

Office Hours: Gender-affirming Approaches to Data Collection

Ryan White HIV/AIDS Program Services Report (RSR)
HIV/AIDS Bureau
June 29th, 2023

A project of  CAI in partnership with  and  MISSION ANALYTICS

Good afternoon everyone and welcome to today's DISQ Office Hours presentation on Gender-Affirming Approaches to Data Collection. My name is Ruchi Mehta, my pronouns are she/her, and I am the Director of the DISQ Team. DISQ is one of several groups engaged by HAB to provide training and technical assistance to Ryan White HIV/AIDS Program recipients and providers on their data management processes. Today, we are very excited to have a few guest presenters join us to talk about a very important topic – how to engage in data collection and data management in a way that is affirming to trans and gender-expansive Ryan White clients. Today's presentation will only be a small piece of this important conversation so we encourage you to check out the resource document that we've shared with you all, which includes links to the work of many other folks who are leading the way in this conversation.

Disclaimer

Today's webinar is supported by the following organizations and the contents are those of the author(s) and do not necessarily represent the official views of, nor an endorsement by, the Health Resources and Services Administration (HRSA), the U.S. Department of Health and Human Services (HHS), or the U.S. government.

The DISQ Team is comprised of CAI, Abt Associates, and Mission Analytics and is supported by HRSA of HHS as part of a cooperative agreement totaling \$4,000,000.00.

Before we get started, a quick disclaimer that today's webinar is supported by the organizations shown on the slide, and the contents are those of the author(s) and do not necessarily represent the official views of, nor an endorsement, by the Health Resources and Services Administration, the U.S. Department of Health and Human Services, or the U.S. Government.

Outline

Introduction

HIV Services for Trans Clients: Cecilia Gentili

Considerations for RSR Reporting Requirements

Case Example: Colorado Department of Public Health & Environment

Questions & Discussion

Our presentation today will be split into a few sections. First, I will start with a *very brief introduction of why this topic is important to be talking about in the context of Ryan White reporting and data management processes.

Then, I will pass things over to our first guest presenter, *Cecilia Gentili, to talk about several facets of trans-inclusive HIV care.

*Next, I will review how data on sex and gender are included in the RSR, and how to ensure your agency's data quality remain high if you choose to update your processes around data collection on these elements.

Finally, *Elisabeth Meyer and Eduardo Gabrieloff from the Colorado Department of Public Health and Environment will take the stage to discuss how they implemented updates to their data collection processes for sex and gender in their new data system, COHEART.

*And as always, we will take time at the end of the office hours session for questions and discussion with our presenters.

Introduction

- **Affirming clients' sexual and gender identities** is an important part of providing **comprehensive, client-centered care**.
- The way we collect data impacts **trans clients' experiences of care** and our ability to understand the **experiences of trans communities with HIV**.
- Because data on **sex and gender are included in the RSR**, updated data elements should be **mapped to current reporting requirements** to ensure continuation of **high-quality data**.

First, I want to provide a brief introduction to frame why this topic is important in the context of Ryan White data management processes.

First, we also know that *affirming clients' sexual and gender identities is an important part of providing comprehensive, client-centered care.

And, *the way we collect data, whether we always think about it or not, absolutely impacts trans clients' experiences of care, and our ability to understand from the data the experiences of trans communities with HIV, which are some of the most historically underserved communities in HIV response efforts.

*Because data on sex and gender are included in the RSR, updated data elements should be mapped to current reporting requirements to ensure continuation of high-quality data.

