Public involvement in decisions
to change health services at a large scale

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Declaration

I, Nehla Djellouli, confirm that the work presented in this thesis is my own. Where information has been derived from other sources, I confirm that this has been indicated in the thesis.

The copyright of this thesis rests with the author and no quotation from it or information derived from it may be published without the prior written consent of the author.
Acknowledgements

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Abstract

As proposals for large-scale change (LSC) to health services are associated by the public with making cuts and downgrading services, public involvement – a dominant motif in national healthcare policy – is thought to be a way to legitimise plans for change and resolve tensions. Yet, little is known about how involvement is understood, interpreted and operationalised in practice or how it may have an impact on LSC plans and resolve controversy.

Through a scoping review and two qualitative case studies, my PhD project aimed to investigate how public involvement is conducted in LSC; to explore how the public organise themselves to be involved in decision-making; and to examine how involvement can be developed to be meaningful in this context.

The scoping review showed that the literature on public involvement in LSC, often adopting a technocratic perspective, focused on ‘invited’ involvement stemming from processes institutionalised within health services, experienced by the public as having no influence on decision-making. The public often actively questioned the evidence for change, opposed LSC plans and sought alternative ‘uninvited’ routes to voice their views.

Using document analysis, 27 interviews (with members of the public, campaigners, politicians, clinicians, Healthwatch, practitioners of involvement and a LSC leader) and over 100 hours of observations, I explored the social and political dynamics underpinning invited and uninvited involvement, and their interplay, in two English communities facing service closures under a regional LSC programme.

My thesis is set against the backdrop of a changing health system. As invited involvement is experienced as inadequate, some members of the public create uninvited routes to challenge and delay change. These uninvited activities become more visible over time than invited ones. By engaging with theories of public involvement and deliberative democracy, this thesis provides a more nuanced understanding of public involvement in LSC and seeks to contribute to debates about involvement in controversial change.
**Impact Statement**

The work presented in this thesis contributes to our understanding of public involvement in the context of large-scale changes to health services, often a source of controversy. Driven by policy initiatives, the dominant approach in Health Services Research to studying public involvement in large-scale change focused on finding technical solutions to healthcare problems, neglecting in the process important aspects of this social and political phenomenon. This research joins a growing body of work advocating for the use of social science in this research area. Using a grounded theory methodology, I provide a more inclusive overview of involvement dynamics at play in large-scale change, anchored in a real-life context, and shed light on omitted dimensions in the literature that I argue are crucial to our understanding of public involvement in this context. Looking at involvement initiated by health planners alongside involvement initiated by members of the public – unlike similar studies on the topic – I further provide a more subtle understanding of public involvement and public opposition in large-scale change and seek to contribute to debates and challenges on this contemporary issue.

My research findings will therefore benefit researchers and academics looking at patient involvement and large-scale change, topics of high interest currently in Health Services Research in the UK. Academic impact should occur via peer-reviewed publications of my empirical results chapters and dissemination at international conferences. Academic interest in my research topic has been high already, as shown by invitations received to present at seminars and during presentations of my early findings at conferences.

Beyond impact on Health Services Research, the findings presented in this thesis have the potential for impact on practice as well. Indeed, this research provides important theoretical insights into how public involvement takes place in large-scale change and how the process could be improved. I thus expect this research to benefit health planners, health service managers and practitioners of public involvement whose responsibility it is to involve the public in large-scale change.

Moreover, I anticipate that the findings of this research will be of interest to members of the public, health campaigners, local authorities, Healthwatch staff as well as patient charities. This assumption is based on the fact that I have already been approached through my research website by an engagement manager working for a local authority, a patient-focused charity and Healthwatch England. Additionally, my first PhD publication was picked up and featured by the Patient Experience Library in their newsletter and website. Following this, I was contacted by two other patient groups.

Finally, to ensure wide dissemination, I have secured open-access funding for all future publications related to my PhD via the Health Foundation, my generous funder for this research. As I
I expect different stakeholders – within and outside academia – to benefit from the findings presented in this thesis, I have also planned to produce lay summaries of my publications that would be available through the research website I have created, like I did for my first PhD publication.
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List of Abbreviations

A&E  Accident & Emergency
CCG  Clinical Commissioning Group
ICS  Integrated Care System
LSC  Large-scale change
NHS  National Health Service
SoH  Save our Hospital
SoN  Save our NHS
STP  Sustainability and Transformation Plan (later changed to Sustainability and Transformation Partnership)
UCC  Urgent Care Centre
Chapter 1 – Introduction

Healthcare systems across the world face the challenge of meeting changing and rising needs for healthcare, as a result of demographic and social changes as well as changing patterns of disease, with clinical advances, workforce pressures and decreased financial resources. Reconfiguring health services at a large scale is often introduced as part of the solution for health systems to adapt to those pressures (World Health Organisation, 2016; McKee et al., 2002). As proposals for large-scale change to health services are associated by the public with making cuts and downgrading services, public involvement – a dominant motif in national healthcare policy – is thought to be a way to legitmise plans for change and resolve tensions. Yet, little is known about how involvement is understood, interpreted and operationalised in practice or how it may have an impact on plans for large-scale change and resolve controversy.

Through a scoping review and two qualitative case studies, my PhD project aimed to investigate how public involvement is conducted in large-scale change; to explore how the public organise themselves to be involved in decision-making; and to examine how involvement can be developed to be meaningful in this context. My thesis is set against the backdrop of a changing health system. As invited involvement, stemming from processes institutionalised within health services, is experienced as inadequate, some members of the public create uninvited routes to challenge decision-making and delay large-scale change. These uninvited activities become more visible over time than invited ones. By engaging with theories of public involvement and deliberative democracy, this thesis provides a more nuanced understanding of public involvement in large-scale change and seeks to contribute to debates about involvement in large-scale change.

This thesis is organised into seven chapters. In this chapter, I provide an introduction to the concepts of public involvement and large-scale change. In Chapter 2, I situate my PhD study within the theoretical literature of public involvement and highlight research gaps in the field. In Chapter 3, I then outline the methodological approach I took in my research aiming to address some of the research gaps identified. My findings are then presented through Chapters 4 to 7. I first focus, in Chapter 4, on the findings of my scoping review and discuss the existing international literature and evidence on the topic of public involvement in large-scale change. In Chapter 5, I move on to my empirical case studies where I depict the social and political processes underpinning invited public involvement initiated by leaders of large-scale change in two English communities. I contrast those findings in Chapter 6 with the portrayal of uninvited actions instigated by some groups of the public in response to those invited processes and large-scale change. Finally, in Chapter 7, I reflect on the ways public involvement is
conceptualised in large-scale change and the omitted aspects of involvement in the literature. I further offer a framework for public involvement adapted to the context of large-scale change, grounded in empirical data. Additionally, I outline the implications of my research for the practice and research of public involvement in this context and present my conclusions.

1.1 What is public involvement?

Public involvement applied to healthcare remains poorly defined (Conklin, Morris & Nolte, 2010; Stewart, 2013; Greenhalgh, Humphrey & Woodard, 2011), thus understanding what public involvement entails is a difficult task. Firstly, there is a plethora of terms that have been used in the literature, sometimes interchangeably, to refer to who should be involved such as: patients, service users, citizens, public, lay people, communities, tax payers, or consumers – reflecting the different ideologies and disciplines of the authors (Stokes & Oliver, 2017; Wait & Nolte, 2006) and a lack of consensus (Mitton et al., 2009). While many authors are vague about whom they are referring to, some have attempted to define the terms they use in the context of healthcare. A number of authors have made a distinction between ‘patients’ and ‘public’ as they have different perspectives and interests pertinent to healthcare and healthcare policy (Florin & Dixon, 2004; Charles & DeMaio, 1993; Harrison, Dowswell & Milewa, 2002). However, some disagree with this distinction because on the one hand the public is constituted of both current patients and potential future patients and on another hand the individuals’ roles and interests are not static with individuals moving between roles and perspectives (Coulter, 2002; Conklin et al., 2010).

Secondly, we encounter a similar situation for the term ‘involvement’. There is a lack of consensus around the definition of this concept reflecting its complexity and diversity, what it entails practically and the term itself is often used interchangeably with other terms like ‘participation’, ‘consultation’, ‘engagement’ and sometimes even ‘empowerment’ (Greenhalgh, Humphrey & Woodard, 2011; Wait & Nolte, 2006; Skelcher, 1993; Stokes & Oliver, 2017). Although several authors have attempted to define and sometimes distinguish between the different terms, definitions remain vague – unlike those used by INVOLVE (2012) for public involvement in research whereby the terms ‘involvement’, ‘participation’ and ‘engagement’ are clearly distinguished – yet do not really clarify what involvement is and entails (see Appendix 1 listing all definitions encountered through this PhD). Adding to the lack of clarity, several authors use a similar definition for different terms. For example, Rowe and Frewer (2005) defined ‘participation’ as “the practice of involving members of the public in the agenda-setting, decision-making, and policy-forming activities of organisations/institutions responsible for policy development” whilst Bruni, Laupacas and Martin (2008) used a strikingly similar definition but for the term ‘engagement’ as “the practice of involving members of the public in the agenda-setting, decision-making and policy-forming activities of priority setting”. As shown here, authors often use one
of the interchangeable terms in their definition. Another example would be Titter et al.’s (2010) definition of ‘involvement’ as “the participation of members of the public or their representatives, in decision about the planning, design and development of their local health services”. However, most definitions encountered suggest public involvement by decision-makers would shape decision-making.

A scoping review (Kovacs Burns et al., 2014) found 15 different terms for “patient engagement” defined by 26 different sources. For the purpose of this thesis, unless referring specifically to the term used by an author, I will generally use the word ‘involvement’ as an umbrella term – as used before by Conklin et al. (2010) and Wait & Nolte (2006) – referring to any initiatives that included any groups of the public (patients, carers, general public, patient/public representatives) in the process of large-scale change to health services.

1.2 Defining large-scale change

To adapt to new pressures on the demand and supply sides of health systems, health services often have been reconfigured at a large-scale affecting multiple organisations and care providers (McKee et al., 2002). Arguments for reconfiguration of services include improving clinical outcomes, tackling staffing level problems and improving productivity (Imison, 2011). Examples of large-scale change include centralisation of acute services to fewer and larger units, relocating services in the community setting, and downgrading or closing services.

Several terms have been used, sometimes interchangeably, to describe those changes to hospital services: ‘large-scale’, ‘major system’, ‘system-wide’, ‘whole-system’, combined with the terms ‘change’, ‘reconfiguration’, ‘redesign’, ‘transformation’, and sometimes ‘decommissioning’, with no established working definition. Fraser, Stewart and Jones (2019) explain the multitude of terms to describe such changes as a reflection of the different meanings of different social groups. In this research, I chose to use the term ‘large-scale change’ (section 3.5) defined as: “large-system transformations in health care are interventions aimed at coordinated, system-wide change affecting multiple organizations and care providers” (Best et al., 2012, p.422). The large-scale change of interest in my empirical case studies discussed in Chapters 5 and 6 included plans to centralise acute services (such as emergency departments, maternity services and paediatrics units) into fewer sites, plans to close some of those services and plans to relocate services in the community setting.
1.3 Rationale for involving the public in large-scale change

A growing number of international and national policies have been promoting the democratic involvement of the public in decision-making in health policy and healthcare, including large-scale change (Department of Public Expenditure and Reform, 2016; Health Canada, 2000; NHS England, 2016a; World Health Organisation, 2016). Many rationales have been put forward to involve the public in changes to health services. One of these is that publicly funded health systems are paid for by the public and therefore the public should be involved in shaping health services (Titter et al., 2010). Thus, it is assumed that involving the public will lead to more democratic decision-making and enhanced accountability (Bruni, Laupacis & Martin, 2008; Florin & Dixon, 2004; Ocloo & Matthews, 2016). Another argument is that the public, and in particular service users, are experts in receiving services and therefore their contribution can improve the responsiveness of service providers as well as tailoring services to their needs (Chambers, 2001; Crawford et al., 2002; Hogg, 2002). Public involvement has also been promoted as a means of improving quality and patient safety (Bruni, Laupacis & Martin, 2008; Crawford, Rutter & Thelwall, 2003).

However, large-scale changes in healthcare have become associated by the public with making cuts and downgrading services, some of which being met with strong opposition from the public as well as from staff and politicians (Barratt, 2014; Fulop, 6 & Spurgeon, 2008; Moon & Brown, 2001). Thus, public involvement has additionally been put forward as a means of improving the public’s trust in the healthcare system (Bruni, Laupacis & Martin, 2008) and resolving tensions during controversial service changes (Dalton et al., 2015). Some countries further pushed for more public involvement in decision-making in this context as a means to lessen tensions and conflicts (Abelson et al., 2007; Dalton et al., 2015).

Furthermore, it is assumed that proposals for change that involved the public would be more legitimate and therefore support for the change could be secured (Titter et al., 2010; Bruni, Laupacis & Martin, 2008; Barnes et al., 2004). However, public involvement in large-scale change can also be used as a political tool referred to in the literature as a “legitimisation strategy” to legitimise decisions that would have been made with or without the public’s support (Church et al., 2002; Flood et al., 2015; Harrison & Mort, 1998; Summers & McKeown, 1996). Regardless of the rationale for involvement, some countries, such as the UK, have actually made public involvement a statutory requirement when health services are to be changed (Health and Social Care Act, 2006).

In the next chapter, I review the existing conceptual models underpinning public involvement in the healthcare literature and evaluate their suitability for the study of this phenomenon in the context
of large-scale change. I further highlight research gaps in the literature on public involvement in large-scale change, setting the background for my research project.
Chapter 2 – Background

In this chapter, I examine how public involvement has been conceptualised in the healthcare policy literature, as no conceptual models specific to large-scale change have been developed, highlighting potential gaps in knowledge. I further explore how large-scale change is often associated by the public with cuts and downgrading services, sparking public opposition to change, particularly in controversial plans for large-scale change. I then reflect on how this particular aspect of involvement was captured in the conceptualisation of public involvement in the literature. The end of the chapter provides some context on public involvement and large-scale change specific to the UK, setting the scene for my empirical case studies.

2.1 Conceptual models underlying public involvement

Many frameworks or typologies of public involvement for different aspects of healthcare policy (e.g. service planning, public health, policy making, patient care) have been put forward. As none of the frameworks available focuses on large-scale change specifically, I discuss here several conceptual models that have been more extensively used in the literature for policy or planning decisions (rather than personal decisions such as patient choice) and consider their relevance to large-scale change.

In the healthcare literature, the most widely cited framework for public involvement is Arnstein’s ‘ladder of citizen participation’ (1969). This framework (Figure 1), originally used in the context of urban development in the US, conceptualised citizen participation in a ladder pattern where eight rungs represent the degree of “citizen’s power in determining the end-product”, since Arnstein defined citizen participation as citizen power whereby power is redistributed to allow “the have-nots citizen, presently excluded from the political and economic processes, to be deliberately included in the future” (Arnstein, 1969). The bottom rungs, manipulation and therapy, are labelled as levels of non-participation. The next three rungs informing, consultation, and placation represent different degrees of tokenism in citizen participation. At these levels, citizens have a voice, but officials retain the decision-making power. The last rungs, at the top of the ladder, correspond to three degrees of citizen power: partnership, delegated power, and citizen power. At these levels power is redistributed; decision-making is thus shared (at the level of partnership) or dominated by citizens (at the levels of delegated power and citizen control). In this framework, only the top rungs allow for redistribution of power and therefore only at those levels can citizens be significantly involved.
Public involvement in decisions to change health services at a large-scale

Some authors (Feingold, 1977; Brager & Specht, 1973; Morgan & Lifshay, 2006; Skelcher, 1993; Burns, Hamilton & Hogget, 1994) adapted Arnstein’s ladder by putting forward similar ladders. Several authors however criticised the use of Arnstein’s ladder to frame public involvement in healthcare policy. Some argued that Arnstein’s linear and static model did not capture the dynamic and multidimensional process of involvement and did not encompass the wide range of approaches used to engage with patients and the public (Coulter, 2011; Tritter & McCallum, 2006). Furthermore, it was argued that the ladder model did not reflect on the fact that some service users or citizens may not wish to be involved, nor did it acknowledge the diversity of service users and citizens as well as their motivation for being involved (Butler & Greenhalgh, 2011; Charles & DeMaio, 1993; Litva et al., 2009; Tritter & McCallum, 2006). The ladder model was also criticised for not acknowledging the various contexts in which involvement might take place and how contextual factors may have an impact on involvement (Butler & Greenhalgh, 2011; Charles & DeMaio, 1993; Rowe & Frewer, 2005; Skelcher, 1993; Carman et al., 2013). Finally, in the context of healthcare, especially when services are changed at a large-scale, is citizen power according to Arnstein desirable or feasible? Therefore, Tritter & McCallum (2006) recommended moving away from Arnstein’s ladder and instead conceptualising involvement as a mosaic to capture the complexity of involvement processes and to capture the

Figure 1. Arnstein's ladder of citizen participation

Source: Arnstein (1969)
“interactions between individual users, their communities, voluntary organisations and the healthcare system”.

Wilcox (1994) produced a model for community participation in the delivery of local services, which presents the most potential for application to the context of large-scale change to health services. In his model, Wilcox (1994) moved away from the ladder analogy and reduced Arnstein’s eight levels of participation to five: information, consultation, deciding together, acting together and supporting independent community initiatives. In his dynamic model, Wilcox did not portray these levels of participation as a hierarchy, but rather clarified that different levels of participation were appropriate in different contexts. Therefore, his model adopts a collaborative lens, recognising that power is not always transferred in participation processes as opposed to Arnstein’s model striving towards citizen control. Moreover, Wilcox proposed two additional dimensions to public participation: the phase of participation and the different stakeholders involved (Figure 2). The second dimension of Wilcox’s framework includes four stages of public participation: initiation, preparation, participation and continuation. Wilcox further advocated in the last dimension of his model that it was crucial to identify the local stakeholders to involve (e.g. activists, residents, local groups, etc.) and their interest to arrange the appropriate degree of participation, suggesting that different degrees of involvement are required for different groups of the public.

Charles & DeMaio (1993) also put forward a three-dimensional framework for lay participation, in the context of healthcare policy this time (Figure 3). The authors in this model kept Arnstein’s notion of citizen control but reduced her ladder to three degrees of participation: at the lowest level of lay participation we find consultation, then partnership between the lay public and traditional decision makers and finally lay control where decision-making is devolved to the public. Additionally, since their
framework is specific to lay involvement in healthcare policy, the authors present three levels of the health system in which patients and the public can participate: treatment (decision-making related to interventions designed to produce health in individuals), service (decision-making related to resource allocation for a defined healthcare facility or region) and macro-level policymaking (decision-making related to resource allocation at the state or national level). Finally, the authors added an original contribution to framing involvement by adding a third dimension: role perspective of the public involved. Indeed, as discussed earlier, individuals involved can be defined in several ways based on the role they adopt when involved: patients, patients’ representatives, potential service users, taxpayers, etc. Therefore Charles & DeMaio (1993) distinguished between two categories of perspectives – service users and public policy – to highlight that each perspective brings out different attitudes and expectations in the individuals involved. Whilst service users would focus on narrow interests affecting the service users themselves, their entourage or a specific interest group, individuals with a public policy perspective would focus on wider interests affecting the broader community or the general public. Although more comprehensive than most frameworks mentioned so far, this framework does not capture the dynamic process of involvement that can take place, as featured by Wilcox (1994), at different stages of policymaking.

![Figure 3. Dimensions to lay participation in healthcare decision-making](image)

*Source: Charles & DeMaio (1993)*

Carman et al. (2013), in a more recent framework for patient and family engagement in healthcare (Figure 4), also distinguished three levels of the health system (rather than levels of involvement) in which patients and their families can be engaged: direct care; organisational design and
governance; and policy making. Degrees of engagement (analogous to levels of engagement in models above) in relation to the different levels of the health system are conceptualised in this model as a continuum and include: consultation, involvement, partnership and shared leadership. At the lower end of the continuum, information flows to patients who have limited power whereas at the higher end of the continuum information is exchanged both ways and power is shared. However, Carman et al. (2013) did not argue that reaching the higher end of the continuum was the end goal, rather they suggested that the best level of engagement was dependent on the topic of involvement. Although this framework did not include the stages of engagement and the identification of stakeholders beyond patients and their families (Wilcox, 1994) or the role perspective of individuals engaged (Charles & DeMaio, 1993), its strength lies in the fact that it identified contextual factors with a direct impact on engagement. Carman et al. (2013) differentiated in particular three types of contextual factors as to whether they relate to the patient, the organisation or the wider society. Patient-related factors such as health literacy, health status or personal experience with health services might influence their will and ability to be engaged. The culture of the organisation wishing to engage with patients and their families could also have an impact on patients’ ability to be involved. Lastly, societal and social norms might affect the willingness and ability of patients to engage in healthcare policy.

Figure 4. Multidimensional framework for patient and family engagement in healthcare

Source: Carman et al. (2013)
Looking outside the academic literature, practitioners of public involvement have also produced their own frameworks, adapted from Arnstein’s ladder. However, only one practitioners model has been referred to in the healthcare academic literature encountered in the course of this PhD: the International Association for Public Participation model (International Association of Public Participation, 2007). This model (Figure 5) also focused on the degree of public impact on decision-making, reducing Arnstein’s ladder to five levels: information, consultation, involvement, collaboration and empowerment. Also presented as a continuum, the levels of involvement are framed as the degree of public impact with at the top empowerment of the public, dropping Arnstein’s notion of power redistribution with citizen control at the top of the ladder. Nonetheless, this model explicitly defines the goal for each level of participation, including the promise made to the public, and provides a couple of examples on techniques that are appropriate under each level of participation.

Figure 5. Spectrum of Public Participation

Source: International Association of Public Participation (2007)

Some authors moved away completely from the ladder analogy in their conceptualisation of public involvement. For instance, Abelson et al. (2007) conceptualised a model for engagement in healthcare policy centred around contextual factors rather than degrees or levels of involvement, postulating that public participation processes were highly context-driven. Here the authors focused on the various contextual variables (political, community, researcher/decision maker relationship, organisational and decision-making) that could impact public participation processes and outcomes.
In summary, Arnstein's (1969) ladder of participation was influential in the healthcare literature as conceptual models for public involvement, albeit losing her notion of citizen control, mostly revolve around the levels of power the patients and the public have over decision-making. Yet, the degree of the public’s power over decision-making is not reflected in the various definitions of public involvement commonly found in the literature (section 1.1 and Appendix 1); with the exception of Contandriopoulos' (2004) definition of consultation. Additionally, in her provocative model anchored in community activism, Arnstein (1969) uncovered levels of involvement described as tokenistic – or even manipulative – whereby involved citizens have no influence in decision-making, an aspect of public involvement that faded out in subsequent models. Stewart (2016) attributed the lack of provocative content in contemporary models to a sociological shift during which it had become “unfashionable” to highlight the possibilities for conflict and domination within healthcare, heightened by the dominant sources of research funding (Scambler, 2001; Jones, Fraser & Stewart, 2019a).

Most of the conceptual models discussed above revolve around the level of public involvement in decision-making. However, the literature lacks consistency over how the term ‘level’ is applied, which can lead to some confusion. Some authors conceptualised levels of involvement in their models as degrees of public involvement whilst other authors distinguished the levels of the health system at which involvement occurs. In particular, Charles & DeMaio (1993) distinguished three levels of the health system in which patients and the public can participate: treatment, service (whereby large-scale changes to health services fit into) and macro-level policymaking. While there is an extensive literature on conceptual models for patient choice and shared decision-making and an extensive literature on procedures for service user involvement in national policy (particularly developing and implementing evidence-informed guidance), the mid-level of resource allocation for services seems to have been relatively neglected.

Furthermore, the conceptual models presented here do not look at the various perspectives on involvement from the different actors nor mention the impact of controversies, common in the context of large-scale change, on decision-making processes. Consequently, none of these frameworks seem to be adapted to analyse involvement in large-scale change nor to provide guidance on how public involvement in large-scale change could be conducted.
2.2 Methods for involvement

Methods of involvement were not the focus of the conceptual models discussed earlier. However, Wilcox (1994) in his three-dimensional framework of participation (Figure 2) suggested methods to use for each of his five levels of public participation that I collated in Table 1 below.

Methods listed in Table 1 just form a small subset of potential methods of public involvement compared to the abundance of methods described in the literature. Yet, some methods were more commonly used in healthcare policy such as: public meetings, surveys, focus groups, citizen juries, advisory panels, board membership, flyers, and drop-in centres (see Chapter 4). However, there is still confusion about what these methods actually consist of and how they might differ from each other. Some of the involvement methods are informative in nature whilst other are deliberative, allowing for the public involved to weight the evidence on the issue as well as allowing for discussion and debate between the public and decision-makers on potential options (Abelson et al., 2003; Rowe & Frewer, 2005, 2000).

Table 1. Methods suggested in Wilcox’s framework for each level of public participation

<table>
<thead>
<tr>
<th>Level of Public Participation</th>
<th>Information</th>
<th>Consultation</th>
<th>Deciding together</th>
<th>Acting together</th>
<th>Supporting local initiatives</th>
</tr>
</thead>
<tbody>
<tr>
<td>Information</td>
<td>Print: leaflets, newsletters, etc. Presentations at meetings Briefing the media through press releases and press conferences.</td>
<td>Advertising through posters, radio, press. Film or video. Avoid: Any methods which imply that people can have a say.</td>
<td>Simulations where the options and constraints are clear. These methods may be used in conjunction with information-giving techniques.</td>
<td>Information-giving methods to start the process. Stakeholder analysis to identify who should be involved. SWOT analysis to understand where you are. Brainstorming, Nominal Group Technique, Surveys to develop some options.</td>
<td>Cost/Benefit Analysis to make choices. Strategic Choice, Planning for Real, and other simulations as powerful overall techniques. SAST and Action Planning to decide what next.</td>
</tr>
<tr>
<td>Deciding together</td>
<td>Information giving methods to start the process. Methods for deciding together to create a shared vision. Team building exercises. Design exercises. Business planning exercises.</td>
<td>Information giving methods to start the process. Methods for deciding together to create a shared vision. Team building exercises. Design exercises. Business planning exercises.</td>
<td>Interim structures like working parties and steering groups as a focus for decision making and accountability. Longer-term structures through which you can work together.</td>
<td>Interim structures like working parties and steering groups as a focus for decision making and accountability. Longer-term structures through which you can work together.</td>
<td>Visits to similar projects. Interim structures like working parties and steering groups as a focus for decision making and accountability. Longer-term structures controlled by community interests. Development trusts.</td>
</tr>
</tbody>
</table>

Adapted from Wilcox (1994)
Few authors, rather than focusing on the levels of involvement, attempted a typology of involvement methods. Some have linked the methods to the flow of information between the public and decision-makers (Rowe & Frewer, 2005) as opposed to the degree of power the public has in decision-making – as seen earlier in the conceptual frameworks. Rowe & Frewer (2005) classified methods under three levels of involvement: communication, consultation and participation. The first two levels, communication and consultation, regrouped informative methods of involvement. In the former, information is relayed from decision-makers to the public while in the latter, information is relayed from the public to decision makers. The last level, participation, regrouped deliberative methods whereby information is exchanged between decision-makers and the public.

Harrison & McDonald (2008), on the other hand, classified methods for involvement under two categories: passive involvement when decision-makers organise involvement activities and active involvement when patients or the public organise themselves, placing pressure on decision-makers. This dichotomy saw involvement differently from the general body of literature on public involvement whereby engaging directly with the public is seen as ‘active’ involvement (Mitton et al., 2009) and activities ran at the highest rungs of the participation ladder seem to be perceived as more ‘active’ involvement than when at the bottom of the ladder. Additionally, in contrast to the other frameworks and typologies discussed so far in which the decision-makers are the sole initiators of public involvement, Harrison and McDonald (2008) widened their conceptualisation of public involvement to include methods used by the public to be involved, giving “pressure group activity to resist hospital closure” as an example of active public involvement.

One might argue, however, that decision-makers would need conceptual clarity regarding the purpose and the level of involvement they require to use these typologies, which might prove difficult giving the plethora of terms, definitions and methods. In the context of large-scale change, these typologies are insufficient to analyse public involvement as it remains unclear which methods are most appropriate under different circumstances and contexts. Additionally, these typologies offer no evidence on how the inputs from the public, when using the different methods, are used in decision-making.

2.3 The public & large-scale change

Proposals to change health services at a large-scale often cause controversy locally (and sometimes nationally), some of which have been met with strong opposition from the public as well as from local staff and politicians (Barratt, 2014; Fulop, 6 & Spurgeon, 2008; Moon & Brown, 2001; Goyder, 1999; Abelson, 2001; Dent, 2003). For example, in the UK, hospital closure protests have been a common response to plans for change (Crane, 2019), resulting in the process of large-scale change
becoming mediatised and politicised (Thomson et al., 2008; Barratt, 2014; Gulland, 2001; Lister, 2011; Stewart & Aitken, 2015). Despite taking part in public involvement mechanisms carried out by healthcare planners, many groups of the public across the UK established ‘Save our Hospital’ or ‘Save our NHS’ campaigns to further contest plans for change, sometimes influencing the outcome of change (Ruane, 2011; Barratt et al., 2015; Stewart, 2016; Crane, 2018; Dyer & Torjesen, 2013; Crane, 2019).

Yet public opposition as a display of public involvement has been given little attention in the conceptual literature. For instance, how the public might find routes to be involved beyond opportunities offered by healthcare planners is an aspect omitted from the models discussed in the first two sections of this chapter, except for Harrison & McDonald (2008)’s typology that included methods initiated by the public. Given the agonistic nature of the public response to large-scale change, the conceptual models discussed so far have limited value for application in this context.

Whilst the self-mobilisation of the public and agonistic public responses have been integrated into conceptual framework of public involvement in the fields of development studies (Cornwall & Coehlo, 2006; Cornwall, 2002; Cornwall & Coehlo, 2004; Gaventa, 2006; Pretty, 1995) and political science (Mouffe, 1999, 2000; Dean, 2017), only a handful of authors have captured these aspects in their conceptualisation of public involvement in healthcare. To address this gap, Stewart (2016), in her typology of modes of participation in health systems, coined the terms “invited participation” to describe public participation initiated by decision-makers and “uninvited participation” as encapsulating modes of participation initiated by the public alongside invited participation. Furthermore, Weale (2016), drawing on political science theories, put forward two models of public participation in priority setting: the consensus and the contestation models. Expanding on Stewart’s (2016) distinction between invited and uninvited participation, Weale (2016) defines his consensus model as an institutionalised one, initiated and organised by policy making institutions. In comparison, his contestatory model – taking part outside institutionalised mechanisms led by policymakers – encompasses the actions from the public to challenge the legitimacy of decision-making, such as public protests, demonstrations, and court challenges (Weale, 2016). Consequently, public opposition to controversial plans for change, such as decisions to downgrade or close services would fall under contestatory public participation (Weale et al., 2016). As contestatory actions from the public have become a routine form of public involvement (Slutsky et al., 2016; Crane, 2019), both Stewart (2016) and Weale (2016) advocate for the inclusive exploration of the plurality of modes of public involvement in priority setting. Consequently, rather than being constricted to the normative conceptual models described earlier, I set out in my empirical research of public involvement in large-scale change to uncover the different routes the public may use to get involved (see Chapter 3). In my empirical case studies (Chapters 5 to 7) for instance, I adopted Stewart’s (2016) terms of invited and uninvited to describe with the former public involvement led by
leaders of large-scale change, and with the latter how the public organised themselves to be involved in decision-making.

Similarly, public opposition as a mode of public involvement has been given little attention in research on large-scale change. Several studies looking at public opposition in this context focused on drawing out the emotional attachment publics displayed to their local hospitals, sometimes portrayed as illogical (Barnett & Barnett, 2003; Lepnurm & Lepnurm, 2001) or focused on the public understanding of risk in large-scale change (Barratt et al., 2015; Barratt, 2014). Other studies explored and reflected on the symbolic role of hospitals for local communities as a social phenomenon (Brown, 2003; Moon & Brown, 2001; Jones, 2015). They provide, however, little for the furtherance of our understanding of public opposition as a mode of involvement. Additionally, two of the studies mentioned above (Moon & Brown, 2001; Lepnurm & Lepnurm, 2001) did not actually include the perspectives of members of the public.

While more research has been conducted in recent years on public involvement in large-scale change, most studies have focused on public responses to invited involvement (Martin, Carter & Dent, 2018; Carter & Martin, 2018; Barratt et al., 2015; Foley et al., 2017; McKevitt et al., 2018). In times where public opposition and activism are a widespread reaction in the UK to large-scale change (Crane, 2018, 2019), only a couple of studies have explored actions initiated by the public to be involved in decision-making (Ruane, 2011; Stewart, 2016, 2019). Ruane (2011) examined a small number of ‘Save our Hospital’ campaigns in England established by members of the public to oppose large-scale change proposals, contesting the evidence base of the case for change. Drawing mainly on internet sources, Ruane (2011) compared the features of the different campaign groups and sought to explore factors that may have contributed to the success of some campaign groups and the failure of others. In her study of different modes of involvement in health systems, Stewart (2016) drew out three categories of tactics used by the public in hospital closures based on the challenge they present to the legitimacy of the decision-making process. Procedural tactics (such as legal challenges, petitions, formation of a campaign group) used by the public acknowledge the legitimacy of the decision-makers by directly appealing to them. Confrontational tactics (such as marches and protests, standing for political election, lobbying, use of external experts to review decisions) challenge the legitimacy of decision-making from the outside. Lastly, disruptive tactics (such as leaking confidential information to media, sit-ins and occupations of buildings), which are less common, actively challenge the legitimacy of decision makers and disrupt daily activities.

Therefore, limited research has been conducted on mechanisms whereby members of the public self-mobilise outside invited routes, seeking to be involved in debates and decision-making around large-scale change, despite calls for more research on mobilised publics in the wider public involvement
literature (Hess, 2015; Marres, 2007; Komporozos-Athanasiou, Renedo & McKeivitt, 2019). Stewart (2016) argues that the confrontational nature of those uninvited mechanisms explains their lack of consideration in the literature on public involvement in large-scale change. Furthermore, while some authors have examined involvement initiated by the public and the interplay between invited and uninvited mechanisms in other contexts (Somerville, 2011; Crompton, 2015; Barnes, 2008; Barnes et al., 2004), no similar studies, at the time of writing, have been conducted in the context of controversial changes to health services. An emerging body of literature on large-scale change has explained these research gaps by the lack of a sociological lens on the topic, which had been framed as a policy issue rather than a social phenomenon (Contandriopoulos, 2004; Stewart and Aitken, 2015; Fraser, Stewart and Jones, 2019; Stewart, 2019). Jones, Fraser and Stewart (2019) argue that research in this field tends to be highly normative, marginalising the multitude of voices and perspectives on large-scale change.

2.4 Large-scale change & public involvement in England

Health policy in the UK has been dominated by large-scale changes, including controversial plans for closure (Stewart et al., 2019). In England, the setting of my empirical research, large-scale change has been high on the agenda, with repeated calls for the centralisation of some acute hospital services (such as emergency departments, stroke services, maternity and paediatric services) into fewer units and the transfer of some hospital services to the community setting (Imison, 2011; Palmer, 2011). Public involvement is an integral part of the large-scale change process in England, tied to a legal requirement to consult the public in substantial change to health services (Health and Social Care Act, 2006). Public involvement has been further promoted at the national level by the Department of Health and Social Care through the establishment of arms’ length bodies to represent public voices – which after a few waves of change (Baggott, 2005) is now Healthwatch – and by NHS England in their strategic documents, such as the Five-Year Forward View (NHS England, 2014) emphasising involvement of “communities and citizens” in health policy planning.

In England, local and/or regional health planners put forward plans for large-scale change, commonly those responsible for commissioning health services in each local authority, such as the Clinical Commissioning Groups (CCGs). Health planners hold the responsibility to involve the public on their plans for change, providing assurances to NHS England that comprehensive public involvement took place, and take the final decision on large-scale change (Stewart et al., 2019; Barratt & Raine, 2012). Local authorities, through their Health Overview and Scrutiny Committees, can scrutinise the plans for change and the public involvement process. Local authorities can further challenge decisions made by health planners by referring the proposals for change to the Secretary of State for Health and Social Care if they contest the case for change and/or the public involvement
process. The Secretary of State then passes on the referral to the Independent Reconfiguration Panel that will review the referral case and advise the Secretary of State (Independent Reconfiguration Panel, 2010). Local authorities can further appeal decisions for large-scale change through judicial review.

In England, inadequate public involvement has been one of the most common reasons that proposals for large-scale change have been referred to the Secretary of State (Independent Reconfiguration Panel, 2010). Yet, public involvement in large-scale change remains an understudied topic, although some research has emerged recently (e.g. Barratt et al., 2015; Stewart, 2016, 2019; Foley et al., 2017; Martin, Carter and Dent, 2018; McKevitt et al., 2018). Only one review (Dalton et al., 2015) on public involvement focused on the context of large-scale change, which found sparse evidence around the impact of involvement on the outcomes of change, supporting previous claims (Chambers, 2001; Wait and Nolte, 2006). Some research further suggests that public involvement in this context is treated as a simple tick-box exercise (Bruni, Laupacis & Martin, 2008), to secure public support in order to legitimise decisions already made (Church et al., 2002; Flood et al., 2015; Harrison & Mort, 1998; Summers & McKeown, 1996). As explained in section 2.3, large-scale change is a mediatised and politicised process (Thomson et al., 2008; Barratt, 2014; Gulland, 2001; Lister, 2011), that often sparks public protests and activism to contest plans for change, with little attention given in research to the multiplication of ‘Save our Hospital’ campaigns (Crane, 2018, 2019; Ruane, 2011; Stewart & Aitken, 2015). In Chapter 4, I expand more on the body of literature on the topic and its findings through a scoping review of public involvement in large-scale change. Therefore, despite involvement being promoted and mandated in England, little is known about how public involvement is conceptualised and operationalised. In addition, it is unclear how public involvement might impact proposed changes or how it resolves the controversy around the changes.

Addressing these gaps in knowledge is relevant to many health systems. England, in particular, has seen several waves of large-scale changes across the country in past decades – some making history like the closure of Kidderminster Hospital’s emergency department (Oborn, 2008; Gulland, 2001; Garnett, 1999) – with plans for large-scale change still underway across the country. For instance, as I started this PhD, NHS England were designing the Sustainability and Transformation Plans (STPs), dividing the country in 44 areas or “footprints” in which local commissioners and Trusts were to reorganise health services at a large-scale, integrating services and transferring care to the community setting (NHS England, 2016b). Plans for change were published by the local NHS bodies in late 2016, attracting negative press and local mobilisation of the public as many plans involved service closures (Quilter-Pinner & Antink, 2017; Kotecha, Spencer & Leys, 2017; Campbell, 2017; Taylor, 2016; Triggle, 2017). At the time, a report from the King’s Fund highlighted that the “patients and the public have been largely absent from the STP process so far” (Alderwick et al., 2016). Subsequent King’s Fund reports (Kershaw et al., 2018; Ham et al., 2017), looking at the implementation progress of the five
London STPs, reported slow progress towards public involvement. As I am ending this PhD, STPs have been implemented and are now due to evolve into Integrated Care Systems (NHS England, 2018a), in which the local commissioning of services would be regionalised with implications for local public involvement (see section 5.6). Thus, furthering our understanding of public involvement in large-scale change has the potential of informing future involvement.

2.5 Research gaps

The first two chapters of this thesis highlighted the context for my PhD research. In spite of the growing interest in involving patients and the public in healthcare policy, in particular from healthcare planners seeking to introduce changes to services, the academic research base is limited. Firstly, terms such as ‘patient and public’, ‘involvement’ and ‘large-scale change’ remain poorly defined and do not appear to match conceptual models developed, mostly focusing on the degree of power patients and the public may have in decision-making. Additionally, commonly used frameworks and typologies in the healthcare literature are insufficient to analyse involvement in large-scale change nor do they provide guidance on how public involvement could be conducted in this context. Furthermore, these models have overwhelmingly omitted contestatory modes of public involvement – especially relevant in the context of controversial service changes – that need to be included in future research (Hunter et al., 2016; Dean, 2017).

Secondly, notwithstanding the growing numbers of international and national policies promoting a democratic involvement of the public in health policy and healthcare (Department of Public Expenditure and Reform, 2016; Health Canada, 2000; NHS England, 2016; World Health Organisation, 2016) and given the resources spent on public involvement in large-scale change (Hunter et al., 2016; Mitton et al., 2009) – one case included in my scoping review (Chapter 4) stated that the public consultation process costed £1.2 million (McKevitt et al., 2018) – little is known about how public involvement is conceptualised and operationalised in large-scale change, and with what effect. This alone justifies efforts to better understand the mechanisms of public involvement, especially in countries where involvement is legally mandated. More specifically, with a large number of approaches for healthcare planners to involve the public in decision-making and the process of change, it remains unclear which methods are most appropriate under different circumstances, especially in the context of rising public opposition and activism (Stewart, 2016; Crane, 2018). Public involvement is thought to be a way to legitimise proposed changes and resolve tensions (Barnes, 2008; Bruni, Laupacis & Martin, 2008; Dalton et al., 2015; Barnes et al., 2004; Abelson et al., 2007), yet it is unclear how involvement influences outcomes of large-scale change or how it may resolve the controversy around them (Titter, 2009; Weale et al., 2016). Because of the limited research base, decision-makers are calling for evidence
on the impact of public involvement and on the most effective ways to conduct involvement in practice (Titter, 2009; Flood et al., 2015).

Finally, whilst involvement initiated by decision-makers is thought to endorse democratic decision-making (Somerville, 2011), there is little research on how members of the public seek to engage in debate outside of invited mechanisms, particularly in the context of large-scale change (Grompton, 2015; Stewart, 2019, 2016; Ruane, 2011). Given that health systems have been notorious for their inadequate public involvement in the decision-making process (Casebeer et al., 2008), more research is required to understand the invited and uninvited mechanisms of involvement and their interplay (Weale et al., 2016; Stewart, 2016; Crane, 2018) in order to develop ways to make public involvement meaningful, rather than just a tick-box exercise (Bruni, Laupacis & Martin, 2008; Edwards, 1995).

In the next chapter, I give an overview of my research project and its methodology, designed to address these research gaps. This research project consisted of a scoping review of the international literature mapping existing knowledge and evidence for public involvement in large-scale change and highlighting gaps in knowledge and practice. The scoping review was further supplemented by empirical case studies, located in England, which explored qualitatively the social and political processes underpinning invited and uninvited involvement in response to a regional programme for large-scale change and offered the base for the development of a conceptual model for involvement adapted to the context of large-scale change.
Chapter 3 – Methodology

3.1 Thesis aims & research objectives

I designed my PhD research project to address research gaps I identified in section 2.5. Thus, the aims of this project were to:

- To investigate the ways public involvement is conducted by decision-makers in the context of large-scale change to health services;
- To explore how the public organise themselves to be involved in decision-making processes of large-scale change;
- To examine how our conceptualisation of public involvement in large-scale change can be developed to be meaningful.

Accordingly, my research objectives were to:

1. Conduct a scoping review (Chapter 4) of the international literature with the aim of mapping the literature on the specific scope of public involvement in large-scale change and identifying key concepts and gaps in knowledge and practice;
2. Use two qualitative case studies in order to empirically explore invited mechanisms of public involvement (Chapter 5) and uninvited processes of public involvement (Chapter 6) taking place in large-scale change;
3. Synthesise the findings from the literature and the empirical case studies (Chapter 7) in order to develop our understanding of public involvement in large-scale change and explore a conceptual model for public involvement adapted to the context of large-scale change.

3.2 Methodology

For my PhD research, I sought to understand the day-to-day practice of public involvement in large-scale change, which could not sufficiently be captured through existing frameworks and typologies presented in Chapter 2. Additionally, my interest was to better understand uninvited public involvement and its role in large-scale change. As I called attention to in Chapter 2, this is a missing component of research on large-scale change.

Given the lack of sociological lens in research on involvement in large-scale change identified by Stewart (2016) and the exploratory nature of my research, employing grounded theory (Glaser & Strauss, 1967) as a methodology allowed a way to remain open and explorative of social processes
underpinning public involvement in large-scale change. A grounded theory methodology provided the opportunity to examine the process and related behaviours from the participants’ various perspectives on invited public involvement. It also facilitated a study of the way logic and emotion might influence how the public may seek uninvited routes to get their voices heard in large-scale change (Corbin & Strauss, 2015). Consequently, using grounded theory assured that I did not miss important aspects of the social and political phenomenon that public involvement is; that I could adapt my data collection to evolving findings; and that I could gain new insights into the problem (Glaser & Strauss, 1967; Corbin & Strauss, 2015).

My PhD research was guided by Strauss and Corbin’s (1994, 2015) approach to grounded theory, from sampling, data collection, data analysis to patient and public involvement in this research. My first research objective was to systematically review the literature in order to assess the current evidence on public involvement processes in the context of large-scale change. I selected for this review a scoping review design – that I describe in section 3.3.1 – which enabled the inclusion of different types keeping with grounded theory tradition. Findings of the scoping review (presented in Chapter 4) then aided initial theoretical sampling (Corbin & Strauss, 2015).

I subsequently aimed to explore invited and uninvited processes of public involvement empirically through case studies (Yin, 1994). Case study research provides rich descriptions and insightful explanations of the studied phenomenon (Yin, 2012), which suited my descriptive and explanatory research questions. Case study research further allowed me to investigate a contemporary large-scale change programme, grounded in a real-world context (Yin, 2018, 2012). Using qualitative methods to collect and analyse the data, I was able to gain a much deeper understanding of the study phenomenon. Additionally, grounded theory is one of the four strategies promoted to analyse case study evidence (Yin, 2018). In sections 3.3.2 and 3.4.2 I provide a description of the case studies design and the qualitative methods used.

### 3.3 Study designs

#### 3.3.1 Scoping review

As mentioned in section 2.4, the only academic review looking specifically at public involvement in large-scale change is Dalton et al.’s (2015) rapid review on service user engagement in health service reconfiguration. This review, rapid in nature, focused on the English NHS. Given the scarce literature, the body of literature could benefit from a different approach to reviewing, as well as a review looking at international evidence. A scoping review design is particularly suited “where an area of research is
complex or has not been reviewed comprehensively before” (Arksey & O’Malley, 2005); both of which apply here as established in the first two chapters of this thesis.

A scoping review is a form of knowledge synthesis that reviews the studies available to address broad research questions, maps relevant key concepts and study designs underpinning the topic of interest and identifies gaps in research (Colquhoun et al., 2014; Arksey & O’Malley, 2005; Daudt, van Mossel & Scott, 2013). I conducted a scoping review to assess the existing evidence and potential research gaps on how public involvement is conceptualised and operationalised, and with what impact, in the context of large-scale change. Building on Dalton et al.’s (2015) findings specific to large-scale change and using a different study design, I broadened the scope of the review to international studies and included relevant important studies published subsequently (Barratt et al., 2015; Foley et al., 2017; Jones & Exworthy, 2015; Martin, Carter & Dent, 2018; McKevitt et al., 2018).

