

Suffering in silence

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

1. 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.ⁱ

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.
- + 1 in 4 (23%) said this was because they did not know who to complain to.
- + Even amongst those who had complained, almost half (47%) had found it difficult to find out how to do so.

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

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.ⁱⁱⁱ

+ Just 14 per cent of those who complained were clearly told what to expect from the process.^{iv}
+ Only 1 in 5 people said they had to make their complaint just once to one person or organisation.

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.^v
+ Fewer than 1 in 10 were provided with formal independent advocacy support.

+ 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.

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.

+ 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. ^{vi}

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

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 wholesale 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 wholesale 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 wholesale 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.^{vii}

Recommendations for wholesale 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.

References:

- i. Health and Social Care Information Centre (2014) Data on Written Complaints in the NHS - 2013-14: <http://www.hscic.gov.uk/catalogue/PUB14705>
- ii. YouGov Complaints Survey for Healthwatch England (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. Healthwatch England Complaints Atlas, October 2014
- iv. YouGov Complaints Survey for Healthwatch England (August 2014)
- v. Healthwatch England survey (2014)
- vi. YouGov Complaints Survey for Healthwatch England (August 2014)
- vii. 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.

2. Introduction

“A health service that does not listen to complaints is unlikely to reflect its patients’ needs.

“One that does will be more likely to detect the early warning signs that something requires correction, to address such issues and to protect others from harmful treatment...”

Sir Robert Francis QC

Why do complaints matter?

Over our lifetimes, many of us will experience something not going quite right with the care we receive. It might be that we weren't treated with dignity or respect by a care worker, or that a doctor prescribed the wrong medicine.

We all have a right to complain when something goes wrong with the care or treatment we receive. And we should all be able to expect that if we raise a concern about a service we are (or a loved one is) receiving, then we will be dealt with compassionately and see a positive response as a result.

We know that an effective complaints system is crucial to allow consumers to speak up and be heard when things go wrong. As well as providing resolution for individuals, complaints offer health and social care services invaluable learning opportunities. Complaints provide services with vital information about whether they are performing for the people they serve. Complaints hold the potential to act as an early warning system that can prevent further deterioration and crisis. Complaints are vital to improving standards and services.

When complaints are discouraged or ignored, isolated incidents can escalate into the shocking events like those that occurred under the Mid Staffordshire and Morecambe Bay Trusts and at Winterbourne View Hospital.

The Clwyd-Hart report¹ on patient complaints in hospitals, along with the reports of Sir Robert Francis QC², Professor Don Berwick³ and Sir Bruce Keogh⁴ all demonstrate the failures with complaints processes and arrangements. The legacy of these reports must be the urgent improvement and reform of the way that complaints are handled and resolved across health and social care. It is vital that we build a system that embraces continuous improvement. People with concerns about the treatment and care they receive have the right to know that their concerns are listened to, addressed appropriately, resolved quickly, and learned from.

Healthwatch England's approach to complaints

This is why one of Healthwatch England's first priorities was to look into people's experiences of raising concerns and making complaints. Our aim was to understand what the barriers are to complaints being resolved in a timely and compassionate manner, and what is stopping complaints being used to improve the services that people receive. And, because our remit spans health and social care, we looked not only at hospitals, but across all health services and social care to identify how concerns are dealt with.

Since April 2013, Healthwatch England and local Healthwatch have been talking to people across the country who use health and social care services – and their families, carers and friends – to find out about their experiences of complaining.

This report draws on all of the evidence we have captured over this period. As the consumer champion of health and social care we always start with people's experiences and needs. We wanted this report to be told as much as possible through the words of people who have had concerns but not felt able to raise a complaint, as well as those who have used the complaints systems. We wanted to provide an opportunity for the system to learn from its users' experiences. That is why we draw so extensively on the experiences and insights of health and social care consumers throughout this report.

To understand people's experiences we held workshops in Manchester and London, and used these to develop a set of consumer-led principles⁵ that underpin all our recommendations for the complaints system.

We commissioned two national surveys⁶ and one self-selecting survey⁷. We gathered detailed cases from people who had significant concerns about how their complaints had been handled, those who had had positive experiences, and those who were still waiting for a resolution. We then conducted detailed interviews to understand their experiences in more depth. The experiences and quotes we draw on come directly from consumers, with their permission, and have been anonymised.

We also held more detailed workshops with people who have raised concerns and made complaints while being treated under the Mental Health Act (MHA) and Mental Capacity Act (MCA). We took a particular focus on people treated under the Acts because being detained, treated against their will or being deprived of liberty can put people in an extremely vulnerable position and make it even harder to raise concerns or make a complaint.

Healthwatch England's work on complaints

This report is one part of our programme of work on complaints.

Following the publication of *Hard Truths*⁸, Healthwatch England worked with the Department of Health to establish a Complaints Programme Board that is responsible for improvement and reform across the complaints system. Our contribution to this Board is to ensure that the needs, experiences and ideas of consumers are at the heart of improvement and reform in health and social care complaints systems.

To ensure people are better supported, we have worked with Citizens Advice to produce accurate and accessible information about how to make a complaint, and training resources for staff in local Healthwatch and frontline advice organisations, equipping them with the knowledge required to support people who want to make a complaint.

We are also developing national standards for complaints advocacy services, to ensure that all those who need additional help to make a complaint have access to good quality support that enables them to do so.

We have worked with the Parliamentary and Health Service Ombudsman (PHSO) and Local Government Ombudsman (LGO) to develop a consumer-led vision of complaints handling across health and social care. This vision sets out expectations at each stage of making a complaint and provides a framework for good practice in complaints handling which will be relevant to providers, commissioners, regulators and professional bodies.

Much remains to be done

However, all our work shows how much more there is to be done to create a complaints system that meets people's need for compassionate resolution. This report sets out what we have learned, and makes a series of recommendations for change.

3. What is wrong with the complaints system?

“Reporting complaints is a nightmare as there are so many different agencies and providers ...”

Jeanette, who complained about a care home.

The scale of complaints

Last year, the NHS received 174,872 written complaints.⁹

That’s the equivalent of more than 3,300 NHS written complaints a week, or 20 complaints every hour of the day.

Of these:

- + around two thirds of complaints were about hospitals and community health or mental health services;
- + around one third were about GPs and dentists;
- + only half were fully or partially upheld.¹⁰

If people cannot get their complaint resolved at the local level by the provider or commissioner of an NHS service, then they are able to refer their complaint to the Parliamentary and Health Service Ombudsman (PHSO) as the second tier of the NHS complaints process.

Last year, PHSO:

- + received 6,093 complaints;
- + completed 1,178 investigations.¹¹

In contrast to the data collected on NHS complaints, the Health & Social Care Information Centre does not currently collect national data on complaints to councils about social care. As a result, there is no national oversight of the volume of complaints made to councils about social care services, nor is there any analysis of the local trends. Important failings and crises may be being missed. At best we have estimates – such as the 2008 National Audit Office study which suggests that there would have been over 17,000 complaints being made to adult social care services at that time.¹²

Recommendation:

The Health & Social Care Information Centre must urgently commission data returns from local authorities on social care complaints, in line with the development of existing returns for NHS complaints.

As such, national oversight is totally reliant on the reporting of data about the complaints that reach the second tier of resolution if they cannot be resolved by the provider or council. Last year the Local Government Ombudsman (LGO) dealt with over 4,000 complaints and enquiries from the public about adult social care¹³. The three areas most complained about were:

- + assessment and care planning;
- + fees, grants and payments;
- + treatment in residential care.¹⁴

Whilst this shows that complaints are trickling through the system, we know that these figures represent a small portion of the concerns and complaints that people have.

Our recent survey found that over half of people who have problems with health and social care, do not make a complaint.¹⁵

Similarly, 3 in 5 who have experienced or witnessed a problem with health or social care services in the last two years have not made a complaint.¹⁶

This means that services are still missing out on a huge amount of valuable information about failure in treatment and care. It also means that people have to face significant failings in their treatment in care without any hope of justice.

So what is stopping people from complaining?

Our research revealed a number of key barriers that are preventing many people from getting their concerns resolved. This report goes on to explore each of these barriers in more detail.

