

Lead: Strengthening the Role of – and Respect for – Patient-Generated Data

A discussion on the towering opportunities and unexpected challenges this historic moment presents for patient organizations

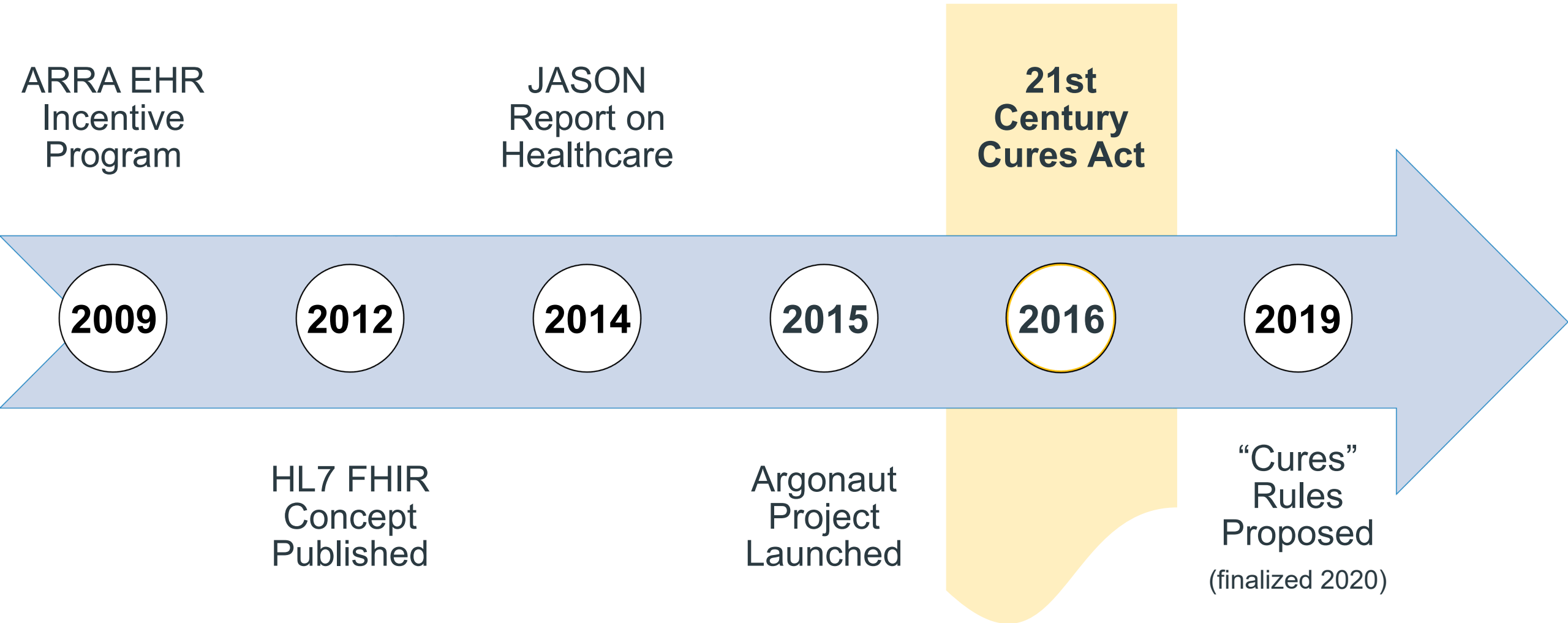
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A series of seemingly disparate events led us to this moment



