



Public and Patient Involvement and the Right to Health: Reflections from England

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In this paper, we reflect on public and patient involvement (PPI), the right to health and how human rights principles provide values for implementing mechanisms of participation and accountability. Globally, new models of formalized participation, imposed top-down by State institutions, have emerged in recent health system reforms. There is an on-going challenge to ensure that the prescribed mechanisms, or procedural rights, for implementing the substantive right to health influence social accountability. Participation is linked to procedural rights, e.g., through right to information and fair decision-making processes. We explore recent examples from England to illustrate the challenges posed by formalized participation. Inquiries into health-care failures have found participatory mechanisms to be in place but evidence and data collected through formalized participation often ignored. Complaints procedures have not been sufficiently robust to hold duty bearers to account. The examples expose how weak formalized participation and weak accountability have only come to light through civil society-led participation. It is argued that by embracing participation not merely as a mechanism but also as part of a set of values linked to the right to health, formalized participation could be strengthened. Data, evidence, and knowledge gathered through formalized participation and civil society-led participation should be valorized alongside other forms of evidence. The indivisibility of the right to health should be recognized through participation across sectors. Adopting PPI as comprising mechanisms and values poses renewed challenges to those with obligations of service provision and to public participants to integrate diverse forms of participation and knowledge that contributes to social accountability.

Keywords: right to health, participation, accountability, public and patient involvement, mechanisms of participation, procedural rights, values of participation, valorize diverse knowledge

INTRODUCTION

In recent health system reforms in England, there have been a myriad of mechanisms implemented as part of formalizing participation. However, as this paper illustrates, there are shortcomings with such approaches to formalized participation. It is argued in this paper that the right to health and a focus on participation as a value are important aspects of promoting genuine participation and accountability in health systems. In the recent past, there has been some investigation by the National Health Service (NHS), England into rights-based approaches. In 2007, the British Medical Association and Commonwealth Medical Trust published “The right to health: a toolkit for health professionals,” however, this was largely aimed at health-care professionals going to work abroad and reflected the belief that human rights was something for the “overseas development”

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agenda, not relevant or necessary in England. Also in 2007, the British Institute for Human Rights published “Human Rights in Healthcare—A Framework for Local Action” which focused on the UK context for implementing the right to health and signaled the start of several pilot projects in the NHS as part of the Human Rights in Healthcare Program. This program was suspended in 2013. Nevertheless, some local programs continued. For example, Mersey Care’s Learning Disability Service continued using a human rights-based approach.¹ As part of this approach, participation of service users was maximized, and human rights were seen as a unifying framework to integrate equality and diversity into risk management (Dyer, 2010). The evaluation of the program found that service user involvement led to patients reporting improved well-being as well as to health services changes (Dyer, 2015). Embedding participation as a value and as a mechanism was facilitated by a human rights-based approach and led to improved patient reported outcomes.

Participation is a component of strengthening health systems (Hunt and Backman, 2008). Public and patient involvement (PPI) includes participation in decisions relevant to health care at all levels, from individual personal care to national policy. For the purposes of this paper, we distinguish between formalized participation, which is instigated by the State, and civil society-led participation, which is initiated by civil society. Participation is linked with the right to health and social accountability (Potts, 2008a,b). The right to health is enshrined in international, regional, and domestic law. As such, realizing the right to health relies on States ratifying international covenants and including the right to health in legislation and having a judicial process and democratic structures to uphold the right. United Nations (UN) General Comment 14 on the right to the highest standard of health details State obligations to respect, protect, and fulfill the right to health and this includes ensuring that mechanisms of participation and procedural rights are in place (UN, 2000). Procedural rights are the formal mechanisms necessary for implementing substantive rights such as the right to health. They are an “important aspect in the participation of the population in all health-related decision-making at the community, national and international levels” (UN, 2000, paragraph 11) and include access to information and involvement in fair decision-making processes. In addition to the legal framework, in order for the right to health to become a reality, civil society participation and action is necessary (London, 2007). Participation and accountability are interdependent (Potts, 2008a). We draw in particular on the work of Bovens (2010) who argues for the virtue of accountability to be developed alongside the mechanisms of accountability. We apply this use of the concept of virtue to participation, arguing that values of participation require development alongside the mechanisms of participation. For the purposes of this paper, we use the Oxford English Dictionary definition of values as: “one’s principles or standards.” We prefer the term “values” where Bovens uses virtue for several reasons. The term virtue implies something morally good, and it is possible that participation may not always be for benevolent

purposes or have positive outcomes. The term “values” is a more inclusive term acknowledging that there may be a diversity of principles and lived experiences of participation. Bradby (2016) posed the challenge “to interrogate the social processes of health and illness, to contribute to more humane, equitable, and effective health that integrates scientific evidence with people’s values and experience.” We explore the values of participation as part of these social processes.

The focus here is on the benefits of rights-based approaches to health, including the ability to hold States accountable (Yamin, 2008). We acknowledge the critique of rights-based approaches to health (Preis, 1996; De Cock et al., 2002; Mchangama, 2009; Reubi, 2011) including that such an approach may silence the voices of the most vulnerable (Ferraz, 2009). Linked to this is the argument that a vocal elite drives the “judicialization of health” with access to the legal system and resources necessary to file lawsuits. However, research from Brazil shows that it is in fact the most vulnerable that make use of judicial accountability and that participation is an important instrument of civil society organizations (CSOs) (Biehl et al., 2016, p. 2010). We also acknowledge the wealth of literature on participation and research (e.g., Evans et al., 2010) and participation and health improvement (e.g., Rifkin, 2014) but we focus here on participation and accountability. We draw on our experiences from these fields. We acknowledge the reality that participation is becoming mainstreamed and the danger that participation becomes appropriated and another word for limited consultation. In order to guard against this, human rights defenders need to find ways of reclaiming participation and of ensuring it influences social accountability and the enforcement of legal remedies through compensation, prevention and redress of human rights violations (Boaz et al., 2014).

