

What is Design at LFPH?

Linux Foundation Public Health
Design Special Interest Group

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v.01, 7.Jan.21

harvey

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A photograph of a man lying on his back on a gravel surface, looking up at a parking lot. He is wearing a dark zip-up hoodie and light-colored pants. In the background, there is a row of parked cars and houses under a clear blue sky.

juhan@mit.edu
@jsonin

Today's Session

What are we doing here?

What is the Linux Foundation Public Health (LFPH) effort?

What is Design at LFPH?

Why are you here?

What do you want to do?

Global issues

- 1 Energy
- 2 Education
- 3 Population
- 4 Food
- 5 Clean water
- 6 Sanitation
- 7 Open governance
- 8 Fiscal parity
- 9 Health



*I will share my medical knowledge
for the benefit of the patient and the
advancement of healthcare*

Declaration of Geneva, 1948

*Our black box algorithm risk-adjusts
and care plans for half of US residents.*

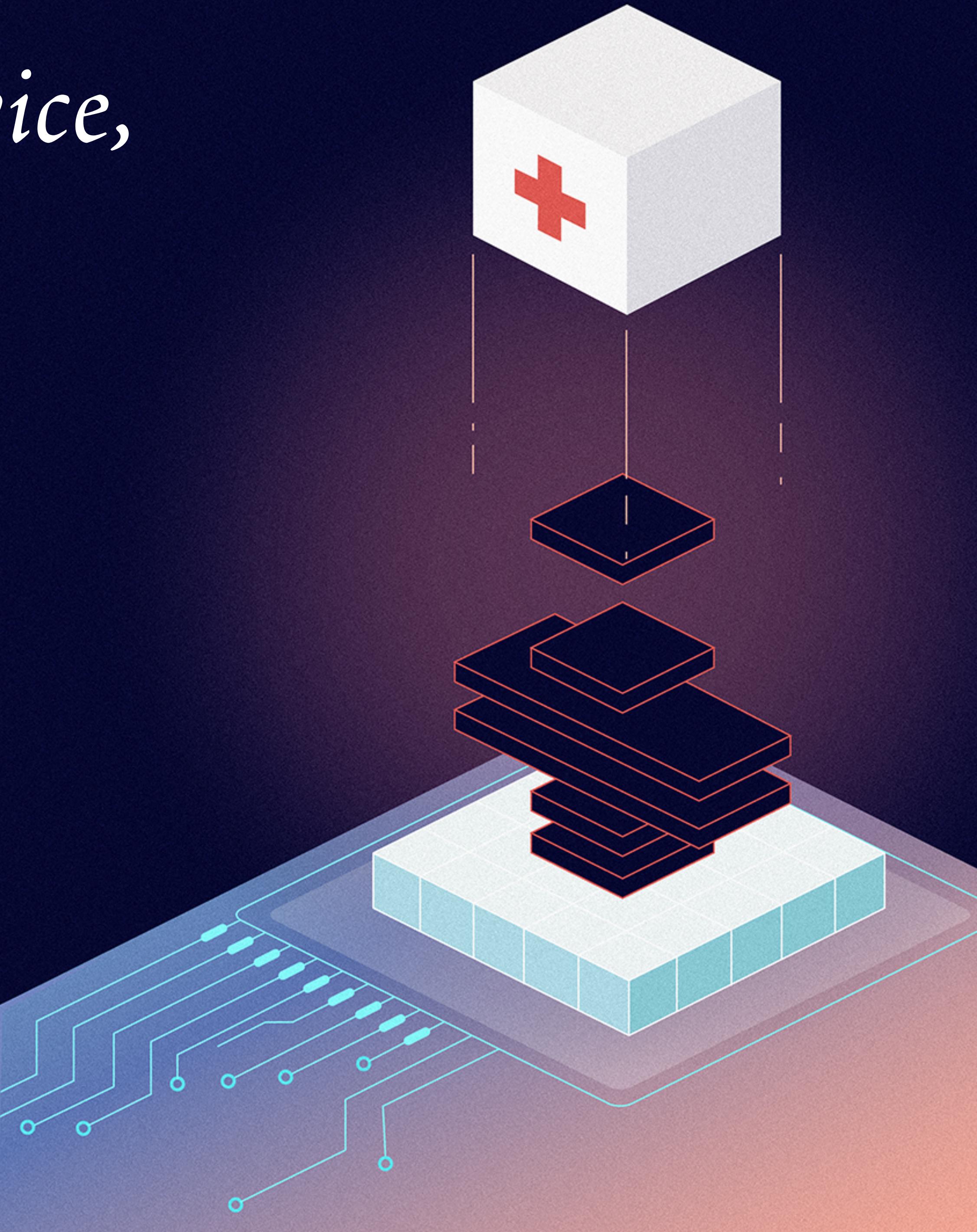
Pharmacy Benefit Manager, 2020

**HEALTHCARE IS A
HUMAN RIGHT**



*When you use a HC service,
you don't know...
+*

*how it works,
why it works,
who it works best for, and
if the results are true.*