Patient data access is now dramatically improving in the US

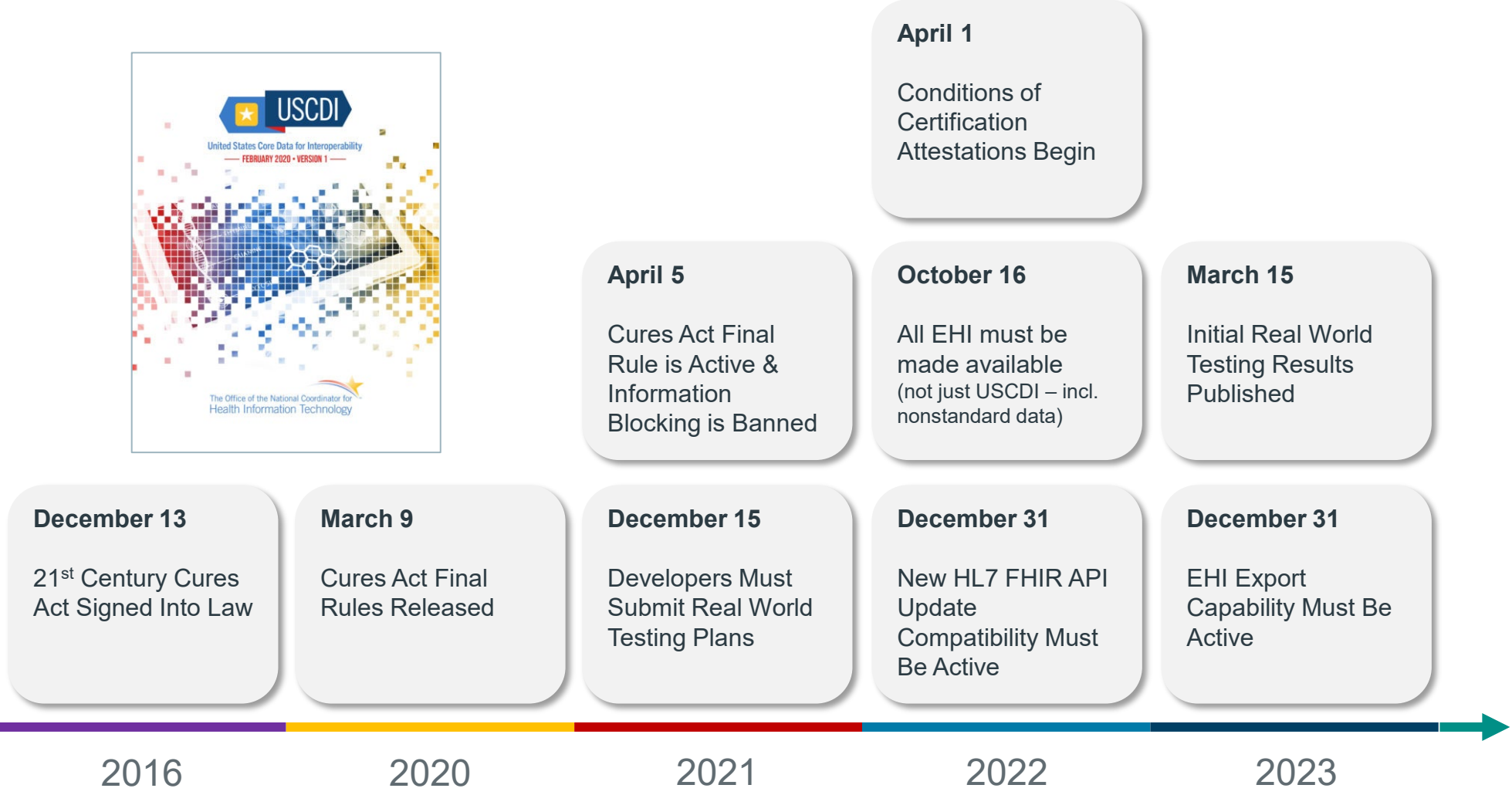
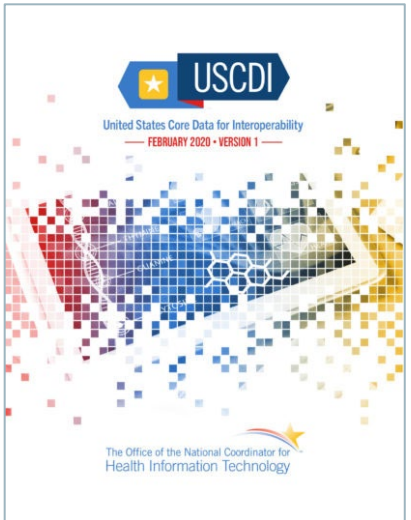


The rule provides patients and their providers secure access to health information. It is also expected to increase innovation and competition by creating an ecosystem where new applications that provide patients with more choices in their healthcare can flourish.

