

>> THANK YOU ALL FOR COMING AND WE HOPE WE'LL HAVE A LIVELY DISCUSSION.

IT'S A LITTLE BIT SMALLER THAN WE HAD HOPED BECAUSE OF -- I THINK BECAUSE OF THE CHALLENGES WE'RE FACING, BUT WHAT WE WANTED TO DO WAS TO FOCUS AGAIN ON GETTING A VARIETY OF INPUTS, GETTING INPUT ABOUT AN AREA THAT'S CRITICAL TO OUR DEVELOPMENT AND TO WHAT WE WANT TO PROMOTE FROM OUR BRANCH, AND SO OUR PURPOSE -- THIS IS THE FOURTH IN A SERIES THAT WE WANTED TO DO TO SOLICIT YOUR OPINIONS AND I DON'T HAVE TO GO THROUGH THE WHOLE PIECE, AND FOR YOU, HOPE TO LEARN A LITTLE BIT AND TO ALSO GIVE YOU SOME -- YOU MEANING INGRID AND ARNIE IN PARTICULAR ON THIS CALL SOME SENSE OF WHERE WE'RE GOING OVERALL AND WHAT SOME OF THE ISSUES ARE.

SO WE'RE LUCKY TO HAVE WITH US TODAY GLYN ELWYN, VISITING FROM THE U.K. AND WORKING AT DARTMOUTH, HAS VOLUNTEERED TO GIVE UP SOME OF HIS TIME TO COME SPEND TIME WITH US AND TO TALK ABOUT A COUPLE OF EXAMPLES OF SHARED DECISION-MAKING AND THE CHALLENGE OF IMPLEMENTING SHARED DECISION-MAKING AND ACTUAL MEDICAL PRACTICE. SO SARAH, DID YOU WANT TO ADD ANY OTHER INTRODUCTIONS? SARAH AND MIHO ARE ON THE CALL, THEY'RE PART OF OUR BRANCH, THEY'RE WORKING NOW IN ORGANIZING SOME WORK ON DECISION-MAKING OVERALL WITH NBRP AND OF THAT OVERALL PROBLEM.

SARAH, MIHO, DO YOU WANT TO ADD ANYTHING?

>> WELL, I THINK WE COULD SAY NOW ARNIE AND PEOPLE FROM THE OUTSIDE COMMITTEE KNOW WE'VE BEEN TALKING ABOUT THE CONSEQUENCES OF SHARED DECISION-MAKING AS OUR PARTICULAR AREA OF INTEREST AS A PROCESS IN PRIMARY CARE, WHAT ARE THE IMPLICATIONS OF DOING THAT, SO I'M LOOKING FORWARD TO HEARING GLYN'S CONVERSATION ABOUT THAT AND ALL OF OUR DISCUSSING HOW IT RELATES TO THE REALITY OF SHARED DECISION-MAKING ON CANCER AND PRIMARY CARE AND OTHER TOPICS.

>> TAKE IT AWAY, GLYN.

>> THANK YOU VERY MUCH.

DELIGHTED TO BE SPEAKING TO YOU.

CAN I LET YOU KNOW, I'M PART OF A POSTDOCTORAL GROUP HERE AT DARTMOUTH COLLEGE, FIVE OF THE POSTDOCTORAL PEOPLE ARE HERE WITH ME.

I'M GOING TO ASK THEM JUST TO SAY THEIR NAMES AS THEY GO AROUND THE TABLE.

THEY'RE WATCHING THE BIG SCREEN WITH ME AT THE MOMENT.

>> HI, I'M TOM WALSH.

STEWART GRANDY.

RACHEL THOMPSON, PAUL BARR.

>> AS YOU CAN PROBABLY HEAR FROM THE ACCENT, THEY'RE FROM AN INTERNATIONAL GROUP, SO YOU'VE GOT MORE PEOPLE ON THE CALL THAN YOU THINK.

>> THAT'S GREAT.

WELCOME.

>> THANK YOU.

SO THIS GROUP HERE IS INTERESTED IN RESEARCHING AND MEASURING SHARED DECISION-MAKING, SO LET ME JUST TALK TO THE SLIDES VERY BRIEFLY.

I'M VERY AWARE THAT WE NEED TO HAVE A CONVERSATION RATHER THAN ME TALKING FOR A LONG TIME, SO LET'S GO TO THE FIRST SLIDE, PLEASE.

>> I THINK IT'S THE ONE AT DARTMOUTH OR THE ONE THAT SAYS CASE DISCUSSIONS?

>> YOU'VE GOT -- I THINK YOU'VE COVERED THAT.

>> THAT'S RIGHT.

>> SO IF YOU GO TO THE DARTMOUTH SLIDE, THIS IS -- I'LL KICK OFF THERE.

JUST TO EXPLAIN THAT, WE'RE PART OF A NEW CENTER, WHICH IS REALLY INTERESTED IN INVESTIGATING HEALTHCARE DELIVERY SCIENCE.

SO MORE THAN A SINGLE DISEASE, IT'S REALLY FOCUSING ON HOW CARE IS DELIVERED TO ADD MAXIMUM VALUE TO PATIENTS AND THE SYSTEM.

I'M NOT GOING TO GO INTO ANY GREAT DEPTHS ABOUT THAT. YOU CAN SEE MORE ON THE WEBSITE ACTUALLY.

BUT WE'RE PART OF AN EFFORT HERE AT DARTMOUTH TO FOCUS ON DELIVERY AS A SCIENTIFIC ISSUE.

LET ME GO TO THE NEXT SLIDE.

SO I'VE BEEN TALKING AND YOU MAY HAVE READ SOME PAPERS FROM THE PMJ ABOUT THIS CASE STUDY OF LINDA AND SUSAN, TWO WOMEN WHO BOTH GOT BREAST CANCER, BUT THEY'VE GOT DIFFERENT KIND OF CHARACTERISTICS.

ONE'S YOUNGER, ONE'S OLDER.

AND ACTUALLY ONE WAS KIND OF DIAGNOSED AS HAVING A CANCER AND THEN FOUND OUT ON THE -- WHEN SHE HAD THE NEEDLE BIOPSY THAT SHE'D HAD UNNECESSARY SURGERY, BECAUSE THERE HAD BEEN AN ERROR MADE ON HER NEEDLE BIOPSY.

THAT'S SUSAN.

SO LINDA ON THE OTHER HAND -- SORRY, I'M MIXING IT UP. SO LINDA IS THE ONE WHERE NO CANCER WAS FOUND IN THE BREAST BUT SHE HAD SURGERY.

AND SUSAN HAD MASTECTOMY BUT DIDN'T REALIZE THAT SHE HAD OTHER TREATMENT OPTIONS.

BASICALLY SHE COULD HAVE RECEIVED HORMONES WITHOUT HAVING SURGERY.

WHERE THERE WAS LINDA, THERE WAS TREMENDOUS UPSET IN THE HOSPITAL BECAUSE SHE'D HAD UNNECESSARY SURGERY, WHEREAS WHEN SUSAN MADE AWARE THAT SHE FELT SHE'D HAD UNNECESSARY SURGERY, NOBODY MUCH GAVE ANY ATTENTION TO THAT.

WE'VE BEEN CALLING THAT A SILENT MISDIAGNOSIS.

WE THINK THAT ISSUE IS MUCH MORE COMMON THAN WE GIVE RECOGNITION TO PEOPLE THAT HAVE HAD TREATMENTS THAT IF THEY'D KNOWN, THEY PROBABLY WOULD NOT HAVE CHOSEN IN FULL KNOWLEDGE AS IT WERE, SO WE'RE CALLING THIS AN ISSUE OF PREFERENCE DIAGNOSIS AND THE GENERAL ISSUE OF SILENT MISDIAGNOSIS OF PREFERENCES.