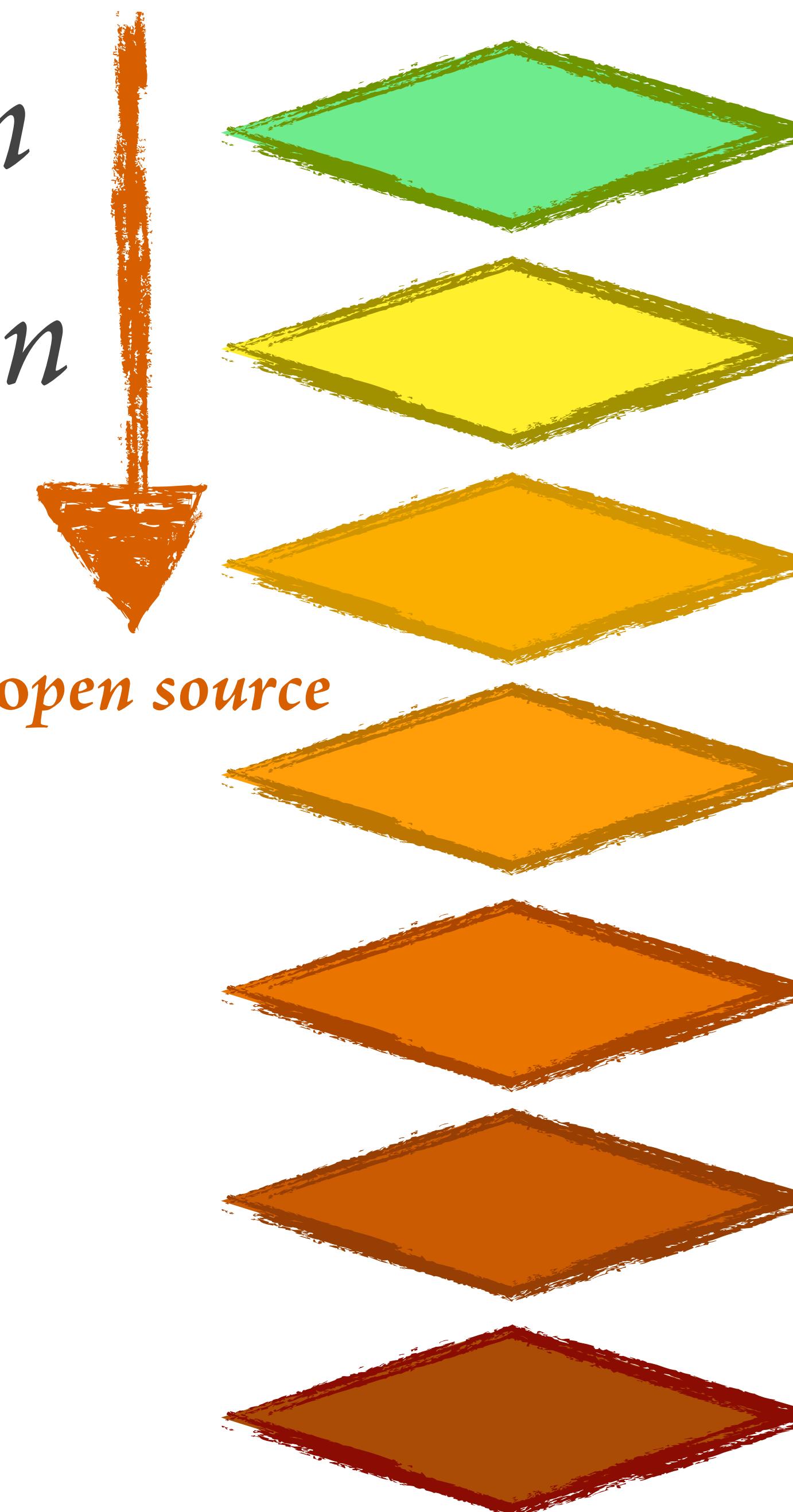
*If healthcare is so noble,
if it's key to our life on earth,
if we don't have choice...
.*

...we demand healthcare to be open.