Outline

Introduction

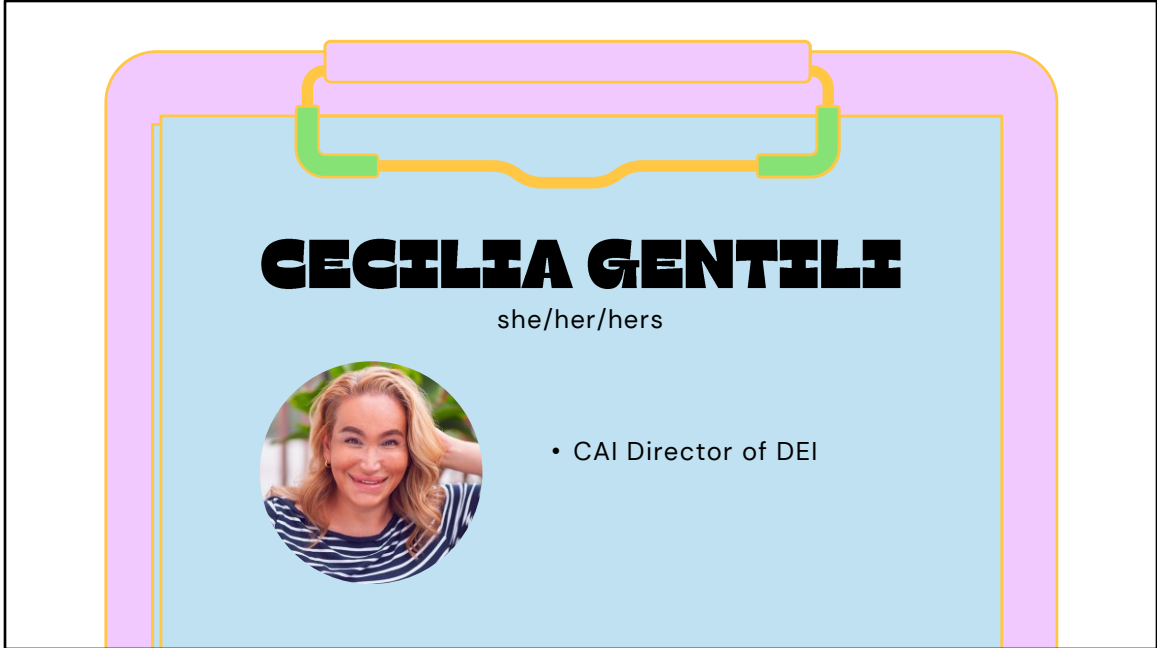
HIV Services for Trans Clients: Cecilia Gentili

Considerations for RSR Reporting Requirements

Case Example: Colorado Department of Public Health & Environment


Questions & Discussion

Next, I would like to introduce our *first guest presenter today, Cecilia Gentili, who will speak about considerations for providing inclusive services to trans clients and how data collection processes can make trans clients feel more or less safe when receiving services.






Cecilia Gentili is CAI’s Director of Diversity, Equity, and Inclusion. She is also an advocate, organizer, and storyteller working at the intersections of sex work, immigrant rights, incarceration issues, and trans liberation. She has years of experience in direct services and policy advocacy, working with organizations such as Apicha CHC, GMHC; and as a founding member of both DecrimNY and Trans Equity Consulting. Today Cecilia will speak about considerations for providing inclusive services to trans clients and how the way data is collected can make trans clients feel more or less safe when receiving care. Cecilia, I will pass it over to you.





THE DATA

-  **Trans people are at high risk for getting HIV.** Globally, the risk is 13 times higher for trans people than for other adults aged 15–49 years.
-  **Trans women are disproportionately impacted by HIV.** Studies show that between 22–42% of trans women in the U.S. are living with HIV compared to less than 1% of the general population.
-  **Trans people of color are among the most at risk for HIV.** In 2019, Black women comprised nearly half of new HIV diagnoses among trans women in the U.S.

Sources: [UNAIDS](#); [CDC](#); [National LGBTQ Task Force](#)

SLIDE IS ANIMATED

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***Trans women are disproportionately impacted by HIV.** Studies show that between 22–42% of trans women in the U.S. are living with HIV compared to less than 1% of the general population.

***Trans people of color are among the most at risk for HIV.** In 2019, Black women comprised nearly half of new HIV diagnoses among trans women in the U.S.



THE DATA

Trans people individuals may face **intersecting vulnerabilities**, such as experiences of homelessness, sex work, substance use, and mental health challenges, which can increase their risk of getting HIV.



HIV RESPONSE

Historically, the HIV response has often **excluded or marginalized transgender people**, leading to disparities in access to HIV services and inadequate care.