LET ME GO ON TO THE NEXT SLIDE.

NOW IN AN EFFORT TO ADDRESS THIS ISSUE OF PREFERENCE DIAGNOSIS, THIS IS MAYBE JUST A DIFFERENT TERM FOR SHARED DECISION-MAKING, ESSENTIALLY, THERE'S BEEN AN ENORMOUS -- IN PRESENTING PATIENTS WITH DECISION SUPPORT TOOLS.

HERE IS AN EXAMPLE OF A PATIENT AT THE BENEFITS AND RISKS OF SURGERY.

YOU WILL BE AWARE OF THE COCHRAN REVIEW AND SHOWING THE RESULTS.

LET ME MOVE ON TO THE SLIDE SUMMARIZING THE COCHRAN REVIEW RIGHT NOW.

I'M NOT GOING TO GO INTO THIS IN GREAT DETAIL.

YOU'LL KNOW THE BACKGROUND.

BUT ESSENTIALLY THERE ARE OVER 80 PROBABLY ALMOST CLOSE TO 100 TRIALS NOW SHOWING THAT PEOPLE HAVE GREAT OUTCOMES IN TERMS OF KNOWLEDGE, MORE ACCURATE RISK PERCEPTIONS AND FEEL MORE INVOLVED IN DECISIONS WHEN WE USE THESE TOOLS.

THE DEVIL OF THE JOB, THE DEVIL IS IN THE DETAIL, REALLY. THERE ARE HARDLY ANY INSTITUTIONS IN THE U.S. THAT ARE USING THESE TOOLS ROUTINELY.

WE KNOW THAT.

THERE ARE EXCEPTIONS, OFTEN, IN DARTMOUTH, AND IN GROUP HEALTH RECENTLY THEY'VE PUBLISHED A LOT OF PAPERS ABOUT

A LARGE EFFORT MADE TO USE THESE TOOLS WITH GOOD OUTCOMES.

IF WE'RE HONEST WITH EACH OTHER, IF I GO TO COULD BE CORD, MANCHESTER, ANYWHERE IN NEW ENGLAND, YOU WON'T SEE THESE TOOLS IN USE.

SO WHY IS THAT, IS ONE OF THE QUESTIONS THAT I THINK IS FACING US.

LET'S GO TO THE NEXT SLIDE.

I'M DRAWING HERE ON SOME WORK THAT WE'VE DONE ON THE REVIEW OF IMPLEMENTATION, SO WE'VE LOOKED NOT AT THE TRIALS BUT AT 18 STUDIES THAT HAVE TRIED TO PUT THESE TOOLS INTO ROUTINE CARE.

IN EFFECT THEY'VE BEEN WORKING WITH CLINICAL PRACTICE IN THE NORMAL ROUTINE, AND THEY'VE TRIED TO GET PRACTITIONERS TO USE THESE TOOLS.

THIS REVIEW WAS ACCEPTED AND IT WILL BE OUT IN A FEW MONTHS.

SO I'M DRAWING ON THAT REVIEW WHEN YOU SEE THE NEXT SLIDE.

SO THERE'S EMPIRICAL DATA BETWEEN THESE SUMMARIES.

ANOTHER PIECE OF WORK IS ALMOST 60 INTERVIEWS WITH PROVIDERS THAT WE DID IN A PROGRAM CALLED THE MAGIC PROGRAM, AND WE'VE GOT A PAPER JUST ON THE WAY TO BEING SUBMITTED TO IMPLEMENTATION SCIENCE WHICH IS CALLED PATCHY COHERENCE.

STRANGE TITLE.

I'M GOING TO EXPLAIN THAT TO YOU IN A MOMENT.

LET ME HAVE THE NEXT SLIDE.

SO THE CHALLENGES WE FEEL ARE AROUND THESE ISSUES OF IMPLEMENTATION, THERE'S A RELUCTANCE ON THE PART OF PATIENTS, AND WE'LL TALK A BIT ABOUT THAT, AND PARTICULARLY ABOUT THE INFORMATION LOAD THAT -- LONG TOOLS, AS I CALL THEM, ARE INTRODUCING.

THE IMPLEMENTATION BARRIERS --

>> OKAY.

I NEED TO COVER THE IMPLEMENTATION BARRIERS.

YOU'LL SEE THAT THIS WORK HAS BEEN PUBLISHED BY MANY OTHERS AS WELL, BUT HERE IS THE ISSUES.

CLINICIANS HAVE UTTER DEMANDS ON THEM.

THERE ARE TIME PRESSURES.

TRYING TO USE A LONG DECISION TOOL INSIDE THE CLINICAL ENCOUNTER DOESN'T WORK.

IT'S JUST NOT FEASIBLE.

AND TRYING TO GET THESE TOOLS TO PATIENTS AHEAD OF TIME IS ACTUALLY VERY DIFFICULT.

WE KNOW THAT PROBABLY 30 OR 40% -- PEOPLE USE THEM IF THEY'RE SENT OUT AHEAD OF TIME AND WE DON'T ALWAYS KNOW IF YOU'RE SENDING IT TO THE RIGHT PATIENTS.

IN CANCER, THAT'S A PARTICULAR ISSUE BECAUSE YOU WOULD NOT WANT TO SEND ANYBODY A TOOL IF THEY WEREN'T AWARE OF THE DIAGNOSIS.

THAT'S FOR SURE.

AND TYPICALLY, THERE'S A LACK OF ORGANIZATIONAL SUPPORT FOR DISSEMINATING THESE TOOLS.

YOU NEED AN OFFICE, AN INFRASTRUCTURE, STAFF AND SO ON, TO MAKE SURE THAT PEOPLE ROUTINELY GET THESE TOOLS AT THE RIGHT TIME IN THE WORK FLOW.

SO THESE ARE SYSTEM PROBLEMS, AND THEY'RE VERY LARGE. THE GROUP HEALTH EXPERIENCE SHOWS THEY INVESTED A LOT OF MONEY AND AN ENORMOUS AMOUNT OF EFFORT TO GET THESE INTO ORGANIZATIONAL ROUTINES.

NEXT SLIDE, PLEASE.

HERE ARE SOME OTHER MORE DEEPER ISSUES AT THE PROVIDER LEVEL.

WE'RE FINDING THAT CLINICIANS ARE ACTUALLY QUITE RESISTANT TO THE TOOLS AND HOW TO USE THEM.

THEY DON'T ALWAYS AGREE WITH THE CONTENT IN THEM.

THEY SAY I DON'T AGREE WITH THAT EVIDENCE AND HOW IT'S PORTRAYED.

THEY CERTAINLY SAY EVIDENCE IS NOT RELEVANT TO THE PATIENT IN FRONT OF ME TODAY.

IT'S MORE GENERALIZED EVIDENCE.

THEN NOT COMFORTABLE TO USE THE EVIDENCE.

OFTEN THEY SAY THEY COMPETE WITH OTHER INFORMATION THAT THEY'RE GIVING TO PATIENTS, AND THEY DON'T FEEL THAT GIVING THESE TOOLS OUT IS A PRIMARY PART OF THEIR JOB ROLE.

THIS IDEA OF NORMALIZATION PROCESS THEORY, THIS IS A THEORY DEVELOPED BY A SOCIOLOGIST IN SOUTHAMPTON AT THE MOMENT.

