## Improving interoperability of personal dental data while upholding privacy



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## A decentralized architecture for sharing dental records



## Dental sector landscape

- 91% of active dentists worked in <u>private practice</u> settings
- 46% of private practice dentists were in solo practice
- Lack of human and financial resources
- Technical barriers
  - $\circ$  Incompatibility between different electronic records systems.
  - $\odot$  Data duplication.
  - $\odot$  Outdated data.
  - $\circ$  Scalability issues.
  - $\odot$  Inefficient data processes.

## Benefits of using dental data in other areas of medicine

Physicians require dental records:

- To diagnose and evaluate systemic diseases and the health status of their patients. More than 200 systemic diseases can present oral symptoms and/or signs
- Monitoring the progress of these diseases
- For coordination and collaboration of healthcare
- For research purposes
- For forensic purposes

## Taiwan medical information system - dental data model



There is no balance in data control between stakeholders.

This architecture depends on the availability of a central node.

Data model defined by the government : There is no interoperability and restricts what information is stored

#### **Dental treatment and surgical records**

- 1. Medical institution
- 2. Primary diagnosis
- 3. Medical order code
- 4. Medical order
- 5. Treatment part
- 6. Start time
- 7. Finish time
- 8. Medical order amount
- 9. Uploaded images inquiry



#### Medical visit records

Specific dental treatment	All 🗸	
Selected dental notation	All	~
Sorting item Visit data (stadias	from the andiant'	

ll mouth	Visit date	Medical institution	Primary diagnosis	NHI card sequence number	Medical order code	Medical order	Medical order amount
	2017/7/8	You-Yue Dental Clinic	Chronic gingivitis caused by dental plaque	0012	91004C	Scaling-full-mouth	1
	2017/7/8	You-Yue Dental Clinic	Chronic gingivitis caused by dental plaque	0012	91014C	Scaling-full-mouth	1
	2016/5/3	You-Yue Dental Clinic	Chronic gingivitis caused by dental plaque	0012	91004C	Scaling-full-mouth	1
	2016/4/10	You-Yue Dental Clinic	Cavity	0012	89009C	Posterior teeth composite resin restoration-two surfaces	2
ords	2015/12/8	You-Yue Dental Clinic	Cavity at the tooth- enamel level	0012	89005C	Anterior teeth composite resin restoration-two surfaces	1

Source: National Health Insurance Administration, Ministry of Health and Welfare, R.O.C. (Taiwan). IMM UserGuild NEW V3.3.

### Taiwan medical information system - architecture diagram



## EHR VS PHR

#### Electronic Health Data

- Designed for professional use
- Different data sources can coexist
- Store clinical data

#### Personal Health Records

- Used by individuals
- One unique source of data
- Store health data and well-being

	Electronic Health Data	Personal Health Records
Goal	Professional activity performance	Data self-management
Common technologies	Information repository	Set online tools
Competition in management	Professionals	individuals

## PHR approach



#### Personal Domain

Organizational Domain

## Some PHR tools

PHR name	Website for PHR
Avado	http://www.avado.com
My Doclopedia	http://www.doclopedia.com
Dr. I-Net	http://www.drinet.com
Mayo Clinic Health Manager	http://healthmanager.mayoclinic.com
HealthVault	http://www.healthvault.com
HealthyCircles	https://connect.healthycircles.com/Public/Consumer/ Home.aspx
Juniper Health	http://juniperhealth.com
Koozala	http://www.koozala.com
Lifeclinic	https://www.lifeclinic.com/member/login/login.asp
Mymediconnect	http://www.mymediconnect.net
Medsfile	http://www.medsfile.com
MyMedSafe	http://www.vitalesafe.com
Myphr.ca	http://myphr.ca
NoMoreClipBoard	http://www.nomoreclipboard.com
Patient Power	http://gtipatientpower.com
RelayHealth	http://app.relayhealth.com
YourHealthRecord	http://www.yourhealthrecord.com
WebMD Health Manager	http://www.webmd.com/phr
ZebraHealth	https://www.zebrahealth.com/PersonalHealthRecord/ Personal_Health_Records.ztml

Source: Fuji et al. - 2012 - Standalone personal health records in the United States: meeting patient desires Data availability depends on application availability.

Data model defined by companies: There is no interoperability and restricts what information is stored

"Substitute applications"

Individuals must enter data.

Individuals still have no control over their health data



## Solid: Social Linked Data Platform



Source: Sambra et al. - 2016 -Solid: A Platform for Decentralized Social Applications Based on Linked Data

Main advantages of Solid

- Allows Interoperability
- Brings Security & Privacy
- Enables Data Portability
- Gives users control over their data
- User empowerment

## General architecture diagram



Personal Domain

#### **Organizational Domain**

## Privacy

#### Principles



#### Laws & Standards

- **Privacy:** In medical ethics, the concept is associated with maintaining a patient's dignity and autonomy and with the doctor's duty of confidentiality.
- Autonomy: Literally 'self-rule', the capacity for reasoned self-determination in thought and action. There is not unlimited.
- Confidentiality: Ethical and legal obligation that requires doctors to keep information about their patients private.
   Concise Medical Dictionary (Oxford Quick Reference).

• HIPAA – GINA laws (USA)

- ISO 27799
- Regulation 2016/679 General Data Protection Regulation

Security measures

#### Security Requirements

- Confidentiality
- Integrity
- Availability

Security Measures

- Access control policies
- Role system
- anonymization techniques
- encryption technics

## Interoperability

"The ability of two or more systems or components to exchange information and to use the information that has been exchanged"- IEEE



Autonomy issues

- The data or information being managed (domain).
- The **representation** (data model, query language) and the **naming** of the data elements (or the ontology used)
- The **conceptualization** or semantic interpretation of the data (or the context).
- **Constraints** used to manage the data.
- The functionality of the system.
- Association and sharing with other systems.

## Interoperability



**RDF** is the recommended format for sharing health data due to its semantic interoperability, granular representation, and alignment with linked data principles, enabling efficient integration and exchange of diverse healthcare information.



**FHIR** is one of the most widely used standardized formats for health information exchange. It has resources to define standards for bi-directional information exchange between a medical and a dental provider or between dental providers.

SNOMED CT

**SNOMED CT** is a comprehensive clinical terminology used globally for standardized healthcare data encoding.



Representation of a knowledge graph

## Interoperability



**Shape Expressions (ShEx)** is a language that allows modeling graphs (sets of RDF triples) in a precise and formal way.

ShEx allows us to define the topology of the stored data. A fundamental requirement when we are trying to represent complex entities.

These schemas facilitate an inference testing service, employing the provided schema on the input graph, and employing a reasoning mechanism capable of deducing requisite transformations to adapt the information to the output model, through the addition of new triples and execution of transformations. PREFIX : <http://example.org/clinic>
PREFIX schema: <http://schema.org/>
PREFIX xsd: <http://www.w3.org/2001/XMLSchema#>

#### :Observation {

}

:identifier :effectiveDateTime :BodySite :code IRI @:Identifier; xsd:date? ; IRI @:CodeableConcept; IRI @:CodeableConcept;

# :CodeableConcept { :code xsd:string ; :system xsd:string ; :display xsd:string ; } :Identifier { :use xsd:string ; :system xsd:string ; :value xsd:string ;

Representation of a Shape Expression

## Interoperability: An example with Legos



Shape Expression



Personal Domain

Organizational Domains

## Approach



## User side layer



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