The Internet is
infrastructure
... open source
... a human right.

OSI MODEL

*Application
Presentation
Session
Transport
Network
Data
Physical*



Human-computer interaction layer, where apps can access the network services

Ensures that data is in a usable format, where data encryption can occur

Maintains connections, responsible for controlling ports + sessions

Transmits data using transmission protocols (TCP, UDP)

Decides which physical path the data will take

Defines the format of data on the network

Transmits raw bit stream over a physical medium



Linux



Apache



Arduino



Android



MySQL



Open Gov



PLOS



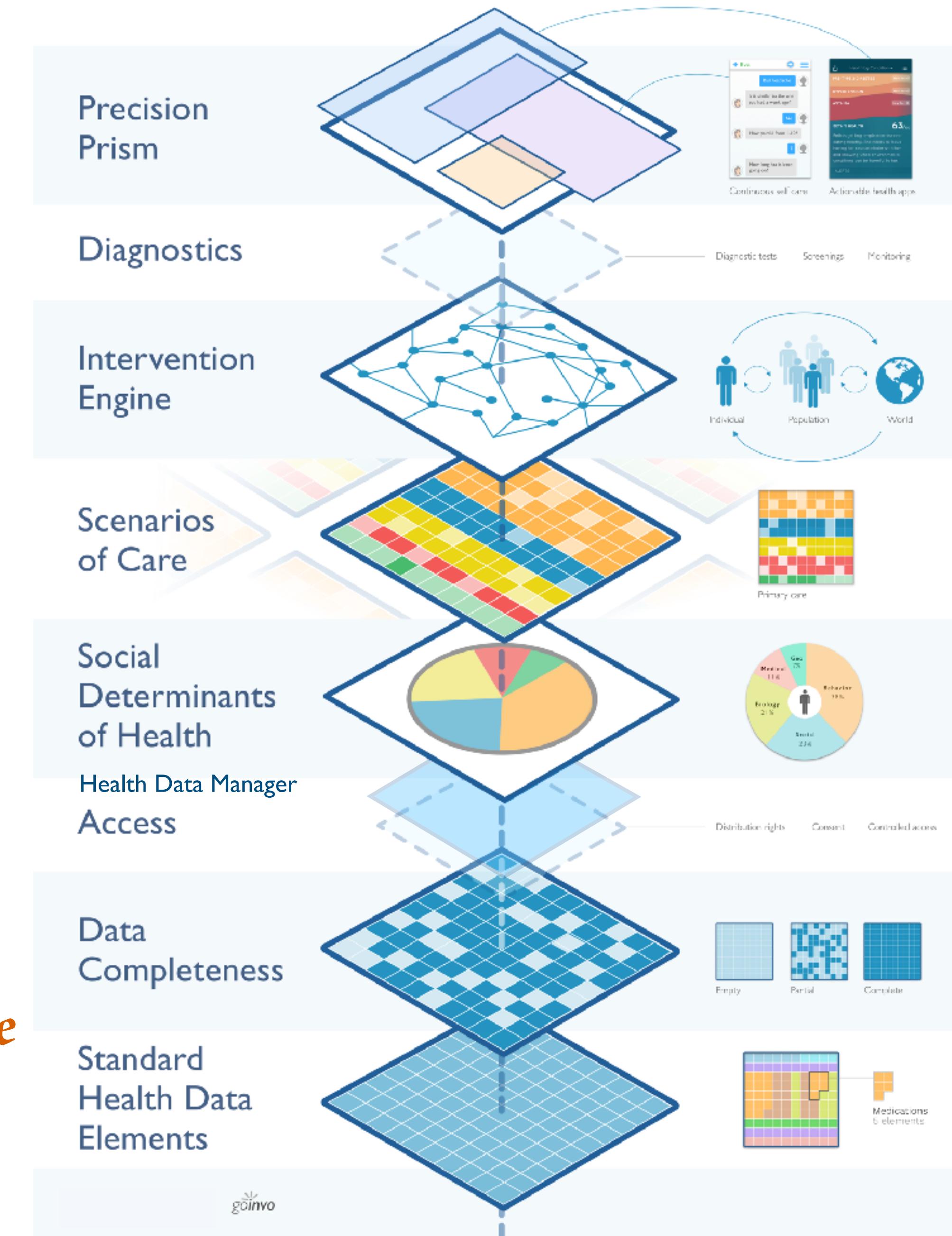
W3C



Wikipedia

HEALTHCARE SYSTEM MODEL

should be
open source



*most healthIT
is closed*



Eric Topol, MD

*"We have
anti-open source."*

“Epic EHR should be open source.”