I WANT YOU TO JUST BEAR WITH THE TERMINOLOGY IT'S USING BECAUSE IT'S KIND OF ACADEMIC AND SOCIOLOGY TALK.

IF I JUST USE FOUR WAYS OF TRYING TO MAKE THOSE TERMS A BIT MORE UNDERSTANDABLE.

COHERENCE IS ABOUT WHAT IS THE WORK, WHAT IS THE WORK WE'RE TRYING TO ACHIEVE.

COGNITIVE PARTICIPATION IS ABOUT WHO DOES THE WORK, WHO IS GOING TO DO THE WORK.

COLLECTIVE ACTION IS ABOUT HOW DID THE WORK GET DONE.

>> ARE YOU ALL THERE?

>> I'M PAUSING A SECOND JUST IN CASE THE INTERFERENCE IS AFFECTING YOUR ABILITY TO HEAR THIS.

>> IT DID, BUT NOW IT'S GONE.

>> OKAY.

I WONDER IF IT'S WORSE WHEN I'M TALKING ACTUALLY.

>> ASK EVERYONE TO PUT THEIR PHONES ON MUTE, OTHER THAN THE SPEAKER.

>> OKAY.

I PROMISE I'LL LET YOU KNOW WHEN I WANT SOME REACTION. SO THE COLLECTIVE ACTION IS ABOUT HOW DID THE WORK GET DONE, BY PEOPLE WORKING TOGETHER, REFLEXIVE MONITORING, HOW WE GOT -- THE WORK GOT DONE IS THE MEASUREMENT PIECE. LET ME GET TO THE MORE PRACTICAL ISSUES ON THIS.

THE COHERENCE IS ABOUT SENSE MAKING, HOW PEOPLE UNDERSTAND THE WORK THEY'VE GOT TO DO.

LET'S TAKE THAT RIGHT DOWN TO A PRACTICAL EXAMPLE NOW. LET'S GO TO THE NEXT SLIDE.

WE WERE WORKING WITH, IN THE MAGIC PROJECT, WITH AN ENT CANCER TEAM.

PEOPLE WITH ENT CANCERS, VERY DISTRESSFUL CANCERS, TREATMENT IS DEBILITATING IN TERMS OF RADICAL SURGERY, LOSING YOUR ABILITY TO SWALLOW, TO SPEAK AND SO ON, AND THE TREATMENT MODALITIES ARE SURGERY, RADICAL SURGERY, OR DEEP RADIOTHERAPY WITH QUITE A LOT OF SIDE EFFECTS, INCLUDING PLUS OR MINUS CHEMOTHERAPY.

SO THE TRADEOFFS IN TERMS OF THE QUALITY OF YOUR LIFE, THE ABILITY TO SPEAK, THE ABILITY TO SWALLOW, ARE QUITE IMMENSE, AND TOUGH DECISIONS PEOPLE HAVE TO MAKE ABOUT HOW TO TREAT THESE CANCERS.

NOW, WE TALKED TO THE ENT ABOUT MAKING OPTION GRIDS TO THESE TOOLS, TO PATIENTS.

AND WHAT WE DISCOVERED IS THAT SOME HAD FELT THAT THEY ALWAYS INVOLVE THE PATIENTS IN THESE DECISIONS.

AND YET ANOTHER SPECIALIST SAID IT ACTUALLY WASN'T THE ROLE TO PRODUCE TOOLS THAT PROVIDE OPTIONS TO PATIENTS THAT THE ROLE OF THE TEAM WAS TO PROTECT PATIENTS FROM THE AGONY OF CHOICE, AS HE PUT IT.

IN OTHER WORDS, IT'S NOT OUR JOB TO PRESENT PATIENTS WITH OPTIONS AT ALL.

AND HE SAID OUR JOB IS TO QUITE CLEARLY HELP PEOPLE TO

MAKE WHAT WE THINK IS THE RIGHT DECISION.

WE KNOW FROM CONVERSATIONS WITH PATIENTS THAT THEY HOLD VERY DIFFERENT VIEWS IF YOU ASK THEM, THEY SAY ONE MAN SAID I DON'T CARE WHAT YOU DO, PROVIDED YOU DON'T TAKE OUT MY LARYNX.

I WANT TO BE ABLE TO SPEAK, I DON'T CARE IF I DIE MORE QUICKLY, I JUST WANT TO BE ABLE TO SPEAK.

SO WE CLEARLY HAVE A CONFLICT HERE BETWEEN THE VIEWS OF SOME PEOPLE IN THE TEAM AND SOME VIEWS OF PATIENTS.

WHAT WE'VE DISCOVERED, IN FACT, IS A LACK OF COHERENCE IN THE TEAM ABOUT SHARING DECISIONS WITH PATIENTS.

WHAT THE LEADER OF THE TEAM IS QUITE SURPRISED OF THIS, HE FELT THAT PEOPLE WORKING ON THE TEAM ALWAYS HAD THE SAME ATTITUDES TO SHARING DECISIONS.

HE FELT THAT THEY ALWAYS WORKED IN THE SAME WAY, THAT THERE WERE -- THEY LIKE TO INVOLVE PATIENTS IN DECISIONS.

IT WAS QUITE A SURPRISE TO HIM THAT THEY HAVE EQUAL POLARIZED VIEWS ABOUT WHAT SHOULD HAPPEN.

SO RATHER THAN HELPING THIS TEAM BY INTRODUCING THEM TO THE IDEA OF DECISION SUPPORT, WE CREATED AN INTERNAL CONFLICT IN THIS TEAM, AND ACTUALLY THEY HAD MANY ARGUMENTS WITH EACH OTHER ABOUT HOW BEST TO MANAGE PATIENTS WITH THESE CANCERS.

I'M NOT SURE THAT WE LEFT THIS TEAM IN A BETTER STATE THAN WHEN WE STARTED WITH THEM.

SO WE'LL ASK TO GO TO THE NEXT SLIDE AND SAY WHAT DID THE RESEARCH QUESTIONS THIS ISSUE OFFERS?

WHAT MEASURE DOES WE HE MOMENT SAID WE HAVE COHERENCE AGAINST TEAM MEMBERS AND HOW MIGHT THESE ISSUES RELATE TO EXISTING IDEAS OF MEASURING PATIENTS ASSOCIATED WITH DECISION-MAKING.

LET ME PAUSE THERE, ASK PEOPLE TO UNMUTE THEIR MICROPHONES AND JOIN IN THE CONVERSATION.

>> SO GLYN HAS OFFERED SOME QUESTIONS, WE ALSO DIDN'T GIVE PEOPLE ON THE PHONE A CHANCE TO TALK ABOUT THE CASE ITSELF IN THE BEGINNING, AND I THINK -- SO I'M SURE GLYN IS OPEN TO ALL OF THE ABOVE.

>> ABSOLUTELY.

I'M SORRY, YES, OF COURSE WE CAN GO BACK TO THE CASE AT THE BEGINNING.

I DIDN'T REALIZE THAT YOU WANTED TO PAUSE THERE. APOLOGIES FOR THAT.

>> THIS IS ARNIE IN CHAPEL HILL.
THIS IS VERY, VERY HELPFUL AND I THINK VERY RELEVANT TO
WHAT THE BRANCH IS TRYING TO DO.
ONE QUESTION FROM THE VERY BEGINNING, HOW WAS THIS
DIFFERENT FROM WHAT HEALTH SERVICES RESEARCH HAS BEEN
TRYING TO DO FOR A LONG TIME?

