STANDARD HEALTH RECORD

DESIGN BRIEF v01

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PROJECT:

Define and implement the core components of a standard, digital health record that will be used for US patients.

The US has failed to define a standard health record, which is found in all top-performing healthcare systems around the world.

Health System Ranking

United Kingdom	Summary Care Record
Switzerland	Statutory Health Insurance Smart Card
Sweden	National Patient Summary
Australia	Personally Controlled Electronic Health Record
Germany	Electronic Health Card
Netherlands	het Electronisch Patiëntendossier
New Zealand	National Health Index
Norway	National Health Network
France	Dossier Médical Personnel
Canada	
United States	No standard health record

Cost Per Capita

United States	$8,713
Switzerland	$6,466
Norway	$6,177
Netherlands	$5,217
Germany	$5,002
Sweden	$4,904
Canada	$4,429
France	$4,124
Australia	$3,866
New Zealand	$3,328
United Kingdom	$3,235

Data from OECD, 2015

PROBLEM:

- The US has failed to define a key component found in all top-performing healthcare systems.
- A common operational picture of the patient does not exist. What does exist is fragmented, non-standard, and poorly shared.
- We have over 120 incompatible private and regional Health Information Exchanges.
- There are significant questions around standards, data models, mapping, terminology, exchanging, merging, storing, securing, and authorizing 3rd party access.

SOLUTION:

By providing tightly-defined data elements, terminology mappings and value sets, a **standard health record** will improve health data interoperability in the US and improve patient experience, data access, quality of outcomes, and reduce cost.

The standard health record will:

Allow a single source of truth for complete patient health data needed for patient identification, emergency care, and primary care. It will improve care coordination by providing a common operating picture.

Define core components of a standard, digital health record for US civilian, DoD, and VA patients. It will contain all the critical data needed to support patient identification, emergency care, and primary care.

Improve information transfer by providing rightly-defined data elements, terminology mappings, and value sets. This will allow medical information to be stored, transferred, and merged using the SHR specification. It will leverage existing standards such as a constrained version of HL7 FHIR.

Follow informed practices within the US and internationally, taking cues from the UK Summary Care Record, Sweden's National Patient Summary, and the ONC Common Clinical Data Set, among others.

Project

- Define the core components of a standard, digital health record v01.
- Demonstrate a centralized, open source, pilot HIE with SHR for Massachusetts.
- Conduct limited pilots using Personal Health Information (PHI).
- Conduct a large scale trial in Massachusetts using Personal Health Information.
- Establish a new certification for HIEs, based on the ability to store merge, and disseminate SHRs (certified HIE).
- Establish a DURSA (Data Use and Reciprocal Support Agreement) that permits SHRs to be passed between HIEs and authorized parties.
- Work with Commonwealth of Massachusetts to establish digital healthcare policies, including an opt-out HIE policy.

Outcomes

- Improve patient quality of outcome.
- Improve the health care experience for patients.
- Reduce health care system costs.
- Improve patient access to quality care.
- Allow the SHR to be available to the patient and all authorized care staff nation-wide with a robust security and patient consent model.
- Allow health care data to be stored, transferred, and merged according to unambiguous national standards.

TIMELINE

2016 — **Health Data Interoperability 10x begins**

- Define Standard Health Record (SHR) version 1.0
- Standard Health Record is open sourced
- Conduct field demonstrations with synthetic data

2017 — SHR adopted by ONC, Department of Defense, and Veterans Affairs

2018 — Pilot using protected health information (PHI) data

- Conduct a large scale trial in MA using PHI data

CURRENT CONCEPTS

The following designs are iterative works in progress. Designs are expected to be added and changed as the project progresses.

Standard Health Record v01

Tentative SHR v01 content
* ONC Commmon Clinical Data Set
For future addition

Patient Identification

Patient name(s)*
Date of Birth*
Administrative Sex*
Address(es)
Telephone number(s)
Email address(es)
Emergency contact(s)
Legal guardian (if minor)
Preferred language*

Patient Support

Payment source
Insurance identifier(s)
Care team members*
Consent for data sharing
Healthcare proxy
Advance directives
*Health goals**
Preferred pharmacy

Current Health and Care Plan

Current medications
Allergies (drug*, food, environ)
Problems*
Contraindications and intolerances
Vital signs*
Blood type
Medical appliances or devices*
*Lab tests and results (recent)**
*Health concerns**
*Plan of treatment (care plan)**
Disabilities

