



# Involving the public in decision-making about large-scale changes to health services: A scoping review



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## ABSTRACT

**Background:** Public involvement in large-scale changes (LSC) to health services is strongly promoted – and even mandated – in several health systems. This scoping review aimed to describe the evidence about how public involvement is conceptualised and conducted in LSC, with what impact, and how different stakeholders perceived this process.

**Methods:** After searching eight databases, 34 publications were included. Data were extracted and charted using a standardised form. Findings from the literature were discussed with frontline stakeholders.

**Results:** Public involvement remains poorly defined and its aims lack clarity in LSC. Public meetings are most often used to gather public views but raise the issue of representativeness. However, evidence in the literature is scarce about which involvement methods – informative and deliberative – are appropriate for the different stages of the LSC and with what impact. In several cases, the involved public felt they had no influence on decision-making regarding LSC proposals, sometimes leading to an environment of mistrust. In those instances, the public understood the technical arguments for change and actively questioned them, opposed LSC plans and sought alternative routes to voice their views.

**Conclusion:** More research and consideration are needed regarding who should be involved, with what purpose and how. We argue that in practice two models of involvement, invited and uninvited participation, coexist and therefore interactions between the two should be given further consideration in LSC.

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## 1. Introduction

Healthcare systems across the world face the challenge of meeting rising needs for healthcare with decreased financial resources. Reconfiguring health services at a large-scale is often introduced as part of the solution to this dilemma [1,2]. An array of terms are used to describe those changes to health services, here we use the term large-scale change (LSC) to describe “interventions aimed at coordinated, system-wide change affecting multiple organisations and care providers” [3], such as centralisation and other changes to the regional distribution of services. LSC proposals have become

associated by the public with making cuts and downgrading services, some being met with strong opposition from the public, staff and local politicians [4–6].

Many international and national policies promote a democratic involvement of the public in health policy and healthcare [1,7–9]. Rationales for involving the public are multiple and include increasing the legitimacy of decision-making, tailoring publicly-funded services to local needs and resolving tensions in controversial proposals [10–15]. Some countries, like the UK, have made this public involvement a legal requirement in the context of LSC [16,17].

Yet, it is difficult to grasp what public involvement means in LSC. Firstly, understanding what public involvement entails is a complex task. A plethora of terms are used to refer to who should be involved such as: patients, service users, citizens, public, lay people, communities or consumers [14,18–20]. Similarly, the term involvement – often used interchangeably with other terms like participation,

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**Table 1**  
Search terms and approach.

Key concept 1	Key concept 2
(“patient” OR “public” OR “service user” OR “PPI” OR “lay” OR “citizen” OR “communities” OR “consumer” OR “healthwatch” OR “community health council” OR “local involvement network”)	((“large-scale” OR “major” OR “extensive”) NEAR (“change” OR “transformation” OR “reform” OR “modification”) NEAR (“service” OR “healthcare” OR “system” OR “care” OR “hospital”))
NEAR/3 (“involvement” OR “engagement” OR “participation” OR “collaboration” OR “consultation” OR “representation” OR “voice” OR “coproduction” OR “advocacy”)	OR (“reconfiguration” OR “reorganisation” OR “redesign” OR “restructuring”) NEAR (“service” OR “healthcare” OR “system” OR “care” OR “hospital”))
	OR (“service” OR “healthcare” OR “system” OR “care” OR “hospital”) NEAR (“closure” OR “relocation” OR “merger” OR “centralisation”))

consultation or engagement – remains poorly defined [14,19–21]. For the purpose of this review, we define public involvement as an umbrella term covering any initiatives that included any groups of the public (patients, carers, general public, patient/public representatives) in the process of LSC.

Secondly, despite being strongly promoted, or even mandated, in several health systems, little is known about how involvement is understood, interpreted or operationalised in practice [15,19,22–24]. Moreover, with a large number of approaches available to healthcare managers seeking to involve the public [25] in the LSC process, it remains unclear which methods are most appropriate under different circumstances, especially in contested LSC plans, and evidence about the impact of involvement is sparse [10,14,15,26].

The review thus sought to answer the following questions:

- How is public involvement conceptualised in LSC?
- How is this involvement carried out in LSC?
- How do different stakeholders perceive the involvement process?
- What kind of impact does public involvement have in the LSC context?

## 2. Methods

A scoping review approach was chosen to answer our exploratory research questions with the aim of mapping the literature on the specific scope of public involvement in LSC and identify key concepts and gaps in knowledge and practice. It includes sources with different designs (e.g. qualitative research, commentaries, reviews, grey literature) and combines the review with inputs from stakeholders via a consultation [27,28].

### 2.1. Literature search methods

This scoping review was conducted using Arksey & O'Malley's [27] framework stages, incorporating the enhancements proposed by Levac et al [29]. The search strategy, developed and piloted in consultation with a health librarian, focused on the following databases: Health Management Information Consortium, PsycINFO, Cumulative Index to Nursing and Allied Health Literature, Cochrane Library, Scopus, Medline, Embase and Applied Social Sciences Index and Abstracts. The databases were searched to identify studies addressing the two key concepts that took into account the plethora of terms used to describe public involvement and LSC (Table 1).

The retrieved articles were screened by ND based on the following inclusion criteria: a) publications describing any method(s) of involvement (e.g. public consultation, citizen jury, surveys, etc.) targeting any group(s) of the public (patients, carers, public, patient/public representatives); b) in the context of LSC to secondary and tertiary healthcare; and c) published from database inception to February 2018. The database search produced 3830 results (after removal of duplicates), which we reviewed by title and abstract according to the inclusion and exclusion criteria. 115 publications were identified for full-text review (Fig. 1). To ensure reliability of the review, a random sample of 35 full-text publications was reviewed by all authors to refine the inclusion and exclusion criteria (including agreeing if the changes described qualified as large-scale change) and discuss key themes. ND then continued the screening process alone. Additionally, the reference lists of included articles were examined to look for additional relevant articles.

