My expectations
for raising concerns
and complaints
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Foreword

When the government published *Hard Truths*, its response to Robert Francis’ inquiry into the failings at Mid Staffordshire NHS Foundation Trust, the Parliamentary and Health Service Ombudsman (PHSO), the Local Government Ombudsman (LGO) and Healthwatch England committed to developing a user-led ‘vision’ of the complaints system.

This vision aims to align the health and social care sector on what good looks like from the user perspective when raising concerns and complaints about health and social care. It also allows measurement of progress so that organisations can determine the action they need to take to improve.

We are pleased to share this report, which sets out the outcome of that work, and the evidence base that supports it. It demonstrates the powerful contribution that users of services can make when they have the opportunity to contribute to the design of what ‘good’ looks like. It builds on the work that has gone before, carried out by organisations such as the Patients Association and National Voices.

This work matters because it creates an ‘outcomes framework’ that the leaders of the health and social care system are already committing to implementing.

We are delighted that the Care Quality Commission (CQC) will use the framework in its new inspection regime, and that NHS England will also use it as a performance management tool to be built into the NHS Outcomes Framework. And closer to home, PHSO and the LGO will use the framework to improve the way we work by integrating the vision into principles of good complaint handling.

The vision forms part of Healthwatch England’s wider programme of work on complaints, including a report which gives a series of recommendations for structural reform in complaint handling, and work to improve standards in health and social care complaints advocacy. Healthwatch England will also use the vision to support their national and local influencing work.

The collaboration of everyone working together to improve the way concerns and complaints are handled is inspiring. This is only the beginning. Over the coming period we hope that commissioners, providers, regulators and consumer groups will take the opportunity to give us feedback on the framework, consider how they will use it, and work with us on the next stages of development.

By the end of March 2015, we aim to have worked with the Department of Health Complaints Programme Board and others to develop measurement tools. These tools will enable the health and social care system to measure their impact on those wanting to raise concerns or make a complaint.

Ultimately, we want all service users to be able to say: ‘I felt confident to speak up and making my complaint was simple. I felt listened to and understood. I felt that my complaint made a difference’.

This work is the first step to making this a reality.

**Dame Julie Mellor, DBE**
Chair and Health Service Ombudsman

**Dr Jane Martin**
Local Government Ombudsman

**Anna Bradley**
Chair, Healthwatch England

November 2014
Acknowledgements

The Parliamentary and Health Service Ombudsman (PHSO), the Local Government Ombudsman (LGO) and Healthwatch England (HWE) would like to thank the researchers and authors, Dr Robin Pharoah and Alex Dark from ESRO Ltd., who undertook the primary research and analysis for this report.

We are especially grateful to all those individuals (service users and health and social care professionals) who participated in the research interviews and workshops with ESRO Ltd. – their contributions have played a significant role in understanding users’ expectations of what ‘good’ looks like when raising concerns and complaints across health and social care.

We would also like to thank the health and social care organisations who participated in the August workshops – their contributions and insights have considerably supported the development of the vision.

Lastly, we wish to acknowledge members of the Department of Health Complaints Programme Board for supporting this research.

Summary

In 2013 a Complaints Programme Board was set up by the Department of Health, following the Inquiry into the failings at Mid Staffordshire NHS Foundation Trust, the Clwyd-Hart Review into NHS complaints systems, and the Government’s response to both, Hard Truths.

As part of the Complaints Programme Board, the Parliamentary and Health Service Ombudsman (PHSO) was invited to lead the development of a vision for good complaint handling across both the health and social care sectors, in partnership with Healthwatch England (HWE) and the Local Government Ombudsman (LGO).

This report presents the vision that was created and the findings of the primary research with patients, service users, frontline staff and stakeholders that lay behind it.

The development of the vision was driven by certain key principles:
- the need for a tool that will ensure that patient and service user expectations lie at the heart of any system or approach to complaint handling;
- the need to define what the outcomes of good practice should look like for patients and service users;
- the need for a complaint handling framework that is relevant and practical for providers of both health and social care;
- the need for a set of expectations of complaint handling that make sense to patients and service users themselves, so that they can hold complaint handling services to account.

The vision as it stands, lays out a comprehensive guide to what good outcomes for patients and service users look like if complaints are handled well. It does this by presenting a series of ‘I statements’ laid out across a complaint journey. The ‘I statements’ are expressions of what patients and service users might say if their experience of making a complaint was a good one. The journey describes the different stages that patients and service users must go through when making a complaint, from initial consideration, through the communications with staff and institutions, to final reflection on the experience.

Both the ‘I statements’ and the stages of the journey were built directly from patient and service user testimony. In other words, from the first hand experiences patients and service users had had of making complaints in health and social care settings. It presents a challenge to those charged with creating policy and practice guidelines, procedures and to those who receive and handle complaints to truly recognise the complexity of the patient and service user experience, understand what the outcomes of good complaint handling should be, and consistently deliver them.
A user-led vision for raising concerns and complaints

1. Considering a complaint
   - I knew I had a right to complain
   - I was made aware of how to complain (when I first started to receive the service)
   - I understood that I could be supported to make a complaint
   - I knew for certain that my care would not be compromised by making a complaint

2. Making a complaint
   - I felt that I could have raised my concerns with any of the members of staff I dealt with
   - I was offered support to help me make my complaint
   - I was able to communicate my concerns in the way that I wanted
   - I knew that my concerns were taken seriously the very first time I raised them
   - I was able to make a complaint at a time that suited me

3. Staying informed
   - I always knew what was happening in my case
   - I felt that responses were personal to me and the specific nature of my complaint
   - I was offered the choice to keep the details of my complaint anonymous and confidential
   - I felt that the staff handling my complaint were also empowered to resolve it

4. Receiving outcomes
   - I received a resolution in a time period that was relevant to my particular case and complaint
   - I was told the outcome of my complaint in an appropriate manner, in an appropriate place, by an appropriate person
   - I felt that the outcomes I received directly addressed my complaint(s)
   - I feel that my views on the appropriate outcome had been taken into account

5. Reflecting on the experience
   - I would complain again, if I felt I needed to
   - I felt that my complaint had been handled fairly
   - I would happily advise and encourage others to make a complaint if they felt they needed to
   - I understand how complaints help to improve services
1. Why a vision is needed

The report of the Francis Inquiry into the failings at Mid Staffordshire NHS Foundation Trust was published in February 2013 and placed heavy emphasis on the need, across the NHS, for organisations to recognise the importance of patient complaints and to create robust systems and cultures that were able to deal with and learn from them.

The Clwyd-Hart Review into NHS complaints systems followed swiftly, reporting its findings later in the same year. It made a series of recommendations around how such systems and cultures might be created, in the process securing a number of ‘pledges to act’ from different organisations, including the Parliamentary and Health Service Ombudsman (PHSO). Much of the focus of these recommendations was on the need to take patients’ perspectives on complaint handling more seriously, a sentiment which very much lay at the heart of the government’s own response to the Francis Inquiry in *Hard Truths*, published November 2013.

The sub-titles of both the Clwyd-Hart report and *Hard Truths* (respectively, *Putting Patients Back in the Picture* and *The Journey to Putting Patients First*) provide the point of departure for the work here, and set the founding principle for the creation of this ‘user-led vision for raising concerns and complaints’.

The addition of the term ‘service user’ is important. Whilst the Francis and Clwyd-Hart reports both shone a spotlight on complaint handling in the NHS, the boundary between the delivery of health services and the delivery of social care services (and therefore between ‘patients’ and ‘service users’) has become increasingly blurred. National bodies such as the Care Quality Commission (CQC) and the Department of Health (DH) have oversight across both the health and social care sectors, and at a local level the focus on ‘integrated services’ has meant that health and social care professionals find themselves working more closely together than ever before. What is needed then, is a cross-sector framework for complaint handling that can be applied in a wide range of contexts; from hospital wards and GP surgeries, to residential care homes and social work appointments.

The vision for complaint handling presented here aims to respond specifically to these needs:

1) the need to ensure that patient and service user expectations lie at the heart of any system or approach to complaint handling; and
2) the need for a framework of good practice in complaint handling that is relevant to providers of both health and social care.

To these goals is added the ambition of making the vision of complaint handling of practical use to all involved. It would give patients and service users a set of questions they can ask themselves about their experience of making a complaint; frontline staff a guide to how they should be dealing with those complaints; organisational leaders a way of measuring the performance and capacities of their complaint handling system; and regulators a means of identifying good practice across different organisations.

In order to achieve these ambitions, this research and the vision framework itself have built on a pre-existing body of work. In particular: the six core principles for complaint reform formulated by Healthwatch England; the work by National Voices in developing principles for integrated care, and especially their use of ‘I statements’ which imagine what a patient or service user might be able to say if their care was being delivered in the ‘right’ (integrated) way; the tools created by the Patients Association to assess the performance of NHS trusts in relation to complaint handling; and finally the robust primary research with patients.
and service users conducted by the likes of the CQC and the consumer rights organisation Which? The vision also builds on previous work by PHSO into NHS complaint handling, the results of which can be found in the publication Designing Good Together (August 2013).

Whilst the influence of the work cited above will be immediately apparent, the vision itself (and the guidance that goes with it) was developed on the basis of unique primary research with over 100 patients and service users, and with the input of representatives (frontline, managerial and executive) from over 40 different organisations across the health and social care sectors.

2. How the vision was created

The creation of this vision for raising concerns and complaints across health and social care involved the amalgamation of many different sources of input. Primary among these was the voice and opinions of patients and service users themselves, but it is also based on several other sources including existing research, policy, and expert opinion.

2.1 Research and consultation

A scan of existing complaint handling literature (both research and policy documents) was complemented by a desk-based examination of live complaints systems in various settings including hospitals, GP surgeries, local authorities and care homes, and an exploration of best practice in the commercial sector. These sources were used to construct interview schedules and discussion guides for the phases that followed, as well as to inform the language and tone of the research and the construction of the patient and service user ‘I statements’ used throughout the vision framework.

Primary research was then conducted with over 100 patients and service users across the country. Discussions and interviews took place with pre-existing patient and service user groups where researchers attended pre-scheduled sessions. They included: diabetes outpatient support groups, cancer sufferer support groups, a teleconference group for blind and partially sighted people, and day care centres, among others.

These group discussions were supplemented by face-to-face in-depth interviews with a number of patients and service users with different kinds of complaint and service experiences.

Workshops were then held with frontline staff, complaints service managers, policy makers and executives representing a wide variety of organisations from across the health and social care sectors. In all, representatives from over 40 different organisations attended these workshops.

2.2 Language and definitions

One of the challenges in creating a vision with such a broad remit, which emerged in discussion with both frontline staff and patients and service users alike, was the definition of terms like ‘complaint’. Many argued cogently that using the word ‘complaint’ was inherently antagonistic, and that it tended to encompass everything from well intentioned, friendly comments and feedback, to serious, formal and litigious complaints and grievances.

It is recognised that the exact meaning of the term ‘complaint’ is the subject of on-going debate in the sector, and that further thought and discussion needs to take place around the best language to be used when thinking about patient/service user dialogue with health and social care organisations. Nonetheless, for the purposes of creating this vision and keeping language simple, the term ‘complaint’ has been used as shorthand for describing all of these different kinds of communication, feedback and grievance.

In most cases however, the patient and service user ‘I statements’ that follow could be easily and simply rewritten using the language of ‘feedback’ or ‘concerns’, and most would remain relevant to the ambition of listening to the concerns of patients and service users, and embedding their expectations in organisational learning processes.

‘What is needed then, is a cross-sector framework for complaint handling that can be applied in a wide range of contexts’
Similarly, the term ‘patients and service users’ has for simplicity been used in this report in the broadest possible sense. It is acknowledged that as well as those raising a concern on their own behalf, complaints within health and social care might also be made by the family, friends and carers of patients and service users; by those instructed on their behalf (including advocates); by uninstructed advocates; or indeed by worried bystanders. The expectations of these wider groups have been taken into account in the research and in constructing the vision. Family, friends, carers and worried bystanders were all explicitly included in the primary research, and their experiences were included in the analysis process described. Advocacy groups were included in stakeholder workshops and their input has directly impacted on the construction of the vision.

In the final versions of the vision statements and diagrams, we have simplified the term ‘patient and service user’ to simply ‘user’.

2.3 From expectations to ‘I statements’

Interviews and discussions with patients and service users revealed that most found it difficult to articulate generalised thoughts about what a good complaint handling service experience should look like. They found it easier to describe their own experiences and their own complaints, and then relate to where they thought things could have been done better, or where things had gone well. In other words, real life studies of complaints generated a list of outcomes, some good, some bad, in terms of how patients and service users felt about their experiences with complaint handling.

