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The snakes and ladders of user involvement: Moving beyond Arnstein

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Abstract

For 35 years, Arnstein's ladder of citizen participation has been a touchstone for policy makers and practitioners promoting user involvement. This article critically assesses Arnstein's writing in relation to user involvement in health drawing on evidence from the United Kingdom, the Netherlands, Finland, Sweden and Canada. Arnstein's model, however, by solely emphasizing power, limits effective responses to the challenge of involving users in services and undermines the potential of the user involvement process. Such an emphasis on power assumes that it has a common basis for users, providers and policymakers and ignores the existence of different relevant forms of knowledge and expertise. It also fails to recognise that for some users, participation itself may be a goal. We propose a new model to replace the static image of a ladder and argue that for user involvement to improve health services it must acknowledge the value of the process and the diversity of knowledge and experience of both health professionals and lay people.
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1. Introduction

Recent health service reforms in Western countries emphasise public and patient involvement [1,2]. Increasing participation of users in decisions around treatment, service development, and evaluation has been central to this process. The consequences are becoming clear as relationships between the state and citizens and between the public, patients and organisations within the healthcare system are redrawn. This shift in health policy has generated significant debate in both Government and the media. The key document that continues to shape the theoretical framework for user involvement is Arnstein's "A ladder of Citizen Participation" published in 1969 [3]. Despite its important in shaping thinking this model continues to be applied uncritically, despite thirty-five years of progress in our understanding of the factors that drive engagement.

In this article, we explore the relevance of Arnstein's typology of user involvement to current developments in healthcare, particularly within the English National Health Service (NHS), and draw on comparisons from the Nordic countries, the Netherlands

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and Canada. The choice of these countries is based on common claims to provide universal healthcare, commitments to equity and expectations that health services engage with community organisations [1,4,5]. In addition Canada and England consider lay members on the boards of healthcare organisations as the primary form of public involvement [6,7].

We use these examples, and the published literature, to critique Arnstein's claim that "citizen participation is a categorical term for citizen power. It is the redistribution of power that enables the have-not citizens, presently excluded from the political and economic process, to be included in the future."[[3]: p. 216]. We elaborate a more nuanced model of user involvement. We argue that user engagement and empowerment are complex phenomena through which individuals formulate meanings and actions that reflect their desired degree of participation in individual and societal decision-making processes. Patient and public involvement is more likely to fail, therefore, when there is a mismatch of expectation *or* method. Rather than rely, as Arnstein does, on models of participation constrained by a specific conceptualisation of activism, we conclude that user involvement requires dynamic structures and processes legitimised by both participants and non-participants. These processes must be empowering and enabling at four levels: healthcare system, organisation, community, and individual. Users must have agency and the ability to shape the methods used for their involvement; these may change over time. Such an approach is more likely to lead to efficient and effective user involvement, building a better health service from the perspectives of users and health professionals.

1.1. Stepping on to Arnstein's ladder

An urban redevelopment specialist, Arnstein illustrated her typology of citizen participation in decision making with examples from the U.S. Department of Housing and Urban Development Modern Cities programme. Despite the particular context of her evidence, she suggested that her model was more broadly relevant. "The underlying issues are essentially the same – 'nobodies' in several arenas are trying to become 'somebodies' with enough power to make the target institutions responsive to their views, aspirations, and needs."[[3]: p. 216].

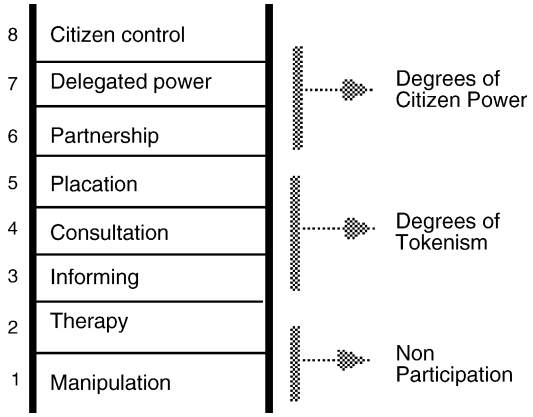

Fig. 1. Arnstein's ladder of citizen engagement ([3]).