>> I DON'T THINK IT IS DIFFERENT, IT'S A BIT OF A
REBRANDING EXERCISE.
IF TRUTH BE TOLD.
BUT I THINK THE FOCUS ON IMPLEMENTATION AND MAKING
SYSTEMS OF DELIVERY FOCUSING ON THAT RATHER THAN ON
CLINICAL OUTCOMES IS PROBABLY THE MAIN DIFFERENCE.

>> I THINK THAT'S A VERY IMPORTANT THING.
PLUS IT RAISES THE WHOLE QUESTION OF SUSTAINABILITY.

I'M USING THE TERM NORMALIZATION OF THE I THINK ONE OF
THE THINGS IN IMPLEMENTATION RESEARCH WHICH HAS NOW BEEN
ACCEPTED WITHIN THE PEOPLE IN HEALTH SERVICES RESEARCH
WHO ARE CONCERNED ABOUT THESE THINGS AS OPPOSED TO SIMPLY
THE ECONOMICS -- ECONOMIC COLLEAGUES, IS THE
SUSTAINABILITY OF THINGS, AND ONE CAN POINT OUT OTHER
EXAMPLES LIKE THE CHECKLIST AND HOW DO YOU IMPLEMENT AND
SUSTAIN THAT KIND OF THING.

WHICH GETS INTO SORT OF A FUNDAMENTAL MANAGEMENT PROBLEM
OF THE ORGANIZATION

>> PART OF WHAT ARNIE'S RAISING IS SOMETHING THAT WE'VE
BEEN EMPHASIZING IS THE WHOLE ISSUE OF MULTILEVEL -- THE
MULTILEVEL CONTEXT OF CARE.

I DON'T KNOW THE SHARED DECISION-MAKING LITERATURE WELL,
BUT -- NOT THE RECENT LITERATURE BUT WHEN THIS WAS TALKED
ABOUT BEFORE, I THINK THERE WAS A FOCUS ON THE DYADIC
DISCUSSION BETWEEN THE PROVIDER AND THE PATIENT AND THAT
IT WAS FOCUSED ON THE DECISION.

IF YOU JUST GOT THE DECISION RIGHT, PROVIDED THE
INFORMATION RIGHT, THEN IT WAS -- IT'S THE PROCESS AND
THE DECISION, BUT THINKING ABOUT IT, HOW IT FITS INTO
THE SYSTEM WHETHER THE PROVIDERS AGREE WITH THE OPTIONS
PRESENTED BY THE DECISION-MAKING TOOL AND HOW THE
ORGANIZATION PUTS IT INTO THE FLOW AND WHAT THE
IMPLICATIONS ARE FOR AN ORGANIZATION THAT'S
IMPLEMENTING THAT.

I HAVEN'T SEEN AS MUCH ABOUT THAT.

I'D BE INTERESTED IN WHETHER THOSE ARE RESEARCH QUESTIONS.

>> LET'S FOLLOW UP ON THAT A LITTLE BIT, BECAUSE I THINK ONE OF THE WHOLE ROLES OF IMPLEMENTING THESE KINDS OF THINGS AND NORMALIZING IT IS THE ROLE OF MANAGEMENT WITHIN THESE ORGANIZATIONS.

I RECALL MANY YEARS AGO WHEN PAUL BATELLE AND A NUMBER OF COLLEAGUES INVOLVED WITH JCHO TRYING TO IMPLEMENT ALL THE IMPROVEMENT UNDER THEIR AGENDA FOR CHANGE AND SO FORTH, AND I WAS VERY INTRIGUED WITH HOW PAUL WAS GOING ABOUT THIS.

THIS IS BEFORE HE CLEANED UP HIS ACT AND WENT TO DARTMOUTH, AT HCA, BUT IT WAS KIND OF INTERESTING BECAUSE I'LL NEVER FORGET THIS, HE SAID, ARNIE, IT'S REALLY NOT A PROBLEM.

I GO FROM CORPORATE HEADQUARTERS TO THE HOSPITAL AND TALK WITH THE ADMINISTRATOR OF THE ORGANIZATION, THE VALUE OF QUALITY IMPROVEMENT AND IMPLEMENTATION AND SO FORTH AND SO ON, AND I SAID WELL, WHAT HAPPENS IF HE DOESN'T THINK IT'S A GOOD IDEA OR THE TIMING ISN'T BAD OR WHATEVER THE CASE MAY BE, AS ONLY PAUL CAN DO IN HIS VERY QUIET SORT OF WAY IS I JUST REMIND HIM THAT WE CAN HAVE A NEW ADMINISTRATOR HERE TOMORROW.

THAT'S A VERY POWERFUL THING.

IT'S A LITTLE CRUDE, BUT IT DOES EMPHASIZE THE ROLE OF A TOP-DOWN KIND OF ACTIVITY, AND GOING BEYOND SIMPLY THE PARTICIPANTS AT THE PROVIDER LEVEL, BUT INVOLVING MANAGEMENT STRUCTURE.

>> CAN I REACT TO THESE EXCELLENT COMMENTS?

AND I THINK YOU'RE ABSOLUTELY RIGHT BECAUSE ALL THOSE THESE ARE STRANGE TERMS, IN TERMS OF REFLEXIVE MONITORING WOULD RELATE BACK TO THAT IMMEDIATELY, BECAUSE THE ORGANIZATION WOULD CARE ABOUT THE FACT THAT THIS IS HAPPENING ROUTINELY, AND IF IT'S NOT HAPPENING ROUTINELY, SHARING DECISIONS, USING TOOLS, MEASURING WHETHER PEOPLE ARE MAKING DECISIONS THAT ARE CONGRUENT WITH THEIR BOUNDARIES, THAT ISN'T THE POLICY ISSUE IN THE ORGANIZATION, THEN SOMEBODY GETS HAULED UP TO THE MANAGER'S OFFICE OR CHIEF EXEC BE SAYING WHAT ARE YOU DOING, RATHER THAN WAITING TIMES OR PROFIT OR WHATEVER THE OTHER TARGETS MIGHT BE IN THE ORGANIZATION I DON'T THINK THESE ISSUES HAVE RAISED UP TO THE LEVEL OF MEASUREMENT IN THE ORGANIZATION AND, THEREFORE, THEY'RE

NOT TAKEN SERIOUSLY.

>> THAT'S EXACTLY RIGHT.

AND THAT'S THE REASON WHY THE MEASUREMENT QUESTION,
WHICH IS THE THIRD ONE HERE, IS SO CRITICAL TO THIS.
UNLESS WE CAN COME UP WITH GOOD METRICS.

OTHERWISE YOU NEVER GET THE ATTENTION OF THE PEOPLE WHO
CAN REALLY DRIVE SOMETHING HOME IN THE ORGANIZATION
BECAUSE THEY'VE GOT ALL THESE OTHER METRICS THEY HAVE
TO PAY ATTENTION TO.

>> THIS IS MARGIE GODFRIED.

HELLO, EVERYONE.

>> HELLO, MARGIE.

HOW ARE YOU?

>> I'M WELL, THANK YOU.

I WANTED TO FOLLOW UP ON THIS AS FAR AS LEADERSHIP
ATTENTION.

IT APPEARS TO ME THE -- DECISION-MAKING, HOW -- ARE
BEING DRAWN TO PAY ATTENTION THROUGH THIS IS THROUGH A
MEANINGFUL USE -- DO OTHERS FIND THAT ALSO, THAT YOU HAVE
TO HAVE -- [INAUDIBLE]

>> YOU'RE BREAKING UP, MARGIE.

>> DID YOU HEAR THAT?

>> YOU BROKE UP AT THE END.

I HEARD SOME OF IT.

