



CaN-D

Community Care
Network for Dementia



Community Care Network for Dementia Kick-Off

Quarterly Network Meeting 1
December 1, 2023

WELCOME!

In the chat: Share your name, affiliation, pronouns

Network Team



Andrew Dick
(RAND)



Esther Friedman
(University of Michigan)



Teague Ruder
(RAND)



Katherine Sun
(Emory)

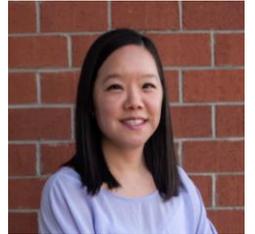
Lori Frank
(NYAM)



Jordan Harrison
(RAND)



Regina Shih
(Emory, RAND)



Elena Fazio
(NIA)



Priscilla Novak
(NIA)



Dan Siconolfi
(RAND)





CaN-D

Ice Breaker Question



In the chat, please share:

If you could only eat one candy for the rest of your life, what would it be?

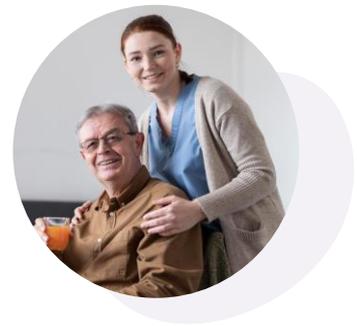


Kick-Off Meeting Outline

- 1 Definition of HCBS and Motivation for Network
- 2 Goals
- 3 Activities
- 4 Overview of Data Hub
- 5 Snapshot of CaN-D Members
- 6 Working Groups Topics: Break Out Rooms
- 7 Looking forward: Next set of activities



What are Home and Community-Based Services (HCBS)?



- Person-centered care in the home and community
- Address functional limitations and assistance with activities
- Enable aging in place rather than moving to a facility
- Medicaid is the largest single payer of HCBS
- Types:
 - Home health and personal care
 - Transportation
 - Homemaker services
 - Caregiver and client training
 - Hospice care
 - Case management
 - Human services supports (e.g., center-based care, meal delivery, home repairs and modifications, and financial and legal services)

Motivation for Network



- Relative to the rapid movement towards more HCBS, research on the affordability, access, delivery, quality, and outcomes of dementia HCBS is behind
- Existing structure, process, and outcome measures of HCBS do not always consider the unique needs of persons with dementia or their caregivers, and are fragmented by setting, service, and payer
- Dementia HCBS measures can be better aligned across the research community to improve detection of changes in outcomes
- NIA Research Networks provide infrastructure support to advance high-priority areas relevant to Alzheimer's disease and Alzheimer's disease-related dementias (AD/ADRD), as well as integrate a focus on health disparities
- Network funding acknowledgement: NIA U24AG077110



Goals of Community Care Network for Dementia (CaN-D)

01

Foster formal communications and **knowledge sharing** to quickly advance innovative dementia HCBS research;

02

Grow and diversify the bench of dementia HCBS researchers;

03

Generate data tools to facilitate examination of structure, process, and outcome measures of dementia HCBS;

04

Facilitate **policy-relevant dementia HCBS research** and rigorous dissemination approaches; and

05

Develop a Network infrastructure and products through a **diversity, equity, and inclusion (DEI)** lens.

Activities



Meetings

- Quarterly Network Meetings
- Monthly Working Group Meetings
- Ad Hoc Learning and Development Sessions



Training

- Annual Data Workshops
- Writing Retreats
- Translation/ dissemination Seminars
- Proposal development/ feedback



Dissemination

- Dementia HCBS Data Hub
- Share data resources
- Collaborate with other NIA BSR networks



Overview of Dementia HCBS Data Hub



Data Hub Activities

- Annual data workshop
 - Hands-on learning experience to address research questions of interest
- Methods seminars
 - Potential topics
 - Intro to observational data sources (e.g., NHATS, HRS)
 - Intro to LINKAGE for accessing claims-linked data
 - Qualitative/mixed methods for dementia HCBS research



Dementia HCBS Data Resource Matrix



An overview of observational and claims-based data sources for dementia HCBS research

