The Vision for Data Exchange in California

The Data Exchange Framework (DxF) creates new connections and efficiencies between health and social services providers, improving whole-person care.

The DxF is California's first-ever statewide Data Sharing Agreement (DSA) that requires the secure and appropriate exchange of health and human services information to enable providers to work together and improve an individual's health and wellbeing.

DATA EXCHANGE FRAMEWORK

Agenda

1:00 PM
Welcome

1:05 PM
Informational Item: Sharing Reproductive and Gender Affirming Care Data

- Review Technical Requirements of AB 352
- Invited Guest Speakers Include:
  - Steven Lane, MD,
  - Raymonde (Ray) Uy, MD
  - Mohammad Jafari, Ph.D.
  - Hans Buitendijk, M.Sc.

1:35 PM
Discussion Item: Sharing Reproductive and Gender Affirming Care Data

1:50 PM
Public Comment

1:55 PM
Next Steps and Closing Remarks

DATA EXCHANGE FRAMEWORK

Public Comment Opportunities

Public comment will be taken during the meeting at the approximate time listed on the agenda and limited to the total amount of time allocated for public comment.

Members of the public may also use the Zoom's Q&A feature to ask questions or make comments during the meeting, or can email their questions or comments to DxF@chhs.ca.gov.

DATA EXCHANGE FRAMEWORK

TASC Members

Name	Organization
Rim Cothren (Chair)	Center for Data Insights and Innovation
Cindy Bero	Manatt Health Strategies
Hans Buitendijk	Oracle (EHRA)
Cassie-Ann Bush	Adventist Health
Sarah DeSilvey	Gravity Project
Mohit Ghose	Anthem Blue Cross
Prashant Gupta	LabCorp
John Helvey	SacValley Medshare

Name	Organization
Kameron Mims-Jones	Nourish California
Kimberly Krause	Providence Administrative Consulting Services
Michael Marchant	UC Davis
Chris Muir	Office of the National Coordinator for Health IT
Ken Riomales	CalMHSA
Jess Sanford	California Department of Public Health
Hanan Scrapper	People Assisting the Homeless (PATH)
Joe Sullivan	California EMS Authority
Brian Thomas	Alameda County

TASC Series 3 Guest Attendees:

Name	Organization
Mohammad Jafari	Arizona State University
Steven Lane	Health Gorilla
Kelby Lind	Planned Parenthood Affiliates of California
Lisa Matsubara	Planned Parenthood Affiliates of California
Raymonde (Ray) Uy	National Association of Community Health Centers (NACHC)

DATA EXCHANGE FRAMEWORK

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TASC Series 3 Objective

The TASC Series 3 meetings will center on discussing the technical and operational challenges to protecting reproductive and gender-affirming information under the DxF to comply with AB 352 and explore opportunities to address these challenges.

DATA EXCHANGE FRAMEWORK

Informational Item: Sharing Reproductive and Gender Affirming Care Data

Review of Technical Requirements of AB 352

(1) A business, as described in Section 56.06, that electronically stores or maintains medical information on the provision of sensitive services, including, but not limited to, on an electronic health record system or electronic medical record system, on behalf of a provider of health care, health care service plan, pharmaceutical company, contractor, or employer, shall develop capabilities, policies, and procedures, on or before July 1, 2024, to enable all of the following:

- (A) Limit user access privileges to information systems that contain medical information related to gender affirming care, abortion and abortion-related services, and contraception only to those persons who are authorized to access specified medical information.

- (B) Prevent the disclosure, access, transfer, transmission, or processing of medical information related to gender affirming care, abortion and abortion-related services, and contraception to persons and entities outside of this state in accordance to this part.

- (C) Segregate medical information related to gender affirming care, abortion and abortion-related services, and contraception from the rest of the patients record.

- (D) Provide the ability to automatically disable access to segregated medical information related to gender affirming care, abortion and abortion-related services, and contraception by individuals and entities in another state.

DATA EXCHANGE FRAMEWORK

Infrastructure to Manage Sensitive Data

Data Segmentation

Define / Identify	Analyze / Report	Tag	Rules / Enforcement

Consent Management

Requirement	Content	Format	Function

Coordination with related industry initiatives:

- Sequoia Project **Privacy & Consent Workgroup** - Gaps, methods, pilots

- Shift Interoperability **Terminology Workgroup** - Value set definitions, stewards

What does AB 352 do?