I further chose to do a scoping review as my research questions were exploratory in nature and the methodology allowed the inclusion of publications with different designs (e.g. qualitative research, commentaries, reviews, grey literature). The scoping review design further allowed me to combine the review’s findings with inputs from stakeholders via a consultation. I provide more details on the scoping review methods later in section 3.4.1.

### 3.3.2 Case studies

Given my exploratory research aims, I conducted two embedded anonymised case studies (Yin, 2014). I defined each case study as the public involvement processes – both invited (initiated by decision-makers) and uninvited (initiated by the public) – that have occurred in the local authority since 2011 in response to a regional large-scale change programme that I refer to throughout this thesis as ‘the LSC programme’. The LSC programme aimed to centralise acute services in an urban region in England and to reorganise care provided in community settings. Although the LSC programme was regional and covered several local authorities, I focused my research on the case studies of two of the local authorities, that I refer to as ‘Bluchill’ and ‘Grandvalley’. These sites were the only ones who had faced service closures in their local hospitals and plans were still underway for further closures under the LSC programme at the start of my fieldwork. As a result, I studied invited and uninvited processes in response to the LSC programme in both communities using a retrospective and a prospective lens.

Each of those two local authorities are served by their own local council whose role in large-scale change is to scrutinise plans for change through their Health Overview & Scrutiny Committee (see section 2.4). Established by the 2012 Health and Social Care Act, a Clinical Commissioning Group (CCG) is responsible for commissioning health services in each local authority as well as deciding on
changes to those health services (Barratt & Raine, 2012). Bluehill and Grandvalley are further served
by their own NHS Trust that provide secondary care services in Grandvalley Hospital and in two
hospitals in Bluehill. Before the start of my fieldwork, under the LSC programme, several waves of
change saw the closure of the maternity and paediatrics services in Grandvalley Hospital and the closure
of the emergency department in one of Bluehill’s hospital. At the start of my fieldwork, there were
further plans under the LSC programme to close the emergency departments in Grandvalley Hospital
and in the second hospital in Bluehill (see detailed timeline of events in section 5.1). Plans for closures
were contested locally and some members of the public in response formed ‘Save Our Hospital’ (SoH)
campaigns at each case study site. Additionally, the 2012 Health and Social Care Act established the
body Healthwatch in each local authority in England, commissioned and funded by local authorities
through money allocated by the Department of Health and Social Care. Bluehill and Grandvalley both
had local Healthwatch organisations whose statutory responsibilities were to seek the views of the public
about local health and social care services and to feedback those views to those commissioning or
providing the services.

Therefore, following theoretical sampling (Corbin & Strauss, 2015), the embedded unit of
analysis within each case study were ultimately:

- the local council,
- the local CCG,
- the local Trust,
- the local Healthwatch,
- the local SoH campaign,
- and the local public.

Furthermore, in 2016 the region covered by the LSC programme became a Sustainability and
Transformation Plan (STP) footprint steered by a joint CCG including representation of members of
all local CCGs within the footprint, including Bluehill and Grandvalley’s. I have therefore
conceptualised this as a joint unit of analysis since the LSC programme implementation continued
under the STP umbrella. Figure 6 below provides a diagrammatic representation of the case studies
and their units of analysis.

This thesis focuses on public involvement surrounding the LSC programme in Bluehill and
Grandvalley. I first explored the invited processes of involvement that I describe in Chapter 5. I then
explored the uninvited actions taken by some local members of the public who formed SoH campaigns
to be involved in decision-making and to oppose the LSC programme, described in Chapter 6.
Figure 6. Diagrammatic representation of the case studies and their units of analysis
3.4 Study methods

3.4.1 Scoping review

In designing the protocol for this scoping review, I drew upon Arksey & O’Malley’s (2005) framework stages, incorporating the enhancements proposed by Levac, Colquhoun, & O’Brien (2010). I developed and piloted the search strategy in consultation with a health librarian and searched 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. As I described in Chapter 1, several terms are used, often interchangeably, to refer to public involvement and large-scale change. I therefore accounted for this when I searched these databases to identify studies addressing the two key concepts of my research as shown in Table 2. The detailed search strategies can be found in Appendix 2.

Table 2. Search terms and approach in the scoping review

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<th>Key concept 1</th>
<th>Key concept 2</th>
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<tbody>
<tr>
<td>(“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”) NEAR/3 (“involvement” OR “engagement” OR “participation” OR “collaboration” OR “consultation” OR “representation” OR “voice” OR “coproduction” OR “advocacy”)</td>
<td>(“large-scale” OR “major” OR “extensive”) NEAR (“change” OR “transformation” OR “reform” OR “modification”) NEAR (“service” OR “healthcare” OR “system” OR “care” OR “hospital”) OR (“reconfiguration” OR “reorganisation” OR “redesign” OR “restructuring”) NEAR (“service” OR “healthcare” OR “system” OR “care” OR “hospital”)</td>
</tr>
</tbody>
</table>

The database search produced 3830 results (after removal of duplicates). I screened the titles, abstracts and keywords of retrieved references to determine eligibility for full-text screening based on the defined inclusion and exclusion criteria in Table 3. At this stage, my aim was to be inclusive. Therefore, I included, for example, articles on large-scale change or people’s opposition to change, even if public involvement was not explicitly mentioned in the abstract, to avoid excluding potentially relevant articles whereby public involvement might not be the sole focus of the study. I identified, at this stage, 115 publications for full-text review.
Table 3. Inclusion and exclusion criteria applied in the scoping review

<table>
<thead>
<tr>
<th>Inclusion Criteria</th>
<th>Exclusion Criteria</th>
</tr>
</thead>
<tbody>
<tr>
<td>Time period: Studies from database inception to 2016</td>
<td>Studies that do not discuss PPI processes</td>
</tr>
<tr>
<td>Data source: Primary studies, reviews, grey literature</td>
<td>Studies on PPI that do not take place in the specific context of large-scale change (e.g. PPI in research, PPI in treatment/care)</td>
</tr>
<tr>
<td>Members of the public involved: Patients, carers, public, patient or public representatives</td>
<td>Studies on public’s perception of the change itself</td>
</tr>
<tr>
<td>Methods used for PPI: Any method (e.g. public consultation, citizen jury, surveys, etc.)</td>
<td>Studies only reporting outcomes of large-scale change</td>
</tr>
<tr>
<td>Type of change: Large-scale change (interventions aimed at coordinated, system wide change affecting multiple organizations and care providers) in secondary and tertiary care</td>
<td>Studies focusing on primary care reorganisation</td>
</tr>
<tr>
<td>Type of studies: studies describing how PPI was carried out during large-scale change</td>
<td>Studies on small-scale change in a single organization (e.g. within a ward)</td>
</tr>
</tbody>
</table>

I then screened articles included for full-text review, this time applying the inclusion criteria more strictly. Moreover, I picked a random sample (n = 35) of publications selected for full-text screening for my supervision panel to review for quality control; to test and refine the inclusion and exclusion criteria (including agreeing if the changes described qualified as large-scale change); and to discuss key themes in the literature retrieved. Additionally, I examined the reference lists of included articles to look for additional relevant publications. Ultimately, I included for the scoping review 34 publications describing public involvement processes in the specific context of large-scale changes to secondary and tertiary care health services (Figure 7).

Following scoping review guidelines (Levac, Colquhoun & O’Brien, 2010), I extracted and charted the data using a standardised form based on the research questions such as: study location; aims of the study; type of change; perspective reported; definition of public involvement; methods used; duration and timing of public involvement; impact of involvement; evaluation of involvement; barriers and facilitators of involvement. I met regularly with my supervision panel to agree on data extraction and discuss emerging themes. As a result of 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’. I then conducted a thematic analysis to identify concepts and themes in the data extracted. Additionally, I used the software EPPI-Reviewer 4 to manage the data and support my analysis (Thomas, Brunton & Graziosi, 2010).
The last (optional) stage of a scoping review is a consultation with stakeholders to inform and validate findings from the review (Arksey & O’Malley, 2005; Levac et al., 2010). Here the purpose of the consultation was to obtain feedback from frontline stakeholders to determine if my preliminary findings resonated with their experience; to sensitise me to issues that may or may not appear in the literature; and to signposting relevant literature (in particular grey literature) that was not retrieved in my search. I targeted participants as anyone who is or was previously involved in public involvement in large-scale change – be that as a manager, member of the public, patient, clinical staff, campaigner, practitioner of public involvement, consultant, academic, etc.

In order to reach people from different backgrounds and countries, I decided to conduct a virtual consultation (Wright, 2005). I therefore created a website with a section about the research and a presentation of the preliminary findings in a concise and lay manner (to make it more accessible to

**Figure 7. Flow diagram of study selection process in the scoping review**
members of the public). Website visitors had the opportunity to comment on the findings presented, either anonymously or not, and had the option to contact me and receive updates on the research. I advertised the website through social media and professional networks (see Appendix 3). This online consultation was available from July 2017 to February 2018 at [www.involvingpeopleinchange.com](http://www.involvingpeopleinchange.com). 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 my research advisory panel (n = 5) (see section 3.6).

![Screenshot of the online consultation website](image)

### 3.4.2 Case studies

As argued by Stewart and Aitken (2015) and Stewart (2016), qualitative methods are best suited to investigate public involvement processes. Additionally, based on the research gaps identified in sections 2.3 and 2.4, I aimed to include public perspectives, including those participating in uninvited modes of involvement. In this section, I describe my methods for data collection and data analysis. I gained ethical approval for my study from University College London’s Research Ethics Committee under approval ID number: 11197/001.

#### Data collection

I used three methods of data collection in the case studies: document analysis, non-participant observations and semi-structured interviews. I collected documents (before, during and after my fieldwork) relevant to the LSC programme and the public involvement process as well as related local media coverage of the cases. I used the document analysis to familiarise myself with and gain an understanding of my case studies and their contexts; to identify potential categories of participants to
Public involvement in decisions to change health services at a large-scale

Interview; and to complement my observations and interviews with artefacts produced by the invited and uninvited processes of public involvement (Bowen, 2009). The type of documentation, all in the public domain, included:

- documents on public involvement produced by NHS England,
- national documents on the Sustainability and Transformation Plans and Integrated Care Systems,
- local public consultation documents,
- reports of public engagement and consultation under the LSC programme,
- minutes of local and joint CCG meetings,
- minutes of local Trusts meetings,
- minutes of local councils’ Health Overview and Scrutiny Committees and Health & Wellbeing Boards,
- minutes of the joint Health Overview and Scrutiny Committee,
- local council correspondence to LSC leaders,
- Healthwatch correspondence to LSC leaders,
- local campaigners’ correspondence to LSC leaders,
- Healthwatch newsletters,
- minutes of local Save Our Hospital campaigns meetings,
- leaflets and documents produced by local Save Our Hospital campaigns,
- local Save Our Hospital campaigns newsletters,
- local and national media coverage of the LSC programme.

In order to explore understandings and perceptions of public involvement in large-scale change, I also conducted semi-structured interviews with local stakeholders, including members of the public, as their perspectives are often marginal in the literature (Fraser, Stewart and Jones, 2019; Stewart, 2019). Keeping in mind that I aimed to interview actors in all embedded units of analysis in Bluehill, in Grandvalley and at the STP level (Figure 6), I first identified participants on the basis of whether they qualified as an ‘insider’ of the invited public involvement process or an ‘outsider’ using the documents I had collected up to that point. I then extended my theoretical sampling (Corbin & Strauss, 2015), based on the analysis of studies included in my scoping (Chapter 4) as well as my first interviews and observations, to actors who took part in invited processes of public involvement and/or uninvited processes. As I opened up the categories of participants, I developed more topic guides tailored to each category (see Appendix 4) that I continuously refined as I progressed through my data collection and analysis. Although I had topic guides, I aimed to let the participants speak freely and not constrain them with my topics. Therefore, I used probes and follow-up questions based on the participants’ answers to make sure that my topics were addressed while the participants were still in control of the flow of the interview.
I approached participants via email or during the course of my observations. Additionally, I asked participants after interviews if they could refer me to people in their social network that could contribute to my study. I aimed to include different groups of the public in my qualitative study. These were members of the public who only took part in invited processes, lay members, members of the public campaigning against the LSC programme and members of the public who interacted with both the invited and uninvited spheres of involvement. I further approached decision-makers and practitioners of public involvement as well as other actors, such as local politicians and Healthwatch staff that I identified during fieldwork as actors in public involvement in large-scale change. As I explain in more details in section 3.5, the majority of potential participants considered the LSC programme to be politically sensitive and controversial. Therefore, participant recruitment proved more difficult than I had anticipated. Originally aiming to recruit about sixty participants for interviews, I was able to only recruit twenty-seven participants after seventeen months of fieldwork. I compensated for the lack of interviewees by increasing the hours originally targeted for observations (from about twenty hours to over a hundred). By expanding the ethnographic component of my research, I was able to: build trust with potential interviewees; gain in-depth knowledge of public involvement activities in the LSC programme; strengthen the triangulation of findings emerging from the scoping review, document analysis and interviews; and reach saturation. My interviews were then recorded and transcribed. Table 4 provides an overview of the participants I interviewed per case study. Three participants at the STP level were also involved in the same capacity in Bluehill or in Grandvalley.

I provided the participant with an information sheet and obtained written informed consent from all the participants I interviewed. Given the controversy around the LSC programme, many potential participants approached were reluctant to take part in my research. A handful of interviewees further expressed concerns about how their anonymity would be assured before taking part in the interview. I explained to participants that my research and funding were independent from the NHS and from the LSC programme and that anonymity would be preserved. For that reason, I took the following measures to ensure confidentiality: interviews were conducted in a place and at a time chosen by the participant; I removed all personal identifiers from the interview transcripts; I kept the data on a password protected computer; and I asked my supervision panel to be attentive when providing feedback on my chapters related to the case studies and highlight any areas whereby anonymity of the participants might be compromised. Accordingly, to avoid individuals being identifiable when quoting from interviews, I grouped interviewees into generic categories (see Table 4). Within these categories, I specified the location (Bluehill, Grandvalley or STP level) and allocated numerical identifiers to individuals.
Table 4. Participants interviewed in case studies

<table>
<thead>
<tr>
<th>Interview Participants</th>
<th>Bluehill</th>
<th>Grandvalley</th>
<th>STP level</th>
</tr>
</thead>
<tbody>
<tr>
<td>LSC leaders (decision-makers)</td>
<td></td>
<td></td>
<td>1</td>
</tr>
<tr>
<td>Practitioners of public involvement (NHS staff whose role is to conduct public involvement activities)</td>
<td></td>
<td></td>
<td>3</td>
</tr>
<tr>
<td>Members of the public</td>
<td>3</td>
<td>1</td>
<td></td>
</tr>
<tr>
<td>Campaigners (members of the public belonging to a ‘Save our Hospital’ campaign)</td>
<td>3</td>
<td>5</td>
<td>N/A</td>
</tr>
<tr>
<td>Lay members (members of the public employed by the CCG to serve as a lay member on the governing body)</td>
<td></td>
<td></td>
<td>1</td>
</tr>
<tr>
<td>Healthwatch (staff employed by local Healthwatch organisations)</td>
<td>2</td>
<td>1</td>
<td>2</td>
</tr>
<tr>
<td>Local clinicians</td>
<td>1</td>
<td>1</td>
<td></td>
</tr>
<tr>
<td>Local politicians</td>
<td>2</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Experts commissioned by local politicians</td>
<td>N/A</td>
<td>N/A</td>
<td>1</td>
</tr>
</tbody>
</table>

Finally, I considered observations to be a crucial element of my fieldwork. Firstly, because a case study should take place in the real-world setting of the case (Yin, 2014). Secondly, because observations are a way to triangulate the data. In particular, observations helped contrast what was said in the interviews about the practices of public involvement with what happened during observations. Finally, public involvement events can become sites for intense emotions, tension, confrontation and drama (Goffman, 1963, 1959; Harvey, 2009) that are not necessarily conveyed in the documents I retrieved for analysis (e.g. minutes of meetings in public). Those elements can also be downplayed or overplayed during interviews. Resonating with points made by Harvey (2009), Cefaï et al. (2012) in their “Ethnographies of participation” describe several elements that should be taken into consideration when conducting observations of public involvement. One example based on Goffman’s work (1959, 1963), is to conceptualise public involvement events as the staging of a play. Accordingly, observations should take into account the individuals taking part or “actors” and their actions and behaviours or “performances and roles” and the “platform format” (e.g.: layout of the venue, availability of microphones for all participants to hear or be heard). “Timings” of the event (e.g.: opening and closing markers, time allocated for public input) and “styles of discussion” (e.g.: formal or informal, agonistic tone) are additionally important. Therefore, I based my observation template (appendix 5) on the elements covered in Cefaï et al. (2012). I found the analogy of the staging of a play accurate during my observations and data analysis, which informed how I have reported my findings in Chapters 5 and 6. When observing invited and uninvited events, I recorded my observations using a tablet device at times and pen and paper at others. I focused my attention on the interactions between actors and the main issues they discussed, and where possible, I noted the language used verbatim. I also made notes of informal discussions I had on occasions with various actors.
I conducted my fieldwork for seventeen months and aimed to conduct observations at the level of each embedded unit of analysis (Figure 6). These observations included local and joint CCG board meetings, Trust board meetings, Health Overview and Scrutiny committee meetings at local and joint levels, public involvement activities stemming from both invited and uninvited mechanisms. Specifically, my observations of uninvited participation were focused on the campaigners’ monthly meetings, events organised by campaigners in the community and public demonstrations. In total I conducted 120.5 hours of observations; Table 5 shows a breakdown of the observation hours for each unit of analysis.

<table>
<thead>
<tr>
<th>Unit of Analysis</th>
<th>Type of observations</th>
<th>Bluehill</th>
<th>Grandvalley</th>
<th>Regional level</th>
</tr>
</thead>
<tbody>
<tr>
<td>CCG</td>
<td>Board meetings in public</td>
<td>11 hours</td>
<td>10 hours</td>
<td>10 hours</td>
</tr>
<tr>
<td>Hospital Trust</td>
<td>Board meetings in public</td>
<td>8 hours</td>
<td>8 hours</td>
<td>N/A</td>
</tr>
<tr>
<td>Council</td>
<td>Health Overview &amp; Scrutiny committee meetings, Health &amp; Wellbeing board meetings</td>
<td>10 hours</td>
<td>7.5 hours</td>
<td>3 hours</td>
</tr>
<tr>
<td>The public &amp; Invited involvement</td>
<td>Engagement workshops, public consultation events (public meetings, workshops, street stalls), lay partners meetings, Healthwatch activities</td>
<td>16 hours</td>
<td>N/A</td>
<td>2 hours</td>
</tr>
<tr>
<td>The public &amp; Uninvited involvement</td>
<td>Campaigners monthly meetings, campaigners’ street stalls and public meetings, community events, public protests</td>
<td>15 hours</td>
<td>20 hours</td>
<td>N/A</td>
</tr>
</tbody>
</table>

**Data analysis**

A central tenet of grounded theory is that it is an iterative process whereby each data collection session is followed by data analysis (Corbin & Strauss, 2015; Glaser & Strauss, 1967). Keeping this in mind, I aimed to analyse the data soon after collection. Data analysis was therefore mostly carried out concurrently with fieldwork to inform theoretical sampling; this ongoing immersion was crucial in my developing understanding of the data.

I analysed all the data collected (documents, observation notes and interview transcripts) in NVivo 12. In line with grounded theory methodology, my analysis involved three stages of coding: open, axial and selective coding (Corbin & Strauss, 2015). This coding strategy offered greater levels of abstraction at each step towards theory building. I further employed constant comparison strategies at each stage of coding in order to compare new data with previously collected data, emerging concepts and their linkages (Corbin & Strauss, 2015). I kept track of my coding, linkages, ideas and reflections emerging at all stages of the analysis by writing memos.
I started my analysis with open coding where I coded and divided the data, remaining open to the data and unrestrained by pre-existing theories, in order to form preliminary categories and compare them to each other through constant comparative analysis. I then undertook axial coding where I used my codes and memos to show how the categories relate to each other and form themes. My coding process became more focused, looking at clustering open codes into fewer, broader codes, that best captured the perspectives of participants and significant data patterns. At this stage, drawing on my coding and memos, I further constructed diagrams to map my understanding of the relationships between the core categories and other dominant concepts and themes. Codes, memos and diagrams were presented to my supervision panel in regular meetings to discuss and refine the emerging theory. The last stage of my analysis was selective coding where I integrated the themes to present a story about how the theory explains the core process of public involvement in large-scale change. From this process, I developed a theoretical model, grounded in my empirical data that I presented to my supervision panel and to my Research Advisory Panel (made up of patients, carers and members of the public – see section 3.6) for discussion and feedback. This allowed me to identify and address conflicting viewpoints, verify and challenge emerging categories, and refine the model (presented in Chapter 7). Additionally, extensive periods of observations during fieldwork provided many opportunities for informal (sometimes off the record) discussions with interviewees and other participants who declined taking part in interviews. I used those opportunities to clarify the concepts, themes, linkages and contextual factors I identified during analysis. These informal discussions also contributed to refine my diagrams and emerging model. In appendix 6, I provide an overview of my final NVivo codes.

During the data analysis I triangulated, when possible, what was said in the interviews with data from other interviews, observations and documents. Given the iterative process of grounded theory, time limitations for my fieldwork and the similar timeline of large-scale changes in both case studies, it was not possible for me to analyse the data for each case study separately. Therefore, I conducted a cross-case synthesis as promoted by Yin (2018) when conducting two case studies. I therefore compared the findings from the two case studies as I went along to look for commonalities and contextual factors.

3.5 Reflexivity

Coming from a global health background, with no previous experience of health service research in the NHS context, and conducting this research on my own, I started fieldwork as an outsider adopting an etic approach. As Stewart (2016) pointed out, since Arnstein's (1969) activist-oriented ladder, it had become unfashionable to bring up controversy and confrontation in large-scale change in Health Services Research. On the contrary, controversy and confrontation in this context attracted my
research interest as a French citizen (where in contrast activism from the late sixties is still enshrined in collective memory). Additionally, I was intrigued, doing health service research in the NHS context for the first time, by the fact that Patient and Public Involvement in research and in health services was framed as a novel approach in this setting. Coming from a global health background, community involvement and participatory research has been a long-held standard.

Conducting research in the context of a controversial LSC programme in case studies where distrust ran high proved to be fraught with challenges. The tension started with what words to use to describe my research. As I have shown in Chapter 1, a plethora of terms are used to describe involvement and change. What I realised during my fieldwork is that particular words have certain connotations to different people. For example, I started this project referring to ‘Patient and Public Involvement’ or ‘PPI’ as it is the phrase used in research and more broadly in the NHS. I then decided to only use the phrase ‘public involvement’ as I noted that most participants I targeted for observations and interviews did not really use ‘PPI’, especially the members of the public. As the phrase ‘Patient and Public Involvement’ came from the NHS jargon and was not used by members of the public, I decided in my analysis to retain the phrase ‘public involvement’. In my case studies I also took note that the ‘insiders’ refer to ‘public engagement’ or ‘public consultation’ denoting specific parts of the process (see Chapter 5). Therefore, I decided to keep using the term involvement as it seems more inclusive and this way, I would be less likely to overlook other aspects of public involvement. With the words for change, I decided to use ‘large-scale change’ and when talking to members of the public ‘large-scale change to health services’ as it seemed that it was the term freest of connotation. For example, after a public Trust board meeting, a board member asked me about the reasons that brought me to the meeting. I explained I was doing a PhD study on patient and public involvement to the board member who seemed enthusiastic about the topic and eager to know more. After a few minutes of conversation initiated and led by the board member, I came to explain that I was looking at patient and public involvement in the context of ‘service reconfiguration’. As soon as I pronounced the word ‘reconfiguration’, the board member immediately stopped the conversation and evaded me. Finally, I thought about using the word ‘redesign’ as I noticed during my observations that some CCG members use it as a euphemism for changes that involved service closures. However, I felt this word did not capture the scale of the change I was looking at for this study and could be applied to small change (e.g. a ward redesign) as well as large.

In the context of a controversial LSC programme and issues of trust that I describe in Chapters 5 and 6, it proved difficult to gain access to the different groups for observations and recruit participants for interviews. Local LSC leaders were the most inaccessible group to recruit in this study. Repeated emails and interactions during observations were fruitless. A local LSC leader and a local practitioner of involvement explained implicitly to me during observations that they needed permission from the
STP level to sit down for an interview with me, permission that never came. After the LSC programme was dropped towards the end of my fieldwork, I contacted again LSC leaders with an invitation for an interview. Some of those invitations were forwarded to an LSC leader at the STP level who accepted to sit down with me for an interview but at the last minute requested instead a short phone interview. Due to the controversy around the large-scale change studied and issues of trust, many actors were more willing to have informal ‘off the record’ conversations with me rather than taking part in interviews. After months of observations of meetings in public as a member of the public, I eventually became part of the landscape in invited public involvement, facilitating recruitment for interviews with Healthwatch staff, practitioners of public involvement and lay members. In addition, it was easier to recruit participants after the announcement from the government that the LSC programme had been dropped.

Gaining access to campaign groups for observations and interviews was also difficult. However, I was able to recruit both campaign groups for this research relatively early on my fieldwork. The first campaign group accepted to let me introduce myself the group and present my research and the preliminary findings of my scoping review before I was granted access. The second campaign group ignored my invitation to take part in this research project until the chair of the first campaign “vouched” for me. Following this, I was given full access during fieldwork to all campaign meetings and community activities, minutes of campaign meetings and email chains between campaigners.

My choices regarding research questions, data collection and data analysis was primarily driven by my research interests. As a result, reflectivity was important to make sure my results did not become a simple reflection of my own pre-existing biases. For this purpose, I also noted in my field notes my reflections, thoughts and feelings as I progressed through data collection and analysis. Of particular note, as I was present in many invited and uninvited events over the course of 17 months, local actors grew accustomed to my presence and were curious of the progress and direction of my research. I was often asked by various actors during fieldwork about my thoughts on the topic – I suspect to gauge where I stood in the debate of the controversial LSC programme. Rather than answering, I used this as an opportunity to informally discuss my project, using participants perspectives to reflect and guide my theoretical sampling.

3.6 Patient and public involvement in this research

In addition to having a practitioner of patient and public involvement in research (who has previously done the same in the context of large-scale change) on my supervision panel, I collaborated throughout my doctoral project with the CLAHRC North Thames’ Research Advisory Panel, made up...
of patients, carers and members of the public. Some members of the Panel had experience with public involvement in large-scale change as lay representatives or by taking part in public consultation in large-scale changes where they lived.

I found the Research Advisory Panel to be a surprisingly diverse group, that impressed me with their knowledge and critical thinking. I therefore aimed to use my time with the Panel using a focus group approach rather than a presentation. I only used slides as visual aids in case they did not understand my points or my accent. I would introduce a couple of discussion points and then lead the discussion like a facilitator rather than a presenter, which, in my opinion, led to a more interesting and open conversation. I did not feel worried about presenting my work to them and instead took the opportunity with as much enthusiasm as I have when conducting fieldwork. I also made sure to include a slide explaining how I addressed their previous feedback. Moreover, after our second meeting as the Panel had a chance to familiarise themselves with my project, I asked the members how they pictured their involvement in my project. Given the interest sparked by my research topic and some funding I could spare for training interested members of the panel, I asked them in particular if they would like to be further involved in my project beyond the scheduled meetings. Two members showed interest in helping me recruit participants and assist during interviews. However, after following-up with them, they preferred to keep their involvement to the meeting format and one of them offered to be a participant for a pilot interview. Finally, the Panel had the opportunity to contact me after the scheduled meetings if they had further comments, which some of them took.

I met with the Research Advisory Panel twice before my PhD upgrade. I presented the Panel with an introduction to my topic, my research questions, research design, data collection tools and preliminary findings; giving the opportunity for the Panel to provide feedback at a formative stage of my research. For example, one of the meetings focused mainly on the scoping review, during which the Panel could comment on my emerging findings. The Panel further tested my consultation website and shared their recommendations on accessibility, format, content and possible ways to advertise it. Following the Panel’s feedback, I 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 adding elements requested by the Panel; explaining how the feedback from the consultation would be used; and creating a mobile-friendly version of my website.

The Panel also had an opportunity to comment on my qualitative fieldwork design before I sought ethical approval. Perhaps the most surprising comment I had from the Panel on the topic was when I asked them whether or not I should compensate my participants. I had never financially or materially compensated my participants in previous fieldworks because in low-income settings, even a small compensation would have skewed my results. However, I had observed several times the Panel
members criticise other researchers about the lack of or low compensation for participants. Expecting similar comments for my question I was taken aback when I was told that I should not offer any as my topic was too important in their opinion. Members of the panel felt that my participants should take part because they also felt it was an important topic and not because they pursued compensation.

Additionally, I made use of the CLAHRC North Thames’ virtual reviewer panel (also made up of patients, carers and members of the public) to get their inputs on my participant information sheet and consent form which I amended based on their feedback. My interactions with both panels made me think much harder about ethical considerations than my ethics form did. As a result, for example, I realised that potential participants, in particular members of the public, might mix up their negative experiences of health services with the topic of my research. I therefore added this issue to my ethics form along with my plan to mitigate it.

My last meeting with the Panel took place during the data analysis and write-up stage of my PhD project. The Panel contributed to the interpretation of my emerging qualitative findings, which sparked a lively debate. My findings resonated vividly with their experience of public involvement particularly for members of the panel who had been involved in large-scale change as lay representatives. The panel further commented on my developing ideas at the time about my model for public involvement in large-scale change (presented later in Chapter 7). Several members of the panel further framed my findings within the wider contemporary political landscape and encouraged me to disseminate my findings particularly to members of the public, for example through a movie. Although doubtful I would use a film format for my dissemination plans, I have planned to turn my consultation website into a dissemination platform for my findings, including lay summaries to make sure my findings are accessible to the wider public that would like to engage with my research.
Chapter 4 – Involving the public in decision-making about large-scale change to health services: a scoping review

4.1 Introduction

Considering the research gaps I identified in Chapters 1 and 2, I conducted a scoping review with the aim of mapping the international literature on the specific scope of public involvement in large-scale change and identifying 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 (Arksey & O’Malley, 2005; Colquhoun et al., 2014). The findings from this chapter have been published in Health Policy (Appendix 7).

4.2 Type of literature

After screening for eligibility, 34 publications were included. Four publications are reviews that are described in Table 6. The two older academic reviews focused on change (but not exclusively large-scale change) within health and other public services (Crawford, Rutter & Thelwall, 2003) or within mental health services (Rose & Fleischmann, 2003). 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 my findings below. The Independent Reconfiguration Panel’s review (Independent Reconfiguration Panel, 2010) offers an insight into the reasons large-scale change proposals are referred to this governmental body, with relevant information regarding the public involvement process integrated to my review findings. The most recent academic review (Dalton et al., 2015) is a rapid review of service user engagement in health service reconfiguration in the UK, which overlaps with eight of the studies and the three reviews mentioned above that I included in this scoping exercise.
Table 6. Description of the reviews included

<table>
<thead>
<tr>
<th>Source</th>
<th>Description</th>
<th>Affiliation of authors &amp; Type of analysis</th>
</tr>
</thead>
<tbody>
<tr>
<td>Crawford et al., 2003</td>
<td>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.</td>
<td>Academic Review (organisational perspective)</td>
</tr>
<tr>
<td>Dalton et al., 2015</td>
<td>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.</td>
<td>Academic Review (health services perspective)</td>
</tr>
<tr>
<td>Independent Reconfiguration Panel, 2010</td>
<td>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.</td>
<td>Government Review of reasons LSC proposals were referred to the panel</td>
</tr>
<tr>
<td>Rose et al., 2003</td>
<td>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.</td>
<td>Academic Review (organisational perspective)</td>
</tr>
</tbody>
</table>

The remaining publications have been classified in Table 7. Those publications are diverse in their affiliations and types of analysis and cover public involvement in large-scale changes relating to various kinds of health services. Table 7 further suggests that large-scale change to acute services are accompanied by a higher intensity of public involvement, in many instances reaching thousands of people. The findings are presented below under the main review questions.
Table 7. Description of included publications

<table>
<thead>
<tr>
<th>Source</th>
<th>Type of LSC, Location &amp; Duration of LSC</th>
<th>Methods used for public involvement &amp; their timing in relation to LSC timeline</th>
<th>Affiliation of authors &amp; Type of analysis</th>
</tr>
</thead>
</table>
| Airoldi, 2013   | LSC: Priority setting in eating disorders services  
Location: England – Sheffield  
Duration: Not specified | Methods: 2 decision conferences including 5 patients & caregivers and 1 follow-up meeting  
Timing: Not specified | Affiliation: Academic  
Analysis: Academic study (socio-technical system perspective) |
| Gold et al., 2005 | LSC: New cancer care system with transfer of responsibility to the regional level  
Location: Canada – Ontario province  
Duration: Not specified | Methods: Regional councils and network planning committees that included consumers or patients of cancer care  
Timing: Not specified | Affiliation: Academic  
Analysis: Academic study (social science perspective) evaluating the processes of involving patients in network development |
| Greenhalgh et al., 2009 | LSC: Whole scale transformation kidney, stroke and sexual health services  
Location: England – London  
Duration: 3 years | Methods: Patients representatives in projects steering groups and subgroups, with occasional patient chair (Kidney and Stroke); mystery shoppers (Sexual health)  
Timing: Not specified | Affiliation: Academic  
Analysis: Academic study (organisational perspective) evaluating the LSC (Public involvement not the main focus) |
| Rutter et al., 2004 | LSC: Merger with other provider of mental health services  
Location: England – London  
Duration: Not specified | Methods: User representatives from existing user groups at Trust meetings  
Timing: Not specified | Affiliation: Academic  
Analysis: Academic study (social science perspective) |
| Thurston et al., 2006 | LSC: Regional reorganisation including hospital closure (focus on women’s health services)  
Location: Canada – Alberta province  
Duration: Not specified | Methods: Advisory committee, planning committees, partnership with the Salvation Army  
Timing: Not specified | Affiliation: Academic  
Analysis: Academic study (social science perspective) |
<table>
<thead>
<tr>
<th>Publication</th>
<th>LSC:</th>
<th>Description</th>
<th>Methods</th>
<th>Timing</th>
<th>Affiliation</th>
<th>Analysis</th>
</tr>
</thead>
<tbody>
<tr>
<td>Abelson &amp; Lomas, 1996</td>
<td>Healthcare restructuring process with reallocation and reconfiguration of health services</td>
<td>Public meetings &amp; over 30,000 letters, tear-off forms, calls, petitions and flyers were received in response to the options proposed</td>
<td>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].</td>
<td>Academic</td>
<td>Academic study (social science perspective)</td>
<td></td>
</tr>
<tr>
<td>Abelson, 2001</td>
<td>LSC: Restructuring of hospitals</td>
<td>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.</td>
<td>1st series took place in October and November 1994. 2nd series took place after the release of the Final Report in October 1995.</td>
<td>Academic, consultancy &amp; health service management</td>
<td>Participant analysis</td>
<td></td>
</tr>
<tr>
<td>Axler et al., 1997</td>
<td>LSC: Consolidation of emergency care on fewer sites</td>
<td>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</td>
<td>Not specified</td>
<td>Academic</td>
<td>Academic study (organisational/policy perspective)</td>
<td></td>
</tr>
<tr>
<td>Barratt et al., 2011</td>
<td>LSC: Centralisation of inpatient and emergency services</td>
<td>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; 3,700 full consultation documents; creation of website; provided information contributing to more than 140 news articles and letters in the local press</td>
<td>A two-month discussion period preceded the formal consultation</td>
<td>Health service management</td>
<td>Participant analysis</td>
<td></td>
</tr>
<tr>
<td>Carver et al., 2011</td>
<td>LSC: Reconfiguration of acute services</td>
<td>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; 8,000 questionnaires returned; 1,306 calls, emails and letters received submitted</td>
<td>Not specified</td>
<td>Consultancy</td>
<td>Participant analysis</td>
<td></td>
</tr>
</tbody>
</table>
Edwards, 1995

**LSC:** Centralisation of acute services, including closure
**Location:** England – London
**Duration:** Not specified

**Methods:** More than 10,000 consultation documents; 150,000 summaries; 50 public meetings held; 500 letters (most opposing the proposals)
**Timing:** Not specified

**Affiliation:** Consultancy
**Analysis:** Participant analysis

Foley et al., 2017

**LSC:** Region-level reconfiguration of urgent and emergency care systems
**Location:** Ireland – North East, Mid-West and South regions
**Duration:** Not specified

**Methods:** 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]
**Timing:** Not specified

**Affiliation:** Academic
**Analysis:** Academic study (policy/health service research perspective)

Garnett, 1999

**LSC:** Acute services reconfiguration
**Location:** England – Kidderminster
**Duration:** Not specified

**Methods:** 13 public meetings
**Timing:** 3-month public consultation launched a year after publications of plans

**Affiliation:** Unclear
**Analysis:** Unclear (Management perspective)

Goodwin & Rhodes, 1996

**LSC:** Acute services reconfiguration
**Location:** England – Manchester
**Duration:** Not specified

**Methods:** 40 meetings; 3 large public meetings; home visits; 80,000 leaflets, 6,000 full consultation documents; Freephone line; survey with 1,000 participants
**Timing:** Changes implemented 6 months after public consultation

**Affiliation:** Health service management (Leadership level)
**Analysis:** Participant analysis

Jones & Exworthy, 2015

**LSC:** Centralisation of emergency and maternity services
**Location:** England – A county
**Duration:** Not specified

**Methods:** Public meetings; board meetings (in one instance, about 200 members of the public in attendance)
**Timing:** Not specified

**Affiliation:** Academic
**Analysis:** Academic study (social science perspective)

Mahadkar et al., 2012

**LSC:** Reorganisation of community services
**Location:** England – A county
**Duration:** Not specified

**Methods:** 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
**Timing:** Not specified

**Affiliation:** Academic
**Analysis:** Academic study (asset management perspective)
<table>
<thead>
<tr>
<th>Author(s)</th>
<th>LSC</th>
<th>Methodology</th>
<th>Timing</th>
<th>Affiliation</th>
<th>Analysis</th>
</tr>
</thead>
<tbody>
<tr>
<td>Martin et al., 2018</td>
<td>System-wide health service reconfiguration</td>
<td>Public involvement groups/committees for transformation programmes; formal consultation</td>
<td>Not specified</td>
<td>Academic</td>
<td>Academic study (policy/health service research perspective)</td>
</tr>
<tr>
<td>McKevitt et al., 2018</td>
<td>Major system change to acute stroke services</td>
<td>Stakeholder information and consultations events; lay membership of governance structures [GM &amp; London]; 300 people attended 11 events, 46 health fairs, website with 14,000 visitors, consultation document, adverts, social media, 8,611 questionnaires returned, 1,010 emails, letters and calls received from individuals and organisations [London]</td>
<td>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]</td>
<td>Academic</td>
<td>Academic study (social science perspective) based on evaluation of LSC implementation (McKevitt et al., 2018), participant analysis (Ipsos MORI, 2009)</td>
</tr>
<tr>
<td>Moore (2006)</td>
<td>Downgrading of acute services</td>
<td>Pre-consultation engagement followed by public meetings, consultation document that can be responded to, workshops</td>
<td>Period of engagement before consultation – Public consultation started a year after publication of plans</td>
<td>Journalistic</td>
<td>Unclear</td>
</tr>
<tr>
<td>NHS Clinical Commissioners (2015)</td>
<td>Reorganisation of maternity and paediatric services [East Sussex], hospital services &amp; health and social care integration [GM]</td>
<td>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]</td>
<td>3-month engagement to draft plans followed by formal consultation from January to April 2014 [East Sussex]; not specified [GM]</td>
<td>Health service management (Commissioning level)</td>
<td>Independent</td>
</tr>
<tr>
<td>NHS Confederation (2013c)</td>
<td>Reorganisation of maternity services (including closure)</td>
<td>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</td>
<td>Formal consultation took place between October and December 2009</td>
<td>Health service management (Leadership level)</td>
<td>Participant analysis</td>
</tr>
<tr>
<td>Author</td>
<td>LSC</td>
<td>Location</td>
<td>Duration</td>
<td>Methods</td>
<td>Timing</td>
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<tr>
<td>NHS Confederation (2013a)</td>
<td>LSC: Acute services centralisation</td>
<td>Location: England - Buckinghamshire</td>
<td>Duration: Not specified</td>
<td>Methods: public meetings, online surveys, website, printed materials, short video featuring interviews with lead clinicians</td>
<td>Timing: 3-month public consultation took place in 2012</td>
</tr>
<tr>
<td>NHS Confederation (2013b)</td>
<td>LSC: Reorganisation of emergency services</td>
<td>Location: England – Northumbria</td>
<td>Duration: Not specified</td>
<td>Methods: about 100 public meetings during engagement period before the formal consultation</td>
<td>Timing: 3 months of engagement before consultation and 3 months of formal consultation</td>
</tr>
<tr>
<td>Roberts (2014)</td>
<td>LSC: Reconfiguration of maternity and paediatric services (including closure)</td>
<td>Location: England – Greater Manchester</td>
<td>Duration: Reconfiguration took place between 2000 and 2012</td>
<td>Methods: 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; 5,000 standalone response forms; 4,000 posters; 50,000 booklets aimed at children; 320 DVDs; a website with 14,000 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</td>
<td>Timing: Pre-consultation took place from 2000 to 2005 (mainly between 2003 and 2004). Formal consultation between January and May 2006.</td>
</tr>
<tr>
<td>Scottish Health Council (2006)</td>
<td>LSC: Redesign of children services</td>
<td>Location: Scotland – Inverclyde</td>
<td>Duration: Not specified</td>
<td>Methods: 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</td>
<td>Timing: 6-week consultation took place between June and July 2006. Proposals for redesign approved in August 2006.</td>
</tr>
</tbody>
</table>
4.3 How is involvement conceptualised in large-scale changes to health services?

The literature included provides few insights into how public involvement is understood and interpreted by the relevant actors in relation to large-scale change. Definitions of involvement (and associated terms) are scarce as only two publications provided a definition. Indeed, Abelson (2001) refers to ‘participation’ as “actions taken with the objective of influencing a decision-making process” while Rutter et al. (2004) 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 NHS 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 (Health and Social Care Act, 2006; CEL 4, 2010). 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 or shape their involvement activities, except in one instance (Scottish Health Council, 2008) where it was mentioned that the draft interim guidance issued by the Scottish Executive Health Department (Scottish Executive Health, 2002) was followed. Authors of four academic studies (Gold, Abelson & Charles, 2005; Rutter et al., 2004; Thurston et al., 2006; Rose & Fleischmann, 2003) either mentioned or referenced Arnstein’s ladder (Arnstein, 1969), while another academic study (Foley et al., 2017) described the International Association for Public Participation’s spectrum (International Association of Public Participation, 2007).

Some academic authors and external consultants (Abelson & Lomas, 1996; Axler et al., 1997; Edwards, 1995; Gold, Abelson & Charles, 2005; Roberts, 2014; Rutter et al., 2004; Crawford, Rutter & Thelwall, 2003; Dalton et al., 2015) 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 managing the public’s expectations. Conversely, some of those academic studies (Gold, Abelson & Charles, 2005; Thurston et al., 2006; Crawford, Rutter & Thelwall, 2003; Dalton et al., 2015) indicated that little formal thinking was done at the planning level, regarding what public involvement is, who to involve and how to conduct involvement. Another academic study (Mahadkar, Mills & Price, 2012) further explained that the purpose of involvement is often lost during implementation, and is reduced
to the need to evidence involvement was undertaken rather than achieving its aims and benefits. Looking at the participant analyses, only a few (NHS Confederation, 2013c, 2013a, 2013b, 2013d; Scottish Health Council, 2006) 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.

4.4 How is invited involvement carried out in large-scale change?

4.4.1 Who is the involved public?

The first point of interest when examining how public involvement was carried out in large-scale change 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 (Jones & Exworthy, 2015; NHS Confederation, 2013c; Roberts, 2014), “parents and children” – without further details. It is not clear either (except in 3 cases (Caseley, 2010; Ipsos MORI, 2009; NHS Clinical Commissioners, 2015)) 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 (Martin, Carter & Dent, 2018; McKevitt et al., 2018) offer limited details about lay representatives involved. In one case (Martin, Carter & Dent, 2018), 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 (McKevitt et al., 2018), 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 (Abelson & Lomas, 1996; Abelson, 2001; Axler et al., 1997; Martin, Carter & Dent, 2018; McKevitt et al., 2018; Rutter et al., 2004; Gold, Abelson & Charles, 2005) 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 (Abelson, 2001; Abelson & Lomas, 1996; Axler et al., 1997). 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 (Martin, Carter & Dent, 2018; McKevitt et al., 2018; Gold, Abelson & Charles, 2005; Rutter et al., 2004). Hence some authors from
Public involvement in decisions to change health services at a large-scale

variou affiliations (Axler et al., 1997; Carver et al., 2011; NHS Confederation, 2013d; Roberts, 2014; NHS Clinical Commissioners, 2015) 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.

4.4.2 Methods for public involvement

Public meetings (also called town hall meetings) were privileged by healthcare managers in 20 out of the 27 large-scale changes described in Table 3; these were all cases of high public involvement intensity. Publications from various affiliations (Abelson & Lomas, 1996; Axler et al., 1997; Edwards, 1995; Garnett, 1999; Rutter et al., 2004; Scottish Health Council, 2006) 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 the community. Such meetings were also described by an academic study (Abelson & Lomas, 1996) 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” (Garnett, 1999). This non-executive director further explained that public meetings are popular amongst large-scale change managers because “they are cheap to set up, you can tick the box and you have done the public consultation and move on” (Garnett, 1999). Additionally in public meetings, the information presented and the decision-making power remain in the hands of those managing large-scale change (Edwards, 1995; Garnett, 1999).

Four participant analyses with health management, consultancy and academic affiliations (Axler et al., 1997; Carver et al., 2011; Edwards, 1995; NHS Clinical Commissioners, 2015) 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 for service changes; and offers the opportunity to answer a feedback questionnaire. Members of the public in a few publications (Barratt et al., 2015; Roberts, 2014; Independent Reconfiguration Panel, 2010) criticised consultation documents for being very lengthy (in one large-scale change the document was 80 pages long (Barratt et al., 2015), in another 131 pages long (Roberts, 2014), complex in its layout and language and generally not adequate for a lay audience. The
Independent Reconfiguration Panel (Independent Reconfiguration Panel, 2010) and members of the public in two publications (Barratt et al., 2015; Scottish Health Council, 2006) 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 large-scale change (Barratt et al., 2015) commented on how the questions were either leading or gave no scope 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 (Caseley, 2010; Edwards, 1995; NHS Confederation, 2013c; Roberts, 2014; Independent Reconfiguration Panel, 2010; NHS Clinical Commissioners, 2015; Ipsos MORI, 2009; Scottish Health Council, 2006). Who communicates the messages is also important with various participant, independent and academic analyses (Carver et al., 2011; Edwards, 1995; Foley et al., 2017; Goodwin & Rhodes, 1996; NHS Confederation, 2013b, 2013d; Roberts, 2014; Dalton et al., 2015; Independent Reconfiguration Panel, 2010; NHS Clinical Commissioners, 2015) 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 plans for change. Nonetheless, in one large-scale change (Barratt et al., 2015) 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 (Barratt et al., 2015; Foley et al., 2017; Jones & Exworthy, 2015) further indicated that the public understood the technical arguments and actively questioned them, opposing plans for large-scale change.

