Collecting Patient Race and Ethnicity Data

ISP PTO Touchbase
March 8, 2023

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Overview

01 Race & Ethnicity Basics

02 Considerations for Data Collection

03 Resources

How many of your practices routinely collect race and ethnicity data from patients?

None	**A**	100%
Some	**B**	
Most	**C**	
All	**D**	

What do you think is the biggest barrier that keeps practices from collecting race and ethnicity data from patients?

They don't see the importance	100%
The electronic medical record	
It would take too much time	
Concerns about pushback from patients	
Something else	

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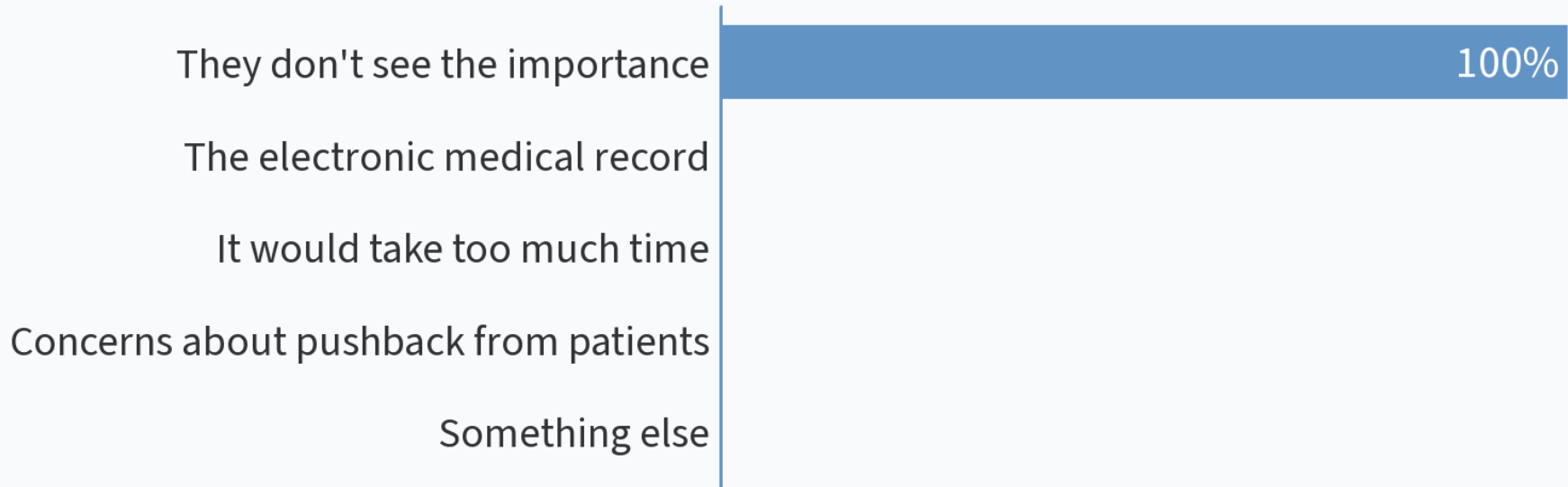
How many of your practices routinely collect preferred language data from patients?

None

Some

Most

All

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What do you think is the biggest barrier that keeps practices from collecting race and ethnicity data?

They don't see the importance

The electronic medical record

It would take too much time

Concerns about pushback from patients

Something else

What are the other barriers to collecting race, ethnicity, or language information from patients?

Race & Ethnicity Basics

What are the Definitions of Race and Ethnicity?

Race

A social construct based on skin color and other physical differences. No basis in biology.

Ethnicity

A construct that encompasses common cultural characteristics including language, religion, dietary practices, and nationality; it may also reflect common ancestry or geographic origin.

(Lu 2022)

Why It is Important to
Collect Race & Ethnicity Data

1. Identifying the populations you serve
2. Uncovering and addressing inequities in quality of care
3. Meeting the needs of populations you serve through tailored care, fostering an inclusive environment, recruiting personnel that reflect your patients' communities

Self-reported race and ethnicity can change over time, depending on…

Stage of life

Leaving childhood home, getting married, etc.

Context where it is being disclosed

Home vs work vs school vs other

Bi/Multi-racial identity

In general, this can be a slowly changing dimension

(Lu 2022)

Accuracy of Electronic Medical Record Data...

Studies have shown that EMR data may underrepresent BIPOC and multiracial patients.

