



The Huge Power of Connected Data:

Digital Transformation of Patient Registries

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TOPICS TO BE COVERED

- Introduction to Patient Registries
- A broad view of a patient registry
- Challenges
- Connecting data in registries
- Vision for the Future

ABOUT PATIENT REGISTRIES

A patient registry is a secure, centralised database, containing health data on people with a specific diagnosis or condition.

Aims:

- provide information to the public on the number of people with a particular diagnosis in Ireland and their health status
- collect and analyse health information to help assess and plan health services for people with the diagnosis or condition
- monitor the safety and effectiveness of treatments
- compare the health of people with a condition in Ireland to the health of those in other countries
- produce publicly available reports each year that summarise registry information on the health status of people with a condition in Ireland
- provide an information service to governmental agencies, health boards, hospitals, health care professionals, approved researchers and patient advocacy organisations
- contribute to research at home and abroad.

CF REGISTRY TIMELINE

CFRI established
2001



Independent organisation
with a constitution
2005



Service Level
Agreement with
HSE
2011

Change
governance to
CLG
2018



Setup
funding
CFAI &
Dept of
Health



Annual Grant
DoH - HSE



2008
HRB-funded
research project
allowed addition
of internal
personnel



Contract
funding



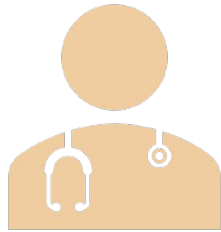
The Cystic Fibrosis Registry of Ireland

REGISTRIES – A BROAD VIEW - PRESENT

- 2017 - 120 National Health & Social Care Data Collections – HIQA
 - Less than 20 are disease registries
- MRCG/HSE – 2012 Patient Registry Survey – 47 identified
 - 69% less than 3 staff members
 - Often dependent on a single visionary / mentor
 - Majority operating on limited funding
- Without the proper resources it is an uphill battle



CONNECTING DATA IN REGISTRIES - CHALLENGES



Domestic

Registries are too paper dependent
Silos of unconnected data that could feed
registries
Centre to national
Patient connectivity



International

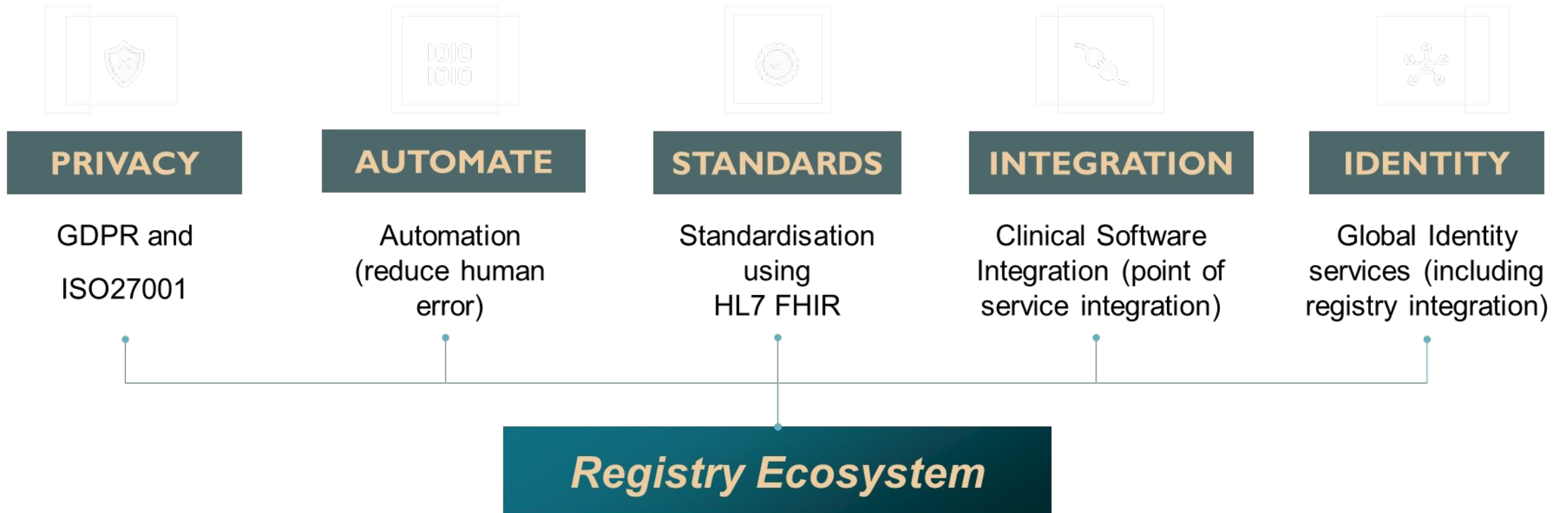
Be part of an international community
Retain ownership
Common standards and definitions

CONNECTING DATA IN REGISTRIES – A REGISTRY ECOSYSTEM

REGISTRY ECOSYSTEM

The registry ecosystem encompasses various elements that work separately but also together to ensure the successful functioning of registries and their contribution to healthcare research, patient care, and public health.

