Introducing the Public Health: xShare priority use cases

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About me

- Research Fellow at Core Unit Digital Medicine and Interoperability at the Berlin Institute of Health at Charite

- Co-lead of xShare WP4: Public Health and Cross Border Health Threats

EHDS Priority areas and xShare Public Health use cases

Laboratory

- Infection surveillance
- Antimicrobial resistance
- One Health approach

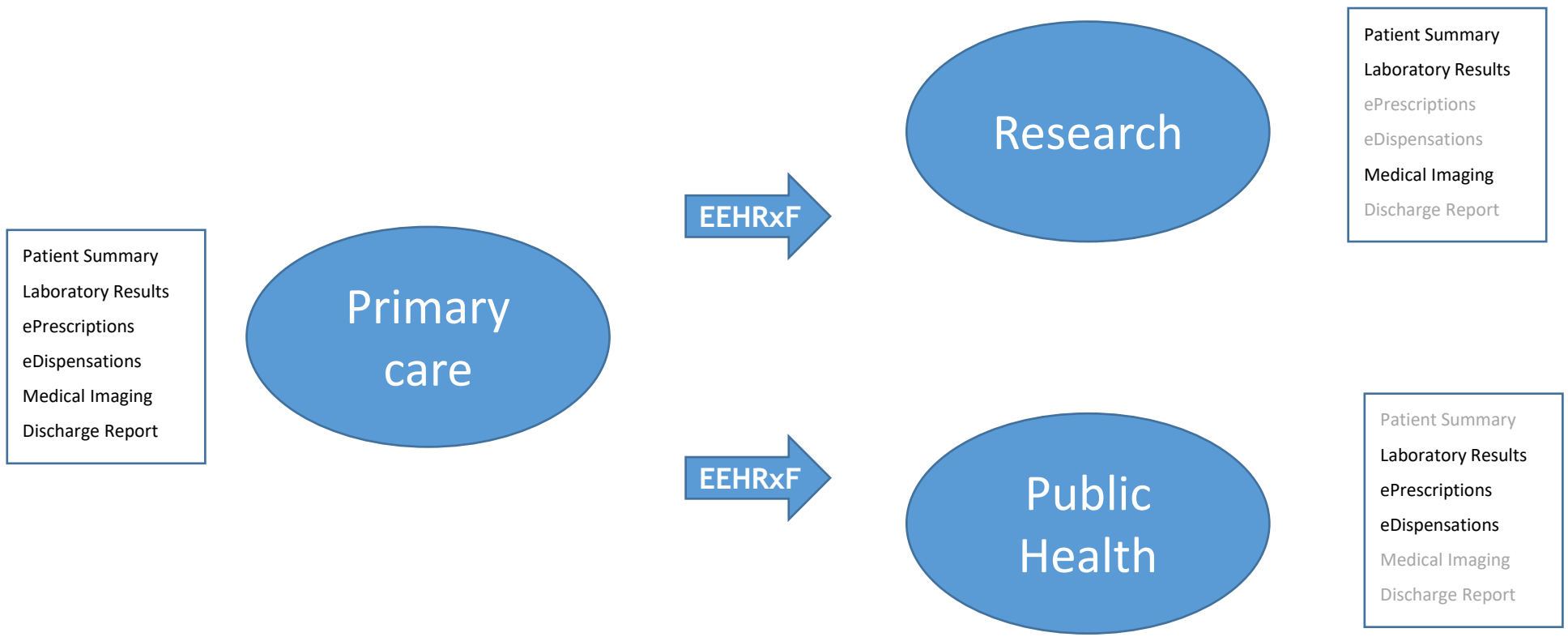
Patient summary/Discharge report

