Accelerating Medicines Partnership in Alzheimer's Disease (AMP-AD)

COMMUNITY OVERVIEW

The Accelerating Medicines Partnership in Alzheimer's Disease (AMP-AD) is a precompetitive partnership among government, industry, and nonprofit organizations to transform the current model for developing new diagnostics and treatments for Alzheimer's disease. The community maintains several working groups that collaborate around data processing, analysis, and publications; making data and tools available to the rest of the research community through an online platform. The goal of the second iteration of this transformative partnership is to expand the open-science, precompetitive enterprise and enable a true precision medicine approach to target and biomarker discovery.

► Website: adknowledgeportal.org

KEYWORDS

Disciplines / skills
► INTERDISCIPLINARY
► DATA SCIENCE
► SOFTWARE AND CODE
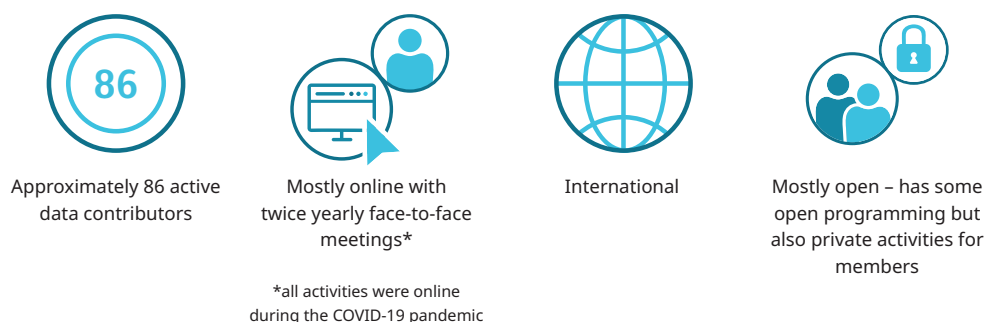► HEALTH / MEDICINE
► BIOTECHNOLOGY
► SYSTEMS BIOLOGY

Programming and goals
► STANDARD SETTING
► INFRASTRUCTURE DEVELOPMENT
► OPEN SCIENCE
► KNOWLEDGE GENERATION
► OUTREACH AND EXTERNAL COMMUNICATIONS

Stakeholder relationships
► MULTI-STAKEHOLDER
► INDUSTRY-ACADEMIA

COMMUNITY BASICS

86
Approximately 86 active data contributors

Mostly online with twice yearly face-to-face meetings*

International

Mostly open – has some open programming but also private activities for members

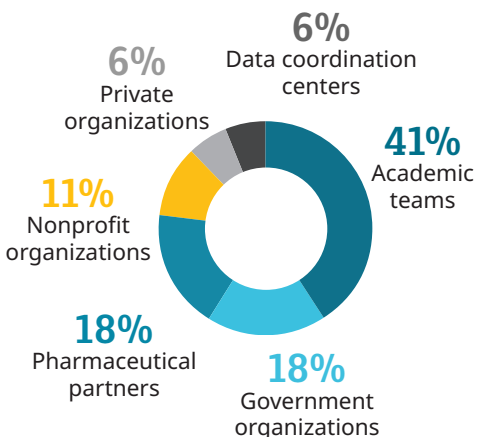*all activities were online during the COVID-19 pandemic

COMMUNITY STRUCTURE

Community Management
Community management is provided by a full-time **Communications Manager** with additional 4.0 FTE split between the **Data Coordination Center** and **AD Translational Research** teams at Sage Bionetworks, who help generate content for the newsletter and gather data use statistics.
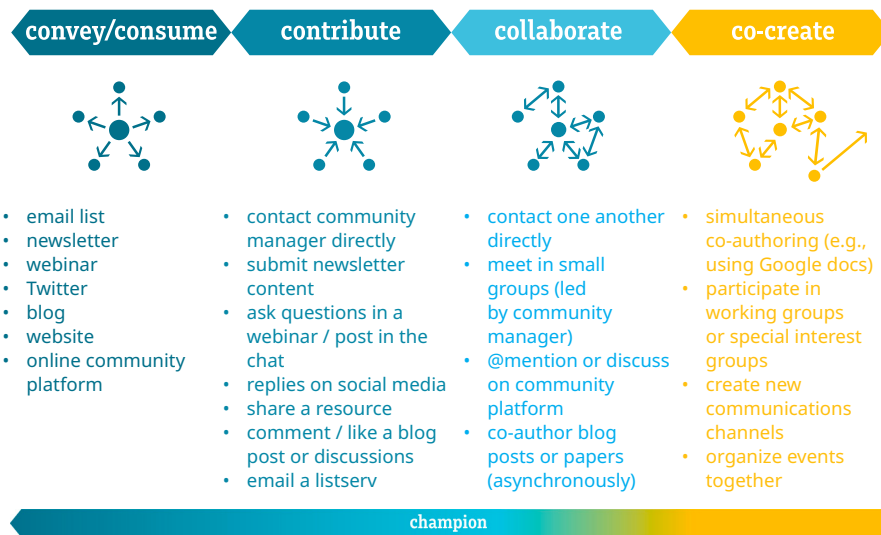
Members

