



THE 14th NATIONAL
Health Summit

PATIENTS KNOW BEST®
MANAGE YOUR HEALTH

*How can innovative
technology get to scale?*



@patientsco



enquiries@patientsknowbest.com



www.patientsknowbest.com



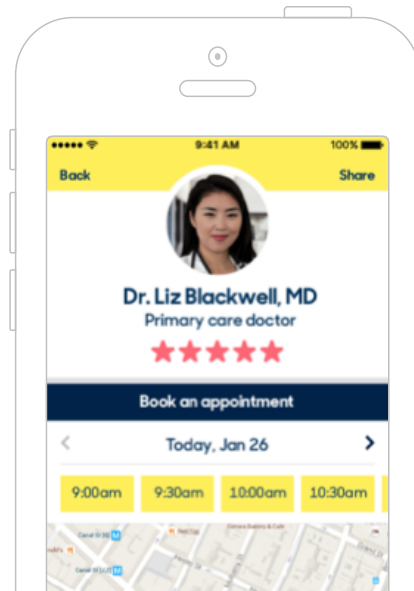
“Healthcare is
the world’s
largest cottage
industry”



PATIENTS KNOW BEST®
MANAGE YOUR HEALTH

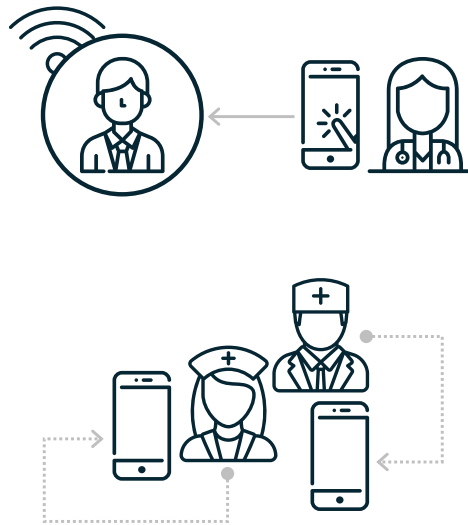
Reaching scale is hard in *digital health*

Zocdoc



Fighting to scale
practice by practice

Cerner

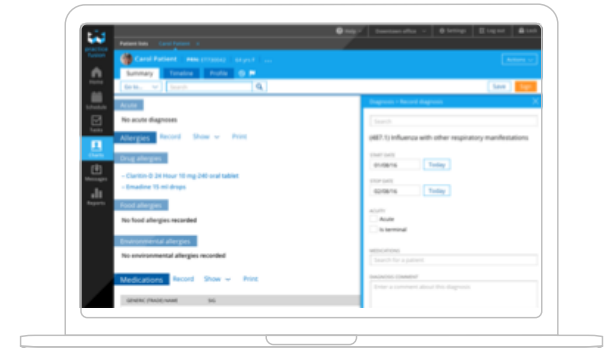


**World's most scalable
health IT company**

"If you've seen one Cerner site
you've seen one Cerner site"

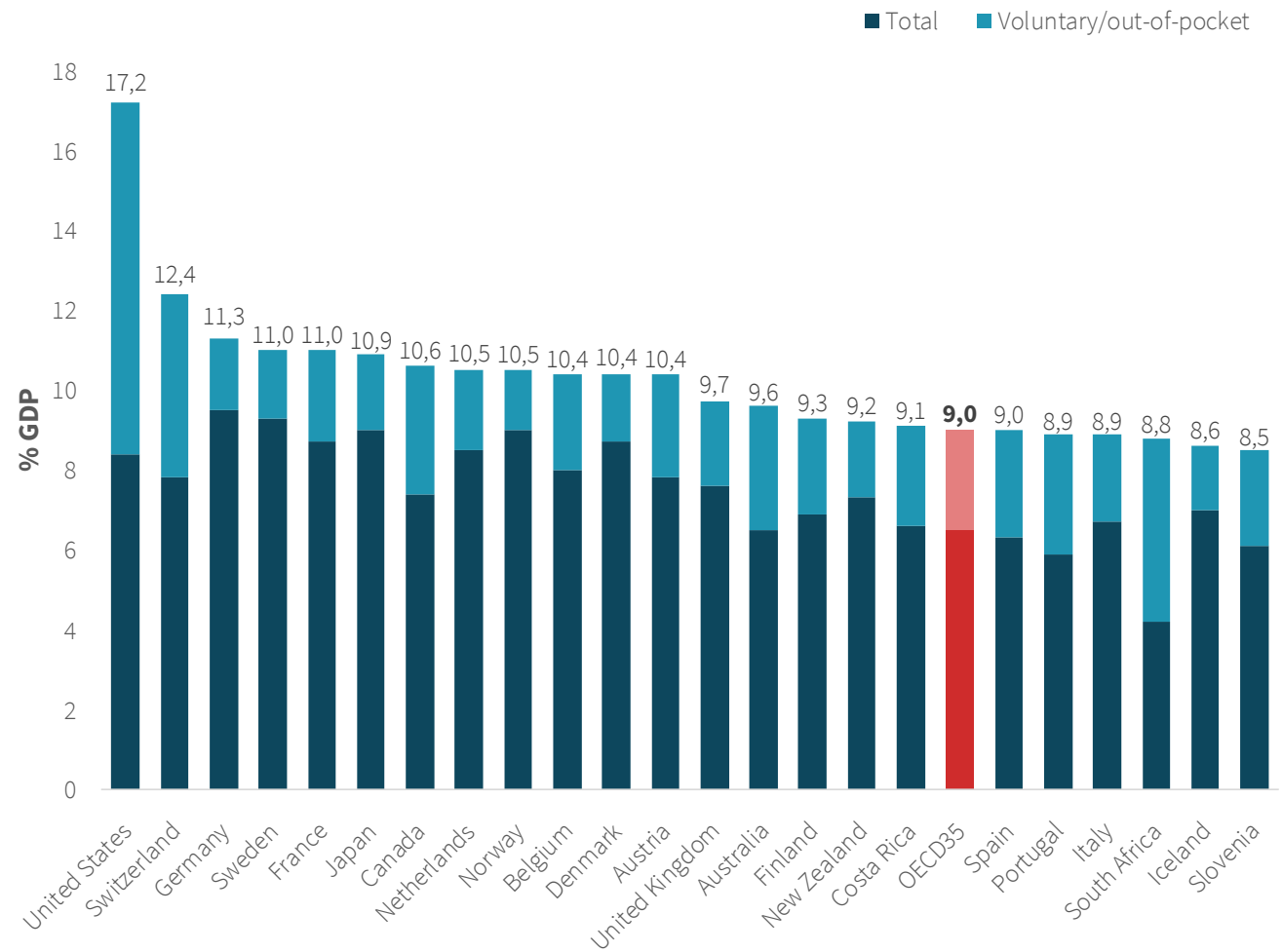
**ALLSCRIPTS BUYS PRACTICE FUSION
FOR \$100 MILLION**

After expanding its hospital footprint with the McKesson acquisition this past summer, Allscripts now broadens its ambulatory presence by scooping up the cloud-based EHR vendor.



Even when you reach scale
it still may not be enough

*10% of
OECD GDP*





Healthcare is world's
largest information
industry and needs
technology for its
information



PATIENTS KNOW BEST®
MANAGE YOUR HEALTH

*Modern
medicine
is about
behaviour
change*



Robotic surgery
is very cool



But chronic conditions are very common:
pharmaceuticals to digiceuticals
The Economist “[A new sort of health app
can do the job of drugs](#)”

Healthcare's unique needs for information technology

MOBILITY:
ENTER THE SMARTPHONE

SAFETY:
YOU CAN'T ACT LIKE UBER...

PRIVACY:
...OR LIKE FACEBOOK



Healthcare's unique needs for *information technology*

MOBILITY:
ENTER THE SMARTPHONE

SAFETY:
YOU CAN'T ACT LIKE UBER...

PRIVACY:
...OR LIKE FACEBOOK

Arizona residents are getting refunds on Theranos tests
Posted Dec 18, 2017 by Sarah Buhr (@sarahbuhr)

drop off + pick up
theranos lab testing

Theranos is issuing refund checks to all Arizona residents who used the company's blood-testing services, thanks to a recent settlement by Arizona Attorney General Mark Brnovich.

Between 2013 and 2016, Theranos offered testing at several locations throughout the state in a partnership with Walgreens. However, the drug store chain **severed ties** with Theranos in mid-2016, citing myriad bad test results and an ongoing federal investigation.

Co-founder Elizabeth Holmes was **banned** from operating in her own labs shortly after.

Sun Sentinel

Uber ignored Florida's rules, may get break from Legislature
By Randy Schultz

SHARE THIS
f t

Statewide regulations for Uber will help the company's executives, not its drivers.

Get the Sunday Splash newsletter, a weekly roundup of insightful commentary from around Florida

Enter your email SIGN UP
Privacy Policy

APRIL 26, 2017, 5:00 PM

Uber asks forgiveness, not permission. The **Florida Legislature** wants to give both.

Legislation that would set statewide rules for so-called transportation network companies — Uber, Lyft and any competitors — passed the House and Senate with just one dissenting vote. Gov. Rick Scott likely will sign House Bill 221. After four years, Uber finally would win.

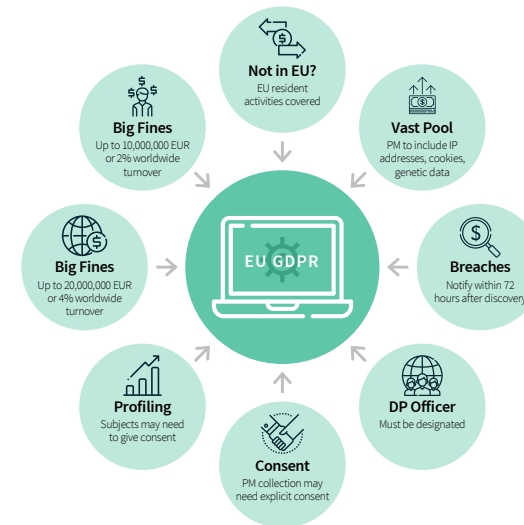
Healthcare's unique needs for *information technology*

MOBILITY:
ENTER THE SMARTPHONE

SAFETY:
YOU CAN'T ACT LIKE UBER...

