

FTC Spring Privacy Series: Consumer Generated and Controlled Health Data
May 7, 2014
Rough Transcript (final transcript to be posted soon)

>> IF YOU HAVE A QUESTION, FILL
OUT YOUR CARD, RAISE YOUR HAND
AND ONE OF OUR PARALEGALS WILL
COME AND GET IT.
FOR THOSE OF YOU PARTICIPATING
BY WEBCAST, YOU CAN EMAIL YOUR
QUESTION TO CONSUMER HEALTH
DATA@FTC.GOC, TWEET IT OR POST
TO THE F.T.C. Facebook PAGE IN
THE WORK STATUS WINDOW.
PLEASE UNDERSTAND WE MAY NOT GET
TO ALL THE QUESTIONS.
WE'LL WELCOME THE COMMISSIONER
TO THE PODIUM FOR BRIEF
WELCOMING REMARKS.
>> THANKS.

I WANT TO BE REALLY BRIEF.
THIS IS A GREAT TOPIC.
ETTES GREAT TO SEE YOU AND THANK
YOU FOR ALL OF YOU WATCHING ON
THE WEB.

THIS IS AN INCREDIBLY IMPORTANT
ISSUE, THOSE OF YOU WHO KNOW
SOME OF THE THINGS I TALK ABOUT
WHEN I GO OUT AND SPEAK AND
WRITE KNOW THAT THIS IS AN
ISSUE, THE ISSUE OF
CONSUMER-GENERATED HEALTH
INFORMATION IS NEAR AND DEAR TO
MY HEART.

LET ME BRIEFLY PAINT THE BIG
PICTURE AND TALK ABOUT THE
BENEFITS AND SOME OF THE
CONCERNS, WHICH I KNOW YOU ARE
ALL THINKING DEEPLY ABOUT AND
WILL KEEP IN MIND AS THE DAY
PROGRESSES.

BIG PICTURE --
CONSUMER-GENERATED HEALTH
INFORMATION IS PROLIFE RATING
NOT ONLY ON THE WEB BUT WITH
RESPECT TO CONNECTED DEVICES,

THE INTERNET OF ANYTHING AND EVERYTHING.

THE POTENTIAL BENEFITS TO CONSUMERS ARE SIGNIFICANT.

THE POTENTIAL BENEFITS TO SOCIETY ARE INCREDIBLY SIGNIFICANT.

ALSO, THERE ARE RISKS, I BELIEVE, AND I HOPE WE WILL TALK ABOUT TODAY, WITH RESPECT TO HEALTH DATA FLOWS THAT ARE OCCURRING OUTSIDE OF HIPAA, OUTSIDE THE MEDICAL CONTEXT AND, THEREFORE, OUTSIDE ANY REGULATORY REGIME THAT FOCUSES SPECIFICALLY ON HEALTH INFORMATION.

SOME OF YOU KNOW BECAUSE YOU WERE THERE AS WELL, I WAS AT THE CONSUMER ELECTRONICS SHOW IN JANUARY, AND WAS REALLY WOWED BY MUCH THAT I SAW.

SOME OF THE DEVICES THAT I SAW WERE PARTICULARLY FOCUSED ON HEALTH AND THE MEASURED LIFE, QUANTITATIVE LIFE.

ONE IN PARTICULAR THAT STRUCK ME WAS THE MEMO, A ONE THAT WAS DEVELOPED TO MEASURE THE HEART BEAT AND RESPIRATION RATES AND OTHER VITAL SIGNS OF AN INFANT, A NEWBORN.

IT COULD SEND INFORMATION TO AN APP, IT COULD SEND INFORMATION TO THE PARENT'S MOBILE DEVICE AND WHATNOT.

THINK ABOUT THE BENEFITS OF ANYONE WORRIED ABOUT SIDS OR MIGHT WANT TO GET THEIR BABY TO SLEEP BETTER OR GET THEMSELVES TO SLEEP BETTER.

MONITORING SOME OF THESE IMPORTANT VITAL SIGNS WOULD BE A REAL BENEFIT IN ALL THOSE AREAS.

WE'VE SEEN TONS OF WEARABLE STEP COUNTERS, MILEAGE MONITORS.

THERE HAVE ALSO BEEN INTERESTING ARTICLES ABOUT DOCTORS WHO ARE FINDING OUT MORE ABOUT THEIR PATIENTS BY GOING ONLINE, GOOGLING THEM.

THERE WAS A "NEW YORK TIMES" WELL BLOG POSTED ON THAT. OR AN INTERESTING DEBATE IN THE MEDICAL COMMUNITY ABOUT WHETHER DOCTORS SHOULD BECOME FRIENDS WITH THEIR PATIENTS ON Facebook OR OTHER SOCIAL MEDIA.

THEN, OF COURSE, ANOTHER TOPIC WHICH I'M SURE WILL BE DISCUSSED TODAY IS THE NOW INFAMOUS EXAMPLE OF COMPANIES THAT ARE GENERATING THEIR OWN HEALTH DATA ABOUT THEIR CUSTOMERS BASED ON PURCHASES SUCH AS TARGETED WITH RESPECT TO THE PREGNANCY PREDICTOR SCORE.

SO TAKING THE STEP BACK, THINKING OF THE SIGNIFICANT BENEFITS THAT CONSUMERS CAN GAIN FROM SOME OF THESE DEVICES AND SOME OF THE MEASURED -- THEIR ABILITY TO MEASURE THEIR HEALTH CONDITIONS AND WHATNOT.

THEY CAN MONITOR THEIR HEALTH, THEY CAN MONITOR THEIR FAMILY MEMBERS' HEALTH IN THE EVENT THEY HAVE AN ELDERLY PARENT OR YOUNG CHILD.

THEY CAN FIND MOTIVATION TO EXERCISE, EAT HEALTHIER, CONNECT WITH PEOPLE WITH A SIMILAR MEDICAL CONDITION OR DISEASE, THEY CAN PARTICIPATE IN RESEARCH, ALL INCREDIBLY BENEFICIAL.

AGAIN, WHEN HEALTH DATA IS STORED OUTSIDE THE HIPAA SILO CREATED A FAIRLY LONG TIME AGO, NOW, SEEMS LIKE EONS AGO IN TERMS OF THE DIGITAL AGE, IT

WILL BE HEALTH DATA THAT IS NOT BEING CONTROLLED BY DOCTORS OR HOSPITALS OR INSURERS.

WHEN YOU LOOK AT HIPAA AND HIGH-TECH, FOR INSTANCE, THERE SEEMS TO BE A CONSENSUS IN THIS COUNTRY THAT HEALTH DATA IS SENSITIVE AND DOES NEED SPECIAL PROTECTIONS, THEN THE QUESTION BECOMES, THOUGH, IF WE HAVE A LAW THAT CREATES THESE PROTECTIONS BUT ONLY WHEN THEY'RE FLOWING IN CERTAIN CONTEXTS, BUT THE SAME TYPE OF INFORMATION OR SOMETHING VERY CLOSE TO IT IS FLOWING OUTSIDE OF THOSE SILOS THAT WERE CREATED A LONG TIME AGO, WHAT DOES THAT MEAN?

AND ARE WE COMFORTABLE WITH THAT?

AND SHOULD WE BE THINKING ABOUT BREAKING DOWN THE LEGAL SILOS IN ORDER TO BETTER PROTECT THAT SAME HEALTH INFORMATION WHEN IT'S GENERATED ELSEWHERE?

OF COURSE, THERE'S ALSO THE PROBLEM OF RE-IDENTIFYING INDIVIDUALS THROUGH INFORMATION THAT HAD BEEN DE-IDENTIFIED.

LATANYA SWEENEY IS NOT GOING TO NECESSARILY TALK ABOUT THAT TODAY, BUT WE SO LOVE HAVING HER HERE AT THE F.T.C.

SHOWS ONE OF THE -- SHE'S ONE OF THE NATION'S EXPERTS, AS MANY KNOW, ON THAT AND SO MANY OTHER ISSUES.

THERE ARE SOME OTHER INTERESTING THINGS I'VE READ ABOUT AND I DON'T KNOW IF PEOPLE WILL BE TALKING ABOUT THIS TODAY, BUT WE RECENTLY READ ONE INSURANCE COMPANY, AETNA, HAS DEVELOPED AN APP FOR ITS BENEFICIARIES TO USE WHERE

IT WILL ALLOW CONSUMERS TO SET GOALS, TRACK PROGRESS ON ALL SORTS OF HEALTH INDICATORS -- WEIGHT, EXERCISE, THINGS LIKE THAT.

IT'S WONDERFUL AETNA SET THIS UP, I THINK IT'S GREAT, BUT I DON'T KNOW PRECISELY WHAT THEY'RE DOING WITH THIS INFORMATION.

WE'VE LOOKED AT THE TERMS OF SERVICE.

IT RAISES INTERESTING QUESTIONS TO WHAT EXTENT THIS INFORMATION COULD BE USED FOR RATING PURPOSES, AND WE ALL KNOW UNDER THE FCRA IT OUGHT NOT TO BE, BUT WHAT ARE THE RULES OF THE ROAD HERE?

THE OTHER INTERESTING EXAMPLE I REMEMBER READING ABOUT RECENTLY WAS AN ENTITY CALLED BLUE CHIP MARKETING, WHICH WAS BEING USED BY PHARMACEUTICAL OR HIRED BY PHARMACEUTICAL COMPANIES TO HELP THEM FIND CANDIDATES FOR CLINICAL TRIALS.

BLUE CHIP MARKETING DIDN'T WORK WITH DOCTORS AND DIDN'T WORK WITH HOSPITALS.

INSTEAD, IT SURFED SOCIAL MEDIA. IT SURFED CABLE TV SUBSCRIPTIONS AND GOT LOTS OF INFORMATION THAT ALLOWED IT TO INFER WHETHER CONSUMERS WERE OBESE, POTENTIALLY HAD DIABETES AND POTENTIALLY HAD OTHER MEDICAL CONDITIONS, THEN OFFERED TO THEM TO JOIN A CLINICAL TRIAL.

NOW, SOME CONSUMERS WOULD THINK THAT'S GREAT, YES, I WOULD LIKE TO BE PART OF A CLINICAL TRIAL, BUT OTHER CONSUMERS WERE REALLY SHOCKED WHEN THEY GOT CONTACTED BY THIS COMPANY OR OTHERS THAT GOT THE INFORMATION FROM THE

COMPANY AND SAYING WHAT MAKES YOU THINK I'M OBESE OR HOW DID YOU KNOW I WAS A DIABETIC? REALLY INTERESTING ISSUES. SO, AGAIN, I'M REALLY LOOKING FORWARD TO THE DAY -- I'M GOING TO SIT HERE AS LONG AS I CAN AND SAY HELLO TO AS MANY OF YOU AS I CAN DURING THE BREAKS, BUT MY PLAN IS TO SIT HERE AND I KNOW THERE WILL BE A DEEP DISCUSSION ABOUT ALL THE HEALTH DATA BEING GENERATED BY NEW DEVICES AND ONLINE SERVICES AND APPS. I KNOW WE WILL BE EXPLORING THE BENEFITS BECAUSE THEY'RE SIGNIFICANT. I DO HOPE WE'LL ALSO EXPLORE THE RISKS, AND I WOULD LIKE EVERYONE TO KEEP IN MIND THAT HEALTH DATA, FROM MY PERSPECTIVE AS ONE COMMISSIONER, IS HIGHLY SENSITIVE, EVEN THOUGH IT MAY NOT BE CREATED AND OPERATING BEEN A HIPAA CONTEXT. SO WITH THAT, I'M REALLY LOOKING FORWARD TO THE CONVERSATION, AND THANKS SO MUCH TO MISHA, CORA AND KRISTEN FOR ORGANIZING THIS GREAT DAY AND WELCOME TO ALL OF YOU, THANKS.

>> THANKS, COMMISSIONER. TO BEGIN THE PROGRAM TODAY, WE'LL START OFF BY A PRESENTATION BY F.T.C. TECHNOLOGIST LATANYA SWEENEY ON HEALTH DATA FLOWS. LET'S WELCOME LATANYA (APPLAUSE)

>> IT'S GREAT TO BE HERE. I, TOO, WANT TO THANK YOU FOR HAVING ME AND GIVING ME THIS OPPORTUNITY TO SPEAK. THERE'S A DUALITY IN THIS TALK. I LOVE BEING AT THE F.T.C., BUT MOST OF YOU KNOW THAT MY REAL

JOB, IN A SENSE, IS AT HARVARD,
A PROFESSOR.
SO THE WORK I'M GOING TO TALK
ABOUT IS ACTUALLY WORK NOT DONE
AT THE F.T.C., BUT THAT
CERTAINLY HAS SOME INTERSECTION
POINTS WITH RESPECT TO THIS
WORKSHOP.

FOR THAT REASON, I HAVE TO START
OUT WITH A DISCLAIMER THAT
ANYTHING I SAY IS NOT THE VIEWS
OF THE COMMISSIONERS OR THE
COMMISSION, AND I HAVE TO TELL
YOU THEY'RE ALSO NOT OFFICIALLY
MY VIEWS

(LAUGHTER)

I WANT TO TALK ABOUT THE
RELATIONSHIP BETWEEN TRANSPARENCY
AND TRUST.
THE COMMISSIONER MADE A GOOD
POINT ABOUT HOW INDIVIDUALS HAVE
CONTROL OF THEIR OWN DATA, THE
DATA THEY GENERATE, THE DATA MAY
PULL OUT OF THE HIPAA SYSTEM AS
FAR AS ASKING FOR IT FROM THEIR
PHYSICIAN AND SO FORTH, AND WHAT
THEY DO ABOUT IT IS UP TO THEM.
WE WANT THEM ALL TO LIVE THEIR
LIVES BET WERE THAT DATA.
THE QUESTION IS IF YOU HAVE THAT
KIND OF CONTROL OVER YOUR
INFORMATION, HOW DO YOU MAKE
DECISIONS AND HOW DO YOU KNOW
THAT THOSE DECISIONS WON'T COST
YOU HARMS?

AFTER ALL, HOW DID THEIR
DECISION-MAKING COMPARE TO A LOT
OF THE REGULATORY TYPE
DECISION-MAKING IS ONE OF THE
QUESTIONS.

MY SLIDE JUST MESSED UP BECAUSE
WELCOME THE WORLD OF
PowerPoint, SO I'LL JUST
SKIP AHEAD.

I THINK WHEN WE THINK ABOUT
HEALTH DATA, FOR MOST PEOPLE, IT

COMES DOWN TO THE RELATIONSHIP BETWEEN THE PHYSICIAN AND PATIENT.

IF THERE'S NOT TRUST IN THAT RELATIONSHIP, THEN THE PATIENT RISK -- THE PHYSICIAN DOESN'T GET ALL THE INFORMATION AND THE PATIENT MAY HOLD BACK INFORMATION, AND IF THE PATIENT HOLDS BACK INFORMATION THEY RISK NOT GETTING GOOD CARE.

SO I THINK WE ALL UNDERSTAND THE NEED FOR A KIND OF TRANSPARENCY AND HONESTY OF INFORMATION GOING THERE.

BUT WHAT WE DON'T ALWAYS KNOW IS WHERE THE DATA GOES AFTER IT LEAVES THERE.

INDEPENDENT OF OTHER PLACES, AN INDIVIDUAL MIGHT PLACE THE DATA. SO A COUPLE OF YEARS AGO, WE STARTED A PROJECT THAT HARVARD CALLED THE DATAMAP.org AND OUR GOAL WAS TO TRY TO DOCUMENT ALL THE FLOWS OF DATA.

AFTER ALL, HEALTH DATA HAS BEEN GOING AROUND ALL THE TIME. WHERE ARE ALL THE PLACES IT GOES?

TO OUR SHOCK, IT'S REALLY NOT CLEAR.

IT'S NOT EASY TO KNOW ALL OF THE PLACES IT MIGHT MOVE.

SO WE USE ALL KINDS OF DEVICES, MINING WEB PAGES AND NOTICES, MINING BREACH NOTICES AND BREACH NOTICE DATABASES AND ALSO PUBLIC REQUEST.

SO IF THERE WAS A GOVERNMENT AGENCY GETTING THE DATA, WE WOULD ISSUE A PUBLIC REQUEST TO ASK HOW THEY GOT IT, WHAT'S THE DATA AND SO FORTH.

IN 1997, THERE WAS A COMMISSION HEADED BY PAUL CLAYTON AT THE NATIONAL RESEARCH COUNCIL WHO

ATTEMPTED TO DO THIS, THIS WAS RIGHT IN THE MIDDLE OF THE HIPAA DEBATES, AND THEY SAT DOWN, THROUGH COMMITTEE, AND DOCUMENTED ALL THE PLACES THE HEALTH DATA MAY GO.

IT'S INTERESTING.

THIS IS A MODEL OF THEIR GRAPH, AND YOU SEE ALL OF THE PLACES THAT YOU MIGHT THINK, AND SOME OF THEM MIGHT BE A LITTLE SURPRISING.

SO WITH OUR EFFORTS, THIS IS WHAT IT LOOKS LIKE TODAY. SORT OF EIGHT YEARS AGO AFTER HIPAA.

AND WHAT YOU SEE NOT ONLY IS AN EXPLOSION IN THE NUMBER AND TYPES OF DATA BEING GIVEN AWAY BUT ALSO -- THERE'S ALSO JUST DIFFERENT KINDS OF ENTITIES ALSO RECEIVING THE DATA.

IF YOU VISIT THE DATAMAP.org YOU CAN CLICK ON ANY NOTE AND IT WOULD GIVE YOU INSTANCES OF HOW WE CAME TO KNOW THAT, IT WILL GIVE YOU THE COMPANY AND WHAT IT IS THEY'RE DOING.

ANOTHER QUESTION, ONCE WE HAD THIS MAP, WE BEGAN ASKING QUESTIONS.

ONE OF THE QUESTIONS IS WHICH OF THE FLOWS ARE COVERED BY HIPAA AND WHICH ARE NOT?

AND TO OUR SURPRISE, ABOUT HALF OF THE FLOWS ARE NOT EVEN COVERED BY HIPAA.

SO IT'S AN INTERESTING -- SO RIGHT AWAY, WE SAW AN INTERESTING ISSUE THAT, WHEN YOU -- CERTAINLY, WHEN WE SERVE THE STUDENTS, THE STUDENTS SAID THEY EXPECTED MOST DATA OUTSIDE THE DATA THEY GIVE THEMSELVES TO BE COVERED BY HIPAA AND WE FOUND MOST WERE NOT.

ONE OF THE CRITICAL PIECES THERE YOU SEE IS SORT OF IN THE MIDDLE THERE CALLED DISCHARGE DATA. SO WE BEGAN TO FOCUS ON THAT. WE SEE A LOT OF PIECES GOING OUT.

FOR MOST PEOPLE, WHAT THE HECK IS DISCHARGE DATA, ANYWAY? WHATEVER THIS DISCHARGE DATA IS, IT STARTS FROM THE PATIENT, GOES TO THE PHYSICIAN AT THE HOSPITAL AND COMES TO THIS DISCHARGE DATA.

HOW MANY PEOPLE HAVE HEARD OF DISCHARGE DATA, IN THIS ROOM? OKAY.

SO THAT'S ABOUT HALF.

SO WHETHER YOU'VE HEARD OF IT OR NOT, IF YOU'VE HAD A HOSPITAL VISIT AND, IN MOST STATES PHYSICIAN VISITS, INFORMATION ABOUT YOUR VISIT IS IN DISCHARGE DATA.

THESE ARE MANDATED BY STATE LAWS.

A COPY OF THAT DATA GOES TO WHOEVER IS DESIGNATED BY THAT STATE LAW TO RECEIVE THAT DATA. AND WHAT YOU'RE SEEING HERE ON THE DATA MAP IS NOT JUST THAT THEY GOT THE DATA BUT YOU ALSO SEE THAT THEY'RE EITHER SELLING OR GIVING AWAY THAT DATA TO OTHERS.

THE DASH LINE MEANS THAT THEY DID SO IN A WAY THAT DIDN'T HAVE YOUR EXPLICIT NAME, BUT IT WAS, IN FACT, DEIDENTIFIED.

THAT IS, IT DIDN'T HAVE NAME, ADDRESS, SECURITY NUMBERS, BUT INCLUDED DIAGNOSIS CODES, PROCEDURE CODES AND HOW YOU PAID FOR IT.

SO, IN FACT, 33 STATES SELL OR SHARE PERSONAL HEALTH DATA, AND THIS IS A LIST OF THE STATES

THAT DO SO.

THEN WE COULD SAY, OKAY, SO THEY'RE GETTING THE DATA, SELLING IT, SHARING IT, BUT HOW MANY OF THEM ADHERE TO HIPAA? TURNS OUT ONLY THREE OF THEM DO. THE OTHER STATES ARE SHARING AND GIVING THE DATA AWAY IN A WAY THAT'S LESS PROTECTIVE THAN HIPAA, LESS PROTECTIVE THAN THE WAY HIPAA WOULD DESCRIBE HOW YOU MIGHT SHARE OR SELL PERSONAL HEALTH INFORMATION.