For Arnstein, the sole measure of participation is power to make decisions and seizing this control is the true aim of citizen engagement. Thus, the different rungs on her ladder relate directly to the degree to which citizens have attained decision making power with complete citizen control being defined as the highest point (see Fig. 1). Moving from the lower rungs labelled *Manipulation* and *Therapy* through *Informing*, *Consultation,* and *Placation* only the top three steps – *Partnership*, *Delegated Power,* and *Citizen Control* – demonstrate citizen power. Lower rungs are differentiated by the limitations of citizen power and its replacement with participation that does not necessarily influence decision-making. The starkness of Arnstein's framing of citizen participation as an overt struggle for power between government officials and community activists being played out in settings varying from community halls to committee rooms, each party yielding the minimum ground, has been a touchstone for policy makers and activists for 35 years.

Various commentators have redesigned Arnstein's model. Wilcox's [8] ladder has five rungs that reflect various aspects of user involvement: deciding together, acting together, supported independence, while Burns' ladder of citizen empowerment attempts to incorporate degree of participation and quality of engagement [9]. Others have applied the model to working with young people [10,11]. Only Choguill's [12] adaptation, for use in "underdeveloped countries", considers explicitly the potential for organisations to exert a malign influence under the guise of user involvement. Despite the interpretations, refinements, and revisions of Arn-

stein's model, they retain a hierarchical approach and uncritically embrace citizen control as the pinnacle of involvement. The lack of complexity in the conceptualisation of the protagonists in Arnstein's model, its failure to consider the process as well as outcome, or the importance of methods and feedback systems, means that a more nuanced model is required to guide current challenges to user involvement and public participation. In addition other models of user involvement in health have been developed particularly in the last 20 years [13–16] as well as more broadly [17].

2. The justification of user involvement in health policy

This section explores the emergence of user involvement in contemporary health policy. We review British policy, particularly for the NHS in England, before contrasting this with other national settings. Despite widespread public support for the NHS and its principles, its responsiveness to its users has been criticised [18]. User involvement is presented as initiating a constructive dialogue aimed at reshaping the relationship between patients, healthcare professionals and the public and as a catalyst to more widespread cultural change.

The NHS has long sought to demonstrate user involvement and patient centred care; the potential has existed since Community Health Councils (CHC) were established in 1974. Despite their achievements, criticisms including geographical variation in working practices, and an inability to reflect the diversity of local communities led, at least indirectly, to their abolition in 2002 [19,20]. Other developments over the last decade have responded to the growing pressure to be proactive in seeking community views [21] while the Patient's Charter focussed on responsiveness to individual expectations by using the rhetoric of patient rights to clarify service aspirations nationally and from local providers [22–24]. However, the perception of a centralist bureaucracy has remained, reflecting a widespread view that patient-centred services require direct local democracy and demand-led care. In response to these criticisms, new legislation, particularly Section 11 of the *Health and Social Care Act 2001*, mandates more direct forms of user involvement. This requires all NHS organisations to engage with users in service planning and evaluation, and facilitate participation in individual treatment decision-making. The *NHS Reform and Healthcare Professionals Act 2002* established the bodies responsible for implementation while *Shifting the Balance of Power* [25] set out the organisational changes needed to deliver *The NHS Plan* [5].

Further stress on the need for a changed relationship between the public and NHS staff is apparent in the *Health and Social Care* (*Community Health and Standards*) *Act 2003,* which established Foundation Trusts. These new bodies are accountable through local 'members' of the foundation and an elected board of 'user' governors; "empowering patients collectively by increasing the accountability of local health services to local communities." [[26]: p. 13]. The future policy agenda includes changes to the funding of providers and increased opportunities for patient choice over the place and nature of treatment [27].

2.1. User involvement in other countries

The degree of user involvement in developed countries varies but appears to be relatively independent of the type of health system. Developments in the Netherlands, for example, reflect specific aspects of user involvement, with a greater emphasis on legislation than those in the UK [4]. Since 1974, patients and patient organisations have had opportunities to be active in decision-making about treatment and service provision. Until recently, however, representatives, drawn from patient groups, were simply included in consultative bodies charged with developing consensuses on specific healthcare issues. The limited ability of this approach to respond adequately to the rapidly changing and increasingly complex healthcare environment, led The Netherland's government to shift from a consultative to an enabling approach [2].