Health History

Past hospitalizations (past year)
Past major procedures*
Immunizations*
Past outpatient encounters (past year)
Personal health history
Family health history

Behavior

Level of physical activity
Smoking status*
Drug and alcohol use
Medication compliance

Social/Environmental Factors

Race/ethnic group
Religion
National origin
Gender identity
Marital status
Income level
Education/Literacy level
Food status/security
Transportation availability
Health services accessibility
Housing situation/security
Employment status/security
Stress factors
Social isolation/exclusion
Domestic violence or abuse
Risks to patient, provider, or third party

Organization of SHR data

The SHR data is organized into domains and subdomains, which represent the category of data being stored.

These domains are further organized into specific namefields which represent the actual data elements.

The actual value sets are still being determined.

domain	subDomain	nameCommon	nameField	definition		refLOINC	refSNOMEI
Human		"A Human Being"	human	a human being,	the patient or otherwise		
		"Relationship(s) to the Pati	human.relationship				
			human.identifier...				
		"Person's Name"	human.name...				
			human.dateBirth				
Organization		"An Organization"	organization...	non-human entitity that provides services,			e.g. hos
			organization.relationship				
			organization.identifier...				
			organization.name...				
Device		"Device(s)"	device...	applicances, devices or equipment			
			device.relationship				
			device.identifier...				
			device.name...				
Geography		"Geography"	geography...				
			geography.address...				
			geography.geocode...				
Contact		"Telephone number(s)"	contact.telephone...				
		"Email Address(es)"	contact.email...				
Conditions		"Condition(s)"	condition	diagnoses or problems, elements of a health history			
			condition...				
Medications		"Medication(s)"	medication	also includes immunizations			
			medication.adherence...				
Sensitivities		"Sensitivity/(ies)"	sensitivity	allergies, sensitivities, contraindications, intole			
			sensitivity.substance				
			sensitivity.type				
			sensitivity.reaction				
			sensitivity.severity				
Goals		"Goal(s)"	goal				
			goal...				
Resources		"Resource(s)"	resource	links a **contact**, **condition** and **goal**			
			resource...				

Completeness conceptual models

The completeness of a patients SHR can vary depending on the model used to measure it. Three potential models are outlined here.