Fast Healthcare Interoperability Resources is an interoperability standard created by the standards development organization Health Level 7 (HL7). FHIR is designed to enable health data to be quickly and efficiently exchanged between health systems, patients, payers, and apps.

The United States Core Data for Interoperability is a standardized set of clinical concepts and data elements for enabling nationwide, interoperable health information exchange.

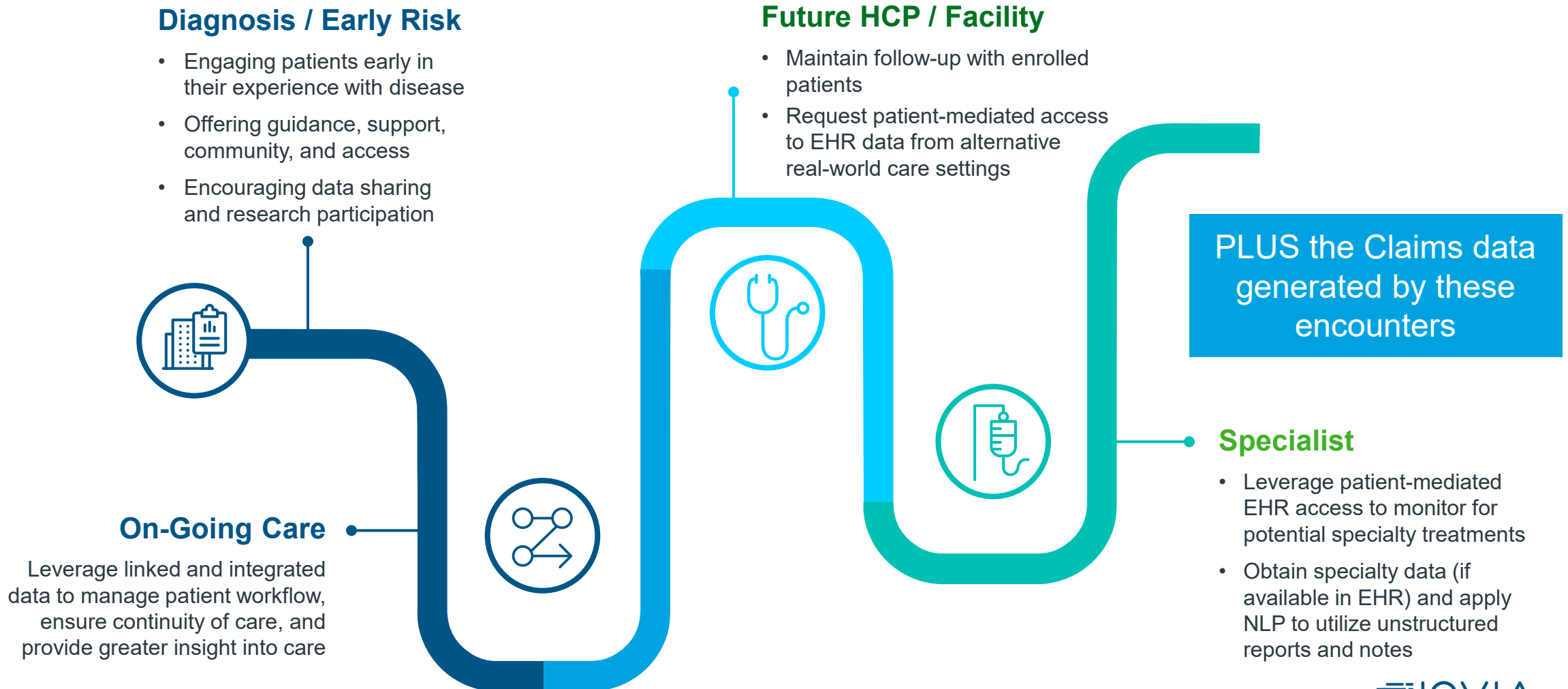
Pushing patient-mediated access from “If” to “When”