When considering whether to make a complaint many people worry about speaking out and the potential impact this might have on their care. Add to this the fact that people do not know that they can complain or how to do it and you end up with many people not raising a concern at all.

If people do decide to make a complaint, they often lack the advice and support they need. This can be a serious barrier, particularly when people have been bereaved, are feeling vulnerable or unwell.

We also heard that people find the complaints system complex and confusing, find navigating it time-consuming, and often end up exhausted by the process. People told us that the complaints system simply fails to resolve their concerns - and that many actually feared complaining in case it had a negative impact on their care. Lastly, many of those we spoke to just did not feel that the complaints they made were used by services to improve things for others.

Our conversations with people who had been treated under the Mental Health Act and Mental Capacity Act, and with their families and carers, highlighted the same set of concerns - though many of these barriers were even stronger for people being treated under these Acts.

What are the Mental Health and Mental Capacity Acts?

The Mental Health Act (MHA) 1983¹⁷ sets out a legal framework for treating people with mental disorders and mental illness. When people object to treatment and are believed to be at risk of harming themselves or other people, the MHA allows them to be detained and treated (to be 'sectioned'). The Act also sets out legal safeguards that allow people to challenge their care and detention for the purposes of treatment in a psychiatric hospital.

Nearly one million people are in contact with mental health services at any given time. At the end of June 2014 **16,586 people were subject to the MHA. About 12,000 of these were detained in hospital, with almost all the rest being subject to a Community Treatment Order.**¹⁸

In contrast, the Mental Capacity Act (MCA) 2005¹⁹ sets out a broad framework to help make decisions for people who are not capable of making decisions for themselves. This might cover people living with dementia, people who have complex learning disabilities or those who have endured traumatic brain injuries. If someone is deemed unable to understand, retain, use, weigh and communicate information needed to make a decision, the Act allows other people to make decisions in that person's best interest.

If a person must be detained or supervised so much that someone else is effectively controlling his or her life, special permission must be sought under the Deprivation of Liberty Safeguards (DoLS). Around 13,000 DoLS applications were made in 2013-2014.²⁰

3.1. People are not given the information they need to complain

“At times of crisis and distress, it must be made easier for consumers to raise concerns and have them addressed...”

Firstly, it is not immediately clear to people if they are able to make a complaint about poor treatment or care. This applies to people using health and social care services, and to carers, relatives, friends and advocates who could make complaints on behalf of someone.

The current complaints regulations²¹ make it very clear that health and social care services are required to accept complaints from patients and service users, or those who are complaining on their behalf with express permission to do so. However, it must also be made clear that providers must accept complaints from ‘worried bystanders’ too.

By ‘worried bystanders’ we mean members of the public who notice incidences of wrongdoing in health or care services, but who may not personally be affected by these wrongdoings. For example, someone going into hospital to visit a relative receiving chemotherapy who, en route, walks through a geriatric ward and notices that an elderly man has fallen out of bed or is crying because he can’t eat. The worried bystander doesn’t know anyone on the ward, and doesn’t know anyone who might use the ward (because it’s not their local hospital), but still wants to raise a concern or make a complaint about what they have seen, even though they may not know who the man is or why he is there.

Recommendation:

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. The Government should publish guidance so that all providers of health and social care realise their duty to treat and record complaints from ‘worried bystanders’ in the same way as complaints from people using services, their families and representatives.

With the plethora of guidance about these regulations²² you might think that this would translate into a simple message for anyone wanting to raise a concern: namely, that you have the right to do so and that health and social care services are under a duty to acknowledge and respond to your complaint. In healthcare, the NHS Constitution²³ sets out patients’, families’ and carers’ rights in the NHS. This includes a description of the rights people have to complain about poor treatment or care.

As the All Party Parliamentary Group for Patient and Public Involvement in Health and Social Care²⁴ and a report by an Independent Expert Advisory Group²⁵ found, the majority of consumers and frontline professionals are unaware of the NHS Constitution. And, of course, the Constitution does not extend to people using social care.

Simon’s experience

Simon wanted to complain about his father’s treatment in a care home.

He told us: **“It was not at all easy to find out how to complain – I was referred back and forth to different organisations with no direct contact.”**

Our own scoping work on resources produced for consumers about making health and social care complaints found inaccuracies in information and advice provided by both providers and by third sector organisations set up to help people make complaints.

Tracey’s experience...

Tracey wanted to complain about the way her daughter had been treated in hospital before her death, but received conflicting messages about who she should complain to. She told us:

“When Sally died, we asked for all her notes from PALS, who told us if we were making a complaint we wouldn’t need to go through the hospital. We decided to ring a solicitor who told us that we had to make a complaint in writing to the hospital first.”

At times of crisis and distress, it must be made easier for consumers to raise concerns and have them addressed.

Healthwatch England has been working with Citizens Advice to produce accurate and accessible information and advice to help people navigate the complaints system. These resources are available at www.adviceguide.org.uk/healthandcarecomplaints.

In addition, we have developed information and advice training resources for staff in local Healthwatch and frontline advice organisations, equipping them with the knowledge required to support people in navigating the health and social care complaints system to make a complaint.

The lack of clear, consistent and accurate information and advice about people's right to complain is inevitably causing unnecessary attrition in the complaints process. And whilst we cannot quantify the full extent of the damage this is causing (a failing of the current system is that it is unable to measure attrition rates) the resulting degree of variation in the ways in which services respond to these types of concerns means that many people are left with their issues unresolved.

In fact, **we found that 1 in 4 of those who did not complain about the poor care they had received or witnessed, said it was because they did not know who to complain to.**²⁶ Even amongst those who had complained, half had found it difficult to find out how to do so.

Where complaints information did exist it was generally not very visible and when complainants asked staff for more detailed information about making a complaint, they were given complicated and technical procedural documents.

Consistent, easily accessible and accurate information is crucial in ensuring people are aware of their right to complain and are able to make their complaint in an effective way.

Recommendation:

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. The Government should co-ordinate a new information standard to ensure quality across all consumer-facing information on complaints.

Work carried out by local Healthwatch has highlighted concerns around the availability of information and advice for people wanting to raise concerns. For example, Healthwatch Camden sent a mystery shopper into every GP surgery in their area to see the response when they asked to make a complaint²⁷. While most front office staff provided the mystery shopper with information on complaints upon request, more than a third had to seek advice on what the practice's procedure was before answering.

Half of the surgeries failed to provide the mystery shopper with any written material about making a complaint (such as their complaints procedure, or a form to make a complaint), and very few alerted the shopper to any sort of support services. Similarly, Healthwatch Barnet visited 15% of the GP surgeries in their area, and found that only 2 of the 11 practices they visited made complaints information readily accessible.

Worryingly, several practice managers wrongly told Healthwatch Camden's mystery shoppers to make their complaints directly to NHS England, and many had websites with out-of-date information on complaints procedures. Similarly, Healthwatch West Sussex in their own work on the issue, noted that many surgeries offer confusing information online, or do not have written complaints policies, simply stating that the practice manager handled complaints.²⁸

Recommendation:

All providers of health and social care should ensure their frontline staff is equipped to direct any person raising a concern or making a complaint to additional information, advice or advocacy support.

3.1. People need support to ensure their voices are heard

“Everybody needs somebody to speak up for them when they can’t speak up for themselves ...”

Alison, a mental health service user

For many, information alone is not enough to enable navigation of the complaints system. People who are unwell, in crisis, or bereaved, or who have particularly complex complaints, may need support to raise their concern. As Seb, who took part in one of our workshops, put it:

“A right to make a complaint is meaningless if there’s no support to do so.”

In addition to knowing about their rights to complain, some people need additional information about the support and advocacy they are entitled to, to help them raise a concern or make a complaint. The kind of support people need varies according to their circumstances. Support could range from help to decide whether to complain, to assistance with letter-writing or representation in meetings.

This was a particular concern for people who had been treated under the Mental Health Act. Most of those we spoke to who had been detained in psychiatric hospitals had found the experience extremely stressful, and many had concerns about the lack of access to complaints support while they were sectioned.

The psychological and emotional stress of the illness itself and the nature of the treatment made people feel vulnerable and unprepared for the process of complaining, which people perceived as time-consuming and tiring. Many felt that the process of complaining placed too much onus on the patient to investigate and to identify evidence and to chase organisations for responses.

