















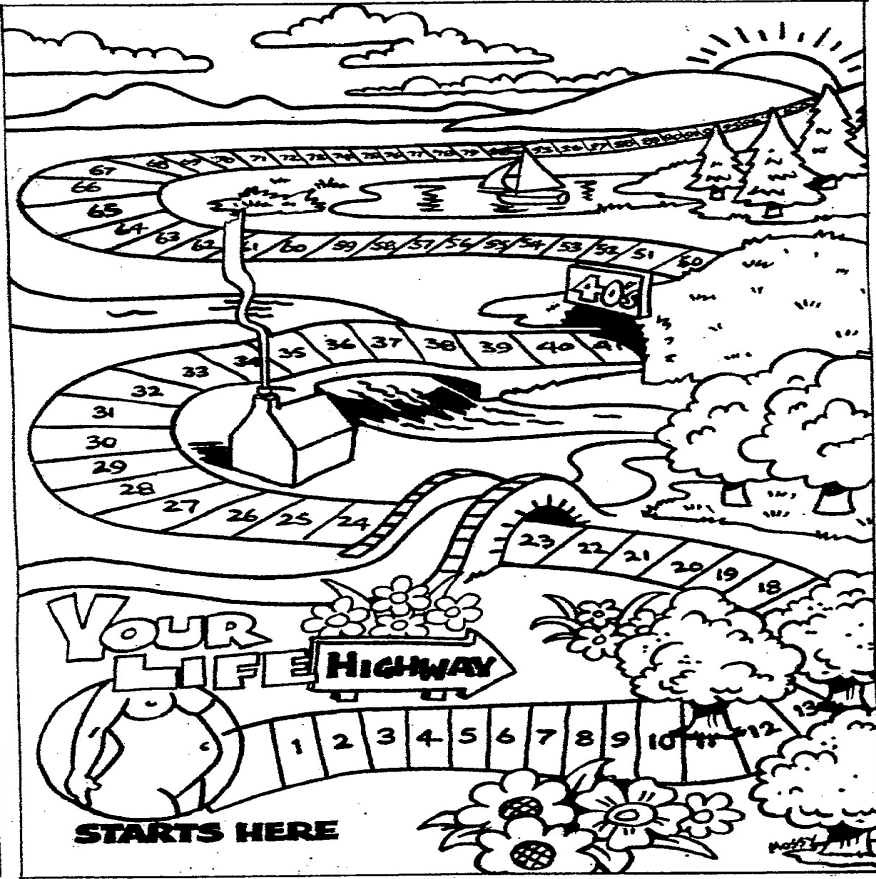
December 15<sup>th</sup> 2024 – Palermo  
**Can, will, - or do - patients own their  
life-long records?**

















**GNU Solidario**

# EHRs serve lifelong prevention of disease, health promotion, and immediate and continuing care pathways.

 <b>COMPANIONSHIP PARTNER</b>	 <b>MONEY</b>
 <b>MOODS</b>	 <b>THOUGHTS</b>
 <b>NATURE</b>	 <b>ILLNESS</b>
 <b>ACCOMODATION</b>	 <b>TRAVEL SHOPPING</b>
 <b>PETS</b>	 <b>EXERCISE</b>
 <b>FAMILY</b>	 <b>LAUGHTER ENJOYMENT</b>
 <b>POSSESSIONS</b>	 <b>PLACE IN SOCIETY</b>



 <b>FRIENDS</b>	 <b>EMPLOYMENT</b>
 <b>ADVENTURE EXCITEMENT</b>	 <b>CREATIVITY</b>
 <b>SEXUAL ACTIVITY</b>	 <b>FOOD DRINK</b>
 <b>CLOTHES</b>	 <b>MUSIC ART</b>
 <b>HOLIDAY</b>	 <b>PERSONAL HYGIENE</b>
 <b>SLEEP</b>	 <b>SELF RESPECT</b>
 <b>EDUCATION</b>	 <b>BELIEFS</b>

# The EHR is becoming a digital avatar

The digital avatar builds up during a citizen's life. It should be referred to again and again along the life cycle if it is created and maintained in a "standard" way.