- Cancer Monitoring
- Care plan
- Vaccination
- Long COVID

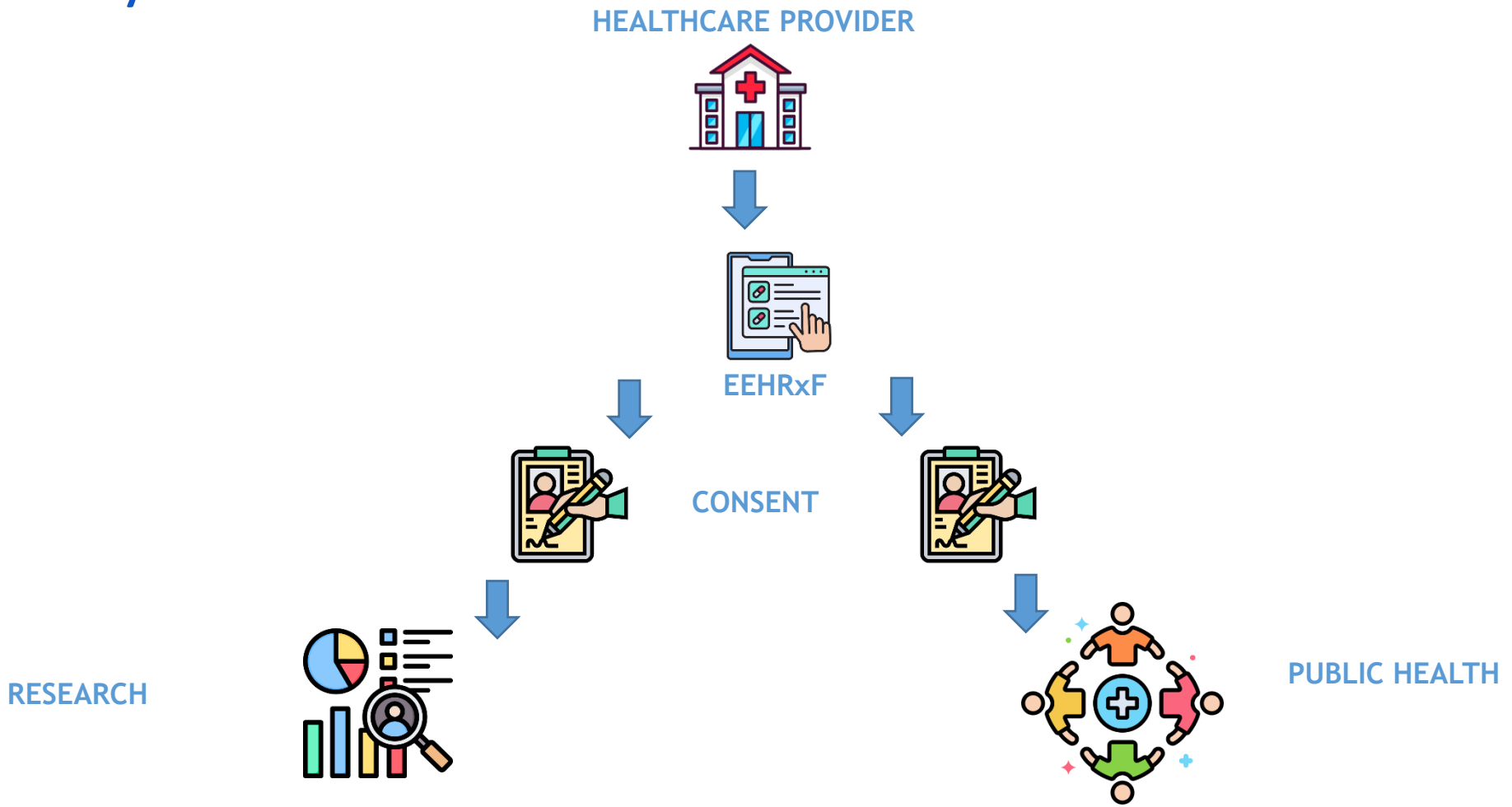
ePrescription/eDispensation

- Antibiotic prescription/administration

Same data, same format



Data entered once at source, available for secondary use



Leveraging the EEHRxF: from primary data collection to secondary use

- Real time Monitoring
- Administrative simplification
- Disease/infection surveillance
- Shared analysis/AI algorithms
- Availability, quality and consistency of data
- OneHealth Approach
- Patient empowerment

