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TECHNICAL REPORT

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

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Preface

This report provides the Bertelsmann Foundation with an update of both the conceptual and the empirical evidence for public involvement in healthcare policy and a tentative evaluative assessment tool for public involvement in healthcare policies. It draws on a review of the published literature that is supplemented by exploratory observations from selected public involvement initiatives in different health system contexts.

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Executive summary

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.

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We gratefully acknowledge the very helpful and insightful comments provided by Sharif Ismail and Mirella Cacace on an earlier draft of this report. We are also very grateful to the Bertelsmann Foundation for their support and interest in debating the ideas that led to this report.

The views expressed in this report are those of the authors alone and do not necessarily represent those of the Bertelsmann Foundation. The authors are fully responsible for any errors.

Public involvement policies have been advocated as a means of enhancing the responsiveness of healthcare systems. However, despite its obvious appeal, the concept of public involvement remains poorly defined and its rationale and objectives are rarely specified when applied to the healthcare sector. Florin and Dixon (2004) define public involvement as “the involvement of members of the public in strategic decisions about health services and policy at local or national level”, thus distinct from patient involvement, which refers more specifically to “the involvement of individual patients, together with health professionals, in making decisions about their own health care”.¹

Yet this distinction between public and patient involvement is often not clear cut, with the term “involvement” often used synonymously with “engagement” or “participation”, while “public” is frequently used interchangeably with “citizen”, “consumer”, “lay (person)”, “(service) user” or “patient” – largely reflecting the different perspectives researchers have adopted to conceptualise public involvement. Coulter (2002) suggested that the twenty-first-century health service user is at once “a decision-maker, a care manager, a co-producer of health, an evaluator, a potential change agent, a taxpayer and an active citizen whose voice must be heard by decision-makers”.²

Involvement of the public has been sought in various fields of health policy, including health service planning and delivery, health research and priority-setting. Accordingly public involvement policies may take several forms, including regional/local health councils, as for example in the UK, Australia and Canada;^{3 4} citizen juries;⁵ public consultation, such as the state of Oregon’s attempt to guide rationing and priority-setting decisions for state Medicaid funding;⁶ and regional health conferences, such as in France. The rationale behind introducing relevant policies has however differed across settings, ranging from a grassroots active citizen movement as a key driver as in Italy to top-down approaches following major failures in quality of care as in England and France.⁷

Evidence for the impact of public involvement on healthcare policy remains difficult to ascertain however. A systematic review by Crawford *et al.* (2002) on the effects of involving patients in the development and planning of health services found a minority of studies describing the impact of involvement.⁸ These tended to show that involving service users did contribute to changes in the provision, such as the commissioning of new health services. However the review focused on patient involvement in the area of service delivery rather than on broader aspects of public involvement in healthcare policies such as priority-setting and health service planning. Furthermore the review by Crawford *et al.* (2002)

examined work that was published until 2000 only, so not capturing initiatives and policies initiated during the past decade.⁸

Within this context it is timely to revisit the concept of public involvement in health policy, examining systematically the recent evidence for the outcomes of related initiatives and policies as a means to identify the key contextual factors that call for, promote or hinder the implementation of relevant policies and so provide a framework for advancing public involvement in the healthcare policy process.

This report aims to contribute to this process through:

- (i) conceptualising public involvement in healthcare policy and so contributing to the development of a typology of public involvement;
- (ii) assessing the research evidence for outcomes of public involvement in healthcare policy; and
- (iii) developing a tentative evaluative assessment tool of public involvement in healthcare policies.

In doing so the report also aims to identify the key features of good practice in public involvement in healthcare policy.

1.1 **Methods**

This report builds on an earlier comprehensive review by Wait and Nolte (2006) which explored some of the underlying concepts, definitions and issues underpinning public involvement policies and proposed a preliminary framework for the evaluation of public involvement strategies and their impact on the health policy process.⁹ This report seeks to advance this work further towards the development of an evaluative assessment tool for further analysis.

1.1.1 **Literature review**

We carried out a two-stage review of the literature. To develop further a conceptual framework for classifying public involvement initiatives and strategies, we performed a “conceptual synthesis”,^{10 11} a qualitative approach to literature review with the aim of identifying key ideas, concepts and debates or issues to develop a better understanding. We used a network approach to identify health-related literature, building on earlier work on public involvement in healthcare and following up references from more recent work. We used PubMed, Institute for Scientific Information (ISI) Web of Knowledge, Google and Google Scholar to identify relevant work. The search was not designed to be exhaustive. Articles were included if they added new information or fresh insights to the existing body of knowledge used to develop the conceptualisation. Particular focus was given to material that had a practical policy orientation, as opposed to those which explored theoretical concepts.

Further, we carried out a systematic search of the published literature on the evidence for outcomes of public involvement in healthcare policy of bibliometric databases PsychINFO and PubMed. We applied broad search terms, using combinations of (“/” indicating “or”) “public/consumer/user/civic/citizen/lay/client”, “engagement/involvement/participation/

representation”, “planning/priority setting/decision” and “health”. Appendix A provides details of the search strategies.

This review concerned evidence of outcomes of “public” involvement as it relates to healthcare decision-making, priority-setting, resource allocation and/or health service planning at the macro and meso level, with a focus on involvement conceptualised as taking a broader societal perspective as opposed to an individual patient’s perspective. We therefore excluded studies that examined involvement in terms of service development, shared decision-making of individual treatment, clinical decisions, participatory action research, therapeutic and service delivery decisions; and clinical guidelines. We also excluded studies examining preferences for participation among healthcare professionals or healthcare users as these concerned the structure and process of involvement strategies rather than their outcomes.

The search was limited to studies published from 1 November 2000 onwards as our review sought to update existing evidence that had reviewed earlier work.⁸ We generally included empirical studies that reported on original research only. We excluded review articles except as a source for the identification of studies measuring the outcomes of public involvement not identified by our search. We further excluded editorials, letters and commentaries. Studies in languages other than English, German or French were also excluded.

Titles and abstracts were screened for eligibility for inclusion. We identified 137 studies that, following screening of title and abstract, were considered eligible for inclusion, including duplicates across search term entries. After removal of duplicate eligible studies and further examination of the abstract, we excluded 35 papers and retrieved a total of 30 studies. Of these one reference was followed up. Of a total of 31 studies thus considered eligible, a further 12 were excluded as they did not match our inclusion criteria, leaving a total of only 19 studies to be included in the review.

Studies were analysed using a common template which extracted the following information:

- stated study objective
- study type (review, case, empirical)
- study design (quantitative/qualitative)
- year
- population(s) studied
- geographical setting
- definition of “public”
- definition or form of “involvement”
- stated goal of the public involvement initiative (if relevant)
- outcome measure(s)
- key findings
- source.

1.1.2 Exploratory analysis of selected public involvement initiatives

The review of the literature was complemented by exploratory analysis of selected public involvement initiatives or programmes in five countries. The analysis was informed by the published and grey literature and by interviews with key informants with responsibility for public involvement in the relevant initiative or programme. The selection process was

informed by the literature and guided by the desire to examine initiatives or programmes with broadly similar remit but set in different health system contexts. We thus selected three examples of public involvement in healthcare decision-making at the macro level and two examples of public involvement in priority-setting and/or commissioning at sub-national (local/regional) level. Furthermore we selected one example of an experimental tool in the United States aimed at promoting participatory decision-making in healthcare priority-setting funded by the National Institutes of Health (Table 1).

Table 1 Public involvement initiatives/programmes

| Public involvement in healthcare decision-making at macro level | Public involvement in healthcare decision-making at sub-national/local (meso) level |
|---|--|
| <ul style="list-style-type: none"> • National Institute for Health and Clinical Excellence (NICE), United Kingdom • Joint Federal Committee (G-BA), Germany • Healthcare user participation in collective decision-making, The Netherlands | <ul style="list-style-type: none"> • Cambridgeshire Primary Care Trust (PCT), United Kingdom • Toronto Central Local integration Health Network (LHN), Canada • Choosing Healthplans All Together (CHAT), USA |

Of these initiatives/programmes, four were informed by interviews with five key informants (LHN, Canada; CHAT, USA; NICE, UK; PCT, UK) while the remainder were based on the published literature only. Key informants were identified from the literature (LHN, CHAT) and/or the authors' professional networks (NICE, PCT). Interview protocol and a brief summary of each initiative/programme are given in Appendix B.

1.2 This report

This report begins with Chapter 1 outlining the aims and objectives of the work and identifying the methods of the research presented here. Chapter 2 offers a conceptual framework that elaborates on earlier work,^{7 9} and discusses issues and understandings of public involvement in healthcare. Chapter 3 presents our review of the research evidence of the impact of public involvement and Chapter 4 sets out a checklist for planning and evaluating public involvement activities. The report closes with Chapter 5, which offers concluding points for the consideration of public involvement initiatives in the German context and highlights gaps in our understanding and requirements for future work.

What is public involvement in healthcare policy?

There seems to be no clear consensus in the literature on when public engagement should be sought, how it should be obtained, or how it might be incorporated by decision-makers into priority setting and resource allocation processes

(Florin and Dixon, 2002: p. 220)¹

This chapter aims to conceptualise public involvement in healthcare policy as a means to contributing to the development of a typology of public involvement. It builds on earlier conceptualisations,⁷⁻⁹ and considers the motivations of policy-makers and the public. It draws on the published literature, supplemented by observations from our exploratory analysis of selected international public involvement initiatives. To distinguish these sources we have indicated information derived from our exploratory cases by using *italicised* text. We begin by discussing how public involvement has been conceptualised as a theoretical construct before moving on to exploring public involvement policies, and we conclude with a summary of key points.

2.1.1 Who is “the public”?

The term “public” is variously defined or applied in the literature on public involvement in healthcare policies. Synonyms include “citizens”,⁹ “consumers”,⁹ “tax-payers”,¹²⁻¹⁴ “lay people”, “service users”, “patient”⁹ and “the community”.¹⁵

Florin and Dixon (2004) differentiate between patient and public involvement, where “patient” involvement refers to decisions about one’s own care.¹ Harrison *et al.* (2002) also distinguish between “service users (or consumers, or patients)” as they have different interests relevant to policy-making.¹⁶ However Coulter (2002) argues that it is an artificial distinction – the public includes both individuals who are currently patients and those who may become patients and service users in the future.² Available evidence indicates that individuals move between roles and purpose (see below), a notion supported by our observations from selected international initiatives: *informants moved comfortably through a range of terms when describing “the public”,² referring to “customers”, “consumers”, “stakeholders”, “service users”, “Joe Public” and “patient and community experts”. One key informant had a statutory obligation to engage with “the public”, and interpreted the broad legislative definition as meaning “everyone – since each person uses the healthcare system and many work in it” (e.g. the public, healthcare providers, healthcare professionals and others who work for the healthcare system).* This reflects an imprecision in terminology in the literature, with terms being used interchangeably or as proxies for one another.

Observations further suggested *that definition of the public depends on the type of engagement, which may vary according to the issue/priority of interest (e.g. a public consultation*

about reconfiguration of hearing services will involve stakeholder groups specific to an elderly population).

2.1.2 What is meant by “involvement”?

The term “involvement” is used interchangeably with a number of others. For example Harrison and MacDonald (2008) note that “[p]ublic and user ‘*involvement*’ refers to *participation* in some aspect of governance, design or availability of public services, that is something more than simply using the service” (p. 103);¹⁷ while Rowe and Frewer (2005) reverse these terms: “A general definition of *public participation* with which few would argue is the practice of *involving* members of the public in the agenda-setting, decision-making, and policy-forming activities of organizations/institutions responsible for policy development” (emphasis added).¹⁸

Besides “participation”, terms include “engagement” and “empowerment”,⁹ which are also used to refer to “advocacy”.¹⁹ Generally the term “involvement” tends to be associated with activities beyond routine democratic processes.

Many view “consultation” as a weak form of involvement,^{18 20-22} for example interpreting consultation as a “model in which professionals retain control of both the process and outcomes of user involvement”.¹³ Such definitions assume that the public involvement is about “being able to change things”²³ rather than enjoying improved confidence or learning, for example. The division of involvement into a relative hierarchy organised by degree of public impact is the predominant conceptualisation in the literature. It is often implicit, and here too terms are used interchangeably or as proxies for one another. Observations from selected international public involvement initiatives illustrate this, with informants using a *range of terms to describe their work, including “involvement”, “participation”, “engagement” and “consultation”*.

Given this lack of clarity, we 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 the potential involvement which is independent of any normative assumptions.

2.1.3 Conceptual models underlying public involvement

Researchers have offered a variety of conceptual models of involvement,^{15 24} including seminal work by Arnstein (1969), who proposed an eight-rung ladder of participation, with manipulation at the bottom and citizen control at the top.²⁰ Tritter and McCallum (2006) are critical of this hierarchy of control approach however, arguing that participation in itself is as relevant an outcome as “control”, but also that involvement genuinely has several dimensions, purposes and categories of participant.²⁵ They therefore propose the notion of a “mosaic” to conceptualise public involvement so as to capture the various complex and dynamic relationships between individual users, their communities, voluntary organisations and the healthcare system.

