



# Library Note

## Service User Representation in Health and Social Care

On 15 December 2016, the House of Lords will debate the following motion, tabled by Lord Harris of Haringey (Labour):

To move that this House takes note of the case for effective service user representation in health and social care, and of the case for enhancing the independence and capacity of Healthwatch England and of local Healthwatch groups.

The first part of this briefing considers definitions of service user representation in health and social care services, sometimes known as patient and public involvement (PPI). Defining what constitutes PPI is difficult and the concept is contested. This has created problems with determining what effective patient involvement looks like. Despite this, the King's Fund has observed that the idea of putting patients first and giving them a stronger voice in the operation of health and social care services had "become the favoured mantra of politicians and senior policy-makers in health". However, the King's Fund suggested that these kinds of policies had been undermined by a lack of clarity about what involving people in health meant and that the policy had not been prioritised.

The second part of this briefing looks at Healthwatch England and its network of local Healthwatch organisations. Healthwatch was created by the Health and Social Care Act 2012 to be an "independent consumer champion for both health and social care". Healthwatch replaced the previous system of Local Involvement Networks (LINks), which it was argued lacked power and were not representative. Healthwatch England and the local Healthwatch organisations have a number of statutory duties, such as promoting and supporting the involvement of local people in the commissioning, provision and scrutiny of local care services.

Healthwatch England was allocated £4.5 million in 2015/16 by the Government to fund core running costs and additional non-recurrent funding, while local Healthwatch received around £31.8 million in the same year. The organisation has recently conducted work into people's experiences of the complaints system, and made a number of recommendations to improve the complaints process in the NHS and social care services. It has also been suggested that local Healthwatch organisations face a number of challenges, such as problems of capacity and resources, accountability, and representation.

Samuel White  
8 December 2016  
LLN 2016/068

**Table of Contents**

- 1. Defining Service User Representation in Health and Social Care..... 1
- 2. Healthwatch England and Local Healthwatch ..... 2
  - 2.1 Background ..... 3
  - 2.2 Statutory Duties ..... 5
  - 2.3 Finances ..... 7
  - 2.4 Work of Healthwatch England..... 8
  - 2.5 Challenges Facing Healthwatch ..... 10

## I. Defining Service User Representation in Health and Social Care

Successive governments have implemented policies designed to improve service user representation in health and social care.<sup>1</sup> The NHS's Involvement Hub, which supports people interested in participating in the design and delivery of health services, stated that public participation is important because it can help improve patient safety, patient experience and health outcomes.<sup>2</sup> The Involvement Hub's website lists a number of examples of participation. For example, it explained that experienced based co-design has been used in London to "reshape cancer services". This involves "listening to the experiences of patients, carers and staff to redesign all or part of a health care process together".<sup>3</sup>

However, what is meant by service user representation is difficult to define and a variety of definitions have been adopted, such as patient and public involvement (PPI).<sup>4</sup> This is the term most often used in UK policy to refer to service user representation in the NHS and social care. However, Bob Hudson, a fellow at Durham University's Wolfson Research Institute for Health and Wellbeing, observed that any such "concept of 'public and patient engagement' (PPE) in health care is broad and contested".<sup>5</sup> Similarly, in 2007, the House of Commons Health Committee published a report on PPI which argued that:

Patient and public involvement often appears to be a nebulous and ill-defined concept, used as an umbrella term to cover a multiplicity of interactions that patients and the public have with the NHS.<sup>6</sup>

The Committee added that:

Discussion of patient and public involvement often focuses on institutions dedicated to securing and promoting involvement; however, in reality, patients and the public are involved in decisions about healthcare and health services at many different levels, ranging from input into individual decisions about their treatment to large scale consultations on the broad direction of national policy and health spending. Some patient involvement is spontaneous, some is systematic; some is well resourced, some depends on the goodwill of interested parties; mechanisms for involving patients and the public are as complex as the many interlacing structures that make up the NHS.<sup>7</sup>

Jonathan Tritter, Professor of Sociology and Public Policy at Aston University, has defined PPI as "ways in which patients can draw on their experience and members of the public can apply their priorities to the evaluation, development, organisation and delivery of health services".<sup>8</sup>

---

<sup>1</sup> Dr Pam Carter and Professor Graham Martin, '[Challenges Facing Healthwatch, a New Consumer Champion in England](#)', *International Journal of Health Policy and Management*, April 2016, vol 5 no 4, p 259.

<sup>2</sup> NHS Involvement Hub, '[Why Get Involved?](#)', accessed 7 December 2016.

<sup>3</sup> NHS Involvement Hub, '[Good Practice Examples: NHS Trusts](#)', accessed 7 December 2016.

<sup>4</sup> *ibid*, p 259; and Bob Hudson, 'Public and Patient Engagement in Commissioning in the English NHS: An Idea Whose Time Has Come?', *Public Management Review*, 2015, vol 17, p 2.

<sup>5</sup> Assistant Professor Bob Hudson, 'Public and Patient Engagement in Commissioning in the English NHS: An Idea Whose Time Has Come?', 2015, *Public Management Review*, vol 17, p 2.

