

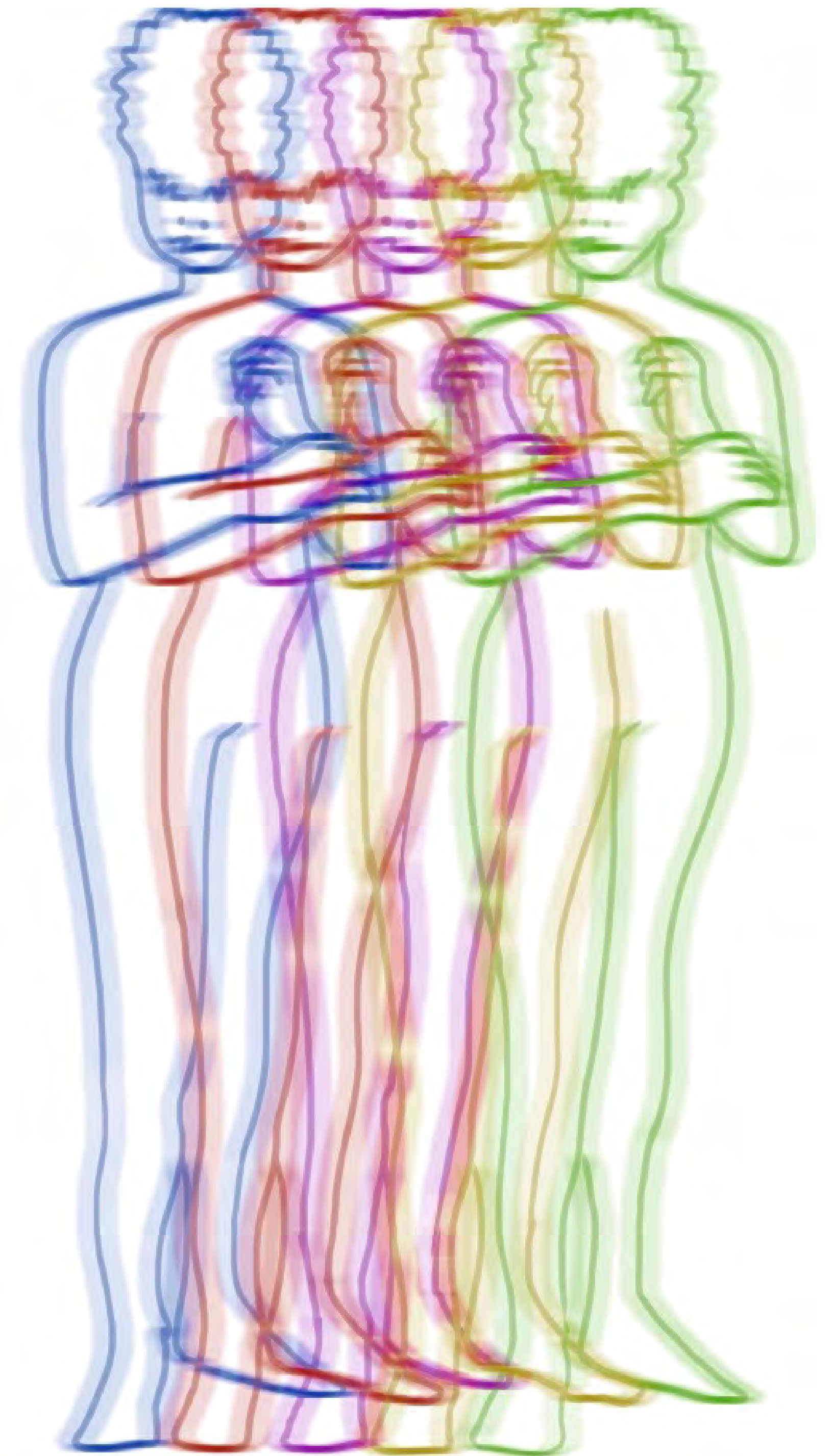
---

# The Trans Youth Health Experiences Study:

Recruitment,  
Representation,  
and Centering Youth Voices  
in Research  
about their Lives

