



I Want the Kit: Addressing the Burden of STIs in Indian Country



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Question for the Viewers



How familiar are you with the impacts of sexually transmitted infections (STIs) in American Indian and Alaska Native communities?

- A. Very familiar
- B. Somewhat familiar
- C. Not familiar
- D. Other (please type in chat)

Background



STIs in Indian Country



Intervention: Self-Collection STI Testing



Preliminary Data



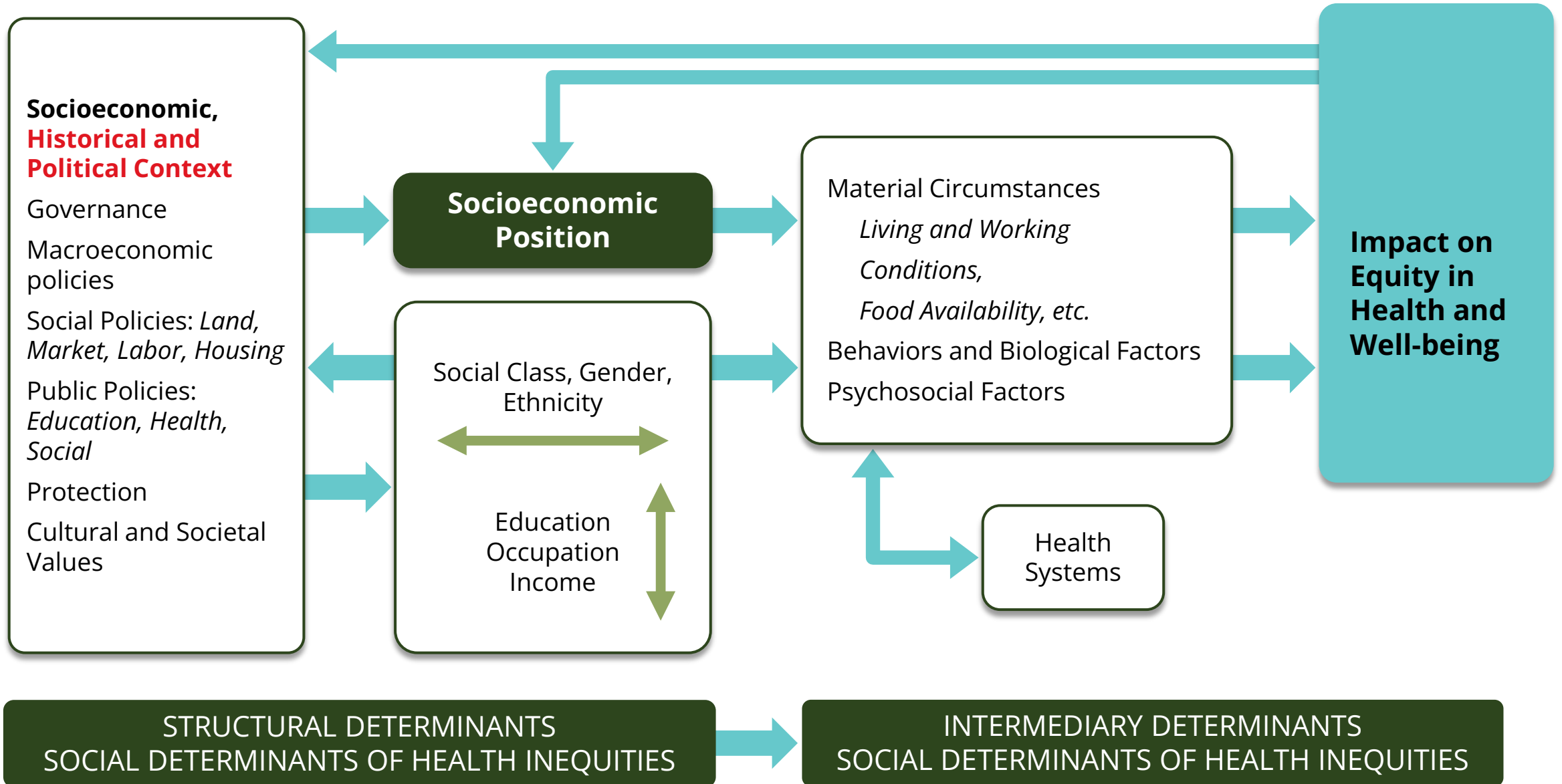
Limitations, Successes, and Next Steps



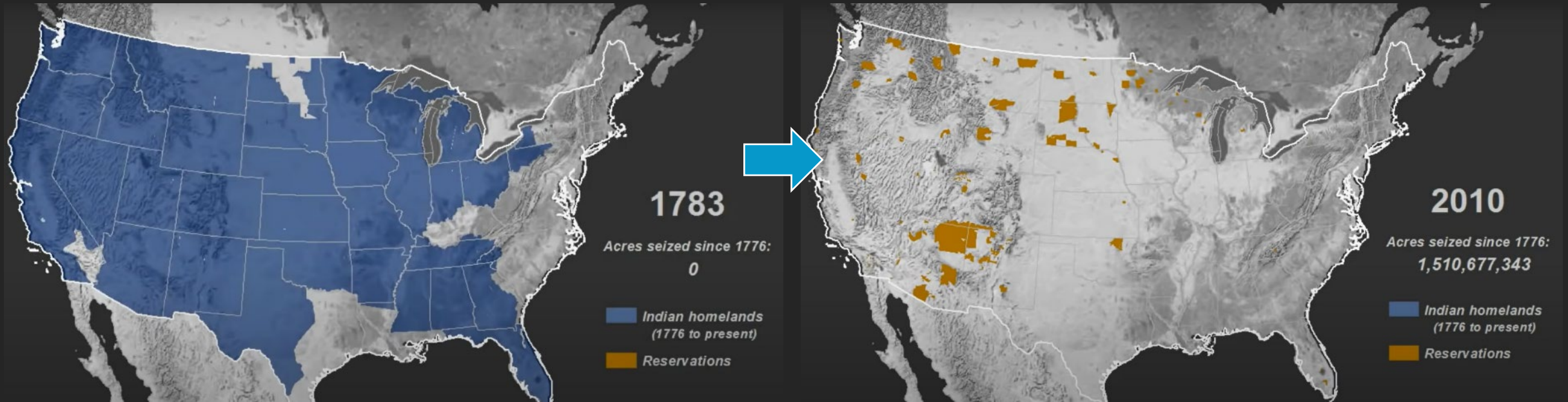
Background



Social Determinants of Health and Health Equity

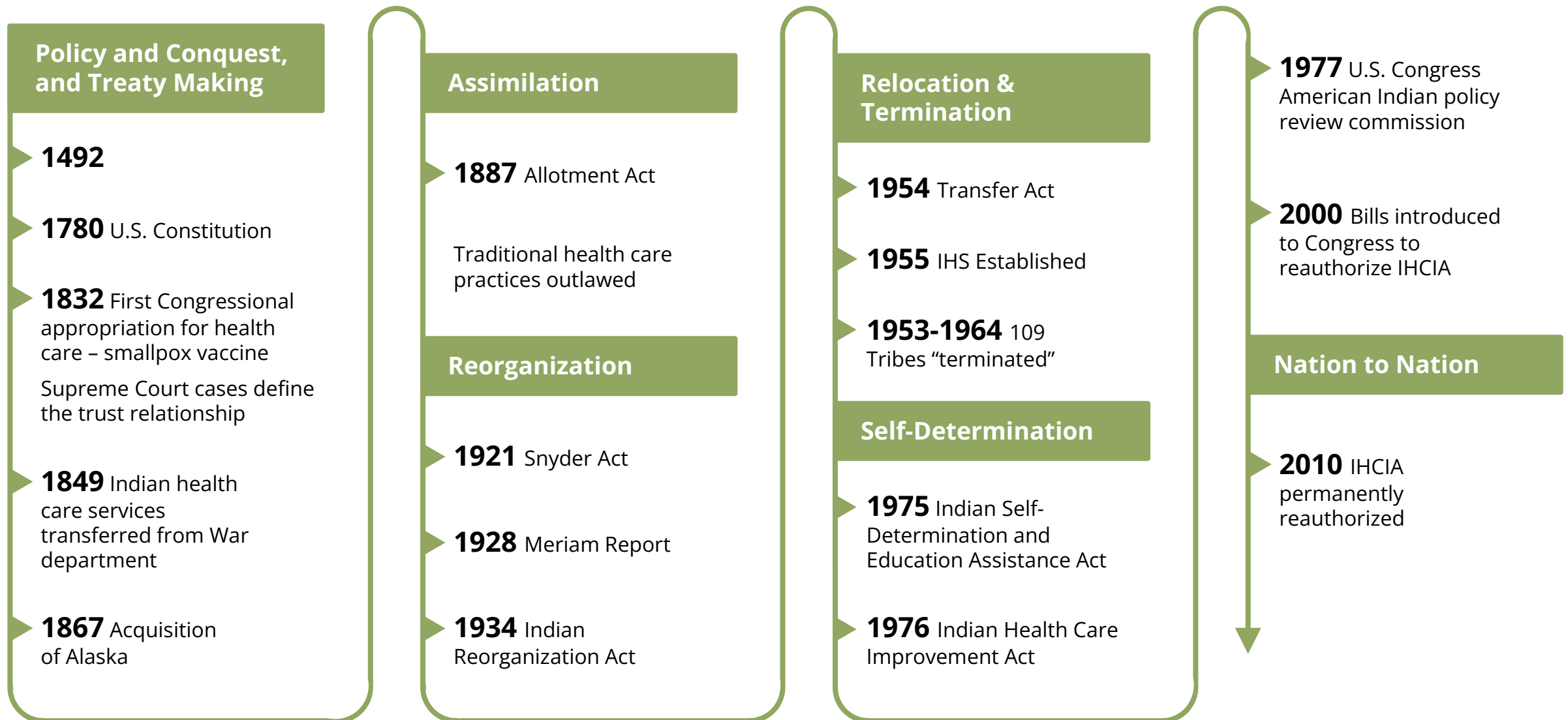


Indian Homelands Lost



Source: <https://youtu.be/pJxrTzfG2bo?si=eJpyzw0TdKey2ncC>

Historical Timeline of Major Events in Indian Health Care



INDIAN LAND FOR SALE

GET A HOME

OF
YOUR OWN

✻
EASY PAYMENTS



PERFECT TITLE

✻
POSSESSION

WITHIN
THIRTY DAYS

Carlisle Indian School



Image Source: John N. Choate, Carlisle Indian School Digital Resource Center

The Indian Relocation Act of 1956



COME TO DENVER.

THE CHANCE OF YOUR LIFETIME!

Good Jobs

- Retail Trade
- Manufacturing
- Government—Federal, State, Local
- Wholesale Trade
- Construction of Buildings, Etc.