<sup>6</sup> House of Commons Health Committee, '[Patient and Public Involvement in the NHS](#)', 20 April 2007, HC 278-I of session 2006-07, p 10.

<sup>7</sup> *ibid*.

<sup>8</sup> Professor Jonathan Tritter, 'Revolution or Evolution: the Challenges of Conceptualising Patient and Public Involvement in a Consumerist World', *Health Expectations*, September 2009, vol 12 no 3, p 276.

However, according to Brad Wright, an Assistant Professor at University of Iowa's Department of Health Management and Policy, the conceptual issues around PPI mean that it is difficult to identify successful practice, "owing to the lack of a clear definition of PPI and conflicting rationales for its existence".<sup>9</sup>

Despite these issues, the King's Fund has observed that over the past 20 years in the United Kingdom, putting patients first had "become the favoured mantra of politicians and senior policy-makers in health", with the aim of giving people a "stronger voice in decisions about health and care, and that services should better reflect their needs and preferences".<sup>10</sup> The *NHS Constitution for England*, first published in January 2009, outlined a number of patient rights and responsibilities, and NHS England's *Five Year Forward View*, published in 2014, advocated involving communities and citizens "directly in decisions about the future of health care services".<sup>11</sup>

On 30 November 2015, NHS England published its patient and public participation policy. This set out its "ambition of strengthening participation in all of our work" and pledged to "work in partnership with patients and the public, to improve patient safety, patient experience and health outcomes; supporting people to live healthier lives".<sup>12</sup> It placed responsibility on all staff to consider the need for patient and public participation and undertake this where appropriate.<sup>13</sup> The policy also outlined the specific responsibilities within NHS England for the Board of NHS England, the chairman and other Non-Executive Directors, the National Director for Patients and Information, regional directors and all managers regarding patient and public participation. For example, the Board of NHS England is "responsible for NHS England's performance in relation to all legal duties, including the duty to make arrangements to involve the public in commissioning".<sup>14</sup>

The King's Fund has argued that, "despite pockets of good practice, there has been a lack of systematic progress", and suggested three reasons why this was the case.<sup>15</sup> First, there was a lack of clarity about what involving people in health meant. Second, involvement in health was difficult because it "challenges orthodoxies, vested interests and established ways of doing things".<sup>16</sup> Third, while greater public involvement had been a policy goal, it had never been a priority across healthcare.<sup>17</sup>

## 2. Healthwatch England and Local Healthwatch

The Health and Social Care Act 2012 established Healthwatch to act as an "independent consumer champion for both health and social care".<sup>18</sup> The Act created a network of local Healthwatch organisations across England's 152 local authorities, and a national body, Healthwatch England.

<sup>9</sup> Assistant Professor Brad Wright, '[Consumers or Citizens? Whose Voice Will Healthwatch Represent and Will It Matter?](#)', *International Journal of Health Policy and Management*, November 2016, vol 5 no 11, p 667.

<sup>10</sup> King's Fund, [People in Control of their Own Health and Care: The State of Involvement](#), November 2014, p 6.

<sup>11</sup> Department of Health, '[The NHS Constitution for England](#)', 14 October 2015; and NHS England, [Five Year Forward View](#), October 2014, p 13.

<sup>12</sup> NHS England, [Patient and Public Participation Policy](#), 30 November 2015, p 6.

<sup>13</sup> *ibid*, p 8.

<sup>14</sup> *ibid*.

<sup>15</sup> King's Fund, [People in Control of their Own Health and Care: The State of Involvement](#), November 2014, p 6.

<sup>16</sup> *ibid*, p 7.

<sup>17</sup> *ibid*.

<sup>18</sup> Local Government Association, [Delivering Effective Local Healthwatch](#), September 2013, p 5.

The Local Government Association (LGA) has stated that the purpose of local Healthwatch is to:

[G]ive citizens and communities a stronger voice to influence and challenge how health and social care services are provided within their locality. Local Healthwatch provides, or signposts, people to information to help them make choices about health and care services.<sup>19</sup>

Healthwatch England is a statutory committee of the Care Quality Commission (CQC) (the independent regulator of health and social care in England)<sup>20</sup> and was created to “give local voice influence at the national level” and to provide leadership and support for the local Healthwatch organisations.<sup>21</sup>

## 2.1 Background

Phoebe Dunn, a policy researcher at the King’s Fund, has observed that “local Healthwatch organisations represent the latest in a long line of attempts to give patients and wider communities an effective collective voice”.<sup>22</sup> Since the 1970s, successive governments have implemented a series of PPI policies, beginning with Community Health Councils (CHCs) in 1973.<sup>23</sup> These were abolished in 2002 and replaced by Patient and Public Involvement Forums (PPIFs). Local Involvement Networks (LINKs) replaced these in 2008.<sup>24</sup> The Department of Health has explained that LINKs were “community-based, locally accountable networks of individuals, groups and organisations designed to strengthen the patient, public and user voice in the commissioning, provision and scrutiny of local services”.<sup>25</sup> Along with health services, they also covered state funded social care and were “designed to reflect a more integrated approach to social care”.<sup>26</sup> Dr Pam Carter and Professor Graham Martin, from the University of Leicester’s Department of Health Sciences, have suggested that “successive reforms arguably demonstrate political commitment to, and sustained high-level interest in, PPI in its various organisational forms”.<sup>27</sup>