Since 1996, patients and the public have also had a right to participate in national and local healthcare decision making. Current user involvement in The Netherlands focuses on *patient platforms*, which have a campaigning and advocacy role and are complemented by condition-specific and general patient groups. Providers are required to establish *client councils* and the Government also envisages that users would be involved in policymaking. Dutch legislation links user involvement to diverse aspects of healthcare processes including assuring rights for compulsorily

detained patients, and independent advocacy (mentoring) for patients whose physical or mental health problems limit their ability to exercise self-determination. While good progress has been made under most aspects of user involvement, participation in policymaking has been slow to develop, in part because of hostility from healthcare professionals [4].

Denmark, like the other Nordic countries, involves patients and the public in the health service through local democratic mechanisms. In addition to patients' rights and complaints systems found in all Nordic countries, patient organisations contribute actively to health service development and debate. By comparison, in Finland, involvement is mostly passive and largely exercised through local elections. In most areas, although agenda and minutes are available health (or health and social services) board meetings are private and patients and the public have no right to contribute. Patient organisations circumvent the limitations of this approach through direct provision of services in response to patient's needs and preferences, and through regular, often unsolicited, communication with municipalities and provider organisations. Their involvement in policymaking is usually limited to participation in working groups established by the Ministry of Health and Social Affairs to tackle specific issues.

Sweden distinctively employs a policy gradient approach to patient involvement in health service development; those most likely to be adversely affected by any policy changes must be consulted, particularly people with mental health problems, physical or sensory disabilities [28]. Some local authorities are developing more extensive dialogues with their local communities, but without a structural or policy framework, this requires the enthusiasm of local politicians and civil servants [29]. Users and voters in Finland and Sweden have few opportunities to challenge the existing power of professionals and politicians despite the local democratic accountability, high levels of voter turnout and, particularly in Finland, the importance of local taxation and co-payments for health service financing.

Despite its long history, the legitimacy of existing forms of user involvement in Canadian health services continues to be challenged. Current structures are similar to those in England with an emphasis on competent citizen governors, public reporting of performance and various mechanisms to ensure that patients can access care and have their complaints addressed. The Romanow Commission (2002) proposed enhancing citizen involvement in policy development and strengthening accountability between citizens and policymakers. Implementation, however, remains at an early stage and a recent review identified shortcomings in consultation and reporting processes [7].

Across these different healthcare systems, the varied approaches to user involvement illustrate the underlying tensions in the relationship between professionals, public and service users. While evidence of their success is mixed, only the Dutch and English systems incorporate a systematic approach to engagement with users, patients and the public in policymaking although in practice the outcomes are more mixed.

3. Theoretical justifications for user involvement: Voters, taxpayers and consumers

The diversity of approaches to user involvement is often a reflection of different theoretical bases but chief among these is the need for health services to be accountable to users as taxpayers, voters and consumers. These three aspects of accountability are highlighted in UK policy and are often used interchangeably as illustrated in the following quote outlining the inspiration for NHS reform.

"...a commitment to give people at a local level the power to make decisions about the range of services that are needs. This means involving all the key stakeholders locally, in partnership with Health Authorities and health professionals. Patients, carers, and the local public therefore have a key role to play in this process...This means giving patients more information, and encouraging healthcare professionals to treat patients as equal partners in the decision making process." [[30]: i].

3.1. Local democracy-accountability to users of the service delivered at a local level

In England, as we have already noted the recent legislation on Foundation Trusts stressed patient and public involvement grounded in local democratic processes. This mandatory approach seeks to ensure that current user's views are not prioritised over other res-

idents (or employees), who may be future service users [26]. Unfortunately, however, delegating power by expanding opportunities for electing local residents does not guarantee local accountability or engagement with the spectrum of users. Current local democratic processes have three key weaknesses that limit their ability to deliver the promised improvements in local ownership and citizen centredness [31].

First, relying on local democratic processes may close off other options because the ballot box is seen as the highest form of user involvement. As already noted countries such as Finland and Sweden offer only limited opportunities for direct user involvement in health service policy and planning. Instead, elected members are included on municipality and health service boards. Effective representation, however, requires a clear mandate, informed decisions by local people on key health issues and an ongoing process of active engagement with users and the public. By comparison, there is scant evidence that public participation has influenced local authority decision-making beyond special initiatives in one Swedish county [29].

