

Closing Disability Disparities: *EHR Data as First Step*

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Data Class	Goal	Use	Who Completes
Disability Status	<ol style="list-style-type: none"> 1. Identify and address care inequities and improve care outcome 2. Examine role of SDoH on care 3. Identify patients who require healthcare accommodations 	Demographic/ Social	Patient reported
Functional Status	<ol style="list-style-type: none"> 1. Care planning 2. Clinical assessments 3. Connecting to medical, social or educational services 	Medical	Patient reported or clinical assessment
Mental Status	<ol style="list-style-type: none"> 1. Care planning 2. Clinical assessments 3. Connecting to medical, social or educational services 	Medical	Patient reported or clinical assessment

1 in 4
Have a
Disability



Significant Health and Healthcare Disparities



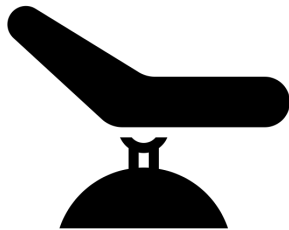
2.7x



3x



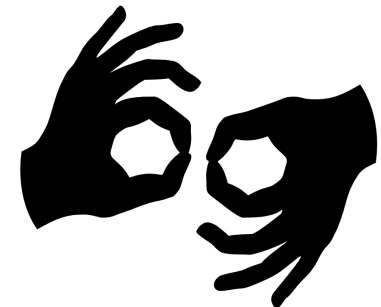
6x




54% v. 83%



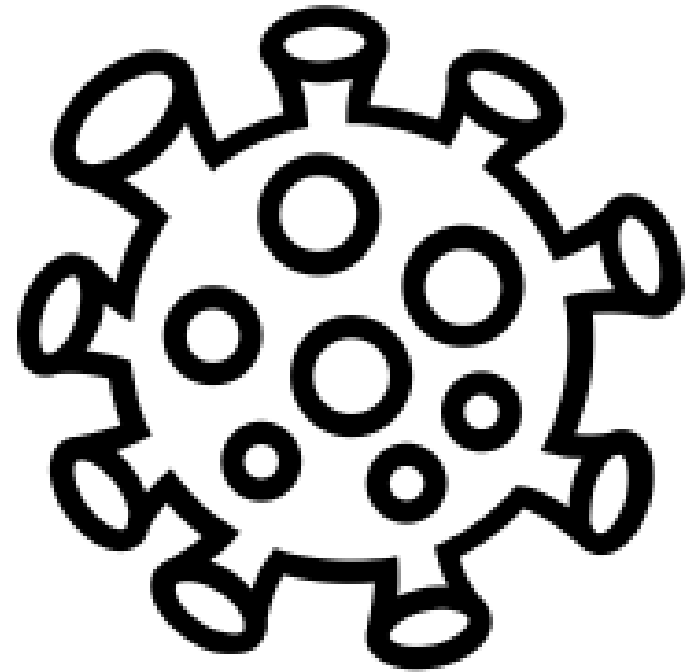
1 in 3



3x



Disability Data Gaps Limit the COVID-19 Response



EHR data is needed to track COVID-19 infection, vaccination, outcomes, and care/equipment allocation

We can't
improve
what we
don't
measure

Data needs:

Quality of health and
healthcare

Effects of equity
interventions

Provision of disability
accommodations



Documenting Disability Status in EHR

Patients are
supportive

Legal requirement

Identified as top
research and policy
priority

Health systems
struggling to implement

ACS and Washington Group Questions

1. Are you deaf or do you have serious difficulty hearing?
2. Are you blind or do you have difficulty seeing, even when wearing glasses?
3. Do you have serious difficulty walking or climbing stairs?
4. Do you have difficulty concentrating, remembering, or making decisions?
5. Do you have difficulty dressing or bathing?
6. Do you have difficulty doing errands alone such as visiting a doctor's office or shopping?
7. Using your usual language, do you have difficulty communicating (for example, understanding or being understood)?



Recommended Future Question Categories



1. Learning Disability

- a) Do you have serious difficulty learning how to do things most people your age can learn?



2. Mental Health Disability

- a) Do you have serious difficulty with the following: mood, intense feelings, controlling your behavior, or experiencing delusions or hallucinations?