Happy Homes

- Beautiful Houses
- Many Churches
- Exciting Community Life
- Over Half of Homes Owned by Residents
- Convenient Stores—Shopping Centers



Training

- Vocational Training
- Auto Mech, Beauty Shop, Drafting,
- Nursing, Office Work, Watchmaking
- Adult Education
- Evening High School, Arts and Crafts
- Job Improvement, Home-making



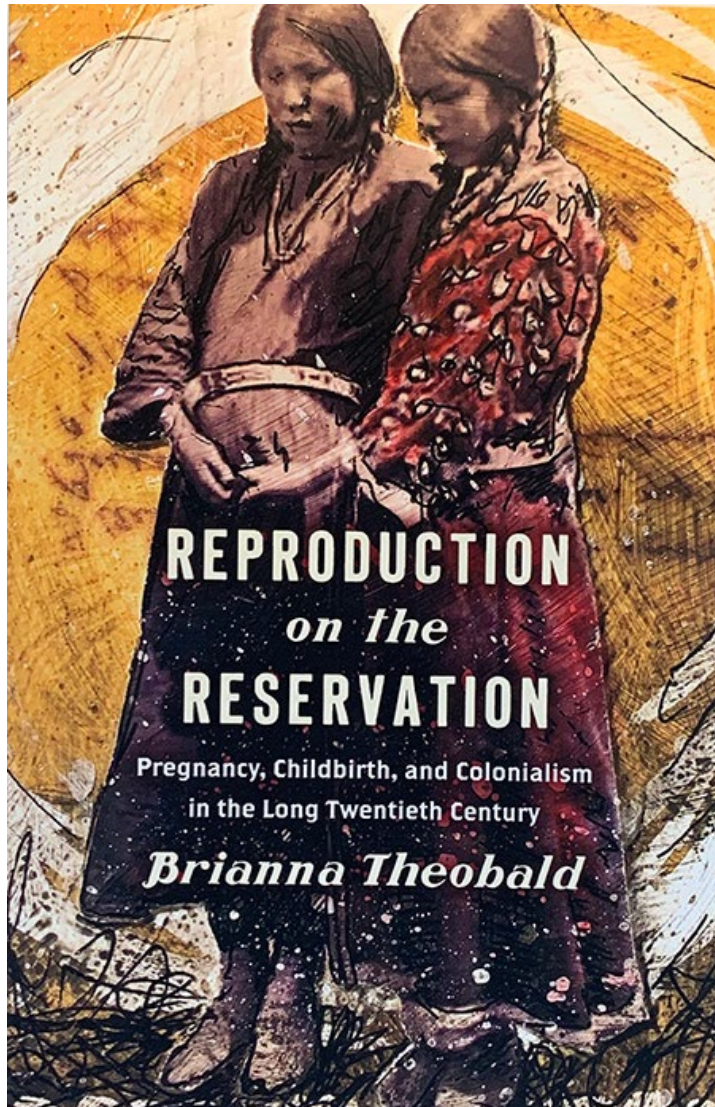
Beautiful Colorado

- "Tallest" State, 48 Mt. Peaks Over 14,000 Ft.
- 350 Days Sunshine, Mild Winters
- Zoos, Museums, Mountain Parks, Drives
- Big Game Hunting, Trout Fishing, Camping



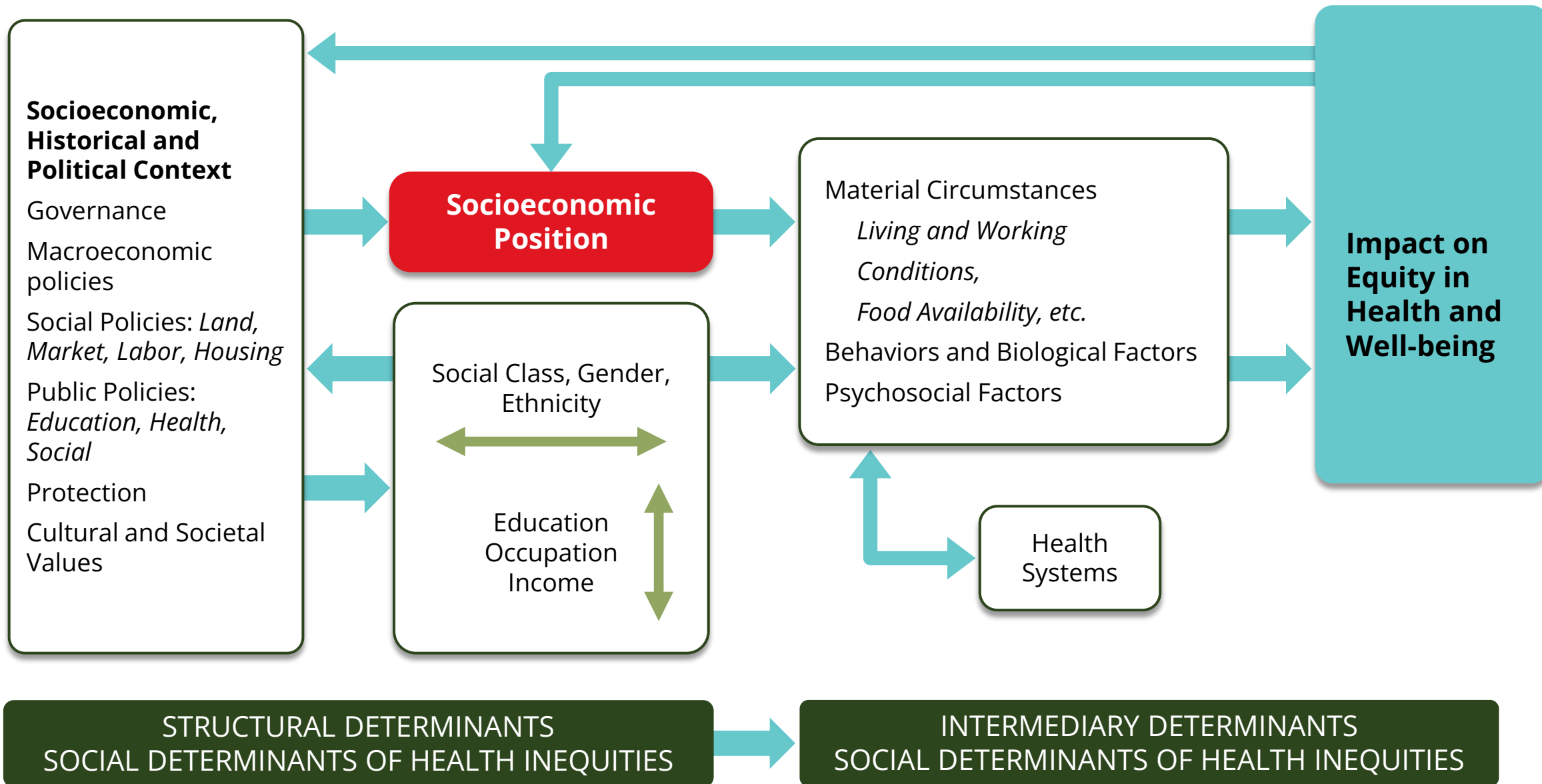
National Archives and Records Administration, College Park, MD, photo no. 75-N-REL-1G

Forced Sterilization



1976: U.S. Government admits unauthorized sterilization of Indian Women

Social Determinants of Health and Health Equity



Education



- In 2019, **84.4** percent of American Indians and Alaska Natives alone or in combination had at least a high school diploma, as compared to **93.3** percent of non-Hispanic whites.
- **20.8** percent of American Indians and Alaska Natives aged 25 and over had at least a bachelor's degree compared to **36.9** percent of non-Hispanic whites.
- **7.6** percent of American Indians and Alaska Natives held an advanced graduate or professional degree, as compared to **13.9** percent of the non-Hispanic white population.



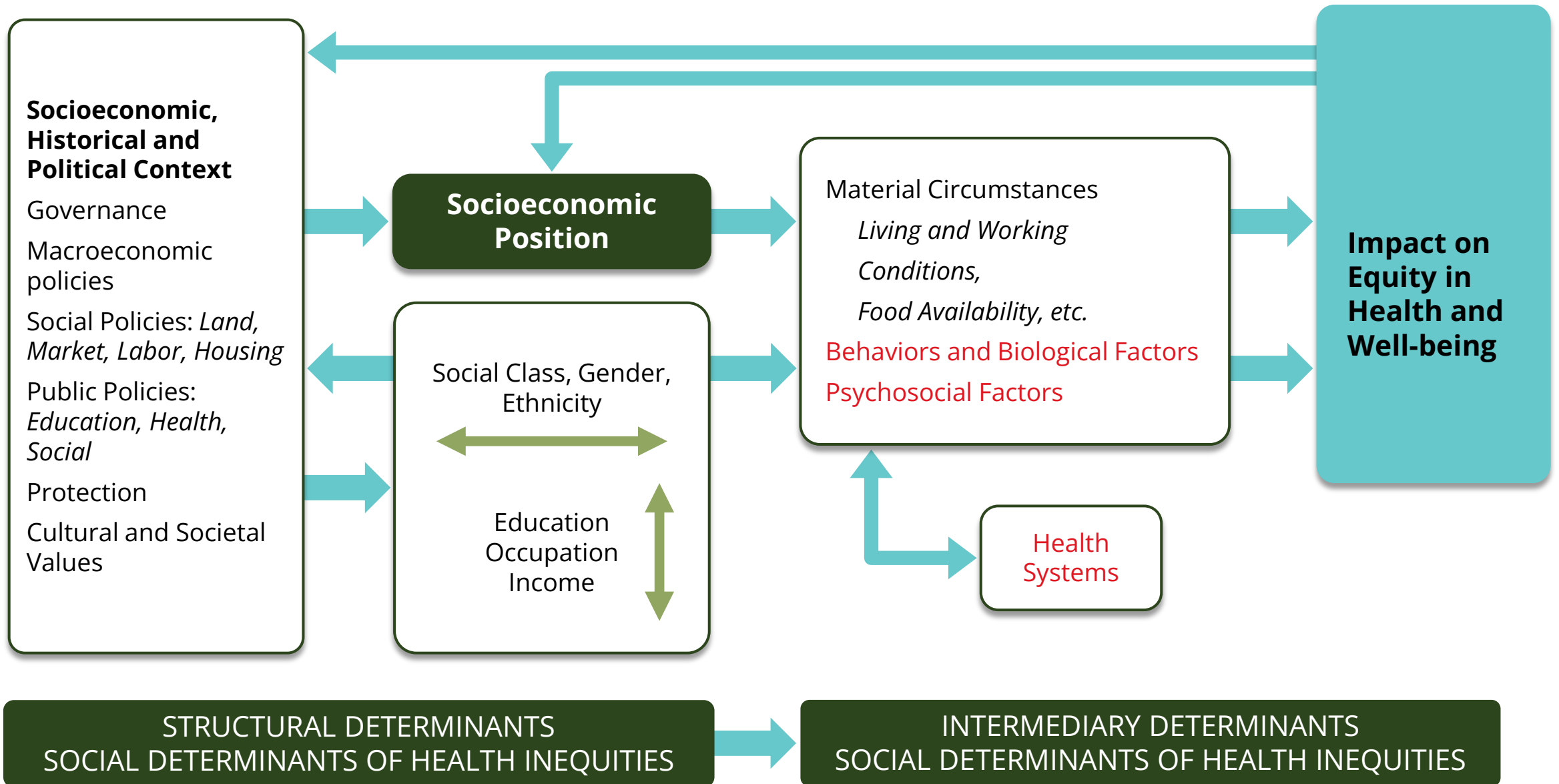
- The median household income for American Indian and Alaska Natives is **\$49,906**, as compared to **\$71,664** for non-Hispanic white households.
- In 2019, **20.3** percent of this population live at the poverty level, as compared to **9.0** percent of non-Hispanic whites.
- In 2019, the overall unemployment rate for American Indians/Alaska Natives was **7.9** percent, as compared to **3.7** percent for non-Hispanic whites.