THE QUESTION -- GO AHEAD.

SHE'S GONE.

WELL, I WANTED TO RAISE AN ISSUE, THOUGH, YES, IT'S ONE
THING TO HAVE TOP DOWN, BUT THERE HAS BEEN, FOR EXAMPLE,
SHARED DECISION-MAKING APPROACHES TO PROSTATE CANCER
TREATMENT, BUT IF YOU'RE SITTING IN AN ORGANIZATION
WHERE WHAT YOU HAVE IS A MACHINE TO DELIVER RADIATION,
OR YOU HAVE JUST INVESTED IN A NEW ROBOT, SURGICAL ROBOT,
AND THE DECISION TOOL IS RAISING THE CHOICES AROUND
TREATMENT AND THE POSSIBILITY OF WATCHFUL WAITING

>> RESPONSE TO PATIENT SENSITIVE DECISIONS, WITH THE
ATTAINABLE CARE THROUGH THE MEANINGFUL -- ALONG THE
RADAR SCREEN THAT THERE HAS TO BE A SET OF TOP PATIENT
SENSITIVE DECISIONS MADE IN ORDER TO GET REIMBURSEMENT
AND INCENTIVIZES THE ACTIONS TO BE TAKEN.

HAVE OTHERS OF YOU SEEN THAT HEARD OF THAT?

>> THIS IS STEVE.

NO, I WASN'T AWARE OF THAT.

IT WOULD BE VERY INTERESTING, AND IT WOULD BE RELEVANT TO WHILE YOU WERE OFF THE CALL, MARJORIE, I RAISED THE ISSUE OF WHAT'S --

WITH MUCH MORE -- MUCH LESS QUALITY OF LIFE, THEY COULDN'T SPEAK OR COULDN'T SWALLOW. SO THOSE TRAIT OF THE PATIENTS MIGHT MAKE ETHICALLY AND CORRECTLY MIGHT LEAD TO SYSTEM BENEFITS. BUT YOUR QUESTION ABOUT HOW TO PUT THAT MEASUREMENT IN THE PHYSICIAN'S HEAD AND IN THE SYSTEM OF THE ORGANIZATION IS ONE THAT I DON'T THINK WE'VE GOT A HANDLE ON AT THE MOMENT.

>> THIS WHOLE DISCUSSION ALSO MAKES ME THINK TO YOUR SECOND QUESTION WHEN WHAT MEASURE DO WE HAVE OF COHERENCE, AND I -- I THINK ABOUT OUR DISCUSSION, I DON'T KNOW THAT THERE'S A WAY TO MAKE THE WHOLE PROCESS COHERENT UNLESS YOU CHOOSE THE PATIENT PERSPECTIVE AND SAY BECAUSE THERE ARE SO MANY POTENTIAL CONFLICTS IN OUR SYSTEM IN THE U.S. WHICH MAY BE SLIGHTLY DIFFERENT THAN THE U.K., WHERE YOU'VE GOT A SINGLE PAYOR SYSTEM, BUT HERE, IT'S VERY HARD TO THINK ABOUT COHERENCE IN THE FACE OF THE COMPETING INTERESTS OF THE PARTIES INVOLVED. I THINK THE ONLY PATH TO COHERENCE IS FROM A PATIENT PERSPECTIVE, AND I THINK MOST WOULD THINK THAT ULTIMATELY THAT'S REALLY WHAT THEY INTEND TO HAVE HAPPEN.

THEY WILL ALL ARGUE THAT IT'S IN THE INTEREST OF THE PATIENT.

BUT I WONDER WHETHER, YOU KNOW, THE ISSUE -- THE ONLY WAY THAT MAKES THE DECISION THAT YOU'RE SUGGESTING WHERE SOMEBODY WOULD CHOOSE NOT TO HAVE THE SURGERY BECAUSE THEY WANT TO KEEP THEIR VOICE, THE ONLY COHERENT ARGUMENT COMES FROM THE PATIENT.

>> THAT'S RIGHT.

AND WHEN YOU HAVE CLINICIANS SAYING OUR DUTY IS TO PROTECT PEOPLE FROM MAKING THOSE DECISIONS, SOME OTHERS SAY NO, WE HAVE A DUTY TO LET PEOPLE KNOW THE OPTIONS AND LET THEM HELP US MAKE A GOOD DECISION, NOT MAKE A DECISION ON THEIR OWN, WHICH IS ABANDONMENT.

SO WHEN YOU HAVE PEOPLE ON THE SAME TEAM WITH UNPOLARIZED VIEWS ABOUT THIS, THEN WE'RE NOT GOING TO MAKE PROGRESS.

>> BUT I WONDER, GLYN, EVEN IN THAT SITUATION, THAT DOC THAT'S SAYING WE NEED TO PROTECT THEM FROM THE AGONY OF DECISION THINK THAT HE'S ACTING IN THE INTEREST OF THAT PATIENT.

SO IT IS A COMMON COHERENCE IF YOU SAY THE POINT IS TO OPTIMIZE THE OUTCOME FOR THE PATIENT.

WHAT WE HAVE TO DO THEN IS WORK THROUGH WHAT THAT MEANS AND THE DIFFERENCE IN WHAT OPTIMIZATION MEANS TO THE DOC WHO THINKS HE'S PROTECTING THEM VERSUS THE PATIENT WHO THINKS I WANT TO SAVE MY LARYNX.

>> THAT'S RIGHT.

IN A WAY THE DOCTOR WHO THINKS HE'S PROTECTING, HOW MUCH DO WE TOLERATE THAT PATERNALISM, IF YOU LIKE, WITHOUT HEARING THE PATIENT VOICE INTO THE DECISION-MAKING.

>> WHAT DO YOU SEE AS THE RESEARCHABLE QUESTION HERE?

>> I THINK THE RESEARCHABLE QUESTION IS TO FIGURE OUT WHAT ARE THE ATTITUDES OF PROVIDERS AND MANAGERS, ACTUALLY, OF THE DIFFERENT LEVELS, TO THE ISSUE OF LETTING THE PATIENT'S PREFERENCES GUIDE DECISION-MAKING.

WE DON'T REALLY KNOW THAT.

AND WE KNOW THAT THERE'S A CONFLICT IN THERE.

>> I THINK THAT'S EXCELLENT.

I THINK THAT REALLY IS A VERY FUNDAMENTAL QUESTION FOR THE PROBLEM PRESENTED HERE.

TO MAP THOSE THINGS OUT.

THERE ARE SOME THEORIES APPLIED TO HOW ONE WOULD BEGIN THINKING ABOUT RESOLVING THESE OR AT LEAST RECOGNIZING THEM.

>> I THINK THIS WHOLE ISSUE THAT GLYN HAS EXPOSED OF THERE ARE PROVIDER INTERESTS, THERE ARE ORGANIZATIONAL INTERESTS, THERE ARE INDIVIDUAL INTERESTS AND THEY NOT NECESSARILY ALIGN UNTIL YOU DO THAT, THE DYADIC PROCESS IS SORT OF SLIGHTLY IRRELEVANT.

>> SO I'M PLEASED YOU AGREE.

OPERATIONALIZING THOSE QUESTIONS WOULD BE TOUGH, BUT I THINK IT WOULD BE -- THERE WILL BE A WAY OF DOING IT, I THINK.

I'D LOVE TO HEAR MORE ABOUT ARNIE'S THOUGHTS ABOUT HOW TO DO THAT.

>> THAT'S WHAT WE'VE GOT A BRANCH TO DO.

