

STANDARD HEALTH RECORD

DESIGN BRIEF v02

JULY 2016

PROJECT:

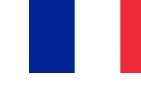
Define and implement the core components of a standard, digital health record that will be used for US patients.

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

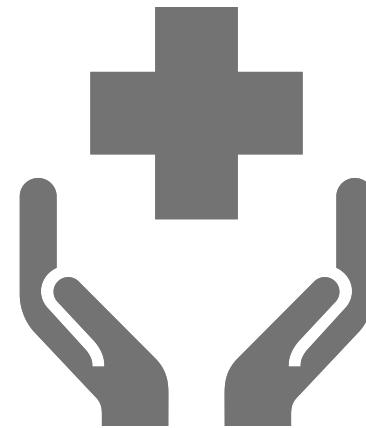
Data from OECD, 2015

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.



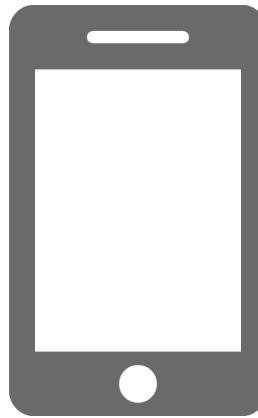
The standard health record will allow a single source of truth

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.



It will 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.



It will 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.



It will 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 Common 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	refSNOMED
Human		"A Human Being"	human	a human being, the patient or otherwise		
		"Relationship(s) to the Patient"	human.relationship			
		"Person's Name"	human.identifier...			
Organization		"An Organization"	organization...	non-human entity that provides services, e.g. hospital, insurance company, home...		
			organization.relationship			
			organization.identifier...			
			organization.name...			
Device		"Device(s)"	device...	appliances, 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, intolerances		
			sensitivity.substance			
			sensitivity.type			
			sensitivity.reaction			
			sensitivity.severity			
Goals		"Goal(s)"	goal			
			goal...			
Resources		"Resource(s)"	resource	links a contact, condition and goal		
			resource...			
Preferences		"Preference(s)"	pref.generic...	dynamic, flexible, complex, factor into decision-making		
			pref.endOfLife			
			pref.languageWritten			
			pref.languageSpoken			
			pref.sexual		Code	472985009 Sexually attracted to men
Assessments		"Assessment(s)"	assessment.generic...	ADLs, IADLs, depression scale, whatever, so long as it is structured, the outcome		
			assessment.ADLxIADLs			
			assessment.socialFunction			

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

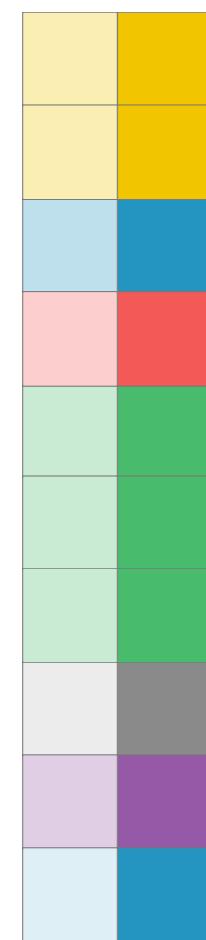
Model 2: Use cases

Model 3: Breadth and depth

Conceptual model I: 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.