# The EHR is becoming a digital avatar

The EHR starts at birth  
and  
Proceeds through  
infancy,  
Childhood, adolescence,  
young adulthood,  
middle and later life,  
dying and death. It can  
be maintained after  
death for research and



# The EHR is becoming a digital avatar

The HER can travel through life with the citizen and across borders if the HER is created and maintained using international codes\*\*, concepts or entities.

(\*\* Snomed etc.)



# The EHR is becoming a digital avatar

The key to the avatar is created by technology companies and regulated by States. The key is held by the patient or by the patient's proxy.



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The avatar can travel fast.

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# The EHR is becoming a digital avatar

“As it turns out, it would only take 0.13 seconds to go around the entire Earth at the speed of light.

This possible fast receipt of patients' notes would have been great when I was working on complicated



# The EHR is becoming a digital avatar

Why don't we do this?  
Because Clinicians,  
governments and tech  
companies require to  
make a cultural change.  
Each citizen is different  
and in a different life.  
Only they know what  
they want to consent to.



**So: - England's aspiration for Life long , nationwide national health and social care records**

- **NHS Federated Data Platform**
- The NHS Federated Data Platform (NHS FDP) aims to enhance patient care and increase efficiency. It will increasingly securely connect data and break down information silos. It will provide insights to assist in decision-making, reduce costs, and improve patient



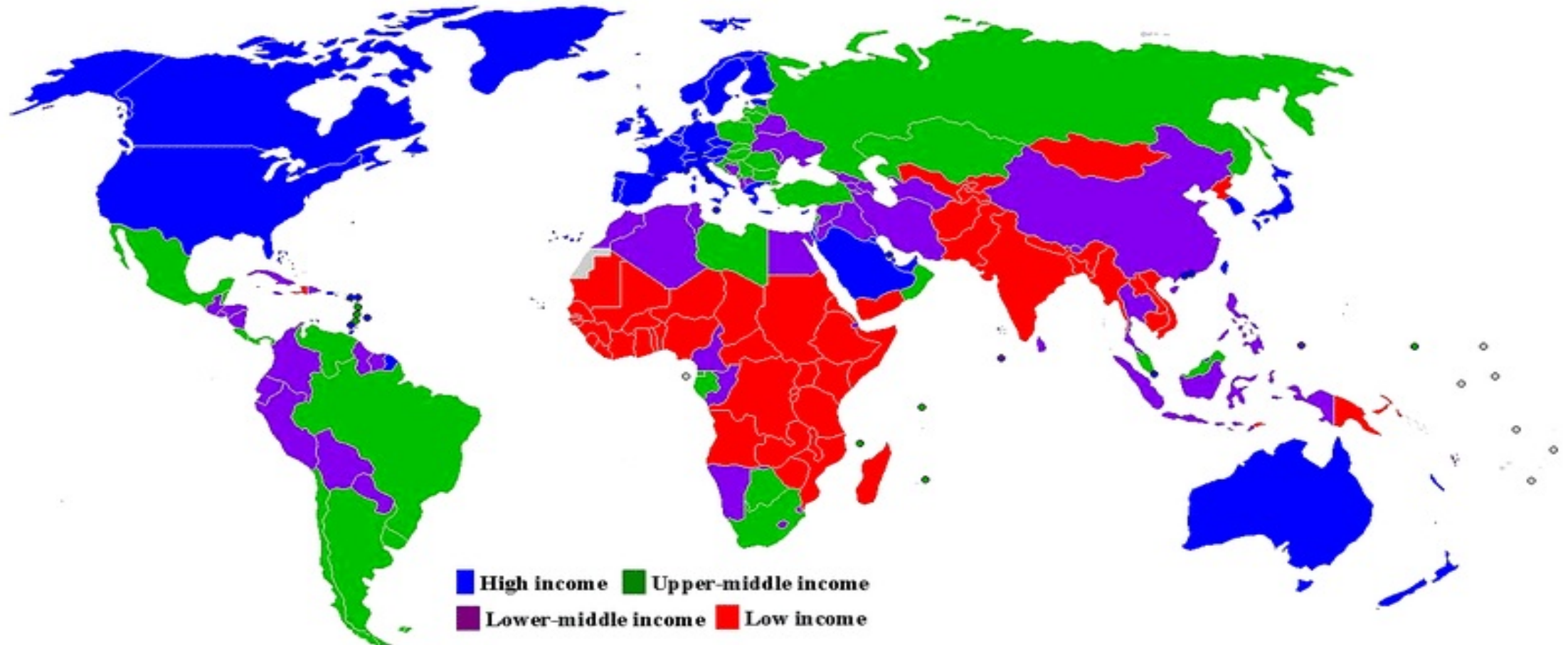
**How do we pass records across country borders – could it be giving the data or its access to the patient?**