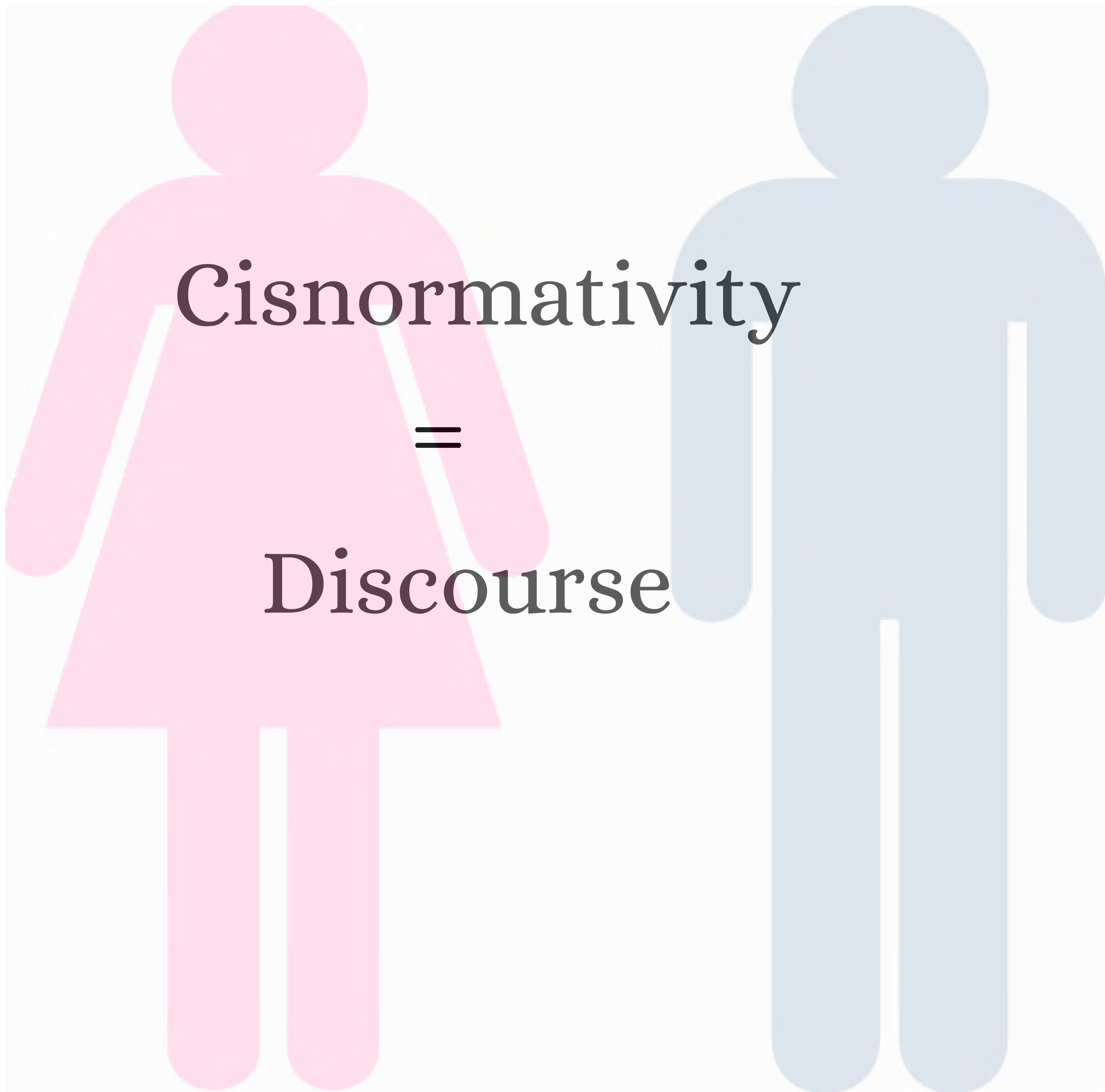
Alic Shook, RN, BSN, PhD  
RWJF Future of Nursing Scholar  
University of Washington, Seattle

