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ANALYSIS

“Nothing about us without us”—patient partnership in medical conferences

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Using their experience at Medicine X, **Larry Chu and colleagues** discuss the benefits of involving patients as partners at medical meetings

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The expression “nothing about us without us” was first coined by disability rights activists to convey the idea that no policy should be reached without full participation of representatives of all stakeholders.^{1 2} More recently, it has been adopted by patient communities seeking broader involvement with the healthcare system.^{3 4} Although the drive for patient involvement has come from patients, the medical community has much to gain.⁵



Patient involvement in health policy, clinical care, and research has gained momentum in recent years.^{5 6} In the US, the Patient Protection and Affordable Care Act has stipulated inclusion of patient centred outcomes on the quality and experience of care, including public reporting and performance payments related to this aim.⁷ Patients are also involved in medical research, including using patient centred outcomes in comparative effectiveness research. The Patient-Centered Outcomes Research

Institute (PCORI) and other bodies were created to help fund these studies and implement the findings.⁸ Despite this progress, the role of patients in academic medical conferences has been poorly defined, discussed, and implemented.⁹ We describe the benefits of patient partnership in academic medical conferences and how it can be enabled. We define medical conferences to include any meeting where health care issues are discussed for the purpose of educating, evaluating or improving medical care.

What patient involvement can achieve

Medical conferences are convened to spark innovation in healthcare by creating networks of experts, sharing knowledge, forming collaborations, and thoughtful challenging of conventional thinking. Patients can make important contributions in all of these areas by helping everyone understand the problems that matter most to patients, caregivers, and their families.¹⁰

The eighth international AIDS conference in 1992¹¹ was one of the first to integrate patient participation. However, progress since then has been slow, and there is little research into patient engagement.¹² The available evidence includes qualitative semistructured interviews and thematic content analysis of publications and conference proceedings. Such studies show that including patients widens the focus of research, changes the culture of conferences and researchers to use more patient relevant outcomes in clinical trials, and leads to wider patient involvement as partners in research.¹²⁻¹⁵ These findings suggest that patient participation is most important in conferences involving research and policy decisions but, as box 1 shows, it can provide meaningful insights at other types of medical

conferences, such as those with a clinical, quality improvement, or leadership and management focus.

Making it work

While most medical conferences that have included patients report modest numbers of patient participants, a few have reported substantial patient inclusion (10% or more of total delegates) and even patient partnership in cocreating programming in their meetings. The degree of involvement, integration, and accommodation made for patients varies greatly. We highlight a few of the conferences with high patient participation and key insights derived from such involvement.

OMERACT

Since 2002, patients have been engaged as collaborative partners in the biannual Outcome Measures in Rheumatology (OMERACT) conference. About 10% of participants of OMERACT are patients.¹³ Patient partnership was facilitated by strong commitment from the organisational leadership, adequate patient selection criteria, inclusive conference design, and support for patients attending the event.¹² Evaluation shows that involving patients has helped identify new patient reported outcome measures and new domains that are important to patients and provided the patient perspective in developing core and patient reported outcome measures.¹³

Medicine 2.0

Over 35 patients (10% of participants) participated in the Medicine 2.0 conference at Stanford University in 2011 through a scholarship programme.²¹ The conference organiser engaged patient leaders to codesign sessions at the conference relating to patient experience and care.²² This was said to “set a new high-water mark for e-patient involvement”²³ in a medical conference. Patients reported that they valued being shown respect before coming to the event and that e-patients were made “part of the conference rather than just attendees.”²²

Stanford Medicine X

Medicine X at Stanford University was created as a patient centred academic medical conference in 2011.²⁴ The conference was launched with a patient advisory board,²⁵ assembled through a global call for patients and selection of patients through a needs blinded peer review process,²⁶ in addition to an advisory panel that included a pharmacist, nurse, physician, and PhD researcher. Importantly, the conference’s founding charter allocated 10% of conference seats to patients through a needs based scholarship programme with integrated patient mentorship and educational programmes. An interprofessional student leadership programme was added a year later to improve inclusivity.