“I didn’t pursue it any further as I had to focus my energy on other things, like my treatment.”

“With the medication, you’re not processing information in the way you need to. You’re in a fragile state.”

“I had no support to challenge complaints decisions. At a meeting with the head nurse, the head nurse was accompanied and I was alone.”

People are sometimes able to access this additional support from family, online support networks or by visiting an advice organisation. However, our recent survey found that **over one third of those who complained had no help to do so.**²⁹ This means that large numbers of people are being left without support.

Where people were able to access support, this most often came from a complaints manager who would handle the complaint, the local Patient Advice and Liaison Service (PALS) or a complaints advocacy service (29%), from a health or social care professional (19%), or from friends and family (13%).³⁰

What are Patient Advice and Liaison Services (PALS)?

Patient Advice and Liaison Services (PALS) were created in 2002 to provide information and on the spot help where patients in the NHS want to resolve a problem without making a formal complaint. PALS are allowed to assist with the filing of a formal complaint in addition to their informal resolution powers.

Good PALS services can be effective in resolving problems quickly and informally, without the need to enter the formal complaints process. However, PALS are set up in different ways around the country and there are currently no guarantees as to the quality or independence of the service.

In some places, PALS are independent of the complaints processes, whereas in others they provide the complaints handling service for the hospital as well as signposting and advice services for patients. Where this is the case, PALS risks having divided loyalties, and this is one reason why they were critiqued by the Clwyd Hart review³¹ for not providing adequately independent support for patients. As Sue, who uses mental health services, told us: “I’m wary of PALS. I was a medical secretary, so I saw how complaints are handled internally – it’s more about damage limitation than actually addressing issues.” As the Francis Inquiry pointed out, PALS may not have experienced staff and may be overwhelmed by workloads. This compounds the risk that people will not get the support they need from PALS.

The Clwyd Hart review also drew attention to the lack of visibility and signage to PALS. Local Healthwatch, including Healthwatch Staffordshire, have similarly told us that the “PALS feedback box on display in the main reception had no indication as to where patients should go to get a feedback form, who PALS actually are, or where they are based.”³²

In addition, there are gaps in PALS services. There is nothing equivalent to PALS to cover social care and while some Clinical Commissioning Groups (CCGs) are commissioning PALS to give general advice and support about wider primary care services, they are not required to do so by law. As a result, many local Healthwatch have observed an increase in the problems local people experience in getting independent support and advice complaints for GPs, dentists and other community services.

Alongside support from the system itself, consumers need an effective and independent complaints advocacy service to raise their concern or make a complaint. As Alison, who complained about a therapist, told us:

“Everybody needs somebody to speak up for them when they can’t speak up for themselves. Complaints systems are set up for people who are assertive and articulate, and when you’re using mental health services you often don’t feel confident enough.”

If people require this tailored support they can choose to use an independent complaints advocate to help them to make decisions about how they want to be engaged in the complaints processes and to ensure the system acts upon their complaint.

What is complaints advocacy?

Complaints advocacy is an independent, specialist service that supports people who are thinking about making, or who actually are making, a complaint about health and care services they receive. Specially trained advocates support people to express their views to get them to be taken seriously by the institution that should resolve the complaint.

Complaints advocacy often involves:

- + Listening to what a person wants to say;
- + Supporting them to express what their concern is and what it is they want to get out of their complaint;
- + Providing access to information so they understand their options and choices;
- + Offering them practical support such as writing letters or attending meetings;
- + Explaining responses and correspondence so that the person understands what is happening and the process they are going through;
- + Acting on their behalf and ensuring that complaints professionals are treating them fairly and in a dignified manner.

Through our investigations we have seen a mixed picture of people's experiences of complaints advocacy.³³ Some people have told us about the important role that complaints advocates have played in supporting them to make decisions about whether they want to raise a concern and how they want to articulate their complaint to the system. Others reported that they were unaware of the service, or that the advocate was not familiar enough with the service they were using to help them prepare them for making their complaint.

The variability of services has been well documented in previous assessments of people's access to, and use of complaints advocacy.³⁴ Under the current arrangements, NHS Complaints Advocacy Services (NHS CAS)³⁵ are commissioned by local authorities to provide advocacy support for people wishing to complain about their treatment or care received **under the NHS**. In some areas commissioners have decided to extend the offer to those who have a social care complaint, though **there is no equivalent statutory right to social care complaints advocacy**. Increasingly, councils are cutting the discretionary advocacy they commission as local authority budgets come under significant pressure. The omission leaves people using social care without the vital support they need to raise a concern about their care and have their rights recognised and protected by services. This is of particular concern for home care or residential care settings.

Complaints advocacy data now sits with local providers, with the result that there is currently no national picture or oversight of advocacy support. There are no national standards relating to the provision of services. This results in a significant risk of variability in access to advocacy, as well as difference in the quality and standards of provision across the country. This is a particular concern with social care complaints advocacy, which is discretionary, meaning that there are likely to be even more significant variations in access and quality.

For people who come under the Mental Health or Mental Capacity Acts the inconsistency in service offers can cause additional confusion and distress. In our conversations with providers of Independent Mental Capacity Advocacy and Independent Mental Health Advocacy we discovered that some encourage their advocates to support people to raise concerns, whereas a number said that support to make complaints did not come under their remit. An advocate stepping out of a complaint or signposting someone onto a second (complaints) advocate creates an unnecessary disruption to people's support.

Although independent NHS complaints advocacy services are commissioned throughout England, the Clwyd Hart review found low levels of public awareness about the service and the support that is available.³⁶ They concluded that part of the problem is that there is no national brand unifying all complaints advocacy services. Without adequate support in the setting many people are turning to their local Healthwatch asking for advice and signposting.

The growing concerns about the provision of complaints advocacy provision and need for urgent action was echoed by Sir Robert Francis QC and Ann Clwyd MP, in their oral evidence to the Health Select Committee,³⁷ who both felt that their own concerns about the inadequacies of current complaints advocacy arrangements had not been sufficiently addressed or acted upon at the national or local level.

We believe that the time has come for a national response to the continued fragmentation of complaints advocacy to ensure people have the support they need when raising a concern or making a complaint.

Recommendation:

We propose that the Department of Health **urgently review NHS Complaints Advocacy and Patient Advice and Liaison Services arrangements**, with a view to **establishing a new, easily accessible, consolidated complaints support and advocacy offer** that spans health and social care.

We recommend that a new consolidated complaints advocacy offer should:

- + Be **independent from complaints handling** organisations and processes;
- + **Have a presence in all health and social care settings**, not just hospitals (as is the case with PALS);
- + **Consolidate all support and complaints advocacy into one service offer**, covering all ages and people who come under the Mental Health and Mental Capacity Acts;
- + Introduce a **statutory right to independent social care complaints advocacy services**, creating parity with NHS complaints system;
- + **Be promoted and marketed under a unified and recognised brand**, providing much needed consistency and continuity for consumers;

- + **Be commissioned and kite-marked against new national standards**, based on refreshing the standards for NHS Complaints Advocacy that Healthwatch England has been testing on behalf of the Department of Health . These standards will be informed by the needs of people, generated from workshops with people who use advocacy services, complaints advocates and providers, local authority commissioners and national system players (including the Department of Health, Ombudsmen, Local Government Association, NHS England and the Care Quality Commission);
- + **Collect and share data with local Healthwatch, service providers and regulators**, so that there is greater oversight of complaints advocacy services and so that trends and learning from the case data can be used to improve complaints handling processes and practices locally;
- + Be based on a **sufficient and sustainable financial settlement**.

This new complaints support and advocacy offer should be codified and, through a phased introduction, transform or replace all existing PALS and NHS Complaints Advocacy services, ensuring that expertise, good practice and provision is built upon.

How did complaints advocacy become fragmented?

From the 1970s, Community Health Councils³⁸ had a statutory duty to handle patient complaints about NHS services and provide additional support and advocacy when required. This arrangement is still operating in Wales.

In 2000, the Department of Health announced the introduction of a new Patient Advocacy and Liaison Service (PALS) in every NHS hospital and Primary Care Trust to provide support for patients and carers, and to bring about early identification and resolutions to people's concerns.³⁹ This proposal was endorsed in the report of the public inquiry into failings in children's heart surgery at the Bristol Royal Infirmary⁴⁰ because of their concerns about the adequacy of existing arrangements around complaints handling and advocacy.