---



# Cisnormativity

---



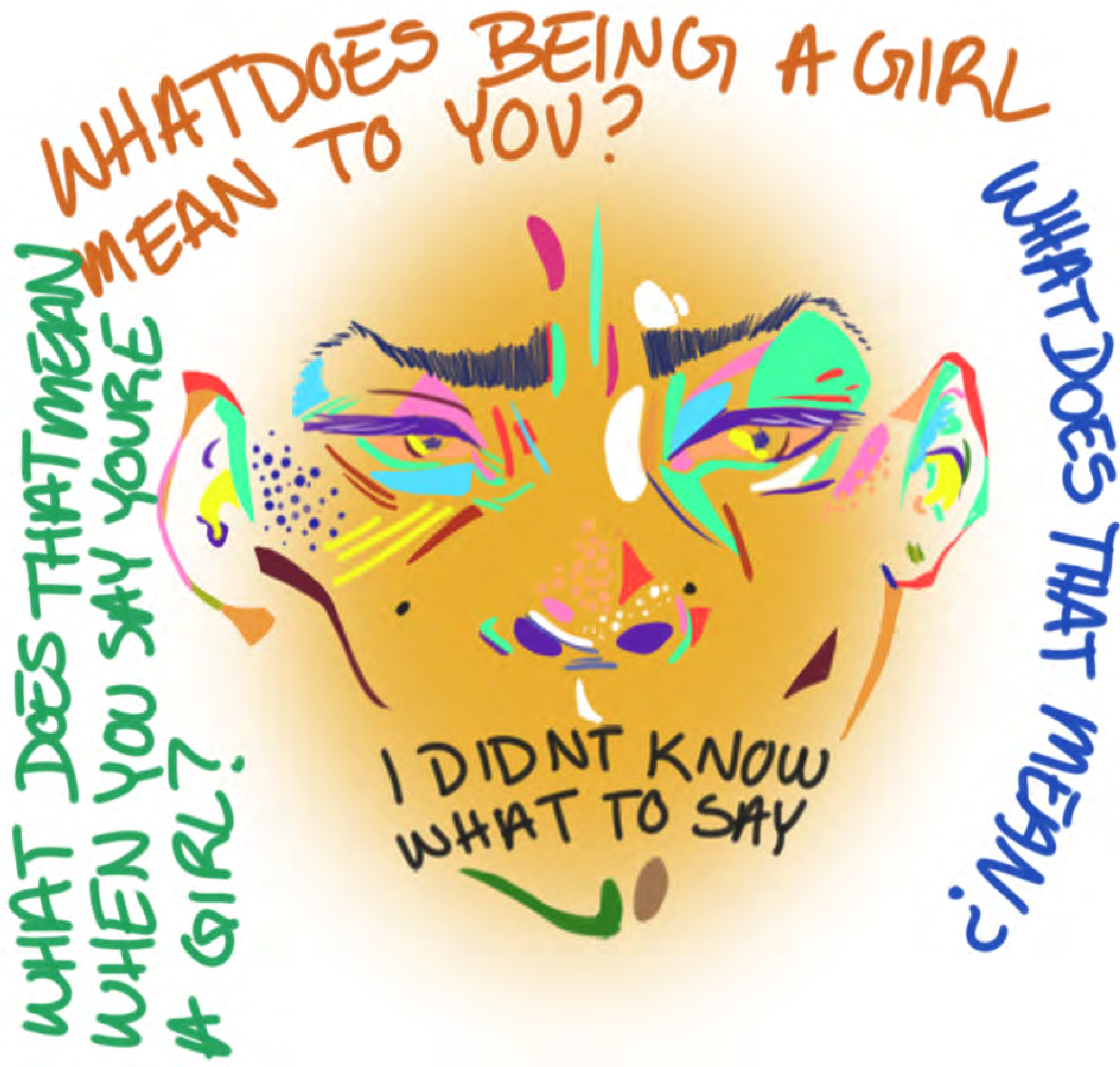
# Cisnormativity

---

- Represents the dominant framework for understanding sex/gender binary
- Grounded in historical privileging and naturalization of cisgender bodies & psychic experiences
- Has changed throughout history as ideas about sex & gender has changed

# Cisnormativity

---



# Background

Adolescents and adults who identify as transgender have high rates of depression, anxiety, eating disorders, self-harm, and suicide.<sup>13-20</sup> Evidence suggests that an identity of TGD has an increased prevalence among individuals with autism spectrum disorder, but this association is not yet well understood.<sup>21,22</sup> In 1 retrospective cohort study, 56% of youth who identified as transgender reported previous suicidal ideation, and 31% reported a previous

suicide attempt, compared with 20% and 14% among youth who identified as cisgender, respectively. Some youth who identify as TGD also experience

gender dysphoria, which is a specific diagnosis given to those who experience discomfort in peer and/or family relationships, school performance, or other aspects of their life as a consequence of the

## Dismantling the Transgender Brain

Eric Llavera Caselles

## Ethical Issues Raised by the Treatment of Gender-Variant Prepubescent Children

by Jack Drescher and Jack Pula

## Understanding Pediatric Patients

## Who Discontinue Gender-Affirming Hormonal Interventions

# Background

---

- Participants already engaged in care in existing gender clinics; issue of consent
- Overwhelmingly White
- Rely on parent report and/or participants 18+
- Limited inclusion/lack of representation of trans youth

—  
What are the experiences of  
transgender youth navigating  
healthcare?

Discourse Analysis

AIM #1

Analyze the discursive framing  
of contemporary transgender  
youth in the extant literature



AIM # 2

Describe the narratives of  
healthcare access among  
transgender youth

AIM # 3

Understand the role that  
consent plays in regulating  
access to care for  
transgender youth



# Discourse Analysis

---

- Arises from linguistic studies, literary criticism, and semiotic performative theories of language
- Explores language as a form of action
- Seeks to understand how people & institutions use language to create & enact identities & activities
- Concerned with power relations
- Issues prominent in DA research include gender issues, issues of racism, media discourses, etc.

## Constructing the gendered body? A critical discourse analysis of gender equality schemes in the health sector in England

**Sarah Payne**  
University of Bristol, UK

Current Sociology  
2014, Vol. 62(7) 956–974  
© The Author(s) 2014  
Reprints and permissions:  
sagepub.co.uk/journalsPermissions.nav  
DOI: 10.1177/0011392114531968  
csi.sagepub.com  


Bone Marrow Transplantation (2017) 52, 292–298  
© 2017 Macmillan Publishers Limited, part of Springer Nature. All rights reserved 0268-3369/17  
[www.nature.com/bmt](http://www.nature.com/bmt)

### ORIGINAL ARTICLE

A qualitative exploration of the informed consent process in hematopoietic cell transplantation clinical research and opportunities for improvement

M Raj<sup>1</sup>, SW Choi<sup>2</sup> and J Platt<sup>1</sup>

“Are You Beginning to See A Pattern Here?”  
Family and Medical Discourses Shape  
the Story of Black Infant Mortality

ELAINE R. CLEETON

*Sociology of Health & Illness* Vol. 38 No. 8 2016 ISSN 0141-9889, pp. 1350–1363  
doi: 10.1111/1467-9566.12478

**Organ donation agency: A discourse analysis of correspondence between donor and organ recipient families**

**Dariusz Galasiński<sup>1</sup> and Magi Sque<sup>2</sup>**

**Metaphors of Distress: Photo-Elicitation Enhances a Discourse Analysis of Parents' Accounts**

Qualitative Health Research  
2016, Vol. 26(8) 1031–1043  
© The Author(s) 2015  
Reprints and permissions:  
sagepub.com/journalsPermissions.nav  
DOI: 10.1177/1049732315575729  
qhr.sagepub.com  


Ira Kantrowitz-Gordon<sup>1</sup> and Roxanne Vandermause<sup>2</sup>

# Critical Trans Theory

- Is a critical social theory e.g. feminist, critical race, disability studies, etc.
- Interdisciplinarity; concerned w/ material conditions & representation practices -->
  - How do representational practices impact everyday lives of trans people?
  - How are embodied differences transformed into social hierarchies?
  - What is the relationship of discourse to regulation of gender as a social category?
- Trans people = experts of their own experience

# Community Based Participatory Research

---

- Focused on issues of equity & empowerment
- Knowledge generation & data arise from within communities
- Re-envisioning of young people...