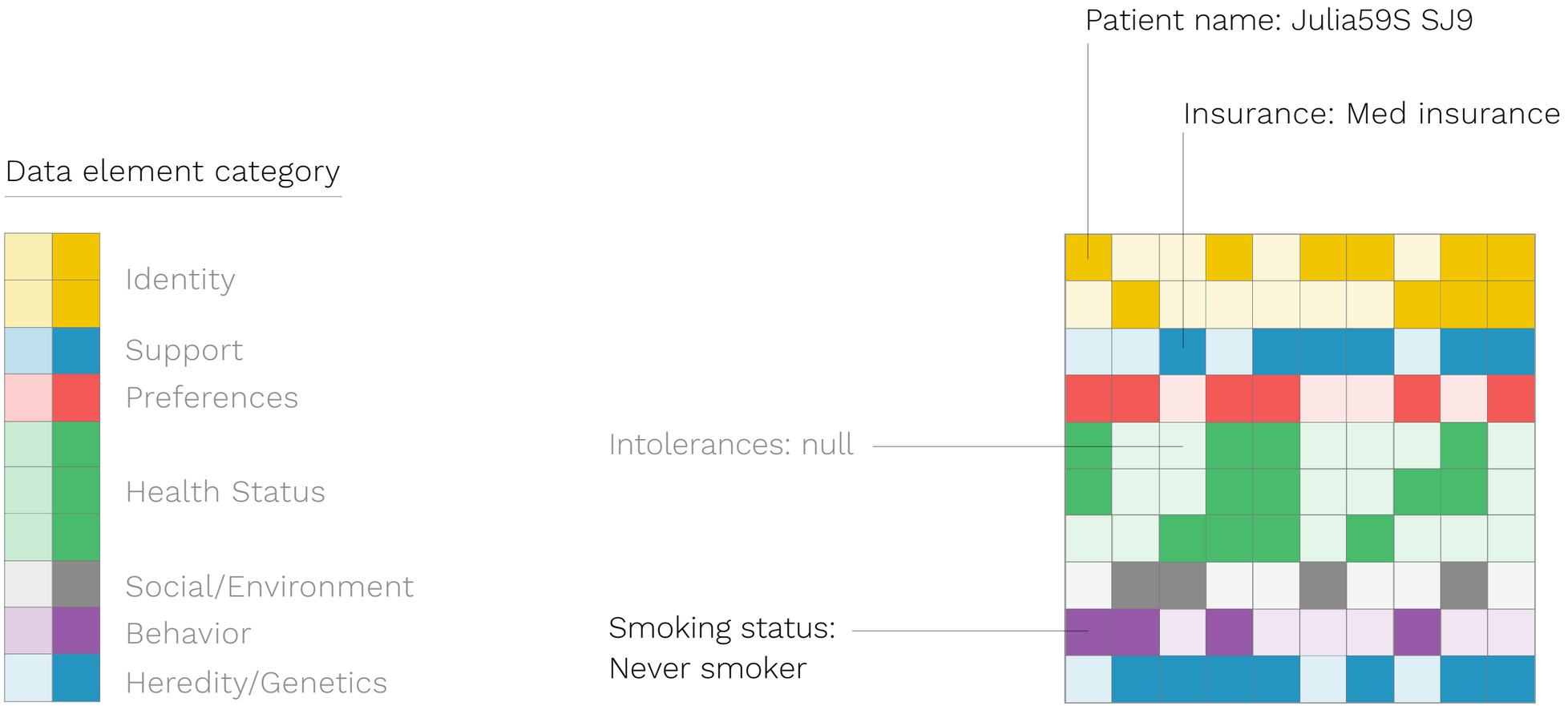
Model 1: Documentation

Model 2: Use cases

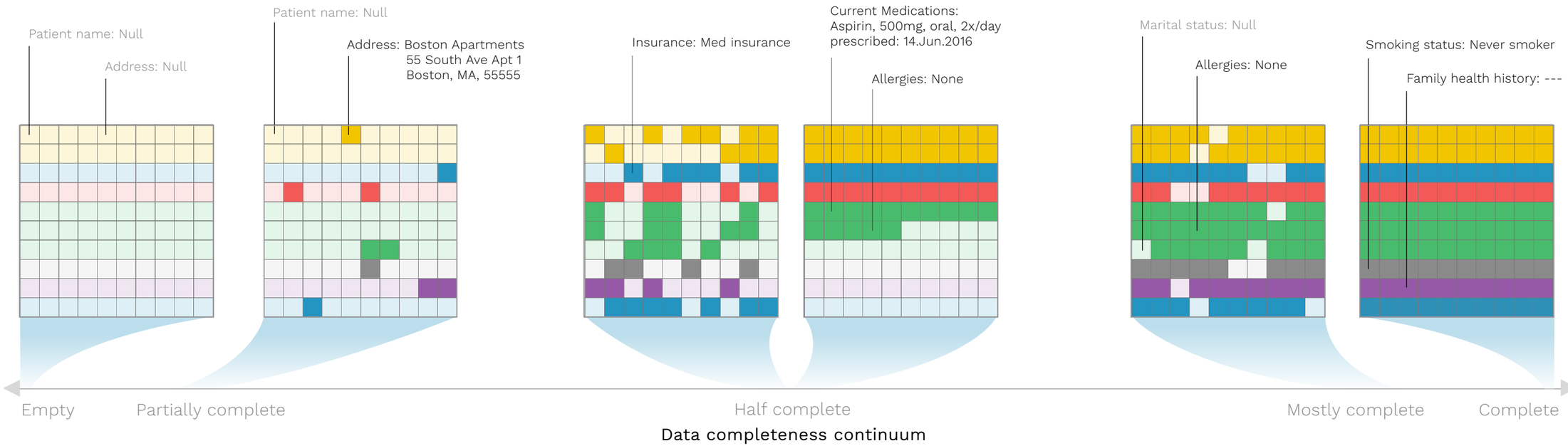
Model 3: Breadth and depth

Conceptual model 1: Documentation

Completeness based on the percentage of the total data elements that have an entry value in the SHR. This illustration breaks the SHR down into 100 modular units of data elements as a visual example.