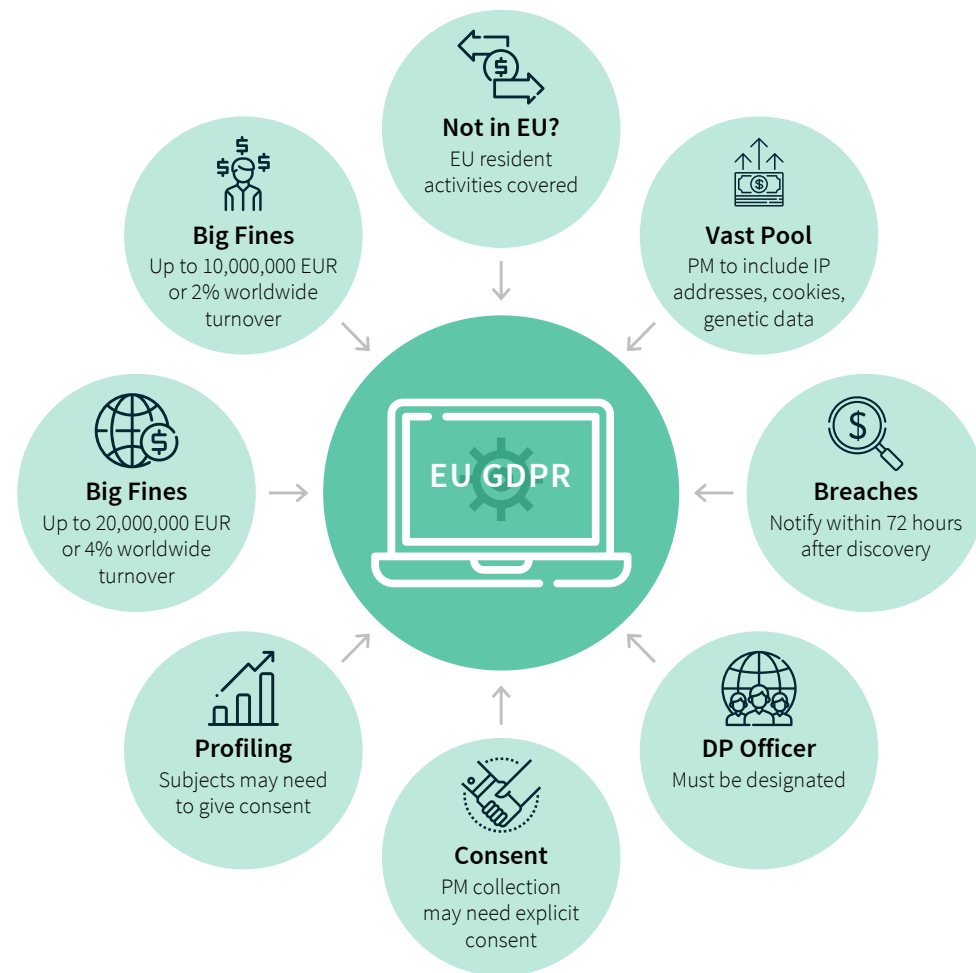
PRIVACY:
...OR LIKE FACEBOOK

EUROPEAN UNION GENERAL DATA PROTECTION REGULATIONS (GDPR) IMPORTANT POINTS



GDPR trains EU start-ups to do it right (and for health, GDPR is model)

*European Union
General Data
Protection
Regulations (GDPR)
important points*



GDPR trains EU start-ups to do it right (and for health, GDPR is model)

My beginning



PATIENTS KNOW BEST®
MANAGE YOUR HEALTH

About me...

PERSONAL HEALTH RECORDS

A GUIDE FOR CLINICIANS

MOHAMMAD AL-UBAYDLI MD



PATIENT:

Rare disease, I help my doctors to help me

PHYSICIAN:

Trained at the University of Cambridge

PROGRAMMER:

Worked as National Institutes of Health Staff Scientist

AUTHOR:

6 books about IT in health care
(and a 7th for chefs)



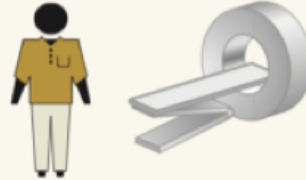
A story I heard



Dr. Jirjis orders a CT angiogram to rule out aortic dissection for patient with ripping chest pain

A story I heard

1



Dr. Jirjis orders a CT angiogram to rule out aortic dissection for patient with ripping chest pain

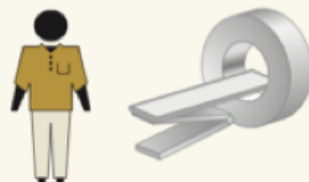
2



Dr. Jirjis reads 'no aortic dissection' in radiologist's summary and sends to patient through MyHealthAtVanderbilt

A story I heard

1



Dr. Jirjis orders a CT angiogram to rule out aortic dissection for patient with ripping chest pain

2



Dr. Jirjis reads 'no aortic dissection' in radiologist's summary and sends to patient through MyHealthAtVanderbilt

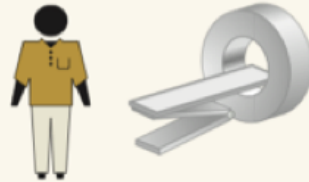
3



Patient reads 'thyroid lump' buried in radiologist's full report and sends message to Dr. Jirjis asking 'what about my thyroid?'

A story I heard

1



Dr. Jirjis orders a CT angiogram to rule out aortic dissection for patient with ripping chest pain

2



Dr. Jirjis reads 'no aortic dissection' in radiologist's summary and sends to patient through MyHealthAtVanderbilt

3



Patient reads 'thyroid lump' buried in radiologist's full report and sends message to Dr. Jirjis asking 'what about my thyroid?'

4

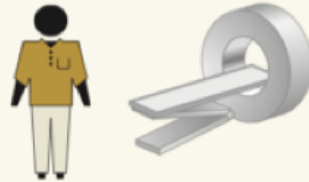


Biopsy reveals thyroid cancer and cancer successfully excised

A story I heard

Dr. Jirjis was not unusual in making a mistake, but in recognizing it and asking patients to help

1



Dr. Jirjis orders a CT angiogram to rule out aortic dissection for patient with ripping chest pain

2



Dr. Jirjis reads 'no aortic dissection' in radiologist's summary and sends to patient through MyHealthAtVanderbilt

3




Patient reads 'thyroid lump' buried in radiologist's full report and sends message to Dr. Jirjis asking 'what about my thyroid?'

4



Biopsy reveals thyroid cancer and cancer successfully excised

A doctor and a patient are looking at a tablet together. The doctor, a woman with blonde hair, is pointing at the screen. The patient, a man with dark hair, is looking at the screen. The background is a blurred hospital setting.

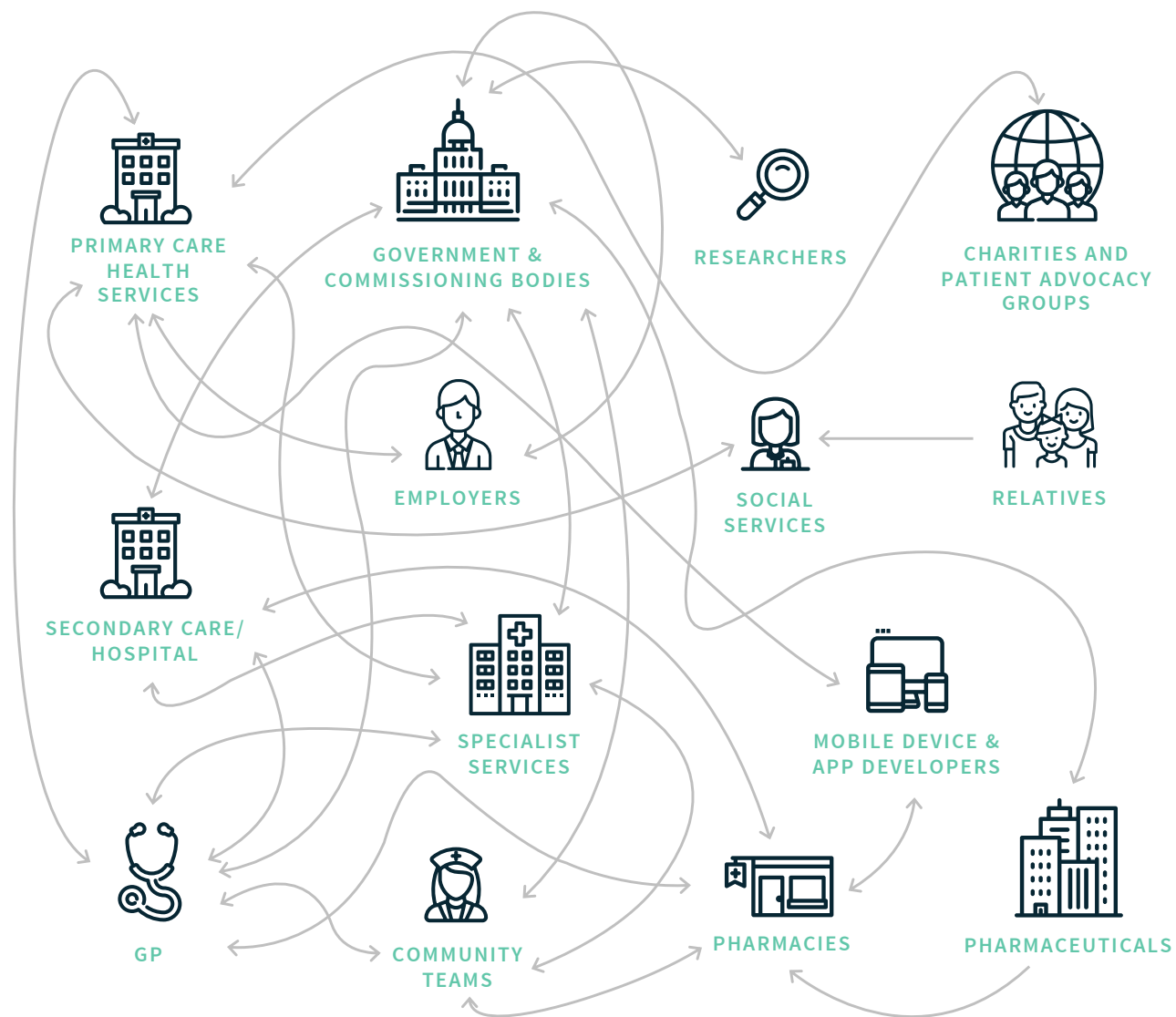
PKB: dealing
with the biggest
problem of all