Klinger 2015
Samalik 2022

Patient attitudes about data collection

White	Black	Hispanic/Latino
It is important for hospitals and clinics to collect information from patients about their race and ethnic background. (somewhat or strongly agree)		
68%	76%	55%
It is important for hospitals and clinics to conduct studies to make sure all patients get the same high quality care regardless of their race or ethnic background (somewhat or strongly agree)		
87%	93%	86%

Patient attitudes about data collection

White	Black	Hispanic/Latino
High levels of comfort telling registration staff race/ethnicity information.		
75%	68%	58%
How worried would you be that this information could be used to discriminate against you? (Somewhat or very worried)		
18%	47%	72%
How worried would you be that this information could be used to find undocumented immigrants? (Somewhat or very worried)		
43%	47%	85%

Small Practice Perspectives

Concern about pushback from patients

Uncertain of benefit/usefulness

EMR is a significant facilitator

Concerns about patient privacy

Questions about legality

Staff discomfort

Hasnain-Wynia 2010.

Race/Ethnicity Categories

	MINIMUM OMB STANDARD	EXPANDED OMB CATEGORIES*		
ETHNICITY Are you Hispanic, Latino or Spanish origin?	Hispanic or Latino	• Mexican, Mexican American, Chicano	• Puerto Rican	• Cuban
	Not Hispanic or Latino	Not of Hispanic, Latino, or Spanish origin		
RACE What is your race? (One or more categories may be selected)	White	• European • Armenian • English	• French • German • Irish	• Italian • Polish • Scottish
	Black or African American	• Black/African American • African • Botswanan	• Ethiopian • Liberian • Namibian	• Nigerian • Haitian • Jamaican
	American Indian or Alaska Native	American Indian or Alaska Native *(over 800 defined tribal groupings)*		
	Asian	• Asian Indian • Chinese • Filipino	• Japanese • Korean • Vietnamese	• Pakistani • Thai
	Native Hawaiian or other Pacific Islander	• Native Hawaiian • Guamanian or Chamorro	• Samoan	• Other Pacific Islander

Granular Ethnicity Categories (CDC)
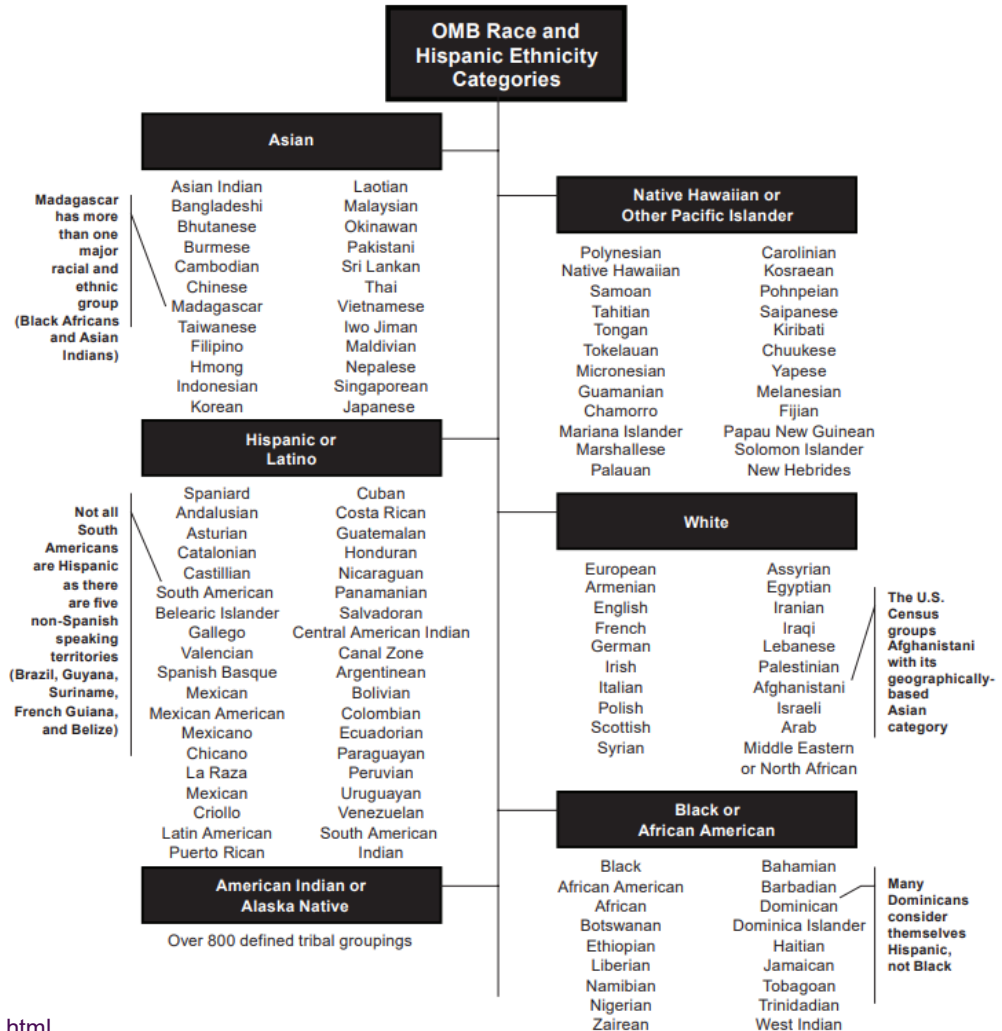
Tribal Designations