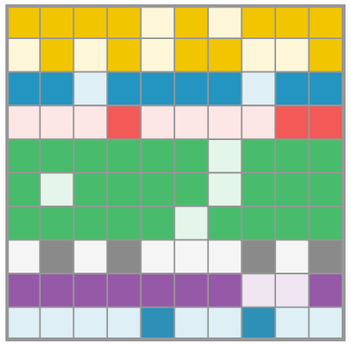
A spectrum exists within the documentation model of completion. This model does not take into account depth of data (metadata, frequency of data).



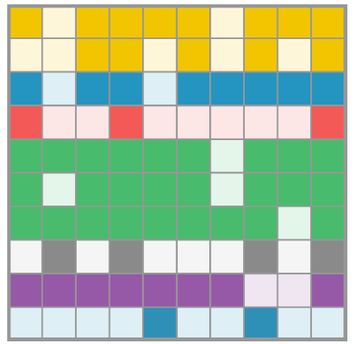
Data completeness continuum

Conceptual model 2: Use cases

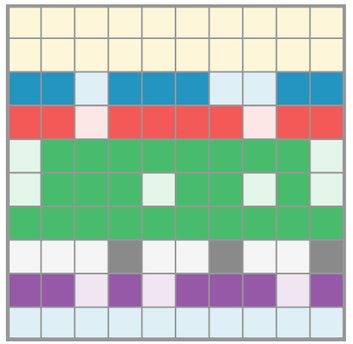
Different data elements may be necessary depending on the use case. The more use cases the SHR can account for, the more complete the record.



