

RSA[®]Conference2017

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POWER OF
OPPORTUNITY

SESSION ID: IDY-R03

Designing a New Consent Strategy for Digital Transformation



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@xmlgrrl

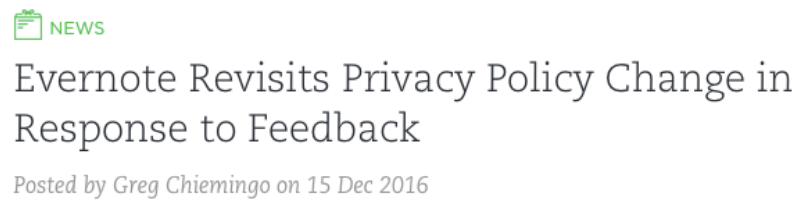
Digital transformation challenges



End-users: increasingly mistrustful but still demanding in other ways

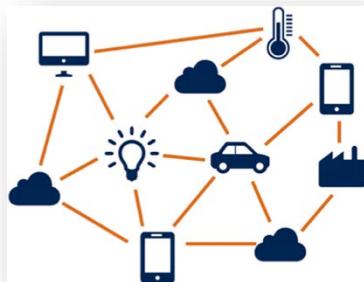
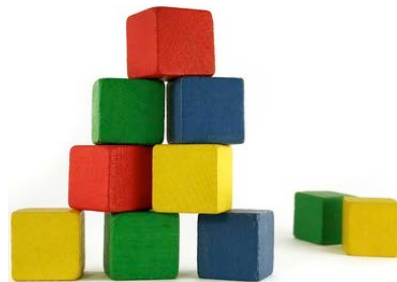
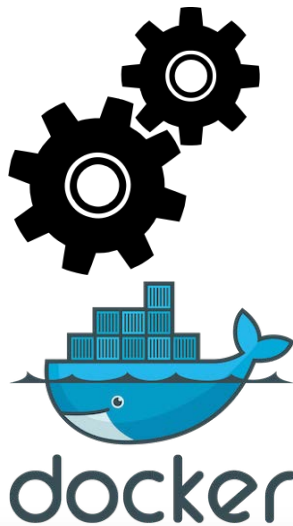
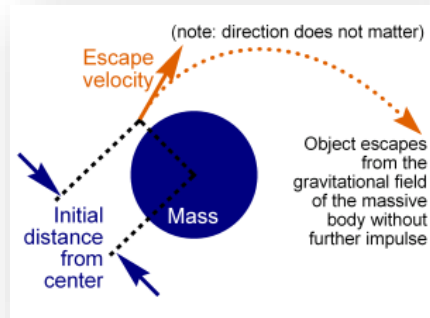


BUT

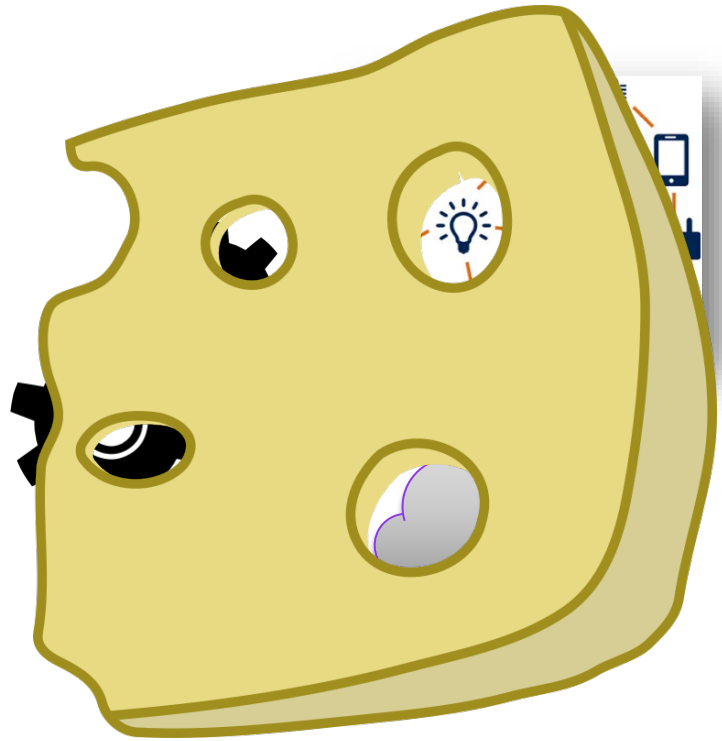


The innovation and industry context: never more...interesting

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The risk context: forever playing not to lose