Young people = expert co-creators of knowledge

- Engages youth & their expertise in research conducted about them

# Waiver of Parental Permission

- Issue of disclosure/safety
- May be better informed than parents about their health needs
- Represent a vulnerable segment of the larger population of trans youth
- Previously used in research w/ queer youth & research related to HIV/STI testing & services
- Added option of youth advocate during consent & during/after interviews

50%

of youth

participated without their parents.

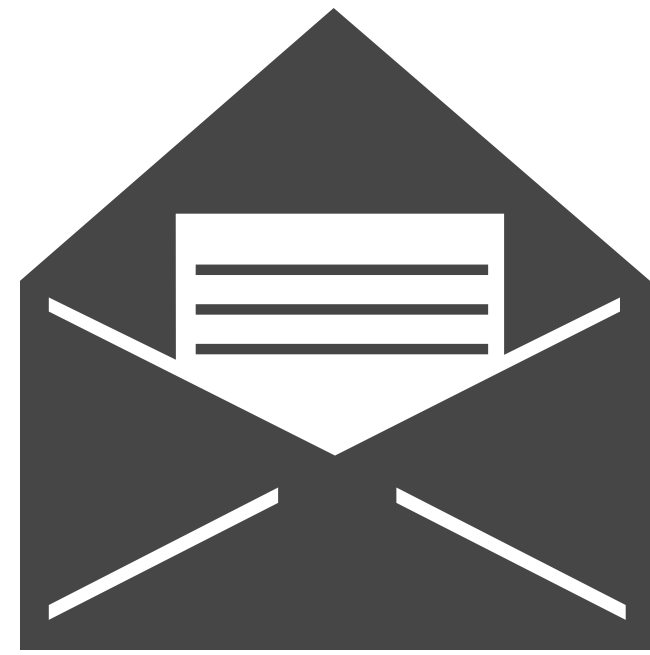
# Recruitment

- Only recruited outside "clinical samples"
- Outing myself in recruitment materials
- Issue of dominant discourse in strategy & materials

**Gender Diversity  
Gay City  
Lambert House  
Facebook  
Instagram  
Ingersoll  
Camp Ten Trees  
UW Rainbow Grads  
GLSEN**

**Public Libraries  
Youthcare  
Friends of Youth  
45th Street Clinic  
Alphabet Alliance of Color  
Entre Hermanos  
Garfield Teen Life Center  
Oasis Youth Center  
The Rainbow Center  
Stonewall Youth**

