WAS A LITTLE BIT OF DISCUSSION THAT WOULD COME UP AROUND USING THEY IN A SENTENCE WHERE THE SUBJECT WAS SINGULAR THE PARTICIPANT HAD THEIR BLOOD DRAWN AND THAT WAS NOT SEEN AS GRAMMATICALLY CORRECT AND FOLKS WANTED TO SEE PERHAPS THE SENTENCE REWORKED TO NOT HAVE IT BE THE SINGULAR PRONOUN OR HAVE IT CHANGED TO SOMETHING LIKE THE PARTICIPANT HAD HIS/HER BLOOD TAKEN. WE KNOW FROM AN INCLUSION PERSPECTIVE THIS CAN BE IMPORTANT FOR FOLKS WHO ARE TRANSGENDER OR DON'T IDENTIFY ON THE GENDER BINARY.

IF WE'RE TRYING TO BE MORE INCLUSIVE EVEN IN LITTLE THINGS LIKE THAT THAT MAY NOT BE SUPER

OBVIOUS AT FIRST BUT IT'S AROUND TRYING TO CREATE A RESOURCE THAT IS SOMETHING THAT PEOPLE CAN COME TO AND FEEL LIKE IT'S FOR THEM FOR THEM IN SOME WAY.

WE'VE BEEN THINKING A LOT ABOUT HOW TO MAKE CULTURE AND LANGUAGE SOMETHING THAT WE CONTINUE TO BUILD INTO THIS WHETHER THAT'S IN IMAGES AND GRAPHICS OR MULTIMEDIA FOR PARTICULAR TERMS SO WE CAN HAVE MORE REPRESENTATION EVEN IN WHAT WE SEE IN TERMS OF WHAT'S ASSOCIATED WITH THOSE TERMS AND DEFINITIONS ARE THOSE ASPIRATIONAL ASPECTS THAT WE'RE THINKING FORWARD TO.

SO IN TERMS OF THINKING ABOUT CULTURAL AND LINGUISTIC AREAS WE TALKED ABOUT THAT A LITTLE BIT.

I WONDER WHEN WE THINK ABOUT EXPANSION, MOVING FORWARD, LOOKING ON THE HORIZON, WHAT ELSE COULD WE INTEGRATE INTO THE NEXT PHASE OF THIS GLOSSARY THAT COULD JUST EVEN BRING IT UP A LEVEL?

>> SOMEBODY WAS ASKING A QUESTION ABOUT THE GLOBAL VIEW.

ONE OF THE THINGS THAT I THINK WE SHOULD LOOK AT OPPORTUNITIES IS TO CREATE THE TRANSLATION SPACE.

SO WITH TRIALSUMMARIES.COM WHERE WE PUT THE CLINICAL TRIAL RESULT SUMMARIES OR WHEN -- I HAVE SAID A QUESTION ABOUT PLAIN LANGUAGE SUMMARIES, I KNOW PLAIN LANGUAGE SUMMARIES IS A PUBLICATIONS TERM BUT SOME PEOPLE USE THEM TO DESCRIBE THE LAY LANGUAGE SUMMARIES THAT ARE OUT OF THE EUCTR, WHICH HAS BECOME QUITE POPULAR, AND WE CALL THEM TRIAL RESULTS SUMMARIES. SO THEY ARE AN EASY-TO-UNDERSTAND SUMMARY OF WHAT HAPPENED IN THE STUDY AIMED AT THE GENERAL PUBLIC AND PARTICIPANTS WITHIN THE STUDY.

WHEN I'M INTERCHANGING THE TERMS TRS, PLAIN LANGUAGE SUMMARY, LAY SUMMARY, IT'S THAT THAT IS FOCUSED ON THE GENERAL PUBLIC MADE AVAILABLE FROM OUR PERSPECTIVE THROUGH TRIALSUMMARIES.COM AND IN THAT CASE IT'S NOW AVAILABLE IN 50 LANGUAGES OR SOMETHING. THE ABILITY TO TAKE WHAT YOU'VE LANDED TO BE THE RIGHT HARMONIZED DEFINITION AND CREATED IT IN ENGLISH AS THIS TEMPLATED LANGUAGE AND TRANSLATE IT USING THE BEST PRACTICES IN TRANSLATION, USING NATIVE LANGUAGE SPEAKERS, USING CERTIFICATION THAT IT BACK TRANSLATES PROBABLY WOULD BE AN EXCELLENT EXTENSION OF THIS.