- 6% Data coordination centers
- 41% Academic teams
- 18% Government organizations
- 18% Pharmaceutical partners
- 11% Nonprofit organizations
- 6% Private organizations

Community Configuration

- Government organizations
- Nonprofit organizations
- Private organizations
- Pharmaceutical partners
- Academic teams
- Data coordination centers

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PROGRAMMING

Programming includes annual face-to-face meetings, monthly progress report webinars, and regular working group meetings focusing on different scientific areas. Communications include newsletters every two months, a quarterly webinar series, a regularly updated news page and blog posts, and a curated social media presence with feature stories, interviews, and videos. The community connects via an internal data management and collaboration platform, and some staff members communicate via Slack.

convey/consume	contribute	collaborate	co-create
• email list • newsletter • webinar • Twitter • blog • website • online community platform	• contact community manager directly • submit newsletter content • ask questions in a webinar / post in the chat • replies on social media • share a resource • comment / like a blog post or discussions • email a listserv	• contact one another directly • meet in small groups (led by community manager) • @mention or discuss on community platform • co-author blog posts or papers (asynchronously)	• simultaneous co-authoring (e.g., using Google docs) • participate in working groups or special interest groups • create new communications channels • organize events together

champion

THE COMMUNITY PARTICIPATION MODEL

The CSCCE Community Participation Model describes four modes of member engagement that can occur within a community – CONVEY/CONSUME, CONTRIBUTE, COLLABORATE, and CO-CREATE – and one that can occur both inside and outside of it: CHAMPION. All modes may be present at once, with some members interacting in multiple modes – or a community may have member engagement that falls into only some of the modes described. The model enables the mapping of community member behaviors to programming and other infrastructural support that the community manager, convening organization, or funder may provide to the community.

▶ For more information, see the CSCCE community participation model.

Online   In-person

COMMUNITY CHAMPIONS

AMP-AD is currently planning a champions program. At the moment, members may informally act as champions in the following ways:

MAINTAIN
• act as informal community managers

GROW
• reshare resources
• represent the community at external events

EVOLVE
• propose and/or lead subgroups

i CHAMPIONS take on additional activities to support or advance the community. They are sometimes described as emergent leaders.

COMMUNITY TOOLBOX

Communications

Email
MailChimp
Blog
Twitter

Zoom
GitHub
Slack

Productivity

R
Google Drive

Google Analytics
GitHub

Community platform

Slack
GitHub

Synapse (a data management & collaboration platform)

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doi: 10.5281/zenodo.5014074

OUTPUTS & EVALUATION

Success looks like the broad and rapid distribution of research, with open science practices and big data driven approaches used to bring a precision medicine approach to the discovery of targets and biomarkers.

Successes over the last year

Building resilience and adaptability throughout the chaos of COVID-19 (e.g., well attended and engaging face-to-face meetings conducted virtually). The community also launched a second iteration of the program with a new set of private partners (listed at right).

- **Growth** - added new working groups
- **Growth** - launched new program or project
- **Growth** - added new members
- **Activities** - created community outputs together
- **Activities** - an in-person or virtual event
- **Funding -** added a new revenue stream
- **Value** - external recognition of the community's impact

Evaluation and Reporting

- Metrics and data use statistics for members and leadership
- Monthly progress report webinars for members and leadership

Opportunities

More engagement from collaborators and funding partners; increased impact on individual investigators (e.g., career trajectory).

- **Growth** - new working groups
- **Growth** - launch new program or project
- **Engagement** - increase member activity
- **Engagement** - more members acting as champions
- **Activities** - create community outputs together
- **Activities** - host conference(s) / workshops
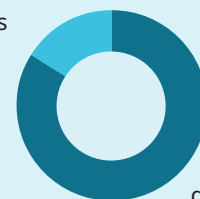- **Value** - more members expressing recognition of the community's value

Challenges

- Streamlining processes
- Sustaining engagement and cohesion for a team with diverse expertise
- Establishing/tracking metrics for community engagement and impact

FUNDING

16% Partners

84% Grants - federal or government

Funding Streams

- 84% from the US National Institute on Aging
- 16% from private partner organizations
- AMP-AD 2.0 partners: National Institute on Aging (NIA), National Institute of Neurological Disorders and Stroke (NINDS), Food and Drug Administration (FDA), Pharmaceutical Industry: Takeda Pharmaceutical Company Limited, GlaxoSmithKline plc, Eisai Inc., Foundation for the NIH (FNIH), Alzheimer's Association, Gates Ventures

AMP-AD does not currently offer funding opportunities to community members.

ABOUT THIS PROFILE

This profile is part of a research project conducted by the Center for Scientific Collaboration and Community Engagement (CSCCE). You can find out more about the project, and view more community profiles, on our website.

Information for this profile was submittedby Zoe Leanza, Communications Manager.

Last updated: 29 June 2021

Cite as: Center for Scientific Collaboration and Community Engagement (2021) CSCCE Community Profile: Accelerating Medicines Partnership in Alzheimer's Disease (AMP-AD). Woodley, Pratt, Kobilka, and Leanza doi: 10.5281/zenodo.5014074