### Representation and Rules

2022 Retirement and Disability Research Consortium (RDRC) Keynote

Marcella Alsan (Harvard and NBER)

August 5, 2022



## Representation matters

- ▶ Representation (e.g., accurate description) in surveys and census data matters because these underlie
  - ► Forecasting (simulations) and retrospective (applied micro) work on policy impact
  - ▶ Allocation of resources (e.g., funds, congressional seats etc.)
  - ▶ Surveillance of health and other issues

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  - ► Forecasting (simulations) and retrospective (applied micro) work on policy impact
  - ▶ Allocation of resources (e.g., funds, congressional seats etc.)
  - Surveillance of health and other issues
- ▶ Representation (e.g., participation) matters because it can affect (perceptions of) legitimacy of the outcome of that process
  - ▶ Legitimacy whether the procedure used was deemed appropriate
  - ► We apply to health

# \*\* The Upshot \*\*\* The Upshot

#### 2020 Census Undercounted Hispanic, Black and Native American Residents

The Census Bureau said that the overall population total was accurate but that counts of minorities were skewed. Advocacy groups threatened to go to court.

## The Missing Statistics of Criminal Justice

An abundance of data has fueled the reform movement, but from prisons to prosecutors, crucial questions remain unquantified.

By Matt Ford

#### Cities risk losing out on trillions in federal aid as census deadline looms

County officials

**POLITICO** 

Local leaders fear federal aid cuts as the pandemic, a shortened timeline and Trump's anti-insmigration rhetoric complicate the national

As coronavirus deaths surge, missing racial data worry L.A.

Recent violence against Asian Americans highlights need for better tracking, reporting

Hate crime data don't capture the full scope of racist incidents against Asian Americans, experts say, so nonprofit groups have been filling the gaps.

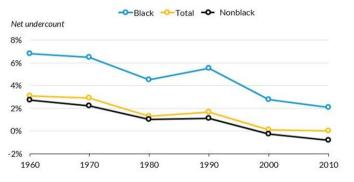
SOCIAL ISSUES

Will Americans be able to trust the results of the 2020 Census?



## Historically, the Census has Disproportionately Undercounted the Black Population

Demographic analysis of net undercount, 1960-2010



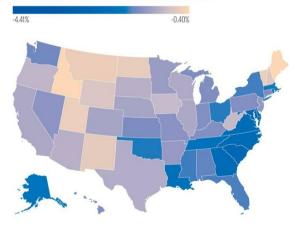
Source: J. Gregory Robinson, Coverage of Population in Census 2000 Based on Demographic Analysis: The History Behind the Numbers (Washington, DC: US Census Bureau, 2010). Note: A negative percentage represents an overcount.

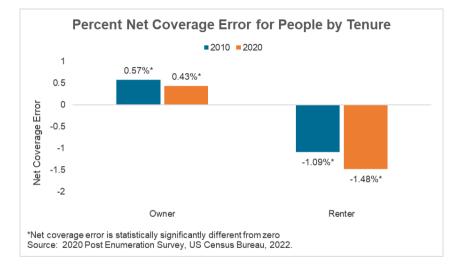
**URBAN INSTITUTE** 

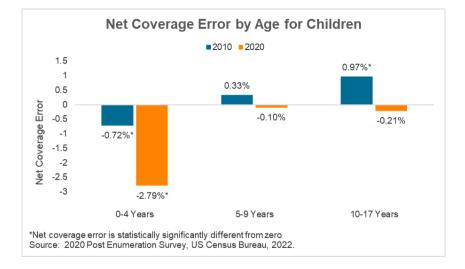
#### Where the Black population count was lower than the estimates

The share of the Black population in the 2020 count came in below the agency's own estimates for some states with the largest Black presence.

