RESEARCH
FOR ALL

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Who inspired my thinking? – Sherry Arnstein

Sally Crowe* – *Crowe Associates, UK*

I have been active in Public Involvement (PI) in health research and services for over 20 years. In 1996, when I started, it was a niche activity that was constantly challenging the status quo. A quotation from John Bell of the Iona Community, 'It's usually people of prestige and affluence who advise people of influence', sums up the culture of the time, and it was hard to see how the public could advise and have influence on health research, services and policy.

A great deal of effort, persuasion and patience was needed to achieve quite modest changes, but along the way lessons have been learnt, and approaches and methods for involvement have developed. I observe now that PI is more in the mainstream and is achieving acceptance, taking its place in healthcare and research systems and processes. While my involvement road is well travelled, there are still many miles before we fully understand what constitutes 'good' PI for everyone involved, how to consistently and effectively involve marginalized and disenfranchised groups and what factors are important in the assessment of impact and change.

I am especially interested in how professional and public groups work effectively together to achieve shared goals in research. This includes the methods and approaches used, as well as the less obvious features of relationship building, sustaining effort and enthusiasm, and supporting and getting the best out of everyone. Recent work in setting priorities for clinical research has provided many examples where there are natural tensions between researchers, health professionals and people using health services. Each group brings different perceptions of what research is important, feasible and likely to make a difference.

In the beginning of my career I was looking for structures and frameworks to help me make sense of this complex work, and I found these in the work of **Sherry Arnstein (1930–1997)**. Born in New York, and living and working in California and latterly Washington, DC, she held many different professional roles, including as a case worker in juvenile court, an advisor at the Department of Health, Education and Welfare, a senior research fellow at the National Centre for Health Services Research and Vice-President of the National Health Council.

It was Arnstein's earlier work in public participation in urban-planning decisions, published in the late 1960s, which captured my imagination 20 years ago. Her ideas helped me structure my thinking and application, and – dare I say it – aspirations for PI. She developed and described a framework of approaches for public participation in community planning decisions. Despite being written at a time of radical change in the US, her ideas were still considered provocative, and challenged the status quo. The model to which I was most drawn was her 'ladder of citizen participation', often referred to as 'Arnstein's ladder' (see Figure 1). The ladder is a hierarchy of participation that illustrates the extent of citizen power in determining the plan or programme under consideration. At the top of the ladder, 'citizen control' represents full public participation and control of decision-making, while at the base are passive non-

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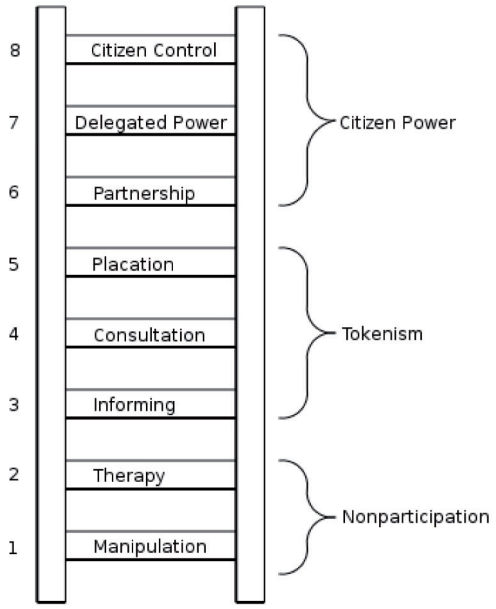
*Email: sally@crowe-associates.co.uk

participatory methods, and even unscrupulous approaches, such as 'manipulation'. Interestingly, she viewed placation, consultation and informing as tokenistic types of citizen participation, and these are in the middle of the hierarchy. While these ideas were not developed for use in health, they have been widely adopted and adapted as experience has grown in public participation in health care decision-making.

Figure 1: A ladder of citizen participation



Source: Arnstein (1969)

I am not fond of hierarchies, so why would this conceptual model of public participation provide inspiration to a fledgling practitioner? Principally it was because it spoke a truth to me. I recognized and had experienced the status quo and hierarchy as a patient, carer and maternity service user; I had felt 'non-participant' in decisions and choices I made for my health, and for that of others. For example, my daughter's birth was problematic and, despite doing my research about the treatments available and their effects (Cochrane Systematic Reviews), I felt disempowered and even subtly manipulated into a delivery plan that was as far away from my aspiration as it could be. In this I experienced the bottom rung of Arnstein's ladder.

