SPRING PRIVACY SERIES

Consumer Generated and Controlled Health Data

MAY 7, 2014

Welcome

Welcoming Remarks

Commissioner Brill

SPRING PRIVACY SERIES

Consumer Generated and Controlled Health Data

MAY 7, 2014

Health Data Flows

Latanya Sweeney

Chief Technologist, FTC

SPRING PRIVACY SERIES

Consumer Generated and Controlled Health Data

MAY 7, 2014

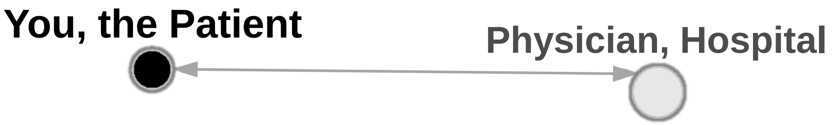
Transparency Establishes Trust

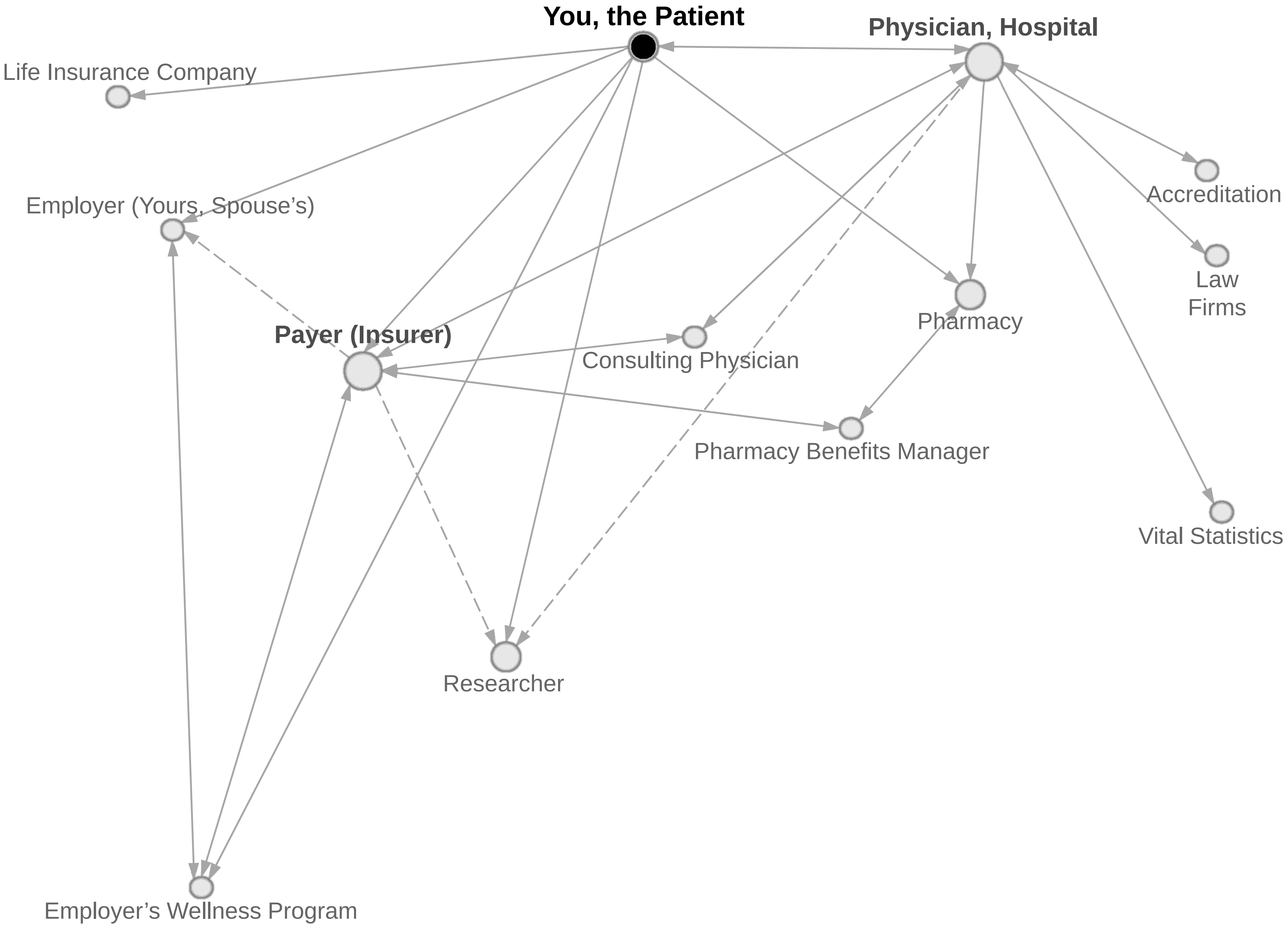
Disclaimer

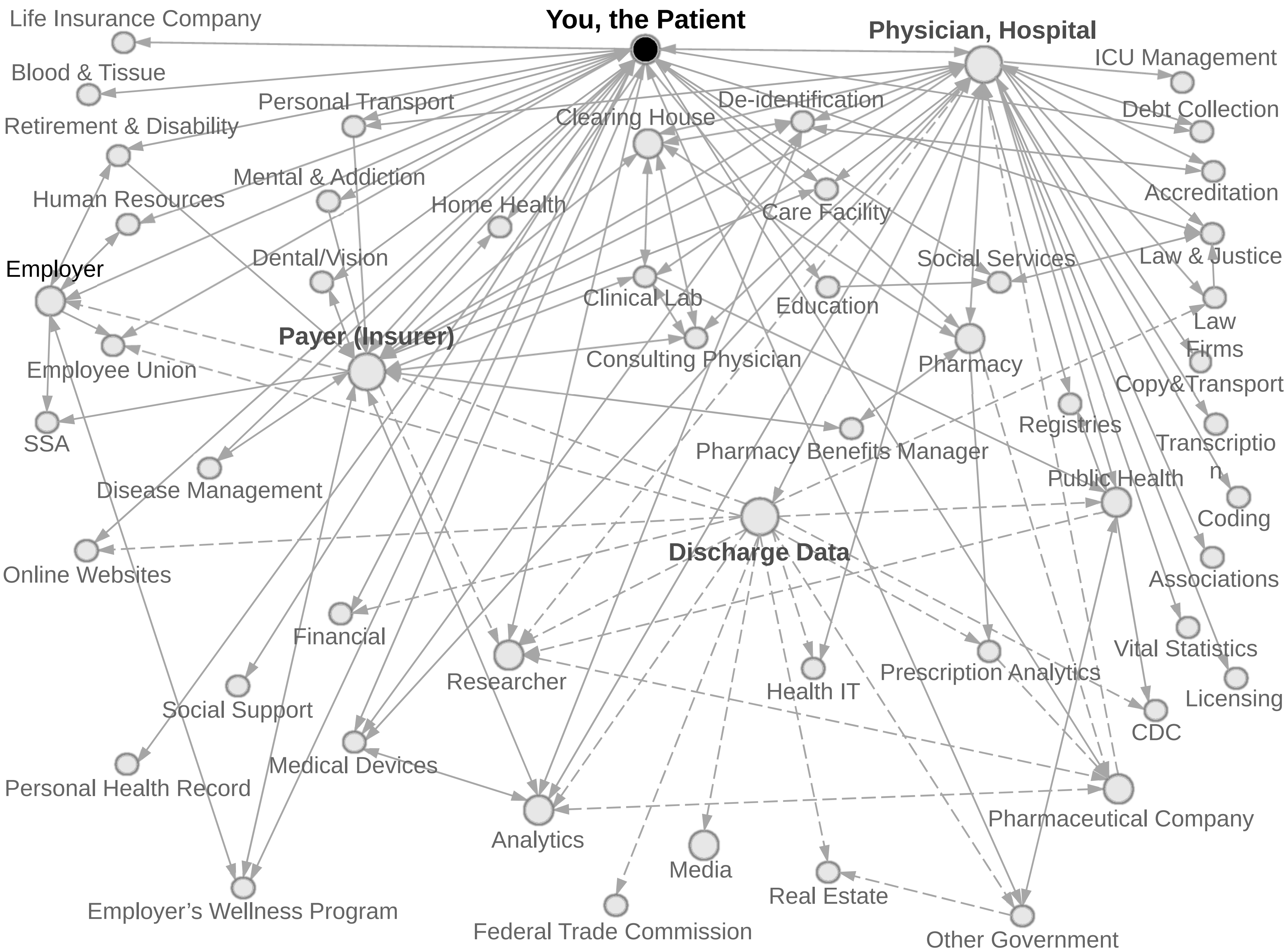
The views and opinions in this presentation represent my own and are not necessarily those of the U.S. Federal Trade Commission. These views are for the benefit of public discourse and public education, and are not necessarily an opinion regarding any position I may take on related issues decided by the FTC.