>> I WONDER IF THERE'S ANOTHER, SARAH, ANOTHER WAY OF MAKING COHERENCE IS THINKING ABOUT WHAT'S THE INTENDED

OUT COME OF THIS SHARED DECISION-MAKING PROCESS.

>> THAT'S RIGHT.

WHAT'S THE OUTCOME OF THIS DECISION PROCESS THAT THE PARTIES --

>> WELL, ACTUALLY WHAT I WAS THINKING WHEN YOU SAID THE ONLY WAY TO UNDERSTAND COHERENCE IS FROM THE PATIENT PERSPECTIVE, I THINK THAT'S ACTUALLY NOT RIGHT.

I THINK THE POINT OF THE PROCESS IS TO RECONCILE THESE PERSPECTIVES ON WHAT IS COHERENT.

AND WHETHER IT'S IN DYADIC WAY OR STRUCTURAL, ORGANIZATIONAL, BUT IT'S HAVING -- IT'S EXTENDING THAT COHERENCE SO THAT PROVIDERS -- YOU AND I WERE TALKING ABOUT THE OTHER DAY THAT THERE ARE PLENTY OF PEOPLE WHO THINK THAT BEING GUIDELINE ADHERENT IS THE ONLY RUBRIC THAT YOU USE FOR EVALUATING WHAT'S THE RIGHT KIND OF PRACTICE CHOICE AND THAT'S A PATIENT IN THIS EXAMPLE WHO WANTS SOMETHING DIFFERENT FROM WHAT THE GUIDELINE RECOMMENDS, THAT OUGHT TO TRUMP, IS THE ARGUMENT, THAT THAT SHOULD TRUMP THE GUIDELINES AND HOW TO INTEGRATE THAT, THEREFORE, INTO PRACTICE GUIDELINES AND SPREAD THE COHERENCE ACROSS ALL THE PARTICIPANTS, I THINK IS ANOTHER WAY OF THINKING ABOUT IT RATHER THAN HAVING THE PATIENT'S COHERENCE --

>> RIGHT.

YOU KNOW THERE'S ANOTHER ISSUE HERE, TALKING ABOUT THE ACTOR, AND IN ANY SITUATION LIKE THIS, THE PATIENT IS NOT A SINGLE ACTOR BECAUSE THERE ARE OTHER -- THE FAMILY MEMBERS INVOLVED, A PATIENT ADVOCATE OR SOMETHING INVOLVED WITH THAT ALSO WHICH IS A VERY IMPORTANT FACTOR IN TRYING TO MAP OUT WHAT IS, IN FACT, THE DYNAMICS GOING ON HERE AT THIS PARTICULAR STAGE OF THE PROCESS.

YOU KNOW WHAT I MEAN?

>> RIGHT BEFORE YOU MAP THE PROCESS.

I REALLY FIND THE SECOND QUESTION OF COHERENCE, MEASURING COHERENCE AS A REALLY TOUGH INTERESTING QUESTION.

IT'S A RESEARCHABLE QUESTION.

AND I WONDER UNDERLYING IT, GLYN, WHEN YOU'RE SUGGESTING THERE IS A MEASURE, A MEASURE OF COHERENCE OR WHETHER YOU MEASURE COHERENCE FROM MULTIPLE PERSPECTIVES AND IT'S SOME SORT OF REGRESSION AFTERWARDS THAT GETS YOU THE COMMON PATH, OR IS IT -- WHERE ARE -- WE'RE USING COHERENCE, THINKING ABOUT COHERENCE, IS THERE A MEASURE

OF COHERENCE.

>> SO I THINK -- I MEAN, IF YOU ARE WILLING, THERE'S A LOT OF SOCIOLOGICAL JARGON IN CALMAY'S PAPER BUT THERE ARE ACTUALLY 16 QUESTIONS ON HIS WEBSITE, PLUS THE OTHER THREE I'VE MENTIONED, BUT I THINK THE STARTING POINT IS ALWAYS THAT YOU START OFF WITH YOUR OWN IDEA OF WHAT COHERENCE WOULD BE AND THEN YOU SEE HOW MUCH OF THAT EXISTS IN THE TEAM.

THE STARTING POINT FOR THIS WOULD BE ALMOST AN A PRIORI DECISION, WE COULD STATE THAT IT IS IMPORTANT TO RECOGNIZE THAT PEOPLE WITH AUTONOMOUS PREFERENCES HAVE A ROLE TO PLAY IN DECISIONS.

IF YOU AGREE WITH THAT A PRIORI DECISION, THEN YOU COULD EXAMINE TO WHAT DEGREE DO CLINICIANS AND TEAMS AT THE INTERPROFESSIONAL LEVEL AGREE WITH THAT A PRIORI STATEMENT.

IF YOU DON'T AGREE WITH THAT A PRIORI STATEMENT THAT PEOPLE'S PREFERENCES HAVE A ROLE TO PLAY IN DECISIONS, I DON'T KNOW HOW YOU WOULD ADDRESS THIS QUESTION.

>> SO IT'S NOT JUST MEASURING THE CONCEPT OF COHERENCE BUT ACTUALLY LOOKING AT WHETHER THERE'S AGREEMENT OR DISPARITY ON A FOCAL CONSTRUCT SUCH AS DECISION-MAKING.

>> EXACTLY.

THERE WOULD BE DISAGREEMENTS ABOUT REPUBLIC AND DEMOCRATIC, YOU HAVE TO CHOOSE YOUR TOPIC.

SO I THINK YOU HAVE TO START WITH A PHILOSOPHICAL ETHICAL PRINCIPLE LIKE AUTONOMOUS INDIVIDUALS NEED TO HAVE THEIR VOICES HEARD, AS IT WERE, IN COMPLEX DECISIONS.

WHERE THERE ARE MAJOR CONSEQUENCES TO THEIR LIVES ON QUALITY OF LIFE.

>> SO I GUESS MY QUESTION IS WHETHER WE CAN ADD TO THE PHILOSOPHICAL PERSPECTIVE IF WE DO MOVE ON TO THIS QUESTION OF CONSEQUENCES AT DIFFERENT LEVELS, THE RELATIONSHIP BETWEEN THE PATIENT AND THE PROVIDER, THE IMPLICATIONS TO THE PRACTICE FLOW IN A DAILY WAY TO HIRING NEW PEOPLE TO THE COSTS SAVED BY NOT DOING UNWANTED TESTS OR PROCEDURES TO THE COST INCURRED BY TREATING PEOPLE LONGER WITH WATCHFUL WAITING THAN WITH RADIATION IN THE SHORT TERM, WHATEVER -- ALL OF THESE LEVELS, IF WE FULLY UNDERSTAND WHAT THEY ARE MIGHT NOT WE BE ABLE TO MAKE ADDITIONAL ARGUMENTS, NOT NECESSARILY IN SUPPORT OF SHARED DECISION-MAKING BUT TO SAY HERE ARE THE CHOICES, HERE IS THE COST BENEFIT OF WHAT IT IS TO DO THIS.

HERE'S WHAT YOU GET.
WHICH INCLUDES THE RESPECT FOR THE AUTONOMY OF THIS
INDIVIDUAL PERSON AND THE PREFERENCES OF THAT AUTONOMOUS
PERSON, BUT ALSO INCLUDES THESE OTHER LAYERS OF BENEFITS
AT THESE MANY LAYERS OF COST.

>> SARAH, I THINK YOU'RE RIGHT.
AND I THINK THOSE ARE CONSEQUENCES OF MAKING THE RIGHT
CHOICES, I WOULD ARGUE.
BUT STARTING OFF BY SAYING SHARED DECISION-MAKING WILL
SAVE US MONEY IS PROBABLY A REALLY DIFFICULT POSITION
TO KICK OFF ON.