I am very grateful to the UK National Health Service staff and system for the ultimate safe arrival of my daughter, but the legacy of that experience sparked an interest in, and passion for, how 'the public' get involved in both micro personal health decisions, and macro societal, policy and research decisions. Up to this point I had been a health professional with a nursing background who was research literate, and had applied this to my personal birth plan. However, I wanted to bring my experiences as a health professional *and* a service user *and* an evidence user together at an organizational level, and I was able to do this with my first PI project working with Maternity Service Liaison Committees (MSLCs). These committees comprised maternity service users, health professionals and service managers working together to improve NHS maternity services in their locality. They were unusual at the time but still exist today. I was excited at the prospect of working with partnerships, my role being to organize, facilitate and evaluate workshops where committee members critically appraised research, and then reflected on how this could inform clinical practice, services and the experiences of maternity service users. Apart from the technical skills of research appraisal, what interested me was the sometimes transformational discussion about the evidence from the multiple perspectives of workshop participants, who viewed the evidence through different lenses.

It felt important to provide a structure and space for equitable and fair discussion and to be prepared to facilitate the sometimes emotive and charged debate in a skilled and respectful way. In some workshops, I observed relationships growing through increased trust and respect between committee members; in others, I observed tokenism and a lack of willingness to really understand and appreciate the different perspectives represented.

MSLCs were expected to operate at the partnership level of Arnstein's ladder, but partnerships rarely come fully formed – they need to be built and nurtured. What I learned in the MSLC project and subsequent partnership working was that they benefit from shared values and goals, effective leadership, mutual respect between members/organizations, time to develop and structures and processes to help discussion and decision-making and achieving consensus.

As well as using Arnstein's ladder for models of public involvement, I have used it as a diagnostic tool for organizations and groups, whereby I ask them to reflect on and map their public involvement activity on the ladder. This can be a revealing exercise; what organizations call public involvement can actually be thinly veiled information giving and information exchange, but nothing that is stretching for the organization or empowering for the public participants. Sometimes I have observed a palpable sense of fear the higher up the ladder we go with public involvement discussions. Citizen control, for example, may be reframed as the public 'taking over' decision-making, with the public being perceived as ill-equipped to make 'good' decisions.

Arnstein's legacy is that we have to acknowledge that hierarchies, power and control are part of public involvement in health, social care and education research and the ways in which we conceive, describe and manage them in our work are vital. As a research community these issues need to be an explicit part of the process of design, application and evaluation of public involvement.

Reflecting on Arnstein's framework in hindsight brings me to a different place from where I started. I have settled on partnerships as my preferred way of achieving change with public involvement. This is primarily affected by ten years of supporting James Lind Alliance Research Priority Setting Partnerships, which produce lists of important research questions from public and professional perspectives and are designed to influence research funding. The James Lind Alliance (JLA) has been a widely adopted model for public involvement in clinical research agenda-setting in the UK. This may be because it has a well-described method that can accommodate thousands of people's perspectives, or it may be because of the set of principles and values that underpin the approach, or the insistence on oversight and neutral chairing of partnerships by JLA Advisors. There are now over 50 partnerships completed, with many more in progress, and I look forward to further evaluation of this approach.

My experience of PI is that it is not linear or simple, is often messy and requires multiple approaches and considerations, but I still respond to the explicit notions of shared involvement and responsibility inherent in the upper rungs of Arnstein's ladder. As well as addressing power in the partnership dynamic, I have other 'Ps' that I think are important. These are: *principles* and values that underpin the *partnership*; a clear *process* and *plan* that takes account of the different *people* that you want to involve and engage with; an acknowledgement of the *politics* that play a part in partnerships; and finally the *product* of the partnership, that is, not losing sight of the *purpose*.

Now, as I work with even more diverse groups and settings, I want to visit the more challenging aspects of partnership working, which are summed up for me by Hilda Bastion (US National Institutes of Health), who spoke about improving the quality of research at Evidence Live 2016: ‘Resist certainty. Stay in the difficult places. Listen to and work with those you disagree with.’

Notes on the contributor

Sally Crowe provides consultancy, training and project management for patient and public involvement in health care research and services improvement and is a Director of Crowe Associates Ltd. She co-authored a *Patient and Public Involvement Toolkit* (BMJ Wiley Blackwell, 2011) and co-chaired the James Lind Alliance (2006–13), a programme of public and professional partnerships that reach research priorities. Sally supports the International Pelvic Pain Partnership, is a member of the Cochrane Collaboration Prioritization Methods Group, Cochrane Consumer Network, British Medical Journal's Patient Panel and a public representative on the Medical Research Council Ethics Regulation and Public Involvement Committee.

Reference

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