Public Health: xShare use cases

- **Administrative simplification and real time monitoring** through standardisation of datasets of ongoing data collections :
  - Use Case 1: AMR
  - Use Case 2: HAI
  - Use Case 3: Cancer monitoring
- **Patient discovery and new knowledge creation** through direct connection between Public Health authorities and citizens:
  - Use Case 4: Long COVID
- **Patient empowerment** through their data control
  - Use Case 5: Survivorship Passport

Prioritized use cases: established datasets

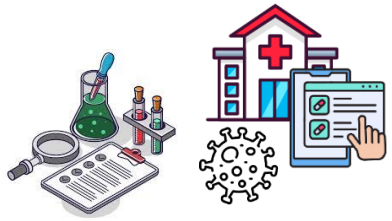
- **Use Case 1:** European Antimicrobial Resistance Surveillance Network (EARS-Net) dataset
- **Use Case 2**: Protocol for the surveillance of healthcare-associated infections and prevention indicators in European intensive care units HAI-Net ICU
- **Use Case 3**: Data Protocol for European Population-Based Cancer Registries

Use case 1: Antimicrobial resistance (AMR)

Goal:

Administrative simplification, real time monitoring

Healthcare Providers/Laboratories



EEHRxF

National Public Health authorities

EEHRxF

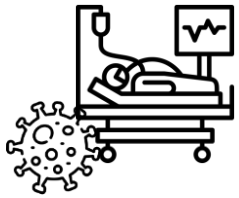
European Public Health authorities

Use case 2: ICU infection surveillance

Goal:

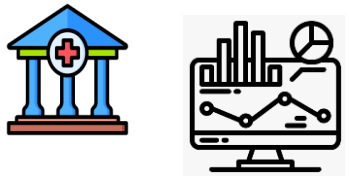
Administrative simplification, real time monitoring

Hospital Intensive Care Units



EEHRxF

National Public Health authorities



EEHRxF

European Public Health authorities

Use case 3: Cancer monitoring

Goal:

Administrative simplification, real time monitoring

Healthcare Providers

EEHRxF

National Cancer Regsistries

EEHRxF

European Cancer Regsistries

European Network of Cancer Registries

Data Sets harmonization

- Match with EHDS priotity areas
- Terminology standards: SNOMED, LOINC
- HL7 Europe data models
- HL7 FHIR

Mapping to standards

Variable	Description	Required	FHIR	Data Type	Result Codi	Answer
9 - LaboratoryCode	Laboratory code unique for each laboratory within the country.	Yes (Error)	Organisation.identifier	Coded Value		
10 – Specimen	The source of the isolate (i.e. blood or cerebrospinal fluid)	Yes (Error)	Specimen.type	Coded Value	SNOMED	VS-Specimen
11 – PatientCounter	Numeric Code for each patient, unique within lab. Anonymous code by lab to specify patient.	Yes (Error)	Patien.identifier	Identifier		
12 – Gender	Administrative gender	Yes (Warning)	Patient.gender	Coded Value	SNOMED/HL7	VS-Gender
13 - Age	Age of the patient when the sample was taken.	Yes (Warning)	Patient.birthDate	Date		
14 – IsolateId	Isolate ID; Code for each isolate, unique within lab and year.	Yes (Warning)	Specimen.accessionId	Identifier		
15 – HospitalId	Unique identifier for the hospital within each laboratory.	Yes (Warning)	Encounter.location.typ	Identifier		
16 – PatientType	Origin of patient. Is the patient at the moment the sample is taken admitted in a hospital (inpatient), or not (outpatient). Patients that go to the hospital for dialysis or other types of day hospital care should be classified as "O" for the field "PatientType". All other patients that ~~are admitted in the hospital as inpatients should be classified as "INPAT"~~	Yes (Warning)	Encounter.class	Coded Value	SNOMED/HL7	VS-PatienType
17 – HospitalUnitType	Hospital department (at time of sample collection)	Yes (Warning)	Encounter.location.typ	Coded Value		VS-Dept
18 – Pathogen	Species and genus of the pathogen which has been isolated from the sample.	Yes (Error)	Observation.code	Coded Value	SNOMED	VS-Microorganism
19 - DateOfHospitalisation	Date of admission in hospital	No	Encounter.period	Date "YYYY-MM-DD"		
20 – ResultPCRmec	Detection of PCR mecA gene	No	Observation.code	Coded Value	SNOMED	VS-PosNeg
21 - ResultPbp2aAggl	Detection of PBP2a-agglutination	No	Observation.code	Coded Value	SNOMED	VS-PosNeg
22 – Serotype	Serotype/group of the pathogen isolated from the sample.	No	Observation.code	Coded Value		VS-SteptPne
23 – ESBL	Detection of Extended-Spectrum Beta-Lactamase	No	Observation.code	Coded Value		VS-PosNeg