Elizabeth Nabel, President of Brigham Health, 2017

*“Open source is fundamental.
The fact that we don’t have open healthcare
reflects the deepness of our problem.”*

Eric Topol, Scripps Research, 2018

National Digital Healthcare the Estonian Experience

Liis Hinsberg Shea

Former Estonian Health System Communication Director



In Estonia,
95%
of health data is digitized

99%
of prescriptions are digital

100%
of billing is done electronically

94%
of citizens are covered by
national healthcare

"Digital healthcare is already a reality in 2018 in Estonia thanks to all the e-solutions we have implemented in the past twenty years," said Estonia's Minister of Health and Labor Ms Riina Sikkut in an interview last year^[1]. Funnily enough, that statement was more newsworthy to people outside of Estonia than people living there and using e-government and e-health services on a daily basis. Estonians are very comfortable using e-services and sharing their data when necessary. Citizens are brought up with the philosophy that we own our data, however, it's both the public and private sector's job to use this data in the best way possible—to run our shared services smoothly and improve life in Estonia.

Data travels on a digital highway

Most public records in Estonia use the government's open source data platform, the X-road or X-tee* data platform for both public and private data. The platform links individual servers, letting information live locally, but can be requested by different participants. The public sector uses X-tee for different registries like the Population Registry, Health Insurance Registry. Private Sector companies in energy, telecom and banking use the platform. Over 900 organizations use it daily^{[2][3]}. The main user interface for citizens, enterprises and public officials is the State Portal "eesti.ee".

Everyday services that people need are all online and necessary information or forms are pre-populated. When you vote, the e-voting platform already knows the necessary data. When you file taxes, the tax forms are filled out for you. You don't have to insert any data more than once and there is no duplicate data.

Estonia

- All residents

\$1.7B

annual budget for all
healthcare services

0.9%

Administrative overhead
for Healthcare budget

1.2MM

or 94% of all Estonians and
residents are covered by
national Healthcare

\$79

is the average cost per
outpatient encounter

United States

- Medicaid, Medicare

\$1.3T

annual budget for Medicare
+ Medicaid healthcare
services

8%

Administrative overhead
for HHS/CMS budget

108MM

or 33% of all US citizens and
residents are covered by
national Healthcare

\$121

is the average cost per
outpatient encounter

- Private

\$1.2T

annual budget for private
health insurance

15%

Administrative overhead
for HHS/CMS budget

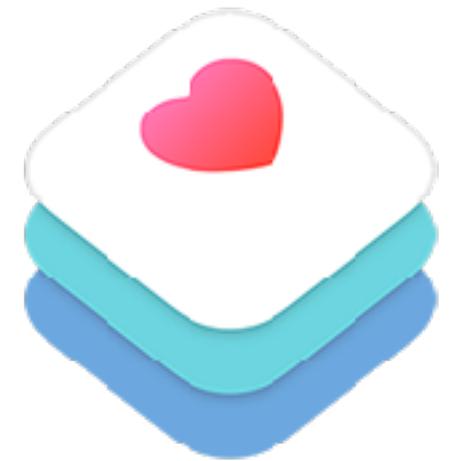
156MM

United States citizens and
residents are covered by
private Healthcare

\$160

is the average cost per
outpatient encounter

* Until 2018, it was named X-Road in English. Since 2018, however, X-Road is only used to refer to the technology developed together by Estonia and Finland through Nordic Institute for Interoperability Solutions. The Estonian X-tee is now also called X-tee in English.