**EHRs are used for mainly the same health issues in all countries but cover different health issues in some parts of the world**



# Records are used differently in high, low, and middle income countries



# Can we do a cross-national borders lifelong record to help migrants?

The current global estimate is that there were around 281 million international migrants in the world in 2020, which equates to 3.6 percent of the global population. Overall, the estimated number of international migrants has increased over the past five decades.



*(See UN World Data Forum and Transformhealth.org at the end of the presentation.)*

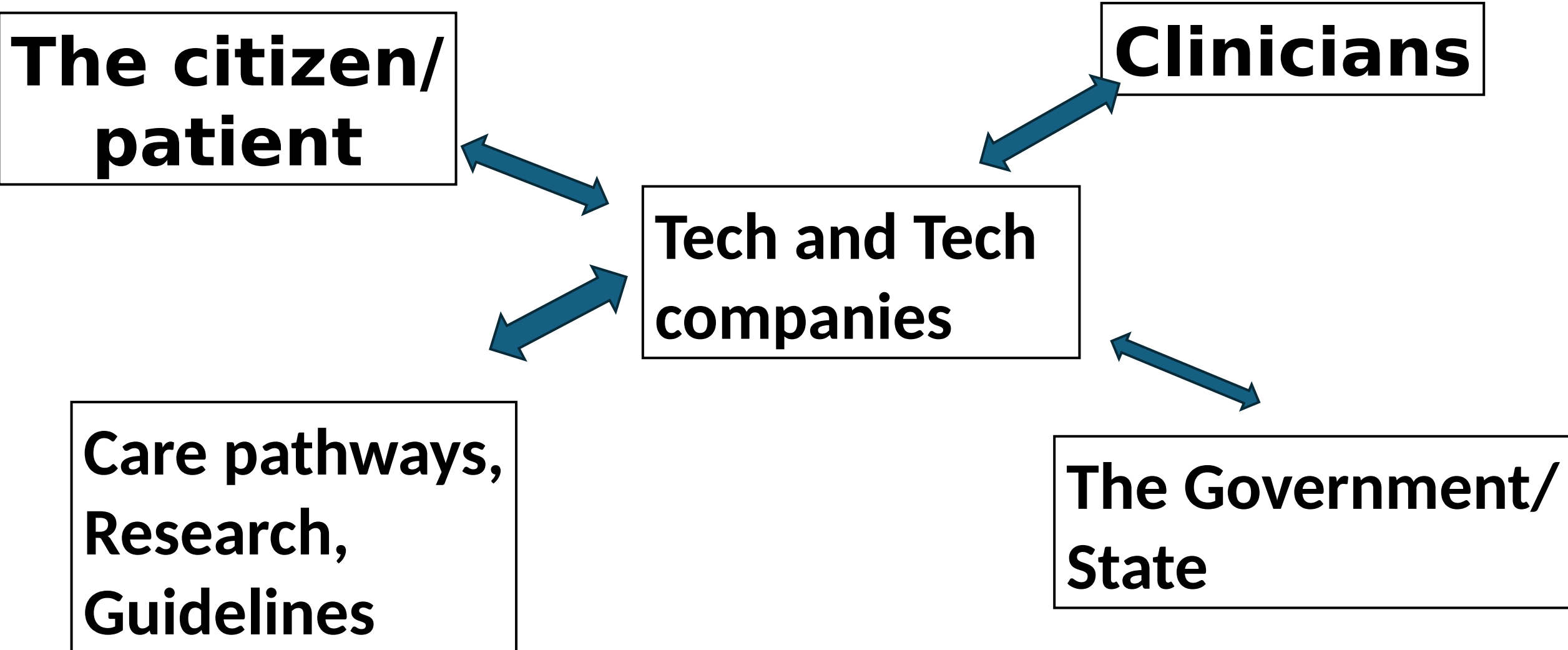


# A cross border record exists - European Electronic cross-border health services

- The eHealth Digital Service Infrastructure (eHDSI) is an infrastructure ensuring the continuity of care for European citizens while they are travelling abroad in the EU.
- (See *UN World Data Forum* and *Transformhealth.org* at the end of the presentation.)