3. Autism/Social Disability



4. Health Care Accommodations

5. Caregiver

1. Caregiver's disability
2. Caregiver regularly attend appointment with patient



No Perfect Disability Questions

Disability is a socially
constructed concept

Not everyone with an
impairment will identify as
having a disability

Language changes over time

*Despite challenges, people
with disability cannot wait
any longer*

Reasons for Urgency

- COVID-19 & Public Health Emergencies: lack of disability information negatively impacted access to PPE, vaccination prioritization, critical support persons, and the ability to recover health
- Lack of disability demographic ID means less funding, less understanding, less inclusion, and greater stereotypes
- Health Equity and SDoH discussions happening **now**
- Lawmakers, policymakers and lawyers need facts and evidence of disparities
- Non-white racial/ethnic and other populations need to know how their disabled members experience discrimination and health/healthcare disparities
- Prepares the way for documenting accommodations and providing higher quality care

Recommended Action Steps

#1

Include Washington Group and ACS disability questions in EHR (demographic)

#2

Ensure a patient-reported data collection approach is used

#3

Recognize this is first step. Future efforts should focus on accommodations

#4

Support use of disability data to improve clinical care and address healthcare inequities

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Appendix

Benefits of the Washington Group and ACS Questions

Standard across other public health surveys
(e.g., CDC surveys)

Culturally and linguistically tested

Pilot tested in large health system with no
patient complaints

Coded in LOINC

Disability	American Community Survey (ACS) Disability Questions	Washington Group (WG) Disability Questions
Hearing	Are you <u>deaf</u> or do you have serious <u>difficulty hearing</u> ?	Do you have <u>difficulty hearing</u> even if using a hearing aid?
Seeing	Are you <u>blind</u> or do you have <u>difficulty seeing</u> , even when wearing glasses?	Do you have <u>difficulty seeing</u> , even if wearing glasses?
Mobility	Do you have serious <u>difficulty walking or climbing stairs</u> ?	Do you have <u>difficulty walking or climbing stairs</u> ?
Cognitive	Do you have <u>difficulty concentrating, remembering, or making decisions</u> ?	Do you have <u>difficulty remembering, or concentrating</u> ?
Self-Care	Do you have <u>difficulty dressing or bathing</u> ?	Do you have <u>difficulty with self-care such as washing or dressing</u> ?
Independent Living	Do you have difficulty doing <u>errands alone</u> such as visiting a doctor's office or shopping?	N/A
Communication	N/A	Using your usual language, do you have <u>difficulty communicating</u> , for example, understanding or being understood?

Disability**Survey
Source****Hybrid Approach - Oregon System**

<https://secure.sos.state.or.us/oard/displayDivisionRules.action?selectedDivision=4206>

Hearing

ACS

Are you deaf or do you have serious difficulty hearing?

Seeing

ACS

Are you blind or do you have difficulty seeing, even when wearing glasses?

Mobility

ACS

Do you have serious difficulty walking or climbing stairs?

Cognitive

ACS

Because of a physical, mental, or emotional condition, do you have serious difficulty concentrating, remembering, or making decisions?"

Self-Care

ACS

Do you have difficulty dressing or bathing?Independent
Living

ACS

Because of a physical, mental, or emotional condition, do you have difficulty doing errands alone such as visiting a doctor's office or shopping?Communicatio
n

WG

Using your usual language, do you have serious difficulty communicating, (for example understanding or being understood by others)?

Learning

Additional
domainDo you have serious difficulty learning how to do things most people your age can learn?

Psychological

Additional
domainDo you have serious difficulty with the following: mood, intense feelings, controlling your behavior, or experiencing delusions or hallucinations?

88% of ALL
patients
believe collection
of disability
status is
important

1,894 patients
asked disability
questions during
registration

ZERO
complaints

Disability status is rarely collected or documented

EHR

Patients' disability status rarely collected



Patient experience surveys

Seldom captures disability



Big Data (e.g., Claims data)

~70% miss disability diagnosis

ICD-10
XXX.XX

Opportunities



We know which questions to ask



Patients are okay disclosing disability status



We can integrate collection with other demographic characteristics