CONNECTING DATA IN REGISTRIES – HOW? KEY FEATURES



CONNECTING DATA IN REGISTRIES – CORE SERVICES



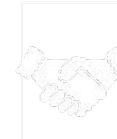
Data Capturing and Quality

Collecting, storing, and organizing patient-related information electronically within a healthcare system reduces human error and enforces quality. EHR's can integrate via standardized protocols (HL7 FHIR) enhancing interoperability.



Consent

Collecting, recording, storing, and managing the informed consent given by individuals ensures that individuals' rights are respected, and their decisions are properly documented and honored.



Registry Collaboration

Engaging in patient pool sharing across registries adopts a comprehensive perspective on interconnected medical conditions, diseases, treatments, or patient populations. This practice facilitates the consolidation of data from various sources, fostering improved research, insights, and outcomes.



Reporting

Empowered by robust reporting tools, users can craft personalized Dashboards and Reports that cater precisely to their unique needs.



Auditing

Auditing serves as a critical tool for maintaining transparency, accountability, and quality in various domains, including operations, information security, and compliance.

DIGITAL CLINICAL WORKFLOW FOR PATIENT

REC

 **John Adams**
Male | 57y 6m | 05/15/1965

Admin Access Clinic
Scheduled: 11/28/2022
Attending: Dr. Albert Davis

Problems Not Documented

Allergies/Side Effects Not Documented

Temp SBP PR DBP Flags

 Med list status could not be loaded

[JOIN](#)

Team Note - TeamNote with Guidelines

- RFV
- CC
- Hx
- Current Meds
- Vitals
- RT
- PFT
- Exacerbation
- PT
- Nutrition
- Social
- Nursing
- Medical
- Tests

Reason For Visit	Edit
Chief Complaint	Edit
Patient History	Edit
Current Medications	Edit
Vitals and Measurements	Edit
Respiratory Therapy	Edit
Pulmonary Function Test	Edit
Pulmonary Exacerbation	Edit
Physical Therapy <small>UPDATED</small>	Edit
Nutrition	Edit
Social and Behavioral	Edit
Nursing <small>UPDATED</small>	Edit
Medical	Edit
Tests	Edit
portCF	Edit
CF Guidelines	Edit

TEAM ACTIVITY CANCEL SAVE

Sources

Medications

Use switch to indicate your activity is complete.

CONTRIBUTORS

- Dr. Albert Davis
Complete
- Dr. Sarah O'reilly
Viewing
- Ms. Alison Nugent
Editing Nutrition



CFF ID: 1187191 First Name: Scott Last Name: Klein DOB: 07/29/1968

Patient General Information
 Patient Demographics ▾
 CF Diagnosis/Possible CF Diagnosis ▾

Annual Review
 Start 2017 Annual Review
 Show All
 No Forms Available For Editing

Patient Care Episode

Care Episode ID	Overall Status	Start Date	End Date
1 ▾ <i>Enter Care Episode</i>	✓	04/14/2015	04/15/2015

Legend

- Pending
- Incomplete
- Complete
- Signed**
- Queried
- Locked
- Created at different Care Center
- Form Options
 - ⊗ Incomplete Section
 - ✓ Complete Section

Encounter

Encounter Date	Overall Status	General Encounter Start	Microbiology	Medications	PFTs	GI Nutrition	Complications	Lab	Symptoms	Act/Exercise
11/14/2016 ▾	✓	✓	✓	✓	✓	✓	✓	✓		✓
07/15/2016 ▾	✓	✓		✓	✓			✓		✓
05/25/2016 ▾	✓	✓	✓	✓	✓	✓	✓	✓		✓
10/19/2015 ▾	✓	✓		✓		✓	✓	✓		✓
04/21/2015 ▾	✓	✓	✓	✓		✓	✓	✓		✓
<i>Enter Encounter Show All</i>										

Phone Note

Phone Notes ID	Overall Status	Date
<i>Enter Phone Note</i>		

File Upload

File Upload

Clinical Studies

Clinical Study	Overall Status	Date
No Forms Available for Editing		

AN INDEPENDENT FEDERATION OF DIGITISED PATIENT REGISTRIES

Vision

- ▶ An Independent Federation of Registries
- ▶ A trusted third party – filling gaps in health intelligence
- ▶ Appropriately funded
- ▶ Sharing common resources

UNLOCKING THE POTENTIAL OF PATIENT REGISTRIES: A GUIDE FOR SUCCESS

Thank you!