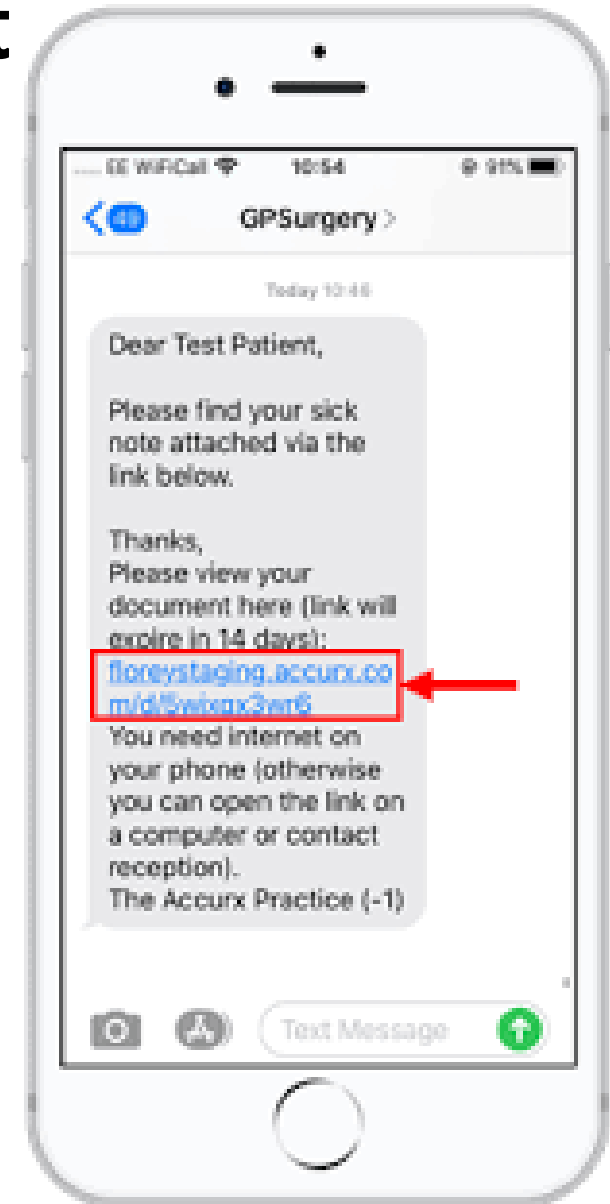
The State, tech, AI, tech companies, the  
citizen and EHRs



# **GOOD NEWS!! - The fabulous evolution of digital electronic health records**



# The EHR, app and attached services are becoming tools of agency for both the patient and doctor



# In England EHRs are becoming “health accounts” for use for normal life events and development.



# How do patients own and use their records?



**They choose who to share their data with**  
**They can check their NHS number**



**Some allow some proxies (relatives, grandchildren, friends, partners, carers) to access their record**





# They use the record to prepare for hospital consultations



# They decide who should not see their records



**They decide who are guardian advocates  
and can act as proxies for them**



# Patients use the record apps to see their results before seeing the doctor or nurse



# Patients use the app to order prescriptions and book and manage appointments

**Order repeat prescriptions on the NHS App**



- 1. easily choose where your prescriptions are sent
- 2. order at a time that suits you
- 3. need help? Access support in the app or visit [nhs.uk/helpmeapp](https://nhs.uk/helpmeapp)

**NHS App**



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**Did you know you can manage some of your Newcastle Hospitals appointments on the NHS App?**

The App is available on the App Store and Google Play

# Patients use the record to know the medicines used in treating their disease.



# {Just a bit about the The NHS App}

- The NHS App gives patients a simple and secure way to access a range of NHS services. Patients download the NHS App on their smartphone or tablet via the [Google play](#) or [App store](#).