Data element category



Identity

Support

Preferences

Health Status

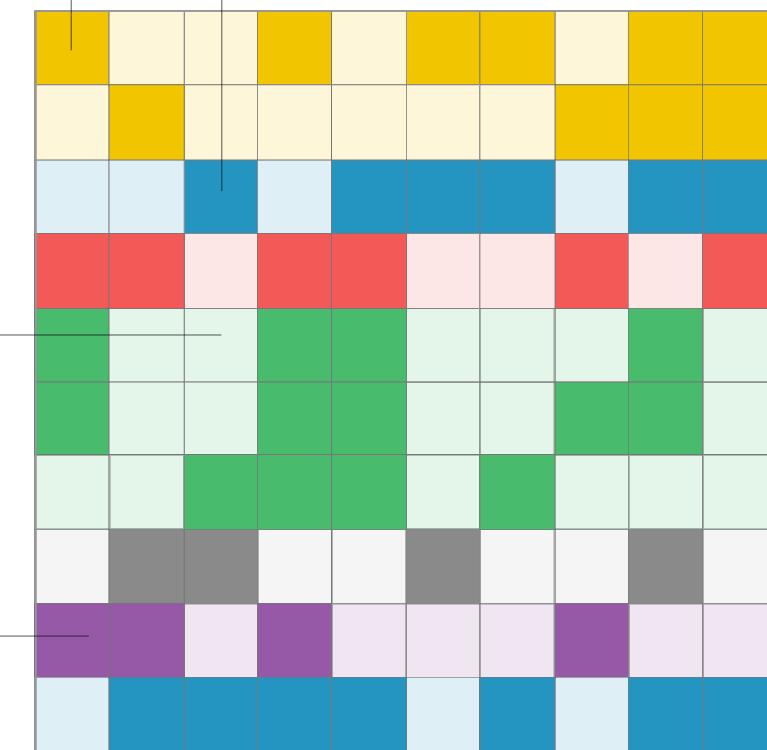
Social/Environment

Behavior

Heredity/Genetics

Patient name: Julia59S SJ9

Insurance: Med insurance

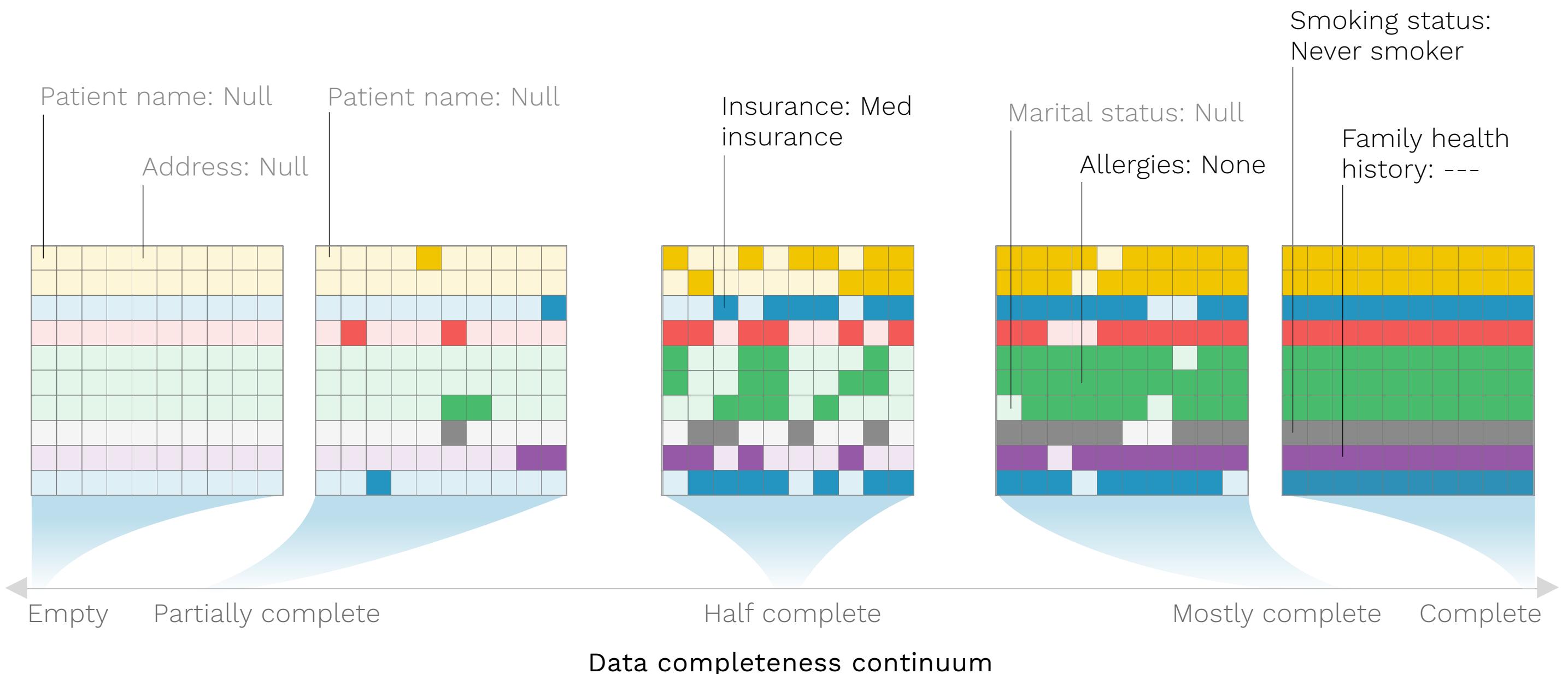


Intolerances: null

Smoking status:

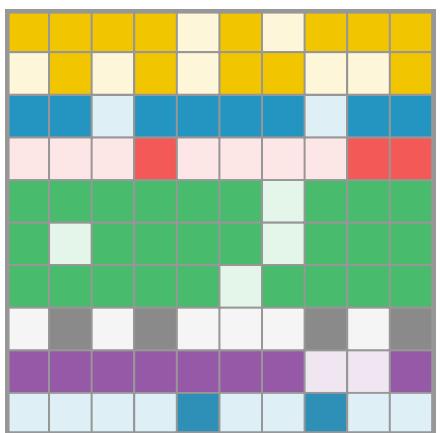