These outcomes, a series of patient and service user statements describing how they felt about different parts of their specific complaint journey, were then used to construct the positive statements of ‘what good could look like’. For example, one story involved the son of an elderly man living in a care home wanting to make a complaint to a manager about the actions of a carer. He describes trying to get in touch with the manager: ‘She did not make herself available. She never came to the ground floor where my father was. That was part of the problem’. His expectation of being able to make a complaint easily was not being met. This failing at the moment that someone is trying to make a complaint is rectified in the Vision in the following good outcome statement: ‘I felt that I could have raised my concerns with any of the members of staff I dealt with’. Were staff at the care home all available and open to his complaint, his problem would never have arisen.

2.4 Scope of the vision

The scope of the vision is to lay out what good outcomes look like from the point of view of a patient or service user who has made a complaint. It is of course recognised that complaints across health and social care are complicated, both in terms of the statutory and regulatory contexts, the potential involvement from multiple organisation and the cultural differences that apply to different types of complainant. To give specific examples, those patients and service users to whom the Mental Capacity Act 2005 and the Mental Health Act 1983 (amended 2007) specifically apply, are entitled, by law, to receive a service that meets specific standards in the event that they make a complaint. One also might want to think about a multitude of specific circumstances as they apply to different types of potential complainant, for example: children and young people who choose to self-advocate when making a complaint. In building the vision presented here however, it would have been beyond the scope of the research to fully represent every one of the myriad potential complaint scenarios that can occur, and address all of the detailed legal and technical specificities of different kinds of complaints and complainant.

Instead the vision is an attempt to build a general set of good outcomes from a patient and service user point of view, in a language that will be recognisable and useable for the vast majority (if not all) of complainants and complaint situations. It is understood that there are specific cases that demand their own kinds of outcomes and service delivery, but it is nonetheless felt that even in these cases, the good outcomes outlined in the vision’s ‘I statement’ will still have relevance.

It is also recognised that further work will need to be done to address how the vision will be applied, or adapted to apply, across different organisations within and throughout health and social care. The vision presented here has not been designed to create a set of specific standards and guidelines for implementation, and should not be taken as such.
3. The vision

The user-led vision for raising concerns and complaints in health and social care presented here has several layers. It starts with the complaint journey: a map of the route a patient or service user will go through when they make a complaint about a service they have received, and a series of simple statements that reflect what a good outcome would look like for the patient and service user at each stage of that journey. Beneath these overarching statements there are further statements that illustrate the expectations that patients and service users expressed when asked about what a good complaint journey would look like to them.

Beyond these core components, there is some guidance as to how the vision might be implemented in practice, and an introduction to different facets of implementation (environment, culture, process, and emotional) that should be considered when thinking about how to use the tool in different health and social care settings.

3.1 The complaint journey

At its heart, the vision is constructed of a series of ‘I statements’ that define a good complaint experience from the point of view of patients and service users of health and social care services. These statements have been divided across the five key stages of the ‘complaint journey’ identified during research.

1. Considering a complaint:
This stage describes the point at which patients or service users find themselves unhappy with the service they have received (or are receiving) and are considering speaking up about it. Here there are a number of factors that might determine whether or not that patient or service user will actually go on to make a complaint.

2. Making a complaint:
This stage describes the act of making a complaint. It includes a patient or service user telling a staff member how they feel face-to-face, writing a letter or email, or dialling a phone number to tell someone about their concerns. Primary research reveals that patients and service users choose many different ways of making complaints or registering dissatisfaction.

3. Staying informed:
This stage describes the complaints process, from the patient and service user point of view. For them, it is less about the specific machinations or details of a policy or system, and more about how they experience the process. More often than not, this consists of a series of communications between the complainant and the organisation or person to whom they have made the complaint. In other words, it is as much about whether and how they are being kept informed as to what is happening.

4. Receiving outcomes:
This stage describes the point at which the complainant is told about the resolution of their complaint and about actions that have been taken (or not) in response to their concerns. It is here that a patient or service user might receive a tangible demonstration that their complaint has been used to shape learning or improvement.

5. Reflecting on the experience:
The final stage takes place after the end of the complaints journey where the patient or service user reflects on the way in which their complaint has been handled. A good reflection would be that they feel confident in the system, that it worked for them and would for others too, and that they would feel willing and able to voice their concerns again.

3.2 The core statements

Accompanying each of the five stages there is a simple overarching ‘I statement’ that embodies the values of the more detailed statements outlined below. When put together, these five statements describe, in the simplest of terms, what a good complaint journey looks like from the perspective of the complainant.

‘I felt confident to speak up and making my complaint was simple. I felt listened to and understood. I feel that my complaint made a difference. I would feel confident making a complaint in the future.’

These statements present a model of good outcomes that can be easily understood by all patients and service users, as well as by staff at all levels within an organisation.
### 3.3 The vision

**Diagram 1: A user-led vision for raising concerns and complaints in health and social care**

<table>
<thead>
<tr>
<th>Stage in the complaint journey</th>
<th>‘I’ statements</th>
</tr>
</thead>
<tbody>
<tr>
<td>1. Considering making a complaint</td>
<td>‘I felt confident to speak up’</td>
</tr>
<tr>
<td>2. Making a complaint</td>
<td>‘I knew that making my complaint was simple.’</td>
</tr>
<tr>
<td>3. Staying informed</td>
<td>‘I felt listened to and understood.’</td>
</tr>
<tr>
<td>4. Receiving outcomes</td>
<td>‘I felt that my complaint made a difference.’</td>
</tr>
<tr>
<td>5. Reflecting on the experience</td>
<td>‘I feel confident making a complaint in the future.’</td>
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</table>

### 3.4 Patient and service user expectations

The following statements reflect the kinds of things that patients and service users would say if their complaint was handled well by health and social care organisations. They were drawn directly from conversations about experiences and expectations of complaints systems with patients and service users who had either made a complaint, or had considered doing so but not followed through. To some extent they are distillations of more detailed patient and service user expectations but wherever possible, the language and sentiments are those that complainants used themselves. Each statement describes the outcome, in patient and service users’ own terms, of a complaint being handled well.

The emboldened ‘I statements’ below are those considered to be essential, as opposed to desirable. Emboldening these selected ‘essential’ statements is also a pragmatic approach to support implementation. During the workshops, feedback from participants highlighted that having fewer ‘essential’ statements would assist implementation.

- I knew I had a right to complain
- I was made aware of how to complain (when I first started to receive the service)
- I knew that I could be supported to make a complaint
- I knew for certain that my care would not be compromised by making a complaint
- I felt I had the right to complain on behalf of someone else
- I was encouraged to give feedback throughout my service journey
- I knew exactly who to complain to
- I had a trusted point of contact within the organisation
- I didn’t feel that making a complaint would be tiring
- I knew that information on the outcomes of previous complaints was easy to find
- I was made aware of the importance of complaining
- I feel that the organisation is open and honest when things go wrong
- I feel that the organisation wants to make things better, and that I can help to do that
## Stage in the complaint journey

<table>
<thead>
<tr>
<th>'I' statements</th>
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<tbody>
<tr>
<td>- I felt that I could have raised my concerns with any of the members of staff I dealt with.</td>
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<tr>
<td>- I was offered support to help me make my complaint.</td>
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<tr>
<td>- I was able to communicate my concerns in the way that I wanted.</td>
</tr>
<tr>
<td>- I knew my concerns were taken seriously the very first time I raised them.</td>
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<tr>
<td>- I was able to make a complaint at a time that suited me.</td>
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<tr>
<td>- I knew where to go to complain.</td>
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<tr>
<td>- I only needed to explain the details of my complaint once.</td>
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<tr>
<td>- I was able to raise my concerns with an independent third party.</td>
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<tr>
<td>- I knew steps I needed to take were made very clear to me.</td>
</tr>
<tr>
<td>- I was able to make my complaint when it suited me.</td>
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### 2. Making a complaint

**'I felt that making my complaint was simple’**

This stage describes the act of making a complaint. It includes a patient or service user telling a staff member how they feel face-to-face, writing a letter or email, or dialling a phone number to tell someone about their concerns.

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## Stage in the complaint journey

<table>
<thead>
<tr>
<th>'I' statements</th>
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<tbody>
<tr>
<td>- I always knew what was happening in my case.</td>
</tr>
<tr>
<td>- I felt that responses were personal to me and the specific nature of my complaint.</td>
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<tr>
<td>- I was offered the choice to keep the details of my complaint anonymous and confidential.</td>
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<tr>
<td>- I felt that the staff handling my complaint were also empowered to resolve it.</td>
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<tr>
<td>- I knew that there was a formal record of my complaint.</td>
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<td>- I felt that my complaint was being taken seriously.</td>
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<td>- I was given updates about the progress of my complaint at regular intervals.</td>
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<td>- I was responded to in the manner which suited me.</td>
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<tr>
<td>- I feel that staff were proactive in dealing with my complaint and I was not asked to do more than I should.</td>
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<tr>
<td>- I felt that my concerns were understood and that staff empathised with my situation.</td>
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<tr>
<td>- I received answers to all of the questions that I asked.</td>
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<tr>
<td>- I was helped to escalate my complaint to a higher level when I needed to.</td>
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<tr>
<td>- I was asked whether I was happy with how my complaint was being handled throughout the process.</td>
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### 3. Staying informed

**'I felt listened to and understood’**

This stage describes the complaints process, from the patient and service user point of view. For them, it is less about the specific machinations or details of a policy or system, and more about how they experience the process.

More often than not, this consists of a series of communications between the complainant and the organisation or person to whom they have made the complaint.

In other words, it is about whether and how they are being kept informed as to what is happening.
### Stage in the complaint journey

<table>
<thead>
<tr>
<th>&quot;I&quot; statements</th>
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<tbody>
<tr>
<td>• I received a resolution in a time period that was relevant to my particular case and complaint</td>
</tr>
<tr>
<td>• I was told the outcome of my complaint in an appropriate manner, in an appropriate place, by an appropriate person</td>
</tr>
<tr>
<td>• I felt that the outcomes I received directly addressed my complaint(s)</td>
</tr>
<tr>
<td>• I feel that my views on the appropriate outcome had been taken into account</td>
</tr>
<tr>
<td>• I was offered support to help me understand the resolution of my complaint</td>
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<tr>
<td>• I understood exactly how decisions had been reached</td>
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<td>• I understood why actions were being taken or not taken</td>
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<tr>
<td>• I could see the difference my complaint had made (both to my own situation and/or to others)</td>
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<tr>
<td>• I was asked about my views on the outcome of my complaint</td>
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<tr>
<td>• I felt like my complaint had been taken seriously at a senior level within the organisation</td>
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</table>

### 4. Receiving outcomes

*’I feel that my complaint made a difference’*

This stage describes the point at which the complainant is told about the resolution of their complaint and about actions that have been taken (or not) in response to their concerns.

It is here that a patient or service user might receive a tangible demonstration that their complaint has been used to shape learning or improvement.

### Stage in the complaint journey

<table>
<thead>
<tr>
<th>&quot;I&quot; statements</th>
</tr>
</thead>
<tbody>
<tr>
<td>• I would complain again, if I felt I needed to</td>
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<tr>
<td>• I felt that my complaint had been handled fairly</td>
</tr>
<tr>
<td>• I would happily advise and encourage others to make a complaint if they felt they needed to</td>
</tr>
<tr>
<td>• I understand how complaints help to improve services</td>
</tr>
<tr>
<td>• I was asked for my feedback on the handling of my complaint</td>
</tr>
<tr>
<td>• I would feel confident making a complaint in the future</td>
</tr>
<tr>
<td>• I have confidence in the complaint handling procedure in the organisation</td>
</tr>
<tr>
<td>• I feel that I know how to get the most out of making a complaint</td>
</tr>
<tr>
<td>• I know how important it is to make a complaint</td>
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### 5. Reflecting on the experience

*’I would feel confident making a complaint in the future’*

The final stage takes place after the end of the complaints journey where the patient or service user reflects on the way in which their complaint has been handled. A good reflection would be that they feel confident in the system, that it worked for them and would for others too, and that they would feel willing and able to voice their concerns again.
4. Issues for implementation

By design, the vision is inherently flexible in terms of how it might be used in different contexts and by different stakeholders. Below are some thoughts and considerations, which emerged from the research, for how staff at different levels and in different organisations might think about creating real world applications and implementations.

Whilst the considerations below apply to different staff within individual organisations, the vision provides a common purpose. For example, a shared commitment or concordant could be developed. This might involve agreement for shared action around certain statements, or a commitment to share the language of user-led outcomes and expectations.

4.1 A vision for patients and service users

The vision has been built upon the direct experiences of patients and service users; therefore, it is written in language that they would use and understand within a health and social care context. This makes the vision a potentially powerful tool. Patients, service users and the public will be able to read the vision and expectations and know what to expect when they want to raise a concern or make a complaint, and so provide confidence when the organisation handles a complaint ‘right’. This will also help users, their family, friends and carers, to challenge where the organisation falls short.

It could also be given to patients and service users before they made a complaint, as a way of encouraging feedback, letting them know what they could and should expect if they did make a complaint. In practice this might involve including the framework in literature that detailed how to make a complaint, or providing it at the point of service induction e.g. in hospital waiting rooms or in hospital ward induction packs, during social care assessments or upon entry to residential care homes. Ideally, carers or friends and relatives would also receive a copy, ensuring that all who might have cause to make a complaint can do so on the same terms.