SO ONE OF THE QUESTIONS THEN IS, WELL, MAYBE HIPAA IS TOO STRONG. YOU KNOW, LIKE, MAYBE THE FEDERAL STANDARD IS JUST KIND OF TOO HIGH AND THAT THERE'S NOTHING WRONG WITH THE LOWER STANDARDS THAT MANY OF THE STATES ARE USING OR IS IT THE CASE THE STATES SHOULD ACTUALLY CHANGE THEIR PRACTICES AND PERHAPS RAISE THEIR STANDARDS TO THE HIPAA STANDARDS FOR THE STUFF THEY COMMONLY GIVE AWAY AND SHARE OR SELL, OR MAYBE HAVE OTHER ALTERNATIVE IF PEOPLE NEEDED MORE SENSITIVE DATA.

SO TO TEST IT, WE WENT BACK TO THE DATA MAP AND BEGAN TO ASK THE QUESTION ALSO WHAT MIGHT BE HARMS IF ANY OF THESE QUESTIONS POSED OUT TO BE TRUE.

SO ONE OF THE KIND OF INTERESTING LOOPS WE FOUND WAS THIS LOOP TO FINANCIAL COMPANIES.

SO THE DATA GOES FROM YOU TO THE PHYSICIAN, FROM THE PHYSICIAN TO THE DISCHARGE DATA AND THEN TO A BANK.

THAT SOUNDS REALLY INTERESTING. SO WE LOOKED AT THE LITERATURE AND MANY YEARS AGO THERE WAS THIS ARTICLE IN THE NEW ENGLAND

JOURNAL OF MEDICINE WHO DESCRIBED A BANKER WHO CROSS DE-IDENTIFIED HEALTH DATA ABOUT CANCER PATIENTS AND IN AN ATTEMPT TO FIGURE OUT IF ANY OF THEM HAD MORTGAGES OR LOANS AT THEIR BANK AND BEGAN TWEAKING PEOPLE'S CREDIT WORTHINESS. I HAVE NO IDEA IF THAT'S TRUE, BUT IF WE COULD SHOW IT'S POSSIBLE BY ASKING QUESTION AT DASH LINE HOW DEIDENTIFIED IS THAT DATA, IS IT SUFFICIENTLY DEIDENTIFIED.

ANOTHER QUESTION IS THE ONLINE WEB SITES.

YOU GIVE INFORMATION TO THE PHYSICIAN AND THE HOSPITAL, YOU GIVE INFORMATION TO AN ONLINE WEB SITE, TO WHAT EXTENT ARE THE WEB SITES RECEIVING THE DISCHARGE DATA REIDENTIFYING YOU TO THE MEDICAL DATA THAT WAS LEFT BEHIND?

THIS BECOMES AN INTERESTING BECAUSE BECAUSE AT THE TIME YOU'RE GIVING THE DATA TO THE ONLINE WEB SITE YOU HAVE NO IDEA WHAT DATA THEY MAY BE PAIRING WITH IT OR MIGHT KNOW AND IF YOU CLICK ON THE WEB SITE YOU MIGHT SEE OTHER COMPANIES.

WE GAVE OUT THE REQUESTS FOR THE TOP BUYERS AND LISTED THE TOP BUYERS ACROSS THE STATES.

IT'S A PRIZING LIST.

YOU SEE A LOT OF ANALYTIC COMPANIES MOST PEOPLE HAVE NOT HEARD OF IT.

WE SEE WEB MD WHO HAS A LARGE ONLINE WEB SITE.

I.M.S. HEALTH USE AS LOT OF PHARMACYDA AT THAT. WE ALSO SEE UNIONS, WHICH I DON'T KNOW THE STORY OF THAT.

CLEARING, THERE'S A GOOD STORY

THERE.

OKAY.

SO LET'S FIGURE OUT HOW
DEIDENTIFIED IS THIS DATA.

IS SAFE?

IS IT OKAY THE WAY THEY'RE
GIVING IT OUT.

SO FOR \$50 WE WENT TO THE STATE
OF WASHINGTON AND PURCHASED
THEIR HOSPITAL DISCHARGE DATA
FOR THE YEAR 2011.

WHAT YOU SEE IS A SAMPLE OF THE
300-AND-SOME-ODD FIELDS OF
INFORMATION FOR THE VISIT.
INCLUDED AGE, MONTHS, YEARS,
GENDER, CODE, WHAT HOPPED THEY
WENT TO, HOW THEY PAID FOR IT
AND SO FORTH.

AT THE SAME TIME, WE WANTED TO
FIGURE OUT HOW TO REIDENTIFY
INDIVIDUALS TO LOOK AT THE KIND
OF THING A BANKER MIGHT KNOW
ABOUT A PERSON WHO HAD A
MORTGAGE.

IN OTHER WORDS, TO WHAT EXTENT
WOULD THAT NEW ENGLAND JOURNAL
OF MEDICINE COULD IT BE TRUE,
COULD A BANKER DO IT?

WELL, A BANKER AND AN EMPLOYER
AND OTHERS KNOW THE SAME KIND OF
INFORMATION THAT OFTEN SHOWS UP
IN NEWS CLIPS ABOUT ACCIDENTS.

SO WE TOOK ONE NEWS SOURCE IN
WASHINGTON STATE AND JUST
SURVEYED THAT ONE NEWS SOURCE
FOR NEWS ARTICLES THAT WERE --
THAT CONTAINED THE WORD
"HOSPITALIZATION" OR REFERRED TO
"HOSPITALIZED" AND WE GOT 81
SAMPLES.

AND THE TYPICAL STORY IS LIKE
THE ONE HERE, OFTEN INCLUDES THE
AGE OF THE PERSON, CITY IN WHICH
THE PERSON IS COMING FROM, WHERE
THE ACCIDENT HAPPENED, A LOT OF
TIMES WILL INCLUDE THE HOSPITAL

AND A DESCRIPTION OF THE ACCIDENT.

SO THEN -- BUT IT DOESN'T INCLUDE THE ZIP CODE, WHICH IS THE HEALTH DATA.

WHAT YOU SEE ON THE LEFT IS WE WENT TO PUBLIC RECORDS, GIVEN THE PERSON'S AGE, RESIDENTS, NAME, WHAT ARE THE ZIP CODES ASSOCIATED WITH THE PERSON. THESE ARE COMMON PUBLIC RECORD SITES.

THEN WE DO THE THING ON THE SECOND, TAKE THE STUFF WE HAD FROM THE NEWS STORY WITH THE ZIP CODE AND LOOK FOR AN EXACT MATCH.

MEANS I'M GOING TO TAKE THE FIELDS, TRY TO MATCH EXACTLY THOSE FIELDS.

IF I GET ONE AND ONLY ONE MATCH, WE FEEL PRETTY CONFIDENT THAT'S THE PERSON BECAUSE STATEWIDE COLLECTIONS IS EVERYBODY, RIGHT? AND IF WE DIDN'T GET A MATCH, WE WOULD RELAX ONE FIELD AND SEE IF WE THEN GOT ONE AND ONLY ONE MATCH BECAUSE THERE COULD BE ERRORS IN THE NEWS STORY.

AND WE WERE ABLE TO CORRECTLY MATCH -- EXACTLY MATCHING, THIS IS NOT STATISTICAL -- 35 OF 81 OF THE NEW SAMPLES OR 43%.

THAT'S EXACTLY THE SAME KIND OF INFORMATION AN EMPLOYER WOULD KNOW ABOUT AN EMPLOYEE TAKING TIME OFF, A CREDITOR WOULD KNOW, FAMILY, FRIENDS OR NEIGHBORS MIGHT KNOW.

SO LET ME STOP THERE.

HOPEFULLY, I'VE INSPIRED YOU TO THINK ABOUT SOME OF THE ISSUES AND QUESTIONS THAT COME UP WHEN INDIVIDUALS ARE SHARING DATA, NOT, YOU KNOW -- THE GOAL HERE IS NOT TO SAY THAT INDIVIDUALS

SHOULDN'T, BUT THE GOAL IS TO FIGURE OUT WHAT ARE THE RISKS AND THEN JOINTLY MOVE FORWARD ABOUT WHAT DO WE DO TO MOVE FORWARD WITH THE BENEFITS WHILE ADDRESSING THE RISKS.

THANK YOU.

(APPLAUSE)

>> THANKS, SO NEXT I WOULD LIKE TO TAKE A CLOSER LOOK AT DATA SHARING BY SELECT HEALTH AND FITNESS APPS WITH A PRESENTATION BY JARED HO, AN ATTORNEY IN F.T.C. MOBILE TECHNOLOGY UNIT.

(APPLAUSE)

>> OKAY.

BEFORE WE GET STARTED, A SPECIAL THANKS TO TINA AND THE MOBILE LAB FOR THEIR SUPPORT AND EXPERTISE, TO CORA HAN AND KRISTEN ANDERSON FOR PUTTING THE SHOW ON, TO DEPIP AND THE MOBILE TECHNOLOGY UNIT FOR THEIR INSIGHT AND INPUT INTO THIS PROJECT.

IT WAS TRULY A COLLABORATIVE EFFORT.

WE START WITH THE UNDERSTANDING THAT CONSUMERS REVEAL SIGNIFICANT AMOUNTS OF INFORMATION ABOUT THEMSELVES WHEN THEY USE HEALTH AND FITNESS APPS.

SO THIS INCLUDES EVERYTHING FROM BASIC INFORMATION ABOUT THE DEVICES AND THE Smartphones TO THE PRECISE METRICS AND CHARACTERISTICS OF THEIR BODIES. SO WHEN WE'RE TALKING ABOUT HEALTH AND FITNESS APPS AND THE WEARABLE SYNCs, THE CHARACTERISTICS METRICS MIGHT INCLUDE RUNNING ROUTES, EATING HABITS, SLEEPING PATTERNS, SYMPTOM SEARCHES, AND EVEN A CADENCE OF A PERSON'S WALK OR

RUN.

UNDER THIS BACKDROP, WE'LL TAKE A LOOK AT A COUPLE OF STUDIES THAT HAVE ALREADY BEEN CONDUCTED IN THIS FIELD.

IN JULY OF 2013, PRIVACY RIGHTS CLEARINGHOUSE EXAMINED 43 PAID APPS, THE POLICY AND THE DATA TRANSMISSIONS TO HAVE THE APPS. THEY ULTIMATELY FOUND A LARGE PERCENTAGE OF THE APPS DID NOT HAVE PRIVACY POLICIES, THAT ABOUT A THIRD OF THE APPS TRANSMITTED INFORMATION DATA TO A PARTY NOT DISCLOSED BY THE DEVELOPER OR THE DEVELOPER'S WEB SITE AND ONLY ABOUT 13% OF THE APPS ENCRYPTED ALL DATA TRANSMISSIONS BETWEEN THE APP AND THE DEVELOPER'S WEB SITE. THEY ULTIMATELY CONCLUDED THAT HEALTH AND FITNESS APPS WERE NOT PARTICULARLY GOOD AT PROTECTING CONSUMERS' PRIVACY.

SINCE WE DID NOT REVIEW THE PRIVACY POLICIES OF REVIEW THEIR OUR SNAP SHOTS WE DO NOT EXPRESS ANY OPINIONS AS TO PRIVACY RIGHTS, CLEARING HOUSE'S FINDINGS OR CONCLUSIONS.

MOVING ON IN SEPTEMBER OF 2013, WE CONDUCTED A SIMILAR STUDY. THEY TESTED 20 HEALTH AND FITNESS APPS AND FOUND THE PRESENCE OF 70 THIRD PARTIES. THEY FOUND THE THIRD PARTIES WERE TYPICALLY ADVERTISING ANALYTICS COMPANIES.

THIS GRAPHIC IS ACTUALLY A PICTURE OF THREE THIRD PARTIES THAT RECEIVED INFORMATION FROM 14 DIFFERENT APPS FROM THE ECONOMIC STUDY.

THE BLUE DOTS REPRESENT THE THIRD PARTIES AND THE CELL PHONES REPRESENT THE APPS. SO WHO ARE THESE THIRD PARTIES,

WHAT KIND OF INFORMATION ARE THEY THESE ARE THIRD PARTIES RECEIVING ABOUT OUR BODIES. DOES THE PICTURE LOOK DIFFERENT IF THEY INCLUDE WEARABLE. WE DESIGNED A SNAPSHOT TO TRY TO FIND OUT AND TAKE A DEEPER DIVE .

WE LOOKED AT 12 HEALTH AND FITNESS APPS.

THEY ALLOWED US TO SYNC OUR WEARABLE.

THIS PROJECT WAS MEANT TO BE A SMALL SNAPSHOT IN TIME SO WE LOOKED AT TWO DAILY ACTIVITY APPS CONNECTED TO WEARABLES.

TWO EXERCISE APPS, TWO DIETARY AND MEAL APPS, THREE THREE SYSTEM CHECKER APPS.

SO USING OUR MOBILE LAB WE EXAMINED THE INFORMATION BEING TRANSMITTED FROM EACH APP WHILE INTERACTING WITH EACH APP, WE WERE AS PERMISSIVE AS POSSIBLE. MEANING THAT IF AN APP ASKED US FOR PERMISSION TO ACCESS A CERTAIN FEATURE OR TO SYNC WITH ANOTHER APP, WE ALWAYS ACCEPTED AND OPTED IN.

WE THEN MAPPED OUT THE DATA SETS TO VISUALLY SEE THE TYPES OF INFORMATION BEING TRANSMITTED FROM EACH APP AND SEE WHERE THIS INFORMATION WAS GOING.

SO A FEW LIMITATIONS.

WE LIMITED OUR SNAPSHOT TO ONE MOBILE DEVICE, AND THEREFORE ONE OPERATING SYSTEM.

OUR SNAPSHOT WAS LIMITED TO THREE APPS SO WE DID NOT TEST ANY PAID APPS FOR IF AN APPED PREMIUM FEATURES WE DIDN'T PURCHASE THOSE FEATURES.

WE ONLY EXAMINED THE DATA TRANSMISSIONS BETWEEN THE APPS AND THE THIRD PARTIES ON THE

FRONT END, MEANING WHILE WE'RE INTERACTING WITH THE APP, WHILE ADDITIONAL INFORMATION COLLECTION AND SHARING CAN CERTAINLY HAPPEN ON THE BACK END OUR SNAPSHOT WOULDN'T HAVE CAPTURED THAT.

AND AGAIN, WE DID NOT REVIEW ANY PRIVACY POLICIES, SO WE DON'T ACTUALLY, WE DON'T MAKE OR EXPRESS ANY OPINIONS AS TO THE ACTUAL INFORMATION COLLECTION PRACTICE OR SHARING PRACTICES OF THE APPS THEMSELVES OR THIRD PARTIES.

SO ON TO THE SNAPSHOT.

WE STARTED WITH 12 DIFFERENT APPS.

DURING OUR TESTING WE FOUND THAT THESE 12 APPS TRANSMITTED INFORMATION TO THEIR DEVELOPER WEBSITES, WHICH ARE REPRESENTED HERE BY THE YELLOW DOTS.

OUR TESTING ALSO FOUND THAT ADDITIONAL INFORMATION WAS TRANSMITTED TO 76 THIRD PARTIES. THEY ARE REPRESENTED HERE BY THE BLUE DOTS.

SO WHAT DOES THIS MEAN.

ZOOMING IN AND TAKING A CLOSER LOOK AT ONE APP AS AN EXAMPLE, WE SEE THAT THIS APP TRANSMITTED INFORMATION TO 18 DIFFERENT THIRD PARTIES.

THESE THIRD PARTIES RECEIVED A VARIETY OF INFORMATION THAT GENERALLY FELL INTO FIVE CATEGORIES.

DEVICE INFORMATION, SUCH AS SCREEN SIZE, DEVICE MODEL OR LANGUAGE SETTING.

DEVICE SPECIFIC IDENTIFIERS SUCH AS A UDID.

THIRD PARTY SPECIFIC IDENTIFIERS WHICH YOU MIGHT THINK OF AS A COOKIE STREAM SPECIFIC TO A

PARTICULAR APP.
CONSUMER SPECIFIC IDENTIFIERS
AND CONSUMER INFORMATION.
IN THIS CASE DIETARY AND WORKOUT
HABITS.
SO LOOKING AT IT FROM ANOTHER
DIRECTION, WE MIGHT ASK
OURSELVES WHAT INFORMATION ARE
THESE THIRD PARTIES RECEIVING
FROM A VARIETY OF APPS.
SO THIS IS AN EXAMPLE OF A THIRD
PARTY ADD SERVICING COMPANY
THAT'S RICHARD INFORMATION FROM
FOUR SEPARATE APPS.
WE FOUND THAT THE SAME UNIQUE
IDENTIFIERS WERE TRANSMITTED TO
THIS THIRD PARTY FROM THE
VARIOUS APPS.
WE FOUND THAT THE APPS OFTEN
TRANSFER ADDITIONAL INFORMATION
TO THIS THIRD PARTY SUCH AS AT
LEAST ONE APP TRANSMITTED KEY
WORD SUCH AS OVULATION,
FERTILIZATION, PREGNANCY AND
BABY SO THAT ESSENTIALLY
IDENTIFIED THE TYPE OF APP THAT
IT WAS TO THIS THIRD PARTY.
AT LEAST ONE APP TRANSMITTED
GENDER INFORMATION, AT LEAST ONE
APP TRANSMITTED WORK OUT
INFORMATION AND ALL OF THE APPS
TRANSMITTED INFORMATION ABOUT
OUR DEVICE.
SO WHILE THE THIRD PARTIES
RECEIVED THE SAME IDENTIFIERS
THAT UNIQUELY IDENTIFIED OUR
APP, OUR DEVICE BETWEEN APPS, WE
DON'T ACTUALLY MAKE ANY
DETERMINATIONS AS TO WHAT THIS
THIRD PARTY DID WITH THE
INFORMATION THAT IT RECEIVED
THROUGH THE VARIOUS APPS.
SO MOVING ON TO OUR FIRST
OBSERVATION, WE FOUND THAT 18 OF
THE 76 THIRD PARTIES COLLECTED
PERSISTENT DEVICE IDENTIFIERS,

SUCH AS A UNIQUE DEVICE ID, A MAC ADDRESS OR IMEI.
IN SOME INSTANCES, THE SAME THIRD PARTY RECEIVED THE SAME IDENTIFIER FROM MULTIPLE APPS.
OUR SECOND OBSERVATION, WE FOUND THAT 14 OF THE 76 THIRD PARTIES ALSO COLLECTED CONSUMER SPECIFIC IDENTIFIER.
IN MOST INSTANCES, THIS WAS A USER NAME.
A FEW INSTANCES WE FOUND NAME AND E-MAIL ADDRESS BEING TRANSMITTED.
IT WASN'T UNCOMMON FOR THIRD PARTY OR AN APP TO IDENTIFY A USER BY THEIR FIRST NAME, LAST INITIAL AND THEN A STREAM OF IDENTIFIERS.
AND OUR THIRD OBSERVATION WAS THAT 22 THIRD PARTIES RECEIVED ADDITIONAL INFORMATION ABOUT OUR CONSUMERS SUCH AS EXERCISE INFORMATION, MEAL AND DIET INFORMATION, IDENTICAL SYMPTOMS SEARCH INFORMATION, ZIP CODE, GENDER, GEO LOCATION.
AND FINALLY, A SUMMARY OF OUR OBSERVATIONS.
HEALTH AND FITNESS APPS COLLECT AND TRANSMIT TO THIRD PARTIES. SENSITIVE INFORMATION ABOUT OUR BODIES AND OUR HABITS.
THE 12 APPS THAT WE TESTED TRANSMITTED INFORMATION TO 76 THIRD PARTIES.
THE INFORMATION INCLUDED DEVICE INFORMATION, CONSUMER SPECIFIC IDENTIFIERS, UNIQUE DEVICE IDs UNIQUE THIRD PARTIES IDs AND CONSUMER INFORMATION SUCH AS DIETARY HABITS AND SYMPTOM SEARCHES.
THERE ARE IMPLICATIONS WHERE HEALTH CONTAINS DIETARY HABITS AND CIRCUMSTANCES ARE BEING

AGGREGATED USING IDENTIFIERS
UNIQUE TO A PERSON PERSON OR
THEIR DEVICE.

THANK YOU.

>> GREAT, THANKS JARED.

[APPLAUSE]

I WOULD LIKE TO WELCOME OUR
PANEL UP TO THE STAGE AND WE'LL
HAVE THE PANEL PART OF THIS.

>> GOOD MORNING EVERYONE, MY
NAME IS KRISTEN ANDERSON AND I'M
ALSO AN ATTORNEY IN PRIVACY
PROTECTION.

CORA AND I WILL BE CO-MODERATING
THIS PANEL.

WE WILL FOCUS ON THE WAYS IN
WHICH CONSUMER ARE GENERATING
AND MANAGING THERE OWN HEALTH
DATA.

WE'LL HEAR FROM OUR
DISTINGUISHED PANEL OF EXPERTS
WHO HAVE DIFFERENT PERSPECTIVES
AND VARIED EXPERIENCES ABOUT HOW
CONSUMERS ARE GOING ABOUT THIS,
WHAT SOME OF RISKS AND BENEFITS
ARE AND WHAT THEY THINK THE NEXT
STEP SHOULD BE TO ENCOURAGE
INNOVATION WHILE PROTECTING
CONSUMERS' PRIVACY.

WE ARE JOINED BY DR. CHRISTOPHER
BORROW WHO JOINED THE EXECUTIVE
TEAM IN 2010 AND IS THE
COMPANY'S PRINCIPAL DATA
SECURITY AND PRIVACY OFFICER.
HE'S A PHYSICIAN SCIENTIST AND
BIOTECHNOLOGY EXECUTIVE
ENTREPRENEUR IN THE FIELD OF
GENOMICS AND PERSONALIZED
MEDICINE.