We begin with an overview of key literature on the right to health and participation. We then present the value of participation and accountability and the importance of valorizing diverse knowledge as our conceptual framework for reflecting on the right to health and participation. Following an outline of methods used, three examples are reflected on. The first is the consultation around the proposed closure of Leeds General Infirmary Children’s Heart Surgery Unit. The second is on the findings of the Mid Staffordshire NHS Foundation Trust Public Inquiry into hospital patient care. The third is the presentation of these two examples to a workshop of two Healthwatch organizations. Healthwatch organizations are a type of formalized participation established by the State nationally to promote PPI at a local level. Workshop participants reflected on their experiences of PPI using the conceptual framework of values of participation and valorizing diverse knowledge in an intersectoral approach. These three examples provide reflections on formalized participation and have relevance to a growing global trend of States implementing participation from the top-down.

THE RIGHT TO HEALTH AND PARTICIPATION

The United Kingdom (UK) has ratified several key international conventions as well as regional treaties relevant to the right to health and participation. Recent health system reforms have

¹<http://www.merseycare.nhs.uk/our-services/a-z-of-services/learning-disability-community-teams/>.

sought to formalize participation, making England a relevant context for reflecting on participation as a value, valorizing diverse knowledge, and how a rights-based approach might assist in developing participation and accountability. The Universal Declaration of Human Rights (1948) established the right to health and the International Covenant on Economic, Social, and Cultural Rights (ICESCR) (UN, 1966) sets out a requirement that legally States parties (countries that have ratified the ICESCR, including the UK) recognize the right of everyone to the enjoyment of the highest attainable standard of physical and mental health. The indivisibility of the right to health from other rights is reflected in the ICESCR and in the inclusion of health in other UN conventions such as the International Convention on the Elimination of All Forms of Racial Discrimination (1965), the Convention on the Elimination of All Forms of Discrimination Against Women (1979), the Convention on the Rights of the Child (1989), and the Convention on the Rights of Persons with Disabilities (2006). In addition to referring to the right to health, the Conventions incorporate participation. For example, the UN Special Rapporteur report on poverty and human rights places participation as a human right in itself and as a requirement or catalyst for overcoming inequalities (UN, 2013). UN General Comment 14 on the right to health, while not legally binding, provides robust and widely accepted guidance on implementing State obligations and stipulates that “the participation of the population in all health-related decision-making at the community, national and international levels” is a part of the determinants of health (UN, 2000, article 5). States are obliged to implement a health strategy that includes participatory methods of monitoring the progressive realization of the right to health. In addition, the right to health includes “the right to seek, receive and impart information and ideas concerning health issues” (UN, 2000, article 12b). Regional frameworks exist not only in terms of individual signatory countries but also in regional charters, conventions, and agreements. Together, these international and regional Conventions and General Comments form the basis for participation and accountability implemented through national law and policies. However, they do not specify who the participants should be or how they should work.

In several countries, alongside health sector reforms, there has been an increase in formalized participation such as Healthwatch in England (Thorlby et al., 2014), health committees (Boullé, 2008; Haricharan, 2012), citizens’ juries (Whitty et al., 2014), and deliberative public participation (Abelson et al., 2007). In the context of the right to health, Potts (2008a) defines participation as individual and group participation with government in decisions that affect the people participating. Furthermore, fair and transparent participation includes institutional mechanisms; capacity building to ensure that people can participate; participation in agenda setting, policy choices, implementation, and monitoring and evaluation; accountability mechanisms and remedies (Potts, 2008a). In the context of human rights, accountability refers to the compliance of duty bearers to fulfilling obligations under international, regional, and domestic laws and treaties (Potts, 2008b). Social accountability is here defined as “citizen action to oversee government conduct” (Potts, 2008b). For the purposes of this paper, we see participation as an element of accountability; participation with government

leading to accountability with concomitant health system reforms and remedies for violations of the right to health.