Housing



- The most significant percentage increase of people experiencing homelessness between 2022 and 2023 was among people who identified as AI/AN, which increased by **18%**
- Unsheltered homelessness is elevated for American Indian and Alaska Native people. **56%** are sleeping in locations not meant for human habitation, compared to **37%** of homeless individuals overall

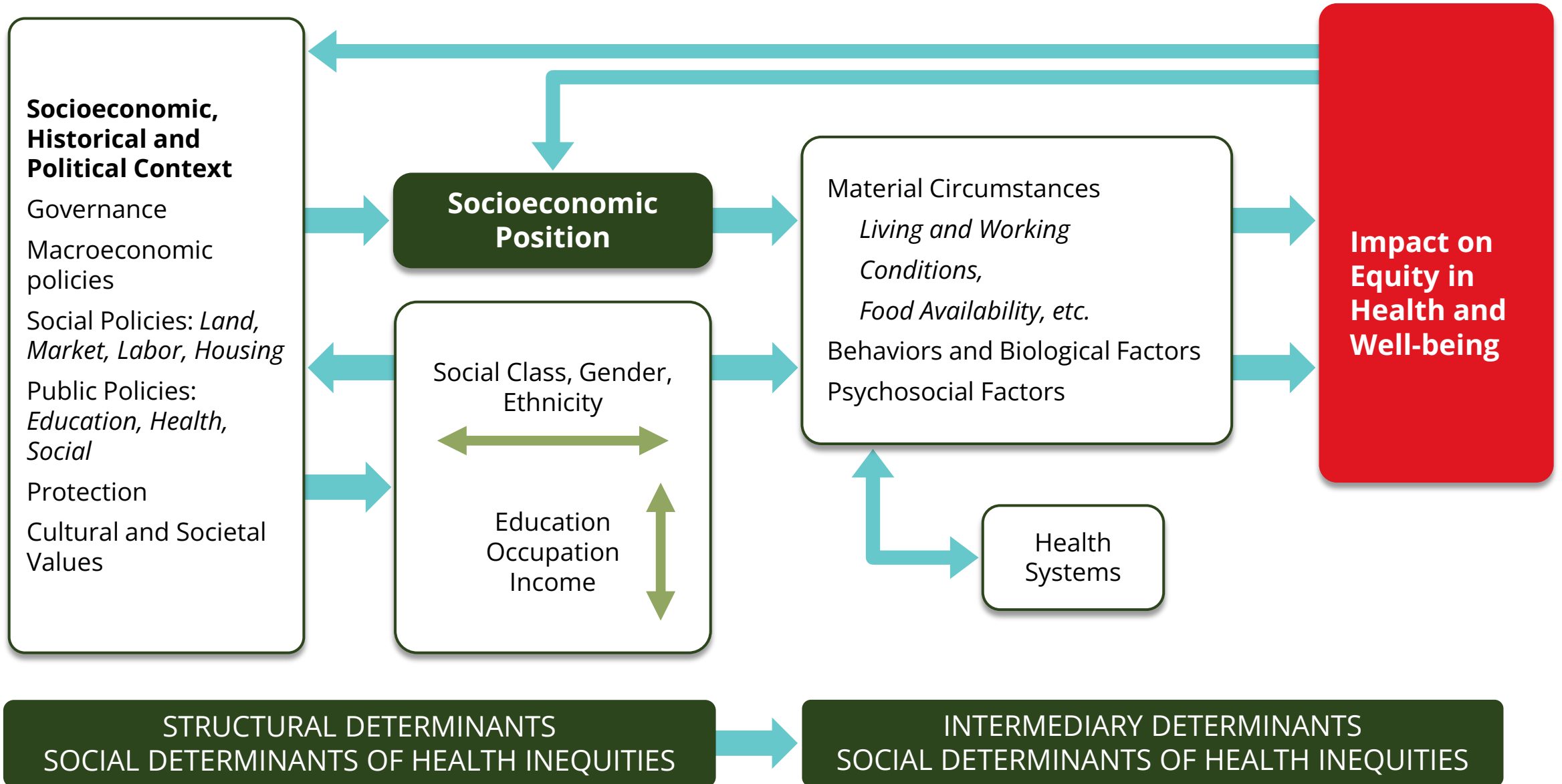
Social Determinants of Health and Health Equity



2021 Budget Data Year Comparisons

	Veterans Affairs (VA)	Indian Health Service (IHS)	Ratio
Patient population	9.2 million	2.6 million	4:1
Total budget	243 billion	6 billion	41:1
Medical budget	91.8 billion	4.5 billion	20:1
Physicians	23,869	776	31:1
Outpatient visits/ physician	5k/119m	18k/14m	1:4
Mental health/Substance Use	9.4 billion	364 million	27:1
EHR	1.6 billion	125 million	13:1
IT	4.3 billion		N/A
HIV	1.3 billion	\$400k	3250:1
Opioid Use Disorder	397 million	~\$6 million	66:1
Hepatitis C	37 million	0	Infinite N/A

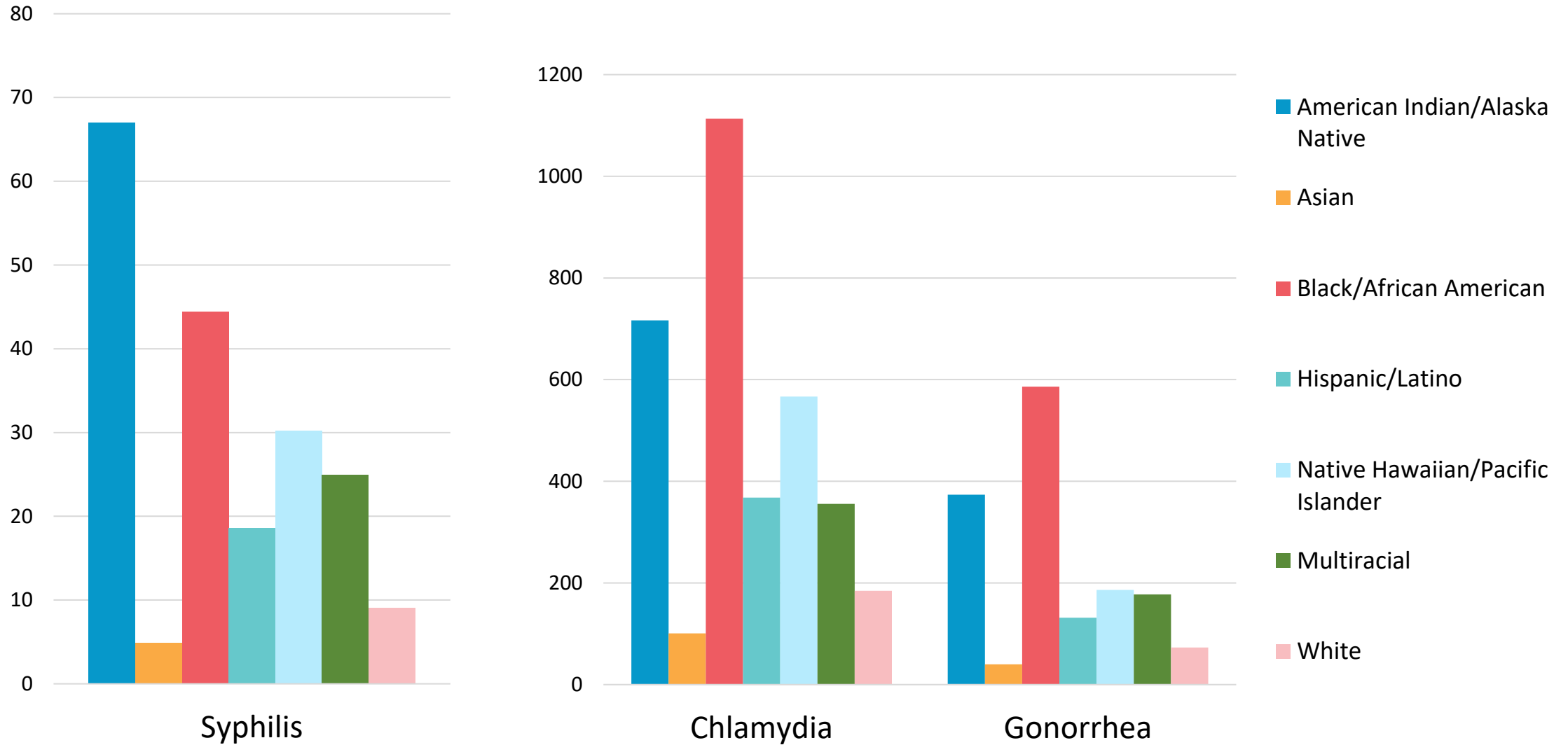
Social Determinants of Health and Health Equity



STIs in Indian Country



2022 Rates of Reported STIs by Race/Ethnicity

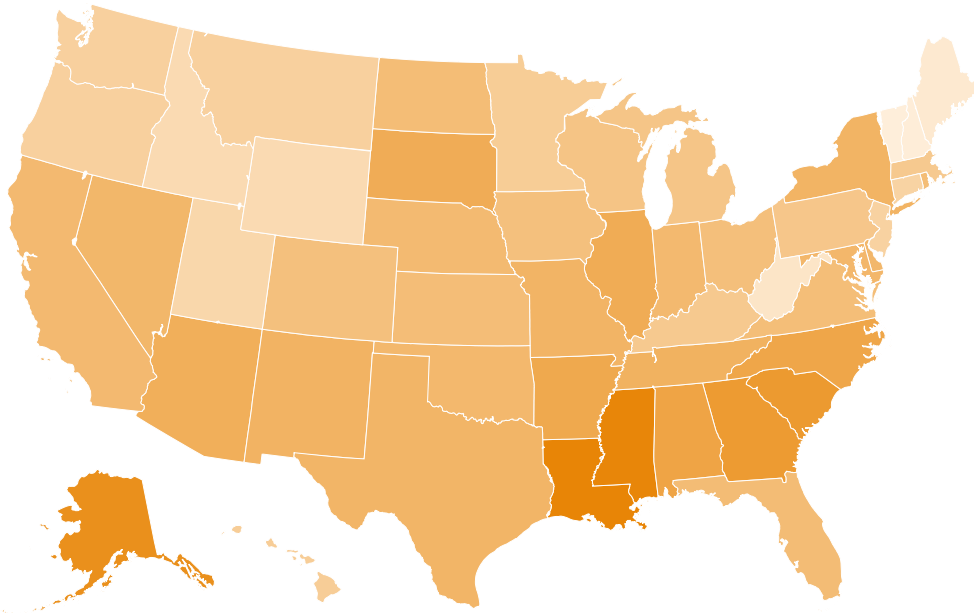


Chlamydia — Reported Case Rates by State, 2022

Rate per 100,000

788.6

198



National average:
495 per 100,000

Powered by Bing
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IHS Service Area Map