Who	Businesses that store or maintain medical information	Providers Plans Contractors Employers	Data Exchange Framework Participants
What	Must **develop capabilities** to segregate and protect medical information related to gender affirming care, contraception, and abortion and abortion-related services	May not knowingly share information related to abortion and abortion-related services outside of California without authorization	Are not required to share health information related to abortion and abortion-related services as part of the DxF
When	July 1, 2024	January 1, 2024* *Safe harbor for good faith effort until January 31, 2026	January 1, 2024

Abortion and Related Services

California AB 352   Maryland HB 812 / SB 786   OCR HIPAA Privacy

Abortion Medications

- Methotrexate Injection
- Mifepristone
- Misoprostol

Abortion, All

- Abortion, 1st Trimester
- Abortion, 2nd Trimester
- Abortion, 3rd Trimester

- Abortion, Spontaneous / Miscarriage
- Abortion, Failed Attempt
- Abortion, Elective
- Abortion, Induced

- Abortion, Medical Management
- Abortion, Surgical Management

Used to approximate fetal age, pregnancy trimester, "how many weeks pregnant"

- Age of Gestation

Gender Affirming Care

California AB 352

- Gender Identity
- Sexual Orientation
- Gender Dysphoria

- Intersex Surgery, All
- Intersex Surgery, Female to Male
- Intersex Surgery, History
- Intersex Surgery, Male to Female Sex
- Intersex Surgery, Non-specific

- Transfeminine Regimens, All
- Transfeminine Regimens, Antiandrogens
- Transfeminine Regimens, Estrogens
- Transfeminine Regimens, GnRH Agonists

- Transmasculine Regimens, All
- Transmasculine Regimens, Testosterone, Parenteral
- Transmasculine Regimens, Testosterone, Transdermal

Contraception

California AB 352   OCR HIPAA Privacy

- Contraception, Counseling
- Contraception, Surveillance

Contraceptives, All
- Contraceptive, Long-Acting Reversible Contraception (LARC)
  - Contraceptive, Implants
  - Contraceptive, Intrauterine Devices (IUD)
    - Contraceptive, Intrauterine Devices (IUD), Non specific
    - Contraceptive, Hormonal Progestogen Intrauterine Devices (IUD)
    - Contraceptive, Copper Intrauterine Devices (IUD)

- Contraceptives, Oral | Contraceptive, Oral Contraceptives
  - Contraceptive, Combination Oral (COC)

Contraceptives, All (con't)

- Contraceptive, Progestogen only or Progestin only Pills (POP)
- Contraceptive, Emergency Contraception Progestogen or Progestin only Pills (POP)

- Contraceptive, Oral Usage

- Contraceptive, Sterilization, All
  - Contraceptive, Sterilization, Female
  - Contraceptive, Sterilization, Male

- Contraceptive, Progestogen only Injectable Contraceptives (POIC)
- Contraceptive, Transdermal Patch
- Contraceptive, Vaginal Rings
- Contraceptive, Cervical Cap Barrier
- Contraceptive, Diaphragm and Cervical Cap
- Contraceptive, Diaphragm Barrier
- Contraceptive, Female or Male Condom Use
- Contraceptive, Spermicides for Contraception
- Contraceptive, Sponges

Infertility

California AB 352   OCR HIPAA Privacy

- Infertility, All
- Infertility, Female
- Infertility, Female Medications
- Infertility, Male
- Letrozole (Aromatase inhibitor)
- Clomiphene (Selective Estrogen Receptor Modulator / SERM)

Miscarriage Management

California AB 352   OCR HIPAA Privacy

Identifying those who have had a miscarriage:
- Abortion, Spontaneous / Miscarriage

IN COMBINATION with above:
- How miscarriages are medically managed:
    - Mifepristone
    - Misoprostol

- Surgically:
    - Abortion, Surgical Management

Prenatal Care

California AB 352   OCR HIPAA Privacy

Confirming that a patient is pregnant, that allows patients to be within the "prenatal" visit windows prior to delivery
- Pregnancy Labs, Bld/Ser/Plas
- Pregnancy Labs, Urine

Surrogate data elements that allow identification of pregnant women within the prenatal period
- Estimated Delivery Date (EDD)
- Last Menstrual Period (LMP)

Prenatal encounters
- Prenatal Supervision or Visit

Encounters with these codes mark the end of the prenatal period due to delivery
- Pregnancy Ending in Delivery

Data elements for patients currently pregnant, with or without confirmatory lab test (e.g., confirmed via imaging/ultrasound)
- Multiple Gestation
- Pregnancy, All