AND ALSO MIGHT BE A DIFFERENTIATOR THAT COULD START TO CREATE THAT GLOBAL HARMONIZATION BECAUSE I TRY TO REMIND PEOPLE WHEN TALKING ABOUT CLINICAL RESEARCH AND TALKING ABOUT TRANSPARENCY IT'S GLOBAL.

WHAT YOU SAY OWN A U.S. WEBSITE DOESN'T JUST BECOME LIMITED TO THOSE IN THE U.S. OR WHAT YOU PUBLISH IN EUROPE ON A WEBSITE DOESN'T ONLY ALLOW ACCESS TO A CERTAIN DEMOGRAPHIC BASED ON LOCATION.

IT'S OUT THERE, IT'S OUT THERE.

AND WE NEED TO TAKE THIS INTO ACCOUNT IN TERMS OF HOW WE SUPPORT GROWING THIS UNDERSTANDING GLOBALLY.

SO TRANSLATIONS WOULD BE MY BIGGEST ASK OR IDEA IN PROMOTING THIS.

>> SOMETHING WE THINK A LOT ABOUT HERE.

HOW ABOUT DESIREE OR IVY?

DESIREE?

>> BEFORE JULIE SPOKE, A THOUGHT CAME TO MIND AND IT SORT OF RELATES TO THE LAST QUESTION,

BUT IT COULD DEFINITELY BE APPLICABLE HERE AND SOMETHING THAT IVY RAISED.

IT'S MAYBE HAVING SOME FOCUS GROUPS WITH THE INDIVIDUALS BECAUSE WE KNOW NOW THAT THERE'S A GREATER FOCUS ON DIVERSITY AND MAKING SURE THAT UNDERREPRESENTED POPULATIONS AND RESEARCH GET INTO THESE TRIALS.

AND I THINK THAT IT WOULD BE IMPORTANT TO REALLY UNDERSTAND THE PERSPECTIVES OF THESE RESPECTIVE GROUPS SO THAT YOU CAN THEN TAILOR WHAT IS GOING TO BE DONE TAKING THAT INFORMATION INTO ACCOUNT.

AND I DEFINITELY FEEL THAT THE TRANSLATION CLEARLY BASED ON SOME OF THE COMMENTS EARLIER, THIS IS AN INTERNATIONAL GROUP HERE, BUT I WOULD DEFINITELY SAY THAT IT'S IMPORTANT THAT WE SPEAK THE LANGUAGE, RIGHT?

AND THE ONLY WAY WE CAN DO THAT TO SAY THAT RESEARCH AND CLINICAL RESEARCH SPECIFICALLY IS GOING TO BE FOR ALL OF US IS THAT WE ACTUALLY MAKE SURE THAT IT IS.

AND SO I AGREE WITH JULIE THAT IT IS GOING TO BE SO IMPORTANT TO MAKE SURE, ESPECIALLY IN THE U.S., WE HAVE SOME DIFFERENT LANGUAGES HERE, BUT THE UNIVERSAL ONE OR NUMBER TWO ONE THAT WE TEND TO SEE IS SPANISH AND I'M AMAZED HOW MUCH MATERIAL IS NOT AVAILABLE IN SPANISH IN 2021.

AND I JUST FEEL THAT THAT IS QUITE UNFORTUNATE BECAUSE THOSE INDIVIDUALS GET DISEASE AS WELL.

AND SO I THINK THAT WE REALLY NEED TO START TO MAKE THE INVESTMENT IF WE'RE REALLY SAYING THAT WE'RE PATIENT-CENTERED TO SAY THAT WE'RE TRYING TO CREATE HEALTHCARE, QUALITY CARE, AT THE END OF THE DAY.