When the new services were implemented the responsibility of PALS was changed from **advocacy to advice**, and the advocacy offer was established under a new parallel service called **Independent Complaints Advocacy Services (ICAS)** across England.⁴¹

ICAS were designed to provide independent and local support and advocacy to those wanting to make complaints about the NHS treatment or care. ICAS services did begin to improve the quality of complaints advocacy and ICAS supported cases were three times more likely to be investigated by the Parliamentary and Health Services Ombudsman.⁴²

In 2012, the Health and Social Care Act transferred the responsibility for commissioning complaints advocacy from the Secretary of State for Health to local authorities under the new auspices of NHS Complaints Advocacy Services (NHS CAS). The transfer from national oversight under ICAS, to local commissioning of NHS CAS in April 2013 resulted in significant national oversight being lost.

3.3. People find the system complex and confusing

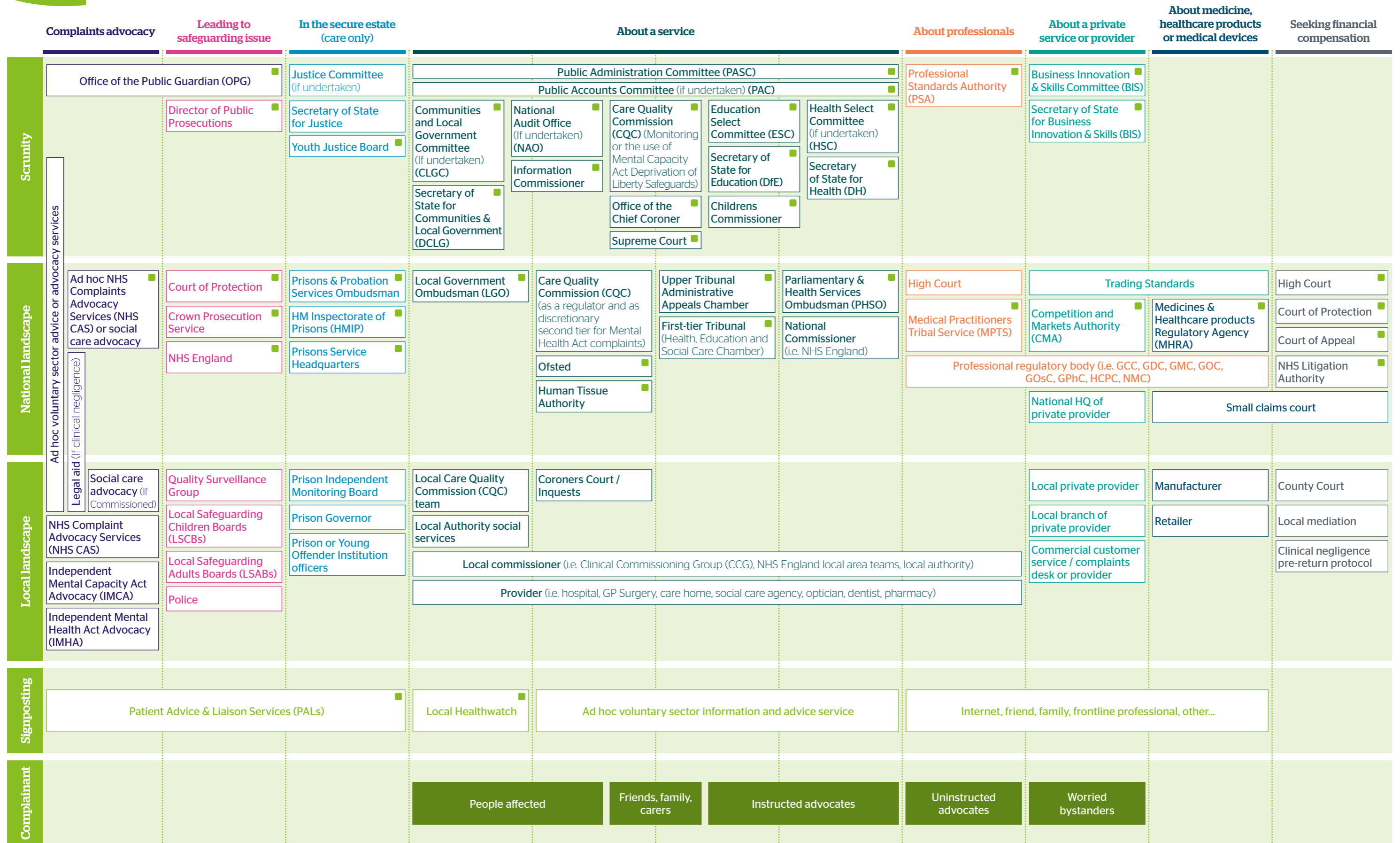
“Reporting complaints is a nightmare as there are so many different agencies and providers.”

Jeanette, who had complained about a care home.

Last year consumers and professionals around the country told us that the complaints system was too complicated. Many said they felt like they needed a doctorate just to navigate all the organisations involved and all the different pathways a complaint could take.

We decided to talk to all of the organisations involved in handling health and social care complaints and, for the first time, to map everyone who might be involved in a complaint. The results were staggering. We found that there are over **70 different kinds of organisations involved in handling and supporting complaints**, including service providers, commissioners, regulatory bodies, and Ombudsmen.

How complex is the complaints system? **This complex...**



Is it any wonder that both consumers and professionals find the process so bewildering and so difficult to navigate?

Recommendation:

There is scope to reduce the number of organisations involved in complaints handling significantly. We would encourage the Department of Health to be bold in its thinking and while we recognise the need to maintain a level of expertise and specialism, there needs to be radical simplification in order to make the system less bewildering for those trying to make a complaint.

Just to illustrate the complexity we found that in a case where you are worried about the dosage of a drug a GP has prescribed you might file a complaint with:

- + the doctor
- + the doctor's complaints or practice manager
- + NHS England (as the organisation which directly commissions GP services)
- + the Medicines & Healthcare Regulatory Agency (to raise concerns about the use of the drug)
- + the Parliamentary and Health Services Ombudsman (if you are not happy with the local procedure)
- + the General Medical Council (as the licensing authority for doctor)
- + and several other organisations, depending on how the complaint was handled.

If you needed to seek financial compensation, you would have to bring a legal case on top of the other complaints procedures you are engaged in.

Sara's experience ...

Sara wanted to raise concerns after being given an X-ray when her consultant had ordered an MRI scan, a decision she feels was made to cut costs. She wanted to find out why the decision had been made, and to stop the same thing from happening in future. However, Sara found it very hard to work out who to direct her complaint to:

“I complained to NHS England, who passed me on to various other agencies, until eventually I was told to contact the Ombudsman. This agency firstly told me they couldn't handle my complaint, but eventually decided that they could.

“I was tired of being contacted and being told that my complaint had been passed on, and it became obvious that a well-organised system was in place making things difficult for someone like myself to get a simple answer.

“When I first complained, I should have been told what information the Ombudsman needed. My complaint was delayed and delayed. I kept on being informed that X or Y had been passed my complaint.

“Eventually, after a year of wasting my time and NHS funds, I was sent a letter asking for information that I had originally supplied in the first instance.

“I realised that there was a huge industry dedicated to making sure nothing would be done, and I would just be passed around until I gave up. So I decided I would give up.”

It is wrong that people are left to navigate this complexity on top of the concern they are trying to get resolved. Ultimately that is why so many, like Sara, give up hope that anyone will ever deal with their complaint.

Consumers have told us that they want to see a new 'no wrong door' policy established in health and social care complaints handling accompanied by a named case handler. This would mean that it would not matter where a person raised a complaint, it would be the responsibility of the complaints handler to navigate the complexity of agencies and institutions on the complainant's behalf and ensure there is collaboration across organisations.

Additionally, a named case handler would respond to people's need to know who is responsible for managing their complaint and would take away the current pain of having to explain over and over again the detail of their complaint, a task that can be traumatic for many complainants.

Recommendation:

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. This should be underpinned by introducing a named case handler who is responsible for ensuring warm transfers of the complainant between agencies.

Consumers told us they want to have choice and control over how their complaint is handled. We heard about situations where people wanted to be in control of the speed at which their complaint had been progressed.

