Schizophrenia

COMMENT OPEN

Bridging Science and Hope: integrating and Communicating Lived experience in Accelerating Medicines Partnership® Schizophrenia Program

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The Accelerating Medicines Partnership Schizophrenia (AMP® SCZ) program integrates lived experience into psychosis research, leveraging over three decades of foundational studies to improve research quality, promote community engagement, and ensure ethical implementation of precision psychiatry. Lived experience is embedded in the program's governance, shaping study protocols, recruitment strategies, and digital tools such as the mindLAMP platform. Study sites also integrate lived experience through youth advisory boards, peer support specialists, and advisory committees, ensuring diverse perspectives inform research design and implementation. These efforts aim to develop predictive tools and therapeutic strategies while maintaining ethical and participant-centered practices. Advocacy organizations, such as the National Alliance on Mental Illness (NAMI), have fostered collaboration among government, industry, and academic partners, shaping outreach and engagement strategies. Dissemination efforts, led by the Website and Outreach Workgroup (WOW), include an accessible, Section 508-compliant website and co-designed resources, building trust and engagement within communities. By integrating lived experience at every stage, the program aims to foster trust, enhance research outcomes, and inform future strategies for treatment and prevention. Watch Dr. Tina Kapur, Dr. Kathryn Eve Lewandowski, and Dr. Carlos A. Larrauri discuss this article and their work at: https://vimeo.com/1050068801.

Schizophrenia (2025)11:57; https://doi.org/10.1038/s41537-025-00572-7

Incorporating lived experience in psychosis research has a long, established history, with foundational studies in the mental health and clinical research fields dating back over thirty-five years[1–8]. The integration of lived experience perspectives offers numerous benefits, including producing higher-quality research, achieving more tangible outcomes for the intended population, improving product or treatment adoption, enhancing trust in research and institutions, fostering empowerment and hope among contributing individuals[9], and ultimately supporting an ethical implementation of precision psychiatry into clinical care[10]. Elevating the voices of individuals with lived experience also ensures that investigators consider all aspects of the research enterprise from a stakeholder perspective, including bioethical issues over privacy, data ownership, and confidentiality that arise from the use of emerging tools, such as digital mental health technologies (see Digital paper in this issue by Wigman et al.), with an understanding of their potential risks and benefits[11].

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Individuals with lived experience played key leadership roles in the creation of the Accelerating Medicines Partnership Schizophrenia (AMP® SCZ) program and continue to provide leadership in its governance and implementation. This program represents the largest international effort to date—spanning 43 sites across 13 countries—to address the critical need for clinical stratification and the development of novel treatments for individuals at clinical high risk (CHR) for psychosis. As a public-private initiative, AMP® SCZ fosters collaboration among government, industry, academia, and advocacy organizations to develop tools and resources for early identification and targeted treatment strategies for schizophrenia[12,13]. The observational study in AMP® SCZ involves approximately 2,000 CHR individuals and 640 matched community controls, and collects extensive clinical, environmental, and cognitive data alongside multimodal biomarkers. These biomarkers include neuroimaging, electrophysiology, fluid biospecimens, speech and facial expression samples, and innovative digital health measures such as smartphone-based daily surveys, passive sensing, and actigraphy. Over a two-year period, AMP® SCZ is examining key clinical outcomes such as transition to psychosis, remission or persistence of CHR status, attenuated positive symptoms, persistent negative symptoms, mood and anxiety symptoms, and psychosocial functioning. With its global reach and harmonized methodologies, AMP® SCZ seeks to catalyze the development of novel treatments to meet urgent clinical and public health needs.

PROJECT INCEPTION

The inception of AMP® SCZ was made possible through the efforts of advocacy groups dedicated to integrating perspectives from lived experience into research. In particular, OneMind, a nonprofit dedicated to improving the lives of those impacted by mental illness, provided seed funding and lived experience perspectives that led to establishing the North American Prodrome Longitudinal Study (NAPLS)—the first major research consortium dedicated to investigating early detection and intervention strategies for psychosis. This support from OneMind was crucial in building a scientific foundation to advance research on early identification and intervention strategies[14]. Building on the discoveries from NAPLS, the National Alliance on Mental Illness (NAMI)—a grassroots organization committed to empowering individuals and families affected by mental illness through education, advocacy, and support— played a central role in bringing together key partners from the National Institute of Mental Health (NIMH) and industry to bring AMP® SCZ to fruition. NAMI continues to lead community outreach and foster collaboration with stakeholders to ensure the initiative's success.