HealthKit



Open Humans



openEMR



SageBionetworks



FHIR



Standard Health Record



Synthea

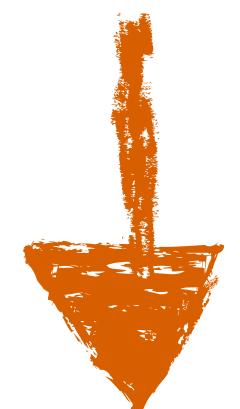
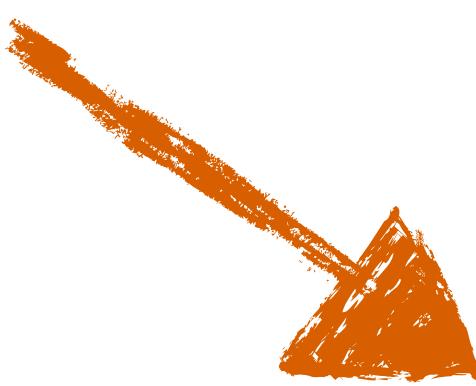
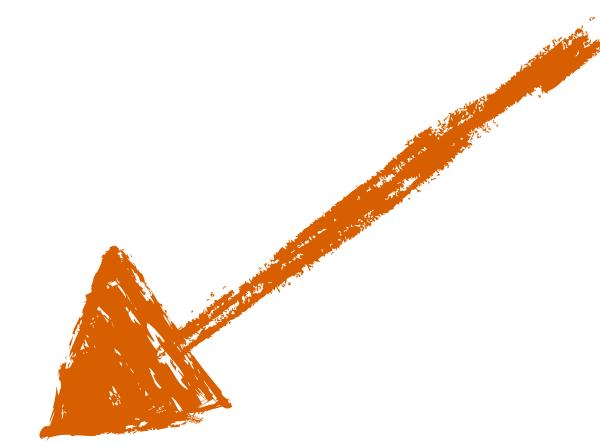
Open Source Healthcare

*suited for...**

*Infrastructure,
Common Good Services*

*Leading Edge,
Speculative Research*

Global Emergency



*We have to be deliberate in
committing to open source healthcare.*

*And the Design of Healthcare
... ain't good enough*

Today's Session

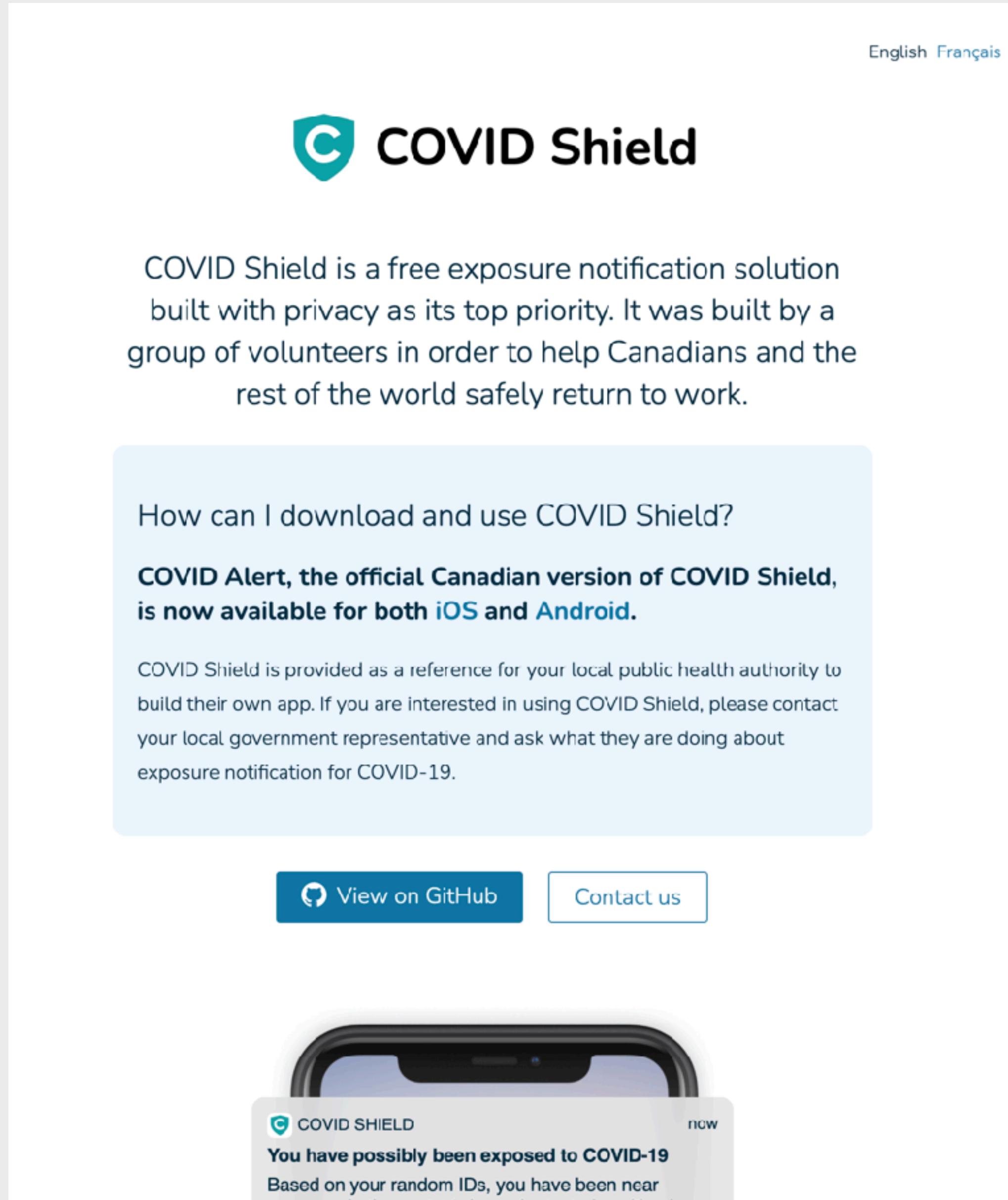
What is the Linux Foundation Public Health (LFPH) effort?