# Recruitment



n = 2

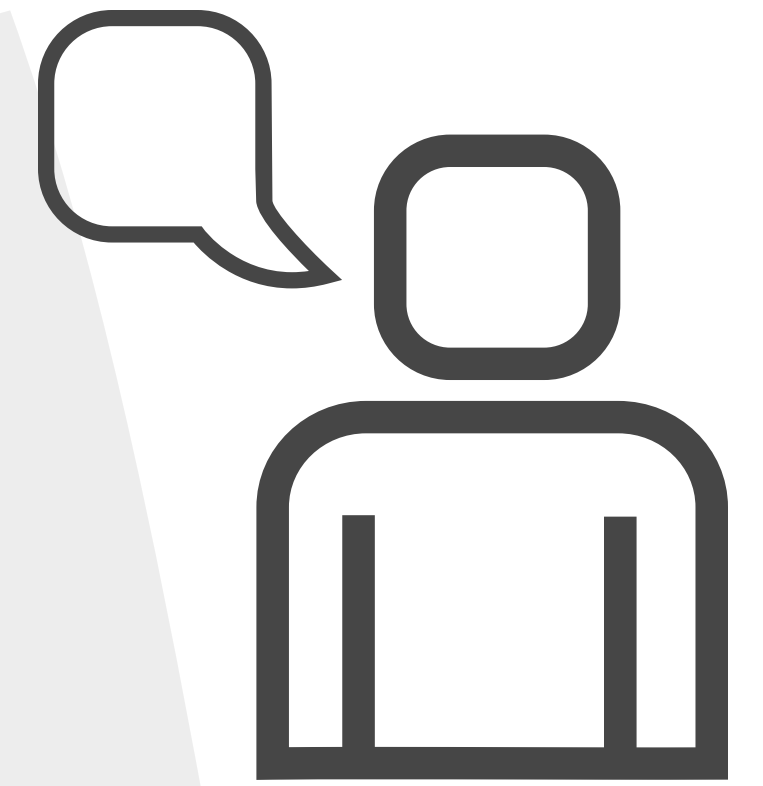


n = 3

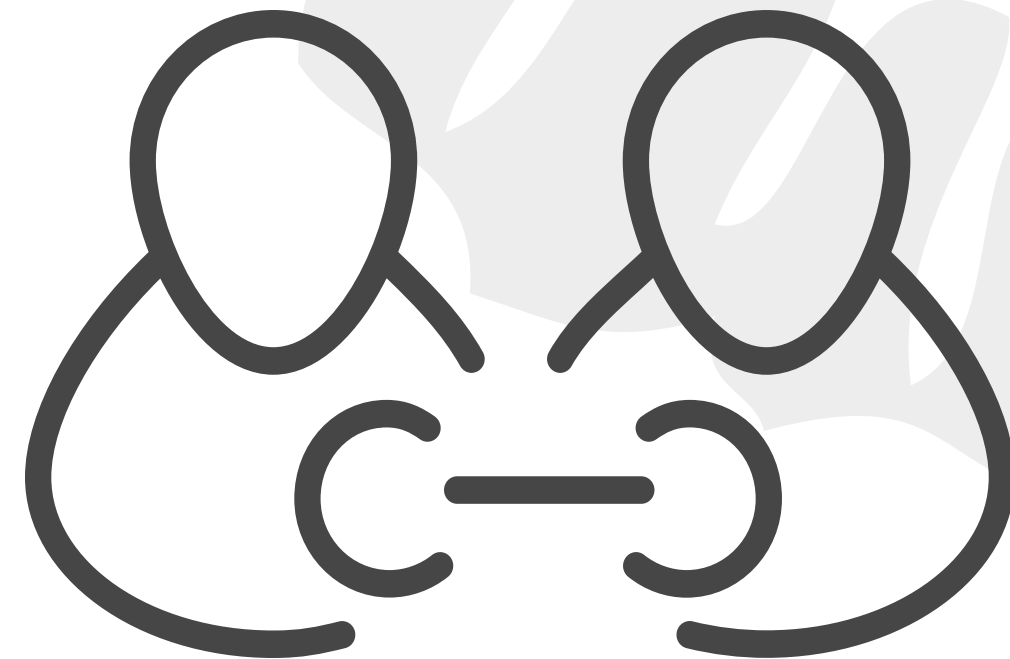
n = 1



n = 2



n = 1



n = 1



n = 4

# Recruitment

Are you or your child between the ages of 6 & 17 years old?  
Interested in participating in a research study about your experiences  
navigating the healthcare system?

## Trans Youth Health Experiences Study



You might be a good fit for this study if...

- ✓ You or your child are between the ages of 6 and 17 years old
- ✓ You identify as transgender or non-binary
- ✓ You are the parent or guardian of a trans or non-binary youth
- ✓ You live in King County, WA

If you decide to take part in this study, you will...

- ✓ Participate in a one to two hour interview and answer brief survey questions
- ✓ Receive a \$25 gift card to thank you for your time
- ✓ Be invited to inform how this study's data is analyzed & shared with healthcare providers


To take part in this study or to learn more  
contact Alic Shook at  
415.265.6575 or [shooka@uw.edu](mailto:shooka@uw.edu)

**About the researcher:**

Alic Shook, BSN, RN is a pediatric emergency medicine nurse and a doctoral student in the School of Nursing at the University of Washington, Seattle. He is a transgender author and activist, works with healthcare systems to create more inclusive environments for transgender and non-binary youth, and provides training on gender diversity.

