FHIR as a vehicle for large scale scientific collaboration:
Patient-Directed Sharing of EHR Data

“With a click of a button, you’ll be able to voluntarily share your health data to help scientists perform groundbreaking research.”
The cornerstone of PMI – led by the NIH

1,000,000+ volunteers reflecting the broad diversity of the U.S.

Opportunities for volunteers to provide data on an ongoing basis

Data shared freely and rapidly to inform many research studies
Direct Volunteer EHR Data Donations – Sync for Science (S4S)
S4S in the Data Science Landscape

S4S leverages Meaningful Use **Stage 3 2015 EHR Certification**

- Patient application access *for patients to share their data via apps*
- Common Clinical Data Set *covers a core set of summary elements*

S4S builds on **open standards** for healthcare data + security

- FHIR®
- OAuth 2.0

Fleet Health’s S4S audit system verifies EHR implementations with an **automated test suite**
Feature: Allergies and intolerances

Scenario: Correct resourceType

Given I have a Allergies and intolerances response
Then the resourceType field will be Bundle
Then the type field will be searchset

Scenario: Resources are valid FHIR content

Given I have a Allergies and intolerances response
Then the resource parses as valid FHIR DSTU2 content

Scenario: Results exist

Given I have a Allergies and intolerances response
Then there should be at least 1 entry

Assertion Failed: Found 0 entries.

Request

--------
GET https://portal.demo.syncfor.science/api/fhir/AllergyIntolerance?patient=smart-1288992
Accept-Encoding: deflate,sdch
Connection: keep-alive
User-Agent: python-requests/2.10.0
Accept: application/json
Authorization: Bearer nsCROXbEoMnsmgIy36Bz9FniUJRZ6f

Response

--------
Tests complete!

92 scenarios passed, 7 failed, 19 skipped, 5 warnings
360 steps passed, 12 failed, 71 skipped

## Coding systems

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One Simple Trick To...

Can FHIR say it?

Can FHIR Reference it?

SNOMED CT?

UMLS Metathesaurus?

Schema.org?

Get things done: app/project/analysis/customer

Congratulations! Your project illuminates a novel facet of reality too insightful or subtle for others to have yet articulated

Argue with peers, confuse others, self
S4S Privacy & Security Assessment Timeline

1 month

2 months

1 month

Identify

Kickoff

Agree!

Protocol Review

Test

Begin

Check 1

Check 2

Finish

Review

Private Provider/Vendor Review

Anonymized Best Practices Report to ONC

Any pressing findings privately communicated
Launch and Beyond

|----------|----------|----------|----------|----------|

In mid-May, *All of Us* launches with **S4S** features

Patients participate by:

1. **Signing up** via app
2. Completing **informed consent**
3. Using **S4S** to **share their EHR** data with *All of Us*