Thankyou for inviting me. It has been a great pleasure to take part in the workshops of GNU Solidario. I have attended seven more GNU conferences before this one:

2016 Gran Canaria “Electronic Health records and the European Union –current legislation and future directions. A perspective”

2017 Gran Canaria "Risks and opportunities for citizens from personal health data processing in the twenty first century.“

2018 Gran Canaria ” Emerging Global Health care records standards
How do we capitalize and direct the revenue from health data?”

2019 Liege Belgium “Medical Information Sharing Agreements, Data Protection Impact Assessments, Staff and administrative Data Security”

2020. “No longer a passenger - being prepared for future patient navigated Medical Records”

2021 Virtual “Open Notes, Patient autonomy, culture change and Patient Agency”

2024 Sicily, Palermo “Can, will, - or do - patients own their life-long records?”

2025 Virtual “"Patients using their records, Dr Bot, and AI to think critically to protect their health”

I have been involved in other international meetings , including with meetings of the WHO as well as with GNU Solidario:----

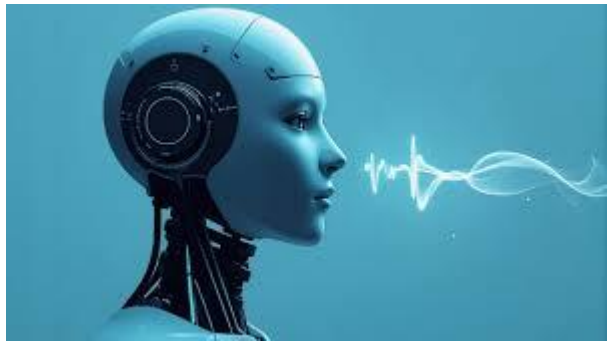
“We are in the middle of a tectonic move in healthcare”

- Every person will be empowered to use their health records and AI to protect their own health and the health of others”.
- Patients, health care professionals, and AI, such as “Dr Bot” will work together globally in what is being called triadic care.

“Every person will be empowered to use their health records and AI to protect their own health and the health of others”?

September 2023 – WHO Patient Safety Charter

GNUHealth



Human-AI teaming in healthcare: 1+1>2?

PengLiu1 , Jiaxin Zhang1,2,ShuaiqiChen1,2 & Shanguang Chen3 Nature HPJournal - Hangzhou and Beijing

"The extent to which human–machine teaming (HMT) realizes the potential of humans and AI-powered machines to complement each other—("1+1>2")—remains uncertain. Results from 52 empirical studies in clinical settings show that medical AI can augment clinician performance. Two factors matter:

(1) teaming mode, - clinicians reviewing diagnostic cases and AI outputs concurrently yields greater benefits than when clinicians make initial judgments before reviewing AI outputs; and

(2) clinician expertise,- junior doctors benefit more than senior doctors.

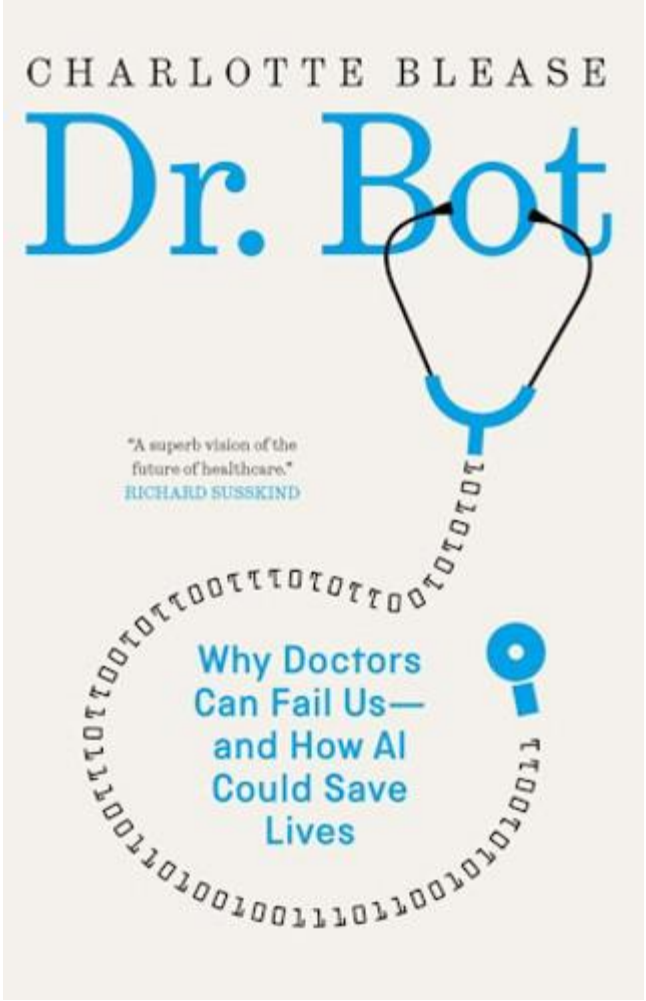
We also addressed how to predict or explain HMT reliability, and how to achieve clinically significant improvements. These findings advance understanding of human–AI collaboration in safety-critical domains"

How does AI compare to a doctor when it comes to saving lives?

Doctors are under-resourced and face unprecedented levels of stress, with rising patient numbers and ever developing medical knowledge. But at the same time, they are all too human, prone to racial, class and social biases that affect the care patients receive.

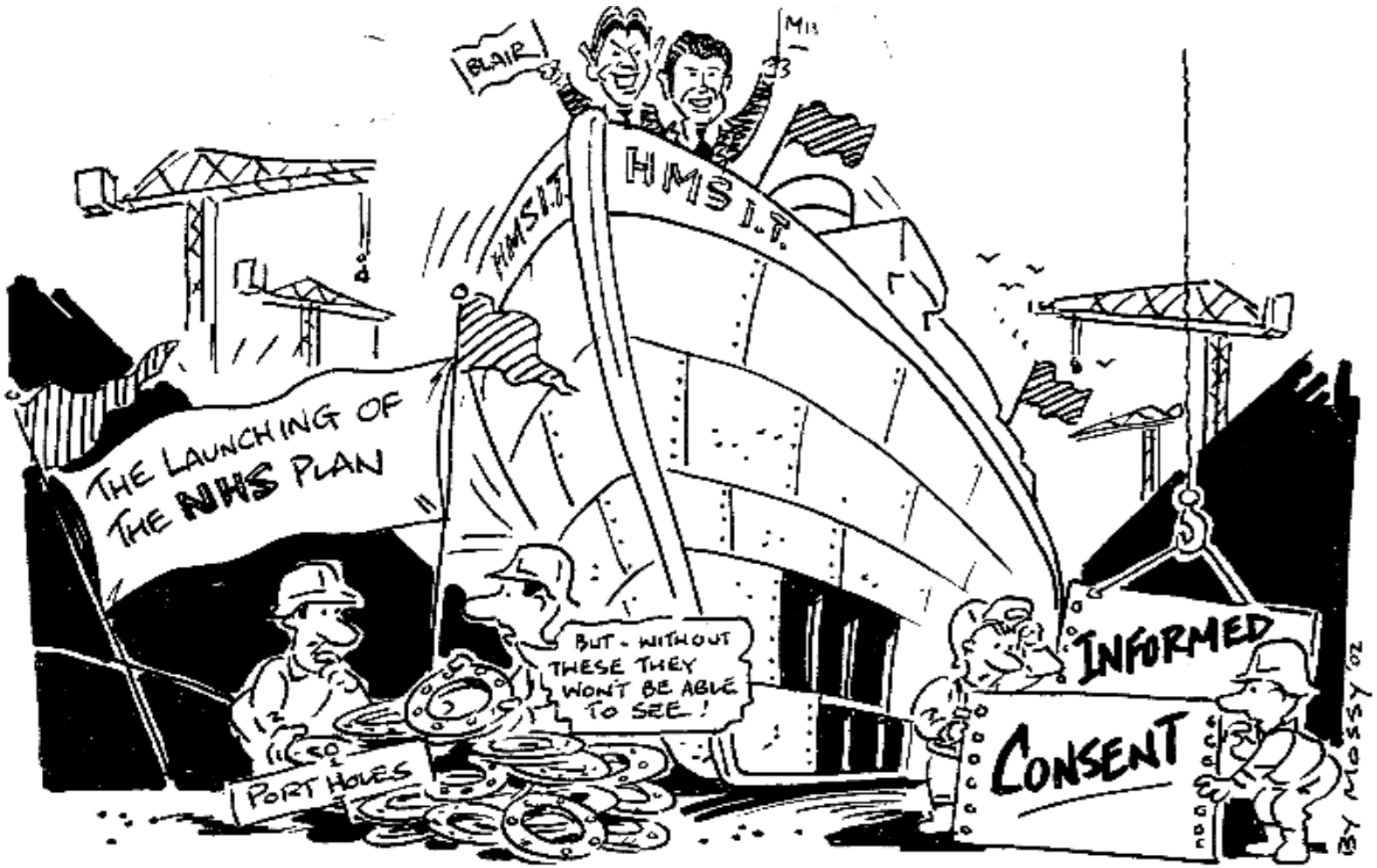
Can we improve patient experience and alleviate the burdens of doctors at the same time?