By implication, sharing the vision with patients and service users would give them the means to hold staff and organisations to account where they failed to deliver against expectations. One way of ensuring that this happened would be to create complaints experience feedback forms based on the statements. Patients and service users could be asked, for example, to what extent they agreed or disagreed that their experience of making a complaint resembled each of the statements.

The vision could also feasibly form the basis of a campaigning tool for advocacy groups. The ‘I statements’ in particular could be employed (either wholly or partly) as a set of patient or service user voiced expectations of a service.

4.2 A vision for staff on the frontline

For staff working on the frontline of service delivery or of complaint handling, the most obvious use for the vision would be as a guide to good practice when dealing with a patient or service user complaint. It could be used during staff induction or incorporated into a handbook that staff use as a point of reference when deliberating over how to handle a complaint, or reflecting after the fact on how they have handled a complaint. The power of the vision lies in its illustration of the expectations patients and service users have when making a complaint. As such it would allow frontline staff to put themselves in the shoes of their patients and clients, and understand how their handling of a complaint might look to the recipient of their service.

4.3 A vision for policy makers and managers

For those charged with overseeing complaints handlers, or with thinking about complaints management systems, the vision framework presents a number of practical opportunities. The first perhaps is to use the statements as a training tool, helping to empower the frontline to be able to deal with the expectations that patients and service users might bring with them. This idea could in fact be taken further, perhaps even considering whether to include the vision in national curricula training tools for frontline staff working in health and social care. It could be used to inform a number of different areas of staff/service user interaction training that might accompany complaint handling such as such as customer service or ‘bedside manner’.

Second, the journey framework and statements could be used as the basis for designing an organisational response to patient and service user expectations: for example, by creating a set of ‘we promise’ statements against each of the patient and service user statements. These promises, in turn, could form the basis for the design and implementation of new complaint handling systems and processes. They could even be used as a mandate for action to be put before senior managers, by frontline staff or complaint handlers and managers.

Lastly, the framework could provide a check and balance to any programme of service or business process design. Policy makers and managers could use the framework as a way of sense checking different policies and procedures against the real expectations of patients and service users. For example, when trying to design a process that is ‘simple’ or ‘transparent’, the vision could serve as a reminder as to what ‘simple’ and ‘transparent’ means for the patient and service user. As one patient put it: ‘Yes, of course I want the system to be simple. But simple for me, not necessarily for them’.

4.4 A vision for leaders in health and social care

Of course, leaders of organisations that deliver health and social care services might want to consider all of the potential implementations of the vision framework described above. Many of the managers and frontline staff consulted during the process of developing the framework spoke positively about the role that leaders can play in ensuring that patients and service users are truly placed at the heart of complaint handling processes on the ground. This was done most notably, by supporting and empowering the frontline staff to deliver services in new ways.

The vision framework should also provide leaders with a way of measuring their own organisation’s complaint handling performance and capacity. In the first instance, a simple measure of whether or not an organisation has the ability to deliver against each of the patient and service user statements. These promises should give an indication of how well it can meet patient and service user expectations. Elected members in local governments for example, could use the vision in this way to support their scrutiny of local health and social care services.

Such scrutiny could even come from external sources, and there is scope to perhaps build some sort of ‘kite mark’ for organisations that could demonstrate that they could deliver complaint handling services that met the ‘I statement’ expectations.
The vision is not prescriptive and does not make fixed recommendations as to what structures or procedures would need to be in place in order to meet each expectation. It recognises that it is difficult to prescribe a one-size-fits-all approach across such a wide range of different organisations and to meet all the different kinds of complaint and feedback that can arise.

This means that if the vision is adapted into a tool against which to measure organisational performance or capacity, there will need to be honest assessment of the ability of different processes, materials and staff to deliver an experience that would truly give rise to the positive outcomes described by the patient and service user statements.

One way of achieving this kind of honest assessment might be to use the vision as the basis for measuring patient and service user satisfaction with a service, and to identify where there may be gaps in certain aspects of service delivery that need to be addressed or filled. This could be done by designing patient and service user satisfaction forms that explored each of the stages of the complaints journey, or directly borrowed the ideal outcome for measuring patient and service user satisfaction.

Facets play different roles in the different stages of the complaints journey. For example, the environment and culture play a very strong role during the initial stages of considering and making a complaint, whilst process becomes more important during the ‘staying informed’ stage. Handling complaints well, and being able to meet all of the desired patient and service user outcomes, will involve careful consideration of each one.

The table below illustrates, against each of these facets, the kinds of considerations that might be made when addressing how well a complaint handling service delivers against patient and service user expectations of a good outcome or experience. Many of these were drawn from comments made by staff themselves (from various levels in health and social care delivery organisations) during the research and consultation process that lay behind the development of the vision.

4.5 Practical considerations: environment, culture, process and emotion

The statements generated by research with patients and service users have implications for a number of different facets of complaint handling, most notably: the physical environment and materials that contextualise the delivery of health and social care services, the organisational and institutional cultures within which a complaint might be made, the complaints processes and systems themselves, and the emotional impacts on patients and service users of making a complaint and going through a complaints process.

These facets play different roles in the different stages of the complaints journey. For example, the environment and culture play a very strong role during the initial stages of considering and making a complaint, whilst process becomes more important during the ‘staying informed’ stage. Handling complaints well, and being able to meet all of the desired patient and service user outcomes, will involve careful consideration of each one.

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<th>Facet</th>
<th>Example statement</th>
<th>Considerations</th>
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<tbody>
<tr>
<td>Environment</td>
<td>‘I was made aware of my right to complain’</td>
<td>• Is our complaints literature visible and accessible to all of our service users?</td>
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<td></td>
<td>‘I knew that information on the outcomes of previous complaints was easy to find’</td>
<td>• Are our complaints communications available in a number of formats?</td>
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<td></td>
<td>‘I was made aware of how to complain when I first started receiving the service’</td>
<td>• Do we make clear how we use complaints to improve services?</td>
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<td></td>
<td>‘I knew where to go to complain’</td>
<td>• Do we communicate our openness to receiving complaints from the moment we first receive a patient/service user?</td>
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| Culture     | ‘I was able to raise my concerns with a neutral third party’                      | • Can we ensure that those who want to make a complaint can do so privately and anonymously if they wish to? |
|             | ‘I was offered support to help me make my complaint’                             | • Do our staff all encourage people to complain, without fear for themselves? |
|             | ‘I knew for certain that my care would not be compromised by making a complaint’ | • Are our frontline staff sufficiently empowered and sufficiently knowledgeable to deal with a patient or service user who wants to make a complaint? |
|             | ‘I felt that I could have raised my concerns with any of the members of staff I dealt with’ | • How well do we communicate the importance of receiving complaints? |
|             | ‘I felt that my complaint was being taken seriously’                              | • Are we transparent about the outcomes of complaints? |
|             | ‘I felt that the staff handling my complaint were also empowered to resolve it’    | • Are all complaints handled equally and treated with equal respect and dignity? |
|             |                                                                                    | • How do we reassure patients and service users that making a complaint won’t have a negative effect on their care? |
|             |                                                                                    | • Do we rely on one person to handle complaints or can all staff be part of the complaint system? |
|             |                                                                                    | • Do those charged with governance have proper oversight of complaint handling? |
### Facet Example statement Considerations

#### Process

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<tr>
<th>Example statement</th>
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<tr>
<td>‘I was given updates about the progress of my complaint at regular intervals’</td>
<td>• Are we transparent about the way we are handling a specific complaint, or only about our processes in general?</td>
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<tr>
<td>‘I felt that responses were personal to me and the specific nature of my complaint’</td>
<td>• Do we acknowledge and address ‘attrition’ in complaints not taken to conclusion?</td>
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<tr>
<td>‘I feel that staff were proactive in dealing with my complaint and I was not asked to do more than I should’</td>
<td>• Are our responses identifiably personal to the complainant and the specifics of their complaint?</td>
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<td></td>
<td>• Do our staff have sufficient understanding of how complaints relate to safeguarding and protection systems?</td>
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<td></td>
<td>• Do we place too much burden on a complainant to produce evidence, fill in forms, or write extensive amounts of detail?</td>
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<td></td>
<td>• Are our staff able to go beyond process guidelines in order to solve specific problems?</td>
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#### Emotion

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<th>Example statement</th>
<th>Considerations</th>
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<tr>
<td>‘I feel that the organisation wants to make things better for me and others, and that I can help to do that’</td>
<td>• Do we always take account of the specific needs and conditions of the patient or service user? For example, when they are feeling unwell, or have mental health issues or physical disabilities.</td>
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<tr>
<td>‘I was told the outcome of my complaint in an appropriate manner, in an appropriate place, by an appropriate person’</td>
<td>• Do our complaints processes take account of the emotional impact of the perception of something having gone wrong in service delivery? For example, the death of a patient or the mistreatment of a loved one?</td>
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<td></td>
<td>• Are the tone and setting of our communications in keeping with the nature of the complaints being made?</td>
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<td></td>
<td>• Do we avoid exacerbating possible trauma by labelling complainants and complaints with stigmatising labels such as ‘vexatious’ or ‘complex’?</td>
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5. Background: Building the vision

As outlined briefly in Part 1 of this report, this study was originally conceived in the wake of the Mid Staffordshire NHS Foundation Trust scandal. The work aimed to do two things:

- to conduct research with patients and service users to establish their expectations of health and social care organisations when making a complaint about a service they have received, and;
- to build a vision, based on the experiences and expectations of patients and service users themselves, of what good complaint handling would look like when measured against the ideal outcomes for patients and service users themselves.

This section lays out some of the background to this piece of work, and summarises the key sources of influence and thinking behind the development of the vision.

5.1 The national context

There is a considerable amount of guidance in place regarding complaint handling procedures in health and social care, most of which is built on the statutory regulations found in The Local Authority Social Services and National Health Service Complaints (England) Regulations (2009). These are a development of the 2004 complaints reforms, which took into account suggestions from a range of reports including NHS Complaints Reform: Making Things Right (2003). Events in recent years, however, have demonstrated that regulations and complaint handling frameworks are not enough to ensure the effectiveness of raising concerns or making a complaint for a patient or service user, most notably those that took place at Mid Staffordshire NHS Foundation Trust.

The final report of the Mid Staffordshire NHS Foundation Trust Public Inquiry, led by Robert Francis QC, was published in February 2013. Whilst examining the systemic failings at the Trust, the findings of the Francis Inquiry had wider implications, calling for a ‘fundamental culture change’ and placing a strong emphasis on the notion that ‘patients must be the first priority of all that the NHS does’. And part of this call to make patients the priority, involved reiteration of the importance of addressing complaints well so as to ensure that patients’ needs are being met, and so that they could be used as a tool for organisational improvement. Of the 290 recommendations made by the Francis Inquiry, 14 relate directly to effective complaint handling.

The Government’s initial response, Patients First and Foremost, was issued in March 2013. It contains a statement of common purpose in which a number of organisations pledged to learn from the failings at the Mid Staffordshire NHS Foundation Trust and put the patient at the heart of everything that they do.

The review led by Ann Clwyd MP and Professor Tricia Hart was one of six independent reviews that were also subsequently commissioned to address some of the key points raised by the Francis Inquiry. Their report, A Review of the NHS Hospitals Complaints System: Putting Patients Back in the Picture, published in October 2013, was an exploration of current and best practice and an attempt to ensure that complaints in the NHS are handled positively rather than defensively, and taken as a means toward improved patient experience rather than a criticism or irritation.

The official Government response to the Francis Inquiry, incorporating findings from the six independent reviews, including Clwyd and Hart’s, was published in January 2014 as Hard Truths: The Journey to Putting Patients First. Within this, Annex D is a direct engagement with the Clwyd-Hart review, where the Government presents a series of changes that they want to see in NHS complaint handling so that systems effectively address the needs of the patient. These took the form of recommendations and calls for local and national actions, one of which was a pledge from the Parliamentary and Health Service Ombudsman (PHSO) and Healthwatch England (HWE), along with the Department of Health (DH), to ‘develop a patient-led vision and expectations for complaint handling in the NHS’.

The addition of the term ‘service user’ to the vision is an important one. Following Francis, the Clwyd-Hart report focused on acute hospitals, but they also took on board evidence from, and about, other care providers, and felt that their reflections and comments could equally be of relevance in other care settings. In practice, the delivery of health services and the delivery of social care services are becoming increasingly merged. The emphasis on ‘integrated services’ has meant that health and social care professionals are working more closely together than ever before, whilst at a national level bodies such as the Quality Care Commission (CQC) and the DH have oversight across both sectors. A vision for complaint handling that doesn’t reflect the move toward integrated care risks failing to capture the reality of patient and service user experiences, which is why this aspires to be as applicable to a hospital ward or GP’s surgery as it is to a care worker visiting a private home or a social work appointment.