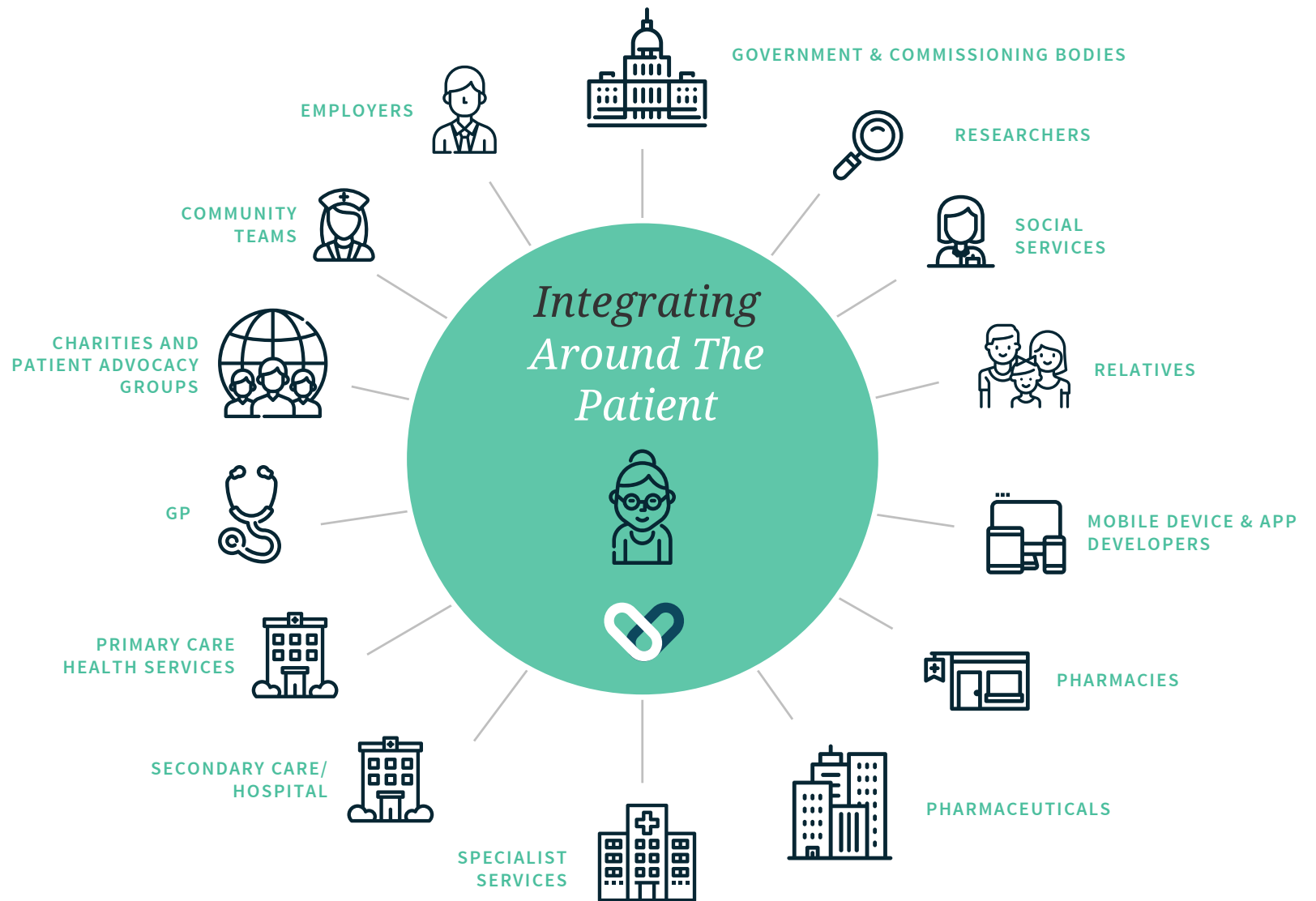


PATIENTS KNOW BEST®
MANAGE YOUR HEALTH

The Problem everywhere

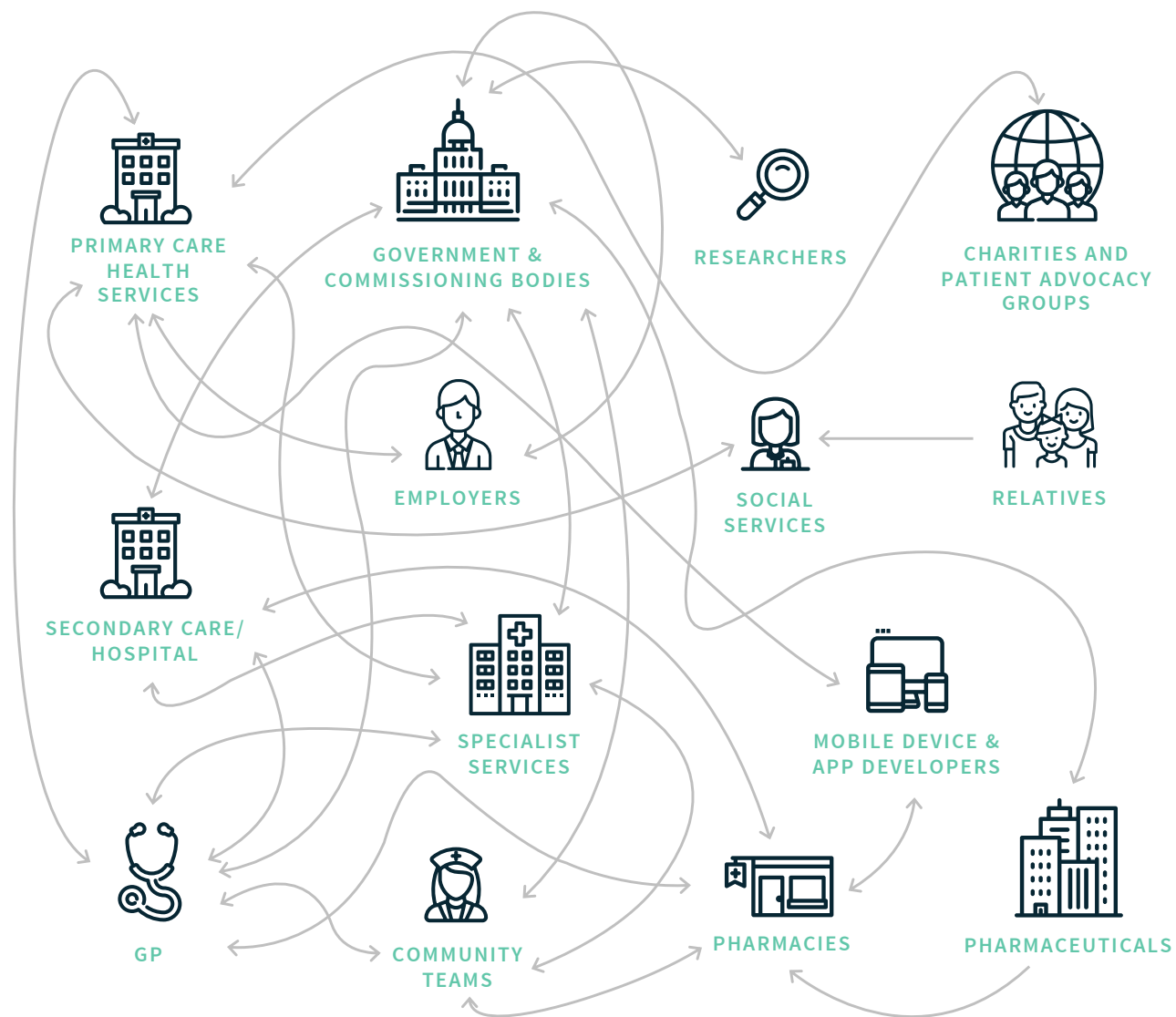
Every health economy
is like this





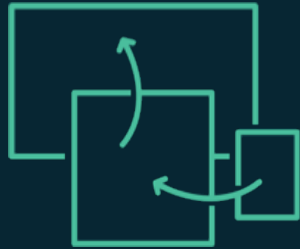
How do you get there from here?