Transparency Establishes Trust

Establishes Distrust


You, the Patient
Physician, Hospital


You, the Patient
Physician, Hospital
Life Insurance Company
Employer (Yours, Spouse's)
Accreditation
Law
Firms
Pharmacy
Payer (Insurer)
Consulting Physician
Pharmacy Benefits Manager
Vital Statistics
Researcher
Employer's Wellness Program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Personal Transport
De-identification
Clearing House
Debt Collection
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Dental/Vision
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Pharmaceutical Company
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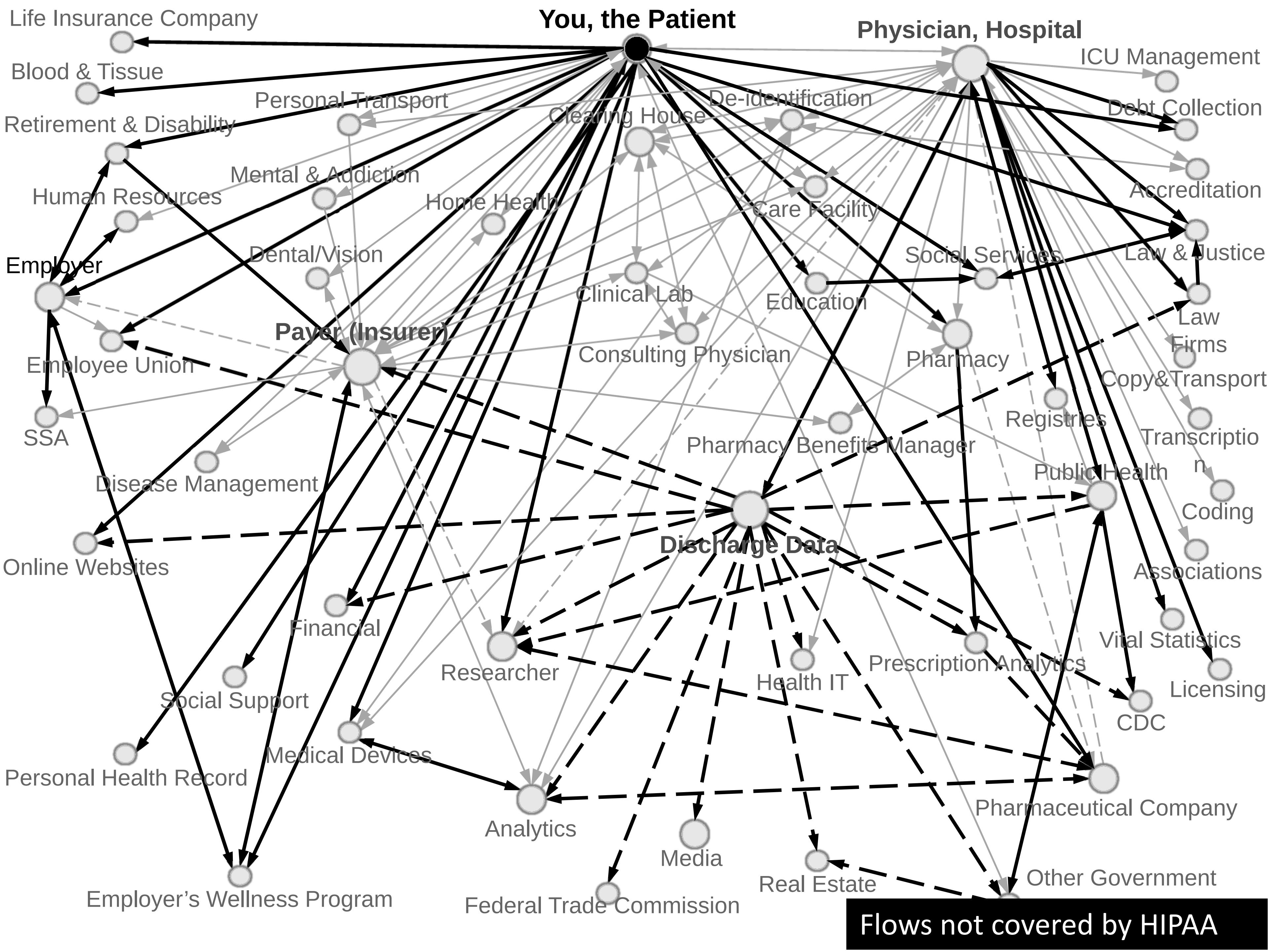
Employer’s Wellness Program
Federal Trade Commission
Other Government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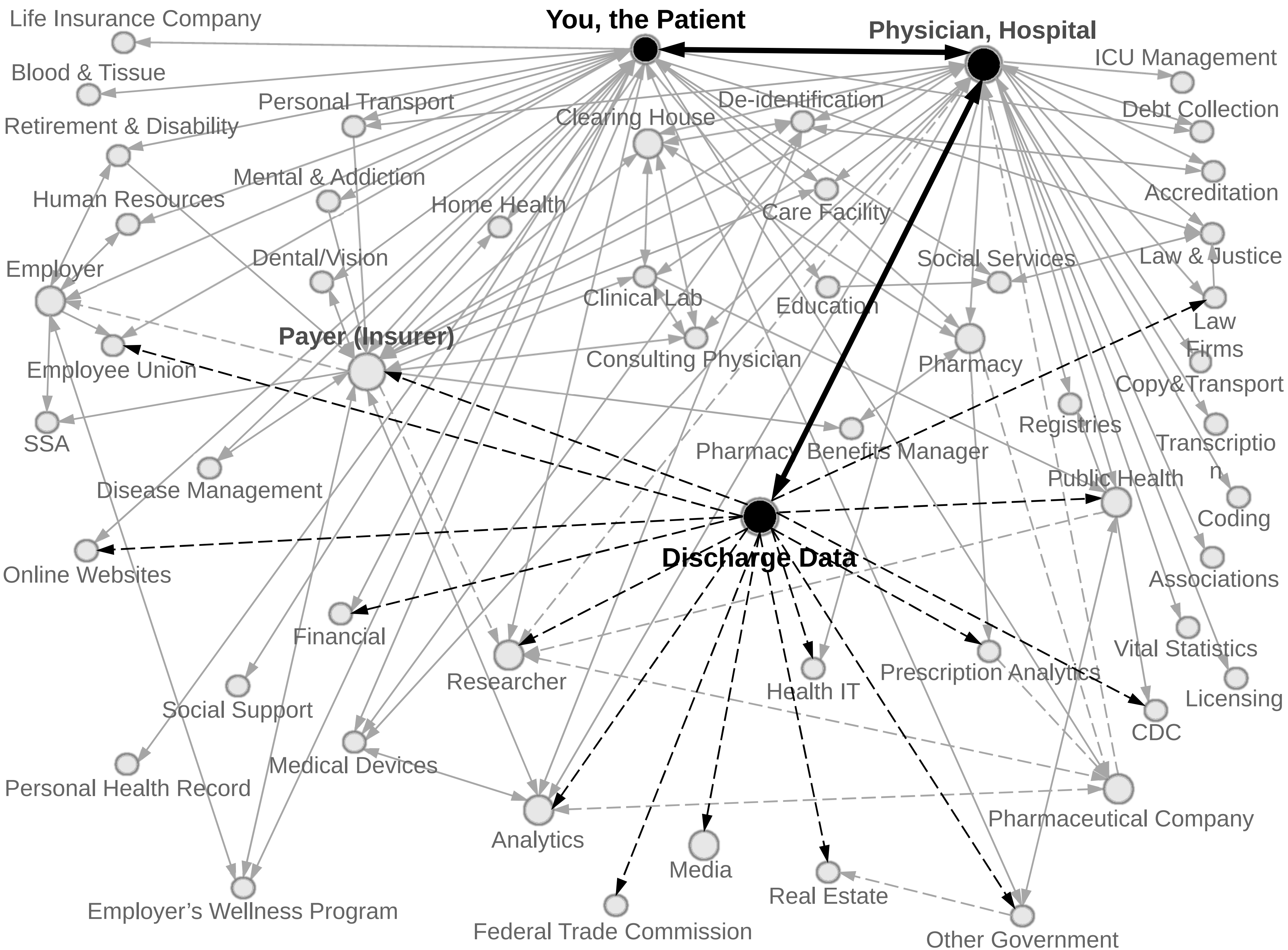
Employer's Wellness Program
Federal Trade Commission
Flows not covered by HIPAA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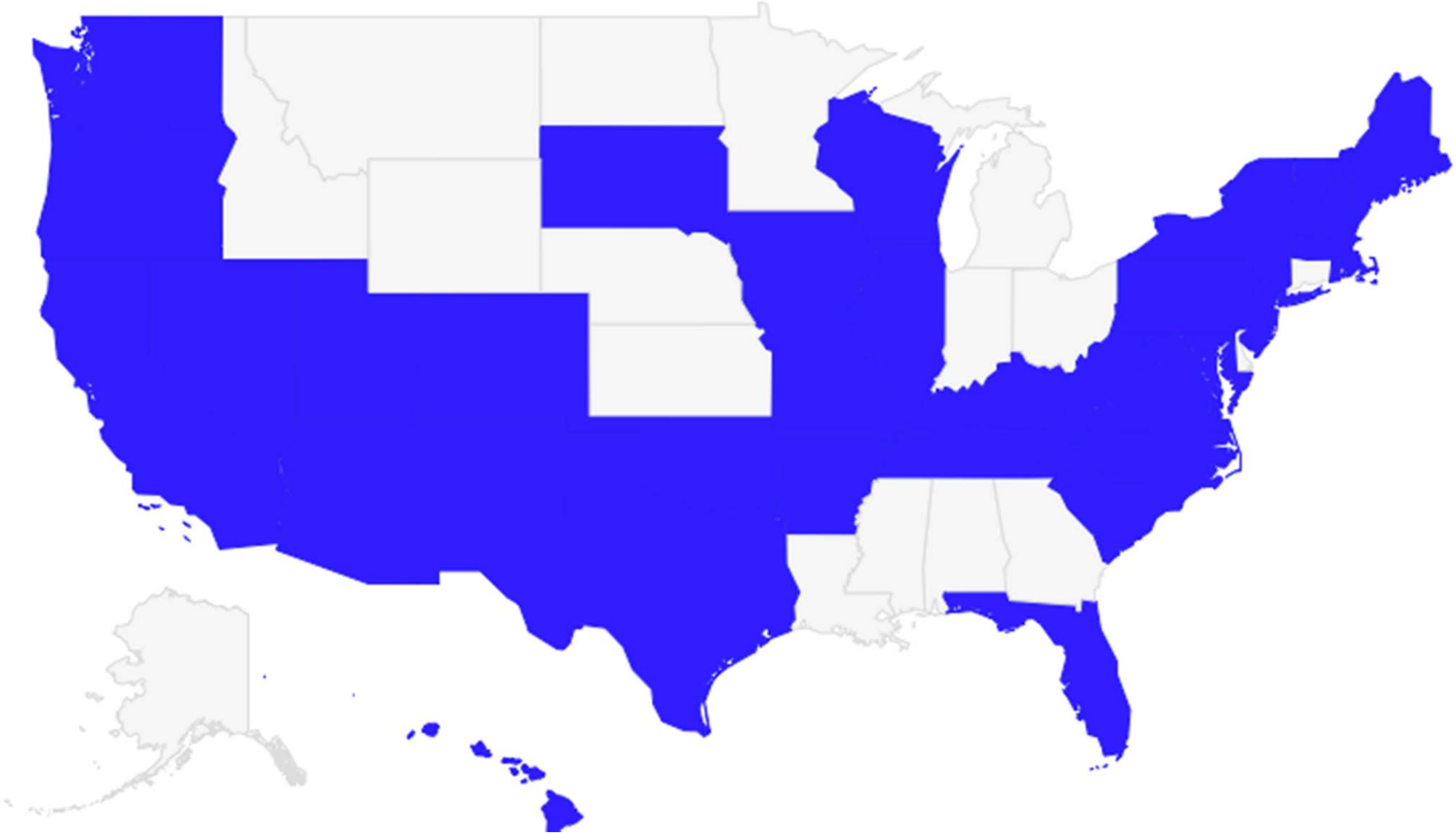
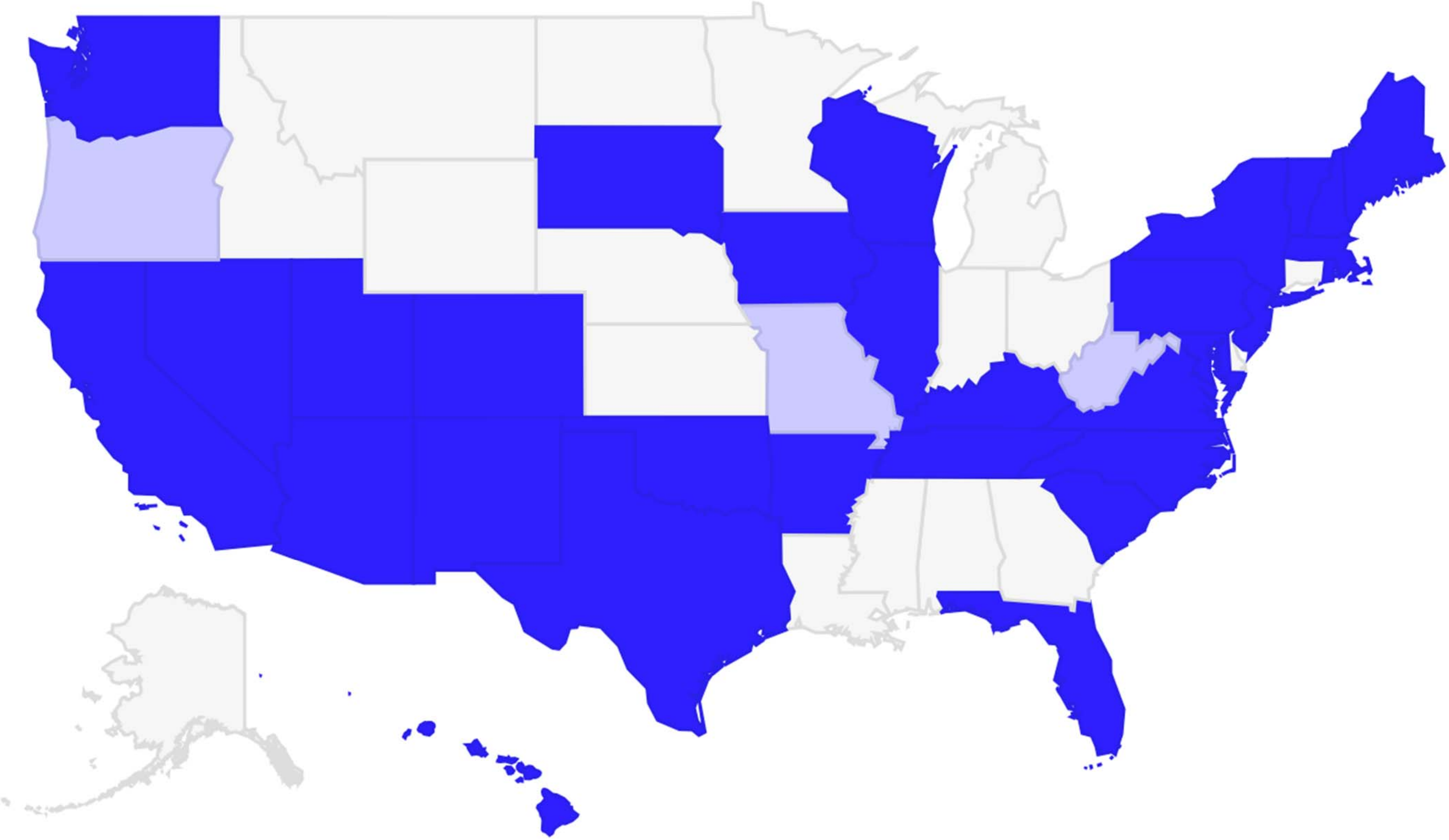
33 States Sell or Share Personal Health Data



Hooley S and Sweeney L. Survey of Publicly-Available State Health Databases. Paper 1075. 2013.
thedatamap.org/states.html

Only 3 States Use HIPAA Standards



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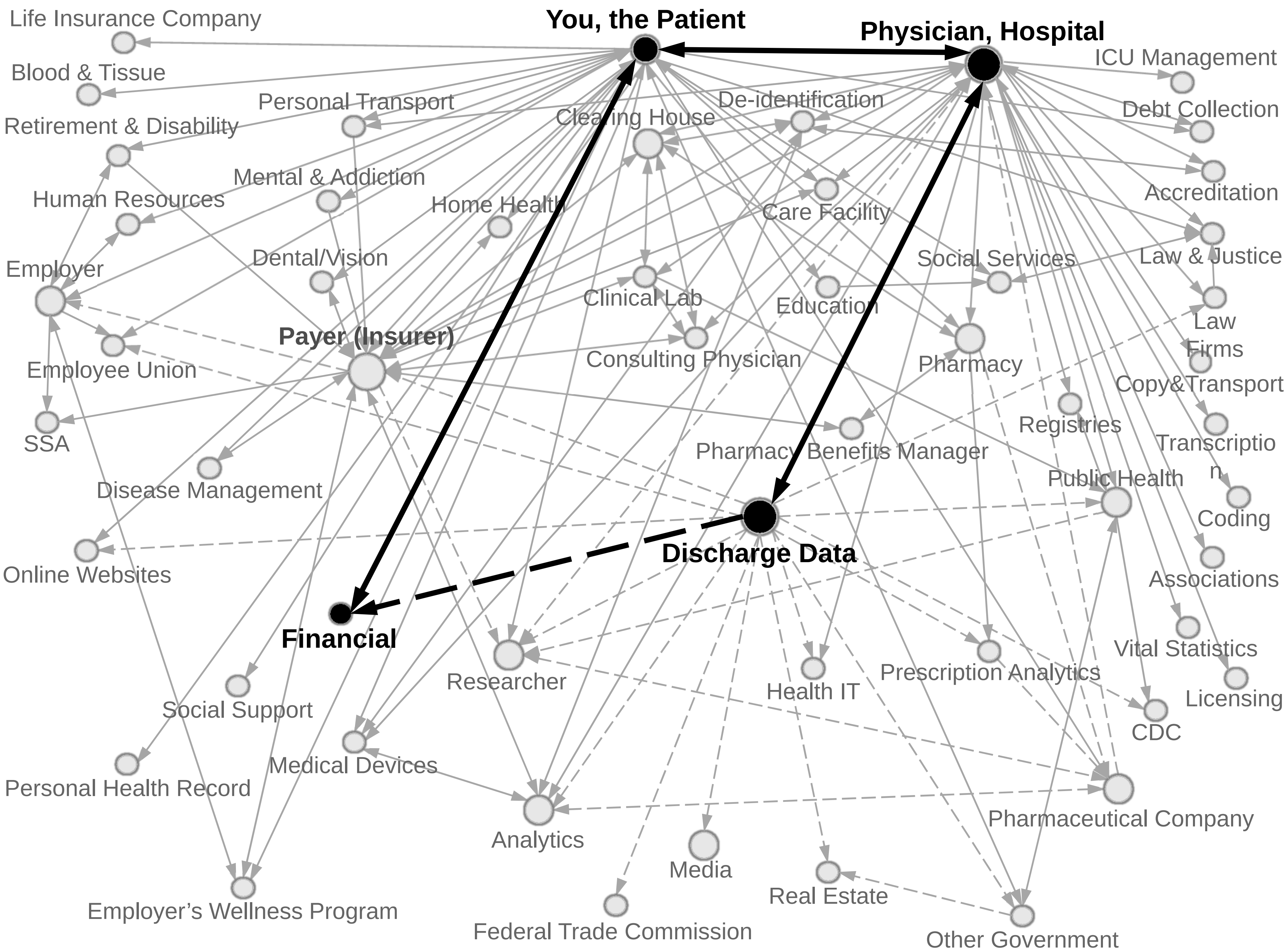