With this in mind the Local Government Ombudsman (LGO) has been involved in creating this vision. As social care ombudsmen they are able to look at complaints about publicly and privately funded and arranged social care, and advise on the role that complaints play in this developing sector.

5.2 Previous work on complaint handling

There has been no shortage of work on what constitutes good complaint handling. The Principles of Good Complaint Handling, published by PHSO in November 2008, laid out six guidelines for good complaint handling in public bodies. Under each guideline are examples of best practice, designed to be applied by individual organisations in such a way that best suits their own purposes. These principles form the core of PHSO’s position on effective complaint handling throughout subsequent publications, as well as being adopted by other organisations.

PHSO has increasingly been aware that effective complaint handling should focus on outcomes for patients and service users rather than on the process itself. In April 2013 they published The NHS Hospital Complaints System. A case for urgent treatment?, which began to explore complaint handling from the perspective of the patient experience journey, drawing lessons from analysis of cases brought to them over the proceeding five years. The report concludes with suggestions for changes that could be made on both within individual organisations and on a systemic level.

In Designing Good Together (2013) PHSO commissioned a collaborative workshop involving staff and patients to attempt to develop an understanding of opinions on the current complaints process and move toward a shared model of good complaint handling. They continued previous work in dividing the complaint handling process into a user journey, providing a picture of what ‘good practice’ might look like at each stage.
For Healthwatch England (HWE) the emphasis has been on the consumer's right to complain. In a report on the current state of complaint handling, launched at their first annual conference in June 2013, HWE put forward a compelling case (in the voice of patients and service users) that the complaints system is ‘simply not good enough’ to meet the expectations that patients have. In November of the same year they published Improving the health and social care complaints systems, which outlines six core principles for complaint reform in health and social care.

Takingsimilar vantage point, the Patients Association (PA) has been consistent in representing the interests of the patient, and their 12 standards of good complaint handling, generated from the findings of a peer review panel, were endorsed by the Francis Inquiry as guidance for best practice in the NHS. In their Good practice standards for NHS Complaint handling (2013) the PA build on PHSO's Principles of Good Complaint Handling to develop a set of 12 practical standards to ensure that complaints are handled according to good practice. Eight of these are designed to be used by any NHS organisation that has to handle formal complaints, and form a basis by which practice can be measured and evaluated. The last four are organisational standards designed to be adopted at a higher level and relate to the overall performance of the complaint handling process and how lessons are learned from it within an organisation. Whilst the Patients Association's standards (September 2013) form a useful means of evaluating a complaints process, they are distinct from the aims in developing this vision, which is concerned less with process and more with positive outcome from the patient and service user perspective.

A integral tenet of the vision is an acknowledgement that improvements to complaint handling systems do not necessarily fully address patients and services users’ expectations. A 2012 survey for PHSO, What People Think About Complaining, explored experiences of complaining. It addressed issues such as the demographics more or less likely to make a formal complaint, and general barriers to complaining. From this, lessons were drawn about ways in which people might be helped to overcome these barriers.

Similarly, research by the Care Quality Commission (CQC) Fear of raising concerns about care (April 2013) looks at why people might not raise concerns about their experience of services in the health and social care sector. In a survey of over 1000 respondents, there was a strong demonstration that a more open and supportive culture is needed surrounding complaints and concerns, rather than reform of the systems per se for handling complaints.

In the social care sector, the Local Government Ombudsman (LGO) has conducted research into complaint handling in adult social care, such as the 2011 Complaints about privately funded and privately arranged adult social care, that reflect the changing provision and delivery of social care, and the way it can impact on service users ability to, and likelihood of, making a complaint. In the same year they published Aiming for the best – using lessons from complaints to improve public services, which emphasised the opportunity that complaints can provide to help improve service delivery by social care providers.

Significantly for the viewpoint of the vision, National Voices undertook a piece of work looking at the patient experience of integrated care. In a paper for the NHS Future Forum they point out that ‘care is care’ for those that use it, and that in the realm of patient and service user experience, the distinction between health care and social care is essentially meaningless. As well as this move toward joined up thinking in health and social care, they also presented a set of ‘I Statements’ - first person perspective statements drawn from their Principles for Integrated Care (2011) - that describe good service integration from the perspective of the patient or service user. Whilst not founded in actual patient and service user experiences, the approach and presentation ensures that the patient is foremost, and their work played a part in influencing the construction of the vision outlined above.

5.3 Looking beyond the literature
In order to see how the various guidelines and principles discussed above worked in practice, the websites of different health and care providers were visited, their policy documents on complaints procedures examined, and in some cases telephone calls made to the relevant departments. For further context and comparison, examples of best practice in complaint handling in consumer organisations outside of health and social care were also reviewed. Here, in the commercial world, there was found to be a far greater emphasis on the use of friendly and familiar tones to communicate with consumers, and less obvious (or publicly stated) adherence to procedural guidelines. It served to remind that whilst there is an obvious need for the regulatory framework that underpins complaints procedures, there are lessons that can be learnt in terms of how organisations might best communicate or build dialogue with their clients and users.

That said, even in the live health and social care contexts examined, it was generally found that complaints procedures were easily accessible, clearly written and well signposted. With a few exceptions (often smaller organisations such as GPs' surgeries), process and procedures adhered to statutory regulations and closely resembled, in word at least, best practice. They were also generally easy to find, and laid out in reasonably simple terms, on websites especially. That patients and service users remain dissatisfied with the way in which complaints are handled in spite of these facts, provides an obvious point of departure for the primary research conducted with patients and service users. It was clearly necessary to look beyond process and procedure, and into the actual lived experiences of patients and service users.
6. Findings from qualitative research

This section reports the findings of the qualitative research, which aimed to explore the views of patients and service users on the requirements of a complaints framework, test standard concepts and the different ways service users could describe and evaluate their involvement in making complaints. The complaints handling vision set out above, and the guidance that goes with it, was developed on the basis of this primary research with over 100 patients and service users, and with the input of representatives (frontline, managerial and executive) from over 40 different organisations across the health and social care sectors. A more detailed outline of the methods used is contained in Appendix B.

To say that the stories of making, or failing to make, complaints that were collected throughout primary research with patients and service users (and their carers and friends and relatives) were diverse, would be to underestimate the case. Different people in different contexts offered a wide array of opinions, reflections and expectations, and experienced a wide range of different outcomes, as the next sections of the report show.

Note on language:
The term ‘outcome’ here, refers not only to the specific outcomes of individual complaint cases, but rather to the impact on patients and service users of making a complaint and of the ways in which it was handled. In other words, if a complaint was handled badly then the ‘outcome’ that referred to is a poor one, regardless of the complainant’s subsequent level of satisfaction with the specific resolution to their complaint. This is because in the event of a complaint being handled badly, the complainant is unlikely to reflect positively on their experience, and is unlikely to relish the prospect of making a complaint in the future.

6.1 Experiences and expectations of complaint handling

Complaints came in all shapes and sizes. Some had led to litigation, others an angry exchange of words or letters, and others no more than a raised eyebrow. Some complaints had been resolved instantly; others had taken months and years.

Some complainants had almost professionalised themselves in order to achieve desired outcomes; other (potential) complainants were too shy or fearful to ever make a public or formal complaint at all. Some people sought retribution; some wanted compensation. Some wanted system wide (or even governmental) change; others wanted no more than a letter of acknowledgement, or the simple right to let off steam. For some, the experience had been positive, leaving them happy with, for example, the efficiency of the system or the attitude of key staff; others were deeply dissatisfied, left feeling that their complaints had made no difference to themselves or anyone else: ‘What’s the point of complaining if it’s not going to make any difference?’

And all of the different experiences encountered with them different sets of expectations, many flatly contradictory: ‘If only someone had listened in the first place. I would never have had to involve anyone’s managers or bosses. No matter how small my feedback, I expect it to be taken seriously by senior staff and not just left to the nurses to deal with’.

One way of tackling this diversity of experiences and expectations is to try and understand the different factors that people took into consideration when making a complaint.

The examples and case studies that appear below are anonymous, and all names have been changed.

Considering a complaint: whether to complain or not?

For many, the issue of whether to complain or not is as far as they ever get. Even in the face of dreadful experiences, some simply do not want to raise their voice.

For John, a single man in his early 60s, a cancer diagnosis had left him so lacking in confidence, that when he wanted to complain about the way in which treatment pathways had been offered to him, he simply did not have the ‘fight’ in him to do so: ‘At the time I wasn’t in the right frame of mind to make a formal complaint. I had gone from competent to a gibbering wreck after being diagnosed’. In fact, it took sessions with a counsellor before John was able to even describe what had happened to him and why he had been left so traumatised by the way in which his consultant had spoken to him.

‘You get worried that you may be victimised even more for making a complaint. You are very vulnerable in this situation’

Evan (43), cancer patient

Others similarly spoke of being too tired, busy or traumatised at the point at which a need to complain might have arisen, to be able to, or willing to, make a complaint: ‘I just gave up in the end. You’ve got other priorities haven’t you, when you’ve got a newborn,’ explained one new mother. And this could affect even those who may outwardly seem strong. In one group, for example, an ex-police man now suffering from multiple sclerosis, described a carer in his own home: ‘She had a terrible manner. Very unfriendly. She treated me very badly. I wanted to complain, but I’d have upset myself even more if I had pushed it’.

For some (and as has been documented at length by other research) the fear of stigma, negative impact on care and even of retribution, stopped them from voicing concerns. This was particularly noticeable in those cases in which someone had wanted to make a complaint about a specific person. One cancer patient, Evan, felt that he had been spoken to insensitively on account of his sexuality, but: ‘You get worried that you may be victimised even more for making a complaint. You are very vulnerable in this situation. […] Look, every...
complaint you make is spread throughout the hospital. Complaining is risky - it makes you even more vulnerable than you already are.

Although perhaps an extreme view, Evan’s fear was not uncommon. Nils, who had recently begun legal proceedings against a hospital for the way in which they handled the diagnosis and treatment of a brain tumour, spoke in similar terms: ‘I was worried about retribution. The people at PALS reassured me that this wouldn’t happen but I had a gut feeling. I think good people work at the hospital, but this is human nature’.

Less dramatically, for others, the idea of complaining or even of offering feedback was simply not something they had ever considered. Comments like, ‘I just don’t think I am the type of person to complain. Stiff upper lip and all that’ were not uncommon. This unwillingness to complain, might be put down to the peculiarities of British culture, but they also perhaps suggest that people are not finding themselves in an environment in which complaint or feedback is encouraged. This idea was reflected in comments respondents made about dealing with a ‘closed shop’ when it came to complaints. They seemed to suggest that organisations would close rank, deflect complaints into long-winded processes, or ultimately ignore the views of the complainant. ‘It was too much hassle to complain. I just thought I’d let it go. I didn’t think anything would be done about it anyway,’ said one woman, despite having had an experience which scared her during her antenatal care, and being encouraged by a health visitor to make a complaint in writing.

This lack of faith in the idea that complaints could make a difference was expressed by many patients and service users in relation to multiple contexts, often with vague accusations of conspiracy, closed ranks or commercial self-interest. One man who wanted to complain about the drugs that were being prescribed by a GP for example, spoke of giving up on the idea after realising that he could only make a complaint to the GP himself, or to a practice manager who he felt would back the GP’s case for using cheaper drugs. In another case, when asked if she had considered going to PALS for help, one woman said bluntly: ‘PALS are just working for them. They are all employed out of the same pot aren’t they? They aren’t working for me’. And in another, a man considering a complaint about a local care provider in relation to his elderly mother’s in-home care service complained: ‘I could speak to the council about it – but the whole point of privatising care is to make them unaccountable, isn’t it?’ Political discussions on accountability and responsibility aside, the unwillingness to make a complaint was evident.

Perhaps more worryingly still was the fact that some simply did not see themselves as having any right to complain at all. Amina, a Bangladeshi woman living in East London, simply didn’t see herself as being in any position to complain to her GP or to the community mental health team she was involved with. As she said: ‘They are doctors and nurses. They are professionals. They know what they are doing. Who am I?’

All of the situations described above indicate barriers to complaint that would need significant efforts to overcome. But there are also those for whom complaining seems trivial, or irrelevant. Linda, a registered blind woman in her 60s, had gone to a large hospital to visit her husband who was recovering from major surgery. When she arrived, she went to the front desk receptionist and asked where to go. She was told that she was in the wrong part of the hospital, and that she would have to take a bus. The receptionist then left the desk. Linda found herself standing in a busy hallway, with no clear idea of where to go to get the bus, or how to hail it even if it did come. She managed to grab the arm of nearby porter, who told her where to go to get the bus, but simply described a series of signs and corridors, none of which she could see clearly. Again, the porter left her alone. Linda was distressed, but eventually found her way: ‘I never thought to complain. It seemed a trivial matter. And by the time I found my husband... well it was over with. Nothing could be done about it. I would never have even thought about it if you hadn’t asked about it’. This issue of a complaint ‘passing its sell-by date’ (as one respondent put it), or seeming more trivial over time, is a significant barrier to complaining or providing feedback, especially over issues that patients or service users themselves see as trivial. Often the issue is that mentioning it after the fact seems both pointless and unnecessarily time-consuming.