Jennifer's experience ...

Jennifer, an elderly lady, was going back into hospital because she was extremely unwell and coming to the end of her life. She and her family wanted to suspend a complaint about a previous service she had been receiving. The family were entering a difficult time coping with her escalating condition and coming to terms with her death, so complaining about a previous service was not their highest priority. However they were keen to ensure that no one else would have the same poor experience that Jennifer did. Broaching the subject with the complaints handler, they were met with an uncompassionate response suggesting they would either need to continue with the complaint or close it as Jennifer was dying.

Mike's experience ...

Mike had made a complaint about a complex needs service his son had been receiving treatment in but, because it was the only specialist centre in the region, his son would need to use the unit again in the following months. Mike was anxious for the complaint to be resolved before his son returned, but could not get the complaints manager to speed up the standard processes internally.

People talked to us about wanting to signal to complaints handlers the status of their complaint and the nature of resolutions they are hoping for.

We feel that people must be given the opportunity to choose the kind of resolution they want to achieve, reflecting whether they are seeking a speedy resolution to an immediate problem, a simple explanation and apology, or calling for a full investigation leading to legal claims, disciplinary action and long-term system change.

Recommendation:

The Department of Health should work with Healthwatch England to explore and introduce new guidelines on consumer choice and control in complaints handling. Consumers should have control over the pace of their complaints, including being able to ‘stop the clock’ whilst dealing with illness, trauma or bereavement. People should also 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

The report of the Public Administration Select Committee⁴³ recommends the creation of a single point of contact – likely to be available online and over the telephone – for the public to make complaints about Government departments and agencies. We agree with the Committee that there should be simpler, online platforms available to complainants.

Recommendation:

The Government should explore the scope for online platforms to provide a well-publicised point of access for complaints, enable greater consumer choice in how complaints are handled and resolved, and allow complaints to be made anonymously where required.

Consumers have also told us that they want to see a streamlining of the second tier of complaints handling, specifically the roles of the Parliamentary and Health Services Ombudsman and Local Government Ombudsman.

We are encouraged by the closer working between the two ombudsmen, and support the proposals of the Public Administration Select Committee⁴⁴ for a new joint ombudsman that would deal with complaints relating both to NHS services and local authority-commissioned social care.

This holds the potential to simplify the process for consumers by removing the need for people to complain to two bodies when complaints concern both health and social care. Under the current system, it is up to the consumer to decide on which ombudsman is responsible for the service they want to complain about. As integration between health and social care progresses, there will be an increased need for a complaints system that reflects the new ways services are delivered.

Currently the health and social care ombudsmen may only investigate issues when they receive a complaint from an individual. Introducing a single body that can escalate multiple cases (a ‘super-complainant’) would provide a way for those who do not, or cannot, complain to have their voices heard by the system. Such a role would complement our existing statutory powers to raise concerns about health and social care with system players.

This new Public Sector Ombudsman should build on the work of the work of the Parliamentary and Health Services Ombudsman and Local Government Ombudsman by playing a **key role in scrutinising and promoting the quality of complaints handling** across health and social care settings. This could take the form of an annual publication to parliament (as is currently the case), with Healthwatch England playing an advisory role as a ‘super-complainant’ on progress from a consumer perspective.

Recommendation:

As part of structural reform to national complaints systems, the Government should establish a unified Public Services Ombudsman for England, covering health and social care. This Unified ombudsman should learn from expertise and good practices within the Parliamentary and Health Services and Local Government Ombudsmen, and be supported by Healthwatch England acting as a ‘super-complainant’ able to take up issues of national concern.

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

“There has been no outcome to my complaint; simply more distress, inconvenience, injury and injustice.”

James, who complained on behalf of his friend after an operation went wrong and his medical records were lost.

Too often, people do not complain because they do not feel it will achieve anything for them.

At worst, consumers often worry that raising a concern or making complaints will adversely affect the care they receive. This is a particularly powerful disincentive for people who are receiving ongoing or long-term care, especially when it is not viable or easy to change to a different provider.

This concern can be a powerful force in silencing people, particularly those facing long treatment pathways, where people tell us they already feel battle-worn by the process.

Our recent survey⁴⁵ showed that although just under one third had experienced or witnessed a relative, friend or partner receiving poor care from a health or social care service within the last two years, just 2 in 5 had made a complaint.

We asked those who had not complained to think about what had stopped them from making a complaint. Worryingly 1 in 4 told us that they were worried about repercussions on their treatment or care.

Dina’s experience ...

“I made a complaint about my treatment, ‘lack of proper diagnosis’ initially, to the hospital Governance Department with the help of an advocate. I received an official response in September 2012 that was unsatisfactory. I then contacted an advocate and my MP who took up the matter with the Chief Executive. No response.

“Following further complaints by the advocacy service and my MP to the Ombudsman the next year, the matter was referred back to the hospital to set up a meeting. The meeting was never arranged but I received another formal response 18 months later.

“This second response was unsatisfactory and the matter was officially taken up the Health Ombudsman in January 2014. The Ombudsman is currently investigating the complaint to the hospital - 2 years later.

“Since making the complaint to the hospital I have been bullied by nursing staff while an in-patient and been intimidated. I have also experienced discrimination with long delays in treatment, lost letters and notes. Notes have been altered and I have been branded as some kind of patient who makes complaints for no reason, ‘a serial complainer’, as well as a ‘frequent flyer’ type patient. I am 60 years old, disabled, and have to visit the hospital for recurring health problems.”

Dina is not alone in feeling that making a complaint changed the way that staff treated her. The sense that the complaints process is adversarial and biased against them is prevalent throughout the consumers' accounts that we have been collecting.

Moreover, many of those we spoke to were extremely reluctant to raise concerns that might jeopardise their relationships with staff. This was particularly the case for patients being detained or treated against their will. When we spoke to people who had been treated under the Mental Health Act, it was clear that maintaining good relationships with staff was absolutely crucial, and complaining was seen as a 'risky' move that could affect their recovery or discharge journey. Like consumers of health and social care more broadly, people treated under the Mental Health Act often fear retribution from staff, or a decline in the quality of their treatment, if they complain. These sentiments were also found in the reports of Sir Robert Francis, who found that concerns of retribution acted as a significant deterrent for people considering making a complaint.

“Your family are meant to look after you, but when you go into hospital that transfers to the staff. If you fall out with the hospital staff, you're in difficulty.”

For those who are detained, or at risk of being detained, this fear can be extremely powerful.

One person we heard from had serious concerns about the medication and dosage levels she had been prescribed after being released from psychiatric intensive care. She wanted to raise concerns about this, but knew that if she didn't take the medication she would be detained again. Being detained, or at risk of detention, puts patients in a vulnerable situation where it is very difficult to speak up. Many patients felt that it would simply not be in their best interests to raise a concern about someone providing their day-to-day care. As one former patient put it:

“If you were to complain, you'd feel you were digging your own hole, you want to get out of there so you don't want to cause a fuss. You're at such a big disadvantage. It's an unwinnable situation.”

Where people fear that complaining will lead staff to treat them unfavourably, an option to complain anonymously may provide a valuable way for people to raise concerns. It must be made clear to patients that an anonymous complaint, containing sufficient information for the complaint to be investigated, will be treated in the same way as a complaint from a named person.

Recommendation:

All services should promote people's right to have their concern or complaint logged and dealt with anonymously, and this should be treated on an equal basis as those made by complainants who disclose their names.

People have told us that the way their complaint is handled makes them question the independence of the system.

Complaints resolution is often experienced as uncompassionate and overly defensive, failing to acknowledge and apologise when treatment or care has been poor or has gone wrong. In so many of the accounts we have explored, people told us that they were simply looking for an acknowledgement, an apology and a guarantee that no one would go through the same experience.

This is worrying as many of the people we spoke to explained that achieving recognition and an apology for their treatment was an important part of their resolution. Some described an apology as a pre-cursor to them finding solace and a sense of justice in any resolution that was offered by a provider or ombudsman. Where an apology was not forthcoming, people often felt aggrieved and frustrated, which frequently led to an unnecessary escalation in their complaint and a feeling that the system was re-traumatising them over and over again.