Others have attempted to introduce dimensions other than control to their conception of involvement. For example Contandriopoulos (2004) offered a three-dimensional conceptual model of public involvement focused on formal representation (method), descriptive representation (degree of representativeness) and symbolic (view of participant

as to the “origins of consent and legitimacy” (p. 322)).²³ Documented models as identified from the literature are limited in scope however as they focus only on a few dimensions.

2.1.4 **Revealing key assumptions**

Some authors have expressed concern that the existing literature on public involvement is unreflecting in its assumption that involvement is “a good thing” either in itself or in terms of the benefits it delivers.^{23 25 26} The following is a not untypical comment in this vein:

Patient and public involvement has a vital role to play in democratising healthcare, and also in developing systems and ways of working that are truly focused on the individual, to ensure we deliver the best quality of care.²⁷

Not unsurprisingly this belief was reflected by our observations from our exploratory analysis of selected public involvement initiatives, describing *public involvement in healthcare policy as essential to better healthcare, and better politics. Informants spoke of how “gratifying” and “rewarding” they found public involvement.*

2.2 **Public involvement policy**

2.2.1 **Perspectives on public involvement**

There are a number of different perspective on involvement.²⁸ These are the so-called “pure types”, and there is considerable overlap between them.

The **democratic perspective** tends to assume that involvement is a good thing either in principle,^{1 14 29 30} or for some instrumental purpose, where the process of involvement is expected to impact positively on public decisions¹⁴ or to protect citizens from others making decisions against their interests.¹⁷ Within this broad perspective is a republican or communitarian position where participation is also viewed as a social obligation,³¹ referring to the notion that entitlement is tied to a duty to engage actively in constructing or shaping the community.¹⁷

The **consumerist perspective** assumes that the public as consumers or customers of healthcare have a right to demand services how they want them and that the expression of this demand will influence outcomes.⁹ Consumer preferences are viewed as the lever to enhance the responsiveness of service providers³² while no social action is implied beyond exercising individual choice as an expression of demand.¹⁷

Less commonly presented in the literature is a **developmental perspective**. This would include those who view involvement as “expressive”,³³ that is an opportunity to express political identity and belonging, or “educative”.^{16 17} This view interprets involvement as a means to increase citizens’ capability and confidence for political engagement,³³ their understanding of the challenges of policy-making or, in the case of service-level involvement, increasing their knowledge of their condition and services.³⁴

Critical perspectives tend to question the authenticity and ultimate purpose of public involvement, arguing that it may be viewed as a “strategy that legitimates unpalatable change (rationing and/or increased charges), allowing politicians to deflect criticism by suggesting a broader consensus”¹³ (p. 1973), or providing greater credibility for something decision-makers would have done anyway. Others have argued that public involvement defers responsibility to citizens for difficult decisions and means they take on risks

previously owned by the state³⁵, thus requiring some groups that are relatively powerless to take on additional responsibilities.³¹

Observations from our exploratory analysis of selected public involvement initiatives did not indicate a particular perspective taken by those involved. Indeed, public involvement tended to be seen as a good thing, as a right as citizen (democratic) and as service user (consumerist). In policy and practice there appears to be considerable merging of democratic and consumerist perspectives.

2.2.2 Perceived benefits of public involvement

The rationale for most calls for public involvement in healthcare policy tends to relate to perceived benefits. Such benefits may be intrinsic (participation is a good in itself). Others also identify *instrumental* and *developmental* effects – the former referring to whether public involvement makes a difference and may be assumed to improve decision-making and policy in terms of processes and/or outcomes.¹⁷ Developmental effects include presumed benefits such as increasing individual participants' confidence, providing an opportunity to express views, contribute to enhanced understanding and so forth. Table 2 lists perceived benefits of public involvement in healthcare policy as identified from the literature.

Table 2 Perceived benefits of public involvement in healthcare policy

Intrinsic benefits

- a good in itself^{30 36}
- in keeping with the principles of democracy,^{1 14} fairness and justice¹²
- in principle, provides a proper role for the public as tax-payer in universal health services¹²⁻¹⁴
- addresses “democratic deficit”,¹⁷ helping to ensure a strong democracy capable of reconciling various interests and cleavages⁹ (p. 152).

Instrumental benefits

- corrects the power imbalance between public and professional power^{14 17 30}
- helps reduce “free-riding” in healthcare services¹⁷
- can provide an values-based antidote to technical evidence-based medical decisions¹⁴
- can support a change in balance between different parts of the policy system,¹⁵ for example public participation is associated with increased localism
- increases accountability of healthcare to users, tax-payers or consumers^{1 13 15 25 30 33 37}
- improves quality^{12 14 38 39}
- improves responsiveness of services^{12 37}
- “improves outcomes for patients”³⁴ (p. 1)

Developmental benefits

- helps citizens “fulfil their obligations of citizenship”⁹ (p. 152)^{12 17 32}
 - improves citizens' understanding of policy and the constraints on it⁹ (p. 152)
 - provides an expression of self-help¹⁷
 - builds “self-worth and empowerment”³⁷
 - mobilises energy and commitment from local people to help bring about change³⁹
 - helps patients and public understand how changes will affect them and make them more accepting of change¹⁴
-

Observations from our exploratory analysis of selected public involvement initiatives indicate that the perceived benefits of public involvement in healthcare policy summarised in Table 2 are both instrumental and developmental. However a higher degree of importance seemed to be attributed to the instrumental effects of public involvement as a means to increase the public's input and influence over decisions relevant to them as patients and as social or geographical communities. Key informants expected public involvement to have an impact on the provision of services that was more responsive to the public preferences and therefore of higher quality. Some also thought involvement helped the public understand the constraints of policy choices. Box 1 provides an overview of perceived benefits identified from selected public involvement initiatives and programmes.

Box 1 Observations from exploratory analysis of selected public involvement initiatives, direct benefits or other effects

National Institute for Health and Clinical Excellence (NICE) (England) – influence on strategic decisions, awareness and other perceived benefits

The impact of public involvement activities varies from the “very generic” to influencing strategic decisions; impacts include influencing dynamics of stakeholder discussions and possibly rising awareness of professional groups of lay perspectives, enabling networking, raising awareness and understanding of decision-making processes, and influencing strategic decisions (e.g. in the form of guidance).

Federal Joint Committee (G-BA) (Germany) – influence on strategic decisions, enhancing awareness and understanding⁴⁰

The impact of public involvement includes influencing strategic decisions on healthcare benefits funded under the statutory system, raising awareness and competencies of participating patient / service-user organisations through improved understanding of the decision-making process, and rebalancing processes and discussions among expert groups towards enhanced awareness of service user perspectives.

Primary Care Trust (PCT) (England) – influence on strategic decisions

The PCT purchases healthcare on behalf of its local population and must consult with the public to do so. In one example the PCT had consulted on a proposal for service reconfiguration, giving several options to the public but indicating the PCT's preferred option and reasons for this preference. When public consultation showed strong disagreement with the PCT's preferred option and a strong preference for a different option, the PCT chose the option with most public support.

Local Health Integration Network (LHIN) (Toronto, Canada) – influence on strategic decisions, enabling interaction

A consumer advisory panel contributed to the LHIN first Strategic Plan (2006–2009), following which selected services were changed on the basis of perspectives provided by panel members. However the impact of this contribution was not perceived as being “far-reaching” as this form of involvement engages only a small group of people. Other perceived benefits or impacts included the creation of a common vision and balanced scorecard for the LHIN as a result of engaging all LHIN providers, and enabling the interaction of different stakeholder groups.

Choosing Healthplans All Together (CHAT) (USA) – direct participant effects and wider uptake effects

As an experimental tool, the extent to which collective choices about benefits using the CHAT tool

can influence policy is limited. However reported impacts included attitudinal/educational change of participations (e.g. enhancing public understanding of inherent limitations of priority-setting); and “spill-over” effects, with a CHAT project in one state leading to the creation of a particular health plan chosen by participants – as a result the use of CHAT was subsequently taken up by other municipalities in that state.

In contrast to the growing body of work examining perceived benefits of public involvement activities in relation to healthcare decision-making, fewer studies appear to have looked directly at benefits of involvement to the public from their perspective. Those that have done so find that expected benefits include the “desire to improve services, social opportunities, increasing knowledge of stroke, and accessing services”.³⁴

2.3 Public involvement in practice

This section describes the means by which the public may be involved in healthcare policy, including the type of decisions and the mechanisms that are being used. It draws attention to the fact that public involvement in practice is multi-faceted, and needs to take account of an array of complex factors, such as public preferences and capabilities; such attention is unlikely to succeed with any one approach.²⁴

2.3.1 Policy levers to strengthen involvement

In line with our earlier discussion of perspectives on public involvement, support for public involvement in healthcare policy has been justified in a number of ways: as an individual right, as part of organisational governance procedures and as a legal obligation to involve the public.

Of the six exploratory public involvement initiatives examined here, four have emerged as a consequence of a statutory obligation to involve the public in aspects of their decision-making process (LHIN, PCT, NICE, G-BA). *Key informants noted that the legal duty to involve the public (however defined) gave strength to something they would be doing anyway. However the difficulty of achieving the sort of involvement they aspired to was also highlighted, as was how they were seeking to develop the activities of their organisations in this regard.*

There is a suggestion that most public involvement in healthcare policy (as in other domains) involves a top-down approach by organisations to engage sometimes reluctant participants, a notion we shall explore below.

2.3.2 Decision levels and domains

Healthcare systems are complex and there are different approaches to conceptualising their various levels and components.⁴¹ One simplified approach is to look at the different levels of decision-making within a healthcare system: the primary process of patient care (micro level), the organisational context (meso level) and the financing and policy context (macro level).⁴² Each level is characterised by distinct rationales, addressing different dynamics in the healthcare system; for each level it is thus possible to identify specific issues that pertain to public involvement, and this perhaps pragmatic distinction has been adopted widely (not only) in the literature that sought to understand and conceptualise public involvement in healthcare policies better. It describes the macro level as that at which strategic decisions

are being made, for example on general principles of organisation and financing; while the meso level is seen to refer to specific services and programmes and the micro level to pertain to decisions about individual patients or classes of patients,^{22 30 33 43} with Minott (2009) adding a fourth category of monitoring and evaluation.⁴⁴

Within the exploratory countries’ examples of public involvement initiatives there were recognised difficulties in the need to reconcile meeting local public preferences with national targets. Both the Canadian LHIN and the English PCT mentioned this difficulty. Both are involving the public in order to inform local decisions about healthcare policy in general. In contrast organisations operating at the macro level, such as NICE and the G-BA, make specific decisions for national implementation.

A critical question regarding public involvement practice relates to the public’s willingness to be involved in healthcare policy-making. Wiseman *et al.* (2003) surveyed Australian citizens to elicit views on public involvement in healthcare priority-setting.³⁰ They found that 80 per cent of respondents wanted preferences expressed by the general public to be used to inform priority-setting. Those who did not support the principle of public involvement did not wish public preferences to be used at all. In terms of decision level, public preferences were considered to be important in setting priorities across healthcare programmes and population groups, but not for individual healthcare interventions – there doctors’ priorities were considered to be the most important. Similarly, Litva *et al.* (2002), in a study of user involvement in rationing decisions in England, demonstrated variations in the willingness of members of the public to be involved, with a strong desire to be involved in decisions on resource allocation between (system level) and within (programme level) service areas, but not at the individual (i.e. patient) level (Table 3).³³

Table 3 Perceived benefits of public involvement in healthcare policy

| Level of decision | Agreement to public involvement n (%) | | | |
|---|---------------------------------------|---------|--------|-----------|
| | Yes | No | Unsure | No answer |
| System level: determining the location of services within a health authority | 39 (68) | 4 (7) | 9 (16) | 5 (9) |
| Programme level: determining the funding of particular types of specialist services | 29 (51) | 15 (26) | 4 (7) | 9 (16) |
| Patient level: determining the particular patient who should receive a treatment | 12 (21) | 30 (53) | 7 (12) | 8 (14) |

Source: adapted from Litva *et al.* (2002)³³

2.3.3 How to involve the public

Critical to any attempt to involve the public is an understanding of how best to do it. As noted earlier, most initiatives appear to assume a top-down approach, engaging a “formal” agency seeking to involve the public rather than the public demanding involvement. Knowing how to involve the public requires complex judgements and trade-offs. For example, Litva *et al.* (2009) argue that “all-encompassing strategies of user involvement may only appeal to a limited range of users, and this could impact significantly on their use and usefulness”.²⁴ In this section we map the literature on methods of involvement and other aspects of the process highlighting key dimensions. These are used to help organise

our review of evidence of outcomes of public involvement activities described in Chapter 3.