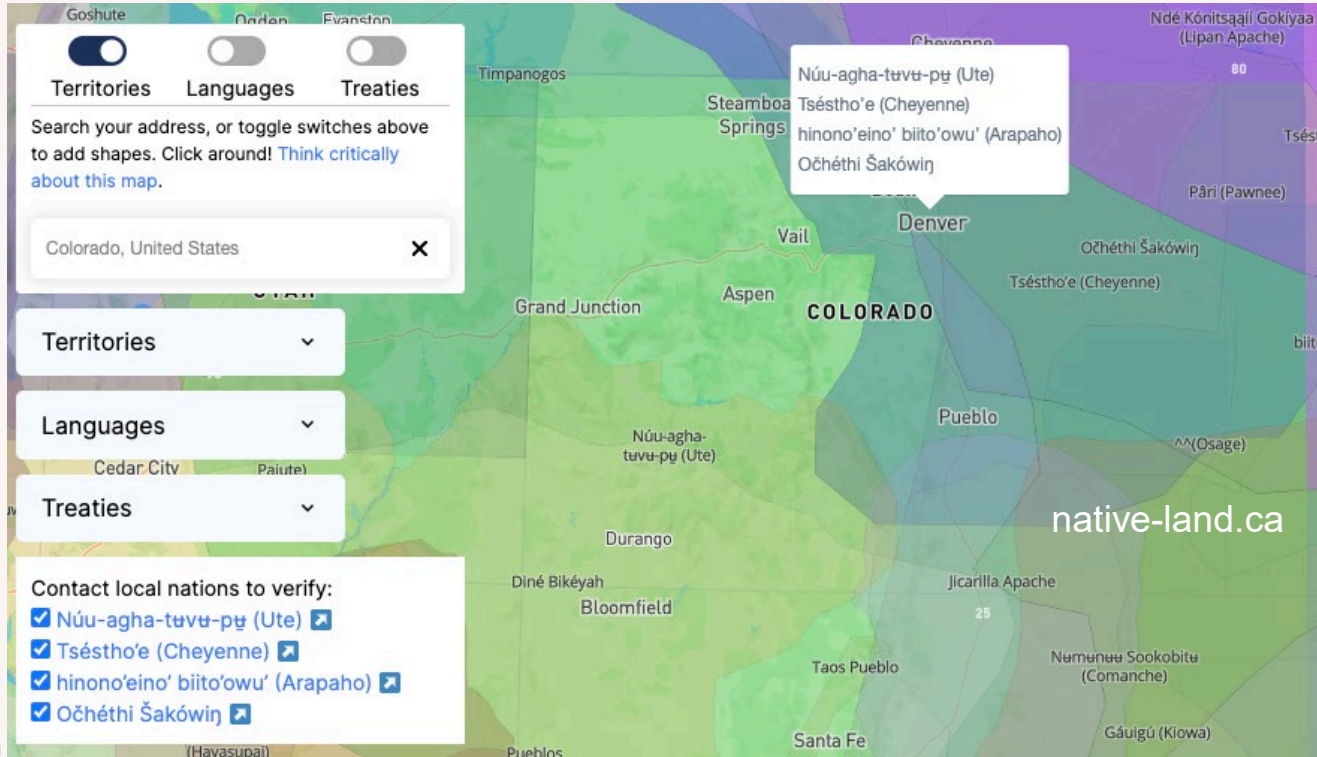## Federally Recognized Tribes in Colorado

- Southern Ute Tribe
- Ute Mountain Ute Tribe

CDC Race Category and Ethnicity Group

List of concepts present in CDC Race Category value set which is based upon OMB recommendations and list of concepts present in Ethnicity Group value set which is based upon OMB Race & Ethnicity.