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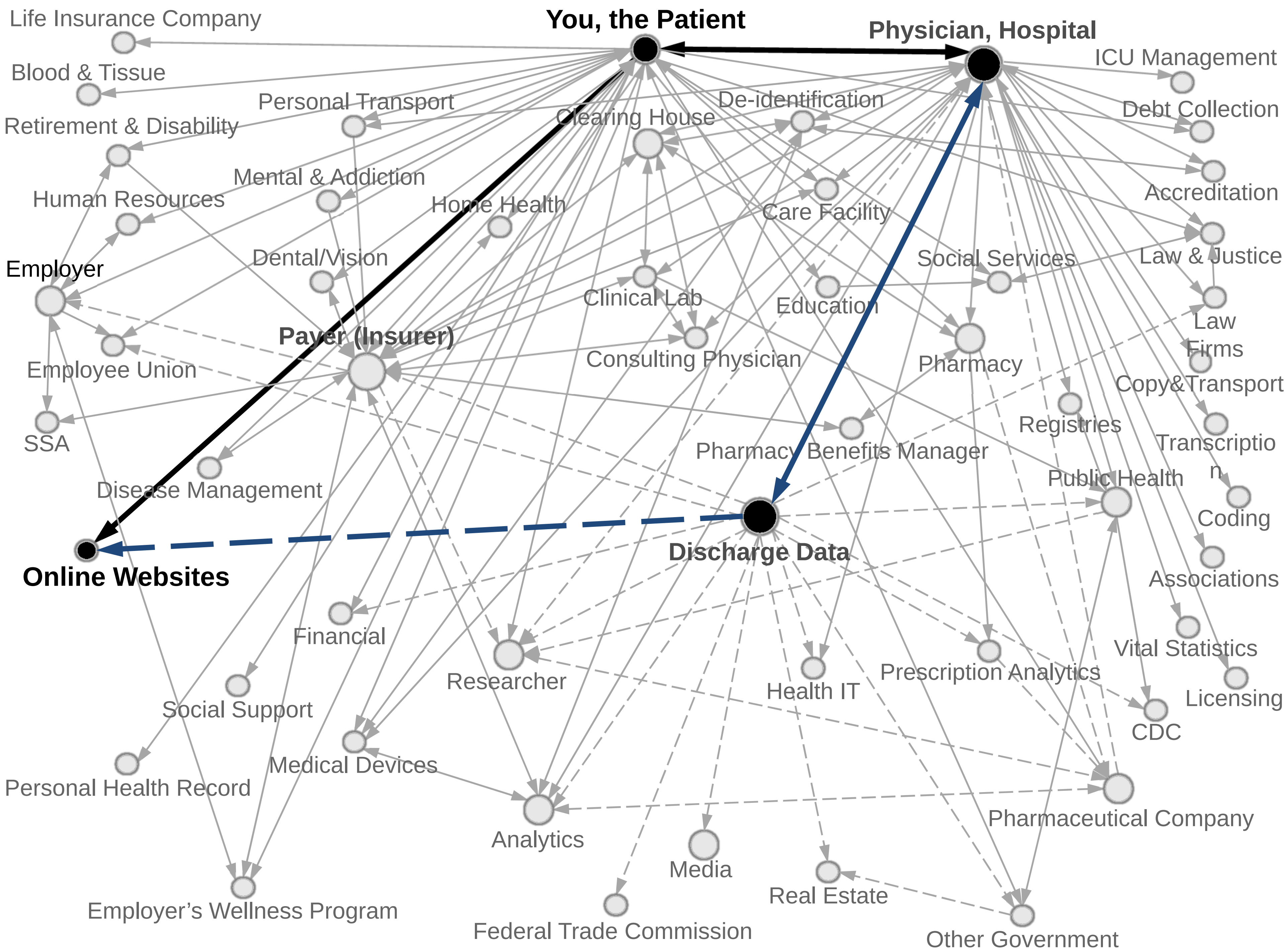
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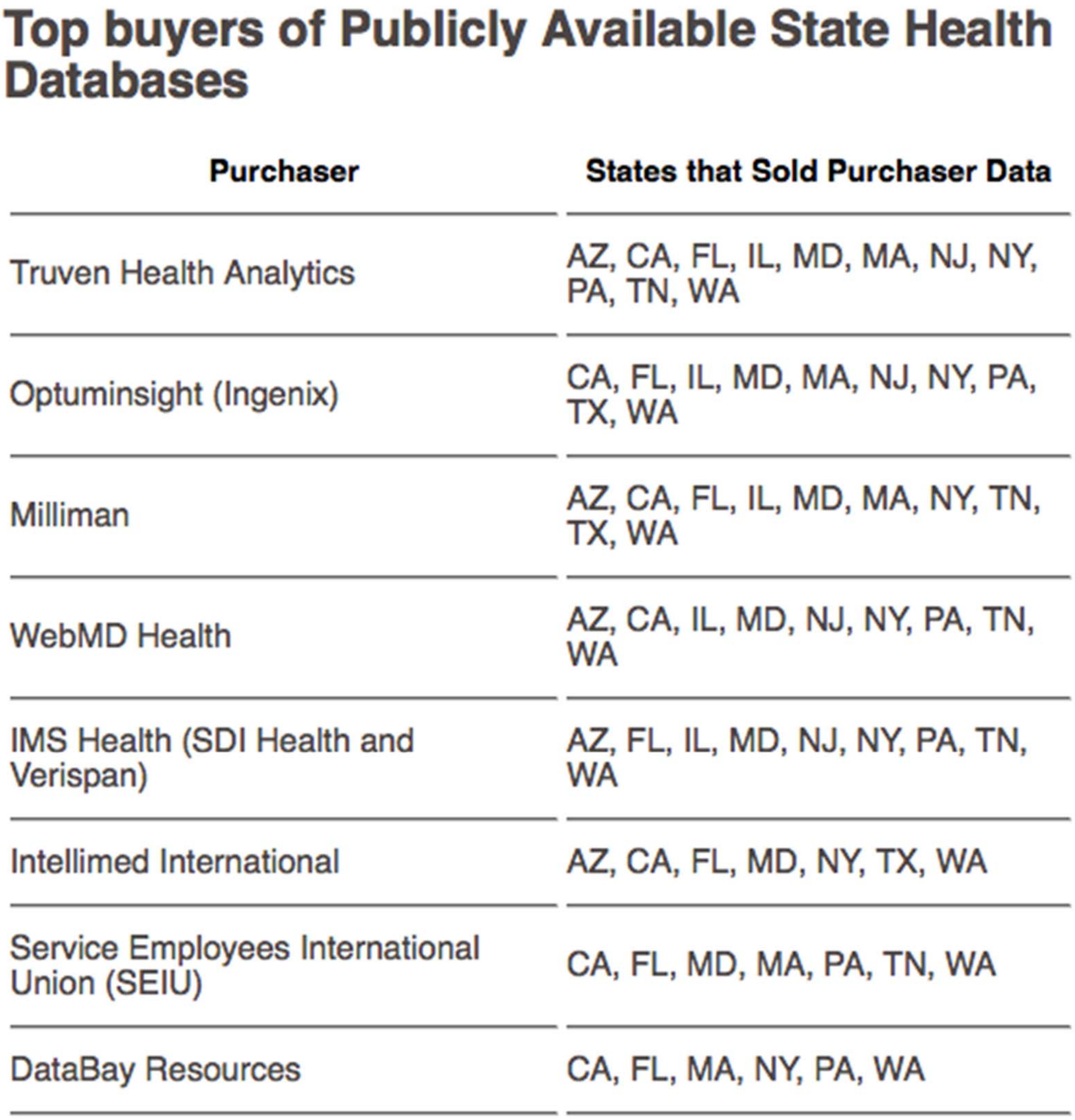
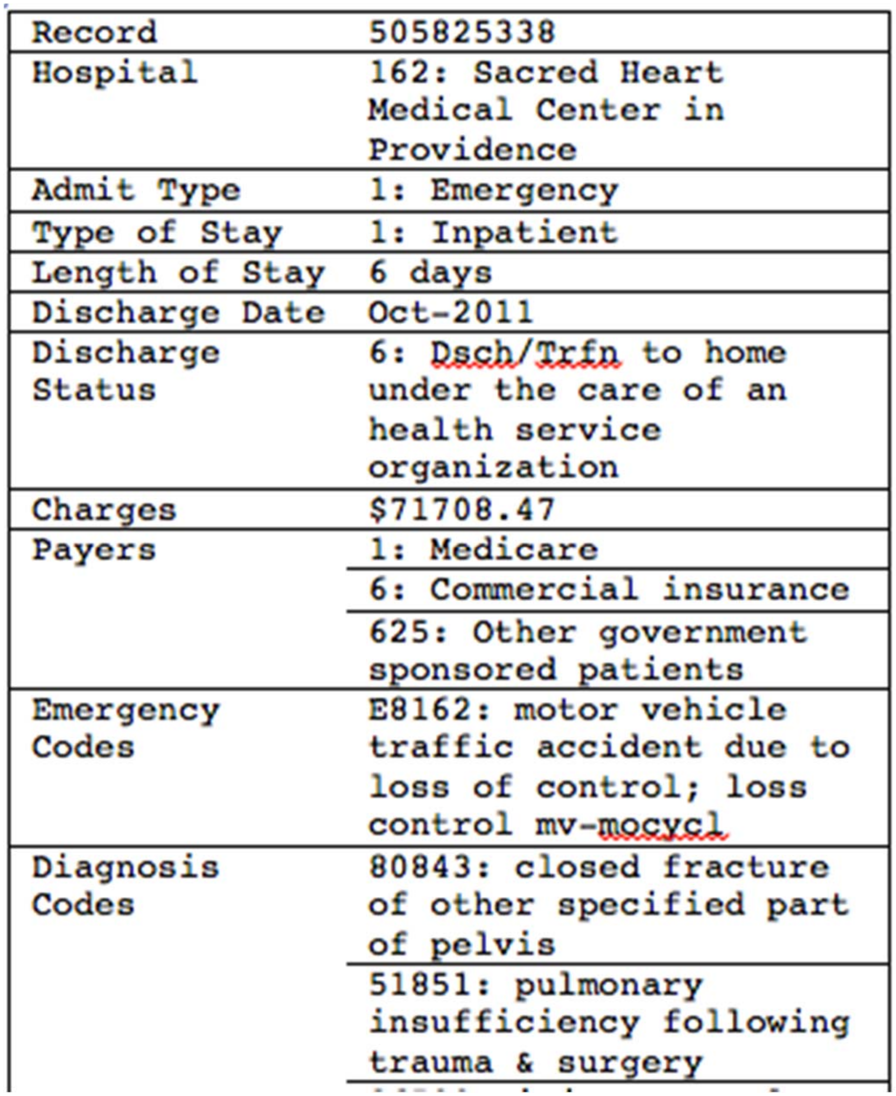
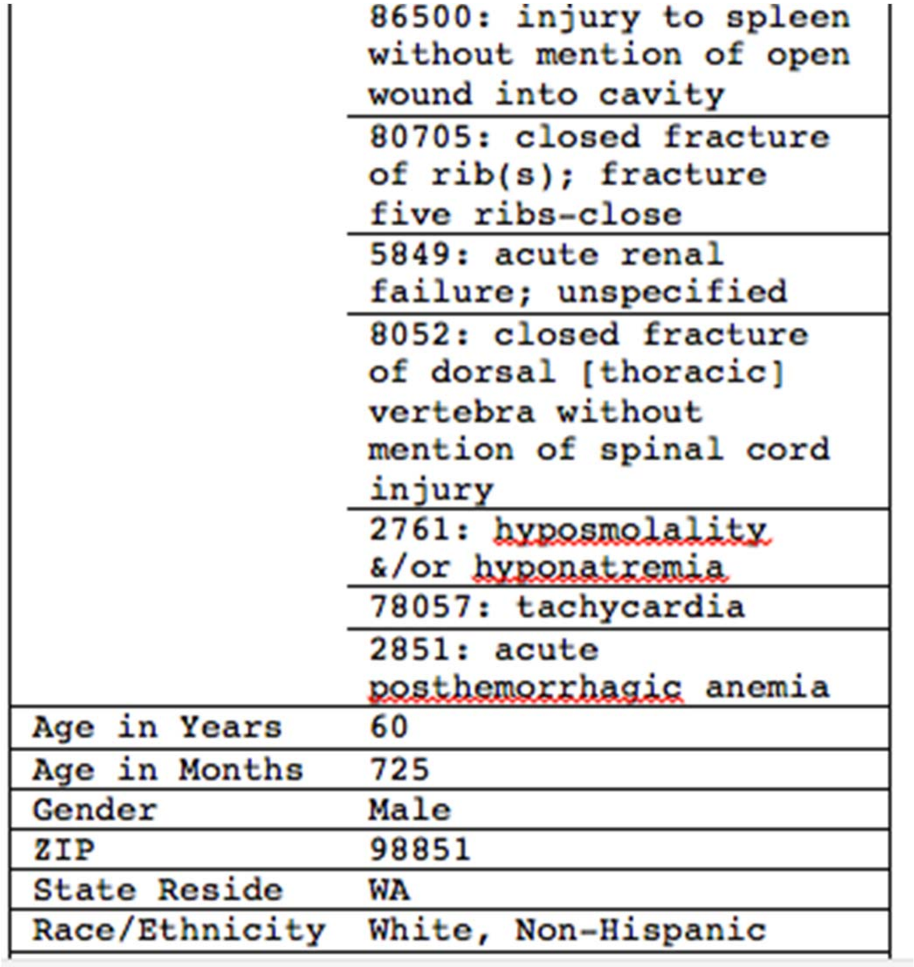


Top buyers of Publicly Available State Health Databases

Purchaser	States that Sold Purchaser Data
Truven Health Analytics	AZ, CA, FL, IL, MD, MA, NJ, NY, PA, TN, WA
Optuminsight (Ingenix)	CA, FL, IL, MD, MA, NJ, NY, PA, TX, WA
Milliman	AZ, CA, FL, IL, MD, MA, NY, TN, TX, WA
WebMD Health	AZ, CA, IL, MD, NJ, NY, PA, TN, WA
IMS Health (SDI Health and Verispan)	AZ, FL, IL, MD, NJ, NY, PA, TN, WA
Intellimed International	AZ, CA, FL, MD, NY, TX, WA
Service Employees International Union (SEIU)	CA, FL, MD, MA, PA, TN, WA
DataBay Resources	CA, FL, MA, NY, PA, WA





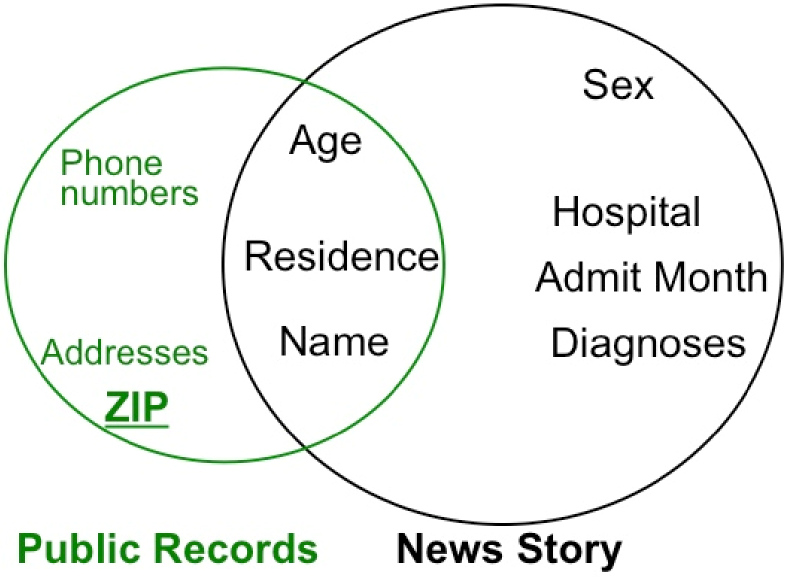
Record	505825338
Hospital	162: Sacred Heart Medical Center in Providence
Admit Type	1: Emergency
Type of Stay	1: Inpatient
Length of Stay	6 days
Discharge Date	Oct-2011
Discharge Status	6: Dsch/Trfn to home under the care of an health service organization
Charges	$71708.47
Payers	1: Medicare
	6: Commercial insurance
	625: Other government sponsored patients
Emergency Codes	E8162: motor vehicle traffic accident due to loss of control; loss control mv-mocycl
Diagnosis Codes	80843: closed fracture of other specified part of pelvis
	51851: pulmonary insufficiency following trauma & surgery
	86500: injury to spleen without mention of open wound into cavity
	80705: closed fracture of rib(s); fracture five ribs-close
	5849: acute renal failure; unspecified
	8052: closed fracture of dorsal [thoracic] vertebra without mention of spinal cord injury
	2761: hyposmolality &/or hyponatremia
	78057: tachycardia
	2851: acute posthemorrhagic anemia
Age in Years	60
Age in Months	725
Gender	Male
ZIP	98851
State Reside	WA
Race/Ethnicity	White, Non-Hispanic

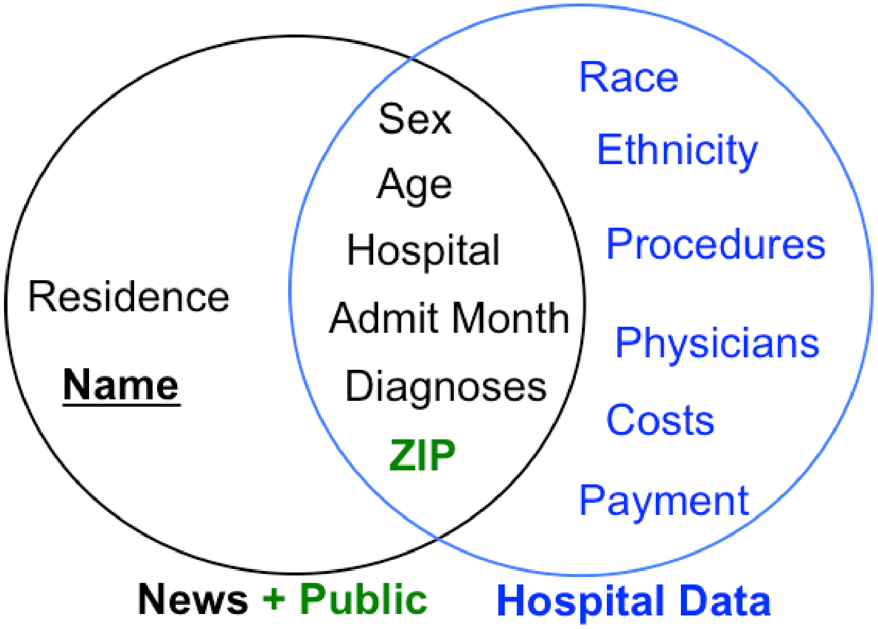
MAN, 60, THROWN FROM MOTORCYCLE

A 60-year-old Soap Lake man was hospitalized Saturday afternoon after he was thrown from his motorcycle. Ronald Jameson was riding his 2003 Harley-Davidson north on Highway 25, when he failed to negotiate a curve to the left. His motorcycle became airborne before landing in a wooded area. Jameson was thrown from the bike; he was wearing a helmet during the 12:24 p.m. incident. He was taken to Sacred Heart Hospital. The police cited speed as the cause of the crash.