Never smoker

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

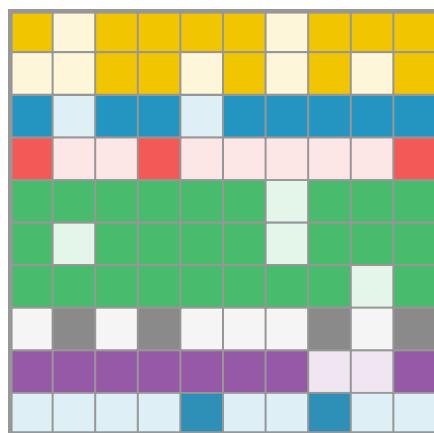


Conceptual model 2: Use cases

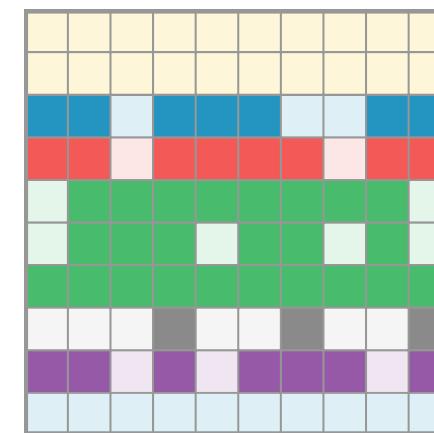
Different data elements may be necessary depending on the use case. The more use cases the SHR can account for, the more complete the record.