In this groundbreaking study, Charlotte Blease reveals how AI, if handled with care, could emerge as the most reliable physician in history. Drawing on interviews with authorities in AI, doctors and patients, Blease shows how technology – despite some resistance – is already making a difference. From diagnosis and second opinions to treatment and aftercare, AI has the potential to revolutionise our healthcare.

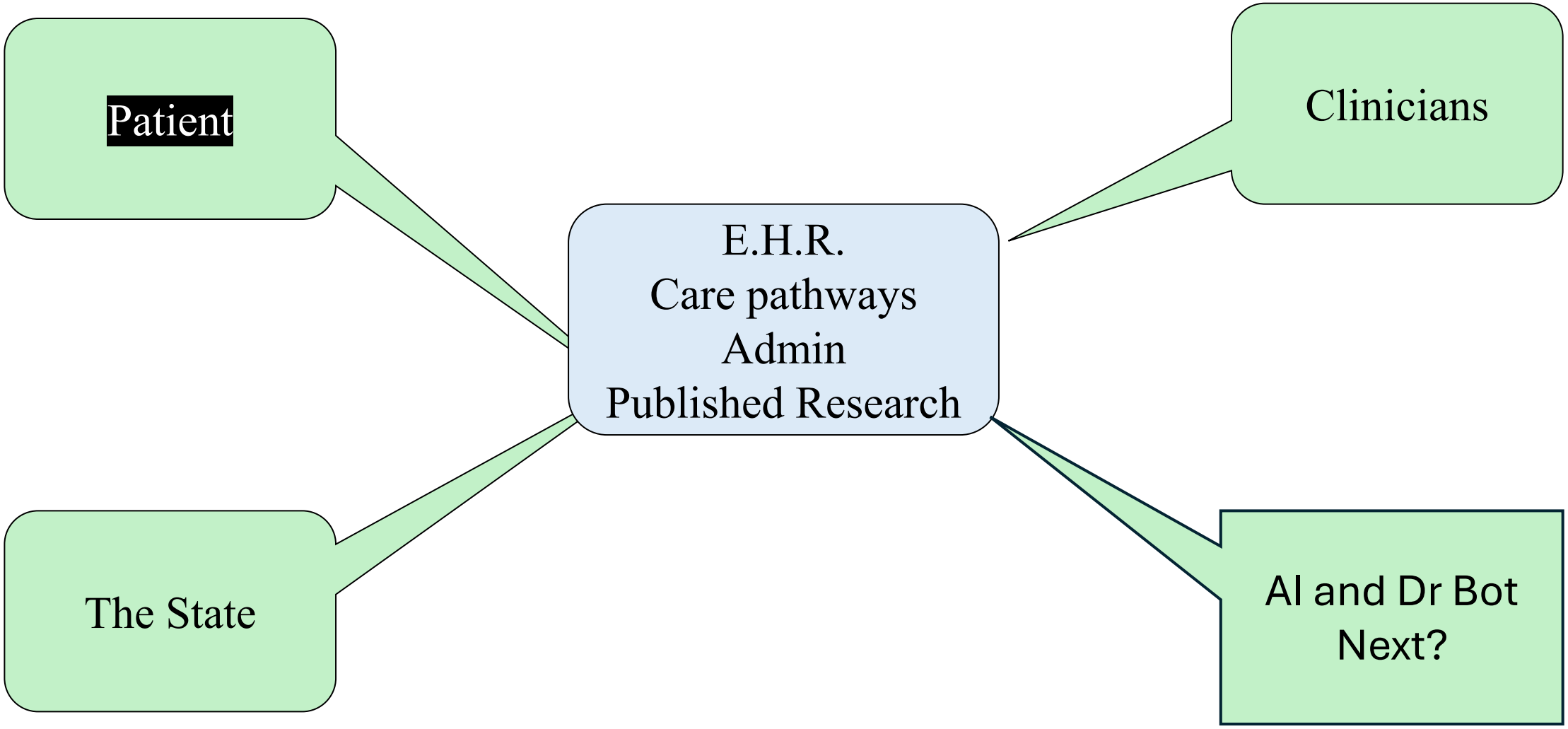


"Patients using their records, health apps, portals, Dr Bot, and AI to think critically about their health and diseases

The NHS Plan 2000 had bold ambitions



25 years later, the NHS app portals is beginning to realise that plan. Patients can now access the Electronic Health records, care pathways, research, and explanatory information,



Patients can use the NHS app to:

To See medical record

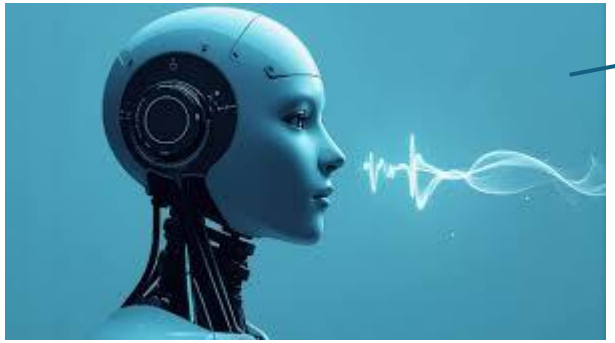
To order prescriptions

NHS App

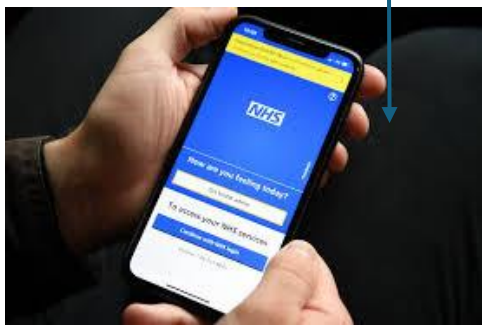
To search trusted NHS information

To books appointments

Patients who still cannot work out what to do can consult a healthcare professional, or AI



AI



If the patient chooses to consult with the HCP, the HCP examines, diagnoses, explains, chooses a care pathway, and creates a record. The patient reads the record, and can share the record with a trusted partner

The patient consults the doctor,

the doctor examines the patient,

The doctor makes A diagnosis

The doctor chooses a care pathway

The doctor explains to patient

The doctor creates a record

patient checks the record

shares record with partner

Each step may be executed face-to-face, by post, by telephone, e-mail, app, telecommunication or by other means and has a digital code to represent the steps of the clinical care pathways.

Yes! I understand.

Oh! I don’t understand.

