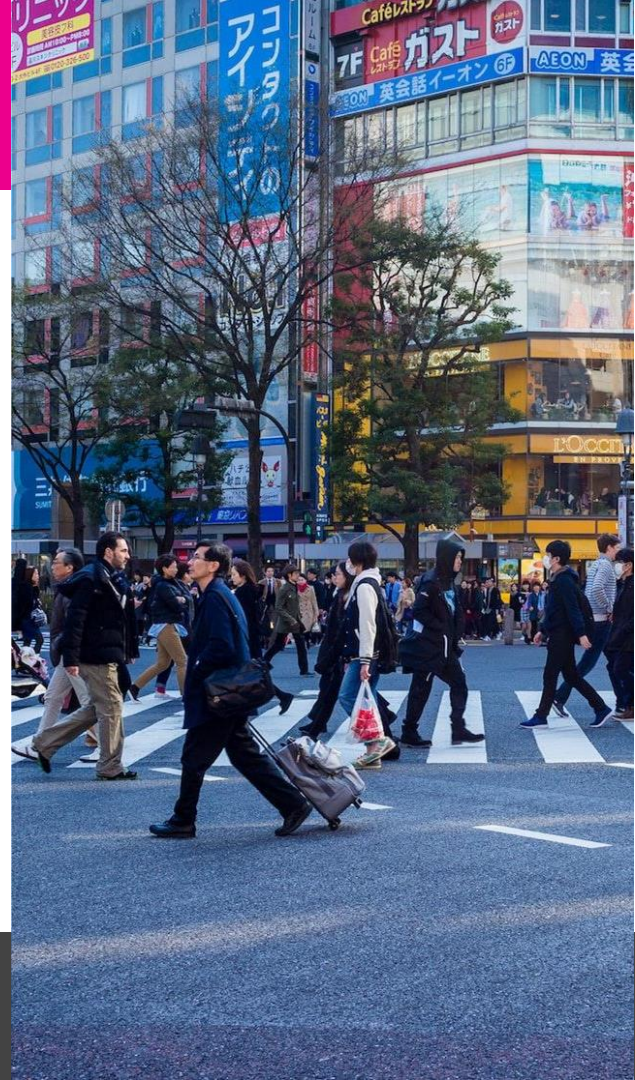


# Making Accessible Futures: *Bringing Function and Disability into the Informatics Conversation*

**Denis Newman-Griffis** *(they/them)*  
University of Sheffield

**Gillian Mason** *(she/her)*  
Hunter Medical Research Institute



# A note on language

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## **Person-centred**

Person with a  
disability

## **Identity-centred**

Disabled person



1

Go to [wooclap.com](https://wooclap.com)

2

Enter the event code in the top banner

Event code  
**EYBBSD**



# Disability is an everyday experience



*Population identified as disabled\**

22%

14.6M



18%

4.4M



\*Methodologies differ!



27%

89.6M



Figures from:

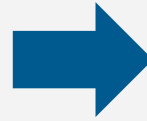
(UK) <https://www.gov.uk/government/statistics/family-resources-survey-financial-year-2020-to-2021/family-resources-survey-financial-year-2020-to-2021#disability-1>

(AUS) <https://www.aihw.gov.au/reports/disability/people-with-disability-in-australia/contents/people-with-disability/prevalence-of-disability>

(US) <https://www.cdc.gov/ncbddd/disabilityandhealth/infographic-disability-impacts-all.html>