[News Review 10/18/2011]

Washington State Health Database
43% news stories re-identified





News stories have same information that others know.
Employers, Creditors, Family, Friends and Neighbors

Transparency Establishes Trust

A Snapshot of Data Sharing by Select Health and Fitness Apps

FTC Staff's Preliminary Observations

SPRING PRIVACY SERIES

Consumer Generated and
Controlled Health Data

MAY 7, 2014

Jah-Juin "Jared" Ho
Sheryl Novick
Mobile Technology Unit
Federal Trade Commission

Christina Yeung
Division of Planning and Information
Federal Trade Commission

Screen Size

DOB

Symptom Searches

Device Model

Age

Telephone #

Physician Searches

Language

Workout Routine

Height

Meals Eaten

Name

Calories Burned

Physical Address

Unique Device Identifier

Geolocation

Sleeping Patterns

Cadence

Weight

OS

E-mail Address

Hydration

IMEI

Username

Gender

Running Route

Walking Stride

MAC

Carrier Provider

Privacy Rights Clearinghouse

Mobile Health and Fitness Applications and Information Privacy- July 2013

- Examined 43 free and paid health and fitness apps
  - Wearables not included
- Traffic analysis and privacy policy review
- Findings:
  - 26% of the free apps and 40% of the paid apps did not have a privacy policy
  - 39% of the free apps and 30% of the paid apps sent data to someone not disclosed by the developer either in-app or in any privacy policy they found
  - 13% of the free apps and 10% of the paid apps encrypted all data connections between the app and the developer's website.
- Conclusion:

  "Our research brought us to the conclusion that, from a privacy perspective, mobile health and fitness applications are not particularly safe when it comes to protecting user privacy."

Source: https://www.privacyrights.org/mobile-medical-apps-privacy-consumer-report.pdf

Evidon

A Healthy Data Set- September 2013

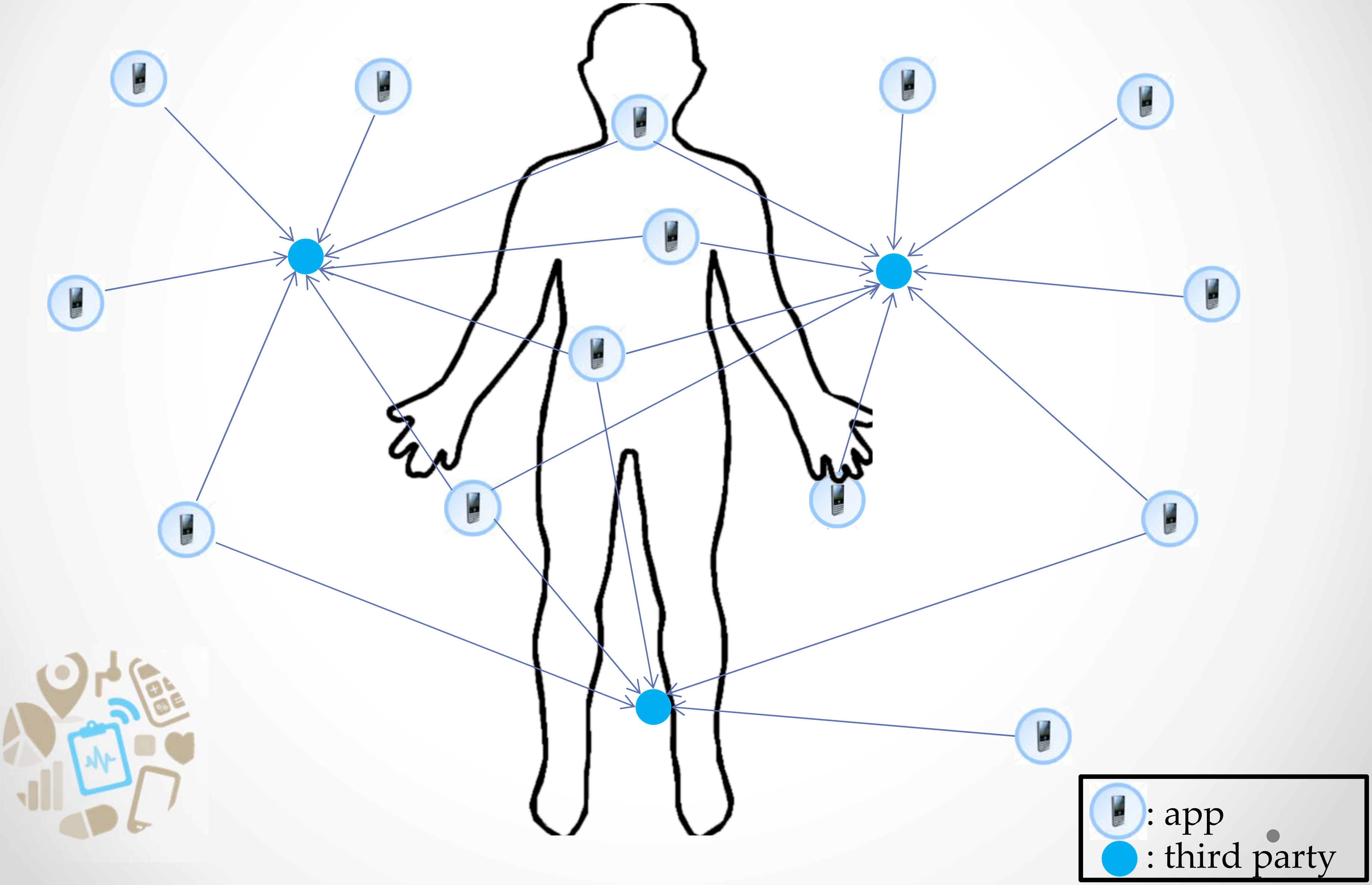
- Tested 20 health and fitness apps
- Found the presence of 70 third parties

- “These companies are typically advertising and analytics companies, who attempt to better match advertisements to users who will buy; and who work to help app developers increase functionality and usability, respectively.”

Source: http://www.evidon.com/blog/healthy-data-set

WHO and WHAT?

Reconceptualizing the Evidon Study



📱 : app

● : third party

Health & Fitness App Snapshot

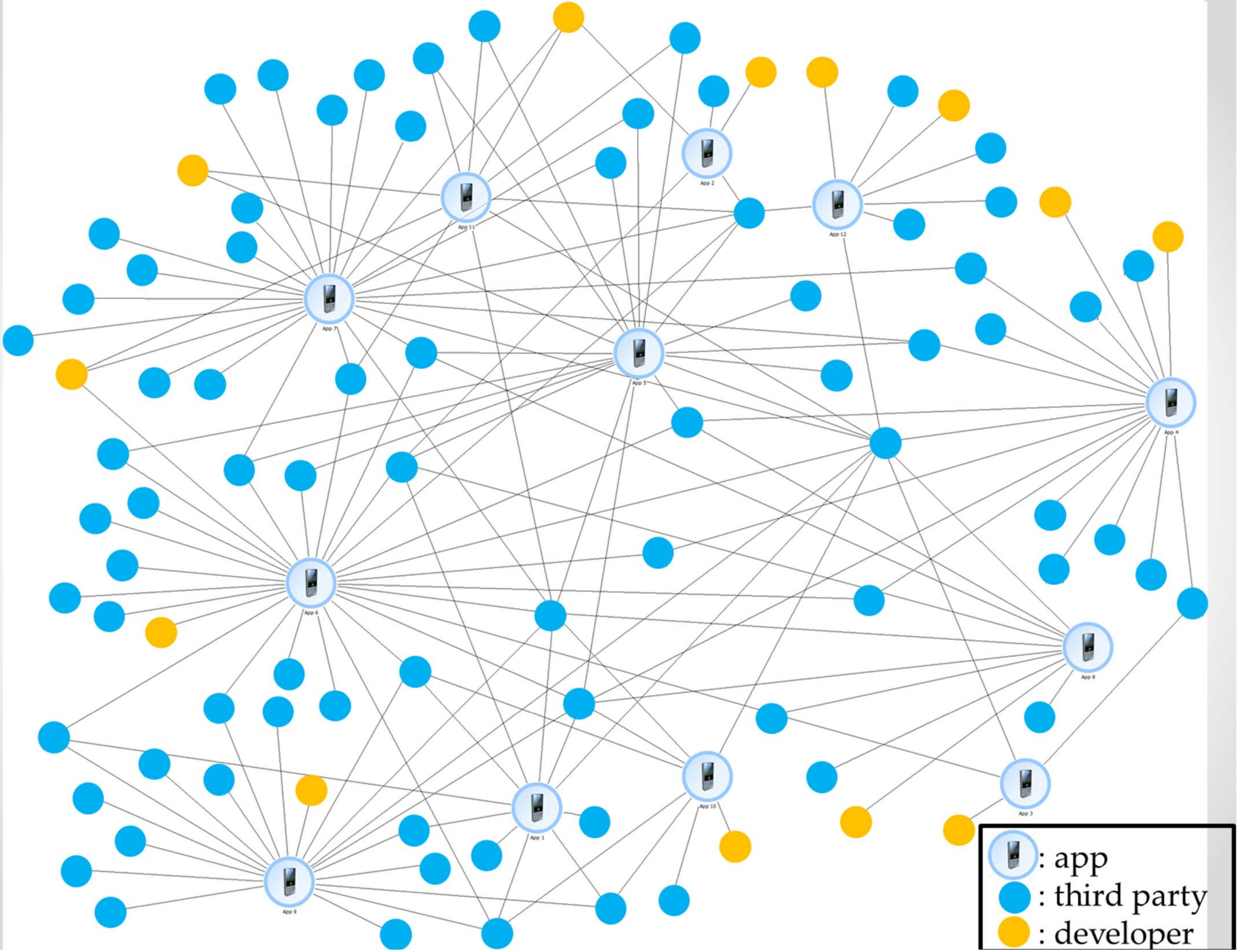
Methodology

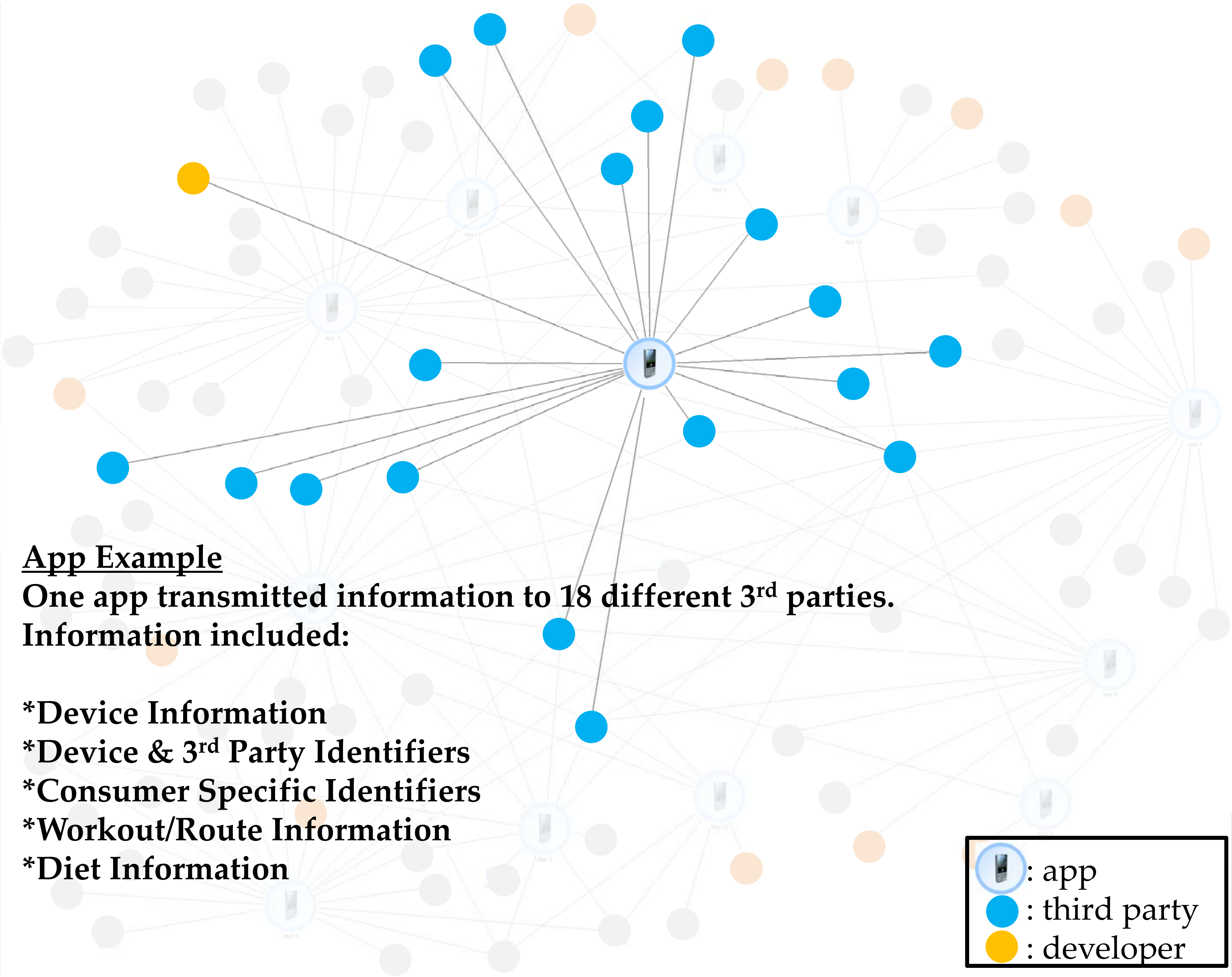
- Twelve apps and two wearables
- App traffic analysis
- Mapped the data sets

Health & Fitness App Snapshot

Limitations

- One device
- Only Free Apps
- Front-end testing only
- Did not review privacy policies


App 2
App 11
App 12
App 7
App 5
App 4
App 6
App 8
App 10
App 3
App 1
App 9
: app
: third party
: developer



App Example

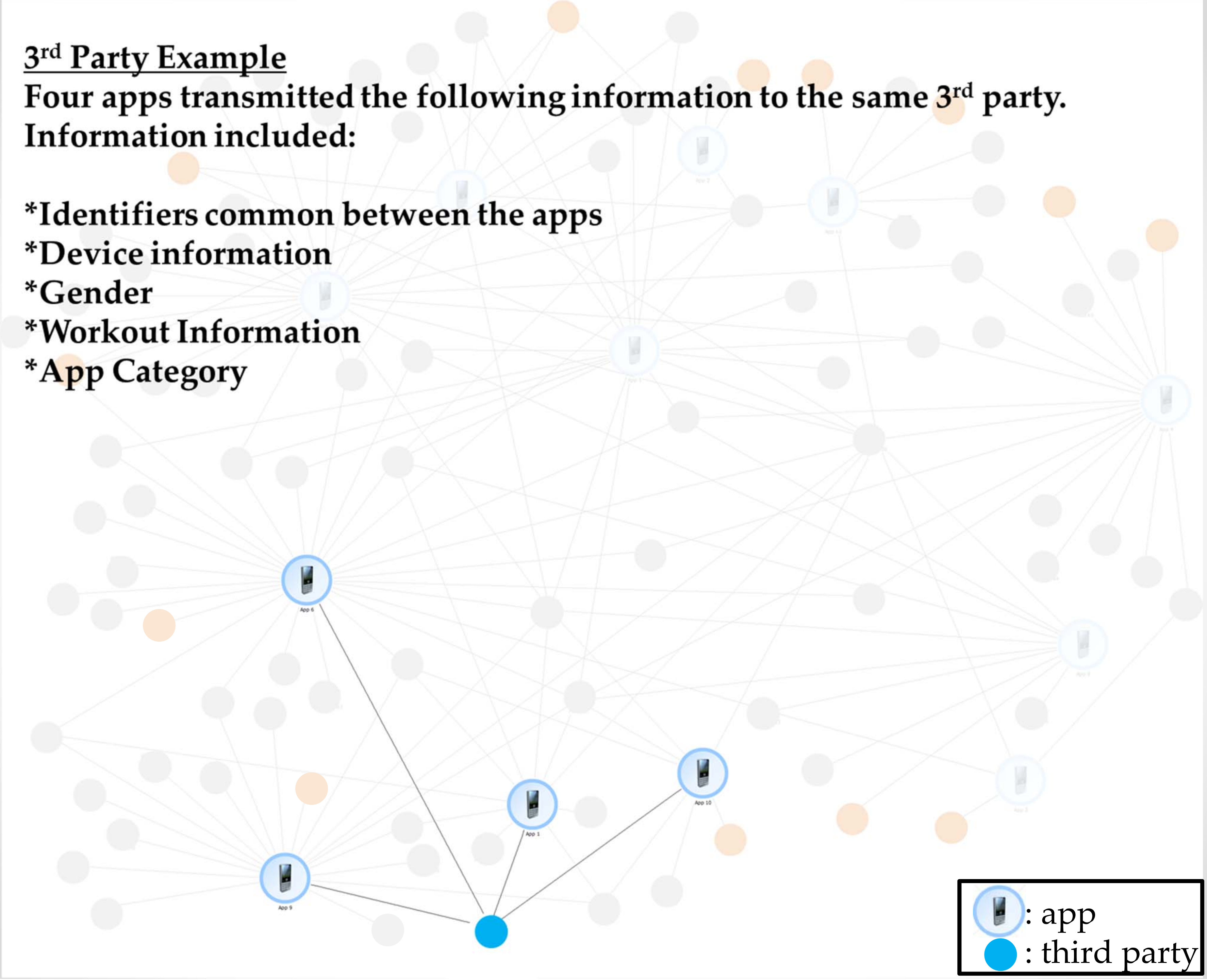
One app transmitted information to 18 different 3rd parties.
Information included:

***Device Information**
***Device & 3rd Party Identifiers**
***Consumer Specific Identifiers**
***Workout/Route Information**
***Diet Information**

3rd Party Example

Four apps transmitted the following information to the same 3rd party.
Information included:

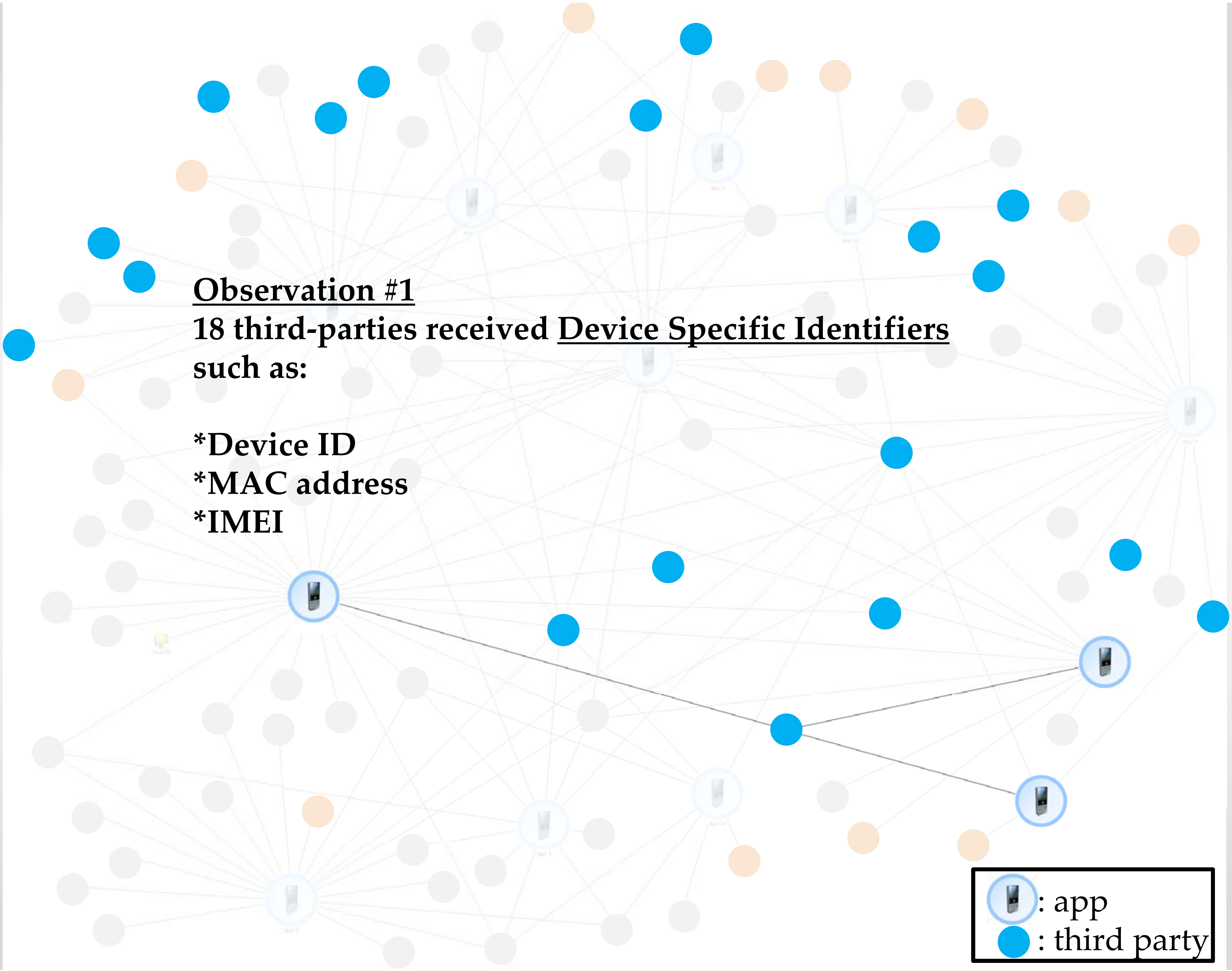
***Identifiers common between the apps**
***Device information**
***Gender**
***Workout Information**
***App Category**

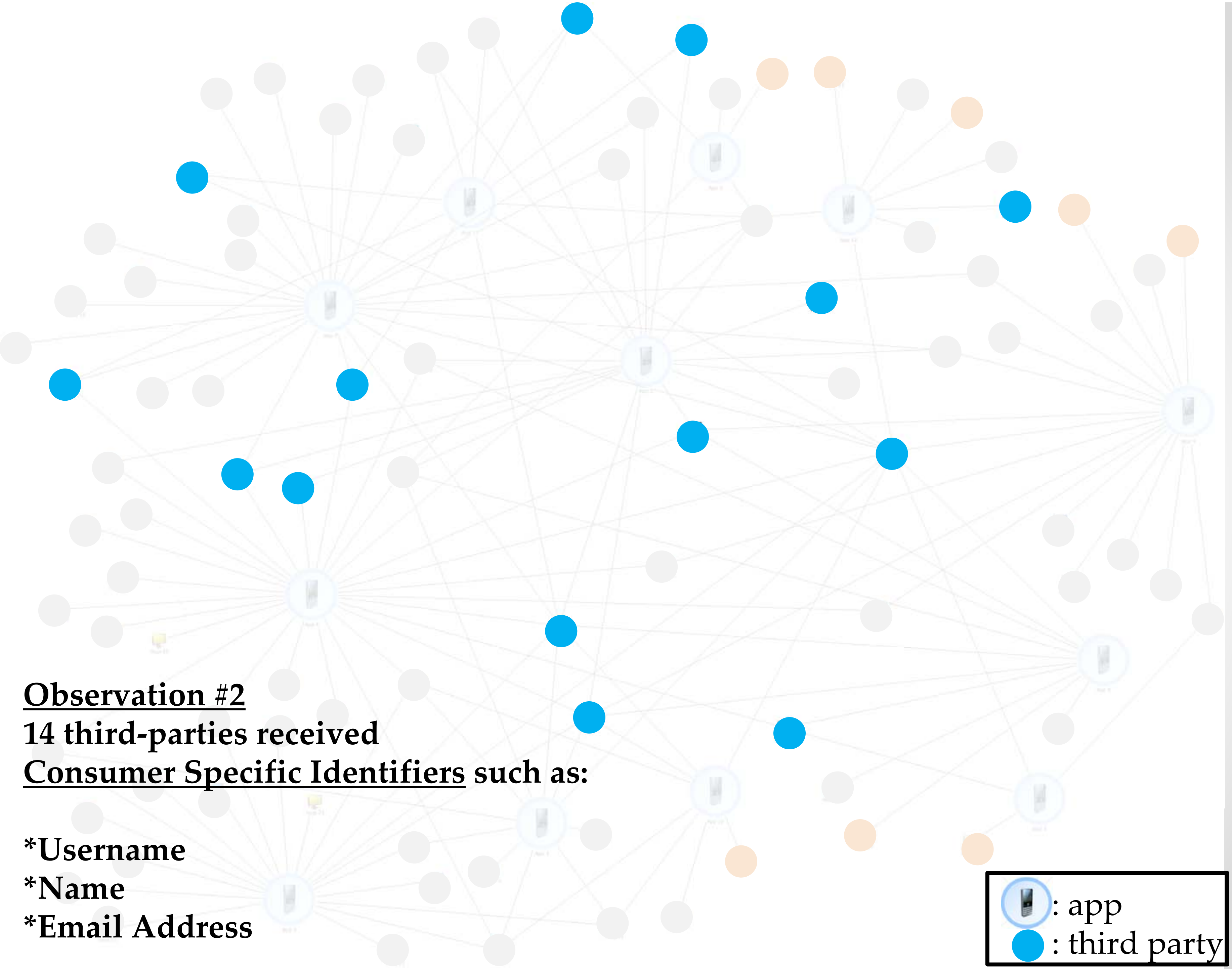


Observation #1

18 third-parties received **Device Specific Identifiers** such as:

*Device ID
*MAC address
*IMEI

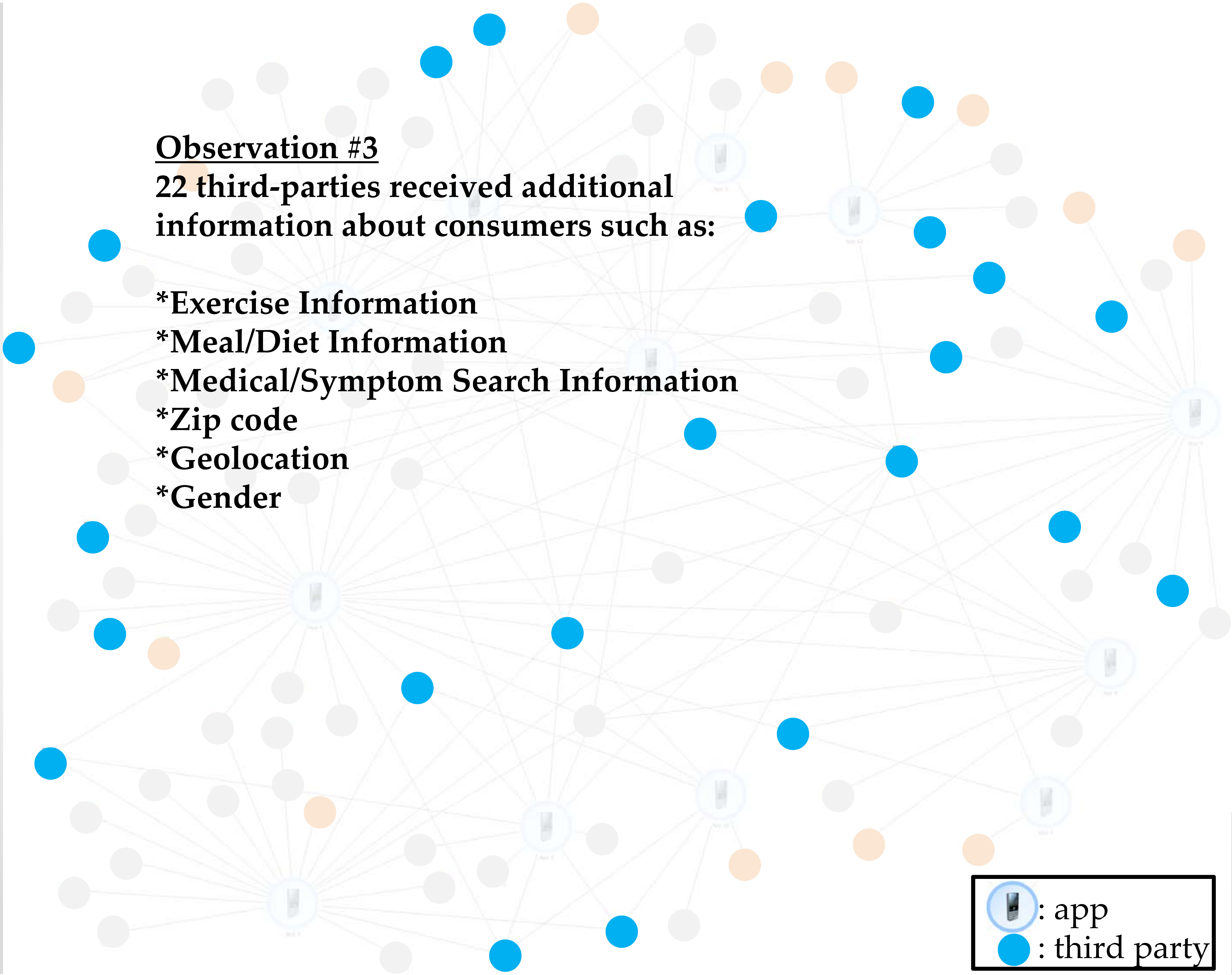




Observation #2

14 third-parties received
Consumer Specific Identifiers such as:

*Username
*Name
*Email Address



Observation #3

22 third-parties received additional information about consumers such as:

***Exercise Information**
***Meal/Diet Information**
***Medical/Symptom Search Information**
***Zip code**
***Geolocation**
***Gender**

Summary of Observations

- Health and fitness apps collect and transmit to third parties sensitive information about our bodies and our habits.

- The 12 apps tested transmitted information to 76 different third-parties. This information included:

  -Device Information;

  -Consumer specific identifiers;

  -Unique device IDs capable of allowing 3rd parties to track users' devices across apps;

  -Unique 3rd party IDs capable of allowing 3rd parties to track users' devices across apps; and

  -Consumer information such as exercise routine, dietary habits, and symptom searches.

- There are significant privacy implications where health routines, dietary habits, and symptom searches are capable of being aggregated using identifiers unique to that consumer.

Panel Discussion

- **Christopher R. Burrow**, M.D., EVP Medical Affairs, Humetrix
- **Joseph Lorenzo Hall**, Chief Technologist, Center for Democracy & Technology
- **Sally Okun**, RN, MMHS, Vice President of Advocacy, Policy & Patient Safety, PatientsLikeMe
- **Heather Patterson**, Postdoctoral Research Fellow, New York University
- **Joy Pritts**, Chief Privacy Officer, Office of the National Coordinator for Health Information Technology, Department of Health & Human Services

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Consumer Generated and Controlled Health Data