Overview:

[https://docs.google.com/presentation/d/
1Zq0cef97o85kR3Zry_4K3KZD5HpiENfRvFpVxlrNIJE/
edit](https://docs.google.com/presentation/d/1Zq0cef97o85kR3Zry_4K3KZD5HpiENfRvFpVxlrNIJE/edit)

COVID Shield

<https://www.covidshield.app/>



The screenshot shows the COVID Shield website. At the top right are language links "English" and "Français". Below them is the COVID Shield logo, which consists of a teal shield icon with a white letter "C" inside. The text "COVID Shield" is next to it. A large paragraph describes the app as a free exposure notification solution built with privacy in mind, developed by volunteers to help Canadians and others return to work safely. A blue callout box contains the text: "How can I download and use COVID Shield? COVID Alert, the official Canadian version of COVID Shield, is now available for both iOS and Android." Below this, another paragraph states that COVID Shield is provided as a reference for local public health authorities to build their own apps, and encourages users to contact their local government representative about exposure notification for COVID-19. At the bottom are two buttons: "View on GitHub" with a GitHub icon and "Contact us". A small image of a smartphone displaying the app interface is at the very bottom.

English [Français](#)

 **COVID Shield**

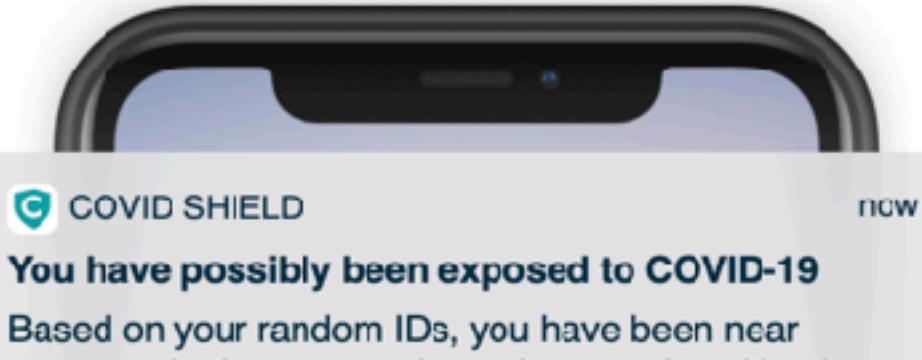
COVID Shield is a free exposure notification solution built with privacy as its top priority. It was built by a group of volunteers in order to help Canadians and the rest of the world safely return to work.

How can I download and use COVID Shield?

COVID Alert, the official Canadian version of COVID Shield, is now available for both iOS and Android.

COVID Shield is provided as a reference for your local public health authority to build their own app. If you are interested in using COVID Shield, please contact your local government representative and ask what they are doing about exposure notification for COVID-19.

 [View on GitHub](#) [Contact us](#)



COVID SHIELD
You have possibly been exposed to COVID-19
Based on your random IDs, you have been near

COVID Green

<https://www.covidshield.app/>



Why Linux Foundation Public Health (LFPH)?

Build an ecosystem around open source [healthcare] projects

Large, sustainable systems need collective resources + effort

LF is a globally known name, services

++

Who is the leading LFPH?



Jenny Wanger

jennywanger@gmail.com

<https://www.linkedin.com/in/jennywanger/>

Jenny has design DNA and recognizes its potential in OS + LF + public health.