# {Just a bit about the The NHS App}

- **The NHS App now has more than 34 million registered users, - around three quarters of the adult population in England. The average number of NHS App logins per weekday is nearly**





# The NHS App

- **Patients must be aged 13 or over to use the NHS App. They need to be registered with a GP surgery in England.**



**The NHS app allows patients to book and manage COVID-19 vaccinations and to register organ donation decision**



# Patients are beginning to use the records to know which parts of the body are affected

Anatomy is the oldest scientific discipline of medicine.

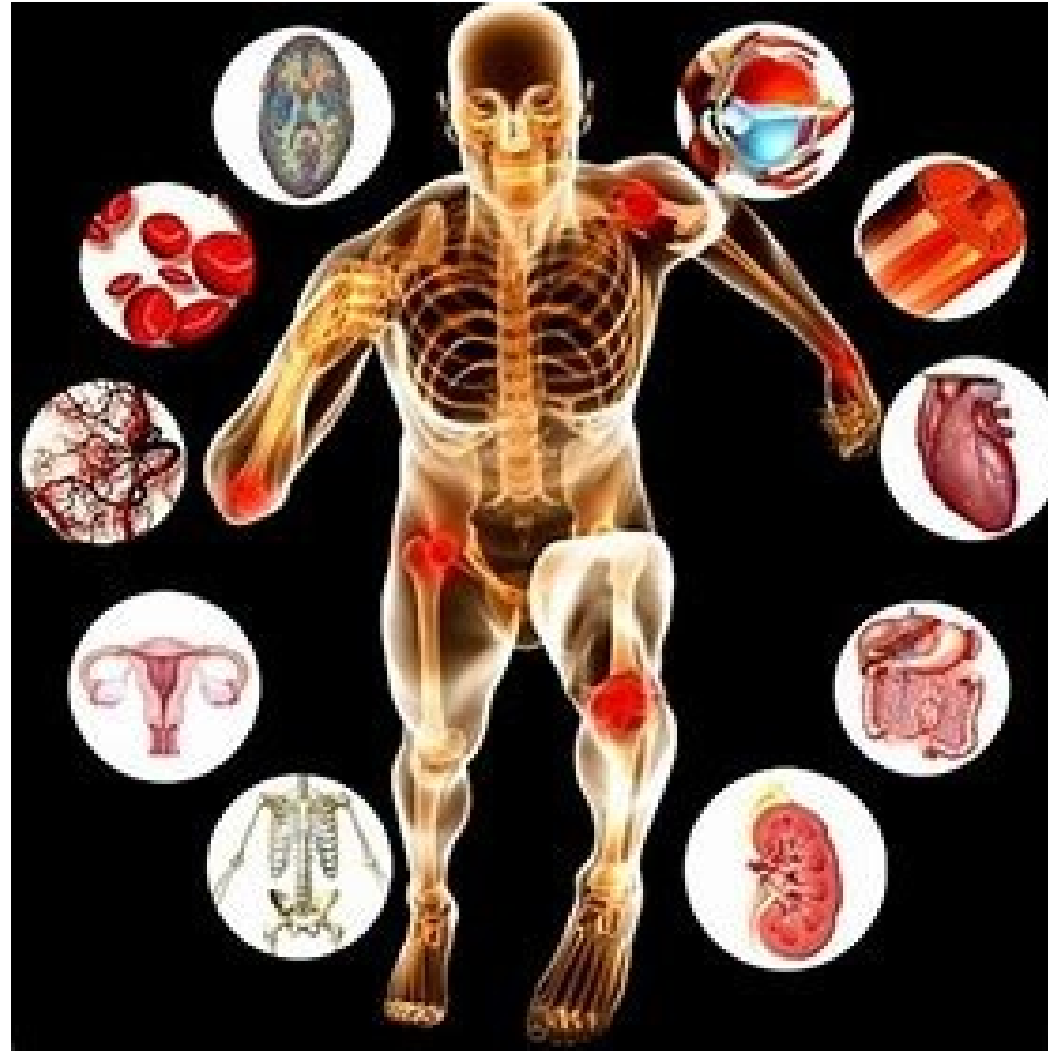
- use NHS 111 online to answer questions and get instant advice or medical help near



*Fasciolo de Medicina, Depiction of an Anatomy Lecture, 1493. Dissections of human bodies remained an exception to the rule. On few occasions, the professor would read from the books of the ancient physician Galen (131–201) while his assistants performed the actual dissection without paying much attention to the anatomical findings revealed by opening the body.*