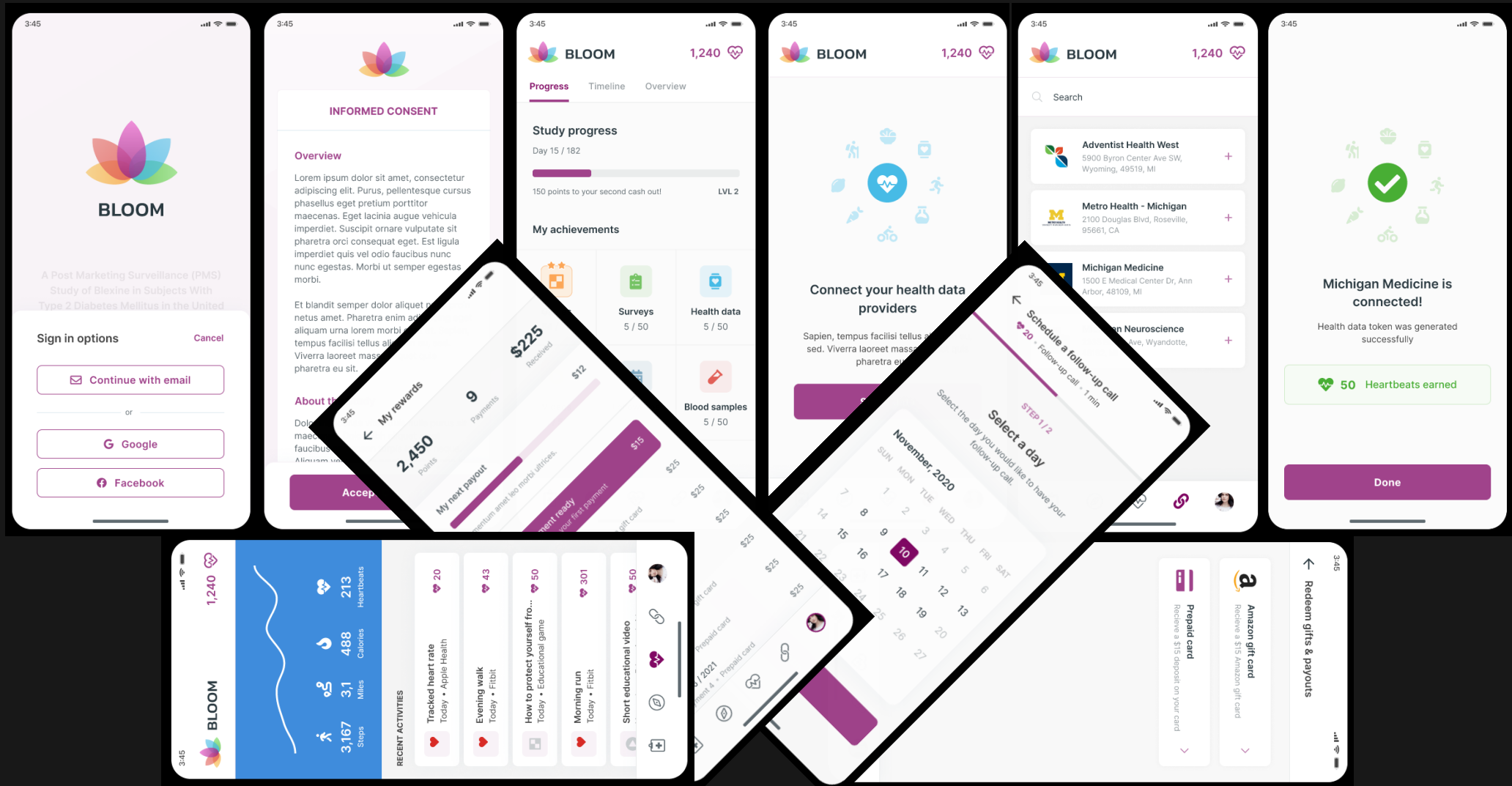
Adapted from: USCID / ONC Resources <https://www.healthit.gov/isa/united-states-core-data-interoperability-uscdi>

Creating unprecedented opportunities to access EHR data

The ability to digitally follow a patient on their care journey is fast becoming a reality in the US



Driving a new generation of patient-centric designs



(Illustrative)

That need equally modern real-world data capabilities

Patient / Person / Provider Applications

- Support for Direct-to-Patient / Consumer / Clinician
- Bring your own device (BYOD)
- Mobile-friendly Web + iOS / Android apps
- Heavily focused on daily / weekly connections
- Dynamic recruiting channel

