

# PROs and Equity Considerations

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LINEBERGER  
Cancer Outcomes Research Program

# Disclosure

- Angela Stover, faculty for this educational event, was a paid consultant to Navigating Cancer in 2021 (<\$5k).
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- All of the relevant financial relationships listed for these individuals have been mitigated.

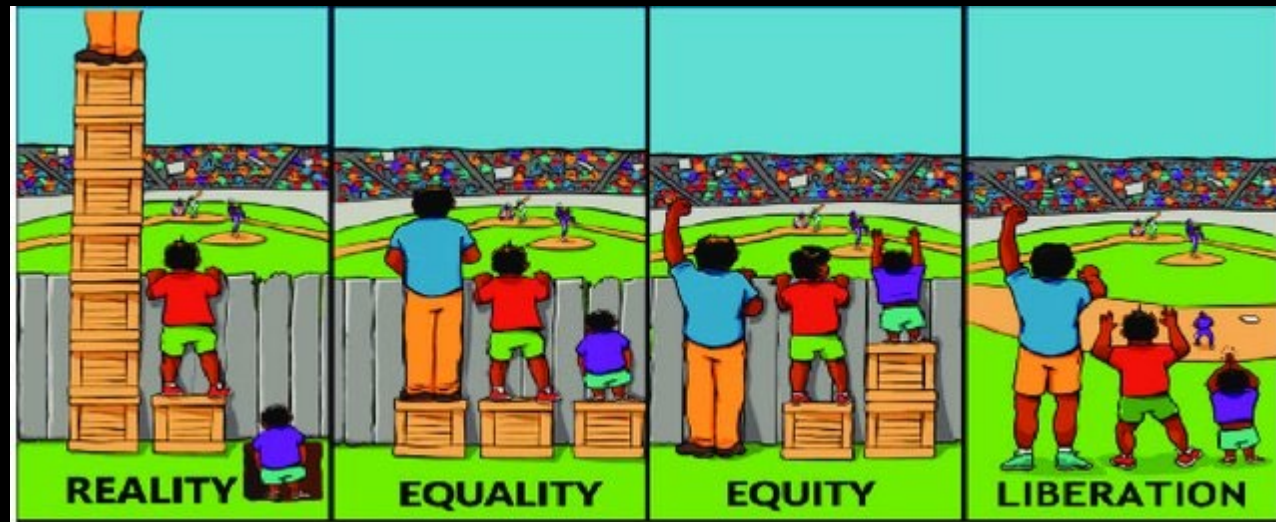
# Learning Outcomes

Upon Completing this session, participants will be able to:

1. Identify barriers to PROM completion by historically underserved groups.
2. Describe PROM equity issues happening in health systems.
3. Describe solutions for improving equity for PROMs.

# Defining Health Equity

A widely used definition of health inequity has been proposed by Whitehead (1992) and built upon by the WHO's Commission on Social Determinants of Health (CSDH) (4;5). It posits that health inequities are not merely differences in health status (termed "inequalities") but differences between groups that are unnecessary, avoidable, unfair, and unjust (6). The criteria of fairness and justice can be understood as systematic differences considered avoidable (5). Thus, all should have a "fair and just opportunity to be as healthy as possible" (7).