AS A CLINICIAN AND HEALTH
INFORMATION DATA SPECIALISTS,
DR. BORROW HAS PLAYED A KEY ROLE
IN MOBILE APPEARS INCLUDING BLUE
BUTTON AND ICE BLUE BUTTON
WORKING CLOSELY WITH THE
SOFTWARE DEVELOPMENT TEAM.

NEXT WE ARE HAVE SALLY OKUN
WHERE SHE'S RESPONSIBLE FOR
PATIENT VOICE AND ADVOCACY
INITIATIVES.

PARTICIPATES IN HEALTH POLICY
DISCUSSIONS WITH THE NATIONAL
AND GLOBAL LEVEL.

OVERSEAS THE COMPANY'S PATIENT
SAFETY INITIATIVES AND ACT AS
THE COMPANY'S LIAISON WITH
GOVERNMENT AND REGULATORY
AGENCIES.

NEXT WE HAVE JOSEPH LORENZO HALL
WHO IS THE CHIEF TECH NULL GIST
AT THE CENTER FOR DEMOCRACY AND
TECHNOLOGY.

HIS WORK FOCUSES ON THE NEXUS
BETWEEN TECHNOLOGY, LAW AND
POLICY AND ENSURING THAT
TECHNOLOGY AND TECHNICAL
CONSIDERATIONS ARE APPROPRIATELY
IMBEDDED IN LEGAL POLICY
ENVIRONMENTS.

FINALLY WE HAVE JOY PRITTS WHO
JOINED THE OFFICE OF THE
NATIONAL COORDINATOR FOR HEALTH
INFORMATION TECHNOLOGY IN THE
DEPARTMENT OF HEALTH AND HUMAN
SERVICES IN FEBRUARY OF 2010 AS
ITS FIRST CHIEF PRIVACY OFFICER.
MS. PRITTS PROVIDES CRITICAL
ADVICE TO THE SECRETARY AND THE
NATIONAL COORDINATOR IN
DEVELOPING AND IMPLEMENTING
ONC'S PRIVACY SECURITY PROGRAMS
UNDER HIGH TECH.

AND UNFORTUNATELY OUR FINAL
PANELIST WHO IS SUPPOSED TO BE
HERE IS HEATHER PATTERSON BUT
HE'S UNABLE TO JOIN US.

>> THANKS TO ALL OF OUR
PANELISTS.

WE'D LIKE TO START BY SETTING
THE STAGE WITH WHY WE ARE HAVING
THIS DISCUSSION ABOUT CONSUMER
GENERATED AND CONTROLLED HEALTH

DATA.

AS LATANYA SWEENEY NOTED IN HER PRESENTATION, HIPAA DOESN'T COVER ALL HEALTH DATA BUT CONSUMERS DON'T KNOW THAT.

JOY A QUESTION TO YOU.

COULD YOU SKETCH OUT THE BOUNDARIES OF HIPAA FOR US, AND DESCRIBE UNDER WHAT CIRCUMSTANCES A CONSUMER MIGHT GENERATE HEALTH DATA THAT WOULDN'T DECOVERED BY HIPAA.

>> I WILL BE HAPPY TO.

THANK YOU.

PEOPLE NOT PROBABLY MOST OF THE PEOPLE IN THIS ROOM, BUT LAY PEOPLE THINK THAT HIPAA COVERS ALL HEALTH INFORMATION.

THEY'RE FAMILIAR WITH GETTING THE NOTICE IN THEIR DOCTOR'S OFFICE, AND SO THEY ALSO RECEIVE NOTICES FROM PEOPLE WHO AREN'T COVER BY HIPAA SAYING WE FOLLOW HIPAA.

BUT HIPAA ACTUALLY IS PRETTY SECTOR SPECIFIC.

BY THAT I MEAN IN THIS COUNTRY, WHEN WE REGULATE INFORMATION REALLY APPLIES TO THE PEOPLE FOR THE MOST PART WHO HOLD THE INFORMATION OR WHO GENERATE THE INFORMATION.

AND IN THIS CASE, HIPAA ORIGINALLY IMPLIED TO HEALTH PLANS, MOST HEALTH PROVIDERS AND THESE THINGS CALLED HEALTHCARE CLEARING HOUSES THAT WERE KIND OF ESSENTIAL TO THE TRANSMISSION OF CLAIMS DATA.

ONE OF THE INTERESTING THINGS ABOUT HIPAA THAT MANY PEOPLE DON'T REALIZE IS THAT IT REALLY GENERATED FROM A MOVEMENT TO STANDARDIZE CLAIMS DATA.

IT WASN'T REALLY ABOUT PRIVACY AT ALL ORIGINALLY, IT WAS

PRIVACY WAS INCLUDED AS A PROTECTION, BUT THE FOCUS WAS ON SIMPLIFYING THE ADMINISTRATION OF HEALTH CLAIMS AND HOW THEY WERE PROCESSED.

WHEN YOU KNOW THAT, A LOT OF WHAT HAPPENS UNDER HIPAA MAKES A WHOLE LOT MORE SENSE.

SO THE WAY IT WORKS IS THAT HIPAA DIRECTLY APPLIES AND DIRECTLY REGULATES MOST OF THESE HEALTHCARE PROVIDERS AND HEALTH PLANS.

AND IT PUTS LIMITS ON HOW THEY CAN USE AND DISCLOSE THE INFORMATION.

SO IT REALLY FOCUSES ON WHO HOLDS THE INFORMATION AND WHAT THEY CAN DO WITH IT AND WHO THEY CAN SHARE IT WITH.

THE GENERAL RULE IS THAT THEY CAN'T SHARE IT EXCEPT UNDER CERTAIN CIRCUMSTANCES WITHOUT THE PATIENT'S PERMISSION EXCEPT UNDER CERTAIN CIRCUMSTANCES.

AND THERE ARE A LOT OF EXCEPTIONS UNDER HIPAA WHICH WERE AIMED AT TRYING TO MAKE THE CORE PURPOSE OF PROVIDING HEALTHCARE AND PAYMENT FOR HEALTHCARE EASY AND SIMPLE. SO YOU HAVE HEALTH PLANS AND HEALTHCARE PROVIDERS.

AND UNDER THE RELATIVELY RECENT ENACTMENT OF THE ECONOMIC RECOVERY ACT, THERE WAS A PIECE IN THERE WHERE CONGRESS ALSO IMPROVED THE PRIVACY PROTECTIONS.

AND THAT WAS REFERRED TO EARLIER BY COMMISSIONER S. BOROUGH HIGH TECH.

UNDER THAT ACT CONGRESS EXPANDED THE PRIVACY PROTECTIONS SO YOU NOW HAVE A SITUATION WHERE IT'S NOT JUST THE HEALTH PLANS AND

THE HEALTHCARE PROVIDERS BUT THE PROTECTION ALSO OF HIPAA FLOWS TO PEOPLE AND ORGANIZATIONS THAT UNDERTAKE REALLY CORE ACTIVITIES ON BEHALF OF THOSE WHAT THEY CALL COVERED ENTITIES AND BUSINESS ASSOCIATES.

SO, UNDER HIGH TECH, THE DATA MAP THAT LATANYA SHOWED US A LITTLE BIT EARLIER, IT STILL PRESENTS A VERY INTERESTING, AN INTERESTING DIAGRAM.

BUT THERE WOULD BE MORE SOLID LINES, A FEW MORE SOLID LINES. BUT THEY ALSO DEPEND ON WHAT FUNCTION THAT ORGANIZATION IS PERFORMING.

SO FOR EXAMPLE, IN THAT MAP LATANYA HAD AN ARROW THAT WENT TO LAWYERS.

WELL NOW, IF LAWYERS WERE PERFORMING A SERVICE ON BEHALF OF A DOCTOR FOR EXAMPLE, THEN THEY MUST ALSO FOLLOW HIPAA. THE HIPAA RULES FOR PRIVACY AND SECURITY.

ON THE OTHER HAND, IF A LAWYER SUBPOENAS THOSE DOCUMENTS FOR LIKE ANOTHER PURPOSE, IT'S NOT PROTECTED BY HIPAA.

SO YOU CAN SEE THAT IT'S A LITTLE COMPLICATED FOR PEOPLE AND PARTICULARLY LAY PEOPLE TO UNDERSTAND HOW THIS WORKS BECAUSE WHETHER INFORMATION IS PROTECTED, IT OFTEN DEPENDS ON HEALTH INFORMATION'S PROTECTED, DEPENDS ON WHO IS HOLDING IT AND FOR WHAT PURPOSE.

>> YES.

NO, THAT'S GREAT.

SO COULD YOU DESCRIBE A SITUATION FOR EXAMPLE WHICH A CONSUMER MIGHT UNWITTINGLY MOVE OUTSIDE THE HIPAA BUBBLE.

>> THAT'S A VERY INTERESTING

SITUATION.

SO ONE OF THE RIGHTS THAT INDIVIDUALS HAVE UNDER THE HIPAA PRIVACY RULE IS A RIGHT TO GET A COPY OR TO GET ACCESS TO THEIR OWN HEALTH INFORMATION AND THAT INCLUDES GETTING A COPY OF THAT INFORMATION.

HIGH TECH CONTAINS A PROVISION WHICH REALLY CLARIFIED THAT INDIVIDUALS HAVE A RIGHT TO GET ANY ELECTRONIC COPY OF THEIR INFORMATION WHEN IT'S AVAILABLE. WE THINK THAT THIS IS A REALLY IMPORTANT ASPECT OF HEALTHCARE AS WE GO FORWARD, BECAUSE UNDER THE AFFORDABLE CARE ACT, PATIENTS ARE REALLY PUTTING AT THE CENTER, BEING PUT AT THE CENTER OF THEIR CAREER TRYING TO MOVE FROM A PARADIGM WHERE HEALTHCARE IS JUST PROVIDED ON AN EPISODIC BASIS.

AND REALLY TREAT THE PATIENT MORE HOLISTICALLY.

WHAT THAT MEANS IS IN ORDER TO DO THAT YOU NEED INFORMATION GOING BACK AND FORTH BETWEEN A DOCTOR AND A PATIENT THAT IS RELATED NOT ONLY TO THEIR DOCTOR VISIT BUT HOW THEY'RE LIVING AND WHAT THEY'RE DOING IN THE OUTSIDE WORLD.

BECAUSE THEN YOU GET THE ENTIRE PICTURE.

ONE OF THE EFFORTS TO DO THAT IS TO MOVE THAT INFORMATION TO THE PATIENT, SO PATIENTS DO HAVE THE RIGHT TO GET ACCESS TO THEIR OWN HEALTH INFORMATION.

AND FEDERAL GOVERNMENT HAS UNDERTAKEN A NUMBER OF INITIATIVES TO ENCOURAGE THEM TO DO THAT.

ONE OF THOSE IS UNDER THE INCENTIVE PAYMENTS FOR DOCTORS

AND HOSPITALS UNDER THE AFFORDABLE CARE ACT TO ADOPT ELECTRONIC HEALTH RECORDS. ONE OF THE KEY FUNCTIONS THAT THEY NEED TO UNDERTAKE IS TO ALLOW PATIENTS TO VIEW, DOWNLOAD AND TRANSMIT THEIR OWN HEALTH INFORMATION.

BUT WHAT HAPPENS THEN IS WE HAVE, WE ARE ENCOURAGING PEOPLE AT THE PLATE TO MOVE THEIR INFORMATION POTENTIALLY OUT OF THE HIPAA-COVERED BUBBLE AND INTO THE HANDS OF OTHERS WHO MAY NOT BE SUBJECTED TO HIPAA.

HAVING SAID THAT THERE ARE CIRCUMSTANCES FOR EXAMPLE WHEN YOU HAVE A PERSONAL HEALTH RECORD THAT IS OFFERED ON BEHALF OF A HEALTH PLAN OR HEALTHCARE PROVIDER.

BECAUSE THEY ARE TIED TO THE PLAN AND PROVIDER THAT INFORMATION WOULD REMAIN PROTECTED WITHIN HIPAA.

IF YOU TRANSMIT YOUR INFORMATION, YOU'RE A PATIENT AND LOOKING ON THE WEBSITE AND YOU JUST FIND YOUR OWN PERSONAL HEALTH RECORD WEBSITE AND YOU SAY HEY I WANT MY INFORMATION SENT THERE, THEN IT WOULD NOT BE PROTECTED.

SO YOU CAN SEE HOW IT'S VERY, IT'S A LITTLE COMPLICATED.

>> THANKS, JOY.

SO TURNING NOW TO SOME OF THE OTHER PRODUCTS AND SERVICES LIKE WEBSITES, APPS AND DEVICES THAT INCREASINGLY PUT MEDICAL SCHOOLS AND HEALTH DATAS IN CONSUMER HANDS WHAT ARE SOME OF THOSE PRODUCTS AND BENEFITS.

SALLY WE MIGHT START WITH YOU.

>> SURE.

THANK YOU VERY MUCH.

THERE'S SUCH AN ARRAY OF THEM AND WE HEARD A LITTLE BIT ABOUT THAT IN JARED'S TALK IN TERMS OF THE KINDS OF APPS AND OTHER DEVICES CENSORED DEVICES AVAILABLE TO PEOPLE TODAY. SO I THINK I WON'T SPEND A LOT OF TIME THERE BECAUSE I THINK YOU GAVE US A REALLY NICE OVERVIEW OF THAT BECAUSE I THINK WE NEED TO BE STARTING TO THINK ABOUT FIRST OF ALL THE HABITS THAT PEOPLE AS CONSUMERS ALREADY HAVE IN USING THE INTERNET LOOKING FOR INFORMATION ABOUT THEIR HEALTH.

WE KNOW THAT NEARLY 75% OF ADULTS IN THE UNITED STATES ARE ALREADY ON-LINE LOOKING FOR INFORMATION AND MANY OF THOSE, ABOUT 60% OF THOSE ARE ACTUALLY LOOKING FOR HEALTH INFORMATION. SO THERE'S A VARIETY OF THINGS THAT THEY'RE GOING TO FIND THERE THAT COULD HAVE VARYING DEGREES OF USEFULNESS UTILITY, AS WELL AS PRIVACY PROTECTIONS.

SO THERE'S ONE OF THE THINGS THAT I THINK IS IMPORTANT IS FOR US TO ALL THINK ABOUT HOW WE PRACTICE ON THE INTERNET AND WHERE ARE WE GOING AND THAT WILL HELP US TO UNDERSTAND I THINK SOMETIMES AS THE KINDS OF THINGS THAT ARE AVAILABLE.

SO THERE'S A VARIETY OF THINGS. WE HAVE ACCESS TO WEBSITES THAT ARE PARTICULARLY FOCUSED ON A PARTICULAR DISEASE, SO YOU'LL HAVE A LOT OF WEBSITES MAYBE DEDICATED TO DIABETES WHERE A LOT OF INFORMATION CAN BE PULLED IN FROM AN APP FOR EXAMPLE OR A MOBILE DEVICE AND IT COULD CREATE A PROFILE ABOUT YOU INDIVIDUALLY.

THERE'S OTHERS THAT ARE REALLY MORE AROUND SUPPORT. I'M THINKING ABOUT I HAVE HAD CONDITION YOU HAVE THIS CONDITION, LET'S TRY TO FIND WAYS OF BEING ABLE TO SHARE WHAT WE KNOW AND THEN FIND SOME WAYS OF SUPPORTING EACH OTHER.

AND THEN THERE ARE APPS LIKE PATIENTS LIKE ME WHICH I'LL GIVE YOU JUST A BRIEF OVERVIEW IS REALLY OF A RESEARCH-BASED CONCEPT ON OUR PLATFORM WHERE WE'RE ACTUALLY HELPING PATIENTS CREATE HEALTH PROFILES USING QUANTIFIED SURVEY TYPE TOOLS WHERE THEY'RE ABLE TO CREATE INFORMATION AND THEN LONGITUDALLY TRACK THAT OVER TIME.

IT HAPPENS TO BE BUILT UPON A SOCIAL NETWORK SO THE CONCEPT BEING THAT PATIENTS HAVE THE OPPORTUNITY TO NOT ONLY CREATE THEIR OWN PERSONAL RECORD BUT ALSO TO SHARE THAT AND BE TRANSPARENT ABOUT THAT WITH OTHER PEOPLE LIKE THEMSELVES.

I THINK THE OTHER PIECE I WANT TO MENTION ABOUT PHR AND PERSONAL HEALTH RECORDS IS ONE AREA THAT HAS NOT NECESSARILY TAKEN OFF IS THE FACT THAT PERSONAL HEALTH RECORDS ARE ACTUALLY RATHER BORING.

REALLY, THERE'S A LOT OF THINGS YOU CAN DO THERE IN TERMS OF TRANSACTIONAL THINGS LIKE MAKE A DOCTOR'S APPOINTMENT OR MAYBE CHECK YOUR LABS, PULL IN SOME INFORMATION WHETHER YOU'RE GOING TO VIEW DOWN AND TRABLES MITT THAT INFORMATION BUT THERE'S NOT A LOT ELSE TO DO.

SO I THINK CONSUMERS IN GENERAL ARE LOOKING FOR SOMETHING A BIT

MORE INTERACTIVE AND INFORMATIVE
AND YEW BIG WITH US WITH
INFORMATION.

THERE'S A WHOLE HOST OF WAYS
OFFICES BEING ABLE TO FIND USES
ON THE INTERNET TO START
ANSWERING QUESTIONS YOU MIGHT
HAVE EITHER ABOUT YOUR HEALTH
THE HEALTH OF OTHERS OR YOUR
DPAMILY OR THOSE YOU CARE ABOUT
BUT IT'S DIVERSE WHERE YOU HAVE
TO THINK ABOUT WHAT IS THE
PURPOSE I WANT TO USE IT FOR AND
UNDERSTAND WHAT YOUR RISKS MIGHT
BE AND USING IT FOR THAT
PARTICULAR PURPOSE.

>> JOE, DID YOU HAVE ANYTHING
YOU WANTED TO ADD.

>> THAT'S A WONDERFUL OVERVIEW.
THERE'S A ZOO OF MEDICAL APPS
AND WEBSITES OUT THERE.
A COUPLE HAVEN'T BEEN MENTIONED.
FOR EXAMPLE YOUR PHONE CAN
INTEGRATE WITH THINGS THAT CAN
PROVIDE SOME ASPECT OF MEDICAL
MEASUREMENTS, SO THERE ARE
SIMPLE THINGS LIKE WIRELESS
SCALES THAT CAN UPLOAD YOUR
WEIGHT TO A PHR OR SOME OTHER
SERVICE.

WE HAVE WEARABLES.
THERE'S ONE IN THE FRONT ROW I'M
NOT GOING TO POINT TO THE PERSON
WEARING IT.

SHE OUTED HERSELF.
BUT THERE'S A LOT OF SORT OF
RECORDING YOUR DAILY HABITS SO
THAT YOU CAN KEEP TRACK OF YOUR
HEALTH AND WELLNESS.

IN SOME CASES THESE MAY BE MAYBE
NOT PRESCRIBED BY A PHYSICIAN
BUT AT LEAST AT THE MOMENT
RECOMMENDED HEAVILY BY A
PHYSICIAN.

YOU HAVE SORT OF THE VANGUARD OF
INTEGRATION OF SORT OF HEALTH

WELLNESS AND MEDICAL TOOLS SO
THERE ARE FOR MEDICINE
REMINDERS, YOU HAVE THINGS LIKE
A PILL YOU TAKE EVERY DAY THAT
ACTUALLY HAS A MICRO CHIP IN IT
THAT INTERFACES WITH YOUR SMART
PHONE TO MAKE SURE THAT IF YOU
HAVE MENTAL PROBLEMS THAT MAY
CAUSE YOU TO FORGET TO TAKE YOUR
MEDICATION AND WILL ACTUALLY
ASSIST YOU IN DOING THAT.
FINALLY THERE ARE REALLY
INNOVATIVE THINGS WE DON'T KNOW
WHAT TO DO.

GOOGLE ANNOUNCED PROJECT IRIS
WHICH IS A SMART CONTACT LENS
THAT WILL MEASURE, HOPES TO
MEASURE I GUESS THEY WOULD SAY
YOUR BLOOD GLUCOSE LEVEL BY
MEASURING THAT QUANTITY IN YOUR
TEARS.

AND YOU PUT YOUR ANDROID DEVICE
CLOSE TO YOUR HEAD AND IT WOULD
LET YOU KNOW OH GEEZ YOU
PROBABLY NEED TO TAKE SOME
INSULIN OR SOMETHING LIKE THAT.
THERE'S A REAL ZOO AND I'LL BE
BRIEF.

WE HAVE PLENTY.

>> THANK YOU.

CHRIS, WITH A KNOW YOUR COMPANY
HAS A GREAT PRODUCT BUT WE WOULD
LIKE TO GIVE YOU AN OPPORTUNITY
TO TALK ABOUT.

SO IF WE CAN SEE THE PERSONAL
HEALTH RECORD IN ACTION, THAT
WOULD BE GREAT.

SO IF YOU CAN GIVE A
DEMONSTRATION.

>> OKAY.

LET ME START BY SAYING THANK
YOU TO KRISTEN AND CORA AND I'M
DELAYED TO FIND THE COMMISSIONER
IS HERE AND WONDERFUL TO MEET
YOU.

COULDN'T ASK FOR A BETTER SET

UP.

HIPAA'S BEEN EXPLAINED.

I CHOSE THAT AS MY FIRST SLIDE.