Agenda v.01

Establish a Design... agenda

Why is Design important to healthcare?

Why is Design needed (vs design)?

Agenda v.01

Establish a Design... agenda

Healthcare doesn't need as much design.

design is a commodity

Healthcare does need Design.

the what to design & why, the
strategy & vision, the ethical
paths forward, healthcare for all

Agenda v.01

LFPH Design Missionette

1. Demand healthcare infrastructure design be open source.

The algorithms that drive our care are governed by black boxes.

The Design of those services, from modeling to user interface and experience are often plagued by crooked biases.

We aim to democratize healthcare technology for all participants through open source design.

Agenda v.01

LFPH Design Missionette

2. Infect LF Public Health projects with Open Design.

Many LF projects already have interface design, but they may not have Design.

The Design process needs to be transparent and open to all...

to grow community buy-in,

to receive and respond to design feedback, and

to democratize design knowledge management.

We will work with, guide the community about, and ship good design.

Agenda v.01

LFPH Design Missionette

3. Make user experience guidance and best practices for open source healthcare services.

Co-create guidelines for user interface, user experience, and product strategy that anyone can use to increase the human happiness quotient when using LF health services.

These best practice examples will

- ... improve readability and understandability of a person's or populous' health status,
- ... vaccinate LFPH efforts with good design research process
- ... establish measurable metrics that show design success

(with the people that use the service and within community development)

Agenda v.01

LFPH Design Missionette

4. All work will be open source, licensed under the Apache 2.0 license, and produced, discussed, and critiqued in the open, from day 1.

Agenda v.01

Draft Starting Point

Design-SIG starts by working with newly, incoming projects being brought into the LFPH fold... as a technical advisor and assessment service.

Are there well-founded needs, use cases? Is this an actual need in the field, with humans, with governments, etc? 1st investigate the UIs, then assess design of APIs (v2 activity).

Work with the LFPH Technical Advisory Committee (TAC) to mark particular projects to engage with (provides organizational push for design assessments/guidance)

Incubation levels of TAC projects (aka maturity “model”) 1, 2, and 3... start with level 1, newly entered-into-the-LFPH-fold projects.

Agenda v.01

Draft Starting Point

Possible activities include heuristic evaluations, use case & feature probing, UI analysis, field needs vs engineered features, etc.

Map out design maturity with TAC levels and corresponding design leveling.

... ie projects Run of Rules. So should Design... Design Rules

Design-SIG ultimately needs investment.

Show value, benefit... start small + focused.

Start with Level 1 new project in LFPH, Herald Project (<https://vmware.github.io/herald/>).

Agenda v.02

Start a design community

What projects need Design?

Assessing project and organizational design “maturity”.

What kind of design is needed?

Onboarding designers into the LFPH effort is key

... seeing needs from graphics to UI to UX to strategy to policy to HealthIT design strategy

... seeding a LFPH mini tutorial and walkthrough of the org's mission, key objectives, etc.

... project rulebook, designbook (TBD)

Why are you here?

What do you want to do?

Agenda v.03

Plan the next 120 days, year

Introduction to the next LFPH service: Herald
Herald assessment (what can the Design-SIG work on)

Guidelines for the design of Tracking Patients services w/
consent (best practices in consent, health literacy in
tracing/tracking, notifications, etc)

Create a Code of Ethics

Agenda v.03

Plan the next 120 days, year

Introduction to the next LFPH service: Herald
Herald assessment (what can the Design-SIG work on)

Guidelines for the design of Tracking Patients services w/
consent (best practices in consent, health literacy in
tracing/tracking, notifications, etc)

Create a Code of Ethics

Plan.

Make.

Ship.

Change the world.

<https://github.com/lfph/sig-ui-ux>

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Credo

Protect

... the patient

... the clinician

... the integrity of HC & Design

How...

By modeling the problem first...

with evidence,

with ripple effects,

then design,

then prototype,

then test.

GOINVO

CODE OF ETHICS 2021

SPEAK THE TRUTH

We will be honest and objective. We will be transparent, and provide insight into our thinking and work.

MAKE THE WORLD USEFUL, BEAUTIFUL, AND DELIGHTFUL

We exercise the discipline to produce ideas and things that are useful to and beautiful in the world.

LEARN, BUILD, AND SHARE

We are curious, open creators who welcome new ideas and the input of others.