Study/dataset	Data type	General description	Time period	Frequency/mode of data collection	Population represented
Health and Retirement Study (HRS)	Observational	Nationally representative longitudinal panel study of US adults ≥51 years designed for multidisciplinary research on work, aging, and retirement. A new cohort of individuals ages 51–56 is added every 6 years. Spouses or partners of potential subjects are also recruited into the study. HRS enrolls community-dwelling individuals and follows them in and out of nursing home settings.	1992 to present	Individuals or their proxy respondents are interviewed in-person or by phone every two years until death.	Community-dwelling U.S. adults aged 50+, grouped into generational cohorts
Medicaid Analytic Extract (MAX)/T-MSIS Analytic Files (TAF)	Claims	Medicaid administrative data. Files include person-level information on Medicaid eligibility, service utilization, and payments. MAX is the previous generation of Medicaid claims data; TAF is the new generation. (Files for 2013, 2014 and 2015, while in the MAX file format, may have been created using a combination of T-MSIS and MSIS data).	1999-2015 (MAX); 2016-present (TAF)	Data collected by state Medicaid agencies and submitted to CMS	Medicaid enrollees
Medical Expenditure Panel Survey (MEPS)	Observational	Set of large-scale surveys of families and individuals, their medical providers, and employers across the United States. MEPS is the most complete source of data on the cost and use of health care and health insurance coverage.	1996 to present	MEPS Household component (MEPS-HC) is a panel survey featuring several rounds of interviews covering two full calendar years	U.S. civilian noninstitutionalized population
Medicare Current Beneficiary Survey (MCBS)	Observational	Nationally representative rotating panel survey of aged and disabled Medicare beneficiaries administered by CMS. The MCBS collects comprehensive data on beneficiaries' health insurance coverage, health care utilization and costs, access to care, and satisfaction with care, and links survey responses to administrative claims.	1991 to present	Beneficiaries or their proxy respondents are interviewed up to three times annually (fall, winter, and summer) for three consecutive years, and approximately 25% (one of	Medicare population, including enrollees aged 65 and older and disabled enrollees under age 65



Additional Data Resources (under development)



- Helper code (e.g., SAS, Stata) to derive relevant variables related to dementia HCBS from observational data sources
 - e.g., National Health and Aging Trends Study (NHATS), Health and Retirement Study (HRS), Medicare Current Beneficiary Survey (MCBS)
- Guides on data analysis approaches related to equity



Data Hub Advisory Committee



- **Verena Cimarolli, PhD**
*Director of Health Services
Research and Partnerships
LTSS Center @UMass Boston;
LeadingAge*



- **Tetyana P. Shippee, PhD**
*Professor, Division of Health
Policy & Management
School of Public Health,
University of Minnesota*



- **Jeff Klein, FACHE**
*President & CEO
Nevada Senior Services Inc.*



- **Cara Stepanczuk, MPA**
*Researcher, Health Unit
Mathematica*



- **Yue Li, PhD**
*Professor of Public Health
Sciences
University of Rochester
Medical Center*



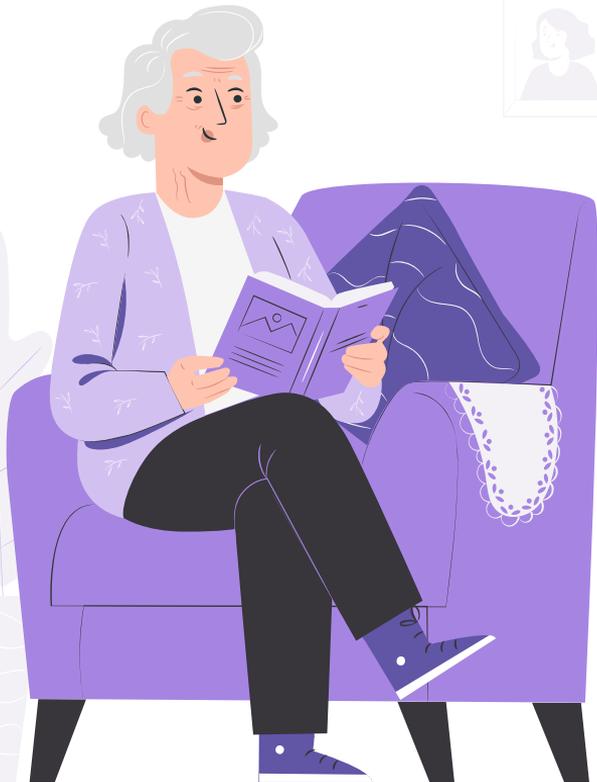
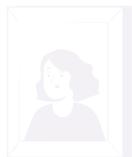
Poll



Which data sources are of interest for a data-intensive workshop focused on dementia HCBS? (select all that apply)