>> I COMPLETELY AGREE, AND THAT'S WHY I'M SAYING I THINK
WE NEED TO LOOK AT THE MANY LAYERS OF CONSEQUENCE AND
THE LAYERS OF BENEFIT, IF YOU WERE, IF THE CONSEQUENCES
ARE POSITIVE AND NEGATIVE.

AND THEN LOOK AT THEM IN A PICTURE THAT MAKES SENSE.
THE COHERENCE THEN COMES FROM AN INDIVIDUAL PRACTICE
EVALUATING HOW MUCH TIME CAN THEY SPEND, WHAT DO THEY
GET FROM DOING IT, HOW MUCH DO THEIR PATIENTS WANT TO
DO IT, RATHER THAN --

>> I THINK YOU'RE ABSOLUTELY RIGHT.
THERE ARE SOME INTANGIBLE POSITIVE CONSEQUENCES, I
THINK, SUCH AS THAT IF PEOPLE ARE MAKING DECISIONS WHICH
HAVE WELL DELIBERATED AND WELL CONSIDERED, THE
LIKELIHOOD THAT THEY HAVE REGRET AND THEN WILL LITIGATE
IS LESSENED.

WE WOULD ARGUE.

WE'VE BEEN DOING A SYSTEMATIC REVIEW ON THAT ISSUE AND
WE CAN'T FIND ANY EVIDENCE REALLY ON THAT ISSUE, BUT ALL
THE KIND OF LARGE STUDIES SHOW THAT PEOPLE COMPLAIN WHEN
THEY FEEL THEY'VE NOT BEEN COMMUNICATED WELL WITH.

>> I GUESS ONE QUESTION I'M ASKING IS A ROLE
OF -- GENERATE THAT EVIDENCE THAT YOU'RE NOT FINDING,
PROMPT PEOPLE TO DO THAT RESEARCH.

>> I THINK ONE OTHER POINT, GLYN, YOU MENTIONED GROUP
HEALTH HAS IMPLEMENTED THIS?

>> GROUP HEALTH, THEY PUBLISHED TWO PAPERS RECENTLY,
THEY'VE BOTH BEEN -- ACTUALLY ONE HAS BEEN AT HEALTH
AFFAIRS, BOTH HAVE BEEN IN HEALTH AFFAIRS OVER THE LAST
FEW MONTHS.

SO THEY HAD A MAJOR ORGANIZATIONAL INVESTMENT TO
INTRODUCE SURGICAL DECISION AIDS, HEAD, KNEE, BACK, SO
ON, AND THEY'VE DEMONSTRATED SOME SAVINGS ON

OBSERVATIONAL STUDIES.

AND THERE'S BEEN A LOT OF INTEREST IN THEIR PAPERS. IT HAS TO BE SAID THAT THERE ARE SOME WEAKNESSES IN THE PAPERS BECAUSE THERE'S OTHER CONFOUNDING ISSUES IN THERE, BUT THERE'S A FIRST ROUTINE DEMONSTRATION OF DECISION AIDS AT WORK AND IT HAS TO BE SAID THAT THERE WAS AN ENORMOUS INVESTMENT IN THE ORGANIZATION TO GET THESE THINGS DONE, BUT IT'S BEGINNING TO SHOW GOOD BENEFIT THERE.

>> I THINK THOSE TWO PAPERS WOULD BE WORTH WELL PURSUING, I'M SURE THE BRANCH KNOWS ABOUT THEM.

I DIDN'T KNOW ABOUT THAT, BUT IT WOULD SEEM TO ME THERE IS NOW A SERIES OF PAPERS COMING OUT ON SOME OF THE IMPLEMENTATION OF THESE, I THINK IT PROVIDES AN OPPORTUNITY TO ASK VERY SPECIFIC FOLLOW-UP QUESTIONS BUILDING ON THAT RESEARCH BASE.

>> I JUST THINK THAT WHAT WE'VE ALREADY -- WHAT WE'VE TALKED ABOUT IS ACTUALLY PRETTY STRONG BASE FOR RESEARCH, I'M STILL INTRIGUED BY THIS ISSUE OF COHERENCE AND THE TWO CASES THAT WE STARTED WITH.

I THINK IF YOU PRESENTED THOSE CASES TO MOST PEOPLE, MOST DOCS, AT LEAST, CERTAINLY IN THE FIRST CASE, IT WOULD BE NO QUESTION THAT THAT WASN'T A COHERENT OUTCOME. TAKING OFF A BREAST FOR SOMEBODY THAT DOESN'T HAVE BREAST CANCER, THERE'S NO QUESTION ABOUT THAT.

THE SECOND CASE IS YOU'VE ALREADY ARGUED, GLEN, DOESN'T ALSO PROBABLY NOT A COHERENT END POINT FOR THIS WOMAN. SHE'S NOW LIVING WITH REGRET AND ANXIETY BECAUSE SHE ACTUALLY DID SOMETHING SHE THINKS MAYBE SHE DIDN'T HAVE TO DO.

>> EXACTLY.

>> SO I'M INTRIGUED AFTER THIS DISCUSSION WITH SARAH'S POINT THAT COHERENT ISN'T NECESSARILY A MEASUREMENT UP FRONT, IT'S A GOAL, IT'S AN OUTCOME OF THE PROCESS AS A WHOLE.

AND THAT BUILDING RESEARCH THAT FOCUSES ON WHAT IS THE APPROPRIATE OUT COME, AND WHAT ARE THE CONSEQUENCES THAT THIS DECISION-MAKING PROCESS FOR THE INDIVIDUAL AND INDIVIDUALS INVOLVED, THE PROVIDER TEAM, THE ORGANIZATION, SEEMS TO ME TO BE A REFRESHING AND EXCITING POTENTIAL AREA OF WORK.

>> I WANTED TO COMMENT ON THAT WHEN YOU TALK ABOUT THOSE THAT IT IMPACTS, AND I THINK -- I HEARD A LITTLE BIT ABOUT THIS IN THIS CONVERSATION, BUT I THINK A GROUP, AND GLYN, YOU CAN HELP ME WITH THIS, I DON'T THINK THERE'S ENOUGH EMPHASIS WITH THIS DECISION-MAKING AS A FAMILY, AND I THINK THE IMPLICATIONS AND RAMIFICATIONS WHEN SOMEONE MAKES A DECISION THAT RESOLVES IN STAYING HOME AND NOT DOING ANY TREATMENTS AND REQUIRING A LOT OF FAMILY RESOURCES, WHAT DOES THAT MEAN?

AND HOW IS THE FAMILY INVOLVED IN THAT?

MY FATHER JUST DIED OF PANCREATIC CANCER, AND HIS DECISION-MAKING, IT WAS ALL QUANTITATIVE, YOU KNOW, THE SURVIVAL, HOW MANY YEARS SURVIVAL, THIS TREATMENT, THAT, THERE WASN'T ENOUGH QUALITATIVE INFORMATION AND SHARING OF WHAT HE WANTED TO FIND ON THE WEBSITE.

HE WANTED TO TALK TO OTHER PEOPLE.

HE WAS A STAGE I, AND WE REALLY THOUGHT THE DECISION-MAKING THAT WENT ALONG WITH THIS, WE DID THE BEST WE COULD WITH THE INFORMATION WE HAD, BUT THERE WERE BIG IMPLICATIONS FOR THE FAMILY AS WE WENT DOWN THIS PATH THAT I'M NOT SURE THERE WAS ENOUGH SUPPORT OR INSIGHT TO INTO THE PLANNING OF THE DECISIONS.