Following scoping review guidelines [29], data were extracted and charted using a standardised form, agreed by all authors, based on the research questions. The initial form was developed at the protocol stage to chart the following key information: study location; aims of the study; type of change; duration of the change; definition of public involvement; methods used; duration and timing of public involvement; who was involved; impact of involvement; evaluation of involvement; barriers and facilitators of involvement; views on the process; other relevant points. All authors met regularly to agree on data extraction and discuss emerging themes. In case of divergent views, consensus was reached following group discussion. During these meetings, the data extraction form was refined to include for example the perspective reported; and the public opposition, which was originally extracted under 'other relevant points'. A thematic analysis was then conducted by ND and reviewed by all authors, to identify concepts and themes in the data extracted. Codes and overarching themes were established both inductively from the data extracted and deductively from previous reviews of the literature on public involvement in other contexts. EPPI-Reviewer 4 was used to manage the data and support analysis.

### 2.2. Stakeholder consultation methods

A consultation with stakeholders was designed to inform and validate findings from the review [27,29]. Here the purpose of the consultation was obtaining feedback from frontline stakeholders to determine if our findings resonated with their experience; sensitising the research team to issues that may or may not appear in the literature; and signposting the researchers towards relevant literature (in particular grey literature) not retrieved in this search. Participants targeted were anyone who is or was previously involved in public involvement in LSC – may that be as a manager, member of the public, patient, clinical staff, campaigner, consultant, academic, etc.

In order to reach people from different backgrounds and countries, the consultation took the form of a virtual consultation [30]. The consultation website – advertised through social media and professional networks – included a section about the research; a concise lay summary of the findings with the opportunity to comment on those, either anonymously or not; and the option to contact the researchers and receive updates on the research. 18 individuals from the UK and Canada chose to take part in the consultation and self-identified as a member of the public (n=3), a member of a patient's group (n=4), a service user (n=5), a lay representative on Patient and Public Involvement locally (n=1) and a member of our research advisory panel (n=5) – see section 2.3

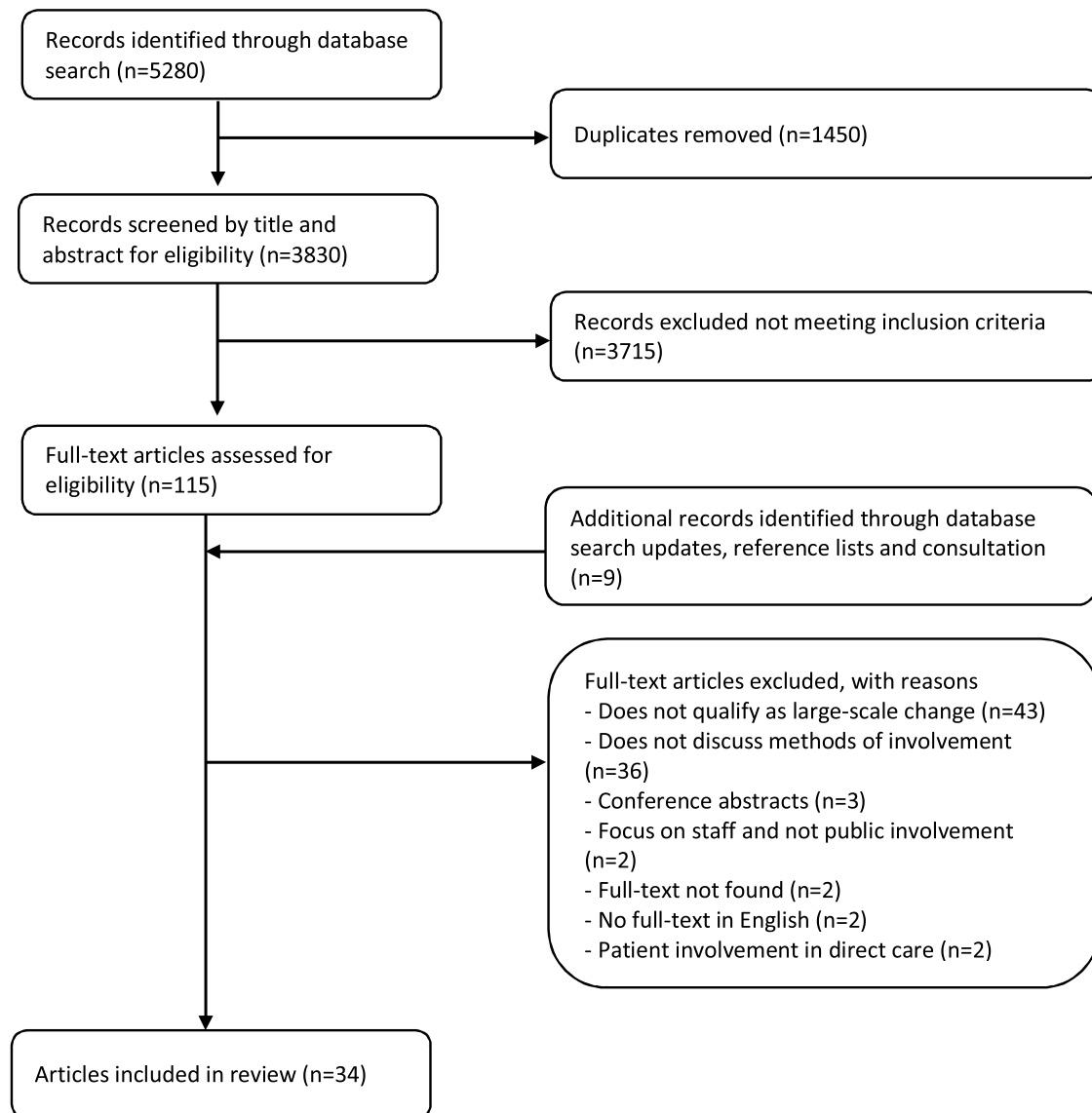


Fig. 1. Flow diagram of study selection process.