Perhaps because of this inherent reticence from some, it is understandable that many people spoken to during the research had either made a complaint on behalf of someone else (often a loved one who felt vulnerable), or had been encouraged to make a complaint by someone else (sometimes by a formal advocacy service, but more often than not by a care provider like a nurse, GP, carer, etcetera). There seemed to be two key motives here. First, for those who had made complaints on behalf of others, there was concern that there were people who would struggle to make a complaint themselves or are perceived as being vulnerable. As one son of an elderly father suffering from MS and living in a care home put it: ‘He is a sitting duck – vulnerable’. And second, professional service providers sometimes felt that patients and service users were unaware that a complaint could make a difference either for themselves or others in the future, and had therefore gone out of their way to encourage a complaint to be made: ‘It was the counsellor who wanted me to make a complaint. He encouraged me to put it all down in writing. He said that it wasn’t acceptable and that I had a responsibility to stop it happening again’.

Of course there are those that have no problem making a complaint, and are likely to do so whenever faced with a situation that raises their concern. They do so in many different ways. Some complain straight away, and directly to the members of staff involved. Others prefer to wait, and deliver critique or complaints in writing. For some, the complaint is a considered action. They will spend time thinking about who to complain to and how. For others it is about letting off steam and they will complain to whoever is around at the time. The considerations that people go through when they finally do make a complaint are dealt with below.

Throughout the research with patients and service users however, it became very clear that this initial consideration of whether to make a complaint or not was one of the more critical moments in the complaints journey. Whilst support sometimes could be found, and there were many stories of staff, friends and relatives encouraging people to make a complaint, it was also true that, as with Linda, many potential complaints never happened. Some of these ‘missed complaints’ were minor, others more serious, but each perhaps represented a missed opportunity for the relevant organisation to learn from the patient or service user experience...
of their service. What is important is that no matter how efficiently or effectively designed a complaints process, policy or guideline is, it will make no difference if the environment and culture discourages people from making a complaint or raising a concern in the first place.

Different types of complaint: culture and semantics

In speaking to different types of people, hearing about the variety of different service experience they had had and the different kinds of issues that they had raised, one discussion that emerged was about trying to define exactly what a complaint was.

For some, the language of complaints should only be used when a formal written complaint has been made to a senior member of staff. For others, the term was adequate for covering everything from feedback or constructive comments will simply be referred to as ‘complaints’ in order to make the report readable. Furthermore, the vision itself outlined at the beginning of the report also uses the language of ‘complaints’ in this all-encompassing sense. It is important to remember that despite being phrased in the language of ‘complaints’, the vision, and especially the ‘I statements’, were constructed very much with the inclusion of less formal ways of raising suggestions or concerns less alongside more serious complaints.

These vastly different types of ‘feedback’ and ‘complaint’, and the choice to include them when constructing the vision for complaint handling, gives one very clear indication as to why this report has steered away from prescribing complaint handling process standards. Patients and service users bring more than one type of expectation to the process. And as will be demonstrated, there is more than just one way to reach the kinds of outcomes that patients and service users desire.

What is being complained about?

‘It’s often systems that fail. Not staff failure. I feel like my complaint was really at the government as much as anything else’

‘I didn’t want to get her [a carer in a residential care home] in trouble. It’s not her fault’.

‘The staff were doing as much as they could with the resources they had. The person who needed to take notice was their manager. And when I found out that he didn’t have the power to change things, then apologised for bringing it to him and went to the chief executive’.

‘He was rude. Rude to me. Rude to my partner. Rude to the nurses’.

‘I didn’t need any formal replies, or letters. I just wanted that carer taken out of my father’s house’.

What the quotes above illustrate is that many of those spoken to during the course of this research were very well aware that they had considered or had made complaints about different things. One respondent, a heart patient who had also suffered with cancer for many years expressed this particularly clearly: ‘Look, sometimes you are complaining about the system’. This might be about resourcing, or over burdening bloody bureaucracy. At other times you might be complaining about a person or about something that’s happened; an incident.

This distinction between complaints about the ‘system’, a ‘person’ and an ‘incident’ is useful. The specific object of a complaint was often a large influencing factor in determining people’s expectations of the ways in which complaints should be both handled, and resolved. For example, the desire for anonymity, and the expectation of being able to make a complaint confidentially came through far more strongly when a complaint was being made about a specific person, than when a complaint was being made about a system.
fact, many felt as strongly that ‘system’ complaints should be public, as felt strongly that ‘personal’ complaints should remain private.

To give an example, Phillip, an elderly patient who had spent a six week period in recovery from an operation on a Nightingale ward, told of being kept up all night by distressed patients shouting. This, he felt, was unacceptable on a ward containing patients who were recovering from major surgery. Together with a group of other patients who felt similarly, Phillip organised a joint complaint. First they went to the matron of the ward, who explained that there was very little she could do about it, and after various other steps they finally wrote a letter to the chief executive, copying in as many stakeholder bodies as they could think of, including the local press. All of the group were happy to be signatories to the letter. Phillip explained, that in reality, he understood that very little could be done about this specific ward, but that making a public statement might make some difference to ‘those that matter’.

He expected no more (and no less) than a public acknowledgement of the systemic problem, from the chief executive.

Phillip’s story was in marked contrast to many others, who described being fearful of making a public complaint: of their name being recorded; or of confronting certain people in order to make their complaint. Another patient who wanted to complain about the quality of her treatment declining in the hands of a locum doctor, for example, said: ‘I wanted to complain to my GP, because they were having so many locums in. I queried it with the receptionist who said I would have to put it in writing to the practice manager. Well I didn’t want to do that, because I didn’t want it to affect me’. Her expectation that she could make her comment anonymously, and still be taken seriously had not been met.

I wasn’t complaining about the hospital’s care of me… I was complaining about the consultant. And it wasn’t the place that had the problem. It was him. He’s now taken the problem out of the place, himself. And probably taken it somewhere else!

On the other hand, Simon, who had cause to complain about the management of a care home in which his elderly father was living, felt that a six-month complaint handling process (which was actually longer than the timescale in the case described above) was an appropriate time in which to look into management and systemic failures: ‘I do think the process happened fast enough. The specific trigger incident happened just before Christmas 2011, and the final meeting happened in June or July of the same year – so that is relatively quick! Don’t you think?’

So the expectations of timing and action can differ significantly depending on the nature of the complaint. What seemed to be important was that the complaint was handled in a way appropriate to its specific nature. And there were many who noted that though they had had verbal or printed information about the complaints procedure for their case that by no means meant it was appropriate. As one person put it: ‘I read that their principle for complaint handling was that it should be simple. That’s all well and good. But simple for who? Me or them?’

When is the complaint being made?

The effects of ill health or vulnerability that may prevent patients and service users from complaining at what might seem, from the service provider point of view, the best time for them to complain, have already been mentioned. But what also emerged as important was how a consideration of when to complain affected expectations of how a complaint is handled.

Broadly speaking, two main time frames emerged from the research in terms of when a complaint might be made:

1. in the moment (while receipt of the service is ongoing)
2. afterwards (post care or when a particular service has ended).

As noted, for some, the only option may be to wait until they have stopped receiving the service to make any complaint they have. Many of the cancer patients, for example, said that during chemotherapy it was almost never an option to raise a complaint, due to the physical and mental toll of the treatment itself. But other factors also influenced choice of timing around complaints. For some, it was simply inconvenient to make a complaint at a certain time, but others felt it was better to wait and put more energy into a complaint when there was sufficient time and resource to do so, outside the immediacy of receiving treatment or care services: ‘I prefer to consider things and then put it in writing. Also, you may not be complaining to the right person if you just go in all guns blazing’. Of course for others, complaining at the very moment that they have a concern is a matter of principle: ‘Yes. It is my right to complain. And if I think something is wrong, I am not going to hold back!’ For others the moment of complaint is determined more by emotion than any rational consideration: ‘I just went ballistic, and stormed down there!’

Often, when people were making complaints about individuals, they wanted fast actions. These cases were amongst the most likely in the sample to express dissatisfaction with the way complaints were handled. Where complaints were being made about something that had already happened, and could no longer be changed, or about overarching systemic problems, complainants expected issues to be taken seriously and addressed, but the time consideration became less important, and the necessity for immediate action likewise.

For example, one man who had made, as he described it, a ‘formal complaint against a consultant’, spoke of the frustration he felt at the length of time the process had taken: ‘Look my worry now is that by the time they get round to resolving my case, the staff will all be completely different in the unit. He [the consultant] has already moved on. What is the point any more? What are they trying to fix? I keep receiving letters relating to “my care” at “such and such place”… but
The important thing to recognize is that the moment of complaint is significant for the complainant’s expectations. A good example of this arose in relation to someone in receipt of multiple services from his local authority, as well as from mental health professionals. He was struggling to cope with the impact of various different assessments on his housing and income, which upset him very much. He complained many times verbally, and had been given many different appointments, but felt that no one truly took account of the immediacy of his problem. The longer he waited for appointments the worse his situation became. His problem was eventually resolved, but neither process nor adherence to guidelines had provided a resolution in a timescale relevant to him. He said, however, that had he then made a further complaint about the way his case was handled (something he was actively considering), the timescale would no longer have been so relevant.

Expectations around timing also arose where complainants expected to have to do something themselves to change a service, such as providing information or taking phone calls. The perceived burden of having to speak to professionals seemed reduced by the fact that the complaint was being addressed immediately. On the other hand, those who had finished with the services wanted less disruption, especially once nothing for them could be changed. One young mother had suffered a traumatic childbirth only to be, she felt, ‘abused’ by an unsympathetic Health Care Assistant on the ward during the night. Her midwives encouraged her to complain in writing, but by the time she felt able to do so, the ordeal was over and she felt complaining was not going to change what had happened.

How is a complaint being made?

The research confirmed what is already well known to complaint handlers, that patients and service users employ a variety of different ways to communicate their concerns. Some raise issues face-to-face (with more or less volume); others prefer to use the telephone, or email. One respondent still preferred to fax, so that his signature was very clearly present. Others didn’t like to register a complaint at all and would rather use an advocacy service of some kind or have someone else make a complaint on their behalf.

For someone like Amina (mentioned above), the question of how to make the complaint was critical. Though she said she preferred to write things down, she also confessed that she didn’t have the confidence to write to someone professional. Nor did she want to complain face-to-face to the object of her complaint; or his/her colleagues. What she wanted was to be able to go to a very clearly identified and signalled third party. In other words, she almost imagined a doorway bearing a large sign saying, ‘Make your complaint here’.

For others, only written letters were appropriate; a message that is reinforced by some service providers themselves. Their literature often encourages people to make ‘a formal complaint’ only in ‘written’ form: ‘It’s more formal isn’t it. I would expect them to take my letter more seriously than if I had sent an email…The phone is no good. Once you put down a phone, the conversation is gone away. What record do I have that anything has happened?’

On the other hand, whilst writing things down had a symbolic value and seemed to elevate a complaint to a more ‘serious’ level, there had often been attempts to address concerns over the phone preceding any letters or email: ‘Well I phoned them several times and asked them to sort the problem out’. Or, ‘The care home company, whatever they’re called, they must have a call centre. They were useless. I don’t have time to write letters. I just needed to speak to the right person. It was impossible’. Or ‘I told the receptionist/secretary/administrator over the phone’.

There are clear implications from these findings for the creation of complaints channels. The method of complaint actually changed the expectations people had of how the complaint should be handled. Complaints made over the phone were often expected to be handled immediately, without ‘procedure’ and by a specific person. Complaints made in writing invited the term ‘formal’ and respondents immediately started to raise expectations of formal procedure, formal responses, written replies and signatures from senior members of staff.

‘As soon as you write something down that’s it isn’t it. If they don’t take it seriously then… and by that I mean… seriously putting some effort into thinking about what you’ve said, and coming back and talking to you… then what use is any system at all?’

Who is the complaint being made to?

Expectations of who should handle complaints also differed. Some felt that complaints should get the attention of chief executives; others felt this was both unrealistic and unnecessary. ‘Give me the organ grinder not one of the monkeys’. With that phrase, one respondent summed up the views of many who felt that there was simply no point in complaining to frontline staff: ‘They’re not the ones causing the problem’. ‘Look I have a lot of sympathy for the carers; they leave early because they have to go halfway across the county for their next appointment. It’s not their fault’. ‘If I am going to the trouble of making a complaint; I want something done. It’s a letter and it’s going straight to the chief executive’.

On the other hand, there were those who didn’t want to make too much of a fuss and really didn’t want to involve senior executives: ‘If you want something done, just speak to the person then and there. Some people take themselves too seriously. Say something quickly and problems usually get sorted’.