Secondly, expecting people to participate in formal election processes may exclude members of populations that are both more likely to require health services and, historically, have been less well served. Such approaches may perpetuate institutional discrimination by emphasising the election process over inclusion of a range of views. Typically, this form of user involvement presumes an adversarial method of selection that may be problematic in a culturally diverse society where not everyone shares a common understanding of dialectic-based approaches. Others may not trust the democratic process or public organisations such as those who have been homeless, used street drugs or have experienced mental illness [32–34].

Thirdly, there are difficulties recruiting and retaining involved users and once elected, user members may not participate. Most user involvement initiatives require a critical mass of interested people who will stand for election, attend regular meetings and participate in training. In one North London area, during 1999–2000, more than half of the members attended less than two-thirds of the full CHC meetings and only a third attended more than two thirds of the meetings of project groups for which they had volunteered [20]. The results of the elections of the Board of Governors of Foundation Trusts and the composition of Patient Forums in England reinforce this trend [35].

Health services rely, in part, for their legitimacy on engaging local people to reinforce perceptions of local democratic accountability. This may increase user and public frustration and lead to the development of parallel national processes. Sweden, for example, undertakes parallel consultation over national health policies and strategies with specific user groups or their representatives (‘gode män’) [36]. In practice, most user involvement systems rely instead on indirect mechanisms and passive forms of representation which reinforce existing power hierarchies and social inequality [37] limiting opportunities for influencing service design [38].

3.2. *‘Citizenship-taxpayers’ fund public health services*

A second justification for greater user involvement relates to the public funding of national health services. Emerging from a decade of neo-liberal inspired public sector reform [39], many Governments remain concerned with ‘value for money’ justifications for public spending and increasingly feel the need to strengthen the public’s voice in decisions about the organisation and delivery of health services. More recent reforms embrace this philosophy by seeking to empower staff to be responsive to the expressed needs of users [25].

The shift from *patient* involvement to *patient and citizen* involvement and the current categorization as *public and patient* involvement appears to recognise that most residents who are not citizens remain taxpayers and potential patients. Within EU countries, media representations of the impact of health tourists and asylum seekers on strained health services and Government concerns may lead to the evaluation of patient entitlement on the basis of citizenship and country of residence [40,41]. While all citizens of EU countries have a right to access health services in any other member state these are limited to services at the equivalent level as those provided by their home country. That is, the level of health care provided as part of a public health service, and the costs to the individual vary significantly across the EU. A more rigid evaluation of the definition of ‘patient’ has the potential to return user involvement to the realms of citizenship and

deny a role for the larger public that includes residents and taxpayers who are not citizens of the country the live in.

3.3. Consumerism-informed consent

The shift from patient to customer, user, or consumer has been central to neo-liberal approaches to rationalising health services, facilitated by managerialism [42] and marketization [43]. Promotion of a *patient choice* agenda, however, redefines the focus of health service provision and reframes healthcare providers as *vendors*. User involvement is then presented as the feedback mechanism for the expression of consumer views; an essential component of markets. However, to be consumers, patients must have the necessary information to choose, and their choices must change service provision.

Health policy in England has moved steadily towards the creation of market relationships. As Marinker observed, "In contemporary Britain, citizenship is confused with consumerism and democracy with marketing. Choice and individualism are elevated to the status of moral imperatives,. . .The consumer is characterised not only by the right to choice but also by entitlement to redress." [[44]: p. 13]. Indeed, greater scope for patients to choose where they will be treated has already been piloted in London [45] and is currently being implemented more broadly. Policies that fragment populations raise particular problems for public health, as health services rely on risk sharing which, like equity, is undermined, not by flexibility or responsiveness, but by individualism.

The evolution of consumerism in health policy is, in part, justified as promoting patient-focused care and as the logical extension of informed consent. Similarly, consumerism is presented as a mechanism for redressing the power inequality between health professionals and patients. These intentions are apparent in British health policy. "NHS care has to be shaped around the convenience and concerns of patients. To bring this about, patients must have more say in their own treatment and more influence over the way the NHS works." [[5]: p. 88]. Longley suggests, however, that "The preference for consumerism and individual choice is more about customer relations than any enhanced rights which entail true partnership or power sharing." [[46]: p. 147].