### 2.3. Patient and public involvement in this research

The NIHR CLAHRC North Thames's Research Advisory Panel, made up of patients, carers and members of the public, reviewed the consultation website and provided written and oral feedback on accessibility, format and content. Following the panel's feedback, we made several changes to the website such as adding an introduction to the home page, rewriting the section 'About the research' to simplify the language and add elements requested by the panel, explaining how the feedback from the consultation would be used and creating a mobile friendly version. The panel additionally gave suggestions on how to advertise the consultation. Given that some members of the panel had been involved in LSC, they also took part in this scoping review's consultation, as specified in section 2.2.

## 3. Results

### 3.1. Type of literature

After screening for eligibility, 34 publications were included. 4 publications are reviews that are described in Table 2. The two older

academic reviews focused on change (not exclusively focused on LSC) within health and other public services [31] or within mental health services [32]. Those reviews presented no overlap between their included studies and the studies included in this scoping review but offer some learnings for involvement in the context of change, integrated to our findings below. The Independent Reconfiguration Panel's review [33] offers an insight into the reasons LSC proposals are referred to this governmental body, with relevant information regarding the public involvement process integrated to our review findings. The most recent academic review [15] is a rapid review of service user engagement in health service reconfiguration in the UK, which overlaps with 8 of the studies and the 3 reviews mentioned above that we included in this scoping exercise. We therefore built on their findings focused solely on LSC; using a different methodology; broadening our scope to international studies; and including relevant important studies published since [34–38].

The remaining publications are diverse in their affiliations and types of analysis; covering public involvement in LSCs to various kinds of health services and have been classified in Table 3. Interestingly, Table 3 suggests that LSCs to acute services are accompanied by a higher intensity of public involvement, in many instances

**Table 2**  
Description of the reviews included.

Source	Description	Affiliation of authors & Type of analysis
Crawford et al., 2003 [31]	1108 papers included to review the literature on user involvement in change management within health and other public services; and organisations in the voluntary and private sectors. Majority of included papers from the UK.	Academic Review (organisational perspective)
Dalton et al., 2015 [15]	Rapid review to assess knowledge on effective patient and public engagement in large-scale health service reconfiguration. 32 UK studies included looking at reconfiguration in eating disorder, emergency, maternity, mental health, cancer and acute services; and health and social care integration.	Academic Review (health services perspective)
Independent Reconfiguration Panel, 2010 [33]	Review of proposals referred to the Independent Reconfiguration Panel. Review looked at proposals to reconfigure maternity, children, emergency, surgery, geriatrics, mental health, microbiology and cancer services and at public engagement.	Government Review of reasons LSC proposals were referred to the panel
Rose et al., 2003 [32]	112 publications (from UK, USA, Canada mainly) included to examine how users and/or carers have been consulted about or involved in planning or implementing organisational change within mental health services.	Academic Review (organisational perspective)

reaching thousands of people. The findings are presented below under the main review questions.

### 3.2. How is public involvement conceptualised in LSC?

The literature included provides few insights into how public involvement is understood and interpreted by the relevant actors in relation to LSC. Definitions of involvement (and associated terms) are scarce as only two publications provided a definition. Indeed, Abelson [46] refers to ‘participation’ as “actions taken with the objective of influencing a decision-making process” while Rutter et al [43] mention that ‘consultation’ is “a model in which professionals retain control of both the process and outcomes of user involvement”.

Yet it is worth mentioning that the UK non-academic literature uses the terms ‘consultation’, ‘involvement’ and ‘engagement’ distinctively. Namely ‘consultation’ is used to describe the formal period required to fulfil the NHS’ legal duty to consult the public when health services are to be changed [16,17]. In contrast, the term ‘engagement’ is used to refer to involvement activities undertaken before the formal ‘consultation’. ‘Involvement’ – employed less often – is used to refer to public involvement in general, when not referring to a timeframe, or to refer to involvement of other stakeholders such as clinicians and local politicians.

Moreover, there is little or no mention of conceptual frameworks or guidelines that may have been used in this context. None of the participant analyses mentioned models or guidelines used to plan their involvement activities, except in one instance [63] where it was mentioned that the draft interim guidance issued by the Scottish Executive Health Department [64] was followed. Authors of four academic studies [32,40,43,44] either mentioned or referenced Arnstein’s ladder [65], while another academic study [35] described the International Association for Public Participation’s Spectrum [66].

Some academic authors and external consultants [15,31,40,43,45,47,50,61] highlighted that clear aims for involvement activities and linking those aims to how the public’s input will be used are prerequisites for success and will contribute to manage the public’s expectations. Conversely, some of those academic studies [15,31,40,44] indicated that little formal thinking was done at the planning level, regarding what is public involvement, who to involve and how to conduct involvement. Another academic study [53] further explained that the purpose of involvement is often lost during implementation, and is reduced to the need to prove involvement was undertaken rather than achieving its aims and benefits. Looking at the participant analyses, only a few [57–60,62] mention the purpose of involving the public, namely because it is

a legal duty (in the UK) to consult the public in service delivery changes.

### 3.3. How is public involvement carried out in LSC?

#### 3.3.1. Who is the public involved?

The first point of interest when examining how public involvement was carried out in LSC is that there is little reference to which groups of the public were involved. Most sources refer to “service users”, “patients”, or “members of the public” being involved – and in some maternity and/or paediatric service changes [36,57,61], “parents and children” – without further details. It is not clear either (except in 3 cases [49,54,56]) if population groups generally most affected by inequalities to healthcare access, such as populations from disadvantaged areas and ethnic minorities, have been involved.

Only two publications [37,38] offer limited details about lay representatives involved. In one case [37], a lay member was identified as having musculoskeletal problems and another lay member had a background “as a non-executive director of primary care trust”. In the other case [38], the authors describe “the lone activist who was appointed to the project board as effective because of previous professional political experience, his ability in committee work, history as a campaigner for stroke service quality and even his challenging approach”. The impact of their backgrounds on their role as lay representatives is not discussed, only their recruitment and their potential representativeness (or not) of the general public.