- Difficult to connect
- Technical problems
- Legal issues
- Patient excluded
- No one feels in control



“Obvious” options are wrong options

*Governments and organizations
keep on getting this wrong*



- Patients' PHRs are useless without integration with provider EHRs
- Organisational portals prevented shared care
- Disease portals ignored multiple diseases
- Regional portals locked out other regions, local non-NHS... and the patient

GP



HOSPITAL
SERVICES

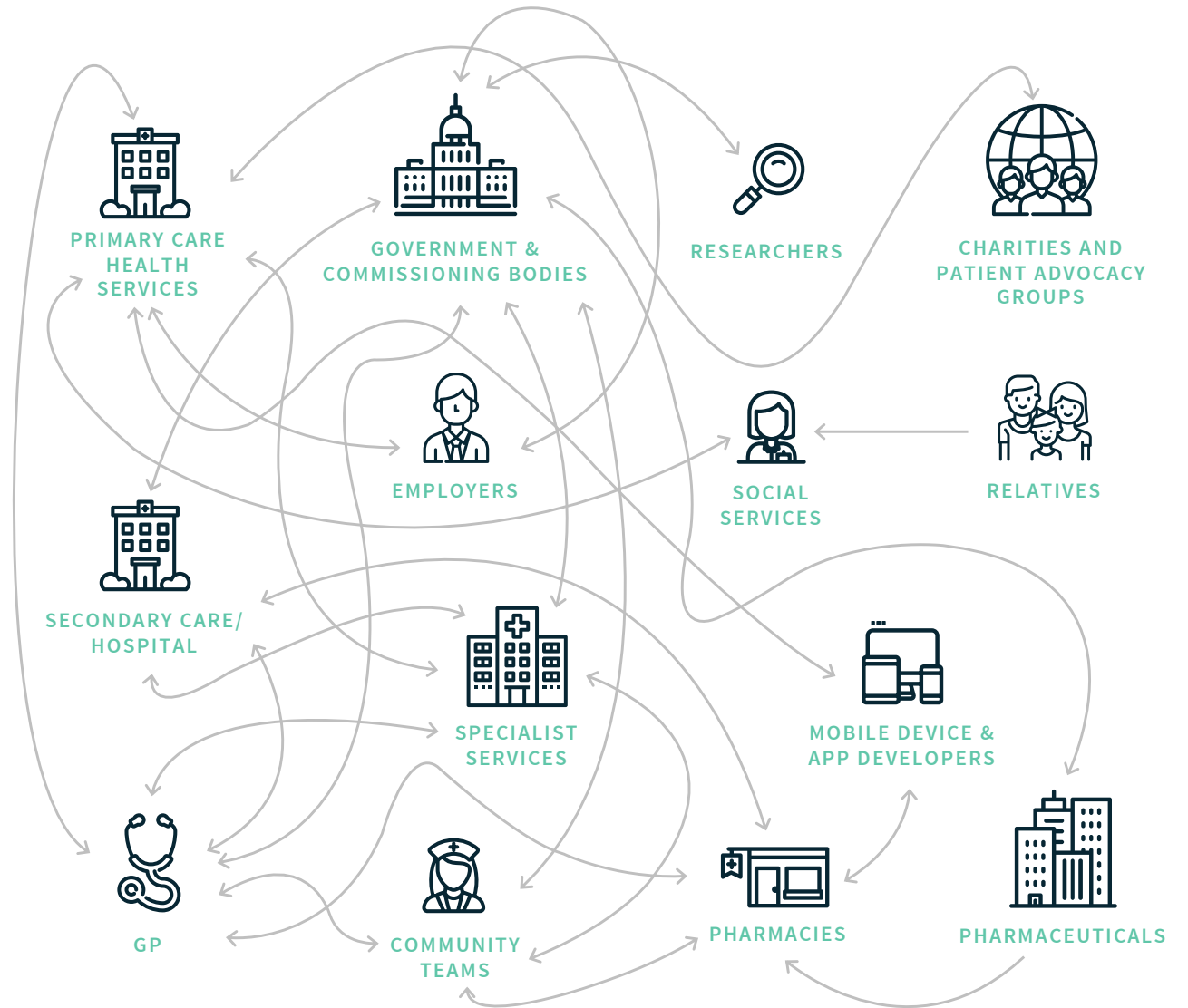


APPS &
DEVICES





*All these
approaches
forgot to use
the patient*





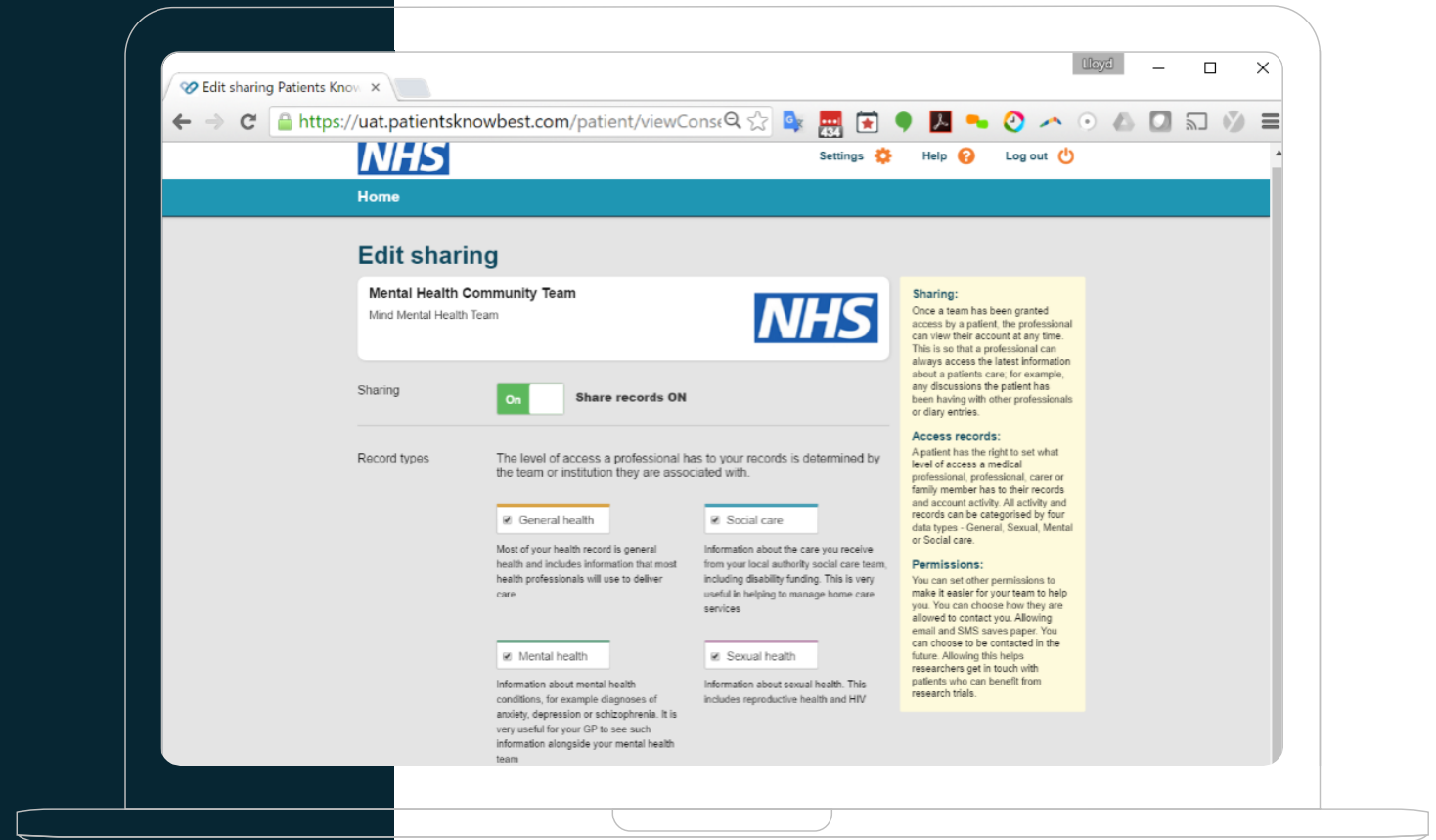
Patients *can* read records
And it's useful when they do



PATIENTS KNOW BEST®
MANAGE YOUR HEALTH

1. Sharing of information

- Patient control solves legal problems
- Explicit consent with granular privacy powers a **shared care record**, under the **patients control**
- Legally auditable '**break glass**' for professionals to manage access when permission cannot be obtained



2. *Digital first*

- Patients registering **saves cash and spreads information**
- Immediately send all letters electronically
 - Appointments
 - Lab results
 - Discharge summaries
- Impact:
 - All information in one place
 - Secure
 - Becomes embedded as part of the patient's healthcare experience
 - Immediate cash savings from reduced postal costs