Finally, there is some indication (Axler et al., 1997; Caseley, 2010; Edwards, 1995; NHS Confederation, 2013d; NHS Clinical Commissioners, 2015) that different involvement methods and dissemination mediums are required at different stages of the large-scale change 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.

4.4.3 Timing of public involvement in relation to the large-scale change

Authors with health service management, journalism, consultancy, government and academic affiliations (Foley et al., 2017; Goodwin & Rhodes, 1996; Moore, 2006; NHS Confederation, 2013b, 2013d; Roberts, 2014; Scottish Health Council, 2006; Dalton et al., 2015; Independent Reconfiguration Panel, 2010; NHS Clinical Commissioners, 2015) 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 large-scale change (Foley et al., 2017; Goodwin & Rhodes, 1996; NHS Confederation, 2013d).

It was difficult, however, to assess at what stage(s) of the change process public involvement took place (Table 7). Only 6 large-scale changes included (McKevitt et al., 2018; NHS Confederation, 2013c, 2013b, 2013d; Roberts, 2014; NHS Clinical Commissioners, 2015) 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 large-scale changes reported doing (Barratt et al., 2015; Airoldi, 2013).

4.5 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; they believed that decisions for change had been made prior to public consultation, leaving the public sometimes dissatisfied with the process (Abelson & Lomas, 1996; Abelson, 2001; Rutter et al., 2004; Gold, Abelson & Charles, 2005; Scottish Health Council, 2006; Thurston et al., 2006; Independent Reconfiguration Panel, 2010; Airoldi, 2013; Roberts, 2014; Barratt et al., 2015; Jones & Exworthy, 2015; NHS Clinical Commissioners, 2015; McKevitt et al., 2018; Scottish Health Council, 2008; Foley et al., 2017).

This sentiment of not being able to influence decision-making on change proposals led in some cases to an atmosphere of mistrust where the public felt that the large-scale change was driven by the need to cut costs rather than improve services (Abelson & Lomas, 1996; Barratt et al., 2015; Jones & Exworthy, 2015; Moore, 2006; Roberts, 2014; Scottish Health Council, 2006; NHS Clinical Commissioners, 2015). Mistrust was directed at those leading the change 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 (Barratt et al., 2015; Edwards, 1995; Roberts, 2014; Scottish Health Council, 2006; Independent Reconfiguration Panel, 2010; NHS Clinical Commissioners, 2015).

Some authors with health service management affiliations (Carver et al., 2011; NHS Clinical Commissioners, 2015) briefly offered their own perspective on the process, which was very positive. On the other hand, a participant analysis written by an external consultant (Edwards, 1995) 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” (Edwards, 1995).

In this context of mistrust, recommendations put forward in several publications (Barratt et al., 2015; Caseley, 2010; Edwards, 1995; NHS Confederation, 2013b; Roberts, 2014; Independent Reconfiguration Panel, 2010; NHS Clinical Commissioners, 2015) for those leading change 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.

### 4.6 What kind of impact does public involvement have in decision-making?

The kind of impact public involvement may have in large-scale change is rarely discussed in the literature, in particular how such involvement influenced decisions regarding the proposed changes – a lack of reported impact also established by academic reviews (Dalton et al., 2015; Rose & Fleischmann, 2003; Crawford, Rutter & Thelwall, 2003).

The literature 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 (Carver et al., 2011; Moore, 2006; NHS Confederation, 2013c, 2013a, 2013b; Roberts, 2014; Scottish Health Council, 2006) 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.

Alternatively, authors of an academic study (McKevitt et al., 2018) – who argued involvement in their study was used to secure support on decisions already made – identified that the value of public involvement was to facilitate the implementation of the large-scale change rather than influence decision-making. In particular, they identified that public involvement was used by LSC leaders as a tool to manage agitation by for example including an “activist” as a lay member. The authors identified two other values of public involvement for large-scale change implementation: verification, by involving lay people to anticipate potential public concerns regarding the plans and to develop information materials; and substantiation, whereby having patients physically present demonstrated that involvement policy was acted out.
A wide range of methods to involve the public as well as various mediums to disseminate information about large-scale change proposals are described in the literature included (Table 7). 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 four large-scale change cases (Gold, Abelson & Charles, 2005; Greenhalgh et al., 2009; Greenhalgh, Humphrey & Woodard, 2011; Roberts, 2014; McKeivitt et al., 2018) in this review included an evaluation covering public involvement and two other cases (Carver et al., 2011; NHS Confederation, 2013b) 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 change 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 intensive involvement – brought about by large-scale change, especially to acute services, appears to have more of an impact on plans for change 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 (Barratt et al., 2015; Edwards, 1995; Foley et al., 2017; Garnett, 1999; Jones & Exworthy, 2015; Moore, 2006; Roberts, 2014; Independent Reconfiguration Panel, 2010; NHS Clinical Commissioners, 2015). Local opposition can be further fuelled by the media and local politicians (Abelson & Lomas, 1996; Abelson, 2001; Carver et al., 2011; Edwards, 1995; Garnett, 1999; Moore, 2006; Roberts, 2014; NHS Clinical Commissioners, 2015; Foley et al., 2017). In cases with strong local opposition (Edwards, 1995; Garnett, 1999; Jones & Exworthy, 2015; Roberts, 2014; Independent Reconfiguration Panel, 2010; NHS Clinical Commissioners, 2015), proposals for change 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 vehicle for public voices to be heard in large-scale change proposals than the inputs of public involvement.

Leaders of change in two participant analyses and one academic study (Foley et al., 2017; Carver et al., 2011; NHS Clinical Commissioners, 2015) 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.
4.7 Consultation with stakeholders

The stakeholder consultation helped me interpret the findings of this review. My findings were in line with the consultation stakeholders’ experiences. Moreover, my findings on the public’s perception of the involvement process sparked the most responses amongst the consultation stakeholders. Indeed, consultation stakeholders felt the public could not influence plans for large-scale change 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 stakeholders further pointed out the lack of feedback after involvement activities, in particular on how the public’s inputs were used (or not), reinforcing their belief that public involvement in large-scale change is tokenistic.

A few stakeholders further discussed that the different terms ‘engagement’, ‘consultation’, ‘involvement’ and ‘participation’ are poorly defined and allow for tokenism in public involvement. Therefore, they suggested the different terms should be explicitly defined in the large-scale change context and linked to specific aims.

Some of the stakeholders additionally brought up the role of arms’ length bodies in large-scale change – an aspect not captured in my scoping review. In particular, they were critical of the different changes to arms’ length bodies in England as Community Health Councils were replaced by LINks and later by Healthwatch. They further referred to the role of arms’ length bodies as one of a “watchdog” and associated the current body, Healthwatch, with “a dog that doesn’t bark”, compared to previous bodies.

4.8 Discussion

This review showed that, in large-scale change cases with a high intensity of invited public involvement, involvement often takes the form of a public consultation model in which information flows one-way and, as defined in section 4.3, “a model in which professionals retain control of both the process and outcomes of user involvement” (Rutter et al., 2004). Reflected in the technocratic perspective adopted 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, despite the common conceptualisation that the purpose of public involvement (regardless of the definition used – see section 1.1) is for the public to influence decision-making, this model is associated with feelings from the public of not having any influence on decision-making regarding the proposals, often only being consulted on set options pre-determined by leaders of change.
Publications offered recommendations such as involving the public at the earliest stages of change; formulating clear aims for involvement activities; and listening and taking under consideration concerns raised by the public. All resonate with those found in national guidance documents on public involvement in large-scale change in England and Scotland (Scottish Health Council, 2010; NHS England, 2016a, 2018b), on public involvement in decision-making in health policy in Canada (Health Canada, 2000) and on public consultation by public bodies in Ireland (Department of Public Expenditure and Reform, 2016), yet those do not seem to be enacted often in practice. Ultimately, this public consultation model of involvement contributes to an information deficit model (Bucchi & Neresini, 2008; Rowe & Frewer, 2000) where public opposition to the change is attributed to a lack of understanding from the public of the technical arguments made 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 – such as citizens’ juries or panels, deliberative polling or mapping and consensus conferences (Abelson et al., 2003).

However, some studies indicated that the public understood well the technical arguments and actively questioned them, opposing large-scale change plans and seeking alternative routes to voice their views. In this review, there was evidence of both procedural and confrontational tactics (Stewart, 2016) used by the public to challenge the legitimacy of decisions. 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. Yet, more empirical work on this model of involvement is needed since information on the local opposition in large-scale change was generally peripheral in the literature included and often framed in participant analyses as an obstacle to large-scale change implementation. In fact, evidence presented in this literature review, as well as in Dalton et al.’s review (2015), tends to be from the perspective of the LSC leaders, largely assuming a ‘top-down’ model of planning (Farmer & Nimegeer, 2014) and reinforcing public perceptions of tokenistic involvement. This also reflects the ‘technicist’ orientation of Health Services Research (Cribb, 2018), – partly exacerbated by the dominant sources of funding (for example in the UK where Health Services Research has attracted substantial government funding since 2006 [Jones, Fraser & Stewart, 2019a]) – focusing on finding technical solutions to healthcare problems whilst neglecting the political dimensions of healthcare planning, in particular in controversial large-scale changes [Jones, Fraser & Stewart, 2019a]. In this review, leaders of large-scale change 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 large-scale change.

The findings of the scoping review were very informative for my empirical research and initially guided some of my fieldwork strategies and data collection tools. As a result, my empirical findings
addressed the research gaps identified in this scoping review. For instance, in the following chapter, I present a more detailed account of invited processes that have taken place in the case studies put in motion as a result of a regional programme for large-scale changes. Most of the findings of this scoping review are echoed in that chapter and explored in more depth. Furthermore, as indicated earlier, the literature on large-scale change often omitted or lessened the public opposition and the actions the public took outside the invited model of public involvement. Chapter 6 aims to bridge this gap by exploring how uninvited involvement materialised in the two case studies. Both chapters, based on my empirical findings, further suggest that processes of invited and uninvited involvement are not taking place independently but have an effect on each other. In the final chapter, I thus reflect on those interactions between invited and uninvited involvement in the context of large-scale changes to health services.
Chapter 5 – Exploring invited involvement in large-scale change: a process controlled by decision-makers

5.1 Introduction

In this chapter, I explore the social and political processes underpinning invited involvement in the Bluehill and Grandvalley communities, in response to an LSC programme which had plans to change the way acute hospital services were distributed across a region in England. This region became a Sustainability and Transformation Partnership (STP) footprint in 2016 as described in section 3.3.2. At the time of writing, each community was served by a local Clinical Commissioning Group (CCG), local Trust, local council, local Healthwatch and a joint CCG (for the entire STP footprint). Furthermore, each community had an active ‘Save Our Hospital’ campaign group (see Figure 6).

Based on documentary analysis and a few interviews, I produced a timeline of the LSC programme against the backdrop of changes in regional and national governance systems (Figure 8). This timeline is not meant to be exhaustive but provides context to the findings of this chapter. As shown in Figure 8, in 2012, the LSC programme plans were put out to public consultation throughout the whole region, only a few months after they had been made public. Following the public consultation, the local council in Grandvalley wrote to the Health Secretary who then referred the LSC programme plans to the Independent Reconfiguration Panel – an advisory non-departmental public body, described by the government as “the independent expert on NHS service change”. The recommendations of this body were to proceed with two of the emergency department closures, and to halt the other two. As shown in the timeline, several waves of change took part under the LSC programme umbrella:

- in 2014, one of Bluehill’s emergency departments was closed alongside the emergency department in Redtown (a neighbouring local authority) which affected residents in both Bluehill and Grandvalley – plans under the LSC programme were to further close Bluehill’s other emergency department;
- in 2015 and 2016, the maternity and paediatrics services in Grandvalley were closed down and plans were to further close the emergency department at Grandvalley Hospital.

The LSC programme was dropped by the government towards the end of my fieldwork (see Figure 8). Eighteen of the twenty-seven interviews I had conducted took place before this announcement was made. Most of the sections in this chapter and the next one depict the situation before plans were dropped.
Public involvement in decisions to change health services at a large scale

Fieldwork

Figure 8. Timeline of events in the two case studies
5.2 The case for change

The LSC programme was presented to the public as clinically-led and evidence-based to improve the efficiency of health services in the region, improve quality of care and “save more lives”. The plans mainly centred around the centralisation of acute services in the region. This was framed as keeping some hospitals as “major hospitals” (i.e. a district general hospital) and others would become “local hospitals”. Albeit not clear for the reader in the consultation document, downgrading a hospital to the status of a “local hospital” meant that acute services would then be closed on those sites including the full emergency department (referred to by participants in quotes as A&E). These would be replaced by a 24 hours/7 days Urgent Care Centre – hosting maternity and paediatrics services, as well as an acute stroke unit (if the “local hospital” had one).

In documents related to the initial public consultation in 2012, opposition to the plans for change were attributed by LSC leaders to the attachment to local hospitals by the public and by local staff working there. Hence public opposition was interpreted as an emotional response to the plans for change, instead of rational decision based on the “best available evidence” put forward by LSC leaders. While exploring invited and uninvited processes in both communities, I observed that when the public got emotional (or in my observations more frustrated than emotional) in involvement avenues, it was not because of their attachment to their local hospitals, but because they were actively scrutinising and challenging the evidence put forward by the LSC leaders.

Many arguments made by LSC leaders to support the case for change were contested by other stakeholders, such as members of the public and local campaigners, as well as local clinicians and local politicians. As a result, during fieldwork, invited involvement forums were the scene of a back and forth between LSC leaders (such as commissioners and NHS managers – see section 5.4.1) and the public (such as campaigners – see section 5.4.3) disputing the evidence the LSC programme was built upon. This included: centralisation of services, travel times and providing care in the community to relieve pressure on acute services.

From the onset of the LSC programme, LSC leaders supported their argument for centralising acute services based on findings from an evaluation of the reconfiguration of stroke services in London. They further stated during the public consultation that “other countries around the world have used exactly the same approach successfully”. However, for some of the members of the public, one clinician and all campaigners, the LSC leaders failed to show evidence that travelling further for specialist care, as a result of emergency department closures, was beneficial to emergency patients other than stroke patients. Their counter argument was that the vast majority of emergency patients were not stroke patients, and for those patients, increasing their travel time could potentially be fatal.
“We were told if we look at the way they have consolidated stroke services at [another hospital in the region], if they consolidate other services as well, to specific hospitals, then all the expertise will be centralised in that particular place. But with all due respect, although the centralisation of the stroke unit has been very good acting and they are an excellent unit, may I add. You can’t centralise something like A&E in just a few hospitals, and people would suffer detrimentally.” (Member of the public 01 – Grandvalley)

“I’m not against changes, per se, because I know that sometimes consolidating services is a really good idea. So, I was quite careful to look at this and try and not just have an emotional response, but actually look at what the evidence seems to be saying. […] I feel as if my kind of support is evidence-based, I suppose is what I’m saying, as opposed to just simply, obviously I’ve got an emotional connection with the hospital. But if [LSC leaders] had been presenting evidence like there is for specialist cardiac units or stroke units, where actually you’re better to be taken somewhere different, but to close down our Emergency Department and send us elsewhere where they’re clearly not coping at the moment, seems to me, it’s going to kill people, or harm people.” (Member of the public 04 – Bluehill)

The additional travel times as a result of centralisation of acute services were a concern for many of the participants interviewed, that they often associated with worsened health outcomes and potentially with lives being lost. This public concern was anticipated by LSC leaders in the initial public consultation document, but largely dismissed in the following way: “These days so much more care can be provided at the scene of accidents, actually within ambulances, or in the community. […] Travel times need to be within an acceptable limit, but are not as critical as they used to be in deciding exactly where services such as emergency care should be located”. Therefore, the additional travel times presented during the initial consultation and in a later consultation in Bluehill around the Urgent Care Centre (section 5.3.8) were deemed acceptable by LSC leaders. However, the travel times advertised were heavily contested by members of the public in both consultations, that they described as far from the realities of the public transportation system and traffic conditions. One member of the public interviewed, who had been involved in the initial consultation as a lay member for LINks (predecessor of Healthwatch), described a series of meetings with LSC leaders during which lay members strongly disputed the travel time evidence at length without convincing LSC leaders.

In the case for change, centralisation of acute services was intended to be accompanied by improving out-of-hospital provision and developing health services in the community. This was a part of the case for change that was initially supported by the public, including campaigners. However, according to public claims, a few years after the initial public consultation and service closures, out-of-hospital service development had not been delivered. Campaigners in particular, during fieldwork, repeatedly pointed to the lack of a published up-to-date business case by LSC leaders, indicating they
could not scrutinise community plans. Additionally, in invited involvement forums they brought up how it was not clear how LSC leaders planned to measure the out-of-hospital service performance in light of closed acute services under the LSC programme. This further highlighted their concerns that LSC leaders were focused on hospital changes, and not on community services. From the outset, LSC leaders argued to the public, that their plans for community services would reduce demand on hospital services. Campaigners, according to interviews and observations, have been asking LSC leaders in invited forums (and through uninvited actions described in Chapter 6) for the evidence underpinning their initial argument, as they refuted the idea that acute services in the region could be closed, and care could instead be provided in the community (this was also the view of clinicians supporting the local campaigns). In a 2017 public document from Bluehill Healthwatch asking LSC leaders about available evidence that out-of-hospital provision reduces demand on hospital services, LSC leaders replied that there was national evidence from an early evaluation of similar programmes. They later added that the capital required for their community plans was lacking, and that evidence for the plans that had already been implemented was “just emerging”. A year later, campaigners who attended (invited) meetings in public (see section 5.3.3 about such meetings) confronted the LSC leaders with evidence from independent studies including a Nuffield Trust report (Vaughan et al., 2018) supporting the campaigners’ claim, but LSC leaders disregarded their comment.

A recurrent grievance over the lifetime of the LSC programme from campaigners and local politicians, was regarding the lack of an up-to-date business case of the programme made available to the public. Campaigners used, amongst other tactics described in section 6.3, Freedom of Information requests and mobilised their local politicians to attempt to gain access to an up-to-date business case without success. Their request for an up-to-date business case stemmed from campaigners’ views that the pre-consultation business case was based on flawed assumptions with sparse evidence on how the LSC programme would be cost-saving. Additionally, years after the initial public consultation, campaigners were not assured, without an updated business case, that changes in population and the impact of closures were taken into account by LSC leaders. Over the years, campaigners and local politicians claimed that without an updated business case it was not possible to demonstrate that the LSC programme was affordable, deliverable and anchored in the current regional context. They further asserted the LSC programme, as it was implemented, did not represent value for money and had not delivered its promises for better community care. They further described the programme as “a waste of precious public resources” given its original claim for the amount of saving it would generate became, over the years, the amount needed for capital investment to deliver the LSC programme. Local politicians also repeatedly put forward that they could not conduct meaningful scrutiny of the LSC programme without an updated business case. Until the end of 2016, they were unsuccessful in requests to LSC leaders to provide this information. At the time of my fieldwork, campaigners in Grandvalley were told
by LSC leaders that the current business case was still the 2016 version. According to campaigners, this was not a business case demonstrating that the LSC programme could be implemented, but was considered a case asking for capital funding.

The case for change was further critiqued by members of the public, campaigners, and some local clinicians for targeting service closures in the most deprived areas of the region, that were already experiencing health inequalities and whose population was not involved in invited involvement activities.

“So, all in all, all these changes are happening in the poorest part of Grandvalley, and it’s the poorest who are going to suffer the most, or who are suffering the most now.” (Member of the public 01 – Grandvalley)

“Those most affected by health inequalities do not have a voice” (Bluehill campaigner to LSC leaders in public workshop)

During fieldwork, whenever a member of the public, a campaigner or a Healthwatch member brought up health inequalities and asked how LSC leaders were mitigating the negative impacts on deprived populations, the answer was always the same: equality impact reviews had been conducted in the context of the STP and were available to consult online.

Therefore, during the lifetime of the LSC programme, LSC leaders promoted the case for change as evidenced-based, but did not seem willing to engage with alternative evidence put forward by the public in invited forums of involvement. As another example, after the first emergency department closures in 2014 (Figure 8), Grandvalley campaigners researched the impact of those closures on the remaining services in the region using NHS data and produced graphs illustrating that the performance of the remaining emergency services in the region had declined since the closures. They further suggested that the remaining emergency services would not be able to cope with further closures of the emergency departments in Grandvalley and Bluehill hospitals. The LSC leaders’ response to this evidence, according to documents retrieved, was that they had planned the closures well enough to maintain patient safety. However, according to a Healthwatch respondent, it would seem that a Trust leader in Bluehill explained during a meeting in public during fieldwork that it would not be safe to cut down emergency bed numbers given the pressures faced by clinicians.

When public involvement was invited, the public challenged the evidence put forward by LSC leaders while LSC leaders avoided engaging with alternative evidence brought forward by the public. This intensified public feelings of distrust towards LSC leaders expressed by the majority of interviewees. In line with the findings of the scoping review (Chapter 4), most participants distrusted LSC leaders’
motives for change and believed that the LSC programme was financially motivated rather than clinically-led. Indeed, a recurrent theme in my analysis was that rather than their stated aim of improving and integrating services in the region, LSC leaders were responding to central pressures to reduce costs. This was also reflected in the discourse of the public and local politicians I observed during fieldwork, as well as some local clinicians, who did not refer to large-scale change as “change” but instead as “cuts to health services”. On the other hand, LSC leaders during observations and through documents collected, did not use words such as ‘closure’, ‘reconfiguration’, ‘cuts’ or ‘downgrading’ when discussing the LSC programme. For example, in the lengthy public consultation document, the words ‘reconfiguration’ or ‘downgrading’ were not used at any points whilst the word ‘closure’ was only used once, in the foreword of the document, to explain that if change did not happen the region would face the risk of “unplanned closures”. Further fuelling feelings of distrust towards the LSC leaders’ motives behind the LSC programme, campaigners criticised the excessive and costly use of management consultants in developing the plans for change. Campaigners in Grandvalley particularly, had been making this claim and had tried for years to get more transparency from LSC leaders on the topic through their own research and Freedom of Information requests. From the data they could trace, they estimated that at least £72 million had been spent on consultants. A few months after the LSC programme was dropped, a leaked NHS document confirmed that £76 million was spent on management consultants during the lifetime of the LSC programme. In summary, the main concern from members of the public – echoed by some local politicians and local clinicians – was that the LSC programme was built on contested evidence, was financially-driven and did not take into account the public’s perspectives. As a result, levels of distrust were high in both Grandvalley and Bluehill; a distrust towards LSC leaders that persisted beyond the lifetime of the LSC programme. For many interviewees, their experiences of the model of invited involvement chosen by LSC leaders, that I describe in the following section, further exemplified the LSC leaders’ lack of sincerity, reinforcing their perception that LSC leaders could not be trusted.

5.3 The stage of public involvement

Having described the case for change and its critiques, I now describe in this section the forums made available to members of the public in Bluehill and Grandvalley to be involved in decisions around the LSC programme.
5.3.1 LSC leaders’ differentiation of ‘Engagement’ and ‘Consultation’ and its implications for public involvement

As uncovered in the scoping review (section 4.3), the terms ‘consultation’, ‘involvement’ and ‘engagement’ are distinctively used in the UK literature. During fieldwork, LSC leaders and practitioners of public involvement only referred to ‘consultation’ and ‘engagement’, each having a particular meaning for those actors. Namely, ‘consultation’ was tied to the NHS legal requirement to consult the public in case of “substantial” change to health services. ‘Engagement’ seemed to be used as an umbrella term referring to all other invited activities with the public not tied to the formal consultation. No documents retrieved during my fieldwork shed further light on the definitions of ‘engagement’ and ‘consultation’ in the LSC programme. Additionally, practitioners of involvement and LSC leaders were very careful about which word they used to describe public involvement. I first noticed this at a meeting in public I observed where a Healthwatch member raised the need for public consultation but was corrected and asked to use the word ‘engagement’ by one of the LSC leaders. The LSC leader also argued that a public consultation had already taken place four years earlier and that “a full public consultation would be required in the event of a new and substantial service change”; which was not the case. Later in interviews, the practitioners of public involvement and an LSC leader confirmed their careful use of the word chosen to describe how the public is involved. The LSC leader interviewed in particular emphasised how “engagement is not a legal term” while ‘consultation’ was tied to legal processes and could be challenged in court, resulting in delays to the implementation of the change.

“I think ‘consultation’ has the legal thing and ‘engagement’ doesn’t. But I know I sometimes use the wrong word, because [a practitioner of public involvement] tells me, ‘We’re not consulting, we’re engaging’, [chuckling], okay, whatever.” (Lay member – STP level)

“And if you do not follow that [consultation] process correctly, you end up in court and the whole process grinds to a halt. So, I’m very careful about my use of words, and when I say consultation, I mean that legal process.” (LSC leader – STP level)

Additionally, if ‘engagement’ could take place at any point of the LSC programme and was “not reserved for specific change initiatives”, ‘consultation’ could only take place in case of “substantial change” to health services as explained by the LSC leader interviewed. Several campaigners, local politicians or Healthwatch staff when interviewed, had questioned how ‘substantial’ change was defined by LSC leaders as they argued that many changes introduced under the LSC programme umbrella were substantial in their opinion and would have required public consultation. The Healthwatch respondents further raised the lack of existing guidelines on substantial change and public involvement in large-scale change, resulting in no shared understanding between actors of the level of public involvement required in large-scale change. One of the local politicians, on the other hand, conducted their own research to
understand what changes qualified as substantial and explained that the guidelines were vague but had discovered that LSC leaders needed to discuss with the local authority potential substantial changes:

“[The guidance] says you have to reach a determination of ‘substantial’ working together or alongside – that’s the word they used – the local authority. I think they can still take the ultimate decision themselves, but they have to have a conversation with us, not about the substance of the document, but about whether we think their plan overall is substantial service change and therefore needs a full public consultation.” (Local politician 01 – Bluehill)

This local politician deemed that such discussion around substantial change had to take place through a public forum such as the local authority’s Health Overview & Scrutiny Committee. Exemplifying their distrust of LSC leaders, the politician consequently instructed their officers to be careful in discussions with LSC leaders outside the public forum “that enables them to say they’ve consulted you”, which according to the politician would result in the matter not being discussed in public, avoiding public scrutiny and consultation.

Although the public consultation process in the region was heavily criticised (discussed in sections 5.3.2 and 5.3.8), campaigners and politicians during fieldwork seemed to agree that the public was more likely to have a voice in the LSC process through consultation than engagement. Indeed, if consultation was to be triggered it would open the plans for change to public scrutiny and prompt high intensity invited public involvement, both elements that could potentially be legally challenged in courts. Alternatively, engagement processes were not tied to any standards in terms of its intensity, who was invited and its influence on decision-making.

“Well that is actually an interesting thing about the term you used, ‘engaged’. And there have been arguments about this. For major changes the law says [LSC leaders] must consult with the public including local authorities, which are elected bodies. They have chosen to engage. There are no – a bit like a battlefield – rules of engagement here, so very often engagement is small, it’s low key, it’s already full of bodies and sometimes of bodies who directly are funded by the CCG and who really have an interest in not rocking the boat funding them.” (Campaigner 01 – Bluehill)

The Councillor relayed to the campaigners the points he raised at a meeting with LSC leaders about public engagement and consultation: “For each of these cuts, they will decide what type of engagement to have with residents. Are they going to have public workshops? Call that engagement so they can say they have done their jobs? Which is pretty much what has happened so far. Are they going to go to an online consultation? And have a rubbish series of questions? Or are they going to go to full public consultation? If they are going to full public consultation, it’s what we want, so we can have more input.” (Field observations – Bluehill Save Our Hospital campaign meeting)
In the following sections, I describe the avenues made available to the public to be involved in the LSC programme, which I thus organised according to whether the local NHS bodies qualify the forums described as ‘engagement’ or ‘consultation’.

5.3.2 Consultation: Initial regional public consultation on LSC programme – A top-down approach to health planning and public involvement

Public consultation on the plans for the LSC programme took place in 2012 which led to the closure of one emergency department in Bluehill and one in Redtown that were both replaced by Urgent Care Centres open around the clock. Later, the closure of maternity and paediatrics services followed at Grandvalley Hospital. The next planned closures – that were halted a year after public consultation following the recommendations of the Independent Reconfiguration Panel – were the emergency departments in Grandvalley and in one of Bluehill’s hospitals (see Figure 8). At the beginning of my fieldwork, the emergency department closures (that were supposed to take place in 2019) were delayed to 2021 and beyond. Towards the end of my fieldwork, the government announced that the LSC programme was dropped and therefore the two emergency departments were to remain open. Therefore, the initial regional public consultation in 2012 on the LSC programme formed the basis of closures taking place years later.

Thirteen participants (2 members of the public, 7 campaigners, 2 members of Healthwatch, 1 clinician, 1 lay member) interviewed had taken part in the initial public consultation in 2012 and raised several criticisms of the process. Firstly, respondents expressed that the public consultation was poorly advertised and that, at the time, most members of the public did not know that the consultation was taking place. Interestingly, a group of members of the public – who later became ‘Save Our Hospital’ campaigners – were holding stalls at Grandvalley hospital in 2012 to inform the public about the consultation and encourage them to complete the consultation questionnaire. Some campaigners further added that for members of the public who were aware of consultation events, there was little, or no information provided in advance by the LSC leaders. Additionally, the public consultation was triggered rapidly (see Figure 8), which meant that not all the consultation documents were available when the consultation started, according to interviewees’ accounts.

“So that is how I knew about it, but if you were not a member of LINks back then – translate into Healthwatch now – you wouldn’t have heard about it. It was not widely publicised even in the local paper.” (Member of the public 01 – Grandvalley)

“So [a campaigner] and other people – there was a group of people who were very linked to Grandvalley Hospital – who basically ran stalls in Grandvalley Hospital every day for months
trying to get people to fill the questionnaires. They didn’t tell them how to fill them in, but they told them how important it was so there was people who did stuff like that. There were lots of us who did put materials out, we produced loads of leaflets to encourage people to take part.” (Campaigner 02 – Grandvalley)

“It was dense, impenetrable, repetitive consultancy speak and they reviewed that at a meeting on 25th June 2012 and said ‘yes, it should go ahead’ on this basis and the consultation began about a week later, with no consultation documents, no information in the public domain. […] [LSC leaders] have been very reluctant to divulge any information and a lot of the time they will divulge information that is simply made up on the spot. So, for example when I said: ‘the consultation documents are not available for this consultation, they’re not in my GP surgery, they’re not in my library but your website says they are now available in GP surgeries and the libraries and this and that’, they said that they had delivered tens of thousands of documents. Well they hadn’t, I knew that, and they said that 2,000 of them had gone to the Bluehill library so I got in touch with them and I’ve got emails which say ‘have you got them? No, we haven’t. We got some posters by about two weeks in, but nothing about documents’. So, people didn’t know what was happening right up until about [3 weeks into the public consultation] when the documents finally started dribbling through.” (Campaigner 03 – Grandvalley)

Secondly, echoing the findings of the scoping review (Chapter 4), the public involved in the consultation was not representative of the local communities according to participants who took part in the initial regional consultation. Participants highlighted that minimal effort was made by LSC leaders to include vulnerable groups most impacted by closures in consultation events, or by making the consultation accessible for all. This was highlighted, as several interviewees identified people not included in the consultation that were living in deprived areas served by the hospitals at risk of closure as not included in the consultation.

“And I hope that you are able to speak to as many people as possible who have experienced this past blindly dogmatic way of implementing change. Because as far as I’m concerned, it doesn’t matter what the organisation is, but if you want to implement change, you need to consult the people who are most going to be affected and find out what their needs are, and then when you collate that information based on locality, you will find a pattern, and then you use that to formulate your policies. Rather than coming with something that has already been prepared and you already know your conclusion from the beginning and you come and you impose it. And then you invite a few people through a few charities or local organisations, and then you say ‘Oh take part in this, this is what we’re doing’ or ‘What do you think?’, and even the recommendations they give, doesn’t get looked at, because that is how we see it, that’s how I personally perceive what they’re doing. You can never implement change without consulting the people who are most at risk of that change.” (Member of the public 01 – Grandvalley)

“So, the consultation was shammed, you know, it wasn’t… I don’t know, I think consultations always exclude the very people that are going to be affected most. Because, you know, you probably need to have a certain level of education to understand what’s happening. […] And I think that’s
why we [clinicians] often need to be advocates for the people who are voiceless.” (Local clinician 01 – Grandvalley)

Thirdly, public meetings were one of the main involvement methods chosen by LSC leaders in this public consultation to gather the public’s views. Respondents described the format of those meetings as a long PowerPoint presentation – not suitable for a lay audience – followed by short discussions at each table. Members of the public were given pre-determined discussion themes for their table and had a “restricted” opportunity to ask some questions to NHS staff at their table who were involved in the consultation and/or the LSC programme. Some participants mentioned that the NHS staff at their table were not able to answer the public’s questions. All participants who attended public meetings conveyed that these meetings were difficult to participate in, and that there was little opportunity to have their views heard.

“Only the most articulate and forceful [members of the public] would be able to participate in that process.” (Campaigner 02 – Grandvalley)

“The first thing I remember was a lot of people talking and not much opportunity to actually say much. It was more a sort of a listening exercise. And I got the impression that they were trying to sell this great new future and this great vision, but I don’t think there was much substance to it. But I still felt that a lot of the general public and a lot of people who went to the meeting were quite angry and quite upset by things.” (Local clinician 01 – Grandvalley)

Public meetings were followed by the publication of a consultation document and a questionnaire. These were both heavily criticised by the interviewees who took part in the public consultation. Again, resonating with the findings of the scoping review (Chapter 4), respondents found that the consultation document – despite displaying the Crystal Mark logo for plain English – was not suitable for a lay audience. Its length and complexity were criticised, as well as the lack of clarity on how the public would access local health services if plans for change were to move ahead. The consultation document mirrored the 34 questions forming the consultation questionnaire that members of the public were required to complete to share their views on the proposals and choose between three options of service closures in regional hospitals. Two campaigners explained that they found it difficult to navigate the consultation document whilst answering the questions, some of which they found misleading. Some hence resorted to using “a crib sheet” developed by another campaigner to help them complete the questionnaire.

“The problem with the questionnaire was that the way they were written, made it very difficult for you to have a different position that didn’t put you either saying ‘close that’ or ‘close this’. So, it would say things like – I’m trying to remember because it’s been a long time – so it would say things like do you agree that it’s a really good idea to bring together community care and acute care...
in hospitals. Well yes and then you would want to say but you don’t know if it means cuts and cuts and cuts. So, it would give people sort of impossible choices where you were forced to say actually I think it’s my hospital that should stay and you should cut another one. […] So, I think that was the problem, that it wasn’t a genuine consultation, there was not enough time, it was far too long for most people and as I explained to you there was this problem with language.”  
(Campaigner 02 – Grandvalley)

“So, you know, I have a medical degree and a PhD, but I still struggled with that consultation document, getting through it, and still struggled with the questions. Because I thought they were leading, I still felt that they were trying to, you know, they’d already decided beforehand that one hospital would be pitched against another hospital.” (Local clinician 01 – Grandvalley)

Consultation-related documents described an array of methods used to involve the public, and of channels for the public to share their views during this public consultation. This included: 500,000 leaflets distributed through GP surgeries, libraries, hospitals, town halls, local LINCks; a website with over 18,500 visits during the consultation period; advertisements in 13 local newspapers in the region; over 70,000 consultation documents and response forms distributed; over 200 events including public meetings, GP events, focus groups and roadshows. The focus of the post-consultation report was on the responses (over 17,000) to this questionnaire. None of the interviewees who took part in this consultation remember other methods and channels used apart from the public meetings, the consultation document and the questionnaire (paper- and online-based).

Fourthly, the participants perceived the LSC programme plans and the consultation process to be imposed on the region, as pitting local communities against each other. Indeed, the aim of the consultation was to gather the public’s views on three options for change, all involving service closures – framed by LSC leaders as having some hospitals as “major hospitals” and others as “local hospitals” – but in different hospitals of the region (section 5.2). Some hospitals were to remain ‘major hospitals’ regardless of the option chosen. Therefore, in the region, the communities facing the downgrade of their hospitals were Bluehill, Grandvalley, Redtown and two other communities. However, one could note that for Redtown, there was no option to retain the hospital as major, and that Grandvalley and Bluehill communities only had one option to vote to keep their hospitals as major (not the same option) unlike the other two communities who had two options they could vote for to keep their hospitals as major. This gave interviewees from Grandvalley and Bluehill the impression of a skewed public consultation. This feeling was reinforced by the timing of the consultation perceived as rushed and by the fact that another hospital Trust strongly internally promoted voting to keep the hospital as major, whilst that was not done by Trusts operating in Granvalley and Bluehill’s hospitals. This was furthered as uninvited actions such as the number of people who signed petitions and attended demonstrations against the LSC programme were not weighted in the public consultation.
Altogether these elements contributed to a unanimous feeling amongst the participants who took part in this consultation that decisions were made before the consultation and invited processes of public involvement would not impact decisions on the LSC programme. From this fieldwork, it was clear that two outcomes emerged from this public consultation: mistrust from the public directed at the LSC leaders and public opposition to the LSC programme, both experienced for years following this consultation. This will be unveiled through the remainder of this chapter, and Chapter 6.

“Under this Government Strategy called [the LSC programme], the local CCG, claimed they were holding consultations with members of the public, who use NHS services within the area. Unfortunately, they came not with an open-mind to find out what the locals, who use the services, what services they use, and the withdrawal from those services, the effect it will have on them and things like that. Unfortunately, the way I put it is that they came with their own pre-planned agenda, and the decisions had already been made. So, the false consultation was unproductive from the point of view of local residents and the services they use.” (Member of the public 01 – Grandvalley)

“Generally, the consensus was that [the public] didn’t want them closed. Everyone. No matter what was said [by LSC leaders]. Basically, it was like the meeting I told you about. ‘This is what we are going to do’, that’s what they are proposing but it was already fait accompli. I think it was only because of the involvement of Bluehill and Grandvalley councils that they got the closure date pushed back to 2021.” (Member of the public 02 – Bluehill)

“[LSC leaders] were using this public consultation to just tick a box. I don’t know who they were ticking the box for. But it wasn’t for us. And I think it was someone high up in the government that tried to sort of put it over that you’ve got to use patient and public involvement in a constructive way. And I think they’ve done it just as limited as they can, and not take as much. […] We just knew that this was decided before they ever came to talk to us. […] And it came near the end, it was coming to the point where I was like, it’s not worth going [to consultation meetings]. These plans are already drawn up.” (Member of the public 03 – Bluehill)

“At that stage the NHS became almost quite entrenched and not really engaging with people who were concerned about the hospital.” (Healthwatch 02 – representing Bluehill at the STP level)

Some participants explained that there was a lack of feedback to the public from LSC leaders after this consultation on the outcomes of public involvement and implemented changes. This was echoed by recommendations to LSC leaders provided by the Independent Reconfiguration Panel in 2013 that highlighted the need to shift their approach from communicating to the public what was going to happen to an active engagement in co-designing and evaluating services. According to documents from 2015, the Heathwatch in Bluehill expressed that the “process of engagement with the public has been very
“So, you know, once you’ve done a consultation like this and you start making changes, and they don’t work, you’ve got – if you’re going to carry the people with you – then you’ve got to debate these things.” (Campaigner 04 – Grandvalley)

“I think that was also one of the problems from [this LSC programme], I don’t think there’s anywhere near enough feedback to patients about the outcomes of the changes that were made. Patients were put into difficult situations which involved more travelling, more difficult places to reach and that sort of thing, but they never really got any sort of end result as to… Because they did that and helped the thing to happen, you know what benefits actually came out of their efforts? And that, I think is one of the messages I always try to get across to all meetings.” (Healthwatch 03 – representing Grandvalley at the STP level)

When I started my fieldwork, no public consultation had taken place in the region since 2012. For most of my fieldwork, this was the case; and thus, members of the public who wished to take part in invited involvement regarding the LSC programme had a limited choice of avenues. Indeed, the public wishing to be involved could only do so by attending meetings in public held by different actors such as: their local or the regional Clinical Commissioning Group (CCG) governing body; their local council’s Health Overview & Scrutiny Committee or Health & Wellbeing Board; and/or their local Trust’s board meetings. Residents of Bluehill could further take part in public engagement workshops. Over the next few sections, I describe those invited avenues available to members of the public who wished to be involved in the LSC programme.

5.3.3 Engagement: CCG meetings in public

When asked what methods were used to engage with members of the public, practitioners of involvement and the LSC leader mentioned CCG meetings in public as part of their engagement methods. However, when asked why the CCG meetings were held in public, the LSC leader interviewed responded that, as part of their constitution, “CCG governing bodies have an obligation to hold a certain number of meetings in public”. This suggested that CCG meetings in public were not designed primarily for the purpose of engaging with the public.

Local CCG governing body meetings took place every few months. For a member of the public interested in attending a CCG meeting, they could find out through their CCG website when meetings were taking place and could download the meeting papers from the website. However, time and/or venues were sometimes only confirmed a day or two before the meeting; (the large amount of) meeting papers – which were not adapted for lay people – were often only made available a day or two before
the meeting. Sometimes meetings were cancelled or rescheduled at the last minute without an explanation. My observations were confirmed by several interviewees, some (including a practitioner of public involvement quoted below) further suggested that the meetings in public were deliberately made difficult for the public to be involved.

“When we started going to the CCG board meetings — as you know they can be quite tedious — there was a lot of frustration from campaigners at these meetings. They were meetings that were not public meetings, but meetings held in public, so that it was hard to take part. And because papers were only available online a couple of days before, or at the meeting, and hard to follow, and they were very procedural sort of papers, very hard to make sense of particularly if you didn’t come from a background where you’d had to deal with board type papers. Meetings can get very frustrating and some people would start showing and well, I mean I guess a lot of those people stopped going and started saying ‘why do you go? It’s a waste of time’. Some of us who are more used to working in those contexts took a deep breath and said ‘we’ve got to do this, we’ve got to find out what’s going on, and put up with the tedium.’ But it took a long time. It took a long time to learn what sorts of questions to ask. It took a long time to get a feel for the meeting and it certainly took an even longer time for people on the board to realise that we did have questions to ask that were… They were usually hostile but weren’t stupid [laughing]. […] We had to find questions that tried to show the weakness in their campaign, in their plan, and we worked very hard at that and my God it was tedious and boring at times, but you did have to look for weaknesses.” (Campaigner 05 - Bluehill)

“The papers, well as you know, the NHS is very, very bad at producing any papers that anybody from the general public can understand and, they are all too long. […] The papers are written in such a way that it’s almost impossible for people to really take part in them. There’s a lot of, I know what it’s like, there’s a lot of loading up of papers to try and make it difficult. I mean people wouldn’t say it, but you know you get twelve appendices in a paper which actually just needs to be a short paper because there’s a view that if you load it up basically people won’t spend too long on it.” (Practitioner of public involvement 01 – STP level)

CCG meetings took place in two parts: the first part of the CCG meeting was not open to the public whilst the second part was. As reiterated several times by the chairs of the local and joint CCG when opening the public part of the meetings, these were “meetings in public and not public meetings”. The set-up of the CCG meetings was similar in Grandvalley and Bluehill whereby tables were arranged in a U-shape with a few chairs facing the open-end of the table for the public. All members of the CCG governing body had their names in front of them as well as microphones. Twenty to thirty minutes were left at the end of the meetings for questions from the public that were supposed to be lodged at least 24 hours in advance (although in most instances I observed, this rule was not applied). Sometimes, the chair would call the meeting to a close before taking on questions from members of the public. The main actors actively taking part in the meeting were the chair, the managing director and the STP accountable officer. Most of the meetings seemed, from the perspective of sitting with the public, as if
the items presented were just for noting and not up for discussion. In the meetings I observed, the only actors asking questions and trying to have a critical discussion were some of the lay members. With the exception of one meeting I observed in Bluehill, the GP members of the governing body did not speak during the meeting in public.

“Well the first meeting I went to a few lay members said something and nothing else basically.”
(Practitioner of public involvement 01 – STP level)

The lay member I interviewed explained that the lack of critical discussion during the meetings in public was because the “real meeting” had already taken place in the first part not open to the public:

“Yes, but that’s because those meetings are pretend meetings, because the real meeting has happened before in private. [A lay member in Bluehill] she kind of does a [chuckling] rehearsal of the arguments that have gone on before, because she is… I remember her saying that she thinks it’s important that for the public meeting, we rehash some of the same issues. […] They hold the real meeting in private. And that’s why when you come to the public meeting, there’s no debate, because all the debate has been had. Which is why having meetings in public, is a waste of time.”
(Lay member – STP level)

The presence of the public was not always acknowledged by the chairs or other members taking part in the meeting, with the exception of some of the lay members who often turned towards the public when they spoke. The CCG meetings were not well attended by the public, with usually only a handful of members of the public in presence, which happened to be ‘Save Our Hospital’ local campaigners in the meetings I observed. One of the practitioners of public involvement interviewed attributed the lack of attendance to meetings taking place on weekdays, when most members of the public were at work:

“How the nature of it CCG meetings are held at the time that most people can’t go to them and you know why? This is because the staff don’t like working evenings. […] When you look at who goes to the CCG meetings we are not surprised that they are mainly elderly people basically who are retired.”
(Practitioner of public involvement 01 – STP level)

Additionally, in Bluehill, a few local councillors as well as a local journalist sporadically attended the CCG meetings. Questions from the public were sometimes passionate and confrontational, an element omitted from minutes of the meeting. In essence, participants interviewed who had attended CCG meetings, expressed that this is a limited forum for public involvement, with little opportunity for discussion with LSC leaders.