#### Percentage point difference between estimated and actual counts







## Percent net coverage error by race and Hispanic origin

2010 and 2020 over-counts by race ACS coverage rate

ACS response rate

	2010	2020
	(1)	(2)
Total	0.01	-0.24
Non-Hispanic White	0.83*	1.64*
Black or African American	-2.06*	-3.30*
Asian	0	2.62*
American Indian or Alaska Native, Overall	-0.15*	-0.91*
American Indian or Alaska Native, on Reservation	-4.88*	-5.64*
Native Hawaiian or Other Pacific Islander	-1.02*	1.28*
Some Other Race	-1.63*	-4.34*
Hispanic or Latino	-1.54*	-4.99*

Notes: \*Net coverage error is statistically significantly different from zero.

Data: Tennessee State Data Center, (2022).

## Why **census** representation matters

- ▶ Census data undercounting affects accuracy of other survey datasets
  - ▶ Other surveys often rely on census sampling or weight respondents based on census counts (Survey of Income and Program participation, General Social Survey, Current Population Survey)

## Why <u>census</u> representation matters

- ► Census data undercounting affects accuracy of other survey datasets
  - ▶ Other surveys often rely on census sampling or weight respondents based on census counts (Survey of Income and Program participation, General Social Survey, Current Population Survey)
- Researchers depend on survey-based datasets to understand equity implications of policies and programs
  - ▶ After SSA discontinued publication of race and ethnicity, researchers interested in Social Security disparities link to surveys to obtain these variables

#### A view from Minnesota food shelves

#### The State of Minnesota wants to know how COVID-19 is affecting you.

The State of Minnesota is conducting a survey to better understand how the COVID-19 pandemic is affecting the Twin Cities area and what the barriers to care are in your community

#### You May Qualify if You

- . Am 18 years oroider . Speak English or Spanish
- . Have access to a phone or computer to take the survey

#### Participation by oben

. Completing an online survey that will take approximately 15 minutes

#### Potential Bonefits

- . Participating in this survey may help improve access to COVID-19 testing in your community
- . Participants will be compensated with a \$10 dollar gift gard for their time

- To take the survey, please visit the following link and enter the passcode below:
- Liek: minne sota myldsurvey.com (Please note that the survey link expires in 4 days.) Passonder (nassonde)

We have to have from members of your community. You can uses this floor about to family and friends.

This survey short is a partnership between measurehers at Hancard University the Mannach undit health to of Technology, MIT). the State of Mirra rote, and local community based proprietions. All appears to the survey are confidential and will kept on secure servers at Harvard. Personal data will not be shared.

#### FOR MORE INFORMATION Please contact covidmostudy@gmail.com

Panel A: Government Low-Incentive Flyer

#### How is COVID-19 affecting you? Share your experience.

A amun of academic researchers from Harvard University is conducting a survey to better understand how the COVID-19 pandemic is affecting the Twin Cities area and what the barriers to care are in your community

#### You May Qualify if You

- . Are 18 years or older
- Speak English or Spanish . Have access to a phone or computer to take the survey
- . You have not previously taken the survey.

#### Participation Involves

. Completing an online survey that will take approximately 15 minutes

. Partidpants will be compensated with a \$20 dollar gift card for their time . Companiation will be sent through text message to the participant's cell phone.

#### Take the Survey:

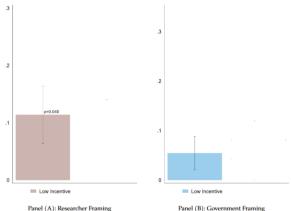
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#### FOR MORE INFORMATION Disease contact covidens shall offer all com-

Panel B: Researcher High-Incentive Flyer Source: Alsan, Avers, Baneriee, Breza, Chandrasekhar, Duflo, Goldsmith-Pinkham, Kim, Merrick, Olken, Shankar

## Response rates to intervention



#### Figure 1: Treatment effects of Unit Non-Response Intervention

Notes: Figure shows the treatment effects of unit non-response interventions on survey initiation. The data are at the foodshelf-date level and exclude repeat takers. Bar represents the average level of survey initiation, which is calculated as the fraction of survey initiation out of the total number of flyers distributed. The numerator is the number of respondents who started the survey with a given floor type. The denominator is the number of floors distributed on a given foodshelf-date. p-values show statistical significance of the effect of each treatment against the government framing with low incentives treatment (light blue), 95% confidence intervals are shown in gray.