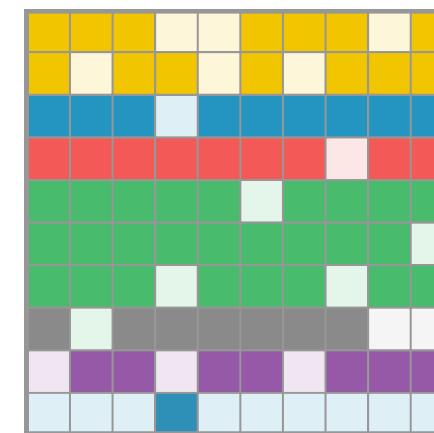
Inpatient visit



Outpatient visit



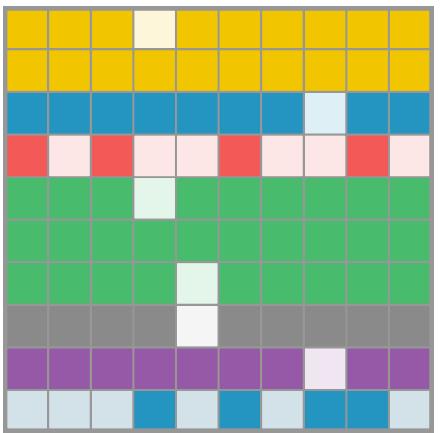
Emergency department



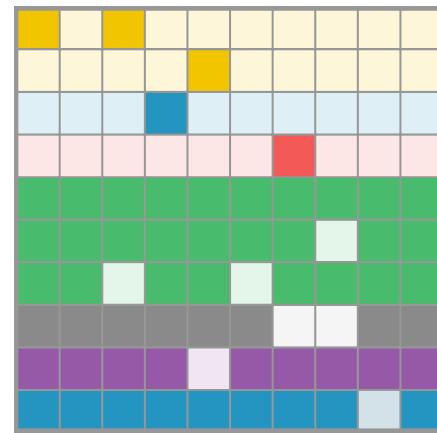
Physician office visit

Less common individual use case

More common individual use case



Public health policy