“They may think they are [involving us], but they don’t work. No, I mean you sit in CCG meetings in the public, you wait two and a half hours to get them to answer your question. You know their attitude to us is that we should go away, they don’t want to answer difficult questions.”
(Campaigner 06 – Grandvalley)
“You sit at the back and you are barely allowed to ask a question. And yes, it’s not a public meeting, it’s a meeting in public and who in their right mind apart from the dearly dedicated souls is going so sit there? I mean, I don’t even want to go myself and I have to go [laughter]. You know these meetings have a particular format, a particular purpose, you can barely ask a question, it’s never going to get answered or responded fully you know. I find working behind the scenes better.” (Healthwatch 01 – Grandvalley)

“I don’t know what you thought of the meetings, but I find them quite… they are not very stimulating. It’s difficult to get debate going, I mean people say something, but not much if you know what I mean. And there seems to be a kind of let’s get through it, tick the box, we’ve done the business, tick that box, tick that box, tick that box and then let’s go home basically and well let’s add the half an hour for the patients and then we could tick the box and that we’ve done it. […] At the moment it’s too token, it’s tokenistic. The other week most of the questions [by the public] weren’t answered. They are not really answered, they are, you know, they’ll come back to you maybe, but they’re not answered really. They are the usual fluff that people say whereas it would be better to say: ‘I can’t answer your question’, ‘I don’t know’, ‘I’ll come back to you’ or ‘I do know and it’s going to be unpleasant’. But people don’t really want to do that, do they? So, they don’t.” (Practitioner of public involvement 01 – STP level)

My observations of CCG meetings in public were in line with my participants’ accounts. Mirroring the comments made the campaigners, the Healthwatch staff, the lay member and the practitioner of public involvement cited so far in the above quotes, that meetings felt staged, presenting decisions already made elsewhere. The meetings were not designed in their format or in their setting for deliberations with the public and LSC leaders seemed reluctant to provide proper answers to public questions. For example, during one of the CCG meetings I observed in Grandvalley, the Chair repeatedly said “we will take this out of the room” or “we will get back to you” whenever a difficult question was asked about the LSC programme by a member of the public. Notably, based on the LSC leader’s response quoted at the beginning of this section, CCG meetings were held in public primarily to fulfil obligations of public transparency rather than involving the public, despite being considered by LSC leaders and practitioners of involvement as a method for engaging with the public.

The joint CCG meetings at the STP level were similar except that they were video recorded and then made available online “for transparency”. Several respondents, as illustrated by the quotes below, viewed both local and joint CCG meetings in public as a “performance” or a “staged window display” where “decisions are made backstage”.

“It is about putting on display a show but actually all the decisions are being made backstage.” (Healthwatch 04 – Bluehill)
“You see before the joint CCG committee [in public] there’s a meeting of the Chair with the Chairs with the Accountable Officer every other week. And a meeting with the Accountable Officer and the Chairs and the managing directors every other week. So, I think there is quite a lot of that – which is typical of the NHS – where actually things have been decided outside of meetings.”
(Practitioner of public involvement 01 – STP level)

“There’s a front stage and a backstage.” (Practitioner of public involvement 02 – STP level)

“INT: When you sit on that [joint CCG] committee, does it mean that you get access, for example, to all the papers even though they are confidential, or do you get the same as the public?
RES: No, I get all the papers, I’m not a voting member I said that I didn’t want to be a voting member because [Healthwatch] want to maintain that position of independence.
INT: So, you still can know what’s happening before the plans are being …
RES: Yes, except that to be honest, I mean a lot of what goes on actually goes on outside the meeting. So, I would have access to anything that was coming and being performed at the meeting. But there will usually be, well there is a regular meeting of the chairs of the CCGs, which isn’t a public meeting and which we don’t attend and that is where things are thrashed out.”
(Healthwatch 02 – representing Bluehill at the STP level)

“But definitely, genuine conversations – that’s always going to be the case, if you have a public meeting – the genuine conversations happen somewhere else.” (Lay member – STP level)

5.3.4 Engagement: Lay representation

Another way for a handful of members of the public to be engaged was to apply to be a lay member of the local CCG governing body. From my observations, it would seem that all the lay members I encountered during fieldwork were also contributing to various other NHS groups. The joint CCG also included a few lay members, selected from lay members already contributing to one of the CCGs covered by the STP footprint.

In the context of these case studies, it was difficult to understand the role of lay members, in particular regarding the LSC programme. From a local job advert for a lay member it would seem that the role of the lay member is to “help ensure that the interests of patients and the community remain at the heart of discussions and decisions; decisions are taken with regard to securing the best use of the public money;[…] the CCG is responsive to the views of local people and promotes self-care and shared decision-making in all aspects of its business.”

Some of the respondents also raised that they were unsure of the role of lay members:

“There seems to be a problem here with lay members, the lay members not being clear what their role is or what they are supposed to be doing or what they are not supposed to be doing.”
(Practitioner of public involvement 01 – STP level)
"Well I often, I honestly don’t know what their role is to be honest. And I think they are too cosy with the CCG, that’s my view. They’ve become part of a system and so they defend it rather than being a critical friend within, so I honestly don’t know what their role is." (Healthwatch 04 – Bluehill)

The idea that, as part of their role, lay members should be critical members of the CCG was also raised by several campaigners. Indeed, they considered that the role of lay members was to be critical of the evidence for change put forward by LSC leaders. They further questioned how lay members were recruited and their representativeness of the general public. For Grandvalley campaigners, the role they envisioned as critical and accountable to the public was not being fulfilled by their local lay members, described as “people who are willing to say yes”. On the other hand, the Bluehill campaigners acknowledged that their lay members in the last few years had been more critical in meetings in public. The lay member interviewed similarly alluded to being critical as an important feature of the lay member role:

“But patients like me, the more you do engagement, you end up having the perspective of the NHS and you lose the perspective of the patient. So, the better you are to work with, the easier you are to work with, the more everyone feels that it works. It is because you’re no longer interfering with the process and you understand the argument and all of that. And therefore, you stop adding value.” (Lay member – STP level)

Some of the local lay members as well as representatives of local Healthwatch groups were further invited by the STP leadership to form a “lay partner group” that met monthly and could engage directly with LSC leaders at the level of the STP. Their role in terms of representativeness was difficult to pinpoint in this forum. When asked if the role of the lay member in this group was to represent the catchment area of their CCG at the STP level, the lay member replied:

“I think in reality no. I think there is an element of that, because I’m a patient [of my CCG], but I think I do it more in terms of my role as, for the BME Health Forum and representing BME groups. I think that’s why they want me there. I think that’s the box I tick.” (Lay member – STP level)

While observing one of the STP lay member meetings with practitioners of involvement and LSC leaders, I noticed the lay partners were quite critical in that setting and did not seem to hesitate to ask difficult questions to the LSC leaders presenting to their group. Three interviewees who were members of this lay group felt they could directly interact with LSC leaders but with little or no impact on decision-making. They expressed having more impact when fulfilling a substantiation and verification role (as described by one of the studies included in the scoping review – see section 4.6), anticipating potential public concerns regarding the plans and developing information materials.
“Well we had the guy who runs the engagement side... He came to our last meeting, and so they come to ask our opinions. We give our opinions and recommendations and they take them away and hopefully implement them. So, we don’t actually set things ourselves, we don’t have an authoritarian role like that, but we are a sort of a recommendation and engagement and, that side of things.”

(Healthwatch 03 – representing Grandvalley at STP level)

“And I was like, ‘No don’t say that to patients, don’t do that’. So that’s what I mean, so you have an impact in terms of attempting to save the reputation of the CCGs, where you only say: ‘You’ll be slaughtered alive if you go out to the public like that, let me tell you that you’re an idiot now, so that when you go to the public, you do a better job’. Is that having an impact you know [chuckling]? I mean I think sometimes we kind of help in terms of reputation of the CCGs, because they can try things out on us, before they try them out on the general public.”

(Lay member – STP level)

In contrast, practitioners of public involvement interviewed disapproved of the lay group as a choice of involvement methods; criticising the resources spent on a small group, familiar with NHS language and not always representative of the wider public. This reinforces the notion that this lay group was set up by LSC leaders to fulfil a role of substantiation and verification. Consequently, this lay group was not envisioned by LSC leaders as a space for deliberation with lay people familiar with the NHS language and potentially with the ability to engage in-depth on the technical aspects of large-scale change.

5.3.5 Engagement: Public engagement workshops

In Bluehill, members of the public could also be involved via a series of public engagement workshops organised by their local CCG. The topic of the workshops was the financial situation of the CCG but over time those workshops evolved into a backdrop for pre-consultation engagement about plans for change to the local Urgent Care Centre and GP out-of-hours provision (see section 5.3.8). The workshops lasted three hours and took place during the week, in the daytime.

In reality, members of the public would find it difficult to be involved in this forum. The workshops were poorly advertised, or not at all. After months following the local CCG website and social media and attending their meetings in public, I did not know about those workshops. I discovered the engagement workshops were taking place during observations of the local campaign’s monthly meetings, as did the local politicians interviewed. This lack of advertisement was reflected in the workshops I attended where the ‘members of the public’ present were either campaigners, Healthwatch, representatives of a local charity, local councillors or lay members that I had seen (except for the charity representatives) in other meetings. At one of the workshops I observed, it seemed that there were more members of the public in attendance than usual and that they were not from the categories described
above. At the end of the workshop, I realised they were CCG staff who were not wearing their NHS lanyards. This was also noted by a campaigner who attended an earlier workshop:

“Actually, the one I attended nearly a lot of the people were CCG members almost and they were just keeping quiet about their work and they were there to make up numbers it seems […]. And they weren’t all wearing their NHS ID.” (Campaigner 07 – Bluehill)

One of the practitioners of involvement interviewed was also conscious that the public invited to workshops was made of “regulars”, identifying this as a barrier to meaningful engagement with the local population:

“But we are still asking the same people [to attend workshops] and that is not engagement, that is not democracy, that is not ensuring that your population… Well, you are failing on your duty to involve and engage. If we organise a workshop in the NHS and we get ten, fifteen people that turn up or say if we get thirty people turn up, I guarantee you 80% of them I will know and that’s a problem. That’s a problem you know.” (Practitioner of public involvement 02 – STP level)

Additionally, the content and format of the workshops were not adapted to a lay audience despite the workshops being supported by practitioners of public involvement (with a background in communication and/or public engagement). As an example, the first workshop I attended was a lecture rather than a workshop. The slides were not suited for a lay audience and their content was generally difficult to follow. It seemed that the slides used were from a presentation that was given with the NHS and had been re-used for the purpose of this workshop, an impression also recalled by interviewees who had taken part in the workshop. Twenty minutes were left at the end of the (two and a half hours) presentation for table discussion with CCG staff. It was further unclear how public workshops were to contribute to decisions that seemed already in motion or finalised and how the feedback from the attendees was captured by the CCG members. The CCG member leading the workshop presentation however, made efforts to speak clearly, avoided the use of acronyms and did not turn down any questions from the public. Several members of the local campaign and Healthwatch in attendance raised criticisms on the content and format of the day to CCG members during the workshop. It seems that those criticisms were taken into considerations for the next workshops that were improved to be better suited for a lay audience.

“I mean the first [workshop] I went to I don’t know if you went to it, it was terrible… They gave us this tiny printed table about the cuts as though, but as though they were a fait accompli sort of thing.” (Local politician 02 – Bluehill)

The campaigner reacted to that by saying that after the presentation she was sitting at the table with one of the ‘doctors’ (this was the CCG vice chair – that was the table I observed) and said ‘the doctor at our table he spoke when we finally broke up into little groups… and honestly it was

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no more than a big lecture’. (Field observations – Bluehill Save Our Hospital campaign meeting)

“INT: So, for example, for that particular workshop what would have been your recommendations to make it more lay friendly?
RES: I would have said: this is the overall budget, these are the things we have to do, these are the constraints, so clinical, safety, quality, this is what the variables are. These are the only areas in which we can effect change, so what do you think? Would you prioritise one rather than the other? Or this is what the NHS constitution says we have to provide, so now we are left with having to provide all those other things with this amount of budget. So that’s the inevitable conclusion, that we can’t do it all, we have to do it to a lesser degree. So, I think I would have done some presentations at the start and made the information that they provided more understandable. And then you could have done workshops around the table, but I would have also given it more time and have more space because that room is too small. I mean these are just simple things, aren’t they?” (Healthwatch 05 – Bluehill)

5.3.6 Engagement: Local council’s forums

In these case studies, although not initiated by LSC leaders, members of the public could further be involved by attending their local council’s Health Scrutiny & Overview Committee when the LSC programme was on the agenda. Occasionally, the LSC programme could also be on the agenda of the council’s Health & Wellbeing Board. Both meetings took place in public and members of the public could consult their council’s website for the dates, agenda and meeting papers.

In those meetings, unlike the CCG meetings in public, the public did not have to wait until the end of the meeting to ask questions and could ask questions at the end of each agenda item directly to the NHS representatives present at the meeting. The meetings were set up in a similar way to the CCG meetings. In Bluehill, a table with a microphone was set up for members of the public who would come and sit as part of the meeting whilst asking their questions.

Mirroring the regionalisation of the LSC programme, councils in the local authorities covered by the LSC programme created a joint Health Overview & Scrutiny Committee, convened sporadically, looking specifically at scrutinising plans for change. After the programme was dropped in 2019, the joint committee focused their scrutiny towards the case for change for the merger of their local CCGs into an Integrated Care System (discussed in section 5.6) in response to national changes (Figure 8). The joint council meetings took place in public; although the public could attend those meetings, they were not allowed to ask questions. Therefore, the value of those meetings for members of the public was to observe the scrutiny process and obtain information regarding the LSC programme, rather than as an opportunity to have a voice. Some of the local politicians I met during fieldwork informed me they were
trying to get those meetings open to questions from the public. In the meeting I observed, only Grandvalley campaigners were in attendance who, despite finding the fact they were not able to ask questions regrettable, considered those meetings a good source of information regarding the LSC programme, that they would not necessarily be able to get through CCG meetings or their local Health Scrutiny & Overview Committee meetings.

5.3.7 Engagement: Trust Board meetings in public

Finally, the last avenue for members of the public in these case studies to be involved was attending their local Trust board meetings in public. However, the local Trusts did not seem to be leading the LSC programme – at least at the time of my fieldwork – and therefore attending their meetings in public represented little value in the context of the LSC programme. In the meetings I have observed, the only members of the public present were local campaigners who used the Trust board meetings as a channel of communication with their local Trust about the LSC programme but also about wider issues as part of their campaigns (see section 6.3). On the other hand, this forum for involvement might have been more valuable for the public in the times leading up to the emergency department closures in 2014, the maternity closure in 2015 and the paediatrics service closure in 2016.

5.3.8 Engagement & Consultation: Changes in Bluehill – Improvements to public involvement but the same underlying issues remain

Towards the end of my fieldwork (see Figure 8), the CCG in Bluehill proposed plans that underwent public consultation to change the provision of the Urgent Care Centre – that had replaced the closed Emergency Department as a result of the 2012 public consultation – combined with changes in the provision of out-of-hours GP provision. This change was introduced under the umbrella of the regional LSC programme.

The Bluehill public consultation was preceded by an ‘engagement’ period of seven months referred to in CCG documents as the “pre-consultation engagement period”. However, the public consultation was originally due to start four months after the pre-consultation engagement started but was delayed by three months as the local CCG was waiting for NHS England to sign off on the consultation. According to CCG documents collected, it did not seem that any engagement activities with the public took place during those extra three months of pre-consultation engagement.

Of particular note during this period, the local CCG presented their consultation plans to their local Health Overview and Scrutiny Committee, at a meeting in public where local campaigners, Healthwatch staff and a journalist were present in the audience. At the time, the public consultation
was intended to start the following month. The local CCG and their practitioners of public involvement sought the views of the committee specifically on their consultation process and whether the committee felt that additional activities and/or groups of the public should be included. They additionally asked the committee for their advice regarding suitable venues for activities during the public consultation and whether they could use the council communication channels with local residents to raise awareness on the upcoming public consultation. Some of the committee members, as well as the local Healthwatch, mainly criticised the public consultation process for the consultation document produced by LSC leaders that they judged not suitable for a lay audience. Additionally, committee members explained the consultation document, that was over a hundred pages long and perceived to not be adapted to a lay audience (despite the inclusion of an executive summary), made it difficult to understand what the public was being consulted on – a point the local CCG disagreed on – and what services would be available if the plans for change were implemented. The local Healthwatch offered to collaborate with the CCG in order to help them improve the consultation document for the general public.

The LSC leaders, during the meeting, wanted to focus on the technical aspects of the public consultation. Their stated motivation for presenting to the scrutiny committee was “to ensure proper scrutiny as to the quality of the consultation”. Conversely, members of the committee kept bringing the topic back to the case for change, which they described as “cuits” that had already been decided. In response, the LSC leaders recognised that some of the changes were financially driven but argued that the proposals were up for discussion and that their decision had not already been made. The two main arguments put forward at this meeting by LSC leaders for closing down the Urgent Care Centre overnight were that:

- the service was underutilised by patients – an argument that the committee members dismissed by explaining that the service was underutilised not because of a lack of patient need, but by the lack of information given to the local population on what services were available out-of-hours;

- and from a clinical perspective, the Urgent Care Centre’s effectiveness was limited as it was not co-located with an emergency department – some committee members pointing out what they perceived was a contradiction since the centre was created in the first place as a replacement to the closure of the emergency department in 2014.

This scrutiny meeting became heated and confrontational over the case for change and the public consultation process. Whilst confrontation was often attributed to local campaigners in participant interviews, the confrontation in this meeting was led by the councillors and not by the campaigners. The only contribution of the campaigners during the debate was to highlight that the changes would affect primarily the people living in deprived areas who were not taken under consideration when the plans were being drafted and who were not a target group for the public consultation.
The public consultation – that lasted six weeks – was only advertised as it was starting (most likely because the CCG was waiting for approval from NHS England and could not plan accordingly). The report produced by the LSC leaders on the outcomes of the public consultation mentioned they had used varied methods to advertise the consultation to the public such as: their website, social media, emails to their networks, advertisements in a local newspaper, and by distributing posters in local GP practices, gyms, in community settings and during events. Yet, I found that the consultation was poorly advertised to the public throughout the consultation period. The public consultation was the main focus of my fieldwork at the time and I myself struggled to find out when and where consultation events were taking place, despite having an established network of local informants. My most helpful sources of information regarding public consultation events were the local campaigners (who encouraged members of the public to take part in the consultation) and the local Healthwatch whilst I found that LSC leaders mainly advertised their consultation through their website, displaying a list of consultation events not always kept up-to-date. In addition, public events consultation events were added at short notice, translating into poor public attendance at all consultation events I observed. For instance, I attended a public meeting advertised merely two days before it was due to take place, resulting in only three members of the public in attendance – all members of their GP’s Patient Participation Group or local Healthwatch. Furthermore, it was not clear from the list of events on the website which groups of the public were invited until late in the consultation period. In events open to all members of the public I observed, I expected to see more diverse groups of the local public, not affiliated with a campaign or an involvement group. However, in all events I observed, the public present was made of campaigners, Healthwatch staff and members, local charities and/or members of the public involved in their GP’s Patient Participation Group.

Nevertheless, the organisers of the public consultation did listen to criticisms during the pre-consultation engagement period (and during the scrutiny committee described above) about previous public involvement lacking community events. LSC leaders and practitioners of public involvement for instance relied less on public meetings and organised public workshops, street stalls in the community, focus groups and sessions at Bluehill Urgent Care Centre as well as a few closed events in the community targeted at specific members of the local community (e.g. religious, LGBTQ and BME groups). Additionally, the consultation document had significantly improved since the scrutiny committee described earlier. Via the local Healthwatch collaboration on the consultation document after the scrutiny committee, the document was reduced from 100 to 12 pages and used lay language along with infographics. Accessible versions of the new consultation document were also made available. The consultation document was accompanied by an 8-question survey for the public to complete, which served as the main channel for the public to voice their opinions on the plans for change, although it was possible to write directly to the local CCG. Organisers of the public consultation also listened to
some of the criticisms they received at the beginning of the consultation regarding who should be involved in the consultation. For example, at a public event I observed early in the consultation, local campaigners pointed out that ironically, as governance arrangements are shifting from local to a joint CCG overseeing NHS services for the whole region (see section 5.6), Bluehill CCG had failed to look beyond Bluehill and include in their public consultation neighbouring communities that also used Bluehill Urgent Care Centre. Local campaigners further pointed out to LSC leaders that plans to close Redtown Urgent Care Centre (which also replaced the hospital’s emergency department after its closure under the LSC programme) were being drafted by Redtown CCG. This was of importance as the Redtown Urgent Care Centre was presented in the consultation document as an alternative for patients if the overnight closure of Bluehill Urgent Care Centre was to go ahead. Those comments were taken into consideration as a few events were later added for neighbouring communities and it was later announced that plans in Redtown were put on hold until decision for Bluehill was made, after public consultation.

Public views on the plans for change were captured during public meetings through notes taken by practitioners of involvement on flipchart paper. In all events I attended during the time of the consultation, it appeared that all groups of the public had similar views on the change and opposed the closure of the Urgent Care Centre overnight. The common position held was that LSC leaders could not close a service intended to replace the local emergency department closed under the LSC programme given the service was poorly advertised to the public after its implementation. The public situated their view within the local context, arguing that LSC leaders had not included in their engagement and consultation process local communities experiencing more barriers to healthcare access than the general population.

“Not many of the residents in Bluehill are aware of [out-of-hours service provision] because there’s been no advertising or marketing done. And I can’t work out whether that’s because the CCG doesn’t want patients to use the service, so they save money, or whether they’ve just got no idea how to do the marketing. I mean they’ve done absolutely nothing in terms of advertising that really apart from posters in GP receptions.” (Local clinician 02 – Bluehill)

“Consultation. At present, the CCG are saying they plan to fully consult on their cuts proposals. It is not clear just what this might mean, and they seem to want the council to resolve this issue for them! We need to be alert, particularly for those in the north of Bluehill where there are larger concentrations of poverty, of more culturally diverse populations, of those with shorter life expectancy and of greater concentration of those without English as first language. Consultation needs to go beyond voluntarily groups funded by the CCG.” (Bluehill Save Our Hospital campaign meeting document)
Two of the practitioners of involvement interviewed, involved in this consultation, also shared this view and criticised the lack of communication between decision-makers and the public. In light of poor communication with the public, one of the practitioners interviewed actually described going ahead with the change as “immoral”:

“Now how can we close a service or how can we change a service if people don’t even know exist? Just say it was about urgent care and you say: ‘we are looking to close a section of urgent care from this hour to this hour because no one uses it’. Now if the majority of those patients said: ‘I didn’t even know it was there’, you know it’s immoral to say you are going to close something if you hadn’t promoted it successfully. And you’ve got to assess whether you’ve promoted it successfully in the first place, then you’ve got an argument – if no one uses it – to say: ‘well no one uses it and we know we went out, we know we did all this’. If you just leave posters on walls and leaflets and think that is communication and people know about it, well you are deceiving yourself …” (Practitioner of public involvement 02 – STP level)

Many consultation participants suggested an alternative to postpone a decision for a year, during which the LSC leaders could focus on informing the local population about their options for out-of-hours service provision and reassess then utilisation of the service. This was not perceived as a realistic course of action by LSC leaders present at those events, as illustrated by this quote on the topic from a LSC leader at the STP level:

“The Bluehill Emergency Care Centre is mitigating point. So, the Bluehill Urgent Care Centre sees a very small number of patients during the night time period and the cost of seeing those patients is more than if they’d have just gone to the A&E department. To me, that represents a demonstrable case of poor value for money when these services are easy access. But clearly not everyone thinks the same way, and they sort of… The suggestion back seems to have been: ‘well you should publicise this more, so people use it more’. And if our role is to encourage people to attend Urgent Care Centres… It just infuriates me. So, I accept we’re not going to reach an aligned view on that.”

The main concern amongst all groups of the public I observed was that a closure was likely to worsen existing local health inequalities and that the extra travel time at night would negatively impact disadvantaged groups more than others. The public in attendance put forward several examples to illustrate their concern such as: the deprived population living at the doorstep of the Urgent Care Centre would have to travel more; the area, with high knife crime, was unsafe for women, youth and other protected groups to travel at night; the public transportation at night was limited and did not match the consultation document’s predictions on additional travel time; disabled patients and their carers would have difficulties reaching alternatives locations at night. The local Healthwatch reported similar findings and one of the practitioners of public involvement interviewed after the consultation took place also confirmed most groups of the public they had interacted with shared these views:
“So, they were happy to do [the survey], but of course as I said earlier, not happy with the consultation. Hardly anyone, maybe a few white English middle-classes, I would say, supported the consultation because of the finance. And of course, I understand why, because they probably haven’t got any problem or trouble, they probably all have cars and they don’t have the travel problems to get to somewhere else. But 90%, 80-90%, of the population of patients we spoke to, they are just not happy. They don’t support this.” (Practitioner of public involvement 03 – STP level)

Additionally, all groups of the public I observed during the public consultation mentioned that they did not trust that plans for change under consultation were supported by clinical evidence. They instead perceived the proposed changes as the LSC leaders’ response to central pressures for financial savings. Feelings of distrust towards LSC leaders (but not towards practitioners of public involvement – see section 5.4.2) ran high during the consultation, resulting at times in a confrontational tone from the public in attendance. It was clear from observations and interviews, that those involved in the public consultation were cynical of the public involvement process as they believed that decisions for large-scale change in the region were always made before consultation. They further thought that given the financial imperatives behind the change, it was unlikely that the public consultation would impact decision-making.

“RES: I also know with absolute certainty that those services are closing.
INT: Why is that?
RES: Why they are closing?
INT: Why do you know that the services are closing for sure?
RES: I’ve seen the financial arguments for closing them and I am certain that this is going to happen. The Urgent Care Centre, they say is being used by five people every night on average, there’s no way that’s going to stay open. […] So, I feel that engagement works better when there is money and we are talking about how to make services better. That works better than when we are talking about closing services, because we are in situations where the financial arguments are overwhelming and therefore, very little else matters. […] I kind of think that there should be some kind of threshold on engagement, where people think: ‘are we genuine? What are the chances that we are not going to do this?’ If there is like 30% chance that we won’t do this, then fine, go and consult with people. But if, as it is in this case, it’s like non-existent then why are we bothering? To which [a practitioner of public involvement]’s argument is: ‘but there might be, what people say, there might be mitigating argument’. I mean I think especially with the Urgent Care Centre, there isn’t going to be any mitigating action whatsoever.” (Lay member – STP level)

“This is what we’ve said of so many consultations: it’s not a consultation if you’ve already decided what you’re going to do. So, what we did say to [the CCG] is: ‘okay then so we do this survey what happens if the answers which come back are not to your liking? Are you going to take notice of the public? Are you going to look again? Or are you just going to say: oh well, there we are. If you’re going to do that, there’s no point in having a consultation.’ We [Healthwatch] are assured that the views of the public will be taken into account when making future policy… watch this
space. Forgive me for being cynical but… Well I’m cynical because we’ve seen it happen so many times in the past, they’ll talk of localism, local participation and when push comes to shove forget it.” (Healthwatch 04 – Bluehill)

Some consultation participants explained at early consultation events that the timing for decision-making exemplified their sentiment of distrust. Indeed, at the onset of the consultation, it was advertised that decision regarding the plans for change was to be made during a CCG meeting in public two weeks after the end of the consultation. After repeated criticisms from several members of the public (and local councillors) that this would not leave enough time to process public inputs – hence confirming for them that decisions had already been made – LSC leaders announced during a public event I observed that decision was postponed to another CCG meeting in public, without providing a new date. During consultation events, the public was informed that by providing their email addresses they would be kept updated about the consultation process and outcome, including the new date for the CCG meeting. Having provided my email address at all events I attended, I never received anything regarding the consultation. The CCG meeting in public where the decision was announced took place seven weeks after the consultation ended but was only advertised on the CCG website a few days beforehand. Only a handful of local campaigners and Healthwatch were in attendance.

In summary, despite improvements in the (invited) consultation process (e.g. more community events, consultation document suitable for a lay audience) and a commitment to listen to different actors’ (e.g. local councillors, local clinicians, local campaigners) views on the consultation process, some fundamental issues persisted since the initial consultation in 2012:

- a lack of representativeness of the public involved in consultation events open to all, in particular the wider public (i.e. not involved in Healthwatch, a Patient and Participation Group or the local Save Our Hospital campaign) and population groups already experiencing healthcare access inequalities and/or groups most likely to be impacted by the change;

- mistrust of the public (and other actors such as the local Healthwatch or the local council) whereby LSC leaders were perceived to push for change for financial reasons rather than a clinical rationale. This mistrust was compounded by the fact that the second consultation in Bluehill focused on the Urgent Care centre, a structure was put in place to replace the emergency department closed as a result of the first regional public consultation;

- a tokenistic process for invited involvement where decisions for change were perceived to have been made before public consultation.
5.4 Actors involved in invited processes of public involvement

Having described the main forums for invited involvement in Bluehill and Grandvalley, I now turn to the main actors in invited processes of public involvement that I identified as: the LSC leaders, the practitioners of public involvement, the public, the local Healthwatch organisations, the local councils and the clinical community.

5.4.1 LSC leaders: not visible & not trusted

Early on in my fieldwork, through document analysis, observations and interviews, I attempted to uncover who were the LSC leaders driving the LSC programme. At the start of the programme, it seemed clearer as some of the LSC leaders became the faces of the programme during the initial public consultation. In the initial public consultation document for instance, the foreword was signed by the chairs of each CCG in the region and by the programme’s medical director who introduced themselves as a local GP. Beyond this, it was not clear who else was driving the change and what role the local Trusts’ executives played in the leadership of the programme. At the time of my fieldwork, it was more difficult to identify who was leading the LSC programme as there had been a high staff turnover during the lifetime of the programme (only one LSC leader identified in the initial consultation document was still involved in the programme during fieldwork). The extract below taken from a 2015 report on the LSC programme by an independent commission indicates that it was not clear for local actors either who the LSC leaders were:

“Through the course of the public hearings there emerged a widespread confusion as to just who or what is driving the [LSC] programme and who is responsible for making major decisions on implementation and delivery. The evidence of NHS witnesses suggests that this responsibility is split across, yet shared by, a coalition of the eight CCGs. This does not explain, however, the role of the NHS trusts, which also seem to be making decisions of their own on closure or expansion plans that may, or may not, be directed by the CCGs.”

Strengthening their sentiment of distrust, participants in several interviewees questioned at what level of the NHS decisions were made and by whom, unsure whether or not the LSC programme was being pushed by the central government or if the programme was entirely regionally led. When asked about pressures from NHS England or from the central government, the LSC leader interviewed responded that there were none.

“And that, then, makes me wonder who is actually in control? With [the LSC programme], I never knew who was in control. I never knew who was calling the shots. I never knew if it was coming from government level or who was actually deciding. And that is terrifying, when you actually see that you are heading towards an iceberg, or you are heading off a cliff edge, and nobody knows who’s in control. And when you’re in that situation, then you don’t trust.” (Local clinician 01 – Grandvalley)
Whilst unclear for local actors who the decision-makers were in the LSC programme, in the field local commissioners in Bluehill and Grandvalley alongside the executives at the STP level (commonly referred to as “NHS bosses” by the public, particularly the campaigners), embodied the leadership of the LSC programme for local actors. Distrust of LSC leaders was a recurrent theme across all interviews when discussing invited involvement. As described in sections 5.2 and 5.3, invited processes were controlled by LSC leaders. By choosing a top-down approach to conduct public involvement as well as to implement the change, LSC leaders reinforced local opinions that they could not be trusted. Indeed, documents not suited for a lay audience across all forums of invited involvement; limited engagement opportunities; paternalistic attitude from LSC leaders in their interactions with the public and their dismissal of alternative evidence; cancelled meetings in public at short notice; meetings in public as a performance where deliberations and decisions were made backstage; decisions perceived as already made because of the timing and format of public consultations; are all elements that fed, in those participants, a distrust towards LSC leaders, that did not fade over the LSC programme lifetime and still persisted after the programme ended.

Distrust was further fuelled by a perceived lack of transparency from LSC leaders regarding the clinical and financial evidence underpinning the LSC programme (see sections 5.2 and 6.3); suspicions that the regional and local changes were driven by the need to cut costs pushed by the central government rather than improve services; the use of consultancy firms in designing the LSC programme; the lack of clarity regarding who was leading but also who was accountable for decisions related to the LSC programme; and evidence that services closures put additional pressures on other services in the region.

“It seems to me obvious that [LSC leaders] can’t be trusted, because the plan that they came up with was so abysmally wrong. So, the fact that they have been presented with good evidence for not pushing [the LSC programme] ahead and still seem determined to, just says to me that there is either more to it than meets the eye than what they are saying, or they are actually not to be trusted with the evidence. Because the evidence should be telling them not to do it as well as us. So yeah because of that really, and because it just has felt like a very high-handed approach throughout.” (Member of the public 04 – Bluehill)

Invited processes of involvement compounded by distrust towards the LSC leaders triggered in Bluehill and Grandvalley agonistic responses to public involvement with some heated involvement activities, public protests, a multitude of petitions, creations of ‘Save Our Hospital’ campaigns, and the involvement of local politicians to oppose the LSC programme (see Chapter 6). The LSC leader interviewed acknowledged that distrust made invited involvement more difficult. But in the LSC leader’s
opinion the distrust experienced came from “a sceptical public who find it hard to believe an NHS manager would ever be interested in anything other than saving money” and not from the way invited public involvement was conducted in the case studies nor from a perceived lack of transparency from LSC leaders.

Exemplifying several interviewees’ feelings of distrust and invited involvement not being genuine, a confidential joint CCG internal document was leaked to local campaigners and to the press after the LSC programme was dropped. According to news articles, the document acknowledged that the LSC programme had failed and offered a plan on how to “spin” the failure by referring for example to improvements in maternal and child care in the region. Of particular interest regarding public involvement, the leaked document included a crib sheet, aimed at LSC leaders, on “how to reply to [the LSC programme] questions” that could be asked by members of the public during involvement activities regarding the LSC programme failures. On difficult questions, for example related to accountability of the programme, the crib sheet did not include much besides a ‘no’ or a question mark.

5.4.2 Practitioners of public involvement: pushing for meaningful involvement

Practitioners of public involvement were actors in the case studies, conducting engagement and consultation activities around the LSC programme, but had no influence in its decision-making. Practitioners of public involvement interviewed and observed during fieldwork had a background in communication and/or patient involvement and appeared to press for more meaningful involvement of the public. This was evident in Bluehill for instance when engaging with the local scrutiny committee on better ways to reach and involve the local population around the consultation and when increasing community forums during the consultation rather than just rely on public meetings. All practitioners interviewed further conveyed how they pushed for involving more diverse groups of the local population, for conducting more activities in the community and for avoiding the use of NHS jargon. One of the practitioners interviewed provided the example of how they had to push LSC leaders, so practitioners could conduct consultation activities directly in the Urgent Care Centre, since it was the focus of the public consultation in Bluehill, in order to collect the views of users of the service who would be affected by the change.

Hence, if practitioners of public involvement interviewed felt using different approaches to involvement was more appropriate, they described not having the power to challenge governance structures. One practitioner interviewed additionally gave an example of how another practitioner regularly used legislation on public involvement as a tactic to push for more meaningful involvement with the results of getting the LSC leaders “to do more things and to take into consideration more things than they otherwise would”. Another tactic described by two practitioners interviewed was to adapt on their own
some involvement tools when interacting with the public. For example, they explained that surveys used to capture the public’s views were not always suitable for lay people. As a result, rather than just distributing the survey away to people, they preferred to conduct “a mini-interview” with respondents during which they included the survey questions “in the conversation” in order to help clarify the survey questions or its topics.

Practitioners evoked being further limited by the “secretive” nature of the NHS and by the rushed and tight timing imposed on them regarding public engagement and consultation; as one practitioner interviewed described: “what we do when we engage is we engage because we have to do it yesterday”. Additionally, two practitioners interviewed further explained that they were not always informed on the outcomes of involvement activities they conducted, as after their analysis of involvement inputs, they would provide a report to LSC leaders and would have to move on to the next project.

Several campaigners, Healthwatch members, local politicians and lay members acknowledged during interviews and observations the efforts made by practitioners of public involvement. I further observed during engagement and consultation activities led by practitioners of public involvement that the public present was much less confrontational than when they interacted with LSC leaders. Several members of the public explicitly expressed that their criticisms of the public consultation were not directed at the practitioners but at the LSC leaders.

“In the NHS, there are those that want to do public involvement - usually those with a communications background, and those who don’t - usually the decision-makers.” (Local politician 01 – Bluehill)

“It’s not [the practitioner of involvement]’s fault that she does all this work that will lead to nothing. I really feel like I should stop telling her that it will lead to nothing, otherwise I would tell her every time I see her. But she does her bit to the absolute best, and they get meaningful feedback from hard-to-reach people.” (Lay member – STP level)

The three practitioners involved were quite critical of invited involvement processes, as evidenced in quotes throughout section 5.3, confirming the experiences of members of the public. They all described that in the case studies, public involvement was treated as a tick-box exercise during which the public’s views were not taken into account. It was clear from the interviews that this made them feel disillusioned with invited public involvement:

“And the other issue from my point of view is most of the stuff about patient engagement is rhetoric over reality in my experience. Real involvement of patients is I think pretty rare. If I hear the phrase ‘we put the patient at the centre of everything’ again I think I’ll be sick because it’s generally not true. […] I’ve seen that in my experience in the NHS, either people are consulted when the decision
has already been taken or when the decision is so self-influenced it’s hardly worth consulting anybody anyway.” (Practitioner of public involvement 01 – STP level)

“If [the UCC] really closes down, that means they haven’t listened to the patients. That is my view. I can’t say it out loud to [the LSC leaders], because myself, our team, we can’t decide for them. We work for the commissioners, but we just help them around engagement basically. But, if it really closes down that means they haven’t listened to the patients, they have already made a decision, that is just a tick-box thing which they have done, which is not right. And, what was the point of us doing [the consultation]? You know because it is not easy to go out and talk to patients and get to the people where we really hardly do, you know it’s really hard to reach them. So, it is difficult for us as well, it is not successful for us either.” (Practitioner of public involvement 03 – STP level)

5.4.3 The public: issues of representativeness

As described in section 5.3, during fieldwork I observed that the public present in invited involvement activities, especially during engagement, was mainly made up of ‘Save Our Hospital’ campaigners, lay representatives, Healthwatch members and sometimes local politicians (in Bluehill). Mirroring the findings of the scoping review (see section 4.4.1), issues about the representativeness of the public were raised by a majority of interviewees.

Firstly, according to the LSC leader, two practitioners of involvement and three Healthwatch respondents, campaigners were overrepresented in invited public involvement and were the most vocal group of the public involved. In particular, the LSC leader, one practitioner of involvement and one Healthwatch respondent believed that the campaigners’ view on the LSC programme was only one amongst a whole range of public views. They acknowledged the need to widen who was involved, for the purpose of “diluting” or “balancing” the campaigners’ views. However, from my observations, it did not come across that LSC leaders were taking steps towards involving the wider public; except during Bluehill consultation when practitioners of involvement pushed for involving service users and minority groups (for example by conducting a consultation activity in a local mosque). Additionally, in Bluehill consultation, views seemed uniform across various groups of the public involved and campaigners were not always the most vocal against the change during the activities I observed. Taking the stance that campaigners were a group of the public overrepresented in invited involvement undermines one of the fundamental issues with the involvement process in the case studies: the lack of information provided to the wider public on involvement opportunities and on the LSC programme as demonstrated in section 5.2. It further suggests that campaigners were more ‘invited’ than other groups of the public. On the contrary, in Chapter 6, I describe how campaigners developed tactics to be informed of what was happening regarding the LSC programme and invited involvement opportunities in order to scrutinise
the programme and voice their concerns or opposition. Besides, during fieldwork, campaigners advertised invited involvement opportunities to their ‘wider’ local communities more than the LSC leaders. Members of the public interviewed in Grandvalley and Bluehill for instance were often made aware of public involvement forums via their local campaigners, as were the politicians interviewed in Bluehill and as was I on many occasions during fieldwork.

Secondly, lay representatives were criticised for being unrepresentative of the public by some participants, particularly practitioners of public involvement. One reason cited for the lay members’ lack of representativeness was the lack of diversity among lay members: “they are all white English middle class, where they all have the same views” (Practitioner of involvement 03). Another was that lay members became part of the system over time, understood and spoke the NHS jargon and therefore could not be critical anymore nor represent patients’ or public’s views, as described in section 5.3.3. Nonetheless, all the invited forums for involvement described in section 5.3 – and especially CCG meetings – were not suited for lay people. Therefore, to a degree, lay members had to become part of the system and understand the NHS language in order to have the ability to critically question LSC leaders. In a similar way, campaigners have educated themselves to understand the opaque language around the LSC programme in order to be able to question the evidence put forward by LSC leaders (see Chapter 6).

Thirdly, issues of (un)representativeness of the public present can be explained by other factors related to the pitfalls of invited involvement as it was conducted in these case studies. In line with my observations and according to many campaigners interviewed, some members of the public and a few Healthwatch respondents, reasons of underrepresentation of other groups of the public could be explained by:

- involvement activities not suitable for lay people;
- the “apathy” from the public, for whom involvement could not influence decisions already made by LSC leaders;
- the public’s lack of knowledge of involvement opportunities;
- the lack of awareness around the LSC programme.

Campaigners and one local clinician interviewed further pointed out that LSC leaders did not reach out to involve more diverse groups of the public, representative of their local communities. In particular, they often brought up in invited forums during fieldwork that those most affected by the LSC programme – and who were also most affected by health inequalities – such as ethnic minorities and people living in deprived areas near the emergency departments, had not been included in discussions around the LSC programme. Some Healthwatch respondents and the lay member suggested that LSC
leaders could involve the voluntary sector working with disenfranchised groups locally to address this issue.

5.4.4 Healthwatch: what role for Healthwatch in large-scale change?

In this section, I focus on the two local Healthwatch branches in Grandvalley and Bluehill that replaced the previous arms’ length body LINks in April 2013 (see Figure 8) and that I identified as actors in invited processes of involvement. The most striking feature of both Healthwatch organisations was that they identified themselves to the public and other actors as an “independent voice” making sure that local public voices were shaping local health and social care services. Yet, according to documents from 2015 and 2016, the role of Healthwatch in large-scale change in relation to scrutinising and challenging the LSC programme was not very clear. During fieldwork, when asked about the role of local Healthwatch in the context of the LSC programme, Healthwatch respondents referred to gathering patient experience information and the public’s concerns using their two statutory powers: one to “enter & view” any health service and one to receive a response to any questions put to the LSC leaders within twenty working days.

A Healthwatch staff in Bluehill further added that, as part of their role in large-scale change, they ensured that public involvement guidelines were respected:

“I mean we try to ensure that there is a proper process and that [LSC leaders] follow their own guidelines in terms of involving people or communicating and that kind of thing like flagging patients and people’s concerns about the ramifications of the further changes going forward. I mean we can’t stop them, but we can challenge them to think. And because health is so political sometimes if that political cloud is spinning then it might be about to change.”

Bluehill Healthwatch was indeed more involved in scrutinising the public involvement process in the LSC programme than Grandvalley’s. For instance, the local Healthwatch was quite vocal in expressing their concerns regarding the inadequate consultation document for the Bluehill consultation (section 5.3.8). But rather than just being involved during pre-consultation in helping LSC leaders produce a consultation document suitable for lay people, they took on the role of critically “monitoring the UCC public consultation”. They further provided a formal response to the consultation, based on patients and public views they had collected themselves through their own engagement with the local community.

Using surveys and community events, both local Healthwatch wrote up public reports around issues related to the LSC programme (e.g. survey in the community showing that 60% of public surveyed did not know what an Urgent Care Centre was), flagging up issues within the local communities and
making recommendations to LSC leaders. Bluehill Healthwatch in particular seemed to use their statutory power to obtain a response from LSC leaders on their reports. For instance, during fieldwork, Bluehill Healthwatch published a report on the future of the local hospital (in light of the plans for closing down the emergency department) based on public’s concerns and perspectives they collected. They used the report as a basis to ask LSC leaders several questions regarding the LSC programme (and particularly its future). However, despite receiving responses from the local and joint CCGs, as well as their local Trust, and the report being discussed briefly in one of the local CCG and Trust board meetings, their report had limited impact beyond flagging up local concerns. The answers from LSC leaders were quite vague, reminiscent of the way LSC leaders answer public questions in invited forums. For example, when asked how they were planning to involve members of the public and health professionals in the development of the plans for the hospital, they briefly replied that they were “committed to involving patients and the public in their development” and that Healthwatch and their lay partners would be part of the process. Additionally, the need identified by the local Healthwatch to conduct this research and write up this report for LSC leaders exemplifies claims from interviewees about the lack of invited involvement of the public past the consultation stage.

Beyond this, the two local Healthwatch were represented at their local Health & Wellbeing Board, and their local scrutiny committee in Grandvalley, giving them another platform to scrutinise the LSC programme via local authority forums. Both Healthwatch were also represented at the joint STP level, where they could get information regarding the LSC programme and report to their Healthwatch. For example, according to documents from 2015 and 2016, it appeared that chairs of both Healthwatch organisations were able to see the business case for change (which campaigners repeatedly tried to access via Freedom of Information requests as explained in section 5.2).

Healthwatch respondents further indicated that their impact in large-scale change was limited due to their lack of funding and their lack of human resources. With a small budget, the local Healthwatch role was to bring up local voices not just in large-scale change but in a wide range of health and social care services. Therefore, both Healthwatch in these case studies relied on community volunteers to conduct their work (one Healthwatch branch for example had only funding for four staff, most of them on a part-time basis). Other difficulties mentioned by some Healthwatch respondents included the lack of support from Healthwatch England and the fact that most members of the public did not know about their local Healthwatch.

However, the main tension around the role of the local Healthwatch in large-scale change revolved around their funding sources and how that might impact their “independent voice”. Most Healthwatch respondents and several campaigners and members of the public described that the
intended role of Healthwatch was to be “independent”, “a watchdog”, “a critical friend to the CCG” or “at arms’ length”. Yet, local Healthwatch branches in England are commissioned and funded by their local council. In Bluehill, this was experienced as a difficulty in the context of the LSC programme in particular, but all Healthwatch respondents were adamant that without their independence from the local council and from the local CCG, they had no value. Based on fieldwork observations and some interviews, both local organisations distanced themselves from the local campaigners in the spirit of remaining an independent body (even when in agreement with the campaigners’ views).

“The value that we [Healthwatch] bring is that independence. And if we lose that then we would just be like any other voluntary organisation and lobbying group and that’s not what we are supposed to be here for.” (Healthwatch 05 – Bluehill)

Bluehill Healthwatch was perceived as independent by other Bluehill respondents. This following quote from a local campaigner supports this claim but interestingly also offers an insight into the kind of tension that the local Healthwatch might experience to remain independent, in this case from the local council:

“[Bluehill Healthwatch] publish their findings as well. So, their research is good, and they are independent, certainly independent of us [campaigners]. And although the council pays them, and occasionally one hears mutters from the council ‘they are not fully on our side’, and we say: ‘just leave them alone, they are independent, they think, and you pick what you want from them’.” (Campaigner 01 – Bluehill)

On the other hand, Grandvalley Healthwatch was perceived by local campaigners and the member of the public interviewed in Grandvalley as having compromised their independence. Due to their limited resources, Grandvally Healthwatch also received external funding from the local CCG and sat on the CCG board meetings (however Healthwatch representatives did not speak during the CCG meetings I observed in Grandvalley). This was perceived by local campaigners as a conflict of interest that undermined Healthwatch’s independence, which could therefore not be trusted to critically challenge the LSC programme or the way the public was involved. Aware of such criticisms, a Healthwatch respondent in Grandvalley defended their position as one adopting to work in partnership with the local CCG:

“I know [campaigners] have some issues with us because we adopt a partnership approach and they think we should be criticising you know all the time, all the time, and we don’t find that effective.”