GOVERNANCE AND RESEARCH DESIGN

A key feature of the AMP® SCZ program is its governance by a steering committee chaired by three co-leads, one of whom has lived experience of psychosis. This inclusion of lived experience within the governance structure has enabled the program to move forward with a greater understanding of the fundamental challenges, needs, and aspirations of those living with schizophrenia, youth at clinical risk for psychosis, and their families[14]. Moreover, AMP® SCZ has adopted an open-door approach for partners with lived experience, fostering transparency and enabling the genuine integration of diverse perspectives into the project's design. For example, Carlos Larrauri, a steering committee co-chair with lived experience, alongside youth representatives from study sites, played a key role in shaping the AMP® SCZ research plan. Their contributions included feedback on the study protocol, recruitment strategies, accessibility concerns, and the selection of assessments, with particular attention to minimizing perceived burden.

The study sites within the AMP® SCZ consortium, part of either the PRESCIENT or ProNET networks, bring extensive expertise in conducting observational and clinical studies focused on CHR populations. Lived experience is thoughtfully integrated into their organizational structures through a variety of effective methods. For instance, the PRESCIENT network, comprising 17 sites led by the University of Melbourne, incorporates youth board members, site-specific advisory committees, youth peer workers, and a Director of Lived Experience. One site uniquely includes representatives with lived experience on its central ethics committee. Similarly, the ProNET network, which consists of 26 sites led by Yale University, engages peer support specialists who provide valuable feedback on research and clinical operations to the leadership team. These efforts collectively ensure that lived experience remains central to the program's governance and research design, fostering a more inclusive and impactful approach.

IMPLEMENTATION

In addition to the governance structure, lived experience integration has been included in the development and implementation of study tools and the selection of key outcomes for analysis. For example, the mindLAMP[15] digital assessment platform used in AMP® SCZ was developed over five years with over 200 updates[16,17] based largely on stakeholder input. MindLAMP is a smartphone-based app for real-time data collection, and its design directly reflects the input of various stakeholders with lived experience, ensuring that it meets the needs of study participants. This collaborative co-design approach, along with the active sharing of app-generated data back to user[18,19], has fostered trust and led to high engagement rates, with over 80% of participants consistently using the app. The resulting data from this strong user engagement is now proving valuable in supporting AMP® SCZ's goal of creating a foundation for developing new treatments with digital phenotyping.

Contributions from individuals with lived experience have also been central to advancing tools to measure early identification and diagnosis. At ProNET, young people with lived experience of CHR are advising on a US FDA-sponsored project to evaluate the content validity of the PSYCHS, which measures symptoms and severity of early psychosis[20]. As examples, participants are providing feedback on whether the PSYCHS items capture health experiences that are important to them and whether health experiences that are important to them are missing. Similarly, in collaborative work sessions with researchers, data scientists, and clinicians, Mr. Larrauri shared his personal experiences with psychosis—including insights into key features such as identity changes, isolation, suspiciousness, altered salience processing, trauma/stress, anxiety, and cognitive shifts—to aid in the selection of target features for a natural language processing (NLP) project. His input helped identify key distinctions between CHR and community control participants. Researchers then explored how NLP and large language models (LLMs) could extract these features from interviews. The result was a method that combined lived experience narratives, research, and advanced technologies to track symptoms and improve early detection[21].

OUTREACH AND DISSEMINATION

In early 2021, a Website and Outreach Workgroup (WOW) was established to oversee the outreach efforts of the AMP® SCZ program, aimed at serving both researchers and stakeholders within the program and individuals interested in learning about resources available to anyone experiencing the CHR syndrome. Led by investigators at Brigham and Women's Hospital and McLean Hospital, NAMI, NIMH, and the Foundation for the National Institutes of Health (FNIH), the WOW group works closely with all the other cores and domain teams within the program to deliver a consistent message about the AMP® SCZ program across participating sites and to the broader community. Advocates from

NAMI were joined by OneMind, a nonprofit focused on research that was introduced at the beginning of this article, and Mental Health America, a leading nonprofit organization dedicated to advocating through education, support, and public policy initiatives, to ensure that the voices of lived experience were front and center in discussions held in the WOW group and all materials disseminated from the AMP® SCZ program. These presentations were aimed at guiding the research effort towards a lived experience-informed understanding from the outset.