Approaches to public involvement

Methods for public involvement (also referred to as processes/techniques/instruments/approaches)^{13-14 15} are particularly well developed in the literature. Methods are often related to conceptual models about power and are frequently viewed as being arranged hierarchically, from consultation methods to participative methods. Table 4 provides an overview of approaches to public involvement as identified in a scoping review of public participation in healthcare priority-setting by Mitton *et al.* (2009), identifying three levels of participation (or involvement) in line with a typology of involvement mechanisms offered by Rowe and Frewer (2005).^{18 45} Bruni *et al.* (2008) add board and committee membership to the list.¹⁴

Table 4 Approaches to public involvement

| |
|--|
| Communication |
| <ul style="list-style-type: none"> • traditional publicity • public hearing or public meeting • drop-in centres • information (e.g. print, world wide web, hotlines) |
| Consultation |
| <ul style="list-style-type: none"> • opinion poll / survey • referendum • consultation with select groups / persons (print, electronic, face to face) • focus group • standing citizens' advisory panel • study circle |
| Participation |
| <ul style="list-style-type: none"> • citizens' jury or consensus conference • negotiated rule-making; task force • deliberative poll • town meeting with voting • committee and board membership¹⁴ |

Source: Adapted from Mitton *et al.* (2009)⁴⁵

Approaches may be linked with the wider involvement process. Rowe and Frewer (2005) for example provide a typology^a of public engagement mechanisms for evaluation purposes that is organised by a number of characteristics, such as the extent to which the method is expected to elicit open responses from the public involved in them, or whether they need to be face to face.¹⁸

Others have focused on the level of formalisation of a given process of involvement. Harrison and McDonald (2008) differentiate between passive and active involvement,

^a This typology was originally developed for public participation in health research.

where passive involvement occurs when it is “officially organised, either through agents such as elected representatives or an allocated advocate or through surveys” (p. 109).¹⁷ In contrast *active* involvement refers to activities where users or the public organise themselves proactively, for example in the context of public pressure groups to achieve particular developments or services. This conceptualisation presents quite an unusual use of “active” and “passive”, and much of the literature seems to imply that involving the public by approaching them directly represents “active” involvement if the particular method used to involve them engages them that way, although again this interpretation will vary with the extent to which the public are “consulted” or “participate”.

Other aspects of the involvement process include whether an involvement initiative requires one-off involvement or continuous involvement. Again there is no clear best approach. Fudge *et al.* (2008) found that the public were less willing to engage in continuous programmes.³⁴ Mitton *et al.* (2009) noted administrators’ preference for one-off approaches to reduce the burden on the public.⁴⁵ In contrast Wiseman *et al.* (2003) highlighted the potential problems of one-off activities in that these tend to fail to recognise “that people require time to form a view or opinion and to discuss the issues with their peers”.³⁰ For example Dolan *et al.* (1999) reported that the public’s views about priority-setting in healthcare are “systematically different” when they have been able to deliberate, reflect and actively discuss the issues with other lay persons”.⁴⁶

Observations from our exploratory analysis of selected public involvement initiatives indicate a range of mechanisms used to involve the public. Some approaches were perceived as to not “work well” in attracting the public to getting involved. These included open meetings aimed at the general public. There was also a notion of a benefit in using methods that are not necessarily active, participative or representative to engage groups who would be unheard otherwise. For instance one organisation undertakes one-off consultations with young people about specific issues as the (perceived) only way to bring in their views.

2.3.4 Roles for public involvement

This last point illustrates a fundamental concern about public involvement activities: namely that of the role the public is meant to take in the process – that is whether it is prescribed for them or one they choose for themselves. The literature identifies a number of roles that the public may take during an involvement process:

- those representing their individual interests⁴⁵
- those speaking on issues broader than their own personal experience, self-appointed or otherwise
- those overseeing and scrutinising decision-making²⁴
- as representatives of “organized interest groups supposedly speaking on behalf of their membership”.⁴⁵

It is important to note that these are *roles*, which means that the individuals taking them on may move around within them.⁴⁷

In practice the assumed role links with one or more decision domains, and this may be influenced by the type of public, which further underlines the complexity of public involvement. For example Litva *et al.* (2009) conducted focus groups with different types of lay people in north-west England to explore their perceptions of public involvement in

different aspects of clinical governance policy. While concluding that the public wanted to scrutinise decisions rather than “control” them, Litva *et al.* (2009) found people’s willingness to participate in particular themes varied by type of group and by their assumed role (Table 5).²⁴

Table 5 Perceived benefits of public involvement in healthcare policy

| | Improving and accessing services | | Dealing with poor performance | | Education and training | |
|---|----------------------------------|-------------|-------------------------------|-------------|--------------------------|-------------|
| | Role | Type | Role | Type | Role | Type |
| Citizens | Citizen | Overseeing | Citizen | Overseeing | No desire to be involved | |
| Group of patients with a history of activism | Citizen | Partnership | Citizen | Partnership | No desire to be involved | |
| Group of patients without a history of activism (“typical” patient group) | Citizen | Informing | Citizen | Overseeing | No desire to be involved | |
| Health interest groups | Advocate | Overseeing | Advocate | Overseeing | Advocate | Partnership |
| Frequent health service users | Consumer | Informing | Citizen | Overseeing | No desire to be involved | |

Source: Litva *et al.* (2009)²⁴

One programme reviewed in our analysis of selected public involvement initiatives seeks to involve individuals who are directly affected by the issue under discussion, but on the understanding that their involvement is not about their individual needs – rather their role is seen as that of guardians or advocates. However all initiatives and programmes included in our exploratory work identified a range of roles and contributions. In some cases the aim of the involvement exercise was to “consult” with “service users” where it was expected that individuals would speak about their own experiences. One organisation with a duty to engage “the community” saw service providers as critically important. Yet service providers would clearly have a different role from those set out above.

Representation

A challenge to public involvement in healthcare policy is ensuring that those who participate are ‘appropriate’ – that is they are who and what the public is meant to represent. Parkinson (2004) provides a helpful distinction between “representativeness” (a descriptive population sample) and “representation”, which relates to inclusion.⁴⁸ The need for healthcare is not distributed proportionately across populations, no more than is the propensity to become involved in policy. The proactive pursuit of representation has the potential to address the “the inverse law of participation” by including those groups with most need for healthcare and a profound interest in the decisions being made, which are at the same time those least likely to get involved without support to do so.⁴⁹

Likewise hand selecting individuals for the purpose of population representativeness (e.g. white, female, age 55–75 years) does not make those individuals representatives in the “political” sense as they have not been elected by the people they are supposed to represent. Parkinson (2004) argues that many voices with different roles can contribute helpfully to a process of dispute by providing different contributions.⁴⁸ The wider literature reports the practical benefit of involving social and community groups in order to provide a link

between public and healthcare policy-making bodies,^{26 37} with for example Parkinson (2004) noting that interest groups can offer expertise and access to networks and other resources absent from the process.⁴⁸

Observations from our exploratory analysis of selected involvement initiatives and programmes suggest that representation was an important objective for many. Respondents all described the approaches they used to involve sections of the public who would not normally seek representations. They did this through patient and community groups, for example. However there was also awareness of the challenges of involving the public from all or part of their communities. There was a perception of a need to engage those considered to be most affected by particular decisions, or least have their voices heard. This was translated in practical terms by engaging with patient and community groups in order to try to reach those groups, complemented by attempts to involve the general public.

2.3.5 Barriers to involving the public effectively

A number of barriers to involvement are mentioned in the literature (Table 6). These may be organised around three interlinked themes. The first set of barriers relates to the public getting involved in the first place, such as lack of time and inappropriate mechanisms. The second set of barriers relates to issues in the process of involvement that limit the effective participation of the public in decision-making. These include attitudes of professionals and/or “experts” towards the public’s capability to contribute or a given organisation’s lack of capability to know how to involve the public. The final set of barriers clusters around public involvement as a component of the wider policy framework. Issues here include the limitations of public organisations to cede power to the public, and concerns about public involvement systems that run parallel to but independent of the health services they wish to influence.

Table 6 Barriers to public involvement in healthcare policy

Getting the public involved: “individual” barriers

- Costs (mainly in time)^{34 45}
- Lack of mechanisms appropriate for the target public⁵⁰ – in particular methods to address disempowerment⁵¹
- Participation exercises are viewed as a waste of money⁴⁸
- Citizens seeing public involvement as inappropriate³³
- Limited demand from the public because of a perception that influence will be low⁹
- User groups may have other priorities that compete with involvement in healthcare policy – e.g. offering peer support¹³
- Conflict in the process may put people off³⁷
- The public do not see decision-making as their role²⁴
- The public do not see public participation as necessary because they feel there should not be a choice between services in the first place, or that the public would be too emotional³³

Making involvement work: organisational and procedural barriers

- Attitudes of service managers (as they are “paid to take responsibility for decisions”)^{13 19}
- Lack of capacity within organisations to deal with participation¹³
- Lack of clarity of purpose⁵⁰
- Professional concerns that participants are not representative^{13 19 24 33 50}
- Professional concerns that lay people who learn the complexity of healthcare decision-making cease to be lay¹⁹
- Concern about the ability to remain independent or not to be co-opted to show the service provider in the best light¹³
- Lack of skills³⁷
- Lack of interpersonal continuity³⁸
- Need to pay participants is problematic but essential¹³

Supporting public involvement policies: system level barriers

- “officials are rarely in the 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”²⁵
- Frequent changes to the system may be seen to dissipate lessons and experience^{52 53}
- Inconsistency of policies and contradictory policies (e.g. between choice and communitarian models or between greater centralisation and standardisation and localism)⁵³
- New organisations and arrangements may not necessarily build on weaknesses identified in earlier initiatives (England)⁵²
- Lack of integration of “patient involvement” with other parts of the system^{34 52}
- Public involvement may increase the difficulty of decision-making¹³

It is worth noting that Abelson’s sample of involved members of the public in Abelson *et al.* (2004) showed that they remained committed to the process despite frustrations.⁵⁴

Observations from our exploratory analysis of selected public involvement initiatives suggest that the main barriers to public involvement seem to relate to the difficulties in getting particular groups – for example young people or those who are socially marginalised – involved. While expressing strong commitment to the process of involvement, key informants identified areas of difficulty they were trying to address, noting constraints such as the small size of team responsible for public involvement, lack of opportunity to work with some groups, and the need to be “creative”.

2.4 Summary

One clear message from our attempt to develop further earlier conceptualisation of public involvement in healthcare is that, despite a growing conceptual and empirical literature base, the concept of “public involvement” remains poorly defined in that lack of clarity of and consensus about definitions and purpose seem to persist. This chapter has however confirmed that public involvement is a complex and multidimensional phenomenon which may resist attempts for simple clarification and elude simplistic approaches. Public involvement practice will vary by policy rationale, public motivation, specific mechanism and how all these link to wider social processes.

This chapter aims to update the research evidence for outcomes of public involvement in healthcare policy since 2000. We examine “public” involvement initiatives as opposed to “patient” involvement, noting that there will be some overlap between these two notions. As noted earlier, our focus is on areas of public involvement in healthcare decision-making, priority-setting and resource allocation, so informing further our discussion developed in Chapter 2, with a view towards identifying studies reporting on promising practices for planning and evaluating public involvement.

We included studies of public involvement where the public appeared to be (1) lay citizens / community members; (2) representatives of organised social interest groups, including coalitions, partnerships, and so on; and (3) organisations of staff members / employees and/or patients/customers/clients, but only in so far as they provide input from a broader societal perspective.

Although there is a history of public engagement efforts in other sectors such as environmental sciences and urban planning, we did not include literature from these and other non-health fields in our review of evidence for outcomes. We focus on the published peer-reviewed literature, while acknowledging that our search as described in Section 1.2 may have missed a wider body of evidence reported in the grey literature (such as governmental and technical reports, dissertations, chapters in books) that may be relevant to this topic although some of this has been reviewed elsewhere.⁴⁵

3.1 Characteristics of studies of outcomes of public involvement

We identified 19 eligible studies of public involvement outcome or effects. They mainly report on work undertaken in an Anglo-American contexts (England,⁵⁵⁻⁶⁰ Canada,⁶¹⁻⁶⁵ the USA⁶⁶⁻⁶⁸ and Northern Ireland⁶⁹), with a smaller body of work examining public involvement in countries such as France,⁷⁰ The Netherlands,⁷¹ Italy⁷² and Israel.⁷³ Studies largely report on work undertaken between the mid-1990s and the mid-2000s, with length of observations ranging from one year to seven years; four studies did not report on the period of study.^{57 60 64 71} Appendix C provides an overview of the information extracted from the 19 studies, following a common template.