Healthwatch respondents in Bluehill acknowledged the difficult position the other Healthwatch was in to fulfil its role because of its financial situation. However, they also questioned having Healthwatch sitting at the CCG board meetings and their aptitude to remain independent.
“Well I can understand [Grandvalley Healthwatch] sitting at the table with them [local CCG] in order to make a contribution. But I think it has to be very much – because of the kind of organisation we are – it has to be very much arms’ length. I can’t see how you can scrutinise and be a critical friend at the centre of the table.” (Healthwatch 04 – Bluehill)

My document search as part of the document analysis did not retrieve any official guidance from NHS England on the role of Healthwatch in large-scale change and it would seem that the role of Healthwatch in this context remains unclear. These case studies suggest that the level of Healthwatch activity at the local level regarding the LSC programme is dependent on funding constraints and on the make-up of its staff and volunteers. Indeed, the organisation in Bluehill, better resourced, was more active regarding the LSC programme and public involvement than Grandvalley’s that had additionally undergone several changes in structure, staff, leadership and contracts since its creation. Moreover, given the lack of national guidance on the role of Healthwatch in the context of large-scale change, it appeared as if the Healthwatch in Bluehill had taken it upon themselves to be active and critical in this area rather than acting on formal guidance.

5.4.5 The local politicians: partners or adversaries of the LSC leaders?

During fieldwork, it became apparent that local politicians were playing a role in invited involvement processes and in challenging the LSC programme. Local councils embodied local accountability in the LSC programme through their scrutiny powers that were displayed through the Health Overview & Scrutiny Committee, and sometimes through the council’s Health & Wellbeing Board. In Grandvalley, the Health Overview & Scrutiny Committee for instance wrote to the Health Secretary to refer the LSC programme proposals to the Independent Reconfiguration Panel and later filed a judicial review on the grounds that public engagement and consultation was inadequate particularly among the population that would be affected by the changes (see Figure 8). In Bluehill, one of the politicians interviewed suggested that the council’s scrutiny powers (in particular threats of a judicial review) helped putting pressure on their local CCG to conduct a proper consultation around the Urgent Care Centre closure. Based on my observations and some interviews, the push to scrutinise the LSC programme and to oppose potential closures came from a handful of local politicians at the leadership level of the council who had more knowledge of the LSC programme. This meant that local politicians sitting on the scrutiny committee were not always aware of the complicated system related to the LSC programme and their legal options. They thus relied on their clerks’ expertise as well as briefings from local campaigners (described in section 6.3.1). A few interviewees further suggested that local politicians in other local authorities in the region were not using their scrutiny powers or were not aware of their legal options unless their constituency was at risk of service closures.
With the emergence of the STPs, “NHS organisations and local councils [were to] join forces” (NHS England document) as partners to develop plans for improved local health services. Five interviewees expressed that the local authorities covered by the STP footprint had very little time in 2016 to review the STP plans. Grandvalley and Bluehill council leaders were particularly under “intense” pressure to sign the plans from STP leaders and other councils in the region “who did not have a hospital to worry about”. One of the local politicians interviewed explained that, after a team of officers reviewed the STP plans, they had realised that signing off on the partnership meant also signing off on the remaining emergency departments’ closures – under the LSC programme umbrella – in Grandvalley and Bluehill. As a result, Grandvalley and Bluehill council leaders refused to sign the STP plans. Consequently, the Grandvalley and Bluehill councils had been excluded of the decision-making process related to the STP plans since then. However, one of the local politicians in Bluehill also explained that despite “never formally becom[ing] part of the partnership”, the local council adopted with their local CCGs a collaborative approach and were working together on other areas of the STP plans that were not related to the LSC programme.

Therefore, during the lifetime of the LSC programme, local politicians tended to oscillate between collaboration and confrontation with the LSC leaders. In section 6.4.2, I describe how local politicians also took part in uninvited actions to challenge and oppose the LSC programme. Sometimes, this antagonism transpired through invited forums. During fieldwork in Grandvalley, local politicians were generally less adversarial or challenging to the LSC leaders in council meetings compared to Bluehill’s politicians with the notable exceptions of the joint Health Overview & Scrutiny Committee I observed as well as a scrutiny committee in Grandvalley that took place shortly after the announcement that the LSC programme was dropped. This oscillation between collaboration and confrontation was more pronounced in Bluehill during fieldwork because of imminent plans to close down the Urgent Care Centre.

Confrontation stemmed from the history of the LSC programme in Bluehill and, like members of the public and campaigners, local politicians distrusted LSC leaders’ motives for change. A vivid example of this confrontation during fieldwork was the scrutiny committee I described in section 5.3.8 during which local LSC leaders and their practitioners of involvement presented their plans for the public consultation. During a heated debate that lasted two hours over the case for change and the public consultation, it was clear that local politicians distrusted the LSC leaders, their evidence for change and their commitment to genuine public consultation. Issues of distrust dominated the meeting that got very hostile at times – it was referred to in interviews with a politician and a Healthwatch staff present as a “bloodbath”; most of the confrontation was led by local politicians. Discussing this meeting with the local politicians interviewed, one explained that confrontation was necessary when LSC leaders were deflecting questions and not answering them whilst the other did not find the confrontation
constructive and wished for a more collaborative approach with LSC leaders. However, both were concerned that, in the context of the LSC programme, a lack of confrontation from local politicians might be interpreted by LSC leaders as them agreeing to “cuts to services”.

Local politicians further conveyed that a barrier to a more collaborative relationship was the LSC leaders’ lack of transparency. Politicians pointed out in particular to their “convoluted” way of communicating with them often leading to “reactive scheduling” from the scrutiny committee and the difficulty sometimes experienced to get documents related to the programme’s case for change and public involvement. One politician described that they had stopped going to informal meetings with LSC leaders “because the conversations did not lead anywhere and did not justify not using a public forum”. The other politician described that a scrutiny committee, due to take place just before the Bluehill consultation, was cancelled at short notice because LSC leaders had not provided the documents requested for scrutiny. Leaders justified this by expressing that, in their opinion, everything regarding the consultation had been discussed four months before at an earlier scrutiny meeting. Leaders suggested instead holding a “consultation workshop” with the scrutiny committee during the public consultation period that was not open to the public. Invited by local politicians, I was the only person in attendance not sitting at the table. Rather than a workshop, I found it to be set like a normal scrutiny committee meeting but without the presence of the public. A few members of the committee also brought up this observation during the meeting who further suggested that the meeting should have taken place in public. In the consultation report written by Bluehill CCG, this ‘workshop’ was reported as the CCG consulting with the local scrutiny committee.

Finally, both politicians interviewed as well as a couple of others in Bluehill sporadically attended local and joint CCG meetings in public as well as public engagement workshops during my fieldwork. The reasons they put forward when asked about their attendance to other invited forums were: “to keep track” of the LSC leaders because of the lack of information they provided, “to get a sense of what materials they are producing, how clear it is [for the public]” and because LSC leaders “need to be challenged” across different forums.

Hence, despite the framing at the national level of local authorities as partners in the STPs, in these case studies, local councils oscillated between partners and adversaries to LSC leaders that they did not trust when it came to changes related to the LSC programme.

“I think that because we didn’t sign up for [the STP], we became a lot more engaged in health matters. And I think we are quite a politically, a sort of active council, one of the most who really has got their heads around NHS changes and documentation. So, that’s the positive from it. But at the same time the big negative is that it has created this suspicion and this sort of tradition of giving [LSC leaders] quite a hard time for scrutiny.” (Local politician 02 – Bluehill)
5.4.6 Local clinicians: a missing voice?

During the course of my document analysis and observations, LSC leaders consistently framed the LSC programme as “clinically-led”. However, during fieldwork I found that the clinical voice was only expressed through commissioners. For instance, during the involvement activities I observed in Bluehill consultation, commissioners leading those activities presented themselves as “local doctors” rather than commissioners. One commissioner in particular responded to any claims from members of the public that the change was financially motivated and not taking into consideration local patient needs with “I am a GP here”; implying that their support for the change was based on their clinical knowledge of Bluehill although no clinical evidence was presented to the public during those consultation activities. Similarly, the LSC leaders who signed the foreword of the initial public consultation document were all commissioners and put forward their role as local GPs.

The initial consultation document on the LSC programme further stated that: “changes, above all, must lead to improvements in the quality of care and so it is important that GPs, hospital clinicians, nurses, community service staff and others lead the way in how these changes are designed and put in place” suggesting that local frontline staff had a voice at the table. The document further implied that the clinicians were to be the bridge between patients and senior managers “to make sure that proposals are good for patients as well as being realistic”. In contrast, the two local clinicians I interviewed, which were not involved in the LSC programme implementation, indicated that little involvement of local frontline staff had taken place in the lifetime of the LSC programme and that it had been superficial in nature. In their experience, local frontline clinicians had “never been specifically invited to the table” to discuss proposals and that the “clinicians’ voice was never there” in the LSC programme. When asked how they were made aware of the various plans for change, they both indicated they had mainly found out from “hearsays”, “word of mouth” and “gossip” among the local clinical community.

The clinician in Grandvalley found out about the initial public consultation through word of mouth and attended a public meeting. Their experience of the public consultation was that it lacked evidence to support the clinical case for change and as a result opposed the LSC programme, voicing their opposition in invited public forums during and after the initial public consultation.

“We went to medical school and we were taught to practice evidence-based medicine. So, if you are going to come to us with a proposal then show us the evidence. It’s very disrespectful to actually turn around to a whole bunch of doctors and say: “black is white,” when it’s very clear we can see black is black. […] If you are going to try and engage clinicians then engage with them on an intellectual level, putting forward evidence-based arguments. Not just pie-in-the-sky ideas.
Sometimes [LSC leaders] just talked about this vision that they had for community services, but it wasn’t a vision, it was a delusion, or it was a mirage. There was nothing concrete that we could see, that we could believe in. And I think when someone disrespects a group of intelligent professionals like that then you lose their cooperation from the outset.” (Local clinician 01 – Grandvalley)

The participant further explained that they had challenged LSC leaders on a few occasions to provide data for the evidence put forward during the public consultation with no result:

“So, constantly, I was always asking [the Medical Director]: “do you have any data from the community? Do you have any data to support that admission avoidance has led to a reduction in non-elective admission?” And she said she would try to find that data. I was a bit disappointed that the Medical Director of [the LSC programme] told me she would try to find some data. I’d expect them to actually have the data. And I’ve never seen that data. So, I always got the impression that they didn’t like the evidenced-based sort of quantitative arguments that we [clinicians] were making, but could never counter-argue with evidence or data.”

Reminiscent of how members of the public perceived their involvement in the initial public consultation, the interviewee was very critical of the consultation processes and did not feel heard as a clinician. Along with a group of colleagues, the interviewee had been quite vocal about their opposition after the consultation ended. As a consequence of making their view very clear, the interviewee felt that they were not invited to any meetings organised by LSC leaders. In section 6.4.4, I describe how some clinicians thus turned to uninvited actions to voice their concerns and opposition to the LSC programme.

The local clinician in Bluehill, speaking of the public consultation on the Urgent Care Centre and out-of-hours GP provision, indicated that all GP practices in Bluehill were notified of the upcoming public consultation two months before the start of the consultation; although, at the time, the public consultation was to start “anytime soon” according to meetings I observed. As the interviewee describes below, local GPs were consulted on the process of the public consultation rather than on the case for change (similarly to when commissioners engaged with the local scrutiny committee):

“They sent a note around to all practices about the end of January I think saying: this is what the plan was, this is what their proposals would be, did anyone have any comments – on the process not necessarily on the content. So, they were asking for a bit of feedback and giving us notification that they were going to go out to consultation. So, one of the questions they were asking was how they could make sure that they maximised the engagement of patients. […] But they were asking for comments on the process, they weren’t asking for comments on what they were actually consulting on.” (Local clinician 02 – Bluehill)

The interviewee attributed the lack of involvement of local GPs in the development of plans for change to an apprehension from the local commissioners to be perceived as having a conflict of interest; to the
“adversarial relationship between a commissioner and a provider”; and to the busy schedule of local GPs. Although here local GPs received a note about the upcoming public consultation with an option to provide feedback, the interviewee felt that “with public consultations, by the time it has been published and [LSC leaders] are wanting responses, it is probably too late to influence things”. Therefore, for the interviewee, they needed with their colleagues to find out about proposals for change and talk to commissioners before public consultation.

It would seem from these accounts and other data I collected that it was not evident to the public and local clinicians how the LSC programme was “clinically-led” and that local clinicians had not been specifically invited to be involved in the design and implementation of the plans or during public consultation.

5.5 Impact of invited public involvement on decisions for large-scale change

In these case studies, it was clear that all respondents (with the exception of the LSC leader interviewed) did not believe invited involvement of the public could impact decisions regarding the LSC programme, regardless of the method used to involve the public. This was based on the pitfalls of invited processes used by LSC leaders (such as the lack of information provided to the public, the lack of suitability for lay people, issues of representativeness of the involved public). Engagement processes were experienced as “window dressing” or “lip service” by several participants, in line with my observations. As LSC leaders did not need to produce an audit trail for involvement activities which fell under the ‘engagement’ category, it was further difficult to uncover how the engagement processes shaped decision-making. When it came to the impact of public consultations, the consensus among the interviewees was that decisions were already made by LSC leaders before plans for change were presented for public consultation. Indeed, there was no evidence in the timing of public consultations in the case studies (see Figure 8) or in the data collected that the public consultations took place “when the proposal [was] still at a formative stage” (NHS England, 2016a). At odds with the data collected, the LSC leader interviewed expressed that it would be “unusual” for public involvement to have no impact on decision-making and framed the impact of public involvement as a mitigating factor in decision-making, without providing an example:

“I guess that would be unusual for [involvement] to have none whatsoever. What is much more common is that the proposal might go ahead in principle, but the change got moderated.”

Additionally, invited involvement in these case studies offered little opportunities for members of the public to debate the case for change. Any attempt by the public to debate or use counter evidence was avoided by LSC leaders. This was also the case with local actors, such as local politicians and local
clinicians, who were asked by LSC leaders to comment on the processes of public involvement rather than seek their views on or debate the case and plans for change.

“And I think, in my experience, most of their so-called ‘consultations’ are ‘engagements’ rather than what I consider consultations around their agenda. When they have you there to ask, they want you to ask questions, it’s really saying: ‘so what do you want us to clarify for you?’ not ‘what do you want us to change?’. I think that’s our experience of what consultations mean.” (Campaigner 05 – Bluehill)

“It seems to me people have rather had to fight to be heard, than being a welcome participant at the table and that for me is the critical thing. If you really want the public at the table, there are ways of making them welcome and really listening to them and it seems to me that that’s not the case in this process.” (Member of the public 04 – Bluehill)

Campaigners, who were the most visible group of the public in invited processes (although not formally invited), were in attendance to show their opposition, collect information and add a layer of scrutiny on the LSC programme (see Chapter 6), not because they believed public involvement could influence decision-making.

Whilst the impact of public involvement on decision-making seemed to be lacking in the case studies, invited involvement – a process completely in the control of LSC leaders – had clear impacts on the public and local actors: a distrust of LSC leaders, prompting some groups to oppose the change not only in invited forums but also by taking part in uninvited actions (described in the following chapter). Even by addressing, more recently, some of the pitfalls of invited involvement on who to involve and where (section 5.3.8), distrust towards LSC leaders remained a central issue in public involvement, fuelling public opposition to change. Accordingly, many participants called for more genuine conversations between the LSC leaders and the public. A couple of Healthwatch respondents further indicated that, in their experience, better involvement from LSC leaders, allowing for public deliberation, would lessen opposition to change.

Ultimately, the participants interviewed had expectations on what meaningful involvement in large-scale change should be. These were not met by LSC leaders and invited involvement mechanisms. Those expectations of meaningful public involvement centred around who to involve, how to involve and when to involve. On who to involve, most participants suggested that a mixture of people with an array of socio-economic backgrounds, ethnicities, age and healthcare needs should be involved by LSC leaders. They further indicated that local and frontline clinicians should be involved in the development of the plans. On how to involve, the comments provided by interviewees resonated with the themes identified in Chapter 4 and this chapter, namely to inform the public about the LSC programme and
involvement opportunities; to provide the public with lay documents and use lay language when interacting with the public; and to go directly to the community instead of invitations to attend meetings. Several interviewees further brought up doing involvement “*well and honestly*” by listening to diverse views, including those opposing plans, and demonstrating to the public how their concerns were taken into consideration. Finally, interviewees conveyed that LSC leaders should allow time for public involvement, often perceived as rushed, and that involvement should continue beyond the consultation, especially when changes are not delivering as expected.

5.6 From Sustainability and Transformation Partnerships to Integrated Care Systems as a new model of governance: implications for public involvement, local scrutiny and local accountability

As evidenced in Figure 8, the LSC programme took place against the backdrop of changes in regional commissioning arrangements instigated at the national level. At the beginning of the LSC programme for instance, Primary Care Trusts, made up of health managers and responsible for commissioning, were replaced under the 2012 Health & Social Care Act by GP-led organisations, the CCGs, covering each a local authority in the region. Approximately three years later, under the NHS Five Year Forward View, the Sustainability and Transformation Partnerships or STPs (originally called Sustainability and Transformation Plans) were introduced. Under the STP, local CCGs in the same STP footprint – here covering the whole region targeted by the LSC programme – were to work together in collaboration with partners, including local councils, to commission services. Two years later, under the NHS Long Term Plan, those STPs were to be replaced by Integrated Care Systems (ICSs) by 2021. In the case studies, under the ICS, local CCGs were to disappear and merge into a single CCG covering the whole region. Towards the end of my fieldwork, these changes were still in motion with LSC leaders presenting the ICS case for change to the public whereby the joint CCG would become a single CCG covering the whole region and commissioning services for over two million people. Originally set to merge in spring 2020, the CCG merger was pushed back to spring 2021 due to complains from local actors that the rushed timing would not allow for meaningful public engagement.

Towards the end of my fieldwork, LSC leaders announced that the CCG merger would not require public consultation. Although no reasons were put forward as to why this change was not considered ‘substantial’ enough to trigger a consultation, I suspect that the reasons were that the change was not a “*patient facing service change*” (ICS case for change document for the public, 2019) and that a national online public consultation already took place in October 2018 on this topic. As a result, LSC leaders focused on public engagement strategies. Under the ICS, public engagement would take place through the representation of Healthwatch at the ICS level and through meetings in public of the single
CCG, rotating localities each time. However, the main method of public engagement in the ICS, according to some practitioners of involvement and the LSC leader interviewed, would be a virtual citizen panel of over 4,000 people, although later the case for change document for the public stated that it would include 3,000 citizens and did not mention that the panel would be a virtual one. The citizens’ panel would be selected by an external company and would be “demographically representative” of the region; would reach members of the public who normally do not get involved; would rely less on lay members; and would “dilute” the voices of local campaigners as this subset of interviewees believed that the campaigners views were not representative of the general public. Yet, regarding the last point, LSC leaders acknowledged after the LSC programme was dropped the need to engage to a certain extent with local campaigners on the case for change for the ICS and consequently invited representatives of each campaign to private meetings with LSC leaders. Finally, the change in discourse from ‘public’ to ‘citizen’ implies that future invited involvement would be more democratic. Yet given that engagement is not tied to a legal requirement to take into account public views it was unclear at the time of writing how the views of the citizens’ panel would be included in decision-making.

During fieldwork, local campaigners were sceptical of the public engagement strategies under the ICS and argued that local public involvement would be undermined. For instance, about Healthwatch representation, campaigners questioned why not all Healthwatch organisations in the whole region were represented. Additionally, campaigners were concerned that under one CCG, meetings in public would be reduced to five a year and would involve members of the public travelling to other localities for almost all meetings in public. Citizens panels were brought up by several campaigners interviewed as a meaningful method of public involvement early on in my fieldwork. Thus, local campaigners welcomed the ICS citizens panel but expressed reservations, given the limited details provided by LSC leaders on the functioning of the panel, that the panel “will be no more than a banal focus group”.

The move towards the ICS would have implications not only for local public involvement but also for local scrutiny and local accountability, which were the focus of the campaigners’ and local politicians’ scrutiny of the case for change. LSC leaders acknowledged that work was still needed in this area. The concerns of local campaigners, echoed by local politicians, focused on the potential loss of local scrutiny and accountability, particularly worrying that any future controversial large-scale change or “backdoor privatisation” could be pushed at the regional level and bypass local opposition. Furthermore, campaigners seemed doubtful that the healthcare needs as well as the social and economic diversity of the various communities included in the region would be taken into account by ICS decision-makers without local oversight. The ICS change from several CCGs to a single one was framed by LSC leaders...
as a cost-saving measure. Campaigners calculated that the savings would be minimal, especially when compared, in their opinion, to the possible loss of local accountability and scrutiny.

Similarly, local politicians had started scrutinising the ICS case for change, which became the focus of the joint Overview & Scrutiny Committee since the LSC programme was dropped, and shared similar concerns with the local campaigners. In particular, Bluehill and Grandvalley councils, since they had refused to sign the STP plans, were further excluded of the ICS decision-making. As a result, local politicians were active, towards the end of my fieldwork, in the scrutiny of the case for change. They raised concerns around the lack of democratic involvement in the future single CCG, around the unclerarness of the role of local councils within the ICS and how they would scrutinise future large-scale changes.

5.7 Summary of the main findings in this chapter

In this chapter, I explored how invited involvement took place in the context of a regional LSC programme, focusing specifically on two communities: Bluehill and Grandvalley. I first reviewed the case for change of the LSC programme aiming to centralise acute services in the region on fewer sites, leading to the closure of services in Bluehill and Grandvalley. During the public involvement process of the programme, the public questioned the evidence underpinning the case for change. In particular, local campaigners and other local actors actively scrutinised and challenged LSC leaders, collecting evidence to support their counter-arguments. Whilst LSC leaders promoted the case for change as evidence-based, they did not seem willing to engage with alternative evidence put forward by the public in invited forums. In line with the findings of the scoping review (Chapter 4), most participants distrusted the motives for change, perceived as financially motivated rather than clinically-led. Many participants did not trust LSC leaders when arguing that the aims of the programme were to improve and integrate services in the region and believed instead that LSC leaders were responding to central pressures to reduce costs.

I then described the stage of public involvement in the case studies. Processes for public involvement were initiated and controlled by LSC leaders who limited public involvement to two degrees (section 2.1). ‘Consultation’ was tied to the legal requirement for the NHS to consult the public in case of substantial change to health services. At this degree of involvement, high intensity public involvement had to be initiated by LSC leaders and plans for change had to be presented for public scrutiny, both elements that could potentially be legally challenged. Two public consultations took place during the lifetime of the LSC programme: a region-wide initial consultation that took place early in
the programme and a local consultation in Bluehill towards the end. On the other hand, ‘engagement’ was used as an umbrella term to refer to all other invited activities with the public taking part outside formal consultations. This degree of involvement was not tied to any standards in terms of its intensity, who was invited and its influence on decision-making. Engagement intensity, in contrast to public consultation, was limited to a handful of forums: members of the public could attend meetings in public of commissioners at the local and regional levels and, for a few members of the public, become a lay member at those meetings. Members of the public could further engage with LSC leaders through their local authority’s scrutiny committee meetings, also taking place in public or attend their local Trust board meetings in public. In line with the findings of the scoping review (Chapter 4), invited involvement was criticised by participants in this study for: its rushed timing, the lack of information provided to the public, the representativeness of the involved public, the lack of suitability for lay people and the limited opportunity for public deliberation. Additionally, participants (including practitioners of public involvement) pointed to the lack of impact public involvement had on decision-making. In particular, that the public had been consulted on decisions already made, echoing the findings of the scoping review. They further described engagement as a “performance” or a “staged window display” where “decisions are made backstage”. Therefore, by choosing a top-down approach to health planning and public involvement, LSC leaders created an environment of distrust fuelling local opposition to change.

In my analysis, I further drew out the different actors participating in invited processes. LSC leaders were the initiators of those processes and the decision-makers, although some participants questioned whether decisions were centrally-led. Conducting public involvement on behalf of LSC leaders, practitioners of involvement were critical of invited processes chosen but revealed they had little power in shaping them. The public involved in engagement activities I observed during fieldwork was mainly comprised of ‘Save Our Hospital’ campaigners, lay representatives, Healthwatch members and sometimes local politicians (in Bluehill). The wider public was invited during public consultations and events were held in the community. However, in the public meetings and workshops I observed during Bluehill consultation, only a handful members of the wider public were in attendance, all affiliated to their local Healthwatch or local GP Patient Participation Group.

I further identified in my theoretical sampling three other actors in invited involvement that were absent or peripheral in the literature included in the scoping review (Chapter 4): local Healthwatch branches, local politicians and local clinicians. First, as a champion for public voice, the local Healthwatch were represented in invited structures. Albeit unclear in the context of large-scale change, many participants envisioned the role of the local Healthwatch as an independent body representing local voices as well as a critical partner of LSC leaders. Furthermore, as elected representatives of the public, local politicians played a role in invited involvement through their scrutiny powers enabling
them to challenge LSC leaders on the case for change and public involvement. When the region covered by the LSC programme became a Sustainability and Transformation Partnership (STP) – a change introduced at the national level – local authorities in the region were to become partners with LSC leaders. Since the LSC programme was still running under the STP plans with further planned closures of emergency departments in Bluehill and Grandvalley, local politicians (elected on the platform of saving their local hospitals) refused to sign the STP plans, excluding them consequently from the decision-making process. Therefore, during the lifetime of the LSC programme, local politicians tended to oscillate between collaboration and confrontation with the LSC leaders, and even took part sometimes in uninvited actions (see Chapter 6). Finally, in spite of LSC leaders’ assertions that the programme was clinically led and involved frontline clinicians, it would seem from the accounts of local clinicians interviewed and other data I collected that frontline clinicians had not been specifically invited to be involved in the design and implementation of the plans or during public involvement. In the recent local consultation in Bluehill however, LSC leaders consulted local GPs by informing them of the upcoming consultation and asking for their feedback on the public consultation process rather than the case for change.

Ultimately, the participants interviewed had expectations for meaningful public involvement in large-scale change that were not met by LSC leaders and invited involvement mechanisms. A recurrent theme in all interviews was the climate of distrust in invited forums that persisted through the years. After the LSC programme was dropped by the central government towards the end of my fieldwork, distrust was still driving the scrutiny by local campaigners and local politicians of LSC leaders who had started to engage with the public about another change introduced at the national level: the move from the STP towards the Integrated Care System (ICS). Under this change, local commissioners in the region would merge into a single body of commissioners responsible for service delivery for the whole region. As implications of this change for local accountability were unclear at the time of fieldwork, local campaigners and local politicians worried that any future controversial large-scale change could be pushed at the regional level, bypassing local public involvement, local scrutiny and local opposition.

In the next chapter, I turn my analysis to uninvited processes in the case studies that arose in response to the invited model of public involvement described in this chapter.
Chapter 6 – Exploring uninvited involvement in large-scale change: a reaction to invited involvement

6.1 Description of the campaigns & their inception

In this chapter, I explore the social and political processes underpinning uninvited involvement in the Bluehill and Grandvalley communities in response to the LSC programme. Those uninvited processes, although involving several actors (as described later in section 6.4), were embodied by Save Our Hospital campaign groups in this study.

Shortly after the initial public consultation on changes to acute services in the region (section 5.3.2), several Save Our Hospital campaign groups emerged in the localities facing the potential loss of their emergency departments to contest the rationale for change and its clinical case. In Grandvalley, two Save Our Hospital campaign groups were created, one led by some of Grandvalley’s local politicians and one initiated and supported by local residents, the local Trades Union Council, local clinicians and local politicians. The former, focusing solely on saving Grandvalley hospital, had been inactive for a couple of years at the time of my fieldwork and was described by one of the campaigners interviewed in the following way:

“It’s not like a campaign in the way that you would understand, or you and I would understand a campaign because it doesn’t involve people, it’s a campaign that does things ‘on behalf of’ rather than ‘with’ [the public].” (Campaigner 02 – Grandvalley)

Some local residents, members of the latter campaign group, decided to create an independent campaign that could be led by local residents – and “free” from the Trade Union Council and local politicians – allowing for “more democratic decision-making” (Campaigner 02 – Grandvalley). This campaign group named themselves Grandvalley Save Our NHS (GSoN) and was the group studied in the case study of Grandvalley. Initially, the group focused on saving their local hospital and later expanded on the wider lens of the regional NHS changes. Their focus then diversified and broadened over the years (see section 6.2).

In Bluehill, the campaign group Bluehill Save Our Hospitals (BSoH) was set up after the initial public consultation in 2012 by local residents with the support of one of their Members of Parliament. They focused at the time on campaigning to save the emergency departments in their two local hospitals, and later broadened their scope of action to the regional level, like Grandvalley’s campaign.
In Redtown, a group identifying themselves as a patient group, and not a Save Our Hospital one, had also been opposing the LSC programme. They declined the invitation to take part in this research and were minimally involved at the regional level, unlike the other two campaign groups studied.

Although the circumstances of the emergence of the two campaign groups were different, they shared many characteristics. Campaigners in each group had various political affiliations and declared that their campaigns, although political, were not affiliated to any political parties.

“I think everyone agreed that it should be non-party political although it was obviously going to be political because it was a government imperative that the NHS save all this money.”
(Campaigner 03 – Grandvalley)

“BSoH is not party political but we are political because the government politicised our NHS.”
(Field observations – campaigner at a BSoH public meeting)

Both groups were composed of a core team of campaigners, about 20 to 30 people depending on the campaign, that could mobilise a larger public when they needed to show numbers for example for petitions and demonstrations. The profile of the core campaigners was varied (and described in more detail in section 6.3.1). Additionally, both groups held monthly meetings – open to the public – to organise their campaigns and used similar tactics to voice their opposition to change (described in section 6.3.1). Finally, the two campaigns were funded through public donations.

The campaigners interviewed were all core campaigners involved from the onset (or shortly after) of the campaigns and had all taken part in at least one of the initial public consultation’s activities (section 5.3.2). Accounts of the motivations to become a campaigner were homogenous among the interviewees. Firstly, distrusting the motives of LSC leaders (sections 5.2 and 5.4.1), they wished to save their local services from closures concerned that the clinical case for change was flawed and threatened equitable access to services in the region. Secondly, many brought forward their desire to join the campaign after taking part in the initial public consultation (section 5.3.2) which they perceived as flawed in terms of the case for change presented and in terms of listening to and taking into account local public voices.

“I got involved [in the consultation] because friends of ours had got involved and made me aware of a huge public consultation on [the LSC programme], so once I read that [the consultation document] I was very concerned. And I sort of took it from there.” (Campaigner 06 – Grandvalley)
“And when the plans to reorganise the health services came first and a glossy book [the consultation document] came through the door and on first read, to me it sounded very good. Really, very good. And then I looked again, for no good reason, and what one was presented with was a set of very closed options, this or this, this or this, this or this, and you put a comment but there was no way of inflecting the options given. But it then struck me that one would lose one very good hospital to save another so there was a gun to one’s head which is the least bad option, but there was no good option. So, at that stage I went along to a meeting of Save Our Hospital which was very chaotic in those days but was full of enthusiasm […] and here we are six years later.” (Campaigner 01 – Bluehill)

6.2 The scope of the campaigns over time – from saving local services from closure to scrutinising all types of changes

The campaigns emerged as a means for local residents to voice their opposition to the closure of their local emergency department. What started as a short-term action to protest the closures evolved into a sustained campaign running for years as some of the closures went ahead and the campaigner remained dissatisfied with invited processes of public involvement. Over time, the scope of those campaigns also evolved from saving their local hospitals to scrutinising all changes – not just those under the umbrella of the regional LSC programme – happening in their local NHS such as changes to non-acute hospital services, changes to primary care services, out-of-hospital contracts, privatisation, workforce, digitalisation of NHS services, the NHS Long-Term Plan and Integrated Care Systems.

“We kicked off primarily just around the cuts [to the local hospital] and then as the campaign grew and developed we felt we had to be part of the wider picture. […] The primary focus of the campaign is trying to halt the downgrading of Grandvalley Hospital and to stop it being turned into a local hospital, to maintain the A&E, to retain the beds. […] But we are also campaigning to oppose the fragmentation of our services which is currently taking place with a proposal for this huge community health services contract which we actually think is part of fragmenting our NHS services. So, we’re in favour of services being linked up and integration where it can be shown it works but not the way that it’s been done with huge contracts, restructuring and … which is happening across not just Grandvalley but everywhere.” (Campaigner 02 – Grandvalley)

Campaigners interviewed admitted that they did not expect this to be a long-term campaign, but despite periods of campaign fatigue, the campaigners continued their activities as the multiplication of changes in their local NHS – according to campaigners continuing to affect disproportionally deprived areas, minorities and patients with complex health needs – renewed their perceived need for the campaign.
“[The campaign] had been going for some months and when it originally started it had, as I recall, a wide social range of people, from people from upper middle class to people who were very poor working class and all kinds of strata in between. And it then became quite clear that this was a long rather than short-haul battle. People who, like us, gradually peeled off. And that’s what happens with campaigns I presume. So, it’s waned at times and then it’s waxed again, and it has gone like that.” (Campaigner 05 – Bluehill)

The stated aim of both campaigns was to oppose “cuts” to local health services and the “privatisation” of those services. Campaigners developed two main strategies to enact their aim. Their first strategy was to raise awareness in their communities on changes to local NHS services by informing the public of changes and explaining to them what the changes entailed and meant for access and quality of services. Their second strategy effectively was to scrutinise local NHS bodies and “lobby” to hold decision-makers accountable to the public on the principle that NHS services are publicly funded. In the next section, I explore how those strategies were enacted, focusing on the tactics used by the campaigners and the network they created.

6.3 Uninvited actions of the campaigns

Both campaigns used similar tactics to act out their strategies. Those uninvited tactics, used concurrently, had four purposes: organising the campaign; informing the public about changes; scrutinising and challenging local NHS bodies and LSC leaders; and mobilising actors to oppose change. Furthermore, both campaigns developed a network of relationships with key actors in large-scale change at the local and regional levels, a network they used to enact their campaign strategies. Although both campaigns used similar tactics, the GSoN group had a stronger focus on conducting research than the BSoH group who, on the other hand, focused more on their visibility with the community and with LSC leaders. Both campaign groups however shared information and on occasions coordinated their uninvited actions, referring to each other as a “sister campaign”. In the rest of this section, I describe first the various tactics of both campaigns and then the networks they developed with key actors in large-scale change.

6.3.1 Tactics of the campaigns

Organising the campaign: monthly meetings, learning from other UK campaigns

Each campaign held 2-hour monthly meetings that were open to the public and attended by the core team of campaigners (about 20 to 30 people, depending on the campaign). Those campaigners
were from various socio-economic backgrounds. Some of the campaigners had complex health needs, some were carers, some had a clinical background and a majority of them were retirees. Bleuhill core campaigners were more ethnically diverse than Grandvalley’s (however their community events and wider supporters did reflect the ethnic make-up of Grandvalley). Both campaigns were similarly set up with a chair, a secretary, a treasurer, officers – all elected annually at the campaigns’ annual general meeting by all members – and members of the campaigns.

During those monthly meetings, some of the campaigners fed back to the group what had been discussed in the various meetings in public they attended (section 5.3) or what they had learned from specific research. Those meetings were also the forum for the campaigners to decide as a group the campaign’s course of action and strategies, with all members of the campaign in attendance voting on decisions. The end of those meetings was generally devoted to the planning and organisation of community events for the month and to the review of the upcoming meetings in public happening over the next month that needed to be attended by campaigners.

There were a couple of differences between how those monthly meetings were run in each campaign. Grandvalley’s monthly meetings also included a short presentation, either by a campaigner or an external speaker, followed by a group discussion, on a specific topic of interest to the campaign (e.g. the campaign’s research on the use of management consultants in the LSC programme, national public consultations, changes to service provision at the local hospital not publicised by LSC leaders). Turning to the Bluehill campaign, their monthly meetings were attended by local politicians who, as part of the meetings’ agenda, reported on their actions towards “saving local services from cuts”. In one of their monthly meetings I even observed a councillor from another locality in attendance who wanted “to learn more from the campaigners’ work and about changes in the NHS”, as plans to close a local hospital were being developed in their constituency. A Bluehill politician interviewed explained that they attended the campaigners’ monthly meetings because they found those informative and valued the views of the campaigners:

“Well it's to find out what they are up to. Again, they always give a very good account of a summary of the CCG meetings. So, you always get something very sensible from [Campaigner A] and [Campaigner B]. And just really to give support because I do think they are an amazing resident group actually. […] But their meetings can be quite… there are quite a lot of strong personalities there and they can be quite… Because they are not politically affiliated into that, so you know, there's a bit of infighting… makes the [scrutiny] committee looks like a tea party [laughter]. They can be quite… you know people arguing on different approaches and particularly the media and how they use social media and that sort of thing. So yeah, it's always informative. I like to go to hear different residents talking about… Because they have really got a core, I mean they've got real residents who have got real mental health problems and physical problems
and people who are really sort of struggling to cope themselves. So, I always find it valuable to go and listen to what they have got to say.”

As the politician alluded to, and in agreement with Bluehill campaigners interviewed, meetings could become quite emotional and argumentative in the BSoH group to the point they had to address the situation in their ground rules to allow for “healthy debates”. The BSoH monthly meetings I observed, however, did not get as argumentative as depicted by some of the interviewees. In Grandvalley, the monthly meetings did not get ‘heated’, but emotions were still present. The campaigners were very passionate about the changes to their health services and how they would affect the community’s health. They would sometimes get angry discussing the LSC programme and often were cynical when discussing invited involvement.

Furthermore, both campaigns organised themselves by liaising with each other and by learning from other Save our Hospital campaigns in the UK. Indeed, they kept apprised of the challenges and progresses made by other campaigns elsewhere facing similar changes. They also sought advice from other UK campaigns that successfully opposed large-scale change. Likewise, through their affiliations with national campaign movements such as Health Campaigns Together and Keep Our NHS Public, they kept informed of issues and changes in the NHS and regularly attended meetings and conferences organised by those national groups.

**Scrutinising and challenging local NHS bodies and LSC leaders: attendance to meetings in public, conducting research, Freedom of Information requests, engaging with local and frontline clinicians, lobbying, contacting NHS England & NHS Improvement**

Both groups of campaigners attended a wide range of meetings in public: their local CCG governing body meetings, their local Trust’s board meetings, their local council’s Health Overview & Scrutiny Committee meetings, their council’s Health and Wellbeing Board meetings, their local Primary Care Commissioning Committee meetings, the joint CCG Committee meetings and the joint Overview & Scrutiny Committee. All meetings listed were platforms in which campaigners could interact with their local NHS bodies as well as the LSC leaders. Additionally, those meetings were a source of information for campaigners who would go through all the meeting papers to scrutinise what was happening regarding the LSC programme and more broadly to monitor their local services. Above all, campaigners attended those meetings to demonstrate their scrutinising presence to LSC leaders, especially during times of the programme lifetime without any other public engagement or consultation activities taking place.
“[Campaigners] attend all of these meetings, the dire, dreadful, official NHS meetings and even the pretty dire council ones and try to… obviously it’s part of the process of educating ourselves but it’s also part of the process of saying that we haven’t gone away.” (Campaigner 02 – Grandvalley)

‘We need to keep going to CCG meetings, so they don’t think we lost interest’
‘We usually go [to meetings in public] and irritate [LSC leaders] by raising issues’
(Field observations – campaigners’ comments during GSoN campaign meeting)

The Chair moved to the topic of the CCG meeting by saying ‘Still more of the same’. One Campaigner responded: ‘we are seen as troublemakers, so they are careful about what to say, it is important we keep asking questions’. Another Campaigner commented that the information presented at those meetings was very difficult to understand for a member of the public and that it could be difficult to ask questions. The first Campaigner replied that ‘the answers are always general and vague, but the questions need to keep coming because it worries the CCG’.
(Field observations – BSoH campaign meeting)

Some of the campaigners further spoke (during interviews and often in their monthly meetings) of the need to not appear to be passive in invited public forums as this could be interpreted as acceptance or collaboration by LSC leaders. For those campaigners, a degree of confrontation was therefore needed for example at meetings in public. This echoes one of the quotes in my scoping review (section 4.4.2) describing the set-up of public meetings creating “either an atmosphere of passive acceptance or one of hostile resistance”.

In addition to attending meetings in public, campaigners scrutinised the evidence put forward by LSC leaders and investigated local changes through their own research. Grandvalley campaign was particularly research active, setting up a formal research group within their campaign, with contributions at times from local clinicians (section 6.4.4). The campaign shared their research with Bluehill’s when relevant to them. In relation to the LSC programme specifically, they researched in depth, mostly quantitatively, the business case for the LSC programme; the effect of the two emergency department closures on other emergency services in the region – monitoring service performance in the whole region for a few years; and the financial costs associated with the use of external consultants in the LSC programme (section 5.2). Research findings were used to support their arguments in invited public meetings and were disseminated to local councillors and the public via their uninvited forums.

Campaigners in Grandvalley distrusted LSC leaders and were in a more adversarial position with their local NHS bodies, who appeared reluctant to engage with and provide information to campaigners (and more broadly to the public). As a result, campaigners had been supplementing their research using Freedom of Information requests as a tool to access information, particularly regarding
the business case for change. According to campaigners’ accounts, LSC leaders remained reluctant and
evasive through their responses to Freedom of Information requests as well, reinforcing the lack of public
trust.

“I must have done at least 50 freedom of information requests to get information out of them. I
would say the majority of the answers came at 5 o’clock on the 19th, the 20th day, that they are
allowed under the act. I haven’t done a tabulation, but I’m quite confident that most of them will
delay as long as possible and very often they say ‘sorry we can’t get the information to you, we
need another two weeks’. I’d give them another two weeks and then I’d write to them and say ‘you
still haven’t answered’, ‘sorry it’s been delayed again’. They don’t like giving out information
because I think they know that what they have is not workable. […] It’s been incredibly frustrating
because I would say the majority of my freedom of information requests have returned unsatisfactory
answers… So, they are very reluctant to reveal what it is that they are doing, and I think the
reluctance comes from the fact they know it’s not going to work.” (Campaigner 03 –
Grandvalley)

On the other hand, the Bluehill campaign was more likely to get the information they requested
from local NHS bodies, therefore not having recourse to Freedom of Information requests as frequently,
as explained by this campaigner in Bluehill:

“One of the reasons is that because we’ve been so persistent, we tend to get the information we
want without needing to go to freedom of information requests. I mean that quite honestly, when I
think about what we might want freedom of information requests for, usually we get it when we
ask. I think that’s different from what I’ve seen elsewhere but ultimately our CCG these days
coughs up our stuff and certainly [our local Trust] gives us the information.”

Furthermore, both campaigns engaged with a few local and frontline clinicians. Those clinicians
were often feeding information to the campaigners about their situation in frontline services; about what
they thought of – and why they opposed – the LSC programme; about the impact of the closures already
carried out on remaining services; and about what changes were being introduced to frontline services.
Additionally, sometimes local clinicians were co-opted by the campaign groups to talk at their monthly
meetings and their public meetings to share their perspectives on the impact of the LSC programme.
The following extract from GSoN public newsletter illustrate how local clinicians informed the
campaigners about upcoming plans for change in their local hospital (not publicised as part of the LSC
programme) and how campaigners acted on this by bringing forward this information to the Trust
leaders and lobbying them:

“We recently received disturbing reports from Consultants that there were plans by some managers
to move Orthopaedic services from Grandvalley to [another] Hospital. […] Although we did not
know the full extent of the proposed cuts at that time, we were able to raise our concerns [at a meeting
with local Trust leaders] about the impact of reducing Orthopaedic surgery in Grandvalley, in
particular, how it would further undermine the A&E and the Hospital and seriously affect local

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people if forced to travel to [another hospital]. The Chief Executive told us they were not aware of these plans, which she said would have to be agreed at Senior Management level. However, the plans still seemed to be progressing until last Wednesday when the Consultants, who have been collectively resisting these cuts, were formally told that: ‘Grandvalley Save Our NHS (GSON) had gained knowledge of the proposed plan and had raised concerns to the Chief Exec and Chair, who in response had recommended the proposed plans be withdrawn’ - It is really nice to know we are seen as a force to be taken seriously! Also, great that joint action by Hospital Consultants and GSON was so effective - let’s keep it up to stop further cuts and hopefully get some of our lost services restored." (GSoN newsletter)

Despite this, campaigners interviewed did not feel they had managed to involve local clinicians in their day-to-day campaign in the same manner as some of the more prominent Save our Hospital campaigns in the UK. In particular, the majority of the local clinicians they engaged with were feeding information to the campaigners and supporting their work but were not willing to come on the record.

“I have been liaising with frontline health workers. I think I’ve been quite disappointed really in how the GPs are prepared to do things off the record and there’s been a few honourable exceptions. And actually, I don’t think that’s going to change now because it’s just so terrible. You know I’m also understanding of that, especially actually what the nurses and health professionals do, because the record of how the NHS treats whistleblowers is very cruel and I would be extremely cautious.” (Campaigner 07 – Bluchill)

During fieldwork, I observed that campaigners further lobbied against changes through letters they wrote to their local commissioners, to their local Trust and to LSC leaders at the regional level. The topics of these letters revolved around the reasons they opposed change; requesting information and evidence on the clinical and business cases for change; and demanding accountability for decisions already made or changes already implemented. When their letters remained unanswered or when answers were not satisfactory for the campaigners, campaigners would contact NHS England and NHS Improvement to get information. For instance, when the campaigners could not get access to the business case for the LSC programme, in addition to their Freedom of Information requests, they contacted NHS England in the hope of putting pressure on the local LSC leaders. Campaigners also wrote to the Independent Reconfiguration Panel, at the time the initial proposals for the LSC programme were referred to the Panel, with the aim to provide their own evidence that the case for change was flawed and that the public was not consulted adequately.

**Informing the public about changes:** leaflets and street stalls, newsletters, website & social media, public meetings, informing the public of invited involvement opportunities.
Another tactic of both campaigns to enact their strategies was focused on informing the public about changes to health services and the LSC programme mainly by holding street stalls in their community. Those street stalls took place on Saturdays weekly or bi-weekly in various parts of the community and in all weather conditions. Each campaign had a few regular spots in the community where they held their street stalls, strategically chosen to make sure they would reach people living in all parts of the locality and people from all socio-economic backgrounds. In addition, the campaigns held their stalls in community events such as markets, carnivals, festivals, marathons, etc.

The purpose of street stalls for campaigners was to inform the public about changes to local services, closures and future plans for change. Campaigners thus directly interacted with a broad range of members of the public in their community, distributed leaflets on current issues the campaigns were “fighting”, ‘Save our Hospital’ posters (for people to hang at the front window of their house) and car stickers. Those street stalls were also a forum for campaigners to collect and discuss the perspectives of members of the community on access and experience of healthcare services as well as to mobilise supporters for the campaign. Sometimes the campaigns added a bit of drama to their stalls by staging a “die-in” or taking part in local carnivals’ parades with big banners, colourful hats, pulling a hospital bed with a campaigner acting as a patient. The street stalls were run by campaigners but were also manned in bigger events by supporters of the campaigns (mostly members of the public) who distributed leaflets and discussed with passers-by changes to local health services and the work of the campaign.