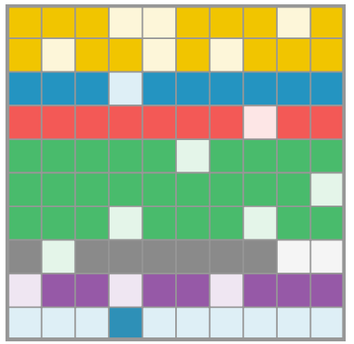
Inpatient visit



Outpatient visit



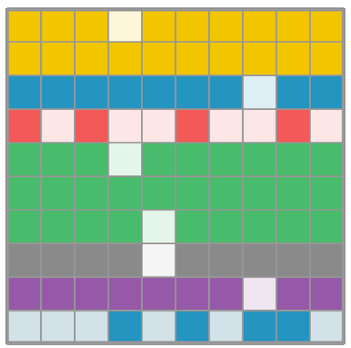
Emergency department



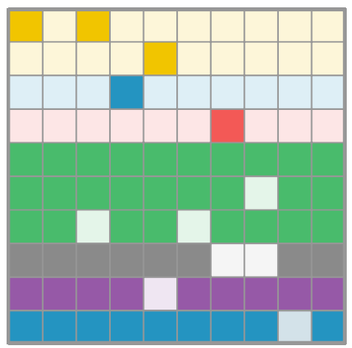
Physician office visit

Less common individual use case

More common individual use case



Public health policy



Clinical research

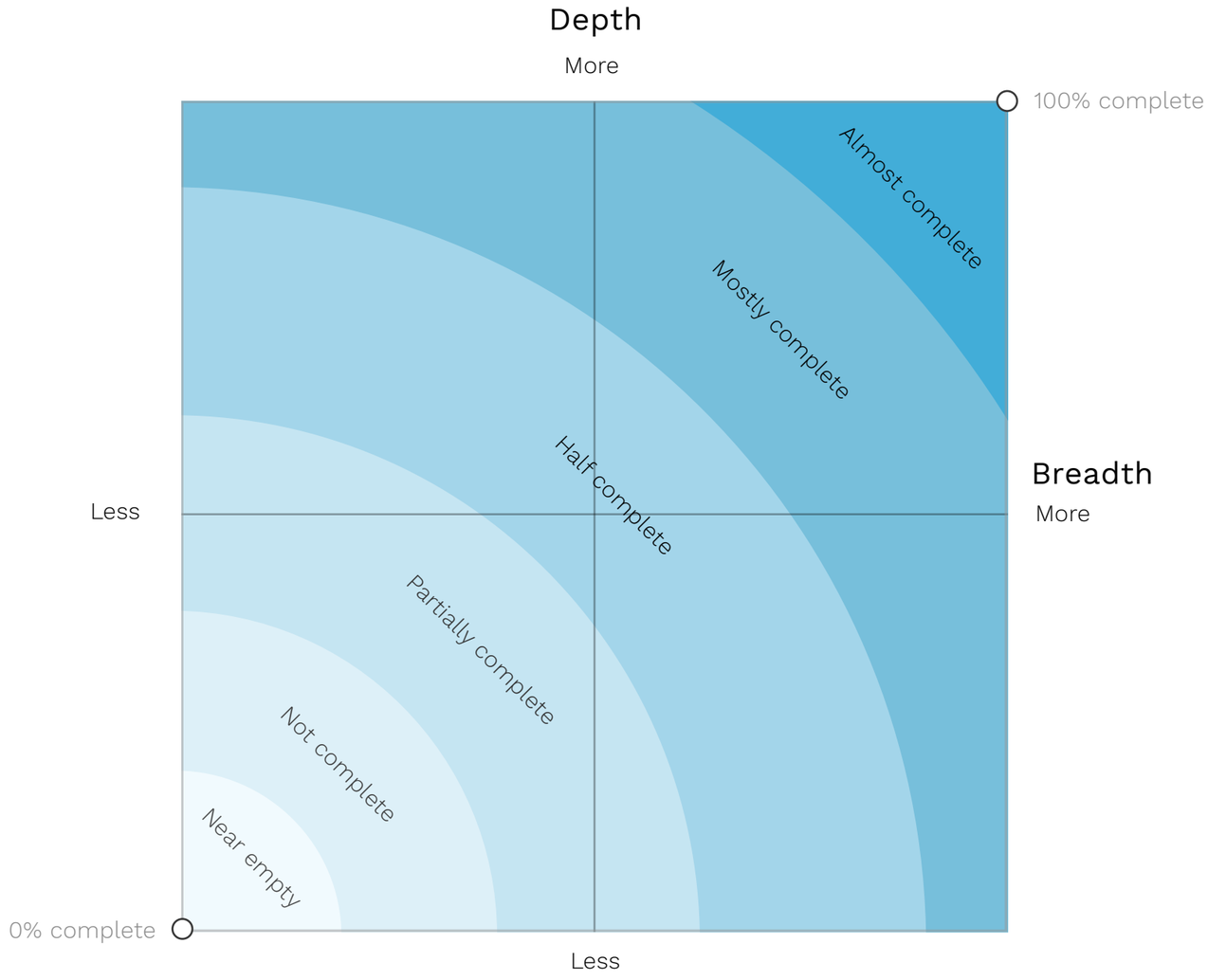
Non individual use case

Conceptual model 3: Breadth and depth

Completeness based on total volume of data within the SHR, taking into account two factors:

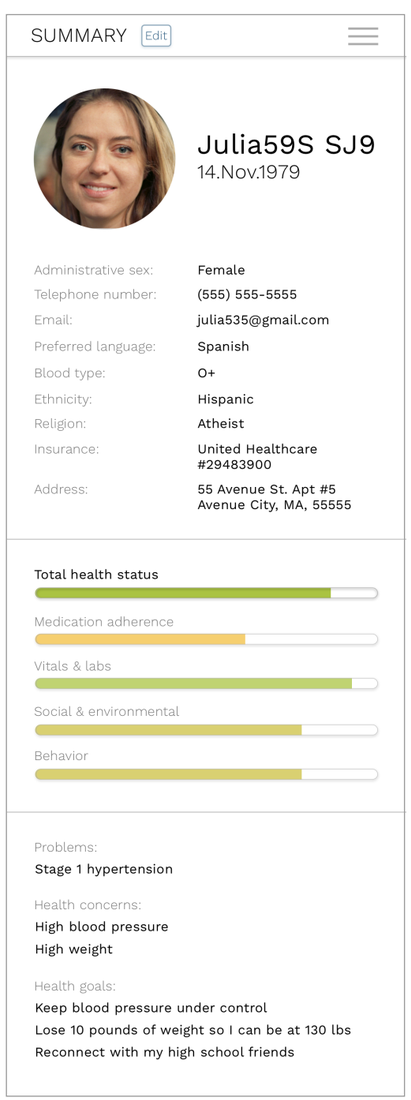
Breadth of data: the amount of different data elements that have been recorded.

Depth of data: completeness of each individual data element, which includes the value entry and completeness of metadata entry.