- National Health and Aging Trends Study (NHATS)
- Health and Retirement Study (HRS)
- T-MSIS Analytic Files (TAF)
- Medical Expenditure Panel Survey (MEPS)
- Medicare Current Beneficiary Survey (MCBS)
- Panel Study of Income Dynamics (PSID)
- National Post-acute and Long-Term Care Study (NPALS)
- State-based or other local studies
- Private-pay dementia HCBS data
- Other (please specify in the chat)





Snapshot of Network Members

- Demographics, affiliations, disciplines
- Topical areas of interest



Member Demographics



Demographics

Gender

Female	78%
Male	21%
Transgender, Two-Spirit, or another identity	1%

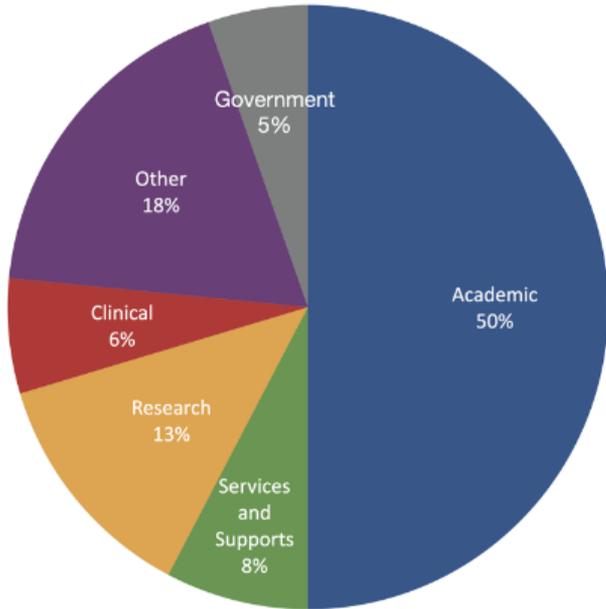
Racial identity

Asian	13%
Black or African American	3%
White	78%
Multiple identities or another identity	6%

Hispanic ethnicity 4%



Primary Affiliation, Stakeholders, Roles ✨



Stakeholders represented

- Advocacy organizations
- Area Agencies on Aging
- Universities
- Contract research organizations
- Dept. of Health & Human Services
- State office/departments of aging
- Philanthropic organizations
- Providers; Provider organizations

Roles (select all)

Research	66%
Public policy	19%
Advocacy	18%
Non-medical services	18%
Medical/clinical services	15%
Other	15%
Healthcare administration	9%
Philanthropy	3%