>> THERE'S A GROUP AT HOPKINS WHO RUN AN ACTIVE SURVEILLANCE ALTERNATIVE TO ACTIVE PROSTATE CANCER TREATMENT PROGRAM AND I KNOW THAT THEY ARE JUST UNDERWAY IN COLLECTING QUALITATIVE DATA FROM MEN WHO ARE PARTICIPATING IN THE PROJECT AND ALSO THEIR SIGNIFICANT OTHERS, BE THEY WIVES OR OTHER KINDS OF PARTNERS, AND ASKING THEM PROSPECTIVELY ABOUT THEIR DECISIONS ALONG THE WAY TO PARTICIPATE IN THE ACT OF SURVEILLANCE AND THE EXPERIENCE OF STAYING ON IT, AND SOME OF THEM MAKE THE SPONTANEOUS CHOICE WITHOUT THE ADVANCEMENT OF THE DISEASE BUT JUST FOR THEIR OWN PREFERENCES TO GO INTO ACTIVE TREATMENT.

SOME OF THEM STAY ON SURVEILLANCE FOR A LONG PERIOD OF TIME, SO THIS IS QUALITATIVE INTERVIEWING PROSPECTIVELY TALKING TO MEN AND FAMILY MEMBERS PRIMARILY ABOUT WHAT IT'S LIKE TO LIVE WITH THAT AND TO MAKE THOSE DECISIONS.

>> I THINK IT WOULD BE A THING SIMPLY TO FOCUS ON THE PATIENT, I THINK THE ROLE OF THE FAMILY AND RELEVANT OTHERS AS A UNIT, AS A MICROSYSTEM TO USE, YOU KNOW, SORT OF THE TERM THAT -- I DON'T KNOW WHETHER IT'S STILL POPULAR OR NOT, BUT CLEARLY I THINK IT'S POPULAR HERE BECAUSE IT IS GROUP DECISION-MAKING, IT'S NOT JUST

SIMPLY THE PATIENT AS IT INTERACTS WITH THIS OTHER TEAM OF PROVIDERS.

>> AGREED.

THANK YOU.

>> ADDING ON TO THAT RESEARCH, I WAS SAYING THAT I HAVE A COLLEAGUE HERE AT YALE WHO IS DOING RESEARCH, LOOKING AT THE IMPACT ON CARE GIVERS AND THEIR INTERACTIONS AND HOW THEY DEAL SUBSEQUENTLY, WHICH MIGHT BE ANOTHER OUT COME YOU CONSIDER, LOOKING ACROSS LEVELS.

>> THEY'RE LOOKING AT CONSEQUENCES OF SHARED DECISION-MAKING OR CONSEQUENCES OF AN INTERVENTION LIKE A SURGERY?

>> NOT

>> NOT A SPECIFIC INTERVENTION BUT LOOKING AT THE EFFECTS OF BEING THE CAREGIVER.

PART OF WHAT WE'RE TALKING ABOUT WITH THE SHARED DECISION-MAKING IS THAT PATIENTS MIGHT ACTUALLY CHOOSE NOT THE MORE INTENSIVE TREATMENT APPROACH BUT THE WAITFUL WATCH, FOR EXAMPLE, AND WHAT ARE THE IMPLICATIONS OF THAT FOR NOT JUST THEM BUT EVERYONE ELSE IN THEIR SOCIAL SYSTEM.

>> AND HOW PLAN.

SOMEONE MAKES A DECISION THAT'S GOING TO REQUIRE MORE RESOURCES, HOW IS THERE -- HOW DO WE PLAN ACCORDINGLY. SO PEOPLE AREN'T CAUGHT OFF GUARD OR THEY REALLY REALIZE WHAT THE IMPLICATIONS OF THAT DECISION ARE ON HOME, FAMILY, OTHER ADDITIONAL RESOURCES FROM THE COMMUNITY.

>> WE COULD ALSO MENTION THOSE ARE BIDIRECTIONAL EFFECTS, PEOPLE THAT ARE IN DIFFERENT KINDS OF SOCIAL SYSTEMS TO BEGIN WITH PERHAPS FACE THE SHARED DECISION-MAKING PROCESS DIFFERENTLY THAN PEOPLE WHO HAVE LESS WELL DEVELOPED SUPPORT SYSTEMS, IN ADDITION TO THEM, A DECISION HAVING AN EFFECT ON THIS BROADER SYSTEM AS IT PLAYS OUT.

>> I WANT TO SAY ALSO COULD BE THINKING ABOUT IT AS ANOTHER OUT COME AS THE CONSEQUENCES FOR THE CAREGIVERS AND THE PEOPLE AROUND.

BOTH PSYCHOLOGICALLY AS WELL AS JUST PRACTICALLY.

>> I THINK -- WASN'T DOUG FOLEY IN MINNESOTA DOING SOMETHING ON CAREGIVERS, AND THERE WAS AN EXPERIMENTAL PROJECT THAT -- NOT UNITED HEALTH CARE BUT ONE OF THE OTHER HEALTHCARE SYSTEMS THAT CONTRACTED WITH HIM TO

EVALUATE THAT KIND OF SHARED DECISION-MAKING THAT GOES ON BETWEEN THE PROVIDER, THE PATIENT AND THE CAREGIVERS FOR EXTENDED CHRONIC DISEASE -- CHRONIC CANCERS OVER THE, YOU KNOW, LONG-TERM CARE OF THE PATIENT.

>> WHO IS THAT?

>> YEAH, WHAT WAS THAT NAME YOU SAID?

>> ISN'T IT DOUG WHOOLEY FROM MINNESOTA?

WHOLLEY?

INGRID U KNOW HIM.

>> I DO, YES.

>> DOUG WHOLLEY.

>> I THOUGHT I SENT SOME STUFF UP THAT HE WAS DOING.

>> I DON'T RECALL THAT, BUT --

>> I'LL RESEND IT.

>> THAT WOULD BE GREAT.

YEAH.

>> QUITE A CHARACTER TOO.

I THINK HE DOES SOME VERY RELEVANT WORK, AND IT'S EVIDENTLY FUNDED BY THE HEALTH SYSTEM.

IT'S NOT FUNDED BY NCI OR -- THE FEDERAL GOVERNMENT IN ANY WAY, SHAPE OR FORM.

>> WELL, THIS HAS BEEN AN EXCELLENT DISCUSSION.

I THINK, GLYN, YOU DID A NICE JOB OF SETTING IT UP AND BRINGING IN SOME REALLY INTERESTING AND DIFFERENT ISSUES.

IS THERE ANYTHING YOU WANTED TO SAY IN CLOSING?

>> NO, JUST THANK YOU FOR BEARING WITH MAYBE A NEW THEORY OR MODEL OF NORMALIZATION.

IT'S REALLY A WORD FOR SUSTAINABILITY OR IMPLEMENTATION, BUT I THINK IT'S A WAY OF THINKING ABOUT WORK IN A VERY INTERESTING WAY FOR THE PURPOSE OF UNDERSTANDING SOME QUITE DEEP ISSUES.

>> ABSOLUTELY AGREE.

AND I THINK -- I COMPLIMENT YOU ON WHAT YOU'VE DONE AND LOOK FORWARD TO SEEING MORE OF IT.

>> THANK YOU VERY MUCH.

>> AGREED.

THANK YOU ALL.

>> OKAY.

>> TIME WE ALL GET BACK TO WORK.
TAKE CARE.
BYE-BYE.