In each case, however, examples of disappointed expectations about who should have responded to a complaint were heard. For example, one man had written a letter to a department manager to complain about the appointments procedure, and had been put directly in touch with the person responsible for the failings who apologised personally: ‘Well she said she was sorry. And that’s all well and good. But I felt it was more serious than that. I don’t for a moment believe I was the only person being passed from pillar to post, and I don’t believe that the difficulty in getting decent appointment times was down to that lady. I had written to the manager; raising my concern. It was him who should have written back! Well he did write, but not much, and it is him who should have phoned me to apologise!’
On the other hand, another respondent said: ‘I would try to sort it out in situ... It was a problem on a ward. I would have tried to sort it out there and then. Why did she [matron] feel the need to send it up?"

It was also found, among those who had made complaints, that there was a reasonably good understanding that they could make complaints at different levels if need be. The level to which a complaint was addressed reflected either the level at which patients and service users felt the problem could be resolved, or the level appropriate to how serious they felt their complaint was. And with each level came a different set of expectations. Not all of these expectations were ‘demanding’ as such. Many were shot through with sympathy. Most respondents did not expect chief executives personally to spend their time writing letters and investigating, but neither did they expect nurses and carers to take responsibility for systemic failure. They wanted letters and lists of actions from managers, verbal apologies from frontline staff, and acknowledgements from senior staff.

How serious is the complaint? And what is appropriate to complain about?

The question of how serious is any given complaint, partly because they did not know themselves how serious their issue was: ‘Mine is sort of half a complaint, half a comment. Just some ideas really. Is that even a complaint?’. ‘Look I don’t even know what is appropriate. Is it appropriate to write a letter over this? Should I just speak to someone? Problem is that I don’t know who to speak to’.

These comments reflected a general call for more knowledge about complaints. Many expressed the desire to know more about how their concerns and complaints fitted into the overall picture, for example. Was theirs more or less serious than other people’s? And who should they expect to take notice of their specific issue? Many couched their uncertainty in terms of ‘appropriateness’. They wanted to know what was ‘appropriate’ to complain about. Serious things were obvious, but what about little things? And what means of making a complaint were ‘appropriate’ to the level of complaint they were making? A suggestion in a suggestion box? A phone call? A letter to the chief executive? They also wanted to know what were the appropriate levels of expectation they should have about when they should receive a response, and from whom? All of these discussions of appropriateness seemed to stem from the vital question of how serious a complaint should be deemed to be.

If patients and service users themselves cannot judge the seriousness of a complaint and set their own level of expectation of a complaint handling system or service, it is very difficult to determine how to construct a service for them that would meet expectations. Two obvious solutions suggest themselves: i) to make sure that complainants are better informed about how previous complaints were handled, and ii) to provide a set of expectations to patients and service users that they can use as a reference.

Many respondents talked of the need for some kind of third party to decide on the level of seriousness of any given complaint, partly because they did not know themselves how serious their issue was: ‘Mine is sort of half a complaint, half a comment. Just some ideas really. Is that even a complaint?’. ‘Look I don’t even know what is appropriate. Is it appropriate to write a letter over this? Should I just speak to someone? Problem is that I don’t know who to speak to’.

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Expectations and experiences of complaint outcomes

While this report is more concerned with how complaints are handled than with their specific outcomes, which can vary enormously, to the patient or service user, the notification of their complaint outcome is the point at which they are most likely to deem the process a success or failure. This is not to say that a complainant will only be happy if they have received their desired outcome, but rather that the way in which the news is delivered, along with any explanations and rationales and the specific details of the outcome, will all influence a complainant’s judgement of the way their complaint was handled.

In Simon’s case, involving a complaint to a care home escalated to the local authority, the complaint handling experience was largely positive and he was impressed. But though this was a positive outcome, he was not happy with the resolution of the case and the resulting action which removed someone from her job. This was inappropriate in his view since he felt the responsibility for an injury sustained by his father lay with the management for putting staff under too much pressure. In this situation, the way in which Simon received the outcome is likely to give him confidence to complain again, despite his differing views over what actions should have been taken. In other stories, complaint resolutions and the ways in which they were presented, were more aligned.

In general, people spoke about how complaints and ‘cases’ were ‘resolved’, and for most, a good experience of being given complaint outcomes, was one in which they felt that the final communication resolved outstanding issues: ‘I received a letter. And the letter used the same numbered point as the ones that I had sent to them, so I knew they had addressed each one. That is a good letter’. Letters were very often the end to the matter but outcomes were delivered in other ways too. Phone calls were more likely to result in people feeling a little ‘hard done by’, in terms of how they were dealt with, especially where there had been some kind of process or back and forth over their complaint: ‘They tried to fob me off on the phone I wanted it down in writing’. But phone calls were seen as appropriate in shorter cases or when issues were not seen to be as serious.

The most important consideration for most was that the delivery of the complaint resolution should be appropriate to the complaint itself, and the resolution that is being offered. For example, one man who had been fearful of complaining to a doctor face-to-face was offered the chance to have an arbitrated meeting with that same doctor. When he declined, he was told that there may be no other way to truly resolve the issue. This upset him greatly as he felt that the only way to reach an outcome was to do what he least wanted. Others however, relished the chance of a face-to-face meeting, especially with more senior staff, believing that this was a sign that they could have a direct impact on the outcome of their complaint: ‘I think it was right for them to invite me in. They needed to hear my side of the story before they could act’.

The idea of a ‘appropriateness’ was raised time and again by respondents: ‘The whole of the complaint had been done in writing (emails really) with the manager at the area team centre, not with the local team manager woman who answered the phone to me and gave me the information I wasn’t happy with. So it wasn’t right or appropriate that she should be the one to get back to me about it. She wrote me an email saying what they were going to do, and why it wouldn’t happen again, but I wrote straight back to the area manager, with her copied in, saying that I wanted a formal letter from the company itself promising that it wouldn’t happen again to anyone – not just me. And that all their staff would be trained so it couldn’t happen again... I am still waiting for a reply’.
For others, appropriate delivery of messages is about being sensitive to the circumstances around the complaint or to the specific requirements and needs of the individual making the complaint. Was there an untimely death? Is someone in ill health? Does the person making a complaint have a disability which makes it hard for them to receive certain types of messages? Is a letter appropriate for a blind person, for example? Or should a message be recorded and sent via audio? And at a very mundane level, some spoke of being asked to attend meetings, or receiving phone calls, during working hours, rather than at times when they might be free to deal with the matter. Appropriateness works on many levels.

My expectations for raising concerns and complaints

6.2 Understanding the diversity of experience and expectation

The findings from the qualitative research outlined above illustrate the huge diversity of views and individual meanings attached to various key components in the experience of complaints and their handling. Differences in the expectations people may have for the ways in which complaints are handled are driven by the ways in which they evaluate a number of different variables, from the question of who they should complain to, to the seriousness of their complaint, and what form they should make the complaint in.

To some extent, these different variables could be understood and potentially modelled as a ‘decision tree’ or ‘decision matrix’, with each ‘choice’ that the complainant makes having an impact on their expectations for the way in which the complaint should be handled.

Diagram 2: The complaint variables decision tree

The diagram above shows the main variables that a complainant is likely to consider when they make a complaint or offer feedback. Under each of the headline variables, there are choices, or directions, each of which carries with it a different set of expectations.

For example, the first variable ‘Should I?’ has two possible routes:

1) a decision to complain
2) a decision not to complain

It might also involve discussing the decision with various stakeholders. This will be closely followed by consideration of the ‘type’ of feedback or complaint to make, for example a comment, or a suggestion, an offer of feedback, raising of a concern, a complaint, etcetera?

Each relevant variable could be unpacked in the same way. The diagrams below show two further examples. They are simple summaries of the discussions and analysis of the qualitative data outlined in the previous section of the report.
Diagram 3: What is being complained about?


- complaint about a system
- complaint about a person
- complaint about an instance of care/treatment

Diagram 4: When is a complaint being made?


- immediately, during ongoing receipt of service
- post care, post treatment or when a service has been stopped or removed when physically and mentally able

Given the potentially large number of variables at play, and the subsequent variety of different expectations or priorities that a complainant may bring to a complaint, to draw out any simple magic bullet messages for those charged with creating a unified complaint handling process would be difficult. Simply put, (and as echoed by frontline professionals during later phases of fieldwork), the research revealed that no one-size-fits-all, processual solution will always satisfy the expectations of all patients and service users making complaints, in all contexts provided by the health and social care complex.

This being said, the results of the research also show that an approach to evaluating patient and service user experience of complaints by focusing on individual experience, rather than on an objective assessment of an outcome or the level of adherence to procedure, can be enlightening. Through a focus on the patient and service user experiences in terms of the impact and outcome of the complaint handling process, there is scope to build a more unified approach and framework.

The following section outlines how the research further explored the question of outcomes with respondents, and moved from ‘expectations’ and ‘outcomes’ to the ‘I statements’ which populate the vision.

6.3 The complaint journey: building the ‘I statements’

The sections above describe patient and service user experiences in terms of the themes and variables that are likely to influence their expectations of a complaint handling service. Much of this analysis indicated the existence of a diverse landscape of complaints and complainants. In order to build a vision that would have relevance to all however, an overarching framework needed to be identified that would be common to all, and within which patients and service users could talk about the best outcomes for them, and of their experiences of making a complaint.

The overarching framework that was developed came to be known as the ‘complaint journey’. Initially comprising many steps, the simplified version encompassed just four key phases of a complaint journey. These were designed to be immediately recognisable to all of the patients and service users spoken to. This meant that patients and service users were guided in their responses through a common framework that was both open enough to allow for great diversity in individual stories, and yet with sufficient parameters to be able to compare findings across different respondents.

The four key journey steps were:
1. considering a complaint
2. making a complaint
3. staying informed
4. receiving outcomes.

For the purposes of applying the journey in the real world, a fifth step of ‘reflection on the experience’ was added, which captures the patient and service user response to their experience of having made a complaint, and the way it was handled.

1. Considering a complaint:
   This stage describes the point at which patients or service users find themselves unhappy with the service they have received (or are receiving) and are considering speaking up about it. Here there are a number of factors that might determine whether or not that patient or service user will actually go on to make a complaint.
2. Making a complaint:

This stage describes the act of making a complaint. It includes a patient or service user telling a staff member how they feel face-to-face, writing a letter or email, or dialling a phone number to tell someone about their concerns. Primary research reveals that patients and service users choose many different ways of making complaints or registering dissatisfaction.

3. Staying informed:

This stage describes the complaints process from the patient and service user point of view. For them, it is less about the specific machinations or details of a policy or system, and more about how they experience the process. More often than not, this consists of a series of communications between the complainant and the organisation or person to whom they have made the complaint. In other words, it is about whether and how they are being kept informed as to what is happening.

4. Receiving outcomes:

This stage describes the point at which the complainant is told about the resolution of their complaint and about actions that have been taken (or not) in response to their concerns. It is here that a patient or service user might receive a tangible demonstration that their complaint has been used to shape learning or improvement.

5. Reflecting on the experience:

The final stage takes place after the end of the complaints journey where the patient or service user reflects on the way in which their complaint has been handled. A good reflection would be that they feel confident in the system, that it worked for them and would for others too, and that they would feel willing and able to voice their concerns again.

This complaint journey allowed a breakdown of the various aspects of a patient or service user experience of making a complaint into different steps along the journey. Respondents could then be asked to describe what they felt the outcome of that step had been for them. It allowed a move from expectations, to reflections and outcomes. It was this exercise that formed the basis for the generation of the ‘I statements’ that populate the vision outlined at the outset of this report.

For example, Simon (whose case is outlined above) described how his complaint to the manager of a care home had been referred to the CQC and the local authority. When asked to reflect on the ‘staying informed’ stage of his journey he said: ‘I had to take it as read that the CQC were involved, as I never heard from them. I wasn’t too impressed with that. I only ever heard from the local authority’.

Simon’s statement obviously implies that he felt that he should have been contacted by the CQC, and so it is possible to construct a version of his experience that reflects what good would look like, in the form of an ‘I statement’. In other words, what Simon would have said, had his expectations of the complaint handling service been met. His negative ‘I wasn’t too impressed with that’, becomes ‘I was contacted by all parties involved in handling my complaint’.

Of course Simon’s story is just one among many, and in fact, this particular reflection and particular outcome was only one of many that Simon described. However, exploring the patient and service user experiences in this way, asking them to reflect on the outcomes of their experience across the four stages of their complaint journey, enabled the generation of hundreds of individual narratives around what an ideal experience might have been, and the way that patients and service users would express this as an outcome for them.

The most natural language to use, was that of patients and service users themselves: ‘I statements’.

The diagram below shows a snapshot of the analysis framework that was built in order to develop the ‘I statements’. Each individual story was listed on the left, broken down into different stages along the complaint journey, and then reflections on the experience turned into individual ‘I statements’. By generating so many individually applicable ‘I statements’, across the four key journey stages, it was possible to find patterns and themes among them and build the series of statements that are now seen populating the vision set out in the opening sections of this report.