Patient Experience

- Tiered marketing-level permissions support
- Self-service enrollment and consenting support
- Dynamic patient engagement
- Rewards Management and Gamification
- Deep partnerships with advocacy organizations

Patient Rewards

- Digital Wallet
- Daily opportunity to earn points
- Points → Dollars / Gift Cards / Discounts
- Support for Hyperwallet, Tremendous, etc.
- Historical Ledger



EMR / EHR Data Provisioning

- Patient-mediated EHR data sharing
 - No site permissions needed
 - Patient can provision with a few clicks
- Site-mediated EHR integration

Claims Data Provisioning

- Patient-mediated claims / admin data sharing

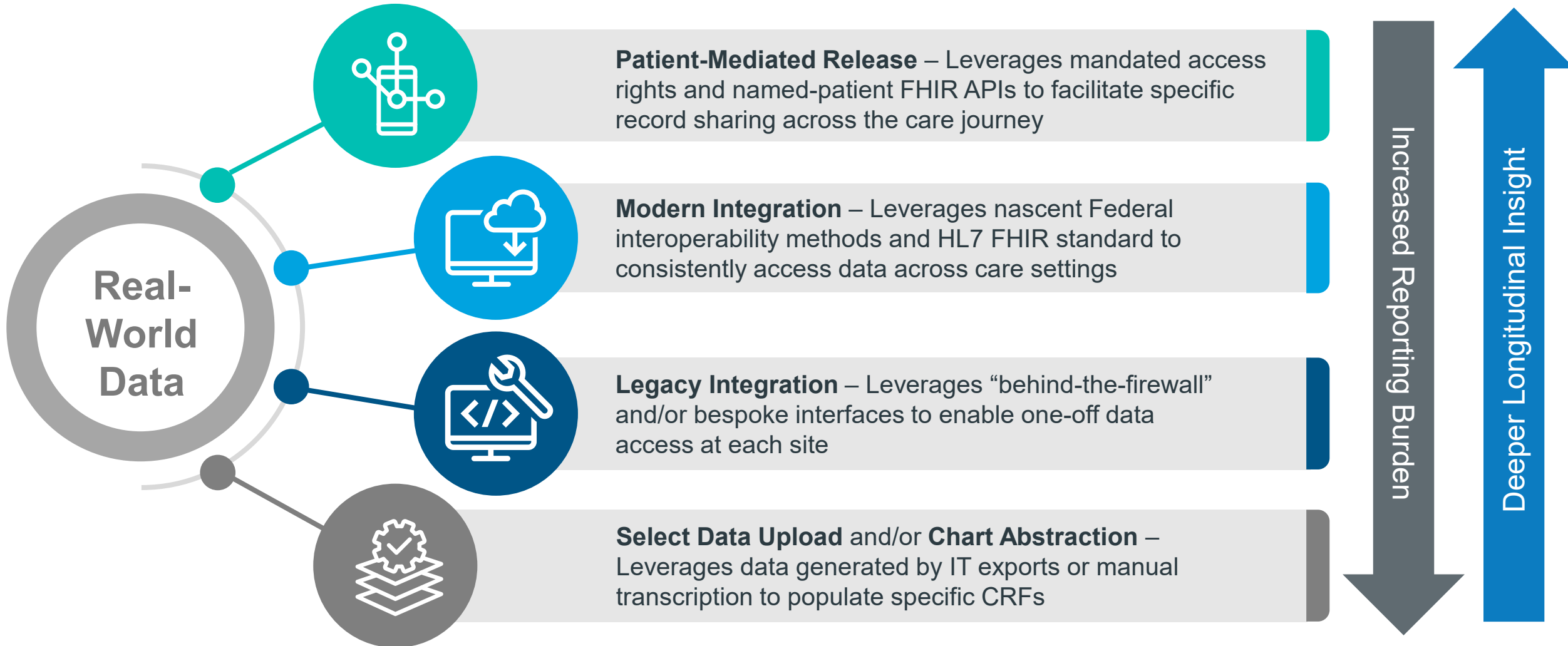
Device Integration

- Support for patient-mediated sharing of summary and time-series data from wearables and devices

Longitudinal Engagement

- PROs, Pulse, and Experience surveys
- Support for complex protocols, events, notifications, and return of information
- Support for biospecimen collection