MAY 7, 2014

humetrix®

ONC I2 Award Winner™

BlueButton®

Mobile Anytime/Anywhere Access to Personal Health Records

FEDERAL TRADE COMMISSION
PROTECTING AMERICA'S CONSUMERS

100 YEARS

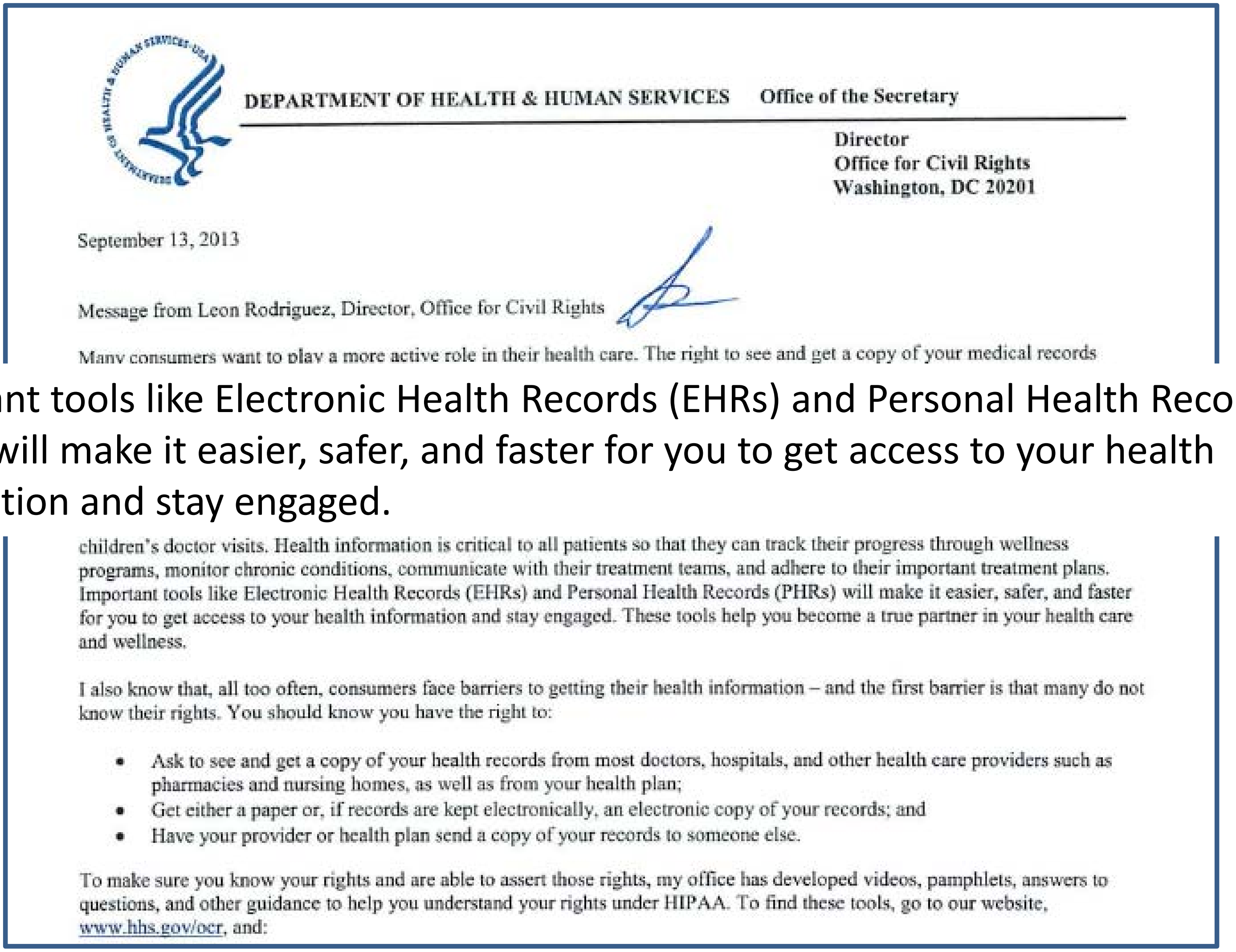
SPRING PRIVACY SERIES

Consumer Generated and Controlled Health Data

MAY 7, 2014

Access to e-Health Records is a Right Ensured by HIPAA

Important tools like Electronic Health Records (EHRs) and Personal Health Records (PHRs) will make it easier, safer, and faster for you to get access to your health information and stay engaged.



DEPARTMENT OF HEALTH & HUMAN SERVICES Office of the Secretary

Director
Office for Civil Rights
Washington, DC 20201

September 13, 2013

Message from Leon Rodriguez, Director, Office for Civil Rights

Many consumers want to play a more active role in their health care. The right to see and get a copy of your medical records

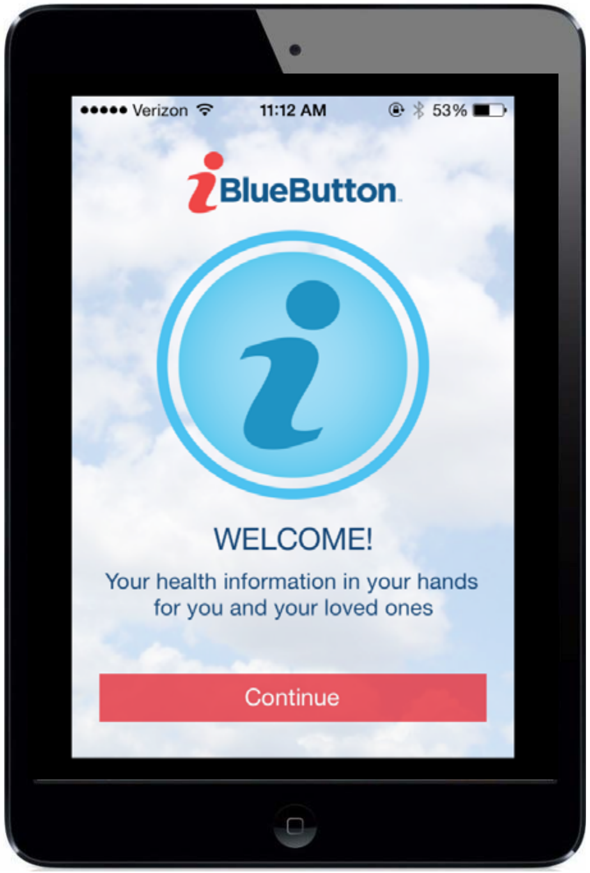
children's doctor visits. Health information is critical to all patients so that they can track their progress through wellness programs, monitor chronic conditions, communicate with their treatment teams, and adhere to their important treatment plans. Important tools like Electronic Health Records (EHRs) and Personal Health Records (PHRs) will make it easier, safer, and faster for you to get access to your health information and stay engaged. These tools help you become a true partner in your health care and wellness.

I also know that, all too often, consumers face barriers to getting their health information – and the first barrier is that many do not know their rights. You should know you have the right to:

- Ask to see and get a copy of your health records from most doctors, hospitals, and other health care providers such as pharmacies and nursing homes, as well as from your health plan;
- Get either a paper or, if records are kept electronically, an electronic copy of your records; and
- Have your provider or health plan send a copy of your records to someone else.

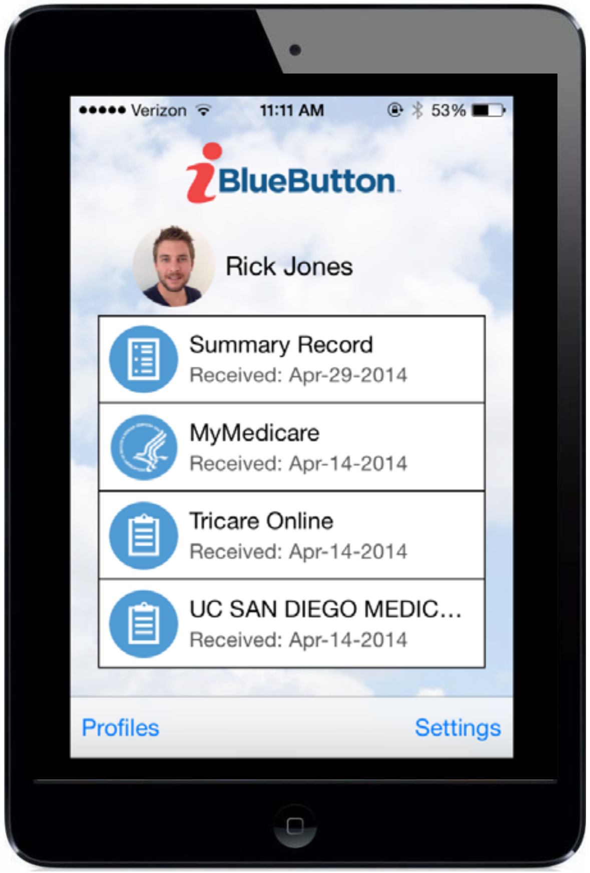
To make sure you know your rights and are able to assert those rights, my office has developed videos, pamphlets, answers to questions, and other guidance to help you understand your rights under HIPAA. To find these tools, go to our website, www.hhs.gov/ocr, and:

iBlueButton Display & Aggregation of TRICARE, VA, Medicare Blue Button and EMR Records (Epic, Cerner, Allscripts etc…)



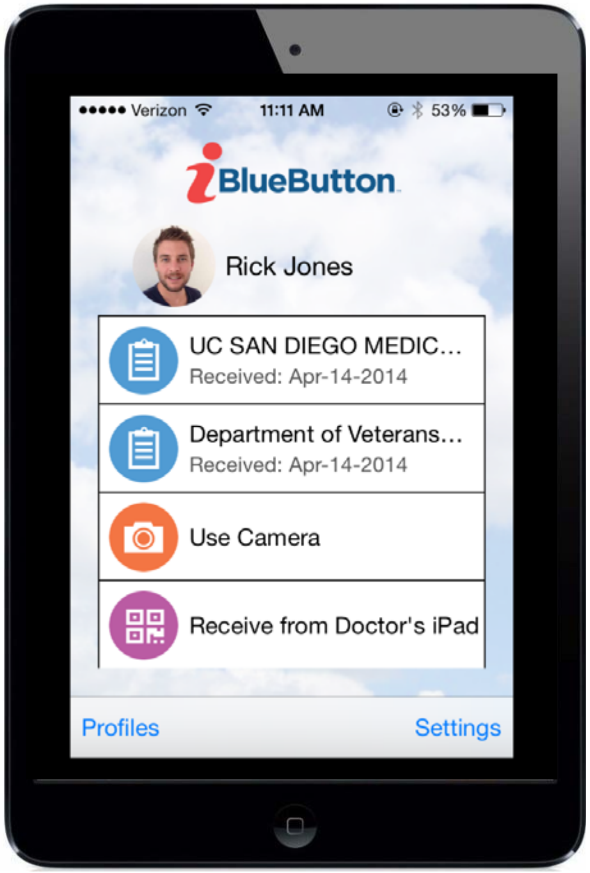
WELCOME!

Your health information in your hands
for you and your loved ones



Rick Jones

- Summary Record
  Received: Apr-29-2014
- MyMedicare
  Received: Apr-14-2014
- Tricare Online
  Received: Apr-14-2014
- UC SAN DIEGO MEDIC…
  Received: Apr-14-2014

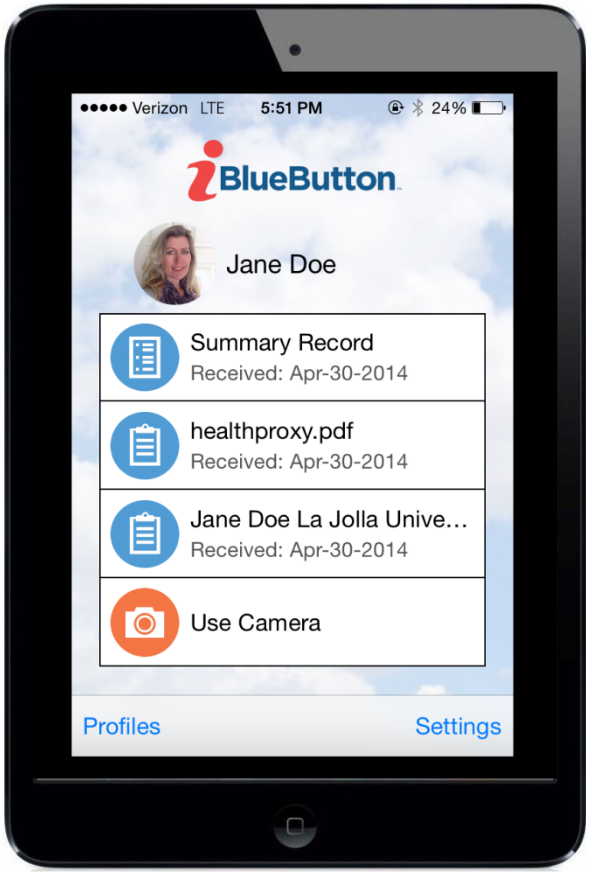


Rick Jones

- UC SAN DIEGO MEDIC…
  Received: Apr-14-2014
- Department of Veterans…
  Received: Apr-14-2014
- Use Camera
- Receive from Doctor's iPad

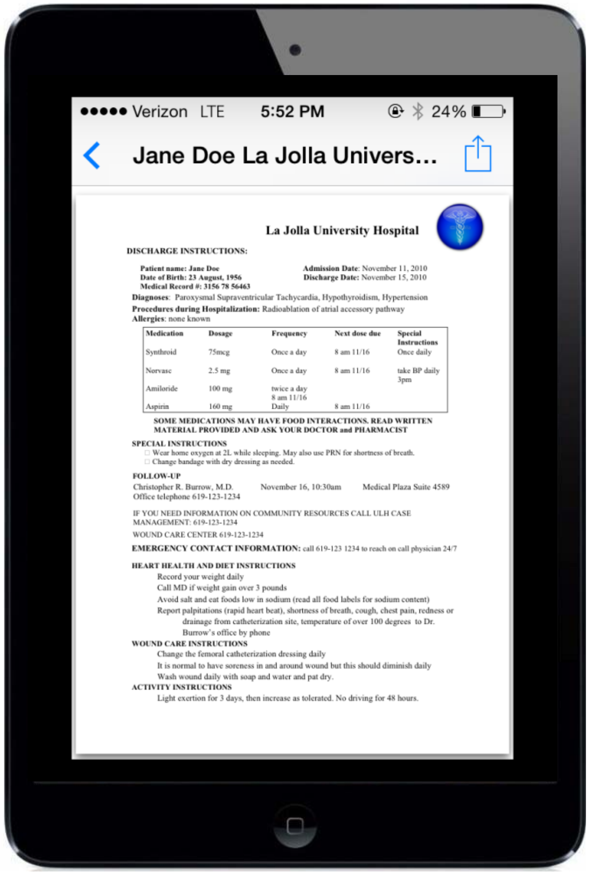
humetrix®

Patient Generated Data
Health Care Proxy and Prior Discharge Summaries
Imported into iBlueButton



Jane Doe

- Summary Record Received: Apr-30-2014
- healthproxy.pdf Received: Apr-30-2014
- Jane Doe La Jolla Unive… Received: Apr-30-2014
- Use Camera



La Jolla University Hospital

DISCHARGE INSTRUCTIONS:

Patient name: Jane Doe **Admission Date**: November 11, 2010
Date of Birth: 23 August, 1956 **Discharge Date:** November 15, 2010
Medical Record #: 3156 78 56463

Diagnoses: Paroxysmal Supraventricular Tachycardia, Hypothyroidism, Hypertension
Procedures during Hospitalization: Radioablation of atrial accessory pathway
Allergies: none known

Medication	Dosage	Frequency	Next dose due	Special Instructions
Synthroid	75mcg	Once a day	8 am 11/16	Once daily
Norvasc	2.5 mg	Once a day	8 am 11/16	take BP daily 3pm
Amiloride	100 mg	twice a day 8 am 11/16		
Aspirin	160 mg	Daily	8 am 11/16	

SOME MEDICATIONS MAY HAVE FOOD INTERACTIONS. READ WRITTEN MATERIAL PROVIDED AND ASK YOUR DOCTOR and PHARMACIST

SPECIAL INSTRUCTIONS

□ Wear home oxygen at 2L while sleeping. May also use PRN for shortness of breath.
□ Change bandage with dry dressing as needed.