Recognizing and addressing these **historical exclusions is essential to ensure an inclusive and effective HIV response for trans communities.**

Efforts should focus on:

- comprehensive data collection
- healthcare provider training
- policy reform
- anti-discrimination measures
- integration of gender-affirming care within HIV services.

NAVIGATING THE HEALTHCARE SYSTEM

- trans people may be on guard when approaching a service provider.
- they are often asked insensitive, ineffective, and unnecessary questions by providers out of habit, curiosity, or ignorance.
- It may be hard enough to expose and talk about their bodies.
- for many trans people, genitals and/or secondary sex characteristics may feel incongruent with their gender identities, and may be charged with feelings of shame.
- others' beliefs or perceptions of their genitals have been used against them to oppose, deny, or try to destroy their gender identity and self-esteem.

HOW TO COMMUNICATE

- trans people might pay increased attention to the language a provider is using, as a way to assess whether they are safe and will receive adequate care.
- as a provider, rather than focusing on which is the "correct" terminology, use the terms each person chooses.
- remember that trans experiences are diverse and unique to each person, and so are the terms that represent each experience!

- this applies to:
 - identity labels
 - personal history
 - body parts
 - pronouns
 - names
 - other important aspects of a person's life
- trans people are the only experts on their identities. **honor the language they choose.**

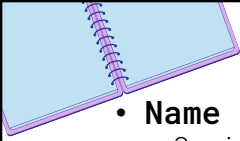




TRANS INCLUSIVE DATA COLLECTION

We'll see examples of items that are important to include on a trans-inclusive client form, including questions about client identification and sexual activity.

A full-length sample client form, including the example questions discussed here and others, is included in the "Additional Resources" handout for this session.



CLIENT IDENTIFICATION

- **Name**
 - Social name
 - Communicate how and when legal name may be used
- **Sex at birth**
- **Intersex diagnosis**
- **Gender identity**
- **Gender-affirming medical procedures**
- **Pronouns**
- **Sexual orientation**



SLIDE IS ANIMATED

*Name

*Sex at birth

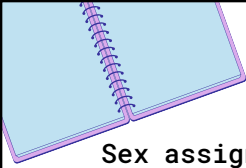
*Intersex diagnosis

*Gender identity

*Gender-affirming medical procedures

*Pronouns

*Sexual orientation



EXAMPLE ITEMS

Sex assigned at birth

- male
- female

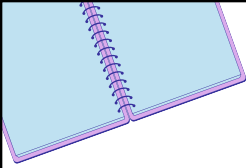
Have you been diagnosed as intersex?

- yes
- no

Gender identity

- trans woman / transfeminine
- trans man / transmasculine
- trans non-binary
- genderfluid
- genderqueer
- gender non-conforming
- agender
- bigender
- queer
- two-spirit
- cis woman
- cis man
- self-identify:.....





EXAMPLE ITEMS

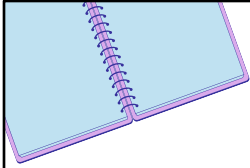
Pronouns (*mark all that apply*):

- he/him/his
- she/her/hers
- they/them/theirs
- all pronouns
- no pronouns, I use my name
- other, specify:

Sexual orientation:

- gay
- lesbian
- bisexual
- pansexual
- asexual
- queer
- heterosexual
- self-identify:

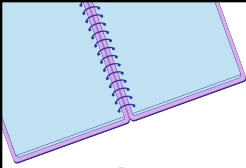




SEXUAL ACTIVITY

- Reiterate that the purpose of these questions is to gather information that may be relevant for health providers. Providing adequate care is our priority.
- Validate that some questions may be difficult or uncomfortable to answer, and that there are no wrong answers when it comes to sexual activity. We all have different experiences.





EXAMPLE ITEMS

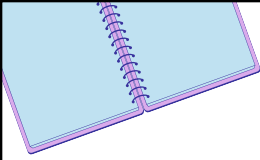
Do you currently have sex?

- yes, I've had sex in the past 6 months
- yes, but I haven't had sex in the past 6 months
- no (*GO TO NEXT SECTION*)
- other, specify:

With how many people on average do you have sex each week?