Recent reviews of research into the benefits of participation (McCoy et al., 2011; Mockford et al., 2011; Rifkin, 2014) have found weak evidence in support of the added benefit of participation and little reported research of good practice in relation to the implementation of participation. Nevertheless, participation has been found to improve: quality and coverage of health care; health outcomes; service planning and development; information development and dissemination; and attitudes of service users and providers (McCoy et al., 2011; Mockford et al., 2011). Achieving successful participation, whether implemented in a formalized way or civil society led way, faces numerous challenges, related to contextual factors and power relations. These include resources, skills, access to appropriate media, trust, ethics, and motivations for participating (Fienieg et al., 2011). In addition, an exclusionary “participatory mainstream” (Philo and Metzler, 2005, p. 77) comprising a self-selecting, unrepresentative minority might dominate or, people may seek to influence the encouragement of “uncivil” society not motivated by benevolence (Mosse, 2001, p. 16). Finally, one of the limitations of participation is that people may become “voices without influence” (Cornwall and Gaventa, 2001, p. 40) in which people are repeatedly engaged with but then without any action being taken as a result of the engagement. Furthermore, while in this paper we focus on the local we recognize there is a global context which influences and may even manipulate local participation (Mohan and Stokke, 2000, p. 263). Human rights defenders need to guard against participation being about a discrete State and a discrete civil society and rather acknowledge the need to transcend local/global and State/civil society binaries (Mohan and Stokke, 2000, p. 263). Participation is therefore situated at the intersection of different forms of power, spheres of influence, and levels of actions and policies, creating sites for health rights across spheres of power and influence (Stuttaford et al., 2014). These sites may support or hinder the implementation of the right to health (Stuttaford et al., 2009). There are different mechanisms of participation relevant to different contexts. Participation, whether formalized, civil society-led, or a combination of these, can all have weaknesses. We argue that the focus has remained on mechanisms of participation rather than a consideration of the values of participation. Not all knowledges and evidence gathered through different formal and civil society-led participation has been treated equally and there have been limited attempts at intersectoral formalized participation. In order for formalized participation to not simply be consultation, the values of participation need to be embraced along with valorizing diverse knowledge and adopting intersectoral approaches that achieves the fair and transparent participation defined by Potts (2008a) as a part of wider social accountability.

VALUES OF PARTICIPATION AND ACCOUNTABILITY

Accountability is not only about remedying violations but also about participating in health system reform (Yamin, 2008). In designing accountability mechanisms, attention needs to be paid to the values of health sector management, public, and patients

(Cleary et al., 2013). In order for there to be accountability, i.e., in order for States parties to engage in accountability processes, it is important for accountability to be seen as a virtue as well as ensuring that mechanisms of accountability are in place (Bovens, 2010). In the same way, there are mechanisms for accountability, there are mechanisms for participation. Similarly, in the same way, accountability needs to be seen as a virtue, we argue that participation should be seen as part of a set of values.

General Comment 14 highlights human rights principles of non-discrimination, participation, and accountability in relation to the accessibility, availability, acceptability, and quality of health services and the determinants of health (UN, 2000). A human rights-based approach to health uses the full complement of international covenants and soft law (non-legally binding instruments, e.g., policies, codes of conduct, professional guidelines, and patient charters) and includes the principles of information, transparency, accountability, and participation (WHO, 2002). Potts' monographs on participation and the right to health (Potts, 2008a) and accountability (Potts, 2008b) illuminate and describe in clear terms State obligations around participatory processes. She identifies five broad mechanisms of accountability, which are linked to participation: judicial, quasi-judicial, administrative, political, and social accountability. While civil society may participate in all five mechanisms of accountability in some way, it is the social mechanisms that are focused on in this paper. Potts is also clear that accountability is not the same as responsiveness, responsibility, answerability, or evaluation because none of these necessarily lead to a remedy of past violations or mitigation of current or future violations. Remedies to redress violations include restitution, compensation, rehabilitation, and satisfaction and guarantee of non-repetition of human rights violations (Potts, 2008b). The guarantee of non-repetition includes health system and organizational changes through, for example, changes in accountability, policy formulation, budgeting, and training (Potts, 2008b). In implementing the right to health and social accountability, participation by CSOs is vital (London, 2007). CSOs may participate in advocacy, developing policies and programs, monitoring State obligations, and addressing violations of the right to health (London, 2007). Participation in these ways should lead to restitution, compensation, rehabilitation, and satisfaction and guarantee of non-repetition of human rights violations. However, there is a danger that social accountability mechanisms become focused on simply monitoring. While this monitoring may collect valuable evidence of violations or data to support health system reform, if there is no remedy then such participation through monitoring fails to link to social accountability. Simply monitoring, without leading to a remedy is a weak form of participation leading to weak accountability. In order for participation to lead to social accountability with a remedy, both participation and accountability need to be seen as values.

Accountability as a virtue has positive implications and is often synonymous with norms of behavior (Bovens, 2010) congruent with human rights norms that include transparency, responsibility, and participation. As a mechanism, accountability can be seen as a social relationship that involves an obligation to explain decisions and actions. This means there is a relationship of participation between the rights duty bearers (actors, usually

State actors, with obligations to protect, respect, and fulfill human rights) and rights holders (people entitled to the rights). Potts (2008a,b) and Bovens (2010) make the link between participation and accountability. We propose extending this link in two ways. First, by arguing that in the same way that accountability should be seen as both a mechanism and virtue, so participation should also be seen as both a mechanism and a value. Second, we suggest that a human rights framework provides guidance on what these values of participation might be.

VALORIZE DIVERSE KNOWLEDGE

General Comment 14 on the right to health includes an obligation of State parties:

To adopt and implement a national public health strategy and plan of action, on the basis of epidemiological evidence, addressing the health concerns of the whole population; the strategy and plan of action shall be devised, and periodically reviewed, on the basis of a participatory and transparent process; they shall include methods, such as right to health indicators and benchmarks, by which progress can be closely monitored; the process by which the strategy and plan of action are devised, as well as their content, shall give particular attention to all vulnerable or marginalized groups (UN, 2000, article 43f).

While this establishes participation as part of accountability mechanisms, it suggests only a narrow definition of evidence and gives primacy to epidemiological evidence alone. Furthermore, there is little guidance on who will participate or how they will participate.