Justifications and definitions of user involvement in public services occupy a continuum between democratic and consumerist models [47–49]. Typically, the distinctions relate to rights inherent in citizenship versus those of individual choice in the marketplace. As Ignatieff has asserted "It is a symptom of the crisis of citizenship,. . .that most political rhetoric, whether left or right, addresses the electorate not as citizens but as taxpayers or as consumers. It is as if the market were determining the very language of political community." [[50]: p. 71]. The aims of user involvement and the methods used to engage users can only be understood with regard to the relative primacy of one of these justifications.

4. Problems with Arnstein's ladder

Our critique of Arnstein's model has three main strands: missing rungs, snakes and multiple ladders. We outline missing rungs that relate to key factors in user involvement that Arnstein's model does not consider. Secondly, we identify some adverse effects of applying Arnstein's model; we refer to these as snakes. Our third category of criticisms reflects the limitations of a model that focuses on the single dimension of power – a single ladder – and is interested only in outcomes, rather than processes, of involvement. These arguments create the basis for constructing a new model and metaphor for user involvement.

5. Missing rungs

Arnstein ignores several aspects of user involvement by failing to differentiate between method, category of user and outcome. The pre-conditions for users to become involved, trusting in the process and the outcomes and the tension between involving some people intensively and involving many people in a limited way, are also excluded from her model. Finally, the hierarchical approach embraced by Arnstein's ladder leaves little opportunity to engage in evaluating the nature of involvement.

Different user involvement methods are required to secure active user participation in health service decision-making at individual, care group, and organisational levels. Arnstein's ladder of participation is

an over-simplification as it conflates means and ends, implying that user empowerment should be the sole aim. Arnstein is vague about the methods adopted to involve users and sees no relationship between the aims of an involvement exercise, users who participate and the methods adopted to involve them. Its application to healthcare is problematic because, on its own, it does not meet the needs of patients, carers or staff.

Further, the model fails to reflect the different forms of participation desired in health related decision-making, or the range of users that exist. There is an imperative to improve the care of invisible users, for example, those who must rely on others to facilitate physical participation [51]. The Swedish system provides specific safeguards, ensuring that the views of potentially disenfranchised groups are sought. Few other countries provide the opportunity to learn from the views of those who avoid the healthcare system; in Finland, where around 22% of specialist ambulatory care takes place in the public sector [52], there are no mechanisms for feeding back the views of non-users [53].

Most user involvement in the British NHS is indirect [54]; a simple collation of users' views or what Arnstein labels *consultation*. Yet, the dominant method of user involvement that shapes policy development at Trust level is membership of various boards; categorised by Arnstein as *placation*. In Foundation Trusts, for example, staff, local residents and patient members must make up over half of the Board of Governors. Similarly, several schemes that train users for involvement[1] concentrate on improving confidence and developing skills required for committee and board membership. This approach while admirable does not alter the scarcity of board level posts available to users. Consequently, health organisations will inevitably fail to involve the diversity of users or capture their views and aspirations for services [55,56].

Arguably the most important missing rung in Arnstein's ladder associated with methods is the failure to consider the essential role of users in framing problems and not simply in designing solutions [57]. Other than the ultimate aim of citizen control, Arnstein provides limited help to guide the formulation of clear objectives for initiatives designed to increase the role of users or the public and espouses vague principles without specifying rights or considering the need for process and outcome evaluation. In Arnstein's model, the need to devote time and expertise to the process of developing trust, capacity to participate effectively and to build consensus around the agenda and goals are not considered [58–60].

There is also no attempt to balance the intensity of user involvement and the proportion of people from a population or community of interest who participate. Examples of time-intensity-numerical involvement trade-offs arise from a combination of economic theory and analysis of participation in specific initiatives, but they fit with everyday experience [61,62]. While improved methods might increase the proportion and diversity of the population involved, it is unlikely that it will ever be possible to avoid the use of proxies for the voice of users and the public. Capacity building initiatives can disseminate the skills and authority that are a prerequisite for involvement among users and members of the public, but officials are rarely in a position to transfer their workload or responsibility. For this reason, concentration on the delegation of power from officials to users does not lead to citizen control unless authority and responsibility are also delegated.