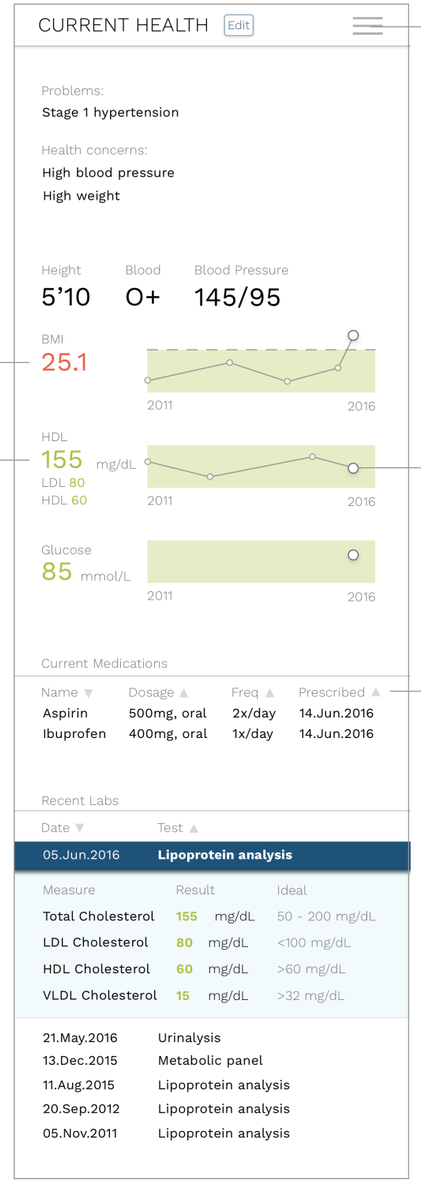
Design concepts using synthetic patient data

The following design concepts are a visual representation of a clinicians view of a SHR using synthetic patient data.



Patient identification

Status bars display health quality at a glance



Colors indicate whether the patient is within a healthy or non healthy range of values

Physiological data, current and trends over time

Medications organized by prescription date. Ability to sort

Labs organized by date, interact to reveal detailed lab results and information

CARE PLAN

Edit

Daily

Take aspirin 2x/day
Take Ibuprofen 1x/day

Calendar

Refill aspirin 14.July.2016
Dr. Clarissa Gabe, internist

Consultation 20.July.2016
Dr. Nick Cline (555) 555-5555

Plan

Ensure adequate time for rest and relaxation
Follow medication routine

Develop healthy eating habits and routines

Eat breakfast everyday to boost the body's metabolism, improve energy and alertness, and reduce risk of obesity

Avoid junk and processed foods

Get 4 servings of calcium everyday for bone growth and strength

Consume vitamin D enriched milk, eggs, and fatty fish like salmon to improve absorption of calcium

Maintain regular physical activity
Strengthen bones and muscles
Get on a regular sleep schedule

Select to enter edit mode for adding and changing data values

Care plans can be changed by designated providers

Select a part of the plan to reveal detailed instructions

SOCIAL & ENVIRONMENTAL

Edit

Ethnicity:	Hispanic
Religion	Atheist
National Origin:	US
Gender Identity:	Female
Marital Status:	Single
Income Level:	45,000 USD/year
Education & Literacy:	Bachelors degree
Risk to Patient or Provider:	None

Social factors

Behavior

Physical Activity:	
Medication Compliance:	
Smoking Status:	2x/week
Drug	None

Behavioral factors

Environmental

Food Security:	
Transportation Availability:	
Employment Status:	

Working as a contractor
Half the company may be laid off this month
Have not received a wage increase in 5 years

Housing Security:	
Health Services Availability:	
Social Isolation:	None
Domestic Violence:	None

Stress Factors:

Have not heard from cousin Jessica Smith in a year
Getting used to the new home
There's a lot of noise in the new neighborhood
Persistent headache

Selected data element reveals information on the reason for the score

CONTACTS

Emergency

Jose Smith
Father
Data consent

Debra Smith
Mother
Data consent

Amanda Reese
Aunt
Data consent

Indication of SHR data sharing permission. If there is no data consent, limited data will be displayed