Healthwatch’s establishment was part of the Coalition Government’s desire to increase public involvement in how the health and social care system worked. The 2010 white paper, *Equity and Excellence: Liberating the NHS*—which set out the Coalition’s vision for the future of the NHS—stated that “we will put patients at the heart of the NHS, through an information revolution and greater choice and control”.<sup>28</sup>

---

<sup>19</sup> Local Government Association, [Delivering Effective Local Healthwatch](#), September 2013, p 5.

<sup>20</sup> Care Quality Commission, [‘About Us’](#), accessed 7 November 2016.

<sup>21</sup> Department of Health, [Local Healthwatch: A Strong Voice for People—The Policy Explained](#), 2 March 2012, p 4.

<sup>22</sup> Phoebe Dunn, [‘Local Healthwatch: Progress, Promise and Power’](#), King’s Fund blog, 16 September 2015.

<sup>23</sup> Dr Pam Carter and Professor Graham Martin, [‘Challenges Facing Healthwatch, a New Consumer Champion in England’](#), *International Journal of Health Policy and Management*, April 2016, vol 5, no 4, p 259.

<sup>24</sup> *ibid.*

<sup>25</sup> Department of Health, [Equity and Excellence: Liberating the NHS](#), July 2010, Cm 7881, p 6.

<sup>26</sup> *ibid.*

<sup>27</sup> Dr Pam Carter and Professor Graham Martin, [‘Challenges Facing Healthwatch, a New Consumer Champion in England’](#), *International Journal of Health Policy and Management*, April 2016, vol 5, no 4, p 259.

<sup>28</sup> Department of Health, [Equity and Excellence: Liberating the NHS](#), July 2010, Cm 7881, p 3.

As part of this aim, the white paper called for the creation of a new organisation to represent the views of patients:

We will strengthen the collective voice of patients and the public through arrangements led by local authorities, and at national level, through a powerful new consumer champion, Healthwatch England, located in the Care Quality Commission.<sup>29</sup>

It further stated that Healthwatch England would be a “new independent consumer champion” and that the existing LINKs would become local Healthwatch instead.<sup>30</sup> The Department of Health provided further details on the purpose of Healthwatch in a subsequent policy document:

Healthwatch will strengthen the collective voice of local people across both health and social care, influencing Joint Strategic Needs Assessments and joint health and wellbeing strategies—on which local commissioning decisions will be based—through its seat on every statutory health and wellbeing board. Establishing successful Healthwatch organisations, rooted in communities and responsive to their needs, will mean working differently in many cases. It will also mean working much more collaboratively so that local Healthwatch organisations can operate as part of existing local community networks ensuring they can have maximum reach across the diversity of the local community and drawing on information, advice and local knowledge that already exists.<sup>31</sup>

The Department of Health argued that the previous system of PPI in the NHS and social care system had been “inaccessible and fragmented” and “constrained by a lack of real power”.<sup>32</sup> The Department of Health suggested that the LINKs had faced a number of problems, including difficulties in attracting a wide range of people from their local community which made it “impossible for them to be truly representative of their local population”.<sup>33</sup> In addition, the Department of Health argued that there had been a “lack of awareness of the work of LINKs among the public and health and care professionals” and that they had lacked a consistent identity, which hindered their “potential to reach different groups within the local community”.<sup>34</sup> The Department of Health suggested that the “tripartite structure of local authority, host organisation and LINK” had led to a “lack of visible accountability for LINKs, and a confusion about the roles, relationships and responsibilities of each of the three partners”.<sup>35</sup> On top of these issues, the Department of Health added that there had also been “no organisation to provide national leadership for LINKs”.<sup>36</sup> Writing for the King’s Fund, Phoebe Dunn agreed that LINKs were:

Constrained by a lack of real power, often criticised for not being representative of their local populations, and hampered by cases of internal disputes and a lack of awareness of their work.<sup>37</sup>

<sup>29</sup> Department of Health, [Equity and Excellence: Liberating the NHS](#), July 2010, Cm 7881, p 3.

<sup>30</sup> *ibid.*, p 19.

<sup>31</sup> Department of Health, [Local Healthwatch: A Strong Voice for People—The Policy Explained](#), 2 March 2012, p 4.

<sup>32</sup> *ibid.*

<sup>33</sup> *ibid.*, p 6.

<sup>34</sup> *ibid.*

<sup>35</sup> *ibid.*

<sup>36</sup> *ibid.*

<sup>37</sup> Phoebe Dunn, ‘[Local Healthwatch: Progress, Promise and Power](#)’, King’s Fund blog, 16 September 2015.