GAINSHARE MODEL AVAILABLE FOR TRUST-WIDE OR REGIONAL SERVICES BASED ON E-LETTERS PROGRAMME

Create your account

Required fields *

Invite code *

Access code *

Date of Birth * Month

Email address *

Confirm email address *

Password *

Confirm password *

Security question *

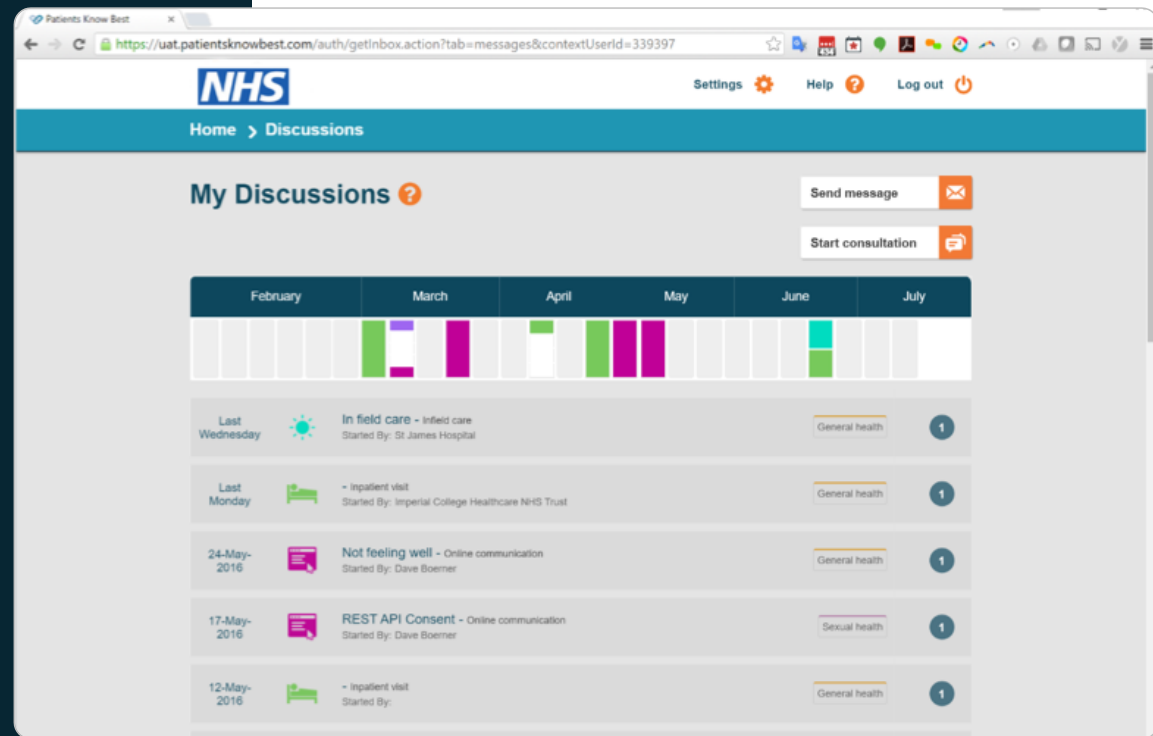
Answer *

☐ I have read and accept the Privacy Policy

☐ I have read and accept the User Agreement

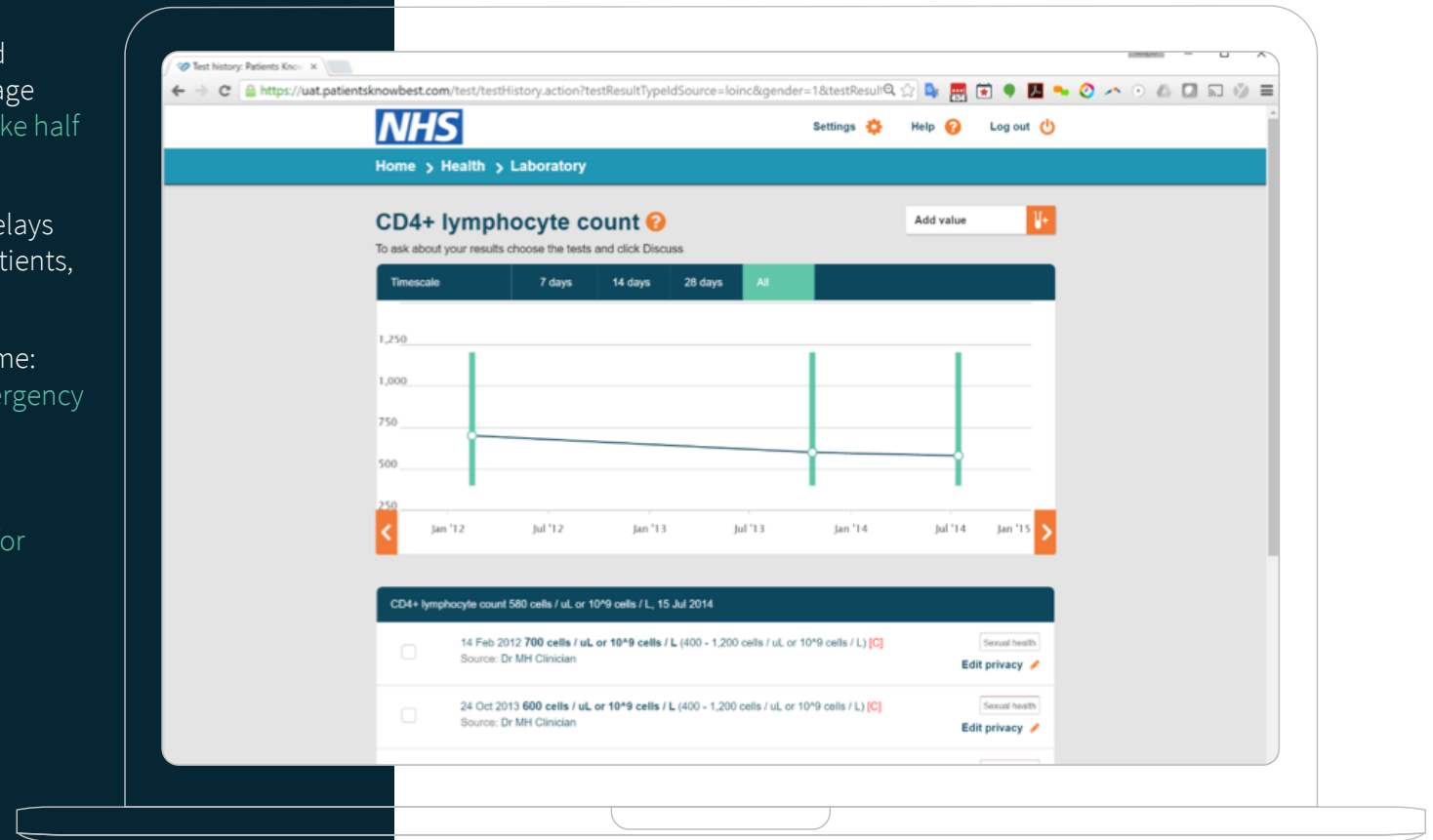
3. Messaging

- Mother of child with rare diseases knows more than most doctors treating the child... **she now has power and proof**
- Just-in-time better than just-in-case: push follow-up care to remote appointments and see more new patients in clinic
- Impact:
 1. Improved patient experience
 2. Increased throughput and efficiency of outpatient follow-ups
 3. Reduces unplanned appointments



4. *Tests and symptoms*

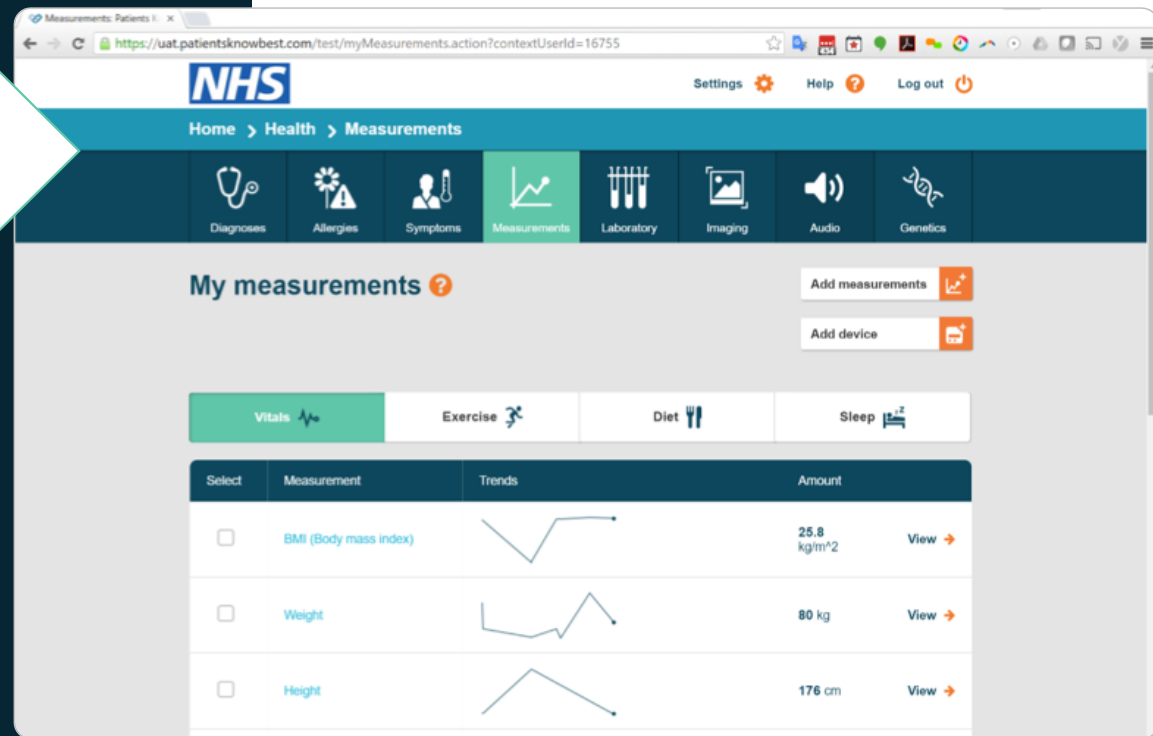
- HIV patients: 70% stable, need appointments to learn test results and update symptoms. Most are working age patients who don't want or need to take half a day off work to do this.
- Patient Online explains test results. Delays for distressing results (doctors, not patients, ask for this).
- IBD patients tracked symptoms at home: avoided clinic appointments and emergency room admissions.
- Impact:
 1. Reduces telephone calls/emails for checking lab results are back
 2. Reduces unplanned emergency admissions as deterioration spotted earlier
 3. Improves clinical safety as all lab results in one place



5. Telehealth, app and device connectivity



- Diabetes patients have more data than doctors do and administer dangerous drugs
- Patients' devices record clinically useful data which professionals' record systems cannot cope with
- Connected to over 100+ consumer devices and medical grade technology



6. Shared care planning

- Most care plan actions already carried out by patients
- Traditional care plans: patients rarely see and never edit so often make mistakes and sometimes give up
- PKB care plans: viewed and edited by everyone including patient
- Future care plans:
 1. Reduces unplanned admissions and service burden
 2. Provides continuity of care between services
 3. Allows lower cost services to provide care
 4. Empowers patients to self-assess and self-manage



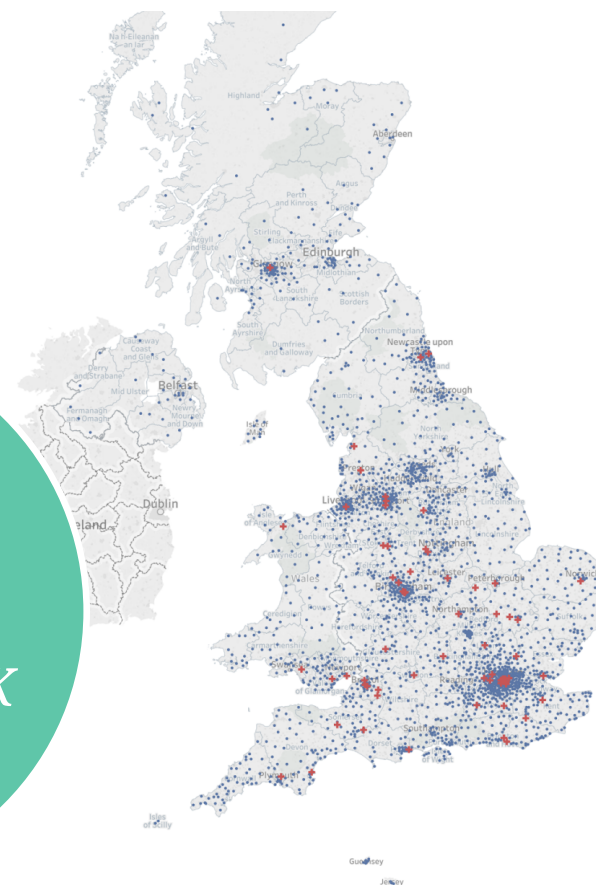
Borderless care is critical

*London: 20%
turnover in
GP patients*

*PKB now has
patient records
from every
county in the UK*



*Ireland:
highest
migration
in EU*



Borderless care is critical



A world map with a dark blue background and white location pins. Pins are located in North America, Europe, Asia, and Australia. A line connects the European pins to a text box.