Microsoft House London
opening of Microsoft
Healthvault

24th September2008
Microsoft Healthvault
closed in 2019

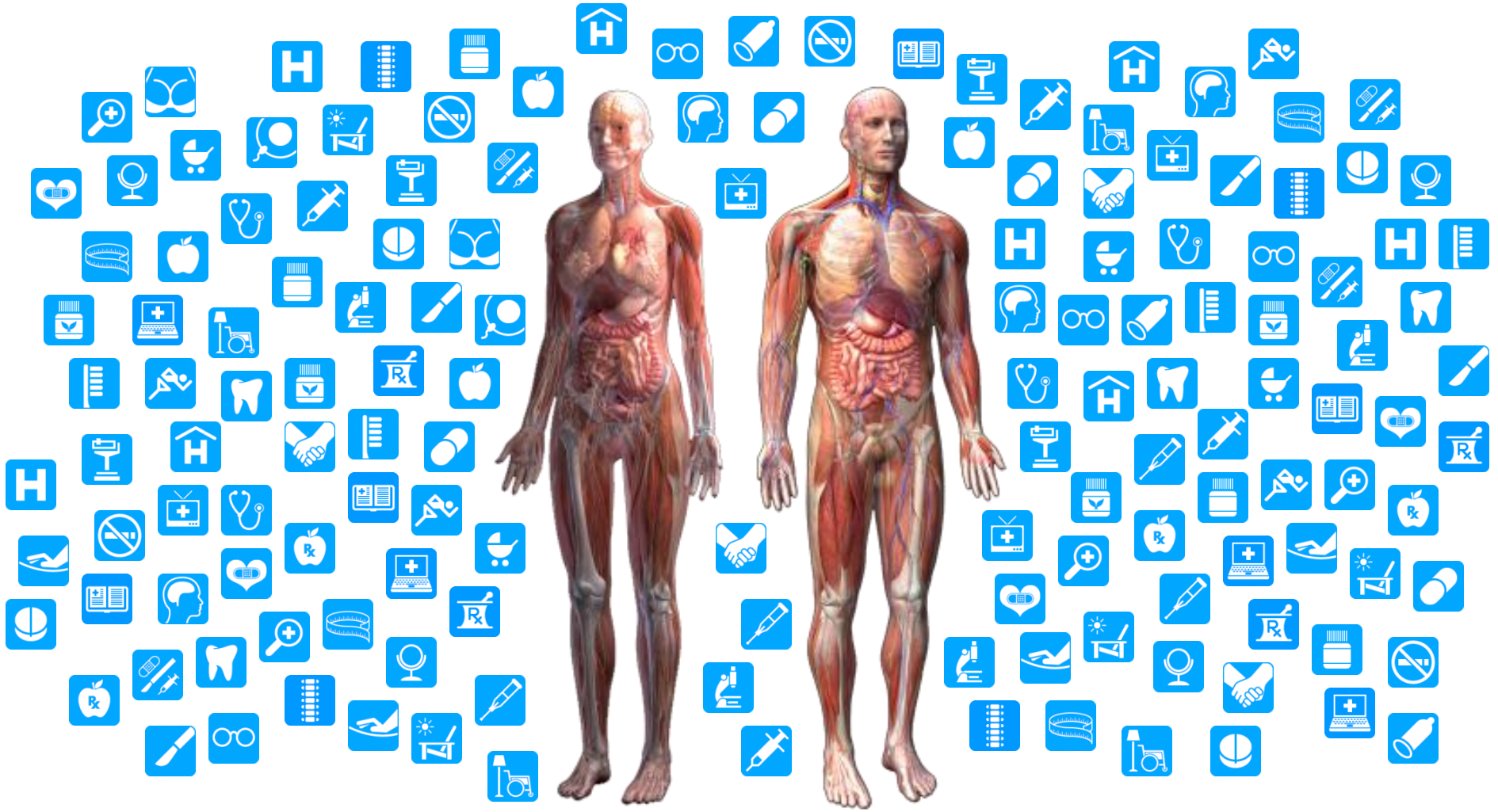
copernican shift

CHANGING THE HEALTHCARE PARADIGM

Microsoft

Health Management 100’s of care pahways

Health Management – 100’s of care pathways



Patient understands, agrees and consents to take part in care pathway

We figured out how healthcare *really* works — health is managed in the *home*

Family Health Manager (FHM)

FHR

"Family Health Manager" or **FHM** runs the **FHR**

Prioritized Family Health Record (FHR)

PHR

Minor
FHM has **FULL ACCESS**

PHR

Minor
FHM has **FULL ACCESS**

PHR

Senior
FHM may have **FULL** or **PARTIAL ACCESS**

PHR

Pet
FHM has **FULL ACCESS**

PHR

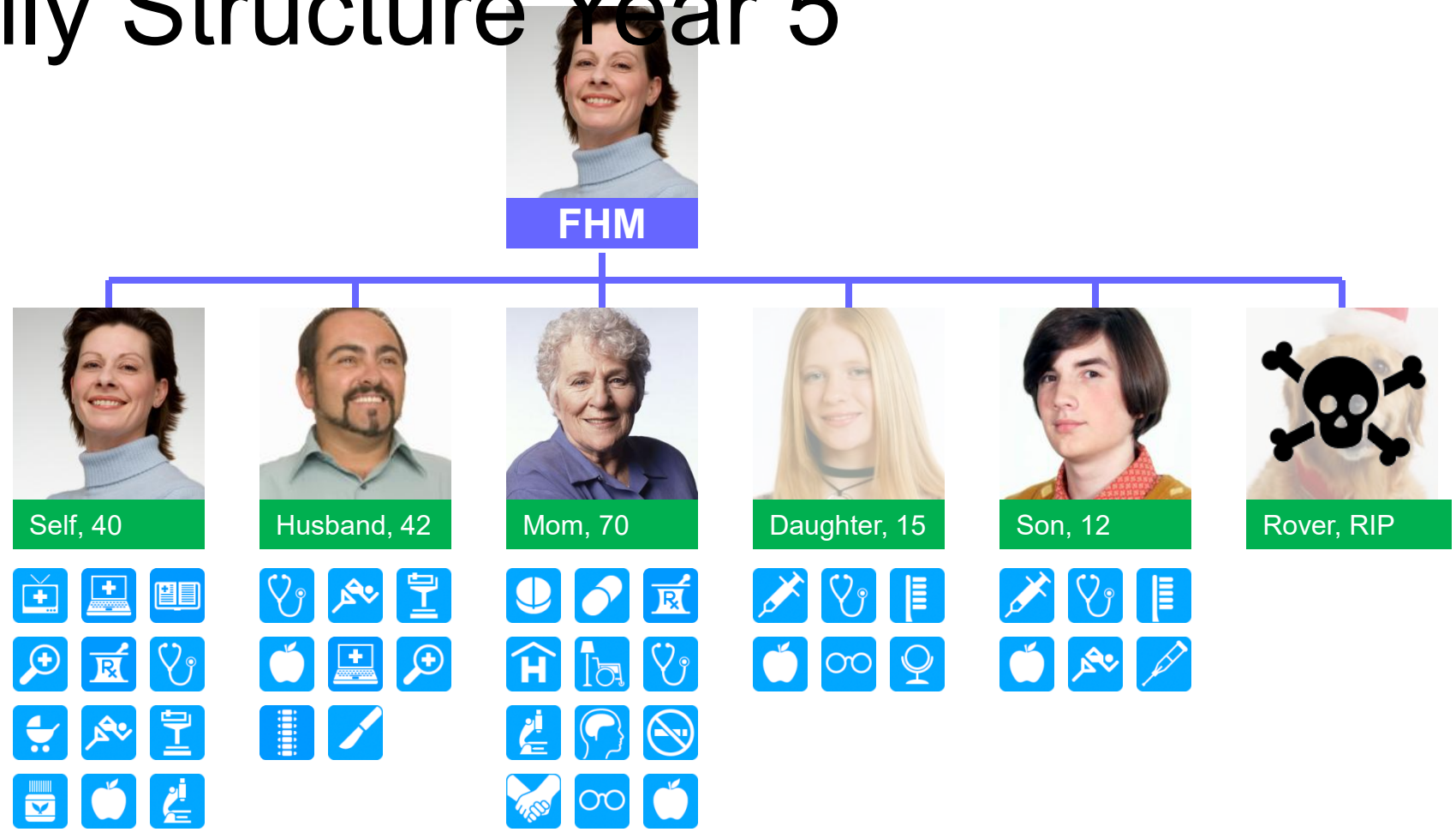
Self
FHM has **FULL ACCESS**

PHR

Spouse
FHM has **PARTIAL ACCESS**

High Priority → *Low Priority*

Family Structure Year 5



Family Structure Year 0

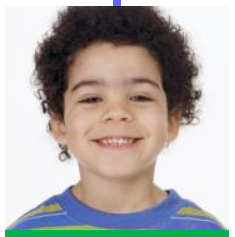
The "Family Health Manager" or **FHM**

FHM

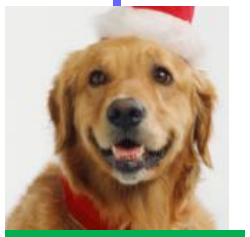
Self, 35

Husband, 37

Daughter, 10



Son, 7



Rover, 8

Family Structure Year 10

FHM

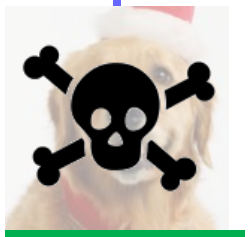
Self, 45

Former Husband, Who cares how old he is?