I WANT TO HIGHLIGHT WHAT JOY SAID WHICH IS WITH HIPAA WE AS CITIZENS ALL HAVE A RIGHT TO OUR HEALTHCARE DATA.

WITH THE UPDATED VERSION OF HIPAA THAT YOU HEARD ABOUT IN A HIGH TECH HAT WE ALL HAVE A RIGHT TO ELECTRONIC DATA.

AND I LIKE THIS THAT WAS PREPARED.

ANY CITIZEN WHO GOES TO HIS HEALTHCARE PROVIDER OR HOSPITAL CAN TAKE THIS MEMO AND IT REALLY DETAILS EXACTLY WHAT MY RIGHTS ARE AS A CITIZEN AND SO THERE. BUT ONE IMPORTANT THING AND THAT MEMORANDUM IS THAT IT DRAWS ATTENTION TO THE FACT THAT WITH NEW ELECTRONIC HEALTH RECORD SYSTEMS AND PERSONAL HEALTH RECORD SYSTEMS, PATIENTS CAN NOW HELP.

THEY CAN NOW HELP TO KEEP THEMSELVES SAFER ASK TO MAKE MEDICAL CARE BETTER.

AND SO THIS IS A VERY POSITIVE DEVELOPMENT AND WE'RE AT THE DAWN OF TOOLS BEING OFFERED TO PATIENTS THAT CAN HAVE THEM DO JUST THAT.

SO WHAT I WILL HIT VERY QUICKLY IS THE DESCRIPTION OF THE I BLUE BUTTON APP WHICH E METRICS STARTED BUILDING.

THIS RUNS ON ANDROID OR IOS DEVICES THAT ALLOWS YOU TO TAKE CARE OF YOURSELF AND YOUR FAMILY MEMBERS BY COLLECTING HEALTH RECORDS EITHER FROM PLACES LIKE MEDICARE OR THE VA OR TRY CARE OR THE EMR SYSTEMS.

AS YOU CAN SEE HERE, THIS PARTICULAR PATIENT HAS SEVERAL

RECORDS.

THIS PATIENT HAS A MEDICARE RECORD, HAS A RECORD THAT HE'S OBTAINED FROM TRI CARE ON-LINE WHICH IS THE ON-LINE SITE WHERE ACTIVE DUTY SOLDIERS AND THEIR FAMILIES CAN GO GET AN ON-LINE BLUE BUTTON RECORD OR SUMMARY RECORD.

THIS FICTIONAL PATIENT HAS ACQUIRED A DATA FROM AN EMR SYSTEM CALLED EPIC FROM THE UNIVERSITY OF SALESAN DIEGO ALL OF THESE RECORDS ARE CAPTURED IN THE APP WHERE THEY ARE STORED LOCALLY ON THE DEVICE.

AND THE SYSTEM ALLOWS YOU TO CREATE A SUMMARY RECORD. THAT IS YOUR MEDICATIONS IMMUNIZATIONS, ALLERGIES AND CONDITIONS EXTRACTED FROM ALL OF THOSE RECORDS.

THERE ARE SEVERAL WAYS TO GET DATA INTO THIS APP.

BY THE WAY ALL THE DATA IS STORED LOCALLY ON THE DEVICE.

THERE IS NO CLOUD.

THERE IS NO CLOUD.

EVERYTHING IS LOCAL ON THE DEVICE WHERE EVERYTHING IS SAFELY ENCRIMPED.

ANY DOCUMENT YOU MIGHT HAVE ON YOUR DESKTOP YOU CAN UPLOAD.

OR YOU CAN USE THE CAMERA FUNCTION ON THE APP.

IF YOU BURNED YOUR HAND, YOU MIGHT WANT TO SHARE THAT WITH YOUR PHYSICIAN WHEN YOU SEE THEM OR IF YOU HAVE OTHER SKIN LESIONS SO THEY CAN FOLLOW THE COURSE OF WHAT'S HAPPENED.

NOW THIS IS A SUMMARY OF THE FEATURES OF THE SYSTEMS WE CREATED.

ON YOUR LEFT, YOU SEE THE VERSION OF THE APP RUNNING JUST

HERE ON A, SORRY GO BACKWARDS
RUNNING ON ANDROID DEVICE AND
APPLE APP WHERE THE USER CAN
DOWNLOAD RECORDS.

WHAT KIND OF RECORDS ARE THOSE.
THEY'RE CALLED A BLUE BUTTON
RECORD.

YOU CAN SEE IT ON MY LAPEL HAVE
I A BLUE BUTTON.

THIS IS A FEDERAL INITIATIVE
THAT JOY WAS COMMENTING ABOUT.
THEY HAVE GOTTEN TOGETHER WITH A
GROUP AND DEVELOP STANDARDS THAT
ALLOW INDIVIDUALS TO SAFELY
SECURELY RECEIVE THAT DATA IN A
DEFINED FORMAT FOR THEIR
BENEFIT.

NOW, MEDICARE AMONG THE VA LED
THE WAY, AND ANY ONE OF YOU, IF
YOU'RE COVERED BY MEDICARE OR
FAMILY MEMBERS ARE COVERED BY
MEDICARE CAN GO TO THE MY
MEDICARE.GOV WEBSITE GO THROUGH
AN AUTHENTICATION PROCESS THERE
ACQUIRE YOUR LOG-IN CREDENTIALS
AND THEN ENTER THOSE IN THE APP
STORED ON YOUR PHONE AND YOU CAN
DOWNLOAD THE RECORD AND THE APP
WILL PRESENTATE IN A VERY USER
FRIENDLY FORMAT SHOWN THERE
WHERE YOU CAN SEE THE RECORD.

AND ALSO MOST IMPORTANTLY WHAT I
DIDN'T SAY IN THE LAST SLIDE IS
YOU CAN PUSH THAT RECORD OVER TO
YOUR DOCTOR'S iPad WITH A
SECURE DEVICE TO DEVICE DATA
TRANSFER.

AGAIN NO DATA RESIDING OR
PERSISTING ON-LINE WHERE THE
PHYSICIAN CAN SEE YOUR DATA PLUS
ANY ANNOTATIONS THAT YOU MADE.
WE'RE GIVING YOU A SECURE WAY TO
RECEIVE YOUR RECORD STORE YOUR
RECORD AND SHARE YOUR RECORD.
I JUST MIGHT SAY IN PASSING THAT
37 MILLION AMERICANS COVERED BY

MEDICARE CAN USE THIS TECHNOLOGY TODAY TO RECEIVE CRITICAL INFORMATION ABOUT ALL THE MEDICATIONS THAT THEY RECEIVED IN THE LAST THREE YEARS THAT HAVE BEEN PAID FOR THROUGH PART B, AS WELL AS ALL CONDITION THAT WILL HAVE BEEN CODED -- CODED FOR BY ALL PHYSICIANS.

LET ME TELL YOU WHY I'M FOR ALL THIS.

THERE ARE SOMEWHERE BETWEEN 100,000 TO 400,000 DEATHS DUE TO MEDICAL ERRORS EVERY YEAR.

THERE ARE AT LEAST 700,000 ADVERSE DRUG EVENTS THAT RESULT IN INJURY OR DEATH.

JUST HAVING YOUR MOM'S MEDICATION RECORD AVAILABLE TO HER WHEN SHE SEES HER DOCTOR OR YOU YOURSELF HAVING YOUR OWN GOES A LONG WAY TO PREVENTING ADVERSE DRUG REACTIONS.

THIS REALLY CAN BE CRITICAL CRUCIAL INFORMATION AND WE'RE PASSIONATE ABOUT DELIVERING THIS SERVICE TO OUR USERS.

THE NEW WAY TO GET DATA, YOU HEARD ABOUT DOWNLOADING DATA FROM THE MEDICARE BLUE BUTTON OR V.A., THE NEW STANDARDS HAVE BEEN PUT IN PLACE CALLED THE BLUE BUTTON PLUS STANDARDS REQUIRE THAT HOSPITAL INFORMATION SYSTEMS USE SOMETHING CALLED DIRECT, WHICH IS A SECURE E-MAIL PROTOCOL TO SEND A DEFINED MACHINE AND HUMAN READABLE SUMMARY OF YOUR ENCOUNTER OR YOUR HOSPITAL DISCHARGE TO YOU TO AN E-MAIL ADDRESS.

OUR APP PROVIDES YOU WITH THAT SECURE ADDRESS AND THE PHYSICIAN OR PHYSICIAN EXTENDER NURSE PRACTITIONER CAN SEND THE RECORD

DIRECTLY TO YOUR APP.
OUR APP WILL DOWNLOAD IT, LET
YOU VIEW IT AND LET YOU
ASSIMILATE IT WITH OTHER RECORDS
THAT YOU HAVE TO CREATE THAT
SUMMARY RECORD.
HERE'S AN EXAMPLE.
THERE'S THE MEDICARE RECORD ON
THE LEFT SHOWING ALL THE
DIAGNOSIS AND ALL THE
MEDICATIONS THAT WE COULD SCROLL
DOWN AND SEE ALL THE ER VISITS
AND MINUTING STUDIES.
THE NEXT RECORD IS AN EPIC EMR
RECORD FROM THE UNIVERSITY OF
CALIFORNIA SAN DIEGO.
THE NEXT RECORD IS FROM THE V.A.
THE LAST DISPLAY OVER THERE, THE
SUMMARY RECORD IS WHAT IT'S
TELLING YOU ABOUT WHERE THE APP
HAS NOW GONE AND RETRIEVED IF
YOU WILL BY PARSING THROUGH ALL
THE DATA AND THE OTHER RECORDS
ALL OF THE MEDICATIONS THAT YOU
RECEIVED AS WELL AS ALL YOUR
CONDITIONS.
JUST TO FINISH UP HERE QUICKLY
BECAUSE I THINK THIS IS QUITE
IMPORTANT.
IF WE LOOK AT BOTH MEDICATIONS
AND CONDITIONS, YOU CAN HAVE A
DETAILED VIEW OF YOUR
MEDICATION.
YOU CAN TAP THIS DPRAIFT
RESOURCE FROM THE NATIONAL
LIBRARY OF MEDICINE CALLED MED
LINE PLUS.
YOU CAN EASILY SEE MEDICATIONS
ABOUT YOUR CONDITION IN ENGLISH
OR SPANISH.
OUR APP LET'S YOU INDICATE
WHETHER OR NOT A DRUG YOU'RE
ACTUALLY TAKING IT OR NOT,
WHETHER YOU'RE HAVING ANY SIDE
EFFECTS OR NOT AND WOULD YOU
LIKE TO KEEP THIS ENTRY PRIVATE.

THE SAME THING FOR YOUR
CONDITIONS.

THERE ARE FREQUENT ERRORS IN
MEDICAL RECORDS.

OUR APP INDICATES WHETHER A
PARTICULAR CONDITION WAS AN EAR
OR WHETHER IN THE PAST OR
WHETHER OR NOT YOU WOULD LIKE TO
KEEP IT PRIVATE.

SO THE WAY OUR SYSTEM WORKS WHEN
YOU SHARE THAT DATA WITH YOUR
PHYSICIAN, IF YOU'RE SHARING THE
SUMMARY RECORD, THE ONLY THING
THAT THEY WILL SEE IS THE ITEMS,
ITEM BY ITEM THAT YOU'VE DECIDED
YOU WANT TO SHARE.

FOR YOU TO SHARE THE ENTIRE
MEDICARE RECORD OR THE ENTIRE
RECORD FROM THE V.A., THAT
RECORD GOES ACROSS UNALTERED.
SO YOU THE CONSUMER ARE IN
CONTROL OF THIS APP.

ONE THING I WOULD LIKE TO FINISH
ON IS THE PRIVACY POLICY.

SO WITHIN THE APP THERE IS A
PRIVACY POLICY.

AND YOU CAN SEE, WE ALSO HAVE AN
ABOUT STATEMENT AND AN FAQ
STATEMENT THAT EXPLAINS HOW TO
USE THE APP.

IF YOU TAP ON THE HERE, IN THE
PRIVACY NOTICE, YOU CAN SEE THE
ONC'S MODEL PRIVACY NOTICE THAT
WE PUT INTO THE APP SO YOU CAN
SEE IT RIGHT AWAY.

AND THIS SHOWS YOU WHETHER OR
NOT WE RELEASE ANY OF YOUR DATA.
WELL, FIRST OF ALL SINCE WE
DON'T HAVE YOUR DATA, WE CANNOT
RELEASE IT, SO NO WE DON'T
RELEASE IT.

DO WE REQUIRE ANY LIMITING
AGREEMENTS.

AGAIN, NOT APPLICABLE.

AND WITH REGARD TO ANY
PARTICULAR DETAILS, WE

ESSENTIALLY DON'T RELEASE
ANYTHING.

SO IF WE GO BACK TO THE DATA
MAP, I LOVE THAT DATA MAP THAT
LATANYA SWEENEY SHOWED AT THE
START.

THIS IS A NEW KIND OF PHR.
PURE PHR IS ESSENTIALLY
IRREVOCABLY.

SHOULD YOU CARE TO OR CHOOSE TO
YOU OF COURSE HAVE A RIGHT TO
BUT USING THIS APP YOU DON'T
HAVE TO.

SO WITH THAT I WOULD LIKE TO
CONCLUDE AND KRISTEN AND CORA
AND EVERYBODY THANKS SO MUCH FOR
GIVING US A CHANCE TO SPEAK.

>> GREAT.

THANKS.

[APPLAUSE]

SO TURNING FROM THE MARKETPLACE
TO PRIVACY CONCERNS, WE SPENT
SOME TIME THIS MORNING TALKING
ABOUT DATA FLOWS.

AND CERTAINLY ONE OF THE MOST
SIGNIFICANT PRIVACY CONCERNS
WE'VE HEARD ABOUT IS THE
POTENTIAL FOR SENSITIVE HEALTH
INFORMATION TO BE SHARED IN WAYS
CONSUMERS WOULD NOT REASONABLY
EXPECT OR ANTICIPATE.

SO WE'D LIKE TO SPEND A LITTLE
BIT OF TIME ON TALKING ABOUT
THESE FLOWS.

AND I THINK WE'D LIKE TO ASK THE
PANELS AND PERHAPS JOE YOU COULD
START OFF AND THEN OTHERS COULD
JUMP IN.

CAN YOU TELL US ABOUT THE TYPES
OF DATA SHARING YOU'VE SEEN IN
THE APP WORLD AS WELL AS PHRS
AND ELSEWHERE.

WHAT SORTS OF BUSINESS MODELS
ARE IN THAT SPACE.

>> OKAY.

SO YOU WANT ME TO SPECIFICALLY

TALK ABOUT BUSINESS MODELS.
THERE ARE SORT OF TWO PIECES TO
YOUR QUESTION.

>> HOW ABOUT WE START WITH THE
SHARING.

>> OKAY, SHARING.

>> THEN THE BUSINESS MODEL.

>> AS LATANYA'S MAP SORT OF
SHOWED THERE'S QUITE A BIT OF
SHARING IN THE TRADITIONAL SORT
OF MORE CLINICAL MEDICAL
SERVICES DELIVERY HEALTHCARE
INDUSTRY CONTEXT.

WE DON'T KNOW A WHOLE LOT ABOUT
THE SHARING OF APPS OTHER THAN
WHAT WE SEE FROM THE PR AND
PRIVACY RIGHTS CLEARING HOUSE
STUDY THE STUDY AND NOW FTC IS
ADDING TO THAT SET OF RESULTS.

BUT THERE'S OTHER RESEARCH.

SO FOR EXAMPLE HEATHER PATTERSON
WHO COULDN'T BE HERE WITH US
TODAY HAS DONE A REALLY
INTERESTING FASCINATING DEEP
QUALITATIVE STUDY OF FIT FIT
USERS.

IF YOU DON'T LIKE QUALITATIVE
METHOD BOY YOU'RE MISSING OUT
AND YOU MAY NOT LIKE THIS WORK.
BUT TALK TO ME LATER.

I HAVE A DEGREE IN ASTRO PHYSICS
SO I CAN TELL YOU WHY THEY
MATTER.

BUT ANYWAY THE TOP CONCERNS FROM
PEOPLE THAT THEY STUDIED USING
FIT THAT'S PRETTY BENIGN
INFORMATION.

IT'S SORT OF TO SOME EXTENT HOW
MANY STEPS DO YOU WALK FROM AN
AL TIM TER SENSE YOUR ACTUAL
MOTION TRANSMITTED INTO HOW FAR
YOU WALKED.

BUT THE THINGS THAT PEOPLE CARED
ABOUT WERE THE TOP THREE WERE
TORT OF EMBARRASSMENT, PHYSICAL
SAFETY AND THEN IMPLICATIONS FOR

EMPLOYMENT AND ENSURABILITY.
AND SO IN TERMS OF
EMBARRASSMENT, FIT FIT HAS A
GREAT CASE STUDY ITSELF WHERE
THEY WERE ACCIDENTALLY SHARING
INDIVIDUAL SEXUAL ACTIVITY
PUBLICLY ON-LINE WITHOUT KNOWING
BECAUSE YOU DON'T TYPICALLY WEAR
YOUR FIT FIT WHEN YOU'RE
ENGAGING IN THAT KIND OF
ACTIVITY.

BUT YOU CAN SELF REPORT THAT
KIND OF ACTIVITY.

IF YOU'RE SHARING EVERYTHING
YOU'RE SHARING THAT AS WELL.
THAT WAS VERY EMBARRASSING TO
THOSE USERS AND FIT FIT VERY
QUICKLY TO THEIR QUIT RECOGNIZED
SOME CATEGORIES OF PHYSICAL
EXERGS MAY BE A LITTLE MORE
SENSITIVE THAN OTHERS.

I DIDN'T INTEND THAT TO BE A
JOKE.

BUT PHYSICAL SAFETY IS ANOTHER
THING SO IF YOU TALK ABOUT
ROUTES, RUNNING ROUTES AND
THINGS LIKE THAT YOU MAY BE ABLE
TO PREDICT WHERE SOMEONE IS
ALONE WHEN THEY'RE NOT AT HOME
AND THAT CAN BE AN EXTREMELY
SENSITIVE GIVEN YOUR OWN
PERSONAL CONTEXT.

FINALLY EMPLOYABILITY INSURANCE
RATING.

WE TALKED A LITTLE BIT ABOUT
INSURANCE RATING BUT TO SOME,
TEND THESE KINDS OF DEVICES OR
THESE KINDS OF PATIENT GENERATED
OR CONSUMER GENERATED I SHOULD
SAY HEALTH DATA ARE INCREASINGLY
BEING USED IN WELLNESS PROGRAMS
TO REWARD PEOPLE OR TO ENCOURAGE
THEM TO BE MORE HEALTHY, IF NOT
THE BOTTOM LINE GIVEN YOUR
HEALTH INSURANCE PREMIUM OTHER
THING AS WELL IN TERMS OF MAKING

IT A BETTER WORKING ENVIRONMENT.
THERE ARE OTHER THING BUT I
WON'T TALK ABOUT THEM.

CERTAINLY IN THE BUSINESS MODEL
SIDE, AND THIS IS SOMETHING THAT
CHRIS MAY BE ABLE TO ENLIGHTEN
US A LITTLE BIT TOO SINCE HE
ROLLS WITH A LOT OF PEA HULL
THAT WORK WITH THE HEALTH APP.
IT'S UNCLEAR TO ME THAT THE
MONETIZATION MODELS ARE NOT
DIFFERENT FROM OTHER HEALTH
MOBILE APPS AT ALL.

FOR EXAMPLE THERE ARE THINGS
THAT ARE PURELY AD SUPPORTED AND
CLEARLY THE TOP 12 ONES WE'VE
SEEN ARE THOSE KINDS OF THINGS.
THERE ARE PREMIUM APPS AND YOU
CAN GET SOMETHING FOR FREE BUT
IF YOU WANT EXTRA SERVICE
KNOWING EXACTLY WHAT THAT DRUG
DOES OR SOMETHING LIKE THAT YOU
MAY HAVE TO PAY A LITTLE BIT
MORE.

THERE ARE SORT OF ONE TIME
PAYMENT.

YOU PAY FOR AN APP AND YOU NERVE
HAVE TO PAY AGAIN AND THERE ARE
SUBSCRIPTION APPS.

THERE ARE ONE THAT FEEL THEY
PROVIDE SUCH A SERVICE AND
PEOPLE PAY FOR THESE THINGS BUT
ON A MONTHLY BASIS YOU PAY SOME
MONEY FOR THAT KIND OF STUFF.
AND THE ONES THAT DEFINITELY
SEEM TO ENGAGE IN A WHOLE LOT OF
SHARING TEND TO BE THE AD
SUPPORTED MODEL ONES WHERE YOU
HAVE SOMEWHERE LIKE AN AVERAGE
OF 15 DIFFERENT SERVICES
RECEIVING VARIOUS KINDS OF
DETAILS ABOUT THE USER.

>> THANK YOU.

>> SURE.

SO WITH REGARD TO THE BUTTON
APP, WE HAVE A PREMIUM MODEL.

SO FOR THE CONSUMER, THE
CONSUMER ANY ONE OF YOU CAN GO
ON iTUNES TO GOOGLE PLAY STORE
AND DOWNLOAD THE BUTTON APP AND
IT'S A FREE DOWNLOAD.

CURRENTLY, SINCE THAT VERSION OF
THE APP THAT I JUST SHOWED ALL
OF YOU IS BRAND NEW, WE JUST
RELEASED IT AT THIS YEAR'S HIMS
CONFERENCE.