WE NEED TO PUT THE MONEY INTO WHAT IS GOING TO MAKE EVERYONE FEEL LIKE YOU SAID, SYLVIA, THAT THIS IS FOR ME, AND THAT YOU SEE ME, AND THAT YOU'RE TRYING TO CARE FOR ME, AND THAT TOUR NOT TRYING TO USE A BROAD BRUSH TO SAY THAT I NEED TO FALL IN WITH EVERYONE ELSE. BECAUSE WE'RE ALL INDIVIDUALS BASED ON OUR DNA.

>> THANK YOU, DESIREE.

IVY, I SEE YOU'VE COME OFF MUTE

>> I'M THINKING ABOUT PEDIATRIC STUDIES WHEN WE TALK ABOUT ALL OF US AS WELL.

HAVING DONE SOME PEDIATRIC RESEARCH IN THE PAST, HOW CAN WE USE THIS GLOSSARY TO EXPAND IT USING TERMINOLOGY FOR CHILDREN.

AND WHAT WOULD THAT LOOK LIKE FOR THEM.

I THINK THAT'S REALLY IMPORTANT FOR CHILDREN TO FEEL EMPOWERED ABOUT THEIR HEALTHCARE AND ABOUT THE RESEARCH THAT THEY WILL BE PARTICIPATING IN.

AND SO I KNOW IRB'S SOMETIMES HAVE CHALLENGES WITH HOW ASCENT IS WRITTEN AND OBTAINED FROM CHILDREN.

SO I SEE AN OPPORTUNITY HERE TO EXPAND ON THAT AND TO INCLUDE THOSE AGE GROUPS LIKE SIX TO 12 OR SEVEN TO 14 TO INCLUDE THEM IN THE GLOSSARY.

>> I LOVE THAT IDEA.

IT'S AS IF YOU KNEW, LIKE I PLANTED THAT ANSWER WITH YOU BECAUSE THE MRCT CENTER IS ACTUALLY RUNNING A WHOLE PEDIATRIC PROJECT RIGHT NOW AROUND DEVELOPING RESOURCES AND IMPROVING ACCESS TO RESEARCH FOR PEDIATRIC POPULATIONS AND THERE'S GOING TO BE MORE OF THAT IN THE FUTURE.

SO THIS IS A FABULOUS IDEA OF INTEGRATING PEDIATRIC PERSPECTIVES INTO THE GLOSSARY AS WELL. SO THE WAY WE CAN MAKE IT REFLECT ALL OF US.

SO WE HAVE A FEW -- WE HAVE QUITE A FEW QUESTIONS IN THE CHAT SO I'M GOING TO SEE IF I CAN GET THROUGH SOME OF THESE AND ANY THAT I DO NOT GET TO WE'LL TRY TO RESPOND TO FOLKS AFTER AS LONG AS THEY'RE NOT ANONYMOUS AND I DON'T KNOW WHO YOU ARE.

BUT I WILL GO THROUGH AS FAST AS POSSIBLE.

LET'S SEE HOW WE CAN DO THIS.

SO THERAPEUTIC AREAS.

THERE'S A LOT OF AROUND THERAPEUTIC AREAS AND WHETHER TO BUILD THE GLOSSARY OUT.

WE'LL START WITH STILL TRYING TO EXPAND TO MORE CLINICAL RESEARCH SPECIFIC TERMS.

AND SEE HOW THOSE CONNECT POTENTIALLY TO THERAPEUTIC AREAS.

WE KNOW THERE ARE STILL SOME DISEASE-SPECIFIC PATIENT ADVOCACY GROUPS AND ORGANIZATIONS THAT ARE CREATING GLOSSARIES FOR THEIR OWN CONDITIONS AND AREAS.