Mom, RIP

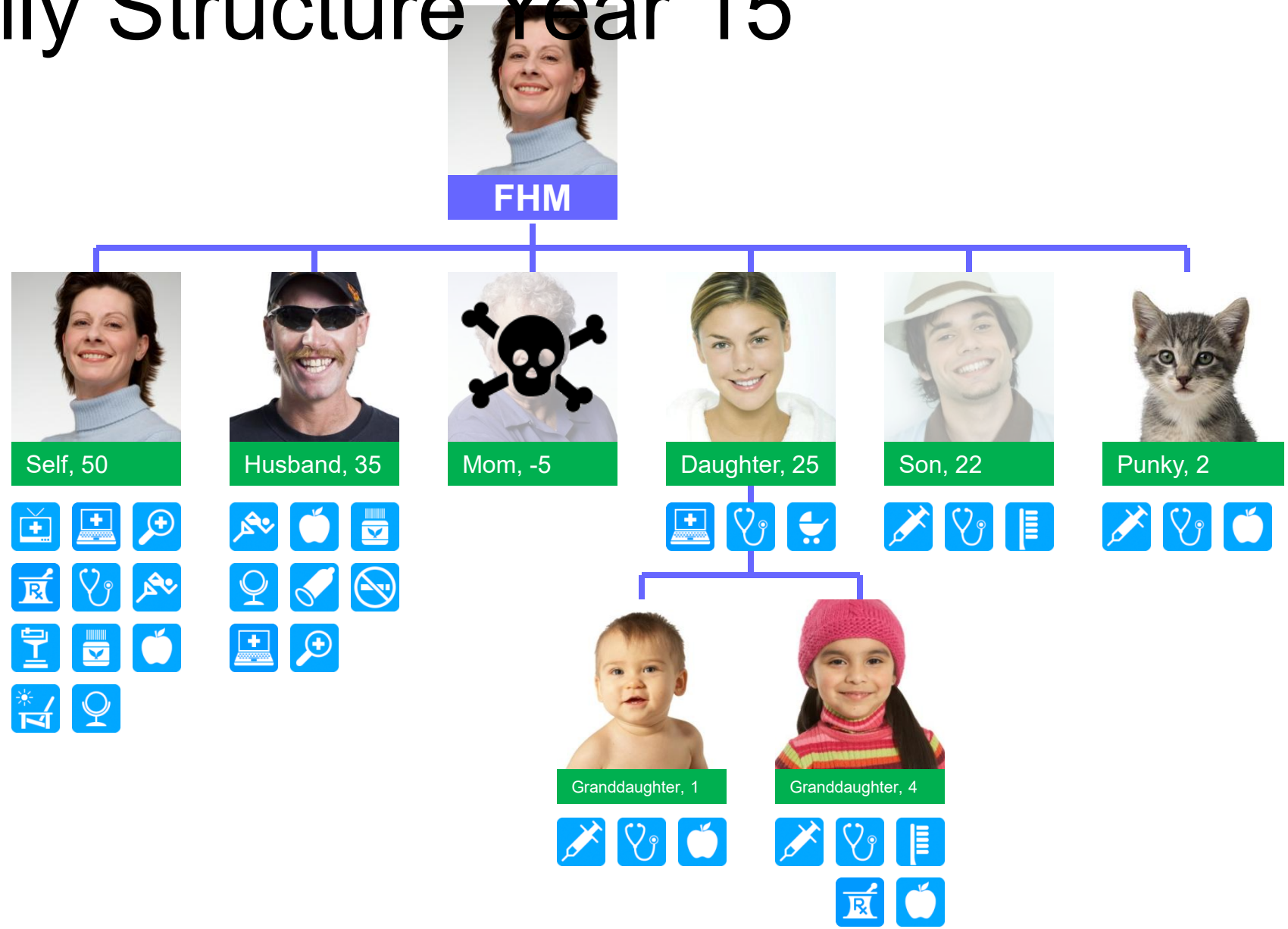
Daughter, 20

Son, 17



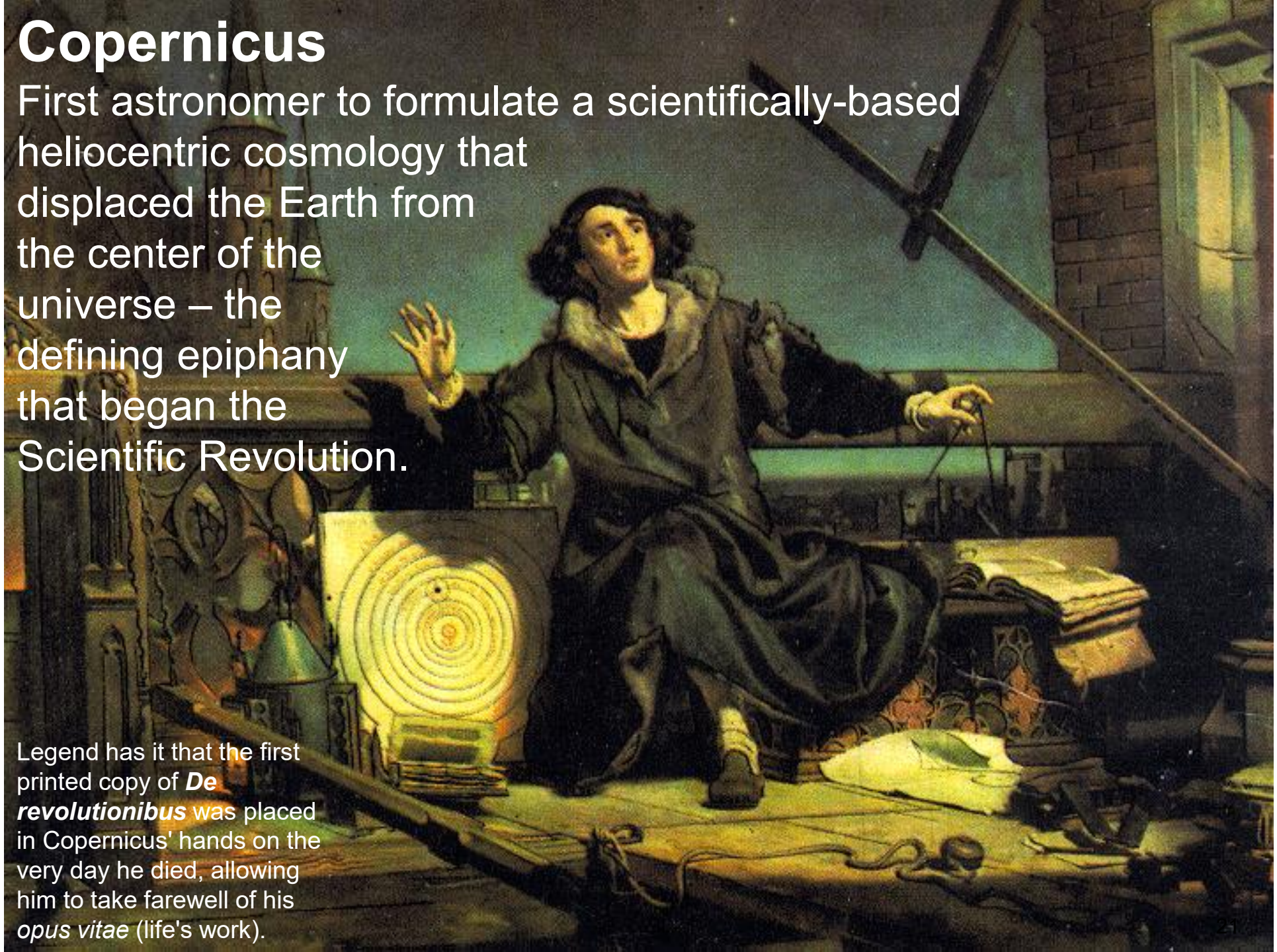
Rover, -5

Family Structure Year 15



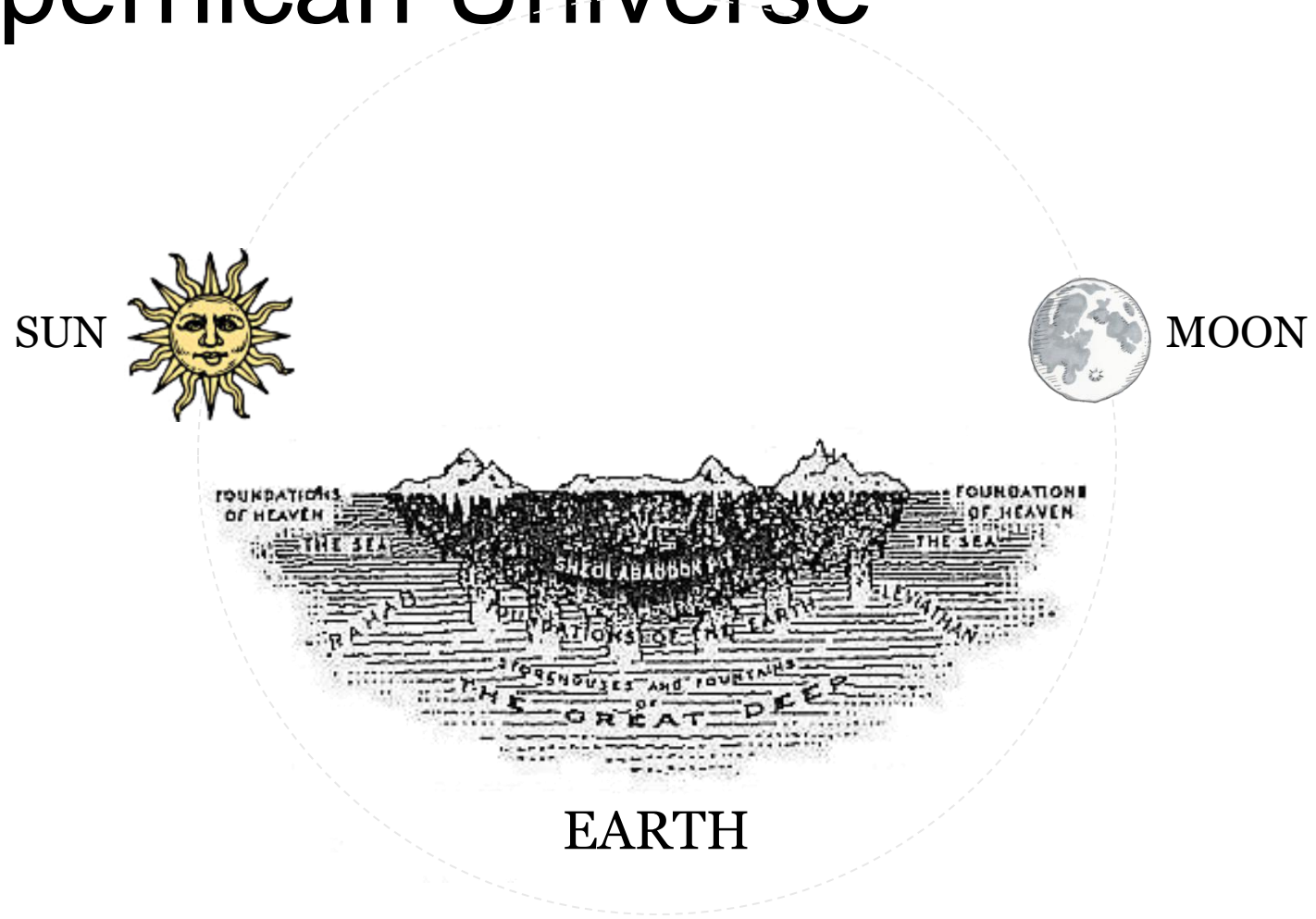
Copernicus

First astronomer to formulate a scientifically-based heliocentric cosmology that displaced the Earth from the