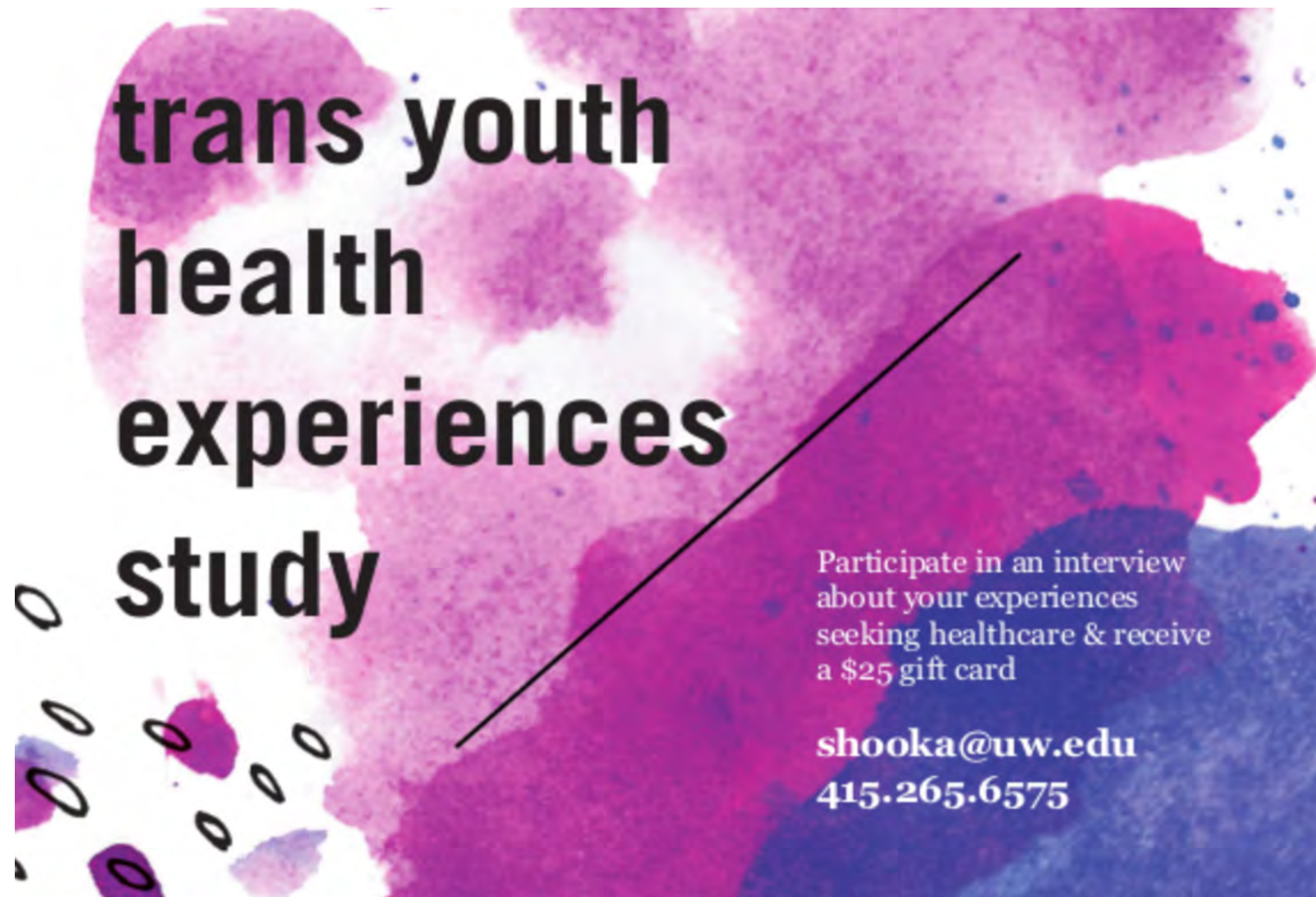
**W** UNIVERSITY *of* WASHINGTON

powered by

 PIKTOCHART



# Recruitment



## trans youth health experiences study

Participate in an interview  
about your experiences  
seeking healthcare & receive  
a \$25 gift card

**shooka@uw.edu**  
**415.265.6575**

Are you between the ages of 13 and 17?

Identify as trans and/or non-binary?

Have something to say about your experiences with healthcare?

Participation involves a one time interview

& you receive a \$25 gift card.

Interviews take place anywhere you are comfortable &  
where we can ensure your privacy.

You *\*do not\** need parental permission to consent to participation.

For more info contact:

shooka@uw.edu

415.265.6575

### ABOUT THE RESEARCHER:

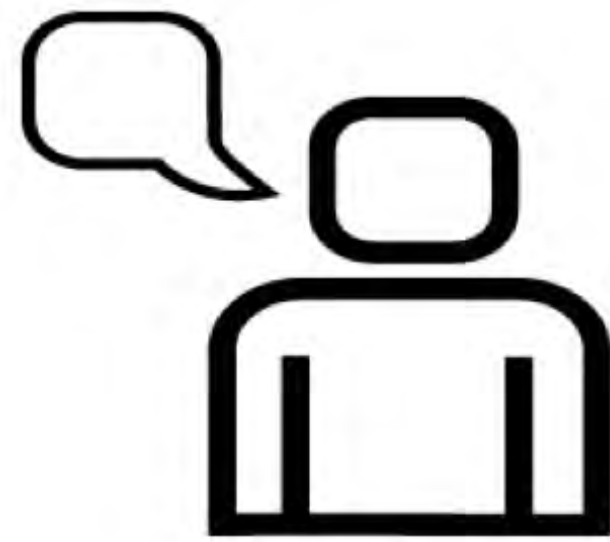
Alic Shook is a trans nurse & health researcher. He is a PhD candidate in the  
School of Nursing at the University of Washington.

# Recruitment

## TRANS YOUTH YOUR VOICE MATTERS.



The Trans Youth Health Experiences Study is seeking participants between the ages of 13 & 17



Share your thoughts about your experiences accessing healthcare & receive a \$25 gift card


**CONTACT US**  
(e) SHOOKA@UW.EDU  
(p) 415-265-6575

About the researcher: Alic Shook, RN, BSN, is a pediatric emergency medicine nurse and trans health researcher. He is a PhD candidate in the School of Nursing at the University of Washington. In the past, he has worked with hospitals and other institutions to create safer healthcare encounters for trans young people.

**W** UNIVERSITY of WASHINGTON

IRB#00005443

[www.transyouthspeak.com](http://www.transyouthspeak.com)

 @transyouthhealthstudy

powered by

 PIKTOCHART

# Interviews

## Presence of Youth Advocate

---

7/14

participated without parental permission.

3/7

chose to have youth advocate present.

1/7

youth advocate for consent process only.

2/7

youth advocate for consent process & interviews.