Source: Alsan, Avers, Baneriee, Breza, Chandrasekhar, Duflo, Goldsmith-Pinkham, Kim, Merrick, Olken, Shankar

## Response rates to intervention

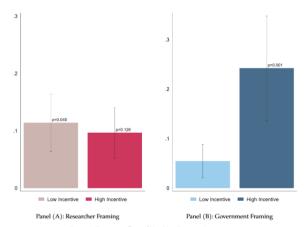


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Source: Alsan, Ayers, Banerjee, Breza, Chandrasekhar, Duflo, Goldsmith-Pinkham, Kim, Merrick, Olken, Shankar

## Census participation rates in field and online surveys

Census self-response by state

	MN Field Survey		Online Qualtrics Panel			
	Overall	Black	White	Overall	Black	White
	(1)	(2)	(3)	(4)	(5)	(6)
Never Filled out Census	41.8%	50.0%	31.8%	34.2%	36.2%	32.2%
$\Delta$ Black and White Respondents			18.2%			4.0%
Never Filled out Major Survey $\Delta$ Black and White Respondents	39.5%	48.0%	31.1% 16.9%	x	x	x x

Data: Alsan, Ayers, Banerjee, Breza, Chandrasekhar, Duflo, Goldsmith-Pinkham, Kim, Merrick, Olken, Shankar; Alsan & Eichmeyer

## Proprietary health data























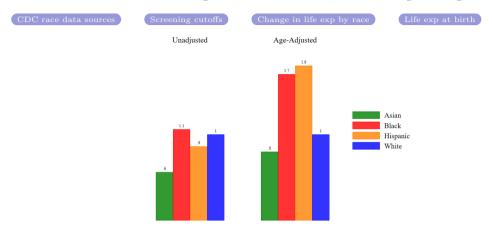


#### Public health data

- ► Medicare
  - ▶ Older patient population
  - ▶ Medicare Advantage insurers enter and exit, change products
- ► Veterans Affairs or Tricare
  - ► Predominately male
  - ▶ VA: selected on vet status (and seeking care at VA)
- ► National Vital Statistics System
  - ▶ Death reporting, also decentralized
    - ► Coroners (elected) vs. medical examiner system differential reporting
    - Varying lag times in reporting rates (stop payments related to death records)

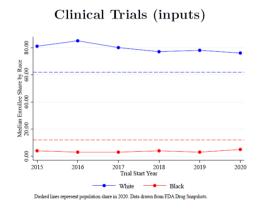
Death certificates

## COVID-19 rate ratios compared to White, Non-Hispanic persons

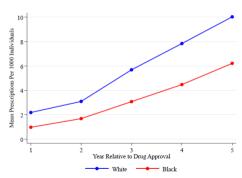


Data: CDC, (2022). I Data reported by state and territorial jurisdictions (accessed July 20, 2022). Numbers are ratios of age-adjusted rates standardized to the 2019 U.S. intercensal population estimate. Calculations use only the 66% of case reports that have race and ethnicity; this can result in inaccurate estimates... 2 Data source: COVID-NET (March 1, 2020 through July 9, 2022). Numbers are ratios of age-adjusted rates standardized to the 2020 US standard COVID-NET catchment population. Starting the week ending 12/4/2021, Maryland temporarily halted data transmission of COVID-19 associated hospitalizations...Hospitalization rates are likely underestimated. 3 Data Source: National Center for Health Statistics provisional death counts. Numbers are ratios of age-adjusted rates standardized to the 2019 U.S. intercensal population estimate.