center of the universe – the defining epiphany that began the Scientific Revolution.

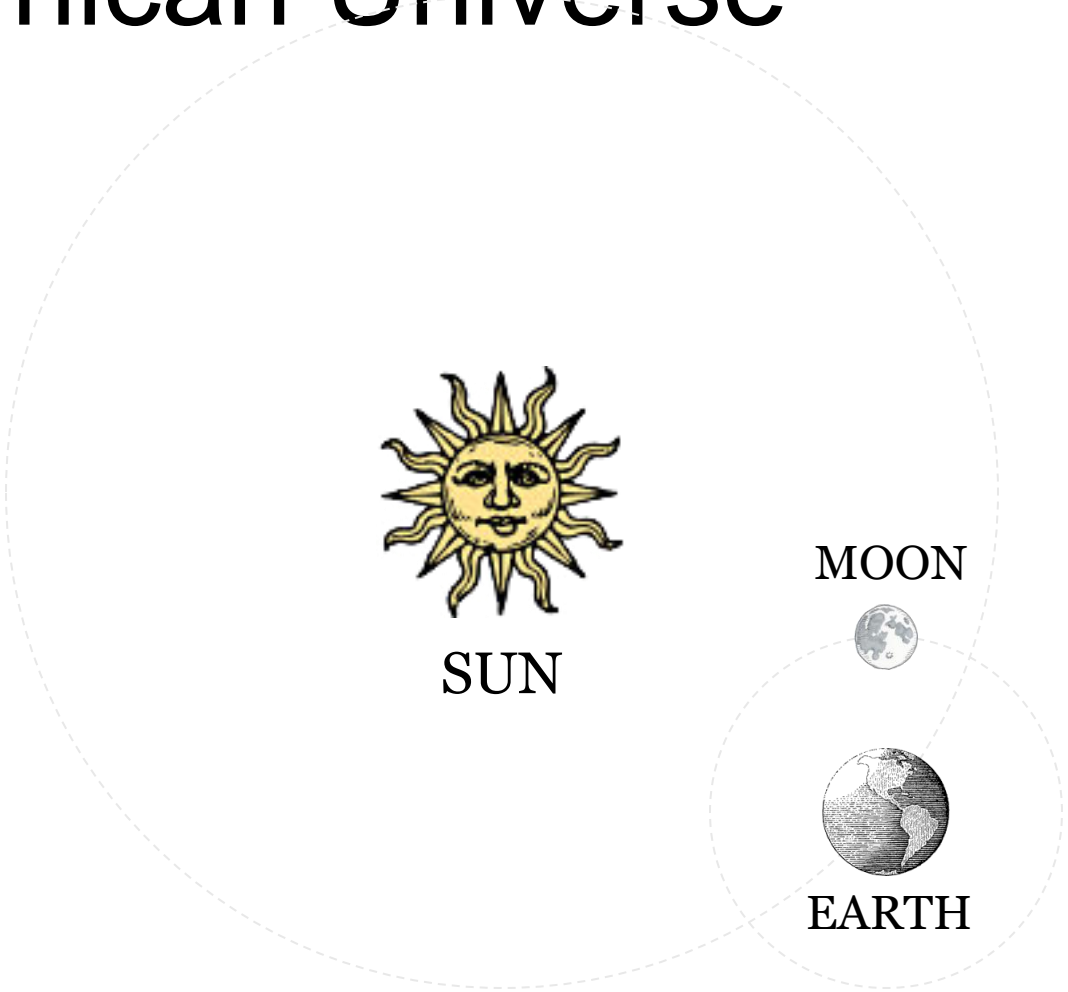


Legend has it that the first printed copy of ***De revolutionibus*** was placed in Copernicus' hands on the very day he died, allowing him to take farewell of his *opus vitae* (life's work).