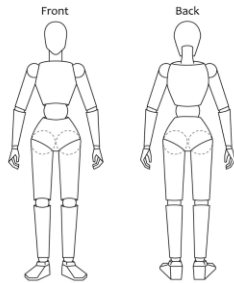
Please remember that the answer can be different for everyone. Some people might say 1 and some might say 100. Both answers are great!



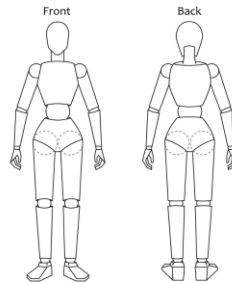


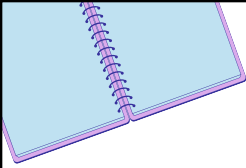
EXAMPLE ITEMS

Using the following BODY MAP, please circle the parts of your body you use during sex:



Using the following BODY MAP, please circle the parts of your partner(s)' body that get in contact with your body when having sex:





EXAMPLE ITEMS

When having sex, do any fluids get exchanged with your sexual partner?

yes

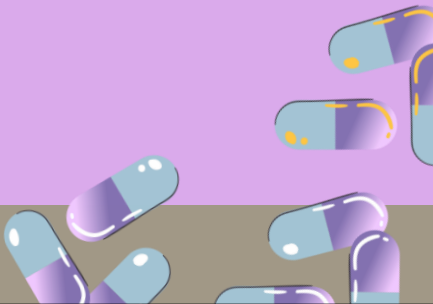
no

Please describe how you usually have sex:

.....
.....
.....
.....
.....
.....



THANK YOU!



Outline

Introduction

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Considerations for RSR Reporting Requirements

Case Example: Colorado Department of Public Health & Environment

Questions & Discussion

Thank you so much Cecilia. As Cecilia illustrated, comprehensive data collection is one of the ways that agencies can build a more inclusive environment for trans clients. Based on your community's needs, there are many ways agencies might choose to update the questions that you ask clients about gender, sex, sexual orientation, and sexual activity, in order to be more inclusive. Next, I'm going to talk briefly about how to make sure that your new process, if you choose to develop one, *considers the RSR reporting requirements to ensure your data quality remains high.

RSR Considerations

- RSR data matter! The RSR is the one of the **largest client-level dataset available** to help us understand outcomes and health disparities for PWH in the U.S.
- 2021 RSR CLD included over **13,000 trans clients**, compared to less than 10,000 in 2017.
- Your data collection process must be able to be **mapped to the current RSR reporting variables** in order to ensure your clients are counted in the RSR.

Source: [Ryan White HIV/AIDS Program Annual Client Level Data Report 2021](#)

First, I want to quickly review why the data you report in your RSR matter.* The RSR is one of largest client-level dataset available to help us understand outcomes and health disparities for people with HIV in the U.S. This is hugely impactful for communities who typically have small sample sizes within a single population, like trans clients.

*The 2021 RSR Client-level data included data on more than 13,000 trans people with HIV across the country, compared to less than 10,000 just four years earlier in 2017.

So, regardless of the data collection process you choose for your agency and your community, *your process must to be able to be mapped to the current RSR reporting variables to ensure your data quality remains high throughout any changes you make, and all of your clients are appropriately counted in the RSR in the gender category that best suits them.

Now I'm going to show the two items in the RSR that your collected data will need to map to – gender and sex at birth.

Gender in the RSR

3.3.9 GenderID



Field	Description
Reference ID	7
Element Name	GenderID
Parent Element	ClientReport
Definition	<p>Client's current gender.</p> <p>This is the variable that is used for the encrypted unique client identifier (eUCI).</p> <p>Note: Although value 3 (Transgender) is no longer an acceptable value, the eUCI encryption algorithm remains unchanged and only accepts value 3 for Transgender. If using the eUCI generator, please continue to use 3 as the input for Transgender clients. TRAX, on the other hand, will map value 6 (Transgender Male to Female), 7 (Transgender Female to Male), and 8 (Transgender Other) to 3 (Transgender) when generating the eUCI. Refer to page 3 of the eUCI Application User Guide for additional details.</p>
Required	All
Occurrence	1 per client
Allowed Values	<p>GenderID:</p> <ul style="list-style-type: none"> 1 = Male 2 = Female 4 = Unknown 6 = Transgender Male to Female 7 = Transgender Female to Male 8 = Transgender Other <p>The allowed value below has been removed: 3 = Transgender (<i>Removed</i>)</p>
Schema	<GenderID>1, 2, 4-7</GenderID>