Holly complained after a frightening experience during a smear test, when hospital staff continued the procedure even though Holly was in great pain. The response she received after writing to the chief executive of the hospital contained inaccuracies and failed to address her concerns. Crucially, she never got the apology she wanted. She does not feel the complaints process has helped her to resolve her concerns; rather, it has left her emotionally exhausted. She told us:

‘This ‘fight’ has robbed me of my flesh, dignity and energy.’

Recommendation:

All complaints should receive a personalised and compassionate acknowledgement within three working days, in line with complaints regulations. This should outline the next steps in the process, and where possible should provide a sincere apology.

Some people find that their complaints are ignored or misunderstood, both by frontline staff and complaints managers, and that staff handling complaints can be insensitive and uncompassionate.

For example, the Parliamentary and Health Services Ombudsman reports that “in one case a hospital responded to a grieving relative by writing that ‘death is rarely an ideal situation for anyone.’”⁴⁶

Too often, complaints are seen as something to be ‘managed’ or ‘mitigated’ rather than as vital information about the performance of an organisation. Without listening to people and their families and learning from what they have to say, the NHS and social care systems will be doomed to repeat their mistakes.

Sadly, some of the people we spoke to had been labelled as ‘vexatious’ or as ‘nuisances’. People told us that finding out they had been labelled this way unnecessarily positioned them in an adversarial way with staff and demonstrated a lack of compassion for their experiences. This resulted in some dropping their complaint. For others, it fuelled their fire.

As Stephen told us: **“How can it be vexatious to simply ask for an apology?”**

A further complexity in NHS complaints is the cultural values that many people hold about the institution. People have told us that they feel really conflicted over complaining about NHS services. This came out as a strong theme amongst the people we spoke to, and it echoes the conclusions reached in a recent study commissioned by the Parliamentary and Health Services Ombudsman.⁴⁷

People told us that they felt a huge amount of empathy for frontline NHS workers and thought many were not to blame for the poor treatment they had received.

June’s experience ...

June told us last year that she was really satisfied with her stay in a geriatric ward in a hospital, really pleased with her care. When we asked her to share her experience we were shocked to hear that beneath her satisfaction lay a far more complicated story.

June told us about not being able to eat or drink because she was too weak to feed herself; about wetting her bed because she wasn’t able to get to the toilet in time; and about being anxious about not knowing what medicine was in her drip.

Surprised that such negligence could be characterised by June as a ‘satisfactory experience’ and not have resulted in her raising a concern about the way she was being treated, we dug deeper.

June told us that she understood why this had happened. She told us that the nurses had been ‘run off their feet’, too stretched, with too few of them to properly look after the patients on her ward. And her doctor had prioritised the woman next to her who was older and less well than she was. She told us that it wasn’t their fault and that she was satisfied because at the end of the day she returned home safe and sound.

June was not the only person we spoke to who had a concern about their treatment, but had explained it away because they knew the staff were under pressure and because they were reluctant to criticise the NHS.

Too often, people have told us they feel that they are met with defensiveness and even hostility when they raise a complaint. In place of adversarialism, we need a culture where complaints are welcomed and valued.

Instead of fearing complaints, health and care providers should welcome opportunities to see where standards are slipping, and to act on these early warning signs to avert serious failings. This depends on staff and feeling safe and supported to be open and honest when things go wrong, and being receptive to complaints from anyone who raises them.

Perhaps then people would have more confidence that their complaint would be resolved and acted upon. Of those who have complained **3 in 5 did not feel their complaint was taken seriously enough.**

This seemed to be particularly acute in mental health services, where the people we spoke to felt that, because of the nature of their condition, staff simply did not believe them.

“What I said wasn’t seen as worth listening to; it was just seen as the utterances of a mad woman. Everything you say is seen through the prism of illness.”

“I do not complain in a hospital environment because my complaints are usually about psychological events, so when I complain I’m told I’m insane, or hearing voices or seeing things.”

As a result, many of those we spoke to lacked confidence to raise concerns. The nature of the conditions people experience also make raising concerns a serious challenge, as they did not feel confident in their ability to judge the seriousness of situations while unwell or taking strong medication.

Mental health patients’ experiences ...

Jim, who had experienced paranoia, lacked the confidence in his own perception and so did not complain when he felt he had been mistreated by a nurse. He told us:

“I knew what was done to me was wrong but I doubted myself.”

Charlotte, who had been treated for depression, both in hospital and in the community, told us:

“Responses to the various concerns I raised about my care and medication were underpinned by the assumption that I was unwell so I didn’t know what was good for me.”

Another patient told us:

“After I was released, I found out that the staff had had a meeting about [my complaint], but I was never told about it, or about what was discussed. It did nothing to improve my experience in hospital.”

This sense of powerlessness was a common theme in many of the discussions we had with people who had been treated under the Mental Health Act, and this had a serious impact on their ability and willingness to raise concerns.

People tell us that what they want from a complaints procedure is an acknowledgement that something has gone wrong, an apology and a supportive and compassionate resolution that not only enables them to move on, but ensures others will not go through the experiences they have endured.

Shockingly, our survey found that only half (49%) of complainants ever received an apology for the poor treated or cared they received.⁴⁸

The NHS Litigation Authority's guidance makes it clear that NHS Trusts should 'issue a verbal apology to patients as soon as staff are aware that an incident has occurred [and provide] a written apology, which clearly states the healthcare organisation is sorry for the suffering and distress resulting from the incident.' This is because they know that **'saying sorry is not an admission of legal liability; it is the right thing to do.'**⁴⁹

Recommendation:

Mandatory training for all frontline professionals across health and social care should ensure they are confident they can apologise without fear of legal implications.

Demystifying the consequences of apologising will be an important step in cultivating a more honest and compassionate culture in complaints handling, but improvement will need to go further to meet consumer expectations. The people we spoke to wanted to see a fundamental shift in the nature of conversations that are had in health and social care settings. And whilst there has been incremental progress in asking patients for feedback (for example through satisfaction surveys or the Friends and Family Test), the results are snapshots of moments in people's experiences and fail to change the nature of the conversations between patients and professionals.

The people we spoke to cited examples from the private sector where professionals or staff would actively and regularly ask for feedback on their services and openly and constructively deal with challenge or concern.

'Check-in' points should be introduced to remind staff to ask people using services, or their families and carers, to reflect on the experience so far and suggest ways their practice could be changed. Another example would be offering an invitation for feedback and the raising of concerns in all communications sent by email and letter to individuals, family members or carers. Such simple steps would allow concerns to be raised earlier and prevent unnecessary escalation.

Recommendation:

All staff should be trained, encouraged and incentivised to invite and respond positively to feedback.

The renewed focus on creating a culture in health and social care of honesty and openness should also address the defensiveness or hostility many complainants face. In response to the reports of Sir Robert Francis QC and Professor Don Berwick, the Government is introducing a new duty of candour that will ensure that health and social care providers speak up when mistakes are made and frontline staff are inappropriately blamed for failings.

To make this duty of candour work for complaints though, more focus needs to be given to embedding reflection in professional practice. Introducing a compulsory module into professional revalidation and creating spaces for reflexive practice would be a positive move toward this goal.

One such method is Schwartz Center Rounds, where staff at all levels are given a safe and confidential space to share and reflect on their experiences and feelings about those they care for. Pilots by the Kings Fund have shown the potential of this kind of intervention to reduce staff stress and isolation, increase empathy, encourage openness, and improve patient care.⁵⁰

Recommendation:

To support the duty of candour, providers must be incentivised to offer staff safe and supportive spaces to share and reflect on learning from feedback, concerns and complaints. Professional supervision is key to this and wider use of methods like the Schwartz Center Rounds.

To formalise reflective practice further, regulators must ensure that processes of professional revalidation meaningfully reflect staff learning from complaints.

At the same time, there must be strong and effective sanctions where staff are not open and honest. In particular, there must be methods of redress for occasions where staff seek to cover up concerns or complaints that have been raised. The introduction of new criminal offences⁵¹ in health and social care will provide a mechanism for prosecuting those who wilfully bury a serious complaint.

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

“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. The complaint remains completely unresolved as far as I am concerned. I feel very unhappy about the whole affair.”