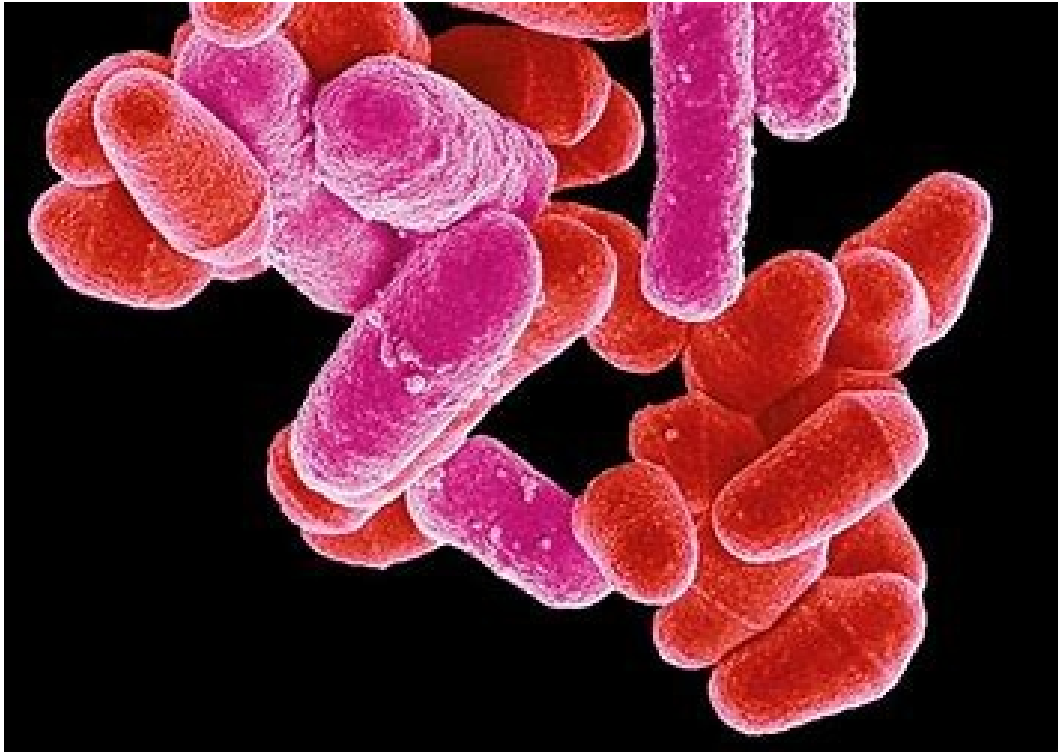
# Patients are beginning to use the records to begin to know how the body works

Heart and circulation  
Muscles, bones and movement  
Breathing and lungs  
Digestion and stomach  
Water and kidneys  
Reproduction, breast feeding  
and babies  
Brain and nerves  
Hormones and growth  
Eyes, ears, nose  
Immunity



•use  
**NHS  
111  
online  
to  
answer  
questions and  
get  
instant  
advice  
or**

**Patients are beginning to use the record to know about diseases and bacteria and viruses**



**use NHS 111 online to answer questions and get instant advice or medical help near you**



# Patients are beginning to use the record to know the chemistry of the body



- use NHS 111 online to answer questions and get instant advice or medical help near you





Customer friendly apps and  
HER's – provide for 5 levels  
health of literacy\*\*

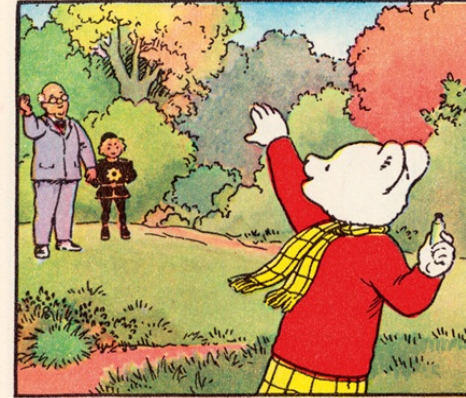
Use pictures, tell stories,  
relate information to  
citizen/patients' health  
literacy and make it  
interesting and “fun”.