## Interview Locations

---

9 interviewed at home

2 lived independent of parents

2 community spaces for queer & trans youth

2 private spaces on UW campuses

1 public library

# Interviews

HE WAS VERY HAPPY TO GIVE A RECCOMENDATION  
BUT HE WANTED TO ASK



ALL  
SORTS  
OF  
QUESTIONS

BEFORE HE DID THAT

# Interviews

- Discursive interviews focus on understanding how identity informs healthcare encounters
- Both interviewer/interviewee engage in dialogue
- Interviewer probes for intertextual meaning
- Youth advocate as active participant
- Invite youth to comment on interview process

# Analysis

- Multiple, overlapping, iterative steps
- Continuous feedback between analysis & data collection

---

---

What is discourse doing in the context of the healthcare encounter?

What narratives about trans embodiment does it produce, normalize, pathologize, or disregard?

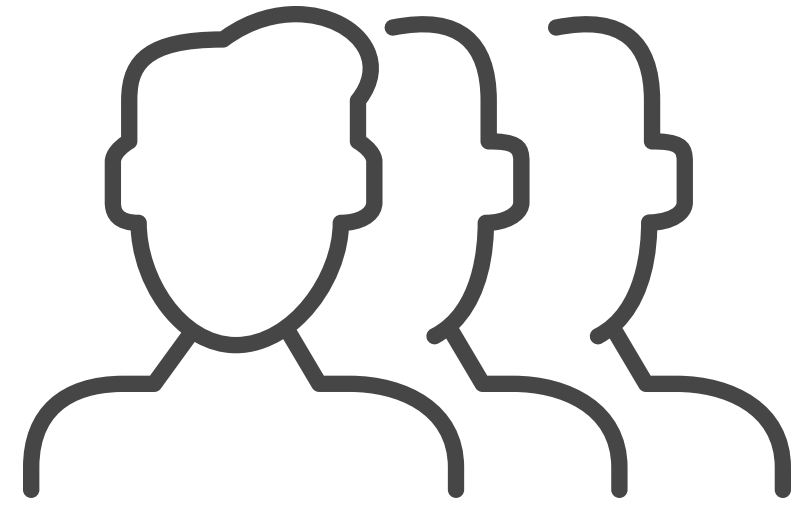
How do participants make use of the dominant discourse, engage with it, or decide to disregard it entirely?

How do issues of age, autonomy, and authority of knowledge show up for youth in seeking health services & interventions?

---

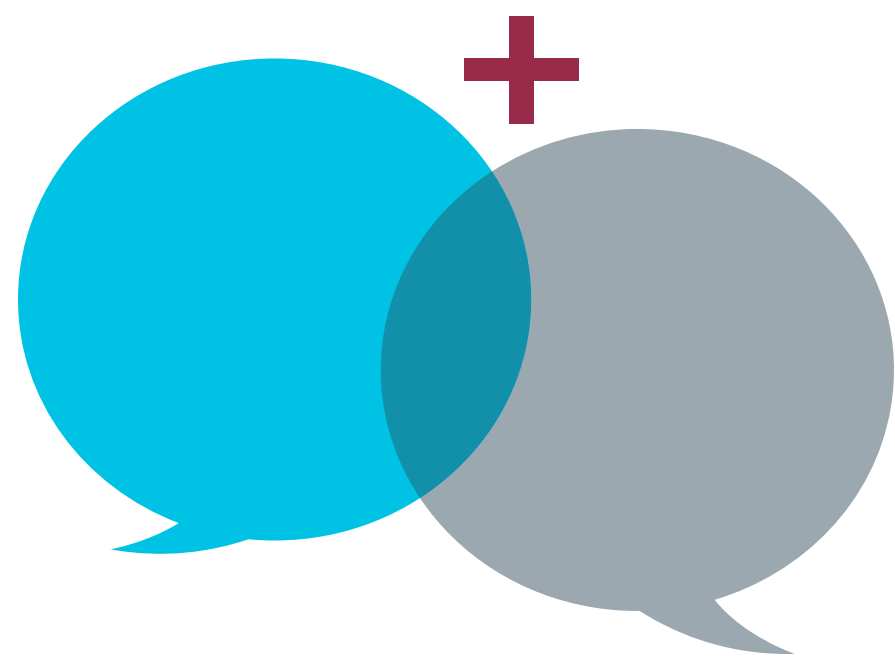
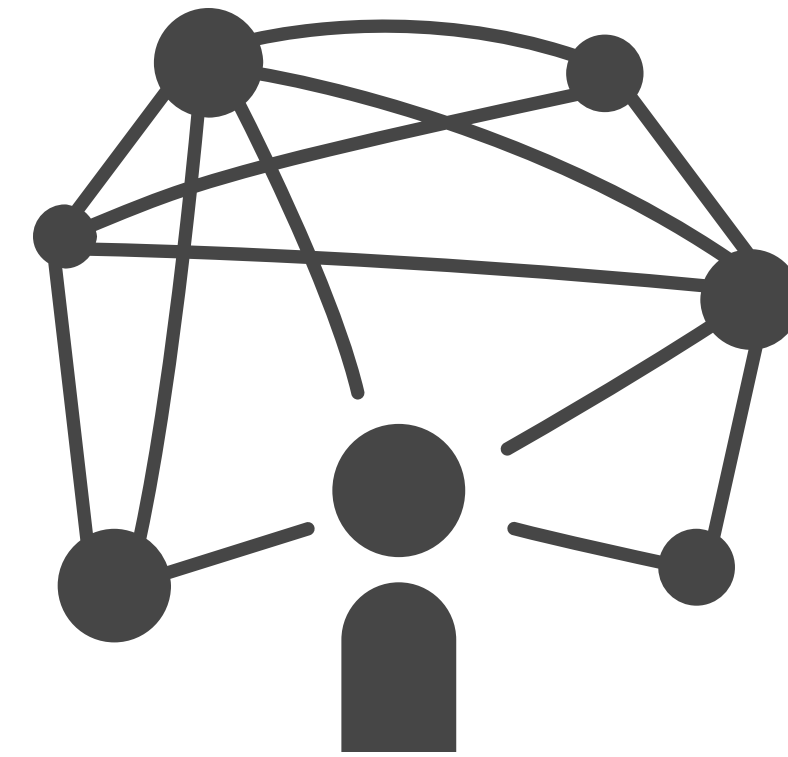
---