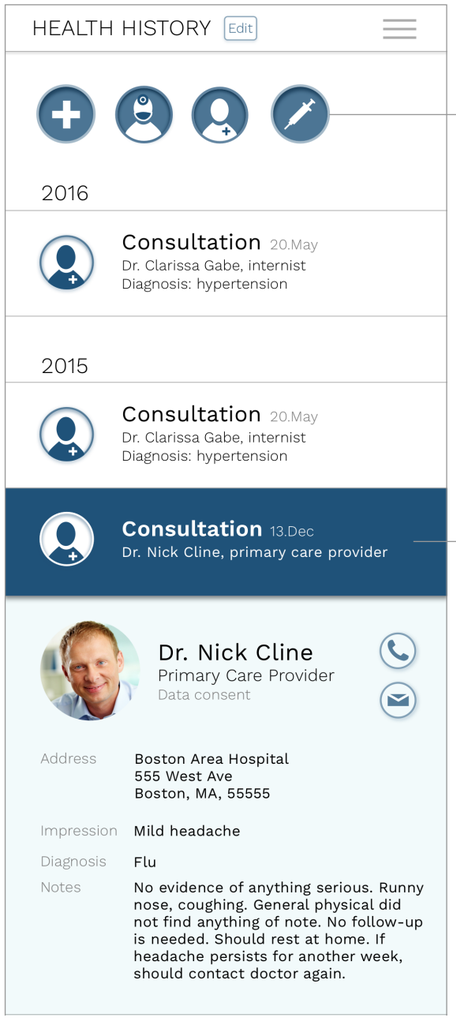
Team

Dr. Nick Cline
Primary Care Provider
Data consent

Dr. Clarissa Gabe
Internist
Data consent

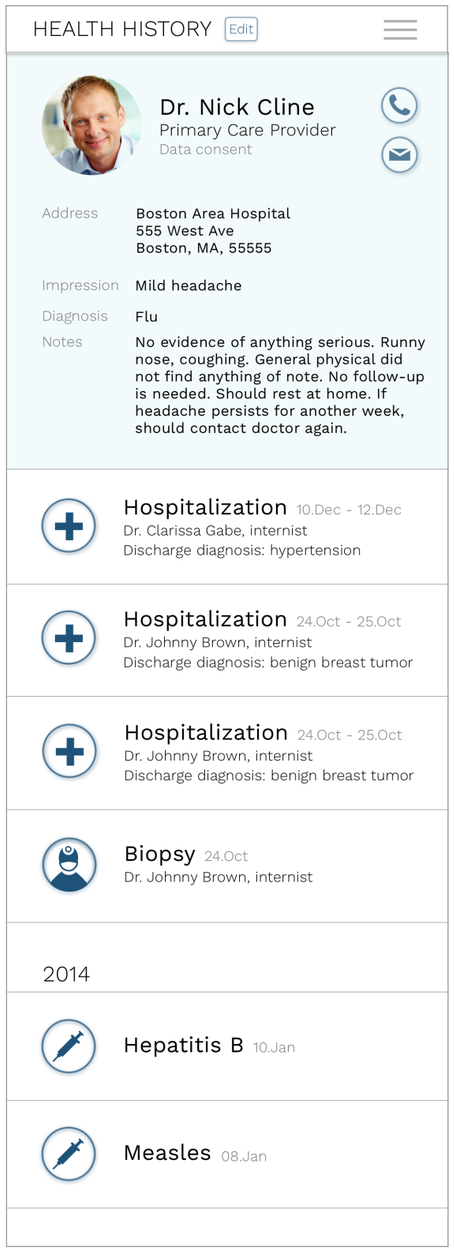
Jon Blake
Physician Assistant
Data consent

Design concepts using synthetic patients



Health history filters from left to right: inpatient encounters, surgeries, outpatient encounters, immunizations

Selection reveals detailed information on the history entry such as physician notes and related documents and values



Several versions are still needed based on frequent use cases such as emergency care, acute vs chronic conditions, among others, in order to view how the design accomodates varying data scenarios.

Designs will need to be expanded to show progressive additions of data completeness.

Feedback must continually be collected from users outside MITRE in order to reiterate on SHR designs.

(Link to prototype)

NEXT STEPS

- Structure and definition for SHR values for each data element must be specified.
- Display how all tiers of the SHR interact, from the population level, to the individual, to the data elements and the data values. This can be used to gather further feedback on the project.
- Synthetic data, free of protected health information (PHI) and personally identifiable information (PII) contraints, must be created in order to enable experimental prototyping for common medical use cases.
- Expanded completeness models to include detailed methods for measuring the amount and quality of completeness.