IT'S ON SPECIAL IT'S ABSOLUTELY
FREE NOW.

BUT COMING SOON WE WILL HAVE THE
EQUIVALENT OF A SUBSCRIPTION
MODEL.

AGAIN, WE BELIEVE THAT THE
CLIENT WHO PAYS FOR THE APP IS
IN FACT THE CLIMATE.

IF YOU'RE NOT PAYING FOR
SOMETHING, YOU KNOW, YOU'RE
PROBABLY NOT THE CLIENT.

SO WE BELIEVE THERE'S REAL VALUE
IN LETTING PEOPLE HAVE ACCESS TO
THIS KIND OF TOOL WHERE THERE'S
ABSOLUTELY NO DATA SHARING
OUTSIDE OF THE CONFINES OF YOUR
DEVICE.

AND SO THAT'S HOW WE MARKET THIS
DIRECTLY TO CONSUMERS.

>> CORA, I WOULD LIKE TO JUMP IN
AND SAY ONE OF THE AREAS THAT'S
KIND OF INTERESTING IS THAT
PEOPLE MIGHT SAY I'M WILLING TO
GIVE YOU MY INFORMATION TO GET
THIS PRODUCT FOR FREE.

AND THEY MIGHT NOT REALIZE WHAT
SOME PEOPLE OR SOME
ORGANIZATIONS DO WITH THE
INFORMATION AFTER THEY RECEIVE
IT.

SO THERE'S A CERTAIN AMOUNT OF
LACK OF TRANSPARENCY IN GOING
BACK TO THE DATA MAPPING OF WHAT
HAPPENS WITH THE INFORMATION
AFTER IT IS COLLECTED BY THE
FIRST THIRD PARTY.

BECAUSE MANY OF THOSE FIRST,
THOSE THIRD PARTIES ACTUALLY GO
AHEAD AND THEY RESELL THE DATA
TO OTHER ENTITIES.

AND SOMETIMES THAT INFORMATION
IS ANNA MUSTIZED SO THE
INFORMATION IS NOT BEING TO
ACTUALLY ASSOCIATE THAT
INFORMATION FROM THAT DEVICE
WITH INFORMATION THAT'S
COLLECTED FROM OTHER SERVICES.
SUCH AS YOUR CVS CARD, YOUR
FREQUENT FLIER CARD FROM GIANT
OR SAFEWAY OR CVS OR EVEN YOUR
FREQUENT FLIER MILES.

THERE ARE DATA AGGREGATORS THAT
ARE IN THE BUSINESS OF
COLLECTING THIS INFORMATION NOT
FROM WHAT WEHEALTH YOUR CORE HEALTH PEOPLE
WHO ARE ORGANIZATIONS THAT ARE
COVERED BY HIPAA BUT BY THESE
OTHER KIND OVER 'J' OUTSIDE MARKET
RIGHT NOW WHERE PEOPLE DON'T
HAVE A GOOD IDEA WHAT'S
HAPPENING WITH THEIR
INFORMATION.

>> SO IDENTIFICATION IS
DEFINITELY AN EXPLANATION AND WE
WILL BE CIRCLING BACK TO IT A
LITTLE BIT LATER TODAY.

BUT I HAD ANOTHER QUESTION I
SORT OF WANTED TO FOLLOW UP HERE
WITH AND THAT'S TO ANY OF YOU
HERE TODAY, ARE YOU AWARE OF
SELF REGULATORY EFFORTS LIMITING
THE USE OF HEALTH DATA FOR
MARKETING PURPOSES.
WHAT SORTS OF THINGS HAVE YOU
BEEN SEEING?

>> THERE ARE A SMATTERING OF
SELF REGULATORY GUIDELINES AND
CODES AND PRINCIPLES.
THE AMA, AMERICAN MEDICAL
ASSOCIATION AND AMERICAN MEDICAL
INFOMATICS ASSOCIATION HAVE
ELECTRONIC COMMUNICATION WITH

PATIENTS.

THAT'S VERY DIFFERENT THAN
CONSUMER, VERY NARROW COMPARED
TO CONSUMER-GENERATED DATA.
THE DEPARTMENT OF COMMERCE HAS
SOMETHING THAT TOUCHES ON THIS
WHICH IS THE NTAA MOBILE APP
TRANSPARENCY CODE OF CONDUCT AND
I KNOW PEOPLE IN THE ROOM HAVE
BEEN THERE WITH ME HAMMERING
THAT OUT AND IT ACTUALLY
REQUIRES VERY CLEAR SHORT FORM
DISCLOSURE TRYING TO GET AT THE
TRANSPARENCY ISSUES FOR
COLLECTIONS OF BIO METRICS
HEALTH MEDICAL AND/OR THERAPY
INFORMATION.

AND FINALLY THE DIGITAL
ADVERTISING ALLIANCE AND THE
NETWORK ADVERTISING INITIATIVE
THAT THE TWO MAIN ADVERTISING
GUIDELINE BODIES I GUESS IS THE
WAY TO SAY IT HAVE MOBILE
BEHAVIORAL ADVERTISING
GUIDELINES THAT APPLY TO
SENSITIVE HEALTH INFORMATION
REQUIRES EXPLICIT CONSENT
BEFORE SOME KINDS OF USES LIKE
BEHAVIORAL REQUIRES THE USER TO
GIVE EXPLICIT CONSENT BEFORE
THEY CAN DO THINGS LIKE
BEHAVIORAL ADVERTISING.
BUT THERE'S NOTHING THAT SORT OF
THAT I KNOW OF AND I WOULD LOVE
TO BE PROVEN WRONG AND MORE J
THAT IS -- GENERIC THAT IS FOR
GUIDELINES USING MORE SENSITIVE
DATA AND I WOULD LOVE TO BE
CORRECTED BUT IT'S THE KIND OF
THING THAT I THINK THE TIME HAS
COME.

>> THANKS.

ANYONE ELSE HAVE ANYTHING TO
ADD.

>> I WOULD JUST ADD THAT
CONSUMERS THEMSELVES WHEN

THEY'RE STARTING TO USE SOME OF THE FEATURES AVAILABLE TO THEM I THINK LATANYA MENTIONED TRANSPARENCY ESTABLISHES TRUST. ONE OF THE THINGS WE RECOGNIZED EARLY IN CREATING PATIENTS LIKE ME IS WE NEEDED TO ESTABLISH THE TRUST OF THE PATIENTS WHO ARE GOING TO BE USING THE SITE IN SEARCH WAY THAT WE HELD THAT AS ONE OF OUR VERY CORE HIGHEST CORE VALUES.

WITHOUT IT WE WON'T HAVE A SITE. WE PAID A LOT OF ATTENTION TO OUR USER AGREEMENT TROONS PARENCEY AND OPENNESS POLICY THAT ARE VERY PROMINENTLY DISPLAYED TO LET PEOPLE KNOW FIRST OF ALL THAT THEIR DATA WILL BE USED. WE ACTIVATE, DEIDENTIFIED AND MAKE THAT DATA AVAILABLE TO INTOOD>!\\$9 PARTIES THAT ARE PHARMACEUTICAL COMPANIES, COMPANIES OR CLINICAL RESEARCHERS WHO WANT TO LIVE WITH PEOPLE WITH CHRONIC ILLNESSES OVER TIME. THAT'S SOMETHING THAT'S CRITICALLY IMPORTANT.

WE ALSO ENCOURAGE PEOPLE IN TERMS OF OUR OWN GUIDELINES NOT TO USE THEIR REAL NAME AND BE CAREFUL WHAT THEY'RE SHARING AND TO RECOGNIZE IT'S THEIR CHOICE. WITH A WILL OFTEN TIMES SEE PEOPLE WITH REAL PICTURES ON THE SITE AND IT'S NOT NECESSARILY SOMETHING WE PROMOTE BUT WE RECOGNIZE THAT'S A CHOICE THE CONSUMER HAS MADE.

BUT I THINK THE OTHER PIECES IN TERMS OF OUR SITE AGAIN, I JUST WANT TO BRING THAT BACK. ONE OF THE THING WE'VE LEARNED IS IN TERMS OF DATA SHARING RESEARCH THAT WE'VE DONE IS THAT

FOR THE MOST PART PEOPLE ARE REALLY WILLING AND INTERESTED IN SHARING THERE DATA FOR A COUPLE OF REALLY IMPORTANT REASONS. ONE IS THEY WANT TO KNOW IN OUR EXPERIENCE ANYWAY IS MY EXPERIENCE NORMAL. THEY'D LIKE TO BE ABLE TO SHARE WITH OTHER PEOPLE LIKE THEMSELVES TO BETTER UNDERSTAND WHETHER OR NOT WHAT THEIR EXPERIENCE SEEMS TO BE WHAT OTHER PEOPLE LIKE THEM MIGHT BE EXPERIENCING. ONE EXAMPLE IS AN EPILEPSY. WE LEARNED EARLY ON ABOUT ONE THIRD OF THE PEOPLE WITH EPILEPSY ON OUR SITE HAS NEVER TALKED TO OR MET ANOTHER PERSON WITH EPILEPSY BEFORE AND IT'S A VERY STIGMATIZING CONDITION. THE OTHER THING THEY GIVE IS ALTRUISM I WANT MY EXPERIENCE TO BENEFIT OTHER PEOPLE. I THINK WE NEED TO FIND A WAY OF UNPACKING SOME OF THE WAYS WE CAN MAKE IT EASIER FOR PATIENTS TO SHARE THIS KIND OF INFORMATION WITHOUT NECESSARILY COMPROMISING THEIR PRIVACY TO THE DEGREE POSSIBLE. RECOGNIZING THAT WHEN YOU'RE ON THE INTERNET YOUR PRIVACY IS SUBJECT TO BEING REVEALED AND THAT'S NOT SOMETHING ANY OF US CAN FULLY PROTECT. BUT WHEN CONSUMERS ARE AWARE OF THAT IN THE MOST EXPLICIT AND TRANSPARENT WAY, I THINK WE ACTUALLY ELEVATE THEIR WILLINGNESS AND THEIR APPRECIATION OF WHY SHARING HEALTH DATA CAN BE ACTUALLY QUITE BENEFICIAL. NOT ONLY FOR THEM BUT FOR OTHERS LIKE THEM.

>> I FORGOT TO MENTION ONE THING THAT MY EMPLOYERS WOULD BE MAD ABOUT.

SO AT CDT WE'RE ALSO WORKING ON BIG DATA IN HEALTH AND EXPLICITLY LOOKING AT THE FAIR INFORMATION PRACTICES AND TO WHAT EXTENT THEY NEED TO BE TWEAKED BECAUSE WE DON'T BELIEVE THAT THEY ARE RELEVANT ANYMORE. THAT'S AN ONGOING PROJECT THAT'S GOING TO TAKE A GOOD CHUNK OF THE REST OF THIS YEAR BUT MYSELF AND JUSTIN BROOKMAN THE DIRECTOR OF PRODUCTS ARE WORKING ON THIS AND IF YOU'RE INTERESTED LET US KNOW.

>> JOY THERE WAS AN ASPECT OF DATA THAT WE WANTED TO ASK YOU ABOUT AND THAT WAS IN THE CONTEXT OF ELECTRONIC HEALTH RECORDS.

AND THE DATA THAT CAN FLOW FROM THEM.

>> WELL, EVERYBODY RECEIVES A HIPAA PRIVACY NOTICE. HOW MANY OF YOU HAVE EVER READ THEM?

SO PEOPLE HERE VFER.

I WILL TELL YOU MOST OF THE TIME WHEN YOU ASK THIS.

I WILL ALSO TELL YOU WE'VE DONE, WE HAVE IN THE COURSE OF WORK WHERE WE'VE BEEN NOT AT OMC BUT IN MY PAST WHERE WE DID FOCUS GROUPS, THERE IS INFORMATION IN THOSE NOTICES THAT PEOPLE JUST DON'T READ.

THERE'S BEEN A REVISED VERSION THAT PUTS PATIENTS RIGHTS OUT FIRST INSTEAD OF THE USES AND DISCLOSURES TO TRY TO HIGHLIGHT SO OF THOSE USES.

BUT ONE OF THE USES OF INFORMATION THAT MANY PEOPLE ARE SURPRISED ABOUT IS THEIR USE OF

HEALTH INFORMATION FOR RESEARCH.
AND THERE ARE WAYS ABOUT HEALTH
INFORMATION CAN FLOW FOR
RESEARCH PURPOSES THAT HAPPEN
WITHOUT THE INDIVIDUAL'S
EXPRESSED PERMISSION.
THAT SURPRISES A LOT OF PEOPLE.
IT'S TOTALLY LEGAL BUT IT'S
SURPRISING.

ONE OF THE WAYS THE RESEARCH
COMMUNITY IS HEADED IS VERY
IMPORTANT FOR US AS WE MOVE
FORWARD IS PATIENT OUTCOMES
RESEARCH AND THAT'S LOOKING TO
NOT ONLY CLINICAL TRIALS BUT
LOOKING AT A PERSON
LONGITUDINALLY TO SEE NOT ONLY
HOW THEY ARE TREATED BUT HOW
THEY'RE LIVING AND WHAT
ACTIVITIES THEY ARE UNDER DOING,
UNDERTAKING.

AND AFTER THEY'VE BEEN CARED,
HOW DID THAT CARE WORK AND HOW
WERE THOSE HEALTH INCOME, HEALTH
OUTCOMES AFFECTED.

THERE ARE SOME ORGANIZATIONS
THAT ARE DOING, THAT HAVE FORMED
THEIR INDEPENDENT THIRD PARTY
ORGANIZATIONS TO REALLY
UNDERTAKE THIS RESEARCH.
AND THEY HAVE FOUND THAT IT'S
REALLY VALUABLE FOR THEM TO
COLLECT THE INFORMATION NOT ONLY
FROM THE HEALTHCARE ENTITIES BUT
ALSO FROM THINGS LIKE WE
MENTIONED A LITTLE BIT EARLIER,
YOUR SAFEWAY CARD.

YOUR FREQUENT FLIER CARD, YOUR
PURCHASE DATA, YOUR FINANCIAL
DATA.

BECAUSE THERE ARE OFTEN
CORRELATIONS IN OTHER TYPES OF
DATA THAT WHEN MATCHED WITH
THEIR HEALTH DATA THEY BELIEVE
ME PROVE VERY INFORMATIVE ABOUT
PREDICTING WHAT WILL WORK AND

WHAT WILL NOT WORK WITH PEOPLE
IN TERMS OF TREATMENT.
SO IT'S SOMETHING THAT'S I THINK
A LOT OF PEOPLE FIND A LITTLE
BIT SURPRISING HOW ALL OF THESE,
ALL OF THOSE LITTLE, EXCUSE ME,
ALL OF THOSE LITTLE NODES ON
LATANYA'S MAP CAN ACTUALLY ALSO
BE BROUGHT TOGETHER.

>> THANKS.

SO BUILDING UPON SOMETHING YOU
TOUCHED ABOUT, LET'S PIVOT A
LITTLE BIT AND THINK ABOUT
CONSUMER PERCEPTIONS OF THESE
DATA FLOWS.

AND PERHAPS SALLYING I'LL
ADDRESS THIS NEXT QUESTION TO
YOU BUT YOU WERE RECENTLY
INVOLVED IN AN INSTITUTE OF
MEDICINE STUDY REGARDING SOCIAL
NETWORKING SITES AND CONTINUING
LEARNINGS HEALTH SYSTEMS AND
REACHED SOME INTERESTING
CONCLUSIONS ABOUT SOCIAL MEDIA
USERS AND THE SHARING OF THEIR
HEALTH INFORMATION AND WHAT TYPE
OF SHARING THEY'RE COMFORTABLE
WITH AND THE TYPE OF SHARING
THEY MAY BE LESS COMFORTABLE
WITH.

COULD YOU COMMENT A LITTLE BIT
ABOUT THAT.

>> SURE.

THE STUDY WAS ACTUALLY DONE AS A
FOLLOW UP STUDY TO ONE THAT WAS
DONE BY CONSUMER'S REPORTS THAT
ACTUALLY HAVE JUST A COUPLE
QUESTIONS IN IT THAT RELATED TO
HEALTH DATA SHARING THAT PEAKED
OUR INTEREST OF PATIENTS LIKE
ME.

AND THEY HAD TO DO, THE QUESTION
HAD TO DO WITH WOULD YOU BE
WILLING TO SHARE YOUR HEALTH
DATA IF IT WERE TO IMPROVE YOUR
CARE OR THE CARE OF OTHER PEOPLE

LIKE YOU.

AND NEARLY 90% OF NATIONALLY REPRESENTED SAMPLE WITHIN THE COUNTRY AGREE THAT THEY WOULD BE WILLING TO DO THAT.

NOW WHEN ASKED WHETHER OR NOT THEY THOUGHT IT WAS HAPPENING MOST PEOPLE EITHER DIDN'T KNOW OR SAID NO.

SO THERE'S SORT OF A SENSE THAT I WOULD BE WILLING TO DO THIS BUT I'M NOT SURE IF IT'S BEING DONE AND IF IT IS BEING DONE THEN I NEED TO KNOW MORE ABOUT HOW THAT WORKS AND I THINK THAT'S JOY.

WE ACTUALLY LEARNED QUITE A BIT. WHAT WE DECIDED TO DO WAS TAKE THAT QUESTION AND EXPAND UPON IT WITH OUR POPULATION OF CHRONICALLY ILL PEOPLE.

WE WERE ABLE TO TEASE OUT A LITTLE BIT.

WE KNOW PATIENTS LIKE ME ARE ALREADY SHARING THEIR DATA ST. WASN'T SURPRISING TO LEARN THAT 98% OF THEM WERE WILLING TO SHARE THEIR DATA IF IT WAS GOING TO BENEFIT THEMSELVES OR SOMEONE ELSE.

WHAT WE WANTED TO FIND OUT ALSO IS WHO WERE THEY WILLING TO SHARE THEIR INFORMATION WITH BESIDES SOMEONE LIKE ME AND WHAT WERE THEIR CONCERNS.

WE LEARNED A LITTLE BIT MORE OF WHAT MAKES SOMEONE HESITANT TO SHARE DATA OUTSIDE OF THE WALLED ENVIRONMENT OF PATIENTS LIKE ME. CERTAINLY WE'VE HEARD SOME ALREADY.

76% OF THE PATIENTS INTERVIEWED THOUGHT THAT THEIR DATA COULD BE USED WITHOUT THEIR KNOWLEDGE.

SO WE ALREADY KNOW THAT IT IS BEING USED WITHOUT THEIR

KNOWLEDGE.

IT'S MOVING ON TO DIFFERENT PLACES SO THAT ACTUALLY, THAT VALIDATES THAT CONCERN.

72% WERE CONCERNED ABOUT THEIR WITHIN FITS AND BEING DENIED BENEFITS.

NOW WHETHER WE REASK THAT QUESTION TODAY IN THE LIGHT OF MORE HEALTH COVERAGE THAT MIGHT BE AN INTERESTING FINDING.

THIS WAS ABOUT TWO YEARS AGO THAT WE DID THE SURVEY.

AND THEN 66% REALLY WERE WORRIED ABOUT LIMITING JOB OPPORTUNITIES.

SO THERE'S REAL CLEAR REASONS WHY PEOPLE WOULD BE RETICENT TO CONSIDER HAVING THEIR PAYER LEARN MORE ABOUT THEIR HEALTH DATA, WHETHER OR NOT THEIR EMPLOYER AGAIN TIED OFTEN TIMES TO PAYER MIGHT BE LEARNING ABOUT THIS INFORMATION.

THOSE ARE THINGS I THINK WE NEED TO BE SENSITIVE TO.

BUT WHEN WE STARTED ASKING OUTSIDE OF PATIENTS LIKE ME, WHO ARE YOU ALREADY SHARING SOME OF THIS INFORMATION WITH, WE WERE ACTUALLY SURPRISED HOW LITTLE PEOPLE WERE SHARING.

SO GIVEN AN ENVIRONMENT WHERE THEY FELT SAFE TO DO THIS, THEY WERE UBIQUITOUSLY SHARING.

WHEN WE ASKED HOW MANY WERE SHARING WITH THEIR SPOUSE OR SIGNIFICANT OTHER ONLY 30% SAID THEY SHARE THE INFORMATION ON THEIR PROFILE WITH THEM.

AND IT WENT DOWN ARE FROM THERE. THEIR HEALTHCARE PROVIDER 19% SAID THEY WERE SHARING IT WITH THEM.

WE FOUND THAT INTERESTING AND WE HAVEN'T TEASED IT OUT.

CHRIS AND I WERE TALKING ABOUT THIS BEFORE.

WE KNOW SOME OF OUR PATIENTS ARE BRINGING THEIR DATA TO THEIR CLINICIANS ONLY TO BE REJECTED. TO SAY I DON'T KNOW WHAT TO DO WITH THIS INFORMATION SO I'M NOT SO SURE LET'S NOT EVEN GO THERE. SOME OF THE CONDITIONS WHEN WE LOOKED AT MORE SPECIFICALLY WHERE THAT KIND OF INFORMATION IS BEING USED AT THE POINT OF CARE IS IN THE MOOD CONDITIONS AND PSYCHIATRIC CONDITIONS WHERE THERAPISTS AND PATIENTS ARE USING THIS DATA QUITE EFFECTIVELY TO MONITOR MOODS AND THINGS LIKE THAT.

ANOTHER PATIENT OUTSIDE OF PATIENTS LIKE ME, THEY WERE ABOUT 16% WERE WILLING TO SHARE WITH OTHER PATIENTS.