“We do street stalls, we produce leaflets, we make sure that the public understand what’s going on. So of course, when you are out on the streets you talk to people, you meet GPs, you meet people that work in the NHS, you meet people from the voluntary sector, you meet just ordinary members of the public, workers of all kinds, mums, you know older people, everybody. So, we are trying just to keep on trying to spread the message. We are quite… You know with our limited resources we are quite effective. We don’t have the kind of resources that the NHS has. I mean they have like, I think a PR department with public engagement, publicity officers, they can churn out thousands of leaflets very quickly you know. We have one or two people, we have one person who produces our leaflets, we print you know thousands, we have done hundreds of thousands of leaflets over the time you know. And we get them out. But we get them out on street stalls and some people – we’ve got some valiant souls – who give them out in cafes and on buses and other places.” (Campaigner 02 – Grandvalley)

As a result of the campaigners’ community activities, the campaigners kept the LSC programme in the public eye. Additionally, both campaigns made themselves very visible by being a common sight in the community and approachable in contrast to invited public consultation activities as conveyed below by three members of the public interviewed.
“You see because you’ve got high profile people constantly in the public eye it’s not gone away. You go around Bluehill and you see the posters in the windows saying ‘Save Bluehill Hospital’. Go to Bluehill Hospital, most days of the week there is somebody there from the campaign.” (Member of the public 04 – Bluehill)

“They [campaigners] regularly are in the High Street, which is our main sort of road.” (Member of the public 02 – Bluehill)

“I don’t personally remember seeing any [consultation] roadshows in the part of Grandvalley where I live. On the contrary what I have seen most of is an organisation called “Grandvalley Save Our NHS”. Yes, they are the ones you see organising roadshows and leafleting. And their way of leafleting and organising themselves and informing people is more widely and it’s positive. Because I see their leaflets at [my] train station for example, but I didn’t see anything from [the LSC programme] at [my] station. I have seen the “Save our NHS” organisation organising local stalls whereby they are on the High Street, and they have a microphone, you know that kind of thing and they have people leafleting, and they do it in [other parts of Grandvalley], everywhere. And also, when we have the local carnivals, they are there. So, they have rather reached out to a lot more people than this whole NHS consultants, clinicians ever did.” (Member of the public 01 – Grandvalley)

The frequency of street stalls intensified before local and national elections in both Grandvalley and Bluehill which resulted, according to the campaigners, in “making NHS issues part of the elections” (Field observations – GSoH campaign meeting) in their local communities.

Occasionally, the campaigns would hold public meetings in their local Town Hall to inform the public on changes affecting their local services. The 2-hour meetings, taking place in the evening, were well-attended (about 200 people in those I observed) by a diverse audience with some people having to stand up. The public meetings took the format of a panel discussion with panellists from the local campaign, campaigners or clinicians from other UK campaigns, external speakers (usually from the national campaign Keep Our NHS Public), local clinicians and local politicians. About twenty to thirty minutes were left towards the end of the meeting for questions from the audience to the panellists. The meetings were informative in nature and were not urging attendees to take part in uninvited actions (at least in those I observed). If attendees were interested in taking part in uninvited actions, a campaign stall at the entrance was available with leaflets, petitions, sign-up sheets for the campaign newsletter and donation boxes.

Campaigners used complementary methods to inform the public via their electronic newsletter, a website and social media. One of the campaigns further produced an online glossary of NHS terms for the public related to their local context of change with over 200 terms and acronyms explained. In summary, campaigners reached out regularly to hundreds of people through their street stalls and public

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meetings; thousands of subscribers to their newsletter and websites; and distributed tens of thousands of leaflets (the Grandvalley campaign stated at one of their meetings that they had distributed a quarter million leaflets in the lifetime of the LSC programme).

Interestingly, both campaigns also informed the public in street stalls and via their newsletters of upcoming invited involvement activities, particularly for consultation events, and encouraged members of the public to take part.

“We [campaigners] participate in all the consultations that take place. So, if they’re doing a consultation, as they are now on integrated care providers, we actually encourage people to participate in that.” (Campaigner 02 – Grandvalley)

**Mobilising actors and opposing change:** taking part in invited involvement, petitions, demonstrations, briefing local councillors, mobilising local scrutiny powers, contacting the media

As described earlier, campaigners in Grandvalley and Bluehill took part in all activities stemming from invited involvement at both engagement and consultation levels in order to voice their opposition and to show their scrutinising presence. Both campaigns wrote formal responses to plans for change through invited forums. They further opposed change by challenging LSC leaders in meetings in public. Moreover, campaigners were able to mobilise relevant local actors to oppose change.

With members of the public, the core team of campaigners could mobilise large numbers when they needed to show numbers for petitions and demonstrations. Petitions against the LSC programme (and later against specific changes or “cuts” not related to the LSC programme) were used by the campaigners since the inception of their campaigns. Petitions were often found at their street stalls and more recently on one of the campaigns’ website. I observed during fieldwork that campaigners were usually able to collect between 100 and 300 signatures in a single community stall. According to campaigners, petitions were liked by members of the public who wished to engage with uninvited processes to express their voice.

“So of course, we [campaigners] all did petitions because petitions were something that people could relate to, they could understand, they could fill in, they could express their feelings.” (Campaigner 02 – Grandvalley)

One of the campaigners raised the importance of having petitions at the street stalls: “People ask ‘Is there something I can sign?’ so frequently. People want to sign things as a way of getting engaged and a way of getting heard.” (Field observations – BSoH campaign meeting)
Furthermore, the campaigners were able to mobilise the public for demonstrations. Demonstrations seemed more frequent in the early years of the campaign. In the course of my fieldwork, I only observed campaigners demonstrating a few times. In Grandvalley for example, the campaigners found out a couple of days before that a private provider bidding for the CCG’s out-of-hospital care contract – scrutinised by the campaigners worried about potential privatisation and fragmentation of their community services – was holding a public engagement meeting. The campaigners managed with short notice to mobilise about 50 members of the public supporting GSoN and two local councillors for a demonstration outside the Town Hall where the meeting was taking place. A dozen campaigners also attended the meeting “to give them a hard time” (Field observations – GSoN Campaign meeting).

Campaigners further mobilised members of the public to take part in national demonstrations called by the national campaign groups Keep Our NHS Public and Health Campaigns Together. I observed a national demonstration in London called by those two national groups for the NHS 70th birthday and in which both GSoN and BSoH campaigners and their supporters took part. The peaceful demonstration was attended by 40,000 people according to the organisers (20,000 by Grandvalley campaigners’ estimates). During the demonstration, I managed to count at least 16 different ‘Save our Hospital’ campaigns from all over the UK, suggesting that this type of uninvited campaigning was a popular method among the public to be involved in large-scale change. Among the ‘Save our Hospital’ protestors, nurses and doctors groups, union groups, local politicians and members of the public also marched to express widespread concerns regarding the underfunding and privatisation of the NHS and to oppose service and hospital closures. The demonstration ended with a rally in front of Westminster with speakers including politicians, clinicians, TV stars and union leaders.
Over the years, campaigners could also mobilise their local politicians in opposing the LSC programme in several ways. They regularly briefed the relevant local councillors or Members of Parliament on health issues and access to care in the community, the case for change for the LSC programme and other issues they were campaigning against. They further lobbied their local councillors to get the LSC programme (or other changes campaigners were opposing) on the agenda of the council’s Overview & Scrutiny Committee and Health & Wellbeing Board meetings therefore mobilising the scrutiny powers of their councils. Consequently, they could get LSC leaders at the table of a meeting in public where campaigners could ask them questions directly during the time allocated to the public at the end. During fieldwork, I noted that this tactic yielded different levels of success in the two communities. Indeed, as the council in Grandvalley was not working with the local campaign – albeit supporting them – local campaigners had not been successful, for example, in lobbying the council to request the CCG through the Scrutiny committee for an impact assessment of proposed plans for change.

Moreover, campaigners opposed the LSC programme by mobilising the local and national media. Over the years, campaigners developed contacts with journalists to inform them about the situation on the LSC programme and the local opposition. Journalists also shared information with local campaigners relevant to their campaigns. This quote below is an example of how the Grandvalley campaigners received information about the LSC programme from journalists and how, in combination
with other tactics discussed earlier (such as contacting NHS England), they used that information to bring scrutiny on the LSC programme outside the sphere of invited processes.

“[SoH campaigns] are big research groups. They know how to raise money, they know how to organise themselves, who can write press releases, who can get the T.V, who can organise events. So, the NHS are going to have to deal with this one way or another. [...] We found out from a journalist that, at the level of NHS England, they've turned down [the capital bid for the LSC programme] and through a journalist we got a copy of the turned down letter. And of course, the NHS bosses have kept quiet about it, so we publicised it. I got this research group together, which actually does involve one senior NHS person secretly, and we wrote a short paper saying: ‘here are some facts and some trends – which you may or may not be aware of – which would make the allocation of this money for building work pretty much impossible’. We hand-delivered those letters [to NHS England] three days before there was going to be a meeting whereby [LSC leaders] were going to make another bid for this money. Now, I don’t know whether it’s because of the letter, but the meeting was cancelled at short notice and through it we got a reply. The reply said: please be aware – oh by the way we didn’t give them an address, we just gave them the website, they found the address on one of our groups right – please be aware that there will be a very high bar for assurance on this and we will not approve anything unless we are convinced that you know the change – I think that was the word, the change – there is clear evidence that the intended change will carry out, so they wrote to us. Then, we leaked that. And then the [local] NHS I think was very worried about that ‘oh Christ, they're talking to NHS England’. [...] But I mean the whole fiasco [of the LSC programme] and the STP wanted to do a health care and social care integration, you know, neither of them were working. And we [campaigners] exposed this day after day, by demonstrations, by newsletters, by getting the media involved.” (Campaigner 06 – Grandvalley)

In conclusion, since the initial public consultation, campaigners learnt to navigate the invited processes of public involvement as well as the NHS language and coordinated themselves in organised campaigns. Using a combination of tactics, they initiated three concurrent levels of uninvited actions: informing the public about changes; scrutinising and challenging local NHS bodies and LSC leaders; and mobilising actors to oppose change. In contrast with invited involvement activities that were infrequent during the lifetime of the LSC programme and revolved around formal public consultations, uninvited actions from campaigners were conducted uninterruptedly by campaigners who remained dedicated to their cause over the years despite their limited resources and relying on public donations. This was also acknowledged by several participants, including this clinician in Grandvalley:

“A group of campaigners made sure they attended every single meeting. Lots of meetings. [Laughter] Every single meeting. That group of campaigners knew the strategic business case better than [an LSC leader] knew it. That group of campaigners had done Freedom of Information requests, dug deeper and deeper, that was evidence-based. And that group of campaigners deserve a PhD for their work. You know that’s the level of research that they went into for this. And that’s just the intellectual side. As Louise Irvine [GP that chaired the high profile Save Lewisham Hospital campaign] would say: ‘That’s the head side’. But then, they also put their heart into it. And they
also put their hands into it, because they were out distributing a quarter of a million leaflets. Or out on the stalls, or out in the community. And so many people would say to the campaigners, when they were out in Grandvalley: ‘You are not going to win this, you are not going to win this, you are not going to win this’. And, here they are, against the odds.”

6.3.2 Networks of the campaigners

Both campaigns operated within networks and relationships they developed over the years. I mentioned earlier that the two campaigns liaised with each other as well as with other ‘Save Our Hospital’ campaigns in the UK, but they also built networks and relationships with the main actors of large-scale change with various degrees of success. Firstly, both campaigns interacted to a large extent with their local commissioners, identified sometimes by campaigners as the “main enemy”. The type of relationship between the local campaigns and their commissioners varied. In Grandvalley, this relationship was described as “confrontational” by the campaigners. The reason, according to them, was that they were limited by the local LSC leaders in how they could interact with them within the invited forum of meetings in public. Campaigners used uninvited tactics such as writing letters and submitting Freedom of Information requests to further interact with LSC leaders but were still not satisfied with their answers.

“So, with the CCG, the only way to interact is going to public meetings and waiting two and a half hours and asking questions. Or writing letters. Or writing freedom of information requests. In fact, with the managing director of the CCG we've had some really snotty letters and some snotty faces in meetings. So, no, it's a very bad relationship.” (Campaigner 06 – Grandvalley)

In Bluehill, the campaigners’ relationship with their commissioners had evolved over the years and became less confrontational. Local campaigners explained that this was partly due to the attitude of the commissioners, which “didn’t quite stone wall in that way [referring to Grandvalley’s]” the Bluehill campaigners at the start and partly due to the fact that the campaigners were persistent and used confrontational discourse “strategically”. Additionally, the Bluehill campaign had, in the last few years, the full support of their council and were therefore in a position to ask the council to request information on their behalf or confront their commissioners at the local council’s meetings. Two of the campaigners interviewed in Bluehill further added that recently (at the time of my fieldwork) some of the commissioners had been less supportive of the LSC programme, and thus their relationship with those members went from “hostile” to “more friendly” with some of them telling the campaigners off the stage of meetings in public to “keep up the good work” and “without the campaigners, the A&E closures would have not been delayed”. I further observed during my fieldwork that the Bluehill campaigners were able to meet their commissioners outside the meetings in public, which was later confirmed in interviews. At the time of my fieldwork,
the local commissioners had recently started to specifically invite the local campaigners to engagement activities.

“RES: I think we are lucky with our Save our Hospitals because I think they are so reasonable. I think the CCG quite like and respect them, so they often meet with them. I don’t know if they’ve told you, but they seem to meet with [the CCG managing director]. So, the people, the leadership of the CCG respect and take their point of view.
INT: So, do you feel that they are heard then?
RES: Yeah, I think they are actually. Well in the same way that we [the council] are heard but then ignored [laughter].” (Local politician 02 – Bluehill)

“[The CCG] invited me over a year ago to join the patient reference group because in their view we represented a wide perspective of the local people because we are on the streets all the time. So, I think in terms of our influence on the CCG, things like the invite on to the patient reference group and those financial recovery meetings are things that have happened because of our constant attendance at board meetings. They wouldn’t have happened, except they know the eye of the public is on people’s resources and then we use the information in public and that I think is really important. They may not particularly like us, or a lot of them don’t particularly like us, but they have realised that we do have an effect.” (Campaigner 05 – Bluehill)

At the beginning of my fieldwork, the joint CCG was in shadow form and gradually evolved into a more formal structure, holding meetings in public. When asked, early on, if the Grandvalley group was able to build a relationship with the joint CCG, I was told that it had not been possible as the regional health planners were “even more glacial and unapproachable [than the local commissioners]”.

The recollection, below, of a practitioner of public involvement interviewed about one of the early meetings in public of the joint CCG supports the campaigners’ claim and illustrate the attitude of LSC leaders in response to dissenting voices (as highlighted in the previous chapter):

“When the public came in – some of the public are regulars, they come regularly, Save Our NHS generally – I got up and went around and started talking to them. […] Nobody else much did, and I just find that quite strange as well. If you want to get the public on your side at least acknowledge that they exist, and you know, have a conversation with them because you do, to some extent, defuse real problems if you do that. Because otherwise it looks very them and us all the time.” (Practitioner of public involvement 01 – STP level)

Both campaigns’ networks included their local Trust, with whom they had a much less adversarial relationship than with LSC leaders at the time of my fieldwork. In Grandvalley, over the years, the campaigners lobbied the local Trust at their Board meetings in public and via letters. During my fieldwork, it appeared that the Trust leaders’ agenda aligned with some of the issues raised by the campaigners. Consequently, campaigners had ‘backstage’ meetings with their local Trust leaders, who gave the appearance during fieldwork to support the campaigners on certain aspects of their campaign.
“So, I think we’ve moved up another level of lobbying, where I think six years ago, we were certainly afraid to try and deal directly with these people but now we’ve had a meeting with the head of the local Trust. […] And we’ve had subsequent phone calls with them as well.” (Campaigner 06 – Grandvalley)

“We can talk to the Trust. We don’t always agree with them, but I mean it’s much… They are much more accessible than the CCG most definitely. I’ve got their phone numbers and I can ring them up.” (Campaigner 03 – Grandvalley)

In Bluehill, the consensus among campaigners and Healthwatch respondents was that the local Trust improved, in the last few years, their engagement processes with the public and the local campaigners coinciding with a change in CEO. An engagement that continued under the next two Trust CEOs. As a result, in addition to attending the Trust Board meetings in public, the local campaigners were invited to regular private meetings with the Trust leaders to raise their issues falling under the remit of the Trust. Those issues were sometimes related to the LSC programme and sometimes unrelated to it. For example, I observed on a couple of occasions local campaigners relay issues to the Trust related to patient experience in the Trust hospitals, that were brought up to campaigners by the local community during their street stalls. Furthermore, participants from both campaign groups hinted that conflict in the commissioner-provider relationship of their local CCG and local Trust was an important contextual factor in getting a channel of communication with their local Trust and in gaining their support on certain issues related to their campaign.

Finally, both campaigns cultivated relationships with their local politicians. In Grandvalley, although the local council supported the local campaign group, they were not working with them. For several interviewees, the local party being in power for a decade with safe seats, explained their lack of involvement with a campaign group they supported. The campaigners, in turn, did not fully trust their political motives were aligned with theirs as they felt their local council were not fully using their scrutiny powers when it came to the LSC programme.

“[Local politicians] tend to get more and more interested when there’s an election coming up. They have got a different agenda to us: it’s about being elected. Ours is about maintaining a health service that is public and adequately resourced and financed and accessible to all. So, they have a political objective, we have a kind of social objective if you like so it’s difficult. […] If you had a local council that you could trust, and they worked with you, then you would have a better relationship and they’ve got the money right.” (Campaigner 06 – Grandvalley)

On the other hand, Bluehill’s current council (at the time of fieldwork) had unexpectedly won their seats two years after the initial public consultation on the LSC programme – and a few months before the
first emergency department closures in Bluehill and Redtown – running on the platform of “Saving Bluehill Hospitals”, as the previous party supported the LSC programme, endorsing the local campaign group. Once elected, the local politicians collaborated with politicians in Grandvalley to oppose the LSC programme and continued working with their local campaigners. Although welcoming of the political support, campaigners interviewed explained that they only worked with their local council when their interests were aligned as they wished to remain an independent campaign. Additionally, the Bluehill campaign group had the support from one of their Members of Parliament since the inception of the campaign.

6.4 Actors involved in the uninvited process

In the previous section, I described the different tactics used by campaigners at different levels of uninvited actions. In this section, I turn my focus to the local actors taking part in uninvited involvement that I identified in both case studies as: the local campaigners – initiators and main actors of the uninvited process, the local politicians, members of the public and local frontline clinicians.

6.4.1 Local campaigners: main actors of uninvited processes

In these case studies, the main actors initiating and driving uninvited involvement were embodied by the ‘Save Our Hospital’ campaigners in Bluehill and Grandvalley. Some of the campaigners referred to themselves as “activists”, a term also used by some LSC leaders, but in most occasions during my fieldwork, campaigners referred to themselves as “health campaigners”, a term also used by members of the public.

By contrast, in interviews with Healthwatch staff, a local clinician and a practitioner of public involvement, campaigners were labelled as a “lobby group” or a “pressure group” – illustrating the intensity of the campaigners’ uninvited actions in the two case studies – that was opposing change. The campaigners’ opposition to the LSC programme was framed by the LSC leader (in line with my own observations) as a resistance to change from a politicised group who was not representative of the wider community:

“So, a lot of patient activism is dominated by people who are perhaps members of “Save our Local NHS”, or you know, seem to have a wider political interest. And they often approach change with a somewhat sceptical mindset, not necessarily thinking that you are motivated by benefiting patients, so much as saving money. And if you pick a hundred people at random, you tend to get a more open-minded approach.” (LSC leader – STP level)
Two practitioners of public involvement and one Healthwatch representative in Grandvalley also commented that they did not consider that campaigners were representative of the general public’s views. In comparison, for members of the public interviewed (and the public observed during the campaigners’ activities in the community) ‘Save Our Hospital’ campaigners were representative of the local public as they were seen spending time campaigning in the community and discussing the LSC programme with a wide group of local people.

“RES: I am not being funny, but have they invited any of the Save Bluehill people onto their patient committees?
INT: Why do you feel the campaigners should be invited?
RES: Because they got a lot of knowledge and a lot of impact and they listen to people. They listen to the general people. They get out there, they talk to people, they go to meetings, they spend hours talking to people in the street about what their needs are. So, they have a greater knowledge of what the general populace wants. [...] Someone from Save Bluehill speaks to thousands of people and know about their opinions. But I doubt they would want someone from Save Bluehill on there because I think there is some antagonistic stuff.” (Member of the public 02 – Bluehill)

“I’m very glad that [the campaigning] is happening. They do represent the worries and concerns of local people and I’m very pleased that somebody is being very active doing that.” (Member of the public 04 – Bluehill)

6.4.2 The local politicians: a role in both invited & uninvited processes

In section 5.4.5, I described the role of local politicians in invited processes of involvement. During fieldwork, it became apparent that local politicians also played a role in uninvited processes. In Grandvalley, for instance, local politicians started their own ‘Save Our Hospital’ campaign shortly after the initial public consultation in 2012. They further attended demonstrations and sometimes public meetings called by the campaign groups. Sporadically, they challenged the case for change in both invited and uninvited forums. In Bluehill, the campaign had the support of a Member of Parliament from the onset. In addition, the local council after winning their election on the platform of ‘saving the hospitals’ remained very visible to the community as being vocal against the LSC programme by:
- co-opting a member of the Bluehill campaign into the Health Overview & Scrutiny Committee,
- speaking at public meetings called by local campaigners,
- attending demonstrations called by the Bluehill campaign,
- attending the campaign’s monthly meetings,
- using the media and social media to criticise the changes that had taken place in the region and to voice their opposition to the LSC programme,
- producing their own ‘Save Our Hospital’ window posters – with the council logo – and distributing them to their constituents with their annual statements,
- actively questioning the case for change and the evidence put forward by LSC leaders in both invited (including those led by LSC leaders) and uninvited forums,
- attempting to mobilise politicians in other local authorities covered by the STP footprint.

One politician interviewed justified supporting uninvited processes of involvement by the need to deliver their electoral promise:

“It’s very simple, we said if we are elected we will fight to save the hospital so it should – and it was there in our manifesto and it was there in every statement we made – so it should really be no surprise to everybody that when we were elected, we fought to save the hospital in every possible way, we’re not just fighting half-heartedly.” (Local politician 01 – Bluehill)

Another politician further commented they found the contribution of the co-opted campaigner on the Scrutiny committee as “invaluable” and “representative of the resident voice”:

“I think it’s very good to have someone like [the co-opted campaigner] who has a very balanced view. He doesn’t oppose everything. He reads all the papers, which, when I’ve been to other committees, other members don’t necessarily read the papers in enough detail to be able to say on page five they have this amount of people. He goes to the CCG meetings, so I think it’s invaluable having him there. And he’s not politically affiliated so he is sort of impartial and really seems to be a true representative of the resident voice.” (Local politician 02 – Bluehill)

Local politicians in both communities took a further step in uninvited actions by commissioning an independent commission of experts after the first closures took place in 2014. The objective of this independent expert commission was to scrutinise the evidence around the case for change for the LSC programme, the impact of the closures on remaining health services as well as to review how the 2012 public consultation was conducted (Figure 8). A few LSC leaders, both campaign groups, as well as local Healthwatch organisations, local politicians, local frontline clinicians and members of the public “provided evidence” to the independent commission. According to one of the experts involved in the commission interviewed, “it gave the local people a chance to have their voice heard”. Overall, the findings of the independent expert commission backed up the arguments made by the campaigners regarding the case for change and the public consultation process. However according to interviewees, the commission’s findings had little or no impact on the proposals for change or on subsequent invited processes of involvement.

“I think [the commission] was important in showing that the arguments that we were making were not just political, which a lot of people were dismissing about. But there was an intellectual underpinning to them. And I think that was essential.” (Local politician 01 – Bluehill)
“[The commission] raised the profile of the whole thing, so it gave [the councils] a chance to underpin their case with very good sound evidence and raise the profile across the country. […] I doubt it had any impact. I mean I don’t know that it did or not, but other than to annoy [LSC leaders]… I mean I’m sure they were very annoyed by it, so they prefer to just get on and do what they want to do, what they are told to do at the centre. So, it’s unlikely to have had any.” (External expert)

“[The independent commission] showed the aspects which they were quite worried about and I think that slowed down the impetus which had been behind [the LSC programme] initially.” (Campaigner 01 – Bluehill)

Some participants criticised how local politicians were instrumentalising the campaigns and the LSC programme for political purposes. In Grandvalley, campaigners during interviews and their monthly meetings certainly seemed to think their local council took credit for the campaign’s activities. In Bluehill, the local campaigners seemed to trust their local politicians involved in opposing the LSC programme, and because their local council was not as safe as Grandvalley’s, found it was easier to communicate and collaborate with them than Grandvalley campaigners did.

6.4.3 The public: uninvited actions as a means to have a voice

Two of the five members of the public interviewed did not take part in uninvited actions. One of them supported the work of the campaigners but had moved away since the initial public consultation in 2012 and the other did not believe that campaigners could have an impact on decisions about the LSC programme without the local council taking actions.

The three other members of the public interviewed took part in uninvited actions. All, as a patient or a carer, opposed the service closures. Before interacting with their local campaigners, all three interviewees had taken part in invited involvement activities and felt that public concerns were not taken into account as decisions were already made before consulting the public. As a result, they expressed that taking part in uninvited actions was “a way of having a voice”. All expressed that they would have liked to be more involved in uninvited processes but could not due to other time-consuming commitments. Meanwhile, all three interviewees signed petitions led by their local campaigners; one supported local campaigners by leafleting occasionally for them; another took part in a demonstration organised by local campaigners; and all attended public meetings called by campaigners.

A common sight in residential areas around the hospitals in Bluehill and Grandvalley was ‘Save Our Hospital’ posters on people’s home front windows or car. I therefore asked all three interviewees if they had one as well and why. One participant explained that they would but could not afford to print
the poster they had received by email. The other two participants had put up a poster as a way to show their opposition to further closures, which they “felt very strongly about it” and as a way to express their voice:

“The reason I put [a poster] up is because again, it’s a way of having a voice. And I think if you can get enough, then it becomes more than individuals, it becomes more of a picture of people’s voice being expressed visually. So that’s why, because I want to say unequivocally where I stand on this issue. Because right in the beginning I didn’t, because I thought I need to understand the evidence first, because of what I do, where I work. So, I was cautious to start with, but once I understood more about the plans and the evidence about services elsewhere then I just became certain that this was a bad idea. So that’s when I was more inclined to sign things [petitions] and put things in my window etc.” (Member of the public 04 – Bluehill)

As highlighted in the quote above, before taking part in uninvited actions, all three interviewees explained that they had considered the evidence for consolidating health services in the region and believed their access to them, particularly in an emergency situation, would be much more difficult. Additionally, beyond their emotional attachment to their local hospital as a patient or a carer, they were not convinced that remaining services could cope with the additional pressure exerted since the first closures and thought that further closures would be detrimental to service users.

Therefore, all three interviewees, despite participating in invited involvement activities, decided to take part in uninvited actions to voice their opposition to the LSC programme. They chose uninvited actions instigated by their local campaigners because they were visible and accessible in their communities. Hence, in contrast to LSC leaders in invited involvement, local campaigners widely advertised opportunities to take part in their actions. Additionally, the three interviewees deemed that their local campaigners were well-organised, dedicated, efficient and had extensively researched the LSC programme and its implications for local communities.

“I signed the petition not because of talking to people there, because I already knew what the issues were, so I signed the petition because it was there, but I already knew how I felt about it.” (Member of the public 04 – Bluehill)

“I do some of the leafleting for them. And as and when some of their events, the date and the time is convenient for me, I do go there, and they attract a lot of people, because they do it by locality and they advertise it a lot. And they also advertise the venue of their own meetings, the venue and the time, so that anybody who wants to go to that meeting is welcome to attend. And also, when they want to organise a demonstration, again, they publicise it a lot, through leafleting and they have a network of people who do the leafleting for them, including me.” (Member of the public 01 – Grandvalley)
“[Campaigners] are local people. They are very direct and efficient. They have gone through little tiny details about it. One of the scrutiny meetings I went to at the town hall, there were 3-4 campaigners there. And the inside knowledge that they had to challenge the [LSC leaders] was amazing. It was very impressive. They were very knowledgeable, they have done a lot of research, spent a lot of time dealing with it. Spending a lot of time campaigning in all weather. When I signed the petition in the main street it was raining a lot and they were all campaigning. They are a very dedicated bunch of people and I feel thankful that they are on our side.” (Member of the public 02 – Bluehill)

Therefore, campaigners provided the public with new avenues to voice their concerns or opposition to the LSC programme, in parallel to invited processes. In particular during most of my fieldwork, members of the public did not have invited platforms to be involved in besides attending commissioners’ meetings in public not designed for a lay audience and taking place during working hours. Towards the end of my fieldwork, there were more invited opportunities in Bluehill around the Urgent Care Centre consultation (section 5.3.8), which campaigners encouraged members of the public to take part in to give their views on the proposals.

6.4.4 Local clinicians: a discreet involvement in uninvited processes

Local frontline clinicians were not visibly involved in plans for change under the LSC programme. It further appeared that to be involved, local clinicians had to use invited public involvement forums as highlighted in section 5.4.6. One of the clinicians interviewed in Grandvalley, along with a group of colleagues, did not feel heard during the initial public consultation and therefore turned to uninvited actions. Based on this interview as well as interviews with campaigners, observations of campaign events and documents collected (such as newspapers, academic papers and campaign documents), a group of clinicians in Grandvalley opposed the LSC programme and, besides being vocal about it in invited forums, further took uninvited steps to voice their opposition at the commissioning level, at the Trust level, and in meetings of the British Medical Association. They further gave their view on the LSC programme in newspaper articles; wrote several letters to the Secretary of State for Health and Social Care; took part in TV debates; organised meetings for local frontline clinicians; compiled and published data to highlight that closures under the LSC programme were targeted at services in deprived areas and that the implemented closures put pressure on remaining services in the region; and provided evidence against the LSC programme to the independent expert commission.

Some local frontline clinicians additionally supported their Save Our Hospital campaign. That support was more overt in Grandvalley with local clinicians speaking at rallies, demonstrations and public meetings organised by the campaigners. Sometimes, local frontline staff would assist campaigners in their street stalls. Some further assisted campaigners in their research on the LSC programme. The
clinician interviewed in Grandvalley expressed that the local campaign engaged with frontline clinicians better than LSC leaders did during invited processes. Clinical support for the campaigners in Bluehill was more covert and often under the cover of anonymity when providing campaigners with information. One of the campaigners in Bluehill argued that frontline staff did not feel safe to speak up about the changes (section 5.4.6). The situation seemed to slightly begin to change after the government announcement that the programme was dropped as I observed a local GP attend a campaign meeting to discuss their disapproval of the proposals for the Urgent Care Centre and the upcoming national reconfiguration of primary care.

“The community actually engaged with me better than anyone else did. And then I started attending the [GSoH] meetings. […] Whenever there was a rally, or whenever there was a public meeting, or even when Bluehill would put up public meetings, even others would ask me to speak. So, in part, I started off almost becoming part of the sort of spokesperson for that group. But then, also the one who could bring medical information and make reasoned medical arguments amongst that group. And then, towards the end, we actually started forming a group where we would analyse data together. And we were writing to NHS England, we were writing to NHS Improvement, we were putting out reasoned arguments to NHSE and NHSI. We were even all submitting the things for the Parliamentary Enquiry into STPs led by the Health Select Committee. So, if you can see, whilst [the LSC programme] was supposed to be this group of clinicians causing this reconfiguration, they had no evidence-based arguments. They had no reality-based arguments. Yet, with all due respect, I had this group of pensioners [Laughter] who had incredible professional backgrounds, […] there were people with so many different backgrounds who, collectively, made more sense than any of the people managing [the LSC programme].”

Both campaigns further mentioned that they had many NHS staff signed up to their newsletters. At the time of my fieldwork, involvement of local clinicians in uninvited processes was more discreet than in the first years of the LSC programme. For a local clinician interviewed, clinical involvement faded because of campaign fatigue:

“I think people became tired or people felt that they weren’t being listened to. And eventually, you get to a point where people start thinking, ‘what’s the point?’. And actually, so many of my colleagues kept saying to me ’you need to get over this now, you know. What’s the point? This is a losing battle.’”

6.5 Impact of uninvited involvement

Campaigners did not foresee that “their battle” would last so long and several campaigners in interviews and during fieldwork expressed their lack of impact on stopping the closures under the LSC programme. In particular, campaigners in Grandvalley framed the closure of the maternity in their
hospital as a failure of the campaign despite their intense uninvited actions (such as lobbying,
demonstrations, petitions) in the year before the closure.

“I mean the only time we dented that is when we took over one of their meetings once with the
mums during the maternity process. And that was the only time I think they were really genuinely
quite scared, but it did not stop them closing the maternity, but I think they got quite nervous.”
(Campaigner 02 – Grandvalley)

Yet, through the combined work of the campaigners over time, uninvited involvement had
some impact on the LSC programme by slowing down the pace of change. Campaigners since the initial
public consultation in 2012 remained active in scrutinising and questioning the evidence put forward
by LSC leaders in both invited and uninvited forums. Campaigners, as part of their tactics, focused on
scrutinising the LSC programme even when information was not available through for example
Freedom of Information requests, contacting NHS England and NHS Improvement, working with the
media and used invited public involvement forums to challenge LSC leaders. Their work added an extra
layer of scrutiny to planned changes, more in depth and continuous than the periodic scrutiny of local
authorities in the region. Additionally, the campaigns, through their research, contributed to
demonstrate some of the failures related to changes implemented under the LSC programme such as
the lack of implementation of community services and the pressure put on remaining emergency
departments in the region to cope with demand after the two closures in 2014 (Figure 8). Accordingly,
campaigners raised the profile of the LSC programme by mediatising and (re)politicalising the large-scale
changes, mobilising in the process – with various degrees of success – local actors such as members of
the public, local politicians and local clinicians. For the majority of interviewees, by politicising and
scrutinising large-scale change, the campaigns contributed to delay the closures of the Emergency
Departments in Bluehill and Grandvalley.

“I don’t think [campaigners] are going to have an impact on the closure long-term but I think they
will have an impact on putting it off, putting it off. Hopefully if [LSC leaders] put it off for long
enough they will change their minds. They have already put it back 2 years so I think the council,
and I think Grandvalley’s was involved as well, and BSoH campaign have had an impact. And
the meeting I went in in the Town Hall, I must admit the [LSC leaders] were squirming a little
bit. I don’t think they realised how knowledgeable the campaign people were and what research
they’d done. And they had access to documents, their own documents, that obviously someone in
that organisation gave them.” (Member of the public 02 – Bluehill)

“The Bluehill hospital changes that I mentioned, they’ve been going on for years and years… And
not much has been agreed because there’s been such push back from the local patient pressure group
and also the council. So, none of that has managed to progress and so that’s an example where the
feedback has stopped the changes being implemented.” (Local clinician 02 – Bluehill)
“Well they’ve made the thing so high profile [laughter]. They have a very large following, a lot of members so that’s verifiable. And they have Bluehill Council’s support, so you’ve got quite an impact together.” (Healthwatch 02 – representing Bluehill at the STP level)

“I think if we hadn’t been involved [LSC leaders] would have been able to proceed easily. We wouldn’t have had a change in the council, we would not therefore have had a public voice around. I mean the CCG knows that we have a huge public audience and that we got the council elected. They know that and that has meant that they’ve had to slow down. That also gave time to get the voice out that the A&Es were being overworked, so they couldn’t just go ahead.” (Campaigner 05 – Bluehill)

Hinted at in the above quotes, several participants (Healthwatch, members of the public, external expert, lay member), including campaigners, attributed the impact of uninvited involvement on the LSC programme to the fact that campaigners were able to mobilise and collaborate with their local councils – that had a legal (invited) route to challenge the LSC leaders – and to keep the LSC programme on the political agenda. Many respondents highlighted that the support of local politicians was crucial in delaying the closures. The independent expert interviewed further compared the local campaigns to other campaigns in England that did not have an impact on closure plans because they could not mobilise their local politicians and their scrutiny powers.

“I think we are part of the process of building a movement to defend the NHS and it’s absolutely important that those messages are going out and I think we have a big political impact. I think we hold the councils nervous and I know it’s not as good as we would like but I think we’ve kept the Grandvalley council going, not as good as I would like and not as good as Bluehill. We’ve certainly kept them going but it’s been important that they have been out and vocal and I think our presence has kept that going. I don’t know if they would’ve kept it up if there’d be no campaign in the community, who knows? Maybe they wouldn’t have carried on, we don’t know. (Campaigner 02 – Grandvalley)

“I think we’ve had a significant effect on local politicians who actually knew nothing – with one or two very honourable exceptions – about health. I think we’ve got a council that is much more clued up about health than it was before and that listens to us about health. It doesn’t always follow what we want but, but it does listen to us and I think that that’s very important.” (Campaigner 05 – Bluehill)

“Some people in the focus group said to [a practitioner of public involvement]: ‘What’s the point of us telling you this? Because it’s not going to make any difference anyway’. And there’s me, suddenly springing up the NHS defence, and saying ‘Well that’s not true, it was because of people opposing the closure of the A&E that it didn’t happen’. [The practitioner] is grateful and at the same time, I’m thinking well, that’s one way of putting it [chuckling]. It’s not like the NHS chose that, it’s not like they ever decided that they were going to listen to the opposition. It was something that got imposed on them, politically imposed on them. Again, it wasn’t the group of residents, it’s
"part of a massive political thing that it happened. The campaigners without the politicians would never have been heard.” (Lay member – STP level)

Therefore, opposing voices through the initial public consultation initiated by LSC leaders in 2012 did not have an impact on the plans for change. However, over the years, uninvited involvement was more successful in influencing decisions about the LSC programme than invited involvement. Interestingly, uninvited actions also had an impact on invited involvement processes. First, by politicising the issue and undertaking visible actions in the community, campaigners maintained the LSC programme in the public eye. As described in section 6.3.1, one of the campaigners’ strategies was to raise awareness in their local community on the changes to health services, mobilising their support but also informing them of invited involvement opportunities, and encouraging the public to take part. Moreover, during fieldwork, both campaigns consistently brought up in invited forums the inadequacies of invited public involvement and called for better engagement and consultation with the public. In Bluehill in particular, between an omnipresent campaign (sections 5.4.3 and 6.3), vocal local councillors elected on the platform of saving the local hospitals (section 6.4.2), and an active local Healthwatch monitoring public involvement (section 5.4.4), the local commissioners were pressured into conducting more public engagement activities than Grandvalley’s.

6.6 The LSC programme is dropped: the end of the campaigns?

A couple of months before I ended my fieldwork (Figure 8), the Secretary of State for Health and Social Care unexpectedly announced that the LSC programme was no longer supported by the Department for Health & Social Care, NHS England or NHS Improvement and as a result the emergency departments of Bluehill and Grandvalley hospitals were to remain open. Although the announcement was unexpected it did not come as a surprise to several local actors as in the months before the announcement, they had disclosed to me confidentially during interviews or in informal chats during observations that the LSC programme was “dead in the water”. No reasons were put forward by the government for dropping the LSC programme that ran for almost a decade. Speculations by local actors during fieldwork were that public opposition delayed the closures but ultimately the lack of capital funding was the main reason for dropping the programme. Furthermore, for local actors, the decision to drop the LSC programme was a unilateral decision from the central government without involving the LSC programme’s leaders.

Indeed, the local LSC leaders – although guessing it might happen as their financial bid for the implementation of the remaining closures was turned down several times – were notified through that government announcement as well according to some participants. In fact, the LSC programme was
still on the agenda of several meetings in public I observed in the month leading to the government announcement. By coincidence, the day after the announcement, four meetings in public were scheduled to take place. In the morning, Trusts in both communities held their board meetings. Trust leaders in Grandvalley seemed taken aback by the announcement and applauded the decision, congratulating the campaigners in attendance for their work after the meeting ended. Meanwhile, the same was happening at the Trust board meeting in public in Bluehill, according to interviewees. In the afternoon, the Grandvalley commissioners were also holding their meeting in public. Local campaigners did not attend this meeting as they had gone to the morning Trust meeting and were planning to attend the Scrutiny meeting happening in the evening with the regional and local LSC leaders. The local commissioners were pleasantly surprised to see that no campaigners were in attendance (I was the only member of the public present) and went through their meeting in 45 minutes instead of the usual 2 hours. Finally, in the evening, came the time for the Grandvalley Scrutiny committee meeting whose main agenda item was to discuss the strategic case of the LSC programme and the public involvement strategy led by the STP level going forward in light of the recently published NHS strategic document The Long-Term Plan. Given the announcement made the day before by the government, the LSC leaders instead provided their statement about the announcement focusing on the programme’s achievements for example in maternity and paediatric care (in a manner reminiscent to what was written in the leaked document mentioned in section 5.4.1). The local politicians in the committee were more critical this time about the LSC programme than in previous meetings I observed, mainly around how invited involvement was conducted in the past. Given that the programme had been dropped, they particularly welcomed the new opportunity for better public involvement as plans were being drafted for the move to the Integrated Care System in line with the Long-Term Plan (section 5.6). One of the LSC leaders responded by explaining that cautious consideration should be taken around the involvement language “as this would not be a formal consultation, but more of an engagement process in which officers would explain the aspirations contained within the NHS Long Term Plan, whilst also exploring the public’s views and priorities” – in line with the findings of section 5.3.1.

Did the government announcement mean the end of the campaigns in Bluehill and Grandvalley, since their local hospitals had been ‘saved’? As mentioned in section 6.2, the scope of the campaigns had evolved since 2012 beyond just opposing the closure of local services to scrutinising all types of changes in their local NHS, focusing in particular on changes to service provision when private providers were involved. Therefore, after a couple of celebrations in their communities, the campaigns remained as active as before, moving their attention towards the case for change for the Integrated Care System (ICS) (section 5.6). Towards the end of my fieldwork, as the LSC leaders prepared the ICS change, campaigners and local politicians did not believe that LSC leaders had reflected on the lessons learnt from the LSC programme and started to campaign for accountability over the failures of the
programme. Some campaigners admitted it will be harder to mobilise the public without the focus of saving the local hospital, something described as more concrete for the public. The campaigners might further have to adapt their tactics under the new governance model of ICS as their local NHS decision-makers might be one layer further removed from the public, with uncertainties, at the time of writing, where local councils would fit in the new model in terms of local scrutiny and accountability. On the other end, the LSC leaders, after the LSC programme was dropped, decided to ‘engage’ with the ‘Save Our Hospital’ campaigners and held private meetings with representatives of each campaign to discuss the ICS case for change.

6.7 Summary of the main findings in this chapter

In this chapter, I bring into focus how some members of the public, local residents in Grandvalley and Bluehill, feeling that their opposing views during the initial public consultation had not been considered, self-mobilised and formed local ‘Save our Hospital’ campaign groups. Both campaign groups shared many characteristics and focused their actions on opposing plans for closures of their local hospital services under the LSC programme. Over time, the scope of those campaigns evolved from saving their local hospitals to scrutinising all changes – not just those under the umbrella of the regional LSC programme – introduced by local and regional health planners. Distrusting the motives of LSC leaders for change, local campaigners aimed to oppose “cuts” to local health services and the “privatisation” of those services. To enact their opposition, campaigners developed two strategies: on one hand raising awareness in their local communities about the plans for change and on the other scrutinising and “lobbying” decision-makers.

Since the initial public consultation (described in 5.3.2), campaigners learnt to navigate the invited processes of public involvement, as well as the NHS language, and coordinated themselves in organised campaigns. Using a combination of tactics summarised below in Table 8, they effectively initiated three concurrent levels of uninvited actions: informing the public about changes; scrutinising and challenging LSC leaders; and mobilising actors to oppose change. In contrast with invited involvement activities that were infrequent during the lifetime of the LSC programme and revolved around legal requirements for public consultation (section 5.3.1), uninvited actions from campaigners were conducted uninterruptedly by campaigners who remained dedicated to their cause over the years despite their limited resources and relying on public donations. As a result of their continuous uninvited actions (summarised in Table 8), both campaigns became – and remained – very visible to their local communities, to LSC leaders and to local politicians, hence keeping the LSC programme and public involvement in the public eye and on the political agenda.
Yet, despite their presence at most invited involvement opportunities and their sustained uninvited actions, LSC leaders evaded the opposing views and the counterevidence presented by those local residents turned “health campaigners” (see sections 5.2 and 6.3). Instead, the LSC leaders framed the campaigners’ opposition to the LSC programme as a resistance to change from a politicised group, who was not representative of the wider community. Whilst LSC leaders avoided engaging with the evidence put forward by campaigners – based on patient experience, knowledge of the community and research conducted to disprove the clinical and business cases for change – local politicians valued it. Perceived as true representatives of the local community, themselves local residents and in touch with many others through their community activities, both campaigns briefed their local politicians on the LSC programme, healthcare and health planning issues and mobilised their scrutiny powers, with various degrees of success.

While a couple of interviewees also questioned the representativeness of the campaigners’ opposition of the wider public, members of the public interviewed (and the public observed during the campaigners’ activities in the community) found their local campaign representative of the local views as they were seen spending time campaigning in the community and discussing the LSC programme with a wide group of local people. Members of the public interviewed had been involved in invited processes before taking part in uninvited actions that they supported as another way to voice their opposition to the LSC programme.