The Mid Staffordshire NHS Foundation Trust Public Inquiry (the Francis Report) also commented on the various PPI policies. In the case of Stafford's main hospital, the Francis Report argued that "patients and relatives felt excluded from effective participation in the patients' care".<sup>38</sup> It also suggested that the policies that followed the Community Health Councils (CHCs) did not succeed in giving patients a voice. These were:

[A]most invariably compared favourably in the evidence with the structures which succeeded them. It is now quite clear that what replaced them, two attempts at reorganisation in 10 years, failed to produce an improved voice for patients and the public, but achieved the opposite. The relatively representative and professional nature of CHCs was replaced by 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. Neither of the systems which followed was likely to develop the means or the authority to provide an effective channel of communication through which the healthcare system could benefit from the enormous resource of patient and public experience waiting to be exploited.<sup>39</sup>

## 2.2 Statutory Duties

Both Healthwatch England and the local Healthwatch organisations have a number of statutory duties set out in the Health and Social Care Act 2012 and the Local Government and Public Involvement in Health Act 2007.

Section 181(2) of the Health and Social Care Act 2012 established Healthwatch England as a statutory committee within the CQC. This stated that the purpose of the organisation is to provide advice to the Secretary of State, NHS England, Monitor and English local authorities on:

- (a) the views of people who use health or social care services and of other members of the public on their needs for and experiences of health and social care services, and
- (b) the views of local Healthwatch organisations and of other persons on the standard of provision of health and social care services and on whether or how the standard could or should be improved.<sup>40</sup>

Under the Health and Social Care Act 2012, Healthwatch England can provide local Healthwatch with general advice and assistance regarding their duties under the Local Government and Public Involvement in Health Act 2007. Healthwatch England explains that "local Healthwatch are corporate bodies and within the contractual arrangements made with their local authority must carry out particular activities".<sup>41</sup> The Department of Health suggested this would "allow local authorities some flexibility to commission a local Healthwatch organisation that best suits local need" and added that this would allow local authorities to use existing "voluntary and community expertise in engaging local communities and delivering outcomes [...]".<sup>42</sup> Further, section 183 of the Health and Social Care Act 2012 states that local

---

<sup>38</sup> Mid Staffordshire NHS Foundation Trust Public Inquiry, [Report of the Mid Staffordshire NHS Foundation Trust Public Inquiry: Executive Summary](#), February 2013, p 46.

<sup>39</sup> *ibid.*

<sup>40</sup> Health and Social Care Act 2012, s 181.

<sup>41</sup> Healthwatch England, [Understanding the Legislation: An Overview of the Legal Requirements for Local Healthwatch](#), August 2013, p 1.

<sup>42</sup> Department of Health, [Local Healthwatch: A Strong Voice for People—The Policy Explained](#), 2 March 2012, p 17.

Healthwatch organisations must be social enterprises and section 184 enables them to contract with others organisations and individuals.<sup>43</sup>

Section 221 of the Local Government and Public Involvement in Health Act 2007 (as amended by the Health and Social Care Act 2012) requires that each local authority in England must contract with a local Healthwatch organisation for the purpose of involving local people in the commissioning, provision and scrutiny of local health and social care services.<sup>44</sup> In addition, local Healthwatch organisations must undertake a number of activities, as required under section 221(2) of the Local Government and Public Involvement in Health Act 2007. Healthwatch England has published a summary of these activities, which include:

- Promoting and supporting the involvement of local people in the commissioning, the provision and scrutiny of local care services.
- Enabling local people to monitor the standard of provision of local care services and whether and how local care services could and ought to be improved.
- Obtaining the views of local people regarding their needs for, and experiences of, local care services and importantly to make these views known.
- Making reports and recommendations about how local care services could or ought to be improved. These should be directed to commissioners and providers of care services, and people responsible for managing or scrutinising local care services and shared with Healthwatch England.
- Providing advice and information about access to local care services so choices can be made about local care services.
- Formulating views on the standard of provision and whether and how the local care services could and ought to be improved; and sharing these views with Healthwatch England.
- Making recommendations to Healthwatch England to advise the Care Quality Commission to conduct special reviews or investigations (or, where the circumstances justify doing so, making such recommendations direct to the CQC); and to make recommendations to Healthwatch England to publish reports about particular issues.
- Providing Healthwatch England with the intelligence and insight it needs to enable it to perform effectively.<sup>45</sup>

A local Healthwatch organisation also has the right to attend its local Health and Wellbeing Board.<sup>46</sup> In addition, part 4 of the Local Authorities (Public Health Functions and Entry to Premises by Local Healthwatch Representatives) Regulations 2013 established a duty for service providers to allow entry by local Healthwatch organisations or contractors.

---

<sup>43</sup> Local Government Information Unit, [Policy Briefing: Update on Healthwatch](#), 14 May 2012, p 3.

<sup>44</sup> *ibid.*

<sup>45</sup> Healthwatch England, [Understanding the Legislation: An Overview of the Legal Requirements for Local Healthwatch](#), August 2013, pp 1–2.

<sup>46</sup> *ibid.*, p 9.