3.1.1 Study design

Studies considered eligible for inclusion in our review were reported as of two types: descriptive case studies (N=9) and empirical studies (N=10), each with wide variation in study design and methodologies used. Three empirical studies reported a comparative pre-post design with sub-group analysis,^{61 62 66} and two studies by Abelson *et al.* (2003, 2007)

used stratified random sampling to recruit local citizens for participation in the deliberation method under evaluation.^{61 62} Three empirical studies used qualitative methods,^{67 68 71} with another four using mixed methods involving both qualitative and quantitative approaches.^{55 62 64 70} Where reported, quantitative methods tended to involve the use of participant surveys (cross-sectional or longitudinal)^{55 57 62 64} and qualitative methods employed interviews,^{55 70 71} direct observation / ethnographic fieldwork^{62 64 69} and document review.^{70 71}

Among the case studies the design or methodology was often reported simply as “qualitative”.^{56 59 63 65 69} Mixed methods were also used for case studies,⁵⁸ including details of the approach taken to analyse qualitative data collected. One case study in Italy was reported as employing “quantitative” methods,⁷² while Guttman *et al.* (2008) did not give any information about their case study design or methodology.⁷³

3.2 Defining “the public” and approaches to involvement

While all studies reviewed here report on the goal of the public involvement initiative analysed, definitions of what constitutes “the public” varied and were generally unclear among eligible studies. The vast majority of studies did not provide an explicit definition or statement of how “the public” was operationalised for the study.^{55-58 60 62 65-70 72} This lack of definition and operationalisation is problematic for purposes of evaluation that aim to assess the effects of public involvement. Against the background of a general lack of consensus of who is “the public” (Chapter 2), this finding is not surprising and reinforces the challenges of determining the evidence for positive or negative effects of “public” involvement.

Where “the public” was defined and/or operationalised, definitions included:

- representatives of patient organisations⁷²
- ordinary citizens,⁷³ further operationalised as “individuals with no particular axe to grind and whose voices might not otherwise be heard”⁶⁴
- individuals who lives in [area]⁵⁹
- citizen members of a community / local residents⁶¹
- community.⁶³

Although studies reported the form of, and frequently approaches to, public involvement, systematic comparison of studies remained a challenge. First, studies reviewed tended to use terms for different approaches to public involvement interchangeably (e.g. representation, participation, involvement) even within studies, despite formal definition of the form of involvement being analysed (e.g. consultation) (Table 7). Second, the form of public involvement (e.g. consultation) and the range of methods used (e.g. surveys, conference and website, community health councils – CHCs, public meetings, local patient groups) were sometimes difficult to match to the common typologies found in the literature, suggesting a great degree of overlap in practice of different methods and sub-types of public engagement.¹⁸ These observations contribute a level of conceptual ambiguity that raises concerns about: (1) the form(s) of involvement reported to have an effect and (2) the effect(s) or outcome(s) that may be reasonably expected for the particular type and methods of public involvement studied.

Table 7 Definitions and terminology of “public involvement”

| Stated form of public involvement under study | Terms used to describe form of involvement under study | Example |
|---|--|-------------------|
| Consultation | involve, engage, lay representation, deliberation, participation | 55 57 59 61 62 73 |
| Participation | involvement, representative, deliberation, engagement | 66-68 |
| Engagement | involvement (community), partnership, empowering, collaboration | 56 |
| Partnership | participation (public), involvement (community/consumer), representative, collaboration, empowerment, engagement (community) | 65 69 72 |
| Community development | involvement, participation | 58 |
| Representation | consultation, involvement, participation | 60 |

Table 8 summarises the form of public involvement, types of methods used (if reported) and the goal of the initiative for each eligible study, as reported in studies reviewed here.

Table 8 Summary of public involvement type methods used and goals

| Stated form of public involvement under study | Involvement method(s) used | Goal(s) of initiative | Source |
|---|--|---|--------|
| Consultation | Round tables, town hall meetings, open houses + population-specific events + issue-specific groups | To engage, enable and empower people for health through resource-allocation function of local health integration networks | 63 |
| | Citizen panel, using mail survey, telephone survey or face-to-face group meetings | To obtain citizen input to inform a community-wide health goal-setting process | 61 |
| | Meeting (6 hours, plenary and small-group sessions) | To provide the sponsoring regional health authority (RHA) with public input on an issue of importance | 62 |
| | Community health councils (CHCs) + local patient groups + public meetings | To involve and engage all stakeholders in shaping policies and decisions about primary care provision and delivery, including consulting and engaging local communities | 55 |
| | Surveys + service audit + group meetings + delivering staff training + board membership | To involve service users in the planning and delivery of psychiatric services | 57 |
| | Citizens' jury of 5 days | To understand better the needs of all sections of the community so that appropriate primary care services can be provided | 59 |
| | Regional meetings (6) + survey | To elicit ordinary citizens' views on pertinent healthcare priorities | 73 |
| Participation | Various: e.g. consultative role to government, guideline or indicator development groups, negotiation of collective contracts, lobbying activities | To contribute the patient perspective | 71 |
| | Client representation at council meetings | To develop a structure for gathering client information that will be useful for improving organisational performance | 68 |
| | Group simulation game using a roulette wheel | To promote participatory decision-making in healthcare priority-setting | 66 |

Table 8 Summary of public involvement type methods used and goals

| Stated form of public involvement under study | Involvement method(s) used | Goal(s) of initiative | Source |
|---|--|---|--------|
| | | that is inclusive, deliberative and accessible for a diverse lay audience, especially low-income, low-education groups | |
| | Consumer council + policy review process + hospital's performance improvement system | Varied by involvement method | 67 |
| Engagement | Jury session of 2.5 days | To engage the public in priority-setting for health technology assessment | 64 |
| | Partnership-based collaboration among a collection of agencies, groups and individuals | To explore mechanisms for breaking through current organisational boundaries to tackle inequalities and deliver better services and better healthcare | 56 |
| Partnership | Representation from community groups in collaborations | To reduce health inequalities through co-ordinated activity of different agencies | 69 |
| | Various: e.g. training courses, collaborative initiatives, website | To involve lay people, patients' associations and scientific-medical representatives in the health debate | 72 |
| | Several strategies, e.g. Women's Health Express Advisory Council, Salvation Army Health Council | To establish a formal mechanism for public participation in health policy decisions regarding the delivery of women's health services | 65 |
| Community development | Inclusive process of networked representation, especially for marginalised community members | To promote community participation in decision-making about local health services | 58 |
| Representation | Various: e.g. consumer groups participating in regional health conferences | To serve as a mechanism for rendering debates more transparent and concrete | 70 |
| | Various: e.g. user representation on NHS Trust board, on locality reference groups, on staff training groups and on Joint Commission Board | To enable listening to and consulting users; to enable and enhance users' and carers' voices | 60 |

3.3 Outcomes of public involvement

Most studies of public involvement documented in the literature appear to focus on assessing the impact of the public (however defined) on power-sharing or on decision outcomes. Of the studies reviewed here, the nature of outcomes they aimed to measure in order to determine the effect of public involvement was often unclear. Where reported explicitly, detailed information about the outcome measures was rare. This lack of clarity regarding measurable indicators of public involvement effect or outcome meant that systematic comparisons of approaches to measurement and choice of indicators of outcome was not feasible. Instead relevant information had to be extracted from authors' discussions of reported results. This finding is not surprising, given that other authors have noted that effectiveness of public involvement is poorly defined,¹⁸ as are other potential outcomes.⁷⁴ Evidence suggests that this is partly because of the variation in purpose of and approaches to involvement that are often not made explicit.

It should be noted that in certain settings identification of specific outcome measures was not relevant because the study effectively presented a review of process as an account of the nature and development of a public involvement initiative, although authors reported finding some positive “impact”.^{59 60 63 70} This observation may be explained by the normative argument that “good deliberative democratic processes are of value in and of themselves”,⁶⁶ and thus related studies may have used quality of deliberative procedures as the criterion for tacitly defining “impact”.

Table 9 summarises the outcome measures reported in and inferred from eligible studies. A few points are worth noting from the studies reviewed here:

- “participant views” is a common outcome measure across studies of public involvement, whether explicitly stated or not;
- “change” features among measures aimed at assessing the influence of public involvement on decisions, policies or practice, yet few evaluative studies are designed to be comparative or have sufficiently long observation periods to measure “change”;
- specific and, especially, *measurable* information about the indicators of effect are generally lacking;
- a small number of studies examine the “developmental use” of public involvement in terms of participant knowledge or empowerment or social ties.

Table 9 Summary of public involvement outcome measures

| Outcome measure(s) | | Source |
|---|--|--------|
| Reported study design | | |
| <i>Case studies</i> | Emergent themes | 65 |
| | Participant views | 58 |
| | The ways in which local health service planning and delivery changed | 62 |
| <i>Empirical studies</i> | Effects on: <ul style="list-style-type: none"> • participating citizens • sponsoring decision-makers • the decision-making it [local citizen meeting] was designed to inform | 62 |
| | Extent of CHC in primary care group work | 55 |
| | Nature of public consultation | |
| | Perceived impact | |
| | Specific changes to policy or practice | 57 |
| | Effects on: <ul style="list-style-type: none"> • influence on policy-making • patient organisations | 71 |
| | Participant knowledge/learning | 66 |
| | Effect of participation exercise on changing individual health benefit selections between rounds towards more “public-spirited orientations” | |
| Study design not explicitly stated | | |
| <i>Case studies</i> | Participant views and satisfaction | 72 |
| | Frequency of project website hits | |
| | Participant views | 73 |
| | Compatibility of policy recommendations and impact (defined as decisions about actions that will be taken) | |
| | Proximal “benefits” identified as: <ol style="list-style-type: none"> “individual empowerment” “bridging social ties” “synergy” (defined as “creative solutions to intractable problems”) | 69 |
| | Extent of realisation of goal of “involving and empowering local communities to achieve sustainable development” | 56 |
| | Factors that affected this process | |
| <i>Empirical studies</i> | Content of jury deliberations | 64 |
| | Participant views | |
| | Participant views and satisfaction | 61 |
| | Realisation of council meeting action decisions | 68 |
| | Changes to policy achieved | 67 |

Given the general lack of clarity in the reporting on specific outcome measures, there is uncertainty about the reliability of reported findings regarding impact, as well as about the nature and scope of reasonable outcome of public involvement that may be measured given stated objectives.

It has been noted that there is a lack of evidence about when involvement is effective.^{8 14 25 27 45} Mitton *et al.* (2009), in their review of public involvement in healthcare priority-setting, showed that conclusions about the “success” of a given public involvement initiative appear to be independent of any formal evaluation.⁴⁵ Specifically they find that studies in which the engagement process (however defined) was intended to influence or

affect an actual decision, 60 per cent concluded that an impact had been achieved, while only 10 per cent stated that this had not been the case.

3.4 Evidence for outcomes

Several studies found the impact or influence of public involvement on shaping strategic decisions in health policy to be minimal,^{55 56 60}, geographically variable^{62 70} or mixed.⁷¹ This is confirmed by findings from other evaluations of public involvement, which conclude that involvement policies have had little impact^{12 17 37 52} or little independent impact. That is, where participants' preferences "match" policy or service preferences, the public's requests are more likely to be met.^{26 38}

In the case of mixed effects for example, van de Bovenkamp *et al.* (2009) identified 18 examples of unsuccessful attempts to influence organisational decision-making, while also reporting several examples of influence and self-reported positive effect on the well-being of participants.⁷¹

Other studies noted a direct effect of public involvement in terms of its developmental use for improving lay participants' learning or knowledge of either the consultation topics or the process of healthcare priority-setting,^{66 72 73} or for changing service providers' perceptions and ways of operating – for example by exposing them to issues of minority groups of which they were previously unaware.⁵⁸ There may also be a benefit of deliberative procedures in terms of a mechanism for building consensus among diverse views as well as for changing the orientation of individual choices towards more societal perspective.^{65 66 73} One study also highlighted the (potential) negative aspects of the deliberative process, noting the opportunity cost of time-consuming public involvement for accessing additional funding and the consequence of being ostracised for community partners who challenged statutory sector partners.⁶⁹

At the same time several studies demonstrated how public involvement had influenced decision-making, giving examples of "discernible actions" being accepted and implemented,⁶² of practical changes/improvement achieved,^{57 67 68} or of priorities becoming the object of a regional programme.⁷⁰ In some cases new financial means were leveraged for new services as a result of priority needs identified through a public involvement activity.⁵⁸^{59 69} A public involvement initiative in Israel was interpreted as having had a positive impact, as evidenced by the observation that it had resulted in replication of the deliberative procedure by two of the largest health fund directors.⁷³ Finally, there is some evidence of how the bottom-up initiatives of particular stakeholders can change policy or practice.⁵² Furthermore Crowley *et al.* (2002) suggest a number of practical changes to substantiate the "demonstrable impact" of "community development".⁵⁸

Finally, it is important to consider different aspects of context that influence the performance of the public involvement method,⁶² such as attitudes of healthcare managers towards the impact of "users" involved in deliberative processes (see also Chapter 2).⁵⁷ It has been recognised that the public still rely on the goodwill of professionals in wanting the change that is expected from involvement.²⁶ This dependence of the public exists partly because generally the public are invited to be involved with a set of issues and through a process that is set and controlled by formal agencies at the various tiers of a given system,³⁴ an issue also raised in relation to participation in macro-level decision-making of patient organisations in The Netherlands.⁷¹

3.5 **Summary**

A key finding from this chapter is that despite the growing body of work on public involvement in healthcare policy, sound evidence of the impact of public involvement remains scarce. Thus the concept of public involvement that is under study and the indicators used to examine and determine any resultant effect/impact remain poorly specified and inconsistent. Lack of clarity in the reporting of the “evidence” makes it difficult to draw any firm conclusions about the evidence base that would inform the policy development of involvement activities that are appropriate and effective.