FILE: 2022 RaceAndEthnicityFinal_TablesforPub_Final.xlsx - Race and Ethnicity Download File (Full Code System, relationships, and Hierarchy codes)

| Concept	Synonym	Race Category (Concept Name)
RACE		
AMERICAN INDIAN OR ALASKA NATIVE		Race
AMERICAN INDIAN		AMERICAN INDIAN OR ALASKA NATIVE
Abenaki Nation of Missisquoi		AMERICAN INDIAN OR ALASKA NATIVE
Absentee Shawnee Tribe of Indians of Oklahoma		AMERICAN INDIAN OR ALASKA NATIVE
Agua Caliente		AMERICAN INDIAN OR ALASKA NATIVE
Agua Caliente Band of Cahuilla Indians		AMERICAN INDIAN OR ALASKA NATIVE
Ak-Chin Indian Community		AMERICAN INDIAN OR ALASKA NATIVE
Alabama Creek		AMERICAN INDIAN OR ALASKA NATIVE
Alabama Quassarte Tribal Town		AMERICAN INDIAN OR ALASKA NATIVE
Alabama-Coushatta Tribe of Texas		AMERICAN INDIAN OR ALASKA NATIVE
Algonquian		AMERICAN INDIAN OR ALASKA NATIVE
Allegheny Lenape		AMERICAN INDIAN OR ALASKA NATIVE
Alpine		AMERICAN INDIAN OR ALASKA NATIVE
Alsea		AMERICAN INDIAN OR ALASKA NATIVE
Alturas Indian Rancheria		AMERICAN INDIAN OR ALASKA NATIVE
Ani-stohini/Unami		AMERICAN INDIAN OR ALASKA NATIVE
Apache		AMERICAN INDIAN OR ALASKA NATIVE
Apache Tribe of Oklahoma		AMERICAN INDIAN OR ALASKA NATIVE
Arapaho		AMERICAN INDIAN OR ALASKA NATIVE
Arapaho Tribe of the Wind River Reservation, Wyoming		AMERICAN INDIAN OR ALASKA NATIVE
Arikara (Sahnish)		AMERICAN INDIAN OR ALASKA NATIVE
Aroostook Band of Micmacs		AMERICAN INDIAN OR ALASKA NATIVE
Assiniboine		AMERICAN INDIAN OR ALASKA NATIVE
Assiniboine and Sioux Tribes of The Fort Peck Indian Res		AMERICAN INDIAN OR ALASKA NATIVE
Assonet Band of the Wampanoag Nation		AMERICAN INDIAN OR ALASKA NATIVE
Atakapa		AMERICAN INDIAN OR ALASKA NATIVE
Atsina		AMERICAN INDIAN OR ALASKA NATIVE

https://phinvads.cdc.gov/vads/SearchVocab.action

native-land.ca

Considerations for Data Collection

Design Question	Options	Considerations / Suggested Method
Who should collect the data?	• Registration staff • Medical assistant • Registered nurse	• Using registration staff has been proven to increase collection rates, although one study found patients preferred being asked in the exam room by nursing staff.[8] Providers should assess staffing levels and determine who is best suited to collect the data. • **Suggested: Registration staff**
When should the data be collected?	• At time of check-in • Over the phone • Pre-exam	• Collecting preferred language data over the phone when a patient is scheduling an appointment can help in planning for interpretation services. • **Suggested: At check-in or over the phone**
What format should be used to collect the data?	• Paper format • Electronic kiosks / tablets • Verbal discussion	• Paper forms, kiosks and tablets allow for patient privacy, although one study has shown that collection rates are highest when patients have the option to also report REAL data verbally.[9] • Paper forms, kiosks and tablets may pose a challenge for patients with limited literacy. • Kiosks or tablets will eliminate the need for staff to transcribe data into the electronic medical record. • **Suggested: Provide options for a more private form of entry (paper form, kiosk or tablet) as well as verbal discussion**

Source: American Hospital Association, 2013.