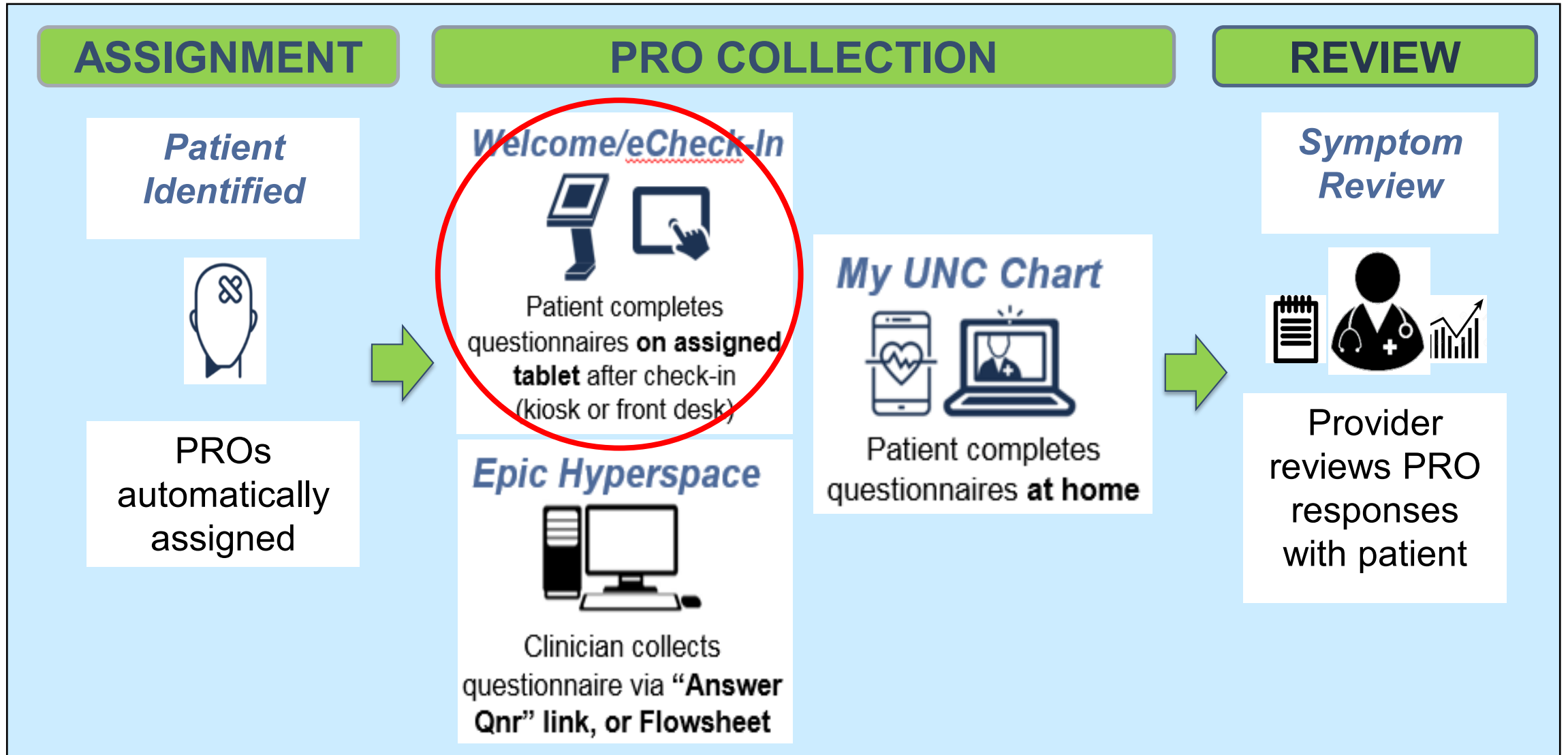


# PROM Equity Issue: Example

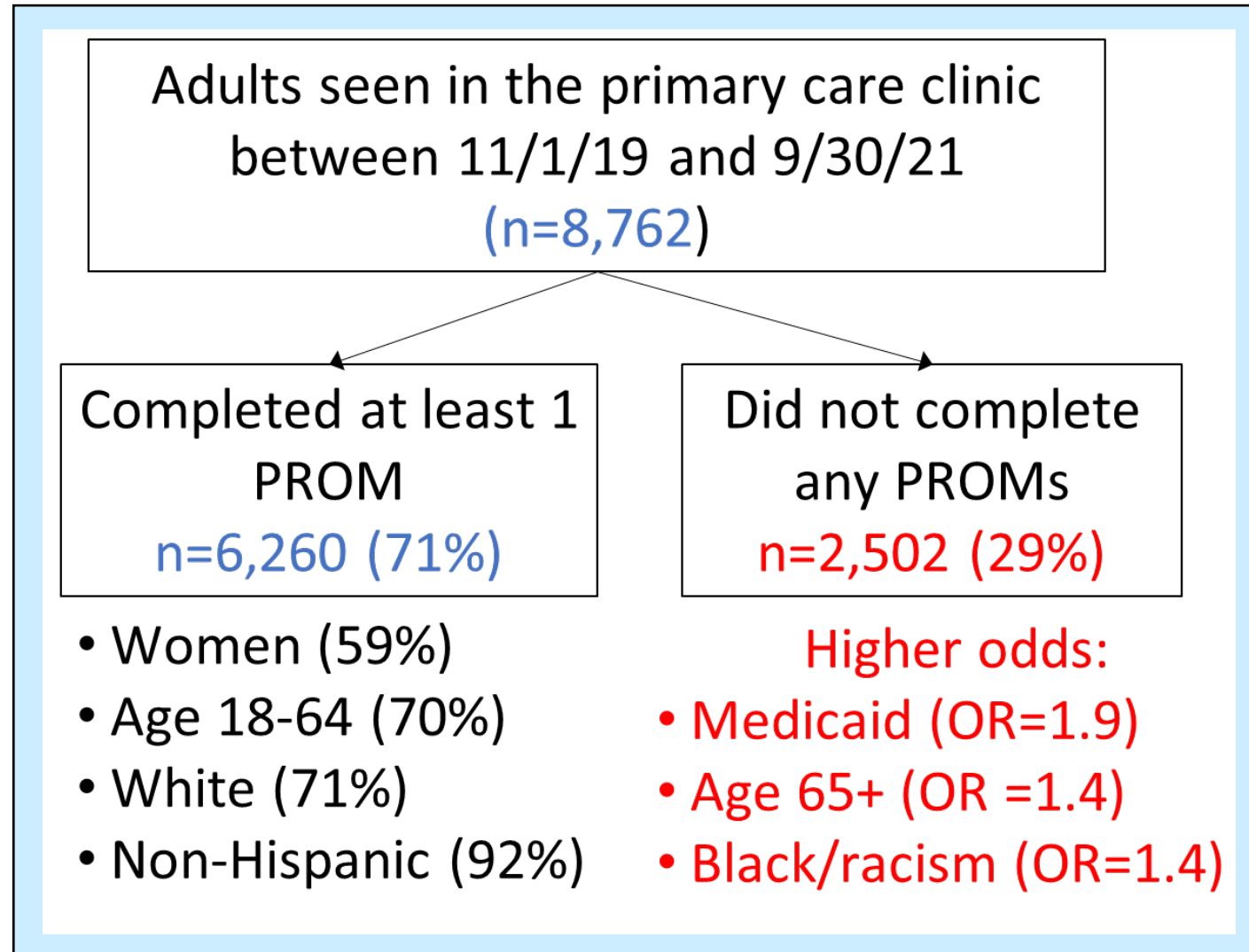


- UNC Health clinics implemented clinic-wide PROMs in select clinics
  - EHR integration, Best practice alerts for concerning responses
- Primary care: PHQ-2 and PHQ-9
- Compared demographic and clinical characteristics of patients completing at least one PROM vs. those who were missed (equity)

# Epic@UNC PROM Workflow



# Disparity in PROM Completion



# Disparity in PROM Completion

Downstream implications for performance measures

Adults seen in the primary care clinic  
between 11/1/19 and 9/30/21  
(n=8,762)

Completed at least 1  
PROM  
n=6,260 (71%)

- Women (59%)
- Age 18-64 (70%)
- White (71%)
- Non-Hispanic (92%)

Did not complete  
any PROMs  
n=2,502 (29%)

- Higher odds:
- Medicaid (OR=1.9)
  - Age 65+ (OR =1.4)
  - Black/racism (OR=1.4)



# What Can We Do?

# Nature Medicine 2022 Paper

## Patient reported outcome assessment must be inclusive and equitable

Patient-reported outcomes are increasingly collected in clinical trials and in routine clinical practice, but strategies must be taken to include underserved groups to avoid increasing health disparities.