Since its debut, Stanford Medicine X²⁴ has changed how healthcare providers and patients engage with and learn from one another by amplifying the patient voice in academic medicine. Including the patient voice has moved providers beyond knowing how to treat a disease to learning what it is like to live with a disease. The event has shown that there is more discussion and engagement when a balanced and diverse stakeholder mix is present,²⁷ the importance of patient stories to create a culture of shared values and collaboration at the meeting,²⁸ and the benefit of patient mentorship and educational programmes in preparing patients for contributing to conference educational activities as both participants and educators.^{29 30}

Charters and frameworks for patient involvement

Recently, several organisations have created charters or frameworks for patient involvement in medical conferences. Published in May 2015 by a group of 25 individuals, comprised primarily of patients, patient advocates, and people related to the drug industry, the Patients Included charter consists of five clauses that aim to provide conference organisers “with a means of demonstrating that their events are committed to incorporating the experience of patients as experts in living with their condition while ensuring they are neither excluded nor exploited.”³¹ The European Patients’ Forum has also recently released a charter on patient empowerment for conference organisers.³² Patient advocate Regina Holliday has also shared her best practices for including patients in medical conferences.³³

Finally our group has recently published the Stanford Framework for Patient Partnership,³⁴ which is composed of charter guidelines for including patients as partners in medical convenings³⁵ as well as leadership principles, implementation aids, design principles, and an Everyone Included declaration intended to nurture respect and trust between patients and delegates.³⁶ Our Everyone Included ideal aspires to help cultivate the shared values that all stakeholders have an equal seat at the table throughout the design, prototyping, and implementation process.

Based on our work over five years partnering with patients in a large academic medical conference,³⁷ the framework sets out four pillars of patient involvement for conference organisers (accommodation, codesign, engagement, and education and mentorship). The framework could also be used by prospective delegates to evaluate conferences they are contemplating attending. Our framework was codesigned with patients and has been tested and refined during the organisation of Medicine X over four years. Box 2 provides advice on how to implement the four pillars, and the table suggests ways to overcome some of the obstacles conference organisers might encounter.

Measuring engagement

Use of social media is growing in medical conferences worldwide to disseminate information and spark discussion between delegates. Social media can also be used to study the effect of patient participation on the quantity and quality of discussions at medical conferences—for example, by counting the number of discussions using patient centred words and terms. We examined evidence from global social media discussions from a random sample of 100 medical conferences in 2013 with at least 1000 tweets (median number of patient participants=1). Compared with the 50 conferences with no or one patient participant, the 50 with one or more patient participants had a higher average number of tweets, a higher average number of participants, and a higher average tweet count per participant (fig 1⇓). Analysis of tweets at the 2013 Medicine X conference showed a balanced number of patient, physician, and third party members in the discussion along with a diverse connection of social media interactions between the cohorts, suggesting an exchange of ideas between the participant groups (fig 2⇓).

Conclusion

Patient involvement in academic medical conferences is an important step to bring patients closer to the conversations driving the future of healthcare. Current data suggest that meaningful patient inclusion can help drive discussion and

Box 1: Examples of medical conferences that have included patients

*International AIDS Conference*¹¹—Early (1992) conference that included patients and provided initial evidence that physicians valued patient participation as a means to improve discussion of ethical and policy issues related to healthcare

*Outcomes Measures in Rheumatology (OMERACT) medical conference*¹³—Long term engagement with arthritis patients in the biannual conference has influenced outcome research and contributed to the research agenda by identifying new patient reported outcome measures and new domains that are important to patients

*Neurological Emergencies Treatment Trial (NETT)*¹⁶—Reports growing interest in including patients and patient advocates in the design of clinical trials for neurological disorders and advocates for their inclusion in medical conferences on the topic

American Medical Informatics Association (AMIA)—Included representatives from patient groups to formulate recommendations of the society on health data use, stewardship, and governance¹⁷