*CarePoint.nl
and CMyLife
rolling out in
Holland*



A map of the United Kingdom with a dark blue background and white location pins. Pins are scattered across England, Scotland, and Wales. A line connects the pins in Wales to a text box.

*Patients'
data follows
patients'
care*

*Wales first
nation to put
patient
control*

A photograph of a male doctor with a beard and a female patient looking at a tablet together. The doctor is wearing a white lab coat and a stethoscope. The patient is also wearing a white lab coat. They are both smiling and looking at the tablet. The image has a dark blue overlay.

What should start-ups do

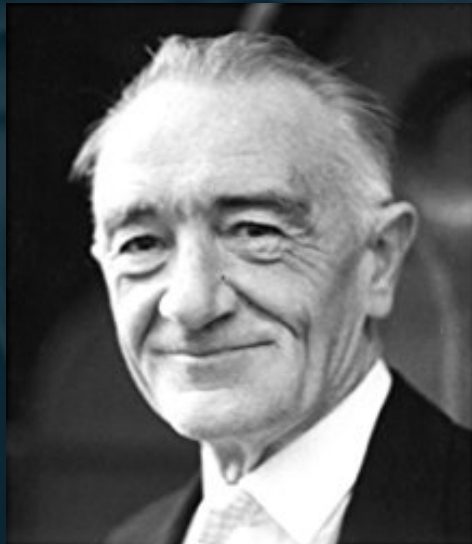


PATIENTS KNOW BEST®
MANAGE YOUR HEALTH

Stay alive long enough for health care's decision cycle

ONE MAN'S MACHINE

An autobiography of
Professor Archie Cochrane



Archibald L. Cochrane with Max Blythe

"An investigation into the workings of the clinical sector of the NHS strongly suggests that the simplest explanation of the findings is that this sector is subject to severe inflation with the **output rising much less than would be expected from the input**". According to a review in the British Medical Journal, "the hero of the book is the randomized control trial, and the villains are the clinicians in the "care" part of the National Health Service (NHS) who either fail to carry out such trials or succeed in **ignoring the results if they do not fit in with their own preconceived ideas**." [14]

Source: Dollery CT. [Constructive attack. Effectiveness and efficiency. Random reflections on health services \(AL Cochrane\)](#). Book reviews. Br Med J 1972;56.

Publish your processes

Great practice

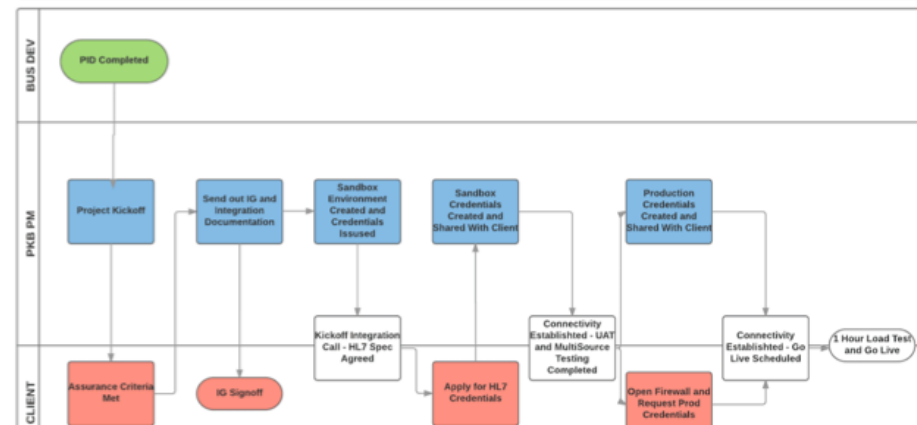
- Initially did for faster safer staff training
- Reduced customer support costs
- Increased customer trust
- Which increased customer acquisition: is your competitor so scared they need an NDA for their API?

But you must become great

HL7 Integration

We have created a generic task list to use with our deployments for HL7 integrations to give you an insight into what is usually involved (see image below). Each site has varying specifications so some additional tasks can be needed. We have based the due dates on the premise that the customer has a technical lead available for one day a week to work on integration.

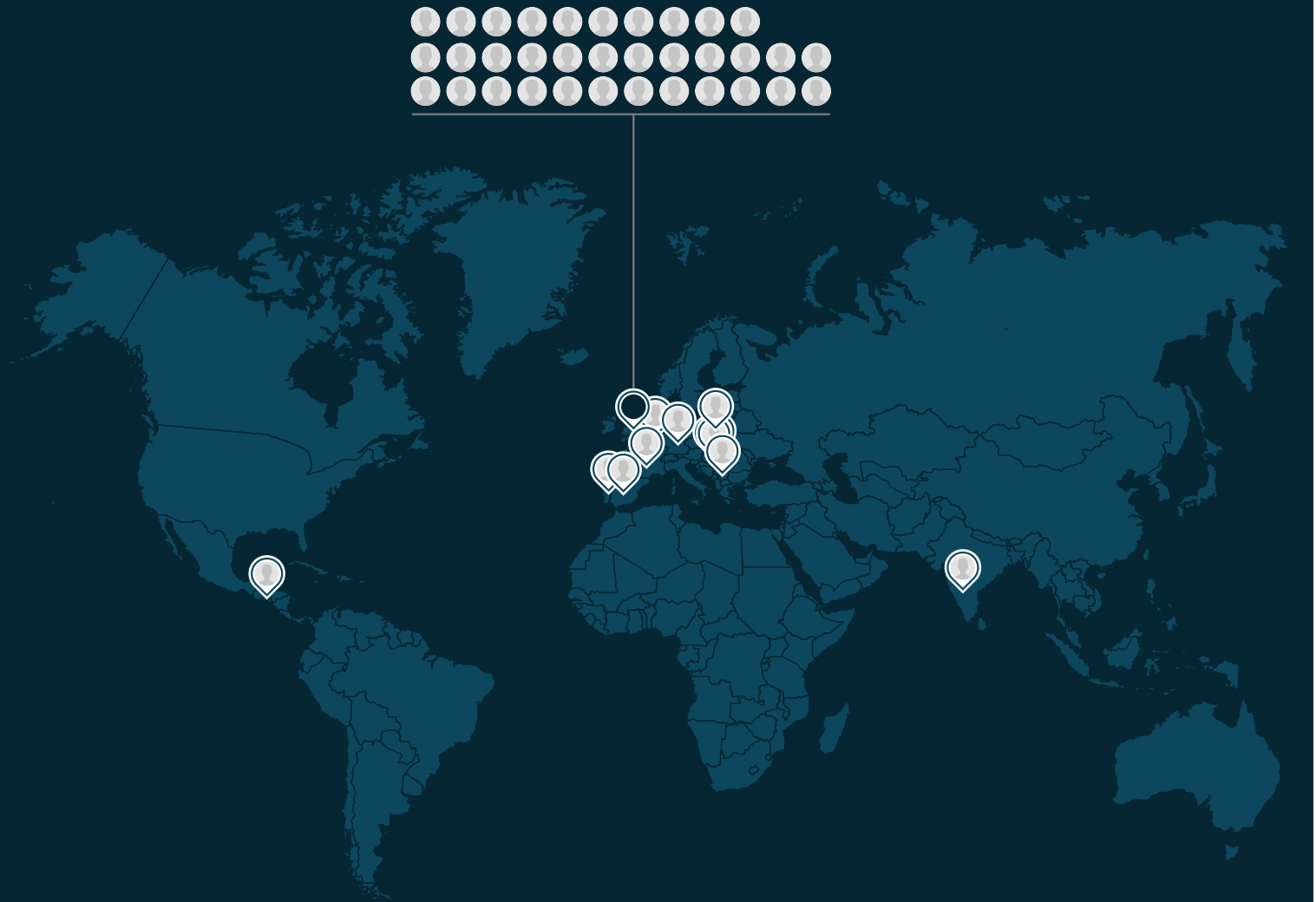
INTEGRATION STEPS



Hire locally, scale globally

Digital health allows doctor and patient to work without being in the same room... so you should know how to work with colleagues without being in the same room