Kelvin, who complained about delays in his wife’s cancer treatment

Our survey found that **half of those who had complained about poor health or social care felt that their complaint had not been resolved and only around 2 in 5 were told about changes that were made as a result of their complaint.**

Even for those who did see services improve as a result of their complaint, progress was far too slow, as Jackie told us.

Jackie’s experience ...

Jackie had been caring for her mother, who suffered from vascular dementia, for many years. Eventually, her mother started walking around the house at night and Jackie, worried for her mother’s safety, felt unable to care for her mother alone.

After finding a care home she thought would be suitable, Jackie’s mother moved in. Jackie soon began receiving calls from the home telling her about her mother’s ‘challenging behaviour’, specifically that she was wandering around the facility at night and inconveniencing the staff.

These were the precise problems which Jackie had discussed with the staff prior to her mother’s placement but, still, the staff were upset and told Julie that she should visit her mother less often and for shorter periods of time.

When Jackie tried to comply, her mother became very upset and told Jackie that she felt sad, lonely and sometimes wished she was dead.

When Jackie raised concerns with the care home manager, she received a frosty response. Because her mother had dementia, the care home staff felt that ‘they knew best’, when they should have paid more attention to the needs and wishes of Jackie’s mother, and those who knew her best.

Jackie complained to the care home about their treatment of her mother, since she felt they were illegally depriving her of her liberty. When she received a letter from the care home’s solicitor, she felt intimidated and reluctant to pursue the complaint on behalf of her mother. It was only when Jackie got in touch with an advocate that she realised she ‘had rights’ and should pursue the complaint.

Nevertheless, Jackie was concerned about the potential implications of complaining. Having raised her concerns about her mother’s liberty with the care home, Jackie felt pressured to turn a blind eye to rough treatment of her mother by care workers in the home, rather than risk further damaging the relationship with the home. Jackie’s mother was eventually made to leave the care home, and Julie feels sure this was because of the complaints she had made.

Jackie filed a formal complaint with several bodies, including the local authority, the then Primary Care Trust and Ombudsmen. Though she was satisfied with the findings of the Ombudsman – and the subsequent apologies she has received from the local authority and the NHS – she has never received an apology from the care home, and is still pursuing this.

Jackie still feels that the NHS, the local authority and the Care Quality Commission (who regulate care homes) were too focused on defending the care home, and as a result let down her mother and other residents too.

Jackie had to continue to make complaints to different agencies for years to have her concerns properly addressed.

As a result of Jackie’s complaint, the care home has reluctantly made changes to the way it operates, and has amended its admissions policy and complaints procedure, although this has been ongoing for five years.

Inaction at Winterbourne View

The experiences of people at Winterbourne View Hospital paint a stark picture of what can happen when complaints are ignored and unaddressed in care homes. The Serious Case Review of Winterbourne View Hospital noted that while on paper, the hospital seemed to have an excellent complaints policy, the reality was extremely different. It notes that people 'were not listened to or believed when they told people about abuse'.

The hospital, like many similar facilities, starkly limited the visiting opportunities for families and others, particularly to the wards or patient living areas. Patients could only speak to advocates by going through the Nurse in Charge, meaning that even independent assistance was restricted. As a result, no complaints were received from patients or their representatives.

The message was also given to the Care Quality Commission inspectors, who were informed that there had been no complaints for years, and as a result 'complaints either embedded in a patient's care notes or logged during the unit-led clinical governance committee meetings were not investigated'.

Shockingly, when people living at Winterbourne View tried to go to the police to make an assault complaint, it was dismissed, as the police believed staff over the patients.

Despite patients and their families repeatedly raising serious concerns about shocking acts of mistreatment and violence, they were not adequately recorded or dealt with, which resulted in further neglect and abuse.

People are often motivated to make a complaint in order for others not to experience the same problems they have. 83% of people told us that they would be more likely to complain if they knew that their complaint would be used to improve the performance of staff and services for the future.⁵²

When we asked Eric what had motivated him to complain about the service he had received at his GP practice, he told us:

“Obviously enough, I hoped to get better treatment. But also, especially as my GP surgery is a teaching practice, I wanted them to provide better medicine.”

If complaints are to be genuinely valued, the way that they are handled and learned from must be at the heart of delivery and regulation of health and social care services.

To grow good practice, Healthwatch England has worked with the ombudsmen in health and social care (PHSO and LGO) to develop a consumer-led 'vision' of complaints handling across the sectors. This vision sets out consumer expectations at each stage of complaining, and provides a framework for good practice in complaints handling which will be relevant to providers, commissioners, regulators and professional bodies.

We are working closely with stakeholders to ensure that the vision is used to put consumer expectations at the heart of complaints systems across health and social care, in every setting and at every level, from the 'frontline' of services to the ombudsman. It will also provide a practical tool to ensure that regulators and inspectors of services can scrutinise the way organisations handle and learn from complaints. We hope that the vision will provide a useful resource for complaints managers to improve practice among frontline staff, as well as for governing forums.

Recommendation:

To ensure that the consumer-led vision (developed by PHSO, LGO and Healthwatch England) becomes embedded in the improvement of complaints handling, the Care Quality Commission (CQC) should develop guidance for its inspectors on complaints handling and learning. This guidance should be based on the vision and form a core part of new inspection processes across health and social care.

Recently, the Care Quality Commission (CQC) has taken significant steps towards fulfilling this recommendation, and embedding it into their approach to inspecting NHS acute hospitals, community health and specialist mental health services, as well as primary care and adult social care.⁵³

The new approach includes a greater focus on using experience and learnings from concerns and complaints to inform the focus of inspection activity. It also means that, from now on, complaints handling will be taken into account when providers are rated by the CQC and will direct any action the provider is required to take as a result. This will be underpinned by new regulations and fundamental standards coming into force from April 2015 (subject to parliamentary process).⁵⁴

Within this activity is a focus on using the data and intelligence around existing complaints about the provider to inform where inspectors should focus their attention when visiting a provider. The CQC has been testing out how this could be done since the publication of the Government's response to the report of Sir Robert Francis QC in November 2013. Healthwatch engagement with the pilot CQC inspections suggests that progress is being made and we would be keen for this to be built upon as the new regimes are rolled out.

Recommendation:

The Care Quality Commission (CQC) should make greater use of complaints data and intelligence to inform the focus of their inspections.

Building on this new approach being implemented by the CQC, we feel that if progress is not fast enough the Government should explore further whether additional disincentives be put in place to address services that consistently fail to learn or fail to meet the CQC's expectations for complaints handling. This could include putting providers into a complaints 'special measures' regime to enhance the progress on complaints handling, introducing financial penalties on providers who have significant failings in complaints processes, or the decommissioning of services that fail to listen to, respond to, and act upon complaints.

Recommendation:

The Government should explore broader action that could be taken when providers consistently fail to meet the expectations for complaints handling and learning set out by the CQC.

There is also a role local Healthwatch can play in using this vision to improve local complaints handling systems. Many local Healthwatch are already using local relationships to play a crucial role in improving local complaints handling systems and ensuring services learn from complaints. There is scope for local Healthwatch to play a more formalised role in providing challenge and scrutiny to assess the quality of complaints handling by local commissioners and providers.

Complaints are central to the work of local Healthwatch, and across the network Healthwatch are working closely with consumers, using their experiences to call for improvement both in health and social care services and in complaints handling. Many local Healthwatch have developed close working relationships with complaints advocacy services, sharing information to identify where services are not working and where complaints are not being dealt with well. Local Healthwatch have used this intelligence to call local service providers to make real changes to the way they work with consumers and respond to their concerns.

Local Healthwatch working with partners to learn from complaints

Local Healthwatch around the country have been working with providers and commissioners to improve local complaints systems.

Healthwatch Cambridgeshire's experiences

Right from the launch of Healthwatch Cambridgeshire in July 2013, it was clear there was a problem with the local health and social care complaints system.

“From early on we were receiving calls from people who didn't know how to report complaints about the care that they, or their relatives, had received,” explains Julie McNeill, Healthwatch Cambridgeshire Information Officer.

Even those who managed to lodge a complaint found the process long and exasperating. “Some said it almost felt like they were being strung along until they gave up,” explains Julie.

Julie and her team looked at evidence from a Healthwatch England survey that found just under half of people believed complaints were not dealt with effectively. This helped them develop a major project to improve the system locally so that people feel they are listened to and taken seriously.