## 2.3 Finances

For 2015/16, the Department of Health allocated £4.5 million to Healthwatch England to fund core running costs and programme funding, but had only spent £3.72 million at the end of the financial year.<sup>47</sup> In 2014/15 the organisation received around £4.16 million and in 2013/14, £4.08 million.<sup>48</sup> Healthwatch England's core and programme funding sit within the CQC's budget and are ring-fenced.<sup>49</sup> For the 2015/16 financial year, the CQC had a budget of £249 million while the overall NHS budget for England in 2015/16 was around £116 billion.<sup>50</sup> Local authorities fund local Healthwatch organisations. On 31 October 2016, Healthwatch England published the results of its survey on the funding for the 148 local Healthwatch organisations working across 152 local authority areas. It found that:

- For 2016/17 local Healthwatch have reported that the amount received to perform their statutory activities was £29,940,078. This compares with the 2015/16 figure of £31,812,823 received by local Healthwatch to deliver statutory functions.
- Half of local Healthwatch will maintain the same level of funding as 2015/16 or receive an increase in funding.<sup>51</sup>

For a breakdown in funding by local Healthwatch group, see Healthwatch England, [State of Support—Local Healthwatch Funding Survey: Key Findings](#), 31 October 2016.

Healthwatch England explained that local authorities received funding from the Government to commission a local Healthwatch organisation, although this funding was not ring-fenced.<sup>52</sup> For 2013/14, the Government had announced that £43.5 million would be given to local authorities to fund a local Healthwatch organisation. However, research by Healthwatch England found that only £33.5 million reached local Healthwatch organisations, with £10 million unaccounted for.<sup>53</sup> In March 2014, Lord Harris of Haringey (Labour) asked the Government why this money had not been used for its intended purpose. In response, the then Parliamentary Under Secretary of State for Quality, Earl Howe, stated that:

The Government have made no assessment. We welcome transparency in funding for local Healthwatch—something we called for in response to the Francis inquiry report—and Healthwatch England's findings are a helpful contribution to that. We remain of the view that local authorities are best placed to decide local funding arrangements based on local needs and priorities, which is why the funding made available to them is not ring-fenced for a specific purpose.<sup>54</sup>

---

<sup>47</sup> Healthwatch England, [Annual Financial Statement 2015/16](#), 2016, p. 2.

<sup>48</sup> House of Commons, '[Written Question: Healthwatch England: Finance](#)', 21 March 2016, 31167.

<sup>49</sup> Healthwatch England, [Annual Financial Statement 2015/16](#), 2016, p. 2.

<sup>50</sup> Care Quality Commission, [Annual Report and Accounts 2015/16](#), 21 July 2016, HC 467, p 10; and NHS Choices, '[The NHS in England](#)', accessed 7 November 2016.

<sup>51</sup> Healthwatch England, [State of Support—Local Healthwatch Funding Survey: Key Findings](#), 31 October 2016, p 1.

<sup>52</sup> *ibid.*

<sup>53</sup> *Health Service Journal*, '[Exclusive: £10m of Healthwatch Cash "Goes Missing"](#)', 13 February 2014.

<sup>54</sup> [HL Hansard, 19 March 2014, col 158.](#)

Earle Howe argued that it was “up to local authorities to make judgements about what are the needs and priorities of their areas” and added that:

[T]here cannot really be any direct comparison between the money made available by central government and the funding provided to local Healthwatch. It is not the case that £10 million has somehow disappeared. It is, rather, that councils have made local funding decisions which mean that £33.5 million was invested in local Healthwatch last year. What matters here is the transparency. That is what we very much welcome. It enables local Healthwatch to hold local authorities to account for their funding decisions and thereby, perhaps, influence them to give them a bit more money if that is required.<sup>55</sup>

## 2.4 Work of Healthwatch England

In its latest annual report, Healthwatch England discussed some of the areas it had focused on in the previous year, including its work on making sure health and social care services learn from complaints and improving people’s experiences of leaving care.<sup>56</sup>

### Complaints

There were 198,739 written complaints in the NHS between 1 April 2015 and 31 March 2016, down 4.2 percent on the 207,407 complaints in 2014/15.<sup>57</sup> These were calculated based on the data collected from two forms, the KO41a (NHS Hospital and Community Health Service (HCHS)); and the KO41b (Family Health Service (GP including Dental) (FHS)).<sup>58</sup>

On 14 October 2014, Healthwatch England published a report on the user experience of the health and social care system.<sup>59</sup> The report based its findings and recommendations on a variety of methods, including detailed case studies and from two national surveys conducted by YouGov in 2014 and 2013.<sup>60</sup> Healthwatch England found that “through our research and our conversations with patients, care users and the public, we found that fewer than half of those who experience poor care actually report it” and estimated that 250,000 incidents went unreported in 2013.<sup>61</sup> Healthwatch England suggested that “people do not feel that existing complaints systems listen to their concerns and put things right” and that the process was adversarial and bureaucratic.<sup>62</sup> The report found that 61 percent of people who complained “did not feel they were taken seriously enough” and 26 percent of people said that they had not complained because they were “worried it would have negative repercussions on their treatment or care”.<sup>63</sup>

<sup>55</sup> [HL Hansard, 19 March 2014, col 158.](#)

<sup>56</sup> Healthwatch England, [Annual Report 2015/16](#), 18 October 2016.