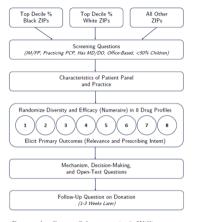
# Representation and legitimacy: evidence from clinical trials Medical innovation and prescription inequality



#### Prescriptions (outputs)



#### Physician Experiment

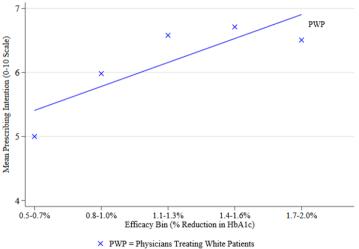


Alsan, Durvasula, Gupta, Schwartzstein & Williams

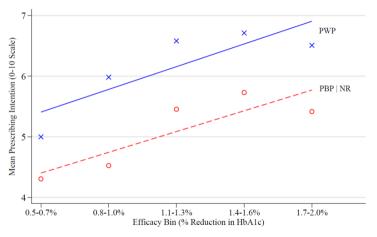
#### Patient Experiment



## Physician prescribing intent by patient panel and trial representation

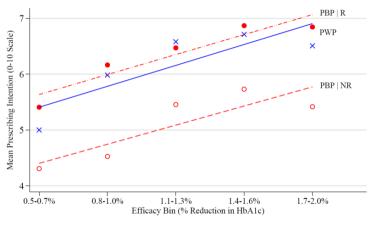


## Physician prescribing intent by patient panel and trial representation



- × PWP = Physicians Treating White Patients
- O PBP | NR = Physicians Treating Black Patients (Non-Representative Trial)

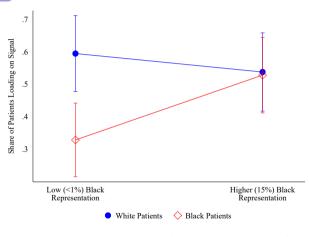
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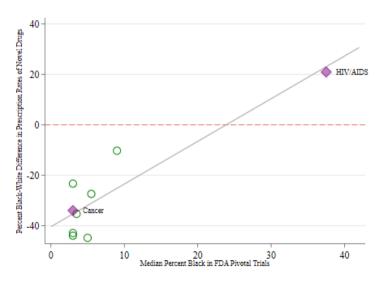
- × PWP = Physicians Treating White Patients
- O PBP | NR = Physicians Treating Black Patients (Non-Representative Trial)
- PBP | R = Physicians Treating Black Patients (Representative Trial)

## Patient updating on efficacy by trial representation





## Prescribing gaps and representation gaps





## Rules - OASDI (Old Age, Survivors, and Disability Insurance)

Insurance Program	Eligibility Criteria (Rules)	Potential Equity Impact
OASDI	Historically excluded agricul- tural and domestic workers	Excluded $1/2$ of Black Americans in the labor force and $3/5$ of Black southern workers
	Minimum age of 62	Disadvantages retirement benefits for Black Americans and low-income individuals, as well as others who have lower life expectan- cies
	Benefits tied to earnings	Higher-earners may gain more in benefits. Progressive formula may redistribute
	Work credit requirement	Excludes people who are primarily in uncom- pensated care-taking roles or leave the work- force for care-taking roles
	10-year min for marriage-based benefits	May disqualify individuals with marriage in- stability, late entry into marriage, or historical exclusion from legal marriage
	Not incarcerated	Disqualifies people in prisons, jails, halfway houses

# Rules – SSDI (Social Security Disability Insurance) and SSI (Supplemental Security Income)

Insurance Program	Eligibility Criteria (Rules)	Potential Equity Impact	
SSDI	Definition of disability	Requires health literacy and access to medical care and examiner; standards of disability may be gendered	
	Work credit requirement	Excludes people in care-taking roles	
	Marriage	Disabled Adult Children (DAC) lose benefits once married	
	Not incarcerated	Disqualifies people in prisons, jails, halfway houses	
SSI	Definition of disability	Requires health literacy and access to medi- cal care and examiner; standards of disability may be gendered	
	Limited income / resources	Limits income and resources to \$2000 for individuals and \$3000 for couples, which reduces or eliminates benefits for married couples	
	Not incarcerated	Disqualifies people in prisons, jails, halfway houses	