Different Ways to Ask Race and Ethnicity
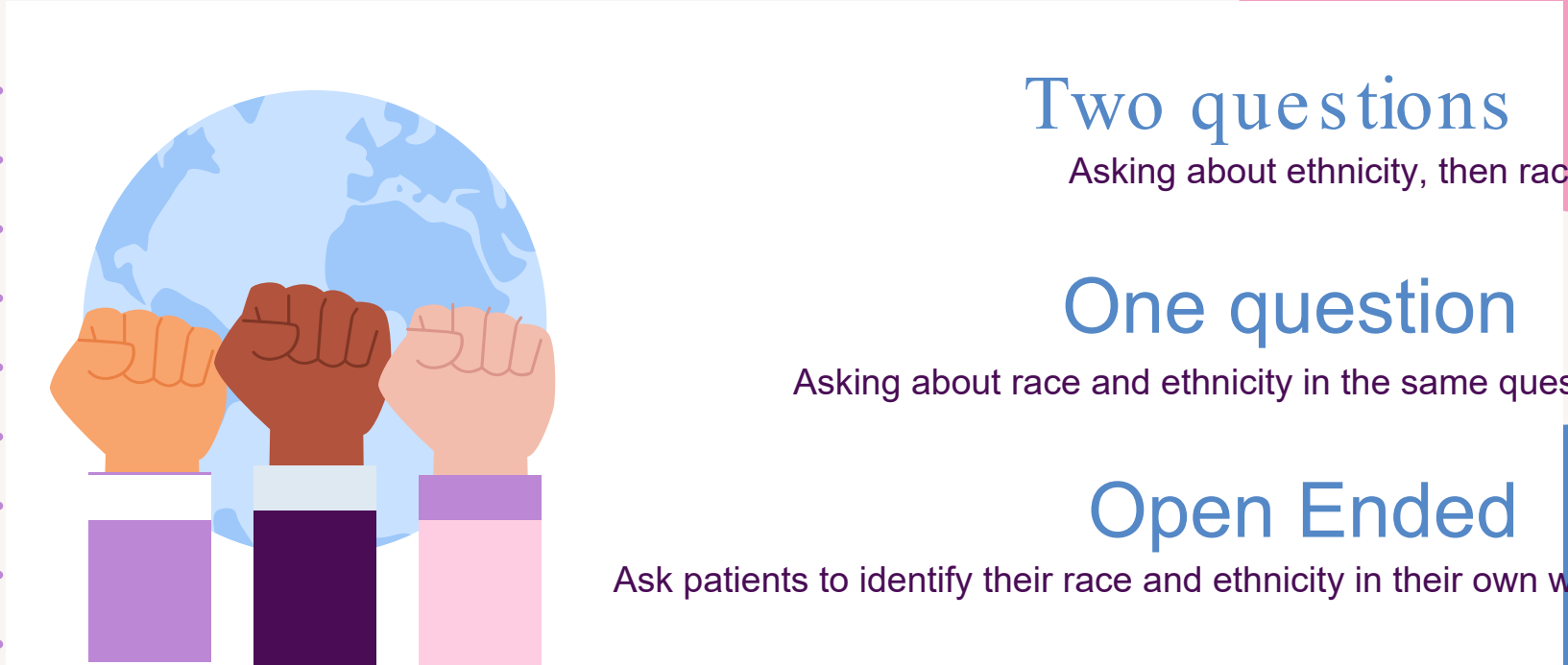
Two questions
Asking about ethnicity, then race

One question
Asking about race and ethnicity in the same question

Open Ended
Ask patients to identify their race and ethnicity in their own words

Different Ways to Ask Race and Ethnicity

Preferred!

Two questions
Asking about ethnicity, then race

One question
Asking about race and ethnicity in the same question

Open Ended
Ask patients to identify their race and ethnicity in their own words

Scripting – Introductory Statement

"In order to guarantee that all patients receive the highest quality of care and to ensure the best services possible, we are asking all patients about their race, ethnicity, and language."

- Tailor to your practice's uses, context, and experience
- Consider adding comment about confidentiality

Scripting – Ethnicity

"Are you Hispanic, Latino/a/x, or Spanish origin?"

- No
- Yes

OR

- No
- Yes, Mexican, Mexican American, Chicano/a
- Yes, Puerto Rican
- Yes, Cuban
- Yes, Another Hispanic, Latino/a/x or Spanish origin:_____

Scripting – Race

"Which category or categories best describe your race? (You may choose more than one."

- American Indian/Alaska Native
- Asian
- Black or African American
- Native Hawaiian/Other Pacific Islander
- White
- Some other race:_____
- Declined
- Unavailable/Unknown
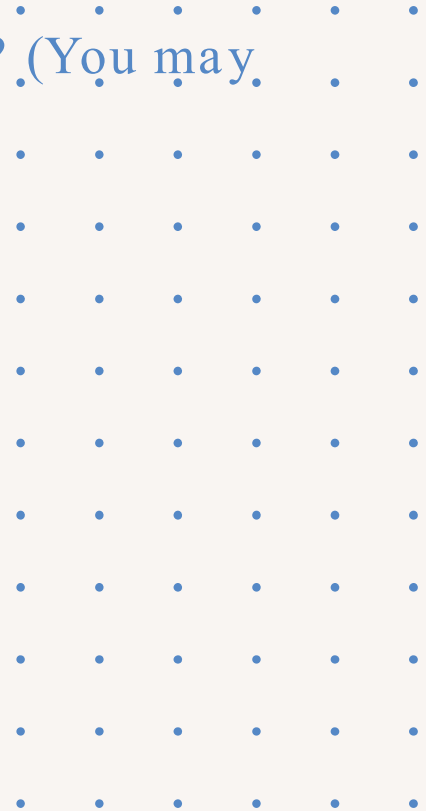
Responding to tough questions from patients