The observed scarcity of formal evaluations of public involvement efforts is not new.⁴⁵ However keeping these limitations in mind, evidence reviewed here does seem to support the notion that public involvement initiatives or activities can influence the healthcare policy process through influencing strategic decisions on, for example, decisions of service delivery or priority-setting. There is also empirical evidence supporting the notions of the developmental role of public involvement in terms improving lay participants’ knowledge of subject areas and/or decision-making processes, and of increasing awareness among decision-makers and/or service providers of ways of operating in the healthcare sector – a finding also illustrated by the observations from the exploratory analysis of selected public involvement initiatives in different settings described in Chapter 2. Empirical evidence for instrumental benefits from public involvement initiatives is less well documented, with the possible exception of related strategies contributing to consensus building.

This chapter proposes a structured instrument that aims at informing the design and evaluation of public involvement activities. It draws on the evidence discussed in Chapters 2 and 3, further informed by observations from the exploratory analysis of public involvement initiatives and programmes in selected settings. This chapter takes an applied policy perspective, emphasising those factors that have been identified as conducive to effective public involvement in practice. At the outset it is however important to emphasise the selective nature of international examples of public involvement initiatives that informed this research. Thus any “guidance” derived from these data will have to be interpreted as preliminary and in need of further confirmatory work.

4.1 **Evaluation frameworks for public involvement**

Our review of the literature presented in Chapter 2 and 3 identified a number of proposed frameworks for evaluating public involvement activities. The work by Abelson *et al.* (2006) has contributed substantially to advancing this field, seeking to identify measures of process and outcome of public involvement to understand better what “works” in what circumstances (see Appendix D for an overview of evaluation assessment tools proposed in the literature).⁷⁵ Based on interviews with health system decision-makers in Ontario and Quebec, Canada, they identified at least four broad criteria against which a successful public involvement initiative should be judged:

- representativeness
- inclusive and engaging processes
- ensuring access to information in a way that promotes improved understanding and knowledge among participants, and
- legitimacy of the process.

Abelson *et al.* (2003) have also offered a set of general principles that may guide the design and evaluation of public involvement programmes, including considerations around representation, such as inclusiveness or exclusiveness of participant selection; processes such as degree of control given to participants; information as it relates to presentation, accessibility, source and others; as well as the actual outcomes or decisions being made as a consequence of involving members of the public (see also Appendix D).²⁹

Although not explicitly explored in this report, there is an opportunity to learn from experiences of related areas such as participatory health research, with recent work developing a high-level evaluation framework of this type of public involvement.⁷⁴ It highlighted a set of key dimensions to be considered in evaluation: efficiency, effectiveness, equity, ethical considerations and empowerment (ownership and capacity-building) (see Appendix D for an overview). However, although helpful frameworks exist for the evaluation of public involvement, they tend to pay less attention to how different dimensions of public involvement discussed in Chapter 2 relate to each other. Indeed developing a public involvement strategy that aims to serve a certain purpose appropriate to a certain setting will almost inevitably involve trade-offs. For instance, while one-off involvement is less effective in developing general understanding of certain areas,³⁰ it may be the preference of the public³⁴ and some professionals.⁴⁵

Evidence-based understanding of what works and when is improving as researchers attempt to disaggregate and draw a more finely grained picture of “involvement”. Though this information is derived from empirical studies, those are mainly concerned with service delivery.^{19 24 33 37} In practice engaging “the public” is a many-to-many mapping. That adds complexity to programme design but may increase the likelihood of success.

Building on existing work and our observations from the exploratory analysis of public involvement initiatives and programmes in selected settings, Box 2 offers a checklist as a suggested analytical tool to inform the planning and evaluation of public involvement activities.

Box 2 Proposed checklist for the design and evaluation of public involvement activities

- | |
|---|
| <p>(i) Rationale for introducing the initiative/programme/activity</p> <ul style="list-style-type: none"> • What is involving the public expected to achieve? <p>(ii) Scope of the initiative/programme/activity</p> <ul style="list-style-type: none"> • To inform planning / priority-setting / resource allocation / service delivery / other? • At what level of the decision-making process will the public be involved? • To what extent is the activity formalised (if at all)? • Is this a one-off, regular or continuous activity? • What is the role of the public? <p>(iii) How is the public represented?</p> <ul style="list-style-type: none"> • Who is leading? • Who decides who is involved and how? • Who is involved? • Is this an isolated public exercise or is the public part of a multi-stakeholder decision process? <p>(iv) Equity of policy being adopted</p> <ul style="list-style-type: none"> • Are all relevant sections of the public represented? • Does the policy run the risk of furthering the interests of some to the detriment of others? • Do any other factors potentially discriminate between those in the involvement process who may have true power or may not? <p>(v) Process of involvement</p> |
|---|

- What strategies will be used to engage the public?
- What is appropriate for the public and the requirements of the activity?
- How will be ensured that the public receive the appropriate information?
- How will it be ensured that decisions and reasons for a decision are fed back to the public?

(vi) Accountability

- Is the policy legally binding?
- Who has the power to change things?
- How are control and responsibility organised?
- How open or closed will the process be?
- What processes are in place for resolving conflict?
- What is the likelihood of acceptance of public involvement outputs by different stakeholders (e.g. professionals, interest groups)?

(vii) Potential barriers

- What are the anticipated constraints on implementing this activity and what are the strategies to overcome those?
- How will it be ensured that the public understands the constraints?
- What needs to be in place to support the public in their role (e.g. training, community development strategies)?
- How will public expectations be managed?

(viii) Evaluative framework

- What are the desired outcomes of the activity?
- How will you know whether the initiative was a "success"?
- What is the timeframe for assessment?
- Who is carrying out the assessment (external/internal, formal/informal)?
- What feedback mechanisms are in place to make use of data to guide policy?

5.1 **Our key findings**

In this report we provide an update of both the conceptual and the empirical evidence for public involvement in healthcare policy. We demonstrate that despite a growing literature base the concept of “public involvement” remains poorly defined, with little evidence of consensus on how “public involvement” should be defined and what it is supposed to achieve. Indeed, as we also show, public involvement is a complex and multidimensional phenomenon. Thus a call for simple clarification of the concept may not be appropriate or indeed desirable. Instead public involvement practice varies by underlying rationale, public motivation to become involved, and specific mechanisms and their relationship to wider social processes.

Against this background we propose interpreting 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.

Given the absence of a consensus on defining public involvement, it is perhaps not surprising that sound empirical evidence of the outcomes of public involvement activities in healthcare remains scarce. This observation is not new and has been documented elsewhere,⁴⁵ although there may have been an expectation that a growing body of empirical work might have advanced the evidence base. Indeed although existing empirical work does have limitations, what is available does appear to support the notion that public involvement initiatives or activities may influence the healthcare policy process by affecting strategic decisions, on for example service delivery or priority-setting. In particular we find evidence supporting what has been defined as the *developmental* role of public involvement, such as enhancing awareness, understanding and competencies among lay participants of healthcare decision-making; while the evidence for the *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.

It is worth noting though that the emphasis placed on assessing outcomes or impact of public involvement risks missing the normative argument that “good deliberative democratic processes are of value in and of themselves”.⁶⁶ Thus it seems important that any evaluation of public involvement outcomes also includes criteria to assess the quality of deliberative procedures. For example Thurston *et al.* (2005) suggest that “success should not be limited to whether high-level governance decisions are made” but instead may be determined in terms of the establishment of a formal partnership capable of informing the

development of health policy by challenging the status quo and adding priorities to the agenda.⁶⁵

On the basis of our overall findings, we have developed a tentative evaluative assessment tool for public involvement in healthcare policies that aims to help inform the design and evaluation of public involvement strategies in healthcare policy. However it is important to recognise the challenges to implementing public involvement policies in practice, an issue we shall explore further in the next section. We shall conclude with thoughts on the implications of these findings for advancing public involvement in healthcare policy in Germany.

5.2 Policy challenges

Enacting true public involvement in healthcare policies may have significant implications for healthcare systems as it may require redistribution of power between health professionals, governments, managers and the public. For example Milewa (2004) has argued, in the context of welfare-based health systems, that the state has to retain the supervision and control of regulating and co-ordinating the “key services and associated structures for participatory governance” to ensure that equity and cohesion associated with the provision of collective services is maintained.¹² This implies that there may be instances in which involving the public in healthcare decision-making may be interpreted as not desirable. However, by the same token, it has also been suggested that public involvement can serve as a “legitimation” strategy by which the decisions and activities of decision-makers in healthcare may be justified.⁷⁶ In either case the success of public involvement will be contingent on policy-makers’ genuine willingness to yield power to the public and on the public’s genuine engagement in the health policy process.

The multidimensional nature of public involvement means that developing a public involvement strategy that aims to serve a certain purpose and that is appropriate to a certain setting will almost inevitably involve trade-offs. These act at different levels, for example trade-offs in what is feasible with what is “ideal” – Coleman *et al.* (2009) suggest there is greater success if the public are asked to comment on rather than draw up plans.¹⁹ Organisations seeking to encourage public involvement in healthcare policy may face trade-offs between public representativeness and representation. Where involvement is seen as supporting localism and community, local priorities may have to be balanced against, or reconciled with, national targets or objectives.

Fudge *et al.* (2008), in the context of service redesign, raise the question of whether, given the expense associated with recruiting the public and the apparent lack of impact, the effort is justified.³⁴ However the costs of involving the public are not well known.⁴⁵ It is notable in this context that issues around the cost and efficiency of public involvement activities are rarely mentioned in published literature.

5.3 Lessons for the German healthcare system?

It is notable that the majority of empirical, and indeed conceptual, studies reviewed here tend to originate from England, Canada and Australia. This ostensible “Anglo-Saxon bias” in the literature may reflect a lack of debate of public involvement in other countries or a

lack of *published* debate, or both. As our review, in particular of the empirical evidence, focused on studies published in the peer-reviewed literature, we may have missed important ‘grey’ literature. It is however worth noting that England, Canada and Australia are characterised by tax-funded healthcare systems, and we have previously hypothesised that the experience of public involvement in healthcare policy may be different in insurance-based healthcare systems or in private healthcare markets, or indeed in any system where the policy environment is not dominated by the themes of accountability, patients’ rights and/or choice.⁹

However in the case of Germany the apparent lack of peer-reviewed published work on public involvement initiatives in healthcare policy is certainly not a reflection of a lack of discussion in this area, for that dates back at least to the early 1990s. At the outset it is important to note however that historically citizens have a legally formalised role as members of the statutory system in the management of the statutory health insurance funds⁷⁷ and in that respect that are, at least in theory, actively involved in healthcare decision-making, either through direct participation or indirectly through electing representatives to the supervisory board of funds.^b

Early debates on public involvement in healthcare have mainly centred around the consumerist approach, aimed at strengthening the role of individuals as consumers in the healthcare sector,⁷⁸ while later debates emphasised the role of citizen participation (*Bürgerbeteiligung*) and competency (*Kompetenz*) as a means of improving the performance of the healthcare system.⁷⁹ The 2004 Health Care Modernisation Act introduced a legal basis for the participation of representatives of organised patient interests and self-help groups in an advisory function at the federal level, in the newly established Joint Federal Committee (*Gemeinsamer Bundesausschuss*, G-BA), the highest decision-making body in the German healthcare system.

The representation of patients’ interests and self-help groups in the G-BA has been interpreted as an important advance in German health policy-making as previously patients, or more broadly citizens, were generally not represented by any powerful organisation(s).⁷ Indeed it has been suggested that involving patients’ and consumers’ representatives at this level has contributed to enhancing the transparency of healthcare decision-making at the national level,⁸⁰ with evidence of both instrumental and developmental benefits through influencing strategic decisions on the basket of services funded under the statutory system, and through enhancing awareness and competencies of participating patient/consumer organisations in understanding the decision-making process and others (Chapter 2, Box 1).⁴⁰

At the same time, patient/consumer involvement in the G-BA is facing many of the challenges described in Section 2.3 of this report, in particular as it relates to lack of resources in order to support patients’ and consumers’ representatives in their role as advisors to the G-BA.⁴⁰ Furthermore it has been argued that there is still considerable scope

^b Statutory insurance funds are based on the principle of self-government, in most cases comprising an executive board and a supervisory board. The latter is responsible for regulatory and budgetary aspects and also for electing the executive board. The supervisory board is usually composed of representatives of the insured and employers who are democratically elected for a six-year term; many representatives are linked to trade unions or employers’ associations.

for expanding the role of patient/consumer representatives in other sections of the healthcare system, such as health service planning and quality assurance. However the feasibility of such approaches remains uncertain against the background of the German institutional and governance context, with overall healthcare governance shared between the federal government, the governments of the 16 federal states (*Länder*) and corporate actors – although it is important to note that there is some experience at the state and district level.