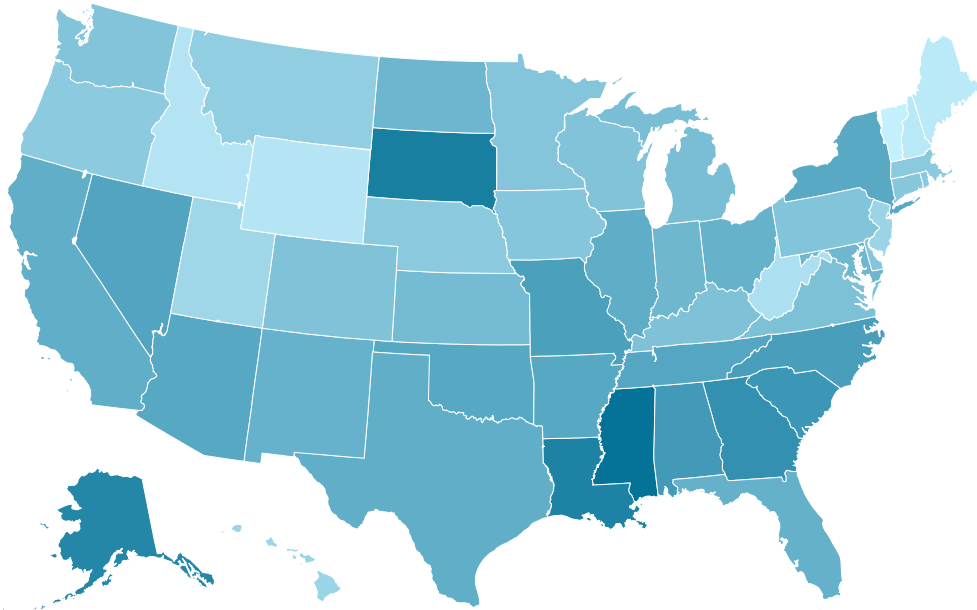


Gonorrhea — Reported Case Rates by State, 2022

Rate per 100,000

372

27



National average:
194 per 100,000

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IHS Service Area Map

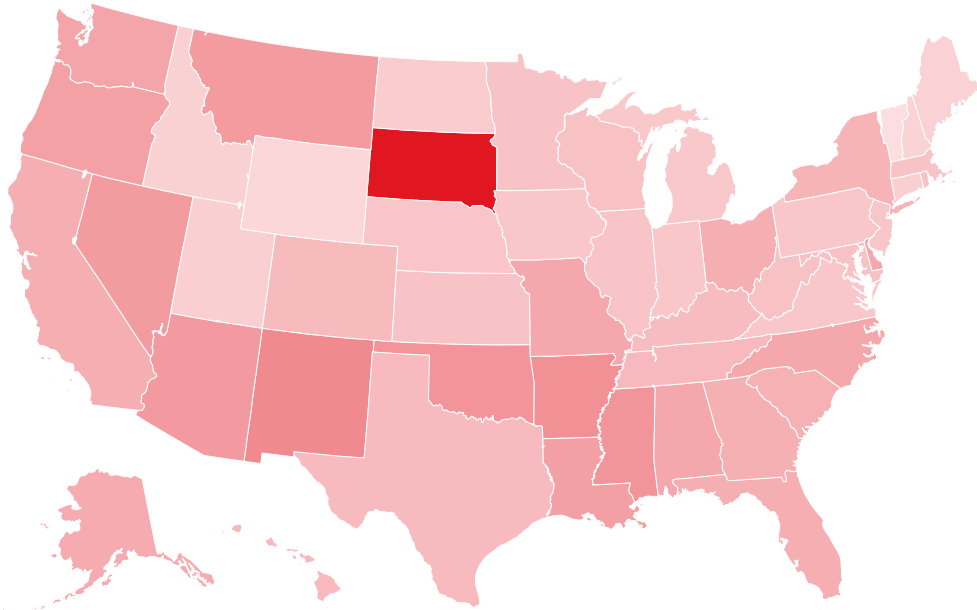


Primary and Secondary Syphilis — Reported Case Rates by State, 2022

Rate per 100,000

84.3

0.5



National average:
17.7 per 100,000

Powered by Bing
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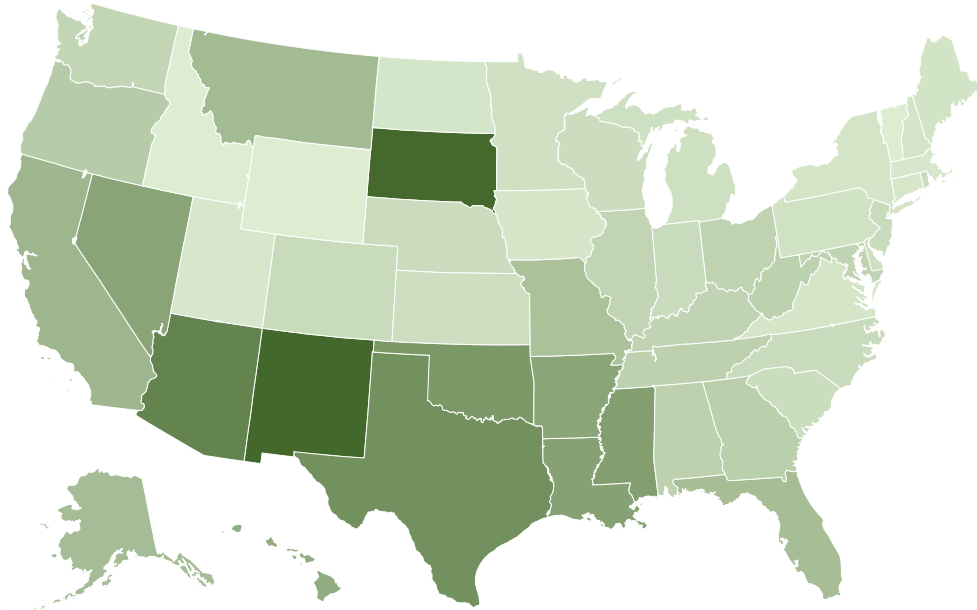
IHS Service Area Map



Congenital Syphilis — Reported Case Rates by State, 2022

Rate per 100,000
355.3

0



National average:
102 per 100,000

Powered by Bing
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IHS Service Area Map



U.S. syphilis numbers haven't been this high since 1950

[Health](#) Jan 31, 2024 1:51 PM EDT

Syphilis on the rise in Arizona

Tribal Leaders Urge HHS Secretary to Declare Syphilis Emergency

PRESS RELEASE • FEB 27, 2024

PUBLIC HEALTH

Native Americans are hardest hit by syphilis surge

MARCH 21, 2024 • 7:01 AM ET

By Cecilia Nowell

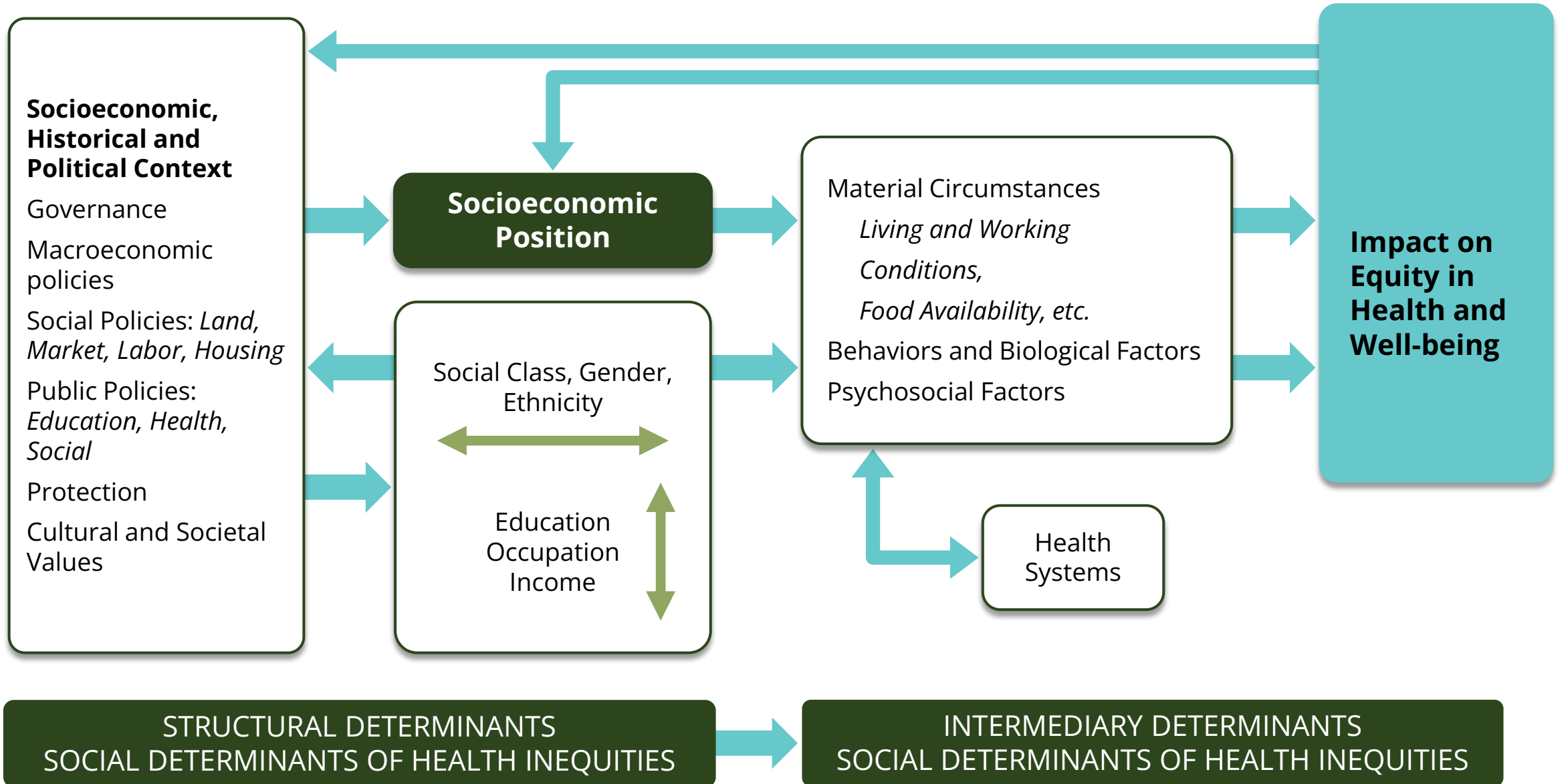
FROM **KFF** Health News

What Does This Data Say?



- We need to acknowledge that numbers alone are not meaningful to us.
- Numbers and data need to be put into context for us to understand it.

Social Determinants of Health and Equity



Efforts in Equity

Socioeconomic and Political Context

Structural Racism and Privilege

Public Policies

Governance and Structure

Health Systems

Pro Equity Policies

Community and Policy

Affordable Housing

Safe Neighborhoods

Supportive Policies

Quality Education

Healthy Environment

Access to Healthcare

Access to Transportation

Pro Equity Policies

Family and Individual

Substance Use Disorder

Houselessness

Congenital Syphilis

Mental Health

Syphilis and other Health Problems

Pro Equity Policies

Political structures & institutional practices that assure fairness & opportunity for all

Social, economic, & physical conditions that allow people to reach their full being

Services for individuals and families to treat problems

Intervention: Self-Collection STI Testing



Collaborating Partners



NORTHWEST PORTLAND AREA
INDIAN HEALTH BOARD
Indian Leadership for Indian Health



CENTER FOR
INDIGENOUS HEALTH



JOHNS HOPKINS
M E D I C I N E

Supported by the Indian Health Service with resources from the Minority HIV/AIDS Fund.