Able to leverage the full spectrum of patient data access methods



- Allergies and Intolerances**
 - Substance (Medication)
 - Substance (Drug Class)
 - Substance (Non-Medication) *
 - Reaction
- Care Team Member(s)**
 - Care Team Member Name
 - Care Team Member Identifier
 - Care Team Member Role
 - Care Team Member Location
 - Care Team Member Telecom
- Clinical Notes**
 - Consultation Note
 - Discharge Summary Note
 - History & Physical
 - Procedure Note
 - Progress Note
- Diagnostic Imaging**
 - Diagnostic Imaging Test
 - Diagnostic Imaging Report
- Encounter Information**
 - Encounter Identifier *
 - Encounter Type
 - Encounter Diagnosis
 - Encounter Time
 - Encounter Location
 - Encounter Disposition
- Facility Information ***
 - Facility Identifier *
 - Facility Type *
 - Facility Name *
- Goals**
 - Patient Goals
 - SDOH Goals
 - Treatment Intervention Preference *
 - Care Experience Preference *
- Health Insurance Information**
 - Coverage Status
 - Coverage Type
 - Relationship to Subscriber
 - Member Identifier
 - Subscriber Identifier
 - Group Number
 - Payer Identifier
- Health Status Assessment** 
 - Health Concerns
 - Functional Status
 - Disability Status
 - Mental/Cognitive Status
 - Pregnancy Status
 - Alcohol Use *
 - Substance Use *
 - Physical Activity *
 - SDOH Assessment 
 - Smoking Status
- Immunizations**
 - Immunizations
- Laboratory**
 - Tests
 - Values/Results
 - Specimen Type
 - Result Status
 - Result Unit of Measure *
 - Result Reference Range *
 - Result Interpretation *
 - Specimen Source Site *
 - Specimen Identifier *
 - Specimen Condition and Disposition *
- Medical Device** 
 - Unique Device Identifier - Implantable 
- Medications**
 - Medications
 - Dose
 - Dose Unit of Measure
 - Indication
 - Fill Status
 - Medication Instructions *
 - Medication Adherence *
- Patient Demographics /Information**
 - First Name
 - Last Name
 - Middle Name (Including middle initial)
 - Name Suffix
 - Previous Name
 - Date of Birth
 - Date of Death
 - Race
 - Ethnicity
- Patient Demographics (cont.)**
 - Sex
 - Sexual Orientation
 - Gender Identity
 - Preferred Language
 - Current Address
 - Previous Address
 - Phone Number
 - Phone Number Type
 - Email Address
 - Related Person's Name
 - Relationship Type
 - Occupation
 - Occupation Industry
- Patient Summary and Plan** 
 - Assessment and Plan of Treatment
- Problems**
 - Problems
 - SDOH Problems/Health Concerns
 - Date of Diagnosis
 - Date of Resolution
- Procedures**
 - Procedures
 - Time of Procedure *
 - SDOH Interventions
 - Reason for Referral
- Provenance**
 - Author Organization
 - Author Time Stamp
- Vital Signs**
 - Systolic Blood Pressure
 - Diastolic Blood Pressure
 - Average Blood Pressure *
 - Heart Rate
 - Respiratory Rate
 - Body Temperature
 - Body Height
 - Body Weight
 - Pulse Oximetry
 - Inhaled Oxygen Concentration
 - BMI Percentile (2 - 20 years)
 - Weight-for-length Percentile (Birth - 24 Months)
 - Head Occipital-frontal Circumference Percentile (Birth- 36 Months)

U.S. Core Data for Interoperability: The mandatory set for sharing

- Set by Office of the National Coordinator for Health IT (ONC)
- Mandated in the Cures Act “Final Rule” on Interoperability
 - Compliance dates delayed slightly due to COVID-19*
 - Widespread adoption was already underway in 2022*
 - Widespread adoption required by end of 2023*
- Implemented in the HL7 FHIR international data standard
- Leverages industry-consensus clinical concepts
- Draft Version 4 released in Jan 2023 and expands to include Facility information and much further improved granularity

Key: * New Data Class or Element |  Changed Data Class or Element Name |  Data Element Reclassified

Fireside Chat