While it goes beyond the scope of this report to provide a systematic assessment of public involvement initiatives and activities at the different governance layers of the German healthcare system, it is worth highlighting the experience of involving organised groups of the public in local healthcare decision-making through the implementation of local and regional health conferences which involve a range of stakeholders including charities and self-help groups.^{81 82} However regional/local health conferences are not statutory bodies and their recommendations are not legally binding; also their implementation is uneven across Germany. This is in contrast to two examples of international public involvement activities explored in this report that act at a similar administrative layer of governance and involve the public in informing local priority-setting and, to a certain degree, service planning. These are the Local Integration Health Network (LHN) (Ontario/Canada) and Primary Care Trust (PCT) (England). In both of these public involvement is guided by the equivalent of local/regional health authorities which are responsible for planning and co-ordinating or purchasing healthcare for their local population and on which public involvement is a statutory obligation.

In summary, several initiatives and regulations have been implemented in the German healthcare system to promote public involvement (of patients and citizens), and there is evidence supporting the notion that involving patients' and consumers' representatives has contributed to enhancing healthcare decision-making at the national level. However there is a need to understand better how the public may be involved in activities at levels other than the national level through the G-BA so that they may contribute to local decision-making beyond a somewhat patchy system of local/regional health conferences. The common conceptualisation of "the public" in the German system seems to be that of representation, namely the involvement of organised groups of patients or consumers. Although we have not, within the remit of this report, been able to assess this systematically, the notion of "representation" is in contrast to public involvement activities being pursued in Canada and England, as we have explored in this report, which tend to focus on engaging "everyone" (Joe Public). This observation may reflect a fundamental difference in what "public involvement" is supposed to achieve in different system contexts, in relation to healthcare organisation and financing as well as to the wider political and institutional setting, an issue that requires further investigation.

5.4 Conclusions

Public involvement in healthcare policy has received considerable attention over the past decades. Yet the scope, objectives and desired outcomes of existing public involvement policies remain poorly defined. The lack of clarity about who the public is and what involvement is intended to achieve has been well described.^{47 83}

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 so on. 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.

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APPENDICES

Appendix A: Search terms for evidence of impact

Search terms for evidence of impact of public involvement

| Database | Terms | Results | Relevance to | |
|-----------|---|---------|--------------|---------|
| | | | Impact | Concept |
| PsychINFO | (Public OR Consumer OR User OR Civic OR Citizen OR Lay OR Client) AND (Involvement OR Engagement OR Participation OR Representation) AND (Priority setting OR Planning OR Decision) AND Health | 1389 | 137 | 124 |
| PubMed | ((“Consumer Participation”[Mesh:NoExp] OR (“Consumer Participation/statistics and numerical data”[Mesh:NoExp] OR “Consumer Participation/trends”[Mesh:NoExp]))) AND (“Decision Making”[Mesh] OR “Decision Making, Organizational”[Mesh]) | 532 | 9 | 10 |
| | ((“Consumer Participation”[Mesh:NoExp] OR (“Consumer Participation/statistics and numerical data”[Mesh:NoExp] OR “Consumer Participation/trends”[Mesh:NoExp]))) AND “Health Priorities”[Mesh] | 9 | | 3 |
| | ((“Consumer Participation”[Mesh:NoExp] OR (“Consumer Participation/statistics and numerical data”[Mesh:NoExp] OR “Consumer Participation/trends”[Mesh:NoExp]))) AND (“Regional Health Planning”[Mesh] OR “Health Planning Councils”[Mesh] OR “Community Health Planning”[Mesh] OR “Hospital Planning”[Mesh] OR “Health Planning”[Mesh] OR “Health Facility Planning”[Mesh] OR “Ambulatory Care Facilities”[Mesh] OR “Health Systems Agencies”[Mesh] OR “Health Care Rationing”[Mesh] OR “Organization and Administration”[Mesh] OR “Health Priorities”[Mesh]) | 215 | 1 | 9 |

Appendix B: Overview of selected public involvement initiatives and interview protocol

National Institute for Health and Clinical Excellence (NICE), United Kingdom

Background

The National Institute for Health and Clinical Excellence (NICE) is a national body (England and Wales) which makes recommendations to the National Health Service (NHS) regarding new and existing medicines, treatments and procedures (called technology appraisals), treating and caring for people with specific diseases and conditions ("clinical guidelines") and the NHS and other bodies on public health issues. Implementation of technology appraisal recommendations by NHS organisations is statutory. NICE has a legal duty to involve the public.

Key public involvement activities

- *NICE has a Citizen's Council of 30 members of the public who meet twice a year for three days at a time to give input on what the public social and ethical values.*
- *Members of the public, including representatives of patient and community groups, are invited to sit on the standing committee concerned with developing guidance.*
- *Members of the public, including representatives of patient and community groups, are invited to provide expert input into committee meetings on an ad-hoc basis.*
- *NICE uses ad-hoc consultation to hear the views of particular stakeholders they wish to involve.*

Joint Federal Committee (G-BA), Germany

Background

The Joint Federal Committee (*Gemeinsamer Bundesausschuss, G-BA*) Established in 2004, the G-BA is the highest decision-making body in the German health system and has assumed functions previously distributed across a number of corporatist committees such as the Federal Committee of Physicians and Sickness Funds (for ambulatory care), the Federal Hospital Committee and the Federal Committee of Dentists and Sickness Funds. The G-BA is technically supported by the Institute for Quality and Efficiency in Health Care (IQWiG), an independent scientific institute funded through a levy on contributions to sickness funds¹.

Key public involvement activities

- *Joint Federal Committee meetings are attended by up to nine representatives from patient organisations.*
- *The role of patient organisations role is advisory, and they do not have a vote in the decision-making process.*

The Dutch model of patient participation in collective healthcare decision-making

Background

In the Dutch model of patient or healthcare user participation, there is a strong emphasis on the involvement of organised civil society (i.e. patient organisations) and it is described as “neo-corporatist” (rather than being a pluralist model where interest groups try to influence decision-making outside the system).⁷¹ The way in which citizen participation is organised in the Dutch model contrasts with two other options: (1) inviting a representative group of average citizens to voice their opinion on a certain subject and (2) asking a specific group of citizens, the ones who are affected by a certain decision, to participate. The opportunity structure for participation in the Dutch model has been found to be part of “institutionalised formal decision-making on different levels” with many possibilities for participation; however the goal of making the public an “equal party” in healthcare decision-making is not reached in practice and many organisations find it difficult to comply with all the requests to participate.⁷¹

Key public involvement activities

- *Consultation by the Ministry of Health Welfare and Sport, parliament, government supervisory and advisory bodies and municipalities.*
- *Healthcare providers use quality criteria developed by some patient organisations or by the Dutch Healthcare Inspectorate that invite their contribution.*
- *Patient organisations can negotiate collective contracts for insurer members, both content and pricing, and also provide insurers with information for healthcare purchasing.*
- *Consultation on the development of research agendas and in research proposal assessment.*

Local Integration Health Network (LHN, Toronto Central), Canada

Background

The Local Integration Health Network are mandated to plan, co-ordinate and manage healthcare within specified local areas. They are tasked with ensuring a comprehensive package of service. LHINs have a duty to involve “the community” in this process. The community as referred to here includes providers or health and healthcare services. Within their community Toronto Central LHIN has identified four priorities areas on which they are focusing.

Key public engagement activities

- *Consultation over priorities.*
- *Consultation with relevant stakeholders around particular aspects of service redesign.*
- *Consumer advisory panels for each of the priority areas.*
- *Making use of “accountability agreements” to encourage providers to involve the public*

Primary Care Trust (PCT Cambridgeshire), United Kingdom

Background

Primary Care Trusts (PCTs) are responsible for commissioning (purchasing) healthcare for their local residents. They are organised regionally, but deliver national targets. They have a duty to do so through consultation: “In order to make commissioning decisions that reflect the needs, priorities and aspirations of the local population, world class commissioners will engage with the public, and actively seek the views of patients, carers and the wider community. This new relationship with the public is long term, inclusive and enduring, and has been forged through a sustained effort and commitment on the part of commissioners. Decisions are made with a strong mandate from the local population and other partners.”⁸⁴

Key public involvement activities

- *Consultation with the general public and specific groups over strategic priorities.*
- *Consultation with relevant stakeholders around particular service redesign.*
- *Runs a “customer panel”.*

Choosing Healthplans All Together (CHAT), National Institutes of Health, Department of Bioethics, USA

Background

Choosing Healthplans All Together (CHAT) is a simulation exercise in which players decide which benefit types they would like to include in their health insurance package, and what level of service (basic or high) they prioritise.⁸⁵ The CHAT tool was developed in 1995 by physician ethicists at the National Institutes of Health and the University of Michigan. It was tested mainly in a research context and is being trialled in Switzerland. The game has been applied to Medicaid in Texas and in policy planning in Oklahoma; its current use in practice is not well developed but growing.⁸⁶

Key public involvement activity

- *Simulation game used to identify public preferences within insurance packages.*

Appendix C: Interview protocol

Involving the public in healthcare policy

Interview Topic Guide (except CHAT)

We are interested in understanding why members of the public get involved (or not) in healthcare policy and planning, and to hear about their experiences.

1. Please describe your involvement in [this programme]?

Please consider the following:

- What is your role?
- How do you approach members of the public to become involved?
- Do you approach particular members of the public and if so why (e.g. representatives of patient organisations)?
- How much opportunity does the member of the public have to define her/his role?

2. What were the reasons for your organisation for wanting to get the public involved in [this programme]?

3. What are/were your expectations from involving the public?

4. What has been your experience of involving the public so far?

Please consider the following:

- Has involving the public met your expectations?
- How do you feel have members of the public been able to contribute to the process?
- Do you think that the opinions and views of those involved have been valued and in what way?
- How do you think has involving the public made an impact?

5. Is there anything about involving members of the public [in this programme] that should be done differently to help the public participate effectively?

6. Is there anything about involving members of the public [in this programme] that is done particularly well?

7. What do you get out of the process of involvement yourself?

8. Would you consider continuing to involve the public in healthcare decision-making or planning initiatives or programmes?

9. Do you have any general comments you would like to share?

Involving the public in healthcare policy

Interview Topic Guide (CHAT only)

We are interested in understanding why members of the public get involved (or not) in healthcare policy and planning, and to hear about their experiences.

1. **What were the reasons and expectations of your organisation for wanting to get the public involved in the CHAT research programme?**
2. **Please describe your involvement in CHAT.**
Please consider the following:
 - How do you approach members of the public to become involved?
 - Do you approach particular members of the public and if so why (e.g. representatives of patient organisations)?
 - Who defines the role of the public and is there scope for changing role definition?
3. **What has been the uptake of the CHAT tool outside the research project and to what effect?**
4. **What has been your experience of involving the public so far?**
Please consider the following:
 - Has involving the public met your expectations?
 - How do you feel have members of the public been able to contribute to the process?
 - Do you think that the opinions and views of those involved have been valued and in what way?
5. **Is there anything about involving members of the public [in this programme] that should be done differently to help the public participate effectively?**
6. **Is there anything about involving members of the public [in this programme] that is done particularly well?**
7. **Do you have any general comments you would like to share?**