Authorized Access to Sensitive Data
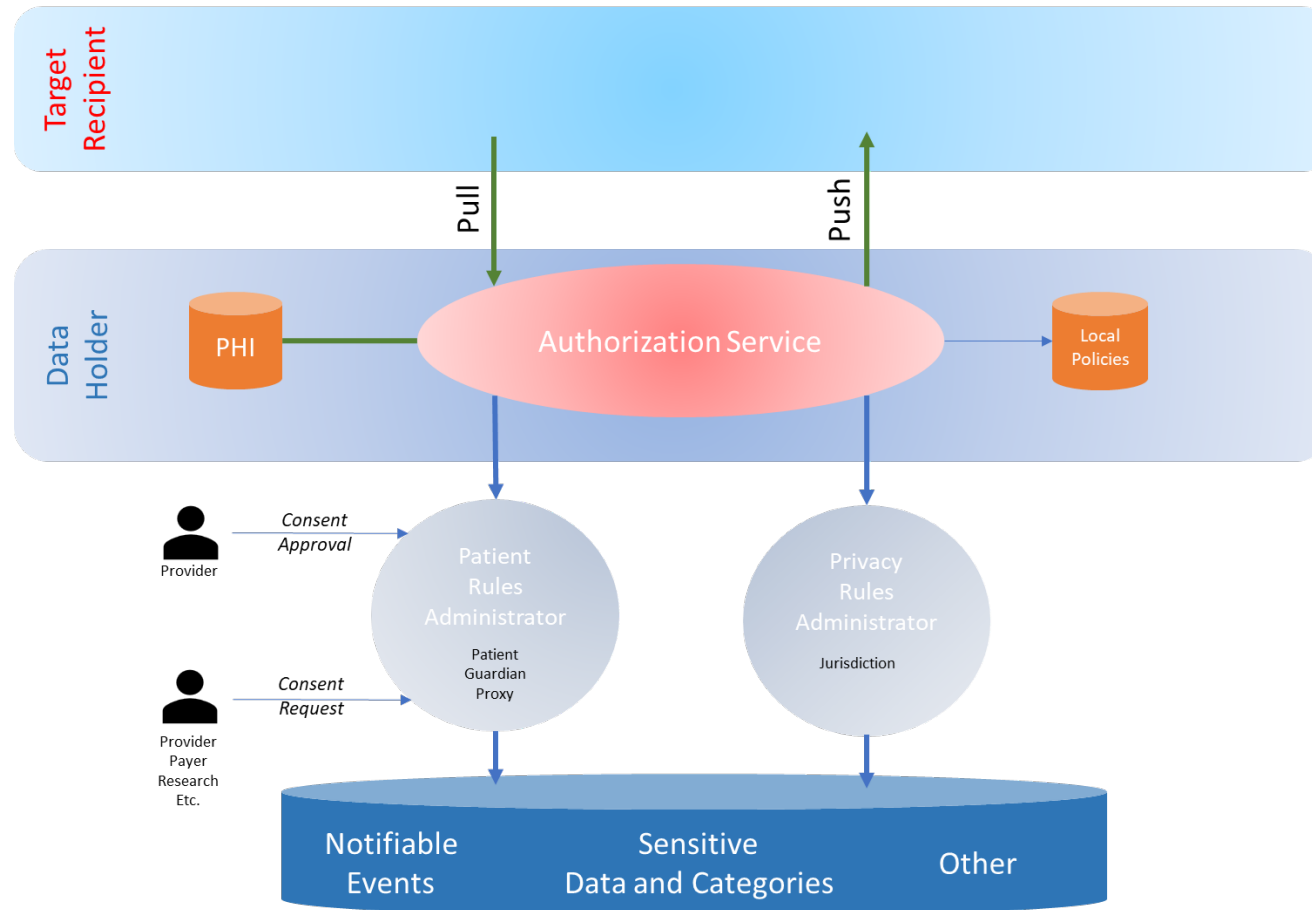## *Framework for Essential Elements*

Hans J. Buitendijk, M.Sc., FHL7
EHRA

August 21, 2024

EHRA
HIMSS ELECTRONIC HEALTH RECORD ASSOCIATION

General Framework

Essential Requirements for HIT-Facilitated Authorized Data Sharing

	Challenges	Need	CA DxF and AB 352
Privacy Rules	● Computability/ambiguity of rules ● Sensitive Data ● Sensitivity Flags (Context, Data, Documents, Data Sets)	● Defined, ● Agreed, ● Promulgated	Immediate need
Patient Rules	● Computability/ambiguity of consent to share or not share beyond general opt in/out ● Any data considered sensitive by data	● Documentation and maintenance tools ● Common rules and data sets (starter set)	Can evolve over time
Infrastructure	● Rules maintenance & access: Jurisdiction, Provider, Patient Centric ● Assumption?: Cross-jurisdictional organizations manage access internally. Requesting (sub-)organization/provider's location used to assert ● Any exchange method or format involving sensitive data	● Rule repositories ● Jurisdiction of target recipient ● Any exchange method or format involving sensitive data	Any data holder must support capabilities: automated or manual Effort to build

Managing Authorized Access to Sensitive Data is a Balance

While enabling privacy and patient rules based data sharing,
we also must consider the impact on patient safety, which has two sides:

The need for a complete patient record to make the best possible clinical decisions

The potential harm to patients when sharing sensitive data

There is no perfect balance,
but there is a critical need for having privacy and patient rules based data exchange
enabling a better balance than sharing all or nothing.

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Discussion: Sharing Reproductive and Gender Affirming Care Data

For Discussion: Sharing Reproductive and Gender Affirming Care Data

- What additional challenges will need to be addressed related to the segmentation and sharing of reproductive and gender affirming care data?

- How does the information technology available today help health care providers support the segmentation and appropriate sharing of sensitive data?

DATA EXCHANGE FRAMEWORK

Public Comment

Next Steps and Closing Remarks

Next Steps

Members to:

- Reflect on today's discussion
- Be prepared to continue discussing Reproductive and Gender Affirming Care Data sharing at the next meeting.

Upcoming Meetings

TASC Meeting Series	Date
Meeting #3B: Reproductive and Gender Affirming Care Data: Continued Discussion	September 4, 2024, 1:00 PM – 2:00 PM

DATA EXCHANGE FRAMEWORK

Note: Additional TASC meetings are being scheduled.
Meeting information will be posted to the CDII DxF webpage once confirmed.