The WOW group launched the AMP® SCZ website (https://www.ampscz.org) in May 2022 to establish and maintain the AMP® SCZ internet presence for dissemination and outreach. The website conveys the aims and activities of the AMP® SCZ in plain language for a wide range of research, clinical, and lay audiences. The website features and regularly updates information regarding (a) study participation, including study purpose, eligibility criteria, FAQs, and information for clinicians; (b) a map of study sites with contact information and educational information on schizophrenia and clinical high-risk; (c) materials for the scientific research community including the study design and protocols, data sharing information, and software tools used for the study; (d) study news and events including study recruitment updates, published papers, videos, and other resources.

In the 29 months since launching, the site has garnered more than 24,000 visits and more than 47,000 page views. As noted above, the WOW group coordinates closely with NAMI advocates and individuals with lived experience, ensuring content alignment in the website creation process. Under the guidance of NIMH and FNIH leadership, Booz Allen Hamilton, a renowned consulting firm, guided the team through crafting a Section 508-compliant website. This ensures the website meets specific accessibility standards, making it usable for individuals with visual, auditory, motor, or cognitive impairments. The website includes links to partnering advocacy organizations, and it regularly features content by individuals with lived experience including articles, podcasts, and recorded talks.

As previous literature suggests, we have seen positive effects of our deliberate inclusion of lived experience throughout all phases of AMP® SCZ, including through the WOW group's efforts at outreach and dissemination. For example, approximately 20 percent of the AMP® SCZ website traffic is referral traffic, i.e., visitors click a hyperlink on a different website that takes them to the AMP® SCZ website. The second highest source of referral traffic is the NAMI website, indicating that those with lived experience and their family members have likely been visiting the AMP® SCZ website. This suggests that including people with lived experience and advocacy groups at all stages of the program builds a bridge of trust between potential research participants and the scientific community, which is critical both to recruitment efforts and to ensure that participants are being treated by the research community with respect and proper consideration.

In addition, the second and third most popular pages of the website are the Study Sites and the Schizophrenia and Clinical High-Risk pages. The Study Sites page displays a searchable map of the world where visitors can search for study sites near them. The Schizophrenia and Clinical High-Risk page is an information page about Schizophrenia and Clinical High Risk. Only the website homepage receives more page views than these two pages.

Beyond the website, lived experience partnerships have significantly advanced innovative and impactful approaches to research dissemination. ProNET has collaborated with experts by experience to co-design, co-write, and co-produce articles published in leading psychiatric journals, showcasing a commitment to participatory initiatives as a means of dissemination[2,3]. Additionally, AMP® SCZ holds Annual Meetings, which conclude with a panel of lived experience experts sharing their stories and experiences, with suggestions on how to better center patient voices. The feedback we have received on these sessions from investigators, leadership, and partners has been overwhelmingly positive and unanimously confirms that these portions of the annual meetings are highly powerful and motivating and that the contributions of people with lived experience to this study not only enhance outreach and dissemination but deepen our commitment to the work.

A VISION FOR INCLUSIVE RESEARCH

The AMP® SCZ program has seen tremendous value in embedding the lived experiences of individuals with psychosis into each stage of the research process. However, given the inherent diversity within schizophrenia, one limitation of our current approach is the reliance on input from key thought leaders and small sample groups from the patient advocacy community at only some of the sites in the network. This method may not fully capture the range of experiences and perspectives across the schizophrenia spectrum. Moving forward, future research efforts should adopt more systematic approaches that include larger, more diverse samples, particularly involving youth, young adults, and individuals from global backgrounds, to ensure insights that are inclusive and representative of schizophrenia's varied manifestations.