Indeed, several authors and some participants in academic studies [37,38,40,43,45–47] raised the issue of representativeness. The concern was that public meetings are dominated by interest groups and therefore are not representative of the general public’s views [45–47]. Whilst concern with lay representatives in committees was that as individual contributors, sometimes selected for their previous experiences as lay contributors, they are unrepresentative of the public [37,38,40,43]. Hence some authors from various affiliations [47,48,56,60,61] commented that involvement activities taking place directly in the community rather than the boardroom or town hall meeting are more effective in engaging with the general public.

#### 3.3.2. Methods for public involvement

Public meetings (also called town hall meetings) were privileged by healthcare managers in 20 – all cases of high public involvement intensity – out of the 27 LSCs described in Table 3. Publications from various affiliations [43,45,47,50,51,62] criticised public meetings for being poorly attended by the larger community and for providing a platform to overrepresented interest groups to put forward their interests rather than being a platform to represent the views of

**Table 3**  
Description of included publications.

Source	Type of LSC, Location & Duration of LSC	Methods used for public involvement & their timing in relation to LSC timeline	Affiliation of authors & Type of analysis
<b>Publications describing LSCs with low public involvement intensity defined as: unique method used and/or less than 50 people included</b>			
Airoldi, 2013 [39]	<u>LSC:</u> Priority setting in eating disorders services <u>Location:</u> England – Sheffield <u>Duration:</u> Not specified	<u>Methods:</u> 2 decision conferences including 5 patients & caregivers and 1 follow-up meeting <u>Timing:</u> Not specified	<u>Affiliation:</u> Academic <u>Analysis:</u> Academic study (socio-technical system perspective)
Gold <i>et al.</i> , 2005 [40]	<u>LSC:</u> New cancer care system (with transfer of responsibility to the regional level) <u>Location:</u> Canada – Ontario province <u>Duration:</u> Not specified	<u>Methods:</u> Regional councils and network planning committees that included consumers or patients of cancer care <u>Timing:</u> Not specified	<u>Affiliation:</u> Academic <u>Analysis:</u> Academic study (social science perspective) evaluating the processes of involving patients in network development
Greenhalgh <i>et al.</i> , 2009 [41]; Greenhalgh <i>et al.</i> , 2011 [42]	<u>LSC:</u> Whole scale transformation kidney, stroke and sexual health services <u>Location:</u> England – London <u>Duration:</u> 3 years	<u>Methods:</u> Patients representatives in projects' steering groups and subgroups, with occasional patient chair (Kidney and Stroke); mystery shoppers (Sexual health) <u>Timing:</u> Not specified	<u>Affiliation:</u> Academic <u>Analysis:</u> Academic study (organisational perspective) evaluating the LSC (Public involvement not the main focus)
Rutter <i>et al.</i> , 2004 [43]	<u>LSC:</u> Merger with other provider of mental health services <u>Location:</u> England – London <u>Duration:</u> Not specified	<u>Methods:</u> User representatives from existing user groups at Trust meetings <u>Timing:</u> Not specified	<u>Affiliation:</u> Academic <u>Analysis:</u> Academic study (social science perspective)
Thurston <i>et al.</i> , 2006 [44]	<u>LSC:</u> Regional reorganisation including hospital closure (focus on women's health services) <u>Location:</u> Canada – Alberta province <u>Duration:</u> Not specified	<u>Methods:</u> Advisory committee, planning committees, partnership with the Salvation Army <u>Timing:</u> Not specified	<u>Affiliation:</u> Academic <u>Analysis:</u> Academic study (social science perspective)
<b>Publications describing LSCs with high public involvement intensity defined as: combination of methods used and/or more than 50 people included</b>			
Abelson & Lomas, 1996 [45];	<u>LSC:</u> Healthcare restructuring process with reallocation and reconfiguration of health services	<u>Methods:</u> Public meetings & over 30,000 letters, tear-off forms, calls, petitions and flyers were received in response to the options proposed	<u>Affiliation:</u> Academic
Abelson, 2001 [46]	<u>Location:</u> Canada – 3 Ontario communities <u>Duration:</u> 1995-1999	<u>Timing:</u> Multiple opportunities for public input and discussion before proposals were developed [Community 1]. A very short period of time for public input into a limited set of proposals [Community 2]. Public input sought after plans were formulated [Community 3].	<u>Analysis:</u> Academic study (social science perspective)
Axler <i>et al.</i> , 1997 [47]	<u>LSC:</u> Restructuring of hospitals <u>Location:</u> Canada – Toronto <u>Duration:</u> Restructuring study took place between 1993 and 1995	<u>Methods:</u> 1st series of public forums, public deputations, written submissions, cable television call-in program. 2nd series of public forums advertised through announcements in community and ethnic papers, radio, TV stations, poster and flyer distribution to community centres and malls, and notices in hospital newsletters. <u>Timing:</u> 1st series took place in October and November 1994. 2nd series took place after the release of the Final Report in October 1995.	<u>Affiliation:</u> Academic, consultancy & health service management <u>Analysis:</u> Participant analysis
Barratt <i>et al.</i> , 2015 [34]	<u>LSC:</u> Consolidation of emergency care on fewer sites <u>Location:</u> England – Urban area <u>Duration:</u> Not specified	<u>Methods:</u> Public meetings and debates; focus groups; road shows; meetings in hospitals; GP events; consultation document (distributed to GP practices, libraries, hospitals, other health sites, pharmacies, patient groups and local authority offices); website created with possibility to respond online; advertisements placed in local papers; other publications (factsheets, frequently asked questions, public letter outlining senior local clinicians' support); final engagement event to present consultation findings to local stakeholders and gather views about further issues; a number of petitions submitted <u>Timing:</u> Not specified	<u>Affiliation:</u> Academic <u>Analysis:</u> Academic study (organisational/policy perspective)