Patient Response	Suggested Response	Context (Historical, etc.)	Recommended Documentation
"I'm American"	Typically, we would classify this as your nationality. Is there another term to describe your ethnicity/race?	People may question the validity of racial identities. The grouping of race can be interpreted as divisive.	Respect their answer and refer to your data plan for classification.
"Can't you tell by looking at me?"	We think it's better to let people tell us. I don't want to put in the wrong answer. I'm trained to not make assumptions.	Never assume someone's identity.	This can be classified as unknown or did not answer. Refer to your data plan for classification.
"Why do you care? We're all human beings."	We are all human. However, our social identities (age, race, gender, abilities etc,) can impact health. With this information we can correctly set up a healthcare plan with resources relevant to your needs and our communities needs.	People may question the validity of racial identities. The grouping of race can be interpreted as divisive.	Respect their answer and refer to your data plan for classification
"I was born in Nigeria, but I've really lived here all my life. What should I say?"	*show choices* There is value in understanding how we classify race/ethnicity to ensure quality of care, however if these don't work for you, it is more valuable that you use the terms you prefer.	Our categories for race and ethnicity can't fully capture a patient's lived experiences. Self-identifying honors their experience.	Document how they chose to identify. Understanding groups of people that emigrated from other countries can be valuable to determining needs, describing, and stratifying your patient population
A patient returning for care with the "DECLINED" code	Respect their decision to decline.	Work on building trust, then utilize an annual visit to try again	Document that they declined.
A patient returning for care with the "UNKOWN" or "Unable to provide information" code.	Proceed to ask for the information per routine.	As we are constantly building trust with patients, they may be more willing to share their social identities.	Review your PDSA. Utilize a pre-specified periodic visit to try again

DO

Ask patients about their concerns/ comfort level (e.g. patient experience assessment)

Have a data plan! Consider how the data will be linked to clinical data and analyzed

Train and retrain staff on demographic scripts / PDSAs

Allow patients to select multiple races

Ask about demographic data periodically –racial and ethnic identity can change over time

Understand and disclose why this data will be useful to your clinic and staff

Asking About Language

How well do you speak English?
- Very well
- Well
- Not well
- Not at all

Would you like an interpreter?
- Yes
- No
- Declined
- Unavailable

What language do you feel most comfortable speaking with your doctor or nurse?

In which language would you feel most comfortable reading medical or healthcare instructions?

Provide a list of languages reflecting languages spoken in the practice's community

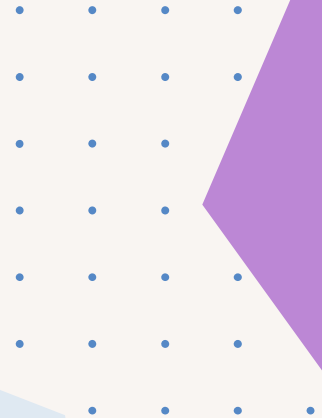# Resources

http://forces4quality.org/node/4185.html

Resources

More Resources

Flip the Script Collecting Race & Ethnicity Data

HHS Data Collection Standards

REAL Data Collection Script and Definition

HCUP Race and Ethnicity Data Improvement Toolkit (SCRIPTS)

References

Baker DW, Cameron KA, Feinglass J, et al. Patients' attitudes toward health care providers collecting information about their race and ethnicity. J Gen Intern Med. 2005;20(10):895-900.

Baker DW, Hasnain-Wynia R, Kandula NR, Thompson JA, Brown ER. Attitudes toward health care providers, collecting information about patients' race, ethnicity, and language. Med Care. 2007;45(11):1034-1042.

Hasnain-Wynia R, Van Dyke K, Youdelman M, et al. Barriers to collecting patient race, ethnicity, and primary language data in physician practices: an exploratory study. J Natl Med Assoc. 2010;102(9):769-775.

IOM (Institute of Medicine). 2009. Race, Ethnicity, and Language Data: Standardization for Health Care Quality Improvement. Washington, DC: The National Academies Press.

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Lu C, Ahmed R, Lamri A, Anand SS (2022) Use of race, ethnicity, and ancestry data in health research. PLOS Glob Public Health 2(9)

Samalik JM, Goldberg CS, Modi ZJ, et al. Discrepancies in Race and Ethnicity in the Electronic Health Record Compared to Self-report. J Racial Ethn Health Disparities. 2022;10.