Clinical research

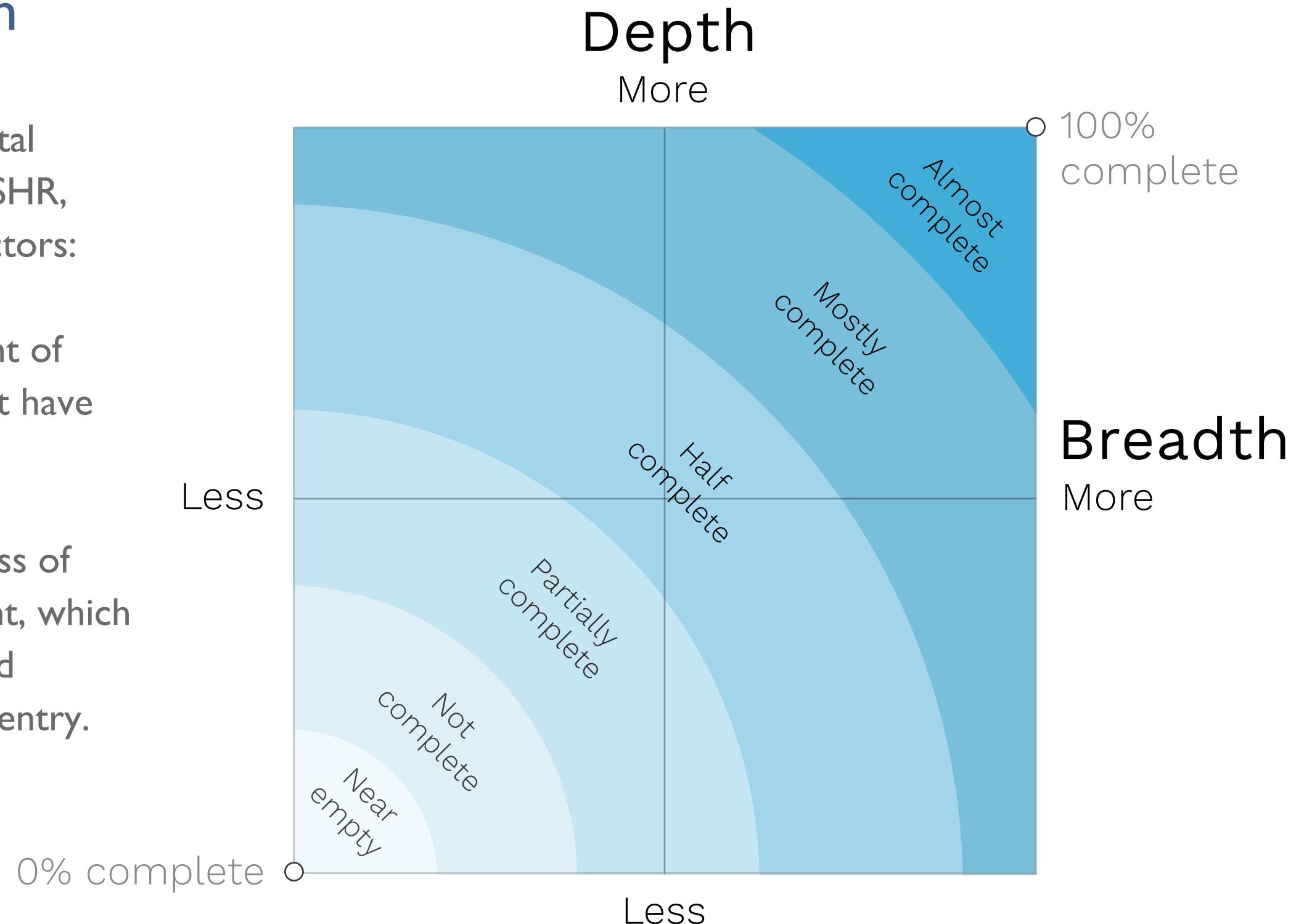
Non individual use case

Conceptual model 3: Breadth and depth

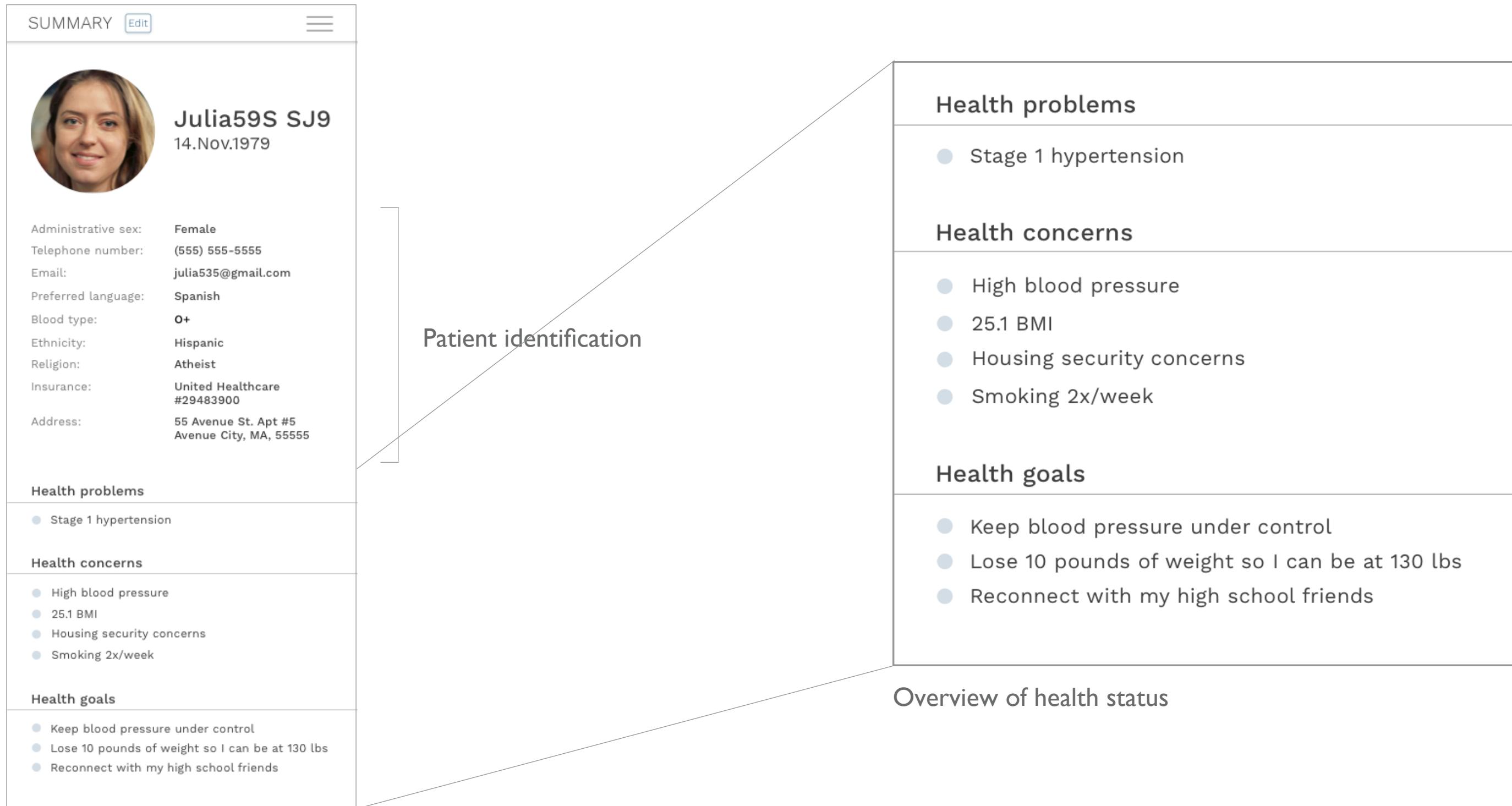
Completeness based on total volume of data within the SHR, taking into account two factors:

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.