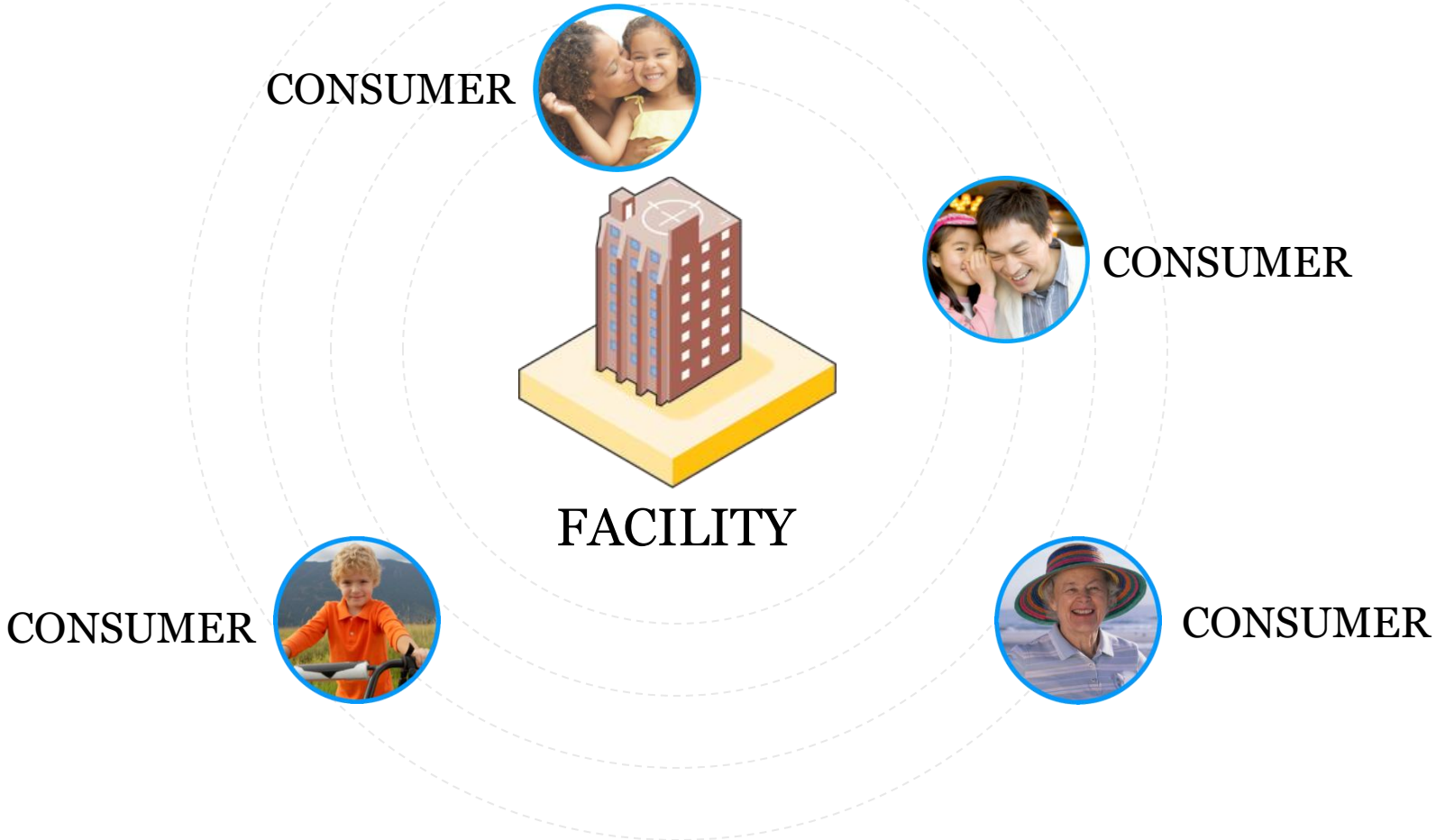
Pre-Copernican Universe



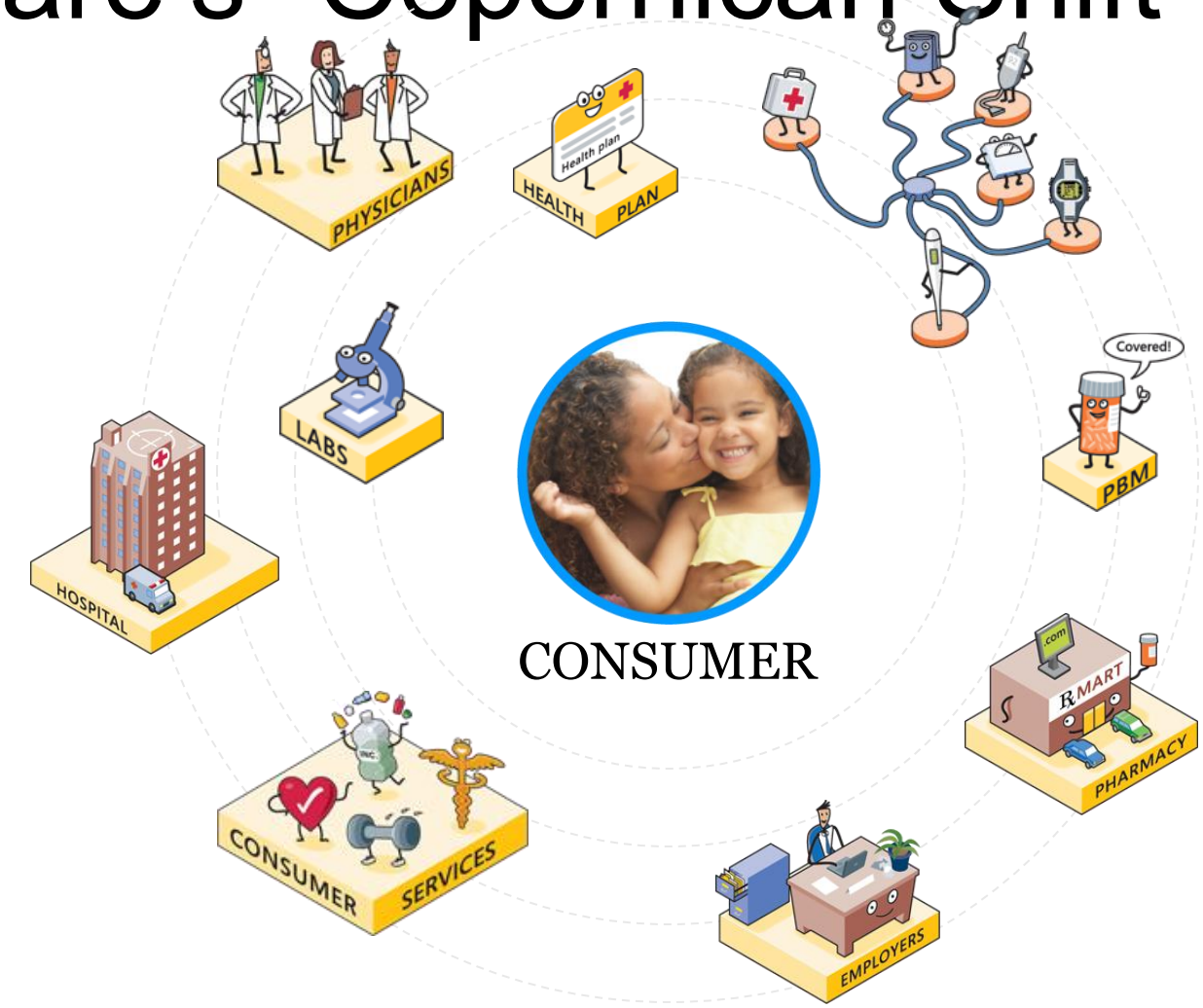
Post-Copernican Universe



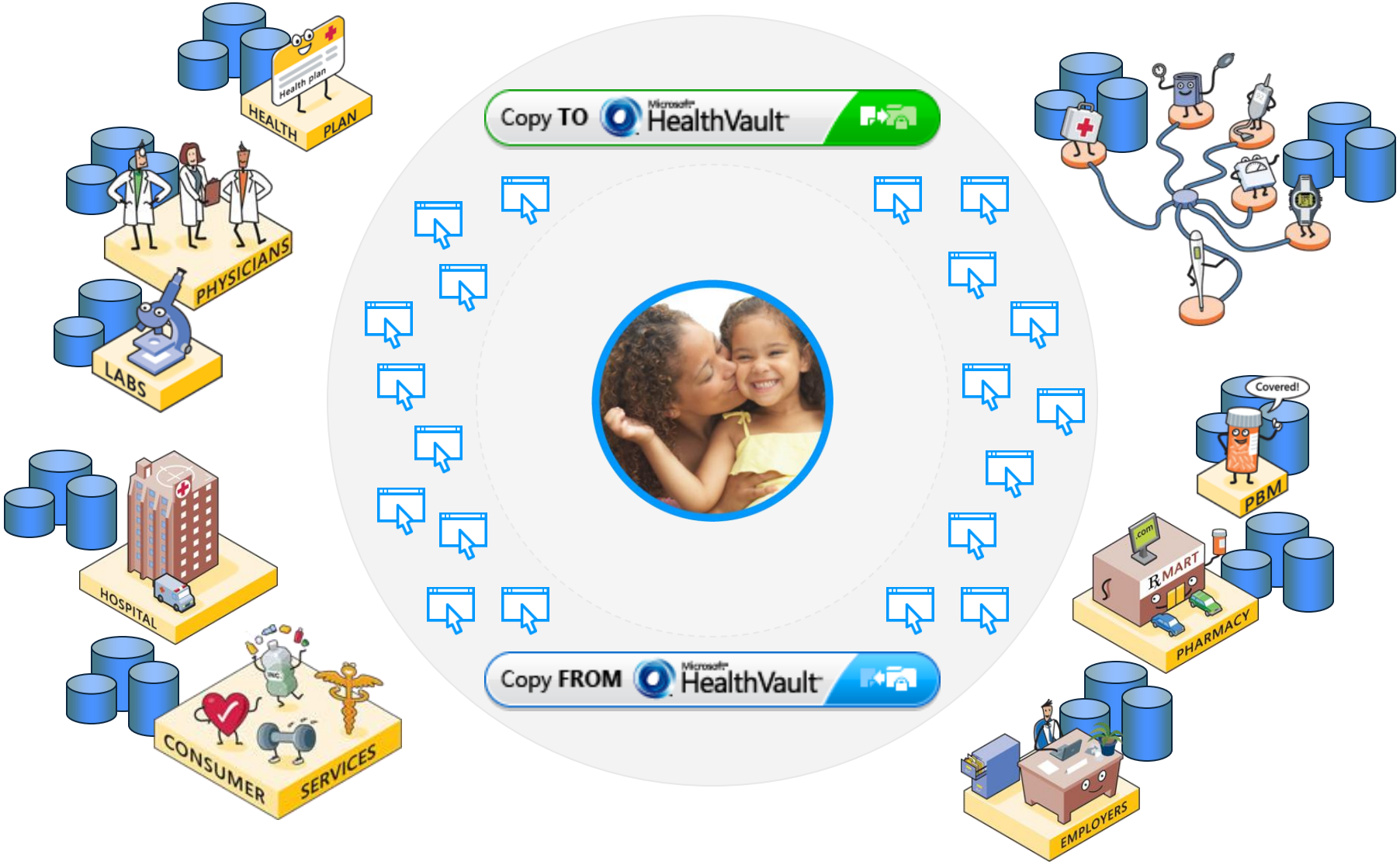
The Traditional Healthcare Universe



Healthcare's "Copernican Shift"



Consumers as the Aggregators



What if the patient does not understand?

Health literacy refers to the personal characteristics and social resources needed for individuals and communities to access, understand, appraise, and use information and services to make decisions about health and to enact these decisions.

Many patients don’t understand – here is an example:

(Colon clinic data sheet as seen by illiterate patient)

“Your naicisyhp has dednemmocer that you have a ypocsonoloc. Ypocsonoloc is a test for noloc recnac. It sevlovni gnitresni a elbixelf gniweiv epocs into your mutcer. You must drink a laiceps diuqil the thgin erofeb the noitanimaxe to naelc out your noloc.”

“Your physician has recommended that you have a colonoscopy. Colonoscopy is a test for colon cancer. It involves inserting a flexible viewing scope into your rectum. You must drink a special liquid the night before the examination to clean out your colon.)

North America Adult literacy Survey 2003

- 22% individuals are at NALS level 1 considered “functionally illiterate.” They can perform basic tasks such as signing their name or finding a word or fact in a short, written article.
- 27.5% Individuals at NALS level 2 are marginally literate. They are substantially limited in their ability to read and understand text.
- 50.5% Individuals at NALS levels 3, (31.5%0) 4, (16%) and 5 (3%) have sufficient literacy skills to permit full functioning in society. Those at NALS level 5, can perform complex tasks, such as writing lengthy documents and extracting data from tables and graphs.

How can critical thinking and AI help literacy

"The goal of critical thinking is to form a judgment through the application of rational, sceptical, and unbiased analyses and evaluation.

ChatGPT and large language models can help with this – especially if patients can allow ChatGPT and Large language models to access their records

Transposing personal health data into knowledge and understanding

Personal health data can be digitally linked through portals and AI to knowledge, understanding, critical thinking, and intelligence. AI can transpose data and information into knowledge to aid patient literacy and understanding. Linkage of AI to the patient's records would permit patients to ask questions and AI to interpret and allow patients to read full texts of suitable literary level.

Oh! I don't understand

Yes! I understand.

Foldercare

Unified Viewer

for

Integrated care records

Giving patients their EHRs

At Hadfield, North England, we built patient centred surgery to be able to give patients copies of their health data on CDs which had been coded according to the ICD into a lifelong format giving context and a sense of ownership to the patients -