## Concluding thoughts



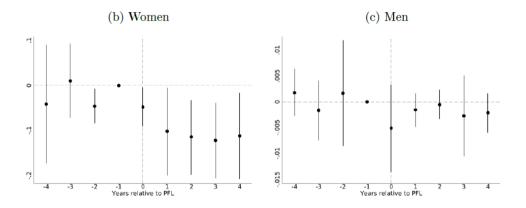
## Concluding thoughts



- ▶ Better representation can change the rules. Rules can change who gets represented.
- ▶ **Data:** Where do data come from? How were the data collected? Who is missing?
- ▶ **Rules**: When were rules created? How do the they impact inequality (specifically, are they making things worse)?

## Evidence paid family leave mitigates family health shocks

Benefit of Federalist system – lessons from states making rules that may not worsen inequality.



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Source: Coile, Rossin-Slater, Su

Thank you!





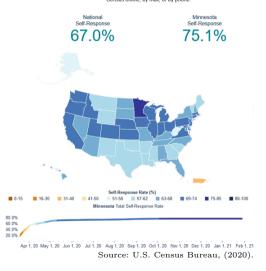






#### 2020 Census Self-Response by State

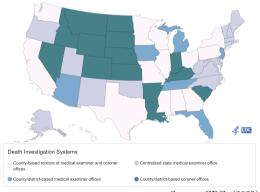
This map features self-response rates from households that responded to the 2020 Census online, by mail, or by phone.

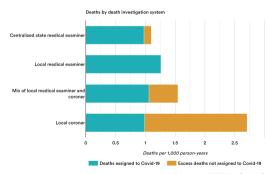


#### Death certificates

#### Back

- ► Coroners: usually elected laypersons, can be partisan
- ▶ Medical Examiners: appointed physicians with specialized training in death investigation



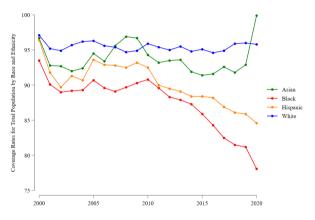


Source: CDC, (2022).

Source: STAT, (2021).

# ACS coverage rates by race and ethnicity over time



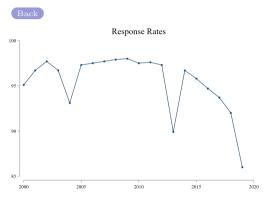


Population Coverage rate for group A (state x, year y) is defined by:

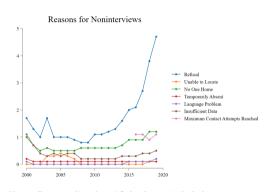
uncontrolled ACS estimate of total persons for group A for state x in year y official estimate of total persons for group A for state x in year y

Data: U.S. Census Bureau, (2020). 2000-2020 ACS Coverage Rates.

# ACS response rates and reasons for noninterviews (in percent) — housing units



Notes: Response rates for year 2020 (71.2%) not included.

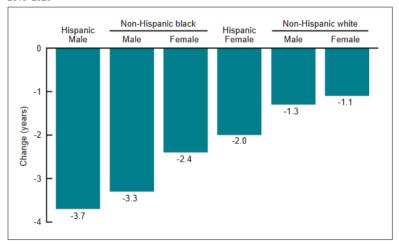


Notes: Reasons listed as "Other" not included.

# Change in life expectancy by race



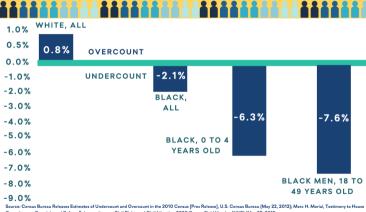
Figure 4. Change in life expectancy at birth, by Hispanic origin and race and sex: United States, 2019–2020



NOTES: Life expectancies for 2019 by Hispanic origin and race are not final estimates; see Technical Notes. Estimates are based on provisional data for 2020. Provisional data are subject to change as additional data are received.