SO WE CAN SEE WHERE THERE'S ALSO PLACES FOR SORT OF LEVERAGING OF THE EXISTING RESOURCES TO BE ABLE ON CROSS-REFERENCE AND KIM, IF YOU HAVE SPECIFIC EXAMPLES OF GROUPS THAT WOULD BE GOOD TO WORK WITH OR THERAPEUTIC AREAS OR DISEASE AREAS WHERE THERE MAY BE EXISTING RESOURCES TO BUILD OFF OF, PLEASE FEEL FREE TO REACH OUT TO US SEPARATELY.

SIMILARLY, THERE WAS ONE AROUND A QUESTION AROUND COGNITIVE DISORDERS AND WHETHER FOLKS WITH COGNITIVE DISORDERS WERE INCLUDED IN THE CREATION OF THIS GLOSSARY.

I CAN'T SAY THAT'S SPECIFICALLY IN THIS PILOT THERE WERE, BUT THESE ARE DEFINITELY AREAS WE CAN SEEK TO EXPAND REPRESENTATION IN DEVELOPING DEFINITIONS MOVING FORWARD AND HAVING REVIEW BY DIFFERENT GROUPS LIKE THAT.

ONCE AGAIN, FOR THAT ATTENDEE IF THERE ARE GROUPS TO INCLUDE IN FUTURE INITIATIVES THAT WE CAN PARTNER WITH TO GET FEEDBACK AND BE ABLE DO SOME USABILITY TESTING WITH DIFFERENT GROUPS LIKE THAT WE'RE MORE THAN OPEN TO THAT.

SO PLEASE FEEL FREE TO REACH OUT ON THAT.

THERE WAS A QUESTION SPECIFICALLY, I THINK, AROUND IMPLEMENTATION OF DIFFERENT LITERACY LEVELS.

JULIE, I THINK YOU WERE STARTING TO ANSWER THAT AROUND IMPLEMENTATION OF DIFFERENT LITERACY LEVELS FOR DIFFERENT AGE LEVELS AND ALSO A QUESTION FOR YOU AROUND BARRIERS TO ADOPTION YOU SEE AT AZ WHICH MAYBE SOMETHING WE CAN EACH SPEAK TO IN TERMS OF OUR AREAS.

WHAT ARE TERMS TO ADOPTION AND HOW WE MIGHT BE ABLE TO OVERCOME?

>> ON THE FIRST QUESTION AROUND TARGETED TERM, I FIND THAT MANY OF THE PLACES WE'RE TALKING ABOUT EASY TO UNDERSTAND LANGUAGE ARE TARGETING THE 12-YEAR-OLD, SOME PEOPLE CALL IT THE 11 TO 13-YEAR-OLD MIDDLE SCHOOL AGE RANGE OF UNDERSTANDING.

WE TRY TO KEEP THAT IN MIND WHENEVER WE'RE THINKING ABOUT EASY TO UNDERSTAND LANGUAGE.

SO I THINK IT'S IMPORTANT TO UNDERSTAND TARGET AUDIENCE, TARGET AUDIENCE WE'RE TALKING ABOUT FOR THIS GLOSSARY IS ABOUT THE AVERAGE PERSON, NOT THE SCIENTIST.

THERE WAS A LITTLE BIT OF CONVERSATION ABOUT PUBLICATION PLS'S AND THEY TARGET DIFFERENT AUDIENCE AND OFTEN TARGET THE DOCTORS WHO AREN'T INTERESTED IN THE RESEARCH BUT STILL



TARGETING A SPECIALIZED LEVEL OF COMMUNICATION SO I THINK IT'S IMPORTANT TO SAY WHAT WE FOCUSED ON HERE WAS THE SORT OF GENERAL PUBLIC AVERAGE AGE 12 GIVE OR TAKE PLUS OR MINUS A YOUR OR TWO.

IN TERMS OF ADOPTION AT A COMPANY LIKE AZ THE BIGGEST THING IS BACK TO THAT HARMONIZATION VALUE PERSPECTIVE AND THE FACT THAT SO MANY DIFFERENT GROUPS ARE TRYING TO DO THIS BECAUSE IT'S IMPORTANT.