6. The Snakes lurking in Arnstein's ladder: critiques of the model

In addition to its limitations – the missing rungs – Arnstein's ladder also ignores the appearance of several dangerous snakes all of which limit or undermine the ability of this model to increase user involvement in healthcare. Particular snakes relate to the impact of the model on users and voluntary organisations, its potential to limit sustainability and promote decisions based on 'the tyranny of the majority'.

Arnstein says little about ensuring the sustainability of any development designed to increase user involvement. Evidence of effective ways of improving engagement, participation and implementing organisational change suggests that they must also be reflected in professional and management relationships with patients, carers and other representatives of the lay pub-

[1] See for instance the programmes run by Cancer Care Macmillan (www.cancervoices.org.uk) and the British Heart Foundation (www.bhf.org.uk).

lic [63]. Involvement is different from empowerment. The acknowledgement of a user's agenda may be as important as involvement in decision-making. Creating more opportunities for users to be involved in different aspects of the health service may produce a shift in power structures. However, while power relationships may change, reliance on Arnstein's hierarchical model may lead to assumptions that power will trickle down from involvement and limit the sustainability of such efforts if change is slower or more limited than expected [8].

In practice, user involvement is often based on 'subcontracting' the responsibility to a local voluntary organisation; an example of Arnstein's category of *Delegated Power*. Yet such an approach may result in significant opportunity costs for the voluntary organisation and is likely to realign the group's aims [64]. More importantly, such an approach allows health organisations to disengage from user involvement activities; it is the process rather than the outcome that has the greatest potential for changing organisational culture. Thus, while superior in Arnstein's typology, *Delegated Power* may be less effective in ensuring that user involvement affects the work or orientation of health organisations. Furthermore, such approaches take little account of diversity, and have the potential to reinforce existing patterns of inequality.

There is also a danger that citizen control will lead to service provision that meets the needs of some people more than others. Arnstein's ladder takes no account of the comprehensiveness or depth of participation. A truly empowering system would demonstrate safeguards to protect the rights of people with rare diseases, provide space for people with dissenting views, or those for whom services need to be tailored differently. An emphasis on direct citizen control, therefore, risks producing services that reflect the weight and volume of opinion even when this 'tyranny of the majority' would disadvantage others [65]. Unthinking use of Arnstein's ladder allows us to eschew employment of expert proxies or enablers who can facilitate involvement by those whose participation would be otherwise limited, for example younger people [11,66], people with learning disabilities and prisoners. It also provides limited space to adopt the innovative methods required to actively engage and empower members of these groups who might otherwise be ignored [67].

7. Multiple ladders

Arnstein's definition of user involvement is one-dimensional, based on user's power to act in formal decision-making processes. Such an approach, as we have already noted, takes little account of the distinct, but overlapping, theoretical justifications or types of user involvement. Involvement may be a governance mechanism, a method of releasing or enhancing social capital, or a feature of service delivery [61]. Within these categories, user roles vary from participation in decisions about treatment and care, service development, evaluation and research and teaching.

Patient participation in treatment decisions is one type of user involvement but as a form of patient centred care is not innovative. Similarly, involvement in service development, typically a consultation exercise with the local community, has a long history in the NHS. Attempts to ask users to prioritise services (for example, care for one condition over another) occur less frequently [68], particularly in primary care [69]. The evaluation of services by users, however, has become common practice; simple satisfaction questionnaires, and more robust investigations, are now part of many audit exercises. Complaints and appeals are seen as a source of service evaluation data [70]. Indeed some NHS organisations are integrating their patient advice and liaison service, patient forums and complaints handling without considering the significant differences between the populations involved and the nature of the evidence they collect. For instance in Bradford the complaints manager is responsible for "the development of the PALS service within the trust and the implementation of the patient and public involvement agenda" [71].

One final category of user involvement relates to participation in research. The promotion of randomised controlled trials as the gold standard research methodology has increased calls for greater user involvement in research strategy [72,73][2]. The advice on research governance in the NHS identifies the involvement of users in developing good practice [74]. Users, as patients, have been involved in teaching medical students through testimonials about their own experience

[2] See also Involve, previously Consumers in NHS Research www.invo.org.uk.

and, more recently, through participation in curriculum development [75].