Melanie J. Calvert, Samantha Cruz Rivera, Ameeta Retzer, Sarah E. Hughes, Lisa Campbell, Barbara Molony-Oates, Olalekan Lee Aiyegbusi, Angela M. Stover, Roger Wilson, Christel McMullan, Nicola E. Anderson, Grace M. Turner, Elin Haf Davies, Rav Verdi, Galina Velikova, Paul Kamudoni, Syed Muslim, Adrian Gheorghe, Daniel O'Connor, Xiaoxuan Liu, Albert W. Wu and Alastair K. Denniston

**P**atient-reported outcomes (PROs) collected in clinical trials can provide valuable evidence of the risks and benefits of treatment from a patient perspective, to inform regulatory approvals, clinical guidelines and health policy. PROs are increasingly collected routinely in clinical settings, at an aggregate level for audit and benchmarking, for real-world evidence generation, and as an input or predicted output for clinical decision tools

and artificial intelligence (AI) in health<sup>1,2</sup>. At an individual patient level, PROs can be used to facilitate shared decision making, screen or monitor symptoms, and provide timely care tailored to individual needs<sup>3</sup>. PROs are also increasingly used in value-based healthcare initiatives<sup>4</sup>.

Efforts to capture and report PRO data should be inclusive and equitable, addressing the diverse needs of all patients with the condition of interest, including groups

historically and currently underserved by research<sup>5,6</sup>. Issues of diversity, equity and inclusion (Box 1) have recently been highlighted in PRO ethical guidelines, which have identified a number of concerns to be addressed in PROs research<sup>5</sup>.

### Lack of representation

Underserved groups are often poorly represented in research and may receive suboptimal clinical care due to a range



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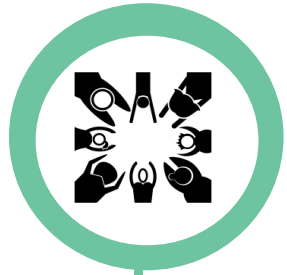
NATURE MEDICINE | VOL 28 | JUNE 2022 | 1110-1127 | [www.nature.com/naturemedicine](http://www.nature.com/naturemedicine)

# Nature Medicine 2022 Paper

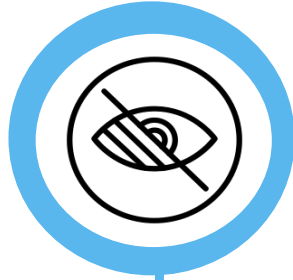
Patient-reported outcomes are increasingly collected in clinical trials and in routine clinical practice, but **strategies** must be taken to **include underserved groups** to avoid increasing health disparities

Recommendations derived from literature review and international expert consensus

# Barriers to Equitable PROMs



Under-served groups poorly represented



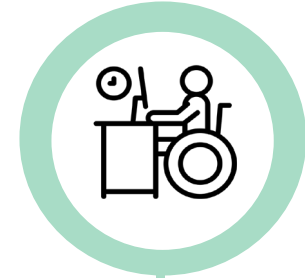
Clinical characteristics and symptom burden



Cultural needs, languages, mistrust, racism



Literacy, health literacy, digital exclusion



Functional barriers (e.g., arthritis, visual, etc.)

# Actions to Promote Equitable PROMs



**Include diverse patients & clinicians in PRO planning**



**Train clinicians to look for missing PROs in workflow**



**Address participant acceptability & concerns**



**Provide feedback mechanism to clinic on characteristics of patients they are missing**



**User-centered design to minimize barriers**



**If used in clinical care, review PROM responses with all patients**



**Minimize eligibility requirements (e.g., language)**



**Provide alternative ways to complete PRO**



**Ongoing training and support for clinics**

# Conclusions

- ✓ Representative patient populations are vital in PROs
- ✓ Downstream implications for assessing quality of care
- ✓ Targeted initiatives are necessary to avoid unintentionally exacerbating health inequality
- ✓ Build in equity from the beginning
- ✓ Seek input from representative patients throughout
- ✓ User-centered design to promote accessibility

# References

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- Calvert M, et al. Nature Med. 2022;28:1110-1127.
- Sisodia RC, et al. JAMIA. 2021;28(10):2265-2268.

# Thank You!

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