Participation requires engagement with a diversity of knowledges from civil society, the rights holders, and also the multiple knowledges of the duty bearers. Whereas General Comment 14 emphasizes epidemiological evidence, this is only one form of data, emanating from one source. A broader and deeper view of evidence and who provides evidence is required than simply relying on epidemiological data. Self-reflection on diverse views of human rights, forms of oppression and resistance, and social practices leads to the production of a plurality of knowledge (de Sousa Santos et al., 2007). From this practice, we learn that "there are neither pure nor complete knowledges; there are constellations of knowledges" (de Sousa Santos et al., 2007, p. xl). While General Comment 14 focuses on epidemiological data that is reviewed using participatory mechanisms, here we argue that the data and evidence considered should itself be sourced from participatory approaches and methods. If participation through social accountability is to lead to restitution, compensation, rehabilitation, and satisfaction, guarantee of non-repetition of rights violations and health system reform, a deeper form of participation beyond simply reviewing epidemiological data is needed. All data, whether collected through traditional methods such as epidemiological studies, civil society-led participation or formalized participation should be valorized to ensure constellations of knowledges contribute to participation that is part of social accountability.

When seeking the inclusion of diverse knowledges in participation and accountability, from a range of CSOs, an intersectoral approach is necessary. In addition to developing the values of participation and valorizing all knowledge, there needs to be participation across sectors. General Comment 14 emphasizes the right to health as including the determinants of health as well as health care (UN, 2000) and in this way provides guidance on the indivisibility of socio-economic and cultural rights and civil and political rights. The groundwork is therefore laid within international guidance for an intersectoral approach at the national and local level for participation in a rights-based approach to health. In order for the right to health to be implemented as integral to the health system, collective civil society participation is necessary (London, 2007). As Yamin (2008) points out, “a rights-based approach calls for an authentic devolution of power within and beyond the health sector, with a transfer of planning and decision-making capacities to the individuals and communities served” (Yamin, 2008, p. 13). Individual litigation (e.g., a case of medical malpractice) at the national level might be useful in specific cases and at an international level, the UN Committee on Economic, Social and Cultural Rights has the authority to link international norms to individual complaints (Murphy, 2013). However, the strength of a rights-based approach lies not so much in individual litigation but rather in the recognition that where there are individual cases of poor care, this is usually symptomatic of wider health system failures (Yamin, 2008). In Argentina and Colombia, there are examples of judicial accountability in which the Constitutional Court has not only sought to remedy rights violations through compensation, restitution, and guarantees of non-repetition but have also called for reform of the health system in terms of greater public participation (Yamin, 2008). In Brazil’s health system, the establishment of a legal framework for participation, the engagement with participatory institutions, and the link to social accountability mechanisms have led to “extend[ing] the capillary reach of the democratizing effects of engagement” into the whole of the health system (Cornwall and Shankland, 2008, p. 2173). Valuing diverse knowledge not only extends who participates and what evidence is gathered but also extends participation to include all sectors across society to deepen the recognition of the indivisibility of the right to health.

In this paper, we apply the above framework of recognizing diverse knowledge in participation and implementing both mechanisms and values of participation to three examples of formalized participation in England. The first example is a reflection of a consultation process in Leeds. The second example is a reflection on monitoring patient care in Mid Staffordshire. The final example is from a workshop with two Healthwatch organizations that reflected on their own experiences, based on the findings from the first two examples.

METHODS

The research was primarily a desk-based study reviewing and reflecting on examples from England and as such did not obtain institutional ethical approval. We originally prepared this paper as a comment piece on the right to health, participation, and accountability. It came about as a result of a series of conversations

between the authors during which we encouraged each other to read and reflect on each of our differing contexts. Maria Clasina Stuttaford identified examples from England, reflecting on them with colleagues as examples of formalized participation.

Following the process of reflection on the examples, Maria Clasina Stuttaford was invited by two Healthwatch organizations to develop a joint workshop on the right to health and participation. Healthwatch organizations are social enterprises and a type of formalized participation established nationally to promote PPI at a local level. Maria Clasina Stuttaford presented a draft of this paper to the two Healthwatch organizations and their partners in London, England in June 2016. At the outset of the workshop, the participants asked Maria Clasina Stuttaford if the workshop could be recorded for dissemination to wider members and this was agreed. Maria Clasina Stuttaford explained that participants could complete paper handouts in groups or individually, anonymously, if they so wished. At several moments, the presentation was paused, and Maria Clasina Stuttaford asked small groups to discuss key questions and capture key points on the handouts. Responses about individual affiliations on the 11 handouts returned at the end of the workshop were incomplete but it is likely that 2 handouts were completed as a whole group (about 20 people in total) and individuals completed 9 handouts. Participants included health professionals, patient participation group members, trustees of patient networks and academics. During the presentation, workshop participants were asked to reflect on elements of participation and accountability in their practice and experiences of Healthwatch activities. The aim of the workshop was to move away from simply listing the well-rehearsed and -documented challenges of participation to attempt to consider more broadly how the right to health might inform PPI and accountability. Maria Clasina Stuttaford typed up responses on the handouts and disseminated these back to the Healthwatch organizations for their further use. Participants verbally consented that material captured on the handouts would contribute to this paper and that they would receive copies of the paper upon publication.