Clearly, there are interactions and linkages between different categories of user involvement: service development may have a direct impact on the range of individual treatment options that exist and service evaluation may identify inequities in access that affect individual participation in treatment. User participation in setting a research agenda may have an impact on shaping provision and service organisation, and therefore options for treatment [76].

Several methods may be employed to generate user's views, proposals for research and to change the organisation and delivery of services. The methods – whether questionnaire, focus group or membership of a board – are not particular to the category of involvement being sought or the type of users being involved; often multiple methods are necessary to reflect the diverse range of relevant users and their views [54,77,78].

One adaptation of Arnstein's model would be to incorporate different ladders for the different types of user involvement. Arnstein's approach concentrates on vertical approaches – the relationship between public sector organisations and the individuals being served - and fails to consider horizontal accountability. The responsiveness that communities require of local groups and public authorities require from governance mechanisms is often horizontal rather than vertical. For instance in England, local government overview and scrutiny committees relate to local primary care trusts, hospital trusts and regionally to strategic health authorities. A multiple-ladder model that accounts for different types of user involvement would also need to incorporate bridges between ladders producing horizontal integration. This 'scaffold model' captures some of the structural variation but retains the hierarchical structure premised on power and cannot accommodate outcomes associated with process [10].

7.1. Lay expertise

Policy documents often acknowledge categories of user expertise distinct from that of health professionals and managers [5,30]. While this has been stressed most strongly in relation to chronic illness and the promotion of self-management, it also underpins the increasing stress of patient participation in treatment decision making and has been labelled by others as the 'autonomous patient' [79] or the 'resourceful patient' [80]. Despite this, the nature and extent of such expertise may be contested [81]. In launching the Expert Patient programme in 2001, which draws heavily on peer learning, the Chief Medical Officer of England Professor Sir Liam Donaldson said,

"It has long been recognised that people with chronic diseases have considerable knowledge and experience of their own illness. Research has shown that with proper training this can be turned into practical skills to enable the patient to play a bigger part in managing their own condition. . . . Patients will receive the support to help them take more control of their own health and treatment, to make more appropriate use of health and social services and feel empowered in their relationship with healthcare professionals" [82].

This gives the impression that it is only when users are appropriately trained and supported that they can be regarded as 'experts'. While there is a clear difference between participation in a specific research-based programme and being an 'expert by experience', some categories of user may be valued over others. A typical response to user involvement is that participants are not 'representative' of all users; this is often mirrored in the response that vocal health professionals are also atypical. Central to the utility of involving users is the acknowledgement of the applicability of their experience, and a perspective distinct from that of health professionals.

While acknowledging the limitations of experiential knowledge [83] we suggest that the key contribution users make arises from their distinct personal experience and non-medical or technical frame of reference; it is asking questions that health professionals have not considered. One aim of user involvement may be to break down boundaries, share experience, and build understanding. This suggests not a hierarchy of knowledge – relevant professional versus irrelevant lay – but rather a complementarity between forms of knowing, set within a willingness to acknowledge differences. Arnstein's approach conceptualises user involvement activity as a contest between two parties wrestling for control over a finite amount of power. This adversarial model seems to exclude opportunities for collaboration and shared decision-making and may simply lead to the creation of a new class of user elite. Further,

this approach assumes that lay knowledge is as valid in all types of decisions about service evaluation, service development, treatment, and research as clinical knowledge.

8. A new approach: avoiding the snakes and the ladders

Developing and applying a more realistic model of user involvement requires a move beyond the dichotomy of representative versus other, inclusion versus exclusion that are Arnstein's focus. Instead, a variety of involvement methods that tap into complementary communities of users, draw people at different points in their life, illness or care pathway is required to ensure relevance for different types of user involvement. Effective user involvement must be founded on connections to a multiplicity of individuals and groups and the integration of one-off and more continuous involvement. A linear, hierarchical model of involvement – Arnstein's ladder – fails to capture the dynamic and evolutionary nature of user involvement. Nor does it recognise the agency of users who may seek different methods of involvement in relation to different issues and at different times. Similarly, Arnstein's model does not acknowledge the fact that some users may not wish to be involved. Models of user involvement should incorporate the range of potential involvement desired by the diverse members of a multicultural society engaging with a complex, changing system like the health service. They must also acknowledge that user involvement requires that the structure and process be dynamic and negotiated by users themselves.

