# Suffering in silence

# Listening to consumer experiences of the health and social care complaints system

## EXECUTIVE SUMMARY

"In order to use complaints to drive improvements, we must first have a system that is simple, compassionate and responsive to those making the complaints…"

Healthwatch is unique in that its sole purpose is to understand the needs, experiences and concerns of people who use health and social care services and to speak out on their behalf.

Using the views of the public we identify where and why things are not working and, most importantly, how people want things done differently. It is through this lens that we have examined the current failings of what the public tells us is an overly complex, incredibly frustrating and largely ineffective complaints system in health and social care.

Making a complaint can be tough, particularly for those who are unwell, have been bereaved or are feeling vulnerable. We need a complaints system that above all deals with people compassionately, delivers a swift and professional resolution and demonstrates that lessons have been learned from complaints.

## The Numbers

According to the official records, there were 174,872 complaints about the NHS in 2013/14.

Yet 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. ii

As a result, we estimate that 250,000 incidents went unreported last year. This means that one person every two minutes is experiencing poor care but feels unable to even report it.

Add to this the fact that there is no national oversight of the number of complaints about social care services, and it becomes clear that the official figures are just the tip of the iceberg.

## Slow Progress

We recognise and applaud the work already done during the Francis Inquiry and the various subsequent reports to look into the failings around complaints. Indeed, the consensus established around the need for urgent improvement is encouraging.

Yet, whilst the efforts of the system to date deserve an 'A' for good intention, the public and the numbers are

both telling us that, on the ground, complaints handling still scores an ‘F’.

Change so far has only tinkered with the existing bureaucratic arrangements for complaints handling, and looked largely at things from the system’s perspective. This is the wrong starting point for change.

For this report we have taken a step back and asked people what they want, listening in detail to people’s experiences through surveys, focus groups and interviews.

From what they told us it is clear that in order to use complaints to drive improvement, we must first have a system that is simple, compassionate and responsive to those making the complaints.

To do this the system needs to appreciate complaints for what they really are: real life experiences of what happens when mistakes are made, with real physical and emotional consequences.

There is no single, simple answer for how to do this. Ensuring that those who have suffered are treated correctly at every stage of the complaints process is no easy task. But we must start from what people need from the complaints system
and build solutions from there.

So what did we hear when we asked people about their experiences of the complaints system in health and social care?

## People are not given the information they need to complain

Esther's experience…

Esther wanted to complain about problems in the funding for her continuing healthcare. She told us: "It wasn't easy to find out who to complain to as no information was provided regarding the complaints/appeals process."

Too often, people simply lack the information they need to complain. People also told us that members of staff were often unable to tell them how to complain, resulting in people having to find out for themselves.

- A staggering two thirds of people who experienced or witnessed poor care in the last two years did not complain about it.[iii]
- 1 in 4 (23%) said this was because they did not know who to complain to. [iv]
- Even amongst those who had complained, almost half (47%) had found it difficult to find out how to do so. [v]

## People do not have confidence in the system to resolve their concerns

Kelvin's experience…

Kelvin wanted to raise concerns after his wife, who had been diagnosed with cancer, was kept waiting for two hours – without explanation or support – for her first chemotherapy appointment. He wanted to ensure the experience would not be repeated during the rest of his wife's treatment, and that other patients received better care on their first visit:
"I received a written reply two months after the incident. No fault was admitted, no regret expressed and, as far as I know, their practice remains unchanged. My complaint remains completely unresolved as far as I am concerned."

People do not feel that existing complaints systems listen to their concerns and put things right. Many of those we spoke to simply wanted an explanation, an apology, or a simple change. Instead, they found themselves drawn into a bureaucratic and adversarial process that did not reflect their reason for complaining. Most worrying of all, people aren't complaining because they are scared of the repercussions, such as being victimised by staff.