What has been built is a framework which can both embrace the complexity and diversity of individual experiences of complaint handling, and also presents a usable tool for policymakers, decision makers and other researchers. Furthermore, it is a tool that is built directly on the feelings and experiences of patients and service users themselves, as each ‘I statement’ in the vision relates back directly to one or more stories collected during primary research.

Diagram 5: The analysis framework

The most natural language to use, was that of patients and service users themselves: ‘I statements’. The diagram below shows a snapshot of the analysis framework that was built in order to develop the ‘I statements’. Each individual story was listed on the left, broken down into different stages along the complaint journey, and then reflections on the experience turned into individual ‘I statements’. By generating so many individually applicable ‘I statements’, across the four key journey stages, it was possible to find patterns and themes among them and build the series of statements that are now seen populating the vision set out in the opening sections of this report.

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### 7. The view from the frontline

Whilst the bulk of the contents of the vision were created by analysing the findings from the qualitative research with patients and service users, workshops were also held with frontline staff and professionals, including complaint handlers themselves, along with policy and decision makers from various national bodies involved in both the delivery of health social care services, complaint handling services, and patient and service user advocacy services.

The thoughts and expert opinions collected during these workshops played a critical role in helping to identify the way in which the vision should be constructed: the format; the more and less important aspects of service delivery that needed to be highlighted by the ‘I statements’; the reflections on implementation etcetera. Most of the key thoughts that were generated during these workshops have been included in the guidance notes and construction of the vision outlined in the first three sections of this report.

However, it is recognised that the frontline staff, and professionals in particular, play a critical role in determining the experience and outcomes of making a complaint that a patient or service user will have. Also, interactions with these frontline staff are at the heart of many of the stories and experiences written about above.

With that in mind, it was felt that it was also critical, especially when thinking about how the vision and the research might be used going forward, to understand the view from the frontline.

#### 7.1 Feedback from the frontline

The empathy that was expressed by many patients and service users toward frontline staff was echoed in the recognition amongst staff that making a complaint can be a stressful experience for those that might be implicated as culpable when something goes wrong. There was a warning that for some staff the prevailing mood was that complaints were seen as fundamentally a criticism rather than as an opportunity for improvement. And because of this, they risk becoming a ‘taboo’ subject, not openly discussed amongst staff. It was suggested that a complaint could even affect staff confidence in their ability to perform their role effectively.

Reducing the stigma around complaints, they argued, would be a beneficial cultural change both for patients and service users and for members of frontline staff, helping turn the complaint handling experience into a positive experience for all parties involved.

Staff stated that, when patients or service users want to make a complaint they don’t necessarily want to apportion blame for a mistake, or begin a formal process that may end in censure, but rather they are often seeking merely to ‘point out things that may be upsetting them or may need changing’. Certainly the patients and service users often felt anguish that making a complaint might see repercussions for staff they liked, admired and had great sympathy for.

Staff in workshops acknowledged this distinction in complainant intentions, but described having few options for dealing with this type of ‘feedback’, other than by initiating a formal complaint process. They argued that what was needed was greater flexibility in how complaints can be handled to ensure that the response to a complaint best suits the needs of the person that made it.

The rigid adherence, they argued, to formal complaints procedures, may in some cases be undermining the confidence of staff in dealing with complaints themselves, since it is simply easier to initiate complaint proceedings than address the underlying issue.

There were also those that wanted to feel more empowered to deal with complaints themselves. For some, this sense of empowerment was associated with a feeling of support from management or senior executive levels, including boards. For others, it simply meant receiving more training and being more aware.

Some staff reported lacking confidence in handling complaints themselves; that they are ‘lacking the confidence to know how to handle a complaint or worrying that [they’ll] do something wrong’. This is in part due to lack of training on complaints handling. In fact several of the frontline staff reported a lack of awareness about the very complaints handling processes that were in place where they worked, so were unable to advise patients and service users or direct them down this route. Training, they argued, could include communication skills as well as education about processes, so that staff could feel more confident in understanding the needs that patients and service users are expressing in making a complaint.

Among those staff who were less experienced and confident with handling complaints and feedback from the patients and service users they come into contact with, there was a great deal of uncertainty about under what circumstances a complaint should be escalated, and if it is escalated, where it should be taken to. One doctor questioned whether he should direct the complaint to senior members of staff, or whether the complainant should be steered toward PALS and for the patient to go through that route.

This uncertainty almost directly mirrors the uncertainty that patients and service users felt when trying to judge the level of seriousness of their own complaints, and the ‘appropriate’ mode and channel that they should be using.

This can lead some frontline staff to feel that some patients and service users have unrealistic expectations about what might happen as a result of their complaint, which is in turn, difficult for staff to manage, and adds to a feeling that complaints cannot be effectively dealt with at a frontline level. Many on the frontline felt that they were in an inherently strong position to deal with the complaints and feedback that came from patients and service users. This was because they were more familiar with their care needs; often worked most closely with them; and were likely to be attuned to their expectations, but felt unable to put that advantage into practice.

In summary, there was an assurance that staff would like to feel able to bring about a positive experience for people using their services, including those that complain, but felt that they needed support and understanding in order to do so.
8. Conclusion

Even within the constraints placed on the research presented above in terms of scope and scale, the findings present an enormously diverse picture. And within the myriad different complaint contexts and complaint experiences that exist across health and social care, lie a dizzying array of potential recommendations for those charged with creating and implementing complaint handling policy. The risk of course, is that in trying to rationalise or simplify recommendations for practice, the richness and diversity of patient and service user experiences is likely to be lost. Therefore, tying down too rigid a set of bureaucratic or process principles is only ever likely to create a situation in which the particularities of some cases simply cannot be dealt with.

This report and the vision it presents flip the perspective away from concentrating solely on the bureaucratic challenge of how to provide a complaint handling service, to a focus on the real experiences of patients and service users themselves in making complaints. Placing these at the front and centre of a construction is an example of what ‘good’ looks like.

It is fully understood that to some extent this leaves open the question of how service providers might implement the vision, or deliver services that ensure the good outcomes described (though some thoughts and considerations for how it might be done are included in the guidance to the vision laid out in Part 1). However, this should be seen as a strength as much as anything else. Readers of the report will have noticed that many of themes and issues raised by the research with patients and service users themselves, is the vision’s strength. It is a bold attempt to articulate their voice in such a way as to ensure that it is listened to by those making and implementing complaint policies across health and social care. The fact that it is not, in its current form, a prescription, also recognises the fears of the frontline of a vision that allows little room for flexibility.

Ultimately, the vision is a sincere attempt to rethink complaint handling from the patient and service user perspective. It is a challenge to those charged with creating policy, practice guidelines and procedures, and those who receive and handle complaints, to truly recognise the complexity of the patient and service user experience, and to truly understand what the outcomes of good complaint handling should be.

Similarly, many respondents described being disappointed with the level of seniority of the person who had dealt with their complaints; in some cases they were disappointed because the person was not senior enough; at others, they were disappointed at the fact that the problem had not been dealt with by someone less senior. These seemingly mutually exclusive concerns are both addressed by the ‘I Statement’: ‘I was told the outcome of my complaint in an appropriate manner, in an appropriate place, by an appropriate person’.

This direct relationship between the ‘I statements’ and real patient and service user experiences, and the focus on what ‘good’ looks like from the point of view of the patients and service users themselves, is the vision’s strength. It is a bold attempt to articulate their voice in such a way as to ensure that it is listened to by those making and implementing complaint policies across health and social care. The fact that it is not, in its current form, a prescription, also recognises the fears of the frontline of a vision that allows little room for flexibility.

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Appendix A: A user-led vision for raising concerns and complaints

There are different ways of presenting the vision. In the main body of our report (p.9), we show it as a simple step-by-step journey. Here, it is presented as a cycle, recognising that there are different points at which people will join or leave the complaints journey.
Appendix B: Emerging good practice

During the course of the research, patients, service users and professionals gave many examples of emerging good practice in terms of the complaint handling process, and of specific practices that had been handled particularly well, leading to positive outcomes for complainants. Outlined below are some of those examples, drawn from a range of different contexts and presented as they apply to different stages of the complaint journey. For the most part, the focus is on examples in which the ‘outcomes’ for the patients and service users involved were positive, rather than focussing on ‘principles’ of good practice as seen from a systemic point of view. The distinction is important. The vision outlined above was built specifically from the point of view of patients and service users, and focuses on outcomes rather than procedure. With this in mind it is important to realise that it is the localised and specific interactions of a given complaints system with a complainant that truly determine the experience and outcome.

These examples should be considered alongside those provided in the Clwyd-Hart review of NHS complaint handling systems, which focus on the localised and specific interactions of a given complaints system with a complainant that truly determine the experience and outcome.

The distinction is important. The vision outlined above was built specifically from the point of view of patients and service users, and focuses on outcomes rather than procedure. With this in mind it is important to realise that it is the localised and specific interactions of a given complaints system with a complainant that truly determine the experience and outcome.

One adult social care directorate in a city council has been redesigning the way in which it assesses (and reassesses) social care entitlements and care packages. This has involved a radical rethink of the way in which all consumer-facing staff (from telephone staff, to brokers, social workers and team and patch managers) communicate with service users. All staff are given the permission to take a more personalised and individual approach with service users, going beyond their formal assessment and recording duties if and where possible.

This has meant that social workers (in particular) are able to form more responsive working relationships with service users and design solutions to problems in partnership with them. It has also meant that reassessments provide a new, less formal, opportunity for service users to raise concerns about any aspect of the services they receive without having to go through the sometimes awkward possibility of confronting those who are delivering the services directly to them. Given that many of these services are being provided in service users’ own homes, and that often these service users are vulnerable, these more trusting and flexible relationships with council staff have become invaluable.

A cancer patient described how, when he had first been diagnosed, his specialist cancer nurse had been very explicit with him that he was now going to go through a long and painful journey, and that, if there was anything he ever needed help with, or that if he was not happy with any part of the service he received, he should go straight to her. Sure enough, when he found that he wanted to complain about the way he had been treated by various hospital staff, he went straight back to his specialist nurse and made a complaint: ‘My specialist nurse had told me to always come to her — so I did.’ By making herself available at the outset of a programme of service provision, the nurse had created an environment in which the patient felt comfortable making a complaint, as well as providing a simple and trusted route for the patient to make a complaint.

### Example One

**Openness to complaints - Postnatal ward**

**Key features:**
- strong communication of openness to receiving complaints and feedback
- active creation of a culture in which complaints and feedback are encouraged
- making complaints channels clear

In one postnatal ward in an NHS foundation trust hospital, the nursing and midwifery teams have created a series of posters with pictures of the ward matrons on them. They are emblazoned with the words: ‘Don’t take your worries home with you.’ This openness with patients is backed by an internal culture of openness around admitting to and dealing with things that go wrong, and a specific service that encourages women to ‘debrief’ their experiences in the ante and postnatal wards with nurses and midwives. These kinds of efforts help to create an environment and culture in which it is acceptable for patients to make a complaint, raise a concern or offer feedback. It also helps to empower nurses and midwives to listen without fear to patient concerns.

### Example Two

**Strong communication and relationships with service users - Social workers and social care staff**

**Key features:**
- creating a trusted point of contact at the outset of service provision
- single point of contact
- proactive seeking of service user feedback

One of the more complicated complaints encountered during research started with a complaint to the manager of a residential care home for the elderly. The local authority escalated the complaint (independently of the complainant) to the level of formal inquiry. The complainant

### Staying informed

**Example One**

**Thorough and personalised complaint handling communication - Local authority inquiry into complaint about care in a residential care**

**Key features:**
- regular, personalised updates on complaint progress
- single point of contact
- proactive complaint handling

One of the more complicated complaints encountered during research started with a complaint to the manager of a residential care home for the elderly. The local authority escalated the complaint (independently of the complainant) to the level of formal inquiry. The complainant

### Considering a complaint

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- making complaints channels clear

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This has meant that social workers (in particular) are able to form more responsive working relationships with service users and design solutions to problems in partnership with them. It has also meant that reassessments provide a new, less formal, opportunity for service users to raise concerns about any aspect of the services they receive without having to go through the sometimes awkward possibility of confronting those who are delivering the services directly to them. Given that many of these services are being provided in service users’ own homes, and that often these service users are vulnerable, these more trusting and flexible relationships with council staff have become invaluable.

### Making a complaint

**Example One**

**Trusted point of contact for a complaint - Specialist cancer nurse**

**Key features:**
- openness to receiving a complaint
- providing a trusted point of contact for complaints
- providing support when it was needed
- providing upfront knowledge of where/who to complain to
described being very happy with how this formal inquiry had been handled. Although he was never asked to submit any further evidence beyond his initial complaint, a member of the inquiry board took it upon herself to provide him with weekly phone calls describing the process of the case, and supplemented this with post-meeting phone calls to describe in detail to him what had been said, by whom, and the potential implications. As the complainant said himself: ‘She was telling me what was going on; probably in more detail than she needed to. She was very good. I think this should be standard practice. I think if you are making a complaint you should be told not only the procedure but also - in reality - the way that procedure is being adhered to in your specific case’.