*European Congress for Social Psychiatry (ECSP)*¹⁸—A discussion of use of physical restraint included a patient describing the sense of invasion, humiliation, and fear from being restrained and forcibly injected with medication

*National Breast Cancer Coalition (NBCC)*¹⁹—Provides science training to patients to help them engage in a range of local and national conferences where breast cancer decisions are made

Stanford Medicine X (Med X)—Since its founding, patients have been included as delegates (10% of seats), speakers on the main stage, and members of the executive programme committee. Patients also codesign physical spaces at the convening and its educational and mentorship programmes for patients

*European Haemophilia Consortium (EHC) Congress*²⁰—A satellite symposium identified the importance of representing the patient voice in key policy discussions, especially in healthcare technology assessments

Box 2: Four pillars of patient involvement at academic medical conferences

Accommodation—Consider the medical, nutritional, and accessibility needs and financial assistance with travel and lodging arrangements as practical. For example, include patients in designing a designated physical space such as a wellness room that provides attendees with an area to rest or attend to personal care.³⁸ Use of social media and free live streaming should be explored to allow participation by patients unable to travel

Codesign—Patients should be placed on an equal footing with programme creators to help identify core conference themes, select speakers, and evaluate abstracts that relate to patient centred issues.

Engagement—Meaningful numbers of patients should be included in the audience and speaking roles. Patients invited to attend or speak should be able to attend all sessions open to others attending the conference. Patient speakers might be found through local patient advocacy groups, hospital patient and family advisory committees, or targeted social media efforts

Education and mentorship can help patients learn how to collaborate and partner with providers, researchers, and third party stakeholders to fulfil the mission and goals of the conference organiser, hosting society, or institution.¹⁵ They enable patients to participate in creating future conferences and are crucial for a long term, sustainable strategy. Medicine X's programme incorporates peer-to-peer mentoring, advice and coaching on presentation before the event, discussion on how to generalise their experiences to others, a preconference orientation meeting, and postconference educational and support activities through social media and massive open online courses (MOOC)^{39 40}

knowledge dissemination at academic medical conferences and widen research agendas to include new patient centred domains.⁴²⁻⁴⁴ Conference organisers should work towards patient involvement not only to foster the patient voice in academic medicine but also to realise true partnership and collaboration with patients as a means to drive truly meaningful innovation in health care.

Contributors and sources: LFC contributed to writing, editing, and approving the final draft of this article and is the guarantor. LFC has studied and created engagement programs that bring patients as partners into academic medicine and is the founder of the Medicine X programme at Stanford University. AU is the co-founder of Symplur, a healthcare social media analytics venture and creator of the Healthcare Social Graph, which has been used internationally by researchers to gain a deeper understanding of the perspectives of patients, providers, and stakeholders in real time. BK's foundation provides support for patients to attend the Stanford Medicine X conference. He strongly believes that a patient centred and interdisciplinary approach to knowledge discovery and dissemination is effective at accelerating the translation of the sciences from bench to bedside. SEK is CEO/chairman and founder of FMD Chat, a non-profit medical organisation. She has served as an advisor to the Robert Wood Johnson Foundation and keynote speaker at Planetree's International Conference on patient centred care. HC has contributed to and is patient coinvestigator in patient centred outcomes research teams and has served as a member of the Stanford Medicine X Executive Board. JC is a healthcare advocate, healthcare administrator, and is focused on activating patients, community stakeholders, hospital professionals, and businesses to invest in meaningful, inclusive dialogue within the healthcare space. She has also served as an ePatient executive board member for

Stanford Medicine X. ND works on reinventing healthcare delivery to be modern and more desirable by everyone. For Stanford Medicine X, he is part of a team progressing a dialogue around including everyone as equal stakeholders in designing a better health system. He is involved in national level work on patient empowerment, design, and community health and has worked with federal agencies, local governments, and professional organisations. KAC has partnered with patients on identifying research questions and developing research initiatives, is a charter member of the Society of Participatory Medicine, and has served as a reviewer for PCORI and as chair of the scientific advisory panel for Stanford Medicine X. All authors have served in varying advisory roles during Medicine X initiatives; those experiences, conversations, and research efforts have informed their contributions to this manuscript. All authors participated in writing and approving this paper.