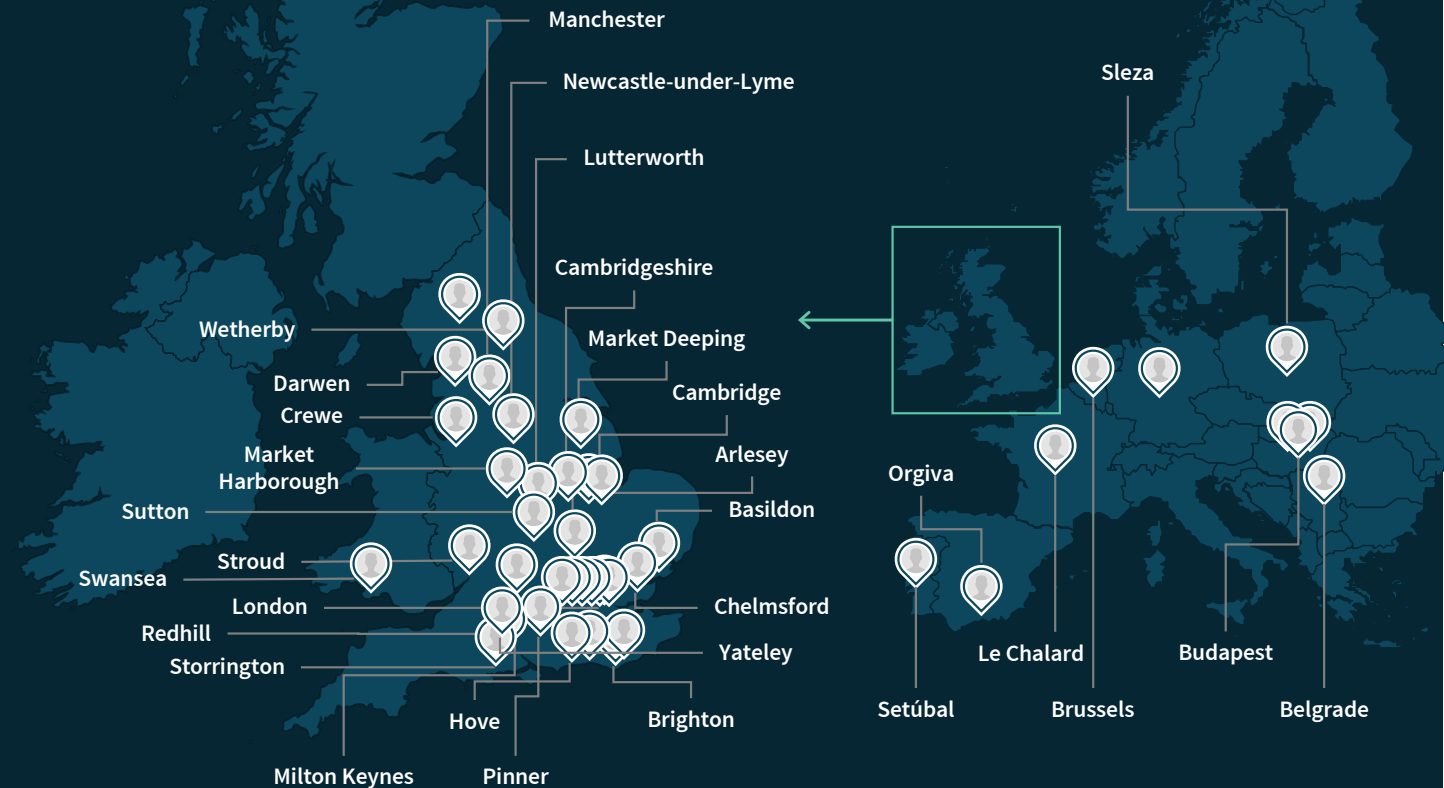
- Hire higher quality talent as they gain time with family
- Customers want your team working next to customer hospital not company home
- Distributed working forces good management habits
- Distributed working attracts independent hard workers (and scares off the rest)



Hire locally, scale globally

Digital health allows doctor and patient to work without being in the same room... so you should know how to work with colleagues without being in the same room

- Hire higher quality talent as they gain time with family
- Customers want your team working next to customer hospital not company home
- Distributed working forces good management habits
- Distributed working attracts independent hard workers (and scares off the rest)



Partner locally, scale globally

Health care's trust built on highly local relationships

- Lastminute.com found fellow entrepreneurs across Europe
- CarePoint.nl's approach: iterative, innovative, effective
- Easy to bring on partners if already distributed team and publish processes
- Want to partner with PKB in Ireland? (We're looking!)



The screenshot shows the CarePoint website. The header features the CarePoint logo (a red square with a white grid and a person icon) and the tagline "De schakel tussen Zorgproces en ICT Oplossing". Below the header is a grey navigation bar with a "MENU" button and a search bar labeled "Typ zoekwoord". The main content area has a sidebar on the left with a red header "IK BEN..." and a list of roles: "Medisch specialist", "Verpleegkundige", "ICT", and "Inkoop". The main content area displays a headline "VIPP-Portaal-PGO-Transmuraal? 5,5 miljoen Britten hebben een PGO!" in red. Below this is a paragraph of text and a sub-headline "Portaal achterhaald?". A large graphic of a blue infinity loop with the text "PKB uw PGO" is shown. To the right of the graphic is a paragraph of text. At the bottom, there is a small paragraph of text.

CAREPOINT
ZORGPROCES ICT

De schakel tussen **Zorgproces** en **ICT Oplossing**

MENU

Typ zoekwoord >>

HOME / PGO - PATIENTSKNOWBEST.COM

IK BEN...

- Medisch specialist
- Verpleegkundige
- ICT
- Inkoop

VIPP-Portaal-PGO-Transmuraal? 5,5 miljoen Britten hebben een PGO!

's Werelds eerste patiënt-gestuurde elektronisch medisch dossier Patients Know Best (PKB) (www.patientsknowbest.com) is nu al beschikbaar voor 5,5 miljoen Britten. "De patiënt staat bij ons centraal" is daardoor voor hen een feit en niet een goedbedoelde volzin in het jaarverslag van een zorginstelling.

Portaal achterhaald?

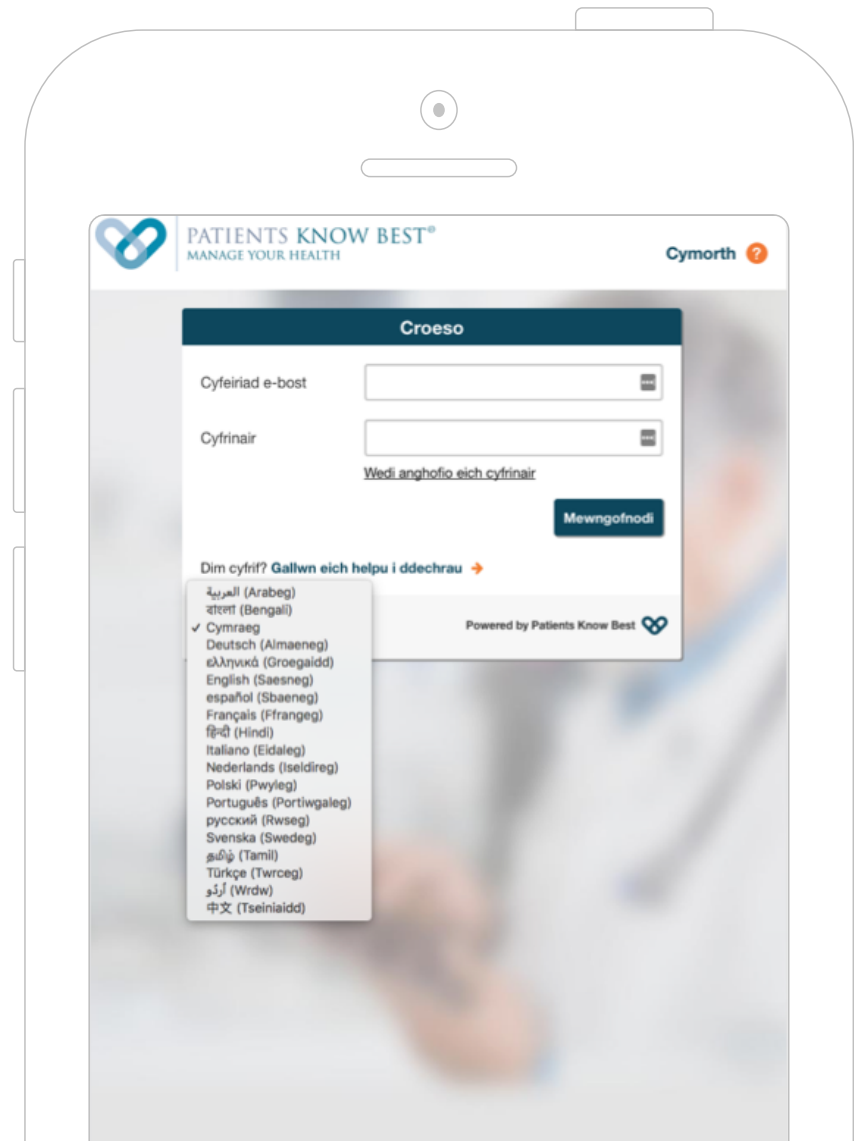
PKB ondervangt de vaak gehoorde klacht van de Patiëntenfederatie dat zijn/haar zorgverleners te weinig met elkaar communiceren. De reden is dat PKB rondom de patiënt is opgebouwd en van alle betrokken zorgverleners het dossier en de actuele aanvullingen daarop ontvangt, zoals door MedMij beoogd.

Een portaal is meestal door een bepaald ziekenhuis opgezet en geeft slechts inzicht in het ziekenhuisdossier. De patiënt heeft echter behoefte aan een totaalbeeld. Een dossier dat in termen van Value Based Healthcare waarde heeft, moet dus ook de dossiers van huisarts, apotheker, andere ziekenhuizen en niet te vergeten zijn eigen toevoegingen bevatten.