I Want The Kit (IWTK) Overview

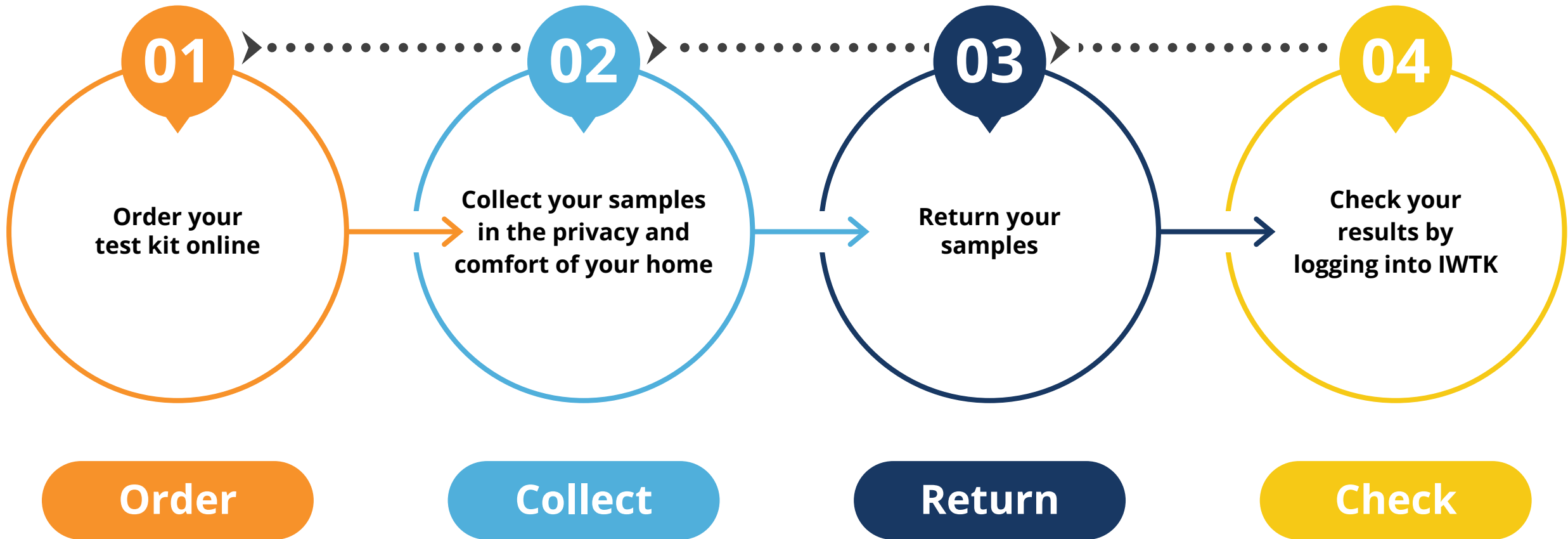


IWTK (iwantthekit.org) was founded in 2004 at the Johns Hopkins University School of Medicine.

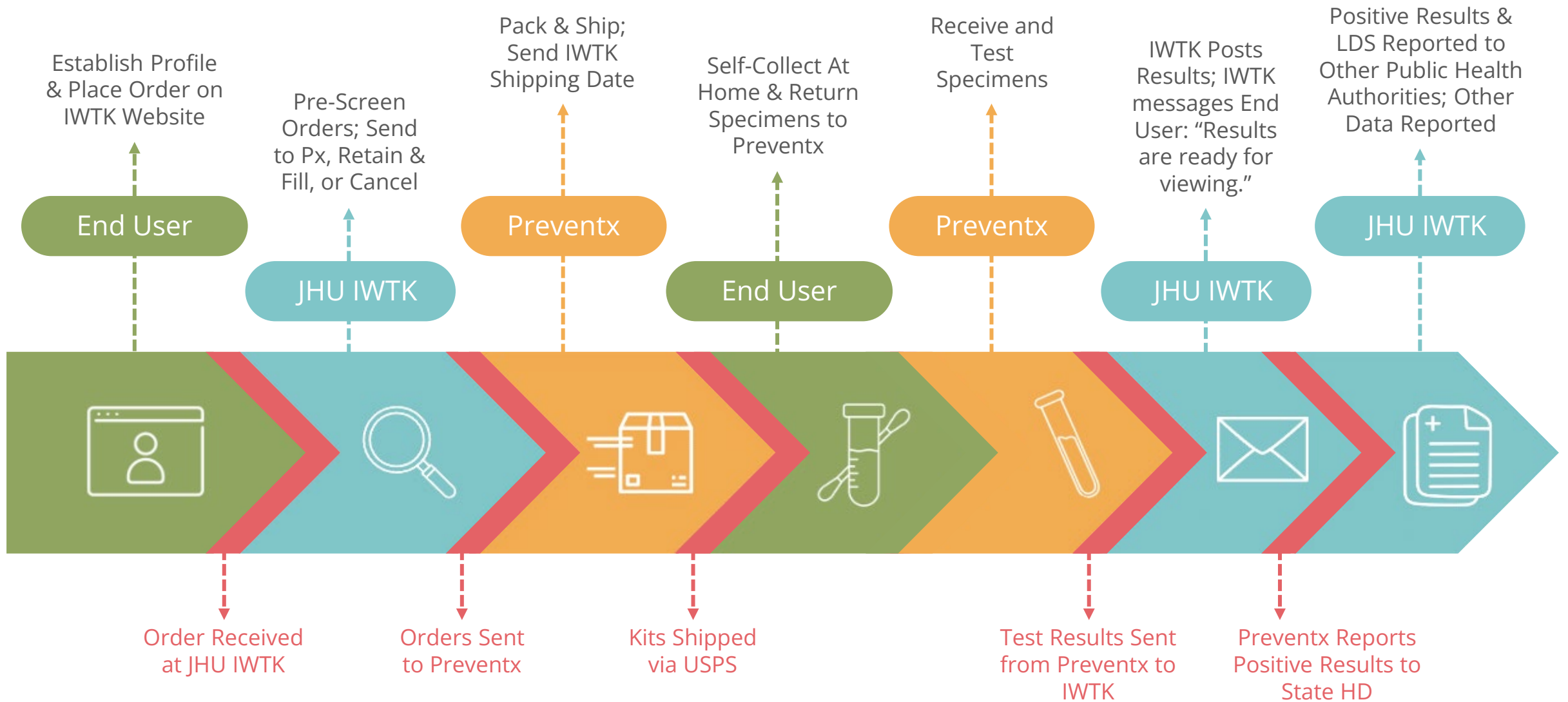
- **Tests currently offered:** Chlamydia, Gonorrhea, Trichomoniasis (female vaginal samples only), Hepatitis B*, Hepatitis C*, Syphilis*, HIV*
- **Anatomical sites tested:** Genital, Rectal, Pharyngeal, Blood*
- **Specimen collection devices:** Flocked Swabs in Dry Tubes (Vaginal Swab, Rectal Swab, Throat Swab), Urine container, Microtainer
- **Cost for a client:** Free (including postage)
- **Age requirements:** 14 years old+ to order an STI kit

**Expanded blood testing offered in certain states only.*

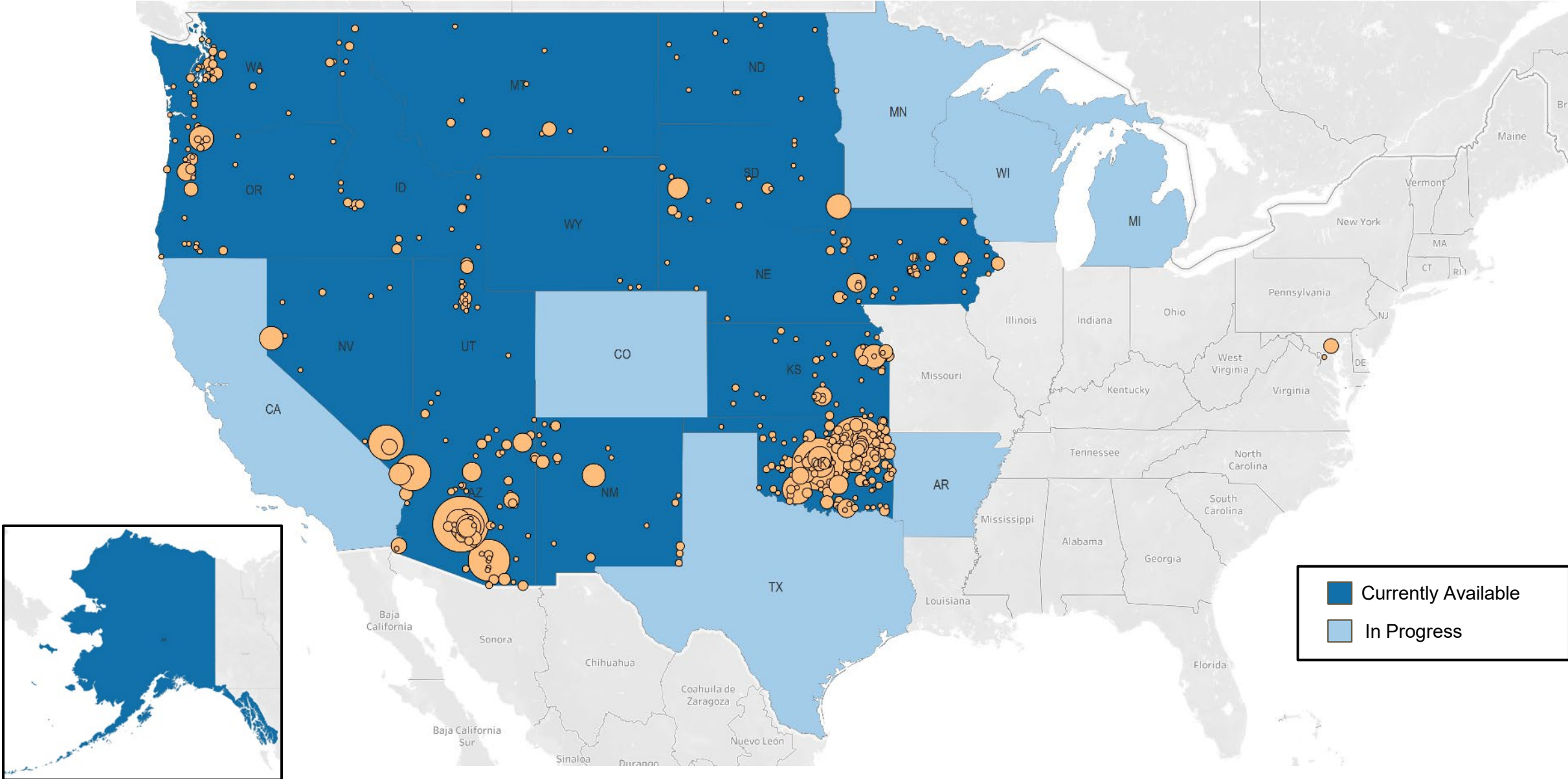
How IWTK works—user perspective



How IWTK works — complete Process



IWTK Availability & Expansion



Order Page

Option 1: "The Works"

Recommended

Includes Chlamydia, Gonorrhea, Trichomonas (vaginal samples), Hep C, Syphilis, HIV

- Hep B – can be added as an individual test

Option 2: Individual tests

Best for re-tests

Individuals have the option to select individual tests they would like to order

PLACE ORDER

Please select your tests.

Select Tests

Bundles

The Works - Kit for people with vaginas
Includes testing for vaginal, throat, and butt Chlamydia and Gonorrhea, vaginal Trichomonas, HIV, Syphilis, and Hepatitis C. To order a Hepatitis B test, please select it under the Individual Tests list.

The Works - Kit for people with penises
Includes testing for genital, throat, and butt Chlamydia and Gonorrhea, HIV, Syphilis, and Hepatitis C. To order a Hepatitis B test, please select it under the Individual Tests list.

Individual Tests

Vagina Swab
Have you received vaginal sex (meaning someone put their penis or sex toys into your vagina) OR have you received oral sex? If the answer is yes, order a vagina swab. This swab will be tested for Chlamydia, Gonorrhea and Trichomoniasis.