<sup>57</sup> NHS Digital, [Data on Written Complaints in the NHS, 2015/16](#), 15 September 2016, pp 1 and 4.

<sup>58</sup> *ibid*, p 1.

<sup>59</sup> Healthwatch England, [Suffering in Silence: Listening to Consumer Experiences of the Health and Social Care Complaints System](#), 14 October 2014.

<sup>60</sup> YouGov’s 2014 poll surveyed 1,676 people across England and the 2013 poll had a total sample size of 2,076 adults, weighted to be representative of all of Great Britain’s adults. See: Healthwatch England, [‘NHS Complaints Data is Just the “Tip of the Iceberg”](#)’, 28 August 2014; and [Suffering in Silence: Listening to Consumer Experiences of the Health and Social Care Complaints System](#), 14 October 2014, p 9.

<sup>61</sup> Healthwatch England, [Suffering in Silence: Listening to Consumer Experiences of the Health and Social Care Complaints System](#), 14 October 2014, p 2.

<sup>62</sup> *ibid*, p 3

<sup>63</sup> *ibid*.

In addition, Healthwatch England found that the complaints system “remains utterly bewildering” with “over 70 different kinds of organisations involved in handling complaints”.<sup>64</sup> The report found that 84 percent of people “would be more likely to complain if they knew that their complaint would be used to develop the performance of staff and services”.<sup>65</sup> In June 2015, Healthwatch England published its *Every Complaint Matters* report, which outlined a number of recommendations for improving the complaints system in the NHS and social care.<sup>66</sup>

Healthwatch England proposed to:

- Make it easier for everyone to complain by giving one national organisation responsibility for providing patients and the public with improved information and education about how to raise concerns.
- Create a single, properly funded complaints advocacy service, provided under the Healthwatch banner and to national standards, which provides users of both the NHS and social care with the same level of support.
- Drive up the quality of complaints handling.
- Require every organisation involved in complaints handling to make sure people’s complaints reach the right destination.
- Ensure clear responsibility for capturing system-wide learning from complaints, identifying trends and ensuring national policy and practice change properly address concerns.
- Make it mandatory for every commissioner, provider and regulator across health and social care to report every complaint to the Health and Social Care Information Centre [now NHS Digital]—regardless of how it is made or which service it is about—enabling a national measure of consumer experience of the complaints process to track progress in improving this experience.
- The Government to conduct a review of the whole complaints landscape to simplify and streamline processes across the many organisations involved.<sup>67</sup>

Problems with the complaints system had also been raised in the Francis Report, which argued:

Whilst a uniform process of complaints handling should be applied, the making of a complaint should be easy to do, and any expression of concern made by a patient should be treated as a complaint, unless the patient’s permission is refused. The clarity of the responsibility of a senior clinician and nurse for each patient, and their obligation to be involved in responding to any complaint, should facilitate access to the complaints system and facilitate a speedy resolution, wherever possible.<sup>68</sup>

---

<sup>64</sup> Healthwatch England, [Suffering in Silence: Listening to Consumer Experiences of the Health and Social Care Complaints System](#), 14 October 2014, p 4.

<sup>65</sup> *ibid*, p 5.

<sup>66</sup> Healthwatch England, [Every Complaint Matters: A Seven Point Plan for the NHS and Social Care](#), June 2015.

<sup>67</sup> *ibid*, pp 1–3.

<sup>68</sup> Mid Staffordshire NHS Foundation Trust Public Inquiry, [Report of the Mid Staffordshire NHS Foundation Trust Public Inquiry: Executive Summary](#), February 2013, p 72.

The Government accepted the recommendation in the Francis Report that “local Healthwatch should have access to detailed information about complaints, although respect needs to be paid in this instance to respect for patient confidentiality”.<sup>69</sup>

### Experiences of Leaving Care

In July 2015, Healthwatch England published the findings from its special inquiry on people’s experiences of leaving hospital and care settings. Evidence was gathered by the Healthwatch network “through the most relevant means locally” which included, surveys, focus groups and visits to services, for example.<sup>70</sup> The report identified five core reasons why people felt their departure was not handled properly:

- People are experiencing delays and a lack of coordination between different services.
- People are feeling left without the services and support they need after discharge.
- People feel stigmatised and discriminated against and that they are not treated with appropriate respect because of their conditions and circumstances.
- People feel they are not involved in decisions about their care or given the information they need.
- People feel that their full range of needs is not considered.<sup>71</sup>

Healthwatch England did not include recommendations in its report but said its findings posed a “challenge to the health and social care sector to take action now to improve people’s experiences of leaving services”.<sup>72</sup>

## 2.5 Challenges Facing Healthwatch

A number of commentators have considered how Healthwatch England and the local Healthwatch network has performed since it was established. For example, on 26 March 2015, the King’s Fund published a report, commissioned by the Department of Health but based on independent research, which considered the progress made by local Healthwatch organisations in the first 18 to 21 months since they started and suggested how the system could be improved.<sup>73</sup>

The King’s Fund reported that local Healthwatch organisations were “positive about the progress they are making, with particularly positive assessments of progress in gathering people’s views and influencing providers and commissioners”.<sup>74</sup> It found that local Healthwatch organisations “vary widely in how they are organised, how they conduct their activities and how effective they are in carrying out their statutory activities”.<sup>75</sup> The report suggested that

<sup>69</sup> Department of Health, ‘[Government Response: Mid Staffordshire NHS Foundation Trust Public Inquiry](#)’, 19 November 2013.