Setting

We selected England for the focus of this paper because the introduction of formalized mechanisms of participation has been a part of recent health system reform. England provides an opportunity to consider the extent to which participation is seen as part of a set of values and the how diverse knowledge is valorized. The UK has ratified the ICESCR (1966) and several other key international conventions as well as regional treaties relevant to the right to health and participation. Formal mechanisms of participation and social accountability in England include national and local elections, boards of enquiry, judicial reviews, and cross party parliamentary committees. In this paper, we consider direct participation through local structures. The focus is on England as some of the functions of health and social care in the UK are devolved to Scotland, Wales, and Northern Ireland.

The mechanisms for public participation and accountability in England are set out in The Health and Social Care Act (2012).²

²<http://www.legislation.gov.uk/ukpga/2012/7/contents/enacted>.

A key mechanism of formalized participation is through local Healthwatch organizations that are social enterprises established within national, set guidelines and with specified functions. They operate locally with government and primary and secondary health and social care providers and are inclusive of other sectors such as housing, education, and transport. They also engage with other community-based and non-government organizations. Local Healthwatch organizations are represented nationally by Healthwatch England, which reports to the Secretary of State for Health.

In terms of the values associated with participation and accountability, these are enshrined in the NHS England Constitution. The principles of the NHS Constitution include accountability to elected parliament and local people and the: “system of responsibility and accountability for taking decisions in the NHS should be transparent and clear to the public, patients and staff” (NHS, 2015, p. 4). The NHS Constitution also includes the values of: “[w]orking together for patients... We fully involve patients, staff, families, carers, communities, and professionals inside and outside the NHS” (NHS, 2015, p. 5). These values include core human rights principles of dignity and non-discrimination. The NHS Constitution explicitly sets out rights of participation to include:

the right to be involved, directly or through representatives, in the planning of healthcare services commissioned by NHS bodies, the development and consideration of proposals for changes in the way those services are provided, and in decisions to be made affecting the operation of those services (NHS, 2015, p. 9).

As part of these rights, the NHS Constitution pledges, “to make decisions in a clear and transparent way” (NHS, 2015, p. 7) and “to provide you with the information and support you need to influence and scrutinize the planning and delivery of NHS services” (NHS, 2015, p. 10).

In England, whereas mechanisms of formalized participation and accountability are enshrined in the Health and Social Care Act, the values of participation are detailed simply in the soft law of the NHS Constitution. Reflecting on the examples below illustrates how greater emphasis on human rights principles may assist in enhancing the application of the soft law and hard law to improve overall participation and accountability, not only in individual care but also in health system reform.

EXAMPLES AND DISCUSSION OF PARTICIPATION IN ENGLAND

Formalized participation in England is moving ahead as local Healthwatch organizations extend their work. However, it is useful to consider the challenges of other formalized participation to ensure that the mechanisms and values of participation and accountability are embedded in these relatively new and evolving structures. Examples of consultation around changes in service provision in Leeds and monitoring care in Mid Staffordshire are now presented. They are used to reflect on the challenges of

more recent mechanisms of formalized participation, namely Healthwatch, and the importance of civil society-led participation and the need to embrace the values of participation, to valorize all knowledge, and to work across sectors.

Leeds General Infirmary Children’s Heart Surgery Unit: Values of Participation in Health System Reform

The debacle about the closure of Leeds General Infirmary Children’s Heart Surgery Unit highlights some of the challenges of participation when there is weak or flawed participation and the importance of following values of participation in health system reform. The Leeds example illuminates the importance of the right to information as part of the right to health, as stipulated in the UN General Comment 14 which States that the right to health includes “the right to seek, receive and impart information and ideas concerning health issues” (UN, 2000, p. 12b) and that there should be “the participation of the population in all health-related decision-making at the community, national and international levels.” The Leeds example is an illustration of civil society-led participation and how such non-formalized accountability engages with and amplifies judicial accountability.

Between 1991 and 1995, 30–35 more children under 1-year old died after open-heart surgery at Bristol Royal Infirmary than would have been expected at a typical, similar unit in England (Kennedy Report, 2001). In 2008, a review of child heart surgery was launched and in February 2011, it was recommended that 4 out of 11 units in England no longer offer surgery. On the 1st of March 2011, parents led a delegation to parliament to lobby to save the surgery unit at Leeds and on the 15th of March the “Save Our Surgery” (SOS) campaign was launched comprising patients, activists, and health workers. In July/August, there was a formalized consultation exercise. The civil society-led campaign by SOS continued in parallel to the formalized participation. In July 2012, the NHS Joint Committee of Primary Care Trusts announced surgery at Leeds would stop, however, the SOS campaign continued and in October SOS applied to the High Court for a judicial review.

Social rights are not recognized as such in English law and there is therefore no right to health on which to hang legal arguments about participation. Other grounds for the right to health are required. Therefore, SOS did not challenge the legal merits of whether the Joint Committee of Primary Care Trusts decision was right or wrong. The challenge was to the process of participation. As part of the review of services, a panel of experts visited each unit and a score based on performance was assigned to a Quality of Services assessment. The sub-scores were not made available to all involved in the participation process. In the High Court decision, issues were raised about the lack of disclosure of all relevant information to all parties, the reliability of data in the assessment, the weighting of scores related to quality, and the importance assigned to factors related to accessibility and availability. On the 7th of March 2013, the High Court quashed the decision to stop surgery at Leeds ruling that the participation process and decision-making process underpinning the assessment was unfair and legally flawed. Cheng (2013) from SOS said:

Winning this case in the High Court proves once and for all that the supposed consultation was a rubber-stamping exercise conducted with an outcome in mind, with clinicians, MPs and patients fooled into feeling they had influence.