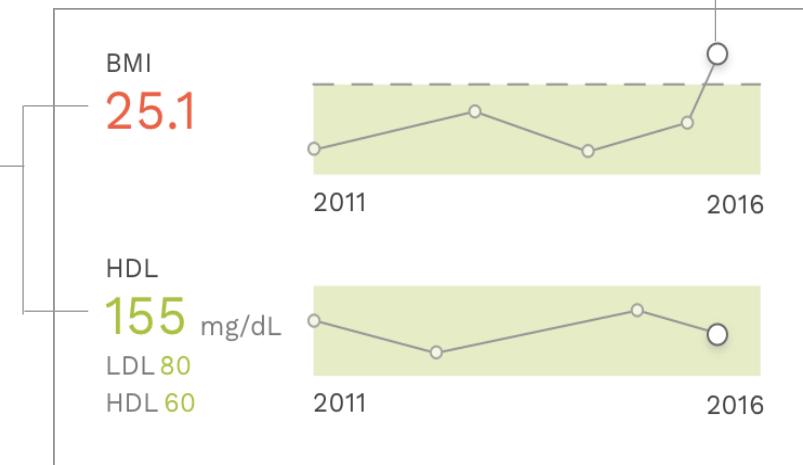


Design concepts using synthetic patient data



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

Physiological data, current and trends over time



Colors indicate severity

Allergies		
Pollen	Severe	Respiration issues
Peanuts	Mild	Small rash
Gluten	Moderate	Moderate diarrhea

Reaction/contraindication

CURRENT HEALTH [Edit](#) ≡

Problems:
Stage 1 hypertension

Health concerns:
High blood pressure
High weight

Height: 5'10 Blood Type: O+ Blood Pressure: 145/95

BMI: 25.1

HDL: 155 mg/dL

LDL: 80

HDL: 60

Glucose: 85 mmol/L

Allergies

Allergy	Severity	Reaction
Pollen	Severe	Respiration issues
Peanuts	Mild	Small rash
Gluten	Moderate	Moderate diarrhea

Current Medications

Name	Dosage	Freq	Prescribed
Aspirin	500mg, oral	2x/day	14.Jun.2016
Ibuprofen	400mg, oral	1x/day	14.Jun.2016

Recent Labs

Date	Test
05.Jun.2016	Lipoprotein analysis

Measure Result Ideal

Total Cholesterol	155 mg/dL	50 - 200 mg/dL
LDL Cholesterol	80 mg/dL	<100 mg/dL
HDL Cholesterol	60 mg/dL	>60 mg/dL
VLDL Cholesterol	15 mg/dL	>32 mg/dL

21.May.2016 Urinalysis
13.Dec.2015 Metabolic panel
11.Aug.2015 Lipoprotein analysis
20.Sep.2012 Lipoprotein analysis
05.Nov.2011 Lipoprotein analysis

Summary
Current Health
Care Plan
Health History
Social & Environmental
Contacts

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, primary care provider

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

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

Select a part of the plan to reveal detailed instructions.
Care plans can be changed by designated providers

HEALTH HISTORY		Edit	≡
	Inpatient encounters		Surgeries
	Outpatient encounters		Immunizations
	Consultation		Biopsy
	Dr. Nick Cline Primary Care Provider Data consent		Dr. Johnny Brown, internist
	(222) 222 - 2222		cline@areahospital.com
	View data consent		
Address	Boston Area Hospital 555 West Ave Boston, MA, 55555	Address	Boston Area Hospital 555 West Ave Boston, MA, 55555
Impression	Mild headache	Impression	Mild headache
Diagnosis	Flu	Diagnosis	Flu
Notes	No evidence of anything serious. Runny nose, coughing. General physical did not find anything of note. No follow-up is needed. Should rest at home. If headache persists for another week, should contact doctor again.	Notes	No evidence of anything serious. Runny nose, coughing. General physical did not find anything of note. No follow-up is needed. Should rest at home. If headache persists for another week, should contact doctor again.
	Hospitalization 10.Dec - 12.Dec Dr. Clarissa Gabe, internist Discharge diagnosis: hypertension		
	Hospitalization 24.Oct - 25.Oct Dr. Johnny Brown, internist Discharge diagnosis: benign breast tumor		
	Hospitalization 24.Oct - 25.Oct Dr. Johnny Brown, internist Discharge diagnosis: benign breast tumor		
	Biopsy 24.Oct Dr. Johnny Brown, internist		