Beyond the mobilisation of other local actors to oppose change, such as members of the public, local politicians, local clinicians and the media (Table 8), both campaigns operated within networks and relationships they developed over the years. By directly informing and engaging with the public in the community, engaging with local clinicians – mostly overlooked in invited involvement (sections 5.4.6 and 6.4.4), liaising with other campaigns in the country, building relationships with local Trust leaders and involving local politicians in their mobilisation, local campaigners developed over time a network of influence, becoming a local actor of their own in large-scale change and public involvement. As local actors, campaigners initiated uninvited processes in parallel to invited ones and developed the capacity to scrutinise and challenge decisions made by health planners regarding changes in provision, financing and access to health services in the region.
Table 8. Summary of tactics used by local campaigners to oppose plans for change

<table>
<thead>
<tr>
<th>Degree of uninvited actions initiated by local campaigners</th>
<th>Tactics used by local campaigners</th>
</tr>
</thead>
<tbody>
<tr>
<td>* Informing the public about change</td>
<td>* Producing information leaflets and ‘Save our Hospital’ posters for the public</td>
</tr>
<tr>
<td></td>
<td>* Monthly street stalls in the local community and in community events</td>
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<tr>
<td></td>
<td>* Public meetings</td>
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<td></td>
<td>* Campaign website and social media</td>
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<td></td>
<td>* Newsletters for the public</td>
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<tr>
<td></td>
<td>* Informing the public of invited involvement opportunities</td>
</tr>
<tr>
<td>* Scrutinising and challenging LSC leaders</td>
<td>* Attending meetings in public held by commissioners, local trust and local authority (invited involvement)</td>
</tr>
<tr>
<td></td>
<td>* Conducting research to verify and counter the arguments put forward by LSC leaders</td>
</tr>
<tr>
<td></td>
<td>* Writing Freedom of Information requests to LSC leaders for information on the evidence underpinning the case for change</td>
</tr>
<tr>
<td></td>
<td>* Engaging with local frontline clinicians</td>
</tr>
<tr>
<td></td>
<td>* Lobbying</td>
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<tr>
<td></td>
<td>* Contacting NHS England and Improvement</td>
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<tr>
<td></td>
<td>* Providing evidence to the Independent Reconfiguration Panel &amp; external experts commissioned by local politicians</td>
</tr>
<tr>
<td></td>
<td>* Writing formal responses to public consultations</td>
</tr>
<tr>
<td>* Mobilising other actors to oppose change</td>
<td>* Maintaining a visible presence in invited public engagement and consultation</td>
</tr>
<tr>
<td></td>
<td>* Mobilising the public via petitions</td>
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<tr>
<td></td>
<td>* Mobilising the public and local politicians for local and national demonstrations</td>
</tr>
<tr>
<td></td>
<td>* Briefing local politicians on the LSC programme, healthcare and health planning issues</td>
</tr>
<tr>
<td></td>
<td>* Lobbying and mobilising local scrutiny powers</td>
</tr>
<tr>
<td></td>
<td>* Contacting the media (including leaks)</td>
</tr>
<tr>
<td></td>
<td>* Co-opting frontline clinicians to share their views at campaign meetings and public meetings</td>
</tr>
</tbody>
</table>

Therefore, opposing voices through the initial public consultation initiated by LSC leaders in 2012 did not have an impact on the plans for change. However, over the years, uninvited involvement was more successful in influencing decisions about the LSC programme than invited involvement, mainly by slowing down the pace of change and delaying service closures. Through their tactics and continuous work, campaigners added an additional layer of scrutiny to planned changes and their implementation, emphasising public and patient perspectives, even after the public consultation ended. Moreover, the campaigns, through their research, contributed to demonstrate some of the failures related to changes implemented under the LSC programme. Accordingly, campaigners raised the profile of the LSC programme by mediatising and (re)politicising large-scale change. This chapter further highlighted the role of politicians in public involvement in large-scale change. Described in the previous chapter (section 5.4.5) as oscillating between collaboration and confrontation with LSC...
leaders, local politicians further supported uninvited actions, which for several interviewees enabled the impact of the campaigns on decision-making.
Chapter 7 – Discussion

I start this chapter by bringing together the findings from my scoping review presented in Chapter 4 and my qualitative study presented in Chapters 5 and 6. In exploring the dynamics of public involvement in my case studies, I first present an alternative model of public involvement, adapted to the context of large-scale change and grounded in empirical data. This model presents, in detail, involvement processes in large-scale change looking at involvement mechanisms initiated by health planners and by members of the public campaigning against the change. It addresses some of the gaps identified in conceptual models in the wider healthcare literature. I then discuss my empirically grounded model in relation to other studies and debates around public involvement, bringing out omitted aspects of involvement in large-scale change. In this, I further consider the implications of my research for practice, policy and research, reflecting on the strengths and limitations of my research. Finally, I conclude this thesis noting the contributions of my research and future steps.

7.1 Towards a model for understanding public involvement adapted to the context of large-scale change

This thesis explored the dynamics of public involvement in decisions to change health services at a large-scale, looking at the international evidence in the literature on the topic (Chapter 4) and using empirical case studies (Chapters 5 & 6). The findings of this thesis demonstrate that two modes of public involvement take place in the ecosystem of large-scale change: invited public involvement led by leaders of the LSC programme in my case studies, was limited to three levels of involvement representing different degrees of involvement (as depicted on the left-side of Figure 9). The two main public involvement levels were ‘consultation’ – tied to the NHS legal requirement to consult the public in substantial change (Health and Social Care Act, 2006) – and ‘engagement’ – regrouping all types of involvement not tied to the legal requirement. This corroborated one of the findings of the scoping review (section 4.3). Defined vaguely by LSC leaders at the outset, these two levels of involvement as conceptualised in large-scale change were not reflected in the multitude of definitions for involvement encountered during my PhD (Appendix 1). Furthermore, I argue that there was an additional, albeit
implicit, degree of involvement in the case studies: ‘information’. First in Wilcox’s (1994) model of involvement, and described as a degree of tokenism in Arnstein’s (1969) ladder (section 2.1), this level is a pre-requisite to engagement and consultation activities. However, accounts from participants and observations indicated that this degree of involvement was often lacking when informing the public about the case for change and opportunities to take part in engagement and consultation activities. Two thoughts are striking when comparing these three levels of involvement (information, engagement and consultation) with the involvement frameworks presented in Chapter 2. Firstly, none of the frameworks based on Arnstein’s ladder (Feingold, 1977; Brager & Specht, 1973; Morgan & Lifshay, 2006; Skelcher, 1993; Burns, Hamilton & Hogget, 1994) reduced to three levels the complexity of public involvement. Secondly, none of the frameworks included an ‘engagement’ level.

Furthermore, these levels of invited involvement were not conducted in parallel to the process of large-scale change. The data collected in the case studies pointed to the fact that public involvement, in particular at the level of consultation, was rushed and not taking place at a formative stage of the proposals for change as advocated in national guidance documents (NHS England, 2016a, 2018b). Participants also brought up the lack of involvement opportunities following the initial public consultation, even at the first level of information. This was exemplified by the lack of information provided to the public after the consultation stage regarding the implementation of the changes, services put in place as a replacement to closed services and future plans for change. Therefore, based on the evidence collected in the case studies, it appears clearly that the degrees of invited involvement in large-scale change are dictated foremost by the legal imperative to consult the public. The motivation for LSC leaders – who were always careful with their use of the word consultation and correcting other actors when using it – to conduct public involvement was to adhere to their legal requirements and avoid judicial review, which was perceived as a delay to the implementation of change. This was further illustrated by my observations of local politicians in one case study, who used the threat of a judicial review to pressure LSC leaders into conducting more public involvement in the context of local changes to out-of-hours provision. The motivation to conduct public involvement to adhere to legal requirements and avoid judicial review and delays in implementation was also noted in other studies (Mahadkar, Mills & Price, 2012; Carter & Martin, 2016; Martin, Carter & Dent, 2018; McKevitt et al., 2018; Carter & Martin, 2018).

The question of which publics were involved in invited mechanisms, and their representativeness of the wider public, was a common theme in my qualitative study (sections 5.3.4, 5.4.3 & 6.4.1) and in studies included in my scoping review (section 4.4.1), thereby reflecting wider debates in the involvement literature (Weale et al., 2016; Dean, 2017; Barnes et al., 2004). On the top left-side of Figure 9, I placed LSC leaders on top of invited involvement (associated by participants with
a rushed timing in relation to change), depicting their control over the process. Under each invited level, I further indicated which publics were commonly sought by LSC leaders. Informing the local public about plans for change and involvement opportunities was an implied level in the change process but not explicitly identified by LSC leaders and involvement practitioners in interviews – I have therefore used a dotted arrow onto the next level of the invited process to denote this. Aimed at the wider local public, the information level in practice was limited in its aim to reach the local public. The next degree of involvement – engagement – regrouped any involvement activities taking place outside the legally mandated consultation period. In practice, engagement activities were much lower in intensity than consultation ones, in terms of the number of people involved and the number of methods used. Methods of engagement during fieldwork were limited to the possibility for the public to attend meetings in public held by different actors such as LSC leaders, local authorities or local Trusts (sections 5.3.3, 5.3.6, 5.3.7) and, in one case study, to attend public workshops (section 5.3.5). These meetings – not tailored for lay people (section 5.3.3) – were attended by a public, that I qualify, in Figure 9, as a public of ‘regulars’ (building on descriptions from practitioners of public involvement in my case studies) since members of the public in attendance tended to be either lay members sitting on committees, local campaigners, Healthwatch representatives and/or members of GPs Patient Participation Groups, rather than the wider public. Characterised by being the highest involvement intensity in change, the level of consultation re-opened to the local public as LSC leaders actively sought to involve large numbers of the public, using a mixture of methods (e.g.: public meetings, surveys, consultation document for the public, focus groups, streets stalls, roadshows, events in the community) (see sections 4.2, 5.3.2, 5.3.8). However, consultation was not aimed at the local campaigners, the mobilised alliance of politicians and the local frontline clinicians but claims legitimacy through larger numbers of participants rather than the degree to which they engage with information in-depth and deliberated together. Additionally, after consultation, there was no further involvement of the public, for example during the implementation of the large-scale change.

Like most studies included in my scoping review (Chapter 4), the LSC leaders in my case studies used a ‘top-down’ model of planning (Farmer & Nimegeer, 2014). Adopting a technocratic approach to involvement (Jones, Fraser & Stewart, 2019a), the invited processes were controlled by LSC leaders – from agenda-setting to the information provided to the public, methods of involvement, location, how the public could interact with LSC leaders, how the public feedback was gathered and how it was used in decision-making – with little opportunity for other actors to contribute to its design. This also applied to practitioners of public involvement who, despite their professional backgrounds, had little power in influencing LSC leaders in their choice of invited methods when pushing for more meaningful and representative ways to involve the public, better suited for lay people. Furthermore, the mandated public consultation, as conducted by LSC leaders, constrained public input by using superficial ‘one-off’ and
rushed methods of involvement – with no opportunity for in-depth reflection over time or deliberation together. Owing these processes, invited involvement in large-scale change is therefore under the complete control of decision-makers, as reported in other studies (McKevitt et al., 2018; Ocloo & Matthews, 2016; Fudge, Wolfe & McKevitt, 2008). Critically, this leaves the public taking part in invited activities feeling that decisions are already made before they are consulted (Abelson & Lomas, 1996; Abelson, 2001; Rutter et al., 2004; Gold, Abelson & Charles, 2005; Scottish Health Council, 2006; Thurston et al., 2006; Independent Reconfiguration Panel, 2010; Airoldi, 2013; Roberts, 2014; Barratt et al., 2015; Jones & Exworthy, 2015; NHS Clinical Commissioners, 2015; McKevitt et al., 2018; Scottish Health Council, 2008; Foley et al., 2017). As put forward by McKevitt et al. (2018), this technocratic approach to involvement relegates the public to a role of substantiation and verification in facilitating the implementation of large-scale change rather than having a more significant role in actually influencing decision-making. In my case studies, some participants further suggested that invited processes were designed by LSC leaders to get their preferred outcome, a critique also found in the literature (Boyle & Steer, 2008; Turner et al., 2016). Consequently, participants in my qualitative study perceived invited involvement as a “legitimisation strategy” (Summers & McKeown, 1996; Harrison & Mort, 1998; Church et al., 2002; Flood et al., 2015) for decisions that would have been made with or without the public’s support.

As a consequence, invited involvement was experienced by the public as not adapted for a lay audience, lacking transparency and offering few opportunities for public deliberation. This rendered the public with no real possibility to influence decisions already made, fuelling feelings of mistrust towards the motives for change – in line with several publications included in my scoping review (Abelson & Lomas, 1996; Barratt et al., 2015; Jones & Exworthy, 2015; Moore, 2006; Roberts, 2014; Scottish Health Council, 2006; NHS Clinical Commissioner, 2015). This was further symbolised, in my case studies, by the setting and format of most invited forums described in Chapter 5, whereby the public was usually situated as an audience for a stage of decision-makers rather than participants at the table. In addition, like in other studies (Ruane, 2014; Abelson & Lomas, 1996; Garnett, 1999; Edwards, 1995; Independent Reconfiguration Panel, 2010; Roberts, 2014; Barratt et al., 2015; Scottish Health Council, 2006), involvement was rarely ‘inviting’ given that efforts were rarely made to adapt to a lay audience. Indeed, involvement activities were hardly advertised to the wider public and usually took place at times inconvenient for most members of the public. Invited processes were further designed in ways that offered very little or no opportunity for public deliberation. As a result, the evidence mobilised by different groups of the public and other local actors on the case for change was often ignored by LSC leaders and difficult topics (such as the finances related to the LSC programme) were mostly avoided in invited forums. Moreover, LSC leaders routinely omitted from minutes or reports on invited activities public emotions as well as confrontational and agonistic public responses, as part of the process of
downplaying the political and controversial aspects of change (Weale, 2016; Stewart et al., 2019; Martin, 2008; Barnes, 2008). Consequently, several participants described invited involvement as a “staged window display” where decisions were made “backstage”, resonating with Goffman’s (1959, 1963) conceptualisation of public involvement events and perspectives reported in another study (Coultas, Kieslich & Littlejohns, 2019). Combined with the “secrecy culture of the NHS” evoked by the practitioners of public involvement that I interviewed, LSC leaders treated public involvement as a public relations exercise rather than an exercise of public deliberation (Carter, Dent & Martin, 2019), abiding by scripted answers, dismissing alternative evidence, avoiding conflict and de-politicising the issue of large-scale change.

As conducted in my case studies, invited involvement initiated and overseen by LSC leaders aimed to de-politicise the issue of large-scale change (Flinders & Wood, 2014; Jones, 2019; Buller, 2017) and framed public involvement as a technocratic exercise and represented on the left side of Figure 9. Such an approach to involvement resulted in the public (and other local actors) feeling distrustful of decision-makers and fuelled public opposition, in line with both the findings from the scoping review (section 4.5) and a more recent study in the context of other Sustainability and Transformation Partnerships (Coultas, Kieslich & Littlejohns, 2019). Levels of distrust towards the LSC leaders by the public and other local actors ran high during the lifetime of the LSC programme and persisted beyond the end of the programme, prompting, for example, more scrutiny by local ‘Save our Hospital’ campaigns.

As a result of invited involvement being experienced as inadequate and feeling unheard, some members of the public self-mobilised and further created their own uninvited processes of involvement to influence decision-making, reminiscent of Gaventa’s (2006) power analysis of spaces for public engagement in policy. Whilst Stewart (2016, 2019) identified different forms of public action in large-scale change, I focused my theoretical sampling towards members of the public “fighting” (Stewart, 2019) the change as a reflection of their visibility in the context of my case studies. In Chapter 6, I thus described how some local residents, feeling public involvement in the initial consultation instigated by LSC leaders had no influence on decision-making (sections 5.3.2 & 6.2), learnt to navigate the invited processes of involvement, as well as the institutional language of the NHS, and coordinated themselves in organised ‘Save our Hospital’ or ‘Save our NHS’ campaigns. Such campaign groups are a common response to proposals for large-scale change in the UK (Ruane, 2011; Crane, 2019; Stewart, 2016, 2019; Stewart & Aitken, 2015) and other countries such as Canada (Goyder, 1999; Abelson, 2001) and Ireland (Foley et al., 2017). Unlike some of the campaigns in the UK initiated and/or chaired by local clinicians (Dent, 2003; Dyer & Torjesen, 2013; Ruane, 2011; Gulland, 2001), both campaigns in my case studies were led and chaired by local residents. Embodied by local campaigners – hence positioned at the top
of uninvited involvement on the righthand of Figure 9 – the uninvited mode of involvement stemmed from the strategies and tactics they used to voice their opposition to change and challenge decision-making. Uninvited involvement was reactive to invited processes in large-scale change and to actions taken by LSC leaders.

In my qualitative study presented in Chapter 6, I explored the processes of uninvited involvement created by local campaigners in more depth, a critical aspect which has been omitted in the literature (Crompton, 2015; Stewart, 2019, 2016; Ruane, 2011; Djellouli et al., 2019). Both campaigns shared many characteristics and used a combination of procedural and confrontational tactics (Stewart, 2016) to challenge the legitimacy of the decision-making process with and outside invited involvement mechanisms (for a summary of tactics used, see Table 8). Many tactics used by local campaigns (e.g. petitions, protests, public information campaigns, lobbying, collaboration with the media) have been listed in other studies looking at public campaigners (Ruane, 2011; Stewart, 2019; Crane, 2019). In my analysis I further argue that those tactics are employed strategically by campaigner. Hence, I distinguished between three levels of involvement in the uninvited sphere in large-scale change, representing different degrees of uninvited actions by local campaigners: informing the public about large-scale change; scrutinising decision-makers within and outside invited opportunities; and mobilising the public, local politicians, local clinicians and the media to oppose the change. While invited degrees of involvement culminated at the consultation level and waned after that point, uninvited levels were concurrent and constant, reacting to invited processes and the implementation of large-scale change. I called attention to this feature of uninvited involvement in Figure 9 with the use of double arrows between levels. In addition, distrusting the motives of LSC leaders for change, the scope of campaigners’ uninvited actions evolved, over time, from saving the local hospitals to scrutinising all changes – not just those under the umbrella of the regional LSC programme – introduced by local and regional health planners.

Mirroring the invited process, I indicated in Figure 9, the actors targeted by local campaigners under each degree of uninvited involvement. At the level of information, local campaigners focused on the ‘local community’ (as described by campaigners in my case studies) with the purpose of informing other members of the public about changes to local health services and the LSC programme. To this end, campaigns held weekly or bi-weekly street stalls in regular spots in the community chosen strategically to reach out to members of the public from all parts of the community and from all socio-economic backgrounds. In addition, the campaigns held stalls in local community events such as markets, carnivals, festivals, marathons, etc. Campaigners further produced information leaflets for the public on current issues and ‘Save our Hospital’ posters and stickers, distributed mainly during their community events.
Figure 9. Dynamics of public involvement in large-scale change
Those street stalls were also a forum for campaigners to collect and discuss the perspectives of members of the community on access and experience of healthcare services as well as to mobilise their support for the campaign (mainly via signing petitions and signing up to their newsletter). Other methods used by campaigners to inform the public included: public meetings (similar to invited ones but better attended by the wider public and suited for a lay audience), electronic newsletters, a campaign website and forms of social media. Therefore, since the start of the campaigns, campaigners made themselves more visible and engaged with more diverse groups of the public than LSC leaders had anticipated and contacted in their invited processes, reaching out to hundreds of people through their community events; thousands through their newsletters and websites; and distributing hundreds of thousands of leaflets to the public.

With the next degree of uninvited involvement – scrutinisation – local campaigners directed their actions at LSC leaders (Figure 9). Arising from their distrust of LSC leaders, campaigners aimed at this level to scrutinise and challenge LSC leaders, both from the outside and during invited involvement. The focus of their scrutiny was the clinical and financial evidence put forward by LSC leaders in their case for change (section 5.2). In addition to the information provided by LSC leaders in invited forums, campaigners conducted their own (mostly quantitative) research to verify and counter the arguments of LSC leaders. When requested information was not provided by LSC leaders in invited forums, campaigners resorted to writing Freedom of Information requests. Additionally, through their own research and by engaging with local frontline clinicians, campaigners collected evidence on other aspects of the large-scale change not discussed by the LSC leaders with the public (e.g. regional health inequalities in access, performance of remaining emergency departments in the region after the first closures, use of external consultancy firms) to further dispute the case for change and challenge the decisions made by LSC leaders. Campaigners operated at this level from the outside, lobbying through letters the LSC leaders directly, but also through letters and meetings with other local actors (such as their local Trust), contacting NHS England and NHS Improvement and sharing their evidence with the Independent Reconfiguration Panel and external experts commissioned by local politicians. Their scrutinising and challenging presence was further performed in invited forums, whereby campaigners were always in attendance in meetings in public at commissioning, Trust and local authority levels and participated in invited activities directly aimed at the public.

In line with other studies reporting public opposition in large-scale change (Ruane, 2011; Edwards, 1995; Garnett, 1999; Moore, 2006; Roberts, 2014; Barratt et al., 2015; Jones & Exworthy, 2015; NHS Clinical Commissioners, 2015; Foley et al., 2017; Abelson & Lomas, 1996; Abelson, 2001; Carver et al., 2011; Crane, 2019), uninvited actions included the mobilisation of the public against change via petitions and demonstrations, fuelled by the involvement of politicians and the media. Those
studies, however, did not focus on who initiated this mobilisation and by which mechanisms. In my case studies, I analysed such mobilisation in more depth that I found was initiated by campaigners and used strategically at different points of the large-scale change (see Chapter 6). In mobilisation – the last degree of uninvited actions – campaigners sought to mobilise other local actors to oppose the large-scale change: their community, their politicians (local and national), the media and local clinicians (Figure 9). Campaigners, drawing on the uninvited level of information, were able to mobilise large numbers of the public when needing to show numbers, for example in petitions, demonstrations or specific invited activities. As described before by Stewart (2016, 2019) in the context of hospital closures in Scotland, both campaign groups further opposed the plans for change by bypassing LSC leaders, lobbying and mobilising elected local politicians to whom LSC leaders are accountable via the Health Overview & Scrutiny Committee in each locality (section 2.4). Campaigners also mobilised some frontline clinicians to speak at campaign meetings and public meetings or to take part in demonstrations (section 6.4.5) but were not as successful in bringing in clinicians overtly into their campaigns like other campaigns in the UK (Ruane, 2011; Gulland, 2001; Dyer & Torjesen, 2013). Finally, both campaigns mobilised the media, sharing information with local and national journalists to mediatise and to bring in more scrutiny on the LSC programme.

Consequently, while the technocratic model of invited involvement aimed to de-politicise large-scale change, campaigners initiated uninvited actions as a process of re-politicising large-scale change. Unlike invited involvement that was sporadic in large-scale change and dictated by legal requirements, uninvited involvement was uninterrupted over the years, despite the campaigns running on limited resources and public donations. Nevertheless, outcomes of uninvited involvement were not immediate unlike invited ones Figure 9, and they built up over time, eventually having some influence on large-scale change but also on invited involvement. Indeed, as a result of their continuous uninvited actions, both campaigns became – and remained – highly visible to their local communities, to LSC leaders and to local politicians, hence keeping the LSC programme and public involvement in the public eye and on the political agenda. Furthermore, by re-politicising large-scale change through uninvited involvement, campaigners added another layer of scrutiny on decision-makers and contributed to the delay of service closures.

The impact public involvement may have on decisions in large-scale change is rarely discussed in the literature, as highlighted by my scoping review (section 4.6) and other related academic reviews (Dalton et al., 2015; Rose & Fleischmann, 2003; Crawford, Rutter & Thelwall, 2003). Like in other cases of large-scale change included in my scoping review (section 4.5), all but one participant (the LSC leader) in my qualitative study held the opinion that invited public involvement had no impact on decision-making as the decision was already made, especially in a climate of austerity pushed by the central
government. In contrast, only one study (Ruane, 2011) inquired into the impact of uninvited involvement in large-scale change. Examining the factors that may have contributed to the success or the failure of eight English ‘Save our Hospital’ campaigns, Ruane (2011) concluded that impact of the campaigns were not dependent on the methods used by campaigners but on their use of evidence and their relationships with other actors. While acknowledging the difficulty of making such association, Ruane (2011) suggested that the use of quantitative evidence by campaigners (demonstrating their ability to engage with the evidence in the case for change) to undermine facts put forward by decision-makers contributed to the success of the campaign. In my case studies, campaigners were research active and similarly aimed to counter the evidence underpinning the case for change, mostly quantitatively but were mostly dismissed by decision-makers. Ruane (2011) further argued that the extent to which campaigns reached out to different sections of the community and collaborated with other campaigns and the local clinicians contributed to the success of the campaigns; all elements present in my case studies. In contrast however, my participants, including campaigners, attributed the joint impact of the campaigns in delaying closures to the fact that they had mobilised local politicians and their local scrutiny powers. In line with studies on other aspects of healthcare, that encompassed uninvited modes of involvement (Weale et al., 2016; Kieslich et al., 2016; Hunter et al., 2016), opposing voices in invited involvement could not impact the plans for change. Whilst uninvited involvement, over the years, was more successful in influencing the implementation of change – mainly by slowing down the pace of change and delaying service closures.

Some research (Slutsky et al., 2016; Coultas, Kieslich & Littlejohns, 2019) further suggests that forms of uninvited involvement intensify when invited public involvement is not effective. My findings in the context of large-scale change support this assertion and I aimed in my analysis to further examine the interplay between the two modes of involvement. Campaigners initiated uninvited – and sometimes confrontational – actions, as a result of the first invited public consultation that they experienced as inadequate. Additionally, as invited involvement waned after the consultation stage, uninvited involvement strengthened, with campaigners becoming a local actor of their own in large-scale change, more visible to the local public than invited involvement. Even after the LSC programme was dropped, both campaigns continued, aiming to monitor all changes introduced by health planners at the local and regional levels and to influence decision-making, similarly to other ‘Save our Hospital’ or ‘Save our NHS’ campaign groups in England (Ruane, 2011; Crane, 2019). Interestingly, campaigners also informed their local community of upcoming invited involvement activities, in particular for consultation events, and encouraged members of the public to voice their views (without pressing them to oppose change).
Dynamics of invited and uninvited involvement included other actors besides decision-makers and self-mobilised members of the public, that are included in Figure 9 based on their relationship with the public. For example, local Healthwatch bodies participate in invited involvement as a champion for public voice. As mentioned in section 2.4, public involvement has further been promoted at the national level in England by the Department of Health through the establishment of an arms’ length body to represent public voices. Following a few waves of changes to this body (Baggott, 2005; Carter & Martin, 2016), the 2012 Health and Social Care Act established the body Healthwatch in each local authority in England, commissioned and funded by local authorities through money allocated by the Department of Health and Social Care. Local Healthwatch organisations have the statutory responsibilities to seek the views of the public about local health and social care services and to feedback those views to those commissioning or providing the services, yet few studies on public involvement in large-scale change in England have included Healthwatch members in their sampling (Martin, Carter & Dent, 2018; Carter & Martin, 2018; Coultas, Kieslich & Littlejohns, 2019; Stewart et al., 2019) or focused specifically on the role of arms’ length bodies in this context (Stewart et al., 2020). In my research, the role of Healthwatch in large-scale change was first brought up by participants in the scoping review consultation (section 4.7), who associated the role of the different versions of arms’ length bodies through time (Baggott, 2005) with one of a “watchdog”. They were however critical of their current form and associated Healthwatch with “a dog that doesn’t bark”, concerns later repeated by campaigners in one case study. Carter and Martin (2016) as well as Coultas, Kieslich and Littlejohns (2019) further associated public distrust with the local Healthwatch’s concern of being seen as independent. This concern was also visible in my case studies with local Healthwatch organisations distancing themselves from local campaigners and expressing their need to remain independent despite their source of funding. In one of the case studies for example, the local campaigners distrusted their local Healthwatch for being funded by the CCG they were meant to be critical of. However, this situation is common in England as a recent survey of local Healthwatch organisations showed that 62% receive external funding from a CCG (Desai et al., 2019). Although being critical of health planners’ decisions as a representative of public voices was perceived as the role of Healthwatch by several participants, the case studies highlighted the lack of guidance on their role in large-scale change specifically. Carter and Martin (2016) pointed out to Healthwatch limited impact on decision-makers as although CCGs are required to consult their local Healthwatch, they are not required to act on their recommendations, as evidenced in my case studies. Healthwatch respondents further indicated that their impact in large-scale change was limited due to their large portfolio of activities and their lack of funding and their lack of human resources (Desai et al., 2019; Carter & Martin, 2016). As a result, it seems that the role of Healthwatch in large-scale change is left to the discretion of local Healthwatch branches. In my case studies, one local Healthwatch adopted a collaborative approach with local commissioners (criticised by other
participants as it received funding from the CCG). The other Healthwatch took on the role of actively monitoring how invited involvement was conducted by commissioners.

My empirical research identified further actors in public involvement in large-scale change such as practitioners of public involvement and local clinicians. Practitioners of involvement have only been the focus of one study, recently published in the context of communication and engagement in emerging STPs (Carter, Dent & Martin, 2019). In my theoretical sampling (Corbin & Strauss, 2015), I had originally categorised practitioners of involvement as ‘insiders’ of invited involvement along with LSC leaders. However, during interviews with practitioners, it was evident that although they involved the public on behalf of the LSC leaders and had a background in public involvement, they had little power in influencing how invited involvement took place (section 5.4.2) – as indicated by the unidirectional arrow in Figure 9. Practitioners interviewed in my study evoked being further limited by the “secretive” nature of the NHS and by the rushed and tight timing imposed on them regarding public engagement and consultation (Carter & Martin, 2018; Stewart et al., 2019). Local frontline clinicians, having the knowledge of patient’s needs and local services, were also an actor in public involvement in large-scale change. However, in the case studies, they had not been formally invited in the process of change or involvement. Participants in McKevitt et al.’s (2018) study explained their lack of involvement by decision-makers with the fact that requirements for public consultation had occulted involvement of local clinicians. As a result, some clinicians would attend consultation events aimed at the public and/or participate in uninvited processes as indicated by the dotted arrows in Figure 9.

I found in my empirical research that local politicians deserved more attention in research on public involvement in large-scale change than hitherto given by studies included in my scoping review (Chapter 4). Indeed, as depicted in Figure 9, local politicians, representing their local electorate, played a pivotal role between the two types of involvement: on one hand, scrutinising invited processes as elected representatives of the public and, on the other, also contributing to uninvited actions (section 6.4.2). The local authority also commissioned their local Healthwatch, whose role as a champion of public voice is to contribute to invited involvement. In my model, health planners retain control of the decisions and seek to control public involvement processes (left-hand side of Figure 9) by constraining the methods for public involvement. However, wider political processes (right-hand side of Figure 9) ride roughshod over their efforts to control decision-making and constraint involvement because local authorities – through their Health Overview and Scrutiny Committees – have the right to scrutinise both the plans for change and the public involvement process (section 2.4). In my case studies, whilst LSC leaders avoided engaging with the evidence put forward by campaigners – based on patient experience, knowledge of the community and research conducted to disprove the clinical and business cases for change – local politicians valued it. Both campaigns briefed their local politicians on the LSC
programme, healthcare and health planning issues and mobilised their scrutiny powers, with various
degrees of success. As a consequence, local politicians refused to sign the STP plans – since the LSC
programme was still running under the STP with plans for further closures – excluding them
consequently from the decision-making process. Despite the framing at the national level of local
authorities as partners in the STPs and future Integrated Care Systems (ICS) (Brennan, 2019a; NHS
England, 2018a, 2016b), I observed that local politicians oscillated between partners and adversaries to
LSC leaders that they did not trust either when it came to large-scale change. Other local authorities in
England have acted similarly and refused to sign STP plans over controversy of large-scale change
(Thomas & Gammie, 2016; Brennan, 2019b, 2019c, 2018). Hence, more consideration should be given
in research to local politicians as actors of public involvement in invited and uninvited processes,
considering political support facilitate the impact of uninvited actions on decision-making. This has
further relevance to the future of the NHS, as English STPs are to become ICSs by spring 2021 (NHS
England, 2018a; Brennan, 2019a), King’s Fund reports identified that the full involvement of local
authority would be needed in ICSs (Humphries, 2019; Charles et al., 2018), involvement that was lacking
in the development of STPs (Ham et al., 2017; Alderwick et al., 2016).

In conclusion, I have presented here a framework exploring the dynamics of public involvement
specific to large-scale change, grounded in empirical data and contrasted with the findings of other
studies. In doing so, I aimed to address some of the weaknesses identified in conceptual models
commonly used in the healthcare literature (Chapter 2). Firstly, as noted in section 2.1, the literature
lacks consistency in how the term ‘level’ is applied. In my model, presented in Figure 9, levels of
involvement represent different degrees of public involvement in a regional large-scale change, which
would be situated at the “service” level of the health system according to Charles and DeMaio (1993)
and at the “organisational design and governance” level of the health system for Carman et al. (2013).
Secondly, conceptual models and typologies of involvement highlighted in Chapter 2 have, by and large,
focused on involvement initiated by decision-makers, without addressing their motivations for involving
the public. Accordingly, levels of involvement have been arranged as a ladder (Feingold, 1977; Brager
& Specht, 1973; Morgan & Lifshay, 2006; Skelcher, 1993; Burns, Hamilton & Hogget, 1994; Arnstein,
1969) or a continuum (International Association of Public Participation, 2007; Carman et al., 2013)
according to the power held by the public in influencing decisions, whereby the public could only
influence decisions at the higher end of the ladder or continuum. Based on my research, I argue that
such conceptualisation lacks nuance and fails to account for the (controversial) context of large-scale
change in the UK. Decision-makers in this context have opted for a technocratic model of involvement,
ddictated by legal requirements to involve the public in the process. Involvement was limited to three
levels, reminiscent of Arnstein's (1969) levels of non-participation and tokenism, and its processes
completely under the control of decision-makers – a feature not highlighted in the conceptual models

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presented in Chapter 2. In contrast, in the literature about patient and public involvement in research, there is a common ideal that patients and members of the public influence the methods of involvement (Oliver et al., 2008).

As highlighted in my research and by other studies, in this model the public has no power to influence decision-making, including at the higher level of the invited continuum: consultation. I highlight in my model (Figure 9) that, in contrast to most models presented in Chapter 2, some members of the public, as a direct result of experiencing invited involvement as inadequate, created their own influence via uninvited routes. An aspect that has been omitted in the conceptualisation of public involvement in the healthcare literature (Stewart, 2016; Weale, 2016). Thirdly, whilst bottom-up actions or involvement initiated by the public remain neglected in the literature on large-scale change (Djellouli et al., 2019; Stewart, 2016; Harrison & McDonald, 2008), I offer in my model a detailed account of the different levels of uninvited actions initiated by local residents organised into ‘Save our Hospital’ or ‘Save our NHS’ campaigns, taking place in parallel and in reaction to invited processes. Fourthly, I uncover in my model the interplay between invited and uninvited mechanisms, which have been given little attention in research (Crompton, 2015; Stewart, 2019, 2016; Ruane, 2011) and brought to light other actors taking part in involvement dynamics in large-scale change, omitted in conceptual models focusing on involvement of the public by decision-makers. In so doing, I assert that the invited route chosen by health planners aimed at de-politicising large-scale change and downplaying controversy in order to secure public support instead of promoting public deliberation, resulted in long-lasting distrust of the public and other actors. I further argue that uninvited actions led by local campaigners aimed on the other hand to re-politicise large-scale change, which had more influence on the outcomes of large-scale change than public inputs via invited routes. Finally, my model for public involvement adapted to the context of large-scale change, unlike models found in the healthcare literature (Chapter 2), is a mosaic (Titter & McCallum, 2006) capturing the complexity of involvement dynamics and calling attention to other dimensions besides the levels of public involvement, such as:

- how both invited and uninvited modes of public involvement are enacted and how they are interrelated,
- who initiates public involvement and their motivations,
- who is involved and why,
- what methods are used in each level of involvement,
- the timing of each mode of involvement in relation to large-scale change,
- the outcomes of each mode of involvement,
- and the power relations and interactions between actors not just focused at the relationship between health planners and the public; but also between 1) health planners and other local actors (such as practitioners of involvement, local campaigners, local politicians, local
Healthwatch and local clinicians); 2) the campaigners and other actors (members of their community, their politicians, their local clinical community, the media, other campaigns); and 3) the public and other actors (practitioners of involvement, local politicians, Healthwatch).

7.2 Contributions of this thesis to debates on public involvement in large-scale change & implications for practice and research

In my scoping review of the international literature (Chapter 4), I drew out that the research on public involvement in large-scale change tends to be from the perspectives of LSC leaders, largely assuming a ‘top-down’ model of planning (Farmer & Nimegeer, 2014) and reinforcing public perceptions of tokenistic involvement. This reflects the ‘technicist’ orientation of Health Services Research – exacerbated by the dominant sources of funding – focusing on finding technical solutions to healthcare problems whilst neglecting the political dimensions of healthcare planning, in particular in controversial large-scale changes (Cribb, 2018; Jones, Fraser & Stewart, 2019a; Stewart & Aitken, 2015). Driven by policy initiatives [Mockford et al., 2012; Stewart, 2016], this dominant approach in Health Services Research to studying public involvement in large-scale change often lacked a social science-based analysis, neglecting in the process important aspects of this social and political phenomenon (Jones, Fraser & Stewart, 2019a; Stewart, 2016, 2019; Ferlie, 2016). Using a grounded theory methodology (Chapter 3), I therefore provided a more inclusive overview of involvement dynamics at play in large-scale change and anchored in a real-life context (Yin, 2018, 2012), and shed light on omitted dimensions that I argue are crucial to our understanding of public involvement in this context.

Based on the findings of my scoping review (section 4.8), I discussed how the dominant approach in Health Services Research frames public involvement as an information deficit model (Bucchi & Neresini, 2008; Rowe & Frewer, 2000; Stewart & Aitken, 2015), where public opposition to the change is attributed to a lack of understanding from the public of the technical arguments made for change. Such research implies that communication with the public should focus on improving the transfer of information from experts to non-experts rather than opening the way to more deliberative methods of involvement (Jones & Exworthy, 2015). Turner et al. (2016) in their analysis of centralisation of stroke services bring attention to this point by showing that public involvement was used instrumentally by decision-makers to secure support for change rather than public deliberation, deliberation in which technical knowledge is seen as a requirement. Looking empirically at the processes of involvement from a social science perspective, I offer more insight into the issue. The findings of my research indicate that the public understood the evidence put forward by health planners and were capable of challenging it, in particular local campaigners who conducted their own research to disprove
the evidence advanced. In fact, my in-depth description of invited involvement initiated by leaders of change (Chapter 5) shows that health planners dismissed the use of deliberative methods of involvement, that would allow public involvement in weighing the evidence for change and in discussions and debates on potential options (Abelson et al., 2003; Rowe & Frewer, 2005, 2000). On the contrary, health planners dismissed public concerns brought up in invited forums and deliberately avoided alternative evidence presented by members of the public and other local actors such as Healthwatch. This was also the case when the evidence compiled by local campaigners to support their arguments against change was corroborated by external experts commissioned by local authorities and by academic studies (sections 5.2 and 6.4.2). Accordingly, many participants relayed that the public “had to fight to be heard”, demonstrating that the central issue of invited involvement, controlled by leaders of change, is actually the democratic deficit (Warren, 2009; Milewa, Valentine & Calnan, 1999; Walker et al., 2018) in decision-making in large-scale change.

The technocratic model of involvement chosen by health planners in large-scale change defined in my conceptual model (Figure 9) was also described in other Health Services Research studies (Turner et al., 2016; McKevitt et al., 2018; Martin, Carter & Dent, 2018; Barratt et al., 2015). As invited processes are initiated and controlled by decision-makers with little or no input from other actors (Barnes et al., 2004; Ruane, 2011; Carter, Dent & Martin, 2019; McKevitt et al., 2018), the technocratic model of involvement in large-scale change raises issues on the legitimacy of the decision-making. Such issues are often reported in the literature; such as the lack of impact of invited involvement (Dalton et al., 2015; Rose & Fleischmann, 2003; Crawford, Rutter & Thelwall, 2003), the lack of representativeness of the public (Abelson & Lomas, 1996; Abelson, 2001; Axler et al., 1997; Martin, Carter & Dent, 2018; McKevitt et al., 2018; Rutter et al., 2004; Gold, Abelson & Charles, 2005; Martin, 2008), the lack of suitability for lay people (Abelson & Lomas, 1996; Axler et al., 1997; Edwards, 1995; Garnett, 1999; Rutter et al., 2004; Scottish Health Council, 2006; Independent Reconfiguration Panel, 2010; Roberts, 2014; Barratt et al., 2015), and public confusion about who the decision makers are since change is perceived as a response to national pressure for cost-saving measures (Stewart et al., 2019; Carter & Martin, 2018). Looking at social and political processes in my research, similar issues were brought up and the public further questioned and challenged the legitimacy of decision-making, despite the evidence of formal consultations, in regard to: the timing of invited involvement in relation to large-scale change; the lack of deliberative spaces and genuine deliberation where alternative evidence is considered; where the decisions are made; the lack of public involvement in large-scale change after the consultation level; and the lack of transparency of health planners. Whilst I acknowledged in Chapters 1 & 2 that there are many methods available to health planners to involve the public and little conceptual clarity, my research shows that, despite national guidance on involvement (NHS England, 2016b, 2018b), practitioners of involvement lack power to address the shortcomings of the technocratic model.
suggesting that the invited model is deliberate and not arising from a lack of conceptual clarity. Indeed, public involvement is not conceptualised by health planners as a space for public deliberation but rather motivated by legal requirements and operationalised to gain support for change and manage potential barriers to large-scale change implementation (such as referrals to the Independent Reconfiguration Panel, judicial reviews and public opposition) (Stewart et al., 2019; McKevitt et al., 2018; Carter & Martin, 2018; Jones, Fraser & Stewart, 2019a; Turner et al., 2016). I further argue that the invited mode of involvement in large-scale change aims to de-politicise change (Flinders & Wood, 2014; Jones, 2019; Buller, 2017) to limit conflict rather than include public perspectives in decision-making. Public opposition in this model is therefore framed as a vocal minority resistant to change who cannot be reasoned with. By only allowing certain modes of expression from the public (creating an “atmosphere of passive acceptance or one of hostile resistance” (Garnett, 1999)), certain forms of arguments (such as Health Services Research evaluations and not the evidence presented by the public) and certain groups of the public (“regulars” rather than those most affected by the change and health inequalities) within this technocratic model of involvement, health planners have excluded the voices of certain groups of the public, challenging the legitimacy of their decision-making.

Jones, Fraser and Stewart (2019b), raising the lack of social science in Health Services Research, argue that instrumentalising public involvement to manage opposition on controversial plans is “likely to ‘backfire’ by eroding trust” with the public because they are seen as strategic and manipulative. My grounded theory study confirms their argument showing that the major outcome of invited involvement initiated and limited by health planners was public distrust that fuelled public opposition and self-mobilisation of the public. Distrust of health planners was an omnipresent theme in my empirical study and was also expressed by other actors besides members of the public and campaigners such as local politicians, clinicians and some Healthwatch participants. Rather than address issues of public opposition and distrust, health planners in the case studies became “entrenched”, evident in the adversary discourse used by many participants, further feeding uninvited actions from local campaigners and public distrust.

Distrust as a result of invited involvement deserves further consideration in Health Services Research. While issues of trust in involvement on large-scale have been brought up in several studies (Ruane, 2011; Abelson, 2001; Brown, 2003; Oborn, 2008; Thomson et al., 2008; Stewart, 2019; Crane, 2018; Djellouli et al., 2019; Coulats, Kieslich & Littlejohns, 2019), it remains an underplayed aspect of involvement. By focusing on the information-deficit model to frame public opposition, Health Services Research has overlooked issues of trust, which will be long-lasting and shape future relationships with the public and other actors in large-scale change, even after controversial plans are dropped, as shown in my qualitative study and other studies (Coulats, Kieslich & Littlejohns, 2019; Crane, 2018; Ruane,
2011). As argued by Jones and Exworthy (2015), it is trust rather than simply empirical evidence that is the key to acceptance of change in intractable controversies. The issue of trust is crucial in the context of a changing health system in the NHS relying on the collaboration of health commissioners with providers, local authorities, Healthwatch and the public (Coultas, Kieslich & Littlejohns, 2019) – a context under further pressure to deliver savings (Stewart et al., 2019). Looking at trust issues in this process from a social science perspective, I argue that public opposition needs to be framed in terms of addressing the democratic deficit in the technocratic model of involvement, for instance by opening invited involvement to deliberative methods (Crompton, 2015; Mitton et al., 2009). Consideration should therefore be given by health planners on opening up invited forums to public deliberation and opposition. Leaders of change in two participant analyses and one academic study included in my scoping review (Foley et al., 2017; Carver et al., 2011; NHS Clinical Commissioners, 2015) found that engaging with local voices opposing change strengthened, rather than hindered, the consultation and decision-making processes as well as lessened public opposition to the change. Additionally, invited processes are controlled by health planners, whereby even practitioners of involvement found it difficult to shape the process. I therefore recommend in this context of distrust, based on my findings, to revisit the timings of invited involvement as engagement and consultation have been perceived as rushed by many actors, allowing time for involvement, and continuing to engage the public during implementation of change and past the consultation stage (Stewart, 2019; Martin, Carter & Dent, 2018). Moreover, invited processes should be opened up for members of the public to be involved in the design, agenda and venue (Dean, Boswell & Smith, 2019).

Introduced in Chapter 2, common conceptual models used in the healthcare literature have omitted actions initiated by the public to be involved in decision-making. Additionally, Stewart (2016, 2019) argued that the lack of social sciences in Health Services Research translated into public perspectives being missing from our understanding of public involvement and opposition in large-scale change. Stewart (2019) further pointed out that public responses have been negatively reported in the large-scale change literature, classifying the perspectives reported into whether or not they are perceived as a manageable barrier to public involvement in change. My research therefore contributes to addressing this gap in knowledge by providing some nuance on public perspectives and their interactions with health planners. Firstly, several studies on public opposition in large-scale change focused on drawing out the emotional attachment, sometimes depicted as irrational, of the public to their local hospitals (section 2.3) that, according to Stewart (2019), “is easy to dismiss from a technocratic perspective which seeks measurable health outcomes”. In contrast, in my case studies, members of the public observed in the public consultation brought up arguments based on the case for change they perceived as flawed from a service user perspective rather than an emotional attachment to the local hospital. Additionally, opposition from local campaigners was evidence-based and anchored in data
produced by NHS bodies, with continuous efforts to get information on the LSC programme and produce their own research to verify and counteract the arguments of health planners. These findings are in line with Crane's (2019) history of ‘Save our NHS’ movements, that described the rise of ‘information-based activism’ since the 1980s whereby experiential and emotional forms of expertise were not used by campaigners. Yet, both types of arguments, as well as public opposition, were also easily dismissed from a technocratic perspective (Crane, 2018). Therefore, my research frames public opposition as a means to challenge the evidence-base for change and the legitimacy of decision-making.