Butt (Rectal) Swab
Have you received butt (rectal) sex? (This means someone put their penis or sex toys into your butt.) If the answer is yes, order a butt swab. This swab will be tested for Chlamydia and Gonorrhea.

Throat Swab
Have you given oral sex? (This means you have given someone a blow job, given someone head, gone down on someone.) If the answer is yes, order a throat swab. This swab will be tested for Chlamydia and Gonorrhea.

Packaging



Dimensions: 9" x 4.5" x 1.2"

Kit Contents

For Blood Samples (if ordered):

- Alcohol Wipes
- Safety Lancets (3)
- Collection Tube
- Tube Holder
- Bandage
- Small Transport Bag

For Swabs and Urine (if ordered):

- Swabs (1-3 depending on order) labeled by body part
- Transport Bag for Each Swab
- Pouch (Male Urine Sample Only)
- Bottle ((Male Urine Sample Only)

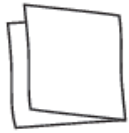
Additional Items for All Kits:

- Condoms
- Welcome Card
- Resource Booklet
- Pregnancy Tests (2) (Only if Vaginal Swabs Ordered)



Blood Testing

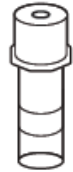
Provided Materials



Alcohol
wipe



Safety
lancets



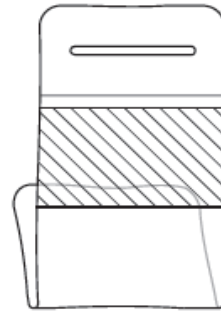
Collection
tube



Tube
holder



Bandage

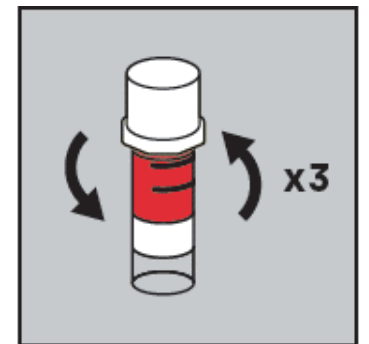
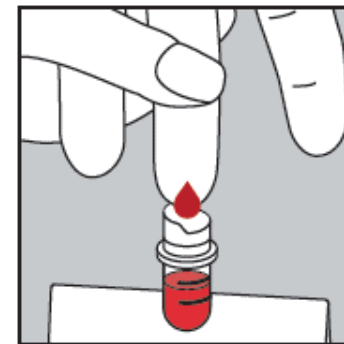
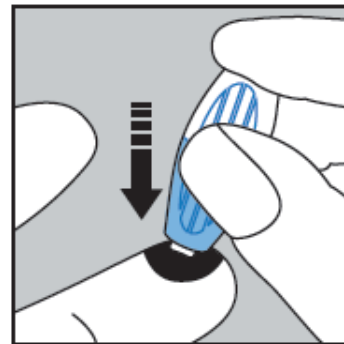
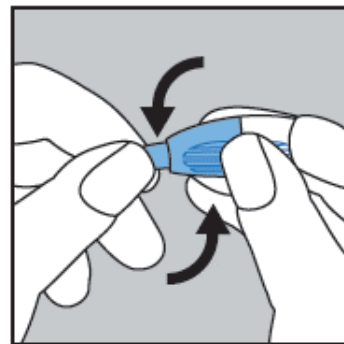
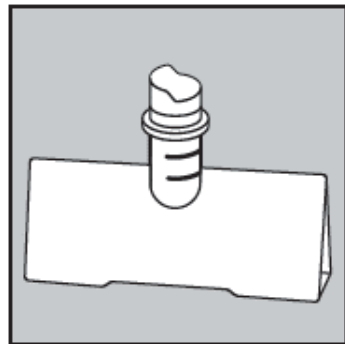
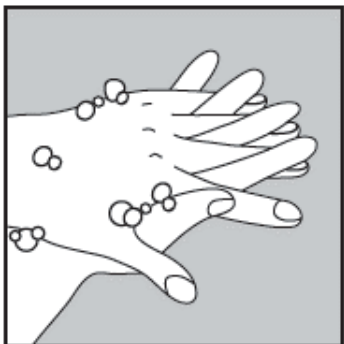


Small
transport bag

Sample Quantities

- **450 μL** minimum required
- **650 μL** preferred

Procedure



Welcome Card

Welcome to Indigi-IWTK!

At Indigi-IWTK we believe that getting tested for STIs (sexually transmitted infections) is an act of love, responsibility, and respect. We encourage you to read the information on this card and the instruction sheet that is included in your kit.

FREQUENTLY ASKED QUESTIONS

How do I know what's happening with my order?

You will receive an email or text notification from Indigi-IWTK when:

- 1) We receive your order
- 2) We mail your kit to you
- 3) We receive your specimens in the mail
- 4) Your test results are ready for viewing

What will the notifications say?

To protect your privacy, every message is the same, "You have a new message from IWTK. Please login to <https://www.iwantthekit.org> to read it."

How do I find out my test results?

Go to <https://www.iwantthekit.org> and login. Your order will show as Complete. Click on View Results.



More questions about IWTK?

Please scan the QR code with your smartphone.



Contact us at any time.

Email iwantthekit@jhmi.edu, call us at 443-500-3071, or scan this QR code for our contact page. We will respond within 1-2 working days.

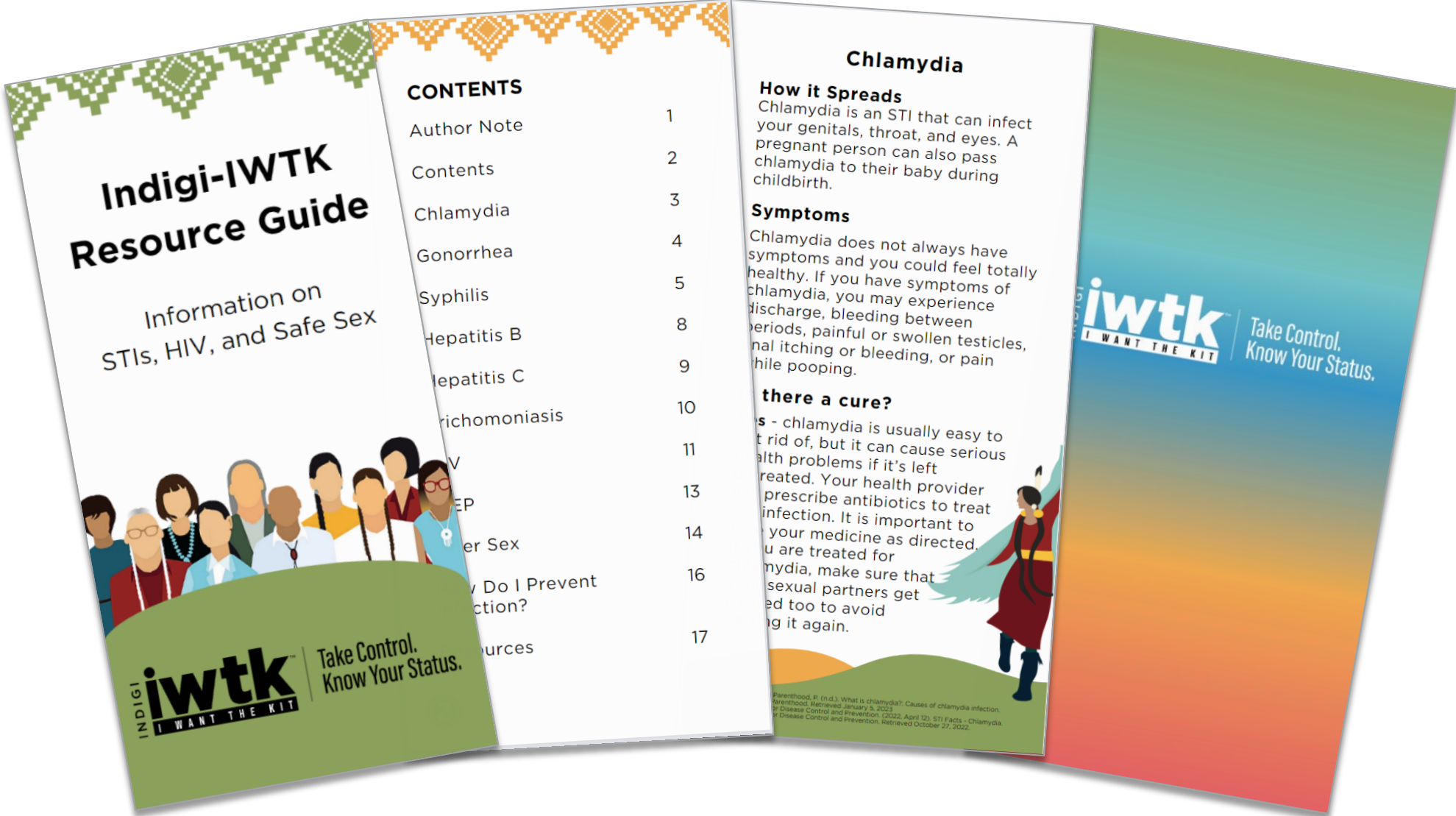


This kit is special for you to take control and know your status. Please do not give your kit to anyone else. Everyone must order their own kit. Here is the QR code for the ordering page.

Please share information about Indigi-IWTK with others who may want to use the service!



Resource Booklet



Expanded Results Reporting

Results sheet for clients:

- Provides guidance on the next actions to take
- Includes supportive resources

Syphilis Result	Result Text for Client
	symptoms may include enlarged lymph nodes, an unexplained rash, and/or a small sore around the genitals, rectum, or mouth. If untreated, syphilis will go latent (silent) in the body with no symptoms. However, the infection is still present and can cause severe medical problems. Syphilis is curable with penicillin injections. The number of shots you need will depend on your syphilis stage.
Treponemal Ab+ & RPR Invalid	<p>Your screening test is positive but we did not have enough sample to confirm whether it is a current or previous syphilis infection. We are sending you another kit. Please Contact Us, email iwantthekit@jhmi.edu, or call 443-500-3071 for more information and contact your care provider.</p> <p>Syphilis is a sexually transmitted infection that can cause serious health problems if it is not treated. It is transmitted through direct contact with a syphilis sore during vaginal, rectal, or oral sex or from a pregnant person to their unborn baby. Early syphilis symptoms may include enlarged lymph nodes, an unexplained rash, and/or a small sore around the genitals, rectum, or mouth. If untreated, syphilis will go latent (silent) in the body with no symptoms. However, the infection is still present and can cause severe medical problems. Syphilis is curable with penicillin injections. The number of shots you need will depend on your syphilis stage.</p>
Unconfirmed Ab+ & RPR Invalid	We were unable to complete full testing. We are sending you another kit. Please Contact Us , email iwantthekit@jhmi.edu , or call 443-500-3071 if you do not receive it within 7-10 working days.
Unconfirmed Ab+ & RPR Insufficient	We were unable to complete full testing. We are sending you another kit. Please Contact Us , email iwantthekit@jhmi.edu , or call 443-500-3071 if you do not receive it within 7-10 working days.

- A new campaign led by our coalition, called Indigi-IWTK, launched in 2023 to expand IWTK services across Indian Country.
- Outreach material designed by Native communities for Native communities.
- Localized linkage to care provided by regional partners
- Incorporation of priority areas into implementation plan

Updated IWTK Logo



**Many genders.
One kit.**

Love yourself. Love your community.