\*\*\* Barry Weiss

Health literacy and patient safety: Help patients understand.



## RUPERT HEEDS A WARNING



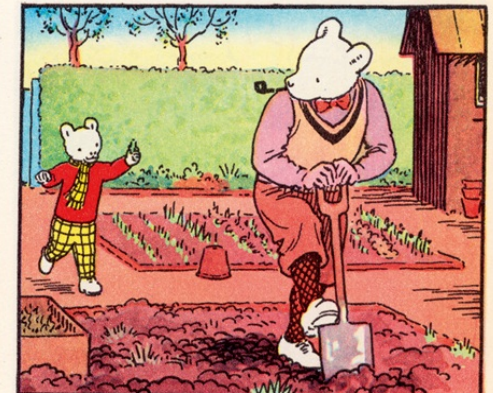
He's told, "Be careful not to fall,  
That scent will spill—you'll lose it all."



"I think a thief is hiding here,"  
Warns P.-c. Growler. "Don't go near."



The wood is risky, Rupert knows,  
And so another way he goes.



"Just look what I have," Rupert cries,  
And Mr. Bear turns in surprise.

In his excitement over the phial of essence Rupert forgets all about his bunch of flowers as he starts for home. "Mind you keep that thing tightly corked," laughs the Professor, "or you won't be able to see where you are going because of butterflies!" Running quickly, the little bear starts to take a short cut through a wood when he is startled by Constable Growler who appears from behind a tree. "Don't go through there," warns the policeman. "There has been a big robbery

and I suspect that the thief is hiding in the wood. Go home another way!" Thanking the constable for his warning, Rupert avoids the wood. He reaches his own cottage and finds his daddy busy with the spade. "Well, did you see that butterfly?" says Mr. Bear. "Yes, I had tremendous luck," cries Rupert. "I found it and it sat on a flower and I carried it all the way to the Professor's house. And just look at this. It will bring us as many rare butterflies as ever we want!"

# Foldercare

2004 how patients  
designed a “Unified  
Viewer  
for  
Integrated care records”



# 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.

**So, can, or should, patients own their records? Consider  
last year's WHO meeting-**



**The WHO Patient Safety day was on September  
17<sup>th</sup> last year**



**World Health  
Organization**



**World  
Patient Safety  
Day** 17 September 2023



# The WHO Patient Safety team and workshop delegates

## Geneva September 2023



# Patient Safety - WHO workshop Geneva September 2023



# WHO Patient Safety Charter

**The Patient safety rights charter is to support the Global Patient Safety Action Plan 2021–2030: eliminating avoidable harm in health care.**



# Patient Safety Charter rights

- 1. Timely, effective and appropriate care.
- 2. Safe health care processes and practices.
- 3. Qualified and competent health workers.
- 4. Safe medical products and their safe and rational use.
- 5. Safe and secure health care facilities.





# Patient Safety Charter rights

- 6. Dignity, respect, non-discrimination, privacy and confidentiality.
- 7. Information, education and supported decision-making.
- **8. *Access to medical records.***
- 9. To be heard; and fair resolution.
- 10. Patient and family engagement.





# **Group 5 discussed “the right to information and right to access to medical records” You can see what the whole group decoded with the next slides**

- Moderator: Mr Richard FITTON
  - WHO focal point: Dr Mondher LETAIEF      United Arabs Emirate
- |                             |                    |
|-----------------------------|--------------------|
| 1. Ms Lynn GENTILE          | United Nations     |
| 2. Mr Hussain JAFRI         | Pakistan           |
| 3. Ms Nagwa METWALLY        | Egypt              |
| 4. Dr Olabisi OGUNBASE      | Ghana              |
| 5. Dr Nuria PRIETO          | Italy              |
| 6. Dr Julia TAINIJOKI-SEYER | France and Germany |
| 7. Dr Shin USHIRO           | Japan              |
| • Ms Isabelle WACHSMUTH     | Switzerland        |



# The right to obtain a copy

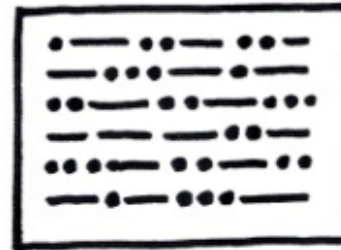
- Patients have the right to access or obtain a copy of their records in a usable and an understandable format. This includes both physical and electronic records that are accurate and up to date