<sup>70</sup> Healthwatch England, [Safely Home: What Happens When People Leave Hospital and Care Settings?](#), July 2015, p 9.

<sup>71</sup> *ibid*, p 9.

<sup>72</sup> *ibid*, p 56.

<sup>73</sup> King’s Fund, [Local Healthwatch: Progress and Promise](#), 26 March 2015, p 3.

<sup>74</sup> *ibid*.

<sup>75</sup> *ibid*.

given the wide-ranging nature of their activities, but limited capacity, “local Healthwatch will only ever be effective through prioritising their focus and working effectively in partnership with others”.<sup>76</sup>

On this issue of capacity and resources, Dr Pam Carter and Professor Graham Martin from the University of Leicester’s Department of Health Sciences, observed that because local authority budgets had been under pressure in recent years, this potentially made local Healthwatch organisations vulnerable. Moreover, they argued that local Healthwatch organisations were potentially operating in “compromised contractual relationships” because they were “expected to scrutinise services that are provided by their main source of funding”.<sup>77</sup> Consequently, the authors argued that there was a “delicate balance to be achieved between having a seat at the table in order to exert influence and acting independently as a critic”.<sup>78</sup>

The King’s Fund has also commented on the difficulties facing local Healthwatch organisations through being both a ‘critic’ and ‘friend’ of the NHS and social care services, and explained that local organisations had adopted different models of operation. The report observed that some favoured the model of:

[A]n independent public voice, rooted in the community (the ‘critic’)—some Healthwatch organisations seem to principally define themselves as the source of independent evidence of local people’s views, and essentially see their core role as communicating this evidence to local bodies and in some cases holding them to account for action.<sup>79</sup>

In contrast, other organisations operated as:

A strategic local partner working within the system (the ‘friend’)—some Healthwatch organisations seem to focus more on working in partnership with providers and commissioners, sharing views and evidence to support improvement in services and getting involved in how their local evidence is used and acted upon.<sup>80</sup>

According to the King’s Fund, these different approaches determined the activities they conducted and the perception of their overall tone.<sup>81</sup> For example, some organisations focused on community engagement rather than attending decision-making committees, while others were perceived to be more or less supportive of providers.<sup>82</sup> Writing for the King’s Fund, Phoebe Dunn has suggested that “it appears that striking the balance between being strategic partner and critic is one that Healthwatch organisations are finding tricky and still working to refine”.<sup>83</sup>

The King’s Fund’s *Local Healthwatch: Progress and Promise* report suggested that because local Healthwatch organisations relied on building relationships with other local stakeholders to “build legitimacy, influence and create impact”, their “effectiveness in doing this is in part mediated by the receptiveness of local stakeholders to the involvement of local Healthwatch

---

<sup>76</sup> King’s Fund, [Local Healthwatch: Progress and Promise](#), 26 March 2015, p 3.

<sup>77</sup> Dr Pam Carter and Professor Graham Martin, ‘[Challenges Facing Healthwatch, a New Consumer Champion in England](#)’, *International Journal of Health Policy and Management*, April 2016, vol 5 no 4, p 261.

<sup>78</sup> *ibid.*, pp 261–2.

<sup>79</sup> King’s Fund, [Local Healthwatch: Progress and Promise](#), 26 March 2015, p 36.

<sup>80</sup> *ibid.*

<sup>81</sup> *ibid.*

<sup>82</sup> *ibid.*

<sup>83</sup> Phoebe Dunn, ‘[Local Healthwatch: Progress, Promise and Power](#)’, King’s Fund blog, 16 September 2015.

and to the value of public involvement more widely”.<sup>84</sup> On this issue, Phoebe Dunn argued that a “wider challenge faced by local Healthwatch organisations” was that evidence fed into the system “is still fed into structures that can choose to act, or not act, on the intelligence laid before them”.<sup>85</sup>

Overall, the King’s Fund suggested that:

Fundamentally, the role that local Healthwatch are expected to play in the health and social care system is a demanding one, with great potential for improving how responsive and inclusive the system is of local people’s concerns and priorities, but also great challenges in defining a distinct local role and balancing being an independent voice with being part of decision-making processes as one of the local system leaders. As local Healthwatch organisations continue to mature and develop, addressing both the practical and these more deep-seated challenges will be crucial to maximising their effectiveness and impact.<sup>86</sup>