Appendix D: Empirical studies of outcomes of public involvement

| Stated study objective | Study type | Study design | Year | Population studied | Geographical setting | Definition of "public" | Definition or form of "involvement" | Stated goal of PI initiative (if relevant) | Outcome measure(s) | Key findings | Notes | Source |
|--|------------|--------------|-----------|---|----------------------|--|--|--|--------------------|---|---|-------------------------------|
| To review the development process of LHIN as Ontario's approach to planning, co-ordinating, and funding healthcare on a regional basis | case study | qualitative | 2006 | 14 local health integration networks in Ontario | Canada | "community" | "engagement" via consultations (n=1200): 1. round tables, town hall meetings, open houses 2. population-specific events 3. Issue-specific groups (consumer, provider mix) | Co-operative network-based endeavours to "engage, enable and empower people for health" through resource allocation function of LHIN | not relevant | Early initial stakeholder involvement and development of LHIN's capacity to work as a team prepared them for development of integrated health service plans based on community engagement and using a common framework derived from cross-LHIN co-operation | Review of case study was a process evaluation with no specific outcome measurement | Eliasoph <i>et al.</i> (2007) |
| To describe an intersectoral collaboration that took the form of a partnership between a RHA and a faith community, and how this type of public participation informed women's health policy development | case study | qualitative | 1993–2000 | Calgary and surrounding areas (980,000) | Canada | not explicitly stated (individual women) | partnership between Calgary Health Region and Salvation Army (SA), several strategies (e.g. Women's Health Express Advisory Council, SA Health Council) | A formal mechanism for public participation in the health policy decisions regarding the delivery of women's health services | emergent themes | Few study respondents could distinguish between strategies for public participation and access to services, or between process and outcome. Case showed that mutual goals could be met on certain topics by two organisations with different values. While appropriateness of SA was critiqued, document review found that no programme on | Findings are exploratory only – i.e. based on a pilot study of deliberative methods in a single community, however sampling ensured proportional representation | Thurston <i>et al.</i> (2005) |

| Stated study objective | Study type | Study design | Year | Population studied | Geographical setting | Definition of "public" | Definition or form of "involvement" | Stated goal of PI initiative (if relevant) | Outcome measure(s) | Key findings | Notes | Source |
|--|-----------------|---|--------------|---|----------------------|---|---|---|---|--|--|----------------------------|
| | | | | | | | | | | women's health might have existed without SA advocacy. Key – study demonstrates that success should not be limited to whether high-level governance decisions are made; success here was the development of a formal partnership that was able to inform the development of women's health policy in the region. The partnership was found both to open up political space for prioritising women's health and to allow women's organisations to challenge the status quo in health service delivery. | | |
| To assess feasibility of using a citizens' jury to elicit public values on health technologies and to develop criteria for setting priorities for health technology assessment (HTA) | empirical study | qualitative (jury sessions, open survey questions), quantitative (participant survey) | not reported | random sample of 1600 residents of the Capital Health Region in Alberta | Canada | "ordinary citizens" (defined by authors as "individuals with no particular axe to grind and whose voices might not otherwise be heard") | "engagement" via jury session of 2.5 days | To pilot the citizens' jury as an approach to engage the public in priority-setting for HTA | not explicitly stated (content of jury deliberations + participant views) | The jury identified 13 criteria, ranked in order of importance (top 2 were "potential to benefit a number of people" and "extends life with quality"). Scope of questions jurors were asked to address, time allowed for deliberations and full jury session, and number of witnesses were "adequate" or "about right". Also presentations, jury deliberations and small-group discussions were helpful or very helpful. Jurors viewed experience of process for engagement positively, expressing interest in participating in future juries. | Pilot study methods of sampling and conduct of the jury well described for replicability; care was taken to ensure jury sample included a diverse range of stakeholder characteristics that reflected the local population | Menon and Stafinski (2008) |

| Stated study objective | Study type | Study design | Year | Population studied | Geographical setting | Definition of "public" | Definition or form of "involvement" | Stated goal of PI initiative (if relevant) | Outcome measure(s) | Key findings | Notes | Source |
|---|---|---|-----------|--|----------------------|--|---|---|--|---|---|------------------------------|
| To examine the effects of introducing different opportunities for deliberation into a process for obtaining public input into a community health goals priority-setting project | empirical study (controlled pre-/post-design, with stratified random sampling) | quantitative | 2001 | 2 local health agencies for small communities in Ontario (90,000 each) | Canada | "citizen members of a community" – i.e. "local resident" | "consultation" via citizen panel: 1. mail survey 2. telephone survey 3. face-to-face group meeting | To obtain citizen input to inform a community-wide health goal-setting process | not explicitly stated (participant views and satisfaction) | Deliberation makes a difference to participant views and as more deliberation is introduced participant views may be more amenable to change in some instances, e.g. before–after rankings of priority health concerns showed greater observed changes in the face-to-face citizen panel than in the telephone group. Changes in top-priority health-concern ranking occurred in same direction, showing effect of increased deliberation on consensus building and persuasion. Deliberative process may have greater impact on more specific health concerns than more broad determinants of health. | Findings are exploratory only – i.e. based on a pilot study of deliberative methods in a single community, however sampling ensured proportional representation | Abelson <i>et al.</i> (2003) |
| To assess the performance of a generic public participation method implemented in 5 Canadian regionalised health settings between 2001 and 2004 and to explore the real-time influences of contextual variables | empirical study (3-year comparative quasi-experimental design, with stratified random sampling) | quantitative (surveys) + qualitative (direct observation) | 2001–2004 | general population of the different regions (46,000 to 1 million) | Canada | not explicitly stated (local citizens) | meeting (6 hours, face-to-face, with plenary and small-group sessions) | To provide the sponsoring RHA with public input on an issue of importance varying by region | effects on: (1) participating citizens (2) sponsoring decision-makers (3) the decision-making it was designed to inform | Consultation process was favourably received by meeting participants but decision-makers' assessment of the consultation varied. Variable effects of citizen consultation on organisational decision-making across sites: the "recommended decision" in Quebec was accepted and implemented by the RHA within the study follow-up period; whereas in Ontario and Nova Scotia the reports on the consultation outcomes | A single public participation method was implemented uniformly across all study sites, ensuring robust findings. Study was well planned and described. Study identifies which features of context influence the consultation outcome. | Abelson <i>et al.</i> (2007) |

| Stated study objective | Study type | Study design | Year | Population studied | Geographical setting | Definition of "public" | Definition or form of "involvement" | Stated goal of PI initiative (if relevant) | Outcome measure(s) | Key findings | Notes | Source |
|---|------------|---|-------------------------|---|----------------------|--|---|---|---|---|---|------------------------------|
| | | | | | | | | | | presented to respective RHA boards did not appear to result in discernible actions that could be identified from organisational documents. 4 aspects of context influence the performance of the consultation method. | | |
| To describe a community development approach (Community Action on Health) to public participation in terms of how far it met its core aim | case study | mixed methods, mainly qualitative (range of data sources) taking a stakeholder approach | April 1997 to June 1998 | Newcastle West Primary Care Group (114,000) | England | not explicitly stated (local residents and members of marginalised community groups) | "community development" (inclusive process of "networked representation", especially for traditionally marginalised members of community) | To promote community participation in decision-making about local health services | participant views and experiences (intermediate outcome); output of consultation (i.e. ways local health service planning and delivery changed) | (1) Community development can be successful in sustained active participation in a diverse range of local interests (5% disabled; 16% ethnic minorities) and involve people beyond most accessible and active local residents. (2) Demonstrable impact on service planning – new services resulted from priority needs identified at Community Action on Health conference and follow-up work, attracting new funds to the health service from joint finance and regeneration funds: (i) access for deaf community to trust via installation of minicomms (+ organised deaf awareness days at the trust); (ii) counselling service targeting ethnic minority communities; (iii) a community family support project that employs local people to support isolated families; (iv) a youth project where health services are brought to marginalised young people on their own "territory"; (v) a project | One case study about 10 years old, although article makes distinction between one-off consultation exercises with individual members of public; several terms are used interchangeably to refer to the project (e.g. community involvement, community development, participation) | Crowley <i>et al.</i> (2002) |

| Stated study objective | Study type | Study design | Year | Population studied | Geographical setting | Definition of "public" | Definition or form of "involvement" | Stated goal of PI initiative (if relevant) | Outcome measure(s) | Key findings | Notes | Source |
|---|------------|----------------------------|--------------|---|----------------------|---|--|---|--|---|--|----------------------------|
| | | | | | | | | | | to increase local access to community care services. Service providers perceived that project changed they way they operated by making them aware of perspectives and issues of minority groups. Provider doubts about unrealistic community expectations successfully overcome. | | |
| To assess the nature and development of service user involvement over a 30-month period in a specific English locality | case study | qualitative + quantitative | not reported | mental health service users and staff members in Somerset | England | unclear | "user representation" on JCB ³ , on trust board (as non-executive), on locality reference groups and staff training group | "To enable listening to and consulting users ... an enhanced user and carer voice" | not relevant | User consultation around service management and planning appeared to increase as a consequence of creating JCB, but the impact of user representatives on JCB appeared minimal despite regular contributions – e.g. the 2 user representatives had no direct means of setting the JCB agenda. User membership on trust board perceived as positive, especially if made in the "appropriate way" (i.e. rational) | Review of case study was a process evaluation with no specific outcome measurement | Peck <i>et al.</i> (2002) |
| To answer a series of research questions that concerned assessing processes, as well as outcomes and impact, and ascertaining how and whether | case study | qualitative | 1997–2001 | varied (200,000 to 1.4 million) | England | not explicitly stated (community members) | "engagement" via partnership-based collaboration among a collection of agencies, groups and individuals | To harness the dynamism of local people and organisations "to explore mechanisms for breaking through current | not explicitly stated (extent to which HAZs realised the goal of "involving and empowering local communities to achieve sustainable development" + factors affecting this process) | Overall HAZs did not do what they set out to achieve; in terms of community engagement HAZ contribution was relatively unbalanced and there was little evidence of communities or service | Paper gives no detail about the evidence of the impact of community involvement on decisions | Bauld <i>et al.</i> (2005) |

³ JCB stands for Joint Commissioning Board

| Stated study objective | Study type | Study design | Year | Population studied | Geographical setting | Definition of "public" | Definition or form of "involvement" | Stated goal of PI initiative (if relevant) | Outcome measure(s) | Key findings | Notes | Source |
|--|-----------------|--|-----------|--|----------------------|---|--|--|--|--|--|-----------------------------|
| objectives of Health Action Zones (HAZs) were achieved | | | | | | | | organisational boundaries to tackle inequalities, and deliver better services and better healthcare" | | users shaping the strategic directions. Below the strategic level, there was evidence of community involvement in governance processes (e.g. making or scrutinising decisions) within some localities. Even here there was awareness that formal rules constrained the extent to which accountability for health services and policy can be realised by local communities (i.e. priorities were set centrally and thus the partnership-based initiative was top-down). | | |
| (1) To assess how primary care groups and trusts in English NHS have informed and consulted local communities and (2) to examine perceived impact of this consultation on decision-making | empirical study | quantitative (longitudinal survey) + qualitative (interviews with chief officers and chairs) | 1999–2000 | random sample of 72 (15%) of primary care groups (PCGs) established April 1999 | England | not explicitly stated (lay representatives or local people) | "consultation" – 3 main methods: (1) consulting community health councils; (2) holding public meetings; (3) consulting local patient groups | To involve and engage all stakeholders in shaping policies and decisions about primary care provision and delivery, including consultation and engagement with local communities | (1) extent of CHC in PCG work (2) nature of public consultation (3) perceived impact | 41% of lay board members rated their own influence on PCG decision-making as low or none. 77% of chairs said consultation had little or no impact on decisions relating to clinical governance, and 48% said it had little or no impact on local service developments. CHC respondents, when consulted, felt their impact on policies and decisions was fairly limited. Most PCG/Ts are struggling to develop effective ways of involving local communities; effective consultation requires new methods and adequate resources as well as stronger lay voice in governance | Several different terms used interchangeably for public involvement – e.g. lay representation and local consultation | Alborz <i>et al.</i> (2002) |

| Stated study objective | Study type | Study design | Year | Population studied | Geographical setting | Definition of "public" | Definition or form of "involvement" | Stated goal of PI initiative (if relevant) | Outcome measure(s) | Key findings | Notes | Source |
|---|-----------------|---------------------------------------|--------------|--|----------------------|------------------------------------|--|---|--|--|---|-------------------------------|
| | | | | | | | | | | structures. | | |
| To identify methods for involving users, examine views of users and providers concerning success of these methods, and explore factors that may promote or hinder successful user involvement | empirical study | quantitative (cross-sectional survey) | not reported | mental health service user groups and trusts in Greater London (7,400,000 residents) | England | unclear | "consultation" via range of methods: surveys, service audit, group meetings, delivering staff training, board membership | To involve service users in the planning and delivery of psychiatric services | specific changes to policy or practice | Most specific changes resulting from public involvement were attributed to responses of complaints made by users; 11 trusts listed a range of changes including improvements to ward environments, organisation of out-patient services and systems for supporting patients in crisis. Attendance by service users at planning meetings had influenced service development and policies in 8 trusts. Attitude of managers and staff has central role in determining the impact users have. | Review explores the practice of user involvement, but results of survey questions about impact of different methods are only briefly summarised | Crawford <i>et al.</i> (2003) |
| To describe the process of a "grounded" citizens' jury | case study | qualitative | 1999 | South-west Burnley (18,000 residents) | England (north west) | "individuals who live in the area" | "grounded" consultation" of 5 days via a citizens' jury | To understand better the needs of all sections of the community so that appropriate primary care services can be provided | not relevant | Jury process (1) acted as a grass-roots health needs assessment and (2) resulted in funding to set up a community health centre run by a board consisting of community members (including 2 jurors) with local agencies. Juror process resulted in over 80 specific recommendations that | Review of case study was a process evaluation with no specific outcome measurement | Kashefi and Mort (2004) |