Secondly, since information on the local opposition in large-scale change was generally peripheral in the literature included in my scoping review (Chapter 4) and often framed in participant analyses as an obstacle to large-scale change implementation, I further call for more empirical work on the uninvited model of involvement. Using a social science approach to studying public involvement, I aimed to gain further insights into public opposition focusing in particular on self-mobilised publics, that have become a common sight in the UK and yet have been given little attention in research (Crompton, 2015; Stewart, 2019, 2016; Ruane, 2011; Djellouli et al., 2019; Crane, 2019). I therefore contribute to the existing knowledge by showing that as a result of a top-down approach to health planning and a democratic deficit in the invited processes of public involvement, some groups of the public organised themselves into campaigners and turned to uninvited actions to voice their concerns about the rationale and evidence underpinning the LSC programme. I provided in Chapter 6 and the first section of this chapter, a detailed account of uninvited mechanisms and their interplay with invited involvement, contributing to the under-researched topic of how members of the public seek to engage in debates outside invited processes and how uninvited actions take shape and interact with invited processes (Habermas, 1991; Somerville, 2011; Crompton, 2015). I uncovered in particular how local campaigners, using a combination of tactics, initiated three levels of continuous and concurrent uninvited actions: informing the public about large-scale change; scrutinising decision-makers within and outside invited opportunities; and mobilising the public, local politicians, local clinicians and the media to oppose the change (Figure 9) – and further discussed the outcomes of uninvited actions and their interaction with invited involvement. While Health Services Research, following the “technicist” (Cribb, 2018) paradigm, has on the whole framed large-scale change as a technical solution and public involvement as a process within, my research provides an alternative approach to understanding large-scale change from a political paradigm (Jones, Fraser & Stewart, 2019a; Dean, 2017). Therefore, if involvement is experienced as tokenistic and not allowing for public deliberation, members of the public will contest change and some groups of the public will re-politicise large-scale change via uninvited routes.
Moreover, distrustful of health planners’ motives for change and that public perspectives had been included in decision-making via invited routes, local campaigners over time broadened their scope of action not just to local services under threat of closure but to all types of changes introduced by health planners. In contrast to the literature on public opposition in large-scale change focused on the emotional attachment to local hospitals (Barnett & Barnett, 2003; Lepnurm & Lepnurm, 2001), I argue that the self-mobilised public in large-scale change over time became familiar with health planning and scrutinised, in a context of distrust, all decisions made by health planners (e.g. contracts awarded by local commissioners, finances of local NHS bodies, pathways of care, staffing conditions, etc.) and their implementation of changes introduced by the central level (such as Integrated Care Systems). Therefore, their campaigns were more than just an emotional response to save hospital services from closure. Effectively, campaigners demanded a voice in commissioning and service provision in the region emphasising equitable access for those living in the region and pushing back any forms of privatisation – in line with the history of public campaigns in England (Crane, 2018). Campaigns are therefore not waning in this context of a changing health system and distrust, even when controversial plans are dropped (Ruane, 2011) and even with the turnover of health planners who inherit mistrust issues by continuing to adopt a technocratic approach to involvement and large-scale change. Whilst invited involvement was sporadic in the lifetime of the LSC programme and dictated by legal requirements, campaigners remained dedicated to their cause, a strenuous commitment given their limited resources, reliance on public donations and their own health issues (Crane, 2018; Ruane, 2011). Over the years, local campaigners became a coalition of actors (Weible & Sabatier, 2007), omnipresent in large-scale change, by mobilising local actors and developing networks of influence. Campaigners remained more visible over time that invited involvement, keeping public involvement and the large-scale change in the public eye and the political agenda, and contributed to delaying the pace of change. More attention in research should therefore be given to uninvited involvement in large-scale change and its relationship with invited involvement, as the technocratic model favoured by health planners fuels public opposition and uninvited actions (Slutsky et al., 2016), as illustrated in my qualitative research.

As a result of their three levels of uninvited actions, local campaigners claimed and created (Cornwall & Coelho, 2006; Gaventa, 2006) their own deliberative space to address the democratic deficit resulting from the technocratic approach in invited involvement, strengthening invited involvement lacking public deliberation. In such a space, they set out an additional layer of public scrutiny concerned, like other local and national campaigns, that the dismantlement and privatisation of the NHS has been taking place outside public scrutiny (Hunter, 2016; Crane, 2019) and that the future Integrated Care Systems will undermine local scrutiny (KONP, 2018). However, the evidence in my empirical research indicates that, although campaigners created a deliberative space where other members of the public and other actors such as local clinicians could get involved, it was not the factor
that had an impact on the outcomes of large-scale change. Instead, it was their continuous actions and their mobilisation of the local politicians – who valued their public deliberation and evidence unlike health planners – that had an influence on large-scale change.

A common framing of public opposition in large-scale change as an obstacle to implementation is reflected in the following words written by management consultants promoting centralisation of services in the Health Service Journal: “Huge amounts of time and resources have been wasted on programmes to redesign and reconfigure services which have foundered on the rocks of opposition from the public – who see only cuts to local services – and politicians – who feel obliged to oppose change to appease this public opinion” (Burrows & Woolland, 2014). My in-depth study, anchored in social science, offers a more nuanced understanding of public opposition. Firstly, my research shows that public opposition is fuelled, along with public distrust, by the technocratic model chosen by health planners to involve the public. If health planners aim to resolve controversy through involvement, reflections should be made on opening up invited involvement to public deliberation. Secondly, members of the public and campaigners in my study have shown that they associated large-scale change with cuts. But this association was made after considering the evidence of the case for change presented by health planners and evaluating that the evidence underpinning change was not clinically motivated but financially motivated. Local campaigners further actively researched and contested the evidence presented, demonstrating some of the failures related to changes implemented under the LSC programme, some of which were later confirmed by external experts, academic studies and leaked NHS documents. Campaigners further linked national changes to their claims of local cuts to health services – claims that years later made national news headlines (e.g. rationing of treatment, privatisation) in the build-up of the 2019 general elections and Brexit negotiations. Finally, I dispute the claim that politicians feel obliged to oppose change to appease public opinion. Indeed, my case studies show that political opposition has occurred as a result of continuous efforts from both campaigns to mobilise their local politicians and scrutiny powers.

Stewart (2016) argues that “hospital closure protests are an example of profoundly challenging public action”. Following my empirical research in the English context, I support her argument. Additionally, given the penchant for large-scale changes of national politicians and decision-makers (Fraser, Stewart & Jones, 2019) and the growing movement of public campaigns in response (Crane, 2019), Health Services Research should give more attention to public opposition and public activism, beyond reiterating the prevailing policy framings it as an obstacle to large-scale change. Alternatively, by looking at both invited and uninvited modes of involvement from a social science perspective, as I have done in my research, authors can depict a more complete picture of the dynamics of public involvement in large-scale change and the interplay between invited and uninvited modes. Public
involvement in healthcare, as promoted by national and international policies (Department of Public Expenditure and Reform, 2016; Health Canada, 2000; NHS England, 2016; World Health Organisation, 2016), is rooted in public opposition and activism on health issues claimed from the outside (Brown et al., 2004). The NHS in large-scale change, has here appropriated the involvement language and implemented symbolic mechanisms of public involvement – closer to public relations tactics than its emancipatory roots (Komporozos-Athanasiou, Renedo & McKevitt, 2019; Carter, Dent & Martin, 2019; Hunter et al., 2016) – and depoliticised it, removing the ‘heat’ and the debate to gain support for change and legitimise decisions already made (Milewa, Valentine & Calnan, 1999; Harrison & Mort, 1998). Instead of fulfilling promises of a new relationship between health planners and the public (Komporozos-Athanasiou et al., 2018; McKevitt et al., 2018) and engaging alternative and opposing views, the invited mode of involvement fuelled public distrust and prompted uninvited actions led by ‘Save our NHS’ campaign groups. There have been waves of activism in the NHS history, ‘Save our NHS’ movements are contemporary, arising from activism around closures in large-scale change and widening to health planning more broadly locally and nationally (Crane, 2019) – movements unlikely to disappear against a backdrop of a changing health system and austerity. This has implications for research and practice of public involvement in large-scale change. Therefore, I advocate in research for a more inclusive and critical approach to our understanding of modes of involvement in the context of large-scale change. In practice, health planners, if their aim is to truly involve the public in large-scale change (Hunter, 2016), have to move beyond the notion of public involvement as a way to manage implementation of large-scale change (McKevitt et al., 2018) and ought to look at the public as partners, including opposing voices (Stewart, 2016; Crane, 2018). Additionally, Wilcox (1994) in his model proposes to identify the different groups of the public (including activists) that need to be involved and their interest, suggesting that different degrees of involvement are required for different groups of the public as some might have a bigger appetite for involvement. I concur with this approach although health planners need to also address the issues of trust and lack of public deliberation for more meaningful involvement.

In conclusion, political conflict is an inherent, and potentially beneficial, part of healthcare planning (Mouffe, 1999; Weale et al., 2016) that health planners should acknowledge. In practice and in research, thought should be given to reframing the conflict in large-scale change as positive, rather than an obstacle to implementation, and how it can be incorporated into meaningful methods of public involvement (Hunter et al., 2016).
7.3 Strengths & Limitations of the PhD study

This PhD study has a number of strengths in contributing meaningfully to a small body of literature which has thus far given limited attention to who initiates public involvement in large-scale change. Using a social science lens on the issue and including a wide range of perspectives, I have brought to light the social and political processes underpinning public involvement in large-scale that have often been omitted in the Health Services Research literature such as issues of public trust. Looking at both invited and uninvited modes of involvement, unlike similar studies on the topic, I provided a more subtle understanding of public involvement and public opposition. Hence, I captured how some members of the public, after taking part in invited involvement, self-mobilised and organised their own uninvited processes of involvement and explored the interplay between the two modes of involvement.

This research has some limitations. Firstly, in the context of the scoping review, empirical research on the topic is limited and therefore the most informative material is grey literature, which was difficult to locate. Additionally, a strict inclusion criterion of public involvement in large-scale change was applied but, in some instances, it proved challenging to determine what qualified as large-scale change – even with the use of the definition provided in section 1.2 – when including studies. To mitigate these limitations, I consulted a health librarian while developing and piloting the search strategy; discussed with my supervisory panel cases where applying the definition was challenging; and used an innovative method to get frontline perspectives and locate additional literature.

In the context of the qualitative study, although I aimed for a broad and inclusive range of perspectives, some perspectives were in minority compared to others. For instance, the perspectives of LSC leaders was only captured through one (short) interview with a decision-maker at the STP level, observations and document analysis due to difficulties in recruiting LSC leaders, reticent to be interviewed given the controversy around the LSC programme. As a result, I was not able to link empirically how pressures from national actors (Stewart et al., 2019) might have an influence on how invited involvement is conducted. I further encountered difficulties recruiting members of the public that were not campaigners – a reflection of the public involved in invited activities I have observed during fieldwork – therefore this sample of participants included: 2 members of the public volunteering for Healthwatch (or its predecessor LINks), 1 lay member and 2 members of the public not affiliated to any invited or uninvited structures.

Additionally, as fieldwork took place over the last year of the LSC programme (although its end was not foreseen), findings might have been different at other points of the LSC programme. To mitigate this, I have relied on a document analysis, using a variety of sources, going as far back as 2011.
Simultaneously, conducting fieldwork at that stage of the LSC programme was a strength as I was able to observe the ‘day-to-day’ engagement and a public consultation and was able to assess the fully enacted mechanisms of uninvited involvement and its influence on the outcomes of the LSC programme.

As a result of my qualitative study, I was able to build a model of public involvement in large-scale change, grounded in empirical data. Emerging from two real-life case studies and discussed in relation to other studies, this model still needs to be tested in other case studies.

7.4 Conclusion

In spite of the growing interest in involving the public when health planners are seeking to introduce large-scale changes to services; little is known about how public involvement is conceptualised and operationalised in large-scale change, and with what effect. The dominant approach in Health Services Research to studying public involvement in large-scale change focused on finding technical solutions to healthcare problems and lacked a social science-based analysis. Particularly, public opposition as a mode of public involvement has been given little attention in research on large-scale change. Overall, the existing literature has failed to adequately capture the political nature of large-scale change. Consequently, my research brings to light omitted aspects of involvement and offers a more inclusive understanding of public involvement in large-scale change.

My thesis is set against the backdrop of a changing health system, as invited involvement initiated by decision-makers is experienced as inadequate, members of the public create uninvited routes to challenge and delay large-scale change. These uninvited activities become more visible over time than invited ones. Using social science as a lens, this thesis further explored the interplay between the two modes of involvement and the complex dynamics between health planners, different groups of the public as well as other local actors such as local politicians. By engaging with theories of public involvement and deliberative democracy, this thesis provided a more nuanced understanding of public involvement in large-scale change and provides a significant contribution to debates and challenges on this contemporary issue. I conclude this thesis by encouraging future research and practice to reframe conflict in large-scale change as positive rather than an obstacle to the implementation of change.
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Jones, L., Fraser, A. & Stewart, E. (2019b) *Why social science can help us to better understand organisational change*.
Public involvement in decisions to change health services at a large-scale


Public involvement in decisions to change health services at a large-scale


Public involvement in decisions to change health services at a large-scale


### Appendix 1. List of definitions for public involvement encountered in the literature

This table gives an overview of the definitions encountered in the literature around public involvement in health.

<table>
<thead>
<tr>
<th>Term used</th>
<th>Definition of the term</th>
<th>Authors</th>
</tr>
</thead>
<tbody>
<tr>
<td>Public and User Involvement</td>
<td>“Participation in some aspect of governance, design or availability of public services that is something more than simply using the service.”</td>
<td>Harrison &amp; McDonald (2008)</td>
</tr>
<tr>
<td>Public Participation</td>
<td>“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.”</td>
<td>Rowe &amp; Frewer (2005)</td>
</tr>
<tr>
<td>Involvement</td>
<td>“The participation of members of the public or their representatives, in decision about the planning, design and development of their local health services.”</td>
<td>Titter et al. (2010)</td>
</tr>
<tr>
<td>Community Engagement</td>
<td>“Dynamic relationships and dialogue between community members and local health department staff, with varying degrees of community and health department involvement, decision-making and control.”</td>
<td>Morgan &amp; Lifshay (2006)</td>
</tr>
<tr>
<td>Public Engagement</td>
<td>“The practice of involving members of the public in the agenda-setting, decision-making and policy-forming activities of priority setting.”</td>
<td>Bruni, Laupacis, &amp; Martin (2008)</td>
</tr>
<tr>
<td>Patient Involvement</td>
<td>“The active participation in the planning, monitoring, and development of health services of patients, patient representatives, and wider public as potential patients.”</td>
<td>Crawford et al. (2002)</td>
</tr>
<tr>
<td>Patient Engagement</td>
<td>“Working together to promote and support active patient and public involvement in health and healthcare and to strengthen their influence on healthcare decisions, as both the individual and the collective level.”</td>
<td>Coulter (2011)</td>
</tr>
<tr>
<td>Public Involvement</td>
<td>“The involvement of members of the public in strategic decisions about health services and policy at local or national level – for instance, about the configuration of services or setting priorities.”</td>
<td>Florin and Dixon (2004)</td>
</tr>
<tr>
<td>Participation</td>
<td>“Taking part in the process of formulation, passage, and implementation of public policies [through] action by citizens which is aimed at influencing decisions which are in most cases, taken by public representatives and officials.”</td>
<td>Parry, Moyser, &amp; Day (1992)</td>
</tr>
<tr>
<td>Public Participation</td>
<td>“Encompasses all possible ways in which the public can influence a decision.”</td>
<td>Contandriopoulos (2004)</td>
</tr>
<tr>
<td><strong>Public Consultation</strong></td>
<td>“Describes a situation in which the public can voice its opinion without any direct possibility of decision in the end.”</td>
<td>Contandriopoulos (2004)</td>
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<td>------------------------</td>
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<tr>
<td><strong>Patient and Public Involvement</strong></td>
<td>“An activity that is done 'with' or 'by' patients or members of the public rather than 'to', 'about' or 'for' them'. This definition sees the involvement process as a partnership between patients, the public and health professionals. This is important given major power differentials exist between those involved in a lay capacity and paid healthcare professionals.”</td>
<td>Ocloo &amp; Matthews (2016)</td>
</tr>
<tr>
<td><strong>Patient and Family Engagement</strong></td>
<td>“Patients, families, their representatives, and health professionals working in active partnership at various levels across the health care system— direct care, organizational design and governance, and policy making—to improve health and health care.”</td>
<td>Carman et al. (2013)</td>
</tr>
<tr>
<td><strong>Public Consultation</strong></td>
<td>“A local attempt to seek the views of a broad constituency of persons (whether or not current service users) about some potentially important policy decision; in practice it is likely to be initiated by a health authority (HA), though other institutions such as NHS Trusts and Community Health Councils may be involved.”</td>
<td>Harrison &amp; Mort (1998)</td>
</tr>
<tr>
<td><strong>User Involvement</strong></td>
<td>“A local attempt to include organised groups of service users in the planning, and occasionally the management of such services.”</td>
<td>Harrison &amp; Mort (1998)</td>
</tr>
<tr>
<td><strong>Participation</strong></td>
<td>“Actions taken with the objective of influencing a decision-making process.”</td>
<td>Abelson (2001)</td>
</tr>
<tr>
<td><strong>Involvement</strong></td>
<td>“A relationship between the local public service agency and individuals or groups in the community. Implicit in the concept is a desire to move away from the tradition of bureaucratic paternalism in which agencies are closed to the views of consumers and citizens and believe that they alone know best when designing and delivering policies and services.”</td>
<td>Skelcher (1993)</td>
</tr>
<tr>
<td><strong>Patient and Public Involvement</strong></td>
<td>“Ways in which patients can draw on their experience and members of the public can apply their priorities to the evaluation, development, organization and delivery of health services”. Author further distinguishes 5 categories of involvement: in treatment decisions; service development; evaluation of services; education and training; and research.</td>
<td>Tritter (2009)</td>
</tr>
<tr>
<td><strong>Public Involvement</strong></td>
<td>“A generic term that encompasses the notions of participation, consultation, and engagement.”</td>
<td>Wait and Nolte (2006)</td>
</tr>
<tr>
<td><strong>Public Engagement</strong></td>
<td>“Public engagement is used as an umbrella term. The terms communication, consultation and public participation are used with more limited specific meanings, representing three different levels or intensities of engagement.”</td>
<td>Mitton <em>et al.</em> (2009)</td>
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<td><strong>Citizen Participation</strong></td>
<td>“A categorical term for citizen power. It is the redistribution of power that enables the have-not citizens, presently excluded from the political and economic processes, to be deliberately included in the future.”</td>
<td>Arnstein (1969)</td>
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<td><strong>Consultation</strong></td>
<td>“A model in which professionals retain control of both the process and outcomes of user involvement.”</td>
<td>Rutter <em>et al.</em> (2004)</td>
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<td><strong>Involvement</strong></td>
<td>“A descriptive umbrella term for the spectrum of processes and activities that bring the public into the decision-making process.”</td>
<td>Conklin, Morris and Nolte (2010)</td>
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<td><strong>Public Involvement</strong></td>
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<td>Gauvin <em>et al.</em> (2011)</td>
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<td>“individuals or groups taking part in processes of policy making that shape the determination of priorities in health care and the conditions of access of different groups in society.”</td>
<td>Weale <em>et al.</em> (2016)</td>
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Appendix 2. Search strategies for the scoping review

**Database:** HMIC

**Date:** 25.07.16

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Public involvement in decisions to change health services at a large-scale

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**Database:** Medline

**Date:** 25.07.16

**Results:** 991

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Public involvement in decisions to change health services at a large-scale

Database: EMBASE

Date: 25.07.16

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Public involvement in decisions to change health services at a large scale

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**Date:** 25.07.16

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**Public involvement in decisions to change health services at a large-scale**
Public involvement in decisions to change health services at a large-scale

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**Database:** CINAHL Plus

**Date:** 26.07.16

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Public involvement in decisions to change health services at a large-scale
Public involvement in decisions to change health services at a large-scale

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**Date:** 28.07.16

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Public involvement in decisions to change health services at a large-scale
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**Date:** 28.07.16

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#18 **MeSH descriptor:** [Hospital Restructuring] explode all trees

#19 ((large-scale or major or extensive) near/3 (change* or transform* or reform* or modif*) near/3 (service* or healthcare or system* or care or hospital*)):ti,ab,kw (Word variations have been searched)

#20 ((reconfig* or re-configure* or reorganiz* or re-organiz* or redesign* or re-design* or restructur* or re-structur* near/3 (service* or healthcare or system* or care or hospital*)):ti,ab,kw (Word variations have been searched)

#21 #18 or #19 or #20

#22 **MeSH descriptor:** [Health Facility Closure] explode all trees

#23 **MeSH descriptor:** [Health Facility Merger] explode all trees

#24 **MeSH descriptor:** [Health Facility Moving] explode all trees

#25 ((service* or healthcare or system* or care or hospital*) near/3 (closure* or close* or relocat* or re-locat* or merg*)):ti,ab,kw (Word variations have been searched)

#26 #22 or #23 or #24 or #25

#27 #17 and #21

#28 #17 and #26

#29 #27 or #28
Appendix 3. Strategies used to advertise the stakeholders consultation on the scoping review findings

Dissemination list for consultation website

☑ Twitter
  o Re-tweeted or promoted by other UK and Canadian academics
  o Picked up by the Socialist Health Association and Patient Commando
☑ The Health Foundation
  o Promoted on Twitter
  o Included in February 2018 newsletter
☑ CLAHRC North Thames
  o Promoted on Twitter
  o Included in CLAHRC North Thames August 2017 newsletter
  o Included in CLAHRC August 2017 newsletter to all CLAHRCs
☑ Scottish Health Council
  o Promoted on Twitter
☑ National Voices
  o Disseminated to team members
  o Included in January 2018 members’ newsletter
  o Promoted on social media
☑ Conferences
  o Oral presentation, academic poster and flyers at HSRUK 2017
  o Academic poster & flyers at ISQua 2017
☑ Healthwatch England
☑ CLAHRC Research Advisory Panel
  o Promoted to their networks
☑ The Patients Association
  o Included in December 2017 weekly news
☑ Involving people in research (Australia)
☑ Patients4NHS
☑ Doctors for the NHS
☑ Keep our NHS public
☑ NHS support federation
☑ Health Emergency (John Lister)
☑ Big Up the NHS
☑ Nuffield Department of primary care health sciences (Oxford)
☑ Verve (PR consultancy)
☑ NHS Confederation
☑ NHS Clinical Commissioners
☑ Office for Public Management (Consultancy involved in high profile LSCs)
☑ Health Campaign Together
Appendix 4. Interview topic guides

**Topic guide for members of the public**

**Introduction**: Purpose of interview/confidentiality/recording/leave interview anytime

**Background**: Gender/age group/occupation

**Ice Breaker**
- Tell me a bit about yourself
- What they know about local changes to health services & how they get their information about changes

**Invited participation**
1) Probe for activities they took part in during LSC programme. For each activity probe for:
   a. Description of the activity
   b. What they thought of the activity
   c. How they were invited
   d. Who else took part (+ representativeness)
   e. Why they took part (or not)
   f. Expectations of taking part in activity + have those expectations been met
   g. What they think was done particularly well & why
   h. What should be improved & why
2) If ‘mistrust towards LSC leaders’ theme comes up probe for trust issues and how it can be resolved
3) Probe for what they know about Healthwatch and their thoughts on process, representation and impact
4) Probe for Impact of invited participation
   a. How do you feel the public has been able to contribute to the process in the region? (Probe for whether opinions and concerns were valued and how)
   b. Do you think the public participation had an impact on the LSC?

**Uninvited participation**
1) What do they know about local opposition to the change?
2) Probe for activities they took part in or know of (flyers in windows, petitions, protests, etc)
   a. Description of the activity
   b. What they thought of the activity
   c. How they found out about it
   d. Why they took part (or not)
   e. What impact do they think it might have?
3) If they know about local campaigners
   a. What do they think of the local campaign?
   b. Do they support it? Why?
   c. What impact do they think the campaign may have?

**Conclusion**
1) If they took part in both invited & uninvited participation, probe for what type of participation do they feel more heard/represented
2) From your perspective, what would meaningful public involvement look like?
3) Questions/Comments
4) Snowball sampling
**Introduction:** Purpose of interview/confidentiality/recording/leave interview anytime

**Background:** Gender/age group/occupation

**Part I: Motivations for campaigning & initial public consultation**

*When did they join the campaign?*
- *When funded*
- *After 2013*
- *Did not take part in LSC consultation*

- Motivations (Role in the campaign/why & when)
- Why the need for a campaign

Explore LSC consultation
- Could you describe how/type of events you attended? + Opinion of methods
  - What was and wasn't done well?
  - Who else was present (probe Representativeness)
  - How did you feel the PPI process went?
  - Probe for trust issues & how to resolve
  - Why did you get involved in the first place?
  - Has being involved met your expectations? Probe for public expectations and why
  - What did you get out of the process yourself?
  - Do you feel members of the public have been able to contribute to PPI process? How/Why?
  - Did public consultation had an impact on LSC?

- Took part in LSC consultation
- Motivations to join the campaign (Role in the campaign/why & when)

- Have they attended public engagement activities in STP context? If yes,

**Part II: Role in LSC & Strategies of the campaign**

- How would you describe the campaign?
- Why the need for a campaign?
- Scope of the campaign
- Probe Strategies & Methods
- Probe Networks of the campaign
- Impact of the campaign to date
- Probe Successes/Failures of the campaign
- Challenges encountered by campaigners
- Future of the campaign
- How do they get personally from being involved in campaign?
- What possible integration to PPI process?
Conclusion
- What does meaningful involvement mean to you?
- How could it be achieved?
- Any comments/questions?
- Snowball sampling

Topic guide for Healthwatch

Introduction: Purpose of interview/confidentiality/recording/leave interview anytime

Background: Gender/age group/occupation

Ice breaker
- Could you please tell me a little bit about your role at Healthwatch X?
- Could you also please tell me a little bit about the role of Healthwatch X in locality A/B?

Role of Healthwatch in invited participation
1) How is Healthwatch X ‘working to ensure public voices count when it comes to shaping and improving local health and care services’ that have/are being/will be changed under the STP plans?
2) Probe for Nature of Healthwatch role in LSC and activities conducted (e.g. CCG representation, reports on future of hospital, PPI activities on LSC, Joint CCG letters, events)
   a. Are they any plans for Healthwatch to conduct a consultation on STP changes on behalf of NHS or CCG?
3) For each activity:
   a. Why this activity
   b. What do they think of this activity
   c. How was the activity representative of the public
   d. What impact for this activity (+ probe for responses from different stakeholders to reports and their impact)
4) In what ways does Healthwatch can/has influenced STP plans on behalf of the public?
5) Probe for barriers & facilitators of role of Healthwatch

Healthwatch perceptions of uninvited participation
What do they think of the fact that some of the public is protesting the change (leaflets & demonstrations), signing petitions & joining campaigns? (+ link to role of Healthwatch)

Conclusion
1) If they know a lot about both invited & uninvited participation, probe for what type of participation they feel the public is more heard/represented
2) From your perspective, what would meaningful public involvement look like?
3) Questions/Comments
4) Snowball sampling
Introduction: Purpose of interview/confidentiality/recording/leave interview anytime

Background: Gender/age group/occupation

Ice breaker
- Could you please tell me a bit about your role at X? (E.g. Job title, responsibilities)
- How were you involved in the changes of case A/B? Since when?

Methods of PPI LSC consultation
1) Could you describe the methods you have used for PPI?
2) For each activity:
   a. Probe for reasons it was chosen
   b. Probe for guidelines/framework used
   c. Describe whom you involved/how did you approach them (Probe for representativeness)
3) Probe for timing of PPI in relation to LSC
4) What were the aims of public involvement?
5) Is there anything in PPI activities that was done particularly well? Why?
6) Is there anything in PPI activities that you feel should be done differently? Why?
7) Probe for barriers and facilitators of PPI

Methods of PPI STP
1) How is the public involved under the STP plans?
2) If activities are described, cf. questions Methods of PPI LSC consultation
3) What are their opinion on public CCG/Trust meetings?

Perceptions on the process
1) How did you feel the PPI process go?
   a. Probe for trust issues and how it can be resolved
2) What did you do in situations where different groups disagreed on the reconfiguration plans?
3) Has involving the public met your expectations? Why?
4) What did you get out of the PPI process yourself?

Impact of PPI
1) How do you feel have members of the public been able to contribute to the PPI process and plans for reconfiguration?
   a. Probe for whether opinions and views of those involved been valued and how
2) How do you think has involving the public made an impact?

Uninvited participation
1) Changes under the LSC programme and now STP have brought about protests, campaigns, media attention etc. What is your opinion on the matter?
2) What do you know of the local SoH campaign?
   a. What do you think of their work?
   b. What is their relationship with your organisation?
   c. Has the campaign had an impact on plans or the way PPI is conducted?
3) Probe for ways to move from confrontation to working together

Conclusion
1) From your perspective, what would meaningful public involvement look like?
2) Questions/Comments
3) Snowball sampling

**Topic guide for local politicians**

**Introduction:** Purpose of interview/confidentiality/recording/leave interview anytime

**Background:** Gender/age group/occupation

**Ice breaker**
1) Could you tell me a bit about yourself and your role?
2) What do you know about substantial local changes to health services?
3) How did you find out about those changes?
4) What do you think of the changes?

**Public involvement process**
1) Have you ever taken part in public involvement activities related to STP changes or the LSC programme?
   a. Description of the activity
   b. What they thought of the activity
   c. How they were invited
   d. Who else took part (+ representativeness)
   e. Why they took part (or not)
   f. Expectations of taking part in activity + have those expectations been met
   g. What they think was done particularly well & why
   h. What should be improved & why

2) Do you know about upcoming public consultation?

3) Probe for Impact of invited participation
   a. How do you feel the public has been able to contribute to the process in your locality?
      (Probe for whether opinions and concerns were valued and how)
   b. Do you think the public participation had an impact on the LSC?

**Uninvited participation**
What do you know about local campaigners/opposition to the changes?
   a. Probe for relation council-campaigners
   b. Probe for relation council-public
   c. What do they think of the local campaign
   d. Do they support it? Why?
   e. What impact do they think the campaign may have

**Local council**
1) How does the local council fit in the larger picture of large-scale change?
   a. Probe for scrutiny/power to challenge plans
   b. Are all councils aware of their powers/willing to use them?
   c. What did this council do in this context?
2) Explore relationship between CCG and local council
   a. Probe for interactions during Health Overview and Scrutiny committees
3) Explore relationship between Trust and local council
4) Ask about Independent Commission
   a. Why commission the work?
   b. What impact?
5) What lessons can we learn from council doing public involvement in the context of drastic council cuts?

Conclusion
1) From your perspective, what would meaningful 1) political and 2) public involvement look like?
2) Questions/Comments
3) Snowball sampling

Topic guide for local clinicians

Introduction: Purpose of interview/confidentiality/recording/leave interview anytime

Background: Gender/age group/occupation

Ice breaker
- Could you tell me a bit about yourself and your role?
- What do you know about substantial local changes to health services?
- How did you find out about those changes?
- What do you think of the changes?

Clinician involvement
1) Have you (or colleagues) been involved in decisions about those changes?
   a. If yes, probe type of involvement + what they thought of it
   b. If no, probe for why
2) Probe for relationship with local CCG and STP CCG
3) Probe for relationship with local Trust
4) Probe for relationship with Healthwatch

Public involvement
1) Have you ever taken part in public involvement activities related to STP changes or the LSC programme?
   a. Description of the activity
   b. What they thought of the activity
   c. How they were invited
   d. Who else took part (+ representativeness)
   e. Why they took part (or not)
   f. Expectations of taking part in activity + have those expectations been met
   g. What they think was done particularly well & why
   h. What should be improved & why
2) Do you know about upcoming public consultation?
3) Probe for Impact of invited participation
   a. How do you feel the public has been able to contribute to the process in the region? (Probe for whether opinions and concerns were valued and how)
   b. Do you think the public participation had an impact on the LSC?
4) What do you know about local opposition to the changes? // Changes under the LSC programme and now STP have brought about protests, campaigns, media attention etc. What is your opinion on the matter?
5) If they know about local campaigners
   a. What do they think of the local campaign
   b. Do they support it? Why?
   c. What impact do they think the campaign may have
Conclusion

1) From your perspective, what would meaningful 1) clinical 2) public involvement look like?
2) Questions/Comments
3) Snowball sampling
Appendix 5. Observation template

Who & what to observe and describe?

When, where, how?

The When
- Markers of opening and closing
- Duration of event
- Time allocated for public input
- Timing in context of change

The Where
- Type of location, size of the room, accessibility
- Setting of the room
- Equipment present (e.g. microphones so everyone can hear, cameras, visual aid…)
- ‘Platform format’
- Where is the public in relation to the insiders?
- How much room is available for the public?

The Who
- Who are the actors present?
- Demographics (gender, age) and affiliations of those present
- ‘Performances & roles’: Who has a main role, secondary role, co-opted role or other types of role?
- What ‘interactional identities’ they attribute themselves
- Do the different actors know each other?
- Who do the participants speak for?
- Who takes the floor and how? (e.g. is the chair determining when participants speak and for how long? Is it self-regulated?)
- Are key roles monopolised by interest groups?
- Are there tactics to limit other groups to make their voice heard?
- Who stays silent?

Interactions in invited participation
- How was the participation forum advertised?
- What position/pre-determined role is given to the public by insiders? (e.g. respondents, participants, decision-makers…)
- Is the public addressed to? In what manner?
- Are documents provided for involvement? How? How much in advance?
- What are the styles & tones of discussion (formal, informal, relaxed, agonistic, conciliatory, sarcasm, etc.)
- Describe any accompanying emotions / tensions / confrontations / dramas
- Describe measures taken by the public to participate within invited modes of participation, such as:
  - Learning of jargon
  - Conveyor of alternative perspectives
  - Tactics to spread their messages: personal stories, agenda ruptures, humour, silences, boos, argumentation
- Describe flow and nature of information discussed (one way, two ways, deliberative, informative…)
- Are there power asymmetries?
- Are there any disruptions?
- Are some actors disruptive or misbehaving?
- What are the effects of participation? (e.g.: collaborations with other groups, coordination of efforts…)
- What happens after? Are they further interactions between insiders and outsiders after closing? What kind?
- Does what happen during the meeting available to the wider public not present? (videos, twitter, minutes…)
- If there are minutes available, compare observations notes on public questions (& reactions) with minutes

Uninvited participation
- Follow invited participation template (when applicable)
- Are they similarities with invited participation?
- What are the differences with invited participation?
- Are the outsiders’ complaints about invited participation (from interviews) resolved? (e.g.: deliberative forum)
- How is uninvited participation interacting with invited participation?
Appendix 6. Overview of NVivo codes

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Beyond service closures
Campagners’ profiles and numbers
Creation of BSoh
Creation of GSOH
Reward of being in campaign
Roles in the campaign
Accountability & Scrutiny
Exposing LSC failings
Halting closure
Heard voices
Impact for frontline NHS staff
Impact on local council
Keeping LSC & PPI in the agenda and public eye
Lack of impact
Public perception of campaign impact
Raising awareness and informing the public
Other actors’ perceptions of campaigners
Attendance to CCG, Trust and council public meetings
Briefing local councillors
Contacting the NHS
Demonstrations
Engaging with frontline clinicians
FoI requests
Lobbying
Media involvement
Monthly meetings
Newsletters
Petitions
Providing evidence for independent commission
Providing help to answer public consultation
Public meetings
Research
Secret contacts with NHS leaders
Street stalls & leafleting
Website & social media
Writing letters
Campaign – Health Campaign Together
Campaign – Joint CCG
Campaign – Keep Our NHS Public
Campaign – local CCG
Campaign – local council
Campaign – local NHS staff
Campaign – local Trust
Relationships between the campaigns
Concerns about LSC consultation
Personal motivation (as patient or carer)
Confrontation
Mistrust
Oscillation between confrontation and collaboration
Public actions from non-campaigners
Funding

Characteristics of the campaign
Impact of the campaign
Methods used by campaigns
Networks & relationships of the campaigns
Motivations to be a campaigner
Other aspects of uninvited involvement
Healthwatch
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<td>NHS England</td>
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<td>Out-of-hospital contracts</td>
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<td>Public consultation ICP (national level)</td>
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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 unlimited 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 these 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 with the public with making cuts and downsizing 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 [14,16–20]. Similarly, the term involvement – often used interchangeably with other terms like participation,
consultation or engagement – remains poorly defined [14,19–21]. For the purposes 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).

Table 1

<table>
<thead>
<tr>
<th>Key concept 1</th>
<th>Key concept 2</th>
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<tr>
<td>(‘patient’ OR ‘public’ OR ‘service user’ OR ‘PPP’ OR ‘lay’ OR ‘citizen’ OR ‘community’ OR ‘consumer’ OR ‘healthwatch’ OR ‘community health council’ OR ‘local involvement network’)</td>
<td>(‘large-scale’ OR ‘major’ OR ‘extensive’ NEAR ‘change’ OR ‘transformation’ OR ‘ref orm’ OR ‘modification’ NEAR ‘service’ OR ‘healthcare’ OR ‘system’ OR ‘care’ OR ‘hospital’)</td>
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<tr>
<td>NEAR/3</td>
<td>OR</td>
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<tr>
<td>(‘involvement’ OR ‘engagement’ OR ‘participation’ OR ‘collaboration’ OR ‘consultation’ OR ‘representation’ OR ‘voice’ OR ‘coproduction’ OR ‘advocacy’)</td>
<td>INTERFACE ‘reconfiguration’ OR ‘reorganisation’ OR ‘redesign’ OR ‘restructuring’ NEAR ‘service’ OR ‘healthcare’ OR ‘system’ OR ‘care’ OR ‘hospital’</td>
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<tr>
<td>OR</td>
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<tr>
<td>(‘service’ OR ‘healthcare’ OR ‘system’ OR ‘care’ OR ‘hospital’)</td>
<td>OR</td>
</tr>
<tr>
<td>NEAR (‘closure’ OR ‘relocation’)</td>
<td>OR ‘merger’ OR ‘centralisation’</td>
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</table>

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 reinforce 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 to the protocolising. Key data extracted included: study design; 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 [27,28]. 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 for the researchers 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.
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 [35] 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
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 fulfill 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 Aristotle’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 [17,38] 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.

<table>
<thead>
<tr>
<th>Source</th>
<th>Type of LSC, Location &amp; Duration of LSC</th>
<th>Methods used for public involvement &amp; their timing in relation to LSC timeline</th>
<th>Affiliation of authors &amp; Type of analysis</th>
</tr>
</thead>
</table>
| Aird et al., 2013 [39] | LSC: Priority setting in eating disorders services  
Location: England – Sheffield  
Duration: Not specified  |
| - Methodology: 2 decision conferences including 5 patients & caregivers and 1 follow-up meeting  
- Timing: Not specified | Academic (socio-technical system perspective) |
| Gold et al., 2005 [40] | LSC: New cancer care system (with transfer of responsibility to the regional level)  
Location: Canada – Ontario province  
Duration: Not specified  |
| - Methodology: Regional councils and network planning committees that included consumers or patients of cancer care  
- Timing: Not specified | Academic (social science perspective) |
| Greenhalgh et al., 2009 [41]; Greenhalgh et al., 2011 [42] | LSC: Whole scale transformation  
Location: England – London  
Duration: 3 years  |
| - Methodology: Patients representatives in projects’ steering groups and subgroups, with occasional patient chair (Kidney and Stroke); mystery shoppers (Sexual Health)  
- Timing: Not specified | Academic (organisational perspective) |
| Rutter et al., 2004 [43] | LSC: Merger with other provider of mental health services  
Location: England – London  
Duration: Not specified  |
| - Methodology: User representatives from existing user groups at Trust meetings  
- Timing: Not specified | Academic (social science perspective) |
| Thornton et al., 2006 [44] | LSC: Regional reorganisation including hospital closure (focus on women’s health services)  
Location: Canada – Alberta province  
Duration: Not specified  |
| - Methodology: Advisory committee, planning committees, partnership with the Salvation Army  
- Timing: Not specified | Academic (social science perspective) |

Publications describing LSCs with low public involvement intensity defined as: unique method used and/or less than 50 people included

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<thead>
<tr>
<th>Source</th>
<th>Type of LSC, Location &amp; Duration of LSC</th>
<th>Methods used for public involvement &amp; their timing in relation to LSC timeline</th>
<th>Affiliation of authors &amp; Type of analysis</th>
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</table>
| Abelson & Ioman, 1996 [45] | LSC: Healthcare restructuring process with reallocation and reconfiguration of health services  
Location: Canada – 3 Ontario communities  
Duration: 1995-1999  |
| - Methodology: Public meetings & over 30,000 letters, tear-off forms, calls, petitions and flyers were received in response to the options proposed  
- Timing: 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) | Academic (social science perspective) |
| Abelson, 2001 [46] | LSC: Restructuring of hospitals  
Location: Canada – Toronto  
Duration: Restructuring study took place between 1993 and 1995  |
| - Methodology: 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;  
- Timing: 1st series took place in October and November 1994; 2nd series took place after the release of the Final Report in October 1995. | Academic, consultancy & health service management (participant analysis) |
| Asler et al., 1997 [47] | LSC: Consolidation of emergency care on fewer sites  
Location: England – Urban area  
Duration: Not specified  |
| - Methodology: 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 (leaflets, 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  
- Timing: Not specified | Academic (organisational/policy perspective) |
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<tr>
<th>Source</th>
<th>Type of LSC, Location &amp; Duration of LSC</th>
<th>Methods used for public involvement &amp; their timing in relation to LSC timeline</th>
<th>Affiliation &amp; Type of analysis</th>
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<tr>
<td>Causer et al., 2011 [40]</td>
<td>LSC: Centralisation of inpatient and emergency services Location: England – Hertfordshire Duration: Not specified</td>
<td>Methods: 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 Timing: A two-month discussion period preceded the formal consultation Analysis: Not specified</td>
<td>Affiliation: Health service management Analysis: Participant analysis</td>
</tr>
<tr>
<td>Casey, 2010 [49]</td>
<td>LSC: Reconfiguration of acute services Location: England – London Duration: Not specified</td>
<td>Methods: 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, NGOs and community organisations; 8000 questionnaires returned; 1306 calls, emails and letters received submitted Timing: Not specified Analysis: Not specified</td>
<td>Affiliation: Consultancy Analysis: Participant analysis</td>
</tr>
<tr>
<td>Edwards, 1995 [50]</td>
<td>LSC: Centralisation of acute services, including closure Location: England – London Duration: Not specified</td>
<td>Methods: more than 10,000 consultation documents; 150,000 summaries; 50 public meetings held; 500 letters (most opposing the proposals) Timing: Not specified Analysis: Not specified</td>
<td>Affiliation: Consultancy Analysis: Participant analysis</td>
</tr>
<tr>
<td>Foley et al., 2017 [55]</td>
<td>LSC: Region-level reconfiguration of urgent and emergency care systems Location: Ireland – North East, Mid-West and South regions Duration: Not specified</td>
<td>Methods: 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] Timing: Not specified Analysis: Not specified</td>
<td>Affiliation: Academic Analysis: Academic study (policy/health service research perspective)</td>
</tr>
<tr>
<td>Goodwin &amp; Rhodes, 1996 [52]</td>
<td>LSC: Acute services reconfiguration Location: England – Manchester Duration: Not specified</td>
<td>Methods: 40 meetings: 3 large public meetings; home visits; 80,000 leaflets, 6000 full consultation documents; Freephone line; survey with 1000 participants Timing: Changes implemented 6 months after public consultation Analysis: Not specified</td>
<td>Affiliation: Health service management (Leadership level) Analysis: Participant analysis</td>
</tr>
<tr>
<td>Mahadikar et al., 2012 [53]</td>
<td>LSC: Reorganisation of community services Location: England – A county Duration: Not specified</td>
<td>Methods: 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 Timing: Not specified Analysis: Not specified</td>
<td>Affiliation: Academic Analysis: Academic study (asset management perspective)</td>
</tr>
<tr>
<td>McKevitt et al., 2018 [38]</td>
<td>LSC: Major system change to acute stroke services Location: England – Greater Manchester (GM) &amp; London Duration: Not specified</td>
<td>Methods: Stakeholder information and consultations events: lay membership of governance structures [GM &amp; London]: 300 people attended 11 events, 46 health fairs, website with 14,000 visitors, consultation document, adverts, social media, 861 questionnaires returned, 1010 emails, letters and calls received from individuals and organisations [London] Timing: 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] Analysis: Not specified Analysis: Not specified</td>
<td>Affiliation: Academic study (social science perspective) based on evaluation of LSC implementation [38], participant analysis [54]</td>
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<tr>
<td>Source</td>
<td>Type of LSC, Location &amp; Duration of LSC</td>
<td>Methods used for public involvement &amp; their timing in relation to LSC timeline</td>
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<td>NHS Confederation (2013a) [57]</td>
<td>LSC: Reorganisation of maternity services (including closure) Location: England – Sandwell and Birmingham Duration: From April 2000 to October 2011</td>
<td>Methods: Pre-consultation engagement; public feedback gathered during formal consultation via a response form, online and at a series of public meetings, stakeholder's meetings, letters, articles in relevant local and national media, and website updates; a 'ground-breaking' event; distribution of posters and postcards Timing: Formal consultation took place between October and December 2009</td>
<td>Affiliation: Health service management [Leadership level] Analysis: Participant analysis</td>
</tr>
<tr>
<td>NHS Confederation (2013c) [59]</td>
<td>LSC: Reorganisation of emergency services Location: England – Northumbria Duration: Not specified</td>
<td>Methods: about 100 public meetings during engagement period before the formal consultation Timing: 3 months of engagement before consultation and 3 months of formal consultation</td>
<td>Affiliation: Health service management [Leadership level] Analysis: Participant analysis</td>
</tr>
<tr>
<td>NHS Confederation (2013d) [60]</td>
<td>LSC: Reorganisation of hospital services &amp; health and social care integration Location: England – Greater Manchester Duration: Not specified</td>
<td>Methods: 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. Timing: Not specified</td>
<td>Affiliation: Health service management [Leadership level] Analysis: Participant analysis</td>
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<tr>
<td>Roberts (2014) [61]</td>
<td>LSC: Reconfiguration of maternity and paediatric services (including closure) Location: England - Greater Manchester Duration: Reconfiguration took place between 2000 and 2012</td>
<td>Methods: 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 Timing: Pre-consultation took place from 2000 to 2005 (mainly between 2003 and 2004). Formal consultation between January and May 2006.</td>
<td>Affiliation: Consultancy Analysis: Independent evaluation</td>
</tr>
<tr>
<td>Scottish Health Council (2008) [63]</td>
<td>LSC: Relocation of maternity services Location: Scotland – Clyde Duration: Not specified</td>
<td>Methods: Review before consultation engaging a small number of service users. Consultation: 8 drop-in sessions, 3 public meetings Timing: Consultation took place between March and June 2008</td>
<td>Affiliation: Governmental Analysis: Participant analysis</td>
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Public involvement in decisions to change health services at a large-scale

the community. Such meetings were also described by an academic study [45] as inappropriate as they are confrontational, “putting 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 more 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 commented consultation documents for not being transparent (in one LSC [34], 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 feeling influence involvement 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, 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, 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, 51, 52].

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 [33,35,45–56,51,55–58,61]. 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.

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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 [76,77], on public involvement in decision-making in health policy in Canada [80] and on public consultation by public bodies in Ireland [81], yet those do not seem to be enacted often in practice. Ultimately, this public consultation model of involvement contributes to an information deficit model [85,70] where public opposition to the change is attributed to a lack of understanding from the public of decisions made by LSC, 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, 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 cost £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]. Slutzky et al [76] further suggest that tokenistic invited participation leads to more active counter-territory action. In this review, LSC leaders who chose to acknowledge and engage with the opposition
found that it strengthened public involvement and lessened pub-
ic opposition to the change. Thus, interactions between invited and
uninvited participation should be given further consideration in
Scoping. 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,

5. Conclusions

This review shared some insights into how involvement is
classified and conducted in LSC, yet more research and con-
cerns 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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