The business and risk teams *must* meet in the middle

Risk perspective

“Consent should not be regarded as freely given if the data subject has no **genuine or free choice** or is unable to **refuse or withdraw consent without detriment**. ...

In order to ensure that consent is freely given, consent should not provide a valid legal ground for the processing of personal data in a specific case where there is a **clear imbalance** between the data subject and the controller...”

Business perspective

We value personal data as an asset

Our **customers'** wishes have value

Our customers have their **own reasons** to share, not share, and mash up data, which we can address as value-add

The traditional system of user consent



Opt-in consent

Your Email Address: *

Please fill in your email address.

Your Comment: *

Please fill in your comment.

Checkbox Example:

☒ Yes

Submit

Opt-out consent

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Implied consent



Eve Maler <eve@xmlgrrl.com>

12:45 PM (21 hours ago) ☆

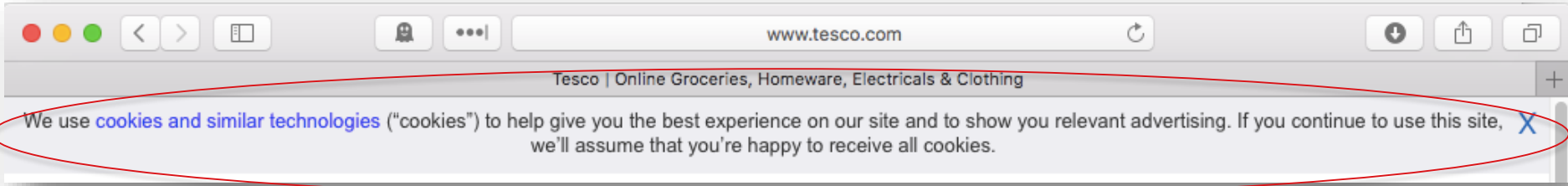
← Reply ▾

to Justin, bcc: me ▾

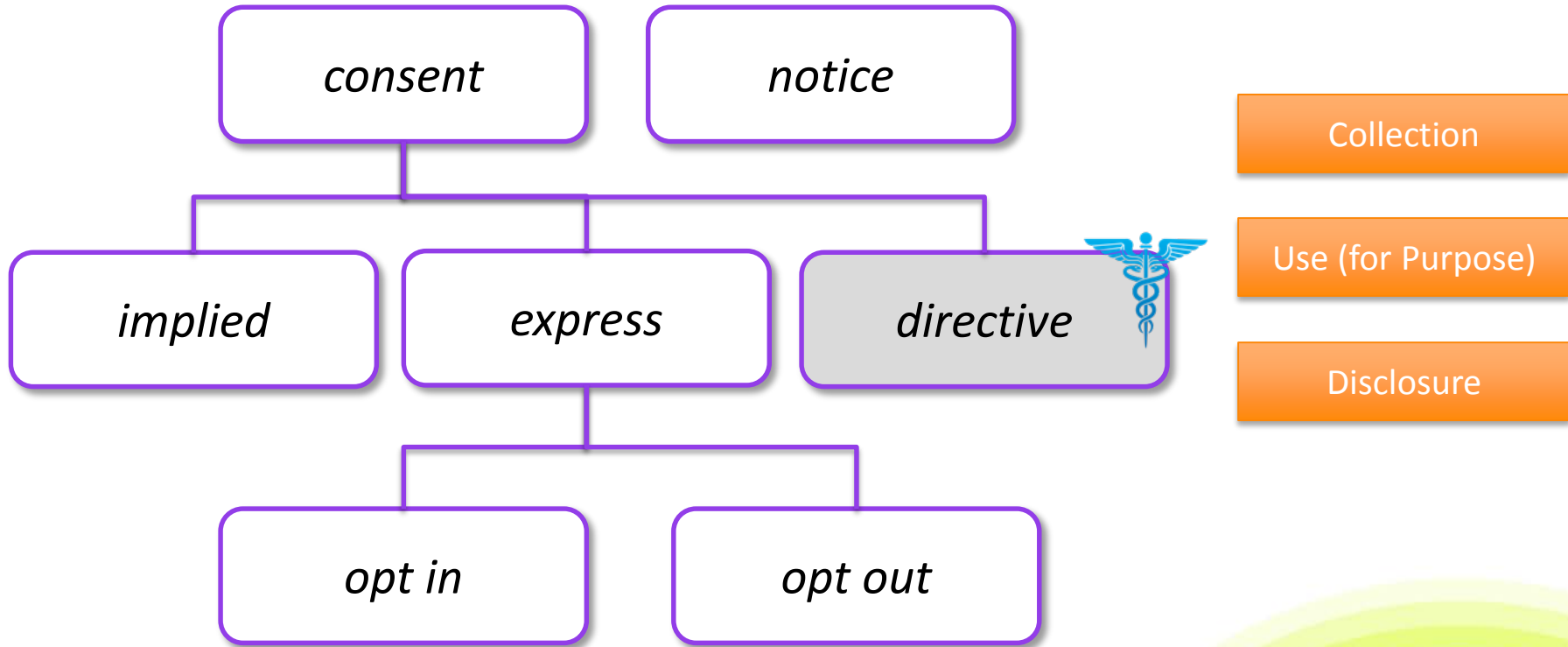
Sounds like a perfect opportunity to catch up on all that vectors of trust reading I haven't been doing. :-) I probably can't get to it till Friday at least, though. I'll give it a try.

Eve (sent from my iPhone, possibly with Siri's "help": [+1-425-](#)

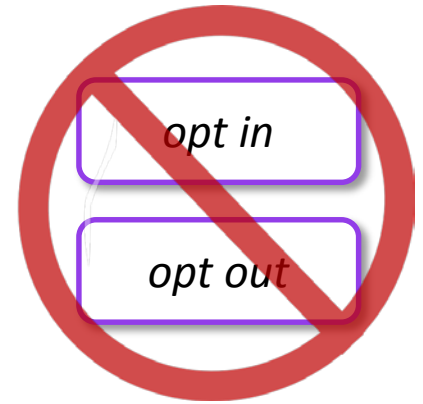
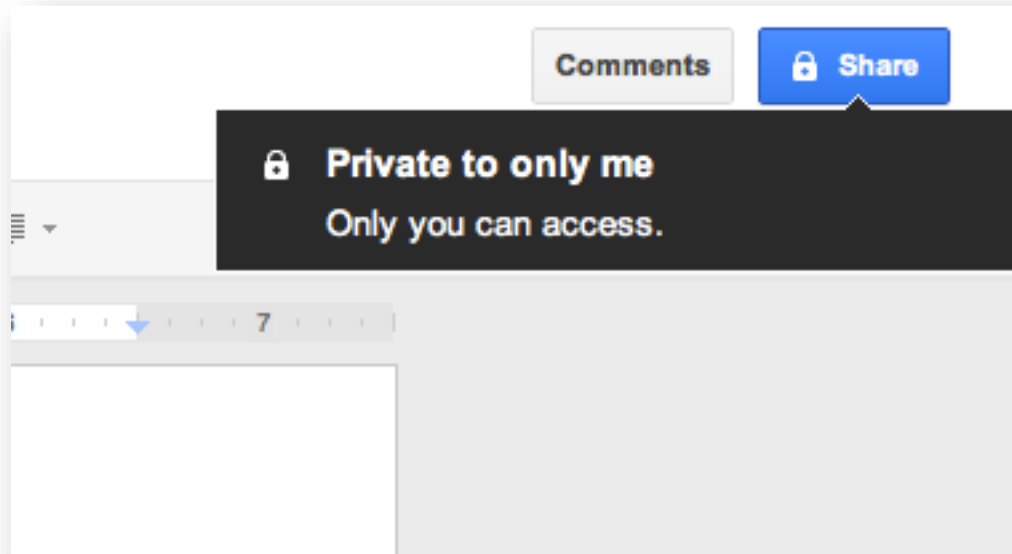
Cookie directive