SO AGAIN WHEN YOU START TO GET OUT OF THIS ENVIRONMENT WHERE THEY FELT A SENSE OF TRUST, THEY WERE A LITTLE BIT LESS SURE THAT THEY WANT TO.

AND THEIR CHILDREN, ONLY 9% FELT THAT THEY WANTED TO SHARE THIS INFORMATION WITH THEIR CHILDREN. NOW NOT OUT OF THIS STUDY BUT ANOTHER SURVEY WE HAD DONE A COUPLE YEARS AGO WE ALSO ASKED WHAT KIND OF INFORMATION ARE YOU NOT SHARING WITH YOUR HEALTHCARE PROVIDER.

AND IT WAS QUITE NOT SURPRISING THAT THEY ARE THEY WEREN'T SHARING THINGS ABOUT THEIR SEXUAL DYSFUNCTION OR SEXUAL HEALTH OR BEHAVIORAL THING LIKE DRINKING AND THAT SORT OF THING. AND NOT BEING QUITE AS HONEST ABOUT THEIR DIET.

OFFICER WHEN ASKED ARE YOU SHARING THE SAME INFORMATION

WITH YOUR PEERS ON PATIENTS LIKE ME, ALMOST 100% WILL SAY I'M MORE COMFORTABLE SHARING IT WHO ARE.

IT'S ANONYMOUSING, I FEEL I CAN SHARE THAT AND BE HONEST ABOUT IT AND PEOPLE CAN RESPOND TO ME IN A WAY I CAN APPRECIATE AND RESPOND MYSELF BEHAVIORALLY. IT'S INTERESTING TO SEE HOW WE SHARE SOME THINGS WITH SOME PEOPLE BECAUSE WE'LL GET SOME SORT OF REACTION POSSIBLY OR NOT AND THEN WITH OTHERS BECAUSE WE MIGHT GET SOME BENEFIT FACT BY SHARING THAT THAT MIGHT ACTUALLY HELP US BEING ABLE TO DEAL WITH WHATEVER IT WAS WE WERE SHARING THAT WITH.

>> CHRIS.

>> YES.

I JUST MAKE AN EXTRA COMMENT. SO, ONE THING THAT WE'RE FINDING IS, AND THIS IS BECAUSE SOME OF OUR USERS CALL US UP.

WE HAVE ACTUALLY NO WAY OF KNOWING ANYTHING ABOUT OUR USERS.

I DON'T KNOW ANY OF THEIR NAMES, I DON'T KNOW ANYTHING ABOUT THEM.

THEY HAVE ALL THEIR OWN DATA. BUT PEOPLE DO CALL US UP.

AND ONE THING WE'RE BEING TOLD IS THAT WITH REGARD TO PHYSICIANS, WE'RE NOW PUTTING IN THE HANDS OF PATIENTS FULL MEDICAL DATA SET.

SO LET'S SAY DRUGS, BRANDS NAME, DOSAGE TYPE, DOSAGE FORM, NDC CODE, EVERY DATE IT WAS EVER FILLED YOU HAVE IT ON YOUR APP. YOU CAN SHARE THAT WITH YOUR PHYSICIAN.

THIS IS HARD DATA.

AND ANECDOTALLY, I'VE HAD

PATIENTS SHE THIS TO ME.
THE DOCTOR LOOKS AT HIS COMPUTER
SCREEN AND THEY ARE LOOK AT ME,
TYPES AND EVERYTHING.
SUDDENLY I HAVE SOMETHING ON MY
SCREEN AND HE'LL HAVE TO TURN
AROUND.
IT'S LIKE LOOK AT MY SCREEN
BECAUSE NOW SUDDENLY WE'RE AT
THE DAWN OF THIS NEW AGE AND
THAT'S WHAT WE'RE PASSIONATE
ABOUT OF GIVING CONSUMERS THE
ACTUAL WHEREWITHAL
TECHNOLOGICALLY TO HAVE A
COMPLETE OR AS COMPLETE A DATA
SET AS POSSIBLE TODAY.
SO THAT'S SUDDENLY PUTTING
CONSUMERS IN A MUCH MORE
POWERFUL POSITION TO HELP THEIR
PHYSICIAN TAKE BETTER CARE OF
THEM.
SO THIS IS THE START OF
SOMETHING NEW AND VERY VERY
IMPORTANT.
TECHNOLOGY, VERY SOPHISTICATED
IN THE HANDS OF PATIENTS THAT
THEY CAN USE TO BE HELPING WITH
THE HEALTHCARE SYSTEM INSTEAD OF
JUST BEING PASSIVE RECIPIENTS.
>> LET ME FOLLOW UP ON ONE
TOPIC.
ONE OF THE THING THAT PATIENT
CENTER OUTCOME RESEARCHES IS
DOING IS SORT OF SUGGESTING WE
ACTUALLY START MAKING GOOD USE
OF ROUTINELY COLLECTED DATA AT
THE POINT OF CARE.
SO WE'RE NOT NECESSARILY DOING
THAT WELL IN TERMS OF QUALITY
IMPROVEMENT AND CONTINUOUS
LEARNING.
SO THIS IS SOMETHING THAT AS
CONSUMERS WE CAN BE TEACHING
PEOPLE THAT IT'S REALLY
IMPORTANT FOR YOU TO UNDERSTAND
AS WE COLLECT ROUTINE DATA AT

THE POINT OF CARE, WE'RE GOING TO START TRYING MAKE USE OF THAT SO WE CAN START TO UNDERSTANDING THINGS ABOUT COMPARATIVE EFFECTIVENESS PERSPECTIVE AND THAT SORT OF THING.

WHAT WE ALSO NOW NEED TO START DOING IS HAVING POLICY CLINICIANS CATCH UP WITH CONSUMER-GENERATED DATA SAYING THIS IS VALUE AT THE POINT OF CARE.

IT HAS A UNIQUE PERSPECTIVE WE PREVIOUSLY HAVE NOT COLLECTED AND WE HAVE TO FIND WAYS OF BEING ABLE TO EXPECT THAT THAT DATA WILL BE RESPECTED AND HONORED AT THE POINT OF CARE.

WHILE AT THE SAME TIME NOT OVERLOADING CLINICIANS SO THAT IT DOESN'T FIT INTO THEIR WORK FLOW.

SO WE AS APP DEVELOPERS OR WEBSITE OWNERS AND PEOPLE WHO ARE WORKING FROM THIS PERSPECTIVE HAVE TO UNDERSTAND THAT THE CLINICIANS NEED TO RECEIVE THIS DATA AND INFORM US SO THEY CAN MAKE USE OF IT AND NOT FEEL THEY'RE OVERWHELMED BY IT SO WE HAVE A BALANCING GOING ON THERE.

THANK YOU.

>> THANKS.

JOE.

>> I'M GOING TO PUT MY HEATHER PATTERSON.

PART OF WHAT THEY ARE TRYING TO FIGURE OUT IS WHAT TO FIT BIT USERS FIGURE OUT WHAT FIT BIT IS DOING, WHAT IS THE FUTURE OF FIT BIT'S MODEL.

I'M SORRY I TALK SO MUCH ABOUT THE BRAND BUT THE STUDY IS ABOUT A SPECIFIC USER COMMUNITY PAND A SIGNIFICANT BRAND.

WHAT KIND OF MANAGEMENT DATA PRACTICES DO PEOPLE EMPLOY TO MANAGE THAT KIND OF UNCERTAINTY. THE ONE THIN THAT IS INTERESTING IS PEOPLE HAVE NO CLUE HOW FIT BIT IS A BUSINESS.

IS IT SELLING DEVICE OR DOING OTHER THINGS WITH DATA THEY JUST DON'T KNOW.

AND TO MANAGE THAT UNCERTAINTY, THEY EMPLOY A WHOLE BUNCH OF REALLY INTERESTING TACTICS.

FOR EXAMPLE PEOPLE DON'T SIGN UP WITHOUT USING THEIR REAL NAME BECAUSE IT'S HARD FOR PEOPLE TO, IT'S A SOCIAL CHALLENGE I RUN OR I WALK FARTHER THAN YOU KIND OF THING.

SO THERE'S AN IMPORTANT ROLE HAVING YOUR REAL NAME INVOLVED WITH THAT.

BUT PEOPLE WILL ONLY SHARE WITH FOLKS THAT THEY'VE MET IN REAL LIFE OFTEN OR THEY'LL ONLY SHARE WITH PEOPLE THAT NEVER MET BECAUSE THEY DON'T WANT ANYONE KNOWING ABOUT THEIR, DAILY HABITS.

SO THERE'S THIS SORT OF REALLY INTERESTING SOCIAL DIVIDE WITH HOW PEOPLE ARE USING THESE KINDS OF TOOLS.

AND THE FASCINATING THING IS THAT PEOPLE ARE THINKING A LOT ABOUT HOW FIT BIT SPECIFICALLY BUSINESS MODEL MIGHT CHANGE SO THEY DON'T KNOW WHAT MAY HAPPEN IN THE FUTURE.

IN SOME CASES, YOU SEE WORRIES ABOUT THINGS LIKE YOU KNOW WHO HAS ACCESS TO THE DATA, WHO HAS POTENTIALLY HAS ACCESS TO THE DATA, DOES THE GOVERNMENT HAVE ACCESS TO THIS DATA.

UNDER WHAT CIRCUMSTANCES, IF THERE'S A FIST FIGHT IN A BAR,

CAN THE ACCELERATOR BE ON FIT
BIT TO IMPROVE THINGS ABOUT
WHATEVER.

THERE'S A WHOLE BUNCH OF
INTERESTING SOCIAL MANAGEMENT
PRACTICES THAT ARE SORT OF
APPEARING IN AND EVOLVING WITH
THE USING MORE WELLNESS DEVICES
AND I THINK WE'LL SEE THAT TOO
WITH HEALTH AND WITH SPECIFIC
MEDICAL INTERACTIONS.

>> THANKS.

>> SO ONE OF THE OTHER
SIGNIFICANT PRIVACY ISSUES WE'VE
HEARD A LOT ABOUT IS
TRANSPARENCY SPECIFICALLY VIA
NOTICE AND CHOICE.

WHAT ARE SOME OF THE CHALLENGES
PROVIDING EFFECTIVE NOTICE AND
WHAT ARE SOME OF THE WAYS OF
MEETING THOSE CHALLENGES.

WE HEAR A LOT ABOUT INFORMATION
RESULTING FROM POORLY CRAFTED OR
VERY LONG PRIVACY POLICIES.

WOULD YOU LIKE TO TAKE THAT.

>> SURE.

SO, IT'S OFTEN SAID THAT NOTICE
AND CHOICES, NOTICE AND CONSENT
IS DEAD.

WE DON'T BELIEVE THAT AND WHAT
PEOPLE TEND TO SAY WHEN THEY SAY
THOSE THINGS ARE NO ONE READS
PRIVACY POLICIES AND THAT'S SO
TRUE EXCEPT FOR A FEW OF US WHO
FOR SOME REASON GET A KICK OUT
OF IT, RIGHT.

I GUESS THERE ARE PEOPLE PART OF
OUR JOB WE HAVE TO READ THESE
THINGS.

BUT AT THE SAME TIME, IF YOU'RE
EXPECTING PEOPLE TO READ 30
PAGES OF LEGALESE AND UNDERSTAND
IT YOU'RE GOING TO HAVE A BAD
TIME ACTUALLY COMMUNICATING WITH
PEOPLE ABOUT WHAT YOU'RE DOING.
THAT'S WHY THERE'S A BUNCH OF

OTHER EFFORTS.

SO FOR EXAMPLE, THERE ARE SOME PLATFORMS LIKE APPLE'S IOS PLATFORM USES JUST IN TIME NOTIFICATION SO THIS APP IS TRYING TO ACCESS LOCATION DATA AYE OR NAY.

IF YOU SAY NAY IT'S NOT GOING TO GET THAT.

IF IT'S AN APPING APP WHERE YOU DENY IT AND MAY NOT BE ABLE TO DO THINGS LIKE DIRECTIONS AND STUFF LIKE THAT.

THERE'S ALSO I MENTIONED AN EFFORT THAT MOBILE APP TRANSPARENCY CODE OF CONDUCT THAT FOCUSES ON SHORT NOTICE AND THERE'S A WHOLE OF ACADEMIC RESEARCH THAT IS EVOLVING AND TENDS TO BE SORT OF ON THE SHORT NOTICE, EVEN SHORT NOTICE IS VERY HARD TO COMMUNICATE EFFECTIVELY WITH PEOPLE.

I LIKE TO THINK THAT THE NTAA PROCESS WHICH SHOWS HERE'S THE DATA THAT'S COLLECTED ABOUT YOU USING THIS APP.

HERE ARE THE ENTITIES WITH WHICH THE APP SHARES THIS DATA ON ONE SCREEN OR A COUPLE SCREENS OF EASY POPPING ACTIVITY.

I WAS HOPING THAT WOULD EVOLVE AND PEOPLE TEND TO RECOGNIZE SORT OF LIKE A NUTRITION LABEL. IT'S SOMETHING WHERE YOU KNOW WHERE IT IS UNLESS IT'S TOO SMALL TO HAVE A NUTRITION LABEL ON IT.

YOU CAN FIND IT AND KNOW HOW TO INTERACT WITH THOSE KINDS OF THINGS.

IN THE LONGER TERM I DO THINK IT WOULD BE NEAT TO HAVE JUST IN TIME NOTIFICATION FOR STORING AND ACCESS HEALTH DATA.

IF WE COULD GET MOBILE PLATFORMS

TO ACTUALLY CARVE OUT A LITTLE
CHUNK OF ITS OPERATING SYSTEM TO
STORE THINGS LIKE A CCD, A
COMMON CARE I FORGET WHAT THE
ACRONYM STANDS FOR, A SUMMARY OF
YOUR CLINICAL INTERACTION.
AND THEN IT COULD SAY THIS APP
IS TRYING TO ACCESS YOUR MEDICAL
RECORD OR TRYING TO STORE
SOMETHING IMPORTANT TO YOU, THAT
COULD BE A REALLY NEAT THING AND
COULD ALLOW PEOPLE TO HAVE SOME
OF THE THINGS THAT HUMETRIX AND
BLUE BUTTON DO IN THIS VERY
CONTROLLED SORT OF ENVIRONMENT
BUT MAKE THAT AVAILABLE ON A
MORE PLATFORM AND MORE GENERIC
WAY.

>> WE STARTED THAT WHERE YOU
CONTROL YOUR OWN DATA.
WE ALSO BUILT IN PRIVACY
WARNINGS.

FOR EXAMPLE, EVEN THOUGH THE
DATA TRANSFER TO THE PROVIDER'S
iPAD IS COMPLETELY SECURE USING
A ONE TIME CRYPT GRAPHIC KIWI
STILL PUT UP A LITTLE WARNING
SAYING WE'RE ABOUT TO SEND YOUR
HEALTH DATA TO THIS PERSON WITH
AN iPAD.

BE SURE IT'S THE RIGHT
PHYSICIANS AND YOU BOTH
AUTHENTICATE EACH OTHER AND LOOK
AT EACH OTHER.

WE THINK THAT'S GREAT.

WITH REGARD TO THE ONC'S MODEL
PRIVACY NOTICE, WE THINK THAT'S
A STEP IN THE RIGHT DIRECTION.
IT'S WHAT JOE REFERRED TO AS THE
SOUP CAN LABEL IDEA.

I'M NOT SURE THAT PEOPLE REALLY
READ SOUP CAN THAT MUCH JOE.

>> I'M HYPERTENSIVE.

>> THAT'S A GREAT IDEA.

AND SO THERE ARE NOS AND YES,
SIR THAT ARE PRETTY CLEAR.

I THINK THERE NEEDS TO BE THOSE KINDS OF SIMPLE NOTICES TO MAKE IT CLEAR.

I MIGHT WANT TO SET YOU UP AGAIN TO COME BACK TO DEIDENTIFICATION BECAUSE I ALSO READ PRIVACY POLICIES.

OURS IS SIMPLE, IT'S ONE PAGE. BUT I'VE READ OTHER PRIVACY POLICIES THAT SAY WE'LL SHARE DATA BUT IT WILL BE DEIDENTIFIED BUT THEY DON'T SPECIFY WHAT THAT TERM MEANS.

I'M ALSO A SIGN TILS AND SO GEE I WONDER WHAT THAT MAINS.

I THINK THERE'S A PROBLEM WITH TRANSPARENCY THERE.

>> WE WILL DEFINITELY GET MORE DETAILS IN DEIDENTIFICATIONJUST A BIT.

THERE'S A SECOND COMPONENT TO THE TRANSPARENCY AND NOTICE AND CHOICE THING AND THAT IS ABOUT CONTEXTUAL USE OF INFORMATION. YOU MIGHT HAVE A SOUP LABEL TYPE NOTICE UP FRONT BUT BACK END USE.

YOU HEARD A LITTLE BIT ABOUT THAT IN THE PRESENTATIONS AND SOME OF YOU MENTIONED THAT AS WELL.

WHAT ABOUT WHEN DATA ABOUT PATIENTS IS LINKED OR REPURPOSED AFTER THE FACT.

IT MIGHT BE COVERED IN THE PRIVACY POLICY BUT THEN USED AFTER THE FACT.

HOW DO YOU WORK TO PROVIDE EFFECTIVE NOTICE AND CHOICE AROUND THAT.

>> I CAN SPEAK TO PATIENTS LIKE ME.

I MEAN, WE ACTUALLY IN OUR PRIVACY POLICY TRANSPARENCY AND OPENNESS STATEMENTS ARE PRETTY CLEAR THAT THE DATA THAT YOU ARE

GOING TO BE PROVIDING WILL BE AND CAN BE USED FOR AGGREGATION DEIDENTIFICATION AND THEN SHARED WITH OUR PARTNERS WHOMEVER IT IS THAT WE'RE WORKING ON A PROJECT WITH.

THAT SAID, SO THAT'S THE BASIC PROFILE DATA.

THAT SAID, WHEN WE ARE ACTUALLY IN THE PROCESS OF WORKING ON A PARTICULAR PROJECT OR WE'RE DOING AN INITIATIVE OR A SURVEY STUDY, THAT REMINDER COMES IN AS PART OF THE CONSENTING TO PARTICIPATE IN THAT SURVEY. SO THAT INFORMATION WOULD CLEARLY TELL THEM WHO OUR PARTNER IS.

IT WOULD CLEARLY TELL THEM HOW THAT DATA'S GOING TO BE USED IN THE CONTEXT OF THIS NEW SURVEY OR THIS STUDY THAT WE'RE WORKING ON AND WE ALSO PROMISE THEM TO GIVE THAT DATA THE FINDINGS FROM THAT DATA BACK TO THEM WITHIN A REASONABLE PERIOD OF TIME.

THAT'S A PROMISE WITH MAKE, GET SOMETHING GIVE SOMETHING MANTRA WE HAVE.

SO EVERY TIME WE GIVE YOU A PIECE OF DATA WE GIVE YOU A GRAPHIC DISPLAY OF WHAT THAT MEANS IN THE CONTEXT OF EVERYONE ELSE ON THE SITE OR WHEN WHEN WE'RE DOING A SPECIFIC SOCIETY QUESTIONS WE WILL BRING THAT DATA BACK TO THE USERS EITHER IN A BLOG POST OR IN A FORM OR SOME FORMAT FOR THEM TO BE ABLE TO KNOW HERE'S WHAT YOU CONTRIBUTED, HERE'S WHAT THE FINDINGS WERE AND THEN GENERATE SOME CONVERSATION ABOUT THAT.

>> OKAY.

SO WE'VE ALSO HEARD ABOUT PRIVACY BEING A SHARED

RESPONSIBILITY.

WE HEARD A LITTLE BIT FROM SALLY AND OTHERS ABOUT THAT.

AND WE JUST WANTED TO FOLLOW UP A LITTLE BIT ON WHAT CONSUMERS SHOULD BE DOING IF THEY ONLY HAVE CONTROL OVER SAY ENTERING THE INFORMATION ONCE INTO THE APP THEY ARE INTERFACING WITH RIGHT THEN AND IT GOES ON TO BE SHARED IN THE BACK END.

HOW CAN THEY KEEP THEIR DATA IN THE CONTEXT THAT THEY WOULD EXPECT?

>> SO, ONE OF THE DOUBLE EDGED SWORD WITH NO HANDLE SO TO SPEAK, WELL MAYBE THAT'S NOT RIGHT.

THE DOUBLE EDGE SWORD VIEW DOWNLOAD TRANSMIT IS AWESOME. PEOPLE HAVE THE DATA IN THEIR HANDS, THEY CAN DO A BUNCH OF STUFF WITH IT.

ONE OF THE DIGITTED SWORD PART OF THIS IS PEOPLE CAN DO REALLY SILLY STUFF WITH THEIR OWN DATA NOW AND THEY CAN DO THINGS THAT ARE SORT OF IRRESPONSIBLE.

BUT THAT'S PART OF SORT OF THIS NATIONAL NEGOTIATION PROCESS WE'RE HAVING WITH THIS INCREASED CUSTODY SO TO SPEAK ON THE PATIENT'S SIDE TO BE ABLE TO USE AND DO THINGS WITH THIS DATA.