Table 3 (Continued)

Source	Type of LSC, Location & Duration of LSC	Methods used for public involvement & their timing in relation to LSC timeline	Affiliation of authors & Type of analysis
Carver <i>et al.</i> , 2011 [48]	<u>LSC</u> : Centralisation of inpatient and emergency services <u>Location</u> : England – Hertfordshire <u>Duration</u> : Not specified	<u>Methods</u> : More than 160 public events (along 120 internal events for staff); 22 public meetings/drop-ins; events in 32 different towns and village; distribution of 400,000 summary leaflets and consultations questionnaires; 3700 full consultation documents; creation of website; provided information contributing to more than 140 news articles and letters in the local press <u>Timing</u> : A two-month discussion period preceded the formal consultation	<u>Affiliation</u> : Health service management  <u>Analysis</u> : Participant analysis
Caseley, 2010 [49]	<u>LSC</u> : Reconfiguration of acute services <u>Location</u> : England – London <u>Duration</u> : Not specified	<u>Methods</u> : 309 meetings with stakeholder groups (111 of these meetings with organisations working with under-represented groups); 4 major public events (attended by almost 700 people); 700,000 consultation documents distributed to households, businesses, NHS and community organisations; 8000 questionnaires returned; 1306 calls, emails and letters received submitted <u>Timing</u> : Not specified	<u>Affiliation</u> : Consultancy  <u>Analysis</u> : Participant analysis
Edwards, 1995 [50]	<u>LSC</u> : Centralisation of acute services, including closure <u>Location</u> : England – London <u>Duration</u> : Not specified	<u>Methods</u> : more than 10,000 consultation documents; 150,000 summaries; 50 public meetings held; 500 letters (most opposing the proposals) <u>Timing</u> : Not specified	<u>Affiliation</u> : Consultancy  <u>Analysis</u> : Participant analysis
Foley <i>et al.</i> , 2017 [35]	<u>LSC</u> : Region-level reconfiguration of urgent and emergency care systems <u>Location</u> : Ireland – North East, Mid-West and South regions <u>Duration</u> : Not specified	<u>Methods</u> : Public meetings to share information [North East]; Engagement meetings with local stakeholders to inform of changes [Mid-West]; Public meetings, press releases, media campaigns, representatives from various backgrounds in planning and implementation groups [South] <u>Timing</u> : Not specified	<u>Affiliation</u> : Academic  <u>Analysis</u> : Academic study (policy/health service research perspective)
Garnett, 1999 [51]	<u>LSC</u> : Acute services reconfiguration <u>Location</u> : England – Kidderminster <u>Duration</u> : Not specified	<u>Methods</u> : 13 public meetings <u>Timing</u> : 3-month public consultation launched a year after publications of plans	<u>Affiliation</u> : Unclear <u>Analysis</u> : Unclear (Management perspective)
Goodwin & Rhodes, 1996 [52]	<u>LSC</u> : Acute services reconfiguration <u>Location</u> : England – Manchester <u>Duration</u> : Not specified	<u>Methods</u> : 40 meetings; 3 large public meetings; home visits; 80,000 leaflets, 6000 full consultation documents; Freephone line; survey with 1000 participants <u>Timing</u> : Changes implemented 6 months after public consultation	<u>Affiliation</u> : Health service management (Leadership level) <u>Analysis</u> : Participant analysis
Jones & Exworthy, 2015 [36]	<u>LSC</u> : Centralisation of emergency and maternity services <u>Location</u> : England – A county <u>Duration</u> : Not specified	<u>Methods</u> : public meetings; board meetings (in one instance, about 200 members of the public in attendance) <u>Timing</u> : Not specified	<u>Affiliation</u> : Academic  <u>Analysis</u> : Academic study (social science perspective)
Mahadkar <i>et al.</i> , 2012 [53]	<u>LSC</u> : Reorganisation of community services <u>Location</u> : England – A county <u>Duration</u> : Not specified	<u>Methods</u> : County wide questionnaire; responses received by e-mail, in paper-based form (including petitions and letters from various organisations) and via a web-based questionnaire; total of 876 questionnaires and 78 letters received <u>Timing</u> : Not specified	<u>Affiliation</u> : Academic  <u>Analysis</u> : Academic study (asset management perspective)
Martin <i>et al.</i> , 2018 [37]	<u>LSC</u> : System-wide health service reconfiguration <u>Location</u> : England – 2 regions <u>Duration</u> : Not specified	<u>Methods</u> : Public involvement groups/committees for transformation programmes; formal consultation <u>Timing</u> : Not specified	<u>Affiliation</u> : Academic <u>Analysis</u> : Academic study (policy/health service research perspective)
McKevitt <i>et al.</i> , 2018 [38] Ipsos MORI, 2009 [54]	<u>LSC</u> : Major system change to acute stroke services <u>Location</u> : England – Greater Manchester (GM) & London <u>Duration</u> : Not specified	<u>Methods</u> : Stakeholder information and consultations events; lay membership of governance structures [GM & London]; 300 people attended 11 events, 46 health fairs, website with 14,000 visitors, consultation document, adverts, social media, 8611 questionnaires returned, 1010 emails, letters and calls received from individuals and organisations [London] <u>Timing</u> : 3 stakeholder engagement events GM Over 8 months between 2007–2008 [GM]; First consultation ran from November 2007 to March 2008 and the second one from January to May 2009 [London]	<u>Affiliation</u> : Academic [38], consultancy [54]  <u>Analysis</u> : Academic study (social science perspective) based on evaluation of LSC implementation [38], participant analysis [54]

Table 3 (Continued)