Arnstein's model uses the term citizen uncritically as a catch all for any individual resident within a community who wishes a voice. While there is an acceptance that citizens are not homogeneous, diversity is considered primarily in terms of disability, socioeconomic status, and ethnicity. This limited conceptualisation allows Arnstein's model to be framed in purely competitive terms; a zero-sum game [84] in which the decision makers hold all the power. A more appropriate approach must recognise the multiple sources of potential user power, the dependence of decision makers on user support, and redraw the context within which conflict over the ability to influence decisions occurs.

We propose the term '*social citizenship*' to differentiate actions that illustrate the relationship between individuals in a population and their local institutions, from citizenship as applied in the more restrictive, legal sense. User, public, and patient involvement is better conceptualised in relation to the effectiveness of the relationship in reflecting the degree to which particular localities and health organisations relate to each other and encompass the diversity of the local, regional and national population.

To incorporate such diversity, user involvement models must have multiple ladders - reflecting different categories of user - some with more rungs than others. Multiple bridges between the ladders are also required. The resulting scaffold, while capturing the complexity of the situation, loses utility while still being dependent on hierarchy. Rather than a ladder-based model, we propose a different analogy to aid understanding of how user involvement systems should be created; the mosaic. A completed mosaic creates a picture that is the product of the complex and dynamic relationship between individual and groups of tiles. Tiles of different colours and shapes are essential to creating a complete picture, which without systematic integration reveals only chaos. This analogy captures interactions between individual users, their communities, voluntary organisations and the healthcare system on which successful user involvement depends. The importance of user involvement is the engagement of diverse users and health professionals as co-producers. The mosaic illustrates the relationship between horizontal and vertical accountability and enables user involvement to be mapped and monitored.

Building a successful user involvement system requires connecting with diverse individuals and groups at local, organisational, and national levels. One approach might be to invite all identifiable community groups and individuals interested in health. This form of self-selected engagement, while not necessarily representative of particular populations, would seek to provide equality of opportunity. More importantly, it would establish a form of user involvement in which participants bring their own experience while drawing on their constituencies of interest. This set of mediated relationships brings with it a diversity of views and breadth of engagement, adding validity and depth while grounding the process in a particular context. User participants and local groups become co-producers of

healthcare policy and practice at individual and community level rather than being passive recipients of services. The need to link active and intelligent patients to participation in their ongoing care, and the centrality of patient and public involvement to the design and delivery of health services has been championed for 30 years by Tudor Hart [85,86].

Evaluation of the quality of user involvement receives little attention in Arnstein's approach. There is an assumption that the transfer of power will improve the quality and the quantity of involvement. User involvement must engage at the micro level but also feed into organisational planning. Meaningful user involvement requires that users' views have a direct impact on shaping healthcare activities and processes, but this cannot ensure service improvement. Cycles of evaluation must be inherent in user involvement systems. Such evaluation must explore users' satisfaction with the process and measure the effect of involvement activities on decisions about treatment, service development, and research. Without clear evidence that involvement is linked to change, there is little chance that individual users or groups will remain engaged. Without evaluation, professionals will have little confidence in user involvement and resist attempts to engage them in this agenda.

9. Conclusions

For 35 years, Arnstein has been central to developing our thinking on the engagement between individuals and public sector elites. The world has changed and the policy concerns and conflicts that shape contemporary health environments are different. Policy makers need to be aware that applying Arnstein's model closes off options. Just as an overemphasis on ensuring statistical representativeness in user involvement blocks attempts to begin to involve users, Arnstein's emphasis on the transfer of power assumes that power has a common basis for users and providers (or policy makers). Such an approach limits the potential for sharing experience, knowledge and the harnessing of multiple perspectives inherent in successful user involvement.

Ultimately, what is needed is greater attention to evaluating the impact of user involvement on the practice of healthcare and health outcomes. Processes of user involvement seek to transform the culture of healthcare. This requires as much focus on the professional development of providers as the education and recruitment of users. Understanding user involvement as a small part of a larger system helps bridge the divide between micro level changes and system-wide reforms.

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