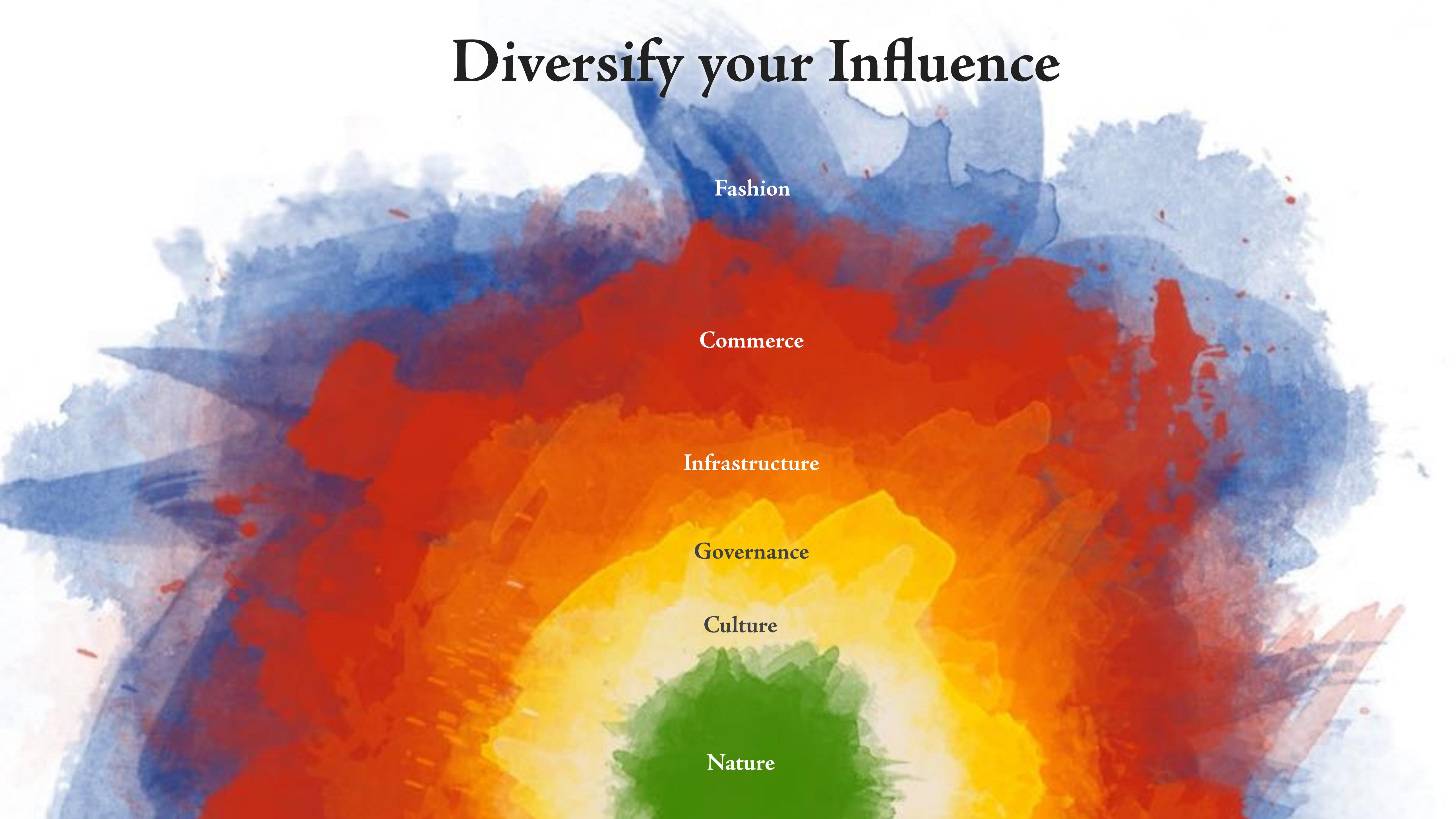
COMMIT TO COMMUNITY

We protect the public by holding paramount the safety, health, welfare, and rights of human beings.

GO LIKE HELL

We are driven and committed to what we do, putting extra effort in our quest for exceptional results.

Diversify your Influence



Fashion

Commerce

Infrastructure

Governance

Culture

Nature

Clarity of Vision,
Flexibility in Process

Design Outcomes

When patients need a health nudge or use healthcare, we make it easy for them to see their health (see personal insights), work with clinicians, and see how to change their upcoming health.

We make it dead simple for clinicians to see and predict health outcomes for patients.

We will protect and expand the patients' data rights, so World Citizens always have their health data one click away (they never have to ask permission).