Valuesets

Local code	Microorganism	Code	FSN
STAAPNE	Streptococcus pneumoniae (STRPNE)	9861002	|Streptococcus pneumoniae (organism)|
STAAUR	Staphylococcus aureus (STAAUR)	3092008	|Staphylococcus aureus (organism)|
ENCFAE	Enterococcus faecalis (ENCFAE)	78065002	|Enterococcus faecalis (organism)|
ENCFAI	Enterococcus faecium (ENCFAI)	90272000	|Enterococcus faecium (organism)|
KLEPNE=	Klebsiella pneumoniae (KLEPNE)	56415008	|Klebsiella pneumoniae (organism)|
PSEAER	Pseudomonas aeruginosa (PSEAER)	52499004	|Pseudomonas aeruginosa (organism)|
ACISPP	Acinetobacter species (ACISPP)	7757008	|Genus Acinetobacter (organism)|
ESCCOL=	Escherichia coli	112283007	|Escherichia coli (organism)|

HealthDCAT-AP

EHDS involves the development of national and EU dataset catalogues, providing standardised metadata for Datasets

HealthDCAT-AP category	Element	Value
Data Discovery	Title	EARS-Net
	Description	European Antimicrobial Resistance Surveillance Network (EARS-Net) dataset
Data Access	Distribution Title	Antimicrobial resistance (AMR) reporting protocol 2023
	Distribution URL	https://www.ecdc.europa.eu/en/publications-data/ears-net-reporting-protocol-2023
Technical Metadata	Dataset Identifier	https://www.ecdc.europa.eu/sites/default/files/documents/EARS-Net-reporting-protocol-2023_1.pdf
	Metadata Revision Date	13.05.2025

Public Health: xShare use cases

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Yellow Button

- xShare envisions everyone sharing their health data in European Electronic Health Record Exchange Format (EEHRxF) with a click-of-a-button.

- To be featured across health portals and patient apps, allowing people to exercise their data portability rights under GDPR.

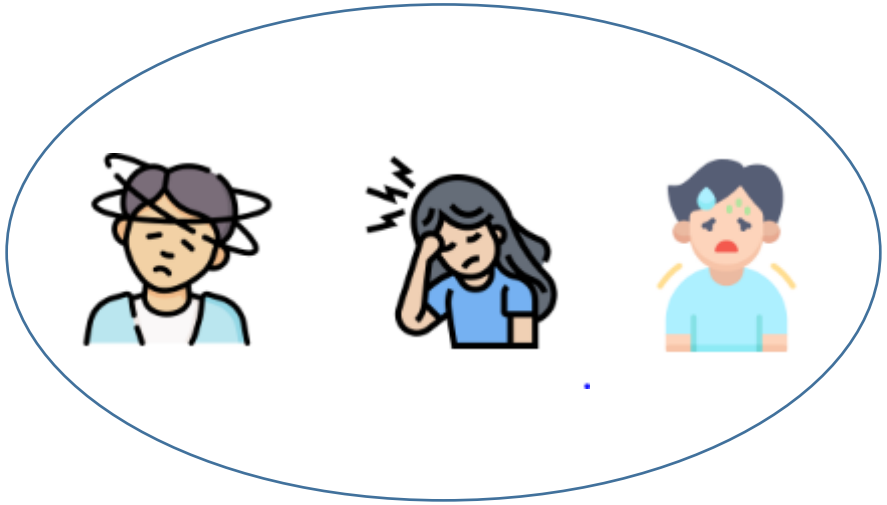
Use case 4: Patient reported outcome measures on Long COVID