Despite this limitation, AMP® SCZ remains committed to centering patient voices in its work, aiming to expand its impact through the outreach and dissemination efforts of the WOW group. Our vision is a future in which young people at risk for psychosis are empowered with knowledge and provided with preventive treatment options that foster hope, optimism, and confidence. To realize this vision, we will continue to engage individuals with lived experience in developing outcome prediction tools, establishing a global network, setting the foundation for testing new preventive treatments, and sharing data with the wider research community. We hope these efforts will pave the way for sustained and increased involvement of people with lived experience, making them central stakeholders in every phase of research, implementation, and dissemination.

DATA AVAILABILITY

The AMP SCZ program data are available to the larger research community for further study on the National Institute of Mental Health (NIMH) Data Archive (NDA)[22].

Received: 9 September 2024; Accepted: 24 December 2024;
Published online: 07 April 2025

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ACKNOWLEDGEMENTS

The Accelerating Medicines Partnership® Schizophrenia (AMP® SCZ) is a public-private partnership managed by the Foundation for the National Institutes of Health. The AMP® SCZ research program is supported by contributions from the AMP® SCZ public and private partners, which include NIMH (U24MH124629, U01MH124631, and U01MH124639) and Wellcome (220664/Z/20/Z and 220664/A/20/Z). A full list of AMP SCZ members and affiliations can be found at https://www.ampscz.org/members/ and within the Supplementary File.

AUTHOR CONTRIBUTIONS

The manuscript was drafted by A.A.T., B.Y., C.L., K.E.L., and T.K. All authors contributed to the discussion presented in this comment. A.A.T. and B.Y. share the co-first authorship.

COMPETING INTERESTS

Prof. Thompson has received honorariums and/or grants from Ostuka, Boehringer, Eli Lilly, Janssen Cilag, Lundbeck, Pfizer, and Sunovion. Prof. Arango has been a consultant to or has received honoraria or grants from Acadia, Angelini, Biogen, Boehringer, Gedeon Richter, Janssen Cilag, Lundbeck, Medscape, Menarini, Minerva, Otsuka, Pfizer, Roche, Sage, Servier, Shire, Schering Plough, Sumitomo Dainippon Pharma, Sunovion and Takeda. Dr. Dwyer has received honorary funds for one educational seminar for CSL Sequiris. Prof. Kane is a consultant to or receives honoraria and/or travel support and/or speakers bureau: Alkermes, Allergan, Boehringer-Ingelheim, Cerevel, Dainippon Sumitomo, H. Lundbeck, HealthRhythms, HLS Therapeutics, Indivior, Intracellular Therapies, Janssen Pharmaceutical, Johnson & Johnson, Karuna Therapeutics/Bristol Meyer-Squibb, LB Pharmaceuticals, Mapi, Maplight, Merck, Minerva, Neurocrine, Newron, Novartis, NW PharmaTech, Otsuka, Roche, Saladax, Sunovion, Teva Advisory Boards: Alkermes, Boehringer-Ingelheim, Cerevel, Click Therapeutics, Karuna/BMS, Lundbeck, Merck, Newron, Novartis, Otsuka, Sumitomo, Teva, Terran Grant Support: Lundbeck, Janssen, Otsuka, Sunovion Shareholder: Cerevel (public/stock), HealthRhythms (private/stock options), Karuna/BMS (public), LB Pharmaceuticals, Inc. (private/stock options), North Shore Therapeutics (private/stock), Vanguard Research Group (private/40% owner) Receives Royalties: Up to Date. Prof. Fusar-Poli has received research funds or personal fees from Lundbeck, Angelini, Menarini, Sunovion, Boehringer Ingelheim, Proxymm Science, and Otsuka, outside the current study. Prof. Kahn is consulting Alkermes, Boehringer-Ingelheim. Prof. Woods has received speaking fees from the American Psychiatric Association and from Medscape Features. He has been granted US patent no. 8492418 B2 for a method of treating prodromal schizophrenia with glycine agonizts. He owns stock in NW PharmaTech. Mr. Larrauri, on occasion, consults or is remunerated for lived experience presentations with industry partners. All other authors report no biomedical financial interests or potential conflicts of interest.

ADDITIONAL INFORMATION

Supplementary information The online version contains supplementary material available at https://doi.org/10.1038/s41537-025-00572-7.

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THE ACCELERATING MEDICINES PARTNERSHIP® SCHIZOPHRENIA (AMP® SCZ)

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A full list of members and their affiliations appears in the Supplementary Information.