# Disability is multidimensional

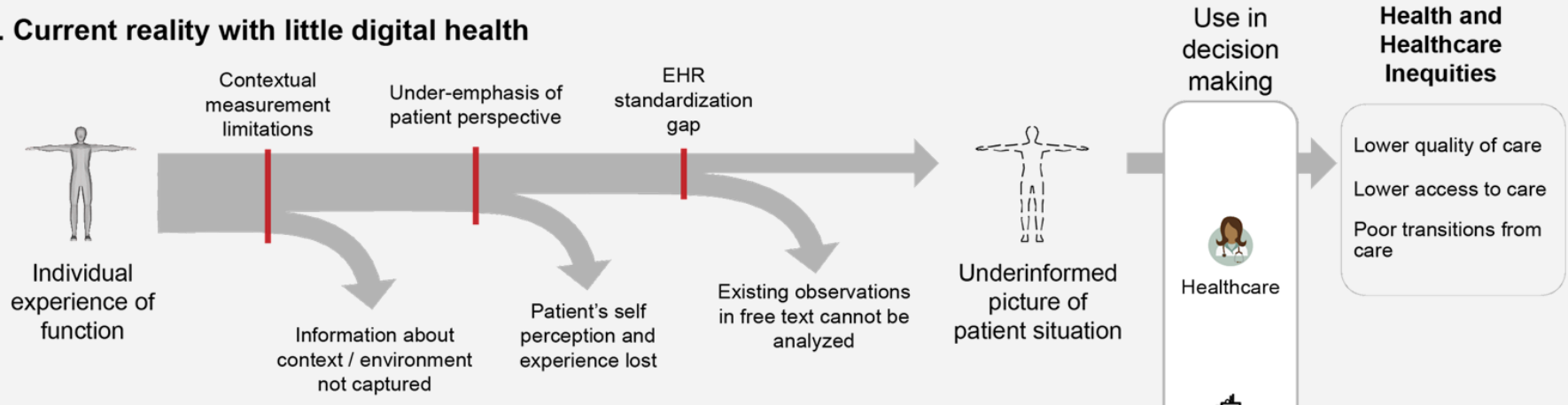
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- Experienced function
- Different situations
- Perception of self
- Identity
- Medical conditions
- Interdependent networks
- Assistive devices
- ...

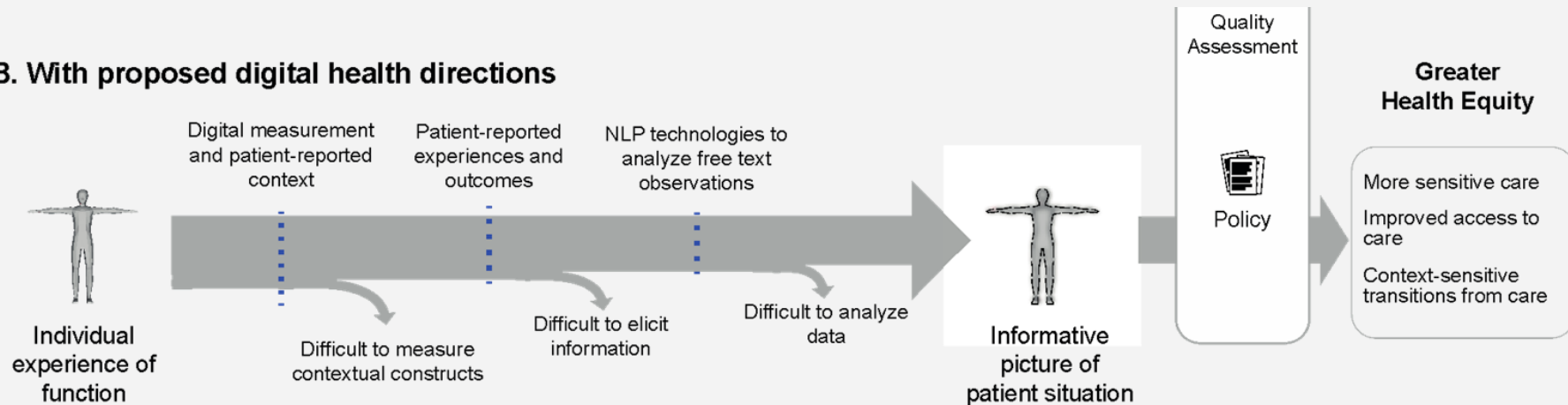
# Information loss contributes to disability inequities

## A. Current reality with little digital health



# Multidimensional data capture can help get better information about disability experience

## B. With proposed digital health directions



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## HEALTH AFFAIRS FOREFRONT

### RELATED TOPICS:

DISABILITY | PUBLIC HEALTH | PANDEMICS | COVID-19 | HEALTH DISPARITIES | ACCESS TO CARE | POPULATIONS

# A Need For Disability Data Justice

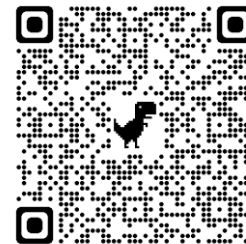
[Bonnielin K. Swenor](#)