Source	Type of LSC, Location & Duration of LSC	Methods used for public involvement & their timing in relation to LSC timeline	Affiliation of authors & Type of analysis
Moore (2006) [55]	<u>LSC:</u> Downgrading of acute services <u>Location:</u> UK – Surrey and Sussex <u>Duration:</u> Not specified	<u>Methods:</u> pre-consultation engagement followed by public meetings, consultation document that can be responded to, workshops <u>Timing:</u> Period of engagement before consultation - Public consultation started a year after publication of plans	<u>Affiliation:</u> Journalistic <u>Analysis:</u> Unclear
NHS Clinical Commissioners (2015) [56]	<u>LSC:</u> Reorganisation of maternity and paediatric services [East Sussex], hospital services & health and social care integration [GM] <u>Location:</u> England <u>Duration:</u> Not specified	<u>Methods:</u> discussion phase with the public followed by focus groups, interviews, events in the community (shopping centres, community venues and networks) and articles in the press [East Sussex]; community events (market, shopping centres, football matches, tram), public meetings, partnership with local radio [GM] <u>Timing:</u> 3-month engagement to draft plans followed by formal consultation from January to April 2014 [East Sussex]; not specified [GM]	<u>Affiliation:</u> Health service management (Commissioning level) <u>Analysis:</u> Independent
NHS Confederation (2013a) [57]	<u>LSC:</u> Reorganisation of maternity services (including closure) <u>Location:</u> England – Sandwell and Birmingham <u>Duration:</u> From April 2009 to October 2011	<u>Methods:</u> Pre-consultation engagement; public feedback gathered during formal consultation via a response form, online and at a series of public meetings, stakeholders' meetings, letters, articles in relevant local and national media, and website updates; a 'ground-breaking' event; distribution of posters and postcards <u>Timing:</u> Formal consultation took place between October and December 2009	<u>Affiliation:</u> Health service management (Leadership level) <u>Analysis:</u> Participant analysis
NHS Confederation (2013b) [58]	<u>LSC:</u> Acute services centralisation <u>Location:</u> England -Buckinghamshire <u>Duration:</u> Not specified	<u>Methods:</u> public meetings, online surveys, website, printed materials, short video featuring interviews with lead clinicians <u>Timing:</u> 3-month public consultation took place in 2012	<u>Affiliation:</u> Health service management (Leadership level) <u>Analysis:</u> Participant analysis
NHS Confederation (2013c) [59]	<u>LSC:</u> Reorganisation of emergency services <u>Location:</u> England – Northumbria <u>Duration:</u> Not specified	<u>Methods:</u> about 100 public meetings during engagement period before the formal consultation <u>Timing:</u> 3 months of engagement before consultation and 3 months of formal consultation	<u>Affiliation:</u> Health service management (Leadership level) <u>Analysis:</u> Participant analysis
NHS Confederation (2013d) [60]	<u>LSC:</u> Reorganisation of hospital services & health and social care integration <u>Location:</u> England – Greater Manchester <u>Duration:</u> Not specified	<u>Methods:</u> informal pre-consultation with: a series of 'roadshow' events with voting handsets and table discussions, a website, frequently asked questions, a newsletter and presentation materials, patient panels, partnership with local radio and tram company, events in the community (market, football matches, shopping centres). Formal consultation not started at time of writing. <u>Timing:</u> Not specified	<u>Affiliation:</u> Health service management (Leadership level) <u>Analysis:</u> Participant analysis
Roberts (2014) [61]	<u>LSC:</u> Reconfiguration of maternity and paediatric services (including closure) <u>Location:</u> England – Greater Manchester <u>Duration:</u> Reconfiguration took place between 2000 and 2012	<u>Methods:</u> 1) Pre-consultation: 300 separate engagement projects (e.g. telephone survey, 2 citizen councils, local PPI leads undertook wider engagement with local people, public meetings) leading to publication of a discussion document on the case for change. 2) Formal consultation: distribution of 30,000 consultation documents of 131 pages; 320 summary leaflets; 5000 standalone response forms; 4000 posters; 50,000 booklets aimed at children; 320 DVDs; a website with 14000 hits; online engagement exercise for young people; 750 meetings and activities in places of work, local venues (supermarkets, playgroups, leisure centres) and community group settings; more than 50,000 responses in different formats <u>Timing:</u> Pre-consultation took place from 2000 to 2005 (mainly between 2003 and 2004). Formal consultation between January and May 2006.	<u>Affiliation:</u> Consultancy <u>Analysis:</u> Independent evaluation
Scottish Health Council (2006) [62]	<u>LSC:</u> Redesign of children services <u>Location:</u> Scotland – Inverclyde <u>Duration:</u> Not specified	<u>Methods:</u> 6-week formal consultation consisting of 1 public event including workshops advertised through leaflets; posters; press releases on NHS website; letters to parents of local school children; presentation to Inverclyde PPI group <u>Timing:</u> 6-week consultation took place between June and July 2006. Proposals for redesign approved in August 2006.	<u>Affiliation:</u> Governmental <u>Analysis:</u> Participant analysis
Scottish Health Council (2008) [63]	<u>LSC:</u> Relocation of maternity services <u>Location:</u> Scotland – Clyde <u>Duration:</u> Not specified	<u>Methods:</u> Review before consultation engaging a small number of service users.Consultation: 8 drop-in sessions, 3 public meetings <u>Timing:</u> Consultation took place between March and June 2008	<u>Affiliation:</u> Governmental <u>Analysis:</u> Participant analysis

the community. Such meetings were also described by an academic study [45] as inappropriate as they are confrontational, “pitting the public against the decision-makers”; or as one non-executive director explained, the setting of the meeting with the health authority “up on stage and the public down below” creates “either an atmosphere of passive acceptance or one of hostile resistance”[51]. This non-executive director further explained that public meetings are popular amongst LSC managers because “they are cheap to set up, you can tick the box and you have done the public consultation and move on”[51]. Additionally in public meetings, the information presented and the decision-making power remain in the hands of the managers [50,51].