- 3 in 5 (61%) of those who complained did not feel they were taken seriously enough.vi

- Fewer than half (49%) ever received an apology.vii
- 1 in 4 (26%) said they had not complained because they were worried it would have negative repercussions on their treatment or care.viii

## People find the complaints system complex and confusing

Jeanette's experience…

Jeanette became concerned that the care home her mother was living in did not provide the facilities she needed to have a bath. After raising the concern with the care home and receiving only excuses, she did not know where to go next, and resorted to a 'scatter-gun' approach to getting the complaint resolved. Going to the press eventually prompted a response from the council, but Jeanette told us: "Reporting complaints is a nightmare as there are so many different agencies and providers."

The complaints system remains utterly bewildering, and people find navigating it time-consuming and exhausting.

- There are over 70 different kinds of organisations involved in handling complaints, including service providers, commissioners, regulatory bodies, and ombudsmen.ix

- Just 14 per cent of those who complained were clearly told what to expect from the process.x

- Only 1 in 5 people said they had to make their complaint just once to one person or organisation.xi

## People need support to ensure their voices are heard

Seb's experience…

Seb, who was detained in a psychiatric hospital for treatment for schizophrenia, was very concerned about his medication and the lack of contact with his doctor. It was not until he heard about an advocacy service that he had the information and help he needed to get his concerns listened to. As he put it: "A right to make a complaint is meaningless if there's no support to do so."

When people are unwell or in crisis, or when their complaint is complex, information alone is not always enough to enable them to navigate the complaints system.

- Of those who did complain, over a third had no formal or informal help or support.xii

- Fewer than 1 in 10 were provided with formal independent advocacy support. xiii
- Two thirds (70%) of those who experienced poor care but did not complain said they would be more likely to in the future if they were offered advocacy and support. xiv

## People need to know that health and social care services learn from complaints

Ahmed's experience…

Ahmed complained to his dentist after problems with his treatment: "They acknowledged many of the points I made. They said 'lessons had been learnt' but it was not at all clear what they were actually going to do about it in the future."

People told us that their main motivation in complaining was a desire to make sure health and social care improves for the future.

- 84% of people told us that they would be more likely to complain if they knew that their complaint would be used to develop the performance of staff and services. xv
- 82% reported that they would be more likely to complain if they knew they would be used to inform the Care Quality Commission's (CQC) inspection processes. xvi

- 81% said that seeing other people's complaints having impact would encourage them to make their own voices heard. xvii

## Recommendations

Our recommendations reflect what the public told us they want to see in a complaints system.

Decades of piecemeal change has resulted in the current bewildering mess of over 70 different types of organisations involved in complaints handling. This set-up is not working because it was never designed as a single system around the needs of people.

To reset the dial and put people at the heart we need wholescale reform and culture change, to create a system that is simple, seamless and stress-free from the consumer perspective and offers users meaningful resolution.

Some of this can be achieved through immediate changes to improve things as they stand – and we have made a number of practical and concrete suggestions for these. But as the evidence in this report shows, the problems go too deep for minor adjustments.

That is why we are calling for the government to send a clear signal that the issue of complaints is a priority. We believe that in the first session following the General Election the incoming government must

dedicate legislative time to this issue. There must be commitment across the parties and both houses to look in depth at the change needed in order to create a compassionate complaints system. This would signal that the issue of complaints is being given the attention it deserves.

## Make it easier to complain

The following recommendations outline ways in which the system could make it quicker and easier for everyone to register their concerns and complaints, and crucially, feel safe and supported to do so.

### Recommendations for change in the current system:

- All institutions to understand that everyone has the right to complain, including 'worried bystanders' – third parties who wish to report incidents of poor care experienced by others.
- All institutions to accept complaints made anonymously by those who fear reprisal.
- All staff required to proactively and continually seek feedback from patients and respond positively to complaints and concerns.
- All parts of the health and social care sector to ensure people have access to clear, up-to-date, consistent and accessible information on how to complain – clearly displayed in all settings including waiting rooms and appointment letters.

- All patients to be directed to additional information, advice and advocacy support when making a complaint.