They developed visual maps for the Healthwatch Cambridgeshire website that signpost people to the right place to raise a concern or make a complaint. These maps were sent to hospital trusts, the clinical commissioning group and adult social care for their comments, as well as to Healthwatch Cambridgeshire's consultation network, which is made up of over 60 members of the public.

“We've had great feedback which has enabled us to adapt the maps so they work better for everyone,” says Julie.

The work has also involved alerting local trusts to out-of-date or misleading information on their websites, such as reference to the Primary Care Trust, which hasn't existed since April 2013. The project will continue with a survey about the experiences of people whose complaint case has recently closed.

Healthwatch Stockport's experiences

Healthwatch Stockport has worked closely with its local complaints advocacy provider and NHS Foundation Trust to help get quicker responses to local residents' complaints.

Though the Trust aims to respond to complaints within 25 days, Healthwatch Stockport found that 70% of complainants were waiting longer – and some had to wait up to 7 months for a response. Responses were often impersonal, inaccurate, and failed to answer the questions people had asked.

Healthwatch Stockport and NHS Complaints Advocacy Stockport (NHSCAS) met with the Trust's senior staff and achieved some excellent outcomes:

- + NHSCAS organised an open day where current complainants came to their office to meet other complainants for peer support, to give feedback to NHSCAS on the advocacy they have provided, and to discuss how complaints can be used to improve health services;
- + The Trust has recruited 2 new members of staff to handle complaints, increasing their capacity;
- + There is better co-ordination of responses between the business teams (medical department) and the team who handle complaints;
- + The Head of Quality and Director of Nursing and Midwifery will play a more active role in the responses and during investigations;
- + People now have easier access to recordings of face-to-face meetings regarding complaints.

4. Conclusions

“I now understand why people are reluctant to make a complaint. The devastating effect it has had on me is unbelievable.”

Kate, who complained about a therapist, and had to wait two years for a resolution. She only found out later that advocacy support was available to her.

Our work with consumers has highlighted that, despite a weight of reports on the matter, people still experience finding making complaints overly complex, incredibly frustrating and largely ineffective.

When people have had poor experiences in their own care and treatment, or have witnessed others receiving the same, it is crucial that a system is in place that gives them the confidence to raise a concern or make a complaint and to deliver the resolution they need. For many people, a satisfactory resolution will be as simple as “Sorry”. Others will want simple things put right quickly. For some, a sense of resolution depends on knowing that lessons have been learned and changes made to stop the same thing happening to others. Regardless of the route people want their complaint to take, those brave enough to raise concerns must be treated with the respect, dignity and compassion they deserve.

This report has set out the key challenges that people who complain continue to face.

We know that there is some scope for improvement in the current system, and that change must happen quickly to avoid more unnecessary suffering among people already dealing with ill health, trauma or bereavement. That is why in this report we have made a series of recommendations for immediate change.

However, the depth of the problems in the current system means that minor adjustments to the current system will not be enough. What is needed is a step change.

To date, though much positive work is underway, too much of this still starts from the point of view of organisations rather than the people who depend on complaints systems for redress and justice. To reset the dial on complaints, it is clear that broader structural and cultural reform is needed to create a system that works for consumers.

That is why we are calling for cross-party commitment to structural and cultural change to create a complaints system that works for people and the dedication of legislative time, at the earliest possible opportunity, to look in depth at the change needed to create a compassionate complaints system. This would send a clear signal that complaints are finally being given the level of attention they so badly need.

Recommendations for immediate change	Call to action
<ul style="list-style-type: none"> + 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 all complaints including those made anonymously by those who fear reprisal. 	<p>We are calling on the Department of Health to publish guidance so that all providers of health and social care realise their duty to:</p> <ul style="list-style-type: none"> + accept complaints from worried bystanders, and treat and record them in the same way as other complaints; + accept complaints made anonymously, and treat and record them in the same way as other complaints.
<ul style="list-style-type: none"> + All staff required to proactively and continually seek feedback from patients and respond positively to complaints and concerns. 	<p>We are calling on professional bodies, professional regulators and Health Education England to explore ways to train, encourage and incentivise staff to invite and respond positively to feedback from consumers.</p>
<ul style="list-style-type: none"> + 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. 	<p>We are calling on the Department of Health to co-ordinate a new information standard to ensure all consumer-facing information is accurate, up-to-date, clear and accessible.</p>
<ul style="list-style-type: none"> + All patients to be directed to additional information, advice and advocacy support when making a complaint. 	<p>We are calling on all providers of health and social care to ensure all frontline staff are equipped to direct people raising concerns or complaints to additional information, advice and advocacy support.</p>
<ul style="list-style-type: none"> + 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. 	<p>We are calling on all providers to meet their duty under the 2009 complaints regulations to acknowledge complaints promptly, and to do so in a way that is compassionate, personalised and informative.</p>
<ul style="list-style-type: none"> + Mandatory training for all frontline professionals across health and social care to include making sure they realise that they can say “sorry” without fear of legal implications. 	<p>We are calling on professional bodies, professional regulators and Health education England to ensure that existing training programmes enable staff to feel confident to apologise.</p>
<ul style="list-style-type: none"> + Recognise the stress that complaints place on staff involved and provide them with safe and supportive spaces to share and reflect on lessons learnt. 	<p>We are calling on providers of health and social care to create spaces for staff to reflect on learning from complaints and use this to improve practice.</p>
<ul style="list-style-type: none"> + National oversight of complaints in social care in line with that for complaints about the NHS. 	<p>We are calling on the Health and Social Care Information Centre to urgently commission data to give clear national oversight of social care complaints.</p>
<ul style="list-style-type: none"> + CQC inspections of hospitals, GP surgeries and care homes to be informed by local complaints data. 	<p>We are calling on CQC to make better use of complaints data to inform the remit and focus of its inspections.</p>
<ul style="list-style-type: none"> + CQC to develop and implement guidance for inspectors on raising concerns and complaints based on the user-led vision developed by PHSO, LGO and Healthwatch England. 	<p>We are calling on CQC to use the vision to inform their inspections of complaints handling, and ensure that scrutiny of complaints handling processes is central to the inspection process.</p>

Recommendations for wholesale reform

To make it easier for people to complain and ensure adequate support for consumers we recommend:

- + Establish a 'no wrong door' policy, so that wherever a complaint is raised it is the system, not the complainant, which is responsible for routing it to the appropriate agency to get it resolved.
- + 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.
- + Undertake 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.

To ensure an appropriate and compassionate response and resolution we recommend:

- + 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.
- + 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.

To hold to account those who fail to listen to complaints we recommend:

- + Stronger measures to hold to account those who consistently fail to meet the expectations for complaints handling and learning set out by the CQC. The Government must explore the breadth of action to be taken when providers fail to respond appropriately to complaints, which may include putting providers into 'special measures', issuing financial penalties and decommissioning failing services.

Annex 1: Consumer-focused principles for complaints improvement and reform

We worked with complainants and their families to create six core principles to shape the reform of complaints handling and support. These principles have guided this report and must guide complaints improvement and reform to ensure that it is consumer-focused.⁵⁵

People told us that they want a system of complaints handling and support in health and social care that is:

Independent and confidential: A service that they can trust to look at things impartially; that ensures that raising a concern will not adversely affect their treatment or care and that respects their privacy and progresses their complaint to a satisfactory resolution.

Responsive and non-judgemental: A service that listens to the needs, preferences and anxieties of the people making complaints; that does not judge them, their behaviours or their lifestyles, and that responds to them in a timely manner, in a way that works for them.

Supportive: A service that helps and supports complainants to navigate through any complex or difficult stages in making a complaint.

Simple: A system that is easy to understand, whereby people know what their rights are and what they should expect from complaints handling, support and advocacy services.

Joined up: A system where people only have to raise a concern or make a complaint once, where any door is the right door and any complexity of case handling (like coordinating multiple complaints to a provider, professional body and regulator) all happen behind the scenes (rather than the person having to navigate this themselves). This would be accompanied by one complaints support and advocacy offer so complainants know who is supporting them from the start to the resolution of their case.

Transparent: A system that is up-front about the processes that are being used and the decisions that are being made, keeping people up to date with any changes in their case.

Annex 2: Endnotes

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