Four participant analyses with health management, consultancy and academic affiliations [47,48,50,56] thus recommend to managers involving the public not to rely only on public meetings and instead look at alternative methods for involvement such as events in the community (shopping centres, train stations, road shows), focused interviews, surveys or inviting written submissions. These alternatives are thought to be more helpful for managers to capture a range of public opinions, less likely to underrepresent the views of the general public and may better address issues of equity.

In the UK, planners also publish a consultation document for the public. This document presents the case for change and proposals to service changes; and offers the opportunity to answer a feedback questionnaire. Members of the public in a few publications [33,34,61] criticised consultation documents for being very lengthy (in one LSC the document was 80 pages long [34], in another 131 pages long [61]), complex in its layout and language and generally not adequate for a lay audience. The Independent Reconfiguration Panel [33] and members of the public in two publications [34,62] further critiqued consultation documents for not being transparent about the implications of the proposals for patients – in particular when it concerned service closures – and how and where they will access relevant services in the future. The feedback questionnaire can also be lengthy and respondents in one LSC [34] commented on how the questions were either leading or not opened for disagreement.

Communicating the messaging effectively, using accessible language and providing greater clarity about the clinical evidence base underpinning proposals for change were recurrent themes in several participant and independent analyses [33,49,50,54,56,57,61,62]. Who communicates the messages is also important with various participant, independent and academic analyses [15,33,35,48,50,52,56,59–61] advising that clinicians or local GPs rather than managers should be presenting the case for change to the public to give clinical credibility to the LSC plans. Nonetheless, in one LSC [34] where clinicians presented the case for change, public participants remained sceptical, questioned the rationale for change, and felt the issues they raised had not been considered when developing plans. Three studies included [34–36] further indicated that the public understood the technical arguments and actively questioned them, opposing LSC plans.

Finally, there is some indication [47,49,50,56,60] that different involvement methods and dissemination mediums are required at different stages of the LSC with different purposes such as informing, discussing with, consulting with and partnering up with the public. Unfortunately, no further details are provided in the literature about such methods.

### 3.3.3. Timing of public involvement in relation to the LSC

Authors with health service management, journalism, consultancy, government and academic affiliations [15,33,35,52,55,56,59–62] advocate that public involvement must be a staged process starting at the very earliest opportunity, for example when plans for change are being considered rather than after they have been finalised. Accordingly, defining the issues

calling for change together with the public would create a shared understanding and vision of the future of local health services and would prepare the local community for the LSC [35,52,60].

It was difficult however to assess at what stage(s) of the LSC process public involvement took place (Table 3). Only 6 LSCs included [38,56,57,59–61] reported having involved the public when plans for change were being drafted. Similarly, some authors suggested to keep the public informed and engaged beyond the end of the formal consultation, which only 2 LSCs reported doing [34,39].

### 3.4. How do different stakeholders perceive the involvement process?

A recurrent theme in publications exploring how the public perceived the involvement process is that although the public had the opportunity to contribute during involvement activities, they felt they could not influence decision-making regarding the proposals for change; as they believed that decision for change had been made prior to public consultation leaving the public sometimes dissatisfied with the process [33–36,38–40,43–46,56,61–63].

This sentiment of not being able to influence decision-making on LSC proposals led in some cases to an atmosphere of mistrust where the public felt that the LSC was driven by the need to cut costs rather than improve services [34,36,45,55,56,61,62]. Mistrust was directed at those leading the LSC and further fuelled in cases where a weak rationale for change was presented during involvement activities and when information about implications of the change were not clearly stated [33,34,50,56,61,62].

Some authors with health service management affiliations [48,56] briefly offered their own perspective on the process, which was very positive. On the other hand, a participant analysis written by an external consultant [50] was more critical of the involvement process and confirmed that decisions were made before consultation. As a result, consultations can be seen by the public as “a front for persuading communities to accept decisions which have already been made – and which were probably motivated by a desire for cost reductions”[50].

In this context of mistrust, recommendations put forward in several publications [33,34,49,50,56,59,61] for those leading LSC are to acknowledge that the public may have different priorities and concerns, and those should be listened to, understood and taken under consideration, in a manner that the public can see.

### 3.5. What kind of impact does public involvement have in the LSC context?

The kind of impact public involvement may have in LSC is rarely discussed in the literature included, in particular how such involvement influenced decisions regarding the proposed changes – a lack of reported impact also established in the academic reviews [15,31,32].

The literature included does not describe how the public's feedback – especially when involvement activities yielded thousands of responses – was processed and included in the decision-making. Some participant and independent analyses [48,55,57–59,61,62] stated that managers were committed to take on board the public's feedback and in some cases modifications were made to proposals as a result, but without providing further details. Additionally, an academic study [38] argued that even though decisions for change were made before public consultation, public involvement had three types of values (managing agitation, verification and substantiation) for LSC implementation.

A wide range of methods to involve the public as well as various mediums to disseminate information about LSC proposals are described in the literature included (Table 3). Whilst methods used to involve the public are all listed, most of this literature does not



comment on or evaluate the methods used. Indeed, only 4 LSC cases [38,40–42,61] in this review included an evaluation covering public involvement and 2 other cases [48,59] mentioned that an external agency evaluated it without references that could be followed-up. Due to the lack of evaluation, it is difficult to grasp what involvement methods might be most effective or the kind of impact involvement has on LSC proposals nor to establish any links between impact and the methods used to gather the public's feedback.

Conversely, the local opposition – described only in cases of high involvement intensity – brought about by LSC, especially to acute services, appears to have more of an impact on LSC plans than public involvement. Local opposition in this literature took the form of a large amount of letters received opposing the proposals; petitions against the proposed changes (with more than a million signatures in one case); large demonstrations and rallies; and “Save our hospital” campaigns [33–36,50,51,55,56,61]. Local opposition can be further fuelled by the media and local politicians [35,45,46,48,50,51,55,56,61]. In cases with strong local opposition [33,36,50,51,56,61], LSC proposals were altered, sent for judicial review or referred to the Independent Reconfiguration Panel (England) as a result of local opposition. Consequently, it would seem that local public opposition is a more important driver for public voices to be heard in LSC proposals than the inputs of public involvement.