| Stated study objective | Study type | Study design | Year | Population studied | Geographical setting | Definition of "public" | Definition or form of "involvement" | Stated goal of PI initiative (if relevant) | Outcome measure(s) | Key findings | Notes | Source |
|--|-----------------|--|-----------|--------------------|----------------------|--|---|---|--------------------|---|--|------------------------------|
| | | | | | | | | | | were fed back to the wider community and agencies in a public meeting 3 months after publication of the report. | | |
| To examine the "true reality" of participation of consumers in health decision-making, and what it brought to definition and implementation of health policy | empirical study | qualitative (interviews, document review) + quantitative | 1996–2002 | not specified | France | not explicitly stated (consumers/citizens) | not explicitly stated (representation from consumer groups) | To serve as a mechanism for rendering debates more transparent and concrete | not relevant | Study demonstrates different levels and types of participation, predominantly in the form of consumer group representation rather than of elected citizens. National level – participation of representatives of consumer associations was marginal. Regional level – participation of consumers was appreciated and felt to be legitimate and useful, with consumers able to participate in developing regional health priorities following regional health conferences, and some priorities became the object of regional programmes. General finding was that the closer the regional health programme is to a territory, the more consumers are associated with it. | Review of case study was a process evaluation with no specific outcome measurement, yet the authors conclude that the study demonstrates that consumers were associated with and implicated in the development and implementation of national, regional, and local health policies | Bréchat <i>et al.</i> (2006) |

| Stated study objective | Study type | Study design | Year | Population studied | Geographical setting | Definition of "public" | Definition or form of "involvement" | Stated goal of PI initiative (if relevant) | Outcome measure(s) | Key findings | Notes | Source |
|--|------------|--------------------------------------|-----------|--|----------------------|---|--|---|---|---|--|------------------------------|
| To implement a public consultation initiative (the Health Parliament) | case study | not reported (descriptive analysis?) | 2003 | general population | Israel | "ordinary citizens" (defined by authors as "individuals with no particular axe to grind and whose voices might not otherwise be heard") | "consultation" via: (1) 6 regional meetings, and (2) survey | To elicit "ordinary" citizens' views on pertinent healthcare priorities | not explicitly stated (participant views + compatibility of policy recommendations + impact as decisions on future actions) | "A dramatic increase among most participants in self-knowledge regarding consultation topics following sessions." Participants also viewed the policy issue beyond their individual perspective as a result. Comparison of summary documents of each regional group's recommendations showed that consultation process enabled the elicitation of divergent views as well as shared conclusions within and across groups. Health Parliament summaries were presented to the Minister of Health (MoH) and the Health Council – recommendations were addressed in detail by the MoH and views were incorporated in documents drafted by professional MoH staff for discussions in the Basket Committee. 2 of the largest health fund directors implemented their own public deliberative initiatives as a result. | Study focuses on direct output of the deliberative process | Guttman <i>et al.</i> (2008) |
| To describe an Italian pilot project (PartecipaSalute) to involve lay people, patients' associations and scientific-medical representatives in the health debate | case study | quantitative | 2004–2006 | 10 patients' federations and Italian federation of medical societies | Italy | not explicitly stated (lay representative / consumer groups / public advocates) | (1) survey, (2). shared initiatives (conference), and (3) active participation (website) | To create a partnership among lay people, patients' associations and the scientific-medical community | not explicitly stated (participant views and satisfaction + frequency of project website hits) | Training course increased lay knowledge of health debate and decision-making. Large number of project website visitors (mean of 14,000 contacts between April and October 2006 and | Paper was a descriptive case study, not a direct evaluation of outcomes of the pilot project | Mosconi <i>et al.</i> (2007) |

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|---|-----------------|---|--------------|----------------------------|----------------------|--|-------------------------------------|--|--|--|--|---------------------------------------|
| | | | | | | | | | | average of 200 people per month subscribing to weekly newsletter). Consensus conference working group between patients' groups, scientists and clinicians shared data collection on patients' and families' needs and suggested quality improvement interventions (conference results available in Italian on website) | | |
| To study whether the Dutch participation model is a good model of participation | empirical study | qualitative (interviews, document review) | not reported | actors in healthcare field | The Netherlands | "representatives of patient organisations" | "participation" | "To contribute the patient perspective" | (1) influence on policy-making, and (2) influence on patient organisations | Several examples of influence of decision-making – e.g. policy change regarding medication distribution and reimbursement criteria of health insurers, development of Healthcare Consumer Act, use of new quality criteria for children in hospitals changing hospital services accordingly, attention to diabetes protocols and dentist guidelines. Successful influence derived from strategies other than formal decision-making process (e.g. media and lobbying). Results also noted that there were 18 examples of unsuccessful attempts to influence policy outcomes. Positive effect of participation on the well-being of participants reported. However questions were raised about "representativeness", "professionalisation" requirement, and the | Study offers a scoping of the opportunities for and effect of participation by representatives of patient groups, but is not an evaluation of the effectiveness of the model | van de Bovenkamp <i>et al.</i> (2009) |

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|---|------------|--------------------------------------|-------------------|---|----------------------|--|---|---|--|---|---|----------------------------|
| | | | | | | | | | | risk of "instrumental use" of participation from patient groups | | |
| To describe the benefits of working in partnership derived from 2 health action zones in Northern Ireland | case study | qualitative (ethnographic fieldwork) | 2003–2004 (March) | partners of the Armagh and Dungannon Health Action Zone and the North and West Belfast Health Action Zone | Northern Ireland | not explicitly stated (community groups) | "representation" from community groups partnering in collaborations | To reduce health inequalities through co-ordinated activity of different agencies | not explicitly stated (focus was on conditions for change + proximal "benefits" – e.g. individual empowerment, bridging social ties, synergy ("creative solutions to intractable problems")) | Direct action included: (1) health services becoming more user-friendly and accessible, (2) much stronger community engagement processes, and (3) partnerships leveraging money from external funding sources. Impact examples were: (1) a local energy-efficiency project in a rural area in which community group involvement was central to decisions about who receives energy-efficiency measures and how the project is carried out, and (2) creation of a community convention 2 years afterwards which engaged fractured communities in jointly contributing to plans for a number of health-related services (e.g. housing and education). Negative aspects of partnerships also noted (e.g. time- | Case studies are used to induce a conceptual model describing how effective partnerships may impact on distal outcomes (e.g. determinants of health and inequalities) | Boydell and Rugkása (2007) |

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|---|-----------------|--------------|------|---|----------------------|--|--|---|---|--|---|-------------------------------|
| | | | | | | | | | | consuming nature meant opportunities for accessing funding were lost, partners from the community were ostracised when they challenged statutory sector partners). | | |
| To describe a consumer council within a public psychiatric hospital and to evaluate its achievements | empirical study | qualitative | 1998 | forensic population in St Louis Psychiatric Rehabilitation Center in Missouri | USA | not explicitly stated (consumer / hospitalised patients) | "participation" via client representation at council meetings | To develop a structure for gathering client information that would be useful for improving organisational performance | not explicitly stated (realisation of council meeting action decisions) | The council had made practical improvements for facility clients' daily living, with a sample list of 18 changes in which the consumer council played a significant role – impact was not evidenced at the facility policy level. One planning-related change was to "increase the diversity of pastoral services offered! | | Linhorst <i>et al.</i> (2001) |
| To examine client involvement in decision-making at the hospital related to treatment planning, residential units, organisational decision-making and mental health policy-making | empirical study | qualitative | 1998 | forensic population of a public long-term psychiatric hospital in Missouri | USA | not explicitly stated (clients) | "participation" defined as "clients' involvement in the process of setting policies and procedures that governed operation of the hospital and applied to all clients" | varied by involvement method | not explicitly stated (changes achieved) | Document review identified 5 formal structures or processes with potential to involve clients, although not all methods were perceived by clients, staff or both to be a means for clients to influence decision-making. Impacts: consumer council – several practical changes were achieved; policy review process – clients' input resulted in: (1) major content change to 4 hospital policies, (2) match policy to practice, (3) change procedural timelines, and (4) write more | Findings serve as a descriptive impact assessment, but are limited to one site-specific hospital population | Linhorst <i>et al.</i> (2005) |

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|---|-----------------|--|-----------|-----------------------------|----------------------|------------------------------------|---|--|---|--|---|----------------------------|
| | | | | | | | | | | clear and concise policies. Performance improvement system – clients participated in several public involvement projects that resulted in changes to hospital policies or operating procedures. Grievances filed by individual clients – 4 changes to hospital policy. | | |
| To evaluate the feasibility of using the CHAT exercise as a tool to learn about public priorities for health benefits | empirical study | quantitative (pre-/post-comparisons, by sub-group) | 1999–2000 | residents of North Carolina | USA | not explicitly stated (laypersons) | "participation" in group simulation game using a roulette wheel | To promote participatory decision-making in healthcare priority-setting that is inclusive, deliberative, and accessible to a diverse lay audience, especially low-income, low-education groups | participant knowledge/learning; effect of exercise on individuals' health benefit selections between round 1 and 4 towards public-spirited orientations (e.g. home healthcare, "last chance therapies", specialty care) | Learning from playing the game and motivation to learn more about their own health insurance was reported by most participants (73% and 69% respectively). CHAT exercise altered choices among participants from all groups (with and without insurance): (1) number of services chosen for benefit package increased significantly, (2) group deliberation resulted in acceptance of trading off more restrictive levels of services, (3) choices of particular services changed after exercise for participants, (4) slight increase in percentage of Medicare group participants choosing to extend coverage to uninsured but not in commercially insured group | Study reveals group differences in extent of direct effect of deliberative exercise on knowledge and decision-making, but results need to be replicated in other contexts | Goold <i>et al.</i> (2005) |

Appendix E: Evaluation assessment tools

This appendix provides an overview of evaluation assessment tools proposed in the literature on public involvement that may be considered relevant to understanding the impact or outcomes of public involvement.

Potential process evaluation criteria proposed by Abelson *et al.* (2006),⁷⁵ following Rowe and Frewer (2005)¹⁸

| Process criteria | Outcome criteria |
|--|--|
| <ul style="list-style-type: none"> • representativeness • inclusivity • participation rate • early involvement / obtaining early input in early planning processes • process fairness • process flexibility • subjective assessment of previous evaluator • perceived openness of process • transparency • structured decision-making • resource accessibility • task definition • independence • interaction • continuity • comfort • convenience • satisfaction • deliberation • fairness • competence • identification of common good • incorporation of values/beliefs into discussion • effectiveness of method process | <ul style="list-style-type: none"> • policy/decision influence • time to develop regulations • reduce/eliminate judicial challenges • agency responsiveness to participants' policy demands • public views incorporated into decision-making • influence on public • social impact • impact on general thinking • effect on public and plan support • participants' values/opinions changed • interaction with lay knowledge (impact on lay learning) • effect on staff and planning process • impact on training • staff awareness • conflict resolution • restoring public trust in public agencies • perceptions of consultations by MPs, public, media (i.e. perceived success/failure) • effectiveness and cost effectiveness • procedural impact of the mechanism |

Principles for the design and evaluation of public participation processes as proposed by Abelson *et al.* (2003) ²⁹

Representation

- Legitimacy and fairness of selection process
- Is there a representative sample?
geographical/demographic
- Political community
- Participant selection vs. self-selection
- Inclusiveness (broad) vs. exclusiveness (narrow)

Procedural rules

- Degree of citizen control/input into agenda-setting, establishing rules, selecting experts, information
- Deliberation
- Amount of time
- Emphasis on challenging experts, information
- Mutual respect
- Credibility/legitimacy of the process
- At what point in the decision-making process is input being sought?
- Who is listening? (e.g. influential decision-makers, junior staff)

Information

- Characteristics
- Accessibility, readability, digestibility
- Selection and presentation
- Who chooses the information? Who chooses the experts?
- Interpretation
- Adequacy of time provided to consider, discuss and challenge the information

Outcomes/decisions

- Legitimacy and accountability of
 - decision-making
 - communication of decisions
 - responses to decision or input
 - More informed citizenry
 - Achievement of consensus over the decision
 - Better (or different) decisions
-

Outcome evaluation framework for public participation in health research⁷⁴***Dimensions of efficiency***

- Monetary cost of research
- Time taken to complete research projects
- Recruitment and retention of participants for research projects

Dimensions of effectiveness

- Reliable impact on the quality of the research process
(e.g. formulation of the research question, validity of the research process)
- Reliable impact on the quality of research outcomes

Dimensions of equity

- Representation of “socially excluded” groups and sub-groups
- Form and extent of representation in the research process
- Distribution of access to resources in support of the research

Ethical considerations

- Accountability of scientific researchers, and of the research process as a whole
- Processes of consent for participants in research and prevention of exploitation
- Realisation of the “rights” of research participants
- Health and safety considerations

Empowerment

- “Ownership” by participants in the research
- Capacity-building among research participants