IF ANY OF YOU SEE ANY INFORMATION POSTED ON FACEBOOK THAT'S A GOOD OPPORTUNITY TO HAVE A CONVERSATION WITH THAT PERSON ABOUT WHAT'S APPROPRIATE AND HOW THAT MIGHT NOT EXACTLY BE THE THING YOU'D WANT TO READ BEING AN AUDIENCE MEMBER FOR THAT PERSON'S FACEBOOK PROFILE. I THINK THERE'S A WHOLE SET OF SOCIAL PRACTICES PEOPLE WHO ARE MORE KNOWLEDGEABLE ABOUT THESE

THINGS SHOULD KEEP YOUR EYES OUT FOR THAT KIND OF STUFF.

CONSUMERS IN GENERAL ARE GOING TO NEED TO THINK HARDER ABOUT THESE THINGS.

THEY'RE GOING TO BE SOME FANTASTIC MISTAKES THAT HAPPEN THAT WILL SERVE FOR FOLKS LIKE US WHO ARE CONSUMER ADVOCATES CAN GO OUT AND SAY LOOK, DON'T END UP LIKE THIS, PLEASE PROTECT YOUR INFORMATION MORE LIKE THAT. AND WE'RE ON THE NSA SNOWDEN SIDE WE'RE DOING A WHOLE LOT OF STUFF MAKING SURE THAT PEOPLE CAN PROPERLY PROTECT THEIR DATA, BE IT A COMMUNICATIONS SESSION OR DATA AT REST, STUFF YOU HAVE ON YOUR COMPUTER OR YOUR MOBILE DEVICE.

AND SO I THINK THERE'S A LARGER TREND OF EVERYONE NEEDS TO SORT OF BONE UP ON THEIR DIGITAL HYGIENE SO TO SPEAK AND UNDERSTAND THINGS LIKE PASSWORD MANAGERS, I HAVE 1200 PASSWORDS, I ONLY HAVE TWO OF THEM. YOU SHOULD NEVER HAVE TO KNOW MORE THAN THAT BECAUSE THERE'S REALLY GOOD TOOLS TO HELP YOU CREATE SECURE ONES AND YOU NEVER HAVE TO REMEMBER ANOTHER ONE AGAIN.

THERE'S A WHOLE SLEW OF THINGS LIKE THAT THAT AS A SOCIETY WE'RE GOING TO HAVE TO LEARN TO INCORPORATE INTO THE SORT OF FABRIC OF HOW WE DO THINGS.

>> I THINK THAT ONE OF THE ISSUES THAT I CONTINUOUSLY HEAR IS THAT THERE ARE MANY PEOPLE WHO THINK FROM MY CONSUMER PERSPECTIVE THAT PRIVACY IS DEAD, NOBODY CARES ANYONE. PEOPLE SHARE ALL THIS INFORMATION ON FACEBOOK, THEY

ARE ON SOCIAL NETWORK SO THEY
DON'T REALLY CARE.

I THINK THERE ARE ALSO A LOT OF
RESEARCH STUDIES THAT HAVE COME
OUT WITHIN THE LAST YEAR OR SO
THAT REALLY QUESTION THAT
PERSPECTIVE.

BECAUSE PEOPLE WHO HAVE HAD
SOMETHING HAPPEN TO THEM OR KNOW
SOMETHING THAT'S HAPPENED TO
SOMEBODY DUE TO INFORMATION THAT
WAS POSTED ON THEIR WEBSITE OR
SOMETHING OF THAT NATURE HAVE A
RENEWED RESPECT FOR THEIR OWN
PRIVACY AND HOW THEIR
INFORMATION MAY BE USED.

I ALSO THINK THAT PEOPLE,
THERE'S A SEGMENT OF PEOPLE WHO
CARE A LOT ABOUT PRIVACY AND
THERE ARE PEOPLE WHO WOULD SHARE
EVERYTHING WITH ANYBODY AGAIN.
SOMETIMES THOSE PERSPECTIVES
CHANGE WHEN YOU REALIZE WHAT THE
CONSEQUENCES OF THAT SHARING
MIGHT BE.

SO I ALSO THINK THAT WHEN YOU
HEAR THOSE CONVERSATION IT'S
LIKE WELL ONLY 10% OF THE PEOPLE
IN AMERICA REALLY CARE ABOUT
PRIVACY.

BUT THAT 10 OR 20% IS FLEXIBLE.
IT'S NOT, IT'S NOT A STATIC
NUMBER.

PEOPLE COME AND THEY FLOW INTO
AND OUT OF HOW MUCH AND WHETHER
THEY CARE ABOUT HOW THEY'RE
SHARING THEIR INFORMATION
DEPENDING ON AGAIN ON THE
CONTEXT.

SO I THINK THERE ARE A LOT OF
NUANCES TO THE DISCUSSION ABOUT
FIRST OF ALL PEOPLE'S
PERSPECTIVES ON PRIVACY AND WHAT
THEY ARE WILLING TO DO TO
PROTECT IT.

SOME PEOPLE HAVE A LOT MORE AT

RISK THAN OTHERS DO AS TO, AND THAT CHANGES OVER TIME.

IT'S A VERY DYNAMIC ISSUE.

>> I WOULD JUST ADD, I THINK THAT ALL OF THIS IS SO TRUE.

AND I THINK WHAT WE ARE ENTERING A TIME WHEN CONSUMERS ARE GOING TO BE EXPECTED TO HAVE A LOT MORE OWNERSHIP OF THEIR OWN HEALTH AND THEIR HEALTHCARE. AND WHETHER YOU WANT THAT RESPONSIBILITY OR NOT, IT'S COMING YOUR WAY.

SO I THINK THERE'S A LOT ON ALL OF OUR PARTS TO BE ABLE TO START THINKING ABOUT WHAT IS IT THAT I NEED TO KNOW, WHO DO I NEED TO LEARN IT FROM AND WHERE MIGHT I GET THIS INFORMATION TO START PROTECTING MYSELF.

I THINK IT'S JUST VERY CLEAR THAT WE PROBABLY CAN'T PROTECT OURSELVES FROM A LOT OF THIS THIRD PARTY PUSH THAT'S GOING ON BECAUSE FIRST OF ALL WE MAY NOTN'T BE AWARE OF IT.

WHEN WE DO BECOME AWARE OF IT WE BEGIN TO HAVE AN INCREASED SENSITIVITY AS JOY ALREADY SAID.

I WANT TO REINFORCE THAT EVEN PEOPLE WITH CHRONIC ILLNESS WHO ARE PARTICIPATING IN DATA SHARING SIGNIFICANTLY ON PATIENTS LIKE ME HAVE AN EXPECTATION THAT WE PROTECT THEIR DATA.

THEY HAVE AN EXPECTATION THAT WE AN MISE THAT DATA AND WE IDENTIFY THAT DATA.

THAT EXPECTATION IS SOMETHING THAT AGAIN I SAID EARLIER WERE WE TO VIOLATE WE WOULD BE NOT ABLE TO HAVE THE TRUST OF OUR PATIENTS.

SO I THINK THERE IS AN EXPECTATION ESPECIALLY AMONG

THOSE WHO FEEL THAT THEY HAVE A LOT TO LOSE IF SOME OF THAT INFORMATION WERE TO BECOME AVAILABLE OUTSIDE OF THE SPHERE THEY EXPECTED IT TO BE USED IN. BUT AT THE SAME TIME EACH OF US I THINK AS CONSUMERS ARE GOING TO NEED TO EXPAND OUR AWARENESS AND UNDERSTANDING WHAT CAN WE DO PERSONALLY SINCE WE WILL BE GIVEN A LOT MORE RESPONSIBILITY TO HAVE OUR ACCESS TO OUR MEDICAL INFORMATION THAT WE PREVIOUSLY HAVE NOT HAD AVAILABLE TO US AS WELL AS SHARE IN PLACES THAT MAYBE ARE KNOWN AS PROTECTED AS WE MIGHT THINK THEY ARE.

>> THE COMMISSIONER MADE THIS POINT EARLIER TODAY. WE SPENT A LOT OF TIME TALKING ABOUT THE COST AND RISK OF PRIVACY AND THOSE ARE ALL VERY REAL AND WE'RE DIGGING DEEP. BUT THE BENEFIT CAN BE EXTRAORDINARY TO HAVING THESE KINDS OF TECHNOLOGIES AVAILABLE. YOU DON'T NECESSARILY HAVE TO UNDERSTAND YOUR RECORD. I'M NOT TRYING WITH THE IVORY BUTTON APP TO MAKE ALL OF YOU PHYSICIANS OR SPECIALISTS AS PHYSICIANS BUT I AM TRYING TO GIVE YOU THE BASIC BUILDING BLOCKS SO THAT THAT DATA WILL BE AVAILABLE WHEN YOU GO SOMEWHERE ELSE AND SEE ANOTHER PHYSICIAN. SO THAT'S REALLY I THINK, THERE'S ENORMOUS BENEFIT AND I DON'T WANT TO GO, DON'T HAVE TIME TO GO INTO ALL THE STUDIES THAT SHOW JUST HAVING A MEDICATION LIST THAT'S UP TO DATE AND CONDITION LIST THAT'S UP TO DATE CAN ADVERT ALL SORTS OF MEDICAL MISADVENTURES OR

CATASTROPHES THAT YOU AND YOUR PARENTS OR CHILDREN CAN BE USEFUL TO THIS DATA.

SO THAT'S TREMENDOUS BENEFIT TO PRIVACY.

>> WE WON'T SEE THAT BENEFIT UNLESS YOU PROTECT THE DATA.

>> YES.

>> OKAY, THANKS.

WE'D LIKE TO MOVE ON TO DEIDENTIFICATION WHICH HAS COME UP A COUPLE TIMES TODAY.

AND FIRST THERE'S A QUESTION FROM THE AUDIENCE.

SO THERE'S TALK, AND THIS IS WHAT WE'VE BEEN DISCUSSING A FEW TIMES, ABOUT SHARING DATA IN DEIDENTIFIED FORM.

SO COULD PEOPLE COMMENT ON LATANYA'S FINDING HER GROUP WAS ABLE TO REIDENTIFY 43% OF THE SAMPLE.

AND WOULD CONSUMERS APPRECIATE THIS AND HOW SHOULD POLICY MAKERS ACCOUNT FOR CONSUMERS NOT BEING ABLE TO UNDERSTAND.

SO THERE'S A LOT THERE.

>> I'LL JUMP IN AND MAKE THE FIRST OBVIOUS COMMENT, ALTHOUGH IT MAY NOT BE OBVIOUS TO A LOT OF PEOPLE IN THE ROOM.

BUT IN THE HIPAA GUIDANCE ON DATA DEIDENTIFICATION, IT'S STATES CLEARLY GENDER FIVE DIGIT ZIP CODE AND DATA OF BIRTH MONTH DAY AND YEAR CAN IDENTIFY 50% OF ALL AMERICANS S THAT'S PRETTY EXTRAORDINARY.

SO THERE IS A REAL NEED TO HAVE WAYS OF AVOIDING, PUTTING THOSE THREE, JUST THOSE THREE SIMPLE FACTS TOGETHER.

>> I WAS JUST GOING TO MAKE ONE SLIGHT CORRECTION WHICH IS LATANYA'S ORIGINAL STUDY SHOWED A HIGHER NUMBER THAN THAT.

I THINK IT WAS 70 SOMETHING AND THEN THERE WAS A FOLLOW UP USING THE 2000 CENSUS DATA WHICH DROPPED THAT DOWN TO LIKE 60 SOMETHING.

SO IT'S BIG.

>> THANKS.

>> I THINK THERE'S A LARGE VARIABILITY IN HOW DEIDENTIFICATION IS DEFINED.

>> OH, THANKS.

I WAS GOING TO FOLLOW UP WITH YOU ABOUT THIS.

>> SO I THINK THE HIPAA PRIVACY RULE PROBABLY HAS ONE OF THE MOST STRINGENT DEFINITIONS OF DEIDENTIFICATION OF ANY PRIVACY RULE THAT I'VE EVER READ.

THE PARADIGM IN PROTECTING HEALTH INFORMATION OR ANY KIND OF INFORMATION IS DRAWN IN JUST EVERY STATUTE REGULATION I'VE EVER READ, AND IT'S LIMITED TO IDENTIFIABLE DATA.

AND IT'S NOT IDENTIFIABLE DATA DEPENDING ON HOW YOU DEFINE IT. THEN THE REGULATION OR THE STATUTE GENERALLY DOESN'T APPLY BECAUSE THE IDEA IS TO PROTECT THE IDEA, NOT JUST RANDOM DATA. SO THE QUESTION THEN IS WHEN DOES INFORMATION BECOME IDENTIFIABLE TO THE POINT WHERE YOU CAN ACTUALLY ATTACH IT TO SOMEBODY.

AND THAT IS KIND OF A MOVING TARGET.

AND THAT HAS CONTINUE TO CHANGE OVER THE YEARS.

AND AS TECHNOLOGY ADVANCES. SO THE PRIVACY, THE HIPAA PRIVACY RULE HAS TWO MEANS OF UNDER WHICH INFORMATION CAN BE CONSIDERED DEIDENTIFIED.

ONE IS THE SAFE HARBOR METHOD WHERE YOU HAVE TO REMOVAL OF

THE ELEMENTS THAT CHRIS MENTIONED EARLIER WHICH ARE ALMOST ALL DATES.

ZIP CODES.

NAME THE OBVIOUS ONES, YOUR NAME, SOCIAL SECURITY NUMBER MEDICAL RECORD NUMBER TO THE POINT WHERE DURING THE COMMENT PERIOD WHEN THE RULE WAS BEING WRITTEN AS SOME IN THE AUDIENCE WOULD ATTEST, THAT THERE WAS A BIG BLOW BACK BECAUSE RESEARCHERS ARE SAYING WE CAN'T POSSIBLY USE THIS INFORMATION BECAUSE WE CAN'T ASSOCIATE IT WITH ANYBODY AND WE NEED TO DO LONGITUDINAL, LONGITUDINAL ASSOCIATIONS.

SO IN THE PRIVACY RULE, IT'S KIND OF TIERED.

THERE'S ALSO A TIER OF INFORMATION OF WHICH THE MAJOR OBVIOUS IDENTIFIERS HAVE BEEN REMOVED, BUT MANY OF THE OTHER INFORMATION CAN STILL BE RETAPED SUCH AS DATES OF SERVICE.

AND THAT INFORMATION, THERE'S A RECOGNITION THAT THERE IS SOME POTENTIAL THERE FOR REIDENTIFICATION, AND SO THAT INFORMATION CAN BE SHARED PARTICULARLY FOR RESEARCHER JUST GOES FOR RESEARCH WITH A DATA USE AGREEMENT THAT THE RECIPIENT WON'T REIDENTIFY IT.

AND THAT IS ONE OF THE WAYS THAT PEOPLE ARE ADDRESSING THIS ISSUE IS KIND OF STRATIFYING THE INFORMATION OF HERE'S REALLY YOU'LL SEE THIS ON PUBLIC USE SITES AND I THINK NCI DID THIS AS WELL, NATIONAL CANCER INSTITUTE.

HERE'S INFORMATION WHERE WE BELIEVE WE'VE DONE A REALLY GOOD

JOB AND THERE'S SOME TESTING
DONE TO SEE HOW GOOD A JOB
THEY'VE DONE.

AND THAT INFORMATION IS
AVAILABLE IN A PUBLIC USE FILE.
THE NEW INFORMATION WHERE THERE
IS LARGER POTENTIAL OF
REIDENTIFYING THE INFORMATION
THEY MAKE SUBJECT, THEY MAKE
AVAILABLE BUT IT IS SUBJECT TO
SOME SORT OF A DAILY USE
AGREEMENT.

HAVING SAID THAT, SOME OF THE
INFORMATION THAT WAS FOR EXAMPLE
THE STATE RELEASE OF INFORMATION
IS FROM ENTITIES THAT AREN'T
NECESSARILY SUBJECT TO THE HIPAA
PRIVACY RULE.

FOR EXAMPLE, PUBLIC HEALTH
DEPARTMENTS IN STATES, IT'S A
COMPLICATED ISSUE BUT MANY OF
THOSE ARE NOT COVERED BY THE
HIPAA PRIVACY RULE.

THEY ARE OFTEN, THOUGH, COVERED
BY THEIR OWN STATE LAWS.

AND HOW STATED LAWS DEFINE WHAT
KIND OF INFORMATION CAN BE
SHARED OR HOW IT HAS TO BE
ANONYMOUSIZED OR DEIDENTIFIED
VERY MUCH.

AND THEY TOO ARE SECTOR
SPECIFIC.

WHAT IT SAYS OVER HERE IN A RULE
THAT GOVERNS DOCTORS OR OTHER
HEALTHCARE PROVIDERS MAY BE
DIFFERENT THAN THE EQUIVALENT OF
THEIR PRIVACY ACT.

SO DEIDENTIFICATION, IT'S,
THERE'S NOT A SINGLE RULE THAT
GOVERNS EVERYBODY.

>> THAT WAS ACTUALLY GOING TO BE
MY FOLLOW UP QUESTION.

THIS IS SOMETHING CHRIS YOU ALSO
REFERRED TO.

THERE'S NO STANDARD DEFINITION
OF DEIDENTIFICATION ACROSS

VARIOUS PRODUCTS AND SERVICES.

HERE'S A QUESTION.

IF SO, WHAT ARE YOUR THOUGHTS.

>> I'M GOING TO SAY YES THERE SHOULD BE AND I'M GOING TO SAY THERE ALSO SHOULD BE WITHIN THE BUSINESS MODEL OF THE COMPANY SOME INHERENT RESPONSIBILITY FOR ACKNOWLEDGING THE ABILITY TO REIDENTIFY IDEATION THAT COULD BE USED APPROPRIATELY.

WE'RE NOT A REGULATED ENTITY UNDER HIPAA BUT WE ADHERE TO THE DEIDENTIFICATION PROCESSES AND PROTECTED DATA AND THAT'S PART OF OUR STANDARD OPERATING PROCEDURES.

SO ANY TIME WE'RE WORKING WITH A PARTNER THEY UNDERSTAND THAT, THEY UNDERSTAND THE DATA USE AGREEMENT THEY WILL ASSIGN WITH US IN TERMS OF RECEIVING INFORMATION WILL BE FREE OF ANYTHING THAT WOULD BE CONSIDERED THAT.

NOW THAT SAID IN THE ENVIRONMENT OF WORKING WITH THEM IN A RESEARCH PROJECT WE WILL TAKE THAT INTO CONSIDERATION SO THAT THAT USEFULNESS OF THAT DATA COULD ACTUALLY BE CONSIDERED IN THE CONTEXT OF WHETHER WE WANT SOME GEO CODING KIND OF INFORMATION TO UNDERSTAND WHAT ARE WE LOOKING AT REGIONALLY AND THAT SORT OF THING.

ALSO WITHIN OUR OWN COMPANY WE HOLD EACH OTHER TO DIFFERENT LEVELS OF ACCESS.

SO NOT EVERYONE IN THE COMPANY HAS ACCESS TO ALL OF THE INFORMATION.

THOSE OF US WHO ARE IN THE PROCESS OF DOING CERTAIN RESEARCH ACTIVITIES OR DATA SCIENCE ACTIVITIES WILL HAVE

DIFFERENT LEVELS OF ACCESS AND THAT'S SPELLED OUT IN OUR STANDARD OPERATING PROCEDURES. I THINK THERE'S A CERTAIN LEVEL OF RESPONSIBILITY THAT COMPANIES DO NEED TO RISE TON'T WHEN USER NOT A REGULATED ENTITY. AND START THINKING ABOUT WHAT THAT RESPONSIBILITY LOOKS LIKE. I'M NOT ONE NECESSARILY TO SAY WE NEED MORE REGULATION. BUT POSSIBLY WE NEED GUIDANCE AND POLICIES THAT CAN HELP FRAME THIS CONVERSATION MORE SO THAT IT'S MORE TRANSPARENT TO CONSUMERS.

>> OTHERS?

>> SURE.

SO AT CDT WE'RE A BIG FAN OF THE FTC'S DEIDENTIFICATION, I DON'T KNOW IF YOU CALL IT A STANDARD RUBIK OR GUIDELINE.

I FORGET THE FIRST TWO PIECES OF IT BUT IT DOES SEEM LIKE IT BINDS DOWN STREAM RECIPIENTS.

YOU HAVE TO ENTER INTO A CONTRACTUAL RELATIONSHIP TO MAKE SURE THAT THAT DOWN STREAM RECIPIENT DOESN'T DO CERTAIN THINGS LIKE TRY TO REIDENTIFY STUFF.

I DON'T KNOW A STANDARD COULD BE REALLY DIFFICULT.

IT'S SORT OF GENERIC IN THE SENSE THAT BEING A PRIVACY AND SECURITY GUY WHO SPENT MY PH.D. HACKING VOTING MACHINES FOR EXAMPLE, YOU START TO REALIZE SOME OF THESE THINGS ARE CASE BY CASE KINDS OF CONSIDERATIONS AND DEIDENTIFICATION YOU WANT TO THINK ABOUT THE UTILITY THAT IS GOING TO, THAT YOU WANT TO RETAIN IN THE DATA AND YOU CAN'T REALLY DO THAT IN A GENERIC WAY. YOU ALSO WANT TO THINK ABOUT THE

THREATS, THE THREATS TO REIDENTIFICATION THAT MIGHT EXIST DEPENDING ON WHAT YOU'RE GOING TO DO.

IF YOU'RE GOING TO POST STUFF ON-LINE PUBLICLY THAT YOU HAVE A SEVERE, VERY LARGE SORT OF THREAT SURFACE.