# Analysis



- 2 trans youth participant-researchers
- 2 trans/queer grad student researchers
- 1 faculty mentor

Analyst examines own place  
in the discourse(s)



\*Centrality of member-checking

# Research & Practice Implications

---

- Improve delivery of care models
- Increase access to care
- Improve quality of healthcare encounters across multiple sectors of health service provision
- Inform policy development, particularly related to consent for minors
- Inform what questions get asked in research about trans people & trans-therapeutics



# Research & Practice Implications



OVER THE SUMMER MY MOM FOUND MY BINDER. I DONT KNOW IF SHE EVEN FIGURED OUT WHAT IT WAS BUT SHE DEFINITELY GOT RID OF IT AND DIDNT MENTION IT TO ME.

# Illustrator

---

DEAN WEILER  
deanweiler3@gmail.com  
@blinking.fish

# References

- Bryant, K. (2006). Making gender identity disorder of childhood: Historical lessons for contemporary debates. *Sexuality Research & Social Policy*, 3(3), 23–39.
- Castañeda, C. (2015). Developing gender: The medical treatment of transgender young people. *Social Science and Medicine*, 143, 262–270. <https://doi.org/10.1016/j.socscimed.2014.11.031>
- Gill-Peterson, J. (2018). *Histories of the Transgender Child*. Minneapolis: University of Minnesota Press.
- Gridley, S. J., Crouch, J. M., Evans, Y., Eng, W., Antoon, E., Lyapustina, M., ... Breland, D. J. (2016). Youth and Caregiver Perspectives on Barriers to Gender-Affirming Health Care for Transgender Youth. *Journal of Adolescent Health*, 59(3), 254–261. <https://doi.org/10.1016/j.jadohealth.2016.03.017>
- Karkazis, K. (2008). *Fixing Sex: Intersex, Medical Authority, and Lived Experience*. Durham, NC: Duke University Press.
- Mak, G. (2012). *doubting sex: Inscriptions, bodies, and selves in nineteenth-century hermaphrodite case histories*. New York, NY: Manchester University Press.
- Meadow, T. (2018). *Trans Kids: Being Gendered in the Twenty-First Century*. University of California Press.
- Meyerwitz, J. (2002). *How Sex Changed: a History of Transsexuality in the United States*. Cambridge, Massachusetts: Harvard University Press.
- Olson-Kennedy, J., Cohen-Kettenis, P. T., Kreukels, B. P. C., Meyer-Bahlburg, H. F. L., Garofalo, R., Meyer, W., & Rosenthal, S. M. (2016). Research priorities for gender nonconforming/transgender youth. *Current Opinion in Endocrinology & Diabetes and Obesity*, 23(2), 172–179. <https://doi.org/10.1097/MED.0000000000000236>
- Pickles, J. (2019). Including and involving young people (under 18's) in hate research without the consent of parents. *Qualitative Research*, 1–17. <https://doi.org/10.1177/1468794118816622>
- Plemons, E. (2017). *The Look of A Woman*. Duke University Press.
- Roen, K. (2011). The discursive and clinical production of trans youth: Gender variant youth who seek puberty suppression. *Psychology and Sexuality*, 2(1), 58–68. <https://doi.org/10.1080/19419899.2011.536316>
- Roen, K. (2018). Rethinking queer failure: Trans youth embodiments of distress. *Sexualities*, 1–17.
- Sadjadi, S. (2013). The Endocrinologist's Office - Puberty Suppression: Saving Children from a Natural Disaster? *Journal of Medical Humanities*, (34), 255–260.
- Serano, J. (2007). *Whipping Girl: A transexual woman on sexism and the scapegoating of femininity*. Berkeley, CA: Seal Press.
- Starks, H., & Trinidad, S. B. (2007). Choose your method: A comparison of phenomenology, discourse analysis, and grounded theory. *Qualitative Health Research*, 17(10), 1372–1380. <https://doi.org/10.1177/1049732307307031>
- Stryker, S. (2016). (De) Subjugated Knowledges: An Introduction to Transgender Studies. In S. Stryker & S. Whittle (Eds.), *The Transgender Studies Reader* (pp. 1–17). New York: Routledge.
- Stryker, S. (2017). *Transgender History: The Roots of Today's Revolution*. New York: Seal Press.
- Travers, A. (2018). *The Trans Generation: How Trans Kids (and Their Parents) are Creating a Gender Revolution*. New York: New York University Press.
- Wodak, R., Meyer, M. (2001). *Methods of Critical Discourse Analysis*. <https://doi.org/10.1017/CB09781107415324.004>