Screenshot from: [RSR Data Dictionary & Schema Implementation Guide](#)

This is the gender element in the RSR. Gender is also one of the data elements used to determine the client eUCI or unique client identifier. As you'll see here, HAB's options for gender in the RSR are Male, Female, Unknown, Transgender Male to Female, Transgender Female to Male, and Transgender Other.



Now I'd like to ask a quick poll question to accompany this item to gauge how all of your agencies are currently collecting this data.

Does your agency collect gender data using:

- a) The same options as the RSR (Male, Female, Unknown, Transgender Male to Female, Transgender Female to Male, and Transgender Other)
- b) Different options from the RSR
- c) I'm not sure

Thanks so much for this information – it's really helpful to know the extent to which folks are aligned with the current reporting requirements and how many agencies are collecting these data differently.

Sex at Birth in the RSR

3.3.8 SexAtBirthID

Field	Description
Reference ID	71
Element Name	SexAtBirthID
Parent Element	ClientReport
Definition	The biological sex assigned to the client at birth
Required	All
Occurrence	0-1 per client
Allowed Values	1 = Male 2 = Female
Schema	<SexAtBirthID>1-2</SexAtBirthID>

Screenshot from: [RSR Data Dictionary & Schema Implementation Guide](#)

Second, this is the Sex at Birth data element. HAB's current allowable values for Sex at Birth are Male and Female.

RSR Crosswalk

The [RSR Crosswalk](#) is designed to compare data in your current system to the required RSR data

RSR				Your System		
ID	Variable	Definition	Value	Variable	Value	Notes
71	Sex at Birth	The biological sex assigned to the client at birth	1. Male 2. Female			
7	Gender	Client's current gender identity. This is the variable that is used for the encrypted unique client identifier (eUCI).	1. Male 2. Female 4. Unknown 6. Transgender Male to Female 7. Transgender Female to Male 8. Transgender Other			

One resource I'd like to plug here to encourage you all to use in mapping your source data to the RSR reporting requirements is the RSR Crosswalk, which is available on TargetHIV. The RSR crosswalk includes each data element included in the RSR schema, as well as the definition and current allowable values. For each element, you can add information about your own system's variables, values, and important notes for recoding.

Outline

Introduction

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Considerations for RSR Reporting Requirements

Case Example: Colorado Department of Public Health & Environment

Questions & Discussion

With that bit of context, next, I'd like to introduce our next presenter, which will be a *case example presentation from the Colorado Department of Public Health and Environment.

Colorado Department of Public Health & Environment

Transition to COHEART

Elisabeth Meyer, MPH
Program Evaluation Unit Supervisor

Eduardo Gabrieloff, MFA
Care and Treatment Analyst



To present on Colorado's transition to their new data system, COHEART, I will pass things over to Elisabeth Meyer and Eduardo Gabrieloff.

Overview

- **CDPHE Then and Now**
- **Updates to Sexual Orientation & Gender Identity Data Elements**
- **Buy-in**
- **Lessons Learned**

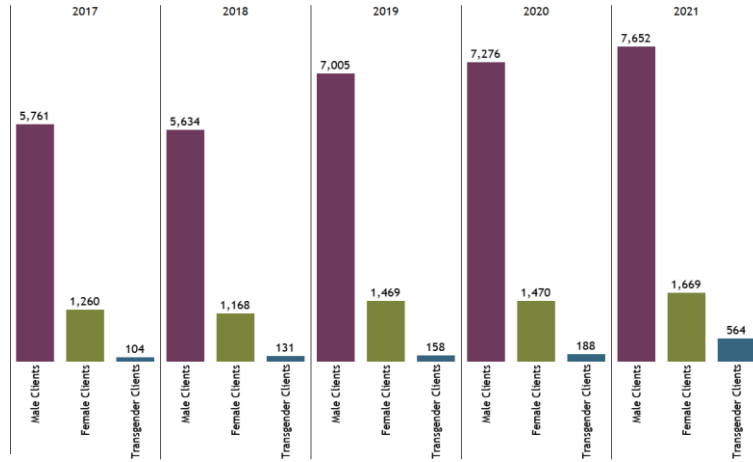
Adult Transgender Population of Colorado 2022