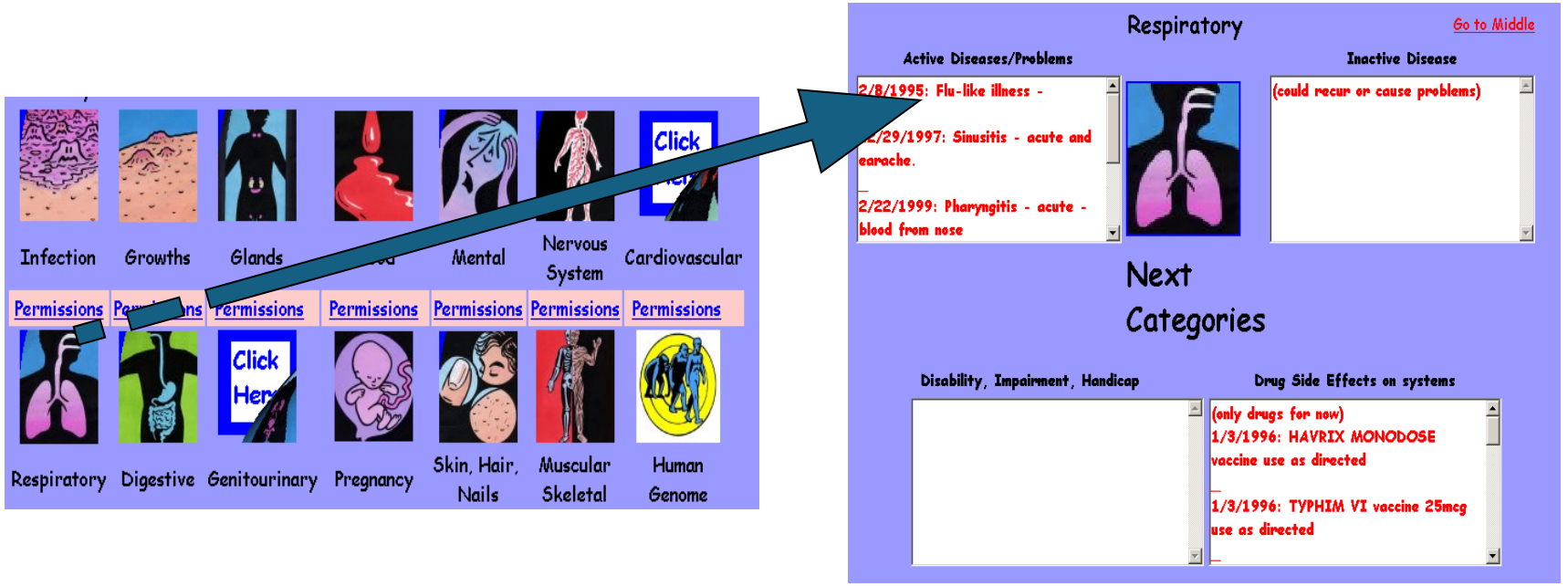
Patient Care Record **(Extracted from Torex)**

```
PRINT RECORD_DATE,CODE,VALUE1,VALUE2,TEXT
FROM JOURNALS (ALL FOR PATIENT)
   WHERE NHS_NUMBER IN (“**********")
*RSP_IDENT,HMC,Hadfield Medical Centre
*RSP_AUTHR,USER1,Temporary HQL User
*RSP_RDATE,********,**/**/****
&1,"RECORD_DATE","CODE","VALUE1","VALUE2","TEXT"
$1,"20000628","-12","","","*PROMPT* Check family history"
$1,"20000628","-136","","","*PROMPT* Ask about alcohol"
$1,"20000628","-137","","","*PROMPT* Smoking history"
$1,"20000628","-229","","","*PROMPT* Check height"
$1,"20000628","-22A","","","*PROMPT* Check weight"
$1,"20000628","-22K","","","*PROMPT* Calculate BMI"
$1,"20000628","-246","","","*PROMPT* Blood Pressure Check"
$1,"20000118","06..","","","Managerial occupations - ********. -"
$1,"19950208","23..","","","Examn. of respiratory system - nad."
$1,"19950208","2D..","","","Ear, nose + throat examination - nad."
$1,"19990222","2DC1","","","O/E - pharynx hyperaemic"
$1,"19990224","41B3","","","Faeces test due"
$1,"19960124","652.","","","Typhoid vaccination typhim vi  lo411 4.98 given"
$1,"19960124","6564","","","Booster tetanus vaccination e54452u 97.01"
$1,"19960124","6584","","","Booster polio vaccination s124j10 8.96"
$1,"19960124","65C.","","","Yellow fever vaccination given"
$1,"19960124","65FA","","","1st hepatitis A vaccination vha419b6 7.96 right"
$1,"19951205","67E1","","","Recommend travel vaccinations, enquiry re"
$1,"20021017","934Z","","","Computer record NOS-request"
$1,"20000202","982A","","","Night visit claimable - higher"
```

Foldercare Is .....

- **A browser-based viewer for displaying personal health data from specified sources**
- **Structured user-friendly interface that can utilise all the patient data delivered from floppy disc, CD or other secured location**
- **Will link to the internet for further information for a given disease, condition, treatment or drug.**
- **Structured according to the World Health Organisation international classification of disease.**

Selection and display



- **At the category selection page animated icons change from the category icon to the "invitation to view" icon and back again which indicates current conditions or issues.**

- **Clicking on the desired icon will show the record detail for that disease category.**

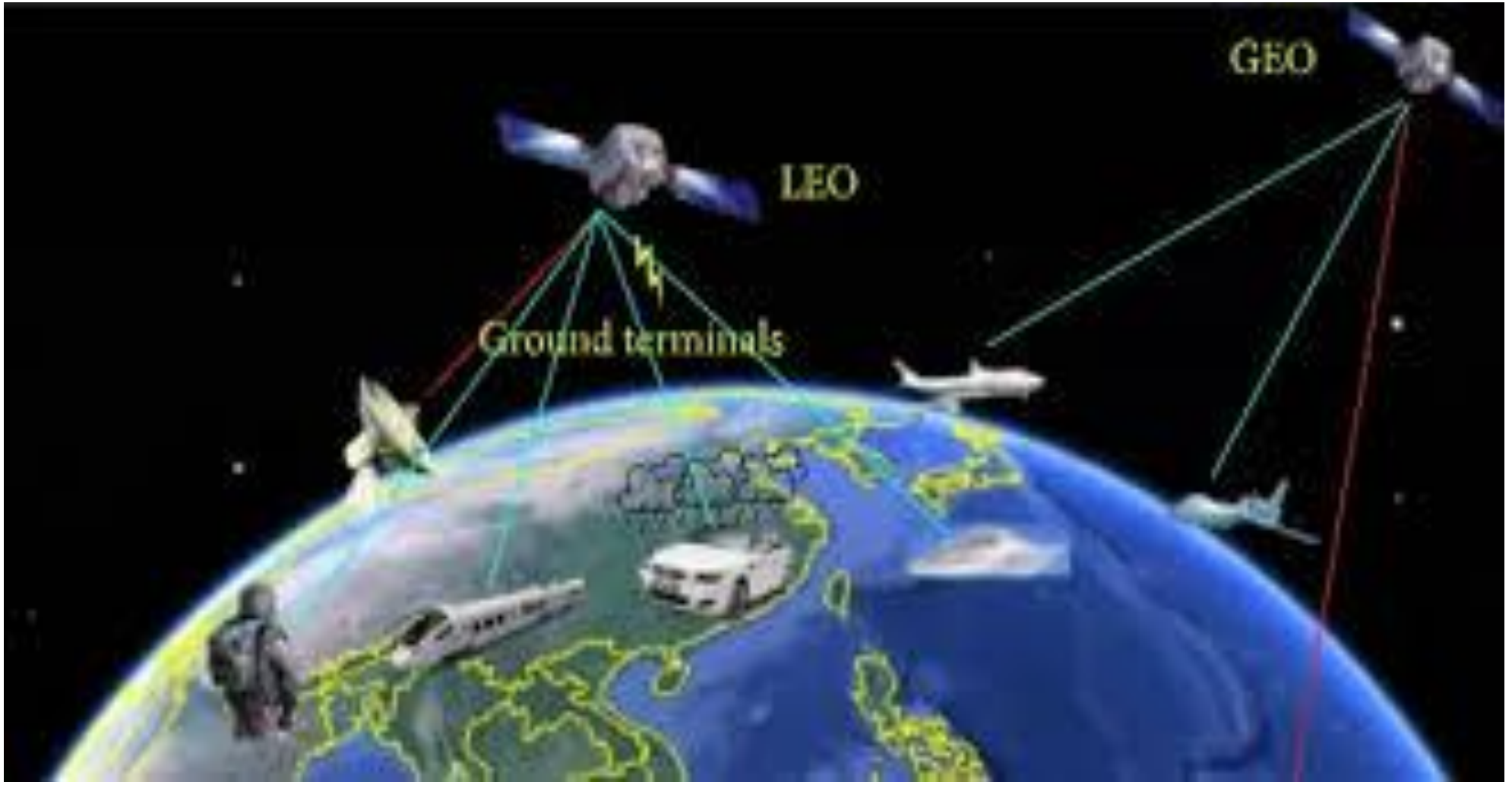
The patient understands, agrees and consents to take part in care pathway

Patient and family undertake care pathway

Patient and family enters results into records

Home visits Nurse, health visitor, midwife, and physiotherapist access, and add to, the record

Radio-telemedicine allows distant care and advice



Universal coding and foreign languages
translation apps aid travel collaborative data research, and migration

Citizens can use the NHS App, their EHRs and AI to plan reproduction and pregnancy

Citizens can use the NHS App, their EHRs and AI to plan maternity care

Citizens can use the NHS App, their EHRs and AI to plan infant and child health and diseases

Citizens can use the health App, their EHR and AI to plan Childhood self medication and side effects

Minors and adolescents can use the health App, their EHR and AI to manage and plan their health

Citizens can use the health App, their EHR and AI to plan better health promotion

Citizens can use the health App, their EHR and AI to understand incomprehensible information

Citizens can use the health App, their EHR and AI to understand and receive bad news

Citizens can use the health App, their EHR and AI to better utilise complex technologies

Citizens can use the health App, their EHR and AI to manage ageing

Families can use the health App, the EHR of their frail or elderly family members AI to manage later life and frailty

Families can use the health App, their EHR and AI to manage wishes for later life, dying and after death