The Leeds case raises a number of important issues. First, it provides helpful guidance to those embarking on formalized participation as to what constitutes lawful involvement. In its decision, the High Court set out that:

Lawful consultation requires that: i) it is undertaken at a time when proposals are still at a formative stage; ii) it must include sufficient reasons for particular proposals to allow those consulted to give intelligent consideration and an intelligent response; iii) adequate time must be given for this purpose; iv) the product of the consultation must be conscientiously taken into account when the ultimate decision is taken (EWHC, 2013).

While this guidance speaks to the mechanisms of participation, it also speaks to the values of participation in that the product of discussion must be “conscientiously taken into account.” Second, the case alerts us to the potential limits of relying purely on formalized participation. Ultimately, the rights holders, through civil society-led participation by SOS, took responsibility for establishing social accountability first through the formation of SOS and then by engaging with judicial accountability mechanisms to hold the rights duty bearers which in this case was, the Joint Committee of Primary Care Trusts, to account. While formalized participation is meant to be a way of leveling the participatory playing field, where such participation is weak it may be as unequal and unrepresentative as civil society-led participation can be. Third, the High Court ruling illuminates the importance placed on social accountability and the need for the duty bearer to ensure all relevant data and evidence is made available to the rights holders.

Save Our Surgery took action to influence formalized participation and power relations in physical spaces of protest and courts, creating sites in which duty bearers were held accountable for the right to health. Through their actions, SOS influenced future policies related to information sharing and participation. It is possible to think of the mechanisms of participation as relating to procedural rights. In the Leeds example, the State has not been held accountable in relation to the substantive right to health, but rather to procedural rights related to transparent information sharing and fair participation in decision-making. This example provides useful lessons in demonstrating the importance of human rights principles of access to information, transparency, and accountability through participation as part of a set of values linked to the norms of procedural rights.

Mid Staffordshire NHS Foundation Trust Public Inquiry: Valorizing Diverse Evidence

The Mid Staffordshire example highlights the importance of not simply putting mechanisms or procedural rights in place but also valorizing all evidence and adopting values of participation.

Following a failure in patient care between 2005 and 2008, the Mid Staffordshire NHS Foundation Trust Public Inquiry was launched and its findings published in February 2013 by Robert Francis QC. In his introduction, Francis (2013) acknowledged that it was only as a result of the concern for care and attention to mortality rates by a “a determined group of patients” called Cure NHS and led by Julie Bailey, that the situation in Mid Staffordshire NHS Foundation Trust came to light. Francis (2013) found not only a failure of the Foundation Trust Board but also of the regulatory system that was meant to ensure governance and care standards were met. Evidence and information were not given sufficient importance: “Statistics and reports were preferred to patient experience data, with a focus on systems, not outcomes” (Francis, 2013). For example, the 2007 in-patient survey, for some items, placed the Trust in the worst performing 20% of Trusts in the country yet no action was taken (Francis, 2013).

Trust management had no culture of listening to patients. There were inadequate processes for dealing with complaints and serious untoward incidents. Staff and patient surveys continually gave signs of dissatisfaction with the way the Trust was run, and yet no effective action was taken and the Board lacked an awareness of the reality of the care being provided to patients. The failure to respond to these warning signs indicating poor care could be due to inattention, but is more likely due to the lack of importance accorded to these sources of information” (Francis, 2013).

Furthermore, there was a failure of LINKs—the precursor to Healthwatch—as well as locally elected representatives. Although the mechanisms for social accountability were in place through formalized participation, these procedural rights failed.

The Francis Inquiry cautioned that reforms established after LINKs, namely the establishment of Healthwatch, are in danger of repeating the same failings as LINKs. There was an exclusion of patients and a failure of participation mechanisms:

[A] system of small, virtually self-selected volunteer groups which were free to represent their own views without having to harvest and communicate the views of others ... The system gave rise to an inherent conflict between the host, which was intended to provide a support service but in practice was required to lead with proposals and initiatives offered to lay members, and members of the forum, who were likely to have no prior relevant experience and to be qualified only by reason of previous contact with the hospital to be scrutinized ... A preoccupation with constitutional and procedural matters and a degree of diffidence towards the Trust prevented much progress (Francis, 2013).

The report went on to recommend that in order to put patients first, there does not need to be reorganization, but a shift in culture, including “Emphasis on and commitment to common values throughout the system by all within it” (Francis, 2013). These reforms are not about changing the accountability mechanisms,

but about shifting values of accountability and ensuring: “There must be real involvement of patients and the public” (Francis, 2013). The 290 recommendations from the Francis Inquiry refer to all aspects of the health system including putting the patient first; simplifying regulation; monitoring and enforcement of compliance; accountability of Board and enhancement of governor’s roles; effective complaints procedures; training and education; patient and public participation; transparency and candor; caring and compassion; and leadership.