Example Two

Recording all levels of feedback and complaint - NHS foundation trust complaint handling service

Key features:
• taking all complaints seriously
• ensuring formal record of patient concerns
• helping to ensure complaints only need to be made once

In one NHS foundation trust, an online complaints reporting tool has been created to allow frontline staff to quickly record all of those complaints and comments that are resolved at the service level. This means that the organisation can ensure that patterns are noticed and that lessons can be learned from incidents or concerns that may not normally reach beyond the frontline.

This also means that patients can be reassured that their concerns have been recorded formally, which, as many found, helps to give confidence that complaints are taken seriously and acted upon.

Receiving outcomes

Demonstrating the difference complaints can make - NHS foundation trust complaint handling service

Key features:
• seeing the difference a complaint made
• support in understanding the resolution of a complaint
• asking the complainants views on the outcome of their complaint

An NHS foundation trust complaint handling team has begun offering all complainants the chance to come to the hospital and be walked through (sometimes in the literal sense of being walked through the wards themselves) the changes that have been made as a result of their complaint and discuss what has been done. So far around 10% of complainants have chosen to take up the offer. This gives the patients a first-hand insight into the difference that complaining can make, in likelihood giving them confidence to complain in the future and a story to tell others about the positive difference that complaining can make.

Resolution and reconciliation

Key features:
• a resolution delivered in an appropriate manner
• outcome directly addressed the complaint, and empowered the complainant
• patient views taken into account

Though not a solution in all circumstances, one respondent was particularly impressed when, in response to what he felt was a very serious complaint, he was offered an afternoon meeting with the consultant he had complained about, a specialist nurse (with whom he had a very good relationship), and a counsellor whom he felt to be a neutral third party. The meeting was to take the form of a ‘clear the air’ talk, in which the consultant would be invited (and required) to listen both to the wishes of the patient (which it was felt had initially been ignored), and also the impacts his alleged poor behaviour had had on the patient.

Reflecting on the experience

The following examples are not reflections from patients and service users on their own experiences, but rather demonstrate ways in which organisations could make good use of complaints in order to promote organisational learning.

Example One

Using complaint handling data - NHS foundation trust complaint handling service

In one NHS Foundation Trust the accurate collection and recording of complaint handling data allowed a complaints team to analyse and present results back to various different medical staff. One doctor in particular was shown that he was receiving a larger number of complaints than other doctors; something he was quite unaware of. Instead of being defensive, the doctor took the results on board and was able to take the matter up further, seeking training opportunities and other learning opportunities in order to improve his own service delivery.

Example Two

Innovative learning from mistakes - Maternity ward

In one maternity ward, a particularly innovative matron had commissioned a film to be made about a patient who had had a bad experience in the unit. The very moving story was then used to train and educate new midwives on the potential impacts of mistakes, and the value of being able to learn from mistakes. The patient was thus able to become involved in making a difference, beyond just the making of a complaint.
Appendix C: Method statement and contributors

Desk research
This involved an exploration of existing research and literature. We looked at complaints and complaint handling across health and social care in England; a scan of complaints systems and user forums from outside of the sector to explore user/consumer expectations when making complaints more widely; and an exploration of ‘live’ complaints systems in hospitals, GP’s surgeries, local authorities etcetera.

Natural groups (over 100 participants)
Interviews and discussions were held with various patient and service user groups around the country. The aim of this part of the research was to explore patient and service user expectations of complaints systems, often in the context of complaints they had actually made; but also more generally. The groups were not artificially convened, but rather made use of existing patient and service user groups.

The groups varied in size. The smallest, a telephone conference group hosted by the Royal National Institute for the Blind (RNIB) contained six participants; whereas the largest, an MS support group, had over 30.

In some cases, researchers became participant observers, using the groups as a site to recruit patients and service users for ad hoc interviews. In others, researchers were allowed to host and run the group sessions themselves, setting the agenda for discussion.

The great advantage of running groups in this way, was that there was no predetermined requirement for patients or service users or carers to have thought about complaints, or to come with specific stories. This allowed a very free discussion of the issues—uncoloured by pre-existing thoughts or agendas, and unencumbered by any predetermined agenda laid out by researchers. It also ensured a very naturally representative sample of patients and service users, some of whom had made complaints; some of whom had considered complaints but not made them; and others of whom had never made a complaint in their life.

The groups included:
- gay men’s cancer support group - London
- cardio/elderly patient group - Midlands
- MS support group - Peterborough
- diabetes support group - Midlands
- cancer support group - North West
- carers’ forum - North West
- daycare centre - Yorkshire and the Humber
- RNIB teleconference - UK
- male prostate cancer group - South East
- ESA claimants support group - London.

10 Patient and service user depth interviews
These face-to-face interviews took place with a range of patients and service users and were designed to explore expectations in relation to both real and imagined cases of feedback and complaint. The interviews gave a rich set of case studies on which to draw, alongside clearly articulated priorities and expectations for the future. The interviews were also used to test the hypothesis that ‘I statements’ could be built from the real experiences and expectations of patients and service users, and were meaningful reflections of them.

The interviews included:
- male, 40: complaints on behalf of both his mother-in-law about in home social care, and about his mother in relation to the prescription of medication by a GP
- male, 50: complaint (now a legal case) against a surgeon over an issue of consent
- female, 30: complaint made on behalf of her father, suffering from MS
- female, 34: multiple complaints about maternity services
- female, 29: MS patient complaint about administrative services in a hospital
- male, 50: complaint on behalf of his elderly mother about how she was discharged from hospital after surgery
- male, 80: several complaints about poor care in a care home
- male, 60: complaint on behalf of mother about carers in a care home
- male, 40: complaint about poor outpatient service
- female, 30: complaint (not made) about poor service from a community mental health team.

Professional/stakeholder workshops
A series of three workshops were held in order to take the findings and thinking from the primary research with patients and service users to stakeholders within the health and social care sector These explored the ways in which user-led expectations could be developed into a pragmatic vision for complaints handling in the future.

1. The frontline: This workshop contained professionals from the frontline of complaints handling across health and social care. The ‘frontline’ here was defined as those who are most likely to be the first point of contact for a complainant (nurses, social workers, receptionists etcetera) and/or those for whom complaints handling is part of their day job and job description (for example, complaint handlers).

2. National bodies and service providers: This workshop contained representatives of various national bodies and service delivery organisations. They came together to discuss existing best practice in complaint handling; the research findings; patient and service user expectations; and to explore the ways in which this knowledge could be turned into a single coherent vision for the future of complaint handling in health and social care.

3. Stakeholders: The final workshop brought together senior stakeholders in complaint handling strategy and delivery, with senior representatives of patient and service user advocacy groups and organisations. The seminar and workshop allowed the presentation of a nearly finalised version of the vision and explored issues of refinement, feedback and implementation.
Appendix D: Case studies

Below are a selection of case studies that were presented for discussion during the workshop phases of the research.

Case study 1 - Amina
Amina does not work, is fairly isolated, struggles to articulate her emotions and says she knows little about the ways in which public services work. Her ex-husband has been suffering from paranoid schizophrenia for more than 15 years and she provides care to him daily, though they no longer live together.

She thinks that the community mental health team do not take her seriously, and wants to complain about it. She also wants her ex-husband’s medication to be reviewed, and says she has asked for this several times but has been ‘fobbed off’. Her GP, she says, will not intervene on her behalf with the community mental health team.

Amina’s journey
- Amina is nervous about complaining to professionals. She sees nurses and doctors as being socially distanced and unapproachable.
- She feels intimidated by medical staff and the bureaucracy of hospitals and the health system.
- Amina says she would complain if she saw others do it. If there were somewhere to queue behind others, she says, she would queue.
- She was unaware that any formal complaints procedures or professionals existed, and had never heard of PALS or any other advocacy group beyond CAB (to whom she has complained before about benefit payment).

Case study 2 - Simon
Simon’s father, Phillip, didn’t go into a residential care home until he was in his early nineties. The after-effects of a stroke, and the onset of dementia had left him unable to communicate, and was increasingly unable to look after himself. Phillip had enjoyed giving himself a wet shave every day for many years. However, his increasingly unpredictable behaviour had led to a plan being put in place that he would not be allowed to keep his razor in his room. His wet shave would be carried out by a carer in the care home.

One day, Simon received a call to say that there had been a serious accident. One of the carers had accidentally allowed Phillip to get hold of the razor, and he had cut his inner thigh very seriously.

Simon’s journey
- Simon had stormed in to see the manager.
- He pointed out that he had been in many times before to meet staff about complaints he had with the care home’s service.
- Simon blamed the management for overworking their staff.
- An area manager for the care home company contacted Simon and told him that the CQC and the local authority had been informed.
- Simon never heard from the CQC, but says the local authority held an inquiry, which he was informed about, in great detail, by phone.
- Simon was told that the carer had been barred from working in care homes, and that the manager would subsequently resign. Simon was unhappy as his father had liked the carer very much.

Organisations represented at these workshops and who helped with carrying out the research with natural patient and service user groups included:
- Action Against Medical Accidents (AVMA)
- Association of Directors of Adult Social Services (ADASS)
- Barts Hospital
- Berkshire Healthcare Foundation Trust
- Citizens Advice Bureau (CAB)
- Care England
- Care Quality Commission (CQC)
- Dementia UK
- Department of Health
- Diabetes UK
- East Kent Hospitals
- Foundation Trust Network
- General Dental Council
- General Medical Council (GMC)
- Guys and St Thomas NHS Foundation Trust
- Health and Care Professions Council (HCPC)
- Heart of England NHS Foundation Trust
- Healthwatch England
- Ideas4Use
- John Radcliff, Oxford University Trust
- Lewisham Hospital
- Local Government Association
- Local Government Ombudsman
- London Borough of Havering
- London Borough of Richmond
- Metro
- Monitor
- National Complaints Managers Forum
- National Voices
- NHS Confederation
- NHS England
- Patients Association
- Royal National Institute for the Blind (RNIB)
- Royal College of Nursing (RCN)
- Royal Free Hospital
- Support Empower Advocate Promote (SEAP)
- South West London and St. George’s Mental Health Trust
- St Georges Healthcare
- St Helens and Knowsley Teaching Hospitals
- NHS Trust Development Authority (TDA)
- VoiceAbility
- Wandsworth Council
- Westminster City Council
- Which?
- Wigan Council
Case study 3 - Rupert

Rupert had a ganglion cyst on his foot for which the consultant recommended a minor surgical procedure. He opted to wait, and asked that the doctor keep the file open in case he changed his mind. Several months later he decided to have the surgery, found the file had been closed, but was told that he could make an appointment to have it re-examined.

Two appointments were cancelled, and a third was inconvenient, so no progress was made with the case.

Rupert’s journey

- Rupert was very unhappy with the appointments team.
- He assumed that since the problem was with the appointments team it was their responsibility.
- Rupert wrote a letter of complaint to the address of the team, as written on the original appointment letter.
- He received no response to his letter or acknowledgment that it had been received.
- Rupert contacted the PA to the consultant directly, who was able to arrange a new appointment.
- He never received any response to the complaint.

Case study 4 - Linda

Linda is registered blind. She was in a hospital to visit a relative who had just undergone major surgery. When she arrived she was told that she had come to the wrong part of the hospital by staff at the reception desk. She was told that she needed to be at another unit that was some distance away.

Linda left the reception desk and then realised that she was lost. Someone from the reception desk, she says, then came over to her and told her that she would need to take a bus and gave her the bus number. The person then left. Linda was left disorientated, not knowing the way to the bus stop. As she put it: ‘And then how would I have hailed the bus, even if I knew where the bus stop was? But the person was gone’.

Linda never made a complaint. She felt the matter was trivial, and by the time she had the wherewithal to do so, the matter seemed too distant and unresolvable.

Case study 5 - John

John’s elderly mother lives at home, but following an operation had lost a good deal of mobility and had deteriorated mentally (loss of memory and faculties). She needed carers to visit four times a day to cook, clean and administer medication. These carers were provided by a contracted agency.

John was concerned from the outset about the level of care, largely because the flat was often untidy when he came to visit. He was also concerned that his mother wasn’t eating properly at weekends, so asked a carer to spend some time feeding her. The carer responded in a manner that offended John, and claimed there was no food in the flat, a fact that John knew to be untrue.

John’s journey

- John was upset by the manner of the carer, and concerned for his mother.
- He called the care provider, and spoke to a manager who said that he would file a report but that John should call back on Monday.
- John called back, and found that no report had been filed, so had to repeat his complaint.
- The complaint was then corroborated by the report of the weekend manager.
- John demanded that the particular carer had no further contact with his mother.
- He was informed, by phone, that the carer would be disciplined. She has had no further contact with John’s mother and he is satisfied with this outcome.
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