 **ORDER A FREE,
CONFIDENTIAL
STI TEST KIT**
iwantthekit.org

INDIGI iwtk Take Control.
Know Your Status.

The project is funded through the Indian Health Service and the Minority HIV/AIDS Fund.

Snag a Kit Today!

ORDER A FREE, CONFIDENTIAL STI TEST KIT

 **ORDER A FREE,
CONFIDENTIAL
STI TEST KIT**
iwantthekit.org

INDIGI iwtk Take Control.
Know Your Status.

iwantthekit.org

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**Snag Something You
Didn't Want?**

 **ORDER A FREE,
CONFIDENTIAL
STI TEST KIT**
iwantthekit.org

INDIGI iwtk Take Control.
Know Your Status.

The project is funded through the Indian Health Service and the Minority HIV/AIDS Fund.

Indigenous-Centric Marketing



Keep Calm
& Swab On

ORDER A FREE, CONFIDENTIAL STI TEST KIT
iwantthekit.org

INDIGI iwtk
Take Control. Know Your Status.

This project is funded through the Indian Health Service with backing from the Minority HIV/AIDS Fund.

A poster featuring a photograph of a slot canyon with warm, orange and red rock walls. The text is white and positioned in the upper left and lower right areas.

Snag a Kit for the Greater Good.

Love yourself.
Love your community.

ORDER A FREE, CONFIDENTIAL STI TEST KIT
iwantthekit.org

INDIGI iwtk
Take Control. Know Your Status.

This project is funded through the Indian Health Service with backing from the Minority HIV/AIDS Fund.

A poster featuring a photograph of a young woman with long dark hair, wearing a black dress, smiling and leaning against a light-colored brick wall. The text is white and positioned in the lower right and bottom left areas.

Laughter is the best medicine

INDIGI iwtk
Take Control. Know Your Status.

This project is funded through the Indian Health Service with backing from the Minority HIV/AIDS Fund.

A poster featuring a photograph of two young women laughing joyfully against a solid purple background. The text is white and positioned in the lower left and bottom center areas.

Knowing your status helps too.

ORDER A FREE, CONFIDENTIAL STI TEST KIT

INDIGI iwtk
Take Control. Know Your Status.

iwantthekit.org

This project is funded through the Indian Health Service and the Minority HIV/AIDS Fund.

A poster featuring a photograph of a mountain range with snow-capped peaks and green valleys. The text is white and positioned in the upper right, center, and lower right areas. A QR code is located in the upper right quadrant.

Indigenous-Centric Marketing



Question for the Viewers



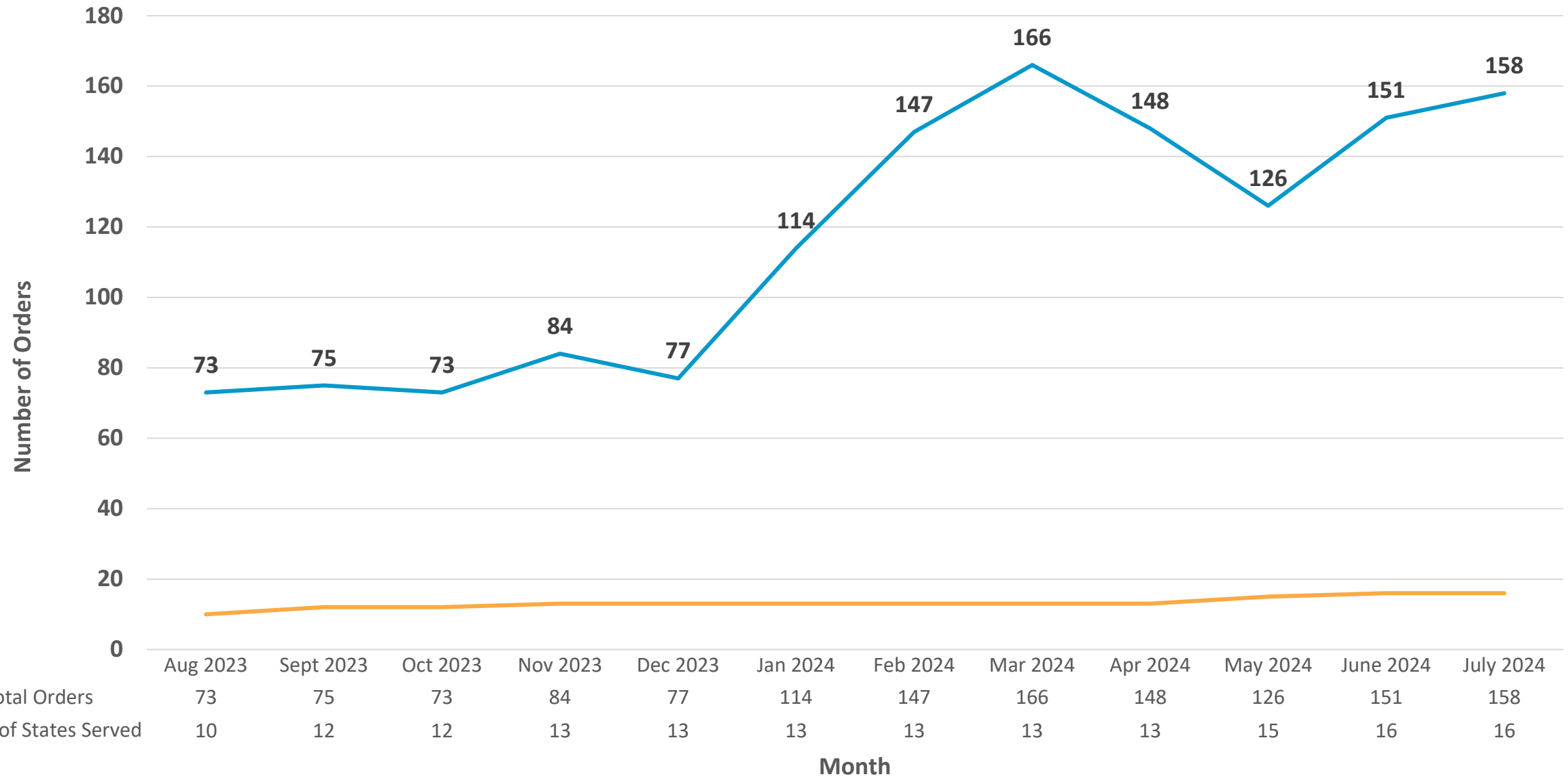
What are some strategies your organization has implemented to ensure that your outreach and programming is culturally responsive to the populations you serve?