In addition to the ongoing reform of the NHS as set out in the Health and Social Care Act (2012; see text footnote 2), the government presented its response to each of the Francis Inquiry recommendations in *Hard Truths: The journey to putting patients first* (Department of Health England, 2013). *Hard Truths* accepts that the NHS Constitution should be the main reference point for patients and staff, including where services are outsourced (i.e., private sector accountability) and that patients should be put first. Methods of making a complaint or comment must be readily available to patients—both individually and collectively and should be investigated and handled appropriately. Commissioners, scrutiny committees, and others with oversight must have access to complaints [response to recommendations 109–122 (Department of Health England, 2013)]. Local oversight and scrutiny of quality of care will take place through local authorities, Health and Wellbeing Boards, NHS commissioners and providers, and local Healthwatch organizations. While each Healthwatch develops their own roles and responsibilities locally, there is national guidance encouraging joint working to improve the quality of services (response to recommendations 145–147). It is recognized that training for people volunteering for these structures is important (response to recommendation 148 and 149) and that some functions, such as inspections may be better suited to local authority scrutiny committees than patient participation structures (response to recommendation 149). Furthermore, “Every healthcare organization and everyone working for them must be honest, open and truthful in all their dealings with patients and the public” (recommendation 173) and in response to this the Government has introduced a new statutory duty of candor on providers that will ensure patients are given the truth when things go wrong, and that honesty and transparency are the norm in every organization (response to recommendations 173–184). The government response, at least on paper, therefore includes the values of participation, valorizing all data, and working across sectors.

One year after the Francis Inquiry, the Nuffield Trust explored the implementation of its recommendations (Thorlby et al., 2014). They found that hospital trusts had welcomed the Inquiry as it added legitimacy to ongoing efforts to improve care, while also meeting financial and performance targets. In particular, the Inquiry was said to be useful for developing work on handling complaints, and improving both staffing levels and engagement with staff. It was found that Trusts had developed their own initiatives to gather data about quality of care, particularly at hospital ward level, including combining clinical and patient reported data. This is evidence of a move toward valorizing clinical data alongside other data including that provided through the

participation of patients. However, writing in a national newspaper *The Sunday Telegraph* (2 February 2014), the head of the Care Quality Commission, David Prior, highlighted two on-going concerns. First, the division between managers and clinicians leading to poor quality care. Second, inappropriate forms of accountability, such as waiting time targets, diverting attention from achieving quality care. In order to implement the Inquiry recommendations, the voices of patients and health professionals need to be listened to. The scrutiny powers of elected local authorities and the participation of civil society through local Health and Wellbeing Boards will be essential (Roderick and Pollock, 2014). As the Chair of the Commons Public Administration Select Committee, Bernard Jenkin, commented in April 2014, “Unless and until we have a culture of leadership in public services that listens to, values and responds to complaints, from service users and staff, there will always be the potential for tragedies like Mid-Staffs.” These concerns highlight the need to establish appropriate targets and for participation to include managers, health professionals and patients in holding duty bearers accountable to targets.

In Mid Staffordshire although the mechanisms for accountability were in place through formalized participation, these procedural rights failed. The duty bearers did not “conscientiously take into account” evidence and listen to rights holders. The government response to the Francis Inquiry in *Hard Truths* includes embracing the values of participation through, for example, a renewed emphasis on the NHS Constitution. There is also evidence of a move away from valorizing clinical data and toward finding new ways to include evidence provided through the participation of patients. However, concerns remain about the extent to which new formalized mechanisms of participation will also embrace values of participation. In a recent review of the process for drafting Sustainability and Transformation Programmes for the latest round of NHS reforms, it was found that PPI has been largely absent and in some areas has been actively discouraged (Alderwick et al., 2016). This is in direct contravention of the NHS Constitution as well as contradicting lessons learned from previous weak formalized participation as detailed in the Francis Inquiry. With these cautions about the implementation of participation as values, following the Leeds example and the Francis Inquiry, we used a framework of the right to health to ask two Healthwatch organizations about their experiences of participation.

Workshop with Two London Healthwatch: Reflections on Participation through a Right to Health Lens

Since the 1990s reform of NHS, England has been moving away from State-provided comprehensive health care toward discretionary health care (Pollock et al., 2012). There has been a simultaneous formalization of participation. Scrutiny powers of elected local authorities and participation of civil society will be essential to holding in check the reduction of State-provided services (Roderick and Pollock, 2014). Healthwatch is an example of formalized participation and accountability in the UK. While Healthwatch has been established by the State as a mechanism

of participation and accountability, following Potts (2008a,b) and Bovens (2010), it is vital to ensure that the State also engage with Healthwatch as part of a set of values of participation.

At a workshop involving two Healthwatch organizations from London, small groups of workshop participants were asked to list the various mechanisms of participation that individuals were involved in. These included being active in patient groups around particular conditions or issues such as stroke, accident, and emergency, older people, disability; accountability roles such as governor or trustee; working across sectors for example with transport and housing bodies; and engaging with formalized participation mechanisms such as Healthwatch public meetings, responding to local authority consultations, submitting evidence to members of parliament. Participants were therefore engaging across sectors, demonstrating recognition of the indivisibility of the right to health.

Participants were then asked: “Do you experience fair and transparent participation in decisions that affect you?” Responses to this question were variable. One respondent wrote: “everyone’s views and opinions are taken into consideration” and another wrote “the advisory group can change and influence the way our services are led” with “ample opportunity to become involved.” However, other people described limitations to participation, mainly around communication and, similar to the Leeds example, access to information. One person wrote “groups may not have access to information so wouldn’t know if it was fair” and another person commented “local authority’s information provided too late so not real consultation.” Other people said that people do not know about opportunities for participation. The reported lack of information provided to the Healthwatch organization, as with the Leeds example, does not adhere to the guidance offered in UN General Comment 14 or the NHS Constitution related to providing access to information and involvement in decision-making.