Disciplinary Background

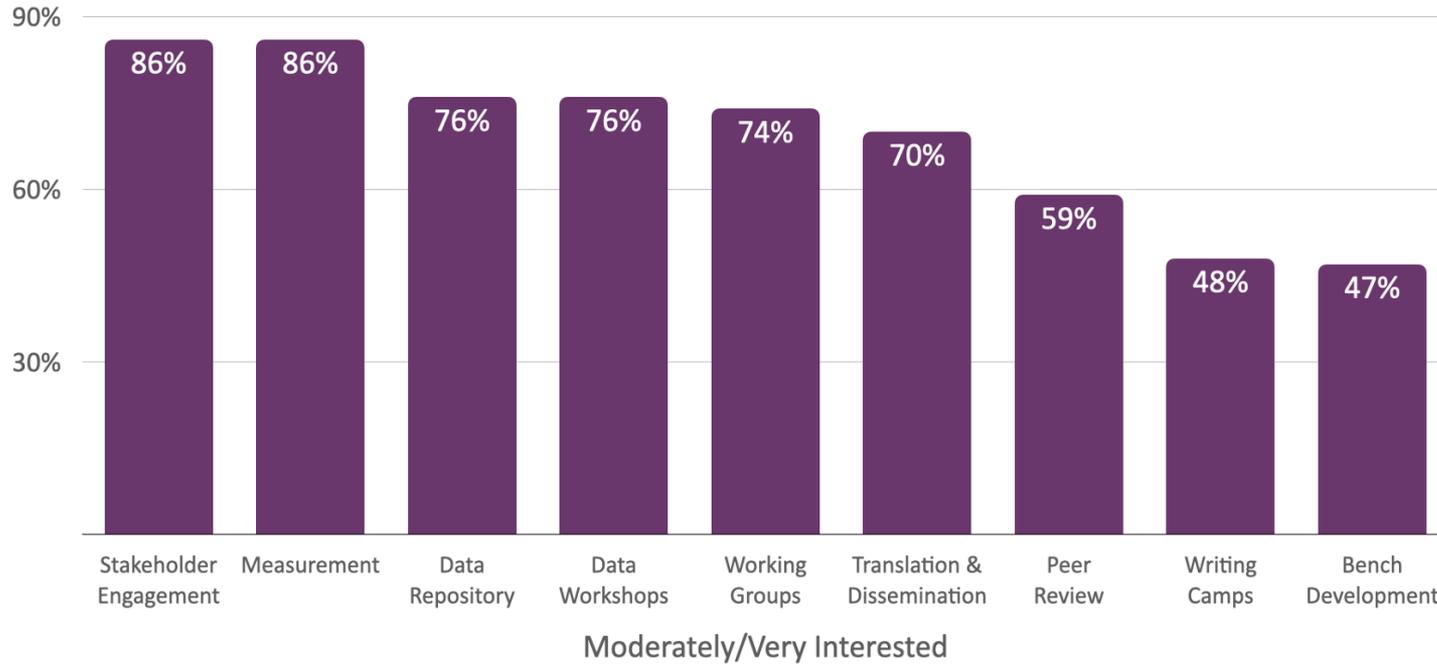


Discipline (select all)

Other	33%
Gerontology	30%
Public Health	25%
Medicine	13%
Public Policy	13%
Nursing	11%
Social Work	10%
Economics	9%
Sociology	9%
Demography	2%



Interest in Network Activities



Thematic Areas of Interest



Theme

Access and/or utilization

Caregiving

Disparities, equity, cultural competence

Interventions (development, implementation)

Specific HCBS or other services

HCBS workforce

Other



Breakout Rooms



- **Room 1:** Dementia HCBS State Policies
(Facilitators: Jordan + Andy)
- **Room 2:** Dementia HCBS Interventions
(Facilitators: Dan + Lori)
- **Room 3:** Dementia HCBS Access & Unmet Needs
(Facilitators: Esther + Teague)

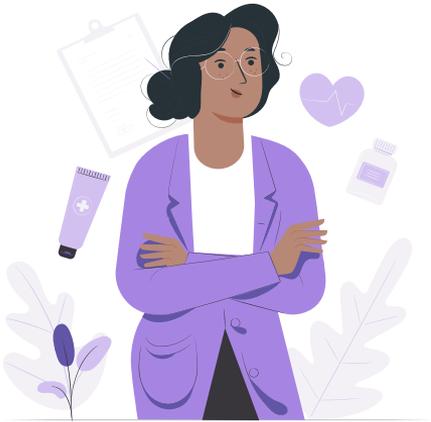


Breakout Rooms: Reporting Back ✨

- **Room 1:** Dementia HCBS State Policies
(Facilitators: Jordan + Andy)
- **Room 2:** Dementia HCBS Interventions
(Facilitators: Dan + Lori)
- **Room 3:** Dementia HCBS Access & Unmet Needs
(Facilitators: Esther + Teague)



Looking Forward!



Grant/Proposal Feedback



- Opportunity for constructive feedback on Specific Aims or Research Strategy
- Peer- and/or Senior-level reviewers
- Connect for ad hoc or sustained mentorship



- Starting in 2024
- Stay tuned for an upcoming survey



Learning and Development Sessions



- Equitable team-building, mentorship, and bench development
- Researcher, provider, policymaker engagement and equitable partnerships
- Policy translation and equitable dissemination



- Starting in 2024

Poll



Which session would you like to see first in 2024?