Please type your answer in the chat

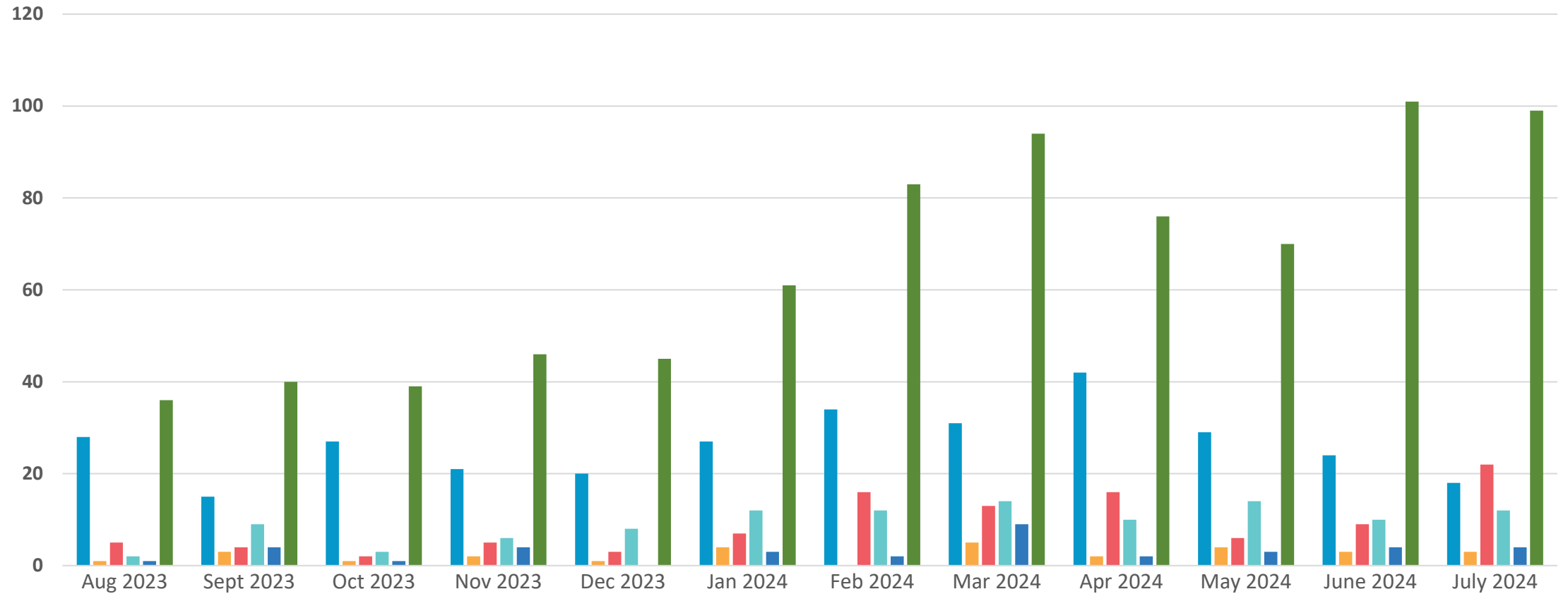
Preliminary Data



Indigi-IWTK Total Orders

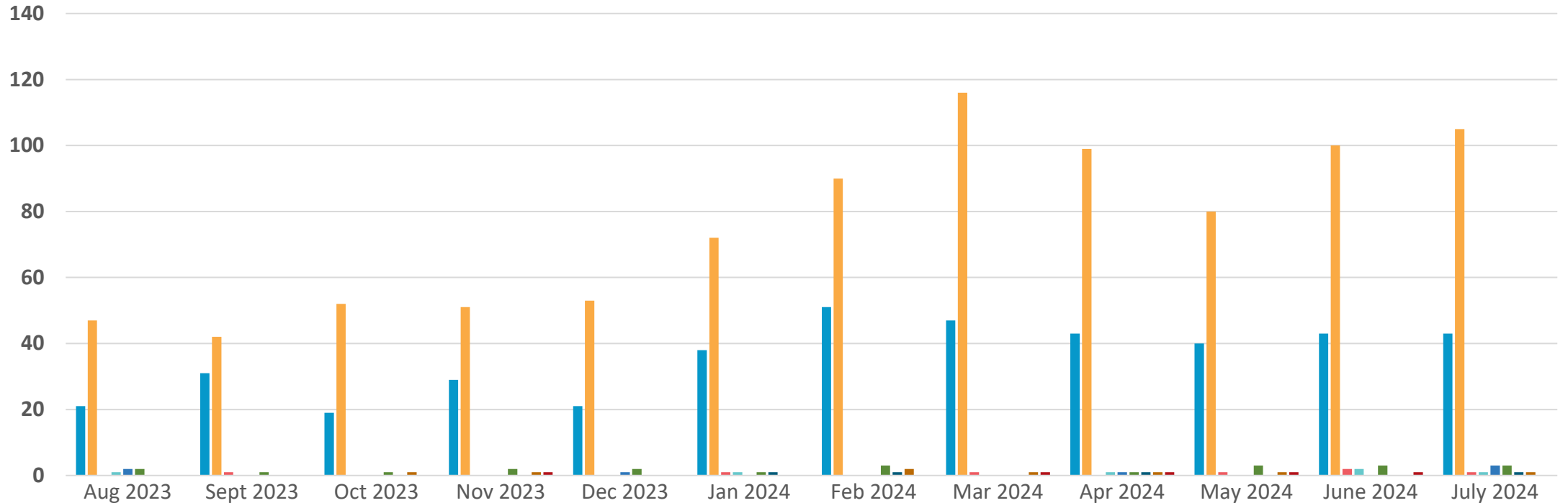


Indigi-IWTK Orders by Race



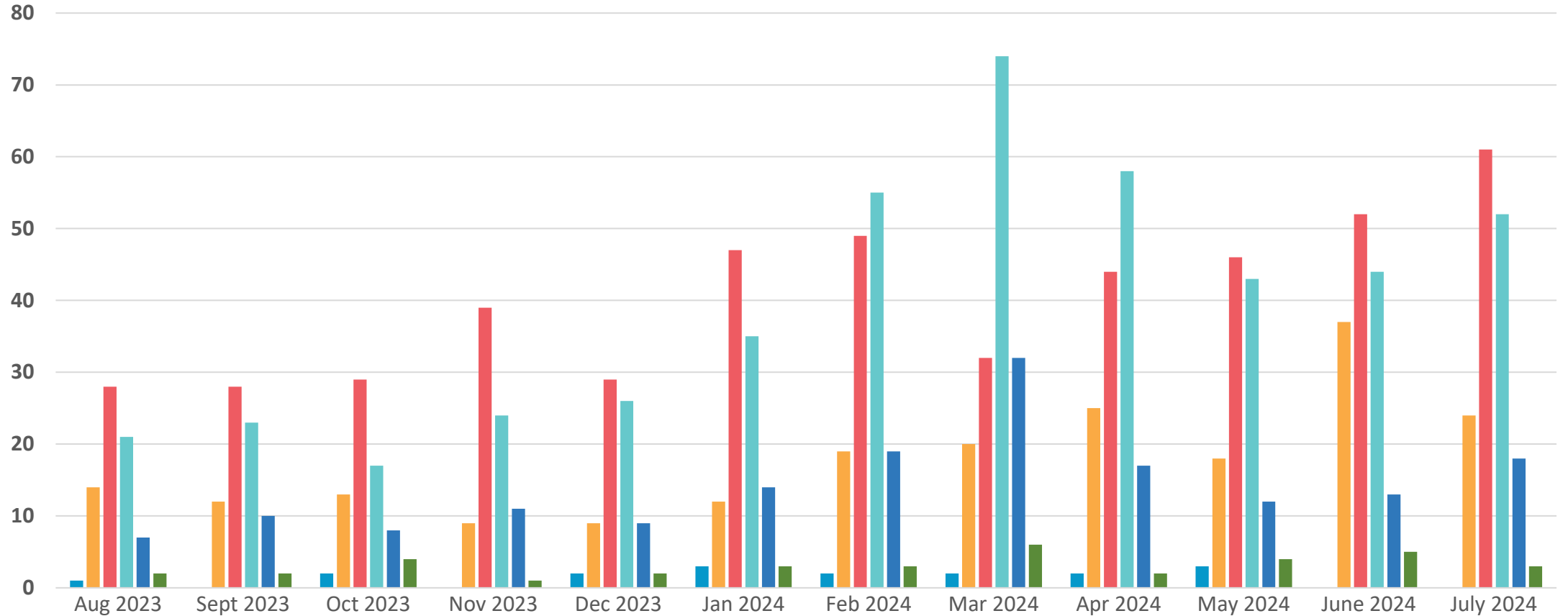
	Aug 2023	Sept 2023	Oct 2023	Nov 2023	Dec 2023	Jan 2024	Feb 2024	Mar 2024	Apr 2024	May 2024	June 2024	July 2024
AI/AN	28	15	27	21	20	27	34	31	42	29	24	18
Asian/Pacific Islander	1	3	1	2	1	4	0	5	2	4	3	3
Black	5	4	2	5	3	7	16	13	16	6	9	22
Multiracial	2	9	3	6	8	12	12	14	10	14	10	12
Unknown	1	4	1	4	0	3	2	9	2	3	4	4
White	36	40	39	46	45	61	83	94	76	70	101	99

Indigi-IWTK Orders by Gender Identity



	Aug 2023	Sept 2023	Oct 2023	Nov 2023	Dec 2023	Jan 2024	Feb 2024	Mar 2024	Apr 2024	May 2024	June 2024	July 2024
Male	21	31	19	29	21	38	51	47	43	40	43	43
Female	47	42	52	51	53	72	90	116	99	80	100	105
Transgender Man	0	1	0	0	0	1	0	1	0	1	2	1
Transgender Woman	1	0	0	0	0	1	0	0	1	0	2	1
Genderqueer	2	0	0	0	1	0	0	0	1	0	0	3
Non-binary	2	1	1	2	2	1	3	0	1	3	3	3
Other	0	0	0	0	0	1	1	0	1	0	0	1
Gender Fluid	0	0	1	1	0	0	2	1	1	1	0	1
Two Spirit	0	0	0	1	0	0	0	1	1	1	1	0

Indigi-IWTK Orders by Age Group



	Aug 2023	Sept 2023	Oct 2023	Nov 2023	Dec 2023	Jan 2024	Feb 2024	Mar 2024	Apr 2024	May 2024	June 2024	July 2024
17 and younger	1	0	2	0	2	3	2	2	2	3	0	0
18 - 24	14	12	13	9	9	12	19	20	25	18	37	24
25 - 34	28	28	29	39	29	47	49	32	44	46	52	61
35 - 44	21	23	17	24	26	35	55	74	58	43	44	52
45 - 54	7	10	8	11	9	14	19	32	17	12	13	18
55 and older	2	2	4	1	2	3	3	6	2	4	5	3

Return Rate: Oklahoma, July 2023 – July 2024

	July	Aug	Sep	Oct	Nov	Dec	Jan	Feb	Mar	Apr	May	June	July
Order number	14	20	12	18	25	27	31	41	64	41	36	49	26
Returned in 30 days	7	6	4	5	8	5	11	11	10	10	7	3	
Returned in 60 days	9	8	5	7	11	9	16	13	10	12	10		
Returned in 90 days	10	9	5	7	13	10	17	13	11	12			
Returned in 120 days	10	9	5	7	13	10	17	13	11				
Total returned	10	9	7	7	13	10	18	14					
30-day return rate	50.00%	30.00%	33.33%	27.78%	32.00%	18.52%	35.48%	26.83%	15.63%	24.39%	19.44%	6.12%	
60-day return rate	64.29%	40.00%	41.67%	38.89%	44.00%	33.33%	51.61%	31.71%	15.63%	29.27%	27.78%		
90-day return rate	71.43%	45.00%	41.67%	38.89%	52.00%	37.04%	54.84%	31.71%	17.19%	29.27%			
120-day return rate	71.43%	45.00%	41.67%	38.89%	52.00%	37.04%	54.84%	31.71%	17.19%				
Total return rate	71.43%	45.00%	58.33%	38.89%	52.00%	37.04%	58.06%	34.15%					

How Did You Hear About Indigi-IWTK? July 2024

Social Media (Facebook, Instagram, TikTok, etc.)	12
Indian Health Service (IHS)	2
Tribal Clinic	1
Urban Indian Clinic	0
School Clinic	0
Community Event	1
Dating or Hookup App	1
Radio Ad	2
Billboards	1

Flyer or Poster	4
Video Clip	0
Internet Search	95
Word of Mouth (From a Partner, Friend or Family)	15
iKnowMine.org	4
NativeTest.org	12
WERNATIVE.org	1
Other	7

**Clients can select up to 3 How Heard options*

Limitations, Successes, and Next Steps



Limitations

USPS service times when mailing to and from rural communities

- Specimens, especially blood, must be received at the laboratory in a timely manner while the sample is still viable

Client learning curve with expanded testing mechanism

- Self-collection of blood via a fingerstick may be difficult for some individuals

Healthcare provider acceptance of test results

- Some providers may decide to retest due to lack of familiarity with IWTK and concern regarding laboratory and test quality

Delays in testing and treatment due to transit times

- Mail-in testing may not be best for symptomatic individuals

Accomplishments

- IWTK and Native Test offer an alternative to clinic-based testing
- Our multisectoral partnership with culturally congruent messaging is launched and orders are starting to rise
- Close working relationship with Preventx, our laboratory, to bring about quality improvements such as reduced shipping times
- Linkage to care model: really the meat of the program
 - Each region has customized to meet the needs of their communities

Indigi-IWTK: Return on Investment

Costs

- Salaries
- Kit supplies
- Laboratory
- Web design
- Advertisement

Cost-Savings

- Using CDC STIC FIGURE model
- **Direct** medical costs and indirect productivity costs saved:
 - Averted PID, epididymitis, congenital syphilis, syphilis sequelae
 - Averted ongoing transmission of chlamydia, gonorrhea, syphilis, STD-attributable HIV

$$\frac{\text{Total cost}}{\text{Number of tests}} = \text{cost per person tested}$$

$$\frac{\text{Total cost}}{\text{Number of positive cases}} = \text{cost per case identified}$$

$$\frac{\text{Total cost}}{\text{Estimated cost-savings}} = \text{cost-benefit ratio}$$

Next Steps (3-5 years)

- More rural-based, Native individuals may complete testing, know their status, receive treatment → reduce STI/HIV incidence
- Further expansion is needed to maximize reach for all states/regions
- Evaluation to improve service & implementation approach
- Evaluating new testing technologies

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Thank You!



Take Control. Know Your Status.



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Key Takeaways

- ✓ There are different ways to be tested for STIs. Self-collection with laboratory testing is one important tool to include in the testing toolbox.
- ✓ Tailored self-collection STI testing programs can meet individuals where they are while acknowledging their social determinants of health.
- ✓ Using community and familiar imagery in the marketing creates a more relatable and accessible program.
- ✓ Continuous community feedback, evaluation, and adaptability are important pieces of IWTK's success and sustainability.

A Chat with Alicia, Cody, and Gretchen



Sue
Grinnell



Alicia
Edwards



Cody
Knight



Gretchen
Armington

QUESTIONS?

To ask a question, please click the



icon in the Zoom toolbar to open your Q&A Pod.

Resources

I Want the Kit

<https://iwantthekit.org/>

IWTK Demo Video

I Want the Kit

<https://app.box.com/s/ze53w6btjtw7143lutgs97iium6afhpm>

The Invasion of America

eHistory.org

<https://youtu.be/pjxrTzfG2bo?si=eJpyzw0TdKey2ncC>

Uprooted: The 1950s plan to erase Indian Country

APM Reports

<https://www.apmreports.org/episode/2019/11/01/uprooted-the-1950s-plan-to-erase-indian-country>

Forced Sterilization

<https://www.wernative.org/articles/history-of-the-sterilization-of-native-women>

<https://www.nlm.nih.gov/nativevoices/timeline/543.html>

Homelessness

<https://endhomelessness.org/blog/state-of-homelessness-a-look-at-race-and-ethnicity/>

<https://ncuih.org/2024/03/08/new-report-shows-increase-in-homelessness-disproportionately-affects-american-indian-and-alaska-native-people/>

American Indians travel great distances for obstetrical care: Examining rural and racial disparities

Thorsen, et al.

<https://www.sciencedirect.com/science/article/abs/pii/S027795362300254X>