PKB kan nu al aan meer dan 100 wearables en apps koppelen. Een portaal van uitsluitend het ziekenhuis is dus een "Ziekenhuisportaal" en geen "Patiëntenportaal of PGO"

Make scalable product decisions

- Aim for internationalisation from day 1 (PKB works in 19 different languages including Welsh)
- Avoid home country's idiosyncrasies





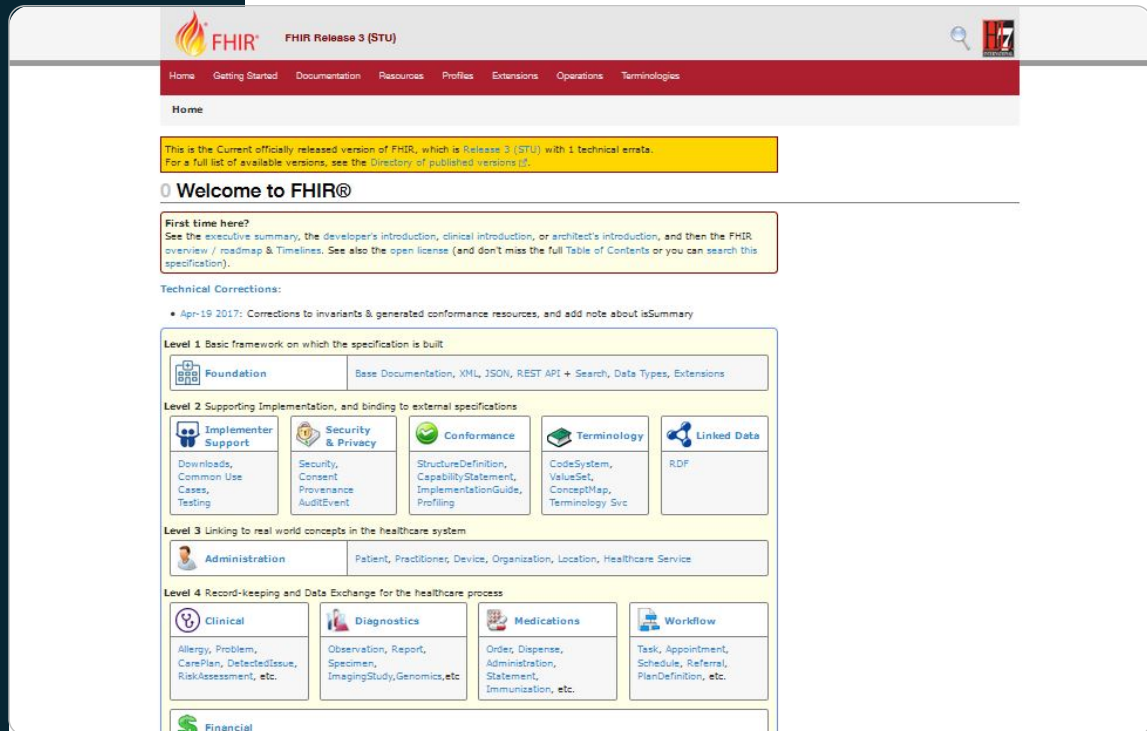
What should governments do



PATIENTS KNOW BEST®
MANAGE YOUR HEALTH

Don't lock your start-ups into small national market through local standards

- NHS England complains about GP oligopoly even as it heaps more England-only specifications. They cannot buy the best from the world
- Denmark and Estonia started world-leading infrastructure but companies only local. They will soon be overtaken by larger markets' offerings
- Australian government still failing with MyHR
- Governments should build local roads so cars from anywhere can drive on them
- FHIR, LOINC, Snomed, etc.



Allow *pension funds* to invest in *venture capital funds*



VAN PHILLIPS,
inventor of Flex-Foot Cheetah

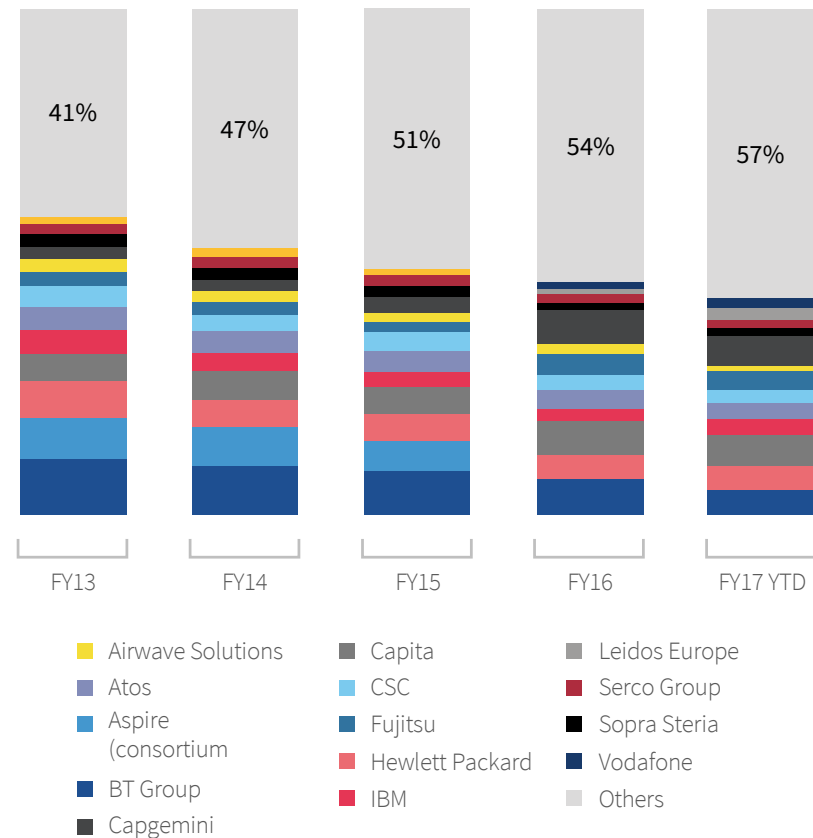
- 1979: US government relaxes “prudent man rule” allowing pension funds to invest in venture capital funds
- Today 50% of US VC funds are from pension funds
Source: [Entrepreneurship and Innovation in Evolving Economies: The Role of Law p9](#)
- Back your inventors by backing your investors
- Adding the tax-payer as an investor: two wrongs don't make a right

Buy from SMEs you need the innovation. Buying big doesn't mean reducing risk



Source: [The Guardian](https://www.theguardian.com)

PROPORTION OF GOVERNMENT ICT & BPO PROCUREMENT SPEND GOING TO TOP SUPPLIERS (%), FY13-FY14YTD



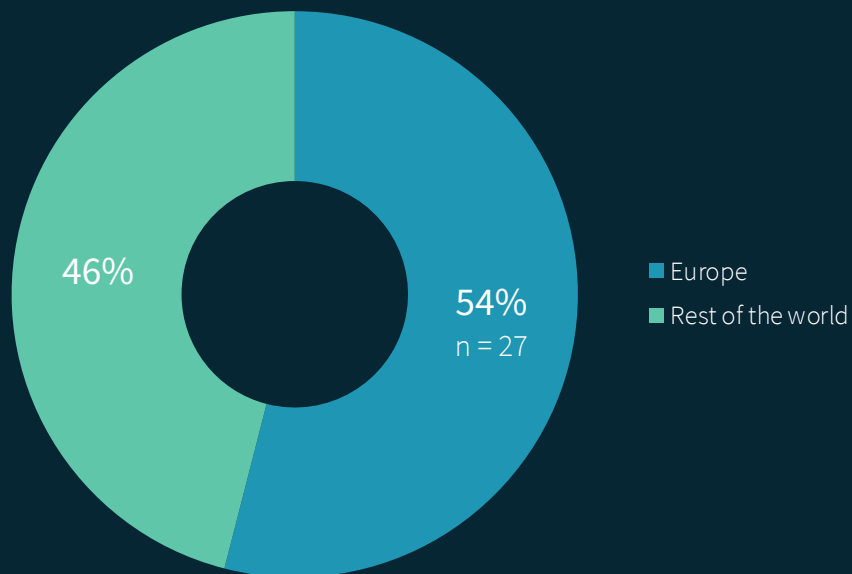
Source: [State of the UK Govtech market](https://www.gov.uk/government/news/state-of-the-uk-govtech-market)

"Europe accounts for just over 7% of the world's population, 25% of its economy, and 50% of global social welfare spending."

George Osborne, 15 January 2014, quoting German Chancellor Angela Merkel

GOVERNMENT EXPENDITURE, PERCENTAGE OF WORLD TOTAL

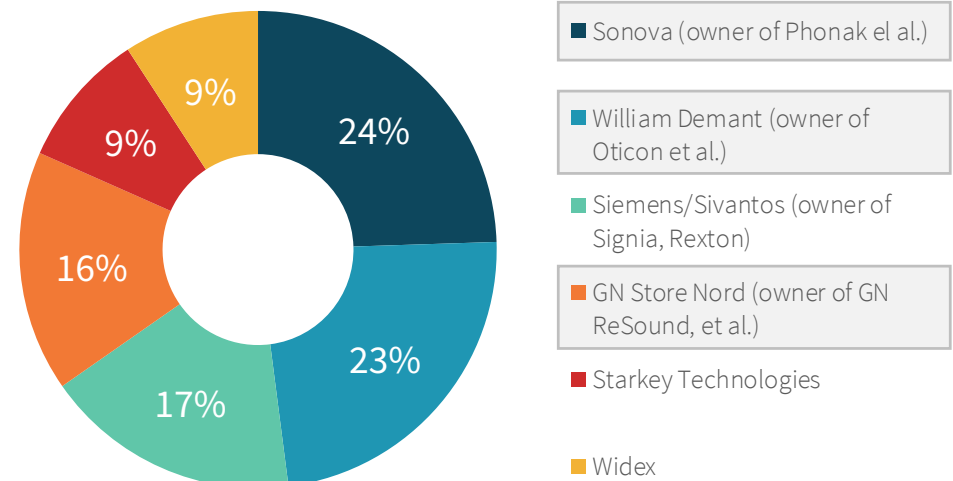
Social protection (n = 96)
2004-09



Source: [Full Fact](#)

Done right, this is *Europe's opportunity*

3 DANISH HEARING AID MAKERS ACCOUNT FOR 63% OF GLOBAL MARKET



1961

Denmark one of first countries to provide universal healthcare.
Hearing aids provided free of charge to Danish citizens.

Source: [Hearing Health and Technology Matters](#)



PATIENTS KNOW BEST®
MANAGE YOUR HEALTH

PATIENT PORTAL

CITIZEN RECORD

IDCR (CLINICAL PORTAL)



@patientsco



www.patientsknowbest.com



enquiries@patientsknowbest.com