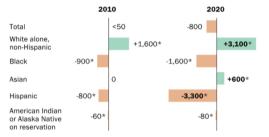
Committee on Oversight and Reform Subcommittee on Civil Rights and Civil Liberties, 2020 Census Field Hearing (NYC) (May 28, 2019

Source: Thurgood Marshall Institute, (2020).



# Overcounts and undercounts for racial and Hispanic groups generally grew in 2020

Net overcount or undercount, in thousands



<sup>\*</sup> Error is statistically significant.

Notes: Positive numbers indicate overcounts; negative numbers indicate undercounts. **Bold** numbers indicate a statistically significant change from 2010. Black, Asian and American Indian or Alaska Native include those groups alone or in combination (including Hispanics and non-Hispanics).

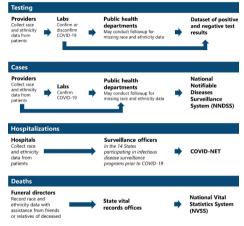
Source: Pew Research Center estimates based on U.S. Census Bureau Post-Enumeration Surveys and P.L. 94-171 census counts by race and Hispanic origin.

#### PEW RESEARCH CENTER

Source: PEW, (2022).

Back

Exhibit 1: CDC collects racial and ethnic data for COVID-19 testing, cases, hospitalizations, and deaths from providers and public health departments.



Note: This exhibit represents racial and ethnic data on COVID-19 hospitalizations that CDC obtains through COVID-NET reporting. CDC's additional sources of COVID-19 hospitalizations data, such as the National Syndromic Surveillance Program and the Premier Healthcare Database may also contain racial and ethnic data.

Source: Office of Inspector General (OIG) review of CDC and GAO documents, 2021.

Source: U.S. Department of Health and Human Services, (2022).



# Screening Some Sooner May Reduce Racial and Ethnic Disparities in Diabetes Diagnosis, Researchers Show

Written by: Jacqueline Mitchell | Contact: Chloe Meck, cmeck@bilh.org
MAY 10, 2022

Share



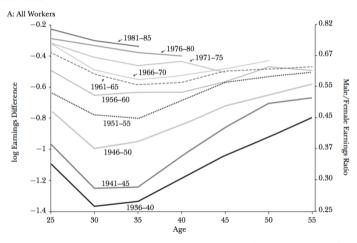
# Asian, Hispanic and Black Americans are at increased risk for diabetes at lower weights and younger ages than white Americans

BOSTOM: Diabetes is a leading cause of death and diabetlity in the United States, affecting more than 34 million adults and generating \$330 billion in annual healthcare expenditures. Excess body weight is one risk factor that increases one's odds of developing diabetes, and federal guidelines recommend stating screening at age 35 for all overweight adults – defined as those who have a body mass index (BMM of 25 or higher).

However, Asian, Hispanica, and Black Americans are all increased risk for disbettes at lower weights and younger ages than white Americans. In a new study published in the Amissi of Internal Medicine, a team of physician-scientists at the Smith Center for Outcomes Research in Cardology at Bith Instell Deaconess Medical Center (BIDMO) pooply to reduce racial and ethnic disparities in disbetted diagnosis. The team used statistican modeling to determine the BMI stever and age at which the prevalence of disabetes in racial and ethnic minority populations in the United States is equivalent to the prevalence of disabetes in which the minority populations in the United States is equivalent to the prevalence of disabetes in racial and ethnic misority populations in the United States is equivalent to the prevalence of disabetes in racial and ethnic misority populations of disabetes and age at the prevalence of disabetes in the experiment of the prevalence of disabetes in racial and ethnic misority of the prevalence of disabetes in the experiment of the preval