SO THE IMPORTANCE OF THIS CONFLICTS WITH THE ABILITY TO HARMONIZE AND WHEN YOU HAVE DIFFERENT EFFORTS THAT PEOPLE ARE INVESTED IN TO GET TO THIS POINT HOW DO WE BRING THEM TOGETHER, ESPECIALLY WHERE THERE'S CONFLICT, FOR EXAMPLE.

AND I THINK IT'S ABOUT AWARENESS.

I THINK IT'S ABOUT DISCUSSION.

I THINK IT'S ABOUT SOMETIMES PEOPLE SORT OF CHOOSING TO BURY THEIR PRIDE AND SAY I'LL GO THIS WAY.

SOMETIMES IT'S GOING TO BE ABOUT HAVING OPTIONS OUT THERE.

WE MAY NOT ALWAYS HAVE THE EXACT SAME DEFINITION OF BLOOD DRAW.

BUT HOPEFULLY IT'S CLOSE, HOPEFULLY IT'S IN SIMPLE AND EASY TO UNDERSTAND LANGUAGE AND HOPEFULLY IT IS A LOT CLOSER TO BEING EASILY UNDERSTOOD BUT SOMEBODY WHO IS CONSENTING IN A STUDY THAN SOME OF THE TECHNICAL TERMS WE'VE SEEN USED.

IT'S ABOUT THE COMMITMENT AND THE WILLINGNESS TO COMPROMISE AND REMEMBERING HARMONIZATION IS MORE IMPORTANT THAN MY PARTICULAR INITIATIVE.

I'M NOT SAYING WE CAN'T OVERCOME THOSE BUT WHEN YOU HAVE A LARGE GLOBAL ORGANIZATION AND YOU HAVE A SIGNIFICANT FOCUS ON TRYING TO BE PATIENT CENTERED OR IN EVERYTHING THAT YOU'RE DOING YOU HAVE DIFFERENT INITIATIVES FOCUSING ON THESE THINGS.

SOME OF IT TA SPECIFIC, I SAW SOME QUESTIONS ABOUT TA SPECIFIC WHEN I WAS LOOKING THROUGH THE CHATS.

IT'S THE SAME THING WE'RE FACING WITHIN OR ORGANIZATION WHERE THERE'S PARTICULAR FOCUS FOR A TA TO SAY WE WANT ALL OUR STUDIES WHEN WE'RE FOCUS ON THESE IT HAS A SPECIFIC TERMS TO USE THIS DEFINITION.

THAT'S AWESOME.

I IMAGINE IF WE COULD MAGICALLY PUSH THE EASY BUTTON AND BRING ALL THESE INITIATIVES ACROSS DIFFERENT ORGANIZATIONS TOGETHER WE WOULD HAVE SOMETHING TO REVIEW AND SYLVIA YOU AND YOUR TEAM WOULDN'T HAVE TO START FROM SCRATCH ON THIS.

MAYBE THAT'S AN OPPORTUNITY, WHO WANTS TO DONATE THE GLOSSARIES THEY'VE BUILT TO THIS INITIATIVE.

AND THEN START TO USE THOSE TO REACT.

I KNOW YOU DON'T JUST WANT A DATA BUMP BUT THERE'S A LOST WORK THAT'S GONE INTO IT AND WHEN THERE'S A LOST ENERGY AROUND IT IT'S AN OPPORTUNITY AND A CHALLENGE AT THE SAME TIME.

AND SO THAT'S TO ME THE JOURNEY IN SUCCESSFUL ADOPTION ACROSS A COMPANY SUCH AS ASTRAZENECA.

WE WANT TO MAKE THIS ACCESSIBLE AND THAT'S OUR COMMITMENT.

>> UH-HUH.

ANY OTHER COMMENTS FROM OUR PANELISTS JUST ON THE BARRIERS OR -- IMPLEMENTATION AND POTENTIAL OPPORTUNITY TO OVERCOME?

>> YES.

