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Involving the public in healthcare policy

An update of the research evidence and proposed evaluation framework

Annalijn Conklin, Zoë Slote Morris, Ellen Nolte

Sponsored by the Bertelsmann Foundation
The research described in this report was sponsored by the Bertelsmann Foundation.
Public involvement has been advocated as a means to enhance the responsiveness of healthcare systems and it has been sought in various fields of health policy, including health service planning and delivery, health research and priority-setting. Yet despite its obvious appeal, the concept of public involvement has remained poorly defined and its rationale and objectives are rarely specified when applied to the healthcare sector. Also, evidence for its impact on healthcare policy has remained difficult to ascertain. This report aims to update existing work on both the conceptual and the empirical evidence for public involvement in healthcare policy. It also seeks to advance existing work towards the development of an evaluative assessment tool for further analysis. We draw on a comprehensive review of the published literature, supplemented by exploratory observations from selected public involvement initiatives in different health system contexts.

We find that, despite a growing literature base, the concept of “public involvement” remains poorly defined. However as it is a complex and multidimensional phenomenon a call for simple clarification of the concept may not be desirable. Public involvement practice varies by underlying rationale, public motivation to become involved, and specific mechanisms and their relationship to wider social processes. We therefore propose to interpret the term “involvement” as a descriptive umbrella term for the spectrum of processes and activities that bring the public into the decision-making process. We argue that this inclusive term has the benefit of providing a fuller picture of potential involvement, which is independent of normative assumptions.

Sound empirical evidence of the outcomes of public involvement activities in healthcare remains equally underdeveloped. We find evidence for the developmental role of public involvement – such as enhancing awareness, understanding and competencies among lay participants of healthcare decision-making – while the evidence for instrumental benefits of public involvement initiatives, that is whether public involvement improves decision-making and policy in terms of processes and/or outcomes, is less well documented. Yet overly focusing on outcomes of public involvement risks missing the normative argument that involving the public in the process may be seen to be of intrinsic value in itself.

Our tentative evaluative assessment tool of public involvement in healthcare policies aims to help inform the design and evaluation of public involvement strategies in healthcare policy. Yet we recognise the challenges to implementing public involvement policies in practice; these are not well understood and require further exploration.
Thus there may be instances in which involving the public in healthcare decision-making may not be desirable because it threatens equitable access to services. Likewise public involvement initiatives risk losing credibility where they are being reduced to a “legitimation” strategy to justify (predetermined) healthcare decisions. Thus if public involvement is to be successful, it will require careful identification of what any given strategy is aimed to achieve while also requiring policy-makers’ genuine willingness to yield power to the public to ensure the public’s genuine engagement in the health policy process.

Likewise any public involvement strategy that aims to serve a certain purpose and that is appropriate to a certain setting will almost inevitably involve trade-offs. It will therefore be important to identify and communicate these trade-offs for any such strategy to gain credibility and to ensure its support by those who are involved.

Finally, much of the literature seems to assume the dichotomous position of a powerful health service versus a powerless public, in which power is assumed to be a zero-sum game. However in practice there are a number of divisions: between levels of the system, between areas of service, and others. Thus from a research perspective we need to further our understanding of whether and how individuals assume the different roles of active citizen, user and potential user; and how individual expectations and motivations for involvement may be influenced by the structure of the healthcare system, and by social and political values.