FOLLOW-UP

Christopher R. Burrow, M.D. November 16, 10:30am Medical Plaza Suite 4589
Office telephone 619-123-1234

IF YOU NEED INFORMATION ON COMMUNITY RESOURCES CALL ULH CASE MANAGEMENT: 619-123-1234

WOUND CARE CENTER 619-123-1234

EMERGENCY CONTACT INFORMATION: call 619-123 1234 to reach on call physician 24/7

HEART HEALTH AND DIET INSTRUCTIONS

Record your weight daily
Call MD if weight gain over 3 pounds
Avoid salt and eat foods low in sodium (read all food labels for sodium content)
Report palpitations (rapid heart beat), shortness of breath, cough, chest pain, redness or drainage from catheterization site, temperature of over 100 degrees to Dr. Burrow's office by phone

WOUND CARE INSTRUCTIONS

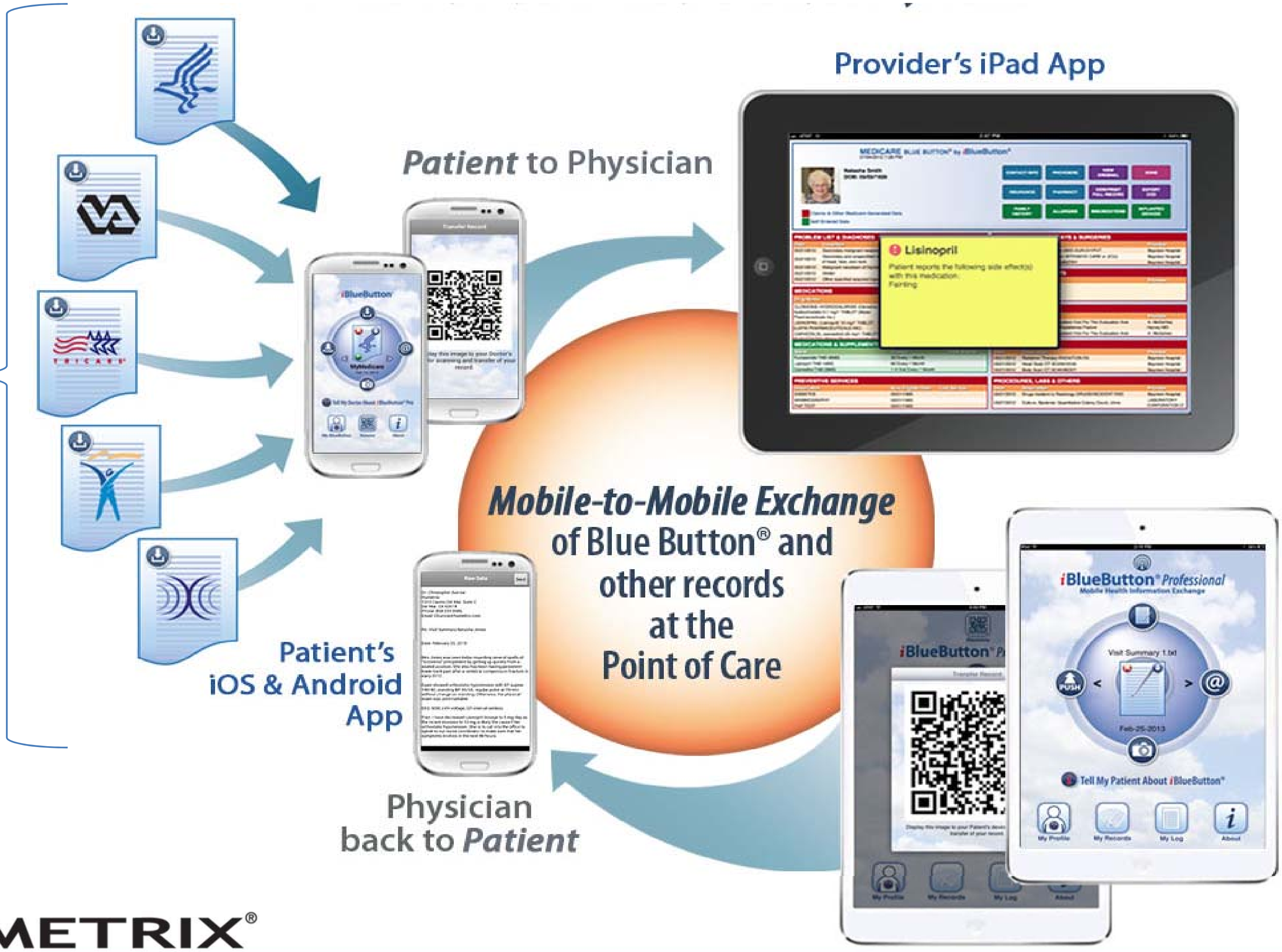
Change the femoral catheterization dressing daily
It is normal to have soreness in and around wound but this should diminish daily
Wash wound daily with soap and water and pat dry.

ACTIVITY INSTRUCTIONS

Light exertion for 3 days, then increase as tolerated. No driving for 48 hours.

Consumer-Controlled Mobile Health Record Access & Exchange

EHRs from diverse sources (e.g. hospitals, payers, HCP groups)



Provider's iPad App

Patient to Physician

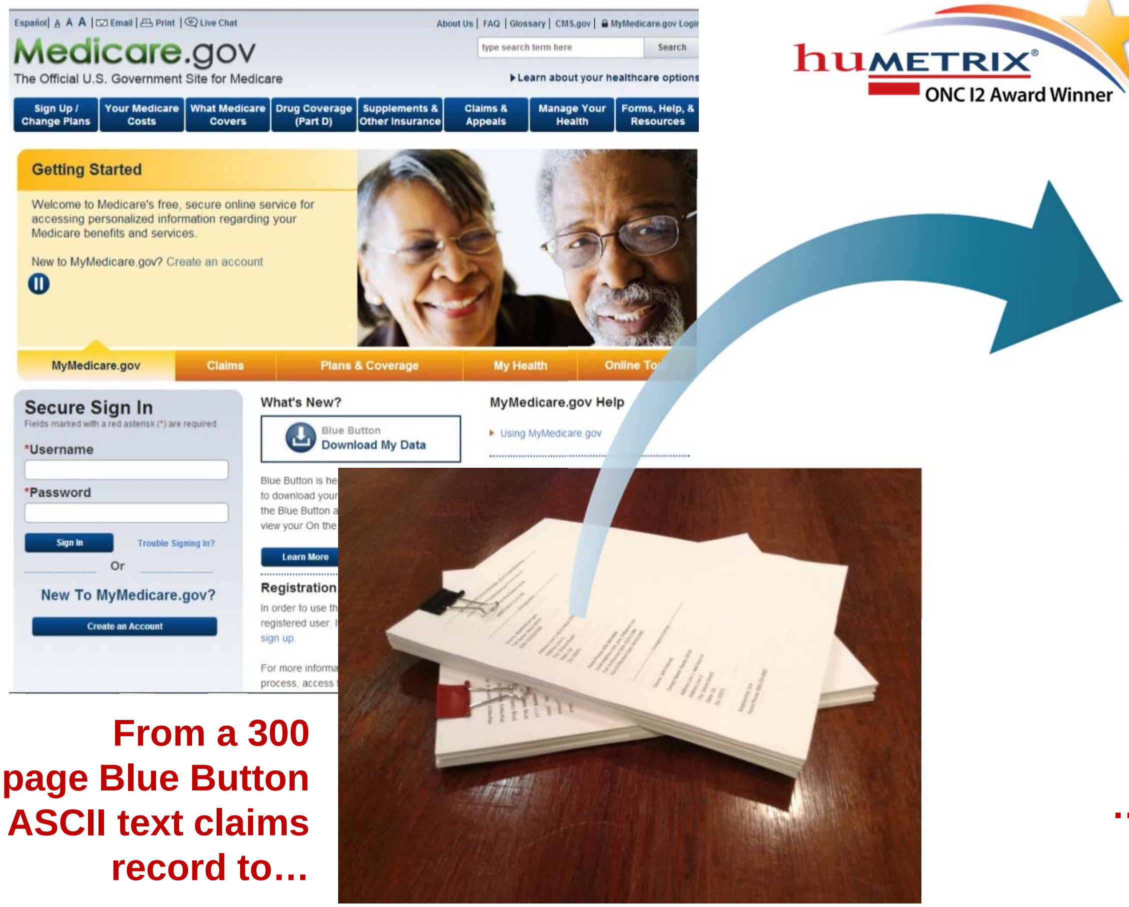
Patient's iOS & Android App

Mobile-to-Mobile Exchange of Blue Button® and other records at the Point of Care

Physician back to *Patient*

iBlueButton for Medicare Beneficiaries: Three Years of Medical History in Patients’ Hands for their Safety

From Blue Button… to iBlueButton®



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Medicare.gov

The Official U.S. Government Site for Medicare

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New to MyMedicare.gov? Create an account

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Secure Sign In

Fields marked with a red asterisk (*) are required

*Username

*Password

Sign In | Trouble Signing In?

Or

New To MyMedicare.gov?

Create an Account

What's New?

Blue Button Download My Data

Blue Button is he… to download your… the Blue Button a… view your On the…

Learn More

Registration

In order to use th… registered user. I… sign up.

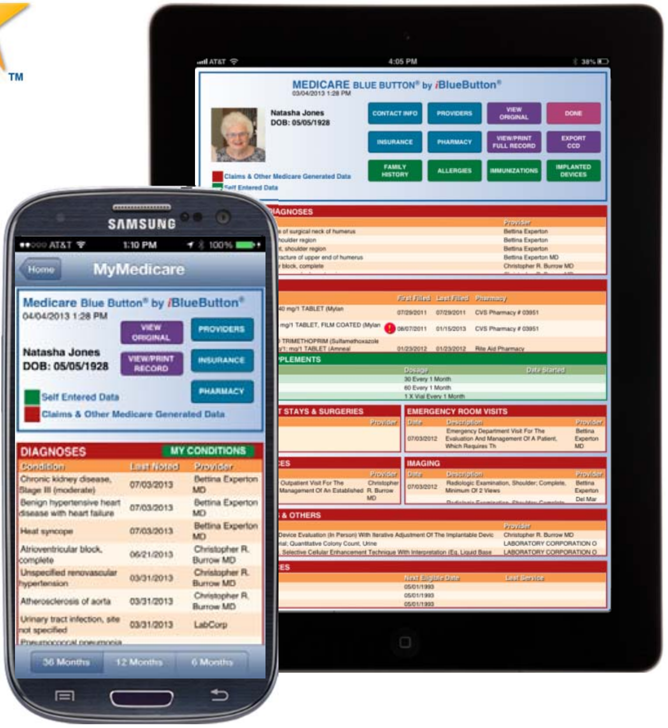
For more informa… process, access t…

MyMedicare.gov Help

Using MyMedicare.gov

From a 300 page Blue Button ASCII text claims record to…

humetrix® ONC I2 Award Winner™



MEDICARE BLUE BUTTON® by iBlueButton®

03/04/2013 1:28 PM

Natasha Jones

DOB: 05/05/1928

CONTACT INFO | PROVIDERS | VIEW ORIGINAL | DONE

INSURANCE | PHARMACY | VIEW/PRINT FULL RECORD | EXPORT CCD

FAMILY HISTORY | ALLERGIES | IMMUNIZATIONS | IMPLANTED DEVICES

🟥 Claims & Other Medicare Generated Data

🟩 Self Entered Data

MyMedicare

Home

Medicare Blue Button® by iBlueButton®

04/04/2013 1:28 PM

Natasha Jones

DOB: 05/05/1928

VIEW ORIGINAL | PROVIDERS

VIEW/PRINT RECORD | INSURANCE

PHARMACY

🟩 Self Entered Data

🟥 Claims & Other Medicare Generated Data

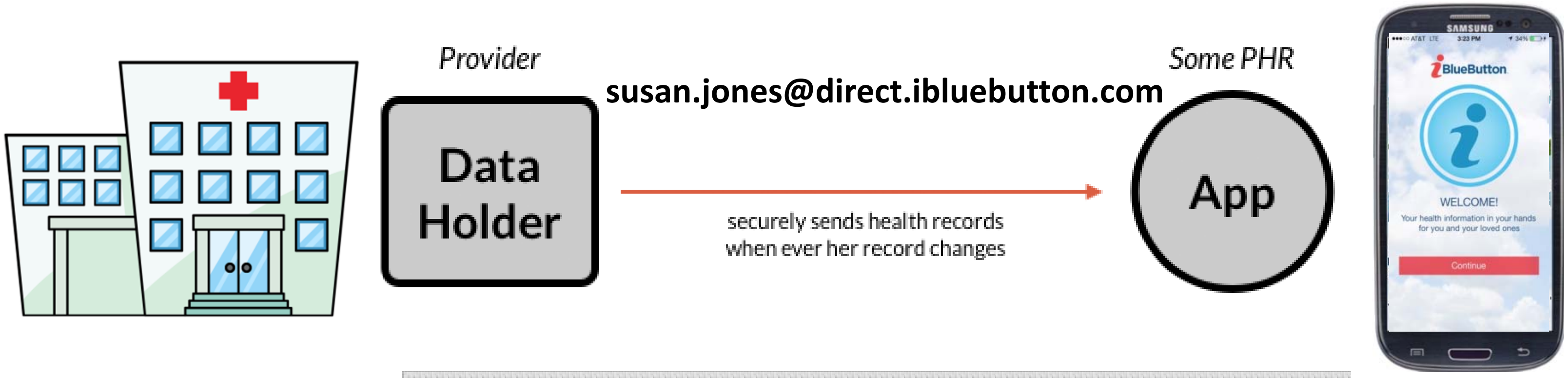
DIAGNOSES — MY CONDITIONS

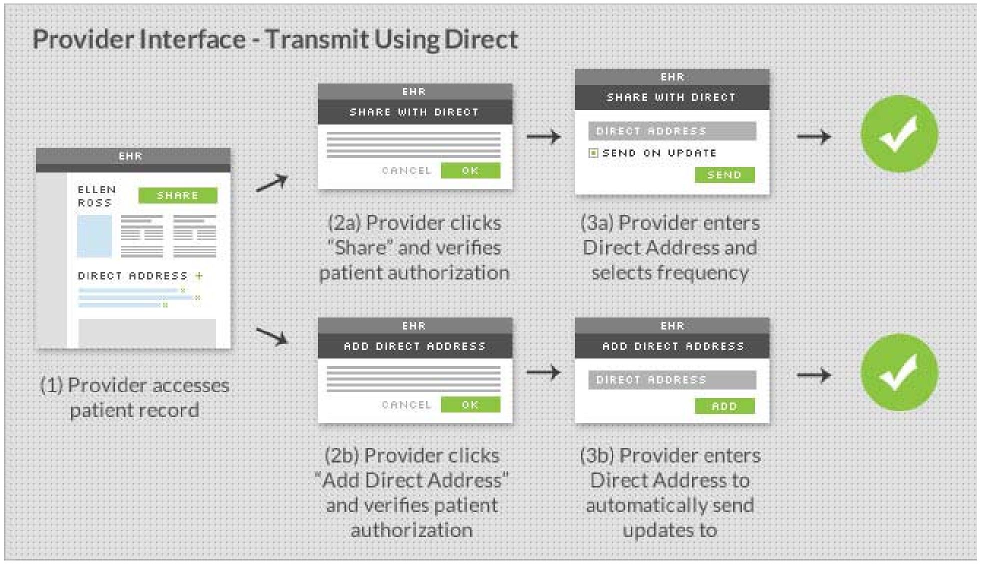
Condition	Last Noted	Provider
Chronic kidney disease, Stage III (moderate)	07/03/2013	Bettina Experton MD
Benign hypertensive heart disease with heart failure	07/03/2013	Bettina Experton MD
Heat syncope	07/03/2013	Bettina Experton MD
Atrioventricular block, complete	06/21/2013	Christopher R. Burrow MD
Unspecified renovascular hypertension	03/31/2013	Christopher R. Burrow MD
Atherosclerosis of aorta	03/31/2013	Christopher R. Burrow MD
Urinary tract infection, site not specified	03/31/2013	LabCorp
Pneumococcal pneumonia		

36 Months | 12 Months | 6 Months

…a mobile longitudinal health record available at every Point of Care

Providers Transmit Records to their Patients' Unique iBlueButton Address using the Secure Federal Direct Transport Standard


Provider
Data Holder
susan.jones@direct.ibluebutton.com
securely sends health records when ever her record changes
Some PHR
App
SAMSUNG
iBlueButton
WELCOME!
Your health information in your hands for you and your loved ones
Continue


Provider Interface - Transmit Using Direct

(1) Provider accesses patient record

(2a) Provider clicks "Share" and verifies patient authorization

(3a) Provider enters Direct Address and selects frequency

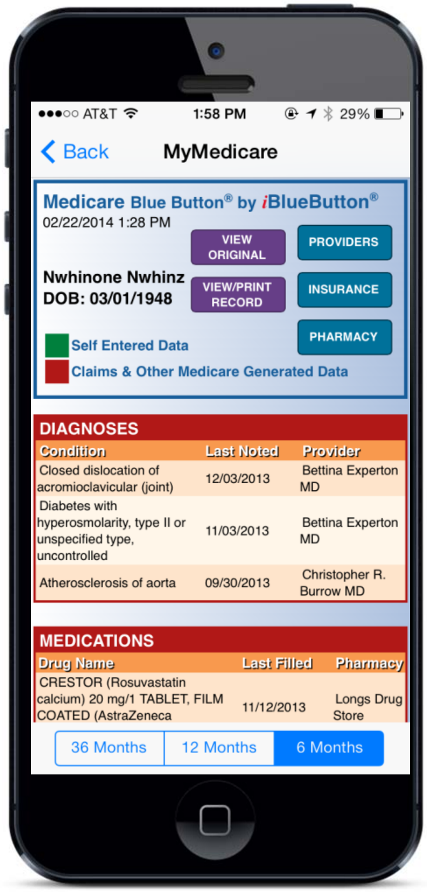
(2b) Provider clicks "Add Direct Address" and verifies patient authorization