ANYWAY, JUST THE LAST POINT IS THAT MAKING SORT OF GLOBAL COMMENT, THERE'S A REALLY NEAT PAPER ISSUED BY SOMETHING FROM EUROPE CALLED THE ARTICLE 29 WORKING PARTY WHICH WAS ON BASICALLY ANONYMOUSIZATION AND TECH MUST FOR DOING ANONYMOUSIZATION SO EVEN STRONGER THAN DEIDENTIFICATION. AND THEY HAD A WHOLE BUNCH OF REALLY NEAT SORT OF LIKE WALKING YOU THROUGH HOW TO DO CERTAIN THINGS.

LIKE IF THIS IS WHAT YOU WANT TO DO WITH THE DATA, YOU CAN SHUFFLE THESE AND YOU'RE NOT GOING TO RUIN THE STATISTICAL INFORMATION IN THERE BUT IF SOMEONE DOES END UP REIDENTIFYING THAT ROW, THEY WON'T REALLY HAVE MUCH CONFIDENCE IN THE INDIVIDUAL THAT WAS REIDENTIFIED TOO BECAUSE IT'S A MIX OF A BUNCH OF PEOPLE'S STUFF BUT YOU HAVE TO BE VERY CAREFUL HOW TO DO THAT. SO THE STANDARD, AN EFFORT TO DO A STANDARD MAYBE REALLY INTERESTING.

I JUST WONDER IF IT WOULDN'T BOIL DOWN TO YOU KNOW A FEW CLEAR CUT CASES WITH SOME MORE GENERIC CASE BY CASE KIND OF GUIDANCE.

AND I DO, ALSO A BIG FAN OF THE VERSION OF THE HIPAA DEIDENTIFICATION THAT ISN'T TO

REMOVE THESE 19 OR WHATEVER IDENTIFYING KINDS OF QUANTITIES BUT YOU KNOW ENGAGE WITH AN EXPERT TO ACTUALLY PROBABLY STATISTICALLY GIVEN YOUR YOUTH TO WHAT EXTENT THIS MIGHT BE REIDENTIFIABLE.

THAT'S HARD IN EXPENSES BECAUSE YOU HAVE TO ENGAGE WITH AN EXPERT AND THERE ARE NOT A LOT OF PEOPLE WHO DO THAT.

YOU TRY TO FIND MORE THAN TWO OR THREE OF THEM AND IT GETS PRETTY DIFFICULT PRETTY QUICK AND WE TRY TO DO THAT WHEN PEOPLE ASK US HOW DO WE DO THIS WELL AND IT ENDS UP BEING A FEW PEOPLE THAT ARE OVERWHELMED AND SUCH.

>> I THINK WE NEED TO GET BEYOND BEING BEYOND THE STANDARD PRIVACY POLICY.

WE SHARE, UNLESS YOU OPT IN, WE WON'T SHARE.

IF YOU OPT IN, WE WILL SHARE YOUR PERSONAL INFORMATION BUT IT WILL BE DEIDENTIFIED.

THE NEXT SENTENCE SHOULD BE WE'RE SHARING, COULD BE, WE'RE SHARING IT WITH A LARGE EXTREMELY COMPETENT SOPHISTICATED DATA ANALYTIC SHOP THAT'S RUNNING BIG DATA THAT WILL PROBABLY BE ABLE TO REIDENTIFY MOST OF YOUR DATA.

BUT YOU KNOW THAT'S A DIFFERENT STATEMENT SO THERE'S A SENTENCE MISSING, AND I WOULD, I'M JUST A LONG WAY OF ANSWERING THIS QUESTION I THINK WE DO NEED TO MOVE TOWARDS MORE TRANSPARENCY ON THIS ISSUE.

>> WE HAVE ANOTHER AUDIENCE QUESTION.

HOW DO THE PANELISTS THINK WE CAN COME TO A COMMON DEFINITION OF WHAT INFORMATION AND WHEN

INFORMATION IS HEALTH
INFORMATION.

>> I'M NOT SURE WE CAN.

I THINK EVERYONE, FIRST OF ALL
FROM A CONSUMER'S PERSPECTIVE,
WE ALL VALUE AND QUANTIFY OUR
HEALTH IN DIFFERENT WAYS.
SO WHAT I VALUE AS BEING PART OF
MY HEALTH PICTURE MAY LOOK
DIFFERENTLY THAN IT DOES TO
SOMEONE ELSE IN THE ROOM.
SO I THINK THERE'S PROBABLY
CERTAIN SOCIO, PSYCHO SOCIOKINDS
OF PARAMETERS THAT WILL APPLY TO
HEALTH BROADLY AND THERE'S
PHYSICAL CHARACTERISTICS AND
MENTAL CHARACTERISTICS BROADLY
BUT WHEN YOU START TALKING ABOUT
HEALTHCARE YOU START TALKING
ABOUT VERY SPECIFIC THINGS.
SO TALKING ABOUT IT FROM A
CONSUMER'S PERSPECTIVE AND
ASKING THEM WHAT CONSTITUTES
THEIR HEALTH MIGHT LOOK VERY
DIFFERENT THAN IF YOU'RE TALKING
TO A PAYER OR A CLINICIAN AS TO
WHAT CONSTITUTES HEALTH.
SO COMING UP WITH A COMMON THING
THAT'S CRUST CUT WOULD BE
PROBABLY VERY CHALLENGING.
WE NEED TO RECOGNIZE HEALTH
MEANS A LOT OF DIFFERENT THINGS
TO MOST OF US AND FINDING WAYS
BEING ABLE TO UNDERSTAND THAT
AND THEN PUT THAT INTO CONTEXT I
THINK IS PROBABLY MORE
IMPORTANT.

>> CERTAINLY THERE ARE CORE
THINGS THAT WE ALL AGREE ARE
HEALTHCARE DATA.

NAMES FOR MEDICATIONS AND
MEDICAL CONDITIONS, ALLERGIES,
IMMUNIZATIONS YOU'VE HAD THE
TREATMENTS YOU HAD THE SERVICE
YOU HAD.

WE CAN AGREE ON THAT INNER

CIRCLE WE CAN AGREE ON A LOT.
WHEN YOU GET LARGER AND LARGER
CIRCLES YOU START TO GET
DISPARITIES AND WHAT PEOPLE
THINK OF AS HEALTH DATA.
SO THAT'S WHERE THE TROUBLE
STARTS.

BUT TO KEEP IT SIMPLE WE CAN
ALSO FOCUS ON THIS INNER CIRCLE
OF DATA WE CAN AGREE ABOUT IS
HEALTH DATA WITH REGARD TO
POLICY.

>> THE ONLY PROBLEM I WOULD
SUGGEST IS WE THEN LOSE THE
NUANCE OF THE CONTEXT OF HUMAN
ELEMENT OF WHAT HEALTH IS.
I WOULD SAY THAT GIVES US A
NARROW PICTURE PROBABLY A VIDER,
CLINICIAN CENTRIC PICTURE SO WE
NEED TO BE CAREFUL ABOUT THAT.

>> IT'S REQUIRED BUT NOT
SUFFICIENT.

>> TO ELUCIDATE THAT A LITTLE
BIT MORE, WHEN I WAS ON POST
DOC, YOU MAY NOT HAVE KNOWN YOU
PULL FROM YOUR PANEL A SIMILAR
TEAM BUT HEATHER COULDN'T MAKE
IT SO NOW IT'S JUST ME.

WE DID A STUDY OF GAY MALES AND
MSM, MEAN HAVING SEX WITH M,
THIS IS A POPULATION THAT GUARDS
THEIR HEALTH INFORMATION VERY
CAREFULLY BECAUSE IT'S NOT
SOMETHING YOU CAN TELL BY JUST
LOOKING AT THEM.

AND THERE HAVE TO BE VERY
SPECIFIC KINDS OF CIRCUMSTANCES
IN WHICH THEY FEEL COMFORTABLE
TALKING ABOUT THEIR HEALTH
INFORMATION.

THE SAMPLE WE TALKED TO WAS 30
MEN OF PRETTY STRATIFIED AGE
GROUP, VERY YOUNG AND VERY OLD.
WE FOUND EXTREMELY SURPRISING
THINGS LIKE MOST OF THESE MEN
WHILE WE DIDN'T ASK THE

QUESTION, IT'S CLEAR THEY ARE HIV POSITIVE OR HAD AIDS. AND THAT WASN'T SO MUCH OF A BIG DEAL SORT OF HOW AIDS IS DEVELOPED NOW IN HIV IS DEVELOPED NOW IN THE SENSE THAT IT'S A MANAGEABLE DISEASE, IT'S KIND OF LIKE SOMETHING EVERYONE HAS TO KNOW IF YOU'RE GOING TO INTERACT WITH FOLKS EVEN IN A NON-SEXUAL MANNER. BUT THERE ARE THINGS THAT THEY FOUND REALLY SENSITIVE THAT WE COULD NEVER PREDICT. SO FOR EXAMPLE ONE OF THEM WAS REALLY CONCERNED ABOUT HIS SISTER WHO WAS 25 AND STILL WET THE BED. THAT WAS SUCH A SENSITIVE THING IN THEIR WHOLE FAMILY WAS PART OF THEIR SORT OF WAY THAT THEY OPERATED WAS MAKING SURE THEY PROTECTED THAT KIND OF STUFF AND TO MAKE SURE THERE WAS ALWAYS SOMEONE WHO WAS SORT OF INDOCTRINATED HOW TO MANAGE THAT CONDITION. SO IF SHE'S AT A BAR DRINKING AND PASSES OUT, RED LIGHTS GO OFF AND YOU NEED TO MAKE SURE THAT CERTAIN THINGS HAPPEN. BUT THAT'S NOT THE KIND OF THING WE WOULD HAVE EVER PREDICTED AND THOSE ARE KINDS OF THINGS THEY ARE CONCERNED BECAUSE THE WHOLE STUDY IS WE GO FROM PAPER RECORDS TO ELECTRONIC MEDICAL RECORDS DOES THAT AFFECT THE ABILITY, THEIR TENDENCIES TO DISCLOSE INFORMATION TO THEIR PHYSICIANS. THOSE ARE THE ANECDOTES I NEVER THOUGHT WE COULD ENCAPS LATE IN A DATA STRUCTURE AND THAT'S THE ELEMENT I THINK INEVITABLY WILL INVOLVE AS SOCIETY AND CULTURE

EVOLVE AND AS OUR HEALTH DELIVERY SYSTEM AND TECHNOLOGIES AND TECHNIQUES WE USE TO DO THAT STUFF.

>> THANKS.

>> I THINK THE RECENTLY RELEASED WHITEHOUSE REPORT ON BIG DATA MAKES A VERY GOOD POINT WHEN IT POINTS OUT THAT WHAT IS HEALTH DATA AND WHAT'S FINANCIAL DATA AND OTHER TYPES OF DATA IS REALLY MERGING.

AND AS WE ACCRUE THIS DATA IN COLLATE IT AND USE IT, IT IS GOING TO BE HARDER AND HARDER TO DRAW THAT LINE WHAT'S HEALTH AND WHAT ISN'T.

I THINK PEOPLE SPENDING PATTERNS FOR EXAMPLE WOULD NEVER OCCUR TO YOU TO BE HEALTH DATA YET THAT MODEL MAY BE USED AT SOME POINT TO TREAT YOU AND THEN IT DOES BECOME YOUR HEALTH INFORMATION DOESN'T IT.

>> UNFORTUNATELY WE ARE JUST ABOUT OUT OF TIME SO WE JUST WANTED TO GIVE YOU EACH A MINUTE TO CLOSE BY SHARING YOUR THOUGHTS ABOUT ESPECIALLY IF YOU HAVE ANY THOUGHTS ABOUT BEST PRACTICES.

TO PROTECT PRIVACY AND SECURITY OF THEIR DATA IN THESE CONTEXT.

>> WELL I THINK IT'S BEEN A GREAT DISCUSSION AND WE'VE REALLY FOCUSED ON UNEXPECTED AND TO CONSUMERS UNKNOWN DATA FLOWS THAT BY THESE MODERN DEVICES THAT WE'RE ALL NOW ACQUIRING CAN LEAK OUT AND MAYBE COME BACK AND HAVE IMPORTANT EFFECTS.

WE'VE ALSO HEARD THAT PATIENTS DON'T READ PRIVACY NOTICES OR CONSUMERS DON'T READ PRIVACY NOTICES.

SO I THINK WE ALL HAVE TO WORK

TOGETHER TO COME UP WITH SOME EASIER BETTER MORE CONSOLIDATED WAY TO SIGNAL TO PEOPLE WHAT ARE THE RISKS THAT THEY'RE TAKING WITH THEIR DATA AND HOW THEY MIGHT MITIGATE THOSE RISKS. AND THEN EACH CONSUMER CHOOSES. ON ONE END THE LUMETRIX IS PROVIDING YOUR OWN DATA THAT STAYS WITH YOU AT ALL TIMES AND YOU ARE IN COMPLETE CONTROL OF THAT DATA.

THE FACEBOOK EXAMPLE IF YOU ARE UNWISELY POSTING A LOT OF UNIDENTIFIABLE DATA THERE, THAT'S REALLY A BAD CHOICE. SO I THINK IT'S GOING TO BE SITUATIONAL AND WITH REGARD TO DEVICES AND SPECIFICALLY TO APPS, I DO BELIEVE THERE NEEDS TO BE BETTER AND CLEARER INFORMATION IN THE PRIVACY POLICIES PRESENTED IN A VERY SIMPLE GRAPHICAL FORMAT THAT WILL GIVE YOU A HEAD'S YOU DISPLAY RIGHT AWAY WHEN YOU USE THE APP.

>> THANK YOU VERY MUCH.

AND THIS HAS BEEN A DELIGHTFUL PANEL TO BE ON AND I'M ACTUALLY LOOKING AROUND THE ROOM THINKING THERE ARE QUESTIONS THAT WOULD HAVE BEEN FUN TO GET INTO TO. SO MUCH TO COVER IN SO LITTLE TIME.

FROM MY PERSPECTIVE THE MOST IMPORTANT LAST COMMENT I WOULD LIKE TO MAKE IS THAT WE HAVE TO REALLY TRY WAYS OF REINFORCING THE VALUE OF SHARING INFORMATION TO CONTINUOUSLY LEARN ABOUT HOW TO IMPROVE HEALTH AND HEALTHCARE IN THIS COUNTRY.

AND TRYING TO FIND WAYS OF BEING ABLE TO DO THAT BY ENGAGING WITH PEOPLE AND CONSUMERS ON A

REGULAR BASIS ABOUT THAT VALUE AND MAKING THAT VALUE EQUATION COME TO LIFE.

SO SHARED DATA ALONG WITH SORT OF ALLOWS YOU TO HAVE A MORE ROBUST SHARED DECISION-MAKING PROCESS AND ULTIMATELY ALLOWS US TO HAVE SHARED ACCOUNTABILITY FOR THE OUTCOMES WE HAVE BUT ALSO THE DISPOSITION OF THE DATA.

SO I THINK IT'S REALLY AN IMPORTANT PIECE AS CONSUMERS EACH OF US NEEDS TO START THINKING MORE CONCRETELY WHAT IS IT THAT'S CONSTITUTING MY ROLE IN HEALTH AND HEALTHCARE MY FAMILY'S ROLE MY CHILDREN'S ROLE MY GRANDCHILDREN'S ROLE ON HOW DO I HELP THEM APPRECIATE AND UNDERSTAND THAT VALUE WHILE BALANCING AND FINDING THAT AREA THAT SWEET SPOT THAT SAYS I'M EXPLORING THE RISKS AS WELL AND I'M BEGINNING TO UNDERSTAND THEM BETTER BUT I DO THINK WE NEED TO START HOLDING A HIGHER LEVEL OF ACCOUNTABILITY AROUND THE USE OF APPS AND THINGS THAT ARE SENDING DATA IN PLACES THAT MAY NOT NECESSARILY BE IN OUR BEST INTEREST.

UNTIL WE CAN DO THAT, I THINK WE NEED TO BE MUCH MORE AWARE OF OPTING IN AS CHRIS SAID OR OPTING OUT WHEN SAFETY OR ACCESS TO OUR INFORMATION MIGHT BE AT RISK.

>> THANK YOU CORA AND KRISTEN AND FTC FOR HOLDING THIS FORUM. SIMILARLY I DEFINITELY THINK THIS IS ALMOST A FULL EMPLOYMENT ACT FOR MYSELF AND IT HAPPENS ALL THE TIME WHEN SOMEONE WANTS TO DO SOMETHING COOL MAKE A HEALTH APP OR SOMETHING THAT'S

FUN.

THEY DON'T THINK ABOUT A LOT OF THESE THINGS UNLESS THEY'RE DEVELOPING A PRIVACY APP, PRIVACY AND SECURITY APP. IT'S NICE TO HAVE FRAMEWORKS AND HAVE PEOPLE DEVELOP NOT JUST GUIDELINES AND STUFF BUT DEVELOPMENT ENVIRONMENTS, TECHNICAL TOOLS THAT WILL ALLOW PEOPLE WHO HAVE A COOL IDEA TO NOT HAVE TO WORRY ABOUT SOME OF THE, I MEAN SOME EXTENT YOU WANT THEM TO WORRY ABOUT THAT BUT IT WOULD BE GREAT TO HAVE SOME OF THESE CORE SECURITY THINGS. SECURITY AND PRIVACY ISN'T THAT DIFFERENT IN THAT SECURITY ENABLES YOU TO PROTECT YOUR PRIVACY.

AND SO I WOULD REALLY LIKE TO SEE SOMETHING LIKE THAT THAT WOULD, AND I DON'T KNOW WHO I'M ASKING TO DO THAT.

MAYBE IT'S US, FOR EXAMPLE OR IN COOPERATION WITH SOME OF THE APP INDUSTRY FOLKS.

BECAUSE WE WANT PEOPLE TO MAKE COOL STUFF BUT WE ALSO DON'T WANT TO KEEP ON HAVING THESE COMMON FAILURES.

AND I DON'T WANT TO RELY ON ENFORCEMENT ENTIRELY OR THE PRESS ENTIRELY TO SORT OF SHAME OR WHATEVER PEOPLE INTO DOING THE RIGHT THING BUT ACTUALLY HAVE SOME THINGS THAT ARE SORT OF EMBEDDED INTO HOW THESE TOOLS ARE CREATED.

>> THANKS.

JOY.

>> AT FIRST I WAS KIND OF REGRETTING GETTING THE END SPOT WORRYING I WOULDN'T HAVE ANYTHING LEFT TO SAY. BUT I THINK IT GIVES ME A GREAT

OPPORTUNITY TO FINISH WITH
PUBLIC SERVICE ANNOUNCEMENT IN
SOME WAYS.

OF THE PRESENTATIONS WE GIVE
BECAUSE WHAT'S REALLY ONE OF THE
THING THAT WE FIND IS REALLY
IMPORTANT IS THAT EVERYBODY HAS
A ROLE TO PLAY IN PROTECTING
THIS INFORMATION.

THE GOVERNMENT CLEARLY HAS AN
IMPORTANT ROLE HERE IN
ESTABLISHING A REGULATIONS THAT
ARE BOTH EFFECTIVE AND THAT ARE
WORKABLE FOR PEOPLE.

THE PROVIDERS AND THE PLANS OF
COURSE HAVE THEIR ROLE IN
PROTECTING THE INFORMATION WHEN
IT'S IN THEIR HANDS AND WHEN
THEY ARE TRANSMITTING IT.

THE VENDORS, THE DEVELOPERS, THE
DEVICE VENDORS, THEY'RE
ALSO RESPONSIBLE FOR BUILDING IN
PRIVACY AND SECURITY INTO THEIR
PRODUCTS.

AND WE CAN GO ON WITH ALL THE
OTHER PEOPLE OR THE ENTITIES
THAT TOUCH THIS BUT IT'S REALLY
A CULTURAL CHANGE THAT WE'RE
TRYING TO MAKE HERE.

AND IT GOES ALL THE WAY DOWN TO
THE PATIENT BECAUSE THE PATIENT
IS ALSO RESPONSIBLE.

IT'S GOING TO TAKE A LOT OF
EFFORT FOR ALL OF US TO REALLY
EVER BRING ABOUT THIS CHANGE.

I DO THINK THAT WE ARE KIND OF
AT A DEFINING MOMENT HERE
ALTHOUGH WE'VE SAID THAT MANY
TIMES OVER THE LAST SEVERAL
YEARS.

BUT THERE'S A HUGE MOVEMENT HERE
WITH BIG DATA AND HOW IT'S BEING
SHARED AND HOW ALL THIS
INFORMATION IS FLOWING.

AND IT'S REALLY MOMENTOUS AND
IT'S VERY DIFFERENT THAN THE WAY

THINGS WERE EVEN TEN YEARS AGO
AND I THINK WE'RE ALL
RESPONSIBLE FOR SITTING BACK AND
THINKING HOW ARE WE GOING TO
MANAGE THIS IN A WAY THAT'S
RESPONSIBLE.

>> THANKS.

SO THANK YOU ALL FOR COMING.

I THINK THIS IS IT.

A SPECIAL THANK YOU TO OUR
PRESENTERS AND PANELISTS.

WE WILL BE ACCEPTING COMMENTS ON
THESE ISSUES UNTIL JUNE 9TH, AND
INSTRUCTIONS FOR SUBMITTING
THOSE COMMENTS ARE AVAILABLE ON
OUR EVENT WEB PAGE.

SO THANK YOU AGAIN ALL FOR
COMING.