I SAW A COMMENT ABOUT LEGAL REPRESENTATION AND HAVING YOUR LEGAL OFFICE REVIEWING YOUR CONSENT DOCUMENTS AND THAT'S OUR EXPERIENCE IN THE ACADEMIC MEDICAL CENTERS THAT WE HAVE MANY STAKEHOLDERS WHO HAVE SPECIFIC LANGUAGE THAT HAS TO BE IN THESE DOCUMENTS AND SO FORTH.

AND I THINK IT GOES BACK TO WHAT JULIE IS SAYING, GETTING EVERYBODY ON BOARD AND UNDERSTANDING THE IMPORTANCE OF HAVING A PLAIN LANGUAGE DOCUMENT FOR PARTICIPANTS. AND IF ANYONE HAS BEEN ABLE TO DO THAT WITH THEIR LEGAL, I WOULD LOVE TO HEAR ABOUT THEIR EXPERIENCE BECAUSE WE'RE GOING TO EXPLORE THIS AS WE BEGIN TO BREAK DOWN OUR CONSENT DOCUMENTS USING THIS GLOSSARY.

>> THANK YOU.

SO WE HAVE ONE MINUTE LEFT.

MAYBE I'LL GIVE DESIREE, IF YOU HAVE A LAST WORD AS OUR PATIENT ADVOCATE, AROUND THE GLOSSARY AND OPPORTUNITY, THEN I'LL WRAP US UP ON THE HOUR.

IF YOU HAVE ANYTHING ELSE YOU WANTED TO SHARE.

>> I JUST WANTED TO SAY THIS IS AN EXTREMELY IMPORTANT TOOL.

AND I'M EXCITED AND I'M SURE MY FELLOW PATIENT ADVOCATES ARE EXCITED TO HAVE THIS AND THOSE THAT ARE ALSO INVOLVED AS RESEARCH ADVOCATES I THINK THAT THIS IS A GREAT OPPORTUNITY.

SO I WANTED TO SAY THAT IVY SPOKE ABOUT INTRODUCING AND MAKING SURE THAT THE MEDICAL STUDENTS HAVE THE OPPORTUNITY TO LEARN ABOUT THIS EARLY SO IT'S JUST PART OF THEM BEFORE THEY EVEN BECOME TRIALISTS BUT I ALSO SAY FOR THE ADVOCATE COMMUNITY, THERE ARE DIFFERENT ORGANIZATIONS THAT ACTUALLY TRAIN AND PROVIDE EDUCATION AND THIS WOULD DEFINITELY BE SOMETHING THAT THEY CAN ADD AS A SECTION OF THEIR TRAINING TO ENSURE THAT THE ADVOCATES NOW, THEY HAVE THE CORRECT LANGUAGE TO BE USING.

AND I WOULD SAY THAT ADVOCATES DEFINITELY HAVE VOICES, AND THEY WILL BE THE WAY IN ALL THE DIFFERENT AREAS THAT THEY SERVE, TO BE ABLE TO PUT THIS OUT AND TO INTRODUCE IT ON VARIOUS PLATFORMS AS WELL.

AND SO I'M EXCITED, I LOOK FORWARD TO WHAT'S TO COME, AND CONGRATULATIONS ON GREAT WORK.

>> THANK YOU SO MUCH TO OUR WONDERFUL PANELISTS, DESIREE, IVY, JULIE, THANK YOU FOR JOINING US AND THANK YOU TO OUR WONDERFUL ATTENDEES FOR STICKING FOR AN EXTRA MINUTE IN OR ZOOM CENTRIC WORLD RIGHT NOW.

THANK YOU FOR HELPING CELEBRATE THE LAUNCH OF THE GLOSSARY.

GO FORTH AND USE IT AND SEND US YOUR FEEDBACK.

THERE ARE PLENTY OF PLACES THROUGHOUT THE WEBSITE TO SEND US FEEDBACK AND STAY TUNED FOR FUTURE OPPORTUNITIES AND WE MAKE THIS AN EVEN MORE WONDERFUL RESOURCE IN THE FUTURE.

THANK YOU, EVERYONE.

I HOPE ALL HAVE A WONDERFUL INDEPENDENCE DAY AND I WONDERFUL SUMMER.

ENJOY.

>> THANK YOU.