AUGUST 22, 2022

10.1377/forefront.20220818.426231







JOURNAL ARTICLE FEATURED

# Engaging the disability community in informatics research: rationales and practical steps

Get access >

Rupa S Valdez ✉, Sophie E Lyon, Claire Wellbeloved-Stone, Mary Collins, Courtney C Rogers, Kristine D Cantin-Garside, Diogo Gonclaves Fortes, Chung Kim, Shaalini S Desai, Jessica Keim-Malpass ... Show more

*Journal of the American Medical Informatics Association*, Volume 29, Issue 11, November 2022, Pages 1989–1995, <https://doi.org/10.1093/jamia/ocac136>

**Published:** 16 August 2022    **Article history** ▼

# Today's workshop

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Generate **ideas, challenges, and provocations**

To the **global** medical informatics **community**

To bring our **work together** with function and disability

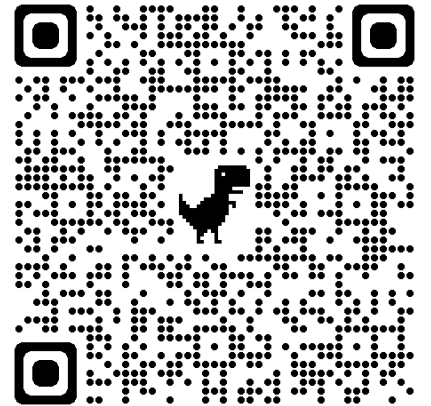
# Breakout discussions (20 minutes)

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1. **Strategies for co-designing** patient-facing digital health solutions with and for the disability community
2. **Activities and challenges** to grow research and **scientific programming activity** for function and disability informatics
3. **Opportunities/needs for research** on disability data collection and informatics impact

QR code for

Google Jamboard



# Discussion insights

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1. **Strategies for co-designing** patient-facing digital health solutions with and for the disability community

# Discussion insights

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2. **Activities and challenges** to grow research and **scientific programming activity** for function and disability informatics

# Discussion insights

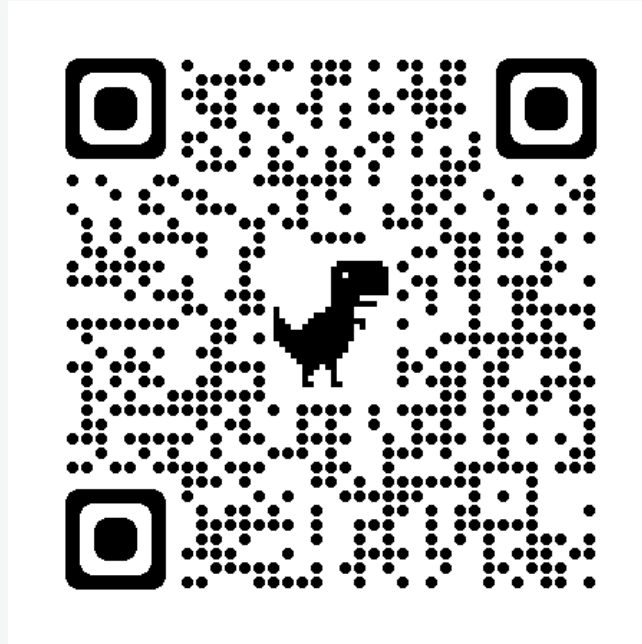
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## 3. Opportunities/needs for research on disability data collection and informatics impact

# Wrap up

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<https://forms.gle/QyZquYqsvk1hTwbG6>



## Thank you!

### Workshop team

- Vera Kaelin (Univ. Illinois Chicago)
- Hongfang Liu (Mayo Clinic)
- Bonnielin Swenor (Johns Hopkins Univ.)
- Suzanne Tamang (Stanford Univ.)
- Rupa Valdez (Univ. Virginia)

