



## Editorial

# Public and patient participation in health policy, care and research



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Public and patient participation in health has evolved considerably since the World Health Organization's Alma Ata Declaration asserted people's "right and duty to participate individually and collectively in the planning and implementation of their health care" in 1978.<sup>1</sup> The expansion of neoliberal policies in the 1980s, and mounting disillusionment with the "democratic deficit" observed in the 1990s, prompted social movements across the world to demand greater public accountability and the inclusion of lay citizens in decision-making processes.<sup>2</sup> At the same time, governments in several countries began to look for strategies that could bring them closer to the people. One of the methods used to promote dialogue between the state and ordinary people was the creation of institutional participatory spaces in which lay citizens could come together with policy-makers, managers, professionals, and other members of the public, to discuss policy and service provision.<sup>3</sup> This move towards participatory governance was also extended to the health sector. The idea that participation "makes for better citizens, better decisions and better government",<sup>4</sup> together with increasing evidence that participation can improve the quality of health research, health care and public health interventions,<sup>5–7</sup> fostered investment in public and patient participation in health across a variety of countries throughout the 2000s.

At present, participation is both a means to facilitate an interface for state-citizen dialogue and a goal in its own right.<sup>8</sup> Moreover, it is considered a fundamental element of patient-centred care, i.e. the process by which health professionals and patients establish fruitful partnerships to put people at the centre of the system by identifying and valuing patients' needs, preferences and values, while supporting them in making informed decisions.<sup>9</sup> Ultimately, public participation aims to produce transformative change. In other words, it aims to elicit alternative forms of knowledge and expertise that can help identify and implement strategies to address the root causes of health inequities.<sup>10</sup>

Public and patient participation can take multiple forms and enable different degrees of power sharing regarding decision-making processes. At one end of the continuum are one-off participatory spaces, such as listening exercises or health consultation events, in which citizens are asked to contribute their views without further commitment to follow-up action. At the other end

of the continuum are more durable participatory spaces, including health councils and national health bodies, in which citizens can engage in shared leadership. Countries tend to navigate through this continuum as they achieve their goals or switch between priorities.<sup>11</sup> In Brazil, for example, public and patient participation in health care policy is a right enshrined by the Constitution.<sup>12</sup> In the Netherlands, health care services are entrusted the responsibility of creating participatory spaces to involve patients and their family members in care planning and evaluation. Canadian citizens participate at various levels across the health care system, including in health technology assessment.<sup>13</sup> Several funding agencies in the UK demand researchers to state how they plan to involve lay citizens in research projects.<sup>14</sup> And online platforms such as Patient-innovation.com facilitate dialogue between patients and caregivers and enable the sharing of solutions, treatments and devices, which often result from patients own capacity for innovation.

Public and patient participation is also gaining pace in Portugal. Initiatives aimed at fostering the implementation of new participatory spaces<sup>15</sup> that can enable lay citizens to have a voice in health decision-making have recently emerged. In 2016, the forum *Mais participação, melhor saúde* coordinated by GAT – Grupo de Ativistas em Tratamentos was held at the Portuguese Parliament. It gathered representatives of patient and civil society organisations, decision-makers, service managers, health professionals and researchers with the goal of increasing support and advocacy for developing a partnership between government and the citizenry to share responsibility over health care governance. Showcasing a critical mass of stakeholders, the forum set the tone for reinvigorating the goal proposed by the National Health Plan (2012–2016) to promote health citizenship, namely through citizen participation – an idea supported by the Minister of Health who has recently stated that "the individual should be considered an ally in transforming the system".<sup>16</sup> The recently launched National Mental Health Council and the Community Councils at Agrupamentos de Centros de Saúde (Health Centres Clusters) are two examples of consultative health participatory spaces through which this goal can be achieved.<sup>17,18</sup>

Researchers in Portugal, and elsewhere, are also increasingly resorting to innovative methods (e.g. creative visual methods, think tanks, social fora) to involve people who would otherwise be inappropriately excluded from research due to speech or cognitive disabilities, the inability to disclose personal identities to the

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public (e.g. gamete donors), physical distance, or any other constraints that impede them from participating through conventional methodologies.<sup>19,20</sup> These innovative methods carry potential to increase the inclusiveness of research, as well as of other participatory initiatives.

Taking part in health participatory spaces for consultation and shared decision-making will require a new dynamics of collaboration and co-production between the various stakeholders. Moreover, it will require the dissemination of knowledge about and the acquisition of skills for participation. Lay citizens, decision-makers, service managers, health professionals, students and researchers should all be entitled to receiving training adapted to the specificities of the health participatory spaces and initiatives in which they are expected to participate. Future research, practice and policy should therefore focus on allocating human and financial resources to participatory initiatives, designing trainings and building stakeholder capacity for participation, and adapting participation impact assessment tools to the Portuguese context. Despite the financial constraints levied on the National Health Care Service by the financial crisis,<sup>21</sup> it is of utter importance that public authorities and civil society organisations join efforts to address these needs in order to promote transformative participation in health.