Patient involvement: Patients participated in writing and reviewing this article.

Competing interests: We have read and understood BMJ policy on declaration of interests and declare the authors are all involved with the organisation of Medicine X conferences.

Provenance and peer review: Commissioned; externally peer reviewed.

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Key messages

- Involving patients in medical conferences can help delegates to understand problems that matter most to patients and their caregivers
- Involving patients can spark collaborations with patients in healthcare design, education, research, and clinical care improvements
- Patient should be included in the creation of conference programmes and selection of speakers
- Requirements of attending patients, such as facilities for self care and travel expenses, should be considered when planning conferences

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Table

Table 1 | Challenges to involving patients in medical conferences

Challenge	Example	Potential solutions
Terminology	Operational definition of "patient"	The definition of who counts as a patient can depend on local customs and cultures. Patients can partner with healthcare professionals to define the term for each conference context
Tokenism	Checklist-type inclusion of patients and co-opting of patient narratives	Undesirable outcomes can be avoided when patients are meaningfully included in the design, implementation, and creation of a conference
Paternalism	Fears that patients are not able to transcend their personal experience, generalise their experience to others, and understand the rigor of scientific discussions ^{12 14}	Strong leadership, structured patient recruitment, full and equal participation, and multistakeholder design approach with support and training of patients for participation ^{12 14}
Compensation/conflicts of interest	Patients receiving payment for their time or having a conflict of interest	Patients should be compensated in the same ways as other conference presenters and be held to the same competing interest policies
Financial	Cost of registration and travel scholarships for patients, especially where 10% of the audience is allocated to patients	Many events should be able to afford to fund 1-2 patients. Sponsorship or grant support may be needed for greater numbers ¹³