PEDIATRIC PARTNERS
Glenwood Springs

Pediatric Partners at Valley View

- Glenwood Springs, CO
- EHR: Office Practicum
- Pediatricians: Dr. David Brooks, Dr. Ellen Brooks, Dr. Galka, Dr. Gardner, Dr. Loveless-Hoffman, Dr, Martin, Dr. Stevenson
- Active Patient Population: 5550

ISP Inclusivity and Equity Milestones

- IE1: Practice leadership incorporates health equity into quality improvement initiatives

  Action Item: Health equity is considered and included in practice AIM statements and goals

  Action Item: Health equity is considered and included in practice AIM statements and goals

- IE2: Practice develops and implements a process to routinely gather and update patient demographics information, including race, ethnicity, language and communication needs, sexual orientation and gender identity.

  Action Item: Practice identifies fields in Electronic Health Record (EHR) where patient demographics can be captured

  Action Item: Practice develops a standardized process to capture and/or update demographic data at each patient visit

- IE3: Practice includes consideration of patient demographics and health equity in quality improvement efforts.

  Action Item: Practice understands baseline capture rate of these patient demographics and uses that data to drive practice quality improvement work

  Action Item: Practice stratifies performance on clinical quality measures by collected patient demographics to identify disparate outcomes if they exist

- IE9: The practice identifies and addresses equity issues impacting patient access to care including telehealth services

  Action Items: Practice undertakes a comprehensive, critical examination of policies to identify clinic policies and procedures that create avoidable barriers to care

Interpretive Services Review

- Valley View switched to a new interpretive services provider hospital wide

- Clinic has a large bilingual staff (Front desk, MA and biller). Providers can use this staff (and prefer to) when working with Spanish speaking families

- Behavioral Health clinician uses interpretive services daily when working with patients. This includes telephone conversations (via conference calls) and using the iPad for services during in person visits.

- Can we add a discreet field to document when translation services are used? Either in house or using the app

- We receive a monthly minutes used report from translation services - could we get a more detailed report from them to review?

Resources and Communications available in Spanish

- What communications are sent to patients who are due or overdue for Well Child Checks?

- Are we collecting data from the patient regarding preferred language?

- What are the practices current WCC rates?

- Are due or overdue WCC different for English speaking patient's vs Spanish speaking patients?

- Does preferred language affect no show rates?

Baseline Data and Tasks to complete prior to testing October 2022
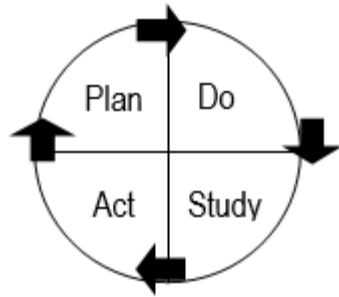
- Translate reminders scripts into Spanish
- Pull preferred language reports monthly
- Send reminders in patient's preferred language
- Unknown sent in English

	English Language Preference	Spanish Language Preference	Unknown/ Not Answered
Active Patients	3877	1161	321
Due for Preventative Visit	1222 31%	407 35%	124 38%
No Show Rate (July total 60)	45	15	

Project Aim
PDSA Cycle 1

Our aim is to decrease the percentage of patients past due for Wellness Visit-Targeting Spanish speaking population in the next year

PLAN:

Briefly describe the test: We will continue to send monthly recalls to patients via text/email/mail we will now send them in **patient's preferred language**. We pulled baseline data and found that a greater % of Spanish speaking patients were due for their WCC. We hope by sending recalls in patient's preferred language this will decrease. We will re-measure data quarterly. We hope to decrease this % from 35% to 33% in the first quarter.

How will you know that the change is an improvement? There will be a decrease in the % of WCC past due.

What do you predict will happen? More patients will come to their recommended preventative visits.

PLAN

List the tasks necessary to complete this test (what)	Person responsible (who)	When	Where
1. Have recall documents/no show letters translated to Spanish	KatieBeth	Oct 1st	Office
2. Upload Translated letters into OP	Ellen/Katie Beth	Oct 10th	Office
3. Run monthly recalls around 15th of each month-recalls (text/email/letter) will be sent in preferred language	KatieBeth/Admin	Oct 15th	Office
4. Pull quarterly data	Ellen	Jan 15th	Office
5.			