Pretty much the entire *official* world of consent

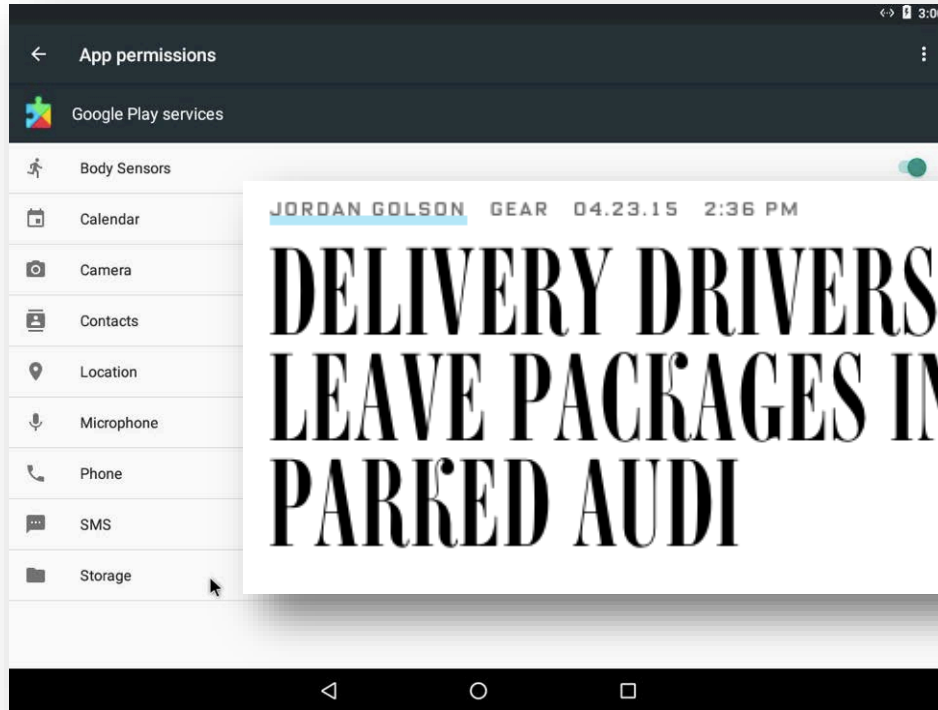


What about Google Docs “Share”?



What about Android upgrades? Or unattended package deliveries?

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Disclosure



What about GA4GH's ADA-M machine-readable conditions for use of genomic data?

Purpose



FINAL (15 December 2016)



Global Alliance
for Genomics & Health

"use for non-profit purpose" [plus an associated free text field]

"use for profit purpose" [plus an associated free text field]

"use for research purposes" [plus an associated free text field]

Automatable Discovery and Access Matrix ("ADA-M") v1.0

GUIDANCE DOCUMENT

***Global Alliance for Genomics & Health (GA4GH)
International Rare Disease Research Consortium (IRDiRC)***

Permissions Section

The Permissions section covers 26 different data concepts ('items') for types of use of a resource. This comprises considerations generally covered by, or otherwise included in, laws, institutional policies (Data/Sample Access Policies, Material/Data Transfer Agreement, Data Access Agreement, etc) and consents. It therefore represents aspects of control which are useful to know about in resource discovery contexts, and also when seeking to actually access a particular resource.



www.kazimdoku.com

A deeper classification system



A proposal for a new permission classification system

Modes:

Directed



Reactive



Long-Term



Methods:

Concrete



Abstract

Controls:

Scope



Grantee



Environment

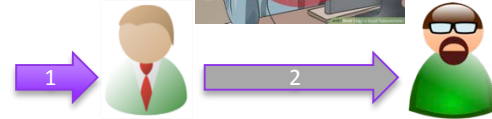


Usage



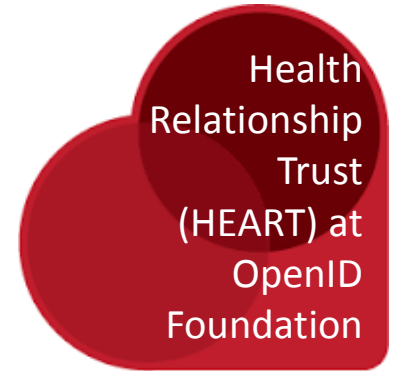
Purpose

Downstream



More “consent tech” is arising to meet the digital transformation challenge

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Active Projects:

- Consent Receipts
- User Submitted Terms





Working an example with the User-Managed Access standard

(tinyurl.com/umawg)

patient view

proactive sharing flow

doctor view

The screenshot displays three overlapping views of a healthcare application interface:

- patient view (left):** Shows a header "CloudyHealth DeviceConnect" and a "SmarteeBody smartee-body-1" resource. It displays two data points: "Weight 73" and "Body Fat 34", each with a "READ" button.
- proactive sharing flow (center):** A modal titled "Share the resource" for "smartee-body-1". It shows a "Not shared" status and a list of permissions: "Weight", "Bodyfat", and "BMI". A "CLOSE" button is at the bottom right.
- doctor view (right):** Shows a header "Hospital Portal" and a "Smartee Body" resource. It displays a "Body Fat 34" data point with a "READ" button and an "IMPORT INTO PATIENT RECORD" button.

Remember consent directives?



directive



AUTHORIZATION TO DISCLOSE PROTECTED HEALTH INFORMATION Michigan Department of Health and Human Services

Directions: Type or Print all requested information, with exception of signatures on Page 2.

Individual's Name (Beneficiary, Recipient, Patient, Consumer, etc.)			Individual's ID Number (Medicaid, SSN, Other)
Individual's Name			0123456789
Street Address			Individual's Date of Birth
Individual's Address			/ /
City	State	ZIP Code	Phone
			() -

I AUTHORIZE THE MICHIGAN DEPARTMENT OF HEALTH AND HUMAN SERVICES (MDHHS) TO SHARE MY HEALTH INFORMATION:

List the amount or type of information you would like to share in the section below.

For example, you can say all my health information or list certain types of information you would like to share.

"All my health information, any time until authorization revoked."

(or any specific information you want to include)

MDHHS MAY SHARE MY HEALTH INFORMATION WITH THE FOLLOWING PERSON OR ORGANIZATION:

Representative and/or Organization Name

Name of Person/Organization

Address of Authorized Representative

Street Address

City, State, ZIP Code

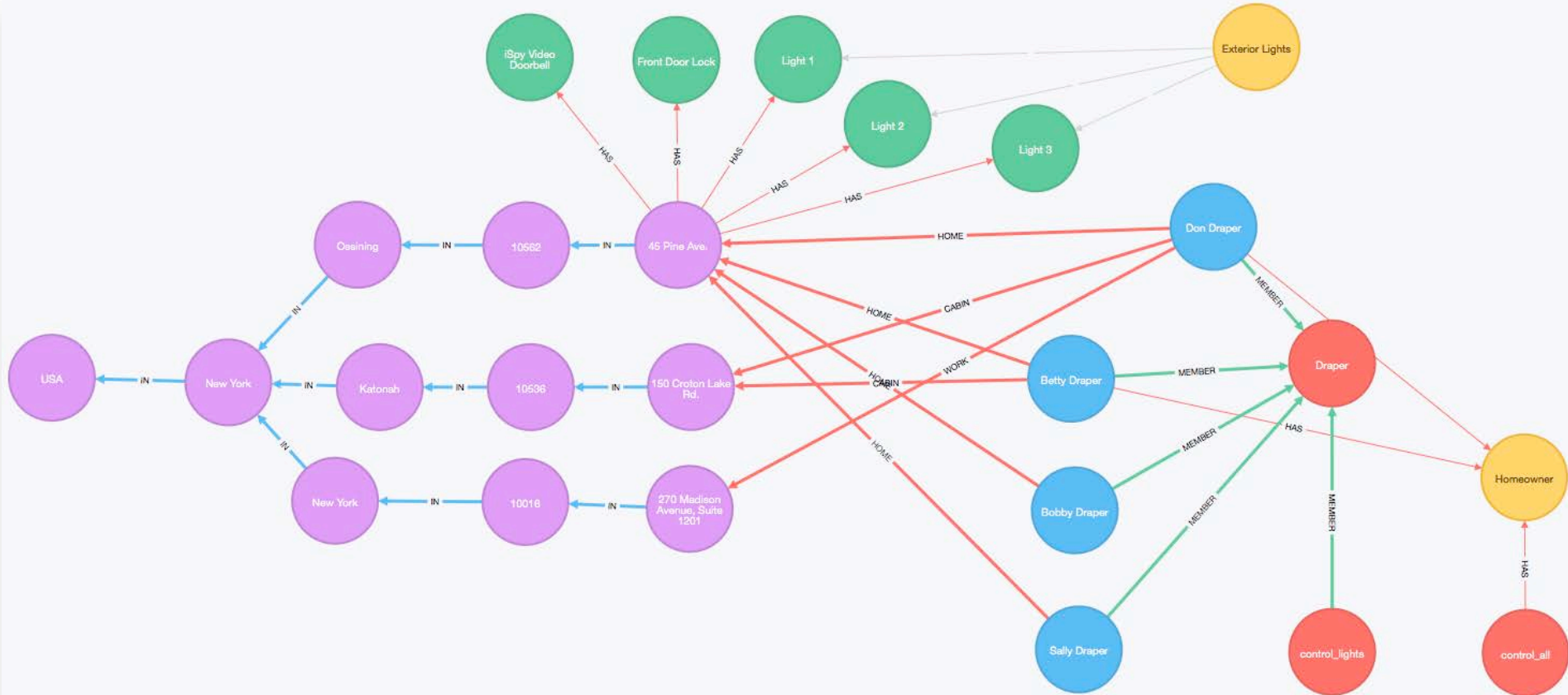
() -

Phone Number

() -

Fax Number

Access sharing can even be driven off relationships with people and devices



UMA capabilities (each deployment may differ)

Modes:

✓ Directed



✓ Reactive

opt in

opt out

✓ Long-Term



Methods:

✓ Concrete



I gave permission right there

✓ Abstract

I set up permissions in a larger context

Controls:

✓ Scope



✓ Grantee



✓ Environment

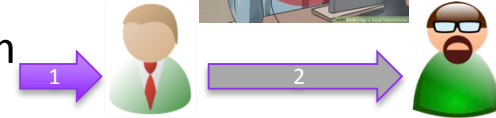


⚖ Usage



Purpose

⚖ Downstream



A large, gnarled tree trunk leans over a white wooden fence in a wooded area. The tree's bark is rough and peeling in places. The fence is made of horizontal wooden rails and vertical posts. The ground is covered with dry leaves and twigs. The background shows more trees and a bright sky.

Take action to build
trusted digital relationships

The most robust and strategic option: *lean in to consent*

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- Business owners: Engage proactively in regulatory shifts
- Risk teams: Recognize that positive sharing use cases exist
- Business owners: Conceive of personal data as a joint asset
- Go beyond policy to digital transformation “consent tech”

Applying what you've learned

- Next week, find out:
 - Who the **consent stakeholders** are/should be
- By three months, work towards an an **as-built description** of current consent flows against the classification system and analyze:
 - Silos of uncertainty?
 - Consumer trust gaps?
 - Opportunities for directed modes (“delegation”)?
- By six months, investigate **opening consent flows** for the classification axes that would make the biggest impact on business goals and compliance posture

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Thank you!
Questions?



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