Information Repository



Paper Information



Electronic Data



# Correcting and sharing their records

- Patients are entitled to request corrections to factual inaccuracies and control the use of their information.
- Patients may designate a representative to access or obtain their records.
- Patients have the right to easily transfer their medical records when seeking second opinions or changing health care facilities



Guardian, advocate



Antagonist, detractor



# Exercising their data protection rights

- Patients are entitled to expect their health information to be kept secure and restricted to those directly involved in their care.
- Patients have the right to exercise their data protection rights, including understanding how their data are being used, shared and stored.



# Being informed about AI, telehealth and automatic decision making

- Patients are entitled to be informed about any automated decision-making and associated risks involving their data, particularly in the context of telehealth, telecare, and the use of AI in health care.



# Security and consent for medical record processing

- Patients need security measures in place to protect records from breaches or cyberattacks.
- Patients should only have their information shared beyond legislated provisions with their explicit consent.



"The Law"



Firewall



Security Lock



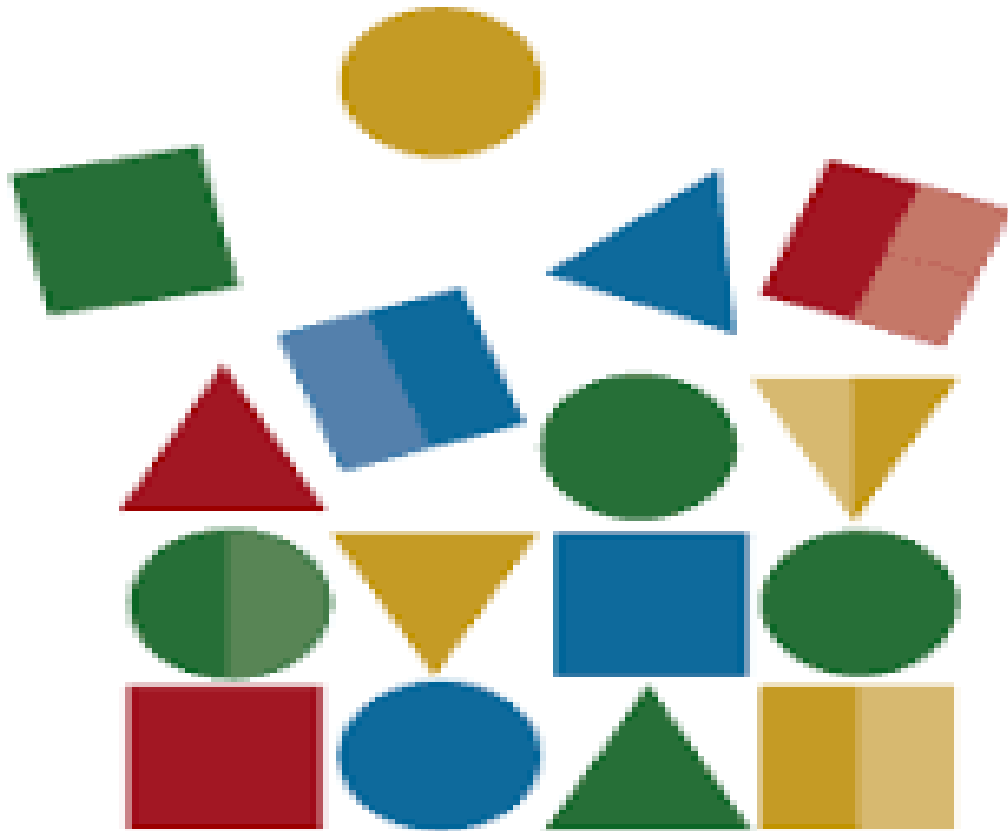
(Jail) Data Offenders



Patient safety rights charter

# United Nations World Data Forum

- Hangzhou, China April 2023.



United Nations  
**WORLD**  
**DATA**  
**FORUM**

# We are trying to develop a global personal health data governance with the UN



Transform Health

Transform Health is calling for a global framework to strengthen the equitable governance of health data

Statement ahead of the 75th World Health Assembly