LSC leaders in two participant analyses and one academic study [35,48,56] who decided to engage with local voices opposing change found that it strengthened, rather than hindered, the consultation and decision making processes as well as lessened public opposition to the change.

### 3.6. Consultation stakeholders' response

The stakeholder consultation helped the research team interpret the findings of this review, which were in line with our consultation stakeholders' experiences. The findings on the public's perception of the involvement process sparked the most responses amongst our consultation stakeholders. Indeed, they felt the public could not influence LSC plans as the public is consulted on “a done deal”. Many further described the involvement process as a “tick-box exercise” and as “tokenistic”, causing some participants to be quite cynical about the process. Some further pointed out the lack of feedback after involvement activities, in particular on how the public's inputs were used.

A few stakeholders further discussed that the different terms ‘engagement’, ‘consultation’, ‘involvement’ and ‘participation’ should be explicitly defined in the LSC context and linked to specific aims as the use of general and poorly defined terms allows for tokenism in public involvement.

## 4. Discussion

This review shows that, in LSC cases with high public involvement intensity, involvement often takes the form of a public consultation model in which information flows one-way and, as defined in 3.2, “a model in which professionals retain control of both the process and outcomes of user involvement” [43]. Reflected in the technocratic perspective taken in many publications included, this model of public involvement abides by processes – holding a certain number of public meetings and certain types of information campaigns, ensuring that consultation reached a certain number of people – and is reinforced in cases where public consultation is a legal requirement. However, this model is associated with feelings from the public of not having an influence on decision-making regarding the proposals, being consulted on set options.

Publications offered recommendations such as involving the public at the earliest stages of LSC; formulating clear aims for involvement activities; and listen and take under consideration concerns raised by the public. All resonate with those found in national guidance documents on public involvement in LSC in England and Scotland [7,67,68], on public involvement in decision-making in health policy in Canada [8] and on public consultation by public bodies in Ireland [9], yet those do not seem to be enacted often in practice. Ultimately, this public consultation model of involvement contributes to an information deficit model [69,70] where public opposition to the change is attributed to a lack of understanding from the public of the technical arguments for change; implying that communication should focus on improving the transfer of information from experts to non-experts rather than opening the way to more deliberative methods of involvement.

However, some studies indicated that the public understood the technical arguments and actively questioned them, opposing LSC plans and seeking alternative routes to voice their views. As a result, two models of involvement co-exist in the LSC ecosystem: the public consultation model stemming from institutionalised processes and a model stemming from the local opposition to the LSC. A duality coined by Stewart [71] as “invited and uninvited participation”. This uninvited participation model can be more of a driver for public voices to be heard than inputs from the public consultation model described earlier. Stewart [71] describes three tactics used by the public to challenge the legitimacy of decisions: procedural, confrontational and disruptive. In this review, there was evidence of both procedural and confrontational tactics. However, more empirical work on this model of involvement and how it interacts with invited participation is needed.

Indeed, information on the local opposition in LSC was generally peripheral in the literature included and often framed in participant analyses as an obstacle to LSC implementation. In fact, evidence presented in this literature review, as well as in Dalton et al.'s review [15], tends to be from the perspective of the LSC leaders, largely assuming a ‘top-down’ model of planning [72] and reinforcing public perceptions of tokenistic involvement. This also reflects the ‘technicist’ orientation of Health Services Research – exacerbated by the dominant sources of funding – focused on finding technical solutions to healthcare problems whilst neglecting the political dimensions of healthcare planning, in particular in controversial LSC [73,74].

Given the resources spent on public involvement in LSC – one case [38] stated that the consultation process costed £1.2 million – and its legal mandate in some countries, efforts should be made to better understand the mechanisms of involvement and improve the current model of public involvement. We found that the purpose of involving the public was not always made clear by health service planners and commissioners. Attention should be given to the development of clear aims for public involvement activities; including explicitly clarifying how public inputs will be used which would help manage the public's expectations. More research is needed to understand which involvement methods – informative and deliberative – are appropriate for the different stages of the LSC and with what impact as evidence in the literature is scarce. Representativeness of the public involved, with particular attention given to underrepresented groups, also needs consideration when planning involvement with involvement activities taking place in the community more likely to be representative of the different communities rather than the boardroom or town hall meeting.

Opposition to LSC from local voices can become confrontational within the public consultation and the uninvited participation models but is often an omitted aspect of public involvement [71,75]. Slutsky et al [76] further suggest that tokenistic invited participation leads to more active contestatory action. In this review, LSC leaders who chose to acknowledge and engage with the opposition

found that it strengthened public involvement and lessened public opposition to the change. Thus, interactions between invited and uninvited participation should be given further consideration in LSC. Political conflict is an inherent, and potentially beneficial, part of healthcare planning [77,78]. Thought should be given to reframing the conflict in LSC as positive, rather than an obstacle to implementation, and how it can be incorporated into meaningful methods of public involvement [79].

This review presents some limitations. Empirical research on the topic is limited and therefore the most informative material is grey literature, which was difficult to scope and to locate. Additionally, a strict inclusion criterion of public involvement in LSC was applied but in some instances, it proved challenging to determine what qualified as LSC – even with the use of the definition provided in the introduction – when including studies. To mitigate these limitations, we consulted a health librarian while developing and piloting the search strategy; discussed as a team cases where applying the LSC definition was challenging; and used an innovative method to get frontline perspectives and locate additional literature.

## 5. Conclusions

This review shared some insights into how involvement is conceptualised and conducted in LSC, yet more research and consideration are needed regarding who should be involved, with what purpose and how. We further argue that in practice there are two models of involvement, invited and uninvited participation, and therefore interactions between the two should be given further consideration in LSC.

## Conflicts of interest

The authors report no conflicts of interest.

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