## References

1. World Health Organization. Health for all series, number 1. Alma-Ata 1978. In: Primary health care. Geneva: WHO; 1978.
2. Fung A, Wright EO. Deepening democracy. Institutional innovations in empowered participatory governance. London: Verso; 2003.
3. Gaventa J. Towards participatory governance: assessing the transformative possibilities. In: Hickey S, Mohan G, editors. Participation: from tyranny to transformation? Exploring new approaches to participation in development. London: Zed Books; 2004.
4. Cornwall A, Coelho VS. Spaces for change? The politics of citizen participation in new democratic arenas. London: Zed Books; 2007.
5. Mockford C, Staniszewska S, Griffiths F, Herron-Marx S. The impact of patient and public involvement on UK NHS health care: a systematic review. *Int J Qual Heal Care*. 2012;24:28–38, <http://dx.doi.org/10.1093/intqhc/mzr066>.
6. O'Mara-Eves A, Brunton G, McDaid D, Oliver S, Kavanagh J, Jamal F, et al. Community engagement to reduce inequalities in health: a systematic review, meta-analysis and economic analysis. *Public Heal Res*. 2013;1. <http://hdl.handle.net/10552/3349>
7. Brett J, Staniszewska S, Mockford C, Herron-Marx S, Hughes J, Tysall C, et al. Mapping the impact of patient and public involvement on health and social care research: a systematic review. *Heal Expect*. 2014;17:637–50.
8. Organization WH. Ninth futures forum on health systems governance and public participation. Copenhagen: WHO Regional Office for Europe; 2006.
9. Pulvirenti M, McMillan J, Lawn S. Empowerment, patient centred care and self-management. *Heal Expect*. 2014;17:303–10.
10. De Freitas C, Martin G. Inclusive public participation in health: Policy, practice and theoretical contributions to promote the involvement of marginalised groups in healthcare. *Soc Sci Med*. 2015;135:31–9.
11. Marston C, Hinton R, Kean S, Baral S, Ahuja A, Costello A, et al. Community participation for transformative action on women's, children's and adolescents' health. *Bull World Health Organ*. 2016;94:376–82.
12. De Freitas C. Aiming for inclusion: a case study of motivations for involvement in mental health-care governance by ethnic minority users. *Heal Expect*. 2015;18:1093–104.
13. Abelson J, Giacomini M, Lehoux P, Gauvin F. Bringing "the public" into health technology assessment and coverage policy decisions: from principles to practice. *Health Policy*. 2007;82:37–50.
14. Auckland S. BRC guidance: involving users in research. London: Guy's and Thoma's NHS Foundation Trust; 2010.
15. De Freitas C. Equidade, diversidade e participação dos cidadãos em saúde. In: Padilla B, Hernández-Plaza S, Rodrigues E, Ortiz A, editors. Saúde e cidadania: equidade nos cuidados de saúde materno-infantil em tempos de crise. Braga: CICS-UM; 2014. p. 141–52.
16. Brickman S. Panorama meets Dr Adalberto Campos Fernandes, medical doctor, public health specialist and, since November 2015, Minister of Health of Portugal. *Public Heal Panor*. 2016;2:264–7.
17. Portugal. Ministério da Saúde, Regime Jurídico dos Agrupamentos dos Centros de Saúde. Decreto-Lei no 28/2008 de 22 de Fevereiro. <https://www.ers.pt/uploads/document/file/92/05.pdf> [accessed 21.12.16].
18. Portugal. Gabinete do Secretário de Estado Adjunto e da Saúde. Despacho n.º 7306-B/2016 – Diário da República n.º 106/2016, 1º Suplemento, Série II de 2 de Junho de 2016. <http://www.sg.min-saude.pt/NR/rdonlyres/CE1B2B55-9244-46E7-8629-CBEF56793C9B/43945/0000200002.pdf> [accessed 21.12.16].
19. Wilson E, Kenny A, Dickson-Swift V. Using blogs as a qualitative health research tool: a scoping review. *Int J Qual Methods*. 2015;14:1–12.
20. Ferreira V, De Freitas C, Videira P, Krasnewich D, Morava E, Silva S, et al. Needs and opportunities from congenital disorders of glycosylation (CDG): results from the first world think tanks. *Mol Syndromol*. 2015;6:327.
21. Legido-Quigley H, Karanikolos M, Hernández-Plaza S, De Freitas C, Bernardo L, Padilla B, et al. Effects of the financial crisis and Troika austerity measures on health and health care access in Portugal. *Health Policy*. 2016;120:833–9.