Health history filters



Inpatient encounters



Surgeries



Outpatient encounters



Immunizations

Consultation 13.Dec
Dr. Nick Cline, primary care provider

Dr. Nick Cline
Primary Care Provider
Data consent

(222) 222 - 2222

cline@areahospital.com

[View data consent](#)

Address Boston Area Hospital
555 West Ave
Boston, MA, 55555

Impression Mild headache

Diagnosis Flu

Notes No evidence of anything serious. Runny nose, coughing. General physical did not find anything of note. No follow-up is needed. Should rest at home. If headache persists for another week, should contact doctor again.

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

SOCIAL & ENVIRONMENTAL	
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
Behavior	
Physical Activity:	3x/week
Medication Compliance:	High
Smoking Status:	2x/week
Drug	None
Environmental	
Food Security:	No concerns
Transportation Availability:	No concerns
Housing Security: 3 Concerns	
More than 3 moves the previous year	
More than 2 people per bedroom	
Will have to move again in a few months	
Health Services Availability:	No concerns
Social Isolation:	No concerns
Domestic Violence:	No concerns
Employment Status:	Full-time employee
Stress Factors	
Haven't heard from cousin Jessica S. in a year	
Getting used to the new home	
There's a lot of noise in the new neighborhood	
Persistent headache	

Social factors

Behavioral factors

Housing Security: 3 Concerns

- More than 3 moves the previous year
- More than 2 people per bedroom
- Will have to move again in a few months

Health Services Availability: No concerns

Social Isolation: No concerns

Domestic Violence: No concerns

Employment Status: Full-time employee

CONTACTS		
Emergency		
Jose Smith Father Data consent		
Debrasanndra Smith Mother Data consent		
Amanda Reese Aunt Data consent		
Johannathasen Castaneda Grandfather Data consent		
Jonathan Mcclough Nephew		
Team		
Dr. Nick Cline Primary Care Provider Data consent		
Dr. Clarissa Gabe Internist Data consent		

CONTACTS		
Emergency		
Jose Smith Father Data consent		
Debrasanndra Smith Mother Data consent		
Amanda Reese Aunt Data consent		
Johannathasen Castaneda Grandfather Data consent		
Jonathan Mcclough Nephew		
Team		
Dr. Nick Cline Primary Care Provider Data consent		
Dr. Clarissa Gabe Internist Data consent		

	Johannathasen Castaneda Grandfather Data consent
	(206) 206 - 2222
	Castaneda@gmail.com
	View data consent
	Patient support
	Current health and care plan
	Health history
	Social/environmental factors
	Behavior

Selecting SHR data sharing permission for specific data elements

SUMMARY Edit



Julia59S SJ9
14.Nov.1979

Administrative sex:	Female
Telephone number:	(555) 555-5555
Email:	julia535@gmail.com
Preferred language:	Spanish
Blood type:	O+
Ethnicity:	Hispanic
Religion:	Atheist
Insurance:	United Healthcare #29483900
Address:	55 Avenue St. Apt #5 Avenue City, MA, 55555

Health problems

- Stage 1 hypertension

Health concerns

- High blood pressure
- 25.1 BMI
- Housing security concerns
- Smoking 2x/week

Health goals

- Keep blood pressure under control
- Lose 10 pounds of weight so I can be at 130 lbs
- Reconnect with my high school friends

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 accommodates 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.

View the prototype:

https://invis.io/377ZT7P48#/174805378_Summary

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) constraints, 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.