## Recommendations for wholescale reform:

- A ‘no wrong door’ policy, so that wherever a complaint is raised it is the system, not the complainant, that is responsible for routing it to the appropriate agency to get it resolved.
- The Government to explore the scope for online platforms to provide a well-publicised point of access for complaints, enable greater consumer choice, and allow anonymity where required.
- A review of PALS and NHS Complaints Advocacy arrangements, with a view to establishing a new, easily accessible and consolidated complaints advocacy and support offer that is:
- Available to all users of health and social care regardless of age, condition or where they live.
- Independent and acts only in the interests of the individual.
- Well-publicised and easily recognised by everyone so that when they need help they know who to turn to.
- Underpinned by a set of new national standards to ensure everyone is able to access high quality support.

- Healthwatch England to be given the power to act as a 'super-complainant' on behalf of groups of consumers on national issues.

## Ensure a compassionate response and resolution

The following recommendations set out a number of key principles to ensure that, no matter who it is raised by or how they raise it, every complaint is taken seriously and offered a meaningful resolution.

### Recommendations for change in the current system:

- A compassionate response to all complaints within three working days, which acknowledges the person's experience, outlines next steps and, where appropriate, provides an apology.
- Mandatory training for all front line professionals across health and social care to include a clarification that they can say 'sorry' without fear of legal implications.
- Recognise the stress that complaints place on staff involved and provide them with safe and supportive spaces to share and reflect on lessons learnt.

### Recommendations for wholescale reform:

- Consumers to have control over the pace of their complaints, including being able to 'stop the clock' whilst dealing with illness, trauma or bereavement.
- People to have choice over the route their complaint takes by identifying the type of resolution they are looking for at the outset e.g. stating whether they are seeking a:
    - Speedy resolution to an immediate problem
    - Simple explanation and apology
    - Full investigation leading to legal claims, disciplinary action and long-term system change.

- Named case handlers for every complaint so people have a consistent point of contact. Simplification of national complaints systems, maintaining specialism but radically reducing complexity.
- A single public services ombudsman covering complaints in health, social care and those that involve both.

## Hold to account those who fail to listen

The following recommendations demonstrate how the system as a whole can step up a gear in how it handles and learns from complaints, as well as outlining how those who fail to move with the times can be held to account.

## Recommendations for change in the current system:

- National oversight of complaints in social care in line with that for complaints about the NHS.
- CQC inspections of hospitals, GP surgeries and care homes to be informed by local complaints data.
- CQC to develop and implement guidance for inspectors on complaints handling and learning based on the user-led vision developed by PHSO, LGO and Healthwatch England.[xviii]

## Recommendations for wholescale reform:

- Hold to account those who consistently fail to meet the expectations set out by the CQC, including putting providers into 'special measures', issuing financial penalties and decommissioning failing services.

i. Health and Social Care Information Centre: Data on Written
Complaints in the NHS – 2013-14. Available online at: http://
www.hscic.gov.uk/catalogue/PUB14705
ii.YouGov survey, August 2014. Total sample size was 1676 adults.
The survey was carried out online. The figures have been weighted and are representative of all English adults (aged 18+).
iii.YouGov survey, August 2014
iv.YouGov survey, August 2014
v.YouGov survey, August 2014
vi.YouGov survey, August 2014
vii.YouGov survey, August 2014
viii.YouGov survey, August 2014
ix.Healthwatch England Complaints Atlas, October 2014
x.YouGov survey, August 2014
xi.YouGov survey, August 2014
xii.YouGov survey, August 2014
xiii.Healthwatch England survey, 2014
xiv.YouGov survey, August 2014
xv.YouGov survey, August 2014
xvi.YouGov survey, August 2014
xvii.YouGov survey, August 2014
xviii.The Parliamentary and Health Service Ombudsman, the Local Government Ombudsman and Healthwatch England have developed a user-led vision and expectations for raising concerns and complaints (forthcoming). The vision, based on research with consumers and tested with stakeholders, sets out what

good outcomes look like, and is applicable in all settings across health and social care.