1. Equitable Research Teams and Mentorship
2. Developing Equitable Partnerships
3. Dissemination with Impact & Equity



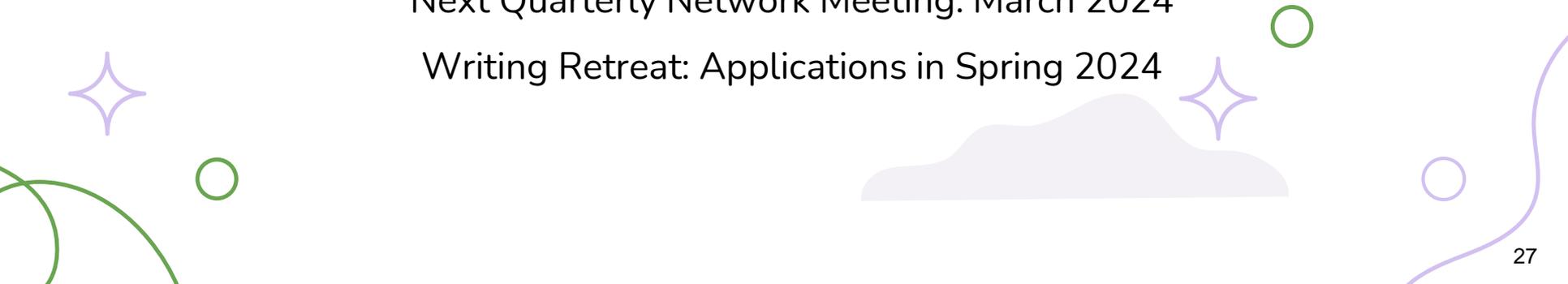


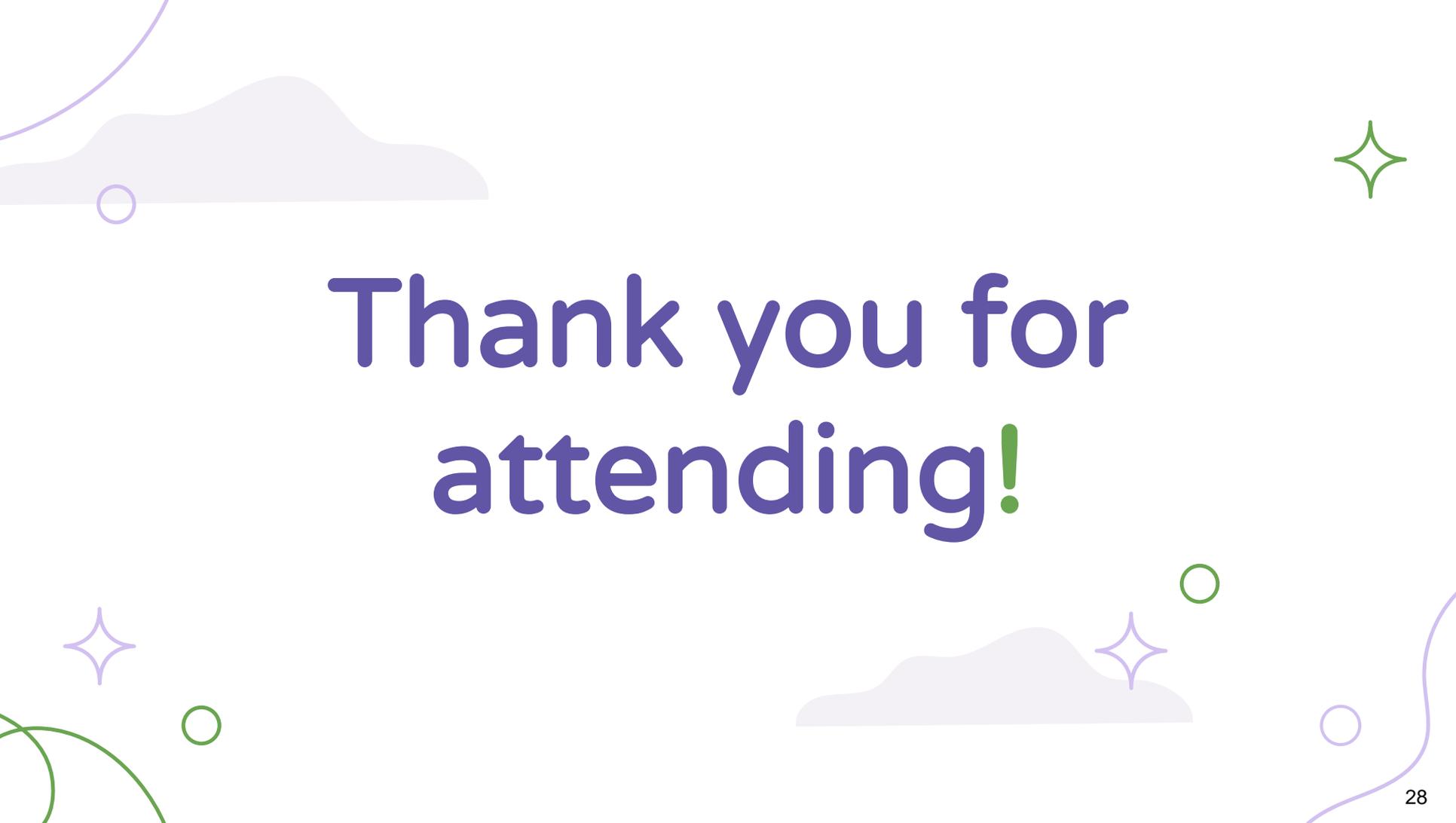
Upcoming Meetings!

Working Groups Meetings: Monthly, 2024

Next Quarterly Network Meeting: March 2024

Writing Retreat: Applications in Spring 2024





Thank you for
attending!