Goal:

Patient empowerment, patient discovery, knowledge creation

Patient discovery

EEHRxF

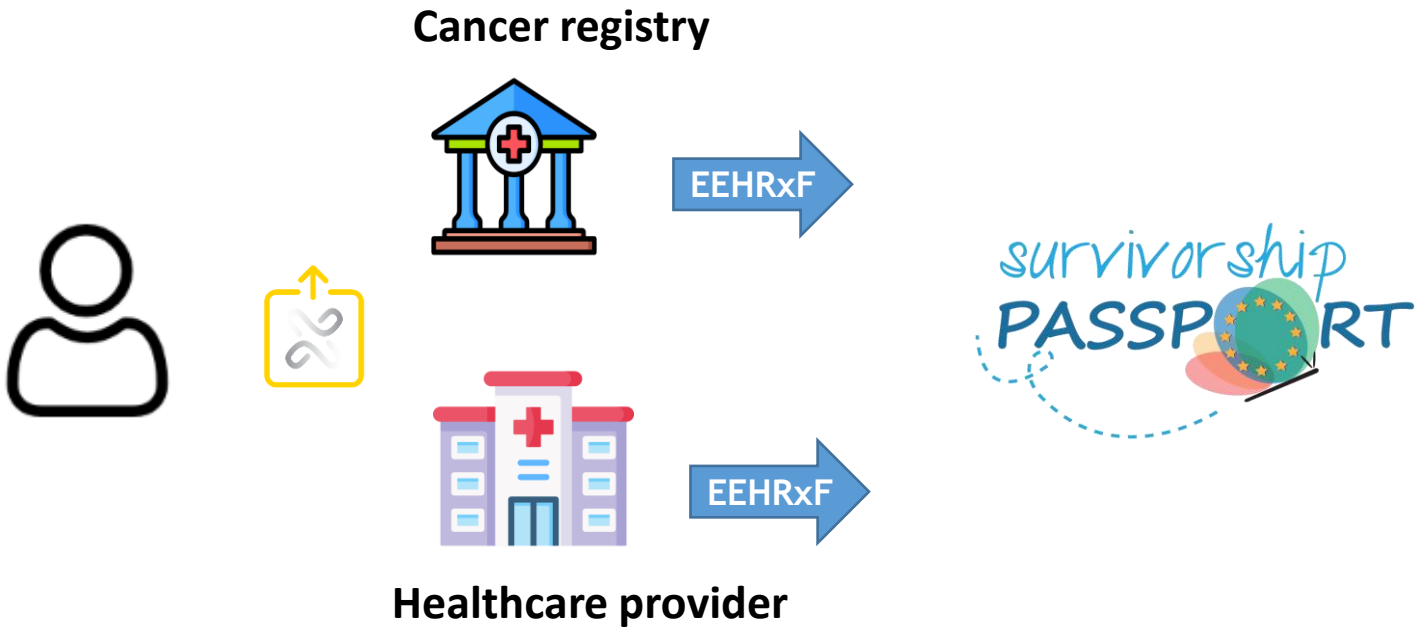


EEHRxF

Use case 5: Updating the survivorship passport

Goal:

Patient Empowerment



Conclusions

- Support ongoing data collections at EU level by facilitating „only once“ strategies
  - Cross-border monitoring and surveillance

- Prospective use cases to exploit the EEHRxF
  - Patient discovery
  - Knowledge Creation

- Patient empowerment
  - Control of their own data
  - Transparency in sharing data

Contact

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https://xshare-project.eu