- 27,000 Transgender Individuals in Colorado
- HIV Prevalence Among Transgender Women is under-researched, but studies say between 14% and 42%
- With these hugely broad numbers, we estimate between 1,890 and 5,670 transgender women in Colorado living with HIV

Statewide Ryan White HIV/AIDS Program Data



Clients By Gender



COLORADO
Department of Public Health & Environment

Source: Ryan White HIV/AIDS Program Annual Client-Level Data Report for years 2017 through 2021

ARIES Sex and Gender Options (2016)

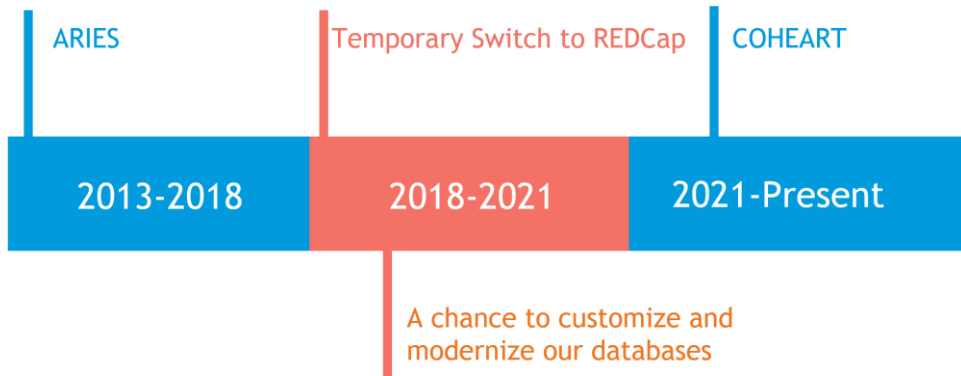
One Field for Gender:

- Male
- Female
- Transgender MTF
- Transgender FTM
- Other
- Unknown

One Field for Sexual Orientation:

- Bisexual
- Declines to State
- Heterosexual
- Homosexual
- Lesbian
- Pediatric/Not Applicable
- Unknown, Unsure

ARIES to COHEART Timeline



Steps in the transition



STEP 1

Try to understand where we need to be

Talk to Community Partners

Reach Out Across The Country For Best Practices

STEP 2

Come Up With A List Of Options For Sexual Orientation and Gender Identity

Map the Gender Identity List to HRSA's RSR Schema

STEP 3

Roll Out and Buy In

Explain Importance of Data

Train Staff



COLORADO
Department of Public Health & Environment

Community Feedback

- Capacity Building Staff worked with trainers across the country
- Discussed with One Colorado and utilized their Colorado-specific reports
- Once we had selected gender identities, we reached out to our Data Sharing Task Force

First, we did an assessment of all our data systems to see how SOGI data was collected, if at all

Secondly, we did literature reviews for studies that highlighted best practices
We spoke with different trainers throughout the country, as well as a few RW recipients

We also reached out to One Colorado, a Colorado advocacy organization that has conducted varied research into the LGBTQIA+ population in the state to help learn how people identify

Once we compiled a list of gender identities, we took these options to our Data Sharing Task Force to get community feedback and ensure we had the right options for our clients

REDCap and COHEART Sex and Gender Options (2019-2023)

Pronouns Options:

- He/him/his
- She/her/hers
- They/them/their
- Ze, zir, zirs
- No pronouns
- Self-described

REDCap and COHEART Sex and Gender Options (2019-2023)



Sex At Birth Options:

- Female
- Male
- Unknown or Intersex

Gender Identity Options:

- Man or Boy
- Woman or Girl
- Transgender Woman or Girl
- Transgender Man or Boy
- Non-Binary
- Genderqueer
- Gender nonconforming
- Not sure/Questioning
- Refused
- Unknown
- Other



New vs. Old Gender Options

ARIES Gender Identity Options:

- Male
- Female
- Transgender MTF
- Transgender FTM
- Other
- Unknown

COHEART Gender Identity Options:

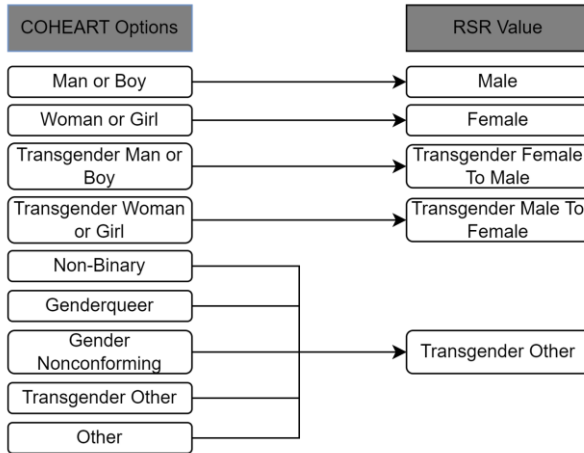
- Man or Boy
- Woman or Girl
- Transgender Woman or Girl
- Transgender Man or Boy
- Refused
- Unknown
- Non-Binary
- Genderqueer
- Gender nonconforming
- Not sure/Questioning
- Other

REDCap and COHEART Sexual Orientation Options (2019-2023)

Sexual Orientation Options:

- Gay or Lesbian
- Straight/Heterosexual
- Bisexual
- Other
- Unknown
- Queer
- Pansexual

Mapping to RSR



Mapping to RSR

Risk Factor Mapping Choices:

1=1 = Male to Male sexual contact (MSM)

What makes a person a male? What does “Risk MSM” tell us about a person’s transmission factors?

Staff Buy-in

- Capacity-Building Staff Developed Transgender 101 Training for Staff and Partner Agencies
- Pronoun Pins for entire Department
- New options launched and officially rolled out on Transgender Day of Visibility

Lessons Learned

- RW and Surveillance Databases linked on both Primary Key and Demographics
- Client Data cannot be changed by RW users, users must email admins to request changes
- Integrating systems means more buy-in from disparate staff and conflicts between reporting requirements

THANKS!

Thanks to our colleagues who helped launch this effort:

Ashley Armstrong, Megan Canon, Matt Fischer, Leslie Frank, Chris Grano, Ryan Howe, Colleen McGuinness, Rose-Marie Nelson, Courtney Nichols, Christine Record, and Erin Starzyk

More questions?

Elisabeth Meyer

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Eduardo Gabrieloff

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Outline

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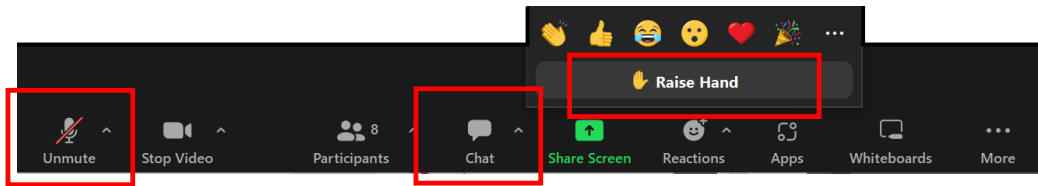
Considerations for RSR Reporting Requirements

Case Example: Colorado Department of Public Health & Environment

Questions & Discussion

Thank you so much Eduardo and Elisabeth for that presentation. Now, let's transition to your questions and make space for discussion.

Questions & Discussion



We are going to open up the chat for folks to put in their questions and comments, and we also encourage you to unmute and ask questions live if you'd like to share. To raise your hand, click on the "Reactions" button on the settings bar at the bottom of your screen. To unmute yourself, you can click on the microphone button on the left end of the bar.