"The simplicity of a single screening threshold for all Americans is alturing, but it is deeply inequilable," and since arized from Lax IM. DM.Sc., Mis. associate director or the Smith Center and associatel professor of medicine at Harvard Medical School. "Our findings suggest that Asian, Hispanic, and Black Americans may need to get screened at lower BMI or younger ages than white Americans. If the current thresholds are universally applied, without accounting for differential risk in racial/defining groups, clinicians may underdiagnose diabetes in Asian, Hispanic, and Black Americans. On the other hand, applying a more tailored approach may allow refusor rates or the control of the con

# Age Profiles of Female/Male Earnings Ratios across Five-Year Birth Cohorts, Born $1936{-}1985$



Source: Juhn et al. (2017)

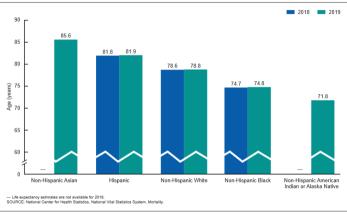
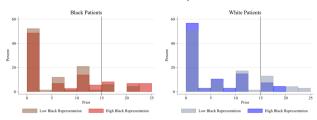
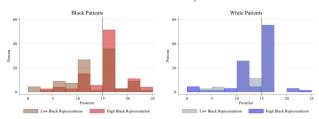


Figure 2. Life expectancy at birth, by Hispanic origin and race: United States, 2018 and 2019

Panel A. Prior Beliefs



Panel B. Posterior Beliefs



Source: Alsan, Durvasula, Gupta, Schwartzstein, Williams

# Gender differences in disability benefits

## Back

- ▶ Low and Pistaferri show that women with a severe, work-related, permanent impairment about 25pp more likely to have their application rejected
  - ▶ About 5ppt is due to the medical evaluation step assessing whether the health condition is severe and long lasting
  - ▶ About 19ppt is due to the vocational stage step whether condition prevents the applicant from doing alternative work
- ▶ Cabral and Dillender, studying the Texas workers' comp system, show that women are more likely to be denied by male evaluator and the gap closes with a female evaluator
- ▶ Low and Pistaferri note:
  - ▶ It is also possible that the screening system evolves (with lags) to fit the gender composition of applicants, who were initially mostly men. However, this is rapidly changing, with women representing in 2016 almost half of the stock and half of the flow of new entrants into DI.

# Rule example: workers' comp evaluation training materials



# Upper Extremity Case 5 MMI/IR CTS

#### **Treatment History**

hand.

- The patient has been a meatpacking worker for 30 years.
- His most recent job is with a whizzard knife cutting shoulder flanks of pork product.
   This involves a line speed of 780 per hour.
- This involves a line speed of 780 per hour.
   He is right handed, using the whizzard knife with the right hand and a hook with the left



### Upper Extremity Case 5 MMI/IR CTS

### **Designated Doctor Physical Examination:**

- He is a pleasant male 5'8" tall and 300 pounds.
- Examination of both hands indicated no thenar atrophy.
- · He has full ROM of both wrists.

## Upper Extremity Case 5 MMI/IR CTS

#### **Designated Doctor Medical History:**

- He presents to the DD exam with c/o bilateral numbness and tingling worse at night.
- He has been able to return to playing frisbee golf. (For ADLs to use for Grade see T. 11, P. 48)
- · He is not working.
- His surgeon recommended surgery, but he does not want to do this



Relationship of Impairment of Upper Extremity to Impairment of Whole Person T. 3, P. 20

Convert:
 22% UE = 13%
 Whole Person

% tespairment of			% Impairment of			% Impairment of		
Upper		Whole	Upper		Whole	Upper		Whol
0	-	0	20	22 : 21	70	-	42	
			37		22	72 73 74	-	43
	-			-			-	44
	-		2.5	-	23		-	-64
			40		24	75		45
			41		25	76	-	465
			67		29	77		460
ñ			43		26	70	-	47
9			44		26	79	-	47
					20	81		49
12			47		28	92		
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29	-	17	64		36	99	-	59
20	_	19	65		29	100	-	60

222

22