Workshop participants were then asked, “Is the participation you are involved with seen as a virtue?” People said that participation “works and has improved services” and that it provides “good advice and feedback.” Patient “involvement in their care is seen as important” and “working together is key.” However, others wrote how “cynicism about consultation is deeply engrained.” Similar to SOS in Leeds, people see participation as consultation toward “a politically decided outcome.” There needs to be “process and human willingness.” This demonstrates how people see participation as not simply monitoring but also about remedying human rights violations and/or influencing health system reform.

Next, workshop participants were asked “Is all knowledge and evidence treated equally in the participation you are involved with?” One respondent wrote, “Everyone has their say and a right to question anything they’re not happy with.” However, others said that “in theory, yes—the records are good (e.g., the data) but in practice, no” and another person wrote, “patient voice not really ‘heard’” and there is “tick box superficial information.” These mixed experiences reflect the concerns following Mid Staffordshire where data were collected but not utilized and in which evidence gathered through participation was not valorized alongside other forms of evidence.

Finally, participants were asked, “Does the participation you are involved with include all sectors? Respondents named links

with several organizations, including the local authority, housing, education, transport and other organizations in the health sector. They also wrote that “we are constantly looking for new members from different backgrounds and sectors as it will help us to cover different aspects” recognizing that “person-centered healthcare is necessarily multidisciplinary with multi-stakeholder involvement.” However, others said that there is currently no involvement with other sectors or that while there is the potential for working across sectors, this is “not yet evident in decision-making.”

The Mid Staffordshire example demonstrates the importance of not simply collecting indicators but also analyzing and reacting to them; a role that Healthwatch organizations can adopt. In a review of Healthwatch, Patient Library (2016) highlighted Healthwatch as the biggest single contributor to the qualitative evidence of patient experience, offering analysis that extends statistical performance indicators. The role of Healthwatch organizations as providers of evidence and users of information in participation therefore potentially extends the forms of evidence available to duty bearers and rights holders. However, Patient Library (2016) also found that across Healthwatch organizations there is variability in terms of quality of reporting and joining up learning indicating the need for support and development of Healthwatch organizations to ensure they can fully realize their role.

The relationship between the rights duty bearer (here the State) and the rights holder (here the Healthwatch) relies on three elements of accountability (Bovens, 2010): (1) the State feels obliged to inform the specific Healthwatch organization about performance, procedures, and outcomes; (2) the Healthwatch organization has the opportunity to question the information provided; and (3) the Healthwatch organization has the possibility of applying positive or negative consequences. These three elements of the accountability relationship can be classified according to three questions adapted from Bovens (2010). First, who is the rights holder? Here, it is local Healthwatch organizations engaging in social accountability. Second, who is the duty bearer? Here, it might be locally elected officials, local civil servant managers, and front line workers from several sectors. Third, do these duty bearers feel obliged to appear to the Healthwatch? Here, there are obligations of participation and accountability as part of the right to health—which crucially assume a legal framework and that duty bearers will embrace values of participation and accountability to appear before the rights holders. From the data presented, it is not clear that duty bearers do feel obliged to appear in front of Healthwatch. Workshop participants were found to have mixed experiences of social accountability and mixed experiences of values that would lead to involvement in health system reform and restitution, compensation, rehabilitation, and satisfaction and guarantee of non-repetition of violations.

CONCLUSION

The consideration of shortcomings in values of participation and valorizing knowledge gained through different forms of participation at the Leeds Children’s Heart Surgery Unit and Mid Staffordshire NHS Foundation Trust serves to underscore the importance of procedural rights of participation and accountability

in implementing the right to health and also the challenges of implementing formalized participation. In both cases, violations of procedural rights to health were brought to light through civil society-led participation, rather than through formalized mechanisms. The development of PPI in England has focused on mechanisms of participation. Even where legislation and soft law exists, the Leeds and Mid Staffordshire cases demonstrate that implementation of the values of participation and accountability can be as challenging as the implementation of the right to health itself.

We have framed this paper using a rights-based approach to health, which is enshrined in international and regional conventions and includes participation as a vital part of holding State parties accountable. All mechanisms of participation have weaknesses and in order to overcome these, human rights defenders could consider a combination of formalized (e.g., Healthwatch) and civil society-led participation (e.g., SOS Leeds) where different mechanisms counter the flaws of other mechanisms. However, for this combination to lead to accountability and remedy of human rights violations participation needs to be seen as part of a set of values within health systems. There is a danger of relying on flawed civil society-led participation or weak formalized participation alone. Participation in whatever form needs to be strong in order to ensure accountability. PPI in health could draw on values enshrined in human rights-based approaches such as transparency, access to information, and fair decision-making processes to guide the implementation of the procedural rights of participation. We have argued for extending General Comment 14 on the right to health in two ways: first, by strengthening the values of participation and accountability in the integration of civil society-led and formalized participation. Second, by valorizing data and knowledge gathered through participation alongside more traditional forms of evidence such as epidemiological data.

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AUTHOR NOTES

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All authors contributed to the development of the conceptual framework adopted in the research. MS identified the examples and presented an early analysis of the examples to co-authors. The examples were discussed as part of an iterative process of reflection by all authors. MS drafted the paper and co-authors provided detailed feedback on drafts.

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