Dr Pam Carter and Professor Graham Martin argued that some of the challenges Healthwatch faced were structural.<sup>87</sup> They suggested that the “remit set out for them by government [...] and their places within local healthcare economies, create tensions for local Healthwatch”.<sup>88</sup> They added that the “jurisdictional misalignment of Healthwatch with key NHS organisations with which they are to interact [...] is compounded by rather loose arrangements for accountability between Healthwatch and other organisations”.<sup>89</sup> For example, they noted that Clinical Commissioning Groups (CCGs) were required to consult with Healthwatch, but there was no requirement to accept their recommendations. This meant that “Healthwatch’s ability to hold decision-makers to account is limited”.<sup>90</sup>

They also argued that the complex governance of the NHS envisioned by the NHS England’s *Five Year Forward View* and the Government’s localism agenda:

[M]eans that a health and social care economy is not a hierarchically ordered system accountable through traditional local representation, but an increasingly complex network of relationships of influence. This poses challenges to Healthwatch’s remit to represent the view of local populations, its claims to legitimacy and its ability to exert influence.<sup>91</sup>

In addition, the authors questioned whether local Healthwatch had a unique role, observing that Healthwatch England was not the only body that sought to gather data on patient opinions and influence change.<sup>92</sup> For example, data on public opinion and patient experiences was also gathered through the Friends and Family Test (where patients are asked whether they would recommend the service they had received to a friend and family) and National Voices (a coalition of health and social care charities that works for a strong patient and citizen voice).

<sup>84</sup> King’s Fund, [Local Healthwatch: Progress and Promise](#), 26 March 2015, p 3.

<sup>85</sup> Phoebe Dunn, ‘[Local Healthwatch: Progress, Promise and Power](#)’, King’s Fund blog, 16 September 2015

<sup>86</sup> King’s Fund, [Local Healthwatch: Progress and Promise](#), 26 March 2015, p 4.

<sup>87</sup> Dr Pam Carter and Professor Graham Martin, ‘[Challenges Facing Healthwatch, a New Consumer Champion in England](#)’, *International Journal of Health Policy and Management*, April 2016, vol 5 no 4, p 260.

<sup>88</sup> *ibid.*

<sup>89</sup> *ibid.*, p 261.

<sup>90</sup> *ibid.*

<sup>91</sup> *ibid.*

<sup>92</sup> *ibid.*

Equally, Dr Carter and Professor Martin noted that CCGs and NHS providers potentially duplicated the work of Healthwatch through their own initiatives. They observed that:

NHS organisations are still required to undertake their own PPI activities, and may or may not choose to draw on the services of Healthwatch in delivering these, while general practices are also expected to have their own PPI structures.<sup>93</sup>

Commentators have also raised the issue of representation with regards to Healthwatch. Brad Wright, Assistant Professor at University of Iowa's Department of Health Management and Policy, has said that "successful PPI must be intentional about who is to participate, how they are selected, what role they are to play, and what ends they are to pursue".<sup>94</sup> However, he argued that these questions were often unanswered and "this appears to be the case with Healthwatch".<sup>95</sup> He added that local Healthwatch's reliance on a voluntary model was concerning as "prior PPI failures can be traced in part to challenges getting an adequate number of consumers to participate".<sup>96</sup> Moreover, although there was a requirement for local Healthwatch to be inclusive, there were a number of reasons why certain groups could be excluded. He suggested that some groups, such as those on low incomes, may find it costly to participate. Further, there was a question as to why particular individuals were selected to participate, and there was confusion over whether service users were participating as consumers or citizens, for example.<sup>97</sup>

The Francis Report also raised concerns about the flexible framework of Healthwatch, suggesting that:

As is the position with LINKs, the DH does not intend to prescribe an operational model, leaving this to local discretion. It does not prejudice local involvement in the development and maintenance of the local healthcare system for there to be consistency throughout the country in the basic structure of the organisation designed to promote and provide the channel for local involvement. Without such a framework, there is a danger of repetition of the arguments which so debilitated Staffordshire LINKs.<sup>98</sup>

---

<sup>93</sup> Dr Pam Carter and Professor Graham Martin, '[Challenges Facing Healthwatch, a New Consumer Champion in England](#)', *International Journal of Health Policy and Management*, April 2016, vol 5 no 4, p 260.

<sup>94</sup> Assistant Professor Brad Wright, '[Consumers or Citizens? Whose Voice Will Healthwatch Represent and Will It Matter?](#)', *International Journal of Health Policy and Management*, November 2016, vol 5 no 11, p 667.

<sup>95</sup> *ibid.*

<sup>96</sup> *ibid.*, p 668.

<sup>97</sup> *ibid.*

<sup>98</sup> Mid Staffordshire NHS Foundation Trust Public Inquiry, [Report of the Mid Staffordshire NHS Foundation Trust Public Inquiry: Executive Summary](#), February 2013, p 46.

House of Lords Library Notes are compiled for the benefit of Members of the House of Lords and their personal staff, to provide impartial, politically balanced briefing on subjects likely to be of interest to Members of the Lords. Authors are available to discuss the contents of the Notes with the Members and their staff but cannot advise members of the general public.

Any comments on Library Notes should be sent to the Head of Research Services, House of Lords Library, London SW1A 0PW or emailed to [purvism@parliament.uk](mailto:purvism@parliament.uk).