Plan for collection of data: We will pull data quarterly.
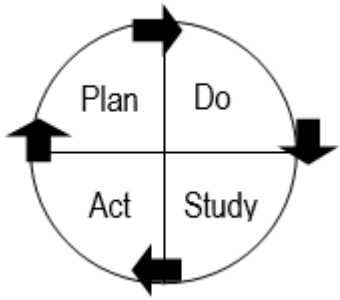
PDSA Cycle 1 Data
January 2023

	English Language Preference	Spanish Language Preference	Unknown/ Not Answered
Active Patients	3969	1266	401
Due for Preventative Visit	1414 35.6%	490 38.7%	168 41.8%

Project Aim
PDSA Cycle 1

Our aim is to decrease the percentage of patients past due for Wellness Visit-Targeting Spanish speaking population in the next year

DO: Test the changes.

Was the cycle carried out as planned? ■ Yes □ No

Record data and observations.
That data from Q1 showed a slight increase in patients due for WCC in all 'preferred language' categories (English, Spanish/Other, Unknown). English due for WCC increased from 31% to 35.6%, Spanish due for WCC increased from 35% to 38.7% and Unknown due for WCC increased from 38% to 41.8%. The total overall patient population also increased…

What did you observe that was not part of our plan?
During the months of October-January the practice had to reduce availability of WCC openings on our schedule to accommodate the influx of patients being seen during RSV/flu season. We had predicted that the rate due for WCC would decrease, however it increased, and we feel this is due to reduced schedule availability for WCCs.

STUDY:
Did the results match your predictions? □ Yes ■ No

Compare the result of your test to your previous performance:

What did you learn?
ACT: Decide to Adopt, Adapt, or Abandon.

| X | Adapt: Improve the change and continue testing plan. Plans/changes for next test: Provide training to registration staff to collect preferred language for all patients that do not currently have designation/ensure all new patients have preferred language field populated in chart. |

| | Adopt: Select changes to implement on a larger scale and develop an implementation plan and plan for sustainability |

| | Abandon: Discard this change idea and try a different one |

PDSA Cycle 2
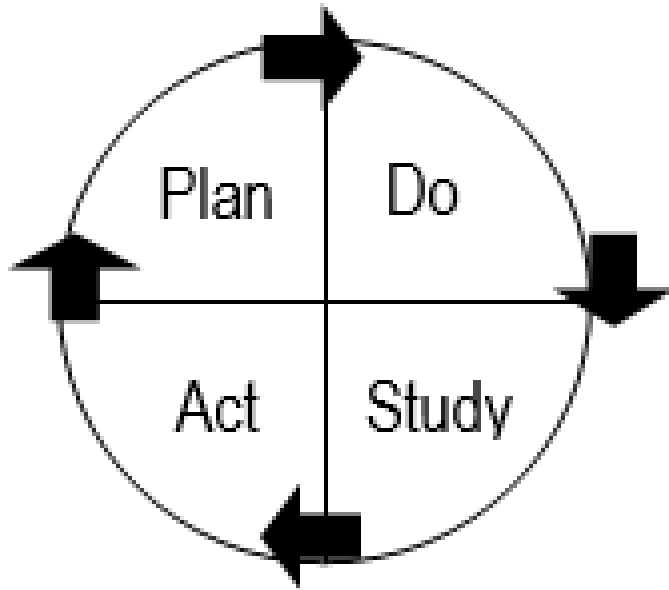
Testing Cycle:

2/1/23-5/1/23

PLAN:

Briefly describe the test: Provide training to registration staff to collect preferred language for all patients that do not currently have designation/ensure all new patients have preferred language field populated in chart. Designate a preferred language for all patients who have Unknown listed as language.

How will you know that the change is an improvement? There will be a decrease in the % of WCC past due.

What do you predict will happen? With more availability of WCC openings, and a more accurate depiction of patient's preferred language due to better staff training, we will begin to see more patients come to their recommended preventative visits.

PLAN

List the tasks necessary to complete this test (what)	Person responsible (who)	When	Where
1. Run report of 'unknown' language preference, review what language demographics were completed in. Make preferred language selection in patient's chart. Begin sending recalls in preferred language.	Ellen	2/15/23	Office
2. Provide training for registration staff to collect preferred language and document in patient chart	Ellen	2/15/23	Office
3.			

Plan for collection of data: Collect Data for Q2

Conclusions

Look at the quantitative data

- What is the practice's demographic make-up?

- Do you have a workflow to collect patient demographic information including race, ethnicity and preferred language?

- Are you collecting data on language preference? Can it be documented in a structured data field?

- Use of interpretive services data collection. Are these services captured in a structured data field that can be analyzed?

Examine Current State

- Patient resources available in languages other than English

- Is the website accessible for patients who do not speak English?

- Do patients use the patient portal? If so, can they receive information in their preferred language?

- Are you sending patient reminders or communications from your EMR via text or email? If so, are they translated into patient's preferred language?

Start planning a small test of change to implement into your practice