(3b) Provider enters Direct Address to automatically send updates to

iBlueButton App generates a Direct Address for each Profile

huMETRIX®

iBlueButton: Display of Medicare, EMR, VA and TRICARE records with Real Time Aggregated View



Medicare Blue Button® by iBlueButton®
02/22/2014 1:28 PM

Nwhinone Nwhinz
DOB: 03/01/1948

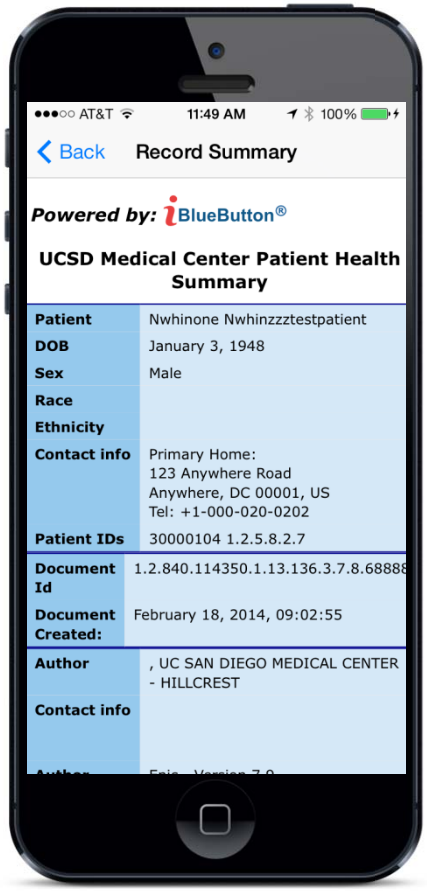
🟩 Self Entered Data
🟥 Claims & Other Medicare Generated Data

DIAGNOSES

Condition	Last Noted	Provider
Closed dislocation of acromioclavicular (joint)	12/03/2013	Bettina Experton MD
Diabetes with hyperosmolarity, type II or unspecified type, uncontrolled	11/03/2013	Bettina Experton MD
Atherosclerosis of aorta	09/30/2013	Christopher R. Burrow MD

MEDICATIONS

Drug Name	Last Filled	Pharmacy
CRESTOR (Rosuvastatin calcium) 20 mg/1 TABLET, FILM COATED (AstraZeneca	11/12/2013	Longs Drug Store



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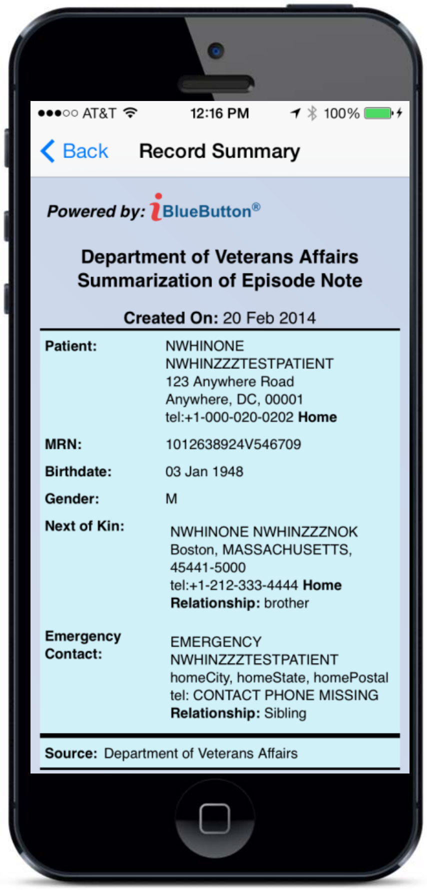
UCSD Medical Center Patient Health Summary

Patient	Nwhinone Nwhinzzztestpatient
DOB	January 3, 1948
Sex	Male
Race	
Ethnicity	
Contact info	Primary Home: 123 Anywhere Road Anywhere, DC 00001, US Tel: +1-000-020-0202
Patient IDs	30000104 1.2.5.8.2.7
Document Id	1.2.840.114350.1.13.136.3.7.8.68888
Document Created:	February 18, 2014, 09:02:55
Author	, UC SAN DIEGO MEDICAL CENTER - HILLCREST
Contact info	
Author	Epic - Version 7.0



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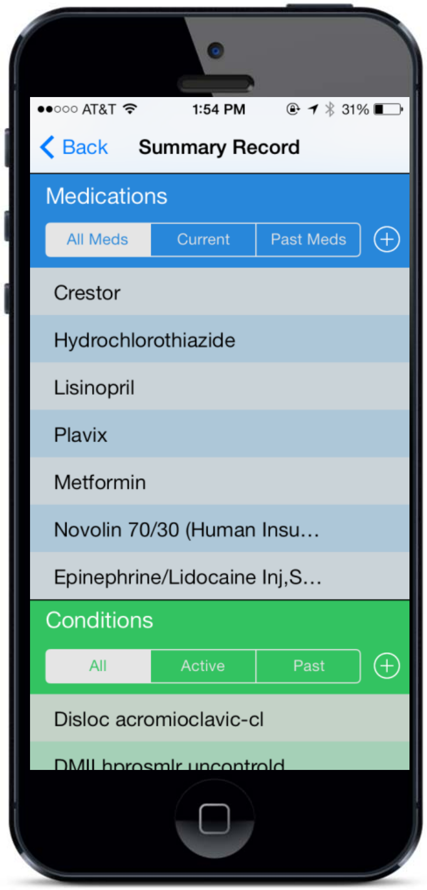
Department of Veterans Affairs Summarization of Episode Note

Created On: 20 Feb 2014

Patient:	NWHINONE NWHINZZZTESTPATIENT 123 Anywhere Road Anywhere, DC, 00001 tel:+1-000-020-0202 **Home**
MRN:	1012638924V546709
Birthdate:	03 Jan 1948
Gender:	M
Next of Kin:	NWHINONE NWHINZZZNOK Boston, MASSACHUSETTS, 45441-5000 tel:+1-212-333-4444 **Home** **Relationship:** brother
Emergency Contact:	EMERGENCY NWHINZZZTESTPATIENT homeCity, homeState, homePostal tel: CONTACT PHONE MISSING **Relationship:** Sibling

Source: Department of Veterans Affairs



Medications

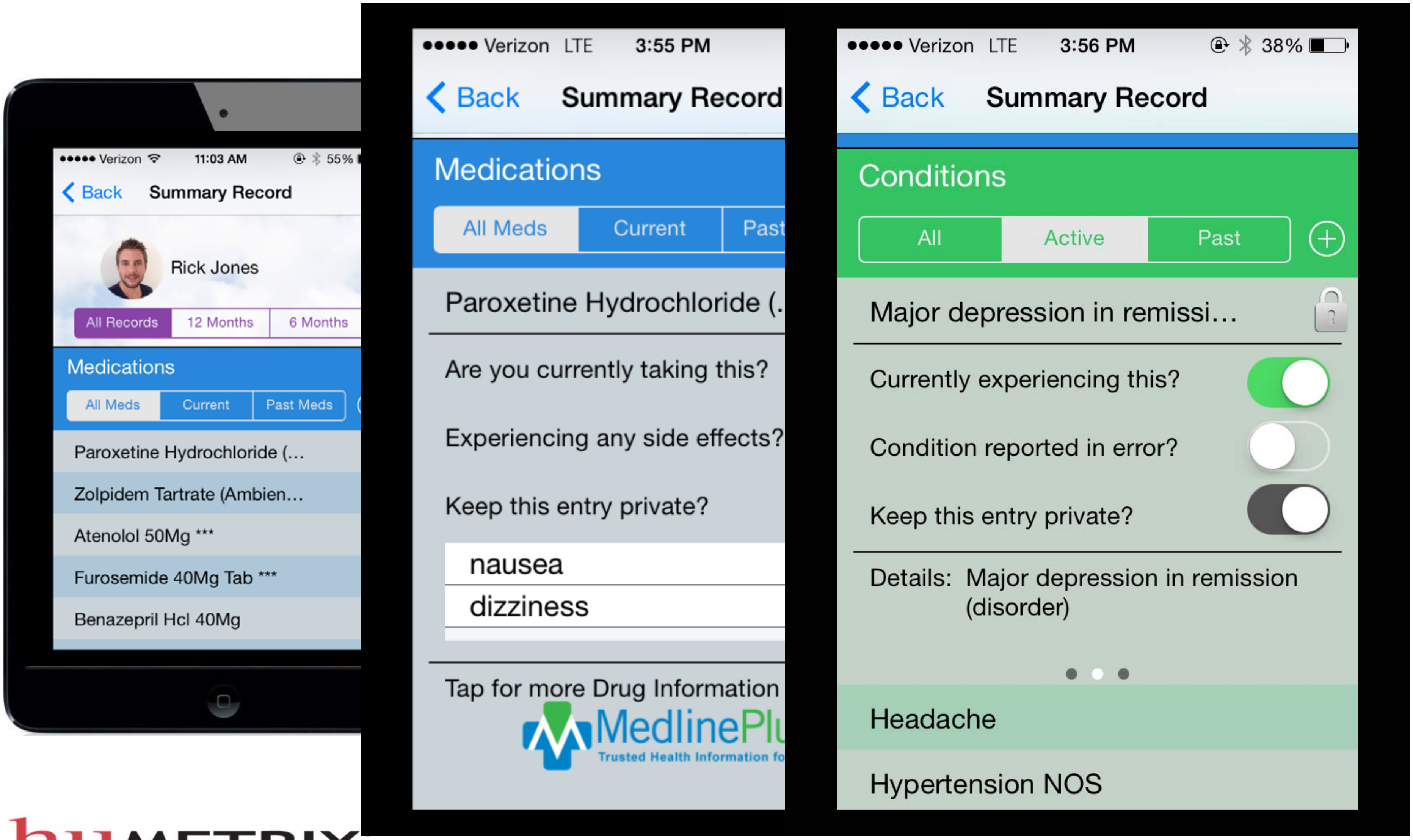
- Crestor
- Hydrochlorothiazide
- Lisinopril
- Plavix
- Metformin
- Novolin 70/30 (Human Insu…
- Epinephrine/Lidocaine Inj,S…

Conditions

- Disloc acromioclavic-cl
- DMII hprosmlr uncontrold

humetrix®

Patient Generated Data
Medication and Condition Annotations and Privacy Settings



Rick Jones

Paroxetine Hydrochloride (...

Zolpidem Tartrate (Ambien...

Atenolol 50Mg ***

Furosemide 40Mg Tab ***

Benazepril Hcl 40Mg

Paroxetine Hydrochloride (.

Are you currently taking this?

Experiencing any side effects?

Keep this entry private?

nausea

dizziness

Tap for more Drug Information

Major depression in remissi...

Currently experiencing this? ●

Condition reported in error? ○

Keep this entry private? ●

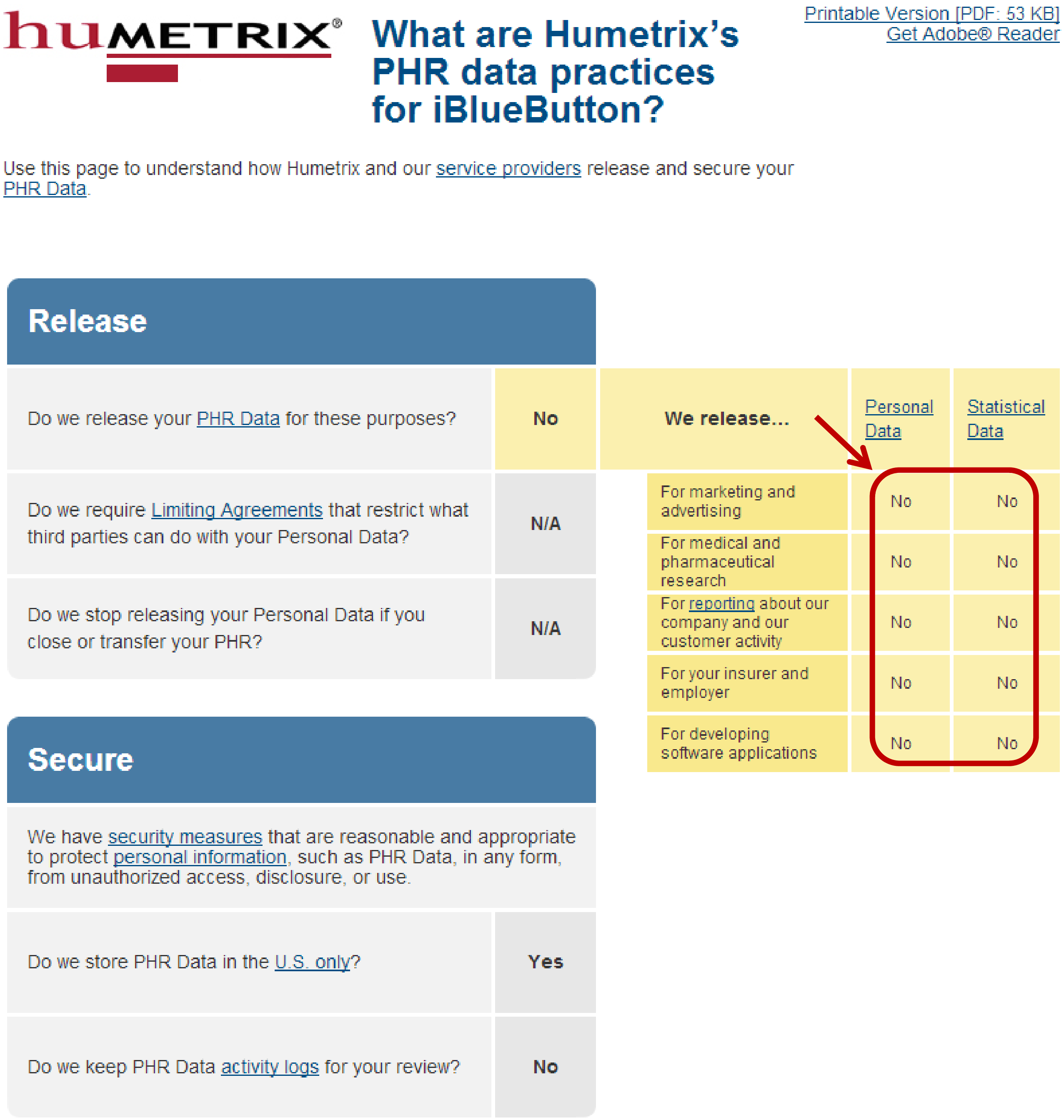
Details: Major depression in remission (disorder)

Headache

Hypertension NOS

iBlu

tice



What are Humetrix's PHR data practices for iBlueButton?

Printable Version [PDF: 53 KB]
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Use this page to understand how Humetrix and our service providers release and secure your PHR Data.

Release

Do we release your PHR Data for these purposes?	No
Do we require Limiting Agreements that restrict what third parties can do with your Personal Data?	N/A
Do we stop releasing your Personal Data if you close or transfer your PHR?	N/A

We release...	Personal Data	Statistical Data
For marketing and advertising	No	No
For medical and pharmaceutical research	No	No
For reporting about our company and our customer activity	No	No
For your insurer and employer	No	No
For developing software applications	No	No

Secure

We have security measures that are reasonable and appropriate to protect personal information, such as PHR Data, in any form, from unauthorized access, disclosure, or use.

Do we store PHR Data in the U.S. only?	Yes
Do we keep PHR Data activity logs for your review?	No

Panel Discussion

- **Christopher R. Burrow**, M.D., EVP Medical Affairs, Humetrix
- **Joseph Lorenzo Hall**, Chief Technologist, Center for Democracy & Technology
- **Sally Okun**, RN, MMHS, Vice President of Advocacy, Policy & Patient Safety, PatientsLikeMe
- **Heather Patterson**, Postdoctoral Research Fellow, New York University
- **Joy Pritts**, Chief Privacy Officer, Office of the National Coordinator for Health Information Technology, Department of Health & Human Services

SPRING PRIVACY SERIES

Consumer Generated and Controlled Health Data

MAY 7, 2014