Figures

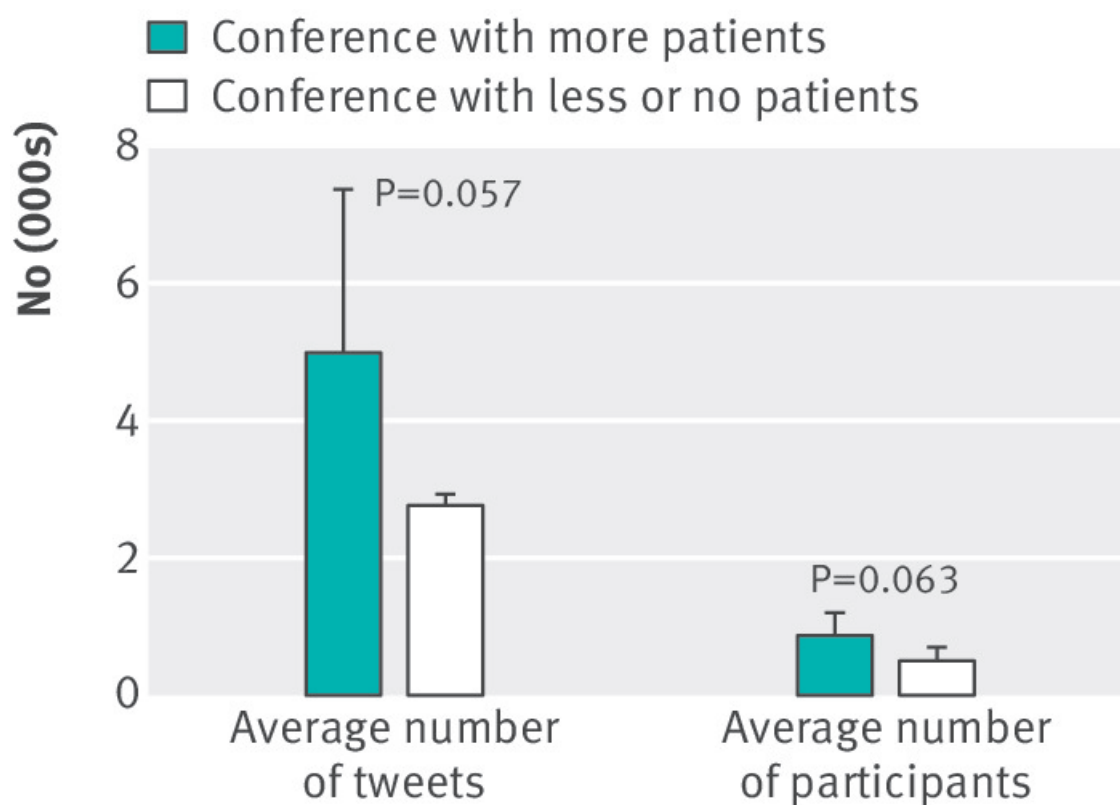


Fig 1 Mean (SD) tweets between academic conferences with more and less patients

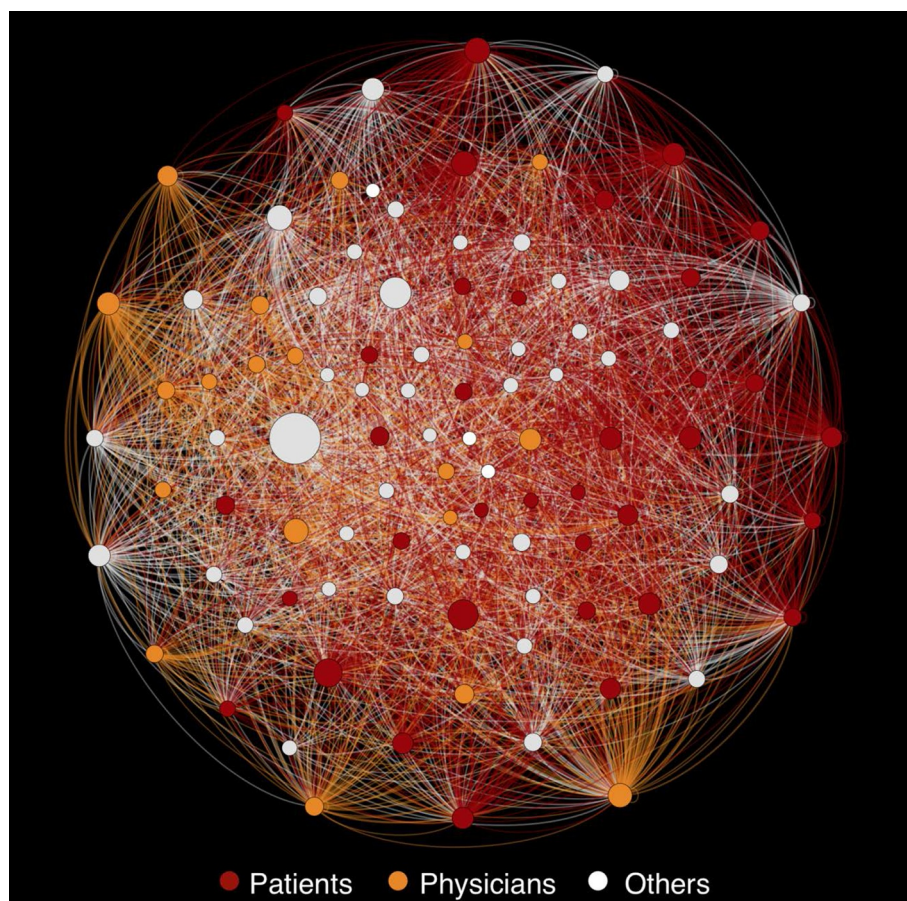


Fig 2 Network centrality graph⁴¹ of the social media conversations on Twitter during the 2013 Stanford Medicine X conference